

Summary of ECD Global Alliance chat held on Saturday 16th July 2011

9 Present

- A message was posted prior to the chat asking whether anyone had any experience with the treatment Sprycel (aka Dasatinib)? If you have any comments on this please post them in the chat room.
- A member who is currently on Kineret and experiencing good results is interested in others experience with this treatment. If you or your loved one has tried Kineret, please post your thoughts in the chat room, positive or negative.
- One patient diagnosed fairly recently has been advised by their neurologist that interferon would be the most appropriate treatment at present. The side effects on interferon (tiredness and flu like symptoms) were discussed. One patient has been on the treatment since November 2005 and has been told by doctors that it is keeping the disease stable. Several other patients on the chat had experience of taking interferon.
- One patient has been particularly ill this week with a fever.
- One patient is suffering from spinal stenosis and is due to see a back specialist shortly.
- Problems with crumbling/broken/infected teeth were discussed. There are articles written specifically about ECD and teeth issues and these may be found on the website under 'Technical Papers'. It is also possible to search on PubMed (www.pubmed.gov) and query 'erdheim chester oral' or 'erdheim chester dental'.
- A number of members have sent records to Dr. Vaglio recently. Those members who have not yet done this were encouraged to do so if at all possible. If you need any help, please send an email support@erdheim-chester.org. Details on the information that Dr. Vaglio requires is on the website. Other studies are due to start in the near future (the study at NIH is close to beginning) so it is important that copies of medical records are kept up to date so that they are available promptly for submission.
- There are some business cards on the website that may be printed and used for raising awareness of ECD. Instructions and a template can be found at <http://www.erdheim-chester.org/BusinessCards.html>.
- The next chat will be held on Saturday 23rd July 2011 at 3pm EST.