

FSH Society 2012 International Patient/Researcher Network Meeting
Saturday, June 30 and Sunday, July 1
Atlanta Marriott Marquis, 265 Peachtree Center Avenue NE, Atlanta, Georgia 30303
Tentative Program (January 2012)

Friday, June 29

4:00-6:00 p.m. Registration

6:30 p.m. Informal dinner(s), to be arranged (optional)

Saturday, June 30

Breakfast on your own

8:00 a.m. Registration continues

9:00 a.m. to noon Keynote address and panel discussion

The State of FSHD research and what patients might expect in the decade

Noon Lunch (included in registration) Luncheon speaker

2:00-3:30 p.m. Concurrent sessions

Getting to know each other: Introducing ourselves

Teenagers and young adults

Parents of teenagers and young adults

FSHD adults

Spouses and partners of FSHD adults

IFSHD parents

Brothers and sisters of FSHD patients

3:30-4:00 p.m. Break

4:00-5:00 p.m. Speaker or panel: Yoga, massage and other relaxation therapies

Dinner on your own

Sunday, July 1

Breakfast on your own

9:00-10:15 a.m. Improving the quality of patient living Speakers: Clinician on best practices and three patients speak about their lives

10:15-10:45 a.m. Break

10:45-noon Improving the quality of patient living continued: Physical therapy and exercise, and Breathing and respiratory health

Noon Lunch (included in registration)

Luncheon panel Psychological, spiritual and social dimensions of FSHD

1:30-2:30 and

3:00-4:00 p.m. Small breakout sessions; Concurrent and repeating

Possible topics

- Caregivers; sharing triumphs and trials
- Maintaining a good diet and good nutrition
- Leisure time and the freedom to travel
- The expert patient: managing dialogue with your physician
- Parents: preparing for the education and work life of your children
- Taking stock of your future in the workplace
- Advocacy and disability rights
- Teenagers: Dating and forming lifelong relationships
- Adults of any age: Dating and finding relationships
- Deciding to have children

4:00 p.m. Meeting concludes

Registration for Network Meeting, lunches Saturday and Sunday, \$190 per adult (with current membership), \$210 nonmembers, \$105 per young adult age 12 – 18 and no charge for children under 12.

Reservations at Atlanta Marriott Marquis; overnight accommodations are available at Atlanta Marriott Marquis. The FSH Society has a special conference rate of at \$109 per night (single or double occupancy), plus taxes. The hotel guarantees 25 accessible rooms, 9 with roll-in showers. For the best selection of accessible rooms and showers, please make your reservations early. The closing date for the Society's block of rooms is Thursday, June 7. For reservations, call (800) 266-9432 or (506) 474-2009, or reserve online at:

https://resweb.passkey.com/Resweb.do?mode=welcoming_ei_new&eventID=6304468

