

Summary of ECD Global Alliance chat held on Saturday 30th January 2010

12 Present

- The following is an overview of the ECD-related details and updates of those who were in, or represented in, the chat:
 - Patient 1 reported enrolling in a 2 week cleansing and juice diet. Everyone was promised that they would hear how it progressed.
 - Patient 2 was reported as being in the hospital with a chest infection. Antibiotics, antivirals, and oxygen were being administered and a slow improvement was being seen.
 - Patient 3 recently began a Gleevec treatment and has been doing ok with a new pain in the back where a mass is, but having more energy at the end of the work day.
 - Patient 4 has been declared in remission by her medical team. This patient has been on no meds for ECD since August. The MRI, bone scans and blood work continue to look good. The patient was blinded by ECD and also had bone involvement (without pain) and a heart issue that was resolved with a treatment of cladribine (2cda).
 - Patient 5 received a denial for interferon from their insurance company when the company has been paying for the medicine for two years now. When the patient questioned the denial, the response was that interferon is not an approved treatment for ECD. When pressed, the people at the insurance company admitted that not only did they not have an approved drug for ECD, but ECD wasn't even on their list.
 - Patient 6 has granulomas on the lungs and rib cage. This patient also has involvement of the optic nerve of the left eye resulting in some sight problems. This patient is on Imuran and during a recent outing experienced a problem with the eyes becoming 'over stimulated'.
 - Patient 7 took a stress test this past week with good results and is scheduled for a pulmonary function test in two weeks.
 - Patient 8 is on no ECD medicine at this point.
 - Patient 9 had Dr. Arceci review their latest scans and he found no essential changes. This patient is now back on "good" interferon having been informed recently that previously shipped interferon had issues associated with it. This patient had a bad week, but is now able to eat and sit up right for a few hours at a time.
 - Patient 10 received a motorized wheelchair this week.
 - Patient 11 has recently begun taking Kineret (immune suppressant drug marketed for relief of rheumatoid arthritis pain) for bone pain and finds it very effective for this purpose. This patient's medical team is also looking to see what effects ECD might be having on the patient's short term memory loss and cognitive functions. The patient suffers from a large mass in the pelvic bone that vinblastine previously shrunk from about 13cm to just over 7.5cm. Other lesions were removed surgically. Today the doctors don't know what causes the bone pain, which seems to be everywhere, but with no lesions appearing on the scans.

- Patient 12 has recently been suffering from knee and leg pain although is still managing to walk most days.
- It was noted that a local center in the UK, dedicated to serving those with neurological disorders, is planning to have an article placed in the newspaper for Rare Disease Day on February 28.
- One participant stated that she had received Rare Disease Day proclamations from the Governors of Alabama, New Mexico, and Montana!
- Everyone was encouraged to get their photos into our newsletter editor along with their signed consent forms. Please send them to stanceforlance@hotmail.com.
- Members who are interested were encouraged to send their stories into Mystery Diagnosis. (If you have questions regarding how to do this, please email support@erdheim-chester.org.)
- There was some discussion about diabetes insipidus (DI). The symptoms of DI are an abnormal increase in urine output, fluid intake and often thirst. Those in the chat room that have been diagnosed with DI discussed the extreme amounts of fluid that were being consumed prior to being diagnosed. For most cases of DI there is a pill that can be taken to relieve the symptoms.