AN INDEPENDENT SUPPLEMENT BY MEDIAPLANET TO USA TODAY

Be someone's match
Join the bone marrow registry

Understanding rare disorders
What is PTCL?

The only solution
Making a cure our priority

MEDIA PLANET

June 2011

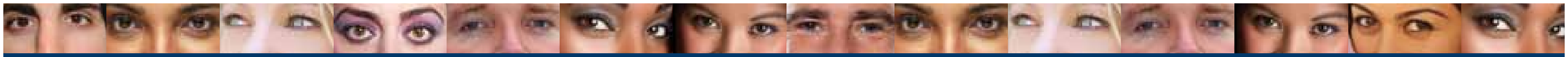
BLOOD HEALTH

3 FACTS

THE GIFT OF LIFE

Niki Taylor explains how blood donors gave her—and her family—a second chance

PHOTO: RAINER BEHRENS, BEHRENS VISUALS, 2011



CHALLENGES

Hematology is the study of blood. Many are unaware of the important role it plays in the advancement of medicine. A single drop can reveal clues about even the most obscure or complex health conditions.

FACT 1

NEARLY ONE MILLION PEOPLE IN THE U.S. HAVE SOME FORM OF BLOOD CANCER

Turning research into treatment

Because blood performs a variety of essential functions in the body, any abnormality can affect a person's overall health in a number of ways. For example, a patient with sickle cell anemia is at risk for a multitude of other health complications, including blindness, organ damage, and even stroke. However, not many people understand the complexities that surround sickle cell and other blood disorders that affect millions of people around the world. Additionally, many people are unaware of the role that hematology has played in the advancement and transformation of medicine.

The American Society of Hematology (ASH) celebrated its 50th anniversary in 2008. In the past half-century, there have been momentous strides taken in the fields of normal blood cell production, and abnormalities associated with blood diseases and cancers in terms of research, prevention, and treatment. We have seen the rapid development of blood-forming stem cell transplant techniques, first with bone marrow, then with cord blood and peripheral blood; advances made in blood transfusion science leading to more effective methods and safer products; and perhaps one of the greatest success stories in the history of cancer treatment—the discovery of a cure for pediatric acute lymphoblastic leukemia, a blood cancer that as recently as the 1960s had a 100 percent fatality rate for children diagnosed with this disorder.

New discoveries

In the current climate of blood health, all eyes are trained on translational research, the movement of information from the laboratory to the clinic which merges concepts of laboratory animal and cell research and clinical investigation, turning discoveries in basic biological research into new and better treatments for some of the most life-threatening diseases. Two excellent examples are the rapidly evolving fields of regenerative medicine and stem cell biology. It has been known for years that stem cells extracted from cord blood can be used to treat diseases such as leukemia, lymphoma, sickle cell disease, and immune deficiency and metabolic disorders through life-saving transplants, and I am fortunate to have the pleasure of being involved in this fascinating and promising area of hematologic research.

Yet blood health goes beyond the concept of disease and clinical care—it involves policy and advocacy work to ensure that strides continue to be made. For those interested in learning more about blood health, the importance of supporting federal funding of biomedical research, and how you can get involved, please visit ASH's consumer education website, Blood: The Vital Connection, at www.bloodthevitalconnection.org.

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President, American Society of Hematology

FACTS

A single drop

1 Blood contains many cell types and molecules necessary for the maintenance and well-being of the body—a single drop can reveal clues about even the most obscure or complex health conditions that might otherwise remain undiagnosed.

Translational research

2 In the current climate of blood health, all eyes are trained on translational research, the movement of information from the laboratory to the clinic.

WE RECOMMEND

PAGE 6

Dr. John Letterio
Chief of the Division of Pediatric Hematology and Oncology, University Hospitals Rainbow Babies and Children's Hospital

"Your child is not a statistic. Every child has the ability to be cured, and we go in with that expectation."

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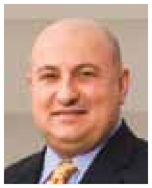


- **What do I need to know about the diagnosis of blood cancer?**

You are not alone. Approximately every four minutes one person in the United States is diagnosed with a blood cancer according to the Leukemia and Lymphoma Society.

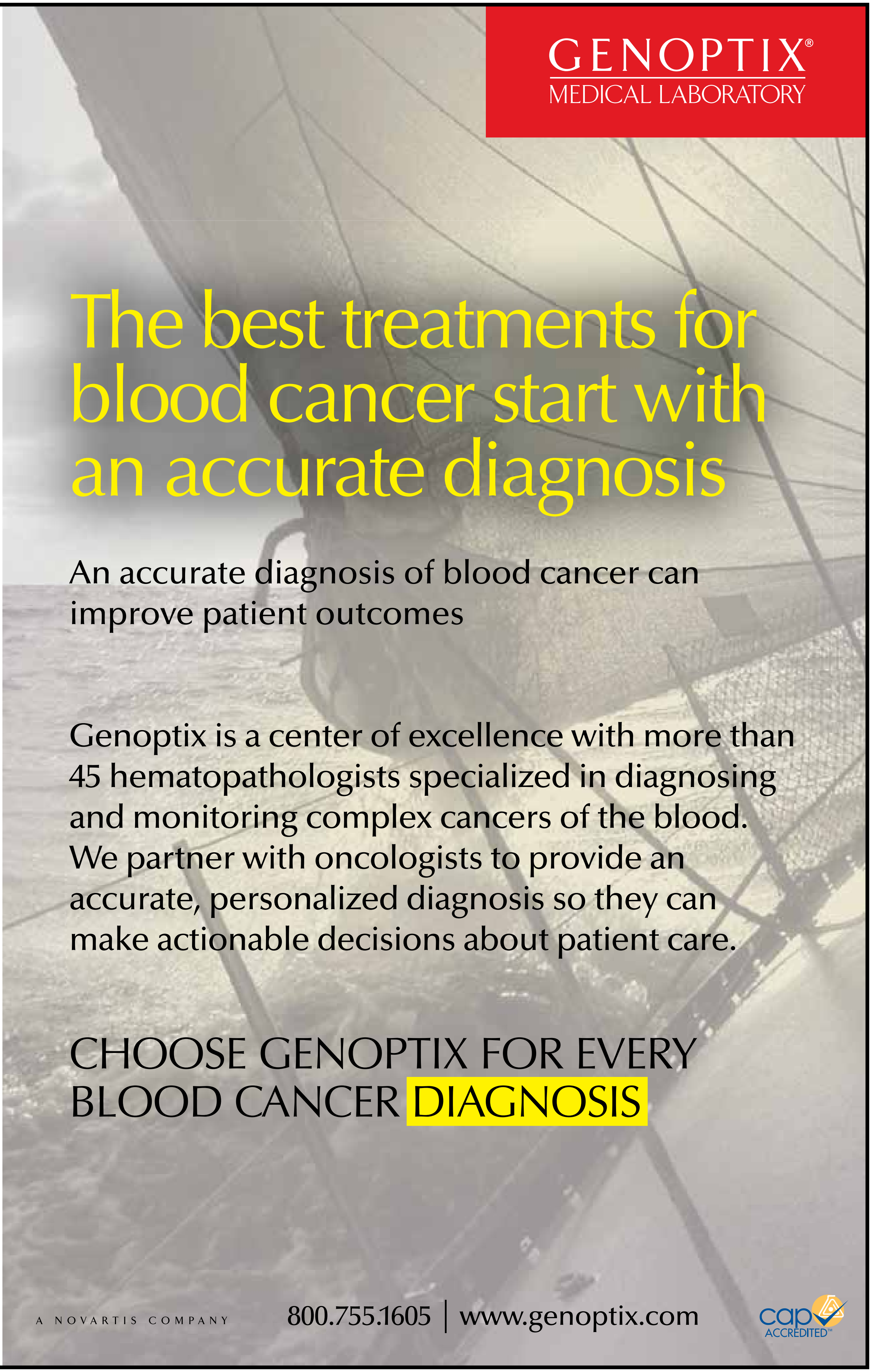
If your doctor suspects you may have a blood cancer, he may conduct a bone marrow biopsy and send it to a laboratory for analysis. Your bone marrow should be sent to a laboratory that specializes in the diagnosis of blood cancers and has hematopathologists on staff.

Hematopathologists are pathologists who specialize in the diagnosis of blood cancers and related disorders. They can best determine if you have a blood cancer and if so, what type. Accurate diagnosis is important to help your doctor determine which treatment may be right for you.

If you have blood cancer, your doctor may order additional bone marrow biopsies over the course of your treatment to determine how you are responding to therapy. Expert guidelines recommend that your doctor should select a laboratory with a dedicated hematopathologist to monitor your progress. This includes the ability to compare previous test results with new test results. Only a few laboratories can actually offer this service.

Tell your oncologist what you expect from a laboratory:

- Specialization in diagnosing blood cancers and related disorders
- Hematopathologists on staff to guide analysis and diagnose your case
- Collaboration between your doctor and the hematopathologist for optimal care
- Ability to compare previous test results with new test results



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Question: According to Niki Taylor, what is the ultimate gift someone can give?
Answer: The gift of life by donating blood. Blood centers typically face summer shortages, so donating now is more important than ever.

FACT

2

WORLD DONOR DAY IS JUNE 14TH—GET OUT AND DONATE!

Saving a life is always in style

LEADER TO LEADER

In 2001, supermodel Niki Taylor's life changed in the blink of an eye.

Taylor was in a near-fatal car accident and required over 100 liters of blood. Without blood donors, and the doctors treating her, Niki Taylor believes she would not be here today.

"As someone who owes her life to donors who gave to help someone they didn't even know, I think giving blood is a critical community service that cannot be overlooked. Currently, however, only about eight percent of those who can donate blood do so each year," she says. "Through the Nexcare and American Red Cross give program, I hope to educate people about the impact each person can have, and help them realize that helping to save a life is always in style."

The ultimate gift

Strictly in 2011, nearly six million people in America alone will require a blood transfusion. With this in mind, The American Red Cross and World Health organization have come together to continue the tradition of holding World Donor Day on June 14th. World Donor Day comes at an important time each year. As local blood centers typically face summer shortages, the nation's blood supply comes under strain due to fewer donations because of increased vacation schedules and other seasonal distractions.

PHOTO: RAINER BEHRENS, BEHRENS VISUALS, 2011

"I owe my life to blood donors. It has affected everything in my life. I would not be here to raise my twin boys, and my beautiful two year old daughter would not be here," says Taylor. "These are some of the things that are very difficult to put into words. I sometimes think, what strangers donated the blood that saved my life? What blood drives in Georgia supplied the hospital with the blood that saved my life?"

The aftermath of Taylor's accident has inspired her to create awareness on the importance of blood donation. "I flatlined twice," Taylor says. "The one thing a human being can do to save a life is give blood. It is the ultimate gift that a person can give to another."

Messages of hope

With the support of The American Red Cross, Taylor and the Nexcare give program inspire people with a message of hope. Running from June 14th through June 19th, the program will be giving away a collection of five fashion bandages inspired by the latest runway trends and emblazoned with the word "give." "Doing good looks good too. Saving a life is always in style," says Taylor.

On May 18th, 2011, Niki Taylor made an announcement that directly reflects the importance that blood donors had, not only in her life, but the life of her family. "YES!! We are expecting our fourth child! So happy and blessed!" That child represents another life directly affected by strangers that took the time to donate blood.

TIM RADWAY
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WE ALL HAVE THE POWER TO GIVE HOPE

Every year, more than 10,000 patients in the U.S. are diagnosed with life-threatening diseases such as leukemia or lymphoma, and their best or only hope of a cure is a transplant from an unrelated marrow donor or cord blood unit.

They depend on a stranger, someone like you, to help give them a second chance at life.

The tissue types used for matching patients with donors are inherited, so patients are most likely to find a match within their own racial or ethnic heritage. There are nine million people on the Be The Match Registry, but only 2.5 million—or 28 percent—are from racially and ethnically diverse backgrounds.

The challenge to find a matched donor is greatest among minority communities. The chances of Caucasians finding a match on the registry is 93 percent, but for minorities, the chances can be as low as 66 percent. And finding a matched donor on the registry is just the first step. Other barriers, such as access to medical care and adequate health insurance, further limit the number of minorities who receive transplants.

More people of diverse heritages are needed on the registry so that more lives can be saved. Every person who joins in fight and becomes a donor has the chance to save a life and to give every patient hope.

How to join

The first step to becoming a marrow donor is to join the Be The Match Registry. Doctors search the Be The Match Registry to find donors who match their patients. Myths about marrow donation often prevent people from signing up. But, joining is simple and the majority of donations today do not require surgery. Most donors say they would do it again to save a life.

You can join the Be The Match Registry in person at a donor registry drive or online. To join, people need to be between the ages of 18-60, willing to donate to any patient in need, and meet health guidelines. Registration involves completing a health history form and giving a swab of cheek cells.

If a member of the registry is called as a potential match for a patient, he or she will be asked to give another cheek swab sample or blood sample to confirm that he or she is the best possible match. The donor will also attend an information session to learn more.

There are two ways to donate if called. Most donations do not involve surgery. About 76 percent of the time, the patient's doctor requests a peripheral blood stem cell (PBSC) donation, which is a non-surgical, outpatient procedure. If the patient's doctor requests marrow (about 24 percent of the time), the donation process is a surgical procedure performed in a hospital. General or regional anesthesia is always used for this procedure. The doctor decides which method is best.

We all have the power to help, the power to give hope. To learn more about becoming a marrow donor, or to join the Be The Match Registry online, visit BeTheMatch.org.

NATIONAL MARROW DONOR PROGRAM
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HELP SAVE A LIFE

Tevita
Just a swab of your cheek and you may be the lucky person to save Tevita's life.

February 7, 2011, days after Tevita's (also know as Vita) eigth birthday, he came down with a flu. The flu lasted two weeks. Vita's parents knew something wasn't right when his nose began to bleed and wouldn't stop. He was taken to the hospital where doctors took multiple tests. Vita's mother was met by the pediatric oncologist and knew immediately from the look on the doctor's face that the news was not good. February 18, 2011, Vita was diagnosed with Severe Aplastic Anemia (AA), a disease where the bone marrow cannot produce enough blood cells to keep the body safe from infection. The disease is fatal if not treated. There are two treatments Vita will undergo to try and cure this disease. The first treatment is called Immune Suppression Therapy (IST) also referred to as a mini chemotherapy. For this, Vita will be given medicine to help shut down part of his immune system in hopes that his body will respond by resetting itself and producing blood products normally. If his body doesn't react to the IST, the only way to cure this disease is a bone marrow transplant. Tevita is a very active eight year old who loves contact sports. He plays tackle football, rugby and loves baseball! Before his diagnosis, when asked "what do you want to be when you grow up?" his answer was" I want to be a professional football player and a policeman when I have no football games."

Just a swab of your cheek and you may be the lucky person to save Tevita's life. To do your part, join the Be The Match Registry.

PROJECT MARROW
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INSIGHT

Childhood Leukemia is not a death sentence

FACT 3

1 OUT OF EVERY 250 ADULTS IS A SURVIVOR OF CHILDHOOD CANCER

The term leukemia refers to cancers of the white blood cells. When a child is diagnosed with leukemia it means that a large number of abnormal white blood cells are produced in the bone marrow. The abnormal white cells flood the bloodstream, while crowding and putting pressure on the bone marrow. Because the cells are defective, they cannot perform their proper role of protecting the body. Acute childhood leukemia is divided into acute lymphocytic leukemia (ALL) and acute myelogenous leukemia (AML), with ALL being the most common. Dr. John Letterio, chief of the division of pediatric hematology and oncology at University Hospitals Rainbow Babies & Children's Hospital, says "regardless of the subtype, each form of leukemia will have stats on success rates. However, every child has the ability to be cured andwe go in with that expectation. What a parent needs to know is that their child is not a statistic."

The survival rates are very promising. Indeed, a recently published international study led by one of Dr. Letterio's colleague's, Dr. Joe Matloub, shows that greater than 95 percent of children diagnosed today with standard risk all will be cured. "No matter your location, parents and children have access to outstanding medical care," says Dr. Letterio. "In almost every city there is a children's hospital that can help. As pediatric oncologists, we work together to define the best possible cure and treatment for our patients, whether they live in Cleveland, Ohio or Los Angeles California."

Dealing with any disease is difficult, but a life-threatening disease that the patient has little knowledge about makes things even more problematic. While there is still work to be done, doctors are making a lot of progress treating pediatric cancers. "We are here to support each other," Dr. Letterio says. "If a patient needs an advanced form of treatment we refer to one another in order to provide that treatment." Learning your child has pediatric cancer will never be easy, but it's good to know you have an entire network of doctors working to save your child's life.

TIM RADWAY

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John J. Letterio, M.D.
Chief, Division of Pediatric Hematology/Oncology, Rainbow Babies & Children's Hospital

> "What a parent needs to know is that their child is not a statistic."

Cures must be a priority

Once again, the Annual Report to the Nation on the Status of Cancer shows a continued decline in diagnoses and deaths for many types of cancers.

This encouraging news can be attributed primarily to preventive measures such as cessation of smoking and improved diet, and early detection.

But for many cancers, such as the blood cancers, early detection is rare, there are no measures that can be taken to prevent the onset of the disease, and they are still killing too many. In these cases, the only solution is continued research to find better treatments and cures once the diagnosis is made.

It is for this reason that many voluntary disease organizations have created programs to accelerate therapies from laboratories to patients. We recognize that funding research is costly and difficult, particularly in these trying economic times, particularly for orphan diseases such as blood cancers where producing these treatments may not always be cost-effective for drug companies.

We have to be more proactive and innovative in our approaches to funding drug development, not only funding laboratory research, but also partnering with biotech companies on high-prospect research projects, or by providing much needed expertise to help academics bring their discoveries to market. We are continually searching for new ways to ensure that scientific discoveries are not stuck collecting dust on academic shelves, but are given the boost they need to cross the chasm that swallows so many promising findings.

Moving discoveries forward

The Federal government also recognizes this need to get more treatments to patients faster. A key provision of the federal Affordable Care Act that has received little attention is the creation by Congress of the Cures Acceleration Network (CAN). This program, which would be administered by Frances Collins, Ph.D., director of the National Institutes of Health, would authorize grants to patient advocacy organizations, universities, biotech companies, research institutions or pharmaceutical companies, and would also provide the expert guidance necessary to move those discoveries forward.

The potential for these public-private partnerships to succeed is great, but only if there is real funding behind it. Congress is weighing drastic cuts to cancer research funding that would jeopardize this and other critical programs. Nonprofit organizations such as The Leukemia & Lymphoma Society, Cystic Fibrosis Foundation, Multiple Myeloma Research Foundation and Michael J. Fox Foundation have seen these partnerships bear fruit. If Congress gets on board and funds this program, there is no doubt that more lives will be saved.

ANDREA GREIF

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DON'T MISS!

Common symptoms of lymphoma include:

- Swelling of lymph nodes—may or may not be painless
- Fever
- Unexplained weight loss
- Sweating (often at night)
- Chills
- Lack of energy
- Itching

Most people who have these non-specific symptoms will not have lymphoma. However, it is important that anyone with persistent symptoms be examined by a doctor to make sure lymphoma is not present.

LYMPHOMA RESEARCH FOUNDATION

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Understanding a complex disease

Lymphoma is the most common blood cancer. There are two main forms of lymphoma; Hodgkin lymphoma and non-Hodgkin lymphoma.

Lymphoma occurs when lymphocytes, a type of white blood cell, grow abnormally. The body has two main types of lymphocytes that can develop into lymphomas: B-lymphocytes, called B-cells and T-lymphocytes, called T-cells. Cancerous lymphocytes can travel to many parts of the body, including the lymph nodes, spleen, bone marrow, blood or other organs, and can accumulate to form tumors.

Peripheral T-Cell Lymphoma Unspecified comprises a group of diseases that do not fit into any of the other subtypes of PTCL. PTCL-US is the most common subtype, making up about one quarter of all diagnosed PTCLs. It is also the most common of all the T-cell lymphomas. The term PTCL can be confusing as it can refer to the entire spectrum of mature T-cell lymphomas or sometimes to this specific subtype, PTCL-US, only. Although most patients with PTCL-US present with lymph node involvement, sites outside the lymph nodes, such as the liver, bone marrow, gastrointestinal tract and skin, may also be involved. This group of PTCLs is considered aggressive and requires standard combination chemotherapy upon diagnosis.

> "The rarity of these diseases also means that the most novel treatments are often only available through clinical trials."

Treatment options

For most subtypes of PTCL, the frontline treatment regimen is typically a combination chemotherapy, such as CHOP (cyclophosphamide, doxorubicin, vincristine, prednisone) or EPOCH (etoposide, vincristine, doxorubicin, cyclophosphamide, prednisone) or other multi-drug regimens. Because most PTCL patients will relapse, some oncologists recommend giving high-dose chemotherapy followed by an autologous stem cell transplant to some patients who had a good response to their initial chemotherapy program. While promising, there is no firm clinical data to support that undergoing a transplant in this setting is better than not undergoing a transplant.

Clinical trials

Clinical trials are crucial in identifying effective drugs and determining optimal doses for lymphoma patients. Because peripheral T-cell lymphomas comprise such a rare group of diseases, clinical trial enrollment is crucial to establishing more effective, less toxic treatments. The rarity of these diseases also means that the most novel treatments are often only available through clinical trials. Patients interested in participating in a clinical trial should talk to their physician.

LYMPHOMA RESEARCH FOUNDATION

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THERE ARE 65 TYPES OF LYMPHOMA. BUT THE ONLY ONE THAT MATTERS IS YOURS.

Knowing how to treat lymphoma starts with knowing what kind you have.

It’s not just one disease, but 65 different types of diseases that fall into two main categories—Hodgkin or non-Hodgkin lymphoma—which are further characterized as B-cell or T-cell lymphoma. Knowing the specific type is equally as important as knowing the stage, because it can help doctors make personalized treatment decisions. For more information about your type of lymphoma, talk to your healthcare professional.

So be in the know. Know your type.

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