

Iceland
Liechtenstein
Norway



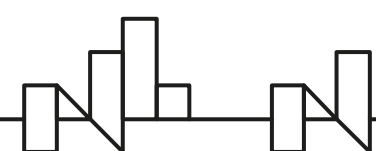
**Active
citizens fund**



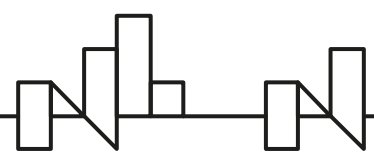
FRAMBU

KOMPETANSEENTER FOR SJELDNE DIAGNOSER

A brief presentation of FRAMBU and our services



A BRIEF HISTORY

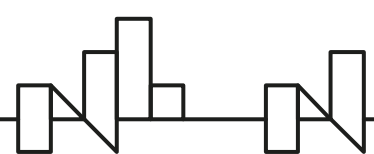


**Frambu was founded in
1955**

*Substantial voluntary
initiativ and work by
members of post war
workers union*

*Established as Health
center focusing on Rare
disorders in 1975*

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

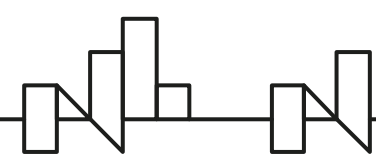


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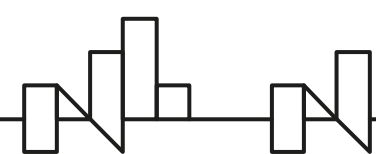


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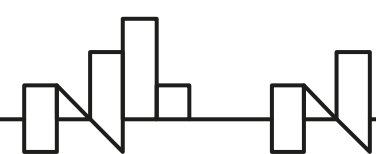


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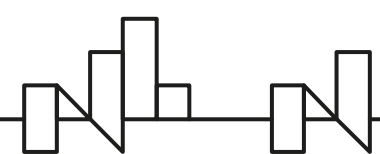


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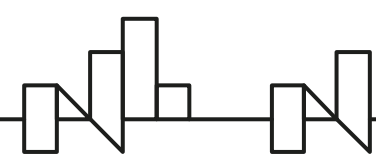


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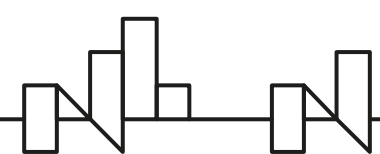
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OUR RESOURCES AND FOCUS



72 Permanent staff

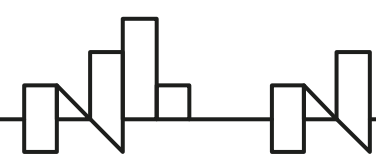
**(~70% professionals
working directly with
provision of services)**

200 Intermittent staff

(summer camps)

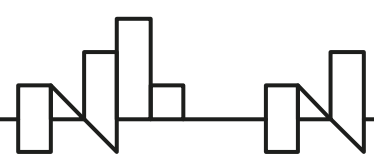


FRAMBU
RESOURCE CENTRE FOR RARE DISORDERS

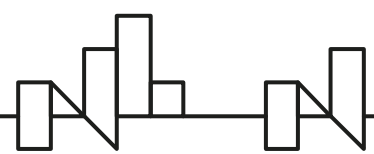




- **The center is large, functional and facilitated for persons with disabilities.**
- **Responsible for over 450 rare diagnoses – lifespan – low threshold service for PWRD, families and professionals. Diverse interdisciplinary approach.**
- **Life is lived and services provided at home and in local environment - as far as possible.**
- **Core principals; Family centered care, Knowledge based practice, Salutogenesis and Empowerment (Health Pedagogy) and User involvement.**
- **The Ministry of Health and Care services allocates funding, and the diagnoses we are responsible for through NAURD. Focus and framework for our work and services defined by national legislation.**
- **Fundraising receiving increased focus.**



OUR SERVICES



Courses

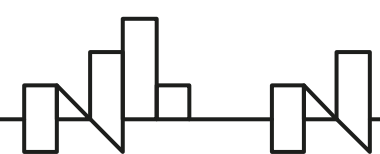
Summer camps

*Local Guidance and
development of expertise*

*Documentation and
communication*

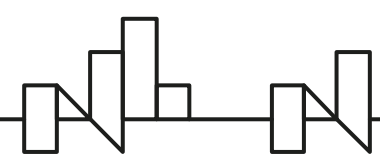
Research and innovation

*National and International
visits and collaboration*



Courses

- Courses for patients, family and local service providers
- Courses for professionals
- Internet based courses – eLearning
- Webinars
- Mini seminars and courses organized for visitors of the center
- (Summer camps)



Courses

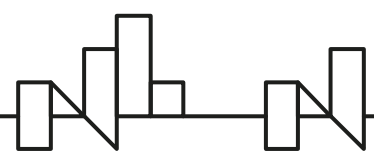
Summer camps

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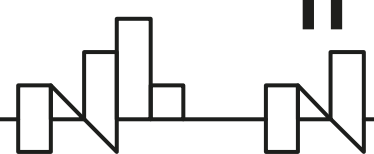
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Summer camps

- Our camps are courses, rather than a holiday service.
- We offer;
 - Holiday experiences in a safe and inclusive environment
 - Activities and learning opportunities which promote better coping and strategies to overcome challenges related to everyday life.
 - An inclusive arena, where participants can meet others in similar life circumstances and with the same diagnosis
- Our goal;
 - To build personal insight, empowerment and useful social networks for the participants.
 - Promote participation in social and leisure time activities, promoting increased participation in home environment.



Courses

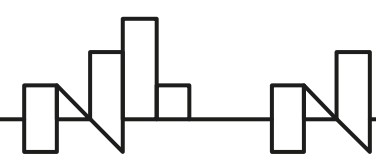
Summer camps

**Local Guidance and
development of expertise**

*Documentation and
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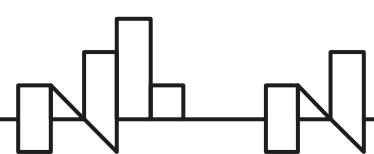
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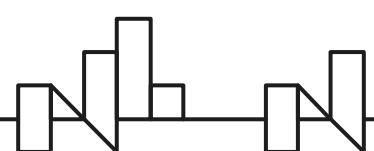
Local guidance and development of expertise

- Patients and their families must apply for our guidance services (application form);
 - Multidisciplinary approach based in knowledge based practise
 - Supplement to local service, not a substitute
 - We require and facilitate participation and cooperation between local service-providers (medical, educational, work, housing, social services etc.)
 - Family centered approach to services and care



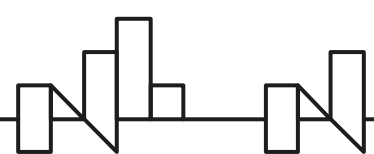
Local guidance and development of expertise

- General criteria;
 - Themes and issues to be covered related to specific diagnosis
 - Local professionals not in a position to offer same service
 - Same service not previously given
- Criteria for local guidance;
 - Purpose of service is to build knowlegde base
 - Education/training of employees providing local services
 - Newly diagnosed patients and rapidly progressive diagnoses
 - Complex cases



Local guidance and development of expertise

- Professionals, local and regional service providers can also apply for our guidance services (application form);
 - Increase knowledge base locally related to the diagnoses we provide services to
 - Helps facilitate local network of professionals
 - Typically local/regional professionals and service providers apply, but also user associations.
- Frambu also contributes to the dissemination of knowledge about rare diseases to schools and students at all levels of educational system





Frambu tilbyr | Kurskalender | Diagnoser | Tema | Forskning

Finn diagnose Klikk på aktuell diagnose for beskrivelse av diagnosen og oversikt over

0-9 A B C D E F G H I J K L M N O



Kurskalender



Frambu tilbyr

Gjestekurs - NevSom kompetansesenter
20.02.17 - 24.02.17

Kurs og leire

Informasjons- og veiledningstjenester

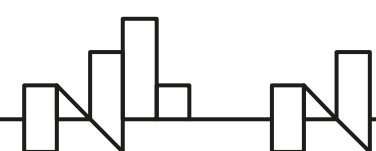
Cri du chat syndrom
27.02.17 - 02.03.17

Forsknings- og utviklingsarbeid

Courses
Summer camps
Local Guidance and development of expertise
Documentation and communication
Research and innovation
National and International visits and collaboration

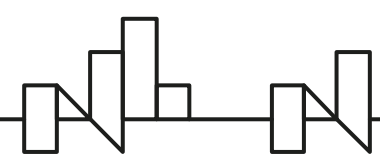
Velg språk
Drevet av Google Oversetter

Om Frambu



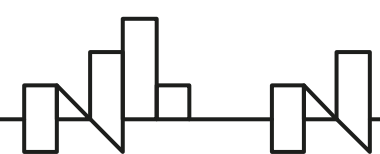
Documentation and communication

- We produce and disseminate knowledge on rare diseases that is;
 - State-of-the-art and based on the principles of Knowledge based practice
 - Understandable to a wide audience
 - Related to themes and issues that are relevant to our patients/primary target group
- Web-page is most important channel, however;
 - Facebook, Vimeo, Twitter, Youtube, web – Chat and various media are also relevant channels
- We use and promote the use of a wide range of media tools and methods to best reach our audience and to adapt our products...



Documentation and communication

- Frambus knowlegde summaries;
 - 2 main types
 - Describing the diagnoses that we are reponsible for
 - Describing themes that are relevant to a wider spectrum of diagnoses
 - 4 levels of detail and depth
- Frambus reseption and front desk;
 - First line of entry to Frambus provision of low threshold services
 - Employees have experience and indepth knowlegde related to provision of our services
 - Serves as "Helpline" - offloading National Helpline for rare and ultra rare disorders



Phone contact via Front desk

Clarify questions, need for services and answer as far as possible - Guide to relevant information on our website and other relevant resources – If further need for assistance forward call as described below

1 . Questions about Frambu diagnosis related to registered patient

Q related to diagnosis

Forward call to Frambus contact for diagnosis

(Check list of contacts)

Q related to profession

Forward call to appropriate professional, primarily in relevant diagnosis team

Practical Q related to services

Answer as far as possible. Forward call to appropriate secretary for relevant service;

Guidance counseling

Courses

Professional courses

Q related to diagnosis

Forward call to Frambus contact for diagnosis

(Check list of contacts)

Q related to profession

Forward call to appropriate professional, primarily in relevant diagnosis team

Practical Q related to services

Answer as far as possible. Forward call to appropriate secretary for relevant service;

Guidance counseling

Courses

Professional courses

3. Questions about diagnosis not connected to Frambu (Check Rarelink)

If Rarelink does not point to appropriate center;

Answer as far as possible

and

Refer to service phone

800 41 710

Rarelink points to appropriate center;

Refer to appropriate center, with phone number and e-mail address

If patient is "referred"/ recommended by professionals to contact Frambu;

Forward call to one of Frambus doctors or appropriate professional in relevant diagnosis team


No contact when forwarded;

Send e-mail with necessary anonymous details to one of Frambus doctors or professionals in relevant diagnosis team

No contact when forwarded;
Ask caller to send e-mail to appropriate professional in relevant diagnosis team or send necessary details via EMR system

No contact when forwarded;
Ask caller to send e-mail to appropriate professional in relevant diagnosis team or send necessary anonymous details on their behalf

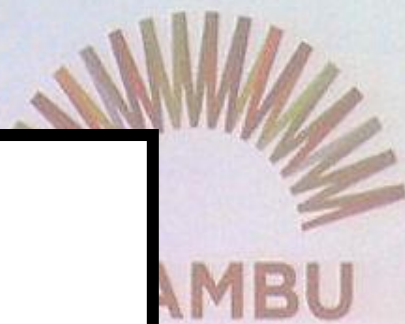




UiO : Institutt for medisinske basalfag
Det medisinske fakultet

Obesity, Lifestyle and Cardiovascular Risk in Down
syndrome, Prader-Willi syndrome and Williams syndrome

Marianne Nordstrøm, Cand. Scient.



Courses

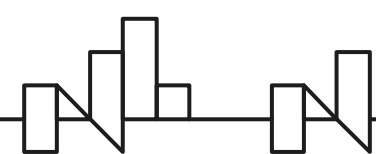
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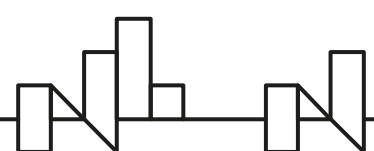
Research and innovation

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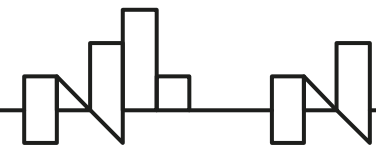
Research and Innovation

- Over the last 10 years Frambu har significantly increased its own contribution to research and innovation in the field;
 - We have substantially increased staff with Ph.D´ s and focus on research
 - We have established clear guidelines and routines related to research- and developmental projects
 - Yearly allocation of funds and opportunity to apply internal funding for projects
 - External funding is also prerequisite for research projects
- We are also tasked with stimulating national research networks and have active collaboration with external researchers and institutions
- Frambu modell gives a unique opportunity in this field





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