

CANCER AND YOUR FINANCES

A six-word narrative about living with blood cancer from patients in our LLS Community

Stay strong and keep moving forward. Find the positive in every day. Be your own best patient advocate. Changed my life for the better. Accept, learn and focus on present. Learning to live a different life. Sudden and life changing-be positive. Waiting, worrying, anxiousness/ happy I'm alive! Embrace a new normal each day. 5 years, 41 infusions, constant fatigue. Patience, positive attitude, hope and faith. Test to test, I will survive! Treatment, fatigue, treatment, fatigue and survival. Love life, live better every day. I don't look back only forward. So far, so good, live life. Meditation, mindfulness, wellness, faith, nutrition and optimism. Finding the joy while living with uncertainty. Watch, wait, treat, regroup, rest, re-energize. Blessed to be doing so well! Eve opening needed learning and healing. Feel great: uncertain travel plans annoying. Renewed faith, meditation, diet, mindfulness, gratitude. Watchful waiting can be watchful worrying. Scary, expensive, grateful, blessings, hope, faith. Thank god for stem cell transplants! Do not know what to expect. Extraordinarily grateful, I love my life. Diagnosed; frightened; tested; treating; waiting; hoping. I'm more generous, impatient less often. Embrace your treatment day after day. Live today, accept tomorrow, forget yesterday. Strength you never realized you had. Challenging to our hearts and minds. Life is what we make it. Live life in a beautiful way.

Discover what thousands already have at www.LLS.org/Community

Join our online social network for people who are living with or supporting someone who has a blood cancer. Members will find

- Thousands of patients and caregivers sharing experiences and information, with support from knowledgeable staff
- Accurate and cutting-edge disease updates
- The opportunity to participate in surveys that will help improve care.

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Acknowledgement

The Leukemia & Lymphoma Society appreciates the review of this material by

Monica Fawzy Bryant, Esq.

Cancer Rights Attorney & COO Triage Cancer Chicago, IL

The information that is provided in this booklet is for general information purposes only and should not be used as a substitute for professional guidance or services. The information about the Affordable Care Act is correct at the time of publication and is subject to change. If you have questions or are looking for additional information, please speak with our LLS Information Specialists at (800) 955-4572 or visit the Affordable Care Act website at www.healthcare.gov.

This publication is designed to provide accurate and authoritative information about the subject matter covered. It is distributed as a public service by The Leukemia & Lymphoma Society (LLS), with the understanding that LLS is not engaged inrendering medical or other professional services. LLS carefully reviews content for accuracy and confirms that all diagnostic and therapeutic options are presented in a fair and balanced manner without particular bias to any one option.

Introduction

Paying for healthcare is a major concern for many people who are living with blood cancers-leukemia, lymphoma, myeloma, myelodysplastic syndromes and myeloproliferative neoplasms.

Millions of people in the United States do not have health insurance and the number of people who are underinsured is rising rapidly. They include:

- People who let their health insurance lapse when they leave or change jobs, or because they cannot afford it
- People who cannot afford the cost of private insurance and may not realize that they gualify for government programs or other types of assistance
- Patients who find out after they are diagnosed with cancer that their insurance does not cover the prescription drugs or treatments they need
- Patients who may not be able to afford their co-pays, deductible or co-insurance

This booklet describes health insurance options and resources to help patients and their families who are coping with the financial aspects of cancer care. You may want to skim all the content of this entire booklet and then return to the sections that cover the specific information you need.

The Information Specialists at The Leukemia & Lymphoma Society (LLS) offer guidance about health insurance, government programs, disability benefits, financial assistance programs and advocacy. LLS staff at our chapters can help you connect with LLS programs and other community resources. Call (800) 955-4572 to find out more.

Health Insurance

Health insurance helps pay for costly medical treatment and can protect patients and their families from financial hardship. There are different types of private and public health insurance programs.

Private health insurance coverage can come from:

- An employer
- A union
- Another association
- A health insurance company that offers individual and/or family policies

Government-funded health insurance programs include:

- Medicaid
- State Children's Health Insurance Program (S-CHIP)
- Medicare 0
- Other government programs

How Do I Learn About My Healthcare Options?

Healthcare.gov, a website hosted by the US Department of Health and Human Services. provides information about healthcare reforms and about the health insurance options available to you in your geographic area. For more information about different types of health insurance options, see Types of Health Insurance Plans on page 5. The Leukemia

DID YOU KNOW?

The LLS Co-Pay Assistance Program can help pay your insurance premiums and your out-of-pocket costs like co-pays and deductibles associated with expenses covered by the program. Visit www.LLS.org/copay or call (877) 557-2672.

& Lymphoma Society has partnered with other cancer advocacy organizations to develop the Cancer Insurance Checklist. You can use this checklist to help you figure out which health insurance plan will work for you. For more information, see Other Organizations on page 30, or visit

www.CancerInsuranceChecklist.org.

Know Your Coverage. It is not uncommon for some patients diagnosed with a serious illness, such as cancer, to discover that they are underinsured. Newly diagnosed patients need to know just what medical treatment and services are covered by their insurance, how to protect their benefits, what resources are available to deal with any gaps in insurance coverage, and what out-of-pocket expenses there will be. Cancer survivors, who will need follow-up care, also need to know what is covered by insurance.

People with health insurance must read their policies carefully to understand the health and medical services that are covered. Expenses incurred may include:

Premiums

- The cost of participating in the plan
- Premium payments are usually made monthly

Deductible

- A fixed amount of money that must be met (paid out of pocket) by a patient each year before the insurance plan will cover medical expenses.
- For example, John has a deductible of \$1,000. After John meets his deductible, his insurance company will start paying for his covered services.

Co-payments/Co-pays

- A set dollar amount paid by the patient at the time of service for certain medical services and prescription drugs
- Are not applied against the insurance plan deductible amount(s) (this will be plan specific)
- May vary depending on whether the patient is seeing a specialist (eg, a hematologist-oncologist) or a primary care provider (PCP)
- For example, Patty needs to see her PCP and a specialist. Her plan determines that she has co-pays of \$30 at the PCP's office and \$50 at the specialist's office. A co-pay is a set amount; it does not depend on the amount of her bill.

Co-insurance/Cost Share

- These specify certain percentages of medical expenses that are shared by the patient and the health plan.
- For the patient, this cost is in addition to any deductibles and co-payments.
- Charges may apply to hospital services and certain laboratory tests, and also when a patient receives medical care from a health provider outside of the plan's network.
- For example, if Patty has an 80/20 plan, the insurer pays 80 percent of covered expenses and Patty pays the remaining 20 percent of the medical and prescription drug charges.

Out-of-Pocket Maximum

- The out-of-pocket maximum is the limit on the total payment a patient pays per year.
- After reaching the out-of-pocket maximum, the patient no longer pays co-insurance because their plan begins to pay 100 percent of covered medical expenses.
- Many plans will include everything a patient pays in deductibles, co-insurance and co-payments in the

out-of-pocket maximum. However, some plans will exclude certain payment (eg, co-payments).

• Members are still responsible for services that are not covered by the plan.

Members must continue to pay their monthly premiums or their insurance will be canceled.

In-Network and Out-of-Network

- An in-network provider is contracted with an individual's health insurance company to provide services to plan members at a pre-determined rate.
- An out-of-network provider is not directly contracted with an individual's health insurance plan.
- The amount that the patient pays for an in-network provider is usually much less than the amount a patient pays for an out-of-network provider.

See *Health Terms* on page 33 for an expanded list of health insurance terms.

The Affordable Care Act (ACA). Under the ACA, also known as "Obamacare," most US citizens and individuals who are lawfully living in the United States are required to have minimum essential health insurance coverage as of January 1, 2014. This requirement is often referred to as the "individual mandate." Because of policy changes, beginning in 2019, consumers in most states will be able go without coverage and not face a fine, which was the penalty in the original law. However, the following states have imposed this penalty at the state level: California, D.C., Massachusetts, New Jersey, Rhode Island, and Vermont. The ACA is still law in the United States and the consumer protections it created still exist. For up-to-date information about the ACA and healthcare reform, you can visit www.triagecancer.org/HealthInsurance.

Health Insurance Marketplace Plans. The ACA

provides financial assistance in two ways. It creates:

- New options for accessing health insurance coverage
- New protections for healthcare consumers.

Through the ACA, individuals and small businesses (with fewer than 50 employees) are able to buy health insurance coverage through state-based Health Insurance Marketplaces. In order for insurance companies to sell policies through the Marketplaces they must:

- Provide a minimum level of essential health benefits
- Place a cap on annual out-of-pocket costs (in 2022, \$8,700 for an individual and \$17,400 for a family).
 Amounts typically increase each year.
- Provide five levels of standardized plans (Bronze, Silver, Gold, Platinum and Catastrophic), each with a different cost. In *Health Terms* starting on page 33 you can get a rough definition of each plan so that you can compare them and see what is best for you.

Note that individuals with incomes up to 250 percent of the federal poverty level and who have purchased a Silver plan are eligible to receive help paying for their health insurance coverage through cost-sharing subsidies.

For information about the Health Insurance Marketplaces visit www.healthcare.gov, go to Get Coverage and select your state.

Healthcare Consumer Protections Under the ACA.

The following list explains the protections for people under the ACA.

- Insurance cancellations (rescissions). Insurance companies can no longer cancel nor can they "rescind" your policy unless you commit fraud, intentionally lied on your application, or you stop paying your premiums. In the past, insurance companies could cancel coverage for an error or technical mistake in a person's insurance application. This practice is now illegal.
- Pre-existing condition protection. Insurance companies are no longer allowed to deny a health insurance policy to children or adults who have a pre-existing medical condition, such as cancer. Insurance companies also can no longer impose preexisting condition exclusion periods on their policies.
- **Premium rating.** Insurance companies are no longer allowed to consider an individual's pre-existing condition, health history, or gender when determining the cost of a policy's monthly premium. Insurance companies can only look at age, geographic location, and (in some states) tobacco use, to determine the cost of a policy's monthly premium.
- Annual or lifetime limits. Most private health plans are not allowed to place annual or lifetime limits (sometimes known as "caps") on the dollar amount

of a person's coverage. This means that insurance companies cannot refuse to pay for care after a person has reached a specific total dollar amount for that year for all benefits covered under the plan. An individual still may be responsible for paying for benefits that are not covered.

Insurance Coverage for Tests and Treatments Related to Cancer or Cancer Treatment. The

following tests and treatments are covered by insurance when they are related to cancer or cancer treatment.

Preventive services. Most private insurance companies are required to provide free coverage for certain preventive services, such as cancer screenings (for example, colonoscopies and mammograms). This means that you can access these services without having to pay a co-pay, co-insurance or any amount towards a deductible. The list of preventive services is available at www.healthcare.gov. Type "Preventive Services" into Search box at the top of the page.

Clinical trials. Participating in a clinical trial might be an excellent option for someone with cancer. As of January 1, 2014, insurers are not allowed to limit or drop coverage for an individual who chooses to participate in a clinical trial. This applies to clinical trials designed to treat cancer in addition to other life-threatening diseases. The ACA requires most insurance companies to cover "routine costs" for individuals who participate in an eligible clinical trial. Routine costs may include doctor visits, blood tests, magnetic resonance imaging (MRI) and other scans, etc. Other laws that may provide additional protection for clinical-trial participants are in place in 36 states and the District of Columbia. Coverage may differ for individuals with Medicare, Medicaid, or military-related coverage.

Genetic testing. Genetic testing has changed the face of cancer diagnosis and treatment, ultimately improving patient care. By identifying gene mutation carriers, providers can determine who is at increased risk for getting a specific cancer. Doctors can then offer patients high-risk screening, prevention strategies and promising targeted therapies. Many health plans require genetic counseling by a board-certified genetic counselor or provider prior to covering certain tests. Genetic testing can be expensive. Ask your health insurance provider which genetic tests are covered under your policy.

Stem cell transplantation. Stem cell transplantation is expensive and may not be fully covered by health

insurance. In addition to the cost of the treatment, patients may have significant expenses for travel, lodging, meals, donor testing and aftercare. Patients and caregivers may need to use multiple strategies to secure enough funding to cover these costs.

Chimeric Antigen Receptor (CAR) T-Cell Therapy

(CAR-T). This type of therapy is expensive and may not be fully covered by health insurance. In addition to the cost of the treatment, patients may have significant expenses for collection of cells, the prep regimen, time off work, transportation and lodging costs, the need for a caregiver and for that caregiver to take time off, meals and childcare. If patients are undergoing CAR-T as part of a clinical trial, there may be additional financial resources available. It is important for patients and caregivers to speak with their healthcare team for referrals to organizations to be sure they can cover these costs.

Some of the organizations listed in *Other Organizations* on page 30 provide information, support, financial assistance, support services and patient advocacy for patients and their families. The Leukemia & Lymphoma Society also maintains a resource directory that provides lists of organizations that may be helpful for patients. Visit www.LLS.org/ResourceDirectory for more information.

To learn more about how these and other healthcare reforms might apply to you, visit www.healthcare.gov.

Young Adults. Young adults diagnosed with cancer have concerns that are different from those of other patients. Young patients may have to make difficult decisions, whether they are in high school, in college, or living on their own. They may live far away from their families. Young adults may not have insurance or they may worry about staying insured. The following suggestions may help:

- If a family's insurance plan covers dependents, the ACA allows young adults to stay on their parents' insurance plan until they are age 26. Contact your insurance company or visit www.healthcare.gov for more information.
- Fertility preservation and treatment coverage varies state by state. Check your state to find out about coverage. See the free LLS booklet *Fertility Facts* and *Other Organizations*, on page 30 for additional information. You can also review this quick guide for additional information:

https://triagecancer.org/QuickGuide-Fertility

 The Leukemia & Lymphoma Society has programs that focus on the young adult patient. Visit www.LLS.org/YoungAdults for access to resources and programs about employment, survivorship, insurance, managing cancer and other pertinent topics. For additional resources, visit www.LLS.org/ResourceDirectory.

Types of Health Insurance Plans

Private Plans. The following general descriptions of different types of plans and the coverage they provide may not be exactly the same as the description of the coverage in your plan, so always check the coverage in your own plan.

Health Maintenance Organizations (HMOs).

A health maintenance organization is a network of providers (doctors, hospitals and clinics) that provide reduced costs for medical services for plan members. When they belong to an HMO:

- Plan members choose a primary care doctor who oversees the patient's needs.
- Access to a specialist often requires plan members to get a referral from their primary care provider (PCP).
- Patients may need pre-certification before non-emergency hospital visits and some types of specialist care.
- Patients receiving emergency care may be required to notify their HMO within 24 hours of service.

Preferred Provider Organizations (PPOs).

A preferred provider organization is a group of physicians, hospitals and other healthcare professionals who agree to provide healthcare services for PPO plan members at a reduced fee. When they are enrolled in a PPO plan:

- Members may pay a standard co-pay amount for an office visit.
- Members can choose between either an in-network or an out-of-network provider, instead of being restricted to designated providers.
- A member may go to an in-network or an out-of-network specialist without needing a referral from their PCP. An in-network specialist is usually the least expensive choice.

- A member who sees an out-of-network specialist may have to pay the entire bill to the doctor, and then submit a claim for reimbursement.
- Patients who go to an out-of-network doctor may have to pay a separate deductible or pay the difference between the fee charged by the in-network doctor and the fee charged by the out-of-network doctor; this practice is referred to as "balance billing."
- Members may need to get precertification (sometimes referred to as "preauthorization") for some types of care, especially if the facility or doctor is out of network. Some types of services may not be covered.

Exclusive Provider Organizations (EPOs).

The EPO and PPO plans both provide their members with reduced costs and charge members a co-pay amount for an office visit. However, if they are enrolled in an EPO plan:

- Members may not need a referral to see a specialist, but they must select providers from a limited list.
- A plan member consulting an out-of-network doctor may incur from 20 to 100 percent of the costs.
- Patients who require a number of unique specialists may find an EPO plan problematic.

Point-of-Service (POS) Plans. The POS plans blend the features of HMO and PPO plans. If they are enrolled in a POS plan:

- Members of the plan can choose the type of provider network that best suits their needs every time they seek care.
- Plan participants can designate an in-network provider to be their PCP.
- Plan members usually see their chosen PCP first for any medical issues. If necessary, the member is referred to a specialist.
- A POS plan member may need a referral to see a specialist.
- Members may visit a licensed provider outside the network and still receive coverage, although this would usually cost more.

Fee-for-Service (FFS). FFS plans are more flexible than other plans, but involve higher premiums and higher out-of-pocket expenses. They also require more paperwork. If enrolled in an FFS plan:

• Members can choose their own doctors and hospitals.

- Plan members can visit a specialist without having to get a referral from their PCP.
- Members of an FFS plan may have to pay the doctor directly for medical services and then submit a claim for reimbursement.

COBRA (Consolidated Omnibus Budget

Reconciliation Act) Coverage. Cancer survivors who lose, leave or change jobs, or children who "age out" of their parent's health insurance plan may be eligible to remain on the same plan under COBRA. This federal law also applies to dependents (a spouse or child) who experiences divorce or legal separation from a covered employee, dependents of a deceased employee and dependents of an employee who becomes eligible for Medicare.

Continuation of health insurance through COBRA:

- Requires companies with 20 or more employees to offer continuous health coverage to employees and their covered dependents for a period of 18 to 36 months depending on the qualifying event
- Requires individuals to pay the entire premium (including the portion that the employer used to pay on their behalf and a 2 percent administrative fee)
- Will provide continuation of coverage

There may be other options available through plans found on the state Health Insurance Marketplace; however, the coverage may be different. There is no requirement for small employers to offer COBRA coverage. However, many states have a state COBRA law that addresses the employee coverage required from smaller businesses. There is a chart of state laws at https://triagecancer.org/health-insurance-statelaws#hioptions for more information about options offered in your state.

Medicaid. Medicaid provides coverage for certain individuals and families who have limited income and assets. Each state has its own Medicaid program with its own rules about eligibility and coverage. Visit https://www.medicaid.gov/state-overviews/index.html for more information.

Under the Affordable Care Act (ACA) states have the option to expand their Medicaid programs to cover all adults with incomes up to 138 percent of the federal poverty level (\$18,754/year for an individual or \$38,295 per year for a family of four in 2022). Only some states have chosen not to expand their Medicaid programs. Visit https://triagecancer.org/medicaid-expansion to find out if your state has expanded Medicaid. For more information about Medicaid, visit www.healthcare.gov or www.Medicaid.gov.

State Children's Health Insurance Program

(S-CHIP). This program provides both free and subsidized health coverage for eligible children. It is part of the Medicaid program in many states. Most states cover children with family income up to 200 percent of the federal poverty level. Visit www.insurekidsnow.gov for more information.

Medicare. Medicare provides health insurance coverage for people aged 65 years and older, people under age 65 years with certain disabilities (as defined by the Social Security Administration), and anyone with end-stage renal disease requiring kidney dialysis or amyotrophic lateral sclerosis (ALS). Medicare does NOT cover some services, such as long-term care; most dental care; eye examinations related to prescription glasses; dentures; cosmetic surgery; acupuncture; hearing aids; and routine foot care. These services may be covered by some Medicare Advantage (Part C). Call (800) MEDICARE ([800] 633-4227) or visit www.medicare.gov for more information.

Medicare provides basic medical coverage and is divided into the following parts or benefits:

- **Part A** (hospital insurance) helps pay for inpatient hospital care, some home healthcare services, care at a skilled nursing facility, psychiatric hospital care and hospice care services.
- Part B (medical insurance) helps pay for medical services; doctor visits; laboratory testing; outpatient therapy; and other professional services as well as some preventative services.
- **Part C** (Medicare Advantage Plan) is similar to private plans (see *Types of Health Insurance Plans*, page 5) and
 - Is approved by Medicare and run by private companies that will provide all of your Part A and Part B coverage
 - Often includes Medicare prescription drug coverage (Part D)
 - May offer extra coverage, such as vision, hearing, dental, and/or health and wellness programs
 - Must follow rules set by Medicare
 - Can charge different out-of-pocket costs and have different rules for how to access services (for example, whether a referral is needed to see

a specialist or if the insured can see only certain doctors, facilities or suppliers that belong to the plan for nonemergency or nonurgent care)

- The rules of individual plans can and do change each year.
- Part D (prescription drug coverage)
 - Provides coverage for both brand-name and generic prescription drugs
 - Patients may elect and enroll in a stand-alone prescription drug plan (PDP) or Medicare Advantage prescription drug (MA-PD) plan.
 - Patients are charged a monthly premium, which varies by plan, and must pay a yearly deductible.
 - Co-insurance or co-payments apply.
 - Assistance with drug benefit premiums, (and also deductibles and co-payments) is available to beneficiaries with low incomes and limited assets (more information about the Low Income Subsidy [Extra Help] program is available at www.cms.gov/limitedincomeandresources)
 - After a patient pays their deductible for the year, the most they will pay for covered drugs is 25%. The "donut hole," which limits drug coverage so that patients have to pay 100% of their drug costs out-of-pocket, has been phased out.

TRICARE®. TRICARE is the healthcare program serving uniformed service members, retirees and their families. There are many different types of TRICARE available which depends on your status and location. For information about TRICARE, visit www.tricare.mil.

Veterans Affairs (VA) Benefits. Veterans' benefits include comprehensive healthcare services and other benefits for veterans and dependents of active-duty, retired or deceased members of the military. Veterans who were exposed to Agent Orange while serving in Vietnam or Korea and have a diagnosis that the VA recognizes as associated with Agent Orange may be able to get help from the United States Department of Veterans Affairs. For information, call the Department of Veterans Affairs at (800) 749-8387 or visit www.publichealth.va.gov/exposures/agentorange. For general VA information call (800) 827-1000 or visit www.va.gov.

Disability Insurance Options

Disability insurance provides income replacement to people whose medical condition keeps them from being able to work for either a period of time or permanently. There are different types of disability insurance. Some private disability insurance plans may be purchased directly from an insurance company and others may be available through your employer. A few states (CA, HI, NJ, NY, RI) and Puerto Rico have shortterm disability insurance programs. There are also two federal long-term disability programs: Social Security Disability Insurance and Supplemental Security Income.

Social Security Disability Insurance (SSDI). This option is an income-replacement program for people who are unable to work because of a disability. Call (800) 772-1213 or visit www.ssa.gov for information.

Supplemental Security Income (SSI). Supplemental Security Income provides a monthly cash benefit for low-income people who are disabled, blind or aged 65 years and older. Call (800) 772-1213 or visit www.ssa.gov for information.

Compassionate Allowances. Social Security provides an expedited application process to applicants who have certain serious medical conditions that meet Social Security's disability standards. Social Security has identified a list of these diseases and medical conditions. Several blood cancers, including acute leukemia, adult non-Hodgkin lymphoma and childhood lymphoma, are included on this list. For more information, visit www.ssa.gov/compassionateallowances or call (800) 772-1213.

Flexible Spending Accounts (FSAs) and Health Savings Accounts (HSAs). These are special

accounts that allow people to set aside pre-tax dollars and use them to pay their medical expenses. Many employers provide FSAs or HSAs to employees enrolled in private health insurance plans. This gives participants the opportunity to plan for specific medical expenses and to accrue tax benefits.

At the start of the healthcare plan year, participants can deposit money in an FSA and then use it later to pay for anticipated out-of-pocket medical expenses. The funds in the FSA must be used before the end of the calendar year; however, employers can either provide a roll-over option of up to \$500 or a 3-month extension to the next year, when employees can use the remaining funds. Check with your employer to learn the specific policies of the FSA.

HSA funds (unlike FSA funds) do not expire. An HSA can only be used along with a high-deductible health insurance plan. The money in an HSA account can also be invested and, if necessary, it can be taken with the owner to another job.

Getting Organized

When you obtain health insurance, you must review the insurance plan and make sure the personal information is correct for all covered individuals.

Individual policyholders should

- Look on the Declarations page (often the first page of the policy) and review the information.
- Review the Summary of Benefits & Coverage (SBC) and highlight any exclusions or limits on coverage.
- Make sure not to overlook any riders or endorsement forms. These are additional pages of the policy developed as updates to the initial plan. They describe changes to the plan benefits that may affect medical coverage.

Here are some proactive steps that patients and families can take to make the most of their insurance coverage.

- 1. Don't be afraid to ask questions. You never know who might be able to help you and how they might be able to help you.
 - Make friends with your doctor, nurse, social worker, billing person and other people that you see at your treatment appointments. If you have a problem with an insurance claim, some of these people may be able to help and advocate for you.
 - Question items that the insurance company does not pay—do not assume that you have to pay for all of the treatment expenses, or that all charges are correct.
- 2. Be proactive and be informed. Pay premiums on time and in full to avoid either a lapse in or cancellation of coverage. Check health policies often to determine what services and medications are covered.
- **3. Request a case manager from the insurance company.** This will be the patient's or family member's direct contact, the person who will answer questions about claims or the policy. When many medical treatments are necessary, it is useful to have a case manager at the insurance company so you are always talking to the same person. You can also check if your employer has a benefits advisor or an advocate who can assist you, or you can call organizations, including The Leukemia & Lymphoma Society, to get help.

- 4. Create a filing system that works for you. This will allow you to find information quickly and easily. Keep a copy of all claims and related paperwork in an organized folder by category. This will include letters of medical necessity, bills, receipts, requests for sick leave, etc. Also keep a written record of any phone conversations with insurers, including the name of the person you spoke with, what was said and the date.
- **5.** Use technology as an organization tool. Some people prefer to use a computer or smartphone to keep track of important information. You can create a spreadsheet to list information including doctors' names, amount(s) paid, insurance claim status, authorization numbers and other relevant information. An increasing number of websites and smartphone apps provide tools to help people evaluate their choices and navigate the healthcare system.
- 6. Plan ahead. Make sure to follow the insurance company's rules, such as whether you must call a toll-free number before you go to the hospital. You can also:
 - Check to see if pre-authorization or pre-certification is needed for any procedures or treatments.
 - Use an in-network doctor or facility, when possible, to avoid unnecessary out-of-pocket expenses.
- 7. Know your rights. Certain laws are designed to protect patients and provide continuation of medical coverage, for example, ACA, COBRA, the Family and Medical Leave Act (FMLA), the Americans with Disabilities Act (ADA), and state laws. See *Federal Employment Protections* on page 14.
- 8. Keep track of all unreimbursed medical expenses. This may include the dates of each service, the amount paid and the name of the medical provider. For expenses not reimbursed by insurance, it may be possible to claim these expenses for tax purposes. This information may also be submitted to an FSA or an HSA.

Explanation of Benefits and Denial of Insurance Coverage

Explanation of Benefits (EOB). Typically, after a person receives medical care, the provider sends a claim to the insurance company. The insurance company handles the claim and sends the patient an EOB statement. This is a summary of the services the patient received, how much the provider charged the insurance company and how much the insurance company paid. This is not a bill. If the patient is charged for any remaining costs not covered by the insurance plan, the provider of services will send a separate bill. If the insurance plan owes you money, you will receive a reimbursement. The EOB statement may also include the amount the patient has paid toward their deductible. Most EOB forms start with identifying

 Claim Processing Office: the location of the claims processing office. You can write to customer service at this location

- 2 Customer Service Information: the customer service number you can call with questions regarding your claim
- 3 Claim Number: the unique identification number assigned to this claim. Refer to this number if you call or write about this claim
- **Group Name:** the name of your Group (generally, this is your employer)

5 **Group Number:** the identification number for your Group. Refer to this number when you call or write about your claim

6 Member Information: this may include the member's name, social security number, patient number or other identification number

- **7 Provider:** the name of the person or organization who provided the service or medical supplies
- 8 Dates of Service: the date(s) on which services were rendered
- 9 Procedure Code: the Current Procedural Terminology (CPT) codes listed on the provider's bill
- **10 Amount Billed:** the amount your provider bills for the services
- 11 Allowed (Covered) Amount: the total amount the provider will accept for the service

information specific to the patient and the insurance plan, as well as a list of services received. If any of this information is incorrect, it is important that the patient contact their plan.

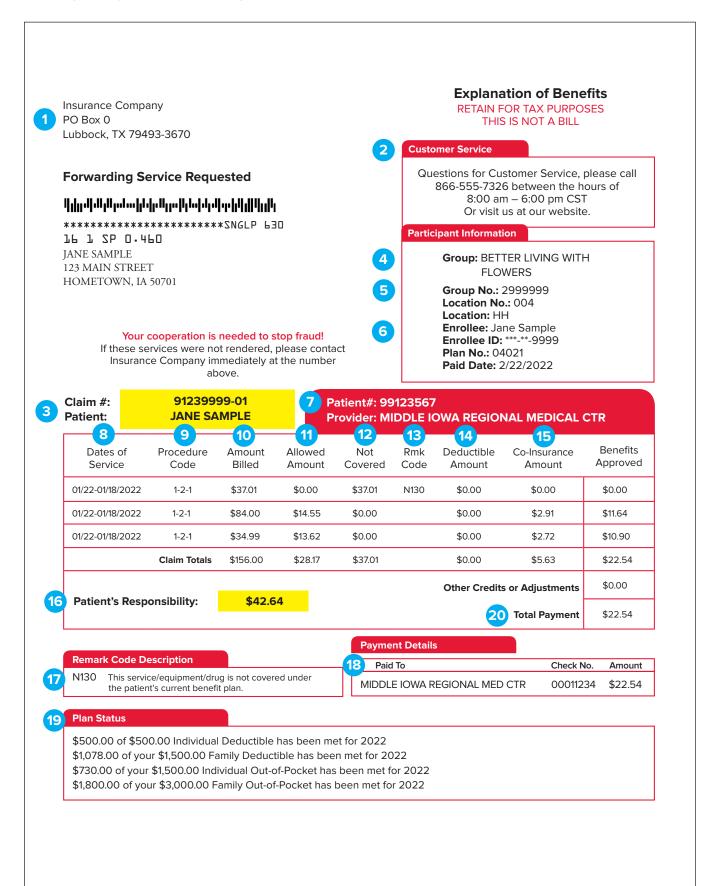
For each service reimbursement required by the provider, there is a description of the service along with a corresponding code and the date the service was provided.

Explanation of Benefits (EOB) Form. On the facing page, there is a sample of an EOB statement. Each insurance plan has a different way to provide information in an EOB. If you do not understand your EOB, call the insurance company and speak to a representative. The numbers below, in blue, correspond with the numbers on the sample copy of the EOB (on page 11).

- 12 Charges Not Covered: charge that is not eligible for benefits under the plan
- **13 Remark (Rmk) Code:** code relating to the "Charges not covered" amount. Also used to request additional information or provide further explanations of the claim amount. Could be called something different on another EOB
- **14 Deductible Amount:** the amount of allowed charges that apply to your plan deductible that must be paid before benefits are payable
- **15 Co-Insurance Amount:** the member pays a specific portion of the cost of covered healthcare expenses out of pocket. This amount is based on their health plan policy. This example shows what a patient would pay with an 80/20 plan
- 16 Patient's Responsibility: the amount the patient or insurance plan member owes after the insurer has paid everything else
- 17 Remark Code Description: a note from the insurance plan that explains more about the costs, charges, and paid amounts for your visit
- 18 Paid To: individual or organization to whom benefits are paid
- **19 Plan Status:** Either deductible or out of pocket status for the current year
- 20 Total Payment: signifies what the insurance company paid to the provider on the patient's behalf

To understand the patient's responsibility (#16), first, look at the allowed amount (which is what the in-network provider has agreed to receive for treating patients with this health insurance). Then since the patient has met the deductible, the insurance covers 80% (benefits approved column) and the patient is responsible for 20% (co-insurance amount column). When added up, the total amount the patient needs to pay is anything not covered (\$37.01) plus the co-insurance amount (\$5.63). The patient's responsibility is \$42.64

An EOB is not a bill, so no payments should be made based on the information found in that statement. The hospital or provider will bill the patient if there is a balance due.



Denial of Insurance Coverage. If an insurance company denies coverage for a recommended treatment, procedure, or prescription medication, a patient may be able to get the decision overturned by filing an appeal. Before you file an appeal, you may want to contact your insurer to find out why payment was denied. The reason may be a mistake, such as a coding error. See the worksheet **Health Insurance Appeal Tracking Form** on page 25.

However, if the payment was denied for another reason (for example, because the insurance company wants you to use a generic when your doctor wants you to stay on the name brand or because the insurer did not think the treatment was medically necessary), then you can appeal the decision. Submitting all necessary paperwork and key documents by stated deadlines is important to improve the likelihood of a successful appeal. Patients or their advocates should keep track of:

- The date, time and method of any correspondence to the insurance company (by phone, email or in writing)
- The name and contact information of any insurance agent or claim reviewer with whom you communicate
- Summaries of your conversations and any written documents issued by the insurance company

Beginning with healthcare plan years starting after July 1, 2011, insurance companies that deny payment for a treatment or service are required to conduct internal appeals at the patient's request within the following specific timelines:

- 72 hours after receiving an appeal for urgent medical care
- 30 days for non-urgent care that the patient has not yet received
- 60 days for services that the patient has already received

You can get information on the appeals process by calling your insurance company, visiting the insurer's website, or reading your plan's documents and the Explanation of Benefits.

The Appeals Process. If you choose to call your insurer, the following questions may be useful when appealing a denial of coverage:

1. Can you send me a copy of the denial letter?

- 2. What is the specific reason the claim was denied? (This information should be included in the denial letter.)
- 3. Can I get a current copy of the plan document and the plan's Summary of Benefits and Coverage (SBC) on the internet? If not, how can I get a copy of that information? Can you mail it to me?
- 4. Who can I contact at the insurance company to discuss the denial? May I have that person's direct phone number?
- 5. What are the steps for requesting a doctor peer review? (A peer review provides the opportunity for the patient's doctor to discuss the patient's treatment in detail with other doctors who are usually within the same geographic area and medical specialty.)
- 6. Is there anyone else I can speak to if I have questions about the appeals process?
- 7. If a particular drug is not on the prescription plan's covered drug list (formulary), is there a process by which an exception can be made? Can my doctor obtain approval by submitting a letter explaining why the drug is medically necessary?

In most cases, there are three levels of appeals. These are

- An internal review by the insurer
- A second-level appeal to the insurer, if the first is denied. That appeal will be reviewed by people who were not involved in the first appeal.
- If that appeal is also denied, a third-level appeal (external appeal) to an independent outside organization is made. To begin this type of appeal, you can contact your State Insurance Department, who may refer you to an independent organization that can handle this level of appeal. You may also choose to get help from a social worker or an attorney.

If you get health coverage through your employer, your plan may have to follow certain regulations set by a law called the Employee Retirement Income Security Act, known as "ERISA." This law has specific rules about the appeal timelines, your rights, and the type of information the insurer is required to give you. Your plan may have to follow specific state laws too.

Visit the Patient Advocate Foundation at www.patientadvocate.org for more information and resources regarding navigating the insurance appeal process.

Financial Assistance

There are a number of ways to find financial assistance for expenses related to treatment. Some organizations can also help with transportation costs, living expenses or prescription costs. Use the worksheet **Financial Assistance Record** on page 27 to keep this information organized. It is important to work closely with the financial services department at your treatment center to obtain the highest reimbursement from the insurance company.

The following strategies will help you to get funding for treatment expenses:

- Negotiate with healthcare providers to reduce or waive medical fees or adjust the payment schedule in cases of financial hardship.
- Apply for grants and financial aid from employers, labor unions, community service agencies, religious and fraternal groups or cancer support organizations, such as LLS.
- Form a committee of volunteers to conduct fundraising events, sales, raffles, canister collections, or letter-writing and publicity campaigns.
- Cash in benefits from life insurance policies through life insurance loans; viatical settlements (selling a life insurance policy at a discount to someone who will collect the face value when the policyholder dies) or accelerated benefits, which can provide cash payouts to seriously ill policyholders. Be sure to discuss a strategy such as this with a financial advisor before pursuing it.
- Use online tools and social media. You may want to participate in a fundraising campaign through websites such as www.youcaring.com or www.gofundme.com. Be aware that using these options could cause the loss of public assistance as well as other problematic issues.

The Leukemia & Lymphoma Society's Financial

Assistance Resources. LLS has resources for patients who need financial assistance.

- The Leukemia & Lymphoma Society's Co-Pay Assistance Program helps eligible patients with assistance toward the cost of insurance premiums and copays for prescription drugs, labs, scans, tests, etc. For more information call (877) 557-2672 or visit www.LLS.org/copay to submit an application.
- The Leukemia & Lymphoma Society's Information Specialists provide general information about other types of non-copay financial assistance programs. To reach our Information Specialists call (800) 955-4572. Additional financial information can be found at www.LLS.org/finances.

 The Leukemia & Lymphoma Society is part of the Cancer Financial Assistance Coalition (C-FAC) which encourages communication and collaboration among the member organizations that have joined forces to address cancer patients' needs. This group educates patients and providers about resources, and advocates for cancer patients who are facing the financial burdens of cancer care. To use this resource visit www.cancerfac.org.

Help with Prescription Drugs. Health insurance plans may not cover all the costs of cancer care, but there are a number of resources to find assistance in paying for prescription drugs.

Patients who have prescription drug plans may find that their plan's formulary does not cover certain drugs they need. A formulary

- Is a list of prescription drugs that has been approved by either a state, health plan or hospital
- Typically includes processes that enable access to nonformulary drugs when they are documented as medically necessary. A plan sponsor must have an exceptions process for these situations and denials of exceptions must be subject to an appeals process (see *Denial of Insurance Coverage* on page 12).

People without adequate insurance to cover the cost of prescription medications for cancer treatment may want to explore the following options:

- Major pharmaceutical manufacturers provide patient assistance or prescription assistance programs. These pharmaceutical companies may be able to help by providing both insured and uninsured patients with free or reduced-cost medications. Contact Rxassist at www.rxassist.org for a current list of patient prescription assistance programs. You can also contact Partnership for Prescription Assistance (PPA) at www.pparx.org to find a prescription assistance program that meets your needs.
- The National Association of Counties (NACo) (View their website www.naco.org. Click on Cost Saving Tools under "Resources") and various other state programs also provide ways to cut drug costs.
- Co-pay assistance programs and foundations help pay for prescription drug co-pay obligations or insurance plan premiums.

Contact our LLS Information Specialists, at (800) 955-4572, for information about the LLS *Co-Pay Assistance Program* or other co-pay assistance programs.

Federal Employment Protections

These programs can assist eligible patients, families and caregivers with time off from work and reasonable accommodations at work, if needed. (Note: Eligible federal employees have access to similar protections under the Rehabilitation Act [Rehab Act] of 1973, as Amended.)

Typically, employees are not required to disclose a cancer diagnosis. However, if an individual is trying to access protection under the American Disabilities Act of 1990 (ADA) or the Family and Medical Leave Act of 1993 (FMLA), employers may need to obtain some information about the person's medical condition so that they can certify that they are eligible for those protections.

Americans with Disabilities Act (ADA).

The Americans with Disabilities Act is a comprehensive federal civil rights law that prohibits discrimination on the basis of disability.

This law ensures equal opportunity for individuals with disabilities in:

- Employment
- Public accommodations
- Transportation
- State and local government services
- Telecommunications

The ADA defines a disability as:

- A physical or mental impairment that substantially limits one or more major life activities (eg, breathing, talking, concentrating, thinking, sleeping or operation of major bodily functions)
- Having a record of such an impairment
- Being regarded by others as having an impairment

To learn more about the ADA, visit

www.eeoc.gov/laws/types/disability.cfm or call (800) 669-4000. Individuals with disabilities may also be protected by their state anti-discrimination laws, some of which are more protective than the federal law. To learn more about rights under state laws, visit the Department of Labor (DOL) website at www.dol.gov/dol/location.htm or Triage Cancer's website at https://triagecancer.org/employment-state-laws to see a chart of state laws. For more information about reasonable accommodations, visit the Job Accommodation Network (JAN) website at www.askjan.org or call (800) 526-7234.

Family and Medical Leave Act (FMLA). Eligible

employees (who have worked at least 1,250 hours over the last 12 months for private companies with 50 or more employees) can take unpaid, job-protected leave for specified family and medical reasons under FMLA provisions. Employees continue receiving their group health insurance coverage under the same terms and conditions as if they had not taken leave.

Eligible employees are entitled to:

- Twelve workweeks of FMLA leave in a 12-month period to care for the employee's
 - Own serious health condition that prevents the employee from performing the essential functions of their job
 - Spouse, child or parent who has a serious health condition
- Twenty-six workweeks of FMLA leave in a 12-month period to care for a covered service member with a serious injury or illness who is the spouse, child, parent or next of kin to the employee (military caregiver leave).

Note: As of February 2015, the US Department of Labor's Wage and Hour Division announced a Final Rule to revise the definition of "spouse" under the Family and Medical Leave Act of 1993 (FMLA). The Final Rule amends the definition of spouse so that eligible employees in legal same-sex marriages will be able to take FMLA leave to care for their spouse or family member, regardless of where they live.

There are three kinds of FMLA leave. They are

- Continuous FMLA leave—an employee is absent for more than 3 consecutive business days and has been treated by a doctor.
- Intermittent FMLA leave—an employee is taking time off in shorter blocks of time due to a serious health condition that qualifies for FMLA. Intermittent leave (can be in hourly, daily or weekly increments) is often taken when an employee needs ongoing treatment or follow-up appointments for their condition.
- Reduced-schedule FMLA leave—an employee needs to reduce the amount of hours they work per day or per week, often to care for a family member or to reduce fatigue or stress.

To access more information about this program, please visit the Department of Labor website at www.dol.gov/whd/fmla or call (866) 487-9243.

Our Information Specialists can provide patients with further information about these programs and refer patients to appropriate organizations for additional assistance. To reach other organizations on our LLS website that may be able to help, please visit www.LLS.org/ResourceDirectory.

Advocacy

Advocating for yourself or a loved one with cancer is important. Advocacy means speaking and/or writing in support of a cause. You may be interested in advocating for policies that can provide additional benefits and protections for people who have cancer, or you might want to support policies that promote faster progress toward cures for blood cancers. To find out more about advocating for policy changes at the state and federal level, contact LLS Advocacy at advocacy@LLS.org or visit www.LLS.org/advocacy.

Talk About Insurance and Financial Issues. Talk to members of your healthcare team about your insurance coverage for all medical tests, treatments and procedures. Discuss any concerns you may have about your ability to pay for any out-of-pocket expenses related to your care with team members. They may either be able to help you themselves or direct you to resources that can offer appropriate guidance and support.

You may feel uncomfortable sharing personal financial information with the members of your healthcare team. However, it may be necessary to share this information and to ask questions so that your financial concerns can be resolved. It is important to limit stress as much as possible and make sure that you can get your necessary treatments, prescription medications and support services. It is likely to be helpful to:

- Talk about payment options with members of your healthcare team or people in the financial services department.
- Talk to your doctor about the cost of a new prescription for medication.
- Ask how to find information online about prescription assistance programs (see *Help With Prescription Drugs*, on page 13)

- Check with your insurance company to find out if your medication is covered on their drug list (formulary).
- Talk to your doctor about your medications. If the drugs you are taking are not the generic formulations, ask if generics are available and, if so, whether these can safely be prescribed for you.
- Ask about reviewing your medication list to find out whether you are taking unnecessary drugs.
- Ask the members of your healthcare team about scheduling your treatments around work (if you work and plan to continue working during treatment).
- Discuss whether to disclose or not disclose your diagnosis at work, especially before asking members of your healthcare team to complete paperwork for medical leave, reasonable accommodation, or disability.
- Request a referral to a social worker, navigator or case manager.

Speak to a social worker or caseworker who can:

- Help you better understand your insurance coverage
- Help you submit insurance claims
- Refer you to assistance programs
- Offer guidance on submitting all the necessary paperwork for Medicare or Medicaid
- Help you to find out about organizations that can help with housing expenses, such as The Homes & Communities section of the United States Department of Housing and Urban Development (HUD). See its website at www.hud.gov.

Find an Advocate. Find someone (parent, child, friend, relative, associate, etc) who can help you to pay your bills on time, deal with insurance company concerns and manage other financial matters.

Your advocate should be an organized and reliable person, someone you can trust. An advocate can help manage your financial health and offer ongoing emotional support. For more information about coping with cancer, see the free LLS booklet, *Each New Day: Ideas for Coping with Blood Cancers* which can be found at www.LLS.org/booklets or by contacting our Information Specialists.

Getting the Help You Need

Ways That Family Members and Friends Can Help.

If you have family members and/or friends who you trust to get things done, then count on them to help you. Family members and friends can:

- Organize fundraising efforts
- Set up a record-keeping system to track bills and insurance claims that have been submitted, are pending or have been paid
- Call public and private agencies to determine your eligibility for financial assistance, entitlement programs and other benefits and services
- Gather documents to support insurance claims and appeals and any follow-up with the insurance company

Caring for Dependents. You may need to start treatment right away. This can feel overwhelming and it is hard to stay organized. You will want to remember to make plans for:

- Finding children rides to school and other activities
- Finding transportation to get to and from treatment
- Deciding who will cook meals and shop for groceries
- Deciding who will update friends and family members on treatment progress
- Deciding who will take care of children or aging parents

You might find help by:

- Using online programs, such as the care calendar website at http://lotsahelpinghands.com, to organize and schedule help from family members and friends
- Talking to other patients at the treatment center to get ideas about juggling responsibilities
- Putting together a list of the people who are part of your support system, such as friends, family members, church members and volunteers, who could help you either on a regular basis or in an emergency
- Talking to others online at LLS Community at www.LLS.org/community, or on LLS online chats at www.LLS.org/chat
- Working with local agencies to help find ways to support the rest of the family
- Keeping a medical notebook to record all your doctors' contact information as well as insurance, medical bills, disability information, etc

It is hard to believe that you might be living like this for a while. Some things that might be hard to do but will decrease stress include:

- Relaxing your standards, such as being okay with
 - A messier house
 - Fewer home-cooked meals
 - Accepting less (or different) things from a spouse, children or parents
- Keeping dependents informed of progress
- Keeping dependents informed of scheduled appointments for treatment or doctor's visits
- Writing everything on a wall calendar—when everyone knows the schedule, there is less frustration.

Ways in Which Professionals Can Help. The

professionals who staff the national organizations that support people with cancer can help patients learn how to advocate for themselves more effectively. They can provide expert advice on:

- Preserving assets
- Reducing debt
- Accessing community resources
- Handling employment issues
- Minimizing insurance problems
- Using legal remedies, if and when necessary

LLS Information Specialists can provide expert advice and/or help you to find additional organizations that offer assistance to cancer patients. To reach our Information Specialists, call (800) 955-4572.

Financial Checklists

This section includes checklists that can help when you are thinking about the many financial concerns that come up after you have received a diagnosis of a blood cancer. Use these lists to keep track of questions to ask your healthcare and financial team members. Keeping organized helps decrease many financial stressors and allows you to focus on feeling better. For additional copies of the following worksheets, please visit www.LLS.org/worksheets.

PART 1: Preparing for Expenses	Comments/Notes
I have thought about my anticipated medical expenses.	
I have considered the impact of treatment and recovery on the household income.	
I have considered additional expenses related to treatment and recovery, such as travel and child care.	
I have thought about reducing or eliminating non-essential expenses.	
I have researched disability insurance options, if needed, during my treatment and recovery.	
I have checked to see if I have home mortgage or car payment insurance to help cover expenses during my illness.	
I have looked at life insurance loans or other programs to help cover expenses.	
I know I must speak to creditors early if I will have difficulty making payments.	
I have reviewed my disability/time off/COBRA benefits from my employer (and I have a copy of that information).	
I have information about my rights as an employee.	

PART 2: Organization	Comments/Notes
I have an advocate—a family member, friend or other trusted person—who can help me get and stay organized.	
I know the names of my doctors/nurses/social worker, and how to contact them.	
I keep and organize all my medical records and copies of tests and know how to access my electronic medical records via patient portals.	
I know what information I need to keep copies of for tax purposes.	
I have kept a log of each person I have spoken to and when I have spoken to them regarding insurance concerns, payment questions or other details about medical records.	
PART 3: Treatment Benefits	Comments/Notes
I know how I will pay for treatment.	
If I don't have health insurance, I will learn about possible resources available at www.healthcare.gov.	
If I have gaps in my insurance coverage, I will learn about possible resources available.	
I know what insurance expenses I pay (co-pay, co-insurance, deductible) each month/year, and the amount of my plan's out-of-pocket maximum. See page 21.	
I either have a copy or I know where to get a copy of my insurance plan or Summary of Benefits and Coverage (SBC).	
I know my insurance plan's oncology benefits and what treatments and charges are covered, partially covered and not covered.	
I know when I need a referral from my doctor.	
I know my doctor(s) is/are covered under my insurance.	
I have asked my insurance company about coverage for a second opinion.	
I know what visits/procedures from my doctor/specialist are covered by my insurance.	
I know the timeline for my treatment.	

PART 4: Treatment Authorizations	Comments/Notes
I know why the procedure is being done.	
I know when I need to call the insurance company for pre-authorization/pre-certification.	
I have a pre-authorization/pre-certification for the treatment (if required).	
I know within what time frame a procedure/treatment needs to be done before the pre-authorization or pre-certification expires.	
I have a case manager at the insurance company who I can speak to directly if I have a concern.	
I have discussed payment options with my doctor's office and/or the hospital's billing department.	
I know I can appeal a claim to the insurance company if a treatment or procedure is denied, and I can seek outside help, if needed.	
PART 5: Medication	Comments/Notes
PART 5: Medication I know my prescription drug plan and how to find out if a drug is covered or not.	Comments/Notes
I know my prescription drug plan and how to find out if a	Comments/Notes
I know my prescription drug plan and how to find out if a drug is covered or not. The drugs I have been prescribed are covered under my	Comments/Notes
I know my prescription drug plan and how to find out if a drug is covered or not. The drugs I have been prescribed are covered under my prescription plan. I know if I have a mail-order pharmacy benefit and if it is	Comments/Notes
I know my prescription drug plan and how to find out if a drug is covered or not. The drugs I have been prescribed are covered under my prescription plan. I know if I have a mail-order pharmacy benefit and if it is required that medicines are filled by mail. I have asked about drug access and co-payment programs	Comments/Notes
I know my prescription drug plan and how to find out if a drug is covered or not. The drugs I have been prescribed are covered under my prescription plan. I know if I have a mail-order pharmacy benefit and if it is required that medicines are filled by mail. I have asked about drug access and co-payment programs for which I am eligible. I have asked my doctor if the drugs I am taking are available in generic form and, if so, for the generics to be	Comments/Notes

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Insurance Costs Checklist and Budget Form

Budgeting Worksheet

Step 1: Understand Your Health Insurance Costs

To estimate the cost of medical care, you must understand your health insurance plan. Use this chart to view all the plan specifics in one place.

Plan Name		
Type of Plan		
Primary Care Provider	Covered In Network	Covered Out of Network
Specialists	Covered In Network	Covered Out of Network
Treatment Center	Covered In Network	Covered Out of Network
Other Medical Service Providers (Lab Tests, Infusions, Radiology)	Covered In Network	Covered Out of Network
Premium	Per Month: \$	Per Year: \$
Maximum Out-of- Pocket Expense	Per Individual Per Year: \$	Per Family Per Year: \$
Co-pays and/or Co-insurance	Primary Care Visits: Specialist Visits: Hospitalization: Emergency Room: Urgent Care: Prescription Drugs:	\$% \$% \$%
Plan Status as of this Date: 	\$ of patient's \$ fami	ily deductible has been met vidual maximum out-of-pocket ense has been met

Once a treatment plan is in place, talk to the treatment center's financial department about estimated costs and payment plan options to better estimate your health insurance costs.

Step 2: Anticipate Monthly Expenses

Fill in the following chart to prepare a monthly budget. Write in the actual amounts as you pay bills.

Expense Changes to Consider

- Transportation and lodging for the caregiver and patient if the treatment center is far from home
- Additional medical expenses such as nutritional supplements, over-the-counter medications, hygiene products, wig, etc
- Child care and/or pet sitter for when you are away for treatment or at appointments

Tips to Reduce Expenses

- Shop around for a different phone/cable plan or home insurance quote.
- Reach out to family members and friends to help with childcare or pet care.
- Use coupons when grocery shopping; save money by eating at home instead of in restaurants.
- Apply for financial assistance programs offered by both government and nonprofit organizations
 - Supplemental Nutrition Assistance Program (SNAP) (food stamps)
 - Low Income Heating Energy Assistance Program (LIHEAP)
 - Prescription assistance programs
 - Co-pay assistance programs

Monthly Expenses	Expected	Actual
Health Insurance Premium and Other Anticipated Medical Bills		
Rent/Mortgage		
Utilities (Electric, Gas, Water)		
Groceries/Food		
Phone/Cell Phone		
Cable/Internet/Streaming Services		
Transportation (Car Payment, Gas, Bus Fare)		
Debt Payments (Credit Cards/Loans)		
Insurance Premiums (Car/Life)		
Housecleaning/Landscaping		
Child Care		
Other Expenses		
Total Monthly Expenses		

Step 3: Determine Income

Sources of Monthly Income	Expected	Actual
Salary (net income*)		
Supplemental Security Income (SSI)/Social Security Disability Insurance (SSDI)		
Employment Benefits: Disability (Short- or Long-Term)		
Retirement (Private and/or Social Security Administration [SSA])		
Financial Assistance		
Other Forms of Income		
Total Monthly Income		

*Net income is your take-home pay after taxes and other payroll deductions.

Income Changes to Consider

• When determining income, remember to take into account lost wages due to time away from work for treatment.

Tips to Supplement Income

• If the patient is unable to work due to treatment, consider applying for Social Security Disability Insurance or other disability insurance options to replace lost income.

Step 4: Final

	Expected	Actual
Total Monthly Income:		
Total Monthly Expenses:		
After Expenses: (Total Income minus Total Expenses = After Expenses)		

Now that you have completed the budgeting worksheet, continue using it to calculate actual expenses and income and make adjustments as necessary. Consider moving any income left over after you have met your expenses into a savings account as a backup in case of unexpected expenses or loss of future income.

To learn more about available financial assistance programs, contact one of The Leukemia & Lymphoma Society's Information Specialists at (800) 955-4572 or visit www.LLS.org/finances.

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Health Insurance Appeal Tracking Form

Step/Action	Date	Contact Name and Information	Comments/Notes
Before the appeal is started			
Date of Service (when medical service was received) and what service was received			
Claim sent to Insurance Provider			
Received response from insurance company (Explanation of Benefits and/or other written communications)			
If claim denied, date I talked to my healthcare team and asked for supporting documentation I need			
Received supporting documentation from healthcare team			
Internal appeal			
Sent insurance company my first appeal form (1st internal appeal)			
Received a response from my insurance company			
If internal appeal was denied, I received a written explanation from my Plan stating the reason it used to deny my claim			
I filed my second appeal form (2 nd internal appeal)—(only in cases where it is required by state law or company policy)			
If claim denied, I talked to my healthcare team and asked for any additional supporting documentation			
Received supporting documentation from healthcare team			
External appeal			
 Filed forms and documentation for external appeal with the appropriate agency Triage Cancer has the contact information for every state's health insurance agency available at www.triagecancer.org/stateresources 			
Received a response to my external appeal from the independent review organization/entity			

This form was adapted from Triage Cancer—Health Insurance Appeal Tracking Form ©2014. The original form is available at: www.triagecancer.org/AppealTrackingForm.

NOTES

Financial Assistance Record

Assistance/ Organization	Date Application Submitted	Status	Frequency: For example: one time, every month, etc	Amount of Assistance Received
		Applied/Pending Granted Denied		
		Applied/Pending Granted Denied		
		Applied/Pending Granted Denied		
		Applied/Pending Granted Denied		
		Applied/Pending Granted Denied		
		Applied/Pending Granted Denied		
		Applied/Pending Granted Denied		
		Applied/Pending Granted Denied		
		Applied/Pending Granted Denied		

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Resources and Information

LLS offers free information and services to patients, caregivers and families affected by blood cancers. This section of the book lists various resources that can be helpful to you. Use this information to learn more, to ask questions and to make the most of your healthcare team members' knowledge and skills.

For Help and Information

Consult with an Information Specialist. Information Specialists are highly trained oncology social workers, nurses and health educators. They offer up-to-date disease and treatment information. Language services are available. For more information, please

- Call: (800) 955-4572 (Monday through Friday, 9 am to 9 pm ET)
- Email or live chat: www.LLS.org/InformationSpecialists

Clinical Trials Support Center (CTSC). Research is ongoing to develop new treatment options for patients. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. Patients and caregivers can work with Clinical Trial Nurse Navigators who will help find clinical trials and personally assist them throughout the entire clinicaltrial process. Please visit www.LLS.org/CTSC for more information.

One-on-One Nutrition Consultations. Access free one-on-one nutrition consultations provided by registered dietitians who have experience in oncology nutrition. Dietitians assist callers with information about healthy eating strategies, side-effect management, and survivorship nutrition. They also provide additional nutrition resources. Visit www.LLS.org/nutrition for more information and to schedule a consult.

Free Information Booklets. LLS offers free education and support booklets that can either be read online or ordered. Please visit www.LLS.org/booklets for more information.

Financial Assistance. LLS offers financial support including insurance premium and medication co-pay assistance as well as travel and other needs to eligible individuals with blood cancer. For more information, please

- Call: (877) 557-2672
- Visit: www.LLS.org/finances

Telephone/Web Education Programs. LLS offers free telephone/web and video education programs for patients, caregivers and healthcare professionals. Visit www.LLS.org/programs for more information.

Podcast. *The Bloodline with LLS* is here to remind you that after a diagnosis comes hope. Listen in as patients, caregivers, advocates, doctors and other healthcare professionals discuss diagnosis, treatment options, quality-of-life concerns, treatment side effects, doctor-patient communication and other important survivorship topics. Visit www.LLS.org/TheBloodline for more information and to subscribe.

Free Mobile Apps.

- 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 for free.
- LLS Health Manager[™] Helps you track side effects, medication, food and hydration, questions for your doctor, and more. Visit www.LLS.org/HealthManager to download for free.

Suggested Reading. LLS provides a list of selected books recommended for patients, caregivers, children and teens. Please visit www.LLS.org/SuggestedReading to view the titles.

Community Resources and Networking

LLS Community. This is the one-stop virtual meeting place for talking with other patients and receiving the latest blood cancer resources and information. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff. Please visit www.LLS.org/community to join.

Weekly Online Chats. Moderated online chats can provide support and help cancer patients to reach out and share information. Please visit www.LLS.org/chat for more information.

LLS Chapters. LLS offers support and services in the United States and Canada, including the *Patti Robinson Kaufmann First Connection Program* (a peer-to-peer support program), local support groups, local education programs and other great resources. For more information about these programs or to contact the nearest chapter, please

- Call: (800) 955-4572
- Visit: www.LLS.org/ChapterFind

Advocacy. The LLS Office of Public Policy (OPP) engages volunteers in advocating for policies and laws that encourage the development of new treatments and improve access to quality medical care. For more information

- O Call: (800) 955-4572
- Visit: www.LLS.org/advocacy

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. Please visit www.LLS.org/ResourceDirectory for more information.

Additional Help for Specific Populations

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 the service of a sign language interpreter. Often these services are free.

Information for Veterans. Veterans who were exposed to Agent Orange while serving in Vietnam may be able to get help from the United States Department of Veterans Affairs. Please visit www.publichealth.va.gov/exposures/agentorange or call the Department of Veterans Affairs at (877) 222-8387 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.

World Trade Center (WTC) Survivors. People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be eligible for 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, lived, worked or were in school in the area
- Responders to the Pentagon and the Shanksville, PA, crashes

For more information, please

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

People Suffering from Depression. Treating depression has benefits for cancer patients. Contact your doctor if your mood does not improve over time—for example, if you feel depressed every day for a 2-week period.

For more information, please

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at www.nimh.nih.gov Enter "depression" in the search box.

Other Organizations

Contact our LLS Information Specialists at (800) 955-4572 for more information.

Blood & Marrow Transplant Information Network (BMT InfoNet) (888) 597-7674 www.bmtinfonet.org

The Blood & Marrow Transplant Information Network is dedicated to providing transplant patients, survivors and their loved ones with emotional support and high-quality, easy-to-understand information about bone marrow, peripheral blood stem cell and cord blood transplants.

CancerCare (800) 813-HOPE ([800] 813-4673) www.CancerCare.org

This national nonprofit agency provides free services, support, information and practical help to anyone affected by cancer, including individuals with cancer. The organization offers guidance on financial issues and gives financial assistance to help with some types of costs.

Cancer Insurance Checklist www.CancerInsuranceChecklist.org

The checklist was designed to help individuals who are diagnosed with cancer, have a history of cancer, or are at risk for cancer, when they are shopping for insurance on a state's Health Insurance Marketplace. This resource was created through a partnership of various health information and cancer support organizations.

FAIR Health www.FairHealthConsumer.org

FAIR Health is a national, independent, not-for-profit corporation whose mission is to bring transparency to healthcare costs and health insurance information and to provide resources for healthcare consumers.

Fertile Hope (855) 220-7777 www.FertileHope.org

Fertile Hope is a national LIVESTRONG initiative dedicated to providing reproductive information, support and hope to cancer patients and survivors

whose medical treatments present a risk of infertility.

Healthcare.gov

www.healthcare.gov

This government-maintained website includes information about the healthcare changes happening as a result of the Affordable Care Act of 2010 (ACA), also called "Obamacare." The site has information about insurance options in your state; compared quality of care in hospitals, home healthcare agencies and nursing homes; an overview of the healthcare law; and healthcare options for different groups of people (ie, families with children, individuals, people with disabilities, seniors, young adults and employers).

Medicare Rights Center (800) 333-4114 www.MedicareRights.org

The Medicare Rights Center works to ensure access to affordable healthcare for older adults and people with disabilities through counseling and advocacy, educational programs and public policy initiatives.

National Council on Aging (571) 527-3900 www.ncoa.org

A respected national leader and trusted partner helping people aged 60 and older meet the challenges of aging. Resources include a search option to find benefits to pay for food, medicine and other daily expenses, get tips and resources to manage a budget, and ways to make the most of Medicare benefits and find the best plan.

National Cancer Legal Services Network (NCLSN) www.NCLSN.org

NCLSN is a coalition of more than 30 programs that offer free legal assistance and referrals for individuals coping with cancer.

National Conference of State Legislatures (NCSL) (202) 624-5400 www.ncsl.org

The NCSL mission is to improve the quality and effectiveness of state legislatures, promote policy innovation and communication among state legislatures, and ensure that state legislatures have a strong, cohesive voice in the federal system. Use the search box to find information about state laws related to insurance coverage for infertility treatment.

National Foundation for Transplants (NFT) (800) 489-3863 www.transplants.org

The NFT provides fundraising assistance, financial assistance through fundraising and grants, advocacy and support to transplant patients nationwide.

National Marrow Donor Program (NMDP) (800) MARROW2 [(800) 627-7692] www.BeTheMatch.org

NMDP is dedicated to creating an opportunity for all patients to receive the bone marrow or umbilical cord blood transplant they need. NMDP supports patients, educates doctors, and educates the public about donating to their bone marrow registry.

National Patient Advocate Foundation (NPAF) (800) 532-5274 www.npaf.org

The National Patient Advocate Foundation is the advocacy affiliate of the Patient Advocate Foundation. The organization works at the local, regional and national level to promote access to affordable and quality healthcare for people with chronic, debilitating or life-threatening illnesses.

nbmtlink

(800) LINK-BMT [(800) 546-5268] www.nbmtlink.org

The mission of the National Bone Marrow Transplant Link is to help patients, caregivers, and families cope with the social and emotional challenges of bone marrow/stem cell transplant from diagnosis through survivorship by providing vital information and personalized support services.

NeedyMeds (800) 503-6897 www.NeedyMeds.org

NeedyMeds is a central source of information for people who cannot afford medicine or other healthcare expenses. Programs such as assistance for specific diseases and conditions, application assistance, state-sponsored programs and Medicaid sites are listed.

Partnership for Prescription Assistance (PPA) (888) 4PPA-NOW ([888] 477-2669) www.pparx.org

PPA brings together pharmaceutical companies, doctors, other healthcare providers, and patient advocacy and community groups to help eligible patients (who lack prescription drug coverage) get needed medicines at little or no cost. The partnership offers access to many public and private patient assistance programs, including programs offered by pharmaceutical companies.

Patient Advocate Foundation (PAF) (800) 532-5274 www.PatientAdvocate.org

The Patient Advocate Foundation draws upon the expertise of case managers, attorneys and doctors who work with patients and their insurers, employers and creditors to resolve insurance problems, job discrimination issues and debt crisis matters. The PAF website features a comprehensive state-by-state directory of financial resources for housing, utilities, food, transportation, medical treatment and children's needs. On the PAF website you can find the National UNinsured Resource Directory and the National UNDERinsured Resource Directory, which are intended to help uninsured and under-insured individuals and families locate valuable resources and seek financial assistance, alternative coverage options or methods for better reimbursement. Also available on the website under PAF Publications, is "Your Guide to the Appeals Process," a step-by-step guide to appealing a denied insurance claim. The PAF Co-Pay Relief Program offers financial assistance for qualified persons. Call (866) 512-3861 or visit www.copays.org for more information.

State Health Insurance Assistance Program (SHIP) www.shiphelp.org

SHIP can answer questions about Medigap policies, long-term care insurance, Medicare health plan choices, Medicare rights and protections, and can also help with filing an appeal.

Triage Cancer www.TriageCancer.org

Triage Cancer is a national, nonprofit organization that provides free education on the legal and practical issues that may impact individuals diagnosed with cancer and their caregivers, through events, materials, and resources. Triage Cancer created an on-line toolkit (www.CancerFinances.org) for navigating finances after a cancer diagnosis and provides one-on-one assistance through their Legal & Financial Navigation program.

Health Terms

Affordable Care Act (ACA). The 2010 health reform law also known as "Obamacare." (Formerly the Patient Protection and Affordable Care Act [PPACA]).

Annual Maximum. The most that a health insurance plan will pay in a "plan year" may be different from what it will pay in a calendar year. As part of the Affordable Care Act (ACA), most health plans cannot impose an annual maximum for "essential health benefits" such as hospital stays or prescription drugs.

Balance Billing. Patients who go to an out-ofnetwork doctor may have to pay a separate deductible or pay the difference between the fee charged by the in-network doctor and the fee charged by the out-of-network doctor; this practice is referred to as "balance billing."

Bronze Plan. In the Health Insurance Marketplace, plans that cover an average of 60 percent of the cost of providing essential health benefits. With a Bronze plan, you will pay an average of 40 percent of the cost of essential health benefit services. This means your monthly premium will be low, but your out-of-pocket costs will be higher when you need health services.

Catastrophic Plan. In the Health Insurance Marketplace, plans that will not cover any benefits other than three primary care visits per year before you pay off your deductible. Premiums for these plans are low, but out-of-pocket costs (deductibles, co-pays, or co-insurance) are high. This type of health plan is only available to people younger than age 30 or those who cannot afford health coverage and have been given a hardship exemption.

Claim. A detailed bill that a healthcare provider (doctor, clinic, hospital, lab, infusion, scans, physical therapist) sends to your health plan. This bill shows the services you received.

COBRA (Consolidated Omnibus Budget Reconciliation Act). A federal law that lets some people who lose their group health coverage stay on their insurance plan for a limited time, but they must pay for it themselves. For example, if you lose your job, you might be able to keep your health plan for a while longer by paying the premium to your employer.

Co-insurance (cost sharing). Co-insurance is a cost-sharing feature of many plans. It requires a member to pay a specific portion of the cost of covered healthcare expenses out of pocket. The defined co-insurance that a member must pay out of pocket is based on their health plan policy.

Co-pay (Co-payment). This is a set dollar amount (for example, \$40) that you pay for a healthcare service covered by your insurance plan. The dollar amount can vary by the type of healthcare service received (primary care provider, specialist) and you pay at the time of service. This fee is specified in your health insurance policy and also may be listed on your insurance card.

Deductible. A fixed dollar amount that you owe for healthcare services covered by your plan before your insurance provider will begin to pay for them. For example, if your deductible is \$1,000, until you have paid this amount out of pocket towards your deductible, your healthcare plan will not pay your medical bills. Many insurance plans have both "per individual" and "per family" deductibles. The per family deductible helps limit the number of deductibles a family must pay in order to have all covered members of the family eligible for claim payments.

ERISA (Employee Retirement Income and Security Act). A law that sets standards and protections for most employee health insurance and pension plans.

Essential Health Benefits. A set of 10 categories of services health insurance plans must cover under the Affordable Care Act. These include doctors' services, inpatient and outpatient hospital care, prescription drug coverage, pregnancy and childbirth, mental health services, and more. Some plans cover more services. Plans must offer dental coverage for children. Dental benefits for adults are optional. Specific services may vary based on your state's requirements.

Explanation of Benefits (EOB). Your insurer will provide you with an EOB after a provider has submitted a claim to your insurer on your behalf or after you have paid a doctor bill and submitted the claim. The EOB includes a detailed explanation of how your insurer/administrator determined the amount of reimbursement made to your provider or you for the medical service. The EOB will also include information on how to appeal or challenge your insurer's reimbursement decision.

Fertility Preservation. A procedure to help a person keep his or her fertility, or to have children if treatment causes infertility. The procedure is done before a person receives medical treatment (for example, chemotherapy) that may cause infertility. Some examples of fertility preservation procedures are sperm banking and egg freezing.

Gold Plan. In the Health Insurance Marketplace, plans that cover an average of 80 percent of the cost of providing essential health benefits. With a Gold plan, you will pay an average of 20 percent of the cost of essential health benefit services.

Health Insurance Marketplace/Exchange. A resource that allows individuals, families, and small businesses to learn about their options for health coverage; compare health insurance plans based on costs, benefits, and other important qualities; choose a plan; and enroll in coverage.

In Network. Refers to treatment from doctors, clinics, health centers, hospitals, medical practices and other providers with whom your plan has an agreement to provide care for its members. Usually, individuals have lower out-of-pocket costs when they receive treatment from in-network providers.

Lifetime Maximum Benefit. The total amount of money that a plan will pay for a member during their lifetime. As part of the Affordable Care Act (ACA), most health plans cannot impose lifetime maximums for "essential health benefits" such as hospital stays or prescription drugs. Dental plans may impose lifetime maximums.

Out of Network. Refers to treatment from doctors, clinics, health centers, hospitals, medical practices and other providers that do not have an agreement with your health insurer to provide

care to its members. Individuals will typically have more out-of-pocket costs when they receive treatment from out-of-network providers.

Out of Pocket. This term applies to any fees for medical care that you must pay on your own, without help from your insurance provider. Deductibles, co-insurance, and co-pays are all out-of-pocket expenses. If you need a service that your health insurance plan does not cover, you will pay the total cost of that service out of pocket.

Out-of-Pocket Maximum. The limit on the total amount a health insurance company requires a plan member to personally pay in total deductibles plus co-insurance in a year. After reaching an out-of-pocket maximum, a member no longer has to pay co-insurance or co-pays and the plan will begin to pay 100 percent of covered medical expenses. Members are still responsible for services that are not covered by the plan even if they have reached the out-of-pocket maximum. They must also continue to pay their monthly premiums.

Platinum Plan. In the Health Insurance Marketplace, plans that cover an average of 90 percent of the cost of providing essential health benefits. With a Platinum plan, you will pay an average of 10 percent of the cost of essential health benefit services. Though your out-ofpocket costs are low when you receive health services, your monthly premium may be higher.

Pre-authorization. A decision made by your health insurer that a specific healthcare service, treatment, or kind of medical equipment is medically necessary for your health care. A pre-authorization is needed before the service, treatment or medical equipment can be received. Also called "prior approval," "prior authorization," or "pre-certification."

Premium. The dollar amount that you must pay for your health plan coverage. If you have health insurance through your employer, you and your employer may each pay a part of the premium monthly, quarterly, or yearly. **Preventive Services.** Routine healthcare that includes screenings, check-ups, and patient counseling to prevent illness or other health problems.

Referral. A written order from your primary care provider (PCP) for you to see a medical specialist or to get certain other medical services. Insurance plans may require that you get a referral before you can receive medical care from anyone except your PCP. If you do not get a referral first, often the plan will not pay for the healthcare services you receive.

Silver Plan. In the Health Insurance Marketplace, plans that cover an average of 70 percent of the cost of providing essential health benefits. With a Silver plan, you will pay an average of 30 percent of the cost of essential health benefit services.

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NOTES



LLS PATIENT FINANCIAL Assistance programs

For more information, please visit www.LLS.org/Finances or call (877) 557-2672



Co-Pay Assistance Program provides assistance toward the cost of insurance premiums and co-pays for prescription drugs, labs, scans, tests, etc. Visit the website for full list of covered expenses. **www.LLS.org/Copay**. Eligible patients may receive up to \$13,000. Award amounts vary by disease.



Urgent Need Program provides assistance for non-medical expenses including rent, mortgage, lodging, utilities, childcare, elder care, food, transportation, car repair, car insurance, phone service, and acute dental work related to treatment. Eligible patients receive a grant of \$500.



Susan Lang Pay-It-Forward Patient Program provides assistance for treatment-related transportation and lodging expenses. Eligible patients receive a \$500 grant.



Patient Aid Program provides a *one-time* \$100 stipend to offset expenses.



Susan Lang Pre CAR T-cell Therapy Travel Assistance Program provides assistance for treatmentrelated transportation and lodging expenses for patients who are being evaluated to receive CAR T-cell therapy as either standard treatment or a clinical trial. Eligible patients receive a \$2,500 grant.

Get support. Reach out to our **INFORMATION SPECIALISTS**

The Leukemia & Lymphoma Society team consists of highly trained oncology social workers, nurses and health educators who are available by phone Monday through Friday, 9 a.m. to 9 p.m. (ET).

- Get one-on-one personalized support and information about blood cancers
- Know the questions to ask your doctor
- Discuss financial resources
- Receive individualized clinical-trial searches

Contact us at 800-955-4572 or www.LLS.org/ InformationSpecialists

(Language interpreters can be requested)



For more information, please contact our Information Specialists **800.955.4572** (Language interpreters available upon request).

National Office 3 International Drive, Suite 200 Rye Brook, NY 10573

The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. Find out more at www.LLS.org.