

First Dutch patients meeting

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By Caroline Kooy, Volunteer, Chordoma Foundation Europe

On September 17, 2016 more than 70 doctors, patients, and their families came together for the first Dutch patient conference of the Chordoma Foundation. This day was organized in cooperation with the Leiden University Medical Center. In the morning session the medical specialists presented the state of the art with regard to the different treatment methods. During the afternoon the patients spoke about their experiences and the expert panel answered questions of the patients.



WELCOME

A representative of the Chordoma Foundation Europe opened the day and described the two goals of the Foundation, which were also a guideline for the program of the conference: to accelerate finding a cure and helping patients with chordoma.

PART 1: WHAT IS CHORDOMA?

Pathologist Prof. Dr. Pancras Hoogendoorn started with an overview of how chordoma looks under the microscope. "It is a smart cell, which manages its own energy supply by storing sugar so no blood supply is needed to survive. The cells lie in a gelatinous mass that can grow indefinitely and therefore chordoma is difficult to remove in one piece without spillage. If a small portion is spilled, it can grow into a new chordoma."

A logical next step was the more 'zoomed in' story of Dr. Karoly Szuhai about the molecular structure and how further insight is used for the development of a drug. "Proteins from specific genes form the hidden code that can ensure that a medicine recognizes the tumor and can destroy it, for example by ensuring that it does not grow."

Dr. Carmen Vleggeert discussed the importance of tracking and recording of experiences of patients with different treatment methods in a European database. Patients attending the day could indicate by a survey if they wanted to cooperate.

PART 2: SUMMARY OF TREATMENTS

The situation regarding the three current treatment methods — surgery, radiation, and systemic therapy for a more advanced stage of the disease — were discussed by Prof. Dr. Wilco Peul (Clival Chordoma), Dr. Sander Dijkstra (Sacral Chordoma), Dr. Stijn Krol, and Prof. Dr. Hans Gelderblom. “It is important that the treatment method is discussed with the patient, depending on the medical options, but also on the balance between survival and possible side-effects”. Prof. Gelderblom also gave an overview of current clinical trials, in which research results on drug development are tested on patients.

PART 3: EXPERIENCES OF PATIENTS

Chris te Stroet, representative of the Chordoma Foundation in the Netherlands, presented his experiences as a patient participating in a trial in the US, where a drug is tested using research by Prof. Adrian Flanagan (London, UK). The Brachyury protein has been proved to be present in 97% of the chordoma. This protein is used to recognize the tumor by attacking cells in the blood system and thus to initiate an immune reaction.

Hans Labrijn talked about his experiences with the patient forum on Facebook and asked whether there was a need for a Dutch FB group.

Caroline Kooy, representative of the Chordoma Foundation in the Netherlands shared her own experience with fundraising and showed an overview of what has been achieved in the Netherlands with regard to fundraising. One large sum or many small ones, it does not matter; everyone can contribute in his/her own way. “If we as patient community will not do it ourselves, who else will do it for us?”

The presentations of patients were concluded by Kim van den Enden, who told a touching story about her quest for a proper diagnosis and treatment. She wrote the book: “It's between your ears.”

ASK THE EXPERTS

The day ended with open questions from the participants to the experts panel. This became a long and lively dialogue, the doctors answered open and accessible and noted that there is still room for improvement in the coordination between the patient and the multidisciplinary medical team. The possible role of the Dutch section of the Chordoma Foundation in helping the patient to connect to other parties, such as insurance companies, was discussed.

CLOSING & THANKS

After a summary of the day there was an opportunity to talk to each other over drinks. Many thanks go to the LUMC and its doctors for helping organize this very useful day!