



“ Hello ! My name is Anastaia ! My blood is sick and I need special help to make it get better. I have graft versus host disease (GvHD).

Children's Extra Corporeal Photopheresis (ECP)

ECP works by making my white blood cells behave better. It stops my skin and tummy being very sore, and helps me fight off infections. Hopefully I then won't have to visit hospital so much or have to take as many tablets. My treatment is over two days.

The day before treatment a nurse will telephone my mum or dad to make sure that my red blood levels are ok (Parents: HB above 90g/L / Platelets above 20) and that I am well enough for ECP so that my crossed matched blood can be ordered if it is needed.

On the first day of my arrival I have blood samples taken and I am seen by the children's doctor. The nurses check to make sure everything is all right with me before the treatment starts.

To have ECP I had to have a special central line fitted into my chest. I call this my 'wiggly' line.

The nurse takes my blood samples from this line and then sends my blood to have it cross matched in the blood bank

(Models have been used in this leaflet)



I have to wait about 2 hours for my blood to be cross matched. So mum and I played in the play room



To be able to have ECP treatment I need to have a crossed matched bag of donated blood to fill up the spinning bowl in the ECP machine. When the blood is ready the nurse brings it and she checks it with another nurse.

The bag of blood is then attached to the machine and it fills up the spinning bowl. When the bowl is full (it takes about 15 minutes) the Nurse switches the bag off and then connects the machine tubes to me by my wiggly line.



The photopheresis machine collects my blood, and separates the red blood cells from the white blood cells.

It gives me my red blood cells back but keeps lots of the white blood cells which are causing the problem.

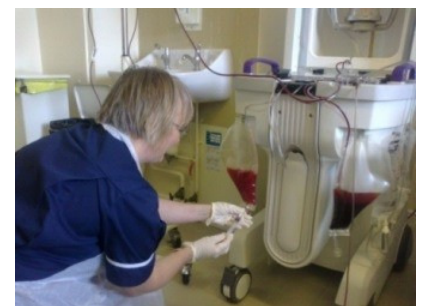
When we have collected enough white blood cells the machine stops and the nurse adds a special medicine called uvadex.



Once this is added the nurse switches on the special UVA lights.

The lights shine on my white blood cells and make the uvadex stick to them.

It changes my white blood cells and makes them behave. At the end of the the treated blood cells go back to me.



During my treatment the ECP nurse stays with me all the time and I have to have my blood pressure, pulse, temperature and breathing checked. I am allowed to play games, and make things. The play nurse finds me lots of things to do or I watch TV or play video games. I can eat and drink while I have my treatment.



“That’s day one done ! It’s time for me to leave now, my first day treatment has finished but I will be back tomorrow for my second ECP treatment when I do all of this again! ☺

I won’t have to wait for the blood to be cross matched in the morning though... so day 2 will be a lot quicker ! ☺”

Over the two days of ECP I have to keep to a low fat diet.

I also have to take care of my skin because ECP makes the skin and eyes very sensitive to light.

So for 48 hours after treatment I have to wear very high factor sun cream and dark UVA wrap-around sun glasses ...Even in the winter... or make sure all my skin is well covered before I leave.



Future visits

The doctor will arrange these with you and your mum for the next few months as need them.

Everyone at Hospital has made my stay lots of fun! I can’t wait to tell my friends what I have been up to! ☺

For more information please contact Rotherham photopheresis dept or see our website : www.rotherhamphotopheresis.co.uk

Information leaflet devised by T.Maher RGN
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(NB crossed matched blood is only required for children with low body weight or a low HB)

