

GAAPP Activity Report 2011-2012

May 23, 2012

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Introduction

Active in its 3rd 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 last general meeting.

It is important to keep our objectives in mind to work as effective as possible in an organization, which still is young, fast 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 29 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 11, 2011 at Istanbul until the end of 2012. The activities 2013 will be central content of our General Meeting on June 22, 2013.

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

Natalio Salmún
GAAPP President

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, in Istanbul we decided to elect people for the vice positions as well.

Natalio Salmún, Argentina	President
Per-Åke Wecksell, Sweden	1 st Vice President
Yu Zhi Chen, China	2 nd Vice President
Otto Spranger, Austria	Treasurer
Rob Lanteigne, Canada	Vice Treasurer
Anna Andralojć	Secretary
Irene Krcmowa, Czech Republic	Vice Secretary

Office

Antje-Henriette Fink-Wagner	Executive Director
Julia Reiter	Coordination Officer

Members (May 2013)

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

The Asthma Foundation of Victoria, Australia

National Asthma Council Australia, Australia

Österreichische Lungen-Union, Austria

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

PIPA-Programa Infantil de Prevencia de Asma, Brazil

Asthma Society of Canada, Canada

Chinese 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

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

Association Asthme & Allergies, France

ANIKSI, Greece

Allergy Care, India

Asthma Society of Ireland, Ireland

Food Allergy Italy, Italy

Lithuanian Council of Asthma Clubs, Lithuania

CREAA, Mexico

Panamanian Association of Asthma and Sport, Panama

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

Portuguese Asthma Patients Association APA, Portugal

National Asthma Education Programme NAEP, South Africa

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

aha! Swiss Allergy Center, Switzerland

Fundación Ramón Guerra Somma Moreira, Uruguay

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

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. For that reason GAAPP will continue with this fee at least until the next General Meeting.

To have voting rights in general meetings all members need to pay the annual fee.

Memberships/ Cooperation

The board decided to become an associate member of the **IPCRG** - International Primary Care Respiratory Group. As consequence GAAPP Executive Director became a member of the planning group for IPCRG's next Biannual Meeting at Athens 2014.

WHO-GARD – Global Alliance against chronic Respiratory Diseases accepted GAAPP as new member and elected GAAPP Executive Director at their 2011 assembly meeting as patient representative into its planning committee. New elections to be hold July 3, 2013.

WAO, the world allergy organization asked GAAPP Executive Director to assist in organizing its first patient meeting 2012 at Hyderabad, India. The meeting was combined with a painting competition for children wizth allergies and took high media interest.

The board also decided to support the European Union research project request **SPASSO** – Social Predictive Allergen Search via Streaming Objects Detecting and Accessing Suspected Adverse Reactions to Allergen Products from People reports, Social Media, and Streams of User-generated content. The project has not been approved yet, but in the case that this is going to happen GAAPP will represent the patient views by its Executive Director together with EFA.

Interasma, the world asthma association invited GAAPP Executive Director to serve as board member, May 2013.

SLaai - Sociedad Latinoamericana de Alergia, Asma e Immunologia invited the GAAPP president and executive president and Mexican member to present special patient issues and activities at its conference 2012.

GAAPP itself to the leadership of **AAAAI, ATS, EAACI** and **ERS**, the main health care professional organizations in America and Europe. All of them offer since 2012 booth's at their annual meetings, free of charge to GAAPP. To become fully accepted GAAPP will need to find also relations to the relevant Asian and African organizations and to start cooperation in projects with these organizations to represent the patient voice more powerful. However, at least in Europe our member EFA is fully integrated into projects with EAACI and ERS. In Asia GAAPP started with 2013 to increase the relation with health care professional organizations especially in Asia.

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 2011 the GAAPP office focused on the installation of the organization. From autumn 2011 on GAAPP promoted the existence of the organization to health-care professionals, national patient groups, European policymakers and potential industry partners. Fundraising is of key importance to make GAAPP an active and powerful organization as well as GAAPP's support to build new national organizations.

Main Activities

General Meeting Istanbul, June 11, 2011

The last General Meeting draft minutes will be approved at the General Meeting, June 22, 2013 at Milan. The participants of this meeting wrote the current mission and objectives of GAAPP, elected the board and put the executive director in place, selected the GAAPP logo out of several suggestions and approved initial content of the GAAPP website as well as the working plan until the next general meeting.

Fundraising

As soon as we had initial material like the branded letter paper and templates, the 1st promotional brochure and the initial website we started to advocate funding of GAAPP. Our focus is currently the pharmaceutical industry. However, 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). 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 provided all founding members with the 1st promotional brochure to advocate it on national level. Activity reports about national activities of GAAPP members are requested to be presented at the general meeting in Milan.

GAAPP's first stand is used since 2012 at health care professional conferences.

GAAPP board and executive director introduced the organization to the leadership of the largest and most powerful health care organizations, including AAAAI, ATS, EAACI, ERS, but also to the European Commission.

Beginning of 2012 the GAAPP office invited all members to nominate national advisors and GAAPP ambassadors following several criteria:

Criteria national advisor (for the time being one advisor per member organization)

The national advisor (co-operating mainly with the GAAPP members in the region) needs to be

1) In a leading position regarding allergy and asthma for adults and paediatricians in the entire region (e.g. Latin America, North America, Africa, Asia, East Europe, West Europe)

- 2) People full filling criteria 1 do not need to live in a country with a GAAPP organization
- 3) Preference will be given to persons with highest number of relevant publications
- 4) Preference will be given to persons who are a member in all relevant regional and global organizations like GARD/WHO, AAAAI, EAACI, APRS etc
- 5) Preference will be given to people showing strongest presence on international health care professional conferences as chairpersons and speakers on scientific topics of the main programs and industry symposia
- 6) Preference shall be given to those showing long-term interest in co-operation with patients
- 7) If we will have a choice between two or more in a region full filling criteria 1-6 the youngest shall be selected.

Criteria for GAAPP ambassadors (co-operating mainly with the GAAPP board) needs to be

- 1) well known by lay public
- 2) with proofed high level of influence
- 3) with proofed high level of social engagement
- 4) coming from the following areas
 - Policy
 - Sport
 - Culture
 - Economy

Unfortunately only two member organizations came back with suggestions. Therefore the GAAPP office likes to promote this activity at the coming general meeting again since it is useful to have an advisory board and ambassadors in place to work more effective.

Capacity Building

In autumn 2012 GAAPP participated in a show promoting NGO's and asked for volunteers at Vienna. It was there where we met Julia Reiter, GAAPP's coordination officer since the end of 2012. As all board members and the executive director Julia works as volunteer.

We also cooperate with IT specialists, who created the GA2P2 website (GAAPP as name was unfortunately not available) and update the page from time to time. We would need more frequent updates, but this a question of our budget.

Communication and Publications

Communication

Straight after the general meeting in Istanbul GAAPP asked a PR agency to prepare and distribute a press release to the media in English, German and Spanish. You can find the press release here: http://www.ga2p2.org/press-releases/2011_07_05_gaapp_en.htm

All GAAPP members are invited to distribute press releases about GAAPP's existence in their language as well.

All GAAPP members can also 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.

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 and the GAAPP office we add a chapter to inform about member activities.

Publications

Our executive director is co-author of the Guidelines Part I and II for Atopic Dermatitis, published 2012 ([J Eur Acad Dermatol Venereol. 2012 Aug;26\(8\):1045-60](#) and [J Eur Acad Dermatol Venereol. 2012 Sep;26\(9\):1176-93](#))

Several GAAPP members and the executive director also participated in a conference at Monaco to celebrate 100 years of immunotherapy. The outcome of this conference was the publication of the Monaco Charter, published at *Int Arch Allergy Immunol* 2013;160:346–349
DOI: 10.1159/000343883

A publication with ICC leaders and our executive director under the title "ASSETS AND NEEDS OF RESPIRATORY PATIENT ORGANIZATIONS" are expected shortly.

If you wish to have your publications as member announced as well, please share the list of publications with the GAAPP office.

Furthermore GAAPP board members and the executive director gave several presentations at health care professional conferences.

1st GAAPP Symposium

At the XXI World Congress of Asthma, Québec, Canada in August 2012 we had the opportunity to run GAAPP's first symposium as part of the main program of the conference under the title: **The Patient Voice, Allergy and Asthma Patient Activities around the World.**

The session was chaired by Carlos Baena-Cagnani (President of Interasma) and Robert Oliphant, President and C.E.O of the Asthma Society of Canada

The program looked as follows:

- The Global Allergy and Asthma Patient Platform GAAPP advocate the Rights of People with Allergies and Asthma
Antje-H. Fink-Wagner, GAAPP Executive Director
- Moving Asthma Issues forward, National Asthma Patient Alliance and experiences with Patient Engagement,
Results of a Survey of Canadian Asthma Patients
Rob Lanteigne, GAAPP Vice Treasurer & NAPA Representative
- The EFA Respiratory Allergy Project, involving Patient Organisations from 18 European Countries to create better
Awareness of Respiratory Allergies
Erkka Valovirta, EFA Medical Advisor & Head of the Finnish Allergy Project
- Asthma School and Camps for Kids in Austria
Otto Spranger, GAAPP Board Member and Speaker of the Austrian Lungenunion
- Allergy and Asthma Patient Initiatives in Asia
Ruby Pawankar, President of the World Allergy Organization WAO
- Impact of Patient organizations in GARD/WHO
Jean Bousquet, GARD speaker and ARIA Chairman

New members and member support

Since our general meeting in Istanbul the board welcomed the following new members:

- National Asthma Council Australia
- PIPA-Programa Infantil de Prevencia (Brazil)
- Chinese Allergy and Asthma Patient Platform CAAPP (China)
- Asthma and Allergies Association AAA(Ethiopia)
- Allergy Care (India)
- CREEA (Mexico)
- Panamanian Association of Asthma and Sport (Panama)
- Fundación Ramón Guerra Somma Moreira (Uruguay)

- Asthma and Allergy Foundation of America (AAFA) (U.S.A.)
- Allergy & Asthma Network Mothers of Asthmatics (AANMA) (U.S.A.)

In the case of CAAPP and AAA Ethiopia we helped to advocate for the building of both organizations by recommendation letters and in the case of China by participating with two GAAPP speakers at their inauguration meeting.

GAAPP also were able to motivate Goldemund Consulting from Austria to offer a workshop to all GAAPP members free of charge in connection with the next general meeting at Milan to discuss the link between successful fundraising and advocacy with the aim to help all GAAPP members to search for funding partners more systematically. The content of the workshop was selected after asking the members about their most urgent needs.

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

Acknowledgement of Funders 2012

Sustainable corporate partnership

- GSK
- Novartis

Travel support for two speakers at the 1st GAAPP symposium

- ALK Abelló
- Merck
- Stallergenes