In September 2020 the work of the APPG led to a debate in Parliament on delayed diagnosis in axial SpA.

Discussions on the future of hydrotherapy services has resulted in the mobilisation of stakeholders across condition areas.

Conclusion: All All Party Parliamentary Group is already proving to be an effective political lever to improve axial SpA care. It has shown huge variations in the standard of care and provision of services still remain and has brought this to the attention of Parliamentarians, policy makers and clinicians.

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OP0277-PARE

METABERN, THE EUROPEAN REFERENCE NETWORK FOR RARE HEREDITARY DISEASES: STRUCTURE, OBJECTIVES, METABOLIC RMDs AND THE ROLES OF EUROPEAN PATIENT ADVOCACY GROUPS (EPAGs)

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Background: Inborn metabolic disorders (IMDs) currently encompass more than 1,500 diseases with new ones still to be identified¹. Each of them is characterised by a genetic defect affecting a metabolic pathway. Only few of them have curative treatments, that target the respective metabolic pathway. Commonly, treatment examples include diet, substrate reduction therapies, enzyme replacement therapies, gene therapy and biologicals, enabling IMD-patient now to survive to adulthood. About 30 % of all IMDs involve the musculoskeletal system and are here referred to as rare metabolic RMDs. Generally, IMDs are very heterogenous with respect to symptoms and severity, often being systemic and affecting more children than adults. Thus, challenges include certified advanced training of adult metabolic experts, standardised transition plans, social support and development of therapies for diseases that do not have any cure yet.

Objectives: Introduction of MetabERN, its structure and objectives, highlighting on the unique features and challenges of metabolic RMDs and describing the involvement of patient representation in MetabERN.

Methods: MetabERN is stratified in 7 subnetworks (SNW) according to the respective metabolic pathways and 9 work packages (WP), including administration, dissemination, guidelines, virtual counselling framework, research/clinical trials, continuity of care, education and patient involvement. The patient board involves a steering committee and single point of contacts for each sub-network and work package, respectively². Projects include identifying the need of implementing social science to assess the psycho-socio-economic burden of IMDs, webinars on IMDs and their transition as well as surveys on the impact of COVID-19³ on IMD-patients and health care providers (HCPs), social assistance for IMD-patients and analysing the transition landscape within Europe.

Results: The MetabERN structure enables bundling of expertise, capacity building and knowledge transfer for faster diagnosis and better health care. Rare metabolic RMDs are present in all SNWs that require unique treatments according to their metabolic pathways. Implementation of social science to assess the

psycho-socio-economic burden of IMDs is still underused. Involvement of patient representatives is essential for a holistic healthcare not only focusing on clinical care, but also on the quality of life for IMD-patients. Surveys identified unmet needs of patient care, patients having little information on national support systems and structural deficits of healthcare systems to ensure HCP can provide adequate clinical care during transition phases. These results are collected by MetabERN and forwarded to the Directorate-General for Health and Food Safety (DG SANTE) of the European Commission (EC) to be addressed further.

Conclusion: MetabERN offers an infrastructure of virtual healthcare for patients with IMDs. Thus, in collaboration with ERN ReCONNECT, MetabERN can assist in identifying rare metabolic disorders of RMDs to shorten the odyssey of diagnosis and advise on their respective therapies. On the other hand, MetabERN can benefit from EULAR's longstanding experience regarding issues affecting the quality of life, all RMD patients are facing, such as pain, stiffness, fatigue, rehabilitation, maintaining work and disability claims.

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Figure: Examples of inborn metabolic diseases (IMD) with known RMD-symptoms, allocated to the respective subnetworks of MetabERN. However, the list is incomplete.

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OP0278-PARE

PROVIDING SUPPORT TO FAMILIES OF CHILDREN NEWLY-DIAGNOSED WITH CHILDHOOD ARTHRITIS: A PATIENT AND PARENT-LED PILOT STUDY TO DEVELOP AND ASSESS 'A LITTLE BOX OF HOPE' SUPPORT PACKS

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Background: Juvenile Idiopathic Arthritis (JIA) is a heterogenous group of autoimmune disorders characterised by chronic joint inflammation, diagnosed in around 1 in 1,000 children and young people (CYP) under the age of 16. Delays in diagnosis are common [1], awareness is low, and paediatric rheumatological conditions have a considerable impact on young people and their families [2]. A lack of understanding amongst families of newly-diagnosed children leads to uncertainty and anxiety.

Objectives: This patient and parent-led project developed a resource pack for parents of CYP newly-diagnosed with JIA, to provide information and support. Following a pilot, feedback from recipients was collated and analysed to help improve future provision.

Methods: A young person with JIA identified the need for direct family support. Juvenile Arthritis Research (a UK charity) developed a unique pack of support information, containing resources for both children and their families - called *A Little Box Of Hope*. This included information about JIA and support services available for families, as well as Kipo (a children's book about JIA) and accompanying finger puppet. Clinicians at one paediatric rheumatology centre provided information about the packs to newly diagnosed families, who then requested a free box to be posted to them.

Following an initial pilot study, recipients were invited to complete a short online questionnaire and provide feedback to allow refinement of the provision.

Results: Respondents were asked a series of questions, each on a scale of 1-5. Every respondent gave a score of 5 in response to "What do you think of the idea of *A Little Box Of Hope*?"

Every parent of children under ten years old gave a score of 5 for every item when asked "How useful is each item in your *Little Box Of Hope*?"

Respondents also gave free-text comments:

* "It was very well thought out and I felt supported"

* "I know so much more about JIA now than I did before. I cannot thank you enough."

* "It was extremely useful and made me feel supported during a very stressful time and this enabled me to support my son more effectively."

* "It made my daughter feel less alone."

Some parents of older children felt that some information specifically for teens would be useful, and a Teen pack is being developed.

Conclusion: Recipients of *A Little Box Of Hope* have found the information useful and feel supported. Following the pilot study, we have developed *My JIA*, a booklet reviewed by a multi-disciplinary clinical team, with comprehensive information for families affected by JIA. A Teen pack, for children aged around 10 years or older, is being developed to provide targeted support to this group.

The COVID-19 pandemic has adversely affected access to healthcare services, increasing the need for remote parent- and charity-provided support through *A Little Box Of Hope*.

As such, we intend to expedite the roll-out of the project across the country building on the success of the pilot project.

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OP0279-PARE CHRONIC RHEUMATIC DISEASE (CRD) AND SPORT

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Background: In order to study the state of mind of patients with chronic inflammatory rheumatic disease (CRD) regarding physical/sports activity, excluding household activities despite their quantifiable energy value (MET), the CREER group produces this study.

Objectives: Analyze a population in the Ile-de-France region with CRD practicing a physical activity (their motivations, expectations, nature and rhythm). Determine the place of physical activity in the management of an CRD by the rheumatologist (Rh).

Methods: 207 patients, 53 yo average, 56% between 50 and 70 years, 60% are women; 97% of the CRD, Rheumatoid arthritis (RA): 57%) or Ankylosing Spondylitis (AS): 40%, low or moderate activity (66%).

10 years evolution (RA) and 11.5 years (AS), corticosteroids RA/AS as follows (34/5 %), NSAIDs (15/52 %), conventional DMARDs (84/30%) or biotherapies (21/43%).

Co-morbidities are found for RA/AS in 55% vs 44%, includes high blood pressure 20%, overweight 21%, tobacco 13.5%, other 19%.

Results: 7/10 patients are encouraged to engage in physical activity, regardless of gender, age, RA or AS. The most common activity proposed is walking (53%), followed by swimming and/or aquagym (40%) and gym (19%). The practice is regular in 60% more by women, RA=AS, more before 40 yo and after 60 years old (70%). The activity actually practiced is: 1- walking 46.4%, 2- aquatic activities 37%, 3- cycling 29%, 4- home sports 19%.

Once/week minimum is good for cycling and swimming, insufficient for walking, very good for sport at home.

50% have been practicing for 3 years. 60% adapt the rhythm to rheumatism. Their motivations are: to maintain one's health, to de-stress.

A discordance exists between Rh/General physician that advise sport 8 times/10 vs 4.5/10. Nevertheless 50% ignore whether he or she is getting worse or better, hence the need for information.

Rh needs to communicate more about the interest of physical activity and the absence of deleterious effect on CRD which one patient over two ignores.

If 60% of patients modify their activity with CRD, many do not participate in sports because no time, no need, no desire RA=AS.

If the activity is supervised, adapted, prescribed is well-known, its application is confidential due to lack of coaches, and of qualified centers.

Conclusion: If the main activity practiced by patients and advocated by Rh is walking, the patients go beyond this framework by mobilizing for cycling, walking, swimming and gym. But the reluctance persists and we must, through therapeutic education convince of the benefits of the activity on CRD and its co-morbidities, unknown to 50% of patients. To map lesions, judge the ability and desires are necessary to set goals for duration and frequency of activity. Using connected tools improves compliance. Finally, walking which does not require neither schedule nor equipment (otherwise a cane) should become a first-line prescription.

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OP0280-PARE A MINDFULNESS PROGRAM DOSING STUDY TO EVALUATE IMPROVEMENT IN EMOTIONAL DISTRESS AMONG PEOPLE WITH RHEUMATIC DISEASE

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Background: Mindfulness-based interventions for chronic pain and emotional distress have increased in popularity as complementary therapies among people living with rheumatic and musculoskeletal disease (RMD).^{1,2} Despite growing evidence that mindfulness meditation reduces pain and anxiety associated with RMD, more research is needed to specify the optimal duration of mindfulness training necessary to be effective for short- and long-term benefit.

Objectives: To evaluate and compare the effectiveness of full-length versus brief mindfulness training programs for improving anxiety among people living with RMD.

Methods: Adult US participants (pts) within the ArthritisPower registry were invited to participate in the Healthy Mind Healthy You study comparing the effectiveness of two online mindfulness training programs of different lengths accessed via the MoodNetwork platform. The full-length mindfulness based cognitive therapy program lasted 8 weeks, while the brief evidence-based mindfulness program lasted 3 weeks. Pts were randomized to one of the two programs and completed assessments every two weeks during the program and then every four weeks during the 12-week follow-up period. Assessments included World Health Organization-Five Well-Being Index (WHO-5), Five Facet Mindfulness Questionnaire (FFMQ), Perceived Stress Scale (PSS), and two measures of emotional distress, PROMIS Short Forms for Anxiety and Depression. Analyses compared demographic characteristics and assessment scores by program length.

Results: 324 pts completed assessments at baseline and 70 pts completed them at week 8, an attrition rate of 78% in each of the program arms. The majority of pts were female, White, with 67% between the ages of 45-64 years. No statistically significant differences were observed at baseline between participants randomized to each of the two programs, and in their assessment scores at week 8 (Table 1); PROMIS Anxiety and Depression scores improved from baseline to week 8 for pts in both programs (Figure 1). Overall, mean (SD) PROMIS Depression scores improved from 58.4 (7.7) at baseline to 55.4 (7.2) at week 8 (p=0.018), a meaningfully important difference, among the 70 pts reporting scores at both time points.

Table 1. Assessment Scores at Baseline and Week 8, Mean (SD)

	Baseline				Week 8			
	All (n=324)	8-week course (n=163)	3-week course (n=161)	p-value	All (n=70)	8-week course (n=35)	3-week course (n=35)	p-value
WHO-5 ^b	10.6 (4.9)	10.4 (4.8)	10.9 (5.0)	0.378	12.0 (5.1)	12.5 (5.5)	11.6 (4.7)	0.488
FFMQ ^c	42.7 (6.1)	42.7 (6.1)	42.7 (6.1)	0.932	39.2 (5.7)	38.9 (6.1)	39.4 (5.3)	0.741
PSS ^d	18.7 (7.5)	19.2 (6.8)	18.3 (8.2)	0.304	16.6 (7.3)	15.7 (7.8)	17.6 (6.8)	0.291
PROMIS Depression ^e	56.5 (8.3)	57.3 (8.0)	55.7 (8.6)	0.097	55.1 (8.5)	54.8 (9.3)	55.5 (7.8)	0.735
PROMIS Anxiety ^f	58.7 (8.2)	59.0 (8.2)	58.4 (8.1)	0.470	55.4 (7.2)	54.6 (7.4)	56.1 (7.1)	0.404

^a denotes use of Fisher's Exact Test ^b Range 0 (worse) to 25 (better), ^c Range 3 (worse) to 15 (better), ^d Range 0 (better) to 40 (worse), ^e Range 24.7 (better) to 63.5 (worse), ^f Range 25.7 (better) to 62.0 (worse)