

Still going strong after 35 years

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

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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 dont 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!