RareConnect.org

A EURORDIS INITIATIVE

EURORDIS CNA/CEF Meeting October 2015

Key indicators

- **79** rare disease communities
- **269** volunteer moderators
- **660** rare disease patient group partners
- **60,000** visitors/month

By country

1.	United States	20,861 (27.70%)
2.	Italy	6,731 (8.94%)
3.	France	5,881 (7.81%)
4.	Spain	5,616 (7.46%)
5.	United Kingdom	5,346 (7.10%)
6.	Germany	4,593 (6.10%)
7.	Canada	2,420 (3.21%)
8.	Mexico	2,086 (2.77%)
9.	Australia	1,773 (2.35%)
10.	Argentina	1,748 (2.32%)

Current Team

- **Barcelona Office**
  - Denis Costello: Project Leader
  - Rob Pleticha: Senior Manager
  - Marta Campabadal: Community Manager
  - Carmen Lasheras: Community Manager

Rob Pleticha

- Online Communities Manager
- Aged 30, Education in Psychology (Uni. Of Illinois)
- Previous experience: 2 Years at Romanian RD Alliance

Carmen Lasheras

- Online Communities Manager
- From Murcia, Spain
- PhD in Pharmacology
- Focusing on Web-RADR project

Marta Campabadal

- Online Communities Manager
- 26 years old, from Spain
- Social Media Coordination
- Spanish Outreach
- Education in Marketing & Community Management

What?

Team Evolution:

- **Extend EURORDIS RareConnect to include a team in the Balkan region**
  - **In collaboration with Network of Balkan Rare Disease Federations (in line with EURORDIS 2015 Workplan)**

What does it bring to us?

- Extended reach for RareConnect and benefits for more PLWRD
- Visibility for Balkan Alliances on world stage
- Strengthen our capacity to share and work together
- Translation into Croatian/Serbian

Why?

Rationale:

- Bring **new level of Human Resources** to RareConnect to **significantly impact outreach and operational capability** on a global and regional level

Goals

- **Develop outreach capabilities:**
  - **Priority zones:**
    - **Germany**
    - **Bulgaria + Latvia + Lithuania +Belarus + Ukraine + Russia**
    - **Italy**
    - **Greece**
    - **Within Balkans**

Goals

- **Specific indicators:**
  - **Involve more Patient Groups from these countries**
  - **Involve more patients and families**
  - **Increased visibility**
  - **Increased moderators**
  - **Increased involvement of other partners e.g. doctors, students, translators**

How?

- This move represents a **long-term commitment** from EURORDIS
- It will include **regular milestones** and **reviews**
- Needs to be based on **sustainable** and **realistic** approach

What will it look like?

- **2 offices** coordinating locally and with Barcelona team representing and coordinating collaboration with the Network of Balkan Rare Disease Federations
- Offices in Zagreb and Belgrade

Tihana Kreso

- Online Communities Manager, Outreach
- From Istria, Crotia – fluent Italian
- Experienced administrator with Croatian RD Alliance
- Representative on European Helplines Network

Dubrowka Franz

- Online Communities Manager , Web Content
- 7 years in Greece as volunteer coordinator with young people in NGO
- Also proficient in Italian + German
- Excellent online content mgmt experience

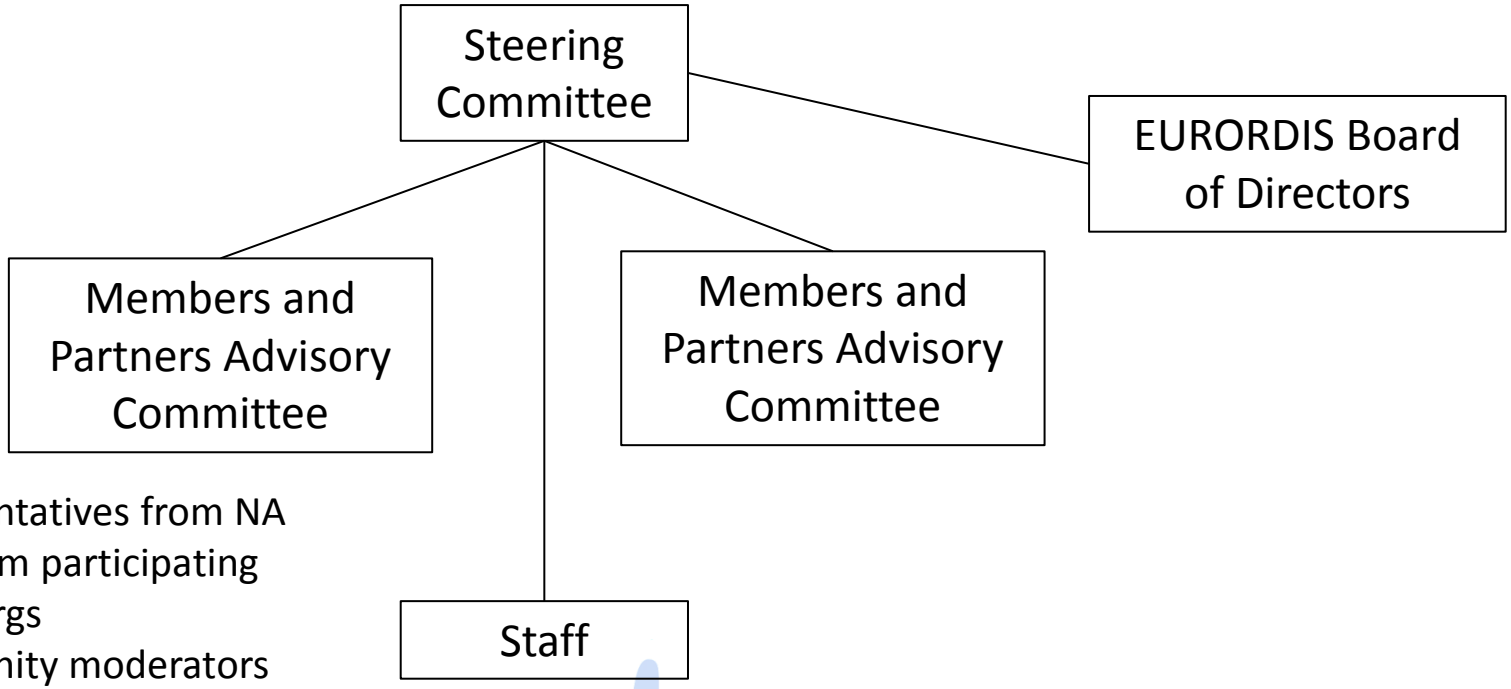
Sandra Pavlovic

- Online Communities Manager, Outreach
- Vice-President of NORBS
- Mother of child with EB
- Fluent Russian speaker with professional background in Marketing

Igor Ban

- Online Communities Manager, Web Content
- 26 years old, from Spain
- Social Media Coordination
- Volunteer in support group for young cancer patients

Governance Evolution II



- 7 representatives from NA
- 2 reps from participating Patient Orgs
- 2 community moderators
- 2 discussion group moderators

Members and Partners Committee (MPAC)

The MPAC should be instrumental in:

(a) providing expert opinion on and input that may be fed into the overall strategy of the programme,

(b) providing feedback from user experience from the use of RareConnect

How to be involved as a National Alliance?

- **Participate in Governance Committee**
- **Co-promotion of RareConnect**
  - On your website, Social Media, Newsletter
  - Promote at Family & association days
  - Integration into information service/helpline
  - Provide a contact person to liaise with patient groups
- **In return**
  - RareConnect shows your logo on it's homepage as an official partner
  - RareConnect regularly informs you of new communities and of # of users from your country/region
  - RareConnect attends some meetings and/or provides material for your volunteers to present the project
  - RareConnect promotes relevant activities to communities via platform & social Media

How to be involved as a European Federation?

- **Start a community or discussion group**
- **Participate in Governance Committee**
- **Co-promote RareConnect**
  - On your website, Social Media, Newsletter
  - Promote at Family & association days
  - Nominate a moderator
- **In return**
  - RareConnect shows your logo on community or discussion group
  - RareConnect regularly informs you of new communities and of # of users in your community
  - RareConnect attends some meetings and/or provides material for your volunteers to present the project
  - RareConnect promotes relevant activities to communities via platform & social Media

EURORDIS
Rare Diseases Europe

New Logo


RareConnect.org
A EURORDIS INITIATIVE


RareConnect.org
A EURORDIS INITIATIVE

Language Roadmap

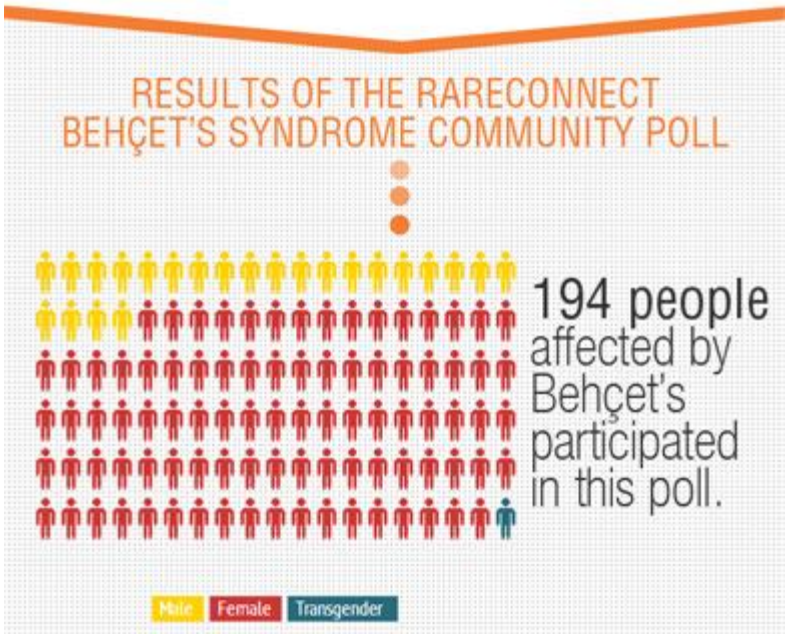
- Currently localised in 6 languages (EN, FR, ES, IT, DE, PT) with 2 pass translation (Google Translate + Human Translation)
- 2015: Croatian/Serbian + Russian (December)
- 2016: Working with EURORDIS National Alliances to translate into more EU languages

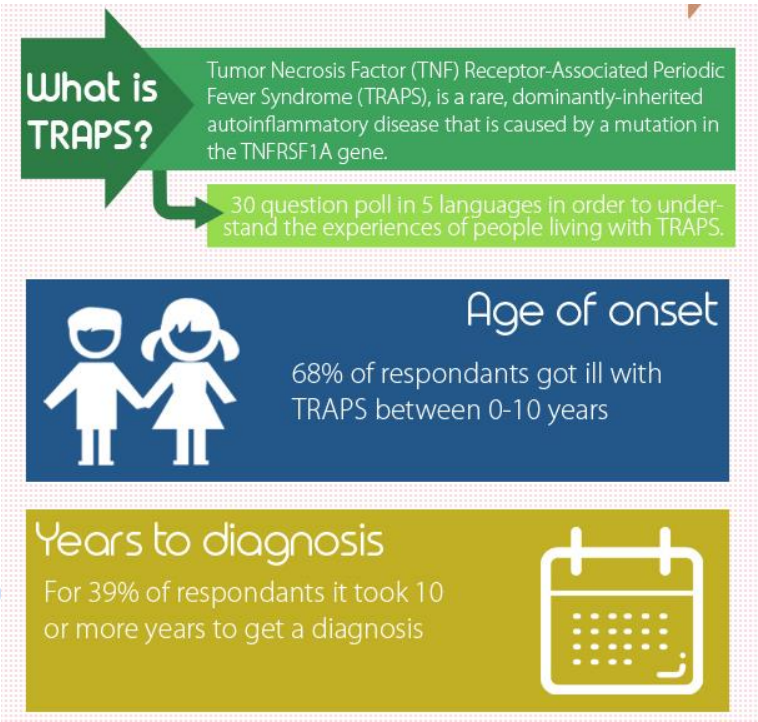
Featured Discussion Groups

- Specialised Social Services
- RD National Plans
- Rare Diseases International
- Patient engagement in Drug Dev.
- Summer School Alumni + Nancy Hamilton
- Crowdfunding
- European Reference Networks + Centres of Expertise + Healthcare Pathways

RareConnect Surveys

- In 2014/2015 we conducted 4 surveys





RareConnect Surveys

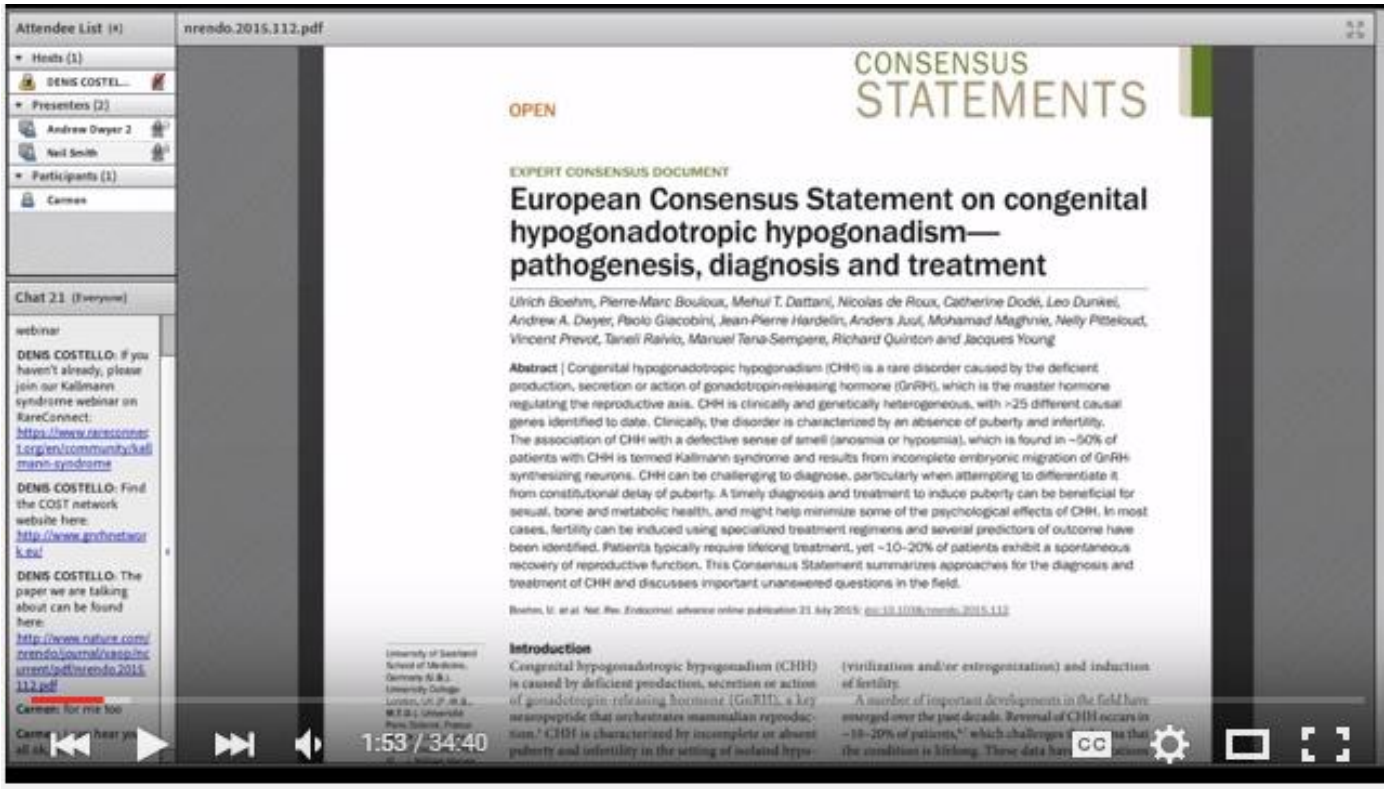
- In 2016 we will scale up survey activity through integration with EURORDIS Patient Voices Program
- Also in discussion with MAPI group to develop qualitative methodologies for assessment of patient experience via in-kind collaboration.

RareConnect Activities

- Crowdfunding campaign with Ectodermal Dysplasia community

RareConnect Activities

- Webinar on Standards of Care for Kallmann Syndrome



RareConnect Activities

- 2 families with FOXP1 mutation meet face to face for first time in video shoot

Registry: Call for pilot

- **OpenApp.ie** is a Registry Provider based in Ireland
- Has developed a specific RD registry product based on EPIRARE
- First 100 patients free then paid model
- Also customisations to data-set are paid model
- Piloting partnership with RareConnect

OpenApp
Making Data Useful

Thanks
And if you'd like to contact us:

Here we are:

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