Welcome to our January 2020 Newsletter and to our expanding global community

Here is the first Newsletter for the new decade !

As we look back at the last 12 months we can be proud of all that we have achieved – an increasing network and community of energised motivated people coming together with the common aim of improving the lives of children, young people and their families.

As part of our plans to further engage and reach out, we wish to promote 'stories' and experiences from around the world to encourage 'working better together'.

We are keen to hear more about exemplars of models of care and initiatives to raise awareness, promote education and training and ways to engage the wider community.

We will be inviting short articles from our regional representatives and if you wish to submit a short piece then please contact us through the group email.

Here we start off with reports from some of the professional meetings that were held in 2019 and which included Task Force activities on the agenda. We also hear from the JAR project and WORD Day as initiatives working to raise awareness.

WORD-Day 2020 in planning

The Paediatric Task Force actively supports WORD Day (WOrld young Rheumatic Diseases Day) to raise awareness of rheumatic diseases in children and young people.

The first WORD Day in 2019 was a great success.

Plans for 2020 are well underway !

Check out www.WORD-Day.com and follow on Twitter and Facebook

Juvenile Arthritis Research
www.jarproject.org

Juvenile Arthritis Research (the JAR Project) is a charitable project, founded in the UK by Richard Beesley two years ago. Having witnessed 'first hand' the impact JIA has on the lives of those living with the condition and their families, Richard created the JAR Project to use his background as a biomedical researcher to work towards finding a cure for JIA. The JAR Project has already expanded into three areas:

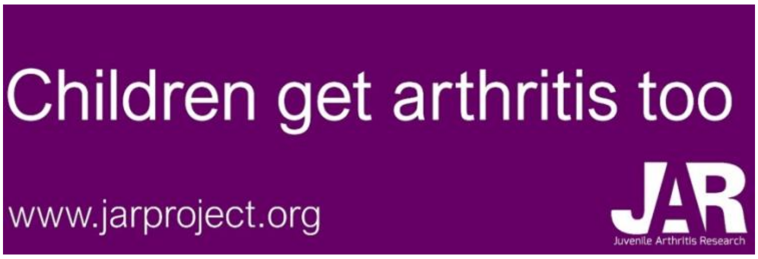
1. **Raising awareness that children and young people get arthritis**. As well as local campaigns and activities, they have been working on the #ThinkJIA campaign which is aimed at parents and healthcare professionals. The hope is that greater awareness will lead to earlier diagnosis and better clinical outcomes. The draft materials, which can be seen at www.thinkjia.org, are currently being reviewed by the BSR
2. **Family support work**, particularly for children and families at the point of diagnosis. The JAR Project have developed A Little Box Of Hope (www.jarproject.org/alittleboxofhope) with information for parents when their child is first diagnosed with JIA. They

are hoping to roll this out across the UK through this coming year. The – Little Box of Hope information packs contain a copy of *Kipo*, a story about a monkey with JIA written by Tsipi Egert and Dror Adam along with other useful information. The JAR Project have started producing smaller support packs for children who have been diagnosed for a while (so don't need the same information) but who would still benefit from receiving the *Kipo* book, along with a certificate and stickers We've been calling these smaller packs "Kipo's Hero" in recognition of the bravery of children with JIA.

3. **Finding a cure for juvenile idiopathic arthritis**. They work by 'joining the dots' between different research disciplines and fields, as well as undertaking their own research projects.

If you would like to know more about their work, please visit www.jarproject.org, or follow Juvenile Arthritis Research on social media; @jarproject on facebook ; @jarproject on Twitter ; _jarproject on Instagram

JAR have also produced car window stickers, to help raise awareness that children get arthritis. These are sold in their online shop for no profit to UK addresses and Richard is happy for anyone else to use the template to have their own window stickers produced if they would like to. JAR Car Sticker Template:



AFLAR CONFERENCE – September 2019

Report from Professor Angela Migowe (Kenya) & Professor Chris Scott (South Africa)

The 2019 African League of Associations for Rheumatology (AFLAR) Congress was held from September 6-8th on the picturesque and enchanting island of Mauritius. This year's conference included significant contributions from Paediatric Rheumatology both in the main programme and in the paediatric parallel sessions. AFLAR was honoured to welcome Paediatric Rheumatologists Prof Helen Foster (United Kingdom and Malaysia) and Prof Ross Petty (Canada) to lead the paediatric rheumatology programme. They were joined by Prof Angela Migowa (Kenya), Dr Kate Webb (RSA), and Prof Chris Scott (RSA) who presented on a wide range of topics relevant to adult and paediatric rheumatologists and general paediatricians.

This included up to date lectures on the diagnosis and management of paediatric rheumatic diseases as well as clinical pitfalls in the diagnosis of arthritis in children. An interactive session on Global Health in Paediatric Rheumatology highlighted the role of the Global Task Force for Paediatric MSK Health and the renewed commitment of the global community to deliver appropriate care for children living with rheumatic diseases demonstrating that with focus and action, much can be achieved in a short time. A separate Adolescent Rheumatology Workshop, with interactive patient cases and an expert panel was very well received and demonstrated potential solutions to the complexities of adolescent care. We also heard about the challenges of training in Africa and the need for relevant and affordable training programmes. One of the biggest outcomes of the meeting was of course the networking and collaboration between friends and colleagues. One direct result was the creation of an AFLAR paediatric subcommittee, with a mandate from the new President of AFLAR, Prof A Kalla to further develop the capacity for AFLAR to deliver on its goal of improving the care of all those in Africa living with rheumatic diseases. Prof Angela Migowa leads this subcommittee.

The conference was concluded with a call to action on the following action items
1.Increase visibility of Paediatric Rheumatology through various initiatives such as WORD Day
2.Consolidate efforts of Paediatric Rheumatology in the African Continent
3.Strengthen local, regional and international partnerships to promote the growth of Paediatric Rheumatology in Africa and beyond
4.Promote career advancement in Paediatric Rheumatology

Australian Paediatric Rheumatology Group (APRG) October 2019

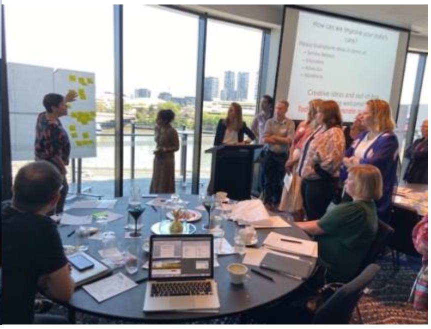
Report from Dr Rebecca James (Australia)

From October 25-27th 2019, the Australian Paediatric Rheumatology Group (APRG) met in Brisbane for our annual Spring Meeting, hosted by the Queensland Children's Hospital and with a decidedly tropical feel throughout. We were delighted to welcome our nursing and physiotherapy colleagues, who also took part in two satellite meetings: the inaugural Australian / New Zealand Paediatric Rheumatology Nurses' Summit, and the inaugural Australian / New Zealand Paediatric Rheumatology Physiotherapists' Summit. This year's meeting theme was 'Branching Out: Brisbane, the Bush and Beyond', with our focus being the provision of high quality care outside the tertiary hospital setting, including for Indigenous, rural and regional populations. We also sought an international perspective, focussing particularly on Paediatric Rheumatology care within the Asia/Pacific region. Our guest speakers - Prof Chris Scott and Prof Helen Foster – were inspiring and enlightening in equal measure, providing a brilliant overview of the current 'state of play' of Paediatric Rheumatology around the world, as well as particular strengths and challenges within the Asia Pacific region. An additional meeting highlight was an update on JIA and jSLE in Maori / Pacific Islander populations from our New Zealand colleagues, presented by Dr Genevieve Ostring and Dr Anthony Concannon from Starship, Auckland. The meeting concluded with the identification of three key goals for Paediatric Rheumatology centres across Australia/NZ:

1. For every site in Australia / New Zealand with a paediatric rheumatology service to organise an awareness event for WORD day 2020.
2. For every paediatric rheumatology service across Australia / NZ to begin to collect cJADAS-3 in some form by next Spring meeting (Oct 2020).
3. To identify a network of local 'champions' in each state / territory / region who have an interest in caring for patients with rheumatic disease, and who are keen to collaborate with their local PR service in terms of education, patient advocacy, etc - by Oct 2020

Additional projects taken on by smaller APRG subgroups include an update to the Wikipedia JIA page, as well as reviewing the WHO list of essential medicines for paediatric rheumatic disease.

We thank Professors Scott and Foster for their leadership and inspiration throughout the meeting, and look forward to collaborating further with the Task Force over coming months and years.

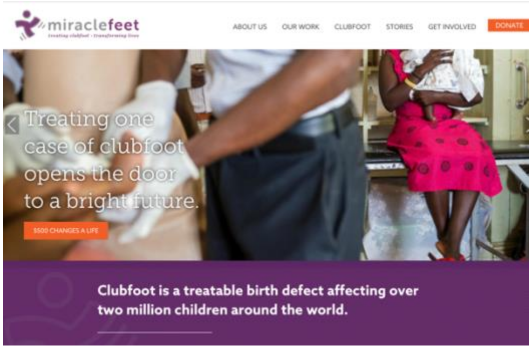


American College Rheumatology 2019 Atlanta, USA

Report from Dr. Laura Lewandowski (USA)

Professor Chris Scott, Co-Chair Paediatric Global MSK Task Force, and Dr. Laura Lewandowski were able to present at the ACR session: Global rheumatology research: Opportunities and Challenges - in Atlanta – on their research collaboration focusing on paediatric SLE in South Africa. The session was opened by comments from Dr. Bob Carter, Acting NIAMS director, and Dr. Peter Kilmarx, Deputy Director of Fogarty International Center at the National Institutes of Health. The session was attended by adult and pediatric rheumatologists, industry representatives, and advocacy groups from around the world. The audience was very receptive to the presentation, with one advocacy group member thanking us for speaking, because they are trying to raise awareness about rheumatic disease worldwide amongst policy makers, and they realized that they had not included pediatric patients, which are a very important part of the story. We were happy to have the chance to raise awareness of pediatric rheumatic diseases at ACR, and look forward to continuing this work at future meetings.

The Paediatric Task Force continues to be engaged in a variety of activities

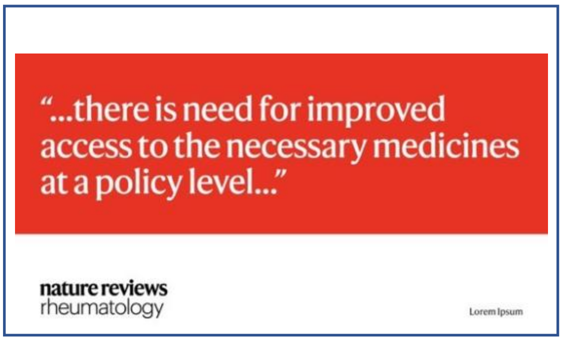


Treating one case of clubfoot opens the door to a bright future.

Clubfoot is a treatable birth defect affecting over two million children around the world.

MiracleFeet https://www.miraclefeet.org

MiracleFeet is a highly successful programme to identify and manage children with clubfeet through training and supporting the workforce in local communities. We are working with the leaders of MiracleFeet to include the elements of recognition and management of rheumatic diseases in children as part of the MiracleFeet training programmes. Watch this space !



"...there is need for improved access to the necessary medicines at a policy level..."

nature reviews rheumatology

Lorem Ipsum

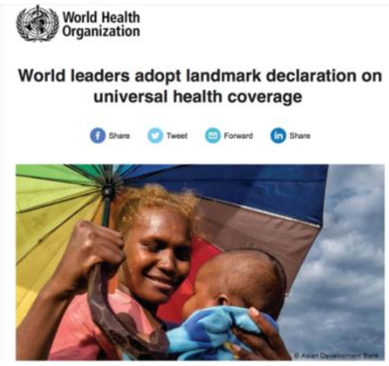
The WHO Essential Medicine List

The World Health Organization Essential Medicines List (EML) informs policy makers about which medications should be prioritised and is particularly important for countries with limited resources.

However, the EML lacks clarity about the vital medicines used in paediatric rheumatology; the inclusion of a few vital medicines could transform the lives of many children around the world.

A recent Commentary in Nature Reviews Rheumatology highlights the needs to revise the EML and provide clarity on the drugs used in paediatric rheumatology. The Task Force is working with colleagues to develop the case of need to revise the EML.

Journal: Nature Reviews Rheumatology. Update the WHO EML to improve global paediatric rheumatology
DOI: 10.1038/s41584-020-0368-6



World leaders adopt landmark declaration on universal health coverage

WHO Universal Healthcare Coverage

Addressing the increasing impact of Non-Communicable Diseases around the world is integral to the work of the World Health Organisation (WHO) and the United Nations (UN) aim for Universal Healthcare Coverage that was recently launched. The Paediatric Task Force aims to raise the profile of paediatric musculoskeletal conditions with the WHO and UN.

https://www.who.int/news-room/detail/23-09-2019-who-welcomes-landmark-un-declaration-on-universal-health-coverage

Surveys of paediatric rheumatology care around the world

- The survey from **ASIA Pacific (ASIAPAC) countries** is now closed.
- Thank you for your input – we have nearly 300 responses! The work is now being written up for publication as a collaboration with colleagues in Thailand.
- A similar survey is currently live in **Middle East and North Africa** countries.
- These surveys include questions about current models of care, education and training for the workforce and access to treatments. The data will have transferable value to our work on a broader scale and inform the call for action.

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

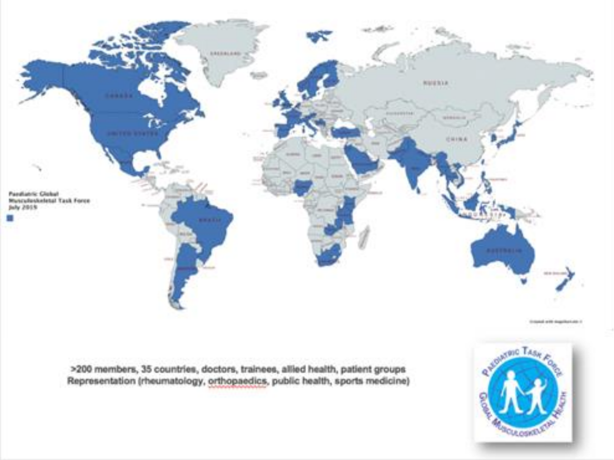
- About the *many* children and young people around the world with MSK problems
- About the considerable long-term impact of *untreated* MSK conditions starting in early life: *impact* on young people, their families, carers and society
- That many conditions are *treatable;* long term disability can 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

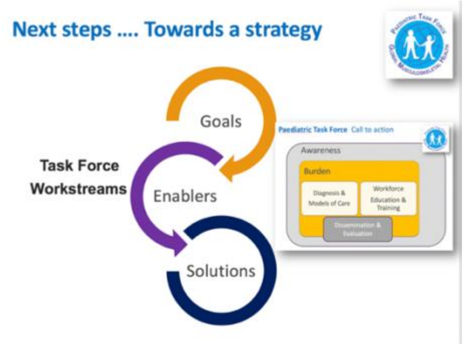


Our Structure and Membership

- 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.

Paediatric Global MSK Task Force (http://bjdonline.org/musculoskeletal-problems-in-children-and-young-people/
Pediatric Rheumatology European Association (https://www.pres.eu)
Paediatric Musculoskeletal Matters (http://www.pmmonline.org)

Follow us:
Twitter https://twitter.com/paedmskglobal
Facebook https://www.facebook.com/groups/2255183164805036/?ref=share



Building on Task Force meetings at existing rheumatology events (APLAR April 2019, EULAR June 2019, AFLAR September 2019) our discussions generated ideas and areas for priority to taken forward in our ‘ call for action’. We aim to share these with our paediatric orthopaedic colleagues and build on them further to develop our strategy to be written up for publication and dissemination.

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

*Arab League for Rheumatology (ARLAR), Amman, Jordan
March 18-21, 2020
https://www.arabrheumatology.org

*PRes KL South East Asia Paediatric Rheumatology course, Kuala Lumpur, Malaysia
March 27-29th 2020
http://www.pres-kl.com

European Paediatric Orthopaedic Society Meeting:
April 1-4 2020 Porto, Portugal
https://posna.org/Physician-Education/Event-Calendar?event=116

PANLAR:
May 2- 5 May 2020 Miami Florida USA
https://congreso-panlar.com

Paediatric Orthopaedic Society of North America
May 13 -16 San Diego, USA
https://posna.org/Annual-Meeting/2020-Annual-Meeting

EULAR
03 Jun-06 Jun 2020 Frankfurt

*APLAR
31 Aug -03 2020 September Kyoto Japan
https://aplar2020.com

South African Paediatric Association
4-6 September 2020, Pretoria
https://www.paediatrician.co.za

*PReS
23-27 September 2020, Prague
https://www.pres.eu/pres2020/

*SICOT (International Society of Orthopaedic Surgery and Traumatology)
Sept 30 -Oct 3 2020, Budapest
http://www.sicot.org

American Academy of Paediatrics
2-6 October 2020 San Diego, USA
https://aapexperience.org

National Conference Paediatric Rheumatology
New Delhi, Oct 4 -6 2020

Asean Paediatric Federation Congress
14th -17th October 2020, Hanoi, Vietnam
http://www.apfc2020.com.vn

European Academy of Paediatric Societies
16-20 October 2020, Barcelona
https://eaps2020.kenes.com

*ACR
6-11 November 2020 Washington DC, USA
https://www.rheumatology.org/Annual-Meeting

International Paediatric Association Conference
August 22-26 **2021**
Glasgow
https://www.ipa2021congress.com