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
  o Responsible for supporting Mowat-Wilson Syndrome Foundation in a manner that guides the organization’s mission as defined by the board.
  o 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.
  o Responsible for working with the Board chair to develop meeting agendas and coordinating meeting dates/times.

• Mission and Strategy
  o Responsible for the implementation of programs that fulfill our mission.
  o Responsible for reviewing and monitoring the strategic plan to ensure that our mission can be carried on into the future.
  o Responsible for representation of our foundation to other professional, civic and private organizations.
• **Financial Performance and Viability**
  
  o Responsible for fundraising and developing other revenues to support our mission.
  o Responsible for fiscal management, maintenance and integrity by operating within the approved budget to ensure a positive financial position.
  o Work with/support Treasurer in monthly financial reporting to Board.
  o Work with the Treasurer and Board to develop the annual budget.

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

• **Research Grants**
  
  o Develops and promotes RFAs
  o Works with the research committee to oversee the application process
  o Works with the research committee to oversee the grant review process

• **Organization Operations**
  
  o Responsible for effective administration of operations.
  o Responsible for adherence to all federal and state laws and regulations as they pertain to non-profits.
  o Responsible for supporting the Medical Advisory Board and Community Advisory Board
  o 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