



Welcome to our March 2022 e-Newsletter and to our expanding global community

An Introduction from Prof Chris Scott and Prof Helen Foster (two of our Task Force Co-Chairs)



As a Global Task Force, we can look back at the last 12 months and be proud of all that we have achieved; an increasing network and community of energised motivated people coming together with the common aim of improving the lives of children, young people and their families.

We have established ourselves as a global voice with representation from all over the world. A voice that is growing louder and more self-assured with time. With every step in the last year we have all been inspired by the wonderful community of paediatric rheumatologists, allied healthcare workers, orthopaedic surgeons and other musculoskeletal specialists who care so deeply about their cause and who give so freely of their time and resources to make a difference.

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The future of the Global Task Force looks bright. A Steering Committee has been established and meets remotely once every month. We have developed workstreams from our Call to Action with several different projects drawing on the expertise and motivation from the entire Global Task Force. Furthermore PReS has agreed to secure the future of PMM (www.pmmonline.org) and this will ensure that the PMM website and all the other resources (e.g. pGALS app and translations) will remain free and open all in perpetuity. The Task Force is integrally involved with PMM and has many members on the recently formed new PMM Editorial Board. A PMM Scoping Review is underway to revise PMM contents and ensure that they serve the global musculoskeletal health community in the best possible way. New websites have been designed for our Task Force and PMM will also have a fresh new look – both will soon go live. The Steering committee has also embarked on a process of succession planning as Professor Helen Foster plans to step down as our Task Force chair to focus on PMM related matters and other key projects with the Task Force.

So, we are busy and our momentum continues to build. In this newsletter, we are delighted to share more news and updates from around the world.

We hope that you find these articles inspiring and energising - working better together is the way forwards and is so neatly encapsulated in this African proverb:

'If you want to go fast, go alone – if you want to go further, go together'

WORD-Day 2022 – March 18th



The Paediatric Task Force continues to actively support WORD Day (WORLD young Rheumatic Diseases Day) to raise awareness about rheumatic diseases in children and young people and that early diagnosis and access to right care can radically improve their lives.

The first WORD Day in 2019 was a great success. Plans for 2022 are well underway! Every action in your own community amplifies the impact, no matter how big or small.

Check out www.wordday.org for more information and follow on Twitter (@WORDDAY_org) and Facebook. Submit your activity on the website to let everyone know how you are involved!

There are lots of free resources from the WORD team that can be downloaded and personalised. <https://wordday.org/promotional-toolkit/#1581170447417-64402c96-4b6b>

PRs and ENCA are organising open and free webinars on March 18th and details about how to register are available <https://wordday.org/webinars/> - please share these details to your colleagues and networks. These webinars will be recorded and available after WORD day.

PRs 2022 – announcement from Prof Claudia Saad Magalhaes (Brasil)

28th European Paediatric Rheumatology Congress (PRs 2022)- *Save the dates*

The 28th European Paediatric Rheumatology Congress (PRs 2022), will be in Prague from 20-23 September 2022 <https://www.pres.eu/pres2022/index.html>, with the overall theme “*State-of-the-art therapeutic strategies in pediatric rheumatology: targets, pitfalls and challenges*”. Apart from updates on management strategies, the congress will have a strong scientific component on novel concepts of immune dysregulation and the potential translation into clinical practice.

It is the largest scientific event dedicated to the field of Pediatric Rheumatology worldwide. In 2021, the 27th PRs virtual congress, attracted more than 1350 participants. We are confident this year’s congress, planned in a hybrid format with either face-to-face or recorded sessions, will offer an opportunity to exchange scientific ideas within an attractive program. It can revitalize the scientific community by bringing together friends from

all over the world in the exciting atmosphere of the beautiful city of Prague, in the historical surroundings of Charles University. The congress venue is just 10 minutes away from the city centre and the highlights of Prague are all close by.

The Young Investigators Meeting (YIM), led by Emerge (EMERging RheumatoloGists and rEsearchers) PReS trainees and young scientists, will be held on 19-20th September, offering exceptional learning and networking opportunities to the next generation of researchers and clinicians.

Besides the traditional state-of-the-art-sessions on clinical practice, basic and translational science, two innovative Workshops will take place in parallel sessions at Charles University on the 20th September, after the YIM, with training on Nailfold Capillaroscopy and Data Analysis with R-Studio. The Muscle skeletal ultrasound satellite course will take place after the Congress from 23-25th September. Educational programs aimed at Health Professionals (HP), as a part of the PReS Academy, has been planned to build up a sustainable training program for HP with a refreshing program with focus on novel therapeutic approaches, management, digital technologies and patients views.

The 2022 PReS meeting will provide a wonderful opportunity of inter-disciplinary learning in partnership with patients, parents, young scientists and trainees, as well as clinicians and health professionals. Abstract submissions will open by end of February and online registration in April 2022.

[Publications report – Prof Sulaiman Al-Mayouf \(Saudi Arabia\) and Dr Djohra HadeF \(Algeria\)](#)



Key Points:

- Juvenile idiopathic arthritis (JIA) is the most common chronic childhood rheumatic disease. It refers to a heterogeneous group of diseases.
- We summarized the available data on the prevalence of JIA and its subtypes in Africa and Middle East and discusses unmet needs for patients in this region.
- There is a paucity of adequate and latest data from the region on the epidemiology of JIA.
- In the absence of databases or registries to track disease progression, JIA data for Africa and Middle East are generally derived from hospital-based studies, providing limited accounts of epidemiology.
- The prevalence rates of the region are relatively lower compared to the global estimates.
- Africa and Middle East countries constitute a diverse group of ethnicities, socioeconomic backgrounds, and climatic conditions.
- Socioeconomic status is associated with delayed access to rheumatology care and worsening disease severity in JIA patients, directly affecting their well-being and quality of life.
- There is a huge unmet medical need in the region for reliable epidemiological data, disease awareness, having regional and local treatment guidelines and timely diagnosis.
- Several factors can contribute to the delays in proper diagnosis and management of JIA which vary region wise.
- The challenges include access to rheumatology services, access to proper diagnosis and therapies, lack of an adequate number of rheumatologists, and lack of awareness of rheumatic musculoskeletal disorders at the policymaker and public level and general paediatricians.

An Update from PReS EMERGE about PReS hybrid courses Dr Erdal Sag (Turkey)

MAS-sJIA hybrid course, 17-18 March 2022, Rome, Italy



The MAS/sJIA working party Core Team are very pleased to announce the 1st PReS Academy Course on MAS and sJIA will take place on **17th and 18th of March in Rome** as a hybrid event. Speakers and a limited number of

participants will join the event live in Rome, while virtual access will be unlimited. The course will cover the current state-of-the-art on:

- sJIA and MAS immunology and pathogenesis
- moving from clinical trials to early treatment to treat-to-target
- handling of refractory cases
- MAS-ILD pathogenesis and management

The program will also feature discussion of clinical cases as well as the patients' perspective on sJIA and MAS and what we can learn from this for future research and care.

See link for details: <https://www.pres.eu/education/mascourse.html>

The program includes three interactive sessions in which young presenters will discuss difficult clinical cases with the experts.

The best clinical abstracts will be awarded with a free virtual registration to the course.

Submit your abstract at emerge.pres@gmail.com before February 28th 2022!

Vasculitis HYBRID Course - In memoriam of Dr Rolando Cimaz - 28-29 March 2022, Barcelona, Spain

The advanced course on Vasculitis will be held as a hybrid virtual/in person course at SJD Barcelona Children's Hospital in **Barcelona, Spain on 28-29 March 2022.**



Join us in this course where our international speakers discuss topics such as imaging, histopathology, laboratory test and biomarkers, and take part in the discussion of the interactive presentations of attendees!

For more details on the current programme and how to register, please see:

<https://www.pres.eu/education/vasculitis.html>

Please send interesting clinical cases illustrated in a few slides that will be discussed in interactive sessions. Send your abstract to vasculitis.course2022@gmail.com.

DEADLINE: March 10th 2022

Announcement – PAFLAR Virtual Congress 2022 – call for abstracts



CALL FOR ABSTRACTS IS OPEN NOW!!!

Click on the link to submit your abstract:

<https://lnkd.in/ekzj76te>

Models of Care; Global Health in Paediatric Rheumatology; Working with migrant families in the US - Dr Emily Hause (US)



Paediatric musculoskeletal conditions affect millions of children worldwide and often go underdiagnosed and undertreated. The disconnect is particularly evident in regions with less access to paediatric specialty care. Vital projects must bridge this gap to increase awareness and specialty-specific knowledge regarding these conditions. Even for patients who immigrate to areas that provide a higher level of specialty access, barriers persist, such as difficulty finding culturally appropriate care or clear communication.

Dr. Emily Hause, a second-year paediatric rheumatology fellow at the University of Minnesota, is leading a project that combines both local and international Global Health to improve care for children with arthritis. The project's local component works with the Somali community in the Twin Cities to help standardize messaging for patients with juvenile arthritis and their families. Through focused interviews of patient families and community members at large, Dr. Hause aims to design a culturally and linguistically appropriate video module to explain the diagnosis of juvenile idiopathic arthritis. A further aim of the project is to bring awareness to and address concerns regarding the appropriate translation of medical jargon during visits, to reduce miscommunication between providers and patients/families.



For the international component of the project, Dr. Hause is partnering with family medicine residency program in Boroma, Somaliland to provide focused teaching to their residents regarding paediatric musculoskeletal conditions. Using the Paediatric Musculoskeletal Matters website and resources, Dr. Hause hopes to increase awareness of juvenile arthritis and other musculoskeletal conditions in Somaliland. Due

to pandemic constraints, these educational sessions will occur virtually, allowing even greater attendance by additional health professionals in Somaliland.

Working directly with a local Twin Cities immigrant population as well as partnering with providers in their country of origin is unique. By focusing both locally and globally, Dr. Hause plans to maximize lessons learned from community members, patients, and physicians in ways that can better serve all Somali patients.

My PReS Emerge Fellowship - Dr. Ayodele Faleye (Nigeria)

Hello,

I am **Dr. Ayodele Faleye**, a paediatric rheumatologist from Lagos State University Teaching Hospital (LASUTH), Lagos Nigeria. I was the awardee of the PReS EMERGE clinical and research fellowship for 2021. My choice center for the fellowship was Alder Hey Children's hospital where I learned more about paediatric rheumatic diseases including juvenile idiopathic arthritis, juvenile systemic lupus erythematosus (JSLE), juvenile scleroderma, juvenile dermatomyositis, vasculitis, paediatric inflammatory multisystem syndrome, periodic fever syndrome, chronic non-bacterial osteomyelitis(CNO) and chronic musculoskeletal pain. I was also an honorary clinical fellow at the University of Liverpool where I participated in a research project titled: "Pulmonary involvement in Juvenile systemic lupus erythematosus: data from the UK JSLE cohort study".





My experience in the fellowship was absolutely amazing as I learned more about spectrum of paediatric rheumatic diseases in another continent, this made me appreciate the differences and similarities in the UK to the approach in Africa. Working with seven paediatric rheumatologists and several paediatric rheumatology trainees exposed me to various approaches to management of paediatric rheumatic diseases. I also learned a lot about data collection, data analysis and research presentation. Although I visited Liverpool primarily for fellowship, I had opportunities to visit some recreation centers in Liverpool and other cities in the UK. As well, I have made new friends, this makes me appreciate diverse cultures on food preparation and family lifestyle.

I believe my experience as a paediatric musculoskeletal physician will benefit African Universities and the continent.



I am grateful to the PReS/EMERGE team for organizing this fellowship.

I also appreciate Alder Hey rheumatology team, especially my supervisors, the University of Liverpool, the University of

Cape Town paediatric rheumatology team and the adult rheumatology team of LASUTH where I started my career. [Find out more about PReS EMERGE Fellowship scheme](https://www.pres.eu/emerge/about-pres-emerge.html)
<https://www.pres.eu/emerge/about-pres-emerge.html>

[The WHO Essential Medicine List - PReS Global Health Research Fellow](#)



The World Health Organisation Essential Medicines List (EML) informs policy makers about which medications should be prioritised within national formularies and is particularly important for countries with limited resources.

The current EML lacks clarity about the vital medicines used in paediatric rheumatology and the inclusion of a more essential medicines could transform the lives of many children around the world.

The Task Force is working with colleagues to develop the case of need to revise the EML. While our initial applications in 2020 for Tocilizumab, Anakinra and Intra-articular steroids were not met with success, we were recommended to submit a revised application.

Thanks to a generous donation from PREs, we are able to recruit experienced researcher Dr. Waheba Slamang from South Africa as the first ever **PREs Global Health Research Fellow** to work with Prof Chris Scott and Prof Helen Foster along with our team of volunteers from the Task Force. Waheba will coordinate our efforts to assemble our revised application to the WHO EML Committee in time for the deadline November 2023. We will keep you updated as to her progress. We wish her all the best!

Christiaan Scott, Nicola Smith, Rebecca James, Ben Whitehead, Rochelle Green and Helen E. Foster. Letter to the Editor. *Pediatric Rheumatology* 2021 19:10 Revising the WHO Essential Medicines List for paediatric rheumatology

Foster HE, Scott C. Update the WHO EML to improve global paediatric rheumatology. *Nature Reviews Rheumatology* 2020

An update on WALK and MOVE!T





Professor Helen Foster
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 • Emerita Professor Paediatric Rheumatology
 • Newcastle University
 @paedmskglobal

as well as impacting on school and social interactions. There is massive unmet need to improve musculoskeletal (MSK) health for children around the globe.

The Paediatric Global MSK Task Force, set up in 2017, is a virtual global community, open to all with representatives from Africa, Asia, Americas, Australasia and Europe to emphasise our multi-professional, multi-disciplinary and multi-cultural MSK world. We believe that all CYP around the globe have the right to walk in a safe environment and to achieve their optimal MSK health. All professionals engaged in the care of children can promote walking, MSK health and wellbeing through advice and encouragement about healthy lifestyle choices (e.g. diet, safe exercise, avoidance of sport and other injury).

As we launch into 2022, the Paediatric

Global MSK Task Force is planning our WALK campaign (World Action for All Kids). Our strategy is to identify and share exemplar models of care to promote walking, optimise MSK health and to identify CYP with MSK conditions and facilitate access to right care. Working better together with wide engagement, partnership and collaboration has to be the right way forward.



Walking improves musculoskeletal health



WALK CAMPAIGN
MANY OF US appreciate the benefits of walking, especially outdoors, as a source of solace, mental wellbeing and healthy exercise. Walking as a form of regular exercise brings many benefits including healthy weight control and prevention of many non-communicable chronic diseases. Unfortunately, many children and young people (CYP) are not able to experience the pleasures and benefits of walking with huge implications for a child's physical and mental health

Royal College of Paediatrics and Child Health magazine [Milestones](#)

Plans are afoot for an exciting new multimedia campaign, aimed at all healthcare workers dealing with children who may come across children with musculoskeletal problems. Working with the incredible team at Tin Soldiers <https://tinsoldiers.org> and BL!NK pictures the Global Task Force aims to use the powerful medium of storytelling and audiovisual means of education to improve access to right care for children with musculoskeletal health problems all over the globe.

The WALK campaign action has blossomed further with an action plan called MOVE!T with the key goals:

- Help Children to Move
- Move quickly for referrals; time is precious
- Get the child moving on the right treatment path; better outcomes depend on it
- Move your own expectations of what can be achieved in treating children with musculoskeletal conditions !!!

We will keep you updated with progress !

The Paediatric Task Force 'Call to Action'

To Raise Awareness

- About the *many* children and young people around the world with MSK problems.
- About the considerable long-term impact of *untreated* MSK conditions starting in early life: *impact* on young people, their families, carers and society with a breadth of impacts on quality of life.
- That many conditions are *treatable*; long term disability can be avoided thus reducing 'cost' to individuals and society,

To Identify, Share and Promote exemplar solutions to better access to 'right' care

- Models of clinical care and care pathways.
- Education and training to expand the workforce capacity.
- Patient and public engagement and participation.

To Promote healthy joints and bones

- Through lifestyle choices (e.g. diet, exercise).
- Reduce the risk of injury.
- Reduce the long term risk to bones and joints.

Our Structure and Membership

- The Paediatric Task Force works in partnership with organisations to address global challenges in paediatric MSK health.
- We have co-chairs and a steering committee comprising multi-professional representation from paediatric rheumatology, paediatric orthopaedics, allied health and parent advocacy groups.
- All roles are voluntary and non-remunerated.

The paediatric global musculoskeletal task force - 'towards better MSK health for all'. Foster HE, Scott C, Tiderius CJ, & Dobbs MB. *Pediatr Rheumatol Online J*. 2020 Jul 14;18(1):60. doi: 10.1186/s12969-020-00451-8. PMID: 32664961

Improving Musculoskeletal Health for Children and Young People – a 'call to action'. Foster HE, Scott C, Tiderius Carl J., Dobbs MB and members of the Paediatric Global Musculoskeletal Task Force (Elizabeth Ang, Sirirat Charuvanij, Wendy Costello, Marja Kinnunen, Laura B. Lewandowski, Angela Migowa, Simon R. Stones, Soamarat Vilaiyuk and Kate Webb). *Best Pract Res Clin Rheumatol*. 2020 Jul 26:101566. doi: 10.1016/j.berh.2020.101566. Online ahead of print. PMID: 32727697 , <https://doi.org/10.1016/j.berh.2020.101566>

Paediatric Global MSK Task Force (<http://bjdonline.org/musculoskeletal-problems-in-children-and-young-people/>)

Paediatric Rheumatology European Society (<https://www.pres.eu>)

Paediatric Musculoskeletal Matters (<http://www.pmmonline.org>)

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