



***** UPDATE *****

Our 1st Annual Fields Center Patient Day was a Rousing Success!
September 19, 2008

The Fields Center thanks the many patients and members of the scientific community that joined us for a fun and productive day discussing issues in the clinical care of people with FSHD and the current state of research. There was a lot to talk about! One of the things people found most beneficial was the chance to talk with other people with FSHD in an informal setting!

We asked for confidential feedback from our attendees, asking for their thoughts about the day. We are proud to announce the following results:

- ✓ **100% of the attendees indicated that they would come back to attend a future Patient Day with us! WOW!**
- ✓ Results on individual questions included:
 - o The topics presented were interesting and relevant to me.
Strongly Agree
 - o Rate the quality of the speakers:
 - Rabi Tawil, MD - **Excellent**
 - Silvere van der Maarel, PhD - **Excellent**
 - Shree Pandya, MS, PT - **Excellent**
 - Chad Heatwole, MD - **Excellent**
 - Ask the Experts - Round Table Discussion - **Excellent**
 - o What did you like most about this conference?
 - Information sharing. (Note, this comment was echoed by many people!)
 - That the meeting was informal (also echoed by many people).
 - Meeting those researching FSH. Optimism of program.
 - Open question and answer. Interacting with others with FSH.

- The clean and concise presentations by all of the speakers and learning about new prospects on the horizon.
- The fact that there was a diversity of topics covered.
- The information and the friendliness of others.
- Amount of information presented on the topic of FSHD that I did not know previously.
- It ran on time and even early for those of us with long drives.
- Opportunity to meet other people and discuss problems.
- Hearing others' symptoms and comparing.
- The mix of attendees who were willing to share personal situations.

Thank you to all that attended! We hope you all will join us for our 2nd Annual Patient Day in the Fall of 2009. Watch our website for details!

Electronic Signature

Rabi Tawil, MD
Director of the Fields Center

Electronic Signature

Silvere van der Maarel, PhD
Co-Director of the Fields Center