

## Summary of ECD Global Alliance chat held on Saturday 20<sup>th</sup> March 2010

6 Present

- A new member, diagnosed three months ago was welcomed. It was mentioned that when you first join the chat, it is difficult to keep track of everyone and remember who everyone is, but it soon gets easier!
- Several patients reported that this had been a good week for them. One patient is still fighting cold symptoms and will have a blood test this week to check whether the blood counts are high enough to complete the last cycle of chemotherapy. One patient has suffered from an increase in leg pain.
- This was the first week of a new initiative. A question will be posed in the chat for discussion the following week.  
The question for discussion this week was, “Can you share with the group how you felt when you first learnt that you had an orphan disease with little knowledge about it? How did you (or how are you) dealing with the medical maze? How has this changed your life and that of your family?”  
Members on the chat shared openly their thoughts on this question; some of these are covered below.
  - One member felt relief that there was a name to describe the myriad of symptoms. The disease had hit the family hard. Their teenage son/daughter was finding it very difficult and was afraid that the parent would not be there for the many special occasions in their life.
  - One patient felt when they were diagnosed that there were too many questions and not enough answers.
  - One patient had to fight for treatment as doctors wanted to disregard the signs/symptoms mentioned by the patient. Their family was not interested in their medical care but they gained strength from the group.
  - Several members mentioned the importance of their faith in dealing with the difficulties caused by the disease.
  - One patient described how they had accepted the diagnosis without anger and that they were grateful for the support from their family.
  - One patient found it difficult (and still struggles) to accept the diagnosis. They and their relative live one day at a time and deal with whatever happens the best they can. The patient is doing well now.
  - One member described their relief at receiving a diagnosis, and felt that it was good news that the diagnosis was not cancer. However, as they read more about the disease, they became scared.
  - Several members described how difficult their teenage children were finding things, and how difficult it is as a parent to know how much to share with them. On one hand you may want to share openly and honestly but another part of you wants to protect them and keep knowledge from them. It was suggested that maybe the teenagers of parents in the group may wish to

correspond, as the frustration of having an ill parent is something they all have in common. One teenager is currently seeing a counselor to talk through some of the issues. Two members on the chat agreed to exchange email addresses to discuss these issues further.

- It was agreed that this had been a good discussion on the topic. This initiative is intended to be a means by which people may express how things are going but are not quite sure how to go about it. It is intended to enable people to share more of themselves so we can get to know each other better. Members should of course feel free only to share what they wish.
- The question for next week is, 'How does stress affect your pain levels, ability to perform daily chores etc. Does it affect your disposition such as depression, lack of focus, feeling tired etc? How do you get past this so you can get through the day?
- The next chat will be held on Saturday 27<sup>th</sup> March at 3pm Eastern time.