



## Waarover gaat dit ?

PARE, People with Arthritis/ Rheumatism in Europe, is het netwerk van reumapatiëntenorganisaties in Europa. Elk jaar organiseert de groep een conferentie voor afgevaardigden van de patiëntenverenigingen. Het gaat om een brede internationale gemeenschap met toegewijde vertegenwoordigers. Die gebruiken op hun beurt de opgedane kennis om op nationaal niveau projecten uit te werken of hun werking te verbeteren.

ReumaNet vzw nam, als lid van PARE, deel aan het jaarlijkse congres. Mireille, vrijwilliger van de RA Liga, was één van de afgevaardigden, naast Ingrid van de CIB-Liga en Anja van ReumaNet. Omwille van de covid pandemie verliep alles voor de eerste maal virtueel, online.

Tijdens de EULAR PARE Best Practice Fair werden de ingediende abstracts /projecten van verschillende organisaties even kort mondeling toegelicht. Elke organisatie kreeg immers de kans om interessante projecten of verwezenlijkingen voor te stellen. Op die manier ontstaat er een dynamische uitwisseling van ideeën. De oRAnje knoop was één van de posters die werd voorgesteld (zie verder). Iedereen mocht stemmen op de persoonlijke top drie, waardoor de beste drie posters in de bloemetjes gezet werden op het einde van de conferentie.

## Rol van de RA Liga ?

Dit jaar diende de RA Liga vzw de Abstract/Poster met het thema "DE KNOOP" als herkensymbool voor reumatoïde artritis campagnes, in. Promotie via video boodschap gebeurde door Mireille Verscheure.

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[An oRAnge button as sign of involvement & raise awareness for the RA campaign in Belgium - Mireille Verscheure, RA LIGA](#)  
[Click here to access the poster.](#)

## An oRAnge button as sign of involvement & raise awareness for the RA campaign in Belgium

Mireille Verscheure, volunteer [www.raliga.be](http://www.raliga.be) Flemish patient organization, part of ReumaNet



### Background : Why oRAnge button

With the oRAnge button, we draw attention to Rheumatoid Arthritis.

Attaching a simple button : for people with RA can be this quite a task.



### Objectives

- ❖ To sensitize patients for an early diagnosis, the earlier the better
- ❖ To improve the recognizability of the oRAnge button at the WAD, activities and the general public
- ❖ To create attention of the Medical World and the political institutes about RMD's



### Methods & Material

- ❖ Visuals : e-banners, posters, newsletters via [www.domusmedica.be](http://www.domusmedica.be), (training general practitioners, doctors, caregivers)
- ❖ Mail campaign by Mediquality .
- ❖ WAD (World Arthritis Day) on October 12th
- ❖ Propaganda via our social media, links , FB, Instagram.
- ❖ A special subdomain created for the national campaign: a link to [De oRAnjeknoop](http://De.oRAnjeknoop) – RA Liga vzw / Reumatoïde Artritis Liga vzw , links to Youtube videos and a contactform to obtain oRAnge buttons, posters, flyers, leaflets.

- ❖ RAAM member magazine January 2022 with interviews from general practitioners.

### Results / Conclusions

- ❖ Distribution of oRAnge buttons, on WALK Family day September 2021, floorstickers with messages
- ❖ YouTube : Family Day Walk <https://www.youtube.com/watch?v=7GCPkKleu4>

Endurance 12hours cycling Zolder circuit [https://www.youtube.com/watch?v=4W3W\\_9Rcp\\_k](https://www.youtube.com/watch?v=4W3W_9Rcp_k)



## Best Practice Fair Posters and Videos

Op het congres kwamen opvallend veel programmathema's zoals digitalisering en zelfzorg aan bod. De weg naar de toekomst?

Runner Up : Ailsa Bosworth, National Rheumatoid Arthritis Society (NRAS) bekwam met haar poster de 2e plaats.

## SMILE-RA (Self-Management Individualised Learning Environment in Rheumatoid Arthritis)

Ailsa Bosworth MBE, National Rheumatoid Arthritis Society, UK

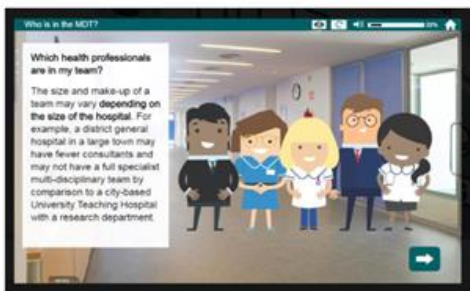


A unique, modular, engaging and interactive e-learning experience for people with RA and their families launched September 2021. Also beneficial for nurses and allied health professionals new to rheumatology.

Currently 4 modules available

- ✓ Foundation
- ✓ Newly Diagnosed
- ✓ Meet the Team
- ✓ Managing Pain and Flares

Next up: Medicines in RA



SMILE has a modular approach to learning, so each module is on a particular subject and takes between 20 mins. and half an hour to complete. There is an intuitive style interface making it easy to use and navigate. After registering and completing the Foundation module which includes baseline evaluation questions, you can direct your own learning experience and choose the modules of interest to explore next. Modules are interactive, contain short quizzes and lots of video and voice-over contributions from rheumatology health professionals, NRAS staff and people with RA. We focussed on making the programme attractive and engaging to work with. Content has been written with input at every stage from the rheumatology professionals, individuals with RA and NRAS staff who have contributed to each module as well as our E-Learning Advisory Board.

### Evaluation

The data we are collecting through the programme is extremely important to us (RA Impact of Disease questionnaire) and will help us to understand the impact the programme is having on those participating over time. Data collection is fully GDPR compliant and will only ever be used in an anonymised and aggregated form to report back to our funders, the users themselves and the rheumatology community. Each module has learning objectives at the start and 3 or 4 questions are asked at the end to gauge how well these are being met for participants and this will help us to understand in broad terms that the structure of the modules is working optimally.

- Total registrations between 170921 and 051121 = >620
- Total no. of RAID scores completed between the above dates = 221 (app. one third)
- Percentage of members/non members participating = 75% non-members
- Limited demographic data also collected.

### 4 more modules to follow in 2022

- How to have the best consultation
- Exercise in RA
- Love your Heart (how to manage cardiovascular disease risk)
- Treatment of RA



Even though my RA diagnosis was many years ago, my involvement as a Volunteer with NRAS has taught me that there is always more to learn. The research, development and information in the world of RA is constantly evolving. I am a strong believer in 'knowledge is power' when it comes to managing your own condition. Therefore, SMILE is a great resource whether you are newly diagnosed or have been living with RA for many years.

Donna Saunders, living with RA



# THE Winner van de Award 2021 is Sjögren Europe Alice Grosjean

## world sjögren's day 2021: a 3-axis campaign about fatigue

A. Grosjean\*, L. Stone\*, A. Vieira\*, C. Bouillot\*, J. Koelewijn-Tukker\*, M. Oosterbaan\*, K. Antonopoulou\*, \*Sjögren Europe



### fatigue

Fatigue is one of the most prevalent and disabling patient reported symptoms of Sjögren's. Fatigue in Sjögren's clearly differs from ordinary tiredness. We describe it as an ever-present, fluctuating, and nonreliable lack of vitality being beyond one's own control. Not everyone experiences it in the same way, but fatigue is undeniably a permanent part of patients' lives. It is a debilitating symptom which is associated with reduced health-related quality of life.

### world sjögren's day

Every 23 July is World Sjögren's Day (WSD), which is dedicated to raise awareness about this condition. For WSD 2021, Sjögren Europe decided to focus on fatigue, with the hope to bring forth a topic often misinterpreted and poorly addressed.



In order to contribute to increase awareness and acknowledgment of fatigue as a major factor in Sjögren's and promote a growing knowledge that Sjögren's is a systemic disease, various activities

and informative material related to fatigue were presented in honour of WSD 2021.



The campaign was disseminated over a month between June and July, culminating with WSD and it was posted on a dedicated webpage on Sjögren Europe's website [www.sjogreneurope.org/wsd](http://www.sjogreneurope.org/wsd), on different social media channels and in a newsletter. It was also disseminated by our members and other patients' communities.

### a 3-axis campaign about fatigue

The campaign was organised in 3 axes, in order to present fatigue from 3 perspectives:

#### 1) the medical perspective

A webinar about fatigue was organised with a rheumatologist from UK specialised in Sjögren's, in order to better understand fatigue.

#### 2) the psychological perspective

A self-help booklet on targeting chronic fatigue in Sjögren's was published with a Dutch psychologist

who was involved in the development of treatment programs and international guidelines for the treatment of fatigue and pain in RMDs. In this booklet, he offers tips for targeting fatigue: personal factors that can influence fatigue are mapped and it explains how those factors can be tackled.



#### 3) the patient perspective

The core of the campaign is to raise awareness about patients' fatigue and express the different ways in which it manifests itself, as experienced by patients. The article by Teri Rumpf, a Sjögren's patient and psychologist from the US, "15 types of Sjögren's fatigue", was shared in a visual campaign available in 13 European languages.

One type of fatigue per day was shared with an expressive picture, the pictorial name of the fatigue and a short sentence summarizing the fatigue. The complete description was shared in addition.

These publications aim to help patients feel understood and validated in their experience of



fatigue, and to put into words what they live and feel so they can better express it to others.

### results

The campaign had a great impact and a lot of visibility. In July 2021, just on Sjögren Europe Facebook page, it had more than 50'000 views. The visits on our website more than doubled to reach 500 visits a day.

This campaign allowed many patients to feel less alone in the face of fatigue as it made visible the invisible, to incorporate them into the discussions and to initiate a rich dialogue. We noticed an increased presence of young people and men during the campaign which is probably due to their representation in the photos.

The involvement and contribution of our member organisations was critical to the success of our campaign. They helped with the translations and the dissemination and made the campaign their own, allowing patients to unite for WSD.