

# GALACTOSEMIA GAZETTE

## GF FOUNDATION CONFERENCE 2017

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### Board Members:

**Kellie Wilcox**, President  
**Scott Saylor**, Vice President  
**Lisa Spiro**, Treasurer  
**Nicole Casale**, Secretary  
**Seth Schwartz**, Communications  
**Cari Miller**, Board Member  
**Layne Long**, Conference Chair

*We welcome feedback on the Galactosemia Gazette. Please reach us anytime at [newsletter@galactosemia.org](mailto:newsletter@galactosemia.org).*



By Layne Long

The Galactosemia Foundation is "Climbing to New Heights" Thursday, July 12 through Saturday, July 14, 2018 at the Marriott Tech Center in Denver, CO. Please mark your calendars! Exciting things are happening in the Foundation and we cannot wait to share them with you! The conference is a great time to see old friends and make new ones.

Registration is set to open in February 2018 and will continue until the start of the conference. You can even register onsite. The Denver Marriott Tech Center has given attendees of the conference the wonderful rate of \$139 per night and will honor this rate three nights prior and post conference dates. This recently renovated hotel has indoor and outdoor pools, an onsite restaurant with accommodating menu, Starbucks and many more amenities for our convenience, including free parking. There are several restaurants within walking distance and the Park Meadows Mall nearby.

If Climbing to New Heights is up your alley, then you will not



want to miss the rock wall and sweet treat buffet on Thursday evening. Everyone is invited to indulge in the always popular buffet of safe treats and this year the buffet will have a twist...DONUTS!! Friday morning, we will begin our program with a message from the new Galactosemia Foundation President, Kellie Wilcox (see pages 2 and 3). Followed by the Key Note Speaker, Mr. Jamie Siminoff, creator of Ring Doorbell.

That evening will be the return

of the Talent Show. Start planning your acts for next year. We cannot wait to see what everyone has been working on! Saturday is packed with informational breakout sessions, along with research studies by our favorite doctors from all around the world. The evening social will begin at 7:30p.m.

If you are interested in being a vendor or conference sponsor, please contact Layne Long at

[layne.long@galactosemia.org](mailto:layne.long@galactosemia.org).

Galactosemia Foundation

...LINKED FOR LIFE

## GF PRESIDENT SCOTT SHEPARD SAYS FAREWELL

Dear Galactosemia Foundation community,

I can't believe that the summer holiday is over, kids are back in school and fall is here. I love the change of the seasons, cooling weather and all of the traditions that come with autumn and harvest time. At the same time, the fall time is bitter sweet for me as memories of lazy afternoons at the pool, fireworks and summer vacations fade.

I am writing to you today to say farewell as the President of the Galactosemia Foundation. I began my term as president about three years ago, just after our 2014 conference in Orlando, Florida. In 2015, the Board of Directors decided to set four-year terms for each board position. We also created a staggered schedule for when board positions would end and staggered the end dates so that a maximum of two board positions would complete at any time. My term as President and as a board member was set at that time to expire at the end of August 2017. Our purpose in establishing defined terms for board positions was to empower and encourage more members of our community to join the board because they know that they aren't signing up for a lifetime.

It has been an honor to serve on the Board of Directors over the past six years and to have met and gotten to know many of you in the community. I am very proud of how we have come together as a team to continue to grow this organization upon the foundations laid by past leaders. Here are some of our accomplishments during the past several years that I am most proud of:

- Becoming a member of the National Organization of Rare Disorders (NORD). As members of NORD we have been able to broaden our reach and influence as an organization.
- Establishing a patient registry (please join the registry at <https://galactosemia.iamrare.org/>) in partnership with and through a grant from NORD.
- Enhancing our ability to communicate and collaborate through a technology grant from Microsoft, which has provided us with unlimited licenses to Microsoft Online/Office 365.
- Moving our website to a platform (SquareSpace) that allows us to easily create and edit our website without having to depend on professional web developers.



GF Past President Scott Shepard

- Establishing a biennial research grant program schedule. The most recent round of the research grant program attracted 14 proposals from researchers around the globe – more than double previous rounds.

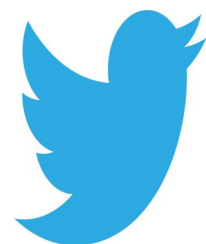
The Board of Directors and other volunteers met on-site at the Denver Marriott Tech Center to plan for the 2018 conference in July 2017. In addition to conference planning, the Board met in executive session in Denver for strategic planning and to hold officer elections. I am pleased to announce that Kellie Wilcox has been elected for a four-year term as the new President of the Foundation. Additionally, Nicole Casale was elected to fill Kellie's previous role as Secretary. I have great confidence in Kellie and the current Board of Directors and look forward to seeing our community "Climb to New Heights" in Denver and beyond.

While my time as President is at an end, I plan to continue volunteering for this great organization and encourage others to do the same. In the short term I expect to continue working with the conference committee to ensure the 2018 event in Denver is a wonderful experience for the community. I thank all of you that have become friends to our family over the years and look forward to connecting with many of you at the Marriott Tech Center next July.

Sincerely,  
Scott Shepard, Past President Galactosemia Foundation



Do you have a success story that you would like to share? If so please e-mail [newsletter@galactosemia.org](mailto:newsletter@galactosemia.org). We are always looking to celebrate achievements and accomplishments.



Follow us on Twitter for updates and information!  
[@GalactosemiaFDN](https://twitter.com/GalactosemiaFDN)

## MESSAGE FROM GF PRES. KELLIE WILCOX

By Kellie Wilcox

I am honored to accept the position of President of the Galactosemia Foundation. I can't express how grateful I am to be given this opportunity. I would like to thank the Board of Directors for the confidence they have in me to fulfill this position.

I would especially like to thank the outgoing President Scott Shepard, for the tremendous amount of time and work he has put into this organization. I am confident that I will be able to continue on, with the objectives that the Board of Directors has set forth. I recognize there will be challenges, which I am prepared to face. I appreciate the support of the Galactosemia community also.

My husband and I were introduced to Classic Galactosemia in 2002 when my first son, Landon, was born and diagnosed. He also had other, non-related health issues and passed away at 15 days old. When our son Paden was born in 2004, we knew a little more about Galactosemia, and again received a positive test result. I had spent 2 years researching and learn-

ing as much as I could, in order to be as prepared as I could, but as many of you know, you are never truly prepared. I needed to find others that I could talk to, that were going through the same situation.

I met some of those people and just a few years later we joined together to create a southern group for Galactosemia support, GFSS. Around the same time, in 2006 I learned what the Galactosemia Foundation was (or at that time "Parents of Galactosemic Children"), and have only missed one conference since that time.

I joined the Galactosemia Board after the 2014 Orlando Conference as a board member at large and shortly after moved into the Secretary position. However, I have volunteered in some manner, with the conferences since 2010.

I have thoroughly enjoyed my time on the board thus far and all the things I have learned. The dedication to funding research, continuing education, and networking within the community; are just a few great things this foundation is made up of and continues to make it great!

*"The dedication to funding research, continuing education, and networking within the community; are just a few great things this foundation is made up of and continues to make it great!"*



Follow us on Pinterest for updates and information!

## GF WELCOMES NEW BOARD MEMBER CARI MILLER

Cari Miller is an aunt to two beautiful nieces; the oldest age 11 has classic galactosemia, and the youngest, age 9, is a carrier for galactosemia. Cari has been attending the galactosemia conferences with her sister-in-law Tracey, since the 2008 conference (and they have some interesting travel stories as a result) !!! Her nieces started attending in 2012 and thoroughly enjoy their time at the conference meeting other children and participating in all of the activities. Looking for a way to give back, Cari volunteered to become an active member of the Galactosemia Foundation and was offered a Board position in late 2017. Cari has extensive professional experience in the healthcare arena, having developed, implemented and directed healthcare projects for more than 20 years. Her activities in the healthcare arena focus on several areas, including working with physicians, practice teams, and hospital/health systems to identify ways to improve the care they are providing to their patients, including access to care, implementation of evidence-based quality care guidelines, and overall patient satisfaction and engagement with the healthcare system. In addition, she has created and presented educational programs to members of the health-

care community. She is currently working for a large health plan with a focus on developing strategic partnerships and relationships among physicians, hospitals and the health plan.

To date, she has worked with more than 1500 physicians in more than 1000 locations on Patient-Centered Medical Home (PCMH) recognition and practice transformation projects, locally, regionally and nationally. PCMH is a model of health care delivery in which the patient and the family is at the center of all activities, and the patient, family and healthcare team work together to generate the best possible outcomes for the patient. Cari presents locally and nationally on PCMH and practice transformation topics including the need to drive value-based transformation and care coordination for high-risk patients.

Cari has implemented projects with national scope, including serving as Lead Regional Faculty Director, overseeing and directing implementation of the Comprehensive Primary Care Initiative for the Centers for Medicare & Medicaid Services in the New Jersey market. While with a state medical association for primary care physicians, she developed and implemented the *Patient-Centered Innovation Award* pro-

gram; a unique statewide program that serves as an opportunity for practice teams to showcase innovations they have designed and implemented that positively impact approaches to patient-centered care. Cari has a Masters in the Science of Management with a focus on leadership and organizational management. In addition, she achieved the designation of Patient-Centered Medical Home Certified Content Expert (PCMH CCE) from the National Committee on Quality Assurance (NCQA), and served on NCQA's Expert Panel to develop the Certified Content Expert Exam.



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## NORD REGISTRIES OFFER RESEARCH PLATFORM



GF attends NORD's IAMRARE Registry meeting to learn best practices.

By XXXXXXXX

Patient registries are a tremendous asset to the development of rare disease research, diagnosis, and treatment. Central collections of patients provide a foundation for scientific investigations and reduce the weight given to individual case anecdotes. For Marshall Summar, MD, Director of the Rare Disease Institute at Children's National Medical Center and Chairman of NORD's Board of Directors, registries are key for attracting researchers and vital for forging relationships with pharmaceutical industry partners. Since 2014, NORD has expanded its I AM RARE Registry Program. Participating NORD members are offered a common software platform for natural history data collection and a partnership with Hummingbird IRB, so that member organizations no longer need to seek and contract these services individually. NORD's I AM RARE Registry Program also represents a shift in ownership of information. Typically, registries are created by individual research institutions and become intellectual property of those institutions. In this project, the information is owned by the individual patient advocacy organizations.

On October 18<sup>th</sup>, Galactosemia Foundation attended NORD's 2<sup>nd</sup> IAMRARE Registry Users Meeting in Washington, DC, thanks in part to NORD scholarship support. The event provided an opportunity to hear some leading practices from other registries on creating disease specific surveys in the platform, encouraging patient enrolment, creating insights from the information, and for communicating the asset of registries to external researchers or industry. For example, The OMS Life Foundation documented that their median time to diagnosis has fallen from 137 days before 2005 to 16 days post 2015. They were also able to observe the underuse of behavioural therapy, an effective method to help address some of the neurological effects of the condition. The Foundation for

Prader-Willi Research (FPWR) has been able to register 1200 participants, have 600 take additional surveys, and have 300 people take all 37 of their surveys with insights to follow. The meeting was also an excellent forum for networking with other patient association board members, and staff, as well as NORD board members and staff.

Going forward there are many areas in which we can take strides to improve our Galactosemia Foundation Registry. Expect to see enhancements to accessing the registry from our website, acknowledging participants with recognition such as Facebook badges, and the launch of customized user guides for our registry including screenshots.

We will also be re-engaging our clinician/researchers to explore expansion of our product with additional surveys. We would love assistance from community members with this project. This information has so much to offer us, and we have only scratched the surface. Contact us at [registry@galactosemia.org](mailto:registry@galactosemia.org) with interest or questions.



**Galactosemia  
Foundation**  
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Do you have a fundraising event or idea? If so please e-mail [newsletter@galactosemia.org](mailto:newsletter@galactosemia.org). We are always looking to celebrate help event coordinators or offer a venue to spread the word!

**MARCH 4, 2018  
VIRTUAL RUNNERS  
1ST ANNUAL  
GLOW FOR GALACTOSEMIA**

**JOIN US FOR A NIGHT OF FUN!**  
We wish you could be with us in Knoxville, but if you can't we would love for you to support by running where you are! Become a VIRTUAL RUNNER!

**5K/10K**  
You choose!  
**\$25**  
per person

**HOW IT WORKS:**  
1. Register online under "virtual"  
2. Build a team where you are  
3. Get a tshirt + participant medal sent to you for each member of your team!  
4. Run/Walk and send us your photos! Let us know details and let us celebrate with you!

MUST register by JAN 10TH to ensure all materials can be shipped in time!

**REGISTER ONLINE AND/OR BECOME A SPONSOR:  
[WWW.GLOWFORGALACTOSEMIA.COM](http://WWW.GLOWFORGALACTOSEMIA.COM)**

# PLANNING YOUR COLORADO VACATION

Looking for exciting adventures to add to your Colorado vacation while attending the 2018 Conference? Here are a few ideas:

Colorado is a scenic state with an abundance of outdoor activities from hiking to white water rafting. Any age and experience level have a magnitude of options to choose from within a short drive from Denver.

Buena Vista, CO is home to several outdoor companies offering ATV rentals, rafting, hiking and horseback riding. This little town is two hours southwest of Denver and has fantastic views along the drive.

Estes Park is home to the beautiful Rocky Mountain National Park located 90 minutes north of Denver. Enjoy fishing, hiking, geocaching or an open Jeep tour.

If you are looking to stay in Denver then consider the Denver Botanical Gardens. The Gardens has two different locations to enjoy. The younger kids or still young at heart will enjoy the Children's Museum of Denver or the Downtown Aquarium.



## RECIPES!!!

### Apple Cake

Ingredients	Instructions
5C granny smith apples-peeled, cored & diced ¼"	Soak apples in the rum for 15 minutes.
¼c amber rum	Oven at 350f.
2¼c ap flour	Butter and flour a 10" springform.
2¼c granulated sugar	Sift together the dry ingredients
2t baking soda	Beat eggs slightly and add vanilla and oil. Stir until blended. Fold in walnuts
1t kosher salt	
1t cinnamon-ground	
1t nutmeg-ground	Drain and fold in the apples stirring just to evenly distribute apples and nuts.
1t allspice-ground	
3ea eggs	
¾c canola oil	Pan and bake approx. 45 minutes or until a toothpick inserted in the center comes out clean.
1t vanilla extract	Cool and remove. Portion at 12.
2c walnuts-toasted and chopped coarse	Serve with pale ale anglaise.

### Vegan Panna Cotta

Ingredients	Instructions
1 Can Coconut Milk	Dissolve agar agar and tapioca flour into the warm water.
1 Tsp Vanilla	Heat coconut milk, add the water mixture, and vanilla, cook until the milk starts to thicken.
2 Tsp Agar Agar	
1/2 Cup Warm Water	Pour into desired containers, cool to allow to set.
2 Tsp Tapioca Flour	
2/3 Cup Sugar	
1 Cup Blood Orange Puree	
	To make fruit vegan panna cotta:
	Add 1 cup desired fruit puree to coconut milk mix and increase agar agar by 2 tsp.

### Sticky Toffee Pudding

Ingredients	Instructions
Sauce:	Preheat to 350
1 qt Apple Juice	Combine dates, water and Jim Beam in saucepan. Bring to a boil. Reduce heat to med. Simmer until dates are soft and mixture is still moist. Cool to room temp and stir in baking soda.
8 oz Brown Sugar	
Cake:	For sauce reduce apple juice and brown sugar to caramel consistency.
3 # dates	Sift flour, baking powder, and salt into bowl. Beat sugar and butter until blended. Beat in eggs 1 at a time and add vanilla.
2 cups water	Beat in dry ingredients. Stir in date mixture pan. Bake for 30 minutes. Poke top of cake with fork and pour caramel sauce over the cake. Return to oven and bake until sauce is cool.
¼ cup Jim Beam	
½ tsp baking soda	
1 ½ tsp salt	
3 ½ cups cake flour (18 Oz)	
1 tsp baking powder	
13 oz brown sugar	
1# Almond Milk	
6 eggs	
1 Tbs vanilla	
2 cups pecans	



## FERTILITY IN ADULT WOMEN WITH CLASSIC GALACTOSEMIA AND PRIMARY OVARIAN INSUFFICIENCY

By van Erven B, Berry GT, Cassiman D, Connolly G, Forga M, Gautschi M, Gubbels CS, Hollak CEM, Janssen MC, Knerr I, Labruno P, Langendonk JG, Öunap K, Thijs A, Vos R, Wortmann SB, Rubio-Gozalbo ME.

### Summary

This study aimed to evaluate the pregnancy chance in adult women with classic galactosemia and primary ovarian insufficiency. Despite dietary treatment, >90% of women with classic galactosemia develop primary ovarian insufficiency, resulting in impaired fertility. Since the chance of spontaneous pregnancy in women with classic galactosemia is considered very low, they are counselled for infertility. Most women with classic galactosemia do not try to become pregnant because they have been told they could not have children. However, a number of pregnancies in women with classic galactosemia and ovarian insufficiency have been reported.

We invited adult women ( $\geq 18$  years of age) with classic galactosemia and primary ovarian insufficiency to participate in our study

from various metabolic centers.

For this study we used a questionnaire that explored the following topics: conception opportunities, time to pregnancy, pregnancy outcome, hormone replacement therapy use, fertility counselling and the participants' vision of fertility. Potential predictive factors for an increased pregnancy chance were evaluated.

In total, 85 adult women participated. 21 women did not take birth control measures or were trying to get pregnant. Of these 21 women, 9 women became pregnant spontaneously (three women conceived four times, two conceived twice, and the other four conceived once). Five pregnancies in four individuals ended in a miscarriage (5 of the 20 pregnancies). This is a higher number than what is seen in other causes of ovarian insufficiency (non-galactosemia related). There were no differences (age at first pregnancy, genotype, age at onset of diet, diet, spontaneous menarche, age at menarche, education level and counselling) between women who became pregnant and women who did not become pregnant

so that no positive predictive factors were identified.

This study showed that after a period of 6 months, 20% of the couples became pregnant. This percentage increased to 27.8% after 12 months, 48.4% after 24 months and to 61.3% after 27 months. Compared to the general population, these percentages are lower.

Although a substantial proportion of women expressed a child-wish, the vast majority of participants considered conceiving to be highly unlikely, owing to negative counselling in the past. If more women would attempt to conceive, and if they would try for a longer period of time than they generally do now (>2 years), potentially more pregnancies would occur group.

The pregnancy rate in women with classic galactosemia and primary ovarian insufficiency in this study was higher than for women with primary ovarian insufficiency of any cause. Reproductive counselling regarding reduced fertility rather than infertility seems more appropriate.

## ANGELINE'S STORY



As a sophomore at the University of Colorado Denver, I still think back to the early years of elementary school, and with these memories comes the recollections of going through school as a child with Galactosemia. I remember at that early age, I wished I could

eat what my friends were eating. Especially when my class threw parties and asked kids to bring treats (most all the treats were unacceptable in the Galactosemia diet) and I missed out on the joy of eating what I wanted.

However, as I grew older, I easily forgot about this insignificant predicament because I learned that it was even more difficult to keep up in school. For me, it was very hard to learn and understand materials taught in school, especially when it

came to math. In elementary school, I was different, and at times I was not in the place I wanted to be in. I was the short girl who had to have extra help in math. And when I was young, I was the one who needed to take speech classes. School came with several difficulties. I was always the last one in each class to finish my tests, no matter what subject (I still am the last one finished to this day). School work was never a breeze to finish, either. While I was in high school, I never went to bed earlier than 1a.m. because I was determined to finish all the work that was assigned. It was so difficult to wake up and do the same thing again the next day. Also, I was never sure if my answers to writing prompts or math problems were good enough because I had such a tough time with grasping ideas. I would second guess myself and check my work several times to be confident enough to turn it in. Then, I learned that if I practice enough, and put all my effort into my work, great things happen. In high school, I no longer thought about how I had it more difficult than my friends. This is when I began to succeed, and by the time I finished high school, I had received an award in math (for most improved) and in science class (for greatest

achievement).

In addition to my difficulties with school work, I had difficulties with speaking in classes and speaking to other kids. I was very uncomfortable and felt massive social anxiety throughout high school. Even today, I am still a bit socially awkward, but I manage to communicate with others, because I know that if I take the risk, I could meet new people. I no longer think of myself as different, which makes me more comfortable with myself. When I meet new people, they cannot judge me because they are unaware that I have Galactosemia.

I believe I was able to graduate high school, and make honor student, because I accepted that I need to work hard and take my time in order to succeed. There is no shame in using all the time you are given, it only makes you even more confident in what you are doing. All these years later, I can say that growing up with Galactosemia was difficult, but it cannot take away the ability to succeed, not only in school, but in life. I am happy where I am at, as a student pursuing a degree in Elementary Education at CU Denver, and as a new Teacher Assistant at Foothills Preschool.

## FALL FUNDRAISING UPDATE

**Blue Jeans for Rare Jeans-** The movement is growing! BJFRJ had several families participate last year and wanted to increase participation again. A simple way to fundraise! Ask at work if on National Rare Disease Day, February 28, workers could wear blue jeans to work for a monetary donation. It can be done every Friday for the entire month of February or the entire last week of February. You choose the amount \$5, \$10, \$20 whatever you wish. You collect the donations and send to Galactosemia Foundation. BJFRJ has had schools, offices and retail stores participate. It raises funds and raises awareness.

**In memory of Loraine Arnold,** known as "Nana" by her grandchildren. Recently Loraine Arnold passed away and her granddaughter, Cecilia has Galactosemia. In lieu of flowers her son and daughter, Jason and Kathryn asked that donations be made in her memory to Galactosemia Foundation. Multiple donations have poured in from friends and family members. We honor Loraine and the entire Arnold family and pass along our condolences for their loss.

**Keegan's Kause** continues to rack up donations to Galactosemia Foundation! The Foley Family is in the process of running another NFL survivor pool. Half the entries, about \$3800 go to the foundation! It is too late to enter this year but the "March Madness college basketball squares challenge will be coming soon!

**The Keegan's Kause** fitness bootcamp was held on August 5th at Vigor Fitness & Wellness Studio in Nashville, TN. The boot



Shawn Booth and Laure Lea Goldberg help Keegan's Kause.

camp was led by Shawn Booth, personal trainer and winner of ABC's "The Bachelor" season 11 and Laura Lea Goldberg, a certified health-supportive chef and author of The Laura Lee Balanced Cookbook. In total we raised about \$1,500 at the event.

**Glow for Galactosemia 5K, 10K, family fun run.** Brittany Cudzilo recently had a daughter, Anise, born with Galactosemia. Brittany is an avid runner and she quickly decided to organize a fundraiser 5K/10K in her hometown of Knoxville. Thus the "Glow for Galactosemia" was born. Their

first event will be held March 4, 2018 at dusk so they can GLOW for Galactosemia! What is great is they are also accepting virtual runners meaning you can organize a group of runners anywhere you are, have them sign up on website and register your results. Visit the website at [www.glowforgalactosemia.com](http://www.glowforgalactosemia.com) to register as a virtual runner or local runner if you are near Knoxville. Special thanks to the Cudzilo family for all they are doing to better the foundation. Please include virtual flier in newsletter.

### \$4000 donation after company

**match.** Joseph and Jessica Lennon made a donation of \$2000 and had a company match of \$2000. Jessica is board member Nicole Casale's sister. Thanks so much to the Casale and Lennon families!

### Not good at fundraising but want to help?

Do you shop at Amazon? Before you place your next order, go to [www.amazon.com/smile](http://www.amazon.com/smile), log in with your amazon ID and select Galactosemia Foundation as organization. Save this to your favorites and a percent of most purchases will go to the foundation. Use only Amazon Smile from now on. Search the internet much? Download Goodsearch at <http://www.goodsearch.com/?charityid=806926>. Register and save Goodsearch to your favorites. GF gets \$.01 for every search.

Making a monetary donation to GF? Always check with your companies HR department to inquire if your company does charitable matching.

## STUDY: DIET AND OUTCOMES FOR CLASSIC GALACTOSEMIA

By Allison B. Frederick

David J. Cutler

Judith L. Fridovich-Keil

### Summary

One of many challenging decisions faced by parents of an infant with classic galactosemia (CG) is how carefully to restrict non-dairy galactose from their growing child's diet. Until recently, many experts recommended strict lifelong dietary restriction of milk and all high-galactose dairy foods as well as some non-dairy sources of galactose including legumes and specific fruits and vegetables. Recently, experts have begun to relax their recommendations; however, the new

recommendations (Van Calcar et al (2014) Mol Genet Metab 112:191-197) were made in the face of uncertainty. The problem was that no sufficiently powered study had been reported testing for possible association between rigor of non-dairy galactose restriction and severity of long-term outcomes in CG.

Here we describe the largest study of diet and outcomes in CG yet reported, conducted using information gathered from 231 patients with CG and 71 unaffected sibling controls. We compared level of dietary galactose restriction at different ages, measured using a 4-point scale by a retrospective survey, with outcomes including growth, adaptive behaviors,

receipt of speech therapy, receipt of special educational services, and for girls and women, a plasma marker of ovarian function (AMH). Our results confirmed the expected differences between patients and controls, but among patients showed no significant association between level of non-dairy galactose restriction in early childhood and any of the outcomes quantified. Indeed, some weak associations were seen suggesting that rigorous restriction of non-dairy galactose may be deleterious rather than beneficial. Despite limitations, these findings support the ongoing trend toward diet liberalization with regard to non-dairy sources of galactose for children and adults with classic galactosemia.

# TREASURER'S REPORT

REVENUE	Total
Gift In Kind Donations	1,308.32
Paul P Scholarship	575.00
Temporarily Restricted Donations	40,833.50
Unrestricted Donations	49,793.31
Interest Income	23.68
<b>Total Revenue</b>	<b>92,533.81</b>
EXPENDITURES	
Research Grants	
Dr. Annet Bosch	51,269.00
Dr. Judith Fridovich-Keil 2015	30,000.00
Dr. Sandy Calcar	40,607.00
Dr. Yue	35,000.00
<b>Total Grants</b>	<b>156,876.00</b>
Printing	435.00
Bank Charges	567.18
Dues & Subscriptions-Nord	3,200.00
Freight & Delivery	30.00
Gifts-Research Team	600.00
Fundraiser Expenses	2,402.80
Stationery & Printing	89.51
Telephone & Website	507.34
Travel- 2018 & 2020 Conference Preplanning Trips	17,708.28
<b>Total Expenditures</b>	<b>184,191.11</b>
<b>NET PROFIT (LOSS)</b>	<b>\$ -91,657.30</b>
ASSETS	Total
<b>Bank Accounts</b>	
BUSINESS CHECKING (XXXXXX 3329)	224,744.08
Research Fund (XXXXXX 6770)	62,428.53
Scholarship Fund (XXXXXX 6788)	2,486.04
<b>TOTAL ASSETS</b>	<b>\$289,658.65</b>
LIABILITIES AND EQUITY	
Dr. Annet Bosch	25,634.00
Dr. Judith Fridovich-Keil 2015	15,000.00
Dr. Sandy Calcar	20,303.50
Dr. Yue	17,500.00
<b>Total Liabilities</b>	<b>78,437.50</b>
Retained Earnings	302,878.45
Net 2017 Profit (Loss)	-91,657.30
<b>Total Equity</b>	<b>211,221.15</b>
<b>TOTAL LIABILITIES AND EQUITY</b>	<b>\$289,658.65</b>



Galactosemia  
Foundation  
Linked for Life.



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Temporarily Restricted Donations are donations to the Research Fund  
Unrestricted Donations are donations to the General Fund.