Transplant Program

Preparing for Transplant
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Introduction

“Cancer is not fair or selective of its victims. What our family has learned through this journey is that we control our attitudes. No matter if our lives are long or cut shorter than normal, we can choose to be happy and thankful for each day.”

Pediatric unrelated transplant recipient, 2000
Welcome
Welcome to the Fred Hutch Bone Marrow Transplant Program at Seattle Cancer Care Alliance (SCCA) where over 400 transplants are performed annually. We are very pleased that you are considering treatment at our center in Seattle, Washington. SCCA brings together the best of three internationally-renowned comprehensive cancer-care programs in the Pacific Northwest: Fred Hutch, UW Medicine, and Seattle Children’s.

Most people have many questions and practical concerns about transplants and treatments. We hope this information answers most of your immediate questions and helps you prepare for consultation or treatment. We suggest that you write down any additional questions you may have. We will be contacting you by telephone to discuss your questions and to make arrangements for your stay in Seattle. You may also use the Important Phone Numbers at the front of this guide to contact us.

About us
Fred Hutch
Fred Hutch is one of 49 comprehensive cancer centers in the United States, as designated by the National Cancer Institute. It is also one of the largest bone marrow transplant centers in the world. It was here that Dr. E. Donnall Thomas pioneered bone marrow transplantation and received a Nobel Prize for his work. The significance of his efforts along with the work of many of the faculty at this center continues to be internationally recognized. Constant research and scientific advances since the 1960s have significantly increased the success of marrow transplantation. In addition to our contribution to science, we are recognized for the highest quality in clinical services.

Mission statement
The mission of Fred Hutch is the elimination of cancer and related diseases as a cause of human suffering and death. Fred Hutch conducts research of the highest standards to improve prevention and treatment of cancer and related diseases.

In fulfilling the mission of Fred Hutch:

- Biological scientists conduct fundamental research to discover mechanisms underlying the life of normal cells and the changes in these processes that cause disease.
- Clinical research scientists develop and test new forms of diagnosis and therapy.
- Public health scientists develop and apply new knowledge to help individuals and communities reduce the incidence and death rate from cancer and related diseases.
- Scientists from all fields share and integrate their findings and insights to foster the development and testing of new approaches.
Fred Hutch is dedicated to:

- Generating new scientific discoveries and translating them into effective medical practices, therapies, and public health approaches.
- Recruiting, supporting, and training highly qualified scientists and physicians in an environment that promotes collaboration and excellence.
- Cooperating with other research and medical institutions to assure worldwide access to new research findings and technical developments.
- Providing sensitive, efficient, and effective care for patients participating in experimental therapies and other studies.
- Promoting the importance of scientific research, responsible medical care, healthy environments, and personal behaviors through public education and advocacy.

**Seattle Cancer Care Alliance vision and purpose**

SCCA’s vision: To lead the world in translating scientific discovery into the prevention, diagnosis, treatment, and cure of cancer. A major focus of SCCA is to speed up the transfer of new diagnostic and treatment techniques from the research setting to patient care. The highly integrated approach to cancer research and treatment among SCCA partner organizations supports the flow of scientific information among researchers, clinicians, and patients, thereby accelerating the development of new knowledge and treatment of various cancers.

SCCA’s purpose:

- Provide state-of-the-art patient and family centered care
- Support the conduct of cancer clinical research and education
- Enhance access to improved cancer interventions and advance the standards of cancer care, regionally and beyond
Phone Numbers and Other Important Information
In addition to specialized medical care, Seattle Cancer Care Alliance (SCCA) provides many services that patients and families find helpful. Below you will find phone numbers for these services, along with other important information about your experience with SCCA.

**Airport transportation service, (206) 606-1075**
Volunteer drivers can provide transportation to and from Seattle-Tacoma International Airport (Sea-Tac) and Boeing Field for SCCA patients and their primary caregivers who come from outside of western Washington. To request transportation, call Volunteer Services at least 3 business days before your arrival or departure. While we do our best to accommodate all requests, please know that we may not be able to provide transportation between 10 pm and 6 am and on major holidays. To request a ride, please leave a message with the following information:

- Names of the patient, family members, or caregivers, and the amount of luggage you have
- For arrivals to Seattle, your arrival date, time, airline, flight number, and city of origin for the flight
- For departures from Seattle, please state the airline and flight departure time; you are advised to arrive at the airport at least 1 ½–2 hours before the departure time.
- The name and address of your hotel or residence in Seattle
- Your hometown, cell phone numbers, and the best time to reach you

**Apheresis unit, (206) 606-2120**
The Apheresis unit, located on the 5th floor of the clinic, is where we collect your stem cells. It is open from 8:00 am to 4:30 pm.

**Child Life volunteers at Seattle Children’s, (206) 987-2100, ext. 3169**
Specially trained Child Life volunteers offer companionship, games, and activities for pediatric inpatients at Seattle Children’s. Siblings may join in play sessions with volunteers in the recreational therapy playroom. Contact the Child Life specialist to request a Child Life volunteer.

**Child Life specialist at Seattle Cancer Care Alliance, (206) 606-7621**
This service helps your child cope with the stresses of illness. The Child Life specialist uses medical play to explain treatments and procedures in age and development appropriate language. Child Life is available to help you or your family members with coping skills to care for a sick child. Contact the Child Life specialist in advance to set a play date with a volunteer in the clinic’s 5th floor play area.

**Guest Services, (206) 606-6701**
Guest Services volunteers can provide information on the SCCA clinic, Seattle area sightseeing, restaurants, transportation, and recreational opportunities. Passes to selected Seattle attractions and free tickets to local events can be reserved by stopping by the desk. The Guest Services desk is located in the main 1st floor lobby of SCCA clinic and is open Monday through Friday, 8:00 am to 4:00 pm.
Housing options, (206) 606-7263
If you are coming to Seattle from out of town to receive care at SCCA, we recommend that you arrange temporary housing as soon as you know your arrival date. Options include two residences for SCCA patients and their families. Both can accommodate people needing extended-stay housing.

For questions or information about housing, please contact a Housing coordinator. Housing information is also available online at https://www.seattlecca.org/housing-information.

Intake office, (206) 606-1024
If you are interested in becoming a patient at SCCA, call the Intake office. You can also reach them toll-free at 1-800-804-8824 or by fax at (206) 606-1025.

Interpreter Services, (206) 606-6419
SCCA can arrange for specially trained medical interpreters for patients or family members who do not speak English. If you are not a citizen or resident of the United States, you will be charged for these services.

Long-Term Follow-Up, (206) 667-6557
Contact Long-Term Follow-Up staff for questions about treatment or the management of symptoms after you leave SCCA.

Living Tobacco Free Services, (206) 606-7766
Living Tobacco Free Services are available at no charge to you, your caregivers, and family members who are thinking about stopping tobacco use. You can call and speak with someone directly to discuss quitting, develop a plan, and get support during the process. Free nicotine patches, gum, and lozenges are available to those who receive counseling. Quitting tobacco use at the time of a cancer diagnosis can lead to improved treatment outcomes, reduced side effects, and improved survival.

Medical Nutrition Therapy, (206) 606-1148
Dietitians at SCCA have specialized training and knowledge about nutrition for cancer prevention, treatment, and survivorship. Most have earned a Master’s degree in their related field and are certified as specialists in Oncology Nutrition by the Commission on Dietetic Registration, the crediting agency for the Academy of Nutrition and Dietetics.

Oral Medicine (dental), (206) 606-1333
For more information on dental health, please contact Oral Medicine services.
Outpatient clinic
For questions about clinic appointments, your treatments or symptoms you are experiencing, call the numbers below.

<table>
<thead>
<tr>
<th>Hours</th>
<th>Phone number</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 am–10 pm, Mon–Fri</td>
<td>(206) 606-7600 adult &amp; pediatric</td>
</tr>
<tr>
<td>8 am–6 pm, Sat &amp; Sun</td>
<td></td>
</tr>
<tr>
<td>8 am–5 pm, holidays</td>
<td></td>
</tr>
<tr>
<td>10 pm–8 am, Mon–Fri</td>
<td>(206) 598-8902 adult</td>
</tr>
<tr>
<td>6 pm–8 am, Sat. &amp; Sun.</td>
<td>(206) 987-2032 pediatric</td>
</tr>
<tr>
<td>5 pm–8 am, holidays</td>
<td></td>
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</tbody>
</table>

Patient and Family Resource Center, (206) 606-2081
The Patient and Family Resource Center, located on the 3rd floor of the clinic, is free to patients, family members, and caregivers. It is staffed by a resource coordinator and offers free brochures and pamphlets on types of cancer, treatments, and supportive care, as well as information on classes and support groups at the clinic. Staff offer free wig fittings and information on classes in the community. Computers with free internet access, a printer, fax machine, and copy machines are available for use. iPads are also available for check-out. The Resource Center is open Monday through Friday from 8 am to 5 pm.

Patient Financial Services, (206) 606-1113
Patient Financial Services can help you manage the financial side of your cancer treatment. They have information on insurance, understanding your bills, and organizations that can help with the costs of cancer treatment.

Patient Relations, (206) 606-1056
If you have concerns or complains about any aspect of your care, let your care team know, or contact Patient Relations. If you would like to speak with a representative outside of SCCA, please contact:
- Washington State Department of Health: 1-800-633-6828 or www.doh.wa.gov
- Joint Commission: 1-800-994-6610, www.jointcommission.org or complaint@jointcommission.org
- Livanta LLC (Medicare and Medicaid concerns): 1-877-588-1123 or www.livanta.com

Physical Therapy, (206) 606-6373
Physical therapists help with concerns related to weakness, balance, scar tissue, lymphedema, range of motion, and rehabilitation equipment.

Pulmonary function testing, (206) 606-1016
Your care team can order pulmonary function tests and studies with this team.

Security, (206) 606-1111
Call Security for lost and found, directions, or help getting a wheelchair.
**Social Work department, (206) 606-1076**
The Social Work department provides counseling and education for patients and their families. Social workers can help you adjust to your illness, navigate the health care system, develop coping strategies, and connect you with other resources.

**Spiritual Health, (206) 606-1099**
Our Spiritual Health team provides respectful spiritual and emotional care for all faiths and spiritualities including those who identify as non-religious or non-spiritual. They provide worship and meditation sessions, and can connect you with religious and spiritual resources. You can visit the sanctuary, located on the 1st floor of the SCCA clinic for quiet prayer, reflection, or meditation.

**Transition Services, (206) 606-2125**
Call Transition Services for transplant education, caregiver issues, homecare planning, and help with discharge planning.

**Volunteer Services, (206) 606-1075**
Volunteer Services helps patients with airport transportation, housing and inpatient tours, and social and practical support.

**Other important information**

**Consultation services**
We recommend you take advantage of our staff’s expertise and experience. This can include physical examinations, diagnostic testing, and a consultation with a physician. Our physicians will provide you options and recommendations for treatment. Tours of both the outpatient and inpatient facilities are available by appointment.

**Location**
Outpatient services are provided at the SCCA clinic, located at 825 Eastlake Avenue, East in Seattle. Inpatient services are provided at University of Washington Medical Center (UWMC), located at 1959 NE Pacific St in Seattle. For driving directions and parking information, please refer to the Maps, Direction, and Parking section at the end of this guide.

**Personal valuables**
SCCA (including Fred Hutch, UW Medical Center, and Seattle Children’s) is not responsible for any loss or damage to your personal property including money, jewelry, watches, or other items of value. We strongly recommend that you not bring any of these items with you when you are in the hospital.
**Smoke-free environment**
Smoking is not allowed at SCCA, UW Medical Center, or Seattle Children’s. Smokers must leave SCCA’s premises to smoke. Washington state law prohibits smoking within 25 feet of all entrances, exits, windows, and ventilation systems of public places. In support of this policy, SCCA provides a smoking cessation program. Call SCCA’s Living Tobacco Free Services for more information or go to [https://www.seattlecca.org/diseases/lung-cancer/prevention-early-detection/living-tobacco-free](https://www.seattlecca.org/diseases/lung-cancer/prevention-early-detection/living-tobacco-free). You can also call the Washington State Quit Line at 1-800-784-8669 (1-800-QUIT NOW) for free treatment and referral to other resources.

**Weapons and illegal substances**
Weapons and illegal substances are not allowed on SCCA property (including Fred Hutch, UW Medical Center, Seattle Children’s, Pete Gross House and SCCA House). To report or request assistance in handling a suspected case or observed violation contact SCCA Security, 24 hours a day, 7 days a week. The existence of a concealed weapons permit does not excuse a person from this policy. Please secure weapons prior to entering the clinic.
The Basics of Transplantation

“I am blessed to be among the fortunate transplant recipients who have virtually no [consequence] of having been given a new immune system 10 years ago. Each year I reflect upon whether I have made good use of the gift, with hopes of making better use of it next year. I am forever grateful to everyone at [Fred Hutch] and to my donor, who as yet remains unknown to me.”

Unrelated Transplant Recipient, 1997
There is a lot to learn about getting a transplant. Below are explanations to some of the basic questions about the process.

**Frequently asked questions**

**Why is transplantation done?**
The purpose of transplantation is to cure or treat fatal diseases using high doses of chemotherapy, radiation or both. The intense treatment decreases the number of stem cells in your marrow that make blood cells. Soon after treatment, stem cells are given to replace the ones that were destroyed. Over time, they settle in the bone marrow and begin to grow and make blood cells.

**What is being transplanted?**
The name for what is being transplanted has changed over the years. The names you might hear include: bone marrow, stem cells, hemopoietic stem cells, peripheral blood stem cell, and pluripotent stem cell transplant. Stem cells are very young cells that can grow into mature red blood cells, white blood cells and platelets or plasma cells (see the figure below). Stem cells are an essential part of a person’s immune system.

Stem cells are made in your bone marrow. Also, stem cells are in your blood. They are called peripheral blood stem cells. Stem cells are also present in the blood of the umbilical cord of a baby. Therefore, there are three places to obtain stem cells for transplantation: the bone marrow, the blood stream, and from the umbilical cord immediately after birth.

![Stem cell diagram](image-url)
Red blood cells (erythrocytes) carry oxygen to other cells in your body.
White blood cells (leukocytes) fight infection.
Platelets (thrombocytes) help your blood to clot.

How long does it take for stem cells to grow?
It takes several weeks for the stem cells to grow (engraft) in your bone marrow space and produce red cells, white cells, and platelets. During this time, you are susceptible to complications and need close monitoring.

What does the transplant process look like?
In general, there are 7 steps to a getting transplant: planning ahead, preparing for transplant, conditioning, transplant, engraftment, short-term recovery, and long-term recovery.

What are the different types of transplants?
The type of transplant you might have depends on your disease and clinical status. There are 4 types or transplants and each has a different source of stem cells.

<table>
<thead>
<tr>
<th>Type</th>
<th>Source of stem cells</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autologous</td>
<td>The patient</td>
</tr>
<tr>
<td>Allogeneic</td>
<td>A related or unrelated donor or cord blood</td>
</tr>
<tr>
<td>Haplo</td>
<td>Parent, child or sibling – half match</td>
</tr>
<tr>
<td>Syngeneic</td>
<td>Identical twin</td>
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</table>

In an autologous transplant, your own stem cells are taken from your bone marrow or collected from your bloodstream. These cells are then stored in a freezer to be given back to you (transplanted) after you have received chemotherapy, radiation, or both.

In an allogeneic transplant, you will receive stem cells from another person, either someone in your family or an unrelated donor. The stem cells can come from the bone marrow, bloodstream, or umbilical cord of the donor. If you do not have a suitable family member donor, you may be able to find a donor in the general population that closely matches your tissue type. We search for donors using a bone marrow registry.

In a cord blood transplant, blood is collected from the umbilical cord and placenta after a baby is born. This blood is rich in blood-forming cells. The donor chosen has a tissue type that matches your tissue type as closely as possible.

A mixed chimerism transplant is a sub-type of an allogeneic transplant where patients receive moderate doses of conditioning.

In a haplo transplant your donor’s cells half match your cells and are usually from a parent, child or sibling.

In a syngeneic transplant, the donor is your identical twin.
Step 1: Planning Ahead

“I have a new perspective on family, what’s important, and the work-life balance.”
-Unrelated Transplant Recipient, 2002
Deciding to have a bone marrow/stem cell transplant is a significant event. It is like embarking on a long, challenging journey. This is the first of 7 sections that describe each step in the transplantation process.

Frequently asked questions

How do I decide if I should get a transplant?
Many patients feel that having a transplant is a major turning point in their lives. They describe this process as an emotional rollercoaster. Research has shown that hope is a helpful force in surviving and coping with illness. At the same time, feelings of uncertainty may continue even after the decision is made.

The “Planning Ahead” phase is a busy time when you are organizing your personal affairs so that you can give your full attention to coping with the treatment experience. Many choices need to be made, from selecting a family member or friend to be your caregiver, to making financial arrangements. If you live outside the Seattle area, you will need to make plans for travel and housing.

How long will my transplant process take?
The total time varies from approximately 2–4 months. The length of transplant treatment is different for each patient, based on disease, the specific treatment plan, and your response to the treatment. Some patients will spend 2–3 weeks inpatient at University of Washington Medical Center and then receive care in the outpatient department for a number of weeks to months. Other patients will receive the majority of treatment at SCCA’s clinic and enter the hospital if needed. Your nurse/doctor will explain the expected length of treatment to you.

What are the donor options?
We will either use your cells (autologous transplant) or cells from someone else (allogeneic transplant). If you are having an autologous transplant, your stem cells will be collected and stored before your transplant. If you are having an allogeneic transplant, you will look for a donor among your family members.

Information on bone marrow or peripheral blood stem cell (PBSC) collection and storage is available in the “Donor Information” section in the back of this guide. If a suitable family member donor is not available, you may decide to search for an unrelated donor through a donor registry.

What are the housing options in Seattle?
You need to live within a 30-minute drive to the clinic. A map showing 30-minute boundaries is located on the back of this book. At SCCA, we have two extended-stay residences for patients and their families. It will be your responsibility to choose the most appropriate place to live and make arrangements directly with housing management. For more information on housing services, contact the Housing coordinator at (206) 606-7263 or housing@seattlecca.org.
Housing information is also available online at https://www.seattlecca.org/housing-information.

Contact your insurance company to learn if there is a housing and/or travel benefit included in your policy. If you have State Medicaid, see the SCCA housing list and follow the instructions for pre-authorization. If you choose housing that is not on the list, be certain that you are clear about the terms of your lease agreement.

Shuttle services are sometimes included with your housing. A shuttle runs Monday–Friday between the SCCA Clinic, Pete Gross House, and SCCA House. There is also a shuttle that runs Monday–Friday between the SCCA clinic, UWMC, and Seattle Children’s. The Patient Guide provides helpful information for your stay in Seattle: https://www.seattlecca.org/new-patients/patient-guide.

What is the weather like in Seattle?
Seattle has a moderate climate, with heavy rainfall from October–June. If you visit Seattle during these months, you should bring a raincoat, sweater, and umbrella. During other months, we suggest bringing layers, as it is often cooler in the morning and evenings, but warm during the day.

What should I bring?
- Comfortable socks, shoes, and slippers that have backs on them and are expandable (no mules or slides)
- Casual, comfortable clothing. Dress in layers, as temperatures vary in the clinic and in Seattle
- Female patients may find sports bras helpful because of the central intravenous line connection
- Paper towels and spray bottle for bleach
- Night light to reduce falls
- Front buttoning pajamas
- Head cover ups, scarves, hats, or wig
- Comfortable loose fitting/oversized shirts, shorts, and sweat pants that are washable
- Something to help pass the time between appointments (such as) books, magazines, an e-reader or tablet, or handwork.
- Meat thermometer for monitoring food temperature for food safety
- Athletic, tennis, or walking shoes
- Cuff weights and heart rate monitor (if you have them)
- Cell phone
- Car (optional); as a patient, you may not be able to drive yourself much of the time in Seattle
- Medical information (history, diagnostic films, reports, notes, and a list of current medications)
- Living will and durable power of attorney for health care
• Insurance card
• Work-related materials if you will be telecommuting

Caregiver requirement

Is a caregiver required?
YES. A caregiver is a responsible family member or friend who is able to provide physical care, observation, and emotional support for you during and after the transplant. You must establish a plan for caregiving and identify specific caregivers who can support you during the outpatient phases of the transplant process. If needed, we will be pleased to assist you in exploring options for caregiver support. The length of time that you require a caregiver will depend on your clinical condition. You will not be accepted for transplantation at this center if you cannot provide a written caregiver plan.

What does a caregiver plan look like?
Below is an example of the type of plan that each transplant patient must provide to their care team.

<table>
<thead>
<tr>
<th>Dates</th>
<th>Caregiver name</th>
<th>Relationship</th>
<th>Length of time</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aug 1‒28</td>
<td>Jane Smith</td>
<td>Sister</td>
<td>4 weeks</td>
<td></td>
</tr>
<tr>
<td>Aug 29‒Sept 5</td>
<td>John Smith</td>
<td>Brother</td>
<td>1 week</td>
<td></td>
</tr>
<tr>
<td>Sept 6‒Oct 1</td>
<td>Mary Smith</td>
<td>Mother</td>
<td>4 weeks</td>
<td></td>
</tr>
</tbody>
</table>

What are typical caregiver responsibilities?
Responsibilities may be shared among family members or friends and include:
• Making arrangements
  o Transportation to and from the clinic
  o Tracking appointments
  o Accompany patient to all appointments
• Providing emotional support
• Providing physical care
  o Caring for the central intravenous line
  o Helping the patient to take oral medications
  o Keeping track of medications taken
  o Giving intravenous fluids and medications using a pump device
  o Identifying changes in the patient’s condition
  o Obtaining medical care if needed
  o Reporting symptoms to healthcare staff
• Maintaining the home environment
- Cleaning
- Food preparation

- Gathering information

- Serving as a communication link with other family members and friends

The caregiver has a demanding role in helping with your treatment and recovery. It is important to consider in advance who is able to be your caregiver. If more than one person will be taking care of you, a written schedule listing each person’s time should be made before arriving for transplant. There are several levels of support your caregiver will need to provide throughout your treatment. Your care team will let you know which of the below support you will need at which time.

**Consistent support:** The caregiver is present the majority of the time; breaks should be less than 3 to 4 hours. Adult patients left alone should have access to the phone, as well as the ability to contact emergency services, operate ambulatory pumps, get to the restroom, and access food and fluids. Pediatric patients should not be left alone.

**Intermittent support:** Does not need a caregiver the majority of hours within a 24-hour period. A caregiver is available 2 to 3 times per day to provide assistance with dressing changes, medications, transportation, and processing information provided during conferences or clinic visits.

**Minimal support:** Patients do not require a caregiver, but do benefit from emotional support during a clinic visit and conferences.

**Respite care at home:** Home assistance services. A respite is an interval of rest or relief. Respite services include meal assistance, dressing assistance, medication supervision, laundry, grocery shopping, light housekeeping, and companionship. Respite care allows you to take some time for yourself. Respite assistance usually is not covered by insurance. Please check with your nurse and social worker for additional information regarding respite care.

**What home assistance services are available?**
Below is a brief list of home assistance services to assist with your homecare planning. Inclusion on this list does not mean endorsement by the SCCA. Exact responsibilities and payment plans need to be negotiated between you and the agency. Most agencies need 48 hours to accommodate a particular request.
Home assistance resources

Care at Home of WA  206-932-5170 or 206-937-3100
CareForce  425-712-1999
Catholic Community Services  206-328-5696
Family Resource Home Care  206-545-1092
Fedelta Care Solutions  206-362-2366
Homewatch Caregivers  206 363-4599
Jewish Family Service  206-461-3240
Maxim Healthcare Services  206-985-4625
ResCare HomeCare Services  206-368-7667, north Seattle
                         206-329-4695, south Seattle
Right At Home  206-774-1100
Synergy HomeCare  206-420-4934
Visiting Angels  1-800-365-4189

What questions should I ask home care services before hiring them?
We’d suggest asking at least a few basic questions such as:
• Is there a different rate depending on the number of hours?
• If the escort is scheduled to drive, does the person have a driver’s license?
• Is there someone to call for a reference?

Do patients and caregivers need any formal training?
Patients and caregivers are strongly encouraged to attend SCCA classes, which are offered weekly. Caregivers are taught how to give medications and intravenous fluids, take care of the central line, prevent infections, recognize symptoms, and help the patient adjust through recovery.

What should my caregiver bring?
• Insurance cards and other important paperwork, passport, birth certificate, and driver’s license
• Comfortable clothing
• Laptop computer (If you have one)
• Camera
• Work-related materials if you will be telecommuting
• Large bag or backpack to carry materials to and from the clinic
• Medical and dental information and contact information
Child-related questions

Should I bring my kids to SCCA?
Decisions regarding care of infants and young children need to be made before you come to Seattle. Spouses with small children have found it difficult to juggle the roles of parent and caregiver at this time. We recommend that you select one person to provide parenting and another person as your caregiver, if possible. The decision of whether to bring your children to Seattle or to arrange for their care at home may be difficult.

There are no age limits for persons visiting you in the hospital. However, it is difficult for infants and young children to be at the hospital for long periods of time since there are few things for them to do. Siblings are not allowed to stay overnight at Seattle Children’s. We do not provide day-care facilities for infants or children, nor do we recommend the use of community day care facilities because of increased exposure to common respiratory viruses. After-school care is not provided.

Financial-related questions

How much does a transplant cost?
Transplantation is a highly technical and expensive treatment and the cost varies according to treatment plan and insurance coverage. SCCA requires a guarantee of funds to cover the costs, either by health insurance or by prepayment. A representative from the Patient Financial Services will evaluate your insurance coverage.

How much does it cost to live in Seattle while we’re there?
It is important that you consider the cost of living in Seattle during transplantation. Many families arrange fund-raising efforts at home before coming to Seattle for a transplant. These funds can help with transportation and living expenses, as well as additional medical expenses not covered by insurance. Please contact your insurance case manager to see if any of these expenses are covered by your insurance plan.

Are there organizations that can help with my treatment and living costs?
Below is a list of resources that may help with various expenses or offer other types of support. Contact the individual organizations for additional information. The assistance available varies among organizations. See the fundraising appendix at the end of this document for suggestions. Inclusion on this list does not mean endorsement by SCCA.

American Cancer Society
Find your local chapter of ACS at www.cancer.org
Angel Flight West
Offers free air transportation on private aircraft for people with health care problems. They need 1 week notice and the patient must be medically stable and able to walk. www.angelflightwest.org

Carlson Wagonlit Travel
(888)-426-2643; www.carlsonwagonlit.com/en/

Children’s Organ Transplant Association (COTA)
(800)-366-2682, www.cota.org

Corporate Angel Network (CAN)
Provides free air transportation for cancer patients traveling to and from recognized treatment centers in the United States without regard to their financial resources. www.corpangelnetwork.org

FHCRC/SCCA Travel Desk
(206) 667-3434

Leukemia & Lymphoma Society
Find your local chapter of LLS at www.lls.org

Marrow Power!
www.marrowpower.org

National Children’s Cancer Society (pediatric patients only)
www.thenccs.org

National Foundation for Transplants
(973)-895-3356, (800) 5-FAMILY, (800)-489-FUND; www.transplants.org

National Patient Travel Center
Free referrals are made to all known charitable and special patient discount commercial services based on the patient’s condition, type of transport, and departure/destination. www.patienttravel.org

National Transplant Assistance Fund (NTAF)
(800) 296-1217 in the U.S., (757) 318-9145 elsewhere; (800) 642-8399, www.transplantfund.org

Social Security Supplemental Income Disability
Contact your local Social Security office to apply for disability. www.ssa.gov
Other important questions

What can I do to prevent infections?
The most important thing you can do to prevent infection is to wash your hands. Plants cannot be in your home for the first three months after transplant. You must minimize contact with pets, including cleaning up after pets or sleeping with them.

What immunizations do my caregivers and household contacts need?
Recommended vaccines are listed below for those who are in direct contact with post-transplant patients. If your caregiver or household contacts have already received the vaccines listed, they do not need to be re-vaccinated. Please talk with your doctor or nurse if you have any questions.

<table>
<thead>
<tr>
<th>Vaccine</th>
<th>Recommendations</th>
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<tbody>
<tr>
<td>Hepatitis A</td>
<td>Routine vaccination is recommended for:</td>
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<tr>
<td></td>
<td>• Children 12 months of age or older; and</td>
</tr>
<tr>
<td></td>
<td>• Other persons at risk for hepatitis A (i.e., food worker)</td>
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<tr>
<td>Inactivated influenza (flu shot)</td>
<td>Vaccination is strongly recommended during each flu season (i.e. October-April). All household contacts should be vaccinated annually.</td>
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<tr>
<td>Intranasal influenza (FluMist®)</td>
<td>The flu shot is preferred over the FluMist® vaccine because FluMist® is a live vaccine that has a low risk of spreading the virus to others the first 7 days after getting the vaccine. If caregivers and household members experience cold and flu symptoms after getting the live FluMist®, they should avoid contact with the transplant patient and visits to SCCA, UWMC, or Seattle Children’s until the symptoms are gone.</td>
</tr>
<tr>
<td>Inactivated polio Vaccine</td>
<td>Vaccination is not routinely recommended for adults but should be given to children that have not been vaccinated.</td>
</tr>
<tr>
<td>Measles, mumps, rubella (MMR)</td>
<td>Vaccination recommended for all persons 12 months or older and who are not pregnant or immunocompromised. Although MMR is a live vaccine, household transmission does not occur.</td>
</tr>
<tr>
<td>Rotavirus</td>
<td>Persons may receive the vaccine without any concern to the transplant patient. The vaccine is recommended for infants.</td>
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### Vaccine Recommendations

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<thead>
<tr>
<th>Vaccine</th>
<th>Recommendations</th>
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| Pertussis, diphtheria, and tetanus | The combined vaccine is recommended without any concerns to the transplant patient. It comes in two different formulas:  
1. Diphtheria, tetanus, and acellular pertussis (DTaP): For under 7 years of age.  
2. Tetanus, diphtheria, and acellular pertussis (TDaP): For adolescents and adults. |
| Varicella (chicken pox)  | Vaccination should be administered to all persons 12 months or older that are not pregnant or immunocompromised. The vaccine is a live vaccine and poses a very small risk of household transmission, usually only if the vaccinated person develops a rash. If the vaccinated person develops a rash, the transplant patient might be placed on an antiviral medication, such as acyclovir, if he or she is not already taking it. |
| Zostavax (shingles)     | Only available to adults 60 and over. Household members and caregivers should talk to their primary care provider about whether or not it is beneficial to receive the vaccine. It is a live vaccine, so there is a small risk of developing a rash after getting the vaccine. In this rare instance, the transplant patient might be placed on an antiviral medication, such as acyclovir, if he or she is not already taking it. |


### What are advance directives? Do I need one?

Advance directives are documents in which you either state your choices for medical treatment or designate who should make treatment choices if you cannot make decisions. The two types of advance directives that we accept are the living will and the durable power of attorney for health care. We recommend that you consider completing an advance directive before transplant. Be sure to bring these documents with you.

### What if I need to use an interpreter?

SCCA can arrange for specially trained medical interpreters for patients or family members who do not speak English. If you are not a citizen or resident of the United States, you will be charged for these services. Interpreters are necessary during medical consultation and consent conferences and are helpful during conferences with your health care team when you are learning how to manage your care and for updates on the progress of your treatment. Your specific needs for interpreter services will be discussed with you and services will be coordinated by your medical team.
What dental care do I need?
The mouth can be a source of infection following transplant. These infections can be traced to pre-existing diseases of the teeth and gums. Receive a thorough dental examination (including X-rays) before coming to Seattle for treatment. Dental cleaning, review of oral hygiene care, and repair of decayed or broken teeth should be done if your medical condition permits. Braces should be removed, and loose or poorly fitting dentures should be adjusted. You can contact Oral Medicine at (206) 606-1333 with any questions.

Will the treatment impact my fertility (ability to have a child)?
Undergoing treatment with radiation and chemotherapy puts both males and females at risk of becoming infertile. Difficulty in conceiving a child as a result of these therapies may be temporary or permanent. Several factors, including your sex, age, type of chemotherapy drugs used, location of radiation, total dose of chemotherapy and/or radiation, and length of time since treatment all influence the ability to have a child after cancer treatment. Predicting the outcome for any individual is difficult. Your oncologist can discuss the fertility risk of your particular treatment with you.

What are fertility preservation options for males?
For some male patients, sperm banking may be possible. If interested, you should investigate the feasibility of sperm banking with your doctor prior to arrival in Seattle. Sperm bank centers are available throughout the country.
- **Sperm banking** services are widely available for males mature enough to ejaculate.
- **Testicular sperm aspiration** (TESE) is the surgical removal of testicular tissues containing sperm. The sperm are then frozen. This procedure is usually performed by a urologist and is an option for teens who are Tanner stage 2 (ask your doctor about this) and for males with documented inability to ejaculate.

What are fertility preservation options for females?
Women may want to consider storage of embryos prior to marrow transplantation. This procedure requires administration of hormones to induce ovulation. Please check with your gynecologist. It may be recommended to continue to take birth control pills. It is best to start the process as soon as possible because of the time and expertise involved. If you are interested in this option, the storage should be completed in a reproductive center prior to treatment so your care won’t be delayed.
- **Embryo cryopreservation** (fertilized egg freezing and storage) the administration of hormones to stimulate ovulation. Eggs are then removed surgically, fertilized with a partner’s or donor’s sperm, frozen, and stored for future implantation in the uterus.
- **Oocyte cryopreservation** (unfertilized egg freezing and storage) is not offered at all fertility clinics but when available is an option for teens and women who do not have a spouse or partner and want to preserve their fertility without having to use donor sperm. Like embryo freezing, this involves the use of hormones to stimulate ovulation. Eggs are removed, frozen and stored unfertilized.
Insurance coverage for fertility interventions varies. Work with your reproductive clinic to determine what may or may not be covered and what the costs will be. Ask them about financial assistance programs such as Sharing Hope, administered by the Lance Armstrong Association.

Fertility preservation services are not available through SCCA. If desired, this will need to be coordinated before you arrive. There are fertility resources available in Seattle. Many patients have appreciated these suggestions and have had positive experiences later in life.

**Do I need to weigh a certain amount before beginning treatment?**
If you are at a normal weight now, you do not need to try to gain weight before transplant. If you are underweight now, it is recommended to try to gain weight. If you wish to take vitamins or supplements, we recommend a one-a-day multivitamin and mineral supplement that is iron-free (usually labeled as vitamins for older adults). Children may take a standard pediatric multivitamin. Check with your pediatrician if an iron-free one is needed. Dietitians can help guide you on appropriate food choices.

**Will I need to do physical therapy before beginning treatment?**
You may be referred to a physical therapist during your visit. This referral before your transplant will help to get a measure of your pre-transplant function, strength, and range of motion in order to have baseline data to compare with your post-transplant progress. You will also be given an exercise prescription (if appropriate) to help improve your cardiovascular strength and function, muscle mass, and range of motion to prevent or minimize post-transplant physical complications.

**What other tests might be done before treatment starts?**
Throughout your treatment you will have pulmonary function tests done. You will be given instructions on how to prepare for these tests once you arrive. These tests measure your lung function. Three types of tests will be completed:
- Spirometry: measures how forcefully and how much air you can exhale in one breath.
- Lung volume: measures the total amount of air in the lungs without forcibly blowing out.
- Testing the diffusion capacity (also called the DLCO): allows the doctor to estimate how well the lungs move oxygen from the air into the bloodstream.
Step 2: Preparation

“I am so thankful every day for this time; time to guide my three children through the precarious teenage years; time to love my husband; time to enjoy the beauty of the world; time to give back and help others.”

Allogeneic transplant recipient, 2003
Preparation
During the preparation step of your transplant, we’ll provide you a comprehensive manual to review and reference throughout your treatment. In addition, we have classes and individual instruction to help you get ready. You’ll go through a complete medical evaluation to help us determine your treatment plan. As part of that, you’ll have a consent conference during which your treatment plan is explained, you’ll sign protocol consent forms, and you’ll have the opportunity to discuss your questions with the doctor. Once that is complete, we’ll insert a central line into your chest so we can easily access your vein throughout your treatment.

As you prepare for your transplant, you may experience a sense of urgency to get started with treatment and feel “in limbo” waiting for test results. However, this period of evaluation and orientation is essential to the success of your treatment

Transplant manual
During your arrival appointment at SCCA, you will receive a transplant manual, which has information to help you navigate the campus and the Seattle area, as well as provide content of classes and individual instruction you will receive during the transplant process.

Classes
In-person and online classes, and individual instruction on topics such as managing your care at home and food safety guidelines are offered to patients, donors, caregivers, friends, and family members. In-person classes are offered on a weekly basis in the clinic. Online classes are posted on the SCCA website: www.seattlecca.org/patient-education; just scroll down to “Patient Education,” and click on the “video” link.

Medical evaluation
Your medical examination will include a physical examination, labs, and diagnostic tests. Studies may include tissue typing, a bone marrow aspiration, pulmonary function studies, chest X-rays, and an electrocardiogram. The attending physician will review your medical records and current condition, then meet with you and your family to outline the proposed treatment and answer your questions. During the evaluation, you and your family will also meet with other health-care providers: a physician assistant or fellow, nurse, social worker, pharmacist, and dietitian.

The length of time needed to complete the evaluation depends on your medical condition. The date your treatment starts depends on your individual treatment plan. If a family member is your donor (that is, your family member is providing bone marrow or stem cells for you as part of the treatment), the family member will undergo a similar, but less extensive, medical evaluation during the beginning of your treatment. Most out-of-town donors make a second trip to Seattle to donate later in the process. Family members who are not donors and have limited time off from work or school may want to delay their arrival in Seattle until you begin treatment.
Data review conference and your consent for treatment
A data review conference takes place before you begin treatment. This conference includes the attending physician and a nurse. Your specific treatment plan is outlined in detail. The reasons for each aspect of your treatment are described, as are the associated risks, complications, and duration of care required.

At this conference, you will sign consent forms that summarize the potential risks and benefits of each aspect of the proposed treatment. It is important that you understand the information received and that you have all your questions answered prior to signing these forms. You must give your written consent for the treatment plan before your therapy can begin. In Washington State, parents or legal guardians must sign for minors (individuals under 18 years of age). You may be asked to participate in additional research protocols during this time; please know that these are optional and do not impact your ability to undergo a transplant with us. You are encouraged to read and ask questions about all protocols before signing them.

Central intravenous line
In preparation for treatment, you will have a small, flexible tube called a catheter inserted into a large vein in your chest. This is called your central line. This serves as a route to give you medications, fluids, and blood products, as well as draw blood samples for tests painlessly. You will have this line in place for several months after transplant until transfusions and intravenous medications are no longer needed.

Insertion of the central line
The insertion procedure is done in the operating room under sedation. A small incision (cut) called the “entrance site” is made on the neck or upper chest. A smaller cut or “exit site” is made lower on the chest. The catheter is then guided under the skin from the exit to the entrance site. Here the catheter is passed into a large vein until it reaches the entrance to the right upper chamber of the heart. The whole procedure takes 45 to 90 minutes.

Communicating with your family
Former patients and family members tell us that when faced with life-threatening illness, there is a benefit to discussing fears and concerns with family and staff. The benefits have been described as, “It has brought our family closer together;” “I thought I was the only one that felt
that way until I talked with others;” and “Talking about my fears helped me put them aside so I could concentrate on curing my illness.”

Even though you or your family members may want to talk about the possibility of dying, it can seem very hard to do so, even with those closest to you. SCCA social workers, chaplains, nurses, physicians, and psychologists are available to talk with you about your concerns and fears. They can also help you identify support and resources that can help you throughout your transplant experience. This can include facilitating family communication.
Step 3: Conditioning

“I hate the word survive. I want to thrive!”
Autologous transplant patient, 1999
Conditioning chemotherapy and/or total body irradiation
During the next step in your transplant process, you will receive therapy called conditioning. Conditioning helps make room for the new stem cells to grow, prevent your body from rejecting the transplanted cells, and kill any cancer cells that are in your body. This involves receiving chemotherapy with or without total body irradiation (TBI). This therapy can be high-dose, marrow-ablative chemotherapy or moderate dose, non-myeloablative conditioning. The two approaches are discussed below.

High dose conditioning chemotherapy and/or total body irradiation
High dose conditioning chemotherapy and/or irradiation is used to prepare you for an autologous or allogeneic transplant. The doses of chemotherapy and irradiation therapy you will receive are much higher than you have received as part of traditional treatment. The conditioning therapy kills rapidly dividing cells, such as cancer cells and bone marrow cells. It also damages healthy cells that are found in your hair follicles, lining of the mouth, stomach, intestines, skin, and nails.

Cells in the bone marrow are an important part of your immune system. Your immune system helps fight infections as well as recognizes cells that are not identical to yours. The high dose therapy will lower your immune system and allow the new stem cells to grow. Many new conditioning treatment plans, such as those using radiolabeled monoclonal antibodies (specifically targeted), are being examined in place of, or in addition to, treatments using chemotherapy and/or TBI.

Side effects of high dose conditioning
Symptoms such as nausea, vomiting, fever, and mouth dryness can occur when receiving chemotherapy and irradiation. We give medications to minimize discomfort and manage symptoms. It is important to follow through with these treatments, which promote healing and relieve symptoms. Let your nurse and doctor know how you are feeling.

Your mouth may become very sore with a condition called oral mucositis. Frequently rinsing your mouth will help. It is a temporary condition that begins to heal with the production of white cells from the new marrow. Side effects associated with the specific chemotherapy prescribed for you will be discussed prior to administration. Both chemotherapy and TBI cause hair loss, starting about five to 10 days after treatment begins. Hair usually starts to grow back in a few months.
**Moderate dose conditioning chemotherapy and total body irradiation**

Moderate dose conditioning chemotherapy and irradiation can be used to prepare you for an allogeneic transplant. The doses of chemotherapy and irradiation therapy you receive are low and work to suppress the cells of the immune system so that the new cells can grow in or engraft. This type of transplant will rely on the new immune system of the donor to destroy remaining cancer cells. This is called the graft versus tumor effect. In this type of transplant, there is a time when there is a mixture of your immune system and the donor’s immune system. This is called mixed chimerism.

**Side effects of moderate dose conditioning**

You may experience symptoms such as nausea, vomiting, and fatigue which are related to receiving chemotherapy and irradiation but are generally mild in nature. If you have non-myeloablative conditioning, you may experience hair thinning not complete loss.
Step 4: Transplant

“As the last bag of my sister’s stem cells was being infused into me, my doctor left me with these words: ‘Now all we need is patience and stamina.’ They became a small but enduring mantra for my recovery. Twenty years later, I do not often find myself thinking about leukemia or transplant or even being a cancer survivor. Yet I live every day in the knowledge of how much illness and survival changed my life, of what I do for a career (social worker), of how my family has evolved (two adopted daughters), of how I conduct myself (with more balance, I hope). Patience. Stamina. Those words have lost none of their power in 20 years.”

Allogeneic transplant recipient, 1986
**Transplant day**
Although the infusion of stem cells is a brief procedure, it is a significant event. You may receive your transplant either in the inpatient or outpatient setting.

**Types of infusions**

**Allogeneic or syngeneic transplants**
The bone marrow, cord blood, or peripheral blood stem cells that were collected from your donor are placed in bags that look very much like those used for transfusions. You will receive the cells through your central line.

**Autologous transplant**
Your own previously harvested and frozen stem cells are thawed and given to you through your central line. The preservative used during freezing has an odor and taste similar to that of garlic.

**Cell infusion side effects**
During the infusion you will rest in bed and can read, watch television, or visit with family or friends. You may experience nausea, vomiting, shortness of breath, flushing, chills, or mild fever. Your nurse and doctor will work with you to control your symptoms.
Step 5: Waiting for Engraftment

“Every day is a good day. Some days may just require more patience than others.”
Unrelated transplant recipient, 2004
**Engraftment**
About 10 to 28 days after transplant, new stem cells start to grow. This is called engraftment. Blood counts are watched daily as the graft strengthens. Often the first sign of a graft is a rising white blood cell count.

**Waiting and watching**
While waiting for engraftment to occur, there’s a lot of “waiting and watching.” During this time, you can keep a daily record of your blood counts to track progress (see below sample record).

In addition to watching for the first signs that the new immune system is working, staff are monitoring you very closely to detect any early signs of complications so they can begin treatment promptly if needed.

In a traditional ablative transplant, where your bone marrow could be destroyed by the conditioning therapy, a rising white count is the first sign of engraftment. However, a rising white count after a “mini” or non-ablative transplant does not necessarily mean donor engraftment. In this type of a transplant, special DNA measurements need to be taken by a blood test, usually done about a month after transplant, to tell the difference between donor cells and your own cells. Your own bone marrow can recover if the donor cells are rejected, an uncommon but real possibility.

<table>
<thead>
<tr>
<th>Sample blood count record</th>
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<tbody>
<tr>
<td>Date</td>
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</tr>
<tr>
<td>7/15</td>
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<td>7/16</td>
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</table>

**WBC**: White Blood Count  
**ANC**: Neutrophils - white blood cells that fight infection  
**Platelets**: Clotting blood cells  
**Hematocrit**: Red blood cells

**Emotional impact**
It is common to feel scared during the time you are not protected by a fully functioning immune system. You may experience intense concerns about physical symptoms and worry about making it through transplant. In fact, you may feel like you are on an emotional roller coaster. You may feel like you have lost personal control of your life as you cope with the daily monitoring and medical procedures. All of these are common feelings during transplant and coping with them can be a challenge. It may help to develop a schedule that provides you some structure during this time.
**Infection risk and other complications**
Until the new cells engraft, you are at high risk for infections, bleeding, and fatigue. If you are unable to eat and drink at this time, you may receive IV nutrition until you can eat and drink adequately.

Possible complications include:

- **Viral, bacterial, and fungal infections** can be serious problems after a transplant. Almost all infections can be treated successfully with antibiotics.

- **Pneumonia** is another complication that may occur in the first months after transplant. You will have regular chest X-rays, and we will watch for early signs of pneumonia.

- **Sinusoidal obstruction syndrome (SOS)** is a complication in which the liver’s job of removing waste products from the body is impaired. If this occurs, it will most likely occur during the first month after transplant. We will give you medication to prevent SOS.
Step 6: Recovery After Engraftment

“I have a few muscle aches, pain, and stiffness when I get up. But what can you expect when you are almost 80!”

Autologous transplant patient, 2007
Coping with recovery
As your new immune system is growing and developing, our goal is to support your recovery and manage any complications you may experience. Most patients feel very tired as they are recovering. You may find it difficult to focus on reading a book, watching television, or keeping up a conversation. During this time it is important to have reasonable expectations of what you will be able to accomplish.

It takes time to recover. Balancing periods of rest with light exercise helps you recover and prevent the complications of bedrest. Progress may seem slow. You may feel frustrated because you want to get well and put this experience behind you. Taking one day at a time is one of the best ways to cope. Work with staff to set manageable goals to achieve each day. By keeping track of the daily goals you achieve, it is easier to see the progress you are making. We will teach you and your caregiver how to manage symptoms that might arise and how to seek medical care quickly.

Graft-versus-host disease
Graft-versus-host disease (GVHD) is a complication that occurs with allogeneic transplants. As your new donor stem cells start growing, they may recognize your body as foreign. The new cells (the graft) may attack some of your organs such as the skin, gastrointestinal tract, or liver. This is acute GVHD, the form that can occur shortly after transplant. Chronic GVHD can begin as early as 3 months after transplant and may continue for months/years after transplant. There are medications that prevent and treat GVHD.

Preparing to leave SCCA

Allogeneic transplants
The average allogeneic transplant patient stays in Seattle for approximately 100 days after transplant. The estimated time you should plan to stay in Seattle including the pre-transplant evaluation and conditioning is about 4 months. After you are producing adequate numbers of red blood cells, white blood cells, platelets, and are medically stable, plans can be made to leave SCCA and return home. A complete medical evaluation will be done at this time and you will receive the results and recommendations in a conference with your health-care team.

Autologous transplants
The average autologous transplant patient stays in Seattle 40 days after transplant. The amount of time in Seattle before transplant will vary depending on the procedure used to collect stem cells.
**Tandem transplants**
Increasing numbers of patients are offered tandem transplants as part of clinical research studies. This is when two transplants are performed within about 2 months of each other. If you are having a tandem transplant, you may be in Seattle as long as 7 to 8 months from start to finish.

**Transitional transplant clinic**
Transitional transplant clinic (TTC) is a clinic for patients with complex conditions such as GVHD that is not well controlled, serious infections, or other complex conditions that require extensive ongoing management. Your transplant team will evaluate your individual case and provide you with the best estimate of time in Seattle based on your proposed transplant plan.

**Departure class**
You will need to attend the Departure class which meets weekly and will provide you with specific instructions on how to care for yourself after leaving SCCA. You can access the video online by visiting www.seattlecca.org/patient-education and scrolling down to Patient Education. Click on “video” and look for “Long Term Follow Up”.
Step 7: Long-Term Recovery

“We all look in the mirror to see changes and limitations we might not like. One either rises to the challenge or is defeated. I have chosen to challenge, which starts with everything from dialysis to overcoming other complications to the simplest of everyday things.”

Autologous transplant patient, 2005
Long-term recovery
It takes time to recover from the transplant procedure, and you may experience a lack of stamina for a period of weeks or months after returning home. It may take up to a year or longer for your immune system to become normal. For this reason, you will be advised to continue measures that will help prevent infections. The decision to return to school or to full-time work depends upon your immune function, medical status, and the nature of your work. Below is additional information you should know about long-term recovery.

Resources
SCCA’s Long-Term Follow-Up staff is experienced in managing the long-term recovery needs of our patients. They are available to your referring physician and to you for consultation should the need arise. The staff is available by telephone to answer questions and assist you in your recovery. They also send periodic requests to you and your physician on at least a yearly basis to assess any prolonged medical, psychological, or social problems you think may be related to your transplant. We recommend that you return to Seattle for a detailed evaluation of your marrow graft and immune system one year after transplant.

Potential chronic problems
Some complications are more likely to arise several months after your transplant. It is important that you report any new symptoms to your doctor promptly.

Chronic graft-versus-host disease (GVHD)
GVHD occurs in about one half of allogeneic transplant patients. It develops 3 to 18 months after transplantation. If you get GVHD, you may experience some of the following symptoms: skin changes, liver abnormalities, vision changes, gastrointestinal distress, or breathing problems. Medications that treat GVHD are given at home as an outpatient in close collaboration with your referring doctor and the SCCA Long-Term Follow-up team. This complication applies to allogeneic patients only.

Infertility
One of the possible side effects of total body irradiation or high-dose chemotherapy is infertility. Many women also experience premature menopause, the symptoms of which can be eased with hormone replacements.

Cataracts
Total body irradiation and steroid therapy can increase the possibility of developing cataracts, a clouding of the lens of the eye. Cataracts can be surgically removed.
**Growth and development**
Growth and development may not progress normally for children who have received total body irradiation or very high-dose chemotherapy or in those who have chronic GVHD. Potential problems will need to be followed closely after transplantation, so appropriate therapy may be given.

**Recurrence**
Unfortunately, even with a bone marrow transplant, some patients experience a recurrence of disease. Despite the risk of serious complications and relapse, bone marrow transplantation does offer the hope of cure. Some of our first transplant patients are now decades post-transplant and living normal, productive lives.

**Quality of life following transplant**
The large majority of long-term survivors after transplantation say they are leading meaningful lives. What did it take to re-establish their lives? For some, it included dealing with chronic physical complications. For others, it required an adjustment in relationships with their spouse, family, and friends. Still others changed their work or other priorities. Re-establishing life varied from easy and smooth with few problems to difficult and rough-going.

Although the initial re-establishing of life often is a challenge, most survivors report that the quality of their lives is now the same or better than before transplant. They report benefits such as becoming more easy going, learning how to rise above personal fears, gaining a greater appreciation of life, and discovering a spiritual strength as a result of the transplant experience. With these gains, there are also some common problems. Some people report that work or outside activities are less satisfying than before, and one of the more common issues survivors face is diminished sex life and sexual satisfaction. Realistically there are tradeoffs, with some gains and some losses.
Summary of Transplant Process
The below chart provides a summary of the 7 steps of the transplant process process that were described in the previous pages of this manual.

<table>
<thead>
<tr>
<th>Step</th>
<th>Things to do</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Planning ahead</td>
<td>• Assess financial coverage, other financial resources; consider fundraising&lt;br&gt;• Select caregiver(s)&lt;br&gt;• Make decisions about child care and schooling&lt;br&gt;• Plan stay in Seattle; arrange transportation, housing&lt;br&gt;• Complete advance directives (this can also be done in Seattle)&lt;br&gt;• Decide on arrival date at Seattle Cancer Care Alliance (SCCA)&lt;br&gt;• Contact the Volunteer office for airport pickup, if needed&lt;br&gt;• Decide if special preparations are needed: dental, nutrition, fertility&lt;br&gt;• For allogeneic transplant: donor selection</td>
</tr>
<tr>
<td>2. Preparation</td>
<td>• Arrive at SCCA; receive your “color” team name and meet your team, physician, physician’s assistant, and nurse.&lt;br&gt;• Meet with other members of your team: nutritionist, social worker, oral medicine, chaplaincy, pharmacist, and psychologist/psychiatrist, as appropriate&lt;br&gt;• Get a medical evaluation&lt;br&gt;• Attend consent conference; read and sign consent forms and protocol&lt;br&gt;• Attend teaching sessions with your team nurse.&lt;br&gt;• Ask questions; talk with staff about any concerns&lt;br&gt;• Make a plan on how to cope with transplant&lt;br&gt;• Attend classes for patients and caregivers&lt;br&gt;• Central line is inserted&lt;br&gt;• Keep active: walking, exercise of choice&lt;br&gt;• For autologous transplant: collection and storage of stem cells</td>
</tr>
<tr>
<td>3. Conditioning</td>
<td>• Receive conditioning therapy&lt;br&gt;• Take medication to prevent and relieve symptoms&lt;br&gt;• Let staff know how you are doing and what you need&lt;br&gt;• Balance rest and activity</td>
</tr>
<tr>
<td>4. Transplant</td>
<td>• Receive infusion of cells through your central line&lt;br&gt;• Celebrate!</td>
</tr>
<tr>
<td>Step</td>
<td>Things to Do</td>
</tr>
<tr>
<td>------</td>
<td>-------------</td>
</tr>
</tbody>
</table>
| **5. Waiting for engraftment** | • Monitor your counts  
• Receive transfusions of blood cells or platelets, if needed  
• Staff will monitor you closely for side effects or complications of treatment and signs of infection; you will be admitted to the hospital or seen in the clinic almost every day  
• Take advantage of support services such as spiritual health and social workers  
• Keep as active as possible  
• Set goals for each day and watch your progress |
| **6. Recovery after engraftment** | • Your caregiver helps you with recovery: giving medications, monitoring your symptoms  
• Get back to eating regular meals  
• Attend support groups  
• Gradually increase activity  
• Take rest periods for recovery  
• Take things “day by day” and keep track of daily goals to see progress  
• Get out and do something fun!  
• Prepare to leave SCCA: meet with Long-Term Follow-Up team, attend Departure class |
| **7. Long term recovery** | • Return to the care of your referring doctor  
• Report any new symptoms to your doctor promptly  
• Contact the Long-Term Follow-Up staff if questions arise |
# Timeframe for recovery process: steps along the road

<table>
<thead>
<tr>
<th>Planning ahead</th>
<th>Preparation</th>
<th>Cell mobilization (auto only)</th>
<th>Conditioning</th>
<th>Transplant</th>
<th>Waiting for engraftment</th>
<th>Recovery after engraftment</th>
<th>Long term recovery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Days -20</td>
<td></td>
<td></td>
<td>Day -7</td>
<td>Day 0</td>
<td>Days +14 to +21</td>
<td>Day +100</td>
<td></td>
</tr>
</tbody>
</table>

- **Uncertainty & loss of control**
- **Hair loss** *(not for Mixed Chim.)*
- **Hair growth**
- **Nausea/loss of appetite**
- **Improved appetite**
- **Mucositis**
- **Diarrhea**
- **Low counts**
- **Increasing counts**
- **Infections**
- **Fatigue**
- **Increased energy**
- **Cognitive changes**

**Potential symptoms and effects:**

- **Hair loss** *(not for Mixed Chim.)*
- **Hair growth**
- **Nausea/loss of appetite**
- **Improved appetite**
- **Mucositis**
- **Diarrhea**
- **Low counts**
- **Increasing counts**
- **Infections**
- **Fatigue**
- **Increased energy**
- **Cognitive changes**
Donor Information

The gift of life is an amazing gift to give. We couldn’t do this without our dedicated donors.
Stem cell information

What is a stem cell?
Within the various tissues of the body are immature cells called “stem cells” that contain basic genetic information about the particular cells of that organ or system. There are stem cells for skin, liver, intestines, ova, sperm, heart, brain, and blood.

The blood-forming or hematopoietic stem cell is the most primitive blood-forming cell. It is the “parent” cell of the blood supply and has the amazing capacity to mature into a red blood cell, white blood cell, or platelet based on the body’s needs. These stem cells produce an unending supply of blood cells. On average, a small number of stem cells produce an ounce of new blood, about 260 billion new cells, each and every day.

Where are hematopoietic stem cells found?
The majority of blood stem cells are found in marrow cavities of the body’s large bones. Normally, only a small number circulate in the blood stream.

How are stem cells used in cancer treatment?
High doses of chemotherapy and/or radiation are necessary to kill cancer cells. Doctors have discovered that bone marrow is very sensitive to the toxic effects of radiation and chemotherapy. In fact, these agents can destroy the ability of the bone marrow to produce blood cells.

Fortunately, bone marrow function can be restored by giving healthy stem cells to the person with cancer after the radiation and/or chemotherapy treatment. The healthy stem cells are given as a transfusion into the blood stream. The transplanted stem cells migrate back to the marrow space and grow into new blood cells.

How are stem cells collected from the donor?
There are two methods used at SCCA to collect stem cells: one is to withdraw bone marrow from the hip bones, called a marrow harvest, and the second is called apheresis, which draws stem cells from the peripheral blood. These two methods of collection will be reviewed in this section.

Bone marrow can be “harvested” from the hip bone (pelvis). This procedure is done in an operating room. The donor usually receives general anesthesia. There is minimal risk involved in anesthesia for a normal donor. Marrow harvest will be discussed later in this section.

Peripheral blood stem cells can be collected from the bloodstream in the clinic by means of a non-surgical procedure called apheresis. This procedure is discussed below.
Peripheral blood stem cell collection process
Stem cell collection includes the below 8 steps, which will be explained in the following pages:

1. Donor evaluation, screening and consent
2. Donor screening for apheresis
3. Assessment of access to the donor’s veins
4. Mobilization of stem cells
5. Stem cell collection by apheresis
6. Stem cell analysis
7. Stem cell transfusion and/or storage
8. Follow-up care

Step 1: Donor evaluation, screening and consent
The first step in the donation of stem cells is a thorough evaluation of the donor by a medical provider. This evaluation may include an extensive health history, physical examination, electrocardiogram, blood samples, and other diagnostic tests. These are done to ensure that the process of stem cell collection will not jeopardize your health, nor will the infusion of your blood cells be harmful in any way to the patient. Female donors must not be pregnant and avoid becoming pregnant during the time of growth factor and apheresis/stem cell collection.

The attending physician will discuss the specific stem cell collection plan. You will be asked to read and sign consent forms for the collection protocol and for the testing of your blood. Donor screening includes a list of questions about your life to determine whether you have risk factors that may affect your suitability as a donor. These questions are very similar to those asked of people giving blood at blood centers. Your nurse will give you information on members of your team, telephone numbers for contacting the clinic, show you how the clinic functions, and how to access resources within the clinic.

Step 2: Donor screening for apheresis
Before your first stem cell collection, you will be scheduled to visit the Apheresis Unit. An apheresis nurse will explain the procedure, answer your questions, and show you the Apheresis Unit and equipment.

Step 3: Assessment of access to the donor’s veins
The collection of blood stem cells by apheresis requires the circulation of large volumes of blood through the apheresis machine. Before your first apheresis appointment, the apheresis team will determine the best way to get access to your blood stream.

In most cases, it is possible to use a large vein in each arm. An intravenous needle with tubing is placed in each arm. The blood moves from the vein in one arm, through the apheresis machine, and is returned to the vein in the other arm. When the stem cell collection is complete, the intravenous needles are removed. This process is repeated each day of apheresis collections. Two days of collection is typical for most donors.
In some cases, a donor’s veins are not large enough to use for this procedure. Then it may become necessary to have a sterile catheter, or tube, surgically placed into a large vein. This catheter remains in place and is used each day during apheresis. When the stem cell collections are complete, the catheter is removed.

You will be thoroughly prepared and instructed for whichever method is chosen.

**Step 4: Mobilization of stem cells**
In order to collect stem cells by apheresis, it is necessary to stimulate the bone marrow with growth factors to produce larger-than-normal numbers of stem cells and release them into the blood stream. The process is called “mobilization.”

**What are growth factors and what do they do?**
Growth factors are naturally occurring proteins that stimulate the production of stem cells in the body. With growth factor mobilization, the white blood cell count will increase dramatically. The number of stem cells in the blood stream will also increase, making it possible to collect these cells by apheresis.

**When and how are growth factors given?**
Growth factors are given by injection. These injections will be given by a nurse daily over several days before the start of stem cell collection. The treatment plan for the patient determines the dose, number of days of growth factor injection, and collection days for the donor. Generally, this is 4 to 6 days of growth factor injections and 1 to 3 days of collection. The doses of growth factor continue until the stem cell collections are complete.

**What are the side effects of receiving growth factors?**
The most common side effects of growth factor therapy are bone pain, muscle pain, or headache. For some people these symptoms may be mild, while others may experience more severe discomfort. Medications can be prescribed to help these symptoms. We will follow your daily blood counts. Your white blood cell count will likely rise 3 to 5 times your usual count.

Other temporary side effects of growth factor therapy may include a rash, mild fever, and flu-like symptoms such as loss of appetite and generalized fatigue. Nausea is an uncommon side effect, but can occur.

**What specifically do I need to do during mobilization?**
The plan selected for you will be carefully explained along with your specific responsibilities. These will include:
- Daily blood draw
- Continue daily injections of growth factor until the stem cell collection is complete or you are instructed to stop
- Report any side effects that you experience to your nurse or doctor so that prompt treatment can be given
Step 5: Stem cell collection by apheresis
Apheresis is a procedure that collects specific blood cells. This is accomplished by passing a donor’s blood through a machine called an automated cell separator, similar to those used in blood banks.

How does the cell separator work?
A cell separator is used to obtain the specific cells we want to collect. After blood from the donor enters the machine, it circulates through a centrifuge. Centrifugal force causes the different types of blood cells to separate into layers. Some of the white blood cells, which include stem cells, are collected while the remaining blood cells and plasma are returned to the donor.

Every precaution is taken to ensure your safety:
• You are closely monitored by an apheresis nurse.
• Your blood never leaves the sterile tubing circuit. Supplies are used for only one collection and then discarded.
• There is only a small volume (a little more than one cup) of your blood in the cell separator at any time; your blood is returning to you at the same rate it is being removed.
• A solution is added to your blood as it circulates through the apheresis device to prevent clotting. This solution is quickly inactivated by your body.

Where are apheresis procedures done?
The Apheresis Unit is located in the SCCA clinic on the 5th floor.

What activities can be done during the procedure?
You will be lying or sitting in a bed. Donors with peripheral intravenous lines in their arms for venous access are able to watch television, listen to music, or participate in any other quiet activity. Donors with a central catheter have less restricted activities (can read, sleep, play cards, do handwork). A companion is welcome to stay with you during the procedure. If needed, a commode or urinal may be used at the bedside. You may bring a snack. A snack station and lunch are also available.

How long does each procedure take?
This varies from one donor to another but will generally take about 2 to 3 hours.

What are the side effects during apheresis?
The daily insertion of intravenous needles or the one-time surgical insertion of a venous catheter is the only uncomfortable part of the apheresis process.

The apheresis procedure itself is painless. In fact, most donors report no noticeable or unusual sensations during the procedure. Though some experience mild side effects such as chilling, a tingling sensation on the face or body, light-headedness, and bone discomfort. Adverse reactions are extremely rare.
What will I feel like when the procedure is over?
Some donors report feeling tired following apheresis. Donors who have intravenous lines placed for the procedure will have soreness or tenderness in their arms at the site of the intravenous lines and will be instructed to limit their activities for several hours. Any sensation of bone discomfort generally eases within a day or two after apheresis, as well.

How many apheresis collections will I need?
Generally, apheresis collections continue daily for a preset number of days or until the desired quantity of stem cells is collected and stored. The number of donor collections varies according to the protocol; the average is 1 to 2 collections.

What do I need to do to achieve a successful stem cell collection?
• Carefully follow your care plan before the collection with growth factor injections, blood draws, care of your intravenous catheter, etc. This is the most important action you can take toward successful stem cell collection.
• Make your stem cell collection top priority for the few days it will take. Pamper yourself and don’t put unnecessary expectations on yourself during this time.
• Eat a normal meal before your appointments. Calcium-rich foods (milk, yogurt, cheese) eaten before an apheresis may help prevent mild side effects from the anticoagulant solution.
• Arrive on time for your apheresis appointment and plan for the procedure to take approximately three hours.
• During the procedure, immediately report any unusual sensations you experience to a nurse.

We are here to make this a safe and comfortable experience for you. Please don’t make travel plans to leave the area until the collections have been completed.

Step 6: Stem cell analysis
Following the apheresis procedure, the types and numbers of different blood cells present are calculated. Samples of each product are also tested for bacterial contamination.

Step 7: Stem cell transfusion and/or storage
Stem cells collected by apheresis may be transfused immediately into the patient, held overnight for next day infusion, or stored by means of cryopreservation (freezing) for later use.

Step 8: Follow-up care
Following your peripheral blood stem cell donations, you will return the next day for a follow-up visit at SCCA. We encourage you to inform your personal physician at your next visit with them, that you have undergone this procedure, and obtain a complete blood count to verify everything has returned to normal. We want to make sure you are in good health.
Bone marrow harvest process
Bone marrow collection includes the below 7 steps which will be briefly explained on the following pages:

1. Donor evaluation and consent
2. Donor screening for anesthesia
3. Storage of autologous blood unit
4. Bone marrow harvest procedure
5. Bone marrow cell analysis, transfusion, and/or storage
6. Follow-up care
7. Long term recovery

Step 1: Donor evaluation and consent
Evaluation for a bone marrow harvest is similar to an apheresis donor evaluation, which includes an exam and a health history by a medical provider, a donor questionnaire by a nurse, possibly an electrocardiogram, and other diagnostic tests. Your nurse will review the team members, telephone numbers to call, overview of the clinic operations, and consents. Consenting for the procedure will be done by the attending physician after the evaluation is complete.

Step 2: Donor screening for anesthesia
There will be an evaluation done by the anesthesia staff at UW Medical Center, either by telephone or in person. They will review, in detail, the choices in anesthesia available to you and complete a plan for surgery and anesthesia.

Step 3: Storage of autologous blood unit
A fairly large volume of bone marrow may be taken, based on the weight of the patient. Anemia, a low red blood cell count, is the most common side effect of the procedure. Anemia can make the donor feel tired and short of breath. A unit of blood is taken from the donor prior to harvest to be stored and returned to the donor at the time of surgery. Storing one’s own blood is called an autologous donation. The minimum time for storage is 7 days prior to surgery, and the unit is good for 6 weeks. This applies to adult and pediatric donors greater than 12 years of age. Because there are medical risks from transfusion when your own blood has been taken and stored, your doctors will determine if it is in your best interest to receive your autologous unit after bone marrow donation.

Step 4: Bone marrow procedure
The night before and morning of the procedure, you will need to shower and scrub with an antimicrobial soap. You should not eat or drink anything after midnight before the surgery, or as directed by your medical team.

Location of surgery
The harvest takes place at UW Medical Center’s surgery pavilion, or Seattle Children’s, and is considered a day surgery procedure. You will be given specific instructions for the location and time you are scheduled for the harvest. You may have someone come with you to the hospital.
You will need to have a responsible adult with you in order to be discharged from the hospital.

**Step 5: Bone marrow harvest**
The bone marrow is harvested by using large-bore needles and syringes to pull the bone marrow from the pelvis. The entry sites are limited to 2 or 3 skin puncture sites on each side, while the bones are punctured multiple times.

**Recovery**
The post-anesthesia team will care for you until you are ready for discharge. It is possible that you will be kept overnight for fluids and further recovery and discharged the following morning. The recovery room and the transplant team assigned to your care in the hospital will make the decision after the procedure to keep you safe and comfortable.

**Step 6: Bone marrow cell analysis, transfusion, and storage**
The amount of bone marrow cells required for harvest is based on the weight of the patient. During the harvest, a cell count is done periodically to determine the amount of cells needed to collect. The collected bone marrow is screened and filtered, collected in a large bag, and taken to the patient receiving the transplant. There are occasional times when the red blood cells or plasma need to be reduced in the bone marrow, which will delay delivery to the patient.

**Step 7: Follow-up care**
You will be discharged from the hospital with a large dressing taped across your lower back to keep pressure on the sites to limit blood loss, if you are released the day of surgery. You will be discharged with pain medication and instructions for care.

The following morning, you will need to return to the clinic to have the bandages removed and replaced if needed. You will receive follow-up care instructions for returning home.

**Step 8: Long-term recovery**
Recovery will take at least a week after the surgery. You should avoid heavy lifting or any situation (such as contact sports) that could result in damage to this area the first 7 to 10 days after surgery. Within 2 to 4 weeks you should be back to your regular physical activity. You should inform your personal physician of your donation the next time you are seen, for your medical records, but no follow-up blood work is recommended.

If you have other questions about the collection of stem cells or bone marrow harvest, please ask any member of the SCCA healthcare team. We are committed to providing you with the best possible care. For additional general information on bone marrow harvest and donation please visit the National Marrow Donor Program at [www.bethematch.org](http://www.bethematch.org).
Notes/Questions to Ask

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Definition of Terms
**Allogeneic transplant (allograft):** A transplant in which bone marrow, peripheral blood stem cells, or cord blood stem cells come from a donor, such as a family member or unrelated person.

**Absolute neutrophil count (ANC):** A laboratory procedure that determines the number of neutrophils (a type of white blood cell) in a blood sample.

**Anticoagulant:** An agent that decreases the ability of the blood to clot.

**Apheresis:** A procedure used to collect certain types of blood cells. Blood from a donor is passed through a continuous-flow blood processor; the type of cell being collected is removed from the blood and the remaining blood components are returned to the donor.

**Attending physician:** A doctor who leads the healthcare team and supervises the medical care provided to the patient.

**Autologous transplant (autograft):** A transplant in which the bone marrow or peripheral blood stem cells are taken from the patient, frozen, and later returned to the patient.

**Bacterial contamination:** The presence of bacteria which makes a solution, surface, or body organ impure, for example, bacterial contamination of the blood.

**Biotechnology:** Engineering of procedures and agents used to alter or influence living organisms and processes.

**Blood Draw:** The removal of a small sample of blood from a vein.

**Bone Marrow:** The soft, spongy material in the center of bones that produces all of the blood cells in the body, such as white blood cells, red blood cells, and platelets.

**Bone marrow aspiration:** Obtaining a sample of bone marrow using a needle and syringe; this is done to obtain a sample for laboratory study.

**Bone marrow harvest:** Collecting marrow from the hip bones with a needle and syringe for use in transplant; marrow is harvested in the operating room.

**Bone marrow transplant:** The process of treating disease with chemotherapy, radiation therapy, or both, and then giving stem cells (directly from bone marrow, peripheral blood, or cord blood) to restore the production of blood cells.

**Cancer:** A general term used for over a hundred different diseases characterized by abnormal, uncontrolled cell growth.

**Caregiver:** A responsible family member or friend who is able to provide physical care, observational care, and emotional support for a patient in the home setting.
**Catheter:** A rubber or plastic tube that is inserted into the body to drain fluids or deliver fluids or medication

**CD 34 + cells:** Lymphocytes (white blood cells) which have a specific antigen marker which allows them to be detected in a sample of cells; the number of CD 34 + cells are counted after stem cell collection to determine if adequate numbers of stem cells are present; it is still unconfirmed scientifically, but CD 34+ cells may, in fact, be a type of stem cells.

**Cell separator:** A mechanical device used to collect blood cells and separate the various blood components, such as red cells and white cells.

**Central intravenous catheter/Line:** A small, flexible tube inserted into a large vein near the heart; this serves as a route for medications, fluids, and to obtain blood samples

**Central line placement:** The process of inserting a catheter into a large vein; this is a minor surgical procedure performed in the operating room under either local or general anesthesia

**Centrifuge:** A device which spins around a central axis to increase gravity, which separates materials of different densities; apheresis machines use a centrifuge to separate and collect blood cells

**Chemotherapy:** Medications used to destroy or slow the growth of abnormal cells, usually cancer cells

**Collection:** The process of accumulating or keeping together, such as collecting stem cells

**Complete blood count (CBC):** A laboratory procedure that determines the number of red blood cells, white blood cells, and platelets in a sample of blood

**Complication:** An undesired symptom or medical problem that is a consequence of therapy, or another disease

**Conditioning:** The treatment given to the patient before transplant, intended to kill cancer cells and prepare bone marrow to receive stem cells; this consists of chemotherapy and/or radiation therapy

**Cord blood:** Stems cells collected from the umbilical cord and placenta when a baby is born and then frozen for future use

**Counts:** Refers to monitoring the ANC (absolute neutrophil count) when watching for engraftment
**Donor:** A person who gives stem cells to be infused into the patient following chemotherapy and/or radiation. A donor may be the patient, family member, or unrelated person

**Erythrocytes:** Red blood cells carry oxygen on hemoglobin from the lungs throughout the body.

**Engraftment:** The process by which the normal growth and production of blood cells and the bone marrow resumes

**Exit site:** The place on the chest where the central intravenous catheter emerges from the skin

**FHCRC:** Fred Hutchinson Cancer Research Center, also know as the “Hutch”

**Graft-versus-host disease (GVHD):** A process whereby the transplanted cells (the graft) attack certain organs in the recipient (the patient/host)

**Growth factors:** Substances naturally occurring in the body that control the production and function of blood cells; these may be given after transplant to speed up engraftment, or given to donors to increase the number of stem cells in the blood stream that will be collected for transplant

**Glycoprotein:** A protein that has carbohydrates attached to it

**Hormone:** Produced by certain organs of the body that stimulates and regulates body functions

**Immune system:** A complex network of organs, cells, and specialized substances distributed throughout the body which defend it from foreign invaders that cause infection or disease

**Immunosuppression:** A decrease in the ability of the immune system to fight infection that can be caused by chemotherapy, radiation, or GVHD therapy

**Informed consent:** How a patient learns about and understands the purpose, potential risks, and benefits of a research protocol and then agrees to participate; patient may decline to participate

**Infusion:** Administration of medications or fluids into a vein over a period of time

**Infusion pump:** A device used to infuse medications or fluids through a catheter into a vein over a specific amount of time

**Intravenous (IV):** A route of administration for fluids or medications that are given into a vein

**Leukocytes:** White blood cells that play a major role in the body’s immune system

**Mixed chimerism:** A transplant that uses stems cells from the patient and a donor
Mobilization: Stimulating the bone marrow to produce and release large numbers of stem cells into the bloodstream

Mucositis: Reddening and soreness of the tongue, lips, mouth, throat, and gastrointestinal tract as a result of chemotherapy or radiation therapy

Neutropenia: Low neutrophil (type of white blood cell) count; a person with neutropenia is at high risk for developing an infection

Neutrophil: A type of white blood cell that provides defense against infection

Non-myeloablative transplant: A transplant in which stem cells are received from a family or unrelated donor and conditioning is done with moderate dose chemotherapy and/or radiation

Oncology: An area of medical science that studies tumors and cancers

Peripheral blood stem cell (PBSC’s): Cells made in the bone marrow that are circulating in the blood stream and that have the ability to develop into white blood cells, red blood cells, or platelets

Peripheral blood stem cell transplant: Stem cells circulating in the bloodstream are collected and later given back to a patient after chemotherapy or radiation therapy is given

Platelets: Tiny disc-shaped blood cells that help the blood to clot and help prevent bleeding

Pneumonia: A disease in which the lungs are inflamed or infected

Protocol: The plan for a specific treatment; may be a scientific study such as a research protocol

Protocol consent forms: A document that outlines the treatment plan/research study that the patient signs to indicate understanding and consent

Radiation therapy: A cancer treatment that uses radiant energy waves to damage/kill cancer cells

Red blood cell: A type of blood cell (also called erythrocyte) that carries oxygen in the body

Rejection: A process by which transplanted cells are attacked by the patient’s immune system

SCCA: Seattle Cancer Care Alliance

Side effect: An additional and usually undesirable effect from a drug or other treatment
**Sinusoidal obstruction syndrome (SOS):** A disease caused by obstruction of blood flow through the small blood vessels in the liver, resulting in damage to the liver

**Standard treatment:** A treatment or other intervention currently being used that has been proven effective on the basis of past clinical studies

**Stem cells:** An immature cell which is the “parent” cell of the blood cell and has the capacity to mature into a red blood cell, white blood cell, or platelet

**Syngeneic transplant:** An identical twin donates stem cells to the other twin for transplant

**Tissue typing:** Tests that determine how closely the tissues of a donor and the patient match

**Total body irradiation:** Radiation treatment of the entire body, used to destroy malignant cells and bone marrow cells in preparation for transplant

**Total parenteral nutrition (TPN):** Nutritional support given intravenously; also called hyperalimentation

**Venous access:** A method used to gain entrance into a vein

**Viable:** Capable of living

**White blood cells:** A group of blood cells, the leukocytes, that helps fight infection
Fundraising Ideas
Why fundraise?
Even if insurance covers most of the treatment costs, you and your family may need additional funds to help pay for transportation, housing, food, and child care.

Take time to think through a strategy, set a timeline, and break up tasks into manageable pieces. Begin by building a team of people who will help you raise money and provide you with support. Ask people who you are close to and who want to help.

Foundation and corporate grants
Large cash donations from foundations and corporations are almost exclusively given to organizations with federal tax-exempt status. It can take six months to a year to be certified as a tax-exempt organization by the IRS.

This is one reason you might want to consider working with an existing not-for-profit organization. Local corporations often are willing to make “in-kind” donations of goods and services.

Set your fundraising goal
How much money do you need to raise? What do you need to pay for? It will help your fundraising if you can give people a very specific understanding of what their contribution will accomplish.

Build a fundraising team
You may want to create a network of people who will join you in asking for money. Each can build their own network of givers. The more people and institutions that you can get involved in asking for money, the easier it will be to reach your goal. For example, rather than ask your friend for $1,000, ask him or her to raise $5,000 from colleagues, organizations you belong to, unions, and/or fraternal organizations.

Build a prospect list of potential givers
This is a brainstorming process, and the more people involved, the better. The most important thing when developing a prospect list is to start close to home. Then widen the net and begin to identify other possibilities, such as calls to a church where you don’t have a relationship, appeals to a local civic group, etc.

Personal solicitations
These can be face-to-face, telephone, or written requests for donations. The more personalized the request for a donation, the better. Face-to-face contact is better than a phone call. A personalized letter is better than a form letter.

Rule #1 of personal solicitations is to ask for a specific amount for a particular purpose.
For face-to-face contacts and telephone calls, practice what you will say in advance. “We will use this to cover housing, procedures, travel, and other treatment costs.” Avoid saying “We need you to give anything you can.”

Ask people if the company they work for “matches gifts”. Many corporations will match an employee’s donation. This is a powerful way to double a gift.

**Special events/benefits**
Special events can be very time consuming to plan and execute and, if you are not careful, very expensive. However, they can be an excellent way to generate publicity and enthusiasm for your cause, and involve a large number of people in the fundraising campaign. The more work you do BEFORE the tickets or invitations are distributed, the more successful the event will be. Get creative with ideas. Here are a few to start:

- Dinner dance
- Auction and raffles
- Golf outings
- Block parties
- Spaghetti dinners
- Car washes
- Bike-a-thons, bowl-a-thons, or dance-a-thons
- Rummage and garage sales

Make a budget and stick to it. The last thing you need is an event that costs as much as it raises. Get things donated such as printing, the event location, food, drink, and other items. Recruit a benefit committee that will be responsible for selling tickets. Get very specific commitments from committee members about the number of tickets they will buy or sell.

**Selling goods and services**
This is usually the least efficient way for small groups to raise money. Not only will a large part of sales revenue be eaten up by the cost of the goods you are selling, but precious volunteer hours may be diverted from more lucrative fundraising activities such as personal appeals. If you do decide to launch a sales campaign, choose a project with low or no upfront costs.

**Keep donors posted**
Being thanked and knowing that the contribution has been put to good use helps turn donors into repeat donors. While it may not be possible to personally thank everyone, it is important to thank your major contributors with a note or phone call.

News releases to local media, notices in church bulletins, and letters to civic and business organizations, etc., are excellent ways to keep the community informed about the success of your fundraising efforts and how their dollars are being spent.
Never miss an opportunity to say “thank you” to the heart and soul of your campaign--your volunteers. Raising funds is hard work, but can be very rewarding if you know your efforts are appreciated.

**Background information**
Prepare a 1 to 2-page all-purpose information sheet that answers commonly asked questions.

For example:
- Who will the fundraising benefit?
- What is your disease? Is a transplant the only chance to save your life?
- What is a bone marrow or stem cell transplant?
- Why do you need donations from the community? How much money must be raised? By when? What time? What specific expenses will the money be used to cover?
- Where should contributions be sent? To whom should the check be made?
- Are contributions tax-deductible?
- Who can be called for further information?

**Identify media/feature stories**
Your local library should have a directory of all media in your area. Try to determine the name of the health reporter if the media outlet has one. Most papers and TV stations regularly do feature or “human interest” stories. Find out who the features reporter is at your local paper or TV station and encourage him or her to do a story about you.

**Media releases/publicity**
- Keep your releases short and focused—no more than one page.
- Summarize your message in the first paragraph and follow up with details.
- Use words and phrases that make your release interesting and convey a sense of urgency.
- If your news release is time-sensitive (for example, announcing a fundraising event), make sure it reaches the media in time to be printed or aired a few days before the event.
- The more stories you can generate on TV, radio, online, and in local newspapers, the more successful your fundraising will be.
- Provide the media with photos of the patient (crisp, clear, glossy black and white photos are preferable)

The previous information is taken from an issue of “BMT Newsletter” at [www.bmtinfonet.org](http://www.bmtinfonet.org).
Maps, Directions, and Parking
SCCA Clinic
825 Eastlake Avenue E
Seattle, WA 98109-1023
(206) 606-7222

UWMC
1959 NE Pacific St
Seattle, WA 98195
(206) 598-3000

Seattle Children’s
4800 Sandpoint Way NE
Seattle, WA 98105
(206) 987-2000

SCCA and UW Medical Center garages (Surgery Pavilion and Triangle) offer same day reciprocal parking. Simply bring your receipt from a participating garage to your next same-day appointment, and it will be honored.
SCCA Map, Directions, and Parking

SCCA Address
825 Eastlake Avenue East, Seattle, WA 98109-1023, phone (206) 606-7222

Directions to SCCA from I-5 north or southbound
1. Take Exit 167 for Seattle Center/Mercer St. and move to the far-right lane
2. Turn right at Fairview Ave N
3. Veer right at the light, staying on Fairview Ave. N (do not turn right onto Valley St)
4. Turn right at Aloha St and go 2 blocks to the SCCA building (it will be on your right)
5. Enter the SCCA Outpatient Clinic parking garage between Yale Ave N and Eastlake Ave E

Parking at SCCA
Patients may park in the SCCA Clinic’s underground parking garage. The parking fee is $4.00 per day when validated at any reception desk. Parking fees are prorated for shorter visits to the clinic and patients also have in-out privileges. The parking garage is open Monday through Friday from 6:30am to 8pm and weekends/holidays from 6:30am-5pm. You must notify the attendant if your car is being left overnight. The height limit in the garage is 6’7”. There is limited metered street parking. Paid parking hours are typically 8 a.m. to 6 p.m. It is extended until 8 p.m. in some areas. Parking is free on Sundays and holidays.
UWMC Map, Directions, and Parking

UWMC address
1959 NE Pacific St, Seattle, WA 98195, phone (206) 598-3000

Directions to UW Medical Center from SCCA:
1. Travel north on Fairview Ave N or Eastlake Ave E (street becomes Eastlake Ave E)
2. Cross the University Bridge
3. Turn right at NE Campus Pkwy
4. Turn right at Brooklyn Ave NE
5. Turn left at NE Pacific St

Parking information for UWMC is below.
Parking at UWMC

All UWMC garages and the SCCA garage offer same-day reciprocal parking. Simply bring your receipt from a participating garage to your next appointment at the other location and any remaining paid time will be honored. Patients have in-out privileges. Keep your parking receipt and present it to the attendant. UWMC offers valet parking on weekdays from 8 am to 5 pm. The valet booth is on the drive to the main hospital entrance. There is limited metered street parking near all buildings.

At UWMC, parking is available in 3 places at the hospital (see map above)

- **Triangle Parking Garage** - Access from NE Pacific Place off of Pacific Street, across the street from the UW Medical Center via a pedestrian tunnel under NE Pacific (garage height restriction is 6’ 8”)
- **Surgery Pavilion Parking Garage** - On Pacific Street, turn left at turning lane toward the Surgical Pavilion. Veer left into the Pavilion Parking Garage. Take garage elevator up to third floor. (garage height restriction is 6’ 8”)
• **S-1 Parking Garage**

On foot, once you get to the main entrance of UWMC 8SE, follow signs for the “Cascade Elevators”. Take elevators to 8th floor (8SE). Turn right from elevators and check in at the 8SE Reception Desk (parking can be validated here).

At UWMC Roosevelt, the parking garage is under the building.
Seattle Children’s Map, Directions, and Parking

Seattle Children’s address
4800 Sandpoint Way NE, Seattle, WA 98105, phone (206) 987-2000

Directions to Seattle Children’s from SCCA:
1. Travel north on Fairview Ave N or Eastlake Ave E (street becomes Eastlake Ave E)
2. Cross the University Bridge
3. Continue north on 11th Ave NE
4. Turn right at 45th Ave NE
5. Turn left at Sand Point Way NE
6. Follow signs for Seattle Children’s

Parking at Seattle Children’s
All parking at Seattle Children’s is free. Inpatient parking is located in the River garage level 1 and outpatient parking is in the Ocean garage.
Live within a 30 minute drive from SCCA