

# **Extracorporeal Photopheresis (ECP) Patient Handbook**

Located in the Apheresis Procedure Unit  
University Hospital Floor 2 Room F225



# Introduction

Welcome to the Apheresis Procedure Unit. Please read through this handbook, which will help guide your ECP treatment.

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## Contact information

### When and how do I call my doctor?

- For emergency situations, call **911**.
- For questions about symptoms or any recent or current illness, call your medical provider.
- For non-medical concerns (scheduling, instructions, etc.), call the Michigan Medicine Apheresis Procedure Unit at **(734) 936-6900** on Monday through Friday from 8:00 AM – 3:30 PM.
- For urgent situations, call the paging operator at **(734) 936-6267**. They will page the doctor on call for you.

### Important phone numbers:

Department or service	Phone number
Guest Assistance Program and Social Work	(800) 888-9825
Med Inn and hotel/lodging support	(734) 936-0135
Art and music services	(734) 647-8626
Pulmonary and Nephrology departments	(734) 936-8535

# **Your ECP treatment: What to expect**

## **What is extracorporeal photopheresis (ECP)?**

ECP is a slow, gentle treatment that helps your immune system recover from different problems like cutaneous T-cell lymphoma (CTCL), graft-versus-host disease (GVHD), and organ transplant rejection.

## **What will my ECP treatment procedure be like?**

- Your nurse and doctor from the Apheresis Procedure Unit will work with your primary doctor to decide how many ECP treatments you will need and how often you will be treated. They will share this information with your primary doctor.
- During treatment, you will be sitting comfortably in a reclining chair or bed. The nurse will check your blood pressure and take measurements, including your body temperature and weight. They'll also ask questions about your current health. Please share any changes to your well-being that you might be experiencing.
- The nurses will collect some of your blood using a special medical machine, which then separates the white blood cells from the red blood cells. Then they'll add a medication called Uvadex® (methoxsalen) to the collection of white blood cells. Finally, the machine will put the white blood cells through an ultraviolet light chamber and return them to your body.

Please note that your appointment with us is for ECP treatment only. If you have any questions about other needs (listed below), please contact your doctor or clinic that referred you to the ECP treatment area.

- **Medical questions:** Your doctor or clinic staff can help answer any medical questions and concerns you have that are not related to ECP. You

can do this at your scheduled appointment, by calling your clinic's phone number, or by sending a message through the online patient portal at [MyUofMHealth.org](http://MyUofMHealth.org).

- **Treatment after a recent emergency room visit or hospital stay:** You are responsible for contacting your doctor or clinic directly if you have had a recent emergency room visit or hospital stay. This is so that your doctor can decide if it is safe for you to continue your ECP treatments.
- **Prescription refills:** To request prescription refills, please use the clinic phone number for your medical provider (for urgent requests) or use the online patient portal (for non-urgent requests).

# Preparing for your treatment

## How do I prepare for my ECP treatment?

- ☐ We recommend finding someone to drive you to and from your first ECP treatment.
  - Depending on how well you tolerate the treatment, you may be able to drive yourself to future treatment appointments.
- ☐ Eat a low-fat meal before your treatment. We recommend you follow this guidance until your ECP treatment plan is completed.
- ☐ Drink at least eight 8 oz glasses of caffeine-free liquid (water, juice, etc.) the day before your treatment.
- ☐ Follow any other recommendations from your doctor or nurse related to diet changes, drinking fluids, controlling your blood pressure, etc.

## How do I follow a low-fat diet before my treatment?

An unusual part of ECP treatment is that the last meal you eat before your treatment must be a low-fat meal. This is because of how the ECP machine to collect your blood works. We recommend that patients follow this guidance until their ECP treatment plan is completed.

## What foods can I eat as part of a low-fat meal?

- Eat lots of fruits, vegetables, whole-grain and high-fiber foods, and fat-free and low-fat dairy.
- Learn about the foods you eat by reading nutrition labels. Look for "low-fat," "nonfat," and "reduced fat" labels on food packages.
- Eat lean meats (fish, chicken, turkey, etc.) and legumes (like kidney, pinto, or black beans). Other good low-fat sources of protein include dried beans and peas, tofu, low-fat yogurt, low-fat milk, low-fat cottage cheese, and tuna fish packed in water.

- Drink skim or 1% milk.
- Eat low-fat (no more than 3 grams of fat per ounce) or nonfat cheeses and spreads. Try low-fat or fat-free versions of margarine, salad dressing, cream cheese, mayonnaise, and fat-free hummus.
- Use soft margarine as a substitute for butter, and choose margarines (liquid or tub varieties) over harder stick forms. Look for “0 g trans-fat” on the Nutrition Facts labels.

### **What foods should I avoid?**

These are general categories of foods that are high in fat. The Cancer Center nutritionists are available for consultation in the Nutrition Clinic. Call (734) 647-8902 to schedule an appointment.

- **Dairy products high in fat** including cheese, cream, ice cream, milkshakes, whole milk, 2% milk, sour cream, egg yolks, and butter
- **Meats high in fat** including regular ground beef and heavily marbled meats (such as prime rib), bologna and most lunch meats, hot dogs, sausage, bacon, salt pork, spareribs, liver and other organ meats, and the skin of poultry (chicken and turkey)
- **Fried foods** such as french fries, fried chicken and fish sandwiches, and burgers topped with cheese, sauces, or bacon
- **Gravy, heavy cream sauces, and dressings with saturated fats** such as creamy salad dressings and mayonnaise
- **Saturated fats and hydrogenated oils** such as shortening, lard, palm oil and palm kernel oil, coconut oil, and some margarines
- **Nuts high in fat** including pistachios, macadamia nuts, cashews, and nut butters
- **Baked goods and snacks that contain saturated fats and hydrogenated oils** (listed above) including doughnuts, cookies, pies, muffins, etc. Check the total fat and saturated fat content of snacks, but generally avoid chips (potato and corn chips, tortilla chips, etc.), microwave popcorn, etc.

### **How should I prepare low-fat meals?**

- Trim all fat you can see off of meats, and remove the skin from poultry.
- Bake, broil, or grill meats on a rack that allows fat to drip from the meat.
- Sprinkle lemon juice and herbs and spices on cooked vegetables instead of using cheese, butter, or cream-based sauces.
- Try plain, nonfat, or low-fat yogurt and chives on baked potatoes rather than sour cream. Reduced-fat sour cream still contains fat, so you must limit the amount you use.

### **How can I make a low-fat meal choice when I'm dining out?**

- Choose simply prepared foods such as broiled, roasted, or baked fish or chicken. Avoid fried or sautéed foods, casseroles, and foods with heavy sauces and gravies.
- Ask them to cook your food without added butter, margarine, gravy, or sauces.
- Ask for a salad with low-fat dressing on the side.
- Get fruit, angel food cake, nonfat frozen yogurt, sherbet, or sorbet for dessert instead of ice cream, cake or pie.
- At fast food restaurants, choose grilled chicken or a baked potato with fat-free sour cream. Choose low-fat milk instead of a milkshake. Choose a salad with low-fat dressing.



# On the day of your treatment

## What do I need to do on the day of my treatment?

- ☐ Call the Apheresis Procedure Unit at (734) 936-6900 to tell us that you plan to come to your treatment appointment.
  - If you have a morning appointment, call before 7:00 AM and leave a message.
  - If you have an afternoon appointment, call before 10:00 AM.
- ☐ Wear loose, comfortable clothing to your appointment. Wear clothing that allows easy access to your arms and chest, such as short-sleeved tops that zipper or button closed. Avoid tight-fitting, pullover shirts.
- ☐ Bring your medications with you, including pain and anti-nausea medications.
- ☐ Bring your PUVA glasses (if you have them). You may also use your own sunglasses if they wrap around your face and provide 98-100% UV protection.
- ☐ If instructed, put on lidocaine (numbing) cream 1-1.5 hours before your appointment to help reduce pain or discomfort with IV insertion or port access.
- ☐ Check in for your ECP treatment at the Apheresis Procedure Unit (on Floor 2 of the University Hospital, close by the cafeteria) 15 minutes before your scheduled time.
- ☐ If you are the parent or guardian of a child (younger than 18) who is getting ECP treatment, you must plan to stay with them in the hospital during their treatment.

## **Why do I need to call ahead?**

The medical machine we use for the ECP treatment is not ready before your call. If you do not call before your scheduled appointment time, you will need to wait at least 30 minutes for us to get the machine ready when you arrive.

## **How do I use lidocaine cream?**

You can use lidocaine (numbing) cream on your skin to decrease the pain you may feel with an IV or before accessing a port. Some brand names of lidocaine cream include Emla®, ELA-Max®, and AneCream™. If you have questions about applying lidocaine cream, you should call the Apheresis Procedure Unit.

- Do not use this cream if you have had an allergic reaction to any numbing medication. If you develop a rash or skin irritation where you applied the cream, stop using it and talk with your doctor.
- For the best effect, you should apply the cream 1-1.5 hours before your scheduled treatment.

### **Steps for using lidocaine cream:**

1. Wash your hands. If you'd like, you may also wear gloves.
2. Open the tube of lidocaine cream. You may have to pierce the tube with the point on the cap.
3. Rub a small amount of cream onto the area of skin where you'll have an IV, or around your port. A nurse can show you the best place to put it.
4. Apply more cream to the same spot. You should put the cream on thick enough that you can't easily see skin through it.
5. Cover the cream with a non-absorbent dressing to increase the numbing effect. You can use Telfa™ (a nonstick dressing), Tegaderm™ (a clear, stick-on dressing), or plastic wrap. Do not use gauze, as this will absorb some cream and reduce the numbing effect.
6. If needed, secure the dressing with tape, Coban™, or BandNet®.

7. Wash your hands again to prevent numbing of your fingers or getting cream on other areas of your body. Be careful not to get lidocaine cream in your eyes, ears, nose, mouth, or on skin that has open cuts or scrapes. If you do, rinse it off right away.
8. Leave the cream and dressing on until you arrive for your treatment.

### **What blood testing will I get before my treatment?**

- You will have your blood drawn at your ECP appointment, as our nurses must review your lab work before each treatment so we can provide your ECP in the safest way possible. If your blood counts are not within our safety guidelines, your treatment may be cancelled.
- Sometimes we may need to give you one or more blood or platelet transfusions before your treatment.

### **What if I'm late for my appointment?**

- Please avoid being late to your scheduled treatments (unless you have an unavoidable situation, like a transportation issue or other emergency). Your ECP treatments may be delayed or cancelled if you arrive later than 15 minutes past your scheduled appointment time. Always call to let us know if you are running late.
- If you arrive late, your ECP nurses and doctors will decide if you can still receive your treatment that day.
- If you are repeatedly late to your scheduled ECP treatments, the ECP medical directors may decide to take you off the clinic schedule. In this case, we will send you a written warning 1 month before we plan to stop your treatments.

## **What if I need to cancel my appointment?**

- Please avoid canceling your scheduled treatments unless you have an unavoidable situation. Let the Apheresis Procedure Unit know as soon as you're aware of a scheduling issue.
- If you need to cancel an appointment, please try to let us know 24-48 hours ahead of time so we can offer your scheduled treatment time to another patient. Call (734) 936-6900.
- If you have an emergency and need to cancel on the same day as your treatment, call (734) 936-6900 by 7:00 AM. We will let your doctor know and develop a plan to reschedule your appointment.
- We will reschedule your appointment for the next available treatment time. We will work with you and your doctors to follow your treatment plan, but rescheduling an appointment may affect or change this plan.

## **What if I'm sick on the day of my appointment?**

If you are sick (you have a fever or flu-like symptoms), do not come to the Apheresis Procedure Unit. Please call your primary or referring doctor.

## **Can I bring family members or visitors with me to my appointment?**

- You may have 1 adult family member or friend with you in the Apheresis Procedure Unit at a time. They can check on you, bring you medications or food during your ECP treatment, etc. Staff may ask visitors to leave the treatment area if there is an emergency affecting any ECP patient, or if they have any concerns about safety, privacy, or behavior.
- Patients younger than 18 years old must have a parent or guardian stay in the building during their ECP treatment. If they leave the Apheresis Procedure Unit to go to another part of the building, they should give staff their cell phone number in case we need to reach them.

- Please review the current visitor policy online at [UofMHealth.org/patient-visitor-guide/visitor-guidelines](https://www.uofmhealth.org/patient-visitor-guide/visitor-guidelines) for any up-to-date changes. The purpose of this policy is to promote a safe, secure, and supportive environment for patients, visitors, and staff. It also helps us ensure privacy and comfort for all our ECP patients.

## **After your treatment**

### **When should I call my doctor?**

Call your doctor if you have any of these symptoms after your treatment:

- Temperature of 100.5 °F or higher
- Feeling unusually tired, weak, dizzy, light-headed, faint, or ill
- Having difficulty breathing or shortness of breath
- New bruises, tiny red dots on your skin, bleeding from your gums, coughing up blood, or seeing blood in your urine (pee) or stool (poop)
- Any other new or unusual symptoms

### **How do I protect my skin and eyes after my treatment?**

The Uvadex® (methoxsalen) medication will be present in your body for up to 24 hours after your ECP treatment. This medication puts you at higher risk for skin damage (burns) and eye damage (cataract development) from the sun. For 24 hours after your treatment, you should protect your skin and eyes by doing the following:

- Continue to wear your PUVA glasses or sunglasses.
  - You do not have to wear the glasses when you are asleep or in the shower.
  - You do not have to wear the glasses after sunset, while watching TV, or while using a computer.
- Avoid sun exposure. Protect your skin with clothing, and wear sunscreen with SPF 30 or higher on exposed skin. You can test the sunscreen on a small area of skin first to be sure it doesn't cause irritation.

### **How do I care for my IV sites?**

Leave the pressure dressings we put on in place for 6 hours after your ECP treatment. If you take the dressings off after 6 hours and you're still bleeding,

apply pressure and put the dressing back on. Make sure you don't put the stretchy dressing back on too tightly - you should be able to fit a finger under it easily.

### **How do I care for my ports?**

Leave the dressings we put on in place for 6 hours after your ECP treatment. If you take the dressings off after 6 hours and you're still bleeding, apply pressure and put the dressing back on.

### **How do I care for my central venous catheter?**

Flush your lumens and change the dressing and caps as directed. Call your doctor immediately if you notice redness, swelling, pain, drainage (pus), or bleeding from the site.

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