

Summary of 1-10-09 ECD Chat

Chat Date:

1/10/09

Time:

3 pm Eastern time

6 Attendees

Summary:

- There was sharing of personal activities from the past week and discussions about one-on-one conversations that were held during the week. It seems more people are communicating one-on-one as well as in the chat sessions.
- Jeri talked about a possible logo concept for the ECD Global Alliance. She was thinking about puzzle pieces that don't connect with ECD written across them. It was suggested that each puzzle piece could somehow relate to possible different symptoms throughout the body.
- There was a question about whether ECD patients have more difficulty healing. One patient fell and hurt her wrist (bruised and strained) a couple of months ago. Even after treatment, her wrist continues to hurt with use or twisting.

Another patient had a similar injury and her doctor said if she had not been on actonel or fosomax, it would have taken a very long time to heal. A third patient is planning to start on one of these drugs in the near future and is hoping to experience a reduction in bone pain as a result. A fourth patient has also experienced problems healing after injury. He is now pursuing therapy for a shoulder injury that occurred a couple of months ago.

- Some of the participants talked about the use of steroids and some of the side effects were discussed. One patient had a bad reaction to steroids that caused her throat to swell and therefore she no longer takes them. Another patient took them previously, but still has some of the lingering side effects. A third patient has been on prednisone (10 mg/day) for 9 years and credits them with making her life tolerable. She still takes Tylenol #3 or hydrocodone when the pain gets to be too much.

Some patients have experienced a reduction in bone pain with the use of steroids. At least one patient is on a low dose (5 mg/day), yet the bone pain returns when he attempts to completely stop the prednisone.

Some side effects that have been experienced with using steroids are high blood pressure, facial hair (for women), weight gain and diabetes.

- One patient sees a very good Osteopath who has made a big difference in alleviating the pain and realigning things.

- Because ECD does not 'sit' with any one specialty, it is often difficult to find an appropriate treating doctor. For some it is difficult to find a caring doctor who is willing to coordinate treatment plans. A couple patients have physicians who seem to share test results and/or treatment thoughts and will speak collectively when warranted. Some patients have taken it upon themselves to share their test and lab work results among all their various doctors. The result is fewer tests and less blood work. At least one patient has found working closely with the nurses helps them as most of the nurses are very caring and willing to go the extra mile.