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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 initially develop deep knowledge of rare diseases (especially MSUD), core programs, operations, and business plans.

### RESPONSIBILITIES

#### Leadership

- Support a strong Board of Directors; serve as an ex-officio member of each committee; seek and build board involvement as appropriate.
- Actively engage and energize MSUD FSG Board members, volunteers, event committees, partnering organizations and funders, and the MSUD community.
- Work with the board to fulfill the organization's mission by scheduling board and community meetings, prepare agendas and background documents, provide minutes for all board and community meetings, and work with board to recruit new qualified board members.
- Recommend timelines and resources needed to achieve strategic goals.

#### Strategy and Program Development

- Seek input from the key stakeholders to better understand what the organization is expected to accomplish.
- Work with the board to refine and update a strategic and business plan, including organizational performance goals.
- With input from patients and families, identify key priorities for programs and resources to support the MSUD community.
- Manage approved resources to accomplish the organization's goals.

- Design resources and programs to benefit the MSUD Community.
- 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.
- Plan and implement webinars for topics of greatest interest to the MSUD community.
- Plan periodic patient meetings with support from volunteers.

### **Day to Day Management**

- Manage the day -to-day needs of the organization, including activities, communications, etc. of the organization and its Board.
- Ensure effective systems to track scaling progress, and regularly evaluate program components. Measure successes that can be effectively communicated to the board, funders, and other constituents.
- 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 from these donors.
- Create and implement fundraising campaigns appealing to the MSUD community.
- Acknowledge donations and other contributions made by all donors.

### **External Relationships**

- Build external relationships and partnerships with our stakeholders (MSUD families, the medical and science community, and policy/political advocates).
- Develop and use the external presence and relationships to garner new opportunities.
- Establish and maintain relationships with metabolic clinics, geneticists, dieticians, and other clinical staff.
- Maintain communication with allied organizations within the Inborn Error of Metabolism community.
- Be the primary spokesperson and representative of the organization.
- Travel to and represent the organization at symposiums and other metabolic conferences.

### **Communications**

- Create a strong organization brand by deepening and refining all aspects of internal and external communications, including web presence, email, social media, and other communication channels.

- Engage the MSUD community by relaying information via Facebook, Website and Email and other available communications channels.
- Publish and communicate program results with an emphasis on the successes of the organization.
- Improve and maintain the organizations contact register.
- Assist the editor in publication of the MSUD FSG biannual newsletter.

## **Compliance**

- Assure that organizational policies are in place assuring compliance with legal, ethical and common-sense standards.
- Assure compliance with these policies.

## **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.
- Past success working with a Board of Directors with the ability to cultivate existing board member relationships
- 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
- Engaging, action-oriented, entrepreneurial, adaptable, and innovative approach to business planning
- Ability to work effectively in collaboration with diverse groups of people
- Engaging and compassionate, highest integrity, positive attitude, mission-driven, and self-directed
- Experience with patient advocacy organizations and knowledge of rare diseases, including MSUD is a plus.

## **COMPENSATION**

- Annual salary in the mid-fifties to mid-sixties range for a full-time position.
- Includes 22 days of paid time off including vacation (15 days), sick leave (5 days), and personal days (2).
- Other benefits (e.g., medical, dental, and 401k) are not provided.