



Executive Director – Job Description

Organization: Spinal CSF Leak Foundation

Job Title: Executive Director

Location: Remote

Employment Type: Full-time (30-40 hours per week)

Salary: Competitive and commensurate with experience

Reports To: Board of Directors

ORGANIZATIONAL OVERVIEW

Founded in 2014, the Spinal CSF Leak Foundation is a 501(c)(3) nonprofit dedicated to advancing research, supporting patients and families, and raising awareness for spinal CSF leak. As a small mission-driven nonprofit, the Spinal CSF Leak Foundation is seeking an experienced and passionate leader to serve as its next Executive Director. This pivotal role in leadership offers a unique opportunity to measurably contribute to an organization committed to positively impacting the lives of anyone affected by spinal CSF leak.

JOB SUMMARY

The Executive Director (the 'ED') works in partnership with the Spinal CSF Leak Foundation (the 'Foundation')'s Board of Directors (the 'Board'), serving as the public face of the organization, managing its day-to-day operations including strategic planning and leadership, conducting administrative activities, managing and implementing critical programming including fundraising, while engaging with valued stakeholders in the spinal CSF leak community. The ED will work to elevate the needs of those affected by the condition through ongoing programming priorities, including annual conferences, the international patient registry, awareness events, and content shared on public channels. Working closely with Board, the ED will support the sustainability and growth of the Spinal CSF Leak Foundation, further research, and continue to enrich engagement with all stakeholders of the spinal CSF leak community.

The Spinal CSF Leak Foundation has a virtual office, and the ED role is a remote position. Travel is occasionally required to attend certain essential programming events such as conferences and/or symposia (approximately 1-2x per year), as prioritized by the Foundation. The ED reports to the Board, acts as a liaison with valued stakeholders, and oversees volunteers and any Foundation staff or vendors.

RESPONSIBILITIES

Strategic Leadership and Vision

- Collaborate with the Board to develop and implement a strategic plan that supports mission driven growth, financial health, and programming impact.
- Serve as the face and voice of the Foundation, championing its mission to stakeholders, including patients, families, physicians, researchers, and donors.
- Attend meetings, conferences, and review literature to maintain current knowledge of the considerations, research, and people influencing the field.
- Analyze all organizational activity to provide informed feedback the Board members need to sufficiently meet their fiduciary responsibilities to the Foundation, including identifying issues and policies that require action from the Board.

- Support the Board through transparent communication, frequent collaboration, and activities that promote member development.
- Coordinate with the President of the Board to schedule and plan virtual quarterly meetings, as well as hold additional special meetings as needed to support organizational integrity and mission centered activities.
- Cultivate and maintain ongoing relationships with the Medical Advisory Board (the 'MAB') in support of the Foundation's mission.

Operational Management and Administrative Tasks

- Collaborate with the Board to develop and implement annual budgets, operational policies, processes, programs, and operational framework of the Foundation, keeping up-to-date existing handbooks and policies as required by law and guided by best practices.
- Oversee financial management, including via coordination with the Foundation's accountant and the Treasurer, to ensure funds are used effectively to advance the Foundation's mission, and that accounting systems meet all federal, state, and local compliance standards and requirements.
- Monitor and manage revenue and expense transactions, including properly posting all transactions within QuickBooks, collecting and filing all appropriate documentation, and reviewing financial statements with the accountant and presenting them to the Board for their review.
- Ensure compliance with all 501(c)(3) and state-level charitable registration requirements, including coordination with the Foundation's outside compliance agent.
- Manage administrative tasks associated with day-to-day operations, including incoming mail.
- Create a stylized annual report that summarizes the top programming notes and accomplishments of the prior year, as well as annual financial statements.
- Manage, train, and retain staff and volunteers who contribute to programming, projects, and fundraising activities, fostering a collaborative and supportive environment as needed to support the mission.
- Ensure that the Foundation is in adherence to all policies and procedures put in place by the Board, maintain careful and accurate recordkeeping, and perform other duties as directed and prioritized by the Board.

Fundraising and Development

- Design and execute a comprehensive fundraising plan to support current and future projects, including grants, individual donations, corporate partnerships, and events.
- Cultivate and maintain relationships with donors, sponsors, and grant-making organizations, ensuring effective stewardship and ongoing engagement.
- Actively identify and develop new sources for revenue such as new donors, encouraging recurring donations, planned giving, and grant opportunities.
- Use the Foundation's Constituent Relationship Management ('CRM') database of donor information and keep the database current as required for accounting and recordkeeping, including technical integrations and generating ongoing reports.

Programming and Community Engagement

- Ensure that all programming is consistent with the Foundation's strategic plan and mission of the organization, and act as a liaison between stakeholders and the Foundation, ensuring open communication and alignment with the spinal CSF leak community's needs.
- In coordination with the Board, plan and manage fundraising and awareness events including annual events such as leakweek and, duradash®, fundraising activities, and other events supporting the Foundation's mission.
- Provide point support for ongoing projects, including the Foundation's international patient registry and serving on the planning committee for the Bridging the Gap Conference.
- Facilitate ongoing communication with the MAB and provide support to its initiatives, including grant award tasks, planning and setting the meeting agenda with the MAB chair, attending, and taking minutes for quarterly MAB meetings, and handling the appointments and reappointments of MAB members and documentation thereof.

- Work closely with the Board and the MAB to create and/or update informational and educational content for social media, the Foundation’s email newsletter, and its website, and ensure that all content is accurate and up-to-date.

Communications and Outreach

- Represent and advance the image and goals of the Foundation in public forums, including with media, and at conferences and community events, raising awareness and advancing advocacy goals.
- Engage with stakeholders—including patients, physicians, other healthcare providers, and policymakers—on complex issues, demonstrating a deep understanding of the condition and its impact.
- Plan, develop, schedule, and share spinal CSF leak awareness programming content, coordinating with volunteers, staff or the Board as needed.
- Take the lead in social media planning and create a social media calendar following nonprofit best practices for timing, frequency, and mission-centered content, to keep the Foundation’s audience engaged. Coordinate deliverables with volunteers, staff, and the Board who help manage the social media channels.
- Draft and send a newsletter sharing updates, announcements, and/or other content pertinent to the spinal CSF leak community with regular frequency that engages stakeholders.

QUALIFICATIONS AND SKILLS

- Minimum of 5 to 10 years in an executive management role within a nonprofit organization, preferably within the rare disease community.
- Demonstrated experience in fundraising and donor development.
- Bachelor’s degree required; advanced degree in nonprofit management, healthcare, or related field preferred.
- Excellent communication skills, both oral and written, and comfortable with public speaking. The candidate may be asked to provide samples of written communications as part of the interview process.
- Strong interpersonal skills, with the ability to listen and collaborate with diverse stakeholders, while navigating sensitive topics and conveying complex information-
- Strong time management and organizational skills, with a keen attention to detail and an ability to manage multiple projects and deadlines.
- Competence in administrative and accounting activities including budget creation, financial forecasting, and reporting for nonprofit operations.
- Sufficient understanding of spinal CSF leak to communicate effectively with patients, families, physicians and researchers, or the willingness to quickly learn. If unfamiliar with the condition, motivated to learn about spinal CSF leak, including ongoing and emerging research and development in the field.
- Commitment to transparency and team-oriented communication including close collaboration with the Board.
- Proficiency in programs such as WordPress, QuickBooks, Excel, Bloomerang, Canva, QGiv, and Box.
- Familiarity with managing social media channels (e.g. Instagram, Facebook, X, Bluesky).
- Has a deep commitment to improving the lives of individuals and families affected by spinal CSF leak.

This role is ideal for a strategic, compassionate, and proactive leader who is committed to advancing the mission of the Spinal CSF Leak Foundation and supporting patients and families impacted by spinal CSF leak.

HOW TO APPLY

Please submit your resume/CV and a cover letter as a PDF to admin@spinalcsfleak.org with the subject line “[Full first & last name] – Executive Director Position”.