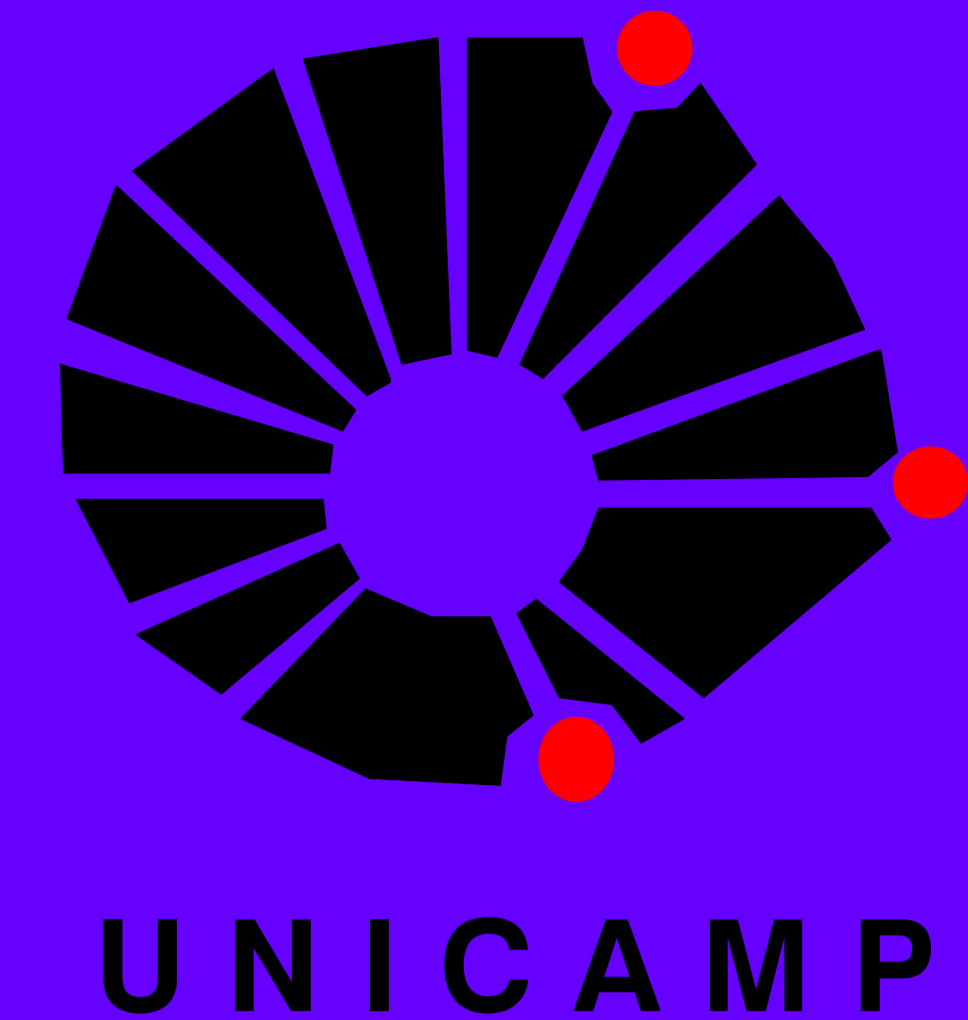




# The development of a software for musculoskeletal evaluation database



Janaina B S Ricciardi, Marcia AP Matta, Glenda Feldberg, Carolina Costa-Lima, Samuel S Medina, Margareth C Ozelo.  
IHTC "Cláudio L P Correa", INCT do Sangue - Hemocentro Unicamp, University of Campinas, Campinas, SP, Brazil



## INTRODUCTION

Musculoskeletal (MSK) complications are the major cause of deterioration the quality of life of hemophilia patients. In order to evaluate and detect MSK changes several groups developed different outcome measurements. The objective of this project was to create a software for MSK evaluation database with the main standardized assessments with free access for those interested in the use of this tool.

## METHODS

In 2010, we started the development of a software that included the main physical, functional and radiological MSK assessments used in hemophilia. This was part of the MSK M.A.D.E. in Brazil (Measuring, Analyzing, Disseminating and Educating) project, supported by Novo Nordisk Haemophilia Foundation. The software was developed in web-based format and contains eight forms: personal data, WFH Physical Examination Score (Gilbert Score), Hemophilia Joint Health Score (HJHS), Functional Independence Score in Hemophilia (FISH), Hemophilia Activities List (HAL and PedHAL), radiological Pettersson Score, MSK assessment (with additional information) and a bleeding episodes form. There are three types of users : standard user, limited user and center administrator user. Each center can specify the role of the professional involved. Users can choose different forms, and a single patient can be evaluated several times in a specific score. All scores are automatically calculated.

## RESULTS

The information can be evaluated in different reports for each patient overtime, or all patients from a single center, with the possibility of establishing up to three different simultaneous criteria. The report can be exported to excel. The website and all forms are available in four languages: English, Portuguese, Spanish and French and has two platforms available, one for real data ([www.mskbrazil.net.br](http://www.mskbrazil.net.br)) (figure 1), and another for training ([www.mskbrazil.net.br/training](http://www.mskbrazil.net.br/training)). There are many possibilities during managing information, such as: create new assessments, visualize previous questionnaires, edit patient data, delete information, transfer patient to another site (when agreed between sites) allow access to data on this patient by another professional authorized by who is managing the data. The software is now located in an independent server at University of Campinas, in Brazil, however all data are confidential and the access is realized through passwords to guarantee patient's and center's privacy. Each center has the access solely to the patients of that same center. Other centers, from different countries were invited to use the software, free of cost.

## CONCLUSIONS

This software was created to provide continuously updated database to allow individual and collective evaluation of the MSK status of hemophilia patients. The main idea is to share, combine and compare information with the objective to have a most complete and comprehensive MSK status possible.

## REFERENCES

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**MUSCULOSKELETAL ASSESSMENT FOR PEOPLE WITH HAEMOPHILIA**  
Measuring, Analyzing, Disseminating and Educating the way to correct, prevent and optimize the treatment

Select Language:  
English  
English  
Português  
Español  
Français

Home About us Contact us Register

**Welcome**  
This web-based MSK registry was created by the multidisciplinary team from IHTC Unit of Hemophilia "Cláudio L. P. Corrêa", INCT do Sangue - Hemocentro/UNICAMP, University of Campinas, in Brazil.  
This project has been endorsed by the Brazilian Federation of Haemophilia and Brazil musculoskeletal care Group. It includes the development of musculoskeletal assessment guidelines, based on data in the literature and recommended by the World Federation of Haemophilia (WFH), for clinical, physical, functional and diagnostic imaging evaluation.  
This tool was adapted from assessment instruments currently used in haemophilia, i. e., WFH Physical Examination Score (Gilbert Score), Hemophilia Joint Health Score (HJHS), Functional Independence Score in Haemophilia (FISH), List of Activities in Haemophilia (HAL and PedHAL) and radiological Pettersson Score. This tool also includes the musculoskeletal assessment designed for clinical practice of physiotherapists working with hemophilia in Brazil.  
This tool aims to facilitate the establishment of protocols for musculoskeletal hemophilia care and create a comprehensive database that can be useful for surveys, to implement strategies on prevention and treatment of musculoskeletal complications. We invite all centers and healthcare providers dealing with hemophilia care to use the registry and help to improve this useful patient management tool. Possibly, in the future, it could serve to create a global MSK database that will allow a better understanding of the status of musculoskeletal conditions of patients and improve their care and treatment leading to better joint health.

**User Login**  
Email:  
Password:  
login  
Register an account  
Reset your password

**Patient forms**  
Below is a list of forms that have been started / completed for Adão Lima. Click on the links provided to access the data.  
Adão Lima (CET000005) [view more]

Action	Form name	Date	Editor
view/edit	PHYSICAL EVALUATION FORM v1	2015-11-18	Ms. Matta
delete	FISH FORM v1	2015-10-29	Mr. mskroot
view/edit	PHYSICAL EVALUATION FORM v1	2015-09-22	Mr. mskroot
delete	PHYSICAL EVALUATION FORM v1	2015-09-18	Ms. Matta

**Staff tools**  
Below are a list of tools that you may use.  
New patient, Centre's patient list, Reports, Contact administrator

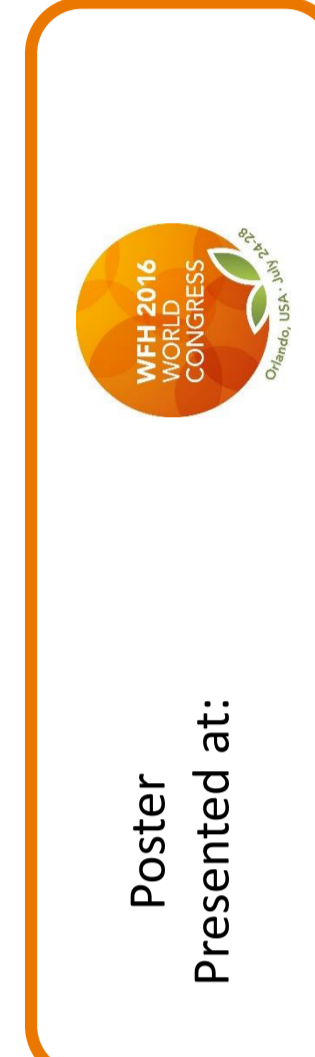
**Administrator tools**  
Below are a list of tools that you as an administrator may use.  
Manage Staff, Create a new account, System logs, Instructions

**User and Elevated Privileges:**  
 [USER]: Create a **standard user** (ie Doctor, Nurse, Clerk,...). This role can manage patients, create forms and run reports for their center.  
 [LIMITED]: If selected, this user will be granted limited instrument privileges for the centre specified above.  
 [ADMIN]: If selected, this staff member will be granted **administrator** privileges in the centre specified above.

**Reports**  
Below is a list of reports that are currently available.  
Adapted evaluation for Functional Independence Score for Hemophilia (FISH) - Data Report  
Musculoskeletal Assessment - Data Report  
Radiological Pettersson Score - Data Report  
Bleeding Episodes - Data Report  
Adapted physical evaluation for Gilbert Score - Data Report

**Project Team**  
www.hemofilia.inctsangue.net.br

Figure 1. Overview of the website with examples of possible forms and reports.



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Outcome Assessment  
Margareth Ozelo

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970ZHM