

Nordic Adrenal and Pituitary Patient Associations (NAPA)

Lars Greiner



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The background of the slide is a close-up photograph of a dense field of small, light blue flowers with white centers and dark stamens. A dark purple rectangular box with rounded corners is positioned in the upper middle of the image, containing the text "OUR JOURNEY AND MISSION". At the top of the slide, there are three horizontal bars: a dark purple bar on the left, a dark purple bar in the middle, and a grey bar on the right.

OUR JOURNEY AND MISSION

NORDIC ADRENAL AND PITUITARY ALLIANCE (NAPA)

HOW IT ALL STARTED

From Scandinavian Network to Nordic Alliance

- Founded in 2007, Copenhagen
- Initiated by Professor Husebye
- First participants: Norway, Sweden, Denmark
- Special thanks to Jette from Denmark – still with us!



2007 i oktober, det første nordiske samarbeidsmøtet i København. Fra venstre: Jette Kristensen, Christian Fabien, Inget Asuquo, Kirsten Tolstrup, Vibs Neesen, Øyvind Lindland og Pia Lindström. Foto: ukjent.



EXPANDING THE NETWORK

- Finland joined in 2015
- Iceland joined in 2017
- Lithuania only in 2020
(under reorganization)



BECOMING NAPA IN 2023- A NEW IDENTITY

New name:
Nordic Adrenal
and Pituitary
Alliance (NAPA)

Representing
patients across
the Nordic and
Baltic region

OUR MISSION

**Striving for the Best
Healthcare and Awareness**



Focused on rare endocrine diseases



OUR MISSION

- **Striving for the Best Healthcare and Awareness**
- Focused on rare endocrine diseases
- Collaboration, advocacy, empowerment



REPRESENTED ORGANIZATIONS

- Addison Foreningen, Denmark
- Hypofysenettverket, Denmark
- Svenska Addisonföreningen, Sweden
- Hypofyse- og binyreforeningen, Norway
- Apeced ja Addison, Finland
- Addison samtökin, Iceland
- LIETUVOS HIPOFIZĖS PACIENTŲ ASOCIACIJA (LHPA), Lithuanian

ADDISONS SAMTÖKIN



DISEASES WHO WE REPRESENT

Addison's
Disease

Pituitary
Insufficiency

Cushing's
Syndrome

CAH

Acromegaly

APS I & II

Adrenal
Carcinoma





NORDIC CONFERENCES

FINLAND 2024 INSIGHTS



- **Shared Experiences:**
- “Expert by Experience” – patient educators
- Collaboration with nursing schools and paramedics
- Focus on influencing health authorities
- Planning next youth and family conferences



Lava cake 🌋 😊



HAVING FUN TOGETHER

DINNERS, LAUGHTER, LAVA CAKE MOMENTS 🍰

HOW WE
LOOK WHEN
WE COME
HOME 🤔





WHAT WE FIGHT FOR

Some Goals:

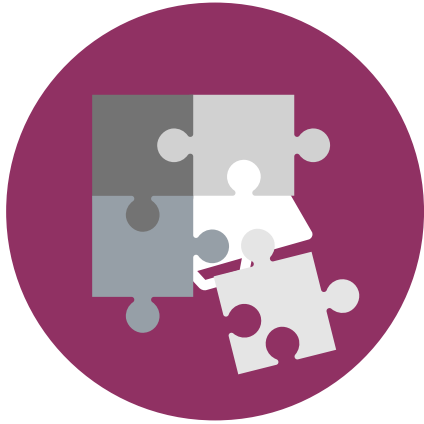
- Access to cortisol pumps for everyone who wants to try
- Recognition of Hidden Disabilities (Sunflower lanyard 🌻)
- Equal access to emergency treatment and medications

PROMOTING GOOD HEALTH

- **How Patient Organizations Promote Change**
- Advocacy for treatment access
- Raising awareness
- Working with decision-makers and the health system



THE FUTURE



STRONGER VOICE THROUGH
COLLABORATION



CONTINUING TO INFLUENCE
RESEARCH, HEALTHCARE, AND
POLICY



NEVER GIVING UP — SMALL
STEPS LEAD TO BIG CHANGES



THANK YOU! ❤️

Together, we make rare diseases
visible.

Together, we are stronger.