



Sandy Bulcher, President of the Board of Directors  
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## EXECUTIVE DIRECTOR POSITION DESCRIPTION

### PURPOSE

The Executive Director (ED) will take the lead in executing the mission of the MSUD Family Support Group (FSG) as determined by its Board of Directors (BOD). The ED will report to an Executive Committee of the BOD and will have overall strategic and operational responsibility for programming and activities related to improving the lives of those with MSUD and their families. She or he will develop knowledge of rare diseases, core programs, operations, and business plans. She/he will build a team of volunteers and paid contractors to facilitate fulfillment of the following responsibilities.

### RESPONSIBILITIES

#### Leadership

- Support a strong Board of Directors; serve as an ex-officio member of each committee; and seek and build board involvement as appropriate. Also, schedule board and community meetings, prepare agendas and background documents, provide minutes for all board and community meetings, and recruit new qualified board members.
- Actively engage and energize MSUD FSG Board members, volunteers, event committees, partnering organizations and funders, and the MSUD community.
- Manage the day -to-day needs of the organization, including activities, communications, etc. of the organization and its Board and any contractors which may be hired.

#### Strategy, Patient Registry, and Symposium Development

- Seek input from the stakeholders to understand what the organization needs to accomplish.
- Work with the board to update a strategic and business plan, including performance goals.
- Create and implement patient and family-oriented resources, (e.g., a new patient kit).
- With input from the board, develop and implement an advocacy plan.
- Facilitate community outreach by planning and implementing webinars for topics of interest to the MSUD community, periodic patient meetings with support from volunteers, etc.
- Grow participation in our patient registry.
- Plan, organize, and manage, the MSUD Family Support Group biennial symposium.

#### Lead and Manage Fundraising

- Provide a compelling narrative about why the organization needs and deserves donor support.
- Identify and build relationships with potential donors, including institutional donors (foundations, corporations, and other businesses).
- Continually seek, obtain, and manage grants opportunities.

## **Communications**

- Build external relationships with our stakeholders (MSUD families, the medical and science community, and with allied policy/political advocates).
- Establish and maintain communication with allied organizations within the metabolic disease community.
- Be the primary spokesperson and representative of the organization.
- Engage the MSUD community by relaying information via Facebook, our Website and newsletters, Email, and other available communications channels.
- Improve and maintain our contact registry.
- Assist the editor in publication of the MSUD FSG biannual newsletter.

## **QUALIFICATIONS**

The Executive Director will be thoroughly committed to the mission of the MSUD FSG and should have proven leadership, coaching, and relationship management experience. Specific qualifications include:

- At least a four-year college degree in a related field. A Master's degree is a plus.
- A track record of successful leadership and organizational management with a non-profit organization is a plus.
- Marketing, public relations, and fundraising experience with the ability to engage a wide range of stakeholders and cultures
- Strong written and verbal communication skills; a persuasive and passionate communicator with excellent interpersonal and multidisciplinary project skills
- Ability to work effectively in collaboration with diverse groups of people
- Be engaging and compassionate, highest integrity, positive attitude, mission-driven, and self-directed.
- Experience with patient advocacy organizations and knowledge of rare diseases, is preferred.

## **COMPENSATION**

This is a part time position, paying between \$30/hour and \$36/hour depending on experience

## **OTHER INFORMATION**

- This is a “work from home” position. The incumbent must be able to work independently and must provide their own office environment, including a dedicated workspace, a secure (VPN) internet connection, etc.
- The incumbent should expect to work an average of 20 hour/week. The actual number of hours/week will vary depending on workload requirements and other needs of the incumbent.
- A laptop dedicated exclusively to MSUD Family Support Group business with back up resources will be provided. Reimbursement for necessary supplies will also be provided.
- The incumbent must be able to travel to and represent the organization at symposiums and other metabolic conferences.

## **FOR MORE INFORMATION**

Interested candidates should email their resume and cover letter to [sandybulcher@gmail.com](mailto:sandybulcher@gmail.com) .