LEUKEMIA & LYMPHOMA SOCIETY®

Amyloidosis

No. 41 in a series providing the latest information for patients, caregivers and healthcare professionals

Highlights

- Amyloidosis is a rare disorder in which a normal protein in the body misfolds and forms amyloid deposits in various tissues and organs. This buildup of amyloid can damage organs such as the heart, kidneys, liver, nerves and the gastrointestinal system.
- Localized amyloidosis affects one organ or one part of the body. Systemic amyloidosis affects multiple organs or tissues. There are many different types of amyloidosis.
- AL amyloidosis (immunoglobulin light chain amyloidosis) is the most common type of amyloidosis.
- Amyloidosis is not a cancer, but it can be associated with certain blood cancers, such as multiple myeloma.
- There is currently no cure for amyloidosis. Treatment can reduce symptoms and extend life.
- Treatment varies depending on the type of amyloidosis. Treatments for amyloidosis can include chemotherapy, drug therapy, immunotherapy, dialysis, stem cell transplantation, organ transplantation, and/or participation in a clinical trial.

Introduction

Amyloidosis is a rare disorder in which proteins produced in the body misfold and clump together. These abnormal proteins form amyloid deposits (also called fibrils) that build up in tissues and organs. The amyloid deposits can develop in one or more parts of the body. Over time, these deposits can cause the tissues and organs to malfunction, leading to symptoms and organ failure.

Amyloidosis can be localized or systemic. When the amyloid deposits build up in a single organ or only one part of the body, it is called localized amyloidosis. Localized amyloidosis most commonly affects the skin, bladder, gastrointestinal system (mouth, throat, esophagus, stomach, intestines, rectum and anus) and the airways. Localized amyloidosis is usually not life-threatening and rarely progresses to systemic amyloidosis.

When the amyloid deposits build up throughout the body, it is called systemic amyloidosis. Systemic amyloidosis is the most common form of amyloidosis. It can affect the heart, kidneys, liver, nerves, joints, skin, blood vessels and the gastrointestinal system. Systemic amyloidosis can cause life-threatening organ damage.

Types of Amyloidosis

There are many different types of amyloidosis. They are generally categorized by the type of precursor protein involved in the disease. The most common types are listed below.

AL amyloidosis. AL amyloidosis is also called "immunoglobulin light chain amyloidosis" or "primary amyloidosis." It is one of the most common types of amyloidosis.

AL amyloidosis results from a disorder of plasma cells. The plasma cells are a type of white blood cell that grow in the bone marrow. Plasma cells produce immunoglobulins, which are proteins that fight infection. Immunoglobulins are made up of light chains and heavy chains. When abnormal plasma cells make too many light chain proteins and misfold, they deposit amyloid in various parts of the body. The "A" in AL amyloidosis stands for amyloid and the "L" stands for light chain.

In AL amyloidosis, the heart is involved in 70 to 80 percent of patients. The kidneys are involved in 60 to 70 percent of patients. Other organs that may be affected are the liver, skin, tongue, nerves and the gastrointestinal system.

Approximately 50% of patients with AL amyloidosis have plasma cells with a cytogenetic abnormality involving chromosomes 11 and 14. This abnormality is called a "translocation," and is written as t(11;14). A translocation refers to a genetic change in which a piece of one chromosome breaks off and attaches to another chromosome. The presence of t(11;14) will influence treatment selection and prognosis (expected course of the disease).

Cytogenetics involves testing samples of blood, tissue or bone marrow to look for changes in chromosomes (the strands of deoxyribonucleic acid [DNA] and protein that contain genetic information in a cell).

AL amyloidosis is associated with a plasma cell disorder that is similar, but not identical to, multiple myeloma. About 10 to 20 percent of AL amyloidosis patients also have multiple myeloma and they are treated for both conditions.

AA amyloidosis. AA amyloidosis is also called "autoimmune amyloidosis," "secondary amyloidosis," or "inflammatory amyloidosis." In AA amyloidosis, the amyloid protein that builds up in the tissues is called serum amyloid A. High levels of the serum amyloid A protein can lead to amyloid deposits over several years, especially in people with chronic states of inflammation or infection. AA amyloidosis is therefore associated with chronic diseases, such as diabetes, tuberculosis, rheumatoid arthritis and inflammatory bowel disease. It may also be linked to aging. AA amyloidosis commonly affects the spleen, liver, kidneys and the gastrointestinal system.

ATTR amyloidosis. There are two main types of ATTR amyloidosis, called "Familial" and "Wild-type." Transthyretin (TTR) is a protein made by the liver. It transports the thyroid hormone thyroxine and vitamin A throughout the body. In amyloidosis, the TTR mutates and forms abnormal amyloid proteins.

- **Familial ATTR amyloidosis.** This type is also known as "hereditary amyloidosis." It can be passed from generation to generation within a family. These proteins can cause problems with the heart, liver, nerves and kidneys, and may also cause carpal tunnel syndrome and eye abnormalities.
- **Wild-type ATTR amyloidosis.** This type has also been called "senile systemic amyloidosis." It occurs when the TTR protein is normal but produces amyloid for unknown reasons, or due to age-related changes. It tends to affect adults 65 years of age and older, and often targets the heart. It can also cause carpal tunnel syndrome.

Dialysis-related amyloidosis. This type is also called "beta-2 microglobulin amyloidosis." Beta-2 microglobulin is a protein that is normally filtered out by healthy kidneys. It occurs in people with kidney failure who have been on long-term dialysis (a procedure to remove extra fluid and waste products from the blood when the kidneys stop working). It commonly affects the bones, joints and tendons.

Possible Signs and Symptoms

Signs and symptoms are changes in the body that may indicate the presence of disease. A "sign" is a change in the body that the doctor sees in an examination or a test result. A "symptom" is a change in the body that a person can see and/or feel.

Signs and symptoms that may be associated with amyloidosis are listed below.

Blood pressure changes (dizziness upon standing, fainting)	**Carpal tunnel syndrome** (pain, numbness, tingling in the hands, wrists or arms)	**Diarrhea or constipation**
Dry mouth	**Discoloration around the eyes**	**Enlarged liver or thyroid**
Enlarged spleen (swelling of the belly, feeling of fullness)	**Enlarged tongue, difficulty swallowing**	**Eye issues** (floaters, abnormal blood vessels)
Foamy urine (from protein in the urine)	**Heart issues** (irregular, rapid or slow heartbeat)	**High cholesterol**
Hoarse voice	**Joint enlargement or joint pain**	**Kidney issues**
Nail changes	**Neuropathy** (pain, numbness, tingling in the hands or feet)	**Severe fatigue and weakness**
Shortness of breath	**Skin changes** (bruising, rashes, thickening, or mouth sores)	**Spinal stenosis** (pressure on the spinal cord and nerves)
Swelling of the legs, ankles, feet	**Weak hand grip**	**Weight loss**

Effects of Amyloidosis on Various Organs and Organ Systems

Effects on the heart. Cardiac amyloidosis, also known as "stiff heart syndrome," is caused by amyloid deposits in the heart. The walls of the heart can thicken and affect the heart muscle's ability to function properly. The heart's electrical signals can also be disrupted, affecting heart rhythm. Fainting, shortness of breath, weakness and swelling of the abdomen or lower parts of the body are possible signs of cardiac amyloidosis.

Effects on the kidneys. Amyloid deposits in the kidneys can affect the kidneys' ability to remove waste products and can lead to kidney failure. Dialysis may be needed as a result. Excess protein in the urine and swelling of the legs and ankles are signs of kidney issues in amyloidosis.

Effects on the nervous system. Amyloid deposits can cause nerve damage such as:

- Peripheral neuropathy (pain, numbness, tingling in the hands and feet)
- Changes in bowel function, causing constipation and/or diarrhea
- Low blood pressure, causing dizziness or fainting

Effects on the gastrointestinal system. Amyloid deposits in the gastrointestinal system (mouth, throat, esophagus, stomach, intestines, rectum and anus) can cause nausea, diarrhea or constipation, weight loss, loss of appetite and difficulty eating due to an enlarged tongue.

Effects on the skin and soft tissue. Amyloid deposits in the blood vessels of the skin can cause bruising. Deposits in the wrist and nerves can lead to carpal tunnel syndrome. Deposits in other tissues can cause changes in appearance.

Visit www.LLS.org/booklets to view the free LLS series Side Effects Management (filter for Side Effect Management) for more information.

Diagnosis

Amyloidosis is often hard to diagnose because the signs and symptoms can be the same as those of more common diseases. It is important to diagnose amyloidosis as early as possible so that further organ damage is prevented. A precise diagnosis is also important because treatment varies depending on the specific type of amyloidosis.

Some tests used to diagnose amyloidosis include:

- Blood tests
- Urine tests
- Tissue biopsy with Congo red staining (next column)
- Bone marrow aspiration and biopsy (next column)
- Cytogenetic testing (various tests that look for changes in the chromosomes of cells from a blood, tissue or bone marrow sample)
- Mass spectrometry (a type of chemical analysis that identifies proteins in tissue)
- Cardiac imaging such as an echocardiogram (see *Health Terms* on page 7)
- Imaging such as a computerized tomography (CT) scan or magnetic resonance imaging (MRI) (see *Health Terms* on page 7)
- Skeletal survey (a series of X-rays performed to evaluate the major bones of the body, used in certain circumstances)
- Other tests, depending on which organ is affected

Tissue biopsy with Congo red staining. This is an essential test to confirm the suspicion of amyloidosis. It is usually done by what is called an abdominal fat pad biopsy. This is an easy test to perform. After a local injection of anesthetic, a very thin needle is inserted into the abdominal fat pad (skin of the belly) and a small piece of tissue is removed. The tissue is then stained to confirm the diagnosis. Occasionally the biopsy will be done on a salivary gland (the gland that produces saliva in the mouth) or other tissue, rather than the abdominal fat pad.

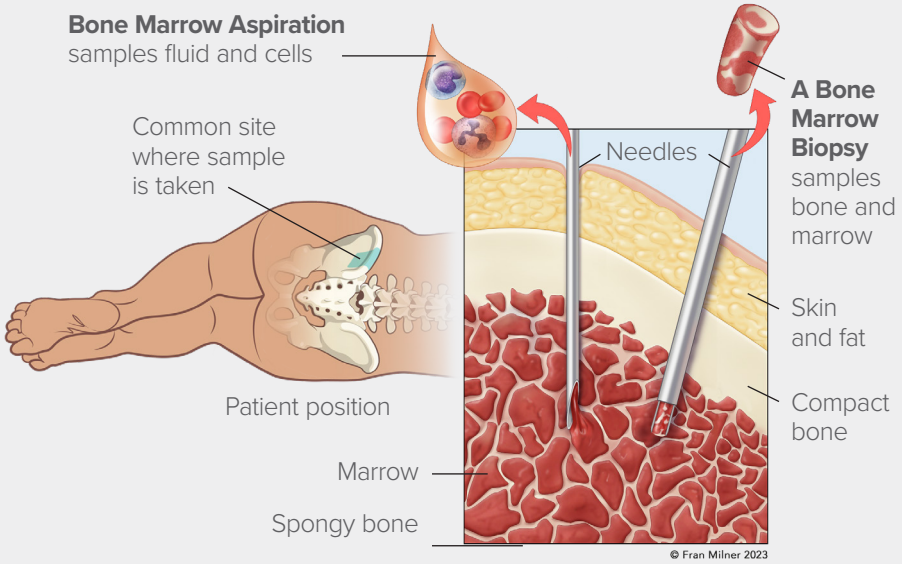
Bone marrow aspiration and biopsy. A bone marrow aspiration is a test to remove a small sample of liquid bone marrow. A bone marrow biopsy is a test to remove a small sample of intact bone marrow. See **Figure 1** on page 4 for an illustration of the bone marrow aspiration and biopsy.

A hematopathologist examines the bone marrow cells under a microscope. Doctors use the findings from the bone marrow aspiration and biopsy to diagnose amyloidosis and related diseases.

A hematopathologist is a doctor who has special training in identifying blood diseases by studying cells under a microscope and performing other specialized tests on the cells.

Visit www.LLS.org/booklets to view the free booklet *Understanding Lab and Imaging Tests* for more information. To view interactive 3D illustrations of various lab and imaging tests, visit www.LLS.org/3D.

Figure 1. Bone Marrow Aspiration and Biopsy



Left: The place on the back of the patient's pelvic bone where a bone marrow aspiration or biopsy is done. **Right:** Where the two needles go inside the bone to collect the liquid sample for aspiration (the needle on the left) and the bone sample for biopsy (the needle on the right). The needles are different sizes for each test.

Treatment Team

Amyloidosis is a very rare disease. It is important to consult a doctor with experience in treating it. Typically, a hematologist (a doctor who has special training in diagnosing and treating blood disorders) or a hematologist-oncologist (a doctor with special training in blood disorders and cancer) is seen. Your treatment team may also include specialists with expertise in:

- Cardiology—to diagnose and treat diseases of the heart, blood vessels and circulatory system
- Dermatology—to diagnose and treat skin problems
- Gastroenterology—to diagnose and treat disorders of the gastrointestinal system
- Nephrology—to diagnose and treat kidney disease
- Neurology—to diagnose and treat disorders of the nervous system

Additional members of your treatment team may include dietitians, nurses, nurse practitioners, pain management specialists, physician assistants, physical therapists, social workers, transplant doctors and others.

Visit www.LLS.org/booklets to view the free booklet *Choosing a Specialist or Treatment Center* for helpful guidance.

Treatment Options

Treatment will depend on the type and extent of the amyloidosis. There is no "one-size-fits-all" approach. Treatment can improve quality of life and prolong survival.

Participation in a clinical trial is a treatment option that provides close monitoring and access to innovative therapies. See page 5 for more information about clinical trials.

Note: A drug that is not FDA-approved for amyloidosis can be used as "off-label" treatment. "Off-label" prescribing is when a doctor gives a drug that is not FDA-approved to treat a patient's condition, but the drug *is* FDA-approved for another condition. An off-label drug may be used if the doctor feels it will benefit the patient. This is a common practice.

AL amyloidosis. Some of the treatments for AL amyloidosis, the most common type of amyloidosis, are similar to treatments for myeloma. For AL amyloidosis, treatment options include:

- **Chemotherapy.** Certain drugs are used to stop the growth of abnormal cells which produce the proteins that form amyloid deposits. Treatment combinations using drugs such as bendamustine (Treanda®), bortezomib (Velcade®), carfilzomib (Kyprolis®),

cyclophosphamide (Cytoxan®), dexamethasone (various brands), ixazomib (Ninlaro®), lenalidomide (Revlimid®), melphalan (Alkeran®), pomalidomide (Pomalyst®), and venetoclax (Venclexta®) may be prescribed.

- **Dialysis.** This procedure removes waste and extra fluid from the blood when the kidneys are not able to do so.
- **Immunotherapy.** Substances are used to improve the immune system's ability to kill the cells that make the abnormal protein. For example, the monoclonal antibody called daratumumab (Darzalex®) attaches to the CD38 protein on the surface of abnormal plasma cells, then signals the immune system to destroy those cells.
- **Solid organ transplant.** A procedure to move an organ from one body to another for the purpose of replacing the recipient's damaged or absent organ.
- **Stem cell transplant.** A procedure that replaces abnormal cells in your bone marrow with healthy cells. In an "autologous" stem cell transplant, your own stem cells are collected from your blood and stored for a short time while you have high-dose chemotherapy. The stem cells are then returned to your body via a vein. In an "allogeneic" stem cell transplant, donor stem cells are used.

AA amyloidosis. Treatment for AA amyloidosis involves getting control of the underlying inflammation or infection. For example, using an immune-suppressing drug for rheumatoid arthritis, or using antibiotics for a chronic bacterial infection.

ATTR amyloidosis. Drug therapies for this type of amyloidosis are generally classified into the following categories:

- Gene silencers—to prevent TTR production by blocking the TTR gene. Examples include eplontersen (Wainua™), inotersen (Tegsedi®), and vutrisiran (Amvuttra®) given by subcutaneous injection, and patisiran (Onpattro®) given by intravenous (IV) infusion.
- Stabilizers—to stop the TTR protein from forming amyloid deposits. Examples include the oral medications acoramidis (Attruby™), diflunisal (generic), and tafamidis (Vyndaqel®/Vyndamax™).

Dialysis-related amyloidosis. For dialysis-related amyloidosis, optimizing the effectiveness of dialysis is key. Kidney transplantation is also an option.

Clinical Trials

Every new drug goes through a series of carefully controlled research studies before it can become part of standard care. These research studies are called "clinical trials," and they are used to find better ways to care for and treat people who have disorders such as amyloidosis or cancer.

In the United States, the Food and Drug Administration (FDA) requires that all new drugs and other treatments be tested in clinical trials before they can be used. At any given time, there are thousands of clinical trials taking place. Doctors and researchers are always looking for new and better ways to treat diseases.

Researchers use clinical trials to study new ways to:

- Treat disease using:
  - A new drug
  - A drug that has been approved, but to treat a different disease
  - A new combination of drugs
  - A new way of giving a drug—by mouth, intravenously (IV), etc.
- Prevent and/or manage treatment complications
- Manage signs and/or symptoms, and ease treatment side effects
- Find and diagnose disease
- Keep the disease from coming back (recurring) after treatment
- Manage long-term side effects

By taking part in a clinical trial, patients can see doctors who are experts in their disease, gain access to new, cutting-edge therapies, and provide helpful information for future patients. The treatments and information we have today are due in large part to patients being willing to join clinical trials.

Talk to your doctor to see if participating in a clinical trial is right for you. It may be helpful to:

- Have a list of questions to ask about the risks and benefits of each trial (visit www.LLS.org/whattoask for lists of suggested questions).
- Ask a family member or friend to go with you when you see your doctor—both for support and to take notes.

You can also visit https://clinicaltrials.gov/ to search for clinical trials for amyloidosis.

Managing Symptoms

Along with any treatment option, managing the symptoms of amyloidosis is important. Coordinated care by your treatment team is essential. Your treatment team may recommend the following options to help you manage your care:

- Pain medication—to help reduce pain and improve quality of life
- Diuretic medication—to encourage the kidneys to make more urine, help the body get rid of extra fluid and salt, and reduce the strain on the heart and kidneys
- Low-salt diet and healthy eating habits—to help with body function, energy and well-being
- Blood-thinning medication—to reduce the risk of blood clots
- Medication—to control your heart rate
- Exercise—to help keep your body and mind healthy

Visit www.LLS.org/booklets to view a variety of free nutrition-related publications. You can also view the free booklet *Pain Management* for helpful information, though it is geared to blood cancer patients.

Supportive Care

Supportive care is an essential part of the management of patients with amyloidosis. Supportive care aims to improve one's quality of life by providing physical, psychological, social and spiritual support. Pain management and nutritional guidance are just two examples.

Coordinated care and a multidisciplinary approach (when doctors of different specialties come together to diagnose and treat patients) are also critical, particularly if the heart or kidneys are involved.

Having a rare disease can feel very isolating. Let your treatment team know if you feel you would benefit from participating in a support group. Speak with a social worker to help with practical concerns (such as finances, transportation, caregiving), or for any social and emotional needs (coping, reducing stress).

Visit www.LLS.org/booklets to view the free LLS booklet *Managing Stress: How Stress Affects You and Ways to Cope.*

At the same link you can access the free LLS booklet *Navigating Life During and After a Blood Cancer Diagnosis: A Workbook for Adults.* Though geared to blood cancer patients, it has useful information about survivorship and a place to log your amyloidosis treatments.

Outlook/Prognosis

While there is no cure for amyloidosis, treatment can slow its progress and improve symptoms. People with amyloidosis can survive with good quality of life for many years.

The prognosis (expected course of the disease) depends on the type of amyloidosis and the individual's response to treatment. Systemic amyloidosis can be life-threatening if left untreated. If chronic infectious or inflammatory conditions are not properly diagnosed and treated, the amount of amyloid deposits will increase, and the disease will worsen. The prognosis also depends on the organs that are affected. For example, if the heart is involved, there is an increased risk of complications.

Significant progress has been made in the understanding and treatment of amyloidosis. Researchers are exploring innovative ways to prevent or disrupt the formation of amyloid, reduce the amount of amyloid, and remove amyloid deposits via novel methods. However, continued research is necessary to increase early detection, find new therapies and improve outcomes. Patients are encouraged to participate in clinical trials to help contribute to medical advances in amyloidosis.

Incidence and Risk Factors

Amyloidosis is a rare disease. The actual number of cases is difficult to estimate because the disease may be underdiagnosed or misdiagnosed.

According to the Amyloidosis Foundation, AL amyloidosis is the most common type. Approximately 4,500 new cases are diagnosed every year in the United States. It mostly affects people between the ages of 50 and 80.

A preexisting diagnosis of monoclonal gammopathy of unknown significance (MGUS, an asymptomatic condition in which abnormal monoclonal protein is present in the blood), or myeloma (cancer of the plasma cells), both increase the risk of AL amyloidosis.

Additional factors that increase the risk of amyloidosis according to the Mayo Clinic include:

- **Age.** Most people diagnosed with amyloidosis are older adults.
- **Sex.** Amyloidosis affects more men and people assigned male at birth than women and people assigned female at birth.

- **Other diseases.** Having a chronic infectious disease (such as tuberculosis) or inflammatory disease (such as rheumatoid arthritis) increase the risk of AA amyloidosis. See AA amyloidosis on page 2.
- **Family history.** Amyloidosis can be hereditary. See Familial ATTR amyloidosis on page 2.
- **Kidney dialysis.** Because dialysis can't always remove large proteins from the blood, abnormal proteins can build up and be deposited in tissue. See Dialysis-related amyloidosis on page 2.
- **Race.** People of African descent appear to be at higher risk of carrying a genetic mutation associated with a type of amyloidosis that can harm the heart and cause carpal tunnel syndrome. See ATTR amyloidosis on page 2.
- **Environment.** There is evidence that some veterans who were exposed to Agent Orange or other herbicides during military service may develop AL amyloidosis. If so, they do not have to prove a connection between their disease and service to be eligible to receive VA health care and disability compensation.

Questions for Your Treatment Team

- Which type of amyloidosis do I have?
- What are my treatment options, including the risks and benefits?
- What are common side effects that I may experience?
- What problems should I report to you right away?
- Are there clinical trials I could join?

Health Terms

Amyloidosis—A group of diseases in which abnormal proteins build up in certain organs or throughout the body. Instead of forming immunoglobulins, the abnormal proteins misfold and form amyloid.

Antibody—A protein made by plasma cells (a type of white blood cell) in response to an antigen.

Antigen—A substance that causes the body to make a specific immune response against that substance. Antigens include toxins, chemicals, bacteria, viruses, etc.

Bone marrow biopsy—A procedure in which a sample of bone containing bone marrow is removed, usually from the hip bone, for examination by a pathologist (a doctor who has special training in identifying diseases by studying cells and tissues under a microscope).

Computed tomography (CT) scan—A test using x-rays to make detailed images of the inside of the body.

Echocardiogram—A procedure used to see how well the heart is working. It uses high-frequency sound waves to display pictures of the heart.

Immunoglobulin—A protein made by B cells and plasma cells (types of white blood cells) that helps the body fight infection.

Immunotherapy—A type of treatment that uses substances to stimulate or suppress the immune system's ability to fight disease.

Light chain—Light chains are pieces of an antibody made by the plasma cells in the bone marrow. There are two types of light chains: kappa and lambda.

Magnetic resonance imaging (MRI)—A test using radio waves and powerful magnets to create detailed images of the inside of the body.

Monoclonal antibodies—Laboratory-produced proteins that target specific antigens on a cell's surface to interfere with the cell's function and destroy it.

Myeloma—A cancer that arises in plasma cells, a type of white blood cell. The abnormal plasma cells multiply in the bone marrow and crowd out the healthy blood cells so they can't function properly. The plasma cells can build up in bone, causing bones to weaken. The plasma cells also produce abnormal proteins which may accumulate in tissues and damage the kidneys, heart or other organs, and affect immune system function. Visit www.LLS.org/booklets to view myeloma-related publications.

Feedback. To make suggestions about the content of this booklet, visit ww.LLS.org/PublicationFeedback.

Acknowledgement

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ONE-ON-ONE SUPPORT

LLS is dedicated to serving patients with blood cancer and their families. Individuals with myeloma-related amyloidosis are encouraged to reach out to us for information, resources and support.

Information Specialists

Our blood cancer Information Specialists are highly trained oncology social workers and nurses who provide free, personalized assistance to patients, families and healthcare providers. Our Information Specialists offer guidance through blood cancer treatment, financial and social challenges, and give accurate, up-to-date disease, treatment and support information. Visit **www.LLS.org/InformationSpecialists** to chat online or call **800-955-4572**.

Clinical Trial Nurses

Our Clinical Trial Nurse Navigators are registered nurses with expertise in blood cancers who conduct comprehensive clinical trial searches and personally assist patients, parents and caregivers throughout the entire clinical trial process. Visit **www.LLS.org/CTSC** to learn more and complete a referral form.

Registered Dietitians

Our registered dietitians have expertise in oncology nutrition and provide patients, parents and caregivers with free nutrition consultations by phone. Visit **www.LLSnutrition.org/consult** or call **877-467-1936** to schedule.

Do you need financial assistance? Call **877-557-2672** or visit www.LLS.org/finances to learn more about financial support programs.

GET INFORMATION AND SUPPORT

We offer a wide variety of free information and services for patients and families affected by blood cancers.

- Peer-to-Peer Support
- LLS Patient Community
- Online Chats
- Podcast
- Webcasts and Videos
- Caregiver Support
- Children & Young Adults
- Information Booklets
- Local Programs
- Advocacy

Visit **www.LLS.org/PatientSupport** or call **800-955-4572** to learn more about all our offerings.

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Visit **www.LLS.org/espanol** for information in Spanish.

FREE MOBILE APPS

LLS Health Manager™

Helps you track side effects, medication, food and hydration, questions for your doctor, and more. Also available in Spanish and French Canadian. Visit **www.LLS.org/HealthManager** to download.

LLS Coloring for Kids™

Allows children (and adults) to express their creativity and offers activities to help them learn about blood cancer and its treatment. Visit **www.LLS.org/ColoringApp** to download.

Both are available on the App Store and Google Play.

Visit **www.LLS.org/PatientSupport** or call **800-955-4572** to learn more about all our offerings.

LEUKEMIA & LYMPHOMA SOCIETY®

Additional Resources

Amyloidosis Foundation
https://amyloidosis.org/
248-922-9610
The Amyloidosis Foundation is a nonprofit organization whose priorities include providing research grants, raising awareness in the medical field for an earlier diagnosis, educating medical professionals, and empowering patients through a comprehensive range of services.

Amyloidosis Research Consortium (ARC)
https://arci.org/
617-467-5170
The Amyloidosis Research Consortium is a nonprofit organization dedicated to driving advances in the awareness, science and treatment of amyloid diseases. Their outreach and education programs inform and empower patients, families, caregivers, physicians and researchers.

Amyloidosis Support Groups (ASG)
https://www.amyloidosissupport.org/
866-404-7539
Amyloidosis Support Groups is a nonprofit organization dedicated to educating and supporting amyloidosis patients, caregivers, families and friends. ASG offers peer support group meetings and webinars to help educate and empower amyloidosis patients and their loved ones.

Información en Español (LLS information in Spanish). Please visit www.LLS.org/espanol for more information.

Information for Firefighters. Firefighters are at an increased risk of developing cancer. There are steps that firefighters can take to reduce the risk. Please visit www.LLS.org/FireFighters for resources and information.

Information for Veterans. Veterans who were exposed to Agent Orange while serving in Vietnam; to airborne hazards and burn pits while serving in Iraq, Afghanistan and other areas of Southwest Asia; to contaminated water at Camp Lejeune between 1953-1987; or to ionizing radiation during service may be able to get help from the United States Department of Veterans Affairs. For more information, please

- Call: the VA (800) 749-8387
- Visit: https://www.va.gov/disability/eligibility/hazardous-materials-exposure/

Language Services. Let members of your healthcare team know if you need translation or interpreting services because English is not your native language, or if you need other assistance, such as a sign language interpreter. Often these services are free.

Mental Health. Caring for your mental health has benefits for cancer patients. Seek medical advice if you are struggling. For more information, please:

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at www.nimh.nih.gov

If you or your loved is experiencing a mental health crisis, call 988 to talk to a trained mental health professional. The 988 Suicide and Crisis Lifeline is free, confidential and always available. For the Crisis Text Line, text HOME to 741741.

MyAmyloidosisTeam.com
https://www.myamyloidosisteam.com/
MyAmyloidosisTeam is a social network for those living with amyloidosis.

Other Helpful Organizations. LLS offers an extensive list of resources for patients and families. There are resources that provide help with financial assistance, counseling, transportation, patient care and other needs. For more information, please visit www.LLS.org/ResourceDirectory to view the directory.

World Trade Center Health Program. People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be able to get help from the World Trade Center (WTC) Health Program. People eligible for help include:

- Responders
- Workers and volunteers who helped with rescue, recovery and cleanup at the WTC-related sites in New York City (NYC)
- Survivors who were in the NYC disaster area and those who lived, worked or were in school in that area
- Responders to the Pentagon and the Shanksville, PA, crashes

For more information, please

- Call: WTC Health Program at (888) 982-4748
- Visit: www.cdc.gov/wtc/faq.html

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