



AGORA ANNUAL REPORT 2019

8th AGORA Conference

Hilton Park, Nicosia
Cyprus
26 - 29 September 2019

Introduction

On the 26th – 29th of September 2019, AGORA, the platform of organisations of people with rheumatic diseases in Southern Europe, held the 8th Agora Annual Conference in Nicosia, Cyprus. The conference was entitled “From Vision, Mission and Goals to Strategic Management of Patient Organizations” and had the aim to facilitate discussions and workshops focusing on the strategic management of patient organizations, how to communicate messages effectively, as well as projects and goals’ implementation. Further to this, special attention was given to best practices of lobbying in national and European level from an empirical perspective. Like previous years, drawing examples from Agora member organisations as well as other umbrella organisations was one of the core components of the conference. Ultimately, one of the main objectives of the conference was to empower and educate patients.

The conference was intended for delegates from Agora member organisations and it was attended by 40 persons from 13 different organisations.

Agora General Assembly briefing

Prior to the official opening of the Conference, Agora hosted the Annual General Assembly, which was attended only by Agora members. During the assembly, Victoria Romezo Pazos, Chair of Agora, presented the Chair’s Report describing the projects and achievements of Agora for the past year, as well as the representation of Agora at various events. Boaryana Boteva, Secretary General, presented the past and new work on projects of Agora and Sebastian Micallef, Treasurer of Agora, presented the financial report of year 2018. During the Annual General Assembly, the members had the chance to discuss and decide on various matters and set the priorities for the organisation.

Agora Supplementary Board Elections

During the Annual General Assembly, Agora had supplementary elections for 3 positions. During the election, Ovidiu Constantinescu, Andri Phoka and Ana Vieira were elected for three years. The board is formed under the structure of: Ovidiu Constantinescu (Chair), Boaryana Boteva (Secretary General / Vice Chair), Sebastian Micallef (Treasurer), Andri Phoka (Board Member) and Ana Vieira (Board Member).

First Day of the Conference

Opening

The official part of the conference was opened by Victoria Romero Pazos, Chair of Agora, Mr. Constantinos Ioannou, Minister of Health of the Republic of Cyprus and Marios Kouloumas, President of CYPLAR. Ms Victoria Romero Pazos, welcomed all delegates and explained the goals and objectives of the conference, while Mr. Ioannou, during his speech expressed his support towards people with RMDs as well as the steps forward in the health system that are currently taking place in Cyprus through the newly implemented National Health System. Mr. Kouloumas welcomed all delegates in Cyprus, thanked the Minister for the continued support and expressed his support towards the national health system as well as the future steps that should be implemented in Cyprus towards supporting people with RMDs.

Following the welcome speeches, Andri Phoka, Secretary General of CYPLAR showcased through a presentation the various innovative campaigns and actions organised by CYPLAR on a national and regional level across Cyprus, with most important the rehabilitation centre for people with RMDs built by CYPLAR.

Keynote Presentation 1

“Communications Strategy: From planning to implementation”, by Dr. Theano Kalavana, Health Psychologist.

Dr. Theano Kalavana, Health Psychologist, elaborated on the term and practice of effective communications. She explained the steps of conducting efficient communication and how to formulate effective and complete messages which can affect the target audience. Dr. Kalavana also explained to the delegates what factors can block the audience from listening and how to overcome challenges that might be faced during communications. Furthermore, she explained the four elements of creating complete and successful messages. Dr. Kalavana spoke about the carve for creating complete messages, as well as the core elements for a successful campaign. The importance of research before formulating a message was explained as well. The delegates were introduced to the key fundamentals their communication should include.

Workshops' Results

Workshops A:

“Building Partnerships & developing sustainable networks”, facilitated by *Elsa Mateus, President of LCPDR.*

Elsa Mateus, President of LCPDR facilitated Workshop A, under the topic of “Building Partnerships & Developing Sustainable Networks”. The workshop aimed at providing advice and strategies from the hands-on experience of the LCPDR initiatives in Portugal.

The case study from Portugal involved the presentation of the partnership initiatives organised by LCPDR on a regional, national and international level, with different partners and networks. The importance of building partnerships was explained. The delegates learned about the types of partnerships they can build such as internal partnerships within the organisation, partnerships with other Patient organizations, partnerships with scientific societies and health professionals as well as partnerships with Faculties and Colleges. All these partnerships can help the associations to achieve greater results and accomplishments for the whole patient community. The varying expertise can help the common goals and joint activities. This kind of partnerships, can help in achieving great results.

Based on the examples, the group in Workshop A came up with a structured step-by-step strategy in order to help patient organisations develop sustainable networks with various types of partnerships.

The discussion led to the phases of building synergies and the key aspects for successful collaborations. Having SMART goals is essential for the collaboration, as well as for measuring the outcomes (KPIs). All participants, ended the session by having in mind that building partnerships and networks is an investment. It needs some time to mature, but with a clear strategy and activities it will definitely become fruitful.

Workshop B:

“Positive outcomes of a successful communication plan”, facilitated by *Dr. Theano Klavana, Health Psychologist.*

Workshop B, facilitated by Dr. Theano Kalavana, outlined the strategy used, aiming through a hands-on experience for the participants to understand and formulate the best practise for setting a successful communication plan. The aim was the delegates to learn how to communicate strong messages and implement in a practical way the steps learned during Ms Kalana’s keynote presentation.

The participants were divided into three groups and while brainstorming during the workshop, engaged in a discussion, which concluded the steps for a successful

communication. According to the workshop's outcome, having a strong objective begins with a good observation which leads to a strong core, following the communicators need to visualise the message they want to pass and structure it in an effective way.

In addition, the discussion was led to the ways the message can be delivered across. As there are different approaches to communicate it and based on the channel one is using, the message can be formulated accordingly.

Guest Presentation:

“How can rheumatologists contribute to patient advocacy”, by Dr. Maria Michaelidou, Rheumatologist.

Through her presentation, Dr. Michaelidou introduced the different ways advocacy can be achieved and emphasized on the doctors' aspect on advocating for their patients. She explained the difficulties the doctors are facing during practicing and the occasional lack of advocating. She elaborated on the doctor's perspective on advocating the priorities that are given. She explained that the lack of time cannot prevent Doctors from advocating and that there are many other ways to support the patients. She showcased via her own experience examples of doctors' advocacy such as group meetings based on the patients' needs instead of one to one, collaboration with rheumatic associations, giving lectures and partnering with pharmaceutical companies regarding gaining grants towards patient treatments.

Workshop C:

Applying for project funding: The practical Steps facilitated by Sophie Christoforou and Elena Tsingi.

Workshop C was facilitated by Sophie Christoforou, deputy CEO of PASYKAF (Cyprus Cancer Association of Patient and Friends) and Elena Tsingi, Project Manager of Summer School of The University of Twente. Ms. Christofou presented the local aspect of project funding and outlined the strategy used for organising the national annual PASYKAF Fundraising. Firstly, Ms. Christoforou explained the practical steps of planning the campaign by determining its goals, doing research on potential competition, identifying the audience and forming a strong team. Following these steps, she showcased methods of recruiting volunteers and ways of securing financial resources. Additionally, she explained to the participants the different marketing methods used through different channels, such as branding the event, having support from famous people, creating a clear call to actions, giving press conferences, having easy donation process and how to coordinate all these actions. Finally, she explained the follow-up plan with the evaluation of the campaign.

On the other hand, Ms. Tsingi introduced the term project-based funding and explained why it is important for NGOs. She elaborated on the international aspect, and explained the different types of projects that can be funded and the different types of funding. She explained what are the main phases of preparing a project and how to develop it. Moreover, Ms. Tsingi explained what are the project's execution steps.

The facilitators led three different group discussions with the participants to brainstorm on the challenges they are facing when setting national campaigns, developing and implementing projects and what help they need from Agora on setting a campaign or developing a project. As a result of the first two groups after brainstorming, it has been explained that the main problems they are facing are the invisibility of RMDs, the lack of paid staff at their associations, the difficulty in recruiting volunteers and receiving funding, as well as the difficulty in convincing politicians and decision makers.

A solution to this problem lies within creating capacity through educated and better-informed patients, while having a supporting network for the procedure of receiving grants which will eventually lead to setting campaigns and projects more effectively.

The third group suggested solutions that can be achieved through Agora as an umbrella organisation. The member associations can be educated via Agora's practices and guidelines on how to set up projects, from practical examples of the procedures followed on writing proposals and grant requests as well as practical workshops, guidelines, booklets and through the creation of umbrella projects. The need for further education can be overcome by enhancing education of patient organisations and relevant Oguidelines.

Cool Down Psychical Activity:

At the end of the first day sessions, the participants had the chance of cool down physical activity at the hotel's gardens by Mr. Andreas Iacovou, physical instructor, who showed them relaxing and stretching exercises easy to be done at any place which can help them relax their body and reduce the pain.

Second Day of the Conference

Keynote Presentation 2

“Advocacy through lobbying – A key to success” by Neil Betteridge.

Neil Betteridge, Strategic Adviser and Public Affairs of Eular, introduced lobbying and the reasons of its importance in various aspects. He explained the key tasks of lobbying organisations and through examples showcased where and how lobbying can be achieved. He continued by introducing the main advocacy instruments that can be used to achieve the pre-set goals. Furthermore, he elaborated that well defined objectives, long term strategy, realistic expectations and stakeholders' mapping, as well as early intervention in the drafting process are some of the principles of effective advocacy. Mr. Betteridge showcased examples of EULAR's advocacy and steps that were followed. At last, the speaker highlighted the main advocacy actions and the results which can be achieved, as well as the do's and don'ts of advocacy.

Panel Discussion

“Improving the employment conditions for people with RMDs through synergies”

Following the keynote presentation, Mr. Neil Netteridge (Strategic Adviser, Public Affairs EULAR) moderated a panel discussion on the employment conditions from four different perspectives. Mr. Marios Kouloumas, represented the patients' perspective, Nicolas Makris the industry and private sector perspective, Mr. Contantinos Charalambous the governmental and public sector perspective and finally Mr. Maarten de Wit the international perspective of the topic. The panel, through a constructive discussion, led to the following realisations:

Patient organisations have a key role in empowering patients by means of providing access to trainings, such as the self-management programmes offered by CYPLAR, but also through organising tailored trainings using their patient experts. Additionally, patient organisations can have an important supporting role and they can provide tools to the patient to accept their condition and adapt to their new needs. Their aim is to help the patients have quality of life and adapted working places in order to be able to remain active at work.

As Mr. Makris explained, especially in larger companies, most employers are supportive towards patients and they are trying to take advantage of the governmental schemes for the benefit of patients. As part of the corporations' social responsibility, many of them, especially larger ones, are employing patients and they have adapted working places, nurses, rooms for resting and they give the option of flexible working hours to patients. Despite the various efforts taking place, not all companies have the ability of giving these options to the patients, as there is a lack of education, culture, policy and fear towards them. Nevertheless, more support and education on these issues by the government and patient associations can be beneficial for both patients and the industry. During the discussion, the disclosure matter was well discussed as it

is one of the most common dilemmas a patient can face. A regular discussion between the patient and the HR managers can be beneficial, however it is up to the patient to decide the information to be disclosed, Mr. Makris said.

Mr. Constantinos Charalambous, Officer at the Department of Social Inclusions, Ministry of Labour of the Republic of Cyprus, described the schemes the Government of Cyprus offers for people with chronic diseases and disabilities and elaborated which persons with RMDs are eligible for applying. Schemes for both individuals and organisations do exist, offering training to individuals to obtain work related skills which can help them with their work, as well as to set their own business. Moreover, there is funding for training for groups of people for which patient associations and professionals can apply for. These synergies between patients, patient associations and government can be proven beneficial for all parties. From his experience, he explained that the interest towards the schemes is increasing from year to year. Mr. Charalambous also announced that the Government of Cyprus intends to pass a new law for social enterprises where 40% of the employees will have to be people with disabilities. Lastly, on the public sector of Cyprus he explained that 10% of the employees must be people with disabilities, as a way to keep them on work. He concluded by explaining that it is more beneficial for the government to keep patients active at work.

In the international point of view, Mr. Maarten de Wit, EULAR PARE collaborator in Netherlands, gave information about what is happening in other countries with similar legislations. More specifically, the example of Netherlands with the “fit for work” initiative which started in 2011. This initiative brought all the stakeholders together to address the issues of each group and come to actions which will be mutually beneficial.

In general, there is an effort through synergies for all parties to take initiative for legislation changes and improvements. As a result, the delegates came to the conclusion that to achieve results and changes in patients working conditions, the process must include multidimensional discussions and campaigns that can support patients and allow them continue working. The opportunities offered can improve the working conditions for people with RMDs and employers will have a better understanding of their employees’ needs. Panellists and participants stressed that it is more beneficial to have active patients at work than having them at home. Eventually, all the panel members agreed on the need of collaboration between the stakeholders and synergies in order to achieve having more patients working and offering better working conditions for patient with RMDs.

Workshops' Results

Workshop D:

***“How Agora can lobby as an umbrella organisation”, by Neil Betteridge
Strategic Adviser and Public Affairs of Eular.***

An umbrella organisation like Agora, can have an important role in advocacy for RMDs and for its member Associations. This can be achieved in both national and European level and there are many practical reasons for both European and national lobbying. Both member associations and umbrella organisations can help each other with various ways in advocacy and lobbying. Each member association, can support the umbrella organisation by participating in meetings with European decision makers, in advocacy action at a national level, but also by sharing information and analysis on relevant policy issues. On the other hand, umbrella organisations can support their members' advocacy actions through sharing information on policy developments at a European level, by sharing material, experiences and good practices with them and also by providing them with support on specific national actions they need.

The participants had to discuss among them and brainstorm on the ways Agora could provide them support at their advocacy work on a national and European level and indicate what regional issues and priorities that Agora should be addressing.

Following the discussion, the delegates concluded to the results that umbrella organisations can offer the position papers to be signed by all members, as well as more educational trainings and workshops to the members. Sharing best practices of other members along with an information channel where all members can communicate and exchange ideas and opinions can be beneficial for all members. Additionally, the need on research on specific topics was expressed.

On the other hand, the members can help Agora by giving feedback on their national situation, legislation changes and implementation of European policies, by sharing their best practices, specific knowledges and contributing to projects. All these can strengthen Agora's network as these practices can be adherence by other member Associations. The members of Agora have many things in common which can help them team up and support each other. Furthermore, the participants agreed that there is a need for Agora to provide additional support to member organisations through more education, contacts and networking information.

Eventually, it was stressed that both the umbrella organisation and the member Associations should have a strategic prioritisation of topics and supporting each other can be proven empowering and beneficial for all involved parties.

Workshop E:

Successful lobbying activities of an Umbrella Organisation – The example of ENFA, facilitated by Ms. Souzi Makri, AGORA Past Chair

Ms. Makri's aim was to showcase European examples of patients' advocacy and their results. Ms. Makri firstly explained the international example of ENFA and the steps followed for the Fibromyalgia Awareness Day in order to raise awareness to politicians, physicians, scientists and the general public on a European level, as well as the results of these actions.

In order to achieve results, the delegates discussed on the competences and the key lessons for lobbying for an organisation. The participants came to the results of the most important competences a patient organisation should have. Some of these should be to ask clear, simple and specific questions, raising common issues and goals, presenting strong data, coalitions and team work, finding the right persons to lobby, prioritising what they are lobbying for, to be diplomatic, to mobilise all relevant stakeholders and to provide solutions to the stakeholders.

Moreover, the participants elaborated on the key competences and skills an individual lobbyist should have and came to the conclusion that the most important are to be trained, to have a clear mission on the goal, to develop a strategy, the ability to contact the correct persons, to have networking skills, to be a team player, to be persistent, to have a good knowledge on the topics, to have speaking and communication skills, as well as being motivated and dedicated.

Closing Remarks:

During the closing remarks of the conference, the new board of Agora took the opportunity to thank the outgoing board members for their excellent work during the past year, as well as to thank the host country and all the partners and sponsors of the conference, since without all of them the conference could not have happened. Special thanks should be given to Victoria Romero Pazos, Chair of Agora (2018 – 2019), Eva Kritza, Chair of Agora (2017 – 2018) and Chryso Yiasoumi, Board Member of Agora (2017 – 2019) for all the work they have done for Agora.

Gala Dinner

Kath' Odon Traditional Restaurant, Nicosia

After the official closing of the 8th Annual Agora Conference, all participants had the opportunity of a guided tour at old Nicosia city, followed by dinner at one of the liveliest streets of the town. During the gala dinner, the delegates had the chance to socialise, relax and taste traditional foods of Cyprus.

Moreover, during the Gala dinner, the Board of Agora thanked the Secretariat for her work and support during the past year that she has been working for Agora.

Special Thanks

Host Country

Agora thanks CYPLAR for their wonderful work in helping to organise the 8th Agora Conference in Nicosia, Cyprus. Special thanks to Chryso Yiasoumi, Souzi Makri, Andri Phoka and all the amazing CYPLAR members for their help during the preparations of the conference.

Partners

Agora is grateful to all its partners Pfizer, Grünenthal, MSD, GSK, BMS and Novartis for their support and faith in Agora. Without their support, the implementation of the conference would not have been possible. Their invaluable support has helped the Agora Conference attain the high standard it has today.







FROM VISION, MISSION AND
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MANAGEMENT OF PATIENT
ORGANISATIONS

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CYPRUS LEAGUE AGAINST RHEUMATISM

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