

Summary of 9-27-08 ECD Chat

Chat Date:

9/27/08

Time:

3 pm Eastern time

4 Attendees:

Summary:

- The new website was discussed. Everyone was very happy that the HAA graciously added a link from the www.histio.org website to the www.erdheim-chester.org website. Some new members have registered with the ECD Global Alliance using the website. Members in the chat were happy with the direction the website is headed.
- We need to work to get the website closer to the top of the list with the search engines, such as google. We need to work to get more websites to link to us and whatever else we can do to move us up on the list. If anyone has any other ideas to do this, please send an email to support@erdheim-chester.org. Since we have not have a budget, paying to move closer to the top is not really an option.
- There was discussion about how we might be able to go about raising awareness of ECD with the pathologists and radiologists. Since these are often the doctors who first suggest ECD as a diagnosis, our efforts might well be spent targeting these doctors with our awareness programs. We are currently compiling a list of all doctors who have written papers on ECD to let them know about our new website and solicit their opinions and ideas.
- The participants discussed how many doctors might not look for a rare disease when presented with the symptoms and signs of ECD. It seems to the patients that more doctors will look for a rare presentation of a more common disease than an extremely rare disease. As a consequence getting a correct diagnosis of ECD is difficult at best.
- At least one doctor even told a patient they were not suffering from ECD when the patient's family asked about that disease specifically as they were searching for a diagnosis. It seems a doctor must have a particular 'mind-set' to do what is necessary to arrive at a correct diagnosis for ECD and most likely other rare diseases.
- Even with biopsies some patients fail to get diagnosed correctly with ECD. The signs are simply missed. Patients have gone completely undiagnosed or have gone years until another doctor looks at the signs and symptoms and goes back to reevaluate a previous biopsy.

- One patient had 2 biopsies of the adrenal gland, skin biopsies, and kidney biopsy and still did not receive a correct diagnosis. Another patient had only one of the signs/symptoms attributed to ECD. A third patient had a biopsy of the tissue behind the eyes which failed to provide a diagnosis until 2 or 3 years later. A fourth patient had a kidney and skin biopsy and it was the skin biopsy that helped with the diagnosis.
- A discussion was held about Dr. Haroche's study and the fact that he will be writing something up for doctors to read about the study.