

Summary of 8-8-08 ECD Chats

Chat Date:
8/8/08

Time:
3 pm Eastern time

5 Attendees

Summary:

Skype

The use of skype for future chats was discussed. A test of a Skype conference call was performed on 8-7-08 with three members. The technology worked great – it was clear, with no apparent lag in the audio transmission and easy to use. It might be somewhat difficult to use this technology with a large number of people in an open chat without an agenda as it would be easy to ‘talk over’ each other. However, with a small number of people or in a chat with a clear agenda, this looks like a great technology.

Everyone is encouraged to download the free software from www.skype.com and register as a user. You will also need a headset or a microphone and speakers. With this you will be prepared to participate in future skype chats as they are scheduled.

Dr. Haroche’s Proposal via Gadi

There is no new real information from Dr. Haroche’s proposed study. Everyone is still encouraged to talk to their doctors about having the HLA test performed and getting the information to Dr. J. Haroche in Paris. Some patients feel they will be able to get the HLA test done by working with their local doctors and using their personal finances. Others are not finding it so easy. Work is still ongoing to find a way to transport the blood samples Dr. Haroche has requested. Some investigative work has been done looking for a simple and cost-effective way to do this. To date none have been found. However, an organization called National Disease Research Interchange (NRDI, www.nrdiresource.org) has a program that MAY be able to help us. Unfortunately their seemingly great service would cost money and more investigation is needed to find a source of funding. As we learn more we will let you know.

Activity to Help Raise Awareness of Orphan Diseases and ECD

One patient talked about his efforts to help raise awareness of ECD in his community and to provide inspiration to others facing a difficult diagnosis. He has begun work to organize speaking engagements. He is wished much luck in his worthwhile activities. We look forward to hearing more about this.

UK Histiocytosis Newsletter

Our English patient and his wife announced there was a section about ECD in the most recent UK Histiocytosis newsletter. It contains an article written by them about their experience. They will work to get us a copy. Their efforts to write the article and get us a copy are much appreciated; can't wait to see it. Perhaps if we talk to the HAA they will follow the lead on this.

Number of People with ECD

A discussion was held about how many people have been diagnosed with ECD. The latest statistic is that there have been a total of 250 published cases of ECD. This does not include undiagnosed or un-published cases. Has anyone ever seen an estimate of how many total cases the experts believe there are?

Website Support

If anyone knows of someone who could help with building an ECD specific prototype website, please let the group know. A suggestion was made that perhaps a school or university could help us. We'll investigate this idea a little further.

Orphan Disease / ECD PowerPoint Presentation

A presentation is being put together for people to use to help raise awareness of orphan diseases and ECD in particular. It will be available to anyone who has use for it. There is a thought that pictures of ECD patients and their families might help drive home the point that this disease (or other orphan diseases) happen to normal, every day people just like the folks who will be listening to the presentation. Please think about this and if you are comfortable with your picture being used, please email it to support@erdheim-chester.com. No names would be used in the presentation.