Welcome to our May Newsletter! The COVID-19 Pandemic has no doubt dominated all our lives, and members of the Taskforce have been driving the Musculoskeletal Health agenda on various fronts, some COVID specific and others less so. Read on to find out more...

**Generation PEP**

Below, our co-chair Carl J Tiderius tells us about Generation Pep from Sweden and their work to promote healthy joints and bones, also one of the major aims for the Paediatric Task Force. Generation Pep is a non-profit organization initiated by the Swedish Crown Princess Couple, with the vision that all children and young people in Sweden should have the ability and desire to live an active and healthy life. Therefore, Generation Pep works to spread knowledge and engage both people and organizations in a joint effort to make it easier for children and young people to live a healthy life. To have a chance to succeed with this long-term vision, Generation Pep wants to involve the whole community in the work - from local enthusiasts to politicians and policymakers. Research in collaboration with the Karolinska Institute in Stockholm in 2018, a questionnaire was sent out to a systematic probability sample of children in Sweden, who were invited to fill in a questionnaire about eating and exercise habits online. All Swedish and foreign citizens aged 4 through 17 years were eligible for the study. The total sample included 29,000 children and the response rate was 40%. Among responders, young children were slightly overrepresented, and teens aged 16-17 are slightly underrepresented compared to the population as a whole. The main findings and modes of action are shown below.

In summary, I think Generation Pep could serve as a role model and inspiration. Their work covers many of the aims of the Task Force, including raising awareness, education and public involvement and engagement. They also work “hands on” to promote a healthy lifestyle, as exemplified above. Furthermore the collaboration with The Karolinska Institute enables scientific data to support both recommendations and actions.
In summary, the results showed that:

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<td>Only 3 out of 10 children get the recommended 60 minutes of physical activity per day.</td>
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<td>Girls are less physically active than boys, and teenagers are less active than younger children.</td>
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<td>Only four children in ten state that they eat vegetables every day, and two out of three say they usually or nearly always eat soft, white bread.</td>
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<td>There are large socioeconomic differences regarding both exercise and eating habits.</td>
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<td>6 of 10 teenagers spend three or more hours a day in front of a computer screen, classroom time excluded.</td>
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<td>Adult role models are important for both physical activity and eating habits. Children whose parents are physically active get more exercise, and children who eat dinner with grown-ups consume more vegetables and fish.</td>
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Modes of action for Generation PEP

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<td>The PEP-Forum: an annual convention with focus on inspiration, information and networking.</td>
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<td>“Up and Jump”- an annual manifestation for physical activity and healthy life-style with celebrities participating and exposure in different social media.</td>
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<td>Collaboration with a major Swedish food chain in order to promote the sales of fruit and vegetables.</td>
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<td>Production and national distribution of a children’s book with facts about our body and what happens to us when we exercise.</td>
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<td>Collaboration with a major clothing company providing an affordable sports collection under the “Generation Pep” label.</td>
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<td>Building of a PEP-park in Stockholm with focus on play, sports and information for all ages; children, parents and grand-parents.</td>
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<td>More parks are under planning.</td>
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PRoS EMERGE

PRoS EMERGE is a group of over 140 young paediatric rheumatologists and researchers from over 35 different countries across the world. PRoS EMERGE is supported by the PRoS council to deliver a number of initiatives and opportunities for its members. We hold an annual young investigator’s meeting (YIM) prior to the PRoS Congress giving young investigators an opportunity to present their work in an international setting and network with peers and senior colleagues. Other initiatives include our fellowship program where trainees can visit a Paediatric Rheumatology Centre in Europe for up to 6 months to complete a project.
A decade of development paediatric rheumatology in Thailand

Twelve years ago, after completing my fellowship training in USA, I returned to the Faculty of Medicine Ramathibodi Hospital, Mahidol University as a lecturer in pediatric rheumatology. In Thailand, a lecturer has to do everything as much as they can, including teaching, doing research, and taking care of patients. I also do an administrative work such as Assistant Dean for my faculty. The first three years that I was an attending, I had to be on call 365 days/year and looked after rheumatic patients from all over the country. I know that it was too much work and made me tired, but my energy returned after seeing my patients improved!! Ever since then, I thought that I had to do something to increase pediatric rheumatologists in Thailand. I began to consider training pediatric rheumatologist for all large regional centers over the next 10 years.

So I started with a one-year fellowship training program under Faculty of Medicine Ramathibodi Hospital. Finally, three fellows completed this training program and they also continued to further their training abroad. At present, all of them are lecturers in medical schools.

In the meantime, the other three colleagues had returned to Thailand after they completed their fellowship training in Canada. So, we developed the program training by changing to the 2-year fellowship training under The Royal College Pediatricians of Thailand. Dr. Sirirat Charuwanij from Siriraj Hospital and I began the latest form of training 6 years ago and it is expected to be accredited by World Federation of Medical Education (WFME) next year.
At present, we have 17 pediatric rheumatologists, 10 trained in Thailand, four of whom are overseas for further training. 15 work in medical school, 2 in private hospital. They are based in Central (Bangkok), Northern, Northeastern, and Southern parts of Thailand. Although we have pediatric rheumatologists in big large centers in each region as planned but we still need more.

By Soamarat Vilaiyuk, MD
Associate Professor of Pediatrics
Program Director of Residency Training
Assistant Dean for Graduate Education
Chief of Rheumatology Division, Pediatric Department
Faculty of Medicine Ramathibodi Hospital
Mahidol University

The coronavirus disease 2019 (COVID19) Global Rheumatology Alliance (GRA) was formed in March 2020, as a grass roots effort by a small group of rheumatologists. Patients with inflammatory rheumatic disease require special consideration with regard to COVID19. In general, these patients are thought to be at a higher risk of serious infections, due to both underlying immune dysregulation and the use of immune-modulating therapies. Drugs commonly used to treat rheumatic diseases, such as hydroxychloroquine, are being investigated as potential therapies for COVID-19. It is not
known whether the underlying disease or the use of immunosuppressive medications influences the risk of severe SARS-CoV-2 in individuals with rheumatic disease. Data about COVID-19 in this population is urgently needed to inform management and identify high-risk individuals during the pandemic.

This need for data was quickly recognized on a global scale by rheumatologists, researchers, and patients with rheumatic diseases. The international rheumatology community acted quickly to create GRA. Within a week, the GRA successfully developed tools to enable health-care providers around the world to enter information on individuals with rheumatic disease who have been diagnosed with COVID-19. As of April 27, 838 patients from 6 continents were captured in the registry.

While children overall seem to be less affected, the risk for children in inflammatory and rheumatic disease is not well defined. This registry provides input for adult and pediatric patients by providers. Additionally, it provides patient organizations with resources to support patient powered registries. This international collaboration has been an exemplar of a global network working collaboratively to identify the risk of a novel threat and to rapidly inform patient care.

For more information:
https://www.youtube.com/watch?time_continue=22&v=oOizZroW7ak&feature=emb_logo
Website: https://rheum-covid.org/

By: Laura Lewandowski and Kate Webb

Wikipedia Juvenile Idiopathic Arthritis Page Update

On WORD day 2020, a multidisciplinary team of health professionals from Australia and New Zealand launched an updated version of the Wikipedia page on Juvenile Idiopathic Arthritis, rewritten for accuracy and currency. The previous version was wildly out of date, with only three subtypes of JIA listed, only one biologic mentioned and prognosis data based on references from 1999. And yet… In the year before our update, the JIA Wikipedia page received 111,385 views. We recognise that there are already many excellent and high quality resources on JIA already available, but also accept that Wikipedia remains the leading single source of healthcare information for patients and healthcare professionals: 50% of doctors use Wikipedia to source medical information (especially for specific or rare conditions like JIA). Of note, Wikipedia is
disproportionately used by younger patients to research healthcare information, so a likely source of information for patients with JIA. (Please read here for more information on this, and here for an article on how the medical community around the world are harnessing Wikipedia to improve access to good quality health information – including Wiki Project Medicine.) You can view the fruits of our labour – the updated Wikipedia entry - right here.

Many thanks to the contributing team, who undertook this project of their own time and on a voluntary basis: Dr Damien McKay, Ishani Perera (Physiotherapist), Dr Bill Renton, Leanne Czerniecki (Specialist nurse in Paediatric Rheumatology), Dr Priscilla Campbell-Stokes, Ali Morrison (Physiotherapist) and Dr Rebecca James for their contributions and assistance. We genuinely believe this will improve the quality of information on JIA that is accessed by patients, parents, GPs, paediatricians, teachers, sports coaches, etc – and hope that you agree. At current projections, more than a million people will read our updated page over the coming decade.

Anyone interested in taking part in a similar project for Juvenile Dermatomyositis is welcome to contact Dr Rebecca James on rebecca.james2@health.qld.gov.au

Children's story book released to help children and young people cope with COVID-19

A new story book that aims to help children understand and come to terms with COVID-19 has been produced by a collaboration of more than 50 organizations working in the humanitarian sector, including the World Health Organization, the United Nations Children’s Fund, the United Nations High Commissioner for Refugees, the International Federation of Red Cross and Red Crescent Societies and Save the Children.

With the help of a fantasy creature, Ario, “My Hero is You, How kids can fight COVID-19!” explains how children can protect themselves, their families and friends from coronavirus and how to manage difficult emotions when confronted with a new and rapidly changing reality.

The book – aimed primarily at children aged 6-11 years old – is a project of the Inter-Agency Standing Committee Reference Group on Mental Health and Psychosocial Support in Emergency Settings, a unique collaboration of United Nations agencies, national and international nongovernmental organizations and international agencies providing mental health and psychosocial support in emergency settings.

During the early stages of the project, more than 1700 children, parents, caregivers and teachers from around the world shared how they were coping with the COVID-19 pandemic. The input was invaluable to script writer and illustrator Helen Patuck and the project team in making sure that the story and its messages resonated with children from different backgrounds and continents.

In order to reach as many children as possible, the book will be widely translated, with six language versions released today and more than 30 others in the pipeline. It is being released as both an online product and audio book.

Download the book here   My Hero is You: all language versions
PRES recommendations for coronavirus outbreak

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

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

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

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

Wash your hands very regularly for at least 20 seconds using soap and water. Dry hands thoroughly afterwards.

Try to avoid touching your face.

Coughing or sneezing should be into an elbow or tissue paper and the latter should be discarded safely.

Use disposable tissues.

Wear a mask when you are ill; if there are no symptoms it is not necessary to wear a mask. The mask cannot completely prevent virus transmission, but it is a good reminder of not touching your face and serves to warn others that you may not be well.

Practice sensible social distancing especially from people who appear to be ill, e.g. coughing or sneezing. One meter is recommended.

We should greet each other without shaking hands, and avoid hugs.

3. At the moment for children with rheumatic diseases on medication, we recommend to continue all therapies as usual.

4. Don’t stop your medications including methotrexate (MTX) and biologics, without consulting your rheumatologist. This may cause a flare of your rheumatic disease.

5. If you are on corticosteroid therapy - consult your rheumatologist regarding possible dose adjustment.

6. Patients in isolation or quarantine (without symptoms) should continue therapy as usual.


8. In the event that you have a routine rheumatology appointment consider to ask your primary care physician, or rheumatologist if this is essential, or can be safely delayed, or if it can be performed by telephone or some other remote device. This facility may vary in availability across different health care settings.
9. For all individuals, including patients with pediatric rheumatic diseases. - avoid unnecessary traveling and crowding.

10. Wishing you good health and back to regular track soon.

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

Download recommendations as PDF

**Task Force Survey to prioritise list of drugs to be submitted to WHO EML**

Members of the task force have recently participated in a survey to assess the relative importance of medication used for the treatment of rheumatic diseases to be considered for inclusion in the WHO EML. In order to assess clinicians perspectives on the most important medications to be motivated for the survey asked not only which drugs should be included, but also to rank them in order of priority. Over 90 responses from all over the world have been received and are being analysed. A globally representative team is being assembled and will undertake the application process for the drugs which have been prioritised by our community. A separate process of consultation is underway for paediatric orthopaedics.

Please see a description of the issues in this commentary here. Thanks to Nicola Smith for support with the survey

**THE ROAD TOWARDS ESTABLISHMENT OF THE PAEDIATRIC SOCIETY OF THE AFRICAN LEAGUE AGAINST RHEUMATISM**

The inaugural meeting of the African League Against Rheumatism (AFLAR) was held in 1989. Subsequent AFLAR conferences and meetings have been held in Egypt (1991); Tunis, Tunisia (1995); Cape Town, South Africa (1999); Rabat, Morocco (2003); Nairobi, Kenya (2007); Algiers, Algeria (2011); Cape Town, South Africa (2013); and Mauritius in 2019 [1]. The foundation work by the members of AFLAR has made it possible to promote the growth of Rheumatology in Africa and launch efforts towards establishment of the Paediatric Society of AFLAR.

Africa is known to have diversity in culture [2]. This diversity percolates through all facets including the clinical symptomatology of patients, clinico-epidemiological profiles and response to therapy for many diseases [2]. Paediatric rheumatology is no exception to this. This offers a unique opportunity for clinicians in the continent who treat children with Rheumatic and Musculoskeletal Diseases (RMDs) to pull their resources and skills together to come up with strategies to improve the outcomes of our patients [3].

In light of the above, under the leadership of AFLAR, a taskforce was appointed to establish the Paediatric society of AFLAR at the AFLAR Scientific Congress held in Mauritius September 2019. Members of this taskforce include Professor Chris Scott of South Africa, Dr Faleyé Ayodele of Nigeria, Dr Yassmin Taha of Sudan, Prof Madeleine Ngandeu of Cameroon, Professor Wafa Hamdi of Tunisia, Professor Hadef Djohra of Algeria, Dr Oscar Mwizerwa (Secretary) of Rwanda and Professor Angela Migowa of Kenya (Chair). Its core mandate is to establish the structural frameworks for operations of
AFLAR’S Paediatric Society and formulate a strategic plan to 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. This can be achieved through effective strategies and programs that impact on the well-being of African children with rheumatic and musculoskeletal diseases through advocacy and enactment of policies adapted to the specificity of the African continent.

Through the support of AFLAR, a survey was carried out among rheumatologists in Africa to help determine the key priority areas in paediatric rheumatology which were delineated as 1) raising awareness of paediatric rheumatology among medical students, residents trainees and healthcare workers, 2) establishment of an African Pediatric Rheumatology Registry, 3) prioritisation of paediatric rheumatic diseases among policy makers and stakeholders, 4) strengthen collaboration with international paediatric rheumatology organisations, 5) establish clinical and community based care, 6) establishment of management guidelines for paediatric RMDs, 7) establishment of specialist training centres for paediatric rheumatologists, 8) promote research in RMDs and 9) mentorship of paediatric rheumatology research fellows in Africa. In order to tackle the above priority areas, plans are underway to begin online discussions to regularly discuss paediatric rheumatology cases across Africa. This e-learning project aims at empowering clinicians to care for children with RMDs on the continent. Participation in some of the global advocacy campaigns such as WORD day celebrations has increased in the continent. In Nairobi Kenya for example, we held a successful WORD Day workshop in March 2020 to raise awareness for paediatric rheumatology among healthcare workers. We had over 50 participants at the Kenya WORD day celebrations with speakers drawn from occupational therapy, physiotherapy, nutritionists, psychology, rheumatology nurses, paediatric rheumatologists and adult rheumatologists. Members of the paediatric arm of AFLAR core working task force group have participated in regional meetings held to raise awareness for RMDs such as the University of Cape Town refresher course held in February 2020. Other regional meetings across Africa are scheduled for later in the year. The official launch of AFLAR’s paediatric society strategic plan is scheduled for 2021 during the AFLAR scientific conference to be held in Kenya, July 2021. We hope that this will lay the framework for the growth of paediatric rheumatology in Africa.

African paediatric rheumatologists, adult rheumatologists, paediatricians, general practitioners, community health workers supported by, allied healthcare workers, international experts, policymakers and patient groups form a formidable team to help transform the growth of paediatric rheumatology in Africa and catapult it to the next level. **The time to act is now.** Let us join hands and commit to ensure that our children with RMD’s across Africa and the world not only survive but thrive to achieve their full potential in the society.

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**Angela Migowa,**

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Secretary Paediatric AFLAR Core Working Task Force Group
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.

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

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

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

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


Pediatric Rheumatology European Association ([https://www.pres.eu](https://www.pres.eu))

Paediatric Musculoskeletal Matters ([http://www.pmmonline.org](http://www.pmmonline.org))

Follow us:

Twitter [https://twitter.com/paedmskglobal](https://twitter.com/paedmskglobal)

Facebook [https://www.facebook.com/groups/2255183164805036/?ref=share](https://www.facebook.com/groups/2255183164805036/?ref=share)

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Update on Resources:
Telehealth – has taken on new and greater relevance in the wake of the COVID-19 pandemic. The Task Force is working collaboratively to develop resources and Top Tips to aid the setting up of Telehealth clinics for paediatric rheumatology. will be available very soon, including a modified version of pGALS (to be called v-pGALS !) and all resources will be freely available on the PMM website – http://www.pmmonline.org We will let you know more in the next Newsletter !

pGALS app: the Task Force has been working to develop more translations of pGALS and these are freely available on the pGALS app – currently > 10 languages and more in the pipeline ! if you wish to add your language to the list and help to translate your language please do get in touch: h.e.foster@newcastle.edu.my

Future meetings with paediatric
MSK focus – Task Force awareness sessions will be included in those marked with* Due to COVID 19 and international travel regulations most if not all conferences are postponed, cancelled or moved online. We have indicated status , if known, by time of publication.

PANLAR: Postponed to 12-15 August 2020 Miami Florida USA https://congreso-panlar.com

Paediatric Orthopaedic Society of North America
Now A virtual Meeting: Available from 13 May,2020 to 31 December 2020
https://posna.org/Annual-Meeting/2020-Annual-Meeting

EULAR
Now a virtual meeting
From 03 Jun 2020
https://congress.eular.org

*APLAR
Postponed to 14-17 November
Kyoto Japan
https://aplar2020.com

*PReS
Will become virtual meeting. Details pending
https://www.pres.eu/pres2020/
Please contact us for more information or contributions. We hope you are stay safe and well and we look forward to sharing more with you in our next newsletter.

Kind regards

Chris and Helen