

## Summary of ECD Global Alliance Internet Chat 01 Sep 2012

9 Attendees

- Kathy had heard from a patient, who has recently seen Dr. Kurzrock in Houston. This patient says that,  
"Dr Kurzrock will probably be seeing patients 9 months after moving at University of California at San Diego." This is referring to Dr. Kurzrock moving from MD Anderson to UCSD. It looks like Dr. Kurzrock's patients from MD Anderson, have been referred to Dr. Janku at MD Anderson.

- We were asked whether Kathy had mentioned to us, the documentary on ECD that is being contemplated. Some members had not heard about it. Kathy has asked our sole member, living in Los Angeles, to make the rounds of documentary filmmakers. This member met with a small shop, which has done much other work for nonprofits. This is all preliminary, but they envision a film told from the point of view of a person recently diagnosed with ECD. Many of our members would give their advice, as this person tries to understand a disease that they, and probably their doctors, have never heard of.

If the documentary turns out as hoped, it would be put on the ECD Global Alliance website, for newly-diagnosed patients and their doctors to see. And, if it's interesting enough, try to get it shown other places.

- The member, who has been having botox injections, to try to reduce leg spasms, had 2 Dr's appointments this week. No botox was injected this time, and our member managed to walk well for the doctor! Something that has improved matters, is the arrival of a disability sticker for the car. Parking will be easier, and Saturdays won't be so horrible!
- A UK member had recently been to a "motability" day at Duxford aerodrome. There were lots of people there, and cars, and scooters, were being displayed. Another member recommended these events. Also, in some areas, there are "motability" companies, that you can hire vehicles from. You go and have a look at the range, and have a short "test drive", before deciding what to go for. Some of these companies will deliver, and collect, the scooter from your holiday destination!
- On UK TV there is a programme about cars, and sometimes other vehicles (Top Gear). Recently they featured a "race" between some of the presenters, and some soldiers, who had been injured in the war in Afghanistan. The soldiers used the disability scooters that they had been supplied with, whereas the presenters were allowed to "soup up" their scooters (petrol engines, caterpillar tracks, winches etc). They had a race up some mountains in Wales. The soldiers won. They had good map-reading skills, so they chose the best route. The feature was to try to provoke the manufacturers of vehicles, to provide better

options for "off-road" activity of the disabled, and for these to be sold at reasonable prices.

- Some members, in the UK, talked about a company (TGA), that makes scooters. One member already has 2 scooters from them, and another member likes the look of them.
- A member is going to have surgery on his kidneys this week, in an attempt to relieve obstruction, and to regain good kidney function. Many of the Chatters wished him luck.
- A member has just had a nephrostomy "redo". This has been difficult to schedule, but has improved things greatly. We were reminded that many of us have ECD-related fibrosis in the kidney area. This often obstructs the ureter, blocking the passage of urine from the kidney to the bladder. One solution for this is to insert a stent in the ureter, to keep it open. A member had had this for several years, but, after a while, the bladder became highly irritated. Then a nephrostomy tube was inserted, by which urine flows directly from the kidney into a bag that is strapped to the leg.
- A member came on who has been troubled with light-headedness. No reason has been found, and it just has to be lived with. Depression has also been a problem, although an upcoming visit to a "listening" mom should help. At least the strawberries and tomatoes, that this member has grown, have done well!