

# Muoviamoci Italian Musculoskeletal Global Project

**Authors:** L. Solimeno, G. Pasta, \* M.E. Mancuso, E. Santagostino, E. Boccalandro, \*\* A. Buzzi, C. Castegnaro \*\*\*

**Hospital:** \* IRCCS CA' GRANDA FOUNDATION Ortho trauma, \*\* IRCCS CA' GRANDA FOUNDATION A. Bianchi Bonomi Hemophilia Center, \*\*\* Paracelso Foundation

## Introduction:

From early childhood, the joints are the most common site of bleeding in haemophiliacs. Haemarthroses tend to recur at the same site (target joint) causing structural damage that gradually involves synovium, cartilage and bone leading to chronic arthropathy (Roosendaal et al. Haemophilia 2006). End-stage arthropathy is painful, disabling and strongly impairs quality of life. In recent decades, the availability of effective and safe clotting factors concentrates has had a dual impact on the natural history of haemophilia, i.e. reducing the incidence of arthropathy and enabling orthopaedic surgeons to perform elective surgery in an increasing number of patients. Nevertheless, very few haemophilia centres around the world have access to an orthopaedic surgeon with experience in haemophilia .

The main aim of this project is to provide medical assistance to those patients who have not routinely access to an orthopaedic surgeon and to those haemophilia centers where the musculoskeletal evaluation (as foreseen in the frame of a regular follow-up schedule) is performed by haematologists. The project will address general and specific aspects. General aspects will concern information on musculoskeletal status, need for rehabilitation and indication for major orthopaedic surgery. Specific aspects will focus on the results of surgery and rehabilitation program. All these information will be included in an Italian Registry of Major Orthopedic Surgery (IREMOS). The results of this project might translate into tangible clinical benefits for patients with haemophilia because they will provide clear figures on the standard of care currently available and the potential for ameliorating it. Especially, our attention will be focused on increased registered number of revision surgery, due to the long period elapsed since primary implant. It is well established that revision surgery is often complicated by more bleeding, this being particularly severe in patients with haemophilia. Clinical and surgical guidelines might be generated in order to guide all the healthcare professionals who usually provide care to these patients.

## Goals and general objectives:

### Materials and methods:

The project will be conducted by Angelo Bianchi Bonomi Hemophilia and Thrombosis Center of Milan.

Two orthopaedic surgeons and a physiotherapist will arrange a time schedule to visit patients at involved Haemophilia Centers across Italy (where patients who have not routinely access to an orthopaedic surgeon). The project will last 3 years.

During the visits the orthopaedic surgeons and the physiotherapist will:

- Evaluate the orthopaedic status by performing orthopaedic score using Haemophilia Joint Health Score and radiological score using Pettersson Score
- Evaluate the need for rehabilitation program
- Evaluate the need for major orthopaedic surgery
- Give instructions for self rehabilitation program
- Evaluate the results of major orthopaedic surgery
- Evaluate the results of rehabilitation program

A proper Case Report Form will be created to record all these data at each visit and its will be included in the registry IREMOS.

- One year to visit all patients at least once
- At the end of the third year all retrospective and prospective data will be included in the registry

## Results assessment:

The results of this project will be assessed under 2 different point of view: clinical and social.

Clinical data gathered from the first visit will be analysed and compared to clinical data obtained at fixed time-points during the study (i.e. the second year, at the last visit, after surgery or rehabilitation program) in order to assess the impact of the project activities on the health status of the patients. Moreover we will evaluate the results of major orthopaedic surgery performed in our country.

A specific questionnaire will be created and used at the beginning of the project and at last visit in order to evaluate if an improvement in the management of the disease has been obtained. This will evaluate specific instruments to assess quality of life and customer satisfaction questionnaires

## References:

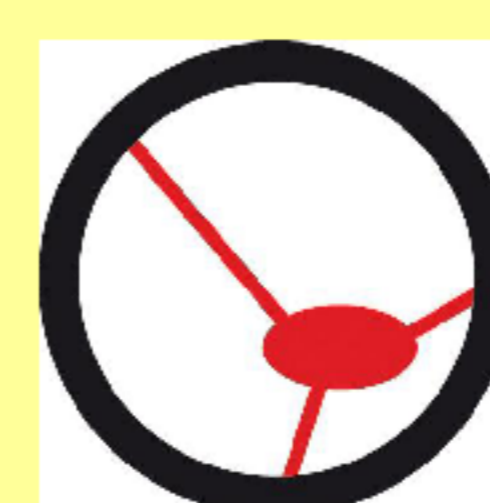
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