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

## WHO IS THE EXPERT PATIENT?

**What does it mean to be an expert patient? Is there an expert patient certification available anywhere, so that they can be officially recognized as expert patients?**

**Jim:** My view about being an expert patient is that I am not an expert patient. If I lived to the age of hundred years then maybe I would be an expert. What I am saying is that I have a lot of experience and the more experience you have, the more expert you can become. But I have not heard of this kind of initiative of expert patient certification.

**Miguel:** If we think of the expert patients, we can think of the fact that the NMOs are nominating some patients to become members of national bodies, for example national haemophilia commission in certain countries, or a tender board or similar. Those patients have been indicated by their organisation to be the expert patients in the room and in the discussions. If we think that even the doctors who are in that room need a special designation, then it makes the patients in the room expert patients. Even though it is not an official diploma or a certificate, it is a formal indication.

**But I agree with Jim that each patient needs to have their own expertise.** The outcomes that they can bring to the discussion are the paramount for the discussion with the doctors, with regulators or other stakeholders, when discussing any issue related to haemophilia or other bleeding disorders.

In conclusion – we are experts, we have the most valuable information to give, and if your NMO gives you a mandate to be in a meeting, you can be considered an expert patient.

**What about need for those expert patients in situations, when a patient has to go to an emergency room and deal with doctors that are not familiar with rare diseases, such as haemophilia. Do you think it would be helpful to be recognized as an expert patient that could support the other patient in that kind of situation?**

**Baiba Ziemele, Latvian Haemophilia Society:** I have heard about an initiative in some countries of a patient-peer who has a better knowledge and better understanding of the disease and the treatment, so when a patient goes to a hospital or has an emergency room situation, he can take this patient-peer with him or call him, and the patient-peer would help asking questions that the patient him/herself would not think to ask and guide him/her through the situation. I think that in our community we are already doing this unofficially.

**Miguel:** Normally, when faced with cases of patients with rare chronic diseases, the emergency room should immediately get in touch with the department of haematology that is designated as a reference centre. As we know to be designated as the European Haemophilia Treatment Centre, a treatment centre should have 24h access to services. So that should guarantee the 24h emergency consultation.

However, in reality it does not always work that way.

**I also want to add that for you to recognize that something is wrong with the evaluation of the doctor who is in front of you, first you need to be expert by yourself.** You need to know what issues to address, if/ when you recognize that something that is not right. So, in order to be able to evaluate what is the situation and whether what doctors are saying to you is correct or not, the starting point is to be your own expert and your own advocate. You can’t just say to a doctor- you understand nothing because you work in the emergency room-, you need to recognize that something is not right. And of course, you need to have with you the haemophilia card (that is available in some countries), put it in front of the doctor and say: this says that you should immediately contact the HTC. It is mandatory, so they need to do it.

