



## Program

### **2012 FSH Society International Patient and Researcher Network Meeting**

Saturday, June 30 and Sunday, July 1, 2012

**Atlanta Marriott Marquis**

265 Peachtree Center Avenue NE, Atlanta, GA 30303 USA

Dear Friends,

Thank you for joining fellow members of the FSH Society, FSHD patients, and families for the 12th biennial International Patient and Researcher Network Meeting.

We invite you to join in partnership with this community, to learn about advances in treatment and research, and to make new friends.

Sincerely,

William R. Lewis, Sr., M.D.  
Chairman, Board of Directors  
FSH Society, Inc.

# Program of Events

## Friday, June 29, 2012

4:00 pm - 6:00 pm

**Registration**

6:30 pm

**Informal dinner(s), to be arranged (optional)**

## Saturday, June 30

Breakfast on your own

8:00 am

**Registration continues**

9:00 am - noon

**Keynote address and panel discussion**

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

Speaker followed by panel discussion

Noon

**Lunch** (included in registration)

FSH Society Development Committee:

Developing our vision for increasing financial resources

2:00 pm - 3:30 pm

**Concurrent sessions**

**Getting to know each other: Introducing ourselves**

1. Teenagers and young adults
2. Parents of teenagers and young adults
3. FSHD adults
4. Spouses and partners of FSHD adults
5. IFSHD parents
6. Brothers and sisters of FSHD patients

3:30 pm - 4:00 pm

**Break**

4:00 pm - 5:00 pm

**Speaker or panel:**

Yoga, massage & other relaxation therapies

**Dinner on your own**

## Sunday, July 1

Breakfast on your own

9:00 am - 10:15 am

**Improving the quality of patient living**

Speakers: Clinician and three patients speak about their lives

10:15 am - 10:45 am

**Break**

## Program of Events

10:45 am - Noon	<b>Improving the quality of patient living</b> , continued Physical therapy and exercise Breathing and respiratory health
Noon	<b>Lunch</b> (included in registration)
Luncheon Panel	<b>Psychological, spiritual and social dimensions of FSHD</b>
1:30 pm—2:30 pm and 3:00 – 4:00 pm	<b>Possible topics - concurrent &amp; repeating</b> <i>Caregivers: Sharing triumphs and trials</i> <i>Maintaining a good diet and good nutrition</i> <i>Leisure time and the freedom to travel</i> <i>The expert patient: managing dialogue with your physician</i> <i>Parents: preparing for the education and work life of your children</i> <i>Taking stock of your future in the workplace</i> <i>Advocacy and disability rights</i> <i>Teenagers: Dating and forming lifelong relationships</i> <i>Adults of any age: Dating and finding relationships</i> <i>Deciding to have children</i> <i>Increasing philanthropy for FSHD research</i>
4:00 pm	<b>Meeting concludes</b>

*Registration for Network meeting, includes lunches Saturday and Sunday, \$190 per adult (with current FSH Society membership), \$210 non-members, \$105 per young adult age 12-18 and no charge for children under 12. Please register by June 1.*

### **For Reservations at Atlanta Marriott Marquis**

*Overnight accommodations are available at Atlanta Marriott Marquis. The FSH Society has a special conference rate of \$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=welcome\\_ei\\_new&eventID=6304468](https://resweb.passkey.com/Resweb.do?mode=welcome_ei_new&eventID=6304468)