



Position	Online Patient Communities Manager
Team	Operations, Projects and Programmes
Responsible to:	Web Communications Senior Manager & RareConnect Project Leader
Contract duration	Permanent
Salary	based on education, language skills and experience
Location	Fundació Dr. Robert, Hospital San Pau, Barcelona, SPAIN.

About EURORDIS

The European Organisation for Rare Diseases, EURORDIS, is a patient-driven alliance of patient organisations and individuals active in the field of rare diseases.

EURORDIS's mission is to build a strong pan-European community of patient organisations and people living with rare diseases, to be their voice at the European level, and to fight against the impact of rare diseases on their lives.

Created in 1997, EURORDIS is today a leading Health International Non Governmental Organisation (INGO) and is recognised as the largest European Rare Disease Patient Organisation. In 2012, EURORDIS has 510 members in 48 countries, 120 volunteers, 25 staff persons in Paris and Brussels and a budget of 3 million €. It has steadily growing and well balanced revenues both from the public sector (European Commission, national authorities) and the private sector (patient groups membership fees and grants, corporate sponsorship, foundation grants, event fees).

EURORDIS has an outreach to 1600 patient groups and works closely with the European Commission, the European Parliament, leading pharmaceutical and biotech companies and European research networks. EURORDIS, plays an essential role in the development and in decision making process in the areas of orphan drugs and advanced therapies, specialised hospital centres of care and their European networks, research activities and national strategies on rare diseases. EURORDIS coordinates the annual Rare Disease Day and manages a platform of web sites and social media communication tools.

Main scope of the post

RareConnect™ is an online social network (available at www.rareconnect.org) whose aim is to promote global conversation and collaboration to improve the lives of rare disease patients. A joint initiative of [EURORDIS](#), the European Organisation for Rare Diseases, and [NORD](#), the National Organization for Rare Disorders (USA) the project was launched as a pilot in 2009 as Rare Disease Communities and renamed as RareConnect in 2012. The initial goal is to create disease-specific online patient communities that enable patients to obtain valuable information about their disease, share experiences, find disease-specific organizations, and network globally. Each community is built in co-operation with respective EURORDIS and NORD member patient groups active in a

specific disease area. The long-term plan for this project is to expand the platform and its capability to connect larger numbers of patients globally, with the objective of supporting clinical trial recruitment and outcomes management, while also increasing knowledge and understanding of rare diseases.

EURORDIS has worked with NORD to complete a strategic plan to expand and enhance the RareConnect Online Patients Communities Project. The Online Patients Communities Manager is an active participant in the implementation of various aspect of that process.

The Online Patient Communities Manager is responsible for supporting the Senior Manager, Web Communications & RareConnect Project Leader in:

- Scaling up the service to create numerous new patient & families rare disease communities in order to meet or come close to projected targets.
- Putting in place a structure of volunteers necessary to expand and support these numerous communities
- Promote good practise community support and generation.

Specific tasks include, in particular, but not limited to:

Scaling up the Service & New Community Setup

- Identifying potential new rare disease communities and liaising with the various stakeholders internationally to integrate them into the RareConnect roadmap in the scale-up phase of the platform's development
- Liaise regularly with NORD (in particular their Online Community Manager based in Danbury, Connecticut) to synchronise efforts in creating communities based on synergies between the NORD/EURORDIS membership base
- Build relationships with Key Opinion Leaders within the international patient community and in each disease community identified
- Gather information from communities in advance of a community launch and report results back to the team
- Identify potential content providers and medical professionals who may wish to participate or intervene in the community at the patients' invitation
- Participate in identifying and building relationships with patient volunteers for each community

Community Support & Networking

- Organise capacity building and best practise workshops in person and online that deliver new communities to RareConnect while maintaining EURORDIS as a leader in the field of online communities.
- Maintain a connection with volunteer moderators through workshops, social media interaction, webinars, email list updates, and presentation of project at relevant conferences.
- Identify RSS feeds and validated treatment and disease information and pass it on to the volunteer structure of each community
- Train moderators to identify and share quality sources of information
- Stimulate conversation in communities through sourcing relevant disease information from quality sources including monitoring of social media channels.
- Organise regular newsletter style digests for each Rare Disease Community
- Organise regular newsletter updates for moderators
- Liaise regularly with volunteers and moderators and act as a support to the volunteer moderator structure to answer their questions while stimulating community activity and engagement
- Attract potential new communities through social media outreach and interaction

- Work effectively on collaborative projects with colleagues working in the United States
- Manage content translation in order to cost-effectively deliver a range of localised content using the appropriate provider.

Promotion

- Give input into the development and review of promotional material in several languages in print and electronic format
- Increase traffic to RareConnect through posting of relevant links on social media channels
- Work with the EURORDIS Manager of Relations with Patient Organisations to communicate the existence of communities and new plans regarding the platform to our membership via mailings from the EURORDIS CRM database.
- Work with the EURORDIS Communications Director to promote the RareConnect platform through the press, social media channels, patient organisation literature, learned society conferences and weekly EURORDIS eNews
- Animate other EURORDIS social media channels (eurordis, rarediseaseday, etc.)
- Contribute to discussion regarding the platform's evolution and outreach plans
- Liaise regularly with the Senior Manager, Web Communications & RareConnect Project Leader to suggest feature improvements and technical innovations based on feedback from patient members
- Communicate new developments with all EURORDIS staff to encourage synergies among rare disease patient groups
- Deliver regular reports on the statistical usage of the platform and the level of interaction by participants
- Participate in strategy review on ways in which to build engagement with the platform and promote maximum benefit from the platform

Profile:

Essential:

- Fluent English speaker (preferably native), knowledge of second European language
- At least 2 years demonstrable experience in professional, brand-oriented or preferably non-profit online community support and bring with her/him a deep communicable understanding of audience engagement through social media.
- Keen understanding of engagement channels and social media channels
- Experience with forum moderation and the nuances involved in maintaining best practises through exchanges in forums even in challenging situations.
- Experience in working with volunteers and effective management and coordination of volunteer efforts
- Ability to organise workshops and training events
- In addition (s)he will demonstrate examples of successful teamwork in her/his professional work
- EU working papers
- Ability to travel up to 25 per cent of the time, in particular within Europe and the United States. The OLPC Manager will travel to EURORDIS Paris headquarters regularly (on average once a month)

Preferred:

- Experience working with directly with patients, care-givers or patient groups in a support or advocacy setting

- Knowledge of the Rare Disease environment
- Significant experience working in the communications area and displaying a high level of sophistication in representing an organisation appropriately.
- Experience with mass-mailing tools such as Constant Contact, Campaign Monitor, MailChimp etc..
- Ability to search for quality medical information on the internet via Pubmed, Orpha.net, Clinical Trials.gov and other sources and source quality RSS feeds (a plus)
- Knowledge of HTML & Photoshop
- Knowledge of video editing and production through creation of videos with patient groups
- Experience using a CRM database (e.g. Salesforce)
- High level of proficiency in spoken and written French

Please send your application to denis.costello@eurordis.org before 24/07/2012