

GAAPP Activity Report 2013-2015

September 2015

	Page
Introduction	2
Organization	3
- Board	3
- Office	3
- Members	3
- Memberships/ Cooperation	5
- Constitution	6
Strategic Priorities	6
Main Activities	7
- General Meeting	7
- Fundraising	7
- Advocacy	7
- Capacity Building	8
- Communication	9
- New members and support of members	9
Acknowledgement of Funders	9

Introduction

Active in its 6th year now, 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.

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 33 member organizations on all continents. We thank especially our new members for their interest in GAAPP and our founding members for their support of the growth of GAAPP.

This report gives a summary of our activities from the last General Meeting on June 2013 at Milan, Italy until the end of 2015.

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

Antje-Henriette Fink-Wagner
GAAPP Executive Director

Organization

Board

The GAAPP constitution requests to have three people in the board: president, secretary and treasurer. However, at the second GM we decided to elect people for the vice positions as well.

Robert Oliphant, Canada	President
Per-Åke Wecksell, Sweden	1 st Vice President
Yu Zhi Chen, China	2 nd Vice President
Otto Spranger, Austria	Treasurer
Marianella Salapatas, Greece	Vice Treasurer
Michael Levin, South Africa	Secretary (left in 2014)
Ashok Gupta, India	Vice Secretary

Office

Antje-Henriette Fink-Wagner	Executive Director
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Members (August 2015)

Fundación para el Estudio del Asma y otras Enfermedades Alérgica, Argentina

The Asthma Foundation of Victoria, Australia

National Asthma Council Australia, Australia

Österreichische Lungenunion, Austria

ABRA-Associação Brasileira de Asmáticos-Regional São Paulo/SP, Brazil

PIPA-Programa Infantil de Prevenção 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
(new member 2013)

Allergy Care, India

Asthma Society of Ireland, Ireland

Food Allergy Italia, Italy

Liberia Asthma Society, Liberia
(new member 2015)

Lithuanian Council of Asthma Clubs, Lithuania

CREAA, Mexico

Norges Astma- og Allergiforbundet, Norway
(new member 2013)

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

Asthma UK, United Kingdom
(new member 2013)

Fundación Ramón Guerra Somma Moreira, Uruguay

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

US Allergy & Asthma Network Mothers of Asthmatics (AANMA), 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 € 100, 00. The last General Meeting participants decided to keep it on this low level of investment to provide the opportunity to become a member of GAAPP also to low income organizations. We stopped to send invoices for membership fee in 2014. This issue has to be discussed at the General Meeting 2015.

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.

WAO and **IPCRG**, the good cooperation is ongoing.

Interasma, the world asthma association invited GAAPP Executive Director to serve as board member since May 2013. Interasma offered a symposium and GAAPP booth at the next World conference of Asthma in March 2016 at Madrid. The symposia timeslot has not been confirmed yet, but the booth.

SLaai - Sociedad Latinoamericana de Alergia, Asma e Immunologia, invited GAAPP Executive Director to present special patient issues and activities at its conference 2014 at Mexico City and GAAPP together with Fundaler was invited to run patient sessions at the 2014 as well as at the 2015 conference (Buenos Aires). At both conferences GAAPP was exhibiting.

APCAACI, Asia Pacific Congress of Allergy, Asthma and Clinical Immunology APCAACI 2013. GAAPP was represented with a booth to build relations to Asian Organisations.

GINA, invited the GAAPP Director to participate in the autumn 2015 briefing meeting of their delegates, which is a completely new sign of acceptance of patient initiatives.

AAAAI and **ATS**, are used to offer GAAPP a stand free of charge. When GAAPP asked for a symposium at ATS in 2014 we were not selected. After checking reasons, we were told that ATS has requests for approximately 3 years ahead. Therefore the GM should decide if we continue to ask for a symposium each year until we get it.

EAACI, offers GAAPP the booth free of charge.

ERS, focuses on European Patient Organizations, but so far we always got a booth free of charge. In 2015 (on 30 September, 08:30-09:00 am) GAAPP got a time slot at the World Village Theatre to present GAAPP. For better acceptance GAAPP needs to submit poster and lectures.

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.

The **Pan African Thoracic Society** recently helped GAAPP by accepting the President of our new member, the Liberian Asthma Society LAS as the first lay member.

In Europe our member EFA is fully integrated into projects with EAACI, ERS and EFA's Director is serving as Vice President of the European Patient Forum, EPF.

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 2013-2015 the GAAPP office, following the decisions of the GM 2013, focused on **new members** and better **awareness** of GAAPP.

GAAPP decided to invest 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.

GAAPP renewed its **webpage** as one small puzzle of better communication. However, the website will only become a lively tool if all GAAPP members contribute to the content.

Finally, GAAPP tried intensively to find a better level of fundraising which is not easy to establish during a period of a global economic crisis.

Main Activities

General Meeting Amsterdam, September 29, 2015

The last General Meeting draft minutes from Milan will be adapted/approved at the General Meeting. The participants of that meeting elected the new board, which mainly will be asked to become re-elected during the General Meeting at Amsterdam again.

Fundraising

Our focus is currently the pharmaceutical industry. It takes a while until the companies realize any new NGO – non-governmental organization. Our sustainable corporate partnership arrangements framework can be found here:

http://ga2p2.org/documents/Sustainable_Corporate_Partnership_Arrangements_GAAPP_June_2011.pdf

So far we could not realize to follow the framework since no one of our discussion partners accepted the suggested grant levels. To have a starting point we negotiated what was possible and won three partners (ALK Abelló, Merck and Stallergenes) for low level travel grants of two of our speakers at the 1st GAAPP symposium in Canada. Two of the biggest existing companies decided to support GAAPP with sustainable corporate sponsorship grants in 2012 (GSK and Novartis), but since 2014 we only have Novartis as partner which is biasing and in a long term not acceptable. GAAPP's main sponsorship currently comes from private funding, especially from board members and the executive director. GAAPP would not be what it is without this significant investment.

Advocacy

GAAPP has small stand banners, posters and a promotional brochure. The GAAPP Director is a co-author of several publications and we are present at the main global respiratory conferences as reported earlier.

GAAPP board and executive director updates the leadership of the largest and most powerful health care organizations, including AAAAI, ATS, EAACI, ERS, GINA but also to the European Commission about GAAPP. The GM has to decide if we should include COPD under the umbrella of GAAPP in the future. In case of positive agreement, we need to define aims for COPD patients.

GAAPP office invited all members to nominate national advisors and GAAPP ambassadors, but received only two suggestions since 2012 and therefore started to invite ambassadors and advisors directly.

For effective work GAAPP needs an advisory board and ambassadors. GAAPP office requests to have the GM approval to name Dr. Moises Calderon, UK, Professor P. Demoly, France, Dr. Maximiliano Gomez, Argentina and Erkkä Valovirta, Finland medical advisors of GAAPP. Additional suggestions are welcomed, also for ambassadors.

Capacity Building

GAAPP's coordination officer Julia Reiter left the GAAPP office already by the end of 2013, due to her wedding and motherhood. She worked as a volunteer as all GAAPP board members and the executive director. Under voluntary conditions we were unable to find a replacement for her and therefore we failed to publish further newsletters. We got offered help from one member at the GM in Milan, but unfortunately the realization failed.

We also cooperate with IT specialists, who are currently updating the GA2P2 website (GAAPP as name was unfortunately not available) and urgently need member updates and input otherwise GAAPP communication never ever will be successful!

Communication

All GAAPP members can use the GAAPP website for national member information and updates of their programs. See currently existing information here:

<http://www.ga2p2.org/activities/member-activities.htm>

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.

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

GAAPP office also distributed few newsletters. The last one you find here:
<http://www.ga2p2.org/documents/1st%20Newsletter%20GAAPP%202013.pdf>

It is clear that 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 Milan 2013 the board welcomed the following new members:

- Magyar Allergia Szövetség (Hungarian Allergy Association), Hungary
- Liberia Asthma Society, Liberia
- Norges Astma- og Allergiforbundet, Norway
- Asthma UK, UK

All GAAPP members can request active support by GAAPP board members and the office to strengthen their activities. GAAPP provides kind support, but is currently not in a position to offer financial support.

In November 2015 GAAPP is invited to run a patient meeting in Bangladesh, as we did already in Kyrgyzstan, Kazakhstan and Iran with the aim to build national patient organizations. Vietnam, Angola and Mozambique announced also interest to have patient education on how to build national patient organizations.

Acknowledgement of Funders 2013-15

- GSK (2013 only) and Novartis.