

# In the Blood — Leukemia

Secrets of the Sequence Video Series on the Life Sciences • Grades 9 — 12  
Teaching materials developed by VCU Life Sciences

V i r g i n i a   C o m m o n w e a l t h   U n i v e r s i t y

## Classroom Tested Lesson

### Video Description

“Secrets of the Sequence,” Show 123, Episode 3

“In the Blood - Leukemia” – approximately 10 minutes viewing time

Leukemias are cancers of the blood – what scientists call “liquid tumors” – unlike the solid tumors in the tissues attacked by other cancers. George Daley has dedicated his career to cracking the mysteries of leukemia. He has had limited success and is now doing research on the use of stem cells from a patient’s bone marrow.

Ward Television

Producer: Paul Gasek

Featuring: Dr. Todd Gloub, Dana Farer Cancer Institute, Harvard Medical School, Dr. George Daley, Whitehead Institute, Harvard Medical School

Lesson Author; Reviewers: Sandy Linskey; Catherine Dahl, Dick Rezba, and Kieron Torres

Trial Testing Teachers: Regina Ahmann, Martin Shields

### National and State Standards of Learning

#### National Science Education Standards Connection

Content Standard C: Life Science

As a result of their activities in grades 9 - 12, all students should develop an understanding of:

- Molecular basis of heredity
- The Cell

Content Standard F: Science in Personal and Social Perspectives

As a result of their activities in grades 9 - 12, all students should develop an understanding of:

- Personal and community health
- Science and technology in local, national, and global challenges

#### Selected State Science Standards Connections

Use <http://www.eduhound.com> (click on “Standards by State”) or a search engine to access additional state science standards.

## Hawaii

### Content and Performance Standards

#### WELLNESS

Students appraise the relationships between their bodily functions and their physical and mental well being.

- Explain how body systems may function poorly and examine factors that contribute to wellness and longevity.

#### INTERDEPENDENCE OF SCIENCE, TECHNOLOGY AND SOCIETY

Students analyze and evaluate the benefits, drawbacks and trade off issues raised by the application of biotechnology in the health fields.

## California

### Genetics

4. Genes are a set of instructions encoded in the DNA sequence of each organism that specify the sequence of amino acids in proteins characteristic of that organism. As a basis for understanding this concept:
  - d. *Students know* specialization of cells in multi-cellular organisms is usually due to different patterns of gene expression rather than to differences of the genes themselves.
5. The genetic composition of cells can be altered by incorporation of exogenous DNA into the cells. As a basis for understanding this concept:
  - c. *Students know* how genetic engineering (biotechnology) is used to produce novel biomedical and agricultural products.

### Evolution

7. The frequency of an allele in a gene pool of a population depends on many factors and may be stable or unstable over time. As a basis for understanding this concept:
  - c. *Students know* new mutations are constantly being generated in a gene pool.

## Overview

The video highlights new developments in the treatment of leukemia made possible through the genomic revolution. Leukemia is a cancer of the blood and until recently only three main types of leukemia have been categorized. As we get a clearer picture of the molecular basis of this disease, it now appears that there are dozens of strains, each with a different genetic imprint. For the most part, today's leukemia patients are offered a relatively generic treatment of chemotherapy in the hopes that their particular leukemia will respond even though statistics have proven otherwise. In other words, there has been a degree of guesswork in picking which anti-cancer drugs will be used in a patient's chemotherapy.

Researchers are now screening thousands of genes with the use of DNA chips to find where the mutations lie in order to match specific mutations in the genome with specific types of leukemia. With this process they are moving towards finding specific inhibitors for those mutated genes. It is these inhibitors, called "silver bullets", that will provide higher success rates in the treatment of this disease. One of the first "silver bullets" to revolutionize leukemia treatment was the development of the drug Gleevec, identified as a gene inhibitor for CML (Chronic myeloid leukemia); Gleevec works for 97% of CML patients. The two other main leukemia strains are ALL (Acute lymphocytic leukemia) responsible for about 2000 new cases annually and AML (Acute myeloid leukemia) responsible for about 8000 new cases a year. Although ALL has a success rate of about 80% with some of its inhibitors, there is still much to be done in matching up AML mutations with inhibitors.

When patients do not respond to the drugs available, their only other option is a dangerous bone marrow transplant. If a family member does not provide a good match, then patients look to the International Registry. However, the rate of a

good match is only about one in four. Hence, researchers are exploring the more controversial customized blood stem cell transplant that will have a far better likelihood of success. The patient's own DNA is used to create a customized embryonic stem cell line that is then differentiated into blood cells to be used in the transplant. The success of this treatment, however, comes at a cost – the destroyed embryo – an ethical issue that is being heavily debated in Congress and the international community.

## Testing: A sample related multiple choice item from State Standardized Exams

Blood is considered a tissue because blood-

- A. flows inside arteries and veins
- B. is necessary to carry oxygen and nutrients to the cells
- C. is pumped from the heart and is carried to the cells through arteries
- D. is composed of red and white blood cells working together and having specific functions \*

Source: Virginia Spring 2003 End of Course Biology

## Video Preparation

Preview the video and make note of the locations at which you will later pause the video for discussion.

## Before Viewing

1. Have prepared microscope slides of blood available for students to observe a day prior to viewing the video. Have them draw and identify each type of cell and complete a cell count, which is the number of each type of cell present. This preview will give students an opportunity to become familiar with normal blood before looking at leukemia cells.

Note: For images of normal and abnormal blood smears including different types of leukemia, go to <http://image.bloodline.net/bd>.

2. Ask: "What do you know about the disease called leukemia? What symptoms are you aware of that would cause someone to be tested for leukemia?"

*Leukemia is a cancer of the blood. A genetic mutation or combination of genetic mutations causes the normal system of blood formation in the body to break down leading to uncontrolled growth and reproduction of cells in the bone marrow, to the detriment of others leading to a complete loss of immunities. Like many other diseases it has symptoms that could be attributed to other health problems such as a sore throat, high fever, and exhaustion. Only when the blood is examined under a microscope is it clear from the pattern of the cells that leukemia is present. If left untreated, the cancerous white blood cells produced may spread through the bloodstream to other parts of the body, a process known as metastasis.*

3. Ask: What treatments are available for someone who is diagnosed with leukemia?  
*Chemotherapy and bone marrow transplants*
4. Ask: What is chemotherapy and how does it work?  
*It involves chemicals that fight off cancerous cells. Traditionally they have killed or disrupted cells that were in the process of dividing. This includes cancerous as well as many normal cells. Newer drugs more specifically target the cancerous cells.*
5. While they watch the video, encourage students to write their thoughts and questions on a sheet of paper to be addressed in the "After Viewing" section, # 5. Promote critical thinking and attentive viewing by asking

students to look for questions that need explanation. Give them an example or two, such as, “What do they mean by a silver bullet?”

## During Viewing

1. **START** the video.
2. **PAUSE** the video ( 3:29 minutes into the video) after the three types of leukemia’s are presented and write them on the board..
  - CML (Chronic Myeloid Leukemia)
  - ALL (Acute Lymphocytic Leukemia)
  - AML (Acute Myeloid Leukemia)

Ask: a) “What do acute and chronic mean and discuss the difference?”  
b) Explain the term myeloid (*relating to bone marrow*).

Discuss how the researchers were able to use the DNA array extracted from the blood cells to distinguish between different types of leukemia, such as ALL and AML.

3. **RESUME** the video
4. **PAUSE** the video (8:21 minutes into the video) after Dr. Daley says “...you would in effect use your own cells to cure your disease.”

Ask: “What are the 4 steps in the bone marrow treatment for leukemia patients that uses the person’s own DNA?” Write the steps on the board and discuss them (explain the steps as necessary).

- *Do skin biopsy of patient to determine DNA*
- *Create customized embryonic stem cell line using DNA of patient*
- *In a Petri dish, differentiate embryonic stem cells into blood stem cells*
- *Transplant blood stem cells into patient*

Note: You may want to point out to students that the patients in the video have no hair due to the chemotherapy rather than the leukemia itself, and that the patients were wearing surgical masks and recovering in large plastic bubbles because their immune systems were compromised as a result of the bone marrow transplant.

5. **RESUME** the video and play to the end.

## After Viewing

1. Ask: “What is the main advantage to using a leukemia patient’s own DNA in a bone marrow transplant?”

*Using the patient’s own DNA to customize embryonic stem cells and create healthy blood stem cells avoids the need to look for a “match” either within family members or through the International Registry of Bone Marrow and markedly increases the success of treatment by eliminating the risk of possible rejection. Presently only about 1 in 4 leukemia patients looking for a bone marrow donor find an acceptable match.*

Note: You may want to inform students that if they are old enough to donate blood, they are also old enough to become a part of this registry.

2. Ask: "What is the main problem associated with using a leukemia patient's own DNA in a bone marrow transplant?"

*In order to create customized blood stem cells with the patient's own DNA, it is necessary to use embryonic stem cells that create an ethical concern for some people because the embryo is destroyed in the creation of a stem cell line.*

3. Review the tools introduced through the genomic revolution that can now aid in the diagnosis and treatment of leukemia.
  - *DNA chip*
  - *"Silver bullet" drugs*
  - *Embryonic stem cells*
4. Ask:
  - a. What is the source of the embryo and the DNA that would be used in a stem cell procedure?  
*The embryo would come from surplus embryos at fertility clinics and the DNA would come from one of the patient's own cells.*
  - b. Would the embryo be implanted into a woman's uterus where it could develop into a fetus?  
*No, it would remain in a culture dish. It would never develop beyond a tiny ball of undifferentiated cells.*
5. Have students share their questions they recorded while watching the video. List them on the board, chart paper or an overhead transparency. Ask the students if anyone can answer any of the posted questions.

Typical student questions might be:

*"How does Gleevec work?"*

*What is a 'silver bullet'?"*

*Why isn't chemotherapy successful?"*

*How do micro arrays determine your gene fingerprint?"*

*What else is this method used for?"*

*Why is there opposition to stem cell research?"*

You may wish to assign one or more of these questions for further investigation or plan additional lessons to address these questions.

## Teacher Notes for the Student Activity: Leukemia Case Studies

The stories used in this activity are of leukemia survivors and they are generally quite uplifting. However, a student with a family member or friend currently battling cancer may be upset by discussing personal accounts of the disease. If you are aware of any such situations, you may want to talk to the student ahead of time and offer them an alternative accommodation for the day of the activity.

1. Provide students with stories written about Leukemia survivors. This will give students a first hand account of the problems leukemia patients face and a better understanding of their treatment. There are many sources for these stories on the Internet. Two examples are included in this lesson – one short and the other long – but more are available at Web sites listed under 'Additional Resources' at the end of the lesson. When visiting the Web sites, use their search box and type in 'survivor story'. Stories can be read individually, in groups, or together as a class. Everyone could have the same story or groups could have different stories depending on what you want the class to accomplish.

2. While students are reading the story, have them answer the questions on the student handout as well as add their own questions. These questions can be the source of future investigations as time allows or they could be used for discussion. If students are working in groups, assign a role to each group member, such as:
  - Leader - makes sure everyone participates
  - Time Keeper - keeps group on task
  - Recorder - records group answers
  - Reporter - shares the group information with the rest of the class
3. After students have had time to read the story and answer the questions on the student handout, have them discuss their responses in their small groups and then have them share their responses with the rest of the class.

Note: You can guide the list of questions toward topics you would like your class to investigate. For example, if your class is studying cancer treatments, focus on the questions related to types of treatments, such as "How can cord blood cells be used to treat leukemia? What are the pros/ cons of its use? What future complications do patients with bone marrow transplants face?"

If, however, your class focus is biotechnology, then guide the discussion toward topics such as micro arrays or silver bullets.

## Student Handout: Leukemia Case Studies

In this activity you will read a first hand account of the problems a leukemia patient faces and gain a better understanding of how this disease is treated. First, read the story silently by yourself. Then, as a group, discuss the story and answer the questions below.

Decide on the role of each group member and record your names.

- Leader \_\_\_\_\_
- Time Keeper \_\_\_\_\_
- Recorder \_\_\_\_\_
- Reporter \_\_\_\_\_

### Questions

1. Describe the patient.
  
  
  
  
  
  
  
  
  
  
2. What problems did the patient have to overcome?
  
  
  
  
  
  
  
  
  
  
3. Explain the treatment the patient received and how that treatment was able to conquer the cancer.
  
  
  
  
  
  
  
  
  
  
4. What do you think you would do if you had leukemia?
  
  
  
  
  
  
  
  
  
  
5. What kind of treatment would you want?
  
  
  
  
  
  
  
  
  
  
6. List a few questions you have after reading this story.

## Survivor Story # 1: Caroline's Miracle

ACS News Center

Article date: 2001/05/01

We can sit here and feel sorry for ourselves or we can do something. We're going to make a difference.

"Caroline's Miracle" is the story of a six-year-old North Carolina girl and her triumph over a second fight against cancer. It is also the story of her family's struggles and hopes, her doctor's research and care that saved her life, and the lifelines provided by the American Cancer Society.

Diagnosed with leukemia at age 2, Caroline had chemotherapy, and seemed to be doing well. Life began to return to normal for Caroline, her parents, Bill and Penny, and four sisters. Two years later, the cancer was back. This time, there was a new complication. Children who relapse while taking cancer drugs cannot be cured with additional drugs. Caroline's best hope became a transplant. Not many parents are faced with such a difficult decision, one that could impact their child's survival: Should their child have a bone marrow transplant or cord blood cell transplant?

The family ultimately found their way to Dr. Joanne Kurtzburg, director of Duke University's Cord Blood Transplant Unit and lab. Dr. Kurtzburg is a pioneer in cord blood transplant, a remarkable technique for obtaining cells capable of replenishing bone marrow. She began working with cord blood, which is saved from a new-born baby's umbilical cord, in the 1980s.

"The American Cancer Society gave me my first grant," says Dr. Kurtzburg. She later received a junior faculty award, which enabled her to spend more time in the lab before she went on to a full-time clinical schedule. "Without that grant, I probably wouldn't be doing what I'm doing today, she says."

In September 1998, Caroline had her cord blood transplant. While she was recovering in the hospital at Duke, her parents heard about the American Cancer Society Relay for Life, a community-based activity that raises money and increases awareness of cancer and cancer survivorship. The whole family took part in the 1999 Matthews/Mint Hill Relay for Life event. In honor of his daughter, Bill Strother ran for 24 hours. Caroline, wearing a mask to protect her still vulnerable immune system, led the survivor's lap. Dr. Kurtzburg was there too, happy to see Caroline doing so well.

Bill explains his decision to run for 24 hours this way: "Caroline has lost her hair three times, had multiple chemotherapy treatments, countless injections, hundreds of blood tests, numerous bone marrow biopsies and spinal taps, and nausea. She spent 180 days in hospitals, missed birthday parties, and also missed kindergarten. "Caroline has gone through more pain in four years than most people will go through in a lifetime," he says.

The American Cancer Society's role in his daughter's story was another motivating factor in his decision to become involved in his local Relay for Life. "The whole story came to life," says Bill. "The American Cancer Society funded the research that Dr. Kurtzburg did as a research fellow at Duke during the 1980's. In 1993, the first cord blood transplant at Duke was done. Five years later, Caroline was the recipient of this new medical technology. She's alive today because of the cord blood transplant, because of Dr. Kurtzburg, and because of the American Cancer Society."

The Strother family continues to be part of Relay for Life. "We just feel like as a family we have to be involved," says Penny. "We can sit here and feel sorry for ourselves or we can do something. We're going to make a difference."

Today, Caroline is healthy and feels fine. She's off all of her medications, and enjoys going to school and doing gymnastics.



## Survivor Story # 2: The Man with the Drive

By [Chris Hutchins](#), Palm Beach Post Staff Writer

Wednesday, September 6, 2000

In June 1991, Jay Feinberg was a year out of college, working as a foreign exchange analyst in New York. He was 22, had graduated magna cum laude from Dickinson College in Pennsylvania and was planning to eventually attend law school. Those were good times. And then came the abdominal pains. They were with him for a few months. Jay didn't think much about them; he was young, after all. But when the high fever came one afternoon and he couldn't walk, Jay's folks took him to the family doctor in West Orange, N.J. By midnight, Jay Feinberg knew he had leukemia. It was chronic myelogenous leukemia, uncommon for someone his age. He was told he had about three-and-a-half years to live. Maybe less.

A week later, Jay was in another doctor's office, this one a specialist in New York. His family had been shoed out of the room. It was just the two of them. "You have a fatal disease," the doctor said. "We know you won't survive this. But I want to reassure you that there are a lot of drugs we can give, to make you feel comfortable. This won't be a painful death." Imagine hearing that. Jay cried that day. He says it was the only day he lost hope.

But he's still alive. He's 32, and lives in Delray Beach. And he has dedicated his life to helping others suffering from the same disease he had. That's right. Had.

It's been a remarkable nine years for Jay Feinberg. He recently recollected it, in his quiet Delray office. The only sound in the place other than his voice is the whirl of five computers near his desk. In those machines is some of the lifesaving information he and countless volunteers have compiled over the past decade. But you can't talk about the present without knowing about the past. You can't appreciate hope until you feel hopelessness. Here is Jay's story.

### June and July, 1991

When Jay Feinberg was diagnosed with chronic myelogenous leukemia, he was told the only way to survive was to have a bone marrow transplant. The doctor suggested Jay should have his immediate family members tested to see if their stem cells -- the master cells that "grow" bone marrow -- were compatible with his. He also suggested conducting a search with national and international bone marrow registries to see if there was a compatible donor out there who was unrelated to Jay. That's a lot harder than it sounds. Here's why.

At its simplest, bone marrow transplants hinge on something called Human Leukocyte Antigen tissue types. HLA is essentially your genetic human fingerprint. Much like "whole" organ transplants (think heart transplants) this genetic compatibility is critical. And unless a patient has a twin sibling, there is no 100 percent compatibility with any other human being.

Ethno-geographic and genetic similarities are critical in these transplants. Jay's family is Ashkenazi, of Eastern-European Jewish descent. In 1991, Ashkenazim were severely underrepresented in the worldwide bone marrow registries. When Jay was diagnosed, less than 1 million people were entered into the worldwide marrow donor databases. Fewer than 5 percent were Ashkenazi. None of them were compatible with Jay. No members of his immediate family were compatible, either. Ironically, Jay's two older brothers -- Steven and Eddie -- had HLA tissue types that were compatible with each other, but not with the brother who needed it. After initial immediate family testing and database searches, the family discovered there was no one in the worldwide registries who was a compatible donor for Jay.

During that first month, Jay began receiving chemotherapy treatment to retard the growth of the leukemia. He and his family also visited several bone marrow transplant centers across the country, so they could be ready when a donor was found.

By July 1991, Jay had selected The Fred Hutchinson Cancer Research Center in Seattle as his transplant center. Named for a baseball player (best known for his stint with the Detroit Tigers in the late 1940s) who died of lung cancer, "The Hutch" is recognized as a trailblazer in the field of marrow transplants. That impressed Jay. What impressed him more were the doctors there: They treated him like a person, not a number. The Hutch's doctors were impressed, too. Jay expressed an interest in learning all he could about his leukemia and about bone marrow transplants. John Hansen, former director of the Clinical Division at The Hutch, remembers meeting the Feinbergs. He was one of the first doctors Jay spoke to.

"Jay and his family approached this crisis, this situation, with full intensity," says Hansen, who is now a medical professor. "He was dedicated from the beginning to learn everything he could ... . He wanted to be on top of this." That would come in handy, especially after Hansen insisted the key to Jay's survival was to find potential donors from a similar Ashkenazi background. Test extended family, Hansen said. Hit the books and do genealogical studies -- find family you never knew you had. Run bone marrow drives. Get complete strangers to test for HLA compatibility. Again, harder than it sounds. But Jay smiles, here in his office, when he tells what happened next. "That's exactly what we did," he says. "We didn't know what would come of it."

### **September, 1991 to December, 1994**

There is no simple way to explain what happened over the next three-and-a-half years. There's no way to convey the virtual unbelievability of the following statistic. From 1991 to December '94, about 55,000 people from all over the world were tested at marrow drives organized by Jay, his family, friends and volunteers. Fifty-five thousand.

When Jay and his family flew back to New Jersey in July 1991, they made a plan. It was a two-pronged attack: They were going to research the family, to see where in Eastern Europe they came from; and they were also going to start raising money for bone marrow drives in New Jersey and California, where other family members lived. His parents, Jack (now a retired accountant, 72 years old) and Arlene (a retired clothing store owner, 68), were going to save their son, no matter the cost. They spent -- as Jay puts it -- "a ton" of money to pay for those first few drives. "And they went to great lengths to spread the word," Jay says. "They talked to friends, businesses, former clients about donating money."

The search evolved into something bigger. Strangers heard about Jay, and sent donations to cover costs for tests and travel. As local support began to grow, Jay and his family decided to go all over the country -- and overseas, if possible -- and test everyone they could. Three drives became 13. Then 30. "We were told not to get our hopes up," Jay says. "The odds of finding a compatible donor are slim. It was explained to us that looking for a donor is like looking for a needle in a haystack. It was pretty overwhelming." And the drives quickly became more than a crusade to find Jay's donor. While he literally became the poster boy for the "Friends of Jay Feinberg" organization he and his family founded, Jay knew these HLA compatibility tests (taken from a small sample of blood) would be entered into national and international marrow databases. If Jay couldn't find his donor, he knew that other patients could.

From '91 to '94, the organization sponsored more than 200 other bone marrow drives. Volunteers for Friends of Jay (many times including Jay and some of his family members) traveled to Russia, Australia and South Africa to run drives. Tests were conducted in major cities in America and Canada. Word spread. Dozens of newspaper stories were written about him. Thousands of flyers were printed, encouraging folks to participate in local drives. In 1993, Jay appeared on the Sally Jesse Raphael show. Friends of Jay had 17 phone lines running in its donated office space in New Jersey, just to keep up with calls from that TV appearance. Volunteers fielded 10,000 calls during the first 48 hours. Forty-five thousand callers got busy signals.

And then the awards started rolling in. From other bone marrow donor organizations. From humanitarian organizations. From cities. In fact, Dec. 4, 1992 was "Jay Feinberg Day" in Brooklyn. Jay was a little embarrassed by that ... but it helped publicize the cause. "Remember, these donors went into a database that helped patients worldwide," he says. "It said Friends of Jay, but it wasn't a campaign for one person. It was a campaign for many people ... . But to say, My name is Jay Feinberg, I'm 22 years old, and dying of leukemia. Will you help save my life with a simple blood test?" was

a very powerful thing." On many levels. In the course of three years, Jay's life was turned topsy-turvy. Before his diagnosis, he collected cartoon animation cels, designed stained glass windows, loved reading and studying art history. Now he and his family would arrive at the office early in the morning and work nonstop into the night. They oversaw everything: Phone calls, bone marrow drives, donations, education. Stop for a sandwich, if they were lucky. Eat dinner at the office. Life had changed for the Feinbergs.

But in a way, Friends of Jay Feinberg became a worldwide phenomenon. More than 100 other patients found bone marrow donors, through the results provided by "Jay's" drives. But by 1995, Jay still hadn't found a donor. It really was like finding a needle in a haystack. And then things got worse. Jay's leukemia began to accelerate.

## 1995

By May 1995, the chemo wasn't doing its job anymore. Jay's white blood cell count was going through the roof. His spleen was enlarging. The disease was spreading. The 26-year-old was running out of time. By the doctors' original estimate, he should have been dead already. In January, Friends of Jay had hosted a donor drive in Israel. They found a donor who was -- as Jay says -- "significantly mismatched," but might be a successful transplant. A decision had to be made. Since this woman in Israel (actually a New Yorker attending college there) was the only option, Jay decided to go for it. "It was as close as it was going to get," he says.

The folks at The Hutch were informed, and they prepared to use the donor, who would be "harvested" in New York. Jay was due to fly out to Seattle to get the transplant in July. But a newfound friend based in Chicago called up the family. The friend, Benji Merzel, wanted to run one more drive -- this one in Milwaukee. (Benji is a story within a story: His friend was saved by a donor from one of Jay's drives. He became interested in the cause, and helped Friends of Jay run local drives.) Just one more, he said. Jay and the family said no. They had found a donor. It was a done deal. The compatibility could be much better, but then again, it could be worse. Besides, the organization hadn't done any fund-raising for this drive.

But Benji and his pal Amir Guttman insisted they could find the money and the support. Milwaukee had never had a bone marrow drive before, they said. And hopefully they'd find Jay's donor, too. "We really wanted to go through with it," says Benji, who is now 25 and studying in Toronto to be a chiropractor. "And when I heard that (Jay's) donor was a major mismatch, that was a red flag. I still hoped we could find someone more compatible."

The Feinbergs relented. Benji and Amir ran the drive on May 14. Benji had several friends there who volunteered their time doing paperwork and such -- Becky Faibisoff, 16, was one of them. About 125 people were tested during the drive. She wasn't. "They were closing down, and Becky was packing up all the medical supplies and she said, I'm afraid of needles, but I want to do this," Jay says. "They took out the supplies, had the blood drawn."

Becky Faibisoff was the last person ... of more than 55,000 ... to be tested for HLA compatibility with Jay Feinberg. Just like the other 225 drives, the blood samples were taken to a special lab and processed. The results were sent to the Feinberg family. The last bar code -- Becky's -- was a very close match to Jay. Much closer than the woman in Israel. Her family's genetic and geographic background, also Ashkenazi, was the key. It was clear she was the best candidate to donate.

Becky Faibisoff volunteered at a drive that shouldn't have happened. She took the test as an afterthought. In fact, if Benji's friend hadn't been saved by one of Jay's drives, Benji wouldn't have been involved at all. He wouldn't have been insistent about hosting one more drive. And Becky wouldn't have come to volunteer, to donate. "We were shocked," Jay says, grinning. "I never thought it would be me, not in a million years," admits Becky, now 21 and studying to be a teacher in Chicago. "It's weird, though. I realized that I was vital to someone else's existence. My life mattered so much to someone I had never met. I realized how important we all are, through this." Needless to say, it shook things up.

## The transplant

Another quick medical lesson: Bone marrow donation is a process shrouded in fear and misconception. Some folks think surgeons crack open the bone, suck out the marrow, and chuck it into a patient. Others have confused it with "whole" organ donation, and believe an actual bone is taken from one body and placed in another. Actually, bone marrow is a human organ that replenishes itself. You can donate it many times.

The most-common process of marrow extraction is called aspiration. After a local anesthetic is applied, a needle is inserted into the lower back, into the hip bone. Quantities of bone marrow containing the "marrow-growing" stem cells are extracted. A person can leave the hospital the same day he or she donates. Aside from some pain (the lower back feels bruised for a few days), that's it. The body replenishes the marrow in about six weeks.

In 1995, that's the process Becky Faibisoff underwent in a Chicago hospital. The marrow was rushed to Seattle, where Jay and the doctors were waiting. By that time, Jay had spent a week at The Hutch, in a preparation phase called "conditioning." It's rough. A catheter was installed into his chest, a series of tubes that would be used for transfusions, chemo, nutrition and the actual transplant. Also, the leukemia -- and his immune system -- was destroyed by "total body irradiation," a process where the entire body is bombarded by cobalt sources.

The side-effects of the radiation are incredibly painful and risky. Short-term: The mucous membranes in the throat and mouth are destroyed, leaving the flesh raw and exposed. (Patients need IV morphine to cope with the pain.) Diarrhea. Platelet, white- and red blood cell counts drop to zero, leaving the body totally unprotected against infection. Long-term effects include increased chance of developing cancers and cataracts, and sterility.

Jay Feinberg's bone marrow transplant took place on July 28, 1995. At around 11 p.m., Hutch doctors hooked up the bag of Becky's marrow to Jay's chest catheter for the infusion. It was over by around 2 a.m. Jay was awake during the process. He was too excited to sleep. Here's the funny thing about stem cells: While they're essentially dumped into a vein during a transplant, they "know" to migrate to the hollow cavities inside a person's bone. Doctors don't know how they do it. It's just generally accepted that stem cells are clever cells.

The rest of the transplant process is waiting -- waiting for the new stem cells to engraft, reproduce and replenish the bone marrow. Jay spent the next two-and-a-half weeks in a sterile plastic bubble room, waiting to see a change in his cell count. Finally, he did. "That day," Jay says, "was unbelievable. There was a lot of shouting going on. We were thrilled."

Not as thrilling as the day he and Becky Faibisoff finally met. It was a year after Jay's transplant. He'd gone through some serious complications to the treatment (as almost all bone marrow recipients do). But he was alive. Thanks to her, he now had a chance at a "normal" life expectancy. "I was so nervous about meeting Jay," Becky says. "But when we met, there was such a comfortable feeling between us, this bond. There was a love there, like a brother and a sister. It was overwhelming." Jay smiles. "That day was very emotional," he says.

## 1996 to present

The story could end there. It doesn't. "I have to believe there's a reason why I went through all of this," Jay says. "I think that reason was that the drives done for me found donors for well over 100 people. They were given a second chance at life, thanks to the volunteers that tried to save my life. If there was a reason to go through it, that's it, I think." And it made Jay and his family ask a question after his transplant: How could we stop doing this? They decided to keep running the organization they founded in '91. The Feinbergs changed its name to Gift of Life Bone Marrow Foundation, but the mission remained the same: To be a nonprofit, public-supported organization that hosts bone marrow recruitment drives. While Gift of Life's recruitment strategy includes increasing overall Jewish ethnic representation within the international donor registries, it accepts donations and tests people from all ethnic backgrounds.

The organization has grown into so much more, too. About two-and-a-half years ago (around the same time Jay moved to South Florida to be with his "snowbird" parents), Gift of Life officially became one of only three bone marrow

registries in the United States. When a person is tested at a Gift of Life drive, the results are entered into the organization's computer database, that whirring wall of information in Jay's Delray office. More than 41,000 entries -- the number of folks the organization has tested since '95 -- are in that database.

In many ways, Gift of Life has become Jay Feinberg's life. He's usually in the office from 8 a.m. to at least 8 p.m., working the phones or processing marrow compatibility searches. When he's not doing that, Jay's writing grant proposals and focusing on fund-raising. And then there's the international role Gift of Life now has, as an official registry. He has to make time to consider that, too.

Eight to eight, six days a week. It leaves little time for his other interests: Star Trek, movies, art history, travel. But Jay can't see it any other way right now. To his knowledge, he's the only bone marrow recipient who is also a search coordinator at a donor registry. He remembers being on the "patient" side of the search. He doesn't want other people to experience that.

"If I get a search request at 4:59, I'm not going to leave. I don't think I could sleep, knowing that someone was waiting for that search," he says. "My friends here say, 'You should have a life', that I should go home at 5 o'clock, go out on the weekends. No offense to my friends, but they don't understand. They've never walked in the patient's shoes ... . Personally, I can't go home wondering, 'What is that patient thinking?'"

So Jay stays and works the hours, on a volunteer basis. His family helps him make ends meet. Jay receives no pay from the donations that support Gift of Life and its services. And it provides many services. Transplant centers around the world access Gift of Life's database to see if it has a compatible donor for the center's patient. If it does, Gift of Life then oversees as much of the donation process as possible: The pre-donation physical exam, the bone marrow extraction, and delivery to the transplant center. All the costs are covered by donations and, eventually, the patient's insurance company.

But that's not all Gift of Life does. "God willing, if all goes well, one year after the transplant, we'll facilitate a meeting between the donor and the recipient," Jay says. "It's a very exciting process." And an expensive one. While Gift of Life is typically reimbursed for its costs by insurance companies, it needs donations from the public to stay afloat. That's hard to do. Jay also wants to create a salaried position for a donor search coordinator, the job that consumes much of his day. But that costs money, too.

It's the plight of the nonprofit organization: A lot of worthy causes, and not many people willing to donate money. "Anyone in nonprofit will tell you that the hardest thing about it is the fund-raising," Jay says. That, and finding a minute to relax. When he can, Jay travels around the country and speaks to groups about his life, and about bone marrow donation. The organization has been recognized by worldwide humanitarian groups, like Hadassah International. And most of Gift of Life's "muscle" is still unpaid volunteers, most of whom are based in the New York/New Jersey area.

His parents still volunteer their time, even in the summer when they go back to Jersey. Jack helps balance the books. Arlene is a counselor for potential donors. Brother Eddie enjoys being a pro bono "bone marrow courier," traveling with the donated marrow to transplant centers. And then there are volunteers who are like family, like Rochelle Sislen of New Jersey. She's been volunteering since 1991.

It's an incredible story, all of it. And how's this for a happy ending? Jay recently returned from a three-day trip to Seattle. He participated in a reunion at The Hutch -- a celebration for folks who have survived five years after their bone marrow transplant.

"Five years is a kind of watermark," Jay explains. "You're looking at a point where your chances of disease-free survival are much greater." And that's what Jay Feinberg's story is all about. Survival. And hope. But not heroics. Jay doesn't want you to think he's a hero. "When you talk about heroes, this is who you should be talking about," he says, and

points to the photograph of Becky on his desk. "Without her, without people like her, I wouldn't be here. The volunteers, the people who gave their time to help me, they're the heroes. Not me." Perhaps. But even Jay admits the last nine years have been remarkable.

"You're not invulnerable when you're 22 years old, I know that now. Things can happen," he says. "It changes the way you look at things. It changed what I'm doing with my life. Running a bone marrow registry is not what I envisioned, a year out of college. "But I can't see myself not doing what I'm doing right now," he says, and smiles. " ... After the transplant, leaving it all behind wasn't an option to me. How could I not keep doing this?"

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## Additional Resources

*Because Web sites frequently change, some of these resources may no longer be available. Use a search engine and related key words to locate new Web sites.*

National Cancer Institute [www.cancer.gov](http://www.cancer.gov)

Cancer page [www.cancerpage.com](http://www.cancerpage.com)

Leukemia Cancer Information <http://leukemia-web.org>

Leukemia Cancer information <http://health.discovery.com/encyclopedias/2538.html>

Cancer Patients and Survivors Find Treatment and Support [www.acor.org](http://www.acor.org)

American Cancer Society [www.cancer.org](http://www.cancer.org)

### Genomic Revolution

[http://www.ornl.gov/sci/techresources/Human\\_Genome/education/education.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/education/education.shtml)

The Web site to the government-funded Human Genome Project with links about genomics, the history of the project, and more.

### Secrets of the Sequence Videos and Lessons

This video and 49 others with their accompanying lessons are available *at no charge* from [www.vcu.edu/lifesci/sosg](http://www.vcu.edu/lifesci/sosg)