

Draft Summary of 9-21-08 ECD Chat

Chat Date:
9/21/08

Time:
8 am Eastern time

6 Attendees

Draft Summary:

One patient told the group about his meeting on Wednesday, 9/17/08 with Dr. Haroche and his division chairman. The following are the points of interest that were discussed.

Please note that this information is for 'discussion only'. Work is underway with Dr. Haroche to make certain their communication was clear and what is written below is correct. It is very easy to misunderstand as the discussions are not being held in anyone's native language. We will forward out the final summary after Dr. Haroche has had a chance to review it.

1. Dr. Haroche is open and available to discuss ECD with doctors. Treating doctors are welcome to or write him. His contact information is as follows:
Haroche, Julien , M.D., Ph.D
Service de Médecine Interne
Hôpital Pitié-Salpêtrière
47-83 Bld de l'Hôpital
75013 Paris, France
julien.haroche@psl.aphp.fr
33 1 42 17 80 37
33 1 42 17 80 32 (fax)
1. Dr. Haroche will submit a white paper within 2 weeks to explain his plans regarding the HLA tests he has proposed. He has agreed the HLA tests can be done locally by the treating physicians. He verbally explained the purpose of this test is to check the connection between HLA I II to the different symptoms of ECD.
2. Dr. Haroche will review our website and will comment if needed. He has given us permission to add his contact information (listed above) to our 'Physicians' page which has been done.
3. Dr. Haroche's primary treatment for ECD with good results is Interferon alpha at 9mil 3xweek. Other suggested treatment for those who do not respond to the interferon is Cladribine with limited success. (Kathy's note for clarification purposes only: This dosage is when the disease is in an active stage if I understood correctly.)
4. Dr. Haroche says he would be happy to work with a team of doctors focused on ECD. He would like to arrange a workshop of such doctors sometime during the next year (in Paris, of course, which may limit the number of doctors who would be able to participate.)
5. The hospital where Dr. Haroche practices is one of the biggest, if not the biggest, in Europe. It is the Pitié-Salpêtrière Hospital. They have treated about 30 ECD patients

6. Dr. Haroche did not have any new information to offer regarding treatments other than interferon and cladribine. Other treatments such as cellcept and methotrexate have not been tested, but they do not believe these medicines will have an impact on ECD.
7. Dr. Haroche is open to working with our team . Kathy's story was presented to Dr. Haroche and he is willing to work with her as well. (Additional information after the chat session.)
8. Dr. Haroche explained how money is needed to pay for additional research activities. He noted that any organization that will be open to contact and donate money will help to promote his activities related to ECD.

We thank our member greatly for sharing with us all he learned in talking with Dr. Haroche.

Please email support@erdheim-chester.org if you have any questions or concerns about these minutes. Thanks.