

Welcome to the July Newsletter: Here on the Southern tip of Africa the days are short and the nights are long, while waves of cold and wet air from Antarctica bring welcome rains and less welcome cold snaps. After months of lockdown our Asian and European colleagues appear to be heading to a new normal, while in the rest of the world the COVID19 pandemic is raging and reaching new peaks. This pandemic has been a time to marvel at our connectedness and also on our ability to adapt, learn and overcome. Our July 2020 newsletter brings information on some of the innovations and technical advances which have propelled us to meet in virtual spaces...*Read on.*



PReS 2020 e-CONGRESS

26th European Paediatric Rheumatology Congress

23 - 25 SEPTEMBER 2020

The PReS Council and Scientific Organizing Committee of the PReS 2020 Congress have decided to that the annual

congress in September 2020. We will go virtual! PReS remain entirely committed to holding an annual congress in order to pursue the PReS mission: Dedicated to advance the care and improve the health and well-being of children and young people with rheumatic conditions. They are sure to provide an innovative, exciting, lively congress, now called **PReS 2020 e-Congress**.

The Scientific Organizing Committee is currently working to adapt the programme, building upon the exciting themes already developed, retaining their principles of high quality, interdisciplinarity and breadth for the meeting, and now including sessions on COVID-19 in children and young people. Of interest for the global health task force, is an ever increasing focus on issues that affect all geographic and socio-economic regions in the world as well as a thematic blending of clinical, basic, translational and patient perspectives. PReS is dedicated to ensuring maximal global reach of the meeting to all of our members and partners, in a safe and accessible manner.



WORD Day presents at EULAR

A summary of the first international awareness day for paediatric rheumatic diseases was presented as a webcast during the EULAR e-Congress of Rheumatology on Friday 05 June 2020.

For those of you who haven't seen the webcast of our WORD Day presentation at the EULAR e-Congress, you can view it via the following link (you will need to login to the EULAR e-Congress platform):

<https://eular.conference2web.com/#!resources/world-young-rheumatic-diseases-word-day-the-first-international-awareness-day-for-paediatric-rheumatic-diseases>

To help improve international awareness and understanding of paediatric rheumatic diseases, World yOung Rheumatic Diseases (WORD) Day was established on 18 March 2019. Its aim was to raise awareness of paediatric rheumatic diseases and the importance of timely referral, early diagnosis and access to appropriate treatment and support.

WORD Day 2019 was the first international campaign focused solely on children and young people with paediatric rheumatic organisations around take action, no matter funded social media dissemination of the Facebook proving to be disseminate messages.



diseases. Individuals and the world were inspired to how small. Organic and content further aided the WORD Day message, with a popular platform to Despite a wealth of different

published content, authentic materials, namely videos, proved to be the most popular with users, particularly when featuring material designed by and with children and young people. It demonstrated that despite awareness events often being resource-light, they can be implemented across a range of diverse settings. WORD Day has now become an annual global awareness event taking place on March 18th, facilitated by a growing network of patient, parent and professional community supporters. Everyone is invited to get involved in celebrating WORD Day and raising much needed awareness of paediatric rheumatic diseases in every corner of society. Find out more by visiting www.wordday.org

The reference for the conference proceeding your publication list is as follows:

Stones, S., Smith, E., Ainsworth, S., Buys, V., Costello, W., Egert, Y., Foster, H.E., Lamot, L., Prakken, B.J. & Scott, C. World Young Rheumatic Diseases (WORD) Day: The first international awareness day for paediatric rheumatic diseases. *Annals of Rheumatic Diseases* 2020; 79(Suppl 1): 163. Doi: 10.1136/annrheumdis-2020-eular.1794 Available from: https://ard.bmj.com/content/79/Suppl_1/163.1



Rare disease are often overlooked in resource constrained environments. Take a look at how a team of committed individuals can

change the world and help them to find more Tin

Soldiers..... What started out as a 'little local film', the Tin Soldiers documentary went on to win numerous awards both locally and globally. The documentary is the story of people afflicted with one of the world's most rare conditions, the story of real life 'Tin Soldiers' overcoming human frailty to show that within a body, sabotaged, can surge the spirit of a survivor.

Beyond a film, the Tin Soldiers Outreach Program is a global call to action in search of the undiagnosed victims of a rare disease, Fibrodysplasia Ossificans Progressiva (FOP).

The program provides education and support for patients, medical professionals, and the general public to raise awareness for FOP and offer access to resources, a network of support and information on medical care. While the focus is on FOP, the program seeks to raise awareness and acceptance of rare diseases in general – ending social isolation and promoting access to improved medical care for thousands of rare disease patients and their families around the globe.



Odette Schwegler and Amanda Cali



Mr Thoz Mciki:
FOP advocate



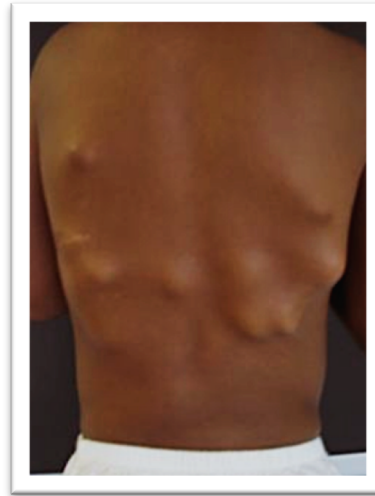
Kereabtswe and
Julia Dufatso
Mofokeng

FOP is manifested by the relentless formation of heterotopic bone, which eventually locks joints and makes movement impossible.

Recognising FOP is quite straight forward with a few pathognomonic signs...

Congenital malformation of the great toes presents as shortened toes that point outwards and often don't bend due to the non-formation of the toe joints.

Valgus and shortening of the 1st toe in an 18 month old with FOP. (Below) as well as bone masses on the back of a young girl with FOP (beside)



Patients then start forming lumps and bumps on their back or neck and even torso, at around the age of 2 to 5. These represent new areas of bone formation. Bone formation can be painful and occur rapidly. Biopsies are absolutely contra-indicated as they exacerbate new bone formation..they are also not needed as the clinical diagnosis is straightforward.

As devastating as the disease is, the most important message regarding the treatment of FOP is first and foremost 'Do No Harm'. Well intentioned procedures like muscular biopsies can have devastating results.

One of the key ways the Tin Soldiers Outreach Program continues to educate medical professionals and primary healthcare workers globally, is through online training and continuing medical education (CME) platforms. An online video series, with experts giving their views on this ultra-rare disease has been developed on the MyCPD online platform and is scheduled for launch late August 2020. In order to get more information and view the globally award-winning documentary be sure to visit www.mycpd.com to register for access.

Discussions with another innovative tech platform are currently underway to find disruptive and relevant ways to engage with communities all over the world, spreading the FOP word and connecting them to much needed resources.

HOT OFF THE PRESS: We're delighted to share that the Discovery Network has joined hands with Tin Soldiers to help share the story internationally. From July 2020, the feature-length documentary will be broadcast on either the TLC or Real Time channels (country dependent).

The Tin Soldiers FOP Outreach Program is more than a movement, it's a journey of hope. If you think that you may know of a patient with FOP, please email chris.scott@uct.ac.za. Find out more at <https://www.facebook.com/TinSoldiersFOP/>

Paediatric Musculoskeletal Matters (PMM) – www.pmmonline.org – is a free online resource developed with global partners to optimise the relevance of the content around the world. The aim of PMM is to aid teaching and learning of essential skills and knowledge in paediatric musculoskeletal medicine.

Since our launch in 2014, PMM has had >600,000 hits from > 200 countries! PMM is endorsed by Paediatric Rheumatology European Society (PReS) as a foundation for the PReS Basic Courses and as a teaching and learning resource. PMM is also endorsed by NICE to promote awareness and implementation of NICE guidance. A PMM app is in development and will be launched soon.



PMM includes e-modules targeting medical students, nurses, allied health, paediatricians and primary care <https://cpd.ncl.ac.uk>.

PMM-Nursing is a stand-alone resource 'developed by nurses for nurses' and endorsed by Royal College of Nursing <http://www.pmmonline.org/nurse>.

pGALS (paediatric Gait Arms Legs and Spine) is a simple musculoskeletal examination which has been validated in clinical practice and is widely taught to medical students. Resources about pGALS available on PMM.

The pGALS app is free and available from Apple and GooglePlay stores. The new version of the app has more language translations – if you can help translate pGALS into additional languages then please do get in touch (h.e.foster@newcastle.edu.my).



With the COVID pandemic the need for remote consultations and Telehealth has become more necessary. This poses challenges for us in rheumatology as clinical examination is

integral to the assessment. V-pGALS (*virtual / video pGALS*) has been developed to aid

remote consultations. Resources to demonstrate V-pGALS and more guidance about setting up telehealth in rheumatology are now available: <http://www.pmmonline.org/doctor/approach-to-clinical-assessment/examination>.

Please share these resources !

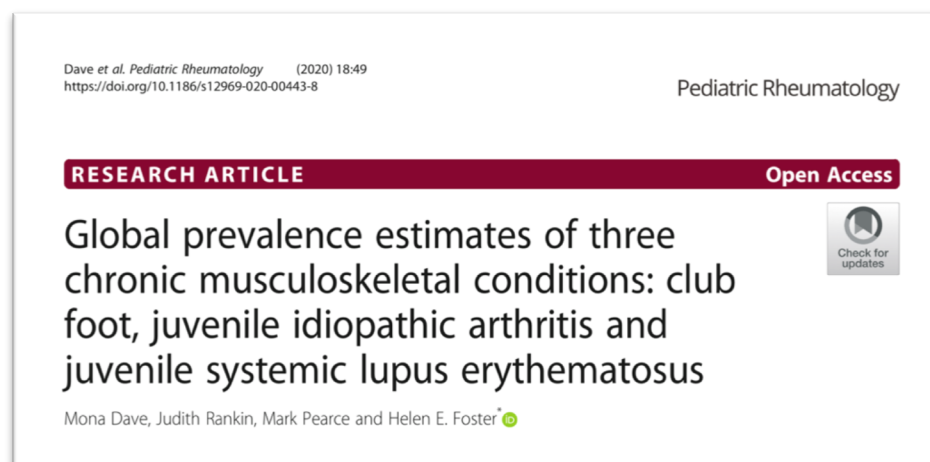
A Duke University qualitative research study seeks to understand barriers and facilitators of global health rheumatology research.



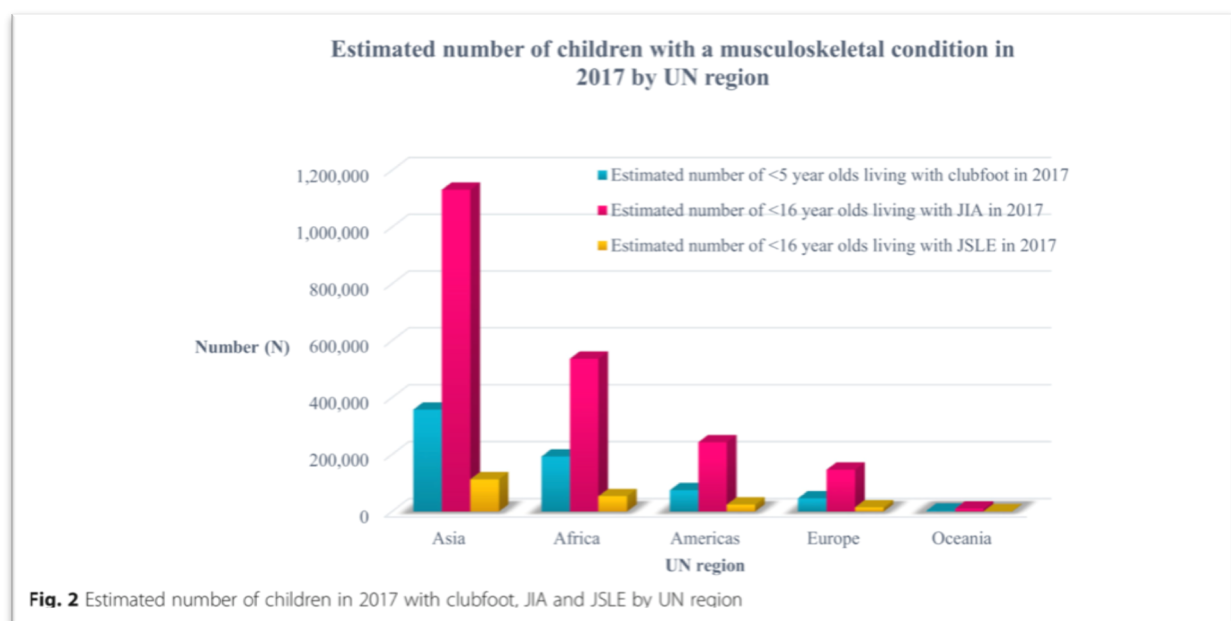
The research team would appreciate it if you could complete this

3-minute survey: <https://www.surveymonkey.com/r/globalrheum>. The survey aims to recruit participants for our study; we want to survey both those who are involved in global health rheumatology research and those who aren't to gain a well-rounded understanding of this field. The research team will review the responses, which will be confidential and securely stored, and reach out to gather a well-represented sample for our research study. By completing this survey, you are providing consent for the team to use your responses for research purposes. The study was approved by the Duke Campus IRB.

Global Prevalence of three chronic musculoskeletal conditions – Clubfoot, Juvenile Idiopathic Arthritis and Juvenile Systemic Lupus Erythematosus



There is a lack of global comparable data on the burden of musculoskeletal conditions in children and young people. This recently published study from Newcastle University, UK has estimated the global prevalence of three chronic musculoskeletal conditions; with Talipes Equinovarus (Clubfoot) in children under 5yrs of age and with Juvenile Idiopathic Arthritis (JIA) or Juvenile Systemic Lupus Erythematosus (JSLE) in the under 16 year olds. The estimates were based on World Bank Population data 2017 and the known prevalence for each condition with data presented for each UN region and sub-region. The data suggests



approximately 3 million children globally are currently living with one of these conditions and over 2 million with JIA. Most affected children are living in Asia and Africa and often in low resource settings. The tragedy is that these conditions are treatable and disability can be prevented. Many of the affected children are living in countries with little or low access to specialist care and without treatment, there is huge lifelong impact with social exclusion and poverty.

Further work is needed urgently to engage with global stakeholders to work together to improve access to effective care for the many who are affected and reduce the otherwise adverse lifelong impact on their health, quality of life and the impact on society.

<https://ped-rheum.biomedcentral.com/track/pdf/10.1186/s12969-020-00443-8>

Updated PRES recommendations for Coronavirus outbreak

Date: 18.05.2020

PReS would like to share important recommendations for patients, families and doctors in the context of the COVID-19 outbreak.

1. Be updated and follow the individual country's Ministry of Health/*National public health care body's recommendations*.

2. Ensure you meticulously follow all hygiene recommendations. Please note that the new coronavirus may remain viable for hour or days on many surfaces such as handles, doorknobs, light switches, mobile phones, computer keyboards, remotes, keys, elevator buttons, toilets, sinks, tables, hard-backed chairs, etc.

Simple measures are likely to help to preserve your health and that of your family and friends:

- Wash your hands very regularly for at least 20 seconds using soap and water. Dry hands thoroughly afterwards.
- Try to avoid touching your face.
- Coughing or sneezing should be into an elbow or tissue paper and the latter should be discarded safely.
- Use disposable tissues.
- Wear a mask when you are ill; if there are no symptoms it is not necessary to wear a mask. The mask cannot completely prevent virus transmission, but it is a good reminder of not touching your face and serves to warn others that you may not be well.
- Practice sensible social distancing especially from people who appear to be ill, e.g. coughing or sneezing. One meter is recommended.
- We should greet each other without shaking hands, and avoid hugs.

3. At present with the current available scientific data showing lower disease incidence, and morbidity among children, we recommend that children with rheumatic diseases on medication, will continue all therapies as usual. Follow the individual country's Ministry of Health/*National public health care body's recommendations regarding school activities*.

Be aware that at this stage recommendations may vary from one country to the other.

With the current knowledge of today, patients receiving MTX or biologics as a monotherapy are not considered to be at increased risk.

Consider that pediatric rheumatic patients might be at higher risk for COVID-19 if they are receiving:

- corticosteroids > 0.5 mg/kg/d

- immunosuppressive treatment (MMF, CysA, tacrolimus, Cyclophosphamide, Rituximab...)
- 4. Don't stop your medications including methotrexate (MTX) and biologics, without consulting your rheumatologist. This may cause a flare of your rheumatic disease.
- 5. If you are on corticosteroid therapy - consult your rheumatologist regarding possible dose adjustment.
- 6. Patients in isolation or quarantine (without symptoms) should continue therapy as usual.
- 7. In case of fever and suspicion of infectious diseases follow your national advice for access to health care and to test for Covid-19. In the meantime, withhold MTX and, if taking biologics, get in touch with your treating rheumatologist for guidance
- 8. In the event that you have a routine rheumatology appointment consider to ask your primary care physician, or rheumatologist if this is essential, or can be safely delayed, or if it can be performed by telephone or some other remote device. This facility may vary in availability across different health care settings.
- 9. For all individuals, including patients with pediatric rheumatic diseases. - avoid unnecessary traveling and crowding.
- 10. Wishing you good health and back to regular track soon.

See also EULAR website: https://www.eular.org/eular_guidance_for_patients_covid19_outbreak.cfm

Join PAFLARs exciting new online Webinars:

The rapid development of the dynamic Paediatric body of AFLAR (African League of Associations for Rheumatology - now known as PAFLAR is evidenced by the educational webinar series that was launched

PAFLAR
PEDIATRIC ASSOCIATION FOR A BETTER FUTURE

Is it Arthritis or Not?
A MEDICAL DILEMMA

SPEAKER
Dr. Angela Migowa
Assistant Professor and Pediatric Rheumatologist
AGA KHAN UNIVERSITY HOSPITAL NAIROBI

JULY 1ST 2020
1-2PM CAT

Join Through: <https://zoom.us/j/94914530157>
To RSVP, email pafiar2020@gmail.com

*** YOU'RE INVITED ***

@pafiar Pafiar Africa Pafiar Africa Afrique

in June. The series allows representatives from the who Africa to present cases of educational value and contextual relevance to trainees and peers across Africa. The first webinar was presented in June, by Chris Scot from Cape Town. A recording is available here. The second has recently been completed by Angela Migowa from Kenya and will be made available online soon. August will see colleagues from Egypt presenting a series of cases. Topics covered will include Chronic recurrent multifocal osteomyelitis, Camptodactyly arthropathy coxa

vara pericarditis syndrome and Amyopathic dermatomyositis with extensive calcinosis by Dr Doaa Mosad

(Mansoura University), Prof *Sheren* (Minia University) and Dr *Naglaa Samy* (Assiut University), respectively.

Please follow this link <https://uct-za.zoom.us/j/5863321549> at 13:00 Central African Time on the 5th of August to join us!

The Paediatric Task Force ‘call for action’

Background

The Paediatric Task Force for Global Musculoskeletal Health was set up in 2017 as part of the Global Alliance for Musculoskeletal Health (G-MUSC) and acknowledges the importance of a ‘life course approach’ to optimising musculoskeletal (MSK) health across the ages.

We are a virtual global community and open to all: clinicians (doctors and allied health professionals) from paediatric rheumatology and orthopaedics, patient and consumer groups, professional societies, healthcare planners and policy makers, non-health professional groups, research consortia, industry (e-technology, pharma).

There is great enthusiasm to ‘work better together’ to improve the lives of children through raising awareness amongst health care planners and policy makers that more needs to be done

We work in partnership with the Pediatric Rheumatology European Society (PReS), The International Pediatric Orthopedic Society (IPOS) and the Paediatric Musculoskeletal Matters (PMM) learning e-platform.

Our Aims

- 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
 - That many conditions are *treatable*; long term disability can be avoided thus reducing ‘cost’ to individuals and society
- To Identify and Promote tangible exemplar solutions to improve access to ‘right’ care
 - Models of clinical care and care pathways
 - Education and training for the workforce
 - Patient and public involvement and engagement
- To Promote healthy joints and bones
 - Through lifestyle (e.g diet, exercise) to prevent obesity
 - Reduce the risk of injury
 - Reduce the long term risk of osteoarthritis and osteoporosis

Our Structure and Membership

The Paediatric Task Force works in partnership with organisations to address global challenges in paediatric MSK health.

There is a group email – anyone can join. Please contact us through the social media contacts.

To date over 260 people from around the world (map below July 2019) receive our Newsletter and we have representation from many countries.

We have a chair and 4 co-chairs, representing paediatric rheumatology, paediatric orthopaedics and MSK health promotion through lifestyle and avoidance of injury.

We have 12 'regional representatives' from around world (clinicians, allied health and parents).

All roles are voluntary, non-remunerated and we have administrative support from G-MUSC.

Next steps Towards a strategy



Building on Task Force meetings at existing rheumatology events (APLAR April 2019, EULAR June 2019, AFLAR September 2019) our discussions generated ideas and areas for priority to taken forward in our 'call to action'. Our strategy is being written up for further discussion at upcoming meetings – see below.

Paediatric Global MSK Task Force

<https://gmusc.com/musculoskeletal-problems-in-children-and-young-people/>

Follow us:

Twitter <https://twitter.com/paedmskglobal>

Facebook:

<https://www.facebook.com/groups/2255183164805036/?ref=share>

Future meetings with a paediatric MSK focus are listed below– Task Force awareness sessions are being planned to be included in those marked*

Please check the meeting websites for details as many have been postponed / moved to online

*Arab League for Rheumatology (ARLAR)

Amman, Jordan

<https://www.arabrheumatology.org>

*PREs South East Asia Paediatric Rheumatology course

Kuala Lumpur, Malaysia

<http://www.pres-kl.com>

European Paediatric Orthopaedic Society Meeting Porto,

Portugal

<https://posna.org/Physician-Education/Event-Calendar?event=116>

PANLAR:

Miami Florida USA

<https://congreso-panlar.com>

Paediatric Orthopaedic Society of North America

San Diego, USA

<https://posna.org/Annual-Meeting/2020-Annual-Meeting>

*Asia Pacific League Against Rheumatism (APLAR)

Kyoto, Japan

<https://aplar2020.com>

South African Paediatric Association

Pretoria

<https://www.paediatrician.co.za>

*Pediatric Rheumatology European Society (PREs)

<https://www.pres.eu/pres2020/>

*SICOT (International Society of Orthopaedic Surgery and Traumatology), Budapest, Hungary

<http://www.sicot.org>

American Academy of Paediatrics

San Diego, USA

<https://aapexperience.org>

Asean Paediatric Federation Congress

Hanoi, Vietnam

<http://www.apfc2020.com.vn>

European Academy of Paediatric Societies
Barcelona, Spain
<https://eaps2020.kenes.com>

*ACR, Washington DC, USA
<https://www.rheumatology.org/Annual-Meeting>

International Paediatric Association Conference
August 22-26 2021
Glasgow, UK
<https://www.ipa2021congress.com>

And Finally...

Thank you for your support, energy and enthusiasm.
We send our very best wishes to you all and ask that you keep safe and well in these challenging times.

Chris and Helen

Professor Christiaan Scott (*Chief Editor*) and Co-Chair Paediatric Global Task Force
Professor Helen Foster *Chair Paediatric Global Task Force*

