

## **Generation G at PGC (Young Adult Galactosemics)**

By Linda Manis

When PGC started 20 years ago, the majority of the members were families whose Galactosemic children ranged in age from newborn to ten-years-old. Now, those same children are in their twenties and early thirties – they are the “1<sup>st</sup> Generation of Galactosemics” — Generation Galactosemics or Generation Gs also known as the GGs. Thirteen Generation Gs (ranging in ages from 18 to 31) participated for the first time ever in the GG Program at the 2006 PGC Conference in Philadelphia, meeting in their own “Boardroom.”

Galactosemics all experience different levels of difficulties, and the GGs were no exception – the program ran the spectrum of difficulties, from mild to more serious – but that didn’t stop this group who quickly became a cohesive unit forming a connection that only they can explain. A few GGs had NEVER met another person with galactosemia, while others had been to previous conferences.

So many Galactosemics are shy, especially in new situations, but by the end of the first hour together any anxieties had disappeared. Jim Svobodny (father of Brett – 18) and Joe Leggio (my new husband, stepfather of Adam Manis – 22; also the father of three grown daughters) ran the program, which Susan Fernstrom (mother of Holly – 28) and I organized and coordinated. Like most dads, Joe and Jim’s enthusiasm and endless joking made the program extra special! Anyone who was in Atlanta or Reno with their kids knows Jim – he’s the one who took the kids to various offsite activities and more.

The GGs toured Philadelphia on “Ride the Ducks,” on land and water in an amphibious vehicle. (See photo). They took a trolley to a state-of-the-art bowling alley and spent one afternoon bowling. They had breakfast with Dr. Judy Fridovich – a biochemist who is doing research on galactosemia – all the GGs gave blood and filled out questionnaires along with many of the other younger Galactosemics for her study.

### **“No Parents Allowed”**

A few of the program activities were for the GGs only – “No Parents Allowed!” Sharon Howell, a 46-year-old woman with Galactosemia had a “Rap Session” with the GGs, where they discussed “What It’s Like to Have Galactosemia.” Laurie Bernstein, one of PGC’s favorite registered dieticians met with the GGs to discuss their feelings and answer questions about the galactosemia diet. World renown Dr. Louis Elsas and Dr. Gerald Berry had a private lunch with the GG group – Holly made sure that no one talked until the parents running the program left the room – telling us, “You parents have to learn how to let go.”

## **Other Stuff**

Those GGs who wanted to were interviewed by Sabrina Honeycutt (mother of an elementary age boy with galactosemia) and her fiancé Nick Elliott, who are putting together a video for a fund raising project in South Carolina. The GGs played Bingo (Matt Hynes – 31 – won \$20)! Then, an incredible interactive magician gave each GG a set of magic materials and taught them magic tricks. On Friday night, the GGs and their families went out to dinner. The GGs sat together and for once were not alone ordering their selections without dairy. The parents sat at another table and compared their kids' experiences – crying, laughing, sharing stories, providing support, learning from one another.

## **In Conclusion**

Over two days, the GGs made friendships that will last a lifetime – they had each been given a disposable camera at the beginning of the conference to record their memories. And at the end of the conference, each GG was given a binder with a photo of each GG and his or her contact information (e-mail addresses and birthdays too) along with a list of his or her favorite things, to use to stay in touch with one another until the next conference or get together. They have been e-mailing one another ever since.

Almost everyone at the conference could not help but notice the GG group, including teenagers who approached us to join the program, which was only open to those Galactosemics who were 18 or older. Every GG and their families along with PGC unanimously agreed that the time has come to start a Generation G group under the umbrella of PGC, which will now include any Galactosemic who is **16-years-old or older**.

Susan Fernstrom, Rhonda Svobodny, and myself are willing to organize this new group. Our vision is a group of all young adult Galactosemics getting together not only at the PGC conferences but once or twice a year – taking trips together (perhaps Disneyworld, a cruise, and/or having GG group get togethers in the towns where various GGs live). If you are a GG young adult (16 to 35) and you and your family are interested in joining us, please contact one of us (contact info is below). If you are a parent who is interested in helping or planning, please let us know.

Words cannot describe the GGs experience, but as one parent said, “This is the most wonderful time my child has ever had!”

## **Contact Information**

For more GG News please check out the Generation G link (which should be up in October) from the PGC Web site [www.galactosemia.org](http://www.galactosemia.org)

To join the group, either you or your parents can contact:

Linda Manis: [LMScript1@aol.com](mailto:LMScript1@aol.com) Phone: 561-862-0748 (Boca Raton, FL)  
Susan Fernstrom: [4willow@adelphia.net](mailto:4willow@adelphia.net) Phone: 508-498-0408 (Amesbury, MA)  
Rhonda Svobodny: [sherry7@aol.com](mailto:sherry7@aol.com) Phone: 916-635-4130 (Rancho Cordova, CA)

At the time of the writing of this article, I am trying to have a GG Section for the GGs to chat with one another on the Galactosemia Discussion Board at [www.galactosemica.com](http://www.galactosemica.com) (please check it periodically to see if I was able to).