

The Williams Syndrome Association

Location: Virtual; manages 6 staff

Position Profile: **Executive Director**

Summary

The Williams Syndrome Association (WSA) seeks a dynamic and visionary Executive Director to build on the WSA's 40-year history as the leading resource for individuals with Williams syndrome and their families while leading this vibrant and close-knit organization through its next exciting stage of growth.

Williams syndrome (WS) is a rare, spontaneously occurring genetic syndrome that causes medical and learning challenges. WS occurs in 1 in 10,000 births without regard to sex, race, or other factors. The WSA is the most comprehensive resource in the United States for approximately 30,000 people and families living with Williams syndrome as well as for doctors, researchers, and educators. The organization provides resources and referrals, funds research, and offers a range of programming and lifetime community support for individuals with WS, their families, and the professionals who serve them. The WSA is based in suburban Detroit, but this position may be remote anywhere in the United States. With an annual operating budget in the \$1.2M range and a paid staff of six, the organization is seeking a new Executive Director to succeed retiring Executive Director Terry Monkaba, who has led the organization for the past 25 years.

Organizational Values & Structure

The mission of the Williams Syndrome Association is *to advance the interests of all individuals with Williams syndrome throughout their lifespan by providing programming and resources, supporting research, promoting partnerships and connections, and ensuring that the infrastructure of the organization has the capacity to lead our community toward its goals.*

The WSA implements the mission by:

- Providing information and community support to individuals with Williams syndrome, their families, and the professionals who work with them
- Developing programs and services to help build strengths and meet challenges from early childhood through adulthood
- Encouraging and funding research that benefits a wide range of issues related to Williams syndrome, including a [Nationwide Clinical Consortium and Research Network](#) to further advance research and treatment opportunities.

The WSA envisions that all individuals with Williams syndrome should have the support they need throughout their lifespan to live healthy, self-directed, productive, and meaningful lives-- and that in order to achieve this vision, individuals with Williams syndrome must be meaningfully included in educational, work, and community settings.

Founded by a handful of families in San Diego, CA in 1982, the WSA today is a volunteer-driven 501(c)(3) non-profit organization. The WSA supports nearly 6,000 families of individuals with WS since its inception, leveraging its paid staff with hundreds of volunteers who help organize events and support families in communities nationwide. Volunteers are individuals with Williams syndrome, their family and friends, and the professionals who work with them.

The Association has an operating budget in the \$1.2M range, following a pre-pandemic operating budget of \$1.5 M. The organization is planning for growth back to its pre-pandemic budget and beyond through robust development initiatives and restructured in-person and online events as appropriate post pandemic and for the next phase of the organization.

Position Summary

The Executive Director (ED) is responsible for the successful leadership and management of the Williams Syndrome Association. The ED is a visionary executive who leads efforts with members, affiliates (i.e. partner organizations, advisory groups and other non-profit alliances/groups), volunteers, and other stakeholders to carry out the mission, advance the goals and objectives, and implement the strategic plan of the WSA. The selected candidate will manage the internal operations of the WSA office, including a paid staff of six mostly based in Troy, Michigan, and will serve as the public face of the organization to external stakeholders.^[1]_[SEP]

The ED reports to the Board of Trustees and is supervised primarily by the Board President and collectively by the Board's Executive Committee. All Board members have a personal connection to Williams syndrome, including two trustees with Williams syndrome.^[1]_[SEP]

Position Priorities

The successful candidate will have the opportunity to grow the reach of the WSA, transforming it to serve an increasing number of individuals and families with Williams syndrome. The new leader is expected to address the following strategic priorities:

- **Develop the staff team** by analyzing staff roles and responsibilities, positioning and supporting staff members as appropriate to implement the strategic plan, and spreading leadership across a wider range of staff members. Cultivate a staff culture based on trust, teamwork, transparency, and accountability.
- **Establish a robust and diversified development program** to provide a greater level of philanthropic funding that will help ensure financial stability and scalability, most likely including the hire of a development director.

- **Facilitate a collaborative process with the Board, staff and stakeholders to develop a new strategic plan** for the organization. This plan should include education & awareness, research, support of the Williams syndrome community, and administration and development. The plan should also include specific targets and goals for each function.

Essential Qualifications, Skills and Attributes

- Demonstrated passion for, and commitment to, empowering individuals with disabilities and their families, with a preference for professional or lived experience with WS, rare diseases or developmental disabilities.
- At least seven years of executive level experience as a successful leader at a similar or related nonprofit organization.
- A college degree, preferably in public, nonprofit or business administration or management, or a related field.
- Demonstrated experience managing an organization through a major transition or change in organizational strategy and/or systems development.
- Experience in successfully managing development efforts and/or a fundraising program, including major gift, event and membership fundraising with understanding of current fundraising practices during the pandemic.
- Experience in fostering an environment of mutual accountability and collaboration, healthy work relationships and partnerships, and inclusivity among organizational staff and board in order to maintain a positive and collaborative work environment.
- Strong business management skills, ideally including demonstrated leadership in small nonprofit organizations and working with both volunteer and paid staff.
- High emotional IQ. Excellent people skills; must be empathetic, patient, and kind, and able to tactfully and successfully facilitate difficult conversations.
- Experience in a leadership role helping to guide an organization or department toward a more diverse, equitable and inclusive future.
- Demonstrated experience with remote work.

Job Requirements

- Ability to travel frequently, locally, nationally and/or internationally.
- Must be able to pass a criminal background check.

Compensation

Compensation: \$130,000-\$165,000 depending on experience and geographic location. Benefits include medical insurance coverage, short term and long-term disability insurance, life Insurance, IRA with contributions matched up to 3% of annual salary, and 4 weeks' vacation.

Application Process

The Williams Syndrome Association has retained Jan Glick & Associates, LLC to facilitate this search on their behalf. To apply, interested candidates should e-mail their cover letter and resume to: wsa@janglick.com

E-mail applications with a cover letter are required. The position is open until filled.

The Williams Syndrome Association is an Equal Employment Opportunity (EEO) employer and values diversity and its role in building a more inclusive culture and ultimately a more capable organization. The Williams Syndrome Association embraces diversity and equal opportunity. We are committed to building a team that represents a variety of backgrounds, perspectives, and skills. The more inclusive we are, the better our work will be.