



Galactosemia GAZETTE

In This Issue . . .

- Getting to the Conference2-3
- Incentive Program.....5
- Research6-7
- General Session Schedule9-14
- Kid's Program17
- AGERS Group.....18-19
- Generation G20-21
- G-Force22-23
- Conference Speakers.....24-27
- Calendar of EventsBack Cover



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

Galactosemia Foundation

Presents the

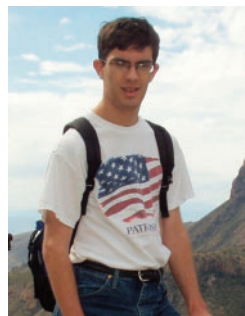
2012 Conference *to be held in Dallas, Texas...* **Empowering Our Future** as we are **Linked for LIFE!**

We hope you and your family are already making plans to join us for our Galactosemia Foundation conference. We will be in the heart of Dallas, Texas, as the beautiful Hyatt Regency Hotel will host our conference on July 19, 20 and 21, 2012. In addition to three days of networking, we are offering something that will interest every member of your family. Our programs are all geared towards making our life with galactosemia a little easier as we meet others who share our same interest and experiences: Empowering Our Future. This is one of the only places you will ever go and not have to worry about checking the ingredients in the food that is served. We have already done that for you! All items we offer during the conference are galactosemic safe!



We will have breakfast, two snacks, lunch and even dinner options that are galactosemic safe. There will be a lunch buffet where your galactosemic loved one can freely indulge their plate with every item on the buffet! We have taken things a step further and taken into consideration the things we consider to be 'questionable' items and those will be placed on different tables, designated with a red tablecloth. A lot of hard work has been put into the preparation of this conference, especially in the area of food. After all, diet is the number one thing those of us living with galactosemia must watch out for. So please make plans now to come and join your galactosemic family for the time of a lifetime for every member of your family!

Paul Pruszynski Memorial Fund GG Scholarship



Paul attended his first PGC/Generation G Conference in 2010 in Minnesota. Paul, who was 23, passed away suddenly in January 2011. Paul was from Texas, so was very much looking forward to attending his second conference in 2012 in Texas.

In Paul's memory, the Galactosemia Foundation created the Paul Pruszynski Memorial Fund to financially assist Generation Gs who because of personal finances may not be able to attend the conferences and participate in the GG program. If you are a young adult between the ages of 18 to 30 years old, and cannot attend the 2012 Galactosemia Foundation Conference because of financial difficulties, you can apply for the scholarship.

All you need to do is fill out a questionnaire if you are interested. Please e-mail Linda Manis at: Lmscript1@aol.com and she will send you the questionnaire. The scholarship will help to cover the cost of the attending the conference. The GG or GGs who are awarded the scholarship will also participate in a ceremony at the conference with Paul's family to honor his memory.

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
boardmember1@galactosemia.org

Dan Lambert, Research Team
research@galactosemia.org

JoBeth Southard
Conference Planning Team
conference@galactosemia.org

Denise Wilburn, Fundraising Team
fundraising@galactosemia.org

Robyn Et Jeremy Meek
Outreach Team
outreach@galactosemia.org

Mark Southard, Media Team
media@galactosemia.org

Karen Haley Et Angela Canul
Newsletter Team
newsletter@galactosemia.org

Printing and Mailing Services
Rick Et Karen Haley, Print Plus
www.myprintplus.com

Website Hosting
Rick Et Karen Haley, Print Plus
www.myprintplus.com

Website Design
Rick Et 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

Getting to the 2012 Conference

The 2012 Galactosemia Foundation conference will be held at the Hyatt Regency DFW hotel. The Hyatt Regency is adjacent to Terminal C at the DFW airport (note that there are two Hyatt hotels at the DFW Airport – the conference is NOT at the Grand Hyatt).

The hotel will be \$116 per night (+12% taxes) with our group rate. You can reserve a room by phone at 888-421-1442 (mention that the Galactosemia Foundation 2012 Conference to receive our group rate) or online at <https://resweb.passkey.com/go/PGC>. There are a limited number of rooms available at our group rate on a first-come first-serve basis.

Hyatt Regency, DFW
2334 N. International Parkway
Dallas-Fort Worth Airport, TX 75261
972-453-1234

Flying into the DFW Airport

The recommended airport for travelling to the conference is the DFW airport. Many airlines fly into the DFW airport, including:

- American Airlines
- British Airways
- Continental
- Delta
- US Airways
- Virgin America

Getting from DFW Terminals to the Hotel

The Hyatt Regency DFW is located in the Dallas-Fort Worth airport. The hotel provides complimentary transportation to and from all the Dallas-Fort Worth airport terminals 24 hours a day. The shuttles are blue vans with "Hyatt" in white letters.

Directions to the hotel from any DFW airport terminal:

Upon arrival at DFW International Airport, first retrieve your luggage, then use the touch screens in the baggage claim area or courtesy phones at the lower level to call Hyatt Regency DFW. A hotel operator will request your terminal and gate location and give you directions to access the shuttle on the lower level, under the gray signs that say "Courtesy Vans". If you prefer to call directly from your cell phone, dial 972-453-1234.

Return transportation is available every 20 minutes from the hotel to all airline terminals at DFW Airport beginning on the hour. Please be prepared to leave for the airport one and a half hours prior to your scheduled departure time.

Flying into Dallas Love Field

The Dallas Love Field airport also services the DFW metroplex, but it is approximately 18 miles from the conference hotel and thus is less convenient than flying into the DFW airport. Three airlines fly into Dallas Love Field:

- Southwest
- Continental
- Delta

To get from Dallas Love Field to the hotel at DFW, you can:

- Take a shuttle service, such as Super Shuttle for ~\$22+ per person
- Take a taxi for \$45+
- Rent a car

Driving to the hotel

There are two entrances to the DFW airport (north and south).

· Enter DFW Airport from Texas 183 (Airport Freeway) from the south or Texas 121 (Sam Rayburn Tollway) / Texas 114 (John W Carpenter Freeway) from the north. The airport itself has one main road, International Parkway, which runs the length of the airport, north to south.

· You must go through the tollgates of DFW Airport to get to the hotel. You will receive a parking/toll ticket as you enter. Use the "public" tollbooths (one that does not say Toll Tag and does not have an Orange T, indicating a Tolltag Lane). If you do go through the toll tag booths and have a toll tag, your toll tag will be charged and can NOT be refunded.

When you depart the airport you must present your parking/toll ticket at the tollbooth. Take your parking/toll tickets to the bell stand, front desk or concierge to be validated so you will not have to pay any tolls.

· Once inside the airport, all exits are on the left. Follow the signs for Terminal C. Exit Terminal C/Hyatt Regency DFW Hotel. Follow the signs – the entrance to the hotel parking lot will be on your right.

Taking the Train

Amtrak provides passenger rail service to the DFW Metroplex. The Texas Eagle provides daily service between Chicago and San Antonio (and on to Los Angeles 3 times per week) with a stop at the DAL station in downtown Dallas. The Heartland Flyer provides daily service between Oklahoma City and Fort Worth.

The Trinity Railway Express (TRE) provides commuter rail service between Dallas and Fort Worth Amtrak stations with a stop at the CentrePort/DFW Airport Station. Shuttle bus service is available from the CentrePort/DFW Airport Station to the Remote South airport parking lot and from there to all DFW airport terminals. See "Directions to the hotel from any DFW airport terminal".

Parking at the Hotel

Hyatt Regency DFW is located adjacent to terminal C and offers free covered self-parking for overnight hotel guests for the nights they stay in the hotel. Be sure to get your airport parking ticket validated at the concierge desk located on the main floor of the hotel. Valet parking is \$12.00 per day for event attendees and overnight valet use is \$25.00 per day with in/out privileges. The valet service is open daily from 5:00 a.m. until 11:00 p.m.

Local Transportation

Grapevine Shuttle

The Grapevine Convention and Visitors Bureau provides a \$5 shuttle service to Grapevine Mills Mall and to Historic Downtown Grapevine. Shuttles stop at other hotels prior to reaching their destination and are available on a first come, first service basis. Shuttle tickets may be purchased at the Front Desk or from the shuttle driver.

Rental Cars

Rental Cars are available at the DFW airport. You can take a shuttle from any airport terminal directly to the Rental Car Center. Alternatively, you can take a shuttle (or walk) from the hotel to Terminal C and then take an airport shuttle to the Rental Car Center to rent a car. Several rental car companies will drop off and pick-up rental cars from the hotel (Hertz and Enterprise).

Public Transportation

The Trinity Railway Express (TRE) provides commuter rail service between Dallas and Fort Worth with a stop at the DFW airport. From the Dallas Union Station, you can transfer to the Dallas Area Rapid Transit (DART) and from Fort Worth you can transfer to "The T" transit system.

To get to the TRE station at DFW, take the hotel shuttle (or walk) to Terminal C, then take the airport shuttle to the "Remote South" parking lot, and then take the shuttle from Remote South to the CentrePort/DFW Airport Station. Buses to CentrePort/DFW Airport Station depart Remote South every 15 minutes, Monday-Saturday.

Conference Location / On-Site Registration

The conference will be in the ballroom and meeting rooms located on the ground floor of the hotel (one level below the lobby).

On-site registration will be on Thursday, July 19th from 6-9 p.m. at the registration desk on the ground floor. Late on-site registration will be available on Friday, July 20th from 7:30 – 8:30 a.m.

All conference attendees should visit the registration desk either Thursday night or Friday morning to register (if you haven't pre-registered online) or to pick up your conference materials.

Galactosemia Foundation 2012 conference has something planned for each and every member of the family. The age breakdown of each program is below. You would determine your child(s) placement based on the age the child will be as of July 15, 2012.

General Session – Adults 18+ who wish to participate in the general session and breakout sessions

The general session will be attended by adults whom will also attend breakout sessions of their choice.

AGERS Program – Ages 26+ galactosemics & siblings

This is the inaugural conference for the all new AGERS (Adult Galactosemics) program. This group was started in an effort to allow Adult Galactosemics to share stories, experiences and education in their own setting. They will join the general session for some sessions. (See detailed schedule herein)

Generation G – (GG) – Ages 18+ galactosemics & siblings

The Generation G program is for ages 18 and older, galactosemics and siblings. This program will be doing activities both onsite and offsite. You may see details on their schedule.

G-FORCE – (GF) – Ages 13 – 17 – galactosemics & siblings

The G-Force program is for ages 13 – 17, galactosemics and siblings. This program will be doing activities both onsite and offsite. You may see details on their schedule.

***Mighty G – (MG) – Ages 9 – 12 – galactosemics & siblings**

The Mighty G program is a new program for 2012 formed for ages 9 – 12 galactosemic and siblings. This program will remain onsite for all sessions. They will be supervised by the contracted professional childcare and will also have some extra sessions each day. These sessions include a cooking demonstration, a magic show, a presentation by Dr. Roxanne Schreiber and much more! These special sessions are being done in addition to the two fun packed days of age appropriate activities.

All of the following programs will be supervised by the professional childcare; all activities will be age appropriate; see ad for details

*Junior G – (JG) – Ages 6 – 8 – galactosemics & siblings

*Tiny G – (TG) – Ages 3 – 5 – galactosemics & siblings

*Mini G – (MG) – Ages 0 – 2 – galactosemics & siblings

**You must register each child with Galactosemia Foundation AND with Corporate Kids Events.*

All payments will be made directly to Galactosemia Foundation. Registration with Galactosemia Foundation AND Corporate Kids Events must be done both online and/or snail mail as well as visiting both registration tables at the actual conference during Thursday night registration at the Hyatt.

Your 2012 Galactosemia Foundation Conference Committee

You may contact your conference committee anytime with any questions or suggestions regarding the 2012 conference at conference@galactosemia.org. Members of the conference committee are:

Michelle Fowler – Conference Coordinator

JoBeth Southard – Conference Coordinator

Lauren Algehn

Nate Bauer

Rhonda Bauer

Jennie Badger

Diane Flynn-Brake

Paul Fowler

Mark Southard

Kristine Saylor

Scott Shepard

Kay Slavens

Susan Smith

Denise Wilburn

Kellie Wilcox

Jason Wilcox

FUNDRAISING INCENTIVE for GALACTOSEMIA FOUNDATION.... Linked for LIFE!
2012 Dallas, TX Conference
July 19th , 20th , & 21st , 2012

Galactosemia Foundation would like to invite everyone to participate in the 2012 incentive program aimed at increasing donations that will be used to fund the 2012 INTERNATIONAL GALACTOSEMIA, TEXAS Conference.

Raise \$250.00 - \$500.00

- Raise \$250.00; one conference registration fee waived
- Recognized on conference handout

Raise \$750.00 - \$999.99

- Raise \$750.00; two conference registration fees waived
- Recognized on conference handout

Raise \$1,000.00 - \$6,999.99

- Raise \$1,000.00; two conference registration fees waived
- Name on conference t-shirt
- Recognized in general session and conference handout
- ****1st Place** - Reimbursement for up to three nights stay in the conference hotel
- ****2nd Place** - Reimbursement for up to two nights stay in the conference hotel
- ****3rd Place** - Reimbursement for up to one night stay in the conference hotel

Raise \$7,000.00 - \$9,999.99

- Raise \$7,000.00; three conference registration fees waived
- Name on conference t-shirt
- Recognized in general session and conference handout
- ****Reimbursement for up to three nights in the conference hotel**
- ***1st Place** - ***Reimbursement for one coach round trip airfare ticket**

Raise \$10,000.00 or more -

All individuals who raise **\$10,000.00** or more will receive

- Four conference registration fees waived
- Name on conference t-shirt
- Recognized in general session and conference handout
- ****Reimbursement for up to three night stay in the conference hotel**
- ***Reimbursement for two coach round trip airfare tickets**

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

Donation checks should be made payable to: Galatosemia Foundation
Donations must be received by **June 1st, 2012** to qualify for the incentive.
Send to: Galactosemia Foundation

P.O. Box 2401
Mandeville, LA 70470

~INCENTIVE PROGRAM DONATIONS ARE ACCEPTED FROM AUGUST 1, 2010 UNTIL JUNE 1, 2012~

~Make sure the 'memo' section of the donation check has "your name" and "2012 conference" to make sure you get credit for the donation~

Join In Dr. Gerard Berry's and Dr. Susan Waisbren's Onsite Research For 2012!

Don't miss this very special opportunity to participate in onsite research. Research being offered right at our Galactosemia Foundation conference. Where else can you meet others who live with galactosemia just like you, and also have some "one on one" time with some of the best galactosemic researchers- all while contributing to research? Nowhere else will you be able to share the same experiences you will when you and your family attend the 2012 conference. Dr. Gerard Berry and Dr. Susan Waisbren are asking for all patients with galactosemia to please participate in their onsite research. They are seeking patients for a clinical research study on "Genetic Modifiers and the Complications of Galactosemia". The goal of the study is to provide families with a brochure that explains the study at the conference. Dr. Berry will personally explain this study to each family and/or patient, and he will obtain consent. What is needed for this study? Dr. Berry and Dr. Waisbren will need to obtain a history from each family and place it on their on-site database using a laptop computer; arrange to have your hometown physician send them your medical records including physical exam findings and lab results. Last would be to arrange for a blood sample to be obtained in the future for DNA isolation and whole genome sequencing. The ultimate goal of this research is to enroll EVERY galactosemic patient in the country for as they will need thousands of participants to analyze the data on gene differences and outcome properly.

Continuing Medical Education Credit Available At Conference!

The Galactosemia Foundation has partnered with the University of Texas Health Science Center in San Antonio to offer Continuing Medical Education (CME) for medical professionals who attend selected sessions of the conference.

The cost to participate in the CME certificate program is \$250.00 in addition to the \$85.00 conference registration fee. Participants must complete pre and post conference surveys in addition to attending conference sessions to receive a certificate.

Target Audience

This educational conference is intended for healthcare professionals who diagnose, treat, and research galactosemia and associated complications.



Objective

The goal of this educational activity is to make participants aware of what is known, and also what is NOT known with regard to the underlying mechanisms and modifiers of long-term complications in classic galactosemia.

Continuing Education Accreditation Statements:

CME:

The UT Health Science Center San Antonio School of Medicine is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

The UT Health Science Center San Antonio School of Medicine designates this live activity for a maximum of 12.0 AMA PRA Category 1 Credits™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.



CALLING ALL PATIENTS WITH CLASSIC GALACTOSEMIA



Did you ever wonder why some people with galactosemia experience more complications than others? We are working to find the answer, and we need your help!!!

We plan to recruit **NEW** and **RETURNING** study volunteers at the 2012 Galactosemia Foundation Conference in Texas. Whether you are old or young, male or female, with or without specific complications – **we need your help!** Participation in this IRB-approved study is **easy and free**. Please sign up ahead of time to reserve a convenient time slot, and then look for posted signs at the conference that will lead you to our study rooms.

What's involved?

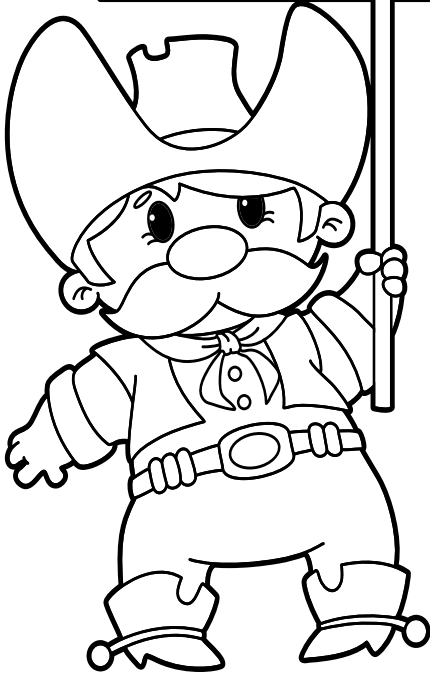
- We will ask you to read, discuss, and fill out some **paperwork**.
- We will offer some participants a brief, painless, free **neurological exam** to test for evidence of tremor or related complications; this exam is voluntary. Dr. Claudia Testa, a neurologist and movement specialist, will conduct these exams at the conference.
- We will have a trained professional on site to conduct brief, painless, and free **ovarian ultrasound exams** for girls and women in the study who wish to participate.
- We will give you a small "blood draw kit" to bring to your next doctor's appointment so that the next time you have a clinical blood draw we can ask for a small blood sample for research, with **no extra needle stick**. With your permission we can help to arrange the details, and we will pay for the overnight shipping.
- Volunteers who donate blood will receive free **GALT genotype analysis** as part of this study, and girls and women will also receive free **analyses of two hormones related to ovarian function**: follicle stimulating hormone and anti-Müllerian hormone.

Interested?

- Please contact Dr. Judy Fridovich-Keil at jfridov@emory.edu or 404-727-3924 **before the conference** to ask questions or reserve a study time at the conference.
- We strongly encourage prospective study volunteers to **reserve specific time slots for the neurological and ultrasound exams**, which will take 15- 30 minutes each to complete; availability may be limited. Please contact Judy at jfridov@emory.edu or 404-727-3924 and make your reservation today!

THANK YOU! THANK YOU! THANK YOU! THANK YOU!

**GET READY FOR
FUN!**



In addition to the raffle we had at the 2010 conference we are adding the 1st Galactosemia Foundation's Silent Auction!!! The silent auction will take place Friday and Saturday during the conference. We are taking donations now and during the conference for both auction and raffle. The raffle will be held at the same time and location as the silent auction, except winners will be randomly chosen as the conference progresses. We need many donations to make this event a success so PLEASE don't hesitate. Those that donate for the raffle or silent auction will receive free advertising and one free raffle ticket. We will have items of different size and value so come prepared. If you have an item to donate please contact Kellie Wilcox at 903.539.8815 or kelliekee@yahoo.com.

TEXAS SIZE SOCIALS

are in order for the 2012 Galactosemia Foundation Conference!!!

On Thursday evening along with registration, we will have the popular – much requested, always awesome, chocolate buffet.

Then, on Friday evening, our dessert social will feature artist James Gabriano. James Gabriano is an artist who plays his instrument with the intensity of an August afternoon in Texas. As a guest at one of his live performances, you are quickly drawn to his "flamenco jazz" style. The Latin rhythms and fiery guitar make you want to get up, stomp your heels, and click your castanets. Just catch his rendition of "Bambaleo" by the Gipsy Kings and you will feel the meaning.



On Saturday night it is time to break out your boots and jeans for a true Texas Country and Western dance!!!!!! Don't know how to two-step or line dance?? No worries! We will even have free Country and Western dance lessons for everyone!! Saturday night we ratchet it up one notch with a rockin' DJ that is sure to get everyone on their feet and having a great time together. He will play a full range of music that will please ALL ages and tastes!!! Charlie McBride is the best inter-active DJ in Texas! He will get us movin' with his fun family games such as hoola hoops, limbo contest, trivia and much more. It will be fun for ALL ages and we will have prizes too!

Don't miss this rare opportunity to join the galactosemic family! Come ready to scoot a boot and have a TEXAS SIZED time in the Lone Star State!!!!

Did Someone Say "Chocolate"?

Back by popular demand! We will be having our ever popular Chocolate Buffet during registration on Thursday night! Come prepared to visit vendor tables, mix and mingle with old and new friends and certainly enjoy the galactosemic safe chocolate buffet!

General Session Schedule

Thursday, July 19th

- 2:00 – 8:00** **On-Site Research:** Please participate in the on-site research being offered!
Dr. Gerard Berry, Dr. Judy-Fridovich-Keil (Et Her Team!), Dr. Penny Greenstein, and Dr. Susan Waisbren will ALL be conducting onsite research during our conference. You can register for this onsite research right at the conference! Don't miss this very special opportunity to participate and be a part of research! Stop by the research wing rooms and get signed up to participate.
- 6:00 – 9:00** **Galactosemia Foundation General Registration & Chocolate Buffet Social**
* Please make sure you register at general registration and then proceed to applicable program registration such as Childcare, G-Force, Generation G, and AGERS.
- 6:15 – 7:00** **New Parents and First Time Attendees – Maureen Bell**
Please join Maureen Bell for an open discussion about her perspectives of life with galactosemia. Maureen hopes to give new parents and first time conference attendees a warm welcome and a great foundation to experience this conference with.
- 7:00 – 8:00** **Galactosemia 101 – Michelle Fowler; Galactosemia Foundation President & Scott Shepard; Galactosemia Foundation Vice-President**
What is Galactosemia 101 and why you should attend!
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.

Friday, July 20th

- 7:30 – 8:30** **Galactosemia Foundation Sponsored Breakfast**
Join in on a galactosemic safe breakfast!
- Childcare Dropoff**
Rooms open at 7:30 a.m. so have breakfast and then drop your child off to their designated room.
- Late Registration**
Those arriving late on Thursday or Friday morning are welcome to register during this time.
- 8:30 – 8:45** **Welcome to Galactosemia Foundation 2012!**
Opening Remarks – Galactosemia Foundation President – Michelle Fowler
- 8:45 – 9:30** **Galactosemia Research in the Fridovich-Keil Lab** – Dr. Judy Fridovich-Keil**
- 9:30 – 9:45** **Galactosemia Foundation Research Update – Research Team Leader – Dan Lambert**
- 9:45 – 10:00** **Break – enjoy a galactosemic safe snack**
- 10:00 – 10:45** **Research Briefing****
The following researchers will give a very brief overview of their current galactosemia research. Further details of each research project will be discussed in their applicable breakout sessions.
• Dr. Anna Mariobotti • Dr. Sandy VanCalcar • Dr. Susan Waisbren
- 10:45 – 11:30** **Speech Characteristics In Galactosemia** – Dr. Nancy Potter**

** These sessions are eligible for AMA PRA Category 1 Credit™

General Session Schedule (cont'd)

Friday, July 20th

11:30 – 1:00	Galactosemia Foundation Sponsored Lunch Join us for a galactosemic safe lunch! All items are galactosemic safe on the buffet line. Questionable and/or NO foods will be indicated as such by being on a separate table and will also be flagged with a RED table cloth to ensure all variations of the diet are covered and also to avoid cross contamination.
1:00 – 2:00	Breakout Session 1 – Select one session from the breakout session 1 list
2:15 – 3:15	Breakout Session 2 – Select one session from the breakout session 2 list
3:15 – 3:30	Break – Enjoy a galactosemic safe snack
3:30 – 4:15	Toward Improved Outcomes in Galactosemia – Dr. Kent Lai
4:15 – 5:30	General Session Closing Remarks – Questions & Answers for Professionals
5:30 – 7:30	Dinner
7:30 – 9:00	Dessert Social

Saturday, July 21st

7:00 – 8:00	Galactosemia Foundation Sponsored Breakfast Join in on a galactosemic safe breakfast! Childcare Dropoff Rooms open at 7:30 a.m. so have breakfast and then drop your child off to their designated room.
8:00 – 8:15	Opening Remarks – Galactosemia Foundation Vice-President – Scott Shepard
8:15 – 9:00	The Galactosemic Diet – Dr. Sandy Van Calcar
9:00 – 9:45	Fundraising & Treasurer Update Denise Wilburn; Galactosemia Foundation Fundraising Team Leader Paul Fowler; Galactosemia Foundation Treasurer
9:45 – 10:00	Break – enjoy a galactosemic safe snack
10:00 – 11:00	Breakout Session 3 – Select one session from the breakout session 3 list
11:15 – 12:15	Breakout Session 4 – Select one session from the breakout session 4 list
12:15 – 1:30	Galactosemia Foundation Sponsored Lunch Join us for a galactosemic safe lunch! All items are galactosemic safe on the buffet line. Questionable and/or NO foods will be indicated as such by being on a separate table and will also be flagged with a RED table cloth to ensure all variations of the diet are covered and also to avoid cross contamination.
1:30 – 2:15	What Causes Complications In Galactosemia** – Dr. Gerard Berry
2:15 – 2:45	Life With Galactosemia – Panel of Galactosemic Speakers
2:45 – 3:00	Break – enjoy a galactosemic safe snack
3:00 – 4:00	Breakout Session 5 – Select one session from the breakout session 5 list

General Session Schedule (cont'd)

Saturday, July 21st

- 4:15 – 5:00** **General Session Closing Remarks**
Questions & Answers for Professionals
Fill out the note card that will be provided to you with the one question you want to know the answer to. If you would like it directed to anyone in particular please make sure you state their name on your card along with your question. This will be a moderated session and your chance to get some answers!!
- 5:00 – 8:00** **Dinner – Enjoy a galactosemic safe menu at the hotel**
Stay onsite and take advantage of the galactosemic safe menu offered at the hotel. If you do choose to go offsite we would like to encourage you to be back on time for the social and dance. A lot of hard work has been put into having a conference wrap up social. So please make sure you are there to join us for a great time.
- 8:00 – Midnight** **Social and Dance**
Saturday night we have planned another night of spending time together! We want you to be surprised as to everything we have in store for you, but we will tell you it is going to be a fantastic time for every member of the family! Everyone is welcomed to join us for music, some galactosemic safe snacks, and a great end to our 2012 conference!

(Some items in schedule are subject to change.)

** These sessions are eligible for AMA PRA Category 1 Credit™

Breakout Session Schedule – Friday

Breakout Session 1 – Choose ONE of the following Friday – 1:00pm – 2:00 pm

A: Human Galactokinase to Treat Classic Galactosemia;
Dr. Kent Lai**

We will talk about recent progress in the drug discovery programs initiated at the speaker's research laboratory that are aimed to develop new modalities of therapy for treatment of Classic Galactosemia and other common diseases, such as cancers.

B: Diet: Birth to 5 years old; Dr. Sandy Van CalCar**

Join Dr. Van Calcar in a diet session. In this session we will discuss diet recommendations and challenges for this age group

**C: Adult Galactosemic Panel:Question & Answer;
AGERS Group**

The members of the Adult Galactosemic Group are willing to share their stories with you. Join them in an open discussion of round table question and answer. This is your time to ask the question you always wanted to know the answer to directly to an Adult Galactosemic from our Galactosemic family!

D: Make It, Take It Workshop; Dr. Nancy Potter

Power Point games to teach and reinforce vocabulary! Bring your laptop computer, loaded with pictures, and come for a fun session creating games using PowerPoint to teach and

reinforce vocabulary goals specific to your preschooler, child, or adolescent. This session will bring-out your creativity! Examples and instruction will be provided.

**E: Special Education/IEP/IDEA/504/State/Tactics
& Strategies; Jason Wilcox**

Discuss special education services, 504, ECI, and other programs related to public schools. Will discuss what programs may or may not pertain to students with Galactosemia. This will also be an opportunity for participants to share their experiences in public schools or to ask specific questions concerning programs. We will discuss preschool age, school age and post-secondary education.

F: Neurological Consequences of Galactosemia;
Dr. Penny Greenstein**

Dr. Greenstein will review the different neurological complications that may occur in patients with galactosemia. She will then entertain questions from the audience.

G: Genotype Sequencing; Dr. Gerard Berry**

Discussion of the many mutations of galactosemia. There are more than 230 mutations in the GALT gene that cause galactosemia. The discussion will focus on how different mutations affect GALT enzyme activity, lactose/galactose tolerance, gal-1-p blood levels, urine galactitol blood levels, galactose breath test results and clinical outcomes. Emphasis will be placed on genotype-phenotype relationships.

** These sessions are eligible for AMA PRA Category 1 Credit™

Breakout Session Schedule – Friday (cont'd)

Breakout Session 2 – Choose ONE of the following Friday – 2:15 pm – 3:15 pm

A: New Mouse Models of Classic Galactosemia;** Dr. Kent Lai
We will talk about recent progress in developing new mouse models of Classic Galactosemia in the speaker's laboratory.

B: Diet: Elementary Age;** Dr. Sandy Van CalCar
Join Dr. Van Calcar in a diet session. In this session we will discuss diet recommendations and challenges for this age group

C: Ovarian Function in Galactosemia;**
Dr. Judy Fridovich-Keil
Come hear the latest research update from the Fridovich-Keil lab about ovarian function in girls and women with classic galactosemia.

D: Cooking Demo & Label Reading; David Levine
Join the owner of IL Nut & Candy Company, Home of Fantasia Confections, David Levine for a fun, interactive session! Learn a few easy Dairy/Casein free, galactosemic safe, recipes for fast and easy desserts. Also learn some tips and tricks to make treats for your kids with non-dairy, galactosemic safe, substitutes.

E: Umm, I don't remember: How to teach your child to recall facts; Dr. Nancy Potter

In this session we will practice an error-less learning approach, Spaced Retrieval, originally developed to improve memory in people with dementia. For this session, bring a verse, a list of telephone numbers, birthdates, or anniversaries that you would like to remember. We will use Spaced Retrieval to commit this information to memory and learn how to help others remember important facts

F: Movement Disorders 101;** Dr. Claudia Testa
What is ataxia? tremor? dystonia? Which do we see in patients with classic galactosemia and why does it matter? Come learn some fundamentals about movement disorders from a specialist in the field, and hear the results of a recent study of movement disorders in children and adults with classic galactosemia.

G: Expanded Research;** Dr. Anna Marabotti
Dr. Anna Marabotti has obtained the Galactosemia Foundation Research Grant 2010 (started in March 2011) with the research project entitled: "Computational biology strategy for the development of ligands of GALK enzyme as potential drugs for people with classical galactosemia". She will describe the activities made for this project, and the results obtained during this year. She will also discuss these results with people interested in possible future collaborations.

Breakout Session Schedule – Saturday

Breakout Session 3 – Choose ONE of the following Saturday – 10:00 am – 11:00 am

A: Fundraising 101; Denise Wilburn, Kristine Lydon, Jo Beth Southard, Scott Saylor
Have you ever thought about doing something to benefit the education and research of Galactosemia? Have you ever thought, "I would like to do something more, but I don't know how?" Have you talked yourself out of planning a fundraiser because you feel too inexperienced or don't know where to start? Well this workshop is for YOU! The presenters of this workshop are parents and/or family members who have successfully organized a fundraiser. We are not expert organizers or planners, just ordinary folks like you. We want to share with you HOW we pulled it off and WHY it is so important for you to give it a try. We will include some tips, some step by step instructions and answer all your questions. This conference you are being educated at was funded in part by families who organized a fundraiser. Most of the research projects you will learn about at this conference were funded by families who organized a fundraiser. A REAL difference is being made by those who give fundraising a try. Won't you come and learn how YOU can MAKE A DIFFERENCE?

B: Diet: Teens;** Dr. Sandy Van CalCar
Join Dr. Van Calcar in a diet session. In this session we will discuss diet recommendations and challenges for this age group.

C: What's Galactosemia and What's Just Kids?;**
Dr. Susan Waisbren
Psychological, emotional and behavioral issues. Parents and teachers often wonder about the impact of galactosemia. This is important because sometimes we need to help the child with counseling or special education if the issue stems from a psychological cause and sometimes we need to find alternative strategies because the issue stems from something related to galactosemia that would be very hard to change.

D: Galactosemia and Speech Disorders;** Dr. Nancy Potter
Children with galactosemia have a 180 times greater risk of a neurological speech disorder as compared to other children. We will be discussing normal speech development, disordered speech development, including childhood apraxia of speech, and practical strategies to help children with speech disorders. Parents will be given time to share what has "worked" for their child.

** These sessions are eligible for AMA PRA Category 1 Credit™

Breakout Session Schedule – Saturday (cont'd)

E: Strategies for Self Esteem; Andrea Topper

Children with Galactosemia are born into an idealized world focused more than ever on food. While having Galactosemia may pose some challenges to your child's positive sense of self, there are ways you can foster and support the health of your child's self-esteem. In this workshop, parents and caregivers will learn skills and strategies to help promote positive self-esteem in our children.

F: Galactosemia Research – Finally Flying Forward; Dr. Judy Fridovich-Keil**

Come hear about recent advances in galactosemia research in the Fridovich-Keil lab using a *Drosophila melanogaster* model. It's amazing what you can learn from fruit flies!

G: Cognitive Foundation; Elles Taddeo**

Many children are unsuccessful in school because they have gaps in their cognitive foundation skills. These skills are such things as being able to systematically search information, being able to determine what is relevant when presented with a problem, being able to inhibit impulsivity, and many more. Most people assume that children "just get it" as they grow up, but in reality these skills are learned from interactions with adults. Gaps are the result of an insufficient amount of interactions, either because those interactions were not offered, or the child is not open to a "normal" amount of such interactions and needs more. Many children with some kind of medical condition may need more specific learning interactions to help them develop those underlying cognitive skills. My talk deals with helping parents recognize the need for "interactive learning" and give them some suggestions as to what they can do to help their children learn those skills and possibly be able to do better in school.

Breakout Session 4 – Choose ONE of the following Saturday – 11:15 am – 12:15 am

A: Pharmacy and Calcium Issues; William Bell

Upon attending the Pharmacy and Calcium break-out session, the attendee will:

1. Understand the importance of Calcium in one's health
2. Discuss ways to locate Calcium supplementations safe for the galactosemic individual
3. Identify key ingredients in prescription and OTC (Over-the-Counter) Calcium preparations which are galactosemic friendly
4. Understand which questions to ask on your next trip to the pharmacy

B: Raising a Happy, Independent, and Successful Child who just happens to have Galactosemia; Dr. Roxanne Schreiber

This session focuses on how parents can increase their child's self-esteem and coping abilities. Parents will leave the session with specific tools and strategies that help their child recognize and capitalize on their personal strengths, while understanding and minimizing their personal limitations. Because effective communication is crucial to accomplish these tasks, innovative and alternative forms of communication are explored. Understanding what types of communication work best for different developmental stages will also be discussed. Parents will leave the session with a greatly expanded way of communicating powerfully and effectively with their child.

C: Parenting a Child With Galactosemia; Dr. Susan Waisbren

Encouraging a strong sense of identity from infancy through adolescence. Galactosemia is only one small part of a child's identity, but sometimes it takes center stage. This session will focus on theories of development as applied to children with a chronic health condition. Adolescents who have a solid sense of identity make an easier transition to adulthood. If the process begins early, the path is smoother for the child and the parent.

D: Roundtable of Grandparents and Parents

Open roundtable welcoming parents and grandparents of galactosemics to join in an open discussion. You would be surprised how much you might learn from others' experiences!

E: POI and Fertility in Galactosemia: Challenges and Options; Dr. Jessica Spencer and Dr. Jen Badik**

Come learn about current challenges and options for girls and women experiencing ovarian insufficiency. This session will include a brief introduction by a specialist in the field followed by opportunities for questions and answers.

F: Expanded Research; Dr. Gerard Berry**

Dr. Berry will host a detailed discussion of the multiple clinical research projects and studies involving patients and basic science research projects. Various topics will be discussed including enzyme replacement therapy, stem cell research and multicenter studies involving the USA and Europe.

G: Scholastic and Behavioral Issues in Galactosemia Research Update; Dr. Judy Fridovich-Keil**

Come hear the results of a recent study of scholastic and behavioral outcomes among school-aged children with classic galactosemia.

** These sessions are eligible for AMA PRA Category 1 Credit™

Breakout Session Schedule – Saturday (cont'd)

Breakout Session 5 – Choose ONE of the following Saturday – 3:00 pm – 4:00 pm

A: Reading and Understanding Food Ingredient Statements; Dr. Kari Ryan

Have you ever wondered what food labels that say "may contain milk" or "processed on equipment that also processes milk" really mean? Join this break-out session to learn the answer to these and other questions like "are there any regulatory or labeling requirements about using galactose as an ingredient?"

B: Diet: Bones and Calcium Issues; Dr. Sandy Van Calcar**

Join Dr. Van Calcar in a session we all want to know about; bones and calcium. This session will discuss new research and diet recommendations for maintaining bone health in the galactosemic patient.

C: Internet & Social Education; Christine Raum

Yes, it is nice to have the Internet as a support but not to give each other medical advice. Don't believe everything you hear or are told, sometimes it's just a fluke of nature. Also we will touch on some issues such as the effects of sodas and caffeine, effects on bones, and the benefit of taking supplements. We don't know everything about galactosemia but we do know how to give the best chance we can by doing the things that are healthy for the body. Please join us in an educational session about the use of internet information and discussion of some other topics such as caffeine use, too. We will also have time for asking questions!

D: Male Issues in Galactosemia; Dr. Gerard Berry**

We will discuss males with galactosemia. Parents are welcome to join me for a discussion of puberty, social skills and relationships, wanting a family, having children, fertility issues and performance in the workplace.

E: Galactosemia in Adulthood; Dr. Penny Greenstein & Dr. Susan Waisbren**

The latest results from two studies in Boston. Penny Greenstein, MD and Susan Waisbren, PhD will review results from a study of 33 adults with galactosemia who received 12 different types of evaluations and a study of 10 adults who received MRI (magnetic resonance imaging), EEG (electroencephalogram), and neuropsychological testing. These new findings may change the way we think about the underlying deficits in galactosemia and how we view the natural course of the condition.

F: Scholastic Challenges and Educational Opportunities: What every parent should know!; Elles Taddeo

Many children are unsuccessful in school because they have gaps in their cognitive foundation skills. These skills include such things as being able to systematically search information, being able to determine what is relevant when presented with a problem, being able to inhibit impulsivity, and many more. Most people assume that children "just get it" as they grow up, but in reality these skills are learned from interactions with adults. Gaps are the result of an insufficient amount of interactions, either because those interactions were not offered, or the child was not open to a "normal" amount of such interactions and needs more. Many children with special needs may require more specific learning interactions to help them develop those underlying cognitive skills. This session deals with helping parents recognize the need for "interactive learning" and gives them some suggestions as to what they can do to help their children learn those skills to help them succeed in school.

G: Being Your Child's Advocate; Denise Wilburn

If your child/family member has galactosemia, he/she needs an advocate. Whether the child has major issues caused by galactosemia or minor inconveniences, someone needs to make sound decisions for the child and educate others in his/her life on the topic of galactosemia. This can be an uncomfortable and frustrating role to play. Licensed Child Counselor, Parenting Teacher, and Mother of a child with galactosemia, Denise Wilburn, will present some ideas to help you be the advocate your child needs.

** These sessions are eligible for AMA PRA Category 1 Credit™

For your convenience (and our's)
register online at
www.galactosemia.org

–OR–

Fill out and send in the form
on the following page.

For questions regarding the
conference please contact
conference@galactosemia.org

REGISTRATION FORM

(or register on-line at galactosemia.org)

Conference Registration (includes breakfast and lunch Friday & Saturday)			
	Cost Each	Quantity	Total Cost
General Conference / Adults	\$ 85.00		
Children in Childcare Program (Ages 0 - 12)	\$ 85.00		
G-Force (Ages 13-17) Includes \$50.00 activity fee	\$ 135.00		
Generation G (Ages 18+) Includes \$50.00 activity fee	\$ 135.00		
AGERS (Adult Galactosemic Ages 23+)	\$ 85.00		
*** You may select ONE program to enroll			
CME Certificate Program (Conference Registration Additional)			
	Cost Each	Quantity	Total Cost
MDs / PhDs and equivalent	\$ 250.00		
Medical Students	\$ 250.00		
Optional Items			
	Cost Each	Quantity	Total Cost
Conference T-Shirts (Adult) (Designs on back of this form)	\$ 12.00		
GF - 01: S M L XL XXL	Indicate quantities by size for each design on reverse		
GF - 02: S M L XL XXL			
GF - 03: S M L XL XXL			
Conference T-Shirts (Child) (Designs on back of this form)	\$ 12.00		
GF - 01: S M L	Indicate quantities by size for each design below		
GF - 02: S M L			
GF - 03: S M L			
Jewelry (Order Form Below)			
Add all of the Total Cost Columns from all sections above			
Method of Payment			
Payment is required at the time of registration in order to attend. Please make all checks payable to the Galactosemia Foundation in U.S. dollars drawn on a U.S. bank.			
<input type="checkbox"/> Check enclosed <input type="checkbox"/> Pay via PayPal: treasurer@galactosemia.org (this will allow you to pay via credit card)			

STERLING SILVER GALACTOSEMIA BRACELET AND NECKLACE

We will be offering the Sterling Silver Galactosemia Bracelet and Necklace again this year ON A PRE-ORDER BASIS ONLY. The jewelry was designed by one mom and handmade by another to honor our family members affected by galactosemia. The jewelry is handcrafted from Swarovski Crystals and Pearls and sterling silver pieces. There are nine crystals representing the missing GALT enzyme on the Ninth Chromosome. There are 3 different colored crystals and a heart charm signify the following:

Violet – signifying the self esteem we strive to ensure our children gain, but sometimes lack due living a challenging life

Blue – signifying sincerity and health we want for our children

Jonquil– signifying hope that through research a cure/treatment will be found
Heart– symbolizing the power of love.

If you would like to PRE-ORDER a bracelet or necklace, please complete the following order form and submit with your conference registration (please include payment). All orders will be available for pick-up at the conference.

SWAROVSKI CRYSTAL BRACELET ORDER FORM

Please write the # of each size you would like to purchase

Bracelet

Size	Quantity	Price	Total
6"		\$30	
7 1/8"		\$30	
7 3/4"		\$30	

Necklace

Size	Quantity	Price	Total
16"		\$35	
4" Extender		\$5	

Extender allows the 16" necklace to extend up to 20"

Purchase total

2012 Galactosemia Foundation Conference Tees

Order yours at time of registration and pick it up when you check-in. Three shirts available.

Name _____
 Address _____
 City/St/Zip _____
 Email _____

All Shirts Only \$12

Conference T:

red and blue on grey
GF-01 — TX State shirt

Indicate Quantity: _____
 Adult Size: S M L XL XXL
 Youth Size: S M L XL

FRONT:
 Linked for Life
 Galactosemia
 Foundation



BACK:
 Galactosemia
 Foundation
 Conference
 Empowering our
 future
 Dallas, TX July
 19th-21st
 Galactosemia.org

No whey T:

black& red on black
GF-02— No Whey shirt

Indicate Quantity: _____
 Adult Size: S M L XL XXL
 Youth Size: S M L XL

FRONT:
 NO
 WHEY



BACK
 Galactosemia.org

Not Milk T:

black on white
GF-03— Not Milk

Indicate Quantity: _____
 Adult Size: S M L XL XXL
 Youth Size: S M L XL

FRONT:
 Not milk!



BACK
 Galactosemia.org



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 age appropriate.

"HOW THE WEST WAS FUN!"

The OK Coral had nothing on us. Kids adventure into the Wild West re-creating themselves as ultimate cowboys and cowgirls!

- Perfect Ponchos
- Cool Cowboy Hats
- A Magician
- Rope the Bull
- Bucking Bronco
- Adult Galactosemic Speaker

We have a full schedule of activities and themes for each day of the conference. Both days will be jammed packed full of games, art projects, team building, costumes, imaginary play and much, much more! Each program will be coordinated to age appropriate.

We have contracted Corporate Kids Events, Inc. to host our childcare program for this year's conference. Their group of highly trained professionals have been coordinating with members of the conference committee to plan a program that your child of any age is sure to enjoy. Above you will see just a highlight of some of the things your child will enjoy while in their session. This program is open to both galactosemic children and their siblings. Your child will be dropped off prior to the starting of the general session so you will not miss anything. The children will remain in their rooms for the duration of the conference with the exception of being checked out for lunch. Everyone will enjoy lunch as one galactosemic family, together! Bring the kids and let them meet other galactosemic children and siblings. Sometimes it makes a big difference in a child's life to see there are others out there like them! Many children form lifetime friendships and bonds at our conferences, and we are encouraging you to let your child be a part of this awesome experience. After all, where else will they be able to mix and mingle with such a wonderful group, so please take the time and register your child today. You will need to register with Galactosemia Foundation; make your payment directly to Galactosemia Foundation for the childcare and then proceed to filling out the additional forms required for safety purposes by Corporate Kids Events, Inc. If you are registering online, you will be able to simply click on their website link for the additional forms. If you are mailing in your registration please contact Paul Fowler at treasurer@galactosemia.org to obtain the forms. We are looking forward to seeing your kids in July!

Corporate Kids Events, Inc • 18414 Alexandra Way • Grass Valley, CA 95949
Phone: 800.757.3580 • www.CorporateKidsEvents.com • www.VIPBabysitting.com

AGERS

(Adult Galactosemic group)

Announcing the new Adult Galactosemics (AGERS) group where Adults will have the chance to meet other Adults living with Galactosemia. This new group will host many Adult speakers who will share their experiences, tips and ideas on how to better improve your life with Galactosemia while giving you, the Adult Galactosemic the opportunity to discuss your life in the "breakout panel" segment. The Adult Galactosemic group also proudly announces guest speakers, Galactosemics and the leaders of this team, Stacy Taylor-Le Roux, Caryl Diengott and Sharon George-Howell. The AG group has many informative guest speakers.

The AGs will have the chance to join our exciting meet and greet segment where spouses of Galactosemics can discuss their journeys with a spouse with Galactosemia. In the past, when Adult Galactosemic spouses met and shared many experiences and journeys with one another, often we have found that spouses shared commonalities and similar experiences with this complex disorder.

We are sure that you will enjoy this new group and also the sharing of experiences with other Galactosemics! Don't miss your chance to sign up for this exciting new group!

Please forward any questions you may have to Stacy Taylor-Le Roux at: stacyleroux@gmail.com

We hope to see you in July!

AGERS Schedule (Adult Galactosemics)

Thursday, July 19th

- | | |
|-------------|--|
| 2:00 – 6:00 | On-Site Research: Please participate in the on-site research being offered! |
| 6:00 – 9:00 | GF General Registration & Chocolate Buffet Social – AGERS room will be open during this time to meet old & new friends |

Friday, July 20th

- | | |
|---------------|---|
| 7:30 – 8:30 | Galactosemia Foundation-Sponsored Breakfast (With your family) |
| 8:35 – 9:45 | Welcome to AGERS 2012!
Opening Remarks & Introduction to AGERS – Stacy Le Roux <ul style="list-style-type: none">• Around the round table, meet each other & introductions |
| 9:45 – 10:00 | Break |
| 10:00 – 10:20 | Life as A Galactosemic – Caryl Diengott |
| 10:20 – 10:40 | Dining Out Tips and Restaurant Safety While Traveling – Sharon Howell |
| 10:40 – 11:00 | Experiences With Galactosemia and Raising a Family – Kimberly Malyn |
| 11:00 – 11:30 | Questions & Answers – Open Forum to Speakers |
| 11:10 – 1:00 | Lunch |

1:00 – 2:00	Breakout Session – Adult Galactosemic Panel
2:00 – 3:00	Paul Pruszyński Tribute – 23 year old Galactosemic male who passed away January 9, 2011
3:15 – 3:30	Break
3:30 – 4:15	General Galactosemia Session – Join the Main Conference Room Session
4:15 – 5:30	Closing Remarks – Questions & Answers for Adult Speakers
5:30 – 7:30	Dinner on your own; a galactosemic safe menu is offered at the hotel restaurant for your convenience.
7:30 – 9:00	Dessert Social

Saturday, July 21st

7:00 – 8:00	Galactosemia Foundation–Sponsored Breakfast (With your family)
8:05 – 8:15	Opening Remarks – Stacy Le Roux
8:15 – 9:00	The Galactosemic Diet
9:00 – 9:45	Open Discussion
9:45 – 10:00	Break
10:00 – 11:00	Life After POF – Adult Female Discussion
11:15 – 12:15	Breakout Session
12:15 – 1:30	Lunch
1:30 – 2:15	General Galactosemia Discussion – Dr. Harvey Levy, Physician from Children's Hospital of Boston
2:15 – 2:45	Fundraising, Getting Involved
2:45 – 3:00	Break
3:30 – 4:00	Breakout Session
4:15 – 5:00	Wrap Up
5:00 – 8:00	Dinner – Adult Galactosemics and spouses will be going to Grapevine Mills for dinner. Pick up time is 5:45pm. We will be back to the hotel around 8 pm.
8:00 – Midnight	Social and Dance

(Some items in schedule are subject to change.)

Generation G

Are You Ready to Have A Whoopin' Good Time?

Then come on down to Texas and let's get started! We have a TON of stuff planned, Texas-style, onsite at the hotel and offsite. Be sure to arrive on Thursday for early GG registration from 3 - 6 p.m. Reconnect with old friends and meet new ones. If you are 18 years or older, you are invited to join in the fun.

The goals of the Generation G Program are to:

- Meet, interact, and have a good time with other young adults with Galactosemia
- Learn more and share your stories and concerns about Galactosemia

Cost per Generation G: \$135
(includes Conference & activities fees)

In order to secure group rates for offsite activities, registering for the GG Program indicates that you will be attending both onsite and offsite activities. This additional cost may be paid at the same time that you do your online or mail-in registration: we highly recommend online payment and registration—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 as counts are needed for group activity costs and transportation.

Plan on having the best time ever! Get a lot of rest before you come because we will be getting up early and hanging out late!

Note to older GGs: An Adult Group for adults with Galactosemia has been created by two women who also have Galactosemia. The program will be quite different from the GG program—if you think it is more along the lines of what you would enjoy, please contact the Adult Group coordinators, listed with their schedule in this Newsletter. (Unfortunately, you cannot do both programs.)

Generation G Schedule (18 and Up)

Thursday, July 19th

- 3:00 – 6:00 pm **Early Registration in GG Room & Hang Out with Other GGs**
***** No Dinner Planned—But check during registration to see what other GGs and their families are doing
- 6:00 – 9:00 pm **GF General Registration & Chocolate Buffet Social**
Note: If you do not make it to GG Early Registration, you can register at the GG Table at GF General Registration
- 7:30 pm **GG Meet & Greet in GG Room**
- 8:00 – 9:00 pm **"Doc Holiday" Cowboy Magician/Comedian (for GGs and GForce ONLY)**
- 9:00 pm and On **On Your Own—There are Pool Tables in the hotel restaurant (No Supervision)**

Friday, July 20th

- 7:30 – 8:30 **Galactosemia Foundation-Sponsored Breakfast (On Your Own) GG Room will be open—eat breakfast with other GGs**
- 8:30 **Meet in the GG Room**

- 8:30 am – 11:15 Sessions will include:
 8:30 – 9:45 Role-Playing: Ordering from Real Menus (GGs will be the Waiters, Waitresses, and Customers!!)
 10:00 – 11:15 Group Talk
 11:15 – 1:00 Lunch with the Doctors & Professionals: Who will present their latest research and answer questions
- 1:15 – 4:45 Bowling at the Main Event
- 4:45 – 5:30 Wrap-Up in GG Room
- 5:30 – 7:30 Dinner on your own; a galactosemic safe menu is offered at the hotel restaurant for your convenience.
- 7:30 – 11:15 GGs & GForce: A Night of Fun with Your Friends at Mountasia
- Miniature Golf
 - Bumper Boats
 - Go Karts
 - And more

Saturday, July 21st

- 7:00 – 8:00 Galactosemia Foundation –Sponsored Breakfast (On Your Own) GG Room will be open—eat breakfast with other GGs
- 8:00 Meet in the GG Room
- 8:00 – 11:30 Sessions will include:
 8:00 – 9:15 Cooking Demo with Dietician Sandy Van Calcar
 9:15 – 10:15 Self-Esteem Workshop with Andrea Topper
 10:30 – 11:30 Living Powerfully with Galactosemia—Dr. Roxanne Schreiber Will Lead This Group Discussion
- 11:45 – 12:15 GGs & G-Force Lunch (Eat lunch with your new and old friends)
- 12:15 – 6:30 Experience the Old West at Stockyards Station
- Participate in a Live Rodeo Show: Professional Cowhands will show us how to lasso, wrangle, and more
 - Ride a Mechanical Bull (you choose your speed)
 - Find Your Way through the Cowtown Cattlepen Maze
 - Watch a Real Cattle Drive
 - And much, much more
- 5:30 – 8:00 Dinner on your own; a galactosemic safe menu is offered at the hotel restaurant for your convenience.
- 8:00 – Midnight Galactosemia Foundation Dance

See you at the Dance at 8:00 PM!!!

(Some items in schedule are subject to change.)

G-FORCE

(Teen Galactosemic and Sibling Program for ages 13-17)

Howdy Partners! Round-up your friends and head on down to Dallas, Texas for some G-FORCE fun. 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 all teens to make new friends and reconnect with others. While parents are attending the conference, teens will learn more about Galactosemia, as well as experience the thrill of many exciting activities Texas 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. Both onsite and offsite activities will be offered including: Bowling, Miniature Golf, Bumper Boats, Cooking Demo, Rodeo Fun and much more! We hope all teens will "saddle-up" and JOIN THE FORCE!

The goals of G-FORCE are to:

- Meet and build friendships, while having fun with teens with Galactosemia and their siblings
- Learn together and from each other about Galactosemia

Included in the cost of your registration fee, Galactosemia Foundation will provide breakfast, lunch and snacks for G-FORCE participants.

In order to secure group rates for offsite activities, registering for the G-FORCE Program indicates that you will be attending both onsite and offsite 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.

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

G-Force Schedule (13 - 17 Year Olds)

Thursday, July 19th

- 3:00 – 6:00 G-Force Early Registration: Come early and meet other friends and their families in the G-Force Room!
- 6:00 – 9:00 GF General Registration & Chocolate Buffet Social
- 8:00 – 9:00 "Doc Holiday" Cowboy Magician/Comedian (for GGs and GForce ONLY)

Friday, July 20th

- 7:30 – 8:30 Galactosemia Foundation-Sponsored Breakfast (With your family)
- 8:30 – 9:00 Welcome to G-Force 2012!
Meet and greet new and old friends and play Friendship Building Group Activities
- 9:00 – 11:15 Activities will include:
 - Living Powerfully with Galactosemia lead by Dr. Roxanne Schreiber
 - Role Playing at the G-Force Café
 - Galactosemia Jeopardy
- 11:15 – 12:00 Enjoy lunch with your new friends!

- 12:00 – 1:00 **Games! Games! Games!**
 •Friendship Building Group Games
 •Board Games
 •Card Games
- 1:15 – 4:45 **Bowling at the Main Event**
- 4:45 – 5:30 **Wrap-Up in the G-Force Room**
- 5:30 – 7:30 **Dinner on your own; a galactosemic safe menu is offered at the hotel restaurant for your convenience.**
- 7:30 – 11:15 **GGs & GForce: A Night of Fun with Your Friends at Mountasia**
 • Miniature Golf
 • Bumper Boats
 • Go Karts
 • And more

Saturday, July 21st

- 7:00 – 8:00 **Breakfast (with your family)**
- 8:00 – 8:30 **Meet in the G-Force Room to sign in and play a greeting game and group activities**
- 8:30 – 11:30 **Activities will include:**
 • Building Confidence lead by Andrea Topper
 • Cooking Demo with Dietician Sandy Van Calcar
 • Group Galactosemia Gab
- 11:45 – 12:15 **Enjoy a delicious lunch with our GG friends**
- 12:15 – 6:30 **Experience the Old West at Stockyards Station**
 • Participate in a Live Rodeo Show: Professional Cowhands will show us how to lasso, wrangle, and more
 • Ride a Mechanical Bull (you choose your speed)
 • Find Your Way through the Cowtown Cattlepen Maze
 • Watch a Real Cattle Drive
 • And much, much more
- 5:30 – 8:00 **Dinner on your own; a galactosemic safe menu is offered at the hotel restaurant for your convenience.**
- 8:00 – Midnight **Galactosemia Foundation Dance**

See you at the Dance at 8:00 PM!!!

(Some items in schedule are subject to change.)

Conference Speakers

Dr. Jennifer Badik, MD, FAAP; Dr. Jennifer "Jen" Badik is currently completing a fellowship in Pediatric Endocrinology and Diabetes at Emory University School of Medicine; her research interests include ovarian function in girls and women with Duarte and classic galactosemia. Jen earned her undergraduate degree from Goucher College in Baltimore and her MD from Temple University in Philadelphia. Prior to assuming her current position at Emory, Jen also completed an internship and residency in Pediatrics at the University of Arizona in Tucson.

Maureen Bell; Maureen (Lindenhofen) Bell was diagnosed with classic galactosemia seven days after her birth in 1972. Now, 40 years old, Maureen has been a patient advocate for galactosemia for many years, speaking at various PGC and NIH conferences, and participating in numerous research projects. Currently, Maureen resides in a suburb of Philadelphia, PA. with her husband of eleven years, William "Bill" Bell. Maureen is currently employed as a full time nanny for two twin girls and an eleven year old boy. Maureen is also active in her local church and with various other causes close to her.

William Bell; William Bell has been a licensed pharmacist for nearly twenty years. Since completing his Bachelors of Science degree in Pharmacy from Duquesne University in 1992, Bill has spent time in various practice settings including community, academia, and institutional practice. Currently, Bill is the Senior Clinical Pharmacist with Gould and Lamb, LLC and is responsible for Medicare Compliance secondary to Workers' Compensation Medicare Set-Asides. Bill is licensed to practice pharmacy in 5 states and will complete his Doctor of Pharmacy degree in 2013. Most importantly, Bill is the husband of Maureen (Lindenhofen) Bell, a past VP of the PGC and a classic galactosemic.

Dr. Gerard T. Berry, MD; Dr. Gerard Berry is a biochemical geneticist and pediatric endocrinologist, is the Harvey Levy Chair in Metabolism and Director of the Metabolism Program at the Children's Hospital Boston, and Professor of Pediatrics at the Harvard Medical School, and Director of the Harvard Medical School Biochemical Genetics Training Program. Dr. Berry received a Bachelor of Science degree from the University of Notre Dame and then completed his MD degree from the Jefferson Medical College in Philadelphia, Pennsylvania. Dr. Berry completed his residency in Pediatrics at the Thomas Jefferson University Hospital. Subsequently, he began a combined fellowship in biochemical genetics and pediatric endocrinology at the Children's Hospital of Philadelphia. Having spent 20 years on the faculty at the University of Pennsylvania, he assumed the position of Division Chief for Metabolism and the Director of the Biochemical Genetics and the Molecular Diagnostic Laboratory at the Children's National Medical Center in Washington, DC. Dr. Berry has been the recipient of both NIH and non-federal grant awards. He has published over 120 peer reviewed papers and over 35 book chapters. Dr. Berry's primary basic science and

clinical research efforts are focused on Hereditary Galactosemia, inositol metabolism in the brain particularly during fetal development, as well as a number of other metabolic disorders.

Diane Flynn-Brake; Diane Flynn-Brake is married to Scott Brake and is the mom of 2 boys: Matthew, age 19, classic galactosemic, and Daniel, age 17, carrier. She lives in Hinsdale, Illinois and is employed full time at Ace Hardware Corporation, Director of Strategy and Business Development. Diane is an active leader in Boy Scouts and has been involved in Galactosemia Foundation for a number of years and she has served on the board of directors since 2009. Diane has personal goals as it relates to Galactosemia Foundation which are to get new families educated on Galactosemia and help in any way she can to support the organization that has helped her to learn along with her galactosemic son.

Michelle Fowler; President – Galactosemia Foundation, Michelle Fowler is the proud Mommie of three children Tori age 16, Landon age 12 (classic galactosemic), and Tela age 10 (carrier). Michelle has been involved with galactosemia for twelve years now, since the birth of her son, Landon. Michelle is married to Paul Fowler and they reside in Mandeville, Louisiana with their three children. Currently, Michelle serves as the President for Galactosemia Foundation, and is also actively involved with the National Organization of Rare Diseases and National Newborn Screening. Working fulltime as a licensed bail bondsman and bounty hunter and also working in a Private Investigation company, along with the responsibilities of a family and volunteering for galactosemia, keep her busy! Michelle's life revolves around her family and the passion she has for helping families and those affected by galactosemia.

Paul Fowler; Paul Fowler is currently the Treasurer for Galactosemia Foundation and has been involved with the organization for twelve years. Paul is married to Michelle Fowler and they have three children, Tori, Landon (classic galactosemic) and Tela. Paul is a Mechanical Engineer for Jacobs Engineering and is also a licensed bail bondsman and bounty hunter.

Dr. Judy Fridovich-Keil, PhD; Judy Fridovich-Keil is a Professor in the Department of Human Genetics at Emory University School of Medicine in Atlanta, Georgia. Galactosemia has been a focus of research in her laboratory for almost 21 years. Judy's training includes an undergraduate degree in biochemistry from Princeton University, a PhD in biology from the Massachusetts Institute of Technology, and postdoctoral work at Harvard Medical School. Judy is also a diplomate of the American Board of Medical Genetics with a specialty in Clinical Molecular Genetics.

Dr. Patricia Greenstein, MD; Dr. Greenstein is the Director of Neurogenetics Clinic at Children's Hospital Boston, MA and is the Assistant Professor of Neurology at Harvard University in Boston. Dr. Greenstein is a neurologist and faculty member of

the Beth Israel Deaconess Medical Center, Department of Neurology with training in both Neurology and Medical Genetics. She has developed a neurogenetics clinic and seen patients and their families with inherited neurological disorders. She is also involved with studies related to Galactosemia as she studies to characterize, in great detail, the neurological phenotype in patients with Galactosemia.

Dr. Kent Lai, PhD; Kent Lai is from the Department of Pediatrics, University of Utah. A native from Hong Kong, Dr. Kent Lai earned his undergraduate degree in Medical Laboratory Sciences from The University of Bradford (U.K.) and his Ph.D. from University of Maryland (U.S.). He was also awarded an M.B.A. from Georgia State University (U.S.). After receiving his Ph.D. in Molecular and Cell Biology; he went on for his Post-doctoral Research Fellowship at Emory University School of Medicine (U.S.). Dr. Kent Lai's career as a researcher and educator began in 2002 at University of Miami School of Medicine, where, within 6 years, he rose from Assistant Professor to Associate Professor of Pediatrics. In March, 2009, Dr. Lai joined the Division of Medical Genetics (Pediatrics) at University of Utah. Dr. Lai's research focuses on the development of novel therapeutics for rare and common diseases, which include Classic Galactosemia, infectious diseases and cancers. He has been the Principal Investigator for numerous research grants awarded by the National Institutes of Health and American Heart Association. Dr. Lai is currently an Associate Editor of Open Journal of Preventive Medicine and a Study Section member for the American Heart Association.

David Levine; David Levine and his wife Melissa are the proud and smiling owners of Illinois Nut & Candy, Home of Fantasia Confections. David began with a Master's Degree in Education, taught high school and held IT positions and worked in a municipality before his candy company. David has been an active supporter of Galactosemia Foundation and the families of the organization for many years. He is currently working on his first novel on the subject of branding and has a current blog called, lifeofthecandyman.blogspot.com where he discusses the ups and downs, surprises and utterly nutty delights of life in a candy store.

Dan Lambert; Dan Lambert is lead for the Research Team and has been a member of the research team since Round 1. He was a member of the South Carolina Newborn Screening Advisory Team for many years. Dan is a Fellow Engineer at the Savannah River National Lab. He has spent the last twenty years doing research and development for processing of high level radioactive waste at the Savannah River Site. Dan is an active member of the American Institute of Chemical Engineers, where he currently serves as chair of the Virtual Local Section and is a member of the Career and Education Operating Council. Dan is married to Nancy and they have two children, Mike and Eric. Dan has been involved with galactosemia since Eric was born whom is classic galactosemic.

Sean and Kristine Lydon are both Police Officers in Braintree, Massachusetts. Sean is a Lieutenant and works the afternoon shift and Kristine is a Patrol Officer and works the day and midnight shifts, she is also a trained sexual assault investigator, and a RAD Instructor. They have three children, Kyleigh age 7 (Classic Galactosemia), Samantha age 6 and Sean age 4. After Kyleigh's diagnosis in 2004, they established a non-profit organization called "Kyleigh's Cure", and since then have raised over \$260,000 for Galactosemia research. They are currently working on the "2nd Kyleigh's Cure Road Race".

Dr. Anna Marabotti, PhD; Dr. Anna Marabotti received a degree in Medicinal Chemistry in 1996 in the University of Parma, Italy, and a Ph.D. in Biochemistry in 2001, in the University of Turin, Italy. She has worked in several Italian Universities, public research institutions, and private institutions/companies. Her research activity is centered on the study of structure-function-dynamics relationships in proteins of biotechnological interest or involved in human diseases, using a computational biology approach coupled to experimental approaches. She is author of more than 50 full papers and of more than 50 abstracts presented in national and international congresses, in the field of Biochemistry and Computational Biology.

Dr. Nancy Potter Ph.D., CCC-SLP, Nancy Potter is an associate professor in Speech and Hearing Sciences at Washington State University. She received her Doctorate in Communicative Disorders and completed post-doctoral work examining speech, language and motor skills in children with galactosemia at the University of Wisconsin-Madison. She has more than 25 years (but doesn't admit to how many more...) years of experience working with children and adults with neurologic speech and swallowing disorders.

Christine Raum, RN, BC, BSN; Christine Raum is the mother of Alexandra Raum galactosemic 22 years old. She has practiced in critical care nursing for 27 years, also have done acute dialysis, hospice care, pediatric home intensive care, telemetry unit(heart floor), and internal medicine. R.N. Board Certified in Cardiovascular Nursing and Bachelors of Nursing' Studying for Masters in Nursing and Nurse Practitioners Degree at present which will be completed in May 2014

Dr. Kari Ryan, PhD; Dr. Kari Hecker Ryan is currently the Director of Nutrition Sciences & Regulatory Affairs for Frito-Lay Inc. Frito-Lay North America is the \$13 billion branded snacks division of PepsiCo, which is headquartered in Purchase, NY. In addition to Frito-Lay, PepsiCo divisions include PepsiCo Beverages North America, Quaker Foods North America and PepsiCo International. In her role at Frito-Lay, Dr. Ryan directs the Healthy Snacking Research Center which involves clinical nutrition research programs, regulatory claims and compliance issues, and oversees nutritional content of health professional outreach programs. During her tenure at Frito-Lay, Dr. Ryan has supported the use and marketing of heart healthy oils, whole

grains, fiber, lower sodium, and nutrition for women, kids and "Boomers" in Frito-Lay snacks. Her team sponsors clinical nutrition research and evaluates up to date science to support product innovation and nutritional enhancement of existing products. Prior to joining Frito-Lay, Dr Ryan was a doctoral student at the Pennsylvania State University where she studied the effects of dietary fats on risk factors for cardiovascular and diabetes. Dr. Ryan has a bachelor's degree in nutrition science from Indiana University at Bloomington and a master's degree in biochemistry from the University of Missouri at Columbia. She completed her dietetic internship at the University of Missouri. Dr. Ryan is a member of the American Dietetic Association and the American Society for Nutrition.

Scott Saylor; Scott Saylor resides in Virginia area with his wife Kristine Saylor and their son Jake, born in July of 2007 with classic galactosemia. After Jake's birth and learning about galactosemia and the severe underfunding for galactosemia research, Scott and his wife Kristine decided to hold a fundraiser. Fore the Cause charity golf tournament has raised over \$60,000 in 3 years for the Galactosemia Foundation. The Saylor's hope is that through fundraising efforts like this a cure is found. Scott is the district manager of Walgreens in Richmond, VA.

Roxanne Schreiber, PhD; Dr. Roxanne Schreiber, is a licensed psychologist and has been in private practice for the past 14 years. She works with children, families, individuals, couples, and groups and specializes in having each individual recognize their personal power and capacity for an extraordinary life. Dr. Schreiber currently provides informative and dynamic communication seminars for adolescent daughters and their mothers as well as communication seminars for couples. The seminars are structured to cause significant and profound changes in one afternoon. Most recently, Dr. Schreiber has synthesized her psychological theory with the latest cutting edge brain research and is offering empowerment seminars and empowerment groups in which participants are trained in accessing their full potential utilizing the inner workings of their brains. Dr. Schreiber's commitment is that each client is empowered, honored, and supported in accessing their full potential. Her life's work is that people tap into their inner greatness and that this greatness gets expressed into the world.

Scott Shepard; Scott Shepard, Vice President of the Galactosemia Foundation. Shortly after his first daughter's birth in 2006, Scott began educating himself about Galactosemia by reading all of the technical articles he could find, talking to medical professionals, and networking with other members of the Galactosemia community. Scott is passionate about increasing the awareness of and interest in Galactosemia among medical professionals, building a stronger Galactosemia community, and advocating for his daughter. Scott has been an integral member of the 2012 Galactosemia Foundation conference planning committee and recently joined the Galactosemia Foundation board of directors as the Vice President.

JoBeth Southard, P.E.; Jo Beth Southard is married to Mark Southard and together they have 13 year old Sarah (classic galactosemia) and 11 year old Ethan. They live in Decatur, TX. Together with much help, they put on the Annual Sarah's Cure Fundraiser to raise money for a treatment or cure for galactosemia. Jo Beth is one of the founders and the President of Galactosemia Families of the Southern States (GFSS). She wanted to have a local chapter for families to get together more often and to have a support system for new families. She also wanted to raise money for galactosemia and do something about it rather than just "deal" with it. Jo Beth graduated from Texas A&M University with a Civil Engineering degree in 1997. In March of 2011 she started her own company, Halo Coatings, which is a coating company in the oil/gas industry. The new business keeps her very busy, but she also loves to work out and participate in triathlons. She plays volleyball, basketball, softball and most any other sport that can keep her competitive drive fulfilled. She coaches Sarah in Volleyball and helps Mark coach Ethan in basketball. She also enjoys hanging out with her friends. Jo Beth's commitment in life is to God, her family, being an advocate for her children, and finding a cure or treatment for galactosemia.

Dr. Jessica Spencer, MD, MSc; Dr. Jessica Spencer is an Assistant Professor in the Department of Obstetrics and Gynecology at Emory University School of Medicine in Atlanta, GA. Jessica is a board certified reproductive endocrinologist who primarily sees women with infertility and ovarian dysfunction. Her research interests include investigating the mechanisms of premature ovarian insufficiency in women with galactosemia. Jessica received her MD from the Sackler School of Medicine, NY/American Program, in Tel Aviv, Israel. She completed her residency in Obstetrics and Gynecology at the David Geffen School of Medicine at UCLA in Los Angeles, and her fellowship in Reproductive Endocrinology and Infertility at Emory University in Atlanta where she also completed a Masters of Science in Clinical Research.

Elisabeth Taddeo Ed., D.; Elles Taddeo is an Educational Specialist in the Department of Psychiatry and Behavioral Sciences at Emory University School of Medicine, in Atlanta GA. Her research and professional interests include cognitive and metacognitive development and control of behavior in young children and children prenatally exposed to toxic substances, and the development of educational interventions that can benefit these children. Recently she has also contributed to a study of scholastic outcomes in children with galactosemia. Elles earned a BA in Psychology from York University in Toronto, CA, an M.Ed. in Counseling Psychology from the University of Toronto, and an Ed.D. from Argosy University in Atlanta, GA.

Dr. Claudia Testa, MD, PhD; Dr. Claudia Testa is an Associate Professor in the Department of Neurology at Virginia Commonwealth University (VCU) and Associate Director of Clinical Care and Research for the VCU Parkinson's and

Movement Disorders Center. Within the Movement Disorders Center she leads the Huntington Disease Program and the Essential Tremor Program. Claudia's professional interests include clinical and translational research in neurodegenerative disorders and movement disorders associated with essential tremor, Huntington disease, dystonia, and galactosemia. Claudia earned an undergraduate degree in biophysics from The Johns Hopkins University, and MD and PhD degrees from University of Michigan. She completed internship at Beth Israel Hospital and neurology residency at Harvard's Partners Program (Massachusetts General Hospital and the Brigham and Women's Hospital), all in Boston. She served as Chief Resident in Neurology. Claudia then moved to Emory University, in Atlanta, GA where she completed a fellowship in Movement Disorders and then joined the faculty in the department of Neurology. Claudia is completing a Masters of Science in Clinical Research at Emory; her thesis project concerns movement disorders in galactosemia. Claudia recently relocated to VCU to assume her current position.

Andrea Topper; Andrea Topper is a bi-lingual and bi-cultural certified social worker. She began her career while working in New York City at a not-for-profit law firm, Lawyers for Children; there she worked with law guardians to represent abused children in foster care. In 1995, Mrs. Topper graduated from the State University of New York in Stony Brook, where she received a masters of social work degree and immediately afterwards received New York State Social Work Certification. In 1997 Mrs. Topper began employment with the Education and Assistance Corporation. EAC is a large non-profit human service organization that serves over 33,000 people throughout Long Island and the five boroughs of New York City. EAC offers programs including many designed for children in trouble at school, children whose parents are recovering substance abusers, children dealing with sexual abuse and supervised visitation programs for children separated from their parents. All of the programs work to improve the health and emotional well being of children, families and communities. Mrs. Topper is the mother of two teenage boys, Keith age 15 and Chris age 14, both diagnosed with Galactosemia. Mr. and Mrs. Topper, along with their two sons and two puppies reside on Long Island, New York.

Sandy VanCalcar, PhD, RD; Dr. Sandy VanCalcar has worked as a metabolic dietitian at the Biochemical Genetics Program, University of Wisconsin in Madison for over 20 years. Her practice includes both patient care and clinical research coordination. She finished her doctorate degree in Nutritional Sciences in 2009 and is an Assistant Professor in the Department of Pediatrics. Sandy has written several educational materials including "Understanding Galactosemia: A Diet Guide." Sandy received a grant for the Galactosemia Foundation last year to organize a task force to evaluate nutrition recommendations for galactosemia. She was a founding member of Genetic Metabolic Dietitians International (GMDI) and is currently President of this organization

Dr. Susan Waisbren, PhD; Dr. Susan Waisbren is Associate Professor of Psychology at Harvard Medical School's Department of Psychiatry, as well as Research Associate at the Children's Hospital in Boston. She is also a psychologist at the Clinic for Inborn Errors of Metabolism and Phenylketonuria in the Developmental Evaluation Clinic and the Division of Genetics at the Children's Hospital. Dr. Waisbren received her Ph.D. in Clinical Psychology from the University of California, Berkeley. Dr. Waisbren directs a research program on the behavioral and developmental aspects of phenylketonuria and other inborn errors of metabolism. Her current research focuses on intergenerational considerations in PKU and the developmental implications of a statewide newborn screening program. She has been a leader in developing national and international networks to address the needs of youngsters and their families with inborn errors of metabolism.

Denise Wilburn; Denise Wilburn is a Licensed Clinical Professional Counselor specializing in the care of children and families. Denise has worked in mental health clinics, schools and has maintained a private practice for 13+ years. Denise has conducted numerous workshops on various topics such as parenting, helping children cope with loss and relaxation techniques. Denise was introduced to Galactosemia in 2007, when her second son, Grant, was diagnosed at 5 days old. Denise remains active in the Galactosemia Foundation, serving on the Research, Fundraising and Conference Planning Committees and is the founder and current president of the Galactosemia Association of Midwest America (GAMA) based in her home state of Illinois.

Jason Wilcox; Jason Wilcox holds a master's degree in education and is currently enrolled in Superintendent Certification for the state of Texas. He is currently an Assistant Principal at a mid-sized rural high school in East Texas. Jason has been in education for 12 years and in administration for the past 4 years. He also has a son, Paden, whom is 8 years old that has Classic Galactosemia. He has experience with some of the programs that he will discuss in his sessions, from directly dealing with his own child. Jason's experience with education and working with individuals within a school system will help give insight within the school system.

BOOK YOUR ROOM FOR THE
CONFERENCE ONLINE TODAY!
<https://resweb.passkey.com/go/PGC>

2012

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
	18 VA Charity Golf Outing for Galactosemia, Richmond, VA	10 2nd Kyleigh's Cure Road Race, Braintree, MA
JULY	AUGUST	SEPTEMBER
19-21 Galactosemia Foundation Conference, Dallas, TX		
OCTOBER	NOVEMBER	DECEMBER

BOOK YOUR ROOM FOR THE CONFERENCE ONLINE TODAY!

<https://resweb.passkey.com/go/PGC>



**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

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

