Rare Diseases Denmark

EUROPLAN
European Project for Rare Diseases National Plans Development

Denmark

EUROPLAN NATIONAL CONFERENCE

in the framework of the EU Joint Action RD-ACTION

Hoeje Taastrup, 17. November 2017

FINAL REPORT

RD ACTION
DATA AND POLICIES FOR RARE DISEASES

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EURORDIS
RARE DISEASES EUROPE

FOREWORD

The EUROPLAN national conferences or workshops are organised in many European countries as part of a coordinated and joint European effort to foster the development of comprehensive National Plans or Strategies for Rare Diseases addressing the unmet needs of patients living with a rare disease in Europe.

These National Plans and Strategies are intended to implement concrete national measures in key areas from research to codification of rare diseases, diagnosis, care and treatments as well as adapted social services for rare disease patients while integrating EU policies.

The EUROPLAN national conferences/ workshops are jointly organised in each country by a National Alliance of rare disease patients' organisations and EURORDIS–Rare Diseases Europe. **Rare Disease National Alliances and Patient Organisations have a crucial role to shape the national policies for rare diseases.**

The strength of EUROPLAN national conference/ workshop lies in its shared philosophy and format:

- **Patient-led**: National Alliances are in the best position to address patients' needs;
- **Multi-stakeholders**: National Alliances ensure to invite all stakeholders involved for a broad debate;
- **Integrating both the national and European approach to rare disease policy;**
- **Being part of an overarching European action** (project or Joint Action) that provides the legitimacy and the framework for the organisation of EUROPLAN national conferences/workshops;
- **Helping national authorities adhere to the obligations stemming from the Council Recommendation of 8 June 2009 on an action in the field of rare diseases.**

Since 2008, National Alliances and EURORDIS have been involved in promoting the adoption and implementation of National Plans and Strategies for rare diseases. Altogether, 30 EUROPLAN national conferences took place in the framework of the first EUROPLAN project (2008-2011) and the EU Joint Action of the European Committee of Experts on Rare Diseases – EUCERD - (2012-2015).

Within RD-ACTION (2015-2018), the second EU Joint Action for rare diseases, National Alliances and EURORDIS continue to get involved in a coordinated European effort to advocate for and promote integrated national policy measures that have an impact on the lives of people living with rare diseases.

The EUROPLAN national conferences or workshops taking place within RD-ACTION focus on specific themes identified by the National Alliances as the most pressing priorities to tackle with national authorities. These thematic priorities are addressed in sessions where all the stakeholders discuss relevant measures to be taken or ways to sustain the full implementation of already approved measures.

Each National Alliance prepares a final report on the national workshop, based on a common format such as the one that follows.

GENERAL INFORMATION

Country	Denmark
National Alliance (Organiser)	Rare Diseases Denmark
Date & place of the national workshop/conference	Handicaporganisationernes Hus, Hoeje Taastrup, 17 November 2017
Website	http://sjaeldnediagnoser.dk/national-strategi/
Members of the Steering Committee	Birthe Byskov Holm, Rare Diseases Denmark Lene Jensen, Rare Diseases Denmark Rune Eeg Nordvig, Danish Health Authority Jan Utzon, Danish Health Authority Matilde Munk, National Board of Social Services
List of Themes addressed	1. Theme A: Sector cooperation and coordination 2. Theme B: Empowerment 3. Theme C: International cooperation 4. Theme D: Hospital services for rare disease patients
Annexes :	I. Programme II. List of participants (by stakeholder category)

Abbreviations

- AUH: Aarhus University Hospital
- BoMS: Board of Member States
- CMS: Center for Metaboliske sygdomme (Metabolic Diseases Centre) – under CSS at RH
- CSS: Center for Sjældne Sygdomme (Rare Diseases Centre) – at RH and AUH
- EUROPLAN: European project for the support of national strategies and action plans for rare diseases
- ERN: European Reference Networks
- EURORDIS: Rare Diseases Europe – umbrella organisation for rare disease patient associations in Europe
- METABERN: The European Reference Network for Hereditary Metabolic Diseases
- PLWRD : Person living with a Rare Disease
- RH: Rigshospitalet (Copenhagen University Hospital)
- SOS: National Board of Social Services
- SST: Danish Health Authority
- VISO: The national knowledge and special advisory organisation (VIdens- og SpecialrådgivningsOrganisation).

Terms :

- Case officer : Public social worker with authority to make decisions about social support and more
- Case manager : Public coordinator for case officers
- Lay representative : Volunteer NGO-person, who supports PLWRD at meetings with case officers, doctors and other professionals
- Navigator : Volunteer NGO-person, who supports PLWRD over a period of time up til 12 months at meetings, in every day life and more

FINAL REPORT

I. Introduction/ Plenary session

The workshop was organised by Rare Diseases Denmark, the Danish Health Authority (SST) and the National Board of Social Services (SOS) working in partnership. The emphasis was on implementation of the national rare diseases strategy. A number of invited stakeholders participated in the workshop. Birthe Byskov Holm, President of Rare Diseases Denmark, talked about the European background for the workshop:

- 2009: Recommendation from the EU's Health Ministers
- 2010: The first Danish EUROPLAN conference – to create the strategy
- 2014: The Danish national rare diseases strategy is published
- 2015: The second Danish EUROPLAN conference – to present the strategy
- 2017: Danish EUROPLAN workshop – to implement the strategy

Rune Eeg Nordvig, special advisor at SST, explained that SST, which published the national strategy, is working on performing a status evaluation of the strategy. The status evaluation must also point forwards and may include new, action-oriented recommendations for the future initiative.

The report being created by Rare Diseases Denmark from the workshop may form part of this work. The expert monitoring group is also involved. The expert monitoring group includes relevant stakeholders, including two representatives of Rare Diseases Denmark. Rune Eeg Nordvig also explained that the themes have been selected on the basis of input from the expert monitoring group. The themes are as follows:

- Theme 1/A: Sector cooperation and coordination
- Theme 2/B: Patient education, coping skills and empowerment
- Theme 3/C: International cooperation
- Theme 4/D: Hospital services for rare disease patients

In addition, a further two themes will also be included in the status evaluation:

- Training and skills
- Registration, documentation and knowledge

In the spring of 2018, Rare Diseases Denmark will be holding a symposium on access to medicine to treat rare diseases.

II. Themes

THEME 1/A: Sector cooperation and coordination

Chair: Director Inge Kristensen, Danish Society for Patient Safety, Rapporteur: Stephanie Jøker Nielsen, secretariat of Rare Diseases Denmark

The national situation

Under theme A, the emphasis was on the challenges in the partnership between the health sector and the social sector when the overall procedure for rare disease patients is organised and implemented in practice. There was also emphasis on the challenges inherent in providing a collective, coordinated initiatives in the municipality.

Professional advisor Matilde Munk and professional advisor Trine Skov Uldall, SOS

Mathilde Munk and Trine Uldall described the work of SOS in a procedure description for citizens aged 0 – 26 with rare disabilities. A procedure description is a set of recommendations and guidelines for the municipality on how the procedure should be organised in respect of social, health, educational and institutional considerations. The procedure description is based on an intersectoral partnership, since SOS devises it in partnership with SST and involves the Ministry of Education and practitioners working with

health, social and educational matters. Patient organisations, daycare services, user organisations and stakeholder organisations are also involved.

Parent Christian Behnke, the Danish Spielmeyer-Vogt Association

Christian Behnke talked about the Spielmeyer-Vogt team, which was created on the basis of a parent initiative. The SV team is a lifelong care offering, and its purpose is to advise parents and provide knowledge to municipalities. The team comprises a basic team made up of a social advisor/coordinator and two special educational advisors. The basic team is supplemented by a professional medical consultant, a psychologist and two parent representatives. There is also a user group which works together with the basic team to discuss cooperation, finances, etc.

Parent Kis Holm-Laursen, Danish Osteogenesis Imperfecta Society

Kis Holm-Laursen talked about Marie, her 20-year-old daughter, who suffers from severe Osteogenesis Imperfecta (OI) and has noted significant changes in social action as she made the transition from childhood to adulthood. In the healthcare service, Marie has one department and a nurse providing access to the system, and coordination works well. But on making the transition to adulthood, Marie has been given at least 15 points of contact in the social system. They do not have access to one another's notes, and they do not share their knowledge.

There is a need for a rare diseases case manager who can coordinate efforts.

European aspects

Results from INNOVCARE and Rare Barometer are communicated to participants in connection with a workshop follow-up.

Suggestions from workshop participants

Better coordination and one point of access to the municipality:

- One point of access to and output from the municipality and social action should be established. There could be a rare diseases manager or coordinator who can guide citizens and obtain and send out relevant information to relevant specialists
- A case manager team should be set up for rare disease patients at both child and adult levels in each municipality. The case officer team must not be divided into sectors. Network meetings should be held with regard to individual citizens – it can be seen from the SV families that these are very valuable.

Collection of knowledge with regard to rare diseases:

- Municipalities should join forces with regard to service offerings for rare disease patients
- A structure must be established which allows knowledge to be accumulated and shared via networks between municipalities and regions, for instance. Whether the regional Health Agreements have a part to play should be explored
- A national resource centre should be set up for rare disease patients
- Several teams should be set up according to the same model as the SV team. There must be a link with CSS/the relevant hospital environment so that knowledge can be accumulated
- CSS must play a larger part in relation to the municipalities.

Other suggestions and viewpoints:

- The regions' advisory obligations should be specified with regard to rare diseases
- The legislation provides a foundation for the initiative and should be reviewed
- A desire for the national coordination structure under the auspices of the National Board of Social Services to be not just for guidance purposes; for instance, it should be possible to insist municipalities allow citizens to receive a specific service. A desire for VISO to take on a more prominent role
- More social advisors/case managers are needed in hospital environments, including CSS.

THEME 2/B: Patient education, coping skills and empowerment

Chair: Departmental manager Vibeke Lubanski, IBOS, Rapporteurs: Lene Jensen and Trine Juul, secretariat of Rare Diseases Denmark

The national situation

Under theme B, the emphasis was on empowerment and user involvement, which both user organisations and public stakeholders can help to promote. This involves empowering individual patients and families to cope with everyday life, and also creating frameworks for the participation and influence of user organisations.

Deputy manager Katrine Bærentzen, National Board of Social Services (SOS)

Katrine Bærentzen talked about the work of SOS with regard to empowerment as a perspective on the framework level. SOS maintains a broad approach to the field of disabilities, and its starting point is that *"Empowerment is all about reinforcing **individuals' self belief** and their own **drive,** and creating opportunities to exercise these. Self belief and drive are crucial to **everyone**. Not least if people's own views or the views of others on disabilities and other **environmental barriers** cause difficulties when it comes to self belief and opportunities to take action".* However, the term "empowerment" is very broad, and it is by no means the only thing that is needed. The right initiative to the right extent at the right time is also needed.

There are two sides to the work of SOS on empowerment – imparting knowledge on empowerment, and communicating methods and instruments that can be used to support empowerment. SOS perceives major potential in the peer-to-peer approach.

Director Lene Jensen, Rare Diseases Denmark

Lene Jensen pointed out that the national strategy is based on the fact that citizens living with rare diseases and disabilities have the same needs as other people. However, there are special prerequisites for meeting these needs due to complexity, seriousness and a lack of knowledge.

As a stakeholder, Rare Diseases Denmark has lifted a number of recommendations from the strategy: establishment of a Helpline in the form of a project, consolidation of the Network for Ultra Rare Diseases, and voluntary rare diseases navigators in the form of a project. There is also a need for a corps of lay representatives in connection with the Helpline and a much stronger, more interdisciplinary initiative with regard to education for rare disease patients. Conditions for the activities of the associations must also be incorporated. Another area for development includes more systematic involvement of the patient organisations in patients' treatment environments and in relation to SST's specialty plan, for instance.

European aspects

European aspects in this respect were not presented explicitly at the actual workshop.

Suggestions from workshop participants

Patient education and patient association courses:

- Patient education must be developed with emphasis on both targeted offerings such as Rare Diseases Family Days and more general offerings of benefit to rare disease patients can use
- Rare diseases citizens are chronically ill patients who have to deal with diseases throughout their entire lives. So, there is a need for lifelong access to patient education and association activities
- It is necessary to clarify whether education and courses will be funded by the municipalities, or by the regions. Why so many rare disease citizens are refused additional expenses for education and courses should be mapped
- The association courses and other association activities should be promoted – these may help to improve cooperation between citizens and specialists/officials
- Efforts should also be made to gather patients and relatives for themed evenings at hospitals, possibly in diagnosis groups in order to upgrade patients' insight into their own diagnoses.

Helpline, the Network for Ultra Rare Diseases and the navigators:

- More information should be provided on the existence of the Helpline
- The Helpline must be supported and continued by Rare Diseases Denmark after the project period so that both experience-based and specialist knowledge can continue to be brought into play directly among rare disease citizens who need it
- Efforts should be made to establish a s corps of rare diseases lay representatives in connection with the Helpline. There is still a need for the rare diseases navigators as well
- More information should be provided on the Network of Ultra Rare Diseases. And there is a need to develop activities within the Rare Diseases Network for adult members in particular, who have nowhere else to turn.

Other suggestions and viewpoints:

- There is a need for greater emphasis on cooperation with the authorities and coordination, and also for good case management
- SOS should offer and support a network for municipal case managers working with rare diseases
- A guideline is needed which relates to how patient associations can establish good working relationships between patients and health professionals, e.g. in Advisory Boards. Norwegian and European experience is available to draw on. Rare Diseases Denmark is creating a proposal in this regard.

THEME 3/C: International cooperation

Chair: President Birthe Byskov Holm, Rare Diseases Denmark, Rapporteur: Søren Lildal, Rare Diseases Denmark R&D and Jonas Lauridsen, secretariat of Rare Diseases Denmark

The national situation

For theme C, the emphasis was on the European cooperation, particular importance being attached to European Reference Networks (ERNs). Presentations were given by chief medical advisor Niels Moth Christiansen, SST, consultant Dr. Allan Meldgaard Lund, CMS RH and Birthe Byskov Holm, president of Rare Diseases Denmark.

Chief medical advisor Niels Moth Christiansen, Danish Health Authority (SST) – member of BoMS for Denmark

Niels Moth explained that the basic purpose of ERNs is to structure cooperation between professionals across nations. Highly specialised environments/specialists can apply for inclusion in ERNs, with the approval of SST: If an environment/specialist is approved in the specialty plan to perform a highly specialised function, an application can be submitted for admission to an ERN in this field. There were 25 Danish applicants in the first round. 16 were approved for participation in a total of 12 different ERNs. Why the rest were not included in an ERN should be determined.

The Board of Member States (BoMS) is where the practical roll-out of ERNs is organised. There are currently 24 approved networks with more than 300 hospitals and more than 1000 highly specialised units, and 26 countries are involved. 2018 will probably see a new round of applications. More information is available here: https://www.sst.dk/da/planlaegning/specialeplanlaegning/ern

Consultant Dr. Allan Meldgaard Lund, CMS RH

Allan Lund is a member of the metabolic network known as METABERN. This is a large network, with 69 participants from all over Europe covering more than 700 different diagnoses. Seven "underboards" have been created, along with interdisciplinary partnerships, e.g. the "renal ERN". METABERN is a multidisciplinary initiative and covers around 40,000 patients, of whom 30,000 are children. Its mission is to focus on patients.

Allan explained the admission process/procedures, which are very extensive. The 9 ERNs represented at RH have contacted Region H for assistance, and an experience exchange forum has been established. A

regional group involving representation of law, fund administration, IT, etc. has also been formed, but with no separate financial resources.

President Birthe Byskov Holm, Rare Diseases Denmark

Birthe Holm explained that the European cooperation for rare disease patients has helped to bring about progress in the field. Rare Diseases Denmark is very much involved, but as a country Denmark is cautious. Rare Diseases Denmark would like to see Danish participation in the Joint Actions in the rare diseases field and full Danish participation in Orphanet. Birthe also pointed out that Denmark also has little representation in European and global rare diseases research initiatives. This situation should be altered. Finally, Birthe spoke about the Nordic cooperation, which is less organised and developed than the European equivalent.

European aspects

There were extensive European aspects under this theme, and experiences and recommendations relating to ERNs, RD Action and Orphanet were brought up.

Suggestions from workshop participants

ERNs:

- A support system should be established that can support specialists with the bureaucratic elements of the application process – by providing information, and specifically with regard to individual applications. It should be possible to use the experience gained by others who have already undergone the process
- SST's information initiative with regard to ERNs should be upgraded, e.g. by
    - Holding an open information meeting when the next deadline for applications is known
    - Actively identifying the functions that should obviously be included in an ERN
    - Revealing the networks in which Denmark has no representation and implementing a special information initiative in relation to these
    - Even stronger partnership with regions and medical learned societies with regard to this initiative
- Experience may be available from the Netherlands as regards mapping and encouraging certain national ERN candidates to apply for admission – the Dutch authorities and patient organisations have worked together on their initiative
- Environments outside CSS must also be encouraged to get involved as rare disease patients and their specialists can be found in many different parts of the health system
- Research and funding of research ought to be a focus area for ERNs
- Patient representatives in ERNs should find one another and support one another's efforts
- One objective could involve ensuring Danish representation in all ERNs after the next round of applications.

Other:

- Denmark should be fully involved in the next rare diseases Joint Action and other European rare diseases partnerships, e.g. the e-rare research partnership
- A description is needed of what involvement in Orphanet means in practice. Problems relating to resources should be incorporated from the outset.

THEME 4/D: Hospital services for rare disease patients

Chair: Unit manager Janet Samuel, SST, Rapporteur: Lene Jensen, secretariat of Rare Diseases Denmark

The national situation

In theme D, the emphasis was on creating continuous patient pathways for rare disease patients. Janet Samuel provided a brief description of SST's specialty planning. The revised specialty plan that came into force on 1 June 2017 includes a number of new features. Rare diseases are described in a number of locations in the plans, CSS is referred to in a number of places, and attempts have been made to achieve

greater consistency between the guidelines. However, there are still a number of rare diseases that are not referred to explicitly.

Director Svend Hartling from Region H/Regions of Denmark spoke about Regions of Denmark's vision for the Citizens' Health Service. One important element involves introducing one healthcare practitioner for each patient.

Challenges and solutions

A panel comprising patient representatives and doctors gave a presentation to the debate concerning the challenges and opportunities regarding diagnostics, making the transition from childhood to adulthood and multidisciplinary, interdisciplinary initiatives.

Jesper Kokkendof, father of eight-year-old Albert, who suffers from the extremely rare disease Helsmoortel-Van der Aa syndrome (ADNP syndrome) explained that it took six years to get a diagnosis for Albert and that better coordination and more coherence are required. Consultant Sabine Grønborg, DSMG, pointed out that there is a need to maintain the investigation process. There is also a need for a combination of genetic and clinical processes and an interdisciplinary approach.

Liselotte Wesley Andersen, mother of 24-year-old Julia, who suffers from tuberous sclerosis, talked about the transition from childhood to adulthood in the health system. Problems occur when the holistic approach in paediatric care is replaced by support from an organ-specific specialisation. There is a need for adult doctors with emphasis on rare diseases and cooperation across specialisms by means of a coordinator function to deal with coordination, for example.

35-year-old Martin Bernth Madsen talked about his life as a cystic fibrosis patient. Martin has an effective range of treatments involving a number of different specialisms. This gives him the opportunity to create an entire life for himself, with education, work and a family life.

Consultant Stense Farholt, CSS RH, pointed out that these presentations show that the healthcare service is unable to work alone when it comes to handling tasks relating to rare disease patients. There is a need for coordinator functions and to reinforce initiatives involving multiple specialisms at centres that communicate externally; psychologists and social advisors, for example.

Consultant Dr. Kirstine Stochholm, CSS AUH, talked about the work currently in progress at CSS AUH. Attempts are being made to transfer the paediatric model to the adult field so that a holistically-oriented initiative is implemented for adults.

European aspects

The presentations were based on national observations. In the debate, the European aspects were included in particular in connection with European Reference Networks and other forms of European cooperation with a great deal of added value as regards rare diseases.

Suggestions from workshop participants

Diagnostics:

- Emphasis should be placed on how new technologies can be applied for people who have not been adequately assessed initially. It should be possible to find patients via the Health Platform (Sundhedsplatformen)
- There is a need for clinicians and geneticists to work in partnership to organise specialised investigations. A description must be given of how the analyses are to be used and the structure of the processes.

Multidisciplinary and interdisciplinary approach, plus coordination:

- The healthcare service's resource problems relating to social advisors and psychologists, for example, must be addressed

- There is a need for a clearer division of labour in the psychosocial field and in relation to the funding and allocation of aids/treatment tools
- All rare disease patients – be they children or adults – need a holistic approach
- There must be one healthcare practitioner/coordinator for each patient. The coordinator must work at a highly specialised level and maintain good cooperation across the board – with general practice, in addition to close cooperation with specialists.

Transition from childhood to adulthood

- Ensuring that children and adults with the same rare disease diagnosis are kept together in the same centre is a good, important factor – it provides security and improves opportunities for collection and development of knowledge.
- For some groups, it will be most appropriate to remain at CSS when they become adults – doctors working with adults should be included in CSS. For other groups, it is more sensible to use the support of organ-specific specialisms, as long as there are links with a coordinator/healthcare practitioner
- When young patients make the transition from CSS to an organ-specific specialism, there has to be a transfer plan in place so that important knowledge is not lost
- There is a need for a plan in relation to how adult patients can remain at/get into CSS, including CSS RH. An agreement was made between CSS RH and Region H to hold a meeting on this.

Structure and specialty plan:

- Pathway descriptions/patient pathways should be created for the major rare diseases groups.
- SST ensures compliance with the specialty plan, but this requires compliance with the procedures for further referral, and it requires reports if there are any problems with compliance
- It is necessary to recognise that highly specialised experts are located all over the country where rare diseases can also be located. Assuming that CSS should deal with the entire task itself is utopian
- Has the new wording in the specialty plan, stating that patients who are not clearly placed elsewhere in the special guidelines can be referred to CSS, led to more referrals? This should be evaluated
- It should be possible to resolve the practical/technical problems in relation to the specialty plan:
    - Establishment of better search options for specific rare disease diagnoses across the 36 special guidelines
    - An even higher degree of consistency between specialty plans, e.g. whereby a diagnosis is not just referred to in paediatric care, but also in organ-specific specialisms for adults
    - Better recording and better search options across CSS and other highly specialised centres in relation to which diagnoses they have – including diagnoses that are not referred to explicitly in the specialty plan.

Other:

- Specialist statements should be created by doctors who know something about the diagnosis in question, and the municipalities must be strongly advised to make use of these doctors
- There is a need to enhance the level of knowledge in respect of rare diseases by means of specialist articles, events, etc.
- A process should be devised for how we can progress when the strategy process is over. There is a need for a set forum that can continue the close discussion. Inspiration may be available in Italy, which publishes a state-of-the-art publication relating to rare diseases every two years, with the involvement of a number of stakeholders.

III. Conclusions

Wrap up of conclusions for each theme addressed (short paragraphs)

Chair Inge Kristensen reported back from workshop on theme A on sector cooperation and coordination. It emerged from the debate that

- There is enormous demand for one point of access to the municipality
- There is a need for better interaction between the social and service legislation and the health legislation – there are different approaches to the fields, and this is not a good thing
- There is a need to transfer information between municipalities and regions:
    - CSS must play a larger part in relation to the municipalities
    - The national coordination mechanism and VISO must be reinforced
    - A national resource centre for rare diseases should be established
- Health agreement between regions and municipalities should be capable of playing a part when it comes to rare diseases

Chair Vibeke Lubanski reported back from workshop B on empowerment. A number of issues of significance to empowerment on a number of levels were discussed here:

- Patient education was a central theme, as this relates to how families cope with their own lives:
    - The work of the associations should be reinforced
    - Patient education is needed from a chronic illness perspective
    - A specific recommendation: working on the basis of the many stakeholders that are already up and running, something should be devised that can help and support rare disease families and adults and young people
- Patients involved in Advisory Boards can help to influence the frameworks available to patients for treatment and control, etc.
- There is an evident need for advice, and having a Helpline at Rare Diseases Denmark is definitely the right thing to do. There is a need to provide support and greater scope by means of corps of lay representatives.

Chair Birthe Holm reported back from workshop C on international cooperation. ERNs were the central topic – there are 24 networks, and Denmark is involved in 12 of them. It is very sensible to participate in these networks when diseases are rare. There were many discussions on how best to provide information on the options for inclusion, SST plays a major part here. Whether Denmark can be included in Orphanet, and if so how, was also discussed. This requires a description of what it is and what it requires.

Special advisor Rune Nordvig explained that information from the sessions is being collated and that all presentations and discussions are summarised in the Rare Diseases Denmark report on the workshop. Working in partnership with SOS and the expert monitoring group, SST will then use the report in its work on SST's status evaluation, the ambition of which is to define statuses within the selected and other themes and point out new recommendations for initiatives relating to rare diseases. SST is expecting to publish this status evaluation in the first quarter of 2018.

Program for workshop on national strategy for rare diseases
17. November 2017, 10 – 16

Handicaporganisationernes Hus, Blekinge Boulevard 2, DK-2630 Høje Taastrup

Program

09.30 – 10.00: Registration and breakfast

10.00 – 10.20: Velcome and introduction, President Birthe Byskov Holm, Rare Diseases Denmark and special advisor Rune Eeg Nordvig, Danish Health Authority

10.30 – 12.00: Three parallel workshops:

Theme A: Sector cooperation and coordination
Theme B: Empowerment
Theme C: International cooperation

12.00 – 13.00: Lunch and networking

13.00 – 15.10: Plenary – Theme D: Hospital services for rare disease patients

15.10 – 15.30: Coffee and networking

15.30 – 16.00: Conclusions – and what is next? president Birthe Byskov Holm, Rare Diseases Denmark and special advisor Rune Eeg Nordvig, Danish Health Authority

About the sessions

Parallel workshops 10.30 – 12.00:

Theme A: Sector cooperation and coordination

Chair: Director Inge Kristensen, Danish Society for Patient Safety
Rapporteur: Stephanie Jøker Nielsen

There are many challenges in the cooperation between health care sector and social support, when the program for the rare disease patient is established and implemented. Also the coordination of the social support from the municipality is a challenge. What does the landscape look like and how to proceed? Inputs by

- Professional advisor Matilde Munk og professional advisor Trine Skov Uldall, National Board of Social services
- Parent Christian Behnke, the Danish Spielmeier Vogt Association
- Parent Kis Holm Laursen, Danish Osteogenesis Imperfecta Society

Tema B: Empowerment

Chair: Departemental manager Vibeke Lubanski, IBOS
Rapporteurs: Trine Juul, Lene Jensen

Promotion of patient empowerment is in focus both for patient associations and public authorities on individual and society level. Input by. Oplæg ved

- Deputy manager Katrine Bærentzen, National Board of Social Services
- Manager Lene Jensen, Rare Diseases Denmark

Theme D: International cooperation

Chair: President Birthe Byskov Holm, Rare Diseases Denmark

Rapporteurs: Jonas Lauridsen, Søren Lildal

Few patients, fewer professionals and a lack of knowledge make the added value in cooperation on rare diseases obvious. At the EU level the initiatives regarding European Reference Networks (ERN) are of huge importance, but also other initiatives is ongoing. Also at the Nordic level cooperation on rare diseases is in focus. How does Danish patients and professionals engage in international cooperation?

- Chief medical advisor Niels Moth Christiansen, Danish Health Authority
- Consultant, dr. Allan Meldgaard Lund, CMS RH
- President Birthe Byskov Holm, Rare Diseases Denmark

Plenary 13.00 – 15.00:

Theme D: Hospital services for rare disease patients

Chair: Unit manager Janet Samuel, Danish Health Authority

Rapporteurs: Lene Jensen, Stephanie Jøker Nielsen

13.00: Setting the Scene, Unit manager Janet Samuel, Danish Health Authority
13.05: Citizen´s Health Service, Director Svend G. Hartling, Region H./Regions of Denmark
13.20: Challenges and solutions:

- Panel of patient representatives
  - Diagnostics, Jesper Kokkendof, father of Albert diagnosed with Helsmoortel-Van der Aa/ADNP-syndrom
  - Transition from childhood to adulthood, Liselotte Wesley Andersen, Mother of Julia mdiagnosed with Tuberos Sclerosis
  - Multidisciplinary services and cross professional cooperation, Martin Bernth Madsen, patient suffering from Cystic Fibrosis
- Panel of professionals:
  - Consultant Sabine Grønborg, DSMG
  - Consultant Stense Farholt, CSS RH
  - Consultant, dr. Kirstine Stochholm, CSS AUH

14.10 – 15.10: Plenary discussion

More information on the national strategy of rare diseases and EUROPLAN >>
http://sjaeldnediagnoser.dk/national-strategi/

Participants list, EUROPLAN-workshop 17. November 2017,10 – 16

Venue: Handicaporganisationernes Hus, Blekinge Boulevard 2, DK-2630 Høje Taastrup

Health Care Professionals

1. Andersen, Brian Nauheimer - afdelingslæge, DPS
2. Bisgaard, Anne-Marie - overlæge, CSS Kennedy-/Rett-Centret
3. Bundgaard, Henning - professor, overlæge, dr.med., LVS - excused
4. Ertmann, Ruth - seniorforsker, praktiserende læge, DSAM
5. Farholt, Stense - overlæge, ph.d., CSS
6. Frederiksen, Anja L. - overlæge, ph.d., Region Syddanmark
7. Grønborg, Sabine - overlæge, DSMG
8. Hammer, Trine Bjørg - læge, ph.d, Klinisk genetisk klinisk, RH
9. Handrup, Mette Møller - afdelingslæge, CSS
10. Lauridsen, Eva - overtandlæge, centerleder
11. Lund, Allan Meldgaard - dr.med., CMS/CSS
12. Nielsen, Irene Kibæk - overlæge, Region Nordjylland
13. Ousager, Lillian Bomme - ledende overlæge, DSMG
14. Stochholm, Kirstine - afdelingslæge, dr.med., Region Midt
15. Svantemann, Margit Feldbak - specialeansvarlig sygeplejerske, CSS
16. Thomsen, Claus - lægefgl. direktør, AUH

Authorities

1. Bærentzen, Katrine - souschef, Socialstyrelsen
2. Christiansen, Niels Moth - chefkonsulent, Sundhedsstyrelsen
3. Hartling, Svend G. – koncerndirektør, Region H - Danske Regioner
4. Iqbal, Zoheeb - fuldmægtig, Sundheds- og ældreministeriet
5. Lond, Rigmor - konsulent, Kommunernes Landsforening - excused
6. Munk, Matilde - faglig konsulent, Socialstyrelsen
7. Nordvig, Rune Eeg - specialkonsulent, Sundhedsstyrelsen
8. Uldall, Trine Skov - faglig konsulent, Socialstyrelsen
9. Utzon, Jan – afdelingslæge, Sundhedsstyrelsen
10. Samuel, Janet - enhedschef, Sundhedsstyrelsen

Patient representatives

1. Andersen, Liselotte Wesley – formand for Dansk Forening for Tuberøs Sclerose
2. Behnke, Christian – medlem af Dansk Spielmeier Vogt-forening
3. Boserup, Betina – medlem af Ehlers Danlos-foreningen i Danmark, rådgiver på Helpline
4. Grentoft, Mette – medlem af Dansk Forening for Williams Syndrom
5. Holm, Birthe Byskov – formand for Sjældne Diagnoser
6. Jensen, Karsten – formand for Dansk Forening for Osteogenesis Imperfecta
7. Holm, Karen Binger – sekretariatsleder i Danmarks Bløderforening
8. Jensen, Lene – direktør for Sjældne Diagnosers sekretariat
9. Juul, Trine – konsulent i Sjældne Diagnosers sekretariat, rådgiver på Helpline
10. Kokkendoff, Jesper – medlem af Sjældne-netværket
11. Lauridsen, Anne-Grethe – formand for Gaucherforeningen i Danmark
12. Lauridsen, Jonas – studentermedarbejder i Sjældne Diagnosers sekretariat

13. Laursen, Kis Holm – medlem af Dansk Forening for Osteogenesis Imperfecta, rådgiver på Helpline
14. Lildal, Søren – medlem af Danmarks Apertforening
15. Lougart, Annemette – bestyrelsesmedlem for Ehlers-Danlos foreningen i Danmark
16. Lougart, Birgitte – næstformand for Ehlers-Danlos foreningen i Danmark
17. Lykke, Dorthe – formand for Foreningen for ATAKSI/HSP
18. Madsen, Martin Bernth – medlem af Cystisk Fibrose Foreningen
19. Nielsen, Anja – medlem af Sjældne-netværket, rådgiver på Helpline
20. Nielsen, Stephanie Jøker - faglig leder for Helpline i Sjældne Diagnosers sekretariat
21. Ousted, Helle – sekretariatsleder i Cystisk Fibrose Foreningen
22. Romlund, Susanne – regnskabsfører i Sjældne Diagnosers sekretariat, rådgiver på Helpline
23. Skramsø, Per – formand for Ehlers-Danlos foreningen i Danmark, rådgiver på Helpline
24. Staureby, Merete – formand for Spielmeier Vogt-foreningen

Pharmaceutical Companies

1. Almen, Lisa – Pfizer
2. Fyhn, Birgitte - Genzyme Sanofi
3. Heymann, Anette – Chiesi
4. Mourad, Yvonne – sobi
5. Tscherning, Karen – Santhera
6. Pedersen, Morten – Shire
7. Stausholm, Gitte - CSL Behring

Others

1. Gabay, Merete Daugaard - socialrådgiver, CSS
2. Hegaard, Lea - chefkonsulent, Komitéen for sundhedsoplysning
3. Kragerup, Karina - socialformidler, CSS Kennedy Centret
4. Kristensen, Inge - direktør, Dansk Selskab for Patientsikkerhed
5. Lubanski, Vibeke - afdelingsleder, IBOS
6. Løhr, Maja Klamer - rådgiver, Hjernesagen
7. Nelander, Charan - direktør, Komitéen for sundhedsoplysning
8. Petersen, Sine Lyng - socialrådgiver, RehabiliteringsCenter for Muskelsvind