> *'I got strength from knowing I am not alone*
> *and I hope that being part of a group of*
> *complex patients will empower each and*
> *every one of us'*
>
> (Orna Resisi)

Report from the patient representatives sessions at the ONCA Conference on 'Optimal Nutritional Care for All' in Madrid, November 20-22, 2016

Compared to the two earlier ONCA conferences in Brussels (2014) and Berlin (2015), this Madrid conference certainly brought in a new and more personal element in the ONCA community, namely the strong patients' and parents' voices reflected in a number of very touching personal experiences on how it is to deal as a person or a parent with long and difficult periods of dependency on medical nutrition.
In addition, there were presentations on scaling up individual patient experiences to lobbying by specific nutritional patient groups and a short reflection on the complexity of care models for patients with comorbidity issues. This all came together in a one-hour plenary session at the beginning of this 130 participants counting conference. On the second day, the concept of 'citizen science' was discussed as a tool to get more information from these individual 'experience based' stories instead of waiting for the results of carefully designed ' evidence based' studies which rarely can be realized in 'real life' settings.

In total, 12 patient representatives came to Madrid to participate in the ONCA-conference as members of National Steering Committees (NSC's) or as member of the joint EPF/EGAN/ENHA Working Party on Nutrition.

Preconference session

For them, a special preconference session was designed just as in Berlin 2015. Cees Smit (EGAN) welcomed everyone and that was the start of an informal' get to know each other, followed by an overview of patient participation and cooperation of European Patient Groups: EPF (European Patients' Forum, eu-patient.eu) and EGAN, (European Patients Network for Medical Research and Health, egan.eu) within the European Nutrition for Health Alliance (ENHA).

Illustration 1: The preconference session for patients (photo: Meike Engfer)

Ceri Green introduced the central theme and the issues at stake for the conference with involvement from all stakeholder groups within ONCA. Gaston Remmers, one of the co-founders of the Dutch Platform Patients and Food (patientENnvoeding.nl) discussed more in-depth the use of individual and citizen-collected data in research and the accompanying ICT and patient-driven governance structures needed to facilitate that. Finally, Laurene Souchet from EPF ended with a reflection on the importance of patient involvement and empowerment. From this very first session on, it became evident that for many representatives it is important to know that many people deal with severe nutritional complications and needs. Many more than they ever expected before they came to this conference.

Plenary Patients’ Session

This 'I am not alone’ experience was reinforced at the first ever, patient-led plenary session of these three ONCA-conferences so far with the personal testimony by Ozlem Kaymaz, the mother of nine-year old Daniel from Turkye. Daniel was born with a very rare disease: Nager syndrome and from his birth it was impossible for him to drink and eat by himself. Not only a large number of operations was necessary in his early years, but also several complicated tube-feeding mechanisms and types of medical nutrition were needed to guide him through these difficult years. At present, the Kaymaz family, including Daniels older sister and his younger brother (without genetic Nager syndrome), is now rather happy and adapted to the situation, which at the beginning of Daniel's life seemed to become so troublesome, (for more information, see www.daniels-life.com).

Illustation 2: Ozlem Kaymaz during her presentation (Photo: Meike Engfer)

The same type of positive thinking was delivered by Orna Resisi from Israel, married and mother of three children. Orna suffers from diabetes type 1 which has effected the digestive system and caused inability to eat. Orna has been on TPN (Total Parenteral Nutrition) feeding for 5 years and on tube enteral nutrition since 2014. The topics, she addressed were medical, emotional, social, and economic issues associated with not being able to eat. Orna came on the stage together with her backpack, filled with 2,5 kg. of enteral nutrition, a load she has to carry with her 24/7. For more information, see Orna her presentation on youtube.com/watch?v=wiqkT8F-br4.

After these two very, personal presentations, the central group issues of persons living on Home Artificial Nutrition (HAN) were addressed by Monika Malickova from the Czech Republic and Marek Lichota from Poland. Both are leading specific-disease groups for patients with strong medical nutritional needs. Monika explained that her organisation ‘Život bez střeva (Life without Intestine, zivotbezstreva.cz) supports patients on HAN and tries to improve their quality of life. One of the topics is also to raise public awareness during the world Home Artificial Nutrition (HAN) weeks, which will take place next year on October, 15, 2017 World HAN Day. Marek‘s organisation in Poland `Stowarzyszenie Apetyt na Zycie` (Appetite for Life, apetytnazycie.org) is doing similar activities since its start in 2012 and with strong inspiration from similar organisations elsewhere like the Oley Foundation in the USA (oley.org) and PINNT in the United Kingdom (pinnt.com). Both organisations avoid to give medical advice, but focus on practical aspects of life with HAN and how to adapt to the therapy.

In this part, Jorge Hinojosa of the Spanish General Patients Alliance (GPA, Alianza General de Pacientes, alianzadepacientes.org) described the Alliance’s special manifest on disease related malnutrition (DRM) and the way they cooperate with the Spanish National Steering Committee, the host also of the Madrid Conference in 2016. The main issues of the manifest are:

- Train health professionals, patients and family members on DRM
- Implement measures that allow an early diagnosis and prevention: screening and nutritional assessment
- Patient monitoring and registries for evaluating patient outcomes
- Develop a plan to evaluate health outcomes
- Foster the development of a framework document for the approach of DRM in the Spanish NHS
- Raise awareness among policy makers

Josefa Kachal from the Ministry of Health of Israel closed this session with a short presentation of a practical guide for caregivers and family members of people with dementia ‘Eating and Living with Dignity’. The purpose of this booklet is to provide families with tools and methods at all stages of the disease. In the early stages `what are the signs that can indicate problems with buying and storing food, preparing the meal, organizing the eating environment, eating the food`, etc. And in advanced stages of dementia, practical advice on what to eat when a person has functional problems. This booklet can be downloaded from:
health.gov.il/PublicationsFiles/Dementia_Nutrition_en.pdf

The plenary session from the patient groups in Madrid was jointly chaired by Laurène Souchet from EPF and Cees Smit from EGAN. Cees closed the session with a couple of more general remarks with regard to the treatment of complex patients, namely that it is important for professionals to understand that most patients come to you with a long personal and medical history, that they are most often experts in self-management and coping with their disease but at the same time there is also a ‘fear factor’ that somewhere in the medical process something goes wrong through a combination of lack of coordination, polypharmacy or a temporary/permanent inability to manage the disease by themselves or their caregivers.

On the second day of the conference, Gaston Remmers (Platform Patients and Food Netherlands) addressed the plenary with the need for a learning-based attitude in a number of domains. Gaston kicked off his presentation proposing a broadening of the debate on nutrition and disease from Disease Related Malnutrition (DRM) to Malnutrition Related Disease (MRD), and from a focus on disease remediation to health promotion through nutrition and food. He illustrated the shift by a short video on the challenge of personalized food (see youtube.com/watch?v=Vt3PS5NW96g). This challenge can be addressed by a much broader cooperation among stakeholders in biomedical research, patients/citizens and food producers, aiming to deliver a repertoire of personalised food systems.

A second theme Gaston addressed was the urgency to go beyond RCT’s and look more carefully to the potential of 'citizen science' as a tool to get more and more information available from all individual ' experience based' stories instead of waiting for the results of carefully designed ' evidence based' studies which rarely can be realized in 'real life' settings (see www.BeyondRCT.net). The data gathered from these individual experiences could and should also be collected in a bottom-up designed and citizen-controlled governance model, that allows from new types of Big Data research. He advanced the Health Data Cooperative model as developed in Switzerland as a very promising governance model (www.midata.org)

Gaston’s third topic was his proposal for ‘European Learning Journeys’, that ENHA/ONCA could organize for interested ENHA-members: two to three day-visits to a specific country or region, getting in-depth and first-hand understanding of 4 to 5 cases, practices, enterprises or policies addressing specific aspects of nutrition and health . All this, to facilitate and accelerate learning throughout Europe on the value of food and nutrition for health, through the organization of hands-on field trips to best practices.

Closing patients’ session

At the end of the second day of the conference another closed session for patients representatives ended the patients part of the ONCA conference. It was here that Dusan Baraga (Slovenia) and Ivica Belina (Croatia) mentioned that they would be glad to take up the challenge to give attention to the patient and citizen input in the follow-up ONCA meetings in 2017 (Prague, May 19, 2017 and Slovenia, November 13/14, 2017) as both were impressed by the input the patients’ experience already had for them in the meetings in Berlin, but certainly here in Madrid.

Karl Haberstig (Germany) mentioned more in general the resistance from stakeholder groups in Germany to involve patients in policy issues and research. Something he experienced in particular because of his own personal change from being a specialist in general medicine and psychotherapist treating ’psychosomatic’ patients, to a patient not being able to find adequate treatment. He suggests to be aware of the wider context of ’body, mind and spirit’ or ’nutrition’ for our biology, our psychology (e.g. empathic Patient-therapist- relationship, the ’Fear factor’) and our ontology (including dignity, intuition, higher awareness etc,). From his double perspective, he can easily see through doctors’ insensitiveness and incapacity, which is not always appreciated.

Robert Johnstone responded that in his view this is certainly a specific topic related to Germany, well-known from other experiences as well, like with the public perception of EUPATI, the European Patient Academy. This EUPATI is a public-private partnership project from the Innovative Medicine Initiative (IMI) initiated by the European Commission but nevertheless perceived most often in Germany as ethically wrong and influencing patients by industry. For the patient participation in nutritional issues this is certainly a topic of attention and in 2017 from EPF an initiative can be expected to address these relationship and governance issues with various groups of stakeholders, like pharma, medical devices, diagnostics, etc.

Karl also mentioned the need for a broader attention for integrative medicine.

Other suggestions at the end were to look more into health insurance challenges around nutrition, a possible revision of the 2013 book ‘Patient perspectives on nutrition' and of course at the next conference, more time for personal exchange of experiences.

It became already clear from the contacts during the conference that there is a need for a large pool of experienced patients' speakers on the use of medical nutrition and new fresh food approaches to health, that could represent this group at other conferences, like the one on Mediterranean Food in Ostuni (Italy) in March-April 2017 and in The Hague at the ESPEN Congress in September 2017.

It was also mentioned as a possibility to meet in between this and the next ONCA conference with a larger group of patient representatives in Brussels. Most probably this meeting will be held at the end of June 2017.
All presentations from the patient representatives during this conference are downloadable from european-nutrition.org through a dropbox download programme.

List of patient representatives present during the ONCA Conference Madrid 2016

Illustration 3: Patients' group picture (photo: Meike Engfer)

(From left to right: Monika Malickova, Marek Lichota, Laurène Souchet, Karl Haberstig, Ozlem Kaymaz, Cees Smit, Gaston Remmers, Robert Johnstone, Dusan Baraga, Orna Resisi and Ivica Belina (Jorge Hinojosa is missing)

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