



David Brennan

EFA Meeting Report

March 2014

Report on the results of the EFA Baltic Alignment Meeting

CONTI Hotel, Vilnius, Lithuania – 15 February 2014

Participants:

EFA

Board Member	Lina Buzermanienė
Membership and Programme Manager	David Brennan
Policy and Programme Assistant	Jan Meissner

Latvian Asthma and Allergy Association

President	Rita Paeglītē
Board Member	Inese Vīcupe

Lithuanian Council of Asthma Clubs

Chair	Lina Buzermanienė
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Association of Allergic Children Clubs

Board Member	Inga Zalnerauskienė
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Association of Asthma Patient Clubs

Chair	Eglė Kvederaitė
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Purpose

EFA's membership has never included patient associations for allergy, asthma or COPD from Latvia or Estonia to date. The meeting in Vilnius served to attract the different patient associations in Estonia, Latvia and Lithuania to meet with the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) and inform of the organisations' structure, representation and to also specify prospects for future collaboration between the organisations. The associations were to identify areas for collaboration and objectives in view of creating facilitating eventual membership for people with allergy, asthma and COPD in EFA throughout each of the Baltic countries.

Introduction

On the 15th of February 2014, EFA coordinated an alignment meeting to familiarise itself with the patient associations of the Baltic nations Estonia, Latvia and Lithuania. The rationale of the meeting was to provide an opportunity for these organisations present at the meeting to identify major challenges confronting them at the national level and to discuss the potential for membership of Baltic associations in EFA. The meeting provided opportunities for the Baltic associations in attendance to present their recent activities and also for EFA to familiarise those attending with its recent work and future plans. As a part of its objectives, EFA aims to expand its membership of patients' associations throughout all of Europe so people with allergy, asthma and COPD are strongly and democratically represented at all levels, including the European institutions. Unfortunately,

although the patient associations for allergy, asthma and COPD were contacted and expressed interest in joining the meeting, they were unavailable to attend the meeting although initially confirming attendance. Nevertheless, the Latvian Asthma and Allergy Association met EFA in the first official meeting where they were able to present activities in Latvia for asthma and allergy patients to EFA. Chairing the event was Board Member Lina Buzermanienė while EFA Membership and Programme Manager David Brennan and EFA Policy and Programme Intern Jan Meissner were present for EFA to help present its recent activities and Mr. Meissner provided Latvian translation.

Overview for the Presentations of the Baltic Patient Associations and EFA

After a working lunch where EFA members and the meeting participants had an opportunity to greet and discuss topics of mutual interest informally, the meeting began afterwards with personal introductions and the opportunity for both EFA and the Baltic association representatives to present their most recent activities, future goals and main objectives. After Mrs. Buzermanienė provided welcoming statements, each of the participants introduced themselves. Many participants became active in their organisations due to first-hand experience with the diseases themselves or among family members. For instance, Inga Zalnerauskienė, a Board member from the Association of Allergic Children Clubs in Lithuania, explained her role in helping a kindergarten for asthmatic and allergic students in Kaunas has been inspired by her own allergies and because many of her children and other family members have asthma and/or allergy. Mrs. Buzermanienė confirmed similarly she became involved with the Lithuanian Council of Asthma Clubs in Lithuania because her son had allergy from birth, later developing asthma and rhinitis.

Afterwards, EFA representatives Mrs. Buzermanienė, Mr. Brennan and Mr. Meissner presented on a wide range of topics, such as the organisation's structure, values, goals and membership criteria. Annual activities were detailed along with EFA's other events, membership training, projects and involvement with European Commission funded projects as well. EFA members responded to questions and provided clarification to the meeting participants in an interactive and engaging fashion. The resulting dialogue between participants and with EFA is described in the **Discussion** portion of the report. The presentation overviewed EFA to provide a comprehensive snapshot into areas where the Baltic associations may have an interest to become members in the future. EFA's presentation is available for download on its [website](#).

The Association of Allergy Children Clubs and the Lithuanian Council of Asthma Clubs work together frequently. The Lithuanian Council of Asthma Clubs was established in 2001 with a membership of mostly children and their carers but has since grown to 21 member organisations from different cities and towns across the country. There is a board of 5 members with a budget coming mostly from its membership and the highest governing body in the organisation is its general meeting of members. In the past they have commemorated World Asthma Day but there have been no major public events since 2011 because of funding issues and this is mostly an activity now in the local communities. The organisation also provides a cycle of seminars of "Asthma at School" for teachers and school nurses. There is still ongoing collaboration with healthcare practitioners in pulmonary and paediatric societies as they often are invited to participate in their annual conferences. As an EFA member since 2005, it has benefited from presentations of experiences and activities of other EFA members as it simultaneously strengthens its acceptance and national image at home in Lithuania.

Next the representatives from the Latvian Asthma and Allergy Association presented their association, which was founded after an asthma patient mountain trekking trip to the Crimea and Central Asia led by a healthcare professional. There are part-time employees at the association who are currently helping to support their activities. A collaborative project with EFA's Swedish member, the Swedish Asthma and Allergy Association, was a very important opportunity to share experiences over a period of five years. However, unfortunately when Latvia gained EU membership this collaboration was discontinued as funding for the activity depended upon Latvia's status as a non-EU nation. They also confirmed continuing activities in SUSTENO, an umbrella organisation of patient

associations in Latvia, is important for influencing decision making at the national level. For fifteen years the association has also continued to hold World Asthma Day celebrations in Riga while recently they have also promoted World COPD Day with spirometry in big shopping centres and a government building. Other regular activities include anti-smoking campaigns in schools and hospitals with several projects including one focusing on children's asthma, a summer camp for parents and their children, a support centre for patients, radio publicity, Nordic walking and maintenance of a website which is approved by healthcare practitioners. While the organisation does not currently represent COPD patients yet, they are searching for ways to include them.

The final presentation was by Eglė Kvederaitė from the Association of Asthma Patient Clubs, which started as a local asthma club in Vilnius in 1997. She cited previous cooperation with the Latvian Asthma and Allergy Association as early as 2003 with a cycling trip, which coincided with the founding of the organisation. For the time being the association is working to represent asthma patients in the Lithuanian government to influence decisions by the health ministry and councils. However, for the last three or four years there have been no large public activities due to a limited budget. Income for the organisation is from donations, where 2% of income tax in Lithuania can be directed by citizens to a nonprofit or charity of their choice. All staff for the organisation are volunteers with full time jobs in other fields. While in the past there were instructional trainings for asthma patients, this activity was discontinued due to low interest from patients and high honorariums requested from the healthcare practitioners. There is an interest to reach out to COPD patients, but few were willing to participate in activities addressed to this disease area.

Discussion: Key Points and Obstacles Observed

Among the first points for discussion was the question of reimbursements for asthma patients in both Lithuania and Latvia. Mrs. Paeglītė recalled that in Latvia state funding for medicines is 3.2% of GDP with 75% reimbursement of asthma medication and 50% reimbursement for COPD. She stated asthma medications were 90% reimbursed, but this has since dropped to the current level in recent years. As a contrast, Mrs. Kvederaitė confirmed that in Lithuania 100% of asthma medication is reimbursed and 80% of COPD medications are currently reimbursed. The only cost to asthma patients is a 'symbolic payment' of approximately 1€ for treatment. Nevertheless, Mrs. Kvederaitė described the preservation of full reimbursement for asthma patients as being a difficult struggle at times because the Lithuanian health minister has issues in communicating consistently to the patient organisations in Lithuania. The majority of her organisation's efforts have been in influencing the national health policymakers and convincing them not to accept a recent proposal to reduce reimbursement to 80%.

EFA requested the patient associations attending to confirm if there are any patient associations representing people with COPD in Latvia and Lithuania. None of the associations attending could confirm having interacted with or hearing about the creation of COPD organisations at the national or local levels in their countries. However, both the Latvian Asthma and Allergy Association and Association of Asthma Patient Clubs both expressed interest in expanding their roles as advocates for patients with COPD in Lithuania and Latvia. In Latvia, while their association has expanded activities like spirometry for the World COPD Day, they have not yet found an effective strategy for bringing COPD patients into the organisation. The COPD patients in both countries typically have multiple comorbidities and many are still active smokers.

It was agreed by those attending that in both Latvia and Lithuania it is very difficult to contact COPD patients because they struggle with a negative image or stigmatisation in the eyes of other patients and the public because their disease is considered self-inflicted. Mrs. Kvederaitė described members of her association with asthma were very reluctant to include COPD patients or activities for COPD within the association because of the notion that COPD is largely 'self-inflicted' and many could still be smokers. She confirmed this is largely the public attitude and as a result COPD patients do not seek recognition and the more serious their condition is, the less they leave home. However, despite

this, her organisation has tried reaching out to COPD patients in the past but activities for this disease area failed to attract more than a handful of patients to participate. Mrs. Buzermanienė hoped this perception among the public and attitude of the COPD patients could be changed in the future with better public awareness that COPD can also result from passive smoking and unsafe working environments.

For allergy and asthma patients in Latvia and Lithuania, there does not appear to be any major problems with 'image' of the disease, but rather problems seem to stem from behaviour of the patients themselves. Mrs. Vīcupe believed patients are not necessarily very active and in the past only when the association offered free informative materials they were popular but interest diminished when these free materials were no longer provided. There appears to be a high interest in the use of medical treatments but a very low interest in learning about or locating information for the medications themselves. All the representatives agreed there is no 'culture' of volunteering at least among older generations but even though young people of their countries are starting to volunteer often, their interest is not commonly in health issues. Mrs. Zalnerauskienė believed locally youths sometimes have their own meetings and then stay involved afterwards in activities through the local clubs. Mrs. Paeglītė believed it was common for people to express support publically when their organisation organises large activities and are happy to participate but they often do not have much interest in helping the organisation afterwards.

All association representatives also agreed among the greatest challenges for their organisations would be finding financial support. In at least Lithuania, there only appeared to be funding available from pharmaceutical industry to sponsor the medical professional organisations during the last 4-5 years while patient organisations have largely lost their support. The Latvian Allergy and Asthma Association identified the key barrier to EFA membership would be finding the financial support necessary to pay the annual membership fee. Both Lithuanian organisations currently depend upon volunteers and agreed there is very short notice for patient organisations to provide feedback when the Lithuanian ministry of health with very complex coding in their content. As a result, with voluntary commitments, it becomes very difficult to assure patient interests are consistently represented because a lack of resources makes the organisations dependent upon committed individuals and their relationship to government contacts.

Conclusions

The alignment meeting in Vilnius allowed for the improvement of EFA's understanding of the situations in Latvia and Lithuania for allergy and asthma patients. In fact, EFA also gained important insights for the situation of patients with COPD in these countries as well. In addition, the sharing of activities and facilitating an opportunity for the Latvian and Lithuanian organisations to meet was able to reveal common problems confronting their activities and provide the opportunity to re-establish contact with each other.

An interesting observation included a contrast between the successful mobilisation of patients at a national level in Latvia to the successful mobilisation of patients at the local level in Lithuania. These opposite success stories highlight areas for collaboration and the sharing of best practices with EFA potentially as a venue for this type of activity to occur in the future. The participants at the meeting expressed interest to increase collaboration and discuss how to build from the best practices of one another since they appear to have great success in different areas of activity.

The Latvian Allergy and Asthma Association expressed interest in furthering their collaboration with EFA in the future and consider application for membership. Nevertheless, membership was viewed as beneficial for their association in helping their understanding of how the EU may affect their disease areas locally and in increasing their leverage influencing decision makers at the Ministry of Health, who could be inclined to take their association's requests seriously with the backing of a larger European organisation. EFA's current Lithuanian members agreed these were key benefits which continue to encourage the continuation of their membership.

A primary challenge that remains for EFA to address in welcoming the Latvian association with membership will be firstly to assist their efforts to locate sufficient funding to cover EFA's membership dues. Apart from this important point, there appears to be an additional challenge presented by the language barrier English could present to communication with the EFA office – nevertheless, increasing the number of staff members at EFA creates a diverse secretariat, which may help to reduce this barrier in the future. The Latvian association had been encouraged to apply for membership despite its financial concerns to demonstrate its interest to the EFA Board as well as the EFA members so at the general assembly they could have the chance to discuss this further.

In retrospect, it is regrettable the meeting did not include any representatives from Estonian associations for allergy, asthma and COPD. It would have been very helpful to have had the Estonian COPD association so they could share their experience in attracting membership and participation in public activities. However, EFA welcomes the interest expressed by the Estonian associations contacted and will assess potential ways to deepen collaboration with the organisations. In the future, EFA may consider increasing follow-up by phone after initial invitation proposals to alignment meetings assure a date can be agreed upon by all parties as far in advance as possible.

Proposed next steps

- EFA to send report to the Baltic patient organisations in attendance for comments
- EFA to share presentations from the meeting on the EFA website
- EFA to send membership application to the Latvian Allergy and Asthma Association
- EFA to provide support, where possible, in discussions with potential funding partners in both Latvia and Lithuania