



University Hospitals Birmingham
NHS Foundation Trust



Photopheresis

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What is photopheresis?

Photopheresis, also known as extracorporeal photopheresis or ECP, is a therapy used to treat certain skin disorders and some complications following stem cell transplantation by targeting specific white blood cells, called T-cells (also known as T lymphocytes).

ECP treatment is used to treat cutaneous T-cell lymphoma (or CTCL) and Sezary syndrome, which are types of skin disorders, and Graft versus Host Disease (or GvHD), which can occur after an allogeneic stem cell transplant – this is where the stem cells received are from a sibling or unrelated donor.

In these conditions the T-cells, which are involved in the body's immune response, have become overactive; these overactive T-cells can become cancerous (in the case of CTCL) or they may start to attack the body (in the case of GvHD).

Photopheresis has also been used as a therapy for other transplant related rejections (in heart and lung transplants for example) and to treat autoimmune disorders such as Crohn's disease.

How will extracorporeal photopheresis (ECP) therapy help?

This is dependent upon the condition being treated.

When photopheresis is completely successful in CTCL the results can include healing of the skin disease as well as a reversal of other symptoms that you have experienced like itching and redness.

In those patients with GvHD successful treatment can eventually result in the disappearance of skin lesions and the reduction in the signs of the disease in other organs, such as mouth and liver. You may also be able to take lower doses of your steroid/ immunosuppressive medication or to be weaned off these medications completely.

How does photopheresis (ECP) therapy work?

During ECP treatment, T-cells are collected into a treatment bag and a medication called Methoxalen is added. Then the cells are exposed to ultraviolet light to activate the drug, which causes the T-cells to stop functioning. At the end of the procedure, treated T-cells are reinfused to produce the desired response in the body.

What will happen during the photopheresis (ECP) therapy?

Before the treatment can start, your veins will be assessed as they need to be in good condition due to frequency of treatment. If your veins are not able to cope with the needles used during the procedure then we would discuss with you and your consultant to arrange for a long-term access line called an apheresis line to be placed in your chest region before you start treatment. On the first day of treatment blood tests will be taken to assess your full blood count before treatment can commence and also to monitor your liver and kidney function. You may require blood or platelet transfusion before the procedure to meet requirements for the procedure. However this is not required very often.



If you are being treated for GvHD and taking

immunosuppressant drugs (i.e ciclosporin, tacrolimus) we can also take bloods to check your levels. If you wish us to do this please ensure it has been at least 8hrs since your last dose was taken.

Your blood pressure, temperature and heart rate will be taken at the beginning of each procedure.

If your veins are suitable we will place a needle in your arm and blood will be drawn out of the vein and into an ECP machine.

The procedure is performed in one of two modes dependent on your venous access; either single needle mode or double needle mode. In single needle mode, one access needle is inserted into one arm and your blood is drawn out and returned via this one access point at separate intervals. In double needle mode, two access needles are inserted (one in each of your arms) at the same time so that your blood is drawn out and returned simultaneously. If you have an apheresis line (not applicable to everyone - only for poor venous access) in situ then this will be connected to the machine and double needle mode will be used for the treatment.

Your blood is drawn into the ECP machine where your white blood cells are separated from the other parts of your blood and collected in the treatment bag at the end of the first part of the procedure. These white cells are then treated by a drug called Methoxalen and then exposed to the UVA lights which activate the drug. All of your blood, including the treated white cells, will be returned to you at the end of the procedure..



You will be attached to an ECP machine for between two - three hours depending if we use single or double needle mode. You may wish to bring something to occupy you during the treatment (i.e. books, tablet) and you can bring a relative or friend for company. We have portable DVD players within the department that you are welcome to use if you wish to bring any DVDs with you. Please be aware that if you are having your treatment in double needle mode you will be unable to move your arms (due to the placing of the access needle) until we have treated the cells. This could be between one - two hours into the treatment so be aware of this. However we will be happy to help you if needed and we advise you bring something with you to occupy your time.

You are more than welcome to bring a family member or friend with you. You will most likely feel very tired after the procedure and so we advise that you do not drive. You will need to arrange for someone to take you home afterwards, especially for the first few treatments. After this you may feel able to drive yourself to and from the treatment. If you need hospital transport at any time please let us know.

Is photopheresis (ECP) therapy painful?

Most patients report little or no discomfort when undergoing photopheresis therapy. There may be however some discomfort when inserting the access needles at the beginning of the procedure. You may occasionally feel different sensations during the procedure that are not painful. These may include a slight pulsing sensation from the machine's pump and a slight cold sensation as the blood is being returned back to you.



Some patients may experience feeling weak or dizzy during or immediately following the procedure. This sometimes occurs due to a slight drop in your blood pressure. We will check your blood pressure before each treatment, and we will monitor you more closely during the procedure if required.

Are there any side effects with photopheresis (ECP) therapy?

More than 500,000 photopheresis treatments have been performed worldwide since 1997. Serious side effects are rare and are usually due to a drop in blood pressure as changes in blood volume occur during the treatment.

The medicine used during the photopheresis treatment will make your skin more sensitive to sunlight for around 24 hours after each treatment. It is vital that you wear suitable clothing to each appointment, which covers as much of your skin surface as possible.

We recommend that you stay out of direct sunlight for 24 hours following each procedure as the drug will still be active within your body. Even if it is not a particularly sunny day, it is important to still cover up, as UVA light is still present and can cause skin damage. Therefore we recommend that you wear a high factor (e.g. factor 50) sun cream during the two days of treatment and for a 24-hour period afterwards. We also highly recommend that you wear a hat and wrap-around style sunglasses.

Other possible side effects are usually minor and go away within a day. These could include fatigue, a temporary increase in itchiness, or a slight redness or fever appearing six–eight hours after treatment.

As with any procedure involving a needle puncture, there is a small risk of getting an infection and bruising from needle insertion.

What are the risks related to extracorporeal photopheresis (ECP)?

There are some minor risks associated with the photopheresis procedure. These include the loss of a small amount of blood in

the machine treatment set because of power failure, machine failure or failure of the tubing set used during the procedure. There is a small risk in regards to the insertion of the needle and it includes small possibility of nerve or tendon damage due to bruising or needle touching the nerve and puncture of artery. According to data available from blood donation services in the UK: inflammation of the arm, tendon injury one in 100000 (NHSBT performance data 2012-14), nerve injury one in 3000 (NHSBT performance data 2010-14), puncture of artery one in 10000 (NHSBT performance data 2010-14).

There is small risk associated with anticoagulant used during the procedure to stop blood clotting in the tubing system. In our unit, Heparin is used as a anticoagulant. It interferes with the blood clotting cascade so there is a small risk of bleeding after the ECP procedure for a short period of time due to blood clotting slower.

Also there is potential risk of interaction between your regular medications and Heparin or photoactivation medication. However, this will be discussed with you and the consultant referring you for ECP if applicable.

How often is photopheresis (ECP) therapy given?

How often photopheresis therapy is given will depend on which disease/condition is being treated and how many treatments you have received. Photopheresis therapy is given as two paired treatments which must be given on two consecutive days, every two weeks to begin with.

Depending on your response, your doctor will then extend the length of time between your pair of treatments when appropriate. The total length of time for photopheresis therapy will vary from patient to patient and your treatment schedule will be tailored by your doctor to suit your needs and individual condition.

Do I need to do anything before the treatment?

We recommend that you eat a low-fat meal the evening before your treatment and for the two days of ECP. You can return to your normal diet after you have completed your two days of treatment. The reason for this is to reduce any fat content within the blood so that the treatment can run smoothly. You may eat and drink as normal throughout the procedure however, if using the double needle mode, you may not be able to move your arms until the procedure is in photoactivation. We do provide tea, coffee, biscuits and sandwiches but feel free to bring in your own items too.

How long before I start to see a result/change?

Response times to photopheresis can be different for each person. Some patients start to see results within a few months, but it may take longer. It is important that you do not give up treatment or feel discouraged if you do not see results quickly. Patient responses will vary depending on the condition of their immune system and the severity of their disease. Improvement is usually a gradual process.

Where will I receive photopheresis (ECP) therapy?

You will receive your treatment in the Apheresis Bay, which is located in the centre for Clinical Haematology.

Centre for Clinical Haematology

Morris House

University Hospitals Birmingham NHS Foundation Trust

Mindelsohn Way

Edgbaston

Birmingham

B15 2TH

Who will carry out my procedure?

A team of specially trained apheresis nurses will carry out all of your procedures. You will be seen by your doctor in clinic on a regular basis to review and assess how your treatment is going.

Free parking (Car Park D only)

If you arrive by car please park in Car Park D and take the ticket as normal. You will be able to exchange your ticket for a free exit one at the main reception. Directions can be found on the Trust's website: www.uhb.nhs.uk.

If you have any further questions or concerns
please contact the Apheresis team

Monday-Friday 08:00-18:00

Apheresis Bay tel no: 0121 371 7820 or 0121 371 7821

For emergencies outside of normal working hours please
contact Ward 625: 0121 371 6252 or 6293 or 6291(24hrs)



The Trust provides free monthly health talks on a variety of medical conditions and treatments. For more information visit www.uhb.nhs.uk/health-talks.htm or call 0121 371 4323.

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