

GAAPP Activity Report 2015-2017 June

June 2017

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Introduction

GAAPP is a global association of organizations advocating the rights and interests of people with allergies and asthma. GAAPP's mission is to support patients with allergies and asthma throughout the world by protecting their rights and insisting on the duties of governments, health-care professional organizations, and the general public. The GAAPP mission and our objectives were defined at the general meeting 2011 in Istanbul. GAAPP is now in its 8th year.

It is important to keep our objectives in mind to work as effective as possible in an organization, which still is young, growing and needs to find into its role.

The objectives are:

- To establish a global network to empower the patient voice.
- To work together with Governmental and health-care organizations to minimize the impact of allergies and asthma.
- To be an equal partner involved in the decision-making from inception to conclusion with global health-care organizations.
- To assist the founding of patient organizations in emerging countries.
- To support patients wanting to have an active role in managing their disease, and to empower patients' families, care givers and health-care professionals to support patients in managing their allergies and asthma.
- To support the health and social policy concerns of member organizations.
- To fight for best-practice therapy.
- To support emerging countries in providing patients suffering from allergies and asthma with the necessary diagnostic and therapeutic remedies.
- To support the demand of allergy and asthma patients to live in unpolluted healthy air.

GAAPP is growing frequently and has currently 34 member organizations on all continents.

This report gives a summary of our activities from the last General Meeting on September 2015 at Amsterdam, Netherlands until the June of 2017.

We are looking forward to have a fruitful discussion at Helsinki.

PIPA-Programa Infantil de Prevencia de Asma, Brazil

Asthma Society of Canada, Canada

China Allergy and Asthma Patient Platform CAAPP, China

Czech Initiative for Asthma, Czech Republic

Asthma and Allergies Association, Ethiopia

European Federation of Allergy and Airways Diseases Patients' Associations,
Europe, Belgium

Allergia-ja Astmaliitto (Allergy and Asthma Federation), Finland

Association Asthme & Allergies, France

ANIKSI, Greece

Magyar Allergia Szövetség (Hungarian Allergy Association), Hungary

Allergy Care, India

Asthma Society of Ireland, Ireland

Food Allergy Italia, Italy

Liberia Asthma Society, Liberia

Lithuanian Council of Asthma Clubs, Lithuania

CREAA, Mexico

Norges Astma- og Allergiforbundet, Norway

Panamanian Association of Asthma and Sport, Panama

Polish Federation of Asthma, Allergy and COPD Patients' Organisations, Poland

Portuguese Asthma Patients Association APA, Portugal

National Asthma Education Program NAEP, South Africa

Asthma and Allergy Association (Astma och Allergi Förbundet), Sweden

aha! Swiss Allergy Center, Switzerland

Allergy UK, United Kingdom

Asthma UK, United Kingdom

Fundación Ramón Guerra Somma Moreira, Uruguay

Asthma and Allergy Foundation of America (AAFA), U.S.A.

Allergy & Asthma Network, U.S.A.

UNASMA Fundación Internacional de Asma y Alergia

Please find the GAAPP membership form here:

http://ga2p2.org/documents/gaapp_membership_form.pdf

The annual membership fee is currently €0,00. The last General Meeting participants decided to keep it on this level to provide the opportunity to become a member of GAAPP also to low income organizations. This issue has to be discussed at the General Meeting 2017.

Memberships/ Cooperation

In the **WHO-GARD** assembly meeting 2015 in Lisbon Mrs. Kristine Whorlow, CEO, National Asthma Council Australia was elected as GAAPP representative into the planning committee. A WHO-GARD planning meeting took place in Geneva on 30 and 31 January 2017. The WHO-GARD meeting 2017 will be in Brussels in autumn.

WAO, the cooperation was ongoing

Interasma, the world asthma association invited GAAPP Executive Director to serve as board member. GAAPP was present at World Conference of Asthma in March 2016 at Madrid. Interasma gave GAAPP the opportunity to give 2 presentations and offered space for free of charge booth.

SLaai - Sociedad Latinoamericana de Alergia, Asma e Immunologia invited GAAPP to present special patient issues and activities at its conference 2015 at Buenos

Aires and GAAPP together with Fundaler was invited to run patient sessions. GAAPP was also exhibiting and creating awareness.

Pulmocon, International Conference on Lung Health Pulmocon in February 2015. GAAPP was represented with 2 presentations at the conference and with patient education trainings done by Otto Spranger with the aim to build national patient organizations.

GINA invited the GAAPP to participate in the 2015 briefing meeting of their delegates, which was a completely new sign of acceptance of patient initiatives. Until now we are still waiting to get a seat.

EAACI, offered GAAPP the booth free of charge at their conferences 2015, 2016 and 2017.

ERS, focuses on European Patient Organizations, until 2015 we always got a booth free of charge. In 2015 (on 30 September) GAAPP got a time slot at the World Village Theater to present GAAPP. For better acceptance GAAPP needs to submit poster and lectures. In 2016 ERS offered no booth, only for European organisations. 2017 ERS formally invited GAAPP to participate in the IPAC (International Patient Advisory Committee) at their congress in September 2017

ASIA, AFRICA: To become fully accepted GAAPP needs to find more relations to the relevant Asian and African organizations and to start cooperation in projects with these organizations to represent the patient voice more powerful.

In Europe our member EFA is fully integrated into projects with EAACI, ERS and EU.

GAAPP Constitution

Please find the GAAPP constitution as approved at the general meeting at Istanbul here: http://www.ga2p2.org/documents/GAAPP_Constitution_ENG.pdf

Strategic Priorities

In 2015-2016 the GAAPP office, following the decisions of the GM 2015, focused on better **awareness** of GAAPP at the scientific organizations conferences. The acquisition of new members was also a focus.

GAAPP invested into an **APP for Urticaria**, since we realized that Urticaria often is understood as an allergy and we try to better educate patients on that. During 2015 and 2016 the Urticaria App become available in English, German, Portuguese and Spanish. In 2017 a photo gallery was added, so patients can photograph the hives and show it to their doctor.

GAAPP was step by step working on its **webpage** as one small puzzle of better communication. It is not finished yet and some content has to be filled in. However, the website will only become a lively tool if all GAAPP members contribute to the content.

GAAPP has intensely tried to get more funds and a better level of fundraising, the departure of Antje-Henriette Fink-Wagner was a big loss and left a big gap, because also the office came to a nearly full stop. Antje is still helping as a kind of “special projects manager”.

Main Activities

Fundraising

Our focus is currently the pharmaceutical industry. It took a while until the companies realized GAAPP. Fundraising suffers from lack of manpower. Since 2015 we only had Novartis, Stallergenes and Roche. GAAPP’s main sponsorship currently comes from private funding, especially from board members. GAAPP would not be what it is without this significant investment.

Advocacy

GAAPP has small stand banners, posters and a promotional brochure. GAAPP is present at the main global respiratory conferences as reported to raise awareness.

GAAPP GM 2015 decided to start cooperation with COPD organizations in the future. Discussion will be continued at the GM 2017.

THE GAAPP ambassadors program is still pending, the office started to invite ambassadors and advisors directly, but this is on hold now due to lack of personnel.

GAAPP needs a global allergy advisory board and ambassadors. GAAPP office requests to have the GM approval to name Prof. Antonella Muraro, Italy, Professor

P. Demoly, France, Dr. Maximiliano Gomez, Argentina and Erkkä Valovirta, Finland medical advisors of GAAPP for Allergy. Additional suggestions are welcomed.

GAAPP is more and more invited by scientific organizations and industry to participate in advisory meetings and boards.

Otto Spranger, as representative of the Austrian patient organization, was invited from the EAACI Guidelines Committee for venom AIT to become a co-worker.

Projects

GAAPP is in discussions with companies about a global severe asthma survey to create a kind of “severe asthma white book”.

GAAPP is working on the Urticaria App in Russian.

Prepare information about atopic dermatitis, as starting point of the allergic march.

Capacity Building

Under voluntary conditions we were unable to find a replacement for A.-H.Fink-Wagner and therefore we failed in making more progress.

Communication

All GAAPP members are asked to inform on their publications about their GAAPP membership and you are invited to include the GAAPP logo where appropriate.

All GAAPP members can use the GAAPP website for national member information and updates of their programs. All members are cordially invited to use this way of communication. You are asked to provide the information for loading on the GA2P2 website in English and your national language.

GAAPP office also started with few newsletters. This tool needs to be used more frequently. All of you are invited to provide information for future newsletters.

New members and member support

Since our general meeting in Amsterdam 2015 the board welcomed the following new member:

- Allergy UK, UK

GAAPP received interest from Vietnam, Angola, Mozambique and other countries to have patient education on how to build national patient organizations. Due to the personnel and financial situation we could not deliver.

Acknowledgement of Funders 2015-17

- Novartis (2015)
- Roche (2016)
- Stallergenes (2016)