

# Lets GLOW up!

Sponsorship and Partnering to help those with Galactosemia

## What is GLOW for Galactosemia?!

We are an event on rare disease weekend that centers around providing a bright future for those who live with Galactosemia.

Hi friend! We are so 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 GLOW, and every fundraising effort is IMPERATIVE to our foundation's success. Without efforts like GLOW, there would be no foundation, no research, no support- so this is a BIG work we are doing here. We covet your support in helping us continue on our mission!



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The little face that inspired GLOWs start



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All the details on what this looks like and where you can plug in



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Lots of frequently asked questions, already answered!

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GLOW2021

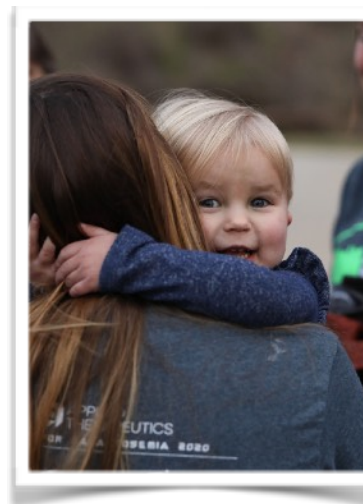
## Meet Ansell + her story

### Our little miracle is one of about 3000 people in the US with Galactosemia

Ansell Elizabeth Cudzilo was born on June 13, 2017 as a premature little fighter. We didn't know then that prematurity wouldn't be her only early fight... and after watching her lose several battles set for newborn thriving, we got THE phone call that changed our lives.

Enter the Newborn Screen. This test, given to all infants born in US hospitals, indicated our sweet sick girl had Galactosemia... a disorder that left her body unable to breakdown Galactose, which is found in the human body, and food such as dairy (including breast milk). Without quick diagnosis, Galactosemia can kill a child in 10- 14 days due to steep internal organ decline (more specific info below).

The Galactose that Ansell consumed with during her first week of life + what her body creates (galactose is necessary for life) damages her vital organs, and leaves her with developmental delays, balance issues, sensory processing disorder, little chance to have her own children, and many other possibilities of complication as she matures such as learning challenges, hormonal and growth deficiencies, etc...



Currently, Ansell is 3.5 years old and attends public school preK to receive speech and adaptive-behavior services in order to help her in some of the developmental hurdles she is facing. We continue to see growth in her abilities but also see the uphill battles she faces due to her disorder. We are also currently awaiting a date to start a clinical trial with Applied Therapeutics that shows promise in helping Ansell reduce some of the toxins galactose causes in her system.

## 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 sets of parents. Because 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 through the 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 after birth is also detrimental.

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 will make throughout their lifetime. More information is on our website at [www.galactosemia.org](http://www.galactosemia.org).

## Sponsorship

We would love to get you plugged in to the brightest spot on RARE DISEASE DAY!

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](mailto:brittany.cudzilo@galactosemia.org).



## SPONSORSHIP LEVELS

### TIER 1- \$200

- Company/brand represented on the t-shirt and website
- 1 FREE race registration, with t-shirt

### TIER 2- \$500

- All the above +
- Company/brand on the GLOW postcard for the race
- 2 FREE race registrations, with t-shirt

### TIER 3- \$1000

- All the above +
- Company/Brand becomes presented by sponsor
- Company/Brand on 2021 banner
- 3 FREE race registrations, with tshirts

### TIER 4- \$5000

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

We also give sponsorship for donated goods and/or donated services!

## FAQ

### Curious about something? Start here!!

We have 3 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... 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 3 years, we've seen steady growth in Knoxville and our virtual event. In 2020, we had over 500 participants between our Knoxville race and the 28 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 in our community who have financial needs. 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 daughter and the others who live with her 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](mailto:brittany.cudzilo@galactosemia.org) with other questions, or contact Brittany Cudzilo at 865-405-1695.



# Preliminary Race Information

## THE SKINNY DETAILS

- Feb 28, 2021
- Local race in Knoxville, TN with virtual races across the U.S.
- FAMILY FUN RUN- 1 mile, \$1 registration (for registration/waiver purposes, encourage donating also), each participant will receive a finisher ribbon
- 5K- Earlybird \$27 registration (increases \$5 each within 2 weeks of race), each participant will receive a t-shirt, and a souvenir at the finish line
- 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 (Tyson park has great bathrooms + playground for the kids, however this is at your own risk with COVID19 this year)

Read more about Galactosemia, the Race event, and other stories from Galactosemia families by visiting our website at [glowforgalactosemia.org](http://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. However, those in person must make decisions for their families knowing the risk of

## 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- 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. 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 sister race or virtual run with friends in your area (if you are not local to Knoxville)

*Thank you!*



For taking time to look through what we have started working on for our fundraiser 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](http://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 February 28, 2021.

*With lots of love,*

Brittany + Ben and the girls

Race Director of GLOW for Galactosemia

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