

Agora



Platform of Organisations
of people with Rheumatic Diseases
in Southern Europe

AGORA ANNUAL REPORT 2017

6th AGORA Conference

Westin Hotel Zagreb, Croatia
21-24 September 2017



6th AGORA Conference

Introduction

On September 21-24, 2017 AGORA, the platform of organisations of people with rheumatic diseases in Southern Europe, held the 6th Agora Annual Conference in Zagreb, Croatia. The aim of the conference entitled “The personalised approach to persons with RMDs and Quality of life” was to facilitate discussions and workshops focusing on improving the quality of life for patients with RMDs via various approaches and methods. Further to this, special attention was given to the personalised approach in healthcare as well as to the concept of “Treat to Target” (T2T). Ultimately, the conference aimed to empower and educate patients in leading a healthier life.

The workshop was mainly attended by patients from Agora member organisations.

Agora General Assembly briefing

Prior to the official start of the Conference, Agora had its Annual General Assembly, intended for Agora members. During the assembly, Souzi Makri, the Chair presented the annual report with the projects and achievements of Agora for 2017, while Marie-Therese Camenzuli, the Treasurer, presented the financial report for the year 2016.

New Agora members

The Agora family was extended by four new members after the General Assembly ratified the membership requests of LIRE (Spain), PCDR (Portugal) as full Agora members and Mifrakim Tzeirim (Israel) and INBAR (Israel) as co-opted members. The Romanian organisation APAA was granted a trial year.

New Board

2017 was an elections year for Agora as a new Board had to be elected. The new Agora Board consisting of Evangelia Kritza (Chair), Victoria Romero-Pazos (General Secretary), Sebastian Micallef (Treasurer), Boryana Boteva (Member) and Chryso Yiasoumi (Member).



First Day of the Conference

Opening

The host country organization officially opened the conference.

Dr. Simeon Grazio shared a presentation about the 25th year anniversary of the Croatian League Against Rheumatism, outlining the history and activities of the organization through the course of the 25 years.

Keynote Presentation|

“Individualised approach to rheumatology”

Dr. Frane Grubisic spoke about the personalised and precise medicine in rheumatology and stressed the importance of T2T in treating RMDs and chronic diseases. Complementary to Dr. Grubisic, Ivan Habulin spoke about the importance of occupational therapy (OT) in RMDs, its benefits and positive effects on patients and family members in everyday life. He also spoke about the role of the occupational therapist in assisting the patients towards increasing their quality of life becoming independent.

Workshops' Results|

Workshop A| “How to achieve an individualised model for treating a person with RMDs? Teamwork and rehabilitation approaches in Rheumatology”

Mateja Znika (Physiotherapist), Julija Tenodi Marakovic (specialised nurse) and Spyroula David (Psychotherapist) facilitated Workshop A. The participants were engaged in a discussion, which concluded that teamwork is crucial in achieving an individualised model for treating RMDs. Specialised nurses, psychologists, occupational therapists and informal carers, alongside healthcare professionals, can indeed play a pivotal role in personalising a patient's treatment by means of making it more efficient, creating a more trustworthy environment and leading towards “autonomous patients”. Despite the various setbacks, such as the financial constraints of hospitals and lack of special education for nurses, a multidisciplinary team can offer many benefits to the patient.

Workshop B| “The people behind the curtains: the role of informal carers and nurses”

Brankica Rimac (specialised nurse), Francisco Javier Carreira Roca (patient, LIRE) facilitated Workshop B in an open discussion with the audience. It became clear that patients, nurses as well as informal carers should receive specific training and education. The panel highlighted that both patients and carers need to be able to communicate and exchange information based on proper education, however individual and “alone” time should also be secured for each person.

Workshop C| “Patients involvement in EMA activities: creating patient awareness on medicines’ safety”

Maria Mavris (EMA) presented the way EMA works towards creating awareness on medication safety amongst patients. By means of various reports on drugs’ side effects and descriptions, patients can be informed and educated leading them to make more conscious decisions for their medical treatments. Further to this, EMA engages patients to aid their work by participating in different committees, sharing their experiences in discussion groups and other events. Further to this, EMA offers the opportunity for patients to work as individual patients and provide their perspectives in matters of medicines.

Workshop D| “Starting a family and RMDs: embracing your sexuality and facing facts (pregnancy and fertility) when considering making a family”

Prof. Krunoslav Kuna, MD, PhD, Ivan Bolanča, MD, Mirna Sentić, MD, Primarius and Codruta Zabalán were the panel members for the discussion over the sensitive topic of pregnancy and sexual life in RMDs’ patients. The discussion concluded that love and dedication are very important factors in maintaining a relationship, however sexual life is of equal importance. Once a patient accepts her/his image, any physical, social and psychological barriers related to her/his sexual life will be removed. The panel also addressed the possible fertility problems RMDs can cause to RMDs patients. The specialises stressed the fact that such problems are manageable and many women with RMDs have had successful pregnancies. However, education is key in order to proceed to correct decisions when deciding to start a family.



Second Day of the Conference

Keynote Presentation|

“Quality of life for people with RMDs”

Prof. Gorka Vuletić developed the topic of Quality of Life (QoL) for people with RMDs. In analysing what quality of life means, she outlined the different factors that affect it which are combined satisfaction with specific life domains. These life domains consist of the standard of living, health, life achievements, relationships building, safety, community connectedness and future security. Even though poor health and illness can have negative influence on someone's life, the presence of chronic illness does not imply low quality of life. Prof. Vuletić provided some recommendations in order to increase the quality of life in patients with chronic diseases:

- Age and gender specific approach for maintaining and improving subjective quality of life and health related quality of life
- Programs and activities should not be the same for everyone.
- Taking care of our own health (physical and mental), nurture good social connections and developing our own interests and psychological engagement in life will maintain and benefit to subjective quality of life.

Guest Presentation|

“Quality of Life for people with Rheumatic Conditions in Europe”

Maarten de Wit (Tools2Use) elaborated further on the Quality of Life by discussing the WHO definition of the term (holistic approach), decomposing its main principles and finally reaching to the conclusion that the definition of the term as is, bears a lot of limitations. Most importantly, one of the definition's biggest limitations lies in the way in which we view health and the fact that it raises the expectation that people with chronic diseases are ill and therefore have low quality of life. Instead, the preferred definition of Quality of Life should be “the ability to adapt and self-manage”. According to this new concept of health, self-management programs will become essential in a holistic and personalised approach of health care and help main an acceptable quality of life. Lastly, health care should always aim for maintenance of a relative level of autonomy or independence.

Workshops' Results|

Workshop E| “The emotional and psychological aspect of living with RMDs”
Prof. Vuletić and Dr. Grubisic explored the multidimensionality of subjective Quality of Life (QoL). Having chronic health condition does not necessarily decrease the QoL, as people develop different coping strategies to cope with illness and symptoms and can live fulfilled life. The results generated from the discussion indicated that factors such as maintaining good relationships (with family, friends, at work), succeeding in personal achievements, being part of the community, remaining active in the work force and being autonomous can significantly contribute in increasing the QoL. On the contrary, conditions such as poor health, the feeling of unsafety and uncertainty, the loss of support from peers and lack of autonomy can significantly lower the QoL.

Workshop F| “Challenges people with RMDs face in the workplace and ways to improve the communication with the employers”

Spyroula David (Psychologist), Nikolas Makris (HR specialist), Boryana Boteva (employed patient) and Cathy van Riel (unemployed patient) led the panel discussion for Workshop F. Many patients are faced with challenges in the workplace, which oftentimes leads to unemployment and affects individuals on a personal as well as societal level. The lack of education as to patients' rights at work, the feeling of discrimination and inequality cause patients to choose to leave the workforce once diagnosed. On the other hand, the lack of education and understanding chronic diseases such as RMDs, as well as the lack of proper office equipment are distinctive in the standard behaviour of many employers. To remedy the standard conditions in the workplace, Agora proposes the development of a booklet addressing employers to educate them and make them more sensitive towards patients with RMDs and other chronic diseases, as well as the facilitation of meetings with patient employees, healthy employees and employers.

Workshop G| “The role of patient organisations in helping people with RMDs achieve a better quality of life”

Souzi Makri (Agora) and Eva Kritza (Agora) led an open discussion concerning about the role of patient organisations in helping patients increase their quality of life via various activities. The workshop participants concluded that patient organisations' activities do have a positive effect on increasing the quality of life for patients with RMDs. By releasing valid and authorised information, patient organisations can educate patients and fill in the gap between naïve and expert patients. Furthermore, by organising physical and social activities, patient organisations enable patients to increase the autonomy and learn how to manage their disease and its symptoms. Finally, the participants concluded to the fact that the use of technology and social media can help organisations carry out their work more efficiently and create a virtual network for patients around the world.

Workshop H| “Be active today! How to use adaptive forms of exercise to be more active and healthy”

Andreas Iacovou (Pool instructor), Vicky Aristidou (Yoga instructor) and Antun Andreić (Tai Chi instructor, Remisjia) facilitated a practical workshop, which aimed to showcase three different forms of exercise – Yoga, swimming/hydrotherapy and Tai Chi. The final conclusions highlighted that all three forms of exercise could help patients improve their physical and psychological condition and subsequently help them increase their quality of life.



Presenting Treat to Target (T2T) | “Treat to Target”: How can Agora use this tool to empower patients in achieving a more patient-centred care” Maarten de Wit (Tools2Use) introduced the concept of T2T to the Agora members. The aim of the workshop was to explore the value, opportunities and barriers of implementing a treat to target strategy in the Agora region. Following an interactive introduction to the T2T strategy, where participants were asked to indicate their knowledge about T2T in their region it became clear that that majority was not familiar with the concept, however they were interested in getting more knowledge and information. After outlining and introducing the T2T overarching principles and recommendations, the audience was engaged into a group discussion which led to the realisation that Agora should explore opportunities for supporting the implementation of tight control strategies in the Agora region/countries. Overall, the potential values of T2T –benefits of multidisciplinary treatment; a targeted treatment potentially reduces the excessive costs for healthcare; increase of the quality of life; improvement of doctor-patient communication– seemed more compelling than the potential barriers –the availability of healthcare specialists varies from country to country; different mentality and culture in each country; increased workload for healthcare professionals.

Gala Dinner

Kaptolska Klet| Zagreb

After the official end of the 6th Annual Agora Conference, all participants had the opportunity to socialise and relax during the Gala dinner. During the dinner, the new Agora Board thanked the past Agora Board for their contribution and hard work throughout the six years of their service.

Agora wholeheartedly thanks Souzi Makri (past Chair), Codruta Zabalan (former General Secretary), Marie-Therese Camenzuli (past Treasurer), Adriana Carluccio (past Board member) and Roula Angelidaki-Stara (past Board member) for their service and remarkable achievements during their term and will be forever grateful for helping Agora reach new skies.



Special Thanks

Host Country|

Agora thanks to the Croatian League for their wonderful work in helping organise the 6th Agora Conference in Zagreb. A special thank you to Frane Grubisic, Hana Skala Kavanagh, Ivan Habulin and Prof. Simeon Grazio, MD, PhD for their help during the preparations of the conference.

Partners|

Agora is grateful to all its partners Abbvie, BMS, MSD, Novartis and Roche for their constant support and faith in Agora. Without their support the preparations for the conference would not have been possible. Their invaluable support has helped the Agora Conference attain the high standard that it has today.



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