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Children and adults with severe hemophilia characteristically bleed into joint spaces with resultant arthropathy and deformity. The use of prophylactic clotting factor replacement has been shown to reduce joint bleeding with the ultimate goal of reducing arthropathy and deformity and improving function and quality of life. Clinical studies in recent years have been undertaken in order to determine cost effectiveness and optimal regimens for prophylactic treatment in children.

In order to analyze the clinical outcomes of prophylactic therapy, a valid measurement tool for joint health with excellent measurement properties must be used in clinical studies, consistent with ongoing trends towards evidence-based practice. Several joint evaluation methods have already been developed, beginning with the World Federation of Hemophilia (WFH) orthopedic score. Concerns regarding the original WFH scale were addressed by two separate groups in

## Hemophilia joint health score: instructional videotape

Denver and Stockholm. Modifications were made to the scale by these two groups in order to improve the tool's sensitivity to mild joint change and its ability to take into account normal developmental change.

A revision of the orthopedic assessment scoring form has recently been developed by an International Prophylaxis Study Group (IPSG) Physiotherapy Expert Working Group. This group consists of physicians and physiotherapists from Sweden, the Netherlands, the United States and Canada. Scoring and explanation sheets have been developed for this new Hemophilia Joint Health Score (HJHS). In order to study its measurement properties, a reliability study on the tool has already been performed and a validity study will follow. One of the important aspects of a scoring system is to ensure that the assessment tool is performed consistently by different assessors.

Although the best way to ensure this consistency is to have training sessions, this is not always feasible or cost effective, especially considering that this tool will be used internationally. We propose to develop a videotape and manual for the new HJHS tool as a teaching and resource guide. The various items contained in the scoring tool (for example swelling, gait, strength) will be demonstrated by Physiotherapists on patients with varying degrees of joint involvement. Detailed explanations regarding testing methods and scoring criteria will be given during the videotaped examinations. We propose using videoconference with the Physiotherapists involved

in the Physiotherapy Expert Working Group in order to present optimal technique and explanations during the patient demonstrations. The accompanying manual will include photographs and /or diagrams to clarify the examination methods and scoring of the items.

The videotape and manual will originally be made in English, with the intention to have them translated into other languages. The scoring sheets and manual will also require translation into other languages. This project will yield an important teaching and reference tool primarily for Physiotherapists involved in the joint health assessment of persons with Hemophilia world-wide.

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