



FRAMBU

KOMPETANSESENTER FOR SJELDNE DIAGNOSER

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Communcation Adviser



Frambu **Resource Centre for Rare Disorders**

National centre

Patients, families,
professionals

Entire life span

Frambu is a private Foundation and is part of the **Norwegian Advisory Unit on Rare Disorders**

The Norwegian Advisory Unit on Rare Disorders consists of 9 resource centres
– Frambu is the largest of these centres



All nine resource centres are **funded** by the state budget

Frambu budget - 6992446 EUR (2015)

Challenges

Rare disorders can be chronic and in some cases life threatening if not treated properly.

May require coordinated assistance from health professionals and others for short or longer periods in their lives.

Facing barriers and a lack of understanding when they are in contact with the health and welfare system.

Lack of knowledge about rare disorders amongst professionals.



Our mission

Frambu's mission is to give children, young people and adults with rare and little known disabilities the possibility to live a life according to their abilities, wishes and needs

120

Frambu caters for more than **120** rare disorders.

Frambu was founded in 1955

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

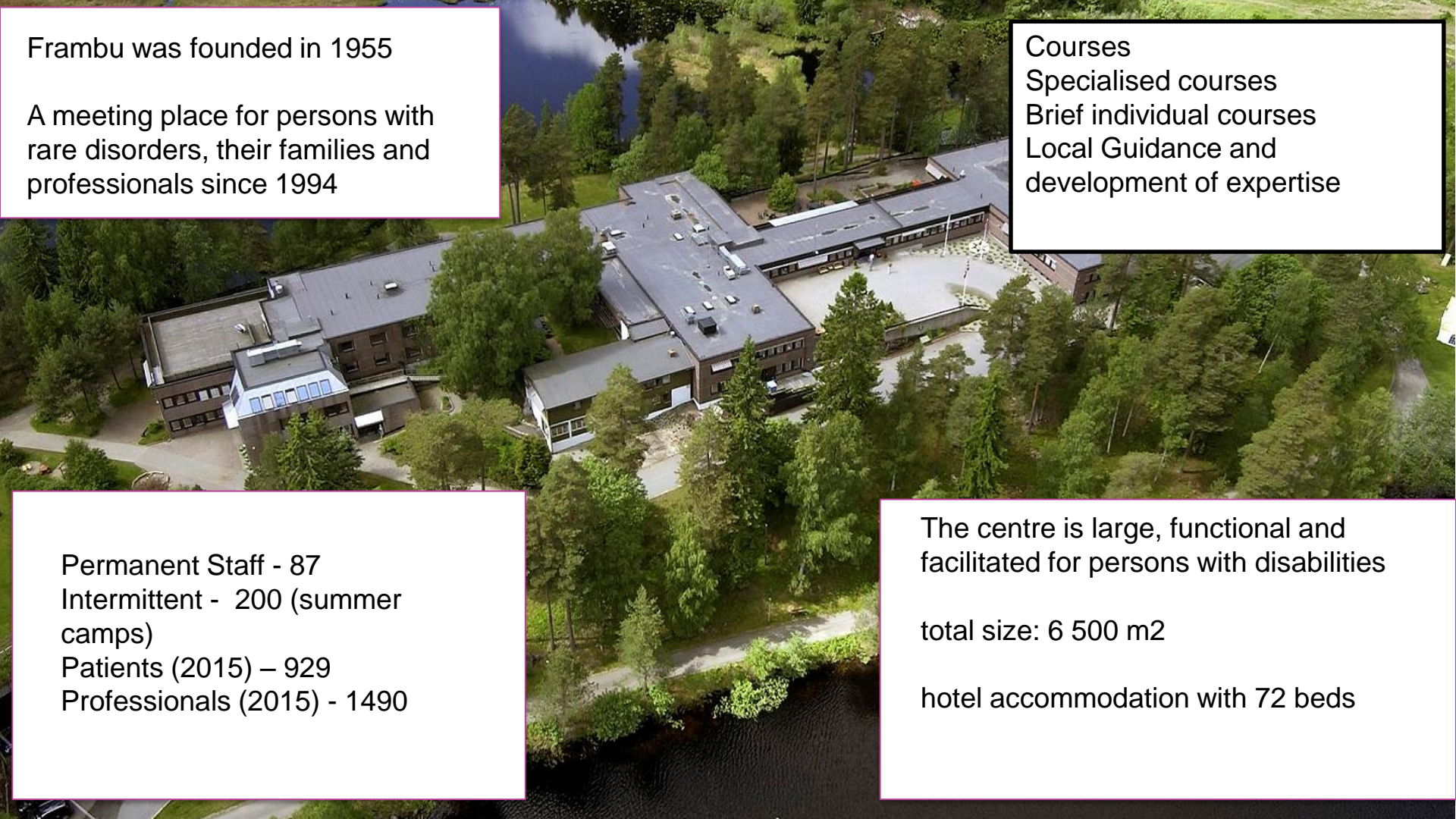
Courses
Specialised courses
Brief individual courses
Local Guidance and development of expertise

Permanent Staff - 87
Intermittent - 200 (summer camps)
Patients (2015) – 929
Professionals (2015) - 1490

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

total size: 6 500 m²

hotel accommodation with 72 beds





Courses aimed at persons with a rare diagnose and families



Frambu camps



Counselling services



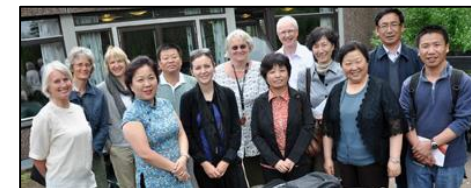
Research



Courses aimed at professionals



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National and international visits



Apprenticeships



Study visits



Documentation and communication

Hovedbudskap 3
Som for alle andre, påvirkes livskvalitet og fungering av:
- Genar
- Familie og oppvekst
- Skole- og jobberfaring
- Fysisk helse
- Venner og støtte m.m.

Patients experience - Frambu

Being taken «seriously» and «believed»

Supported to function as citizens

To be a competent patient – demanding to have more knowledge than the professionals

Service providers accept information – from specialist



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www.frambu.no

