

Summary of 2-15-09 ECD Chat

Chat Date:

2/15/09

Time:

3:00 pm Eastern time

5 Attendees:

Summary:

- One patient saw a consulting doctor, who is knowledgeable and has seen multiple cases of ECD. This knowledgeable doctor laid out a treatment plan, but the local treating doctor is not willing to pursue the plan. For this reason, the patient is searching for a new local doctor who will work with the knowledgeable consulting doctor. This is a difficult situation.
- Another patient shared with the group a recent experience they had when seeing a doctor. Because of the nature of the problem and the timing they ended up seeing a doctor they had never seen. When the doctor heard ECD as a diagnosis the patient says, “he got a look of terror and after looking at the ok x-ray, said I’d just have to live with it.” It was discussed how easily this can make a patient feel like a doctor just won’t take the time to get the background and knowledge needed to best treat the problem.
- Issues with orbit (eye) involvement were discussed.
 - Two of the patients had orbit issues as a first symptom/finding.
 - One of these patients obtained an ECD diagnosis based on a biopsy of the orbits. This patient had surgery to remove a tumor from behind the eye and now wears glasses to help with the double vision.
 - Another patient was initially seen with retro-orbital swelling. It was this finding that began the investigation which eventually led to the ECD diagnosis. However, there was never a biopsy in this area.
 - A third patient has only recently begun to see eye involvement in spite of having dealt with ECD for 18 years. This patient finds their eyes are always running or getting cloudy to the point where reading is impossible. The patient is also finding their sight issues are changing almost weekly. They have an eye doctor who now also suggesting Sjorgren’s Disease because of the constant dry eye and mouth.
 - A fourth patient has had recent cataract surgery on both eyes and finds their vision better now than a year ago.
- Our patient who has an appointment to see Dr. Haroche in Paris will be there in less than 2 weeks. We were reminded that Dr. Haroche has

reportedly seen 40 ECD patients. It will be interesting to hear what is learned during that visit.

- There was some talk about sharing recipes. Those in the chat room shared some recipe ideas and suggested that future newsletters had some space dedicated to further sharing.