



Agora

2014 AGORA

CONFERENCE



Bari Italy 26-28 September 2014



2014 AGORA CONFERENCE



Pietrablu Resort & SPA, Bari, Italy

Bari Italy 26-28 September 2014

AGORA CONFERENCE

Bari Italy 26-28 September 2014

The 2014 Agora conference took place in Bari, Italy and had two major topics. Topic one was on "How to develop a national action plan for rheumatic diseases", with subtopics a) Standards of care and b) Collaboration with third parties for better standards of care. The second topic concentrated on "Recruiting of new members for organizations".

The 3rd Agora Conference began with the General Assembly on the **first day**, where all the Agora members were present to discuss matters within the organisation and be informed over the recent activities of Agora.

Souzi Makri, chairperson of Agora, welcomed the participants and the Agora Board to the 3rd Agora Conference and proceeded with the report to the General Assembly. Mrs. Makri gave an overview of the activities and projects in which Agora was involved during 2013-2014



"Overview AGORA activities 2013-2014"

- 15-17 November 2013- AGORA was present in the 16th Autumn EULAR Congress for PARE in Reykjavik to support the World Arthritis Day (WAD).
- 5-6 March 2014- The International Experience Exchange for Patients Organizations Conference was held for the fifth year in Zurich Switzerland by ROCHE. Souzi Makri, Chair of AGORA was invited as a speaker.
- 7-9 April 2014- Cross Border Healthcare (CBHC) Conference in Athens.
- June 2014- Agora was invited to join a workshop in Brussels arranged by the Fit for Work Europe.
- June 2014- Agora was invited to a meeting in Dublin organized by EFFCA and sponsored by Abbvie. During this meeting, Souzi Makri and four other Agora representatives received training on the introduction of Bio-processing (Biologics and Bio-similar medicines).
- 11-14 June 2014- In 2014 the EULAR Congress took place in Paris. AGORA was represented Chairperson Souzi Makri as well as by our members from Romania, Malta, Italy, Spain Galicia, Serbia, Bulgaria and Greece.

During the Congress, AGORA organised a meeting for its members and partners.

- 28-31 August 2014- Mediterranean Conference on Rheumatism in Istanbul: Souzi Makri was invited as a speaker at the Mediterranean Conference on Rheumatism.
- 13th September 2014- A second training took place in Dublin, organized again by EFFCA. Agora was represented by five member associations from Crete, Bulgaria, Spain, Malta and Cyprus.
- The RA Join the Fight Project 2014

Souzi Makri concluded with a reference to the past and ongoing projects such as the 2nd Agora Conference in Sofia Bulgaria, on 20-22 September 2013 with the topic "Funding – how to find financial resources and how to apply for funds" in combination with "How to maintain quality of care for people with Rheumatic and Musculoskeletal diseases in times of economic crises". She also spoke about the two other main projects AGORA organized for 2014, apart from the 3rd Agora Conference, which were the "Train the Trainers" Workshops.

Mrs. Souzi Makri concluded her introduction by welcoming all participants to the 3rd Agora Conference.

APMAR's efforts to campaign for arthritis- Host Country presentation

The Host country presentation was held by **Antonella Celano**, President of the Italian Organization for patients with Rheumatic diseases **APMAR**.

Mrs. Celano introduced to the work and projects of APMAR in their fight to raise awareness of RA in Italy. She spoke about the innovative ways APMAR approaches its efforts. She then introduced the Mobile Application her organisation developed, as well as other communicational strategies, such as the TV commercials campaign, the social media campaign, and various campaigns they run for adults and children RA patients.

Impressive progress of the Partners in Treatment project

On the first day of the conference, **Codruta Zabalan**, Vice president of Romanian League against Rheumatism and **Souzi Makri**, provided an update about the "Partners In Treatment" project, focusing on the "Train the Trainers" Workshops, organised in Amsterdam during February and March 2014. The workshops were tailored to the needs of patients with RMDs. The project provides a two-day intense workshop aiming to give knowledge on **organizational strategies** and **skills**, which can be modified and tailored to the needs of each organization for patients with RMDs. Gonny Vink and Bertha Maat, from *Work21*, a Dutch training company facilitated the workshops. With this project, Agora aims to engage all its member organisations to organise these workshops to help their members not only share experiences on how to deal with RMDs on a daily basis, but also to help them develop self-management skills. The ultimate goal is to enable the participants to transfer the knowledge from the training workshops and tailor it to the needs of their association and country of origin. As the trainers and trainees need to exchange experiences, knowledge and feedback, Gonny Vink from *Work21*, developed a closed-group website especially for Agora and the "Train the Trainers" courses.

Best practice from Malta

Malta (ARAM) was the first of Agora's member associations, which organised the self-management course on a national level. Mrs. Mary Vella, President of **ARAM** and Mrs. Marie-Therese Camenzuli, Vice-President of **ARAM**, told the audience how they adapted the Dutch "Train the Trainers" course to the needs and culture of Malta. They shared their experience being self-management trainers as well as the difficulties they met while organising and performing the workshops. After the presentation a constructive discussion was held, where participants expressed their opinions on the self-management course and stressed the importance of creating a consistent method of collecting feedback from the member associations that organise these training courses.

European Patient Academy (EUPATI)

On the **second day of the conference**, during the morning session, **Dr. Silvano Berioli, MD**, from EUPATI (European Union Patients' Academy on Therapeutic Innovation-<http://www.patientsacademy.eu/index.php/en/>) was invited to make a short presentation about EUPATI's projects and enlightened the participants on the organisations' activities. EUPATI is created and led by key EU Patient Advocacy Organisations. Its main goal is to offer knowledge to other patients concerning new clinical findings and innovations. Dr. Berioli pointed that there is a great need for patients to understand and have knowledge about recent clinical research and finding, and to communicate this knowledge. He concluded by highlighting the need for a strong alliance between patients, institutions and health care professionals/services.

National strategy for musculoskeletal diseases in Spain

Paloma Casado Durandez is Deputy Director of Quality and Cohesion GD of Public Health, Quality and Innovation Ministry of Health, Social Services and Equality, of the Spanish Ministry of Health Spain. She gave a presentation about the strategy of the Spanish Ministry of Health to bring all the stakeholders together on Rheumatic and Musculoskeletal Diseases on a national level.

For the strategy to work well, Spain ensured the cooperation and involvement of all stakeholders (health care professionals, government, patients and patient associations, doctors, etc.) in identifying the key points and strategic goals. Through research, scientific evidence and situational analysis, the first Draft of the Strategy was produced. One of the main reasons that the Spanish strategy worked, was, according to Mrs. Casado Durandez, the fact that all the stakeholders worked together.

Paloma Casado Durandez also addressed the urgency of creating a strategic plan on a national level for RMDs in other countries as well, as more RMDs patients are diagnosed daily. Not only RMDs patients, but also the economy and community will benefit from such a strategy. The strategy allows patients to have equal rights in the working space and eliminate work absences



caused by health reasons and disabilities, but also to eliminate social discrimination.

The mission of a strategy for RMDs should be to “to establish a set of goals, recommendations and indicators that contribute to the improvement of the quality of interventions and health outcomes, in a realistic way, depending on available resources and based on scientific evidence”. This strategy tries to become a FRAMEWORK at national level, for the promotion, prevention and for the provision of health and social care of people with RMDs, based on scientific evidence and in conditions of equity and sustainability

Mrs. Casado Durandez finished her presentation by highlighting the importance of follow-ups and monitoring the results of the strategy and by giving the participants the five “star words” they must have in mind when being part of decision making processes or on making a strategy for RMDs:

★Participative way of working

★Motivation

★Collaboration

★Patient-focused care

★Political will

After the first presentation, the two morning session workshops followed.

Workshop 1: Sharing best practices

Paloma Casado Durandez facilitated the first workshop on sharing best practices in strategic planning for Rheumatic Diseases. She provided useful information on how to pursue a national strategic plan for RMDs in the home countries of the participants. Depending on the needs and the health system of each country, patients exchanged opinions and questions and made a constructive discussion on this important issue.

Workshop 2: Developing educational materials in Romania

Codruta Zabalán, General Secretary of Agora and President of the Romanian League Against Rheumatism, facilitated the workshop with the question “What could we do to get better at providing a good standard of care through educational material?”. This was an interactive workshop. Participants had been asked to bring along educational material from their home country associations and exchange knowledge and ideas on how to best use educational material to raise awareness of RMDs and help patients to achieve a better quality of life. Codruta Zabalán distinguished various types of material (text, written, digital, online material, visual and audio material, and analysed how these materials can be used. She engaged the participants into an interesting discussion of how each organisation could use the various types of materials.

Maarten de Wit, from Tools2use (The Netherlands), facilitated the Feedback to the Plenary session, where all the participants workshop facilitators engaged in a lively discussion about the two workshops.

Fit for work promotes early intervention in Spain

Mrs. Antonella Cardone, Executive Director of Fit for Work Europe, presented Fit for Work Europe's mission and goals to the participants. Fit for Work piloted the *Early Intervention* Project in Spain.

She went on to explain how the *Early Intervention* project works as an innovative care program. This program provides early diagnosis, immediate specialist examination and support for return to work. This is beneficial not only to the patients but also to the economy, as the patient is treated, educated and encouraged to remain active. The program also helps the patient be rehabilitated with a return-to-work support system. Mrs. Cardone presented the results of the *Early Intervention* Program in Spain, where the program was implemented successfully and resulted in aiding the patients and also indicated important and promising economic

benefits for the country.

She concluded by pointing out that the Early Intervention Project really works because:



- It is a patient-focused project
- There is expert assessment
- It uses a simple pathway and a rapid access

After the end of the presentation, Mrs. Cardone answered the questions of the participants, who were highly interested in learning more about Fir for Work Europe and *Early Intervention*.

Non-pharmacological management of osteoarthritis

The afternoon session of the second day of the conference was introduced by **Dr. Tiziana Nava**, Doctor in physiotherapy, EULAR liaison and university lecturer. Dr. Nava made a presentation on the 11 EULAR recommendations for non-pharmacological management of hip and knee osteoarthritis.

Focusing on the main points of her presentation and the according to the 11 EULAR recommendations, Dr. Nava recommended that treatments should be customized according to the needs, wishes, and individual characteristics of the patient, such as sex, weight, age, lifestyle, etc. and also a biopsychosocial approach should be used for better results. Apart from following an individualized treatment, Dr. Nava concentrated on the importance of the Recommendations 3 and 4, whereby the various health care professionals (podologist, physiotherapist, occupational therapist) must provide the best devices, methods and techniques depending on the patient's needs so that the treatment is truly tailored to each patient. Additionally, she insisted on the necessity of the patient and caregiver to be active.

Exercise is another part of the treatment that must be followed, according to Recommendations 6 and 7, including strengthening, aerobic activity, and stretching. Dr. Nava showed the participants some videos of practices she uses with her patients, including stretching exercised under water and other exercises. She also stressed the importance of having a balanced diet and keep control of the patient's body weight as Recommendation 8 states.

In line with the final Recommendation number 11, Dr. Nava presented her method for helping the patient rehabilitate and return to his or her working environment after being absent from work. She uses a non-pharmacological approach consisting of the following techniques:

- ✓ Relaxation techniques that help avoid stiffness
- ✓ Soft training exercises (yoga, tai chi, Feldenkrais, etc.)
- ✓ Relaxing massage techniques and manual therapies
- ✓ Postural Global Rehabilitation technique (PGR). With this technique the health care professional helps the patient re-educate the whole body and not only the hip or knee.
- ✓ Cognitive-behavioral therapy, which allows the patient to learn and know the way they move

Dr. Nava' presentation was followed by a short Q&A session and two workshops

Workshop 3: Benefits of physiotherapy in osteoarthritis

Dr. Tiziana Nava facilitated the first of the two workshops for the afternoon session, which addressed the EULAR's 11 recommendations from a physiotherapeutic aspect and the use of certain techniques and other material. The first workshop group had the opportunity to be engaged in a more practical and interactive workshop, where Dr. Nava demonstrated more methods and exercise techniques she uses for her patients. She demonstrated breathing exercises, pain management exercises and other exercises that have a link to the lifestyle and everyday life of a patient. Each patient has a different pain system, so the physiotherapist must create a new system to the patient. Dr. Nava concluded by highlighting three steps that any global treatment should have:

- ✓ Spot and recognize the wrong movement
- ✓ Erase the wrong movement from the patient's memory
- ✓ Correct the movement by helping the patient change they way he or she is thinking firstly.

Workshop 4: Tools and benefits of disseminating recommendations

Adriana Carluccio, International Relations for A.P.M.A.R Italia, facilitated the workshop about "Recommendations and Material". This workshop was divided in several assignments. First, the group had to write down the importance of having recommendations and the benefits produced for each Agora-member country. The second aspect of recommendations was the best way to disseminate



recommendations by using various tools, such as the Internet apps, flyers, oral communication. She then engaged the participants into discussing other ways and strategies to disseminate recommendations, not only within the home country, but also in collaboration with other stakeholders from other countries. The group and facilitator came up with the conclusion that it is more powerful to ask support (financial and other) from politicians and other stakeholders, when you have a variety of materials for presenting recommendations. Finally, she presented the results from the PARE dissemination project, which highlighted the importance of patients and patient organisations to be active in disseminating recommendations.

The **third and final day of the conference** consisted of one main presentation and two workshop sessions.

Recruiting members and volunteers in Sweden



Beryl Svanberg, Vice President of the Swedish Rheumatism Association, gave a presentation on the methods the Swedish Rheumatism Association uses to recruit new members and volunteers. Mrs. Svanberg also presented other ways to recruit members, such as using electronic forms via the association's website, using blogs that engage the members into discussion and experience exchange, using a Facebook page and other social media, but also by networking and making new contacts from various lectures and health care meetings. She presented an example of a project called "Patientskolor", a collaboration between primary care and the Swedish rheumatic associations.

"Patientskolor" can offer:

- Exchange of information with other patients in the same situation
 - A long-term, individual activity plan
 - More individual power over treatment and rehabilitation
- Less need for return visits
 - Long-term change based on participation, motivation and role models

Effects of "Patientskolor":

- Increases accessibility to effective treatment
- Improved communication and collaboration between patient, primary care and the rheumatic associations
- Possibility to use experience as a resource
- Continue with activities after "patientskolor" has ended

Mrs. Svanberg also concentrated on the basic aim of this project, which was to define the roles and responsibilities of primary care as well as the rheumatic diseases associations, through active collaboration. Both parties are of great importance and their collaboration and contribution can make things better for patients. From this perspective, Mrs. Svanberg pointed out that an expert patient is always a great source and a good example and should be used for educating health care personnel but also to support patients that suffer from diseases.

After a short Q&A session the two last workshops were introduced.

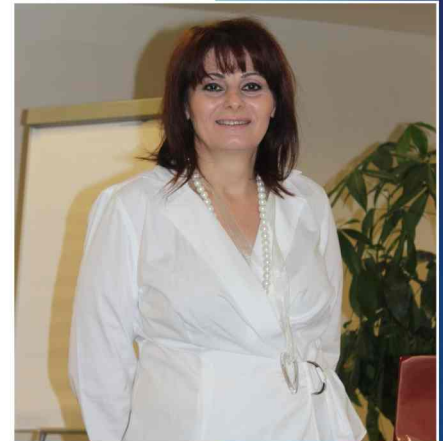
Workshop 5: Recommendations for recruitment

Beryl Svanberg facilitated the workshop with the subject of recruiting new members for organisations and volunteers. The group engaged in a productive discussion and shared experiences from the practices in their home country associations. The participants came up with the following recommendations:

- ✓ Bring people together and engage them into other creative activities, rather than just talk about RMDs and their diseases. Making music, art and other creative activities, physical exercise events and other activities, will attract new members and help them become more interested and active.
- ✓ Collaborate with other organisations.
- ✓ Involve young people in projects

Workshop 6: Role-playing, engaging with new members

Dr. Spyroula David Syrimis, Psychotherapist, facilitated the second workshop entitled "Recruiting and attracting new volunteers". Attracting and maintaining volunteers is difficult and many people are intimidated and afraid of the commitment related to being a member or a volunteer for an organization. Therefore, in order to avoid having these issues, the various RMDs associations should use a strategy that brings volunteers together, makes them feel part of the team, engage them in several activities and educate them. Nevertheless, the association must always control the information of a new volunteer to prevent unpleasant situations within the organisation, its members and patients.



Dr. David Syrimis and Mrs. Souzi Makri demonstrated a role-playing game in order to address three issues:

- ✓ 1. Responding to the feelings of a RMD patient
- ✓ 2. Touching an RMD patient
- ✓ 3. Life Attitude

During the role-playing game, Dr. David Syrimis and Mrs. Makri, demonstrated the wrong and correct approach to the above issues, when dealing with a patient member.

Overall, Dr. David Syrimis focused on the importance of educating and training the volunteers as to:

- ✓ Give them proper guidelines on how to deal with certain situations
- ✓ How to protect themselves to not internalize the stories they are exposed to in the organization. The aim is not to teach them to be de-touched, but to protect them from taking the patients' stories they hear at home.
- ✓ Be there for them, embrace them, and encourage them.

The conference ended with Mrs. Souzi Makri, who made some closing remarks and thanked everyone, participants, speakers and facilitators for being part of the 3rd Annual Agora Conference. She announced Agora's quest for the topics of the 4th Annual Conference as well as the new host country and the new Task Force.

Press Conference:

The press conference took place on Friday 26th of September 2014. The Press Conference was introduced by a message sent from the Italian Minister of Health, Beatrice Lorenzin, in which she expressed the ministries will to improve the conditions for people with RMDs and also greeted the action of APMAR and other associations for people with RMDs in raising awareness of the diseases.

Following the Minister's message, the chair of Agora, Mrs. Souzi Makri, held a presentation about RMDs from a financial point of view. She stressed the point that over 50% of work absences and 60% of permanent work absence are due to musculoskeletal and rheumatic diseases, which bears a huge economic burden in the EU society. Mrs. Makri made a reference to APMAR, the host country of the 3rd Agora Conference, and also announced the 3rd Agora Conference.

Following Mrs. Makri's presentation, Dr. Donato Pentassuglia took the floor. Dr. Pentassuglia a politician representing a local health care office in Apulia works closely with the government for an agreement concerning a health care plan to help deal with the problem of RMDs in Italy. Dr. Pentassuglia focused on the importance of building a network not only for the government and economy, but also involving the patients and encouraging them to be active and participate in this plan.

Prof. Giovanni Lapadula, Professor at the University of Bari Aldo Moro at the Interdisciplinary Department of Medicine, then discussed how such a network in the regional system of Apulia could be built. He highlighted the need of the care system to be easily accessible





and simple, and to provide continuous support to patients with chronic diseases. Prof. Lapadula concluded mentioning his collaboration with APMAR on various projects and stressed that “No network can operate without a communication code”.

Special Thanks

- * **To everyone for their participation and contribution to the 3rd Agora Conference in Bari, Italy.**
- * **To our special guests and speakers.**
- * **To our partners Abbvie, Merck/MSD and Roche. Without their support the conference would not have been possible. Their invaluable support has helped Agora to strive for the highest standard possible.**

Networking

On Saturday the 27th of September 2014 all conference participants enjoyed excellent fish meze and traditional food from Polignano a Mare as well as traditional tarantella live music at the restaurant Abbazia San Vito in Polignano a Mare. All the participants of the conference had an amazing time and also the opportunity to chat and network in a pleasant atmosphere.



Overall feedback

After the conference an evaluation was carried out and the analysis of the overall results showed that the participants found the information presented useful to use within their own organizations. The majority of the participants found that the conference offered a good combination of theoretical, practical and interactive presentations and workshops. Also, for the future the topics/presentations need to be more tailored to the specific needs of the Southern countries.

Links:

<http://bit.ly/1Ey8JR6>

<http://bit.ly/1bAarEN>

<http://bit.ly/1JtIUe>

<http://bit.ly/1GoLYfT>

<http://bit.ly/1HzqwGo>

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

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

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

<http://www.apmar.it>

Fit for Work and *Early Intervention* links:

<http://www.fitforworkeurope.eu/Downloads/Website-Documents/Early%20Intervention%20-%20One%20pager%20-%2031%2003%202014%20-%20FINAL.pdf>

<http://www.fitforworkeurope.eu/About/about.htm>

