

**Oral Testimony of Daniel Paul Perez, President & CEO of the FSH Society
Before the Subcommittee on Labor, Health and Human Services, Education and Related
Agencies on the Subject of FY2008 Appropriations for National Institutes of Health (NIH)
Research on FSH Muscular Dystrophy (FSHD)
March 27, 2007**

Mr. Chairman, thank you.

14 years ago, I walked into this room to testify. Today, I appear before you in a wheelchair.

I am here to remind you that facioscapulohumeral muscular dystrophy (FSHD) is still taking its toll on your citizens. FSHD is the second most common dystrophy, a crippling disease causing loss of all skeletal muscle, and it affects at least 20,000 Americans.

The genetic structure of FSH muscular dystrophy is unprecedented and demands attention.

Today, I ask you for three things.

One.

Please resume the five year doubling of the NIH budget. Appropriate \$32.8 billion as required in the NIH Health Reform Act 2006. At minimum, appropriate the 6.7% annual increase to restore funding. Only America has the ability to solve FSHD. Only NIH can do this. The question is -- does America have the will? Small non-profits such as the FSH Society can not shoulder the burden year after year for new research funding. This is what NIH is designed to do. Congress needs to fund it.

Two.

Tell the Director of NIH to make the Dystrophy Research Action plan viable. The MD CARE ACT authorization needs an appropriation with it. The NIH portion requires \$100 million and \$250 million over the next five years. Tell the Director that the "Pioneer" and "Roadmap" programs have taken funding away from peoples' diseases. Tell the Director to spend the "Common Fund" on research that will have a direct effect on patients' lives.

Three.

\$1.7 million for FSHD research does not cut it. It is absolutely clear, that individuals with FSHD have suffered greatly due to NIH's failure to act. Funding for dystrophy research is not equitable. The funding for FSHD is abysmal. FSHD research and its novel mechanism will help solve other diseases such as cancer, autism and diabetes. Tell the Director to assign \$20 million for FSHD research.

Congress has asked NIH many times for a comprehensive portfolio on FSHD. I have served for six years on the Muscular Dystrophy Coordinating Committee. I have done everything that the Administration and NIH has asked of me. I implore you to ask the Director, why, after all this time and effort, only one of twelve NIH institutes covering dystrophy has funded grants for FSHD?

You know, I know and the American public knows that we have fallen behind when it comes to health care and biomedical research.

We are waiting.

While we wait, our quality of life diminishes.

Research must be funded and hope rekindled.

I ask you to fund NIH, fund muscular dystrophy, fund FSHD.

Thank you. I will answer any questions.