

SUMMER 2020

GALACTOSEMIA GAZETTE

OFFICIAL NEWSLETTER OF GALACTOSEMIA FOUNDATION



President's Message

BY: KELLIE WILCOX, PRESIDENT

It's finally here! Conference time! Unfortunately, we will not be connecting face-to-face in North Carolina, participating in offsite activities or tasting the wonderful safe food.

BUT we still will make new personal connections, talk with our friends we haven't seen in two years and hear the latest research developments and diet updates. We are going to laugh and make memories - just a little differently than we're used to.

When the board decided to cancel the conference, we really wanted to find a way to bring the community together. With Applied Therapeutics' sponsorship, we were able to find that way through the virtual conference. We are excited about how many more people, families, countries and organizations the virtual conference can reach. We know this concept may be unnerving to some but there will be support behind the scenes to help.



There is something for parents, youth, grandparents and those impacted by Duarte Galactosemia. Whether you want to know about the clinical trial or just want to chat with parents who have kids around the same age, the conference will have something for everyone. If you haven't already registered, [now is your chance!](#)

I look forward to connecting with you!



Galactosemia Foundation Virtual Conference: July 17-19

While we were disappointed to cancel our 2020 Galactosemia Conference in Charlotte, North Carolina we are excited to bring you the next best thing – a virtual conference offering many of the same components!

We will have the latest information from doctors and researchers, an update about the clinical trial from our conference sponsor Applied Therapeutics and a chance to network with parents and individuals who can relate to many of the same frustrations and challenges you experience.

While some details are still being finalized, we are paying special attention to how we can provide the wanted information while also offering the interactive component we all look forward to at a Galactosemia conference. We know the friendships made at these conferences last a lifetime and we are not letting that component get lost in the virtual environment. The information you provide when you register will help us link you to individuals with similar situations. You will be connected to them during the conference and will have an opportunity to discuss the information, share personal stories and learn from each other.

General registration is for adults 18 years and older. Children's registration is for children 17 years and younger. Please share the conference registration information with your metabolics team or other galactosemia-related specialists.

There are three options for registration:

Adult General - \$50: Adults 18 years and older

Provider General - \$50: Clinicians and Researchers who provide care or conduct research, related to galactosemia

Children's - \$5: 17 years and younger

Please note, these are suggested age ranges.

You must purchase an adult ticket when purchasing a children's ticket.

All registrations include a swag bag - see the details on page 3.

If you are unable to attend the conference during the scheduled days and times, you can still register to have access to the recorded sessions following the conference.

[Register here](#)



On the Agenda

Each day will have general sessions for adult attendees and breakout sessions, based on interest as well as breakouts for the kids.

General Sessions

General session will include key note speaker Jamie Hiegel, funded research updates, a presentation from our sponsor Applied Therapeutics, information on the importance of joining the Galactosemia registry from NORD, updates from the Galactosemia Foundation board and more.

Adult Breakouts

A variety of breakout sessions are available based on your interest or personal situation. These will include updates from doctors, additional research updates and round tables by age/school level where attendees can learn from other parents with kids the same age.

Kids Breakouts

The different breakout options are still being developed but will include a cooking demo, and yoga.

Conference Swag Included with Registration

A conference swag package is included with each registration.

The package includes a t-shirt, mask, lunch box, diet cards and stickers.

You will select your t-shirt size when you register.



Meet Our Sponsor: Applied Therapeutics

We will have the pleasure of hearing from Applied Therapeutics during general session and breakouts.

You are also invited to learn more about them by visiting the Applied Therapeutics booth during the conference.

Make sure to stop in and say hello!



Meet Our Keynote Speaker: Jamie Hiegel

Jamie Hiegel is a graduate of Bridgewater College and an All-American in track and field.

With a B.S. in biology, Jamie's interests include human anatomy, health, and fitness. He is still a daily runner with hopes of future competitions.

Jamie attributes a lot of his athletic success to learning early on that life's challenges, Galactosemia or otherwise, are best faced with determination, commitment to your goal, and a positive outlook.

Often, it doesn't matter how fast you cross the finish line but that you finished the race and accomplished your goal.



Connect with Us

Follow Galactosemia Foundation on Facebook and visit our website for conference updates.



Contact The Board

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