

# EURORDIS-Rare Diseases Europe

## Job vacancy – Rare Disease Day Campaign Manager

**Responsible to:** Chief Operating Officer

**Contract type:** Temporary (12 months), full-time

**Salary:** 34 – 40 000 euros per annum + one-month performance-based bonus

**Location:** EURORDIS Paris Office (Brussels and Barcelona offices to be considered)

**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 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. A key component of this role will be implementing any new grant objectives. This position can be extended or made permanent depending on funding commitments.

### Main scope of the position

The RDD Campaign Manager is the project lead of this international awareness campaign. S/he is the focal person to steer the campaign in the right direction, work with the governance and national partners to co-create and grow the campaign, with measurable outcomes and impact.

The RDD Campaign Manager (RDDCM) 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.

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Working closely with the COO, and supported by the RDD Communications Junior Manager, the RDDCM is responsible for overseeing programme outreach and governance. This includes managing the RDD Steering Committee and incorporating feedback from the RDD Outreach group.

The RDDCM will also drive the decision process for campaign messaging, co-created with the 67 national patient organisation partners leveraging the analysis from a recent strategic campaign review.

The RDDCM will achieve a more robust outreach and engagement, coupled with new media relation reaching more than 300 million people living with a rare disease globally. Finally, working with the international advocacy team, the RDDCM will produce advocacy toolkits and materials aimed to inform and capacity build patient advocates.

The RDDCM manages one Communications Junior Manager + one intern (6 months / year).

## Key tasks & responsibilities

### Programme management and governance

- Manage relations with National Alliances and the patient community
- Manage relations with external providers including creative agencies
- Manage budget with link to EURORDIS Finance
- Schedule and prepare for Steering Committee meetings, and undertake to keep the Steering Committee informed about our progress throughout the year
- With the Head of Philanthropy and Partnerships and with the COO, manage relationships with donors

### Awareness campaign, social media and digital marketing

- Develop and implement annual marketing, communications and digital plan
- Identify effective tools to engage schools, hospitals, and young people already in place in our networks and help scale up these initiatives
- Drive and participate in the process of determining campaign messaging: co-creation with national patient organisation partners, Steering and advisory committees and with CEO, COO and Communications Senior Manager.
- 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
- With the RDD Communications Junior Manager, develop, coordinate and execute social media and digital plans to effectively disseminate campaign messaging including but not limited to [rarediseaseday.org](http://rarediseaseday.org), Facebook, Instagram, Twitter, YouTube
- Manage the operational budget of the campaign
- Co-ordinate and prepare the advisory committee meetings (multi-stakeholder) and steering committees
- With the Web Technology Manager, refine and constantly improve the RDD website

### 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
- Plan and convene 2-4 capacity building webinars to support national and grassroots campaigners to make progress in their national and local campaigns

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- With the international advocacy team, plan a worldwide gathering or focal movement for the global Rare Disease Day community (when required).
- Lead on the curation and where required adaptation of tools to engage schools, hospitals, and young people already in place in our networks and help scale up these initiatives
- Support the COO with the implementation of the Communications Support Programme-where small grants are given to newer and/or less well-resourced national alliances to support their RDD communication.

### Campaign outreach and communications

- Significantly increase the reach of the campaign to our main target groups, including the over 300 million people living with a rare disease globally, but also focusing on new segments such as clinicians and youth engagement
- 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.

## Experience & skills

- Minimum Bachelor's degree and 4-6 years' professional experience in communications and marketing, ideally for a global organisation or brand (within the health, public affairs, or NGO sector a plus).
- Experience working with a major international awareness campaign highly desirable
- Experience managing communication or campaign budgets and suppliers including marketing agencies and graphic designers.
- Experience working in and with different cultures
- 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.
- Proficiency in Microsoft office suite but also well-trained in Photoshop, InDesign, Illustrator, video editing software and other tools.
- English native speaker or native-level fluency in English with excellent written and oral communication skills is a must (excelling in persuasive and influential writing)
- Additional languages a plus.

## To apply

Please send your CV and cover letter in English to [drsm@eurordis.org](mailto:drsm@eurordis.org)

**Deadline for applications: 30 April 2022**

Job announcement last updated: 6 April 2022