

Summary of ECD Global Alliance Internet Chat on 15 Mar 2014

7 Attendees

- One member had slipped and broken a small bone in his right foot. He had rolled his foot on a basement stair step. He was hoping that the painkillers would “kick in”.
- A member told us that it was a beautiful day in Ohio. In contrast, a member in Rochester NY had had a blizzard this week (with 20 inches of snow!).
- We were told that the husband of a member has had a PET that showed some improvement for the first time. They had also met with a kidney and liver doctor that were “sooo amazing!!!”
- A member, who has recently had a PET scan, is seeing the doc in the next few days to get the result. He has been having some knee and ankle pain, although his last scan didn’t show any active areas. He has been taking methotrexate 40mg once a week, as his only ECD treatment.
- “Remission” continues for another member. She has been treated with LOTS of prednisone, 2CDA and interferon. Her doc has said that all the tumors that she had are either gone altogether or have become scar tissue, and that this scar tissue continues to reduce in size. Unfortunately, her sight had been severely damaged by the retro-orbital tumors before the treatments had been effective.
- A member asked about the deadline for registration for the Global Alliance conference, but nobody had an answer to hand. [Editor’s note: Registration is currently open. Registration is \$20 per person until March 31, 2014. On April 1, the cost will raise to \$40 per person. See www.erdheim-chester.org for more information.]
- A member, who has woodturning as a hobby hasn’t managed to do any since Jan-1-14 because it has been too cold.
- Some of the Chatters had a brief discussion about literary matters (good books to read!).
- We were told that a member who is virtually blind has been getting cooking equipment that is designed for the visually impaired. Braille stick-ons for the

microwave buttons and measuring spoons with Braille markings. We were told that there are actually real measurements for "smidgen," "pinch," and "dash."

- A member has spent most of the last year helping her husband get through chemotherapy and surgery for bowel cancer. He is now cancer free, and "back together". She attends Dr Janku's clinics. She has been taking low dose methotrexate for rheumatoid arthritis for some years. This a chemotherapy drug from way back when that has been found to work in Rheumatoid Arthritis, if given as a low dose just once a week. A UK member has been taking methotrexate as his only ECD treatment for some years, and he has been stable.
- A member came on after we had finished. She had been to her great uncle's funeral. She has been doing pretty well, other than having joint pains and dizzy spells.
- Finally, another member left a message. She had missed the Chat because she had been out partying (at a friend's 50th birthday party). She is on Vemurafenib and is about to go for her 3 month check up. She has a PET- Scan and an MRI booked, one after the other, on the same day! But she said that it was "good to get it done all at once". She is still doing lots of exercise, and hopes that she will be OK for her 6 min walking test!!