

HAPPY HOUR

1/2
with an expert in haemophilia care!

Join and have your questions answered!

Of course
I talk to myself.
Sometimes I need
expert advice.



“How to Become an Expert Patient? Communication with your NMO and HTC”
with expert patients Miguel Crato, Portugal and Jim O’Leary, Ireland

HOW TO SUCCESSFULLY COMMUNICATE WITH YOUR NMO*?

***National Member Organisation**

Even though this is about the communication, the first thing I want to state is that above all it is about recognizing the problems in your NMO and being diplomatic and helpful in addressing them. I have also divided my talk in three parts: 1) Create a plan and follow a strategy; 2) How to find people with inhibitors; 3) Let’s do it! – it means that you need to do something with your information and with your plan.

Step one - create a plan and follow a strategy

Generally, especially in the past (now things are a bit better), the NMOs do not recognize the necessity to have a special plan for people with inhibitors. As a consequence, PWI did not attend the events of the NMO, did not participate, did not talk with each other, did not tell the NMOs what are their problems.

So, the first thing is that you need to do is to create a plan what to do with people with inhibitors and how to involve them.

This plan must come from the board of the association.

Step two - how to find people with inhibitors?

When you have a plan made, you need to find the people. **You need to ask – where are the PWI?** For example, in Portugal, we know that we have around 30 people, but in our NMO we have only 12 PWI, so where are the others? We need to find them, we need to bring them to our NMO and help them with their problems, so that they can help the NMO with the common segment of the inhibitor work. So, a call to join is the

first thing you need to do for PWI. You can do it in several ways.

If you have a newsletter, you can create a call to action and say: we are now creating a plan for PWI, we are starting to develop some activities, some groups, so please join us and start with contacting us!

Also, **the HTC is a very good source for recruiting people. Of course, you have to have good relationship with the HTC, especially the key doctors in each HTC**, so that you can have a frank conversation with them about the needs of PWI

and ask for their help, for example, by giving your number or the

number of the NMO and asking the PWI to contact you. In Portugal it

happens a that the parents of the newly diagnosed children contact us and we are able to support them. You must not forget the nurses, because they have more direct contact with the patients.



When you have made the initial contacts, you need to have a direct contact with them.

Not only the newly diagnosed people or newly recruited people, also those in your NMO that you have not heard from a long time. You need to pick up the phone and call them and ask them how they are doing and what kind of help they may need and explain them what you are doing in the NMO and why it is important to join.

The next step then is to make the face-to-face contact. To meet them in their homes. We did that in Portugal and it worked very well, because they felt they are in a safe environment and they felt more relaxed when talking to us.

Even though we might approach the outreach in a way that does not violate the GDPR, the doctors may be a little afraid and cautious nevertheless. How would you approach that?

This is again about building the relationship of trust with your doctor. If the doctor trusts you and your intentions, naturally, they will pass the message. After all, you are not asking them to give the private details of their patients, you are just asking to pass a message. Sometimes it is also helpful to have numbers of couple of parents of children with inhibitors in your NMO. So that parents can get in touch with parents. That can feel safer to them.

How would you build this relationship of trust with the HTC where you personally are not a patient, maybe in another city than where the NMO is located?

You can start by organizing a national scientific commission in your country, and invite each HTC to nominate a doctor to this commission. It does not mean that this commission has to meet frequently, but when you have events, invite them to attend and to speak at these events. This way they are getting used to speaking with patients. **They will see that you are organised and professional, that you have a plan and are interested in discussing scientific matters.** You need to show that you have at least minimal scientific basis to discuss with them. This way they will start respecting you more, get closer to you and participate more in your events.

Of course, this takes a lot of time to build this.

Step three - Let's do it!

So now we have a plan, we have the people with us, what should we do with all this?

I think the first thing that needs to be done, is creation of a committee. You can call them a committee or call them a group. Give them a special position in the NMO. Also, give them a chance to nominate one or two people to be in charge of this group. This will enforce their self-esteem and show them that you trust them to organize something and give the ideas for the NMO to implement. **So that it is not only the board giving them route to follow, but the other way around – they give advice to the board on what should be done for the PWI.**



It is very important to start building some materials, if you don't have them. EHC is a very rich source of materials right now, so you should ask the EHC what kind of materials they can give you to adapt and use. **Start organizing your materials designated for the PWI. Then, when you will have new PWI, you will have information to give them and you will have your committee that you can direct them to.**

This way you have two very strong point-to-band people can trust you.



Another thing that it is important and for Portuguese society works very well, is to **create a chat group or message group.** I can tell you that almost every day people are exchanging messages about things that are important for PWI, new drugs, side effects, what are the EHC doing, should they join H1/2H etc. This way they can share experiences. **In the world of haemophilia, not only inhibitors, sharing experiences is one of the most important things.**

IMPORTANT MESSAGE!!!

Further, if it is possible for your NMO, **there should be a PWI or a parent of a child with inhibitors on the board of the NMO.** It is very important and sends an important message to the community.

Next point is creating events for PWI. At least once per year or once in two years, there should be an event specifically for PWI. It could be a weekend, it could be a day, two days, it does not matter. Also, if you have an event where all the topics that are addressed are related to inhibitors, it does not matter, if you have eight, thirteen or three people in the room- those are the

people that are interested in inhibitors and they could build this inhibitor community in your country. **You should always ask a doctor and/or a nurse to be there at those events and do their talks, to share their experiences.** It is also very important that they see that you are organizing specialized events and that you are interested in the scientific aspects of haemophilia and inhibitors. And in the same time, you should include in the programme some workshops, have PWI share their experiences, in an environment where the other people have similar challenges, and it is all about inhibitors. Portuguese NMO are doing this for three years now and it is a huge success. Now we have about 22 PWI in our little group.

Finally, go international! EHC has plenty of things dedicated to PWI. There is the Inhibitor Summit, Pre-Conference Workshop, Happy ½ Hour. The face-to-face events several people can attend, and they can share the experience and gain new knowledge that they can then share back home, thus further educating and strengthening the community back home.

Therefore, it is important that each NMO has an **INHIBITOR AMBASSADOR**, to be the interface for PWI and transmit the info directly and send people to the events.



What about different contexts? Would this work also in a situation where you have a very small number of PWI?

It is the responsibility of the whole haemophilia community to be aware of the complexity of inhibitors. If you have small numbers, you can still hold a day meeting for those 2-3 people, you can invite their families, healthcare professionals, other members of the NMO that don't have inhibitors. You can still make something out of this!

You can also go regional and try and join forces with other NMOs. The EHC is always happy to help you both, practically and with the programme, as well as by attending the meeting.