Introduction
Your immune system protects your body against infection and abnormal cellular changes, such as cancer. Cancer cells can hide from the immune system and even trick it into helping—rather than harming—these cells. Immunotherapy helps your immune system work harder and smarter to attack cancer.

Our work focuses on altering the T cells in your immune system to become disease-fighting cells, called CAR (chimeric antigen receptor) T-cells. We currently offer several types of CAR T-cell therapy, some are in clinical trials and others are FDA-approved.

The image above describes how CAR T-cell therapy works.
What you can expect

Your experience is unique
The information below is meant to give you a general idea of the CAR T-cell immunotherapy experience at SCCA. Keep in mind that your experience is unique. It will differ from others based on your disease, treatment plan, and response to treatment.

Phases of immunotherapy
Like other cancer treatments, CAR T-cell immunotherapy is a process made up of several phases:
- Evaluation
- Cell collection
- Cell engineering
- Chemotherapy
- Cell infusion
- Monitoring for side effects
- Follow-up

Your appointments
During each of the phases noted above, you may have one or more appointments. It is important that all appointments are kept as scheduled. We suggest bringing someone with you to help listen and take notes. Most appointments will take place at SCCA. Some of your outpatient care may be provided at the University of Washington Medical Center (UWMC). Your care team will talk to you about your specific treatment plan and appointment locations.

If needed, your inpatient care will be provided at UWMC, which has a team of immunotherapy nurses and physicians, just like our outpatient clinic.

Your location during treatment
For your safety, from the time you start chemotherapy, until the time you are discharged from day-to-day care, you are expected to live within a 30-minute drive to SCCA. If you are coming to Seattle from out of town, we recommend arranging temporary housing as soon as you know your arrival date. You will not be allowed to drive for 4 to 8 weeks following your CAR T-cell infusion, depending on your treatment plan and condition. Your care team will discuss this with you in more detail.

We encourage you to visit our website, seattlecca.org/housing-information, to learn about SCCA’s housing options and to view our housing guide. If you choose a different accommodation, there are a variety of hotels and extended-stay options within a 30-minute drive to our clinic.

Your caregiver
Due to the intensity of the treatment, you will need to have a caregiver with you 24 hours a day during chemotherapy, cell infusion, and for several weeks after your cell infusion. Your care team will determine how long you will need a caregiver following cell infusion (generally, based on our experience with other CAR T-cell patients, it’s about 4 weeks). This is the same time that you are also expected to live with a 30-minute drive to SCCA.

A caregiver provides around-the-clock monitoring, emotional support, and physical care, if needed. You may find it helpful to have one main caregiver, with assistance from other family members, friends, or hired caregivers. Before treatment starts, your team will teach you and your caregiver the symptoms to look for as you undergo treatment.
We recommend bringing your caregiver to appointments even before you start chemotherapy to meet your care team and learn about your treatment plan. See Caring for a Person Receiving CAR T Cells for more information about the role of a caregiver during treatment.

**Evaluation**

As a first step, you will meet with your care team to discuss your medical history, current disease status, and undergo a series of tests to evaluate your health and eligibility to receive CAR T-cell therapy. Examples of the types of tests or procedures you might have include:

- Bone marrow biopsy
- Blood draws
- Chest X-ray
- DEXA bone scans
- EKG (electrocardiogram)
- Lumbar puncture
- MUGA scan or echocardiogram
- PET/CT scan
- Pulmonary function tests

After this is complete, you will have a conference with your care team to discuss whether CAR T-cell therapy is a good treatment option for you. We recommend bringing your caregiver with you to this meeting. Your physician will review information about treatment and side effects. You will be asked to sign consent forms before beginning therapy. The conference is a time for you to ask questions about the forms you are signing and about your CAR T-cell treatment. Please read the forms carefully, but do not write on or sign them before your meeting.

**Cell collection**

T cells are collected from you through a process called apheresis. During apheresis, blood is taken from your body, sent through the apheresis machine that separates and collects your T cells, and the rest of the cells are returned into your bloodstream.

Apheresis generally takes 3 to 6 hours. Your apheresis nurse will have a better idea of how long your cell collection will take once you have started the process. Apheresis will take place on the 5th floor of the SCCA clinic. After your cells are collected, they are sent to a lab where scientists work to turn them into cancer-fighting cells.

**Cell engineering**

It generally takes 2 to 4 weeks for scientists to grow your new CAR T cells in the lab. Your care team will let you know how long you can expect to wait to receive your cells. During this phase, you will be seen in our clinic to make sure your body is ready for your CAR T cells. If your care team approves and you live out of town, you may be able to go home until your cells are ready.

**Chemotherapy**

Before receiving your new T cells, you will get lymphodepleting chemotherapy. The purpose of this is to decrease the number of immune system cells in your body to create space for your new CAR T cells. You will meet with a nurse before chemotherapy to talk about potential side effects and how to manage them.

You will receive your chemotherapy through a central line. A central line allows you to have long-term intravenous (IV) access for the chemotherapy, CAR T-cell infusion, and administration of medications that might be needed after CAR T-cell therapy. If you do not have a central line, you will have one placed (see Central Line Care for more information).
Cell infusion
A few days after chemotherapy, your CAR T cells are infused. Depending on your treatment plan, your infusion may take place at the immunotherapy clinic at SCCA, or at the University of Washington Medical Center (UWMC). Once your cells are infused, you will need to be monitored for side effects (also called “toxicities”).

Monitoring for side effects
CAR T-cell therapies can have serious side effects such as high fevers, unstable blood pressure, and changes in speech, behavior, and memory. Based on our experience, these side effects typically occur within the first 2 weeks after your infusion. We will give you contact information for who to call, day or night, if you experience urgent side effects.

If you experience a fever after receiving your CAR T cells, you will be admitted to UWMC. You and your caregiver will be trained in how to monitor the fever, should it occur, and when to take action. If you are admitted, your caregiver is not required to be with you. However, you may find it comforting to have your caregiver with you in the hospital. UWMC is designed for them to stay overnight.

The two main side effects that you will be monitored for are cytokine release syndrome (CRS) and neurotoxicity.

CRS is a severe inflammatory response that can lead to dangerously high fevers and extremely low blood pressure. Sometimes it goes away on its own with medical intervention and monitoring. But in rare cases, it can be severe and fatal. The most common first symptom of CRS is a fever. If you get a fever, you will be admitted to UWMC for monitoring. Severe symptoms may require intensive care unit (ICU) level care and can be managed with medications.

Another potential side effect is neurotoxicity. If this occurs, you may be admitted to UWMC. The cause of neurotoxicity is unknown, but it typically develops after CRS. When you have neurotoxicity, you can experience symptoms such as confusion, difficulty speaking, memory loss, unsteadiness, or seizures. Often, these symptoms may last less than a few days, are mild, and only need close monitoring. Sometimes, the symptoms may be more severe and last more than a few days. For example, you may not remember where you are, not recognize the people around you, or have difficulty getting to the bathroom on your own.

For symptoms of both CRS and neurotoxicity, you may be treated with steroids which can help slow down the growth of CAR T cells. You may also receive medications to help reduce the risk of seizures during treatment.

You may feel week and fatigued, which can impact your ability to perform your routine, daily activities. Based on the type and severity of side effects you experience, you may need to have special equipment at home (such as a walker, shower chair, or raised toilet seat) and you may require additional help, home care, and/or a physical therapist. Your care team can help you access these resources.

Follow-up
We are committed to providing you the best possible treatment and follow-up care. Following your infusion of CAR T cells, your care team will monitor you closely. Most patients visit the clinic daily.

Based on your progress and treatment plan, we will determine your recommended follow-up plan after you leave SCCA. We will provide your referring physician a discharge summary and letter. You will receive a packet with your medication list and last lab values, other medical records, and a disk with your radiology images.
The FDA asks us to follow patients up to 15 years after treatment to help understand the long-term effects of CAR T cells. This long-term follow-up is usually done through e-mail, regular mail, or follow-up appointments with your primary physician, oncologist, or SCCA care team.

**Frequently asked questions**

**What is a T cell?**
A T cell is a type of white blood cell in the immune system that destroys viruses, bacteria, and cancer. Sometimes, T cells don’t do their job, and viruses, bacteria, and cancer can take over. Using cellular immunotherapy, scientists alter T cells to become cancer fighters.\(^1\)

**What is a CAR T cell?**
A CAR T cell is a T cell with a chimeric antigen receptor (CAR) bound to it. CAR T cells bind to a specific marker on your cancer cells. The job of a CAR T cell is to destroy cancer cells.

**How effective is CAR T-cell immunotherapy for cancer patients?**
When you meet with our team, we will go over the potential benefits and risks of CAR T-cell therapies and discuss if they are the right treatment for you.

**How much do CAR T-cell therapies cost?**
The cost varies based on the intensity of your treatment and insurance coverage. Our Intake team will discuss insurance and other financial considerations with you before your first appointment. You can also contact SCCA’s Patient Financial Services team directly to help you understand what treatments might cost you.

**What is a clinical trial?**
A clinical trial is a type of research study that tests how well new medical approaches work in people.\(^2\) These studies test new methods of screening, prevention, diagnosis, or treatment of a disease. Clinical trials for drugs and medical devices often occur in 4 phases, and each phase has specific research goals. The goals of each phase are to evaluate:

- **Phase I:** safety, dosage, and side effects
- **Phase II:** side effects and effectiveness
- **Phase III:** effectiveness compared to standard treatment
- **Phase IV:** long term effects

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If you are not a Bezos Family Immunotherapy Clinic patient, please contact our Intake team with questions at 1 (800) 804-8824. If you are a patient at our clinic, please contact your care team with any questions about your immunotherapy experience at SCCA.

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\(^1\)https://www.cancer.gov/publications/dictionaries/cancer-terms/def/t-cell