TOGETHER we can be stronger

1st Danish meeting for patients/families with Inborn Errors of Metabolism

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This poster could be a guide for small associations how to cooperate

"Together we can be stronger" – was the slogan we created from the beginning. We do believe that the process and the event have showed us that we were right. Together we have created a Family Conference which each of us would not have been able to carry out as a small association. This conference took place April 2014 in Kolding, Denmark.
More than 75 participants from 5 associations and even some without an association had a fantastic day.

WHO WE ARE

In September 2012 six patient associations met together in a "metabolism group" which has since become an internal working group within the umbrella organization Rare Diseases Denmark.

The associations working together at this point is covering the following diseases:

- Wilson Disease
- Fabry Disease
- Congenital Disorders of Glycosylation Syndrome
- MCAD Deficiency
- Protein Degradation Defect Diseases
- Gaucher Disease

VISION

Our vision and purpose was to create collaboration across associations. In a partnership we believe that we can:

- Create more awareness on Inborn Errors of Metabolism
- Share our experience and knowledge
- Gather our forces and capabilities to organize joint events for our members that would otherwise not be possible in very small associations

The primary idea was to gather our members at a Family Conference, with focus on life with a metabolic disorder and the challenges families are facing.

WHY WORK TOGETHER

Inborn Errors of Metabolism has in total 20-25 new diagnosed children a year in Denmark. Thus each association in the IEM group therefor is small and one of the challenges we all experience is that our associations have few members of a certain age. Working together we were able to offer workshops customized to i.e. children and adolescents with metabolic diseases, their siblings or the elderly, as each of these groups often are outnumbered in the small associations.

HOW WE DID WORK TOGETHER

This was the first time we as a group worked together for a mutual project. We have been working with a flat structure and this has been great, as all have contributed based on experience and knowledge. Our planning and evaluation meetings have been face-to-face and besides that a substantial amount of emails and telephone calls.

FUNDING

An event like this Family Conference is expensive to arrange. Furthermore we made the decision that participants could attend without costs, this in order to ensure that no one was excluded from attending for financial reason. Working together made it possible to invite speakers that were quite expensive and individually it would not have been feasible to invite the keynote speaker and two of the workshop facilitators.

Our two main income sources were:

- Public Disability Funds, these funds could be applied by the associations who have children and young adults and their families as members. For associations with mainly adult members public funds are very limited.
- An international award that we won for the Family Conference made our lives so much easier. The award was USD 15.000 and this donation meant that we did not have to seek funding elsewhere. The award was granted by Sanofi-Genzyme and is called PAL Award.

RAISING PUBLIC AWARENESS

www.stofskiftegruppen.dk

We created a website **www.stofskiftegruppen.dk** where we are telling about our self and the Family Conference.It is possible to see pictures and comments from the day as well as the final evaluation rapport. Future projects will be added.

In collaboration with our main sponsor we had a press release send out in connection with the presentation of the award.

- The Award ceremony were mentioned in local newspaper both before and after the ceremony.
- A representatiive from the Gaucher Association was interviewed and this was published different local newspapers.
- A representative from the PND Association was on live TV, local Copenhagen chanel, this interview was repeated several times during the day.

Rare Diseases Denmark have reported on the event internally several times.

We have also designed two posters.
This was without costs as one from the group is graphic designer and one had access to print facilities.
The poster was displayed at the conference and Center for IEM at Rigshospitalet.

PROGRAM

Clinical presentation: DMSc Allan Meldgaard Lund, Center of Inheritable Metabolic Diseases, Rigshospitalet, Copenhagen talked about Inborn Errors of Metabolism in general, what it is and how the different diseases are connected. We heard about different symptoms, possible treatments. For most participants this was the first time they were given this broader view of IEM, but the systematic approach to the material made it very relevant to all.

Inspirational presentation: This key-note presentation was called "Kiss the old world goodbye", by a former Ranger/professional soldier. The goal was to give motivation to utilize one's full potential, breaking with fear and take responsibility for your own life. Participants were inspired to raise their mental lintel and transform everyday problems into challenges. The message was clear – everyone is unique, we all have a special talent – we need to find it and activate it.

"Now I know there are others like me"

"In the future I will focus on all the things I can do with my sick sibling, instead of what I can't do"

"It was great to speak out loud my feelings"

Workshop: Deciding about the workshops was an ongoing process and they were finally decided when we knew who was going to participate. We ended up with 5 different workshops. They all lasted about 1½ hour and for each workshop we had booked a professional facilitator. After the workshops we gathered all participants in plenary and all groups gave a short feedback on their discussions.

Fathers: This group was facilitated by a father who has a child with a rare disease and who also are active within the Rare Disease community. The group had informal talk about being a father and husband in this special situation.

Mothers: This group was facilitated by a psychologist. The aim was to have an open talk about "how to let go" when children grow up and you as a mother no longer are the most important person for you child.

Siblings: This group was facilitated by a professional who work with similar groups for common diseases. They had a very good, open and lively dialogue around the main topic: "Forbidden feelings".

Young patients: This group was facilitated by a professional who work with similar groups within the Rare Disease community. The main subject was to talk about "How do I tell friends and family that I don't need their protection, that I can handle a lot of things on my own".

Family/ Couple dynamic: The main subjects were "What happen to the term "family" and how to maintain the spark in the relationship when you add "chronically ill". This group was facilitated by a professional therapist.

A SUCCESS CRITERIA

- to reach out to patients/families without an association

We know the importance of being part of a community where you can meet others in the same situation. For several families with a rare metabolic disorder, we are aware that they do not have any association in Denmark, because they might be the only family with this disease or at least one of very few families.

To find and contact these patients and families we asked for assistance from:

- Center for IEM at Rigshospitalet, Copenhagen who gave out our invitations when relevant families came to the center for consultation or treatment
- "The Rare Network", where rare disease families with no association can sign up, which is run by Rare Diseases Denmark. Our invitations were sent by mail to relevant patients/families on the list.

CONCLUSION

Together we have created a Family Conference which each of us would not have been able to carry out as a small association. We do believe that the process and the event have showed us that we were right in saying "Together we can be stronger".

We have experienced that working together we could share ideas and knowledge – something that can be difficult in very small associations which often is a "one-person-activity". It was a positive and inspirational experience to work together and to feel the energy and engagement of working together on this project.

One of our main goals was to reach out to patients/families without an association to give them a network. Since have two new associations, for Pompe and MPS, been founded in Denmark.

Collaboration with Center for IEM at Rigshospitalet and with Rare Diseases Denmark (who runs the Rare Network) on identifying patients/families without an association went well.

Evaluation was done by the workshop facilitators who spend a few minutes at the end of the workshops to gather impressions from each group and also they supplied with their own input to evaluation. After the conference each association have been in contact with our own members for feedback.

In general, we were content with the final program and our choice of external speakers and especially we were happy about the "siblings" and "young patients" workshops.

HOW TO BRING THE COLLABROATION FORWARD

We have decided to continue working closer together. We are planning the next Family Conference, which will take place 1st October 2016. The program will be structured the same way. We will repeat the workshops for Siblings and Young Patients but have chosen two new subjects for the other workshops – focus will be on how to be a cooperative patient and citizen in both the Health- and Social System.
The funding for this second Family Conference will still be split in two parts. The Public Disability funds and funding via applications to the medical industry. We have for this event received grants from several compagnies based on our budget.

We have formally been reconiced as a working group under Rare Diseases Denmark and this gives the steering group opertunity to continue to meet twice a year during the Rare Disease Conventions. We will include other associations covering of Inherited Metabolic Diseases for our future work, only criteria is that they have become member of Rare Diseases Denmark.
We will keep our network-way-of-working. We plan to look for more areas of common interest in order to expand the areas where we can work together. This could be areas like consultations for hospitals and authorities and share experince on daily business within the associations. We want to develop our collaboration but still stay independent for the time being.