



## **Job Description – Executive Director**

### **Organization Background**

The Mowat-Wilson Syndrome Foundation was formed to enhance the lives of people affected by Mowat- Wilson Syndrome by providing family support, raising awareness, and supporting research and education. The founding board was made up of parents and grandparents of Mowat-Wilson Syndrome patients who recognized a need for an organization to support families and to fund research into this very rare (defined in 1998) syndrome.

### **Position**

The Executive Director will report to the Board of Directors and will have overall strategic and operational responsibility for Mowat-Wilson Syndrome Foundation's programs, staff, and execution of its mission. Knowledge of the rare disease community would be preferred. This is a part time (20 hrs. per week), remote position, without benefits.

### **Responsibilities**

- **Board Governance**

- Responsible for supporting Mowat-Wilson Syndrome Foundation in a manner that guides the organization's mission as defined by the board.
- Responsible for communicating effectively with the Board and providing, in a timely and accurate manner, all information necessary for the board to function properly and to make informed decisions.
- Responsible for working with the Board chair to develop meeting agendas and coordinating meeting dates/times.

- **Mission and Strategy**

- Responsible for the implementation of programs that fulfill our mission.
- Responsible for reviewing and monitoring the strategic plan to ensure that our mission can be carried on into the future.
- Responsible for representation of our foundation to other professional, civic and private organizations.

- **Financial Performance and Viability**

- Responsible for fundraising and developing other revenues to support our mission.
- Responsible for fiscal management, maintenance and integrity by operating within the approved budget to ensure a positive financial position.
- Work with/support Treasurer in monthly financial reporting to Board.
- Work with the Treasurer and Board to develop the annual budget.

- **Grant Writing**

- Researches and identifies grant opportunities
- Tracks and creates a calendar of grant opportunities – including deadline dates, required materials, etc
- Completes and submits grant applications to secure a minimum of 20,000 grant funding annually
- Identifies all requirements of grant to ensure all necessary attachments are submitted on time
- Works to develop mutually beneficial relationships with community organizations to strengthen grant proposals.
- Submits required reports for grant funded projects
- Records and maintains required information for funded grants
- Manages and oversees all grant programs to ensure adherence to funding guidelines

- **Research Grants**

- Develops and promotes RFAs
- Works with the research committee to oversee the application process
- Works with the research committee to oversee the grant review process

- **Organization Operations**

- Responsible for effective administration of operations.
- Responsible for adherence to all federal and state laws and regulations as they pertain to non-profits.
- Responsible for supporting the Medical Advisory Board and Community Advisory Board
- Responsible for donor management & communications

## Qualifications

- **Education**

- Bachelor's degree in nonprofit management or business administration.

- **Experience**

- Minimum 5 years of experience as an Executive Director.
- Additional non-profit experience a plus.
- Demonstrated ability to define grant opportunities and successfully obtain grants.
- Knowledge of Aplos a plus.

- **Salary**

- \$30,000 - \$40,000 depending on experience and qualifications