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WFH 2023 Comprehensive Care Summit: New Developments in Bleeding Disorders and MSK

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PP-TH-029 (1462075) | Gross motor development in infants with haemophilia assessed by Alberta Infant Motor Scale (AIMS): Preliminary results

Dimitrios Syrengelas[1], Christina Moschou, Athina Dettoraki[2], Aikaterini Michalopoulou[2], Paraskevi Kleisiouni[1], Tania Siahanidou[3], Miltiades Kyprianou[2], Ioannis Koutelekos[4], Helen Pergantou[2]
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Introduction: There is evidence that the muscle strength in children with haemophilia differs with respect to children without haemophilia. No study has been reported regarding the gross motor development in infants with haemophilia assessed by the Alberta Infant Motor Scale (AIMS). Objectives: To study the gross motor development of infants with haemophilia using the AIMS, which is a reliable and clinically easy-to-use tool for the assessment of the developing infant. The AIMS evaluates 58 items at four different positions (prone, supine, sitting and standing) from birth until independent walking (0 – 19 months). The sum of all the items observed gives the total raw score of AIMS, which may range from 0 to 58. The total raw score can be converted to percentile ranks. High percentile ranks show maturity of the infant's gross motor development, while low percentile ranks show a relative immaturity.

Methods: Eight (8) full-term infants with severe or moderate haemophilia A and B, aged 6 to 18 months were assessed with the AIMS. The scale is already standardized in a group of 1068 full-term Greek infants. It was examined with one-sample t-test whether the mean percentile rank of the sample with haemophilia is statistically significantly different from the median.

Results: The mean percentile rank of the total AIMS score of infants with haemophilia is only 4.4% ± 5.0% which is statistically significantly lower from the expected median of 50%. The highest percentile rank observed was just 14%.

Conclusions: Motor development of Greek infants with haemophilia lags behind that of full-term infants without haemophilia of the same nationality. The study will continue to include a greater number of Greek full-term infants with haemophilia.

Keywords: Infants with haemophilia, Gross motor development, Alberta Infant Motor Scale (AIMS)

PP-TH-028 (1457577) | Creation of a prospective data bank of musculoskeletal pathologies for bleeding disorders patients

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Introduction: Musculoskeletal complications frequently have a negative impact on the quality of life of patients with haemophilia. Treatment for these patients is optimized in a multidisciplinary setting, favouring the concentration of expertise for this rare disease spectrum. However, data regarding the choice of management strategies, and their impact on patients' quality of life is scarce or of limited scientific value.

Methods: We have created an ongoing Canadian multicentre prospective data bank of a comprehensive nature in 2013, with the goal of quality control and increased data accrual to provide scientific evidence to guide treatment. Every patient with a bleeding disorder referred to our orthopaedic clinic for a joint pathology is included in the data bank. Of the data collected, we record the type and severity of the bleeding disorder, prophylactic strategy, non-surgical and surgical treatment, peri-operative factor replacement, physical therapy and complications. These data are collected using patient reported quality of life questionnaires (including Haemo-Qol and the Hemophilia Activity List), and specific site-specific functional assessments (KOOS, Womac, Quick-Dash, PREE), and other data over at least 10 years.

Results: Our single centre has approached 125 patients, of whom 102 patients have been enrolled (others are in the process of enrolment and very few have refused to participate). As some patients are followed for multiple target joints, the data bank has prospective quality of life data for 157 joints, including 3 shoulders, 21 elbows, 15 hips, 61 knees and 57 ankles. Of these 157 joints we have collected data for 94 elective surgical procedures including 3 shoulders, 10 elbows, 15 hips, 38 knees, 21 ankles and 7 orthopaedic surgeries at other sites.

Conclusions: This data bank is a tool that should provide future studies with robust prospective data to permit the generation of high-level evidence. The data bank is well received with a participation rate of more than 97% of our patients. We have integrated two other HTC's and expect several more centres to join the project in the next few years. This expansion is necessary if we are to accrue sufficient data for this niche disease.

Keywords: Prospective, Orthopaedic surgery, Quality of life

CLINICAL CASES

PP-TH-025 (1458796) | Paediatric haemophilic arthropathy of the knee: Treatment with circular external fixator and intra-articular injection of platelet rich plasma

Eleni Pappa[1], Maria Giannakopoulou[1], Aikaterini Michalopoulou[2], Anastasia Pilichou[3], Athina Dettoraki[2], Dimitrios Syrengelas[4], Marios Antoniadis[5], Helen Pergantou[2], John Anastasopoulos[3]
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