



Mid-Atlantic FSHD Family Day Conference

Johns Hopkins University, Charles Commons, Salons B & C
10 E. 33rd Street, Baltimore, Maryland
Sunday, September 30, 2018, 12:00 pm to 6:00 pm

Preliminary Agenda

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| Noon—12:50 pm | FSHD Family Day Conference luncheon (incl. w registration) and self-introductions |
| 12:50 – 1:00 pm | Welcome
Manuel Gomez, Mid-Atlantic chapter director, and Mark Stone, CEO, FSH Society |
| 1:00 – 1:30 pm | Living with FSHD
Kathryn Wagner, MD PhD, director, Center for Genetic Muscle Disorders, Kennedy Krieger Institute |
| 1:30 – 2:00 pm | FSHD genetic testing and counseling
Julie Cohen, MS, genetic counselor, Kennedy Krieger Institute |
| 2:00 – 2:30 pm | Physical therapy, exercise, orthotics and mobility aids
Nikia Stinson and Andrea Jaworek, physical therapists, KKI |
| 2:30 – 3:00 pm | Break |
| 3:00 – 3:30 pm | What whole-body MRI tells us about FSHD
Doris Leung, MD PhD, Johns Hopkins School of Medicine |
| 3:30 – 3:45 pm | The drug development pipeline for FSHD
Highlights from the 2018 FSHD Connect conference (video) |
| 3:45 – 4:15 pm | Clinical research in FSHD
Kathryn Wagner, MD PhD |
| 4:15 – 5:00 pm | Activating the Mid-Atlantic community (panel)
Manuel Gomez, June Kinoshita, and other Mid-Atlantic chapter members |
| 5:00 – 6:00 pm | Social Hour |