

2012

Short Report Invitational Conference EU Groups and the Relevance of Nutrition



**Working together for a voice in research
& health policies and benefiting from
genetics, genomics & biotechnology**

At the 4th of July 2012, ENHA, EPF and EGAN organised an unique meeting. This unique meeting was the first meeting organised by patient organisations on nutrition in Europe to achieve patients and patient organisations are an essential part of the solution to improve health. The slogan 'Nothing about us, without us' does play an important role here as patients experiences in health care can give valuable insights on health and the issues involved. Nutrition is an important topic in health. Nutrition may prevent sickness, but it also provides us with a wider picture to gain understanding and awareness on the relevance of nutrition in Europe.

Objective of the Meeting

The objective of this meeting was to identify concrete tools and to identify the type of support to what patient organisations need to raise awareness on nutritional care. Another objective is to make the EU patient nutritional agenda relevant to the patient community. Concrete actions should be identified and include a strategic implementation plan. Undernutrition is preventable and unnecessary. It must be put on the EU agenda to find coordinated solutions and to include in national plan.

The Meeting

The meeting started with a personal account of Robert Johnstone, board member of EPF and Rheumatic Disease patient. He told the audience that at the age of 15 years, he noticed that acid food such as citrus fruit, made him feel bad. It was always after he ate these kind of products he experienced more pain. When he discussed his findings with his physician it was dismissed as impossible. According to his physician food had nothing to do with Rheumatism. In University he learned about meditation where he learned to listen to his own body. During his life he always had to take many medication to manage his disease and at a certain moment in life his medical specialists recommended him to take joint replacements. Now in his 60's, Robert

EGAN

— *The Patients Network for Medical Research and Health is an alliance of both National Genetic Alliances and European disease specific patient organisations with a special interest in genetics, genomics and biotechnology. 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.*

European Patient Forum (EPF)

— *The umbrella organisation of pan-European patient organisations active in the field of European public health and health advocacy. It is a collective patients' voice at EU level, manifesting the solidarity, power and unity of the EU patients' movement.*

European Nutrition for Health Alliance (ENHA)

— *An alliance of public health, health and social care actors united to promote better nutrition and to tackle undernutrition in Europe.*

Johnstone takes Aryuvedic nutritional supplements. Two weeks later his pain level went down and he achieved a better mobility, and his so badly needed joint replacements weren't necessary anymore. His physicians couldn't understand that nutrition could do so much. Robert Johnstone's story shows that patients too can come to innovative solutions to deal with their situation and to improve their medical condition.

Robert Johnstone also raised his concern regarding the fact that many scientists advocate for genetically modified food. His main concern is that this kind of food hasn't been tested on the impact it has on human bodies in general and on people with certain medical conditions. It is important we know what we are eating and that we don't eat a combination on things we don't understand. He warns it may affect our bodies, without us knowing it.

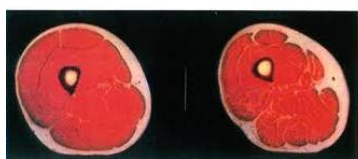
European Genetic Alliances Network "Working together for a voice in research & health policies and benefiting from genetics, genomics & biotechnology"

Perhaps typical to this meeting is that it started with a personal account of a patient experience with nutrition and trying to find ways to treat his condition in such a way that it is beneficial. While listening to his personal story, I realised that I too try to 'find my own way' to get the optimal treatment from physicians, alternative therapies and nutrition. Over the years I learned by experience what kind of foods have a negative effect on me and what foods a positive. It is not scientifically proven, but in my opinion we know ourselves best what is good and not good for us, we must learn to know our body, must be open to it and use our knowledge.

But in spite of our learned by experience knowledge, not much is known about the nutritional effect in diseases in general or in particular diseases. Up till now, patient organisations and science mainly were focussed on getting treatments for the disease, but were not involved in finding the best way of already existing ways and tools to optimise the health of people with a disease. Examples of this are nutrition, physical exercising, methods to become mentally empowered (meditation) or alternative medicine.

Just the fact that approximately 30 Million Europeans are affected by undernourishment and that the costs of undernourishment are about 170 Billion Euro's a year now makes that society becomes interested in the topic of nutrition, especially undernutrition. The challenges of obesity are already knows for some time, but being overweight doesn't mean one is well nourished. Many people who are obese or are too heavy in weight are undernourished as they don't have a well balanced nutrition intake over the day.

Undernourishment happens mainly in elderly and people with a disease. Prof. Jean Michel, chairman of European Union Geriatric Society (EUGMS) stated that the ageing process where we, hopefully, all once will be part in, is a



Sarcopenia, the degenerative loss of skeletal muscle mass, quality, and strength associated with aging.

uniquely individual process. In this process, throughout all life stages, nutrition can greatly interfere with the ageing process. During the process of ageing the body composition will change. Older people lose weight, but their fat tissue will increase. Muscles become replaced by fat. Scientific publications show that the probability of survival of people who can keep their weight stable is higher than people who lose weight. With advancing age, the risk of



It is recommended to take 3 servings of 30g of proteins with a daily intake of 90g.

developing serious nutritional deficiencies increases while often there will be a decrease in food intake, which is increased by the presence of debilitating diseases. Risks of denutrition in the elderly are sadness, eating problems, shopping problems. It is not that sarcopenia (the degenerative loss of skeletal muscle mass and strength associated with aging) and frailty are irreversible as it is proven that physical exercises, also in very old people, can improve skeletal muscle mass with 44%. Besides that sufficient Vitamin D and protein intake with each meal is essential. It is recommended to take 3 servings of 30 g of proteins with a daily intake of 90 g. The distribution of protein intake is relevant as irregular intake does not maximize protein synthesis. Most people tend to eat most proteins at the end of the day, but it is better to spread protein intake equally over the day; 30 g of protein at breakfast, 30 g of protein at lunch and 30 g of protein at dinner. Repeated maximal stimulation of protein synthesis will increase or maintain muscle mass.

This example shows that a lot can be won, if we all become more aware and more active in our nutrition. During discussions in the meeting it became clear that the healthcare system itself also is not active in advertising healthy nutrition. Special diets for metabolic diseases are very limited reimbursed by the healthcare insurance. Patients often need to fund the special diets themselves which leaves the costs to them, while a good dietary nutrition intake may improve their health and reduce costs for society.

After the presentations and discussion delegates had identified 17 key recommendations for further action. These recommendations will be used as a focus for future action on nutrition. The recommendations have been classified into categories that may play a role in the EU nutritional agenda.

The 17 Key Recommendations for Further Action on Nutrition:

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.

Nutrition and awareness

- 4) Dieticians must be 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.

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.

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 of patient health.

Nutrition and regulatory requirements

- 10) Clear labelling 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.

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.

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.

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.

Awareness on the impact of good nutrition on individual people, society and the cost reduction it may bring is important. Patient organisations should play a leading role in it by encouraging further research in this topic as it benefits their target group. EGAN therefore will continue bringing this topic to the attention of patient organisations and other stakeholders as much benefit can be gained.



Preparing for Life; To reduce maternal and child mortality and morbidity...

Every year millions of babies are born with serious disorders. At least 3.3 million children under the age of five die from these causes each year and an estimated 3,2 million of those who survive may be disabled for life.

Data show that deaths and disabilities from such disorders can be reduced significantly and birth outcomes for women and babies can be improved by simple, affordable evidence based preconception care interventions.

There is a dramatic gap in women's health and birth outcomes depending on where a woman lives and where her babies are born. Strategic actions are needed both to empower and educate girls and to provide equitable preconception care for women and their partners before and between pregnancies in order to increase chances that women and their babies will be healthy and survive.

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Full Report of the Conference

You can find the full report of the conference at the EGAN website:

www.egan.eu/en/meetings/meetings-archives/
and then click on '4 July 2012, EU patient groups & the relevance of nutrition'

Presentations given at the Conference

Presentations of the conference can be found at the EGAN website:

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and then click on '4 July 2012, EU patient groups & the relevance of nutrition'

Recent and Current Achievements and Activities

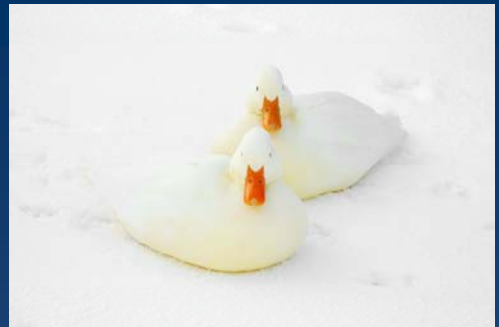
During its 2-year existence, Preparing for Life:

Brought together a worldwide team of experts representing a wealth of knowledge and experience and capable of making a substantial contribution to improving maternal and child health;

Organised a summit for industries in the field of nutrition (March 2011) in cooperation with DSM and the World Life Sciences Forum, resulting in a European consortium of nutritional industries, focussing on life cycle nutrients;

Cooperated with WHO, resulting in an international expert-and consensus meeting (WHO-headquarters Geneva, February 2012). More than 70 international experts, especially from low-income countries, took part. Based on reviews by Erasmus University, Dutch Health Council and the Aga Khan Foundation, consensus was reached on the position of preconception care as an integral of part of the continuum of maternal, newborn and child health. In addition, a plan of action was developed.

As part of this plan of action, Preparing for Life, WHO departments and WHO-related institutions, work together in mapping experiences and initiatives, and in developing demonstration projects and guidelines. A minimum package of pre-conception measures is under development, as a fixed part of primary healthcare services in all countries.



**EGAN wishes you and
your beloved ones a
healthy and joyful**

2013

Important websites:

The Patients Network for Medical Research and Health (EGAN)
www.egan.eu

The European Nutrition for Health Alliance (ENHA)
www.european-nutrition.org

European Patients' Forum (EPF)
www.eu-patient.eu

World Health Organization (WHO)
www.who.int/nutrition/en/

Preparing for Life
www.preparingforlife.net

This EGAN Newsletter is a short report on the Invitational Conference 'EU Patient groups and the relevance of nutrition' held at July 4 2012 in Brussels, Belgium.

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