

# Meet the Organisers



Each year, the EULAR congress continues to grow larger and larger. Ensuring an exciting and fulfilling programme is an enormous undertaking. We spoke to Mr Dieter Wiek and Prof Berent Prakken to discuss their roles in organising EULAR and their experiences at the congress.



## Prof Berent Prakken

President of the Paediatric Rheumatology European Association (PRES), Professor of Paediatric Immunology and Vice Dean for Education at University Medical Center Utrecht, Utrecht, the Netherlands, and co-founder of the Eureka Institute for Translational Medicine

### Q1 What first attracted you to a career specialising in paediatric rheumatology?

The drive to help children with a chronic disease cope with their condition, adapt to limitations, and live their best possible lives.

### Q2 In what ways does paediatric rheumatology represent a unique challenge for the physician?

Compared to adult rheumatic diseases, juvenile rheumatic diseases hit the patient during growth and development, both physically and mentally. This brings special and unique challenges for the paediatric rheumatologist.

### Q3 With an increasingly ageing population worldwide, what steps would you like to see put in place to encourage rheumatological health in the general population?

Obviously, we must support a healthy lifestyle. But this should not be a top-down hierarchy

with us setting guidelines; it should not be one size fits all. Instead, I think we should actively involve patients in managing their own health; only through doing this can we develop true personalised medicine.

### Q4 As President of PRES, you said your personal ambition is to “support the growth of the PRES community by strengthening the patient perspective, encouraging young talent, and by connecting PRES with the outside world”. What steps has PRES taken to work towards these goals?

We have made many small but significant steps towards achieving this goal. These include redefining our mission, setting a strategic plan for the future (PRES 2025), and incorporating the European Network for Children with Arthritis (ENCA) as a patient organisation in PRES.

**Q5** With PRES celebrating its 25<sup>th</sup> conference last year and now co-hosting the EULAR congress, this is an exciting time to be working in paediatric rheumatology. Do you think clinicians working in this field will become even more specialised in the future?

We will need so-called T-shaped professionals, who are both experts in their field and have also learned to navigate across boundaries and specialties.

**Q6** The integration of paediatric rheumatology throughout the congress programme is excellent this year. How vital is the sharing of knowledge between PRES and EULAR and, given your role in planning the event, how did you decide what paediatric sessions to include in the programme?

I strongly believe that it is crucial we learn from adult rheumatologists, while I also feel that we have quite a lot of insight to offer to the EULAR community. Professor Michael Beresford, chair of the PRES scientific committee, did an excellent job in choosing the subjects that might be of interest for both communities. Having said this, choosing was extremely difficult; he could easily have filled twice as many sessions!

**Q7** How has translational medicine shaped paediatric rheumatology treatment and care?

Paediatric rheumatology has a tradition in translational medicine and, in recent years, PRES has specifically supported this; for example, by supporting young investigators (which has led to the Emerging Rheumatologists and Researchers [EMERGE] group of young investigators) and by linking with the Eureka Institute for Translational Medicine. While in some other fields clinician scientists are 'threatened', they flourish in our field. We must make sure that we keep this positive

"I think we should actively involve patients in managing their own health; only through doing this can we develop true personalised medicine."

momentum going, by actively supporting initiatives from clinician scientists.

**Q8** You are the co-founder of the Eureka Institute for Translational Medicine. What is the mission of the institute and how do these ideas and goals interact with your work as President of PRES?

The mission of the Eureka Institute ([www.eurekainstitute.org](http://www.eurekainstitute.org)) is to develop a community of translational medicine professionals equipped to inspire and catalyse the application of discoveries for the benefit of human health. Eureka does this through education and building a community, especially concerning the training and education of our future leaders in PRES to ensure our goals are completely aligned. For that reason, PRES has supported talented individuals from our EMERGE group to participate at the summer school that Eureka organises in Utrecht, the Netherlands.

**Q9** You have published >170 papers, are a regular reviewer for many journals, and sit on several committees and boards. With so many roles and responsibilities across the field, how do you stay motivated?

It is very easy for me to stay motivated as I am constantly in touch with my 'target audience': patients, students, and young investigators. Working with them shows me every day that there is still so much important work to do!

**Q10** What advice would you have for a young paediatric rheumatologist just beginning their career in this field?

Relax, have fun, and enjoy the ride: it is the most rewarding job I can imagine.





## Dieter Wiek

EULAR Vice President representing National PARE Organisations

### Q1 What do you enjoy most about your role as Vice President of EULAR and a representative of the National Organisations of People with Arthritis/Rheumatism (PARE)?

We see that there are discrepancies in European healthcare. So, it is great to support the initiatives of patient organisations to inspire better healthcare in their respective countries, but also to lobby for the interests of people with rheumatological diseases on the European stage, e.g., through the various EU institutions.

A key point is to talk to people with rheumatological diseases about their personal situation, so that I am aware of the aspects I am aiming to bring to attention in all these lobbying talks.

### Q2 What are some of the challenges of the role?

The key challenge is that, as a volunteer, you have to invest a lot of time.

### Q3 The missions of PARE are to improve patients' experiences by giving them a voice, developing strong networks, and creating alliances. How are PARE working towards achieving these goals?

It is a key principle of our PARE sessions to represent patients' experiences by, for example, presenting them at the EULAR Congress. The abstract sessions underline these experiences as well. For the Stene Prize, an annual award, patients write about their experiences on a predetermined topic.

Additionally, the Annual PARE Conference not only has educational purposes, but also enables

networking and the creation of alliances. Other programmes, like the Knowledge Transfer or the Engagement Programme, also support these aims.

### Q4 You have personally discussed the importance of patient engagement. How are you using your position at EULAR to try and encourage patient engagement and communication within rheumatology?

We are trying to engage our patients and colleagues in discussion through workshops at the Annual Conference, sessions at the Congress (e.g., 'How to get involved in Health Technology Assessment'), and through all our activities that support the involvement of patients in research, for instance through our Patient Research Partner network. These sessions encourage the cooperation of patients with clinicians and health professionals, with a focus being on patient engagement and communication in rheumatology.

### Q5 You recently co-authored a paper on the conduction of rheumatology studies: "EULAR 'points to consider' for the conduction of workforce requirement studies in rheumatology". What are the main take-home messages from this paper?

We can see that in some countries there is a lack of rheumatologists, but it is not just the number that counts. When looking at the number, we have to take into consideration the general attitudes towards the scope of practice and work. In the future, we can also consider that e-health solutions may compensate for these deficits.

## Q6 Is there a session that you are particularly looking forward to at this year's EULAR congress in Madrid?

PARE offers lots of great sessions. One of my favourites is this year's e-Health session, as it shows and discusses what personal gains for self-management and healthcare are possible through e-health and how the relationship between patients and health professionals has changed.

## Q7 How important is the consideration of mental health in the treatment of rheumatic diseases?

In my opinion, non-pharmacological treatments should be regarded with higher importance than they have now. Apart from physical activities, physiotherapy, and other considerations, mental health should be a key aspect for self-management.

## Q8 As a patient with ankylosing spondylitis yourself, how have you seen knowledge and treatment of the disease change since you were first diagnosed?

A patient's knowledge has definitely increased through online services, social media, and rehab programmes. But dissemination of knowledge does not mean that these guidelines and recommendations are followed. The point is this: how can we enable that knowledge to lead to sustainable action?

We still see that a person's diagnosis can be delayed, and this is a problem we have to overcome.

Nowadays, patients who are seriously affected, especially young patients, have a good chance that deformities will be prevented. Also, biologics mean patients have got a much better health outcome and can stay in work.

## Q9 How has your experience as a teacher helped you in your role in the rheumatology industry?

Honestly, I do not feel I am in the rheumatology industry. I always regarded my task as a teacher to improve a young person's knowledge and equip her or him with the necessary skills and methods to be a positive and critical citizen. I see myself as a critical person trying to overcome deficits and improve the healthcare situation for patients. This can be achieved with the support of clinicians, and healthcare professionals.

## Q10 What area of rheumatology do you hope to see gain more attention over the next few years?

I still hope that, with the help of testing or screening and appropriate treatment measures, it will one day be possible to prevent the onset of diseases like rheumatoid arthritis, ankylosing spondylitis, or Lupus.

"I always regarded my task as a teacher to improve a young person's knowledge and equip her or him with the necessary skills and methods to be a positive and critical citizen."

