

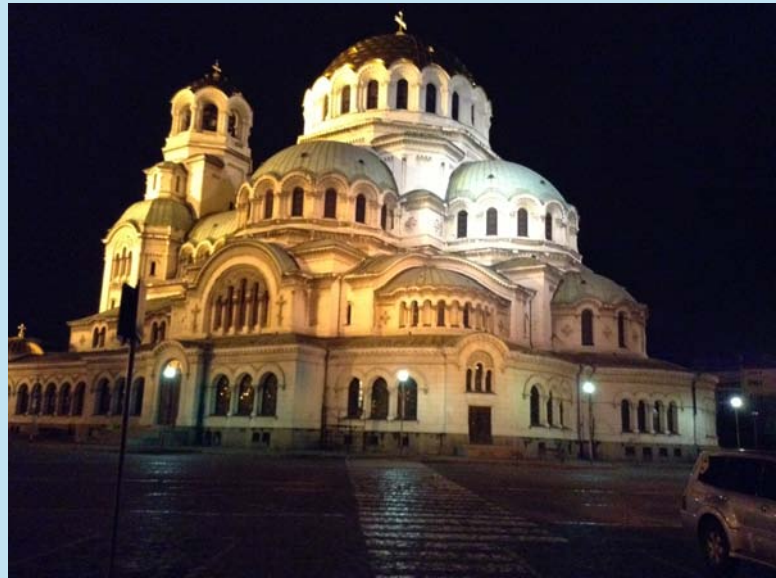
2013 AGORA

conference



Sofia Bulgaria
20-22 September 2013

The 2013 Agora conference was hosted this year in Sofia, Bulgaria. The subject was the crucial issue of Funding, how to apply for funds and how to find financial resources. The above subject was in combination with the topic "How to maintain quality of care for people with Rheumatic and Musculoskeletal diseases in times of Economic crisis".



Souzi Makri, chair person of Agora, welcomed the participants of the conference and proceeded with the report to the General Assembly. Mrs. Souzi Makri also gave an overview of the various activities in which Agora was involved during the last year:



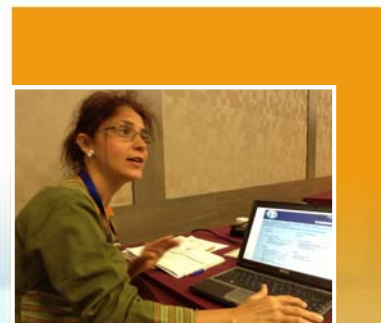
- RA: Join the fight supported by Abbvie. The aim of the project is to be a global source of information to help educate patients living with RA as well as their families. First meeting in Vienna, Austria followed by two more meetings (Amsterdam, Madrid) and two teleconferences. The project and the final results of the Global survey have been presented in Madrid in June 2013. (Link 1)
- Development of a book under the title "The basics of biologics" in the Brussels meeting organized by the EFFCA and other umbrella organizations (IFPA, ASIF). November 2012
- EULAR autumn conference for PARE in Zurich, Switzerland. Update on EULAR strategy 2013-2017 and on past and future activities of PARE. AGORA was represented by Ms. Sandra Canadelo. November 2012
- 5th Annual International Experience Exchange for Patient Organizations supported by Roche (Agora presentation). March 2013
- EULAR congress in Madrid. During this meeting we presented the progress of the activities and projects of AGORA. Ms Adriana Carluccio from APMAR – Italy gave a speech on her organization's activities and structure. June 2013
- Global RA patient Forum in Milan, Italy supported by Roche (Partners in Treatment Presentation). July 2013

Mrs. Souzi Makri concluded with a reference to the past and ongoing projects such as the first conference of Agora in Belgrade, Serbia on September 2012 with the topic "Quality of life for people with RMD's" and the "Partners in Treatment project".

The Host country presentation was held by **Boryana Betova**, Vice president of Bulgarian Organization for patients with Rheumatic diseases, and **Snezhana Bozhinova**, Coordinator of BOPRD, in which the facts and the challenges for people with Rheumatic diseases in Bulgaria were analysed. Also, the structure, goals, past and present projects and international activities of BOPRD were presented.



On the first day of the conference, Codruta Zabalan, the Vice president of Romanian League against Rheumatism and **Yolanda Marron**, International speaker of Conarthritis, facilitated the workshop about the "Partners In Treatment" project. The Romanian case study was presented and analysed. The delegates had the opportunity to exchange ideas and expertise about the advantages and disadvantages of implementing a self-management course on a national level or the Stanford University method. Also, various ways to overcome the barriers and develop a grant application for an organization was a subject for a very creative discussion.



On the second day of the conference, Luisa Avedano, CEO European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA), analysed the crucial issue of Fundraising and how to find financial resources and apply for funds. The potential sources for funding were described analytically and include the below:

- Statutory (Local Government, National government, Intergovernmental organizations)
- Individuals
- Charitable trusts and foundations
- Loans
- Corporate
- Crowd funding

The various ways to approach the above sources were also presented:

- Ask in Person
- Submit a written proposal
- Referral or recommendation from someone well- thought of by donor
- Invite a donor to see your work

Finally, the ingredients for a successful fundraising were as follows:

- Knowing your facts
- Organizational Credibility
- Building a relationship
- Prioritization
- Fundraising strategy



Reference was also made on useful guidelines for an efficient proposal for finding funds and the application process.

Marios Kouloumas, President of Cyprus League Against Rheumatism facilitated the workshop for Fundraising on a National level where participants exchanged experience and knowledge gained from national fundraising campaigns. The results of the questionnaire filled by delegates were presented and the significance of the social media for fundraisings campaigns was underlined. A very constructive approach and discussion inspired the participants to future actions.

The issue of fundraising on an international level was analysed on the workshop facilitated by **Luisa Avedano** in which delegates were involved in the whole process of submitting a project idea to the EU partners for funding. The procedure was presented through an entertaining and constructive game of "Projectpoly" by EFCCA.

Andy Dyson's speech has enlightened the participants on ways to attain a successful relationship between patient organizations and supporting companies. Mr. Andy Dyson, Director and Owner of Advocacy Aligned Limited, analysed the two perspectives (Industry and Patient organizations) and talked about how everybody would benefit from a reciprocal understanding.

Also, the regulatory environment was mentioned:

- EFPIA code
- Patient organization "Working with Industry" Guidelines
- Local codes
- Others (Government guidelines on voluntary organizations, Restrictions on Lobbying etc).



Following the above, Andy Dyson facilitated the workshop "How to become an equal partner with the Pharmaceutical Industry" where the participants had the opportunity to exchange ideas and expertise on methods for working with the Pharmaceutical industry. The discussion also included the patient organizations and Pharmaceutical industry landscapes, partnership success or failure and key partnership success factors.

Adriana Carluccio, International Relations for A.P.M.A.R Italia, facilitated a workshop for the role of Marketing and Social Media in Fundraising. The topics presented and discussed included an example of a practical way to develop an effective newsletter, ways to build a website and ways to use various aspects of social media. Very useful links were provided to delegates for future reference.



Vladimira Bojadzieva of the Rheumatology clinic in the University Hospital "Saint Ivan Riski" presented a speech regarding ways to maintain quality of care in patients with Rheumatoid Arthritis and Musculoskeletal disorders in the context of the economic crisis. Vladimira Bojadzieva gave her perspective on the purpose of medical care in the treatment of RA and stated the economic importance of achieving the overall objectives of treatment.

Janice Mooney, Senior Lecturer at the School of Nursing Sciences University of Anglia – Norwich, gave her own perspective on the crucial role of the nurse in today's challenging economic situations. She referred to the important factors of the future healthcare delivery and the participants discussed and exchanged ideas on the below issues:

- The role of the nurse specialized in rheumatology
- A nurse's contribution/ involvement in patient care
- Ways to evaluate the contribution of the nurse
- Cost effectiveness of employing a nurse
- Particular challenges in participants' countries

Mr. Ovidiu Constantinescu, Former journalist with BBC World Service and currently a PR expert facilitated a workshop that focused on practical ways to run a successful campaign and access the decision making centers. The procedure for a successful campaign was analyzed from the starting point of finding the issues and setting the objectives up to identifying and analyzing the stakeholders (patients, doctors and Pharmaceutical companies and other stakeholders).

Afterwards, the discussion focused on ways to attract media attention to a campaign (public, Journalists) and influence the decision making centers (Politicians).

Maarten De Wit, Tools2use (The Netherlands), described the issue of funding from the Pharmaceutical industry point of view on a panel discussion involving representatives from all partners.



Press Conference:

The press conference took place on Friday 20th of September in which the chair of Agora, Mrs. Souzi Makri, introduced the Southern Platform and described its actions and goals. Also, she referred to the fact that musculoskeletal conditions are amongst the most common causes of long term pain symptomatology and disability in EU. The estimated number of patients suffering from musculoskeletal diseases in Bulgaria is 30000 (Ankylosing Spondylitis), 60000 (Rheumatoid Arthritis) and 20000 (Psoriatic Arthritis). Finally a reference was made to the second objective of the five year plan as defined by the inaugural meeting in Malta in the year 2011, which is to **"Stimulate the education and training of patients, volunteers, staff and health professionals by creating opportunities to exchange knowledge and experiences and to produce templates for educational materials and programs"**. **Bozhidar IVKOV** PhD, associate professor in the Institute for the study of Societies and Knowledge at the Bulgarian Academy of Science, referred to the social aspects of the care for people with Rheumatic diseases in Bulgaria. **Margarita Grozdanova**, Director of the Department for Drug policies at the National Health insurance fund mentioned the achievements of National Health Insurance in the field of maintaining care for people with Rheumatic diseases in Bulgaria.

Special Thanks

To everyone for their participation and contribution to the second Agora Conference in Sofia, Bulgaria.

To our special guests and speakers and to our partners Abbvie, Merck, Novartis, Pfizer and Roche.

Without their support the conference would not have been possible. Their invaluable support has helped the Agora Conference attain the high standard that it has today.

Networking

On Saturday 21 September 2013 all conference participants enjoyed the national cuisine and folklore live music at Hadjidraganov's Cellars having the opportunity to chat in a pleasant atmosphere.



Overall feedback

After the conference a questionnaire / evaluation was carried out and the analysis of the overall results showed that the participants found the information presented useful enough and that for the future the topics/presentations need to be more tailored to the specific needs of the Southern countries.



Links:

<http://rajointhefight.com/about-ra-join-the-fight/>

<http://agora-pait.com/>

<http://www.agora-platform.eu/>

<https://www.facebook.com/pages/Agora-the-platform-of-Southern-European-organizations-of-people-with-RMD>

<http://www.apmar.it>

www.efpia.eu

www.reumatism.ro

<http://blog.revmatologia.org/>