



FRAMBU

Resource Centre for Rare Disorders



Training programmes for professionals working with
People Living with Rare Diseases
Frambu – Resource Centre for Rare Disorders



Lisen Julie Mohr

EURORDIS Membership Meeting - Berlin, May 2014

ABOUT THE TRAINING PROVIDER

- Frambu – Resource Centre for Rare Disorders
 - www.frambu.no
- Norway
 - Frambu is a part of the National competence service in Norway
 - Frambu is a private foundation funded by the government
 - Frambu gives services to about 120 diagnosis
 - About 80 people are working at Frambu
 - A hotel with 74 beds



ABOUT THE TRAINING PROVIDER

- Frambu – Resource Centre for Rare Disorders
 - www.frambu.no
- Norway
 - The focus of the services has always been on the family as a whole
 - Parents of children with the diagnose are being sick paid for a stay
 - The services span the entire life cycle from childhood to old age
 - The professionals are important targets of our service
 - Frambu offers both courses and visits to the local environment in order to train the professionals



ABOUT THE TRAINING PROVIDER

- Act relating to municipal health and care services, etc.
- Health and Care Services Act

The municipality shall ensure that all persons residing in the municipality, are provided with necessary health services

The municipality's responsibilities include all patient and consumer groups, including persons with somatic or mental illness, injury or illness, substance abuse problems, social problems or disabilities



ABOUT THE TRAINING PROVIDER

- Approval of National Services within the Specialist Health Services

Responsibilities of the national competence service – Rare Diseases:

- To ensure the provision of guidance and the dissemination of knowledge and competence to the health services, other services providers and clients / patients



ABOUT THE TRAINING PROVIDER

- The Model of Rare Diseases, Norway
- Frambu Resource Centre for Rare Disorders

A low-threshold service

A supplement

The entire life span



ABOUT THE TRAINING PROVIDER

- Courses at Frambu gather professionals from all over the country
- These courses assure knowledge about the diagnose in the local community
- When the patient receives proper treatment - this is the best investment for the society



ABOUT THE TRAINING FACT SHEET

Costs and Funding

Total costs of the training/person

- Frambu has our own budget
- All costs of the staff and the work of training are included in the budget
- The challenge – the costs of travelling



Costs covered by participants

The participants who attend specialised courses at Frambu usually pay a moderate fee to attend: Euro 100

Funding sources for remaining costs

- Frambu's budget

The local authorities might resist sending more than one professional because of the travelling expenses -
Expenses of temporary help

- **Specialised Courses**
- As a part of our regular courses
- As separate courses
- Frambu s professionals are always responsible
- Invite national and international experts to lecture
- Local or Regional Courses
- Certificate
- Meritorious

- **Brief Individual Courses**
- Primarily for individuals / small groups new to the diagnose
- The content is needs-led - individually tailored to the wishes of individual participants

- **Local Guidance and Development of Expertise**
- Arrange training in the municipality
- Lectures – meetings
- Face to face guidance (nutrition , physiotherapy etc.)

ABOUT THE TRAINING FACT SHEET

- Training Courses arranged at Frambu



Diseases or Therapeutic Domain

Home environment / accommodation

Information about diagnosis

Medical information

Special education / work places

Facilitation

Target Public

Health professionals

- Local health services
- Professionals in the education system
- On behalf of individuals with one of Frambu's rare disorders

ABOUT THE TRAINING FACT SHEET

One day for professionals. A specialised course as a part of a regular course.



Diseases or Therapeutic Domain

Neurofibromatosis type 1 – more than spots on the skin? Visible and hidden challenges

Target Public

- Service providers working in association with children and adolescents with the diagnose:
- Employees in kindergarten, school, service providers and leaders in the municipality.

ABOUT THE TRAINING FACT SHEET

Trainers' Background

- Medical doctor
- Educators in special education
- Nurse

Partners

- National Centre for AD/HD, Tourette syndrome and narcolepsy
- - Specialist in clinical education



ABOUT THE TRAINING MISSION AND OBJECTIVES

The professionals at Frambu experience that the professionals / social service providers who meet individuals with Neurofibromatosis 1 often have difficulties of understanding the challenge and the seriousness of the diagnose.

These patients often needs regular medical care and help to manage daily routine.

We expect that the results of this course are more knowledge and understanding of the diagnose. The professionals / social service providers should be able to give proper care and help to enable the patients to a life suitable to their needs.



ABOUT THE TRAINING PROGRAMME CONTENTS

Medical information
Cognitive aspects
ADHD childhood, youth , adults
Facilitation of everyday life
Friendship and leisure
Experience



- Group discussion – sharing experience
- Video: Young with NF1
 - [Three young adults share their experiences and reflections about life with the diagnose NF 1.](#)
 - Professionals from Frambu commenting on selected topics and the use of film/video as a training instrument.

ABOUT THE TRAINING MISSION AND OBJECTIVES



- **Local Guidance / Training**
- **Application**
- Municipality
- Social Service Providers
- Training might be accompanied by the Patient and / or relatives / next to kin and the care givers

ABOUT THE TRAINING PROGRAMME CONTENTS

Local guidance:

Based on the patient needs
Outreach services based on
issues outlined by the applicant
Cooperation with local support
system
Communication!



Medical information – consequences - care – treatment (local hospital)
To ensure that the patient receive the assistance they need
Kindergarten - school – work
Nutrition
Need for equipment – adaption of the environment
Legal rights - Social support - respite care

A WORK SHEET FOR LOCAL TRAINING

The professionals from the patient's home environment applies for guidance /training

One professional at Frambu prepare the training

He/ her contact everyone (both professionals and family)– to be informed about the need of knowledge / the need of the patient/ special challenges / how have they have worked so far

The date of the visit/training is decided

How many professionals from Frambu will be involved in the training

As many as possible from the home environment (local health service, kindergarten, school, work place etc.) should attend the training

A cooperation of the agenda

could include a visit at the patients home

A result of the training – a plan for the future work

No follow-up from Frambu - but always a possibility for ask for advices or apply for further training

A low-threshold service

ABOUT THE TRAINING

FACT SHEET

- Regional course – located outside Frambu



Diseases or Therapeutic Domain

Velocardiofacial syndrome, 22q11,

DiGeorge syndrome

The main characteristics of vcfs, with emphasis on psychological and pedagogical challenges including nonverbal learning disabilities, anxiety, depression and psychosis

Target Public

Social Service providers who work in this region

Municipalities

Professionals who work with children, adolescent and young adults (ages 6-23 years) with velocardiofacial syndrome

Arranging courses in the regions and municipalities are important targets of the professionals at Frambu

With the help of:

University / Hospitals (medical geneticist)

National service for special needs education

Rehabilitation Units

The County Governor

(to ensure that decisions of the Parliament and Government are implemented correctly)

Patients representatives



ABOUT THE TRAINING FACT SHEET

Trainers' Background

- [Mary-Louise Bertram](#)
- Special Educator
- Working in Australia, Canada and USA
- Specialist in Angelman syndrome

Partners

Frambu invite and collaborate with specialists in rare diseases :

e.g. England, Netherlands, Germany, USA and Australia



ABOUT THE TRAINING PROGRAMME CONTENTS



- Practical communications strategies
- The use of tablets as a working tool
- Experience from communication strategies
- Medical information
- Behaviour challenges
- Legal rights

- [About Angelman syndrome](#)

VIDEOCONFERENCES AND STREAMING

Videoconferences are always possible

Specialised training courses
one diagnose – one topic (nutrition)

Specialised courses / individual/
Face to face

Streaming - training courses / seminars



Possible for several services

Social Service Providers all over the country have the possibility to attend

An area for Frambu s Innovation

All Municipalities are supposed to be equipped with a Videoconference room



ABOUT THE TRAINING FACT SHEET

- E- learning course – 3 hours

Diseases or Therapeutic Domain

- About the diagnose Prader Willi syndrome

Target Public

- The target audience of this course are service providers who work in the homes of people with a Prader Willi syndrome diagnose



ABOUT THE TRAINING FACT SHEET

Format of the programme

Total hours of training 3 hours

Nr. hours of face to face training

Place for face to face training

Nr. hours of eLearning 3 hours

Nr. hours of individual training The possibility to ask questions to the professionals in charge at Frambu.

Nr. hours of group/class training

% of practical training

ABOUT THE TRAINING FACT SHEET

Trainers' Background

- Medical doctor
- Nutritionist
- Physiotherapist
- Special educator
- Communications advisor

Partners

- [Norwegian Centre for Integrated Care and Telemedicine](#)



ABOUT THE TRAINING PROGRAMME CONTENTS



The purpose of the course is to give the service provider a basic knowledge of Prader –Willi syndrome

The main goal of the course is to ensure the best quality of life for the patients. It is desirable that all people working with individuals with the diagnose have gone through this course.

- What is Prader-Willi Syndrome?
- Nutrition
- Behaviour and conflict
- Food and meals
- Cooperation and communication
- Physical activity

ABOUT THE TRAINING CERTIFICATION AND RECOGNITION



- Eight modules
- Each module consists of several pages
- At the end of the course – write a reflection paper – consists of three parts
- To combine experience and learning
- When reflection paper is submitted – 100% completion of the course
- **Certificate**



- [E learning course](#)
- “Very good! Such a solution like this, open that I too, running in a 27% position, have the opportunity to educate myself and learn more. When the course will be conducted at Frambu it will usually be prioritized to those with larger jobs. In addition, there is an interesting course others may take, although they do not necessarily have a close relationship or familiarity with PWS. I study full time and work in the home of patient with PWS in the weekends, so the opportunity to take the course when it suits me, has been quite superb! ”

ABOUT THE TRAINING FACT SHEET

Specialised Course at Frambu



Diseases or Therapeutic Domain

Velocardiofacial syndrome

22q11

DiGeorge syndrome

Precautionary - risk factors and mental health.
What promotes good mental health

Target Public

- Professionals who work with children, adolescents and young adults (ages 6-23 years) with velocardiofacial syndrome.
- Physicians, psychologists, nurses, educators / teachers, service providers
- Certificate
- Meritorious

ABOUT THE TRAINING FACT SHEET

Trainers' Background

Medical doctors

Psychologists



Partners

- Trinity College , Dublin
- Akershus University Hospital

ABOUT THE TRAINING MISSION AND OBJECTIVES

- **Mental health - risks and protection (lecture in English)**
v / **Professor Fiona McNicholas, Trinity College, Dublin**

Presentation of PhD "The 22q11.2 Deletion Syndrome - Clinical, Immunological, Endocrine and dental aspects"

- Nonverbal Learning Disabilities



ABOUT THE TRAINING MISSION AND OBJECTIVES



- **Information to the participants:**
- The course will focus on mental health
There will not be given any general information about VCFS
- It is therefore important that you before the course has gone through:
- Guidelines for follow-up
Velocardiofacial syndrome

This can be downloaded at:

www.frambu.no

ABOUT THE TRAINING PROVIDER

- Frambu Resource Centre for Rare Disorders
- www.frambu.no
- Thank you!

Lisen Julie Mohr

ljm@frambu.no



