EURORDIS-Rare Diseases Europe

Job vacancy – Campaign & Digital Communications Senior Manager

Responsible to: Communications Director
Contract type: Temporary (to June 2022), full-time
Salary: 40 – 45 000 euros per annum + one-month performance-based bonus
Location: EURORDIS Paris
Start date: ASAP

About EURORDIS-Rare Diseases Europe and Rare Disease Day

EURORDIS-Rare Diseases Europe is a unique, non-profit alliance of over 900 rare disease patient organisations from over 70 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.

Since 2008, EURORDIS has led patients and patient groups globally to raise awareness for people living with a rare disease and their families via the communications campaign for Rare Disease Day (the last day of February each year). Up from 16 countries participating in 2008, 2020’s edition saw thousands of events taking place in over 100 countries. EURORDIS coordinates national partners to determine campaign core messaging, to translate and disseminate the campaign. EURORDIS is responsible for producing adaptable visuals and videos which are freely accessed by thousands of patient groups and other stakeholders interested in improving the lives of people living with a rare disease.

The outreach campaign has the ambition to trigger change for people living with a rare disease and to link to the broader advocacy efforts of rare disease patients emphasising equity in human and social rights alongside healthcare needs for people living with a rare disease and their families.

The campaign benefits from public, patient association and private funding. This position comes at an exciting time with potentially new funding for the program which would enable us to scale up the Rare Disease Day. A key component of this role will be implementing any new grant objectives.

Main scope of the position

The Campaign and Digital Communications Senior Manager (CDCSM) develops the marketing, communications and digital strategic plan and is responsible for the design and implementation of the operational plans for the global awareness campaign Rare Disease Day. The CDCSM will also drive the decision process for the messaging, co-created with the 60 national patient organisation partners leveraging the analysis from a recent strategic campaign review. The CDCSM will achieve a more robust outreach and engagement, coupled with new media relation reaching more than 300 million people living

Job announcement last updated: 15 June 2020
with a rare disease globally. Finally, working with the international advocacy team, the CDCSM will produce advocacy toolkits and materials aimed to inform and capacity build patient advocates.

Motivated to work at an NGO and committed to our cause, the CDCSM will also contribute to marketing, international media and digital strategy across the organisations' websites, events, programs, social media and publications, working closely with the Communications Senior Manager and the Web Technology Manager.

The CDCSM reports to the Strategic Communications and Marketing Director and is part of the larger Awareness, Public Engagement and Events team.

The position is recruited for EURORDIS’ Paris Office (Brussels and Barcelona offices to be considered).

Key tasks and responsibilities

**Awareness campaign, social media and digital marketing**

- Develop and implement annual marketing, communications and digital plan
- Drive and participate in the process of determining campaign messaging: co-creation 60 national patient organisation partners, Steering and advisory committees and with CEO, COO and Communications Director.
- Extend messaging for the ecosystem (global, national, local + other stakeholders, especially policy makers).
- Deliver and disseminate adaptable campaign elements, working with marketing agencies and national partners.
- Develop, coordinate and execute social media and digital plans to effectively disseminate campaign messaging including but not only rarediseaseday.org, facebook, Instagram, twitter.
- Participate in the creation and production of social media, print and web visuals as needed for the campaign, including all content on rarediseaseday.org
- Manage the operational budget of the campaign and coordinate and prepare the advisory committees meetings (multi-stakeholder).
- Build brand notoriety alongside EURORDIS’ leadership of the campaign.
- With the web technology manager, develop a new website for Rare Disease Day 2022’s campaign.

**Patient advocacy capacity building tools**

- Develop, write, design and coordinate the production of international advocacy education and outreach elements for patient advocates within the campaign.
- Further develop link to patients and patient groups who participate in Rare Disease Day.
- With the international advocacy team, plan a worldwide gathering or focal movement for the global Rare Disease Day community.

**Campaign outreach and communications**

- Significantly increase the reach of the campaign to the main target group of over 300 million people living with a rare disease globally.
- Determine and report measurements of the campaign reach and engagement (metrics and reporting systems), and compile high level reporting for management, the board, and key funders.
- In partnership with the Senior Communications Manager, cultivate media relationships that enable Rare Disease Day to get more coverage in mainstream press. Support national partners with press packs and messages to better co-ordinate the campaign across borders.

Job announcement last updated: 15 June 2020
EURORDIS communications

- Participate in the creative, communications and marketing plans for EURORDIS publications, websites, social media and events.
- Contribute to social media, branding and digital strategies for other EURORDIS brands websites, events and social media.
- Demonstrate enthusiasm for EURORDIS and a strong commitment to its mission, including its advocacy activities, community building and collaboration with multiple stakeholder groups.

Experience & skills

- Minimum Bachelor’s degree and 6-8 years’ professional experience in communications and marketing for a global organisation or brand (within the health, public affairs or NGO sector a plus).
- Experience building and executing international or global marketing campaigns, communications plans, measurement tools and digital strategies in a complex ecosystem.
- Experience working with a major international awareness campaign highly desirable
- Experience in community and public engagement, engaging participation of multiple partners and actors
- Experience managing communication or campaign budgets and suppliers including marketing agencies and graphic designers.
- Creative with a passion for creating visual elements. Experience in producing video campaign elements a plus
- Autonomous, proactive and highly driven
- Sensitive to working for a cause and with genuine interest in understanding the challenges of people living with a rare disease and their families.
- Enthusiastic and flexible team player with skills including: managing meetings, presenting, reporting to management, co-creating with national partners, strategic planning, verbal and written communication, organisational and time management abilities
- Ability to work with several operational team members and patient organisation partners with varying backgrounds and levels of English understanding.
- Proficiency in Microsoft office suite but also well-trained in photoshop, video software and other graphic design or photo tools.
- Fluent English speaker with excellent written and oral communication skills in English is a must (excelling in persuasive and influential writing)
- Good level in French desirable; other European language(s) a plus

To apply

Please send your CV and cover letter in English to CDSM@eurordis.org

Deadline for applications: 10 July 2020

Job announcement last updated: 15 June 2020