



**2008 FSH Society International Patient and Researcher  
Network Meeting**

Saturday, July 26, 2008 - Monday, July 28, 2008

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Coralville Marriott Hotel & Conference Center

Coralville, Iowa

***Welcome!***

Dear Friend,

Thank you for joining fellow members of the FSH Society, FSHD patients, and families for the 10th 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.

Sponsors of the 2008 Network Conference are:



Dorr Foundation



## Program of Events

### **Saturday, July 26, 2008 - Wallace Room**

4:00-7:00 p.m.            ***Greeting and Reception. Registration***

### **Sunday, July 27, 2008 - Coral Ballrooms A, B, & C**

7:30-8:25 a.m.            ***Registration and Breakfast Buffet***

8:25 a.m.                 ***Welcome***

Daniel Paul Perez, President & CEO, FSH Society  
Nancy Van Zant, Executive Director, FSH Society

#### **I.        *Health Information You Need to Know!***

**8:25-9:55 a.m.**

8:25-8:30 a.m.            ***Welcome***

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

*The William T. "Billy" Michael Memorial Lecture for Research on Infantile FSHD*

8:30-8:55 a.m.            ***Clinical Medicine and Research Advances in Infantile and Adult FSHD***

Katherine Mathews, M.D., Division Head, Child Neurology  
University of Iowa, Department of Neurology, Iowa City, Iowa USA

8:55-9:20 a.m.            ***Advances in Physical Therapy and FSHD***

Wendy M. King, P.T., Assistant Professor, Neurology  
The Ohio State University and the Research Institute at Nationwide  
Children's Hospital, Columbus, Ohio USA

9:20-9:45 a.m.            ***Respiratory Therapy and Issues in FSHD***

Noah Lechtzin, M.D., M.H.S., Assistant Professor, Medicine &  
Neurology, and, Pulmonary Director, Johns Hopkins ALS Center  
Johns Hopkins University School of Medicine, Baltimore, Maryland USA

9:45-9:55 a.m.            ***Break***

#### **II.        *Helping to Solve FSHD!***

**9:55 a.m.-12:30 p.m.**

9:55-10:00 a.m.            ***Reconvene***

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

10:00-10:25 a.m.            ***New Insights in FSHD Research***

Louis M. Kunkel, Ph.D., Professor of Pediatrics and of Genetics at  
Children's Hospital Boston and Harvard Medical School, and Howard  
Hughes Medical Institute Investigator, Children's Hospital, Boston,  
Massachusetts USA

## Program of Events

- 10:25-10:50 a.m.      ***Therapies, Compounds and Strategies to Treat FSHD***  
Kathryn Wagner, M.D., Ph.D., Associate Professor of Neurology and Neuroscience; co-director, John Hopkins MDAUSA Clinic, and; co-director, Johns Hopkins/University of Pennsylvania Senator Paul Wellstone Muscular Dystrophy Cooperative Research Center  
The Johns Hopkins Hospital, Baltimore, Maryland USA
- 10:50-11:15 a.m.      ***Partnering for the Way Forward: NIH Support for Research in FSHD***  
John D. Porter, Ph.D., Executive Secretary, Muscular Dystrophy Coordinating Committee; and Program Director, Neuromuscular Disease Neurogenetics Cluster; and the NINDS Technology Development Program, National Institutes of Neurological Disorders and Stroke NIH NINDS, Bethesda, Maryland USA
- 11:15-11:25 a.m.      ***Break***
- 11:25a.m.-12:30 p.m.      ***Panel/Audience Discussion: Questions and Answers***
- III.      *Lunch***  
**12:30-1:30 p.m.**
- IV.      *Breakout Discussion Groups***  
**1:30-4:15 p.m.**
- 1:30-2:45 p.m.      **First Session: Four Concurrent Workshops**
- Getting to Know You/Taking Care of Ourselves***  
A session to talk with others about FSHD  
Facilitators: Anne Harland and Don Lokerson  
Location: Coral Ballroom D
- Caregivers: Spouses, Significant Others and Family***  
A session to talk to other caregivers  
Facilitators: Judy Lokerson and Henry Walter  
Location: “Duke” Slater Room
- More Q&A with Researchers and Clinicians***  
A session to meet and collaborate with physicians  
Facilitated by Panel Speakers  
Location: Coral Ballroom E
- Teenagers and Young Adults: Networking and Making Plans***  
A session to share experiences and to consider how to take a greater role in the Society.  
Facilitators: Nancy Van Zant and Stephanie O’Meara  
Location: Wood Room

## Program of Events

3:00-4:15 p.m.

### **Second Session: Four Concurrent Workshops**

#### ***Taking Care of Ourselves for Teenagers and Young Adults with FSHD***

A session for patients to talk with each other and with physicians and Researchers about FSHD

Facilitators: Katherine Mathews, M.D.; Carrie Stephan, M.A., R.N.; and Anne Wallace, M.A.

Location: Coral Ballroom D

#### ***Caregivers: Spouses, Significant Others and Family***

A session to talk to other caregivers

Facilitators: John Milne and Henry Walter

Location: "Duke" Slater Room

#### ***More Q&A with Researchers and Clinicians***

A session to meet and collaborate with physicians

Facilitated by Panel Speakers

Location: Coral Ballroom E

#### ***Self-Advocacy and Patient Advocacy***

A session to learn about patient rights and legal issues

Facilitators: Howard Chabner, J.D.

Location: Wallace Room

### **V. Conclusion and Adjournment - Coral Ballrooms A, B, & C**

**4:15-5:00 p.m.**

4:15-4:55 p.m.

#### ***Concluding Remarks***

4:55-5:00 p.m.

#### ***Adjourn***

## Program of Events

### **Monday, July 28, 2008 - Coral Ballrooms A & B**

8:00-10:00 a.m.      *Continental Breakfast at the Coralville Marriott*

8:00 a.m.-5:00 p.m.      *Infantile FSHD Clinic at the University of Iowa Hospitals and Clinic*  
Katherine Mathews, M.D., and Clinic Staff

*Thank you to Dr. Mathews; Carrie Stephan, M.A., R.N.;  
Anne Wallace, M.A.; Christina Trout, R.N.;  
Kris Baldwin, P.T.; Karla Laubenthal, P.T.; other staff,  
and the University of Iowa Hospitals and Clinic for  
providing the clinic.*

*The FSH Society, patients and families are grateful.*

## 2008 Int'l Patient and Researcher Network Meeting

*The FSH Society wishes to thank the 2008 Network Conference Speakers, the 2008 Network Conference Committee and all attendees for their contributions to the success of this meeting.*

*The FSH Society also wishes to thank the sponsors of the 2008 Network Conference:*

*Accelaron Pharma*

*Association Française Contre les Myopathies (AFM)*

*Athena Diagnostics, Inc.*

*Dorr Foundation*

*Genzyme*

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