DESCRIPTION OF INFORMATION SERVICE ON RARE DISEASES

In the Nordic countries

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PHOTOGRAPHER: OSCAR GÄRDEHED
LAYOUT: METTE LARSEN NFSD.SE

Content

SWEDEN

www.socialstyrelsen.se/ovanligadiagnoser

1. NAME OF THE INFORMATION SERVICE:

Socialstyrelsens kunskapsdatabas om ovanliga diagnoser
The Swedish Information Centre for Rare Diseases

2. SUPPLIER/FINANCING

The Swedish Information Centre for Rare Diseases is seated at the University of Gothenburg, but its mission comes from The Swedish National Board of Health and Welfare. The Board also finances the Centre and it is therefore a resource for the whole country. The information Centre has now been in progress for 20 years.

3. TARGET GROUP/-S:

The target groups include healthcare professionals, social workers, public sector employees as well as individuals with rare diseases and their families. However, the information produced at the information Centre may be used by anyone interested in rare diseases.

4. GENERAL DESCRIPTION OF THE INFORMATION SERVICE

The main aim of the information Centre is to increase knowledge about rare diseases by producing information articles for the Rare Disease Database of the Swedish National Board of Health and Welfare. The articles are the result of collaboration between the information Centre and leading medical specialists. Patient organizations are also given the opportunity to comment on the articles. Each disease article includes information about occurrence, heredity, symptoms, diagnostics, treatment, research, resources, patient organizations and reference literature. Short summaries of the disease articles are available as leaflets, accessible for download in PDF format.

The database currently has articles about approximately 325 rare diseases. Information about new diseases is added continuously, and the material is updated on a regular basis. Each year about 10-15 disease articles are added to the database. As a rule the articles are revised approximately every three years, but sometimes changes are made between revisions.

The information is in Swedish and the database has over 100 000 unique page views each month. Thereby the database is one of the most visited parts of the website of the Swedish National Board of Health and Welfare.

Currently seven people work at the information Centre. Although all staff members have different work backgrounds, such as nurse, social worker, occupational therapist and journalist, everyone works as an editor processing the articles to make them easier to understand for the target groups.

In addition to producing the rare disease articles we also answer questions via e-mail and telephone and assist in retrieving further information on rare diseases or give advice on where to turn to within the health care sector.

We also participate in fairs and cooperate with other stakeholders in the field of rare diseases, such as The Swedish National Agency for Rare Diseases (NFSD), Ågrenska, Orphanet and various patient organizations.

5. PROCEDURES FOR QUALITY ASSURANCE AND REVISION

The articles are reviewed and approved by a group of experts on rare diseases to ensure the quality. The group consists of 10 people, including specialists in fields such as genetics, neurology and habilitation, as well as patient representatives.

The rare disease expert group reviews all disease articles before publication, but also evaluates if new diagnoses fall within the definition of "rare diseases" and suggests new diseases for inclusion in the database as well as medical specialists to cooperate with. Group meetings are arranged approximately eight times per year.

6. USER PARTICIPATION

To ensure the presence of a patient perspective, three members of the rare disease expert group are patient representatives. In addition, the articles are also sent to the relevant patient organization for comments before they are published.

7. DISSEMINATION:

The database has over one million unique page views annually. To learn more about who seeks information in the database we conducted a survey in 2014. It contained both a web inquiry which was answered by approximately 750 users and a user survey with both doctors and patients. The results showed that about 60 % of the users were private persons, about 25 % were health-care professionals, and the rest were public sector employees. About 90 % were pleased or very pleased both with the navigation structure and the information in the database.

The free text responses showed that many users found the information useful. Doctors for instance said that the information gave a quick and easily understood introduction to diseases that they seldom came across. Patients and their families also greatly appreciated the information as it facilitated their contacts with health-care professionals.

Many creative suggestions on how to improve the database were also found among the free text responses, and we have made improvements as far as the technology allows. Work is now underway to replace the technical solution on the website of the Swedish National Board of Health and Welfare with the aim to present a responsive site in 2017.

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www.orphanet.se

1. NAME OF THE INFORMATION SERVICE:

www.orphanet.se
Orphanet, RD-action

2. SUPPLIER/FINANCING

RD-action (EC) and Karolinska University Hospital, Centre for Rare Diseases.

3. TARGET GROUP/-S:

Healthcare professionals, patients and their relatives, patient organisations, researchers, biotech and pharmaceutical companies, public health and research institutions, and public authorities.

4. GENERAL DESCRIPTION OF THE INFORMATION SERVICE

The following description is directly extracted from the Orphanet website www.orpha.net:

Orphanet is the reference portal for information on rare diseases and orphan drugs, for all audiences. Orphanet's aim is to help improve the diagnosis, care and treatment of patients with rare diseases

Orphanet offers a range of freely accessible services:

- An inventory of rare diseases mapped with resources as OMIM, ICD10, MeSH and UMLS and a classification of diseases elaborated using existing published expert classifications.
- An encyclopaedia of rare diseases in English and French, progressively translated into the other languages of the website.
- An inventory of orphan drugs at all stages of development.
- A directory of expert resources, providing information on expert clinics, medical laboratories, ongoing research projects, clinical trials, registries, networks, technological platforms and patient organisations, in the field of rare diseases, in each of the countries in Orphanet's consortium.
- An assistance-to-diagnosis tool allowing users to search by signs and symptoms.
- An encyclopaedia of recommendations and guidelines for emergency medical care and anaesthesia.
- A fortnightly newsletter, OrphaNews, which gives an overview of scientific and political current affairs in the field of rare diseases and orphan drugs, in English and French.
- A collection of thematic reports, the Orphanet Reports Series, focusing on overarching themes, directly downloadable from the website.

5. PROCEDURES FOR QUALITY ASSURANCE AND REVISION

Data collection is done through partnerships with official sources. It can also be self-declared by professionals involved in the expert resource. Supranational information (such as EU-funded research networks or multinational clinical trials) is managed by the coordinating team. National and regional information is collected at national level. Validation and revision is carried out at several levels. Data is validated on a national level, and a weekly review of new data on expert resources is held by the coordinating team. Special attention is given to the mapping between the Orphanet nomenclature of rare diseases and the registered expert resources. An international advisory board and a genetic advisory board are consulted on regular basis and each national team is recommended to appoint a corresponding national advisory board to revise and validate the collected and published data. The scientific information included in the inventory of rare diseases is validated by experts.

6. USER PARTICIPATION

An online registration tool is available for professionals to self-declare their activities.

7. DISSEMINATION

The Orphanet database in English (daily visitor 41,644) is also available in six other languages. Each team manages an Orphanet webpage in its national language. Orphanews and Orphanet report series have a broad audience ranging from patients and families to professionals within healthcare and pharmaceutical industry. Orphanet coordinating team and national teams participate in a range of different events and scientific conferences where the database and related on-going projects are presented.

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www.sallsyntadiagnoser.se

1. NAME OF THE INFORMATION SERVICE:

www.sallsyntadiagnoser.se
Rare diseases Sweden, Riksförbundet Sällsynta diagnoser

2. SUPPLIER/FINANCING

State grants and project funding, usually from the Swedish Inheritance Fund (Arvsfonden), but also from The National Board of Health and Welfare (Socialstyrelsen)

3. TARGET GROUP/-S:

People in Sweden living with a rare disease and their closest social network, politicians on a national and a regional level, policy makers, authorities such as The National Board of Health and Welfare (Socialstyrelsen) and The Dental and Pharmaceutical Benefits Agency (Tandvårds- och läkemedelsförmånsverket/TLV), professionals who meet people who have rare diseases, i.a. doctors, and the general public.

4. GENERAL DESCRIPTION OF THE INFORMATION SERVICE

Website with basic information about the various diseases represented by our organisation and links to other websites with more facts about the diseases, brief information about our organisation in English at the website, as well as fact sheet in English, newsletter six times a year to our member representatives and other parties concerned by rare diseases, regular meetings with our members twice a year, phone calls and e-mails, sometimes from people who have an ultra-rare disease, folder with a presentation of Rare diseases Sweden and a brochure describing our vision of how the care for people who have rare diseases should be structured.
On a national level, we are a member of The Swedish Disability Federation.
On the Nordic level, we are a member of The Rare Diseases Nordic Network of Patient. Organisations (SBONN). We also attend the Nordic Meetings for Cooperation in the Area of Rare Diseases (Rarelink).
Internationally, we belong to EURORDIS, the pan-European organisation of co-operation for rare diseases.

5. PROCEDURES FOR QUALITY ASSURANCE AND REVISION

Riksförbundet Sällsynta diagnoser's board, our annual member meeting, checking with partners such as SBONN, Centres for Rare Diseases (CSD) at several places in Sweden, The Swedish National Agency for Rare Diseases (NFSD) and more. Every year, prior to the annual member meeting (årsmöte), a revision is carried out by a professional, certified accountant.

6. User participation

Yes, of course! User participation is the self-evident foundation of our entire work as an organisation for people who have rare diseases and their social network.
Website, newsletter to member representatives and professionals who work with or otherwise are interested in this area.

7. DISSEMINATION

Our main opportunity to access the general public is when we arrange Rare Disease Day (Sällsynta dagen), last time we did it was on February 29 – March 1 2016, when we got quite a lot of attention in the media, with about 30 news articles in newspapers/websites, interviews in television and on the radio with some of those who participated at the Rare Disease Day Our media reached Apr. 6 million users before, after and during the event.

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www.mun-h-center.se

1. NAME OF THE INFORMATION SERVICE:

www.mun-h-center.se
Swedish National Orofacial Resource Centre for Rare Diseases

2. SUPPLIER/FINANCING

The Swedish National Board of Health and Welfare *and* the Public Dental Service, Region Västra Götaland, Gothenburg, Sweden.

3. TARGET GROUP/-S:

Dental care and health care providers, individuals with rare diseases and their families, students.

4. GENERAL DESCRIPTION OF THE INFORMATION SERVICE

The mission is to spread information about oral health and orofacial function in rare medical and dental conditions. This is done through the Mun-H-Center website (www.mun-h-center.se), the MHC-app, social media and educational activities. The information is written in Swedish by co-workers at Mun-H-Center - sometimes in collaboration with other experts in the field. It is then translated into English for presentation on the website and the MHC-app. The text includes reports from the MHC database, ICD-10 code, estimated occurrence, etiology, general symptoms, orofacial/odontological symptoms, orofacial/odontological treatment, sources and links.
One important part of the Mun-H-Center´s activity is research and development aimed at giving people with rare diseases care that is based on the best available scientific knowledge. Research papers are published in medical and odontological journals.

The information about different rare diseases on the website is linked to Rarelink and to the Swedish National Agency for Rare Diseases (NFSD).

5. PROCEDURES FOR QUALITY ASSURANCE AND REVISION

Today, Mun-H-Center provides information about 75 diagnoses. Approximately five new diagnoses are presented each year. The information is based on clinical experience, best practice and scientific knowledge. Common sources are: The rare disease database of the Swedish National Board of Health and Welfare.
The MHC database - The Mun-H-Center database on oral health and orofacial function in rare diseases and The Documentation from the Ågrenska national competence Centre for rare diseases.

6. USER PARTICIPATION

Patient organizations were involved in the production and evaluation of the MHC-app. Parents and patients share information through a questionnaire.

7. DISSEMINATION

Through the Internet, social media, app, educational activities, video conferences, international congresses etc.

2015 mun-h-center.se 50.000 visitors

Facebook scope 300-2500 per posts. Began April 2015

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www.agrenska.se

1. NAME OF THE INFORMATION SERVICE:

www.agrenska.se/vi-erbjuder/informationsmaterial/dokumentationer/
Ågrenska Documentations (Ågrenska Dokumentationer)

2. SUPPLIER/FINANCING

Ågrenska is owned by a foundation. The National Competence Centre, including the family and adult programs and information dissemination, is partly funded by grants from the state and fees from the counties.

3. TARGET GROUP/-S:

Children, teenagers and adults with rare diseases, their families and professionals concerned, eg teachers/preschool teachers, habilitation staff, social services staff.

4. GENERAL DESCRIPTION OF THE INFORMATION SERVICE

Ågrenska is a national competence centre and provides programs, for children, teenagers and adults with disabilities, their families and professionals supporting the family. The Family and adult Program offers a unique opportunity for families and adults, from all over Sweden, to get the most recent knowledge, meet and exchange experiences concerning the same rare disease. The program consists of expert-lectures and discussions about medical, psychological and educational aspects of the condition as well as rights and societal support. Among other things, these programs are one means of spreading information to the target groups. At the same time they form the basis for producing written information materials, the Ågrenska Documentations. These Documentations are processed summaries of lectures and contain facts checked by each specialist. They also include interviews with families and adults about living with a rare diagnosis.

More than 500 documentations are published and possible to download from Ågrenskas website. Some of the Documentations are produced as easy readers a few of these in both Swedish and English. In many cases also new knowledge is created thanks to the interaction and activities going on during these programs (esp. concerning needs of adults, through interviews and consequences for children, through observations).

5. PROCEDURES FOR QUALITY ASSURANCE AND REVISION

Each parent fills out a questionnaire at the end the course. A follow up is also sent out after six months to all parents. The aim is to measure perceived usefulness and effects of family courses for rare disease. One of the statement is about usefulness of the Ågrenska documentation.

6. USER PARTICIPATION

Patient organisations are involved in the planning phase of family and adult courses and give their view of the contents and thus also influence the information spread.

Organisation representatives also often lecture in the program.

The organisations also spread info to their members that courses will take place in Ågrenska.

7. DISSEMINATION

The Ågrenska Documentations is available at Ågrenska website (a responsive website) and had approx. 4.500 viewers during 2015.

Up until today more than 500 Ågrenska Documentations has been published traditionally in paper format and sent to all participating adults, families, professionals and experts after each stay. Approx. 1250 copies per year.

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www.nfsd.se

1. NAME OF THE INFORMATION SERVICE:

- nfsd.se
- Launched Dec 2013.

2. SUPPLIER/FINANCING

- Supplier: Swedish National Agency for Rare Diseases (NFSD, Nationella Funktionen Sällsynta Diagnoser)
- Financing: Included in an agreement and compensation from the National Board of Health and Welfare, Socialstyrelsen

3. TARGET GROUP/-S:

- PLRD & relatives
- Professionals in contact with PLWRD and their relatives
- The public

4. GENERAL DESCRIPTION OF THE INFORMATION SERVICE

- Background: Information about RD is widespread and often hard to find. Available information is often built on the basis of an internal and organizational perspective and does not necessarily take a holistic approach based on the recipient's needs. Parents of children with disabilities experience that it is difficult - and sometimes impossible - to find information where they can get answers to their questions, which as a rule are many. Parents wish that the information should be collected and available on the Internet, it should be easy to find and search, it should be constructed with a receiver view, that it should have clear headings and be easy to read and the texts should be comphensive.

- NFSD has developed the national website with comprehensive information on rare diseases, nfsd.se. Information on nfsd.se takes height in a holistic view.

- Content:

  - Gathered, structured (processed) information mainly provided by other information suppliers, e.g. Training/course calendar
  - Information adapted by NFSD. E.g. financial support. Contact information about stakeholders, patient organisations, Centres of Rare Diseases and Centres of expertise.
  - Compilations of reference materials of various types. E.g. studies and models at the transition child- adult care, studies and essays in the field of rare diseases and best practises
  - Information produced by NFSD. E.g. films about living with a rare disease and professionals in the field , articles, related information and “Link collection per diagnosis”
  - News coverage

- Legal rights and obligations
- Description of the structure in society (state, regions, municipalities)

- Language**:** Swedish, "Talande webb" and responsive web
- Cooperation: A national group of actors involved in information and communication in the field of RD has been formed by NFSD in order to cooperate, find opportunities and synergies.

5. PROCEDURES FOR QUALITY ASSURANCE AND REVISION

- Monitoring and validating links.
- Revision accordance with the approved plan for validation.
- Webpage and social media statistics and surveys.
- Cooperation between information providers and patient organisations with, e.g. updates, new information.

6. USER PARTICIPATION:

- Evaluation by information providers and RD Sweden.
- Invitation to participate and give suggestions for additional information / links in the registry.

7. DISSEMINATION

- Social media: Facebook, LinkedIn, Twitter and YouTube.
- Articles with related information (links) further information (e.g. the link collection, stakeholder's webpages etc.)
- Key messages for each target group.
- Hashtags: #sällsyntaliv and other stakeholder's hashtags.
- Face to face communication: E.g. Meetings, conferences, workshops and education.
- Online newsletter
- Keyword Optimization
- Printed materials. E.g. brochures, leaflets, roll ups, advertising (digital and print) etc.

NFSD's website was launched on December 4, 2013. Traffic to the site has increased significantly since the launch as follow:

Period	Visitors nfsd.se	Numbers of page views nfsd.s
2014	27408	79212
2015	60688	151312
1/1- 30/6	38164	99762

www.nfsd.se/lanksamling-per-diagnos/

1. NAME OF THE INFORMATION SERVICE:

- "Länksamling per diagnos". Link collection per diagnosis with a holistic perspective (both medical and non-medical information) http://www.nfsd.se/lanksamling-per-diagnos/
- Launched May 2016.

2. SUPPLIER/FINANCING

- Supplier: Swedish National Agency for Rare Diseases (NFSD - Nationella Funktionen Sällsynta Diagnoser)
- Financing: Included in an agreement and compensation from the National Board of Health and Welfare, Socialstyrelsen

3. TARGET GROUP/-S:

- PLRD & relatives
- Professionals in contact with PLWRD and their relatives
- The public

4. GENERAL DESCRIPTION OF THE INFORMATION SERVICE

- Background: Surveys shows that information about RD is widespread and often hard to find. Available information is often built on the basis of an internal and organizational perspective and does not necessarily take a holistic approach based on the recipient's needs. Parents of children with disabilities experience that it is difficult - and sometimes impossible - to cope look for information where they can get answers to their questions, which as a rule are many. Parents wish that the information should be collected and available on the Internet, it should be easy to find and search, it should be constructed with a receiver view, that it should have clear headings and be easy to read and the texts should be comphensive.

- NFSD has developed a searchable compilation with RD on the national website with comprehensive information on rare diseases, nfsd.se. Per RD there is links to internal and external sites with quality assured information. Information that takes height in several areas related to each diagnosis, medical information, as well as "non- medical" information.

- Headings with links:

- RD descriptions (Socialstyrelsens kunskapsdatabas om ovanliga diagnoser, Orphanet and Rarelink)
- Orofacial health & function
- National resources
- Healthcare guidelines
- Patient organizations (national and international)
- "To live with a RD" (e.g. films, articles)
- Additional information (e.g. RareConnect)

- Related information (e.g. financial support, training/course calendar)

- Language: Swedish, “Talande webb” and responsive web
- Cooperation: A national group of actors involved in information and communication in the field of RD has been formed by NFSD in order to cooperate, find opportunities and synergies.

5. PROCEDURES FOR QUALITY ASSURANCE AND REVISION

- Monitoring and validating links.
- Revision accordance with the approved plan for validation.
- Webpage and social media statistics and surveys.
- Cooperation between information providers and patient organisations with e.g., updates, new information.

6. USER PARTICIPATION:

- Evaluation by information providers and RD Sweden.
- Invitation to participate and give suggestions for additional information / links in the registry.

7. DISSEMINATION

- Social media: Facebook, LinkedIn, Twitter and YouTube.
- Articles with related information (links) further information (e.g. the link collection, stakeholder’s webpages etc.)
- Key messages for each target group.
- Hashtags: #sällsyntaliv and other stakeholder’s hashtags.
- Face to face communication: E.g. Meetings, conferences, workshops and education.
- Online newsletter
- Keyword Optimization

Per September (launch date May 2016), 5274 page views

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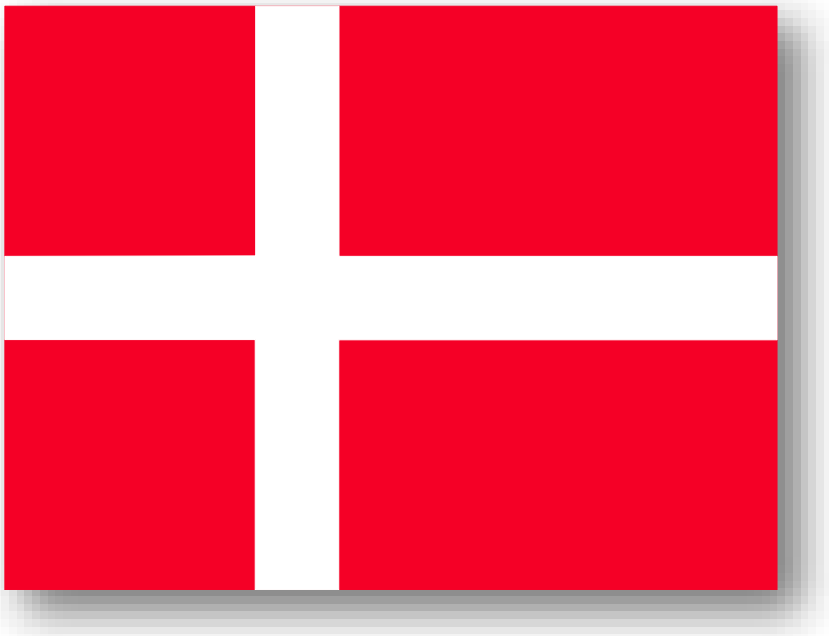
DENMARK



www.laegehaandbogen.dk

1. NAME OF THE INFORMATION SERVICE:

Doctor's Handbook (Lægehåndbogen) www.laegehaandbogen.dk
Doctor's Handbook is part of Sundhed.dk, an open access web site with a wide range of health care information.

2. SUPPLIER/FINANCING

Doctor's Handbook is financed by Danish Regions.

3. TARGET GROUP/-S:

The target groups are medical practitioners and other health care workers, social service workers, patients and their families.

4. GENERAL DESCRIPTION OF THE INFORMATION SERVICE

Denmark/Descriptions of rare handicap (diagnosebeskrivelser). For a number of years, descriptions of more than 400 rare handicap have been available from the web site of the National Board of Social Services (Socialstyrelsen). In 2015, an agreement was reached between the Board and Danish Regions (Danske Regioner, the five regional governments in charge of health care) for the descriptions to be gradually transferred to, updated and maintained by Doctor's Handbook (Lægehåndbogen), an online medical encyclopedia for health care professionals.

The descriptions of rare handicap in Doctor's Handbook include information about the incidence, causes, symptoms, differential diagnoses, treatment, genetics, and social aspects of each disorder. The aim is to provide updated and referenced information in a way that is useful to health professionals, social services and interested laypersons. Links are provided to relevant handicap organizations, national and international patient associations, Rarelink, Orphanet, NORD, among others.

5. PROCEDURES FOR QUALITY ASSURANCE AND REVISION

Drafts of individual descriptions are reviewed by a group of medical experts and representatives from handicap organizations and subsequently by the editorial committee of Doctor's Handbook. Published articles will be updated every third year.

6. USER PARTICIPATION

Users are welcome to contact Doctor's Handbook with comments and corrections, but Doctor's Handbook is not a Q and A-service.

7. DISSEMINATION

Doctor's Handbook is part of Sundhed.dk, an open access web site with a wide range of health care information.

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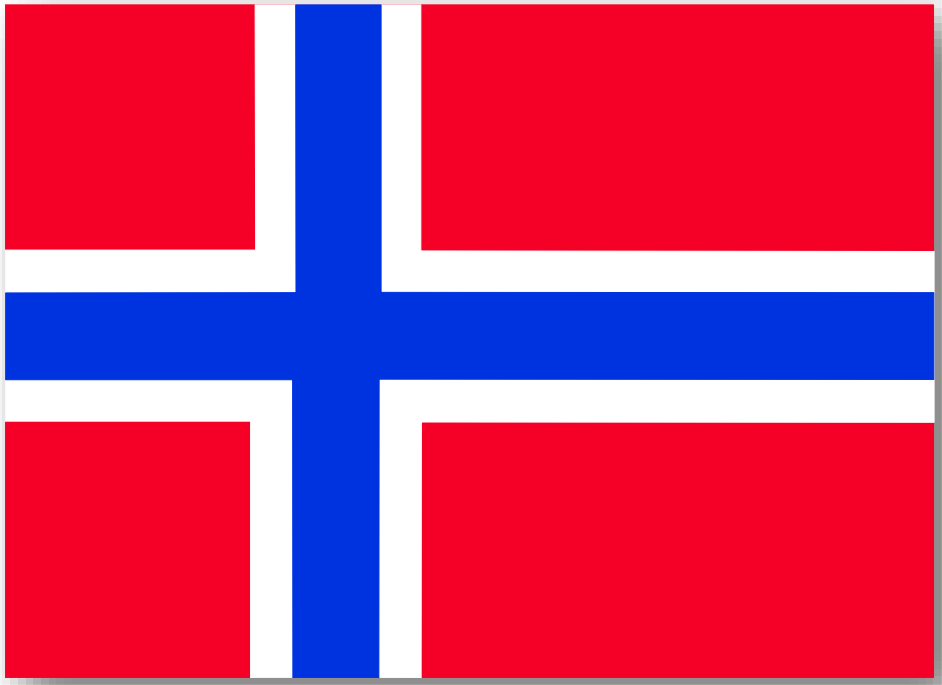
www.patienthåndbogen.dk

NORWAY



Frambu
http://www.frambu.no/

NAPOS
www.helsebergen.no/no/OmOss/Avdelinger/napos/Sider/default.aspx

NK-SE
www.oslouniversitetssykehus.no/omoss_/avdelinger_/sjeldne-epilepsirelaterte-diagnoser_/Sider/enhet.aspx

NMK
https://unn.no/fag-og-forskning/kompetansetjenester-og-sentre/nevromuskulert-kompetansesenter

EMAN
www.oslouniversitetssykehus.no/omoss_/avdelinger_/medfodte-og-arvelige-muskelsykdommer_

NevSom
www.nevsom.no/

NSCF
www.oslo-universitetssykehus.no/omoss_/avdelinger_/norsk-senter-for-cystisk-fibrose_

SSD
www.sjeldnediagnoser.no/

TAKO-senteret
www.lds.no/avdelinger/tako-senteret/nasjonalt-senter-for-oral-helse-ved-sjeldne-diagnoser/diagnoser/

TRS
www.sunnaas.no/omoss_/avdelinger_/trs_

Helsenorge
helsenorge.no

1. NAME OF THE INFORMATION SERVICE:

In Norway, the *Norwegian National Advisory Unit on Rare Disorders* (NKSD) coordinates 10 resource centres/units:

- Centre for rare disorders (SSD)
- Centre for rare epilepsy-related disorders (NK-SE)
- Frambu resource centre for rare disorders
- National Neuromuscular Centre (NMK), Tromsø
  and Enhet for medfødte og arvelige nevromuskulære tilstander (EMAN), Oslo
- National resource centre for oral health in rare medical conditions (TAKO)
- National resource centre for rare disorders (TRS)
- Norwegian Porphyria Centre (NAPOS), Bergen
- Norwegian resource centre for AD/HD, Tourette syndrome and Narcolepsy (NevSom)
- Norwegian resource centre for cystic fibrosis (NSCF)
- The National Autism Unit

Helsenorge.no is the public health portal for residents in Norway. The content is provided by the health sector, and the Directorate of e-health is responsible for the site.

2. SUPPLIER/FINANCING

Governmental

3. TARGET GROUP/-S:

- Users/patients; family, relatives, friends; public
- Health professionals, dentists, schools, kindergartens, researchers, etc.

4. GENERAL DESCRIPTION OF THE INFORMATION SERVICE

Depends on the individual centre. Most centres have one or more communication advisers, working in cooperation with the centre professionals, user organizations, other communicators, media, etc.
Print: Fact sheets, brochures, publications, posters, books
Online: Web pages, PDF versions of publications, Facebook, Twitter, newsletters
Multimedia: movies (site+Vimeo+YouTube), podcasts (SoundCloud+iTunes), e-learning
Interactive: video conferences, courses, meetings

5. PROCEDURES FOR QUALITY ASSURANCE AND REVISION

Depends on the individual centre. Mostly in accordance with established (hospital) procedures.
Quality assurance by resource group members, user representatives and relevant external professionals from the specialized health service.
Revision frequency. Before each new course, or when changes are required for the description of the diagnosis, the treatment or follow-up. For some documents, revision occurs less frequently.

6. USER PARTICIPATION

User organizations and/or users are involved in

- contributing to information material (printed, digital, video, sound)
- quality assurance

7. DISSEMINATION

- Social media: Facebook, LinkedIn, Twitter and YouTube. Targeting, sharing, retweeting, posts with links to website articles.
- Key messages for each target group.
- Hashtags
- Media
- Face to face communication: E.g. Meetings, conferences, workshops and education.
- Some centres submit newsletters
- Keyword optimization
- Printed materials. E.g. brochures, publications, leaflets, roll-ups, posters, etc.

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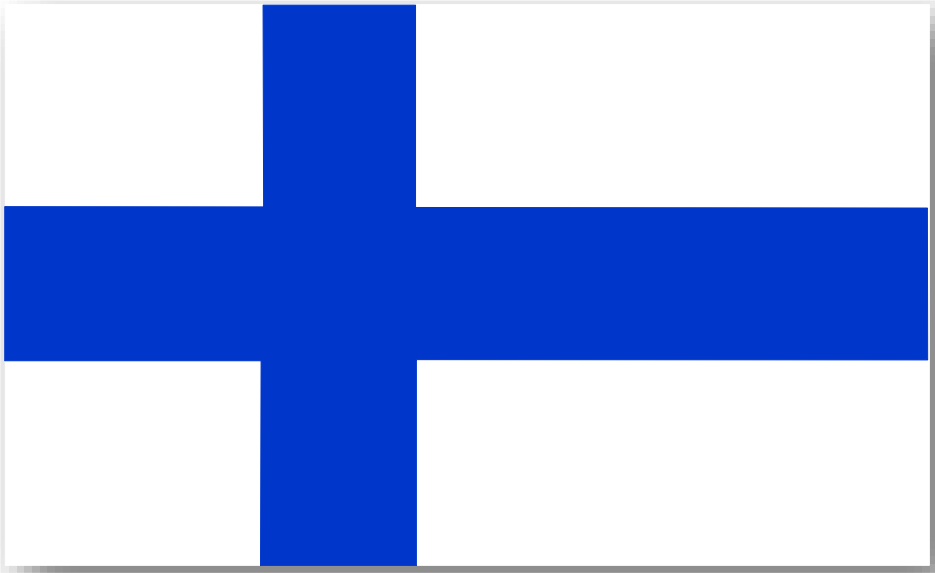
FINLAND



www.harvinaiset.fi

1. NAME OF THE INFORMATION SERVICE:

The Finnish Network for Rare Diseases (Harvinaiset-verkosto), Finland
The Finnish Network for Rare Diseases consists of 18 independent, non-governmental organizations and foundations that work for the interests of rare disease patients.
The information services are provided by the members of the network. All the information is combined by the network to a database on the website www.harvinaiset.fi. The database contains almost 300 diagnoses.

2. SUPPLIER/FINANCING

Mainly Finland's Slot Machine Association (RAY), sometimes medical or pharmaceutical companies

3. TARGET GROUP/-S:

People with rare disease and their families, health care professionals, social services professionals, politicians, decision makers and service providers.

4. GENERAL DESCRIPTION OF THE INFORMATION SERVICE

All the members of the network have their own ways to produce information on rare diseases. There are longer guides, shorter leaflets and very short introductions. Usually everything is also available online.

The great majority of the information in guides and leaflets is medical in character. Still there are more and more information about the social services, benefits, challenges of everyday life and the possibilities about the peer support. Also the stories and views of the rare disease people are introduced in the guides and leaflets.

As the member associations and foundations have hundreds of workers altogether the variety of the writers is also wide. Further freelance writers are also used. Many associations and foundations also have good contacts with medical and social experts working either in public or private sector.

The information is mainly available in Finnish. A tiny part of the information is available also in Swedish and English.

Some of the information includes also the relevant links to national and international sources (E.g. Rarelink, Orphanet). As most of the associations and foundations also provide other services (help lines, counselling, rehabilitation, websites etc.) there is not always need to include all the information to the guides and leaflets.

5. PROCEDURES FOR QUALITY ASSURANCE AND REVISION

The associations and foundations have the responsibility to make sure about the quality and revision of the information. Reprints and revised reprints are made if needed.

6. USER PARTICIPATION

The voice of the users, rare disease people and their relatives are taken into account in different ways in different associations and foundations.

7. DISSEMINATION

The guides and leaflets are free. They are even easily available through the websites. The information is distributed to social and health care professionals free of charge.

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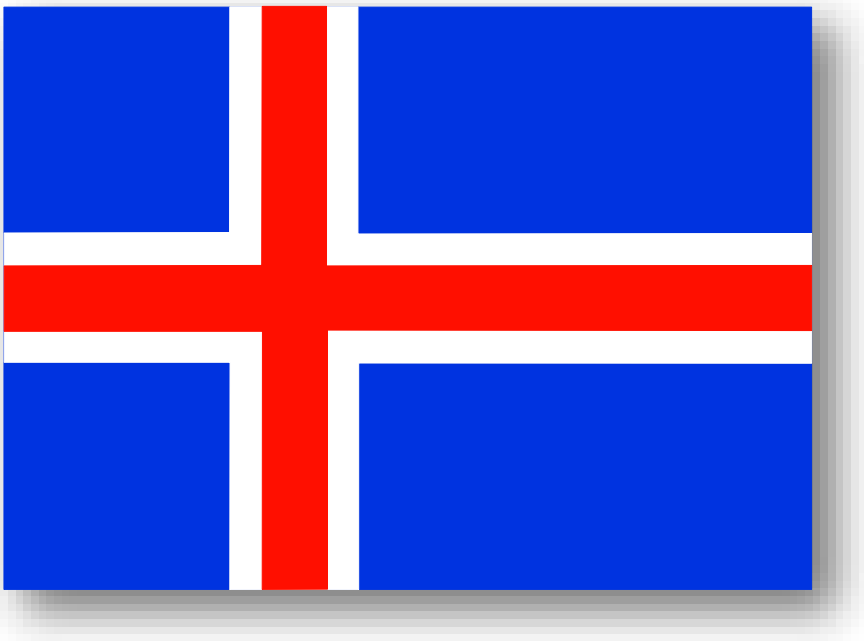

www.greining.is

1. NAME OF THE INFORMATION SERVICE:

The State Diagnostic and Counselling Center.

2. SUPPLIER/FINANCING

The State Diagnostic and Counselling Center. No specific funding is specifically provided for rare Diseases field in our country, but our Center has some legal obligations to serve children with rare Conditions AND disability. The center encourages staff to provide information about rare diseases when time is available due to clinical work.

3. TARGET GROUP/-S:

Parents, extended family, service providers, professionals and students working with people with rare diseases. Public – open access of material via our webpage.

4. GENERAL DESCRIPTION OF THE INFORMATION SERVICE

Most activity, in disseminating information about rare diseases/disability by the center, is probably via verbal communication at meetings about the individuals with rare conditions. This is through our ongoing education program in our praxis set up for each individual by the center to people working with our children in the field and families. These meetings can involve many people. Then the content is similar, by sometime in more depth, as set up at our written information at our website; Introduction – prevalence – etiology – symptoms – intervention – prognosis – further information. We often spread handouts and printed slides at those meetings.

Professionals at the State Diagnostic and Counselling Center write in Icelandic and the text is in layman´s term (to be understood by non-professionals).

Some cooperation is with other professionals working with the child, the Icelandic national hospital (Landspítalinn), with Einstök born /Unique Children (parent organization group) and with RareLink (platform).

We have also had international cooperation with Frambu in the form of videoconferences and meetings. Then professionals at Frambu with more extensive experience have shared their knowledge with the family and professionals in Iceland (E.g. meeting regarding Rett syndrome).

5. PROCEDURES FOR QUALITY ASSURANCE AND REVISION

The information is always reviewed by other professionals at the Center. Revision is not scheduled regularly, but as someone is updating the material and when time is available. Funding is pushing us to put clinical work as a priority at our center, so time for producing material for information is lacking.

6. USER PARTICIPATION

There is participation with users/families. Especially during meetings around each child and cooperation with Einstök börn.

7. Dissemination

Through homepage of the Center (www.greining.is)
Through Rarelink site (www.rarelink.is)
In support groups/parents support groups newsletters.
Social media (Facebook).

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