

## **FSH Society**

### **Position Announcement**

#### **Chief Executive Officer**

FSH Society (Society) is the world's largest grassroots network of facioscapulohumeral muscular dystrophy (FSHD) patients, families and research activists. Based in Lexington, Massachusetts near Boston, the Society is seeking a committed, experienced leader to serve as Chief Executive Officer (CEO). The CEO will lead the Society in meeting its important mission: *to serve as a source of information and support for all patients and families with FSHD; to act as a driving force in the development of research directed towards treatment and cure of FSHD; and to act to bring support to patients and research for FSHD through effective engagement of governmental and private sector organizations and entities.*

#### **The Organization**

FSHD is known to have been around for five centuries in some families and was first described medically in 1885. A genetic disorder that leads to weakening of skeletal muscles, symptoms typically begin in early teenage years with the loss of muscles in the face, shoulders, upper arms, legs or core. FSHD strikes an estimated 1 in 8,000 individuals, or 870,000 people worldwide, of all races and ethnicities. Around 20 percent of patients will need a wheelchair by age 50, and over 70 percent experience debilitating pain and fatigue. There is no effective treatment or cure – but there is hope. In the not too distant past, average time to diagnosis was 11 years, but this is rapidly changing. There is now a genetic test for FSHD, and time to diagnosis has decreased.

The Society has four strategic imperatives:

- **Advance:** Act as a driving force in the development of research directed toward treatment and a cure for FSHD.
- **Empower:** Mobilize patients and communities to take action.
- **Connect and Communicate:** Serve as the leading source of information and support for all patients and families with FSHD.
- **Finance:** Grow and diversify revenues to invest in research, education, patient support, and operational capacity.

FSH Society recently celebrated its 25<sup>th</sup> anniversary. Founded in 1991 by two researchers with the disease, the Society is a world leader in combating muscular dystrophy. The Society relies entirely on private grants, donations and grassroots philanthropy and has raised and invested over \$7 million in research relevant to understanding the molecular genetics and cause of FSHD. The Society organizes an annual symposium for researchers worldwide, patient network meetings, support group meetings, and peer-support. It helped write the MD-CARE Act of 2001 which led to the creation of the National Institutes of Health (NIH)-funded Wellstone Centers for FSHD research. Importantly, the Society is here so that no patient need ever face this disease alone. The Society's vision is to deliver treatments and a cure for FSHD.

The Society has an annual budget of \$2.5 million with a goal of increasing expeditiously to a \$5 million budget. In addition to an engaged national Board of Directors with 20 members, the Society enjoys the support of a distinguished Scientific Advisory Board and a celebrity Honorary Board. The staff consists of 6 employees including Founder Daniel Perez who will transition from the Society's CEO to the newly-created role of Chief Scientific Officer. He will retain responsibility for the Society's science and research programs including representing the Society at the NIH and before Congress as well as coordinating the efforts of the Scientific Advisory Board (in collaboration with the CEO). The Society is planning for a new era of drug development and clinical trials and will increase its impact scientifically while broadening its ability to serve patient, families and clinicians. Please see [www.fshsociety.org](http://www.fshsociety.org).

## **The Position**

The CEO will report to the five-member Executive Committee which represents the full Board of Directors and will have day-to-day responsibility for the Society's fiscal, operations, fundraising, marketing, human resource, technology and programmatic strategies.

## **Key Responsibilities**

### Strategic vision and leadership

- Be an external local and national presence who promotes and represents the Society;
- Refine and implement the strategic plan while ensuring that the budget, staff and priorities are aligned with the vision and mission;
- Provide inspirational leadership and direction to all team members; ensure the continued development and management of a professional and efficient organization;
- Continue to help build a highly-engaged Board; actively engage and energize the Society's volunteers, partnering organizations, and funders.

### Development and communications

- Ensure a flow of funds that permits the Society to make continuous progress;
- Formulate and execute comprehensive marketing, fundraising and development strategies, increasing revenue from major donors, foundations, government agencies and corporations;
- Ensure ongoing local and national programmatic excellence and increasing program impact;
- Managing and handling external communications;
- Responsible for overseeing and maintaining major donor cultivation and relationships.

### Operations

- Create and promote a positive work environment; facilitate and strengthen internal communications;
- Oversee the financial status, developing long and short-range financial plans, setting financial priorities, creating and monitoring the budget, and ensuring sound internal controls are in place;
- Encourage staff and volunteer development and education, and assist program staff in relating their specialized work to the total program of the organization.

## **Qualifications**

- Minimum of a BA, ideally with an MBA, MPA or related advanced degree;
- The equivalent of at least 10 years of overall professional experience;
- Prior nonprofit experience ideal; demonstrated experience in managing a small organization preferred;
- Significant board development, fundraising, marketing/branding and fiscal management a must;
- Financially savvy and politically astute leader with the ability to set clear priorities, delegate, and guide investment in people and systems;
- Keen analytic, organization and problem solving skills which support and enable sound decision making;
- Outstanding presentation skills and the experience and proclivity to be an outgoing spokesperson, relationship builder, and fundraiser;
- A proven ability to be hands-on and effectively and efficiently handle multiple, simultaneous, and complex tasks and projects;
- Strong written and verbal communication skills; a persuasive and passionate communicator with excellent interpersonal and multidisciplinary project skills;
- Strong commitment to the professional development of staff; successful track record of recruiting and retaining a high-performing team.

## **To apply:**

Please send resume and cover letter to Susan Egmont, Egmont Associates, at [segmont@egmontassociates.com](mailto:segmont@egmontassociates.com).