



**European
Reference
Network**

for rare or low prevalence
complex diseases

 **Network**
Neuromuscular
Diseases (ERN EURO-NMD)

ERN Euro-NMD - User guide

<https://ern-euro-nmd.eu/>

Version 16/12 /2024

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TASK LIST URLs

Register / Login: <https://ern-euro-nmd.eu/login/>

Private space: <https://ern-euro-nmd.eu/private/>

Edit profile: <https://ern-euro-nmd.eu/profile/>

Groups Membership: <https://ern-euro-nmd.eu/private/groups-membership/>

Shared files: <https://ern-euro-nmd.eu/private/shared-files/>

Data collaborations forms: <https://ern-euro-nmd.eu/data-collaboration-forms/>

Request a group membership: <https://ern-euro-nmd.eu/data-collaboration-forms/create/group-membership-request/>

Propose a new healthcare provider: <https://ern-euro-nmd.eu/data-collaboration-forms/create/healthcare-provider/>

Propose a new organization: <https://ern-euro-nmd.eu/data-collaboration-forms/create/organisation/>

Create a news post: <https://ern-euro-nmd.eu/data-collaboration-forms/create/post/>

Create an opportunity post: <https://ern-euro-nmd.eu/data-collaboration-forms/create/opportunity/>

Add an event to the website: <https://ern-euro-nmd.eu/data-collaboration-forms/create/event/>

Add a publication to the website: <https://ern-euro-nmd.eu/data-collaboration-forms/create/publication/>

Add a poster to the website: <https://ern-euro-nmd.eu/data-collaboration-forms/create/poster/>

Submit an educational activity: <https://ern-euro-nmd.eu/data-collaboration-forms/create/educational-activity/>

1. REGISTER TO ERN-EURO-NMD

If your name appears on “[Who’s who in EURO-NMD](#)” you already have a profile in the contacts database. You will need an account to edit your profile.

- If you already have the credentials for your account, please log in and edit your profile in the private area.
- If you do not have one, please create a new account.

1.1 - Create your account

<https://ern-euro-nmd.eu/login/>

Login

Members of ERN EURO-NMD
(If you are a member of ERN EURO-NMD)

Email address

Password

Keep me signed in

[Forgot your password?](#)

[You don't have a password yet? Click here](#)

Request to open an account
(Your account opening request will be submitted to a moderator)



Enter your data, create a password and click on “Register”

Register

First Name

Last Name

E-mail Address

Password

Confirm Password

Your password must contain at least 8 characters, one lowercase letter, one capital letter and one number.

[Show privacy policy](#)

Please confirm that you agree to our privacy policy

You'll receive a confirmation e-mail letting you know your account will be reviewed

European Reference Network

Thank you for signing up!
Your account has to be manually reviewed.

Please allow us some time to process your request and review your information.

Thank you!
The [European Reference Network](#) Team

Once your account has been approved, you'll receive an e-mail inviting you to log in.

Your account at European Reference Network is now active

European Reference Network

Thank you for signing up!
Your account is now approved.

[Login to our site](#)

Account Information

Your account email: alvaro@mlcom.fr

Your account username: [alvaro@mlcom.fr](#)

Set your password: https://ern-euro-nmd.eu/password-reset?act=reset_password&hash=6TJf1YSfaB2MjV3mzTF4&login=alvaro%40mlcom.fr

Thank you!
The [European Reference Network](#) Team

If you forgot your password, you can set up a new one by requesting to receive a link in your email.

Password Reset

New Password

Confirm Password

[Change password](#)

1.2 - Create your contact page

After you receive your credentials (username and password), you can either create a profile **if you do not have one** or edit the existing one ([see chapter 2.2](#))

To know if you have a contact profile page, look for your name under “Who’s who in NMD” <https://ern-euro-nmd.eu/whos-who-in-euro-nmd/>.

If you don’t have a contact page, you will be invited to complete your information through this form.

Register – Profile informations

You are not in our database, your account has to be manually reviewed.
Please to fill out your information below to confirm your registration.
(You will get a email when your account will be approved)

Full Display Name *

Prefix

First name

Last name

Suffix

Job Title

Complete this field for a specific role within the ERN. eg Project Manager, Project Assistant

Email

This is the contact's email address

Show email address

Yes

No

Additional emails

Additional contact's email address (it could be multi addresses)

Phone

This is the contact's phone number

Show phone number

Yes

No

2. PRIVATE SPACE

2.1 - Login to your space

<https://ern-euro-nmd.eu/login/>

Enter your login credentials and click “Login” to access your private space.

Login

Members of ERN EURO-NMD

(If you are a member of ERN EURO-NMD)

Email address

test@gmail.com

Password

Keep me signed in

Login

[Forgot your password?](#)

[You don't have a password yet? Click here](#)

Request to open an account

(Your account opening request will be submitted to a moderator)

Open an account


Once you're logged in, your full name will appear on the menu and clicking on it will let you access your private space.

The screenshot shows the top navigation bar of the ERN EURO-NMD website. It features a search bar, social media icons for LinkedIn, YouTube, and Twitter, and the ERN EURO-NMD logo. The main navigation menu is highlighted in orange and includes links for Home, About EURO-NMD, Patient, CPMS, Education, News & Events, and Registry. A user profile dropdown menu is visible on the right, showing the name Emmanuel Achet, which is highlighted with a blue box and an arrow.

<https://ern-euro-nmd.eu/private/>

My Private Space

My profile

 **Alvaro Test**
alvaro@mlcom.fr

[Edit profile](#) [View my profile](#)

[Account settings](#) [Logout](#)

Groups Membership

You are not assigned to any group.

[Edit assignments](#) [View my groups](#)


Latest shared files

Data collaboration forms

2.2 - Edit your public profile

My Private Space

My profile

 **Alvaro Test**
alvaro@mlcom.fr

[Edit profile](#) [View my profile](#)

[Account settings](#) [Logout](#)

Groups Membership

You are not assigned to any group.

[Edit assignments](#) [View my groups](#)

Clicking on your name, photo or “View my profile” lets you see your public profile

Home > Alvaro Testing

AAA

Contact

Eng. Alvaro Test - Project Manager 

Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do eiusmod tempor incididunt ut labore et dolore magna aliqua. Ut enim ad minim veniam, quis nostrud exercitation ullamco laboris nisi ut aliquip ex ea commodo consequat. Duis aute irure dolor in reprehenderit in voluptate velit esse cillum dolore eu fugiat nulla pariatur. Excepteur sint occaecat cupidatat non proident, sunt in culpa qui officia deserunt mollit anim id est laborum



Alvaro Test

alvaro.test@ern.eu

[Edit the profile](#)



[Return](#)

Click on the link indicated by the arrow to edit your profile.

Home > Profile

AAA

Profile

Edit Contact

Full Display Name *

Alvaro Testing

Prefix

Eng.

First name

Alvaro

Last name

Test

Suffix


Job Title

Complete this field for a specific role within the ERN. eg Project Manager, Project Assistant

You can also edit your profile in your private space with “Edit profile” button.



My Private Space

My profile




Alvaro Test
alvaro@mlcom.fr

[Edit profile](#) [View my profile](#)

[Account settings](#)  [Logout](#) 

Groups Membership

You are not assigned to any group.

[Edit assignments](#) 

[View my groups](#)

Edit Contact

Full Display Name *

Prefix

First name

Last name

..

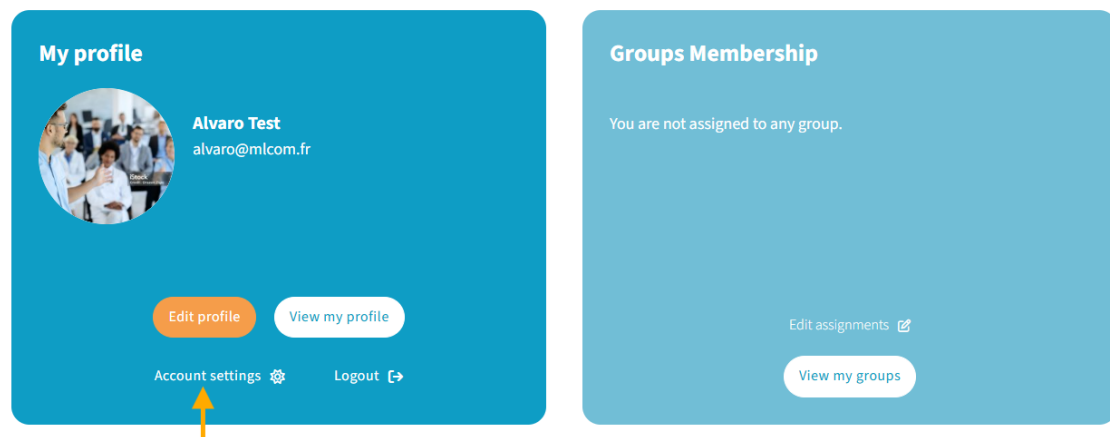
2.3 - Edit your account settings

Click “Account settings” to manage your user account.

Home > My Private Space

AAA

My Private Space



<https://ern-euro-nmd.eu/account/>

Here you can edit the email address associated with your account or change your password.

Change your email address

Username

First Name

Last Name

Email Address

Change your password

Current Password

New Password

Confirm Password

3. Group Membership

Home > My Private Space > Groups Membership

AAA

Groups Membership

My Groups

You are not assigned to any group.

All Groups

<p>DISEASE ALS Chair: Vincenzo Silani</p> <p>Request to join the group</p>	<p>OPERATIONAL Board Members Chair: Teresinha Evangelista</p>	<p>CPMS Admin</p>
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3.1 Join a group

3.1.1 - From the groups-membership page

<https://ern-euro-nmd.eu/private/groups-membership/>

You can request to join a group by clicking the “Request to join the group”

Groups Membership

My Groups

You are not assigned to any group.

All Groups

<p>DISEASE ALS Chair: Vincenzo Silani</p> <p>Request to join the group</p>	<p>OPERATIONAL Board Members Chair: Teresinha Evangelista</p>	<p>CPMS Admin</p>
<p>CPMS helpdesk</p> <p>Request to join the group</p>	<p>OPERATIONAL CPMS representative</p> <p>Request to join the group</p>	<p>OPERATIONAL Education</p> <p>Request to join the group</p>

New group membership request

First Name: Alvaro

Last Name: Test

Group(s) *: Education

Requested action *: I want to join this group

GDPR Agreement

By submitting this form you grant us the rights

- to store your submitted contents in our database
- to generate content on our site based on your data
- to make this content publicly accessible

Don't forget to click the "Submit" button

• to generate content on our site based on your data

• to make this content publicly accessible

Please agree to our privacy police

Submit

For more information on data management, please read our [Privacy Policy](#)

The admin of that group will need to approve your request to join.

3.1.2 - From Data collaboration forms

<https://ern-euro-nmd.eu/data-collaboration-forms/create/group-membership-request/>

In the Group Memberships tab, you can also request to join or leave a group.

Data collaboration forms

This page gives everyone the opportunity to contribute to the content (articles, events, organisations, etc.) of the ERN Euro NMD website. [Logged-in users](#) can also see their submitted forms.

ADD / UPDATE INFORMATION:

- Member's profile
- Group Memberships**
- Healthcare provider
- Organisation
- Article
- Event
- Publication
- Poster
- Educational activity for EURO-NMD endorsement

New group membership request

First Name: Alvaro

Last Name: Test

Group(s) *: Education

Requested action *: I want to join this group

GDPR Agreement

By submitting this form you grant us the rights

- to store your submitted contents in our database
- to generate content on our site based on your data
- to make this content publicly accessible

Please agree to our [privacy policy](#)

Submit

For more information on data management, please read our [Privacy Policy](#)

Once you click on "Submit", you'll get a confirmation message

ADD / UPDATE INFORMATION:

- Member's profile
- Group Memberships**

New group membership request

Your request has been sent. (You can close this window)

For more information on data management, please read our [Privacy Policy](#)

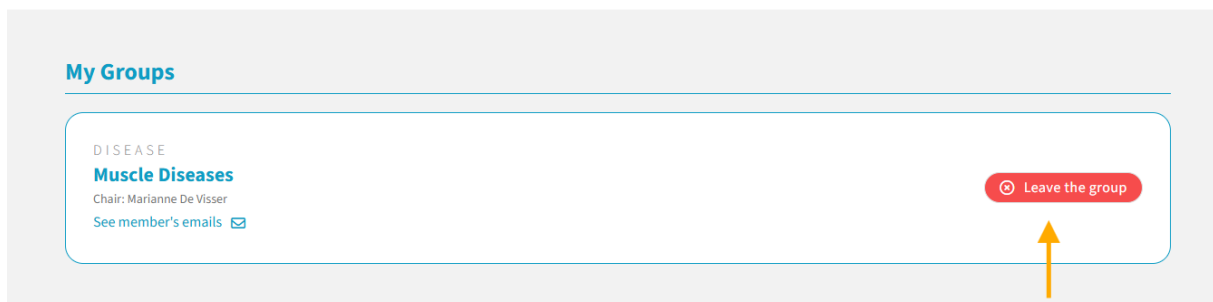
Your private web page will have a blue square with your profile and another showing your group memberships.

My Private Space

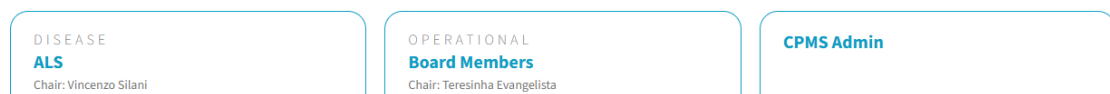


or in the Groups Membership page if you are logged in.

Groups Membership



All Groups



You can also request to leave a Group.

New group membership request

First Name

Last Name

Group(s) *

Requested action *

GDPR Agreement

By submitting this form you grant us the rights

- to store your submitted contents in our database
- to generate content on our site based on your data

3.1.3 - Groups by nomination

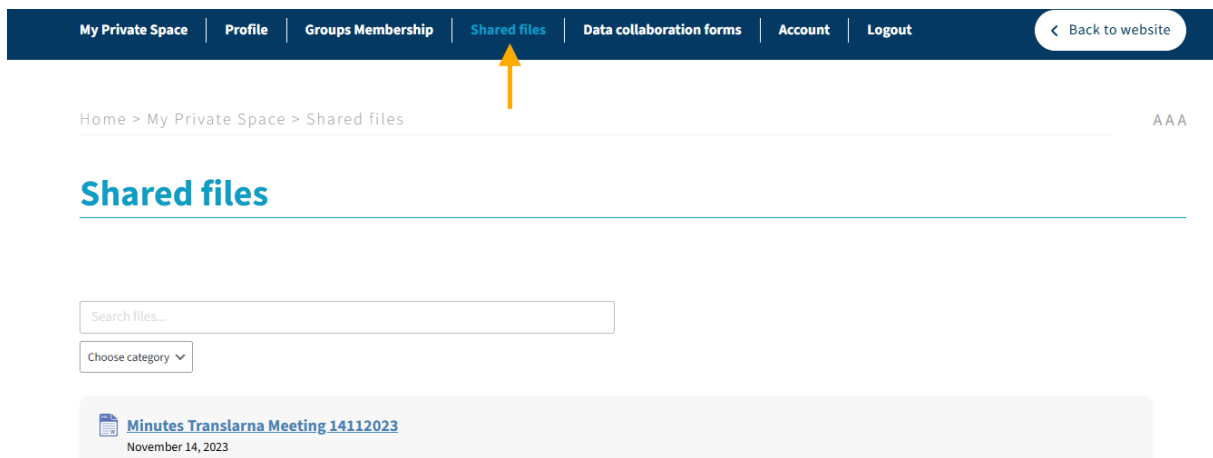
When a group has no “Request to join” button, it means that its members are nominated, so they are not open to anyone wanting to join. They usually have roles defined by the ERN’s governance, and the nomination requires approval from the ERN's Board or Executive. You can send an email to info@ern-euro-nmd.eu for additional details.

All Groups

<p>DISEASE ALS Chair: Vincenzo Silani</p> <p>Request to join the group</p>	<p>OPERATIONAL Board Members Chair: Teresinha Evangelista</p> <p>[Redacted]</p>	<p>CPMS Admin</p> <p>[Redacted]</p>
<p>CPMS helpdesk</p> <p>Request to join the group</p>	<p>OPERATIONAL CPMS representative</p> <p>Request to join the group</p>	<p>OPERATIONAL Education</p> <p>Request to join the group</p>
<p>ADVISORY Educational Board Chair: Jean-Phillipe Plançon</p> <p>[Redacted]</p>	<p>EURO-NMD Coordination team Chair: Teresinha Evangelista</p> <p>[Redacted]</p>	<p>ADVISORY EURO-NMD Patient Representatives</p> <p>[Redacted]</p>

4. SHARED FILES

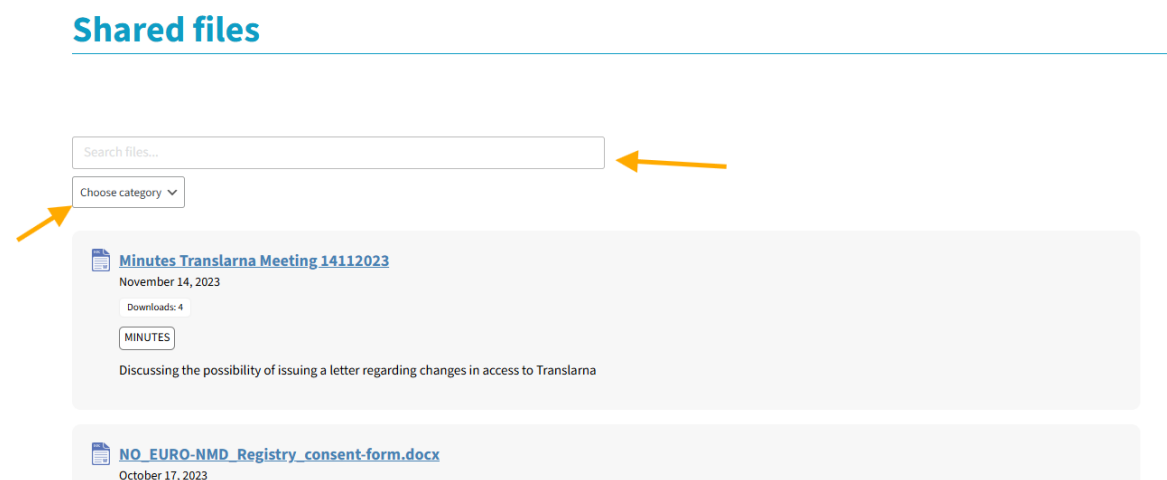
<https://ern-euro-nmd.eu/private/shared-files/>



4.1 - View and download shared files

Shared files can be found in the *shared files* page.

Here you can navigate through the list and use the search bar or “Choose category” to filter them





To download a file, just click on the title

Shared files

Search files...

Choose category ▾

 [Minutes Translarna Meeting 14112023](#)
November 14, 2023
Downloads: 4
MINUTES
Discussing the possibility of issuing a letter regarding changes in access to Translarna

 [NO EURO-NMD_Registry_consent-form.docx](#)
October 17, 2023
Downloads: 6
REGISTRY

A password protects some files. The rule is that the default password is the date indicated under the file following the format ddmmyyyy, but it may depend. Contact support@euronmd.raiseaticket.com when in doubt.

PLEASE ENTER PASSWORD

Password

SUBMIT

5. DATA COLLABORATION FORMS

This page gives everyone the opportunity to contribute to the content (articles, events, organisations, etc.) of the ERN Euro NMD website.










Logged-in users can also see their submitted forms.

<https://ern-euro-nmd.eu/data-collaboration-forms/>

Data collaboration forms

This page gives everyone the opportunity to contribute to the content (articles, events, organisations, etc.) of the ERN Euro NMD website. [Logged-in users](#) can also see their submitted forms.

ADD / UPDATE
INFORMATIONS:

-  Member's profile ▾
-  Group Memberships ▾
-  Healthcare provider ▾
-  Organisation ▾
-  Article ▾
-  Event ▾
-  Publication ▾
-  Poster ▾
-  Educational activity for EURO-NMD endorsement ▾

Click the menu on the left to choose which content to submit or update.

5.0 - The global process of collaboration of the content

All sections (Group, Article, Event, etc.) will offer a similar experience:

- 1 – It will display a form to fill
- 2 – Before sending the form, you can save it as a draft by clicking the “Save” button. (You can edit and send it for submission at a later time)
- 3 – Your submission will then be sent to the admins
- 4 – Once approved, your submission will appear on the website in the corresponding section and your private space.

5.1 - HEALTHCARE PROVIDER - Propose a new healthcare provider

<https://ern-euro-nmd.eu/data-collaboration-forms/create/healthcare-provider/>

ADD / UPDATE
INFORMATIONS:

- Member's profile
- Group Memberships
- Healthcare provider**
- Organisation
- Article
- Event
- Publication
- Poster
- Educational activity for EURO-NMD endorsement

New healthcare provider

Full Display Name *

HCP Type *

Select a type of HCP

Code

This is the code allocated to each HCP.

Name (official)

Name (in english) *

This is the name that will be displayed on the website

Fill in the form with all the information you can provide.

All contacts linked to this HCP/Organisation.

Select

Main Representative

Add the main contact for this HCP/Organisation.

Select

GDPR Agreement

By submitting this form you grant us the rights

- to store your submitted contents in our database
- to generate content on our site based on your data
- to make this content publicly accessible

Please agree to our privacy police

Save

Submit for moderation

For more information on data management, please read our [Privacy Policy](#)

At the bottom of the form, select your representatives in the list (**if you can't find them, it means they have not yet created their account on the ERN-EURO-NMD website**)

Your submission will then need approval from the administrators.

Once approved, the healthcare provider can be found in the list here:

<https://ern-euro-nmd.eu/healthcare-providers/>

5.2 - ORGANISATION - Propose a new patient representatives organisation

<https://ern-euro-nmd.eu/data-collaboration-forms/create/organisation/>

ADD / UPDATE INFORMATIONS:

- Member's profile
- Group Memberships
- Healthcare provider
- Organisation**
 - Propose a new patient representative
 - View my patient representatives
- Publication
- Poster
- Educational activity for EURO-NMD endorsement

New organisation

Full Display Title *

Code
This is the code allocated to each HCP.

Name (official)

Name (in english) *
This is the name that will be displayed on the website

Display Address
The full address of the HCP as it will be displayed.

Fill in the form with all the information you can provide.

All contacts linked to this HCP/Organisation.

Main Representative
Add the main contact for this HCP/Organisation.

GDPR Agreement

By submitting this form you grant us the rights

- to store your submitted contents in our database
- to generate content on our site based on your data
- to make this content publicly accessible

Please agree to our privacy police

Save

Submit for moderation

For more information on data management, please read our [Privacy Policy](#)

At the bottom of the form, select your representatives in the list (**if you can't find them, it means they did not create their account on the ERN-EURO-NMD website yet**)

Your submission will then need approval from the administrators.

Once approved, the organization can be found in the list here:

<https://ern-euro-nmd.eu/organisations/>

5.3 - ARTICLE - propose content for the website

In this section you can create a post

A news post <https://ern-euro-nmd.eu/data-collaboration-forms/create/post/>

or an opportunity <https://ern-euro-nmd.eu/data-collaboration-forms/create/opportunity/>

ADD / UPDATE INFORMATION:

- Member's profile
- Group Memberships
- Healthcare provider
- Organisation
- Article**
 - Add a news post
 - Add a opportunity post (job, ...)
 - View all my posts
- Educational activity for EURO-NMD endorsement

New post

Full Display Title *

Category *

Select a category

Content

Paragraph B I Bulleted List Numbered List Quote Link Image

Visual Text

Just fill in the associated form with all the information and click "submit for moderation"

Healthcare provider

Organisation

Article

Event

Publication

Poster

Educational activity for EURO-NMD endorsement

GDPR Agreement

By submitting this form you grant us the rights

- to store your submitted contents in our database
- to generate content on our site based on your data
- to make this content publicly accessible

Please agree to our privacy police

Save

Submit for moderation

For more information on data management, please read our [Privacy Policy](#)

Your submission will then need approval from the administrators.

Once approved, the posts can be found in the list here:

<https://ern-euro-nmd.eu/all-posts/>

5.4 - EVENT - propose an event to be shared on the website

<https://ern-euro-nmd.eu/data-collaboration-forms/create/event/>

Just fill the associated form with all the information and submit for moderation.

ADD / UPDATE INFORMATION:

- Member's profile
- Group Memberships
- Healthcare provider
- Organisation
- Article
- Event**
 - Add an event to our events page
 - View my events
- Educational activity for EURO-NMD endorsement

Featured Image

Drop files here to upload

Endorsement of educational activity

If you consider asking for endorsement of this event, please check this box and visit also [this page](#).

GDPR Agreement

By submitting this form you grant us the rights

- to store your submitted contents in our database
- to generate content on our site based on your data
- to make this content publicly accessible

Please agree to our privacy policy

For more information on data management, please read our [Privacy Policy](#)

Your submission will then need approval from the administrators.

Once approved, the events can be found in the list here:

<https://ern-euro-nmd.eu/events/>

5.5 - PUBLICATION - add a publication quote to the website

This is mainly for network members to make their work acknowledging EURO-NMD visible

<https://ern-euro-nmd.eu/data-collaboration-forms/create/publication/>

Just fill the associated form with all the information.

If the publication was recommended by a specific group, you can add it at the bottom of the form.

ADD / UPDATE
INFORMATIONS:

- Member's profile
- Group Memberships
- Healthcare provider
- Organisation
- Article
- Event
- Publication

Add a publication to our website
View my publications
EURO-NMD endorsement

Recommended by Groups

Search...

GDPR Agreement

By submitting this form you grant us the rights

- to store your submitted contents in our database
- to generate content on our site based on your data
- to make this content publicly accessible

Please agree to our privacy police

Save

Submit for moderation

For more information on data management, please read our [Privacy Policy](#)

Your submission will then need approval from the administrators.

Once approved, the publication can be found in the list here:

<https://ern-euro-nmd.eu/publications/>

5.6 - POSTER - Propose a poster to be listed on the website

This is mainly for network members to make their work acknowledging EURO-NMD visible.

<https://ern-euro-nmd.eu/data-collaboration-forms/create/poster/>

Just fill in the associated form with all the information and submit for moderation.

Make sure you provide a high-quality image for your poster

ADD / UPDATE INFORMATIONS:

- Member's profile
- Group Memberships
- Healthcare provider
- Organisation
- Article
- Event
- Publication
- Poster

Add a poster to our website

View my posters

Diseases

Select diseases

Select diseases regarding the article

GDPR Agreement

By submitting this form you grant us the rights

- to store your submitted contents in our database
- to generate content on our site based on your data
- to make this content publicly accessible

Please agree to our privacy police

Save

Submit for moderation

For more information on data management, please read our [Privacy Policy](#)

Your submission will then need approval from the administrators.

Once approved, the posters can be found in the list here:

Emmanuel : <https://ern-euro-nmd.eu/publication-type/poster/>

Contact

All email support enquiries should be addressed to support@euronmd.raiseaticket.com