

Getting Started

- Chronic Myeloid Leukemia (CML) Educational/Support Websites
- Cancer Educational/Support Websites



Connecting with Others

- Peer Mentors
- Support Groups
- Online Communities



Financial and Legal Support Resources

- Financial Counseling
- Legal Counseling
- Employment Counseling



Resources During Treatment

- Clinical Trial Resources
- Optimizing Quality of Life and Palliative Care
- Transportation Resources
- Lodging Resources
- Pet Care



Living Well After a Chronic Myeloid Leukemia Diagnosis

- Develop Skills
- Health and Wellness
- Local Resources
- Advocate on Public Policy Issues
- Volunteer
- Global Access



Family and Friends

- Staying Connected
- Care Partner Resources



INTRODUCTION



Receiving a diagnosis of chronic myeloid leukemia (CML), also known as chronic myelogenous leukemia, can be frightening. Learning about CML and the resources available to you, however, can help you feel in control and supported through your CML journey. This **Chronic Myeloid Leukemia Resource Navigator for Patients** was developed together with leading patient advocates, who shared their experiences and insight, with the hope that it will help you connect with patient organizations and resources as you and your care partners navigate through your diagnosis and treatment. These organizations provide education and support for your health and well-being, as well as help with practical matters, logistics, and financial and legal concerns.



A good place to begin to learn about CML would be the **Getting Started** section, which includes both cancer and CML-specific **Educational/Support Websites**. These websites provide a variety of educational resources and support services, with several offering assistance in finding a CML specialist or treatment center in your area. This information may help you to better understand how to make decisions about your care and treatment.



Together with your healthcare team, you are encouraged to play an active role in all medical decisions needed regarding workups, treatment, monitoring, and follow-up. Monitoring your CML is important in order to see how you are responding to therapy and to address any undetected side effects promptly so that your treatment is not interrupted. Being able to quickly detect any changes in your clinical status is also becoming increasingly important because of the growing number of new treatments available.



A diagnosis of CML may be a substantial financial burden with or without health insurance, and it may affect your ability to do your job. You may also need to travel for treatment. You will find numerous resources listed in the **Resources During Treatment** and **Financial and Legal Support Resources** sections that may assist with the cost of medication, travel, and housing.



At the back of this resource guide you will find a **Care Team, Medical History, Treatment Summary, and Care Plan Section** that you may choose to use to track the details of your care. The amount of information that you receive during your journey may be overwhelming, so you may find that using a tracking tool like the one provided here may be helpful for your appointments with your care team, your primary care physician, and other specialists.



We hope you will find this **Chronic Myeloid Leukemia Resource Navigator for Patients** helpful now and throughout your CML journey.

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Checklist for Support Services

This is an alphabetical listing of multiple organizations mentioned in this Resource, with checkmarks indicating the areas in which the organization may provide services.

Organization	Getting Started	Connecting with Others	Resources During Treatment	Financial and Legal Support Resources	Living Well After a CML Diagnosis	Family and Friends
A Fresh Chapter					✓	
Accessia Health				✓		
Air Care Alliance			✓			
American Cancer Society (ACS)	✓	✓	✓			
Calm				✓		
Cancer and Careers (CAC)				✓		
Cancer Financial Assistance Coalition (CFAC)				✓		
Cancer Legal Resource Center (CLRC)				✓		
Cancer Support Community (CSC)	✓	✓	✓	✓		✓
Cancer.Net™	✓				✓	
CancerCare®	✓		✓	✓		
Caregiver Action Network (CAN)						✓
CaringBridge						✓
Center to Advance Palliative Care (CAPC)			✓			
ClinicalTrials.gov			✓			
CML Advocates Network	✓	✓				
Corporate Angel Network			✓			
Family Reach Financial Treatment Program				✓		
Findhelp.org					✓	
HealthWell Foundation				✓		
Help for Cancer Caregivers						✓
Imerman Angels		✓				
Inspire™		✓				
International Chronic Myeloid Leukemia Foundation (iCMLf)	✓					
Joe's House			✓			

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Checklist for Support Services



Organization	Getting Started	Connecting with Others	Resources During Treatment	Financial and Legal Support Resources	Living Well After a CML Diagnosis	Family and Friends
Lazarex Cancer Foundation			✓	✓		
Legal Services Corporation (LSC)				✓		
The Leukemia & Lymphoma Society (LLS)	✓	✓	✓	✓	✓	✓
Livestrong at the YMCA					✓	
Lotsa Helping Hands						✓
The Max Foundation					✓	
Mercy Medical Angels®			✓			
National Cancer Institute (NCI)	✓		✓			
National Center for Complementary and Integrative Health (NCCIH)					✓	
National Coalition for Cancer Survivorship (NCCS)					✓	
National Comprehensive Cancer Network® (NCCN®)	✓					
National Hospice and Palliative Care Organization (NHPCO)			✓			
National Patient Advocate Foundation (NPAF)					✓	
NeedyMeds				✓		
Patient Advocate Foundation (PAF)				✓		
Patient AirLift Services (PALS)			✓			
Pharmaceutical Research and Manufacturers of America (PhRMA)				✓		
RxAssist Patient Assistance Program Center				✓		
Smart Patients		✓				
Springboard Beyond Cancer					✓	
Triage Cancer				✓		
Uber Health			✓			

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Getting Started

»» Chronic Myeloid Leukemia (CML) Educational/Support Websites

Knowledge is power and can help you become an informed patient.

CML Advocates Network

 www.cmladvocates.net

The CML Advocates Network connects 126 patient organizations in 93 countries. Run by patients with CML and their care partners, the network aims to facilitate and support best practice sharing among CML patient advocates. The CML Advocates Network provides a number of patient-friendly educational materials, including the following:

- Educational videos available in several languages
- Patient stories presented as animated videos
- CML glossary
- Clinical trials database
- Treatment recommendation summaries


The website also provides a directory of CML patient and support groups.

International Chronic Myeloid Leukemia Foundation (iCMLf)

 <http://icmlf.org>

The International CML Foundation (iCMLf) is a nonprofit organization whose mission is to improve outcomes for patients with CML. The foundation aims to coordinate global and research collaborations, and to improve clinical practice and disease monitoring in patients with CML. The iCMLf website offers links to trusted partner organizations that provide educational and support resources for patients and their caregivers.

The Leukemia & Lymphoma Society (LLS)

 1-800-955-4572

 www.lls.org/support

The Leukemia & Lymphoma Society (LLS) provides information, resources, and support services for individuals affected by blood cancers, including leukemia, lymphoma, Hodgkin's disease, CML, and multiple myeloma. The LLS offers a variety of educational and support services, including the following:

- Information specialists
- An educational podcast: *The Bloodline with LLS*
- Live, weekly online moderated chats
- Clinical Trial Support Center (CTSC)
- Nutrition consultations



» Cancer Educational/ Support Websites

American Cancer Society (ACS)

📞 1-800-227-2345
👉 www.cancer.org

The American Cancer Society (ACS) offers patients with cancer and their care partners a variety of support programs, services, and resources. Specifically, the ACS offers the following educational and support services:

- *Cancer Information Specialists*
- Referrals to local and national resources
- Patient educational materials
- Community programs and services that provide free information, day-to-day help, and emotional support

CancerCare®

📞 1-800-813-HOPE (4673)
✉ info@cancercare.org
👉 www.cancercare.org

CancerCare® is a national organization that offers free professional support services to anyone affected by cancer. Services are provided by oncology social workers and cancer experts, and include the following:

- Case management
- Counseling
- Support groups
- *CancerCare Connect*® educational workshops, which are accessible via phone or online
- Booklets and fact sheets

Cancer.Net™

👉 www.cancer.net

Cancer.Net™ is the patient information website of the American Society of Clinical Oncology (ASCO)—the voice

of cancer physicians and oncology professionals. Cancer.Net provides trusted information for individuals with cancer, their families, and their care partners, covering such topics as the following:

- Treatments and side effects
- Navigating cancer care
- Coping with cancer
- Survivorship
- Research and advocacy

The *Cancer.Net* Blog and Podcasts provide practical tips, research news, guidelines, and more. Content is available in both English and Spanish.

Cancer Support Community (CSC)

📞 1-888-793-9355
👉 www.cancersupportcommunity.org

The Cancer Support Community (CSC) is a global, professionally led, nonprofit network of cancer support that is dedicated to ensuring that all individuals affected by cancer are empowered by knowledge, strengthened by action, and sustained by community. CSC navigation services empower patients, caregivers, and families to manage the social, emotional, practical, and financial barriers to care by providing them with timely access to quality individualized education and assistance, through all phases of their cancer experience. The organization, which was formed through the merger of Gilda's Club Worldwide and The Wellness Community, provides such educational and support services as the following:

- A *Cancer Support Helpline* that provides proactive navigation services for cancer patients and their loved ones, by phone, chat, and video
- Information about cancer and treatment options
- Radio shows
- Blogs
- Frankly Speaking About Cancer educational videos for patients, survivors, and caregivers
- MyLifeLine



Getting Started

National Cancer Institute (NCI)

📞 1-800-4-CANCER (1-800-422-6237)

✉️ NCInfo@nih.gov

👉 www.cancer.gov

The National Cancer Institute (NCI)—the federal government's main agency for cancer research and training—is a trusted source for cancer information. Information Specialists at NCI's *Cancer Information Service* (CIS) can provide accurate, up-to-date cancer-related information for patients and their care partners, and can answer questions about cancer, clinical trials, and quitting smoking. Patients can reach an Information Specialist by calling, e-mailing, or contacting *LiveHelp*—an online live chat feature. This service is available in both English and Spanish. The NCI website offers the following additional services:

- Information on all aspects of cancer and its treatment
- Downloadable patient education publications
- Information on specific types of cancer, including NCI's *Physician Data Query* (PDQ®) evidence-based treatment summaries
- Dictionaries of cancer terms, drugs, and genetic terminology

National Comprehensive Cancer Network® (NCCN®)

👉 www.nccn.org/patients

The National Comprehensive Cancer Network® (NCCN®) is a not-for-profit alliance of 30 leading cancer centers that are dedicated to patient care, research, and education. Based on the expertise of clinical professionals at member institutions, the NCCN develops resources to facilitate high-quality cancer care. Patient and care partner resources that are available include the following:

- *NCCN Guidelines for Patients*®, which help patients talk to their physician about the best treatment options for their disease
 - Available in multiple languages
 - Available on the website and through the *NCCN Patient Guides for Cancer* app
- *NCCN Quick Guides*™, which summarize key points from the *NCCN Guidelines for Patients*®
- Expert information on various areas of cancer care
- Live and recorded *Know What Your Doctors Know* webinars




Connecting with Others

» Peer Mentors

Peer mentors support patients and care partners through their shared experiences.


Imerman Angels

 1-866-IMERMAN (463-7626)

 <https://imermanangels.org>

Imerman Angels strives to provide comfort and understanding for patients with cancer, survivors, previvors, and care partners by offering a personalized, one-on-one connection with someone who has been there. Individuals using the free service are matched with a Mentor Angel who has been in a similar life experience and understands because they have been there.

The Leukemia & Lymphoma Society (LLS): First Connection Program

 1-800-955-4572

 www.lls.org/support/peer-to-peer-support

The Leukemia & Lymphoma Society (LLS) provides information, resources, and support services for individuals affected by blood cancers, including leukemia, lymphoma, Hodgkin's disease, CML, and multiple myeloma. The *Patti Robinson Kaufmann First Connection Program* is a free service that matches patients and their loved ones with trained peer volunteers who have shared similar experiences.

» Support Groups

Support groups serve as a source of information, education, support, and networking for patients and their care partners. They create a community in which patients can share their own experiences and be empowered to be their own best advocate.

CML Advocates Network

 www.cmladvocates.net/cml-groups-list

The CML Advocates Network connects 126 patient organizations in 93 countries. Run by patients with CML and their care partners, the group seeks to facilitate and support best practice sharing among CML patient advocates. The CML Advocates Network provides a directory of CML patient and caregiver support groups.

The Leukemia & Lymphoma Society (LLS): Family Support Groups

 1-800-955-4572

 www.lls.org/support/support-groups

www.lls.org/support-resources/online-chats

The Leukemia & Lymphoma Society (LLS) provides information, resources, and support services for individuals affected by blood cancers, including leukemia, lymphoma, Hodgkin's disease, CML, and multiple myeloma. The *LLS Family Support Groups* program provides patients and their families with a place to go where they can share information, education, and their feelings in a comfortable, caring environment, with each group facilitated by 2 credentialed healthcare/mental health professionals. Individuals can search for a local support group on the LLS website.



» Online Communities

Private online communities allow patients and their families to connect with others, in order to learn, share information, and provide support in a secure environment.

American Cancer Society (ACS): Cancer Survivors Network (CSN)

<https://csn.cancer.org>

The American Cancer Society (ACS) provides patients with cancer and their care partners with a variety of support programs, services, and resources. The ACS Cancer Survivors Network (CSN)—an online community for individuals whose lives have been touched by cancer—offers discussion boards, announcements, a member resource library, and a chatroom.

Inspire™

www.inspire.com/groups/chronic-myelogenous-leukemia-cml

Inspire™ is a social network for health that connects patients and care partners in a safe, moderated, permission-based manner. The Chronic Myelogenous Leukemia (CML) Support Community connects patients and caregivers affected by CML for support and inspiration.

The Leukemia & Lymphoma Society (LLS): Community

☎ 1-800-955-4572

www.lls.org/article/welcome-lls-community

The Leukemia & Lymphoma Society (LLS) provides information, resources, and support services for individuals affected by blood cancers, including leukemia, lymphoma, Hodgkin's disease, CML, and multiple myeloma. The LLS offers the *LLS Community*—an online community of patients with blood cancer, survivors, and caregivers in which individuals can receive support, stay informed, and let their voices be heard.

Smart Patients

www.smartpatients.com

Smart Patients is an online community for patients with a variety of diseases, including CML, as well as their family members and friends. Through conversations, patients and their families can learn from other patients and care partners about CML, current treatments or therapies being investigated, and the latest scientific developments. On this for-profit site, patients can share their questions and concerns with other members, search for relevant clinical trials, and discuss their findings with the online community.

Resources During Treatment




» Clinical Trial Resources

ClinicalTrials.gov

 <https://clinicaltrials.gov>

ClinicalTrials.gov is a web-based resource that provides information on publicly and privately supported clinical studies. The website, which is maintained by the National Library of Medicine (NLM) at the National Institutes of Health (NIH), is updated regularly by the sponsor or principal investigator of the clinical trial. Patients and their care partners can search for CML clinical studies by topic and location, and view information on the intervention being studied, requirements for trial participation, contact information, and more. The website also provides information on how clinical trials are conducted.

Lazarex Cancer Foundation

 1-877-866-9523

 info@lazarex.org


 <https://lazarex.org>

The Lazarex Cancer Foundation is a nonprofit that focuses on improving the outcomes of cancer care, offering hope, dignity, and life to patients with advanced-stage cancer and the medically underserved. The Lazarex CARE (Creating Access, Reimbursing Expenses) program assists patients with identifying FDA clinical trial options and provides financial assistance, for the patient and a care partner, for travel expenses associated with clinical trial participation.

LLS Clinical Trial Support Center (CTSC)

 1-800-955-4572

 ctsc@lls.org

 www.lls.org/support-resources/clinical-trial-support-center-ctsc

Finding a clinical trial can be overwhelming. Patients are often left to search on their own, leaving them with more questions than answers. Fortunately, The Leukemia & Lymphoma Society provides a free service to take this burden off patients and families. Work one-on-one with an LLS Clinical Trial Nurse Navigator who will help you find clinical trials and personally assist you throughout the entire clinical trial process.

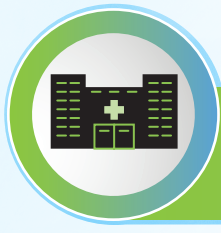
National Cancer Institute (NCI)

 1-800-4-CANCER (1-800-422-6237)

 NCInfo@nih.gov

 www.cancer.gov

The National Cancer Institute (NCI), which is the federal government's main agency for cancer research and training, is a trusted source of cancer information. Patients and their care partners can search for NCI-supported clinical trials, learn about clinical research, and determine how to find the right clinical trial for them. Information Specialists at NCI's *Cancer Information Service (CIS)* can also provide a tailored clinical trials search that patients can discuss with their physicians. Patients can reach an Information Specialist by calling, e-mailing, or using *LiveHelp*—an online live chat feature. This service is available in both English and Spanish.



Resources During Treatment


Optimizing Quality of Life and Palliative Care

Center to Advance Palliative Care (CAPC): GetPalliativeCare.org

 <https://getpalliativecare.org>

The Center to Advance Palliative Care (CAPC) is a national nonprofit organization dedicated to increasing the availability of quality healthcare for individuals who are facing serious illness. CAPC's *GetPalliativeCare.org* website provides educational information on palliative care, including videos, podcasts, and webinars. It also provides a *Palliative Care Provider Directory*, which can be used to locate palliative care in a patient's area.

National Hospice and Palliative Care Organization (NHPCO): CaringInfo Program

 1-703-837-1500


 www.caringinfo.org


The National Hospice and Palliative Care Organization (NHPCO) is a leading group that represents hospice and palliative care providers. NHPCO's *CaringInfo* program provides information on hospice and palliative care for adults and children, along with free resources, to help individuals make decisions about end-of-life care and services. Information is available in English, Spanish, and Mandarin Chinese.

Transportation Resources

Rides

American Cancer Society (ACS): Road To Recovery Program

 1-800-227-2345

 www.cancer.org/treatment/support-programs-and-services/road-to-recovery.html

The *Road To Recovery Program* of the American Cancer Society (ACS) provides transportation to and from cancer-related medical appointments for individuals with cancer who do not have a ride or are unable to drive themselves. Rides are coordinated with an ACS volunteer driver.

Hospice and Palliative Care Are Different

Both hospice and palliative care are intended to provide comfort and pain relief, but in different ways. *Palliative care* aims to ease pain and improve the quality of life of patients with a serious or life-threatening disease. Also called supportive care, palliative care helps patients manage their symptoms and the side effects of their treatment, thus dealing with the overall impact of their disease. In contrast, *hospice* is for individuals who are near the end of their life, with the goal being to control their symptoms, provide comfort, and prepare. Hospice offers physical, emotional, and spiritual support for patients and their families.

Resources During Treatment



The Leukemia & Lymphoma Society (LLS): Susan Lang Pay-It-Forward Patient Travel Assistance Program

☎ 1-877-557-2672

✉ FinancialAssistance@LLS.org

👉 www.lls.org/support/financial-support/patient-travel-assistance-program

The *Susan Lang Pay-It-Forward Patient Travel Assistance Program* of the Leukemia & Lymphoma Society (LLS) is available to patients with blood cancer who have significant financial need. Patients may qualify to receive \$500 in financial assistance for approved expenses, which include ground transportation, tolls, gas, parking, car rental, services, repairs and parts, air transportation, baggage fees, lodging, and ambulance services. Information on the program is available in both English and Spanish. Both national and state funds are listed. National funds include those for blood cancers in general, as well as those specifically for pediatric patients.

Uber Health

👉 www.uberhealth.com

Uber Health provides nonemergency medical transportation services to patients in need. Rides—either on demand or for a future appointment—are free to the patient and are booked directly by healthcare providers who contract for the service. All patients are contacted by text or a phone call with the trip details, both when the ride is booked and again when the driver is on the way to pick them up. Patients will be able to view the driver's information, so they know who will be picking them up.

Flights

Air Care Alliance (ACA)

👉 www.aircarealliance.org

The Air Care Alliance (ACA) is a nonprofit that supports the work of volunteer-based charitable organizations that arrange free air transportation for patients who require care at distant medical facilities. ACA helps

patients find the right charitable aviation organization to meet their needs and connects them directly to service. Free flights are provided by qualified charitable aviation organizations through volunteer pilots flying private aircraft, or through commercial airline partners.

Corporate Angel Network (CAN)

☎ 1-914-328-1313

👉 www.corpangelnetwork.org

Bringing Cancer Patients Closer to Their Cure

Corporate Angel Network (CAN) is a 501(c)(3) organization that helps cancer patients access the best treatment by arranging free travel on corporate aircraft to specialized medical centers. Participation is open to all cancer patients, as well as bone marrow and stem cell donors and recipients. Learn more about CAN: corpangelnetwork.org.

Mercy Medical Angels®

👉 www.mercymedical.org

Mercy Medical Angels® provides free transportation for patients in financial need and their care partners, so they can reach medical care. This nonprofit provides assistance for ground transportation with gas cards, or with bus or train tickets, or arranges air transportation on commercial airlines or flights flown by volunteer pilots.

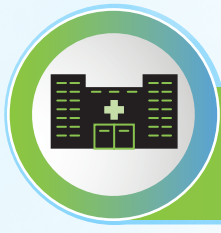
Patient AirLift Services (PALS)

☎ 1-888-818-1231

✉ info@palservices.org

👉 <https://palservices.org>

Patient AirLift Services (PALS) is a nonprofit that arranges free air transportation for individuals who require medical diagnosis, treatment, or follow-up and cannot afford the cost of a flight or are unable to fly commercially. It also arranges volunteer flights for family members, to ensure that patients have support when they are away from home for long periods of time. Services are provided by a network of volunteer pilots.



Resources During Treatment

»» Lodging Resources

American Cancer Society (ACS): Hope Lodge

☎ 1-800-227-2345

👉 www.cancer.org/treatment/support-programs-and-services/patient-lodging/hope-lodge.html

The Hope Lodge program of the American Cancer Society (ACS) provides a free home away from home for patients with cancer and their care partners when they must travel out of town for treatment. Each Hope Lodge provides a nurturing, home-like environment where guests can retreat to private rooms or connect with others. There are more than 30 Hope Lodge facilities located throughout the United States and Puerto Rico. Patients must be receiving active cancer treatment and permanently reside more than 40 miles away from the treatment center.

Joe's House

☎ 1-877-563-7468

✉ info@joeshouse.org

👉 www.joeshouse.org

Joe's House is a nonprofit organization that helps patients with cancer and their families find a place to stay when traveling for medical treatment. Patients and families can search for cancer treatment centers and hospitals across the country. A list of nearby lodging facilities that offer a discount will be provided.

»» Pet Care

CancerCare®: Pet Assistance & Wellness (PAW) Program

☎ 1-800-813-HOPE (4673)

👉 www.cancer.org/paw

CancerCare® is a national organization that provides free, professional support services to anyone affected by cancer. The CancerCare® Pet Assistance & Wellness (PAW) program addresses the distinct needs of patients with cancer who are undergoing treatment and share their home with a cat or a dog. The program provides limited financial assistance to qualified individuals, in order to help offset some of the expenses associated with their pet, including the following:

- Food
- Caregiving services
- Boarding
- Veterinary fees

The PAW program also provides educational materials and webcasts specific to pet care during cancer treatment, as well as free counseling services.



Financial and Legal Support Resources

Takeda is not directing patients or caregivers to any of these organizations. They are listed as potential resources only.

» Financial Counseling

Accessia Health, formerly Patient Services, Inc.

📞 1-800-366-7741

👉 www.accessiahealth.org

Accessia Health, formerly Patient Services, Inc. (PSI), is a nonprofit patient assistance organization that provides financial support and guidance for qualified patients with chronic, rare conditions. Accessia Health offers assistance with insurance premiums, copayments, medical expenses, and travel costs. Accessia Health provides assistance to patients with CML who have public/federal insurance such as Medicare, Medicaid, and Tricare.

Cancer Financial Assistance Coalition (CFAC)

👉 www.cancerfac.org

Cancer Financial Assistance Coalition (CFAC) is a group of 14 financial assistance organizations that have joined forces to help patients with cancer experience improved health and well-being by limiting their financial challenges.

CancerCare®: Co-Payment Assistance Foundation

📞 866-55-COPAY (866-552-6729)

✉ information@cancerarecopay.org

👉 www.cancerare.org/copayfoundation

CancerCare® is a national organization that provides free, professional support services to anyone affected by cancer. Information is available in both English and Spanish.

Family Reach Financial Treatment Program (FTP)

👉 <https://familyreach.org/ftp>

Family Reach is a national nonprofit organization dedicated to removing the financial barriers that often accompany a cancer diagnosis. Their Financial Treatment Program (FTP) offers support services to individuals with a cancer diagnosis who are receiving active treatment or have completed treatment within 1 year.

Financial and Legal Support Resources



Takeda is not directing patients or caregivers to any of these organizations. They are listed as potential resources only.

HealthWell Foundation

📞 1-800-675-8416

👉 www.healthwellfoundation.org

The HealthWell Foundation is a nonprofit that provides financial assistance to adults and children to help with the following:

- Prescription copays
- Health insurance premiums, deductibles, and coinsurance
- Travel costs
- Select out-of-pocket healthcare expenses

When funds are available, the foundation provides assistance to patients with CML who are on Medicare.

Lazarex Cancer Foundation

📞 1-877-866-9523

✉ info@lazarex.org

👉 <https://lazarex.org>

The Lazarex Cancer Foundation is a nonprofit that focuses on improving the outcomes of cancer care. The foundation offers assistance with costs associated with FDA clinical trial participation, including transportation, lodging, and medical expenses not covered by insurance.

The Leukemia & Lymphoma Society (LLS): Patient Financial Assistance Programs

📞 1-800-955-4572

👉 www.lls.org/support/financial-support

The Leukemia & Lymphoma Society (LLS) provides information, resources, and support services to individuals affected by blood cancers, including leukemia, lymphoma, Hodgkin's disease, CML, and multiple myeloma.

NeedyMeds

📞 1-800-503-6897

👉 www.needy meds.org

NeedyMeds is a national nonprofit that connects individuals to programs that can help them afford their medications and other healthcare costs. NeedyMeds provides a number of resources, including the following:

- A drug pricing calculator and a *NeedyMeds Drug Discount Card*
- Patient information and education on the use of medications through its *BeMedWise Program*
- Information on free, low-cost, sliding scale clinics
- Assistance with medical transportation costs
- Help filling out program applications

Information is available in both English and Spanish.



Financial and Legal Support Resources

Takeda is not directing patients or caregivers to any of these organizations. They are listed as potential resources only.

Patient Advocate Foundation (PAF): Case Management Services & MedCareLines

☎ 1-800-532-5274

👉 www.patientadvocate.org/connect-with-services/case-management-services-and-medcarelines

The case management services provided by the Patient Advocate Foundation (PAF) offer one-on-one assistance with a professional case manager to help qualified patients, their families, and their care partners find resources for financial aid, understand coverage options, get prescribed medical treatment and services, and resolve access to care and social needs navigation. To qualify, a patient must be in, just starting, or ending treatment for a serious health condition.

Patient Advocate Foundation (PAF): Co-Pay Relief Program

☎ 1-866-512-3861

👉 www.patientadvocate.org

The Patient Advocate Foundation (PAF) *Co-Pay Relief* program provides direct financial assistance to qualified patients for copayments, coinsurance, or deductibles associated with prescription drugs.

Pharmaceutical Research and Manufacturers of America (PhRMA): Medicine Assistance Tool (MAT)

👉 <https://medicineassistancetool.org>

Pharmaceutical Research and Manufacturers of America (PhRMA) represents the country's leading innovative biopharmaceutical researchers and biotechnology companies. PhRMA's Medicine Assistance Tool (MAT) is a search engine designed to help patients, care partners, and healthcare providers learn more about the patient assistance resources that are available through the various biopharmaceutical industry programs. Resources, including medication cost and health insurance information, are available in both English and Spanish. MAT is not its own patient assistance program; rather, it is a search engine for many of the patient assistance resources that are offered by the biopharmaceutical industry.

RxAssist Patient Assistance Program Center

✉ info@rxassist.org

👉 www.rxassist.org

RxAssist is a web-based, comprehensive directory of patient assistance programs run by pharmaceutical companies to provide free medications to individuals who cannot afford to purchase them. RxAssist also offers the following:

- The *RxAssist Prescription Savings Card*
- Medication access resources for patients
- A list of programs that offer free or low-cost medications and other healthcare services

Financial and Legal Support Resources



Takeda is not directing patients or caregivers to any of these organizations. They are listed as potential resources only.

Legal Counseling

Cancer Legal Resource Center (CLRC)

☎ 1-866-THE-CLRC (843-2572)

✉ CLRC@drlcenter.org

👉 <https://thedrlc.org/cancer>

The Cancer Legal Resource Center (CLRC) is a program of the Disability Rights Legal Center (DRLC)—a nonprofit advocacy organization that supports the rights of individuals with disabilities, including those affected by cancer. The CLRC provides the following:

- Phone and online assistance
- Outreach programs and community activities
- In-person and online trainings
- A resource library, which includes its *Patient Legal Handbook*
- Attorney referrals as applicable, for those receiving resources through the Telephone Assistance line

Legal Services Corporation (LSC)

☎ 1-202-295-1500

👉 www.lsc.gov

Legal Services Corporation (LSC) is an independent nonprofit established by Congress that provides civil legal aid for low-income Americans. These programs offer assistance for individuals, families, seniors, the disabled, veterans and military families, and individuals living in rural areas who have legal matters regarding the following:

- Health
- Family law
- Housing
- Natural disasters

Triage Cancer

☎ 1-424-258-4628

✉ info@triagecancer.org

👉 <https://triagecancer.org/gethelp>

Triage Cancer is a national nonprofit that provides free educational materials on practical and legal issues that may impact individuals with cancer and their care partners, such as health insurance, financial toxicity, disability insurance rights, employment, and estate planning.

Employment Counseling

Cancer and Careers (CAC)

☎ 1-646-929-8032

✉ cancerandcareers@cew.org

👉 www.cancerandcareers.org

Cancer and Careers, founded in 2001, is a national nonprofit that empowers and educates people with cancer to thrive in their work environment by providing expert advice, interactive tools, and educational events. All programs and services provided to patients, survivors, healthcare professionals, and caregivers are offered free of charge. Resources are available in both English and Spanish.



»» Develop Skills

National Coalition for Cancer Survivorship (NCCS): Cancer Survival Toolbox®

👉 <https://canceradvocacy.org/resources/cancer-survival-toolbox>

The *Cancer Survival Toolbox*® is a free audio program created by leading cancer organizations to help patients with cancer develop skills to better meet and understand the challenges of their disease. Produced through a collaboration among the National Coalition for Cancer Survivorship (NCCS), the Oncology Nursing Society (ONS), the Association of Oncology Social Workers (AOSW), and the National Association of Social Workers (NASW), the program contains a set of basic skills and special topics. Each scenario in the program has been inspired by a true story from a real patient with cancer. Patients can listen to the individual audio programs, which are available in both English and Spanish, directly on the website or as free podcasts on iTunes. The full *Cancer Survival Toolbox*® can also be downloaded for free.

Springboard Beyond Cancer

👉 www.hhs.gov/blog/2017/02/02/survivors-springboard-beyond-cancer.html

Springboard Beyond Cancer is a free, mobile-friendly web tool developed by the National Cancer Institute and the American Cancer Society that helps empower cancer survivors and those undergoing treatment to play an active role in the management of their health. This includes dealing with their illness and treatment, their relationships, emotional and psychological stressors, and healthy lifestyle behaviors. The mobile-friendly tool provides information on the following:

- Symptoms
- Emotions
- Self-care during and after treatment
- Receiving support from family and friends

Patients can also create their own *Action Deck*, which comprises a collection of information related to a cancer topic or treatment, to help them manage their health and well-being during their cancer journey. In addition, patients can also create their own *Vision Board*, in order to remain focused on staying positive and hopeful.



Living Well After a CML Diagnosis

» Health and Wellness

Calm

www.calm.com

Calm offers a variety of tools and resources for meditation, sleep, and relaxation through its website and downloadable app. Free offerings include guided meditations, sleep stories, gratitude practices, music soundscapes, and resources for children. It also offers journals, calendars, and workbooks designed to invite more awareness and peace into your life. Individuals can sign up for a free trial of Calm Premium, a paid subscription that unlocks Calm's entire content library. Content is available in several languages.

Cancer.Net™: Counseling

www.cancer.net/coping-with-cancer/finding-social-support-and-information/counseling

Cancer.Net™ is the patient information website of the American Society of Clinical Oncology (ASCO)—the voice of cancer physicians and oncology professionals. Cancer.Net provides trusted information for individuals with cancer, their families, and their care partners, including how they can find social support and information. This page provides a wealth of information about counseling, including when and how it can help individuals cope with the challenges that come with a cancer diagnosis, the different types of counseling and kinds of counselors available, and how to find and choose a counselor. It also provides a list of organizations that can help individuals find a counselor.

Livestrong at the YMCA

www.livestrong.org/what-we-do/program/livestrong-at-the-ymca

The Livestrong Foundation is a nonprofit that has served individuals affected by cancer, identifying those areas in which patients and survivors are not being supported, then investing in advocacy, programs, and services that address their unmet needs. Livestrong has partnered with the YMCA to create *Livestrong at the YMCA*—a 12-week physical activity program designed to get survivors back on their feet. Survivors can search for a participating facility near their home and partake in free or low-cost customized exercise regimens from certified fitness instructors who have been trained in cancer survivorship, postrehabilitation exercise, and supportive cancer care.



National Center for Complementary and Integrative Health (NCCIH)

 www.nccih.nih.gov

The National Center for Complementary and Integrative Health (NCCIH) is the government's lead agency for research on non-mainstream health approaches. These include mind and body practices such as acupuncture, massage, and meditation; nutritional approaches, such as diets and supplements; and integrative health, which is the use of complementary approaches together with conventional medicine in a coordinated way. Part of the National Institutes of Health, the NCCIH's mission is to conduct and support research and provide information about the usefulness and safety of complementary health products and practices. The NCCIH website provides a wealth of health information, including the following:

- *Health Topics A-Z*, which provides detailed information on complementary approaches and their use in specific conditions
 - *Know the Science*, a series of interactive modules, quizzes, and videos to help you better understand topics related to health research
 - How to be an informed consumer
 - Safe use of complementary health products and practices
 - How to find a complementary health practitioner
- Some information resources are available in Spanish.

Volunteer

A Fresh Chapter

 info@afreshchapter.com

 <https://afreshchapter.com>

A Fresh Chapter (AFC) is a nonprofit that believes that we are not defined by the most difficult parts of our story. We empower people impacted by cancer with the tools, support, and community to reclaim and redefine their lives—whether living with or beyond cancer.

Global Access

The Max Foundation

 www.themaxfoundation.org

The Max Foundation is a nonprofit global health organization that works to accelerate health equity by delivering medication, technology, and services to patients facing cancer and other critical illnesses, focusing on those no one else is helping. By partnering with a diverse ecosystem of partners, donors, and stakeholders including major cancer institutions and patient associations in low-income and middle-income countries, the foundation enables effective solutions for access to treatment. Individuals can assist by making a recurring donation, creating a fundraiser, or joining The Max Foundation as a volunteer.



Living Well After a CML Diagnosis

» Local Resources

Findhelp.org – The Social Care Network

 www.findhelp.org

Formerly known as Aunt Bertha, findhelp.org is a free, public access resource site that allows anyone to search anonymously for free and reduced-cost services in their local communities. Visit the site to easily search and connect to social care programs near you.

Some common searches include:

Food assistance;

Help paying bills;

Housing;

Programs for the COVID-19 pandemic; and more!

» Advocate on Public Policy Issues

The Leukemia & Lymphoma Society (LLS): Office of Public Policy

 www.lls.org/policy-advocacy

The Leukemia & Lymphoma Society (LLS) provides information, resources, and support services for individuals affected by blood cancers, including leukemia, lymphoma, Hodgkin's disease, CML, and multiple myeloma. The LLS Office of Public Policy advocates on behalf of patients with blood cancer and their families, to enact policies that break down barriers to care and accelerate the development of new treatments for these diseases. Ways in which patients can participate include the following:

- Sign up to be an advocate to engage with elected officials
- Join the *LLS Mobile Action Network* to receive text updates and tips
- Share their story to convince lawmakers to support a bill

National Patient Advocate Foundation (NPAF)

 www.npaf.org

The National Patient Advocate Foundation (NPAF) is the advocacy affiliate of the Patient Advocate Foundation (PAF). The NPAF represents the patient voice, working at the local, regional, and national levels to promote access to affordable, quality healthcare for individuals with chronic, debilitating, or life-threatening illnesses. The NPAF holds Policy Consortiums and an annual Patient Congress, and offers such resources as the following:

- *Advocacy Toolkit*
- *Advocates in Action* podcast
- *Patient Voices* blog
- *Skilled Communications in Shared Decision Making Toolkit*

Notes to Myself




A series of horizontal dashed lines for writing notes.



Family and Friends

» Staying Connected

CaringBridge

 www.caringbridge.org

CaringBridge is a nonprofit whose mission is to “build bridges of care and communication providing love and support on a health journey.” CaringBridge allows individuals to create a free personal website where they can share news and health updates with everyone at the same time, communicating in a private, ad-free, and secure place. Patients can also do the following:

- Let family and friends know how they can help
- Post photos
- Link to a personal fundraiser or a calendar

Lotsa Helping Hands


 <https://lotsahelpinghands.com>


Lotsa Helping Hands allows participants to create a central place to coordinate meals and help for family and friends in need. Using the free website or app, individuals can create a community with such features as the following:

- *Care Calendar*
- *Well Wishes* to offer support
- Announcements
- Photo gallery

» Care Partner Resources

Caregiver Action Network (CAN)

 1-855-227-3640


 <https://caregiveraction.org>

Caregiver Action Network (CAN) is a nonprofit organization working to improve the quality of life for family caregivers by providing education, peer support, and resources—all free of charge. On CAN’s website, family caregivers can find:

- Instructional videos on a variety of topics and conditions
- Family Caregiver Toolbox
- 10 Tips for Family Caregivers
- Information focusing on specific diseases or conditions
- Care Community—an online forum where family caregivers can find support from each other
- Caregiver Help Desk—available via phone, e-mail, or live chat



Help for Cancer Caregivers

 www.helpforcancercaregivers.org

The Help for Cancer Caregivers website provides information, education, and support for cancer care partners. It is not meant to be medical advice. By answering 6 short questions based on how things have been for them over the past 7 days, care partners will receive a Personal Caregiver Guide that is intended to help them improve their well-being. In addition, the website offers a library of resources to help care partners cope with specific challenges. The website is a collaboration among Anthem, Inc., CancerCare®, Caregiver Action Network, Indiana University, and Michigan State University.

The Leukemia & Lymphoma Society (LLS): Caregiver Support

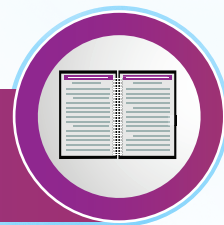
 1-800-955-4572

 www.lls.org/support/caregiver-support

The Leukemia & Lymphoma Society (LLS) provides information, resources, and support services for individuals affected by blood cancers, including leukemia, lymphoma, Hodgkin's disease, CML, and multiple myeloma. The LLS offers a variety of educational and support resources for care partners, including the following:

- *Caregiver Workbook*
- *LLS Community*—an online support community
- Webcasts
- Podcasts
- Online chats
- Educational videos

Care Team, Medical History, Treatment Summary, and Care Plan Section



» Medical History

Name _____ Date of birth _____

Diagnosis

Chronic phase CML _____ Date of diagnosis _____

Risk score _____

Accelerated CML phase _____ Date of diagnosis _____

Blast phase CML _____ Date of diagnosis _____

Cytogenetic/Molecular test results

Date _____ Result _____

Date _____ Result _____

Medical History

Other medical conditions

Past surgeries (Date, Surgery)

Smoking history

Relevant family history



Care Team, Medical History, Treatment Summary, and Care Plan Section

>> Treatment Summary

Name _____ Date of birth _____

Current Treatment

Date started _____ Agent(s) _____

Treatment History

Date _____ Agent(s) used _____

Date _____ Agent(s) used _____

Date _____ Agent(s) used _____

Date _____ Agent(s) used _____

Date _____ Agent(s) used _____

Autologous stem cell transplant (if applicable)

Date _____ Where performed _____

Persistent symptoms or side effects of treatment (if applicable)

Care Team, Medical History, Treatment Summary, and Care Plan Section



>> Care Plan

Name _____ Date of birth _____

Follow-up Care

Your follow-up care with your cancer team will vary according to your current disease state. You may wish to discuss the following topics with your team:

1. How often will I have follow-up visits?
2. Is there any other provider who I have seen during my cancer treatment that I should continue to follow up with regularly?
3. Are there any late or long-term side effects that may occur as a result of my treatment that may affect my follow-up care?
4. If not already done so, is it appropriate for me to return to my primary care physician (PCP) at this time for all my other routine healthcare and screenings?

Follow-up Tests

Often patients treated for CML will have various laboratory tests throughout their disease process and during follow-up care. You may find it helpful to ask your oncology team the following questions at your next clinic visit:

1. How often will I have laboratory tests done?
2. How often will I have my CML-specific labs done?
3. How often will I have bone marrow biopsies?
4. If appropriate, how often will I have imaging tests such as chest x-ray, CT scan, MRI, or ultrasound?

The following may be signs that you should contact your healthcare team:

- A new symptom
- A change in a persistent/chronic symptom that is affecting your daily activities
- Any concerns about how you feel physically or emotionally

You may also wish to ask your healthcare team:

- What symptoms may be signs of potential progression/recurrence of my disease?



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