

#### Welcome to December Newsletter

"Every new beginning comes from some other beginning's end."-Seneca

As we near the end of a roller coaster 2023 it is time (actually overdue, to be fair) to put out another Global Task Force Newsletter. Our community has continued to work together in the spirit of our common cause to improve the lives of young people living with musculoskeletal conditions. We continue to draw strength from the selfless determination of my friends and colleagues in this community. Much has been achieved and much remains to be done. In some sense the Task Force has entered a new, more mature phase. Our place in the space of MSK health is now established and have a platform from which to continue to grow and develop, finding new ways to bring meaningful and lasting improvements in the MSK health system. A major achievement this year was the establishment of the PReS Global Health Working Party, which will be Chaired by our current co-Chair, Claudia with support from Filipa Ramos as the Secretary. This is a major milestone which connects us firmly to the global community of PReS members and conference attendees. The opening quote from Seneca was chosen for this reason, ie The beginning of the PReS Global Health working party is the end of the beginning of the Global Task Force! A



brief report of the meeting follows.

The PreS meeting in Rotterdam also saw the moment of Helen Fosters official retirement. We had a brief moment to honour and appreciate Helens incredible achievments and her visionary leadership in establishing the Global Task Force. The impact of her work will endure, as will the inspiration she has given us.

Chris Scott

### Tin Soldiers Global: Clinicians Alliance Meeting, Cape Town Vanda Harries

Tin Soldiers Global continues to make significant strides in its mission to identify, diagnose, and connect individuals facing Fibrodysplasia Ossificans Progressiva (FOP) and other pediatric musculoskeletal (MSK) conditions with appropriate care pathways. Through a comprehensive three-pronged strategy, Tin Soldiers Global has successfully raised awareness on a global scale, educated over 3400 healthcare professionals, and fostered partnerships to enable the diagnosis and referral of 52 individuals with FOP, one with POH,



and over 60 children with rare musculoskeletal conditions.

A pivotal element in sustaining this impactful work on the ground has been the establishment of the Clinician Champions Alliance (CCA). Comprising dedicated healthcare professionals from 16 countries, including Algeria, Argentina, Brazil, Chile, Kenya, Italy, India, Morocco, Nigeria, Peru, Russia, South Africa, Switzerland, Tanzania,

Uruguay, and the US, the CCA is committed to improving patient outcomes and advancing musculoskeletal medicine. The alliance focuses on driving early diagnoses, building networks and care centres, providing education on FOP and other musculoskeletal conditions, and establishing a unified pathway for patient identification.

The inaugural Tin Soldiers Global CCA Summit, held in October 2023 in Cape Town, South Africa, marked a significant milestone. Themed "Diagnosis Changes Everything," the hybrid event brought together clinicians from 13 countries, both inperson and online, for two days of interactive sessions, including TED-type talks, Grand Rounds, and workshops. The summit aimed to unite



thought leaders worldwide to drive pathways of care for FOP and paediatric musculoskeletal conditions. With a total of five case studies presented in a Grand Rounds format, the summit laid the foundation for ongoing collaboration and knowledge exchange within the CCA. As Tin Soldiers Global continues to make strides in its mission, the CCA stands as a beacon of collective expertise and dedication, fostering a global network committed to transforming the lives of those affected by these conditions.

# Struggle of the lone Pediatric Rheumatologist in resource-limited country: Dr Dharmagat Bhattarai

Pediatric Rheumatology is an unrecognized subspecialty in many developing nations. Nepal is one such Himalayan country (area 147,516 km<sup>2</sup>) in South Asia with a population of around 30 million (49<sup>th</sup> globally). Due to the lack of political stability, administrative commitment, and bureaucratic will, Nepal has been facing many challenges in science and development.

Dr Dharmagat Bhattarai is the only pediatric rheumatologist in Nepal. After his postgraduate (MD) in pediatrics and doctorate (DM) in pediatric rheumatology & immunology from a pioneer centre



in India, he is continuously working for awareness, diagnosis, and treatment of pediatric rheumatological diseases (PRDs) and primary immunodeficiencies (PID). He is the first and only pediatric rheumatologist and immunologist in Nepal. There are lots of misconceptions about these diseases in Nepal like 'rheumatic diseases and immunodeficiencies do not exist',



'rheumatic disease means high uric acid', or 'rheumatic diseases are diseases of joints only'. Low socio-economic status and limited resources coupled with a lack of awareness of PRDs among laity and pediatricians accounted for missed diagnoses, late diagnoses, and poor outcomes in Nepal.



There is no commitment or promise from the government or any academic institutions. Dr Bhattarai has been working singlehandedly for PRDs and PIDs since 2021. He has established a dedicated center for these diseases and developed basic tests needed for the

diagnosis of PRDs.

In his efforts, he has diagnosed and treated a total of 553 children with PRDs and 189 children with PIDs in 2 years. Juvenile idiopathic arthritis (n = 181), connective tissue disorders (n = 118), vasculitides (n = 104), autoinflammatory diseases (n = 61), lymphoproliferation, and immune-dysregulation (24) constituted the major proportions. Monogenic causes of pediatric

rheumatological diseases were diagnosed in 24 patients. All these disorders were reported for the first time in Nepal.

Though his efforts have made many drugs for PRDs available in the country, advanced drugs like biologics, immunosuppressants (like sirolimus), immunoglobulins, and small molecules



(e.g., JAK inhibitors like ruxolitinib) are still difficult to procure. There is neither a nationalized health system nor a dedicated insurance system for citizens. As a result, the cost of health care is a huge burden to the majority of poor people. In this adverse

situation, Dr Bhattarai is struggling with no rays of hope or support from any corners. International rheumatological or immunological societies and conferences provide platforms to researchers from bigger institutes and developed countries only. Endeavors of rheumatologists like Dr. Bhattarai from resource-constrained nations remain unseen and unrecognized in today's world. They are invisible to their government or the rest of the scientific world.

## Enhancing Pediatric Musculoskeletal Health: The pGALS a Breakthrough Screening Tool for Tunisian Children:

#### **Professor Wafa Hamdi**



Pediatric Gait Arms Legs Spine (pGALS) tool, known for its perpetual relevance, was chosen as the foundation for a transformative initiative. This tool, widely recognized for its global impact, has been translated into numerous languages to serve diverse populations. Understanding the critical importance of tailoring healthcare solutions to local contexts, our study aimed to adapt and validate the pGALS specifically for the Tunisian dialect,

focusing on the unique needs of school-age children.

The adaptation process was meticulous and inclusive, employing

the Delphi method to ensure a harmonious cross-cultural alignment of the pGALS with the nuances of the Tunisian dialect. This method, known for its collaborative and iterative nature, facilitated the development of a consensual version of the pGALS that resonates authentically with the local linguistic and cultural context. To rigorously validate the adapted tool, a comprehensive cross-sectional study was conducted in two pediatric centers within Tunisia. This validation phase aimed to assess the tool's

The ever-relevant pGALS has now donned the distinctive attire of Tunisia, marking a significant adaptation to address the healthcare landscape of the country. In fact, in Tunisia, pediatric musculoskeletal disorders account for a substantial 10% of primary healthcare consultations Unfortunately, this high prevalence is accompanied by obstacles such as referral delays and deficiencies in musculoskeletal screening, impeding the early identification and effective management of rheumatic conditions in children. In response to this pressing need, the renowned



performance in real-world scenarios, ensuring its reliability and effectiveness in identifying musculoskeletal abnormalities in Tunisian school-age children.

The results of the study showcased the success of the adapted pGALS in the Tunisian dialect. Ninetytwo participants, including both females and males with a mean age of  $9.4 \pm 2.6$  years, engaged in the study. The test's efficiency was evident, with an average duration of  $3.4 \pm 2.3$  minutes, demonstrating its practicality in a clinical setting. Notably, the participants reported good acceptability and comprehension of the adapted tool, emphasizing its user-friendly nature.

Among the participants, the adapted pGALS successfully identified musculoskeletal abnormalities, with positive results in 19 cases. Importantly, the internal consistency of the test, measured by Cronbach's  $\alpha$ , demonstrated robust reliability at 0.852. The test exhibited high sensitivity at 92.8%, impressive specificity at 92.3%, a positive likelihood ratio of 2.16, and low negative likelihood ratio of https://www.pmmonline.org/doctor/resources/information-for-clinicians/pgals-translation-0.01. tunisienne/. The adapted pGALS test in the Tunisian dialect emerges as a pertinent, swift, and valid tool for screening musculoskeletal abnormalities in school-age children. Its successful adaptation and validation underscore its potential to revolutionize the early detection of rheumatic conditions among Tunisian children. By addressing challenges related to referral delays and screening deficiencies, this screening tool opens up new avenues for timely and effective management of pediatric musculoskeletal health issues in Tunisia. The study's findings hold promise not only for enhancing healthcare outcomes but also for establishing a foundation for similar adaptations in diverse linguistic and cultural contexts. This breakthrough in musculoskeletal screening marks a significant step forward in promoting the well-being of Tunisian children and sets an example for advancing pediatric rheumatology care globally.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10621183/pdf/12969\_2023\_Article\_905.pdf

## Application of the Thai pGALS in clinical practice, education, and research

Asst. Prof. Maynart Sukharomana, MD and Assoc. Prof. Sirirat Charuvanij, MD Division of Rheumatology, Department of Pediatrics, Faculty of Medicine Siriraj Hospital, Mahidol University, Thailand



The research entitled "The Thai Translation of the Pediatric Gait, Arms, Legs, Spine Tool is Useful for Pediatric Residents in Detecting Musculoskeletal Abnormalities in Children" was awarded the Routine to Research (R2R) Award 2023 from the Faculty of Medicine Siriraj Hospital, Mahidol University on September 8, 2023.

Musculoskeletal (MSK) disorders in children are common in

the outpatient settings although some physicians feel less confident when encountering

these patients. As there are very limited number of pediatric rheumatologists in Thailand, when children with MSK complaints visit the hospital, general pediatricians are usually the first to see these group of patients. In this project, we performed translation and linguistic validation of the Thai pGALS and found that it was a promising tool for pediatric residents in detecting MSK abnormalities, having good overall sensitivity and excellent specificity, with excellent acceptability and practicality by evaluated by patients and parents. Teaching the Thai pGALS during pediatric residency training should be encouraged.



We have applied the Thai pGALS to our routine work in providing patient care, medical education, and research. For patient care, children and adolescents who visit our hospital due to MSK complaints have been initially assessed by using the Thai pGALS, performed by pediatric residents and fellows. Patients with pediatric rheumatology consultations have also been evaluated using the Thai pGALS along with complete clinical assessment and MSK examination. For medical education, the formal teaching of the Thai pGALS has been included in the 4-week clinical rotation of pediatric rheumatology for pediatric residents. It is also used as

tool for Entrustable Professional Activity to evaluate the competency for MSK examination upon completion of the pediatric rheumatology rotation. For further research, we have been conducting a medical educational project along with the structured curriculum development for the pediatric rheumatology rotation since the academic year 2020 until now, which included teaching of MSK examination and Thai pGALS. The Paediatric Musculoskeletal Matters (PMM) International (www.pmmonline.org) and the pGALS mobile application have been used as self-study comprehensive educational resources. Our projects support that the pGALS is a convenient and very useful tool for pediatric residents and should be formally taught during residency training.

We would like to thank Professor Helen E. Foster, The Paediatric Global Musculoskeletal Task Force, and the PMM International for the support of our project and the collaborations to help enhance pediatric rheumatology education in Thailand and the global community. Global Musculoskeletal Health Working Party Inaugural Meeting - Brief Report



Rotterdam, October 29, 2023

The Global Musculoskeletal Health Working Party (GMSKHWP) successfully held its inaugural meeting at PReS Rotterdam, with Claudia Saad Magalhaes and Filipa de Oliveira Ramos leading the proceedings.

Highlights:

1. Greetings and Introduction:

- Claudia Saad-Magalhaes welcomed attendees, and Filipa Oliveira Ramos outlined the aims and scope of the Working Party (WP).

Attendees: 35 participants from 16 countries, including Algeria, Brazil, Canada, France, India, Israel, Italy, Netherlands, Norway, Portugal, South Africa, Turkey, UK, USA, with additional presence from Nepal and Taiwan.

2. Summary of Global Task Force for MSK Health:

Chris Scott summarized the two-year activities of the Global Task Force, highlighting the influence of Helen Foster and our contribution to the PReS mission toward. Chris was nominated PMM Director, emphasizing collaboration in research, education, training, and patient advocacy.

3. Election of Global MSK Health WP Leaders:

Leadership positions were proposed and voted upon. Notable appointments:

- Chair: Claudia Saad-Magalhães (Brazil)
- Secretary: Filipa Oliveira Ramos (Portugal)
- Research Pillar Leads: Brian Feldman (Canada) and Laura Lewandowski (USA)
- Clinical Affairs Pillar Leads: Yosef Uziel (Israel), Mehmet Yildiz (Turkey), and Anand Rao (India)
- Education/Training Pillar Lead: Giorgia Martini (Italy)

- EMERGE Representatives: Karla Vanessa (Nicaragua), Jessica Perfetto (USA), and Yulia Vyzhga (Ukraine)

- Parent/Patient Representative: Luciana Peixoto (Brazil)

#### 4. Educational Activities:

- PRES Basic Course in Pediatric Rheumatology proposal announced for Monterrey, Mexico, in 2024-2025.

- PMM app translations in multiple languages to guide the course endorsed by the Education and Training PRES pillar.

5. Awareness Activities:

- Commitment to global replication of the World Day message on March 18th and throughout March 2024.

6. Research Proposals:

- Collaboration proposed in three main areas, including expanding and validating JADAS for adults with JIA globally.

- Initiatives on vaccination coverage, pediatric rheumatic diseases, and unmet needs in pediatric rheumatology were discussed.

#### 7. Future Meetings:

- Regular meetings proposed for core team activities, research collaborations, and any call to action. First meeting to be planned for January 2024.

#### 8. Closing:

- Thanks expressed to all participants, both live and virtual.
- A collective picture was taken, and a signed email list provided.
- Ongoing invitations for new members from all regions were encouraged.

For further inquiries or to join the WP list, contact Filipa O. Ramos at filipa.o.ramos@gmail.com.

#### 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
- We have a chair and 4 co-chairs, steering committee with mutliprofessional representatives from paediatric rheumatology, paediatric orthopaedics and including parent and patient organisations.
- We have 12 'regional representatives' from around world (clinicians, allied health and parents). All roles are voluntary and non remunerated.

Paediatric Global MSK Task Force <a href="https://www.pmskglobal.com">https://www.pmskglobal.com</a> Pediatric Rheumatology European Association (<a href="https://www.pmse.eu">https://www.pmse.eu</a>) Paediatric Musculoskeletal Matters (<a href="https://www.pmmonline.org">https://www.pmse.eu</a>) Follow us: Twitter <a href="https://witter.com/paedmskglobal">https://www.pmmonline.org</a>)



