

## **Julien Haroche, MD, PhD / Conversation with Member of ECD Global Alliance 17-Sep-2008 in Paris, France**

The following information is from Dr. Julien Haroche at Groupe Hospitalier Pitie-Salpetriere in Paris, France. This information was communicated directly by Dr. Haroche to one of our members, Gadi, on 17-Sep-2008. Both Dr. Haroche and Gadi have agreed to have this information posted here.

Please remember, this information is presented here for information sharing purposes only. This is general information and is not meant for treatment purposes. Each individual treatment plan must be tailored to an individual. Consult your treating physician to discuss your personal treatment plan.

1. Dr. Haroche is open and available to discuss ECD with doctors. Treating doctors are welcome to call 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)  
The hospital where Dr. Haroche practices is one of the biggest, if not the biggest, in Europe. They have treated about 30 ECD patients.
2. Dr. Haroche believes treatment for ECD includes steroids, cytostatic agents and double autologous hematopoietic stem-cell transplantation. The efficacy of these treatments is difficult to determine because many of these therapies have been used in few patients or in combination with other drugs and/or with a short follow-up.
3. Dr. Haroche believes IFN $\alpha$  (initiated at 3M X3 per week) should be considered as a first-line therapeutic option on a long-term basis for ECD. When Central Nervous System and/or cardiovascular system are involved the doses should be raised up to 9Mx3 a week as these involvements are often more difficult to treat. Dr. Haroche's recommendation is based on the experience of Braiteh et al (editor's note: this is Kurzrock's team) and Dr. Haroche's team.
4. Failure of treatment by IFN should lead to more aggressive or experimental alternative regimens and should be discussed individually. About 2CDA (cladribine), some case reports have said it was efficacious but Dr. Haroche's team has had 2 failures with this treatment.
5. Dr. Haroche has not tested treatments such as cellcept and methotrexate, but he and his team do not believe these medicines will have an impact on ECD.
6. 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 next year.
7. Dr. Haroche explained how money is needed to pay for additional research activities. He noted he would be open to discussions with organizations able to help with funding of his activities related to ECD.

Please email [support@erdheim-chester.org](mailto:support@erdheim-chester.org) if you have any questions or concerns about these notes. Thanks.