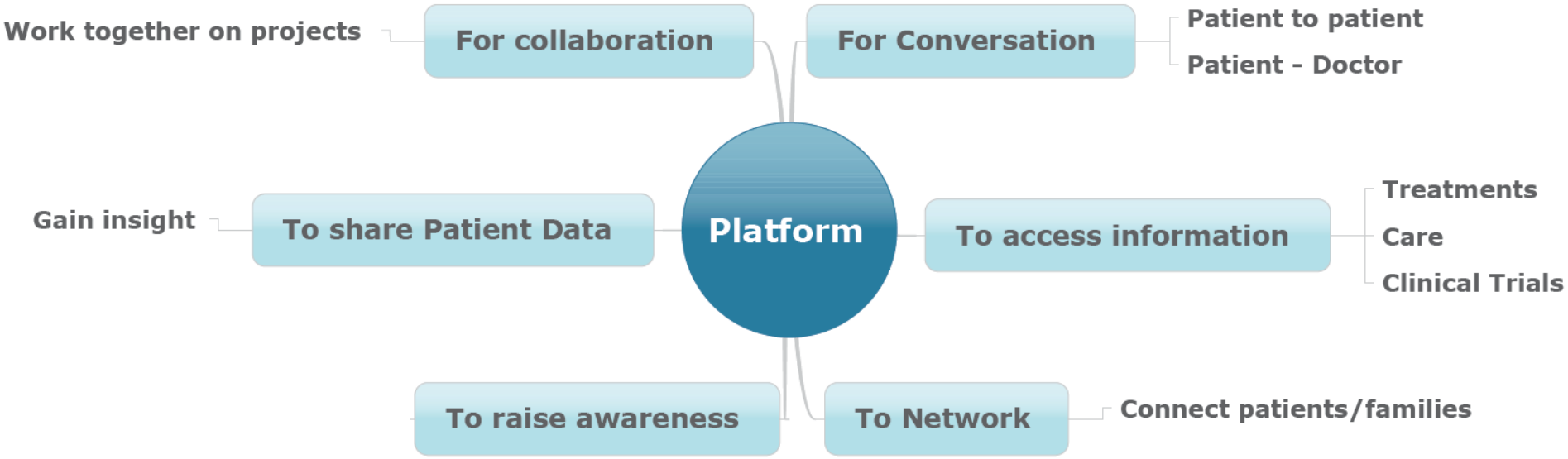
THE IMPORTANCE OF THE ONLINE PATIENT COMMUNITIES

EURORDIS COUNCIL OF EUROPEAN RARE DISEASE FEDERATIONS

Denis Costello
Web Communications Officer, EURORDIS

What is an Online Patient Community?



DuchenneConnect

The Duchenne/Becker testing + treatment resource community for families, healthcare professionals, researchers, industry + policy makers

Home | News | About DMD/BMD | Clinical Trials | NEW! Clinic Services

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.

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 [illegible] hosted by PPMD on June 20, 2011. Chris reviewed AVI's [illegible] company's Phase 2 exon 51 ...

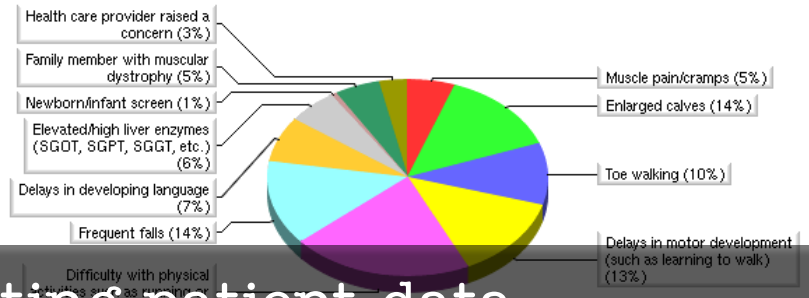
Register Now!

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:



Professionals - Visit the Research Portal

Example – Aggregating patient data

www.duchenneconnect.org

MARSHALL SMITH SYNDROME

HOME | WHAT IS MSS? | FAMILY CIRCLE | RESEARCH | FOUNDATION | CONTACT

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

search...

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

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

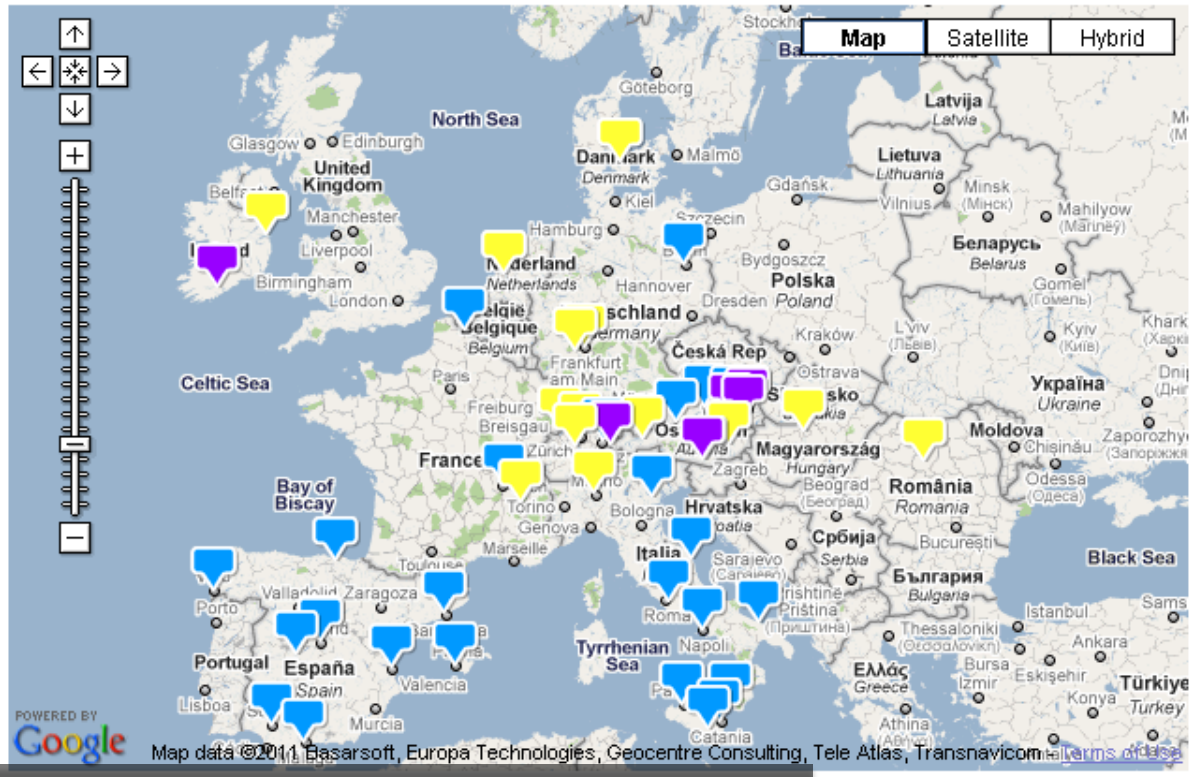
Home | HAE Disease | About HAEi Organization | Worldwide Organizations | HAE Care | Medication | News | Events | Publication

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

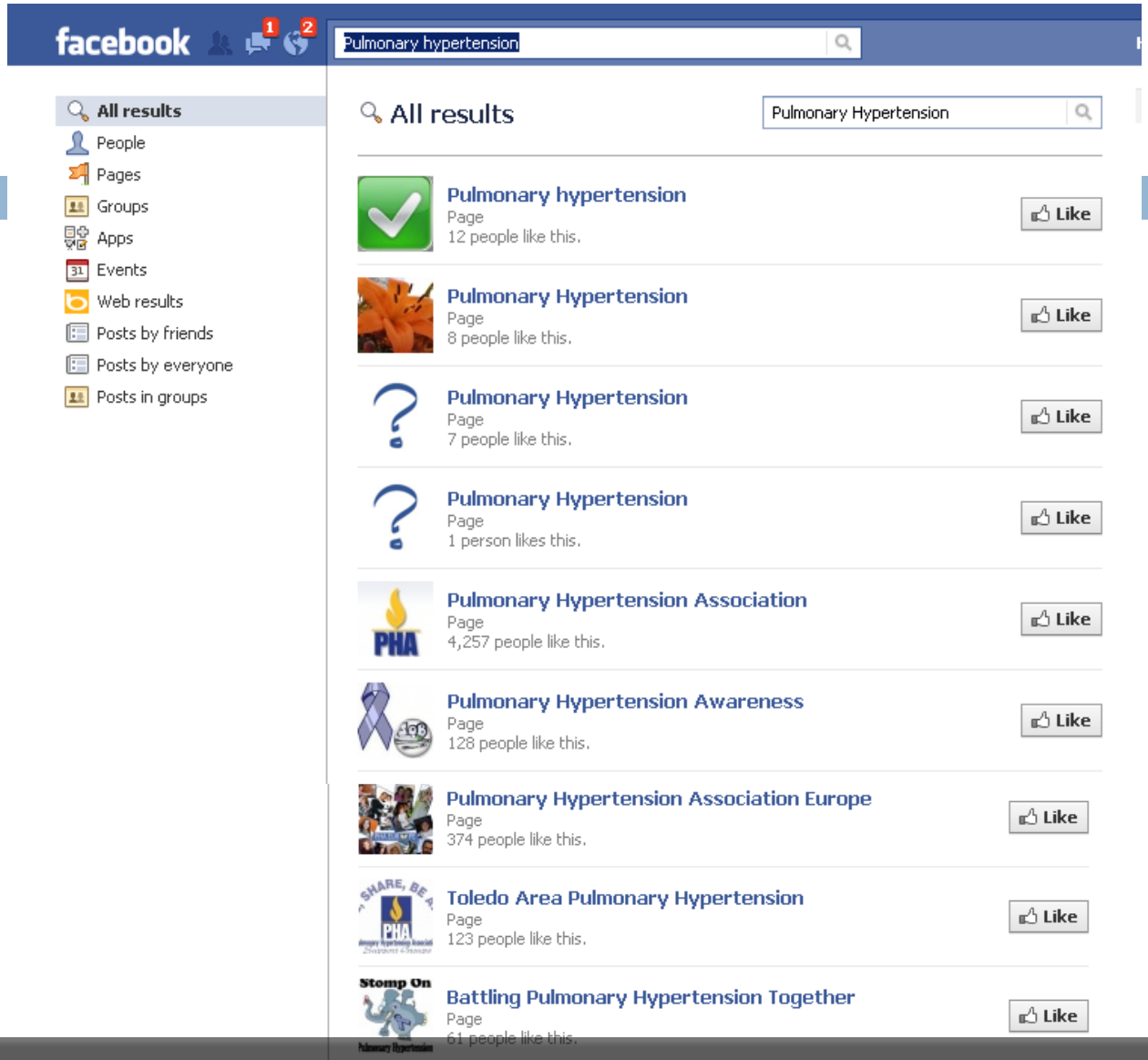
EVENTS

Sat, 2011-09-03 12:00 - 22:00
HAEi – General Assembly

HAE GLOBAL COMMUNITY

Be part of the community

Wed, 2011-06-15
ViroPharma's Cinryze® (C1 Inhibitor [Human])



Example – Your presence on Facebook

www.facebook.com

Example – A Facebook conversation

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

facebook

Search

Wall
Info
Send a kiss
YouTube
Welcome
Photos
Discussions

About

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

More

375
people like this

Likes

Rare Disease Day
FEB 28 2011

Pulmonary Hypertension Association Europe

Non-profit organisation

Wall — Pulmonary Hypertension As... · Most recent

Share: Post | Photo | Link | Video

Write something...

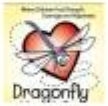
Kimberlee Ford

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

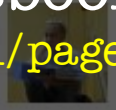
Enjoy our Video. A camp for kids with PH>

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

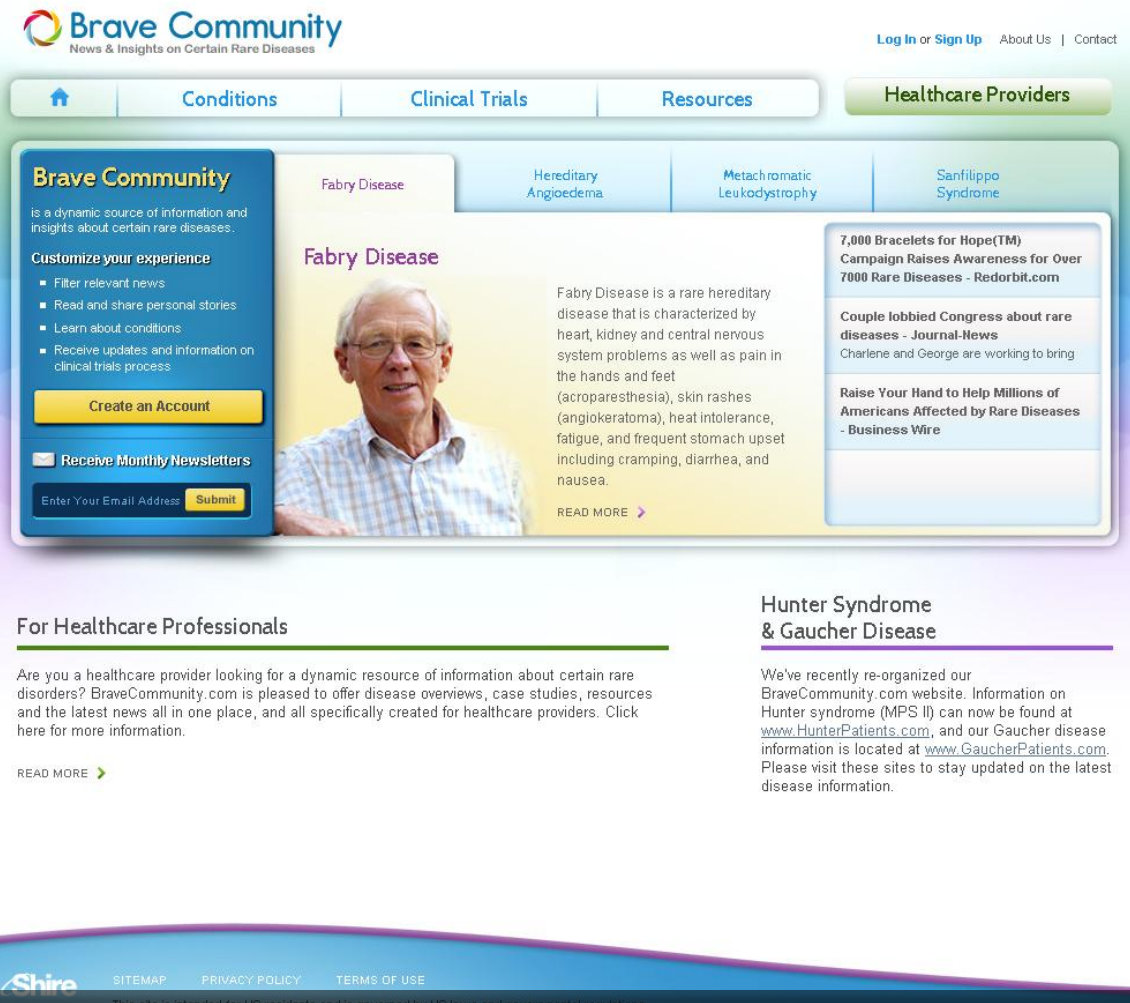
14 June at 18:29 · Like · Comment · Share



Juan Fuertes Guillen

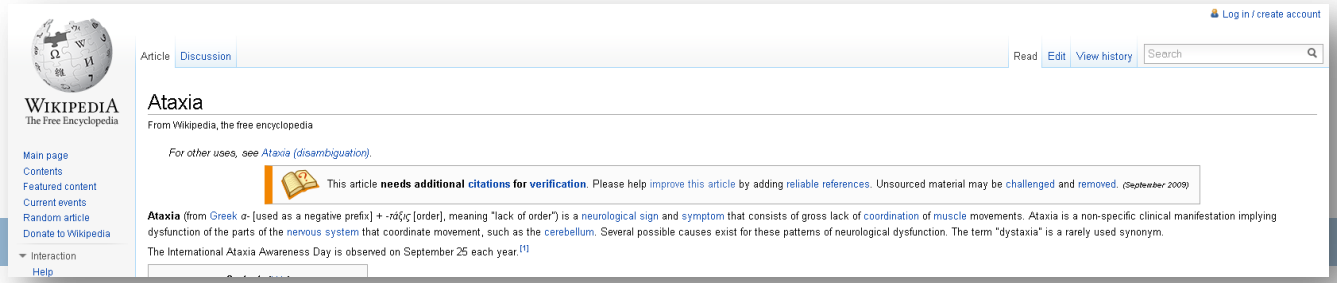
I Seminario de Atención Psicológica para Pacientes de Hipertensión Pulmonar

El I seminario de atención psicológica para pacientes de hipertensión pulmonar,



Example – An industry-led "community"

www.bravecommunity.com



Example – A place for people to find you?

www.wikipedia.org

WIKIPEDIA
The Free Encyclopedia

Article | Discussion

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 20:28, 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. --CliffC 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 imput 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)

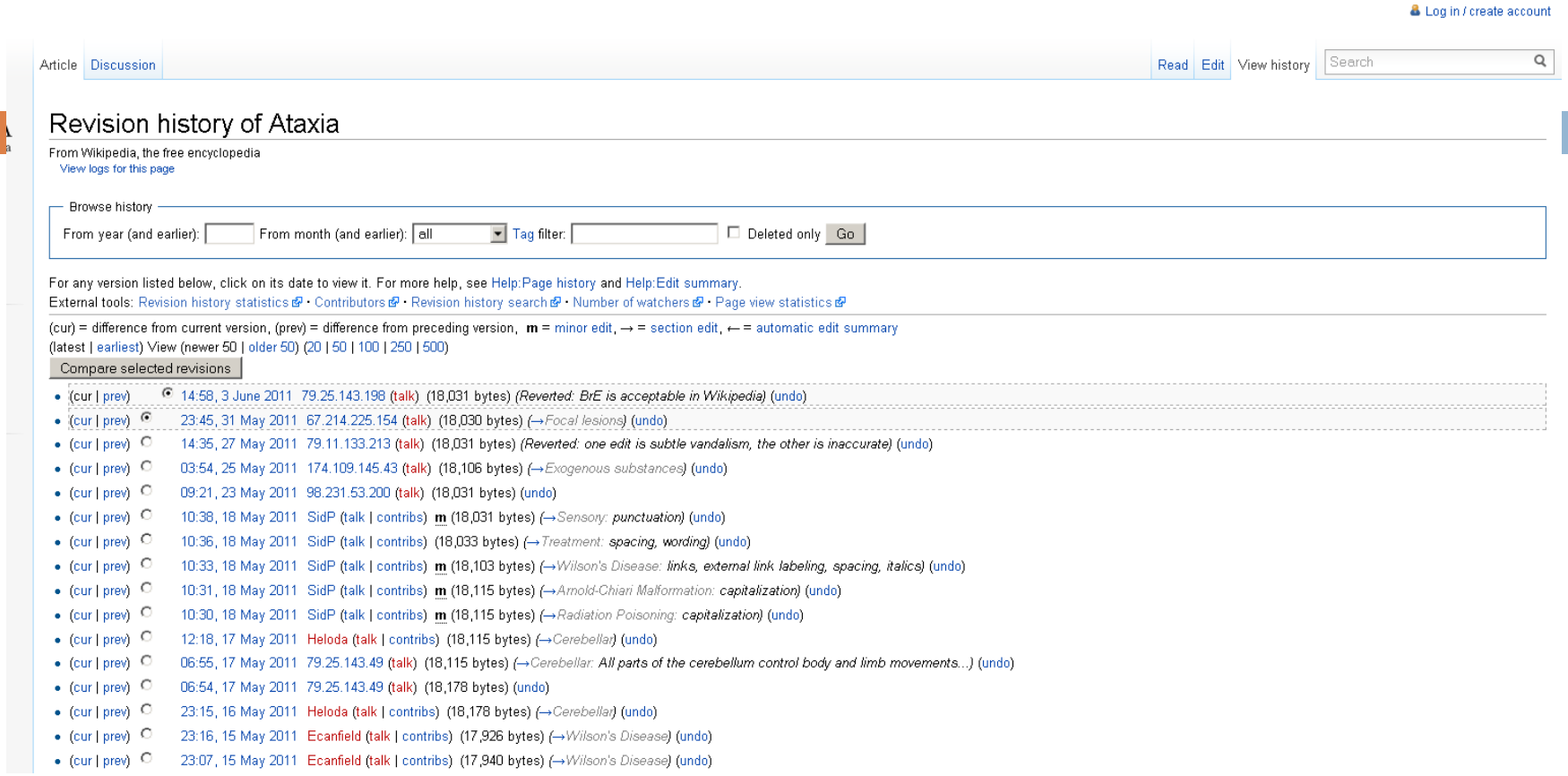
              Regardless of history, I still don't see the pros and cons of separate or merged articles. SandyGeorgia (Talk) 20:02, 6 August 2007 (UTC)

                Well, my reasoning for the "one article" [illegible] practice (in addition to the way it is treated in most [illegible] 20:[illegible], 6 August 2007 (UTC)
- **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?

www.wikipedia.org



Log in / create account

Article | Discussion | Read | Edit | View history | Search

Revision history of Ataxia

From Wikipedia, the free encyclopedia

View logs for this page

Browse history

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

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)

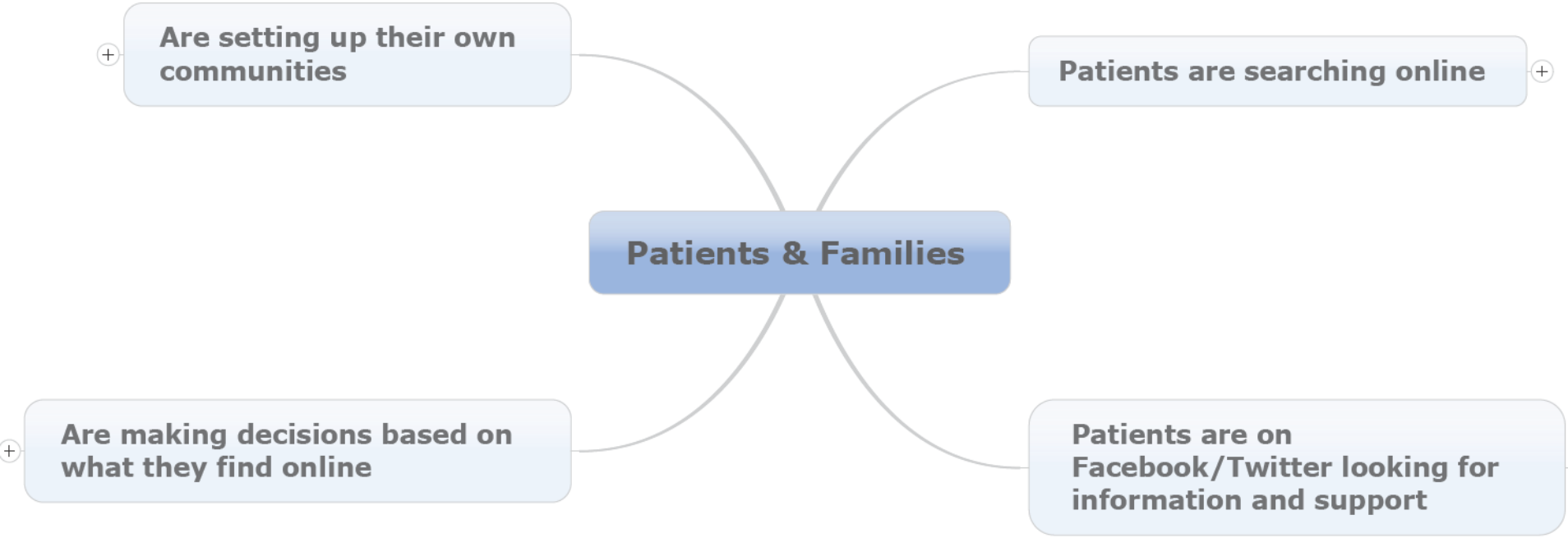
Example – See who's interested in you?

www.wikipedia.org

Why Online Communities are important?

By enabling a community – you are providing value

New Online Patterns



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*

KANTAR HEALTH

Q11ci. Aside from the information given to you about ITP, what information did you actively seek out? Why? Where did you find it?

base: All who have received enough information when diagnosed (123)

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

56%

sought information from the internet

(including Google, forums etc)

33%

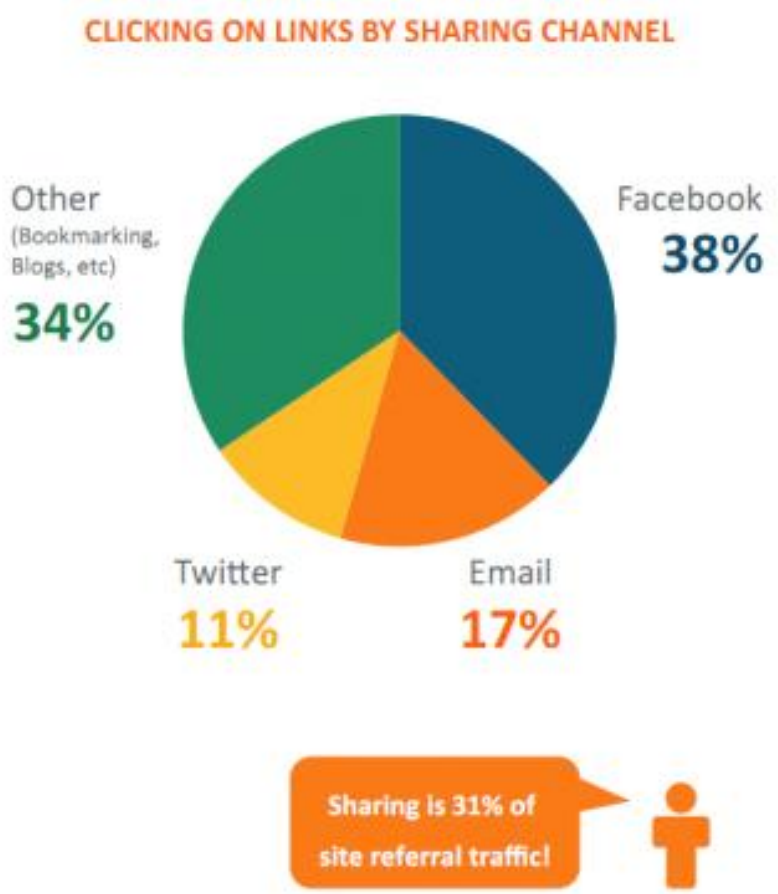
of ITP patients sought information from healthcare professionals

KANTAR HEALTH

Q11ci. Aside from the information given to you about ITP, what information did you actively seek out? Why? Where did you find it?

base: All who have received enough information when diagnosed (78)

The evolving web



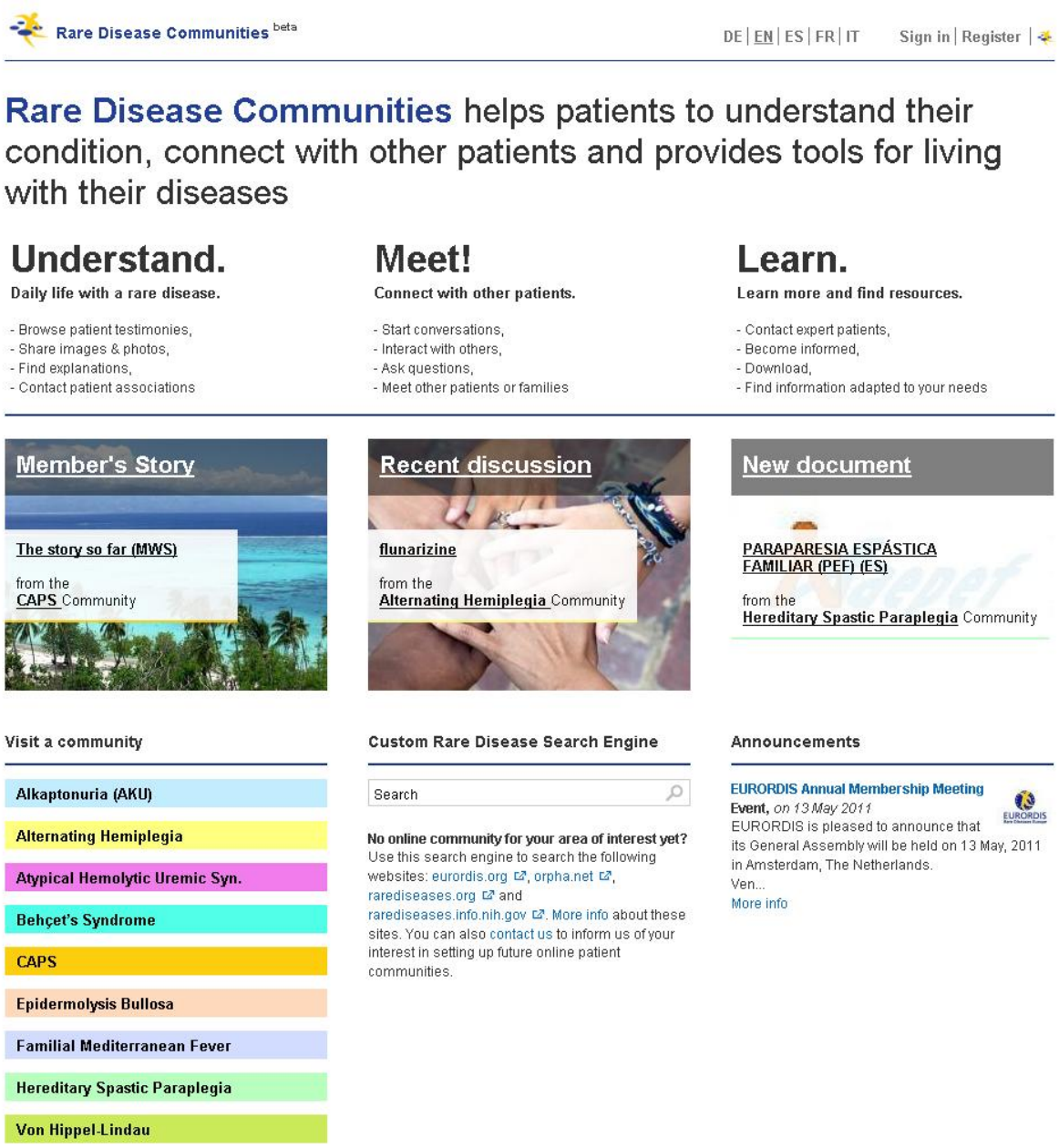
THEN	NOW
BROWSER	APPS
SYNDICATION	SUBSCRIPTION
GOOGLE!!	GOOGLE??
FREE	FREEMIUM

Interim Conclusions

- 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

- 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**



www.rarediseasecommunities.org

Achievements sofar

- 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

Multiple Myeloma community

Search this community

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 tesimonies of patients who live with them.

Living with Multiple Myeloma

by MMRF 1 day ago

Nick Thier talks with Lt. Frank Cronin about living with multiple myeloma, and the efforts of the MMRF to cure this 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

Patient testimonials

User Generated Content

Atypical Hemolytic Uremic Syn. community

Search this community

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

Eculizumab and Transplant

New article presents the first case of a young patient with aHUS who received eculizumab as prophylactic treatment prior to a successful kidney transplantation: www.springerlink.com/content /q176pm6061711...

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.

Thanks for letting us know the process.

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

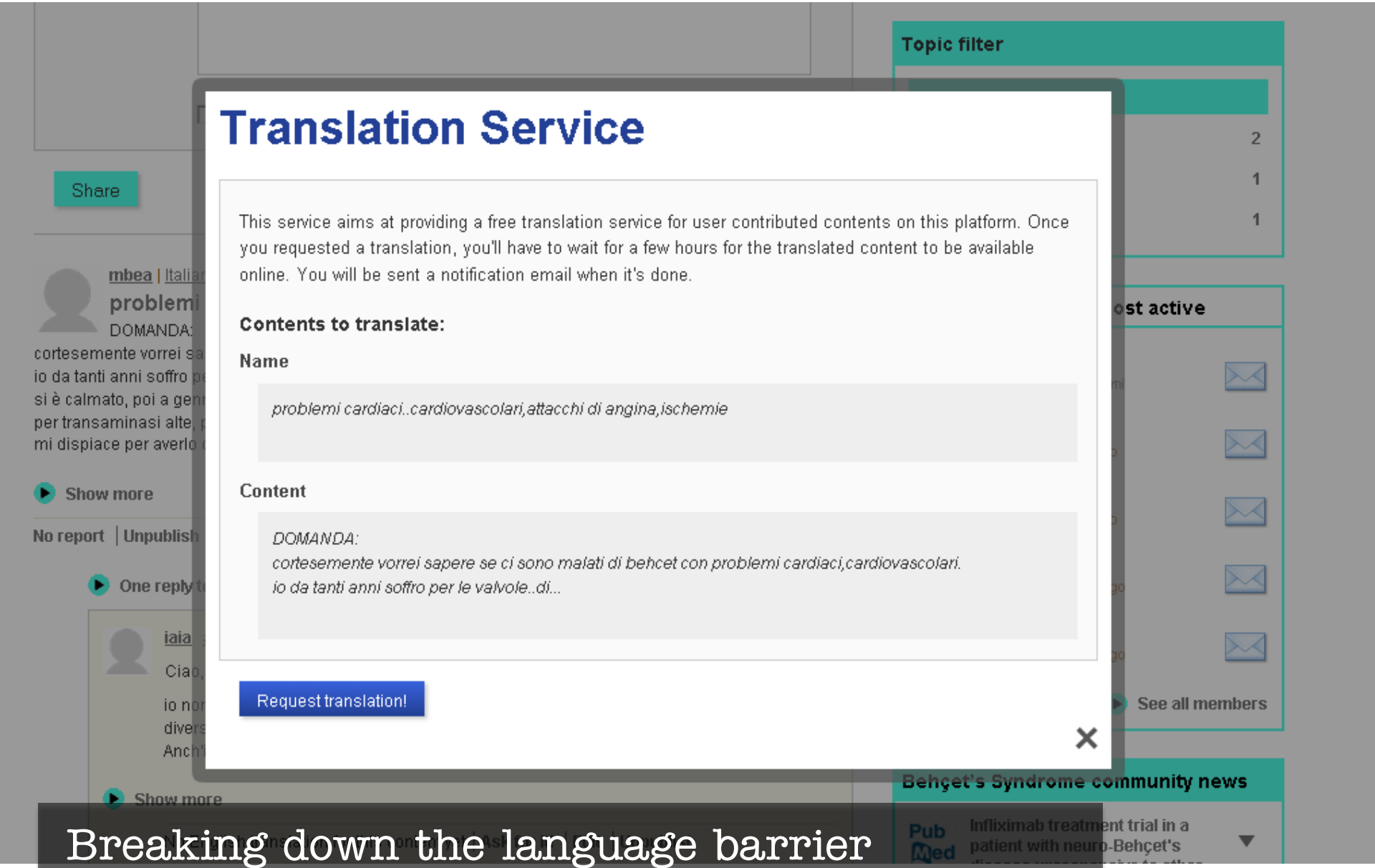
malak
Registered 16 days ago

alex
Registered 19 days ago

livelifelisa
Registered 30 days ago

Online discussion in several languages

More like a stream of conversation than a forum



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 Colcrys

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 Colcrys.

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

17 days ago

[redacted] posted a new topic in the Atypical Haemolytic Uraemic Syn. forum

Eculizumab and Transplant

[redacted] 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!

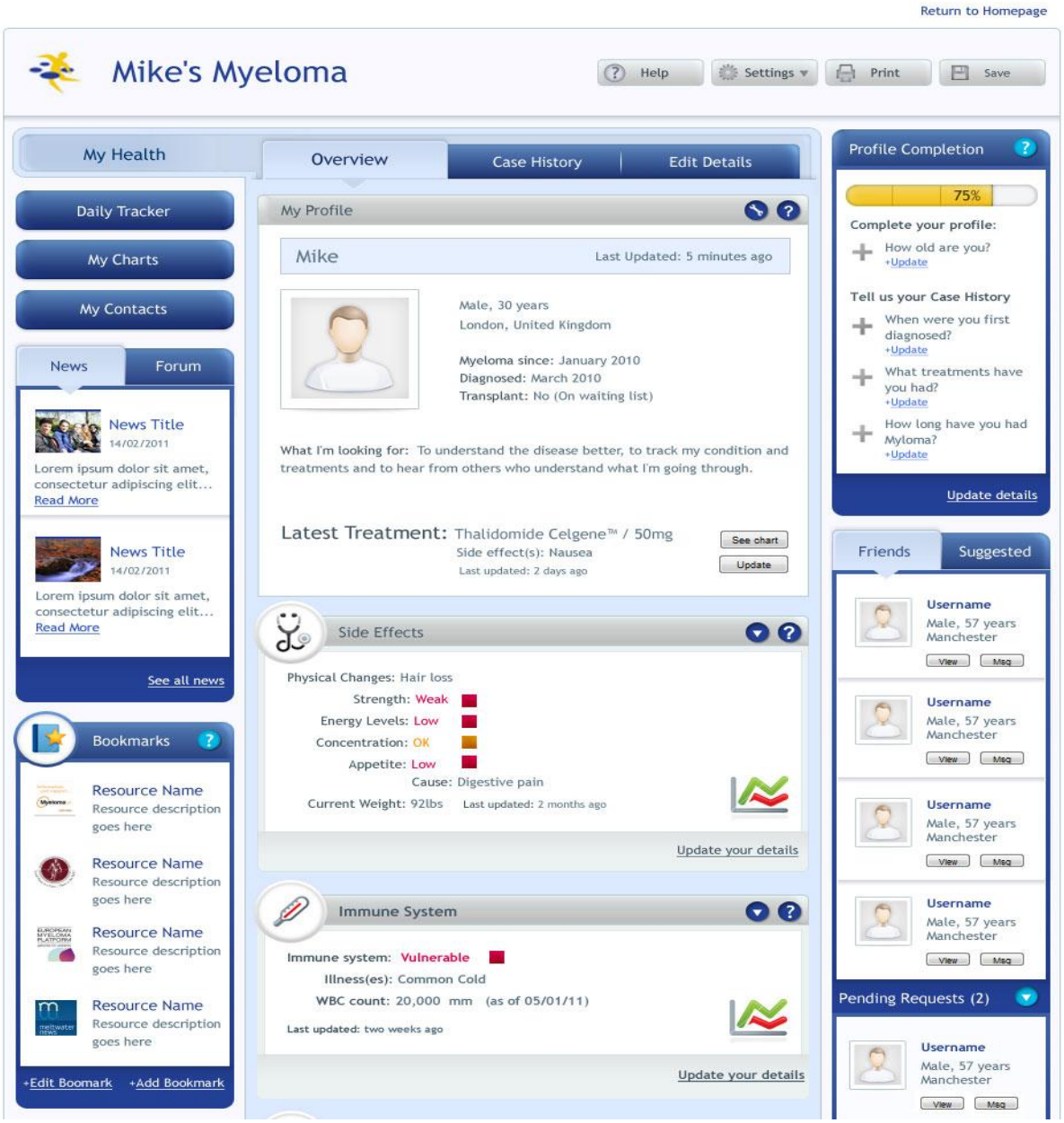
Bookmarks

EURORDIS - Rare Diseases Europe
Wikipedia

Social Networking functionality

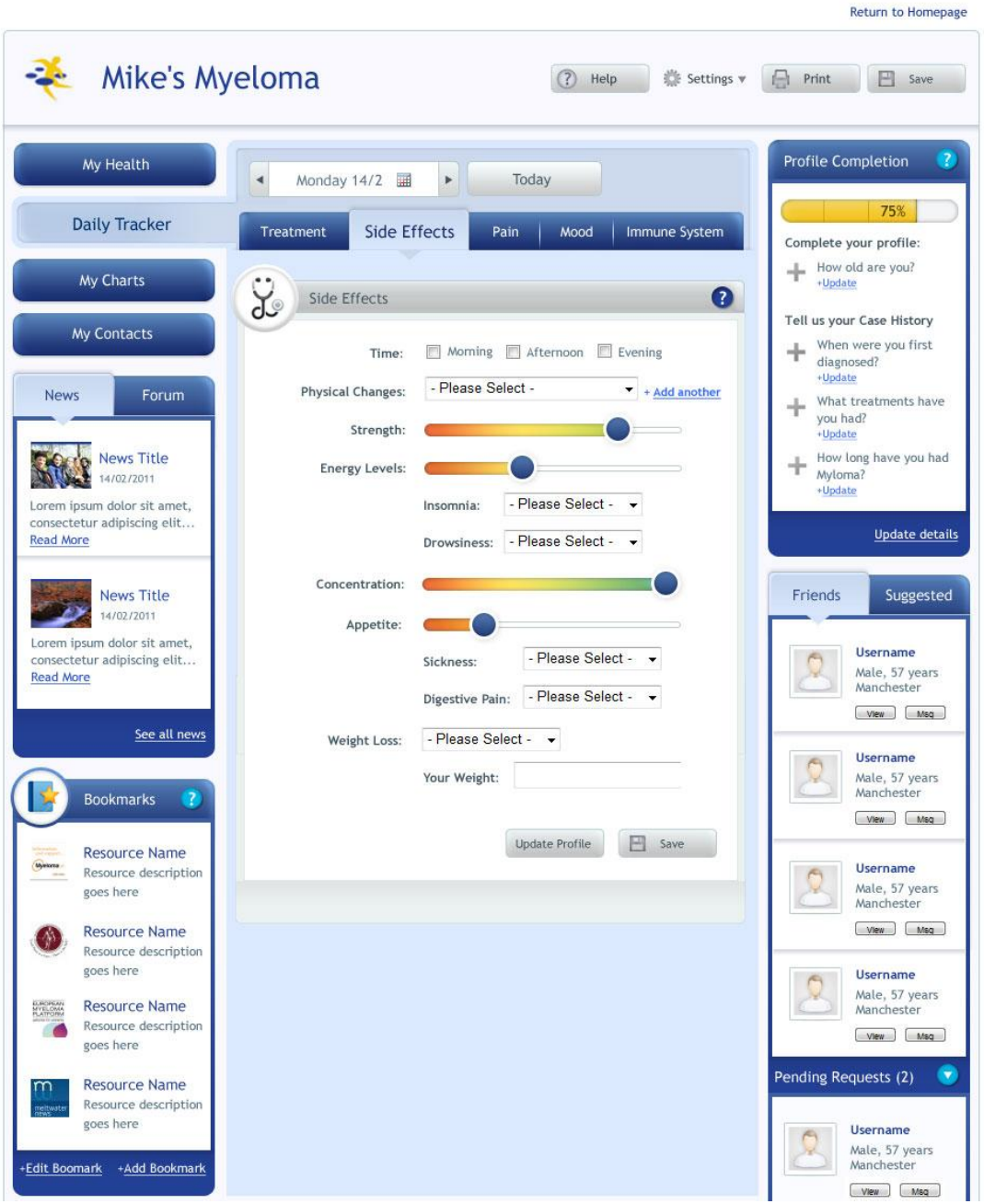
Virtual profile

Patient Disease Management tool



Patient reported outcomes:

- Treatments
- Side effects
- Quality of Life



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

Governance


Moderaters
Patient Stories & Medical info
Promotion
National & International groups
Heathcare professionals
EURORDIS/NORD provide & fund the platform
3rd party software providers

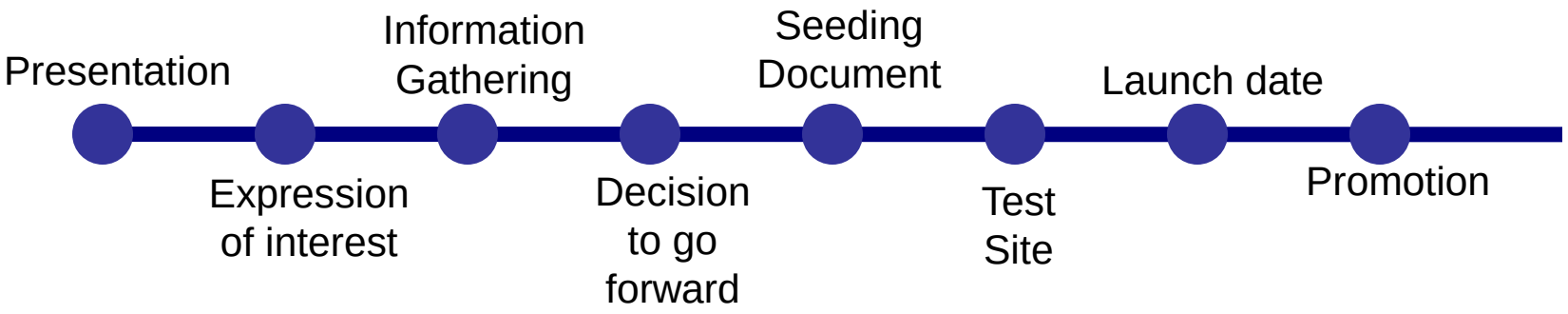
Funding

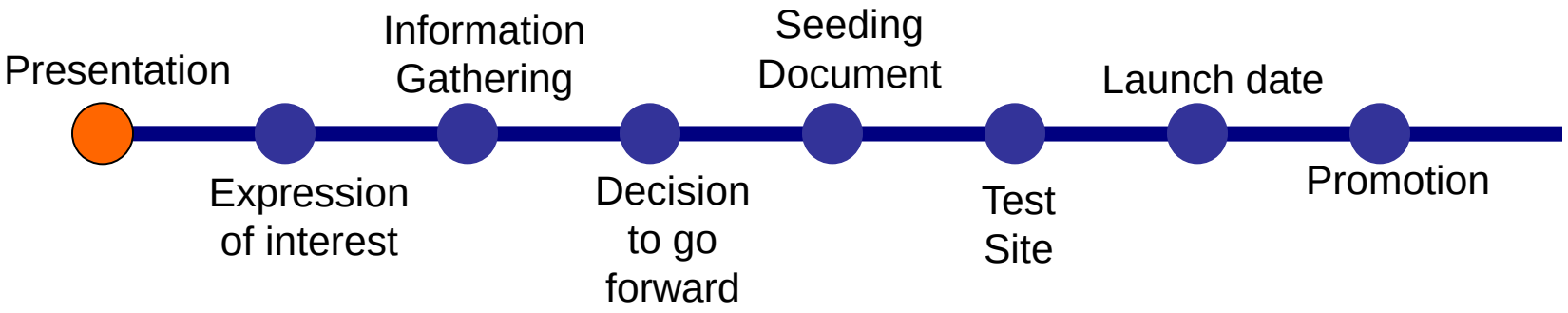
Public/Private funding model

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).

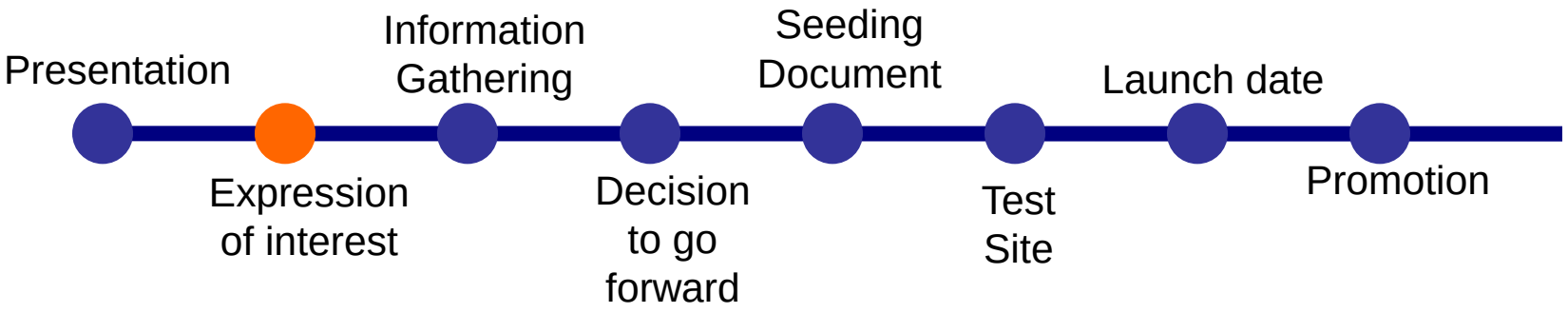
Steps in Creating an Online Community with Eurordis/NORD





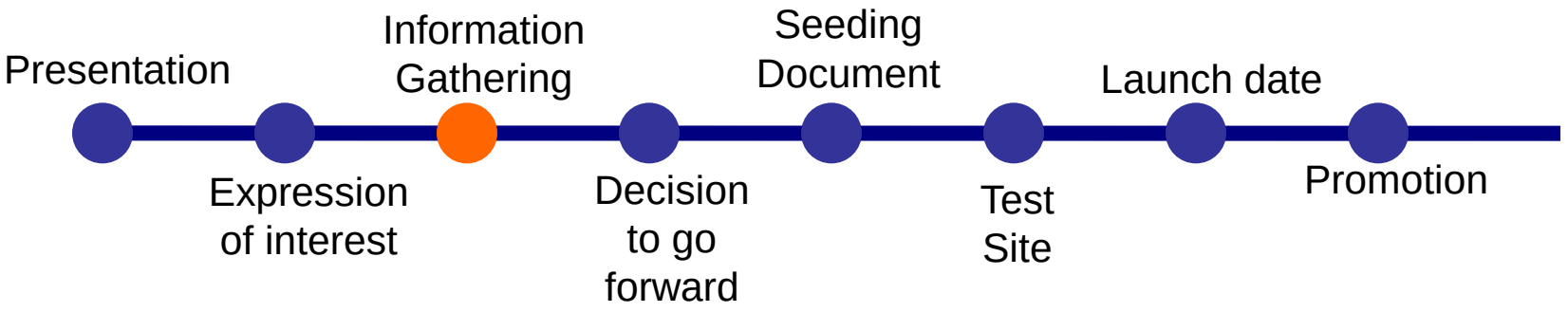
Eurordis and NORD present the project to patients and patient organizations

- 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**



<u>Together</u>, try to determine:

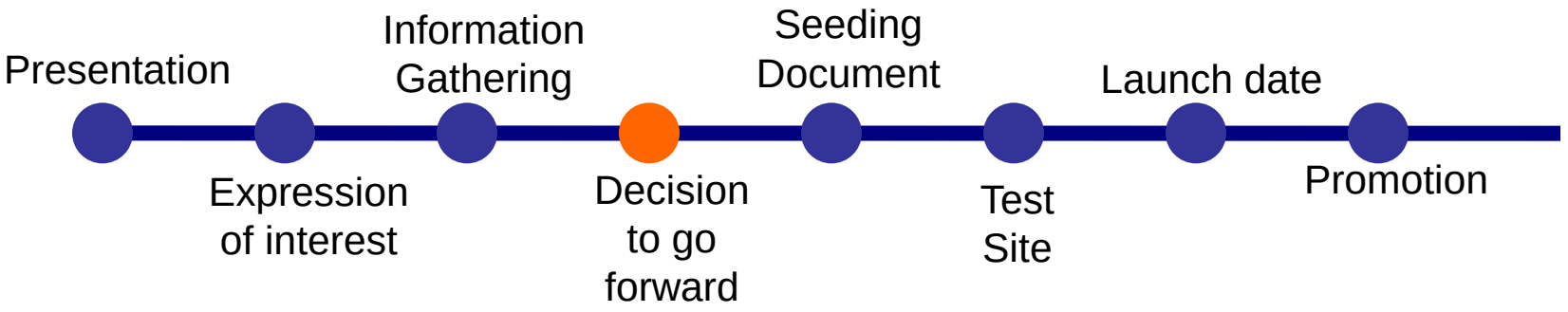
What online tools (forums, websites) exist?

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?

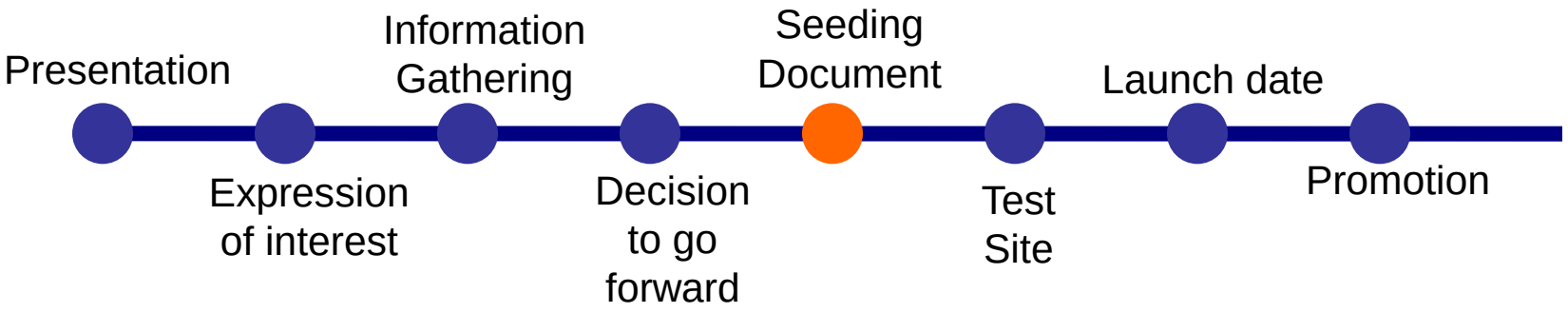
What are the main subjects that the community wants to talk about?

Which patients or patient representatives can be active moderators?



<u>Together</u>, 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

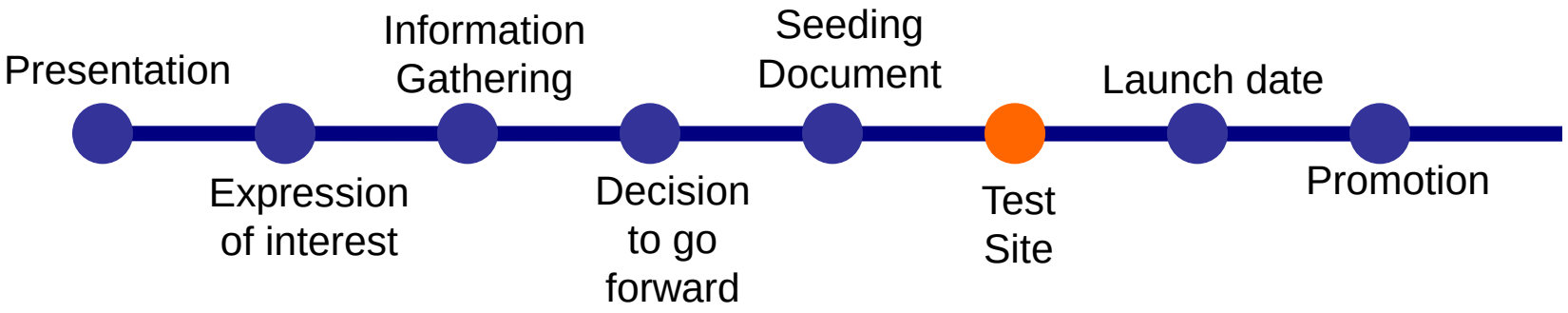


Seeding document -

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!

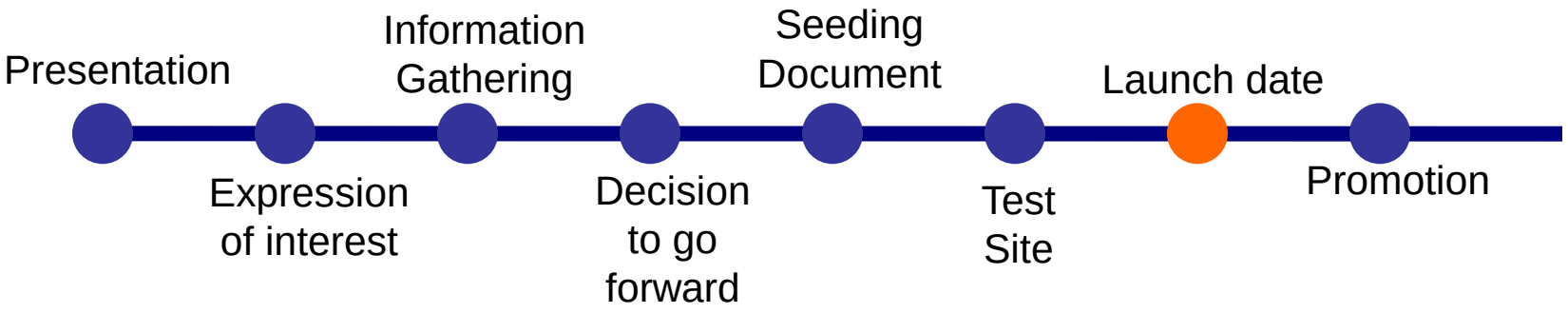


Test Site -

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

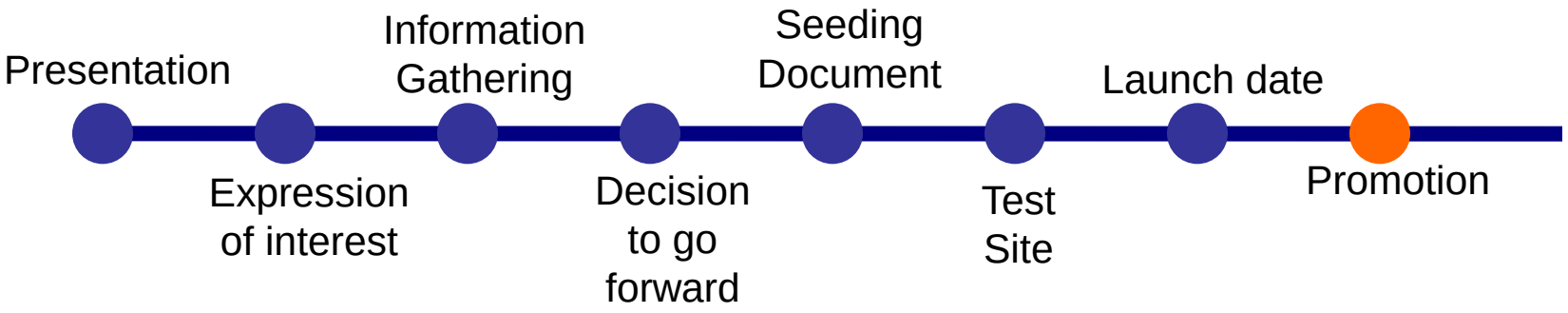
Key information, stories, and documents are translated between the languages, team members are asked to verify both the medical information and translations to ensure maximum quality



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 it's 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

Thank you!

You can also email me:

denis.costello@eurordis.org