



# It's Almost Here! 2014 Galactosemia Foundation Conference in Orlando, Florida



## Galactosemia GAZETTE

**When:** Thursday, July 17 to Saturday, July 19, 2014

**Where:** Buena Vista Palace Hotel & Spa, Orlando, FL.

**Orlando 2014 registration is in full swing!** Please join us as we team up for a bright future with galactosemia. Our conference has something to offer for everyone; including interactive childcare for the little ones with planned programs with licensed professionals.

We will swing things off with our first ever golf tournament on Thursday morning at one of Orlando's pristine golf courses. Following the tournament we will head back to the hotel for registration a few games and the ever-popular candy buffet hosted by IL Nut Company. Educational meetings fill the days and we wrap nights up with eventful socials that will be fun for the entire family on both Friday and Saturday nights.

Friday night we will have a carnival theme social with our very own Generation G Galactosemics serving up some refreshments! We ask that everyone wear their favorite 'team' shirt to our carnival, which will include putt-putt golf, football toss, a dunking booth and other fun things to do.

Saturday night, back by popular demand we will have a DJ, dance floor and photo booth. We ask that everyone wear his or her favorite tropical attire for this social! Who would want to miss to opportunity to see Dr. Berry leading the line dance again?

We have worked hard to find the best professionals that can help to educate us on new findings with galactosemia and hope you will take advantage of joining us at the conference. Life with galactosemia proves to be challenging at times. Why take this adventure alone? Come to this conference and form relationships with others you can keep in touch with long after the conference is over. Make sure to bring your children because your heart will smile when you see the fulfillment and confidence they gain from meeting others like them.

What an experience to be able to watch as the galactosemics enjoy every item on the lunch buffet! Specially prepared lunch menus have been selected that are completely safe, without question! After all, why wouldn't you want to be surrounded by folks that truly, 'get it'?

Please make your hotel reservations today as rooms are limited and will begin to fill up fast. Our conference rate of \$129/night will only be guaranteed for a short time. More details about the hotel can be found on their website and in the hotel section of this newsletter.

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**Galactosemia  
Foundation**  
Linked for Life.

*The Galactosemia Foundation is a national, non-profit, volunteer organization whose mission is to provide information, support, and networking opportunities to families affected by Galactosemia.*

Visit us online at [www.galactosemia.org](http://www.galactosemia.org)

(cont'd)

The Galactosemia Foundation is a non-profit charitable organization. Founded in February 1985 by a small group of mothers in New York, We realize the need for further information and networking between affected families and professionals. Metabolic Clinics across the nation continue to assist The Galactosemia Foundation in researching families and information. Today our mailing list includes over 1000 families and extended families, professionals and clinics, media groups, donors, and numerous international contacts. Objectives and functions are achieved by unpaid volunteers.

**Michelle Fowler**, President  
president@galactosemia.org

**Scott Shepherd**, Vice President  
vicepresident@galactosemia.org

**Diane Flynn-Brake**, Secretary  
secretary@galactosemia.org

**Paul Fowler**, Treasurer  
treasurer@galactosemia.org

**Andrea Topper**, Board Member 1  
boardmember1@galactosemia.org

**Scott Saylor**, Board Member 2  
boardmember2@galactosemia.org

**Theresa Boehm**, Board Member 3  
boardmember3@galactosemia.org

**Christine Winey**, Research Team  
research@galactosemia.org

**Michelle Fowler**  
Conference Planning Team  
conference@galactosemia.org

**Scott Saylor**, Fundraising Team  
fundraising@galactosemia.org

**Robyn & Jeremy Meek**  
Outreach Team  
outreach@galactosemia.org

**Angela Canul & Karen Haley**  
Newsletter Team  
newsletter@galactosemia.org

Printing & Mailing Services,  
Website Hosting & Design  
**Rick & Karen Haley**, Print Plus  
www.myprintplus.com

The Galactosemia Foundation publishes and delivers two mailings per year. These mailings vary depending on the conference years! If you have an article or a fundraising event that you would like to have printed in the newsletter please submit it to:  
newsletter@galactosemia.org

The Galactosemia Foundation  
P.O. Box 2401  
Mandeville, LA 70470-2401

## Orlando Conference (cont'd.)

This year we are having our first ever conference booklet. This booklet will include speaker bios, conference schedules and most importantly, ads that may be purchased by anyone. We hope this will serve as a small fundraiser for the foundation while at the same time allowing you to express words of encouragement to others by placing an ad in the booklet. You will see details and how you can host an ad in this newsletter.

A few highlights of the conference registration - Please register on-line at [www.galactosemia.org](http://www.galactosemia.org). Although we do have a registration form located in this newsletter for those who need it, we strongly urge you to register on-line. The online process is more complete, and significantly less time consuming for the Foundation and it's volunteers. In addition to being able to easily select your breakout sessions, order t-shirts, sign up for golf, etc., the online form allows you to select your future newsletter/contact methods from us. This will help us manage and update our mailing list (both email & print).

We encourage pre-order of t-shirts as there will be only the conference t-shirt available on-site. Also, sizes will be limited. Hoping to see everyone on our team in July! For more details please visit our website at [www.galactosemia.org](http://www.galactosemia.org).

### Reserve Your Conference Hotel Room NOW - Before They Sell Out!

The Buena Vista Palace Hotel & Spa is offering a special rate of \$129 per night for "Resort View" guest rooms for conference attendees. Suites and rooms with other views are also available (starting at \$139 per night) with our group rate. You will be offered an optional "Resort Fee" for an additional \$8 per day at check-in. If you choose to pay the additional \$8 fee, you will get wired and wireless in-room internet access, fitness center access, and a few other resort amenities.

Reserve your room today to take advantage of the Galactosemia Foundation Conference room rate of \$129.00/night. Make your reservations as soon as possible before our room block sells out and the hotel sells out. Summer is the peak season for tourists visiting Orlando and hotels often sell out - book now so you have a room for the conference!

Planning to come to Orlando early or stay after the conference? You can take advantage of our group rate during the weeks before and after the conference.

You can reserve your room in one of two ways:

- Call the Buena Vista Palace Hotel & Spa Reservations department at 1-866-397-6516
- Book on-line (no login required): reserve a room from the Galactosemia Foundation block

### Registering For The Conference

The cost to register for the conference will depend on when you register. The earlier that you register, the lower the cost.

Type	Deadline	Registration Cost* (\$ US)
Early-Bird	On or before May 1st, 2014	\$99
Standard	On or before June 1st, 2014	\$149
Late	After June 1st, 2014	\$199

\* There will be an additional activity fee of \$50 for teens and young adults that participate in the G-Force and Generation G programs. This additional fee covers the costs of the various on and off-site activities that these groups do during their programs.

## What Is Included In The Conference Registration Fee?

**For Each Adult** – the registration fee covers:

- Galactosemic safe breakfasts, lunches, refreshments, and snacks on Friday, July 18th and Saturday, July 19th. (dinner is on your own each night)
- Attend all general session presentations and five break-out sessions
- Join us for fun social activities each evening

**For Each Child (12 & under)** – the registration fee covers:

- Professional on-site child care from 7:00am to 6:00pm on Friday, July 18th and Saturday, July 19th
- Galactosemic safe refreshments and snacks while in child care
- Galactosemic safe breakfasts and lunches (with your family) on Friday, July 18th and Saturday, July 19th
- Attending evening social activities with your family each evening

**For Teens & Adult Galactosemics** – the registration fee covers:

- Galactosemic safe breakfasts, lunches, refreshments, and snacks on Friday, July 18th and Saturday, July 19th.
- Participating in special programs targeted specifically towards galactosemics with a blend of on- and off-site activities
- Attending social activities each evening

## Traveling To The Conference

### Flying to Florida

The closest international airport is the Orlando International Airport (MCO). There are other airports in central Florida that may be cheaper or more convenient, such as Orlando Sanford International Airport (SFB) or Tampa International Airport (TPA), and others.

### To get from the Orlando International Airport to the Buena Vista Palace Hotel & Spa

You can rent a car and drive (about 20 minutes), take a taxi, shuttle bus, or public bus. The Orlando airport website provides some approximate costs for these different options. Mears offers the primary shuttle bus service between the Orlando airport and the Buena Vista Palace Hotel & Spa. The

option that is most cost effective depends on how many people are in your party.

### Driving to the Buena Vista Palace Hotel & Spa

The Buena Vista Palace Hotel & Spa is located at:  
1900 E Buena Vista Drive  
Lake Buena Vista, Florida 32830 USA

There is free parking available to hotel guests at the hotel.

## Dinner On Your Own

There are several restaurants in the Buena Vista Palace Hotel & Spa that will offer a special galactosemic safe menu before, during, and after the conference. The galactosemic safe menu items will also be available from room service.

There are also many restaurants in Downtown Disney which are accustomed to accommodating guests with special diets. You can make reservations up to six months in advance at some Downtown Disney restaurants. If you want to eat dinner at a Downtown Disney restaurant, please make reservations as soon as possible – particularly if you have a large party.

There are many other restaurants and grocery stores near (but not in easy walking distance) the hotel.

## Visiting Other Attractions While In Florida?

There are many attractions and exciting things to see and do while you are in central Florida. Here are a few pieces of information that may be helpful to you as you plan your trip to the conference.

The Buena Vista Palace Hotel & Spa is within walking distance of Downtown Disney where you will find many shops and restaurants

There are free shuttle buses that run approximately every 30 minutes between the Buena Vista Palace Hotel & Spa and the Disney parks

There are no shuttles to Universal Studios, Sea World, Lego Land, or other area destinations – you will need to make your own travel arrangements if you want to go to a non-Disney property.

There is an Alamo car rental desk located at the Buena Vista Palace Hotel & Spa.

**For Even More 2014 Conference Information  
& To Register – Be Sure To Visit Our Web Site:  
[www.galactosemia.org](http://www.galactosemia.org)**

FUNDRAISING INCENTIVE for GALACTOSEMIA FOUNDATION... Linked for LIFE!  
2014 Conference in Orlando, Florida  
July 17<sup>th</sup>, 18<sup>th</sup>, & 19<sup>th</sup>, 2014

Galactosemia Foundation would like to invite everyone to participate in the 2014 incentive program aimed at increasing donations that will be used to fund the 2014 Galactosemia Foundation Conference.

**BRONZE LEVEL - Raise \$750.00 - \$1,499.99\***

- One Conference registration fee waived
- Recognized on conference handout
- Entered into a drawing for an I-pad mini

**SILVER LEVEL - Raise \$1,500.00 - \$4,999.99\***

- Two conference registration fees waived
- Recognized in general session and conference handout
- Entered into a drawing for an I-pad mini
- **1<sup>st</sup> Place\*\*** - Reimbursement for up to two nights stay in the conference hotel\*\*\*

**GOLD LEVEL - Raise \$5,000.00 - \$9,999.99\***

- Three conference registration fees waived
- Name on conference t-shirt
- Recognized in general session and conference handout
- Entered into a drawing for an I-pad mini
- Reimbursement for up to two nights in the conference hotel\*\*\*
- **1<sup>st</sup> Place\*\*** - Reimbursement for one coach round trip airfare ticket\*\*\*

**PLATINUM LEVEL - Raise \$10,000.00 or more\***

- Four conference registration fees waived
- Name on conference t-shirt<sup>†</sup>
- Recognized in general session and conference handout
- Entered into a drawing for an I-pad mini
- Reimbursement for up to three night stay in the conference hotel\*\*\*
- Reimbursement for two coach round trip airfare tickets\*\*\*

**~INCENTIVE PROGRAM DONATIONS ARE ACCEPTED NOW UNTIL JULY 1, 2014~**

Donation checks should be made payable to: Galactosemia Foundation  
Donations must be received by **July 1<sup>st</sup>, 2014** to qualify for the incentive.

Send to: Galactosemia Foundation  
P.O. Box 2401  
Mandeville, LA 70470

\*To qualify for incentive; you **MUST** indicate with your donation(s) you wish to have the donation(s) deposited towards the Incentive Program. All donation(s) must be 'ear marked' as such and will be allocated to the Galactosemia Foundation General Fund. Money donated to the Galactosemia Foundation Research Fund or Paul Pruszyński Memorial Scholarship Fund do not count towards the Incentive Program.

\*\* *1<sup>st</sup> Place* is defined as the individual that raises the most money within a level. There will be one individual eligible for reimbursement for hotel nights from the Silver Level and one individual eligible for reimbursement for airfare from the Gold Level.

\*\*\* Reimbursements will be given after a completed expense report has been filled out at completion of the conference. All airfare reservations must be made at least three weeks prior to event in order to ensure lowest possible rate. Airfare portion is valid only from contiguous 48 states.

<sup>†</sup>Cut-off for qualifying to get your name on the conference t-shirt is 6/15/14.

# Galactosemia Conference

*By Keith Topper*

Although July 2014 seems like an eternity away, the next Galactosemia Foundation Conference is only a few months away! It's very exciting knowing that I'll be able to see my friends. Living so far away from most of them, it's not easy to keep in touch. It's also a relief knowing that for the few days that the conference lasts, I won't have to worry about reading nutrition labels or ingredient lists. After all, the food at the conference is all milk-free. I'm anxious to learn about any new information that researchers have gained since the last conference. It's always good knowing that progress is being made to help further research of our allergy. I'm very excited about the upcoming Galactosemia Foundation Conference!

## Why We Attend The Conference

*By The Saylor Family*

The countdown is on! We are less than six months to the 2014 conference in Orlando. Back in 2008 my wife and I attended our first conference in Chicago. Our son, Jake, was born in July 2007 with Classic Galactosemia. At the first conference we heard so many viewpoints and opinions from other parents. We quickly learned while you have to entrust your doctor and dietician, you also need to do what you are comfortable with in raising a galactosemic child. We decided after that first conference that we would continue to attend to learn and share our experiences.

We always learn new things at every conference from both the experts and especially from other parents. Whether it is new App that tells you what items in which restaurants are dairy free or a website that sells dairy free cookies, it all helps. It is great to talk to the older galactosemics and hear their experiences. They always have so much to share. It is also great to talk to first time attendees and share our experiences. One thing we learned early is don't judge how others do things, different people have different views. We find so many positives as we come away from each conference that encourages our family.

We also think it is important to come together as a galactosemic community and make it known we all have a passion to find a cure and improved treatments. We are only one family but if everyone at once stopped going who would fight for our children? We need to continue to raise awareness and attract researchers. Whether it helps my child or not it is our goal to help the future galactosemics. We can only do this together. That is why we continue to attend the conference and I hope you do as well.

## My Top 10 Reasons I Love Attending the Galactosemia Conferences

*By Kimberley Malyn*

- 10. Great People!** Making new friends and getting acquainted with familiar faces.
- 9. Food!** There is galactosemic friendly food available at meals and there is usually a great chocolate buffet and a dessert social. I also like buying extra chocolate to take home with me.
- 8. Food!** We have a chance to discuss our delicious recipes and we can get tips from each other.
- 7. Information!** I feel like I'm the first to know when there's a new development from research.
- 6. A sense of belonging!** I love to get together with people that are just like me. We can share our own experiences that are unique to each of us and swap stories. We can help each other out by telling our stories.
- 5. Fun!** Great family-friendly activities for diverse interests. We had a dance at the most recent conference and my whole family had a great time.
- 4. Vendor Booths!** We can find out about businesses that sell food that is safe for us and even buy some food at the conferences (like the chocolate). I even know about websites where I can get additional safe food items because of the vendor booths.
- 3. Meeting People!** I can personally meet the Galactosemia Foundation board and see how much work they do for all of us in order to put the conferences together and make sure we have safe food! I can personally tell them thanks for all of their hard work.
- 2. I can participate in some of the research projects!** It is helpful to the doctors and to us; hopefully we can get more answers by participating in the research.
- 1. Something for everyone!** My children like being in groups with people their own age. I got to attend a session for people my age at the last conference too and I encourage you to come. I was in the AGERS group last time and I got to know more galactosemics that are in my age range. My husband and a few other spouses got to join us in AGERS too and it was good for the spouses to be able to talk to each other and get to know each other too. Please come to the AGERS group at the next conference. The conferences really do have something for everyone. Contact Kimberley Malyn at [kmalyn@sbcglobal.net](mailto:kmalyn@sbcglobal.net) if you have any questions about the AGERS group. The AGERS group for the 2014 conference is still in the planning stages so please also contact Kimberley to let her know what expectations and goals you have for the AGERS group. Your opinions are appreciated and if you tell about some of your own expectations AGERS will be more meaningful to you.

## Everyone Is Welcome, However...

We encourage you to bring the entire family! However, everyone must register and pay for the conference. Make sure you select special programs applicable to your child's age, such as Mighty-G, G-Force or even the AGERS and General Session programs. Those registering for childcare will also need to visit the childcare link and fill out necessary paperwork there too. The galactosemic safe lunch buffet will require presentation of your conference badge for entry. Once your payment has been finalized a badge will be awaiting for you at registration. We can't wait to see you in July!

## Galactosemic Safe Recipe Book?

How many of you would love to have a recipe book filled with galactosemic safe recipes?

Tera Mize Jones from Georgia and Tori Fowler from Louisiana are working hard to try and make this possible. Tera and Tori are putting together several galactosemic safe recipes into a booklet that will be available at the conference. Your help is needed to complete this recipe booklet. Choose from as many categories as you wish; appetizers, salads, main dishes, side dishes, sweets, and even drinks!

Maybe you have just the recipe others have been looking for. Our goal is to have several recipes and even have substitutions listed. So, if you have something you use for whip cream, or cream of chicken soup, or sweet and condensed milk, that's what we need you to share with us!

Please send in as many recipes and substitutions as you would like so we can make this a recipe book proven to be loved by many! Make sure to include all the steps of the recipe, starting with the ingredients, measurements, preparation and baking instructions. You want someone to be able to take what you send and make the dish from start to finish.

Have you recently had some great ideas from the holidays? Come on; share those with us so we can help other families ease the holiday stress with some step by step instructions to galactosemic safe dishes. What is your galactosemic loved ones favorite dish? Send us the recipe! The more recipes we have the better this will be and the more taste buds we will enlighten!

*Please submit your recipe and substitutions by emailing [recipe@galactosemia.org](mailto:recipe@galactosemia.org)*

## Conference Program Advertisements

New this year! We are currently selling ads to help support our conference program. The program book will include schedules, speaker bios, highlights and any sponsored ads. The advertisements are open to corporations, individuals, families and friends. This is your opportunity to sponsor a page and deliver a personal message! The conference program will be available to all participants.

Purchase advertising in the Galactosemia Foundation Conference Program that will be given to all participants! The conference program will be 8.5" X 11" and printed in black and white.

Full Page .....\$1,000

Half Page .....\$500

Quarter Page ....\$250

Eighth Page .....\$125

*Sign-up online – send your ad to:  
[conference@galactosemia.org](mailto:conference@galactosemia.org) and pay online*

*Mail-in sign-up – send your ad to:  
Galactosemia Foundation P. Box 2401, Mandeville, LA 70470*

## Shh! Silent Auction

We are very excited to announce the **2nd Bi-Annual Silent Auction And Raffle!** This event is put together by galactosemic parents, in order to raise funds for the conferences; which is exactly what the 2012 auction and raffle proceeds did. Everyone who participated helped raise over \$4,000 to help put on the Dallas conference! As always, we wouldn't be able to put on this silent auction and raffle without the groups, families, individuals, etc., donating items for this event. Please, anyone who is able, consider contributing to this great fundraiser. You supply the item, big or small, **We Do The Rest!**

*If you wish to send any donations between now and a week before the conference, send to:*

Kellie Wilcox  
145 FM 2972 W  
Rusk, Texas 75785

or of course we will be accepting donations at the conference. The silent auction and raffle itself will take place only **Friday Evening During The Social!** Winners will be chosen that night, so see you there. We will have a variety of items, with some silent auction items and some raffle, something for everyone's budget and taste!

## Pre-Order Your Candy

Hello Galactosemia Foundation Families! As Michelle says.... "Back by popular demand", IL Nut Company will once again be supporting our conference and helping to host our Thursday night social.

While preparing for this conference, Orlando 2014, I told Michelle, Orlando would be no problem since it was only four hours longer than getting to Texas. Well, boy was I wrong! After much thought I have realized that those four extra hours will most definitely be too many hours to add to the trip with a truck full of chocolates. This is what has led me to needing to ship out items to the conference instead of doing a marathon drive and risking the melting of items in the summer heat.

I strongly encourage everyone to preorder their galactosemic safe treats, as the amounts that we will have available on-site at the conference will be significantly less than in previous years so not to incur the high cost of shipping. You may order from our preorder form and in addition, you will also have the option of ordering items not included on the preorder form, directly from our website [www.raisingthecandybar.com](http://www.raisingthecandybar.com). Any preordered items will be ready for you to pick up on-site at the conference at no additional charge. (No shipping!)

Please order today by sending your wish list via email, fax, or by ordering from the website. The last day for preorders is July 7, 2014. To do this, place your order as usual, select in store pickup as the delivery option, please make a note in the special instructions area, PICK UP AT GF CONFERENCE. This will let us know we are taking care of getting your items to the conference for you. All you have to do is stop by our booth at the conference and receive your order! If you are paying by credit card, the items will be charged on July 10, 2014. Orders will be available for pick up at our booth in Orlando July 17th-19th 2014. Payment methods include Visa, MasterCard, Discover, cash or check. If you prepay, because the items will be shipped out of Illinois, there will be no sales tax collected. Items paid for in Orlando will be charged Florida sales tax.

Looking forward to seeing everyone, both old and new faces, in July!

Make it a SWEET day and place your order today!

David the Candy Man, David Levine

Illinois Nut & Candy

*You can also find links and an order form at:  
[www.galactosemia.org/conference](http://www.galactosemia.org/conference)*

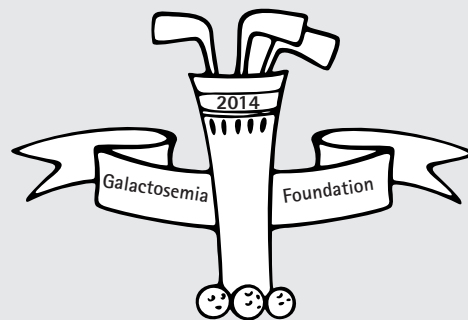
## Calling all Golfers, hackers, and anyone who wants to go out on a beautiful Disney golf course and chase around a little white ball!

Come out and golf with Mickey, Goofy and Pluto at the first ever Galactosemia Foundation Conference golf outing. Okay, maybe the Disney crew will not be there, but for those that have seen me golf definitely would call me Goofy. The outing will be held on Thursday morning with an 8:00am shotgun start and be over in plenty of time to join the festivities of conference registration. It will be a 4 person best ball format. You do not need a full team of 4 to register, we will pair you with other golfers as needed. Whether you're the club pro or only golf twice a year you are sure to have fun while supporting the conference. This is a great way to meet and network with other parents. Full information is available at [www.galactosemia.org](http://www.galactosemia.org). You are also able to register to golf as part of the general conference registration at [www.galactosemia.org](http://www.galactosemia.org). You can also become a sponsor or donate items on-line as well. The cost is only \$100 which includes: green's fees, cart, lunch, transportation and unlimited fun! If you do not want to bring your clubs you can rent them at the course as well.

**Thursday July 17th 2014**

**8:30am shotgun start  
transportation from hotel included.**

**Lake Buena Vista Golf Course**



*Find registration forms, additional information, and sponsorship opportunities at: [galactosemia.org/conference](http://galactosemia.org/conference)*

## Child Care – Leave the Kids to Us

Corporate Kids Events, Inc. has years of experience creating and coordinating the ultimate in themed kids events. This will be an event your child will not want to miss and spaces are limited. So please sign up early to reserve a spot. For more information on Corporate Kids Events, Inc please visit our website. Each program will be coordinated to be age appropriate.

*You can find out more and register children 12 and under for child care at: [galactosemia.org/conference](http://galactosemia.org/conference)*



## Corporate Sponsorships

Join the Galactosemia Foundation in the advancement of nutrition and lifestyle support for individuals and families affected by Galactosemia. With your involvement and sponsorship, you will demonstrate that your company is a significant supporter of education and research for everyone affected by this genetic disorder. Over 500 people – both affected families and scientific professionals – from all over the world will attend the 2014 Galactosemia Foundation conference. They'll learn about the latest scientific and nutritional advancements and take part in informed and relevant dialogue around Galactosemia-safe foods and lifestyles.

As a sponsor, your participation will give you access to a national and international network of dietitians, health professionals, and consumers of galactosemia safe foods. You will have the opportunity to promote your product directly to the conference attendees and speakers. We invite you to be a vital and highly-visible part of the process of supporting nutrition, education and research for individuals affected by Galactosemia.

*For more information download our sponsorship packet from: [www.galactosemia.org/conference](http://www.galactosemia.org/conference)*

## Not Frog Snot!

Finally! A book written by the father of a galactosemic child.

Watching my child, Theron, grow up and learn to read, it occurred to me that there should be a story about a child who has a medically restricted diet. Furthermore, I wanted the story to appeal to the children, which to me meant a healthy mix of adventure, comedy, and heroism. Finally, I wanted the character to step into a situation where his diet gives him an advantage that foils a villain and gives him a chance to be a hero. These ideas came together in my novel Not Frog Snot.

"Theron and I attended the 2010 and 2012 galactosemia conference, and our whole family will definitely be at the national conference in Orlando in July" says Jon McAlister.

Jon McAlister currently sells his book on Amazon for \$6.95 plus shipping and handling. He has been gracious enough to offer this to our galactosemic families for a pre-order price of \$6 and on-site price of \$7. All proceeds of the book will be donated to the Galactosemia Foundation. If you are interested in ordering a copy of the book to pick up at the conference please email [conference@galactosemia.org](mailto:conference@galactosemia.org) and put Book in the subject line.

## The Paul Pruszynski Memorial Conference Scholarship

The Paul Pruszynski Memorial Conference Scholarship was created to honor Paul's memory to provide young people who might not otherwise be able to attend the conference because of personal finances, with the resources to participate. The scholarship has been extended this year with the creation of the G Force Program so that one GG (18-30) and one G-Forcer (13-17) will be selected to receive conference assistance.

Paul attended his first PGC/Generation G Conference in 2010 in Minneapolis, Minnesota. Paul passed away suddenly in January 2011 when he was 23 years old. He was looking forward to attending future conferences.

GGs (between the ages of 18-30) & G-Forcers (between the ages of 13-17) who cannot attend the 2014 Galactosemia Foundation Conference in Orlando, Florida, because of financial difficulties, can apply for the scholarship by filling out a questionnaire. For a copy of the questionnaire, please e-mail Linda Manis at: [Lmscript1@aol.com](mailto:Lmscript1@aol.com).

This scholarship will "assist" in helping to cover the cost of the hotel, the registration fees, and possibly airfare. The GG and G Forcer who are awarded the scholarship will also participate in a ceremony at the conference to honor Paul's memory.



# Welcome AGERS

*Ages 26+ Galactosemics and Their Adult Guests*

Please join the Adult Galactosemics (AGERS Group) during our upcoming conference in Orlando! AGERS is an adult galactosemic group open to adults with galactosemia, their spouses and their siblings. AGERS goal is help adults affected by galactosemia. Many Adult Galactosemics (AGERS) find it helpful to hear from spouses and siblings as we share many of the same experiences and challenges. Additionally, we find we share many commonalities and similar lifestyles. Meeting, interacting, sharing stories and having a great, once in a lifetime experience is what we are all about! The AGERS program will be a fun filled weekend spent with others that truly 'get' things we will share and something you don't want to miss.

Don't miss this chance to meet other adults living with galactosemia and reconnect with others. Everyone will be able to share their own stories, tips, experiences and ideas on how to improve our lives with galactosemia.

AGERS will have some special sessions in our own meeting room and also engage in some general session and breakout sessions too. We will get started with registration on Thursday and getting to know one another. We will join everyone at both the Friday and Saturday night socials and even have a group dinner on our own, at Downtown Disney.

Register today for AGERS and plan on having a great time, making new friends, and most importantly, being with others that truly understand galactosemia! Hopefully everyone will walk away having formed lifetime bonds and made many new friends you can see at future conferences.

If you have any questions about the AGERS group please email Kimberley Malyn at: [kmalyn@sbcglobal.net](mailto:kmalyn@sbcglobal.net).

We look forward to seeing you as part of the AGERS program in July!

**For Bios On All Our General Session  
& Breakout Session Speakers**

**- AND -**

**Even More 2014 Conference Information  
& To Register - Be Sure To Visit Our Web Site:  
[www.galactosemia.org](http://www.galactosemia.org)**

# AGERS Schedule

## - Thursday -

4:00pm - 6:00pm **Meet and Greet**

6:00pm - 9:00pm **Registration**

6:00pm - 9:00pm **Socialize & enjoy the candy buffet & vendors**

## - Friday -

7:00am - 8:00am **Breakfast /Childcare Drop-off**

8:00am - 8:15am **Welcome, Michelle Fowler, GF President**

8:15am - 8:30am **AGERS Welcome in AGERS room**

8:30am - 9:30am **Introductions/Get to know others including spouses**

9:30am - 9:45am **Break**

9:45am - 10:30am **Group Sharing (Share experiences & feelings about galactosemia)**

10:30am - 11:00am **AGERS Trivia**

11:00am - 11:45am **Fertility Discussions/Life After POI**

11:45am - 1:00pm **Lunch**

1:00pm - 2:00pm **Attend a Breakout Session of your choice**

2:15pm - 3:15pm **Game Time**

3:15pm - 3:30pm **Break**

3:30pm - 5:00pm **Attend General Session as a group**

5:00pm **Group Photo of Everyone Who Has Galactosemia**

5:30pm - 7:30pm **Dinner On Your Own**

7:30pm - 10:00pm **Join the entire GF family in a Carnival Social**

## - Saturday -

7:00am - 8:00am **Breakfast/Childcare Drop-off**

8:00am - 8:15am **General Session**

8:15am - 9:45am **Question & Answer Session**

9:45am - 10:00am **Break**

10:00am - 11:00am **Attend a Breakout Session of your choice**

11:15am - 12:15pm **Attend a Breakout Session of your choice**

12:15pm - 1:30pm **Lunch**

1:30pm - 2:45pm **No Whey Tropical Café**

2:45pm - 3:00pm **Break**

3:00pm - 4:00pm **Attend a Breakout Session of your choice**

4:15pm - 5:00pm **General Session**

5:30pm - 8:00pm **Dinner AGERS Group dinner as a group in Downtown Disney Location TBA**

8:00pm - Midnight **Farewell Social**

# Generation G

Teen & Young Adult Galactosemic & Sibling Program For Ages 18+

## Are You Ready for Some Tropical Delight?

This year's GG program in Orlando promises to provide something for everyone! If you're into golfing (or even if you aren't)—plan to arrive on Wednesday so you can participate in the first-ever Galactosemia Foundation Golf Tournament on Thursday! GG Early Registration on Thursday will begin at 4 pm a couple of hours after golfing—so, you won't miss a thing.

The goals for the Generation G program are to:

*Meet, interact, and have a good time with other young adults with galactosemia*

*Learn about the latest research and share your experiences and concerns about galactosemia*

To secure group rates for off-site activities, registering for the GG program indicates that you will be attending both on-site and off-site activities. This year because of generous donations including one from the Galactosemic Families of Minnesota (GFMN), we are able to keep the cost at \$50/per person in addition to registration. We highly recommend online payment registration (mail in registration may be an option)—this will be your only opportunity to sign up for the GG program—it will NOT be possible to sign up for the GG program at the conference because counts are needed for group activities and costs.

This year we plan to interact more with families and younger kids with galactosemia. In addition, GGs and G-Forcers are going to have the opportunity to raise funds for the Paul Pruszynski Scholarship Fund. This program provides financial assistance for one Generation G and this year for the first time, one G-Forcer, to attend the conference, which they might otherwise not be able to attend.

If you are a GG or G-Forcer who is interested in applying for the Paul Pruszynski Scholarship please e-mail Linda Manis (Lmscript1@aol.com) for an application—all applications are due no later than March 1st.

We are also excited to present breakout sessions this year for GGs and G-Forcers—this will give you the opportunity to choose a specific session that you would like to attend, which will focus on one of the issues you might have experienced as a result of galactosemia. You will be able to choose your breakout sessions (there will be two times so two to choose) at the GG Conference Early Registration in Orlando!

So grab your bathing suits, sunscreen, hats, and tropical clothes and get ready for 3 days of nonstop fun!!

See you in Orlando!

# Generation G Schedule

- Thursday -

**7:30am – 2pm Galactosemia Foundation Golf Tournament:**

Everyone who is 13 years and older is invited to participate in the first-ever Galactosemia Golf Tournament—Raffles, Prizes, Lunch & More

**2pm – 9pm On-site Research:** Register for This Awesome

Opportunity. Several of our dedicated galactosemia researchers are conducting on-site research before and during the conference: This is a great way to help the galactosemia research community. Please plan to STOP by the research rooms to sign up!

**4pm – 6pm GG Early Registration:** Be sure to arrive in time for Early Registration—And meet new and old friends!

**6pm – 9pm Galactosemia Foundation Registration:** (This is when your families will register) Enjoy the Sweet Treat Buffet Social - Starring Illinois Nut & Chocolate Fantasia Company's famous, scrumptious chocolates and more!

**8pm – 9pm GGs & G-Forcers Private Magic & Comedy Show by Erick Olson:** Check out his Web site at: <http://www.bookcomedymagic.com/>

**9pm – 10:30pm Exclusively for GGs and G-Forcers Only:** Experience the wonder and fireworks of Disney's Epcot Center from the 27th floor of the hotel

- Friday -

**7am – 8am Galactosemia Foundation Breakfast**

**8am – 11:30am Meet in the GG Room: Getting to Know Old &**

**New Friends:** Demonstration by Canine Companions for Independence (CCI). One of CCI's six campuses happens to be in Orlando—So we will have the opportunity to meet these "assistance" companion dogs and learn how they are trained to assist people of all ages. Check out their Web site at: [www.cci.org](http://www.cci.org)

**Laurie Bernstein:** World Renowned Nutritionist on Galactosemia. Laurie will dazzle us with her diet expertise while answering your questions.

**Andrea Topper:** Empowering You to Be Your Best. Andrea will lead a private group discussion about self-esteem, and the various issues people with galactosemia face.

**Roxanne Schreiber:** Success over Stress. Roxanne will provide tools to overcome anxiety, nervousness, and depression.

**11:30am – 1pm GG Lunch with the Doctors & Professionals:**

Learn and ask questions about the latest research from a variety of different doctors and professionals.

**1:30pm – 4:30pm Bowling:** Back by Popular Demand! GGs and G-Forcers will be boarding buses to Disney Village to bowl and play pool at Splitsville Luxury Lanes where we will also enjoy drinks and snacks. Check out their web site at: [www.splitsvillelanes.com](http://www.splitsvillelanes.com)

**5pm Group Photo of Everyone who has Galactosemia:** AGERS, GGs, G-Forcers, Mighty Gs, Junior Gs, and Tiny Gs!

**5:15pm GG Program & General Session End:** Time to hook up with your family for dinner, take a nap, and get ready for another evening of fun!

**7:30pm – 10pm Galactosemia Friday Evening Social:** Wear your favorite sports team shirt and "Team Up for Fun!". Games, dunking booth, yummy snacks, and more. GGs and G-Forcers can volunteer to "work" at the carnival for donations for the Paul Pruszyński Memorial Scholarship Fund.

## - Saturday -

**7am – 8am Galactosemia Foundation Breakfast**

**8am – 8:15am Paul Pruszyński Memorial Scholarship Presentation:** GGs & G-Forcers Attend General Session for the presentation. 1 GG & 1 G-Forcer each will be awarded.

**8:30am – 12pm No Whey Tropical Café:** You do the cooking (and of course the tasting) Learn how to make some easy, dairy-free treats!

**Breakout Sessions You can choose which session you would like to go to, each will be led by a galactosemia doctor or professional.**

**- Breakout Session 1 - (you will choose one)**

• **Women and POF:** Dr. Judy Fridovich-Keil, Dr. Jessica Spencer, Dr. Cynthia Gubbels, and Dr. Estela Rubio-Gozalbo  
A discussion for GG and 16–17 year old G-Forcer women.

• **Tremors in Galactosemia:** Dr. Claudia Testa  
This session is for any GG or G-Forcer who has experienced tremors.

• **Living with Galactosemia:** Andrea Topper  
A group discussion of what it's like growing up with Galactosemia.

**- Breakout Session 2 - (you will choose one)**

• **Gastrointestinal Issues:** Dr. Judy Fridovich-Keil  
This session is for any GG or G-Forcer who has experienced gastrointestinal symptoms.

• **Galactosemia and Speech:** Dr. Nancy Potter (Speech Therapist) This session is for any GG or G-Forcer who has experienced speech issues.

• **Living with Galactosemia:** Dr. Roxanne Schreiber  
A group discussion of what it's like growing up with Galactosemia.

**12pm – 12:45pm GGs & G-Forcers Lunch:** GGs and G-Forcers mingle and enjoy a delicious lunch together.

**1pm – 4:30pm Disney Quest:** Discover 5 floors of fun including virtual landscapes, 3D encounters, and classic video games. It's a one-of-a-kind experience. Check out their Web site at: <https://disneyworld.disney.go.com/entertainment/downtown-disney/disney-quest-indoor-interactive-theme-park/>

**5:15pm GG Program & General Session End:** Time to hook up with your family for dinner, take a nap, and get your dancing shoes on!

**8pm – Midnight Galactosemia Foundation Saturday Night Social and Dance:** Wear your favorite tropical shirt and dance the night away with your new and old friends!

## Save Your Loose Change!

Working for Tips - Our very own galactosemics will be working during our Friday night carnival social. Some of the Generation G and G-Force group will be working for tips on Friday night. They will be serving refreshments and working the variety of fun booths we will be having at the social. In return for their hard work they are asking for your loose change as their tips. All of the tips they collect will go towards the Paul Pruszyński scholarship fund and the Galactosemia Foundation conference fund. So start saving that loose change so you can come prepared to tip!



# G-Force

Teen Galactosemic and Sibling Program for ages 13-17

## Are You Ready for Some G-Force Fun?

Are you a teen ready for some G-FORCE fun? Since we're linked for life, it's time to take flight, to the place where dreams really do come true! There's so much that we share, that it's time to prepare; it's a small world after all!

We recently corralled together in The Lone Star State not long ago. It's time now to experience the magic and tropical splendor of Orlando!

G-FORCE is named for its meaning of "moving forward" and is designed for all teens affected by galactosemia. This program provides an opportunity for young people to make new friends and reconnect with old pals. While parents are attending the conference, teens will learn more about galactosemia, as well as experience the thrill of many exciting activities Florida style. Teens will be supervised by adult volunteers at all times. G-FORCE activities will be organized into small groups ranging from ages 13-15 years old and 16-17 years old..

The goals for the G-Force program are to:

*Meet and build friendships, while having fun with teens with galactosemia and their siblings.*

*Learn together and from each other about galactosemia.*

We are thrilled to announce our first-ever Galactosemia Foundation Golf Tournament on Thursday! This event is open for golfers at any skill level. It's sure to provide entertainment for all, as well as support our galactosemia family.

Both on-site and off-site activities will be offered including: Cooking at the "No Whey Cafe", bowling in Downtown Disney, having an interactive adventure at Disney Quest and much more! Carefully planned interactive activities and educational speakers such as: dietitians and psychologists at the hotel give us the opportunity to gain important knowledge about galactosemia to better our lives.

In order to secure group rates for off-site activities, registering for the G-FORCE Program indicates that you will be attending both on-site and off-site activities. Online or Mail-in registration will be your ONLY opportunity to sign up for the G-FORCE Program. It will not be possible to sign up for the program at the conference, as counts are needed for group activity costs and transportation. We highly recommend online payment registration. Thanks to support from various donations we are able to keep the cost at \$50 per teen in addition to registration.

This year G-FORCERS are going to have the opportunity to raise funds for the Paul Pruszynski Scholarship Fund. This

program provides financial assistance for one Generation G and this year for the first time, one G Forcer, to attend the conference, which they might otherwise not be able to attend.

If you are a GG or G-Forcer who is interested in applying for the Paul Pruszynski Scholarship please e-mail Linda Manis (Lmscript1@aol.com) for an application—all applications are due no later than March 1st.

Here comes the sun, it's going to be fun in Florida at our 2014 Galactosemia Foundation Conference! We hope all teens will join "G-FORCE" and be a part of our exciting program for all teens! **We Hope You Join The Force!**

NOTE: The G-FORCE program is under the direction of G-FORCE Coordinator, Jeannine Quam. For any questions, please email: [jmquam@edenpr.org](mailto:jmquam@edenpr.org)

## G-Force Schedule

- Thursday -

**7:30am - 2pm Galactosemia Foundation Golf Tournament:**

Everyone who is 13 years and older is invited to participate in the first-ever Galactosemia Golf Tournament—Raffles, Prizes, Lunch & More

**2pm - 9pm on-site Research:** Register for This Awesome Opportunity. Several of our dedicated galactosemia researchers are conducting on-site research before and during the conference: This is a great way to help the galactosemia research community. Please plan to STOP by the research rooms to sign up!

**4pm - 6pm G-Force Early Registration:** Be sure to arrive in time for Early Registration—And meet new and old friends!

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**8pm - 9pm GGs & G-Forcers Private Magic & Comedy Show by Erick Olson:** Check out his Web site at: <http://www.bookcomedymagic.com/>

**9pm - 10:30pm Exclusively for GGs and G-Forcers Only:** Experience the wonder and fireworks of Disney's Epcot Center from the 27th floor of the hotel

## - Friday -

### 7am – 8am Galactosemia Foundation Breakfast

**8am – 11:30am Meet in the G-Force Room –Getting to Know Old & New Friends:** Demonstration by Canine Companions for Independence (CCI). One of CCI's six campuses happens to be in Orlando—So we will have the opportunity to meet these "assistance" companion dogs and learn how they are trained to assist people of all ages. Check out their Web site at: [www.cci.org](http://www.cci.org)

**Laurie Bernstein:** World Renowned Nutritionist on Galactosemia. Laurie will dazzle us with her diet expertise while answering your questions.

**Andrea Topper:** Empowering You to Be Your Best. Andrea will lead a private group discussion about self-esteem, and the various issues people with galactosemia face.

**Roxanne Schreiber:** Success over Stress. Roxanne will provide tools to overcome anxiety, nervousness, and depression.

**11:30am – 1pm G-Force Lunch with the Doctors & Professionals:** Learn and ask questions about the latest research from a variety of different doctors and professionals.

**Roxanne Schreiber:** Super Siblings. Roxanne will lead a private conversation just for siblings to discuss what it is like to have a brother or sister living with galactosemia.

**1:30pm – 4:30pm Bowling:** Back by Popular Demand! GGs and G-Forcers will be boarding buses to Disney Village to bowl and play pool at Splitsville Luxury Lanes where we will also enjoy drinks and snacks. Check out their web site at: [www.splitsvillelanes.com](http://www.splitsvillelanes.com)

**5pm Group Photo of Everyone who has Galactosemia:** AGERS, GGs, G-Forcers, Mighty Gs, Junior Gs, and Tiny Gs!

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## - Saturday -

### 7am –8am Galactosemia Foundation Breakfast

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**Breakout Sessions You can choose which session you would like to go to, each will be led by a galactosemia doctor or professional.**

**- Breakout Session 1 - (you will choose one)**

• **Women and POF:** Dr. Judy Fridovich-Keil, Dr. Jessica Spencer, Dr. Cynthia Gubbels, and Dr. Estela Rubio-Gozalbo  
A discussion for GG and 16–17 year old G-Forcer women.

• **Tremors in Galactosemia:** Dr. Claudia Testa  
This session is for any GG or G-Forcer who has experienced tremors.

• **Living with Galactosemia:** Andrea Topper  
A group discussion of what it's like growing up with Galactosemia.

**- Breakout Session 2 - (you will choose one)**

• **Gastrointestinal Issues:** Dr. Judy Fridovich-Keil  
This session is for any GG or G-Forcer who has experienced gastrointestinal symptoms.

• **Galactosemia and Speech:** Dr. Nancy Potter (Speech Therapist) This session is for any GG or G-Forcer who has experienced speech issues.

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A group discussion of what it's like growing up with Galactosemia.

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**8pm – Midnight Galactosemia Foundation Saturday Night Social and Dance:** Wear your favorite tropical shirt and dance the night away with your new and old friends!

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& To Register – Be Sure To Visit Our Web Site:  
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# Mighty Gs

A Program for 9 to 12 Year-Olds

Your babies are growing up! The Mighty-G program is designed as a transition from the childcare to the groups that have off-site activities; G-Force and Generation G. The Mighty-G program is for galactosemics and siblings ages 9-12. The Mighty-Gs will attend some special sessions during the conference to better engage them in activities and being a part of the conference. Hopefully this will prove to allow those in this program to enjoy themselves and walk away with friendships they have formed to last them a lifetime. An example of one session is the "No Whey Café". This is a session where participants will be in a real life, café setting, making a galactosemic safe dish!

In order for this group to be a success, we need two volunteers. The volunteers will still be able to attend general sessions and breakout sessions. However, at designated timeframes, they would need to take the Mighty Gs to and from their special sessions around the hotel and assist during their sessions.

*If you are interested in helping to make this program more interactive and successful please email: [conference@galactosemia.org](mailto:conference@galactosemia.org) and put Mighty G in the subject line. We need your help!*

**For Bios On All Our General Session & Breakout Session Speakers Be Sure To Visit Our Web Site:  
[www.galactosemia.org](http://www.galactosemia.org)**

## - General Session Schedule -

### - Thursday -

#### **7:30am - 2:00pm Galactosemia Foundation Golf Tournament**

Disney's Lake Buena Vista Golf Course. Proceeds from the tournament will benefit the Galactosemia Foundation. Registration begins at 7:30 AM and the tournament starts at 8:00 AM. Lunch will be served on course.

#### **2:00pm - 9:00pm On-Site Research**

Please participate in the on-site research being offered! Several researchers will be conducting on-site research before and during the conference. You can register for this on-site research right at the conference. Don't miss this very special opportunity to participate and be a part of research. Stop by the research rooms and sign up to participate.

#### **4:00pm - 9:00pm Generation-G and G-Force Registration**

Get an early start on registration for the Generation-G and G-Force programs.

#### **4:30pm - 6:00pm Galactosemia 101**

Michelle Fowler, Galactosemia Foundation President & Scott Shepard, Galactosemia Foundation Vice President. The goal of Galactosemia 101 is to provide a lively, interactive, "upbeat, but honest" presentation of practical material and advice to parents who are new to the world of Galactosemia from parents who have "been there". Also we hope to provide a foundation from which parents can learn more together with their medical professionals. Please make plans to join us, especially if you are new parents or first time conference attendees.

#### **6:00pm - 9:00pm Conference Registration & Sweet Treat Buffet Social**

Check-in at the general registration booth to get your conference material and badge. Also register for any special programs such as Childcare, Mighty-G, G-Force, Generation G and AGERS. Then enjoy a sweet treat buffet hosted by IL Nut & Chocolate Fantasia Company while you mingle with other conference attendees. Also take part in the fun activities for the kids; break the ice and meet some new faces.

#### **7:15pm - 8:15pm My Life with Galactosemia**

Maureen Bell will speak to her life with galactosemia and all of the challenges that she has faced. This will include living with the diet, social issues, and having premature ovarian insufficiency. This talk will be for parents of newly diagnosed children or others who may want to hear an inspiring story.

### - Friday -

#### **7:00am - 8:00am Galactosemia Foundation Breakfast**

Enjoy a galactosemic safe breakfast with other conference attendees. Questionable and/or NO foods will be on a separate, clearly marked table with a RED table cloth. For conference attendees only - you must have a conference badge to eat breakfast.

#### **7:00am - 8:00am Childcare Drop-off**

After breakfast, drop your children off at the appropriate childcare room.

#### **7:00am - 8:00am Late Registration**

For those not able to complete on-site registration on Thursday night.

#### **8:00am - 8:15am Welcome to the Galactosemia Foundation 2014 Conference**

Michelle Fowler, Galactosemia Foundation President

#### **8:15am - 8:45am Opening Remarks**

Tera Mize Jones, Founder of Tyler for Life Foundation

#### **8:45am - 9:30am The Galactosemia Diet**

Laurie Bernstein, MS, RD, FADA

#### **9:30am - 9:45am Morning Break**

Enjoy a galactosemia safe beverage and visit with other conference attendees

**9:45am – 10:00am Galactosemia Foundation Research Team Update**  
Christine Winey, Galactosemia Foundation Research Team Lead

**10:00am – 11:00am Research Briefings:**  
Gerard Berry, MD; Sandy Van Calcar PhD, RD; Kent Lai, PhD, MBA, Judith L. Fridovich-Keil, PhD  
  
Recipients of the four Galactosemia Foundation 2013 research grants will each give a very brief overview of their galactosemia research.

**11:00am – 11:45am Modifier Genes and Epigenetic Effects in Galactosemia**  
Gerard T. Berry, MD

**11:45am – 1:00pm Galactosemia Foundation Lunch**  
Join fellow conference attendees for a galactosemic safe lunch buffet. Questionable and/or NO foods will be on a separate, clearly marked table with a RED table cloth. For conference attendees only - you must have a conference badge to eat lunch.

**1:00pm – 2:00pm Breakout Session 1**  
Attend one session from the breakout session 1 list

**2:15pm – 3:15pm Breakout Session 2**  
Attend one session from the breakout session 2 list

**3:15pm – 3:30pm Afternoon Break**  
Enjoy a galactosemia safe snack and visit with other conference attendees

**3:30pm – 4:15pm Toward Improved Long-Term Outcomes in Classic Galactosemia**  
Judith L. Fridovich-Keil, PhD

**4:15pm – 5:15pm General Session Closing Remarks – Question & Answer with Speakers**

**5:00pm – 5:15pm Children and Age Groups Photo**  
All of the children and age groups will gather for group photos

**5:15pm – 7:30pm Dinner On Your Own**  
Enjoy a dinner on your own at or near the hotel

**7:30pm – 10:00pm Galactosemia Friday Evening Social**  
Wear your favorite sports team shirt and "Team Up for Fun" with fellow conference attendees. This will be a carnival of a time!

## - Saturday -

**7:00am – 8:00am Galactosemia Foundation Breakfast**  
Enjoy a galactosemic safe breakfast with other conference attendees. Questionable and/or NO foods will be on a separate, clearly marked table with a RED table cloth. For conference attendees only - you must have a conference badge to eat breakfast.

**7:00am – 8:00am Childcare Drop-off**  
After breakfast, drop your children off at the appropriate childcare room.

**8:00am – 8:15am Opening Remarks**  
Opening Remarks and the Paul Pruszynski Scholarship Award  
Linda Manis, Founder of PGC and Coordinator of the Generation-G Program & Michelle Fowler, Galactosemia Foundation President

**8:15am – 9:00am Living with Galactosemia from a Galactosemic's Point of View**  
Galactosemic Panel of Speakers

**9:00am – 9:15am Treasurer's Report**  
Paul Fowler, Galactosemia Foundation Treasurer

**9:15am – 9:45am Fundraising**  
If we can do it, so can you!

**9:45am – 10:00am Morning Break**  
Enjoy a galactosemia safe beverage and visit with other conference attendees

**10:00am – 11:00am Breakout Session 3**  
Attend one session from the breakout session 3 list

**11:15am – 12:15pm Breakout Session 4**  
Attend one session from the breakout session 4 list

**12:15pm – 1:30pm Galactosemia Foundation Lunch**  
Join fellow conference attendees for a galactosemic safe lunch buffet. Questionable and/or NO foods will be on a separate, clearly marked table with a RED table cloth. For conference attendees only - you must have a conference badge to eat lunch.

**1:30pm – 2:15pm Speech Characteristics in Classic Galactosemia**  
Nancy Potter, PhD, CCC-SLP

**2:15pm – 2:45pm Psychology**  
Roxanne Schreiber, PhD

**2:45pm – 3:00pm Afternoon Break**  
Enjoy a galactosemia safe snack and visit with other conference attendees

**3:00pm – 4:00pm Breakout Session 5**  
Attend one session from the breakout session 5 list

**4:15pm – 5:15pm**  
Conference Closing Remarks - Question & Answer with Speakers

**5:15pm – 8:00pm Dinner On Your Own**  
Enjoy a dinner on your own at or near the hotel

**8:00pm – 12:00am Saturday Night Social and Dance**  
Wear your favorite tropical shirt, mingle, get your picture taken in the photo booth, and dance with your fellow conference attendees! Tropical Farewell!

## - Breakout Sessions -

### - Friday - Breakout #1 (choose one)

**Diet for Infants and Toddlers:** Sandy Van Calcar, PHD, RD

**Characterization of a New Mammalian Animal Model of Classic Galactosemia:** Kent Lai, PHD

**Ovarian Function in Classic Galactosemia-Childhood & Adolescence:** Judy Fridovich-Keil, Jessica Spencer, Cynthia Gubbels, Estela Rubio-Gozalbo

**AGERS Roundtable**

**Tapping Into Technology!:** Kelly Dittmann

**Transition & Identity Achievement for Teens & Adults w/ Galactosemia:** Susan Waisbren

**Cooking Demo:** David Levine

**'Help me talk!' What you can do to help your preschool or elementary school age child:** Nancy Potter

### - Friday - Breakout #2 (choose one)

**Diet For Teen:** Sandy Van Calcar

**The new infant with galactosemia - What comes next?:** Gerard Berry

**The benefits, risks & types of hormone replacement therapy (HRT) in women w/ Classic Galactosemia:** Cynthia Gubbels, Jessica Spencer, & Estela Rubio Gozalbo

**Galactosemia and the Spine - The relationship between the spine and neurological impairments such as tremors, decreased motor skills, and learning disabilities:** Alli Manis

**Scholastic Outcomes in Classic Galactosemia:** Judy Fridovich-Keil

**Living w/ galactosemia - Quality of life:** Annet Bosch

**Label Reading:** David Levine

**Self Esteem:** Andrea Topper

### - Saturday - Breakout #3 (choose one)

**Determination of Galactose Content in Foods for the Benefit of Galactosemics:** Ronnie Boone

**Modifier Genes:** Gerard Berry

**Fertility Issues in Classic Galactosemia:** Cynthia S. Gubbels, Jessica B. Spencer, Estela Rubio-Gozalbo, Judith L. Fridovich-Keil

**Movement Disorders 101:** Claudia Testa

**Education - Special Education:** Jason Wilcox and Helen Cagel-Crumbley

**Raising a Happy, Independent, & Successful Child who just happens to have Galactosemia:** Roxanne Schreiber

**Galactosemia Foundation Roundtable - The Future of Galactosemia Foundation**

**Umm, I don't remember - How to teach your child (or yourself) to recall facts:** Nancy Potter

### - Saturday - Breakout #4 (choose one)

**Research in Nutrition Management of Classical Galactosemia:** Sandy VanCalcar

**Long-term Outcomes in Classic Galactosemia:** Brainstorming Together: Judy Fridovich-Keil

**Research Registry Database:** Gerard Berry

**Research in Galactosemia Related to Movement Disorders:** Claudia Testa

**Fundraising 101:** JoBeth Southard, Scott Saylor, Cathy Cunningham

**Our Struggles and Triumphs:** Landon Fowler, Keith and Chris Topper

**Current Pharmacy Issues & Galactosemia:** William Bell

**Genotype & Phenotype Correlation In The Galt Gene:** The Italian Experience: Alberto Burlina

### - Saturday - Breakout #5 (choose one)

**Bones, Nutrition & Classical Galactosemia:** Sandy VanCalcar

**European-American network and the creation of an international database for patients w/ Galactosemia:** Estela Rubio-Gozalbo

**Holidays w/ Galactosemia:** Andrea Topper

**Movement Disorders - Advanced:** Claudia Testa

**Education - Communicating with your school & advocating for your children:** Melissa Gamble

**Let's Talk About You - Understanding how you, as a parent, can cope powerfully, efficiently, & peacefully in raising your child w/ Galactosemia:** Roxanne Schreiber

**Diet in Adults w/ Galactosemia:** Pat Portnoi

**Gastrointestinal Health in Classic Galactosemia:** Judy Fridovich-Keil, Kelly A. Shaw



# REGISTRATION FORM (or register on-line at [www.galactosemia.org](http://www.galactosemia.org))

## PRIMARY REGISTRANT

Name, First \_\_\_\_\_ Last \_\_\_\_\_

Address 1 \_\_\_\_\_

Address 2 \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Country \_\_\_\_\_

Email Address \_\_\_\_\_

Phone \_\_\_\_\_

## GALACTOSEMIC STATUS

- Parent
- Grandparent
- AGER (26+)
- Generation G
- Healthcare Prof/Student

## NEWSLETTER PREFERENCE

- E-Mail
- Print
- Both
- Neither

## ADDITIONAL ATTENDEE 1

Name, First \_\_\_\_\_ Last \_\_\_\_\_

### GALACTOSEMIC STATUS

- Parent  Grandparent  Healthcare Prof/Student  AGER(26+)  Generation G(18+)
- G-Force(13-17)  Mighty G(9-12)  Junior G(6-8)  Tiny G(3-5)
- Mini G(under 2)  Sibling(9-12)  Sibling(6-8)  Sibling(3-5)  Sibling(under 2)

### SHIRT SIZE

*(only for Generation G  
and G-Force participants)*

- Child Small  Child Medium
- Child Large  Adult Small
- Adult Medium  Adult Large
- Adult XL  Adult XXL

## ADDITIONAL ATTENDEE 2

Name, First \_\_\_\_\_ Last \_\_\_\_\_

### GALACTOSEMIC STATUS

- Parent  Grandparent  Healthcare Prof/Student  AGER(26+)  Generation G(18+)
- G-Force(13-17)  Mighty G(9-12)  Junior G(6-8)  Tiny G(3-5)
- Mini G(under 2)  Sibling(9-12)  Sibling(6-8)  Sibling(3-5)  Sibling(under 2)

### SHIRT SIZE

*(only for Generation G  
and G-Force participants)*

- Child Small  Child Medium
- Child Large  Adult Small
- Adult Medium  Adult Large
- Adult XL  Adult XXL

## ADDITIONAL ATTENDEE 3

Name, First \_\_\_\_\_ Last \_\_\_\_\_

### GALACTOSEMIC STATUS

- Parent  Grandparent  Healthcare Prof/Student  AGER(26+)  Generation G(18+)
- G-Force(13-17)  Mighty G(9-12)  Junior G(6-8)  Tiny G(3-5)
- Mini G(under 2)  Sibling(9-12)  Sibling(6-8)  Sibling(3-5)  Sibling(under 2)

### SHIRT SIZE

*(only for Generation G  
and G-Force participants)*

- Child Small  Child Medium
- Child Large  Adult Small
- Adult Medium  Adult Large
- Adult XL  Adult XXL

## ADDITIONAL ATTENDEE 4

Name, First \_\_\_\_\_ Last \_\_\_\_\_

### GALACTOSEMIC STATUS

- Parent  Grandparent  Healthcare Prof/Student  AGER(26+)  Generation G(18+)
- G-Force(13-17)  Mighty G(9-12)  Junior G(6-8)  Tiny G(3-5)
- Mini G(under 2)  Sibling(9-12)  Sibling(6-8)  Sibling(3-5)  Sibling(under 2)

### SHIRT SIZE

*(only for Generation G  
and G-Force participants)*

- Child Small  Child Medium
- Child Large  Adult Small
- Adult Medium  Adult Large
- Adult XL  Adult XXL

# REGISTRATION FORM (cont'd) (or register on-line at [www.galactosemia.org](http://www.galactosemia.org))

## Conference Registration (includes breakfast & lunch Friday & Saturday)

*\*Early Bird Registration (Before May 1) is \$99.00 / Regular Registration (on or before June 1) \$149.00 / Late Registration (after June 1) \$199.00.*

	Cost Each	Quantity	Total Cost
Adult General Conference Attendee	\$99		
Children In Childcare Program (ages 0-12)	\$99		
AGERS (adult Galactosemics 23+)	\$99		
G-Force Participants (ages 13-17) Includes \$50 activity fee <i>(includes t-shirt)</i>	\$149		
Generation G Participants (ages 18+) Includes \$50 activity fee <i>(includes t-shirt)</i>	\$149		

### Optional Items

	Cost Each	Total Qty.	Total Cost
<i>**Available for pre-order only. Very limited availability during the conference.</i>			
Conference T-Shirt <i>(not pictured)</i> <input type="radio"/> Child Sml <input type="radio"/> Child Med <input type="radio"/> Child Lrg <input type="radio"/> Adult Sml <input type="radio"/> Adult Med <input type="radio"/> Adult Lrg <input type="radio"/> Adult XL <input type="radio"/> Adult XXL	\$12		
<b>**Contest (Balloons) T-Shirt</b> <input type="radio"/> Child Sml <input type="radio"/> Child Med <input type="radio"/> Child Lrg <input type="radio"/> Adult Sml <input type="radio"/> Adult Med <input type="radio"/> Adult Lrg <input type="radio"/> Adult XL <input type="radio"/> Adult XXL	\$12		
<b>**Team G-Strong T-Shirt</b> <input type="radio"/> Child Sml <input type="radio"/> Child Med <input type="radio"/> Child Lrg <input type="radio"/> Adult Sml <input type="radio"/> Adult Med <input type="radio"/> Adult Lrg <input type="radio"/> Adult XL <input type="radio"/> Adult XXL	\$12		
<b>**Invincible T-Shirt</b> <input type="radio"/> Child Sml <input type="radio"/> Child Med <input type="radio"/> Child Lrg <input type="radio"/> Adult Sml <input type="radio"/> Adult Med <input type="radio"/> Adult Lrg <input type="radio"/> Adult XL <input type="radio"/> Adult XXL	\$12		
Awareness Wristbands	\$2		
<b>**Swarovski Crystal Bracelet</b> <input type="radio"/> 6-3/4" <input type="radio"/> 7-1/4" <input type="radio"/> 7-3/4"	\$30		
<b>**Swarovski Crystal Necklace</b> <input type="radio"/> 16" <input type="radio"/> 18"	\$30		
<b>**4" Necklace Extension</b>	\$5		
Charity Golf Tournament <i>Thursday, July 17, 2014. Teams may include up to 4 players. Please supply player list.</i>	\$100		
Optional Donation <i>Please read about our 'True Cost' on the next page.</i>			
<b>*Regular Registration (on or before June 1)</b>	Add \$50		
<b>*Late Registration (after June 1)</b>	Add \$100		
<b>Grand Total:</b>			\$ _____

Please include check payable to: Galactosemia Foundation - P.O. Box 2401, Mandeville, LA 70470-2401

-OR- Pay via PayPal: [treasurer@galactosemia.org](mailto:treasurer@galactosemia.org)

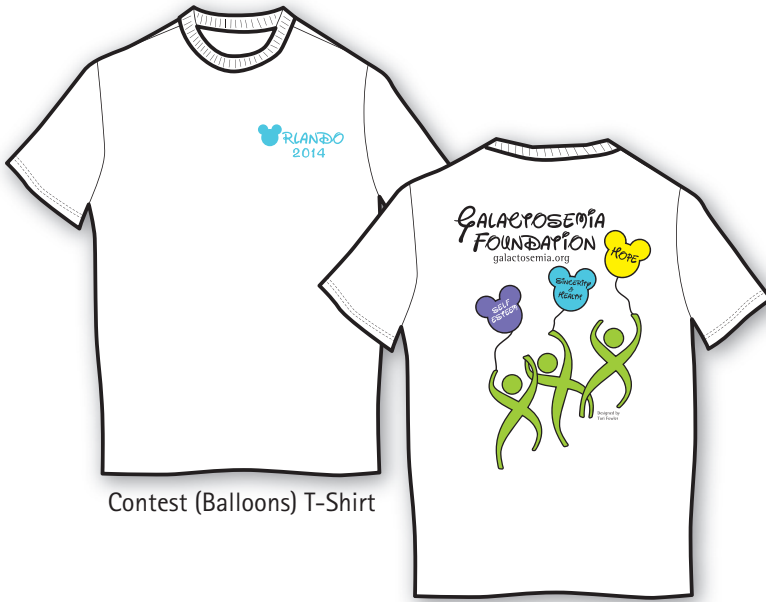
-OR- Register on-line: [www.galactosemia.org](http://www.galactosemia.org)



Invincible T-Shirt



Team G-Strong T-Shirt



Contest (Balloons) T-Shirt



Awareness Wristbands



Swarovski Crystal Bracelet

## A Note About The Conference's 'True Cost'

Through year-long fundraising efforts, generous donations and even corporate sponsorships, we are fortunate to be able to provide such an affordable price for those affected by galactosemia to attend our bi-annual conference. This year we are funding 70% of the cost to attend for each person who pays the set registration fee. The 'True Cost' to the Foundation per attendee is about \$670. This is what it cost to cover food, conference room rentals, speaker expenses, AV equipment, and more.

We all look forward to these conferences, and we understand what an astounding impact they have on the galactosemic community and the important role they play in the lives in families affected by galactosemia, especially the children. The Galactosemia Foundation benefits from donations of any amount and this year we have added the option, for those who are able, to pay the 'True Cost' of their attendance at registration. Whatever you decide, we can't wait to see you in Orlando!

JANUARY	FEBRUARY	MARCH
APRIL	MAY	JUNE
6 .....Bowling for Breyden, The GLO-BOWL Fun Center located at 101 Franks Road Marengo, IL 60152, (815)568-2695.		7 .....Second Annual Race 4 Jase at 9am at Crosslin Park in Enid, OK
JULY	AUGUST	SEPTEMBER
17 .....‘Fore The Cause’ Golf Outing, .....Orlando, FL 17-19....GF Conference .....Orlando, FL		
OCTOBER	NOVEMBER	DECEMBER

Galactosemia Foundation  
 P.O. Box 2401  
 Mandeville, LA 70470-2401



**Galactosemia  
 Foundation**  
 Linked for Life.

If you would like to sign up to receive this newsletter via email please go to our website: [www.galactosemia.org](http://www.galactosemia.org)