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EXECUTIVE POSITION PROFILE

ORGANIZATION

Yaya Foundation for 4H Leukodystrophy

POSITION

Executive Director

APPLICATION DEADLINE

Applications will be accepted until 9:00pm on Friday, September 30th, 2022 with review of candidates beginning immediately.

We encourage and appreciate early applications.



ORGANIZATIONAL OVERVIEW

The Yaya Foundation is driven by the dream that one day, every person with 4H Leukodystrophy will have the chance to live a long, healthy life.

The Yaya Foundation fights for these people and their families by acting as a catalyst and a connector—bringing researchers together to accelerate the pace of discovery, while connecting families with vital educational resources, expert care, and emotional support.

APPROACH + PROGRAMS

Acceleration of Therapy Discovery: They are working to speed progress toward therapies and a cure through an ambitious research strategy, including the mobilization of the best and brightest researchers through the 4H Leukodystrophy Collaborative Research Network (#4HLCN), an actionable Data Collection Program, and grants funding the most promising, cutting edge projects.

Education and Emotional Support for Families: With the Yaya Foundation, no one has to face 4H Leukodystrophy alone. They are with you every step of the way with reliable information, valuable resources and emotional support from others who understand.



PURPOSE and HISTORY

Founded in 2018, The Yaya Foundation for 4H Leukodystrophy is a global rare disease patient organization. Our mission is to fight for patients and families affected by 4H Leukodystrophy (4HL) by accelerating discovery of therapies and providing educational and emotional support to affected families.

The Foundation was created by a group of ambitious, action-oriented parents with a shared frustration that no organization existed to fight specifically for their children impacted by 4HL.

Today, Yaya Foundation has grown to become a million dollar nonprofit and is [the only organization in the world](#) advocating on behalf of people affected by 4HL. We serve an international community from our headquarters in Minneapolis, Minnesota.

WHAT IS 4H LEUKODYSTROPHY?

4HL is a rare genetic neurological disease that gets progressively worse over time, largely affects children, and generally results in loss of life. Today, when a child is diagnosed with 4HL, their doctors tell their parents that there are no therapies available and that “there is nothing we can do.” We envision a world in which children affected by 4HL have therapeutic alternatives available to them that slow, stop, or reverse disease progression and improve and lengthen their lives.

IMPACT & SERVICES

The Yaya Foundation believes in open science, relentless collaboration, and inclusion, diversity and equity that enables the most talented scientists to advance their ideas regardless of race, religion, nationality, or other characteristics to develop therapies that are available to patients no matter who they are or where they live.

Recent Yaya Foundation activities include the following:

- **Conference.** Yaya Foundation hosted its first Virtual Care and Disease Management Day in April 2022, bringing together families, clinicians, and researchers to share their insight and perspective on 4HL.
- **Patient Registry.** We launched an innovative data collection program in collaboration with RARE-X and the Broad Institute of MIT and Harvard to collect patient data that is critical to accelerating diagnosis, understanding, and therapy discovery.
- **Family Calls.** We established an ongoing series of family support and education calls on a wide variety of topics, including caring for an individual with 4HL, self-care techniques, and much more.
- **Family Resources.** We produced an educational guide for newly-diagnosed families as well as a suite of resources for affected families and clinicians who treat individuals with 4HL.
- **Research.** We convened and funded the 4HL Collaboration Network, a cross-disciplinary team of researchers, to develop animal models and a gene therapy treatment that could meaningfully change outcomes for individuals with 4HL.

“In everything we do, we’re working to speed progress toward a cure.”

Yaya Foundation Short-Term Goals

- **Raise funds for pre-clinical research that aligns with our Research Roadmap.**
- **Provide support to families for clinic visits, which can be costly but are extremely valuable to affected families.**
- **Enhance family support programs, education materials and access to resources.**



kpCompanies is leading the search for the next Executive Director for the Yaya Foundation. This will be a highly visible and inspiring leader who possesses the vision to grow and to move the organization forward while building on the foundation's success. The Executive Director will guide all aspects of the organization, supported by a talented staff and a committed Board. Key areas include: strategy development and execution, fundraising, project management, building relationships, organizing community events, team development and fiscal management.

The Foundation's Executive Director must be largely self-directed and able to work productively with the Board President, Research Director, Advancement Advisor, and Board of Directors, as appropriate, to execute the Foundation's operating, development, family support and research plans.

We Are Looking For A..

- **Strategic Leader.** Visionary and collaborative leader with demonstrated knowledge of innovative program design as well as a deep understanding of how to get things done through the rare disease community by building and maintaining meaningful relationships.
- **Fundraising Leader.** Creates effective strategies rooted in the vision of the Yaya Foundation while taking into account social and cultural factors that influence fundraising. This leader leverages and multiplies financial support by inspiring the community to become a part of and support its critical mission.
- **People Leader.** Guides, inspires, trains, develops, and communicates with staff to foster effectiveness, belonging and growth.
- **Community Leader.** Upholds and advances the Yaya Foundation's credibility, brand, and role in the community, working closely with partners as well as private, professional, and civic groups and caring deeply for patients and families.
- **Fiscal Leader.** Sound fiscal manager and a great fundraiser who understands non-profit accounting, using financial analysis to help make appropriate business decisions. Develops and manages resources sufficient to ensure the ongoing health of the organization.
- **Life Sciences Leader.** Demonstrated commitment to improving patient outcomes with an ability to earn trust and credibility from patients, families, clinicians, researchers, and funders, and to be able to navigate the complex rare disease landscape.

JOB DUTIES AND RESPONSIBILITIES:

The Executive Director provides leadership to develop cohesive organizational, administrative and financial plans, policies and procedures with the staff and Board of Directors. This leader has the ability to lead change in a complex environment. The Executive Director oversees design, delivery and quality of new and existing programs and continually monitors for effectiveness and relevance.

Other accountabilities include:

- Collaborate with staff and Board to set, communicate, and execute the Foundation's strategic vision and associated priorities.
- Create and manage the Foundation's budget in support of strategic priorities and operational capacity; grow the Foundation from the \$1M organization it currently is to an organization with a \$6M annual budget over the next 5 years.
- Partner with the Research Director to understand, shape, and help support research roadmap agenda, stakeholders, and associated funding initiatives, to develop a collaborative network of scientists in our space, and to achieve meaningful and measurable outcomes.
- Partner with Advancement Advisor to understand, shape, and help support the Foundation's development strategy and supporting initiatives.
- Compassionately lead a variety of affected individual and family support programs and activities including, but not limited to:
 - Welcome outreach and materials
 - Newly diagnosed process and support
 - Family conferences and bi-monthly calls
 - Foundation and 4H Leukodystrophy overview materials
- Develop and implement a communications strategy for attracting and engaging donors and investors, patient families, scientific allies, and other key stakeholders. Responsibilities include managing key messages and content through the Foundation's website, newsletters, social media, press releases and a range of stakeholder communication.
- Enhance, develop, and implement necessary business and governance policies to ensure compliance with applicable regulations and efficient, high-level organizational performance.

REQUIRED QUALIFICATIONS:

Below are some of the typical requirements for an Executive Director. We recognize that skill sets can be a complex combination of experiences. Even if your background does not exactly match these requirements but you have a passion for our work, we would love to hear from you and we recognize the value of transferable skills.

- Minimum of five (5) years of professional experience in philanthropy, nonprofit management, and/or the life sciences. Experience in a start-up or growth-oriented organization is preferred.
- Bachelor's degree or equivalent.
- Proficient with donor database software (e.g., data input, record updating, gift processing, report production) and MS Office Suite.
- Strong financial management skills including budget preparation analysis, decision making, and reporting.
- Commitment to diversity, equity and inclusion across all aspects of the Foundation.
- Experience and skill working with a Board of Directors
- High-level strategic thinking and planning. Ability to envision and convey the organization's strategic future to staff, board, volunteers, and donors.
- Establishing and maintaining strong relationships with multiple people and organizations, including researchers, healthcare providers, patients, families, funders, and volunteers.
- Success in generating new revenue streams and ensuring strong financial results.
- Active fundraising experience. Excellent donor relations skills and an understanding of the funding community.
- Staff leadership and management experience. Managerial experience at a high-performing organization is preferred.
- High degree of energy and strong work ethic, including a commitment to execution in addition to management.
- Flexibility to conduct occasional meetings and events outside of standard daily business hours.
- Ability to travel occasionally for conferences, meetings with affected families, connections with donors and stakeholders.
- Strong project management and execution skills including managing and working actively on multiple projects, planning backwards, anticipating obstacles, identifying, and involving stakeholders appropriately.
- Ability to collaborate with constituents – affected families, researchers, clinicians, strategic partners, donors.
- Strong communication skills including writing and public speaking.

HOW TO APPLY

Interested candidates should submit a cover letter, resume, and salary expectations later than 9:00pm on Friday, September 30th, 2022. You can apply here:

<https://kprecruiting.catsone.com/careers/28261-General/jobs/15652238-Executive-Director/>

EQUITY + SALARY DISCLOSURE

We believe in practices that create real equity and pay parity regardless of background or identity and we freely discuss compensation with all qualified candidates the first time we interview them. Saving the salary discussion for the first conversation allows us to fully understand the needs of each candidate and to ensure that qualified candidates, even those who've historically been overlooked and/or underpaid, don't self-select out of the processes based on salary alone, as our experience and research suggests. In addition to those who opt out because they fear the salary may be out of reach for them, we equally don't want to miss out on conversations with candidates who are slightly over the range when in some cases the total compensation including factors such as bonuses, flexibility, and better health benefits, etc. may exceed expectations. Finally, as a search firm – we are always looking for top-notch talent to introduce to our clients. Should the salary or any other requirement not be a fit, there is often a chance that someone on our team is working on another position you may be a better fit for. If you would like to discuss your qualifications for this role as well as discuss salary and compensation - just give us a call, we'd be happy to discuss!

EQUAL EMPLOYER OPPORTUNITY

NWAF and kpCompanies are equal opportunity employers and all employees and applicants for employment are afforded equal opportunity in every area of hiring and employment without regard to race, color, ethnicity, religious creed, national origin, ancestry, sex, gender identity, age, disability, mental illness, sexual harassment, sexual orientation, genetics, military/veteran status, citizenship, arrest record, and any other legally protected characteristic.

All submissions received in strictest confidence.