

Dissemination & Communication (WP2)

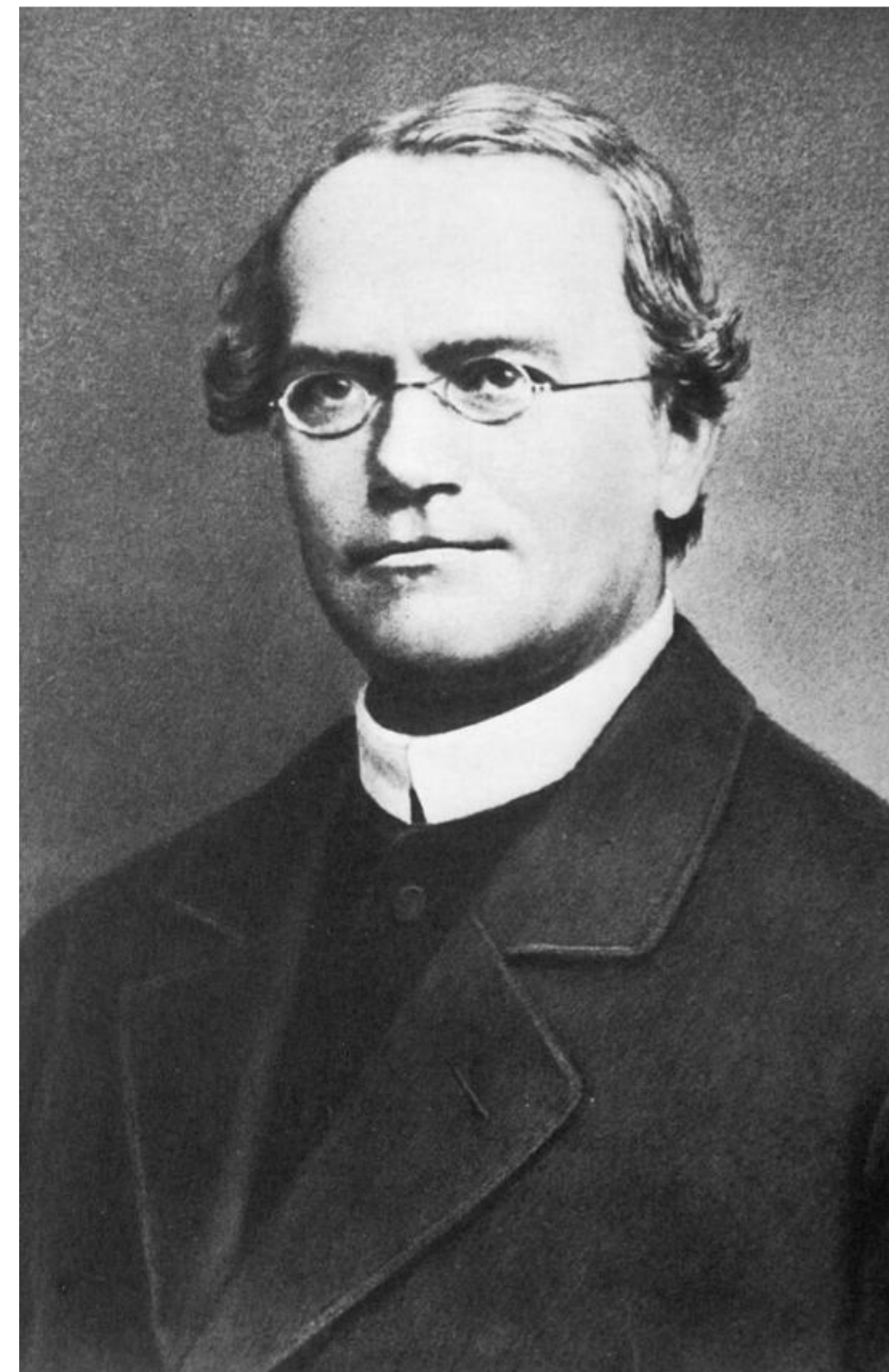
Aimee Casey, Endo-ERN Communication Lead



Funded by
the European Union

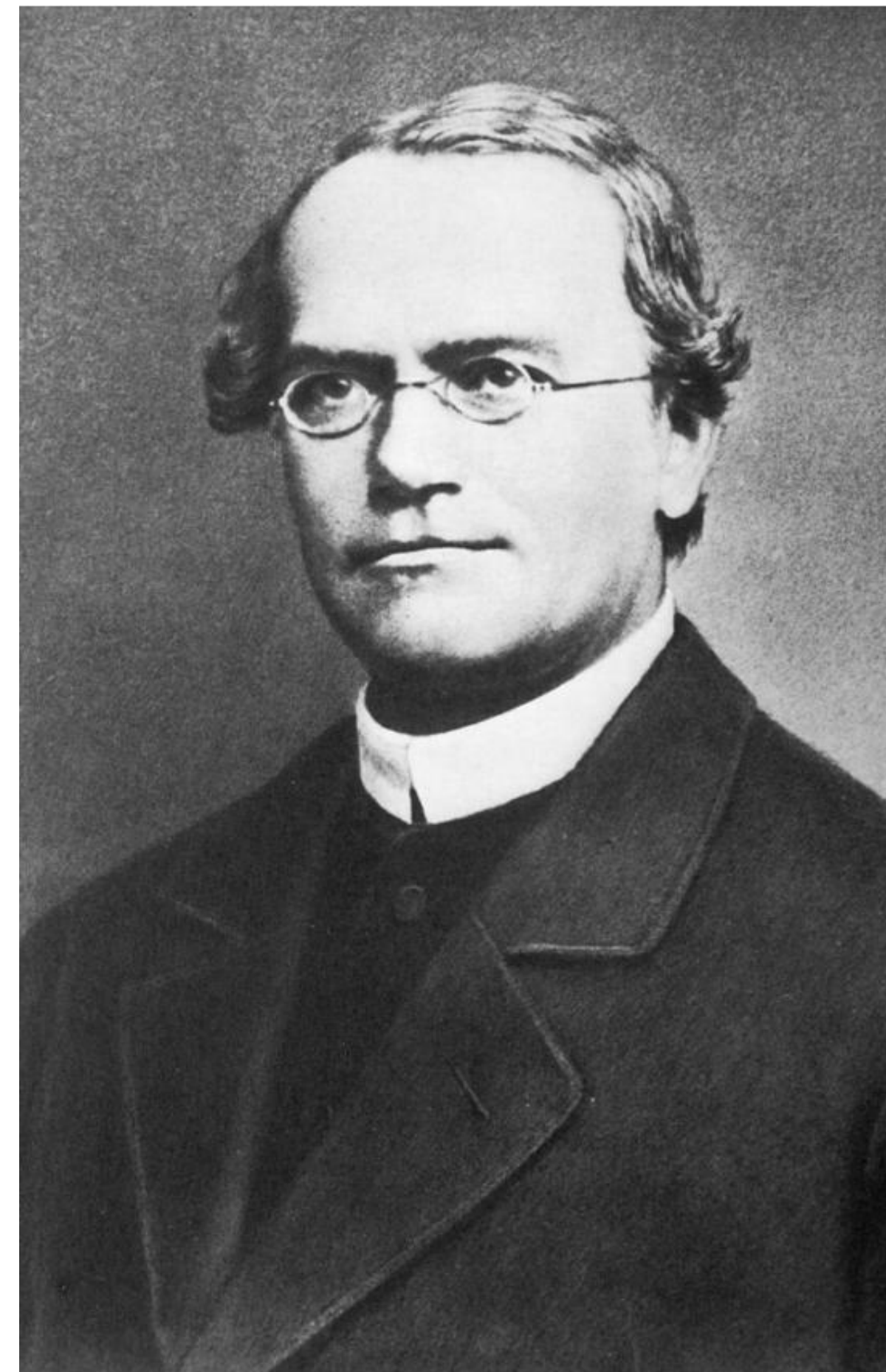
Are you using AI?





Father of genetics Gregor Mendal

“Mendel's scientific biography thus provides an example of the failure of obscure, highly original innovators to receive the attention they deserve.”



Endo-ERN HCP representatives



You contribute your
time voluntarily



You work in a highly
specialised field



Important knowledge
is being generated
across many
institutions and
countries



The challenge is not
just producing
knowledge—
**it's making sure that
knowledge is visible,
accessible, and
actually used.**



ERNs: EUROPE'S RARE DISEASE EXPERTISE NETWORKS

1.600+ SPECIALISED UNITS | 375 HOSPITALS
27 EUROPEAN COUNTRIES & NORWAY

KEY FINDINGS FROM THE
EC CONTINUOUS MONITORING REPORT



ERNs: EUROPE'S RARE DISEASE EXPERTISE NETWORKS

14.000 TRAINING ACTIVITIES | 400,000 HEALTH
PROFESSIONALS TRAINED | 110,000 PATIENTS ENTERED INTO
ERN REGISTRIES

KEY FINDINGS FROM THE
EC CONTINUOUS MONITORING REPORT



**Social media &
newsletter update
May 2025-April 2026**

 **Professional reach**
→ LinkedIn (+47%)

 **Content engagement**
→ YouTube (+34%)

 **Community presence**
→ Facebook (+16%)

 **Updates**
→ Topic Newsletter (+54% open rate)

2025 website activity



Users

↓ Fewer users
60,012 total



Engagement

↑ Views per user
15.49%



Time

↑ Engagement time
44.77%

We are reaching a more targeted and engaged audience.

Endocrine Connections



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

HLM Declaration



- 8 action points
- Over 2000 signatures from ERN ecosystem
- Please sign and share with your respective departments, colleagues and network



Endo-ERN Reflections



Please consider giving your brief (maybe even a sentence) response to one or all of the following questions:

What does Endo-ERN allow you to do that you couldn't do alone?

Endo-ERN in one word?

What difference does the Endo-ERN network make for your patients?

**Follow, Like and
Share**



Thank you!

Please email EndoERN@amsterdamumc.nl



Aimee Casey

EndoERN@amsterdamumc.nl