

Summary of 1-25-09 ECD Chat

Chat Date:

1/25/09

Time:

2:30 pm Eastern time

11 Attendees

Summary:

- A new person joined the chat looking for information about possible treatments. This patient experienced about 10 years of weird symptoms before they were diagnosed at Mayo in 2003.
- Another patient was looking for anyone being treated with cytoxan as he will begin this treatment soon and was wondering what to expect. Unfortunately no one in the chats had any experience with cytoxan as a treatment.
- One patient shared with us his good news concerning his latest PET scan which showed reduced activity. We all love hearing good news!
- Some patients discussed their treatments as discussed below:
 - Patient 1 – Will continue interferon while adding a course of chemo, tapering steroids and adding a drug like actonel for bone pain control. This treatment plan has recently been prescribed by Dr. Arceci at Johns Hopkins.
 - Patient 2 – Back in 1999 Mayo suggested the following treatments that were all tried over several years –
 1. 6 months of Vinblastin (chemo);
 2. Two trials of 2CDA;
 3. Then two radioactive injections of Samarium 265 or 285 can't remember the exact one
- The following eye issues were discussed by various participants:
 - One patient had double vision which seems to be better now. He used to require two pairs of glasses: one for distance and one for reading. He is now able to get by with a single pair.
 - Another patient's first 'presentation' was binocular retroorbital masses. Two sets of glasses are now required: one for distance and one for reading. It seems difficult for eyes affected by ECD to cope with multi-focal glasses.
 - Masses behind the eyes has caused yet another patient to experience double vision.
 - One patient had a mass the size of a nickel removed from behind/to the side of his right eye. There was an attempt to remove the mass through the nose, but ended up going in near the tear ducts.

- Another patient is just learning her double vision might be attributed to ECD. She has been diagnosed with macular edema for several years.
- A question was posed as to whether any patients had odd growing fingernails, especially any issues with ridges in the nail. Some mentioned their nails seemed to grow a lot and need cutting. One mentioned difficulty with chronic ingrown toenails. The question was raised because one patient is experiencing ridges and a doctor suggested it might mean something. One knowledgeable person in the chat room suggested there are multiple diseases that can cause ridges in the nails. The patient with the ridges thinks perhaps the issue has become more pronounced since being on tamoxifen.
- There was a question addressed to those taking interferon on MWF about whether the side effects seemed worse on Tuesday than any other day. It seems some patients find the effects of interferon are worse after '2 days of rest'. A question was raised asking if the side effects might be lessened if the interferon were taken every other day instead. One patient had previously taken interferon every other day and had few side effects. However, it is more difficult to remember what days to give the medicine. This particular patient forgot once and remarkably found the next (delayed) treatment much harder to tolerate.
- Nausea was discussed briefly. One patient is looking for ways to combat this. Few in the chat room experience nausea as a side effect of ECD. However, at least one patient seemed to find the drug zofran helpful in treating nausea. There was mention that some of the drugs patients must take can cause nausea. A couple patients find they can lessen these affects if they are careful to eat when taking their medicines.

An addition by a participant after the session: the patient experiences brief (3 min periods) of nausea with no apparent pattern: feels perhaps related to impaired sense of balance – balance has deteriorated since onset of ECD. This is the same pattern of nausea that was experienced by another patient with most of his nausea periods occurring in the morning hours.

- A couple patients discussed issues they were dealing with regarding hernias. One patient has recently had one repaired and is doing good. Another will have his third hernia fixed this spring. After the chat a third patient mentioned he has also had two hernias fixed (an umbilical hernia and a para-umbilical).
- One patient finds his energy levels increased with more 'up time' since consuming more 'whole foods' recently.

- A request was made for everyone to check out the NORD website (http://www.rarediseases.org/rare_disease_day/rare_disease_day_info) and do what you can to raise awareness of rare diseases. Remember, Feb. 28, 2009 has been designated rare disease day.
- The benefits of Home Health were discussed for those who are home bound and need help. This help can be everything from general nursing, wound care, IV treatments, therapy, general house keeping, bathing help, training for the patient or the caregiver, etc. Doctors will usually order this for their patients when necessary but sometimes the patients must ask the doctors about it to remind them to order it when appropriate.