

Patient Advocacy Advisory Board – April, 21st 2016, Zurich.

A european day meeting organized by Takeda between nurses and associations of patients: the opportunity to share our field experience through myeloma treatment, and even though there are some differences between countries, patients have the same expectations in support and monitoring.



Nicole, Julie, Kate, Elfi, Anne, Roman, Venche, Jacob, Eugenia, Ann, Cecilia, Lise-Lott

First contacts between european **patients** advocacy groups started during a buffet, most representing an association of patients having an haematological disease, from Austria, Poland, Norway, Sweden and France. Quickly, we admire patients with longer path : a woman for 27 years, and a man for 17 years ! The afternoon started with a summary of the morning work of oncology **nurses** from Sweden, Spain, Finland, Norway and Belgium. These nurses in constant contact with patients, listening to them, have assimilated the complex pathway marked by questioning, waiting, intense treatment periods, and lack of moral after several lines of treatment.

This vision was written on the wall : first symptoms with effects up to 2-3 years before the shock of the diagnosis (or a kind of relief once diagnosed), everyone's dealing with the diagnosis according to one's own context (social or cultural) and the difficulty not only to understand illness but also treatment protocol. Without forgetting anxiety of waiting between 2 treatments.... and relapse.

Then, with our experience of the disease and as reporter of our association members, we have completed step by step the scheme of the patient pathway :

- The emotional impact of diagnosis, the (un)capacity of acceptance, the patient is not always in active listening so to receive the information from specialists
- side effects management, and pain management.

Quickly we make the same statement about what can be spread to support patient :

- # develop support care (including follow-up management after intensive therapy by nurses) ,
- # fluidify the patient-physician communication to identify the impact of side effects
- # organize patients support groups, communicate on new drugs (conferences), to reassure and give hope

Coached by Tracy from the beginning, the whole group discussed concrete solutions such as the education of patients but also of nurses.

Then we end this afternoon the patient group only, to identify the means and what would encourage greater adherence to therapy. Most people follow their treatment if the Dr said it so, however the observance seems personal, maybe related to a certain age range !?

Today, the progress of the research and the complexity of the being implies a more global approach of the patient, to help him to live better with myeloma.

It's obviously very important to **provide information** (on every channel, everyone not having the same facilities), and it's also compulsory to create a **positive thinking**.

Conferences, meetings, debates, discussion round tables with families are one of the key of support.

Special thanks to all attendees for having shared their vision the whole day,

Many thanks to our time master, who has also summarized our thought in a structural way,

And thank you to the whole team carried out by Takeda who organized this nurse & patient advocacy group advisory board.

By Anne DELMOND-DAVANTURE
AF3M, France