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**LEUKEMIA &
LYMPHOMA
SOCIETY®**

fighting blood cancers

Cancer and Your Finances



A Message from Louis J. DeGennaro, Ph.D.

Interim President and CEO of The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society (LLS) is the world's largest voluntary health organization dedicated to finding cures for blood cancer patients. Our research grants have funded many of today's most promising advances; we are the leading source of free blood cancer information, education and support; and we advocate for blood cancer patients and their families, helping to ensure they have access to quality, affordable and coordinated care.

Since 1954, we have been a driving force behind nearly every treatment breakthrough for blood cancer patients. We have invested over \$1 billion in research to advance therapies and save lives. Thanks to research and access to better treatments, survival rates for many blood cancer patients have doubled, tripled and even quadrupled.

Yet we are far from done.

Until there is a cure for cancer, we will continue to work hard—to fund new research, to create new patient programs and services, and to share information and resources about blood cancer.

This booklet has information that can help you understand your finances, prepare questions, find answers and resources, and communicate better with members of your healthcare team.

Our vision is that, one day, all people with blood cancers will either be cured or will be able to manage their disease so that they can experience a better quality of life. Today, we hope our expertise, knowledge and resources will make a difference in your journey.



Louis J. DeGennaro, Ph.D.

Interim President and CEO

Chief Mission Officer

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CEO, Triage Cancer

Introduction

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

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

- Some people may let their health insurance lapse when they leave or change jobs or because they cannot afford it.
- Some people who cannot afford the cost of private insurance may not realize that they qualify for government programs or other types of assistance.
- Patients may find out after they are diagnosed with cancer that their insurance does not cover the prescription drugs or treatments they need.
- Some patients 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 cope with the financial aspects of cancer care. It may be helpful to skim through the entire booklet and then come back to specific sections as needed.

The Leukemia & Lymphoma Society's (LLS) Information Specialists [(800) 955-4572] offer guidance about health insurance, government programs, disability benefits, financial assistance programs and advocacy. Patient access staff at LLS chapters can help you connect with LLS programs and other community resources.

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 Patient Protection and Affordable Care Act of 2010 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 Patient Protection and 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 LLS, with the understanding that LLS is not engaged in rendering medical or other professional services.

Resources and Information

LLS offers free information and services for patients and families touched by blood cancers. This section of the booklet lists various resources available to you. Use this information to learn more, to ask questions, and to make the most of your healthcare team's knowledge and skills.

For Help and Information

Consult with an Information Specialist. Information Specialists are master's level 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 (M-F, 9 a.m. to 9 p.m. EST)
- Email: infocenter@LLS.org
- Live chat: www.LLS.org
- Visit: www.LLS.org/information specialists

Free Materials. LLS offers free education and support publications that can either be read online or downloaded. Free print versions can be ordered. For more information, please visit www.LLS.org/publications.

Telephone/Web Education Programs. LLS offers free telephone/Web education programs for patients, caregivers and healthcare professionals. For more information, please visit www.LLS.org/programs.

Co-Pay Assistance Program. LLS offers insurance premium and medication co-pay assistance for certain eligible patients. For more information, please

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

Community Resources and Networking

Online Blood Cancer Discussion Boards and Chats. Online discussion boards and moderated online chats can provide support by helping cancer patients reach out and share information. For more information, please visit www.LLS.org/getinfo.

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), in-person support groups and other great resources.

For more information about these programs or to contact your chapter, please

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

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, locating summer camps and other needs. For more information, please visit www.LLS.org/resourcedirectory.

Clinical Trials (Research Studies). New treatments for patients with blood cancers are under way. Patients can learn about clinical trials and how to access them. For more information, please

- Call: (800) 955-4572 to speak with an LLS Information Specialist who can help conduct clinical-trial searches
- Visit: www.LLS.org/clinicaltrials and click on TrialCheck®

Advocacy. The LLS Office of Public Policy (OPP) enlists volunteers to support policies and laws to speed new treatments and improve access to quality medical care. For more information, please

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

Additional Help for Specific Populations

Información en Español (LLS information in Spanish). For more information, please visit www.LLS.org/espanol.

Language Services. Let your doctor know if you need a language interpreter or other resource, such as a sign language interpreter. Often, these services are free.

Veterans. Vietnam veterans with certain blood cancers exposed to Agent Orange may be able to get help from the U.S. Department of Veterans Affairs (VA).

For more information, please

- Visit: www.publichealth.va.gov/exposures/agentorange
- Call: VA (800) 749-8387

World Trade Center (WTC) Survivors. People involved in the aftermath of the 9/11 attacks and those who were 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

- 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. Seek medical advice if your mood does not improve over time—for example, if you feel depressed every day for a two-week period. For more information, please

- Call: National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at www.nimh.nih.gov, enter “depression” in the search box

Feedback. Like this booklet? Have suggestions? We’d love to know what you think. To tell us

- Visit: www.LLS.org/publicationfeedback
 - Click on “LLS Disease & Treatment Publications—Survey for Patients, Family and Friends”

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
- An individual policy that has been purchased from an insurance company

Government-funded health insurance programs include

- Medicaid
- State Children’s Health Insurance Program (S-CHIP)
- Medicare

- Other government programs

Under the Patient Protection and Affordable Care Act (ACA), most US citizens and individuals 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.”

Minimum essential health insurance coverage includes:

- Insurance that you get through your employer
- Policies that you buy directly from an insurance company
- Medicare
- Medicaid
- State high-risk insurance pools
- Veterans health plans
- Other types of coverage

If you do not have health insurance coverage for at least nine months out of the year, you will be required to pay a penalty. In 2014, the penalty will be \$95 for adults or 1% of your household income, whichever is more; in 2015, it will be \$350 or 2% of your household income; in 2016, it will be \$695 or 2.5% of your household income. There are some exceptions to the requirement, so some people do not need to get this insurance including those who face financial hardship, those who have religious objections, members of Indian tribes, undocumented immigrants or those who are in jail.

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 the different types of health insurance options, see page 10. LLS has partnered with other cancer advocacy organizations to develop the Cancer Insurance Checklist, which can help you figure out which health insurance plan will work for you. For more information, visit www.CancerInsuranceChecklist.org.

Know Your Coverage

It is not uncommon to discover that you are underinsured when you are diagnosed with a serious illness such as cancer. Newly diagnosed patients need to know what is covered by their insurance, how to protect their benefits, what resources are available to deal with 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 need to read their policies carefully to understand the health and medical services that are covered. These expenses 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” or paid out-of-pocket by a patient each year before the insurance plan will cover medical expenses

Co-Payments

- 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)
- May vary depending on whether the patient is seeing a specialist (e.g., hematologist/oncologist) or a primary care provider

Co-Insurance/Cost share

- The percentage of medical expenses shared by the patient and the health plan
 - For example, in an 80/20 plan, the insurer pays 80 percent of covered expenses and the patient pays the remaining 20 percent of the medical or prescription drug charges
- This cost is in addition to any deductibles and co-payments
- May apply to hospital services and certain laboratory tests, or when a patient receives medical care from a health provider outside of the plan’s network

Out-of-Pocket

- The total amount of medical expenses that patients are responsible for paying

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 predetermined rate
- An out-of-network provider is not directly contracted with an individual’s health insurance plan
- The amount you would pay for an in-network provider is usually much less than the amount you would pay for an out-of-network provider

Lifetime & Annual Maximums or “Caps”

- The maximum benefits that will be paid for each individual enrolled in the plan during each year or during the individual’s lifetime
- Under the ACA, for plan years that began on or after September 23, 2010, plans can no longer impose lifetime caps, and as of January 1, 2014, plans cannot impose annual limits on essential health benefits

Get Organized

Once health insurance is obtained, the insurance plan should be reviewed to 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 and describe changes to the plan benefits that may affect medical coverage.

Here are some steps that patients and families can take to get the most from their coverage.

1. Ask a lot of questions. You never know who might be able to help you and what they might be able to help you with.
2. Request a case manager from the insurance company. This will be the patient or family member's direct contact to answer questions about claims or the policy. When many medical treatments are necessary, having only one person to speak to at the insurance company helps.
3. Keep a copy of all claims and related paperwork in an organized folder by category. This would 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 were speaking to, what was said and the date.
4. Check health policies often to determine what services and medications are covered.
5. Dealing with the insurance company can be very stressful. See if your employer has a benefits advisor or advocate who can assist or call organizations, including The Leukemia & Lymphoma Society, to get help.
6. Obtain proof of previous health insurance coverage from your insurance company (called a "certificate of creditable coverage").
7. Pay premiums on time and in full to avoid a lapse in or cancellation of coverage.
8. 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.
9. Check to see if pre-authorization or pre-certification is needed for any procedures or treatments.
10. Use an in-network doctor or facility to avoid unnecessary out-of-pocket expenses.
11. Make friends with your doctor, nurse, social worker, billing person and others

you see at your treatment appointments. If you have a problem with an insurance claim, these people may be able to help and advocate for you.

12. Question items that the insurance company does not pay—don't assume that you have to pay for all of the treatment expenses, or that all charges are correct.
13. Learn what to do if a claim is denied (see *Denial of Insurance Coverage* on page 15).
14. Know the laws designed to protect patients and provide continuation of medical coverage, for example, ACA, COBRA (see page 12), the Family and Medical Leave Act (FMLA) and the Americans with Disabilities Act (ADA) (see page 18).
15. Use Flexible Spending Accounts, a benefit offered to an employee by an employer, which allows a fixed amount of pre-tax wages to be set aside for qualified expenses that are not covered under the employer's insurance plan. Qualified expenses include your out-of-pocket expenses such as co-pays for doctor visits and prescriptions.

Healthcare Consumer Protections

Pre-existing condition protection for adults. As of January 1, 2014, insurance companies are no longer allowed to deny a health insurance policy to adults with a pre-existing medical condition, such as cancer. Insurance companies also can no longer impose pre-existing exclusion periods on their policies.

Premium rating. As of January 1, 2014, 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.

Insurance cancellations (rescissions). Insurance companies can no longer cancel or "rescind" your policy unless you commit fraud, intentionally lie on your application, or stop paying your premiums.

Free preventive services. Most private insurance companies are required to provide free coverage for certain preventive services, such as cancer screenings. This means that you can access these services without having to pay a co-pay or co-insurance. The list of preventive services is available at healthcare.gov.

Access to clinical trials. Participating in a clinical trial might be an excellent option for an individual with cancer. As of January 1, 2014, the ACA requires insurance companies to cover "routine costs" for individuals who decide to participate in an eligible clinical trial. Routine costs may include doctor visits, blood tests, scans, MRIs, etc. Other laws that may provide additional protection for clinical trial participants are in place in 36 states and the District of Columbia.

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

Young Adults

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

- If a family's insurance plan covers dependents, the ACA allows young adults to stay on their parents' insurance plan until age 26. Contact your insurance company or visit www.healthcare.gov for more information.
- Fertility treatment coverage varies state by state. See the free LLS publication *Fertility Facts* and page 26 for additional resources.
- LLS 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 may vary from your coverage, so always check your own plan description.

Health Maintenance Organizations (HMOs)

- HMOs provide plan members with reduced costs for medical services from specific doctors, hospitals and clinics.
- These specific providers must be used for medical services in order to be covered under the plan.
- Plan members choose a primary care doctor and must get a referral from that doctor to see any other healthcare professional.

Preferred Provider Organizations (PPOs)

- PPOs provide plan members with reduced costs.
- Members pay a standard co-pay amount for an office visit.
- Members can choose between an in-network or out-of-network provider instead of being restricted to designated providers.
- A member may go to a specialist without permission from the primary care doctor, as long as the specialist is part of the PPO network.
- An in-network specialist is usually the least expensive choice.
- If a member sees an out-of-network specialist, he or she may have to pay the

entire bill first, and then submit a claim for reimbursement.

- There may be a deductible for out-of-network medical services, or members may have to pay the difference between what in-network doctors charge and what out-of-network doctors charge; this practice is referred to as “balance billing.”

Exclusive Provider Organizations (EPOs)

- EPOs are similar to PPO plans in that they provide plan members with reduced costs and members pay a co-pay amount for an office visit.
- However, members must select providers from a limited list.
- If the plan member visits an out-of-network doctor, the visit may cost the plan member from 20 to 100 percent of the costs.
- This plan may be difficult for patients who require a number of unique specialists.

Point-of-Service (POS)

- POS plans blend the features of HMO and PPO plans.
- Plan participants can choose the type of provider network best suited to their needs each time they seek care.
- This type of plan enables participants to obtain care from a network provider for one type of care and at the next “point of service” to see a provider who has contracted with the POS plan to provide services at a discount.
- In a POS plan, the plan member usually sees his or her chosen primary care doctor first for any medical issues.
- If necessary, the member would be referred to a specialist.
- A plan member may visit a licensed provider outside the network and still receive coverage, but substantially less coverage than if he or she stayed within the network.

Fee-for-Service (FFS)

- FFS plans are more flexible, but involve higher premiums and out-of-pocket expenses, as well as more paperwork.
- Plan members can choose their own doctors and hospitals.
- Members may visit a specialist without getting permission from a primary care doctor.
- There is usually a deductible amount before the insurance company starts paying claims, and then doctors are reimbursed a percentage of the bill, typically 80 percent; members must pay the remaining 20 percent.
- Members of an FFS plan may have to pay up front for medical services and then submit a claim for reimbursement.

- FFS plans pay for “reasonable and customary” medical expenses (a reasonable and customary fee is the amount that your healthcare plan determines is the normal range of payment for a specific health-related service or medical procedure within a given geographic area).
- If a doctor charges more than the average, the plan member has to pay the difference.

Health Insurance Marketplace Plans. The intent of the Affordable Care Act (ACA, also known as “healthcare reform”) is to help individuals to access affordable, quality healthcare. The ACA provides assistance in two ways:

- It creates new options for accessing health insurance coverage
- It creates new protections for healthcare consumers

Your health insurance may not have changed in 2014, especially if your access to health insurance is through your employer or Medicare. However, some new options will be available.

Individuals and small businesses (fewer than 50 employees) will be able to buy health insurance coverage through State Health Insurance Marketplaces. These Marketplaces are similar to a shopping mall for health insurance coverage.

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 (\$6,350 for an individual and \$12,700 for a family)
- Provide five levels of standardized plans (bronze, silver, gold, platinum and catastrophic) with different levels of cost share, to make it easier for you to figure out which plans work best for you

Individuals with incomes up to 400% of the federal poverty level will receive help paying for their health insurance coverage through premium tax credits and cost-sharing subsidies.

For information about the Health Insurance Marketplaces, visit www.healthcare.gov and pick your state.

COBRA. Cancer survivors who lose, leave or change jobs, or “age out” of their parent’s health insurance plan may be eligible to remain on their employer plan under the Consolidated Omnibus Budget Reconciliation Act (COBRA). Continuation of health insurance through COBRA

- Is a federal law
- Requires some 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 (see www.dol.gov/COBRA for information about extending coverage after 18 months)

- Requires individuals to pay the entire premium (including the portion that the employer used to pay on their behalf)
- May not be the least expensive option but it will provide continuation of coverage

There may be less expensive options available through the State Health Insurance Marketplace plans. Note that many states have a state COBRA law that covers smaller employers.

Cancer survivors who are not eligible for COBRA, and/or those who are job hunting, may want to consider seeking employment at a larger company that offers health insurance as an employment benefit. For more information about COBRA, including a list of qualifying events for employees, spouses and dependent children, see www.dol.gov/ebsa.

Medicaid. Medicaid provides coverage for certain individuals and families with limited income and assets. Each state has its own Medicaid program with its own rules about eligibility and coverage. Visit www.cms.hhs.gov/home/medicaid.asp. Under “Medicaid Eligibility,” there is a list of state Medicaid websites.

The ACA gave states the option to expand their Medicaid programs to cover all adults with incomes up to 138% of the federal poverty level (\$15,856/year for an individual or \$32,499/year for a family of 4 in 2014). Only some states have chosen to expand their Medicaid programs. For more information about Medicaid, visit www.healthcare.gov or www.Medicaid.gov.

State Children’s Health Insurance Program (S-CHIP). S-CHIP provides free or subsidized health coverage for eligible children. S-CHIP is part of Medicaid in many states. Most states cover children with family income up to 200 percent of the federal poverty level. Call (877) 543-7669 or visit www.insurekidsnow.gov for more information.

Medicare. Medicare provides health insurance coverage for people 65 years and older, people under 65 years with certain disabilities (as defined by the Social Security Administration) and anyone with end-stage renal disease requiring kidney dialysis. 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, skilled nursing facility, psychiatric hospital and hospice care services
- Part B (medical insurance) helps pay for medical services, doctor visits, labs, outpatient therapy and other professional services as well as some preventative services
- Part C (Medicare Advantage Plan)

- Is similar to private plans (see page 10)
- Is approved by Medicare and run by private companies that will provide all of your Part A and Part B coverage
- Usually 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
- Different Medicare Advantage Plans can charge different out-of-pocket costs and have different rules for how to get services (like whether a referral is needed to see a specialist or if only certain doctors, facilities or suppliers that belong to the plan for non-emergency or non-urgent care can be visited)
- Rules of individual plans can 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
 - Coinsurance or co-payments apply
 - Assistance with drug benefit premiums, 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)
 - The “donut hole,” which limits drug coverage and causes patients to pay out-of-pocket, is being phased out. The ACA will gradually decrease the amount patients pay for all prescriptions once they reach the donut hole. Call (800) MEDICARE ([800] 633-4227) or visit www.medicare.gov

Veterans Benefits. Veterans benefits provide comprehensive healthcare and other benefits for veterans and dependents of active-duty, retired or deceased members of the military. TRICARE is the healthcare program serving uniformed service members, retirees and their families. For information about TRICARE, visit www.tricare.mil. 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 exposure, 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.

High-Risk Pool Coverage. People with cancer may also contact their state insurance agency to find out if their state has a high-risk pool, a program that makes health coverage available to people with pre-existing medical conditions. High-risk pools generally have strict eligibility requirements and may be more expensive than other health plans. Some states are discontinuing their high-risk pool coverage because of the new health insurance options created by the ACA. To find a complete listing of state pools, go to the National Association of State Comprehensive Health Insurance Plans website at www.NASCHIP.org.

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. Submitting all necessary paperwork and key documents by stated deadlines are important elements in improving the likelihood of a successful appeal. Patients or their advocates should write down

- The date and time of each call to the insurance company
- The name, phone number and extension of the insurance company representative who handled the call

Questions to ask an insurer 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 plan Summary of Benefits and Coverage (SBC) on the internet? If not, how can I get a copy of that information?
4. Who can I contact at the insurance company to discuss the denial? May I have that person's direct phone number?
5. How can I request 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?

If the company still denies your claim and you believe the decision is wrong, seek an external appeals process and get the help of your state insurance agency, a social worker or an attorney. See page 26 for organizations that may be able to help.

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. It is important to work closely with the financial services department at your treatment center to obtain the highest reimbursement from the insurance company.

Here are strategies 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. You may want to use www.giveforward.com to help.
- Cash in benefits from life insurance policies through life insurance loans or 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.

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

- The LLS Co-Pay Assistance Program helps eligible patients with certain blood cancer diagnoses pay treatment co-pays and other insurance-related expenses. For more information call (877) 557-2672 or visit www.LLS.org/copy to submit an application.
- LLS is part of the Cancer Financial Assistance Coalition (C-FAC) which encourages communication and collaboration among its member organizations who have joined forces to address cancer patients' needs. This group educates patients and providers about resources, and advocates for cancer patients facing the financial burdens of cancer care. To use this resource visit www.cancerfac.org.

LLS Information Specialists provide general information about other sources of financial assistance. To reach our Information Specialists call (800) 955-4572.

Additional financial information can be found at www.LLS.org/finances.

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 a state, health plan or hospital
- Typically includes processes that enable access to non-formulary 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 15)

People without adequate insurance to cover the cost of prescription medications for cancer treatment may want to explore these 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.
- The National Association of Counties (www.naco.org) and various 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 for information about the LLS Co-Pay Assistance Program or other co-pay assistance programs.

Stem Cell Transplantation Resources. 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, phone calls, child care, donor testing and aftercare. Patients and caregivers may need to use multiple strategies to secure enough funding to cover these costs.

The organizations listed on page 26 provide information, support, financial support services and patient advocacy for transplant candidates, recipients and their families. LLS also has a resource directory with lists of organizations that may be able to help stem cell transplant patients. Visit www.LLS.org/resourcedirectory for more information.

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 of 1973.)

Americans with Disabilities Act (ADA). The Americans with Disabilities Act (ADA) 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 activity (e.g., 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 or call toll-free (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 www.dol.gov/dol/location.htm. For more information about reasonable accommodations, visit www.askjan.org or call toll-free (800) 526-7234.

Family and Medical Leave Act (FMLA). The FMLA enables eligible employees (who have worked at least 1,250 hours over the last 12 months for private companies with 50 or more employees) to take unpaid, job-protected leave for specified family and medical reasons. The employee would continue to receive his or her group health insurance coverage under the same terms and conditions as if he or she had not taken leave.

Eligible employees are entitled to:

- Twelve workweeks of leave in a 12-month period to care for the employee's
 - Own serious health condition, or
 - Spouse, child or parent who has a serious health condition
- Twenty-six workweeks of 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)

There are three kinds of FMLA leave:

- Continuous FMLA leave—An employee is absent for more than three 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. Intermittent FMLA is often taken when an employee needs ongoing treatment or follow-up appointments for his or her condition.
- Reduced schedule FMLA leave—An employee needs to reduce the amount of hours he or she works 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 toll-free at (866) 487-9243.

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

Disability Insurance Options

Disability insurance provides income replacement to people whose medical condition keeps them from being able to work for a period of time or permanently. There are different types of disability insurance. There are private disability insurance plans that you can purchase directly from an insurance company or that may be available to you through an employer. A few states (CA, HI, NJ, NY, RI) and Puerto Rico have short-term 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). SSDI 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.

- **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. For information, visit www.ssa.gov/compassionateallowances or call (800) 772-1213.

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

Advocacy

Advocating for yourself or a loved one with cancer is important. Advocacy means speaking or writing in support of a cause. You may also be interested in advocating for policies that can provide additional benefits and protections or 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 your healthcare team about your

- Insurance coverage
- Ability to pay out of pocket for cancer care

You may feel uncomfortable sharing personal financial information with your healthcare team. It is important to share this information and to ask questions so that your financial concerns can be resolved. Limiting stress and making sure you can get your treatments, prescription medications or support services is important.

- Talk about payment options with your healthcare team or the financial services department.
- Talk to your doctor about the cost of a new prescription for medication.
- Ask about prescription assistance programs (see page 17).
- Ask to be referred to a social worker, navigator, or case manager.
- Ask your insurance company if your medication is covered on their drug list.
- Ask your doctor if the medication you are taking is available in a generic and if he/she will prescribe that for you.

- Speak to the members of the healthcare team about reviewing your medication list to see whether you are taking nonessential drugs.
- Ask your healthcare team about scheduling your treatments around work, if you work and plan to continue working during treatment.
- Talk to your healthcare team about your decision to disclose or not disclose your diagnosis at work, especially before asking them to complete medical leave, reasonable accommodation, or disability paperwork.

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
- Refer you to organizations to help with housing expenses such as The Homes & Communities section of the United States Department of Housing and Urban Development (HUD) website at www.hud.gov

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

Your advocate should be

- Organized
- Reliable
- Trustworthy

An advocate can help manage your financial health while also offering ongoing emotional support. For more information about coping with cancer, see the free LLS booklet, *Each New Day: Ideas for Coping with Blood Cancers* at www.LLS.org/publications or contact our Information Specialists for a copy.

What Family and Friends Can Do. If you have family and/or friends who you trust to get things done, then count on them to help you. Family and friends can

- Organize fundraising efforts.
- Set up a record-keeping system to track bills and insurance claims that have been submitted, pending and paid.

- Call public and private agencies to determine eligibility for financial assistance, entitlement programs and other benefits and services.
- Gather documents to support insurance claims and appeals and 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 may 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 on treatment progress
- Deciding who will take care of children or aging parents

You might find help by

- Using online programs, such as www.lotsahelpinghands.org, to have friends and family help
- Talking to other patients at the treatment center to get ideas about juggling responsibilities
- Putting together a list of your support system such as friends, family, church members and volunteers who could help you on a regular basis or in an emergency
- Talking to others on the LLS Discussion Boards at www.LLS.org/discussionboard, 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 with 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

What Professionals Can Do. 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

Our Information Specialists can provide expert advice and/or help you find additional organizations to assist. To reach our Information Specialists, call the toll-free number (800) 955-4572.

Financial Checklists

Below are checklists to help you think about the many financial concerns that arise after a diagnosis of a blood cancer. Use these lists to keep track of questions to ask your healthcare and financial teams. Keeping organized can help decrease many financial stressors and allow you to focus on feeling better.

Part 1 – Preparing for Expenses

- 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 nonessential 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

- 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.
- 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 him or her regarding insurance concerns, payment questions or other details about medical records.

Part 3 – Treatment Benefits

- 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.
- I have a copy or 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 is 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 a timeline for my treatment.

Part 4 – Treatment Authorizations

- I know when I need to call the insurance company for pre-authorization/pre-certification.
- I know why the procedure is being done.
- 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

- I know my prescription drug plan and how to find out if a drug is covered or not.
- The drug(s) I have been prescribed is (are) covered under my prescription plan.
- I know if I have a mail-order pharmacy benefit.
- 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 him or her to prescribe the generics to save money.
- I will ask for an exception if a drug prescribed is not on the insurance formulary (list of covered medications).
- If I have Medicare coverage, I know when I am eligible to change my Part D prescription plan to meet my changing medication needs.

Resources

Contact our LLS Information Specialists at (800) 955-4572 or visit www.LLS.org/resourcedirectory to find additional organizations that can help.

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

BMT InfoNet 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.cancercares.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.

Fertile Action

www.fertileaction.org

Fertile Action was established to help women touched by cancer become mothers through education, advocacy and financial aid for fertility preservation, sperm donation, egg donation, surrogacy and long-term storage of sperm, oocytes, and embryos.

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 the risk of infertility.

Foundation for Health Coverage Education (FHCE)

(800) 234-1317 • www.coverageforall.org

FHCE educates callers about free or low-cost insurance in the state they live in. FHCE has developed a customized matrix for every state that details insurance opportunities, and has provided this matrix to each state's insurance professionals. The foundation offers downloadable information about each state's public and private healthcare options and locates resources and applications for health coverage programs by state.

Healthcare.gov

www.healthcare.gov

This government-maintained website includes information about the healthcare changes happening as a result of the Patient Protection and Affordable Care Act of 2010. This website includes information about finding insurance options in

your state; comparing care quality in different hospitals, home healthcare agencies and nursing homes; providing an overview of the healthcare law; and providing healthcare option information for different groups of people, i.e, 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 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)

www.ncsl.org/research/health/insurance-coverage-for-infertility-laws.aspx

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. This link provides information about state laws related to insurance coverage for infertility treatment.

National Foundation for Transplants (NFT)

(800) 489-3863 • www.transplants.org

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

National Marrow Donor Program (NMDP)

(888) 999-6743 • www.marrow.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.

NeedyMeds

www.needymeds.com

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 for 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

PAF 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 Underinsured Resource Directory, which is intended to help underinsured individuals and families locate valuable resources and seek alternative coverage options or methods for better reimbursement (www.patientadvocate.org/help4u.php). 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.shiptalk.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 education and resources on the entire continuum of cancer survivorship issues to survivors, caregivers, and healthcare professionals.

someday is today



**LEUKEMIA &
LYMPHOMA
SOCIETY®**

fighting blood cancers

REACH OUT TO OUR **INFORMATION SPECIALISTS**

The Leukemia & Lymphoma Society's (LLS) Information Specialists provide patients, families and healthcare professionals with the latest information on leukemia, lymphoma and myeloma.

Our team consists of master's level oncology professionals who are available by phone Monday through Friday, 9 am to 9 pm (ET).

Co-Pay Assistance

LLS's Co-Pay Assistance Program helps blood cancer patients cover the costs of private and public health insurance premiums, including Medicare and Medicaid, and co-pay obligations. Support for this program is based on the availability of funds by disease.

For more information, call 877.557.2672 or visit www.LLS.org/copay.



For a complete directory of our patient services programs, contact us at

800.955.4572 or www.LLS.org

(Callers may request a language interpreter.)



For more information, please contact:

or:

National Office

1311 Mamaroneck Avenue, Suite 310, White Plains, NY 10605

Contact our Information Specialists **800.955.4572** (*Language interpreters available upon request*)

www.LLS.org

Our Mission:

Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.

LLS is a nonprofit organization that relies on the generosity of individual, foundation and corporate contributions to advance its mission.