

## Summary of ECD Global Alliance chat held on Saturday 8th August 2009

### 9 Present

- One member dropped in briefly to the chat to let others know that they have two speaking engagements in the next couple of months, which they hope will help in raising awareness of ECD.
- One patient has just finished chemotherapy and is not yet on any new medication. Another patient will shortly finish chemotherapy and is due to start interferon.
- Management of leg pain was discussed; one patient used Tylenol, one lortab, another Aleve. One patient finds that massage and cold packs helps ease leg pain.
- A member who is due to start interferon soon asked for comments. One patient who has been treated with interferon for the last 18 months said they felt no worse but no better. Another patient who has had interferon for the last 14 months felt there had been a dramatic improvement. Most people do their own injections as this is more convenient than having to go to the doctor's office. In terms of side effects, one patient had suffered flu like symptoms in the early days, these had been effectively managed with Tylenol. These symptoms only occurred rarely now. Another patient described fevers and chills in the early evening.
- One patient taking Gleevec felt that the side effects from the drug were decreasing.
- Pericardial effusion was discussed. A patient who had suffered from shortness of breath due to pericardial effusion had a pericardial window which had relieved inflammation and fluid build up; this in turn improved the breathing. ECD cells were found in the pericardium as a result of this operation. One patient described how they had had three pericardial windows.
- A patient had suffered from fluid build up in the peritoneal cavity. A shunt had been installed; this had not worked as the fluid had plugged the shunt. Alternative medications had eventually dealt with the problem, until then the fluid required draining every 6-8 weeks.
- A question was raised about weight loss and ECD. Three patients find it easy to put on weight but extremely difficult to lose it! Some patients find it is difficult to exercise, maybe due to lack of stamina or leg pain. It was also suggested that ECD and/or ECD drugs may play a part. Several patients feel that prednisone was a factor in their weight gain. One patient on the chat had lost a significant amount of weight recently.
- A patient described serious complications (large fluid gain) which arose when scar tissue surrounded a port-a-cath.