



## 2021 January Newsletter

The advent of 2021 has been most welcome! It allowed us to leave behind a year most of us would, for so many reasons, prefer to

**forget...**but despite its horrors, 2020 wasn't all bad for the Task Force. We have moved forward on many fronts and have been energised by the support and commitment of our global community. The paediatric rheumatology world seems to have taken 2020 by the horns and become more innovative, more resilient and more united than ever before. In these few pages we would like to share with you some of the highlights...we are always keen to hear stories and so please do get in touch ☺ !

**2020 was the year** everything went virtual.....our colleague Dr Raju Khubchandani was well ahead of the curve with PROMiSe:

### ***Before Zoom zoomed...!***

Paediatric Rheumatology is a relatively new subspecialty and it's teaching in medical schools and learning opportunities for practicing paediatricians are limited

especially in underserved and resource challenged countries. Recognizing this need, an online teaching initiative was launched in late 2018 on the Zoom platform by Dr. Raju Khubchandani in collaboration with ECHO India.



## ***From PROMISE to PROMISE***

PROMISE in its first year was supported by an NGO and received technical support from ECHO India. It began as a 10-module (90 minutes each live interactive) certificate course. In its first year, across 5 batches, 136 delegates across 18 Indian states and 2 countries participated. In all, 58 unique clinical case scenarios were discussed. Two *new* formats were subsequently introduced under the umbrella of PROMISE:

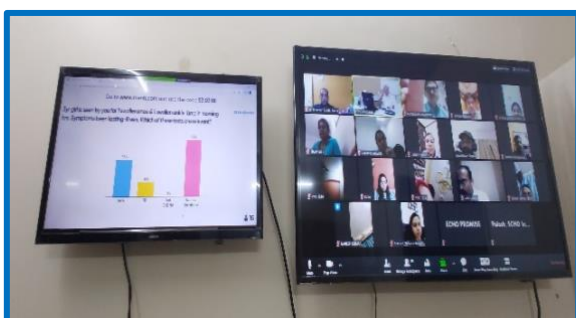
# **PROMISE**

## **Paediatric Rheumatology Orientation Made In Steps electronically**

### **An Online Educational Initiative in Paediatric Rheumatology**

**Half day CME:** 36 clinical cases were discussed across 3 CMEs with individual cities with about 50 paediatricians at each centre.

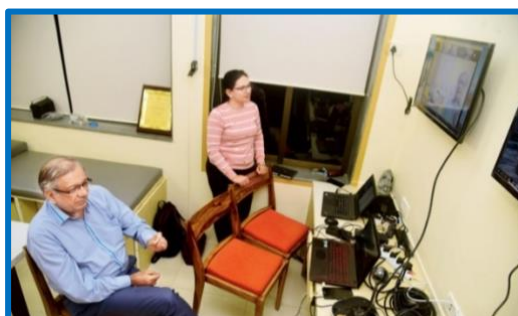
**Exclusive class for Paediatric Rheumatologists by Global Experts:** 12 complex clinical case scenarios of 'Juvenile Dermatomyositis' and 'Kawasaki Disease' were discussed with the global experts



**PROMISE has now been rechristened as PROMISE-** Paediatric Rheumatology Orientation Made In Steps electronically. It is now facilitated by the Section of Paediatric Rheumatology, SRCC Children's Hospital, Mumbai, India and presently is in its 7<sup>th</sup> batch and is open to delegates across the globe. It continuously innovates teaching methods to make the course modules comprehensive, in-depth and above all live case based, interactive and fun. Delegates receive

syllabus-based reading resources before each class and MCQs for the preceding class.

An interesting aspect of the new format is its academic partnership with Paediatric Musculoskeletal Matters - PMM ([www.pmmonline.org](http://www.pmmonline.org)), an online evidence-based learning resource developed by the team from Newcastle University UK led by Prof. Helen Foster. Delegates receive links to relevant pages on the PMM website prior to each session. PROMISE is endorsed by Pediatric Rheumatology Chapter of Indian Association of Pediatrics, India.



***"Excellent course thanks to DR Raju Sir, guest faculty and entire team. Raju Sir has made it so simple and clear, learnt rheumatology as well as how to improvise my teaching skills."- Dr. Sucheta Rao, Associate Professor, Department of Pediatrics, KMC Hospital, Mangalore (Batch 1)***

**Lead Faculty:** Dr. Raju Khubchandani

**Schedule:** Sessions- Every Wednesday of the week

**Time:** 7.00 pm - 8.00 pm Indian Standard Time.

**Medium of Participation:** ZOOM App- Live videoconferencing from their computer,

*"It was extremely interesting, informative, lively, and interactive course which helped to solve my basic queries in rheumatology. It will definitely guide me for diagnosing patients of Paediatric Rheumatology"- Dr. Deepa Phirke, Associate Professor, RSCM Government Medical College, Kolhapur (Batch 1)*

*"Dr Khubchandani is an excellent clinician, but an even better teacher! A few comments: 1) Excellent content of classes, I felt like we discussed enough each class to make it interesting for us to go back and update ourselves. 2) It was good to interact with other national and international faculty and get their perspective 3) I personally enjoyed the general pediatric tips we got as well. Loved the small extra articular tips as well! Would highly recommend to all!" - Dr. Neha Mohan Rao, Pediatrician & DNB Gold Medalist, Bangalore Baptist Hospital (Batch 3)*

laptop, tablet, smart- TV (if in a group) or smart-phone using ZOOM, a free videoconferencing platform.

**For more information, fees and enrolling in**

**the course please click on:** <https://cutt.ly/pedrheumat>

For further queries you may write to us on: [promiserheumatology@gmail.com](mailto:promiserheumatology@gmail.com)

Lead Faculty: Dr. Raju Khubchandani , Invited domestic and international faculty

IT Support: Mr. Pravin Chavan

This piece has been contributed by Dr. Sachi Pandya  
Psychologist, who till recently was the Academic Coordinator

*"It was a great pleasure to participate in PROMISE. It was perfectly organized and very useful. I highly recommend it and I suggest it should be a part of the pediatric rheumatology curriculum. It is mandatory for all the rheumatology fellows and colleagues with interest in pediatric rheumatology. Thank you for this great opportunity dear Prof. Khubchandani, dear Dr. Sachi, best regards to Pravin and all the colleagues who participated."- Prof. Ljubinka Damjanovska-Krstikj, Associate Professor, Rheumatology Clinic, Skopje, Macedonia (Batch 5)*



## RHEUMATOLOGY FOR ALL

Dr Michelle Meltzer, shares an inspirational programme which has improving the care of people living with rheumatic diseases through the creation of self-sustaining training programmes in under resourced areas...Rheumatology for All (RFA) <https://rheumatologyforall.org>

was founded in 2016 after Drs. Meltzer, Hitchon, Colmegna and Scuccimarri (rheumatologists from the United States and Canada) returned from a visit to a rheumatology clinic at Tikur Anbessa Hospital in Addis Ababa. The clinic was managed by Yewondwossen Tadesse Mengistu, MD., a nephrologist, and medical residents who were doing their best to provide rheumatology care in their community. Inspired by the compassion and



professionalism they saw there, the members of Rheumatology for All understood that providing



Birhanu Demelash Desybelew

rheumatology services in underserved areas depended on training motivated local physicians to become rheumatologists. The local leadership recommended: Birhanu Demelash Desybelew and Becky Abdissa Adgna for fellowship training in rheumatology. They have completed their training in Durban, South Africa. Birhanu recently returned to Addis Ababa where he has started practicing and Becky will return in early 2021.

RFA supported a successful on-site visiting professor programme in 2019 followed by a virtual visiting professor program in October 2020. Each program provided five second year medicine residents at Tikur Anbessa with intensive training in Rheumatology. In October Birhanu was instrumental in providing hands

on supervision in the rheumatology clinic. Becky also participated as faculty in the visiting professor program. The residents will teach their junior colleagues rheumatology and each resident provided a one - page information piece about a rheumatology disease or treatment in Amharic (the local language) for the clinic patients.

As a result of our efforts, rheumatology is now recognized as a medical specialty by the minister of health in Ethiopia. Rheumatology for All is continuing to explore the best ways to expand access to rheumatology care in resource limited areas and to expand paediatric rheumatology.



Becky Abdissa Adgna



**AMERICAN COLLEGE  
OF RHEUMATOLOGY**  
**EDUCATION • TREATMENT • RESEARCH**

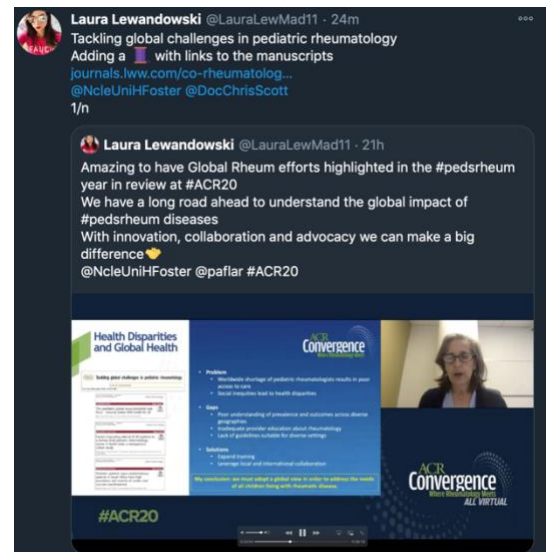
[Dr Laura Lewandowski gives feedback on the global health agenda from the 2020 ACR....](#)At the American College of Rheumatology Pediatric Year in Review, the importance of taking a global approach to paediatric rheumatology was highlighted.

Dr Emily Von Scheven reviewed the work of paediatric Global MSK Task Force members Dr. Helen Foster, Dr Chris Scott, and Dr Laura Lewandowski.



The current gaps in rheumatology care, medication, research, and education were highlighted. Four papers were provided as examples of the current gaps and how they lead to morbidity and mortality in children worldwide. Dr van Scheven concluded this presentation by stating, “ We must adopt a global view to address the needs of all children living with rheumatic disease worldwide”.

It was amazing to see the work of this Taskforce as a highlight of the annual meeting, and demonstrates the importance of the work we do. The global rheumatology ‘call to action’ is gaining traction.



Here is a screenshot of the Tweet (please RT when you can!)

See these links for some of the papers that were featured by Dr van Scheven.

<https://link.springer.com/article/10.1186/s12969-020-0408-4>

<https://ped-rheum.biomedcentral.com/articles/10.1186/s12969-020-00451-8>

<https://link.springer.com/article/10.1186/s12969-019-0382-x>

[https://journals.lww.com/co-rheumatology/Abstract/2020/09000/Tackling\\_global\\_challenges\\_in\\_pediatric.4.aspx](https://journals.lww.com/co-rheumatology/Abstract/2020/09000/Tackling_global_challenges_in_pediatric.4.aspx)



***A mere pandemic was not enough to discourage Simon Stones and the WORD day team from spreading the ...uhm... word.. !***

***World Young Rheumatic Diseases (WORD) Day featured in EMJ Rheumatology***

“Following on from a webcast about the inaugural World Young Rheumatic Diseases (WORD) day at the European League Against Rheumatism (EULAR) e-Congress in June 2020, the author team prepared an abstract about the awareness day for publication in EMJ Rheumatology 7.1. This eJournal is tailored for healthcare practitioners to disseminate the research being undertaken on rheumatic and

musculoskeletal diseases. This issue features, for the first time ever, a review of the EULAR e-Congress 2020 in its debut year as a virtual meeting.

WORD Day was the First International Awareness Day for Paediatric Rheumatic Diseases which took place on March 18<sup>th</sup>, 2019. Events were held in at least 34 countries across six continents on or around WORD Day 2019, and included lectures, workshops, social gatherings, sponsored activities, and media appearances. WORD Day has now become an annual global awareness event taking place on March 18<sup>th</sup>, facilitated by a growing network of patient, parent, and professional community supporters. Although events in 2020 were side-lined due to the COVID-19 global pandemic, people continued to raise awareness online. It is hoped that the 2021 WORD Day will be bigger and better than ever. Despite the threat from the novel coronavirus, the threat from paediatric rheumatic diseases remain. We cannot relent in our commitment to raising awareness and reducing inequalities for children, young people and families around the world.

Take a look for yourself on pages 52 to 54, via the following

link: <https://www.emjreviews.com/rheumatology/journal/emj-rheumatology-7-1-2020/>

<https://ped-rheum.biomedcentral.com/articles/10.1186/s12969-020-00465-2>

Smith *et al. Pediatric Rheumatology* (2020) 18:71  
<https://doi.org/10.1186/s12969-020-00465-2>


Pediatric Rheumatology

**COMMENTARY**

**Open Access**

## Establishing an international awareness day for paediatric rheumatic diseases: reflections from the inaugural World Young Rheumatic Diseases (WORD) Day 2019



Eve M. D. Smith<sup>1,2,3</sup>, Sammy Ainsworth<sup>4,5</sup>, Michael W. Beresford<sup>1,2,3,5</sup>, Veerle Buys<sup>4,6,7</sup>, Wendy Costello<sup>4,8</sup>, Yona Egert<sup>4,9</sup>, Helen E. Foster<sup>10,11,12</sup>, Lovro Lamot<sup>2,13,14</sup>, Berent J. Prakken<sup>2,15</sup>, Christiaan Scott<sup>11,16</sup> and Simon R. Stones<sup>4,17,18\*</sup> 

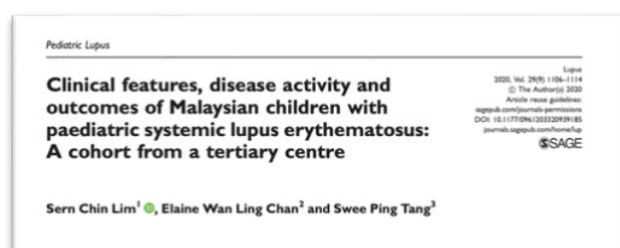
In a recent publication in *Lupus*, Dr Swee-Ping Tan (*below*) and co-



authors report on a large cohort of children with SLE from Malaysia. She shares the

[main findings here..](#) We conducted a retrospective study analysing the epidemiological, clinical and outcome data of all paediatric systemic lupus erythematosus (pSLE) patients seen at Selayang Hospital, Malaysia with at least 6 months follow-up from 2004-

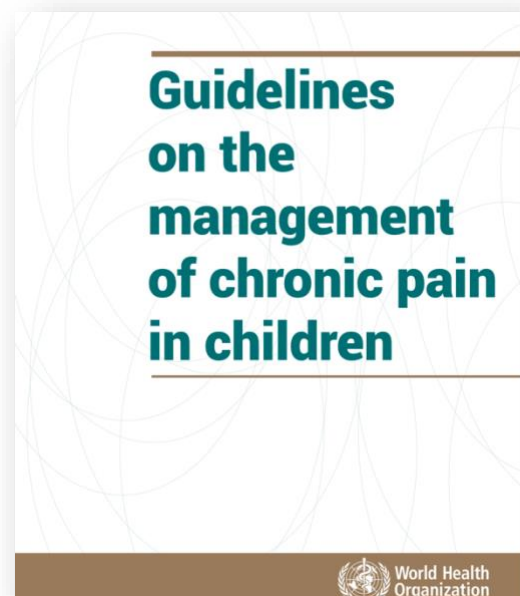
2016. There were 141 pSLE patients, 87.9% females, heterogenous ethnicity reflecting the Malaysian population who were followed up for a median 6.3 years (IQR 3.6 - 9.0). Compared to other paediatric cohorts, our cohort exhibited a higher female to male ratio (7.3:1) and had a younger median age of diagnosis at 10.3 years with the majority (88.6%) having disease onset before the age of 12 years. However, the usual age-related gender differences was similarly seen in our cohort with a female to male ratio of 2.3:1 in the under 5s and 15:1 in those with pubertal or post-pubertal onset. A significant proportion (12%) of our cohort also had 1<sup>st</sup> degree relatives with SLE.



Common presentations on our cohort included fever (87.2%), vasculitic rash (72.3%) and lethargy (69.5%). At diagnosis, leukopenia (51.1%), thrombocytopenia (41.8%), and cutaneous lupus (56%) predominate with significant renal involvement (39.7%). Renal (45.4%), liver (26%) and CNS (17%) were important major organs involved during the disease course. Almost all patients (99.3%) had high disease activity at diagnosis (mean SLEDAI score 20.1±9.6) but majority (62.4%) achieved remission or low disease activity after 6 months, which is maintained over the next 10 years. Unfortunately, despite early use of immunosuppressive, damage still occurred early (39.1% at 1 year) and increased with time. The commonest was ocular damage (29%) which was predominantly corticosteroid related (93%). Growth retardation was significant (38.2%) with no gonadal failure or secondary malignancies. End-stage-renal disease occurred in 3.1% patients whilst 53.1% had sustained renal remission. Despite the high disease activity at diagnosis, the overall mortality was low at 1.4% and comparable with that of developed nations.

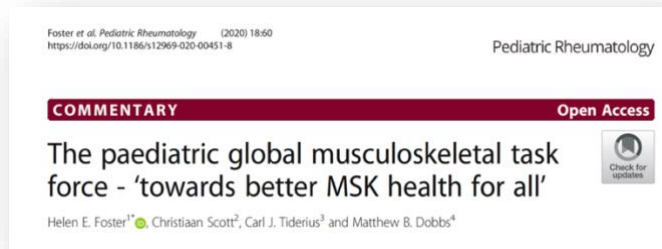
So, a few key achievements about the paediatric Global Task Force in 2020 – roll on 2021 ....

- Amazing buy in to our 'call to action' and a growing list to receive our e-Newsletters with increasing contributions from around the world.
- Growing networks and links with organisations– especially LRIC - Africa, Asia, S America and also with other MSK organisations – e.g. MiracleFeet
- Growing collaborations around our key themes – e.g. telehealth and working to validate v-pGALS, training for the workforce with online learning and research data sets.
- Contributions to existing meetings in 2020 and by way of being remote increased attendance from LRIC colleagues.
- Contributions to [WHO Guideline for Pain in children](#)
- A proposal submitted to amend WHO Essential Medicines List (EML) for joint disease in children – we have proposed new drugs to be added (Tocilizumab, Anakinra and Triamcinolone) and to amend the structure of the EML.
- Links to our recent publications
  - [Telehealth and v-pGALS -](#)





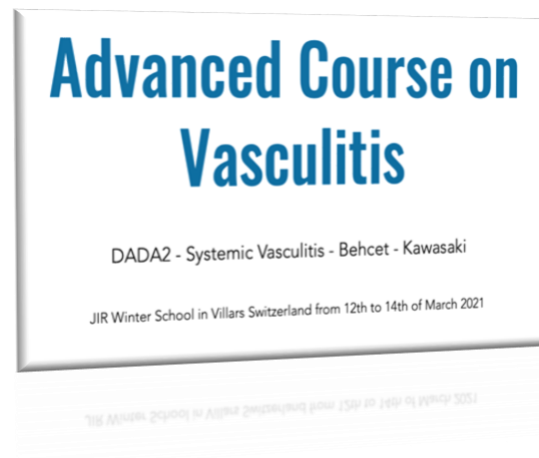
○ The Paediatric Global MSK Task Force -



○ The Paediatric Global MSK Task Force – ‘call to action’



## PReS Courses 2021



## 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 better 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.
- Over 260 people from around the world receive our e-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’ (clinicians, allied health and parents).
- All roles are voluntary, non-remunerated.
- We have administrative support from G-MUSC and Mrs Janet Herdman, Newcastle University, UK

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

**Pediatric Rheumatology European Association** (<https://www.pres.eu>)

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

**Follow us:**

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

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

Future meetings with paediatric MSK focus; Task Force awareness sessions will be included in those marked with\*

**Please check the meeting websites for details as many have been 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>

\*Pediatric Rheumatology European Society (PREs)  
<https://www.pres.eu/>

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

And Finally...

Thank you so much 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*

Associate Professor Christiaan Scott  
*Chief Editor & Co-Chair Paediatric Global Task Force*

Professor Helen Foster  
*Chair Paediatric Global Task Force*

## Our partners :

