



Program

Final

2010 FSH Society International Patient and Researcher Network Meeting

Friday, July 30, 2010 - Sunday, August 1, 2010

Paris/Bally's Las Vegas
3645 Las Vegas Blvd South, Las Vegas, NV 89109 USA

Welcome!

Dear Friends,

Thank you for joining fellow members of the FSH Society, FSHD patients, and families for the 11th 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 2010 Meeting are:



Program of Events

Friday, July 30, 2010

11:00 a.m.-5:00 p.m. **Registration**

12:00 p.m. **Conference Opens with Lunch** (Included in registration)

1:15 p.m. **Welcome Address**

Daniel Paul Perez, President & CEO, FSH Society

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

1:45-2:00 p.m. **Break**

2:00-3:30 p.m. **Afternoon Program, Eight Concurrent Group Sessions**

Getting to Know Each Other: Introducing Ourselves

Teenagers and Young Adults

Facilitators: Kevin Bache and Stephanie O'Meara; patients

Location: Bordeaux

Parents of Teenagers and Young Adults

Facilitators: Barbara and Jeff Bache, Lynn O'Meara

Location: Burgundy

FSHD Adults (1)

Facilitators: Duncan Lewis and Ray Jordan; patients

Location: Champagne 3/4

FSHD Adults (2)

Facilitators: Ann Biggs-Williams and Chris Stenmon; patients

Location: Champagne 1

Spouses and Partners (1)

Facilitators: Marc Younger and Beth Johnston

Location: Chablis

Spouses and Partners (2)

Facilitators: Bill Lewis and Ellen Stenmon

Location: Loire

IFSHD Parents

Facilitators: Group Sharing

Location: Champagne 3/4

Brothers and Sisters of FSHD Patients

Facilitator: Fred Thys

Location: Champagne 3/4

Program of Events

3:40-5:00 p.m. *Keynote Address*

Developing Novel Protein Therapeutics for the Treatment of Muscle Wasting Diseases

H.Q. Han, M.D., Ph.D.

Executive Scientific Director, Metabolic Disorders
Amgen, Inc., Thousand Oaks, California

Dinner by prepaid reservation, or on your own

Saturday, July 31, 2010

Breakfast on your own

9:00-10:00 a.m. *Reports from the Clinical Centers & Clinical Advances*

9:00-9:30 a.m. **FSHD, Clinical Trials and Myostatin**

Kathryn Wagner, M.D., Ph.D.

Director, Center for Genetic Muscle Disorders
The Kennedy Krieger Institute, Johns Hopkins School of Medicine,
Baltimore, Maryland

9:30-10:00 a.m. **Advances in FSHD Research and Genetic Testing**

Rabi Tawil, M.D.

Fields Center for FSHD & Neuromuscular Research
University of Rochester Medical Center, Rochester, New York

10:00-10:30 a.m. *Break*

10:30-11:30 a.m. *Clinical Education*

10:30-11:00 a.m. **Breathing and Respiratory Health for People with FSHD**

Joshua O. Benditt, M.D.

Pulmonary and Critical Care Medicine
University of Washington Medical Center, Seattle, Washington

11:00-11:30 a.m. **Scapular Fixation Surgery for People with FSHD**

Leigh Ann Curl, M.D.

Orthopedic Surgery, Sports Medicine, Knee and Shoulder
Harbor Hospital, Baltimore, Maryland

Program of Events

11:30-12:00 p.m. ***Pre-Clinical Education***

FSHD and Stem Cells: Approaching Understanding and Therapy through iPS Adult Stem Cells

Michael Kyba, Ph.D.

Assistant Professor and Lillehei Endowed Scholar
University of Minnesota, Minneapolis, Minnesota

12:00-12:30 p.m. ***Q&A***

12:30-12:45 p.m. ***Lunch*** (Included in registration)

12:30-2:00 p.m. ***Luncheon Program***

Successful Fundraising Initiatives for FSHD Research: You Can Do It, Too!

Presentations by volunteers successful in their communities and among family and friends

Rich Holmes, Cape Cod: Walk 'n' Roll for FSH Muscular Dystrophy

Chris and Ellen Stenmon, Boston: Annual End-of-Tax Season Fundraiser

Judy Seslowe, New York: Festive Evening of Music and Song

Beth Johnston, New York: Family Picnic for FSHD and Silent Auctions

Rod Fulmer, Georgia: Fulmer Family Dinner

2:00-2:30 p.m. ***Break***

2:15 p.m. ***Group Photo Opportunity***, Location: Champagne 3/4

2:30-3:55 p.m. ***Afternoon Program, Seven Concurrent Discussion Groups***
First Session

Caregivers: Sharing Triumphs and Trials

Facilitators: Judy Lokerson and Jim Chin; spouses of patients

Location: Burgundy

The Expert Patient: Managing Dialogue with Your Physician

Facilitators: Don Burke, patient; Dr. Wagner, The Kennedy Krieger Institute

Location: Versailles 3/4

Parents: Preparing for the Education and Work Life of Your Children

Facilitators: Barbara and Jeff Bache, Lynn O'Meara; parents

Location: Bordeaux

FSHD Adult Patients: Sharing the Journey

Facilitators: Jeri Blom and Roman Greene; patients

Location: Chablis

Program of Events

Advocacy and Disability Rights

Facilitators: Howard Chabner, patient

Location: Champagne 1

How to Motivate Young People to Exercise (for teenagers and young adults)

Facilitators: Mallory Murdoch, patient; Dr. McDonald, University of California, Davis

Location: Loire

Dialogue and Q&A with FSHD Researchers

Facilitators: Drs. Emerson, Ehrlich, Harper, Kyba, and Tapscott

Location: Champagne 3/4

4:10-5:30 p.m.

Afternoon Program, Seven Concurrent Discussion Groups Second Session

Caregivers: Sharing Triumphs and Trials

Facilitators: Judy Lokerson and Jim Chin; spouses of patients

Location: Burgundy

The Expert Patient: Managing Dialogue with Your Physician

Facilitators: Barbara Chin, patient; Dr. Tawil, University of Rochester

Location: Versailles 3/4

Maintaining a Good Diet and Good Nutrition

Facilitators: Carol Chandler, Ph.D., USDA Western Human Nutrition Research Center, and Dr. McDonald, University of California, Davis

Location: Bordeaux

Leisure Time and the Freedom to Travel

Facilitators: Howard Chabner, Ray Jordan, and Cyndi Segroves; patients

Location: Champagne 1

Taking Stock of Your Future in the Workplace

Facilitators: Meg Morris-Aabakken and Rich Holmes; patients

Location: Chablis

Dating and Forming Lifelong Relationships (for teenagers and young adults)

Facilitators: Stephanie O'Meara and David Younger, Licensed Psychologist; patients

Location: Loire

Dialogue and Q&A with FSHD Clinicians

Facilitators: Drs. Benditt, Han, and Wagner

Location: Champagne 3/4

Dinner on your own

Program of Events

Sunday, August 1, 2010

Breakfast on your own

9:00-10:20 a.m. ***Reports from Major Research Centers & Research Advances***

FSHD Research at the NIH NICHD BBRI Wellstone MD CRC: Systems Biology and Biomarker Development

Charles P. Emerson, Jr., Ph.D.

Director and Senior Scientist

Boston Biomedical Research Institute,

NIH NICHD BBRI Sen. Paul D. Wellstone Muscular Dystrophy Cooperative Research Center, Watertown, Massachusetts

New Tool to Aid Molecular Diagnosis and New Approaches to Understanding Gene Malfunction in FSHD Muscle

Melanie Ehrlich, Ph.D.

Tulane Medical School, New Orleans, Louisiana

FSHD Mechanistic Models Involving DUX4

Scott Q. Harper, Ph.D.

The Ohio State University and Center for Gene Therapy, The Research Institute at Nationwide Children's Hospital, Columbus, Ohio

Developments in FSHD Transcriptional Research

Stephen J. Tapscott, M.D., Ph.D.

Fred Hutchinson Cancer Research Center, Seattle, Washington

10:20-10:40 a.m. ***Break***

10:40-11:25 a.m. ***Clinical Education, Q&A***

Physical Activity and Exercise: A Physician's and a Patient's Perspectives

Craig M. McDonald, M.D., Ph.D.

RRTC/NMD Director

Rehabilitation Research and Training Center in Neuromuscular Diseases

University of California, Davis, California

Nils Hakansson, Ph.D., patient

11:25 a.m. - 1:00 p.m. ***Lunch*** (Included in registration)

11:35 a.m. ***"Brown Bag" Q&A***

1:00 p.m. ***2010 Meeting Conclusion and Adjournment***

2010 International Patient and Researcher Network Meeting

The FSH Society wishes to thank the sponsors of the 2010 Network Meeting:

Accelaron Pharma

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**NIH NICHD Boston Biomedical Research Institute Sen. Paul D.
Wellstone MD Cooperative Research Center for FSHD Research**

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RideAway

*We also wish to thank this year's presenters and all attendees for their
contributions to success of this meeting.*

***Photography:** Staff and participants will be taking photos during the meetings for use in FSH Society print and electronic publications. If you do not wish a photo of yourself to be used in this manner, please move out of the picture and/or give one of the Society staff a written note with this instruction.*

2010 Meeting Sponsors



Boston Biomedical Research Institute
Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Center for FSHD Research

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