Northwestern Medicine®

Division of Immunotherapy & Autoimmune Diseases

H.O.P.E.

Handbook Of Patient Education

DIVISION OF IMMUNOTHERAPY & AUTOIMMUNE DISEASES

Handbook Of Patient Education

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Chicago, IL 60611
Phone 312-695-4960 • Fax 312-695-4961
www.stemcell-immunotherapy.com

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WELCOME!

Welcome to the Division of Immunotherapy and Autoimmune Diseases (DIAD) Stem Cell Transplant Program at Northwestern Medicine. Thank you for considering treatment at our center located in Chicago, IL. Dr. Richard Burt, the Chief of the Division, pioneered the field of stem cell transplant for autoimmune diseases and has treated more patients than anyone in the world. Our center is unique as it is dedicated to offering treatment for several different types of autoimmune diseases. To see a list of all diseases that we treat as well as videos and publications, please visit our website at: www.stemcell-immunotherapy.com.

This is the **H**andbook **O**f **P**atient **E**ducation **(H.O.P.E.)**. If you are reading **H.O.P.E.**, you or a loved one is likely preparing to undergo a stem cell transplant. The stem cell transplant process can be a long journey, and most people have several important questions regarding the course and treatments. The DIAD Team understands the importance of educating patients, family members and caregivers about medical care so they can make informed decisions. **H.O.P.E.** will help guide you through each step of the process. It has been divided into sections and does not need to be read at one time.

There is a special section of **H.O.P.E.** dedicated for caregivers as we are aware of how important the caregiver role is. We have outlined what caregivers can expect and tips that may assist with the planning process. There are also sections that outline support services and resources that are available during your stay in Chicago.

In the back of **H.O.P.E.**, you will find several appendices, including definition of terms, maps, and other useful information.

DIAD's goal is to provide safe and high quality care for all patients during their visits to Northwestern Medicine. When treatment is complete, we are hopeful that patients will see an improved quality of life as they heal from their autoimmune disease. We look forward to helping you through this journey.

Best Wishes,
The DIAD Team

DIAD Division of Immunotherapy and Autoimmune Diseases

Meet the Team:

Faculty & Staff

Richard K. Burt, MD
Division Chief, Physician

Kathleen Quigley, RN, BSN, MBA
Division Administrator,
Clinical Research Nurse **(MS)**

Steve Xiaoqiang Han, MD
Postdoctoral Fellow

Dzemila Spahovic, MD, MS, CCRP
Research Project Manager

Indira Arnautovic, MD
Research Associate

Inpatient NP/ PA

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Nurse Practitioner

Allison M. Clendenan, MS, FNP-BC
Nurse Practitioner

Kaitlyn N. Leska, MMS, PA-C
Physician Assistant

Amy L. Morgan, MS, ACNP-BC
Nurse Practitioner

Outpatient Clinical Research RNs

Carol Burns, RN, MSN
Clinical Research Nurse
(SSc & Devic's)

Paula Gozdziak, RN, BSN
Clinical Research Nurse
(CIDP & SPS)

Elizabeth Graber, RN, MSN
Clinical Research Nurse
(MS)

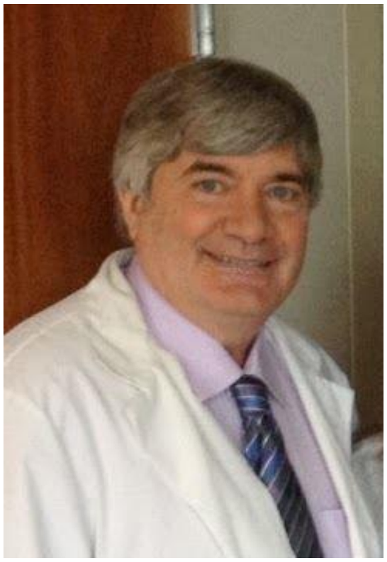
Kimberly Yaung, RN, BSN
Clinical Research Nurse
(MS)

Administrative Assistants

Kim Bracy
Patient Liaison

Monique Steward McQuay
Administrative Assistant

Mayra Rangel
Administrative Assistant



Dr. Richard Burt

(L-R) Kim B., Michelle C., Elizabeth G., Mayra R., Indira A., Kim Y.

(L-R) Dzemila S., Paula G., Allison C., Steve H., Carol B., Kaitlyn L., Amy M., Kate Q., Monique M. (front)

Addresses and Phone Numbers

Division of Immunotherapy and Autoimmune Diseases

446 E. Ontario St
Ste 10-1000
Chicago, IL 60611
Phone: (312) 695-4960
Fax: (312) 695-4961

If you need to make an appointment or to speak to your clinical research nurse, please call during business hours (Monday-Friday 8:30 am-4:30 pm).

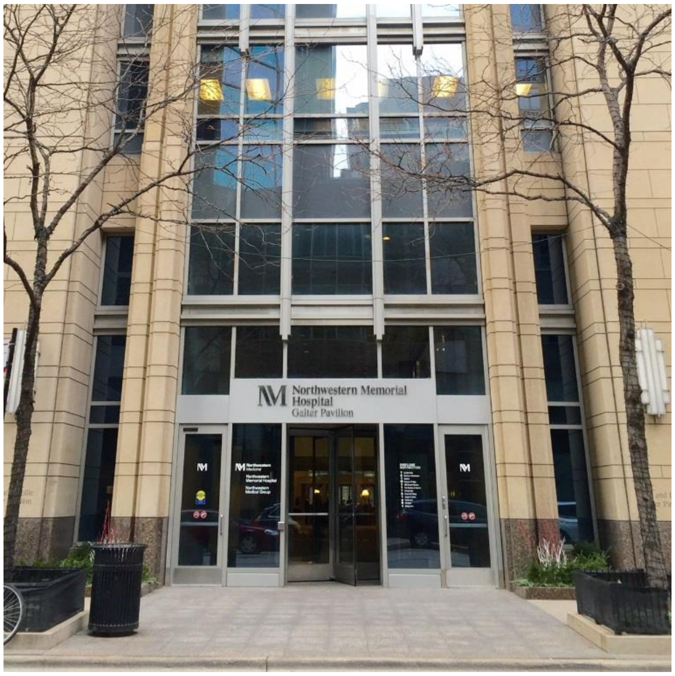
If no one answers, please leave a message and someone will return your call within 1 business day. If it is a weekend, someone will return your call on Monday.

For Emergencies:
Call 911

Northwestern Medicine

Prentice Women's Hospital

250 E. Superior St
Chicago, IL 60611
15th Floor Phone: (312) 472-1500
16th Floor Phone: (312) 472-1600



Galter Pavilion

675 N. St. Clair St
(corner of St. Clair and Huron)
Chicago, IL 60611

Feinberg Pavilion
(Emergency Department)

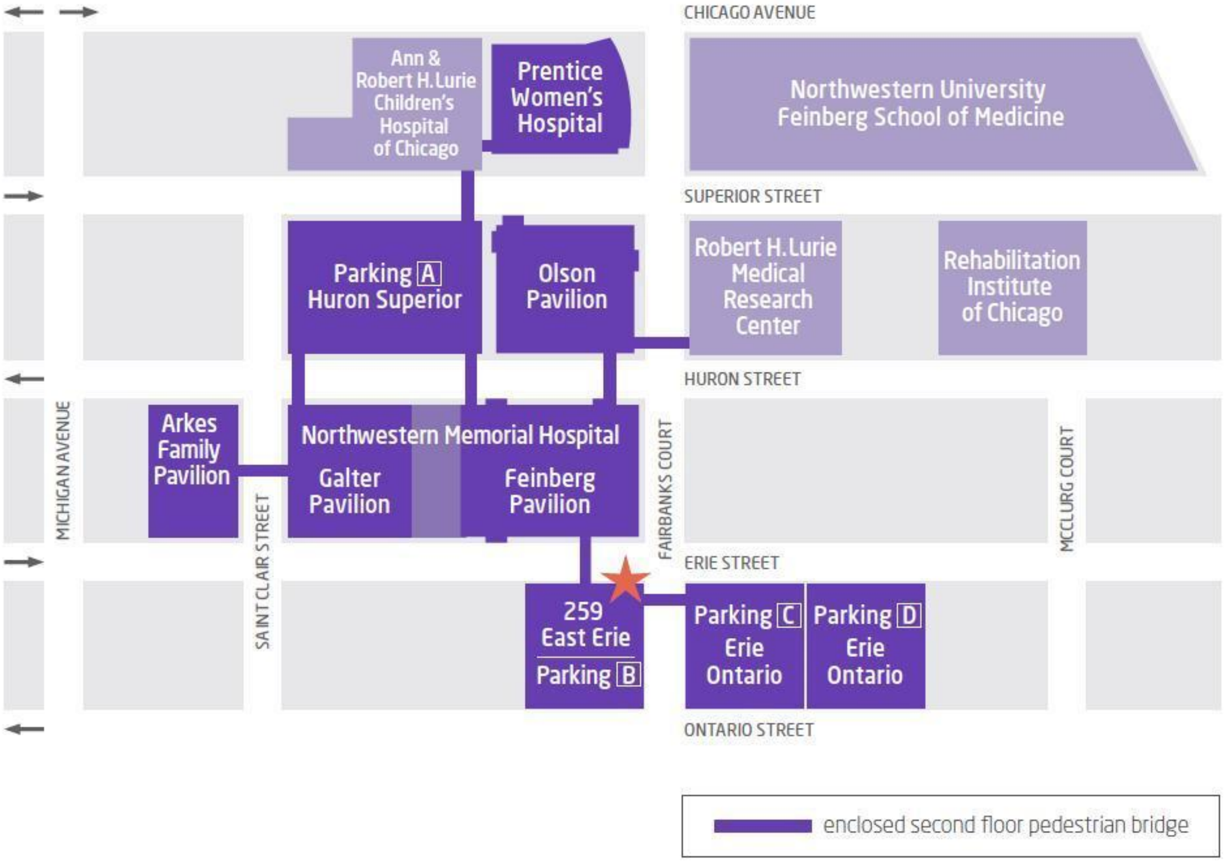
251 East Huron St
Chicago IL, 60611
(312) 926-2000

Diagnostic Center
Arkes Family Pavilion
2nd Floor
676 N. St. Clair St
312-926-0049

Rube Walker Blood Center
Galter Pavilion
11th Floor
675 N. St. Clair St
(312) 926-2342

Medical Records
Galter Pavilion
2nd Floor
675 N. St. Clair St
(312) 926-3375

Walgreens
Galter Pavilion
1st Floor/ Mezzanine
201 E. Huron St
(312) 951-1084



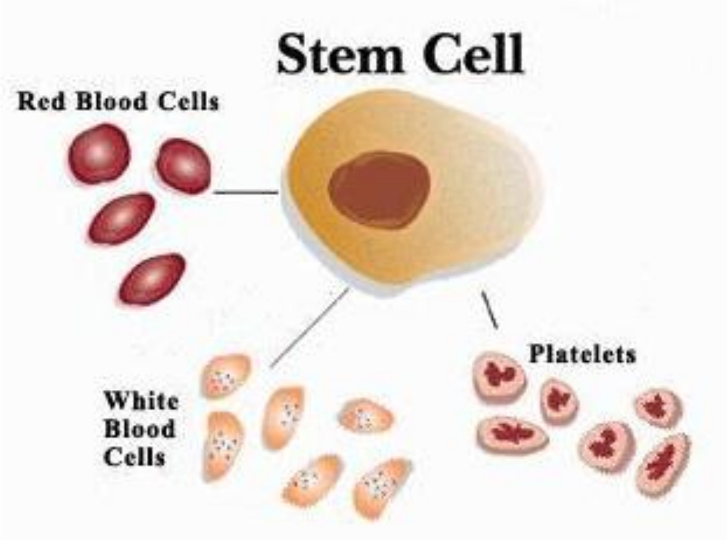
Section

2

BASICS OF STEM CELL TRANSPLANT

What is bone marrow?
The spongy tissue in the cavities of bones where blood cells are produced.

What are stem cells?
Stem cells are undifferentiated cells that have the potential to both self-renew and to differentiate into specialized cells. Stem cells are responsible for generating red blood cells, white blood cells and platelets.



Red Blood Cells (Erythrocytes): oxygen carrying cells
White Blood Cells (Leukocytes): infection fighting cells
Platelets (Thrombocytes): blood clotting cells

Where are stem cells found?

- bone marrow
- peripheral blood
- umbilical cord blood

Is there a difference between bone marrow transplant and stem cell transplant?

No. These words are used interchangeably. In the past, the term *bone marrow transplant* was commonly used because the stem cells were obtained from the bone marrow under anesthesia. Today, stem cells are mostly obtained through the peripheral blood, which subsequently led to the term *stem cell transplant*.

What are the different types of stem cell transplants performed by DIAD?

Transplant	**Source of Stem Cells**
Autologous…………………	The patient
Allogeneic……………………	Matched sibling
Syngeneic……………………	Identical twin

* The type of transplant is determined by the autoimmune disease being treated.

What is a conditioning regimen?

For stem cell transplants performed by DIAD, the conditioning regimen involves chemotherapy and immunosuppressant drugs that target components of the immune system.

What is neutropenia?

Neutropenia means low neutrophil count. Neutrophils are a type of white blood cell responsible for fighting infections. Chemotherapy will cause a reduction in neutrophil count.

What is the difference between myeloablative and non-myeloablative therapy?

Myeloablative and non-myeloablative refers to the potency of the drugs and treatments that are used to eradicate the bone marrow cells.

<u>Myeloablative</u>: The use of a conditioning regimen usually reserved for cancer therapy that causes complete destruction to the stem cell compartment. A stem cell transplant is necessary for recovery and survival.

<u>Non-myeloablative</u>: The use of a conditioning regimen that removes much of the immune system, however, recovery will occur without stem cell transplant.

What are the advantages of using a non-myeloablative conditioning regimen?

- Fewer side effects
- Faster recovery
- Less risk of serious infections
- Less risk of transplant related complications and mortality
- Less risk of developing treatment related cancers later
- Uses a conditioning regimen in which the bone marrow will recover without the infusion of stem cells

All stem cell transplants performed by DIAD are non-myeloablative. Our goal is to provide the lowest risk therapy possible while still achieving maximum benefit.

Total body irradiation is never used in any of the conditioning regimens.

How does stem cell transplant work to treat autoimmune diseases?

Imagine re-booting a computer

A non-myeloablative conditioning regimen of chemotherapy and immunosuppressant drugs is given to destroy components of the immune system. This induces an immediate immune cease fire in a non-inflammatory environment. A new immune system is regenerated that defaults to self-tolerance. Equilibrium is restored in the immune system by "re-booting."

What is the goal of stem cell transplant in autoimmune diseases?

- To restore equilibrium to the immune system
- For the disease to go into remission, stopping the progression and also reversing disease symptoms
- To be medication and treatment free post stem cell transplant

Pre- Stem Cell Transplant Preparation

Initial Evaluation	• Tests completed to determine if candidate for stem cell transplant • Takes 1-5 days • Appointment with Dr. Burt and research nurse • Insurance approval
Pre-Transplant Testing	• Tests completed to ensure safety before proceeding with stem cell transplant • Takes 1-2 weeks to get results
Mobilization	• Mobilization and harvest refers to process of collecting stem cells in advance and preserving them until transplant occurs • **Autologous transplant**- 1 night stay in hospital to receive chemotherapy to prepare stem cells for collection; harvest occurs 10 days later, must remain in Chicago area at local hotel or apartment until harvest is complete • **Allogeneic transplant** (matched sibling)- no chemotherapy or hospital stay required for sibling, mobilization completed outpatient, sibling must be present for harvest
Harvest	• Collection of stem cells • Takes 1-3 days • Once complete, can return home until admitted for stem cell transplant
****2-4 week break before admitted for stem cell transplant****	

Stem Cell Transplant Admission

Conditioning Regimen	**Admission through Day -1** • Period when chemotherapy and immunosuppressant drugs are given • Length of conditioning regimen 5-8 days depending on disease protocol • The days leading up to the stem cell infusion are negative days and the days after the transplant are positive days
Stem Cell Infusion	**Day 0** • Stem cells are thawed and infused through the PICC line in hospital room • Takes approximately 30 minutes
Post- Stem Cell Infusion	**Day +1 to engraftment** • White blood cells, red blood cells, and platelets will decrease • Blood transfusions may be required • IV antibiotics given • Daily lab draws
Engraftment	**Day +8 to Day +12 (Autologous)** **Day +8 to Day +16 (Allogeneic)** • Engraftment occurs when cells begin renewing • Absolute neutrophil count/ white blood cell count > 1

Diseases Treated

Autologous	**Allogeneic** *(Matched Sibling)*
Multiple Sclerosis	Crohn's Disease
CIDP	Rheumatoid Arthritis
Systemic Sclerosis	Vasculitis
Devic's	Systemic Lupus Erythematosus
Stiff Person Syndrome	Pansclerotic Morphea
Crohn's Disease	
Rheumatoid Arthritis	
Systemic Lupus Erythematosus	
Vasculitis	
Polymyositis	

> ***"Systemic Sclerosis- it is like having an anaconda that slowly tightens its grip around you every day."***
>
> **- Systemic Sclerosis Patient, Kentucky**

> ***"[Multiple Sclerosis] strips you of who you are."***
>
> **- Ann Romney, wife of former Governor Mitt Romney, diagnosed with MS 2008**

Common Side Effects

Hair Loss:
Hair loss is also referred to as alopecia. Patients will lose their hair as a side effect of one of the chemotherapy drugs in the conditioning regimen (cyclophosphamide). The hair loss will begin approximately 14 days after receiving the cyclophosphamide and may include hair on the head, facial hair, body hair and eyelashes. It will start to grow back approximately 3 months after receiving the last dose of cyclophosphamide.

Nausea:
Nausea is a common side effect of chemotherapy drugs. Some individuals do not experience any nausea while others are more sensitive. Medications will be given prior to each dose of chemotherapy to prevent nausea. For breakthrough nausea, there are several medications available to help keep nausea controlled.

Diarrhea/ Constipation:
It is not uncommon to develop diarrhea or constipation as side effects from medications during a stem cell transplant. There are medications available to treat both of these side effects.

Fatigue:
The body is under stress during a stem cell transplant, even when it cannot be seen or felt. In addition, it can be difficult to get quality sleep while in the hospital due to being in an unfamiliar environment and from frequent interruptions. It is not unusual for individuals to feel fatigue or have lower energy levels than normal during the process. Fatigue will improve over time.

Suppressed Immune System:
Chemotherapy and immunosuppressant drugs will suppress the immune system for approximately 6-12 months after a stem cell transplant. Handwashing and avoiding sick individuals are two important measures to help keep patients safe from developing infections. In addition, patients will be prescribed medications for 3-12 months after stem cell transplant to help prevent infections.

Risks of Stem Cell Transplant

*These are general risks. Specific risks from medications and procedures are discussed in the consent forms.

Infections:

Infections can occur at any time, however individuals are more susceptible to developing infections while neutropenic. Infections can be bacterial, fungal or viral. Antibiotics and other medications will be given before neutropenia is even present to prevent infections during the stem cell transplant. Antibiotics, anti-fungal and anti-viral medications will also be given for 3-12 months post stem cell transplant as the immune system will be suppressed for several months even after the neutropenia resolves. While infections can potentially be serious, most can successfully be treated with medications.

Bleeding:

In addition to white blood cells becoming low from chemotherapy, red blood cells and platelets will also drop and will recover at engraftment. Anytime platelets are low, there is an increased risk of bleeding in the skin, bowel, lung and head. While bleeding in the skin is usually not serious, a large bleed in other areas can be very dangerous or life threatening. Precautions will be taken by transfusing platelets as needed to keep platelet counts at safe levels to decrease the risk of bleeding.

Blood Transfusions:

Blood and/or platelet transfusions will likely be needed at some point during the stem cell transplant. While blood is screened very carefully, there is always a low risk of contracting HIV or hepatitis from a blood transfusion. There is also a risk of having a blood transfusion reaction that could cause fever, changes in heart rate or blood pressure or allergy like symptoms such as hives or throat tightening. If this occurred, the blood transfusion would be immediately stopped and the symptoms would be treated with anti-histamines, steroids and epinephrine if needed.

Infertility:

There is a risk of becoming infertile after receiving chemotherapy drugs. Age and previous exposure to chemotherapy plays a role in determining this risk. Please refer to ***"Fertility"*** in Section 3 for more information on options for infertility.

Allergic Reaction:

An allergic reaction can result from any medication, transfusion or procedure. While most allergic reactions are mild, some can be dangerous and life threatening. Precautions will be taken to prevent allergic reactions by giving steroids and/ or antihistamines prior to certain medications and blood transfusions. If a severe allergic reaction develops, measures would be taken to treat the reaction immediately. Be sure to tell your doctor and nurse about any known drug allergies. We may have to evaluate you to determine what drugs we can or cannot use.

Hemorrhagic Cystitis:

A potential complication of cyclophosphamide is inflammation and bleeding in the bladder, often resulting in pain and blood in the urine. While uncommon, certain viruses can also cause this complication. A medication called **mesna**, IV fluids, and diuretics are given to prevent this complication. For those who are unable to tolerate large volumes of IV hydration or who have a history of urinary retention, a foley catheter may be placed to allow for continuous emptying of the bladder while receiving cyclophosphamide. If this complication develops, it may take several days to weeks to resolve. This complication is uncommon and when it does occur, is usually not severe.

Mortality:

The risk of mortality is very low, however, a life threatening complication could occur that could lead to death. **The risk increases when you have co-existing diseases (such as heart disease, diabetes, sickle cell disease, prior infections, etc). Be sure to tell your doctor and nurse all of your medical history/ diseases.**

> ***“HSCT can be a scary process to begin, but the benefits far outweigh any risk. I have spoken to people who are afraid of the procedure. I tell them that the short period that you receive medication and treatment is far less scary than the lifetime of medications used to treat the disease and only accomplish slowing it down.”***
>
> **- Multiple Sclerosis Patient, North Dakota**

Section 3

THE TRANSPLANT EXPERIENCE

The following information will give you an overview of the transplant experience. Please let your clinical research nurse know if you have any questions.

The 10 Steps of Stem Cell Transplant

Step 1: Meet your Clinical Research Nurse
Step 2: Initial Evaluation
Step 3: Insurance Approval
Step 4: Planning and Preparation
Step 5: Pre-Transplant Testing
Step 6: Stem Cell Mobilization
Step 7: Stem Cell Harvest
Step 8: Stem Cell Transplant Admission
Step 9: Discharge
Step 10: Follow-up

Step 1: Meet your Clinical Research Nurse

When you inquire about stem cell transplant for your disease, you will be referred to a clinical research nurse who will guide you through the initial steps.

Your research nurse will email you and/ or call you to send you more information about DIAD's program for your specific disease. Your research nurse will ask you questions about your health history and may send you a screening form to fill out to determine if you are eligible for one of the protocols. Before the initial evaluation, an intake form will be sent to you.

- Intake form- includes demographic information (address, phone number, etc.), name and contact information of your doctors and your insurance information. If you have insurance, we ask that you send a front and back copy of your insurance card.
- These forms and records will need to be emailed, faxed, or mailed to DIAD.

Fax: 312-695-4961 (Please limit to 20 pages)

Address: Division of Immunotherapy & Autoimmune Diseases (DIAD)
Attn: Clinical Research Nurse's Name
446 E. Ontario Suite 10-1000
Chicago, IL 60611

Scheduling the Initial Evaluation: You will be referred to one of our administrative assistants who will schedule the initial evaluation based on your availability and appointment availability. After the scheduling is complete, a calendar of appointments will be sent to you. This visit usually takes 1-5 days to complete.

Insurance: It is important that you check with your insurance company to ensure that the evaluation (second opinion of your disease) at Northwestern Medicine will be covered. Please call your insurance customer service phone number to see if services at Northwestern Medicine are covered. If you have a PPO, ask if Northwestern is in-network. If you have an HMO, you will need a referral in order to be seen. Please keep us updated if there are any issues with insurance coverage or if your insurance company will not pay.

Housing: You will need short-term housing during your visit if you are coming from out of town. Please see "***Lodging***" in Section 5 for assistance.

Step 2: Initial Evaluation

The initial evaluation helps us determine if you are a candidate for one of the protocols.

Goals of the initial evaluation include:

- To confirm the diagnosis of the disease being treated
- To confirm that the eligibility criteria for the treatment is met
- To determine if the treatment is thought to be beneficial
- To assess for any contraindications to treatment
- To assess for any conditions that could compromise safety
- To provide information about the treatment and address any questions

What to expect during the Initial Evaluation

- Expect to stay in Chicago for 1-5 days for this visit. The length of stay will depend on the number of physician appointments and tests that are needed.

- Laboratory blood tests and procedures will be obtained. The procedures will vary depending on the disease, however may include things such as a CT scan, MRI or x-ray. Your research nurse will explain the specific testing that you will need.

- Appointments with specialty physicians that are part of DIAD's team may be necessary.

- Appointment with Dr. Burt in which you will undergo a history and physical examination. Please be prepared to answer questions about your disease course. It may be helpful to make a timeline including date of diagnosis, history of symptoms, and medication/ treatment start and stop dates. Please bring an up to date medication list with you.

- If you are thought to be a good candidate after the meeting with Dr. Burt, the transplant process and risks will be explained. A copy of the consent form will be provided for you to take home and read.

- If you are a candidate and feel it would be helpful to speak to others who have undergone a stem cell transplant, notify your research nurse.

Step 3: Insurance Approval

For those who have medical insurance

All candidates who proceed with treatment will be assigned a financial coordinator. The financial coordinator will send a letter and pertinent medical records to the insurance company requesting for approval of stem cell transplant treatment. This process can take 2 weeks to 3 months depending on the insurance company.

What if the insurance company denies treatment?

If the insurance company does not approve the treatment, the financial coordinator will initiate the appeal process. This involves sending additional letters and records to the insurance company for review. In some instances, a peer to peer review between physicians may occur.

What if the insurance company denies the appeal?

Individuals have the right to submit their own appeal to the insurance company. Sometimes it is appropriate to ask the CEO of their employer for assistance.

What if all appeals are exhausted and the insurance still will not agree to pay?

If the insurance company still does not approve, you will be given a contract to pay for the treatment.

For those who do not have insurance or who live outside of the United States

A financial contract of the estimated cost of the procedure will be prepared. The financial contract costs vary depending on what type of stem cell transplant is needed. Your financial coordinator will tell you the cost of your specific transplant. All contracts must be paid in full before any medical treatment can be given. Many people fundraise to help pay for the treatment. Please see Appendix ***Fundraising Ideas*** for additional resources and assistance.

For those who have Medicare or disability

- If you have **Medicare**, you may be eligible for immediate approval of stem cell transplant.
- If you receive **disability**, you are eligible to apply for Medicare after receiving disability payments for 24 months (even if you are not 65 years of age).

Step 4: Planning and Preparation

Staying in Chicago

Duration

The duration will vary for each patient depending on the disease, treatment plan and the response to the treatment. Your clinical research nurse will explain the expected length of stay for you and will provide you with a calendar. Below is a general guideline of expected length of stay:

Initial Evaluation (1-5 days)
*Lodging required

Pre-Transplant Testing (1-2 Weeks)
*Lodging required

Mobilization/Harvest Autologous SCT (10-14 days)
*Lodging required
Admission to the hospital for **one night only** to receive chemotherapy (cyclophosphamide infusion). For the remainder of the stay, appointments and procedures will be outpatient.

Stem Cell Transplant (approximately 16-21 days)
Patient will be hospitalized for the entire stem cell transplant admission. A caregiver is allowed to stay in the room with the patient. There is a pull-out couch to sleep on and showers available for use in the hospital. Upon discharge, patients will need to arrange for housing if not going straight home from the hospital.

Lodging Options

There are many lodging options including hotels and apartments that are close to the hospital. Many nearby hotels offer discounts for Northwestern patients. Please see "***Lodging***" in Section 5 for additional resources and assistance.

Parking

Parking is expensive in downtown Chicago. Unfortunately, Northwestern Medicine does not offer free parking. If possible, we recommend leaving your car at home and travel by plane, bus or train. If you do need to bring your car, you may try calling local parking garages for monthly rates.

Airfare

We recommend that you purchase refundable tickets or tickets that allow you to change your flight time without penalty in the event that your schedule gets changed.

Airports

There are 2 major international airports in the Chicago area:

- Chicago O'Hare International Airport (ORD)
- Chicago Midway International Airport (MDW)

For transportation between downtown Chicago and Airports

Cab: always available, no need to call in advance (approximately $40-$50 from O'hare and $30-40 from Midway)

Shuttle: Many hotels provide shuttles. Check to see if your hotel offers shuttle service. Call in advance to arrange for shuttle pick up

El (Chicago's subway train):

- O'Hare- Blue Line
- Midway- Orange Line

Getting Around Chicago

El/ Bus: Chicago has affordable public transportation. Visit Chicago Transit Authority on the internet to plan your trip.

http://www.transitchicago.com/

Cab: Fares are reasonable for short distances in the downtown area.

Weather in Chicago

Chicago weather can change quickly depending on the season. Summers are usually warm and humid during the day with temperatures ranging from 70-90 degrees Fahrenheit, however it can get cool and breezy in the evenings due to the wind off of Lake Michigan.

Pack a variety of clothes for changing temperatures. Winter weather can be extremely cold, with temperatures in the single digits. It also snows during the Chicago winter. If you are coming in the winter, make sure you bring a heavy coat, gloves, hat, scarf and shoes that can be worn in the snow. It rains during all times of the year. Make sure to bring an umbrella and raincoat.

> ***"If you're bringing a companion with you, make sure they have proper Chicago attire. For example, coats, hats, rain gear... an overcast day quickly turned into a river. I came back to the hospital and rang out my pants."***
>
> **- CIDP Patient Husband, Maryland**

What to Bring

- ID and insurance cards
- Any pertinent medical records
- Ambulation Devices if needed (wheelchair, walker, cane, AFO's)
- All medications in original bottles
- Thermometer
- Blood pressure cuff (if you take blood pressure medication)
- Any needed medical supplies (wound care or central line care supplies, foley catheters)
- Glasses if needed

Bath

- Electric razors only
- Any special toiletries (soap, shampoo, lotion, deodorant, toothbrush, toothpaste)
- Casual and comfortable clothing. We recommend dressing in layers due to varying temperatures in Chicago.

Comfort

- Comfortable shoes
- Several pairs of socks
- Slippers (non-slip)
- Front-buttoning pajamas
- T-shirts (loose fitting)
- Lounge pants/ shorts (loose fitting)
- Undergarments
- Head cover ups (scarves, hats, wigs)
- Things that make you comfortable, such as pictures of family members or friends, your favorite blanket or pillow

Leisure

- Laptop, iPad
- Cell phone and charger
- iPod, MP3 player
- Books, magazines, cards, games
- Yarn/ needle work
- Drawing/ art supplies

Things to leave at home

- Valuables (ex. jewelry)
- Disposable razors
- Fingernail clippers
- Tampons (sanitary pads are fine)
- Plants/ flowers
- Cigarettes/ cigars/ e-cigarettes
- Smokeless tobacco
- Cologne/ perfume/ body spray

> ***"You can wear your own clothes while inpatient, so bring several changes of whatever comfortable clothes you prefer."***
>
> **- Multiple Sclerosis Patient, Idaho**

Child Care

It is not recommended to have small children under the age of 12 visit during the hospital stay. Children are not allowed to spend the night in the hospital rooms. Many people ask family members or friends to help watch their children.

Staying in Touch

Many people use online resources such as Skype or Facetime to keep in touch with loved ones while in the hospital.

Internet

Free Wi-Fi is available at Northwestern Medicine.

Home Care/ Pet Care

Many people ask family members, neighbors or friends to check in on their home, mail, plants, etc. while they are in Chicago. Please arrange for someone to take care of your pet.

Primary Care Physician

We recommend that all patients have an established relationship with a primary care physician. It will be important to have a local physician after stem cell transplant to provide follow up care.

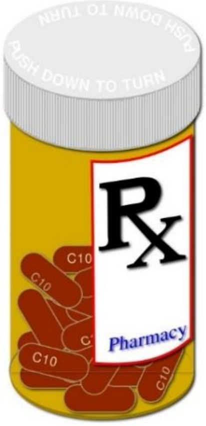
Interpreter

If you prefer communicating in a language other than English, there are interpreter services available to translate during medical consultation.

Medications

Please bring an updated list of all of your medications to all appointments and to hospital admissions. Please include the name of the medication, the dose and the time of day that the medication is taken.

Please bring all of your medications in their original bottles. If one of your medications is not on formulary at Northwestern Medicine, you will be able to take your own medication as long as it is in the original bottle and can be identified by the pharmacist.



Advance Directives

Advance directives, also known as a Living Will or Durable Power of Attorney, are legal documents in which outline your choices for medical treatment or assign someone you trust to make decisions for you in the event that you are unable to make decisions for yourself.

An Advance Directive is not required; however, you may want to discuss your wishes with your family in the event that you are unable to make your own decisions. If you have an Advance Directive, please bring a copy of the documents to your hospital admission.

Medical/ Mobility Devices

If you require any special medical equipment or mobility devices and are unable to bring the equipment with you, please discuss with your research nurse in advance options for obtaining any equipment you may need.

Dental

The mouth can be a source of infection during and after transplant. While a dental evaluation will be obtained as part of pre-transplant testing, we recommend that you are seen by a local dentist for a thorough examination for any cavities, gum disease, or oral infections prior to coming. Dental cleanings and repair or removal of any decayed teeth should be done prior to transplant.

Smoke Free

Northwestern Medicine is a smoke free campus. If you are a current smoker, our goal is to help you quit the habit. In addition to causing several cancers, smoking weakens your immune system and can exacerbate many autoimmune diseases. By stopping the use of tobacco, you will lessen your risk of developing a pulmonary or infectious complication during stem cell transplant. You will also improve your overall health and quality of life.

We are committed to helping you succeed at quitting. Please inform your research nurse if you need assistance. We can provide medications that help manage nicotine withdrawal. If your reasons for smoking are emotional stress, anxiety or depression, we can help get you appropriate counseling or resources.

Please do not bring cigarettes, cigars, smokeless tobacco, e-cigarettes, or vaporizers to the hospital.

Financial Resources

We recognize that medical care, travel, lodging and the cost of living in Chicago can be expensive and cause a financial burden for some families. Many families arrange fund-raising efforts in order to help cover the costs of living and medical expenses not covered by insurance. Please see ***"Fundraising Ideas"*** in Section 6.

Leave of Absence/ Family Medical Leave/ Disability Papers:

We will provide letters for leave of absence or sign papers for work time off needed during the stem cell transplant process. Please contact your employee human resources department in advance to ensure that all procedures are followed. Please allow 2 weeks for paperwork to be filled out and returned.

The Role of the Caregiver

While not required, we highly recommend that you have at least one family member or friend who is able to be a caregiver for you. Many people arrange to have multiple caregivers over the course of the transplant process. If you require assistance with transportation or have special care needs, it is important that you arrange for someone to accompany you to Chicago.

Common caregiver roles and responsibilities:

- Make arrangements
- Accompany to appointments
- Assist with transportation to different testing facilities
- Help with administration of medications and injections
- Care for PICC line (if required)
- Identify changes in condition
- Provide emotional support
- Participate in patient education and ask questions
- Keep family and friends up-to-date
- Maintain a safe environment

During your admission for stem cell transplant, your caregiver will be able to stay with you in your room if you choose. Each room has a sofa that pulls out into a bed.

Fertility

One of the potential risks of chemotherapy for both males and females is becoming infertile. This could be a temporary or permanent complication of chemotherapy. Several factors including age, type of chemotherapy, dose of chemotherapy and history of previous chemotherapy all play a role in determining the risk of becoming infertile.

Below briefly outlines options for fertility preservation in males and females prior to receiving chemotherapy. If you would like additional information, it is recommended to make an appointment to speak with a fertility counselor at a local fertility center. We can also arrange for you to see a fertility specialist at Northwestern Medicine.

More information can be found at: https://oncofertility.northwestern.edu/

Fertility Preservation Options for Males

Sperm banking: Services are available around the country for men who are mature for ejaculation. Sperm are collected and frozen.

Testicular Sperm Aspiration: Surgical removal of testicular tissues that contain sperm which are frozen.

Fertility Preservation Options for Women

Oocyte Cryopreservation: Hormones are administered to stimulate ovulation. Eggs are removed, frozen, and stored unfertilized. Later, the eggs can be implanted back into the uterus.

Embryo Cryopreservation: This usually takes place at a reproductive center. Women are administered hormones to stimulate ovulation. The eggs are then removed surgically and fertilized with a partner or donor's sperm. The fertilized egg is then frozen and stored for future implantation into the uterus.

Psychosocial Evaluation

Deborah Zuskar, Ph.D

Dr. Zuskar is a clinical psychologist trained at the University of Illinois and Northwestern Medical School who has over thirty years of experience working with anxiety, depression, and other stress-related symptoms in individuals and families. In more recent years, she has been focusing on medically ill populations where the challenges of everyday living are greatly multiplied.

Dr. Zuskar is available to HSCT patients before the procedure to consult about the decision making and preparation process. She is also available during transplant for support and intervention as desired, as well as after discharge to facilitate emotional recovery.

It is helpful to contact your insurance company ahead of time to find out if Dr. Zuskar is in-network. Additionally, some insurance companies may require a psychosocial evaluation prior to approving stem cell transplant.

Contact information:
McClurg Court
333 E. Ontario
24th floor Ste 2411B
Chicago, IL 60611
(312) 440-1115

Step 5: Pre-Transplant Testing

A. Pre-Transplant Testing for Patients

Pre-transplant testing is a medical evaluation that includes a series of tests, blood work and specialty appointments that must be completed before proceeding with stem cell transplant. All of the testing will take place at Northwestern Medicine in Chicago and could take up to two weeks to complete. The purpose of the evaluation is to identify any potential contraindications to the study and/or any underlying medical conditions that could make it unsafe to proceed. In addition, baseline assessments are obtained which are used to evaluate outcomes after stem cell transplant.

B. Randomization (if required)

Patients who qualify and who have a disease that is treated on a randomized trial will be blindly selected to receive either the treatment arm or the control arm. Not all protocols are randomized. Please ask your research nurse for more information.

Stem Cell Transplant vs. Standard Therapy

Some randomized studies compare stem cell transplant (treatment arm) to standard therapy (control arm). In this case, all individuals randomized to receive standard therapy can crossover to the treatment arm after one year if the disease progresses on standard therapy.

Difference in Conditioning Regimen

Some randomized trials compare two different types of stem cell transplants. The difference between the control arm and the treatment arm is the conditioning regimen or type of stem cell (autologous or allogeneic). Both arms receive treatment with a stem cell transplant.

Randomization Details

- Randomization occurs after pre-transplant testing is complete.
- Randomization is performed blindly by a statistician who will not know the name or any information about the patient.
- Each patient has a 50% chance of being randomized to either arm.
- Patients will be notified of which arm they receive after the randomization is complete.

C. Tests/ Procedures:

Tests and procedures are also explained in the consent form. DIAD administrative assistants will help you coordinate these appointments at Northwestern.

All patients will complete the following tests as part of pre-transplant testing:

Chest X-Ray

A painless, non-invasive test that takes a radiographic picture of the structures in the chest including the heart, lungs and blood vessels.

EKG

A painless, non-invasive test to look at the electrical rhythm of the heartbeat. This test looks for abnormalities such as a cardiac arrhythmia or heart condition.

Pulmonary Function Test (PFT)

A painless test that measures lung function in which you inhale and exhale through a tube. It measures how well the lungs pass oxygen from the air into the blood (diffusion capacity) and the volume and speed that air can be inhaled and exhaled in one breath (spirometry).

2D Echocardiogram with Doppler

A painless test that uses sound waves (ultrasound) and a computer to look at how various parts of the heart function while you lay on an exam table for approximately 30 minutes.

Laboratory Blood Tests

This will include a basic metabolic panel (BMP) which looks at the kidney function, complete blood count (CBC), coagulation studies (PTT/INR) and Liver Function Tests (LFT). Viral blood tests will also be checked including HIV, hepatitis studies, herpes simplex virus (HSV), varicella zoster (VZV) and cytomegalovirus (CMV). Blood tests specific to your disease such as certain antibodies, immunoglobulin studies and genetic testing may also be checked. Thyroid studies, cholesterol levels and anemia panels will be checked if needed. A urine sample will check for signs of infection or kidney disease. For females, a pregnancy test will be checked.

Dental Evaluation

A consultation to evaluate for cavities, oral infections, or treatments needed prior to stem cell transplant. If you have dental coverage, you may be able to see your local dentist. Your dentist will need to fill out clearance form, available from your research nurse.

Vein Check

An appointment and evaluation at the Blood Center, the facility that collects/ harvest the stem cells after mobilization. The appointment is required within 30 days prior to stem cell mobilization and will take 30-60 minutes. Patients will meet with a nurse in the Blood Center to discuss the stem cell harvest procedure and to fill out paperwork.

Additional Test/ Procedures:

Your research nurse will advise you which of the following tests/ procedures you will need based on your disease state.

Dobutamine Stress Echo

In some instances, this type of echo will be needed in addition to the 2D echo. In the test, the heart will be stressed with a medication called dobutamine which increases the heart rate. This test looks for evidence of heart blockage.

CT Scan Sinus

A painless procedure that requires the ability to lay flat for approximately 5 minutes while an x-ray takes a picture of the sinuses to check for infection. This test will be completed for individuals who are on chronic steroids or who have a history of sinus infections.

Muscle Biops

A procedure in which a small piece of muscle is removed for examination. A local anesthetic will be used to numb the area of the biopsy. This test will help in determining the cause of muscle weakness.

MRI Brain/ Spine

This study uses structural magnetic resonance imaging (MRI) to visualize the brain and spinal cord. Magnetic resonance imaging is a type of brain and spinal cord scan that uses magnetic fields and radio waves to produce a picture of the brain and spinal cord’s anatomy.

Magnetic Resonance Imaging (MRI) of Abdomen and Pelvis

This study uses structural magnetic resonance imaging (MRI) to look at the abdomen and pelvis. MRI is a type of scan that uses magnetic fields and radio waves to make a picture of the abdomen and pelvis in order to find out if there are any changes in structure of organs in your abdomen and pelvis such as infection or tumor.

MR Cardiac

During a MRI, structural magnetic resonance imaging will be used to visualize the heart. Magnetic resonance imaging (MRI) is a type of scan that uses magnetic fields and radio waves to produce a picture of the heart’s anatomy.

Electromyography (EMG)

EMG is a diagnostic procedure to assess the health of muscles and the nerve cells that control them (motor neurons). An EMG uses tiny devices called electrodes to transmit or detect electrical signals. During a needle EMG, a needle electrode inserted directly into the muscle records the electrical activity in that muscle. EMG results can reveal nerve dysfunction, muscle dysfunction, or problems with nerve-to-muscle signal transmission.

Nerve Conduction Velocity (NCV)

NCV (another part of an EMG) uses electrodes taped to the skin (surface electrodes) to measure the speed and strength of signals traveling between two or more points.

Lumbar Puncture (Spinal Tap)A procedure in which a needle is inserted into the lower part of the spinal canal to withdraw cerebrospinal fluid (the watery liquid that surrounds the brain and spinal cord) so that it may be examined to diagnose and investigate disorders of the brain and spinal cord. The procedure takes approximately 20 minutes to perform. Local anesthetic is used.

Swallow Study

A procedure in which you will be asked to swallow several different materials including liquid contrast (barium), soft food, and harder food. Doctors and technicians will use a fluoroscopy (a type of x-ray machine) in order to assess the function of your throat.

Colonoscopy

A standard technique for evaluating bowel that entails the placement of a long tube through the anus. Biopsies are performed as dictated by the findings.

Upper Endoscopy

A procedure that entails the placement of a long flexible tube through the mouth to allow viewing of the GI tract. Biopies are performed as dictated by the findings.

24 Hour Urine Collection

A common test that analyzes the urine to see how well your kidneys are working.

High-Resolution Computed Tomography of the Chest (HRCT)

HRCT is an x-ray procedure where a high-speed computer is used to make multiple images or pictures of your chest.

CT Enterography of the Abdomen

CT is an imaging study that is used to visualize the separate organs and structures inside the body. CT enterography combines a CT scan with oral contrast (solution that you drink to help the inside of your bowel to become visible on the CT images). This helps determine a diagnosis and potential therapies that may be used in your treatment.

Right Heart Catheterization

A test performed to determine how well the heart is pumping and to measure the pressures in the heart and lungs.

Bone Marrow Biopsy

The removal of a sample of bone marrow and a small amount of bone through a large needle. Two samples are taken. The first is bone marrow by aspiration (suction with a syringe). The second is a core biopsy to obtain bone marrow along with bone fibers. After the needle is removed, this solid sample is pushed out of the needle with a wire. Both samples are examined under a microscope to examine the cells and the architecture of the bone marrow

Allergy Testing

A procedure used to identify specific cause of allergies. This test will assist in determining which medication a patient may receive and which should be avoided. Please let us know of any known drug allergies (ex. allergic to penicillin).

Step 6: Stem Cell Mobilization

What is stem cell mobilization?

The purpose of stem cell mobilization is to prepare the body for collection of stem cells. Normally, the bone marrow releases only a small number of stem cells into the peripheral blood circulation. In order to obtain enough stem cells in the blood to harvest for a stem cell transplant, certain medications are used to encourage the movement (or mobilization) of stem cells from the bone marrow into the peripheral blood so they can be collected.

Does the mobilization procedure differ for autologous and allogeneic stem cell transplants?

- Yes. This section will discuss mobilization for autologous stem cell transplants only.
- In allogeneic matched sibling stem cell transplants, the **donor** will undergo stem cell mobilization. Please see "***Stem Cell Donor Information***" in Section 6 for more information.

What Medications are used for Mobilization?

Cyclophosphamide **(Cytoxan)**	• A chemotherapy drug that is an alkylating agent and immunosuppressant. • The medication is infused intravenously (through an IV) • Cyclophosphamide suppresses the immune system and helps mobilize stem cells out of the bone marrow into the peripheral blood. • The infusion will require a 24 hour stay in the hospital. • The cyclophosphamide infusion will take 2 hours, however IV fluids and a medication called **mesna** will infuse through an IV for a total of 24 hours. Mesna is a medication that helps protect the bladder (see side effects below). • The dose is based on weight and height.
G-CSF (Granulocyte colony stimulating factor) **Neupogen**, TBO- filgrastim (**Granix**)	• G-CSF is used to treat **neutropenia**, or low neutrophils. It also helps mobilize stem cells into the peripheral blood system for collection. • G-CSF is given as a subcutaneous injection. The needles used to give the injection are very small. • The medication will start five days after receiving the cyclophosphamide and will continue daily until the stem cell harvest is complete. • The dose is 5-10 mcg/ kg • **Must be kept in the refrigerator until ready for use.**

How long does it take for the stem cells to mobilize and be ready for harvest?

- 5 days after starting neupogen and 10 days after the cyclophosphamide infusion

What are the side effects of cyclophosphamide?

- Nausea: This is the most common side effect, however some people do not experience any nausea. Nausea medications (antiemetics) will be given prophylactically before the infusion to try to prevent or control severe nausea from occurring. Additional nausea medications will be available as needed. If nausea occurs, it should resolve 24-48 hours after receiving the cyclophosphamide.

- Neutropenia: Cyclophosphamide will cause temporary neutropenia which can make one more susceptible to infections. Prophylactic antibiotics will be given to try to prevent any infections from occurring.

- Alopecia: This word means hair loss. Hair loss will occur approximately 14 days after receiving cyclophosphamide. Hair will start to grow back about three months after your last dose of cyclophosphamide.

- Wasabi Nose: Some people experience a burning sensation in their nose and watery eyes during the infusion. This sensation is often relieved by slowing down the rate of the infusion.

- Headache: Some people complain of a headache after receiving cyclophosphamide. The headache is often due to the side effects of the medications that prevent nausea.

- Constipation: This often occurs due to the side effects of the medications that prevent nausea. When you are not in the hospital, we recommend you take over-the-counter stool softeners daily.

- Diarrhea: This may occur from the chemotherapy and can be treated with anti-diarrhea medications (Imodium).

What are the risks of Cyclophosphamide?

- Hemorrhagic Cystitis: As it is excreted through the urine, cyclophosphamide can adhere to the bladder lining and cause bleeding and inflammation. Symptoms may include: urinary frequency, urgency, pain, or blood in the urine. Fortunately, this is a rare complication because of a medication called **mesna**, which helps keep the cyclophosphamide from adhering to the bladder lining. Mesna is infused for a total of 24 hours, beginning 2 hours before the cyclophosphamide infusion. In addition to mesna, IV hydration with normal saline and a medication named **Lasix** is given. Lasix is a diuretic that causes urination. The IV hydration and Lasix helps keep the bladder flushed, helping to prevent hemorrhagic cystitis.

- Infertility: Inability to have children may be an effect of cyclophosphamide. Please see ***"Risks of Stem Cell Transplant"*** in Section 2.

- Teratogenicity: If you are pregnant, cyclophosphamide is contraindicated as it may cause impaired organ development in your fetus. Make sure you inform your doctor and research nurse if there is any chance you could be pregnant.

- Infections: Infections may occur as a result of immune suppression and neutropenia that occurs from cyclophosphamide. Antibiotics are given to protect from infections.

What are some common side effects of G-CSF?

- Bone Pain: usually occurs 24-48 hours prior to stem cell harvest in the hips, thighs, lower back or sternum and resolves within 24 hours after last injection
- Generalized flu-like symptoms
- Low grade fevers (99.0-100.3)
- Nausea
- Headache

Do I have to stay in Chicago between the cyclophosphamide infusion and the stem cell collection (harvest)?

Yes. It is necessary to remain in the Chicagoland area, preferably close to the hospital. 7-8 days after receiving cyclophosphamide, your neutrophil count will drop and neutropenia (low neutrophil count) will occur for 24 to 72 hours. Neutrophils are responsible for fighting off harmful bacteria. There is a higher risk of acquiring an infection as your counts drop. In the case that a fever or infection occurs, it will be necessary to seek immediate treatment at the emergency department at Northwestern Medicine.

What to bring to Mobilization

- ID and insurance cards
- Any pertinent medical records
- Ambulation Devices if needed (ie: wheelchair, walker, cane, AFO's)
- All medications in original bottles
- Thermometer to use after discharge while in hotel
- Blood pressure cuff (if you take blood pressure medication) to use after discharge while in hotel
- Any needed medical supplies (ie: wound care or central line care supplies, foley catheters)
- Acetaminophen (Tylenol) 325mg tabs to use after discharge if needed
- Over the counter stool softeners to use after discharge if needed

What to Expect during Stem Cell Mobilization (for Autologous Stem Cell Transplant)

- Admission to Prentice Hospital for 24-32 hours.
- Upon admission to the hospital, a height and weight will be obtained. An IV will be inserted and blood will be drawn.
- IV fluids and mesna will infuse through the IV for a total of 24 hours.
- A foley catheter may be necessary during hospitalization.
- Lasix will be given every 8 hours. This medication will cause frequent urination.
- Intake and Output will be measured-the amount of fluid that is taken in orally and through the IV and the measurement of urine output.
- Approximately 1.5- 2 hours after the IV fluids and mesna start, pre-medications to prevent nausea and vomiting will be given.
- 30 minutes after taking the pre-medications, cyclophosphamide will begin and will run for approximately 2 hours.
- Discharge from the hospital will happen after the IV fluids and mesna run for 20-24 hours.

Discharge Instructions after Mobilization

- 5 days after receiving cyclophosphamide, you will begin daily G-CSF injections, an antibiotic, and an antifungal.
- **G-CSF injection**- G-CSF comes in pre-filled syringes. Syringes may vary in appearance and **must be kept in a refrigerator**. Remove syringes from refrigerator 20 minutes prior to injection.
- It may be called Granix (tbo-filgrastim) or Neupogen (filgrastim). These are different variations of the same medication. Your dose is determined based on your weight. You may be required to take one, two, or three injections daily. All daily injections should be given at 7am.

- **Antibiotic**- Ciprofloxacin 500mg, one tab twice daily. One tab with breakfast, one tab with dinner.
- **Antifungal**- Diflucan 200mg, two tabs daily. Both tabs with breakfast.
- **Anti-nausea**- Zofran 8mg, one tab every 8 hours as needed for nausea
- **Pain**- Norco 10/325mg, one tab every 4-6 hours as needed for bone pain

- Labs will be drawn 1 week after receiving cyclophosphamide. Additional lab draws may be needed.
- 7-8 days after receiving cyclophosphamide, your white blood cells will drop. Platelets and red blood cells may also drop during this time.
- 10 days after receiving cyclophosphamide, stem cell harvest will occur as long as the blood counts are high enough.
- The morning of harvest, a temporary catheter will be placed in interventional radiology department for use during the harvest procedure.

How to inject G-CSF

1. Wash hands.
2. Remove syringe from packaging.
3. Determine abdominal site where injection will be given. Rotate site daily.
4. Clean site with alcohol swab.
5. Carefully pull needle cap straight off. Do not let anything touch the needle.
6. Holding the syringe like a pencil with one hand, use your other hand to pinch a fold of skin at injection site.
7. Insert needle into skin and use thumb to slowly push plunger until all medication is injected.
8. When all medication is injected, needle guard will deploy and needle will be removed from skin.
9. Apply pressure to injection site with gauze. May use band aid if necessary.
10. Place used syringes in an empty plastic container strong enough that needles will not poke through. For safe disposal, clearly label "Sharps- Not for Recycling" and seal before disposal.

When to call the office or go to the Emergency Room

- Take your temperature twice a day.
- Page the office IMMEDIATELY for a fever of **100.4** or higher. It may be necessary to go to the Emergency Department at Northwestern Medicine to receive IV antibiotics.
- Go to the Emergency Department for chest pain, severe diarrhea, severe vomiting, shortness of breath or any other concerning symptoms. Notify DIAD of any emergency room visits right away.

Activities / Restrictions after Mobilization

Diet/ Cooking

- No restrictions on specific foods, but avoid food that may be contaminated (salad bars, delis where food has been sitting out)
- Wash all fruits and vegetables. Use separate cutting boards for raw meats.
- Wash your hands immediately after handling raw meats.
- Avoid raw foods (eggs, meats, fish).

Fluids

- Make sure to drink plenty of fluids. Aim for 1-2 liters per day.

Movies/ Shopping/ Recreational Activities

- No restrictions, but try to avoid going during highly congested times.

Walking/ Stairs/ Exercise

- No restrictions. Perform as tolerated.

Driving

- Avoid driving while taking medications that cause drowsiness.

Other Instructions

- Avoid sick contacts and large crowds for the next two weeks.
- Remember to wash your hands often.

> ***"When we were making a decision on which HSCT treatment provider we were going to pursue, Dr. Burt and his team really stood out as being highly professional and I felt confident that they had my health and best interests at heart. This was confirmed to me during my time in hospital when I experienced the expertise, medical care and reassurance that everything was going to plan, even during the toughest times in my treatment. It was also reassuring to know that when I wasn't in hospital and I was exploring Chicago that Dr. Burt and his team were only a phone call away if I needed them."***
>
> **- Multiple Sclerosis Patient, New Zealand**

Step 7: Stem Cell Harvest

- The stem cell harvest usually occurs 10 days after receiving cyclophosphamide, as long as the blood counts are high enough.
- It is important to remember to take G-CSF in the morning before the VASCATH placement. It may need to be given early.

VASCATH Placement:

You will need to have a central catheter (VASCATH) placed for the collection of your peripheral blood stem cells. It will be placed the morning of the stem cell harvest and removed when your harvest is complete. The catheter typically has two large bore lumens used to collect your stem cells, draw blood and give IV medication if needed. It is placed in a large vein in your neck that leads to your heart (see picture above). You will be given a local anesthetic before the procedure. It may feel uncomfortable, but should not cause severe pain or discomfort.

The procedure takes place in **Interventional Radiology** (4th floor Feinberg Pavilion).

Prior to your apheresis you will want to do the following:

- Have something to eat, try to focus on foods high in Calcium (milk, cheese, etc).
- Take your prescription medication as prescribed, unless you were instructed otherwise.
- Empty your bladder.

Stem Cell Harvest Procedure

After your catheter has been placed, you will need to proceed directly to the Rube Walker Blood Center, located on the 11th floor of the Galter Pavilion. They will draw lab work. Lab work will include a CBC, Chemistry panel and a CD34 count which will help predict how many stem cells you will collect.

Stem cell harvest is also referred to as apheresis. Apheresis is done by connecting IV tubing from your VASCATH to a machine where the peripheral stem cells are separated and collected. The remaining blood components (white blood cells, red blood cells and platelets) are returned to you through another lumen of your VASCATH.

- Apheresis typically takes 3 to 6 hours
- Goal is to collect ≥ 2 million/ kg CD34 stem cells
- If you do not collect the needed amount of stem cells on your first day, you will return the next day to repeat the process.
- Once the stem cells are collected, they are stored by means of **cryopreservation**, a freezing storage technique, until the time of transplant.

The process is generally well tolerated. During the process, you will sit in a recliner and may watch television, read books, use your laptop computer and/or rest. There is internet access available. You may have a friend or family member with you during the harvest. You will be allowed to eat and drink during the harvest. A member of the transplant team will come visit you to complete a physical examination, review your lab work, answer questions/ concerns, explain the process to you and give you instructions.

Harvest Machine

After Stem Cell Harvest Procedure

Once your stem cell target goal is obtained, your VASCATH will be removed. A small dressing may be placed over the insertion site. Please leave the dressing on for 24 hours, and then you may remove it. You will need to report to your nurse or physician if there is swelling, pain, redness, or drainage at the insertion site. There are no activity or diet restrictions following the procedure.

Risks of VASCATH Placement:

Potential complications include clotting in or around the line, bleeding, air or blood around the lung, or changes in heart beats that could lower your blood pressure. The catheter or line may become infected and require treatment with antibiotics and/or removal.

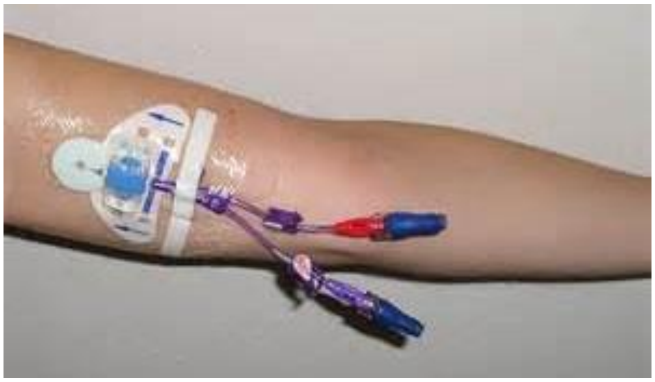
Risks of Apheresis:

The most common complication of apheresis is low calcium caused by the blood thinner used during the procedure. Symptoms of low calcium are usually mild (numbness in the lips and fingers) but may be moderate (cramping in the arms and legs) or rarely severe (nausea, vomiting, or seizure). Such problems can be avoided or minimized with replacement of solutions added during the procedure, slowing the flow rate, and replacing calcium by mouth or IV. If you experience discomfort at your central line site, you may be given Tylenol. Other complications may include fatigue, low blood pressure, fainting, or infection.

Step 8: Stem Cell Transplant Admission

A. Conditioning

The day before your admission, you will have a Peripherally Inserted Central Catheter (PICC) placed in interventional radiology (Feinberg 4th Floor). It will be a triple-lumen PICC line and will be used for IV hydration, medications (chemo, antibiotics, steroids, etc.), blood product infusions, and stem cell infusion. It will also be used for blood draws while in the hospital. The PICC will be removed prior to discharge.



(Note: this is a double-lumen PICC)

The conditioning regimen refers to the chemotherapy and immunosuppressant drugs that are given at the beginning of the transplant admission. The conditioning phase will take place 5-8 days before the stem cell infusion and sometimes the day after the stem cell infusion depending on the disease specific protocol. The regimen has been carefully designed for your specific disease. The purpose of the conditioning regimen is to fully suppress the immune system and to stop inflammation.

The registered nurses who will give your chemotherapy have all been specially trained and certified to administer chemotherapy. The nurses are knowledgeable about common side effects and potential complications of chemotherapy. Below are common medications that are administered as part of the conditioning regimen.

Common Medications to Prevent Nausea

- Zofran
- Ativan
- Compazine
- Marinol
- Kytril
- Emend
- Dexamethasone
- Reglan

Conditioning Regimen Medications

Autologous SCT	Cyclophosphamide Mesna Anti-thymocyte globulin (rATG) Fludarabine (for some regimens) Rituximab (for some regimens) Campath (for Crohn's only)
Allogeneic SCT	Cyclophosphamide Mesna Fludarabine Campath

Pre-Medications

Cyclophosphamide Pre-meds	Zofran Ativan Dexamethasone Emend
rATG Pre-meds	IV Solumedrol (1000mg) Tylenol Benadryl
Rituximab Pre-meds	IV Solumedrol (250mg) Tylenol Benadryl
Campath Pre-meds	IV Solumedrol (1000mg) Tylenol Benadryl Zantac Claritin Chlorpheniramine Singulair
Fludarabine Pre-meds	Nausea medications as needed

B. Stem Cell Reinfusion

After conditioning, you are ready for transplant (often referred to as "Day 0"). The infusion, or transplant, is done very much like a blood transfusion. The infusion will be done in your room. Your nurse, a member of the cell therapy team and either Dr. Burt, a nurse practitioner, or physician assistant will be present. Family and friends are welcome. You may also request that a Chaplain bless the cells prior to the infusion.

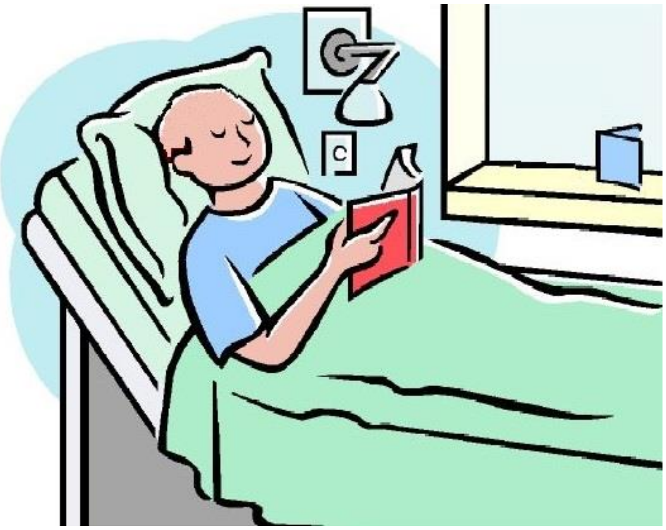
Prior to the infusion, you will take pre-medications which include Benadryl and hydrocortisone to prevent a reaction. The stem cells are mixed with a preservative prior to freezing that keeps the cells nourished and healthy while frozen. In some patients, this preservative causes bothersome side effects such as a flushing sensation, a tickle sensation in the back of your throat, blood pressure fluctuation, nausea, or headache. The pre-medications help prevent or lessen these potential side effects. Your nurse may also adjust the infusion rate to lessen the side effects.

Your vital signs will be monitored during and after infusion. Your stem cells will be brought to your room by the cell therapy team and thawed prior to the infusion. The stem cells will be infused through your PICC line as you are resting in bed. The infusion process takes 20 to 30 minutes. You may feel tired due to the pre-medications, but should not have any significant side effects from the reinfusion.

There is a risk that your stem cells will be contaminated during the collection procedure. The contaminated blood product could cause a serious, life-threatening infection or other unwanted reactions when they are returned to you. Care will be taken to prevent any problems that could cause contamination.

> ***"The time in hospital, I took as a vacation. There was a lot of time to sleep and get rest. I tried to eat well before the procedure as I knew that appetite is not good in time of chemotherapy, so I wanted my body to be strong through the whole process. The hardest days were two days after the day of transplant. That day is called your second Birthday. So the next day, I assume I had a terrible hangover after the birthday party."***
>
> **- Multiple Sclerosis Patient, Ukraine**

C. Waiting for Engraftment



Engraftment is when your bone marrow recovers from the conditioning regimen and the new stem cells start to grow or engraft. The waiting time is a little different for everyone, so it is not possible to predict the exact day. For autologous stem cell transplants, engraftment usually occurs 9-12 days after the stem cell infusion. In allogeneic stem cell transplants, engraftment may take a little longer, but will likely occur 12 to 20 days after the stem cell infusion.

Patients will become neutropenic sometime around day 0, give or take a couple of days. It is expected for white blood cells (WBC) and absolute neutrophil counts (ANC) to drop to <0.1. During this time, platelet and hemoglobin counts will also drop, which is also expected. This is the period when blood transfusions may be needed.

The first sign of engraftment is when counts start to rise. This usually happens very suddenly and rapidly. It is expected that counts will not gradually rise, but rather remain at <0.1 until the time of engraftment, and then will rise quickly, usually within 24 hours. A daily log of blood counts will be posted on the door in the room.

What to Expect While Waiting for Engraftment

This is the time when patients are most susceptible to infections because they do not have any white blood cells or neutrophils to fight off invading pathogens. Patients are at higher risk of developing viral, fungal and bacterial infections. Patients will be on antibiotics during this time to help prevent these infections from occurring. Patients can expect to be started on the medications listed below:

- <u>Antiviral</u>: Acyclovir or Valacyclovir (starts on admission)
- <u>Antifungal</u>: Fluconazole or Voriconzole (starts on day +2)
- <u>Antibacterial</u>: IV Cefepime or IV Zosyn are first choices, but may be altered for patients with drug allergies (starts when counts begin to drop or on day 0)

Other expected supportive care during this time includes electrolyte replacements and blood transfusions as needed.

Possible complications include nausea, vomiting, fever, reactions to medications, blood transfusion reaction.

While waiting for engraftment, often patients may have several concerns or feelings:

- Fear, of not having a fully functioning immune system
    - The physicians, nurse practitioners, physician assistants and nurses have a lot of experience with stem cell transplant and will monitor you closely for any signs of infection. Medications (such as antibiotics) will be initiated as a precaution when blood counts start to drop.
- Worry, that the transplant did not work
    - The recovery and healing time after stem cell transplant is 6 months to 12 months. While you may notice some changes in your disease symptoms right after the stem cell transplant, it will take time for your body to heal.
- Fatigue
    - This is a common feeling and may occur as a side effect from some of the medications and also because you will be neutropenic. Your energy level will return to baseline after the stem cell transplant is complete, however it may take a few weeks to feel back to baseline.
- Difficulty Sleeping
    - Patients often have difficulty sleeping while in the hospital for multiple reasons: being away from their own bed, from side effects of medications, from interruptions during the night for medication administration and vital sign monitoring.
- Emotional Stress, from being away from your family or children
    - Some patients have found it helpful to have scheduled phone conversations once a day, or to communicate through Skype or Facetime.

> ***"Fight hard to not allow the disease to change your lifestyle, rather let your lifestyle change the disease. Keep a positive attitude!***
>
> ***Regarding Dr. Burt and his team: I never worried throughout the HSCT process. I knew I was in the right place."***
>
> **- Systemic Sclerosis Patient, New Hampshire**

- Boredom, from being in the hospital for several days
  - We often tell patients that boredom is a good thing! That is a sign that you are feeling well and likely are having an uneventful day.
- Disappointment, if your body does not respond the way you expected
  - Know that everyone is different. Some are more sensitive to the side effects of medications than others. Some require more blood transfusions than others. Some engraft much earlier than others. There is nothing you can do to change the way your body responds to the treatments. There are things you can do to help prevent complications:
    - Wash your hands thoroughly and often.
    - Eat meals upright in chair.
    - Stay active! You will be given a daily log to post in your room. This will help everyone keep track of your activity (working with PT/ OT, walks around the unit, exercises with bands).
    - Getting out of bed as much as possible helps expand the lungs (prevent pneumonia) and improve circulation (prevent blood clots).
    - **When getting out of bed, sit on side of bed for 1 minute. If you do not feel dizzy, stand up next to bed without moving for 20 seconds. If you feel dizzy or lightheaded, sit down and call your nurse. If you do not feel dizzy after 20 seconds, you may walk.**

> ***"I tried to move a lot, I was getting tired very fast, but it was expected. My condition was monitored very carefully and I tried to inform doctors about everything I felt. I was calm that doctors were aware about my condition and they were probably 100 steps ahead. Now, stem cell transplant is like a common cold treatment or a flu shot."***
>
> **- Multiple Sclerosis Patient, Ukraine**

All of these concerns and feelings are common during transplant. Often one of the most helpful methods of coping with these feelings is to develop a schedule that provides some structure to the day, and to also distract your mind by keeping busy.

Below is a list of things that you can do while in the hospital:

- Exercise
    - Walk in the halls 2-3 times a day
    - Exercise/ spin bike
    - Work with physical/ occupational therapy
    - Yoga
- Read a book or magazine
- Talk to the hospital chaplain
- Listen to music
- Play cards or a game
- Puzzles
- Meditate
- Surf the internet
- Write a letter
- Draw, paint
- Knit, crochet, needlepoint

Resources Available During Stem Cell Transplant:

- Physical Therapy/ Occupational Therapy
- Rehabilitation Institute of Chicago (RIC)
- Nutritionist
- Chaplain
- Psychologist
- Social Work

> ***"Get out of bed every day and walk, even if you feel sick. Walk, spin, find a way to be active. Keep moving. Keep doing this even when you get home from the hospital. It will help you feel better. The days I made myself move around were the days that went the best."***
>
> **- Multiple Sclerosis Patient, New Mexico**

Step 9: Discharge

Each patient varies in how long it takes to recover from transplant. The following criteria must be met for you to be discharged:

- WBC/ ANC > 1
- Platelets > 20,000, stable, and increasing without infusions
- Hemoglobin > 8, stable, and increasing without infusions
- No fever
- Bone pain controlled

Once you are discharged from the hospital, it is safe for you to fly home the same day.

What to Expect When Returning Home

Medications for Autologous Transplant:

Acyclovir 400 mg tabs (anti-viral, protects from viruses such as shingles and herpes)
Take 1 tab by mouth twice a day for 12 months

Fluconazole 200 mg tabs (anti-fungal)
Take 2 tabs by mouth daily for 3-6 months

Bactrim DS (protects from PCP pneumonia)
Take 1 tab by mouth every Monday, Wednesday, Friday for 3-6 months

You may also be prescribed:
Alpha Lipoic Acid 200 mg (this may help with pain from nerve regeneration)
Take 1 tab by mouth three times a day for 3 months

Medications for Allogeneic Transplant:

Acyclovir 400 mg tabs (anti-viral, protects from viruses such as shingles and herpes)
Take 1 tab by mouth twice a day for 12 months

Voriconazole 200mg tabs or Fluconazole 200mg tabs (antifungal)
Take as instructed for 9-12 months

Bactrim DS (protects from PCP pneumonia)
Take 1 tab by mouth every Monday, Wednesday, Friday for 9-12 months

Maginex 615mg tabs
Dose adjusted by blood levels

Cyclosporine 200mg tabs or Tacrolimus 0.5- 1mg tabs
Dose adjusted weekly based on blood levels

**** It is ok to restart vitamins, supplements, and probiotics when you return home. Please notify us when you restart these or start any new medications within the first six months.**

Labs:

CBC w/ Diff, Basic Chem Panel, Mg, Phos, Liver Function Test, CMV PCR (Quantitative)

Please get labs checked:

- every week for 4 weeks
- every other week for 8 weeks
- monthly for 3 months (if needed)
- you may need additional lab draws
- allogeneic transplants may require more frequent lab draws

Please notify us of the name and number of the laboratory you use.
Labs results need to be faxed to 312-695-4961.

Appointments: Follow up visits vary on an individual basis. Further instructions will be provided for you at your hospital discharge. At your follow up visits with Dr. Burt, please bring a list of all current medications.

Return to Work: We encourage you to resume your normal life activities as tolerated. Work can be therapeutic both psychologically and physically. If needed, short term disability can be approved through our office for up to three months. However, after three months, paperwork will need to be completed by your local PCP.

What if I get sick: In the next few months, you may have symptoms. Please notify your primary care physician (PCP) and our office (312-695-4960) if you get sick, have a fever or develop any other concerning symptoms.

Problems to report immediately:

- Fever (temperature over 100.5 F), chills, or sweating
- Chest pain
- Shortness of breath
- Dizziness
- Persistent cough, with or without sputum
- Cold, flu, or sore throat
- Sinus pain
- Persistent nausea, vomiting, diarrhea, or unable to keep fluids/ medications down
- Skin rash
- Burning, itching, or frequency with urination
- Frequent nose bleeds, blood in urine/ stool, or any bleeding that does not stop
- White coating on tongue, sores on mouth or lips

How to avoid getting sick:

- Stay away from large crowds. It is okay to go to movies, shopping and restaurants, but avoid during highly congested times.
- Avoid contact with sick individuals
- Remember to wash your hands frequently and consistently. It is most important to wash your hands related to the following:
  - before eating or preparing food
  - after touching plants or dirt
  - after changing diapers
  - after urinating or defecating
  - after touching animals
  - after going outdoors or to a public place
  - after removing gloves
  - after collecting or depositing garbage

Suggested further evaluation:

- Please make sure you have a Primary Care Provider in case you get sick and need to be seen. If you would like a discharge summary of your hospitalization sent to your PCP, we will need your PCP's name and address. Work with your PCP to taper off of pain medications (if you are taking).
- If you take blood pressure medication, keep a log of your blood pressure every day.

Other Precautions:

Surgeries:

Please avoid any elective surgery, scope, endoscopy, colonoscopy, skin biopsy, major dental procedures, etc. for 1 year. Please check with us before having any procedures done. Have your doctor call us with questions.

Diet: Eat a balanced diet with enough calories and protein. For three months, avoid food that may be contaminated (salad bars, deli meats cut on deli slicers). It is important to wash all of your fruits and vegetables. Use separate cutting boards for raw meats. Avoid eating raw foods (eggs, meats, and fish). Check expiration dates and discard questionable items. Do not keep leftovers for longer than two days. Check for mold and avoid aged (moldy, blue) cheese.

Exercising/ Swimming: It is ok to exercise in public fitness centers or gyms, please wipe down machines before and after use and practice good handwashing.

For three months, avoid swimming in lakes, rivers, hot tubs, and public swimming pools. Friends' and family's pools that have been properly chlorinated are okay. You should never swim when you have a central line catheter (PICC line) in place.

Driving: Avoid driving while taking medications that make you drowsy.

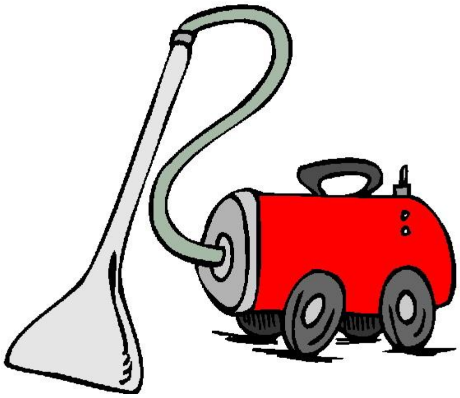
Childcare: We encourage you to be around and interact normally with your children, including hugs. However, for the first three month, if your child has a cold, avoid close physical contact if possible. Also, avoid changing diapers or exposure to urine or feces for first three months. If this cannot be avoided, please wear gloves and wash your hands after exposure.

Cooking: No limitations but wash your hands before preparing food. Wash your hands immediately after handling raw meats.

Cleaning/ Laundry: For three months, avoid taking out the trash if possible. If this cannot be avoided, wear gloves and wash your hands after disposing garbage.

For 3-6 months, avoid dust. You may vacuum but do not change the vacuum bag.

For 3-6 months, avoid construction sites (remodeling in homes).



Gardening/ Yard Work: For 3-6 months, avoid yard work and gardening. Avoid contact with soils, mulch and dirt. Do not introduce any new plants into your home.

Travel: No limitations, but if you are traveling outside of the country for the first three months, contact your doctor.

Pets: It is okay to touch pets but wash your hands afterwards. Avoid bird droppings, exotic animals and reptiles. Avoid contact with stray animals that have not been vaccinated. Do not clean up after any animal for 6-12 months (liter, urine, feces). If this cannot be avoided, make sure you wear gloves and wash your hands afterwards. Do not introduce any new pet into your home for 6 months.

Blood Products: If you need a blood transfusion for any reason, the blood product needs to be **CMV safe, irradiated and leukocyte reduced** (for 1 year). If there are any questions, have your PCP call our office at (312)695-4960.

Dental Care: No restrictions on teeth cleaning or minor dental work. Please check with us for any major dental procedures such as tooth extractions.

Sexual Activity: We recommend waiting 48 hours after discharge before engaging in intimate contact.

Skin and Nails: Wear sunscreen or clothing to protect your skin. Nail changes are common during and after chemotherapy. They may become darker yellow, cracked, brittle, growing less, or breaking more frequently. Your nails may develop lines related to cycles of chemotherapy. These lines are not permanent and will grow out with the nail in about 6 months.

Vaccines: If you would like, you may ask your PCP to have your vaccine titers checked after 1 year. It is okay to get a flu shot 6 months after cell transplant, but <u>**DO NOT**</u> get any live vaccinations. Also, avoid contact with any individual who has had a recent live vaccination.

Live Vaccines: Measles, mumps, rubella (MMR combined vaccine), Varicella Zoster Virus (VZV, chicken pox), Influenza (nasal spray), Rotavirus

Titers: MMR, VZV, Hep B

Fatigue

Fatigue is a common complaint of individuals with chronic illnesses. While in the hospital, the fatigue may seem to lessen. However, once you return home, it is not uncommon to feel increasingly tired, perhaps even more so than prior to your transplant. Some patients may even begin to feel that the transplant was unsuccessful. It is important for you to know that fatigue following stem cell transplant is very common and can last 1-6 months following the transplant. There are a number of possible causes for the fatigue: the intensive treatments, medications, a lower than normal number of circulating red blood cells, disruption of normal resting and sleep habits, or feeling depressed. As your body adjusts to increasing activity levels, you will find that you gradually have more energy. Call the transplant team if you feel your fatigue is getting worse or if you find yourself staying in bed all day.

Suggestions to Improve Energy:

- Set up a regular daily schedule for nap and sleep times
- Stay active and exercise
- Do not overdo it. Be realistic. Decide on the most important activities for the day
- Make sure you drink plenty of fluids (1-2 liters per day) and eat a healthy diet

Physical Therapy and Occupational Therapy

- Recommended for everyone.
- You will go home with a prescription for this and we encourage you to see a local therapist as soon as possible upon returning home.
- Depending on your condition in the hospital, we may recommend acute inpatient rehab or an outpatient day rehab program for more intense therapies.

Step 10: Follow- Up

Depending on your treatment plan, you may be required to come back for your first follow-up appointment at six months. Everyone is required to come back at one year. Tests required for your follow-up visits vary by disease and you may be required to stay in Chicago between two and four days to complete testing. You will get a reminder email regarding your follow-up appointment. However, you may contact our office to begin the scheduling process.

At your follow-up visits, please bring a current list of your medications. Complete all requested surveys and forms. These are important to accurately assess your condition.

How Will I Know if the Transplant Worked?

We will continue to monitor you and repeat tests to check the status of your disease. It is not uncommon for it to take a few months after transplant for your tests to return to normal. This is to be expected. For some patients, it may even be necessary to continue on some of the same drugs (prednisone) that you were taking prior to the transplant. Again, this is normal and does not indicate the transplant did not work. We will always inform you of your test results and examinations in a timely fashion. If you ever have questions or concerns as to whether the transplant worked, or whether your disease has returned, please call us.

Following your progress post-transplant is important for the advancement and development of HSCT and the treatment of autoimmune diseases. Please make every effort to be compliant with your follow-up appointments, procedures, and questionnaires.

> ***"I chose HSCT to save my future. Little did I know it would save my present as well. Is HSCT hard? Yes, but no harder than living with an autoimmune disease. This process is a short moment of time and it will change the rest of your life. During recovery you may have days of exhaustion, nausea or headaches. You may even have times of sickness where the old ugly MS symptoms show their face, but they are nothing compared to the countless times of realization. Realization that you haven't used a cane in over a month, words are flowing clearer, or the simple realization that for the first time in as far back as you can remember, you aren't in pain. I was blessed to be given the gift of a future thanks to Dr. Burt, his amazing team, and HSCT."***
>
> **- Multiple Sclerosis Patient, Texas**

IN THE HOSPITAL

Welcome to Prentice!

Visiting Hours

There are no set visiting hours, however, please limit to only one person staying overnight. Children under 18 years old are discouraged from visiting the transplant floor. Restrictions may vary.

Dining On Call

- Upon admission, you will be given a menu for Dining On Call and instructed on how to use the room phone to order food.
- Hours of operation to call are 6:00 am to 9:15 pm.
- Food takes 1 hour to deliver.
- You may order food to be delivered at a specific time.

Nourishment Room

- Visitors may bring food from home or from a restaurant. Please label food with patient's name and date.
- Food may be stored in the refrigerator in the nourishment room. Food will be disposed after 24 hours.
- No food may enter the nourishment room after it has been in the patient's room.
- For infection purposes, visitors are NOT able to enter the nourishment room.

Visitor Shower Room

- There is a shower facility on Prentice 16 available for visitors.
- Visitors must bring their own towels and toiletries. Please speak with the unit secretary to reserve a time for the room.

Monitoring Intake/ Output

- It is important that we monitor your fluid status while in the hospital, also known as your intake and output.
- Your nurse will provide you with a flow sheet to keep track of the fluids you drink and your urine output.
- Please urinate into the measuring hat in the toilet or in a urinal in order to keep accurate measurements.

Safety

Call Light

- When you press the nurse button on your remote or bedside control, the call will ring directly to the phone of your nurse or to the patient care tech.
- If they are unable to answer the call, it will be transferred to someone that will provide you with assistance.

Hourly Rounding

- Safety and your comfort are a priority while you are in the hospital.
- During your stay, expect that a nurse or patient care technician will check on you hourly. If you are sleeping, you will not be disturbed, however, someone will be checking on you each hour.

Fall Prevention

- Northwestern Medicine has created a Fall Prevention Program, which both identifies individuals at risk for falls and takes steps to prevent falls. On admission, your nurse will ask you questions as part of a fall assessment. At this time, it is important that you tell your nurse about your physical limits. Based on the assessment, you will be placed in one of the following 2 categories:

Standard Fall Precautions

- Light on in room during activity
- Clutter free bedside
- Needed items within reach

Strict Fall Precautions:

- In addition to the standard fall precautions
- Help to and from bathroom or when getting out of bed
- Frequent checks by staff

You can help prevent falls by doing the following:

- Wearing slippers with non-skid soles when walking
- Notifying staff of spills on the floor
- Asking for assistance before getting out of bed if you feel weak
- Using the call light in the bathroom if you need help getting back to bed
- Be aware that many medications may make you feel dizzy. Many medications may also cause fluid shifts, which can make you feel dizzy if you stand too quickly.

Sit on the side of your bed for 1 minute before standing.
When you stand, please remain close to your bed
for 20 seconds before walking.

If you feel lightheaded or dizzy, sit back down in the bed
and call for help.

Infection Control

Handwashing is essential to help protect patients and healthcare providers from infection. There are two methods of hand washing that are accepted at Northwestern:

1. Wash hands with soap and water at sink for minimum of 15 seconds.
2. Use hand cleansing gel located outside of each room. The gel must be rubbed all over hands until completely dry.

- Expect all staff members to wash their hands before entering and after leaving your room. Do not hesitate to remind anyone who enters your room to clean their hands.
- Visitors will be asked to wash their hands before entering the unit and before entering and after leaving your room.
- Patient should wash their hands:
- After using the restroom
- Before and after eating
- When leaving and entering room

- While in the hallways, patients are required to wear gowns and gloves. When neutropenic, patients will also be required to wear a mask in the hallways.
- Patients are not allowed to enter other patient rooms. Patient's visitors are discouraged from entering other patient rooms.
- Patients should not touch or hug other patients.
- The exercise bike and computer keyboards in the common area should be disinfected before use. Your nurse can assist with this.
- Each patient will be screened for Vancomycin Resistant Enterococci (VRE) upon admission and every Tuesday.
- Upon admission, patients will be placed on isolation precautions. Staff will wear gowns in the patient room until VRE has been ruled out. If VRE is positive, patients will remain on isolation requirements throughout the stay.
- No fresh flowers are allowed on the floor.
- No latex balloons are allowed on the floor.
- No tape is allowed on the walls/ windows

> ***"The transplant floor has a single stationary bicycle in a common area that can be used, but only while wearing infection control gown, mask and gloves. Outside the common area is a step platform for stretching, etc. Bring shorts and other light workout clothing to wear under the plastic gown. Plan to get immediately sweaty, even if just walking the halls."***
>
> **- Multiple Sclerosis Patient, Idaho**

Neutropenic Precautions and Eating

Neutropenic precautions are initiated when the absolute neutrophil count is less than 500. We are not strict on food precautions; however, please avoid the following while you are neutropenic:

- Raw or uncooked meat or fish
- Raw eggs
- Deli meat that is sliced on a meat slicer
- Salad bars (where food has been sitting out)
- Unpasteurized beverages
- Unrefrigerated cream-filled products
- Aged (moldy) cheeses
- Fast food is okay, but please use your best judgment.
- Fresh fruits and vegetables are okay, but please make sure they are washed well.

Patient Responsibilities

- Daily Hibiclens bath or shower as instructed. Hibiclens is a special medicated soap that helps prevent infections. The soap contains 4% chlorhexidine gluconate. If you think or know that you are allergic to this soap, do not use and let your nurse know.
- Use your incentive spirometer as instructed and walk in the hallways. This is important to keep your lungs functioning well. Use the incentive spirometer 10 times every hour while awake, as instructed by your RN.
- Before leaving your room, wash hands at sink or use alcohol hand gel for 15 seconds, allow hands to dry, put on gloves and an isolation gown.
- When returning to your room, please take off your gown and gloves and then wash your hands or use alcohol hand gel for 15 seconds.
- Do not allow family/ visitors to visit if they have a cold or any symptoms of infection.
- If you have an infection, your nurse will be instructing you on other necessary practices including restricting you from the patient/family room. We will inform you if you are not permitted into the room.

Oral Care

- Brush teeth with a soft toothbrush after each meal and prior to bedtime.
- If unable to brush teeth, use mouthwash provided by RN when waking up, after meals and before bedtime as instructed by RN (4-6 times/day).

Visitor Responsibilities

- DO NOT VISIT if you have any symptoms of infection: fever, chills, cough, sneezing, diarrhea, vomiting, aches etc.
- In general, bringing children is discouraged. Please do not bring children under 18 years old without staff authorization. Do not bring children who have symptoms of infection. Do not leave children in the patient/ family room unattended.
- Before you enter the patient's room, please use the alcohol hand cleansing gel to clean your hands for at least 15 seconds and let hands dry. When hands are dry, put on gloves.
- When leaving patient's room, please take off gloves and use alcohol hand gel to clean hands.
- If using the patient/ family room, please wipe down computer, exercise bike or other equipment in room after use. Sani-Wipes should be in room. If not, please let your nurse know.
- Do not enter the nourishment room. Please ask for assistance.
- We do not recommend patient's visitors entering other patient rooms.

Section

5

GENERAL INFORMATION

To help you make the most of your stay in Chicago.

- **Lodging**
- **Airport Information**
- **Public Transportation**
- **Parking**
- **Laundry**
- **Groceries**
- **Pharmacies**
- **Hair Salons/ Prosthetics**
- **Dining**
- **Shopping**
- **Entertainment**

Lodging

Northwestern Medicine has negotiated reduced rates at many hotels near the hospital. If additional assistance is needed, call Health Resources at **312-926-ROOM (7666)** from 8 a.m. to 5 p.m. Monday through Friday.

Frequently Used Housing Options

** If you are interested in reduced rates for the following, please contact our Patient Liaison, Kim Bracy at (312)695-8730

Marriott Residence Inn (4 blocks from Prentice, 5 blocks from Galter)
201 E. Walton St (312) 943-9800

- Studios, one bedrooms available
- Free shuttle to the hospital
- Free breakfast bar daily, free dinner 3x/ week, laundry room in hotel

Worcester House
244 E Pearson St (312) 926-2566
Merrily Smith, Leasing Manager (312) 926-2334

- Dormitory style, twin beds, private bath, linens included
- Sink, microwave, fridge, stove, no plates, cups or utensils
- 2 blocks from Prentice, 3 blocks from Galter, no shuttle

DeWitt Place
900 DeWitt Pl (312) 742-7020

- Furnished studio apartments with kitchen
- Rent by week(s), month(s)
- One month plus bookings at $57/ night
- 3 blocks from Prentice, 4 blocks from Galter, no shuttle

Fairfield Inn & Suites
216 E Ontario St (855) 476-6661

Hampton Inn
160 E Huron St (312) 706-0888

- Free hot breakfast buffet, on-site laundry, grocery shopping service
- 1 block from Prentice, across street from Galter

Homewood Suites
152 E Huron St (312)440-3767

- Free hot breakfast buffet, free light dinner Monday- Thursday, free grocery shopping service, on-site laundry available
- 1 block from Prentice, across street from Galter

Airport Information

Chicago Midway International Airport (MDW)

- This airport has international and domestic flights and is 9 miles from the center of Chicago, IL.

Chicago O'Hare International Airport (ORD)

- This airport has international and domestic flights and is 19 miles from Chicago, IL.

Transportation between downtown Chicago and Airports

<u>Cab</u>: always available, no need to call in advance (approximately $40-$50 from O'hare and $30-40 from Midway)
<u>Shuttle</u>: Many hotels provide shuttles. Check to see if your hotel offers shuttle service. Call in advance to arrange for shuttle pick up
<u>El (Chicago's subway train):</u>
- O'Hare- Blue Line
- Midway- Orange Line

Public Transportation (CTA)

Public transportation is an easy and affordable way to traverse the city. Chicago Transit Authority (CTA) buses and the elevated and subway trains will take you from one end of the city to the other in no time.

- Red Line Train: Exit via Chicago Avenue or Grand Avenue and walk east approximately 3 blocks.
- Bus: Thirteen bus routes run along The Magnificent Mile with various drop offs on North Michigan Avenue.
- For bus and train schedules, system maps, CTA bus tracker and to plan your trip, visit www.transitchicago.com or contact the CTA at (312) 836-7000.

Parking

Parking is available at discounted rates for patients and visitors of Northwestern Medicine and Prentice Women's Hospital.

Garage Self-Parking

222 E. Huron St
Chicago, IL 60611

The Northwestern Medicine garage is conveniently located across from Northwestern Memorial's Galter and Feinberg Pavilions. Covered, fully accessible walkways to both pavilions are located on the 2nd level of the garage and the 2nd level of both Pavilions.

Discounted parking is available to Northwestern Medicine and Prentice Women's Hospital patients and visitors. Parking rates are $10 for less than seven hours and $22 for seven to twenty-four hours. Parking receipts must be validated at customer service desks located in Feinberg/ Galter Pavilions, 1st and 2nd floor, or Prentice Women's Hospital, 1st floor, for discount to apply. Please note, parking rates are subject to change.

Valet Parking at Prentice Women's Hospital

250 E. Superior St, 1st Floor- Driveway
Chicago, IL 60611

Valet parking is located at the front entrance to Prentice Women's Hospital on Superior Street in Chicago, Illinois. Valet parking is available for patients and visitors. Valet rates are: $23 for less than seven hours and $33 for seven to 24 hours. Parking receipts must be validated at customer service desks located in Feinberg/ Galter Pavilions, 1st and 2nd floor, or Prentice Women's Hospital, 1st floor, for discount to apply. Please note, parking rates are subject to change.

Laundry

Worcester House

244 E. Pearson
312-926-2566

- Laundry services are available to all Northwestern visitors, even those who are not staying at Worcester House.
- Laundry is located on the first floor
- Northwestern visitors must wear their NMH visitor badge to gain access to facilities.

Cost:
$6 to purchase a laundry card
$1.25 – 1 load washer
$1.25 – 1 load small dryer
$1.35 – 1 load large dryer

Groceries

Farmers Market

- From June 10th thru the end of October on Tuesdays
- Located in front of The Museum of Contemporary Art (on Chicago Ave)

Instacart

- Smartphone app for grocery shopping
- Pick items from one or several stores to be delivered straight to your room the same day.
- Offer free delivery for your first order, often discount codes

Jewel Osco

- Located on the corner of Ohio and State Street
- 15 minute walk from the hospital

Peapod.com

- Excellent resource to utilize online grocery shopping
- Deliver to your room the following day
- No need to struggle carrying groceries
- Often have special offers and offer free delivery

Target

- Located on the corner of Illinois and McClurg
- 10-15 minute walk from the hospital

Trader Joes

- Located on the corner of Ontario and Wabash
- 10-15 minute walk from the hospital

Treasure Island

680 N. Lakeshore Drive (may be accessed at 645 McClurg Street)

- 5-10 minute walk from hospital

Walgreens

- Located on the corner of Michigan Ave. and Chicago Ave.
- Open 24 hours a day

Whole Foods

- Located on the corner of Fairbanks and Grand Ave
- 5-10 minute walk from the hospital

Pharmacies

CVS Pharmacy
205 N. Michigan Ave
(312) 938-4091

CVS Pharmacy
1201 N. State St
(312) 640-2842

Walgreens Pharmacy
201 E. Huron St 1st Floor
Galter Pavilion
(312) 951-1084

Walgreens Pharmacy
680 N. Lake Shore Dr #108
(312) 943-2224

Hair Salons

BLO and Go
323 E. Ontario St
(312)266-1323

Salon 161
161 E. Erie St
(312) 943-4122

Maxine Salon
712 N. Rush St
(312) 751-1511

Zeza Hair Salon & Spa
211 E. Ontario St, Ste #2
(312) 932-9262

J. Crager Alternatives
http://jcrageralternatives.com/index.html
Specialize in hair prosthetics for patients with medically-related hair loss
(773)248-6844

Dining

HOSPITAL DINING

Feinberg Pavilion

- Starbucks on 1st floor
- GRK Greek Kitchen on 2nd floor
- Au Bon Pain on 2nd floor
- Protein Bar on 2nd floor
- Saigon Sisters on 2nd floor

Prentice Women's Hospital

- Cafeteria on 2nd floor
- Argo Tea on 1st floor
- Dunkin Doughnuts 2nd floor

Restaurant Delivery/ Take-out

GrubHub

- Online ordering from restaurants at grubhub.com
- Easy to find restaurants near you with delivery or take-out

NEARBY FAST FOOD

Beatrix
671 N. St. Clair St
(312) 642-0001

Blaze Pizza
227 E. Ontario St
(312) 255-1290

Burrito Beach
200 E. Ohio St
(312) 335-0668

Chipotle Mexican Grill
291 E. Ontario St
(312) 587-7753

Corner Bakery Cafe
676 N. St. Clair St
(312) 266-2570

Cosi
259 E. Erie St
(312) 884-8501

Einstein Bros Bagels
109 E. Pearson St
(312) 881-5056

Epic Burger
227 E. Ontario St
(312) 257-3260

Jersey Mike's Subs
203 E. Ohio St
(312) 923-0950

Jimmy John's
46 E. Chicago Ave
(312) 787-0100

Lyfe Kitchen
259 E. Erie St
(312) 933-1035

M Burger
161 E. Huron St
(312) 254-8500

McDonald's
645 N. McClurg Ct
(312) 944-5665

Panera Bread
635 N. Fairbanks Ct
(312) 274-3955

Potbelly Sandwich
277 E. Ontario St
(312) 337-6488

Shake Shack
66 E. Ohio St
(312) 667-1701

Soupbox
50 E. Chicago Ave #1W
(312) 951-5900

Subway
511 N. McClurg Ct
(312) 644-2811

*The above recommendations are not official endorsements of Northwestern Medicine.

NEARBY RESTAURANTS/ BARS

Bandera
535 N. Michigan Ave
(312) 644-3524

Big Bowl
60 E. Ohio St
(312) 951-1888

The Capital Grille
633 N. St. Clair St
(312) 337-9400

Cheesecake Factory
875 N. Michigan Ave
(312) 337-1101

Chili's Grill & Bar
2 E. Ontario St
(312) 943-1510

Dick’s Last Resort
315 N. Dearborn St
(312) 836-7870

Ditka’s
100 E. Chestnut St
(312) 587-8989

Elephant and Castle
185 N. Wabash Ave
(312) 345-1710

Francesca’s
200 E. Chestnut St
(312) 482-8800

Grand Lux Café
600 N. Michigan Ave
(312) 276-2500

Green River
259 E. Erie St
(312) 337-0101

Mity Nice Grill
835 N. Michigan Ave
(in Water Tower Place)
(312) 335-4745

Portillo's Hot Dogs
100 W. Ontario St
(312) 587-8910

Rosebud
720 N. Rush St
(312) 266-6444

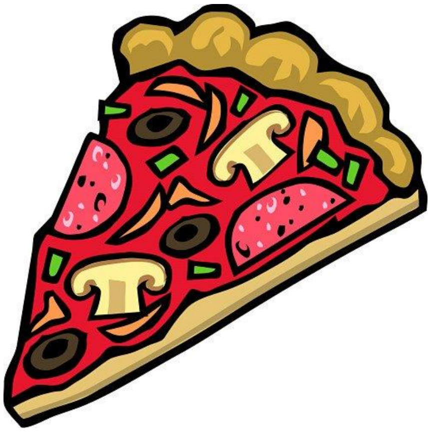
The Signature Room at the 95th
875 N. Michigan Ave
(312) 787-9596

T.G.I. Friday's
153 E. Erie St
(312) 664-9820

*The above recommendations are not official endorsements of Northwestern Medicine.

CHICAGO PIZZA

Edwardo's Natural Pizza
1212 N. Dearborn St
(312) 337-4490



Gino's East
162 E. Superior St
(312) 266-3337

Giordano's
730 N. Rush St
(312) 951-0747

Lou Malnati's
439 N. Wells St
(312) 828-9800

DESSERTS

Do-Rite Donuts & Chicken
233 E. Erie St

Forever Yogurt
42 E. Chicago Ave

Ghirardelli Chocolate Shop
830 N. Michigan Ave

Hershey's Chocolate World
822 N. Michigan Ave

Sprinkles Cupcakes
50 E. Walton St

*The above recommendations are not official endorsements of Northwestern Medicine.

Shopping

The Magnificent Mile, the northern part of Michigan Avenue between the Chicago River and Oak Street, is a grand wide boulevard with shops, museums, restaurants and hotels. Some shops include:

- Disney
- The Apple Store
- Best Buy
- Water Tower Place
- Home Goods
- Marshalls
- Bloomingdales
- Nordstrom
- Bed, Bath, and Beyond

Entertainment

*May need cab

Field Museum
1400 S. Lake Shore Dr

Shedd Aquarium
1200 S. Lake Shore Dr

Chicago Art Institute
111 S. Michigan Ave

Museum of Science and Industry
5700 S. Lake Shore Dr

Museum of Contemporary Art
220 E. Chicago Ave

Navy Pier
600 E. Grand Ave
Restaurants, shopping
Fireworks Sat/ Wed

Millennium Park
55 N. Michigan Ave

Lincoln Park Zoo
2001 N. Clark St

AMC 600 North Michigan
600 N. Michigan Ave

AMC River East
322 E. Illinois St

Section 6

APPENDIX

- **Allogeneic Stem Cell Donor Information**
- **Downtown Medical Campus Map**
- **Fundraising Ideas**
- **Definition of Terms**

> ***"Life is nothing short of a miracle....and to have the opportunity to experience several miracles after my HSCT is truly a blessing. I have reclaimed my "life" from MS and are now able to raise my four children! Thank you Dr. Burt and your wonderful dedicated staff!"***
>
> **- Multiple Sclerosis Patient, Texas**

Allogeneic Stem Cell Donor Information

This information is for a healthy brother or sister who is providing stem cells to their sibling undergoing an allogeneic stem cell transplant.

HLA Typing

HLA stands for "Human Leukocyte Antigen." These are protein molecules that you inherit from your parents. When two individuals share the same HLA type, they are said to be a good match. That is, their immune systems will not see each other as "foreign" and are less likely to attack each other. Therefore, having a good match is important for a successful engraftment following stem cell transplant.

The most likely place to find an HLA match between two people is among siblings (brothers and sisters who have the same mother and same father). If two siblings inherit the very same HLA molecules from both parents, they are said to be an "*HLA identical match*." You have a 25 percent (1 in 4) chance of being an HLA identical match with your sibling. There is a basic rule in HLA inheritance: you have a 25 percent chance of inheriting the same HLA molecules as your sibling, a 25 percent chance of inheriting none of the same HLA molecules as your sibling, and a 50 percent chance of inheriting half of the same HLA molecules as your sibling.

To find out if you are an HLA match, you will need to have about 10ml (2 teaspoons) of your blood drawn. If you live in another city, this may be arranged by having the blood drawn by a local doctor and sent to the HLA testing lab at Northwestern Medicine by Federal Express for processing. The transplant office will help arrange this for you.

Evaluation

If you are found to be an HLA match and your sibling is able to participate in the study, you will be asked to come to Northwestern Medicine in Chicago for an evaluation. This evaluation will include a physical examination by the transplant physician to ensure you are ready to proceed with donating blood stem cells. This evaluation will include a chest x-ray, a painless test that looks at the heart and lungs to evaluate for any heart or lung disease. It will also include an electrocardiogram (EKG), a painless test to evaluate the heart by looking at the rhythm of your heartbeat. Lastly, laboratory work including a blood draw and urine sample will be conducted. These tests will evaluate liver and kidney function and check for certain infections. Females will also have a pregnancy test. Evaluation at Northwestern Medicine will take two to three days.

G-CSF

If the transplant doctor feels that you are a good candidate for donation, you will undergo "harvest," which is collection of blood stem cells. Four days prior to collection, you will begin receiving an injection of a growth factor (a substance which helps blood cells to grow faster), called granulocyte-colony stimulating factor (G-CSF). You will give yourself the injection once daily for around 4 days. You will be taught by a nurse how to properly give yourself the injections. If you do not feel comfortable giving yourself the injections, the nurse can teach a family member or friend how to give them to you.

The common side effects of G-CSF include headache, pain in the muscles, such as the lower back, pelvis, thighs and sternum. This pain is often well controlled with Tylenol, Ibuprofen or a prescription pain medication called Norco. Rare side effects include fever, rapid or irregular heartbeat, sores on the skin and/or wheezing.

Harvest (Stem Cell Collection)

On the morning of the 4th day of giving yourself the growth factor, you will undergo harvest, a process called apheresis. Apheresis is a procedure that removes stem cells from your blood.

Prior to your stem cell collection, you will have a catheter (central line) placed under local anesthesia in a vein in your upper chest or neck in Interventional Radiology. Potential complications of central line placement include pain at the site or bleeding. Rare complications include air or blood in or around the lung, abnormal beating of the heart and collapse of the lung. Like all artificial devices, these lines may become infected and require treatment with antibiotics. It is important to monitor the insertion site for redness, pain, swelling or drainage.

Apheresis will be done as an outpatient at the Rube Walker Blood Center. The process will take approximately 4 to 6 hours. Using the central line, blood will flow from your body into a machine that removes stem cells from your blood and returns the rest of the blood to your body. The most common complication is low calcium caused by a blood thinner used during the procedure. Symptoms of low calcium are usually mild (numbness in the lips and fingers) but may be moderate (cramping in the arms and legs) or rarely severe (nausea, vomiting or seizure). Calcium replacement will be given during the procedure. If symptoms occur, they usually resolve by taking calcium supplements by mouth. Other complications are infrequent, but may include low blood pressure, fainting, or infection.

Once the appropriate number of stem cells has been collected, your catheter will be removed and a dressing will be applied. The dressing can be removed the following day. Continue to monitor the site for redness, pain, swelling or drainage and report any of these findings to your nurse.

You may fly home and/ or return to work the day after stem cell collection.

Northwestern Medicine

Guide to the Downtown Medical Campus

Northwestern Memorial Hospital Feinberg and Galter Pavilions

① Main drive-through entrance
251 E. Huron St.

② Emergency Department
250 E. Erie St.

Galter Pavilion

③ Stone Institute of Psychiatry
201 E. Huron St.

④ Physician offices
201 E. Huron St.

⑤ Robert H. Lurie Comprehensive Cancer Center of Northwestern University
675 N. Saint Clair St.

Same Day Surgery
675 N. Saint Clair St., Fifth Floor

Prentice Women's Hospital

⑥ Main drive-through entrance
250 E. Superior St.

⑦ Entrance
250 E. Superior St.

Robert H. Lurie Comprehensive Cancer Center of Northwestern University
250 E. Superior St.

⑧ Entrance
Corner of Chicago Avenue and Fairbanks Court

Other Locations

⑨ 259 East Erie St.
Entrance and parking

Preoperative Clinic
17th Floor

⑩ Olson Pavilion
Ambulatory Surgery Center
710 N. Fairbanks Court
Sixth Floor

⑪ Northwestern Memorial HealthCare Human Resources
541 N. Fairbanks Court
17th Floor

⑫ Stone Institute of Psychiatry
Administrative offices and outpatient services
Onterie Center
446 E. Ontario St.

⑬ Physician offices
211 E. Chicago Ave.

⑭ Physician offices
737 N. Michigan Ave.
(Entrance on Chicago Avenue)

⑮ Physician offices
150 E. Huron St.

⑯ Physician offices
645 N. Michigan Ave.

⑰ Arkes Family Pavilion
Physician offices
676 N. Saint Clair St.

⑱ Northwestern Memorial Imaging Center
676 N. Saint Clair St.

⑲ Physician offices
680 N. Lake Shore Drive

Prentice Ambulatory Clinic
680 N. Lake Shore Drive

Developmental Evaluation Clinic
680 N. Lake Shore Drive

**Need a physician? Call physician referral at 312-926-8400.
For more information on Northwestern Medicine, visit nm.org.**

Fundraising Ideas

If insurance does not approve the stem cell transplant, fundraising is an option to raise the money that is needed to cover treatment costs. Even if insurance does cover the stem cell transplant, many individuals and families need additional funds to help pay for co-pays, transportation, lodging, food, parking, child care and medications.

There are many organizations and people who are happy and willing to make donations to specific causes. Below is an outline to help guide you through the fundraising process.

Build a Team

Ask people who are close to you such as family, friends, neighbors, church members, etc. for their help. Ask them if they would be willing to assist you with raising money to cover the costs of your medical treatment.

Your nurse can give help you contact patients who have agreed in advance to being contacted regarding fundraising.

Set a Goal, Brainstorm & Plan

Set a Goal: Determine what needs to be paid for and how much will need to be raised.

Brainstorm: Together with the fundraising team, brainstorm on feasible fundraising activities and events. Build a list of potential contributors.

Plan: Take time to develop a strategy and set a timeline.

> ***"We are so grateful for you guys helping her get her life back. The difference in the last 16 months has been remarkable! Our goal is to help support and educate others and try to find a way to help those who need some extra help."***
>
> **- Systemic Sclerosis Patient, California**

Prepare a Letter

- Who will the fundraising benefit?
- What is the disease? Is the disease life threatening?
- What impact does the disease have on quality of life?
- Is a stem cell transplant the only option?
- What is a stem cell transplant? How long does it take?
- What specifically will the contributions cover?
    - Medical costs/ Co-pays
    - Medications
    - Transportation/ Lodging in Chicago
    - Food
    - Childcare
  - How much money needs to be raised and by what time?
  - How to donate: where to send money, who check should be made out to, credit card donation linked to separate donation account, etc.
  - Are contributions tax deductible?
  - Contact information for questions

Decide on Soliciting Methods/ Ways to Disperse Information

- Internet: fundraising websites, email, blogs, social media
- Face-to-Face: Schedule Appointments
- Written Requests/ Letters
- Telephone
- Media: News, TV stations, Newspapers, Radios

Helpful Tips

- Sometimes it is more beneficial to ask for specific amounts of money based on who you are soliciting, their interest in your cause and their ability to give.
- For corporations or businesses, ask if they would be willing to match employee donations.
- For mailed letters, provide a reply card that includes the contributor's name, address and phone number so you have contact information to thank them later.
- For internet blogs and website, provide a space for contributors and supporters to leave messages.

Keep Your Contributors Informed

Let your contributors know where you stand in your fundraising efforts. A contributor may be likely to provide additional support if they see that you have not reached your goal. Letters, bulletins, flyers, blog updates and news releases to local media are good ways to keep the community informed. Make sure to thank your fundraising team and your contributors.

Benefits and Special Events

Planning a benefit can be a successful method of fundraising as it involves a large number of people and can help create public awareness, enthusiasm and support for your cause. Remember, however, that special events and can involve a lot of planning, time and money. Make sure that your event will not cost more money than it will raise. Examples: benefit dinner, walk/ run/ bike event, auction or raffle

- Ask for free use of the facility where the benefit will be held
- Ask local businesses for donations on food and supplies
- Ask for donations for a raffle or auction
- If appropriate, charge money for tickets for the event
- Assign team members the responsibility of selling a certain number of tickets.
- Notify the local media about the event and ask for a news release. Make sure information is provided on how to make donations.

Media

- Call your local media including the news stations, TV stations, newspapers and radio.
- Encourage them to do a special feature or human interest story for the cause.
- If planning a special event, ask for a news release a few days to one week prior to the event.

Political Support

- Notify state elected congressman and representatives and ask for help.

Helpful Websites

Fundraising Website
www.gofundme.com

HelpHOPELive
Nonprofit organization provides support regarding fundraising
Transplant campaigns, tax deductible donations
www.HelpHOPELive.org
(800)642-8399

Transportation Assistance

Public Benefit Flying Organization
http://www.angelflight.com/locator/

Angel Flight West
www.angelflightwest.com
Offers free airfare transportation on private aircraft. They need one week notice and the patient must be medically stable and able to walk

Financial Assistance

National Foundation for Transplants
http://www.transplants.org/become-patient
1-800-489-3863

National Transplant Assistance Fund (NTAF)
Helps organize communities to fundraise on patient’s behalf
Grants may be available
www.transplantfund.org
1-800-642-8399

National Patient Travel Center
www.patienttravel.org
(800)-296-1217 in the US
(757) 318-9145 elsewhere

Patient Advocate Foundation
www.patientadvocate.org
www.copays.org
866-512-3861

Patient Access Network
www.patientaccessnetwork.org
866-316-7263

HealhWell Foundation
www.healthwellfoundation.org
800-675-8416

Prescription Assistance
www.needmeds.com

Caregiver Schedule/Calendar Organization

Lotsa Helping Hands
www.lotsahelpinghands.com

Definition of Terms

Absolute Neutrophil Count (ANC): A lab test that determines the number of neutrophils in a blood sample.

Allogeneic Transplant (allograft): A type of transplant in which peripheral blood stem cells or umbilical cord blood stem cells come from another person (donor).

Alopecia: Partial or complete hair loss, usually a temporary side effect of chemotherapy.

Anemia: A condition that occurs when the body's red blood cell count is low.

Antibiotics: A group of medications used to prevent or treat infections.

Antibody: A protein produced by white blood cells to battle foreign substances that enter the body.

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

Antiemetic: A medication to prevent vomiting.

Antifungal: A medication that limits or prevents the growth of yeasts and other fungal organisms.

Antigen: A self or foreign substance that starts an immune response in the body, especially the production of antibodies.

Antiviral: A medication that kills a virus or suppresses its ability to replicate and, hence, inhibits its capability to multiply and reproduce.

Apheresis: The name of the procedure that is used to collect or harvest certain types of blood cells. Blood is circulated through a continuous flow processor. The type of blood cell being collected is separated and the remaining blood components are returned to the patient.

Aplastic Anemia: A disorder in which the bone marrow is deficient in producing red blood cells, white blood cells, and platelets.

Attending Physician: A doctor who leads the healthcare team and supervises the medical care of a patient while they are in the hospital.

Autologous Transplant (autograft): A type of transplant in which the patient uses his/ her own stem cells. Stem cells are usually collected from the blood (ex. peripheral blood stem cells).

B Cells: Cells that come from your bone marrow and are a type of white blood cell that make antibodies to attack bacteria, toxins, or in the case of autoimmune diseases, your own tissue.

Basic Chemistry Panel: A set of blood chemical tests that is one of the most common lab tests ordered by health care providers. It will provide information regarding kidney function and electrolytes.

Blood Culture: A microbiological culture of blood. It is employed to detect infections that are spreading through the bloodstream (such as bacteremia or septicemia, amongst others). Blood cultures can determine what infection is occurring in the blood because the bloodstream is usually a sterile environment and no organism should normally be present.

Blood Draw: The removal of a sample of blood from a vein. This blood is used for certain testing.

Blood Transfusion: A common procedure in which the patient receives blood through an intravenous (IV) line inserted into one of the blood vessels.

Bone Marrow: The spongy tissue found in the cavities of the body's bones that produces all of the blood cells in the body, such as white blood cells, red blood cells and platelets.

Caregiver: A responsible family member, close friend, or paid helper who is able to provide physical care, observational care, and emotional support for a patient.

Catheter: A rubber or plastic tube that is inserted into the body to drain fluids or deliver fluids or medications.

C. Diff: Clostridium difficile colitis (also known as pseudomembranous colitis) is inflammation of the colon that is caused from an infection with Clostridium difficile, a type of spore-forming bacteria. This bacteria causes an infectious diarrhea called C. difficile associated diarrhea. This infection can occur after a prolonged hospital stay or the use of antibiotics.

CD34+ Cells: White blood cells which have a specific antigen marker which allows them to be detected in a sample of cells. The number of CD34+ cells are counted after stem cell collection to determine if adequate numbers of stem cells are present. It is still unconfirmed scientifically, but CD34+ cells may be a type of stem cell.

Central Line: A small, plastic tube inserted into a large vein near the heart. The central line is used to give medications, fluids and blood products, to draw blood samples and to infuse the stem cells through.

Chemotherapy: Medicine or a combination of medicines designed to stop or slow the growth of cells.

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

Complete Blood Count (CBC): A blood test that gives important information about the kinds and numbers of cells in the blood, especially red blood cells, white blood cells, and platelets. The results of this test will determine if you are at an increased risk for infection and if a blood transfusion is needed.

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

Conditioning: A phase in the stem cell transplant process involving high doses of chemotherapy and/ or antibodies to destroy the immune system.

Consent Form: A form signed by a patient prior to a medical procedure to confirm that he or she agrees to the procedure and is aware of any risks that might be involved.

Continuous Bladder Irrigation: A continuous infusion of a sterile solution into the bladder, usually by using a three-way irrigation system with a triple-lumen foley catheter inserted into the bladder. This continuously washes out the bladder.

Counts: Usually refers to monitoring the ANC (absolute neutrophil count) when watching for signs of engraftment.

Cytomegalovirus (CMV): CMV is a common virus that can infect almost anyone. Once infected with CMV, your body retains the virus for life. CMV usually remains dormant if you’re healthy. This virus can cause flu-like symptoms in patients with normal immunity and more severe problems (lung infections, liver problems, and intestinal problems) in patients with a suppressed immune system.

Daily Weights: A patient is weighed daily while in the hospital, occasionally more frequently. Daily weights help determine if a patient is retaining too much fluid or if they are dehydrated.

DIAD: Division of Immunotherapy and Autoimmune Diseases

DMSO (Dimethyl Sulfoxide): The preservative used to freeze and store the stem cells. The preservative gives off an odor that some people compare to creamed corn or garlic.

Donor: Any person who voluntarily gives blood, tissue, or an organ for use in the treatment of another person.

Electrolyte: Minerals found in the blood such as magnesium and potassium that must be maintained within a certain range to prevent organ dysfunction.

Engraftment: The process in which transplanted stem cells begin to grow in the recipient's bone marrow and produce new white blood cells, red blood cells and platelets.

Erythrocytes: Red blood cells that use their main component, hemoglobin, to carry oxygen from the lungs to all parts of the body.

Foley Catheter: A flexible plastic tube inserted into the bladder to provide continuous urinary drainage.

Follow-up: To maintain contact with a physician so as to monitor the effects of earlier treatment.

GCSF or **Growth Colony Stimulating Factor:** A subcutaneous injection of proteins given to transplant recipient patients before and during the harvest to increase the number of stem cells in the blood. GCSF is also given daily by subcutaneous injection following the stem cell reinfusion.

Graft: An organ or tissue taken from the body and placed into another area of the same body or into another individual.

Graft Versus Host Disease: A condition that can occur following an allogeneic stem cell transplant in which the donor's cells attack the patient's tissues and organs.

Harvesting: The term used for collection of stem cells from the bone marrow or peripheral blood.

Hemoglobin: A protein in your red blood cells that carries oxygen from your lungs to your body's organs/ tissues and also transports carbon dioxide from your organs/tissues back to your lungs.

Hemorrhage: A large loss of blood brought on by injury to blood vessels or by lack of necessary cells (platelets) to clot the blood.

Herpes Simplex: A virus that can produce small, painful, fluid-filled blisters on the skin and mucous membranes. This is a very common occurrence in transplant patients.

Herpes Zoster: A virus that can produce shingles (painful skin eruptions that follow the underlying nerve routes inflamed by the virus)

HLA Typing: Human leukocyte antigen (HLA) typing is a method to determine how closely the tissues of one person match the tissues of another person.

Hormone: A substance produced by certain organs of the body that stimulates and regulates body functions.

Immune System: The group of organs, cells, and protein in the body that fight infection and other diseases.

Immunocompromised: A condition in which the patient has a much higher risk of infection due to a weak immune system.

Immunoglobulin: Proteins that play an essential role in your body's immune system. They attach to foreign substances (such as bacteria) and assist in destroying them.

Immunosuppression: A situation in which the body's immune system is stopped from working or is made less effective.

Incentive Spirometer: A medical device used to help patients improve expansion or functioning of their lungs.

Informed Consent: A formal agreement that a patient signs to give permission for a medical procedure after the patient has learned about and reached an understanding about the purpose, potential risks, and benefits of a research protocol and then agrees to participate.

Infusion: The therapeutic introduction of fluid (other than blood) 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.

Intake Form: A form to be completed prior to being seen in clinic. This form will ask the patient for certain personal information such as demographic information (address, phone number, etc.), contact information for physician's treating the patient, and insurance information.

Intravenous (IV): A needle is inserted into a vein so that fluids, nutrients, or drugs can be injected into the body.

Leukocytes: White blood cells of the immune system which protect the body against infection and fight infection when it occurs

Liver Function Test: A group of blood tests that detect inflammation and damage to the liver. They can also check how well the liver is working.

Lymphocyte: A small white blood cell that defends the body against disease and is responsible for immune responses. The two main types are B Cells and T Cells.
Mixed Chimerism: After an allogeneic transplant when both recipient and donor stem cells coexist in the bone marrow space.

Mobilization: Moving more stem cells from the bone marrow into the bloodstream through chemotherapy and/or a growth factor.

Mucositis: Painful inflammation and sores caused by chemotherapy and/or radiation therapy.

Myeloablative: The severe or complete depletion of bone marrow cells which can occur from the administration of high doses of chemotherapy or radiation.

Neutropenia: A shortage of neutrophils (the good white blood cells) in the blood, which increases the risk of infection.

Neutropenic Diet: A diet for patients with low neutrophils and a weakened immune system. This diet helps protect you from bacteria and other harmful organisms found in some food and drinks.

Neutrophil: A type of white blood cell that helps to destroy harmful substances in the body and helps fight off infection.

NM/ NMH: Northwestern Medicine/ Northwestern Memorial Hospital

Non-Myeloablative: In non-myeloablative treatment, doses of chemotherapy are too low to eradicate all of the bone marrow cells. These treatments run lower risks of serious infections.

Nurse Practitioner: Providers with advanced training that have day-to-day responsibility for your care while you are in the hospital. They work in close collaboration with doctors and other members of the healthcare team.

Occupational Therapy: Occupational Therapists work with patients to teach skills that will help the patient maintain independence in activities of daily living.

Pancytopenia: Reduction in the number or red blood cells, white blood cells, and platelets.

Peripheral Blood Stem Cells: Stem cells (immature blood cells) found in the circulating blood rather than in the bone marrow. These cells have the ability to develop into white blood cells, red blood cells, platelets, and immune cells such as T and B lymphocytes.

Peripheral Stem Cell Transplant: A method of replacing blood-forming cells (stem cells) destroyed by chemotherapy. Immature blood cells (stem cells) in the bloodstream are given to the patient after chemotherapy. This helps the bone marrow recover and continue to make healthy blood cells.

Physical Therapy: Therapy to preserve, improve, or restore movement and physical function impaired by injury or disease. Physical therapy uses exercise, physical modalities (such as massage), assistive devices, and patient education and training to assist the patient.

Physician Assistant: Providers with advanced training that have day-to-day responsibility for your care while you are in the hospital. They work in close collaboration with doctors and other members of the healthcare team.

Peripherally Inserted Central Catheter (PICC): A form of central line inserted peripherally (into the arm) that provides intravenous access for a prolonged period of time.

Platelets: Blood cells that help clot blood and thereby help prevent bleeding.

Pneumonia: An infection in the lungs where the air spaces may fill with fluid or pus, causing cough with phlegm, fever, chills, or difficulty breathing. Bacteria, virus, or fungi can cause infection.

Pre-Transplant Testing: Medical tests that are designed to provide an overall picture of a transplant patient's health. These tests will help identify medical issues which may cause complications during the transplant process.

Primary Care Physician (PCP): A physician that serves as a patient's primary care point of contact. This physician is familiar with the patient and has typically provided medical service to that patient for an extended period of time. This doctor helps provide continuous medical care and helps coordinate the care between different specialists.

Prophylaxis: Preventative treatment taken to maintain health and prevent the spread of disease.

Protocol: A specifically designed treatment plan.

Protocol Consent Forms: A document that outlines the treatment and risks of a plan/ research study that the patient signs to indicate understanding and consent.

Randomization: A process that assigns research participants by chance, rather than by choice, to either the investigational group or the control group of a study.

Red Blood Cells (erythrocytes, RBCs): The cells of the blood which contain hemoglobin and which carry oxygen to the cells and tissues. They also carry carbon dioxide back to the lungs.

Rejection: The failure of a patient's body to accept a transplanted tissue as the result of the body recognizing the new transplanted tissue as "foreign" and turns on the immune system of the body against it.

Relapse: A return of a disease or illness after partial or complete recovery from it.

Remission: The time during which the symptoms of a disease disappear. Complete remission means that all of the disease is gone. Partial remission means that the disease is significantly improved by treatment but some parts of the disease are still present.

Rube Walker Blood Center: The Rube Walker Blood Center is Northwestern Medicine's outpatient blood center, where patients are sent by their doctors to receive a variety of blood treatments. This is where you will have your stem cells collected.

Side Effect: An often harmful and unwanted effect of a drug or treatment that can occur.

Standard Therapy: Treatment that is accepted by medical experts as the routine treatment for a certain type of disease and that is widely used by healthcare professionals.

Stem Cells: The "parent cell." Every type of blood cell in the body begins its life as a stem cell. The stem cells then divide and form the different cells that make up the blood and immune system. A stem cell can turn into an ordinary blood cell such as a red blood cell, a white blood, large cell which can fragment into the platelets for blood clotting, or into new immune cells such as T or B lymphocytes.

Stem Cell Harvest: The collection of healthy stem cells from the circulating blood stream.

Stem Cell Infusion: Previously collected stem cells are given to the patient through an I.V.

Strict Intake and Output: The hospital staff will record how much you eat and drink in a day (this is your intake) and how much there is in output (urine, stool, vomiting). These levels will determine your fluid balance (if you are dehydrated or retaining too much fluid). There are certain medications that might affect the balance of intake and output. This needs to be monitored while you are in the hospital.

Subcutaneous Injection: The needle is inserted below the skin to inject.

Syngeneic Transplant: This is a special kind of transplant that can only be used when the patient has an identical sibling (a twin or a triplet) who can donate stem cells to the patient.

T Lymphocytes: Normally, T cells attack infectious agents. In autoimmune diseases, T cells attack body's own normal tissue.

Thrombocytopenia: Low platelet count.

Titer: A blood test that assesses the levels of antibodies against various germs, such as bacteria or viruses.

Total Body Irradiation: Involves radiation treatment to the entire body. It is typically used with high dose chemotherapy in patients undergoing stem cell transplantation for cancer and other blood conditions. The purpose is to kill cancer cells and to cause a depression in the immune system.

Total Parenteral Nutrition (TPN): TPN is a way of supplying all of the nutrients the body needs by bypassing the digestive system (eating followed by digestion) and instead dripping a nutrient solution directly into a vein. TPN is used when a patient cannot get their nutrition through eating.

Transfusion: The infusion of a product derived from blood cells.

Urinary Tract Infection (UTI): An infection of one or more structures in the urinary system. The urinary system is the tract through which urine passes.

Venous Access: A method used to gain entrance into a vein.

VRE: Vancomycin-resistant enterococci (VRE) are a type of bacteria called enterococci that have developed resistance to many antibiotics, especially vancomycin (antibiotic). This type of bacterial infection cannot be treated by vancomycin. This bacteria can spread from one person to another through physical contact and through contact with contaminated objects. Every patient undergoes a nasal and anal swab during hospitalization to determine if you carry VRE. Someone can carry this bacteria on their body without having an active infection from it occurring.

White Blood Cells: Cells that help fight infection and disease.

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