

Agora



Platform of Organisations  
of people with Rheumatic Diseases  
in Southern Europe

# 5th Agora Conference

30 September-2 October 2016| Bucharest



The 5<sup>th</sup> Agora Conference took place between the 30<sup>th</sup> of September – 2<sup>nd</sup> of October 2016 in Bucharest. The conference’s main topic was “Patient’s right to be partner in research and decision-making process” accompanied by two subtopics: a) “Accessibility and availability of research and educational programs for patients with RMD’s” and b) “RMDs and supportive tools and technology for a better life”.

The first day of the conference started with the General Assembly meeting, where all the Agora members met to discuss matters of the association and take important decisions. The official introductory session of the conference was led by the leading members of the host country association, the Romanian League Against Rheumatism (LRR), who took the opportunity to introduce their association’s work in the local community in cooperation with the medical staff at the rheumatic centre in the Dr. Ion Stoia Hospital. This hospital is an exquisite case of a rheumatic rehabilitation centre, where patients can have their medical treatment along with other services such as physiotherapy, kinesiotherapy and other supplementary treatments.





The first session of the conference focused on patient’s involvement in research. Dr. Sophie Staniszewska from the University of Warwick discussed about the “The benefits of patients’ involvement in research” given her experience in coordinating and leading research project where patients were involved. During the Q&A session following the keynote presentation, patients asked questions around how accessible research is to them (depending on their country of origin) as well as the role patient organisations (should) play to bring research closer to them.

mutual benefits for all stakeholders" facilitated by Nele Caeyers, Chair Elect of PARE, and Workshop B: “The relationship between patients and research: How can patients get involved?” facilitated by Dr. Sophie Staniszewska.

The second session was dedicated to introducing the EUPATI course to the delegates and making them familiar with the ongoing courses and the important tools created to help patients in every aspect when they search for information. Souzi Makri, Chairperson of Agora and EUPATI Fellow was the key presenter of the session and talked about “EUPATI: an efficient training programme for future patient partners in research and National Platforms”, laying the foundations for the two workshops to follow. Workshop C, “The EUPATI experience: the inside story” was facilitated by two EUPATI Fellows, Souzi Makri and Elsa Mateus, where they shared their experience as EUPATI students and then led a discussion on ways to sustain EUPATI and promote the use of the EUPATI tools (toolbox, library, etc.) by all patients and interested parties. Workshop D, “The EUPATI Toolbox – a practical tool for research training in medicine on national and individual level” was facilitated by current EUPATI student Codruta Zabalan, who presented and demonstrated the EUPATI Toolbox to the workshop group.



The first session was followed by two workshops: Workshop A, “EULAR Patient Research Partner educational programme:

The first day of the conference was concluded by the feedback t the plenary session, facilitated by Dr. Frane Grubisic.



The second day of the conference started with the third session, and the two keynote presentations by Dr. Frane Grubisic (Croatia)



and Boryana Boteva (BOPRD, Bulgaria) about “Expectations and challenges in implementing the Shared-Decision Making Process: the doctors’ and patient’s perspectives”. The two presenters discussed this very important issue from two different perspectives and both agreed that the paternalistic approach, which is usually used in the discussions between doctor and patient, should be abandoned and that both doctor and patient should work together as equals to ensure the best possible treatment in favour of the patient.

Workshops E and F had the form of a brainstorming towards creating Agora Patients’ Charter. Workshop E was facilitated by Nele Caeyers (PARE Chair Elect) and Elena Tsigki (Agora Secretariat and project Coordinator) and Workshop F was facilitated by Souzi Makri



(Agora Chairperson) and Boryana Boteva (BOPRD). The two groups discussed the need for creating an Agora Charter for patients’ rights, based on previous research and available material. The brainstorming generated some very good points as to the clarity of the objectives and purpose this chart should have, as well as the addressed audience (patient for empowerment and media as an aware raising, effort, or policy makers for a social change?).



It was clear from both sessions that patients were most concerned about the right patients have to access to their medical records, as well as the accessibility availability of information on treatments and other medical related subjects in lay language. There was also a discussion about the benefits of integrated healthcare and the use of the European Medical card in equal ways throughout Europe, regardless of the national legislation/regulations of each country.

The fourth and final session was led by Florian Klett, EULAR Project Manager the keynote presentation entitled “EULAR-PARE supportive tools and programs for patient organisations: How can Agora utilise and share these tools with its member organisations”. Florian presented the tools developed by EULAR (such as the Knowledge Transfer Program) which member patient organisations can use to support and empower their work. It was highlighted that Agora, as a new co-opted member of the PARE standing committee of

EULAR, can can great benefit from this new relationship.



The presentation was followed by Workshops G and H, themed “The use of supportive tools and technologies for RMDs patients”. During Workshop G, “The use of everyday tools for people with rheumatic diseases”, Codruta Zabalan (LRR) and Nicolae Costin (kinesiotherapist) discussed the importance of using everyday tools to make the life of RMDs patients easier. A variety of helping tools and their use was demonstrated. Finally, Workshop H on “Supportive technological tools and RMDs: how to use to use them to your benefit” facilitated by Agora members Serena Mingolla (APMAR) and Claire Cardi (ACS France) discussed two case studies from Italy and France. Claire presented an online platform ACS France developed called SPONDY+, where patients with spondyloarthritis can register in

order to build a community and share experiences, but also find valid information about their disease and the available doctors near their area.



Serena Mingolla presented the Psoriatic Arthritis App, which is a mobile application generated by APMAR in order to provide patients with useful information such as sending reminders for medication, doctor appointments etc. This app also holds a database of doctors and medical centres. Following the case study presentations, the group was engaged in discussion about the benefits or challenges of using these types of electronic tools.

The second day of the conference concluded with the feedback to the plenary session facilitated by Florian Klett (EULAR Project Manager) and the final remarks by Souzi Makri (Agora’s Chairperson).

## ABSTRACT PRESENTATIONS BY AGORA MEMBERS

For yet another year, the Agora members presented some abstracts to show their work and their activities within their own region.

- ▶ "Green Health – Make the difference: awareness campaign for conscious and waste-less use of drugs", by APMAR (Italy)
- ▶ “Social Activities and quality of life in members of the Greek Association (ELEANA) with Rheumatoid Arthritis”, by ELEANA (Greece)
- ▶ "The connection between the patients, the rheumatologists and the researchers", by ACS France (France)
- ▶ “Chatting Rheumatism Through Every Nook and Cranny” and “Industrial Designs for Patients with Rheumatoid Arthritis”, by Romaturka (Turkey)



# AGORA Gala Dinner

At the last evening of the conference, the delegates enjoyed dinner at a traditional Romanian restaurant, where they had the chance to relax, network and dance to the Romanian music.



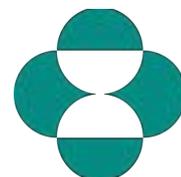
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