

# Perspectives on future participation and integration

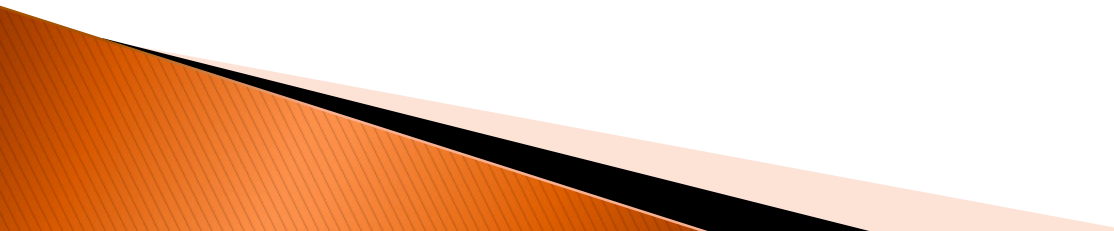
## The Patients

Anne-Grethe Lauridsen  
Patient Representative in MetabERN

# Danish Patient representatives in ERNs

‣ Jette Kristensen	Endo-ERN
‣ Tenna Toft Olesen	ERN BOND
‣ Anne-Grethe Lauridsen	MetabERN
‣ Bente Villumsen	ERN Skin
‣ Lisbeth Vestergaard Andersen	ERN GUARD-HEARTH
‣ Pernille Henriksen	VASCERN
‣ Lone McColaugh	ERN RARE-LIVER

# European Patient Advocacy Groups (ePAGs)

- ▶ ePAGs are supported by Eurordis
  - ▶ Each ePAG is related to an ERN
  - ▶ Each ePAG has a number of 'ePAG advocates'
  - ▶ ePAG advocates represent their disease area in the ERN
  - ▶ Some ePAG advocates also sit in the ERN Boards and horizontal working groups where they represent the broader rare disease patient community that falls under the scope of their ERN.
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# How we structure the work

## MetabERN Patient Governance Structure

Patient Board		
1 Patient Representative per Patient Organisation		
Steering Committee	Patient Executive Committee	
	Single Points of Contact for Subnetworks	Single Points of Contact for Work Packages
Chair	AOA	WP 1
Vice-Chair	C-FAO	WP 2
Medical Liaison	LSD	WP 3
X	PD	WP 4
X	PM-MD	WP 5
X	CDG	WP 6
X	NDMS	WP 7
X		WP 8



European  
Reference  
Network

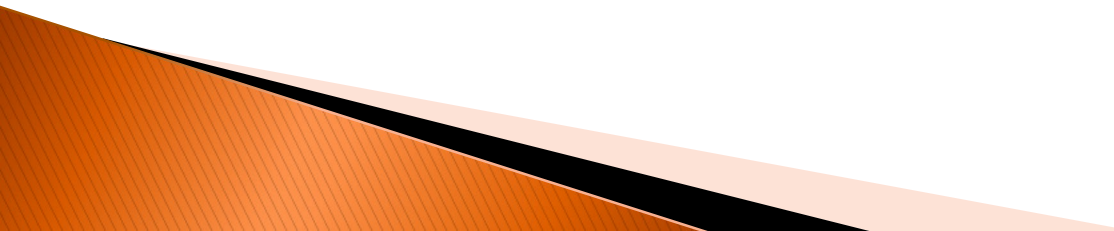
MetabERN  
European Reference Network  
for Metabolic Diseases



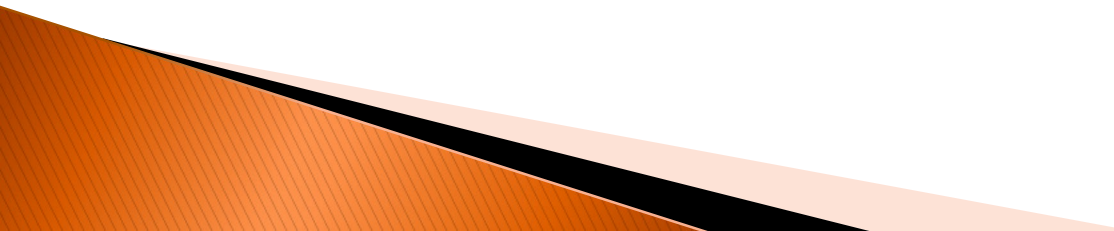
# The role of the Patient Board

- ▶ Contribute to the development and dissemination of patient information, policy, good practices, care pathways and guidelines
- ▶ Contribute to research by helping healthcare professionals to define areas that are important to patients and their families
- ▶ We seek to indentify more patient organisations from more countries to join the MetabERN Patient Board
- ▶ We have set up an approval structure on how to the become a member of the Patient Board
- ▶ The Steering committee has written 2 newsletters and a patient folder
- ▶ We are developing a survey on patients perspective on social assistance needs
- ▶ We share information about MetabeERN, the website and circulate newsletter

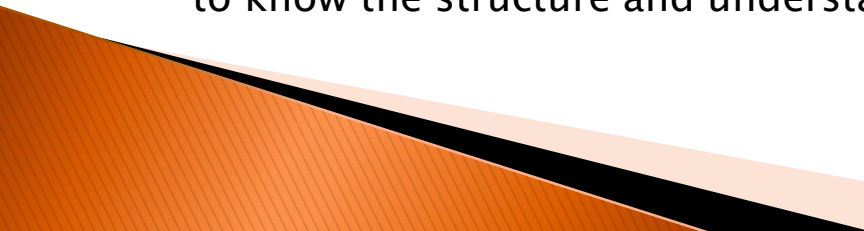
# How do we perceive it to be part of ERN

- ▶ As patient representatives we do experience an uncertainty amongst HCP on how to involve us in the work
  - ▶ Provides a larger network to other patient representatives as well as to other stakeholders – important for especially small and new groups
  - ▶ ERNs is a medical platform but as ePAGs we can raise the patients' voice
  - ▶ It goes without saying – but naturally it is for the benefit of patients that there is cross-border communication
  - ▶ It is important for Danish patients that Danish HCP is active in all ERNs and is active
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# How can EPAGs support the work of the ERNs

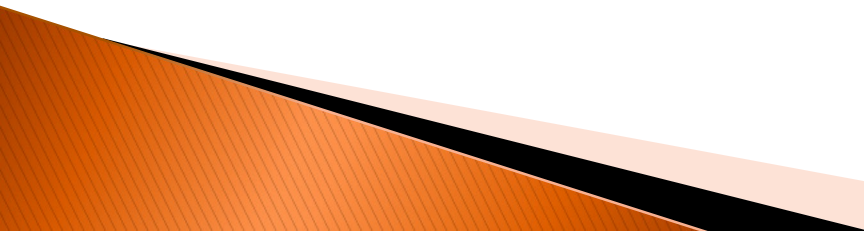
- ▶ It is stated in many connections – the ERNs are all about the patients
  - ▶ This is why ePAGs need to be there – to raise the voice of patients
  - ▶ We can be involved in developing/reviewing  
surveys, registries, studies, guidelines
  - ▶ We have a large and well structured base of support = our members,  
who we can reach quickly and make available eg for studies
  - ▶ We are the patient voice at the annual ERN meetings
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# Challenges as ePAG advocates

- ▶ It can be difficult to explain to patients/families what the benefit is of having ERNs are
  - ▶ It can be difficult to explain the benefit of being active/involved in the work of ERNs to other patient advocates
  - ▶ It can be difficult, within the small rare disease organisations, to find the human resources to do this work
  - ▶ It is a challenge if a patient advocate needs to speak on behalf of other diseases than "you own"
  - ▶ When you first get involved in "your" ERN it will take a lot of resources/time to get to know the structure and understand how you can contribute
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# Wishes from danish ePAG advocates

- ▶ The possibility to meet in a national context, to learn and share
  - ▶ A national coordinator to facilitate this
  - ▶ Hopefully this would also encourage more Danish patient advocates to get involved in the work of their relevant ERN
  - ▶ Set up of collaboration with DK HCP in the respective ERNs on the implementation of the ERN in the daily work
  - ▶ To be a part of the work/to be heard in relation to implementation of the Rare Disease National Plan
  - ▶ Economical support to participate both on a national and EU level
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Thank you for the attention >>

Thank you to the team:  
Jette , Tenna, Birte, Lene, Matt