ePAG ERN BOND

Tenna Toft

ERN BOND / XLH Alliance

‘The importance of a pregnancy module’

EuRREB
European Registries for Rare
Endocrine and Bone conditions

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The Importance of a Pregnancy Module

EuRREB Symposium 2025
Leiden

Friday, September 12th 2025
by **Tenna Toft Sylvest**

INTERNATIONAL XLH ALLIANCE

ERN BOND
EUROPEAN REFERENCE NETWORK ON RARE BONE DISEASES

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About me

Tenna Toft Sylvest

- Masters in Political Science (Cand.Scient.Pol)
- IT Senior Consultant / Application Manager

- Patient with XLH (diagnoses at 18 months)
- Mum to two 9-year-old girls (twins) where one has XLH

- Co-Founder and Chair of XLH Denmark since 2018. XLH Denmark also includes HPP patients and families.
- Co-Founder og Co-Chair af den Internationale XLH Alliance (2019-)
- ePAG since 2019 in ERN BOND (rare bone diseases) and member of the ERN Steering Group Committee (2024-)
- Part of EuRREB patient advisory board and the Data Access Committee.

XLH
ARVELIG RAKITIS

INTERNATIONAL XLH ALLIANCE

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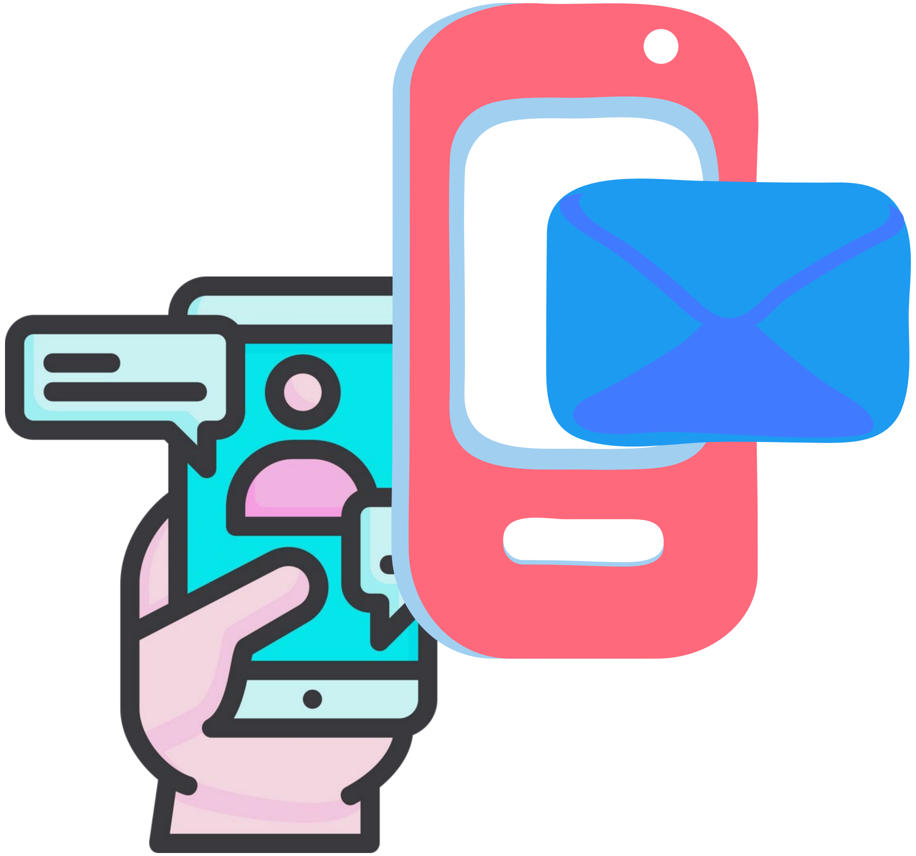
Disclosures

Info

International XLH Alliance is a charitble trust registered in England and Wales has received an unrestricted grant from Kyowa Kirin.

As a patient group…

- We **can share personal experiences** but we can’t answer **questions** with facts
- Myths / **Debunking myths**
- We **have** many **questions**
- ..and we **get** many **questions**



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Some of (our) questions..

- Is it safe for me to become a mother?
- Can I give birth vaginally?
- Should I opt for c-section? (If mid-wife agrees)
- Why did my disease progress under/after pregnancy?
  - Hormones?
  - The extra weight?
  - Impact of breastfeeding?
- How does breastfeeding affect my bone health?
- Are there any treatment available to take better care of my body while pregnant and after?

Challenges

in moving forward…

- **Pregnant** women with RBD are hard to find
- We **lack data** and can't do research.
- **Coding needed** and we need **implementation (Orpha codes)** and competing registries.
- Limited time and ressources for the Consultants / HCPs to collect data.
- **Lack of experiences** in women's health in general.
- Historically **a lack of funding** to do research in women's health.

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Hopes for the future

Pregnancy module in the making

- Gives us the ability to **conduct research** and collect data within the rare bone disease field
- The launch of a pregancy module will also **here and now** create a deeper conversation between a woman and her consultant on her pregnancy.

Research

- **Generally more focus on women's health** and differences between biological men and women and the need to do more research on women.

Perspectives

How can we help the children of today (with current knowledge) and how we can help them in the future. (what do we need to know)

- Although we have and **share our stories** in the communty - we want to do better for our daugthers and help move research forward! We want to be able with more clarity to start answering all of these questions and make sure women get access to the best possible care.

- **A pregnancy module is a big step forward!**
  - We need to work together to overcome some of the challenges in implementing the module and start collect data.
  - With the availability of data we hope and expect there will be a renewed focus on research

Questions and discussion

Thank you for your attention!

https://xlhalliance.org

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