

A welcome from Prof Chris Scott, Co-Chair of the Global Task Force

Dear Friends,

The first half of 2023 is nearly behind us. It feels like we have barely had time to dust ourselves off from the COVID years and we are back to our 'new normal' and going at a pace that seems to be accelerating all the time. There are many new challenges for us as planet and for our social and political systems. I am always amazed at how we as healthcare workers seem to be able to work together to make a better world for the children and families that we serve. In the case of the Global Task Force, we do this on behalf of children and families challenged with musculoskeletal conditions. We know that all the work that you put into the Global Task Force is voluntary, that you have to sacrifice family and social time in order to achieve this and for some of you the burden is exacerbated by having to accommodate international time zones. It is these sacrifices, however, that have seen us achieve globally relevant outcomes for our community and that continue to give hope and inspiration to others.

In this edition of the newsletter we reflect on some of these achievements from our colleagues around the world. We very much welcome further submissions to our newsletter – please tell us about health care in your country, news, events and reports to share with colleagues around the world. All our newsletters are available on our website <https://www.pmskglobal.com/>

News from Columbia – a report from Prof Claudia Saad Magalhaes, Co-Chair of the Global Task Force

The XIX Colombian Congress of Rheumatology and the X Congress of Pediatric Rheumatology took place in Medellin, on March 1-3. The Pediatric Rheumatology Congress was chaired by Dr. Johanna Hernández Zapata, who is the academic co-ordinator of Pediatric Rheumatology at the University of Antioquia, a prestigious 200-years-old higher education institution.



Besides the opportunity of a brilliant scientific program, Johanna introduced the group of specialists practicing in the country and their collaborative network for improving clinical care and education.

Colombia is located in the Caribbean region of South America, with 52 156 254 population, 15 039 915 under 19 years of age. Currently, 24 Pediatric Rheumatologists practice in Colombia, 22 are engaged in Education activities all over the country's principal cities: the capital Bogotá (9), Medellin (6), Cali (4), Barranquilla (1), Bucaramanga (1), Pereira (1), Neiva (1), Valledupar (1). We had the chance to promote the access to virtual educational environment.

The specialists discussed the challenge of practice in limited resources centres and the advantage of a well connected group, that meets every year, sharing the topics about difficult to treat pediatric rheumatic diseases.

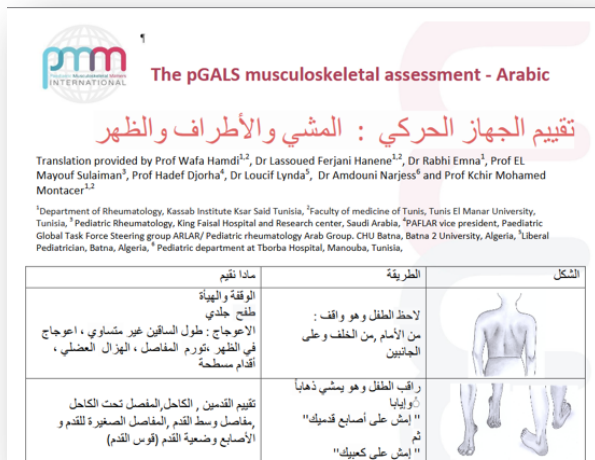
French and Arabic versions of pGALS are now available on PMM: adding to the ever expanding list of translations – a report from Prof Wafa Hamdi, Tunisia



Musculoskeletal (MSK) symptoms are common in childhood and early detection by general practitioners is crucial for timely referral to secondary care. Screening for MSK disorders can reduce diagnostic delays, prevent joint damage, minimize disability, and improve patients' quality of life. A validated tool is essential to ensure timely referral of children and adolescents with suspected MSK conditions. The **p**aediatric **G**ait, **A**rms, **L**egs, and **S**pine (pGALS) assessment tool is a simple and quick tool designed for non-specialists in MSK diseases to differentiate between normal and abnormal findings. It has been validated in school-aged children and has demonstrated excellent sensitivity in detecting abnormalities (Foster et al 2006). However, its use is limited in some countries due to the lack of validated versions in the local language.

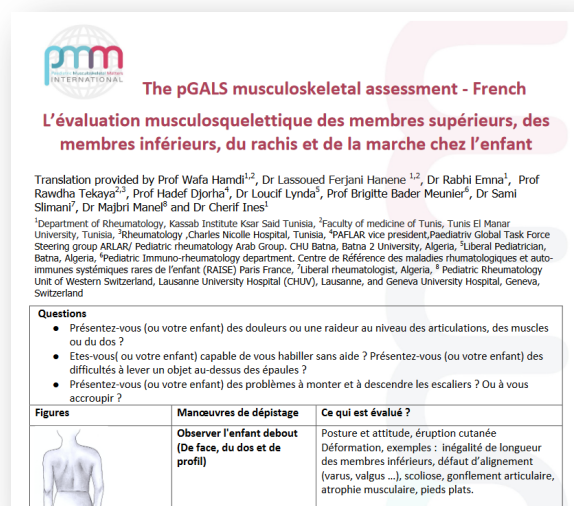
The French and Arabic languages rank as the 5th and 6th most commonly spoken languages worldwide, respectively. Our objective was to translate and validate the pGALS assessment tool in both French and Arabic.

We followed a three-step process for translating the pGALS assessment tool into Arabic and French. In the first step, we performed a cross-cultural translation of the English version into Arabic and French, involving three independent translators who were fluent in both English and the respective target language. This step was crucial to gather diverse interpretations of the items and enhance the quality of the translations. Subsequently, a meeting was conducted between the



study supervisor and a panel of experts, including five experts for the French version and five experts for the Arabic version, which included paediatric rheumatologists, paediatricians, and rheumatologists from Algeria, Tunisia, and Saudi Arabia. Each item was thoroughly analysed and various proposals were discussed in order to select the best translation or to reformulate it as needed, resulting in the first version (V1) of the translated tool. To validate V1, we employed the Delphi method, involving a panel of six expert physicians who were proficient in both French and English for the French version, and proficient in both Arabic and English for the Arabic version. The expert panel comprised of paediatricians from Algeria and Tunisia, rheumatologists from Tunisia, and a paediatric rheumatologist from Tunisia, with additional review by a French paediatrician for the French version. This rigorous process ensured the linguistic accuracy and cultural relevance of the translated versions of the pGALS assessment tool.

The Delphi approach was conducted over three rounds to address disagreements, achieve consensus, and reformulate items as needed. In the first meeting, we successfully validated 80% and 83% of the pGALS points for the Arabic and French versions, respectively. In the second meeting, all the items were validated. Finally, during the third round, the expert committees unanimously approved the final version (V2) of the translated tool. To ensure the accuracy of the translations, V2 was back-translated from French and



Arabic to English to verify that the intended meaning of the text was preserved.

The second step in the validation process involved conducting a pre-test on a small sample of 10 patients with Juvenile Idiopathic Arthritis in Tunisia, to assess the acceptability of V2 and make any necessary adjustments before proceeding to the final step. The final step was conducted as part of a cross-sectional multi-centre international study. For the French version, we included children aged 5-17 years who attended the paediatric rheumatology department of Geneva Hospital in Switzerland, the orthopaedic and rheumatology departments of Mohamed Kassab Institute in Tunisia, and the paediatric rheumatology department in Batna, Algeria. For the Arabic version, we included children from the paediatric rheumatology department of King Faisal Hospital in Saudi Arabia, the orthopaedic and rheumatology departments of Mohamed Kassab Institute in Tunisia, and the paediatric clinics at Tborba Hospital in Tunisia.

Through the various steps outlined above, we were able to assess and confirm the internal consistency, inter-item correlation, and construct validity of the newly translated versions of pGALS in French and Arabic.

These versions are now freely accessible on the [PMM website](#) and the pGALS app, providing more healthcare professionals across the globe with valuable tools for MSK assessment in children and adolescents.



A comment from Prof Helen Foster, Chief Editor PMM and on behalf of the PMM team.

The work by Prof Wafa and colleagues is a fabulous collaborative effort and we have been delighted to help and support their initiative.

All the pGALS resources including the numerous language translations are free and open to all on PMM – the PMM website, the pGALS app and the pGALS e-module – the links are below.

<https://www.pmmonline.org/doctor/clinical-assessment/examination/pgals-paediatric-gait-arms-legs-spine/>

<https://www.pmmonline.org/doctor/clinical-assessment/examination/pgals-paediatric-gait-arms-legs-spine/pgals-translations/>

<https://www.pmmonline.org/doctor/e-modules/>

If you think that other language translations are needed, please do get in touch and we will be happy to assist you.

<https://www.pmmonline.org/doctor/contact-us/>



Word Day 2023 Brazil

'SPREAD THE WORD: CHILDREN AND YOUNG PEOPLE GET RHEUMATIC DISEASES TOO'

Report by Luciana Peixoto

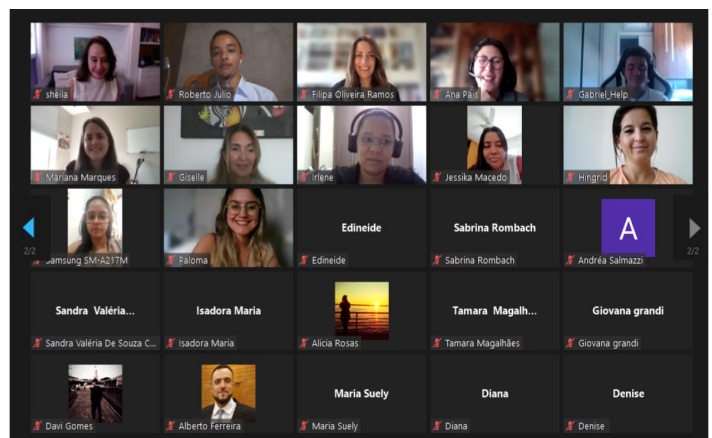
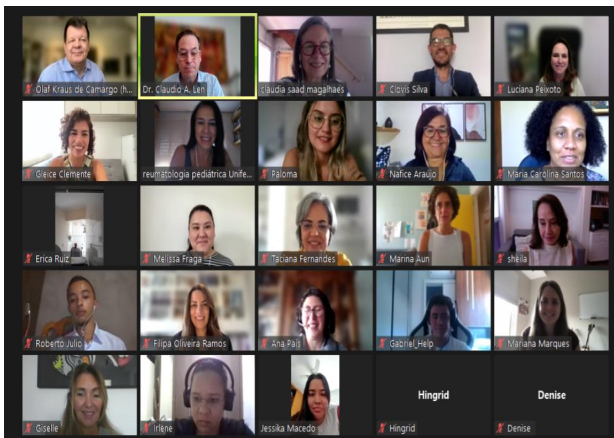
We had our first Brazilian virtual event to celebrate WordDay 2023, March 18th, at 10:30 AM. Around 40 people were on the Zoom Session. Health professionals, Parents and Patients were present.

A very important message was about explaining the importance of WordDay. Physicians, health professionals and patients together can help in the search for a better treatment for childhood rheumatic diseases.

The following topics were discussed on the Session:

- **Treating JIA and other Pediatric Rheumatic Diseases - Where are we?**
- **Best practices – How guidelines are done?**
- **Treatments Access - Inequalities in a continental country.**
- **Shared Decision – Everyone has a role**
- **Patient Stories – Each patient, one story**
- **Support Networks – What can we do to collaborate, support and help?**

After a very emotional session, all participants emphasized the importance of all stakeholders' involvement in the optimization of treatment and care.



Advocacy in South Africa – a report from Catherine McCormack (CEO Arthritis Kids SA)



Local South Africa investigative journalism show, Carte Blanche, recently showcased treatment advocacy work by Arthritis Kids South Africa. The TV segment was followed by a radio interview on Cape Talk. Arthritis Kids SA identified systemic issues in the manner in which applications for biologics are assessed by South African private medical schemes. The work has been ongoing since 2021 and has seen 100% of challenged funding rejections overturned. The interviews were well timed and spoke to the 2023 WORD Day theme of challenging inequity.

WORD Day in Cape Town South Africa **A report from Dr Waheba Slamang**

Cape Town WORD Day 2023.mp4

WORD Day in Cape Town this year was a celebration of the resilience and tenacity of our young patients and their families.

Sponsored once again primarily by the Arthritis Foundation of South Africa (AFSA), the afternoon included motivational speaker, Cleo Otto recounting her journey with JIA, Una van Rheyn of Andreas Gift, a lupus support organisation; as well as Lorraine Mantini and Julie Martin highlighting JIA awareness on behalf of AFSA.

Lots of fun was had by all

https://drive.google.com/file/d/1EBizhAjT_j3b9PwxFxyYzgyZqO--Y1fZ/view?usp=drive_web
especially the 'goodie bag' prizes.

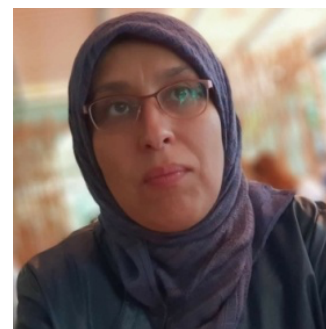
A new collaboration with the community based foundation AJF, was a real coup. The foundation promotes early childhood development by sponsoring food programmes and educational supplies, which now also includes JIA awareness material!

Thanks to a huge team effort; and bolstered by the incredible support offered, the afternoon ended with everyone in high spirits and looking forward to the next WORD Day!

Word day 2023: A week-long awareness raising campaign on young rheumatic diseases in

Algeria

A report from Prof. Djohra HadeF, Algeria



Word day 2023 on 18 March is aimed at raising the awareness and knowledge levels of parents, doctors, primary practitioners, teachers, and the general public to help in early diagnosis of Rheumatic diseases in children, and a quick referral to specialized paediatric rheumatologists.

To achieve these goals, the paediatrics department of the Benflis Touhami hospital and the faculty of Medicine of BATNA 2 University (Batna, Algeria) organised from March 12 to 18 an awareness week on early diagnosis of rheumatic diseases in



children. This campaign targeted doctors, parents, teachers and the general public.

This campaign started in schools (primary and secondary schools). The medical interns led interesting



workshops to explain to parents, teachers and even teenagers the different clinical symptoms that should alert them to consult a doctor.

The same workshops were presented at the hospital during an open house day. More than 600 people attended in the presence of the press (printed and televised media). The majority of the participants were unaware of the existence of these diseases. The key message was to inform the general public of the availability of human and material resources for the diagnostic and therapeutic management of these patients in our hospital. This message was also conveyed by Prof. Djohra HADEF during a one-hour radio show as part of a medical program to target a large number of people.

To close the campaign, a conference on JIA was presented to general practitioners by Prof. Samy SLIMANI and Prof. Djohra HADEF. The objective was to involve them in the early diagnosis of JIA. At the end of the day, recommendations were established during a round table discussion with pediatricians from the Batna region (private and public sector).

A special thanks to my interns in the Pediatrics department led by Djadelhak MEHDI.



WORD Day 2023 Webinar for Portuguese-speaking countries

A report from Dr Filipa Ramos

The Portuguese Society of Paediatric Rheumatology together with the National Association for Patients with childhood-onset rheumatic diseases – ANDAI - organized on the past 18th March a webinar for the Portuguese-speaking countries in order to celebrate the WORD Day 2023. The webinar in Portuguese was composed of two parts: a first one aimed at health professionals about when to suspect rheumatic diseases in children and young people and when to refer and a second part aimed at patients and families with the main topic of how to live with a rheumatic disease, the benefits and limitations of the physical exercise and strategies of how to deal with adverse effects of treatments.

There were 242 people registered in the webinar (160 physicians, 24 health professionals, and 49 patients/parents/caregivers) from 7 countries (Portugal, Brazil, Mozambique, Angola, Cape Verde, Congo and Paraguay). This initiative was a success with great feedback from all the participants and lead to a report on national TV.



Highlights of PAFLAR's First Hybrid Congress



Report from Anthony ODallo, on behalf of Dr Angela Migowa and the PAFLAR Board

The annual scientific congress organized by PAFLAR, an NGO championing paediatric rheumatology in Africa, surpassed all expectations this year. As PAFLAR's first hybrid congress, it successfully blended physical and virtual participants, breaking geographical barriers and uniting experts, healthcare professionals, and stakeholders in the field. Under the theme "Paediatric Rheumatology in Africa: Tackling Emerging Challenges", this event was a resounding success paving the way for future congresses and establishing itself as a cornerstone in advancing paediatric rheumatology in the region.

Therapeutic Patient Education Pre-Congress:

Kicking off the event was an enlightening pre-congress session focused on therapeutic patient education. This session, led by PAFLAR's treasurer, Dr. Wafa Hamdi, and Dr. Kawther Ben Abdelghani, aimed to enhance the understanding and implementation of effective education strategies for children and their families dealing with rheumatic conditions.

Congress Highlights:

The two-day congress featured a diverse array of sessions, workshops, and presentations covering a wide range of topics within paediatric rheumatology. Here are some of the highlights:

1. **Keynote Lectures:** Esteemed researchers and clinicians delivered thought-provoking keynote lectures, shedding light on breakthroughs, challenges, and potential future directions in the field. These lectures sparked engaging discussions among attendees, highlighting the importance of innovative thinking and collaboration.
2. **Workshops:** Day two of the congress was dedicated to workshops that provided hands-on learning experience for participants. Experts led interactive sessions on various aspects of paediatric rheumatology, including diagnosis, treatment strategies, therapies, and interdisciplinary care. These workshops were divided into themes: Clinical Dilemma Cases, Spondyloarthropathies/Rare Bone Diseases, Infections and Paediatric Rheumatology, and Genetic/Metabolic Diseases/other CTDs in Rheumatology. Among the wide array of workshops, one session emerged as the centerpiece of the event – the workshop on musculoskeletal ultrasonography. The

workshop generated immense interest and participation, attracting ultrasonography experts from Ped-MUS, Cincinnati Children's Hospital and the Aga Khan University Hospital in Nairobi. Attendees were exposed to advanced imaging techniques and diagnostic approaches, enhancing their ability to monitor musculoskeletal conditions in children. For this, three ultrasound machines were donated by Phillips and Mindray, in addition to financial support. These workshops offered valuable opportunities for skill development and knowledge sharing.

3. **Emerging Challenges:** The congress theme brought to light the unique challenges faced by paediatric rheumatologists in Africa. Presentations and panel discussions shed light on the prevalence of specific rheumatic conditions in the region, diagnostic dilemmas, limited access to specialized care, and the need for collaborative efforts to address these issues effectively. The congress also allowed PAFLAR the opportunity to update members on two of its groundbreaking projects, the JIA Registry and JIA guidelines.
4. **Election:** The congress included an important election process, allowing members of PAFLAR to choose new leaders to guide the NGO's mission and initiatives. Five new board members were elected with the other four retaining their positions under the presidency of Prof. Angela Migowa, who was also re-elected for another tenure. This democratic exercise demonstrated the commitment to collaborative decision making and ensured representation for diverse perspectives.
5. **Exhibition booths:** The congress also featured a dedicated space for exhibition booths. At the congress, we had a booth occupied by a partner organization called Tin Soldiers. This is an organization that supports people living with Fibrodysplasia Ossificans Progressiva (FOP). This facilitated valuable interactions, fostering potential collaborations and advancements in the field.
6. **Abstracts and Posters:** Researchers and clinicians from around the globe submitted abstracts of their latest studies, presenting their findings in the form of oral presentations and poster sessions. A total of seventy-five abstracts were received and are in the process of being published by Oxford. Thirty of these abstracts were also presented as posters during the congress. This dissemination of research broadened the knowledge base, encouraged constructive feedback and inspired future investigations.
7. **Networking opportunities:** Beyond the scientific sessions, the congress also offered numerous networking and bonding opportunities. Attendees had the chance to connect with like-minded professionals, establish new collaborations, and strengthen existing partnerships. Social events such as the gala dinner held on the evening of the first day of the congress, and interactive activities during breaks from sessions further promoted a sense of camaraderie and community amongst participants.
8. **CSR:** The congress also exemplified the spirit of CSR by incorporating initiatives aimed at making a positive impact on society. This particular congress featured two organizations, Clean Start, and Rare Disorders Kenya. Clean Start's mission is to help reintegrate women, girls and children impacted by the criminal justice system. Rare Disorders Kenya advocates for people living with rare diseases in Kenya. These initiatives highlighted the commitment of PAFLAR and its members towards the welfare of society at large.
9. **Attendance:** The hybrid congress witnessed significant participation and engagement. Over the entire congress we had a total of 169 participants; 90 as physical attendees and 79 as virtual attendees.

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 multiprofessional 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 <https://www.pmskglobal.com>

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

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

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