The Fabry Support & Information Group proudly announces the FSIG Expert Fabry Conference 2015.

This conference is especially for you, the Fabry patient community. You will receive valuable, up-to-date information about Fabry disease. You will have the opportunity to network with others, learn from the experts, relax, and be a little pampered at the same time. Like last February we have an excellent line-up of informational presentations, breakout sessions, focus group discussions, awards, and surprises. You don’t want to miss this Conference!

A very modest conference fee will cover lodging, conference meals and hotel for those with Fabry and their immediate family members, but you must Register by January 7, 2015.

General agenda:
Friday Evening—registration, Fabry 101 and welcoming social mixer
Saturday Morning—registration and general session presentations
Saturday Afternoon—concurrent breakout sessions
Saturday Evening—dinner and awards
Sunday Morning—focus groups

Additional details to come.

Join us for a winter break!
Friday February 13th - Sunday February 15th
Embassy Suites Orlando - Lake Bueno Vista
8100 Lake Street, Orlando, FL 32836

Register at: http://www.cvent.com/d/24q5g3 or use the back of this notice.

Conference hosted by the Fabry Support & Information Group.
Travel to and from the conference is not included. If more than six individuals will be in your party, please complete a second registration form making the first person the same as your first registration. Every person attending must be listed. Registration is $75 for the first person and $25 for each additional person over age 10. Embassy Suites will charge you a $10.95 resort fee per room per night. See FAQs page for additional details.

A very limited number of partial and full travel/conference scholarship will be awarded by random lottery. Request travel assistance if this is the ONLY way for you to attend. To make necessary travel arrangements lottery winners will be contacted by Jan. 9th. To apply for travel assistance complete the last line below.

* Required information

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Contact Person Information: Please print clearly to avoid delays or confusion.

*Name: __________________________
*Address: __________________________________________________________
*City: __________________________ *State: _____ *Zip Code: ________________
*Telephone: ______________________ E-mail: ______________________

Do you need a hotel reservation: Yes No
Room Preference: One King Two Queen
Rooms come with a sleeper sofa - One King room can accommodate 4 - Two Queen room can accommodate 6.

What night(s) will you be staying: ___ Friday, Feb. 13th ___ Saturday, Feb. 14th

Do you need handicap accessible: Yes No

Will your child(ren) be utilizing the Youth Hangout? ___ Yes ___ No

How many guests will need travel assistance: ___ | ___ None ___ Partial Assistance ___ Full Assistance

Request travel assistance ONLY if you cannot attend otherwise. A very limited number of rooms are available for travel assistance.

Conference registration fee may be paid by check or on-line.
Return completed registration form to: FSIG, PO Box 510, Concordia, MO 64020
Have Questions: call 866-30-Fabry (866-303-2279) or e-mail info@fabry.org
FSIG Expert Fabry Conference
Embassy Suites - Lake Buena Vista, 8100 Lake Street, Orlando, Florida
February 13<sup>th</sup> - February 15<sup>th</sup>, 2015

Frequently Asked Questions

**Q: What can I expect if I attend the FSIG Expert Fabry Conference?**
Learn from guest speakers, meet with doctors who are knowledgeable about Fabry disease, and meet new families who share common concerns and experiences. The goal of this conference is to educate Fabry patients and family members. This conference is a fun opportunity to make new friends and reconnects with old friends you have not seen in a while.

**Q: Who may attend the conference?**
The conference is designed for Fabry patients, their family members and caregivers. This includes affected individuals, parents, children, siblings, significant other, grandparents and supportive friends.

**Q: Is there any cost to attend?**
Yes, conferences of this type are very expensive. Travel expenses to the conference and back home are not included. This year there will be a nominal registration fee of $75.00 for the first registrant per room and $25.00 for each additional registrant eleven years and older. Children ten and younger are free. The primary guest is also responsible for a reduced daily resort fee of $10.95 per room per night, which will be due to Embassy Suites upon checkout.

**Q: What is included in the registration fee?**
This conference is a great educational and networking opportunity that benefits everybody. We truly wish the conference could be completely free, but conference sponsorship does not cover all expenses. The registration fee is a real bargain and goes toward the cost of lodging at the Embassy Suites, meals throughout the conference, facility costs, speaker and medical expert costs, plus many additional conference expenses.

**Q: What is included in the resort fee?**
The resort fee is an additional mandatory daily charge by Embassy Suites. We negotiated this reduced rate of $10.95 per day. This fee includes standard parking, WI-FI, local and domestic calls, 10% off Spa Services, two bottled waters daily per room, Walt Disney World shuttle, USA Today and the Wall Street Journal, daily Disney dive-in movie and Activity Concierge.

**Q: How many will a room accommodate?**
All rooms are suites with a bedroom, living room with queen size sofa sleeper, mini-kitchenette and table. Rooms with a King Size bed can sleep four and rooms with two Queen Size beds can sleep six.

Please e-mail or call any questions or concerns to Connie at support@fabry.org or 866-303-2279.
Q: Is there a limit to conference attendance - how do I register?
Yes, there are a limited number of rooms available. We wish we could accommodate everyone in the Fabry community, but funds do not allow this. We have contracted for a block of 52 rooms per night. Availability is limited on a first come, first serve basis. To register, fill out and return the attached document OR visit http://www.cvent.com/d/24q5g3 and fill out the on-line registration form.

Q: Will childcare be provided?
Childcare will be provided. The cost of childcare is included in the registration fee. Children of all ages are encouraged to utilize the Youth Hangout. Activities and supplies will be at your child’s disposal. Dependable and reliable adults will be watching your children. We believe that if parents know their children are safe they will get the most from the conference. If you are bringing children to the conference please let us know their ages and whether they will be utilizing the Youth Hangout on the registration form or on-line.

Q: Can I extend my stay at the hotel?
If you wish to extend your stay, we have negotiated so you may obtain a room for the same reduced rate of $149 plus tax and resort fee for three days before or three days after the conference. You will have to call the hotel and book these rooms yourself, just mention that you will be attending the FSIG Expert Fabry Conference.

Q: Do I have to stay in the conference hotel?
Staying at the same hotel the conference is held at is important and lends itself to the very purpose of the conference. You do not have to stay at the same hotel, but FSIG will not pay for your hotel room otherwise and cannot guarantee anything regarding your alternate choice of hotel.

Q: If I am unable to attend the full conference, can I pay a reduced registration fee?
There is no adjustment to the fee for days not attended. The fee will be the same whether you stay one or two nights. FSIG’s overall event costs remain the same whether you attend part or all of the conference.

Q: May I receive a refund if I am not able to attend the conference?
If you cancel your registration by February 2nd, 2015 you will receive a full refund. After that date no refund will be provided. Refunds for credit card payment will be made through PayPal after the conference and may take up to two weeks to process. Refunds for payment by check will be made by check but may take up to two weeks.

Q: Will I be able to talk to doctors about my/loved one’s Fabry disease?
Many of the doctors are willing to talk about your disease to the best of their ability on an individual basis. Limitations on discussions will probably exist due to available time, available information and other factors. Please feel free to take advantage of this conference time to ask questions of the knowledgeable experts on Fabry disease.

The Embassy Suites are a non-smoking facility.

Please e-mail or call any questions or concerns to Connie at support@fabry.org or 866-303-2279.
Total expenses for the 2014 FSIG Expert Fabry Conference in San Diego, CA came to approximately $119,000.

Industry partner conference support was based on FSIG’s estimated budget. The budget was compiled based on a meetings survey. The number of individual that came to the conference reached nearly 200, which greatly exceeded what the survey results projected. Fortunately FSIG had a sufficient operating reserve to cover the expenses, but this reserve has been depleted to the point FSIG cannot cover additional significant conference expenses for this coming February. For these reasons a registration fee and limit on available rooms is needed to find a balance between the estimated number of attendees and the expected level of industry partner support. FSIG is grateful to all of its partners because without their extremely generous support the FSIG Expert Fabry Conference would not be possible. FSIG is also very grateful to you, the Fabry community for your outstanding enthusiasm and support for this beneficial event.