

## Summary of ECD Global Alliance chat held on Saturday 2nd July 2011

11 Present

- One patient has seen their doctor recently and been told they are doing well and that there is no need to change the stint from their kidney.
- One patient who has been taking kineret each day has tried to reduce the dose recently to a shot every other day. However, it seems as though the patient needs to have a shot every day to help with pain control and energy levels. The patient is paying \$388 a week for the drug as the government has refused to put the drug on the formulary for ECD.
- Members discussed the problem of edema in the feet and legs; a number of patients on the chat have this problem. One piece of advice is to sit with your legs higher than your bottom (and sleep with your legs raised on a pillow). One patient said that the swelling in the legs was caused by the disease constricting the inferior vena cava. This patient also suffers from weeping of fluid from the legs and recently lost 9lb in fluid. Their balance is affected by the extra weight in the legs and they have fallen and sustained rib fractures.
- Members wished each other a happy 4<sup>th</sup> July.
- The next chat will be held on Saturday 9<sup>th</sup> July at 3pm EST.