



THE STURGE-WEBER FOUNDATION

Career Opportunity - Research Director

The Sturge-Weber Foundation (SWF) is dedicated to finding a cure for Sturge-Weber syndrome (SWS) and capillary malformations (CM's/Birthmarks) while improving the lives of those affected. The SWF is uniquely qualified to rally the financial resources, the research, the partnerships, and the sheer will of SWS-affected families and individuals to generate an impact and improve quality of life for this "curious" disease. With an annual budget of \$800,000, we focus our resources on research as well as information and advocacy to individuals and families living with SWS and CM's.

Throughout our history, the SWF has served as a catalyst – first with bringing affected individuals and families together for support and knowledge, second with the discovery of the first SWS gene while collaborating on studies into the genetic pathway, and third in bringing together the research community for research conferences that have led to the interest in and launching of initial clinical trials taking place today. There are currently 26 SWS clinics across the nation who applied to the SWF to be recognized as a multi-disciplinary practice. In 2012, the SWF in partnership with members of the research and scientific community developed the SWS Natural History Database. Today, more than 600 individuals have been entered retrospectively and prospectively.

A new Research Director (RD) position is opened to lead the scientific and clinical programs of the SWF; serves as the primary contact with industry, academic institutions, government agencies, and key research donors to further the mission of the organization; engages scientists and clinicians in basic, translational and clinical science to advance new treatments and ultimately a cure for SWS/CM's; works with the current SWS Network of clinics to reach measurable milestones to ensure the success of the SWS Natural History database; collaborates with SWS clinics to ensure the quality of care for individuals with SWS/CM's.

The Research Director, in collaboration with the CEO and Science and Medical Committee, will review prior goals and achievements and develop a strategic business plan aimed at growth and advancements in new diagnostics, devices and therapeutics for SWS and associated disorders (e.g. glaucoma, epilepsy). This plan will include a model to expand the clinical research network internationally. This expansion will provide infrastructure for future clinical trials; interface with pharmaceutical, diagnostic, device and biotech companies to help streamline drug discovery, diagnostic, device and development process with innovative technology; structure for negotiated collaborative agreements for technology transfer; and incorporate revenue streams to support these new initiatives.

The RD position is crucial for the success of both the SWF mission and our established goals:

The SWF will continue momentum in building organizational and community capacity to:

- Drive and accelerate basic, clinical and translational research.
- Increase the number of identified individuals with SWS to fuel future research and provide information and advocacy to a larger number of individuals with SWS/CM's.
- Promote greater involvement with and within the SWF community.
- Strengthen base of financial support for SWF research from private and public sources.

ORGANIZATIONAL STRUCTURE AND INTERFACES

Reports to:	Chief Executive Officer
Primary Interfaces (internal):	CEO, Controller, COO, Director of Marketing and Communications, Director of Community Engagement
Primary Interfaces (external):	Board of Directors, scientists and clinicians, government agencies, academic institutions, pharmaceutical, diagnostic, device and biotech companies, donors, corporate partners, vendors, volunteers, individuals with SWS and their families/caregivers

ACTIVITIES AND ADVOCACY REPORTS:

Science and Medical staff

- SWS Natural History Database
- Volunteer committee advisors Chief Scientific Officer (CSO), Chief Clinical Strategist (CCO), Director of Pathology Strategies (DPS)
- Activities of the Governance Committee of the SWF Board of Directors.
- Advocacy initiatives of the Education/Government Relations Committee of the SWF Board of Directors.

PRIMARY DUTIES AND RESPONSIBILITIES:

Clinical

- Coordinate the creation and review of educational materials, working with the SWF Clinical Care Network (CCN) and SWF International Research Network (SWFIRN) Advisory Boards.
- Communicate with SWS Clinics/Clinicians and coordinate annual review of SWS clinics.
- Coordinate activities to inform patients about participation in research studies and organize accession of tissue samples by appropriate tissue banks.

Scientific

- Coordinate and oversee all aspects of the SWF Research Grants Program and Courage Fund Awards, including RFP process, scientific review, grant review summaries, and oversight of progress reports and all related administrative functions.
- Attend major scientific meetings relevant to SWS/CM's and issue reports of relevant presentations, to be made available to scientific and lay communities and supply a summary report.
- Act as staff liaison for the CCN/SWFIRN advisory boards and coordinate recruitment efforts and guidelines for membership.

New Therapeutic, Diagnostic and Device Initiatives

- Develop strategic business plan with CEO/COO aimed at getting new SWS/CM's therapeutics and diagnostics to market.
- Lead effort in the identification and validation of biomarkers that predict phenotypes, disease progression and severity, and response to therapy in SWS.
- Interface with pharmaceutical, diagnostic, devices and biotech companies to help streamline drug discovery and development process with innovative technology.
- Seek ongoing support for therapeutic diagnostics and device pipeline through established relationships with industry, venture capital, major donors or governmental grants.

Other

- Prepare an annual "Roots in Research" white paper report on SWS/CM research for the membership and research donors that integrates information from published literature, scientific meetings, and SWS-specific meetings summarizing current state of knowledge in the field.
- Responsible for developing the Research budget.
- Identify and submit grant proposals to fund all or parts of the SWF science and research program and participate in additional fund development activities as assigned.
- Other duties as assigned.

CORE VALUES:

Build Value-Based Relationships: Generating alliances internally and externally by continuously identifying and acting on those things that will create success for the organization and its constituents, researchers, health care professionals and communities.

Contribute to Team Success: Actively participating as a committed member of a team and working with other team members to help complete goals and deliverables.

Customer Focus: Making customers (external and internal) and their needs a primary focus of one's actions; developing and sustaining productive relationships; creating and executing plans and solutions in collaboration with team members internally and externally.

Provide Feedback: Objectively observing, analyzing, and sharing perception of other people's performance to help reinforce or redirect behavior to improve performance and results and providing feedback that is timely, specific, behavioral, balanced, and constructive.

Work Standards: Setting high standards of performance for self; assuming responsibility and accountability for successfully completing assignments or tasks; self-imposing standards of excellence rather than having standards imposed.

Consult: Providing timely, specific information, guidance, and recommendations to help volunteers, Community Alliances, and fellow staff members make informed committed decisions that will lead to sustainable impact.

Establish Collaborative Working Relationships: Developing and using collaborative relationships to accomplish work objectives; developing relationships with other individuals by listening, sharing ideas, and appreciating others' efforts.

Successful completion of the projects noted in the success factors above requires cooperation with our staff team, board, volunteers, donors and key corporate and foundation partners. Quickly establish working relationships to complete projects as scheduled above.

QUALIFICATIONS:

- PhD in a science-related field and/or MD required.
- Strategic business planning and execution of milestone driven plan
- Experience in collaborating with industry to accelerate drug discovery, diagnostics and devices, negotiating agreements, and technology transfer a plus
- Previous experience in developing clinical trial protocols is desirable.
- Excellent oral and written communication skills as well as organizational skills.
- Must be comfortable with public speaking.
- Experience translating and communicating complex scientific and medical information in lay terms to educate all constituencies of the organization.
- Previous experience in scientific grant writing and administration.
- Participation in scientific grant review programs with knowledge of the peer review process. Experience with grants administration within multiple institutions is desirable.
- Ability to network within the patient and scientific community.
- Willingness to travel as well as able to work a flexible schedule, including evenings and weekends.
- Previous non-profit experience preferred but not required.
- Traditional and remote office considered.

Salary commensurate with experience. Please contact Brian J Fisher, Chief Operating Officer, bfisher@sturge-weber.org, 973-895-4445.



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