Summary of ECD Global Alliance Internet Chat
19th May 2012

6 Attendees

- Before the Chat had started, a message had been left, asking whether anyone had any advice to give to a patient's family member, who had written, saying the patient “has an inoperable growth in his right ventricle. It causes fast heart beat, up to 144 beats a minute. He and I are wondering if anyone else has this problem and what they are doing for it." If anyone has any information relevant to this, feel free to post your experiences in the chat room at anytime or send an email to support@erdheim-chester.org.

- A member said that they do get palpitations, but that they blame it on the Intron.

- A member, who is a keen wood-worker, has been making Christmas decorations. Not because there is only 7 months left to go, but because they are going to be on display, and for sale at the Artistry in Wood show in November. It will be held at Dayton Airport expo center, Vandalia, Ohio; and there will be people from all over the country there. The show is on

  Nov 10 & 11 2012, 10am to 6pm on Sat, & 10am to 5pm on Sun (contact info Exposition Center 1-937-454-8600).

- The member, who has been working towards becoming a foster parent, has been contacted about a child today. He has been very light-headed recently, and is concerned.

- A member has recently had surgery to his prostate gland. It had been discovered that he had prostate cancer. The surgery used was a minimal sort, the hospital stay was only 3 days, and he now “feels 100%”. He was asked whether he had been on any testosterone therapy, and he had not. Another member at the Chat is given deep muscle injections of testosterone and, before that, he had used a testosterone gel. These medicines have been needed due to a growth on his pituitary gland, which has messed up his Testosterone and his ADH. This member told us that both of these medicines have a possible side effect of an enlarged prostate or even of prostate cancer.

- 2 members, who have already been to the NIH, said that they would go for another visit, if that would be helpful to the research team. Dr. Estrada had mentioned to one of them, that he would like to follow up with them up, once a year.

- A member had recently e-mailed Dr. Estrada to ask about the study. Dr Estrada had said that they were “taking the summer off” for other commitments, but they would send an e-mail out soon, and start making appointments for this fall.

- We were told that on Sunday, May 20th at 7pm EST, CBS “60 minutes” planned to air a story about the NIH Undiagnosed Diseases program. This is the program run by Dr. William Gahl, the senior researcher involved with the ECD Natural History Study at the NIH.

- A member told us that he had a routine exam by a proctologist to look forward to this week! This was because he is taking hormones. Dizziness has been a great problem recently, and the member thinks that the prescription drugs are to blame. One of these medicines is a fentanyl patch. This is a drug that is derived from morphine. Another member had also been troubled by dizziness, thought to be due to medication. These were a drug to treat high blood pressure, and one for diabetes, and both were changed.

- A new member, whose daughter has ECD, was asked about how things were progressing. The daughter’s eyes are quite bad. One eye surgeon, has suggested enlarging the eye sockets to accommodate the swelling; and then to reduce them in size when the swelling has reduced. The patient is due to back to Rochester, MN for review. It appears that the swellings are just getting larger and larger.

  The doctors in Rochester wish to repeat much of her tests to compare results, and to determine if the medication is helping. The family is most worried about brain involvement. The patient has lesions affecting many organs, and also in the bone marrow. These are in the hand, arm, and jaw bone, and 1/3 of the way up her legs.

  A statement was made that the chat sessions were found to be helpful in seeing that others are working with this disease. It was expressed that although the information is sometimes bad, we need to figure how to work around the disease. It helps to know that others have managed to continue their lives, even with this problem. Patients continued to be surprised that many doctors had never heard of ECD. The new patient began to have lots of medical problems that no one could understand -until she went to Rochester last December at age 50.

  The patient takes shots every week, most likely thought to be interferon, although the member could not be certain. Interferon, or one of its variants, has been successful for some patients. It can take a long time for it to show effects, but the patient doesn't have go to the hospital to use it. The patient’s doctors have said although the treatment can be slow to help, this disease, itself, is slow in its progression. However, the patients eyes got worse very fast. She can still get around, but this will be very difficult if she loses her sight. She has been warned that walking may become more difficult, because of the lesions in the leg bones, and she may suffer fractures more easily. It was expressed by multiple people that it is wise to let the patient remain in control in dealing with ECD when possible.

- A member, whose wife has recently died from ECD, told us that eye problems had been one of her early symptoms. It took the medics over a year to get things under control, and fortunately, she did not lose her sight. She had not been in employment before her illness, but managed to continue with her craftwork (Tapestry, Counter Cross-stitch, Quilting. And she was a master at Ikebana, Japanese Flower arranging and a pianist.) These crafts were possible until ECD took away her motor skills.

  She was treated with cycloblastin, then radiotherapy, then cortisone, and finally Imuran. Each of these seemed to do a little, and this all added up to enough to make the growths quiescent, but they never went away. Without treatment, the lesions don't seem to have a limit and that was certainly the case in the end, especially in regard to the brain lesions which could not be controlled. The blood-brain barrier limits the range of treatments that can have any effect on the brain. However, we do have members, who have had brain involvement for some years now, with it seemingly under control.

  This member also had lesions in the long bones of her legs that were sometimes very painful, but they did not interfere with her ability to get about. She had a number of falls, but never broke a bone. Treatment, that seemed to control things for years, was Imuran and tamoxifen.

- A comment was made that although the disease is slow overall, the effects on sight can be rapid due to optic nerve compression. Similarly, the renal arteries can get compressed very quickly, damaging the kidneys, despite the lesions, themselves, only growing slowly.