

UPDATED

Resource Guide of Helpful Organizations

*For the Bone Marrow and
Stem Cell Transplant Community*



RESOURCES AND REASSURANCE WHEN YOU NEED IT MOST FROM DIAGNOSIS THROUGH SURVIVAL

Established in 1992, the nbmtLINK is a non-profit 501(c)3 independent, patient advocacy organization, funded entirely through the generosity of individuals, corporations, and foundations.

The National Bone Marrow Transplant Link strives to help patients, caregivers and families cope with the psychosocial challenges of bone marrow/stem cell transplant from diagnosis through survivorship. We distribute resource books nationally through our partnering cancer transplant centers, and many resources are available on-line. Additionally, we provide specialized and personalized support service.

Your tax-deductible contributions are welcome and will enable the nbmtLINK to create and sustain programs, services and publications such as:

- Peer Support for Patients and Caregivers
- On-line Resource Guide
- Helpful Newsletters
- Coffee Klatches
- Webinars
- Podcasts and Blogs
- Lunch & Learn Monthly Free Call-In Program
- Chronic Graft Versus Host Disease (cGVHD) Support Programs
- Celebrating Second Birthday Recognition

OTHER nbmtLINK BOOKS & MEDIA FOR SALE

Guide to Bone Marrow and Stem Cell Transplant: What to Expect and How To Move Forward

(available in both English and Spanish)

Graft Versus Host Disease: Living with the After Effects of Bone Marrow/Stem Cell Transplant

Bone Marrow/Stem Cell Transplant: Frequently Asked Questions
(Spanish/English)

Survivorship Guide for Bone Marrow/Stem Cell Transplant, Coping with Late Effects

Caregivers' Guide for Bone Marrow/Stem Cell Transplant

The New Normal: Emmy Winning DVD and USB

To learn more about the nbmtLINK, please visit www.nbmtlink.org or call 1-800-LINK-BMT (800-546-5268)

Cover art by Megan Swoyer
www.greenbushmedia.com
Instagram: meganswoyer

Updated 2023

Butterflies are symbols of hope and have much will and stamina to make it to their migration destinations. The metamorphosis of a butterfly from a caterpillar to a winged creature associates it with new beginnings, rebirth, hope, transformation and change. Some even regard butterflies as spiritual guides for personal growth and change and for embarking on a new journey in life.

LINK PARTNERS

American Society for Transplantation and Cellular Therapy (ASTCT)

Barbara Ann Karmanos Cancer Center

Blood Marrow Transplant Program at Northside Hospital

Center for International Blood & Marrow Transplant Research (CIBMTR)

Corewell Health

Dana-Farber Brigham Cancer Center

DKMS

Fred Hutchinson Cancer Center

Froedtert & the Medical College of Wisconsin Cancer Network

Henry Ford Health – Cancer

Incyte

Memorial Sloan Kettering Cancer Center

Meredith A. Cowden Foundation

Nebraska Medicine

Oregon Health & Science University Knight Cancer Center

Roswell Park Comprehensive Cancer Center

Siteman Cancer Center at Barnes-Jewish Hospital and
Washington University School of Medicine

Stem Cell Transplantation and Cellular Therapy Program, John Theurer Cancer Center at
Hackensack University Medical Center

The Leukemia & Lymphoma Society

University Hospitals Seidman Cancer Center

University of Michigan Health Rogel Cancer Center

Vanderbilt-Ingram Cancer Center

Link Partners are hospitals, organizations and foundations who contribute annually and help the National Bone Marrow Transplant Link support transplant patients and caregivers and expand our mission and outreach. For information about becoming a Link Partner, email Peggy Burkhard, Executive Director, peggyburkhard@nbmlink.org.

Here for You

*with Chronic Graft Versus Host Disease
(cGVHD)*

Resources and Support



The National Bone Marrow Transplant Link (nbmtLINK), established in 1992, strives to help patients, caregivers and families cope with the psychosocial challenges of bone marrow/stem cell transplant from diagnosis through survivorship.

We offer webinars for patients, caregivers and health care professionals related to survivorship, including cGVHD. These cover topics such as quality of life, psychosocial support, nutrition, fatigue, anxiety, mobility and more.

Find webinars at **www.nbmtlink.org** and then click on the webinars tab.



TABLE OF CONTENTS

Apps for Smart Phones	1
Bone Marrow and Stem Cell Transplant Information and Support	3
Caregiver Support.....	5
Coordinating Help and Communicating with Friends & Family.....	7
Chronic Graft-Versus-Host Disease Support.....	8
Clinical Trials.....	10
Cord Blood Resources	12
Disease-Related Support.....	13
Donor Information	16
Fertility	17
Financial Assistance, Fundraising, Legal and Insurance Resources.....	18
General Cancer Information and Support	25
Pediatric, Adolescent and Young Adult Support	28
Transportation Resources	31
Notes.....	33

Apps for Smart Phones

Note: Most of the apps listed are free, but some apps may require purchase.

Attune™

Provides digital version of cognitive behavioral therapy, relaxation therapy, stress management and coping techniques for adults dealing with cancer

BELONG Beating Cancer Together

Offers social and professional network for navigating cancer treatment; patients/caregivers can connect with healthcare professionals

Calm

Offers guided meditations to focus on stress reduction and mindfulness

CancerBuddy

Provides social support network for people facing cancer

Cancer.Net Mobile

Offers tools for planning and managing care

CareZone

Organizes health information and access to health services

CaringBridge®

Offers safe, secure place for patients and caregivers to provide health updates and for family/friends to respond with messages of support

Create To Heal

Focuses on creativity and stress relief; includes guided meditations, soothing music, and art with a view to reducing stress to assist the healing process

CureSearch

Provides support for parents and caregivers of children diagnosed with cancer

Drugs.com Medication Guide

Provides way to look up drug information, identify pills, check interactions, and set up personal medication records

Fooducate

Coaches people on health eating; tools to track food, activity, sleep and mood

Headspace

Offers guided lessons on mindfulness, sleep, and remembering to breathe

LLS Coloring for Kids™

Allows children to express creativity and learn about blood cancer; includes blank canvases and coloring pages

LLS Health Manager

Offers tool to track side effects, medication, food, and hydration and other planning tools and resources; allows caregiver access

Lotsa Helping Hands

Offers central place to coordinate help, communicate updates and receive support; includes calendar tool for scheduling deliveries, rides to appointments, and visiting hours

My Be The Match

Offers patients a secure way to navigate their journey post transplant, including support from patient navigators

NCCN Guidelines for Patients®

Provides list of best-known treatments specific to cancer type; reliable knowledge about the symptoms, stages and side-effects of various cancer treatments

NCCN Reimbursement Resource

Searches for available resources and payment assistance programs

Plant Nanny

Makes a game out of keeping hydrated

Re-Mission2: Nanobot's Revenge

Offers games for young people fighting cancer

Simply Sayin'™

Uses pictures, sounds, and a child friendly glossary of terms to facilitate clear conversations between the healthcare provider, child, and family

Bone Marrow and Stem Cell Transplant Information and Support

American Society for Transplantation and Cellular Therapy (ASTCT™)

- 312-321-6820
- www.astct.org/learn/patient-education

Working to improve the application and success of blood and marrow transplantation and related cellular therapies by promoting research, education and clinical practice in the field. Patient education guide available to learn terms, diseases, and treatments and to find research.

Be The Match®/National Marrow Donor Program

- 888-999-6743
- patientinfo@nmdp.org
- www.bethematch.org/patient-and-families

Educational programs and resources for patients, their caregivers and families before, during and after transplant. Social workers offer individual counseling for patients and caregivers, patient navigators provide one-on-one professional guidance and support, and certified chaplains offer spiritual support. Group support and peer connections are also available. Annual U.S. transplant center searchable directory, financial tools and other resources.

Blood and Marrow Transplant Information Network

- 888-597-7674 or 847-433-3313
- help@bmtinfonet.org
- www.bmtinfonet.org

Peer support, searchable North American transplant center directory, list of U.S. medical centers offering CAR T-cell therapy, a mental health provider directory, support groups and other resources.

Bone Marrow & Cancer Foundation

- 800-365-1336 or 212-838-3029
- patientservices@bonemarrow.org
- www.bonemarrow.org

Financial assistance, educational information and support programs for patients, survivors and families. CancerBuddy app provides social support network for people facing cancer.

Center for International Blood and Marrow Transplant Research (CIBMTR)

- 414-805-0700
- www.cibmtr.org

Data on transplant and post-transplant outcomes.

National Bone Marrow Transplant Link (nbmtLINK)

- 800-546-5268
- www.nbmtlink.org

Supporting and informing people about their cancer diagnosis and the transplant process through personalized support. Services, resources, podcasts and publications are designed to meet the needs of the patient and caregiver community.

U. S. Health Resources & Services Administration (HRSA)

- www.bloodstemcell.transplant.hrsa.gov

Transplant resource and donor information.

Caregiver Support

ARCH National Respite Network and Resource Center

- 312-321-6820
- www.archrespite.org

Tool for families to locate respite and crisis care services in their communities and search for respite funding.

Be The Match®

- 888-999-6743
- patientinfo@nmdp.org
- www.bethematch.org/patients-and-families/caregivers-and-transplant

Support programs and educational resources for caregivers.

CancerCare®

- 800-813-4673
- www.cancercare.org/tagged/caregiving

Support groups, counseling, workshops and information for caregivers.

Cancer Support Community

- 888-793-9355
- www.cancersupportcommunity.org/caregivers

Information and resources about caring for cancer patients and connections to in-person support groups.

Caregiver Action Network

- 202-454-3970
- www.caregiveraction.org

Forums, chat rooms, family caregiver toolbox, and other resources for caregivers.

Caregiving.com

- www.caregiving.com

Forum for connecting with other caregivers, podcasts, videos and other resources and tools.

CaringInfo

- 800-658-8898
- www.caringinfo.org

Resources on palliative care and information to help make decisions regarding end-of-life care and services.

Eldercare Locator

- 800-677-1116
- www.eldercare.acl.gov/public/index.aspx

A nationwide service that connects older Americans and their caregivers with a database to find trustworthy help in their community.

Family Voices

- 888-835-5669
- www.familyvoices.org

National network of families and friends of children and youth with special health care needs and disabilities with searchable database for finding support.

National Alliance for Caregiving

- 202-918-1013
- info@caregiving.org
- www.caregiving.org

National, nonprofit coalition advancing family caregiving through research, innovation and advocacy.

National Bone Marrow Transplant Link

- 800-546-5268
- www.nbmtlink.org

Resources and support for caregivers of transplant patients and survivors, from diagnosis through survivorship; Caregivers' Guide to Bone Marrow/Stem Cell Transplant available to order.

Rosalynn Carter Institute for Caregivers

- 229-928-1234
- www.rosalynncarter.org

Coaching and other supports for caregivers.

Today's Caregiver

- www.caregiver.com

Information, support and guidance for family and professional caregivers with a print magazine, website and conferences.

Well Spouse® Association

- 732-577-8899
- www.wellspouse.org

Education, advocacy and peer support for spousal caregivers (membership based).

Coordinating Help and Communicating with Friends & Family

CaringBridge®

651-789-2300

www.caringbridge.org

CareCalendar

www.carecalendar.org

Lotsa Helping Hands

www.lotsahelpinghands.com

Meal Train®

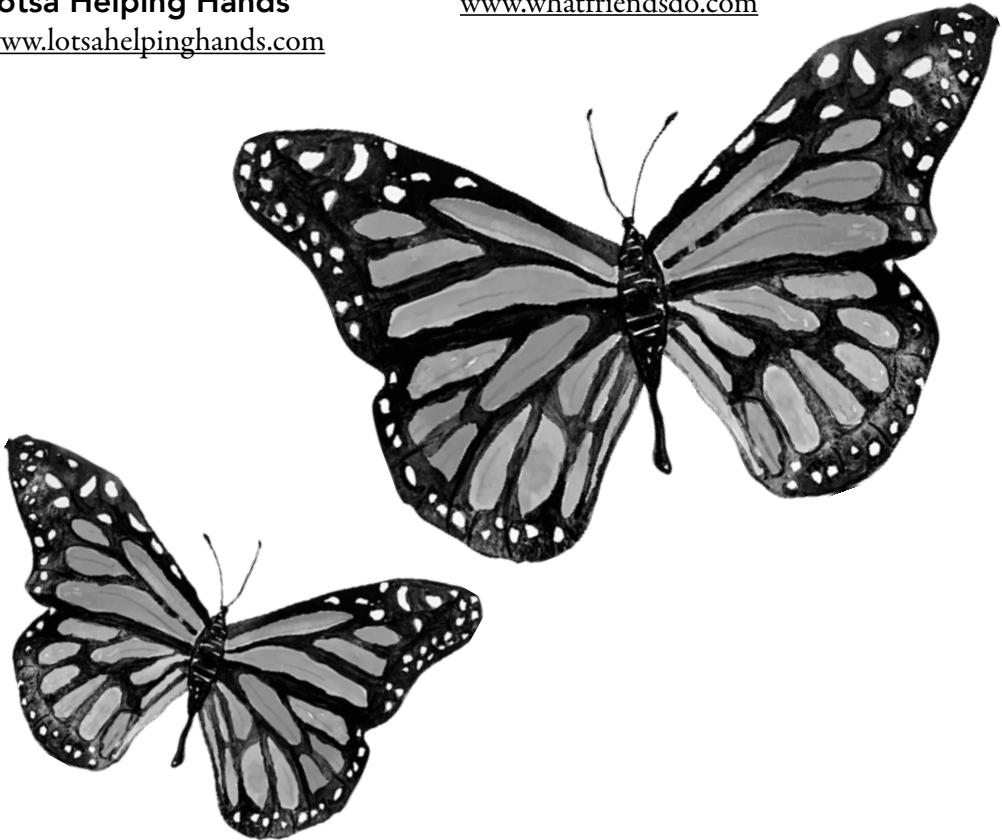
www.mealtrain.com

MyLifeLine

www.mylifeline.org

WhatFriendsDo

www.whatfriendsdo.com



Chronic Graft-Versus-Host Disease

Be the Match®

- 888-999-6743
- www.bethematch.org

Basic disease information regarding GVHD including prevention, signs, symptoms, and recovery.

BMT InfoNet Directory of Mental Health Providers

- www.bmtinfonet.org/mh-directory

Searchable listing of mental health providers – psychologists, social workers and other counselors – who have transplant, CAR T-cell therapy and/or GVHD experience.

BostonSight®

- 781-726-7337
- www.bostonsight.org

Advancing the treatment of dry eye and other ocular complications from graft versus host disease, with information on PROSE® treatment.

ClinicalTrials.gov

- www.clinicaltrials.gov/ct2/help/for-patient

Current information about clinical research studies for patients, families and caregivers, health care professionals, and the public. Patients can schedule an appointment for a comprehensive evaluation of their chronic GVHD.

Medical evaluation costs are covered by the study, and it takes place at the NIH clinical center in Bethesda, Maryland. The program is part of a clinical trial designed to gather a national database of information about chronic GVHD so that better treatments can be developed. To learn more about this study (ClinicalTrials.gov Identifier: NCT00092235), patient or patient's doctor may contact the study research staff at 240-858-3681 or rania.hishmeh@NIH.gov.

Meredith A. Cowden Foundation

- 330-864-1978

- www.cowdenfoundation.org

Grants for the special needs of patients and families battling a blood cancer; sponsors of a national symposium where research doctors present on new and more effective ways to treat GVHD; supports blood cancer and GVHD research.

National Bone Marrow Transplant Link

- 800-546-5268

- www.nbmtlink.org

Offering free webinars and other information regarding GVHD. The publication, *Graft Versus Host Disease: Living with the After Effects of Bone Marrow/Stem Cell Transplant*, is available to order. Education programs make available time for questions and answers from a medical specialist. Previous recordings available on the nbmtLINK website.

Rare Diseases Clinical Research Network

- www.rarediseasesnetwork.org

Advancing medical research on rare diseases by providing support for clinical studies and facilitating collaboration, study enrollment and data sharing; National Institutes of Health patient/family resource listing.

Smart Patients

- [www.smartpatients.com/
communities/gvhd](http://www.smartpatients.com/communities/gvhd)

Online community for patients and their families.

Clinical Trials

CenterWatch

- 866-219-3440
- 617-948-5100
- www.centerwatch.com

Information on global clinical trials; large searchable database to find trials.

ClinicalTrials.gov

- www.clinicaltrials.gov/ct2/help/for-patient

Current information about clinical research studies for patients, their families and caregivers, health care professionals, and the public.

International Myeloma Foundation

- 800-452-2873
- www.myeloma.org

Information about global clinical trials along with patient education, support and advocacy programs.

Jason Carter Clinical Trial Search and Support Program

- 888-814-8610
- clinicaltrials@jcctp.org
- www.ctsearchsupport.org

Patients and their families can locate and join clinical trials pertaining to blood cancers or blood disorders; clinical trial navigators provide one-on-one support.

Lymphoma Research Foundation

- 800-500-9976 helpline
- 212-349-2910 general information
- www.lymphoma.org

Clinical trial information service, with a clinical trials search request form.

Multiple Myeloma Research Foundation

- 203-229-0464
- www.themmr.org/resources/clinical-trial-finder

Search tool to clinical trial information.

Myelodysplastic Syndromes Foundation

- 800-637-0839
- www.mds-foundation.org

Updated clinical trials listed by study name.

National Cancer Institute

- 800-422-6237
- www.cancer.gov/clinicaltrials

Information on cancer clinical trials using a search form; also offers help by phone, email or online chat.

National Heart, Lung, and Blood Institute

- 877-645-2448
- www.nhlbi.nih.gov/research/clinical-trials

Searchable database for finding studies for patients who have heart, lung, blood, or sleep-related diseases or disorders.

U.S. National Institutes of Health – Clinical Trials

- prpl@mail.cc.nih.gov for questions about participating in NIH research studies
- www.nih.gov/health-information/nih-clinical-research-trials-you

Resource for people who want to learn more about clinical trials and better understand the basics of clinical research.

Cord Blood Resources

Be The Match®

- 888-999-6743

- www.bethematch.org

Information on cord blood and transplants, public cord blood donation, and cord banks.

Consumer Affairs

- www.consumeraffairs.com/health/cord-blood/#how-it-works

Listing of cord blood banks, cord banking requirements, types of cord blood banks, and information on who should bank cord blood.

Cord Blood Association

- 630-463-9040

- www.cb-association.org

Information about donating cord blood for public use or storing it for private use.

Parent's Guide to Cord Blood

- www.parentsguidecordblood.org

Educational information for parents about cord blood banking, medical therapies, and cord blood storage options; also analyzes new developments in medical research or public policy that could expand the use of cord blood.

U.S. Health Resources & Services Administration (HRSA)

- www.bloodstemcell.hrsa.gov

Resources for learning about transplantation, planning for a transplant and searching for a marrow donor or cord blood unit.

ViaCord

- 866-668-4895

- www.viacord.com

Provides cord blood and cord tissue collection, processing and storage.

Disease-Related Support

AAMDS International Foundation, Inc.

- 800-747-2820 help line
- www.aamds.org

Patient information for aplastic anemia, MDS, PNH and other bone marrow failure diseases, including conferences, webinars, educational materials, online chat, and access to clinical trials and new research.

Amyloidosis Foundation

- 248-922-9610
- www.amyloidosis.org

Patient resources for those affected by amyloidosis including websites and support groups, toolkits, and webinars; information on treatment centers and clinical trials; and caregiver resources.

Fanconi Anemia Research Fund

- 888-326-2664
- www.fanconi.org

Education and support for patients and their families; advancing treatments and researching a cure for Faconi anemia.

The Foundation for Peripheral Neuropathy®

- 877-883-9942
- www.foundationforpn.org

Education for patients and connections to support groups; promotes research into the causes of and cures for peripheral neuropathy.

Friends' Health Connection

- www.friendshealthconnection.org

Connects people who are currently experiencing or who have overcome the same disease, illness, handicap or injury in order to communicate for mutual support.

HealthTree Foundation

- 800-709-1113
- www.healthtree.org

Information and resources for blood cancer patients to learn about and better navigate their disease.

Immune Deficiency Foundation

- 410-321-6647
- www.primaryimmune.org

Education and outreach to help patients and the medical community gain a broader understanding of primary immunodeficiency diseases.

International Myeloma Foundation

- 818-487-7455
- www.myeloma.org

Information regarding multiple myeloma, including finding a support group, accessing seminars and workshops, and being a caregiver.

International Waldenstrom's Macroglobulinemia Foundation

- 941-927-4963
- www.iwmf.com

Provides information, support and resources for people diagnosed WM.

The Leukemia & Lymphoma Society® (LLS)

- 800-955-4572
- www.lls.org

Education and support for blood cancer patients and families; funder of blood cancer research; and advocates for policy change that accelerates the development of new cancer treatments.

Leukemia Research Foundation

- 847-424-0600
- www.allbloodcancers.org

Information, resources, education programs, and support services for patients and their families.

Lymphoma Research Foundation

- 800-500-9976 help line
- www.lymphoma.org

Information, support services, and education resources for patients and their families; research grants for lymphoma, and programs for healthcare professionals.

Marrow Forums™

- www.marrowsforums.org
- Discussion forums for people affected by bone marrow failure diseases.

MDS Foundation

- 800-637-0839
- www.mds-foundation.org

Information about myelodysplastic syndromes (MDS) with resources for patient and caregivers and listing of clinical trials.

Multiple Myeloma Research Foundation

- 203-229-0464
- www.themmr.org

Information for patients and a patient navigation center; providing funding for research on multiple myeloma.

MyMPNConnect

855-446-2983

- www.mpnconnect.com

Medical information for people living with or treating a myeloproliferative neoplasm (MPN).

National Coalition for Cancer Survivorship

- 877-622-7937

- www.canceradvocacy.org

Offering resources for patients, including a Cancer Survival Toolbox, and specific disease information; advocates for quality cancer care and research.

National Heart, Lung, and Blood Institute

- 877-645-2448

- www.nhlbi.nih.gov

Health education and awareness programs and database for clinical trials for patients who have heart, lung, blood, or sleep-related diseases or disorders.

National Organization for Rare Disorders (NORD)

- 800-999-6673 patient services

- 617-249-7300

- www.rarediseases.org

Patient advocacy and information for individuals with rare diseases, including GVHD. A patient assistance program can help with treatment expenses.

Donor Information

Be The Match®

- 888-999-6743
- www.bethematch.org

Information on how to join the Be The Match Registry and become a bone marrow donor.

BoneMarrowTest.com (Kashi Clinical Laboratories)

- 877-565-3287
- www.bonemarrowtest.com

Private testing resource for identifying a potential donor of bone marrow, stem cells, peripheral blood or umbilical cord blood. An HLA test kit can be ordered on this site.

DKMS

- 212-209-6700
- www.dkms.org

Stem cell donor register, with information for hosting a (virtual or in-person) donor drive or registering as a donor.

Gift of Life Bone Marrow

- 800-962-7769
- www.giftoflife.org

National public registry facilitating transplants for patients in the United States and abroad.

Love Hope Strength Foundation

- www.lovehopestrength.org

Leverages the power of music to expand the marrow registry through its “Get on the List” campaign at concerts and festivals.

U.S. Health Resources & Services Administration (HRSA)

- www.bloodstemcell.hrsa.gov

Transplant resource and donor information.

Fertility

American Society for Reproductive Medicine

- 205-978-5000
- www.asrm.org

Information on reproductive medicine.

Livestrong Fertility

- 855-844-7777
- www.livestrong.org/what-we-do/program/fertility

Reproductive information, resources and financial support to survivors whose cancer and its treatment present risks to their fertility.

Resolve

- 866-668-2566 helpline
- www.resolve.org

Infertility support, access to care, and advocacy and family building options.

Society For Assisted Reproductive Technology (SART)

- 205-978-5000
- www.sart.org/patients/patient-information

Patient information on the practice of IVF or assisted reproductive technologies (ART); this is a professional organization that maintains standards for ART.

Team Maggie's Dream

- teammaggieforacure@gmail.com
- www.teammaggiesdream.org/grants

Financial assistance to young women and men for the purpose of preserving eggs and sperm.

Financial Assistance, Fundraising, Legal and Insurance Resources

Accessia Health

- 800-366-7741
- www.accessiahealth.org

Financial assistance to pay for prescriptions, medical treatments and expenses, and insurance premiums. Services include healthcare education, specialized legal services, and case management.

Alex's Lemonade Stand Foundation

- 866-333-1213
- 610-649-3034 Family Services
- FamilyServices@AlexsLemonade.org (for Travel For Care questions)
- www.alexslimonade.org

Supporting families of children with cancer by funding research and raising awareness. Resources for families include a free childhood cancer treatment journal, SuperSibs support program and a Travel For Care Program to offset travel expenses (transportation and lodging) for families who must travel to receive treatment for a child.

American Cancer Society

- 800-227-2345
- www.cancer.org

Information on how to manage insurance, financial and legal issues. Assistance with locating transportation and lodging needs (Hope Lodge).

Be The Match®

- 888-999-6743
- patientinfo@nmdp.org
- www.bethematch.org/patients-and-families

Educational resources on transplant costs, insurance coverage, fundraising and grants; has a downloadable financial planning worksheet for learning how to pay for transplant costs.

The Blood Cancer Foundation of Michigan

- 248-530-3000
- www.bloodcancerfoundationmi.org

Only for residents of the State of Michigan, resources around financial assistance, including customized financial roadmaps, a Patient Reimbursement Fund for treatment-related expenses, and a Special Needs Grant for urgent, one-time needs such as emergency car repairs, housing, utility bills.

Bone Marrow & Cancer Foundation

- 212-838-3029
- 800-365-1336
- www.bonemarrow.org/support-and-financial-aid/cancer-financial-assistance

Financial assistance programs to help ease the financial burdens for patients and their families; includes Carelines™ (crowdfunding, journaling, volunteer help calendar) and Lifeline Fund (for patients who lack the financial resources necessary for a transplant).

CancerCare®

- 800-813-4673
- www.cancercare.org/financial_assistance

Limited assistance for cancer-related costs and co-pays; oncology socials workers provide help with finding additional resources. Site offers Helping Hand Online Financial Resource Database for financial and practical needs.

CancerCare® Co-Payment Assistance Foundation

- 866-552-6729
 - information@cancercarecopay.org
 - www.cancercare.org/copayfoundation
- Assistance with co-payments for prescribed treatments.

Cancer Financial Assistance Coalition

- www.cancerfac.org
- Helping patients manage their financial challenges with an interactive database to search for financial or practical help by diagnosis, type of assistance needed, and location.

Cancer Insurance Checklist

- www.cancerinsurancechecklist.org
- Designed to help individuals who are diagnosed with cancer, have a history of cancer, or are at risk for cancer, when they are shopping for insurance on a state's Health Insurance Marketplace. Downloadable PDF here:
https://cancerinsurancechecklist.org/site/wp-content/uploads/2013/09/cancer_insurance_checklist.pdf.

Cancer Legal Resource Center (a Disability Rights Legal Center program)

- 866-843-2572
- clrc@drlcenter.org
- www.cancerlegalresources.org

Assistance provided through a telephone assistance line; outreach programs, webinars and community activities educate and support cancer patients, their families, healthcare professionals. Advocates on matters like maintaining employment through treatment, accessing healthcare and government benefits, taking medical leave and estate planning. Downloadable Patient Legal Handbook available.

Children's Cancer Recovery Foundation

- 717-688-7940
- www.childrenscancerrecovery.org

Providing emergency bridge payments to utility companies and landlords through the Helping Hands Fund, camp scholarships, and new toys and gifts to children with cancer.

Children's Leukemia Research Association, Inc.

- 516-222-1944
- [www.childrensleukemia.org/
patients](http://www.childrensleukemia.org/patients)

Co-pay assistance program for reimbursement of leukemia/blood cancer related medical bills.

Children's Organ Transplant Association (COTA)

- 800-366-2682
- www.cota.org

Providing fundraising assistance and support for families of children and young adults who require a transplant.

FAIR Health Consumer

- www.fairhealthconsumer.org

Reliable, transparent information about health care costs and insurance.

Family Reach

- 973-394-1411
- 857-233-2764
- www.familyreach.org

Financial services for families facing cancer, including financial education, resource navigation, financial coaching, and emergency relief grants.

GiveForward

- www.giveforward.com

Free fundraising platform; now part of GoFundMe.

Good Days

- 877-968-7233
- www.mygooddays.org

Lifting the burdens of chronic illness through assistance, advocacy and awareness; assists with co-pays, travel, premiums, and diagnostic testing.

Healthcare.gov

- www.healthcare.gov

Information on state insurance options, comparative quality of care in hospitals, home healthcare agencies, and nursing homes; includes an overview of the healthcare law and healthcare options for different groups of people.

Healthcare Hospitality Network

- 800-318-8861
- www.hhnetwork.org

Professional association of U.S. nonprofit organizations that provide lodging and support services to patients, families and their loved-ones who are receiving medical treatment far from their home community; patients/caregivers can look up lodging near their healthcare provider from the site.

HealthWell Foundation®

- 800-675-8416
- www.healthwellfoundation.org

Assistance with co-pays, premiums, deductibles, out-of-pocket expenses for the underinsured to afford critical medical treatment; assistance is through a number of disease funds.

HelpHOPELive

- 800-642-8399
- www.helphopelive.org

Supporting community-based fundraising for people with unmet medical and related expenses due to cell and organ transplants or other injuries/illness.

Jason Carter Clinical Trials Program

- 888-814-8610
- patientgrants@nmdp.org
- www.ctsearchsupport.org/resources/basics/grants

Financial assistance to help qualified patients pay for travel costs, including air travel, ground transportation and accommodations; online applications available.

Joe's House

- 877-563-7468
- www.joeshouse.org

Resources to help cancer patients and their families find discounted, nearby places to stay when traveling for medical treatment.

The Leukemia & Lymphoma Society® (LLS)

- 877-557-2672
- financialassistance@LLS.org
- www.lls.org/support-resources/financial-support

Providing a number of patient financial support programs, including assistance with co-pays, patient aid, travel, and other urgent needs; additional education on understanding insurance coverage.

Leukemia Research Foundation

- 847-424-0600
- www.leukemiarf.org/patients/grants

Funding research for all blood cancers. Financial assistance for Illinois residents or those within a 100-mile radius of Chicago, for treatment-related expenses not covered by medical insurance that may include medical bills, co-pays, child care, and travel expenses.

Lymphoma Research Foundation

- 800-500-997
- www.lymphoma.org/resources/supportservices/financialsupport

Limited financial assistance for people undergoing treatment for lymphoma and chronic lymphocytic leukemia (CLL) through patient aid grants for medical bills, transportation costs and lodging.

Medicare.gov

- www.medicare.gov
- Explanation of insurance coverage, doctors, medical facilities that accept Medicare; information on home health and transitional care covered services, advance directives, and long-term care.

Medicare Rights Center

- 800-333-4114 help line
- www.medicarerights.org

National nonprofit consumer service organization that works to ensure access to affordable healthcare for older adults and people with disabilities through counseling and advocacy, educational programs, and public policy initiatives.

Medicine Assistance Tool

- 571-350-8643
 - www.medicineassistancetool.org
- Matching patients with resources and cost-sharing programs to help lower out-of-pocket costs.

The National Children's Cancer Society

- 314-241-1600
- www.thenccs.org/financial-assistance

Assistance funds for travel costs associated with children's cancer treatment and other emergency needs while child is hospitalized for an extended time.

National Comprehensive Cancer Network®

- www.nccn.org/business-policy/business/virtual-reimbursement-resource-room-and-app

Search platform for resources and payment assistance programs.

National Council on Aging

- www.ncoa.org

Resources for people aged 60 and older and their caregivers to manage a budget and find and make the best of Medicare payment plans; BenefitsCheckUp search option connects older adults to benefits programs for health care, medicine, food and utilities.

National Foundation for Transplants

- 800-489-3863
- www.transplants.org

Supports for covering costs of organ transplantation. Patients provided with fundraising consultant to assist in connecting with community resources and organizing fundraising campaigns.

National Organization for Rare Disorders (NORD)

- 800-999-6673 patient services
- www.rarediseases.org

Assistance programs to help patients obtain life-saving or life-sustaining medication they could not otherwise afford; links and resources for other medication, financial and legal assistance. Note: GVHD is classified as a Rare Disorder.

NeedyMeds

- 800-503-6897 helpline
- www.needymeds.org

Connecting people to programs that may be able to help them afford their medications and other healthcare costs.

Patient Advocate Foundation

- 800-532-5274
- www.patientadvocate.org

Direct case management services and financial assistance to patients with chronic or life-threatening debilitating diseases and to caregivers. Includes helping people navigate the health care system, working with health care providers, payers and employers to assure that patients have access to affordable care, financial and co-pay assistance and teaching self-advocacy to patients and caregivers.

Patient Resource

- 800-497-7530
- prp@patientresource.com
- www.patientresource.com/Patient_Resources

Provides resource listing for cancer information, financial assistance and caregiver help.

The RX Advocates

- 844-559-8332
- www.therxadvocates.com

Helps eligible patients apply for patient assistance programs offered by pharmaceutical companies to get brand-name medications at no cost.

The Samfund

- 617-938-3484
- www.thesamfund.org

Supports young adults who are struggling financially because of cancer through direct financial assistance and free online support and education.

Single Mothers Grants

- www.singlemothersgrants.org
- Listing of financial assistance programs for to help single mothers with rent, utility bills, child care, education, medication, housing, medical bills, and mortgage, other needs; links to more than 1000 grants to apply for.

State Health Insurance Assistance Programs (SHIPs)

- 877-839-2675
 - www.shiphelp.org
- Local, in-depth, and objective insurance counseling and assistance to Medicare-eligible individuals, their families, and caregivers; search tool to find local Medicare help.

Team Maggie's Dream

- teammaggieforacure@gmail.com
 - www.teammaggiesdream.org/grants
- Financial assistance to young women and men for the purpose of preserving eggs and sperm.

Ticket to Work

- 866-968-7842
 - www.yourtickettowork.ssa.gov
- Federal program to provide Social Security disability beneficiaries the choices, opportunities and support they need to enter and maintain employment.

Triage Cancer

- 424-258-4628
 - www.triagecancer.org
- Education on the practical and legal issues that arise after a cancer diagnosis.

United Way

- 211
 - www.unitedway.org
- Connections for community resources to assist with a variety of daily living needs. The 211 line connects people to health and basic needs organizations for supports such as food or mental health.

Vital Options International

- 800-518-2354
 - www.vitaloptions.org
- Health education, support for the financial needs of qualified patients and their families, and advocacy. Selma Schimmel Vital Grant helps qualified patients and their families who are enduring a financial hardship while battling a chronic, terminal or rare condition; it assists qualified patients with needs like transportation to treatment, groceries and other living expenses.

General Cancer Information and Support

4th Angel Mentoring

- 866-520-3197
- www.4thangel.ccf.org

Service to match patients and caregivers with a trained volunteer who is a cancer survivor or caregiver with similar age and cancer experiences; program of Cleveland Clinic.

American Cancer Society

- 800-227-2345 24-hour helpline
- www.cancer.org

Disease and treatment information; resources for financial and legal matters; Hope Lodge for lodging assistance; and connections for transportation to treatment.

Cancer and Careers

- 646-929-8032
- www.cancerandcareers.org

Educates people with cancer to thrive in their workplace by providing expert advice, interactive tools and educational events.

CancerCare®

- 800-813-4673
- www.cancercares.org

Support services for cancer patients and survivors including support groups (phone, online and in-person), educational workshops, publications, and financial and co-pay assistance.

Cancer Hope Network

- 877-467-3638
- www.cancerhopenetwork.org

Free one-on-one peer support to cancer patients and their families.

Cancer.Net®

- 571-483-1780
- 888-651-3038
- www.cancer.net

Timely, oncologist-approved information to help patients and families make informed health care decisions; all content on this American Society of Clinical Oncology site is peer-reviewed.

Cancer Support Community (formerly Gilda's Club)

- 888-793-9355
- www.cancersupportcommunity.org

Education, tools and support services for cancer patients.

CaringInfo

- 800-658-8898
- www.caringinfo.org

Free guides and resources to help people make decisions about serious illness and end-of-life care and services.

Coping With Cancer (magazine & website)

- 615-790-2400
- www.copingmag.com

Consumer magazine and website sharing information from medical professionals and coping strategies from patients, caregivers and their loved ones.

CURE® (magazine & online resource)

- 609-716-7777
- www.curetoday.com

Leading resources and information that serve as a guide to every stage of the cancer experience.

GRYT Health

- 844-487-4798
- www.grythealth.com

Cancer education resources and virtual events. The Gryt Project opt-in research registry gathers patient, survivor and caregiver input to impact the future of cancer treatment and survivorship by sharing findings with pharmaceutical and biotech companies.

HealthTree Foundation

- 800-709-1113
- www.healthtree.org

Information and resources for blood cancer patients to learn about and better navigate their disease.

Imerman Angels

- 866-463-7626
- www.imermanangels.org

One-on-one peer support for cancer patients, survivors, caregivers and loved ones. Partners anyone, any age, any gender, anywhere and any cancer type seeking support with someone just like them – a “Mentor Angel.” A Mentor Angel is a cancer survivor or caregiver who most importantly has faced the same type of cancer.

Livestrong Foundation

- 877-236-8820 general information
- 855-220-7777 cancer support
- www.livestrong.org

Resources for patients, survivors and caregivers, with searchable database to find targeted information.

National Cancer Institute

- 800-422-6237
- www.cancer.gov

Free, credible, and comprehensive information about cancer prevention and screening, diagnosis and treatment, research across the cancer spectrum, clinical trials, and news and links to other National Cancer Institute websites.

National Coalition for Cancer Survivorship

- 877-622-7937
- www.canceradvocacy.org

Advocacy for quality cancer care; resource for cancer care policy. Offers a Cancer Survival Toolbox and specific disease information.

National Comprehensive Cancer Network® (NCCN)

- 216-690-0300
- www.nccn.org

Alliance of 32 leading cancer centers. NCCN resources (guide books, webinars) assist patients and their caregivers with overcoming the challenges related to cancer.

National Institutes of Health (NIH)

- www.nih.gov

The NIH works to prevent disease and improve health; under the U.S. Department of Health and Human Services, NIH is the nation's medical research agency.

OncoLink

- 215-349-8895
- www.oncolink.com

Educational support for patients, caregivers and practitioners.

Patient Resource

- 800-497-7530
- 913-725-1600
- www.patientresource.com

Cancer guides by diagnosis.

Richard & Annette Bloch Family Foundation

- 800-433-0464 hotline
- 816-854-5050
- hotline@blochcancer.org
- www.blochcancer.org

General cancer information for the patient and their loved ones.

Vital Options International

- 800-518-2354
- www.vitaloptions.org

Advocacy and health education for patients and family caregivers. Grant program helps qualified patients and their families who are enduring a financial hardship while battling a chronic, terminal or rare condition.

Pediatric and Adolescent Young Adult (AYA) Support

13Thirty Cancer Connect

- 585-563-6221
- www.13thirty.org

Support, peer connections, and resources for age-appropriate care for adolescents and young adults living with cancer in or near in Syracuse and Rochester, New York.

Alex's Lemonade Stand Foundation

- 866-333-1213
 - www.alexslimonade.org
- Supporting families of children with cancer by funding research and raising awareness. Resources for families include a free childhood cancer treatment journal, sibling support program, and a program to offset travel expenses.

Along Comes Hope®

- 805-322-1423
 - www.alongcomeshope.com
- Support for the families of children with cancer, through financial assistance with travel for treatment, creative emotional support programs, and advocacy to promote policy changes, awareness, and education.

American Childhood Cancer Organization

- 855-858-2226
- www.acco.org

Resources for children with cancer including community support, information and advocacy.

The Blood Cancer Foundation of Michigan

- 248-530-3000
- www.bloodcancerfoundationmi.org

Only for residents of the State of Michigan, resources around financial assistance, including customized financial roadmaps, a Patient Reimbursement Fund for treatment-related expenses, and a Special Needs Grant for urgent, one-time needs such as emergency car repairs, housing, utility bills.

Children's Cancer Recovery Foundation

- 717-688-7940
- www.childrenscancerrecovery.org

Programs to improve the mental, social and emotional well-being of children with cancer and their families. Providing emergency bridge payments to utility companies and landlords through the Helping Hands Fund, camp scholarships, and new toys and gifts to children with cancer.

Children's Leukemia Research Association, Inc.

- 516-222-1944
 - www.childrensleukemia.org
- Blood cancer research project funding; Patient Aid Program offers co-pay assistance for reimbursement of leukemia/blood cancer related medical bills.

Children's Organ Transplant Association (COTA)

- 800-366-2682
 - www.cota.org
- Fundraising and family support for children and young adults who need a life-saving transplant.

CureSearch for Children's Cancer

- 800-458-6223
- www.curesearch.org

Driving childhood cancer research with measurable results in an accelerated time frame; video library and information on clinical trials available.

Elephants and Tea

- www.elephantsandtea.com
- Helping adolescent and young adult (AYA) patients, survivors and caregivers know they are not alone in their fight with cancer through storytelling; social, informational and caregiver programming; support groups; and conferences. Elephants and Tea is the nonprofit media company of the Steven G. Cancer Foundation.

Group Loop

- www.grouploop.org
- Website for teenage cancer patients about how to cope with being diagnosed with cancer.

Imerman Angels

- 866-463-7626
 - www.imermanangels.org
- One-on-one peer support for cancer patients, survivors, caregivers and loved ones. Partners anyone, any age, any gender, anywhere and any cancer type seeking support with someone just like them – a “Mentor Angel.” A Mentor Angel is a cancer survivor or caregiver who has faced the same type of cancer.

Kids Health

- www.kidshealth.org

Doctor-reviewed advice on physical, emotional and behavioral topics with separate sections for parents, kids, and teens.

The National Children's Cancer Society

- 314-241-1600
- www.thenccs.org

Emotional, financial and educational support to children with cancer, their families and survivors; financial assistance available for travel expenses and living expenses while the child is hospitalized for an extended time.

Patient Advocate Foundation

- 800-532-5274
- www.patientadvocate.org

Direct case management services and financial assistance to patients with chronic or life-threatening debilitating diseases and to caregivers. Scholarship program for undergraduate or graduate studies for legal residents of the United States that have suffered or are currently suffering from cancer or a chronic illness.

The Samfund

- 617-938-3484
- www.thesamfund.org

Supports young adults who are struggling financially because of cancer through direct financial assistance and free online support and education.

Starlight Children's Foundation

- www.starlight.org

Programs to create moments of joy and comfort for hospitalized kids and their families.

Stupid Cancer

- 212-619-1040
- contact@stupidcancer.org
- www.stupidcancer.org

Resources and support to navigate treatment and survivorship for adolescents and young adults with cancer.

Together by St. Jude™

- www.together.stjude.org

Online resource powered by St. Jude Children's Research Hospital that offers dependable information and a community of support for anyone facing childhood and adolescent cancer no matter where the patient receives treatment.

Transportation Resources

Air Care Alliance

- www.aircarealliance.org
- Volunteer pilots offer public benefit flying for health care, patient transportation.

Air Charity Network

- 877-621-7177
 - www.aircharitynetwork.org
- Free air transportation by volunteer pilots for adults and children who must travel for medical necessity or humanitarian needs.

Alex's Lemonade Stand Foundation

- 866-333-1213
 - 610-649-3034 Family Services
 - FamilyServices@AlexsLemonade.org
(for Travel For Care questions)
 - www.alexslimonade.org
- Travel For Care Program to offset travel expenses (transportation and lodging) for families who must travel to receive treatment for a child.

Along Comes Hope®

- 805-322-1423
 - www.alongcomeshope.com
- Support for the families of children with cancer, through financial assistance with airfare, lodging, gas and groceries when they have to travel for treatment.

American Cancer Society

- 800-227-2345
 - www.cancer.org/support-programs-and-services/road-to-recovery
- Volunteer drivers provide transportation to and from medical appointments through the Road to Recovery program.

Angel Wings for Veterans

- www.angelwingsforveterans.org
- Through partnerships with major airlines, provides wounded, ill and injured veterans and active duty service members, along with their families, free travel to clinical care on the ground and in the air with gas cards, bus and train tickets, general aviation flights, and commercial airline tickets.

Corporate Angel Network

- 914-328-1313
- www.corpangelnetwork.org

Arranging free flights to transport cancer patients, and bone marrow and stem cell donors and recipients, who qualify to hospitals on corporate aircraft.

Mercy Medical Angels®

- 800-296-1217
- www.mercymedical.org

Removing barriers to medical care for patients with transportation on the ground with gas cards, bus and train tickets and in the air with flights flown by volunteer pilots and commercial airlines.

Wings of Hope

- www.wingsofhope.ngo/us-medical-transport

Medical air transport services, free of charge, to individuals who need specialized medical care not available locally. Using aircraft outfitted with stretchers to accommodate fragile and non-ambulatory patients, the Medical Relief & Air Transport Program flies individuals to hospitals and treatment centers in 26 states within a 600-mile radius of St. Louis.

NOTES

NOTES

marrow masters podcast

**Listen and Learn through
nbmtLINK's
Marrow Masters Podcasts**

Marrow Masters podcasts cover topics sure to help you throughout your transplant experience.

With multiple seasons on chronic Graft Versus Host Disease (cGVHD), you will feel more supported, less alone in your survivorship and better educated and equipped to advocate for yourself.

Survivors and caregivers have downloaded our podcasts more than 17,000 times to date.

**Get comfy and tune in by visiting
marrowmasters.simplecast.com.**



Visit our online shop to view and purchase our updated publications.

<https://www.nbmtlink.org/shop>



www.nbmtlink.org • 1-800-LINK-BMT (800-546-5268)

[Facebook.com/TheNationalBoneMarrowTransplantLink](https://www.facebook.com/TheNationalBoneMarrowTransplantLink)

[Twitter: twitter.com/nbmtLINK](https://twitter.com/nbmtLINK) • [YouTube: youtube.com/nbmtLINK](https://www.youtube.com/nbmtLINK)