



# CHIEF EXECUTIVE OFFICER

## CINCINNATI, OH

## ABOUT IRSF

Rett Syndrome is a rare genetic neurological disorder that affects approximately 1 in 10,000 females (and even more rarely in males) and begins to display itself in missed milestones or regression at 6-18 months. Rett syndrome leads to severe impairments, affecting nearly every aspect of life: ability to speak, walk, eat, and breathe easily.

Based in Cincinnati, OH, the International Rett Syndrome Foundation (IRSF) is the leading research, family support, and advocacy organization for Rett syndrome. They are transforming lives every day in the fight to treat and cure Rett, presenting the best opportunity to better the lives of families living with this devastating disorder. IRSF funds:

1. Trailblazing research seeking treatments and a cure. The highly comprehensive scientific program—bolstered by unprecedented industry partnerships—is the only one to include genetic approaches, fundamental biology, developing non-genetic approaches, clinical research, and more. Their track record of delivering real results includes funding the discovery that Rett can be reversed, the first gene therapy clinical trial, and the first FDA-approved treatment.
2. Empowering support that helps families cope and offers hope. They connect with and support families every single day to provide easy steps and tools to help them thrive—including building a strong community of parents and experts that help generate key insights that, in turn, inform research.
3. Increasing awareness of this rare disorder that can affect nearly every aspect of any person's life.

For more information visit [www.rettsyndrome.org](http://www.rettsyndrome.org).

## THE OPPORTUNITY

- Lead an international organization focused on the treatment and cure of a rare genetic disorder.
- Collaborate with a passionate Board and staff that have raised and invested over \$58 million for research since 1990.
- Leverage the expertise of 21 Research Centers of Excellence throughout the country.
- Provide support and programming to help families find expert care and connect with other families that are on the same journey.





## POSITION OVERVIEW

The Board is looking for a mission-focused, strategic, and results-driven leader. The CEO will serve as the face of the organization with a diverse group of stakeholders and will oversee execution of the foundation’s strategic goals. The successful candidate will work together with the Board of Directors and a talented, passionate staff. While periodic visits to Cincinnati are anticipated, the CEO can work remotely and lead a team that is dispersed across the country.

## WHAT YOU’LL BE DOING

### Strategic Planning & Goal Setting

- Lead, alongside the Board, the development of the organization’s strategic plan.
- Establish goals and evaluation criteria for each key initiative.
- Report to the Board of Directors on all key goals and outcomes.

### Staff Management & Development

- Recruit, manage, and develop all staff.
- Instill a human capital development culture within the organization by focusing on training, development, compensation, employee relations, performance evaluation, and recruiting.
- Lead the performance management process that measures and evaluates progress against goals.
- Bridge national and remote office operations and cultivate healthy collaboration among all staff

### Fundraising

- Develop the annual fundraising plan in collaboration with the development team and the Board.
- Ensure the organization is meeting its metrics and overall revenue goals.
- Enhance relationships with key partners in the pharmaceutical industry and other potential investors.
- Travel to events and fundraising programs.
- Generate new fundraising opportunities that support annual growth and sustain core programs, including grants, foundation support, major gifts, and corporate sponsorships.

## WHAT YOU'LL BE DOING CONTINUED

### Communication & Advocacy

- Raise public awareness about Rett syndrome and the goals of IRSF.
- Represent IRSF programs and point of view to other organizations, agencies, foundations, and the public.
- Advocate for research funding at the state and federal levels.
- Maintain a working knowledge of significant developments and trends in the field.

### Program Development & Management (Family Empowerment)

- Continue to develop innovative programs to support the needs of families.
- Increase key impact measurements.
- Ensure that all programmatic goals are achieved and within budget.

### Finance, Technology, & Quality Improvement

- Develop and manage the operational budget.
- Ensure the Finance Committee of the Board is active and engaged.
- Work with the outside accountant to provide monthly financial reports, monthly cash reports, and monitor investments.
- Track and interpret data to measure progress and support fundraising efforts.

### Board Development & Engagement

- Work with the Board Chair to identify prospective new board members for consideration by the Nominating Committee.
- Develop the Board committee structure and provide support to ensure committee meetings are productive.
- Develop strategies to keep the Board well informed and engaged.





## THE KEY REQUIREMENTS

- Personal and professional passion for working with families with children through adults with a rare disease.
- Experience being the face of an organization with other organizations, Congressional and agency representatives, employees, Board members, funders, and other key stakeholders.
- Solid educational background—undergraduate degree required, MBA or similar advanced degree desired.
- Fundraising success: ability to build and sustain meaningful and fruitful relationships with public and private funders and donors.
- Active involvement with a mission-driven organization as a Board member or management team member.
- Results driven with a track record of exceeding goals.
- High level of business acumen including successful P&L management.
- Strategic vision and experience leading a strategic planning process.
- An ability to effectively build organizational and staff capacity by developing a top-notch team and recruiting top talent.
- Some understanding of clinical research, drug development and scientific advancements would be a plus.
- Engaged management style that focuses on development, mentorship, and ongoing communication.
- Available to travel nationally once or twice a month plus access to Cincinnati, OH headquarters office for periodic visits.

## THE PAYOFF

- See your efforts have a direct impact on the lives of families every day.
- Work collaboratively with a passionate group of staff members, Board members, world-class researchers, and volunteers.
- Build on the momentum leading to treatments and a cure for Rett Syndrome while serving as a model for other rare neurological disorders.

## LEARN MORE & APPLY

The CEO does not need to be based in Cincinnati, OH, but travel to Cincinnati and other locations is required. The ability to lead a remote workforce is expected as the majority of the team is remote with only a few people in Cincinnati.

To apply please send your resume and a brief cover letter to: **Michele Plessinger, Barry Elkus** or **APPLY ONLINE.**



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