

Let's get GLOWing!

Sponsorship and Partnering to help those with Galactosemia

What is GLOW for Galactosemia?!

A rare disease celebration and fundraiser aiming to provide funds for research and outreach projects serving people who live with Galactosemia.

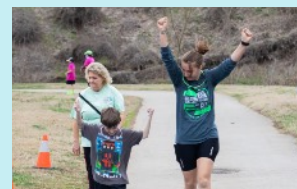
Hi friend! We are excited you are reading this newsletter, and considering a partnership with us as we seek to raise awareness, funds, and support for Galactosemia. This newsletter is set up to help you get plugged in, in the best spot for you! With \$0 government funding, every sponsor, volunteer, and participant is VITAL to the success of the Galactosemia Foundation's research and outreach efforts through GLOW. Without efforts like GLOW, there would be no foundation, no research, no support- so this is a BIG work we are doing here. We long for YOUR support in helping us continue on our mission!



Pg 2 Meet Ansell, Lou, + other faces with Galactosemia in East TN



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All the details on where you can plug in that fits YOU



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Lots of frequently asked questions, already answered!

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GLOW2022

Meet Ansell and her new sister Louise

Our children are a few of about 3000 people in the US with Galactosemia

Meet Ansell! Ansell Elizabeth was born on June 13, 2017 as a premature little fighter. After 7 days of life, while failing to thrive and looking at steep liver decline, amongst other scary symptoms, Ansell was diagnosed with Galactosemia, a disorder that would have killed her within 14 days if it hadn't been for the newborn screen. Now at 4 years old, Ansell faces many challenges because of her disorder, including speech, cognitive, motor skill, and other developmental delays. As she grows, she may face many more challenges (see box below). Continuing to fight the good fight, Anse is enrolled in the first pediatric clinical trial for Galactosemia, where a drug is being studied that could minimize the destruction of galactose in her future (more info can be found at appliedtherapeutics.com). As we watch her mature we are so inspired by her perseverance in the face of her challenges. She keeps us on our toes with her hilarious and strong willed personality, which she uses to draw people into knowing + loving her. (see more of her story on our social media @glowforgalactosemia)



We would love to also introduce you to the newest member of our little women crew- **Meet Louise Josephine**. As we anticipated her arrival, we knew there was a 25% chance she could inherit the same genetic disorder her sister has. In her first few days of life we treaded lightly, waiting for the Newborn Screen result to come back. After a few days of waiting we found out that Louise does have Classic Galactosemia. So as we watch her grow and learn how this disorder will affect her, we add her to the list of people we GLOW for.

WHAT IS GALACTOSEMIA?

Considered a very rare disorder, Galactosemia affects only 60-70 babies born in the U.S. each year (out of 4 million), and must be passed down genetically from both parents. When both parents pass down a mutated recessive gene that carries Galactosemia, it prevents the enzyme GALT from forming, which is responsible for breaking down the simple sugar Galactose. When Galactose isn't broken down, toxins enter the body by attaching to red blood cells and damage vital organs such as the brain, kidneys, liver, eyes, and reproductive organs. It is very likely that damage happens in utero, but any Galactose exposure (including Galactose the body makes) creates a disorder that is progressive, and can worsen as a child grows into an adult with symptoms such as tremors, seizures, increased cognitive delay, Premature Ovarian Insufficiency (POI) that causes infertility in many females, etc.

A baby with Galactosemia will be born healthy, but as days progress will become very ill. If the disorder is not caught in the first 10 days of life the disorder can take a fatal turn due to the fast decline of the liver and the formation of sepsis. After the disorder is caught and the diet is changed, a child may have life long effects from the initial exposure to Galactose + the Galactose their body. More information is on our website at www.galactosemia.org.

Sponsorship

We would love to get you plugged in to the brightest spot for RARE DISEASE weekend!

We have had 20+ sponsors over our past events, and it is SO fun to see them represented forever on the back of our t-shirt!

We are SO grateful to each and every individual and company that donates- and we make sure to publicly acknowledge our gratitude for those who make this all possible. It is our sponsors that provide most of the funds that are donated from our efforts.

Your donation goes directly to the Galactosemia Foundation, a 501c3 charitable organization, which allows a tax deduction at the end of the year in which you donate. We have an IRS certified letter you can keep for your records upon request.

Any inquires about sponsorship, requests for more information, questions, etc can be sent to brittany.cudzilo@galactosemia.org.



SPONSORSHIP LEVELS

TIER 1- \$200

- Company/brand represented on the t-shirt and website
- 1 FREE race registration
- Company/brand on the GLOW postcard for the race (included in swag bags as a thank you card)

TIER 2- \$500

- All the above +
- Company/brand on a yard sign at our start/finish line (**NEW THIS YEAR**)
- 2 FREE race registrations

TIER 3- \$1000

- All the above +
- Company/Brand becomes presented by sponsor (on shirt, printed materials, banner)
- 3 FREE race registrations, with tshirts

TIER 4- \$5000

- All the above +
- Company/brand becomes a headline sponsor, with the name being incorporated on t-shirt front and all GLOW products
- 4 FREE race registrations, with t-shirts

FAQ

Curious about something? Start here!!

We have 4 years under our belt, and although this page won't have all the questions answered, we went ahead and anticipated a few!

Do you have a TAX-id for the 501c3?

Yes, we have an IRS letter we give to each of our sponsors, along with a receipt, so that you can file it away for your yearly taxes, depending on when you make your donation.

Do we get tax credit for in-kind donations?

Yes, as long as the donation is a physical item. There is currently not a way to deduct services for tax purposes... but we do give sponsorship for services!

Any physical items are deductible at their retail value.

How many people do you expect to be at the event?

This one is tricky, but over the course of 4 years, we've seen steady growth in Knoxville and our virtual event. In 2021, we had over 700 participants between our Knoxville race and the 30 states represented in the virtual run. We love the energy that keeps building!



What happens with the money raised through GLOW?

All the proceeds of this fundraiser go straight to the Galactosemia Foundation. The foundation is run by a board of directors who help fund research projects and support families through outreach efforts. Every 2 years the foundation puts on a conference that educates families, builds community in our foundation, and brings together doctors who study this disorder which is funded by the foundation as well. The next bi-annual conference will be held in Orlando, FL in 2022.

Do you benefit financially from this fundraiser?

No... we benefit from being part of the foundation and helping raise funds for research that will have a positive impact on our daughters and the others who live with their disorder. Ultimately, this event is not about us (the Cudzilo family) but our Galactosemia family as a whole. We hope our efforts with GLOW will make a positive impact on our entire community.

Why should I donate to this cause?

The families who make up the foundation are the only source of income for it... we get 0 help from the government because our disorder is SO rare (about 3000 people estimated in the US live with the disorder).

We are seeking financial support from our local communities to help us find some answers to many hard questions our loved ones living with Galactosemia face.

This is a complex disorder, and every penny we can raise toward finding answers + a cure, is a penny we deem priceless.

Please email brittany.cudzilo@galactosemia.org with other questions, or contact Brittany Cudzilo at 865-405-1695.



Preliminary Race Information

THE SKINNY DETAILS

- March 6, 2022
- Local race in Knoxville, TN with virtual races across the U.S.
- FAMILY FUN RUN- 1 mile, FREE, with donations appreciated
- 5K and potential 10K to be offered in Knoxville, chip timed with race swag (including our famous GLOW tshirt!). A virtual option will be available for all those our of our area!
- The race will feature glow in the dark features (such as the ink on the t-shirts), and will take place just before dusk. Food trucks will be in attendance, and activities for kids (We have some VERY fun things in the works for this year, since its year 5!)

Read more about Galactosemia, the Race event, and other stories from Galactosemia families by visiting our website at glowforgalactosemia.org!

REMEMBER

GLOW is a family fun event, where the entire family is invited to hang out, enjoy the family fun run, face painting, food trucks, and playground.

OTHER WAYS WE COULD USE YOUR PARTNERSHIP!

- Volunteer to help at the event
- Talk to people in your life who might be interested in sponsoring our event of participating- word of mouth is our best advertisement
- Help us spread the word by sharing our social media posts and inviting friends to become a participant, volunteer, or sponsor through our Facebook event. You can even create your own team!
- Personal donations can be made on our run signup website or by check made out to the Galactosemia Foundation
- Create a virtual team, and recruit your community to join you in our GLOW efforts!

Thank you!



For taking time to look through what we have started working on for GLOW this year, and thank you for considering partnering with us in our endeavor to build up our foundation!

We would love for you to take the time to check out our glowforgalactosemia.org website, and follow our social media on instagram and Facebook to stay in the know, and receive updates on our efforts!

Our family is so grateful for your support! We can't wait to see you GLOW! Let's do this together March 6, 2022!

With lots of love,

Brittany & Ben + our little women

Race Director of GLOW for Galactosemia

brittany.cudzilo@galactosemia.org / 865-405-1695

