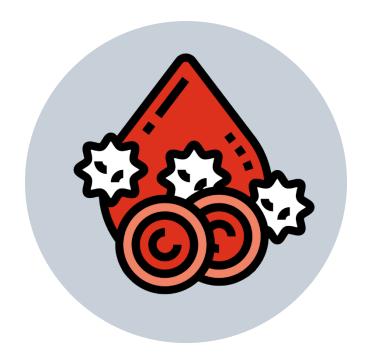
ALL Survivorship



Real World Health Care 2022

Acute lymphoblastic leukemia (ALL) typically gets worse quickly and can be fatal in a few months if it is not treated.

ALL Survivorship is a recently published series of articles that spotlights the organizations and efforts dedicated to helping patients cope with ALL and ensure they get the support they need.

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What is Acute Lymphoblastic Leukemia and Whom Does it Affect?

Leukemia is a blood cancer that affects red blood cells, white blood cells and/or platelets. One type of leukemia, acute lymphoblastic leukemia (ALL) – also called acute lymphocytic leukemia and acute lymphoid leukemia – is a blood and bone marrow cancer that can affect both children and adults. In adults with ALL, the bone marrow makes too many of a type of white blood cell called lymphocytes, while in children with ALL, the bone marrow makes too many immature lymphocytes. This type of cancer usually gets worse quickly and can be fatal within a few months if it is not treated.

The <u>American Cancer Society</u> estimates that about 6,600 new cases of ALL will be diagnosed this year (well under one percent of all new cancer cases). While most cases of ALL are diagnosed in patients younger than 20, most deaths from ALL occur in adults. According to the <u>Leukemia & Lymphoma Society</u>, the five-year relative survival rates for ALL are 72.1 percent overall, 92.5 percent for children and adolescents under 15 and 92.5 percent for children younger than five.

Childhood ALL

ALL is the most common type of cancer in children. Risk factors for the disease include past treatment for cancer and certain genetic conditions. Signs and symptoms of childhood ALL include (but are not limited to) fever, easy bruising or bleeding, weakness, pain or feeling of fullness below the ribs and loss of appetite.

Health care providers may use a number of tests to diagnose ALL and find out if the leukemia cells have spread to other parts of the body:

- Complete blood count (CBC) with differential
- Blood chemistry studies
- Bone marrow aspiration and biopsy
- Cytogenic analysis of blood cell chromosomes
- Immunophenotyping to identify cell surface markers
- Lumbar puncture to test cerebrospinal fluid
- Chest x-ray

Several factors affect the chance of recovery from childhood ALL including:

- How quickly and how low the leukemia cell count drops after the first month of treatment.
- Age at the time of diagnosis, sex, <u>race</u>, and <u>ethnic background</u>.
- The number of white blood cells in the blood at the time of diagnosis.
- Whether the leukemia cells began from B lymphocytes or T lymphocytes.
- Whether there are certain changes in the chromosomes or genes of the leukemia cells.
- Whether the child has Down syndrome.

- Whether leukemia cells are found in the cerebrospinal fluid.
- The child's weight at the time of diagnosis and during treatment.

Treatment options for childhood ALL vary and depend upon:

- Whether the leukemia cells began from B lymphocytes or T lymphocytes.
- Whether the child has standard-risk, high-risk, or very high-risk ALL.
- The age of the child at the time of diagnosis.
- Whether there are certain changes in the chromosomes of lymphocytes.
- Whether the child was treated with <u>steroids</u> before the start of <u>induction</u> therapy.
- How guickly and how low the leukemia cell count drops during treatment.

Treatment for childhood ALL takes about two to three years and is done in three phases. In the first (most intense) phase, remission induction, the goal is to kill the leukemia cells in the blood and bone marrow, which puts the leukemia into remission. More than 95 percent of children with ALL enter remission after one month of induction treatment. The second phase, consolidation/intensification, is designed to kill any leukemia cells that remain in the body and may cause relapse. Maintenance is the third phase of treatment, in which lower treatment doses are given to kill any remaining leukemia cells that may regrow and cause a relapse.

Most children with ALL are cured of their disease after treatment. Sometimes, however, childhood ALL does not respond to treatment or comes back after treatment. For leukemia that comes back after treatment, prognosis and treatment options depend partly on the time between diagnosis and relapse and whether or not the leukemia comes back in the bone marrow or in other parts of the body.

For more information about standard and new types of treatments for childhood ALL, visit the National Cancer Institute's <u>Physician Data Query Summary</u> web page for childhood ALL.

Adult ALL

Risk factors for adult ALL include but are not limited to being male, white, and older than 70; past treatment with chemotherapy or radiation therapy; being exposed to high levels of radiation in the environment; and having certain genetic disorders. Early signs and symptoms may mimic those of the flu and other common diseases, such as weakness, feeling tired, fever, easy bruising or bleeding, shortness of breath and loss of weight or appetite, among others.

Tests to diagnose adult ALL by examining the blood and bone marrow are similar to those used to diagnose childhood ALL. Once adult ALL has been diagnosed, further tests are done to find out if the cancer has spread to the central nervous system or to other parts of the body. Prognosis and treatment options vary depending on:

- The age of the patient.
- Whether the cancer has spread to the brain or spinal cord.

- Whether there are certain changes in the genes.
- Whether the cancer has been treated before or has recurred.

Unlike with childhood ALL, treatment for adult ALL is done in two phases over about two years. The first and most intense phase, remission induction therapy, has the same goal as in childhood ALL: kill the leukemia cells in the blood and bone marrow, which places the leukemia in remission. The second phase is post-remission therapy, which is designed to kill any remaining leukemia cells that may not be active but could begin to regrow and cause a relapse.

Central nervous system (CNS) prophylaxis therapy is usually given during each phase to reach leukemia cells in the CNS that may not be reached by standard doses of chemotherapy.

For more information about standard and new types of treatments for adult ALL, visit the National Cancer Institute's <u>Physician Data Query Summary</u> web page for adult ALL.

Sources:

National Cancer Institute
Leukemia & Lymphoma Society
American Cancer Society

Beyond the Cure: Acute Lymphoblastic Leukemia Survivorship is a Journey

Childhood cancer survivorship is a journey. Survivors and their families need to be prepared for life after cancer, and the <u>National Children's Cancer Society</u> (NCCS) is committed to them every step of the way.

Real World Health Care recently interviewed NCCS's Jessica Cook, MSW, vice president of Patient & Family Services, about that journey and how NCCS supports children with acute lymphoblastic

leukemia (ALL) and their families.

Cook has been with NCCS, serving children with cancer and their families, for 22 years. She oversees all national NCCS programs and takes a "no matter what" approach to creating a clear path through the maze of childhood cancer and survivorship.

"Childhood cancer survivorship is a lifelong journey, where survivors require specialized, long-term follow-up care and support to stay healthy years after their treatment has ended," she said. "The NCCS remains committed every step of the way."



Jessica Cook, National Children's Cancer Society

Support for ALL Families

Real World Health Care: In what ways does the NCCS support children with acute lymphoblastic leukemia and their families?

Jessica Cook: In several ways. Our Family Support Program provides practical and emotional assistance to parents, caregivers and survivors. Our <u>Transportation Assistance Fund</u> ensures children have access to life-saving treatment. Our <u>Emergency Assistance Fund</u> provides an unrestricted stipend to families whose child has been inpatient or relocated for an extended period of time. Our <u>Late Effects After Treatment Tool</u> (LEATT) provides a personal online assessment of potential late effects based on their specific diagnosis and treatment. We also award <u>college scholarships</u> to childhood cancer survivors to help them achieve their future goals. To date, we've awarded 544 scholarships to 203 recipients totaling \$1.9 million.

Late Effects and Long-Term Care

RWHC: You mentioned "late effects." Can you provide a few examples of late effects and their impact on overall health and well-being?

JC: Due to the toxicity of the treatment received, 90 percent of childhood cancer survivors will experience some late effects of treatment and around a third will have severe, disabling or life-threatening chronic conditions. Diabetes mellitus and metabolic syndrome are among the most common late effects in childhood cancer survivors and are major risk factors for cardiovascular disease. Identifying risk factors at an early stage and then aggressively employing risk reduction strategies like dietary changes, physical activity and early treatment of cardiovascular disease is key to ensuring the best quality of life among survivors.

RWHC: Why is long-term follow-up care so vital for children who have been treated with ALL?

JC: Because childhood cancer is rare, most primary care health providers may only see one or two childhood cancer survivors during their medical careers. As a result, they may not be familiar with the <u>late effects</u> of childhood cancer treatment. Long term follow-up clinics educate each patient on specific risks from their treatments. Knowing the possible risks will allow patients to better monitor their health and address any complications early, which leads to overall better health and educational outcomes.

Beyond the Cure

RWHC: What is the goal of the NCCS Beyond the Cure program?

JC: The mission of Beyond the Cure is to help childhood cancer survivors integrate the cancer experience into their new life as survivors, successfully handle the challenges that are ahead of them and celebrate survivorship.

RWHC: What role do patients and their families play in the creation of the program and its ongoing initiatives?

JC: Input from families and childhood cancer survivors led to the creation of the program. Families and survivors still provide invaluable insight when reviewing our print pieces, serving on the Beyond the Cure Scholarship Program review committee and sharing their experiences of unmet needs within the survivorship community.

RWHC: Can you provide a few examples of how the program prepares survivors and their families for life after cancer?

JC: Earlier, I mentioned our Late Effects After Treatment Tool (LEATT), which provides a detailed assessment of potential late effects based on the diagnosis and treatment the individual received. It offers guidance on beneficial screenings and recommendations for healthy lifestyle choices and will be available on mobile platforms later this year. The NCCS also offers <u>educational publications</u> for young

adult cancer survivors and their caregivers that specifically address various aspects of survivorship. In addition, we sponsor <u>survivorship conferences</u> that aim to educate childhood cancer survivors about life after cancer.

We also invite patients and their families to join our Childhood Cancer Support Facebook group. It is a safe, compassionate place for patients and families to connect and find resources and is over 1,000 members strong.

Managing Side Effects of Acute Lymphoblastic Leukemia Treatment

As the largest professionally led nonprofit network of cancer support worldwide, the <u>Cancer Support Community</u> (CSC), including its Gilda's Club affiliates, is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. CSC achieves its mission through three areas: direct service delivery, research, and advocacy.

This article about the side effects of treatment for acute lymphoblastic leukemia (ALL) is excerpted from CSC's <u>Frankly Speaking About Cancer</u> series, which can be downloaded from the CSC web site.

Your Treatment Plan

Cancer doctors use a combination of drugs to kill ALL cells by targeting the fast-growing cancer cells. Some of the most complex chemotherapy combinations and treatment schedules used in the whole field of oncology are used to treat ALL. Most people do well with treatment.

Because of the acute nature of ALL, treatment usually begins as soon as possible after diagnosis. Treatment options will be based on what subtype of ALL you have, your age, your general level of health and whether cancer has spread to other parts of your body.

In general, ALL treatment takes two years for females and three years for males. However, most of the therapy can be done as an outpatient and the majority of therapy is spent on a maintenance phase, which allows you to return to many of the things you did before your diagnosis. If you have trouble obtaining medications or taking them as prescribed, talk to your treatment team about options.

Side Effects Can Be Unpredictable

Because most cancer treatment drugs are not specific to cancer cells, they can affect any cells in your body that grow quickly. This unwanted damage to healthy cells is what causes side effects.

Different types of treatments and dosages can cause varying side effects. The level of side effects you might experience will also depend on your individual body, your general health and your age. Some side effects can appear almost as soon as treatment begins, and others can appear months or even years later.

Research is continuing to uncover ways to lessen side effects, and people who are treated for ALL now are less likely to have long-term effects than people treated in the past. It is also important to remember that many cancer treatments will

decrease symptoms caused by ALL – so you may feel better, and your quality of life may actually improve during treatment.

Immediate Side Effects

The immediate side effects that come while you are having treatment for ALL, or soon after you complete it, may include:

- From reduced red blood cell counts, known as anemia: tiredness (fatigue), dizziness, weakness, headaches, pale coloring.
- From low platelet counts, known as thrombocytopenia: easy bruising, unexplained bleeding, and small red or purple spots on the skin, known as petechiae.
- From decreased white blood cell counts, known as neutropenia: increased risk of infection, especially respiratory, bladder and blood (known as sepsis) and around the eyes, nose, mouth, genital and rectal areas, and catheter sites.
- From damage to hair follicles: hair loss, known as alopecia, ranging from thinning to complete. While most often associated with hair on the scalp, all body hair can be affected.
- From damage to gastrointestinal tract: mouth and throat sores, dry mouth or changes in taste, loss of appetite, nausea and vomiting, diarrhea, or constipation.
- From nerve damage, known as peripheral neuropathy: numbness, tingling, burning sensations, and discomfort or weakness in hands or feet.
- From damage to the reproductive system: women's periods usually stop, and men may stop producing sperm.

Most of these side effects go away soon after treatment is finished. If serious side effects occur during treatment, that type of chemotherapy may have to be reduced or switched to another drug.

Just because a side effect is common does not mean it is guaranteed to occur. Most people undergoing ALL treatment do not experience all of these side effects, and the ones they do may be mild. The most important thing you can do is to let your health care team know when you experience side effects, as there are many treatments available to lessen them, including:

- Drugs to prevent nausea and vomiting
- Drugs or transfusions to increase the numbers of platelets and red blood cells
- Antibiotics to prevent an infection or prevent it from taking hold
- Drugs that help the body eliminate the contents of killed tumor cells that can spill into the blood
- Drugs for pain and discomfort
- Self-care techniques to prevent or decrease severity of mouth sores, skin breakdown, infections and fatigue

Questions to Ask Your Care Team

- What are the possible side effects of this treatment, both in the short term and the long term? How long will they last?
- Is there anything that can be done to reduce side effects? Are there any complementary therapies that may help me cope with cancer treatment?
- When should I contact my doctor about my side effects, and who specifically should I contact?
- Could this treatment affect my ability to become pregnant or have children in the future? If so, should I talk with a fertility specialist before treatment begins? Is there even time to do this?
- Will I have any hair loss? If so, when will my hair grow back? Who can I speak to about getting a wig if I want one?
- Where can I get support and resources if should need them? This can include counseling, support groups, financial and other practical resources

Long-Term Side Effects

ALL requires a very long treatment regimen, with strong chemotherapy drugs that can leave lasting effects for many years, even for the rest of your life. These long-term side effects can show up months or years after your treatment is finished. Most long-term survivors don't have serious late effects, but it is important to catch any problems early to be able to treat them.

Below are some of the more common long-term side effects seen after treatment for ALL. Your risk of developing any of them depends on many factors, especially the specific treatment you receive. You and your doctor should discuss the possibility of these occurring, what to look out for and if anything can be done to prevent them. After treatment, follow-up is critical to be able to catch any of these late effects and figure out ways to help you.

Learning problems are especially common if you receive radiation therapy or intrathecal chemotherapy into your spine. These therapies kill leukemia in your central nervous system, but can also cause problems to the brain, such as Attention Deficit Disorder, Attention Deficit and Hyperactivity Disorder or general academic difficulties. People who experience this do not have any reduction in their IQs, but they are slower at processing information. If it is suspected that you suffer from this problem, a neuropsychiatric evaluation is usually the next step, and possibly meeting with a psychologist. There are a number of things that can be done to address these learning abilities, including developing an Individual Education Plan (I.E.P.) to make up for this deficit if you are still in school. An I.E.P. allows you to get certain accommodations in work or school.

Bone and joint problems can be caused by steroids, a common part of leukemia treatment that can lead to damaged bones and joints or osteoporosis (thinning of the bones). Mild to moderate osteoporosis can be treated with medication and

exercise, but if severe bone or joint problems occur, you may need to stop steroid use and be referred to an orthopedic surgeon.

Heart problems can be caused by certain chemotherapy drugs. Your doctor will likely have you undergo an echocardiogram, a simple painless test to check heart function, before beginning therapy so it will be easy to see if there is any decreased function after therapy. Your doctor may arrange for a consultation with a cardiologist, a doctor who specializes in care of the heart. After therapy, you may have a follow-up echocardiogram to assess heart function, as the cardiotoxic effects of some chemotherapy may not be seen until several years after treatment.

Another cancer – acute myelogenous leukemia (AML) – developing later in life is a risk for around five percent of people receiving certain chemotherapies. Even less frequently, some people who have been cured with ALL therapy will develop non-Hodgkin's lymphoma or other cancers. Discuss this with your health care team so you can better understand what this means for you.

Infertility is a risk after some chemotherapy treatments, radiation therapy to certain parts of your body and stem cell transplant.

Patients and caregivers can find support and additional materials about ALL from the Cancer Support Community's Helpline (888-793-9355) and <u>website</u> as well as your <u>local CSC</u> or Gilda's Club. The Cancer Support Community's <u>Open to Options</u>® program offers help for asking questions of your health care team when facing a cancer treatment decision.

Is a Blood or Marrow Transplant Right for You?

People with acute lymphoblastic leukemia (ALL) may have a range of treatment options available to them, including chemotherapy, targeted therapy, immunotherapy, surgery and radiation therapy. These options will vary depending on the patient's ALL subtype, age, state of health and other prognostic factors.

A patient's cancer care team may also recommend a blood or marrow transplant (BMT) to treat ALL. Sometimes called a bone marrow transplant or blood stem cell transplant, BMT replaces unhealthy blood-forming cells (stem cells) with healthy ones. For some people, BMT can cure their disease.

The decision to obtain a BMT is one that patients should discuss directly with their care team. However, ALL patients have another resource to help them navigate the process: Be The Match®. Be The Match is a global leader in bone marrow transplantation. It conducts research to improve transplant outcomes, provides support and resources for patients, and is part of a global network of partners. In 2021, Be The Match facilitated over 6,000 total transplants.

For the thousands of people diagnosed every year with life-threatening blood cancers like leukemia and lymphoma, a cure exists. Over the past 30 years Be The Match, operated by the National Marrow Donor Program® (NMDP), has managed the most diverse marrow registry in the world. Be The Match works every day to save lives through transplant.

How Does BMT Work for ALL?

Be The Match has a comprehensive <u>website</u> for people who want to learn more about BMT. According to the site, the most common type of transplant for ALL is an allogenic transplant. This type uses healthy blood-forming cells donated by somebody else to replace their unhealthy blood-forming cells. These healthy cells can come from a family member, unrelated donor or umbilical cord blood.

Before the BMT process, patients start with several days of chemotherapy, with or without radiation, to kill their unhealthy cells. Then, the healthy donated cells are given to the patient through an intravenous (IV) catheter. The new cells travel to the inside of the patient's bones and begin to make healthy blood cells.

The entire transplant process, from the start of chemo or radiation, until hospital discharge, can last weeks to months. That is followed by many months of recovery near the transplant center and at home while the transplant team closely watches the patient to prevent and treat any side effects or complications.

Navigating the Transplant Process

Leah Christianson supervises patient navigators in Be The Match's Patient Support Center. Her team provides free, <u>one-on-one support</u> to patients, their caregivers and loved ones from diagnosis through recovery and survivorship.

"We spend time with patients to answer their questions about transplant and help them address any barriers they may face," said Christianson. "We help them understand what BMT is, how it works, what is required in terms of hospital stays and follow up care, and more. Much of what we do focuses on helping the patient come to terms with the unknowns and meeting their needs so they can feel comfortable with their decisions. Patients are always in control, and we always respect the patient's choice of whether or not to use a service or resource."



Leah Christianson, Be The Match

Christianson and her team of navigators and licensed social workers help ALL patients and their loved ones connect to <u>educational materials</u> including webinars, e-newsletters and cancer care guidelines. <u>Group support</u> for survivors and grieving loved ones is available by phone and online chat. Be The Match's <u>Peer Connect program</u> helps patients connect with a trained transplant recipient or caregiver volunteers who have been through the process and can share their experience and tips. Navigators also help patients learn about <u>financial resources and grants</u> to help them pay for medical and other expenses during transplant, identify <u>clinical trials</u> that can help them and future patients, and find a <u>transplant center</u> near them.

Be The Match Registry

A cornerstone of Be The Match is its <u>registry</u>, which connects patients searching for a cure with bone marrow donors. It is the largest and most diverse donor registry in the world, with access to more than 39 million potential donors and nearly 806,000 cord blood units worldwide. The registry can be life saving for the estimated 70 percent of ALL patients who don't have a fully matched donor in their family.

According to Christianson, a patient's doctor can search the registry for potential donors that match the patient's human leukocyte antigen (HLA) type. HLAs are special proteins found on the outside of a body's cells. They act as markers to tell the body whether or not the cells belong, allowing the body's immune system to accept them rather than fighting them off.

Christianson encourages everyone to consider <u>becoming a BMT donor</u>, even those who don't have a family member directly impacted by the disease. She notes that for most donors, the BMT process is similar to donating platelets or plasma – a non-surgical procedure that takes a couple of hours with few side effects aside from a bit of tiredness. About 15 percent of donors will be asked to donate bone marrow. This is a surgical procedure done under anesthesia in which doctors extract the marrow from the donor's hip bone. Upon waking, donors can expect to feel some tenderness in the site.

"BMT donation is not nearly as scary or difficult as it is portrayed on television," Christianson said. "When we speak to BMT donors, we hear over and over again that they feel like heroes and would do it again in a heartbeat."

More information about how BMT donation works can be found here.

American Cancer Society Funds Pioneering Research in Acute Lymphoblastic Leukemia

September is Childhood Cancer Awareness Month, an observance recognized by health care institutions, advocacy organizations, patients and families around the world. While childhood cancer is rare, it is the leading cause of disease-related death past infancy in children and adolescents, according to the National Cancer Institute.

Acute Lymphoblastic Leukemia (ALL) is the most common cancer diagnosed in children, representing about 25% of cancer diagnoses among children younger than 15. Thanks to decades of scientific discoveries, dramatic improvements in survival have been achieved in children and adolescents with cancer. Today, ALL can be considered a cancer "success story," with a survival rate that has improved from about 10% in the 1960s to about 90% today.

As the largest non-profit funder of cancer research in the United States outside the federal government, the <u>American Cancer Society</u> (ACS) has helped to drive many research programs into new and better treatments for ALL. Real World Health Care reached out to the ACS's <u>William L. Dahut, MD</u>, Chief Scientific Officer, to learn how the organization supports children with ALL and delve into some of the pioneering research studies and clinical trials it has funded.

Three Pillars of Support

Real World Health Care: How does the American Cancer Society support children with acute lymphoblastic leukemia (ALL) through its programs, services and research?

William Dahut: The American Cancer Society supports children with ALL through our <u>Patient Support Pillar</u>, <u>Discovery Pillar</u> and the <u>ACS Cancer Advocacy Network</u> (ACS-CAN). The patient support pillar provides cancer information, transportation and lodging to cancer patients as well as multiple other means of support. The discovery pillar is the research arm and in the past 10 years, the American Cancer Society has funded 28 research grants focused on acute lymphoblastic leukemia in the amount of \$14.5 million, including 5 grants totaling \$3.8



Dr. William Dahut, American Cancer Society

million that are currently in effect. (The Society's research investment in leukemia in the past 10 years is approximately 221 grants totaling \$61.2 million, including 48 current grants in the amount of \$20 million.). ACS-CAN is our policy and advocacy arm and works with federal and state legislatures to help ensure access to cancer therapies.

Improvements in CAR-T Therapy

RWHC: How has ACS-funded research changed the treatment landscape for ALL patients?

WD: The American Cancer Society helped fund some pioneering research and clinical trials that helped develop and improve the treatment known as chimeric antigen receptor (CAR) T-cell, which has led to dramatic remissions and cures in patients with ALL. ACS began funding research in 2010 to help scientists conduct the pioneering research and clinical trials that have helped develop and improve successful CAR T-cell therapies for children and adults who have leukemia or lymphoma. Studies today are looking for new CAR-T targets, combining multiple targets into one CAR-T and using CAR-T therapy as a bridge to bone marrow transplants.

Additional T-cell-related research funded by ACS includes a study which showed that whether T-cell ALL leukemia takes off or worsens depends on structural changes in the layout of protein bundles called chromosomes, as well as a study that investigated use of a light-operated nanoparticle to remotely and selectively activate T-cells to attack tumor cells such as those found in some leukemia and lymphoma cancers.

Reducing ALL Treatment Side Effects

RWHC: Some children with ALL relapse after treatment. Is ACS funding any studies or clinical trials to help prevent this?

WD: The ACS provided funding that helped support the research of Barton Kamen, MD, PhD, in support of his work that provided important insights for reducing treatment side effects in children with ALL. Dr. Kamen investigated different ways to help reduce chemotherapy side effects in children. One approach was metronomic therapy: low doses of chemotherapy given frequently or continuously. Although the approach was already in use, Dr. Kamen's research suggested that it could be effective in children while reducing some toxic side effects from higher doses. His research contributed to the understanding of this practice, which some use but is not considered a standard approach.

More recently, ACS funded a Dana-Farber Cancer Center researcher, Kira Bona, MD, MPH, to study "Poverty and Treatment-Associated Neurocognitive Decline in Childhood ALL." It is important to note that nearly one in three childhood ALL

survivors will suffer from changes in attention, memory and learning (neurocognitive function) due to chemotherapy. Dr. Bona's study uses the research infrastructure of a Children's Oncology Group (COG) multi-center clinical trial for ALL to ask whether living in poverty at the time of diagnosis is associated with neurocognitive changes during therapy and markers of biologic stress at diagnosis and during therapy. At the individual level, this study will identify patients at highest risk of neurocognitive late effects (based on biomarkers) who will most benefit from future trials testing medications to prevent neurocognitive deficits. At the population level, results will inform care delivery interventions, such as risk-based neurocognitive screening and poverty-targeted interventions, to reduce survivorship disparities.

Participating in Clinical Trials

RWHC: What advice would you give to a parent of a child with ALL about seeking out or participating in a clinical trial?

WD: All of the advances in childhood leukemia have come in clinical trials. Studies have shown that regardless of tumor type, care for cancer patients is best for those on clinical trials, many of which can be offered locally. Families should discuss clinical trial options with their physicians, reach out to local cancer centers or contact ACS at 1-800-227-2345 or on our web page www.cancer.org.