



Summer Camp



Resources today

Objectives

25 young people (Dutch and French speaking)

HUMAN RESSOURCES (bilingual team)

- 1 Doctor of HTC
- 2 Nurses of an HTC
- 1 Administrator NMO
- 1 Coordinator NMO
- 3 Animators being hemophiliacs
- 2 Animators carriers
- 2 Animators "scout"
- 1 Moderator sports high

INFRASTRUCTURE

Buildings, logistics, meals, sports equipment, sports knowledge: ADEPS Centre (federal) - The Fraineuse at SPA - Belgium

FINANCES

- Participation is required of parents
- Three quarters of the costs are taken in account by the NMO
- Sponsorships are made by pharmaceutical companies



YOUNGSTERS

- Learning autonomy through self-infusion
- Learning the sport with the concept of risk and safety measures and caution
- Getting to know your limits
- Learn to talk about his hemophilia
- Develop contacts and sense of belonging to a group (I am not alone in my situation)
- Learning autonomy through self-infusion
- Learning the sport with the concept of risk and safety measures and caution
- Getting to know your limits
- Learn to talk about his hemophilia
- Develop contacts and sense of belonging (I am not alone in my situation)

PARENTS

- Getting together, sometimes for the first time as a couple
- Some caution messages may have more results if they do not come from the parents
- The autonomy of youth depends on the ability of parents to let go and trust their kid

ANIMATORS

- Many youngsters subsequently want to keep in touch by becoming an Animator
- Keep in touch with NMO to stay informed

NMO

- Only an NMO is credible for organizing such an activity
- A pharmaceutical laboratory or a Hematologist would not have the same unifying message in one country
- Find an ideal location for a week where we take care of kids and their Hemophilia
- Bring together for a week, the best specialists to learn sport safely and getting to know each one's limits
- Work in collaboration with HTC and pharmlabs

History – The overview

For kids between 8-15 years:

1970

- **1974 (Oostduinkerke - Belgium) :**
45 children for 3 weeks
Infusion 1 = 1:15
Education about Hemophilia in a classroom
Sport prohibited
Physiotherapy every morning
The goal is to get together with other Hemophiliacs
Activity : games and walks
- **1978 (Dongelberg - Belgium) :**
Some youngsters (15 years) start Self-Infusion
Introduction to some soft sports
Visit of Princess Paola
- **1978 (Beaugency - France)**
First activities for 15-20 years
Obligation to control Self-Infusion
Cycling activity = (castles of the Loire/France)
- **1980 (Villers -la-Ville - Belgium) :**
Activity = a little more sports and excursions
- **1986 (Arlon - Belgium - ADEPS Centre):**
Self-infusion = 20 min
All young people learn Self-Infusion
Learning method depending their age
Swimming is a compulsory sport
The hemophiliac practice sports under the same conditions as other children
- **2001 (Soraga - Italy) :**
New course for 15-20 years
Autonomy of young people
2 hosts and 1 nurse
- **2002 (Nieuwpoort - Belgium Centre BLOSO) :**
New sports are practiced as sailing and Mountain Bike
- **2005 (SPA - Belgium - ADEPS Centre) :**
25 children for one week
Extra activities : diving and tree climbing
Introduction to all the sports activities possible in the Centre

2014

Self-Infusion

Several stages according to the kid's age:

- 1) Prepare the FVIII-FIX
- 2) First try on the nurse's arm
- 3) Self-Infusion



The internship is a great way to learn self-infusion. We have time (one week) and room mates are a good motivation.



But start studying haemophilia by games.

Sports

RISK AND PRECAUTIONARY MEASURES

We do not tell them about authorized nor prohibited sports. We help the young to assess the risks in each sport and how to practice this sport in the best way. Both from the security point of view (knee, helmet, ...) as from the readiness (warm-ups, regular trainings, advice from the coach, make the right moves ...) to perform a type of sport.



The future

We want to work with other countries to exchange knowledge. Initially with NMO with whom we collaborate already. Then optionally with other countries through a twinning-project.



Contact us



Belgian Haemophilia Society (AHVH)
www.ahvh.be
info@ahvh.be - +32 (0) 346 02 61
 Rue Grisarstraat 38 B1070 Brussels - Belgium

Volunteers-Professionals

CTH : Anne ROCHTUS (KUL), Bert LEENDERS (HUDERF), Katrin VANDER ELST(KUL)
Belgian NMO : Aurélie FINDERS-BINJE, Delphine FINDERS-BINJE, Kara DELRUE, Lucas CEK, Patrick Finders-Binje, Marie-Hélène LEVAQUE, Maxime GREGOIRE, Miguel LOZANO, Remi ARNAUTS, Winand EERENS, Ynse ANDRIES, Yves DELRUE.
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