



My Journey... *Through a Bone Marrow/Stem Cell Transplant*





My Journey...
Through a Bone Marrow/Stem Cell Transplant

By



FRED
HUTCHINSON
CANCER
RESEARCH
CENTER

June, 1999

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Supported in part by grants from **AMGEN** and
CORAM Healthcare

This activity book is dedicated to all of the brave children and families who courageously fight cancer and blood disorders.

We would like to acknowledge the following people who have shared their time, energy, and experiences to make this activity book possible:

Drawings

**Regina Carns, 14 years old
Jeannette Emley, 12 years old
Savannah Rose Jantsch, 6 years old
Rachel Martin, 11 years old
Gaelen McCrary, 11 years old
Teryn Peroff, 18 years old
Justine Slattery, 12 years old**

Photography

Eileen Miller, RN

Other

**Kathy Anderson, illustrations
Valerie Dauzenroth, layout
Brandon Emley, 10 years old, opinions & experiences
Jean Sanders, MD, Ann Woolfrey, MD, and
Alisa Peterson, MSW, expertise
*And many other friends who assisted in this project.***

How Do I Use My Activity Book?

This is an activity book for you to use during your bone marrow/stem cell transplant. This book has pictures to color, games, puzzles, activities, and information. In the back of the book are blank calendar and journal pages to write on.

SHARE THIS BOOK!

Hi! My name is _____. I have
come to _____ to have a
Bone Marrow/Stem Cell Transplant. This book is all
about me and what happened during my transplant.

I am _____ years old.

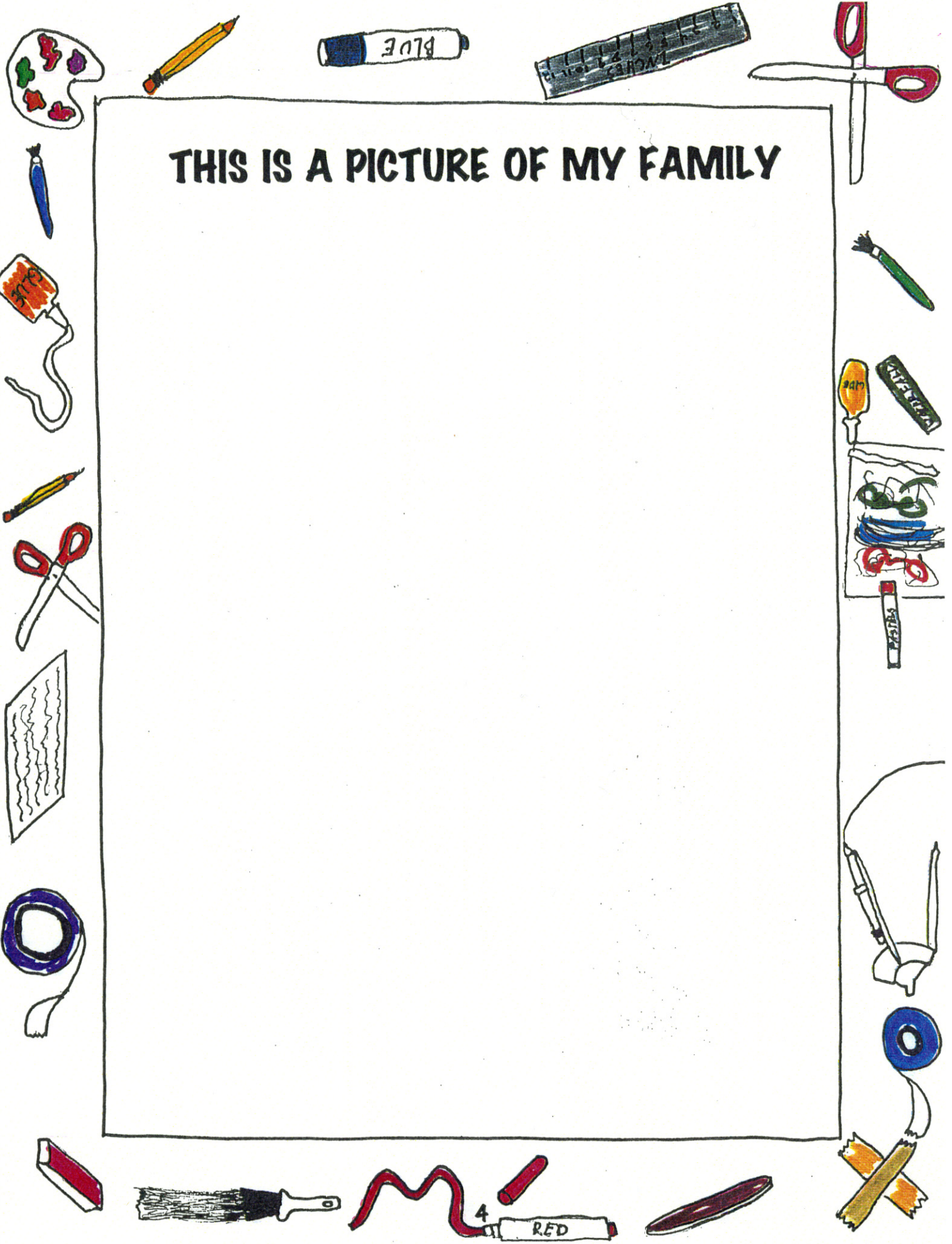
My birthday is _____.

I am from _____.

My favorite food is _____.

I like to play with _____.

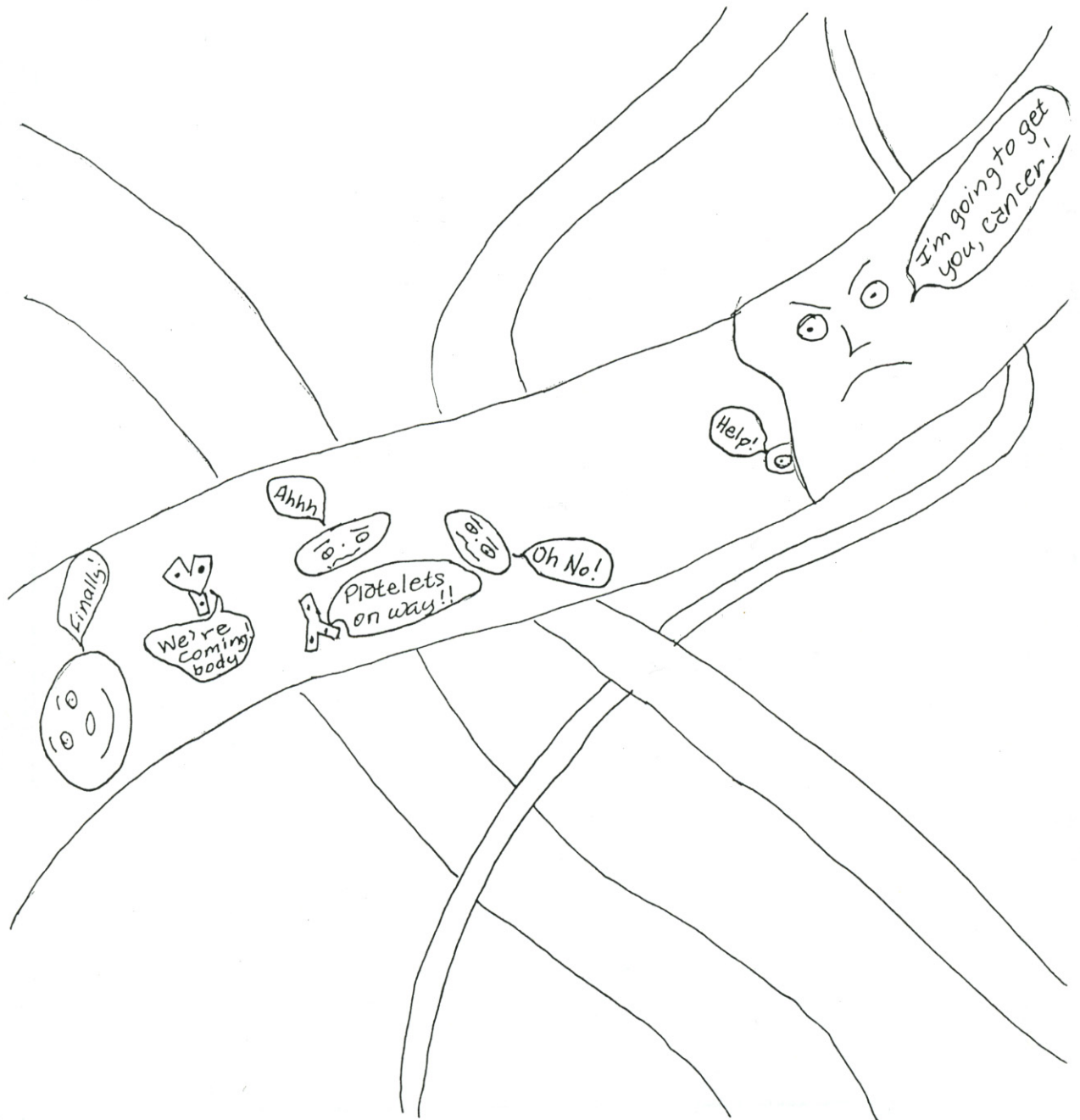
THIS IS A PICTURE OF MY FAMILY



A bone marrow/stem cell transplant is a treatment for different kinds of cancer and blood diseases.

I have a disease called _____.

My donor is _____.





THINGS I WANT YOU TO KNOW ABOUT ME

When I'm happy I _____.

When I'm sad I _____.

When I'm scared I _____.

When I'm tired I _____.

This is a picture that shows how I feel about having a transplant.

FEELINGS

FEELINGS



The first step of my journey involves evaluations of me, my disease and my donor. My parents and I will meet a lot of different people who will help me through my transplant. I will have many tests and check-ups to help the doctors decide how to fight my bad cells.

The name of my hospital at home is _____.

The name of my new hospital is _____.

Some tests that I've had: (circle)

LP

Bone Marrow

X-Ray

Pulmonary function test

MRI

CT Scan

Blood draw

Dressing change

Dental exam

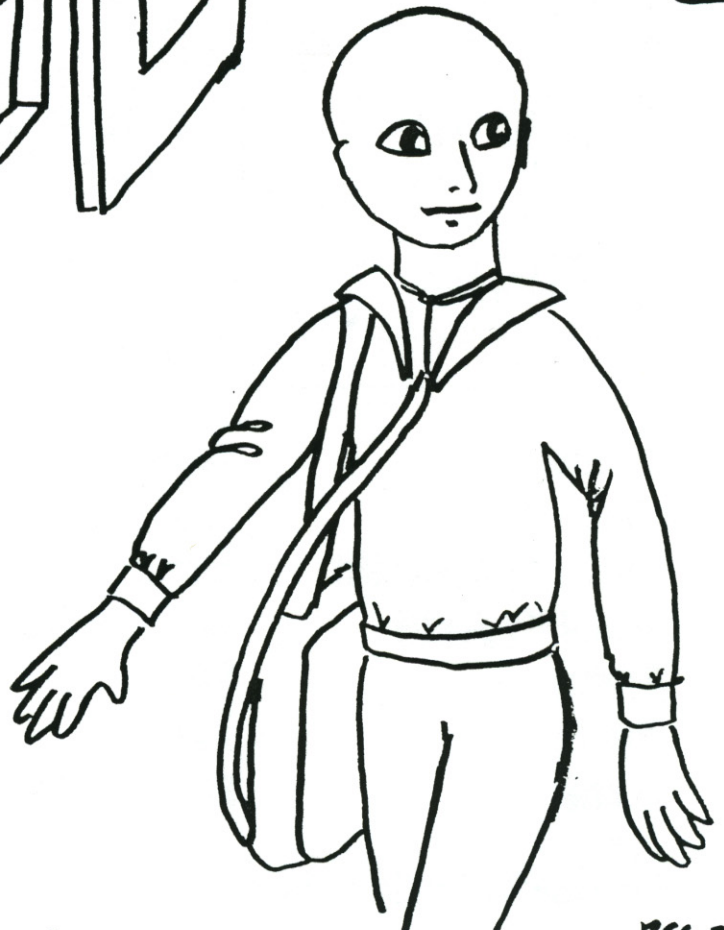
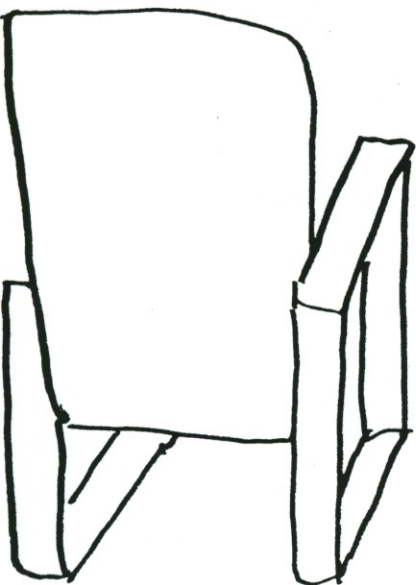
Weight

Temperature

Blood pressure

Muscle size test

Clinic Waiting Room



**Find the names of some of the people you will meet
during your bone marrow/stem cell transplant.**

S	D	D	A	H	J	N	V	S	P	E	E	C	H	T	H	E	R	A	P	I	S	T
L	I	D	Q	A	A	V	B	O	J	F	G	T	T	R	K	J	U	U	H	O	L	G
O	O	E	S	D	V	J	Y	I	L	Z	D	X	V	F	H	E	H	J	Y	J	U	R
C	S	N	F	G	R	H	J	Y	M	U	L	K	I	C	P	N	J	T	W	S	D	E
C	Q	T	E	Y	H	D	E	F	A	E	N	V	E	Q	W	H	J	S	T	R	L	S
U	D	I	F	I	E	N	I	K	K	L	Y	T	I	R	H	N	J	I	N	L	K	P
P	Z	S	A	S	A	U	X	D	S	E	B	G	E	F	D	E	S	N	P	K	J	I
A	C	T	S	D	X	R	Z	A	Q	A	Y	K	J	E	H	E	R	E	H	W	Q	R
T	E	R	W	T	Y	S	R	H	L	J	R	L	O	O	R	I	M	I	Y	P	F	A
I	X	C	V	F	E	E	R	J	L	O	E	I	L	P	Y	H	M	G	S	R	E	T
O	R	A	S	D	G	C	G	F	W	Y	U	J	K	P	A	A	F	Y	I	B	G	O
N	O	A	Q	U	I	K	B	L	R	Q	O	W	N	F	O	B	R	H	C	O	W	R
A	T	N	F	J	U	M	A	P	E	D	R	O	V	R	R	E	T	L	A	H	E	Y
L	C	L	A	C	H	I	L	D	L	I	F	E	S	P	E	C	I	A	L	I	S	T
T	O	Z	Y	S	C	L	E	E	P	I	N	G	H	D	L	O	G	T	T	A	Q	H
H	D	U	I	O	C	K	B	R	O	N	W	F	O	N	U	X	J	N	H	U	M	E
E	N	P	S	U	R	G	E	O	N	E	D	T	O	V	D	E	R	E	E	D	O	R
R	I	V	E	R	T	H	L	F	A	Z	Y	S	E	L	E	E	P	D	R	O	I	A
A	A	N	G	D	G	O	T	E	H	M	E	R	R	A	H	Y	C	H	A	C	R	P
P	P	O	N	C	H	A	P	L	A	I	N	C	E	I	C	W	E	N	P	T	T	I
I	T	T	O	W	N	T	H	L	E	H	U	T	H	C	S	H	S	C	I	O	H	S
S	O	O	L	I	S	S	U	O	P	E	R	D	U	P	E	R	E	L	S	R	O	T
T	N	G	L	I	V	E	T	W	H	E	F	R	E	D	J	U	S	R	T	T	I	C
D	I	E	T	I	T	I	A	N	E	G	N	I	D	N	E	T	T	A	F	R	E	D

Attending

Chaplain

Child Life Specialist

Dental Hygienist

Dentist

Dietitian

Doctor

Fellow

Lab Tech

Nurse

Occupational Therapist

PA

Pain Doctor

Physical Therapist

Respiratory Therapist

Scheduler

Social Worker

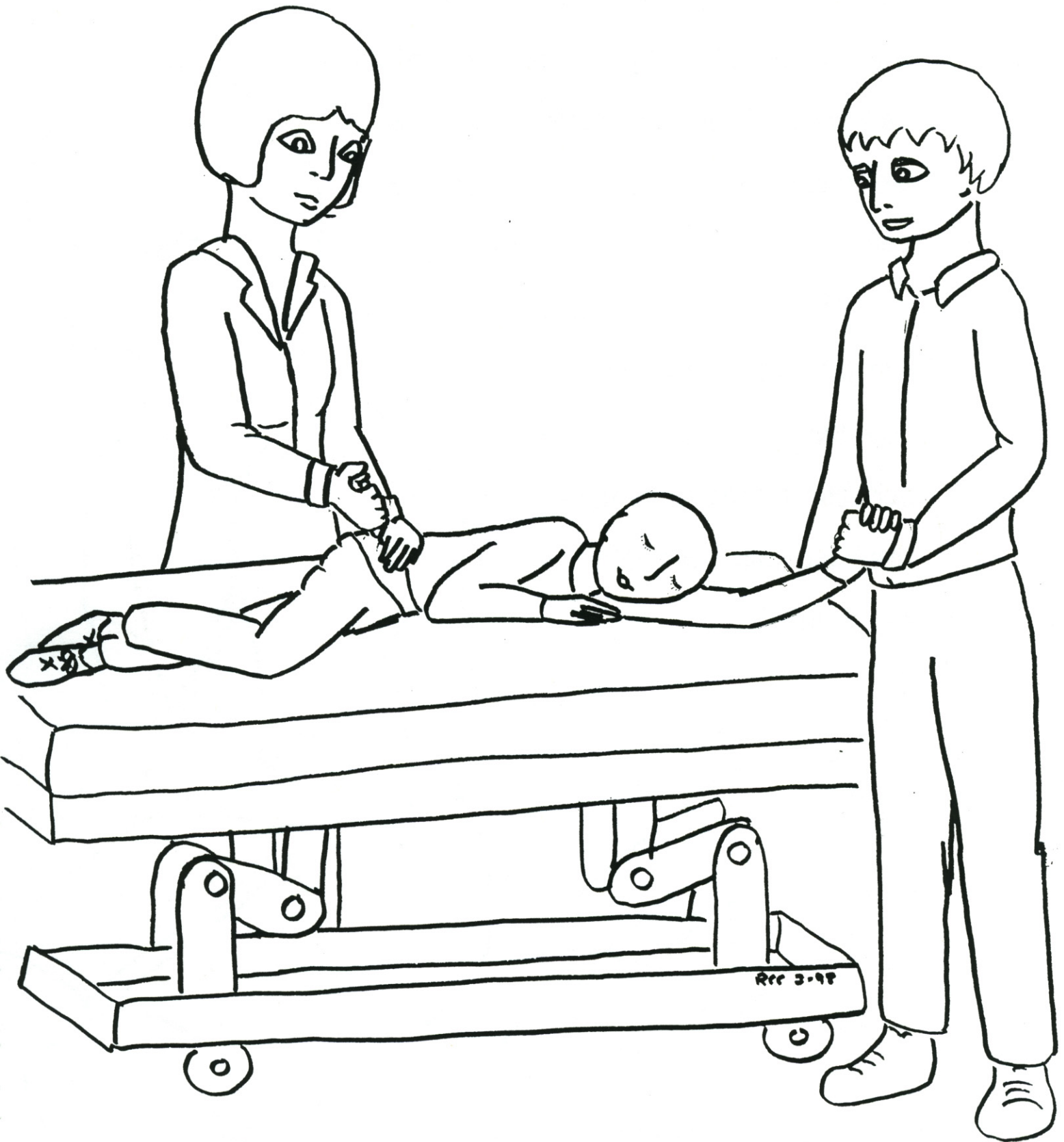
Speech Therapist

Surgeon

Teacher

Volunteer

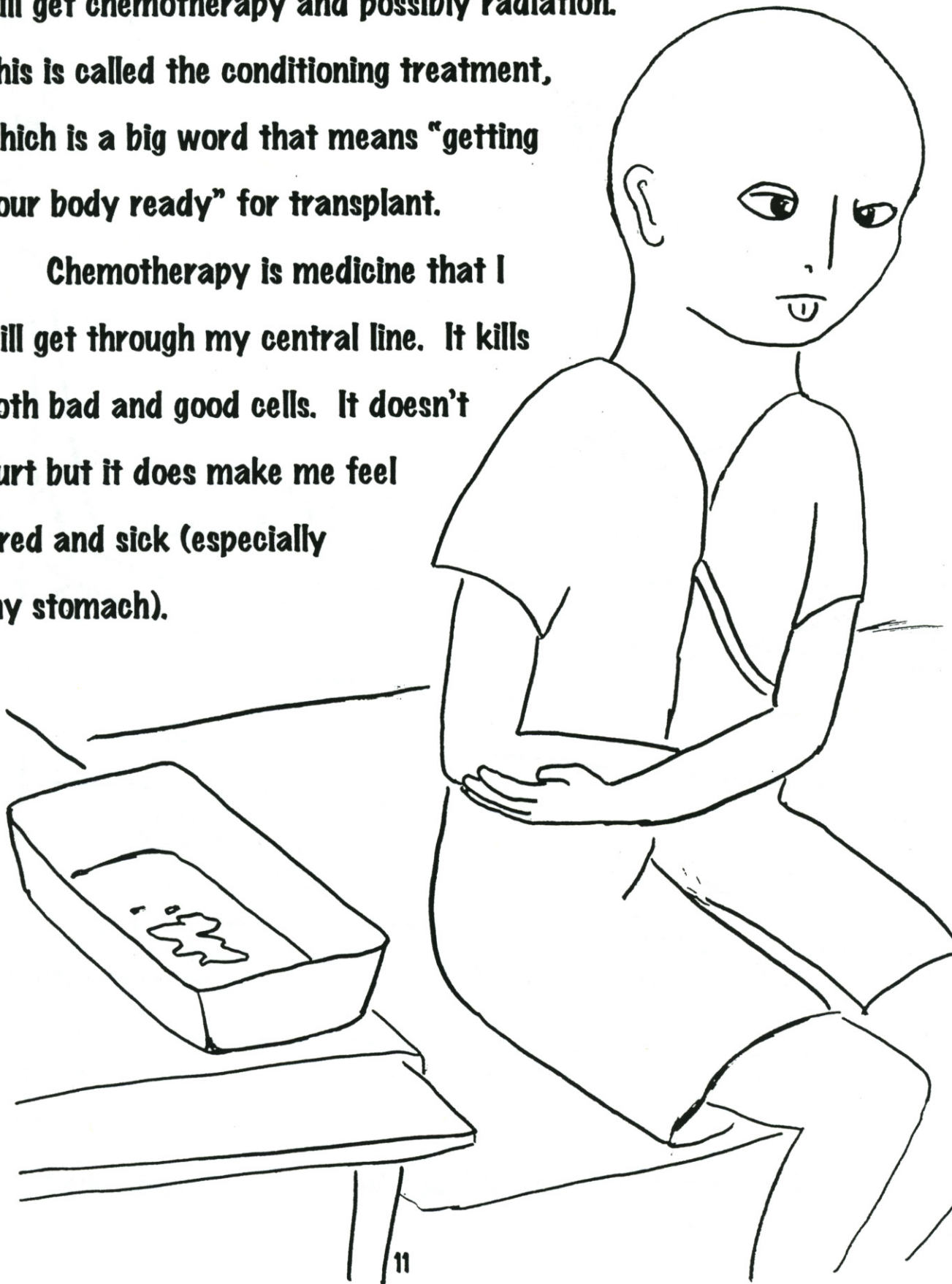
See page 52 for the answers.

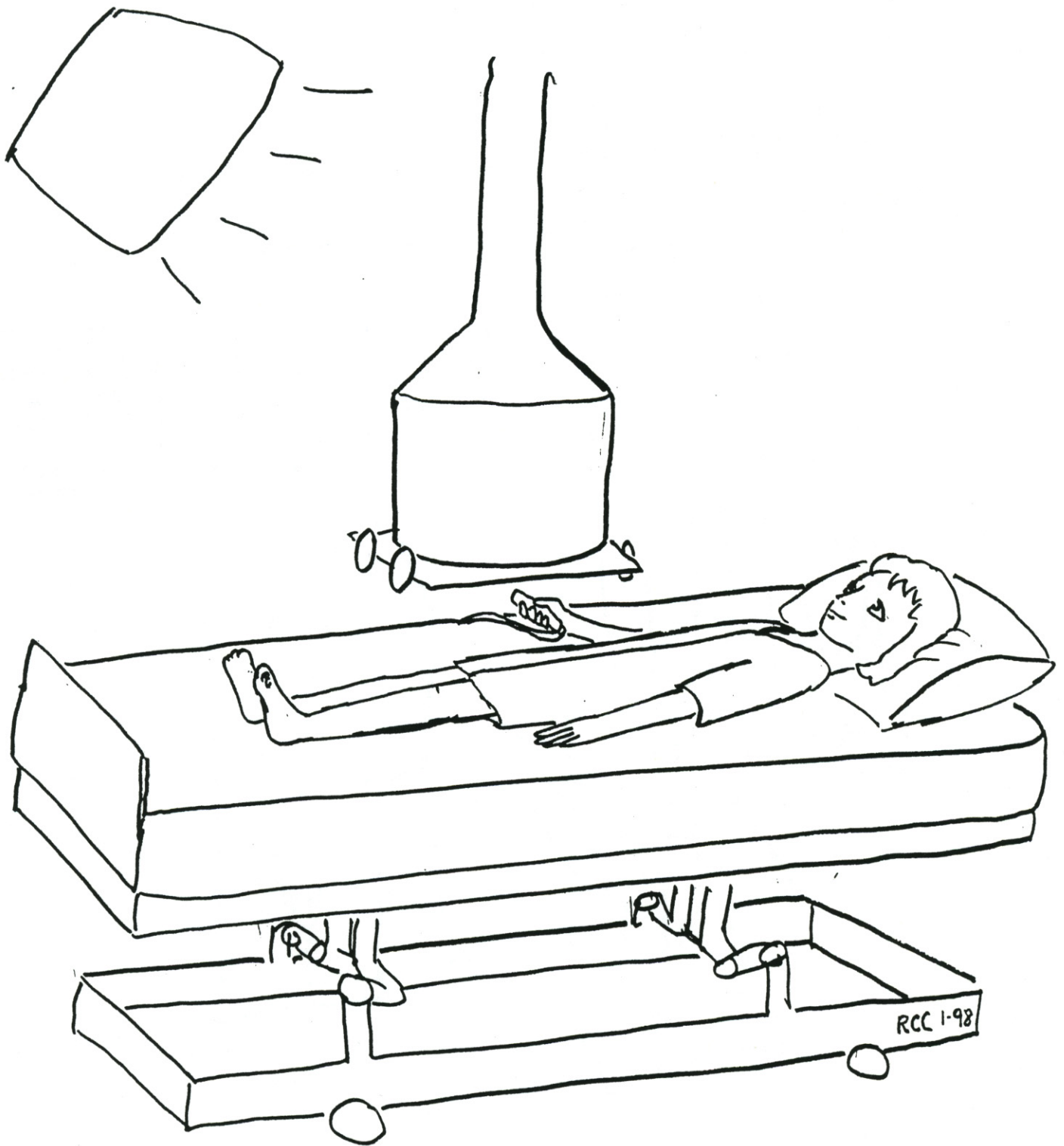


A bone marrow test will be done before I go into the hospital.

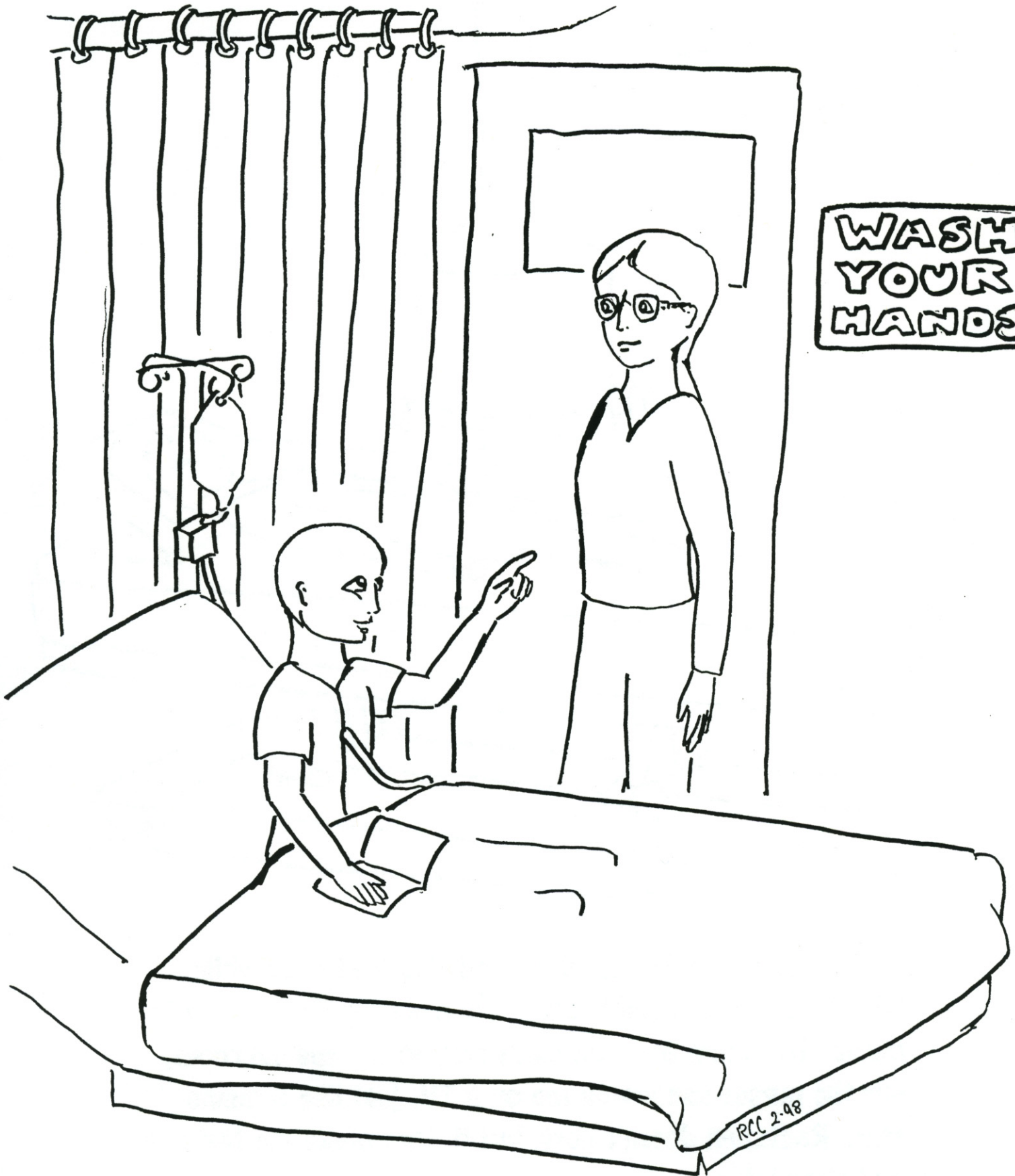
When my transplant starts, I will go to the hospital. I will get chemotherapy and possibly radiation. This is called the conditioning treatment, which is a big word that means “getting your body ready” for transplant.

Chemotherapy is medicine that I will get through my central line. It kills both bad and good cells. It doesn't hurt but it does make me feel tired and sick (especially my stomach).





Radiation is like invisible medicine that I get while lying in a bed in a quiet room. I can watch TV or listen to music. My mom and dad can't stay in the special room, but the nurses can watch me on a TV, just like a movie star. Radiation doesn't hurt, but it does make me feel sick and tired later.



RCC 2-98

After conditioning, I could get an infection. To help protect me from germs, all of my visitors must not have a cold or the flu. Good handwashing is very important. Everyone must wash their hands when they come into my room. It's okay to remind people to wash their hands when coming to see me.

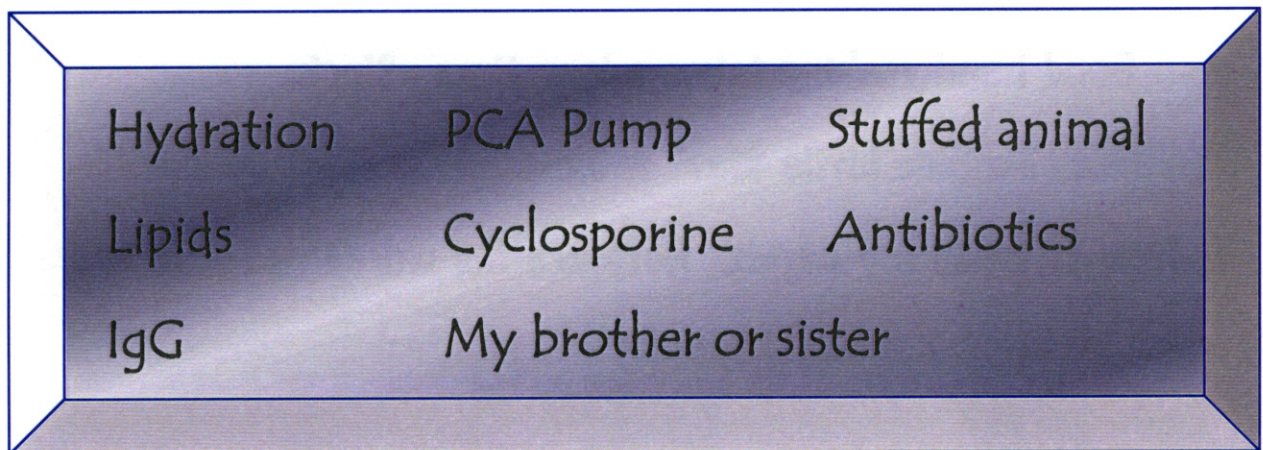
Good handwashing takes a long time. Singing "Twinkle, Twinkle Little Star" is exactly the right amount of time to wash my hands. Here are the words so I can teach all my friends and family:



Twinkle, twinkle little star
How I wonder what you are
Up above the world so high
Like a diamond in the sky
Twinkle, twinkle little star
How I wonder what you are

Eating is also important. I may not feel like eating, so I will probably have to start hyperalimentation, or HA. HA is liquid food given through my central line.

My HA bag will hang on an IV pole. Other things hanging on my IV pole are: (circle)



A really cool project that I can do is to design a bumper sticker for my pole. Turn to the next page for materials and instructions on how to make a bumper sticker.

Cut on the
dotted lines.

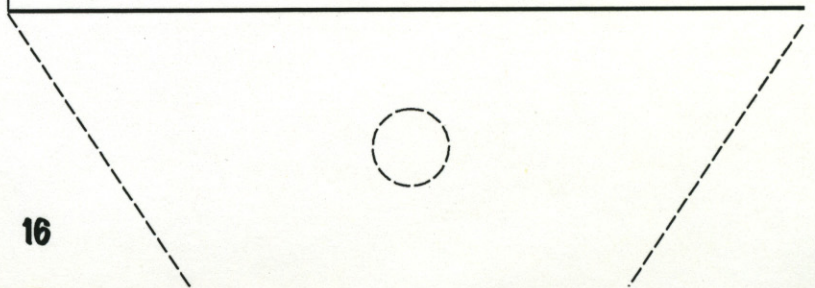


IV Pole Bumper Sticker

**Create a bumper sticker
in the space to the right.
Draw a picture or make
up a saying.**



**Cut on the dotted lines,
and hang from your IV
pole.**



My hair will slowly fall out during conditioning. My head may feel very itchy and I'll want a special haircut.

This is an envelope to keep a piece of my hair to remember what it was like before my transplant.



Today is day "0," my transplant day. Happy New Birthday to me! I get my healthy new cells through my central line. A lot of people are doing different jobs in my room today. I may also have my own special guests.

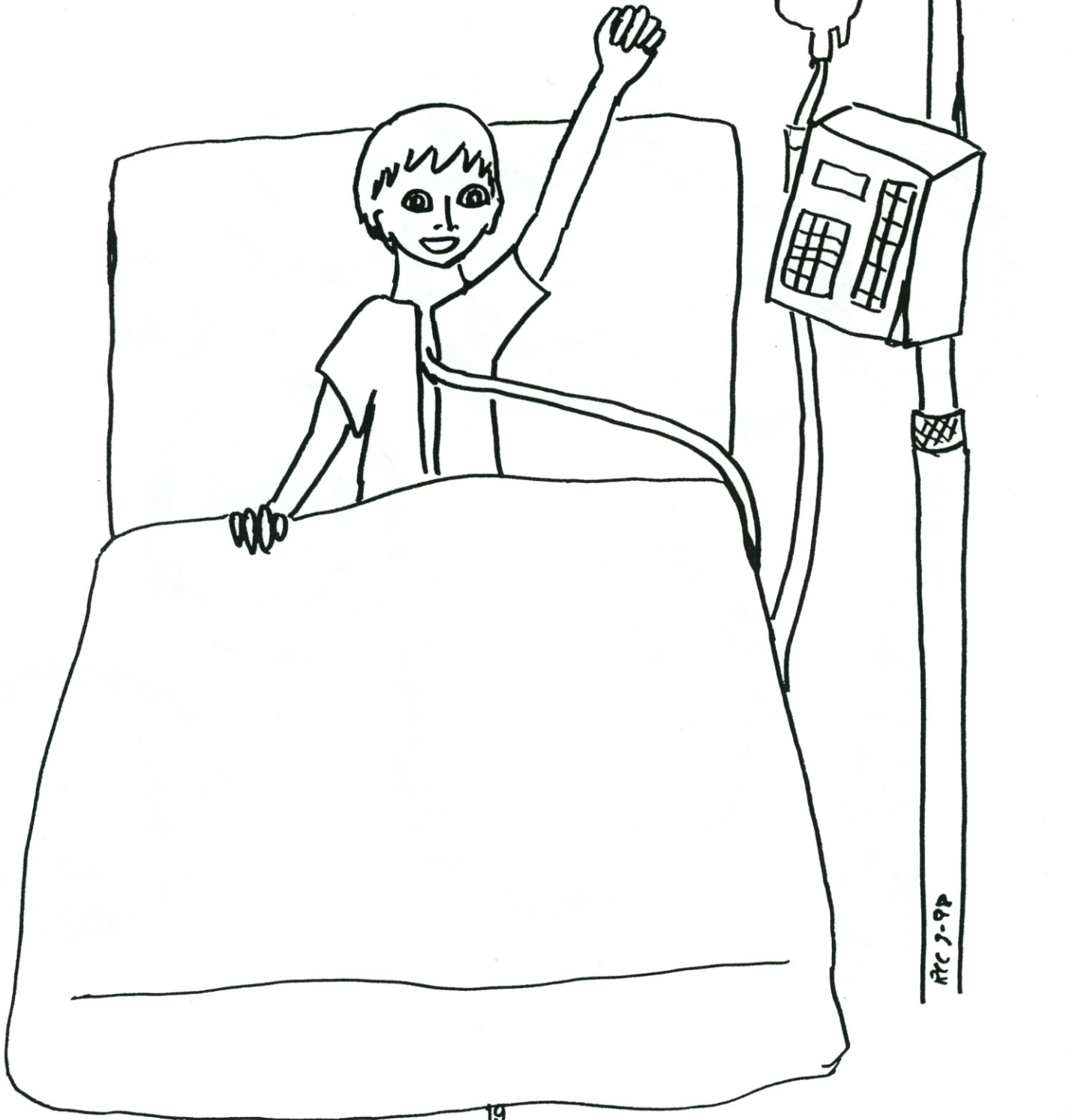
GUEST LIST

NAME	RELATIONSHIP	HOMETOWN
------	--------------	----------

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

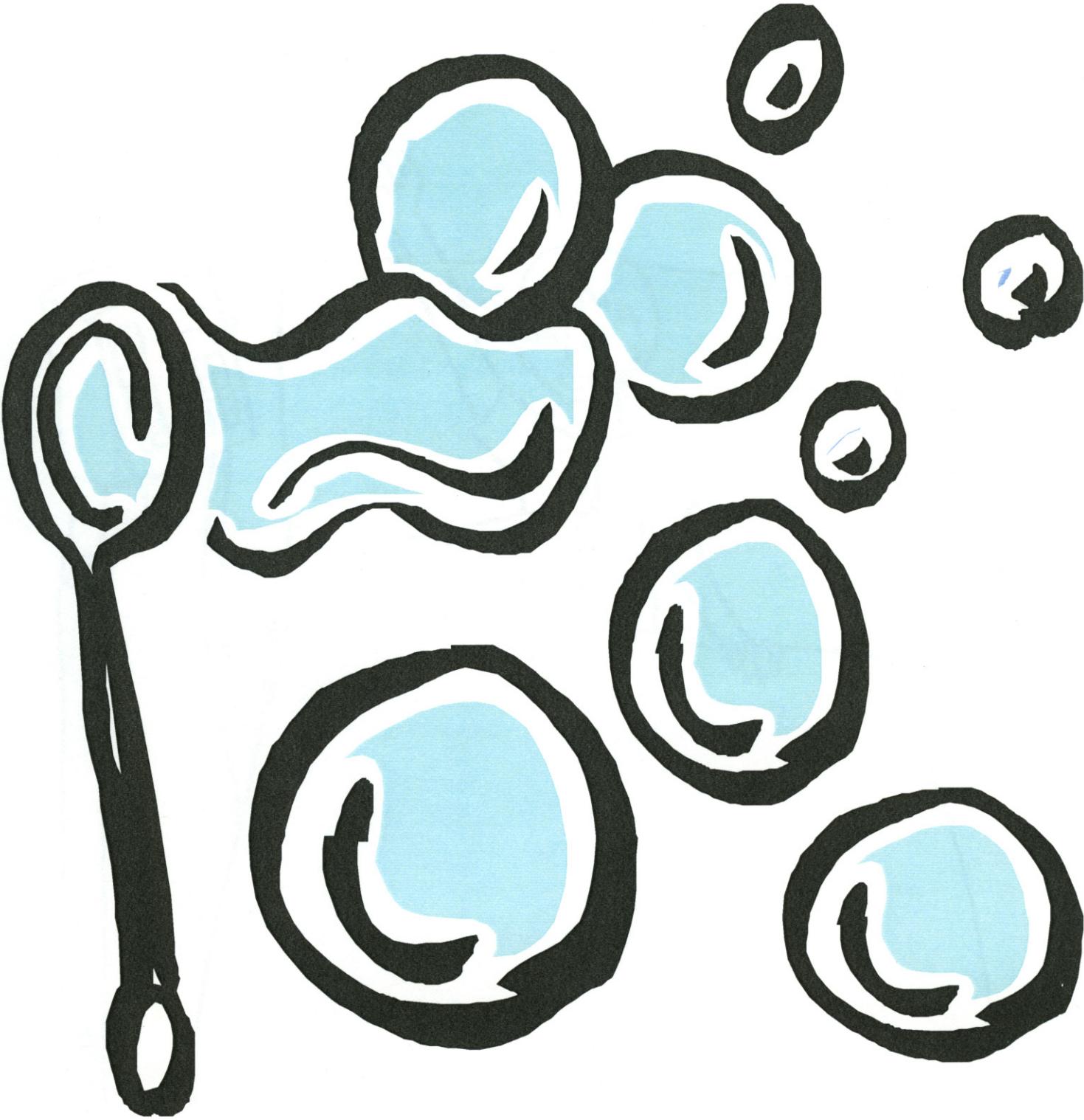
Today I will mark my "new birthday" on the calendar in the back of my book!

DAY 0



REC 7-98

Sometimes I worry about things. I will put my worries in the bubbles and watch them blow away.

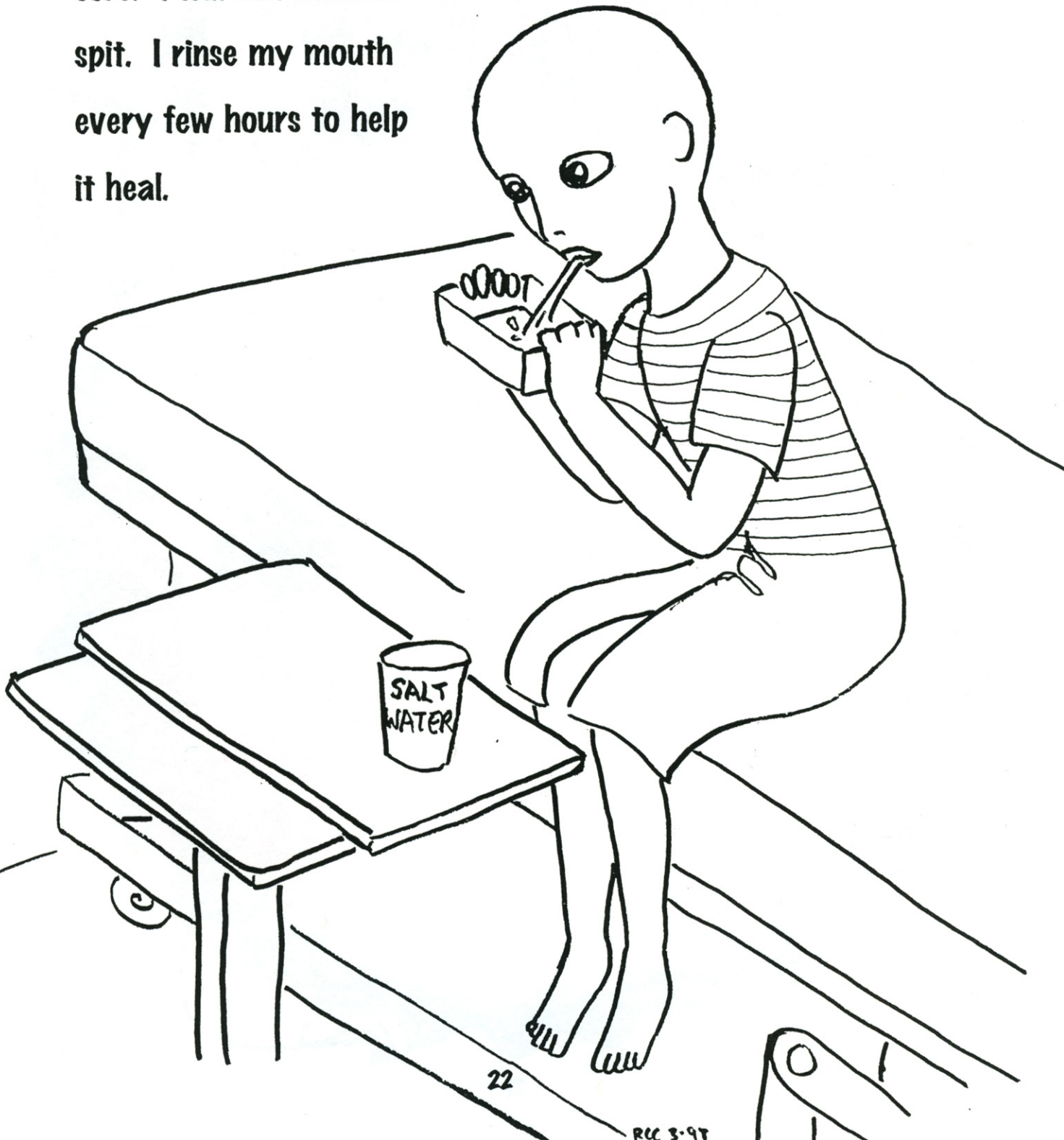


I'm throwing a laughter party!

These are things that make me laugh!



I must wait for my healthy bone marrow/stem cells to grow. It takes time to recover from conditioning. My mouth will be very sore. I will have lots of spit. I rinse my mouth every few hours to help it heal.

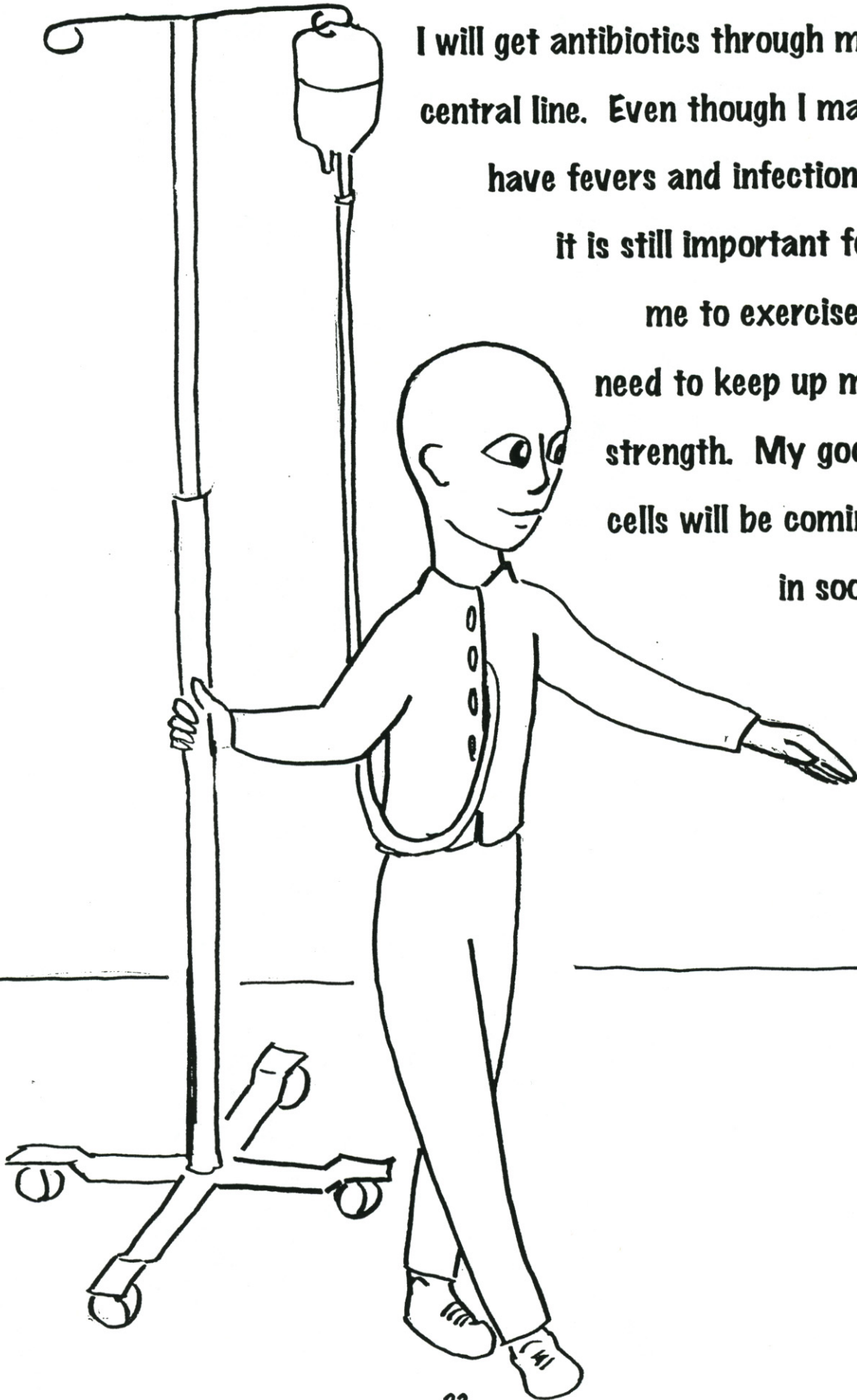


I'm throwing a laughter party!

These are things that make me laugh!

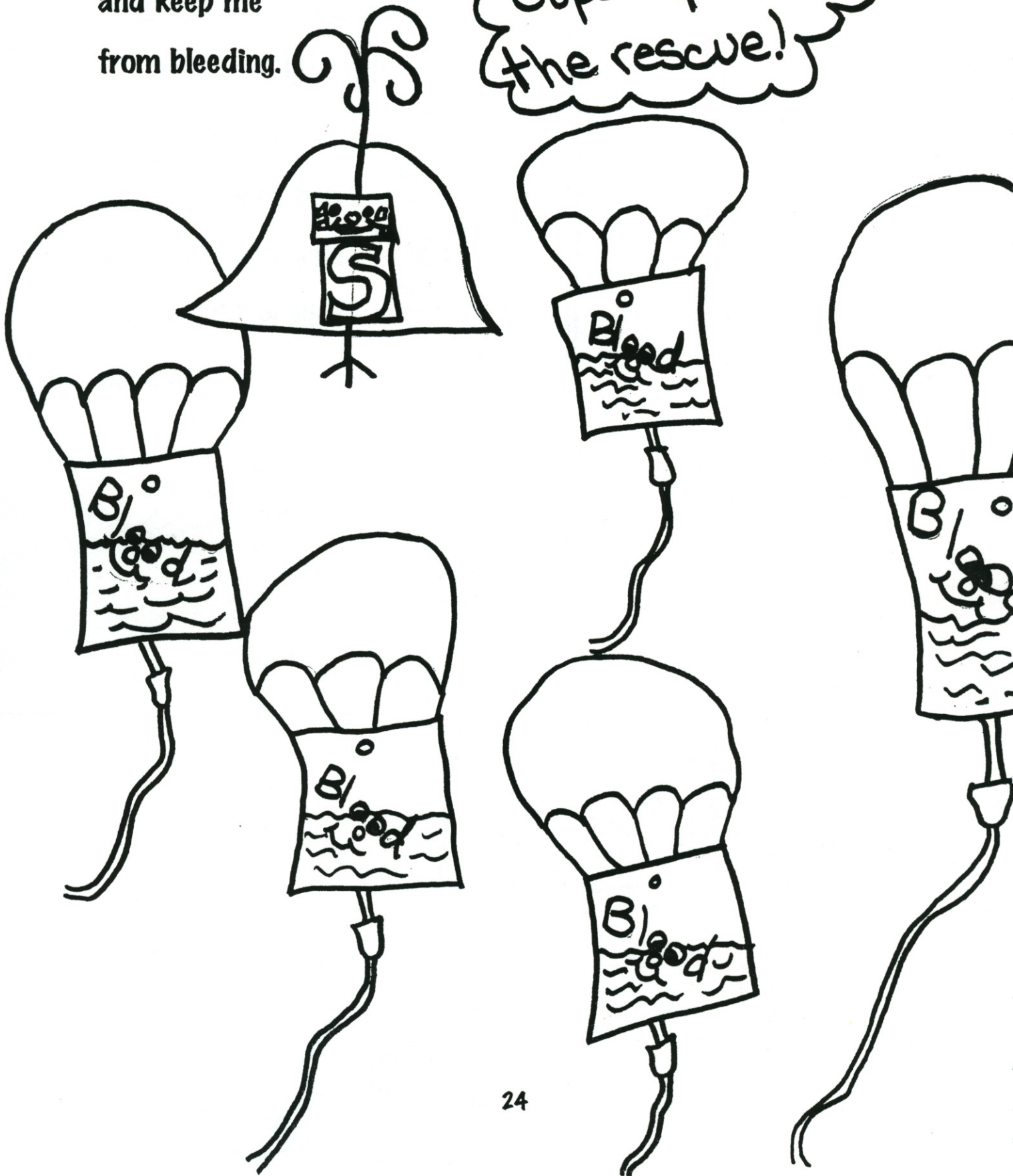


I will get antibiotics through my central line. Even though I may have fevers and infections, it is still important for me to exercise. I need to keep up my strength. My good cells will be coming in soon.



I will also need blood and platelet transfusions. These help to give me energy and keep me from bleeding.

Super pde to the rescue!



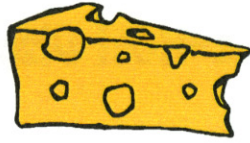
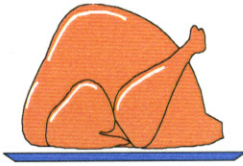
Graft-Versus-Host Disease

When my new cells start to grow, I may get GVHD. If it affects my skin, I'll get an itchy red rash. If it affects my gut, I may have belly pains, throw up, or have diarrhea. If it affects my liver, my skin will turn yellow and my stomach will get bigger.

I will be on special medicine to treat GVHD.

GVHD

PROTEIN



I need protein after my transplant to help make me strong:

Unscramble these foods high in protein.

HIKENCC _____

KRUTYE _____

GEGS _____

LMKI _____

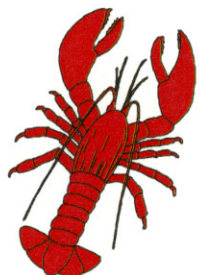
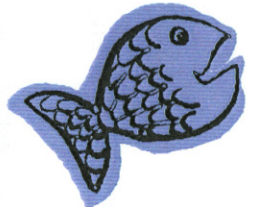
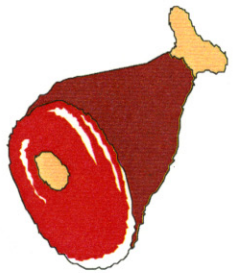
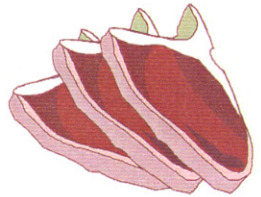
FEEB _____

MAH _____

EHESCE _____

SIFH _____

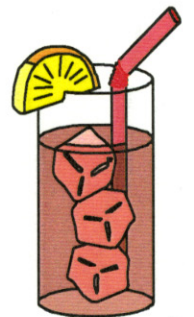
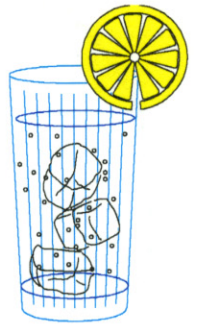
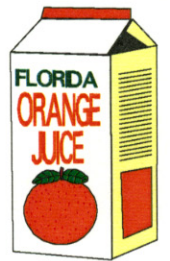
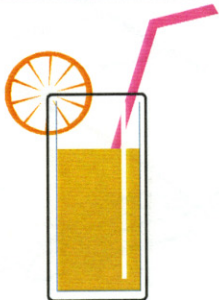
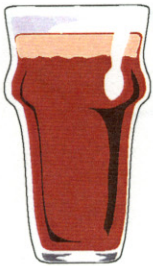
See page 53 for answers.



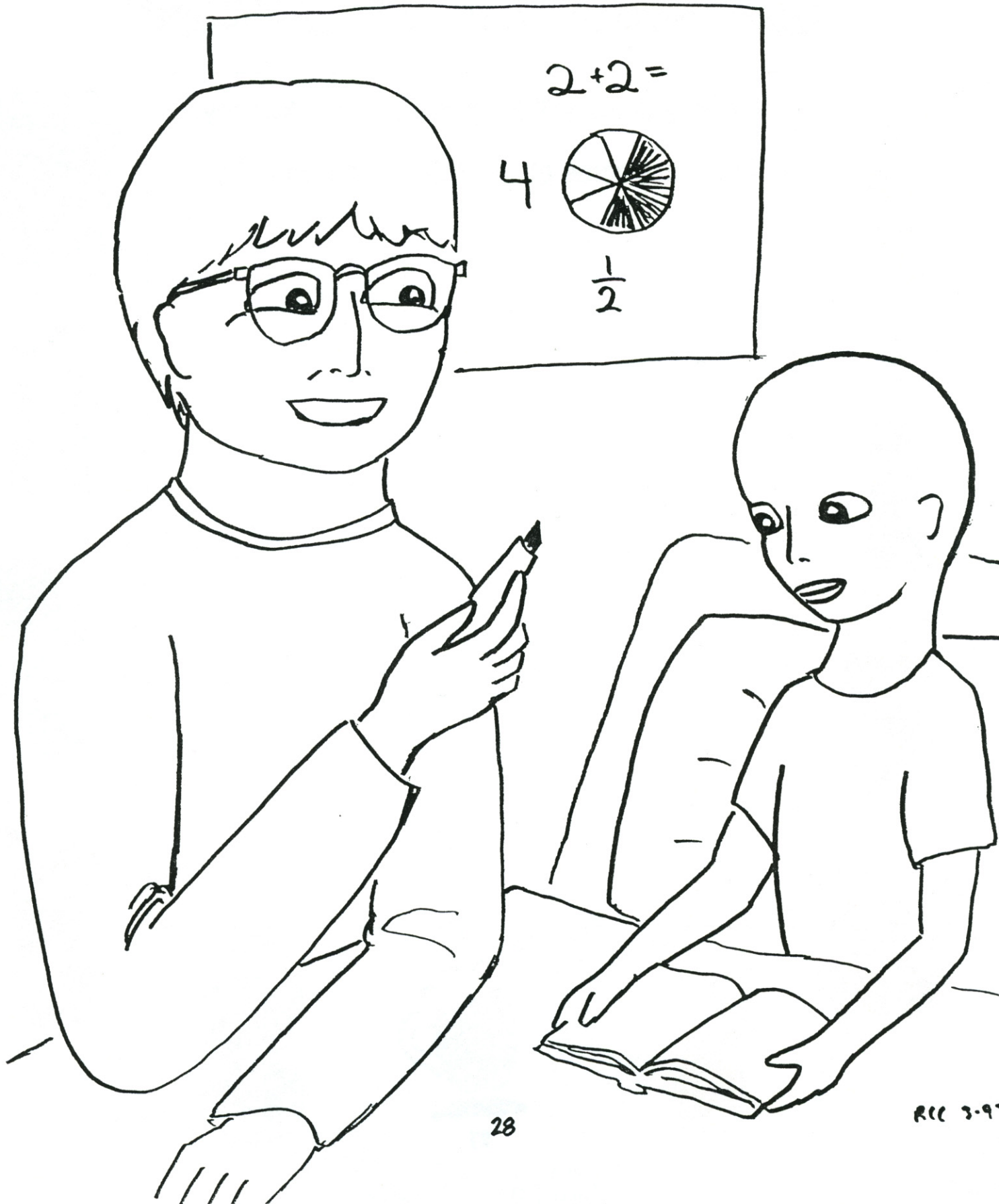
FLUIDS

Drinking fluids will keep my kidneys healthy.

These are some of the things I like to drink.

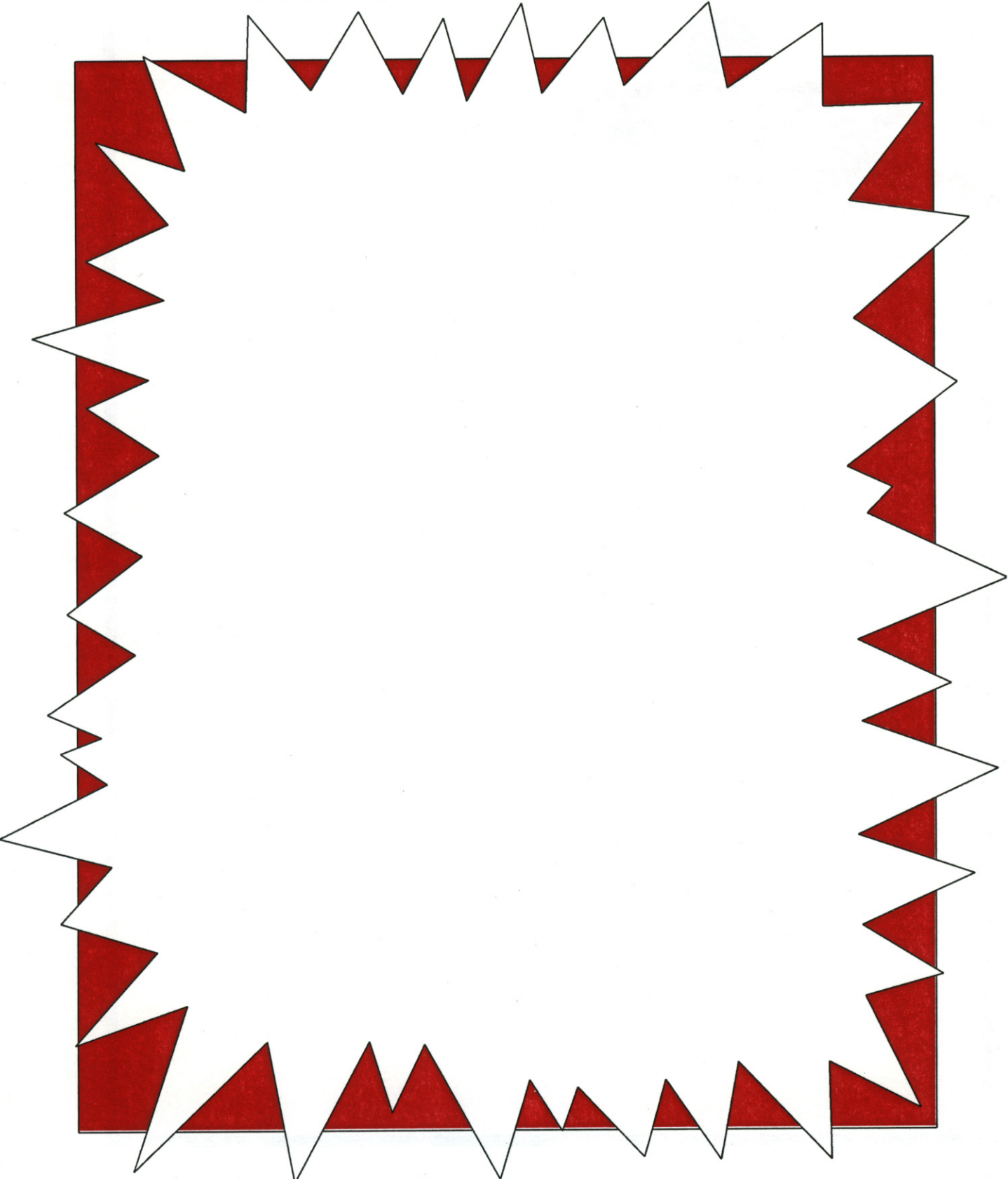


I will have a tutor for at least one year after my transplant because I cannot join my class in school until my new immune system is really healthy. I'll be ready to join my class when I get well.

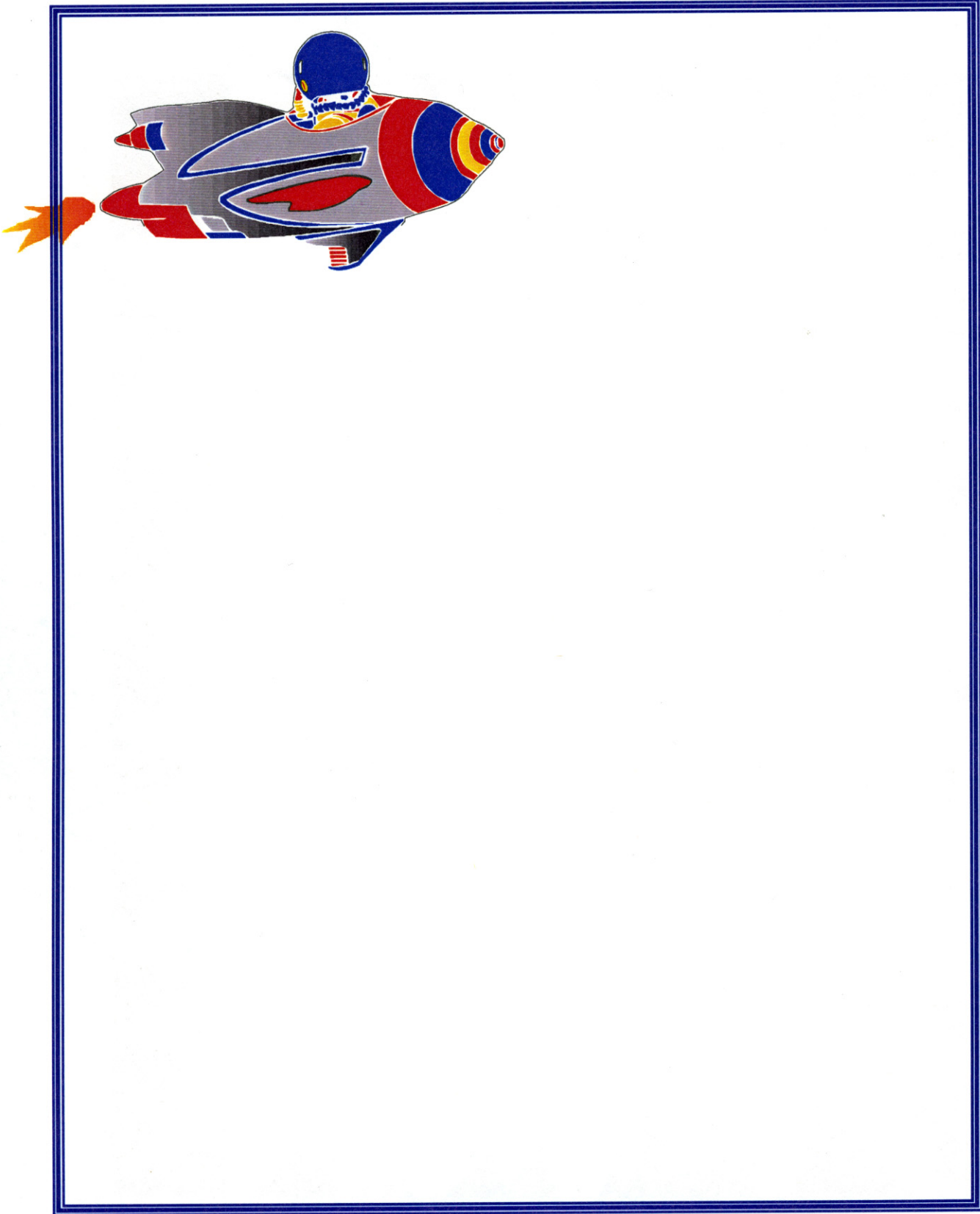


Sometimes I feel angry and don't know why.

This is what my anger looks like:



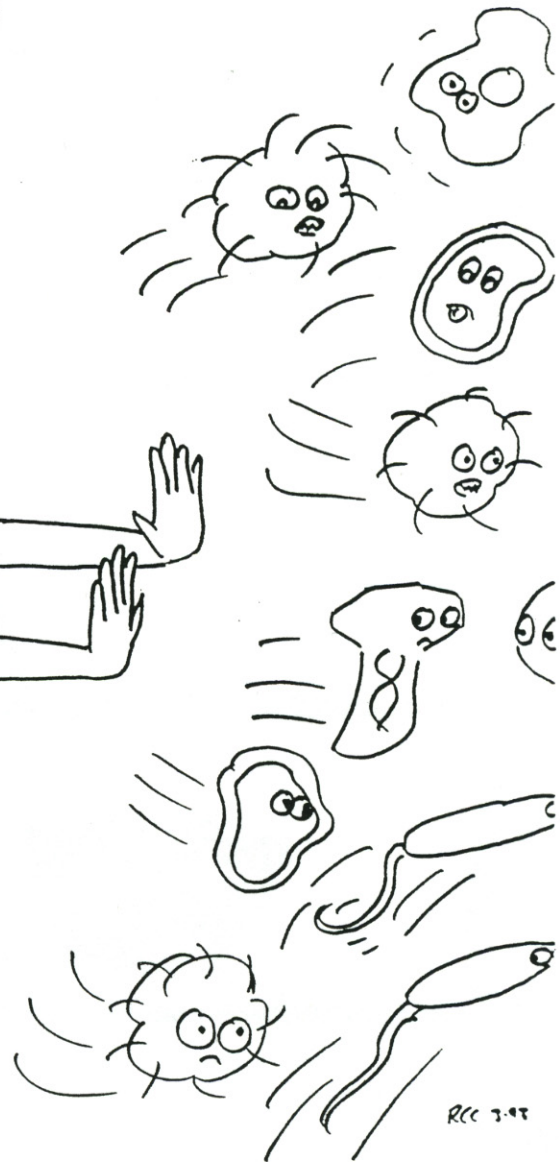
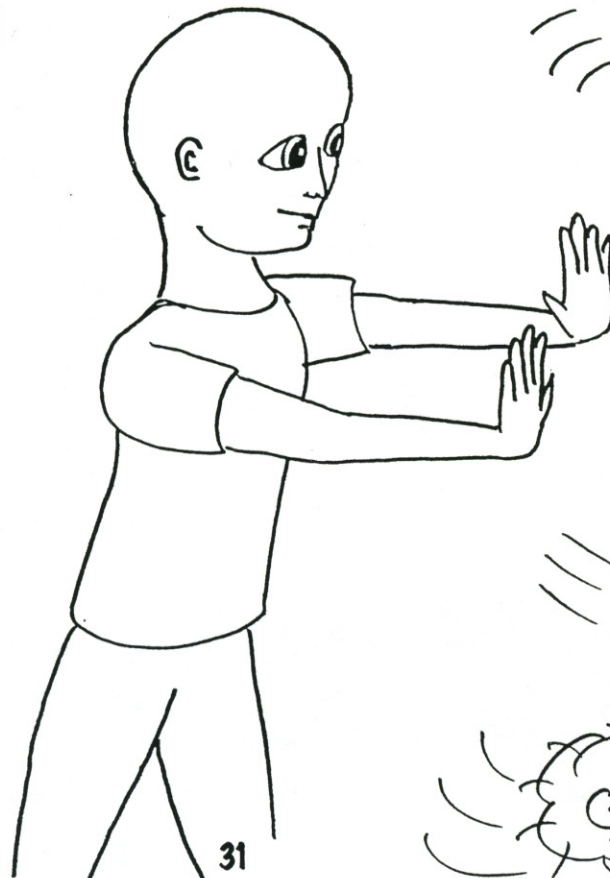
I am the captain of this ship. This is a picture of where I will go.



When my counts reach a magic number and when I start to eat and drink, I may be able to leave the hospital. Now comes more hard work.

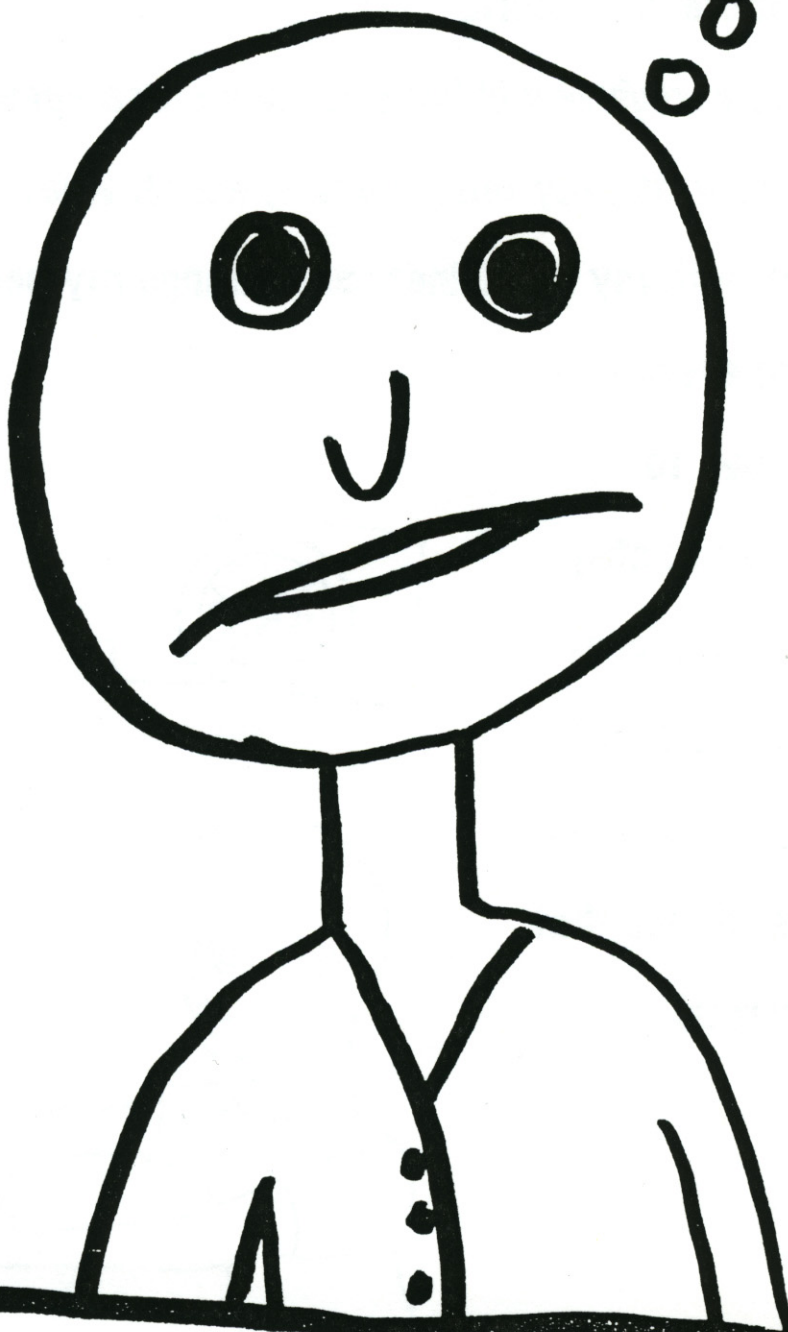
My caregiver will have to take extra special care of me. They will watch my temperature, watch what I eat and drink, help me with my medicines, and change my central line dressing every day.

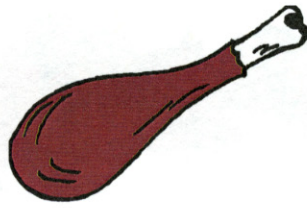
I have to remember to stay away from places that have a lot of people, animals, and flowers (things that have germs).



Names of my pills:

Pills!

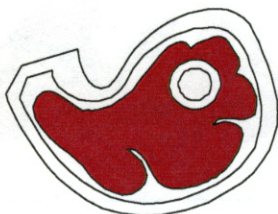
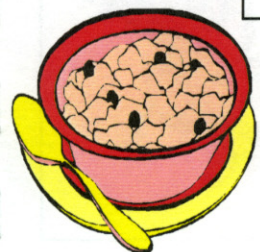
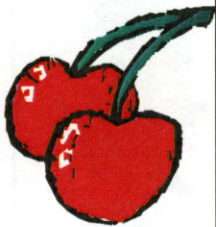
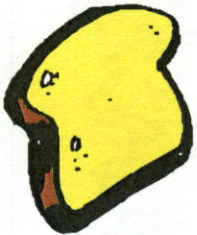
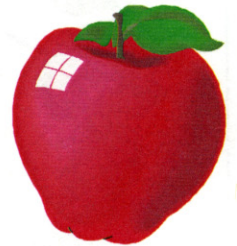
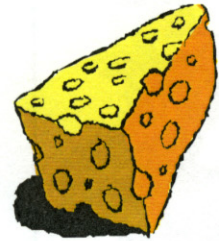




SNACKS

Snacks give me energy and help make me strong.

Here are some of my favorite snack foods.





If I were a tree, this is what I would look like and this is where I would be planted:

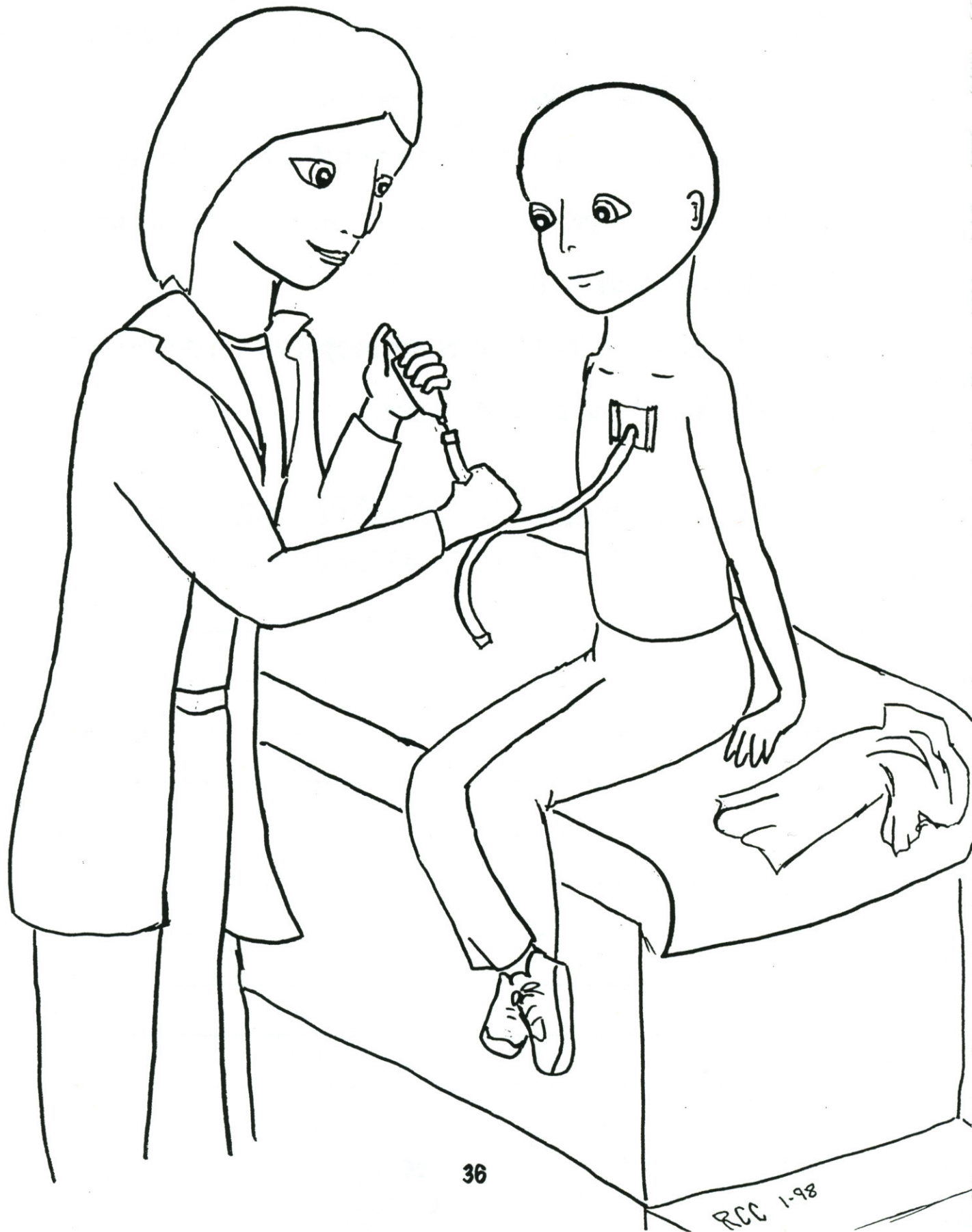
After I leave the hospital, I may need to live nearby the transplant center for several months. I will make many visits to the clinic to get my blood checked. I may get lots of different medicines through my central line.

I know that if I feel crummy or get a fever, I may have to go back in the hospital. It's okay if I do. It's just one more step in the long journey to make me well.

I have met a lot of different people who have helped me get well. Soon I will be going home.

Here are AUTOGRAPHS of some
people who have helped me:

INFUSION ROOM

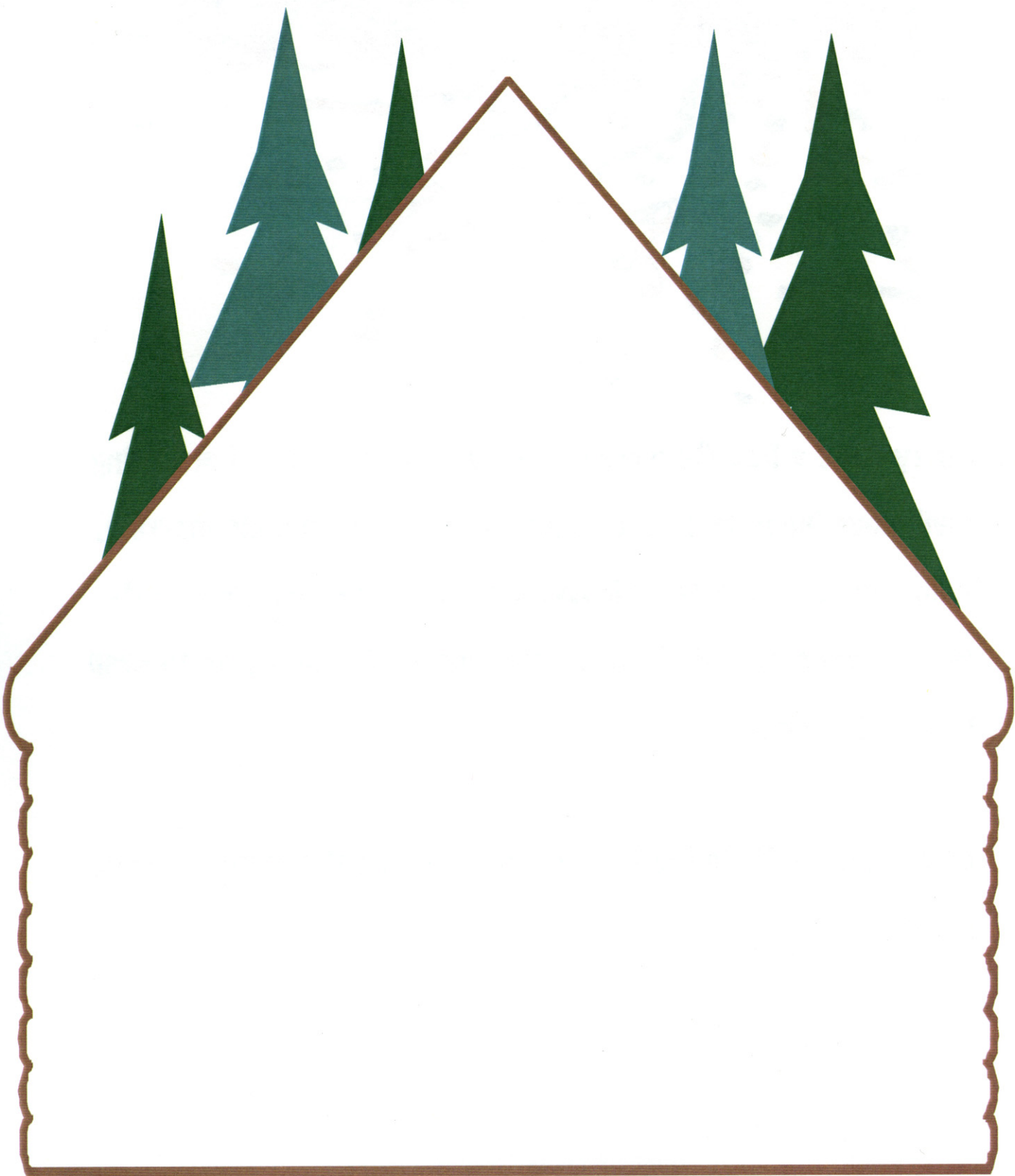




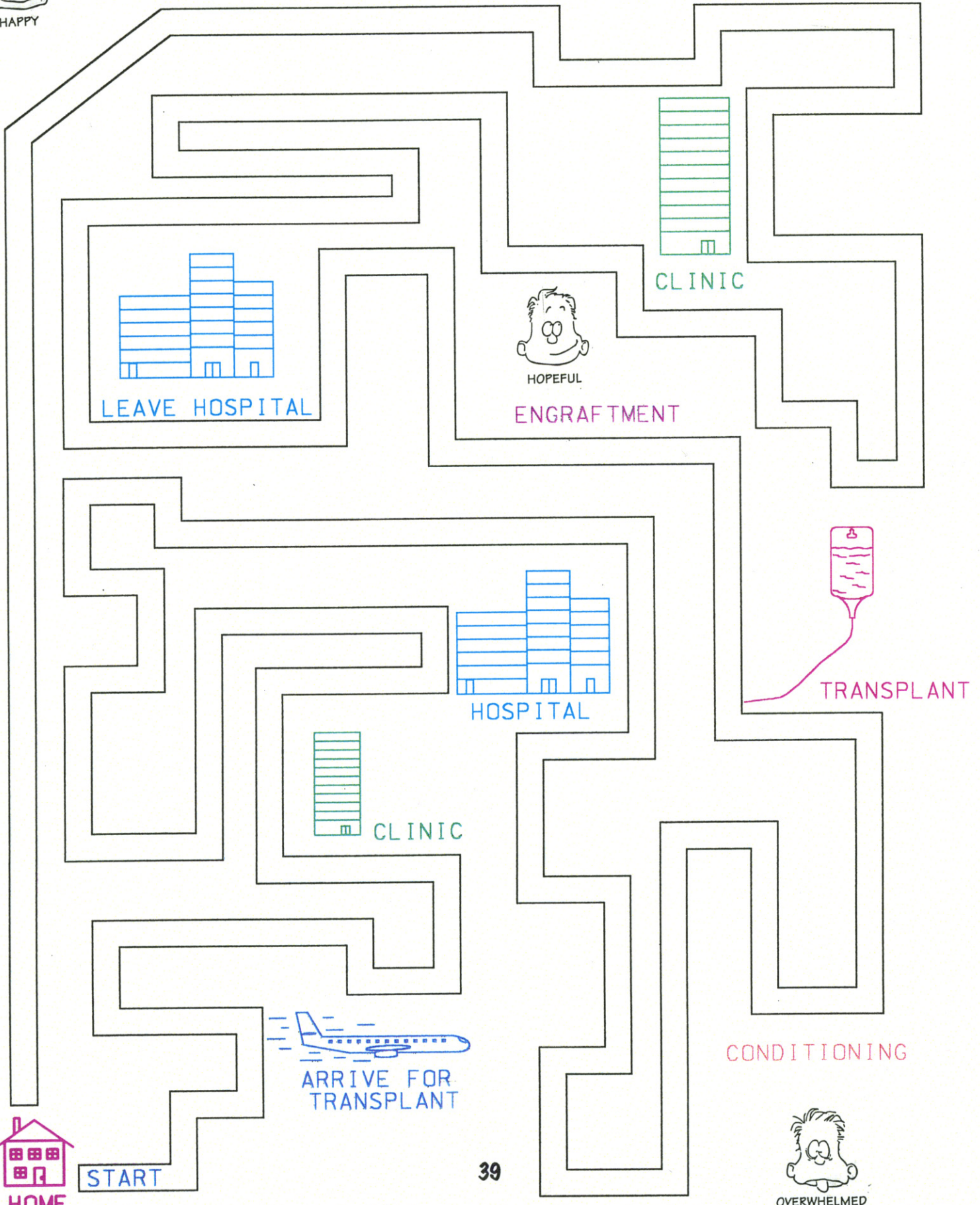
I may have a Day 80 work-up to evaluate how well I am doing. I will have blood tests and other special tests: a bone marrow, a lip biopsy, and a skin biopsy. I will be asleep for these tests. When I wake up I will have a small thread inside my lip to keep it from bleeding.

Look on page 39 to see how you're rounding the corner to going home!

Sometimes I feel sad when I'm away from home. This is a picture of what I miss most about home . . .



Follow me through my transplant journey!



SMILE



JOURNAL

A large rectangular area with a purple border, containing ten horizontal lines for writing.

FACES



JOURNAL





JOURNAL

A large rectangular area with horizontal lines, intended for writing journal entries.

Calendar

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Calendar



Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Calendar



Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

GLOSSARY

- ALL: See "leukemia."
- Allogeneic: Stem cells that come from someone else such as your mom or brother or even someone you don't know.
- AML: See "leukemia."
- Amphotericin: Medicine given for fungal infections. It is given through your central line.
- Antiemetic: Medicine that helps with upset stomach &/or throwing up. It may be given in your central line or by mouth.
- Anesthesia: Medicine that makes you sleep during surgery or for a test. It may be given through your central line or by a mask.
- Antibiotic: Medicine that helps with bacterial infections. It may be given through your central line or by mouth.
- Aplastic Anemia: When your bone marrow doesn't make enough healthy red and white blood cells.
- Attending: Doctor who is the leader of your team.
- Autologous: Stem cells that come from you. They are frozen and may smell funny when you get them given back to you.
- Biopsy: When a sample of a part of your body is taken and looked at under a microscope, such as a small piece of your skin, lip, or bone marrow.
- Bone Marrow: Liquid found in the middle of your bone that makes platelets, red blood cells and white blood cells.
- Bone Marrow Aspirate: Test that is done to check your bone marrow for bad cells or to see how well your new cells are growing. It is the test that is done in the bone above your bum while you are asleep.

- Calcium: Nutrient that helps to build strong bones and teeth.
- Calories: A measurement of how much energy your food gives you.
- Cancer: A word used for many diseases where bad cells grow uncontrollably.
- Central Line: Tube put in your chest while you are asleep. It is used to give all your IV medicine and blood products.
- Chaplain: Person from a church that works with patients/families in the hospital.
- Chemotherapy: Medicine given to kill the bad cells. It is usually given through your central line or by mouth.
- Child Life Specialist: Person who helps make your stay special and teaches you about things that happen in the hospital. They also give you fun stuff to do.
- CML: See "leukemia."
- Conditioning: Medicine or radiation that makes your bone marrow ready for it's new stem cells.
- Constipation: When you can't poop.
- CT Scan: Test that takes a picture of a part of your body. You lie on a skinny table and slide through a "donut hole." The machine makes a whirling sound as it takes the picture.
- Culture: Test to see if you have an infection somewhere such as in your blood, snot, poop or pee.
- Cyclosporine: Medicine to prevent graft vs. host disease.
- Diarrhea: When your poop gets runny and you make lots of it.
- Dental Hygienist: Person who checks your mouth and teeth to make sure they look healthy.
- Dentist: Doctor who fixes cavities or broken teeth.

- Dietitian: Person who works with you to find foods that you can eat to help you feel better and give you energy.
- EKG: (Electrocardiogram) Stickers are put on your body so that a machine can draw a picture of your heart beating.
- Emesis: When and what you "throw up."
- Endoscopy: Test done while you are asleep that takes pictures of your throat and stomach.
- Engraftment: When your new stem cells start to grow.
- Fellow: Doctor who examines you daily and can answer your questions.
- Fluid: Liquid that your body needs. It can be given in your IV or you can drink it.
- GVHD: (Graft versus host disease) A reaction that your skin, liver or stomach ("gut") may have because it hasn't gotten used to your new stem cells.
- HA/TPN: (Total Parental Nutrition / Hyperalimentation) Liquid nutrition that is infused through your central line.
- Hickman: Another name for your central line (Dr. Hickman invented it).
- ICU: (Intensive Care Unit) A special room where you stay when you need extra close monitoring.
- IGG: (Immune Globulin) Medicine given to help boost your immune system to help it fight infections. It is given through your central line.
- Infection: A "bug" found in your body that may cause a fever or make you feel bad.
- IV: (Intravenous) Another name for putting medicines/fluids into your Hickman central line.

<u>Kidney:</u>	A part in your body that makes urine. You have 2 found near your back.
<u>Lab Tech:</u>	Person who looks at your blood under a microscope.
<u>Leukemia:</u>	Cancer that starts when blood cells are very young. They take over the good cells and make you very sick.
<u>Liver:</u>	A part in your body that filters out yucky stuff. It is found near your stomach.
<u>Lungs:</u>	A part in your body that makes you to breathe. You have 2 located in your chest.
<u>Lymphoma:</u>	Cancer cells found in your lymph system (the lymph system helps fight infections).
<u>Magnesium:</u>	Nutrient that helps the cells in your body to work well. You need lots of magnesium when taking cyclosporine.
<u>MMF:</u>	Medicine that is given for "gut" GVHD. It usually comes in a pill.
<u>MRI:</u>	Picture taken by a big camera while riding into a tunnel. It is very loud and sounds like a jackhammer. You may have to wear a helmet if the picture is of your head. It doesn't hurt and you may be asleep during it.
<u>Mucositis:</u>	Sores in your mouth, throat and lips caused by your conditioning.
<u>Nasal Wash:</u>	Test that may be done when you have a runny nose. Water is put in your nose and then taken back out.
<u>Nausea:</u>	When your stomach feels upset.
<u>Neuroblastoma:</u>	Cancer in the nerve that is found in your chest or tummy.
<u>PA:</u>	Physician's assistant.
<u>PFT's:</u>	(Pulmonary Function Test) Test to see how well your lungs work. You will be asked to blow as hard as you can into a big tube.

- Physical Therapist: Person who helps you to get exercise by playing fun games.
- Platelets: Cells that form blood clots and help you stop bleeding. They are given through your central line.
- Pneumonia: Infection in your lungs.
- Potassium: Nutrient that helps your heart beat normally. You need lots of potassium when taking prednisone or amphotericin.
- PRBC's: (Packed Red Blood Cells) Red blood cells carry oxygen from your lungs to the rest of your body. They are given through your central line.
- Prednisone: Medicine used to prevent or control GVHD. It may make you feel moody and hungry and make your cheeks look fat. It can be given in your central line or by mouth.
- Primary Nurse: Special nurse who is picked to take care of you and plan your care.
- Protein: Nutrient that helps you to build strong muscles.
- Radiation: Invisible medicine that kills bad cells. It is not a medicine that you have to take in your mouth or central line. You get to go to a special room and lay in a bed to receive it. It doesn't hurt during the treatment, but it may make you feel sick later.
- Relapse: When your cancer comes back.
- Respiratory Therapist: Person who gives you oxygen or other special medicine to help you breathe better. You just breathe in the medicine.
- Scheduler: Person who sets up your appointment in the clinic.
- SCIDS: (Severe Combined Immune Deficiency Syndrome) A disease where you don't have enough infection fighting cells.
- Social Worker: Person you can talk to about your feelings. They can also help your mom & dad with things during your transplant.

<u>Spinal Tap:</u>	Test done to see if any bad cells live in your spinal fluid (in your back). You will be asleep during this test.
<u>Stem Cells:</u>	Cells that grow into healthy white blood cells, red blood cells, and platelets.
<u>Steroid:</u>	See "prednisone."
<u>Surgeon:</u>	Doctor who operates on you.
<u>Surgery:</u>	Operation done in an operating room with lots of doctors and nurses. You will be given medicine to make you sleep.
<u>TBI:</u>	(Total Body Irradiation) See "radiation."
<u>Transfusion:</u>	Red cells, platelets, or stem cells that are given through your central line.
<u>Ultrasound:</u>	A way to take pictures of a part of your body. Cold jelly is used to help a magic wand see the picture better.
<u>VOD:</u>	(Veno-Occlusive Disease) Your liver gets sick from chemo or radiation. It can make your tummy swell and your skin look yellow.
<u>Volunteer:</u>	Person (who is not paid) who can visit you, play with you, and help your family while you're in the hospital.
<u>Weight:</u>	How heavy you are. You will be weighed on a scale every day while you are in the hospital.
<u>X-Ray:</u>	Picture taken of a part of your body. It doesn't hurt at all.

ANSWERS to word search on page 9.

S	D	D	A	H	J	N	V	S	P	E	E	C	H	T	H	E	R	A	P	I	S	T
L	I	D	Q	A	A	V	B	O	J	F	G	T	T	R	K	J	U	U	H	O	L	G
O	O	E	S	D	V	J	Y	I	L	Z	D	X	V	F	H	E	H	J	Y	J	U	R
C	S	N	F	G	R	H	J	Y	M	U	L	K	I	C	P	N	J	T	W	S	D	E
C	Q	T	E	Y	H	D	E	F	A	E	N	V	E	Q	W	H	J	S	T	R	L	S
U	D	I	F	I	E	N	I	K	K	L	Y	T	I	R	H	N	J	I	N	L	K	P
P	Z	S	A	S	A	U	X	D	S	E	B	G	E	F	D	E	S	N	P	K	J	I
A	C	T	S	D	X	R	Z	A	Q	A	Y	K	J	E	H	E	R	E	H	W	Q	R
T	E	R	W	T	Y	S	R	H	L	J	R	L	O	O	R	I	M	I	Y	P	F	A
I	X	C	V	F	E	E	R	J	L	O	E	I	L	K	Y	H	M	G	S	R	E	T
O	R	A	S	D	G	C	G	F	W	Y	U	J	K	P	A	A	F	Y	I	B	G	O
N	O	A	Q	U	I	K	B	L	R	Q	O	W	N	F	O	B	R	H	C	O	W	R
A	T	N	F	J	U	M	A	P	E	D	R	O	V	R	R	E	T	L	A	H	E	Y
L	C	L	A	C	H	I	L	D	L	I	F	E	S	P	E	C	I	A	L	I	S	T
T	O	Z	Y	S	C	L	E	E	P	I	N	G	H	D	L	O	G	T	T	A	Q	H
H	D	U	I	O	C	K	B	R	O	N	W	F	O	N	U	X	J	N	H	U	M	E
E	N	P	S	U	R	G	E	O	N	E	D	T	O	V	D	E	R	E	E	D	O	R
R	I	V	E	R	T	H	L	F	A	Z	Y	S	E	L	E	E	P	D	R	O	I	A
A	A	N	G	D	G	O	T	E	H	M	E	R	R	A	H	Y	C	H	A	C	R	P
P	P	O	N	C	H	A	P	L	A	I	N	C	E	I	C	W	E	N	P	T	T	I
I	T	T	O	W	N	T	H	L	E	H	U	T	H	C	S	H	S	C	I	O	H	S
S	O	O	L	I	S	S	U	O	P	E	R	D	U	P	E	R	E	L	S	R	O	T
T	N	G	L	I	V	E	T	W	H	E	F	R	E	D	J	U	S	R	T	T	I	C
D	I	E	T	I	T	I	A	N	E	G	N	I	D	N	E	T	T	A	F	R	E	D

Attending

Chaplain

Child Life Specialist

Dental Hygienist

Dentist

Dietitian

Doctor

Fellow

Lab Tech

Nurse

Occupational Therapist

PA

Pain Doctor

Physical Therapist

Respiratory Therapist

Scheduler

Social Worker

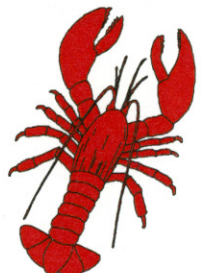
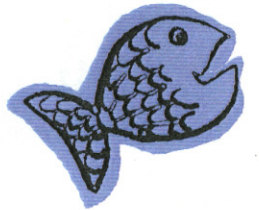
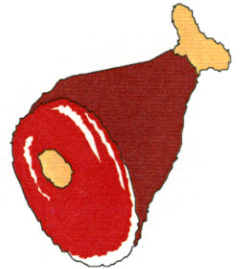
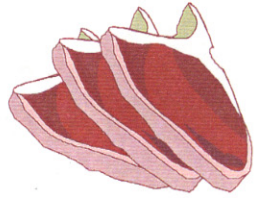
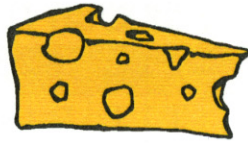
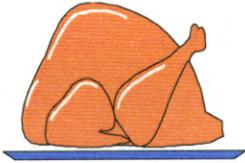
Speech Therapist

Surgeon

Teacher

Volunteer

ANSWERS for Word Scramble on page 26.



P
R
O
T
E
I
N

I need protein after my transplant to help make me strong:

Unscramble these foods high in protein.

HIKENCC

CHICKEN

KRUTYE

TURKEY

GEGS

EGGS

LMKI

MILK

FEEB

BEEF

MAH

HAM

EHESCE

CHEESE

SIFH

FISH



A special thank you to all
the patients who share their
smiling faces in our photo
collage in the front of this
book.

Alex	Alana	Andrea
Ariel	Charles	Danny
Gregory	Jaime	Joshua
Junior	Katy	Marcel
Michelle	Regan	Trevor

Thanks!

