

ECD Global Alliance Internet Chat Summary

27 October 2012

11 Attendees

- A member told us that it was time for their yearly CAT scan, and there was a visit to the oncologist very soon. The member's wife has been ill recently. Many tests have been performed, but no diagnosis, as yet.
- Another member has recently been at the doctor's with a bulge on the elbow.
- A member has had to change their Chat name, for the second time, because the Chat will not allow the old names "in".
- Two members found out that they are both attending MD Anderson.
- Another member's mother was sitting in for her daughter. We were asked whether we had heard of a drug called ZOMETA. This is a biphosphonate drug (zoledronic acid) that it is used to help with bone pain, and to reduce bone weakness, mainly in patients with cancer in their bones. This has been given intravenously, once a month, to her daughter. One other member at the Chat had had this drug, and found it to be very helpful. Another member said that her son, who has ECD, does not seem to have bone pain. At times, it is getting very hard for him to walk. He shuffles his feet, and has missed work lately because of it. He also sometimes finds it hard to eat. Last week the family went out for dinner. He came, but passed on eating.
- Members who had already been to Bethesda, to the NIH research project, all agreed that it had been a good experience. There is a LOT of testing to go through, but you are given all the results to show to your doctors. They may also make suggestions concerning your treatment. Other members will be visiting the NIH later in the year.
- A member had recently had a very bad day with depression and put the details on Facebook. Bupropion has been started. A friend had contacted the member. They had gone out together and had a long chat, which had been helpful. The friend also suffered from depression.
- A member from California, who has had not had an internet connection for a while, came on. Two weeks of radiation treatment have just ended, bone pain is much better. This member was so depressed that they had been put on Fluoxetine (brand name is Prozac), and it seems to be helping. Interferon is also being used.
- A member from Spain came on, whose father received a diagnosis of ECD about 3 years ago. The Spanish Health System picks up the costs of treatment. He was having interferon treatment, but now feels well, and treatment has stopped. His doctor is going to keep him on regular review.
- A member has been told that he has Type 2 diabetes, so he is having to diet (starve)!!

- A member has been told by his wife that methotrexate is difficult to take. Another member, who is on methotrexate once a week, doesn't have any problems at all.
- A member told us that her kidney problems are due to a large abdominal histiocytoma that is pushing on, and has infiltrated the kidneys. She had been on interferon until her insurance stopped paying for it. She hadn't seen any difference with it though. Now, she just has treatment for the symptoms and that seems to work. She has had ECD since the mid-80s. Dr Kurzrock, at MD Anderson, told her once that the symptoms seemed to go into overdrive when interferon was discontinued, and that had been the case for her.
- Problems with insurance and payment for medicines were discussed. We were given the reference details for a US company that assists with the costs, or advises you where to get help: 1-866-363-6379 ACT#, OPTION 3.
- We had been told, at another Chat, that Social Security has now added histiocytic disorders to the Compassionate Allowances List. It is hoped that this will result in speedier processing of ECD SSDI claims.
- A member told us that their relative with ECD is still in hospital. He is having severe problems with ascites (a build up of fluid in the abdominal cavity), which needs to be drained every few days. It is hoped that it will be reduced by the interferon treatment.
- A member told us that she had got to spend 2 weeks with her new grandchild, which is a little boy. She was congratulated over the addition to the family.
- A member had to leave us, to go and "finish preparing for Frankenstorm!" which was on its way!! Her town has gone crazy! She had been out to get gas, and the pumps were all empty! (We hope everyone who lives in the path of Hurricane Sandy is safe.)