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P076 | Development of a haemophilia physiotherapy intervention for optimum musculoskeletal health (Dolphin trial)

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Introduction: Haemophilic arthropathy is associated with muscle weakness and may be reduced prior to the onset of clinical arthropathy. Muscle weakness is strongly correlated to reduced walking distances, slower ascent and descent of stairs, and altered joint motion and forces during weight bearing activities. Our aim was to develop a muscle strengthening exercise intervention for children that could be tested in a randomised clinical trial.

Methods: We conducted modified Nominal Group Technique focus groups with academic experts and specialist physiotherapists, and most importantly in consultation with patients. The exercise programme was demonstrated to five boys with haemophilia and their parents. Children and parents were asked; what they thought about the exercises and whether they could undertake them on a regular basis, where they thought the best place was for undertaking them, and how they would like to receive information on the exercise programme. They were also asked questions about how they would feel about taking part in a study testing the benefits of the exercises, issues around being allocated randomly into study groups, and what would encourage the children to continue on the exercise programme.

Results: Strong consensus from physiotherapists indicated the exercise programme should include exercises focused on strength, balance, proprioception, flexibility and mobility, and a motor learning component. Families noted the best place for the intervention being carried out was at home and that twice per week would be achievable. Parents felt that in order to sustain interest and motivation, it was important to build in an incentive that would be valued by the child. They also said that in order to find out whether or not the exercise programme worked, they would not have a problem with their child being allocated into an intervention or usual care groups.

Discussion/Conclusion: Engaging clinicians and patients in partnership as part of the research process enhanced the design of an exercise intervention ensuring it is acceptable and potentially beneficial for children with chronic disorders. The efficacy of a 24-session progressive exercise programme of stretching, strengthening, balance, proprioceptive and mobility using functional movement patterns is currently being tested in a randomised controlled trial.

Disclosure of Interest: None declared.

P077 | Sacrococcygeal pilonidal sinus surgery in two patients with haemophilia

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Introduction: Sacrococcygeal pilonidal sinus disease (PSD) is a common chronic inflammation of the natal cleft and presents as an abscess or a chronically discharging, painful sinus tract. It has an incidence of 1.2-2.5/1000 in children. Onset is around puberty. Symptoms of recurrent abscess and chronic suppuration may interfere with education and social integration. Treatments should cause minimal disruption while having good cure and recurrence rates. The management of chronic PSD is variable, contentious, and problematic. Although many surgical procedures have been tried, the best surgical method remains controversial.

We presented two haemophilia patients undergoing pilonidal sinus surgery in our hospital.

Methods: We presented two haemophilia patients undergoing pilonidal sinus surgery in our hospital.

Results: Case 1. Sixteen-year-old boy with severe haemophilia B was unresponsive to two-year medical treatment. Excision surgery planned for pilonidal sinus disease. Inhibitory test was negative. His weight was 50 kg. Presurgery 1800 IU plasma derived factor IX was given Presurgery factor IX level was 64%. Tranexamic acid was started. He was removed from the hospital at four days after the surgery.

Case 2. Nineteen-year-old boy with severe haemophilia A was unresponsive to four-year medical treatment. He has family history for haemophilia and has intron 22 inversion mutation. Excision surgery planned for pilonidal sinus disease. Inhibitory test was negative. His weight was 90 kg. Presurgery 2000 IU recombinant factor VIII was given then factor level was 52%. Tranexamic acid was started. We give 2000 unit factor VIII was given every 24 hours, total three doses. He was removed from the hospital at two days after the surgery. Surgical procedure completed with a total of 67 IU / kg factor VIII

After then, 2000 IU prophylaxis was continued for two days a week. Two weeks later, there was no bleeding or discharge. Wound healing was completed. For four months after surgery, the disease was not repeated.

Discussion/Conclusion: There is no case series related to sacrococcygeal pilonidal sinus disease surgery in hemophilia patients. However, if surgical surgeons and hematologists cooperate and communicate closely, these surgical procedures can be performed successfully.

Disclosure of Interest: None declared.

P078 | Haemnet horizons: Enhancing patient care by fostering a growing haemophilia nurse community

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