

Engagement Programme 2019

Visit to LIRE (Spain)

On 2 March 2019, EULAR representatives Johannes Bijlsma, EULAR President, Dieter Wiek, Vice President EULAR representing PARE, and Ricardo Ferreira, representing EULAR's HPR pillar, met representatives of Liga Reumatológica Española (LIRE), representatives of the Spanish Society of Rheumatology (SER) and OpenReuma (the association of Other Professionals in Rheumatology) to debate in Madrid about the future collaborations between clinicians, health professionals and patients in Spain.

Liga Reumatológica Española (LIRE) was founded in 1973 by a group of Spanish rheumatologists, aware of the need to improve healthcare for rheumatic patients. LIRE's main objective is the fight against rheumatic and musculoskeletal diseases and to prevent physical and other impairments. As of 2017, the association is directed and presided over by Victoria Romero Pazos.

The meeting in Fundación Once in Madrid with the title "Let's work together. How clinicians, health professionals and patient organisations can work together for better healthcare" brought together to the joint discussion all three pillars in Spain for the first time. About 25 representatives of different RMD organisations attended the meeting. Several representatives emphasized the need for collaboration nationally, regionally and locally.

Victoria Romero Pazos, President of LIRE, says, "With this meeting we seek to encourage patients, rheumatologists and other health professionals to create more and better opportunities to interact, relate to each other and, above all, work together for a better health system". She adds, "We look at EULAR as a model of integrating the three fundamental pillars in the care of RMDs in Europe as, from the patient perspective, it is essential that these dynamics of collaborative work also happen in Spain".

In her welcome speech Victoria Romero outlined the contribution of patient organisations in healthcare and underlined how an even better outcome can be achieved if patient organisations, health professionals and the scientific society work together.

The meeting started with presentations of the EULAR representatives talking about the advantages of integrating representatives of patient organisations in the work of the scientific and HPR pillars in EULAR, as well as in their home countries (Netherlands, Germany, Portugal). The presentations were followed by a round table discussion with EULAR representatives and Juan Gómez-Reino, President of SER, and Milena Gobbo, President of OpenReuma. The main topics discussed were: how to engage all three pillars to work together in Spain, how to change the national rheumatological congress to integrate patients and patient organisations, how to work with pharma industry when allowing patients to the events of the Spanish society of Rheumatology and how to establish the new ways of collaboration with EULAR.

Several areas of collaboration were identified and a joint declaration consisting of action points was formulated:

The president of SER, and the presidents of OpenReuma and LIRE, decided:

- Hold an annual meeting of the three pillars with a fixed date.
- Include a joint session at the national annual rheumatology congress.
- Establish a communication plan that makes the three pillars and their activities visible.
- Carry out a project to improve early referral of patients to a rheumatologist*.

*This project is already underway by SER, with pharmacists and primary care doctors. OpenReuma and LIRE propose, later, to open it to physiotherapists, psychologists and citizens. Disease leaflets can be provided to pharmacists, as well.

The follow up will be done in several steps. A first teleconference is planned for the first week of April in which the leaders of the three pillars will set up a more specific calendar for the previous actions. The three Spanish pillars have agreed on a face to face meeting during the EULAR congress in which they will evaluate the first semester including the National Congress of Rheumatology and the participation in it of patients and HPs. There will be another opportunity to plan evaluations with the theme of 'Don't Delay, Connect Today' during WAD. Lastly, in the first trimester of 2020 a meeting will be organised in Madrid before LIRE's General Assembly to compare indicators from the starting point (this meeting) and the same date next year, interactions in social media, projects undergone together, other types of collaborations, and the realisation of the actions foreseen in the joint declaration'

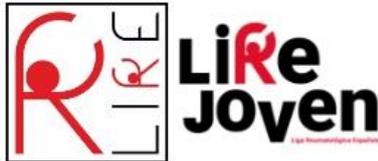
There is a long way ahead to a truly joint work of all 3 pillars in Spain, but the first step has been done. EULAR President Johannes Bijlsma commented the Spanish situation with his final words: "It is not possible to compare the international and national level. Start from something small and continue to join forces together, try to get an equal representation of all 3 pillars for a better care of RMDs. If it's done right, everyone will want to unite".

Victoria Romero Pazos adds, "EULAR is the model we want to follow, especially because we feel like a family. Although the model cannot be transposed directly, we can copy what works here".



Participants of the roundtable discussion (from left to right): Milena Gobbo, Ricardo Ferreira, Dieter Wiek, Johannes Bijlsma, Victoria Romero Pazos, Juan Gómez-Reino and Loreto Carmona

Invitation to the event:



LET'S WORK TOGETHER
**How clinicians, health professionals and patient
organisations can work together for better healthcare**
2 March 2019

Sala Patronato Fundación ONCE
Calle Sebastián Herrera 15. 28012 Madrid

10:00h to 10:30h Arrival of attendees.

10:30h to 11:00h "PARE's successful integration into EULAR"
Dieter Wiek, Vicepresident EULAR representing PARE.

11:00h to 11:30h "How the HPRs, one of EULAR's three pillars,
contribute to healthcare in rheumatology" Ricardo Ferreira,
Representative HPR.

11:30h to 11:45h Break.

11:45h to 12:15h "What is the benefit of integrating patients and
health professionals into EULAR?" Hans Bijlsma, President
EULAR.

12:15h to 13:15h Round table: Hans Bijlsma, Dieter Wiek,
Ricardo Ferreira, Victoria Romero (President LIRE), Milena
Gobbo (President OpenReuma) and Juan Gómez-Reino
(President SER).

13:15h to 13:45h Writing of the decalogue of actions to improve
collaboration among the 3 Spanish pillars.

13:45h to 14:00h Closing.

14:00h to 16:00h Lunch.

With the participation of:

Declarado de Interés Social por:



With the collaboration of:

