FAST FACTS:
EXTRACORPOREAL PHOTOPHERESIS (ECP)

Learning more about ECP, a way to treat graft-versus-host disease (GVHD), can help you make informed medical decisions.

READ ON TO LEARN ABOUT:
• What extracorporeal photopheresis (ECP) is
• Who can get treated with ECP
• What it’s like to be treated with ECP
• When to call your doctor

WHAT EXTRACORPOREAL PHOTOPHERESIS (ECP)?
• ECP is a standard treatment for a blood cancer that affects the skin. It’s also used to treat GVHD that hasn’t gotten better after steroid treatment.
• During ECP, your blood is collected and treated in a machine. The machine adds a chemical that makes the white blood cells sensitive to light. Then the machine shines a light on the cells and then gives your blood back to you.
• No one knows exactly how ECP treats GVHD. Some researchers have found changes in the blood after ECP that decreases swelling and inflammation.
• ECP may have a lower risk of infections than other GVHD treatments, like steroids or medicines that hold back (suppress) your immune system.
• ECP is expensive and not all insurance companies will cover it. So you may have out-of-pocket costs with this treatment.
• ECP is also called extracorporeal photochemotherapy or extracorporeal photoimmunotherapy.

WHO CAN GET ECP?
• People with GVHD who have not gotten better after treatment with steroids

WHAT DO I NEED TO GET ECP TREATMENT?
• Large veins or a central line. Good intravenous (IV) access is needed to collect your blood and give it back to you after treatment. If you have small or scarred veins you may need a central line (central venous catheter) to get ECP. A central line is a long, thin tube that’s put into the large vein in your chest. It either comes out through your skin, or ends in a port just under your skin. It’s used to give medicines, fluid and blood.
• Time. ECP can take 1 to 4 hours to complete depending on the machine used. Most people need treatment for 2 to 3 days every week or month.
• Enough blood counts. You must have enough platelets and red blood cells to get ECP treatment. If your platelet or red blood cell count is low, your doctors may delay your ECP treatment. Or, you may need blood transfusions to increase your blood counts.
WHAT IS IT LIKE TO GET ECP?

- You will be lying down or reclining during treatment. Bring a book or electronic device with headphones for music or entertainment.
- Most people don’t have any side effects during treatment. But, you may feel mild dizziness, nausea, tingling, or cramping or feel cold. Some people have fatigue (tiredness), skin flushing or low-grade fevers for 1 to 2 days afterwards.
- You’ll get a blood thinner to help your blood go through the ECP machine, so you may bruise or bleed more easily for up to 4-6 hours afterwards
- If you take high blood pressure medicines or water pills (for example, furosemide), ask your doctor if you should skip these on ECP treatment days.

WHAT ELSE SHOULD I KNOW?

- You will be more sensitive to the sun for 24 hours after treatment. Avoid the sun and wear sunscreen. You should also protect your eyes and wear protective sunglasses.
- ECP may take a long time to have its best effect. You doctor may wait 2 to 3 months before deciding whether ECP is helping you.
- Long-term treatment with ECP can cause low red blood cell counts (anemia) and fatigue due to lack of iron. Your doctor can test you for this and give you iron pills or infusions if needed.

WHEN SHOULD I CALL MY DOCTOR?

- You have a central line and your arm swells or you feel short of breath. You could have a blood clot.
- You had treatment within the past 1 to 2 days and have a fever, chills or feel unwell. You could have an infection.
- Your GVHD gets worse despite treatment

RESOURCES TO LEARN MORE

Be The Match® has a variety of free resources to help you cope with GVHD after transplant. Visit BeTheMatch.org/patientGVHD to find resources that best meet your needs.

Here are some you might find helpful:

- VIDEO: What is GVHD?
- FACT SHEET: Chronic GVHD of the Skin and Deeper Tissues
- WEBCAST: Living Now – Your Role in Managing Your Chronic GVHD

A clinical trial may offer a GVHD treatment option for you. The Jason Carter Clinical Trials Program helps patients and families find and join clinical trials. To learn more:

- Call: 1 (888) 814-8610
- Visit: JCCTP.org and enter “GVHD” as the keyword in the search box

AT EVERY STEP, WE’RE HERE TO HELP

Be The Match has a team dedicated to providing information and support to you before, during, and after transplant. You can contact us to ask questions you may have about transplant, request professional or peer support, or receive free patient education materials.

CALL: 1 (888) 999-6743  |  EMAIL: patientinfo@nmdp.org  |  WEB: BeTheMatch.org/patient

Every individual’s medical situation, transplant experience, and recovery is unique. You should always consult with your own transplant team or family doctor regarding your situation. This information is not intended to replace, and should not replace, a doctor’s medical judgment or advice.