

## Scleroderma Research Foundation Executive Director

***The leading nonprofit funder of scleroderma research in the US seeks an experienced fundraiser and marketer to drive new philanthropic support for groundbreaking research conducted by the world's top scientists and medical institutions.***

The Scleroderma Research Foundation (SRF) is the nation's largest non-profit investor in scleroderma research. Its mission is to find, fund and facilitate the most promising research that will result in improved therapies and ultimately a cure for patients. It was founded in 1987 by patient Sharon Monsky, who believed that funding medical research was the best way to give hope to those living with the disease by bringing the best of science and technology together in an effort to discover better treatments and a cure. The SRF has raised over \$47M and is internationally recognized as a leader and catalyst for innovation and excellence in scleroderma research.

The [SRF](#) seeks to deepen knowledge and understanding of this life-threatening condition by facilitating research and collaboration among the world's top scientists and medical institutions. One of the deadliest of all rheumatic disorders, scleroderma is chronic, complex and debilitating. It begins as an autoimmune attack and eventually causes devastating fibrosis or vascular damage. Women are disproportionately affected by scleroderma, with approximately 80% of patients being female; however, anyone can develop scleroderma. Due to its rarity (approximately 1/4000 Americans), many healthcare professionals outside of academic centers have little experience in recognizing its symptoms and confirming diagnosis. Scientists are working to understand what biological factors contribute to scleroderma pathogenesis and a number of studies suggest that a combination of genetic and environmental factors may trigger the disease. There are treatments available to address the various complications associated with scleroderma, but there is no cure. One of the goals of SRF is to bring greater awareness to the public and educate healthcare professionals. The SRF has made approximately \$24.5M in direct research grants and it also dedicates significant effort and funding to other research related activities. The research side of the organization is driven by the Board with input from SRF's Scientific Advisory Board (SAB) which comprises some of the world's most distinguished scientists who guide the Foundation's research program, evaluate proposals, and make funding recommendations.

The SRF recently launched CONQUER, a national, multi-center, longitudinal patient registry and biosample repository that will enable sophisticated studies ranging from genetics to biomarkers, and will transform the understanding of scleroderma. Currently enrolling from 12 major academic institutions in the US, the consortium will expand in 2019 and future years to approximately 25 sites. The SRF is the lead sponsor and founding partner of the registry and secures outside sources of funding and other technological capabilities.

The SRF is at an inflection point. The organization wants to grow its funding capacity in order to fund additional research, educational initiatives, further develop CONQUER and other SRF registries, create meaningful engagement with the patient community, and shine a light on its projects. It is imagined that the Executive Director's role will provide a thoughtful, directed approach for:

- Building a well-functioning nonprofit organization that includes recruiting, leading and inspiring a team of development, marketing and event professionals; instituting nonprofit best practices; and developing a strategic plan to increase the prominence of SRF's impact and set a course for increasing contributed revenue.
- Developing new sources of contributed revenue and strategies for cultivating new donors. SRF's signature fundraising and awareness-building event, *Cool Comedy Hot Cuisine* (CCHC) is a 30-year tradition hosted by board member Bob Saget with exceptional cuisine prepared

by Bravo Top Chef Masters Susan Feniger, also an SRF board member, and Mary Sue Milliken. The event is a significant revenue generator for the SRF and has raised more than \$21M to support scleroderma research and introduced millions of people to the disease and the incredible work of SRF. The SRF seeks to enhance its revenue from CCHC, plus significantly diversify its sources of revenue.

- Consistent, informative communications that bring awareness of the SRF's role and work particularly to reach donors and patients; and encourages patient participation and community building (SRF does not provide services or support to patients);

This position has elements of major giving, foundation and corporate relations, peer-to-peer fundraising, planned giving, community outreach and community building as well as collaborations with various SRF supporters. The ED will be adept at collaborating and communicating with diverse personalities and subject matter experts.

Headquartered in San Francisco, the SRF has an operating budget of approximately \$3M and currently a staff of five. SRF is governed by a nine-member board of directors.

## **RESPONSIBILITIES**

The Executive Director will have the following major responsibilities:

- Provide leadership for day-to-day operations: staff recruitment, management and development, administration, finance, HR. Establish priorities, workflows, and metrics for success. Ensure clarity around ED's priorities with Board Chair and Board President so there is accountability and timeliness for important deadlines and decisions.
- Work with the Board to develop a plan to maximize contributed revenue of Cool Comedy-Hot Cuisine, and other smaller-scale special events. Provide energetic and proactive leadership to ensure events are stellar, and that there is appropriate follow-up and stewardship of attendees.
- Develop and lead a development strategy for increasing and diversifying contributed revenue. Create a broad base of philanthropic support by cultivating and soliciting major gifts and developing a value proposition for non-scientific donors; position board members to solicit major donations and funding for specific projects; inject energy into Cure Crew Program (peer-to-peer) and develop recognition programs; shape planned and designated giving programs; identify business donors that may align to SRF's mission.
- Ensure the new website and all communications are delivered to engage the non-scientific community in ways they can grasp, connect with and support. On an ongoing basis, effectively develop and disseminate the mission, brand, story and program successes and research participation opportunities through the website, press, SRF and external publications, and social media.
- Develop content and programs to grow the loyalty and interest of the community of scleroderma patients, families and caregivers that will educate, create community, and, in turn, inspire support of the SRF and its program.
- Develop schedules and agendas for 2-3 in-person board meetings per year, plus additional board calls; present updates on current state of the organization, fundraising activities, financial position, challenges affecting growth of SRF, and potential solutions.
- Partner with and support the Board Chairman and the Development & Nominating Committee to achieve goals relating to Board expansion and development.

## **IDEAL EXPERIENCE & CHARACTERISTICS**

The Executive Director should have the following types of experience and qualifications:

- Demonstrated skills in motivating, directing and managing staff, colleagues and consultants, and in coordinating and supporting the business or fundraising activities of others. Excellent project management abilities.
- Working in an entrepreneurial environment and building an organization; understanding and communicating the appropriate roles of the board vis-à-vis the staff; knowledge of nonprofit best practices.
- A fundraising strategist; understanding of the dynamics of fundraising for scientific, technical, medical, public policy or academic endeavors; a hands-on fundraiser with a track record for significantly strengthening an organization.
- The ability to represent SRF to a wide variety of individuals and groups, both internally and externally; ability to communicate effectively both in writing and verbally, including excellent public speaking skills for both formal and extemporaneous presentations; adept at writing proposals, solicitation letters, donor/investor correspondence, and other kinds of material for publication.
- A keen interest in medical research and the potential for research to improve the lives of patients.
- A high E.Q.; comfortable interacting with patients and their families.
- An excellent listener and an outstanding communicator; comfortable receiving input from many sources, and able to analyze and formulate disparate information into a sound, well-organized plan.
- A person who knows how to collaborate and coordinate, someone that understands how to manage up and down, and who shares information easily and avoids ego games.
- Intrepid yet tactful; determined yet respectful of others' concerns and areas of expertise; someone with the flexibility and creativity needed to find alternative ways to reach funding objectives when barriers arise; a skilled negotiator who does not drive themselves or others into a corner.
- A leader and a hard worker with a high energy level; a "doer" with a willingness to work hands-on in developing and executing a variety of development and marketing activities.
- Emotionally mature with a very good sense of humor and the flexibility and sensitivity to work with diverse personalities and situations.

For more information please contact:

Lisa Grossman  
(650) 323-3565 or [lisag@moppenheim.com](mailto:lisag@moppenheim.com)

Mark Oppenheim  
(415) 283-3256 or [marko@moppenheim.com](mailto:marko@moppenheim.com)

**m/Oppenheim Associates**  
221 Main Street, Suite 540  
San Francisco, CA 94105

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