



2010 FSH Society International Patient and Researcher Network Meeting
July 30, 2010 – August 1, 2010
Paris / Bally's Las Vegas
Las Vegas, Nevada

Young Adult and Parent of Young Adult Evaluation

These educational workshops are sponsored by a generous grant from the Dorr Foundation.

If you are a young adult, elementary through college grade level, or a parent in our audience today we ask you to evaluate these programs so we can provide requested feedback to the Dorr Foundation. We are especially interested in learning from you how we may better develop new and innovative science curricula about facioscapulohumeral muscular dystrophy (FSHD) at elementary through college grade levels.

Thank you for your time and assistance.

Daniel Paul Perez
President & CEO
FSH Society, Inc.

Nancy Van Zant
Executive Director
FSH Society, Inc.

Quality of Clinical Education Talks

Rating Scale: 1=Strongly Disagree, 7=Strongly Agree, N/A=Does Not Apply

FSHD, Clinical Trials and Myostatin

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

| | | | | | | | | |
|--|---|---|---|---|---|---|---|-----|
| Stimulated my interest in the subject of clinical trials and therapies | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Encouraged me to ask questions | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Answered my questions well | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |

Advances in FSHD Research and Genetic Testing

Rabi Tawil, M.D.

| | | | | | | | | |
|---|---|---|---|---|---|---|---|-----|
| Stimulated my interest in the subject of FSHD and genetic testing | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Encouraged me to ask questions | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Answered my questions well | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |

Breathing and Respiratory Health for People with FSHD

Joshua O. Benditt, M.D.

| | | | | | | | | |
|---|---|---|---|---|---|---|---|-----|
| Stimulated my interest in the subject of breathing issues in FSHD | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Encouraged me to ask questions | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Answered my questions well | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |

Scapular Fixation Surgery for People with FSHD

Leigh Ann Curl, M.D.

| | | | | | | | | |
|--|---|---|---|---|---|---|---|-----|
| Stimulated my interest in the subject of scapular/shoulder surgery in FSHD | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Encouraged me to ask questions | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Answered my questions well | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |

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

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

| | | | | | | | | |
|---|---|---|---|---|---|---|---|-----|
| Stimulated my interest in the subject of exercise in FSHD | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Encouraged me to ask questions | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Answered my questions well | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |

Clinical Education Talks

If the FSH Society were to develop new and innovative science curricula about FSHD at elementary grade levels through college, could you kindly comment on:

1. What is the primary unanswered question you have as you leave the Clinical Education talks today?
2. What example, teaching technique, presentation or question helped or did not help you? Please say whether it helped or harmed?
3. Can you think of an innovative teaching style, technique or technology that would be helpful in improving your understanding of the topics?

Quality of FSHD Research Advances & Pre-Clinical Education Talks

Rating Scale: 1=Strongly Disagree, 7=Strongly Agree, N/A=Does Not Apply

Developing Novel Protein Therapeutics for the Treatment of Muscle Wasting Diseases

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

| | | | | | | | | |
|---|---|---|---|---|---|---|---|-----|
| Stimulated my interest in the subject of new drugs and treatments | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Encouraged me to ask questions | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Answered my questions well | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |

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

Michael Kyba, Ph.D.

| | | | | | | | | |
|---|---|---|---|---|---|---|---|-----|
| Stimulated my interest in the subject of stem cells and cell therapeutics | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Encouraged me to ask questions | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Answered my questions well | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |

FSHD Systems Biology and Biomarker Development

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

| | | | | | | | | |
|---|---|---|---|---|---|---|---|-----|
| Stimulated my interest in the the subject of systems biology and biomarkers | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Encouraged me to ask questions | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Answered my questions well | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |

Approaches to Understanding Gene Malfunction in FSHD Muscle

Melanie Ehrlich, Ph.D.

| | | | | | | | | |
|--|---|---|---|---|---|---|---|-----|
| Stimulated my interest in genomic/genetic research | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Encouraged me to ask questions | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Answered my questions well | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |

FSHD mechanistic models involving DUX4

Scott Q. Harper, Ph.D.

| | | | | | | | | |
|--|---|---|---|---|---|---|---|-----|
| Stimulated my interest in molecular biology and FSHD gene research | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Encouraged me to ask questions | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Answered my questions well | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |

Developments in FSHD Transcriptional Research

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

| | | | | | | | | |
|--|---|---|---|---|---|---|---|-----|
| Stimulated my interest in RNA and DNA transcription research | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Encouraged me to ask questions | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |
| Answered my questions well | 1 | 2 | 3 | 4 | 5 | 6 | 7 | n/a |

