



David Brennan

**EFA Meeting Report**

**September 2013**

**Report on the results of the EFA-Maltese Asthma Society Alignment Meeting**

*Intercontinental Hotel, St Julian's, Malta – 28 September 2013*

**Participants:**

**EFA**

President	Breda Flood
Executive Officer	Susanna Palkonen*
Membership and Programme Officer	David Brennan

**Maltese Asthma Society**

Chair	Stephen Healey
Treasurer	Tessie Caruana
Nursing Officer	Doris Borg
Secretary	Anna Caruana
Member	Josephine Ellul
Member	Horace Cachia
Member	Rosemary Ellul
Co-Founder	Professor Stephen Montefort*

*\*Participants who were not available for the entire meeting*

**Purpose**

EFA does not have a member in Malta to date. The meeting with the Maltese Asthma Society (MAS) served to inform the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) of the organisations' structure, representation and to also specify prospects for future collaboration between the two organisations. The associations were to spend time identifying areas for aligning common goals and objectives in view of creating the possibility for the representation of Maltese people with allergy, asthma and COPD in EFA through a Maltese membership.

**Introduction**

On 28 September 2013, EFA coordinated a meeting with the Maltese Asthma Society to familiarise itself with present challenges impeding cooperation between patients' associations at the national level and membership of Maltese associations of people with allergy, asthma and COPD in EFA. The meeting provided opportunities for the presentation of both the Maltese Asthma Society and EFA in order to familiarise those attending with each other's activities. One goal of EFA is to expand membership of patients' associations throughout all of Europe so that people with allergy, asthma and COPD are strongly and democratically represented at all levels, including the European institutions. The meeting was the first of its kind in serving to increase efforts to promote awareness of the needs for Maltese asthma patients with a European federation and the first meeting for EFA with a Maltese patients association with an interest to apply for EFA membership. EFA President Breda Flood and EFA Membership and Programme Officer David Brennan were present for EFA to present its recent activities. EFA Executive Officer Susanna Palkonen arrived later-on in the meeting for final discussions with the Maltese Asthma Society.

## **Overview for the Presentations of the Maltese Asthma Society and EFA**

The meeting itself began with personal introductions and the opportunity for both EFA and the Maltese Asthma Society representatives to present their most recent activities as well as future goals and objectives as an organisation. After Mrs. Flood provided welcoming statements, the current chair of the Maltese Asthma Society, Mr. Stephen Healey, presented on behalf of his organisation. He pointed out approximately 40,000 people in Malta's total population of roughly 400,000 have a respiratory disease, which could be credited to an abundance of dust, pollen and air pollution. As a result, in Malta there is one of the highest prevalence rates among European countries proportionally to its total population for respiratory diseases.

The Maltese Asthma Society was co-founded in 2004 by Professor Stephen Montefort and Dr Anna Mallia, a lawyer by trade, whose original intention was to eventually pass over control of the organisation to asthma patients after initial years in building membership and objectives. The organisation has a committee of 8 asthma patients and 1 non-patient as the main governmental organ; however, the organisation has no office and holds public meetings at Mater Dei Hospital, which is the only one in Malta. The public meetings always invite its members as well as healthcare professionals, providing the chance for a questions and answers session.

Additional events include the commemoration of World Asthma Day, which usually occurs in a hotel with a representative from the Maltese Health Ministry as well as representatives of the press. In the past, the Maltese Asthma Society also had visited schools to provide information to students as well as teachers about how to properly treat asthma. In recent years, these visits were not possible due to a growing amount of bureaucratic restrictions and procedures which exhausted the time of volunteers. Nevertheless, these visits will be restarted in the near future as soon as possible.

Afterwards, EFA representatives Mrs. Breda Flood and Mr. David Brennan 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. The presentation overviewed EFA to provide a comprehensive snapshot into areas where MAS may have an interest to become members in the future. EFA's presentation is available for download on its [website](#).

## **Key Points and Obstacles Observed**

There were several reoccurring points for discussion throughout their organisation's self-presentation and in the discussion which followed. Firstly, representatives of the MAS expressed the most concern for the mentality of Maltese people with regards to asthma more broadly in society. All participants from Malta agreed asthma is a stigmatised disease and Maltese people with asthma are rarely willing to admit they have the condition publically. In fact, when the Maltese Asthma Society organises meetings, they credit this stigmatisation of asthma for a disproportionately low participation from the public. Since it is a known fact there are so many people with asthma in Malta, their low willingness to ask for help indicates a true obstacle for the MAS for recruiting members. As evidence, Prof. Montefort confirmed when he makes appointments for people with asthma in Gozo, Malta's other main island to the north, he returns to Malta to find patients from Gozo waiting because they do not want to be seen by their neighbours at the doctor's office for asthma treatment.

In addition, representatives from the MAS pointed out sometimes children with asthma in Malta are prohibited from using their inhalers in school. While they are usually allowed to bring them to school, there are restrictions on their ability to use them. EFA views this as a crucial impediment for effectively treating children and adolescents for asthma because it discourages them from using their medication when it is needed and reinforces the stigmatisation of asthma as described above. People are already reluctant to admit they have asthma and parents will consider holding their children from sports because it is not considered something that should be 'public.' The children and adolescents, whether inside or outside of school, may also choose not to use the medication. Some schools in Malta may decide to purchase medication themselves in case of an emergency with a student but there are many schools which have no health or safety officers, so there are no measures in place for

support to avoid taking responsibility for episodes. In such schools without appointed health or safety officers, a parent may need to rush home from work or to the school to pick up their child if they have an asthma related episode.

The MAS also confirmed there is no national asthma programme in the country, but there is very good access to asthma treatment. In fact, the representatives believed the provision of free asthma medication for people could be encouraging the abuse of the system in place. However, they were careful to state most people who do abuse the system have not learned how to properly treat their asthma and are in need of better education of their condition. Additionally, asthma patients in Malta were described as passive, where they are normally unwilling to be proactive with their condition as they are less inclined to 'give' time for or invest in proper education on asthma treatment. Nurses offer treatment advice and training to asthma patients in clinics, but it is clear not all asthma patients in Malta are proactive enough to take advantage of these services yet.

There is a very high concentration of people with asthma in Malta, particularly near the most urbanised and industrialised parts of the country. It is widely believed the problems with respiratory health in Malta are attributable to higher concentrations of air pollution as the result of industry and traffic. Even with fresh air from the sea and generally good climate for asthmatics, these factors still allow for Maltese with asthma to experience complications. Nevertheless, Prof. Montefort confirmed asthma has decreasing severity in the country since access to treatment is so good and proper compliance can resolve such issues with ease.

The last major point of discussion was the access to treatment if supplies are exhausted for the free supply of asthma medications. In the experience of the representatives from the MAS during their travels in Europe, they have noted the same medications used in Malta are available for half or a third of the price in other countries, such as Italy and France. When in contact with pharmaceutical companies, they are told the higher price is due to the 'small market' in the country. As a result, treatment for people with asthma when supplies are exhausted becomes extremely expensive and difficult for many Maltese people to afford. However, this problem is generally problematic for the healthcare system in Malta, and not limited to asthma treatments.

## **Discussion**

EFA finds the obstacle of asthma's stigmatisation in Malta to be one of the trickiest obstacles for a patient association to overcome; however it is not impossible. In Ireland, Mrs. Flood cited cystic fibrosis patients have a similar problem and encouraged the representatives present to use positive messages to overcome the stigma. She also provided the example publication of "[Reach Your Peak with Asthma](#)," which was used to help motivate people with asthma in Ireland to live normal lives by seeking appropriate treatment. The publication used famous Irish athletes from football and rugby with international recognition who have asthma to appear as spokespersons to help send positive messages to society. The MAS may consider a similar tactic in the future by finding a high profile Maltese celebrity or athlete in the country who can help them publically fight the stigma for asthma.

With regards to addressing asthma in their school systems, EFA believes it to be imperative that children and adolescents have the right to bring asthma medication and use it there, at the least with adult supervision if necessary. It was also surprising to hear in some schools there is no appointed health or safety representative, which should be considered a point for urgent change. The resolution of both these issues related to school can simultaneously help to remedy problems resulting from the stigmatisation of asthma while assuring a higher level of compliance. If children in school see their peers using asthma treatment, it would hopefully encourage all the children with asthma to do the same thus normalising asthma in the next generation of Maltese society. If children and adolescents have recess during school or physical education courses, instructors just prior should remind students to use medication about five to ten minutes prior so those with exercise induced asthma can prevent any risks beforehand.

During the meeting, it was acknowledged that diabetes patients in Malta are easily the most empowered of all the disease areas, in that they have support groups and links to the healthcare

system which allows for patients to be more 'proactive' with their condition. One option could be to pursue a similar course as diabetes patients in Malta, who were noted as being the most proactive and successful. In addition, a **Maltese Eczema Society** was acknowledged to exist, which may present for an opportunity to create an umbrella organisation for allergy and asthma in Malta, whether a formal or a coalition for collaboration. EFA welcomes these societies to work together and identify areas for future collaboration or even merger if possible.

During discussions, both **COPD and food allergy** were also mentioned, however it was acknowledged neither have official patient organisations to date. However, chronic obstructive pulmonary disease (COPD) has a support group at the Mater Dei Hospital and consideration could be given to for to serve as a starting point for COPD patients to become organised in an association. Ideally, EFA believes if the MAS were to combine efforts with patients in all the disease areas of EFA, it could lead to a national patient organisation for allergy, asthma and COPD. This can create a broader platform for public awareness and efforts to counter the stigmatisation of asthma in society.

## **Conclusions**

The alignment meeting in Malta successfully increased EFA's understanding of the situation for Maltese patients with asthma and the introduction its work; in fact, EFA was also gained important insights for the situation of patient associations in EFA's other disease areas of allergy and COPD as well. The meeting participants expressed interest in collaborating with EFA in the future and consider the possibility for membership to be beneficial for their association for a variety of reasons. For instance, it could help their visibility nationally, as the Ministry of Health could be inclined to take their association's requests seriously with the backing of a larger European federation. In addition, their ability to participate in training activities and at European level events could also provide inspiration for new ideas and approaches to improving the association's status quo.

The MAS also expressed interest to be considered potential partners in EU projects and research of asthma and indoor air quality effects on school children, such as the ISAAC, SINPHONIE and RESPIRA studies. EFA presented its latest project involvement in the European Asthma Research and Innovation Partnership (EARIP), and the MAS expressed interest in being updated on the project activities as the project continues to grow and progress over time.

A challenge that remains for EFA in welcoming the MAS within membership will be primarily to assist their efforts to locate sufficient funding to cover EFA's membership dues. Apart from this important point, the MAS showed interest in becoming members should the organisation's financial situation improve. The suggestion of joining forces with the Maltese Eczema Society and to begin the mobilisation of COPD patients in Malta could provide an important basis for the creation of a broader Maltese patient association including allergy, asthma and COPD. Indeed, this could provide a broader pooling of human resources to help distribute workloads and collaboration with EFA.

In retrospect, it would have been very helpful to have asked prior to the meeting if the MAS was aware of any other societies for EFA's disease areas. However, EFA welcomes the willingness of the MAS to take a leading role in deepening collaboration with the Eczema Society. For future meetings, confirmed attendees for any other national alignment meeting can always be asked if there are any other associations which could be interested in attending.

## **Proposed next steps**

- Send report to the Maltese Asthma Society for comments
- Share presentations from the meeting
- Send application for EFA membership to the Maltese Asthma Society, EFA to provide support, where possible, in discussions with potential funding partners in Malta
- Maltese Asthma Society to internally discuss the potential for EFA membership at next public meeting as well as possibilities to align with the Maltese Eczema Society