



Myotonic Dystrophy Foundation
Communications Associate
Oakland, CA – January 2023

The Opportunity

The Myotonic Dystrophy Foundation announces a search for a new Communications Associate to provide project and communications support for the organization's patient education and development functions. This is an exciting opportunity for an early career professional with strong organizational and writing skills interested in working for an entrepreneurial and fast-moving global leader in rare disease patient advocacy.

Organization Background

Myotonic dystrophy (DM) is the most common form of adult muscular dystrophy and considered the most variable disease in medicine. According to leading researchers' estimates, as many as 1 in every 2,100 people in the United States, are living with DM or are at risk of passing on the disease to future generations; most are undiagnosed. Myotonic dystrophy is an inherited, multi-systemic progressive genetic disorder for which no therapy or cure currently exists. However, it is a hopeful time as drug development is quickly advancing!

Launched in 2007 by a deeply committed board, the Myotonic Dystrophy Foundation (MDF) (www.myotonic.org) is a nimble, strategic global organization devoted to accelerating research efforts focused on the search for treatments and a cure for DM, and enhancing the quality of life of people living with the disease. The organization has a track record of incredible success in growing the drug development pipeline, research, advocacy, patient care and fundraising.

In the last decade, dramatic and exciting changes in research, treatment and the regulatory pipeline for myotonic dystrophy have occurred. DM is now considered a 'hot' disease, and the foundation's work is at a "tipping point" with respect to therapy development, visibility and global reach. The MDF board and leadership believe the organization is poised to benefit tremendously from growing industry interest, additional federal and private research funding, medical advances, and an enormously dedicated international community of patients, families and friends, donors, researchers and advocates.

Key Responsibilities

The Communications Associate works with the Program and Development Departments on patient support and education, including various aspects of program research and content development, communications and fundraising.

Patient Support & Education

- Research and compile information related to disabilities and employment that can be crafted into toolkits for community members.
- Assist the Program Department with organizing and coordinating all aspects of MDF DM Days, a regional program of one-day conferences, including but not limited to: catering requests, agenda creation, collateral acquisition, presentation development and other related projects.
- Contact vendors and presenters for the large events to supplement the creation of a comprehensive program agenda.
- Support in the development, promotion, and execution of the MDF Annual Conference. Including but not limited to design and development of: event registration pages, marketing collateral, a hybrid/virtual platform, post-event surveys, in-person support and event staffing.

Communications

- Provide communications support services for the execution of monthly e-newsletters, website content upload and editing, social media posting, monitoring and troubleshooting, email blast generation and publishing for special events and projects, website content updates.
- Participate in weekly staff calls to gather communications-related information, query group for needs and content for communications channels (newsletters, social media, website, etc.), and to stay abreast of communications and related conversations.
- Monitor and develop new content for relevant social media channels, including the Foundation Facebook (FB) page, other DM-related FB pages, LinkedIn, and Twitter feed to identify potentially problematic posts, inaccurate information, etc. and to identify potential opportunities or interesting information to repost or share.
- Track metrics and reporting for the website, search results, FB page, Twitter feed, e-newsletter distribution, and other items for quarterly reports.
- Other projects as assigned.

Development

- Assist Development Department in planning and supporting grassroots and major/gala fundraising activities, working directly with foundation supporters (families and individuals), including coordinating logistics and marketing for events.
- Maintain a calendar to ensure timely submission of letters of inquiry, proposal deadlines, and reports.

Qualifications

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- Bachelor's degree (or in progress).
- Optimistic problem-solving self-starter with excellent judgment
- Prior experience working in a non-profit setting helpful, but not required.
- Excellent verbal, written communication and project management skills.
- Highly organized and productive.
- Superb and consistent attention to detail and commitment to high quality product.
- Strong customer service skills.
- Able to connect successfully with stakeholders at all levels via phone, email and in person.
- Goal-oriented self-starter; able to prioritize projects and meet deadlines.
- Team-oriented philosophy with the ability to handle multiple projects at once.
- Experience (or quick learner) with donor database systems (e.g., Salesforce) and project management programs (cloud-based storage and project management programs)
- Experience (or quick learner) with HTML/CSS and user-friendly web management programs (Drupal or Joomla)
- Experience (or quick learner) with Email Marketing programs (i.e., Salesforce, MailChimp)
- Event planning and communication development experience a plus.
- Ability to lift 25 pounds, climb stairs.
- Proficiency with Microsoft Office; Adobe CC or Canva experience is a plus.

Compensation and Benefits

The Foundation offers a salary of \$65,000 annually and an excellent benefits package that includes vacation, medical, dental, vision, and a partial 401(k) matching program.

Application Process

Interested and qualified candidates are encouraged to apply by sending a cover letter and resume to kleed.cumming@myotonic.org. Please be sure to include why you are interested in this position at this organization. Applications without a cover letter will not be considered. All correspondence will remain confidential.