WORD DAY 2019

IMPACT REPORT

Delivered by

the European Network for Children with Arthritis (ENCA) and the

Paediatric Rheumatology European Society (PReS)









STEERING COMMITTEE



SAMMY AINSWORTH UK



VEERLE BUYS
BELGIUM



WENDY COSTELLO
IRELAND



YONA EGERT ISRAEL



Dr EVE SMITH



SIMON STONES UK

THANK YOU TO OUR PARTNERS

All this would not have been possible without the help of doctors and patient associations joining forces worldwide.

- A special THANK YOU goes to PReS* and ENCA* who together formulated the idea and worked hand in hand on all aspects of WORD day.
- Local TV- and radio-broadcasting companies who aired programs, content and interviews in preparation for WORD day.
- Post-graduate medical training organisations who showed willingness and flexibility to add new content to their regular training sessions.
- Paediatric and family doctor associations who worked with us to include lectures and written content in their conferences.
- Municipalities that allowed and funded public awareness activities.

^{*}see www.pres.eu and www.enca.org

SUMMARY AND OBJECTIVES

The first ever "World young Rheumatic Disease Day – WORD DAY", aimed at spreading the WORD that "children and young people get rheumatic diseases too", took place on Monday 18 March 2019.

The campaign was jointly launched by the Paediatric Rheumatology European Society (PReS) and the European Network for Children with Arthritis (ENCA), with the main objectives being:

- To raise parental and professional awareness of these illnesses in children
- To reduce diagnostic delays by targeting primary care healthcare professionals and general pediatricians, who are the first clinicians to come into contact with these children

A range of face to face awareness raising events were undertaken across the world, with activities including television and radio interviews, podcasts, lectures to healthcare professionals, awareness stands in public places, patient and parent events, cake sales, sponsored walks and hikes, as well as an extremely active social media campaign including social media live sessions and posts.

A summary of the campaign can be found on this article on "The Lancet Child & Adolescent Health"

https://doi.org/10.1016/S2352-4642(18)30374-2

SOCIAL MEDIA HIGHLIGHTS

The WORD Day 2019 social media campaign ran from 21 December 2018, up until WORD Day on 18 March 2019 on Facebook and Twitter. Both platforms grew in terms of reach, follows and engagement. Social media analytics were used to measure the impact of official WORD Day social media platforms; however, these don't encompass other organic and paid social media content published by other individuals and organisations on multiple social media platforms.

FACEBOOK



2 585 followers



40 000 engagements Likes - Shares - Comments



Video content: Viewership of 26 100 minutes and 959 000 '3-second' views



Posts seen 646 000 times

Top performing post was a video created by young people affiliated with the Irish Children's Arthritis Network (iCAN), which reached 80,522 people with 2,661 engagements alone

https://www.facebook.com/WORDday2 019/videos/252744852274993/



TWITTER



TWEETCHAT

A WORD Day tweet chat was hosted on 18 March 2019, by @JordanCanning_ and @SimonRStones, two young adults living with paediatric rheumatic diseases.

This tweet chat focused on the topic of paediatric rheumatic diseases, and attracted a mixture of patients, parents, healthcare professionals and members of public who engaged in discussion and debate on key challenges, examples of good practice and strategies for raising awareness.



On WORD Day, posts with #WordDay2019 were retweeted 1 112 times, with a total of 1 568 tweets recorded that day. #WordDay2019 was seen by 533 955 unique accounts with 3 334



On WORD Day, original posts from official WORD Day account were retweeted 139 times, with 223 likes



660 followers

699 impressions



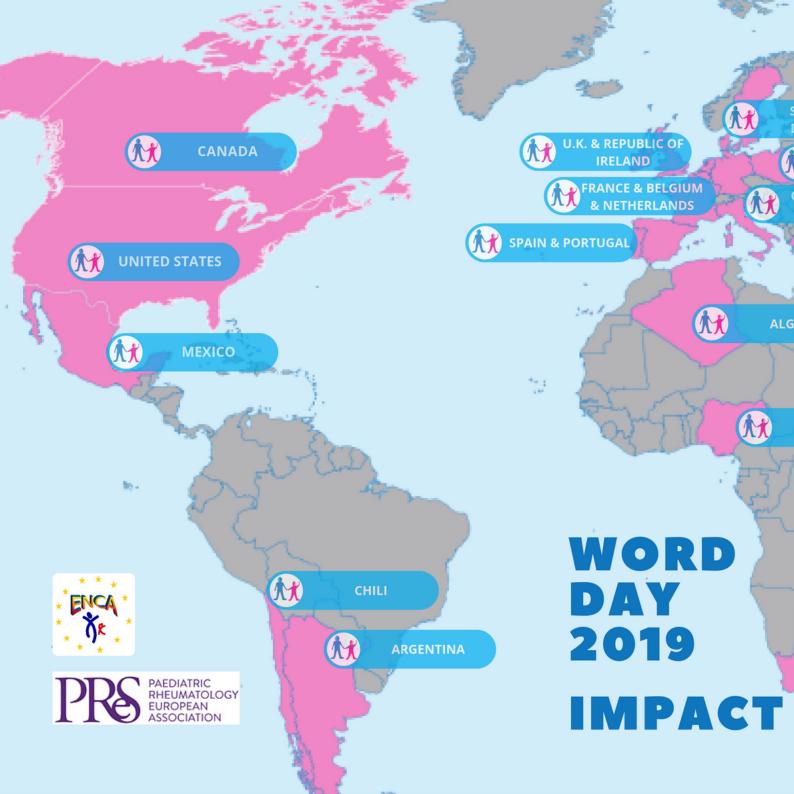
7 000 engagements Likes - Shares - Comments

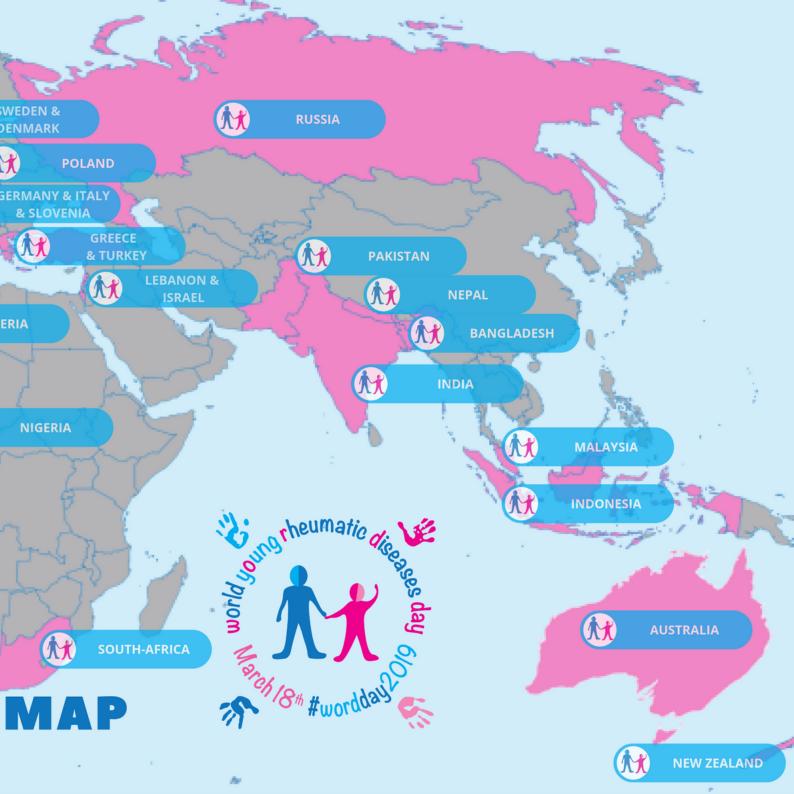


Video content: 8 500 views. Video viewership saw a spike on WORD Day, with 750 video views alone



Posts seen 270 800 times in total





PROMOTION MATERIAL

Official WORD Day video https://vimeo.com/318626431



WordDay FB Profile Frame





IN THE SPOTLIGHT

WORD Day awareness event on top of Table Mountain - Cape Town, South Africa



This is what happens when 100 children and parents, 8 superhero hikers, generous companies, dedicated staff members and teams, influential public figures, talented singers, gamechanging media and social influencers, extraordinary photographers and documenters, all-in volunteers, amazing traffic officers, adventurous event planners and speedy graphic designers come together...

ENGAGEMENT

A specific engagement activity called #ButtonChallenge2019, was launched as part of the WORD Day social media campaign. This activity challenged people around the world to button up their shirt or another piece of clothing while wearing gloves, to simulate the difficulties that children and young people with paediatric rheumatic diseases face when trying to do average, day-to-day activities with inflamed and painful hands.

 The challenge video was viewed for 6,700 minutes and received participation from across the world.







BUILDING

A NETWORK OF GLOBAL CHANGEMAKERS

- Cassie & Friends Society
- Childhood Arthritis and Rheumatology Research Alliance (CARRA)
- European League Against Rheumatism (EULAR)
- EULAR Young PARE
- Paediatric Task Force Global Musculoskeletal Health
- Last but not least: countless (and priceless) local, regional and national patient and parent associations around the world

PRESENTATIONS

- 2018 Paediatric Rheumatology European Society (PReS) Congress
- 2018 PReS Young Investigators Meeting
- 2018 British Society of paediatric and Adolescent Rheumatology meeting
- British Society of Rheumatology
- UK JSLE Study Group Meeting
- Polish first WORD Day conference (with 150 participants)
- Peer Education workshops in schools in Lodz, Poland
- In Israel, paediatric rheumatologists presented peer lectures to doctors in hospitals, and a patient association arranged a webinar for patients and the general public
- Research workshop for children/teens living with rheumatic conditions and siblings in Ireland, delivered by iCAN





TARGETING HEALTH CARE PROFESSIONALS

Paediatricians and family doctors are often the first healthcare professionals to encounter children with rheumatic diseases. Prompt initiation of treatment depends on the practitioner's familiarity with these illnesses and subsequent referral to a paediatric rheumatologist.



Family practitioners & paediatricians were therefore targeted through:

- Social medial campaign in the months preceding Word day, our team profiled and targeted paediatricians and family doctors across Europe, sending them educational materials pertaining to rheumatic illnesses through social media channels.
- Hospital staff education hospital paediatric rheumatologists delivered short lectures on awareness of paediatric rheumatic diseases to fellow doctors.
- Leaflets for paediatricians containing basic information on 'red flags' for rheumatic illnesses were circulated at paediatric conferences to aid future patient referrals.
- Medical journal an article focusing on WORD day was published in the prestigious Lancet Child & Adolescent Health journal, raising the profile of the campaign.



We send a heartfelt THANK YOU to each and every individual or organisation that participated to WORD day 2019

You are part of a global community that has made - and will continue to make - a difference for children and young people with rheumatic diseases.

NEXT STEPS

WORD day's launch was a bigger succes than we dared to dream with activities in all continents, both online as in real life. Now we are ready to increase our impact. During the joint EULAR/PReS congress in June 2019, we will brainstorm on next steps as well as promote our initiative and team up with the community.

Are you ready to get involved for WORD day 2020?
Join us to spread the WORD
Subscribe at
http://eepurl.com/gt8kpj
or scan the QR code



WWW.WORD-DAY.COM

