



Health Facts for You



CAR-T cell therapy

UWHealth



**Carbone
Cancer Center**

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Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 10/2024 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#8241

Who to Call

CAR-T Doctor: _____

Nurse Navigator: _____

Phone: _____

Email: _____

UW Health Carbone Cancer Clinic Nurse Triage Line	608-915-0100 or 1-800-622-8922
Guest Services/Lodging	608-263-0315
Inpatient Nurses Station (B6/6)	608-263-8196
Inpatient Case Manager	608-262-0857 or 608-267-8105
Nutrition	608-275-1700 (clinic)
	608-263-8230 (inpatient)
Pharmacist (clinic)	608-261-1708
Social Worker	608-262-7894
Spiritual Care Services	608-263-8574

Important Dates

Consult Date: _____ **Time:** _____

With: _____

Apheresis Collection Date: _____ **Time:** _____

Location: C5/3, Infusion Center

Consent Date: _____ **Time:** _____

Labs and Procedures

Labs and Procedures			
	Date	Time	Location
Blood Draws			
Pulmonary Function Tests			
Echocardiogram			
Imaging			
Bone Marrow Biopsy			

Lymphodepleting Chemotherapy and Infusion Schedule

Lymphodepleting Chemotherapy and Infusion Schedule							
Day	-6	-5	-4	-3	-2-	-1	0
Date							
Fludarabine							
Cyclophosphamide							
CAR-T Cell Infusion							

CAR T-Cell Therapy Overview

What is CAR T-cell therapy?

Chimeric antigen receptor T-cell (CAR T-cell) therapy uses your body's own T-cells to fight cancer.

What are T-cells?

T-cells are a type of white blood cell called lymphocytes. These cells help the immune system to prevent disease and kill abnormal cells, such as cancer. Sometimes though, these T-cells do not recognize and fight these cancer cells.

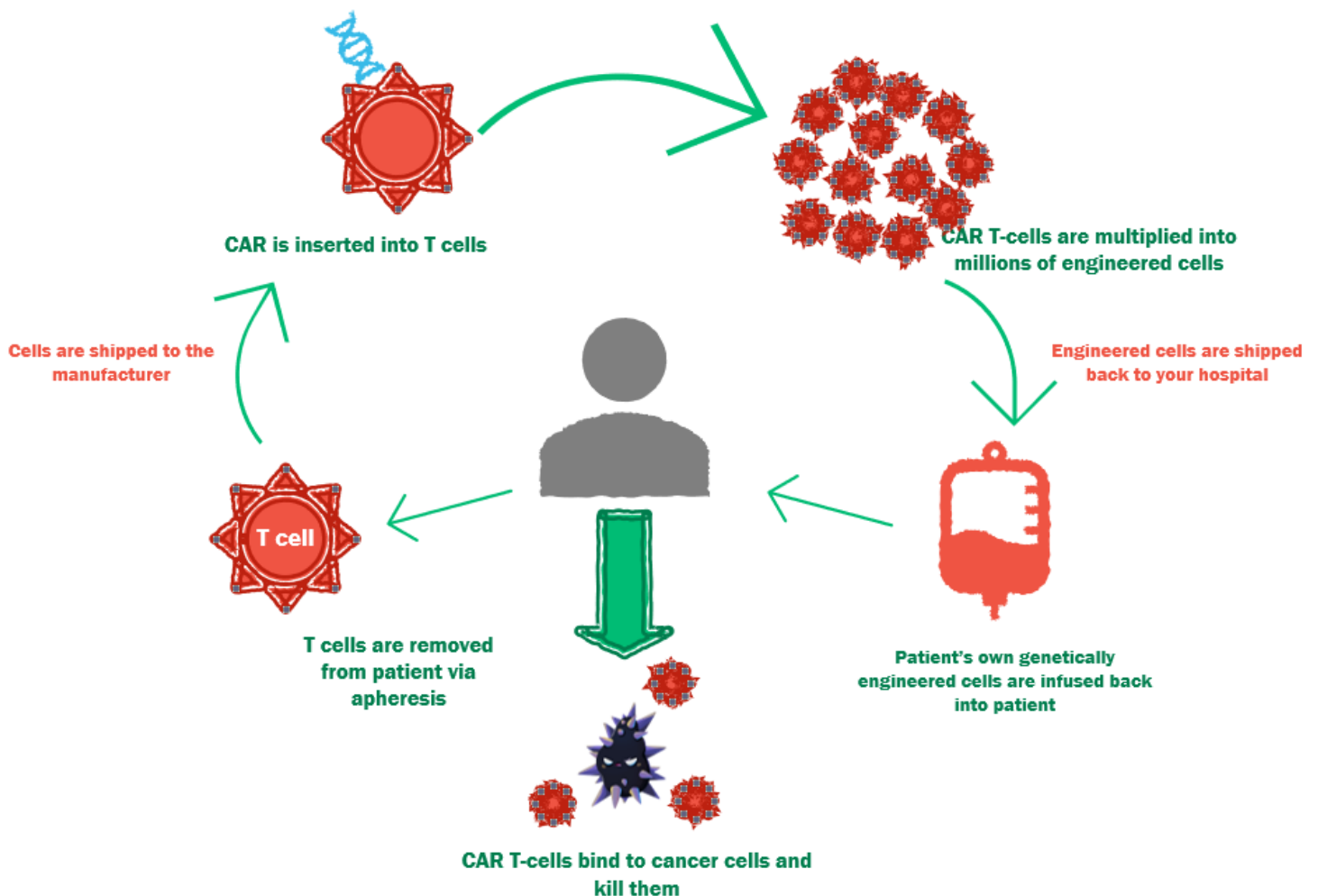
How does CAR T-cell therapy work?

The process for this treatment involves:

1. First, taking out some of your blood that contains T-cells.
2. Then, sending those T-cells to a lab to be modified so they can recognize the cancer cells.
3. Lastly, infusing the modified T-cells back into your blood.

We do not know what effect this treatment will have on you. It may:

- Put you into a complete remission.
- Put you into a remission for a short time before your disease comes back.
- Put you into a partial remission (some disease remains but not as much as there was before treatment).
- Not put you into a remission at all.



What CAR T-cell product will I get?

We offer these CAR-T products:

- ☐ **Abecma** (idecabtagene vicleucel) – for adults with Multiple Myeloma.
- ☐ **Carvykti** (ciltacabtagene autoleucel) –for adults with Multiple Myeloma.
- ☐ **Breyanzi** (lisocabtagene maraleucel) –for adults with:
 - Large B-cell lymphoma
 - Chronic lymphocytic leukemia or small lymphocytic lymphoma
 - Follicular lymphoma
- ☐ **Yescarta** (axicabtagene ciloleucel) – for adults with:
 - Large B-cell lymphoma
 - Follicular lymphoma
- ☐ **Tecartus** (brexucabtagene autoleucel) – for adults with:
 - Mantle cell lymphoma
 - B-cell acute lymphoblastic leukemia (ALL)
- ☐ **Kymriah** (tisagenlecleucel) –for:
 - Children and young adults (up to 25 years old) with B-cell acute lymphoblastic leukemia (ALL).
 - Adults with diffuse large B-cell lymphoma (DLBCL)
 - Adults with transformed follicular lymphoma.

Clinical Trials

You may also be offered a clinical trial. Your doctor will discuss these options with you.

Clinical trials are research studies on patients. The goal of clinical trials is to improve treatments and quality of life for patients. Some clinical trials are testing if an approved CAR T-cell therapy works in other types of cancers. Others test for a new type of CAR T-cell therapy. There are some that study how to manage side effects. Clinical trials may be the only option for certain types of cancer. If CAR T-cell therapy is not an option for you, your doctor may give you the option of a clinical trial.

If a clinical trial works best for your treatment, you will work with a research coordinator to schedule and keep track of your appointments. They will closely watch your progress throughout the clinical trial.

Before CAR T-cell Therapy

Referral

Your primary oncologist may refer you for CAR T-cell therapy. You will first talk with a CAR T-cell doctor about your disease and how CAR-T can help you. The doctor will tell you how the treatment works, the effects of the therapy, and caregiver support. If you agree to this treatment, then you will meet with your CAR-T team.

Meet Your CAR T Team

You will be assigned a nurse navigator from the Stem Cell Transplant and Cellular Therapy (SCTCT) Program. This nurse works closely with your doctor and other staff to:

- Teach you about the process
- Help with any financial planning
- Provide caregiver support
- Help schedule needed labs and procedures
- Schedule collection of cells
- Schedule lymphodepleting chemotherapy
- Schedule infusion of cells

Patient Education

Staff will teach you about every part of the process. They will tell you about the labs and tests you will need, what to expect and what happens after you receive your cells.

Wallet Card

You will be given a **Patient Wallet Card (PWC)**. This card lists the side effects that you may have after your infusion and what to do. You should show this wallet card to all healthcare providers so they know you've been treated with CAR T-cells. Some treatments may interfere with your CAR T-cells. The wallet card tells healthcare providers what to look for and avoid.

Your wallet card also lists other guidelines such as driving and work restrictions and your need to stay near the hospital.

Financial Planning

This treatment costs a lot of money. Many health insurance plans will pay for CAR T-cell therapy, but some may limit the amount they will pay. Other plans may not cover it at all. We have financial planners who will answer any questions you may have.

Arrange for a Caregiver

You must have a caregiver, or team of caregivers. This person can be a family member or friend. The caregiver will bring you to and attend appointments with you before, during, and after you receive your cells. They will also need to monitor you after treatment. This person must be with you 24/7 for up to 4 weeks after the CAR T-cell infusion. If they cannot stay with you for the entire 4 weeks, make sure there are other people who can stay with you. If you do not have anyone who can stay with you, talk to the social worker or navigator about the other options. You may still need a caregiver after 4 weeks because you cannot drive until 8 weeks after your infusion.

Labs and Tests

You must have testing to make sure you are healthy enough to receive this treatment.

Tests may include:

- Blood counts (CBC)
- Tests for infection (hepatitis B and C, HIV)
- Blood tests for kidney and liver function
- Pulmonary function tests to assess your lungs
- Echocardiograms to assess your heart
- Bone marrow biopsy
- CT or PET/CT imaging
- Spinal tap

T-Cell Collection

You will have a procedure called **leukapheresis** (sometimes called 'apheresis') to collect your cells. It is done on an outpatient basis.

Creation of CAR T-Cells

Your collected cells will be sent to a lab where they will be turned into CAR T-cells that can destroy your cancer cells.

Bridging Therapy

Bridging therapy is treatment given between apheresis and lymphodepleting chemotherapy. You may need this to prevent your disease from progressing. Types of bridging therapy could be chemotherapy and/or radiation. Not all people need bridging therapy. The amount of time you are given bridging therapy may also vary.

Lymphodepleting Chemotherapy

Before you receive your cells, you will have lymphodepleting chemotherapy (also called conditioning chemotherapy) to prepare your body to receive these new cells.

Leukapheresis

Your T-cells will need to be collected from your blood using an apheresis machine. If you've had an autologous stem cell transplant in the past, you may know this process. Two arm veins or a catheter are used. One vein is needed to draw blood into the machine to separate the cells. We will use a second vein to return the rest of the blood back to you. If your veins cannot be used for some reason, we will insert a central catheter, most often in the neck or groin. You will be asked to come to the Infusion Center a day before your collection to look at your veins to see if you will need a catheter.

The apheresis process takes 3-4 hours. During this time, you can sleep, watch TV, or bring something from home to do. Wear a loose-fitting or button-down shirt to help the team get to your veins in your arm.

A nurse or doctor will be present throughout the procedure. Your vital signs will be checked often.

Anti-Clotting Medicine

You will need an anti-clotting drug during the collection. This drug may cause tingling in the fingers, toes, and lips. Some people also have body chills. Tell your nurse if you are having any of these symptoms. The tingling can be treated with calcium. These symptoms go away within 30 minutes.

After the cells are collected, the bag of T-cells will be taken to the Cellular Therapy Lab. The lab will then send your cells to be turned into CAR T-cells.

Side Effects

Other side effects from apheresis include:

- Fatigue
- Weakness
- Dizziness
- Sore arms
- Nausea

Transportation

You should have someone drive you home after the collection.

Creation of CAR-T Cells

At a special lab, your healthy T cells will have a gene for a receptor, called a **chimeric antigen receptor (CAR)**, inserted into them. The CARs will bind to specific proteins, or antigens, on the surface of the cancer cells. Millions of CAR T-cells will be made in the lab. These cells will go through testing before being shipped back to our Cellular Therapy Lab. Then, the CAR T-cells will be stored until you are ready to be infused.

It will take several weeks for your CAR T-cells to be made. While your cells are being made, your doctor may want you to have bridging therapy to prevent your disease from getting worse.

Lymphodepleting Chemotherapy

Before your CAR-T infusion you will need to receive lymphodepleting conditioning. This process involves a low-dose of chemotherapy to make space for the new CAR T-cells. The timing for this will vary. It is often done as an outpatient over three days with a couple of days between your last day of chemotherapy and infusion of your cells. Try to stay as active as you can throughout this stage.

Side Effects

This type of chemotherapy may cause:

- Fatigue
- Low blood counts
- Nausea/vomiting
- Lack of appetite
- Infection

PICC Line

You may need to have a PICC line inserted before chemotherapy. If you already have a port, you do not need a PICC line.

Day of Infusion

Infusion of your cells will take place in the outpatient clinic, where you will be watched closely. Expect to spend several hours in the clinic. You will be checked by your care team before the infusion to see how you are doing. Your cells will then be infused just like a blood transfusion. This infusion of cells takes less than one hour.

Infusion Reactions

The risks from the infusion itself are often minor. Some patients can have infusion-related reactions such as flushing, rash, itching, and high or low blood pressure/heart rate. Rarely, patients may have a severe allergic reaction. Your care team will watch you very closely during and for two hours after the infusion. We will give you medicines to manage reactions, if needed.

Wallet Card

We will check that you have a Patient Wallet Card. **Keep this card with you at all times.** If you need to go to the Emergency Room after your infusion you must show ER staff this card, so they know about your CAR-T treatment.

Side Effects of CAR T-cell Therapy

In the first few weeks after the infusion, the CAR T-cells will quickly multiply in your body. During this time, you may have some side effects. Side effects to watch for:

- Cytokine release syndrome (CRS)
- Neurotoxicity (also known as ICANS)
- Infection

Most of these side effects can be treated and are often temporary. In rare cases, some side effects are long lasting or may lead to death. Your care team will tell you what side effects to expect and how to respond to them.

Not all patients will have side effects. Side effects may show up sooner for some patients than others. Ask your provider what side effects are common for your diagnosis and CAR-T product.

Cytokine Release Syndrome (CRS)

When your CAR T-cells start attacking your cancer cells, they release something called cytokines. Cytokines are proteins that control the growth and activity of immune cells and blood cells. Sometimes a large amount of cytokines will be released which can cause serious health problems. This is called cytokine release syndrome (CRS).

CRS often occurs within the first two weeks after infusion, sometimes within hours after treatment. Symptoms may include:

- Fever (100.4°F/38°C or higher)
- Chills/shaking
- Low or very low blood pressure
- Low white or red blood cell count
- Loss of appetite
- Dizziness/lightheadedness
- Fast or irregular heartbeat
- Trouble breathing/shortness of breath
- Nausea, vomiting, diarrhea

- Muscle or joint pain
- Low oxygen levels
- Swelling or fluid retention
- A lot of fatigue

If you are having any of these symptoms, you should call the Cancer Clinic Triage line or go straight to the Emergency Room. You will most likely get admitted to the hospital to watch you closely and treat your symptoms. **Remember to bring your wallet card!**

You may be given IV fluids, medicines, or oxygen. If your CRS is more severe you may need to be treated in the intensive care unit (ICU)

You will be watched closely until all symptoms of CRS are gone. This often takes a few days but can take longer.

If not found and treated right away, CRS can be life-threatening.

Neurotoxicity

This is when there is damage to the brain or nervous system. It may happen after CAR T-cell therapy and is often temporary. It is also referred to as **ICANS**, short for **immune effector cell-associated neurotoxicity syndrome**.

ICANS can occur a week or more after your treatment. Symptoms may include:

- Headaches, which may be severe
- Trouble speaking, slurred words, stuttering
- Confusion/delirium
- Anxiety
- Trouble staying awake
- Dizziness
- Trouble paying attention
- Loss of coordination
- Weakness/shakiness

- Changes in handwriting
- Seizures
- Swelling in the brain
- Memory loss
- Hallucinations

You may be given a medicine at time of your treatment to reduce the chance of seizures. If you show other symptoms, you may be given steroids. In severe cases, you will be treated and watched closely in the ICU.

Low Blood Counts

You may have low blood counts, also called cytopenia, for the first few weeks. This is common. Low blood counts may also last for several months after your infusion. Low blood counts increase your risk of infection and can cause fatigue.

B Cell Aplasia

The CAR T-cells also attacks normal, healthy B cells. This causes B cell aplasia (low number of B cells). This makes it harder for your body to fight germs and can increase your risk for infection. To treat this, you may need immunoglobulin infusions, also known as IVIG. B cell aplasia may first appear in the first 8 weeks after infusion.

Tumor Lysis Syndrome

This happens when cancer cells breakdown quickly and release chemicals into the blood. If the kidneys cannot clear these chemicals fast enough, you can have Tumor Lysis Syndrome. We will give you medicine to prevent this.

Infection

Because your immune system may be weakened, you will need to avoid getting infections. Follow these guidelines:

- Wash hands often
- Practice food safety
- Do not clean up after pets

- Avoid large crowds, or wear a face mask in crowds
- Brush your teeth twice a day with a soft toothbrush and floss
- Shower daily
- Make sure all family members and visitors wash their hands well
- Avoid people who are sick

Immune Effector Cell-Associated Hemophagocytic Lymphohistiocytosis-Like Syndrome (IEC-HS)

IEC-HS is life-threatening with a high rate of death if not found and treated early. Symptoms may mimic those of CRS.

Fetal Effects

This treatment has not been studied in pregnant or nursing patients. Therefore, if you are pregnant or nursing, you cannot have this treatment. Patients must use birth control to prevent pregnancy. Please talk to your care team about birth control for you and your partner.

Infertility

Chemotherapy may cause lasting effects on fertility. It can cause birth defects or infertility. Cancer treatment may cause menstrual periods to become irregular or stop. We do not know how CAR-T products effect fertility.

Secondary Cancers

Patients who receive CAR-T may get new blood cancers. Your doctor will follow you throughout your lifetime to watch for any new cancers.

Weeks 1-8 After Infusion

Monitoring

You may need to stay in the hospital after your infusion to be monitored. This will depend on the type of drug you receive.

If you do not need to stay in the hospital, you need to stay close by. You will need to stay within 1 hour of our site for the first 4 weeks, or as directed by your care team. Exceptions may be made for those who live 1-2 hours from our site on a case-by-case basis.

We will need to watch you closely for:

- Low blood counts
- Infection
- Electrolyte imbalance
- Organ function
- Symptoms of CRS or ICANS

If you show signs or symptoms of CRS or ICANS you will be admitted to the hospital to treat these problems. Your time in the hospital will depend on how well you respond to treatment.

Remember to keep your wallet card on you at all times! You will need to show this to all health care providers.

Fevers

You will need to check for a fever twice daily. Call right away for a fever greater than 100.4°F or if you notice side effects of treatment. You should call UW Cancer Clinics at **(608) 265-1700**. You may be told to go right to the Emergency Room. You may need treatment with IV medicines.

Driving

You will not be allowed to drive a vehicle for eight weeks after infusion. Your caregiver will need to transport you to and from the clinic for check-ups.

Long-Term Follow-Up

Starting at one month after your infusion, you will have routine follow-up visits. At these visits we will check your remission status. You may need imaging, a bone marrow biopsy and blood work. You may require routine IVIG infusions to help prevent infection.

Vaccines

Treatment will wipe out your immunity. You will need to receive vaccines that you may have received before your infusion. Your care team will work with you to schedule getting these vaccines:

- COVID
- Influenza
- Pneumococcus
- Diphtheria, tetanus, and pertussis (DTaP)
- Haemophilus influenzae type B (Hib)
- Polio
- Hepatitis B
- Meningococcus
- Varicella-Zoster virus (shingles)
- Mumps, measles, and rubella (MMR)

For the Caregiver

Your Role

The healthcare team will meet with you to talk about your role. Caring for someone getting CAR T-cell therapy is a big job. You will need to:

- Watch the patient for fever, chills, confusion, or disorientation.
- Make sure the patient follows the treatment plan.
- Make sure the patient takes any required medicines.
- Help schedule and arrange transportation to follow-up visits.
- Watch the patient for new or worsening symptoms.
- Tell the healthcare team about any changes in the patient's condition.
- Make meals.
- Provide emotional support.
- Help with household chores and keep a clean home for the patient.

Your Support System

Although you need to take care of the patient, you must also have your own support system. Taking care of the patient can be tiring and stressful. For this reason, you should make sure to eat healthy meals and keep to a routine as much as you can. Try to get in some exercise and get a good night's sleep. You can talk to the social worker or nurse navigator about groups or websites to help you cope.

Ask others to help you out. Friends and family are often willing to help where able. Ask them to help make meals, clean, do yard work, or grocery shop. Keep a record of who is helping when with what.

Some websites that can help you are:

- LotsaHelpingHands.com
- MealTrain.com
- CaringBridge.org

Resources for Caregivers

Ask your care team for other resources for social, emotional, physical, and practical support.

- CancerSupportCommunity.org/caregivers
- MyLifeLine.org
- Cancer Support Helpline: 844-792-6517
- Blood and Marrow Transplant Infonet
 - Caring Connections Program: www.bmtinfonet.org/get-help
 - Resources on Role of the Family Caregiver: www.bmtinfonet.org/transplant-article/role-family-caregiver
- CancerCare: www.cancercare.org/caregiving
- Caregiver Action Network: www.caregiveraction.org
- Help for Cancer Caregivers: www.Helpforcancercaregivers.org
- Leukemia and Lymphoma Society:
 - Education, resources, and tools: lls.org/support-resources/caregiver-support
- Lymphoma Research Foundation: lymphoma.org

Resources

Leukemia & Lymphoma Society's First Connection Programs

lls.org/support/peer-to-peer-support

This is a free service that connects patients and their loved ones to a trained peer volunteer who has gone through a similar experience.

CAR T Cancer Support Helpline

www.CancerSupportCommunity.org/Helpline

This helpline is staffed by social workers who help to patients and loved ones address social, emotional, practical and financial barriers to care.

Monday-Friday 8 am – 8 pm CST

Saturday-Sunday 8 am – 5 pm CST

844-792-6517

MyLifeLine

www.MyLifeLine.org

This is a private, online community that allows patients and caregivers to connect with friends and family to receive social and emotional support through your journey.

Discussion boards are moderated by a licensed professional and can be reached 24 hours/day, 7 days/week.

Blood & Marrow Transplant (BMT) Infonet

www.bmtinfonet.org/get-help

This is a free service that connects you with a survivor or caregiver so they can share their experience with you and provide support.

References

American Cancer Society, CAR T-Cell Therapy and Its Side Effects, Last Revised March 1, 2022.

<https://www.cancer.org/cancer/managing-cancer/treatment-types/immunotherapy/car-t-cell1.html>

Cancer Support Community. (2021). CAR T Patient and Caregiver Guide.

BMT Infonet. (2023, September) *What is CAR T-cell Therapy?*

<https://bmtinfonet.org/car-t-cell/what-is-car-t-cell-therapy>

Glossary

Anemia—A condition that occurs when the red blood cell count is low.

Apheresis—This is the process used to collect t-cells from the blood. It is also called leukapheresis.

Bone marrow—The spongy tissue found in the cavities of the body's bones where all blood cells are produced.

Chemotherapy—Treatment with one or more drugs to try to stop or slow the growth of cancer cells.

Chimeric antigen receptor (CAR) T-cell therapy—Therapy in which T-cells are removed from the blood and have a new gene inserted into them to make it easier for the T-cells to fight cancer. These cells are then infused into the patient to begin fighting cancer.

Complete Blood Count (CBC)—A blood test done in a laboratory to find out the number of red blood cells (RBC's), white blood cells (WBC's), platelets, hemoglobin, and hematocrit in your blood. These blood cells are made in the marrow of your bones.

Cytokine—Proteins released by immune system cells to communicate with each other.

Cytokine release syndrome (CRS)—The syndrome caused by CAR-T cells attacking cancer cells. Symptoms may include fever, chills, low blood pressure, or shortness of breath, among others.

Cytopenia – a condition in which there is a lower-than-normal number of blood cells: red blood cells (anemia), white blood cells (leukopenia), or platelets (thrombocytopenia).

Granulocyte colony stimulating factor (g-csf)—The drug given to increase the number of white blood cells.

Hematocrit—The part of the blood that consists of packed red blood cells.

Hemoglobin—The part of the red blood cell which carries oxygen.

Immune compromised—A condition in which the patient has a much higher risk of infection due to a weak immune system.

Immune Effector Cell-Associated Neurotoxicity Syndrome (ICANs)—Also called neurotoxicity, this results from impairment to the brain or nervous system caused by CAR-T activity. It often can be reversed. Symptoms may include headaches, confusion, trouble speaking, seizures, or excessive drowsiness, among others.

Immunosuppressed—Lowered resistance to disease. It may be a temporary condition caused by a lowered white blood cell count or a side effect of chemotherapy.

Leukocytes—White blood cells that fight infection.

Lymphocytes—A type of white blood cell that is part of the immune system.

Lymphodepletion—Chemotherapy given to prepare the body to receive the CAR-T cells.

Platelets (Plts)—Blood cells that act as clotting agents to prevent bleeding.

Red blood cells (RBC)—Cells carrying oxygen to all parts of the body.

Relapse—The return of cancer after a period of being cancer-free.

T-cell—A certain type of immune cell that normally find abnormal cells, such as cancer cells, and destroys them before they cause disease. Sometimes, though, T-cells are unable to detect cancer cells. Also called T-lymphocytes.

Thrombocytopenia—Low platelet count.

White blood cells (WBC)—Cells that help fight infection and disease.