



Fall 2013

Galactosemia GAZETTE

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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 galactosemia.org

Join us for the 2014 Galactosemia Foundation Conference in Orlando, Florida

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

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

Teaming Together for a Bright Future

The theme for the 2014 conference is "Teaming Together for a Bright Future". This conference will provide an opportunity for you to learn all about galactosemia today and to be part of the "team" striving for a bright future for all galactosemics. The conference will address real-life situations faced by those with galactosemia and offer practical strategies and tools that can improve the quality of life for individuals with galactosemia and their families. The conference will also feature the results of the latest galactosemia research and opportunities to participate in ongoing research studies.

Through the various age group programs (Mighty-Gs, G-Force, Generation Gs, and AGERs) and optional social activities, the conference provides opportunities for children and adults with galactosemia to meet and make life-long friendships.

All ages are welcome to attend the 2014 Galactosemia Foundation conference. The General Session conference program is targeted for adults ages 18 and older. We offer professional childcare services on-site at the conference by specially trained staff for children from infants through age 12. The various "age groups" have their own programs of on and off-site activities that are designed for teen, young adults, and adult galactosemics.

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!

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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.



2014 Galactosemia Foundation CONFERENCE
ORLANDO • FLORIDA
 July 17th - 19th

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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.)

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

Conference registration will begin in early 2014. Check the Galactosemia Foundation website (www.galactosemia.org) in January to register to attend the conference.

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

* There will be an additional activity fee (amount still TBD) 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.

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

What is included in the conference registration fee?

The conference registration fee entitles each adult conference attendee to:

- 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 and under)

– the conference registration fee covers:

- Professional on-site child care from 7:00am to 6:00pm on Friday, July 19th and Saturday, July 20th
- Galactosemic safe refreshments and snacks while in child care
- Galactosemic safe breakfasts and lunches (with your family) on Friday, July 19th and Saturday, July 20th
- Attending evening social activities with your family each evening

For teens and adult galactosemics

– the registration fee + activity fee covers:

- Galactosemic safe breakfasts, lunches, refreshments, and snacks on Friday, July 19th and Saturday, July 20th.
- 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.

Looking To Stay Connected Even More?



Be sure to 'LIKE' us on Facebook.

www.facebook.com/Galactosemia.Foundation

FUNDRAISING INCENTIVE for GALACTOSEMIA FOUNDATION... Linked for LIFE!
2014 Conference in Orlando, Florida
July 17th, 18th, & 19th, 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
- **1st 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***
- **1st 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
- 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: Galatosemia Foundation
Donations must be received by **July 1st, 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.*

*** 1st 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.*

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 nine 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 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.

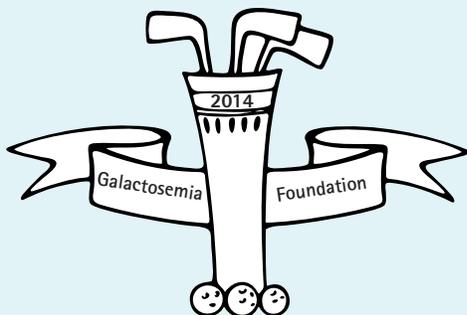
Calling all Golfers, hackers, and anyone who wants to go out on a beautiful Disney golf course and chase around a little white ball!!

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 8:30am 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 on the outing will be posted on www.galactosemia.org in the near future. You will also be able to register to golf on the GF website by the time conference registration opens in January. You will also be able to 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



G-Force Ages 13-17

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!

We've got oodles of fun planned under the sun for galactosemic teens and their siblings. Our G-Force program is designed to give youth between ages 13-17 a meaningful, well supervised, safe, camp-like experience, while parents are attending the conference sessions. Carefully planned interactive activities and educational speakers include dietitians and psychologists at the hotel to give us the opportunity to gain important knowledge about galactosemia to better our lives. Our exciting adventures offsite, such as bowling and arcade games in Downtown Disney provide the chance to have fun and make life-long friends!

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

JOIN THE FORCE!

Mighty Gs A Program for 9 to 12 Year-Olds

As mentioned in previous newsletters, we are moving toward forming a program for this age group.

For the 2014 conference, this group will still be in child care but will be attending various sessions as they did at the last conference. We are looking for two volunteers, who can take them to and from their activities around the hotel and assist during these activities.

If you are interested, please contact:
conference@galactosemia.org

September 2013

Dear Galactosemia Foundation Families:

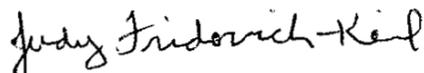
First, a huge **THANK YOU** to all the wonderful volunteers, families, and organizers of the Galactosemia Foundation who have participated in and made our research studies possible. You all are the BEST!

Our projects are moving along nicely and we published a number of papers related to classic galactosemia in the last year that might be of interest to you -- I will list these here and would be happy to send you copies and/or tell you more about them if you email me directly (jfridov@emory.edu):

- Jumbo-Lucioni, PP, K Garber, J Kiel, I Baric, GT Berry, A Bosch, A Burlina, A Chiesa, MLC Pico, SC Estrada, H Henderson, N Leslie, N Longo, AAM Morris, C Ramirez-Farias, S Schweitzer-Krantz, CLT Silao, M Vela-Amieva, S Waisbren, and JL Fridovich-Keil (2012). Diversity of approaches to classic galactosemia around the world: a comparison of diagnosis, intervention, and outcomes. *J Inherit Metab Dis.* 35(6):1037-49
- Liu, Y, B Xia, TJ Gleason, U Castañeda, M He, GT Berry, and JL Fridovich-Keil (2012). N- and O-linked glycosylation of total plasma glycoproteins in galactosemia. *Mol Genet Metab.* 106(4):442-54.
- Ryan, EL, B Duboff, MB Feany, and JL Fridovich-Keil (2012). Mediators of a long-term movement abnormality in a *Drosophila melanogaster* model of classic galactosemia. *Dis Model Mech.* 5(6):796-803
- Jumbo-Lucioni, PP, ML Hopson, D Hang, Y Liang, DP Jones, and JL Fridovich-Keil (2013). Oxidative stress contributes to outcome severity in a *Drosophila melanogaster* model of classic galactosemia. *Dis Model Mech.* 6(1):84-94
- Ryan, EL, ME Lynch, E Taddeo, TJ Gleason, MP Epstein, and JL Fridovich-Keil (2013). Cryptic residual GALT activity is a potential modifier of scholastic outcome in school age children with classic galactosemia. *J Inherit Metab Dis.* Jan 15. [Epub ahead of print]
- McCorvie, TJ, TJ Gleason, JL Fridovich-Keil, and DJ Timson (2013). Misfolding of galactose 1-phosphate uridylyltransferase can result in type I galactosemia. *Biochem Biophys Acta* 1832(8):1279-1293.
- Spencer, JB, JR Badik, EL Ryan, TJ Gleason, KA Broadaway, MP Epstein, and JL Fridovich-Keil (2013). Modifiers of ovarian function in girls and women with classic galactosemia. *J Clin Endocrin and Metab.* 98(7):E1257-65.
- Jumbo-Lucioni, PP, EL Ryan, ML Hopson, HM Bishop, T Weitner, A Tovmasyan, I Spasojevic, I Batinic-Haberle, Y Liang, DP Jones, and JL Fridovich-Keil (2013). Manganese-based superoxide dismutase mimics modify both acute and long-term outcome severity in a *Drosophila melanogaster* model of classic galactosemia. *Antioxidants and Redox Signaling Forum*, 2013 Jun 12. [Epub ahead of print]

Other studies are underway and several newer studies are just getting started... never a dull moment! I will look forward to seeing you all in Orlando in 2014!

Best wishes,



Judith L. Fridovich-Keil, PhD
Professor, Department of Human Genetics
Emory University School of Medicine
EMAIL: jfridov@emory.edu, TEL: 404-727-3924

Galactosemia Foundation
Treasurer's Report
9/9/13

Net Financial Position

Our net financial position as of 9/9/13
Is as follows:

Assets

General Account	\$ 65,586.56
Research Account	\$ 93,258.27

Total Assets	\$ 158,844.83
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Liabilities	(\$ 48,800.00) (2013 Research Grants Remaining)
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Net Position	\$ 110,044.83
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Key Activities

- 2014 Conference Incentive Program: The 2014 Conference Incentive Program is open. This is an easy way to help offset the cost of attending the Orlando conference. All you have to do is get your family, friends and co-workers, even friends of friends to donate money to the 2014 conference and you could earn free registration, free hotel room nights, and even free airfare. The key is all monies donated have to be directed to the 2014 conference to be eligible. Please look for a full breakdown and details of the conference incentive program in this newsletter or contact me at treasurer@galactosemia.org.
- Fundraising: There are tons of simple easy ways to raise money, from lemonade stands to golf tournaments; our Fundraising Committee has put together some helpful information that's a simple email away at fundraising@galactosemia.org. Remember the Galactosemia Foundation is a Non-profit 501(3)(c) so donations are tax deductible.

2014

Share your events with all The Galactosemia Foundation members. If you have a galactosemia event or fundraiser that you would like to have added to this calendar, please email newsletter@galactosemia.org

JANUARY	FEBRUARY	MARCH
APRIL	MAY	JUNE
JULY	AUGUST	SEPTEMBER
17-19 GF Conference, Orlando, FL		
OCTOBER	NOVEMBER	DECEMBER



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www.galactosemia.org

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