

What I saw at #EULAR 2026, London, 3-6 June, OR...

...They came to see me!

**Notes and takeaways following up my
(minimal) attendance as Patient / PARE**

Bsky | @brunellalongo | Sun 14 Jun 2026

Contents

- Why did I go to EULAR 2026?
- Boomerang “United in Motion” Welcome message
- Impressive / overwhelming range of subjects
- Treatments and clinical trials
- Imagination and data drive research but...
- Data conundrums, AI and design
- Language, time and stratification
- Just one thing: personal takeaways
- About me

Why did I go to EULAR 2026?

My reasons to attend

- Ten years ago EULAR Principles and Recommendations pointed me towards non pharmacological / lifestyle interventions. These reinforced my lived experience of what I was finding helpful to manage the typical “constellation of symptoms” of RMDs / autoimmune diseases: walking, cycling, going to the gym.
- Since then, EULAR has been one of my fundamental points of reference, not without perplexities, question marks and differences of opinions, for both my disease management decisions as a patient and my activity as an independent researcher and writer
- Opening to and engagement with patients is the greatest social initiative in medicine of our time: although there are still eyebrows raised and patronising comments among experts, these trends bridge the immense gaps between research and healthcare
- I wanted to see “in action” and in person the enormous alliance of communities represented by EULAR and feel less isolated: thousands of people involved from all over the World, dozens of scientific associations and patients associations... and like many ‘active’ patients I am always on my own!
- I wanted to identify sources of research and know who is working on some specific ideas. The Congress seemed a great opportunity not to be missed!

Boomerang: 'United in Motion' Welcome!

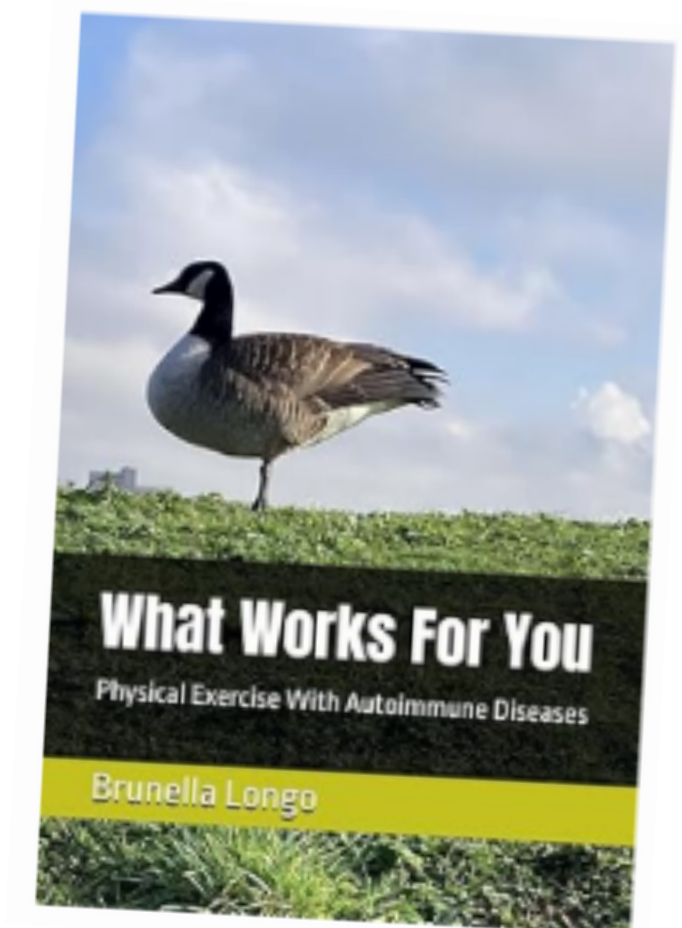
Emotional message about the science of movement opened the Congress

- It sounded like a special Happy Birthday to me since I turned 63 during the Congress!
- Having just published “*What Works For You. Physical Exercise With Autoimmune Diseases*” I couldn’t feel more in tune with the welcoming message of the Plenary session that opened the Congress!

“We do not think about movement until it stops”

“Movement is dignity & quality of life”

- Indeed! These are two of the main messages of “*What Works For You*” a vademecum for doctors, researchers and patients that I wrote explaining what I learned on this subject from lived experiences, starting with mine, guidelines and research in a wide range of disciplines, including exercise immunology, sport psychology, fitness practices. I talk about the science of movement, the *bodymind* connection, the best practices for several autoimmune / RMDs conditions and the existing or emerging healthcare technologies.
- In my view, the ‘science of movement’ is the greatest scientific achievement of the last 25 years in RMDs / autoimmune diseases, with growing global consensus on its benefits.



Impressive / overwhelming range of subjects

Hundreds of presentations, abstracts, papers, studies...

- The strength of the emotional message I heard in the plenary session about the science of movement seemed watered down - or lost - within the Congress' scientific programme: only few sessions, tracks, posters, abstracts mentioned the subject, some engagement ideas, few case histories about physical therapy or physical exercise... nothing on the biology of exercise, the practices, the evidence around the breakthrough notion of **movement is medicine**
- The Congress showed researchers and rheumatologists are focussing on an immense variety of topics and perspectives
- All EULAR contents are published / broadcasted online for you to browse and access starting at eular.org

Treatments and clinical trials

RMDs and autoimmune diseases continue to be incurable BUT

- I exclude here any comment on the massive quantity of data on traditional and innovative drugs and clinical trials on several conditions, in particular Rheumatoid Arthritis, Lupus and Sjögren's that I want to review for other two forthcoming books in my series
- One among hundreds of documents I recommend: the SjögrenEurope e-Leaflet "**Clinical Trials: What patients need to know**" you find in the section 'Information' at sjogreneurope.org
 - Understanding how a clinical trial is done does not guarantee you understand its scientific / molecular or chemical assumptions, its specific purpose, its design and how your condition satisfy the criteria for participation but... it is a safe and very good starting point!

Imagination, data, weird ideas drive research...

But what are the priorities for healthcare and patients wellbeing?

- STEM disciplines advance because of knowledge and creativity: I strongly believe in freedom of research and freedom expression but there are some perplexities
- Interesting research ideas often contradict basic evidence, or scientific principles. Examples:
 - **Smoking** is the single cause of many cancers and CVDs BUT data show it lowers inflammation in some rheumatic and autoimmune conditions.... So what?!?
 - Autoimmune diseases are polygenic BUT investigators found **mitochondrial DNA** can be a driver of immune activation and dysregulation.... So what?!?
- Huge fragmentation of funding + proliferation of correlations / associations of data = a cacophony in which it seems patients have become irrelevant, or seen as obstacles!

Data 'conundrums' can hold back progress

Can artificial intelligence or design help? Lot of questions!

- Consensus on a **new tool (STAR)** to overcome limitations of existing ESSDAI and ESSPRI seems reached BUT ...many do not want “one option only” ... Why?
- Does reliable data show that a ‘RESET of the immune system’ is 1) achievable or 2) desirable for wellbeing and quality of life? So far only gossiping about toxicity and infections or gene therapy deaths, perception **we need transparency on negative results**
- Artificial intelligence lacks social capital but it can embed strong rationale into specific research and clinical decision making. **My view: we need industrial standards for AI**
- **Data registries** continue to innovate also through integration with patients electronic files but more researchers tend to ignore missing data, lack of interoperability or / and accuracy, P values and significance cut off points.

Language and time always matter

Classifications always tends to sort things out

- Researchers still puzzled with the heterogeneity of symptoms in systemic autoimmune diseases like Sjögren's and Lupus are defining **clusters of patients** through **stratification**, using a variety of criteria including new **molecular** taxonomies. However, stratification of patients in static “boxes” could challenge real time personalised medicine...
- Disease activity and patient lifestyle usually **change** by the minute: is the constant metamorphosis of systemic autoimmune diseases considered for new designs of clinical trials?

“Just one thing” 🙄

My personal **takeaways**

- DMARDs and other treatments do not heal fatigue whereas for me **exercise is a painkiller!**
- When rheumatologists talk about ***glandular vs systemic Sjögren's*** they use traditional ‘sicca’ conventions that do not always help the patient: infiltrations of the exocrine glands and the epithelium mean the disease is always systemic, even when we are able to prevent / avoid major complications or slow down its progression
- Immune ‘reset’ therapies may be the way forward but do not heal **autoimmune fibrosis**
- When Sjögren's **overlap** with other diseases, the symptoms of one of the other diseases always prevail!
- We need to **prevent inflammation at all costs!** Another call for movement as medicine!
- Beware patients very often do not report **side effects of medications**

“Whatever works for you, I wish you to be physically and mentally active for many years to come”.



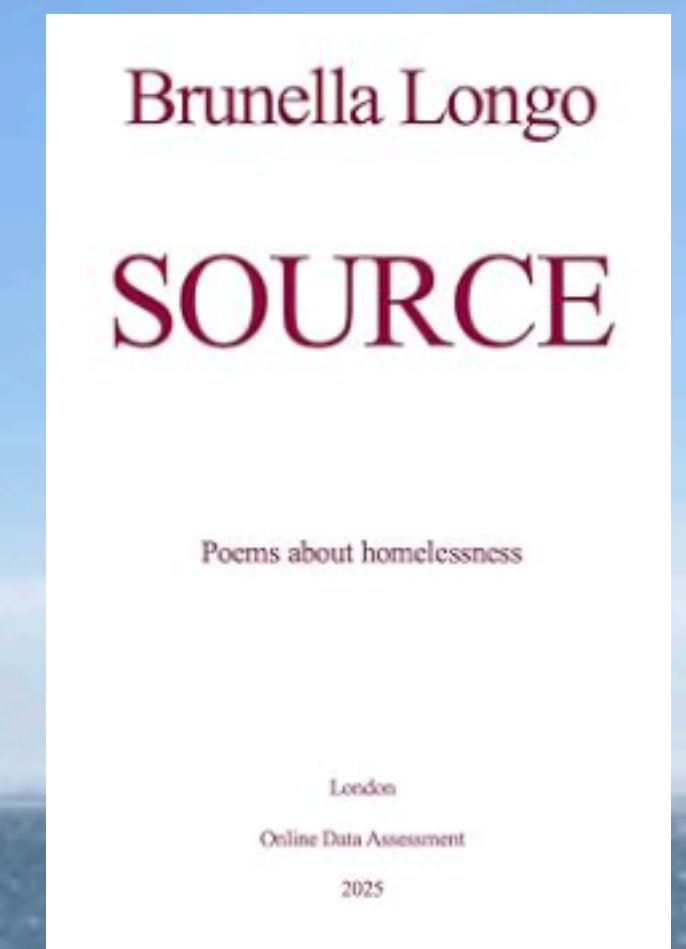
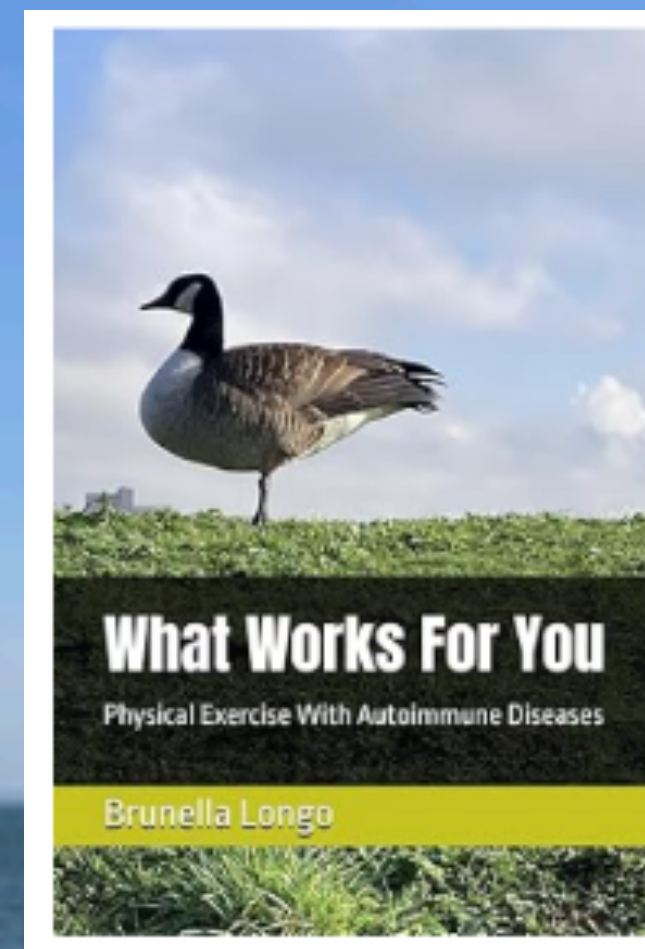
Brunella Longo, What Works For You. Physical exercise with autoimmune diseases (2026)

Thank you!

Brunella Longo

icm2re @ gmail.com

Bsky.app @brunellalongo



Visit www.pantarei.it for my short media bio, updates, links to order the books already published in my “The Sicca Messenger” series!