‘EU Patient groups & the relevance of nutrition’

Report of the first invitational conference for EU Patient Groups on nutrition, organized by ENHA, EPF and EGAN, July 4, 2012, Brussels

Foreword

Nutrition is fundamental to life and good nutritional care can be the difference between living well and living with ill health. However, for some ill health has become a way of life and for those with long term conditions, being a patient is a daily experience. That does not mean that it has to be a negative experience. For many living with a long term condition it is about getting information, understanding and support to tackle the issues they face from day to day living. Patient groups have a key role to play in this support mechanism.

During 2012, EU patient alliances European Patient Forum (EPF) and European Patient Network on research (EGAN) have joined forces with the European Nutrition for Health Alliance (ENHA) to raise awareness of the role that nutrition has to play in managing long term conditions and maintaining optimal health and quality of life for all. We are all EU citizens and regardless of our patient status and whether we are a patient today or become one tomorrow, nutrition has a key role to play in ensuring our health and well being.

This report is of the first joint conference held by EGAN, EPF and ENHA on July 4, 2012 in Brussels to discuss the role of nutrition in the prevention, treatment and management of a range of patient conditions. The conference included contributions from a number of EPF and EGAN members and aimed to establish a set of recommendations and actions for the group to develop as we continue to work together with the aim of improving nutritional care for all.

An outline of the day's presentations is given, followed by a hyperlink to the presentation and if possible a reference to the relevant website of the speaker. After some of the outlines, questions and answers or discussion follow. At the end of the report, the programme as well as a list of the participants is included.

The report starts with the full set of recommendations agreed to by conference delegates and further information about the organisations involved.

We have chosen for a quite extensive way of reporting, because so far there is not so much material available on the issues that play a role for EU patient organisations in relation to nutrition. For that reason, we made the choice for an extensive report and distribution through the website of the organizers.

The organizers of the conference, have also concluded that this topic needs more attention and a possible second conference will be held in May 2013 in Dublin. We also aim to make a more extensive booklet on several of the issues raised in this report, that also should be available in the spring of 2013.

We would like to thank Lisa Wilson of the International Longevity Centre in London for writing this very informative report.

On behalf of the organizers,

Frank de Man, ENHA	Nicola Bedlington, EPF	Cees Smit, EGAN
Olle Ljungqvist, ENHA	Laurène Souchet, EPF	Chantal Gill'ard, EGAN

Recommendations of the first invitational conference for EU Patient Groups on nutrition.

Following the presentations and discussion delegates had identified seventeen key recommendations for further action. These were presented to the group for approval as a part of the actions to follow from the meeting and to ensure that patient groups working together with ENHA could have a focus for future action on nutrition. The recommendations have been classified Into categories that may play a role in the EU nutritional agenda.

a) Nutrition and patient associations

1. Patients and their associations must be seen as key players to drive that quality and equity of care is ensured.
2. Find a collective agenda and increase the engagement and interaction between patients, industry and other stakeholders
3. Knowledge on nutrition must be integrated into patient peer support and management.

b) Nutrition and awareness

4. Dieticians must be a part of a multi-disciplinary health providing team adopting a holistic view on health and it is the responsibility of patients to take the lead in their health.

c) Nutrition and medical education

5. There is a need to improve medical education so that it includes nutrition.
6. Nutrition education must start for all at an early age.

d) Nutrition and health

7. Treatment and management of disease as well as identification of need and nutritional care must be considered individually.
8. Nutritional equivalency in substitute products is vital in ensuring good overall nutrition.
9. It is important to keep a holistic view of disease; nutrition is a part of that view and can have a positive impact on patient health.

e) Nutrition and regulatory requirements

10. Clear labeling of food is fundamental in supporting patients to manage their conditions.
11. Guaranteed access to safe and nutritional food is a right and essential for those who have no choice about what they eat e.g. in institutions.

f) Nutrition and disease specific information

12. It is essential that the importance of dental care in nutrition and its role in ensuring good health, especially in older age is not forgotten.
13. Routine nutritional screening of at risk groups is essential in preventing malnutrition among patients.
14. The area of nutrition in pregnancy must be highlighted as a key influencing health and disease prevention.

g) Nutrition and research

15. There is a need for further research on the impact of nutrition in retinal disease patients.
16. Vitamin D supplementation should be routine for those over 60. It is a cheap, effective intervention and can prevent deficiency and disease as well as presenting an achievable target.
17. Any further research carried out must be supported by patient groups and driven by their needs.

h) Nutrition and reimbursement

18. Innovation is needed in developing products and support for less well known metabolic diseases. Existing products need to be maintained and supplements need to be recognized for their health improving capacity and thus where appropriate reimbursed. Likewise relevant Medical Nutrition products that meet a clear medical need should be reimbursed.

Conclusions

The presentation of these recommendations further emphasized not only the breadth of work patient groups undertake, but also the areas in which groups can work together to increase awareness of the importance of nutrition with their members, funders, EU partners and other groups. In conclusion, nutrition is a cross cutting issue that affects all citizens and incorporates a wide number of stakeholders. By engaging with these stakeholders and acting on the recommendations, it is possible to change the way nutrition is viewed, used and understood, by patients, carers, health and social care professionals and the general public.

About EGAN - www.egan.eu

The Patients Network for Medical Research and Health EGAN is an alliance of both National Genetic Alliances and European disease specific patient organisations with a special interest in genetics, genomics and biotechnology. Especially, but not only, genetic disorders are represented within EGAN.

EGAN is working for a voice in research and health policy and seeks a world in which genetic and other serious diseases are understood, effectively treated, prevented and the people affected supported.

About EPF - www.eu-patient.eu

EPF is the umbrella organisation of pan-European patient organisations active in the field of European public health and health advocacy.

EPF was founded in 2003 to become the collective patients' voice at EU level, manifesting the solidarity, power and unity of the EU patients' movement. EPF currently represent 51 patients organisations – which are chronic disease specific patient organisations operating at EU level and national coalitions of patients organisations.

EPF's vision is high quality, patient-centred, equitable healthcare for all patients throughout the European Union.

EPF facilitates exchange of good practice and challenging of bad practices on patients' rights, equitable access to treatment and care, and health-related quality of life between patient organisations at European level and at Member state level.

About ENHA - www.europeannutrition.org

The European Nutrition for Health Alliance works with key stakeholders to improve nutritional care across Europe by actively promoting:

1. Implementation of nutrition risk screening across Europe
2. Public awareness
3. Appropriate reimbursement policies
4. Medical education

Our research demonstrates the impact of malnutrition on both individuals and health and social care systems. Recent research by the European Nutrition for Health Alliance found that:

- 20% of care home residents were malnourished and a further 30% are at risk
- Malnourished patients spent three additional days in hospital per hospital stay;
- Those diagnosed with nutrition problems in the community consumed an additional £1003/€1,128 in healthcare resources over six months compared to a similar well-nourished patient including twice as many general practitioners visits;
- Malnutrition in the community was an independent predictor of mortality regardless of age and co-morbidity.

With our large network of members, partners and expertise giving a truly European perspective, ENHA is at the forefront of developing good nutritional practice.

Opening by Chantal Gill'ard, EGAN

Chantal Gillard opened the meeting as morning Chair and moderator, welcoming all participants to the event. General introductions were made by all delegates giving an overview of the breadth of organisations present.

Robert Johnstone, Board member, European Patients' Forum, EPF

In his welcome words Mr. Johnstone emphasized the unique nature of the conference, being the first of its type on an EU level.

The European Patients' Forum organization works within the particular and diverse needs of patients with chronic disease and believes that patients and their organisations are the most important part of finding solutions to patient care, disease management and treatment.

The presentation outlined that the patient experience of healthcare provides insight into the gaps in nutrition. A holistic patient centred approach to healthcare is needed to ensure all individuals get the appropriate healthcare for them.

He stressed that the aim of the conference was to gain an understanding and awareness of the urgent need to put adequate nutritional care into healing processes and provided an opportunity to raise additional issues of relevance to patients. However, the need for concrete tools and support organisations to work on nutrition remains as well as support on reimbursement of diets and nutrition among other issues.

In conclusion, the overall aim of the conference was to address the EU patient nutritional agenda, to make recommendations on nutrition for the patient community and see those becoming action. To achieve this it is necessary to coordinate solutions, address age-related undernutrition and look at nutrition on a national level through national implementations plans already being developed by ENHA.

General introduction to the topics

1. The relevance of nutrition for EU patient groups, Cees Smit, policy advisor EGAN

The first presentation of the day outlined the way in which patient groups are organized in the EU and the links between patient groups and nutrition.

It suggested that patient groups can be considered on three levels: Micro (disease specific, Meso (specific to larger diseases e.g. cancer) and Macro (involving national umbrella groups). In terms of definitions, the EPF is the umbrella group for the European 'macro' groups, providing one point for the EC to direct question.

Patient groups started with education, information, peer support and lobbying as their main areas of interest (Patient 1.0). In the last 20 years they have developed through the internet, exchange of information and social media (Patient 2.0). The aim for the last decade and the present is to work together with researchers, industry and patients to address unmet medical needs (Patient 3.0).

Patient groups in the EU context
There are no specific policies regarding the role of patient groups in specific member states. The EC actively asks (through EPF) for opinions, but independent financing of patient groups remains a problem and therefore they are starting to also respond to EU themes such as Active Ageing in order to widen opportunities for funding.

Patient groups have a unique innovative power as their experiences are joined. Patients working together and having mutual experience and interest can support research and provide materials (e.g. DNA, tissue etc. for research purposes). In addition, groups can be involved in fund-raising, sharing data and organizing co-operation both within and between groups (physicians, rsearchers, companies), especially for the long term.

With regards to nutrition, EGAN have been involved in genetics and nutrition for several years, particularly in the area of preconception and pregnancy.

Clearly the relevance of nutrition to patient groups differs between groups and it is important to understand the role of nutrition in prevention, treatment and management of disease. It is vital to ensure that information is widely available across all patient groups. In addition to working in partnership, specific groups must be active participants in the development of nutritional aspects of policies and products e.g. Coeliac disease.

However, it is also necessary to consider the role of the patient versus that of the consumer, as all patients are both. As patients we are looking to get the best care, best doctor, best hospital and best treatment possible. As consumers however we are looking for appropriate insurance policies with low premiums and often high own risk, as consumers speculate on not becoming ill.

Unfortunately consumer groups are often critical of patient groups due to our contacts with the pharmaceutical industry especially with regards to funding. We need to work to dispel these preconceptions and work more closely with other groups who represent our interests.

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2. *Medical Nutrition: the interface between food and pharma, Ceri Green, Nutricia and MNI (Medical Nutrition International Industry)*

MNI is a trade association established in 2005 to bring together the major industry representatives of the Medical Nutrition industry to optimise patient outcomes by working together for a common goal. The aim is to engage at all levels, translating science into standard practice.

MNI's strategic agenda involves a strong focus on malnutrition awareness and screening as well as pulling together the evidence base for malnutrition and oral nutritional supplementation (ONS). The 3rd edition of the evidence core on ONS will be launched at the 2012 ESPEN (European Society for Clinical Nutrition and Metabolism) conference in September. In addition, MNI also works to align its objectives with other relevant stakeholders (including ESPEN, EUGMS and ENHA) and to proactively manage the regulatory environment.

Nutrition has a key role to play in health and disease and must be a part of any public health strategy. It plays a crucial part throughout the lifecycle in growth, development and avoiding disease. However for some a balanced diet is either not possible or not enough. In these cases it is possible to improve patient outcomes through Medical Nutrition, both in managing disease-related malnutrition and through managing disease (e.g. metabolic disorders).

Medical Nutrition is prescribed or recommended by health care professionals and contains unique compositions of specific nutrients tailored to meet patient needs. As a result Medical Nutrition sits at the interface between food and pharma. This is clearly demonstrated by the regulatory framework.

Food, functional foods, vitamin and mineral supplements as well as enteral nutrition (Medical Nutrition given orally or via a tube into the stomach or small intestine) are governed by food legislation, and in the case of enteral nutrition by a specific piece of food legislation known as "dietary foods for special medical purposes". Parenteral (intravenous) nutrition, which is also Medical Nutrition, falls under pharmaceutical legislation. Thus Medical Nutrition is both distinct from and similar to both food and pharma. Like food, Medical Nutrition is nutrient-based, is a mixture of nutritional components, has a broad spectrum of effects and if used correctly has minimal side effects. On the other hand, like pharma, Medical Nutrition is designed to meet a medical need, it must be used under medical supervision, it is presented in formats to maximise compliance, it is clinically tested and is intended to impact on patient outcome. This makes Medical Nutrition unique in terms of its application.

However, awareness of the benefits of Medical Nutrition and of the range of problems it can address is low. MNI aims to drive nutritional care into patient and disease management. Identification of patients at nutritional risk who will benefit from Medical Nutrition is a key step. Other key success factors are an evidence-based approach, integration of Medical Nutrition into nutrition guidelines, and stakeholder involvement at all levels. MNI looks forward to further collaboration with patient groups on both the EU and national level.

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Questions and discussion related to presentation 1 & 2

Regarding compliance we need a greater effort from manufacturers in offering a diversity of flavours.

It was reported that current research is dominated by taste and format improvements. MNI companies are working to make products more palatable and be offered in different formats. This conference provides us with an opportunity to work closer with patients and better incorporate their views in future product development.

Why are some products lost from reimbursement or not available? E.g. yogurt based products are unavailable through reimbursement when milk-based ones are.

The challenge for industry is that each country is different in terms of its reimbursement framework and we should look to patients groups for support on how to ensure this type of exclusion of products does not occur. Both industry and patients also need to engage more fully with insurance companies to tackle these types of issues.

Cees Smit reported that he is involved with the appraisal committee in the Netherlands for health insurance. This group includes representatives from six sections of society and is comparable to NICE in the UK. The group judge which products should be included in insurance documents; including food, dietary supplements and medical nutrition. Three to four years ago, dietitians lobbied for inclusion of medically indicated nutritional supplements. This was then included, but a few years later dietary advice was taken out of the insurance package. The patient perspective on treatments and what should be reimbursed is therefore desperately needed.

What process is needed to engage with insurers and ministers?

Jan van Ermelen (as a representative of the insurance industry) responded that the difficulty is that many EU countries have reimbursement policies in silos with interventions aimed at short term conditions. What is needed is a change from a medical to a holistic care model. Currently the health care system is unwilling to reimburse for a patient centred model as they do not have a budget which is patient centred. The evidence, policy and multi-stakeholder environment needs to be considered, the latter two of which are influenced by the healthcare system which is traditionally very conservative and resistant to change. However, there is confidence within the health insurance industry that new models can be developed with patients, insurance, healthcare and industry all involved.

3. Older persons, frailty and undernutrition, Prof. Jean Michel, chair EUGMS

The European Geriatric Medicine Society was founded in 2000 with the aim of developing geriatric medicine in all EU countries and encourages the provision of geriatric services to EU citizens. It promotes education, continuing professional development, research and high quality evidence based geriatric based medicine.

Prof Michel outlined how ageing and nutrition is a uniquely individual process. Throughout early life stages and along different life stages nutrition can greatly interfere with the ageing process. A theory known as the obesity paradox of old age has shown that with increasing weight loss the probability of survival decreases. In addition, with increasing age the risk of developing serious nutrition deficiencies increases. The presence of disease also increases nutritional deficiencies and so in older age the risks of compromised nutritional status are much greater.

The risk factors for undernutrition in older people can be summed up via the acronym **SCALES:** ***S****adness*, ***C****holesterol* (<160mg/l – low), Albumin (<4g/l – low), ***L****osing Weight*, ***E****ating problems* and ***S****hopping problems*

Undernutrition is defined as >5% of body weight lost in a month or 10% in 6 months. It is defined as severe undernutrition if weight loss exceeds 10% of body weight in 1 month or 15% in 6 months. Body Mass Index (BMI – height to weight ratio) as a measure of weight loss is traditionally used in younger people with a score of below 18 kg/m^2 indicating risk of undernutrition. However in older people a score of <20 kg/m^2 is used as the cut off as BMI does not provide information on body composition and there is both an increase in body fat and a decrease in height with age which will affect any measurement taken. The consequences of undernutrition in older people include immunodeficiency problems, infections, sarcopenia, increased falls and an increase in decubitus ulcers.

Frailty, sarcopenia and nutrition
Frailty is not solely related to older age. It is a lifelong process and a transitional state from robustness to dependency and ultimately death. Physical frailty affects 17% of people aged >65 years in Europe and is linked to both nutrition and sarcopenia. Sarcopenia is a progressive and generalized loss of skeletal muscle mass and strength or function with a risk of adverse outcomes such as physical disability, poor quality of life or death. Several studies were presented which highlighted the risks associated with undernutrition, sarcopenia and frailty (available in presentation slides). In summary, severe sarcopenia is synonymous with physical frailty, but it is never too late to reverse the process. This can be done with muscle strengthening exercise which has been found to increase skeletal muscle mass by up to 44% in some individuals. In addition, supplementation with vitamin D alongside a healthy diet can help. The key is ensuring adequate intake of protein (which is what forms muscle).

Key messages:

- All individuals age individually
- Nutrition acts in every step of the life process
- Exercise both complements nutrition and is essential in its own right
- Sarcopenia and frailty can be prevented and/or delayed.

Recommendation: Patients are a part of the solution and need also to be involved in the nutrition and exercise aspects of processes of treatment and management.

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4. **Link to presentation -** ***An overview of the European nutrition and health arena, prof. Olle Ljungqvist , ENHA, Sweden***

Professor Ljungqvist demonstrated the importance of considering nutrition as a part of overall health and the risks that undernutrition poses to the individual, carer and society. At any given point in time, > 3 million people in the UK are malnourished or at risk of malnutrition, most of whom are in the community. This translates to > 33 million people in Europe.

The presentation emphasized the importance of raising awareness of the risks undernutrition among patients including increased infections and complications, increased hospitalization, longer hospital stays and increased risk of death. The importance of routine screening across all care settings was outlined and several examples were given of successful initiatives in Europe where member states had adopted a multi-stakeholder approach to addressing the challenges of undernutrition.

One example was in Denmark where from the mid-nineties a joint venture between the Danish Veterinary and Food Administration, the Danish National Board of Health (NBH), politicians and an advisory board under the auspice of DAPEN (Danish Society for Clinical Nutrition and Metabolism) has developed a strategic multi-modal approach to fight malnutrition including:

- ✓ The initiative "Better food for patients"
- ✓ National guidelines
- ✓ Accreditation of all Danish hospitals regarding undernutrition.

The importance of multi-stakeholder and multi-disciplinary approaches to tackling malnutrition was emphasized and patient groups were invited to join the groups already developing a synchronized agenda through the European Nutrition for Health Alliance.

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Questions and discussion related to presentation 3 & 4

It was observed that one difficulty with implementing screening is how costly it is in clinical settings.

Olle Ljungqvist responded that screening need not be an expensive process. There are a number of obvious indicators of risk e.g. weight loss, lack of appetite and so we need to educate professionals to keep these in mind when examining patients. There is also good evidence from simple clinical measures such as feeling the arm to assess nutritional reserves. Self-testing is also a possibility, for example in Northern Ireland, simple self-screening tests are being investigated. He agreed that simple tools which can be easily used are very important.

It was suggested that self testing would only work with already those engaged or interested in nutrition. For those who don't have the interest or ability to test themselves, they won't and these people are therefore at risk. This could be a limitation of self-screening.

It was agreed that what is needed is both self-testing and screening by healthcare professionals. This has been done through legislation in Japan. In Denmark, as a result of the intervention they put in place, 86% of patients coming into hospital already had a nutritional plan.

It was agreed that nutrition policy could be looked at and implemented in different ways. Not screening for disease-related undernutrition would mean missing the opportunity to help people now.

It was observed that the group needed to think about driving hard end points and recommendations. I.e. what is meant by screening? Should all those retiring visit their GP for a health check? For this the cost would be prohibitive meaning perhaps work need to be done to prevent malnutrition.

It is well documented that once children reach their teens, research shows that it is not possible to persuade them to change their diets and attitudes. Early interventions around improving understanding of the role of diet and good health throughout the lifecycle may be beneficial. The importance of nutrition as a general public health education issue was highlighted. It is important to start raising awareness with children in schools. Success has happened elsewhere for example with the 5-a-day message and environmental issues.

Cees Smit highlighted the need to think about what the implications of undernutrition could be for those with a disease or disability. The ageing process starts earlier in these groups so the message needs to go out to middle aged groups not just older people about nutrition risk in older age. In combination we need to start research younger to ensure appropriate information and compliance.

It was agreed that as ageing is relative and individual it is vital to look at different models is ageing and risk, to help is understand what is happening as those with long term conditions who could be at risk sooner.

Afternoon session moderator and chair: by Eibhlin Muhlroe (IPPOSI, Ireland)

Specific EU Patient Groups Experiences

Eibhlin Muhlroe started by emphasising her interest in nutritional aspects of health and expressed her interest to learn more about this topic and support for the further exploration and actions in this area. Since 2007, Eibhlin became the first CEO of the Irish Platform for Patients' Organisations, Science and Industry (IPPOSI).

5. The Asthma/COPD experience, Susanna Palkonen, European Federation of Allergy and Airway Diseases Patients Association, EFAnet and Vice-President EPF, Belgium

EFA net is the website of the European Federation of Allergy and Airways Diseases Patients Associations (EFA). There are over 100 million people with asthma, allergy and chronic obstructive pulmonary disease (COPD) in Europe. EFA is a European network of patient organizations that was founded in 1991, prompted by the belief that an international organization formed by European patients associations that share the same aims would be a more effective way to serve the needs and safeguard the rights of patients and their carers.

EFANET represent patients specifically and have a wide view of treatment and care ranging from smoking cessation support, food labelling, patient support and education and will now include nutrition as well.

An example of the need for nutritional care in patients with airway diseases was given in the form of patients with Chronic Obstructive Pulmonary Disease (COPD). Those experiencing COPD burn ten times as many calories breathing as an average person and there is a link between COPD and frailty risk as maintaining a healthy weight can be a challenge.

Asthma and nutrition
In cases of asthma, overweight can be a risk especially in children who don't exercise as the steroids used in medication can lead to weight gain. There are many unproven links which have been suggested between asthma and diet including maternal diet and that of early childhood or a change in diet. Antioxidants and polyunsaturated fatty acids have been suggested as being beneficial but as yet there is no evidence in clinical settings.

The key issue in asthma is ensuring a healthy balanced diet as specialist diets are not required. It is vital to focus on what can be done rather than what cannot.

Other issues regarding allergy marketing were also highlighted. This can be misleading and labeling is often not clear enough. The introduction of new foods can lead to new allergies and this needs to be explored further.

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6. *The experience of people with metabolic disorders, Hanka Meutgeert, VKS (Adults, Children and Metabolic disorders), The Netherlands*

VKS is the Dutch Umbrella organization for metabolic diseases, representing patients with more than 185 different metabolic diseases.

VKS focus on inherited metabolic diseases, which are unrelated to the digestive system. They are caused by an inherited defect of an enzyme which has a biochemical role in the cells of the body. There are many different types of metabolic disorder all of which are very rare, but as a group affect approximately 1 in 2000 Europeans.

In the case of metabolic disease, nutrition can be used to moderate symptoms in conditions such as PKU. However the diet is very different to what is considered healthy in order to avoid the consequences of the metabolic defect. In addition, secondary problems may arise due to the need for this type of diet including osteoporosis, short stature or psychological effects.

Phenylketonuria (PKU) is a disease in which one amino acid (phenylalanine) cannot be metabolised and so must be avoided in the diet, however as protein is needed to grow, children diagnosed with PKU are given special protein mixtures based on amino acids which are devoid of phenylalanine.

Patients need specialist diets and companies which are prepared and able to bring them to the market. Unfortunately as the condition does not affect as many individuals as other conditions there are problems with getting products made and there is little innovation.

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7. Coeliac disease, Sarah Sleet, Coeliac UK and the Association of European Coeliac Societies (AOECS), United Kingdom

Coeliac UK is the leading charity working for people with coeliac disease and dermatitis herpetiformis (DH). Their mission is to improve the lives of people with coeliac disease through support, campaigning and research.

Over five million people in the EU are thought to be affected by coeliac disease. It is a very under recognised condition and often not recognised by GPs.

Coeliac disease is an autoimmune disease triggered by gluten found in wheat, barley and rye (some people are also sensitive to oats). It is a lifelong condition and the only treatment is a strict gluten free diet.
The problem for many people is that wheat is widely used in processed foods such as mayonnaise, yogurt and sausages to add bulk and carry flavour making it extremely difficult to be sure foods are gluten free.

High risk areas include those where there is no choice in food available and little information about its content. These include hospitals, care homes, schools and nurseries and workplace canteens. Coeliac UK has received examples of people coming out of hospital sicker than when they went in as hospitals can't manage their nutritional needs. In care homes fear of ill health can lead to residents not eating.

Research by Coeliac UK has identified that foods which are gluten free often have different nutritional value, being higher in fat and lower in protein than the equivalent gluten-containing foods.

In addition, possible changes in law have led to problems with reimbursement as the proposals plan to make the definition of special medical foods much narrower than previously. As a result it is likely that gluten free foods will be legislated under 'normal' food products in the future making it more expensive for patients to manage their condition.

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Questions and discussion related to presentation 5, 6 & 7

It was noted that there are similarities between coeliac disease and diabetes in that efforts to create a healthy diet which crosses the boundaries between specialist and normal diets has been a challenge. An overall culture of healthy eating is therefore needed.

Sarah Sleet reported that the levels of diagnosis need to increase as once this has taken place consumer power will drive the availability of products, creating a more innovative and wider marketplace. A gluten-free diet is a challenge to stick to, as a result Coeliac UK advocate a pragmatic approach and try to educate individuals. Europeans rely so heavily on wheat ,asking people to avoid it altogether is unrealistic, especially when cooking skills are limited and substitute products are still required.

It was noted that the Renal Society produced a cook book for patient groups. Perhaps there are others available from other organisations that could be combined. Coeliac UK has a database of recipes available to all online via their website.

8. Retinal disease and nutrition, Rainald von Gizycki, Pro Retina Deutschland e.V., Germany

Pro Retina Deutschland e.V. is a self-help organization for people with retinal degeneration based in Germany

The most common of the 150+ forms of retinal dystrophy are Age-related Macular Degeneration (AMD), Retinitis and Refsum, the. Nutritional treatments are available for some syndromes and there is some evidence for the impact of nutrition (see papers on cause and effect of retinol disease).

Three forms of retinal degeneration with relevance for nutritional treatment are exemplified:

Age Related Macular Degeneration
There are two types:

Dry – milder but more common, a build up of drusen. Can turn into wet form over time.
Wet – Leaky blood vessels grow into the macula (centre of retina), meaning the patient becomes severely visually impaired and reliant on care.

Early studies have shown that AMD patients with the dry form might benefit from antioxidant containing vegetables such as spinach, broccoli etc. A large clinical study showed that a combination of supplements (vitamin D, vitamin C, zinc, beta-carotene and copper) decreased the risk of dry AMD becoming wet AMD by 25%. These study results were however disputed, statistics were challenged and transfer of information to doctors and patients was slow and controversial. Reimbursement often unclear due to difficult distinction between nutritional and pharmacological products.

Retinitis Pigmentosa
Disputed clinical and experimental studies have shown that Vitamin A (palmitate form) antioxidants (lutein, zeaxanthin, etc.) fishoil (omega 3 fatty acids) may slow the rate of vision decline in some RP patients. However, there is no evidence-based guidance for patients on the use of any of these nutritional supplements, leaving patients and doctors alone in their treatment decisions. Also, the potential negative effect of Vitamin E in combination with Vitamin A as well as adverse effects of Vitamin A for certain genetic subtypes have not sufficiently been studied.

Refsum
An effective diet for the management of Refsum exists but it is difficult to maintain as it requires a diet low in phytanic acid. Health insurance is reluctant in reimbursement as evidence is small and apheresis may be considered as a more effective alternative (or vice versa).

Hence, there are nutritional treatments for some retinal degenerative diseases, but controversy remains over evidence base, clinical guidelines and recommendations as well as reimbursement. Patients decide on their own what nutritional option to follow.

Questions and discussion related to presentation 8

How many patients receive apheresis?
Apheresis is scarce as some insurance companies won't pay for this type of expensive treatment until diet has been tried.

It was noted that retinal disease is not the only field where there are multi-interpretable outcomes of trials. Perhaps there is not enough investment in trials to provide the statistical power for robust results.

The difficulty is that the causes and pathways leading to retinal disease are still unknown for many forms. The evidence is stronger with AMD, but still not strong enough and authorized nutrition is not available in a supplement in the strength that was used in trials.

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9. The role of nutrition for bone health, Judy Stenmark, IOF (International Osteoporosis Foundation)

The International Osteoporosis Foundation (IOF) is a registered not-for-profit, non-governmental foundation based in Switzerland. IOF functions as a global alliance of patient societies, research organizations, healthcare professionals and international companies working to promote bone, muscle and joint health.

When it comes to nutrition Calcium, vitamin D and protein are all that is needed to ensure healthy bones. However, a large proportion of the worldwide population doesn't have adequate calcium and vitamin D intake.

Calcium helps to preserve bone mass and in youth, calcium helps build strength particularly when the rate of growth is highest. The International Osteoporosis Foundation recommends meeting calcium needs through diet as calcium supplements not only have some links to heart attacks incidence for high levels of intake, but are not effective in isolation as vitamin D is also essential to bone health.

If protein is limited in the diet it can lead to muscle weakness, sarcopenia, frailty, falling and ultimately fractures.

If vitamin D is deficient this can lead to decreased bone metabolism (the rate at which bone is replaced) as well as increased osteoporosis, muscle weakness, falls risk and fracture risk. However, there is not sufficient vitamin D in food to provide sufficient for the body and it is mainly converted from a different form which already exists in the body via exposure to sunlight. Due to the increased risks associated with sun exposure and the difficulties some groups experience in accessing sunlight fortification is on the increase and supplementation is currently recommend by the IOF in all adults aged over 60 years.

Prevention is key to ensuring good bone health in older age and reducing the incidence of osteoporosis. In youth it is vital to build strong bones as well as to maintain this bone and muscle strength and in mid and later life to prevent ill health and falls/fractures.

Discussion regarding presentation 9

Why not add magnesium to calcium intake to prevent the negative impact calcium can have on the bowels?

There is some evidence that magnesium has an impact on bone health and more and more products of this sort are starting to emerge.

It was noted that both rickets and osteomalacia (both diseases resulting from deficiency of vitamin D) are on the increase and observed that perhaps the 'pendulum' had swung too far to the point where people don't encourage/allow children to play outside and actively avoid sun exposure themselves.

The IOF would like to see that pendulum swing back to ensure moderate sun exposure for all as it is essential for bone health, particularly in youth.

IOF: www.iofbonehealth.org
Email: JStenmark@iofbonehealth.org

Roundtable, Q&A and the formulation of an EU Patient Nutritional Agenda

This session moderated by Eibhlin Mulroe from IPPOSI, Ireland aimed to prioritise the objectives of the group towards a common EU nutritional agenda. Delegates were asked for their opinions on the overarching recommendations for patient groups to take to the EU.

It was observed that at the EU level there is currently a big agenda involving nutrition, but that patient groups are not involved or consulted.

Olle Ljungqvist reported on meeting on the Active and Healthy Ageing Group on age related undernutrition held on the 2nd and 3rd of July and hosted by the EC as a part of their European innovation Partnership Active and Healthy Ageing programme. This programme aims to increase healthy life expectancy among EU citizens by 2 years. Patient groups were represented at this meeting and so the conference presented an opportunity and a beginning for patient groups to become further involved, either individually or as members of EGAN or EPF.

One suggestion was that the work done by patient groups should not be restricted to working with pharmacological companies. Food, additives and preservatives can all have an impact as well. Indeed foods imported from emerging economies may not have the same levels of control as those from within Europe.

It was reported that there is a food regulation body in each country and rules are set at an EU level to ensure appropriateness and safety. As a result even those foods produced outside the EU are subject to scrutiny and must meet regulations set by national bodies and the EFSA (European Food safety Agency).

In terms of regulation it was noted that some of the legislation throughout Europe has in fact been counterproductive by blocking products when they are needed, this is particularly the case with lesser known supplements. Some individuals may then take the risk of buying directly from suppliers for products which had previously been included.

A concern was raised over trying to regulate more than can be seen. All patient groups have different needs and if the group as a whole try for consensus then problems may arise. Where consensus is needed is not in terms of regulation, but through determining the important areas where more intention for work is needed and focusing on the areas where common goals become apparent.
Frank de Man from the European Nutrition for Health Alliance (ENHA) suggested that in fact this was a two way discussion between ENHA and Patient Groups and also with the EU. He emphasized ENHA's commitment to developing an agenda for action in the EU with all parties involved.

A question was raised as to whether patient groups could therefore work towards a common goal and one strategy for all stakeholders to sign up to. It was suggested that perhaps committing to including nutritional care as a part of their work and future strategy could be a starting point for all patient groups and that the Danish example of developing widespread nutrition policies for patients could be an example to work towards.

It was also suggested that a group such as those represented at the conference could assist in accessing information for all which could be trusted for use and sourced from reliable and robust research.

The group were asked how they felt about the ECs commitment to research following the lack of evidence available, which in turn leads to the an inability to develop evidence based policy.

It was agreed that there was an issue with regards to building capacity to develop new work and opportunities to work holistically were restricted. In addition research should be made more available as it is too often distorted in reporting by media.

It was noted that what research does to and for patients and how it is presented to them is vital. Position papers of scientific advisory boards are useful, but what is missing is the feedback from patients and assistance from professional nutrition or dietetic associations.

It was agreed that whilst research and its translation is key, there is ample evidence regarding the impact of undernutrition so in this regard the time is right for action. Trials are more challenging as data isn't enough to get a nutritional product available and reimbursed. What is needed is policy change to ensure that reimbursement is approached in a way that is addressing the whole person and relevant to the individual being treated.

Wrap up of the meeting, Lisa Wilson, ILC, UK

Following the presentations and discussion delegates had identified seventeen key recommendations for further action. These were presented to the group for approval as a part of the actions to follow from the meeting and to ensure that patient groups working together with ENHA could have a focus for future action on nutrition. The recommendations have been classified Into categories that may play a role in the EU nutritional agenda.

These recommendations can be found at the beginning of this report.

The meeting was formally closed by Cor Oosterwijk, Director VSOP and board member of EGAN

After the wrap up of the meeting Cor Oosterwijk addressed the relation between nutrition and preconception care in his final closing words. Worldwide patient organizations like IGA, EGAN and VSOP join forces with industry, policy makers and service clubs to focus on pre conception care in the Preparing4Life. Nutrition has special attention in this project.
He ended by eluding the good start of the partnership between ENHA, EPF and EGAN.

EGAN: www.egan.eu
Preparing4Life: www.egan.eu/en/our-activities/projects/preparing-for-life & www.preparingforlife.net
Email: c.oosterwijk@vsop.nl

Annex 1 *Programme & Programme outline*

Invitational conference 'EU Patient groups & the relevance of nutrition'
Organized by ENHA, EPF and EGAN
July 4, 2012, Brussels

9.00	Registration and tea/coffee,
	Morning chair and moderator: Chantal Gill'ard EGAN
9.30	Opening Robert Johnstone, Board member EPF 'EU Patient groups and nutrition, the aim of this meeting'
	General introduction to the topics
9.40	The relevance of nutrition for EU patient groups, Cees Smit, policy advisor EGAN
10.00	The interface between pharma and nutrition, Ceri Green, Nutricia and MNI (Medical Nutrition International Industries)
10.20	Discussion and Q&A
10.45	Coffee/tea break
11.00	An overview of the European nutrition and health arena, prof. Olle Ljungqvist , ENHA, Sweden
11.20	Older persons, frailty and undernutrition, prof. Jean Michel, chair EUGMS
11.40	Discussion and Q&A
12.15	Lunch break

Afternoon session moderator and chair: by Eibhlin Muhlroe (IPPOSI, Ireland)

Specific EU Patient Groups Experiences

13.30	The Asthma/COPD experience, Susanna Palkonen, European Federation of Allergy and Airway Diseases Patients Association, EFANET and Vice-President EPF, Belgium
13.45	The experience of people with metabolic disorders, Hanka Meutgeert, VKS (Adults, Children and Metabolic disorders), The Netherlands
14.00	Coeliac disease, Sarah Sleet, Coeliac UK and the Association of European Coeliac Societies (AOECS) United Kingdom
14.15	Discussion and Q&A
14.45	Tea/coffee break
15.00	Retinal disease and nutrition, Rainald von Gizycki, Pro Retina, Germany
15.15	The role of nutrition for bone health, Judy Stenmark, IOF (International Osteoporosis Foundation), Swiss
15.30	Roundtable, Q&A and the formulation of an EU Patient Nutritional Agenda
16.30	Wrap up of the meeting, Lisa Wilson, ILC, UK
16.40	Closure of the meeting by Cor Oosterwijk, Director VSOP/EGAN

Aim of the conference

The aim of the conference is to discuss among representatives of EU patient groups and European organizations, active in health and nutrition, the relevance and urgency of health and nutrition for patients in Europe. The presentations and discussions will provide the delegates a better understanding of their mutual objectives and priorities in the field of nutrition and health and to come forward with a common EU Nutritional Agenda.

For the moment, this Agenda is directed to routine nutritional screening and follow up care in the setting of hospitals, nursing homes and the community in Europe. But in addition for EU patient groups there are also other important topics, like insurance and reimbursement of medically indicated dietary supplements and more knowledge on the potential, positive effects of nutrition on health.

The meeting will have an interactive character. Every speaker addresses a couple of specific questions and after every two speakers there will be an in depth, plenary discussion.

Participants will receive a reader with information before the conference and a questionnaire to identify their area of interest and work within nutrition.

Organisers

The meeting is organized in joint cooperation by the European Patients' Forum (EPF), the European Health and Nutrition Alliance (ENHA) and the European Genetic Alliances' Network (EGAN).

L**ist of participants**

A group of about 40 experts will be invited for this meeting from EU patient groups, researchers, physicians, geriatrics, dieticians, pharma and food industry.

Where

Wednesday July 4, 2012, from 9 AM till 5 PM at the Renaissance Brussels Hotel in Brussels

Follow-up

A booklet with the presentations and results will be made available after this meeting as well as a summary document for patient groups on the outcomes of this meeting for their internal publications and/or their websites.

For more information, the organizers

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Cees Smit, EGAN at: smit.visch@telfort.nl

Frank de Man, ENHA at: frankdeman@newyield.nl

Annex 2. **List of participants**

Invitational conference 'EU Patient groups & the relevance of nutrition'

Organized by ENHA, EPF and EGAN

July 4, 2012, Brussels

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Suzanne Wait	International Longevity Center, United Kingdom	suzannewait@btinternet.com
Tadeusz Hawrot	European Brain Council, Belgium	t.hawrot@europeanbraincouncil.org

For further information after the conference,
please contact Cees Smit or Chantal Gill'ard