

# Report of the 4<sup>th</sup> Optimal Nutritional Care for All Conference 2017

November 13 &14, Bled

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optimal nutritional care for all

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## **Executive summary** *Our vision: a world with optimal nutritional care for all*

#### 'Every citizen needs good nutrition and if malnourished or at risk of undernutrition is systematically screened and has access to appropriate, equitable, high quality nutritional care'.

Launched in 2014, the Optimal Nutritional Care for All (ONCA) campaign is a multistakeholder initiative, which aims to ensure optimal nutritional care for all European citizens.

Now in its fourth year the ONCA conference is organised and run by the European Nutrition for Health Alliance (ENHA), with the fourth conference held in Bled, Slovenia on the 13<sup>th</sup>-14<sup>th</sup> November 2017.

The conference was hosted by the Slovenian delegation and chaired by Professor Olle Ljungqvist (ENHA Co-Chair, ESPEN representative) and Professor Anne de Looy (President of the European Federation of the Associations of Dietitians, ENHA Trustee). Over 110 delegates representing 18 countries attended the conference including speakers representing the Slovenian Ministry of Health, European patient groups EPF and EGAN, and Igor Šoltes, a Slovenian Member of the European Parliament.

An additional pre-meeting led by Cees Smit (EGAN) was held for the patient group representatives attending the ONCA conference; patient groups also addressed delegates during a dedicated patient advocacy session on the first day of the conference, entitled '*The European Patient Agenda on Food and Nutrition: Best practices and proposals for the future*'.

At past conferences, country delegates had been asked to deliver presentations on their progress in advancing the aims of the ONCA campaign, via the ONCA dashboard system. However, at the 4<sup>th</sup> ONCA conference, delegates were asked to send their completed dashboards to the ENHA Secretary prior to arriving in Bled, so that these could be circulated and reviewed before conference proceeding; these can be downloaded from the ONCA website at: <u>https://european-nutrition.org/campaign/</u>

Following feedback from ONCA members, the 4<sup>th</sup> ONCA conference featured a number of break-out sessions dedicated to different topics, running concurrently throughout the conference.

In addition to the main plenary sessions, country groups were invited to send at least one delegate to each of the conference's five breakout sessions:

- Prevalence and cost benefit of nutritional care in the community: research project design, methodology, pilot sites
- Education and joint collaboration on guideline development and patient versions of guidelines
- Opportunities for future nutritional care innovation: making more of 5 euro a day
- Organisation and finance of the national campaigns
- Government involvement in ONCA and connecting with WHO EURO and EU nutrition initiatives

These breakout sessions featured panel discussions, followed by free flowing conversations where groups of 40 or so delegates representing all of the countries present exchanged comments and ideas.

Plenary sessions focused on educating healthcare professionals, the role of the patient, the role of pharmacists, assessment tools and the 2018-2020 ONCA strategy. A roundtable debate and question and answer session was also held for all delegates to pose their questions on media and stakeholder communications to an expert panel of public relations experts.

Presentations from the conference are available to view and download from the Campaign page of the ONCA website: <u>https://european-nutrition.org/campaign/</u>

#### Our vision: a world with optimal nutritional care for all

#### 'Every citizen needs good nutrition and if malnourished or at risk of undernutrition is systematically screened and has access to appropriate, equitable, high quality nutritional care'.

Launched in 2014, the Optimal Nutritional Care for All (ONCA) campaign is a multistakeholder initiative which aims to ensure optimal nutritional care for all European citizens through nutritional screening and follow up on a national level.

Now in its fourth year the ONCA conference is organised and run by the European Nutrition for Health Alliance (ENHA), with the fourth conference held in Bled, Slovenia on the 13<sup>th</sup>-14<sup>th</sup> November 2017.

It provides an opportunity for countries working on developing optimal nutritional strategies to come together to share best practice, ideas, gain inspiration and access contacts and expertise. This involves building and strengthening functional national stakeholder groups, creating momentum, trust and energy through a multi-country approach. As the driving force behind the campaign, ENHA works with its members and partners to engage with countries looking to develop national nutritional care plans and actively supports them to:

- Strengthen national alliances
- Assess national needs and drive the development of Key Performance
  Indicators
- Connect to national governments and European Organisations
- Tailor communications
- Engage and involve National Industry Groups

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A full attendees list can be found in the appendix.

#### Who is involved?

Eight countries comprised of multi-disciplinary and multi-stakeholder groups have been involved in ONCA since its inception in 2014: Croatia, France, Germany, Israel, Slovenia, Spain and Turkey. A further five countries joined in 2015: Belgium, the Czech Republic, Denmark, Netherlands and the UK. Ireland, Italy and Sweden joined in 2016, and membership is currently being considered for a further two countries in 2018.

#### Working with Patient Groups

ONCA has a long standing collaboration with the European patient groups EPF (European Patients' Forum) and EGAN (Patients' Network for Medical Research and Health), who are able to help countries to develop relationships with their national patient organisations. An additional pre-meeting led by Cees Smit (EGAN) was held for the patient group representatives attending the ONCA conference. The objectives were to introduce the ONCA concept and to discuss the importance of effective engagement with country stakeholders in order to provide the vital patient perspective to the development of national nutritional care strategy and plans.

#### **Conference Programme and reporting**

The two day conference included presentations on a range of topics linked to the ONCA campaign. Presentations from the conference are available to view and download from the Campaign page of the ONCA website: <u>https://european-nutrition.org/campaign/</u>

### **Day 1 – Conference session summaries and key points**

#### **ONCA Slovenia**

Mojca Gobec, Director General of the Slovenian Ministry of Health, opened the conference by welcoming ONCA delegates on behalf of the Slovenian Minister of Health.

She shared her conviction that 'the conference will be an excellent opportunity for

the fruitful exchange of best practice', and introduced delegates to the work that has been done by the Ministry to help ensure optimal nutrition for all Slovenian citizens.

Mojca described how nutrition has been a key focus for the Ministry for 15 years and that in 2015 the Slovenian parliament adopted a 10 year, multi-stakeholder national programme to address nutritional needs; this is being



personally coordinated by the Minister for Health.

The vision of the programme is to 'create an environment that provides healthy nutritional choices', and Mojca outlined the 10 pillars of the programme, which include facilitating healthy choices for the socially disadvantaged, and ensuring safe and healthy food via local production. Between 2017-2019 alone, the programme will support 20 separate initiatives with a fund equivalent to €800,000 per annum.

Milena Kovač, Chair of Slovenian nutritional group SLO-SPEN and Antonija Poplas Susič, Vice-Medical Director, Ljubljana Health Centre presented their three key priorities for extending the nutritional care pathway into primary care, namely:



1. To establish integrated nutritional care on all levels of the Slovenian health system

2. To increase the provision of nutritional educational activities, encompassing training for GPs, nurses, community nurses and medical students

3. To ensure that under and overnutrition is systematically screened, assessed, treated and monitored throughout the primary care clinical pathway. They also exhibited one of the three algorithms that they have developed to help healthcare professionals guide patients to the right care, support and treatment within the primary care clinical pathway.



Nada Rotovnik Kozjek introduced ONCA delegates to the school she founded and currently leads, the School of Clinical Nutrition.

This joint initiative delivered by SLO-SPEN and the Ministry of Health provides postgraduate training to healthcare professionals through modules covering nutritional processes, knowledge and terminology.

Nada also informed delegates that she has recently translated the ESPEN Blue Book into Slovenian, for the benefit of all Slovenian healthcare professionals.

Finally, Tajda Božič, a Slovenian medical student, presented on ONCA's future in

Slovenia. She told delegates of her disappointment when she realised that there were no student projects on clinical nutrition, and how she and three of her colleagues established the 'Happy Stomachs' educational programme, having seen the provision of nutritional support in primary care settings in the UK.

The programme informs medical students about clinical nutrition, and Tajda



stressed that the 'main thing we can do for clinical nutrition is to educate health professionals', before concluding that this is the first year that Slovenian medical students can pick clinical nutrition as an element of their curriculum.

# The European patient agenda on food and nutrition: Best practices and proposals for the future

The next plenary session, moderated by Cees Smit (EGAN) and Dušan Baraga (Slovenian patient group) focused on the patient experience, and the work done by patients and patient advocacy groups across Slovenia as well as beyond, across Europe.



ONCA delegates heard from Sonja Jamnikar about her personal experiences with parenteral therapy, and the impact it has had on her life.

Her powerful account of how parenteral therapies and the support of Nada Rotovnik Kozjek and her team allowed her to fight back from a diagnosis of gastrointestinal dysfunction, walk again and

live her pre-diagnosis life again reinforced the importance of the campaign to ensure optimal nutritional care for all.

Delegates also heard from Kristina Modic and Brina Žagar from the Slovenian Lymphoma and Leukaemia Patient Organisation, who presented on a programme being run at the Department of Haematology, Ljubljana University Medical Centre for the comprehensive rehabilitation of patients with blood cancer. The programme consists of three key modules: physical exercise, psycho-social support and nutrition.

Mojca Senčar and Tania Španic representing Europa Donna Slovenia also presented on the role of the ONCA campaign in supporting breast cancer patients, and how ONCA and Europa Donna can work together to raise awareness about the impact of nutrition on the care of breast cancer patients.



Next, Gaston Remmers shared the outcomes of the EPF/EGAN/ONCA meeting, held in Brussels on 29<sup>th</sup> June 2017. Gaston gave the background on the integral role that patient groups have within the ONCA campaign, and explained the work of the 30 participants from across Europe who gathered in Brussels for the meeting. Key recommendations to come from the meeting include a focus on prevention via optimal nutrition throughout the life-cycle, and strengthening collaboration between key stakeholders.



Cees Smit also talked about the relationship between EGAN and the ONCA campaign, and how these two groups can work together to renew the EU patient agenda in the years to come. Cees outlined opportunities for collaboration including the development of layguidelines together with ESPEN, MNI, EFAD and EUGMS; the creation of educational materials, including patient stories; and joint citizen science initiatives.

Finally, Dušan Šuput, former Dean of Ljubljana's medical faculty talked about the significance of the implementation of a nutrition curriculum for medical students, and the need to educate students on the impact that optimal nutrition can have on patient care and outcomes.

Keynote presentation – From farm to fork: How locally produced food can be more sustainable and meet nutritional needs of the vulnerable *Igor Soltes, Member of the European Parliament, Slovenia* 

Delegates heard from Igor Soltes, Slovenian Member of the European Parliament who spoke about how agriculture and food need to be seen as part of the solution to problems around nutrition and health.

He focused on how promoting the consumption of locally produced food



ensures a shorter time between farm and fork, and therefore more nutrient-rich food for consumers. Igor reminded delegates that we all need to work together for a healthier future for all, and praised the ONCA conference for being an opportunity where different groups can gather to achieve that aim.

#### Increasing the impact of ONCA

This session began with a presentation from Josep Antoni Tur Mari, Pharmaceutical Group of the European Union (PGEU), before delegates split up to attend one of two

break-out sessions: one entitled 'Prevalence and cost benefit of nutritional care in the community: research project design, methodology and pilot sites', and another entitled 'Education and joint collaboration on guideline development and patient versions of guidelines'.



Josep Antoni Tur Mari discussed the role of European pharmacists in ONCA, particularly in relation to the pharmacist as a health agent.

He noted that nutritional advice is part of pharmaceutical advice, and that Plenufar (Plan de Educacion Nutricional por el farmaceutico) surveys have been assessing nutritional habits and raising awareness

on the importance of nutrition for health since 1992.

In the break-out session entitled 'Prevalence and cost benefit of nutritional care in the community: research

project design, methodology and pilot sites', Cornel Sieber (ENHA Trustee) and Marian de van der Schueren, NutritionDay led the group discussion.

Marian highlighted that 90% of malnourished patients live in the community, and attendees agreed that there is a need to identify this cohort.



Attendees considered how best to identify them; the questions to ask to determine malnutrition; and possible partner organisations. Attendees also agreed that given the interest in this area, a research group should be established, and Marian de van der Schueren invited ONCA members to get in touch with her to develop the programme at Marian.devanderSchueren@han.nl.

The 'Education and joint collaboration on guideline development and patient versions of guidelines' saw Cristina Cuerda (Chair, ESPEN Education programme), Cees



Smit (EPF/EGAN representative), Simon Gabe (BAPEN) and Robert Johnstone (IAPO board member) discuss medical guidelines from a professional and patient perspective.

'Emancipation' featured prominently; emancipating both those with scientific knowledge, and patients.

Discussants emphasised that

guidelines should be jargon and acronym free, and that medical professionals should give people permission to 'listen to their own bodies' and experiment to find practical solutions that work for them.

#### Bringing good nutritional care into the public arena

The final session of the first day featured a presentation from Joost Wesseling, ONCA Communications specialist, followed by a roundtable discussion on how to make the media and key stakeholders aware of the campaign.

Joost noted that feedback gathered in the 2017 ONCA survey found that the ONCA message had at times been diffuse, and that limited resource amongst members

made achieving impact difficult.

Acting on ONCA member feedback, Joost re-introduced delegates to the new, stateof-the-art online platform that has been developed for ONCA members to share good practices quickly and simply via <u>www.european-</u> <u>nutrition.org</u>.



The roundtable session brought communications experts from around Europe together to discuss their nutrition-related media work, and public relations more generally.

The panel consisted of ONCA Communications specialist Joost Wesseling; Care with Stars representative Marcel Smeets; ONCA Croatia representative Darija Vranešić; Appetite for Life representative Marek Lichota; Slovenian journalist and patient Mojca Lavrenčič; and PR professional in the Slovenian Ministry of Cultural

Affairs, Boŝtjan Tadel.

Together, the panel discussed identifying target audiences, setting communications goals, utilising different communications channels, making communications attractive and establishing a dialogue with journalists and key stakeholders.



touch', e.g. case studies and patient stories.

Questions from the floor included how journalists select stories to focus on, and what they find attractive. Mojca shared that the number of people affected by a health problem is a factor (although a rare condition can also make for an interesting story) and emphasised that stories needed to have the 'human

#### Tuesday, 14<sup>th</sup> November

The second day of the conference was opened by Regina Roller-Wirnsberger, Co-Chair of the EIP Active and Healthy Ageing Nutrition Group, who presented on the EIP AHA's goal of ensuring an additional two healthy life years for all European citizens by 2020.

She explained the group's headline objective of developing and implementing



sustainable multimodal interventions for the prevention and comprehensive management of functional decline and frailty, and potential funding prospects for ONCA member groups.

#### Malnutrition and frailty: definition and assessment tools



Next, Tommy Cederholm, Chair, ESPEN international group delivered a presentation on the Global Leadership Initiative on Malnutrition (GLIM), a joint effort by ESPEN, ASPEN/AND, FELANPE and PENSA to modify the 'Delphi' process so that a diagnosis of malnutrition requires at least a phenotype criterion and an etiology criterion.

Josefa Kachal, Israeli Ministry of Health delivered a presentation entitled 'Application of MRSA assessment tool for sarcopenia in the community - pilot project in Israel'. Josefa argued that as sarcopenia is still under-diagnosed and undertreated, the population to be screened for sarcopenia needs to be pre-screened with an easy-touse and broadly available instrument.

Josefa also noted that after a request issued to all ONCA member states, the Netherlands forwarded the MRSA, which was then approved by the Israeli Ministry of Health and translated into Hebrew, Arabic and Russian.

Next, Assist. Prof. Dr. Mojca Gabrijelčič Blenkuš, Slovenian National Institute of Public Health presented on the work of the PANGeA (Physical activity and nutrition for healthy ageing) project, consisting of the AHA.SI project (Longevity strategy for Slovenia) and the JA Advantage initiative (defining frailty at an EU level).



Mojca explained how the AHA.SI project seeks to prolong employment and delay retirement; encourage active later lives; and integrate health and social care at a local level. She also went into the details of the JA Advantage initiative, a bid to establish a common European model to tackle frailty.

In the ensuing Q&A session, when asked what nutritional-related initiatives resonate with Ministries of Health, Tommy Cederholm urged delegates to combine nutritional issues with physical activity, as most people have a more positive attitude toward physical activity than nutrition.



Josefa was asked if it would be possible for other ONCA member countries to expand the Israeli screening programme. Josefa responded that the results of the pilot's evaluation would be disseminated to all ONCA members within the next few months.

#### **Break-out sessions**

Delegates then attended one of three break-out sessions: 1. Organisation and finance of the national campaigns. 2. Opportunities for future nutritional care innovation: making more of 5 euro a day 3. Government involvement in ONCA and connecting with WHO EURO and EU nutrition initiatives.

In the 'Organisation and finance of the national campaigns' session, industry representatives agreed that the ONCA campaign allows industry to build closer relationships with patients and healthcare professionals. They also noted that it acts as a knowledge exchange of good practice, and is viewed as a campaign to convince key stakeholders of the value and



benefit of optimal nutritional care for all.

In the session 'Opportunities for future nutritional care innovation: making more of 5 euro a day', Claude Pichard (ENHA Trustee), Gaston Remmers (EPF/EGAN representative), Marcel Smeets (Care with Stars representative) and Dr Laure Cloarec Blanchard (Project restauration et gourmande responsable, FNAQPA,

France) shared advice, such as controlling waste to reduce cost which can be reinvested to improve the quality of food.

Session attendees also noted that the attitude of those serving food must be positive to encourage those with low appetites, and Claude Pichard noted that 'Food is not an option: it is mandatory for life, and mandatory to help cope with disease'.



In 'Government involvement in ONCA and connecting with WHO EURO and EU nutrition initiatives', Ronit Endevelt (Israeli Ministry of Health), Anne de Looy (European Dietetic Action Plan) and Regina Roller-Wirnsberger (Co-Chair, EIP AHA Nutrition group) discussed how to raise the profile of nutrition from a

geriatric perspective; the virtues of focusing efforts locally and nationally; how to focus attention on malnutrition when its effects are not as visible as obesity; and how to encourage collaboration between key stakeholders to gain Government buy-in.

#### **Closing plenary**

Luca Gianotti, Italian ONCA representative briefly presented on the cancer patients' bill of rights for appropriate and prompt nutritional support, a bill written by a group of Italian patients, medical professionals and researchers to ensure that cancer patients' receive the nutritional support they need.



Luca explained that the bill has been submitted to the Italian Ministry of Health, who are now awaiting the ECPC AGM to approve the English version in an attempt to give all European cancer patients this right.

Cees Smit, EGAN representative, gave feedback from the patient sessions that had been held at the conference. He shared that whilst the patients in attendance were

empowered enough to share their experiences, many are not, and that there is a lack of recognition of nutrition in medicine as a whole. The group discussed how to work with healthcare professionals, and the different levels of support needed at different stages of care.

ENHA General Secretary Frank de Man reiterated that the ONCA campaign will continue to step-up efforts to improve the communication of good practices and facilitate knowledge exchange throughout Europe, and beyond. Anibal Marinho, Portuguese ONCA representative formally invited all ONCA members to attend the 2018 ONCA Conference in Sintra, Portugal on 12-13<sup>th</sup> November 2018, and Cornel Sieber, ENHA Co-Chair offered reflections on the 2017 conference.

He noted that ONCA has become a real network, looking ahead to a bright future.

He observed that a number of impressive projects are being undertaken by ONCA member states, and that the conference demonstrated that it is only when patients, industry, healthcare professionals, policy experts and PR professionals work together that we can bring forward the issue of nutrition.



# Appendix

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