



## Dissemination & Communication (WP2)

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## Questions or Comments

Please email [EndoERN@amsterdamumc.nl](mailto:EndoERN@amsterdamumc.nl)



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## Endo-ERN communication



### Internal communication

- Membership network activities and tasks
- Available resources



### External communication

- Raise awareness of network and members with a focus on available resources



## Network Ambassadors



European Reference Network

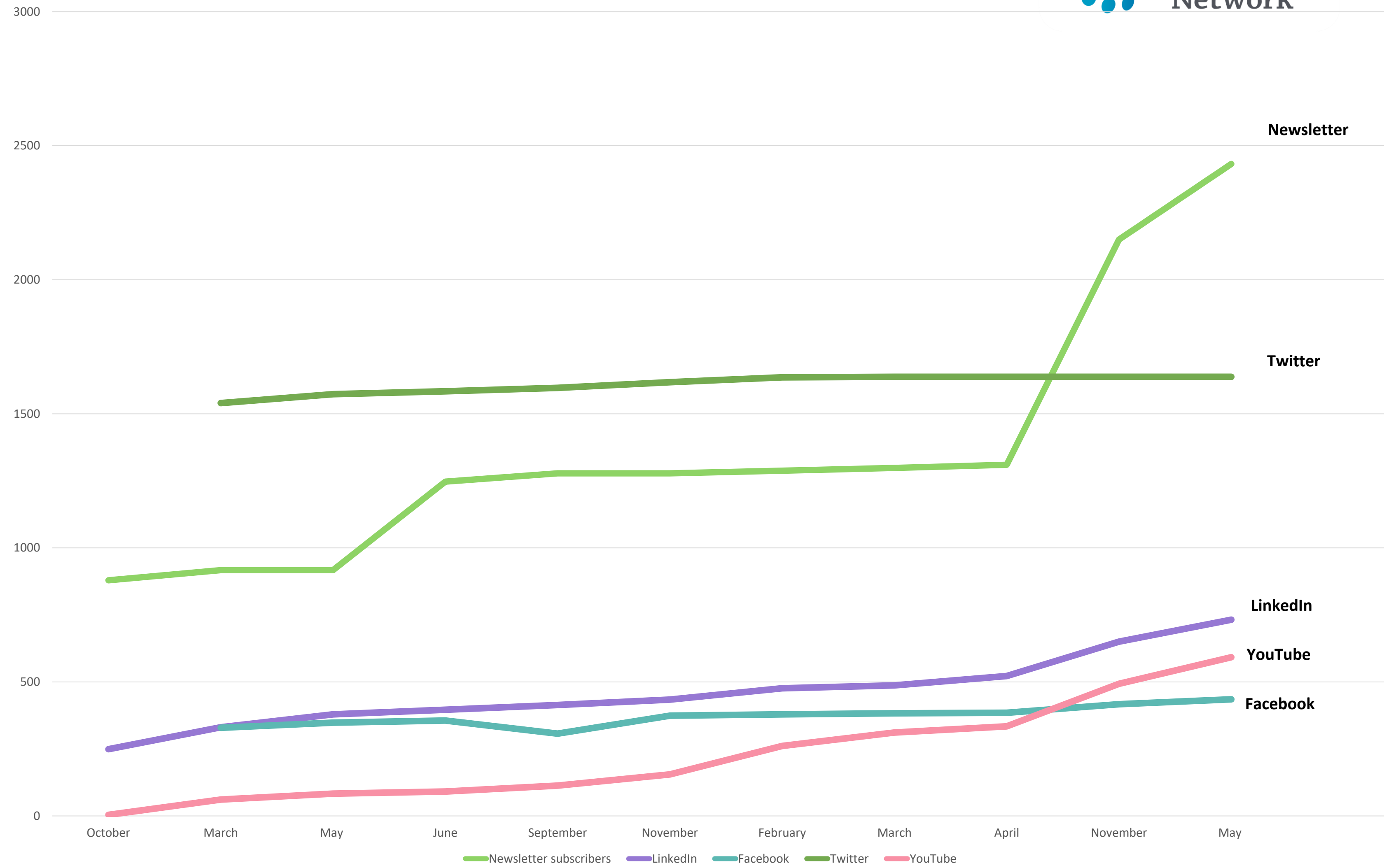


Endo-ERN



# Channels

## User development





## Follow, Like and Share



- If you post on your channels during the GA please tag Endo-ERN and/use #EndoGA2025
- Please follow our channels and reshare with your network

## Topic based newsletters

- Clinical practice information (guidelines and patient materials)
- Rare disease research including registries
- Virtual Consultations
- Education & Training

[Update your preferences](#) when the next newsletter comes in.



Forward to 1 colleague each month that might find the content interesting.



## Website growth 2024-2025



	Total	Increase
Page views	162,995	+50%
Active users	40,329	+113%
Page views per user	1.89	<b>+27%</b>





## Top 5 webpages May 2024-2025

1. Home page (14.22%)
2. Reference Centres
3. About Endo-ERN
4. Webinars
5. Rare Endocrine Conditions overview page



Visit the webpage of your Reference centre and ensure the information is correct including website information



European  
Reference  
Network



Endo-ERN

## Publication database



- Available to search for Endo-ERN rare endocrine publications
- 2022/2024 pubs still being processed
- You can enter your relevant 2025 publications NOW

You need: DOI, ORPHAcode

# Patient Resources

Filter by MTG Filter by Condition Filter by Country Filter by Language


DRAFT

## Future developments WP7



- Showcase Endo-ERN developed/endorsed guidelines
- More user friendly and accessible
- Definitions and processes available online

Endocrine  
CONNECTIONS



[linkedin.com/company/rareendoern](https://www.linkedin.com/company/rareendoern)



[linkedin.com/showcase/endocrineconnections](https://www.linkedin.com/showcase/endocrineconnections)



<https://ec.bioscientifica.com>

# ENDO-ERN Vol II: Rare Diseases and Transition in Care

SPECIAL COLLECTION



IN COLLABORATION WITH:



Endo-ERN

Scan to learn more

## National Associations Outreach

- Develop a database with key contacts
- Outreach to key contacts introducing the network
- Monthly update contact about activities and resources in the network



Do you have information about the contacts in your national association? Please get in touch with me.

Can you get a speaking slot on the agenda to promote Endo-ERN? I can provide slides.

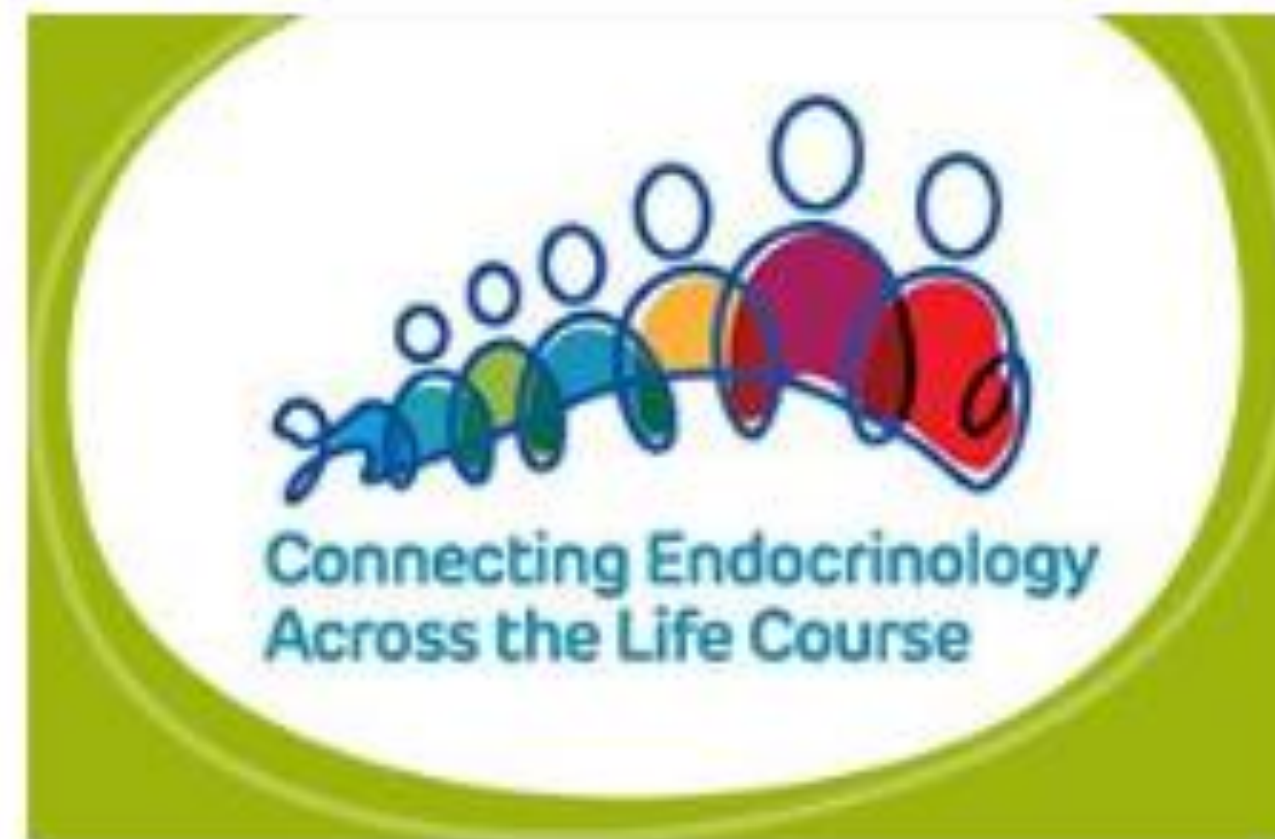
## More in-depth content

- Possible recordings specifically with Clinical Exchange participants
- Showcase member institutions



If you have a story you would like to tell about your involvement with the network. Or a benefit of your membership please reach out.

## Additional activities



**WORLD OrphanDrug**  
Congress Europe 2025

WE ARE SUPPORTING PARTNERS OF  
**THE WORLD'S  
LEADING ORPHAN  
DRUG AND RARE  
DISEASE EVENT!**

27 - 29 OCTOBER 2025  
RAI CONGRESS CENTRE,  
AMSTERDAM

**JOIN US!**    2,000+    250+    130+  
Attendees    Speakers    Exhibitors





**Thank you!**

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