



An opportunity for partnership

Denis Costello, EURORDIS: RareConnect Project Leader

CNA/CEF Eurordis 2014



Understand

Living with a rare disease



Meet

Connect and discuss with other patients



Learn

Get information and find resources

Welcome!

Hosted by trusted patient advocates, this is a place where rare disease patients can connect with others globally. **Come in and learn more >**

Follow Us



Share This



JOIN NOW

It's Free!

Our Communities



Join RareConnect



Member Story



Determination Bears Hope - This is a video about 4 year old Matthew Wuchich, who is the "poster child". **Read more >**

Patient-led Social Network for Rare Diseases.

www.rareconnect.org

RareConnect in numbers

66 disease-specific communities
across **5** languages

80.000 monthly unique visitors
from **190** countries.

12000 members

(each member spends 12 minutes/per visit on avg)

+100,000 words translated each month

Some of our 66 communities

- Alkaptonuria (AKU)
- Alstrom Syndrome
- Alternating Hemiplegia (AHC)
- Amyloidosis
- Apert Syndrome (AS)
- Atypical Hemolytic Uremic Syn. (aHUS)
- Behçet's Syndrome
- CAPS
- Castleman Disease (CD)
- CDG
- Choroideremia (CHM)
- Coats Disease
- Cobb syndrome
- Cone-rod dystrophies (CRD)
- Cryoglobulinemia
- Cutis marmorata telangiectatica congenita (CMTC)
- Cystinosis
- Dravet Syndrome
- DysNet
- Ectodermal Dysplasia

- Ehlers-Danlos Syndrome (EDS)
- Epidermolysis Bullosa (EB)
- Erdheim-Chester Disease (ECD)
- Evans Syndrome
- Familial Mediterranean Fever (FMF)
- Fibromuscular Dysplasia (FMD)
- FOXP1
- Glut1 DS
- Hemiconvulsion-hemiplegia-epilepsy syndrome (HHE)
- Hereditary Leiomyomatosis and Renal Cell Cancer (HLRCC)
- Hereditary Spastic Paraplegia (HSP)
- Idiopathic Pulmonary Fibrosis (IPF)
- Kallmann syndrome (KS)
- Leigh Syndrome
- Lipoprotein Lipase Deficiency (LPLD)
- Lowe Syndrome

- Lymphangi leiomyomatosis (LAM)
- Malignant Infantile Osteopetrosis (MIOP)
- Marinesco-Sjogren Syndrome
- Mastocytosis and Mast Cell Activation Disorders
- Moebius syndrome
- Moyamoya disease
- Multiple Endocrine Neoplasia (MEN)
- Multiple Myeloma
- Multiple System Atrophy (MSA)
- Myasthenia Gravis (MG)
- Narcolepsy
- Neuroacanthocytosis
- Neurodegeneration with Brain Iron Accumulation NBIA
- Niemann-Pick disease type C
- Paraneoplastic Neurological syn. (PNS)
- Pemphigus and Pemphigoid



1. Working together

5

Involvement of 566 Patient Groups from 40 countries

- NOMID Alliance
- AMWS/CINCA
- VHL Family Alliance International
- German Assoc. for VHL Families
- Danish Assoc. for VHL
- Alianza española de familias de VHL
- VHL France
- A Magyar VHL Társaság
- Dutch VHL Organization
- Canadian CAPS Network
- VHL Contact Group U.K.
- AIFP
- Stichting FMF-Community Nederland
- AFFMF
- FMF Montreal
- AKU Society UK
- Alcaptonurie France
- findAKUre
- Foundation for Children with Atypical HUS

- AIRG
- Argentina VHL Assoc.
- SIMBA Italy
- Ass. Française de Behçet
- As. Española de Behçet
- DebRA International
- DebRA Belgium
- DebRA Croatia
- DebRA UK
- DebRA Austria
- EB-Haus Austria
- UK Behçet's Syndrome Society
- DEBRA España
- DebRA Canada
- Fundación DEBRA México
- AHC Assoc. Iceland
- A.I.S.EA
- AESHA
- AHC Foundation
- L'aim AKU

- DebRA Norway
- DebRA Italy
- Cystinosis Support Australia
- Cystinosis Foun. France
- Cystinosis Support Germany
- Cystinosis Foun. Ireland
- Mexican Cystinosis Association
- Cystinosis Group Netherlands
- Cystinosis Foun. UK
- Cystinosis Foun. USA
- Cystinosis Research Network
- South Africa Support Group
- Cystinosis Research Foundation
- Danish HSP Assoc.
- A.SL-HSP France
- Spanish HSP Assoc.
- Italian Assoc. for Living with SP
- Holland Assoc. of Neuromusc. Disease
- Spastic Paraplegia Foundation



2. BREAKING BORDERS

not intended for Behçet's. I have tried through all the old drugs and they have all stopped being effective. Any suggestions from anyone successful in getting insurance approval?
... (Show more)

Report | Reply



moderator

behcet
Mimo
de Be
Firmó u
sobre e

No es l
Enferm
descon
hacerla
arduo y

Transl
Instan
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Report

One re



mod

< Previous

1

Translation Service

This service aims at providing a free translation service for user contributed contents on this platform. Once you requested a translation, you'll have to wait for a few hours for the translated content to be available online. You will be sent a notification email when it's done.

Contents to translate:

Name

Mimo, de la Fundación Barrié, escenificando síntomas de la enfermedad de Behçet.

Content

Firmó un convenio con Fegerec por el que financia unos talleres escolares que sensibilizarán sobre estas dolencias.

No es la primera colaborac...

Request translation!



Machine and Human Translation.

www.rareconnect.org


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3. QUALITY

Over 240 moderators from +20 countries

Tools:

1. Online Community **Charter/Guidelines**
 2. Moderator **Training Guide** (How to be a good moderator)
 3. Day to day **support** via 2 Full time community managers
 4. A private **mailing list** for peer support
 5. **Webinars**
 6. A **Blog** to share best practises
moderators.rareconnect.org
 7. Face to face **workshops**
- 

RareConnect – Oct 2011 Workshop, Paris





Rob Pleticha

- Online Communities Manager
- Aged 28, Education in Psychology (Uni. Of Illinois)
- Previous experience: 2 Years at Romanian RD Alliance

Marta Campabadal

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





- **In 2014 the French Data Protection Agency CNiL accepted our declaration of provision of services as compliant with the EU Directive on Data Protection as implemented in France. Meaning EU compliance.**

Additional quality stamp of approval
French data protection agency CNiL

Activities



The screenshot shows a Zoom webinar interface. On the left is a sidebar with the following sections:

- Attendee List (31)**
 - Photo (1)
 - DEAN COSTELLO
 - Presenters (4)
 - Justin
 - Myriam
 - Ross
 - Victoria
 - Participants (24)
 - andika
 - Denise
 - eggsie
 - Georgie
 - Guest
 - Helen Canfield
 - haloo
- Chat 5 (Private)**

Justin: i may include something about beta carotene later
Timie: Does your sun tolerance get less the older you get?
Victoria: not for me
- Web Links 4**
 - International Porphyria Community
 - Register for International Porphyria
 - Presentations from Lucerne Confere

The main video area shows four participants in a 2x2 grid:

- Top-left: Myriam, a woman with long dark hair and sunglasses, smiling.
- Top-right: Justin, a man with dark hair and glasses, talking on a mobile phone.
- Bottom-left: Ross, a man with glasses and a dark shirt, looking at the camera.
- Bottom-right: Victoria, a woman with long dark hair and glasses, talking on a mobile phone.

At the bottom of the video player, there is a progress bar showing 0:43:09 / 1:26:42 and various control icons.

Living with Erythropoietic protoporphyria (EPP)



eurordis · 131 videos

247 views

Live and on-demand webinars.
Rich Patient exchange

SONIA 2

Prof L. Ranganath
Coordinator for the
DevelopAKUre Project



0:01 / 23:40

Alkaptonuria (AKU) Clinical Trial Webinar: SONIA 2

117 views

Explaining research and clinical trials.
Bridging relationship between patients and researchers

The screenshot displays a video conference interface. The main content area shows an Indiegogo campaign page for "Cure Black Bone Disease". The campaign has raised \$49,030 out of a goal of \$100,000, with 9 days left. A video player is active, showing a man speaking with the text "Active Crowdfunding campaign for AKU." overlaid. The interface includes an attendee list on the left, a chat window, and a speakers panel on the right with three participants. A video player control bar at the bottom shows a progress of 4:09 / 1:30:12.

Learn about Crowd Funding and Rare Diseases

Capacity-building on new trends.
e.g. Crowdfunding

Facebook interface showing a sponsored post for RareConnect. The post includes a search bar, navigation options, and a main image with the word 'HELP' and icons of people and speech bubbles. Below the image is the text: 'Behcet's Syndrome Poll' and 'Nearly 200 people responded to the Behcet's community poll. Here are the results.' The post is marked as 'Sponsored (demo)' and has 103 Likes, 12 Comments, and 12 Shares.

Two additional sponsored posts from RareConnect. The first is titled 'Living with IPF' and features a video thumbnail of a woman with the text 'Imagine not enjoying the simplest things in life because you aren't able to breathe.' The second is titled 'Rett Syndrome Month' and features a video thumbnail of a woman with the text 'Join RareConnect and meet other people living with Rett Syndrome from around the world.'

TIP:
 Don't forget to look at google.com/nonprofits

Targetted online advertising campaigns.
 On Facebook and Google Adwords creating reach of over 3 million people



Creating a poll and infographic for insight into your rare disease

November 8, 2013 - Best practices - 1 comment

Case study: Behcet's syndrome community poll and infographic Background: One of the moderators emailed the RareConnect team and suggested a poll of the international Behcet's syndrome community to better understand what...

[Read Post →](#)



Using Thunderclap to unite your crowd on social media

October 29, 2013 - Tip of the week - Tagged: crowd, Facebook, Social media, twitter - no comments

There are around 985 million new Facebook posts and 400 million new Tweets made every day. How is your disease and message going to stand out? Do you need an...

[Read Post →](#)



October 9 Webinar: Crowdfunding and Rare Diseases

September 26, 2013 - Social media case studies - Tagged: crowdfunding - 9 comments

There has been an increase in crowdfunding projects and websites over the past few years (large amounts of money from individuals) and rare diseases

Tutorials and best practises.

Moderators.rareconnect.org



EURODIS
Rare Diseases Europe

Potential step towards a European Federation

Opens participation in EURODIS Summer School

Opens participation into activity of European Medicines Agency

RareConnect Plan

2015-2020



Structure of the plan 2015-2020

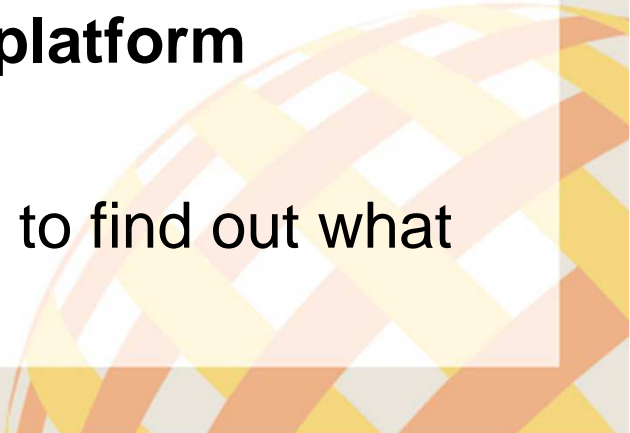
Headings:

1. Governance
2. Management
3. Content Development
4. Funding
5. Communication
6. Design & Technology



Big Picture

By 2020 RareConnect aims to be a platform which:

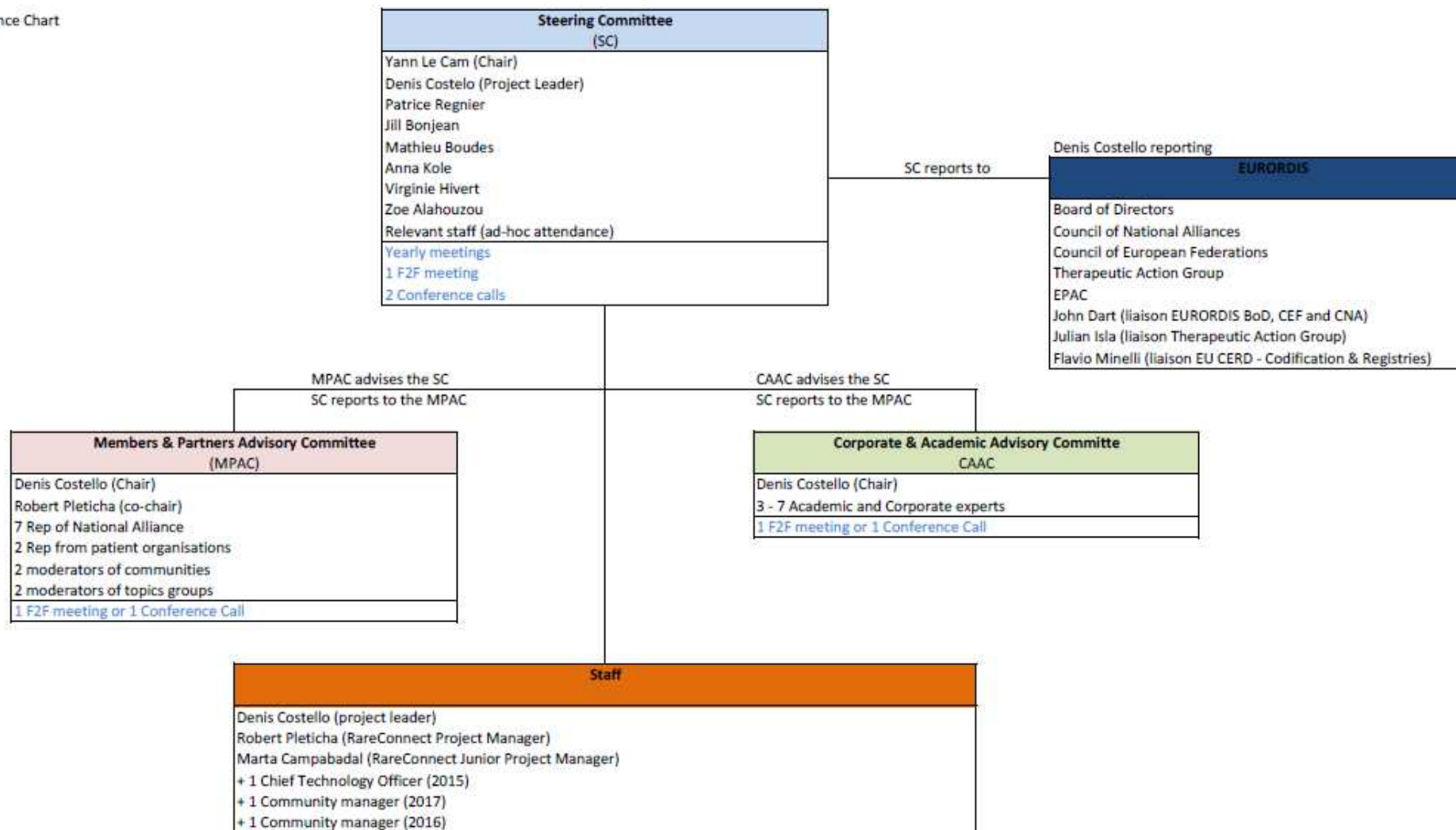
1. Has **300,000** members from 2,000,000 unique visitors annually
 2. Provides over **200** disease specific communities and thousands of discussion groups on issues of relevance to rare diseases
 3. Has partnered with **1000** patient groups providing over **500** moderators
 4. Has become a **reference discussion platform** internationally for rare diseases
 5. Has become a useful **survey platform** to find out what RD patients think about specific issues
- 

Governance

Action items:

- **Develop multi-annual & annual action plans**
 - **Develop a governance chart with Terms of Reference
Implement an annual steering meeting agenda**
 - **Develop partnership with National Alliances (USA & Canada & 2 in EU in 2014; Russia & Japan & 2 in EU 2015; China & 2 in EU 2016)**
 - **Review Charter based on experience, context and academic advice (2016)**
- 

Governance Chart



Governance Model

New approach



- **Partnership signed in 2013**

Basis:

- **Co-promotion of RareConnect**

- Website, Social Media, Newsletter
- Family & association days
- Integration into Information & Orientation service (SIO)

- **In return**

- RareConnect regularly informs FEDER of new communities and of # of Spanish users
- RareConnect attends FEDER and other meetings in Spain and provides material for FEDER volunteers
- RareConnect promotes relevant FEDER activities to communities via platform & social Media



Approach to partnership with National Alliance
Example of FEDER

Model for partnership

Basis (perhaps formalised by short MoU?):

- **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

Management


Action items:

- **Develop HR plan**
 - Hiring 1 Community Manager 2015
 - Hiring 1 Technology Manager 2015
- **Protect the RareConnect brand in key territories**
 - Already done in EU and US (via NORD)
 - In progress for
RU/CH/AU/IN/JP/MX/NZ/NO/AR/CA/TW/CN/BR
- **Define indicators to measure performance**




Content development

Action items:

- **User survey**
 - **Featured Discussion groups**
 - **Launch 25 new communities per year**
 - **Add Portuguese in 2014 and Russian in 2015**
 - **Develop the potential of RareConnect to develop polls/surveys (in conjunction with the EURORDIS Patient Perspective's Pgm)**
 - **EURORDIS Spring School on Social Media for Patient Organisations (2015 Barcelona)**
- 

Communication

Action items:

- **Kindle relationship with journalists from publications of standing to achieve notoriety in the press**
 - **Develop in kind partnership with Third level institution specialised in Social Media communication to provide advice or interns**
 - **Develop the visibility of RareConnect with RDD**
 - **Work with CNA to disseminate country specific survey findings via country/regional press**
 - **Develop partnerships with Learned Societies/Orphanet**
- 

Funding

Action items:

- **Secure current funding**
- **Develop multi-annual funding**
- **Convert users of RareConnect into recurrent donors**
- **Develop Crowdfunding activity**
- **Other fundraising activities**



Design & Technology

Action items:

- **Launch Discussion Group platform on cross-disease topics as well as very rare diseases**
- **New logo**
- **New homepage**
 - Emphasising our Guarantee to users & our competitive advantages
 - No data sharing without consent
 - Data Protection Compliant
 - EURORDIS credentials as a patient-led non profit
 - Partnership with Patient Organisations
 - Multilingual
 - Moderated



DISCUSSIONS GROUPS

Ask questions and search answers from the experiences of people living with a rare disease

450 QUESTIONS ANSWERED | 201 PEOPLE JOINED | 34 STORIES SHARED

[See how it works](#)

Type your question

SEARCH

OR ASK A QUESTION

RECENTLY SEARCHED

- Topic name
- Topic name
- Topic name
- Community name
- Topic name
- Topic name
- Topic name
- Community name
- Community name
- Topic name
- Topic name
- See all topics

Recents

QUESTIONS & ANSWERS

FILTER OPTIONS

10
VOTES

8
ANSWERS



PUBLISHED 1 MIN AGO BY MARC PUBLIC

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- Topic name
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- Community name

QUESTIONS&ANSWERS

FILTER OPTIONS

1 ANSWERS



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ANSWER

5 VOTES



Most active PUBLISHED 1 MIN AGO BY MARC PUBLIC

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Topic name Topic name Community name

VOTE ANSWER

SHARE THIS TOPIC WITH OTHERS



TOPIC INFORMATION

NAM PORTTITOR BLA

Topic description: Lorem ipsum dolor sit amet, adipiscing elit. Aenean commodo ligula eget dolor. Aenean massa. Cum sociis natoque penatibus et magnis...

PEOPLE FOLLOWING THIS TOPIC



FOLLOW THIS TOPIC

MODERATORS



SUGGEST YOURSELF

Discussion Groups

New features





RareConnect.org
A EURORDIS INITIATIVE

Discussion Groups
New features

Involvement in other projects

IMI project (starts 2014 Q4):

- **WEB-RADR, Pharmacovigilance signal detection via Social Media data mining.**
 - RareConnect communities to be one source of data
 - RareConnect to provide 1 community manager to coordinate patient participation and patient input to governance (with Francois Houyez)

Currently exploring possibilities for partnership with other EU projects for H2020



Thanks

And if you'd like to contact us:

Here we are:



www.facebook.com/rareconnect



[@rareconnect](https://twitter.com/rareconnect)



www.youtube.com/user/eurordis



www.rareconnect.org



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