

Summary of ECD Global Alliance chat held on Saturday 5th June 2010

10 Present

- Two patients mentioned their leg pains, which they have suffered from for some time.
- One patient is on dialysis and mentioned a recent paper about an Australian ECD patient with acute renal failure. Another patient in the group has a hospital appointment this week for their kidneys to be checked; it is likely that a stent will be replaced.
- Several members have been exploring opportunities for fundraising. One member has approached six schools and asked them if they would be willing to consider being involved in a fundraiser. Another member had approached local stores about fundraising. One member described how a home health agency and a band made up of orthopaedic surgeons will be doing a fundraiser and the ECD Global Alliance will be one of the organizations to benefit. One member has had contact with a local DJ on a country radio station. One member has contacted the Ellen Show to ask if they would be interested in doing a feature on ECD.
- A patient's young daughter will be describing her experiences about being the child of an ECD patient, at a fundraising event.
- The Mystery Diagnosis TV team has contacted a patient to discuss their experiences, but as yet have not taken it any further.
- The next chat will be held on Saturday June 12th at 3pm EST.