Still going strong after 35 years

What has been the most important factors, enabling us to get to this point?

Berit Otterlei, international contact, Norwegian PWS org
Our 30-year anniversary at Frambu in 2016
Some facts

- Established in 1986 at Frambu
- Members today: 435, 129 with PWS (Norway consists 5 mill inh)
- The members are those with PWS, their families, and some professionals.
- Funding: membership fee + from government
- No one is paid to work for the association, everything is done voluntarily
How it started

• At Frambu who held the first meeting for families with PWS
• Parents decided to make a temporary board
• After a while a professional council was established
• Activities regionally, than nationally
• International contacts were established
• Frambu as a resource centre has been important
The organisation

• The board, made up of parents, general assembly every second year
• Professional council, made up of different professionals - doctors, dentist, psychologist, physiotherapist, nutritionist. Close collaboration with Frambu resource centre,
• Regional peer-persons for contact in different matters, arranging 1 weekend per year for families.
• National peer-person for the youngest; up to 6 years
• National peer-persons for holiday week in Spain every second year
• Facebook-group
• The PWS-news-magazine comes out twice a year
What is the most important

- **That people don't feel alone!** Put people in contact with each other; Telephone, facetime, facebook, teams and so on, if it’s not possible to meet face-to-face.
- Expert sources to guide in the latest news/science and is willing to invest in the organisation
- The national structures/guidelines/network to know how to take the next step – information, professionals to engage.
- Network in other rare disease organisations in your country
- Network and guidance from IPWSO
- Start small, go step by step.
Yes, we are rare, yes, we are small, but that should never stop us!

Thank you for your attention!