

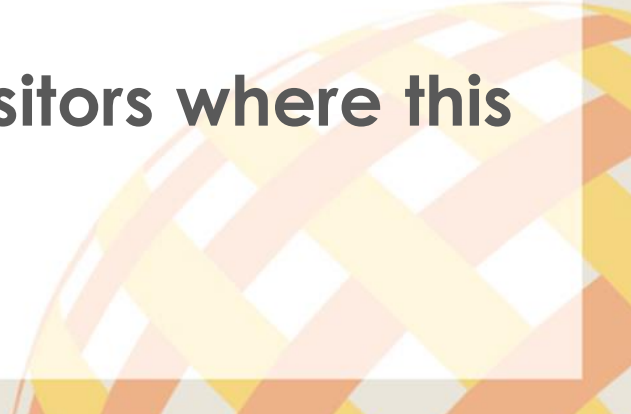


Moderator Webinar
Introducing Moderator Blog,
EURORDIS TV, RDD 2014,
Project Update

RareConnect today

- **43 communities**
- **125 volunteer moderators - THANKS**
- **362 patient group links**
- **5,239 members**
- **40,000 unique pageviews per month, average time on site is 2 min. 30 sec.**

RareConnect – Tech Upgrades 2013


- **Smartphone WebApp**
 - **Adapted design e.g. more of a dashboard feel**
 - **Add sub communities to certain disease communities**
 - **Improved usability of translation features**
 - **New language**
 - **Waiting list / Contact Service for visitors where this is currently no community**
- 

Tech updates

- **Your suggestions? Is there anything you would like improved or changed when using RareConnect?**

By email anytime: team@rareconnect.org

Community updates

- We're sending out 4 email updates per year on community usage to all moderators.
 - Updates include statistics on:
 - number of members, testimonials, forum posts, articles
 - Over last 3 months:
 - #visitors, pages per visit, most visited pages, visitor countries, visitor search terms, referral websites
- 

Dear Kay, Kerry, Michelle, Jan, and Sebastian,

We've been looking over how people find and use the Alstrom syndrome community on RareConnect and wanted to share with you. We encourage you to post an update about your patient group on the community. You can also email the RareConnect team you see on copy here when you have a new event, document, or video to add. Please remind your members that this resource exists and that human translation is available for them to connect to other families across the language barrier.

Alstrom Syndrome on RareConnect:

<https://www.rareconnect.org/en/community/alstrom-syndrome>

Since its creation the Alstrom community has:

- 3 patient groups featured
- 37 registered members
- 7 articles
- 1 testimonial
- 21 forum topics

Data below is from the last 3 months - March 24th - June 24th

Who has visited the Alstrom Syndrome Community over the past 3 months?

217 unique visitors

What do they do when they visit?

These visitors visit 3,20 pages on average

These are the most visited pages of your community:

<https://www.rareconnect.org/en/community/alstrom-syndrome/article/kion-1>

<https://www.rareconnect.org/en/community/alstrom-syndrome/forum/topic/latest-article-alert-from-orphanet-journal-of-rare-diseases-brain-involvement-in-alstrom-syndrome>

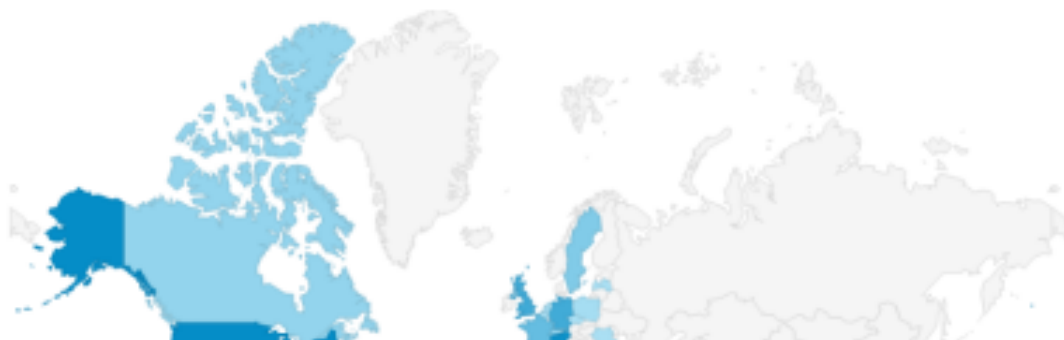
<https://www.rareconnect.org/en/community/alstrom-syndrome/forum/topic/original-language/alstrom-syndrome-international-to-hold-7th-family-conference-and-scientific-symposium>

<https://www.rareconnect.org/en/community/alstrom-syndrome/forum/topic/implugen>

Where are visitors coming from?

Top 10 countries with most visitors:

1. United States 37
2. Italy 35
3. Germany 24
4. United Kingdom 24
5. France 16
6. Sweden 10
7. Spain 7
8. Peru 7
9. Canada 6
10. Switzerland 6



Community updates

Anything else you want to know about how people are using your community?

Are you finding these updates useful?



Moderator Blog

- **Collection of resources for RareConnect moderators and those interested in social media**
- **Four main sections: Best Practices on RareConnect, Social Media Case Studies, Promoting RareConnect, Resources**
- **All webinars, presentations from RareConnect workshops, will be posted there...please share the link**

Best Practices on RareConnect

Category Archives: Best practices



Answering general questions on rare diseases

June 19, 2013 - [Best practices](#) - Tagged: [GARD](#), [Orphanet](#) - [no comments](#)

The RareConnect team receives many general rare disease questions by email through the contact section of the communities. For example, What is/are the treatments for paraneoplastic neurological syndrome and how important...

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RareConnect workshop during the EURORDIS Membership Meeting 2013

June 11, 2013 - [Best practices](#) - [1 comment](#)

The RareConnect team was pleased to welcome over 60 patient group representatives to its workshop on social media during the 2013 EURORDIS Membership Meeting in Croatia. To view the presentations,...

[Read Post →](#)



RareConnect Privacy Checklist

April 24, 2013 - [Best practices](#) - Tagged: [privacy](#) - [no comments](#)

We want to keep you and your health information safe and private online. RareConnect does not sell data to third parties or in any way share the information you add...

[Read Post →](#)



Highlighting the best practices of moderators

April 23, 2013 - [Best practices](#) - Tagged: [HSP](#), [moderators](#) - [no comments](#)

Highlighting the best practices of moderators: Frank on the Hereditary Spastic Paraplegia community Frank Davis is the President of the Spastic Paraplegia Foundation, a person living with hereditary spastic...

[Read Post →](#)

Social Media Case Studies

Category Archives: Social media case studies



Twitter Tips: Useful strategies when writing Tweets

June 25, 2013 - Social media case studies - Tagged: Social media, twitter - no comments

Burston-Marsteller is a PR firm that has archived all of their tips for using Twitter effectively in to one place. We hope you find it as useful as we have....

[Read Post →](#)



Putting a face on the disease: recording a basic patient testimony video

June 13, 2013 - Social media case studies - no comments

The power of patient stories to illustrate how to live with the disease is extremely powerful. When patients can read experiences similar to their own, and gain insight on how...

[Read Post →](#)



Creating a landing page on social media sites

June 11, 2013 - Social media case studies - Tagged: Facebook, social media case studies, twitter - 1 comment

During some of our workshops, people have asked, "What is the minimum I can do on social media?" The answer is to at least create an account and landing page...

[Read Post →](#)



Stay focused

May 27, 2013 - Social media case studies - Tagged: Facebook - no comments

People Liked your page, or Followed your account for a reason: they are interested in the disease your page seeks to support. Don't overuse off topic posts, sharing of pages...

[Read Post →](#)



Adding photos to your posts

May 27, 2013 - Social media case studies - Tagged: Facebook, Social media - no comments

Use photos, videos, memes, and infographics whenever possible to make your posts more engaging and share able. Just a headline and a link may not catch a reader's eye. This...

[Read Post →](#)

Moderating well

Resources

[Starting a community](#)

[Online Communities Charter or terms and conditions](#)

[Moderator Guide detailing how moderators can use the platform to connect with others](#)

[Webinars where moderators can learn and interact](#)

[Mailing list for questions on moderation to other moderators](#)



How can we use the Moderator blog to recognize your volunteer efforts?

Photos of moderators, and name of patient group?

Your ideas?

How would you like to be acknowledged? LinkedIn?

EURORDIS TV:

<http://www.eurordis.org/TV>



Living with MSA: memories for my daughter

Sam has Multiple System Atrophy (MSA), a disorder that will leave her unable to move and speak. Her daughter Rhanna is 16 and has had to grow up fast to care for her mum. Sam is assembling a box of memories, hopes and dreams so a piece of her can always be by Rhanna's side.



INFO

▼ NEWS & CURRENT ISSUES CHANNEL



Remarks on the June 13, 2013 Supreme Court ruling on gene patents - Larry

18.06.2013 12:27



Privacy and security challenges in today's e-health systems: Danny De

18.06.2013 18:26



Key concepts of orphan designation and latest developments

04.06.2013 24:11



BBC Parliament, Petition by aHUS patients & families

15.05.2013 5:38



NIH, EURORDIS and more on globalizing orphan drug access

13.05.2013 38:23

Categories

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▶ HEALTH POLICY CHANNEL

▶ RARE DISEASE DAY CHANNEL

▶ EURORDIS EVENTS CHANNEL

▶ NON-ENGLISH VIDEOS CHANNEL

▶ Your videos can be submitted by email:
tv@eurordis.org OR via Twitter [@EURORDIStv](https://twitter.com/EURORDIStv)

Rare Disease Day 2014 – 7th edition

- **Theme: CARE**
- **Slogan: Join together for better care**
- **New and improved**
<http://www.rare diseaseday.org/> will be launched 100 days before Rare Disease Day in November
- **Know a video producer? Call for RDD 2014 video is open until August. Email Rob for details.**

Involved in registries?

- International Summer School "Rare Disease and orphan drug registries" to be held in Rome in September 2013.
- 5 Fellowships available. Deadline end of July.
- More details here: <http://www.epirare.eu/news/20130916.html>



**The next webinar will be:
Wednesday, July 24th
Same time, same place
20h CET/14h ET USA**