

**FSHD CONNECT****The FSH Society's Biennial International Network Meeting for FSHD Patients, Clinicians and Researchers**

Saturday-Sunday, August 16-17, 2014

The Westin Boston Waterfront, 425 Summer Street, Boston MA 02210

AGENDA**Friday, August 15**

- 4:00 – 6:00 pm Registration
- 5:00-6:00 pm Visit to Prof. Hugh Herr's Biomechatronics Lab at MIT (space limited, by reservation)
- 6:30 – 9:00 pm Informal reception. Gather at a bar at hotel.

Saturday, August 16

- 8:00 am Registration opens. Breakfast on own.
- 8:45 -9:00 am Welcome and Keynote.
- 9:00 am -10:00 am Research Summit Part 1
- Silvère Van der Maarel, Leiden University Medical Center. "Genetics of FSHD."
 - Yi-Wen Chen, National Children's Hospital. "A multicenter collaborative study on infantile onset facioscapulohumeral muscular dystrophy."
 - Peter Jones, University of Massachusetts Medical School. "Genetically similar, epigenetically different: Insights into FSHD from studying discordant families"
 - Louis Kunkel, Children's Hospital of Boston. "Modeling FSHD in Zebrafish for Therapy Development."
- 10:00-10:40 am Panel discussion and Q&A
- 10:40-11:10 am Break
- 11:10-11:55 am Research Summit Part 2
- Stephen Tapscott, Fred Hutchinson Cancer Research Center. "A consensus model for FSHD identifies opportunities for therapy."
 - Michael Kyba, University of Minnesota. "Discovering and testing therapeutics."
 - Alexandra Belayew, University of Mons. "Several ways to go DUX hunting."
- 11:55 am-12:30 pm Panel discussion and Q&A
- 12:30 pm – 2:00 pm Lunch (included in registration)
Advocacy and awareness – The Selfie campaign and beyond.
- 2:00 – 5:00 pm Main hall: exhibitors and clinical center tables
Science corner

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| 2:00 – 3:00 pm | <p>Concurrent Patient-led Breakout Sessions – Living with FSHD</p> <ul style="list-style-type: none"> • Parents of children with FSHD (Facilitator: Ray Huml) • Navigating teenage life and transitioning into adulthood (Facilitators: Ben Brittain & Carden Wyckoff) • Living with constant change (Facilitator: Daniel Perez) • Traveling with FSHD (Facilitators: Cyndi Segroves & Ray Jordan) • Navigating FSHD in relationships for adults (Facilitator: Hilary Michels) • Fundraising and events (Facilitators: Amy Bekier, Ellen Hannan, Beth Johnston) |
| 3:00 – 3:30 pm | Break |
| 3:30– 4:30 pm | <p>Repeat of Breakout Sessions – Living with FSHD</p> <ul style="list-style-type: none"> • Parents of children with FSHD (Facilitator: Ray Huml) • Navigating teenage life and transitioning into adulthood (Facilitators: Ben Brittain & Carden Wyckoff) • Living with constant change (Facilitator: Daniel Perez) • Traveling with FSHD (Facilitators: Cyndi Segroves & Ray Jordan) • Navigating FSHD in relationships for adults (Facilitator: Hilary Michels) • Fundraising and events (Facilitators: Amy Bekier, Ellen Hannan, Beth Johnston) |
| 5:00 – 6:00 pm | <p>Workshops</p> <ul style="list-style-type: none"> • Hands-on Workshop: Mindfulness in managing pain and stress • FSHD Science Journal Club |
| 6:00 pm | <p>Adjourn for the day. Dinner on your own. Sign-up sheets. Special-interest socials (have patients suggest and organize in advance)</p> |
| Sunday, August 17 | |
| 8:00 am | Registration opens. Breakfast on your own. |
| 9:00 -9:05 am | Day 2 welcome and introduction |
| 9:05 am – 10:05 am | <p>Medical Summit Part 1</p> <ul style="list-style-type: none"> • Jeff Statland, University of Rochester. “Opening the clinical trial toolbox.” • Sabrina Sacconi, Nice University Hospital. “Advances in the care of FSHD.” • Kathryn Wagner, Kennedy Krieger Institute. “Animal models and progress towards clinical trials.” • Baziel Van Engelen, Radboud University Nijmegen Medical Center. “Reducing chronic fatigue through exercise and cognitive behavioral therapy.” |
| 10:05-10:30 am | Panel discussion and Q&A |
| 10:30 – 11:00 am | Break |
| 11:00-11:45 am | <p>Medical Summit Part 2</p> <ul style="list-style-type: none"> • Shree Pandya, University of Rochester. “Update on physical therapy and exercise recommendations.” • Kofi Boahene, Johns Hopkins University Medical School. “Surgical and nonsurgical options for facial reanimation in FSHD.” • Ray Huml, Quintiles. Clinical trial readiness and the patients’ roles today. |

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| 11:45 – 12:15 pm | Panel discussion and Q&A |
| 12:15 pm – 1:00 pm | “Reverse Q&A” – Doctors and scientists ask patients questions. |
| 1:00 pm – 2:00 pm | Lunch (included in registration) FSH Society Development Committee: Brainstorming on creative fundraising |
| 2:00 – 5:00 pm | Main hall: Exhibitors and clinical center tables Science corner |
| 2:00 – 3:00 pm | Concurrent Breakout sessions: <ul style="list-style-type: none">• Exercise and athletics (Facilitator: Kristin Duquette)• Nutrition 101 (Facilitator: Sabrina Sacconi. MD)• Genetics – to test or not to test? Families, family planning and beyond (Facilitators: Carol Hoffman, PhD, MS, LGC; Carol Birnbaum MD)• Navigating FSHD in relationships for teens and young adults (Facilitator: Hillary Michel)• Caregiving (Facilitator: Beth Johnston)• Dress and Fashion (Facilitator: Kristina McMullin) |
| 3:00 – 3:30 pm | Break |
| 3:30 – 4:30 pm | Concurrent Breakout sessions (repeat of earlier except for Navigating Relationships): <ul style="list-style-type: none">• Exercise and athletics (Facilitator: Kristin Duquette)• Nutrition 101 (Facilitator: Sabrina Sacconi. MD)• Genetics – to test or not to test? Families, family planning and beyond (Facilitators: Carol Hoffman, PhD, MS, LGC; Carol Birnbaum MD)• Navigating FSHD in relationships for teens and young adults (Facilitator: Hillary Michel)• Caregiving (Facilitator: Beth Johnston)• Dress and Fashion (Facilitator: Kristina McMullin) |
| 4:30 – 5:00 pm | Finale. Assessments, feedback and farewell. |

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