Hope everyone is doing well, there is so much going on with the Foundation now and in the coming months. For now I will only speak on conference, but don't forget about the El-P.F.D.D. on Thursday Sept. 1, 2022 (more information to come).

I'm sure everyone is aware, but CONFERENCE! It's here and I'm hoping to see you, whether in person or virtually. Can you believe the last time we were together was Denver? We have lots of great speakers, topics, and for the first year, if you are unable to attend in person, there is a virtual option for general session and breakouts.

There are so many things that my family and I are looking forward to. Seeing old friends, making new ones, the sweet treat buffet on Thursday makes the list too. And who doesn't love Florida in July? And lastly food! We are looking forward to having safe food to order, how often do you get to go to a hotel and just choose things off the menu without worry!? Probably not very often! We'll have the Foundation sponsored lunch on Friday and Saturday in the Crystal Ballroom. Breakfast will also be sponsored by the Foundation on Friday morning only.
THE COUNTDOWN TO CONFERENCE…
Here’s what you need to know!

CONFERENCE AND HOTEL INFORMATION
Registration is still open for the conference, click here to register today.
General - $250
Childcare - $300
Might G, G Force, Generation Gs - $300
Virtual - $100

Hotel reservations can be made at Renaissance Orlando at SeaWorld. To make your reservations you can call the hotel (407-351-5555) – make sure to let them know you’re attending the 2022 Galactosemia Foundation Conference.

You can also book online using our group block link: Renaissance Orlando at SeaWorld. For more information on rates and what the hotel has to offer, visit the Galactosemia Foundation website.

We are excited to announce that we will be offering a complimentary breakfast on Friday morning!

WHOVA: 2022 GALACTOSEMIA FOUNDATION CONFERENCE OFFICIAL EVENT APP
Download the Whova app for information about the conference and to connect with other attendees. Attendees must register for the conference before downloading the app. The event invitation code is Galactosemia2022
With the app you can:
- Explore the professional profiles of event speakers and attendees
- Send in-app messages and exchange contact info
- Network and find attendees with common affiliations, education, shared networks and social profiles
- Receive update notifications from organizers
- Access the event agenda, GPS guidance, maps and parking directions
We are looking forward to gathering on Friday night for our Talent Together event. Do you have a hidden, or not so hidden, talent? We would love to see it. Calling all singers, dancers, magicians, poets, jugglers, instrumentalists, jokesters and actors! Your deadline to register is July 15. Dress Rehearsal will be Friday evening 5:30-7:30 p.m. with the event from 7:30-9 p.m. All acts should be 4 minutes or under and feature music, lyrics, dress and acts appropriate for a family audience. To register fill out this form. For more info or any questions, please email TalentTogether@galactosemia.org.

Sign up for Friday Night's Talent Together

Silent Auction Items Needed

As always, the Silent Auction will be back with lots of great items for you to take home! The Board has been busy soliciting donations, but we need your help! We know many of you have connections, talents or items that we do not. Some ideas include:

- Homemade crafts or other items
- Theme baskets (movie night, spa, etc.)
- Tickets to an event
- Vacation home or Air B&B rental

All proceeds go into the Foundation’s general fund to help make these conferences possible! For more information contact board@galactosemia.org.
Are you planning to visit any Disney properties while you're in town? If so, we've got great news – because we are holding our conference in Orlando we are eligible for discounted tickets. If you have already purchased your tickets, call the number below to have the discount applied.

To purchase specially priced Disney Meeting/Convention Theme Park tickets, please call 407-566-5600 or CLICK HERE. Tickets are valid 7 days pre, during, and 7 days post meeting dates. The cut-off date for advance purchase savings 7/27/22. With the new Disney Theme Park Reservation System and park capacity limitations, it’s important to lock in your visit as soon as possible. A Park Reservation and ticket are required for entry.

Here are some other helpful links to help you reserve your tickets:
- Park Reservation Availability: https://disneyworld.disney.go.com/availability-calendar/
- Full instructions can be found here: https://disneyworld.disney.go.com/experience-updates/park-reservations/
- Park Hours: https://disneyworld.disney.go.com/calendars/month/

**Contact The Board**

Nicole Casale, President
Brittany Cudzilo, Vice President/Outreach
Scott Saylor, Treasurer/Fundraising
Jodie Solari, Communications
Cari Miller, Secretary
Keith Topper, Board Member at Large
Kelley Foley, Board Member at Large

**Connect with Us**

Follow Galactosemia Foundation on Social Media and visit our website.
THURSDAY, JULY 28
9 a.m. - Yoga/Networking Event on R-Lawn
2-8 p.m. - On-Site Research with Dr. Judy, Dr. Berry & Dr. Rubio-Gozalbo
3-8 p.m. - Generation-G and G-Force Registration
4:30-6 p.m. - Galactosemia 101 with Brittany Cudzillo, Nicole Casale and Maureen Bell
6-8 p.m. - General Registration
6-8 p.m. - Sweet Treat Buffet
6:30 - 7:30 p.m. - Research Committee Meet and Greet with Kelly Foley

FRIDAY, JULY 29
7:30-8:30 a.m.- Galactosemia Foundation Sponsored Breakfast
8:30-9 a.m.- Childcare drop-off, Late Registration for GG and GForce
7 a.m.-7 p.m.- On-Site Research with Dr. Judy, Dr. Berry & Dr. Rubio-Gozalbo
9-9:20 a.m.- Welcome to the 2022 Conference with Ben & Nicole
9:20-9:30 a.m.- Key Note: Speaker with Galactosemia - D.J. Trainor & Dr. Nancy Potter
9:35-9:50 a.m.- Meet the GF Board - what we do and why you should join us!
10-10:20 a.m.- Fundraising; Mobile Cause; Recognition and announce incentive winners
10:30-10:55 a.m. - FDA - PFDD with Debbie Drell
10:55-11:05 a.m.- NORD - Patient Registry with Nicole Casale
11:05-11:30 a.m.- Research Team Updates with Kelley Foley
11:30-11:50 a.m.- Applied Therapeutics Update with Dr. Shoshana Shendelman
11:50 a.m.-12 p.m.- Close of General Session with Ben Cudzillo
12-1:30 p.m.- Galactosemia Foundation Sponsored Lunch
1:30-2:30 p.m.- Breakout Series 1
2:30-2:45 p.m.- Travel to next session
2:45-3:45 p.m.- Breakout Series 2
3:45-4 p.m.- Travel to General Session
4-4:05 p.m.- Welcome Back
4:05-4:35 p.m.- Funded Research: Marching Towards a cure for CG with Dr. Lai
4:35-5:05 p.m.- Funded Research: Back to our roots: harnassing the power of natural remedies to treat CG with Dr. Hagen-Lillevik
5:05-5:15 p.m. - Closing -- Recap/Announcements with Nicole Casale
5:15-6 p.m.- Pick up children from childcare
5:15 - 6 p.m.- Designated meetup time and space for families to connect
5:15-7:30 p.m.- Dinner on your own
7:30-9 p.m.- A Grand Night for Talent Together evening social
SATURDAY, JULY 30

6-9 a.m.- Breakfast on your own
8:30-9 a.m.- Childcare drop-off, Morning Coffee
7 a.m.-7 p.m.- On-Site Research with Dr. Judy, Dr. Berry & Dr. Rubio-Gozalbo
9-9:10 a.m.- Saturday Opening Remarks with Ben Cudzillo
9:10-9:15 a.m.- Galactosemia Angels - we will remember! with Jodie Solari
9:40-10:10 a.m.- Funded Research: Bone Marrow Transplant in a rat model for Classic Galactosemia with Dr. Fridovich-Keil
10:10-10:45 a.m.- Funded Research: Adult Outcomes in Classic Galactosemia with Dr. Berry, Dr. Judy & Dr. Rubio-Gozalbo
10:45-10:55 a.m.- Travel to breakout sessions
11 a.m.-12 p.m.- Breakout Session Series 3
12:15-1:30 p.m.- Galactosemia Foundation Sponsored Lunch
1:30-2:30 p.m.- Breakout Session Series 4
2:30-2:35 p.m.- Travel to breakout sessions
2:35-3:45 p.m.- Coffee & Tea with Breakout Session Series 5 - Roundtable Meet and Greet
3:45-4 p.m.- Welcome to our Final General Session
4-4:10 p.m.- Paul Pruszynski Scholarship Award with Linda Manis
4:10-4:55 p.m.- Panel of Doctors Q&A
4:55-5:10 p.m.- Conference Closing Remarks/2022 Conference location announcement
5-5:30 p.m.- Pick up children from childcare
5:15-6 p.m.- Designated meetup time and space for families to connect
5:15-7:30 p.m.- Dinner on your own
7:30-11 p.m.- Saturday Night Social and Dance

Visit our website to view any updates to the conference and breakout schedules
Visit our website to view any updates to the conference and breakout schedules
NEW ALLSTRIPES RESEARCH PROGRAM TO STUDY TYPE 1 GALACTOSEMIA

We partnered with AllStripes, the rare disease research platform, to grow a galactosemia research program with the goal of helping power multiple studies for galactosemia.

We're excited to share the launch of a new AllStripes galactosemia program to increase knowledge about type 1 galactosemia. This research project can help support and inform clinical development of future potential treatments aimed at addressing the genetic root cause of type 1 galactosemia.

Natural history is the usual course of development of a disease or condition in the absence of treatment. This effort will help us understand more about how symptoms present in different age ranges, whether any symptoms correlate with specific lab values and other potential predictors of disease severity.

The de-identified information provided by families in this program may be used to:
- learn more about how type 1 galactosemia progresses in patients over time
- identify and understand important clinical lab values
- support broader type 1 galactosemia clinical development plans for a potential gene therapy

All data shared is de-identified, meaning no personal information like name or phone number is shared.

We are excited to see how this research progresses and look forward to providing you with updates as they become available. Thank you for all you do to move research for galactosemia forward. Learn more here.
GALACTOSEMIA HANDBOOK AVAILABLE SOON FROM JAGUAR GENE THERAPY

We’re excited to share that a new resource will be available soon! In partnership with members of our community and Jaguar Gene Therapy, we have developed a handbook titled, “Navigating Galactosemia Life Stages: A Handbook for the Galactosemia Community.” The handbook presents detailed information about how to manage galactosemia, up-to-date diet recommendations, and chapters specifically for each stage of life, including symptoms that may appear and how to be proactive about all aspects of your or your child’s care. Recommendations in this handbook from the newborn phase to adult life are based on the international clinical guidelines, peer-reviewed data, and insights from families, medical professionals, and galactosemia experts including Dr. Berry, Dr. Fridovich-Keil, Dr. Longo, Dr. Potter, and others.

This handbook will be available both digitally and in print at the 2022 Galactosemia Foundation Conference, July 28-30. For those who cannot attend, the handbook will be available after the conference on galactosemia.org.

RESEARCH OPPORTUNITY: NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT (NIH)

Classic Galactosemia can cause premature ovarian insufficiency (POI). NIH is conducting a study to learn why POI happens and if cryopreserving (freezing) ovarian tissue might help to preserve fertility for people with galactosemia.

Click here to view the flyer on the right.