

A Feasibility Study of “Managing Hemophilia Online”, An Internet-Based Self-Management and Transitional Care Program for Teens

VR Breakey¹, DM Ignas², VS Blanchette^{2,3} and J Stinson²

¹Division of Hematology/Oncology, McMaster Children's Hospital, McMaster University, Hamilton, Canada, ²Child Health Evaluative Sciences (CHES), Research Institute, The Hospital for Sick Children, Toronto, Canada, ³Division of Hematology/Oncology, The Hospital for Sick Children, University of Toronto, Toronto, Canada

INTRODUCTION

- Adolescents with hemophilia (AWH) have heightened educational needs as they gain independence
- There are no published self-management programs for AWH
- A needs assessment documented current state of the literature and teens' perceived transitional needs
- An interactive eight-module Internet-based education program was developed in English and French (Figures 1 & 2)

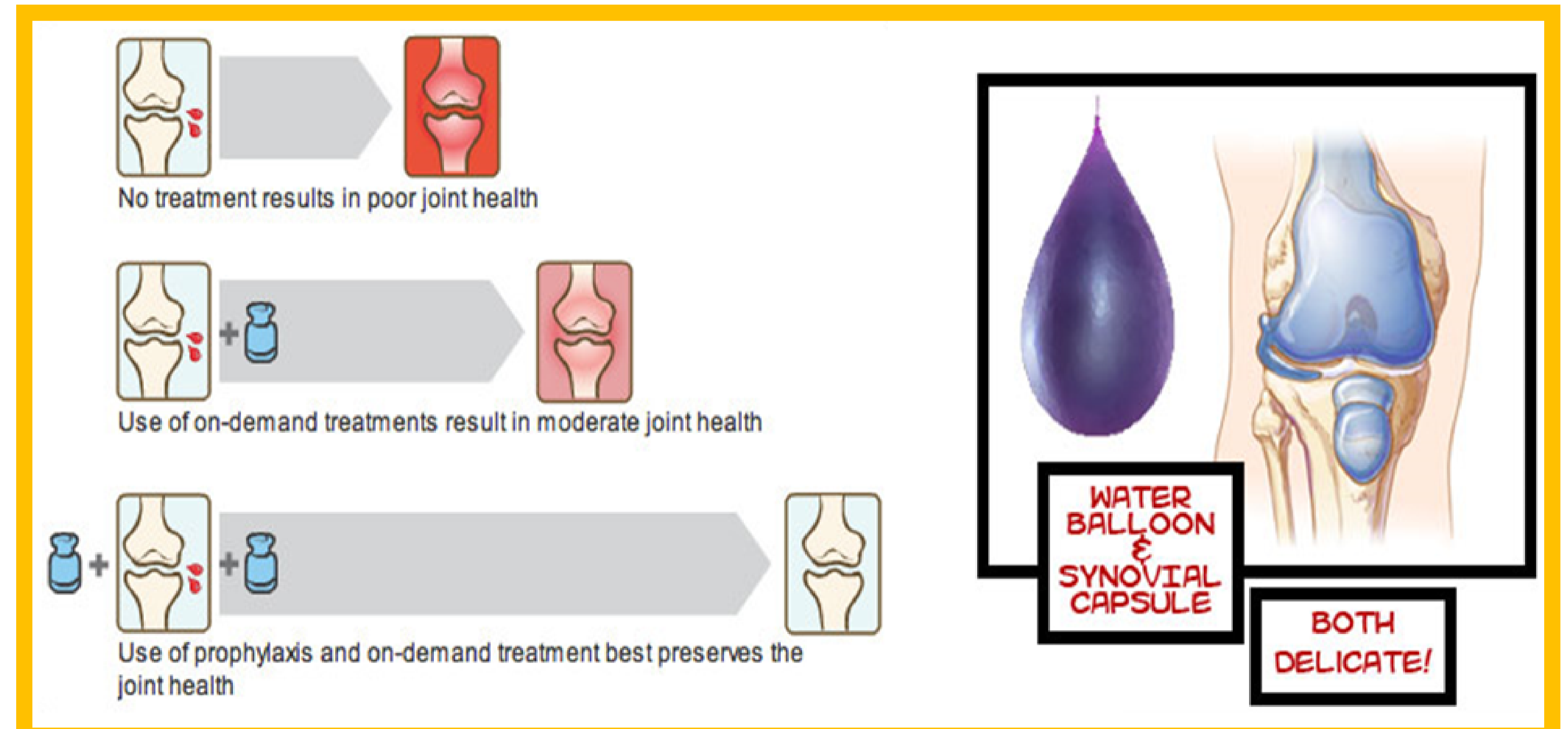


Figure 2. Additional examples from the website. Left: Illustration depicting different treatment regimens and corresponding joint health status. Right: Analogy comparing a water balloon to the synovial membrane.

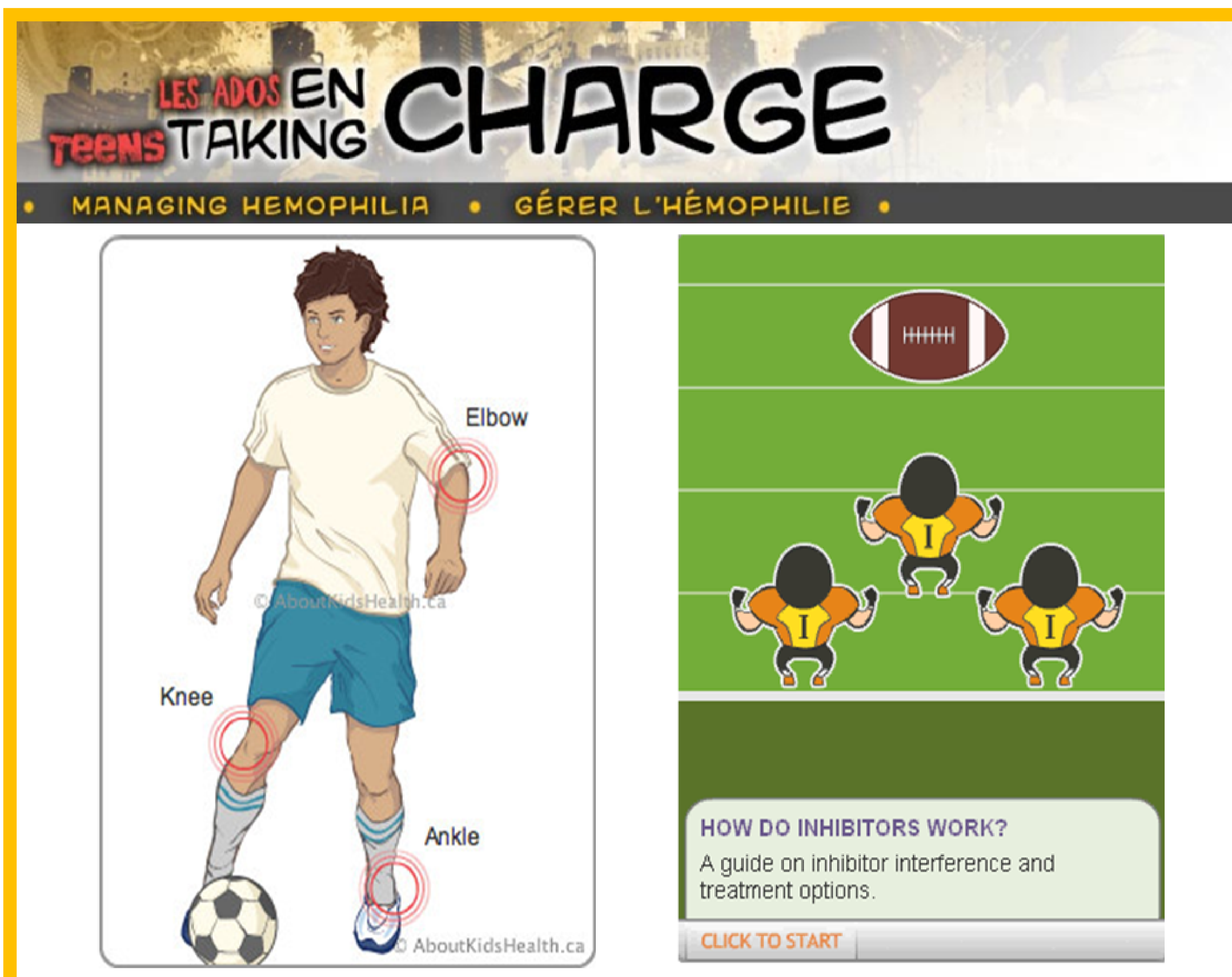


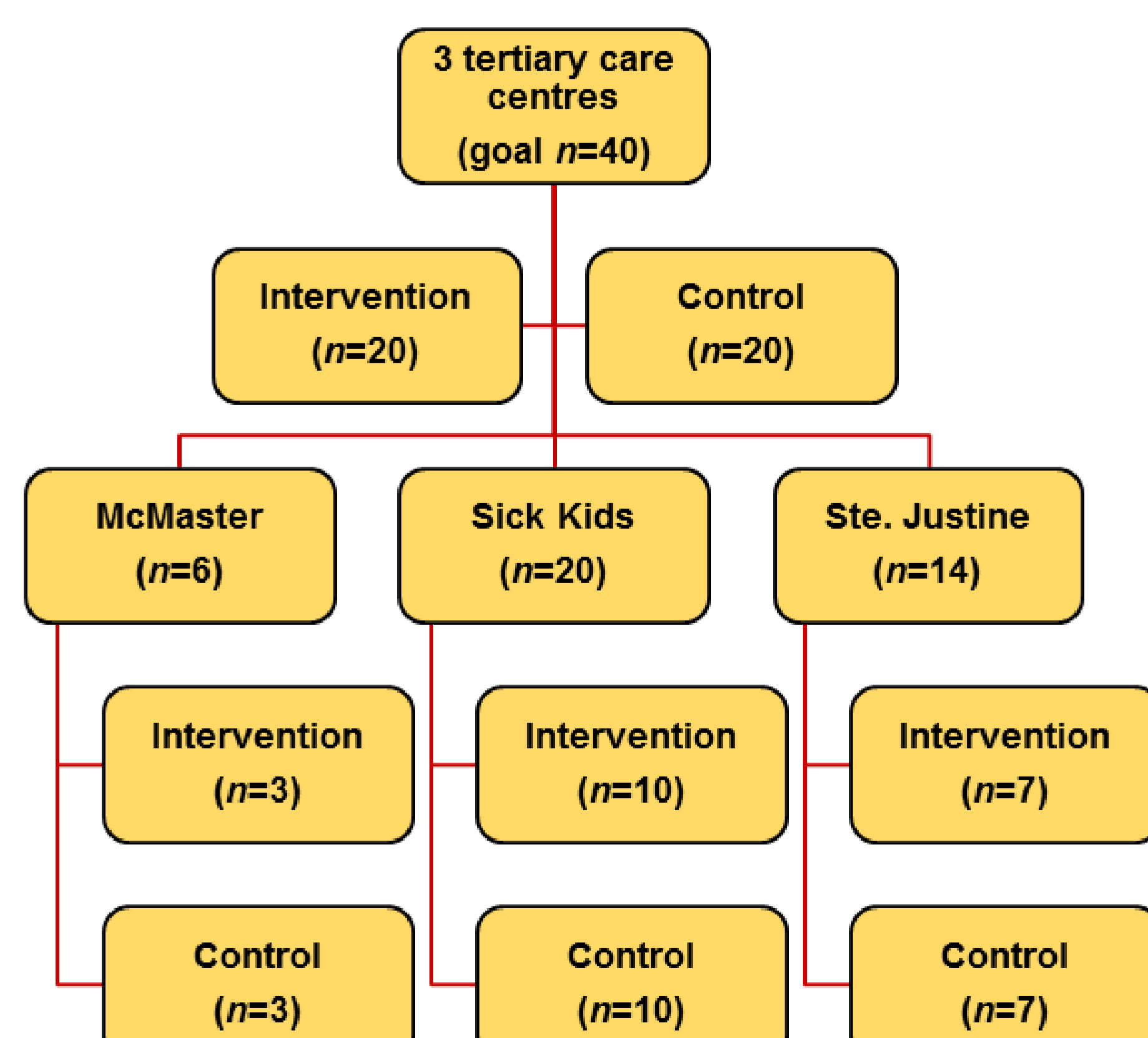
Figure 1. Examples from the website. Left: illustration showing common target joints in hemophilia. Right: First picture in animation using an analogy comparing inhibitors to defensive football players.

STUDY OBJECTIVE

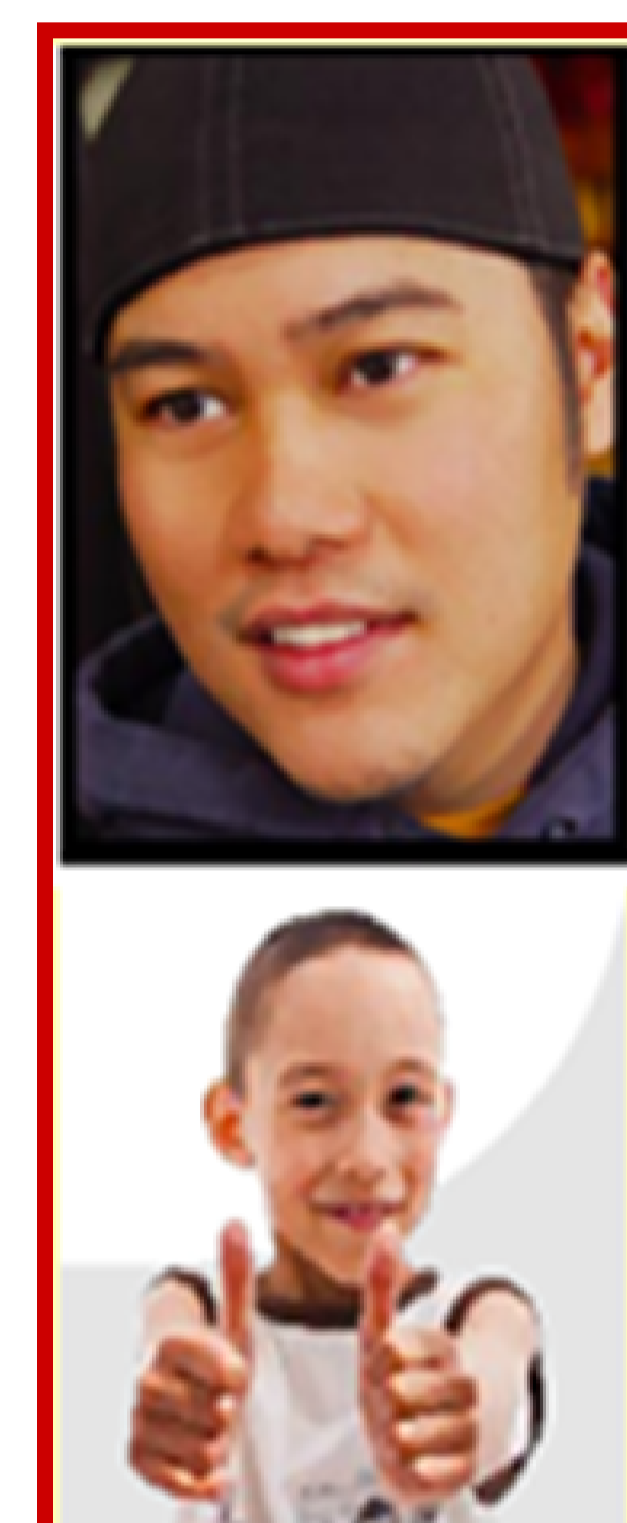
To assess the feasibility and determine the sample size for a prospective RCT of “*Teens Taking Charge: Managing Hemophilia Online*,” a new Internet-based educational program

METHODS

- A feasibility study for a prospective RCT is ongoing to assess:
 - participants' willingness to be randomized
 - accrual and attrition
 - adherence to program/completion of outcome measures
 - program satisfaction
- Participants randomized to intervention with a weekly call from a trained health coach or control with attention-control call



PLANNED OUTCOME MEASURES FOR RCT



Hemophilia Knowledge Questionnaire

Canadian Hemophilia Outcomes - Kids' Life Assessment Tool (CHO-KLAT 2.0)

Sherer General Self-Efficacy Scale (GSES)

Self-Management Skills Assessment Guide

Health Education Impact Questionnaire (heiQ)

Participant Satisfaction Measure

CURRENT STATUS

- Enrollment is ongoing, with 35 participants currently enrolled in the feasibility study
- Response to the program has been positive, with participants expressing improvements in their disease-specific knowledge and an appreciation for the convenience and accessibility of the web-based format
- Expected completion date: December of 2012



LOOKING AHEAD

- Results from the feasibility study will inform the implementation of an RCT to study the intervention
- Estimates of treatment effects from the pilot data will determine the appropriate sample size for the RCT
- Plan in progress for RCT in 2013

With special thanks to the patients and health care providers at participating sites: McMaster Children's Hospital, Sick Kids & CHU Ste. Justine

Funded by “The Care Until Cure” Program of the Canadian Hemophilia Society/Pfizer and a generous unrestricted educational grant from Baxter Bioscience, Canada