

EULAR
04.06.2021
Kilchberg,
Switzerland

THERE IS AN UNACCEPTABLE DELAY TO DIAGNOSIS IN AXIAL SPONDYLOARTHRITIS

Developing a call to action for a global healthcare challenge

The current delay to diagnosis from symptom onset represents one of the greatest challenges in axial spondyloarthritis (axSpA) – a type of inflammatory arthritis affecting the back. Research shows an average delay of around 7 years – and up to 15 years in some cases – during which time the condition can progress and lead to irreversible damage. Data indicates that women wait longer than men for a diagnosis, and there has been very limited progress in reducing the time to diagnosis. This delay has a hugely detrimental impact on a person’s quality of life. Because the disease frequently has early onset, individuals are left untreated – or with incorrectly treated symptoms – at a formative period in their life course.

The Axial Spondyloarthritis International Federation (ASIF) set out to coordinate a comprehensive evidence-based global review of the factors influencing the current diagnosis delay in axSpA, and to produce a definitive report that shines a light on these barriers, as well as providing a resource that can ultimately empower a range of international stakeholders to reduce this delay.

At the 2021 EULAR congress, Dr Dale Webb and colleagues report the results of a full literature review and two virtual global forum events, involving patients and patient group representatives, researchers, rheumatologists, and other healthcare professionals. The aim was to explore key diagnosis challenges across different healthcare systems, to better understand how the delays affect individuals and to identify opportunities for addressing these. Break-out discussions were held, and participants were asked to identify the personal and societal effects of the diagnostic delay, the reasons it occurs, and initiatives to tackle the challenge. Alongside key stakeholder testimonies, best practices from around the world were also identified. In total, 92 stakeholders participated in the events, representing patients and healthcare professionals from 23 countries across five continents.

The findings from these activities were incorporated within a new ‘Delay to Diagnosis’ report, which for the first time definitively sets out the lived realities from a global perspective of the axSpA diagnosis delay. The report identified important commonalities across different countries and healthcare systems contributing to the current average global 7-year diagnosis delay. These include: 1) poor awareness of axSpA amongst those with symptoms; 2) lack of disease recognition amongst the wider population; 3) incorrect diagnosis at the first point of healthcare system contact; 4) poorly defined referral pathways; 5) difficulties in accessing appropriate care and; 6) challenges within rheumatology itself.

The report also highlights the significant impact this delay has on individuals and wider society, providing a foundation for future advocacy work. A series of recommendations has been identified, the implementation of which will help make tangible progress in reducing the delay.

Despite longstanding challenges, there are now clear opportunities for transforming how axSpA is diagnosed around the world. This message needs to be heard and acted upon urgently by all those involved in the management and delivery of axSpA care. The future programme of work for ASIF’s Delay to Diagnosis project will respond to these findings and be centred around supporting axSpA patient associations globally to take this call to action forward throughout 2021 and beyond.

Source

Webb D, et al. The Unacceptable Delay to Diagnosis in Axial Spondyloarthritis; Developing a Call to Action for a Global Healthcare Challenge. Presented at EULAR 2021; abstract OP0275-PARE.

About EULAR

EULAR is the European umbrella organisation representing scientific societies, health professional associations and organisations for people with rheumatic and musculoskeletal diseases (RMDs). EULAR aims to reduce the burden of RMDs on individuals and society and to improve the treatment, prevention and rehabilitation of RMDs. To this end, EULAR fosters excellence in education and research in the field of rheumatology. It promotes the translation of research advances into daily care and fights for the recognition of the needs of people with RMDs by the EU institutions through advocacy action.

About the EULAR European Congress of Rheumatology

Since its introduction in 2000, the annual EULAR European Congress of Rheumatology has become the primary platform for exchange of scientific and clinical information in Europe. It is also a renowned forum for interaction between medical doctors, scientists, people with arthritis/rheumatism, health professionals and representatives of the pharmaceutical industry worldwide. The EULAR congress is usually held in June in one of the major cities in Europe ([see previous congresses](#)).

The [scientific programme](#) at the congress covers a wide range of topics on clinical innovations, clinical, translational and basic science. Meetings set up by associations of people with arthritis/rheumatism, health professionals and the health care industry complement the programme. The poster sessions, offering lively interaction between presenters and participants, are regarded by many as the heart of the congress.

Over the years, the EULAR Congress has gained a reputation of being a most innovative platform for the practicing physician particularly with respect to the acquisition of information on novel clinical research. The congress attracts more than 18,000 delegates from more than 130 countries.

The aim of the EULAR European Congress of Rheumatology is to provide a forum of the highest standard for scientific, both clinical and basic, educational, and social exchange between professionals involved in rheumatology, liaising with patient organisations, in order to achieve progress in the clinical care of people with rheumatic diseases.

Contact

EULAR Press, press@eular.org, Tel. +41 44 716 30 36

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