



Frambu Resource Centre for Rare Disorders

Eastern European Patient Organisation's
Workshop- Share common best practice and
challenges in RD policy

An aerial photograph of the Frambu center, a large, multi-winged building complex with a grey roof, situated in a lush green forest. A body of water is visible in the upper left and lower right corners. The building has several courtyards and a central paved area. A parking lot with several cars is visible in the bottom left corner.

Frambu was founded in 1955

A meeting place for persons with rare diagnoses, their families and professionals since 1994

Courses

Specialised courses

Brief individual courses

Local Guidance and development of expertise

Permanent Staff - 72

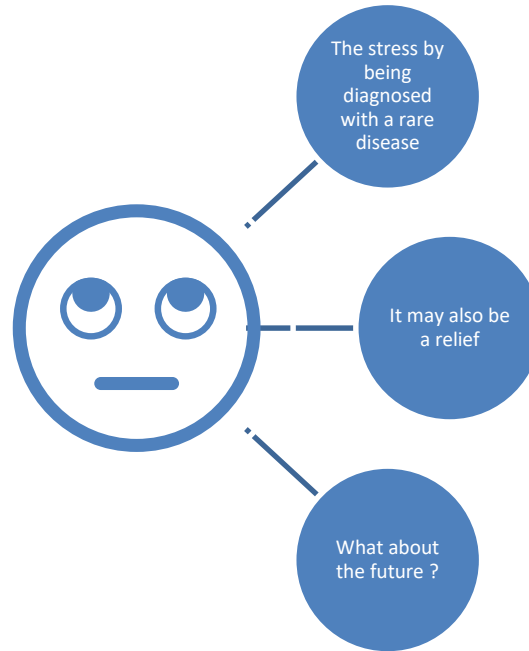
Intermittent staff - 200 (summer camps)

The centre is large, functional and facilitated for persons with disabilities

total size: 6 500 m²

hotel accommodation with 72 beds

Challenges





Facing ignorance: people with rare disorders and their experiences with public health and welfare services. Grut L & Kvam MH. Scand J Disabl Res 2013; 15 (1):20-32



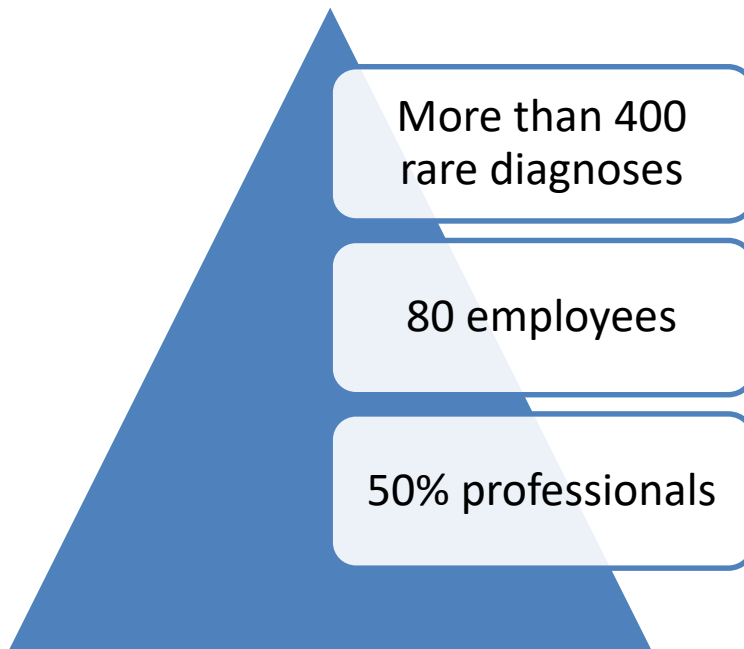
Parental experiences with behavioural problems in Smith-Magenis syndrome: The need for syndrome-specific competence. Nag HE, Hoxmark LB, Nærland T. 2019 May 2



Children's Perspectives on the Experiences of Their Siblings with Chronic Disorders. Fjermestad KW et al. Clinical Social Work Journal 2019 May 4: 1-10



A National Centre



FRAMBU

KOMPETANSESENTER FOR SJELDNE DIAGNOSER



Frambu

Rare Disease Information

www.frambu.no

Consultations

Guidance

Courses

Camps

Studies

Research

FRAMBU

KOMPETANSESENTER FOR SJELDNE DIAGNOSER

EEA Grants / Norway Grants



- Romania
- Portugal
- Czech Republic
- Hungary

RareResourceNet



European Network of Resource Centres for Rare Diseases

Start up 2019

Board

Members 7

Secretary – Frambu Resource Centre for Rare Disorders



Rare Academy in Norway

**– learning on demand on rare disorders
for professionals**

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Norwegian National Advisory Unit on
RARE DISORDERS

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