

## **ECD Global Alliance Internet Chat Summary 21 Jan 2012**

# Attendees: 9

- There were a number of comments about the various weather conditions that were prevalent. Snow was the commonest, although it did seem to vary a lot in depth!
- A member who is getting married shortly has been spending time looking at possible wedding invitations.
- A member who has recently been troubled with a cold, has improved, and managed to return to his hobby of woodworking. He is planning to start making a winged box which rests on its ends rather than its base.
- There followed a fairly long discussion about kidney problems and nephrostomies. A nephrostomy is usually a plastic tube that passes from outside the abdomen, goes through the "pelvis" of the kidney, and thereby allows urine to pass out, if the normal plumbing (each kidney has a tube, called the ureter, for the urine to go down to the bladder) is blocked.

If the urine cannot get away from the "pelvis", then there is back pressure on the kidney tissue, and kidney failure results.

One member had had a blockage to his nephrostomy last week. He had to go to hospital to the "interventional radiology" department. That is where he gets his tube changed. On this occasion, it had become blocked by a blood clot. It was relatively easy to replace, and not painful.

- At an earlier stage of the disease, one patient had had daily injections of interferon (subcutaneous on the abdomen), given by visiting nurses. When he started to do them himself, he was pleasantly surprised how easy it was. He now gives himself daily kineret injections.
- It was suggested that it might be useful to have some sort of publication about ECD, that people could take with them if they need to attend an ER where they were not already known.
- A member who has been having back problems has improved a bit, but her team are now using a "magic" tape. This is used by athletes and people with muscle problems. Real name is kinesiology tape (<http://www.kinesiotaping.com/r>)

- One member has been having dental problems with crumbling of some teeth, and has needed some root canal work. He has also had problems with Gleevec recently. It was not leaving his system properly. The side effects are like taking a muscle relaxant. He wakes, and is so relaxed, that he can't think straight. He would be able to summon assistance if he needed it. He had seen Dr Kurzrock early on. He had chosen Gleevec because he did not fancy all the injections. He sees her every 3 months, although Dr Kurzrock, herself, would prefer to see him every 2 months.
- A member had taken Gleevec for just 2 ½ months and then had to stop because it was destroying her blood cells. But the progression of the ECD appears to have been halted. Things are just being observed now, with no further plans for treatment yet.
- Another member (spouse), who had recent hip surgery, has begun to start walking again, although the right foot has become a bit sore.
- Another member, who has been having problems with swelling of the feet and ankles, reported that these were doing OK. This member has a nephrostomy in each kidney. The nephrostomies have been present for 9 years now and living with them is something you just have to do. The tubes from the kidneys go straight into bags that are strapped to the thigh. If this stops working then dialysis may be the next step. The member had tried urinary stents at first (9 sets in one year!) but these kept blocking and were painful. Stents are short tubes that are placed inside the ureters at places of blockage, to try to let the urine pass through. They are fitted using a ureteroscope, an instrument that goes in through the urethra and bladder. There is no cutting of the skin needed, although a General Anaesthetic IS usually given.
- We were told that some patients in France had had obstructed ureters, and that Kineret treatment seemed to have helped. Another member wanted to obtain the details of this, to discuss with their own medical team.
- A member who has had stents already, is finding that they are doing well.
- Enquiries were made about our member in Australia who has been very ill. No-one had any information to pass on.