

# Sponsoring GLOW

Help us give those with Galactosemia a **BRIGHTER** future



## What is GLOW for Galactosemia?!

We are a spring event that centers around raising awareness, funds, community for the Galactosemia Foundation.

Our inaugural year, 2018, was a hit!! We joyfully joined together with 400+ members of our Knoxville community and 200+ of our virtual community to show support for families who live with Galactosemia, raising over \$17,000!

Our personal story is on page 2, but it's only a small part of the larger story- there are families worldwide living with Galactosemia who need the support of those around them. We need answers. We need financial support in hard times. We need a CURE. And we won't stop until we find one.

We would love to speak with you or a representative of your company on how you can be a part of this event in 2019! This newsletter is set up to inform you on who we are, what the event looks like, plug you into your place in partnership, and answer some questions we think you might have!



### Pg 2 Meet Ansie

The little face that inspired this...



### Pg 3-4 Sponsoring

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



### Pg 5 Race Details

What we are working on for 2019- and how you can help!

## Meet Ansell + her story

Our little miracle- will you help us brighten her future?

Ansell Elizabeth Cudzilo was born on June 13, 2017, 6 weeks early but unbelievably strong. Because of her prematurity, Anse was being monitored in the NICU from her first minutes of life.

Because of her strength, we didn't believe we would be in the NICU but a few days, but as each day passed Anse got weaker... she lost weight, she stopped waking up, and she stopped crying. By day 6 of life, the nurses were expressing some concern with her bowel movements, and they started watching her liver enzyme functions. Something wasn't right. She went from 4lbs 15 oz of strength, to 4 lbs 4 oz of very weak.

The Newborn Screen saved her life. We got her results a week after she was born that indicated she had Galactosemia... a disorder that left her body unable to breakdown Galactose, which is



found in the human body, and food such as dairy.

The Galactose that she was in contact with during her first week of life + what her body creates (its needed for cellular reproduction) damages her vital organs, and leaves her with developmental delays, little chance to have her own children, and many other possibilities of complication as she matures.

Currently, Anse is in physical, feeding, and speech therapy 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.

## 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, 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.glowforgalactosemia.com](http://www.glowforgalactosemia.com).

## Sponsorship

Let us help you get plugged into one of our 4 tiers, each one building on the ones before it

We had 20+ sponsors ranging from \$150-\$1500 for our 2018 event, 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 company that donates- and we make sure to promote them as much as we can in a profitable way.



Your donation makes research and supporting individuals who live with Galactosemia possible. Without the support of our communities the Galactosemia Foundation could not fund projects that change lives. We get no government funding due to the rarity of this disorder. We would love your partnership!

### TIER 1- \$200

- Company name/brand on the t-shirt (vector format)
- Company/brand on our website and promoted on our social media
- 1 race registration, with t-shirt

### TIER 2- \$500

- Company/brand on our race day banner
- Company/brand can have signage on the course
- 2 race registrations, with t-shirts

### TIER 3- \$850

- Company/brand may have a promotional table at the event
- 3 race registrations, with t-shirts

### TIER 4- \$1200

- Company/brand becomes a presented by sponsor, officially part of the title of the event
- 4 FREE race registrations, with t-shirts

## FAQ

### Curious about something? Start here!!

We have 1 year 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 2018 or 2019 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. Our inaugural event had 400+ locally, and 100 virtual participants. We dispersed almost 500 t-shirts and had 300 running participants.

#### **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.

Ultimately, we hope that our funds lead to research that ends in a cure.

#### **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.

#### **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 (1 in every 60,000 births).

We are seeking financial support from our local community to help us find some answers to many hard questions our loved ones living with Galactosemia will 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 [glowforgalactosemia@gmail.com](mailto:glowforgalactosemia@gmail.com) with other questions, or contact Brittany Cudzilo at 865-405-1695.**

# Preliminary Race Information

## THE SKINNY DETAILS

- March 3, 2019
- Local race in Knoxville, TN with virtual and/or sister races across the U.S.
- FAMILY FUN RUN- 1 mile, \$15 registration, each participant will receive a t-shirt + bag, and a ribbon as they cross the finish line
- 5K/10K- Earlybird \$27/\$32 registration (increases \$3 each within 2 weeks of race), each participant will receive a t-shirt, race swag, 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!)

Read more about Galactosemia, the Race event, and other stories from Galactosemia families by visiting

[www.glowforgalactosemia.com](http://www.glowforgalactosemia.com)

## OTHER WAYS WE COULD USE YOUR PARTNERSHIP!

- Volunteer to help at the event (and get a tshirt for your time + energy!)
- Talk to people in your life who might be interested in sponsoring our event
- Help us spread the word by sharing our social media posts and inviting friends to become a participant
- Personal donations can be made via PayPal on our website or by check
- 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 pour resources and funds into Galactosemia research and support.

We would love for you to take the time to check out our website, and our blog called “the faces of Galactosemia” which highlights others in our community- their stories and their life with Galactosemia.

Our family is so grateful for your support! We can’t wait to celebrate the successes of GLOW with you on March 3, 2019!

*With lots of love,*

Brittany Cudzilo

Race Director of GLOW for  
Galactosemia

[glowforgalactosemia.com](http://glowforgalactosemia.com)

[glowforgalactosemia@gmail.com](mailto:glowforgalactosemia@gmail.com)

865-405-1695