

THE IMPORTANCE OF THE ONLINE PATIENT COMMUNITIES

EURORDIS COUNCIL OF EUROPEAN RARE DISEASE FEDERATIONS

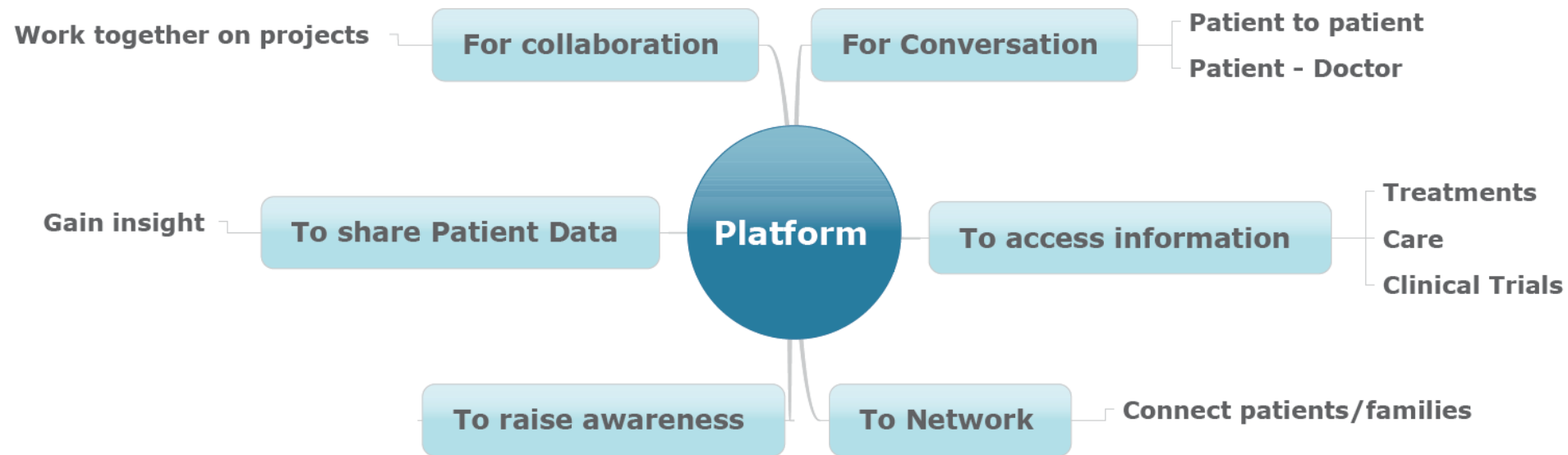


Denis Costello

Web Communications Officer, EURORDIS

What is an Online Patient Community?

2



Explore and Learn

Learn more about the cause of Duchenne/Becker muscular dystrophy, genetics and genetic testing, carrier status, and care and management for you or your family member.



3

Login

Username

Password

Login

[Forgot login?](#)

Newsflash

NEW

Now Available! Clinical Services Resource for Duchenne Muscular Dystrophy

We are pleased to announce an exciting resource coming to PPMD through the DuchenneConnect Registry: The Clinical Services Resource.

Listen to the AVI BioPharma Webinar (6/20/11)

Chris Garabedian, CEO of AVI

BioPharma, participated in a webinar on the latest Duchenne/Becker testing technology. On June 20, 2011, Chris reviewed AVI's company's Phase 2 exon 51 ...

Register Now!

DuchenneConnect serves as a central hub linking the resources and needs of those living with Duchenne/Becker muscular dystrophy and the professional community, including clinicians, policymakers, industry professionals, and medical researchers.

We offer registered members resources to assist with early, appropriate and least invasive diagnosis, care, and management; better understand the benefits and limitations of genetic testing; and assist in understanding and development of new treatment trials.

Learn from the Community!

DuchenneConnect members report the first concerns or symptoms of Duchenne Muscular Dystrophy:



Example - Aggregating patient data

www.duchenneconnect.org

Professionals - Visit the Research Portal



Home

- [Login](#)
- [Profile](#)
- [Register](#)

MSS TRANSLATION

English

GOOGLE TRANSLATE

Select Language

Powered by **Translate**
Google

LATEST NEWS

- [MSS Family Event 2011](#)
- [Nieuws mei 2011](#)
- [Questionnaire](#)
- [Maya](#)

Marshall-Smith Syndrome

MSS Family Event 2011

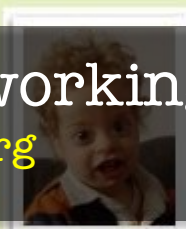


MSS: Reaching for the STARS

Liesbeth Laan, a school nurse based in The Hague, Netherlands, had a smooth pregnancy and delivered Joas at home in July 2006. But for the first six months of his life, the baby boy was in and out of hospital. 'Immediately after his birth, he had breathing difficulties and stayed in the hospital for a month. He had a narrowed throat and nose and he had

Example – Networking patients

www.marshallsmith.org



search...



HAEi

International Patient Organization
for C1 Inhibitor Deficiencies

Choose language English | Français | Deutsch | Italiano | Español

Choose country

Search this site

“SUFFERING FROM HEREDITARY ANGIOEDEMA (HAE)? YOU ARE NOT ALONE.”

[Login](#) or [Register](#)

5

- Home
- HAE Disease
- About HAEi Organization
- Worldwide Organizations
- HAE Care
- Medication
- News
- Events
- Publication

HAE CARE

[show / hide](#)

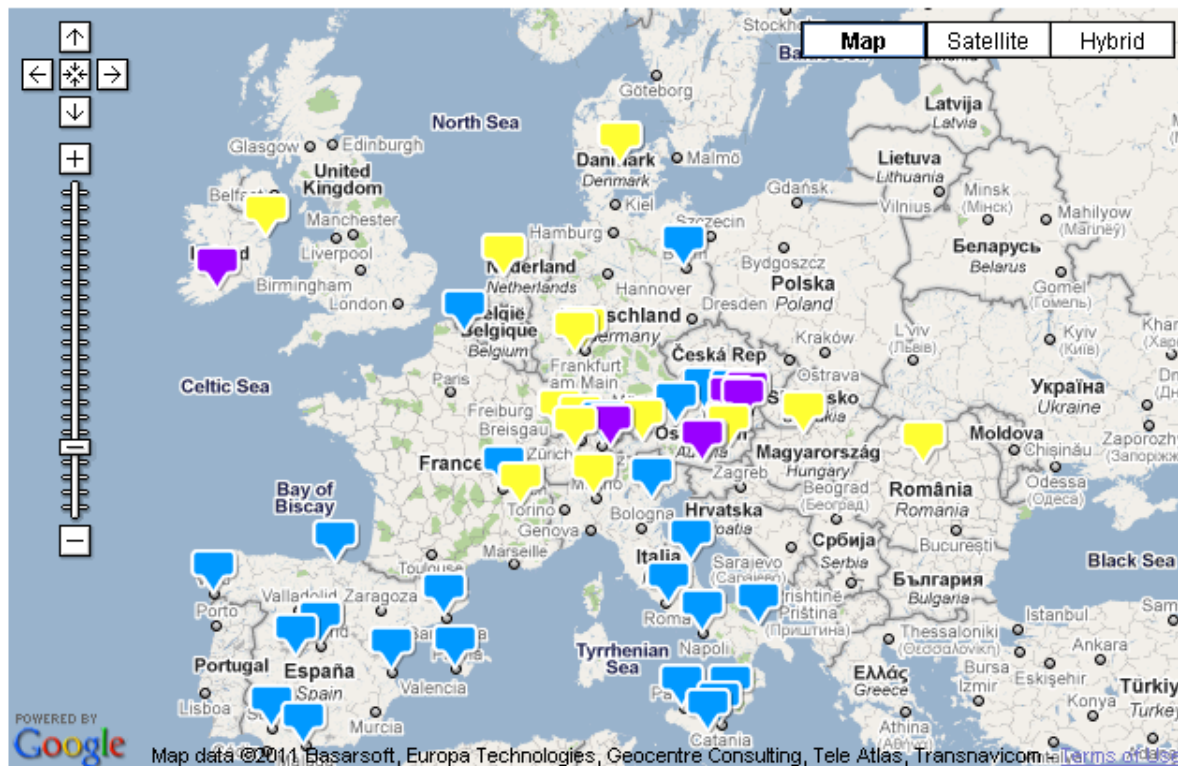
Care Centers

Hospitals

Physicians

Please click the icons on the map to get more information about Care Centers, Hospitals and Physicians.

On this page you can find information about Care Centers, Hospitals and Physicians. Simply zoom in or out on the map and click on the icon for the relevant country and/or region.



Example – Rich way of providing care information

www.haei.org

ViroPharma's Cinryze® (C1 Inhibitor [Human])

EVENTS

Sat, 2011-09-03 12:00 - 22:00

[HAEi - General Assembly](#)

HAE GLOBAL COMMUNITY

[Be part of the community](#)

All results

- People
- Pages
- Groups
- Apps
- Events
- Web results
- Posts by friends
- Posts by everyone
- Posts in groups

All results

Pulmonary Hypertension

**Pulmonary hypertension**Page
12 people like this.**Pulmonary Hypertension**Page
8 people like this.**Pulmonary Hypertension**Page
7 people like this.**Pulmonary Hypertension**Page
1 person likes this.**Pulmonary Hypertension Association**Page
4,257 people like this.**Pulmonary Hypertension Awareness**Page
128 people like this.**Pulmonary Hypertension Association Europe**Page
374 people like this.**Toledo Area Pulmonary Hypertension**Page
123 people like this.**Battling Pulmonary Hypertension Together**Page
61 people like this.

Example – Your presence on Facebook

www.facebook.com



Wall

- Info
- Send a message
- YouTube
- Welcome
- Photos
- Discussions

About

The primary objective of PHA EUROPE is to establish a narrow cooperation be...

More

375

people like this

Pulmonary Hypertension Association Europe

Non-profit organisation



Wall

Pulmonary Hypertension As... · Most recent ▾

Share: Post Photo Link Video

Write something...



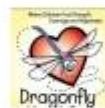
Kimberlee Ford

Time to spread Pulmonary Hypertension Awareness!

Hope you have your PH items ready for July 8th- shirts, hats, bracelets, and pins. Also, if you have wallet cards (green PH cards) or brochures, pass them out to at least 20 people who know nothing about PH. Spread the word and get everyone in the world involved on July 8th!--- It is not...

See more

6 hours ago via FriendCaster for Android · Like · Comment



Dragonfly Heart Camp, Inc.

<http://www.facebook.com/video/video.php?v=2108694398371>

Enjoy our Video. A camp for kids with PH>



Dragonfly Heart Camp Video [HQ]

Enjoy our awesome video of the campers at Dragonfly Heart Camp. Please feel free to share with your friends & family.

Length: 7:14

14 June at 18:29 · Like · Comment · Share

Example – A Facebook conversation

<http://www.facebook.com/pages/Pulmonary-Hypertension-Association-Europe>

🏠
Conditions
Clinical Trials
Resources
Healthcare Providers

Brave Community
is a dynamic source of information and insights about certain rare diseases.

Customize your experience

- Filter relevant news
- Read and share personal stories
- Learn about conditions
- Receive updates and information on clinical trials process


Create an Account

✉ **Receive Monthly Newsletters**

Enter Your Email Address Submit

Fabry Disease
Hereditary Angioedema
Metachromatic Leukodystrophy
Sanfilippo Syndrome

Fabry Disease



Fabry Disease is a rare hereditary disease that is characterized by heart, kidney and central nervous system problems as well as pain in the hands and feet (acroparesthesia), skin rashes (angiokeratoma), heat intolerance, fatigue, and frequent stomach upset including cramping, diarrhea, and nausea.

[READ MORE >](#)

7,000 Bracelets for Hope(TM) Campaign Raises Awareness for Over 7000 Rare Diseases - Redorbit.com

Couple lobbied Congress about rare diseases - Journal-News
Charlene and George are working to bring

Raise Your Hand to Help Millions of Americans Affected by Rare Diseases - Business Wire

For Healthcare Professionals

Are you a healthcare provider looking for a dynamic resource of information about certain rare disorders? BraveCommunity.com is pleased to offer disease overviews, case studies, resources and the latest news all in one place, and all specifically created for healthcare providers. Click here for more information.

[READ MORE >](#)

Hunter Syndrome & Gaucher Disease

We've recently re-organized our BraveCommunity.com website. Information on Hunter syndrome (MPS II) can now be found at www.HunterPatients.com, and our Gaucher disease information is located at www.GaucherPatients.com. Please visit these sites to stay updated on the latest disease information.



WIKIPEDIA
The Free Encyclopedia

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Interaction
Help

Article Discussion

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Ataxia

From Wikipedia, the free encyclopedia

For other uses, see [Ataxia \(disambiguation\)](#).



This article **needs additional citations for verification**. Please help [improve this article](#) by adding [reliable references](#). Unsourced material may be [challenged](#) and [removed](#). *(September 2009)*

Ataxia (from Greek α- [used as a negative prefix] + -τάξις [order], meaning "lack of order") is a **neurological sign and symptom** that consists of gross lack of **coordination of muscle movements**. Ataxia is a non-specific clinical manifestation implying dysfunction of the parts of the **nervous system** that coordinate movement, such as the **cerebellum**. Several possible causes exist for these patterns of neurological dysfunction. The term "dystaxia" is a rarely used synonym.

The International Ataxia Awareness Day is observed on September 25 each year.^[1]

13. Giuseppe Vallar, MD, Spatial Neglect, Balint-Holmes' and Gerstmann's Syndromes, and Other Spatial Disorders CNS Spectr. 2007;12(7):527-536

External links

- Ataxia UK Charity [↗](#)
- Brasil, Rio Grande do Sul - Associação dos Amigos, Parentes e Portadores de Ataxias Dominantes [↗](#)
- University of Minnesota Ataxia Center [↗](#)
- Ataxia Connect Social Network [↗](#)
- Overview [↗](#) at National Institute of Neurological Disorders and Stroke (NINDS)
- US National Ataxia Foundation [↗](#)
- Ataxia UK [↗](#), including guidelines [↗](#)
- GeneReview/NIH/UM entry on Hereditary Ataxia Overview [↗](#)
- International Ataxia Awareness Day [↗](#)
- Ataxia Forums [↗](#)
- LivingWithAtaxia Forums & Community [↗](#)
- Canadian Association for Familial Ataxias - Claude St-Jean Foundation [↗](#)
- The latest news and research on Ataxia [↗](#)
- Video [↗](#) from the US Department of Agriculture of a sheep with scrapie
- GeneReview/NIH/UM entry on Hereditary Ataxia Overview [↗](#)

v · d · e

Symptoms and signs: nervous and musculoskeletal systems (R25–R29, 781.0, 781.2–9)

Movement disorders · Dyskinesia: Athetosis · Tremor · Dyskinesia

Example – A place for people to find you?

www.wikipedia.org



Talk:Ataxia

From Wikipedia, the free encyclopedia

incomplete - missing some common causes of ataxia and going into details in some of the uncommon ones. --Nehwyn 20:26, 25 June 2007 (UTC)

Consensus for splitting?

[edit]

There seems to be a firm intention by an editor to split this article in two ([cerebellar ataxia](#) and [sensory ataxia](#)), either by pasting content from the main article (a proper split), or by writing duplicate info ex novo (a "branching out", if you want). I have repeatedly asked the editor in question to gain consensus for his proposed division on this talk page, but he seems unavailable to do so. Therefore I'll do it in his/her stead: is there a consensus to either paste or duplicate the info on this page on two pages? ----Nehwyn 15:54, 6 August 2007 (UTC)

• **Oppose** - And here is my opinion: I prefer to keep the present article as it is unless the new pages have *more* (not less!) info than the main one. ---Nehwyn 15:54, 6 August 2007 (UTC)

- Please review the [edit history](#). [Sensory ataxia](#) always has been a distinct article, so it's not up to me to demonstrate a consensus to split; it's up to you to demonstrate a consensus to merge. Most of the support for a single ataxia article has been from three single-purpose IP accounts ([87.3.185.18](#), [87.17.214.56](#), and [79.9.191.133](#)). I have no problem with supporting your merge proposal if that's what a consensus of established editors want. But since you're the one that wants the change, you're the one that needs to generate support for it. I don't have a problem with leaving [ataxia](#) alone, to be structured as you desire. But if you're insisting that [sensory ataxia](#) now redirect to ataxia, you're going to have to follow process. Since we disagree, I'd encourage you to list the issue at [Wikipedia:Proposed mergers](#) to get feedback from a broader audience. --Arcadian 17:37, 6 August 2007 (UTC)

Arcadian, the articles were merged at that time without opposition. Had opposition been manifested at that time, consensus would have been requested for it, but since there was no opposition, the change proceeded undisputed. Months later, in order to split the article again, the same process applies, only this time opposition has been manifested, so a consensus debate has been requested. Should consensus emerge for the three-article solution, that is what we will go for. Should the one-article solution be preferred, the duplicate articles will be turned into redirects again. You are free to duplicate info from the main article to other two in the meanwhile. --Nehwyn 17:59, 6 August 2007 (UTC)

• **Oppose** - see my remarks at [Talk:Cerebellar ataxia](#). The editor advocating (and making) the split responded "Within a year this page will be far better than the content currently in [ataxia](#)." Let's keep the existing information in place until then. --Cliff 17:25, 6 August 2007 (UTC)

• Can someone clarify: from the current entries, it appears that [cerebellar ataxia](#) is a recognized diagnosis (hence warrants its own article), [ataxia](#) is a recognized diagnosis (with a separate diagnosis code from cerebellar ataxia), while [sensory ataxia](#) appears as a symptom. Is this correct? If [sensory ataxia](#) has always been a separate article, what is the reasoning for the merge? I don't find any above. [SandyGeorgia](#) (Talk) 18:00, 6 August 2007 (UTC)

Nope; all three terms refer to neurological syndromes (an ensemble of signs and symptoms) and do not represent a "standalone" diagnosis or disease. Note that "cerebellar ataxia" does not have a separate code from ataxia in ICD-10; the one it was assigned in ICD-9 was removed from the current ICD precisely for this reason (that "cerebellar ataxia" is not a diagnosis, just a generic presentation of a variety of cerebellar diseases and intoxications). To make it clearer to non-medics out there: when a patient goes to the doctor complaining of incoordination, first the doctor examines the patient to establish whether that incoordination indeed represents cerebellar dysfunction ("ataxia"), and in that case whether the cerebellum is unable to function properly because it is itself diseased (which would warrant the "cerebellar" adjective) or because it is not getting the input it needs (which would warrant either the "vestibular" or "sensory" adjective, depending on which input is impaired). According to this reasoning and to the current ICD, the content from the articles about sensory and cerebellar ataxia had been merged into the current one, and the pages turned into redirects to that. Now they have just been split again, and I requested the involved editor to gain consensus for that, but he ignored the request, so I opened the debate in his/her stead. --Nehwyn 18:22, 6 August 2007 (UTC)

Please bear with the laypersons here :-). Are you saying that cerebellar and sensory are subsets of ataxia, with different etiologies (dysfunction in the cerebellum or otherwise)? And if that's correct, and if they have different etiologies (questions from a layperson), why then would they not be separate articles? As an analogy I understand, I wouldn't want [Tourettism](#) merged to [Tourette syndrome](#). They have the same symptomatic result, but different etiologies. There is no formal "tourettism" diagnosis, as far as I know, but it still warrants its own article. [SandyGeorgia](#) (Talk) 18:52, 6 August 2007 (UTC)

They are different localisations of ataxia. (Laypersons' note: The term "localisation" has a specific meaning in neurology. When approaching a patient with a neurological complaint, such as "incoordination" or "imbalance", first you establish what neurological sign/symptom corresponds to the patient's complaint, then you "localise it", i.e. you try and determine which part of the nervous system is causing it - since most neurological signs/symptoms may be generated by disease processes in different parts of the nervous system). Responding to your question, sensory and cerebellar ataxia can present either separately or together, and their aetiologies overlap: in other words, some diseases/intoxications produce only one or the other, whereas others produce both at the same time, and the vast majority of hereditary disorders fall in the latter category. They are not mutually exclusive entities as Tourette syndrome and tourettism are. --Nehwyn 19:29, 6 August 2007 (UTC)

OK, I'm with you so far. So what are the advantages and disadvantages of separate articles? Arcadian states that they've always been split; why should we merge them? [SandyGeorgia](#) (Talk) PS, to continue the analogy that I understand, [tourettism](#) and [Tourette syndrome](#) can't be "proven" to be mutually exclusive until there is a definitive genetic test. [SandyGeorgia](#) (Talk) 19:54, 6 August 2007 (UTC)

On the contrary, a quick check to the history of the articles in question will show you that actually they have not always been split. In the beginning, there were three articles with some duplicate info; these were unopposedly merged (based on the reasoning exposed above), and merged they stayed until Arcadian's intention to split them off again a few days ago. He was then requested to obtain consensus before doing so, but he ignored that request and proceeded anyway. As soon as I got back online, I called this debate in his stead in order to verify whether any consensus exists in favour of his "three-article" solution over the "one-article" solution. --Nehwyn 19:58, 6 August 2007 (UTC)

PS - About Tourette's: not quite. I'll be happy to clarify your doubts, but do ask on the talk page of either of those articles, otherwise we'll just create confusion over here. --Nehwyn 20:16, 6 August 2007 (UTC)

In both cases, the article histories reveal they were separate articles (for several years) until you recently redirected them. [SandyGeorgia](#) (Talk) 20:51, 6 August 2007 (UTC)

Regardless of history, I still don't see the pros and cons of separate or merged articles. [SandyGeorgia](#) (Talk) 20:02, 6 August 2007 (UTC)

Wikipedia is not a journal. The only way to ensure that the information on Wikipedia is accurate and up-to-date is to have a large number of editors who are not directly involved in the work of the encyclopedia (in addition to the way it is treated in most other encyclopedias). The only way to ensure that the information on Wikipedia is accurate and up-to-date is to have a large number of editors who are not directly involved in the work of the encyclopedia (in addition to the way it is treated in most other encyclopedias).

• **Support continued separate articles**, as has always been the case. No convincing reason for merging these articles, which have been separate for several years and represent different issues, has been given. [SandyGeorgia](#) (Talk) 20:51, 6 August 2007 (UTC)

It just makes sense for a merge given the neurophysiological overlap in mechanisms for the diseases. I cannot believe that it got to such a major debate. SteveD 3rd may 2008. 13:47. --Preceding unsigned comment added by 58.168.20.223 (talk) 03:48, 3 May 2008 (UTC)

Example – Conversations taking place without you?

Revision history of Ataxia

From Wikipedia, the free encyclopedia

[View logs for this page](#)

Browse history

From year (and earlier): From month (and earlier): Tag filter: Deleted only

For any version listed below, click on its date to view it. For more help, see [Help:Page history](#) and [Help:Edit summary](#).

External tools: [Revision history statistics](#) · [Contributors](#) · [Revision history search](#) · [Number of watchers](#) · [Page view statistics](#)

(cur) = difference from current version, (prev) = difference from preceding version, **m** = [minor edit](#), **→** = [section edit](#), **←** = [automatic edit summary](#)

(latest | [earliest](#)) [View](#) ([newer 50](#) | [older 50](#)) ([20](#) | [50](#) | [100](#) | [250](#) | [500](#))

[Compare selected revisions](#)

- [\(cur | prev\)](#) [14:58, 3 June 2011](#) [79.25.143.198](#) ([talk](#)) (18,031 bytes) (*Reverted: BrE is acceptable in Wikipedia*) ([undo](#))
- [\(cur | prev\)](#) [23:45, 31 May 2011](#) [67.214.225.154](#) ([talk](#)) (18,030 bytes) (*→Focal lesions*) ([undo](#))
- [\(cur | prev\)](#) [14:35, 27 May 2011](#) [79.11.133.213](#) ([talk](#)) (18,031 bytes) (*Reverted: one edit is subtle vandalism, the other is inaccurate*) ([undo](#))
- [\(cur | prev\)](#) [03:54, 25 May 2011](#) [174.109.145.43](#) ([talk](#)) (18,106 bytes) (*→Exogenous substances*) ([undo](#))
- [\(cur | prev\)](#) [09:21, 23 May 2011](#) [98.231.53.200](#) ([talk](#)) (18,031 bytes) ([undo](#))
- [\(cur | prev\)](#) [10:38, 18 May 2011](#) [SidP](#) ([talk](#) | [contribs](#)) **m** (18,031 bytes) (*→Sensory: punctuation*) ([undo](#))
- [\(cur | prev\)](#) [10:36, 18 May 2011](#) [SidP](#) ([talk](#) | [contribs](#)) (18,033 bytes) (*→Treatment: spacing, wording*) ([undo](#))
- [\(cur | prev\)](#) [10:33, 18 May 2011](#) [SidP](#) ([talk](#) | [contribs](#)) **m** (18,103 bytes) (*→Wilson's Disease: links, external link labeling, spacing, italics*) ([undo](#))
- [\(cur | prev\)](#) [10:31, 18 May 2011](#) [SidP](#) ([talk](#) | [contribs](#)) **m** (18,115 bytes) (*→Arnold-Chiari Malformation: capitalization*) ([undo](#))
- [\(cur | prev\)](#) [10:30, 18 May 2011](#) [SidP](#) ([talk](#) | [contribs](#)) **m** (18,115 bytes) (*→Radiation Poisoning: capitalization*) ([undo](#))
- [\(cur | prev\)](#) [12:18, 17 May 2011](#) [Heloda](#) ([talk](#) | [contribs](#)) (18,115 bytes) (*→Cerebellar*) ([undo](#))
- [\(cur | prev\)](#) [06:55, 17 May 2011](#) [79.25.143.49](#) ([talk](#)) (18,115 bytes) (*→Cerebellar: All parts of the cerebellum control body and limb movements..*) ([undo](#))
- [\(cur | prev\)](#) [06:54, 17 May 2011](#) [79.25.143.49](#) ([talk](#)) (18,178 bytes) ([undo](#))
- [\(cur | prev\)](#) [23:15, 16 May 2011](#) [Heloda](#) ([talk](#) | [contribs](#)) (18,178 bytes) (*→Cerebellar*) ([undo](#))
- [\(cur | prev\)](#) [23:16, 15 May 2011](#) [Ecanfield](#) ([talk](#) | [contribs](#)) (17,926 bytes) (*→Wilson's Disease*) ([undo](#))
- [\(cur | prev\)](#) [23:07, 15 May 2011](#) [Ecanfield](#) ([talk](#) | [contribs](#)) (17,940 bytes) (*→Wilson's Disease*) ([undo](#))

Example – See who's interested in you?

www.wikipedia.org

Why Online Communities are important?

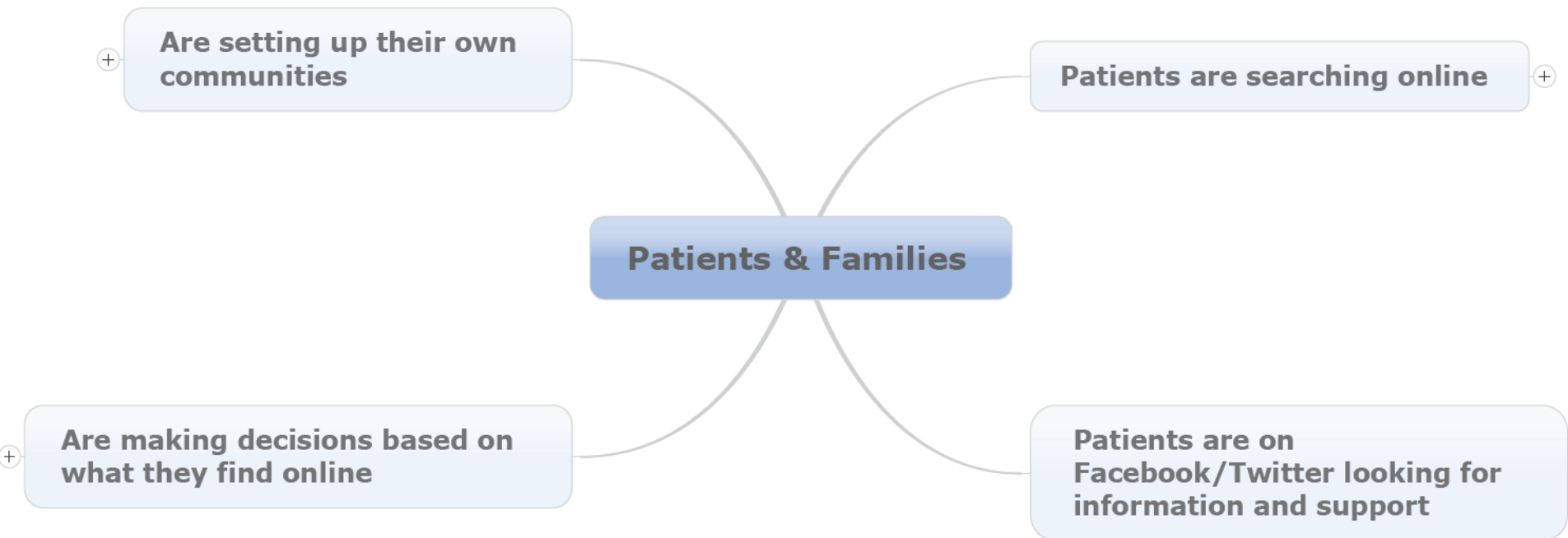
12



By enabling a community – you are providing value

New Online Patterns

13





Patients looked for additional information as they wanted further details about the disease

28%

wanted further details about the disease

14%

Information about management

14%

Out of curiosity

12%

To gain reassurance

3%

To compare own situation with other ITP patients

Details*

More than half of patients seeking additional information on ITP used the internet



56%

**sought information from
the internet**

(including Google, forums etc)

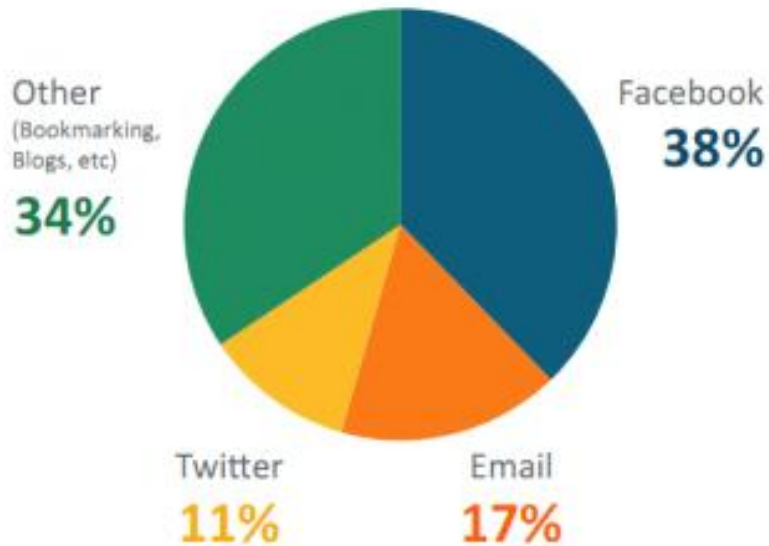
33%

**of ITP patients
sought information
from healthcare
professionals**

The evolving web

16

CLICKING ON LINKS BY SHARING CHANNEL



THEN	NOW
BROWSER	— APPS
SYNDICATION	— SUBSCRIPTION
GOOGLE!!	— GOOGLE??
FREE	— FREEMIUM

Sharing is 31% of
site referral traffic!



Interim Conclusions

17

- Visibility of traditional Rare Disease patient groups in Organic Google Search results and on Facebook or Twitter **could be better**
 - Quite a lot of single voices – **Opportunity for relationship building**
 - Moderate degree of noise & risk of misinformation – **Opportunity** for patient groups to play **Quality Assurance** role
 - Social Media gives great opportunity to **build awareness** of the disease and highlight the patient's perspective
 - So much information – **create value** by synthesising the best information with editorial priority on the patient's perspective
-

Solutions / Ideas

18

- Think about **building a community** and serving that communities information needs
 - Think about **content** (Conference updates, News, Video, Blog, Tweets)
 - Build a **presence on Facebook & Twitter** and/or support existing conversations there
 - Allow users to **share** your content easily (Like Button etc)
 - Invest in **Search Engine Optimisation** (Code & Link Building)
 - Invest in Google & Facebook **advertising** in the short term
 - Participate in collaborative projects e.g. **rarediseasecommunities.org**
-

Rare Disease Communities helps patients to understand their condition, connect with other patients and provides tools for living with their diseases

Understand.

Daily life with a rare disease.

- Browse patient testimonies,
- Share images & photos,
- Find explanations,
- Contact patient associations

Meet!

Connect with other patients.

- Start conversations,
- Interact with others,
- Ask questions,
- Meet other patients or families

Learn.

Learn more and find resources.

- Contact expert patients,
- Become informed,
- Download,
- Find information adapted to your needs

Member's Story

The story so far (MWS)
from the **CAPS** Community



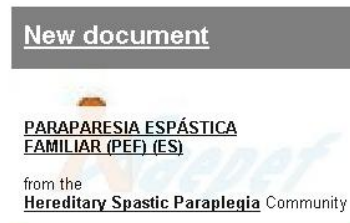
Recent discussion

flunarizine
from the **Alternating Hemiplegia** Community



New document

PARAPARESIA ESPÁSTICA FAMILIAR (PEF) (ES)
from the **Hereditary Spastic Paraplegia** Community



Visit a community

- Alkaptonuria (AKU)
- Alternating Hemiplegia
- Atypical Hemolytic Uremic Syn.
- Behçet's Syndrome
- CAPS
- Epidermolysis Bullosa
- Familial Mediterranean Fever
- Hereditary Spastic Paraplegia
- Von Hippel-Lindau

Custom Rare Disease Search Engine

No online community for your area of interest yet?
Use this search engine to search the following websites: eurordis.org, orpha.net, rarediseases.org and rarediseases.info.nih.gov. More info about these sites. You can also [contact us](#) to inform us of your interest in setting up future online patient communities.

Announcements

EURORDIS Annual Membership Meeting Event, on 13 May 2011
EURORDIS is pleased to announce that its General Assembly will be held on 13 May, 2011 in Amsterdam, The Netherlands.
Ven...
[More info](#)



Achievements sofar

20

- Launched in April 2010
 - 10 rare disease communities live
 - 10 more in active development
 - Addition of on-demand human translation service in summer 2010
 - Attendance at medical congresses (World Auto-inflammatory congress 2010 Amsterdam, European Hematology Association 2010 Barcelona)
 - Winner of the “audience prize” for best new comer at Health 2.0 Paris 2010
-

what?

learn to live with the disease

meet!

discuss with other patients

learn.

information and resources

Multiple Myeloma is a rare form of cancer that manifests in three ways (MGUS, Smoldering/Indolent, and Myeloma). Below you'll find testimonies of patients who live with them.

Living with Multiple Myeloma

by MMRF 1 day ago

Living with Multiple Myeloma



Patient testimonials

User Generated Content

Nick Tiner talks with Lt. Frank Cronin about living with multiple myeloma, and the efforts of the MMRF to help patients live with the disease.

[Read more](#)

Patient groups



European Myeloma Platform



International Myeloma Foundation



Myeloma UK



Myeloma Euronet

[▶ See all patient groups](#)

Filters

All Articles and Stories

Editor's Articles

Patient Stories

Multiple Myeloma Recent Activity



Multiples Myelom Von Patient zu Patient Von Patient zu Patient document, published 13 days ago



The IMF's Living Well with Multiple Myeloma quarterly teleconference series

what?

learn to live with the disease

meet!

discuss with other patients

learn.

information and resources

Meet, discuss & support other patients or families living with Atypical Hemolytic Uremic Syn.. Participate in group discussions. Contribute to topics, or just share what's on your mind

Conversations

View: [Translations \(EN\)](#) [Original language](#)

You must [sign in](#) or [register](#) to post a topic.



[robpleticha](#) | [Soliris/eculizumab](#), [Transplantation](#) | 20 days ago | Originally written in English

Ecuzumab and Transplant

New article presents the first case of a young patient with aHUS who received ecuzumab as prophylactic treatment prior to a successful kidney transplantation: www.springerlink.com/content/jq176pm6061711...

▶ 3 replies to the topic — see all replies



[LindaBurke](#) 20 days ago | Originally written in English

Thanks for posting this abstract and the first page of the actual article - any idea when the complete article will be available on this site? With thanks, Linda



[robpleticha](#) 17 days ago | Originally written in English

Still working with www.patientinform.org/ to include a link to full text articles along with a summary on the site. Hope its coming soon.

Topic filter

All tags

Meetings	3
Soliris/eculizumab	2
Transplantation	1
Dialysis	1
Behavior	1

Members

Most active

	AllieFreitas Registered 2 days ago	
	muriel-1408 Registered 10 days ago	
	malak Registered 16 days ago	
	alex Registered 19 days ago	
	livelifelisa Registered 30 days ago	

Online discussion in several languages

More like a stream of conversation than a forum

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

problemi cardiaci..cardiovascolari,attacchi di angina,ischemie

Content

*DOMANDA:
cortesemente vorrei sapere se ci sono malati di behcet con problemi cardiaci,cardiovascolari.
io da tanti anni soffro per le valvole..di...*

Request translation!



Breaking down the language barrier

On-demand human translation

Denis Costello's profile

 Write a Story



« Hi, I'm Denis a Community Manager with Rare Disease Communities. I'm here to help and support! »

Recent topics

Recent replies

My Friends' Latest Activity

8 days ago



[robpleticha](#) posted a new topic in the [Familial Mediterranean Fever forum](#)
[Results of Colchicine Survey](#)

Here is the "final report" which includes the non-US cases. It doesn't focus too much on the FDA and there is interesting additional information at the end of the results on age at first symptoms, age at diagnosis and years from 1st sign to diagnosis.

<http://download.eurordis.org/documents/pd...>

10 days ago



[robpleticha](#) posted a new topic in the [Familial Mediterranean Fever forum](#)
[Letter from United States Congress to URL Pharma regarding the price of Colcrlys](#)

Thanks to Nancy for sending this along. Senator Herb Kohl, Chariman of the Special Committee on Aging, and three senior Members of Congress have sent the following letters of inquiry to URL Pharma to examine pricing of Colcrlys.

Find it here:

http://aging.senate.gov/hearing_detail.cfm?id=332...

17 days ago



[robpleticha](#) posted a new topic in the [Atypical Hemolytic Uremic Syndrome forum](#)
[Eculizumab and Transplant](#)

This article presents the first case of a young patient with aHUS who received eculizumab as prophylactic treatment prior to a successful kidney transplantation: <http://www.springerlink.com/content/q176pm6061711845/>

Profile

Edit 

Username:
denito (That's you!)

Real name:
Denis Costello

Member since:
Nov 29, 2009

My friends

Pending requests



paul
Registered about 1 year ago



niko
Registered about 1 year ago



karend
Registered about 1 year ago



robpleticha
Registered 9 months ago



CPaduani
Registered 9 months ago



 [View all of denito's friends](#)

Your Story

You currently have 0 stories. [Add one now!](#)

Bookmarks



[EURORDIS - Rare Diseases Europe](#)
[Wikipedia](#)



Social Networking functionality

Virtual profile

Patient Disease Management tool



Mike's Myeloma

Help
Settings
Print
Save

My Health

Daily Tracker

My Charts

My Contacts

News Forum

News Title
14/02/2011

Lorem ipsum dolor sit amet, consectetur adipiscing elit...

[Read More](#)

News Title
14/02/2011

Lorem ipsum dolor sit amet, consectetur adipiscing elit...

[Read More](#)

[See all news](#)

Bookmarks ?

Resource Name
Resource description goes here

Resource Name
Resource description goes here

Resource Name
Resource description goes here

Resource Name
Resource description goes here

+Edit Bookmark +Add Bookmark

Overview
Case History
Edit Details

My Profile ?

Mike
Last Updated: 5 minutes ago

Male, 30 years
London, United Kingdom

Myeloma since: January 2010
Diagnosed: March 2010
Transplant: No (On waiting list)

What I'm looking for: To understand the disease better, to track my condition and treatments and to hear from others who understand what I'm going through.

Latest Treatment: Thalidomide Celgene™ / 50mg [See chart](#)

Side effect(s): Nausea [Update](#)

Last updated: 2 days ago

Side Effects ?

Physical Changes: Hair loss

Strength: Weak

Energy Levels: Low

Concentration: OK

Appetite: Low

Cause: Digestive pain

Current Weight: 92lbs Last updated: 2 months ago

[Update your details](#)

Immune System ?

Immune system: Vulnerable

Illness(es): Common Cold

WBC count: 20,000 mm (as of 05/01/11)

Last updated: two weeks ago

[Update your details](#)

Profile Completion ?

75%

Complete your profile:

- + How old are you? [+Update](#)
- + Tell us your Case History
- + When were you first diagnosed? [+Update](#)
- + What treatments have you had? [+Update](#)
- + How long have you had Myeloma? [+Update](#)

[Update details](#)

Friends Suggested

Username
Male, 57 years
Manchester

[View](#)
[Msg](#)

Username
Male, 57 years
Manchester

[View](#)
[Msg](#)

Username
Male, 57 years
Manchester

[View](#)
[Msg](#)

Username
Male, 57 years
Manchester

[View](#)
[Msg](#)

Pending Requests (2) ?

Username
Male, 57 years
Manchester

[View](#)
[Msg](#)

Patient reported outcomes:

- Treatments
- Side effects
- Quality of Life

My Health

Daily Tracker

My Charts

My Contacts

News Forum

News Title 14/02/2011

News Title 14/02/2011

Bookmarks

Resource Name

Resource Name

Resource Name

Resource Name

Resource Name

Side Effects

Time: Morning Afternoon Evening

Physical Changes: - Please Select -

Strength: [Slider]

Energy Levels: [Slider]

Insomnia: - Please Select -

Drowsiness: - Please Select -

Concentration: [Slider]

Appetite: [Slider]

Sickness: - Please Select -

Digestive Pain: - Please Select -

Weight Loss: - Please Select -

Your Weight: [Input]

Update Profile Save

Profile Completion 75%

Complete your profile:

Tell us your Case History

Friends Suggested

Pending Requests (2)

My Health

Daily Tracker

My Charts

My Contacts

News

Forum



News Title

14/02/2011

Lorem ipsum dolor sit amet, consectetur adipiscing elit...

[Read More](#)



News Title

14/02/2011

Lorem ipsum dolor sit amet, consectetur adipiscing elit...

[Read More](#)

[See all news](#)

Bookmarks



Resource Name

Resource description goes here



Resource Name

Resource description goes here



Resource Name

Resource description goes here

 Monday 14/2  From  To 

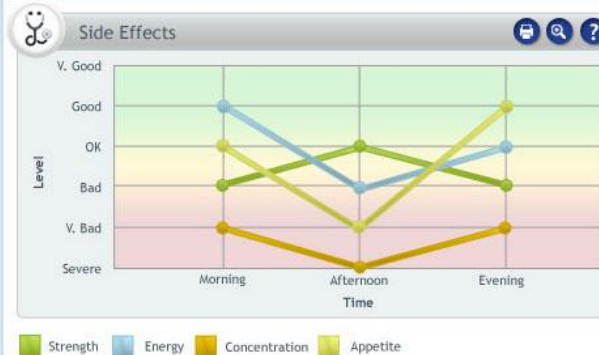
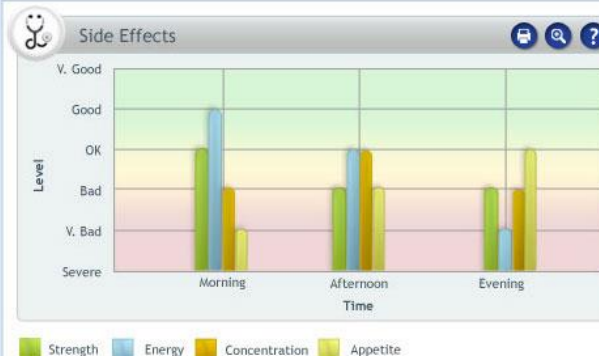

Treatment

Side Effects

Pain

Mood

Immune System


 Time Frame: 
 Daily Monthly Yearly

 Time Frame: 
 Daily Monthly Yearly
Profile Completion 
 75%

Complete your profile:

 + How old are you?
[+Update](#)

Tell us your Case History

 + When were you first diagnosed?
[+Update](#)

 + What treatments have you had?
[+Update](#)

 + How long have you had Myeloma?
[+Update](#)
[Update details](#)

Friends

Suggested



Username

Male, 57 years
Manchester[View](#)[Msg](#)

Username

Male, 57 years
Manchester[View](#)[Msg](#)

Username

Male, 57 years
Manchester[View](#)[Msg](#)

Username

Male, 57 years
Manchester[View](#)[Msg](#)

Compare side-effects over time & against aggregated data from other patients

Governance

28



Funding

29

Public/Private funding model

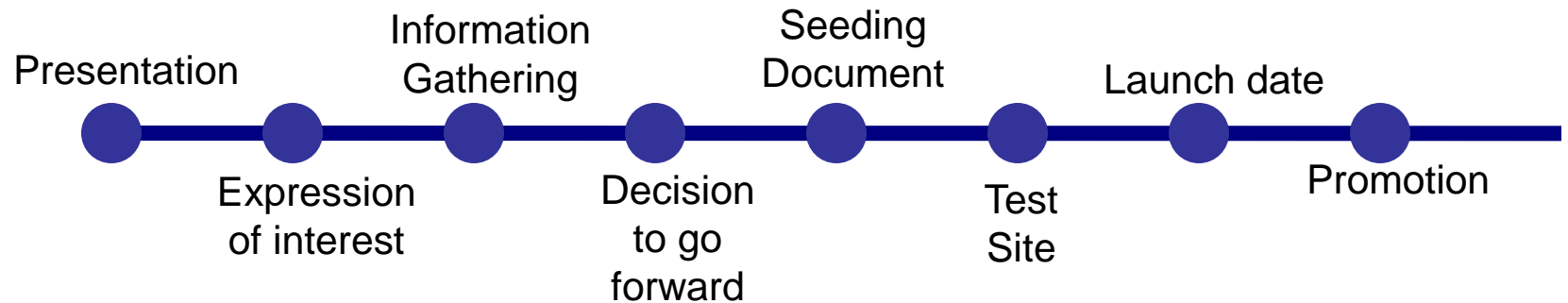
Public funders - 2010

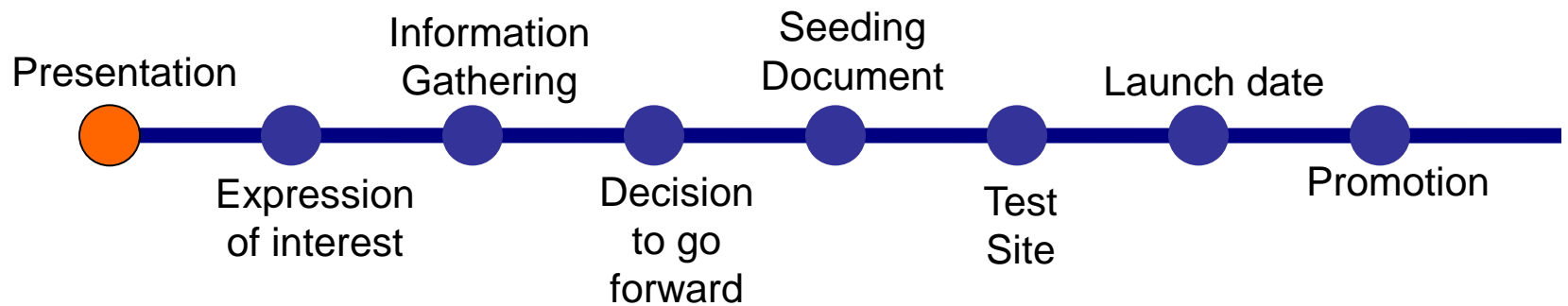


Private funders - 2010 through the EURORDIS/NORD Corporate partnership for Social Media. All private funding is fully independent (funders exercise no influence on decisions related to the platform).



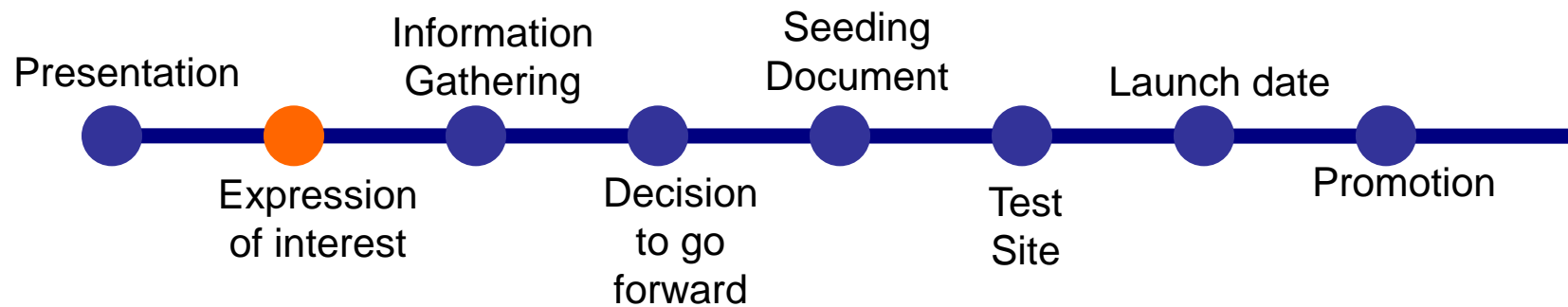
Steps in Creating an Online Community with Eurordis/NORD





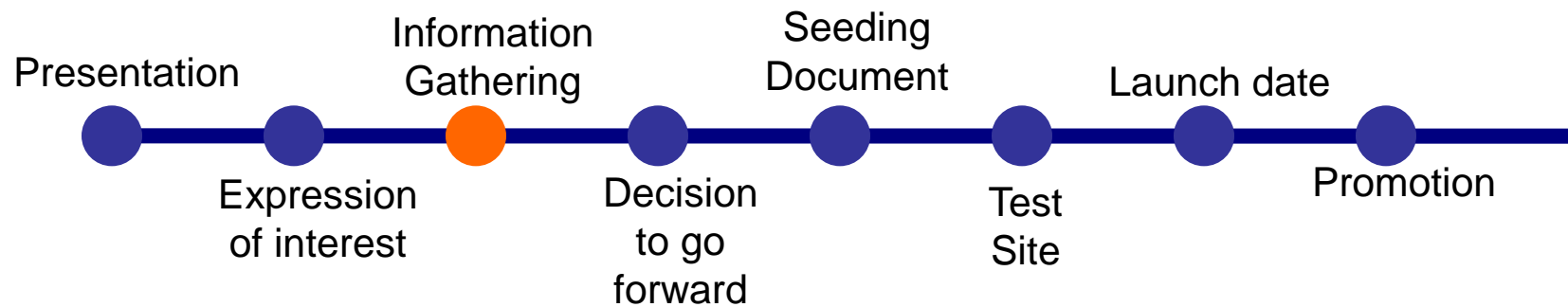
Eurordis and NORD present the project to patients and patient organizations

- Outline strategy and vision for project
- Answer all questions, listen to feedback



Patient organizations express an interest in becoming involved as a partner in the Online Communities project

- **Ideally, a group of patient organizations from different language and cultural backgrounds decides this would add value to their work**



Together, try to determine:

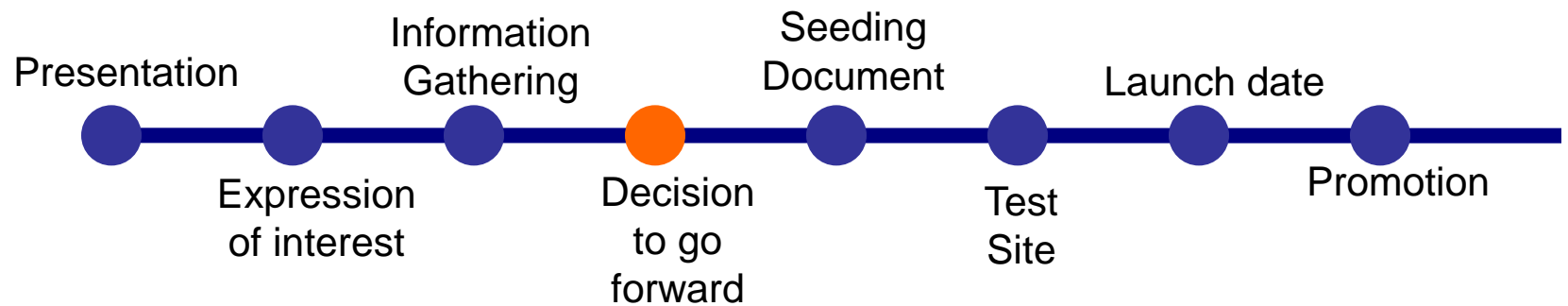
What online tools (forums, websites) exist?

What groups are working together already, what new partnerships can NORD help us in creating?

How could an Online Community support the goals of the organizations involved?

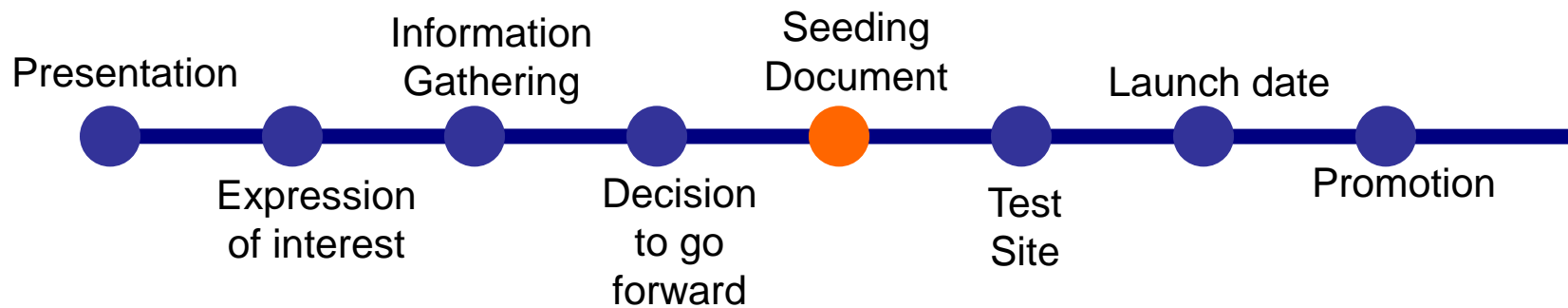
What are the main subjects that the community wants to talk about?

Which patients or patient representatives can be active moderators?



Together, decide to begin to create an online community with international involvement from patient organizations

Assemble a working group with representatives from each patient organization to offer input, verify information, share resources, check translations

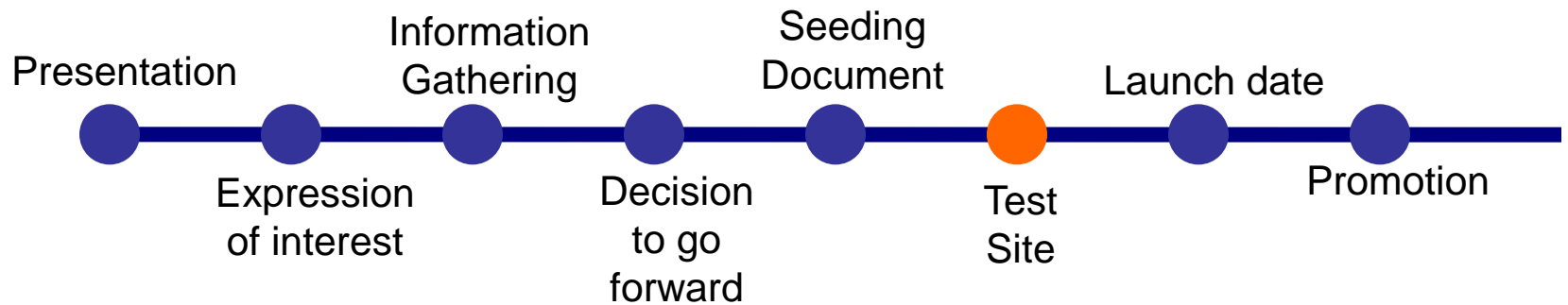


Seeding document -

A way to gather information from involved patient organizations for providing the Start up content for the Community

We want to open the site with stories, pictures, resources reflecting the various experiences of patients and patient organizations around the world

Since each community is different, some parts of this document may not apply to your organization or disease, complete it the best you can and ask questions!

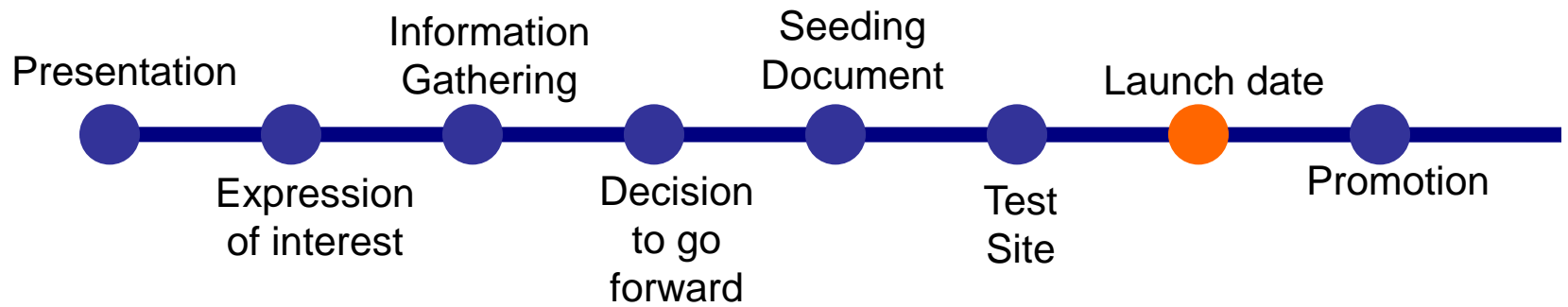


Test Site -

We take information from the different Seeding Documents that have been completed and enter it onto a Test Community that is only viewable with a password

This test site helps us all to envision how the final product will look and what we are missing or how we can organize information

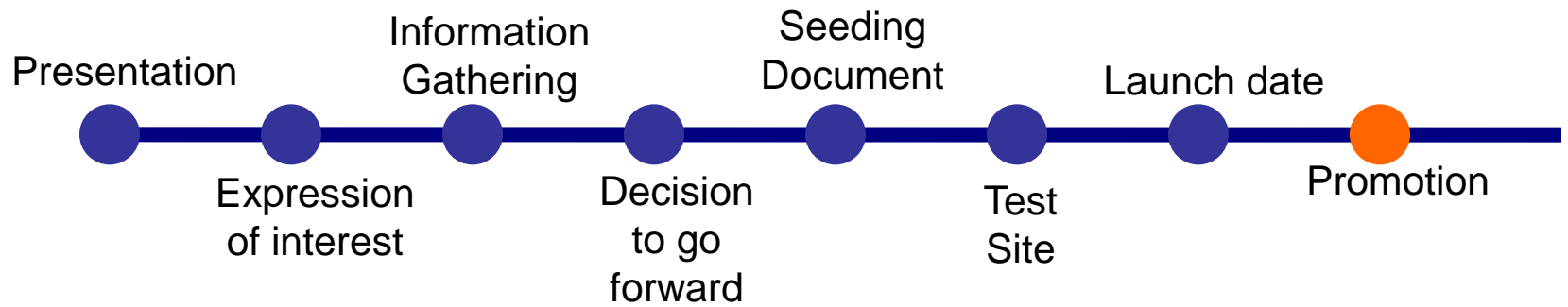
Key information, stories, and documents are translated between the languages, team members are asked to verify both the medical information and translations to ensure maximum quality



Launch date -

Agree on a date when we can make the site public and available for new members to join

Need to remember to have moderators in place who will be regularly checking the Forum based on number of new messages



Promotion -

How can we tell interested parties about the new Community and some of its features?

Need to link to new Community from other quality sites to increase Google Search Ranking

How can Eurordis/NORD support your promotion amongst your members?

Q & A

39

Thank you!

You can also email me:

denis.costello@euordis.org
