

Financial Health Matters

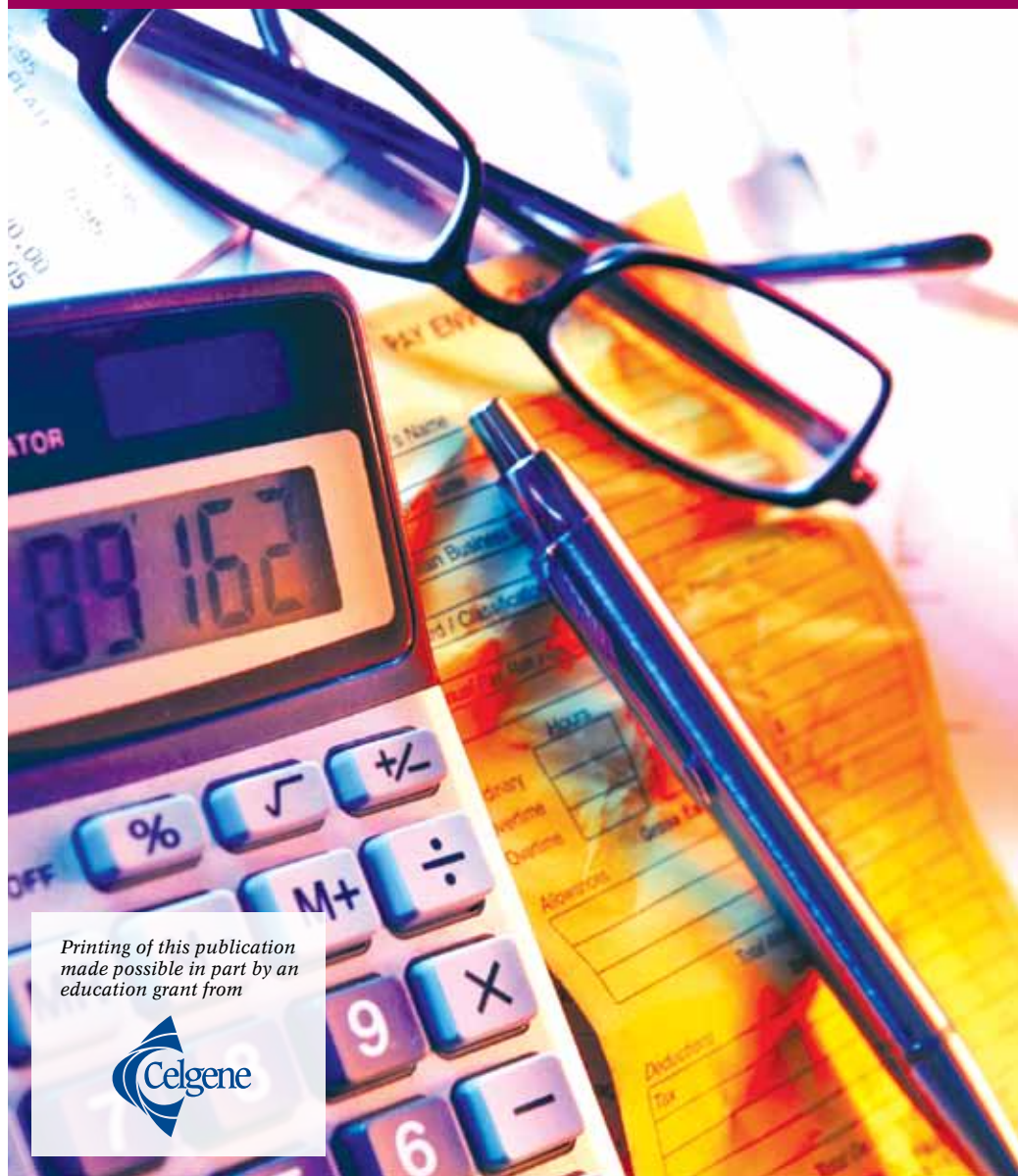
 LEUKEMIA & LYMPHOMA SOCIETY®
fighting blood cancers

INSURANCE INFORMATION & FINANCIAL RESOURCES

LEUKEMIA

LYMPHOMA

MYELOMA



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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 6 pm (ET).

Call 800.955.4572 for a complete directory of our patient services programs. Callers may request a language interpreter.



LEUKEMIA &
LYMPHOMA
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fighting blood cancers

www.LLS.org

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

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Introduction

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

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. Others who cannot afford the cost of private insurance may not realize that they qualify for government programs or other types of assistance. Or, patients may find out after they are diagnosed with cancer that their insurance does not cover the prescription drugs or treatments they need.

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 offer guidance about health insurance, government programs, disability benefits, financial assistance programs and advocacy. Patient services staff at LLS chapters can help you connect with LLS programs and other community resources.

The information in this booklet 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's website at www.healthcare.gov. Please also see page 25.

This publication is designed to provide accurate and authoritative information in regard to the subject matter covered. It is distributed as a public service by The Leukemia & Lymphoma Society, with the understanding that LLS is not engaged in rendering medical or other professional services.

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. Some people have private group health insurance coverage through an employer, union or other association or have an individual policy that they have purchased. Other people qualify for government-funded health insurance programs, including Medicaid, State Children’s Health Insurance Program (SCHIP) and other special interest programs (see *Public Programs* on page 8 for details). In addition, some individuals are covered by Medicare, a federal system of health insurance for people over 65 years of age and people under 65 years of age with certain disabilities.

Know Your Coverage. It is not uncommon to discover you’re underinsured when you are diagnosed with a serious illness, such as cancer. Newly diagnosed patients need to know what is covered, how to protect their benefits and what resources are available to deal with gaps in coverage. Cancer survivors, who will need follow-up care, also need to know what is covered.

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
- **Deductibles**—a fixed amount of money that must be “met” or paid by a patient each year before the insurance carrier 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. Co-pay amounts are not applied against the insurance plan deductible amount(s). The co-pay amount may vary depending on whether the patient is seeing a specialist (e.g., hematologist/oncologist) or a primary care provider
- **Coinsurance**—the percentage of medical expenses shared by the patient and the health plan. For example, for some types of plans, the insurer pays 80 percent of covered expenses and the remaining 20 percent of the medical

charges are the patient's responsibility. This cost is in addition to any deductibles and co-payments. Coinsurance may apply to hospital services and certain laboratory tests, and also to managed care plans for instances when a patient receives medical care from a health provider outside of the plan's network

- **Out-of-Pocket Expenses**—the portion 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. Many insurers maintain a contract with providers in which the provider is given a set fee per patient regardless of treatment required. The amount you would pay for an in-network provider is usually much less than paying for an out-of-network provider
- **Lifetime Maximum or "Cap"**—the maximum benefits that will be paid for each individual enrolled in the plan during the individual's lifetime. For plan years that began on or after September 23, 2010, plans can no longer impose lifetime caps and beginning in 2014, eliminate annual limits on coverage, due to the Patient Protection and Affordable Care Act.

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.

For individual policyholders:

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

Here are steps that patients and families can take to manage their health finances and get the most from their coverage:

- Request a case manager from the insurance company. This will be the patient or family member's direct contact regarding questions about claims

or the policy. When many medical treatments are necessary, having only one person to speak to at the insurance company helps.

- Keep a copy of all claims and related paperwork, such as letters of medical necessity, bills, receipts, requests for sick leave—as well as a written record of any phone conversations with insurers, including the name of the person you were speaking to—in an organized binder by category.
- Check health policies often to determine what services and medications are covered.
- Obtain proof of previous health insurance coverage from your insurance company (called a “certificate of creditable coverage”).
- Pay premiums on time and in full to avoid a lapse in coverage.
- 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.
- Check to see if pre-authorization or pre-certification is needed for any procedures or treatments.
- Use an in-network doctor or facility to avoid unnecessary out-of-pocket expenses.
- Learn what to do if a claim is denied (see *Denial of Insurance Coverage* on page 14).
- Know the laws designed to protect patients and provide continuation of medical coverage, for example, COBRA and HIPAA (see page 12 and 13) and the Family and Medical Leave Act (FMLA) and the Americans with Disabilities Act (ADA) (see pages 19 and 20).
- 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 may include child care or uncovered medical expenses. The amount set aside must be determined in advance and employees lose any unused dollars in the account at year-end.

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.

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) 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 the primary care doctor to see any other health professional.

Preferred Provider Organizations (PPOs) also provide plan members with reduced costs. Members pay a standard co-pay amount for an office visit. They 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. A network specialist would be 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 network doctors charge and what out-of-network doctors charge, often referred to as balance billing.

Exclusive Provider Organization (EPO) plans 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, in this plan 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) 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 would usually see his or her chosen primary care doctor first for any medical issues. If necessary, he or she would be referred to a specialist. A plan member may visit a licensed provider outside the network and still receive coverage, but substantially less than if he or she stayed within the network.

Fee-for-Service (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. They 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 health 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.

Insurance for Young Adults. A young adult diagnosed with cancer has concerns that are different from other patients. Whether in high school, college or living on his or her own, a young patient may need to make difficult decisions regarding his or her care. The patient may live far away from family or not have insurance. Or, patients may worry about staying insured. The following are a few suggestions that may help.

- If a family’s insurance plan covers children, the Patient Protection and Affordable Care Act allows those young patients to stay on their parents’ insurance plan until age 26, as long as the patient does not have his or her own insurance coverage. Talk to your insurance representative or visit www.healthcare.gov for more information.
- Fertility treatment coverage varies state by state. Talk to the Cancer Legal Resource Center for help with information about your state’s coverage (see page 24).
- Each state has its own insurance policies that may be affordable and appropriate. A patient who does not think he or she can afford insurance should look into other options before spending down his or her assets and applying for Medicaid.

- Dealing with the insurance company can be very stressful—call organizations to get help or see if your employer has a benefits advisor or advocate who can assist.
- 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 should be inclined to help and advocate for you.
- Fight everything that the insurance company does not pay—don't think that you have to pay for all of the treatment expenses.
- 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.
- Remember that you can request reasonable accommodations at work through the Americans with Disabilities Act (see page 20) or your state's fair employment laws.
- When looking for a job and your resume shows gaps in employment, consider changing the style of your resume to highlight your skill set and types of work done previously, instead of creating a chronological resume.



LLS has programs that focus on the young adult patient. Visit www.LLS.org/yaconnect for access to upcoming and archived programs about employment, survivorship, insurance, managing cancer and other pertinent topics.

For additional resources, visit www.LLS.org/resourcedirectory.

Public Programs. Cancer survivors who meet certain criteria may qualify for health insurance, disability benefits or cash payments provided through programs that are administered and/or funded by the government. This process can be complicated, but financial case workers and social workers can help patients understand eligibility requirements and enrollment. It is important to get the information you need and apply as soon as you think you may qualify for benefits. Programs may have specific enrollment periods, waiting lists or waiting periods before covered benefits and services take effect.

Programs include:

- **Medicare**

Medicare provides medical 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, 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 6). These plans are approved by Medicare and run by private companies that will provide all of your Part A and Part B coverage. Medicare Advantage Plans may offer extra coverage, such as vision, hearing, dental and/or health and wellness programs. Most include Medicare prescription drug coverage (Part D). These companies must follow rules set by Medicare. However, each Medicare Advantage Plan 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 nonemergency or non-urgent care can be visited). These rules can change each year.
- Part D (prescription drug coverage) provides coverage to enrollees for both brand-name and generic prescription drugs. Patients must elect and enroll in a stand-alone prescription drug plan (PDP) or Medicare Advantage prescription drug (MA-PD) plan. Patients generally pay a monthly premium, which varies by plan, and a yearly deductible. Coinsurance or co-payments also apply. Assistance with drug benefit premiums, deductibles and co-payments is available to beneficiaries with low incomes and limited assets (for more information about the Low Income Subsidy [Extra Help] program, go to www.cms.gov/limitedincomeandresources). Currently, patients who reach their coverage gap “donut hole” after they and their plan have spent a certain amount of money for covered drugs, have to pay all costs out of pocket (up to a limit). The Affordable Care Act will, over time, gradually decrease the amount patients will need to pay for prescriptions, once they fall within the “donut hole,” from 100 percent to 25 percent by 2020. In 2011, patients who reach it will receive a 50 percent discount when buying Part D brand-name drugs. Over the next 10 years patients will receive additional savings on brand-name drugs as well as saving on generic drugs.

Call (800) MEDICARE ([800] 633-4227) or visit www.medicare.gov for more information on all aspects of Medicare coverage.

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 help with filing an appeal.

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.

• Medicaid

Medicaid provides medical benefits 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. The best way to apply, either online, in person or by mail, may vary from state to state (contact the state or local department of social services (or welfare office) for those requirements). You will need proof of income, medical diagnosis and your doctor's contact information. If applying in person, be sure to get the business card of the Medicaid employee who is handling your application. Visit www.cms.hhs.gov/home/medicaid.asp and under "Medicaid Eligibility" there is a listing of state Medicaid websites.

• State Children's Health Insurance Program (SCHIP)

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

• Hill-Burton Program

Under this program, hospitals and other nonprofit medical facilities that have received certain federal aid for construction purposes are required by law to offer free or low-cost medical services to patients who are unable to pay. Call (800) 638-0742 or visit www.hrsa.gov/hillburton for more information.

- **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.

- **Social Security Disability Income (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 or older. Call (800) 772-1213 or visit www.ssa.gov for information.

High-Risk Pool Coverage. People with cancer may also contact their state insurance department to find out if the state has a high-risk pool, a program that makes health coverage available to people who are considered medically uninsurable. High-risk pools generally have strict eligibility requirements and may be more expensive than other health plans. To find consumer health insurance guides by state on the web, go to www.coverageforall.org.

The Pre-Existing Condition Insurance Plan (PCIP) may provide additional help for patients who do not have adequate health insurance. See page 13 for more information.

Foundation for Health Coverage Education (FHCE)

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

FHCE educates callers about free or low-cost insurance in their state. FHCE has developed a customized matrix for every state detailing 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.

Additional Coverage

Consolidated Omnibus Budget Reconciliation Act (COBRA).

Cancer survivors who lose, leave or change jobs may be eligible to remain on their employer plan under COBRA. COBRA is a federal law that 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 the COBRA website for information about extending coverage after 18 months). Even though individuals must pay the entire premium (including the portion that the employer used to pay on their behalf), COBRA may be a better choice than an individual medical insurance plan. The COBRA plan may not be the least expensive option but it will provide continuation of coverage.

Cancer survivors who are not eligible for COBRA, or those who are job hunting, may want to consider seeking employment at a larger company that offers health insurance as an employment benefit. This is because obtaining individual health insurance coverage after being diagnosed with cancer may involve a waiting period before coverage begins. For more information about COBRA, including a list of qualifying events for employees, spouses and dependent children, see www.dol.gov/ebsa.

Pre-Existing Conditions. A patient may be denied coverage for a period of time if his or her cancer is considered a pre-existing condition. The law defines a pre-existing condition as an illness or condition that was present

before an individual's first day of coverage under a group health plan. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) provides several protections for patients who have pre-existing conditions. HIPAA limits exclusions from coverage and bans discrimination against employees and dependents based on their health status. A pre-existing condition exclusion relates only to benefits for your (and your family's) pre-existing conditions. You will receive coverage for the plan's other benefits during that time.

In most cases group health plans cannot exclude a condition from coverage for longer than 12 months. Here are some possible scenarios:

- If an individual was previously uninsured, but takes a job with an employer offering health coverage, the maximum exclusion period for medical coverage related to the pre-existing condition is 12 months.
- If a patient has "creditable" health insurance—coverage in a group health plan, COBRA continuation coverage, Medicare, Medicaid, a state health benefits risk pool, a public health plan or certain other health plans and programs—for 12 continuous months, with no lapse in coverage of 63 days or more, a new group or individual health plan cannot impose the pre-existing exclusion. This has helped to ease the issue of "job-lock," whereby people are reluctant to switch to a different job or company for fear of losing their health coverage. In this case there cannot be a waiting period or breaks in dependent coverage for a pre-existing health condition. Certificates that document prior health coverage periods are issued to individuals by insurance carriers when coverage is terminated.

For individuals who have had less than 12 months of credible coverage uninterrupted by a break in coverage of more than 63 days, HIPAA will reduce any pre-existing condition exclusion period by the length of time that an individual previously had coverage. For example, if an individual had five months of previous coverage with no break of 63 days and a new insurance plan had a 12-month pre-existing exclusion period, that individual would only have seven months left on his or her exclusion period.

The **Pre-Existing Condition Insurance Plans**, created through the Patient Protection and Affordable Care Act, makes health insurance available to people who have difficulty obtaining insurance due to a pre-existing condition. Eligibility requirements include being uninsured for at least the previous six months and having a problem getting insurance due to a pre-existing condition. The Act also prohibits denial of insurance coverage

for children under the age of 19 with pre-existing conditions. For more information and to find your state's plan information, visit www.pcip.gov or call (866) 717-5826.



Contact our LLS Information Specialists at (800) 955-4572 for more information, or access our Employment Disabilities and Discrimination section under “Other Helpful Organizations” on our website at www.LLS.org/resourcedirectory.

Denial of Insurance Coverage

Patients may be able to get a decision overturned by filing an appeal if their insurance company denies coverage for a recommended treatment.

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 record the date and time of each call to the insurance company, and 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 on the internet? If not, how can I get a copy of that information?
4. Whom 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, 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 a state or federal agency, social worker or an attorney. See page 24 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 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 maximum reimbursement from the insurance company.

Here are strategies to secure 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.
- Form a committee of volunteers to conduct fundraising events, sales, raffles, canister collections or letter-writing and publicity campaigns.
- Cash in on benefits from life insurance policies through “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. It is important to discuss this strategy with a financial advisor before pursuing either of these options.

LLS Financial Assistance. LLS has a number of resources for patients needing assistance with their prescription drug costs:

- The **LLS Co-Pay Assistance Program** helps eligible patients with certain blood cancer diagnoses to defray the cost of mounting insurance co-payments and insurance premiums. For more information call (877) 557-2672 or visit www.LLS.org/copay to submit an application.
- The **LLS Patient Financial Aid** program provides a limited amount of financial assistance to help patients with significant financial need who are under a doctor's care for a confirmed blood cancer diagnosis. Before applying for patient financial aid, find out if you are eligible for the Co-Pay Assistance Program, which may offer a larger amount of financial support (see above). To request a patient financial aid application, please contact your chapter. Find your chapter by calling (800) 955-4572 or by entering your ZIP code into 'Find Your Chapter' at www.LLS.org.
- LLS is part of the **Cancer Financial Assistance Coalition (C-FAC)** of organizations joining forces to address cancer patients' needs. C-FAC facilitates communication and collaboration among its members, educates patients and providers about resources and advocates for cancer patients regarding 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. Hear more about these issues by watching LLS's webcast "Financial Health Matters" at www.LLS.org/webcasts or listening to an archived teleconference about financial issues at www.LLS.org/programs.

Help with Prescription Drugs. Health insurance plans may not cover all of the costs of cancer care and there are a growing number of resources to help 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. Formularies typically include 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 14).

Those 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 patients with free or reduced-cost medications for the uninsured, helping patients who have insurance but have met/exceeded their annual limits or assisting with Medicare Part D. Contact **Rxassist** at www.rxassist.org for a current listing of patient prescription assistance programs.
- Prescription discount/savings programs, such as **Together Rx**, are available. Together Rx offers a free prescription savings card for individuals who are not eligible for Medicare, do not have prescription drug coverage and meet certain household income levels. Most cardholders save between 25 and 40 percent on more than 300 brand-name prescription products. For more information visit www.TogetherRxAccess.com. The National Association of Counties (www.naco.org) and various state programs also provide ways to cut drug costs.
- Some patients are participants in clinical trials for promising cancer drug therapies. To determine whether a study drug is available for free or at a reduced cost, check with the healthcare provider, insurance representative or study contact. What an insurer will cover varies significantly depending on the health plan and clinical trial. Patients may be able to gain access to investigational drugs through “Expanded Access” or “Special Exception/Compassionate Exemption” programs, which are sometimes offered by drug companies. Patients may be able to negotiate with their insurance company to get a particular drug added to the formulary.
- Some states have laws in place regarding insurance coverage for clinical trials. Each state has its own laws and special agreements that require insurance plans to cover a patient’s medical expenses during a clinical trial. See www.cancer.gov/clinicaltrials/education/laws. Effective January 1, 2014 through the Patient Protection and Affordable Care Act, insurers will be prohibited from dropping or limiting coverage because an individual chooses to participate in a clinical trial. This applies to all clinical trials that treat cancer or other life-threatening diseases.
- Co-pay assistance programs and foundations will help pay costs for prescription drug co-pay obligations or insurance plan premiums. Funds can be disease-specific. Contact our LLS Information Specialists for information about other co-pay assistance programs.



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

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.

NeedyMeds

www.needy meds.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.

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.



In addition to the organizations listed on page 19—which provide information, support, financial support services and patient advocacy for transplant candidates, recipients and their families—LLS has a resource directory with listings of organizations that may be able to help stem cell transplant patients. Visit www.LLS.org/resourcedirectory for more information.

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.

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.

Federal Employment Protections

These programs can assist eligible patients, families and caregivers with time off from work and reasonable accommodations at work if needed.

Family and Medical Leave Act (FMLA). The FMLA enables eligible employees in companies with 50 or more employees (who have worked at least 1,250 hours over the previous 12 months) to take unpaid, job-protected leave for specified family and medical reasons. The employee would continue getting 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 spouse, child or parent who has
 - A serious health condition
 - A serious health condition that makes the employee unable to perform the essential functions of his or her job
 - Any qualifying need arising out of the fact that the employee’s spouse, child, or parent is a covered military member on “covered active duty;” or
- Twenty-six workweeks of leave in a single 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 separate blocks 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 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 stress.

To access more information about this program, please visit the Department of Labor’s website at www.dol.gov/whd/fmla or call toll-free at (866) 487-2365.

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 in companies with 15 or more employees.

This law ensures equal opportunity for individuals with disabilities in employment, public accommodations, transportation, state and local government services and telecommunications.

The ADA defines a disability as:

- A physical or mental impairment that substantially limits one or more major life activities (i.e. working, 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 and its amendments or to read the full text of the ADA, please visit www.ada.gov or www.disability.gov or call toll-free (800) 514-0301. Individuals with disabilities may also be protected by their state anti-discrimination laws, some of which are more stringent than the federal laws. To learn more about rights under state laws, visit www.dol.gov/odep/state/state.htm.



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

Advocacy

Talk About Insurance and Financial Issues. Healthcare providers do not always ask patients about their insurance coverage or their ability to pay out of pocket for cancer care. Many patients are reluctant to share personal financial information with their healthcare providers. Some patients may not want to divert attention from their treatment. However, it is important to resolve financial issues that increase stress and limit access to needed treatments, prescription medications or support services.

Discuss payment options with members of your healthcare team or the treatment center's financial services department. When your doctor is prescribing your medication, talk to him or her about the cost and if it is affordable. Enroll in a prescription assistance program (see page 17) or ask to be referred to a public agency or social worker. Check the drug list from your insurance company to make sure it is covered. There may be a similar drug that is less expensive (generic) but would still work for you. Speak to the members of the healthcare team about reviewing your medication list to see

whether you are taking nonessential drugs. Patients and providers can work together to devise ways to reduce costs without compromising treatment.

Social workers and caseworkers can help patients better understand their insurance coverage, submit claims, refer patients to assistance programs to help meet the cost of remaining bills and offer guidance on submitting all the necessary paperwork for Medicare or Medicaid. The Homes & Communities section of the United States Department of Housing and Urban Development (HUD) website at www.hud.gov may have helpful information for patients and caregivers with concerns about housing expenses.

Find an Advocate. Patients need to stay on top of bills, deal with their insurance and manage other financial matters; these things take time and energy. Having an organized and reliable advocate from diagnosis to recovery is extremely valuable. This person can help manage the patient's 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/resourcecenter or contact our Information Specialists for a copy.

What Family and Friends Can Do. Patients can delegate time-sensitive tasks to reliable family members or friends who can be counted on to be thorough and meet deadlines. In addition to organizing fundraising efforts, friends and relatives may be especially helpful with

- Setting up a record-keeping system to track bills and submitted, pending and paid insurance claims
- Calling public and private agencies to determine eligibility for financial assistance, entitlement programs and other benefits and services
- Gathering documents to support insurance claims and appeals and following up with the insurance company.

Caring for Dependents. Patients diagnosed with cancer in many cases need to begin treatment right away. This change disrupts routine, leaving little time for organization. The following list may help to prioritize needs.

- Identify immediate concerns such as
 - Finding children rides to school and other activities
 - Finding transportation for the patient to get to 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.

It is important to remember to reevaluate each priority as circumstances change. Using programs such as CarePages on the LLS website allows friends and family to organize help. Other patients at the treatment center may suggest new ways of juggling the many responsibilities in their new roles.

- Put together a list of your support system such as friends, family, church members and volunteers in the community. LLS Discussion Boards, which you'll find at www.LLS.org/discussionboard, may provide you comfort and support; working with local agencies can help find ways to support the rest of the family
- Get organized by using a wall calendar; keeping a key list of relatives, friends and neighbors; keeping a medical notebook with all doctors' contact and other information and keeping all insurance/medical bills/disability information in one place and organized.

Remember that there is a “new normal.” Consider relaxing standards which may include allowing a messier house, fewer home-cooked meals or accepting less or different things from a spouse, children or parents. Make sure to keep your dependents informed of progress or when treatments or doctor's visits are planned. Keeping everyone “in the know” can decrease frustration and stress while leaving communication open throughout treatment and beyond.

What Professionals Can Do. The professionals who staff the national organizations that support people with cancer can provide expert advice on preserving assets, reducing debt, accessing community resources, handling employment issues, minimizing insurance problems and using legal remedies, if and when necessary. This type of guidance can be invaluable in helping patients learn how to advocate for themselves more effectively.



Our Information Specialists can guide you in finding additional organizations that can help. To reach our Information Specialists, call toll-free at (800) 955-4572.

Cancer Legal Resource Center (CLRC)

(866) 843-2572 • www.cancerlegalresourcecenter.org

The CLRC provides free information and resources on cancer-related legal issues to cancer survivors, caregivers, healthcare professionals, and others coping with cancer. The CLRC provides a national education and outreach program to help people navigate issues such as employment and taking time off work; job accommodations; health, disability and life insurance options; genetic discrimination; understanding healthcare reform; insurance navigation and appeals; estate planning; consumer rights; financial planning and the education rights of children and young adults with cancer.

The CLRC provides free educational seminars, teleconferences and webinars; Cancer Rights Conferences and online educational materials on national and state-specific topics.

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, as well as 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.

Additional Resources Related to the Patient Protection and Affordable Care Act of 2010.

Healthcare.gov

www.healthcare.gov

This government-maintained website includes information about the healthcare changes happening due to 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.

InsureUStoday.org

(866) 207-8023 • www.insureUStoday.org

Patient Advocate Foundation (PAF) and Patient Action Council have established this website in an effort to answer the most commonly asked questions about insurance benefit changes due to the Patient Protection and Affordable Care Act of 2010. Personalized services are offered over the phone as well as in a blog format, allowing visitors to post in real time their questions that are then answered by insurance specialists from PAF. The website will continually update information on the insurance reform features of the Act.

Pre-Existing Condition Insurance Plans (PCIP)

(866) 717-5826 • www.pcip.gov

The PCIP was created through the Patient Protection and Affordable Care Act and makes health insurance available to people who have difficulty obtaining insurance due to a pre-existing condition. Eligibility requirements include being uninsured for at least the last six months and having a problem getting insurance due to a pre-existing condition. The Affordable Care Act prohibits denial of insurance coverage for children under the age of 19 with pre-existing conditions.

Financial Checklist

Below is a checklist to help you think about the many financial concerns that arise once diagnosed with a blood cancer. Use this list to keep track of questions to ask your healthcare and financial teams. Keeping organized can help decrease many financial anxieties 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 know I need to speak to creditors early if I expect difficulty making payments.
- I have reviewed my disability/sick/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/stay organized.
- I know the names of my doctors/nurses/social worker and how to contact them.
- I keep all of 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.
- I don't have health insurance but will learn about possible resources available.
- I have gaps in my insurance coverage and will learn about possible resources available.
- I have a copy or know where to get a copy of my insurance plan.
- I know my insurance plan's oncology benefits, what treatments and charges are covered, partially covered and not covered.
- I know what insurance expenses I pay (copay, coinsurance, deductible) each month/year.
- 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 whom 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 denied for a treatment/procedure 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 can be prescribed as generic to save money.
- I will ask for an exception if a drug prescribed is not on the insurance formulary (list of covered medications).
- I have Medicare coverage and know when I am eligible to change my Part D prescription plan to meet my changing medication needs.

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www.LLS.org

Our Mission: Cure leukemia, lymphoma,

Hodgkin's disease and myeloma, and improve the

quality of life of patients and their families.

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