

Prepared for Jack & Kenz 's site on August 17, 2020.

Journal

Max the Angry Macrophage HLH

Kim Ryan, April 30, 2019

<https://youtu.be/Vxoy5328MZc>

Comments

I love this video! Such a good explanation.

—Sarah Jamison, May 1, 2019

God Speed young Man!

—Leon Alan, May 1, 2019

Jack you are a Rockstar!

—clare wrixton, May 1, 2019

Jack you are so strong! I know you will tackle this journey like you tackle everything else with determination, hard work, and confidence. You are an amazing young man.

—Anneke Thompson, May 1, 2019

Jack, you've got this! We're here for you and will be supporting you along your journey. I love this quote, "There's not one GIANT step that does it. It's a lot of little steps." Celebrate all accomplishments no matter how small or big they are.

—Debby Trewyn-Way, May 1, 2019

How can I help? Is a family member coordinating meals/ gift cards that I can connect with? You got this Jack (& Mom)!

—Stacy Schoemann, May 1, 2019

Stacy, we have some amazing friends and family working on fundraisers. Sometime in June. I believe one down here and one in Eagle River.

—Kim Ryan, May 1, 2019

How can we help? Can we help with meals? Gas cards? Let us help you all through this. We are here for you!!

—Melinda Schmidt, May 1, 2019

Crappy Adventure T shirts!

Jeremy Ryan, May 1, 2019

Below is a link to get a custom t-shirt in support of Jack's Journey. You can have them mailed directly to you or pick them up from Kim or I once the t-shirt campaign is over. Should be around June 3rd. In the spirit of keeping Jack's infectious smile on his face, we are hoping to have a little fun with this and have you take a picture in cool places you visit this summer (with your "Crappy Adventure" shirt on) and post them to this page or to our facebook pages. Thanks again so much!

<https://www.customink.com/fundraising/please-help-jack-attack-hlh>

???words by Jack

Kim Ryan, May 1, 2019

Jack wants to make a shirt that says:

Say these words and I might punch you!

1. Atypical
2. Clippers

3. Bone Marrow

For some reason these words really get to him lol.

(Clippers is a general diagnosis for CNS demyelination that responds to steroids)

Sent from CaringBridge iPhone app

Comments

Hi Jack, my name is Diane. I heard about your story from my sister Alice. I have one of her puppies also. His name is Merle and he is a good boy. He has two brother dogs that keep him in line. Alice puppy is so sweet. I'm praying for a full recovery for you.

—*Diane Risner, May 1, 2019*

Hi Jack I'll keep you in my prayers continually until you are healed, Faith believing! Praying God touches and heals you totally! I'll be praying for your mommy too!

—*Connie Coleman, May 1, 2019*

Boston Children's 2nd Opinion

Kim Ryan, May 2, 2019

I received Jack's second opinion from Boston Children's. They were in agreement with the diagnosis and with the treatment plan started with Children's in WI. This is reassuring as it's wonderful to be able to get Jack the best care and as close to home as possible.

Along with the report they included a research study on a few kids that presented with CNS (Central Nervous System) isolated HLH. This is partially why they always say Jack presents atypical... Most kids have systemic HLH. Jack did initially have low blood counts which would classify as systemic but since, all his red cells and platelets have gone back to normal. The only thing still hanging out on the slightly lower end are his WBCs. (Which steroids usually effect by making them seem higher) but not for Mr. Jack...

This was the only difference with the opinions, CHW said CNS isolated and Boston said systemic. From my understanding, this should not effect his treatment plan. Being isolated version would explain why he seems so much healthier than others which we are thankful for. However, if you read the study he is still different in comparison to those kiddos. Those of you who know me know that I will be sure clarify this with our doctor so I can understand their thoughts on it haha. :) There is a possibility he was fighting something at the time (kenz was sick) but that dang white count??

His next appt is next Thursday.

Sent from CaringBridge iPhone app

CNS isolated Research

Kim Ryan, May 2, 2019

<https://nn.neurology.org/content/6/3/e560>

Sent from CaringBridge iPhone app

Comments

Jack, the Holcomb's are pulling for you and your family!! We bought your T-shirts. What an awesome design and I love your "Ryan" sense of humor. Having been through chemo, I think your attitude is great and it will help you get through this. We love your whole

family, and will do all we can to help. Keep that great smile going!!

—dennis holcomb, May 2, 2019

Meet Dakota!! The newest member of our family!

Kim Ryan, May 3, 2019



The kids have been begging and begging... Jack's neurologist is amazing and wrote a letter for him to have an ESA (emotional support animal). Now Dakota is allowed to go to appts and visit him at the hospital! She is a 9 week old Weimador, half lab and half Weimaraner. She is so sweet and fits in perfectly.

Photos









Sent from CaringBridge iPhone app

Comments

So happy for you! Such sweet puppy.

—Diane Risner, May 3, 2019

Omg. So sweet!! Way to go Ryan family. Super happy for you guys!!

—Mandi Goff, May 3, 2019

Look at those smiles!!! This is so great Kim! Beautiful dog!

—Luanne Dikanovic, May 3, 2019

Dakota is so cute. Give hugs to Jack and Mackenzie and that precious dog. Love you All

—Chris Smith, May 3, 2019

Oh wow, Weims are nuts and super fun! Congrats on your new kid!!!! :P

—Jon Schultz, May 3, 2019

He is adorable!!!! The kids will enjoy him! Love & prayers to all of you!!!

—Rich & Darlene Larsen, May 4, 2019

So happy for you guys!! ♥♥

—Lauren Stone, May 6, 2019

So happy for you guys!! ♥♥

—Lauren Stone, May 6, 2019

Go Fund Me

Kim Ryan, May 3, 2019

Kenzie's teacher was so kind to set up a go fund me page and asked me to share here. There is also a fundraiser the kids' teachers are working on for June in Burlington. I will post details when I have them. Thank you all for the amazing support.

<https://www.gofundme.com/jack039s-quotcquot-word-adventure>

Sent from CaringBridge iPhone app

Thank you, thank you, thank you!!!!

Kim Ryan, May 4, 2019

I am completely overwhelmed by the love, support and generosity. So many people coming together to love on us... family, friends, people I don't even know!! There have been so many offers to help and so many of you setting things up, praying, checking in and also sharing things you love about Jack! Thank you so much! My family is truly blessed! My heart is so full.

Sent from CaringBridge iPhone app

link to bone marrow registry- Be a Match

Kim Ryan, May 5, 2019

Some of you have asked how to see if you are a match for Jack. I'm not sure how quickly you get on the registry once the process is completed but here is the link to Be a Match! I believe they send you a kit to swab your cheek, you send it back, that's it! You can save a life!!

<https://bethematch.org/support-the-cause/donate-bone-marrow/>

Sent from CaringBridge iPhone app

Jack's update

Kim Ryan, May 6, 2019

A little update on how Jack has been doing...

After being started on those new meds last week, he started getting really itchy. No rash, just super annoying itching mostly to his chest, arms and hands. Then, he started complaining it felt like burning and itching on his hands. They thought it could be due to a side effect of a medication started. They tried a few medications that were supposed to help but seemed to only make him sleepy. We went back in again today because he was so uncomfortable and not sleeping well. The Doctor and NP think it may be neuropathic pain and just a coincidence as to when it started so added gabapentin to Jack's list of meds.

He also had some labs drawn. They were ok with most of the results. His fibrinogen dropped a good amount from last week. Due to this, they want him to have another lumbar puncture this week. (This will now take the place of the one for next week) He will have labs prior to it to make sure the fibrinogen didn't go too low where it wouldn't be a good idea to do the LP. Since he will be sedated, he will also get a central line so he doesn't have to keep going through so many pokes.

Praying his numbers stay put for the next lab draw and that he feels some relief with this new medication. He is such a strong and brave kiddo!

Sent from CaringBridge iPhone app

Comments

Prayers to you all.

—Diane Risner, May 7, 2019

Jack, I hated the idea of getting a port, but ended up being the best thing. All those pokes get pretty annoying and the port helps so much. Stay strong, Mak Holcomb

—dennis holcomb, May 7, 2019

Thinking of you Jack ... sending my thoughts and prayers. You are one tough kiddo! Keep

fighting!
-Mrs. Walby

—Siri Walby, May 8, 2019

Hi,
I've just found your website via the HLH Facebook page and Jack's story sounds so similar to my daughters', I couldn't read it and not respond. I won't go into too much detail just now but the basics are she started suffering from double vision and balance issues when she was 11 and was diagnosed within a few days with Clippers.. Responded quite well to steroids but still has inflammation in brain and top of spinal cord causing vision and balance issues. Rediagnosed this March with HLH caused by Griscelli syndrome (gene RAB27a) and now waiting to hear from Gt Ormond St about treatment options. We keep being told she is atypical so it is amazing to read about such a similar story. Fingers crossed you find a match soon and sending you lots of love and strength. We have a little website if you want to come and say hello! www.griscellisuper-girl.co.uk

—Sue Chivers, May 8, 2019

update

Kim Ryan, May 9, 2019



Today was a long day for Jack... he had labs drawn to check the status of his HLH. They were especially looking at his fibrinogen (clotting factor). Normal is 200-400. Last week his was 200, Monday it was 120 and today it was 100. Due to the trend downward, he received 2 units of cryo (a blood product). Then they were comfortable with him having the procedures done. He went for PICC (peripherally inserted central catheter) line placement and an LP (lumbar puncture, also called a spinal tap). Since there was a change in his labs they were concerned that the HLH may be active and this can be seen in the spinal fluid. The PICC line is for Jack's lab draws so he doesn't have to be poked anymore, they can just draw off his line. He is very happy about this!

Both procedures went well, however, the HLH is considered active because macrophage cells were seen in his spinal fluid. They said that under a microscope you can actually watch the cells eating the other cells. They let Jack come home for the night but he will need to go back tomorrow morning and be admitted. He will have his labs checked again and to get chemo. They put the chemo right into his spinal fluid. It's the same process as LP but instead of taking fluid out, they are putting the chemo in. It's important to get the HLH under control as they cannot do a bone marrow transplant with active HLH. We are hoping it is a quick admission. This depends on how his labs are and how he tolerates

the chemo. At this point all this other labs they monitor closely for HLH have been stable so that's a good sign and he hasn't shown other signs like fever or rash.

He was able to spend some time lovin on Dakota tonight which lifted his spirits. He did such an amazing job with everything today! I will post tomorrow on how he's doing. Thank you so much for the continued love, support and prayers!

Photos



Sent from CaringBridge iPhone app

Comments

Praying for you Jack!

—Lindsay Deinhammer, May 9, 2019

Thinking of you and sending love from Nottingham, UK

—Sue Chivers, May 10, 2019

Prayer are with you all! Love how Dakota snuggles Jack.

—Alice Polzin, May 10, 2019

in my heart and prayers. I will light a candle for him today at Mass!

—Kathy Zaffiro, May 10, 2019

So precious! Love you guys!

—Kathy Sturycz, May 20, 2019

status on donor match

Kim Ryan, May 9, 2019

I forgot to mention what we know about donor matches at this point. We found out today that Kenzie is a half match with Jack, therefore, she cannot be the donor. We are told that there ARE potential unrelated donors as well as cord blood matches she is looking into. She did not say how many but there are many steps still ahead on her part. We will discuss things further with her early next week. She did mention the benefits to Jack of him receiving the stem cells from cord blood. Cord blood crosses the blood brain barrier and is great in Jack's case due to his demyelination. Also, the cells are immature and haven't been exposed to things marrow from a donor has been. I will let you know what comes of our conversation next week and if she makes progress on finding a donor! Exciting news that there are potential options for him out there!!

Sent from CaringBridge iPhone app

Comments

Praying for perfection on matching!

—Brenda Stratton, May 9, 2019

A change in the plan

Kim Ryan, May 10, 2019

Jack had to go in bright and early today. He had labs drawn first. They all looked good. His fibrinogen was 151. This was up from 100 yesterday and increased due to getting the cryo.

After that, he had an LP (lumbar puncture) and intrathecal chemo (chemo in his spinal fluid). He tolerated this well. The high dose of decadron he's on causes him to have quite the appetite. Since he can't eat from midnight the night before you can imagine how hungry this kiddo gets. Jack requested I have 2 McDoubles waiting for him when he got to his room. (Which he tore up in minutes lol)

He was admitted to the HOT unit (hematology, oncology and transplant). Tomorrow morning he will get labs drawn again as well as start getting chemo called VP-16 through his PICC line. As long as he does well with this and his labs are stable, he should hopefully be discharged by Monday.

The HLH specialist sat down with us and explained the new treatment plan for Jack. He will get labs drawn weekly as previously planned. Each week he will need an LP and chemo as well as the IV chemo. We are unsure of the timing at this point, whether it can be on the same day if he tolerates it well or if it is better spaced out by a day or so. For now the plan is to get the chemo weekly for 4 weeks.

We also briefly discussed the donor matching. She confirmed that Jack has more than one cord blood match that is a 6/6. That's the best match for cord blood but a bone marrow donor is out of 10. There are also potential unrelated donors as I mentioned yesterday but it sounds like there are more pros in using the cord blood for Jack. There is a specific nurse working on all the details of this. We will talk more with her at next weeks appt.

He explored the HOT unit a little today. They have some fun things to keep Jack busy. Today Jack and Kenz played Nintendo Switch..

Sent from CaringBridge iPhone app

Comments

Hi Jack,
Sending you hugs and kisses☺☺
Love Aunt Barb

—*Barb May, May 11, 2019*

Thinking about you guys! Anytime you want to drop off Kenzie, we are happy to have her.

—*Rebekah Raleigh, May 11, 2019*

Mother's Day with my Buddy

Kim Ryan, May 12, 2019



Jack and I are having a low key Mother's Day in the hospital. He got the VP-16 chemo yesterday through his line. Today his fibrinogen went down again. It was 99. Anything 100 or below the doctor wants cryo given so he received that this morning. The chemo can take a little time to kill those HLH cells.

He has to use a special mouth wash 4 times a day to help prevent mouth sores and infection in his picc line. He also has to use chlorhexidine wipes (antiseptic solution) once a day to wash up to reduce bacteria on his skin.

We ventured off the unit a couple times. He has to wear a mask when doing this to prevent picking up germs from others. Jack will need to continue doing this once home.

Jack treated me to breakfast off the hospital menu. ☺☺ We had a lunch date in the cafeteria for a change of scenery. They have a little lounge area where we played Nintendo Switch and watched some hockey together. He also got to visit with Archie, one of the therapy dogs. We had a great day. ♥

On rounds this morning, they discussed how Jack continues to present atypical and

needs to be monitored very closely, reminding us that although he may not realize, Jack is a pretty sick kiddo. We have to take this a day at a time. Tomorrow morning his doctor will be here and we will find out the game plan for this week.

Happy Mother's Day to all of the momma's reading this!

Photos



Sent from CaringBridge iPhone app

Comments

Happy Mothers Day Kim!!!! Love you Jack!!!

—Emily Dumovich, May 12, 2019

Happy Mother's Day , Kim! Jack, that was sure nice of you to treat your mom to breakfast this morning. ☺☺ Keeping you in all of our prayers!

—Debby Trewyn-Way, May 12, 2019

Happy Mother's Day! Sending lots of love and strength to you x

—Sue Chivers, May 12, 2019

Happy Mother's Day, Kim!! ♥♥

—Rebekah Raleigh, May 12, 2019

Happy Mother's Day Kim! Jack thinking of you every day Hugs kiddo ☺☺♥

—Sue Dumovich, May 12, 2019

Happy Mother's Day Kim! Hugs to you all. Hope it was a good day & Jack got along well. ☺☺☺ You get good news tomorrow ☺☺

—Brenda Sutcliffe, May 12, 2019

Happy Mother's Day to one amazing mom. You sure should be proud of those beautiful children that you have. Love you.

—Diane Kreye, May 12, 2019

Happy Mother's Day Kim. Jack couldn't ask for a better mom to have in his corner to help him fight this fight!! Thinking of you all and praying everyday!!

—Melinda Schmidt, May 12, 2019

Happy Mother's Day! Thoughts and prayers are with you!

—Alice Polzin, May 12, 2019

I love your smile Jack! You put a big smile on Mom's face too! I love you so much!

—Diane Ellis, May 13, 2019

Jail break today

Kim Ryan, May 13, 2019



Jack broke free from the hospital today!!!! He was very excited to come home and be reunited with Dakota. The only catch... he has to go back to the day hospital in the MACC Fund Clinic every day this week.

Each day he will have lab draws to check HLH labs but especially to keep an eye on his fibrinogen. They also want to make sure his other labs commonly effected by HLH remain as unchanged as possible. We will take it one day at a time to determine if he needs more cryo due to his fibrinogen being low or if VP-16 (iv chemo) is needed. It's a matter of which day he will need it, he will get that at some point between tomorrow and Thursday. Friday he has a lumbar puncture scheduled along with the intrathecal chemo (in his spinal fluid). Each time they do the LP they will check on the status of the HLH cells in the spinal fluid.

At any point this week they may decide to admit him if needed. Of course, Jack is hoping this is not the case. Jack is at risk for bleeding due to the low clotting factor so we have to make sure he lays low. For now, he is so happy to be sleeping at home and be snuggling his puppy!! One day at a time.

Today his fibrinogen was only 108 so they have him cryo again before we were discharged. We realized that yesterday he was only given 1 unit which is likely why the increase wasn't as significant as before (he got 2 units). This was likely a miscommunication. Today they gave him the 2 units.

I will let you all know how this appts go this week.

There are only a couple days left to get one of Jack's Crappy Adventure shirts. Remember if you order one, to send us pics wearing it this summer so we can share them with Jack! He would love it! Thank you all so much!

Photos



Sent from CaringBridge iPhone app

Comments

You got this Jack!!

—Randy Haas, May 13, 2019

Hi Jack, glad to hear you're out of the hospital for a bit. I figured I would keep you up to date on the shooting competitions and the shenanigans of a few of the athletes. This past weekend we were in Eau Claire. We had several shooters in the 90s, which was good to see. For some reason we always shoot very well in Eau Claire. Our top score was a 97 followed by a 96 and 3 95s. Your fellow rookies took first as a team and 1st 2nd and 3rd individually. They also played a risky game of truth or dare in the hotel. Sounds like one of them licked the hotel window from top to bottom, no doubt your mom just cringed a little. I wish I could say that was the worst, but one was dared to suck on another teammates toe ☹️. Next weekend we're off to Manitowoc which is our last "big weekend" shooting all 3 disciplines. Again glad to hear your home.

—Coach Rob Jones, May 13, 2019

Glad Jack is back at home! Praying for good news each day.

—Jessica Lyons, May 13, 2019

This gives the saying "One Day at a Time" some real reality for us all praying, and going on this journey with ya'll. Praying and believing for miracles, strength, healing, answers and HOPE that passes all understanding! Hugs to you all...I will look for praise reports!

—Connie Coleman, May 13, 2019

Jack, I bet Dakota was so excited to be with you! Hang in there... you're going to come on on top of this "Crappy Adventure"!

—Debby Trewyn-Way, May 14, 2019

Hi Jack,

It's Karen (the Toffee lady) and Jerry....you look SO COMFORTABLE WITH Dakota. He sure looks like a great puppy to curl up with. Thinking of you always with prayers.

—Karen Peltier, May 14, 2019

Kim, it sounds as if you are all doing you're best, and pretty well at that, under some incredibly difficult circumstances. I want you to know I am thinking of you and praying for all good things.

—Luanne Dikanovic, May 14, 2019

Hi Jack

Glad you are back home enjoying your cute puppy. Thinking of you☺☺
Love Aunt Barb

—Barb May, May 15, 2019

Jack, we miss your smiling face!

Kim, all of you are in our thoughts and prayers.

We know the shirt sale has closed is there anyway we are still able to place an order or do you know if extra ones were ordered? We'd love to show our support.

Love,

Your Athletico Family

—Lissa Gittens, May 20, 2019

Girls on the Run! from Yorkville ??

Kim Ryan, May 14, 2019

Girls on the Run from Yorkville School made this awesome video for Jack! He LOVED it and of course it made me cry. What an amazing group of girls! (And those coaches are 2 of my favorites ☺☺)

https://youtu.be/G-YyoDev_7k

Sent from CaringBridge iPhone app

Comments

Made me cry too ☺☺ So awesome and thoughtful!

—Heather Ray, May 14, 2019

Awesome girls!!!!

—Dick Ryan, May 14, 2019

That is so awesome! My husband's dad was a teacher at Yorkville for many years. What a totally sweet thing to do.

—Anneke Thompson, May 14, 2019

This was amazing. Just like Jack! Way to go girls on the run!

—Mandi Goff, May 14, 2019

Wow, loved the creativity, girls, and what a thoughtful way to encourage Jack!

—Carole Moresi, May 17, 2019

playing hooky tomorrow

Kim Ryan, May 14, 2019

Jack had his labs checks this morning and they looked okay. His fibrinogen was 155 after 2 units cryo yesterday!!! Yay! So they said we get to skip tomorrow's appts!!! Thursday he will have labs and VP-16 (chemo in his picc line) and cryo if needed. Friday he will have labs and an LP and intrathecal chemo (spinal fluid tested for the HLH cells and chemo in his spinal fluid). At that point they will let us know what the weekend holds.... Monday he will once again have labs and the VP-16.

We are so excited to have the day off tomorrow! It should be beautiful outside so we'll have to spend some time outside for sure!

Sent from CaringBridge iPhone app

Comments

Glad he gets to enjoy a 'day off.' Keep fighting Jack!

—Angela Hogan, May 15, 2019

Congrats Jack on your day off!!! Hope you're doing well! We miss you!

—Heather Huebner, May 15, 2019

catching up...

Kim Ryan, May 18, 2019

I've been slacking at the updates. I'm sorry. Jack had an appt Thursday and Friday. Labs and VP-16 Thursday. He also needed 2 units cryo due to low fibrinogen. They also started him on a low dose of blood pressure medication. He has been slowly trending upward. This is a common response being on the decadron (steroid). Friday his fibrinogen was 133 but they still gave him cryo due to having the LP and chemo later that day. This time they gave him 3 units. Based on his weight he can get 2-3 so they opted for 3 this time. His platelets also havd started trending downward. Thursday they were 120 and Friday were 90. The concern was the rate of decrease. We were hoping he could make it until Monday for an appt but they want to see him Sunday morning on the HOT unit for a lab draw to be sure his platelets aren't too low and to double check his fibrinogen. If his platelets are 50 or below or fibrinogen 100 or below, he will be admitted tomorrow morning. Otherwise, he has his regular appt Monday for labs and VP-16. He tolerated both chemos well this week and is such a trooper! He has been very sleepy and having a tough time moving around after so many LPs. His back has been really sore.

However, he was very excited to spend a little over a day upnorth this weekend! Although it was a quick trip, it was much needed for him. The kids got to introduce Dakota and Ali too!

Sent from CaringBridge iPhone app

Comments

Thank you for the update Kim. All of you are doing such an awesome job. We love you and are so proud of each of you.

—Diane Ellis, May 19, 2019

NO ADMISSION, YAY!!!

Kim Ryan, May 19, 2019

Platelets 83 and fibrinogen 151! No admission! Back tomorrow. Happy to go home for the rest the of the day! Yeah!

Sent from CaringBridge iPhone app

Comments

Kim, we would love a shirt! Size Adult XL. Please tell me how to order one!
Love,
Jenni Sprague and family

—Jenni Sprague, May 19, 2019

Hi Jenni,

The ordering has been closed for a few days but I can see if they will let jeremy add any more. He tried asking already and he's waiting for a response. I will let you know when I hear. Thank you ♥

—Kim Ryan, May 19, 2019

Jeremy was able to add more shirts so your order is in. ☺☺

—Kim Ryan, May 21, 2019

Great! Just let me know how to pay!

—Jenni Sprague, May 22, 2019

The easiest way now might be Venmo or mailing a check. I can get it to Jeremy

then. Or if another way is easier. Doesn't matter to me. We appreciate your support ☺☺♥
let me know if you need my name on Venmo or my address.

—Kim Ryan, May 23, 2019

That's great news!!!

—Melinda Schmidt, May 19, 2019

So proud of Jack. Keep up the great work Jack!!

—Kelly Francois, May 19, 2019

admission tonight

Kim Ryan, May 19, 2019

Jack was having some pain issues and difficulty moving around/ doing normal activities so his doctor suggested he go to the ER and will be admitted from there. He also is having increased neuropathic pain. He said the steroids can cause bone pain so this might be what Jack is experiencing on top of having so many LPs. They are giving Jack morphine in the ER then plan to start a PCA pump (patient controlled analgesia) when they get to the HOT unit. Jack will be able to control the amount of medication he gets and they will base what they send him home on by how often he pushes the button. Jack is a tough cookie. He has been so strong and brave. I am so glad he will be able to get a comfortable nights sleep tonight!

Sent from CaringBridge iPhone app

Comments

Praying for you Jack!

—Lindsay Deinhammer, May 19, 2019

Praying for comfort Jack! Here's to a good night's sleep for you. Sorry to hear your in discomfort.

—*Debby Trewyn-Way, May 19, 2019*

I'm so sorry Jack that you are dealing with this additional pain. We all hurt with you. Prayers continue for not just a healing but a total Miracle for you. Prayers for the family and your mama Kim as I know a mother's heart...Lifting you all up for peace, comfort, wisdom for the doctors to be aware of any new idea to reach the goal of a total healing! Praying, Faith Believing!!! Hugs and Love

—*Connie Coleman, May 19, 2019*

Praying for comfort for Jack

—*Melinda Schmidt, May 19, 2019*

Jack you are an amazingly strong and brave.
Thinking of you ☺☺
Love Aunt Barb

—*Barb May, May 20, 2019*

I hope he was able to get a good night's sleep! Hugs to you and your babies.

—*Rebekah Raleigh, May 20, 2019*

Love you Jack! Aunt Kathy is praying for you! You are strong buddy.

—*Kathy Sturycz, May 20, 2019*

what.a.day

Kim Ryan, May 21, 2019

It's great that Jack was admitted because his pain is now under better control. He will be going home with pain medication as needed. He has been moving around much better now too and doing a great job being independent with it. He rarely wants us to help him.

Monday his labs were ok and got the VP-16 as planned. They switched him from iv pain medication to oral so wanted to keep him another night to be sure he was comfortable and moving around well.

This morning his labs were on the low side. Platelets were 52 and fibrinogen 92. He got platelets and 3 units of cryo.

He was supposed to have an MRI today but was an add on so unfortunately couldn't eat all day due to needing to be sedated. The scan didn't happen so he went quite a while without food. Poor kiddo! Telling a kid on steroids he can't eat for over 12 hours is terrible! But he was a trooper. They canceled it and hope to shoot for Thursday instead. His are tricky to plan because it's like booking 2, head and spine.

THEN....We were minutes from discharge and he went to pick out a toy with his nurse when someone came to the room to say Jack fell in the hallway. This was very scary as I'm sure you can imagine. He is at risk for bleeding with his numbers where they are at anyway but THANK GOD he got platelets and cryo today to bump the numbers up even a little. We went straight to CT. The scan came back ok! We are here another night to keep a close eye on him. He has been doing ok. Waking him every 4 hours for neuro checks. He has got to be the strongest kid I know!!! I am so very proud of him!

When we got back to the room they drew labs. Platelets were 125 and fibrinogen 184. He has a nice bump and bruise to his forehead but I am so thankful to God that he is okay!

Likely discharge tomorrow if nothing changes. Thursday labs, VP-16 and possible MRI and Friday labs, LP and intrathecal chemo,

He watched a little hockey tonight and is sleeping soundly after a crazy day.

Sent from CaringBridge iPhone app

Comments

So thankful he is ok!!

—Melinda Schmidt, May 21, 2019

Constantly praying fir you guys!!♥

—Kelly Delaney, May 21, 2019

Jack
You are amazing!!!
Love Aunt Barb

—Barb May, May 21, 2019

Praying for strength everyday! Jack YOU ARE A TROOPER BUDDY! So proud of you Jack!
Love you all!

—Kathy Sturycz, May 22, 2019

Jack, You are one STRONG kiddo! Praying that you can manage your pain and that your counts stay where they need to be!

—Debby Trewyn-Way, May 22, 2019

Praying for you all—for strength, peace, and complete healing!!

—Lindsey Waggoner, May 22, 2019

Praying for you Kim & Jack! Let me know if I can do anything at all! ♥

—Alyssa Karasti, May 22, 2019

Give Jack a big hug from us ! He is such a tough kiddo ! Thinking about you all every day.

—Katie Lebron, May 22, 2019

Hugs to you and Him , so scary! Prayers for you-Kim and Jack! For strength and peace and God's love around you.

—Jenni Sprague, May 22, 2019

What an amazing son you have! You both must be so very proud of him!

—Paula Lattergrass, May 24, 2019

Kim, ihope you're taking care of yourself too.thinking of all of you and praying!

—Kathy Zaffiro, May 28, 2019

May 30, 2019

Kim Ryan, May 30, 2019



I'm sorry for the lack of updates. This has all been overwhelming. Last Friday Jack was admitted to the HOT unit with Shiga toxin infection from E. coli in his stool. Although he is immunocompromised, he seemed to be hanging in there. A couple days later he began showing signs of developing HUS (hemolytic uremic syndrome). This is a complication from the E. coli infection where his platelets clump together and make it difficult for his kidneys to function well. This is more complicated for Jack because his platelets are already low. The more platelets he gets infused due to being very low, the worse his kidney function becomes.

They needed to put in a Foley catheter so he was given Ativan for comfort during the procedure. Jack had a difficult time waking up from the medication and hasn't been

himself since. He was saying some things that made sense but others that were out of context or babbling. His temp was 102.5. At 2 am on Tuesday morning Jack was transferred from the HOT unit to the critical care unit.

Jack was started on CVVH (continuous dialysis at his bedside) to help with his kidney function. He has a blood stream infection and is septic. They also found a blood clot in his brain. At this point there is blood flowing on both sides of the clot so they are watching it closely. They would typically give blood thinning medication for this but in Jack's case they cannot due to his labs. He is on long term EEG monitoring to see if he is seizing. Jack has been having jerking movements. So far they don't see seizure activity but are keeping it on as his neurological status has not improved.

Jack's abdomen is very distended. It has gotten worse over the past couple days. He is in obvious discomfort. Today, interventional radiology is going to do a paracentesis at his bedside which basically means they are going to put in a drain to get the fluid out. We hope this helps jack feel more comfortable overall and easier to breathe.

Some of Jack's numbers are looking better due to the dialysis. We are trying to figure out what is causing the neurological part of this. We are told that Shiga toxin can do this as well as a few other possibilities, one being the fact that he has not gotten any meaningful sleep for a couple days.

Jack is fighting hard and is such a amazing kiddo! Please please please keep him in your prayers as he fights this fight to get through this super crappy journey.

Thank you so much for the love, support, and prayers!

Sent from CaringBridge iPhone app

Comments

Always praying!!!! Jack we love you so very much!!! Keep fighting buddy!!!

—Emily Dumovich, May 30, 2019

Oh Kim.... I'm SO sorry!! I'll be on West 5 on Saturday!!! He's a fighter!! He'll get thru this!! BIG HUGS my friend!!!

—Kristen Szajna, May 30, 2019

So many people are praying for you Jack! ♥

—Heather Ray, May 30, 2019

We are praying hard for you Jack and the rest of the family through this battle!! ☐☐

—Jacquie May, May 30, 2019

Praying hard for you Jack, keep fighting buddy ! ♥

—Jennifer Dye, May 30, 2019

We are praying for you all☐☐ Keep fighting Jack

—Kate Johnsen, May 30, 2019

Saying lots of prayers for Jack! He's so tough, I know he can fight through this!

—Madeline Meier, May 30, 2019

Aw this sweet boy! We've added him to our nightly prayers. Please let us know if you or Jeremy need anything throughout the days; we can run them up to you. Or if you need help with Kenz. Keep fighting buddy. Thinking of you all always. ♥

—Heather Dumovich, May 30, 2019

Sending extra prayers for Jack & family. JACK keep fighting!!!!!! Kim let me know if there is anything else I can do.

—Sunny Nelson, May 30, 2019

Sending hugs and prayer along with full hearts of love to you. Your momma talks alot about you at work. She says how strong you are and how much she loves you and your sister. You are such a brave young man. Kim you are such a great momma.... Our continued love is sent to you.

—Clare Young, May 30, 2019

We are praying as much and hard as we can! Love to all, The Holcomb's

—*dennis holcomb, May 30, 2019*

Kim never apologize for being late in updating us. You have your job as "jack's mom, caretaker, and Kim the person" dealing with all of this overwhelming journey. I received my "Jack" shirt the other day and I'm wearing it today and it's a constant reminder to be praying for all of you. When I'm not wearing it, I'll hang it in my room so I can look at it and continue to pray for ya'll through this journey. You have alot of cheerleaders and prayer warriors praying and supporting you.

—*Connie Coleman, May 30, 2019*

Praying and praying up in Eagle River. Sending healing and positive vibes.

—*kristin beyer, May 30, 2019*

Stay strong Jack!! We are all praying for you!

—*Melinda Schmidt, May 30, 2019*

Praying in Oshkosh for our Jack! God is with you. Love you all

—*Julie Sturycz, May 30, 2019*

I will continue to pray for strength and healing for Jack and your family , Kim

—*Luanne Dikanovic, May 30, 2019*

He is constantly in our prayers. I hope that he turns around soon. Please let us know what we can do to help

—*Angela Anderson, May 30, 2019*

Continued prayers for you all.

—*Cindy Baumann, May 30, 2019*

You don't know me, but my cousin Karen asked me to pray and that's what I've been doing. Jack is a brave soldier.

—*Jennifer Hines, May 30, 2019*

Never stopped praying for both Jack & you! We love you & I'll evoke prayer warriors again & again until this is over!

—Brenda Stratton, May 30, 2019

Father God give Jack the strength to fight and fight hard! Heal his body from this illness. I pray this in the precious name of Jesus . Amen. I love you Jack.

—Kathy Sturycz, May 30, 2019

Dear Jack and family, praying for strength and recovery. Sending love and hugs. Please stay strong. ☺☺

—Sue Behrendt, May 30, 2019

We are praying for him everyday Kim.

—Amy Novitski, May 30, 2019

Sending prayers! I think Jack's mom is pretty strong too. Keep it up Kim, you got a lot of love behind you!

—Shelly Petrick, May 30, 2019

Keeping you all in my prayers. Jack is a fighter!

—Jessica Lyons, May 30, 2019

Sending lots of love and prayers to you all ♥☺☺

—Jeri Wade, May 30, 2019

Love and prayers for you all. Stay strong and pick each other up.

—James Ricchio, May 30, 2019

Praying for Jack.

—Carole Moresi, May 30, 2019

Sending love and prayers☺☺
Jack you are an amazing kido !!!

—Barb May, May 30, 2019

Our thoughts and prayers are with you. Keep fighting♥ The Licht Family

—Megan Licht, May 30, 2019

Our family will keep Jack in our thoughts and prayers!

—Tracy Butler, May 30, 2019

Jack will be in our thoughts and prayers. Sending love to you and your family. Stay strong jack☐☐

—Heather Leedle, May 30, 2019

Jack will be in our thoughts and prayers. Sending love to you and your family. Stay strong jack☐☐

—Heather Leedle, May 30, 2019

Praying for Jack so much Kim.. love you

—Kelly Young-Quadraccia, May 30, 2019

Praying for you guys... Stay strong Jack.

—Katherine Becker, May 30, 2019

Praying for you Jack!! Stay strong! You have a huge team here supporting you!

—Abbey Lang, May 30, 2019

Kimmie- we are thinking and praying for you. Lots of love to you. Please please don't be afraid to ask for help. Let us know if you need anything!

—Becky Lanser, May 30, 2019

I am there in spirit with you and please know Jack is a tough young man and will fight hard. I always have you guys in my thoughts and prayers.

—Mike Zoerner, May 30, 2019

Thinking of you and saying lots of prayers! Stay strong Jack, you got this!♥

—Angela Hogan, May 30, 2019

Sending Virtual Hugs of comfort and strength for ALL of you as you endure as you say - "crappy journey". Wish we could do more from here but feel confident Jack's medical team is doing any and everything possible to make him comfortable and get him through this rough part. BIGGEST HUGS ~

—Sally Price, May 31, 2019

Stay strong Jack ! You'll move beyond this "Crappy Adventure" . Praying for you and your family.

—Debby Trewyn-Way, May 31, 2019

Prayers for Jack and your whole family!

—Trina Robshaw, May 31, 2019

Thinking of you every day Jack! I know your Dyer school family is sending so many positive vibes for you and your family every day! Your strength and spirit are an inspiration! ~ Mrs. Hoesly

—Becky Hatfield Hoesly, May 31, 2019

The Andersens are praying for Jack and his family. God bless all of you through this difficult fight. Hugs and prayers.

—Vickie Andersen, May 31, 2019

The Andersens are praying for Jack and his family. God bless all of you through this difficult fight. Hugs and prayers.

—Vickie Andersen, May 31, 2019

Kim, thinking of you guys so much. I will keep sending prayers and positive thoughts your way. I'm here in the hospital, so please let me know if there is anything I can do for you. Xoxo

—J Landgraf, May 31, 2019

Stay strong Jack. Praying for all of you and hoping things turn around soon and he's feeling better! Love & Hugs

—Brends Sutcliffe, May 31, 2019

We are praying for you every day Jack! You've got this buddy. HLH has a new enemy.

Do not fear, for I am with you. Do not be afraid, for I am your God. I will STRENGTHEN you and HELP you. I will uphold you in my righteous right hand.

Isaiah 41:10

—Amber Gilroy, May 31, 2019

Praying for you Jack! May the lord lift you up and give you strength to fight this!! ☺☺☺

—Patty Pias, May 31, 2019

Sending prayers to Jack and your whole family☺☺

—Diane Eliason Misina, May 31, 2019

Prayers to you and Jack! So hard to see our babies going through this. Prayers for peace, healing and strength! <3

—Jenni Sprague, May 31, 2019

Praying continuously! ☺☺♥

—Nicole Stern, May 31, 2019

Jack,

Your classmates think of you everyday. The other day we did "choose how you wanted to be greeted" . They did "Jack wants to be greeted in a loud voice" and they all shouted good morning to you. So we are all cheering you on! Keep tackling this and giving it all you've got! You are the strongest, most determined kid I know.

—Anneke Thompson, June 1, 2019

Praying for a full healing and recovery....that His Shalom and Word give you all comfort, encouragement, and hope..."we are over comers by the Blood of the Lamb and the testimonies of our mouth" And you, Jack, are purposed and blessed by our Heavenly Father who created you with anointing, gifts, and purposes only you can fulfill...God bless you with divine strength, peace, and comfort...in Jesus name, Amen♥♥♥

—Rene Hughey, June 1, 2019

Kim, you may not remember me but I met you and Jack at Nicole's wedding. She told me everything that he's going through and I wanted to let you know that I'm praying for him. I'm sending my prayers for Jack and your whole family to have the strength, trust and faith to pull through this scary journey.

—Destiny Mack, June 2, 2019

Kim we are praying!! Love u and ur family! (Hugs)

—Heidi Beernink-Rivers, June 2, 2019

How is Jack today?

—Jenni Sprague, June 2, 2019

Sending Jack many prayers!!!

—Jennifer Holle, June 3, 2019

June 04, 2019

Kim Ryan, June 4, 2019

I don't know where to begin... Jack is such a strong kiddo and such a fighter. This is difficult for me to do right now so here are big things going on with Jack. He is not neurologically himself and has not really meaningfully communicated with us for a couple days. This could be for a number of reasons and they are trying to figure that out. One being the HUS. The renal Dr said that HUS can affect neuro status for up to 3 weeks but with everything else Jack has going on his other docs are continuing to rule out other things to be sure. The clot in Jack's brain has gotten bigger but there is thankfully still a little room for blood flow through the vein. His body has compensated with the flow so there is not increased pressure at this time.

They took him off CVVH yesterday afternoon and wanted to see how his kidneys handled it for the night. Today they are trialing intermittent hemodialysis. He will have it for 2 hours today. After that, he will have an LP to get steroids as long as his platelets are ok. The LP is to check if he has anything going on in his spinal fluid as well as to give the

steroids. He cannot get the intrathecal chemo as he was due to his current kidney problems and neuro issues. That chemo can cause neuro issues with kids and they don't want to get that into the mix with his current state.

I think I covered the big stuff. He is still having sleep issues but thankfully got a few solid hours last night.

Again, thank you for the prayers and please keep praying hard. ♥

We love you all!

Sent from CaringBridge iPhone app

Comments

Many prayers for Jack and all the family!!!

—Jason Callewaert, June 4, 2019

We're all praying for you, Jack, and your whole family!

—Diane Eliason Misina, June 4, 2019

You are all so strong! We are praying for you.

—Rebekah Raleigh, June 4, 2019

We are praying every day for Jack

—Angela Anderson, June 4, 2019

Thinking of you and the family. Praying for Jack to get better.

—Alice Polzin, June 4, 2019

Continued prayers !! ♥

—Jennifer Dye, June 4, 2019

Stay strong Mom! But take care of you too! Praying for you all!!

—kristin beyer, June 4, 2019

Praying every day that God would bring you courage, strength and peace. Jack is definitely a fighter. He knows he has some important things to do. Stay strong!

—Jennifer Hines, June 4, 2019

Our thoughts and prayers are with you.

—Sharon Stollenwerk, June 4, 2019

Stay strong Kim and we will all keep the prayers coming!!

—James May, June 4, 2019

Praying!!!

—Melinda Schmidt, June 4, 2019

Praying for answers, wisdom for the doctors, quick painless treatments for lil'Jack. Hugs to you Kim

—Connie Coleman, June 4, 2019

Kim and Jeremy and Jack

My Prayers have been going everyday. Please stay strong and know all your Family is here for you All!

Love you guys

—Chris Smith, June 4, 2019

You are an amazing kiddo ☺☺

—Barb May, June 4, 2019

Please stay strong Jack, Kim and family. You are in my thoughts and prayers continuously. Jack, you have so many people in your corner loving and praying for you. ☺☺

—Sue Behrendt, June 4, 2019

Prayers to you all!

—Jen Nelson, June 4, 2019

Jack, this truly is a "Crappy Adventure"! We're praying for you and asking for strength for you & your family. You've got a ton of friends rooting for you! Hugs to you

—Debby Trewyn-Way, June 4, 2019

My thoughts and prayers are with you and your family everyday!! Hugs to everyone♥
Amazing little fighter and so brave Jack!!

—Tanya Purdy, June 4, 2019

Kim,

You must be the strongest person I know. I think about you and Jack all the time and wonder how you are holding up. Tell Jack hello from all of us!

—Anneke Thompson, June 5, 2019

Thinking and praying for Jack so often throughout the day!! Praying also for you, Kim, and the rest of your family. Stay strong! Big hugs to you from afar!

—Marcy Hafeman, June 5, 2019

Jack...stay strong kiddo! Praying for you and think of you often.

—Siri Walby, June 5, 2019

Hugs, kisses and prayers for my precious Jack. Love you buddy. Auntie Kathy

—Kathy Sturycz, June 7, 2019

Praying for Jack and wishing him comfort and healing.

—*sheri rocco, June 7, 2019*

So very sorry to hear of Jack's update. We don't know each other yet, but I first learned about Jack from the Tee it up fore Ty event that my husband and I have been part of over the years. The reason I'm reaching out is to give your doctors another resource through the doc to doc aHUS foundation, located here: <https://www.ahus.org/doc-to-doc> Last year my husband was diagnosed with aHUS- it's very rare but through this journey the last yea...he has made good progress and we have met many people and children with this illness. I reached out to my facebook ahus family group this morning to see if any of them had children with positive shiga toxin results (STEC+) that turned out to be ahus and several did. I trust that you have great doctors and they are doing all that they can for Jack. The doctors listed above know about HUS and aHUS and I just wanted to offer what I could to help. For ahus patients, there is an orphan drug called Soliris or eculizumab that many have used with positive outcomes. Lastly, the Froedert doctors that we see are Kenneth Friedmann, hematology and Dr. El Meanawy, nephrology, they may be worth mentioning to your team. I am praying for you and your family!

—*Carrie Wilks, June 7, 2019*

Hi Carrie,

Thank you for the message and information. They have mentioned this drug and have it in the back of their minds if needed. From what I under from them, they use it in the kind of HUS the kids can get post bone marrow transplant. Jacks team of doctors were doing back and forth if it would be a drug good for him since this is different. When I looked it up, it says it is not good for Shiga toxin HUS but is for the others. Did the families with kids that had Shiga toxin HUS receive the drug? Are these families local?

Thanks again,
Kim

—*Kim Ryan, June 8, 2019*

Glad to hear your docs are aware of Soliris. It
Is a complement mediated

Medicine so it may not be right for Jack. Protocol is to take with antibiotics. Yes, kids with stec+ received the drug with good results. One mom commented on this in particular the other day. She's in Canada I believe. I don't think anyone is local though.

—*Carrie Wilks, June 9, 2019*

Thank you Carrie! They actually decided to start it tonight since his recovery isn't as quickly as they were hoping especially neurologically. The Bone marrow transplant

team was always for it but others weren't so it was brought up a few times. Nice they're all in agreement it's worth a shot. Thanks again! I'll let you know how it goes. ♥

—Kim Ryan, June 14, 2019

Jack and Family you are in my prayers.

—Margaret Babinski, June 8, 2019

If you can think of anything we can do let us know. Prayers are still with you all. Much love

—Karen Peltier, June 8, 2019

Jack- sending prayers from our family to yours!!

—Jennifer Holle, June 8, 2019

Praying so much for Jack, he is such an amazing fighter. Continuing to pray everyday

—Kelly Young-Quadraccia, June 9, 2019

June 11, 2019

Kim Ryan, June 11, 2019

I appreciate all the thoughts, prayers and kinds words from each of you as we go through this difficult journey. Jack has had a few setbacks. He is still fighting hard in the ICU. He had to have another PICC line placed so he has more access. They also placed an arterial line to more closely monitor this blood pressure. He is back on CVVH to help with his fluid balance. Please continue to pray hard and send positive thoughts. He's fighting a hard fight and is such a strong kiddo.

Sent from CaringBridge iPhone app

Comments

Prayers coming your way Jack! ☐☐

—Lindsay Deinhammer, June 11, 2019

Kimie- we are all rooting for Jack and keeping you all in our prayers! ♥

—Becky Lanser, June 11, 2019

Continuous thoughts and prayers for Jack, and his family. Strength and love for all. ☐☐

—Sue Behrendt, June 11, 2019

Keep up the fight Jack! You've got a lot of prayer warriors. Hugs to you Kim

—Luanne Dikanovic, June 11, 2019

Praying for strength and courage for all of you. Keep fighting Jack!

—Jennifer Hines, June 11, 2019

Prayers are being sent up Jack! You've got this! Stay strong and keep on fighting.

—Debby Trewyn-Way, June 11, 2019

Continuing to pray for Jack & his family .

—Sunny Nelson, June 11, 2019

Stay strong and fight this Jack!

—Anneke Thompson, June 11, 2019

Will continue to pray☐☐☐☐†

—Rene Hughey, June 11, 2019

Praying for you all, strength and positive vibes sent your way ! Keep fighting Jack ! ♥

—Jennifer Dye, June 11, 2019

Prayers for strength as Jack continues his fight♥♥

—Patty Pias, June 11, 2019

Stay strong Jack!

—Angela Hogan, June 11, 2019

Sending lots of strength and prayers for Jack and the rest of his family. Stay strong lil man.

—Shayla Pitlik, June 11, 2019

Praying. And praying some more. ((Hugs))

—Heidi Beernink, June 11, 2019

Praying for all of you!

—Paula Lattergrass, June 11, 2019

Praying so hard for Jack and for all of you! Sending much love and hugs always☺☺

—Sue Dumovich, June 11, 2019

What a trooper you are Jack! Praying for you buddy! Love you.

—Kathy Sturycz, June 12, 2019

Prayers for Jack. Prayers for the family also.

—Margaret Babinski, June 12, 2019

Lots of prays and positive energy coming your way!

—laura pulda, June 12, 2019

Praying for all of you!

—Alice Polzin, June 12, 2019

Prayers for all of you!

—Trina Robshaw, June 12, 2019

Wow. So intense! I'll keep praying for him and your whole family...

—Jackie Bladow, June 12, 2019

Praying for all of you. Sending all my positive energy to all of you! Love and hugs to all of you

—Chris Smith, June 12, 2019

Praying that our God, the ultimate healer, will be with Jack. Praying for Jack and all of you
♥☐☐

—Janet Brown, June 12, 2019

Kim- Jack continues to be in my thoughts and prayers. Your work family loves you and is praying for you! ♥

—Cori Matuszek, June 14, 2019

Praying for you to get better. Love you. Great Grandma.☐☐☐☐

—Betty Ellis, June 15, 2019

Praying for Jack & family.

—Nancy Gentz, June 16, 2019

Prayers ☐☐☐☐ Please let me know if there is anything I can ever do for any of you.

—Molly Simmert, June 16, 2019

I'm praying for you all.

—Katelyn Lasse, June 23, 2019

Jack and family, you are always in my thoughts and prayers. Be strong, love to all.

—Sue Behrendt, June 29, 2019

Keep fighting Jack, we're praying for you every day.

—Nancy Gentz, June 30, 2019

Sending love and strength from the Millers xo

—angela miller, July 1, 2019

July 06, 2019

Kim Ryan, July 6, 2019

Jack has had a busy few weeks. He is keeping us on our toes and fighting harder than I've ever seen anyone fight. On a very positive note, Jack is finally back to himself neurologically, which we are so grateful for. Today marks 7 weeks of being inpatient which is hard to believe.

A couple weeks ago Jack was in severe septic shock and had emergency abdominal surgery. They were unsure how he was going to do during and immediately following the surgery. Against the odds, Jack did great that first night and has continued to improve from that aspect. We are still waiting for his kidneys to kick into gear but need to give them a chance to be forced to do work. He has remained on the continuous dialysis. Sunday night he will be taken off continuous dialysis and the intermittent hemodialysis will be starting Monday. He also has an LP and a scan to look at the clot in his brain earlier in the day on Monday.

Since Jack has basically been in bed for 6 weeks, he is weak. Physical and occupational therapy have been big parts of his days lately. They each come twice a day and he works very hard to get his strength back.

One of the hardest things for Jeremy and I to see in Jack is the sadness that he has that he cannot be enjoying the summer like a "normal" kid and like he knows he typically would be. He misses being outside and playing with Kenzie, cousins and friends. He even told me tonight after seeing a picture of me and Kenz that he misses sitting in a car. I thought it might be fun for Jack to get mail from once in a while from some of you amazing family and friends following his journey (that turned out to be even crappier

than we could have ever imagined). I have a room at the Ronald McDonald House so it can be sent there. I think uplifting notes, cards or drawings would make his day! And, we can decorate his room with them when we get over to the HOT unit.

Ronald McDonald House c/o Jack Ryan (Or Kim)

8948 W Watertown Plank Rd

Room 113L

Wauwatosa, WI 53226

I will post an update later in the week to let you know how he tolerated the switch to hemodialysis.

Again, I thank you all for the continued prayers and support! ♥

Sent from CaringBridge iPhone app

Comments

Continued prayers for all of you!!! Jack is proving to be an amazing little guy!!! Stay strong!!!

—Jason Callewaert, July 6, 2019

Thanks for the update. Thinking of all of you & praying you. Stay strong Jack you've got this. You are a tough cookie ☺☺

—Brenda Sutcliffe, July 6, 2019

Thanks for the update Kim! ☺☺. Thinking and praying every day. What a wonderful idea of mail for Jack!! Will send something this week. Prayers, hugs and love to all.

—Sue Behrendt, July 7, 2019

Keep fighting Jack, many prayers sent your way!

—Jennifer Dye, July 7, 2019

Praying for the family.

—Alice Polzin, July 7, 2019

Keep up the fight Jack!! You got this!!!

—Kristen Szajna, July 7, 2019

Praying for Jack & family.

—Nancy Gentz, July 7, 2019

So happy to hear the good news! Jack is getting better, what a strong kiddo --will get a card in the mail for him :)

—sheri rocco, July 7, 2019

Thank you for the update. We're continuing to pray for you and your family during this "Crappy Adventure"! You've got this Jack!

—Debby Trewyn-Way, July 8, 2019

Lifting Jack up in our prayers. May God provide strength in his healing , especially as he coverts to hemodialysis.

Thank you for the update and address to send our love and support to all of you in hopes of brightening Jack's day.

—Jane Pierce, July 8, 2019

Lifting Jack and all of you in prayer. Giving thanks for the progress and the fact that he's back neurologically. Keep fighting Jack, God has big plans for you♥

—Janet Brown, July 8, 2019

Always praying and thinking of Jack and everyone! John will be thrilled to send his baseball buddy a picture and a note! Hugs and love ♥

—Lara Shepherdson, July 8, 2019

Hugs and Prayers and sending strength and love your way.

—Mya Rubach, July 10, 2019

Love seeing pictures of Jack with his puppy and watching Kenzie at the candy counter. So happy to know that Jack was able to get outside! Way to go Jack on fighting back and making progress. Continuing to lift up all of you in prayer each day.

—Jane Pierce, July 20, 2019

July 19, 2019

Kim Ryan, July 19, 2019



Again, Jack has had some very busy days the last couple weeks since my update. He was taken off continuous dialysis as planned that Sunday night and tolerated intermittent hemodialysis. This means he was getting dialysis in his room 2-2.5 each day. Jack was on this type of dialysis and doing well for 8 days.

Jack had a productive cough for roughly 4 weeks. Eventually he began spiking fevers randomly but especially at bedtime. He had a chest and sinus CT done which showed areas of concern which were likely bacterial or fungal. (Both can be seen in immunocompromised patients) About a week and a half ago went to the OR for a sinus washout and biopsy and BAL. They inject salt water into the lungs and pull back for a specimen. Bacteria grew back from his sinuses which they are presuming is also what's in his lungs as his fevers have stopped once the antibiotic was changed. This bacteria has also been known to cause nodules in the lungs. He's half way through the antibiotic course.

An ongoing concern for Jack is his abdominal incision. He had staples initially that were taken out 10 days post abdominal closure. His incision began opening pretty quickly. It was being monitored closely with dressing changes being done twice a day. Due to some further concerns, the surgical team decided to open his incision and pack the incision with the dressing changes. A few days ago a small part of his bowel was showing through the incision. They were watching this very closely, hoping it would not get too big and that his body would be healing properly. Unfortunately the area got larger and Jack emergently needed to go back down for surgery. The fear is that his bowel would come through the incision. When this was decided, he was getting dialysis and being prepped to go without for the next day. Dialysis was stopped early and went to the OR.

The doctor told us that the sutures were very loose and it was only a matter of time before that would have happened. We are so thankful Jack went to surgery when he did. He came back with a wound vac. Three days later he was scheduled to go back for a washout and wound vac sponge change. When he came back, he did not have the vac. This doctor decided to close all layers together with special rubber sutures.

The problem is, Jack's wound has not been healing. This is likely from long term higher dose steroids as well as other meds and being compromised. From this point on, he will have more restrictions with sitting upright less than 45 degrees and with therapy for a couple weeks to promote initial healing and we are working on maximizing his nutrition. He has an NG and is working on increasing feeds while decreasing TPN and lipids. He is able to eat food too but has only been taking bites.

The long term plan remains getting Jack to bone marrow transplant. A few things have to happen. His kidneys have to be recovered. He cannot be on dialysis. Jack has not had any dialysis since Monday and has been making roughly 75% of the volume of urine expected from a healthy child his size. His wound has to completely heal. This is a huge hurdle right now. He also has to work on therapy, nutrition and getting strong.

That's our past couple weeks in a nutshell. In between all the craziness and trips to the OR, intubations, and numerous therapies, Jack was able to get up to a wheel chair for the first time and be free from the continuous dialysis to get outside!!! After 52 days of being stuck inside, Jack was able to feel the sun on his face. He was so happy. He also was able to get his bed turned to the side so his back isn't to the window in his room. You learn to appreciate the little things. Jack also got a surprise visit from his puppy,

Dakota!! They snuggled and took a nap together. He made slime with child life and built a small LEGO set. He is beginning to move a little more each day but still needs our help. We also play games and work on workbooks.

We have been here for 9 weeks now with an unknown number left. We want to thank all of you for helping us get this far! Thank you so much for sending Jack cards, pictures and gifts. Every little note brightens his day. They are hanging on his wall. I can't even begin to put into words how amazing it feels to feel the love and support and thank you doesn't seem like enough to say but thank you, thank you, thank you!! ♥

Photos









Sent from CaringBridge iPhone app

Comments

Thinking about you all everyday! I am so happy he got to get out of his room and get outside for some fresh air! Heads up, spirits up and praying for quick wound healing !

—*Dana Monticelli, July 19, 2019*

Continued prayers and hugs daily for Jack, my hero, and for family. ☺. So glad to hear Jack was out and about, got to feel the sunshine on his handsome face. Stay strong little man, you have so many people sending you love and prayers for recovery.

—*Sue Behrendt, July 19, 2019*

Thinking of you all every day! We are so happy that he got to feel the sunshine on his face! Love you guys!

—Katie Lebron, July 19, 2019

Thinking about all of you and praying everyday.

—Angela Anderson, July 19, 2019

Continued prayers for healing ! #yougotthisjack!

—Jennifer Dye, July 19, 2019

Keep it up Jack! You're a strong kid!

—Christian Javier, July 19, 2019

I love that Jack got to get some sunshine and time with Dakota! Hugs to you all. You are in our prayers.

—Rebekah Raleigh, July 19, 2019

Thank you for this update, I think of you every day and wonder how Jack is doing as we face the same procedure here in the UK with our daughter. So glad Jack got to go outside and spend time with his puppy! Sending lots of strength and love to you- you are both amazing.

—Sue Chivers, July 19, 2019

I'm so happy to hear Jack was able to breathe some fresh air and see some sunshine! Kim, thank you so much for taking the time to keep us updated. You all are in my thoughts and prayers every single day! ♥

—Heather Ray, July 20, 2019

Hi Jack! I'm so glad to hear you're getting stronger and you were able to cuddle Dakota! I know how strong you are Jack so keep fighting! Your whole family continues to be in my thoughts and prayers!

—Heather Huebner, July 20, 2019

Some wonderful news in this update! We are so happy that Jack got out of his room for a bit. Will continue to pray that abdominal wound heals quickly and Jack is soon strong enough for the transplant.

—Paula Lattergrass, July 20, 2019

Hope you can feel prayers coming from DC. Even though Jack has a long way to go, so many of those prayers have been answered. Thank you for the additional prayer requests. I'm on it.

—Jennifer Hines, July 20, 2019

Glad you feel the support and prayers from all of us. Your family is amazingly strong and inspiring.

—Carrie Wilks, July 20, 2019

Praying for you to get well.

—Betty Ellis, July 20, 2019

July 21, 2019

Kim Ryan, July 21, 2019

Please pray hard for Jack. The last couple days have been difficult. We think the days off dialysis have caught up with him, he was positive over 5L of fluid and he began having difficulty breathing. His chest X-ray looks crappy. He's now on bipap. They dialyzed him last night in hopes to help but it wasn't enough so are doing it again today and taking off more fluid. Praying he's more comfortable after this so he doesn't need to be intubated.

Thank you so much for praying.

Sent from CaringBridge iPhone app

Comments

Not a day goes by without keeping Jack in our thoughts.

—Anneke Thompson, July 21, 2019

My Prayers are going and have been everyday for this precious boy. Please keep fighting Jack. Jeremy and Kim my heart and prayers are with you All.
Love you All!

—Chris Smith, July 21, 2019

Praying for you buddy!!! Keep fighting☐☐

—Kate Johnsen, July 21, 2019

Many prayers Jack♥

—Dawn Fessenbecker, July 21, 2019

Praying for you Jack! You've got this!!!☐☐☐☐

—Debby Trewyn-Way, July 21, 2019

Praying for some relief today!! ☐☐☐☐

—Melinda Schmidt, July 21, 2019

Sending many prayers!!!!

—Laura Covelli, July 21, 2019

Praying for you Jack! Love all of you!

—Jessica Lyons, July 21, 2019

I'm praying for Jack.

—Margaret Babinski, July 21, 2019

Keep fighting. Sending lots of love and prayers Jack! Stay strong!

—Brandy Bertzyk, July 21, 2019

praying for you sweet Jack ♥ stay strong

—Rebecca West, July 21, 2019

□□□□□□

—Jennifer Dye, July 21, 2019

Many prayers for you Jack□□ You are such a strong little guy. Keep up the fight buddy□□

—Justin Blanchar, July 21, 2019

Praying everyday for you Jack. You can fight this! Hugs to you and your family!

—Sue Seils, July 21, 2019

Thoughts, Prayers for all!!! Wishing and hoping for happier days

—Brock Brockman, July 21, 2019

Prayed in the wee hours this morning and will continue. May God comfort and bring you His peace.

—Jennifer Hines, July 21, 2019

Praying for Jack and you guys daily. ♥

—Heather Dumovich, July 21, 2019

Oh my. Praying that this too shall pass. Hang in there Jack!

Prayers for ALL the Ryans.□□□□□□□□

—Gina Dabbs, July 21, 2019

Praying for healing for Jack and strength for the entire family.

—Pat Dahl, July 21, 2019

Praying for Jack and God's mercy on him.

—Jane Pierce, July 21, 2019

Jack, you and your family are in our thoughts and prayers daily. Keep up the good fight!

—Jan Engberg, July 21, 2019

Keep fighting Jack ... prayers and strength to you!

—Siri Walby, July 21, 2019

Say strong Jack!!! Lots of thoughts and prayers!!

—Kelly Delaney, July 21, 2019

Praying hard for Jack!! ☐☐ Stay strong! ☐☐

—Marcy Hafeman, July 21, 2019

Prayers for your continued fight Jack. You've done an amazing job fighting....you got this Jack ☐☐

—Anna & Larry Littel, July 21, 2019

Praying for the little tough guy and for the family.

—John Kiehlbauch, July 21, 2019

Praying for our precious Jack! Pray without ceasing everyone! Love you.

—Kathy Sturycz, July 21, 2019

Prayers! Keep fighting you got this

—Tim Wright, July 21, 2019

♥ Continued prayers for Jack ♥

—Janet Brown, July 21, 2019

Keeping Jack in our prayers always ☐☐☐☐☐☐☐☐☐☐
Sending lots of hugs to you all♥

—Holly Benzow-Pittner, July 21, 2019

Dear Jack, I know you can fight through this. You are a warrior! Please be strong, we are all behind you. ☐☐

—Sue Behrendt, July 21, 2019

Praying for you Jack!

—Greg Robotti, July 21, 2019

We're praying for you daily Jack. Stay strong and know our Lord has his arms around you. Big hugs from Bob and me.

—Connie Podgorski, July 21, 2019

So many prayers going to Jack ☺☺☺☺

—Aimee Preuss, July 21, 2019

Oh Kim.my heart hurts for you! Know that all of you are in my constant prayers!!!

—Kathy Zaffiro, July 21, 2019

My prayers are with him every day! ☺☺☺☺☺☺☺☺☺☺

—Heather Ray, July 21, 2019

Dear Jack
We are praying really hard for you ☺☺
Karen and Jerry

—Karen Peltier, July 21, 2019

Hugs and prayers!!! Keep fighting Jack!!

—Jenell Jackley, July 21, 2019

Praying always for Jack and all the family He has been through so much He is so strong. Will make it through this too. We love you buddy.

—Joann Ryan, July 21, 2019

Lots of prayers from our family to yours ☺☺

—Shauna Renee, July 21, 2019

Will be praying...wishing Jack and you all an overflow of strength, refreshing, hope, divine and supernatural healing and recovery... we ask in the MIGHTY NAME OF JESUS!!!AMEN!!!☺☺☺☺☺☺☺☺☺☺♥♥♥

—Rene Hughey, July 21, 2019

Will be praying...wishing Jack and you all an overflow of strength, refreshing, hope, divine and supernatural healing and recovery... we ask in the MIGHTY NAME OF JESUS!!!AMEN!!!
❤️❤️❤️

—Rene Hughey, July 21, 2019

Praying for you Jack. Kim you are such a strong and beautiful person. I still remember all the love you gave my little boy when we were there for so long. Sending you lots of love and prayer. Hang in there Jack you will get through this.

—Jazmin Silva, July 22, 2019

Prayers from PA Dante and Jessica's gram Betty and aunt Bonny ! Keep fighting little guy

—Bonny Geffert, July 22, 2019

Sending many prayers your way!!!!
The Holle family

—Jennifer Holle, July 22, 2019

Sending prayers from my family!

—Stacey Wallace, July 24, 2019

July 21, 2019

Kim Ryan, July 21, 2019



Thank you to everyone who has sent cards and pictures to Jack. This wall is directly in front of his bed. I'm sure he feels the love.

Photos



Sent from CaringBridge iPhone app

Comments

Sending love and prayers to Jack and all of you.

—Margaret Babinski, July 21, 2019

July 27, 2019

Kim Ryan, July 27, 2019



Wanted to send out a quick update...

Thankfully Jack was able to continue on bipap without any problems. He was on high settings initially but was weaned down as of yesterday. He transitioned to high flow nasal canula during the day and bipap at night. If all goes well, he can stay in the high flow.

He has been receiving intermittent hemodialysis again and recently began every other day since Thursday (so 2 days without so far). He's handling this okay. His lungs haven't improved as much as we'd like but they haven't gotten worse.

Jack's abdominal incision is a main focus right now. He is now at full feeds via NG tube. High protein, high calorie feeding is very important for wound healing. They also cut his steroid dose in half again in hopes this will help promote healing. We have to keep a close eye on him with cutting back on steroids as steroids were the only thing that would calm his neurological symptoms when he first became sick. He is now on a lower dose. I

worry about this but the HLH dr reassures me that she thinks it's ok. He hasn't had an LP in quite a while due to being unable to be positioned properly because of the abdominal incision and he can't get an MRI due to his respiratory status and needing to leave the floor.

All that said, he had a great day today because he surprised Kenzie by sitting up in a wheelchair for the first time again when she came to visit. Until yesterday he was very limited with movement to help his incision heal. He is beginning to move his arms and hands more. Jack also has been playing a little ps4 and Nintendo Switch.

Jack continues to amaze us with his strength everyday.

Thank you all for continuing to pray and follow his journey along side him. We tell him daily about all the prayers, love and support he has.

Sent from CaringBridge iPhone app

Comments

WOW Jack you amaze me. Continue to fight, little CHAMP. GOD is looking over you. I will continue to send prayers FOREVER. Sending LOVE & PRAYERS.

Love,
Sunny

—Sunny Nelson, July 28, 2019

Praising God for the good news - keeping fighting Jack! You are awesome. Prayers being said for all of you.

—Jane Pierce, July 28, 2019

Amazing ! Keep up the fight Jack! You got this! ☺☺ continued prayers!

—Jennifer Dye, July 28, 2019

Continued prayers for Jack. He is an amazing fighter. Pictures are so sweet. Thank you!

—Jennifer Hines, July 28, 2019

Good news! Continued prayers for healing and strength. And what a sweet picture of Kenzie and Jack. ☺☺

—Lindsay Deinhammer, July 28, 2019

You've got this Jack! The picture of Kenzie & Jack melts my heart☺☺

—Debby Trewyn-Way, July 28, 2019

You've got this Jack! The picture of Kenzie & Jack melts my heart☺☺

—Debby Trewyn-Way, July 28, 2019

Awwww!! I love that picture. The power of God's love and love from family and friends will bring all of you through this horrible journey. Praying daily for Jack and all of you.

—Jackie Bladow, July 28, 2019

I am so sorry to hear all that you guys are going through. I am lifting Jack up in prayer to our Savior Lord. Praying for strength and total healing along with wisdom and for you and the doctors as you fight this awful disease.

—Nancy Schmidt, July 29, 2019

I will continue to pray for your son and all of you.

—Maureen Klotz, July 30, 2019

update and some news

Kim Ryan, August 12, 2019



Jack has been doing WELL!! We are cautiously optimistic given all this kiddo has been through and all the curve balls he has thrown at us the past 3 months.

Last week he went 3 days without dialysis and this week today was his 3rd day off. From here on out the need for dialysis will be assessed each day and we'll go from there. He is still looking great. His numbers are great and he's breathing comfortably. Jack's kidneys are showing us they are getting back into action and he's been peeing like a champ! He has been on 1L oxygen for the past couple weeks and doing well. His chest X-ray is very slowly improving.

Jack's abdominal incision is still working on healing. The retention sutures are still in. The incision appearing to show signs of healing from the outside but it's hard to know for sure. Surgery would like the sutures in as long as possible. Jack has tolerated the wean in

steroids. There was a slight scare that his HLH was more active so temporarily went back up on his steroids and got an LP but were able to go back down. Jack was a rockstar and did the LP with only versed! This was his first LP in a very long time due to the inability to position him properly with his abdominal incision and the problems with it opening and not healing. The great news is that it was pretty much the same as the last one he had even after all that time and not getting intrathecal steroids.

Jack's fun personality has been shining through so much lately and it is so amazing to see! We've seen him go through so many different stages and phases and to see signs of our real Jack is incredible! Hearing Kenz and Jack bicker is like music to our ears lol! Jack loves going outside to the healing garden, playing games, legos, playing video games and hanging out with visitors! He has gotten to meet a couple members of the Marquette basketball team as well as Mr. Larry Hisle. Mr. Hisle was on the Brewers in 1982 when they won the World Series. He visits Jack almost daily. They have plans to attend batting practice together and meet the players! Jack is so excited!

After sharing the exciting progress Jack has been making, I also have some to share with a very heavy heart. Makenzie also has HLH. She is not currently sick or showing any signs of illness. She has had an MRI and labs, all of which are normal at this time. Next week she will have an LP and we will then discuss timing of a bone marrow transplant. We know she has two 10/10 matches. Once a more specific time frame is chosen, they dig deeper into finding the best match. Never in a million years did I think my family would be in this position but I know we will get through it. There is no easy way for us to handle both kids going through this, especially at pretty much the same time but we feel so blessed to have so much love and support and especially all the prayers for my sweet babies.

I will briefly explain this because I'm sure some will ask why not wait on Kenzie if she is not sick. If we wait, we risk the chance of Kenzie's HLH activating due to a virus or something for example and this would cause her to need additional treatment like Jack did prior to getting the E. coli. If we get her transplanted before she gets sick from the HLH, her journey will hopefully be less eventful and she will only need the chemo prior to transplant.

I think it will be easier for me to update on both kids on the same caring bridge so I plan to make this page for both of them if I can.

Thank you all for following our family's journey and keeping us in your prayers. I know God has been hearing them. ♥

Photos









Sent from CaringBridge iPhone app

Comments

We're with you guys. You have all our love and support! ☺☺

Stay strong!!!

—Sarah Jamison, August 12, 2019

Many prayers for your whole family. I can't begin to imagine how you stay so strong thru this heartbreaking journey!! Know that there are many praying for you and sending positive thoughts!!

—Lynn Horne, August 12, 2019

Praying for Jack's continue progress & Mackenzie's new journey. God be with you.☺☺☺☺☺☺☺☺☺☺

—Janice Marchesini, August 12, 2019

I've been thinking of you all today. ♥

—Rebekah Raleigh, August 12, 2019

Continued prayers for all of you! ☐☐☐☐

—Heather Ray, August 12, 2019

Thanks for the update. Glad to hear the great news on Jack. Jeremy had told me about Kenz and my heart has been aching for all of you. God will get you through it. Sending love and hugs to all & keeping you in my prayers..

—Brenda Sutcliffe, August 12, 2019

Think about you often from here in the UK and wonder how Jack is doing, it's great to read of his improving situation and long may it continue. At the same time shocked to hear you've got to go through it all for a second time and I pray it's more straightforward. Sending love and best wishes. X

—Sue Chivers, August 13, 2019

Thinking of all of you! ♥

—Debby Trewyn-Way, August 13, 2019

Think about you all daily!!

—Melinda Schmidt, August 13, 2019

That's great about Jack!!! Hopefully Kenzie's HLH will stay inactive! Hugs ♥

—Cassy DeSeve, August 13, 2019

Sending hugs to all of you☐☐

—Barb May, August 13, 2019

Your kids are blessed to have you by their side. Can't imagine. You are inspiring. Stay positive.

—Carrie Wilks, August 13, 2019

Thinking of you guys daily , lots of continued prayers sent your way .. ☺☺♥

—Jennifer Dye, August 13, 2019

We are sure that this journey with the two of the most cherished children in your life will get you through knowing all the prayers and support are with you.

Blessings,

Gus, Barb and Glenn

—Barbara Gustafson, August 13, 2019

I do not know your family, but info regarding your situation appeared on my Facebook page. Perhaps a God moment?? In any event, you have my continuing love and prayers. I am a mother, grandmother and great grandmother so I can only imagine the worry and stress you are enduring.

—Pat Dahl, August 13, 2019

Thinking and praying for you guys every day. So happy to see Jack's improving. My heart aches that Jack and Kenzie have to go through all the treatments. They are very fortunate to have such wonderful parents to help them through this. We're here for you guys if you need anything at all.

—Jacquie May, August 13, 2019

So glad to hear the progress Jack is making.... ☺☺, God is good. Heart broken to hear about Kenzie, but praying she will stay strong. Cannot imagine Jack and Kenzie's bond could ever be stronger, but I believe we haven't seen anything yet! God bless all of you. Prayers, love and hugs being sent to all daily.

—Sue Behrendt, August 13, 2019

Love reading your updates. Filled with so much love and hope. All of you stay SO STRONG and the prayers will and have been so strong. Blessings to Jack and Kenzie. Kim, your strength also is amazing. Many hugs to you all. We are cheerleaders for continued strength.

—Karen Peltier, August 13, 2019

Hey Kim! We're praying for all of you!! Oh boy. So much going on. Hugs to you.

—Heidi Beernink, August 18, 2019

BIG things happening today!!

Kim Ryan, August 14, 2019



The picture says it all!

And Jack's 11th birthday is August 25th! He loves getting mail and looks forward to me bringing it over from the Ronald McDonald house so if anyone would like to send him a card he would love it! ☺♥

Ronald McDonald House c/o Jack Ryan

Rm 113L

8948 W Watertown Plank Rd

Wauwatosa, WI 53226

Sent from CaringBridge iPhone app

Comments

Man he looks great and upbeat. I Love it !!!!!!

—Mike Zoerner, August 14, 2019

Way to go Jack!!! So excited and happy for you!!! And happy early birthday!!!

—Heather Huebner, August 14, 2019

Way to go Jack!!! So excited and happy for you!!! And happy early birthday!!!

—Heather Huebner, August 14, 2019

These posts never fail to bring tears. In this case, they're happy tears that Jack is progressing. I hope that Kenzie's transplant can move forward before her HLH becomes active.

—Jackie Bladow, August 29, 2019

August 24, 2019

Kim Ryan, August 25, 2019



So Jack has been on the HOT (hematology, oncology and transplant) unit for about 10 days now. He is making so much progress and doing great in therapy. He stood for the first time last Tuesday and wanted to do it more after therapy! He is so strong and determined! He continues to be on NG feedings but his appetite has been picking up which is great! We have been keeping track of what he eats closely in hopes to wean his feedings at some point soon.

Earlier in the week he also got the bottom 2 retention sutures taken out. The incision is looking good from what we can tell. They are beginning to talk about discharge planning but this can be a long process. We have to be sure he can ambulate safely. From what we understand at this point, he will likely be 3-4 mo out from transplant. He still gets Gamifant every 3 days (his HLH infusion) which takes the place of the chemo he was getting. His HLH can't be present in his spinal fluid in order to get the BMT at that point so the plan for now is to have monthly LPs.

Jack LOVES to sit in his wheelchair all day long! He is being a jokester, goofball, and of course he and Kenzie bicker again! It means he is feeling better and it's amazing! Looking at him, I can't believe there were days we weren't sure he was coming home

with us and how we are talking about discharge planning!! It is truly a miracle with all this kiddo has been through and I thank God every day. This kiddo is meant to do great things in this life. I know I say it all the time but thank you so much for all of the prayers and love sent to our family.

Kenzie had an LP last week, it came back normal!!! This is such great news! Most of her labs are normal as well. There is one HLH marker that is high. It doesn't mean her HLH is active but the doctor just said it's good that we are on the path for transplant now vs later. She is such a brave kiddo as well. Kenz and I are going to the salon Wednesday and she's going to see if she has long enough hair to donate and to get a hair cut so she can get used to short hair for a little while. We have plans to go wig shopping and get tons of cute headbands!

Although Jack and Kenz definitely act like siblings, it's amazing to see the support they have shown each other when having to go through some of this.

Sorry, this is getting pretty long... I will send an update and pictures soon from Jack's birthday. Thank you to everyone who has been sending him mail too! He has about 100 cards and many gifts to open tomorrow! And he was worried about having his bday in the hospital... you all really are making his bday a special one.

Love you all!!

Photos









Sent from CaringBridge iPhone app

Comments

Many prayers to you all!!! Love hearing about all the progress Jack is making!!!

—Jason Callewaert, August 25, 2019

Go Jack and Kenzi!
Prayers are being heard...
Hugs and love to the whole family.♥
Happy birthday Jack! ☺☺☺

—Gina Dabbs, August 25, 2019

This is such great news! Prayers and love to all ! ♥♥♥

—Dana Monticelli, August 25, 2019

Happy Birthday!!!! It 's a blessing to hear such great news. Our family will continue to pray for fast healing so Jack can continue to move forward and do everything he loves! Prayers for Kenzie and the rest of the family that all moves forward smoothly and just know you have a lot of love and support. With continued strength and prayer the Rubach Family

—Mya Rubach, August 25, 2019

Happy Birthday Jack! I hope your day is filled with family and fun!! So glad to hear that things are looking up. You've got this!!! ♥

—Debby Trewyn-Way, August 25, 2019

Happy Birthday Jack. I hope you have a wonderful day with LOTS OF SURPRISES. Keep up the fight young man. God truly is looking over you & taking care of you. Love, Sunny

—Sunny Nelson, August 25, 2019

Happy birthday Jack!

—Rebekah Raleigh, August 25, 2019

Happy 11th Birthday Jack- have a fun celebration today and know that you are loved by so many . You are a super-hero fighter and I know God is smiling down on you today. Prayers for all of you.

—Jane Pierce, August 25, 2019

Wonderful, amazing, incredible progress! This warms the hearts of so many who love you!!

—sheri rocco, August 25, 2019

Happy Birthday Jack!!!♥♥♥

—Allison Ade, August 25, 2019

Kim, you are one strong family! I'm praying for you and your kiddos. They could not have been blessed with a more qualified mama to see them through.

—Katelyn Lasse, August 25, 2019

So glad to hear good news! Jack is an amazing kid and God does have big plans for him!

We continue to pray for him and McKenzie every day! Praying for you too, Kim! Happy Birthday Jack!

—Marcy Hafeman, August 25, 2019

Jack's Birthday and Look who's walking!!

Kim Ryan, August 28, 2019



Jack had a great birthday in the hospital with an overwhelming amount of cards and gifts thanks to all of you!! He was excited to open each one and wants to thank you so much!!! It is appreciated more than you know!

Also, Jack stood with a walker in therapy. The plan was just to stand but Jack wanted to

take a cruise! He walked with the walker and Dad for the first time in 96 days! His drive and determination to work hard in therapy is so amazing. We couldn't be more proud of him!

For Kenzie news, we are getting our hair cut today and she is donating her hair. She said it doesn't matter how short it has to be, she want to donate to help another girl like her. Last night we online shopped and she picked out some cute headbands. We are also so very proud of her for making that choice. She has been so brave!! I may be slightly biased but these are two pretty amazing kiddos!

Photos









Sent from CaringBridge iPhone app

Comments

Wow, this is awesome seeing the progress in such a short time! Keep on pushing for more Jack!!! Kenzie is super brave and generous and I applaud her for it!

—Dan Denman, August 28, 2019

So amazing!!!!

—Mya Rubach, August 28, 2019

EVERYONE is so PROUD of the TWO of YOU.

—Sunny Nelson, August 28, 2019

These are 2 amazing kids, they are destined to make a big difference in this world. We

are so happy and proud we have gotten to know the whole family. You have every right to be biased, and I think the parents are amazing too, for how you are getting through this. Love to all.

—*dennis holcomb, August 28, 2019*

So awesome! Will keep praying for strength and vitality.

—*Jackie Bladow, August 29, 2019*

Thank you for sharing all those pictures. What a precious time. So proud of your kids. They are amazing! I'll keep on praying.

—*Jennifer Hines, August 29, 2019*

Jack! I just saw you on TV with Christian Yelisch!
How exciting for you.
And this is coming from a Cubs fan...

—*Gina Dabbs, September 4, 2019*

Man! I don't even know your family, and I LOVE your kids. I'm new to the Montessori team at Dyer, so I'll look forward to their return as soon as this has passed and they're both healthy. Continued prayers for you all.

—*Jackie Bladow, September 20, 2019*

link to order Kenzie's T shirts

Kim Ryan, September 17, 2019

<https://www.customink.com/fundraising/kenz-kickin-hlh>

Sent from CaringBridge iPhone app

September 19, 2019

Kim Ryan, September 19, 2019



Time seems to get away from me and I am terrible at updating this. Things are constantly changing so sometimes this feels like a hard thing to do...

Jack has been progressing great with his therapies! More quickly than we could have hoped for. He is so determined to do things on his own and pushes himself. We are so proud of him! Yesterday he scored an awesome walker he can turn around and sit with from Katy's Kloset. He loves it!

Jack was supposed to be discharged but we had a slight delay. A couple of his liver labs were off so they stopped the Gamifant thinking it was no longer doing its job and started chemo again. Obviously he was devastated by this news. He also was upset about losing his hair again.

Kenz was sad seeing Jack so sad and decided quickly that since she would lose her hair soon anyway that she wanted to shave her head for her brother. So, yesterday, that's what both kids did. It was emotional but oh my goodness are these kids so brave and strong. We are so proud of Kenzie, she is so beautiful, inside and out. Yes, they have picked back up on fighting sometimes lol but to see the love and support they have for each other going through this is amazing. They are always making projects for each other and giving surprises to make the other smile.

Kenzie is doing very well. We are doing all we can to prevent any potential illness. She has an admission date of October 18th and transplant date of the 25th. Kenz has a 10/10 unrelated donor. She has some anxiety of course there are many unknowns for all of us. The first week of October she has 4 days of appts to get her PICC Line and for testing needed prior to the transplant. The 25th is day zero and from there it can be as little as 25 days.

In the mean time, the kids have started online school and we are going on a lot of passes with Jack. He loves getting out and about! Mastering getting in and out of the took a little practice but Jack has down and does amazing! Kenz is a big help too! Some moments when we're in the car, just talking, I almost forget where we've been the last 4-5 mo.

We are unsure of Jack's BMT date at this time but it sounds like when we know the HLH is calm, they will likely start the work up and get him transplanted. This is sooner than we initially anticipated. But the great thing is, he is doing so great with activity, eating well and his incision is healing. There are still 5 retention sutures in for now. He will likely get a half match parent transplant due to the hit to his kidneys. They use a different type of chemo and medications. We were worked up and Jeremy will be doing this for Jack! Childrens does many of these. A really great thing is that when Jack is ready for transplant, we can jump on it.

Seems like this will be quite the Fall/Winter... we are making it through with all of you! We thank God every day that we are in the position to even talk about discharge with Jack. He continues to fight so hard! And for Kenzie's health prior to the BMT.

Thank you all for continuing to follow the kids and for all the love, support and prayers for our family. ♥♥♥

Photos



Sent from CaringBridge iPhone app

Comments

Continued prayers for Kenzie & Jack! ☐☐♥

—Jennifer Dye, September 19, 2019

You are all in my prayers. You have very strong kids.

—Margaret Babinski, September 19, 2019

I love you two so much! You two are so precious. The love and support you have for each other is AMAZING! I am praying for you both every day!! Someday Kenz, you will know who Auntie Kathy is! ☺☺☺☺

—Kathy Sturycz, September 19, 2019

What an incredible family. I pray for all of you every day and hope for the best outcome for all.

—Peggy Ausloos, September 19, 2019

This so wonderful to hear this update. I have been praying for you all. Hoping this fall/winter goes smoothly for you guys and everyone is on the road to recovery very soon.

—Melinda Schmidt, September 19, 2019

A-MAZING KIDS!!! Jack & Kenz you two rock! You've got this!

—Debby Trewyn-Way, September 19, 2019

Amazing how children are often stronger than adults. You dont know me but I keep you in my prayers. No parent, and especially no child, should have to go through what your family is going through. Thanks to Tee It Up fore Ty for bringing us all together in prayer and support! God bless you all! ♥☺☺

—Pam Lanting, September 20, 2019

All of the family's strength is truly amazing! Continued prayers!

—Becky Lanser, September 20, 2019

we're home!!! and, new dates.

Kim Ryan, October 6, 2019



I have great news to share! Jack was finally discharged after 129 days in the hospital! He is so happy to be home! The kids have 2 new homes now. Both Jeremy and I have moved and they are loving getting settled in to their new houses. He has planned follow up appts twice a week. So far, these appts have gone well. He gets chemo every 2 weeks and monthly LP. We still do not have word on when his BMT will be. Right before discharge, he had a test done on his kidneys and it came back too low to be able to do the transplant now so we are trying to give Jack's kidneys time to recover more. They will repeat the test at some point so see how/when we move forward.

Kenzie was all set last Monday to get her PICC line and LP and an hour before she went down, we were told the donor was no longer able to donate. They could not share any details with us and tell us that it is not a common thing to be canceled so late in the game. Thankfully Kenzie had 2 10/10 unrelated donor matches one being cmv positive and one cmv negative. Kenz is positive so it was best to go with the positive donor if possible but now they will pursue the cmv negative donor and are able to give her some IV medications during and after transplant to help with this. The great news is that so far

we have the green light with this donor and her pre transplant appts are the week of October 14th. She is scheduled to be admitted on the 31st and transplant on November 7th. Kenz said she knew last Monday wasn't the day to get her PICC because nothing happened the right way... she forgot her blanket she wanted to bring and her stuffed animal. So, she feels this new timing will work. ☐☐

It has been so amazing for each of us to spend time with the kids away from the hospital and to have them together again. We are enjoying every minute! I had a stair lift put in my house and Jack has such a sense of independence, I love it! He has been so determined and has made so much progress moving around. They are getting more into online school and getting the hang of it more each day.

Jeremy and I couldn't be more proud of these kiddos!

I know my updates can seem far between but I promise to keep updates coming as I can. It seems things are always changing so when I post, it's different shortly after. Thank you all for baring with me and understanding and for all the continued love and support for our family!!

Photos







Sent from CaringBridge iPhone app

Comments

Such great news!!!! Continued prayers for Kenzie and Jack !!

—Jennifer Dye, October 6, 2019

I am so happy to hear all of this!!! Congrats way to go jack!!

—Dana Monticelli, October 6, 2019

I'm so happy for all of you! It has to feel so good. Continuing prayers for Jack & Kenz! ☺☺

—Debby Trewyn-Way, October 6, 2019

I'm so happy for all of you! It has to feel so good. Continuing prayers for Jack & Kenz! ☺☺

—Debby Trewyn-Way, October 6, 2019

Yay Jack! So proud of you buddy! You are so strong and brave!! Kenzie you are such a wonderful sister! Love you both! Praying for you both always! Auntie Kathy

—Kathy Sturycz, October 6, 2019

Sending many prayers, hugs & loves for both of them and the two of you as well
□□□□□□□□□□□□□□□□□□□□

—Holly Benzow-Pittner, October 6, 2019

No place like home! Hope you all are settling in! Praying all goes well in the upcoming weeks. Love & hugs....□□□□

—Brenda Sutcliffe, October 6, 2019

Yay!! Wow Kim, you have such great and strong kids and their strong bond and love that they share is so evident in these pictures and updates. I know a picture is just a moment and they don't capture all the hard stuff but we can be sure that the hard stuff makes the good all the better. Thank you for the testimony you and the kids are to the rest of us who are lifting you up. We are continuing to pray for you guys and praising God for this news. We love you!

—Stacy St Peter, October 6, 2019

Fabulous news!!

—Brenda Dahl, October 7, 2019

October 18, 2019

Kim Ryan, October 30, 2019

Busy week this week! We almost made it... Kenz is finishing up her pre transplant work up appts today. She got her PICC line Monday so is trying to adjust to that and has been such a rock star with such long days at the hospital. Kenzie's numbers have all been good, she just has a couple more cells in her spinal fluid

so their doctor wanted to be proactive to be sure everything is calm before transplant so they started her on steroids and some other common meds to go along with the steroids. She is nervous about all of this but she has a great big brother who is supporting her too.

With the labs, they determined that Kenzie's bone marrow has not been exposed to CMV, therefore, she is considered to be CMV negative. The great news of this is that initially her results were confusing but after repeats thought she was positive so went with the positive donor but that was the one that couldn't donate at the last minute. Her new donor is CMV negative to it is so perfect! All part of God's plan. ☺☺☺

Jack had an LP this week and we just found out his spinal fluid doesn't have HLH ! It is still calm and he is happy at home and working so hard to get stronger. He has also been a champ at drinking fluids to help those kidneys. He's on iv fluids all day which is helping as well. He will have another GFR (kidney test) Tuesday to see if there was improvement in his kidney function since discharge when he had the last one.

Jack has some buddies on the Marquette basketball team who so kindly gave him amazing tickets to the Bucks game last night. It was so fun! He is also invited to a Marquette practice next week!!

Sent from CaringBridge iPhone app

Comments

Praying for your family every day and so glad to hear positive news!

—Paula Lattergrass, October 30, 2019

Thinking of you all everyday!! Stay strong and stay positive!!! Many prayers coming from us!!

—Jason Callewaert, October 30, 2019

October 30, 2019

Kim Ryan, October 30, 2019

(Sorry, I wrote the last entry and didn't post it as things were changing) So... more slight changes to the plans. Kenzie was supposed to have her transplant Thursday but at her Monday clinic visit postponed it. Her fibrinogen is low so they wanted her to get chemo and increase steroids. At first, this was going to be done as an outpatient but basically on our way out the door for the appt they called and said it would be an admission instead. We are likely here until after the bone marrow transplant but depending on how the days fall we may get to go home a day or two prior to the transplant.

When will the BMT happen for kenz...

Well, there has to be a week between the etopiside (chemo) she got yesterday and the transplant chemo she will be getting. Also, her fibrinogen has to be normal and stay there. Which would be assuming the HLH is "quiet" and not in her liver. All her other HLH markers are fine. She will have a spinal tap later this week to check her spinal fluid again. I may have a theory about why it's happening not related to HLH and pray it's that simple and that they listen.

And, the donor will still donate on Thursday and they will freeze the cells.

—Mary Nelson, October 30, 2019

We continue to pray for Jack and McKenzie every day! You are never far from our thoughts and prayers! You have amazing kids and you are an awesome mom!

—Marcy Hafeman, October 30, 2019

Jack and Kenz are the strongest children I have ever encountered. The love and support have been amazing and so happy that you are surrounded with all of it as a family. The power of prayers continue for you all.

—Karen Peltier, October 30, 2019

Thanks for the update!

—Emily Dumovich, October 30, 2019

Praying for you all every day! ♥

—Heather Coates, October 30, 2019

Continuing to keep Jack & Kenzie in our prayers! ☺☺☺☺

—Debby Trewyn-Way, October 30, 2019

Praying they listen to you, after all a mother's intuition is like no other! Keep sharing your story and staying connected to others- I'm sure its a powerful community and you never know who God has intended to put in your path!

—Carrie Wilks, November 2, 2019

November 05, 2019

Kim Ryan, November 5, 2019



A quicker update than most of mine...

Kenz is still inpatient but gets day passes often (which she loves!). Her fibrinogen was continuing to drop and needed cryo twice so far. Her other HLH lab markers still look ok. But, last week her LP did show 2 macrophages in her spinal fluid which means the HLH is there. She continues to get weekly chemo and will have another LP Thursday. No intrathecal chemo or steroids yet. They said if there is HLH present after this tap they will go that route.

Jack's creatinine (kidney lab) is on the higher end but all labs unchanged from last week so he doesn't have to be back until chemo on Monday! He plans to shoot a deer and go to his first Packer game! Koos for Kids so generously surprised him tonight with indoor box seats to the game Sunday! He is so excited! They also gave Kenzie a sewing machine. She's already planning all the things she's going to make. I can't wait for her to teach me!! Jill and Koos for Kids are amazing and we are so grateful.

Bumpa made Jack a walking stick last weekend and he was been walking so well with it!!! He enjoyed a walk down the trails at their hunting land with Dad and Dakota!

Kenz and Jack were also able to decorate the Christmas tree together tonight which meant so much to me. I'm so thankful she can come home on passes so we can still do things like that.

Ok, maybe it wasn't as quick as I planned but I wanted to share some of the happy things going on with the kids too. ♥

Thank you for continuing to keep Jack and Kenz in your prayers.

Photos









Sent from CaringBridge iPhone app

Comments

Jack and Kenzie ,
You two are so inspiring to all of us to get up and keep going one day at a time. Kenzie, I am so excited that you have a sewing machine! I can help you with some projects when you are ready to get started. Jack, I hope you get that deer and have a story to tell us when you come back. Have a blast at the Packer game!
Anneke

—Anneke Thompson, November 5, 2019

Great job on your Christmas tree ☺☺ Kenz & Jack! You two are so adorable. Think and pray for you ALL the time. Hugs☺☺

—Debby Trewyn-Way, November 5, 2019

Love all the smiles, day passes, and the packer game. Enjoy all the fun stuff. You all deserve it so much. Continued prayers for you all much love kisses and hugs. ☺☺♥

—Sue Dumovich, November 6, 2019

Great to hear all the good things happening. The Packer Game thing is such an incredible thing. And then the sewing machine is awesome. We would like more info on that organization.

You are all always in our thoughts and prayers.

Love to all.

—dennis holcomb, November 6, 2019

Great to hear all the good things happening. The Packer Game thing is such an incredible thing. And then the sewing machine is awesome. We would like more info on that organization.

You are all always in our thoughts and prayers.

Love to all.

—dennis holcomb, November 6, 2019

I'm so happy Jack is doing so well!!! And Kenz, too! I hope you have so much fun at the Packer game! I'll be watching for you on TV! :)

—Madeline Meier, November 6, 2019

Love all the updates long or short. Keep them coming!

—Emily Dumovich, November 7, 2019

Your kids are beyond amazing! We have a whole team of people keeping them both in prayers ☺☺☺☺

—Paula Lattergrass, November 8, 2019

November 16, 2019

Kim Ryan, November 16, 2019



Update on Kenzie....

Kenzie's fibrinogen continues to steadily drop. She has gotten cryo a couple times to help increase her fibrinogen. The doctor doesn't think the chemo is helping so Thursday Kenz got a drug called gamifant. Jack started getting this medication in place of chemo when he was no longer able to get the chemo due to his kidneys and it worked well for him. This drug can only be given when chemo is not tolerated or not working so we are now able to try this with Kenzie.

Thursday Kenz got her first dose of gamifant and also had an LP (spinal tap) with intrathecal chemo (chemo put in her spinal fluid). We found out Friday that she still has HLH in her spinal fluid. The gamifant crosses the blood brain barrier so should help with the CNS involvement. Gamifant is given every 3 days. Since she tolerated the first dose well, Sunday she will get a larger dose.

Tuesday Kenzie will have a diagnostic LP (no intrathecal chemo. Just to see if the HLH cells are present). This will determine if the Wednesday dose needs to be even larger. The plan to is be as aggressive as they can to get her transplanted as soon as they safely can. This can happen when she has a clear LP and is at least a week out from intrathecal chemo.

The donors cells are frozen and ready to go when Kenzie is.

The search is still on for any places doing gene therapy or things like that. Many people have replied saying they don't but are also giving further resources to contact. If there were only more hours in a day and if they were easier to get ahold of...

(Btw- jack is rocking physical therapy! And pushing himself so hard. He is such an amazing kiddo! He surprises me with something new pretty much every day!!)

I should also add that kenz is a rockstar going with the flow with all these changes. I can't how difficult it must be for the plans to continue to change especially for a 9 yr old and these are some big plans changing! She's doing such a great job. She even says, "we have to take it day by day, right mom."

We love all the prayers! Please, please keep them coming.

Photos







Sent from CaringBridge iPhone app

Comments

Jack looks great! I know kenzi will fly thru the path her brother and God and all the prayers have already plowed, your whole family has are thoughts and prayers and our awe in your strength! Love and tightest of hugs possible! ☺☺☺☺☺☺☺

—Therese Schulz, November 16, 2019

So beautiful and inspiring! Continued daily prayers for strength. Sending lots of love. ☺☺

—Sue Behrendt, November 17, 2019

Praying for all of you!!! Your strength and courage during this continued fight is admirable.

Praying this drug kicks butt soon. Love you all!!! Go get em Jack!!!!

—Rachel Maciejewski, November 17, 2019

Sending love!

—Tanya Hoar, November 17, 2019

Continued prayers for all of you! □□□□□□□□□□□□□□□□

—Heather Ray, November 17, 2019

Keeping all of you in my thoughts and prayers □□

—Barb May, November 17, 2019

We've added you to our church prayer list and we are all following and praying here in St. James, MN. You, too, Kim, are a rock star. You are so strong for your kids. We are lifting YOU (and Jeremy) up as well. This can't be easy by any stretch of the imagination, but you are paving a way of faith that will last the rest of your lives. God's got this, and is carrying the 4 of you through.

—Stevie Ciske, November 17, 2019

Prayers and love continue It is so great to see smiles on their faces for everything they are going through. And also you and Jeremy are amazing parents They are the way they are because of both you and the love and faith that you all have will carry you through this journey. Keep on fighting Kenzie and jack. You are both awesome

—Joann Ryan, November 17, 2019

November 27, 2019

Kim Ryan, November 28, 2019



Seems like there is never a dull moment around here....

Kenzie has now been inpatient about 30 days. She has been having LPs 1-2 times a week and the macrophages (HLH) are still seen in her spinal fluid. She has been getting chemo in her spinal fluid weekly but with tomorrow's LP will only be getting hydrocortisone (steroids) in her spinal fluid because... Monday she's getting another central line put in her chest because they need more access temporarily and Wednesday will be starting chemo for her bone marrow transplant. She will get chemo until next week Monday or Tuesday when she gets the bone marrow.

Although the HLH is still seen in her spinal fluid, they are deciding it is best to take her to transplant. Her other labs have been good for the most part and it doesn't seem the HLH is causing issues. Her doctor feels the risk of waiting and her getting sicker is worse than going ahead now.

Earlier this week when she was getting some pre transplant tests done, they found a clot in her right atrium. She has been having issues with her blood clotting previously so was already on a heparin drip. The clot is at the end of her PICC line. They went up on her drip a good amount more to help with the clot. Prior to this, Kenz was able to go on day passes (which she enjoyed and was pretty much all she looked forward to, besides meals lol. Gotta love the high dose steroids!) they would turn off her drip and cap her for

6 hours. Since her heparin was increased, we can no longer leave on pass as it is no longer safe to have it off. It was tough at first but she been a trooper. The hematologist said the clot is small enough that if it breaks free and goes to her lungs, they don't expect to see big problems. Of course tonight she is telling me it feels tense and funny when she breathes and like she has to breathe faster... that bought her being hooked up to a pulse ox all night. So far so good though. Everything looks ok.

Her fibrinogen was consistly dropping but now that the heparin drip has been increased and she's in a good spot there, her fibrinogen levels have been holding steady.

I think I covered the updates on Kenzie.

Jack has been staying busy with clinic appts and physical therapy, and visiting his sister (and some hunting trips in there). His blood pressure has been improving so he could be weaned on one of his BP meds. He is doing amazing with walking. He working hard at strengthening his hips and lifting his legs to get up stairs. He has mostly been using his walking stick and only the walker if we go longer distances. In the near future he may be starting a daily oral medication in place of the chemo he gets every 2 weeks. The chemo is helpful but long term use puts you at a higher risk for leukemia. This other medication is supposed to to continue to help keep the HLH at bay along with the steroids.

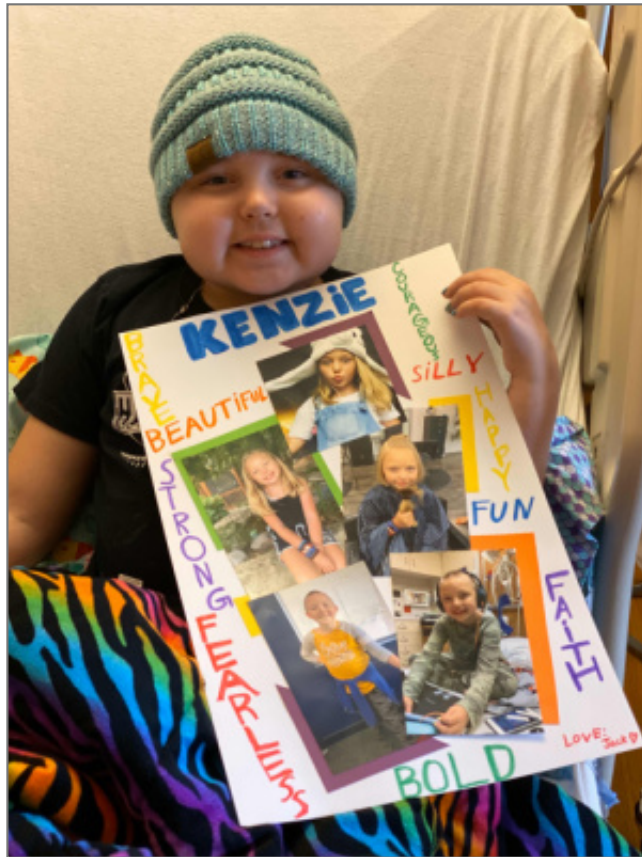
Jack has monthly LPs. He had one about a week ago that did not show signs of HLH thankfully! He has a follow up CT of his head, neck and chest on Monday.

Thank you all for loving on us. It's been extra tough lately but we are hanging in there. Kenz has been feeling down and getting used to all the changes with herself, all the changes in plans and all the unknowns. The kids are thinking ahead to the period of time when they won't be able to see each other (which will be approx 3 weeks if they had to guess). They have been even greater supporters of each other with every day. It warms my heart but at the same time hurts that this is why. Kenz asks me why this is

happening to them and tells me that if there is one good she knows of right now that's coming from this, it is her relationship with Jack. They've always been close but this is taking it to a whole other level.

Please keep us in your prayers especially as the kids head into this next week. ??

Photos









Sent from CaringBridge iPhone app

Comments

Extra prayers were said today for your strong, amazing kids! They are blessed to have such wonderful parents to help them through. Hoping things only get better for them in the coming months.

—Paula Lattergrass, November 29, 2019

So much strength and love between these two and your family. Prayers and hugs continuously for all of you, and your amazing strength. Love to all.

—Sue Behrendt, November 29, 2019

Continued Prayers for Jack and Kenz !! Thinking of you all daily! ☺☺

—Jennifer Dye, November 29, 2019

Continued prayers for all of you. Stay strong.

—Peggy Ausloos, November 29, 2019

Praying for all of you! Jack, Kenzie and mommy you are all so strong and brave and I am so VERY PROUD OF ALL OF YOU! I pray for you every day! Love you so much! Jack did you have any luck hunting with dad?

—Kathy Sturycz, November 29, 2019

Always thinking of you guys and prayers every day!!!!

—Jason Callewaert, November 29, 2019

Praying for you all. May God grant you peace. Such brave and wonderful kids.

—Brenda Dahl, November 29, 2019

That Sibling bond is forever and it is heart warming to see it blossom during these difficult days/weeks/months. Same is said for their relationship with you. I continue to pray hard for your family. Your strength is inspiring. Always always hugs!!!!!!

—Rachel Maciejewski, November 29, 2019

Sending love, hugs, prayers and positive vibes for healing and peace. The strength the kids have shown is humbling. Hang in there mama, many are lifting you up too! Periodically you should make a list of needs so maybe they can be taken care of to lighten your load, let us all know in order what the greatest needs are!

—Connie Coleman, November 29, 2019

Praying for you all. ♥

—Nicole James, November 29, 2019

Sending loves, hugs and continued prayers for these beautiful kids and their family☺☺
Stay strong, we're all with you and praying for
You all☺☺☺☺☺☺☺☺☺☺

—Holly Benzow-Pittner, November 29, 2019

December 02, 2019

Kim Ryan, December 2, 2019

My heart just breaks... yet another change in the plan for sweet Kenzie. Today she had a repeat echocardiogram to follow up on the clot they found last week. She has been on the heparin drip and her numbers have been in the right place. However, the results stated that the clot was about double the size as measured last week. It is questionable if a shadow was in the way of properly measuring the clot last week but either way they are either saying the clot is the same or bigger and that isn't okay due to being on the heparin therapy. Her white blood cell count has also been trending up. They are trying to figure out if this is significant or related to the steroids. The heparin drip was turned off today and they started Lovenox shots twice a day to see if this helps due to the clot not seeming to respond to heparin. They are repeating the echo again in a week. Due to this, Kenzie's conditioning to start the transplant (chemo that was supposed to start Wednesday) will no longer be happening right now. Her transplant will be postponed, once again, until further notice...

Jack had a CT today of his head, neck, and chest and clinic appt. Everything looked okay except for some possible sinusitis so we have an ENT appt tomorrow. Also, they noticed that the compression fractures he had in his spine appear worse. There is no way to tell if they are old or new injuries and they tell us that pain is not an indication of current problems. They are fitting him for a brace this week. In a couple weeks he will have an x Ray with the brace on and an orthopedic appt to assess him. Jack has been on a lot of steroids for going on almost a year and this is terrible for your bones. We will be very slowly weaning his steroids as part of the plan anyway but due to this, he will not transition to the oral medication and will continue getting the chemo every 2 weeks for now. His doctor said that the new medication they were going to start has been know to cause bone problems. We can revisit this once his steroids have been weaned more successfully and we have a chance to get him in the brace and get ortho involved.

What a day today but the kids got to spend some time together doing a craft and playing a couple games having a little fun. ♥

things. Prayers!!!!

—Brandy Bertzyk, December 2, 2019

Be strong & courageous! Joshua 1:1-9. Praying mighty warrior prayers!

—Brenda Stratton, December 2, 2019

Thinking of you both! I pray for you to keep the strength to hang tight and get thru this as we are all rooting for you to do! Sending big hugs! God bless you and your family, may he enlighten 2020 for you all!

—Lisa Ewing, December 2, 2019

Sending prayers...♥...&. Hugs. I just wish these prayers would get answered and you all could catch a break. Keeping the faith & staying positive!

—Brenda Sutcliffe, December 2, 2019

Continued prayers for all of you---the love and support from family and faith will continue to carry you through this journey, you have two amazing kids. Stay strong and God bless you all.

—Joann Ryan, December 3, 2019

I can't begin to imagine what you and your family are going through. Prayers for strength for your sweet kids and you both! ♥

—Lisa Soik, December 3, 2019

Sending many many prayers!!

—Tony Brown, December 3, 2019

In my thoughts and prayers daily

—Carrie Stenholt, December 3, 2019

Hang in there Kim! Our family is thinking, hoping, and praying for you all daily!

—Lee Borchardt, December 3, 2019

Hang in there Kim! Our family is thinking, hoping, and praying for you all daily!

—Lee Borchardt, December 3, 2019

Kim, so sorry to hear about the kids. My prayers are with you.

—Emma Phelps, December 3, 2019

I will be praying that God relieves the chaos so things can go as planned and no more set backs. Love, hugs and prayers for all of you

—Mya Rubach, December 4, 2019

December 06, 2019

Kim Ryan, December 7, 2019



Kenz had a CT a couple days ago (the day after the echo) which showed a couple clots in her lung. We are unsure if this happened before or after the echo. She had the episode when I made the entry not long ago otherwise did not seem to have any significant issues. Her heart rate was in the 150-160s for a couple days and high blood pressures. They played around with blood pressure meds that work best for her to help keep her HR and BP closer to where they need to be. They are both still on the higher end but she's headed in the right direction. They will increase again today to see if that helps. Monday Kenzie will have a repeat echo to check the status of the clot. They are hoping that with the lovenox and time, the clot will get smaller and/or adhere to the wall of her heart. Because of this and the fact that it all takes time to happen, transplant will be postponed for at least a month. KENZ is taking it as well as she can. She is so brave and has been such a trooper with the lovenox injections. She also has a cough and are waiting on results that can take that long. It isn't a serious thing but she can't go to transplant if she's positive for it since her immune system will be taken away.

**update because I'm slow at posting...

They did the repeat echo yesterday instead and found that that clot was the same size. They aren't extremely concerned because she's only been on lovenox 4 days but the great part is that it didn't get bigger! They were thinking about pulling that PICC line but hematology decided the clot is too big to safely do so without the risk of it coming off the end of the line at that time.

Her vitals are looking better.

We were able to get out for a couple hours to have dinner! She was so happy! I'll add a pic of her reaction when I told her.

I am becoming increasingly frustrated watching my baby get sicker and sicker the more that is done to her. There are more complications and are further from transplant when initially she was "healthy" with inactive HLH. I've voiced my opinion that the med(s) are making her sicker and the HLH protocol isn't working as intended. We can't shake the feeling that we have to see what else we can do to make this easier on the kids. And, now that they are both stable, we have the ability to pursue this. Jeremy and I are

looking into getting a second opinion on both kids from Cincinnati Children's. Not that we don't love the care they are getting here but we need to see if there are other perspectives out there.

Photos



Sent from CaringBridge iPhone app

—Nicki Heplin, December 11, 2019

December 12, 2019

Kim Ryan, December 12, 2019

After a great deal of discussion and collaborating of multiple specialties, Kenz will be getting her line out today. They decided the safest place for this to be done is in Interventional Radiology with an anesthesiologist present. She will go to the ICU for 24 hours (maybe less) to be monitored to be sure all is well. She has been such a trooper with her lovenox injections! We are so proud of her! She is so brave and has her own little game plan each time and she does so amazing.

I will keep you posted after her line is out and more of what the longer term plan is.

Thank you so much for the continued prayers. All the love and support from all of you helps us get through.

Sent from CaringBridge iPhone app

Comments

I will keep her and your family in my prayers .

—Margaret Babinski, December 12, 2019

Thank you Kim! Prayers for each of you. ☺☺

—Diane Ellis, December 12, 2019

Praying for a smooth removal.

—Melinda Schmidt, December 12, 2019

Praying for you all!

—Sal Prieto, December 12, 2019

Praying for ALL of you who are going through this very hard time.

—Sunny Nelson, December 12, 2019

Loving thoughts and prayers said everyday.

—pauleyn m nystrom, December 12, 2019

Prayers ♥

—Sandy Petersen, December 12, 2019

Will continue Praying for all of you

—Emma Phelps, December 15, 2019

December 12, 2019

Kim Ryan, December 12, 2019

Kenzie's PICC line removal went well. We are hanging out in the PICU for the night. Tomorrow back to HOT and hoping for a pass home for a few hours as long as all continues to go well tonight.

A couple weeks ago Kenzie hurt her back when she was getting dressed. Since then, she had a few instances where her back bothered her again, pretty bad. Last night she had a problem with her back and she ended up on the bathroom floor crying in pain. Today an X-ray showed a compression fracture. Ortho stopped by today and is talking about a shell brace for support and comfort so things don't get worse as Jack's did. She has not

been on steroids nearly as long as he was but they are saying that this is likely a contributing factor.

There is a possibility for discharge next week. We are cautiously optimistic about getting to go home. As we know, anything can change each day.

Jack got his back brace Monday and has been getting used to wearing that. He picked out a cool military camo design for it. Hopefully that helps with comfort, posture and prevents possible other damage. Although, they tell me it doesn't prevent the fractures from getting worse. Next Monday Jack has his monthly LP and they are doing a pulmonary function test.

He is doing so great at physical therapy!! His determination is amazing! He wants so badly to ditch the walker and cane as soon as he can. Today we used his cane as a bat and tried not to break the windows at PT!!

Things are rolling to get into Cincinatti. We are waiting to hear back about coverage and availability. The staff at CHW have been very supportive of us perusing a second opinion. They know the kids' presentation isn't common and they have each had a crappy road so far with unexpected things happening. Praying to get some fresh perspectives on our babies soon.

Sent from CaringBridge iPhone app

Comments

Praying for positive outcomes on all fronts! You are ALL so amazing.

—Debby Trewyn-Way, December 12, 2019

♥ all the love and prayers....Ella will be there for LP Monday as well maybe we'll run into each other!

—Dana Monticelli, December 12, 2019

Thank you Kim for the update. We were praying today would go well. Kenzie and Jack are amazing and so are you! We love you!

—Diane Ellis, December 12, 2019

Continued prayers for the Ryan family!

Glad to hear you can pick out some good moments amidst the chaos that has become your lives. God bless!

—Gina Dabbs, December 13, 2019

I would do the same thing, Kim. When it comes to our babies, we need to check out all the options. Praying for y'all daily. Thank you for the updates!

—Jenni Sprague, December 13, 2019

Shifting prayer gears to setting up the right doctors looking at your case & making wise decisions to get a faster road to full recovery. Love you my friend!

—Brenda Stratton, December 13, 2019

Keeping all of your family in my thoughts and prayers ☺☺

Love you ☺☺

—Barb May, December 14, 2019

December 20, 2019

Kim Ryan, December 20, 2019



Fabulous News! Kenzie is home! She was discharged on Monday. I was able to celebrate my birthday with both kids home with me which was the best gift in the world!

Her tentative admission date for transplant is January 8th but a few things have to happen before that date and it is coming up quickly. We will keep you posted.

Hopefully we will head to Cincinatti within the next couple weeks.

Other than that, we are having a busy but amazing time being home together and couldn't be happier that we get to be together for Christmas!!

We are so grateful for all of you and all the love, support and prayers. This had been quite the journey and unfortunately we have a long road ahead as well. It is comforting knowing you are all beside us.

Wishing all of you a Merry Christmas!

Photos









Sent from CaringBridge iPhone app

Comments

Best news ever!!!! Merry Christmas ♥️👍♥️👍

—Sandy Petersen, December 20, 2019

Amazing news!! Continued prayers for the journey ahead! Merry Christmas!!

—Lindsey Waggoner, December 20, 2019

Great news♥️Merry Christmas and the best gift spending it with your kids..👍👍

—Sharon May, December 20, 2019

That is some amazing news! I hope you all have a very Merry Christmas and I pray for great things in the New Year for you.

—Sue Seils, December 20, 2019

Best news ever! Merry Christmas Kim!

—Luanne Dikanovic, December 20, 2019

The kids look great and very happy. Enjoy your Christmas together!

—Sharon Stollenwerk, December 20, 2019

A MERRY CHRISTMAS TO YOU ALL ☐☐

♥♥♥

—Holly Benzow-Pittner, December 20, 2019

YAY YAY YAY!!!

A very blessed Christmas to you all, and God bless you on this continued arduous journey. ☐☐♥

—Gina Dabbs, December 20, 2019

Such wonderful news! Merry Christmas Kim, Jack & Kenzie! Here's to a healthy 2020. ☐☐

—Debby Trewyn-Way, December 20, 2019

Such great news---so happy they can be home for Christmas---wonderful !!!!!!!!!!!!!

—Joann Ryan, December 21, 2019

Christmas at home with your kids ~ Heart warming news!!! Happy thoughts & High Hopes that Cincinnati is your other Blessing in 2020!!

—Sally Price, December 21, 2019

So happy to hear the good news! Keep fighting and stay strong! You both are the bravest kids I know! Always sending prayers and positive thoughts your way! ♥♥

—Joan Perugini, December 23, 2019

You all look so happy. Keep up the fight! Our prayers are with you always.

—Dick & Carlyne Yopp, December 30, 2019

My prayers continue for you all! Wishing you many blessings in the New Year.

—Maureen Klotz, January 5, 2020

January 12, 2020

Kim Ryan, January 12, 2020



A lot has happened since Kenz was discharged in December... it is very busy with both kids home but we love it!
We are headed to Cincinatti early tomorrow morning for a 4-5 hour appt for a consult. Praying that new eyes on the kids and may help and that they may have some good insight due to how often they see HLH there and they can work with our doctors here for the best plan for the kids.

I will update in more detail after our trip but some brief info on what's been happening...

Kenz was supposed to be transplanted this week but is not and it's being postponed once again. She has had a cough for over a month and need to get to the root of it to be sure it's safe to transplant first. Her lungs have taken a hit from something and they aren't as well as we need them. She was unexpectedly admitted last Tuesday and during her stay they did a bronchoscopy. Waiting to hear the results. We should have the final viral and bacterial back this week but fungal takes a month or two. If all is ok, possible BMT admission the 22nd ish. It also may depend on how this appt goes tomorrow.

She has also been having significant back pain and muscle spasms intermittently. Nothing seems to help when she has the bad days. This is due to the compression fractures. They aren't sure why both kids have them so early on and they are more severe than they typically see. Thankfully she has been able to move around comfortably the past 4 days or so.

On a positive note, Kenzie's LP last week came back with no HLH in her spinal fluid and Jack has been walking most places without his cane!!! (He even helped me shovel the snow today!)

Please pray for our safe travels tomorrow and for the doctors in Cincinnati to be able to help to our family.

Photos



Sent from CaringBridge iPhone app

Comments

In my prayers always ☺☺. Hoping for some good news in Cincinnati ☺☺

—Sandy Petersen, January 12, 2020

We will be praying! Love you guys.

—Stacy St Peter, January 12, 2020

Keep on keeping on:) Praying for your family! Save travels♥

—Leann Eckhardt, January 12, 2020

Hope you find a miracle. We will be praying for one. Keeping you in our thoughts and prayers.

—Tim Nelson, January 12, 2020

Kim, Jeremy, Jack and Kenz- We send our continued prayers and positive thoughts for all of you! What a (Crappy Adventure) journey it's been already been- to say the least. Hoping your trip to Cincinnati brings some fresh perspective by another group of excellent physicians. Your positive attitudes & strength are an inspiration to many. Keep fighting for answers and count on your faith, family and friends to carry you through! May God bless all of you and Safe Travels.
The DeGarmo Family

—Mike DeGarmo, January 12, 2020

Prayers for some positive news and safe travels to and from. ♥

—Heather Ray, January 12, 2020

Lots of prayers for God to guide the medical teams in the best course of treatment for the kiddos. My families thoughts are with you all.

—Mya Rubach, January 12, 2020

Praying for your trip and for effective treatment!

—Greg Robotti, January 12, 2020

Safe travels. Thinking of you all and saying prayers !

—Sharon Stollenwerk, January 13, 2020

Prayer all goes well. ♥♥♥

—Sharon Blandino, January 13, 2020

Sending prayers & good thoughts to both Jack, Kenz & their family. Have a very safe trip with AWESOME RESULTS,

—Sunny Nelson, January 13, 2020

Thoughts and prayers are with you as you make the trip to Cincinnati and that they have some awesome news for the family☐☐

—Anna & Larry Littel, January 13, 2020

Prayers and positive thoughts sent your way, safe travels. Pauleyn & Steve

—*pauleyn m nystrom, January 13, 2020*

Oh Kim, you are incredibly strong! Praying for you and your family every day!

—*Kathy Zaffiro, January 13, 2020*

Best of luck to you all in Cincinatti! I pray that you get the help you need for your beautiful children.

—*Joan Perugini, January 13, 2020*

Good luck,praying for all of you. Hugs your way Kim

—*Emma Phelps, January 13, 2020*

Thinking of you all and your amazing family! Safe travels.

—*Kathryn Turke, January 14, 2020*

January 21, 2020

Kim Ryan, January 21, 2020

It has been exactly one year this week since I brought Jack to his primary with dizziness and double vision. Then a couple days later we found out how bad his MRI was and this whole journey began. I can't believe it has been a year....

Cincinnati went well. We came back with some more knowledge and a better understanding of why each facility does what they do. However, this did not make it any easier on deciding what is best for the kids. In the end, we understand that each facility believes theirs is better and their practice/ regime is, and listening felt like a sales pitch at times. We found some comfort initially in Cincinnati agreeing that the regime planned for Kenz here was a doable one even though it isn't exactly what they would do. After discussing with their doctor in Milwaukee, we are comfortable proceeding with Kenzie's transplant here. She will be admitted tomorrow. Thursday she will start chemo. This part of her plan is 9 days, with one of those being a day of rest where she doesn't get anything. On January 31st she will get the cells and that is considered day zero.

Otherwise, the kids are hanging in there. They are having a difficult time with the fact that they will have to go so long without seeing each other. Seeing their relationship grow over the past few months warms my heart.

I will post more details soon. I just wanted to let you all know that Kenz will be going in tomorrow and please pray hard for her. Also, in the next month or so we hope to reevaluate where Jack's lungs and kidneys are to get a better picture for him.

We appreciate all the love, prayers and support!

Next Wednesday, January, 29 there is a fundraiser at Texas Roadhouse in Kenosha. It's 4-10 pm. You have to mention the fundraiser or show the flier or pic of it on your phone to get credit for the fundraiser.

And tonight is a special night! The kids get to be on the court at the Marquette game! Someone will be sharing a bit of their story and how the team supports the kids. They also get VIP tickets and to sit on the bench before the game to watch them warm up! They are all decked out in their Marquette gear! I will be sure to add pics soon!

Sent from CaringBridge iPhone app

Comments

Continued prayers for all of you, and extra prayers for Kenz right now. ☺☺☺♥

—Heather Ray, January 21, 2020

We will be at the game looking for you. Continued prayers always going your way! Have fun tonight!

—Luanne Dikanovic, January 21, 2020

I am Praying for all of you.

—Margaret Babinski, January 21, 2020

I remember those freightful conversations a year ago! And praying everyday since! Word of the day: Strength (Phil.4:13 I-I can do ALL things through Christ who Strengthens me)

—Brenda Stratton, January 21, 2020

Our prayers continue for Jack and Kenz and you!

The strength of your kids is truly amazing and we direct our prayers for them to continue to fight against their illness. Much love to the kids and all family members and friends that care for you all.

—Karen Peltier, January 21, 2020

Prayers will continue for all, especially McKenzie right now. ♥ Have fun at the game!

—Marcy Hafeman, January 21, 2020

Much love and prayers to you and your family!

—Katie Omelina, January 21, 2020

Praying that you'll have 9 flawless days and that it's a go on the 31st! Hang in there Kenz! You've got this!!☺☺

—Debby Trewyn-Way, January 21, 2020

Prayers for Kenzie! Hope they have a great time tonight. ☺☺

—Stacy St Peter, January 21, 2020

Sending love and prayers your way:)

—Whittney Koepnick, January 21, 2020

You guys will definitely be in my prayers. I hope the game is a ton of fun.

—Pete Beth, January 21, 2020

My thoughts and prayers are with you all!

—Roberta Graf, January 21, 2020

Continued prayers of course and strength for the days ahead. Griffin hasn't taken off his Jack attack HLH bracelet since he got it almost a year ago. Now he knows he wears it to honor both of them in their fight.

—Mya Rubach, January 21, 2020

Continuing as a prayer warrior. Stay strong Ryans!

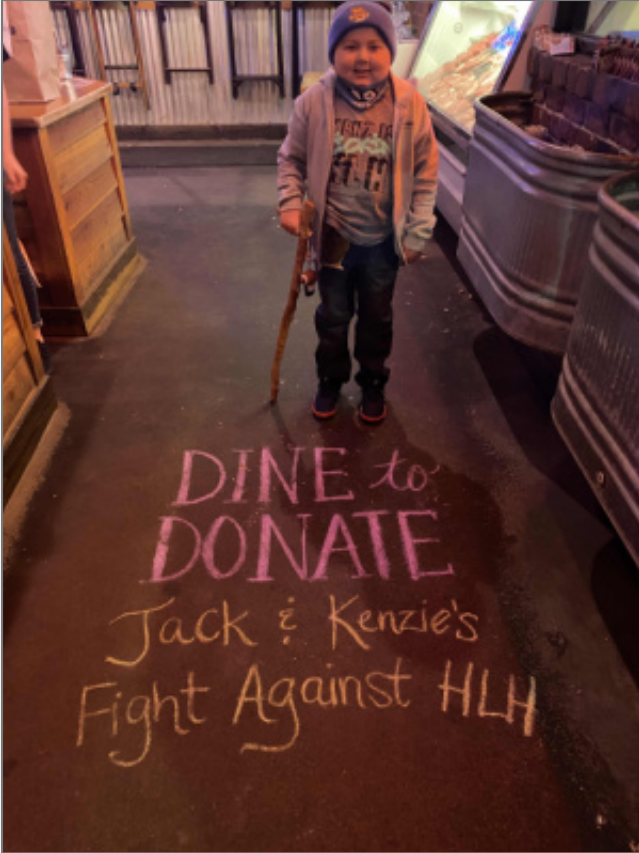
—Kathy Zaffiro, January 21, 2020

Continued prayers and positive thoughts sent your way. Loving thoughts

—pauleyn m nystrom, January 22, 2020

Day -1.... Jan 30th, 2020

Kim Ryan, January 30, 2020



Kenz has been hanging in there, she is so strong and brave! She finished all 7 days of chemo. Overall, she has been tired and had some nausea and vomitted a few times. Her appetite picked up Sunday and she was able to keep some food down so has been taking it slow. Her moods are up and down with her tummy aches of course. Today was a rest day. Her hemoglobin was low so she got a unit of blood. Tomorrow is the big day she will get her donor cells! From there, her numbers continue to drop and we keep her healthy and wait and pray the donor cells engraft. Hopefully her counts begin going up in a couple weeks. In 30 days they do a lab to find out how much of the donor cells are engrafting.

Other than that, she has been kicking my butt at Spot It and I am loving her snuggles when she takes naps. Her and Jack are trying to think of creative ways to keep in touch. They like to play Fortnite together and FaceTime. This time away has just begun but it's already hard on them. Today KENZ got a special visit with Jack and Raylee! It was so great to have them all together! Jeremy and I have been trading off with the kiddo since Jack cannot regularly visit KENZ inpatient due to the flu restrictions.

Jack had his monthly LP on Monday. Unfortunately, he now has HLH in spinal fluid again. They said rare macrophages were seen. The good thing is that they are rare. The plan is to repeat the LP in 2 weeks with intrathecal hydrocortisone (steroids). He will also be getting an MRI of his brain and spine which was part of the plan already but even more so now. Also, once these are completed, they will determine when to do the next GFR to see where his kidneys are at. Hopefully this leads to a plan or timeline for transplant. We have a different possibilities regarding his plan depending on results. Jack is raring to go and can't wait to get this behind him. I absolutely love his determination and drive! He can't wait to get back to playing sports, swimming and just having fun without all these appts and hospital stays. I can't say I blame him one bit!

Thank you for continuing to keep both kids in your prayers! ♥

Also, thank you for all those who came to or ordered Texas Roadhouse last night! We are forever grateful!

(For those of you who didn't see these shared on FB, the kids had an amazing time at the Marquette game!!!)

Photos









Sent from CaringBridge iPhone app

Comments

So nice running into you all today. Good luck and prayers for Kenzie tomorrow!

—Dana Monticelli, January 30, 2020



—Holly Benzow-Pittner, January 30, 2020

Hugs, Kisses and Prayers are sent to you all!

Can we send a card to hospital?

Love you All!!

—Chris Smith, January 30, 2020

Continuing to keep EVERYONE in my prayers.

—Sunny Nelson, January 30, 2020

Prayers for you all!

—Maureen Klotz, January 30, 2020

Continued prayers. Hugs!

—pauleyn m nystrom, January 31, 2020

Comfortable days ahead. With much love and hugs
KP and JP

—Karen Peltier, January 31, 2020

Always in our thoughts and prayers. Praying for continued good days for both of them as they go through all this. Love the determination of them and the love that they have for each other to keep them going strong and encouraging each other. With much love and hugs and prayers to your whole family. Love you guys Aunt Joann (Diane) and UNcle Pat

—Joann Ryan, January 31, 2020

I started following your stories after seeing the kids at the MU game. Something about them drew me in and now they will be in my daily prayers!! I am a mom of a boy who spent years in treatment at the MACC center so I will always hold a special place in my heart for our kids who spend way too much time in the hospital!! ☺☺☺ God bless and fight on sweet Jack and Kenz! (...and Mom & Dad too! I pray for your continued strength!)

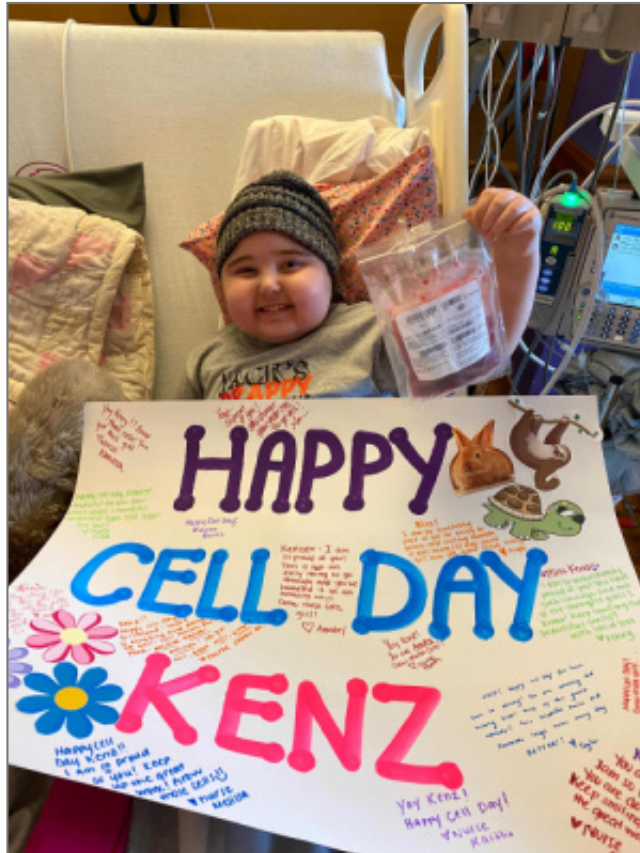
—CarolAnn Braovac, January 31, 2020

Praying all the time for those two precious hearts.♥♥
Ginger ale really helped my sick stomach when I was on chemo.
Maybe give it a try. ☺☺

—sue bernardy, January 31, 2020

DAY ZERO!

Kim Ryan, January 31, 2020



Quick update on how Kenzie is doing after getting the donor cells today. Unfortunately, in true Ryan kiddo fashion we had to have some action today. About half way through the cells, she started having a reaction so the cells were stopped. Her lips and tongue were getting puffy and swollen. She never complained of difficulty breathing. She received more meds and the cells were stopped until she started feeling and looking better.

Just to be on the safe side, she was transferred to the PICU to get the rest of her cells so she could be more closely monitored. Once restarted, everything went well.

The doctor said it is likely a reaction to what the cells were cryopreserved in. Since she was originally supposed to get her transplant in October, but it was postponed, the donor still chose to donate at that point. The cells have been “frozen” waiting for kenz to be ready.

Kenzie is now sleeping comfortably and doing well. It's hard to believe this day is here. Her Re Birthday is officially today, Jan 31st. Hopefully one day we will be able to personally thank the person who saved our baby.

I will update you as we know more as far as how her body is accepting the cells. This takes some time. In the mean time, we need to keep her healthy and keep the prayers going. ♥

Photos



Sent from CaringBridge iPhone app

Comments

Praying for you all!!

—Melinda Schmidt, February 1, 2020

Praying for kenzie and jack! ♥□□□□

—Brynnly Gaal, February 1, 2020

Novitski's are praying too!!!!

—Amy Novitski, February 1, 2020

Praying for you all---much love!!!!!!!!!!

—Joann Ryan, February 2, 2020

Day +14

Kim Ryan, February 14, 2020

Today is 14 days since Kenzie received her new cells. This is roughly when they said we might see her white count going up. However, Kenzie's started going up on Monday! DAY 10! We were cautiously excited at first because it's important to see a rise consecutive days. We are so thankful that there has been an increase in her white count every day since then. Her ANC (absolute neutrofil count) is going up as well. Also, Monday they did a repeat echo on her heart to check on the clot in her right atrium and it was GONE!

Tuesday, we found out that Jack's repeat LP came back with NO HLH seen! Oh my goodness! We did not even know how to handle so much good news at once other than to just cry and be so thankful to God for answering our prayers!

Kenzie seems to be doing well from a transplant perspective as far as numbers they are watching so far. She has been having significant back pain and muscle spasms. They started her on a PCA to help with the pain that also gives her continuous medication

which has helped somewhat. Pain team is helping us figure out how to help her the best we can. She also is having so issues with mucositis and hasn't had an appetite for quite a few days. They have her on TPN (iv nutrition). Overall, she is doing well for a transplant patient though and has found times during most days to be silly, a smarty pants and have a little fun playing a game or craft.

We are currently working on figuring out a plan with their dr for Jack. He is having appts here and there to assess his readiness in different areas for transplant. As always, he continues to do amazing things in PT and get stronger!

The kids have been missing each other like crazy but they've been having fun playing fortnite and roblox together, texting, FaceTime, and made each other the most thoughtful valentines!

I can't thank you all enough for your love and prayers! Please keep em' coming! Praying amazing things keep happening for these kiddos and that 2020 is another beginning of health and happiness for them!

Sent from CaringBridge iPhone app

Comments

I am Praying for Jack & Kenzie and all of you every day. God is so good.

—Margaret Babinski, February 14, 2020

Praying for you. ♥

—Shannon Morgan, February 14, 2020

Such good news!
This is an amazing family.
Continued prayers...

—Gina Dabbs, February 14, 2020

Praying for them everyday. God is great! Loving thoughts sent your way. Hugs to All.

—pauleyn m nystrom, February 14, 2020

Continued prayers and strength for Kenzie and Jack! It makes me so happy to hear such great news and it makes you realize how great God is and the power of prayer.

—Mya Rubach, February 15, 2020

WOW what a fantastic report and health progress. The POWER of prayers- keep them pouring in. With much love and continued prayers and support to you all.

—Karen Peltier, February 15, 2020

♥♥♥

—Holly Benzow-Pittner, February 15, 2020

So happy to hear some good news finally!! ♥☐☐

—Dana Monticelli, February 15, 2020

Rejoicing with you! I believe in the power of prayer! Hugs and love to all!

—Connie Coleman, February 15, 2020

So happy to hear some good news. Thoughts and prayers are with you always.

—Sharon Stollenwerk, February 15, 2020

So happy to hear the great news! Those kiddos are fighters! Sending more prayers and positive vibes your way!!!! ♥♥♥

—Lisa Groetzinger, February 15, 2020

So happy about your good news. Oh believe me those two are in my prayers every single day! You all are! Stay strong your children are amazing! Love, hugs and prayers to you all♥♥♥♥

—Sue Seils, February 15, 2020

Kenzie....SO HAPPY FOR YOU! Keep up the great work. Xoxo ☐☐

—Debby Trewyn-Way, February 15, 2020

Great news! Still praying everyday!

—Katie Omelina, February 15, 2020

So happy things are going in the right direction. Still praying.

—Peggy Ausloos, February 15, 2020

So glad to hear! I always keep them in my prayers♥

—Bonnie Santos, February 15, 2020

Such an answer to Prayer! Praise God! Your faith is amazing. Praying for the kids; for healing; for strength for you and Jeremy!

—Jenni Sprague, February 15, 2020

What wonderful news. Will continue Praying

—Emma Phelps, February 15, 2020

I'm beyond thrilled to hear your news!! All of our love to Kenzie and Jack.

—Rebekah Raleigh, February 16, 2020

Continued prayers and positive thoughts sent your way. Hugs! What wonderful news. Praise God!

—pauleyn m nystrom, February 16, 2020

Hi Kim, this is Amber Gilroy, Travis' mom from Nicole Hyatt-Dantes' class. Trav was just finally diagnosed with a rare GI sarcoma. After a year and a half of tests, they surgically removed the tumor, but it has a very high chance of recurrence and no know treatment

other than future surgeries if possible. As a mom who is battling for and with our kids, I'd love to chat and get Trav and Jack connected again. Letters are hard but maybe FaceTime or fortnite ☐☐

Your stories are so inspiring and we pray for you all daily!

Amber

—Amber Gilroy, February 18, 2020

Day 33

Kim Ryan, March 4, 2020



Quick update on the kids....

Today is day 33 for Kenzie. So far her numbers are great and where they hope they'd be.

She was having pretty significant problems with back pain and muscle spasms due to the compression fractures. New x rays showed worsening of her fractures. Thankfully the past couple days she has been more comfortable and we are praying she continues to move in the right direction. She knows that being completely pain free isn't likely right now but she is being so strong and such a trooper doing all she needs to continue doing to heal and move toward getting out of here.

She did spike a fever over the weekend but all

the cultures came back negative and has been fine since.

Each day some of her IV medications have been spaced out and some changed to oral as they can, and as Kenzie tolerates. She will have her heparin drip discontinued soon so will need to switch back the lovenox injections as long as she has her central line in to prevent future clots.

We see being discharged in the near ish future hopefully. As of right now, Kenz would go home on 24 hour iv fluids, 1-2 iv meds, lovenox injections, and many oral medications. She had made a lot of progress with mobility but is using a walker at this point. She will have 2-3 clinic appts a week and likely 2 physical therapy sessions.

Kenz is doing amazing and still finds reasons to smile (and give a little sass) everyday! She pushes herself further even when she swears there's nothing left. I am so proud of her!

Jack is still kicking butt in therapy and is the strongest he's been! He did some tests today and they showed so much improvement even from the middle of January! Like Kenzie, he also pushes himself so hard and has such great determination. He had so much fun today too which was great to see (and hear all the giggles)!

Jack has an LP next week. We will continue to have more appts as they assess his readiness for transplant. Their plan is for an April admission. He has been so eager to get this done and move forward so we can get back to life and all the things he wants to do, and he has a lot lol!

For now, the kids just want to be home for a little bit of time together so they can play and spend time together before they are separated for a short time again. Praying the flu

season ends soon so Kenz is able to stop in for visits!

I can't say thank you enough for all the prayers, love, and support from all of you! Thank you for the kind gestures and help, the meals, sweet messages/calls, all of it! You are all amazing! It definitely takes a village and we are so grateful for each of you!

Photos







Sent from CaringBridge iPhone app

Comments

So happy to hear all the positive news! Continued prayers every day for both of them.



—Heather Ray, March 4, 2020

You two munchkins are quite inspiring to say the least. Even though we have never met, I think of you two very frequently and pray you stay strong and push through this difficult time in your lives. Your parents are amazingly strong as well. All of you keep up the good fight.

—Romana Groeschel, March 4, 2020

You are all amazing to me! I cannot imagine the strength it takes to fight so hard. Keep fighting kiddos! ♥

—Lisa Groetzinger, March 5, 2020

Your family's strength, and the positivity displayed by the kids during such challenges, are truly amazing! We pray daily for the "Three H's" for them: Home, Healthy, Happy

—Paula Lattergrass, March 5, 2020

This update leaves me speechless with joy. Your kids are strong as you are. Our prayers will continue for all of you for that strength. LOVE is amazing and can conquer so much. Hugs

—Karen Peltier, March 5, 2020

Thank you Kim! We love you all so much!

—Diane Ellis, March 5, 2020

Prayers for your family all the time!!

—Jason Callewaert, March 5, 2020

Such awesome news for ALL of you! Keep up the great work Kenzie and Jack. I love all the great pictures too. You are one AMAZING family. xoxo

—Debby Trewyn-Way, March 5, 2020

Will continue to pray for your family. Kim you should be proud of your kids and yourself. They wouldn't be doing so well without a mom like you

—Emma Phelps, March 8, 2020

Kenzie is HOME!

Kim Ryan, March 10, 2020



After 48 days in the hospital, Kenz was able to come home yesterday! Jack surprised her by redecorating her room and she was so excited! And, he surprised her with a dinner she's been asking for. ☺☺ We couldn't be more excited to have them both home! We have at least one appt a day between clinic and physical therapy so it will be busy around here! Otherwise, we have to lay low and stay healthy. Right now Kenzie's numbers are great and we want to do all we can to keep it that way.

She wrote her donor the sweetest letter we hope to have them send out soon. We are so excited to see if we hear back!

Photos







Sent from CaringBridge iPhone app

Comments

Yay! What a wonderful thing. So happy to hear that Kenz is home and doing so well.

—Jacquie May, March 10, 2020

Yay! So happy for you all !!

—Jennifer Dye, March 10, 2020

The very nest news we could hear□□□□□□□□□□□□□□□□

—Holly Benzow-Pittner, March 10, 2020

Hooray!!!!!!!!!!!!!!!!!!!!!! I'm so happy to hear this news.

—Rebekah Raleigh, March 10, 2020

I am so happy for you guys. I hope this is the beginning of all good things to come

—Emma Phelps, March 10, 2020

Yay!!! WOO HOO!!! PRAISE THE LORD!! So happy to hear this!! ☺♥ ☺ I

—Kathy Sturycz, March 10, 2020

What a blessing to finally have Kenz home and good numbers to boot! Continued prayers and love sent for all of you♥

—Janet Brown, March 10, 2020

BEST. NEWS. TODAY.☺☺

—Debby Trewyn-Way, March 10, 2020

Wahoo! Awesome news! Thank you for sharing! Healthy, healing thoughts and prayers going your way!

—Trina Robshaw, March 10, 2020

We're so happy for you, Kenzie!!!

—Diane Eliason Misina, March 10, 2020

Yay! Answered prayers!
The love is palpable between brother and sister; it's awesome.
Keep those numbers good!

—Gina Dabbs, March 10, 2020

OMG, It brought tears to my eyes I am so happy for Kenzie, but for all of you! What wonderful news. Prayers are answered. Continued prayers and loving thoughts.

—pauleyn m nystrom, March 11, 2020

Prayers for y'all as this COVID-19 pandemic must be hell on earth for your family. Stay safe, stay home, wash your hands!☺☺☺☺☺

—Gina Dabbs, March 19, 2020

Day +50

Kim Ryan, March 20, 2020



Today is Day +50 for Kenz!! Her numbers have continued to be great. She has had some slight issues with nausea and her tummy because she takes quite a few pills. But, overall they are very impressed with how well she's doing. Kenzie's back is feeling better and she's adjusting to getting around the house with the rolling walker. She continues to become more independent too. We are so proud of her!

The kids got a cough last week (yes, extremely convenient timing, I know) so their appts were up in the air for most of this week. They both were supposed to have busy weeks with labs, LPs, Jack's Chemo and Kenzie's echo. Thankfully, we got to go in Wednesday after getting the negative COVID-19 results to know Kenzie's labs were still great and

Jack got chemo. Their LPs are both on hold and it sounds like Kenzie won't be getting hers at all. If all is well overall next week, she will be off decadron for good! Jack still needs his LP but since it is not considered "emergent," his will be postponed until further notice. Also, due to all of this, his bone marrow transplant we were planning for April, will be postponed as well.

(They did get 2 negative swabs and their cold symptoms are improving)

Some great news for Jack is that his creatinine was great this week! Praying his kidneys continue to be happy and show improvement.

The kids were going to PT 2-3 a week, they haven't been able to lately so I am trying to get Jack to help come up with some creative ideas so we don't get too far behind with their rehab.

I know this is a scary time for everyone. We haven't had to change much of the way we've lived for the past year, it's mostly the increased worry than the change in our activities. I am so thankful both kids are home and I can keep them tucked away here as safe as I can but I know germs are everywhere. They still have to leave for appts and walk through the hospital. I know they are doing what they can to minimize risk there.

I worry so much that when I have to run out for groceries or to the gas station that I will cross paths with the wrong person and bring something home to them. Today we all worry more about COVID-19, but really it could be anything. This cold is even tough on their lungs. With them being sick makes it easier to get sicker.

It is so scary to have immunocompromised children during something like this. I know there are many children like mine in the same situation, adults that are compromised themselves, and caregivers that are trying so desperately to keep their loved ones safe and to be able to get the supplies they NEED that are more difficult to come by right now (Partially because people are hoarding and stockpiling. But, I won't even begin talking about that.... ☹️) and my heart goes out to all of you.

Prayers and love to everyone. Try to stay healthy, and stay home (to protect yourself and those that need extra protecting) ☐☐

Photos





Sent from CaringBridge iPhone app

Comments

Thankful the kids are both doing so well, and as safe as they can be in these uncertain times! We've been thinking about them and sending prayers that their treatment & healing continues.

—Paula Lattergrass, March 21, 2020

It's so great to hear such wonderful news in the midst of all the craziness that's going on in the world right now. I'm so happy to hear they're both doing so well. ♥

—Heather Ray, March 21, 2020

What great news. Continued prayers and positive thoughts .

—pauleyn m nystrom, March 21, 2020

Love you all SO MUCH! Praying daily for all of you! You are such troopers! ☺☺☺☺☺ Much love to you, Aunt Kathy

—Kathy Sturycz, March 21, 2020

Thank you so much for your update! I'm so glad the kids are home and doing alright at this time. May your spirits stay strong as this journey continues. I pray for all of you and am sending positive thoughts! All my love!

—Joan Perugini, March 21, 2020

Great news that she is doing so good. Hope the colds gets better. Stay safe and keep those kids safe. Much love to you all

—Joann Ryan, March 21, 2020

We've been praying for you guys everyday. For your protection especially from this coronavirus.

—Amy Novitski, March 21, 2020

Thinking of you often. Glad that Jack and Kenz are home. Love the pictures of them with Dakota. Prayers for you and your families health.

—Alice Polzin, March 22, 2020

Continued prayers , thinking of you all!

—Maureen Klotz, March 23, 2020

Thinking of you all very often! Thank you so much for the updates! Continued prayers!!!!

—Brandy Bertzyk, March 24, 2020

Update & Day 88 for Kenz!

Kim Ryan, April 29, 2020



I hope all of you are doing well and staying healthy! I'm sorry it's been so long since I've updated. The kids are doing well and I can't say enough how happy I am to have them both home. They love spending time together and are both working so hard at getting stronger and becoming more independent. Since it's been a while this might be a long one...

Unless something happens during the week, the kids have typically been going to clinic once a week for labs and Jack gets chemo every other week.

Kenzie's transplant numbers continue to hold steady in a great place. She has been struggling with nausea and eating and some stomach issues we're trying to figure out. They started treating her for mild upper GI graft vs host just in case. Most days it's not more than bites of food. Some medications were just changed so hopefully that helps. There have been slow improvements along the way and she is trying so hard, we couldn't be more proud of her.

She still has a cough that's been hanging around for well over a month. Her back pain is in a much better spot now so she can cough more comfortably but she can't cough up what she needs and is vomiting every couple days. She has a chest CT and pulmonary

function test next week. All of this is a viscous cycle and praying things will start to fall into place for her and she can begin to feel better quickly.

Kenz is down to iv fluids 12 hours a day already! (Same as Jack)

Just a glimpse into how many pills these kiddos have to take each day... they both take about 13 in the morning, 4 in the middle of the day and 12 before bed. And, Kenz still has her lovenox injection every night.

Most of Kenzie's meds can be weaned closer to 6 months after transplant. She has to be on lovenox until she gets her central line out which may be roughly around then as well. They have both come so far with taking pills! I remember being much older and not being able to. Now they are both telling me what each one is, what it's for and keep me on my toes making sure I don't mess up lol.

Mobility wise she is doing AMAZING! She went from using the walker to the cane for only a few days before she ditched it and started walking around with nothing! We are working on distance and conditioning. The kids got recumbent bikes and they have a blast! The smiles and giggles are the best!

Jack's numbers continue to improve and he is getting so strong! He is flushing his own line and hooking himself up to fluids at night! Monday his creatinine (kidney lab) was the lowest it's been and last week was on the low range for him as well! We've never had 2 weeks in a row like this. It is very encouraging.

After speaking with their doctor, she feels the best time to take Jack to transplant is 4-5 weeks. She is very happy with how things are going and that this is the perfect window with it being summer soon and not knowing what the fall brings with covid and flu season. We can get him out so he can be home to recover in a safe place without the extra germs.

This week she is discussing things with the other BMT docs and consulting others on which type chemos they plan to use. Monday Jack will have some labs drawn. We should have a date soon. Once the date is set, they work backwards by planning his pre

transplant work up. I will keep you guys posted when we know a date!

The kids have been working hard on school. Kenz was behind due to being inpatient and not feeling well and is all caught up! Jack is already done with school for the year. He has also already completed boater safety. He plans to move on to ATV safety next!

They are both excited and thinking hard on their Make A Wish wishes. Dakota is getting spoiled with them both being home and loving every second of playing with them and all the love and snuggles. Jack helps cook dinner every night and he's even gotten Kenz into playing Fortnite with him and Jeremy.

Those are some of the highlights of what's been going on around here. Please continue to keep our family, especially the Jack and Kenz, in your thoughts and prayer as we approach the next part of our journey. We think about all of you often and are so appreciative of the continued love and support as I know we are all going through some major changes and challenges during this time.

Sending love and prayers to all of you!

Photos









Sent from CaringBridge iPhone app

Comments

What a beautiful update. Thanks for the detail of bringing this all together for the prayer warriors. Hugs to you and Jack and Kenz. The photos are fantastic. Kids you look great and working on your strength is amazing. Of course you both are amazing. With much love Karen and Jerry. KP and JP xo

—Karen Peltier, April 29, 2020

Keep up the great work kiddos!! We keep you all in our prayers, always ♥♥♥

—Holly Benzow-Pittner, April 29, 2020

Great job kids! I am so impressed with how you guys just keep pushing on. You are setting an example for us all to follow!

—Anneke Thompson, April 29, 2020

Such great news. Thank you for updating. Thinking about all of you. Prayers and hugs and kisses continue. Stay safe and much love to all of you

—Joann Ryan, April 29, 2020

Awesome news. You are in our thoughts and prayers☐☐

—Anna & Larry Littel, April 29, 2020

So glad to hear the good news Kenz & Jack! I think about you two all the time! xoxo Mrs. Trewyn-Way♥

—Debby Trewyn-Way, April 29, 2020

What great news. You have all been so heavy on my mind. God has been answering my prayers! Continued prayers and loving thoughts. Pauleyn

—pauleyn m nystrom, April 29, 2020

Brings a lot of happiness to my heart to hear things are going so well! You all are truly an inspiration to me. Continued prayers and speedy recoveries! Love the Rubach Family

—Mya Rubach, April 29, 2020

I'm so proud of Jack and Kenz. This is a wonderful update! So happy to hear the good news!

Prayers I say every night for them.

Love to You All!

—Chris Smith, April 29, 2020

Prayers to an amazing family.

—Alice Polzin, April 29, 2020

You and your Family are always in my prayers.

—Margaret Babinski, April 29, 2020

Kim, I am so glad things are going so well for you guys. Great pictures of the kids. Continuing with prayers ☐☐

—Emma Phelps, April 29, 2020

Thank you for the update. I continue to pray for all of you every single night☐☐☐☐. Keep up the good work kiddos! Always in my thoughts and prayer♥

—Sue Seils, April 29, 2020

I'm so happy for the update! We think about the kids SO much. Love to hear that things are going well. ♥

—Rebekah Raleigh, April 29, 2020

I'm send love to you all. Your dad stood up for me in one of the most difficult times in my life. He is awesome and strong person. You kiddos are part of him and have his ♥ and strength. Nothing but love for you all!!

—Henderson Darby III, April 29, 2020

So happy for the update! You're all on our minds daily. Sending love and healing hugs your way! Stay well☐☐

—Susan Page, April 29, 2020

Thanks for the update! Continued prayers for your beautiful family everyday!!! ☐☐

—Brandy Bertzyk, April 29, 2020

Stay strong kiddos! We're praying hard for you down here in Florida! ♥ My two little ones (9 & 10 yo.) are now collecting can tabs for you literally everywhere they go, to show their support as well.

—Olivia Boatner, April 29, 2020

So many prayers and so many good highlights here! They are both so strong! Keep up the good work, we've been thinking about you all.

—Laura Covelli, April 29, 2020

So proud of all of you! Praying for continued strength on this journey! Love the new pictures! Thank you for the updates! Hugs and kisses!

—Diane Ellis, April 30, 2020

Praying for you both ☺☺☺ And for Mom & Dad...Proud Of both of you ... You inspire me!!!!
Sending Love , prayers & hugs from Arizona ♥☺☺☺

—Teri Hoffman, April 30, 2020

It was wonderful to hear from you and hear about the kids!!!! So happy things are improving some. It's wonderful to know you are all together. I love the pictures of the kids! It's great to see them active. Continued prayers for all of you!

—Joan Perugini, April 30, 2020

May 12, 2020

Kim Ryan, May 13, 2020



There has been a lot going on for us lately. I should mention that Sunday marked Kenzie’s Day 100 post transplant!! This is a great milestone for her and we are so excited to be a step closer to having this behind her.

Last Monday Kenz was admitted from her clinic appt due to her chest CT not looking good and a couple of labs being off. A couple days earlier she started vomiting more often and feeling worse overall. Her nasal swab was positive for what would be a regular cold to us but can effect compromised kiddos much more as we are seeing, it’s called human metapneumovirus. She spent a couple days in the PICU before transferring to the HOT unit. They did a bronch but some results can take a while so they started broad antibiotics in the meantime. Viral, bacterial, fungal infections or some type of pneumonia were all on their radar. So far nothing has grown back from the bronch. Initially she was needing up to 4L of oxygen but she is doing much better now. She has an increased need for oxygen when she walks and needs a little when she sleeps so we will likely be discharged home with her on oxygen temporarily until this passes. Since she has shown improvement with the antibiotics they think she had a virus and something bacterial. Her vomiting has drastically improved and she has actually been eating!! Kenz has been home for 2 mo and most days barely ate anything more than a few bites. Yesterday she

told me she was hungry!! Praying this is a new beginning for her and things continue improving. The plan is to be discharged Thursday after 10 day course of antibiotics is completed.

Jack and Jeremy are up north this week trying to get a turkey! They haven't seen any around lately so in the meantime they are enjoying the fresh air, working on projects and spending time together.

Last week Jack had a couple pre transplant appts. He had an LP which came back with NO HLH!! He needed an LP so his decadron could be weaned. For one of the chemos he's getting he cannot be on decadron. He also had another GFR (glomerular filtration rate) test done. This test describes the flow rate of fluid filtered through the kidneys. Jack's has this test done twice before, the most recent being in December. The results were 44 and 48. Healthy kidneys would be 100-160. Last Wednesday when this was repeated it was 86!!!!!!!!!!!!!! That is so amazing and brought us all to tears! Jack has worked so hard doing all he can to be healthy and strong! We are so proud of him and all he does every day!

Jack will be admitted June 15th and his cell day will be June 25th. Jeremy will be his donor. He has a work up early in June and goes to Froedtert early on June 25th for the procedure to get the cells for Jack the same day. It was always important to keep everyone healthy but now we feel it more.

Jack is so happy to finally have a date and can not wait because he wants so badly to get this all behind him so he and Kenz can get back to the all things they've been wanting to do for so long and to just be kids!

Please keep them in your prayers! And as always, we are so grateful for all the love from all of you! Thank you for supporting us through this long journey!

Happy belated Mother's Day to all the mommas!!!

Photos









Sent from CaringBridge iPhone app

Comments

Great News! Thank God! We continue to keep all of you in our thoughts and prayers. Your individual and collective strength is inspirational to us and to many. Stay healthy and keep the faith!

—Mike DeGarmo, May 13, 2020

This is wonderful news. So thankful to God for answering our prayers. Sending continued prayers and loving thoughts.

—pauleyn m nystrom, May 13, 2020

Love, prayers and hugs to you all!

—Sue Seils, May 13, 2020

Praying for all of you
The kids are so lucky to have such a great mom♥☐☐

—Emma Phelps, May 13, 2020

Prayers for staying healthy. ☐☐☐☐ Your kids are so resilient and strong. They got this.

—Jennifer Castillo, May 14, 2020

Great news!

—Sharon Stollenwerk, May 14, 2020

You are the best mom ever! Stay strong. You all amaze me. You will continue to be in our prayers. Hope Jack had fun. Any turkeys? Hugs.

—Leah L, May 14, 2020

Congrats on day ☐☐ Kenzie! I'm so happy for you! Jack, I'm praying that things go as planned in June. Praying for all of you☐☐

—Debby Trewyn-Way, May 14, 2020

Awesome news! You are an amazing family! Praying for more miracles!

—Diane Ellis, May 14, 2020

Thinking of you! Such good news. Prayers to stay healthy☐☐♥☐☐

—Alice Polzin, May 14, 2020

So glad to hear the good news! I was just thinking of you (kim) last night and wishing seri g how everything was going and that you're doing well.. sending much prayers and love to all and extra prayers to stay healthy in this uncertain time.

—Dana Monticelli, May 15, 2020

So wonderful to read the positive updates for both Kenz and Jack. God is good and I know He has been on this journey with you. Continued prayers for the kids and mom and dad. Sending hugs and love from the mountains in Georgia.

—Jane Pierce, May 15, 2020



—Holly Benzow-Pittner, May 16, 2020

Saw “someone” with Christian Yelisch on the WTMJ site! How fun!
Anyway...such good and hopeful news! Hang in there; good things are happening.
Stay strong, stay safe, God bless!

—Gina Dabbs, May 16, 2020

I am so happy to read your wonderful news about your beautiful children!!! I continue to pray for strength for all of you and better health and healing for the kids. They are amazing and so strong, as are you, Kim! I pray that the procedure for Jack and Jeremy is a success too! I love their pictures! You can see the love between them. Covering you all with positive thoughts and prayer.

—Joan Perugini, May 18, 2020

As I see your kids and how they have persevered through this difficult time in their lives, I am brought to tears thinking about the selfishness I have recently felt on how inconvenient Covid-19 is to me right now. Feeling like I don't have control to do what I want. You and your family are such an inspiration. Thank you so much for sharing with us. God is so good. I'm so happy Kenz's feeling better and Jack's transplant is moving forward. Will keep them in my prayers.

—Jenni Sprague, May 19, 2020

Kenzie's 10th Birthday Parade!

Kim Ryan, June 2, 2020

Very late notice, I know! I'm sorry! Kenzie's 10th birthday is this weekend. Since we all have to celebrate in different ways this year, we thought we'd do what many have been doing by having a birthday parade for her so she can still feel some birthday love! I haven't participated in one yet but have heard that some people decorate their cars, makes signs, etc. We will be out in the driveway as the weather is supposed to be nice! We would love to say hi just still have to keep social distancing in mind especially since we are sooooo close to Jack's transplant and Kenz has been doing so great. The plan is

for Sunday, June 7th starting around 3. If you can only come at a different time please let me know and we can still have Kenzie be on the look out. (This is a surprise)

Please text, call, or FB message me if you would like to be a part of Kenzie's parade and I will give you our address.

My number is (262) 308-3783

Last year Jack was in the PICU for her bday so they are so happy to be home with each other to celebrate! Thank you for helping me make this day special for her!

Sent from CaringBridge iPhone app

Comments

Hi Klm! This is Juan Pablo's mom. I'm so happy I found this to keep up to date with Jack and Kenzie. We have thought of you guys so much and keep you all in our prayers. Juan Pablo loves his Pablo puppy Jack gave him. What area do you live in so that we can see if we can come out to sweet Kenzie's birthday parade? So glad to hear things are moving along.

—Herlinda Franco, June 5, 2020

Hi!! So great to hear from you!! Yes, I have taken a nice long break from Facebook that has been much needed. ☺☺ I'm glad you found it too! We live in Mount Pleasant.

—Kim Ryan, June 5, 2020

Hope you guys are doing well and enjoying being home together!! ♥

—Kim Ryan, June 5, 2020

So sorry we missed it. We were unable to make it but really hope that Kenzie had a good time. I look forward to seeing pictures!

—Herlinda Franco, June 8, 2020

Happy birthday Kenzie! I remember last year you brought us some cake (to celebrate both our birthdays!) cause we were just a few doors down in the picu with you all! So glad you guys are home for her bday this year!!

—Dana Monticelli, June 6, 2020

Yes! I remember that!! Happy birthday!!! Hope you guys are doing well!

—Kim Ryan, June 6, 2020

Sorry I just saw your post, I hope Kenzie had a great day. Happy belated birthday

—Emma Phelps, June 10, 2020

Thank you!!

—Kim Ryan, June 10, 2020

Happy belated birthday Kenzie!!

—Deanna Mleziva, June 11, 2020

Thank you!!! ♥

—Kim Ryan, June 11, 2020

Day +2 and +148

Kim Ryan, June 27, 2020



Jack FINALLY got his BMT!!! June 25th was the big day so today is day +2. Tomorrow and Monday he gets more chemo. So far he is doing well and in good spirits. He hasn't been wanting to eat much and is nauseous but is hanging in there. Jack has been having fun playing Fortnite with Kenz and his cousins, playing games and making keychains with paracord.

Jeremy donated for Jack the morning of the 25th. He was pretty sore but doing well. They told us they were impressed with the amount of cells they retrieved. They stopped half way through because they had enough. The goal is 2.5-5 million per kg and Jack got 6.6 million per kg!

Thank you to everyone who came out to Kenzie's Birthday parade and those who sent her birthday wishes by calling, texting, or sending cards/gifts! We all had such a great day! They even got to enjoy a water balloon/ silly string fight. Both kiddos said it was the most fun they've had in a long time. It was a perfect weekend before a long hospital stay. (And, Kenz made her own birthday cake this year. She did an amazing job!)

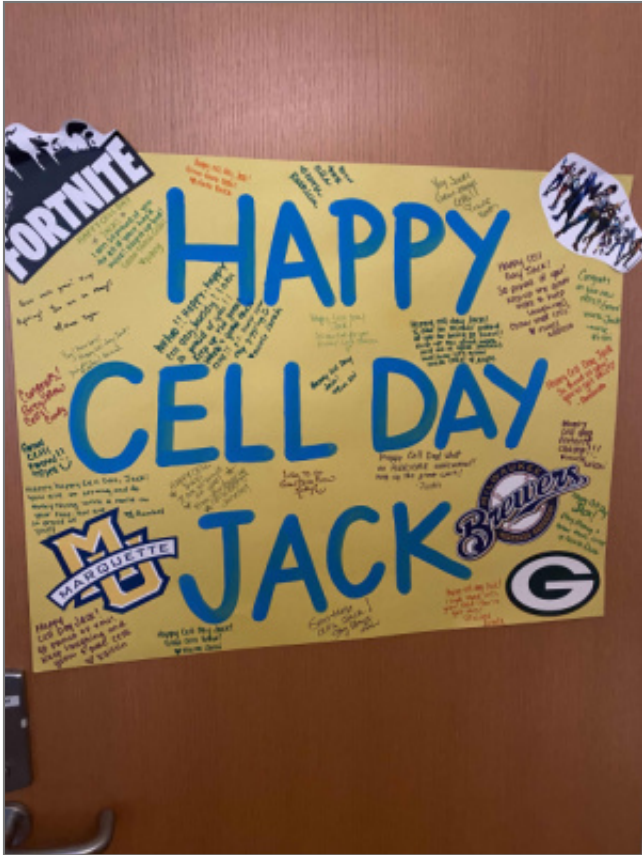
Kenz is day +148 and doing well. She is no longer on IV fluids but needs her line in for a bit longer. Some medications will be able to start being weaned in the next month or so as she is around 6 mo post transplant.

Thank you for continuing to keep us all in your prayers, especially Jack and Kenz. We appreciate all the calls, texts, messages, cards, prayers, EVERYTHING! Even if we can't or don't reply right away, know that we appreciate it all and feel comfort knowing we have so much love and support.

Photos









Sent from CaringBridge iPhone app

Comments

♥♥♥□□□

—*Laura Covelli, June 27, 2020*

Great news! You must be so very proud of these brave and strong kids of yours □□□□□ We keep praying!

—*Paula Lattergrass, June 27, 2020*

Wow, wow, wow! What a great outcome for both kiddos. Prayers for Jack as he continues to heal post transplant. It sounds like Kenzie is getting stronger each day, too. God is good!!

—*Jackie Bladow, June 28, 2020*

Great news! Continued prayers and loving thoughts. God is good!

—pauleyn m nystrom, June 28, 2020

Great news! Continued prayers and loving thoughts. God is good!

—pauleyn m nystrom, June 28, 2020

Continued prayers for all of you. Been praying this whole week a whole lot more. Keep on going Jack and Kenzie. You are both so strong and have such great determination. You have awesome parents . We love you all and continue with hugs and prayers . ♥♥♥♥♥♥♥♥

—Joann Ryan, June 28, 2020

Congratulations to Jack, and happy birthday Kenzie!! Such happy news! :)

—Deanna Mleziva, June 29, 2020

I am so glad things are starting to get better for you guys. Woll continue praying

—Emma Phelps, July 1, 2020

Day +7

Kim Ryan, July 2, 2020



I am definitely slacking on the updates... Of course there has been a lot going on over here. These kids are always keeping me on my toes.

Sunday Jack got his last chemo ever! This chemo required extra iv hydration 12 hours before and 48 hours after it's given. (He got it Saturday and Sunday) Monday he was pretty puffy, especially in his face. They gave him lasix to help him pee off some of the extra fluid and were watching his oxygen saturation. At night when we went to lay down, he began having difficulty breathing and was brought to the PICU. Thankfully he did not need to be intubated and was able to be on bipap for the night. He had to go to the covid PICU and get 2 negative swabs and be transitioned to a regular nasal cannula before he could come back to the HOT unit. We are so happy to be back there now. He is doing much better. It was an extremely scary experience for us all. They are now watching his fluid status very closely and making decisions daily on how to manage this and if lasix is needed. His oxygen is being weaned as he tolerates and is comfortable.

He was spiking fevers but hasn't in the last couple days. All of which they say can be expected given the timing during this process and for the type of transplant he had. It has to do with Jack's and Jeremy's cells "talking" to each other. The chemo given after

the cells is supposed to help with that which seems to be the case as the fevers have stopped.

That chemo can also cause significant nausea. Jack was really struggling with this. They have been trying many things to help. He had a much better day today and actually played a couple games and cracked some jokes. He has a PCA for pain and gets a few different meds to help with nausea.

As some of you may know, Jack wants to be a K9 officer when he grows up and he loves dogs!! He started collecting stuffed police department dogs and I wondered if you guys could help me grow his collection. I will attach a picture so you know what they look like and include the Ronald McDonald House address. They are typically sold as fundraisers for the dept and cost about \$20. I can definitely send money. Please let me know your address as well. So far he has all 5 Racine dogs, one from Vilas County, one from Sturtevant and one from Arizona. He also has Tosca the explosive military K9. To avoid duplicates because I know many of you guys live in the same area, please post in the comments if you are able to get one and from where so everyone can see. Thank you so so much!! He will be so happy! I'll post some pics!

Jack Ryan
c/o Ronald McDonald House

Rm 225L

8948 W Watertown Plank Rd

Wauwatosa, WI 53226

Sent from CaringBridge iPhone app

Comments

“Allied”
Madison PD

—*Scott Nelson, July 2, 2020*

I will work in Washington County's!

—*Beth Gatzow, July 3, 2020*

Glad to here you are back in the macc. I hope in all the moving around you have been able to sleep also. Take care.

—*Pete Beth, July 3, 2020*

We will send him one from Houston Texas where our grandson lives. Prayers are with you for continued health Carol and Rick

—*carol janick, July 3, 2020*

I checked eBay and all that was available is Houston as mentioned above. I am sending it just in case they are different. If the same, please just donate to toy closet. Praying fur continued healing and hooray for last chemo! Gary, Jen & Ty Nelson

—*Jen Nelson, July 3, 2020*

Waukesha county will be getting a package together for him!! My friend who is a K9 officer will be putting the package together for him. He does not work until next week though. I will get it to you as soon as I can!!!

—*Kristen Szajna, July 3, 2020*

My stepson is a K9 police officer in Mississippi! I will be sending one from there!

—*Lynn Bever, July 3, 2020*

Burlington is putting together a pack of the K9 cards for him.

—Anneke Thompson, July 3, 2020

I am contacting friends in IA - I will see what I end up with

—Joanne Davis, July 6, 2020

I am a k9 handler but do not have those stuffed animals. but do have k9 t-shirts nd baseball cards I would love to send. Looking to get shirt sizes please! Please email me lsilgjord@cloquetmn.gov

—Laci Silgjord, July 6, 2020

I found a Fresno Police K9 Dog plush. Malinois - Brown/Long Nose/Camo Vest that I will be sending :)

—Jamie Vitrano, July 7, 2020

I'm getting some from West Allis PD and greenfield PD.

—Laura Wuerzbereger, July 7, 2020

Hero from Marathon County will be there tomorrow!

—Erin Blaschka, July 7, 2020

Sending a package from the Town of Campbell in La Crosse, WI! T-shirts, a K9 flag, cards, and bracelets. Our kiddos wanted to pass on their Adams County K9 dog! Sending our thoughts and prayers!

—Stef Czys, July 8, 2020

Thank you so much ♥

—Kim Ryan, July 8, 2020

Hi Kim!

We are sending Jack the Greendale K9. I'm putting it in the mail today so it should be there soon! Also, not sure if you remember me - we used to work at Children's together back in the day - my maiden name was Hand ☐☐. Hope Jack is getting tons of K9s!

—Tami Reifenberg, July 8, 2020

Yes, I remember you! Thank you!! We appreciate it so much! The support has been

so amazing and overwhelming! It warms my heart!

—Kim Ryan, July 8, 2020

Hi Jack hope you are doing well. I have a gift coming to you from my family to you. We love dogs and knowing you love k-9 dogs we were able to get one for you from Portage WI. We live in Poynette WI but we don't have a K-9 dog but Portage does and if I can get ahold of any more I will be happy to send you them but for now Portage will do. Hope it helps bring a smile to you..

Wendy Tomlinson

—Wendy Tomlinson, July 10, 2020

Jack Day +16, Kenz Day +162

Kim Ryan, July 11, 2020



After a few rough days with our trip to the PICU and getting Jack's fluid balance under control, he is looking amazing. The puffiness is going away, he is still on oxygen but breathing more comfortably. His pain and nausea is under better control and has improved partially due to timing during transplant. His sass is back and he's cracking jokes! He loves to sit up in the chair and play games with us and Fortnite of course!

Jack's white blood cell count has been consistently going up since Day +13!! This is such great news! Jack has been spiking fevers rather frequently but has been seeming ok, actually more annoyed everyone makes a big deal about it. Haha! His kidneys have also been hangin in there. We are so excited for him to have amazing things happening. We are grateful and thank God so much that he is having good days.

There is much of our journey left but praying and praying to continue on this path. He is a rockstar. This kid is meant to do amazing things!

Kenz is kicking butt at home. She has that annoying little cough that comes and goes which has been happening since December. She sees Pulmonary on Thursday so we'll see what they say. Monday we hope to have her decadron discontinued forever!! And, they will start weaning one of her anti rejection meds. Otherwise, she's been keeping busy doing crafts, making slime and picking up her game on Fortnite. She had her first solo Victory! And, she's missing her brother of course.

Thank you so much to everyone who has responded to the dog request! The K9 love from all of you is overwhelming! Our hearts are so full!

Photos









Sent from CaringBridge iPhone app

Comments

Absolutely awesome news!!!!

—Sunny Nelson, July 11, 2020

Such an amazing Family! Continued prayers, Hugs!

—pauleyn m nystrom, July 12, 2020

Such an amazing Family! Continued prayers, Hugs!

—pauleyn m nystrom, July 12, 2020

We will be sending him a K9 Bleu T-shirt this week from all of us at the Spooner Police Foundation. We are thinking of you all!

—Danielle Larson, July 12, 2020

Thank you ♥

—Kim Ryan, July 12, 2020

Your children are amazing! With everything going on in the world people need to step back and look at your children and the very horrible adventure they have gone through! Your kids have fought a battle most adults could never begin to fight! I only know you guys through Rob and Emily but you and your children have become a part of my heart♥ Keep fighting the fight♥

—Sue Seils, July 14, 2020

July 14, 2020

Kim Ryan, July 16, 2020

Another action packed week...

Kenz broke her arm before clinic Monday morning. She was in a lot of pain the first couple of days but she is in much better spirits now. She realized her left arm is in the perfect dabbling position lol. It's quite frustrating to Kenz that she has finally begun being very independent again and now feels she has lost that. The plan is to keep it casted for a month, do an x-ray, then decide based on healing if she needs to be casted longer or one of 2 others for a short period of time. The decadron can affect her bones and healing time so they're going to keep a close eye on it to be sure to give her the time she needs for it to heal properly. We didn't get to stop the decadron, next Monday for sure. Then, the weaning one of the anti rejection meds can finally begin.

Jack is doing well. They continue to work on managing his fluid balance. He's still on oxygen, a scheduled diuretic and one as needed. He has eaten a few bites of fruit so far. Waiting for him to feel more comfortable eating and for his appetite to pick up. This is all very common. Once he starts eating more his TPN and lipids can be decreased or discontinued. Many of his medications have been switched from IV to pills already. The

ones that are left have to wait until he's closer to going home. His tummy pain has improved but is still there. The PCA is helping with that (most of the time). Jack has been working hard and going on more walks and getting stronger. He is doing an amazing job!

Jack is missing Dakota soooo much!!! She gets excited when she hears his voice over the phone and looks everywhere for him. That absolutely makes his day!

Please pray for some uneventful days ahead for both kids. (Only action we want is those cells to keep growing!! ☺☺♥)

As always, thank you for the continued prayers! We are so blessed. Jack continues to get packages and cards from people all over! It's so amazing to read the letters of encouragement some of the officers have taken the time to write and some of you following have as well. Jack reads each one and it touches our hearts.

Thank you! ♥

Sent from CaringBridge iPhone app

July 20, 2020

Kim Ryan, July 20, 2020

Jack was transferred to the PICU yesterday for high flow oxygen. They are trying to figure

out what they see on his chest CT and why he's spiking fevers. He's going down for a bronch and a chest tube.

Please please send prayers to our brave little man!

Sent from CaringBridge iPhone app

Comments

Hang in there. Praying for Jack!!

—Melinda Schmidt, July 20, 2020

Praying!

—laura pulda, July 20, 2020

Thinking of you and your family

—Jon Keiser, July 20, 2020

Hang in there Jack! My thoughts and prayers are with you!

—James May, July 20, 2020

Praying ☺☺

—Siri Walby, July 20, 2020

Praying for Jack!☺☺☺☺

—Debby Trewyn-Way, July 20, 2020

My prayers are going.

—Chris Smith, July 20, 2020

Lifting Jack and all of you in prayer.♥☺☺

—Janet Brown, July 20, 2020

Sending positive vibes to you Jack ♥

—Sharon May, July 20, 2020

Many prayers!!!

—Jason Callewaert, July 20, 2020

Praying for you Jack! Stay strong bud!

—Hannah Borski, July 20, 2020

Thoughts and prayers for Jack!

—Anna & Larry Littel, July 20, 2020

Sending prayers for Jack! Hang in there Jack!

—Nancy Gentz, July 20, 2020

Stay strong Jack. Praying for you and your family Kim.

—Jazmin Silva, July 20, 2020

Prayers being sent☐☐☐☐

Love and strength vibes to everyone!

—Gina Dabbs, July 20, 2020

Praying.

—rebecca jones, July 20, 2020

Praying for you Jack & family ☐☐☐☐☐☐

—Sarika Mandru, July 20, 2020

Prayers sent

—Andrea Patrick, July 20, 2020

Sending prayers for Jack!!!

—Jennifer Holle, July 20, 2020

Praying for you Jack!

—Danny Nguyen, July 20, 2020

Jack you can fight this too!

—Anneke Thompson, July 20, 2020

Oh no!! Stay strong Jack!! You are loved♥

—Susan Page, July 20, 2020

Sending prayers to you all!! Stay strong Jack! ☺☺☺♥

—Becca DeGarmo, July 20, 2020

☺☺☺☺☺☺☺☺☺☺

—Lynn Horne, July 20, 2020

Praying so hard ! Hugs!

—pauleyn m nystrom, July 20, 2020

We are still praying for both of you!! stay strong and courageous; God will never leave you nor forsake you...

—Gail Mallick, July 20, 2020

Prayers!! ☺☺

—Jennifer Dye, July 20, 2020

Hugs and prayers being sent♥Keep up the fight Jack you are so very loved by so many♥

—Sue Seils, July 20, 2020

Quit screwing around. We need you better so you can drive us around in the boat! We will continue to pray for you because that's all we can do right now! We miss you guys and look forward to seeing you soon. Get better damm it!!!!!!

—Fred & Sue Goertz, July 20, 2020

Prayers go out to Iron Man Jack for healing and answers!

—Lisa Wenger, July 20, 2020

on the prayers!

—Kathy Zaffiro, July 20, 2020

□□□□□□□□□□□□□□□□

—Mike DeGarmo, July 20, 2020

Prayers to Jack and family!!

—Jen Nelson, July 20, 2020

Sending prayers! □□□□□□□□□□□□□□

—Paula Lattergrass, July 21, 2020

Hugs and prayers Jack and family. □□

—Sue Behrendt, July 21, 2020

July 22, 2020

Kim Ryan, July 22, 2020

Jack is still intubated and is on a special type of ventilator called a bi-vent and has a chest tube. His final bronch results are pending but nothing has grown back so far. They started steroids to help with inflammation. He's on a bunch of drips to keep him comfortable although he still wakes up and asks about getting the tube out. His lungs are sick so we don't know how long it will take. He is a fighter. Thank you for all the continued prayers! Please keep them coming! ♥♥♥

A beautiful, precious little 2 year old recently lost her courageous battle with SJIA/HLH. Wear purple or pink tomorrow in memory of her and show her amazing, strong mama love and support. ☐☐☐☐

Sent from CaringBridge iPhone app

Comments

☐☐☐☐☐ sending hugs and positive thoughts

—Cassy DeSeve, July 22, 2020

Continued prayers for all of you, especially Jack ♥

—Heather Ray, July 22, 2020

Keeping you guys in my prayers every day! Precious little warriors you have!

—Teri Hoffman, July 22, 2020

Continuing to pray for all of you, especially Jack!☐☐☐☐

—Debby Trewyn-Way, July 22, 2020

Keeping Jack in our prayers- He is a warrior and has won many battles so we pray God's strength and armor be upon Jack.

—Jane Pierce, July 22, 2020

Sending continued prayers for Jack!!!!

—Jennifer Holle, July 22, 2020

Sending good vibes and lots of prayers for Jack and all of you!

—Jacquie May, July 22, 2020

♥□□□□

—Dana Monticelli, July 22, 2020

Praying for Jack. He is definitely a fighter. I am so deeply sorry for your beautiful kids going through this and for baby Hadley and her family. <3

—Herlinda Franco, July 22, 2020

Pulling for you guys! I hope Jack can get off the vent soon!

—Ellend Peterson, July 22, 2020

We have lots of prayer warriors out there for Jack.

—Karen Peltier, July 22, 2020

Continued prayers. Hugs!

—pauleyn m nystrom, July 22, 2020

Many prayers to you all!!!

—Jason Callewaert, July 22, 2020

Keep the fight buddy!!! All the love we can send your way!!!

—Eric Dahlke, July 22, 2020

Prayers for Jack every day. He truly is a hero for his fight keep up the amazing job Jack..

—Wendy Tomlinson, July 22, 2020

Prayers for Jack□□

You are amazingly strong and brave boy□□

Love Aunt Barb□□□□□□

—Barb May, July 23, 2020

Continued prayers for your family ☐☐☐☐

—Stacey Wallace, July 23, 2020

Payers for you Jack. ☐☐ You are a warrior, and my hero. Let's get you strong and back home soon! Love you buddy! ☐☐☐☐☐☐

—Sue Behrendt, July 23, 2020

Payers for you Jack. ☐☐ You are a warrior, and my hero. Let's get you strong and back home soon! Love you buddy! ☐☐☐☐☐☐

—Sue Behrendt, July 23, 2020

We continue to keep you all in prayer! Praying especially hard for Jack right now. Sending love and hugs your way!! You are never far from my thoughts and prayers!!

—Marcy Hafeman, July 23, 2020

Prayers to you and your family

—Katie Omelina, July 25, 2020

Praying so hard for you my friend!

—Lisa Wenger, July 25, 2020

Thoughts and prayers for you and your family!! Keep fighting!!

—dana Mueller, August 11, 2020

day +43 and 6 mo!

Kim Ryan, August 7, 2020



I know it's been too long since I've posted. I'm sorry. Jack is doing great! He transferred out of the PICU last weekend. He had some bumps in the road but right now we're just working on getting his blood pressure in a good place to go home. Some meds were increased and another added to help make this happen so we'll see.. Sometimes he needs extra IV meds to help decrease his blood pressure and he has to not be needing that for a period of time to go home. Jack's IV pole is so much smaller which is SO exciting! That's definitely a sign we are moving in the right direction. He is working hard getting stronger and is looking forward to so many great things ahead.

I can't even begin to explain the roller coaster of feelings throughout the past couple weeks, well, really this entire past 20 months. Somehow Jack defies all the odds and we are able to talk about being discharged home, finally! With so much thanks to GOD, the doctors and nurses that have taken great care of the kids AND us. You really get to know each other after all this time. (Also Of course thank you to all of you!!) ♥

Realizing that these Ryan kiddos didn't follow the typical picture for HLH or for other things as well. We know there is still much of our journey left but once we are home, we can have a big sigh of relief that this part is behind us.

Kenz is now more than 6 mo post transplant and doing amazing! She has an ortho appt

Monday to see what to do about that arm of hers. They are taking off her cast and doing an X-ray. From there, they will decide which type of cast should go on next. She also has her regular clinic appt and will continue weaning some medication slowly.

She has become so responsible and independent with her medication and all she needs to do. We couldn't be more proud of her.

They do a lab test roughly every month to check the graft and what percent donor their marrow is. Typically they begin checking this at day +30 but when Jack was really sick in the PICU they sent his at day +26. Even with Jack's lower intensity regime, his came back that early at 100%!! Kenzie's also has been 100%!!!

Thank you to everyone who has still been spreading the word about Jack and his dream to be a K9 officer! He probably has about 100 dogs, he's gotten many touching cards and letters, dog trading cards, challenge coins, awesome t shirts, along with other police dept items. Some have even sent items personal to them which warms my heart! There are so many good people in this world, we have definitely been reminded of this with the overwhelming outpouring of love for our family.

I hope to be sharing my next post from home!

Photos





Sent from CaringBridge iPhone app

Comments

You all are so inspirational! ☺☺

—Debby Trewyn-Way, August 7, 2020

Jack and Kenzie, so very proud of you two warriors! You are an inspiration to all! Looking forward to continued great news, Jack heading home! Love you all. ☺☺

—Sue Behrendt, August 7, 2020

Jack and Kenzi continue to inspire us all! God has big plans for both of them. Way to go warriors, your friends far and wide are so proud of you♥

—Janet Brown, August 7, 2020

God is good! You all certainly deserve some down time back at home. God bless and we'll keep the prayers coming!

—Paula Lattergrass, August 7, 2020

Such amazing news! Continued thoughts and prayers for all of you. ♥

—Heather Ray, August 7, 2020

Such fantastic news. I'm so inspired by Jack and MacKenzie.

Kim and Jeremy such wonderful Parents!

Love to All of You!

—Chris Smith, August 7, 2020

It is so nice to hear that the kids are doing better. I will continue praying.

—Emma Phelps, August 7, 2020

Just when I'm hesitant to open this journal, such great news! Love that ☺☺!
Prayers will continue; God bless you always, in all ways!

—Gina Dabbs, August 7, 2020

Yay! Praise The Lord!!! Love you!

—Kathy Sturycz, August 7, 2020

Such an awesome update! Prayers will continue....

—Brenda Stratton, August 8, 2020

Such awesome news! Praise God! Continued prayers.

—pauleyn m nystrom, August 8, 2020

So glad to hear the good news! You have the best kids and I pray for them and you all. Where you guys inpatient during July 4th? Juan Pablo sent some gift through Inspire Awesomeness. Would love to hear if you did or if you have any pictures of the 4th of July decor we sent.

—Herlinda Franco, August 9, 2020

We were! I wondered if that was you guys! I knew it sounded familiar but his name wasn't on it. I didn't get any pics because Jack was not feeling great for that period of time. He had a lot of fluid on board too and did not want pics

:(All the puffiness was in his little face. Thank you! We appreciated it so much! It was such a great surprise to wake up to! You are such an amazing family! What a great idea! Hope you guys are doing well!

—Kim Ryan, August 9, 2020

Thank you so much for the kind words and the continued prayers. ♥

—Kim Ryan, August 9, 2020

There was a little card that you may have missed that said it was from Juan Pablo's Inspire Awesomeness.. we do have a Facebook page if you are ever on there, feel free to like us. No worries, we are so glad it went to you guys. Juan Pablo treasures the Pablo puppy and the Ninja Turtles watch he got from Jack. I think highly of you guys and I am so happy to hear every good step moving forward. Sending continuous prayers and love.

—Herlinda Franco, August 11, 2020

I saw inspire awesomeness but I didn't see Juan Pablos name. It was also a rough time so I may have missed it.

—Kim Ryan, August 11, 2020

I'm not on Facebook.

I am so happy that he loves those things make Jack still has the paracord bracelets your other son made!

Thank you so much for the kind words! When I this craziness passes and the kids are well, it would be so great to see you guys! (Not in the hospital!) ☺☺

—Kim Ryan, August 11, 2020

Home!!!!!!!!!!

Kim Ryan, August 11, 2020



We made it home yesterday!! It's so amazing to be under one roof again. It was quite the memorable night! We spent some time in the basement as the sirens went and the power was out for a while. It was a hot night but we made it! With all the weather drama, it was comforting knowing both of them were safe and in the same place. I have to pinch myself to remember this is real and continue to thank God that He made this possible.

Jack had such a warm and amazing send off from such amazing people at Children's! Most of these

truly amazing woman lovingly cared for both of my children. I want to let you guys know who each of them are... his PICU nurses Dakota and Janelle. His HOTA unit day crew Alyse, Anabel, Beth, Sara R., Taylor, Kiera, and his night shift girls Melissa, Kaitlin, Ruthie, and Sarah M.

We can't forget Kelsey from child life who our children stole from the rest of the unit from day 1! Ann, from recreational therapy. Holly, from art therapy who has become Kenzie new BFF lol and inspired her and helped her find something to relax and calm

anxiety in a way nothing else can (she is also an amazing person)!

And, Laurie from what we like to call Jack's comfort care team from back in his PICU days. She was next to us in the scariest of days making sure that Jack's best interest was always #1! And we can't forget his team of BMT doc and NPs, Doctors Talano, Margolis, Sid and Phalan and Andrea and Miranda Kellyn and Amy.

I share all their names because they were by our side during the darkest of the dark and the happiest times, seeing it first hand, being sad with us and happy with us, being a listening ears as well. Like I've said, I am aware the road ahead continues to be long but we have to look back and appreciate and be thankful of where we are today. We will forever have a place in our hearts for each of these wonderful people and could never forget them.

Jack was so excited to see his Dakota! I've never seen her so happy! And, he spent a lot of time organizing his dogs... until the lights went out.

For now, back to clinic Wednesday and Friday. We hope for next week to be 2 times a week from here on out!

Kenzie got her cast off and the X-ray showed great healing of her bones! She has a splint to wear when she's walking around and couldn't be happier to be moving her arm more freely!

We are definitely counting our blessings! ☺☺☺

Photos





Sent from CaringBridge iPhone app

Comments

I'm so happy for you!!! I hope you can enjoy some quiet weeks with continued healing.

—Rebekah Raleigh, August 11, 2020

Thank GOD everyone is home. I don't believe we truly had a storm last night, just a lot of wind & sirens to WELCOME JACK HOME. I will continue to have ALL of YOU in my prayers, Thanks for ALWAYS taking the time for the updates. LOVE YOU GUYS.

—Sunny Nelson, August 11, 2020

Yay! I'm so happy for ALL of you! May God continue to watch over all of you. Enjoy being together...I know you will!☐☐

—Debby Trewyn-Way, August 11, 2020

Love this!!! Welcome home!♥♥♥

—Cassy DeSeve, August 11, 2020

Amazing news!!! So happy you are all home together again!!

—Deanna Mleziva, August 11, 2020

Tears in my eyes as I read this!! Rejoicing with you all and continuing to pray for a smooth road ahead! Hugs and love to all of you! ♥

—Marcy Hafeman, August 11, 2020

Praise the Lord! So thankful you are home together. We will continue to lift you all up in prayer as you continue the journey of healing. Love you all!

—Stacy St Peter, August 11, 2020

Praise God! The shower of blessings! Amazing! Continued prayers for All! Hugs!

—pauleyn m nystrom, August 11, 2020

So happy to hear this! Love the photos especially the one with the HOT unit staff! Blessings for sure!

—Herlinda Franco, August 11, 2020

So happy you are all home. I second the amazing staff at Children's hospital. I hope and pray your home is blessed with continued healing and a return to an active laughter filled house.

—Pete Beth, August 11, 2020

Back too soon

Kim Ryan, August 12, 2020

We had a memorable, hot first night back at home Monday night. We spent some time in

the basement due to weather and the power went out for about 7 hours. We woke up to water in the basement... lol.
Unfortunately, midday on Tuesday, about 24 hours after being home, Jack spiked a fever and had to go to the ED which we already knew bought him an automatic admission to HOT. Blood cultures, antibiotics....

He was and is still looking good and being his silly self. So, here we are. They are going down the list and ruling out what they can.

I will keep you guys posted when we have more information or if anything changes.

Please send love and prayers to Jack! ♥

Thank you all!!!!

Sent from CaringBridge iPhone app

Comments

□□□□□□□□□□

—Jason Callewaert, August 12, 2020

Prayers sent

—Ruth Principe, August 12, 2020

Praying for you, Jack! 🙏🙏🙏🙏🙏🙏🙏🙏🙏🙏

—Debby Trewyn-Way, August 12, 2020

Hugs and prayers Jack (and family). You've got this!! 🙏

—Sue Behrendt, August 12, 2020

Continued prayers, positive and loving thoughts sent Jack's way. Hugs!

—pauleyn m nystrom, August 12, 2020

Love and prayers are going for Jack!

—Chris Smith, August 12, 2020

I hope it will be a quick stay☐☐

—Cassy Hines, August 12, 2020

Continued prayers 🙏🏼 stay strong Jack! ♥

—Heather Ray, August 12, 2020

Love, hugs and prayers to you sweetie ♥

—Sue Seils, August 12, 2020

🙏

—Marcy Hafeman, August 12, 2020

Love you buddy! Stay strong. Praying for you. Hugs to you! 😘 Aunt Kathy

—Kathy Sturycz, August 12, 2020

Sending love and prayers 💕

—Barb May, August 12, 2020

Jack - praying that you will get back home soon. You're the best fighter of obstacles.
👍

—Karen Peltier, August 12, 2020

Jack we are so proud of you! You are so amazing. We send our love and prayers that you will soon be back home. Love Grandma and Grandpa Ellis

—Diane Ellis, August 12, 2020

Ugh, that is sooooo crazy! At least you can still find some humor. Jack you are the toughest guy I have ever met!!! Maybe we should've added some kind of crazy cool tattoo to your loot!! I could come up with so many ideas with your crazy fun attitude!!! I

miss seeing you all and continue praying for you, sister and you amazing mama bear! All our lives go out to you all!

Lisa Wenger

The Healing Haven of Wisconsin

—Lisa Wenger, August 12, 2020

Sending lots of hugs and kisses to all of you and lots and lots of prayers!

—Teri Hoffman, August 13, 2020