



Position Title: Marketing and Communications Specialist

Type: Part-time (25 hours/week)

Location: Fully Remote

Compensation: \$26/hour, paid holiday closure

Reports to: Executive Director

About the United MSD Foundation

Founded in 2016, United MSD Foundation is a 501(c)(3) nonprofit organization serving an international community of Multiple Sulfatase Deficiency (MSD) families, researchers, and care providers. We exist to bring awareness to MSD, fund research toward treatment, and support families through education, resources, and community.

Since inception, our mission has been to cure MSD, an ultra-rare genetic and fatal condition affecting children. To that end, we have funded a gene therapy mouse model and subsequent toxicology study, and a Natural History Study. We run a MSD Biobank and Patient Registry to provide researchers with access to patient data and samples. Currently, we are supporting first-in-human gene therapy trials with our partners at the Children's Hospital of Philadelphia.

Position Overview

The United MSD Foundation seeks an enthusiastic, experienced, and mission-driven marketing and communications specialist to join our team as we advance ever closer to a cure for MSD. The ideal candidate will take initiative, be resourceful, and exhibit a problem-solving mindset. The successful candidate must be able to communicate effectively with a diverse range of stakeholders from patient families to funders to the scientific community. This position gives the right candidate flexibility to be a creative storyteller while changing lives and science.

Duties Include

Communication Strategy

- Develop the annual communication plan to ensure United MSD Foundation's resources, research, public awareness and advocacy efforts are promoted across appropriate platforms; implement plans and monitor results
- Ensure brand consistency across all avenues of communication
- Gather and convey inspiring storytelling content that engages our community and attracts donors, volunteers, and other key constituents
- Assist program staff with outreach goals to reach unidentified patient families through communication strategies
- Generate a quarterly report on communications metrics for Board meetings

Graphic Design

- Create and/or assist with the creation of marketing materials, including flyers, public-facing slides/presentations, infographics, donor communication, merchandise, etc.
- Work with external vendors to ensure quality and timely delivery

Digital and Social Media Management

- Create and manage a social media and editorial calendar
- Plan and create social media content, including content geared at patient families, advocates, donors, and other key audiences
- Drive strategy to increase daily engagement on social media accounts
- Create media campaigns to increase awareness for key initiatives and events, including the annual Zebra Run and MSD World Day

- Field social media comments and questions and direct them to the appropriate staff member for response as needed
- Monitor, report and present on online engagement analytics (web, email, social media, earned media)
- Create social media kits (for ambassadors and volunteer fundraisers) for fundraising campaigns, like Zebra Run
- Leverage key engagement metrics across platforms to optimize content, messaging and distributions
- Manage organization website (www.curemsd.org), including making all content edits, creating new content as needed, and monitoring relevant fee-based services (domain/website/email hosting)

Email Communications

- Create and send the monthly e-newsletter, sourcing content from staff
- Build targeted lists to send special campaign messaging
- Analyze data to improve email engagement

Public Relations and Media

- Create and maintain a media list
- Write and distribute press releases
- Nurture local, regional, and national media partners, and pitch relevant stories
- Monitor news stories covering the the Foundation, MSD, and relevant research

Events and Fundraising Campaigns

- Create and oversee event related marketing materials such as sponsorship forms, flyers, registration pages/website, etc.
- Develop and monitor marketing budgets for events and campaigns
- Ensure sponsor benefits, such as logo placement on marketing materials, are being fulfilled
- Work with Executive Director on fundraising direct mail campaigns to assist on the creative development

Qualifications

- Bachelor's degree in a related field, such as journalism, public relations or communications, or advanced training in marketing, communications, and graphic design
- 3-5 years of relevant professional experience in communications and/or marketing, preferably in a nonprofit organization
- Proficiency in Microsoft Office and Google Suite
- Proficiency with Canva and social media platforms, including Facebook, Instagram, and LinkedIn, and related analytics
- Familiarity with CMS platforms and basic HTML (WordPress, etc.)
- Knowledge of CRMs, with Bloomerang being a plus
- Proven results in creating and implementing marketing and communications plans
- Strong written and verbal communication skills, with the ability to edit, proofread, and ensure the accuracy of finished work products
- Must possess a high level of interpersonal skills to handle sensitive and confidential situations
- Must maintain a high level of poise and professionalism in all circumstances
- Outstanding time management skills with an ability to be responsive to revisions and meet deadlines
- Ability to take initiative, be resourceful, and exhibit a problem-solving mindset, and a desire to learn new skills
- An understanding of or interest in the rare disease space and patient advocacy organizations

To Apply

Email your resume, cover letter, and 3 work samples or link to portfolio to Executive Director, Sarah Cortell Vandersypen, svandersypen@curemsd.org, with the SUBJECT LINE: "Marketing and Communications Specialist." Applications will be reviewed on a rolling basis.