

GALACTOSEMIA GAZETTE



Galactosemia
Foundation
Linked for Life.

OFFICIAL NEWSLETTER OF GALACTOSEMIA FOUNDATION

A Farewell from Outgoing President Kellie Wilcox

Nineteen years ago, my oldest child was born early. Many events happened in his two weeks of life but one of the most significant was my introduction to Classic Galactosemia.

Because of Landon and Galactosemia, I have one of the best friends a woman could ask for, I have visited places and explored cultures that I never would have, I have learned WAY more about genetics than I thought possible, I have a community who can answer my questions within minutes, I am without a doubt a more empathic human because of the shoes I wear in this Galactosemia journey.

Most importantly, I have my son Paden, now my only with Galactosemia. He teaches me daily that life is what you make it so make it fun, make it happy, make it full! I have felt defeat due to an obstacle with Galactosemia, but it is never more than a passing thought because I am immediately reminded of the numerous blessings that outnumber any obstacles that have come up in our walk with Galactosemia.

Almost immediately after I learned how to say Galactosemia I found the Galactosemia Foundation. I started going to conferences and soon realized this is what my focus needed to be. Not only for Paden and Landon but for my future children and your children. It soon became my passion!



It all started in 2011, when I helped launch the silent auction for the 2012 Dallas Conference. In 2014, I officially became a board member and the rest, as they say, is history...and boy have we been making history!!!

As my time as president of the Foundation is ending, my son Paden is graduating high school and interested in becoming involved in the foundation himself; It seems to be lining up as it should be. It has been such a great experience being part of this foundation and helping from within.

I encourage you, **YES YOU** reading this right now, to send that email, send that message, take the jump to ignite YOUR passion and take an active role in supporting a cause we all care so much about! The Galactosemia Foundation is run solely on volunteer passion and is always in need of more of it! Your board of directors and committee members are made up of mothers and fathers of kids with Galactosemia but also of extended family members AND those who have Galactosemia! Everyone can contribute something! Learn more about board opportunities on page 5.



A Hello from Incoming President Nicole Casale

Hello everyone, it's with great pleasure that I introduce myself to you all as the incoming president of the Galactosemia Foundation. As I sit here trying to come up with something insightful, I have come to terms that it may never happen, so I will just start by saying how honored I am to enter the role of President.

My journey into the world of galactosemia started with Joseph my middle child, born in 2012. I won't go into the details as it is a tale many of you are familiar with. Like many of our beginnings it was a rocky start with so many uncertainties. Today Joseph is a thriving and energetic 9-year-old. When I think about the many obstacles he has had to overcome, and how resilient he is, I think about how true this is for every child and adult affected by the disorder. We are all so much stronger because of the experiences we have, and even though we are rare we are "linked for life."

My first conference was in Dallas, here Jojo was only 4 months old. At one point Michelle "borrowed" him. My mom asked where he was; I admitted I didn't know, as the President of the Foundation took him to show him off. While she gave the questioning look of, "really, some stranger has your child?" I just knew that this community was now part of my family. I was amazed at how close the community was, and knew this was something I wanted for Joseph and our family.

In 2014 I joined the Board, and have been hooked ever since. My roles have included Outreach, Secretary, Treasurer and now President. I look forward to meeting you at future conferences, whether in-person, virtual, or both. If I try to recruit you to the Board, just say yes, because we are awesome!

Galactosemia Together: Recognized as a Top Disease Education Website



Applied Therapeutics would like to thank the Galactosemia Community, especially everyone who helped with the co-creation of our Galactosemia Together community-driven website. Due to your creative contributions, valuable insights and continued engagement, we have all earned recognition as being among the top disease education websites in the industry.

Galactosemia Together has been recognized in the PM360 Greatest Creators Showcase, as a Fierce Pharma Finalist for Best Consumer Website, and a DTC National Finalist for Best Disease Education Website. We are so pleased to see all our collective efforts come together with such wonderful acknowledgement of our partnership and hard work.

Congratulations! We have had over 75,000 visitors to our Galactosemia Together website since launch, just 8 months ago. Thank you for being a part of the experience, and please continue heightening the awareness, and sharing these community resources with others! Bookmark our Galactosemia Together website (<http://www.Galactosemia.com>), watch our disease-focused videos on our Galactosemia Together YouTube channel (<https://bit.ly/galactosemiatogetherYT>), and follow us on our Galactosemia Together Facebook page (<http://www.Facebook.com/GalactosemiaTogether>).

Are You Following Us on Social Media?

Connect with us on social media for conference information, clinical trial announcements, monthly observances and more. You can find us on Facebook, Twitter and Instagram. Here is a look at some of our recent content and posts.



Research Study Opportunities

Calling Classic Galactosemia Babies and Children 4 years and younger

A note from Dr. Nancy:

We need more babies and children, age eight weeks to four years, with classic galactosemia for our NIH-funded Babble Boot Camp research study. Babble Boot Camp is an online clinical trial looking at early intervention to prevent or minimize speech, language, and motor disorders in children with CG. To learn more, contact us (Dr. Nancy Potter and BBC colleagues) at **BabbleBootCamp@ASU.edu**. We also need babies and children without CG to serve as controls. There is no cost to you, and you will receive a small stipend as a thank you for your participation.



Calling Classic Galactosemia Adults 30 and Over

Are you, or is someone in your family, an adult with classic galactosemia who is age 30 or over? If so, we need your help designing and conducting a research study to explore the outcomes of adults with galactosemia as they mature.

- Do new complications emerge?
- Do old complications resolve?
- Which interventions help?
- Which don't?

Our goal is to answer these questions and more, and we need your help to do it.

If you want to learn more about this study and how you can help, please contact Judy Fridovich-Keil at **jfridov@emory.edu**. Thank you!

Gerry Berry, Judy Fridovich-Keil, and Estela Rubio-Gozalbo

Share your journey



Jaguar Gene Therapy is a new company dedicated to accelerating breakthroughs in gene therapy. They are currently researching an investigational gene therapy for galactosemia in preclinical (animal) models.

While they are not yet enrolling patients in clinical studies, they are hoping to learn as much as possible from families living with Classic Galactosemia. If you are open to sharing your Classic Galactosemia story with the Jaguar team, please contact May Tobar (mtobar@jaguargenetherapy.com) to schedule a 1-hour introductory call.

The Galactosemia Foundation Seeks New Members

As of Sept. 1, the board has some exciting changes to announce. As you read previously, Kellie Wilcox is wrapping up her time as President. She has been a great president and we are thankful for her leadership. To fill the Presidents role, we had to do some rearranging of board roles.

Effective Sept. 1, 2021 the Galactosemia Foundation Board:

- **Nicole Casale, President** – Nicole joined the board in 2014. She has previously been the Outreach chair and most recently the Treasurer.
- **Brittany Cudzilo, Vice President** – Brittany joined the board in 2018 as the Outreach chair. In addition to supporting the President, she will continue with the outreach responsibilities.
- **Scott Saylor, Treasurer** – Scott has been on the board since 2012. He previously held the Vice President role. He also leads our Fundraising team.
- **Cari Miller, Secretary and NORD liaison** – Cari has been on the board since 2017. In addition to her secretary responsibilities, she will also be taking on our NORD liaison role.
- **Jodie Solari, Board Member** – Jodie has been on the board since 2018 and currently leads the Communications team.
- **Layne Long, Board Member** – Layne has been on the board since 2016 and currently leads the Conference team.
- **Keith Topper, Board Member** – Keith joined the board in 2020 and supports many board initiatives.
- **TBD, Board Member - THIS COULD BE YOU!**

If you haven't considered joining the foundation before, we encourage you to start now. If you have been wanting to get involved but didn't know how - here is your opportunity. We know our community is filled with capable people who want to make a difference for our loved ones with Galactosemia.

While we have one board position open right now, we also need committee members to support the current board members and roles.

Do you like event planning? You could be great on our conference team.

Do you want to be part of the team who reviews and awards research grants? You would be a great fit on the Research team.

Do you enjoy writing, graphic design or social media? You would be great on the Communications team.

Do you have a passion for fundraising? Do you have great ideas for how we could encourage our community to raise money for galactosemia? We would love your help on the fundraising team!

Do you have a talent or passion not listed above? There is a good chance we could find a use for it. Are you a photographer? A cook or baker knowledgeable in dairy-free recipes? We have a need for these and other talents to support our community.

Maybe none of roles mentioned fit your situation, but you just want to get involved and help – we would love that too!

Please [fill out this form](#) and someone from the board will get in touch with you.

GLOW for Galactosemia on March 6, 2022



GLOW 2022 is COMING for our FIFTH year on March 6, 2022, virtually and in person in Knoxville, TN!

In 2021 we had a record breaking number of Galactosemia families participate from 34 different states, and we are hoping we will keep adding to our count of families who are using GLOW as a way to advocate, educate, and fundraise for our Foundation!

In the first four years of GLOW, we've collectively raised over \$100,000 for the Foundation, which goes toward outreach projects and research. We are excited to continue our mission for Rare Disease Day 2022, and hope you'll consider joining us!

For more information on GLOW, please visit glowforgalactosemia.org, or email Brittany Cudzilo at brittany.cudzilo@galactosemia.org.



MARK YOUR CALENDAR:
July 28 - 30, 2022
2022 Galactosemia Conference
Orlando, FL

Connect with Us

Follow Galactosemia Foundation on Social Media and visit our website.



Contact The Board

Nicole Casale, President
Brittany Cudzilo, Vice President/Outreach
Lanye Long, Conference Committee
Scott Saylor, Treasurer/Fundraising
Jodie Solari, Communications
Cari Miller, Secretary