

Patients' involvement in ONCA-conference enlarged

During the last 'Optimal Nutritional Care for All' on November 3 and 4, 2015 in Berlin the participation from representatives from patients and elderly groups was substantially larger than at the first ONCA-conference in Brussels in November 2014. The participation of a large group of patient representatives has been perceived as one of the highlights of the ONCA Conference in Berlin by the other stakeholders, stressing once again the importance of including their voice in the national steering committees.

In 2015, eleven patients/elderly participated as a result of efforts from national steering committees to include at least one of these groups in their delegation and through the initiatives of the joint Working Party on Nutrition from EPF and EGAN.

To introduce this group into the work of ENHA and the background of the ONCA-conferences, an introductory programme was developed before the conference itself. For early arrivals, there was already an informal dinner the evening before and before the start of the conference an early session, starting at 9 o'clock, was scheduled.

At first, the participants introduced themselves and all expressed as their main feeling that they were very glad with the attention for patient participation in this for them important topic as well as the conference itself.

Introduction to the conference background

At this introductory session, Cees Smit spoke about the history of the joint Working Party on Nutrition from the European Patients' Federation (EPF) and EGAN, the European umbrella group for genetic diseases and their cooperation with the European Nutrition for Health Alliance (ENHA). In 2012, the three groups signed a Memorandum of Understanding (MoU) as a starting point for their cooperation. A first conference for European patient groups was organized in Brussels in 2012 and a first patient agenda on nutrition was formulated. This was followed in 2013 by the publication of the book 'Patient perspectives on nutrition', presented during a special nutritional session during the Annual General Meeting of the European Patients' Forum in Dublin.

His introduction was followed by Ceri Green, who introduced the participants into the backgrounds of nutrition and medical nutritional needs. Ceri started

her career as a dietitian and later as a nutritionist and is now Global Medical Affairs Director at Danone. Also the start, the structure and background of ENHA was explained as well as the aims and goals of the ONCA conferences, the first one in Brussels in November 2014 and the second one in Berlin in November 2015.



The third speaker Gaston Remmers, a cancer patient and Patient Advocate for Inspire2Live and one of the founders of Platform Patient and Food Netherlands. He is also a sociologist by training and in professional life working on the development of new food concepts in urbanizing societies. He spoke about the differences between personalised and common food and the development of personalised food systems. He stressed the importance to collect individual patient stories and experiences on nutrition and to analyze them on - in the beginning - a case-based experience to gradually higher levels of evidence and the search for scientists who are willing to work with patient groups along these lines. Gaston showed a short animation that explains the challenges ahead for personalised food (click here for an [English](#) version and here for [German](#) version). The Dutch Platform Patients and Food (patientenvoeding.nl) was started at the end of 2014 and since then met three times. The Platform also organized several high-level meetings with other stakeholders to explore in more depth new business models on nutrition and special needs from consumers as well as patient groups.

Active participation in the conference

With this knowledge in their conference package, the patient delegates actively participated in the conference and in the work of the national committees. On the second day, there was a second meeting of this group, focusing much more on the experiences and insights gained through the conference and suggestions for the future. At least, the delegates from Estonia and Hungary were asking for possibilities to start at their own country a national steering committee on undernutrition.

Furthermore, there was a request to not only focus on malnutrition-related diseases (MRD, meaning 'you have a disease and as a result you have a nutrition problem'), but also of disease-related malnutrition (DRM, meaning 'you follow an certain food pattern, and as a result you develop a disease'). Also, like in earlier meetings with patient groups, the topic of additives in food leading to diseases was brought forward. The partnership relationship between dietitians, therapists, doctors and patients, including their informal caregivers was brought forward as a topic to give more attention. Here, the risk of stigma, social impact, status difference between patient and caregiver and poverty was brought in. These issues build on an ongoing discussion within patient groups: unequal access to medicines between the former Eastern and Western countries as well as north - south, not only for access to medicines but also for optimal nutrition.

Future activities

The group will start contacting the International Alliance of Patients' Organisations (IAPO) especially for users of enteral and parental nutrition and the group aims to consolidate and expand its coherence and effectiveness as a Working Party from EPF and EGAN. In this context, the Working Party will also try to look to ways how personal experiences around nutrition can be built up or transferred into more evidence-based evidence.

Patients/elderly participants at the ONCA Conference in Berlin, 2015



Standing, fltr: Ivica Belina (Croatia), Maria Cevey (AGP, Spain), Gaston Remmers (Inspire2Live, Platform Patient and Food, The Netherlands), Karl Haberstig (EFNA, Germany), Dusan Baraga (EFCCA, Slovenia), Marek Lichota (Appetite for Life, Poland)

Sitting, fltr: Tunde Koltai (AOECS, Hungary), Cees Smit (EGAN, Platform Patient and Food, The Netherlands), Nicola Bedlington (EPF, Belgium, Inare Pomere (ECP, Estonia)

Klara Zalatnai (HOPA, SAHA, Hungary) was not present when this photograph was taken. Robert Johnstone (EPF/ International Alliance of Patient Organizations (IAPO) could not attend the meeting due to illness.

Cees Smit, December 15, 2015

List of E-mail addresses of the patients' representatives

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