



Moderator Webinar
New Features on
RareConnect

Welcome - Waldenstrom Macroglobulinemia Community

What is Waldenstrom Macroglobulinemia ?

Waldenström macroglobulinemia (WM) is a rare form of blood cancer.

source: Participating patient organizations visible below

[Waldenstrom Macroglobulinemia Resources](#)

Latest Member Stories

[More members stories](#)



The 6-month point

by karenarmel published 11 days ago 5 comments

Treanda and Rituxan have worked beautifully for 4 months, dropping by 50% or more his IgM protein and M-Spike numbers. His doctor said he was "goi...

[More](#)



What to do when a family member is diagnosed with WM?

by Lily published 13 days ago 6 comments

I read the cancer is rare in non white people. The disease is so rare in Ethiopia, where we live the doctors are having a hard time on the best opt...

[More](#)

[More](#)

Partners and Patient Groups

RareConnect is a joint venture of EURORDIS and NORD. The following patient groups are official partners of this community.



EWMnetwork



Lymphom Selbsthilfe



CMP-Vlaanderen

Share This



You are a member of this community



Search Community



I want to...

[Tell my story >](#)

[Start a discussion >](#)

[Meet other members >](#)

[Learn about the disease >](#)

Meet our members



[View All](#)

Latest Waldenstrom Macroglobulinemia Community Activity



patient young men with m. of waldenstrom?
reply published 18 minutes ago
[show transcript](#)

New Community Homepage

- > Newest member stories featured
- > Action items to encourage contribution
- > Partners and patient groups displaying more prominently
- > Basic structure of Understand, Meet, Learn is maintained
- > New tab: Members

Translations

- > Option for instant Google Translation now available
- > If not quality translation, or if unclear, ask for the human translation

Reminder: All stories are automatically translated, but you have to request a human translation of forum posts



houche | published about 1 month ago | Originally written in French

Waldenstrom and Nuclear Disease

Hello, I've got WM for 6 years now and I've worked in the nuclear field for 32 years. I've already found other persons working in the same nuclear area et also hit with WM..!! and 2 other persons having worked in the nuclear field (elsewhere in France) also have WM. I wanted to file for recognition of my illness as an occupational disease to the social welfare system but no answer. I have not lost hope if we manage to find other persons with WM linked to nuclear. Answer me if you are interested... (Show more)

Notice: This text content has been translated automatically by a third-party service.

Translate into English:

Instant translation (Google Translate) of entire conversation

Request quality human translation (this message only)

No report | Unpublish | Make private | Delete | Edit | **Reply**

8 replies to the topic — see all replies



moderator

pmanning | published 22 days ago | Originally written in French

Cher Michel

Je crois que Rob Pleticha va vous contacter au sujet des problèmes techniques.

Entre-temps je voudrai vous poser la question si tous les quatre dont vous parlez (y compris vous) ont travaillé... (Show more)

Request quality human translation (this message only)

Edit | Unpublish

More visibility to moderators



barnowl | published 18 days ago | Originally written in English

TMAU Webinar 1 Feb : George Preti et al

Trimethylaminuria webinar
CORRECTION: Friday 1 February
5pm GMT (noon EST)

With guest speakers :

George Preti, Ph.D. (Monell Chemical Senses Center)
Paul Fennessey, Ph.D.(University of Colorado Health Sciences Center)
Danielle Reed, Ph.D. (Monell Chemical Senses Center)

Titles of slideshows :

Updates on genetics of trimethylaminuria (Danielle Reed)
TMAU : evaluation of individuals with malodor problems (Preti, Fennessey, Reed)

We are delighted to announce the upcoming webinar which will feature 2 researchers... (Show more)

No report | Unpublish | Make private | Delete | Edit | **Reply**

5 replies to the topic — see all replies



mariadelatorre | published 9 days ago | Originally written in English

Hi selimara74,

You can use this link to help you translate the time of the program to your time zone. <http://www.timeanddate.com/worldclock/> . I do recommend that you try to call in to attend the webinar... (Show more)

New on Meet section

Discussion Topics

MGUS contro MW

Waldenstrom and Nuclear Disease

newly diagnosed WM (new member)

our pathology

Genetic mutation and Waldenstrom

what can i do?? need some help

Herpes zoster/Shingles

LIVING WITH MACROGLOBULINEMIA

Hello to you all

Possible vaccine for WM in
development

[View All](#)

Members



GigiFanta

Registered about 1 hour ago



[karenarmel](#)

Registered 11 days ago



Lily

Registered 13 days ago



vitopati

Registered 27 days ago



houche

Registered about 1 month ago

[View all members](#)

All Members - getting to know your community

Home / Waldenstrom Macroglobulinemia / Members

Waldenstrom Macroglobulinemia members



Pierluigi Fantasia

Italy

- Contact
- Profile
- Friend



KAREN ARMEL

United States

- Contact
- Profile
- Friend



lily mark

Ethiopia

- Contact
- Profile
- Unfriend



vito pati

Italy

- Contact
- Profile
- Friend



michel houche

France

- Contact
- Profile
- Friend



chiari

- Contact
- Profile
- Friend



Cristina Cagliari

Brazil

- Contact
- Profile
- Unfriend



cornejolaura

Contact

- Profile
- Friend



Joanne Balausiak

United Kingdom

- Contact
- Profile
- Friend



Marco Grasso

Italy

- Contact
- Profile
- Friend



Lynda Nielsen

Contact

- Profile
- Friend



dolores

United States

- Contact
- Profile
- Friend

Have a concern about a member? Let us know.

Contact



Lily

Using this form you can contact this community member who will receive your message via email.

Subject*

Welcome Lily

Message*

Welcome to the Community

My name is Rob and I am a moderator with [EURORDIS](#).

There are some incredibly supportive and compassionate people in this Group.

As many of us have found it's a little easier doing life when there are others that understand what patients and families go through on a daily basis.

This patient group website has a lot of valuable and helpful information on it. www.eurordis.com

We look forward to your participation in the Group!

Put me in copy. This will help you keep a record of this message in your personal email inbox.

Send your message

Get a copy of the message in your email inbox

Send a welcome message

- > Only moderators can send a private message to people they are not friends with
- > To send a private message back to you, the person has to send a friend request first
- > People know the group is still active
- > You can re-use the same text for each message
- > New members find your patient group, or local support in their country
- > An invitation to be involved and contribute means a thriving community full of international experiences

Have you filled out your Profile?

Robert Pleticha's Page moderator



« Hi, I'm Rob and work with EURORDIS <http://www.eurordis.org> as an Online Community Manager. I'm here to support you and answer any questions that come up along the way. Message me here or email robert.pleticha@eurordis.org »

 Share my story

Your profile is 100% complete

[Edit My Profile](#)

My Profile

Username:
robpleticha

Member since:
Sep 1, 2010

Real name:
Robert Pleticha

Country:
Spain

[Edit](#)

Privacy Checklist

- Is your profile set to **Members only?** (*under Edit Profile link*)
- Have you used your full name, or included too much identifying information in your profile or post?
- Do you make your forum posts private?
- Do you check the profile of a person sending you a friend request?
- Have you checked your group membership to ensure members belong in the community?

Moderators backend website

1. Go to: <http://www.rareconnect.org/backend.php/>
2. Type your username and password, as you would do when normally signing in to RareConnect

Username*

Password*

Remember

Moderators backend website

Now, you see:

The screenshot displays the RareConnect moderators backend website. The top navigation bar includes the RareConnect logo, a language selector set to English, a Switch button, and a user profile for 'Hello robmode...' with a Logout link. A dropdown menu is open over the 'Pages' link, listing 'Articles', 'Documents', 'Testimonials', 'Faqs', and 'Comments'. Below the navigation, a note indicates the user is logged in as a community moderator and lists the communities: 'Pulmonary hypertension'. The main content area is titled 'Testimonials' and features a table with 3 results. The table columns are: Name, Communities, Section, Published, Highlighted, Commentable, Original language, Date, and Actions. The table contains three rows of testimonials, all published and commentable. To the right of the table is a form for editing a testimonial, with fields for 'Communities list', 'Testimonial author', 'Reference', 'Original language', and 'Published' (with a 'yes or no' dropdown). A 'Choose an action' dropdown and a 'go' button are located below the table.

Note: Logged in as a community moderator. You can create, edit and manage the some content on the following communities. These communities are: *Pulmonary hypertension*

Testimonials

| <input type="checkbox"/> | Name | Communities | Section | Published | Highlighted | Commentable | Original language | Date | Actions |
|--------------------------|--|------------------------|---------|-----------|-------------|-------------|-------------------|----------|---|
| <input type="checkbox"/> | A rare, serious and depressing illness... | Pulmonary hypertension | What? | ✓ | | ✓ | en | 20/01/13 | Edit Delete Comments Translate |
| <input type="checkbox"/> | Results of the first International PAH Patient and Carer Survey launched at the PHA Europe General Assembly 2012 | Pulmonary hypertension | What? | ✓ | | ✓ | en | 26/09/12 | Edit Delete Comments Translate |
| <input type="checkbox"/> | Sandy from New Zealand | Pulmonary hypertension | What? | ✓ | | ✓ | en | 26/07/12 | Edit Delete Comments Translate |

3 results

Choose an action

Communities list

Testimonial author

Reference
 is empty
Used to create cross-locale permalinks. Will be generated if none provided.

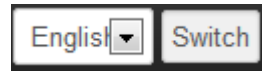
Original language

Published
Page will be publicly accessible if checked

Moderators backend website

Here you can add Documents, Events, and edit existing content on the site.

To view different language sections, use the selector in the right hand corner.



1. Give it a try and ask questions.
2. Instructional videos for each section will be available in February.
3. Send us your feedback.

Rare Disease Day Feb. 28, 2013

Share your photo in the Flickr Photostream or your video in the YouTube playlist:
www.rare diseaseday.org/tellyourstory

If you're in the USA, add your event here:
<http://rare diseaseday.us/events/tell-us-what-youre-doing/>

If you're in Europe, email your event to your national alliance or to:
rare diseaseday@eurordis.org

Ask to speak to a school or group about rare diseases

Share the poster in your neighborhood or at work, add the RDD logo to your social media profile, add the banner to your email signature
<http://www.rare diseaseday.org/article/download>

Follow Rare Disease Day and Rare Disease Day US on Facebook and Twitter.



Conclusions

The success of your RareConnect community is highly dependent on you

Many of the changes to the website resulted from moderator feedback, please keep it coming

If you'd like to try to update your community without the RareConnect team, try the new backend of the website

**Thanks for attending our
5th Moderator Webinar**