

EFA Briefing Update

November 2012

Report of EFA's 1st Meeting to Introduce the Finnish Allergy Programme to EFA Member Delegations

Helsinki, Finland – 8-9 November 2012

Introduction

What do slot machines, biodiversity, allergies and Finland have in common? As for numerous readers of this report, there were not many clear links to be made before an enriching presentation of the *Finnish Allergy Programme (FAP)* in Helsinki, Finland from 8 – 9 November 2012. By the conclusion of this report, it will become evident to the authors how creative approaches to funding are helping to raise awareness for a widespread health condition, allergies, which increase with external pressures caused by diminishing biodiversity and increasing urbanisation across the world.

As an extension of the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) Allergy Project, the EFA meeting to introduce the Finnish Allergy Programme sought to attract delegations from EFA member nations and regions. Delegations from Bulgaria, Italy (Tuscany) and Norway familiarised themselves with Finland's best practice model and reflected upon lessons learned from the presentations of the FAP to determine how they could relate to their own national contexts. As an outcome of the meeting in Helsinki, the EFA Secretariat and Board members hope its members can successfully adapt the best practice model to fit their nations' needs.

Aim of the Meeting

Invitations to the EFA members were sent with the clear aim for participating EFA members to work after their participation in Helsinki in developing their own national allergy programmes. Their willingness to do so was a precondition for their participation with the national and/or regional stakeholders of their delegations. All relevant stakeholders including healthcare professionals, nurses, representatives from pharmacies or health insurance companies, policymakers and patient representatives were encouraged to participate as delegation members. EFA wished to see a delegation from each nation or region, which could assure a comprehensive effort to establish national or regional programmes with the greatest possibility of successful implementation.

Origins of the Finnish Allergy Program (FAP)

The presentation of the FAP began with Mr. Ilkka Repo, the managing director of the *Finnish Asthma and Allergy Federation (FAAF)* presenting on the substantive and funding structure of the programme. He explained the initiation of the FAP was driven by goals to increase the education for professional healthcare personnel, patients and the general public while promoting awareness for allergies at a national level. FAAF, the *Finnish Lung Health Association (FILHA)*, the *The Organisation*

for Respiratory Health in Finland (HELI), and the Finnish Central Organisation for Skin Patients spearheaded the efforts to create the FAP starting in 2008, proceeding without any major funding sources or partners to plan strategic steps required for succeeding in the primary substantive goals. A working group was nominated by the *National Institute for Health and Welfare (THL)* whose members collaborated to assemble a national database for all scientific studies on the topic of allergy. This concentration of scientific knowledge was used as a cornerstone for establishing the substantive goals and provided the convincing evidence necessary for allocating finances for the project by 2011.

All together, the FAP funding partners have committed to providing 960,000 EUR over the course of 2011-2015, with *Finnish Slot Machine Association (RAY)* providing the majority of this sum. As it would turn out, RAY would also be used as a pivotal funding source for the FAP along with the Finnish Ministry of Social Affairs and Health and industry sponsorships. Indeed, RAY not only publically funds the FAP, but it also functions as an external monitor and evaluator for the progress of the project as well, fulfilling a pivotal role in ensuring the success of the programme. FAAF, HELI and the Finnish Central Organisation for Skin Patients are patient associations with presence all over Finland receiving funding from RAY, and are responsible for the administration and organisation of the FAP. FILHA received funding from the national government and was tasked with the implementation of the programme, educating professional healthcare personnel.

RAY itself is a unique entity within Finland's national context, as it was established in 1938 by non-governmental organisations (NGOs) as a public corporation with the main purpose to raise funds through gaming operations while simultaneously promoting health and welfare in Finnish society. While in many countries around the world gaming operations are privately conducted, within the Finnish context RAY retains a monopoly on gaming and casino activities with its members' operations governed strictly by governmental laws and decrees. As a result, RAY retains large revenue annually (739.1 million EUR in 2011) of which up to 40% is used to specifically target the viability of NGOs promoting welfare improvement in society through core funding and projects.

Although most people outside of Finland may see cooperation between a gambling corporation like RAY and a patient association like FAAF as rather unorthodox, within the context of Finland the partnership has proven to be mutually beneficial for decades. The FAP is the latest example of how the clever arrangement has allowed for increasing benefits to Finnish society at large. While it is instinctive for many to point out RAY and the recipients of their funding are benefiting from the plight of gambling addictions, there are in fact safeguards in place to limit this as much as possible. For instance, RAY sponsors funding to NGOs focused on projects reducing gambling addiction in Finland, while its online gambling platform sets daily limits for users to stem gambling abuse.

Reinforcing the Approach for "Allergy Health"

The crux of scientific argumentation to justify the FAP stems from the concept of *allergy health* and the *biodiversity hypothesis*. To further elaborate on these points, Professor Tari Haahtela explained in lay terms how the first four years of the FAP was able to garner significant support from essential stakeholders reach its current level of success. According to Prof Haahtela, asthma and allergy prevalence in a society can be used as an indication for other increasing health problems. The increasing prevalence of allergy and asthma are thus a burden which augments over time in relative 'slow motion,' as the conditions are not symptomatic immediately of fatalities and costs to society.

The increasing prevalence can be attributed to the *biodiversity hypothesis*, which states a loss of biodiversity weakens immune systems. Conversely, a richer environment means richer skin microbes, and a stronger immune system capable of coping with diseases.

The *biodiversity hypothesis* received merit in Finland following the South Karelia Allergy Study, which revealed much higher prevalence for allergy in school children and in their mothers, from Finland than Russia within the very same region. Prof Haahtela argued allergy is indicative of long-term immune dysfunction (hypersensitivity, allergy, atopy) but while symptoms do not escalate over time, risks increase along with the presence of other co-morbidities. In a study surveying 66,000 employees in Finland from 2000-2005, individuals with both asthma and depression showed an increase of 3.5x more days off work due to long-term disability. As a result, the stakeholders of FAP have approached the question of allergy and its negative impact on society through supporting *allergy health*. The strategy for *allergy health* was outlined in a set of 'messages' which were forward onwards to nurses and doctors throughout Finland. These messages for improving *allergy health* focus upon broadly endorsing health (not allergy); strengthening tolerance; adopting new attitude towards allergy (avoidance only if mandatory); using available but limited resources for recognising, treating, and organising follow-ups of severe allergies (prevention); and improving air quality, most importantly through campaigning to curb smoking.

The medical practitioners were consulted to assure effectiveness of the messages and all endorsed them very positively; however, in practice, the processes for treatment unfortunately did not show great effectiveness. This deficiency between positive endorsement of messages and their lack of incorporation in practice can be attributed to a slow reception for change for medical practitioners who may not be accustomed to incorporating new and improved methods. From the public perspective, according to a Gallup poll from 2011, an allergy survey among the allergic adult population of Finland showed 54% of people believe "Support health, not allergy" is an appropriate message, while in contrast, only 13% endorsed "Avoidance of exposure is the best approach."

Within the FAP, the *biodiversity hypothesis* and a new philosophy of *allergy health* fuse together scientific evidence and popular public opinion to change the performance of medical practices for allergies. The FAP attributes trends in the environment, such as climate change, and in human behaviours, especially urbanisation, as key variables influencing the prevalence of allergy sensitivity within the Finnish population. Since such trends match and reflect those of other societies across much of Europe, it presents an intriguing approach towards allergy, which could be adaptable to other national or regional contexts. If indeed allergy and asthma prevalence are key indicators towards the overall health of people across European societies, the emphasis of the FAP upon *allergy health* could be pivotal in facilitating proactive approaches towards promoting awareness of allergy and asthma.

Posturing the FAP for Public Visibility

A contributing factor to the overall success of the FAP to date has been the public awareness campaign. Adjunct Professor Kimmo Saarinen, head of the South Karelia Allergy and Environment Institute as well as Project Coordinator of the Public Awareness Campaign for the FAP, gave specific examples to the national delegations and other visitors in attendance demonstrating different strategies which paid off. The 'target audience' for the FAP was never just "high-risk groups" of patients with severe allergy, but rather the media and general public so as to create momentum in a

genuine awareness campaign to jumpstart the project. Efforts focused upon using mediums like television, radio and internet while simultaneously distributing educational materials like leaflets, posters and hosting public events. As a result, the campaign did not target simply one demographic of Finnish society, but rather it sought to educate the entire society as a whole.

The starting point for the project was a simple questionnaire, which was able to properly orient the FAP towards understanding the needs of the public and find out what people know and think about allergies. At the outset of the media campaign, the questionnaire revealed 77% of the respondents “never heard of FAP” and most attributed allergies to being the result of pollution and increasing presence of chemicals in everyday life. After pinpointing particular topics for the media campaign to target when approaching the general public, the FAP commenced advertising on the radio over the course of two weeks in October 2011. Statistics show the radio campaign reached 85% of families with children, or 1.8 million people. Feedback for the radio campaign described the effort as informative and clear, but not entertaining or inspiring.

The FAP followed up its radio campaign by creating banners and purchasing space on two popular websites in Finland, the yellow pages and another with pregnant women as its primary target audience. While FAP representatives concede web banners are admittedly annoying for users, they are nevertheless extremely efficient in attracting attention. In addition, web banners proved to be even more cost-effective, totalling 11.000 EUR for 6 weeks of advertising divided between the two websites, which was far cheaper than the 48.000 EUR required for radio air time. Another outlet for the media campaign was a well-known social media service called ‘Suomi24,’ which is one of the most popular websites in Finland. The site is a unique social media medium which connects users to common themes or topics as social objects, which is biggest difference between Suomi24 and other social media such as Facebook. The FAP Suomi24 page is successful for attracting a broad demographic (25-49 years old) and to date has attracted 15,000 visitors.

The main lessons learned from the FAP media campaign so far are varied. In 2011 the FAP issued 5 press releases, hosted 2 seminars and 12 lectures, conducted 9 interviews and disseminated 20 publications while campaign posters were provided by an industry sponsor free of charge. These efforts contrast to the radio and internet media campaigns because they are targeting a different demographic. Prof Saarinen urged the delegations present to not exclude any demographics of the population and to “go to where the people are.” He encouraged other national programmes to think creatively for seeking funding and finding innovative inroads to increase appeal for different members of society with a stake in a national allergy program. Lastly, the FAP showed an interesting assessment of its media campaign methods in terms of money invested versus its impact upon the general public. These lessons were clear precedents for any other national allergy programmes and offered credible advice for popularising such an effort at a national scale.

Goals, Indicators and Current Trends

At the outset of the FAP in 2008, stakeholders established six very clear goals for the programme, which were paired with specific indicators in order to gauge effectiveness over time, particularly upon the conclusion of the programme. After four years of the FAP, Professors Erkka Valovirta, medical advisor of FILHA, and Tari Haahtela both presented optimistic results, strongly endorsing the goals as achievable. The goals are listed, along with their indicators and current progress, below:

- Prevent allergies.
 - Indicator:** prevalence of asthma, allergic rhinitis and atopic dermatitis reduces by **20%**
 - Current Trend:** no data yet, but several follow-ups ongoing
- Increase tolerance to allergens in the population
 - Indicator:** avoidance diets to foods decrease by **50%**
 - Current Trend:** Allergy diets in schools **-20%**, in daycare centres **-25%**, large variation across country
- Improve allergy diagnostics
 - Indicator:** all patients are tested in a quality certified allergy-testing centre
 - Current Trend:** On target, **50%** are now tested in a quality certified allergy-testing centre
- Reduce work related allergies.
 - Indicator:** their numbers decrease by **50%**
 - Current Trend:** Asthma down by **24%** (2005-2009 vs 2010)
- Focus to severe allergies and reduce attacks
 - Indicator:** “Good Allergy Care” (meaning individually guided self-management for all allergic diseases) employed in country, asthma attacks reduced by **40%**
 - Current Trend:** Reductions have been reported, studies for more data ongoing
- Reduce Costs caused by allergies.
 - Indicator:** total costs of allergic diseases reduced by **20% in 10 years**
 - Current Trend:** Yes in asthma, all major allergic conditions are taken into account in new estimates

In addition, from 2008-2012 the educational programme had more than 10,000 opinion leaders, specialists healthcare providers and other professionals participate in a three step educational programme. The steps consisted of (1) a launch for 21 central hospital districts (5 university hospital districts) for 2 hours, (2) education in food allergy at healthcare centers for ½ day, and (3) back to the central hospitals for a full Allergy Day event. The educational programme surveyed allergic people with the help of patient organisations for allergy & asthma, skin and lung health in 2011 in tandem with the public media campaign. The educational programme strives to achieve three different goals of short, medium and long-term consequences. The topics for 2011 and 2012 were anaphylaxis and food allergy, while in central hospital districts was tolerance induction and allergy health in children. The topics today, as well as for 2013 and 2014, are asthma and food allergy in central hospitals, and more generally, anaphylaxis and allergy specific immunotherapy, including food allergy.

First, the short-term goal is to hit early and hit hard, or in other word, see patients recover, have less symptoms and for medical professionals to detect severe allergy early and treat inflammation effectively. Second, the mid-term goal is the reduction of the burden of allergy for both patients and society by diminishing days off work, disability, emergencies, hospital days, unscheduled visits and costs while providing patients guided self-management to stop attacks and exacerbations proactively. Lastly, the long-term goal is to level off the incidence of new cases, taking a step from treatment to prevention, with practical advice offered to patients in order to increase immunological tolerance to allergies.

To date, evidence suggests great progress in meeting these goals using tools such as an anaphylaxis guide on allergies for patients. By offering practical advice to increase allergy tolerance in primary prevention highlights a strengthening immunity through increasing connections between patients

and the natural environment and in secondary and tertiary prevention by finding maintenance treatment for long-term control of the conditions. Success has been reported particularly with asthma as data reveals from 2001 to 2010 the number of reported cases for mild asthma has increased from 45% to 62%, while cases of moderate asthma have decreased from 45% to 35% and severe asthma from 10% to 4%. The data indicates greater awareness and better success in treatment for asthma patients as many asthma patients were able to bring their asthma under control within this period of time.

The Involvement of Healthcare Professionals, Nurses and Pharmacists

Representatives of the FAP reiterated success would not have been possible without the tireless persistence of healthcare professionals committed to making changes within the Finnish healthcare system within the framework of the programme. Professor Erkka Valovirta and Ms. Erja Tommila are a physician and nurse respectively who have dedicated significant time to participate in events at medical centers and hospitals, educating their peers by traveling to their regions of Finland for FAP workshops. For the success of a national program like the FAP, the most important resource are the individuals who have a network of national as well as regional contacts, are committed to making a difference, consistently communicate simple messages to increase the reach of their programme and tirelessly work towards fulfillment of the programme objectives.

The main messages given to participants during the meetings to increase effectiveness were “Go where people are, be creative and measure impact” and “A community problem needs a community solution.” Having a solid network of stakeholders across the country both nationally and regionally is a fundamental prerequisite for success which financial resources cannot bring alone. Additionally, the implementation of the project must occur in the everyday work of healthcare professionals, nurses and pharmacists side by side with grassroots stakeholders. However, to assure the healthcare professionals, nurses and pharmacists of Finland are acting towards the aims of the FAP on a daily basis, a strong educational campaign persists in building the momentum necessary across the nation.

In his presentation on the role of healthcare professionals in the FAP, Professor Valovirta detailed how FILHA frequently travels to hospitals and medical centers across Finland to provide educational meetings. These meetings were free of charge, during working hours and either hosted near healthcare units or within their respective units when possible. FILHA tries its best to tailor each meeting to the needs of the site being educated and each session is specifically designed towards facilitating interactions between primary care and specialists. With general practitioners (GPs), the meetings were typically ½ days, with some emphasis placed upon GPs making a few adjustments to their normal approaches with patients. Indeed, in order for patients to receive proper treatment, receiving a correct diagnosis is a prerequisite. As humans are slow to adapt to new approaches, or reluctant to give up old habits, e.g. dietary adjustments for food allergy, it is especially important GPs act assertively with their patients and do not delay in incorporating changes to their own practices. To help such adjustments, FILHA also used small publications, such as pocket booklets and fliers (~15cm x 10.3cm in size), which range from being check lists for GPs/healthcare professionals on how to approach allergic patients to auto-injector instructions for dissemination to patients themselves.

Key points of contact within the hospitals and medical centers apart from the healthcare professionals are the nurses, as the FAP currently boasts 156 nurses as points of contact across Finland. They are actively disseminating new materials and providing advertisements for FAP events,

acting as local representatives responsible for informing patients of their best possible means to increase their tolerance to allergy and reduce inflammation. Their importance was underscored as Professor Valovirta, presenting on behalf of Ms. Tommila, noted that out of “100 anaphylactic cases, only 10 patients received adrenaline shots and many need more than just 1 shot.” This statistic reflects the necessity for nurses to communicate to patients the necessity of adherence to treatment and sufficient preparedness for life threatening medical emergencies.

In addition, nurses must be reliable sources for informing the parents of children with allergy how to properly increase their tolerances. For example, in a survey 33% of parents believed their children have food allergy, whereas in reality, it is estimated only 4-5% of children really have one. A nurse can help ensure parents do not make incorrect diagnosis on their own initiative, especially since they check every autumn with primary and secondary schools in Finland to double check validity of allergy diets available in canteens. Nurses carry a heavy responsibility towards streamlining self-management properly and providing individualized communication and encouragement to patients for cautiously trying foods with positive skin tests to gradually increase tolerance induction.

A final strategic point of contact within the FAP for patients would be pharmacists, as in Finland there has been an attempt among the Association of Finnish Pharmacies (AFP) to professionalise pharmacists and change a ‘market’ image of the pharmacy into one of the ‘medical assistance’ center. Prior to the FAP, the AFP had an asthma programme in its pharmacies which was later adopted to accommodate the needs of the FAP when it came into force. Pharmacists participated in joint education sessions with physicians, nurses and pharmacists, received education through online courses and instructive videos. A long-term goal of AFP is to offer on-site education for patients, who can move to a special room out of the public with a pharmacist to learn how to properly use the treatments for their conditions. However, thus far, an obstacle for this goal has been funding, though private health insurance companies have offered reimbursements for patients who receive a specific prescription for a training session with a pharmacist from their GP or specialist.

EFA Member Delegation Approaches towards National Allergy Programmes

After all the presentations of the FAP, the EFA member delegations from Bulgaria, Italy (Tuscany) and Norway were offered the opportunity to discuss amongst themselves how to implement a similar national or regional programme for allergy. Representatives from EFA member organisations as well as vital stakeholders for any potential national or regional programmes in the countries present were able to brainstorm with each other. This provided an ideal and unique opportunity for delegations, often comprised of individuals who had never worked together prior, to collaborate exclusively on the matter of modeling and customizing the FAP for their local contexts.

The Bulgarian delegation confirmed the situation in their country for allergy is very serious, but there is also a long history and tradition for allergology as a separate specialty in medicine. They confirmed around 100 experienced allergologists currently exist in Bulgaria and patients of allergy have their treatment reimbursed by the National Insurance Fund. The Association of Bulgarians with Bronchial Asthma, Allergy and COPD (ABBA), an EFA member, confirmed they have supported many information campaigns in the country. The delegation maintained a national allergy programme could help reduce the impact of allergies on society and their negative impacts on patients’ quality of life. For it to be possible, they identified cooperation among stakeholders, an updated scientific database and finding alternative funding channels as the primary obstacles.

In contrast to the representation of other delegations, the delegation from Italy only sought the objective of outlining a regional allergy programme for Tuscany. They explained the high population density of Italy and structure of the healthcare system is fundamentally different from those of Bulgaria and Norway, thus making a regional programme more relevant and achievable. They elaborated on the difficulties of trying to pursue a national programme in stating there is a widespread lack of adherence to national guidelines and low awareness. A major obstacle identified by the delegation was the difficulty of assembling a central scientific database for allergy research as there would be a tremendous difficulty in convincing researchers and scientists to bring together all studies relevant to allergy to create a scientific basis for such a program.

Next, they stated an interest in researching possible channels for EU funding to help develop the regional programme because while a comparable association like RAY already exists for lotteries, it currently provides funding to renovate historically significant buildings in Italy and they would not want to become competitors. While the delegation claims their short-term ambition is to improve the situation, their long-term objectives are to create a solid regional network for stakeholders, introduce quality certification for allergy care matching patient needs and the creation of an anaphylaxis register. Lastly, the delegation stated they could measure success by the number of admissions to the emergency rooms of hospitals for asthma and anaphylaxis, through asthma controls with GPs or parental satisfaction and increasing local members to patient organisations.

The Norwegian delegation also differed from the others in that all participants were representatives from the Norwegian Asthma and Allergy Federation (NAAF) because legal restrictions and barriers existed for involving a more diverse group of stakeholders. In addition, the Norwegian government had recently begun extensive collaboration with the Finnish government to begin a Norwegian Allergy Programme in coming years. The model of the programme would be a replica of the Finnish programme tailored to the Norwegian population. The delegation present confirmed NAAF sent a proposal to the government for a 10 year programme funded by the national government. However, the Norwegian government confirmed its commitment would be only for 6 years so far. Within the Norwegian context, the delegation discussed the necessity of a “consensus conference” for all stakeholders, with social media input in advance. They believe it would be the only way to successfully gain an individualistic approach to a national programme as it could lead to the creation of a “programme committee” assigning specific responsibilities to national stakeholders.

Conclusions

The FAP represents an extraordinary effort on the part of its national stakeholders to empower patients and reduce the burden of respiratory allergies on Finnish society. EFA sees the FAP as a standard to which other European countries, and indeed countries around the world, should seek to model themselves after. The opportunity to mobilize a national network to cut the systemic costs and increase benefits to patients’ lives should not be underestimated, even if the national circumstances in Finland were very ripe for such an initiative. The innovative approach towards funding the FAP stands out as a unique basis for additional programmes in Finland, which could ultimately be tailored for other countries striving to reduce the influence of organised crime in gambling and redirect proceeds towards beneficial ends.

EFA strongly encourages all of its members, and relevant stake holders in European countries, to strive for making concrete commitments towards constructing the necessary foundations for national allergy programmes. Future educational meetings will be organised and those EFA members expressing interest first will be given priority to attend. The next delegations to take advantage of this opportunity in Helsinki must reflect the same commitment and diversity of stakeholders to effectively mobilize a national or regional programme. A demonstration of commitment create such a programme would be the most important prerequisite required for participation.

In order to successfully achieve this, EFA members must seek to include all relevant stakeholders of a given country or region in the allergy programme – policymakers, healthcare professionals, experts, specialists, patients, pharmacists, nurses, healthcare insurers, etc. Next, it has been demonstrated by the Finnish experience it is necessary to keep the goals of a national program simple and measurable. This is closely followed by agreement among stakeholders upon clear responsibilities for the implementation of the programme and assurance of the daily actions required to make such a programme effective. Lastly, it is imperative for stakeholders to be creative in finding their funding partners because in a time of financial crisis, there are no easy answers to the question ‘where will the money come from?’ EFA commends the FAP for its successes to date and sincerely thanks the EFA member delegations, FAP representatives and sustainable funding partners, who all made the experience possible and enlightening for those in attendance.

Any further questions on the EFA Allergy Awareness Project can be directed to antje.finkwagner@efanet.org or info@efanet.org while questions regarding the Finnish Allergy Programme can be sent to Erkka.Valovirta@terveystalo.com.