



Job Announcement

The APS Type 1 Foundation Seeks Part-Time Executive Director

Information about the APS Type 1 Foundation

[The APS Type 1 Foundation, Inc.](#) is a 501(c)(3) nonprofit organization whose mission is to raise awareness about APS Type 1, a rare genetic disorder, and to promote and support education and research, with the goal of improving quality of life for patients and caregivers, improving and expanding access to treatment options, shortening time to diagnosis, and ultimately finding a cure. The APS Type 1 Foundation was started by a group of dedicated parents who were determined that their children receive the best care possible and that no one should have to wait for a diagnosis or treatment for APS Type 1. Today, the Foundation is run by an all-volunteer 9-person [board of directors](#), whose members live in California, New Jersey, New York, Ohio, Pennsylvania and Canada.

[APS Type 1](#), also known as APS1 or APECED (short for Autoimmune Polyendocrinopathy Candidiasis Ectodermal Dystrophy), is a rare genetic disorder caused by mutations of the *AIRE* gene. Mutations in the *AIRE* gene lead to multi-organ system autoimmunity. For many years, it was believed that the incidence of APS Type 1 was only one in every 1-2 million people (equating to approximately 160-330 people in the U.S.). Now, we believe that there has been significant under diagnosis, and that there may be up to approximately 3,000 people in the U.S. living with this disorder, and countless more around the globe. As a Foundation, our informal membership consists of approximately 150 families, so there is still a long way to go to find and serve our community. As a Foundation, we have:

- Funded [research grants](#) totaling over \$500,000
- Hosted 5 [international symposia](#) on APS Type 1 (which are held in odd numbered years)
- Organized 1 research summit with the next summit occurring in June 2024 in San Francisco (which are held in even numbered years)
- Built our [own natural history registry](#) (which has approximately 100 patients enrolled)
- Designed a resource-rich [website](#) for patients, families, researchers, and clinicians
- Fundraised to support this critical work

The APS Type 1 Foundation is searching for an experienced and passionate high-achiever to make a real difference in the APS Type 1 community. The organization has been a critical driver in supporting patients and families and in supporting breakthrough research, which has transformed the care and treatment. Over the last decade, we have worked tirelessly to build a community of patients, caregivers, friends, family, donors, researchers and clinicians to support the Foundation's mission. Today, we are at a critical juncture. To continue the Foundation's mission-driven work, we need to find an Executive Director with experience in the non-profit sector to lead us forward and to expand on past accomplishments.

The successful candidate will lead a growing nonprofit as it transitions to a more mature and sustainable organization. A supportive Board of Directors (BOD) and Medical Advisory Committee (MAC) are ready to help develop and implement a 5-year strategic plan. The successful candidate will work remotely and will have the opportunity to influence the future for this Foundation and the community it serves. We hope you will consider taking this journey with us.



Responsibilities

In collaboration with the Foundation's BOD and MAC, the Executive Director's responsibilities include the following:

Leadership and Strategic Planning

- Take primary responsibility for the Foundation's financial well-being, stability, capacity, and strategic growth.
- Lead in the creation of a comprehensive 5-year strategic plan.
- Ensure that organizational plans are well-developed, feasible, and follow the strategic direction.
- Collaborate with the BOD, the MAC, expanded scientific community, patients and other stakeholders.
- Build a volunteer recruitment plan that identifies individuals whose expertise would help fulfill the Foundation's mission and objectives.
- Be the Foundation's visible ambassador to community stakeholders.
- Maintain and cultivate trust and partnerships with leaders representing diverse experiences, backgrounds, and perspectives to advance the Foundation's goals.

Fundraising and Finance

- Develop and implement a successful fundraising strategy to secure financial support for the Foundation.
- Engage in appropriate funding opportunities, including major gifts, corporate sponsorships, grant submissions, online giving, and special events.
- Identify grant opportunities for operational support and programming initiatives, and facilitate grant application submissions.
- Ensure that organizational systems are in place for effective donor acquisition and donor stewardship programs.
- Ensure that existing and new development initiatives, campaigns, events, and outreach programs engage our existing donors, attract new donors and encourage our community to be involved.
- Direct the development of annual budget and work closely with the BOD to ensure financially sound practices.
- Prepare and present to the BOD monthly and annual financial statements.
- Evaluate and ensure the financial viability of existing and new initiatives under consideration by the Foundation.

Management, Operations and Communications

- Provide overall leadership and management to the Foundation.
- Provide administrative support to BOD and committee meetings.
- Develop clear action plans and timelines and allocate time resources to achieve Foundation objectives.
- Clearly communicate goals and responsibilities to ensure continuous improvement in performance.
- Implement a communications and social networking plan to advance brand identity, build awareness of Foundation initiatives, support fundraising efforts, and increase visibility across key stakeholder audiences.
- Manage website, including uploading posts, developing and maintaining integrity of website content and structure, monitoring and reporting key metrics, and replying to inquiries sent via email and web forms.
- Manage email communication with key stakeholders, including quarterly newsletters and fundraising appeals.
- Ensure compliance with non-profit best practices.



Qualifications and Skills

The ideal Executive Director candidate will have a successful track record in the nonprofit sector or other fields with transferrable skills, including the skills listed below. Experience in the rare disease community is a plus.

- Strong marketing, public relations, and fundraising experience with the ability to engage a wide range of stakeholders.
- Excellent communication (verbal and written) with the ability to inspire donors and others.
- Ability to collaborate, connect and leave a good impression with diverse groups of people.
- Action-oriented, entrepreneurial, adaptable, and self-directed.
- Proven track record of managing people and teams, managing budgets, and achieving goals.
- Strong project management skills.
- Ability to use necessary computing tools and social media platforms independently.
- Personable and empathetic when dealing with patients, family members, donors, and board members.
- Adherence to and respect for the privacy of our community members.

Work Schedule

- This position is fully remote and virtual in nature
- Part Time – approximately 20-30 hours/week
- Salary – based on experience
- Benefits – open for discussion
- Occasional travel to conferences

Next Steps

We are excited to take this big step forward for the Foundation and hope to find the right person to join us by Spring 2024. We look forward to connecting with you. Please e-mail your resume, cover letter and contact information for two references to todd.talarico@apstype1.org.

The Foundation is an equal opportunity employer and considers all qualified applicants without regard to race, color, religion, creed, national origin, ancestry, sex, age, sexual orientation, gender identity or expression, marital status, veteran's status, disability or any factor prohibited by federal, state or local law.