

2012

Special Nutrition Edition



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

At July 4, 2012 the conference 'EU Patient groups and the relevance of nutrition' will take place in Brussels. It is the first conference between representatives of European patient groups and members of the European Nutrition for Health Alliance (ENHA).

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 conference is a concrete outcome of the signed Memorandum of Understanding at April 2012 between the European Patient Forum (EPF), the European Nutrition for Health Alliance (ENHA) and the European Genetic Alliances' Network (EGAN).

According to EGAN's mission to provide information and to advocate for children with a genetic or congenital disease, EGAN always has been involved in issues regarding nutrition. Preconception care, for example is a topic where nutrition plays a crucial role. Over the years it became clear that nutrition became more and more important and EGAN felt the need to work on a joint European agenda with other European patient organisations to discuss the relationship

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 malnutrition in Europe.

between nutrition and disease.

Nutrition and Health

In the past nutrition and pharmacology were seen as complimentary that needed to be used next to each other to improve health of people or to treat diseases. The ancient Greek divided medicine into three categories: diet, pharmaceutical and surgical medicine. Also in so called traditional medicinal systems such as Ayurveda and Traditional Chinese Medicine there is no fundamental difference between both disciplines, and nutrition is a normal part of prevention and healthcare. In the western world, nutrition research and pharmacology developed separately. Rapidly expanding population, economical crisis and international crisis and international conflicts, nutrition first had to supply

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

the western world with safe food with enough energy, proteins and essential micronutrients. Micronutrients are nutrients someone needs throughout life in small quantities to orchestrate a whole range of physiological functions, but which the organism itself cannot produce such as vitamins and carotenoids (Alpha - carotene , Beta



-carotene, Lutein, Zeaxanthin etc.) (N.A. Georgiou et al, 2011,1). However in these days, the interaction between pharmacology and nutrition science is on the rise. Nutritional status is considered one of the important determinants of health and disease. Several diseases in our time have a clear link with lifestyle factors including the diet. There is also increasing realisation that a continuum between health and disease often exists without strict boundaries, especially in chronic diseases. The distinction between foods and drugs follows from the primary goal of nutrition which is to maintain, or if possible to improve health. This is an essential difference with pharmaceuticals, which are generally developed to treat, cure or to prevent disease. (N.A. Georgiou et al, 2011, 2). Nutrition plays a key role in human health and wellbeing. This is true through-out the life-cycle: starting from conception, and later at all stages in life: for babies, infants, adolescents, young and older adults. In the developing world the prevalence of malnutrition is high, primarily because of the limited availability of nutritionally adequate foods. There is however, also a lesser known problem of micronutrient deficiency in the developed world. Although the supply of food can be plentiful, some population groups are not achieving the right level of micronutrients in their diets to support good health (IGA Newsletter Special Edition #12, 2011).

Personalized nutrition

Everyone knows from personal experience that one may respond differently to certain food types than other people. Often we already have an unconscious knowing what food we can eat and what food can cause us trouble. Why is this? Does this also mean that some nutrients are more needed in one person than in the other?

Every human being is different, but has this also effect on the need for specific nutrients? Up till now not much is known about this, but it makes sense that this might be the case. Science more and more becomes interested in this aspect and slowly some evidence is gathered that personalised nutrition might be a solution for many people to live an as healthy as possible life. Studies have shown that individuals respond differently to various nutrients. For example, omega-3 polyunsaturated fatty acids, the ' healthy fats' found in oily fish that are believed to protect against cardiovascular disease, have been found to be more beneficial in individuals with a particular genetic make-up (Ferguson et al., 2010). Such research suggests that blanket public dietary advice is not the most effective technique for improving public health. Rather than applying overarching dietary guidance to the whole population, personalised nutrition sets the individual apart to consider their specific physical and genetic characteristics. Personalised nutrition is actually nothing more than a diet tailored for an individual, according to their individual physical and genetic make-up. Unfortunately personalised nutrition is still in its developmental stage. More research must be done to really be able to tailor a personalised diet to someone specific individual needs. One research project focussing on personalised nutrition is the Food4Me project that will investigate the possibility of designing better diets based on a person's genetic make-up. (News-Medical.Net; July 19, 2011).

The difference between the Consumer and the Patient

In marketing and commercial settings we tend to call people who buy products, including food products, consumers. The consumer is a broad label for any individual that uses goods and services. But who is this consumer? In fact the consumer does not exist, as everyone has different wishes, preferences and needs. So who do we want to reach with personalised nutrition? In fact we want to include and target the whole population when it comes to personalised nutrition as every individual, healthy or not healthy needs healthy nutrition to provide the body with that what it needs to stay healthy or to be as healthy as possible. It is important to understand though that there is a difference between healthy individuals and not healthy individuals, often addressed as patients. Patients are not consumers. There is a difference between them. A healthy consumer in general looks at low premium of their health insurance and is willing to take a high risk. A patient, however, wants to have the best physician, wants to know what the best hospital is and what treatment helps best to treat the disease. Consumers and patients have different interests and sometimes they can even be in conflict with each other. The turning point

comes when the consumer becomes a patient. From that moment on one often sees that other questions and issues will be addressed by the previously consumer.

The involvement of patients and patient organisations in the area of nutrition

Up till now patients and patient organisations have not been very involved in the area of nutrition. Some specific disease groups have a history of focusing on nutrition while their diseases are closely connected to specific nutrition needs, but in general patient organisations don't deal with nutrition. The International Genetic Alliance (IGA) and EGAN are so far the only two umbrella organisations that focus on nutrition. There is a growing awareness on the role nutritional aspects can play in the prevention, treatment and management of diseases or disabilities. Many families affected by a disease are looking for information on to best manage their disease outcomes. Pompe patients (Pompe disease is a metabolic disease) for example more and more start to talk about nutritional effects on their health and disease impact. During conversations at a closed email network in which people involved with Pompe disease (patients, parents, family members) discuss topics related to Pompe disease, often nutrition is discussed. The problem, however, is that not much knowledge is known about the impact of nutrition on Pompe disease. Depending on the country they live in or the physician they listen to, Pompe patients are advised either to take a normal healthy nutrition intake advised also for the general population or to minimize the carbohydrate intake and to focus on protein intake. Patients often follow their gut feeling, as no scientific information is available. Pompe patients have addressed the nutrition topic to physicians, but they are understandably busy with other priorities such as improving treatment outcomes, developing improved therapies and treating patients.

Nutrition and the impact on our world

Ideally we would like to see that every citizen is a conscious green consumer. This means that one has awareness on ones body and environment and is aware these two are connected. Conscious green consumers want their children to benefit from the same things as they are doing now and are able to eat the same kind of food. They are also able to behave in a responsible way. They know what the effects of their diet is on their health and is aware of the effect of their diet on the environment.

Often, however, people are not aware of the impact of our consumption. Bad eating habits for example may lead to malnutrition. This

malnutrition also happens in overweight or obese people as they often lack essential micronutrients. People are often not aware that lack of energy and feelings of discomfort are due to our eating pattern. The slogan 'You are what you eat' is true, but additionally we are much more than that. People are emotional beings and the preference for food is also determined by emotion and not always by what is good for someone. Besides that it is often forgotten that people have needs like food and shelter, but that there is also the need for social contact, love and affection. Therefore everyone must understand that if we want to introduce personalised nutrition successfully and we want it to be effective, so that people can benefit from this information and adjust their eating pattern, we need to take all of these issues into account. Most people know what is good for them, but to help people to really change in their habits they must receive the proper support. Much behavioral research is being done to find the solution for the ideal support models.

Some Facts To Think About:

- ◆ Every year 7.9 million children are born with a serious disease or congenital condition.
- ◆ Every year 3.3 million of these children die before the age of 5 years and those who survive have multiple disabilities for the rest of their lives.
- ◆ Every day 30.000 children under the age of 5 years die while it could be prevented.
- ◆ 20% of all pregnancies doesn't result in a healthy baby (10% miscarriages, 7% prenatal births, 5% congenital diseases and 1% perinatal death).
- ◆ 50 - 70% of all congenital disorders can be prevented.



Personalised nutrition before and during pregnancy

The periconceptional period, is defined as one month prior to pregnancy through the first trimester and is the most important period in which reproductive failures originate. Maternal nutrition has been recognised as one of the main

environmental factors influencing the development of the embryo, foetus, and placenta with short and long term health effects. Much knowledge has been obtained on the role of folate in reproduction, but recently the identification of dietary patterns has emerged relationships between maternal malnutrition and pregnancy outcome as well. Outcomes that show optimal nutrition during pregnancy is essential to reduce the risk of birth defects.

Malnutrition

Malnutrition is not given the place it should have on national and international policy agendas. These days the topic of nutrition in policy of mainly focussed on dealing with the problem of over-nutrition, or obesity. This is indeed is a huge health problem in the developed western world, and unfortunately also more and more in the developmental world. However, the equally important problem of malnutrition has been often neglected. Malnutrition is defined as an



imbalance of energy, protein and other nutrients that causes measurable adverse effects on tissue and body form and function as well as clinical outcomes.

The prevalence of malnutrition is undeniably high: up to 40% of patients of all ages are malnourished upon admission to hospital. Certain groups especially are at risk: older people, cancer patients, renal disease, chronic heart failure and patients who have had surgery. In general one can say that all clinical and community settings and across the population, malnutrition, is severely unrecognised. Malnutrition has a high impact of clinical outcomes. For example complication rates in malnourished surgical patients are 2 to 3 times higher than in well nourished patients. Malnutrition also delays the speed of recovery, predispose patients to infections, impair wound healing, leads to pneumonia, impair thermoregulation leading to an increase in falls. A study in the Netherlands by the Vrije Universiteit in Amsterdam upon request

by the Dutch Ministry of Health, showed that 10% of the older people (65+ years) living at home independently is malnourished. Among those who receive home care the percentage of malnourished increases to 35%. Malnourishment in this study was defined so that one should have a decrease of four kilos in the past 4 years and suffered from symptoms of fatigue and hunger. Older people are a vulnerable group who often are affected by chronic diseases or suffer from problems such as depression or mourning the loss a partner or other relatives that causes a lack of appetite. Sometimes it can also be that bad teeth cause pain with eating makes that people eat less food. One can say that the problem of malnutrition in nursing homes with a percentage of 35% is higher, but in absolute numbers it isn't... 95% of the older people (65+ years) in the Netherlands live in their own homes independently.

Malnutrition also poses high cost to society as people suffering from malnutrition have an increased need for medical and social care. A recent UK study estimated that disease related malnutrition cost the UK up to 7.4 billion Pound (Jones et al, 2005; Elia et al, 2005). Effective prevention and nutritional support does exist. Nutritional support for example many include nutritional advise and counselling, oral dietary supplementation, enteral tube feeding and parental nutrition. Early detection and early treatment are essential as much of malnutrition is reversible. Treatment of malnutrition can also have an high impact on mortality and complication rates.

There are barriers regarding the prevention and care of malnutrition as it occurs at a number of levels:

- ♦ General awareness of the issue of malnutrition is poor, The issue has not yet arrived on the political agenda,
- ♦ Unawareness among health care professionals that malnutrition may be a problem f.e. a recent study in the UK showed that 40% of GPs didn't think malnutrition was a problem,
- ♦ Malnutrition is under-recognised and under-treated. Treatment guidelines exist but rarely applied in practice,
- ♦ Nutrition therapy has no place within health and social care budgets.

Fact is that a lot can be won if malnutrition becomes a core topic in society and is addressed properly.

Mel Read, former member of the European Parliament, stated: *'How will history judge the*

early 21st century? If things go on as they are, the verdict will be dismay and condemnation, that wealthy societies and established social protection systems could allow the tragedy of malnutrition to occur in such a large segment of the population. This is just not tolerable, and the European Nutrition for Health Alliance, with growing support, is determined to tackle this issue.'

(Personalized) nutrition in diseases

The relevance of 'nutrition' for patient groups can differ significantly. Its importance strongly depends on the role nutrition or nutritional aspects can play in the prevention, treatment and management of the disease or disability. Many families affected by a disease are looking for information on how to best manage the disease outcomes of themselves or affected children. Besides the personal interest of many patients also society is interested in optimal health outcomes and healthier longer life, longevity. So far, only a number of specific disease groups such as Coeliac disease, COPD and Crohn Disease have addressed nutritional issues directly. It is essential, however, that specific disease groups with nutritional problems actively participate in the development of nutritional products. Of course there are specific groups of diseases and people that can benefit from good and optimal nutrition.

These are:

- Specific diseases: Coeliac disease, Anemia, Obesity, Diabetes, Crohn & Colitis, Asthma, COPD etc.
- Perinatal, maternal and older adults: Nutrition following the life cycle.
- Malnutrition and nutritional supplements: HIV/AIDS, Cancer, Pre-and Post operational patients.
- Nutritional aspects of metabolic diseases: Phenylketonuria, Mitochondrial diseases, Lysosomal Storage diseases, Glycogen storage diseases, Lipid storage diseases etc.
- Global World Issues: Malnutrition, Vitamin D and Iodine deficiency.

It is essential that specific patient groups with nutritional problems actively participate in the

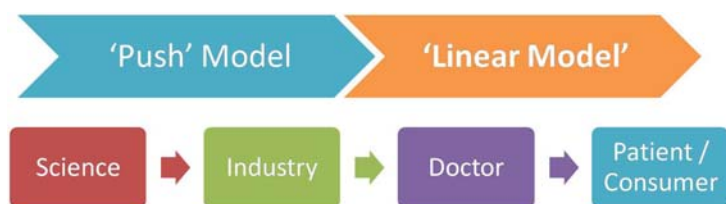


Image 1: Push Model

development of policies and products. The way questions regarding nutrition so far has been addressed were mainly organised via the so called 'push model' (see image 1). The push model is a model where the end users are not being involved in the development of nutrients and decision making process of what is important or should be prioritised. It is science and industry who are 'pushing', the research ahead and the end users waiting until it is ready and can be used.

The 'pull model' (see image 2) shows that there is active interaction between the several parties such as science, industry, doctors and patients/

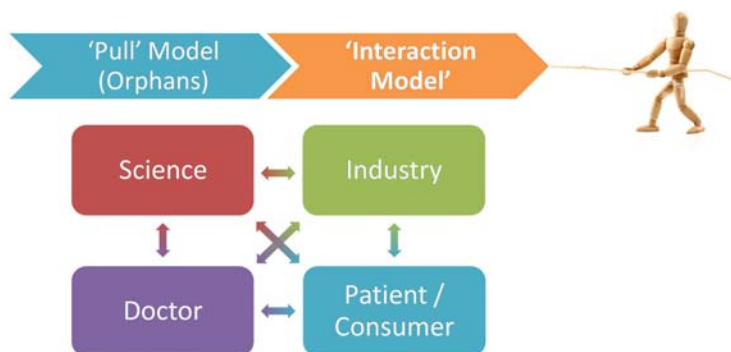


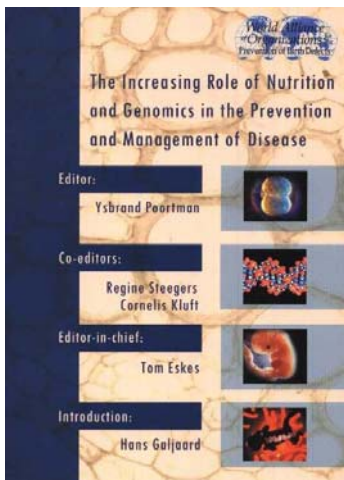
Image 2: Pull Model

consumers. The combination of 'evidence-based' scientific knowledge with the 'practice-based' knowledge of patient groups leads to an 'added' value. There are a number of promising examples of this added value from patient groups in the drug development process (long-term financing biobanks, active involvement in clinical trial design etc.). In the pull model all parties are continuously interacting with each other to set priorities. The advantage is no products will be developed that are not really needed by patients and consumers. Via this model also the needs of patients and consumers can be addressed appropriately without much delay and with the involvement and expertise of all parties, so time is not wasted and experience and knowledge well used. The 'pull' approach can be triggered by stories from 'expert patients' in areas where nutrition plays an important role like in celiac disease. The Dutch Health Council also recommends the pull approach in her reports on 'Agenda Medical Biotechnology' (2006) and 'Medical products: new and needed' (2011)) (IGA Newsletter Special Edition #12, 2011).

EGAN and IGA activities

EGAN and its international umbrella organisation IGA are seeking since 2004 to get more understanding and attention for the role of nutrition during the prevention, treatment, improvement and cure of health disorders. A number of activities have been set up.

The Dutch Genetic Alliance (VSOP) and WAO have written a book on 'The Increasing Role of Nutrition and Genomics in the Prevention and Management of Disease' (2004). This book is one of the first scientific publications that the subject



food combines with genetics and genomics and information provides about new options for prevention and management of disease. This complex interplay between genes, food and environment is not only a fascinating new field of research but a new vital

area for maintaining health and adequate healthcare. The book gives information about the effects on chronic diseases such as neurological and cardio vascular disorders and a number of rare metabolic disorders such as phenylketonuria (PKU) and coeliac disease. The meaning for pregnancy and the first years of life is prominently described. The situation in developing countries (India) is discussed with proposals for structural improvements. The authors have written their contributions on request of patient organisations who wish a scientific basis for health policy and action in this field. The book is published under auspices of the World Alliance of Organisations for the Prevention of Birth Defects.

The IGA and EGAN also participated in the Nutrition Summit at BioVision in Lyon, March 2011. Unexpectedly, many CEO's from nutrition companies joined this exploration on the role of nutrition during impaired health. The Summit produced a call to action on 28 March 2011 to 80 Ministers of Health world wide asking for the best nutritional solutions to meet the needs of patients and other people with impaired health, other citizens and society. The call to action was signed by International Osteoporosis Foundation (IOF), IGA, EGAN, Preparing for Life, Sight And Life, GAIN (Global Alliance for Improved Nutrition), Kraft foods, Unilever and DSM. The Summit also produced a booklet 'A call to act: healthy nutrition throughout the lifecycle' with the speakers contributions.

Following the success of the Lyon Nutrition Summit the Nutrition Summit II was held during the Federation of European Nutrition Societies (FENS) Meeting in Madrid, October 2011. More nutrition industries and ngo's participated. Here it was sought to take the success of the first Summit a step further into a more structured

collaboration on nutrition and health solutions and joint actions. The Nutrition Summit II came out with the intention for a Memorandum of Understanding to jointly focus on inadequate nutrition globally, preventative nutrition interventions during the life cycle and nutrition in risk reduction for non-communicable diseases. The Memorandum of Understanding is still in the process of completion.

In November 2011 Public Advise International Foundation organised a high-level international conference on efforts to respond to the "silent crisis" of malnutrition through sustainable and effective means. EGAN/IGA was asked to present their views from the patient perspective. The conference brought forward a Call to Action asking for a EU policy on nutrition, this was signed by EGAN, IGA, World Food Program (WFP), International Union of Nutritional Sciences (IUNS), Unicef, Gain, Durabilis and Members of the European Parliament. The conference was covered in a special edition of The Parliament Magazine from the European Parliament. See for more information: www.pa-international.org

EGAN/IGA are also actively cooperating with the WHO on a project which is called 'Preparing for Life (Pfl), a joint venture of patients, science and service to meet the UN- millennium development goals: to reduce child mortality and morbidity and to improve maternal and child health.

In February 2012, a succesfull meeting with international scientists from all over the world was organized, followed by a policy meeting with representatives from the WHO in Geneva. More information on this can be found in IGA newsletters, that are regularly published on www.intga.org/newsletters.htm

This EGAN Newsletter is a special publication on the occasion of the conference 'EU Patient groups and the relevance of nutrition' that will be held at July 4 2012 in Brussels, Belgium.

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