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JUVENILE IDIOPATHIC OSTEOPOROSIS: 5-YEAR FOLLOW-UP
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Introduction: Juvenile idiopathic osteoporosis with vertebral fractures and pain is difficult to treat.

Aims: A girl aged 11 years 10 months presented with a 5-month history of increasing back pain. A MRI scan prior to referral demonstrated vertebral collapse. Exercise had been restricted by back pain. Her height was 138 cm (-10th centile) for a predicted mid-parental height of 160 cm (25th centile); her weight had increased recently to 47.3 kg (75–90th centile). Lumbar spine BMD was very low with a Z-score of -4.3. No cause was found for osteoporosis.

Method: She received i.v. pamidronate 1 mg/kg for three doses every 3 months for 3 years then 6-monthly for a 4th year. After the first 6 months she became asymptomatic for bone pain. Spine BMD maintained at 0.855 g/cm2 (Z-score ~1.4), over 1 year post-bisphosphonate therapy. DXA spinal images demonstrate thickening of superior and inferior endplates, reminiscent of a rugger-jersey spine. Resolution of pain resulted in an early return to exercise and normalization of her weight to the 25th centile.

Results: Juvenile osteoporosis is a condition mostly affecting female adolescents. Treatment with bisphosphonates has been proposed but the effect can be difficult to quantify in view of the natural improvement of the condition.

Conclusion: This case underlines the rapid resolution of symptoms and serial improvements of BMD with pamidronate therapy, but with residual endplate thickening.

Disclosure statement: The authors have declared no conflicts of interest.

ABSTRACT 18  BSRAP122

AGREEMENT BETWEEN PHYSICIAN AND PARENTAL ASSESSMENTS OF DISEASE IN CHILDREN WITH JUVENILE IDIOPATHIC ARTHRITIS: AN ANALYSIS FROM THE CAPS
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Introduction: Both physician and parent global assessments form an integral part of the assessment of JIA.

Aims: This analysis aims to understand the degree to which these two measures agree and explore reasons for disagreement.

Method: Physician and parent global scores recorded at first presentation to paediatric rheumatology were compared in 447 children with JIA enrolled in the Childhood Arthritis Prospect Study (CAPS). Concordance, defined as ±10 mm difference in visual analogue score (VAS), was determined and analysed using Bland-Altman (BA) plots. Demographic, disease and social factors associated with disagreement were explored using multinomial logistic regression analysis, using the category Agree as our comparison. The analysis was repeated in 143 participants with paired measures 1 year after presentation.

Results: At presentation, only 29% of scores agreed; 42% of parents scored higher (PH) than the physician and 30% of parents scored lower (PL). Concordance was greater at lower ends of the VAS (lower disease activity). Pain and active joint count were significantly associated with both PH and PL. Higher QAQ scores were significantly associated with PH only. There was no association with age, gender, disease duration, ESR, parents’ General Health Questionnaire. At 1 year, there was a greater degree of concordance (agree: 60%; PH: 25%; PL: 15%) although factors associated with discordance remained largely unchanged.

Conclusion: Parent and physician assessment of disease often disagree, suggesting they may be capturing different aspects of JIA. This strengthens the inclusion of both scores in composite disease activity measures. Identifying these differences may help direct information and treatment.

Disclosure statement: The authors have declared no conflicts of interest.

ABSTRACT 19  BSRAP123

RETROSPECTIVE AUDIT OF VITAMIN D DEFICIENCY AND TREATMENT IN RHEUMATOLOGICAL CONDITIONS
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Introduction: Children with rheumatological disorders are more likely to have vitamin D deficiency (VDD). Two-thirds of children attending rheumatology clinic had VDD or vitamin D insufficiency (VDI). Both VDD and VDI have been demonstrated in children with JIA compared with healthy controls.

Aims: To audit patients seen in paediatric rheumatology (2011) for an overview of VDD and response to treatment, followed by a JIA subgroup (2012).

Method: This retrospective audit included all children referred to rheumatology (2011), followed by newly diagnosed JIA patients (2012). Children with VDD were treated according to the trust protocol (<50 nmol/l) (2011).

Results: Our first group included 44 patients (median interquartile range (IQR) age 12.5 (8.0–15.0) (median (IQR) years) with biomechanical (19), inflammatory (18) and no (7) joint pain. 52% patients attending clinic had VDD and 78% were treated according to protocol (2011). Children referred to rheumatology as a whole and the biomechanical subgroup showed significantly improved pain scores (2011). Our JIA cohort included 29 patients (7.9 (5.3, 13.7) (median (IQR) years). Medications included steroids (86.2%), disease-modifying drugs (75.9%) and biologics (27.6%). JIA ILAR subtypes included extended oligoarthritis (34.5%), polyarthritis (34.5%), enthesitis-related (13.8%) and systemic arthritis (17.2%). 71% patients with JIA had VDD and 90% were treated according to protocol (2012). The inflammatory (2011) and JIA (2012) subgroup did not show significant improvement in pain. CHAQ scores did not improve significantly in all groups.

Conclusion: Our JIA subgroup (2012) showed better compliance of treatment of VDD according to protocol. There was improved pain in the biomechanical group, suggesting that checking for and treating VDD should be considered in non-inflammatory and inflammatory joint pain.

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ABSTRACT 20  BSRAP125

THE PREVALENCE OF VITAMIN D DEFICIENCY IN JUVENILE SYSTEMIC LUPUS ERYTHEMATOUS PATIENTS
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Introduction: Patients with JSLE may be at higher risk of vitamin D (Vit-D) deficiency particularly when patients are dark skinned, photosensitive and adhere to sun protection advice. Vit-D deficiency in JSLE can be associated with higher disease activity.

Aims: The objective of this study was to determine the prevalence of Vit-D deficiency in our cohort of JSLE patients.

Method: This was a retrospective study of JSLE patients over a period of 5 years (2007–2012). Vit-D levels were analysed on Diasorin Liaison Analyser. BILAG2004 index was derived from UK JSLE Cohort study.
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Introduction: Adolescents (10–19 years old) represent a large cohort of patients who have, until recently, received very little attention. Up to 60% of patients with JIA have ongoing joint inflammation or disability into adulthood. They present unique challenges with regard to their growth and sexual development, risk taking behavior, vocational planning, mental health, compliance and attendance.

Aims: We wished to assess current levels of adolescent services in Ireland, and to gather opinions regarding adolescent medicine requirements.

Method: We invited rheumatology consultants (n = 40) and registrars (n = 20) to complete an online survey.

Results: 45 people completed the survey (80% were consultants, 40% SpR registrars). 91% of respondents were aware of the process of transitional care. 81.1% thought this was a useful process. Only 14% of respondents did not treat adolescent patients at all. 72% said that they did not think it was appropriate for adolescents to be managed solely in an adult clinic. 70% of rheumatologists did not know roughly what percentage of JIA patients had persistent inflammatory arthritis as adults. Asked about barriers to providing an adolescent service, replies focused on lack of formal training, lack of time, lack of paediatric input outside of Dublin, and lack of resources. 86% of respondents stated they had not received enough training in adolescent rheumatology, with 92% supporting its addition to the rheumatology SpR curriculum. 100% of respondents supported the need for combined adult and paediatric care during the transition period.

Conclusion: There is a desire among rheumatologists in Ireland for more adolescence services and training.

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ADOLESCENT RHEUMATOLOGY IN IRELAND: AN UNMET NEED

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Introduction: Previous research suggests that, even in the context of an excellent and well-supported clinical service, parents may experience difficulties in managing their child’s JIA and further tailored information and support strategies are beneficial.

Aims: To provide this additional support the Sparks CHARMS JIA Website for Parents was developed and, unlike other websites, designed to be provided as an adjunct to the clinical service.

Method: The website development was systematic. Content was derived from: a review of literature on parents’ experiences of having a child with JIA; review of existing JIA websites; a survey of parents’ views about JIA1; interviews and focus groups with parents and focus groups, written drafts and peer review from healthcare professionals (HCPs). A website consultant designed the site for layout, usability, acceptability, and interactive features. The resulting prototype website was tested by seven parents to evaluate usability, navigation, structure, layout and content.