My Personal Journey and Career With FSHD

Presenter
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My Childhood

Sports, year round
- Traveling Soccer Team for the City of Livermore, CA
- Basketball and Baseball

My Adolescence

Family moved to Illinois where my father had received a position at the University

Played Varsity Soccer and Basketball in High School

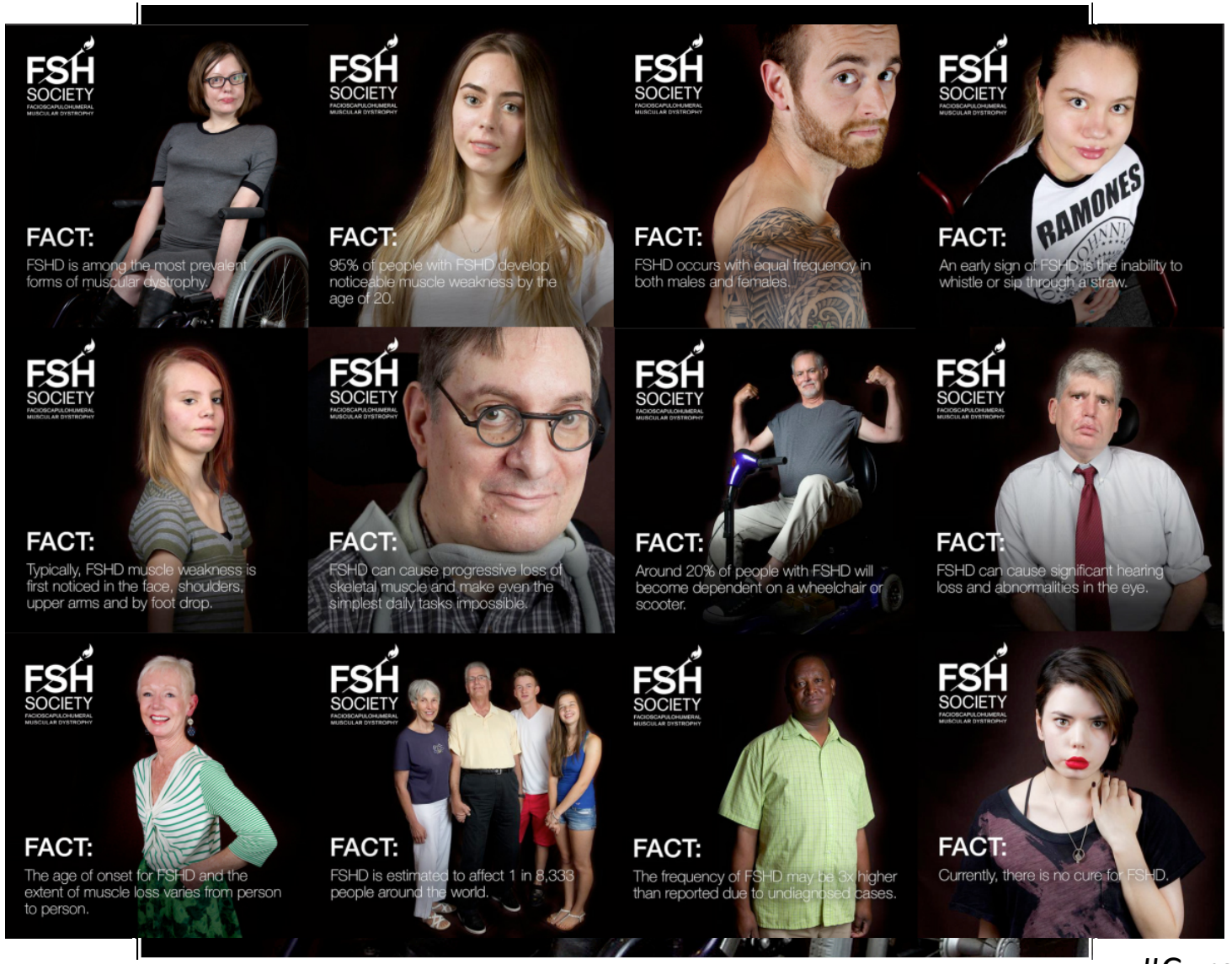
Was accepted as a student of electrical engineering at the University of Illinois
- Weight Lifting
- Scapular weakness

I was diagnosed with FacioScapuloHumeral Muscular Dystrophy (FSHD) at the age of 20.
- Relatively unknown disease
- Looking Back at the signs

The Signs that I had FSHD

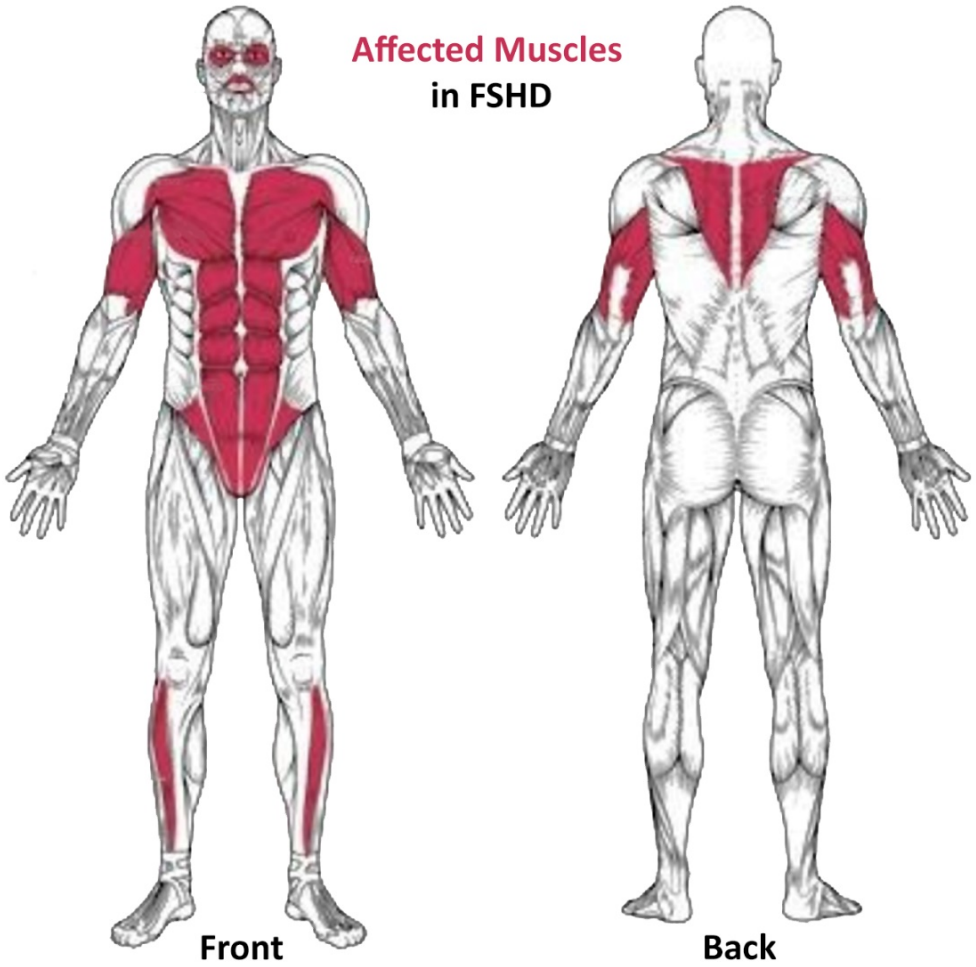
- Congenital absence of the Pectoralis major
- Inability to complete a sit-up at the age of 13
- Loss of speed and jumping height beginning at age 15
- Extreme hamstring weakness at age 18
- Massive scapular winging during weight lifting at age 19
- Difficulty walking up stairs at age 27
- Difficulty getting up from seats at age 29
- Difficulty walking up slopes at age 32
- Difficulty walking period at age 36

Facioscapulohumeral Muscular Dystrophy

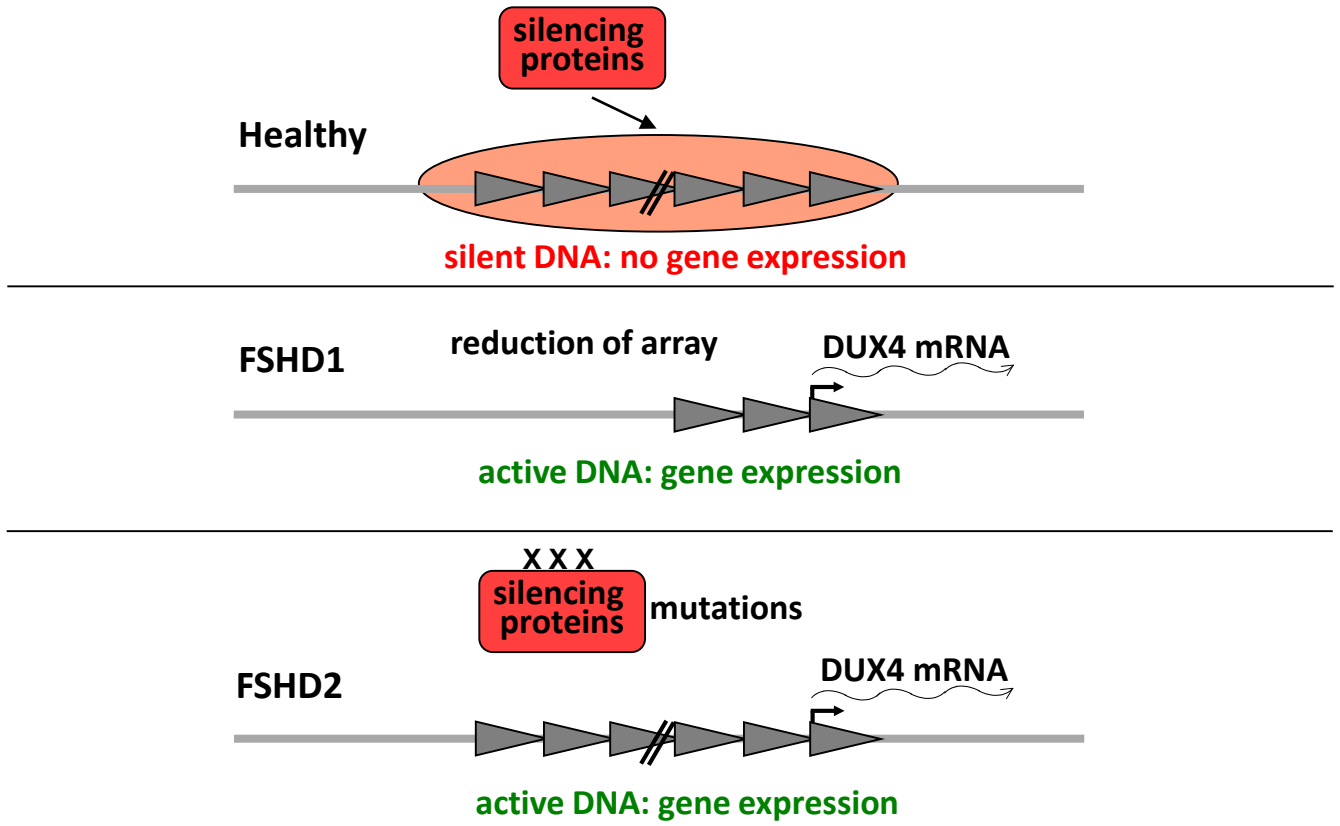


#CureFSHD

FacioScapuloHumeral Dystrophy (FSHD)



FSHD is caused by misexpression of the DUX4 gene in skeletal muscle



DUX4 Expression is Highly Toxic to Most Human Cells!

My Career Choices After the FSHD Diagnosis

- I switched career trajectories towards Chemistry/Biology and away from Electrical Engineering.

- In Graduate School, I approached a newly arrived Professor from NIH by the name of Dr. Peter Jones (now UNR Mick Hitchcock, PhD Endowed Chair in Medical Biochemistry) about working in his lab and studying FSHD.

- As a post-doctoral fellow, I transitioned to Dr. Dean Burkin's lab in the Pharmacology department of the UNR school of medicine to learn about the drug development process and develop treatments for the muscular dystrophies.

- In 2013, Dr. Burkin and I began a company called StrykaGen in order to help transition the Integrin enhancing therapeutics we have developed towards the clinic.

2018 UNR Synapse Article details part of this story

FSHD affect on my role as a UNR Research Associate Professor of Pharmacology

Research (affected)

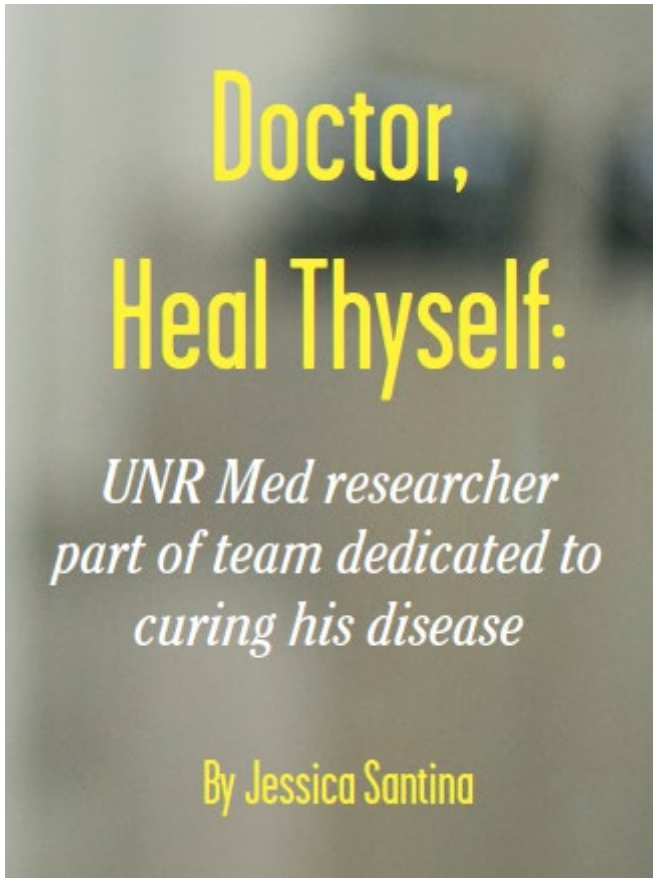
- My physical abilities are declining and thus I am able to do less direct research than I previously could.
- I now have an expanded role in experimental planning and design, data analysis, certain types of data collection.

Grants (Unaffected)

- Like many researchers, I spend a lot of time trying to procure funding.

Publications (Unaffected)

- 4 publications (1 first author) this year.



Synapse Spring/Summer 2018

I am currently finishing a study assessing one of our muscle regenerating therapeutics in a new FSHD mouse model developed by Dr. Peter Jones.

My Perspective on FSHD Patients and Career Opportunities

~46% of FSHD patients between 18-65 are working

Careers requiring any physical activities should be avoided
- This could even include low exertion activities

Competition with non-FSHD patients

Most FSHD patients I have met are in White collar jobs (MD, Lawyers, Accountants, Professors)

My Future Career Goal

To become a Tenured Professor studying cures for muscular dystrophies.

FSHD may make this more difficult than normal.
- High amount of research is expected of junior PI
- Funding is dependent on productivity