Paediatric Task Force Global Musculoskeletal Health

Welcome to our May 2021 e-Newsletter and to our expanding global community

We hope that you are well and keeping safe in these ongoing challenging times. We are pleased to share with you articles and features from around the world to promote all the fabulous work that you are doing to raise awareness, support education and training and improve the musculoskeletal health and clinical care for children. We include updates from our regional groups and aim to have contributions from as many as possible as a regular feature.

Announcements and Good News to share !

Scott *et al. Pediatric Rheumatology* (2021) 19:10
https://doi.org/10.1186/s12969-021-00496-3

Pediatric Rheumatology

LETTER TO THE EDITOR — Open Access

Revising the WHO Essential Medicines List for paediatric rheumatology

Christiaan Scott[1], Nicola Smith[2], Rebecca James[3], Ben Whitehead[3], Rochelle Green[4], Helen E. Foster[5*] on behalf of the Paediatric Global MSK Task Force

On behalf of our collaborative group within the Paediatric Global Musculoskeletal Task Force, we have submitted proposals for changes to the WHO EML - section 29 ‘Joint Diseases in Children’. We have submitted new medicine applications: Tocilizumab, Triamcinolone hexacetonide, and Anakinra

The applications are now published at https://www.who.int/groups/expert-committee-on-selection-and-use-of-essential-medicines/23rd-expert-committee and the outcome is pending (we should know by September 2021).

We acknowledge the many letters of support from around the world and the global contribution from all respondents to our e-survey https://ped-rheum.biomedcentral.com/articles/10.1186/s12969-021-00496-3 **to inform our application.**

Professor Helen Foster has been appointed as member of the WHO External Review Group.

The role is for 2 years and she will be working on guidelines and policy across the life course with focus on musculoskeletal health for children and young people.

Associate Professor Chris Scott will be presenting at the ACR Ped Rheum symposium (May 19-21).

He will be promoting our 'call to action' by presenting Task Force activities and background to the unmet challenges for children and families.

WORDday 2021

A report from Veerle Buys and Wendy Costello on behalf of the WORD Day team

With the ongoing impact of the pandemic, the focus of the 2021 campaign shifted to digital events, which has enabled us and our supporters to increase our reach. Besides Facebook and Twitter, WORDDay is now also on Instagram and TikTok to connect with our young people.

The reach of known WORD Day 2021 activities !

Events around the globe included education sessions, podcasts, social media campaigns, celebrations and webinars. We hosted 2 global webinars with a mix of speakers and different perspectives and an audience that consisted of a mix of parents, young patients, doctors and other health professionals.

The engagement and feedback were overwhelming and in order to reach more medical professionals we plan to offer additional content throughout the year. Among the activities that were submitted through our website WORDday.org we had a webinar hosted by 7 countries in Latin-America, a hack-a-thon, podcasts, education sessions and a street art design on a hospital wall in Thessaloniki.

The WORDday community is growing and we encourage everyone to apply for ambassadorship: together we make a difference for children and young people with rheumatic diseases.

More information: Check out www.WORD-Day.com and follow us on Twitter and Facebook

WORD Day activities from around the world – a few examples

WORD Day 2021 South Africa – a report from Dr Waheba Slamang

The events for WORD Day 2021 were successfully spearheaded by the Arthritis Foundation South Africa (AFSA) and paediatric rheumatologists in Cape Town. WORD Day ambassadors *spread the word* in spot radio interviews in the preceding week. A webinar for the CHAT (**C**hildren **H**ave **A**rthritis **T**oo) programme, which is aimed at primary school learners, teachers and parents, was prepared in conjunction with a WORD Day competition. The competition invited children with rheumatic diseases from across South Africa to express their thoughts and feelings in videos, poems, posters or song. The webinar then shared basic scientific information and introduced the participants to children with JIA via short video clips collated from the entries. Take a look:

Diagnosis

Treatment tips

Exercise

Living with JIA

After a myriad of online meetings this past year, we hoped that observing real children with arthritis would add a personal, more relatable dimension to the information shared, and that learning through games (JIA bingo and word search) would encourage active participation. Information on SLE and support organizations was also included in the webinar and entertainment provided by our very own Prof. Scott! The announcement of the competition winners, with prizes sponsored by the AFSA and Arthritis Kids South Africa, concluded the session.

The reality of living with JIA show-cased in this way, was met with positive responses and a willingness to learn more. However, technical challenges, mostly due to variable WiFi quality, made connecting with learners difficult. Games to introduce the concept of a ‘confused’ immune system were also abandoned. As the pandemic continues, we will need to address these challenges. Playing some of the games before the webinar and managing the learner groups in breakout rooms for better interaction have been considered thus far. We were certainly enlightened and inspired by these glimpses into our patients’ lives and think that you will be too!

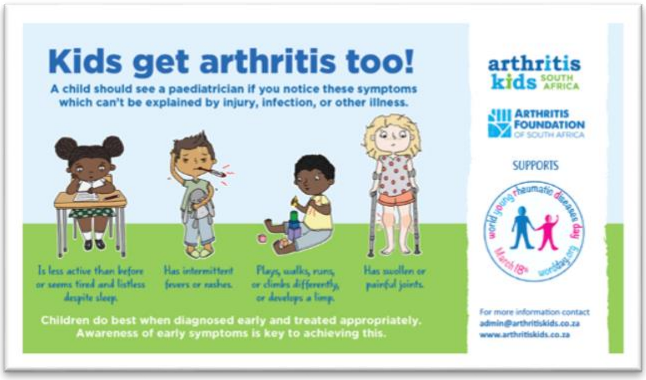
Waheba Slamang
Paediatric Rheumatologist, Red Cross Children’s Hospital, Cape Town, SA

A report from Catherine McCormack Executive Director.

March 2021 was a busy and exciting time for Arthritis Kids South Africa: we launched our website, joined forces with Arthritis Foundation South Africa to celebrate WORD Day, interacted with global WORD Day participants and parents in a series of webinars, and achieved more press coverage than ever before!

Arthritis Kids South Africa Reg No: 2019/364660/08

We were thrilled to launch our newest early symptom awareness posters in four South African languages.


Kids get arthritis too!

A child should see a paediatrician if you notice these symptoms which can't be explained by injury, infection, or other illness.

Is less active than before or seems tired and listless despite sleep.

Has intermittent fevers or rashes.

Plays, walks, runs, or climbs differently, or develops a limp.

Has swollen or painful joints.

Children do best when diagnosed early and treated appropriately. Awareness of early symptoms is key to achieving this.

arthritis kids SOUTH AFRICA

ARTHRITIS FOUNDATION OF SOUTH AFRICA

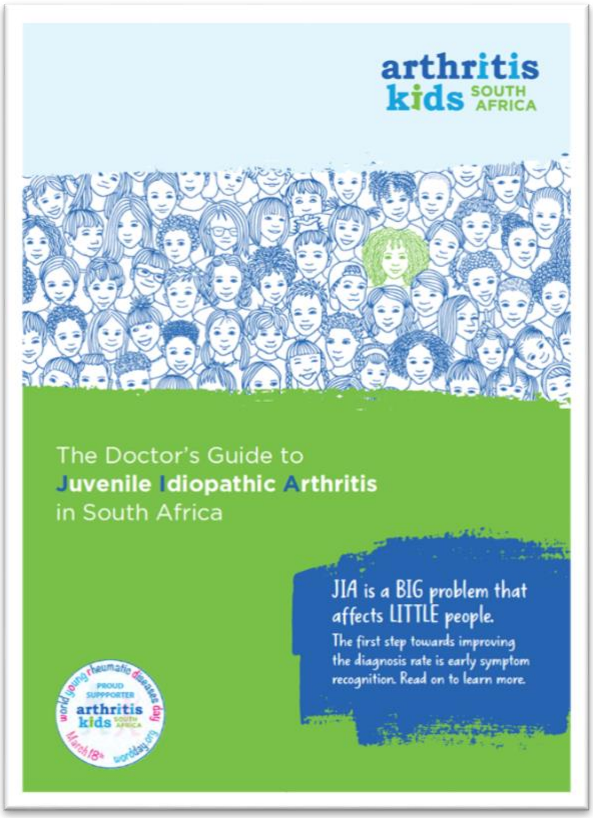
SUPPORTS

For more information contact
admin@arthritiskids.co.za
www.arthritiskids.co.za

We also have our new doctor's guide for evaluating suspected cases of JIA.

It is intended for GPs, paediatricians, or any medical professional interacting with children.

The guide flags up when to suspect JIA and signposts to the free assessment tools on Paediatric Musculoskeletal Matters (PMM)


arthritis kids SOUTH AFRICA

The Doctor's Guide to
Juvenile Idiopathic Arthritis
in South Africa

JIA is a BIG problem that affects LITTLE people.
The first step towards improving the diagnosis rate is early symptom recognition. Read on to learn more.

A highlight was meeting and interacting with some of our global counterparts around the world and putting faces to names that have, until now, only appeared in emails. We look forward to many more opportunities to work with this wonderful group in the future.

We also made a little video for sharing on social media:


Assessment tools:
pGALS

arthritis kids SOUTH AFRICA

pGALS: an evidence-based approach to basic musculoskeletal assessment and widely taught to medical students and physicians in primary care, paediatrics and orthopaedics.*

"The use of pGALS is aimed at the non-specialist in paediatric MSK medicine as a basic clinical skill to be used in conjunction with essential knowledge about red flags, normal development and awareness of patterns of musculoskeletal pathologies. pGALS has been validated in school-aged children and also in the context of acute general paediatrics to detect abnormal joints."

Foster, H.E., Jandial, S. pGALS – paediatric Gait Arms Legs and Spine: a simple examination of the musculoskeletal system. Pediatr Rheumatol 11, 44 (2013).

Information about pGALS, the language translations and the new version (V-pGALS, or telemedicine and virtual clinics in the wake of COVID-19) are freely available: click here.

Get the FREE App!

The pGALS App - Google Play and Apple Store - with multiple language translations, explanatory notes, images, and relevant links to pmm-international.


Assessment tools:
PMM-International

Paediatric Musculoskeletal Matters (PMM) is a **free, evidence-based**, and **peer reviewed open e-resource** for paediatric musculoskeletal (MSK) medicine for all clinicians who encounter children. It is specifically aimed at those who are not MSK specialists. It is the result of a collaboration between Newcastle University and Northumbria University, lead by Professor Helen Foster.

Since its launch in 2018, PMM-International has reached over 200 countries and boasts more than three hundred thousand users. PMM is endorsed by **PReS**, the **Royal College of Paediatrics and Child Health**, and the **Royal College of Nursing**. The information is freely available and is grouped in two websites by profession: doctors, allied healthcare workers and medical students in one, and nurses and nursing students in another.

NB: Remember to register for access to videos and images.

www.pmmonline.org

We achieved some excellent press coverage over the past couple of weeks following a WORD Day article in local newspapers. [Click here for a TV interview](#).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HEALTH

Arthritis in children: a surprising condition

ARTHRITIS is surprisingly common among children, thousands of whom are misdiagnosed, the writer says. | ITUMELENG ENGLISH African News Agency (ANA)

Currently the youngest patients I am seeing are 15 months and 25 months old

DR BHADRISH MISTRY
paediatric rheumatologist


Let's tackle arthritis in children together

Zooming in on juvenile idiopathic arthritis

Question is, how can you treat it?

Challenges faced by JIA patients

Dr Priya Ambaram

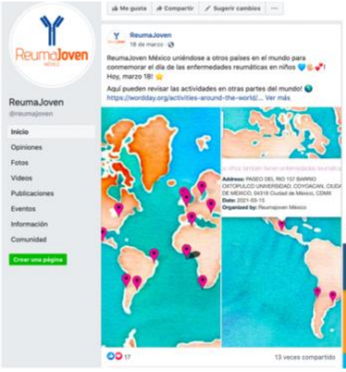
Shall we bust some myths?

WORD Day and Paediatric Rheumatology in Central America

A report from Dr Fernando Garcia Rodriguez, paediatric rheumatologist, Monterrey, Mexico

During WORD Day, enthusiastic colleagues participate in virtual events and social media awareness posting. Some of the works are listed below:

- Young Rheumatologists division of the Mexican College of Rheumatology (Reumajoven) share children's experiences and relevant information about PRDs using social media posts and videos.
- Pediatrics Institute of TecSalud (Monterrey, Mexico) shared a 5-year-old girl experiences with JIA in a conference dedicated to different families and school members.
- Club Rotario Monterrey A.C. organized a conference on the perspectives and problems that patients with PRDs faced in Mexico.
- The University Hospital of the Autonomous University of Nuevo Leon shared virtual flyers to raise awareness that "Children get rheumatic diseases too".



ReumaJoven
18 de marzo

ReumaJoven México uniéndose a otros países en el mundo para conmemorar el día de las enfermedades reumáticas en niños 💙✌️💕!
Hoy, marzo 18! ⭐
Aquí pueden revisar las actividades en otras partes del mundo! 🌍
https://wordday.org/activities-around-the-world/... Ver más

Address: PASEO DEL RIO 157 BARRIO OXTOPULCO UNIVERSIDAD, COYOACAN, CIUDAD DE MEXICO, 04318 Ciudad de México, CDMX
Date: 2021-03-15
Organized by: Reumajoven México

17
13 veces compartido

Te invitamos a nuestra sesión
"Panorama de las Enfermedades Reumáticas Pediátricas en México"

Nuestros oradores huésped:
Dra. Ana Villarreal Treviño
Dra. Nadia Rubio Pérez
Dr. Fernando García Rodríguez

Miércoles 7 de Abril 2021
13.30 Horas

Joing Zoom Meeting
https://us02web.zoom.us/j/7625215157?pwd=NDUrczhZSkQ2dHlneXdMWks3ZE1Tdz09

Meeting ID: 762 521 5157
Passcode: CRMTY

Un Panorama que sucede en México y el mundo, del cual hay poca difusión...

18 de Marzo de 2021
Día Mundial de las enfermedades reumáticas en niños y jóvenes
Los niños también tienen enfermedades reumáticas
1 de cada 1000 niños es diagnósticado con Artitis Juvenil cada año

Future meetings

- Mexican College of Rheumatology Annual Meeting May 14th to 18th, 2021. https://www.reumatologia.org.mx/

Publications

- Psychosocial and economic impact of rheumatic diseases on caregivers of Mexican children. Fortuna-Reyna et al. Pediatr Rheumatol Online J. 2021 Mar 17;19(1):30. doi: 10.1186/s12969-021-00524-2. (https://pubmed.ncbi.nlm.nih.gov/33731150/)
- Shrinking lung syndrome in pediatric systemic lupus erythematosus. Torres Jimenez et al. Lupus. 2021 Apr 22;9612033211010331. doi: 10.1177/09612033211010331. (https://pubmed.ncbi.nlm.nih.gov/33888011/)
- Perineal Erythema in Kawasaki Disease and MIS-C. Sánchez-Alarcón et al. Indian J Pediatr. 2021 Mar 13;1. doi: 10.1007/s12098-021-03717-5. (https://pubmed.ncbi.nlm.nih.gov/33712925/)
- Abnormal Nailfold Capillaroscopy in a Patient With Multisystem Inflammatory Syndrome in Children. Tamez-Rivera et al. Pediatr Infect Dis J. 2021 Mar 1;40(3):e113-e115. doi: 10.1097/INF.0000000000003022. (https://pubmed.ncbi.nlm.nih.gov/33565816/)
- [Kawasaki disease in infants under one year of age. A challenge for the diagnosis and treatment of patients. Experience in a hospital center in Mexico]. Garrido-García et al. Rev Chilena Infectol. 2020 Nov;37(5):584-590. doi: 10.4067/S0716-10182020000500584. (https://pubmed.ncbi.nlm.nih.gov/33399808/)
- Use of Adjunctive Therapy in Acute Kawasaki Disease in Latin America. Fortuna-Reyna et al. Front Pediatr. 2020 Sep 15;8:442. doi: 10.3389/fped.2020.00442. (https://pubmed.ncbi.nlm.nih.gov/33194876/)

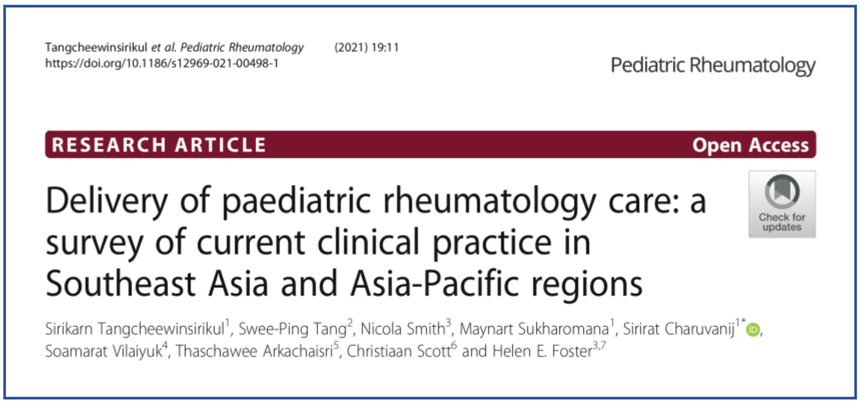
WORD Day and Paediatric Rheumatology in South America – a report from Professor Claudia Saad Magales and describing the challenges of delivering a clinical service during the pandemic.

From our side we had a nice gathering for the Wordday webinar on March 18th organized by Dr Ruben Cuttica and Judith Iglesias supported by Rheumatology Society of Argentina. We had health professionals and parents from 6 Latin America (LA) countries. We had also an active participation in the JIR Winter School with Dr Michael Hofer and Dr Raju Khubchandani in a virtual meeting around the clock from east to west, it was about Vasculitis and thereafter, monthly meeting will come along with interactive case presentation and discussion by experts. The next topics for the monthly meeting will be (May 1st) Granulomatous Diseases in 3 sessions, an overview by one expert, a case discussion session presented by participants and a deep review of the literature and what is new (Journal club) by another expert . There was a representative participation of LA physicians and we are networking for engagement in this CME activity.

We are still facing hard challenges due to pandemics with devastating figures of 5,000 death each day, the threaten of the virus-variants and challenges within the health system. There is a shortage of vaccines what prompted engagement in humanitarian actions, search of international donation of vaccines with distribution by the national immunization programme. Delay in the immunisation coverage will certainly make our COVID crisis even worse. There is also the shortage of all biologics for paediatric rheumatic diseases (anti-TNF, anti- IL6, IVIG and many others...). It is devastating to step back 20 years in paediatric rheumatology…..

An update about paediatric rheumatology in South East Asia

A report from Dr Sirikahn Tangcheewinsikul, Bangkok, Thailand



Tangcheewinsirikul *et al. Pediatric Rheumatology* (2021) 19:11
https://doi.org/10.1186/s12969-021-00498-1

Pediatric Rheumatology

RESEARCH ARTICLE **Open Access**

Delivery of paediatric rheumatology care: a survey of current clinical practice in Southeast Asia and Asia-Pacific regions

Sirikarn Tangcheewinsirikul[1], Swee-Ping Tang[2], Nicola Smith[3], Maynart Sukharomana[1], Sirirat Charuvanij[1*], Soamarat Vilaiyuk[4], Thaschawee Arkachaisri[5], Christiaan Scott[6] and Helen E. Foster[3,7]

Ssince there are several workforce challenges across the world including Southeast Asia and Asia-Pacific Countries (SE ASIA/ASIAPAC), we conducted an online survey about paediatric rheumatology (PR) clinical care and training programmes. The aim was to identify the challenges in delivery of clinical care and to raise awareness about children with rheumatic diseases. The online survey was developed in collaboration with the Juvenile Arthritis Management in less resourced countries (JAMLess) members and distributed to the existing group lists of physicians and allied health professionals who were involved in the care pathway of children with rheumatic diseases in SE ASIA/ASIAPAC.

Our results of the survey from 340 participants in 14 countries highlighted multiple challenges affecting both PR clinical care and training. Paediatric rheumatologists were mainly cared for children with rheumatic diseases only at 44.9%, followed by general paediatricians (38%) and adult rheumatologists (8.1%). There is variation in availability and access to drugs amongst countries in SE ASIA/ASIAPAC. Poverty, drug unavailability and absence of specialists to supervise the use of biological drugs are all major challenges to PR clinical care. The paucity of trained paediatric rheumatologists and specialist multidisciplinary team was reported as the main perceived barrier to improving PR clinical care. There were also limited access to drugs and biological therapies. Additionally, there was a need to encourage PR training and increase awareness amongst allied health professionals.

We do hope that our survey is the first step to address these challenges and improve the quality of care for children with rheumatic diseases in SE ASIA/ASIAPAC and for further collaboration in our regions.

As being a part of this collaborative project, I notice many challenges to the delivery of PR clinical care amongst SE ASIA/ASIAPAC. Over and above my great paediatric rheumatology fellowship programmes at Siriraj Hospital, I have realised multiple factors affect the system of care for children with rheumatic diseases especially in less resourced countries and also the chances to improve them. I have grown and learned a lot from the team as we work together. This is such a great opportunity for me. The full article is available:

https://ped-rheum.biomedcentral.com/articles/10.1186/s12969-021-00498-1

Paediatric Rheumatology Training in Thailand – A report from Associate Professors Soamarat Vilaiyuk and Sirirat Charuvanij, Bangkok, Thailand

Recently, two paediatric rheumatology fellowship training programmes in Thailand were accredited by the World Federation for Medication Education (WFME). Our paediatric rheumatology fellowship training programs have been established since 2014. There are two training centres; Faculty of Medicine Ramathibodi Hospital, where Assoc Prof. Soamarat Vilaiyuk is a programme director and Faculty of Medicine Siriraj Hospital, where Assoc Prof. Sirirat Charuvanij (pictured) is the programme director. Both institutes belong to the Mahidol University located in Bangkok, Thailand. So far, 13 paediatric rheumatologists have completed our training programme. We currently have four paediatric rheumatology fellows in training and two upcoming fellows starting this July. Our programmes welcome international visiting scholars and exchanging elective rotations. We look forward to collaborating with other institutes!

The WFME committee came to audit the fellowship training programmes at Faculty of Medicine Ramathibodi Hospital (1 & 2) and Faculty of Medicine Siriraj Hospital (3 & 4)

More about education and training – report from Dr Lovro Lamot – Chair of PReS EMERGE

- YOUNG INVESTIGATOR METING
- FELLOWSHIPS FOR CLINICANS AND SCIENTISTS
- PEER-REVIEW MENTORING PROGRAM
- EDUCATION AND COURSES
- COLLABORATION WITH OTHER GROUPS
- RESEARCH AND PReS WORKING PARTIES
- SOCIAL MEDIA AND NEWSLETTERS

Despite the current situation with the pandemic, PReS EMERGE is trying to carry on with the activities for young paediatric rheumatologists and researchers.

Therefore, as a part of the PReS main congress, a traditional 25th Young Investigators Meeting will be held on 18th of September. Please encourage your fellows, residents and young paediatric rheumatologists and researchers below 45 years of age to submit an abstract for YIM and to participate in the meeting. More information and a detailed program will be out soon (https://www.pres.eu/pres2021/young-investigators.html).

Moreover, PReS EMERGE is dedicated to enhance the training of young paediatric rheumatologists and researchers by providing an opportunity to visit centres within Europe for a period of up to six months. This year we also had a joint fellowship with an autoinflammatory working party. This year the applications are already closed but in order to prepare for fellowship in the future please have a look at the fellowship website (https://www.pres.eu/emerge/fellowship-programs.html).

Finally, EMERGE members prepared an interesting survey to gain more insight in the practice of biosimilar usage around the globe, so please take this short survey: https://www.surveymonkey.com/r/?sm=y4g3Xq9KZVIyLFPNpe_2Bn2A_3D_3D

In order to stay updated with the PReS EMERGE activities, follow us on Facebook (https://www.facebook.com/PReSEMERGE), Twitter (https://twitter.com/PReSEMERGE) and write us on emerge.pres@gmail.com

Developing pGALS for Slovakia – *a report from Dr Tomas Dallos paediatric rheumatologist, Bratislava, Slovakia*

Other than paediatric rheumatologists, pGALS was not widely known among paediatricians and other paediatric specialists in Slovakia. With the onset of the COVID19 pandemic, due to severe restrictions, a significant number of patient visits in outpatient clinics would not be possible. As the objective examination of the musculoskeletal status is a crucial part of every outpatient clinic visit, we felt there was an urgent need for a tool, caregivers could use to report musculoskeletal finding of their children to their paediatric rheumatologists.

A Slovak translation of the pGALS was distributed to the families of our patients to be returned to us at the time of planned visits. Though formally not assessed, the pGALS was generally well accepted by parents and patients of all ages and returned to us with very relevant findings.

The Slovak version of the pGALS is now freely available at the PMM website (http://www.pmmonline.org/doctor/approach-to-clinical-assessment/examination) and on the free pGALS app. We hope that a recently published article in the local "Pediatria pre prax" journal will promote its use among paediatricians in Slovakia and thus improve recognition of musculoskeletal disorders in children and improve the quality and timing of referrals to specialized care.

https://www.solen.sk/casopisy/pediatria-pre-prax/pgals-efektivny-nastroj-na-rozpoznanie-muskuloskeletalnych-ochoreni-u-deti

Lesson of the Month – a new feature for our Newsletter !

Slipped Capital Femoral Epiphysis (SCFE) – a paediatric hip disease often overlooked by parents, physiotherapists, general practitioners and even radiologists!

An article from Dr Carl Johan Tiderius, Senior consultant and Professor in Paediatric Orthopedics, Lund University, Sweden. Co-chair in the Paediatric Task Force

Background: SCFE affects approximately 1/500 children, typically at age 9-15 years. In SCFE, the growth-plate in the femoral head becomes weak, resulting in a dislocation of the femoral shaft relative to the femoral head. Obesity is a strong risk factor, probably both for mechanical and hormonal reasons. In most cases (90%), the slip occurs gradually over time, (chronic slip) resulting in a slowly progressive deformation of the femoral head-neck junction. In chronic slips symptoms are initially vague and the child suffers from pain that increases over time.

The most common clinical finding is a ***limited inwards rotation*** compared to the healthy hip. The pain is usually located to the hip but ***in 1/4 of the cases only from the thigh or knee***. In few cases (less than 10%) the slip is acute (unstable). This condition is very painful (like acute fracture) and obvious to everyone (Figure 3). The treatment for SCFE is always surgical. The most common surgery is to insert a nail or screw over the physis to prevent further slippage. Since hip deformation in SCFE is progressive ***early diagnosis and treatment is crucial*** to minimize the risk of hip problems in adulthood.

Clinical case: This case illustrates how the most common hip disease in adolescence can be overlooked by several different care givers.

- 14-year old healthy boy, overweight but not obese, BMI 27. Likes to play floor-ball and run kick-bike.
- Autumn 2020: left side thigh pain of various intensity. No related trauma. Slows down in sports. The family thinks it may be related to the growth spurt.
- Worse pain around X-mas. Cannot run anymore. Seeks physiotherapist who prescribes stretching of thigh muscles.
- February, no improvement. General practitioner orders a radiograph of the hip.
- The radiology report says: “Radiographic signs of cam-impingement” (Figure 1).
- The general practitioner refers the patient to the orthopedic department.
- The orthopedic surgeon re-evaluates the radiograph (Figure 1) and notes a chronic SCFE.
- Within 2 days the patient is operated with a Hansson hook-pin to prevent further slippage (Figure 2). The healthy right hip is also operated because of approximately 25% risk of subsequent slippage.

Conclusions:

- Early diagnosis is crucial to prevent subsequent problems after SCFE.
- SCFE may cause only knee pain - always investigate the hip in children with knee pain!
- Long-standing limping in children must be adequately investigated.
- A patient with SCFE always has decreased inwards rotation of the affected hip (compare with the other side).
- A radiograph of the pelvis with Lauenstein (Frog-leg) projection is the most sensitive to detect a subtle slip.

Figure 1: Left hip, chronic slip. The arrow points at the cam-like deformation that has occurred due to progressive slippage. **Figure 2**: Lauenstein (frog-leg) projection of the Pelvis after in-situ fixation. The decreased angle between the growth-plate and the Femur on the left side (arrow) illustrates the gradual deformation that has occurred during the slip.

Figure 3. Acute SCFE of the left hip (the right hip in the figure). A fracture-like separation of the femoral head and the femur through the growth-plate. In this case, the diagnosis is easy!

More information - check out PMM - http://www.pmmonline.org/doctor/joint-pain-by-site/hip-pain/sufe

Fundraising activities : U-Can ride 4 arthritis (UCANR4A) A report from Dr Klaus Tenbrock (Aachen) and Dr Bas Vastert (Utrecht)

The UCANR4A cycling event started in September 2016 to raise awareness for children with rheumatic diseases and to foster collaboration between pediatric rheumatology centers in Europe. Our first tour in 2016 went from Utrecht to Genova, with a team of 8 riders from Aachen, Muenster, Sendenhorst, Utrecht and Groningen. We rode over 1500km in 8 days and visited 9 pediatric rheumatology centers in the Netherlands, Germany, Switzerland and Italy.

This was followed by national events in Germany and Austria in 2017, 2018 and 2019, in which we visited another 14 centers. Altogether the UCANR4A initiative continues to create awareness on pediatric rheumatic diseases and raised over 50.000€, which is dedicated to support collaborative research in Europe like the Understanding Childhood arthritis network (UCAN) and the Pro-Kind initiative. In 2020, we wrote and received a European Union Research grant (Era Per Med program) of 1,1 million euro to continue our collaborative research activities dedicated to refractory JIA patients. For more information see: www.ucanr4a.eu; for support: IBAN:DE 77 8605 5592 1100 6057 34, UCANR4a-Pro-Kind. We aim for an international event after the end of the COVID 19 pandemia.

An update about the growth of Paediatric Rheumatology in Africa – A report from Mr. Evans Omalla (Kenya) ,Dr Angela Migowa (Kenya), Dr Djohra Hadef (Algeria),Dr Wafa Hamdi (Tunisia)

The **Pediatric Society of the African League Against Rheumatism (PAFLAR)** group was established with the core mandate to formulate structural frameworks to advocate for Pediatric Rheumatology across Africa and promote a world where children with rheumatic and musculoskeletal diseases have the same and optimal chance to live, grow and develop like their other normal counterparts. In this endeavour, the PAFLAR Taskforce has developed a 5-year strategic plan that will lay the foundational work that will create an enabling environment that will spur the growth of paediatric rheumatology in Africa.

This is also a step towards the realization of the Sustainable Development Goals (SGD) Goal three (3) for our patients to achieve Universal Health Coverage with an emphasis on paediatric rheumatology patients; where we strive for equity, quality and financial protection when it comes to their much-needed health services.

This strategic plan will be launched in July during the premiere PAFLAR virtual congress. Nonetheless, implementation of the 5-year strategic plan has begun as outlined below;

Capacity Building

Across Africa, there is a huge disparity in accessing paediatric rheumatology health services primarily due to the high patient to paediatric rheumatologist ratio coupled with uneven distribution of the few paediatric rheumatologists available. This has resulted in undiagnosed cases, misdiagnoses and loss of opportunity to promptly intervene for these children to minimize on associated morbidity and mortality. Training specialists to offer these services takes time a luxury that the current paediatric patients don’t have. To improve access to these services and quality of care, The PAFLAR strategic plan has introduced an educational program for health practitioners in Africa; whereby health care workers are equipped with knowledge and skills to diagnose, refer or manage rheumatic conditions in children. These sessions also serve to raise the suspicion index for rheumatic conditions among healthcare workers. This program is being implemented through a monthly continuous medical education program where specialists in the field of paediatric rheumatology share their knowledge with the attendees; who range from specialist, medical students, resident's trainees and other cadres of healthcare workers. These sessions take the form of lectures, case discussions and experience sharing. At the end of each lecture, participants give feedback that informs on the applicability of the knowledge in their day to day work.

Further to this, PAFLAR has partnered with the JIR Academy and sponsored 156 health care workers across the African continent to attend the JIR winter school on vasculitis. Plans are underway to get further participation of the African attendees in the follow up monthly sessions organized by the JIR Academy not just as attendees but as speakers.

Response to the COVID 19 pandemic

In response to the COVID19 pandemic, we have conducted webinars on the pathogenesis of COVID19 among children for the health care providers for the general public, the Chair of the task force developed messages to guide on the precautions to be taken to help optimize safety for children.

Public Awareness Campaigns

We have also been running social media campaigns and TV campaigns to create awareness of rheumatic conditions in an ecosystem that sometimes considered these conditions in children as non-existent. With these platforms, we have been able to reach the general public who among them are caregivers to patients. Video links are available on our website https://paflar.org

Disseminating Research Updates

Key research papers have been uploaded on our website to help disseminate knowledge in the area of paediatric rheumatology. https://paflar.org

Scientific Congress

We have organized to conduct the 1st PAFLAR virtual congress in July 2021; a forum where we will showcase what Africa has to offer in the field of paediatric rheumatology and musculoskeletal diseases. The congress will also provide an opportunity to network and build synergies that will be leveraged to achieving what has been envisioned for paediatric rheumatology across Africa. The slogan for the congress was developed with the belief that it's time to realize what had been envisioned for paediatric rheumatology in Africa in the previous years- hence our slogan **"The Future is Now; if we do not address paediatric rheumatology matters now, these issues will be procrastinated to an unspecified future, maintaining the status quo which in our view is not an option**

Partnerships

Being cognizant that it will not be an individual effort but collective efforts from different stakeholders working in synergy we are forging partnerships with organizations with a similar vision to drive this agenda. So far we are in partnership with African League Against Rheumatism (AFLAR) the mother organization, International League of Associations for Rheumatology (ILAR), JIR Cohort Academy, Pfizer, Roche, Kenya Paediatric Association (KPA) and the list is quickly growing as we strive to bolster and expand our networks and collaborations.

Communication platform
To raise awareness and communicate to the world the current developments in the field of paediatric rheumatism in Africa, we have launched a website and set up social media accounts to connect with members and disseminate information. The website will also serve in the recruitment of members. From the analytics on these sites, we have been able to reach 2,543 individuals who have visited our website between January-April 2021.

In conclusion, the task force is confident that the strategic plan will be a game-changer for the African continent and its impact will be felt far beyond our lifetime.
Paediatric rheumatology patients in Africa and across the globe don't have to bear the burden of the disease alone. Let us join hands in realizing a better future for our children with rheumatology diseases hence our slogan **"Stronger Together for a Better Future."**

And to remind us all of the challenges facing our patients and families and living with arthritis day to day. *Working better together is the way forward !*

Lessons from the trenches

Written by Catherine McCormack, South Africa

I've been an arthritis mom since 2010 when my then two-year-old was diagnosed with juvenile idiopathic arthritis (JIA). In the eleven years since that awful time, we've been through three biologics, a year-long bout of TB, a stint in a wheelchair, many pairs of crutches, night splints, day splints, and more needles, tests, and therapy than I could have ever imagined.

Over the last few years, my daughter's disease has been beaten into submission by a combination of a biologic paired with a variety of other DMARDs. These drugs are nothing short of life changing; my daughter is symptom-free and suffers no discernable side-effects.

The contrast to the first eight or so years is impossible to describe. There's some residual damage from our TB year: I suspect my daughter will always walk with a limp. She also can't fully flex or extend her knees, the calf muscles in her left leg are noticeably atrophied, and her left foot and ankle present some challenges. She's considering her surgical options but isn't terribly keen on disrupting what has become an ordinary life.

I'm happy to say that I have learned a couple of things since Ella's diagnosis. I'm sharing these lessons, revealing as they may be, in the hope that they prove valuable. I do so cognizant of the quote by lifelong teacher Sister Agnes Patricia, who said, "There is no teaching, only learning."

So, here's what I've learned.

I've learned that I can't control Ella's disease. I know because I've tried. Obsessively noting everything she ate, sleep patterns, and where she went never allowed me to pin down the cause of her flares. More importantly, this frantic chasing of an elusive trigger produced more anxiety than it was ever worth.

I've learned that food will not cure my child's disease. On the other hand, regaining some degree of control when the carpet has been ripped out from under us is often an instinctive and necessary reaction. In dismissing this attempt to recover, doctors threaten the essential foundation of trust and crucial partnership with parents in achieving the common objective of the child's health and mobility.

I've learned that nothing lasts forever, even when it seems it might.

I've learned that the mind/body connection and its link to autoimmunity are far too routinely overlooked, underestimated, or outright dismissed by parents and doctors alike. It's informed by an outdated prejudice towards mental health that belies the current global focus.

I've learned that sitting with a child in unrelenting severe pain will undo the strongest among us. It is unbearable, and it renders us less rational and capable than we ordinarily are.

I've learned that everything is easier when everyone gets enough sleep.

I've learned that children prove Newton's third law: for every action, there is an equal and opposite reaction. For the longest time, I pushed my daughter towards a picture of health, she pushed back, and we stood perfectly still.

It was only after I stepped aside and watched in awe as she righted herself and effortlessly took up the reigns of managing her health that I appreciated the true meaning of parenting. I know that it appears to some as though I've lowered my expectations or given up hope. I haven't. I've just learned that my daughter has everything she needs to succeed: I can try to do it for her, or I can support her as she does it herself.

I've learned that the previous lesson is not helpful when the child is three years old. Nothing on earth will convince a toddler to participate in physiotherapy if the toddler doesn't want to. Sometimes you must pause and find a new approach because no matter the pressure from specialists and therapists, your child is a person, not a project.

I've learned not to overthink calling Ella's doctor. I need her less and less as time progresses, but she's still my go-to if something unexpected happens.

I've learned that, in South Africa, at least, access to comprehensive private medical aid can make the difference between a child who can walk and a child that lingers in terrible pain. The injustice of it breaks my heart and fuels my dedication to our nonprofit, Arthritis Kids South Africa.

Lastly, I've learned that I needed to deal with my reaction to Ella's diagnosis before I could move past the panic and fear to a place where it didn't overwhelm me. I know that being asked to get there more quickly left me feeling isolated and afraid. I hope this acquired resilience will stand me in good stead if her disease ever rears its awful head.

NEW!

An Ambitious Global Task Force new Campaign to drive awareness and promote education in Paediatric Rheumatology: RUN and SPRINT

Members of the Global Task Force are feverishly working on a new project to push awareness and education in paediatric rheumatology to a new level. Working closely with PReS and other partners, notably the production company BLiNK, we are excited to announce plans for parallel campaigns to improve awareness by telling the stories of children and families living with rheumatic disease through the RUN (Rheumatology Unmet Needs) campaign as well as a rolling Continuing Medical Education called SPRINT (Supporting Paediatric Rheumatology INternationally Together). Plans for these projects are at an advanced stage and more detail will follow soon and we will be seeking input from our Task Force members around the world. In the meantime, if you want to join the team, please let us (*Helen and Chris*) know!

Meetings and conferences – please let us know of future meetings in your region / country

Abstract deadline May 13th !
https://www.pres.eu/pres2021/abstracts.html

https://paflar.org

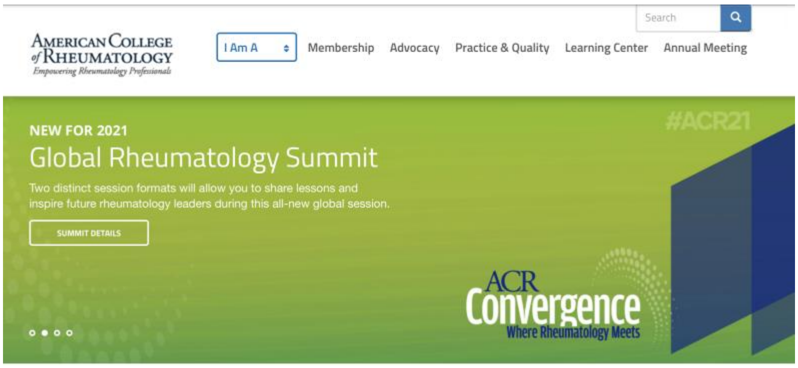
Mexican College of Rheumatology Annual Meeting May 14th to 18th, 2021.
https://www.reumatologia.org.mx/

World Orthopedic Congress – clubfoot congress
https://sicot.eventsair.com/budapest-2021/clubfoot-congress

28-31 August 2021
Kyoto International Convention Centre

23rd Asia-Pacific League of Associations for Rheumatology Congress

https://aplar2021.com/abstracts/ deadline June 1st



NEW FOR 2021

Global Rheumatology Summit

Two distinct session formats will allow you to share lessons and inspire future rheumatology leaders during this all-new global session.

https://www.rheumatology.org/Annual-Meeting/Abstracts deadline June 1st

WELCOME TO EULAR 2021

https://www.congress.eular.org/scientific_programme.cfm