

Summary of ECD Global Alliance Internet Chat

22 September 2012

10 Attendees

- A member came on before the Chat to explain that he was going on a picnic so would not be attending. The dentist has found infection in 2 teeth, and root canal work is planned. The oncologist has contacted his family doctor asking for him to be seen soon. He thinks that this is in regard to his depression.
- A new member came on, having received biopsy results this week, and wanting to learn about ECD, and meet others who have it. The new member's doctor has heard of ECD, but has no experience with it. High blood pressure has been a problem, retroperitoneal fibroses around the kidneys, and dead bone in the legs. There has not been much pain. There is also a cough that has puzzled the doctors.
- Another member gave his story. He was diagnosed in 2004, and is now 72 years old. He started with painful legs and just feeling "bad" all the time. His temperature would go up every night at about 7pm to 101-103F and he would have cold chills. The ECD does some of its "work" in the long bones. He had a CT scan that showed fluid in the sac around the heart (pericardial effusion), and was told that he would survive about 2 years. He had 2CDA (also known as cladribine) chemotherapy, and this halted the progression of the disease.
- Another member told us that he was diagnosed in 2005. He was a Family physician, himself, for 20 years before he got sick, and had never even HEARD of ECD. He had to retire aged 45!! He had interferon, later chemotherapy was added. Then he got a VERY bad chest and it all got stopped. Then steroids, then cladribine injections (under the skin). For the last 2 years he has been just taking methotrexate (another form of chemo) once a week, and has, since, been stable on that treatment. Many doctors had been visited over the UK, but now, the medical team are just a cab ride away in Leeds.
- A member said that their treatment was interferon for the last 5 months and steroids. Side effects of the interferon were flu-like, and relieved by paracetamol.
- Other members, who were not in the ChatRoom today, use Gleevec, or Kineret.
- Another member told us that she had been diagnosed with ECD in 2007. She had already been diagnosed with LCH (Langerhans Cell Histiocytosis) in 2005. LCH is another form of Histiocytosis, and is VERY rarely seen with ECD too. She was 27 when diagnosed. She is now 32, and is getting married in 2 weeks! She had 2CDA for 8 months, and interferon for 18 months, but never had both at the same time. Now she is off all drugs for ECD. An hour before the interferon shot, she took either Tylenol or Advil. She was also on high doses of prednisolone for a while, that caused a large weight gain. This has recently started to reduce, with a lot of hard work! She lives near Philadelphia, and is still seeing the same doctors that she started with.
- We were asked, how often do we see our doctor to assess our response to the treatment. Many patients see their doctors every month, or every quarter, in the beginning, or when things are changing for the patient. However, as time goes on, that

sometimes gets reduced to every 6 months or every year, if the progression of the ECD has been halted.

- A new member lives in Washington State and hasn't yet found a doctor with ECD experience. The member has seen a Rheumatologist and this week an Oncologist. The Global Alliance knows of at least one other patient in Washington State. Kathy will see if she can get that patient to send us the contact details for the treating doctor contact and send it on. We were reminded that no-one really understands ECD well enough, to talk about stages or long term prognosis in a particular patient. There are people in the Chat Room who have lots of experience, and who can tell you their stories directly.
- The new member had seen a survival figure of "40 month after diagnosis". We were told that the 40 months figure is the MEDIAN survival, and NOT the MEAN survival. The MEAN is the average; the MEDIAN is a statistical measure that is more difficult to understand. Stephen Jay Gould, a famous American Science writer, did a piece called "The median is not the message", and this is very good, and can be found at - http://www.cancerguide.org/median_not_msg.html.
- A member came on whose wife died of ECD earlier this year. He is well and was at home this weekend, and so he thought that he would see how things were in the Chat Room. He also wondered whether anybody could tell me knew where the summer had gone. He seemed to have missed it. He had had to give in, and turn the heat on, in the house. It was only 59F indoors.
- A member was asked about a recent short break in London. The hotel stayed in was next door to Buckingham Palace. There was an exhibition of original etchings of Leonardo Da Vinci. They were all anatomy drawings, so they were a bit yucky. The Wellcome Institute on Euston Road was also visited. There was an exhibition called "Superhuman", which was about how people have "enhanced" their bodies (artificial limbs, eyes etc).
- Another new member came on to the Chat. It was her first time "Chatting". She had only had the diagnosis for a week! This new member has been taking methotrexate for a number of years, for the treatment of rheumatoid arthritis, (this was at a smaller dose than that being used to treat ECD in one member).
- Strangely enough, the other new member had also been taking methotrexate, about 3 years ago, as part of her treatment for retroperitoneal fibrosis.
- After the Chat had finished, another new member came on, saying that they were looking for someone to discuss ECD with. This member was given the time details for the Chats, and invited to return next week.