

ASPEN • LEADERSHIP • GROUP

**DIRECTOR OF DEVELOPMENT
THE FSH SOCIETY**
Lexington, Massachusetts
www.fshsociety.org



The Aspen Leadership Group is proud to partner with the FSH Society in the search for a Director of Development.

The FSH Society is a world leader in combating muscular dystrophy. The FSH Society's Vision is to deliver treatments and a cure for facioscapulohumeral (FSH) muscular dystrophy. It has provided over \$6.97 million in seed grants for pioneering FSHD research projects, recruited a world-class Scientific Advisory Board (SAB), created an international collaborative network of patients and researchers, and been at the forefront of advocacy for muscular dystrophy research, including before the U.S. Congress and the National Institutes of Health. The Society serves as an essential educational resource for patients, families, caregivers, and the public. The Society relies entirely on private grants, donations, and grassroots philanthropy.

The FSH Society, a dynamic and growing patient-driven medical 501(c)(3) nonprofit, seeks a Director of Development that will design and implement the organization's fundraising and development programs. The Director of Development will report to the Executive Director, and will also work closely with the Board of Directors and volunteers throughout the United States.

Founded in 1991, FSH Society's mission is to be the premier catalyst for connecting all the stakeholders by promoting research focused on FSHD through thought leadership, networking, and funding. The Society does this by concentrating on four strategic Imperatives: 1) Empower: mobilize patients and communities to take action; 2) Connect and Communicate: serve as the leading source of information and support for all patients and families with FSHD; 3) Finance: grow and diversify revenues to invest in research, education, patient support, and operational capacity; and 4) Knowledge: act as a driving force in the development of research directed toward treatment and a cure of FSHD.

The Society has doubled its revenue in the past five years from \$1.2 million to approximately \$2.3 million and the goal is to grow 15% percent per year. The FSH Society has earned Charity Navigator's highest 4-star rating for its eighth consecutive year. The new Director of Development will have the opportunity to help the FSH Society achieve significant growth in revenue and thereby fund more research and deliver a greater impact for the research and patient communities. During the past five years major progress has been made in understanding the cause of FSHD. Many of these groundbreaking projects have been supported by the Society, and many of the researchers have been supported by the Society at various stages of their careers. FSHD research is at the point where basic findings are supporting translational research. The next stage will require significantly increased financial resources. Clinical trials will require recruiting volunteers with FSHD.

REPORTING RELATIONSHIPS

The Director of Development will report to the Executive Director, June Kinoshita.

PRINCIPAL OPPORTUNITIES

This is an excellent opportunity for a development professional who is seeking to make a significant impact on an organization that is poised for growth, is creative, efficient, and effective in its approach, and enthusiastically committed to the cause.

Given recent advances, the pace of discovery, and number of experts in the field of biological science and clinical medicine working on FSHD are rapidly expanding. Many leading experts and biotechnology companies are now turning to work on FSHD not only because it is one of the most complicated and challenging problems seen in science, but because it represents the potential for great discoveries, insights into stem cells and transcriptional processes, and new ways of treating multiple human diseases. New prevalence data from multiple sources ranks FSHD as the most prevalent form of muscular dystrophy. With this increased awareness, better diagnosis and improvements in genetic testing, a substantial growth is expected and desired in our patient support/education programs.

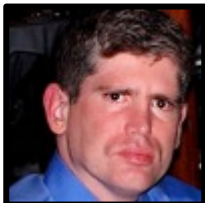
The Society has built mutually rewarding long-term relationships with large and small donors - individuals, families, foundations, and industry. Building on these relationships, and developing new ones, the Director of Development will design and implement a fundraising program that includes identifying, cultivating, soliciting, and stewarding prospects utilizing new technologies and new ideas as well as traditional approaches.

PRIMARY RESPONSIBILITIES

With broad latitude for independent judgment, and in coordination with the Executive Director and the Board of Directors, the Director of Development will:

- create and execute a fundraising plan to include annual giving, major gifts (\$50,000 plus), corporate and foundation relations including sponsorships, government agencies, event planning and stewardship;
- focus on major gift opportunities by strengthening existing relationships and identifying new potential donors;
- match funding opportunities with prospective donors;
- oversee the prospect management database, with information related to donor strategies, contacts, and results;
- develop strategy, draft and submit grant applications;
- manage processes to include membership and gift acknowledgements; and
- help manage and support Board and volunteer fundraising events.

KEY COLLEAGUES



Daniel Paul Perez

President & CEO and Co-founder

Daniel Paul Perez is one of the nation's leading advocates and experts on living with facioscapulohumeral muscular dystrophy (FSHD), FSHD molecular and genetics research, and clinical aspects of the disease. Daniel established the Society in 1987 after meeting

fellow FSHD patient and Society co-founder, Stephen Jacobsen. Daniel developed the by-laws of the Society, incorporated the organization as a nonprofit corporation, and organized the Board of Directors and the Scientific Advisory Board.

He has testified more than 50 times before congressional committees to seek funding for FSHD research and meets regularly with researchers, clinicians, and the heads of the National Institutes of Health and other federal agencies to help organize meetings, symposia, research plans, white papers, and research on dystrophy. In 2001, Daniel was a key architect and force in the passage and implementation of the Muscular Dystrophy Community Assistance, Research, and Education Amendments of 2001 (“MD-CARE Act”), which was signed into law on December 18, 2001. The MD-CARE Act mandates the National Institutes of Health (NIH) and other federal agencies working on FSHD and other muscular dystrophies to rapidly accelerate research and efforts on these diseases. He serves as a Special Government Employee and member of the 18-member Federal Advisory Committee authorized by the MD-CARE Act, called the Muscular Dystrophy Coordinating Committee (MDCC).

A graduate of Harvard College, Daniel started his career in neurobiology and muscle research as an undergraduate. He has an extensive background in software and database design, and works on corporate MIS and financial systems, marketing research software, and data acquisition. He was chief architect and designer of Oracle’s multi-dimensional database application. Daniel’s expertise in data warehousing and databases led to his contributions in bio-informatics and databases for the Human Genome Project in Massachusetts. He also worked as a senior database specialist on software designed for monitoring clinical drug trials.

Daniel and his wife Sue live in Bedford, Massachusetts.



June Kinoshita
Executive Director

June Kinoshita graduated from Harvard College, where she concentrated in physics. She joined the FSH Society in August of 2012. Previously, June co-founded and served as Executive Editor of the Alzheimer Research Forum, the pre-eminent Web community for researchers in neurodegenerative disorders. June has worked closely with a variety of foundations to develop initiatives for multiple sclerosis, schizophrenia, amyotrophic lateral sclerosis, Parkinson’s disease, and other disorders. She is also an entrepreneur, having co-founded N-of-One, Inc., a pioneering personalized oncology company.

June serves on the National Board of the BrightFocus Foundation. June began her career as a science journalist, working as a writer and editor for *Scientific American*, *Science*, *The New York Times Magazine*, and many other national publications. June and her husband Tod Machover live in Waltham, MA, where they tend to teenagers, cats, goats, and chickens. She enjoys music of all genres, from opera to *American Idol*.



William R. Lewis Sr., MD
Chairman, Board of Directors

William R. Lewis has been a member of the Board of Directors since 1991 and Chairman since 2006. As a neurological surgeon with more than four decades of experience—and the husband and father of FSHD patients—Dr. Lewis brings his medical expertise and compelling personal interest to his role as Chairman. He is also a member of the FSH Society Scientific Advisory Board.

Dr. Lewis attended Phillips Academy and received undergraduate degrees from the University of North Carolina and the University of South Carolina. He earned his doctorate of medicine from Duke University Medical Center and completed his residency at Stanford University.

Dr. Lewis enjoys gardening, spending time with his grandchildren, handiwork, and reading medical journals and other educational materials. He is still practicing neurological surgery on a limited basis in California, where he currently resides with his wife Duncan Lewis; they have four children and eight grandchildren.

CANDIDATE QUALIFICATIONS AND QUALITIES

The ideal candidate for the position of Director of Development will have:

- professional fundraising experience with a track record of successful major gift and corporate/foundation solicitations in nonprofit organizations, patient advocacy, university, healthcare, or scientific setting;
- a track record of success in individual gift fundraising, preferably in disease research, medical research or health care, and experience in cultivating and soliciting prospects capable of gifts of \$100,000 or more;
- an understanding of public funding resources (NIH), private philanthropy, and familiarity with disease research (strongly preferred);
- knowledge of medical nonprofit organizations, scientific programs, and the biomedical field (strongly preferred);
- an ability to effectively engage and collaborate with board members, donors, peers, and associates, leading in a way that embodies respect, teamwork, and collaboration;
- an ability to persuasively and passionately represent the Society to funders, patients, families, and other stakeholders;
- superb oral, written, and interpersonal skills;
- proficiency in the use of social media;
- highly developed organizational skills, be detail-oriented, self-motivated with high standards for accuracy and efficiency, and a strong work ethic;
- strong computer skills including Microsoft Office Word & Excel and Internet research capabilities
- personal belief in mission, goals, and objectives of disease research;
- integrity, motivation, and sophistication;
- passion and commitment to going out and getting gifts; ability to close gifts;
- a respectful, kind disposition; and
- enthusiasm, flexibility, adaptability, a sense of humor, and resilience.

A BA/BS degree is required for this position and an advanced degree is highly desirable. Candidates with five or more years of development experience including major gifts experience will be given preference.

SALARY & BENEFITS

The FSH Society offers a competitive benefits and compensation package.

LOCATION

This position is located in the town of Lexington, Massachusetts, 11 miles northwest of Boston and east of Concord, within 2 hours' driving distance of Cape Cod and the beaches of New Hampshire, Maine, Rhode Island, and Connecticut. First settled in 1642, the town has grown to encompass 16.64 square miles with a population of approximately 30,000. Lexington is a community that prides itself on the beauty of town land, the safety of its residents, and the excellence of its public school system. Numerous parks, conservation lands, museums, and libraries provide exceptional opportunities for recreational and cultural activities.

APPLICATION DEADLINE

Before uploading your résumé and cover letter, please read them over for accuracy. Review of applications will begin immediately and continue until the successful candidate has been selected.

To nominate a candidate, contact Shelley Semmler: shelleysemmler@aspenleadershipgroup.com.

All inquiries will be held in confidence.