

**Partnerships, driving patient independence
and innovation**



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Why should a NMO be involved in education fields?

- Hemophilia is a chronic disease. Education programs should be one of our priority.
- In 2008, AFH decided to work closely with healthcare providers on a new concept : including into educational workshop (medical, nursing, physical and psychological workshop) a trained patient in order to improve these program.
- We decided (Université Paris 13) had to help us to build a consensus (play the «third party»).
- Based on a common assessment, we agreed a trained patient a «patient ressource» is able to bring an added value and help healthcare providers to make the patient understand how important is to be well educated and manage hemophilia whatever his/her age.
- Be a Patient Ressource is also a new way to be involved in our association.
- the following slides show the birth of the Patient Ressource



Therapeutic education to patient, a commitment, a French context, 5 good reasons

- *AFH as Hemophilia society claims “we are first concerned, and nothing that concerns us can be done without us”.*
- An assessment between AFH and HP
- WHO statement about Therapeutic education to patient in 1998.
- 2009 July 21st : HPST Act article 84 TEP
- A strong desire to work with healthcare professionals based on a rigorous methodology

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1) Patient association (AFH)'s answer : We are the first ones affected → we need to act
We, as patients, can play a role so as to find solutions for improving lives of patients & their siblings

2) Assessment from healthcare professional & AFH : Generally, good knowledge on disease & treatment BUT Behaviours or events in their lives prevent many of them from following principles. Or, Patients know treatment procedures in theory, but some behaviors or events in their lives can prevent some of them from following the theory they know.

For example :

- Some teenagers give up treating/prophylaxis (gold standard of care), develop risk attitudes, don't dare speak about their disease
- Some young adults undergo serious surgeries
- They may also have joint repercussions even if prophylaxis exists
- Some adults move away from their treatment center, others suffer from HCV or HIV in addition to haemophilia
- Some mild or moderate hemophiliacs don't know well their disease

Thus, what is at stake for our patient association ? What can be our answer to this issue ?

Drug isn't THE solution. Psychosocial and educational aspects need to be considered : if a patient remains silent or if he claims « everything is ok », it doesn't necessarily convey reality. So, taking care does not merely mean injecting factor. Since hemophiliacs live with their disease for a lifetime, they need another richer learning, more sensitive, better related to their daily life. What we shall do as an association is to help patients and healthcare professionals and find a solution, so as to improve the lives of patients and their siblings.

3) WHO statement based on an international scientific movement. History in haemophilia, it is not necessary to underline the involvement of patients.

4) There is law which gives us a definition « Therapeutic education to patient is part of care. The therapeutic education of patients (TEP) permits a sick person to acquire the essential skills needed to live best with their specific chronic illness. The patient is considered autonomous, not just capable of making his or her own health-related decisions, but a full partner in the process of providing care.

Studies have revealed that TEP provides numerous benefits to the patient: better perceived quality of life, better long-term control of complications, less stress and anxiety and fewer acute or emergency situations [1,2]. In addition, TEP confirms the practical utility of knowledge and skills acquired and implemented in the patients' daily lives [1].

5) In the aftermath the contaminated blood drama, the community was looking for/needed an area of long term cooperation
A strong methodology : composition of the working group : 4 doctors, 2 nurses, 1 physical therapist and 2 patients and 1 parent

1. Four seminars, each one lasting a day and a half.

During these sessions, the group shared a common thinking and broached possible decisions.

2. Six meetings with various experts: a psychoanalyst, a diabetologist, a doctor in public health, two

representatives of patients' associations and a haemophilic patient. Notes were taken during these meetings and the information obtained was used to support and elaborate upon the results of our seminars.

3. The process was completed by reading through a bibliography of related works. Nineteen articles were identified in the Medline database as particularly relevant.

After absorbing these seminars, presentations and papers, the group was able to arrive at a number of unanimous decisions. Each proposition was validated only after achieving consensus within the group.

What is a “Patient Ressource” (PR)?

- “Patient Ressource”: Patient AND Ressource
- Patient/Parent – directly concerned by haemophilia
- Ressource – Value of his life, his experience
- Complementary to healthcare professionals (HP)

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A consensus group composed of healthcare professional and AFH gave a definition in 2008
The initiative defines “patient ressource”. What does it mean, who are they ?

In this expression, there are 2 words : PATIENT + RESOURCES

“PATIENT” makes it clear that this “person” is also an haemophiliac (or parent of a child with haemophilia) : let’s say that he is directly concerned by haemophilia.

“RESSOURCE” : expresses that a patient himself can be a help, a support for their peers. He is not a “technical expert”, he lives with haemophilia. And in that way, his experience is the greatest value for his peers.

In that sense, the Patient Ressource can be involved in therapeutic education as an equal partner to healthcare professionals : he brings another point of view of the disease.

What are the goals of developing this new role ?

- Work in complementary manner with HP
- Go further than teaching injection
- Improve disease management over a lifetime
- Increase patient autonomy
- Put patient knowledge to advantage



What are the goals of developing this new role ?

In this project, we work with Healthcare professionals (HP), everybody complementing each other.

We want therapeutic education to go further than teaching injection technique.

**In addition to drug/product, patient needs to be listened to
“Taking care” is more than injecting factor**

Of course, we want that all the patients ultimately benefit from our project, which aims at :

- improving patient's care and their families' everyday lives, all along their lives.
- putting patients' knowledge to advantage, and to increase their autonomy

Who can be a PR ?

Patients

- with moderate or severe haemophilia
- over 18 years old
- treat themselves frequently

AND

Parents

- with an haemophilia patient child
- > 3 years of experience in treating their child themselves



Who can be a « patient ressource » ?

2 types of people can be candidates:

Patients over 18 yr old, with moderate or severe haemophilia, who treat themselves regularly and frequently.

And :

Parents of haemophiliac children, with at least 3 years of experience when treating their child themselves.

These people's role is to participate in therapeutic education training that concerns everybody with haemophilia.

How does a patient become PR?

1. Recruitment
2. Training and evaluation
3. Involvement in therapeutic education sessions

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There are three steps before having patients or parents becoming “patients ressources”.

They are recruited and then they are train so as to develop the required skills and to have the required level of knowledge. They will be evaluated at the end of this training. Finally, these PR will be ready to be involved in sessions dedicated to therapeutic education across the country.

They are able to be part of different workshop (medical, nurse, physiotherapy, psychosocial)

Recruitment and Training

1. Candidates need to enter in a recruitment process.

2. Second, Training

- Capitalize on self experience
- Reinforce knowledge about disease and management
- Develop communication skills
- Help patients improve

What are required skills at the end of training ?

1. Explain haemophilia and its management
2. React appropriately to at-risk and emergency situations
3. Define his role as a PR
4. Implement communication skills in organized meetings with patients (education session with HP)
5. Help patients to learn



Recruitment, training and evaluation.

1) Recruitment :

Haemophilia center and patient association identify eligible candidates.

Recruitment takes place via many ways (posters, leaflets, articles in the association magazine, telephone, individual meetings, internet...). Candidates apply for « patient ressource » status to HTC's.

Candidates need to write a letter where they express their motivations to participate. These candidates should be naturally empathic with their peers, and should be willing to pass on their knowledge.

A next step in the recruitment is that the candidate is invited to an interview with a healthcare professional from the HTC and a member of the national association.

The candidate are reminded all the skills needed to be « patient ressource » before the interview.

2) What are the objectives of « patient ressources » training ?

Based on his proper experience, the patient ressource will reinforce his skills on the disease and its management, so as to feel comfortable within his team and in front of his peers. He also will acquire coordination skills so as to be able to speak during therapeutic education sessions.

Finally, he will learn how to define the scope of his role in facilitating his peers training.

Educational objectives of this PR training consist in being able to :

- Explain what haemophilia is and how it's taken care of (mainly self-training)
- Recognize and describe at-risk or emergency situations encountered in haemophilia, and react with the appropriate behaviour
- Define the role and place for the patient ressource
- Implement coordination skills suitable for therapeutic education meetings with patients
- Help patients to learn

What form does this training take ?

- Previously : PR meet initial requirements for each objective
- 1st : self-training (knowledge)
- 2nd : training on-site (communication skills)
- 3rd : evaluation of skills
- Aware of professional confidentiality
- 10 people trained as PR per year (of 1500 eligible people). In 2011, two trainings (last one in nov and dec)

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For each of these objectives,

The patient resource needs to meet initial requirements before being allowed to train : a self-training programme reminds them with big ideas.

The training itself enables him to reinforce some knowledge and to acquire other skills, so as to meet final educational requirements. Notably, there is a focus on professional confidentiality.

At the end of the process, these people are assessed so as to evaluate how they developed each skill required.

AFH wants to train 20 patients and parents as PR within 12 months (within 1500 people eligible for « patient ressource », according to the national demographic database France Coag).

Step 3 : PR's role in therapeutic education sessions

- Complementary to HP
- Not only the gesture, but the behaviour
- Advice, support, testimony
- PR's role towards their peers
 - Help reformulate
 - Listen to
 - Show experience
 - Help facing difficulties
 - Be a link, support

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This is a great thing that patients can be involved in therapeutic education sessions for patients.

“Patients ressources” can bring a help and support complementary to that of healthcare professional.

PR will not teach how to self-infuse, but would preferably work on behaviours :

he will listen to his peer, and will try and support him to improve in his disease management.

He could be a live example of what to do and what not to do. Since he has the experience, he may be a powerful mode of incitement for others to imitate him or to follow his advice.

The « patient ressource » has the following roles towards their peer = help him to reformulate, listen to him, show him his experience, help him go through difficulties, be a link, prevent him for isolation.

How do we make sure that the process is helpful ?

HP and patients are asked for their assessment of how they perceive :

- training efficacy
- training usefulness
- role in therapeutic education process
- level of skills required for being PR



PR are then invited to evaluate the whole process so as to define if it is as useful as we believe, and so that they suggest improvements :

So as to better assess the interest of having complementary partners, both healthcare professionals and patients are also asked to give feedback on how they perceive :

- 1/ the training efficacy (with regards to the educational operation and to the patients resources expectations)
- 2/ the training usefulness (with regards to the first experiences as patient resources within therapeutic education sessions)
- 3/ patient resources role within therapeutic education operations
- 4/ the level of skills aimed at by the training operation

Action Patient Ressource : a collaboration between



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des hémophiles

Afh (Association française des hémophiles)



Cometh (Coordination médicale pour l'étude et le traitement des
maladies hémorragiques constitutionnelles)



CRMH (Centre de référence de l'hémophilie et autres maladies
hémorragiques constitutionnelles)



Fidel'hem (Fédération des infirmières françaises de l'hémophilie)



Grikh (Groupe de Réflexion et d'Information sur la Kinésithérapie
des maladies Hémorragiques)



Format Santé



Laboratoire de pédagogie de la santé EA3412 - Université Paris 13
(Bobigny)

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You can see on this slide the different partners : french hemophilia society, the scientific society, reference centre, nurse association, physiotherapist group, Education trainer, University Paris 13.

PR was awarded specific grant from French MOH : 80.000 € and published an article in Haemophilia Review in 2010

Haemophilia
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ORIGINAL ARTICLE

Patient resources in the therapeutic education of haemophiliacs in France: their skills and roles as defined by consensus of a working group

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the Ministry of Health awarded this action programm 2011 and a specific grant of 80.000 (eighty thousand euros) to organize an evaluation/an assessment at national level.

the results will be presented during the WFH Congress in Paris

*Many thanks for your attention and see you in
Paris, 8-12 July 2012, WFH World Congress*



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