

IMF Resource Referrals

myeloma.org

1-800-452-CURE (2873)



Improving Lives • Finding the Cure

PATIENT RESOURCES: MEDICAL

- **American Society for Clinical Laboratory Science**
Provides information on laboratory tests, normal results, and how they are collected.
Website: <http://www.ascls.org/labtesting/>
- **American Society of Hematology (ASH)**
Provide information on blood-related diseases and helps find a hematologist in your area.
Website: <http://www.hematology.org/Patients/>
- **Cancer.net**
Oncologist-approved cancer information from the American Society of Clinical Oncology (ASCO)
Website: <http://www.cancer.net/portal/site/patient>
- **ClinicalTrials.gov**
ClinicalTrials.gov is a registry and results database of federally and privately supported clinical trials conducted in the United States and around the world. ClinicalTrials.gov gives you information about a trial's purpose, who may participate, locations, and phone numbers for more details.
Website: <http://clinicaltrials.gov/ct2/results?term=myeloma>
- **Lab Tests Online**
Explains various lab tests and helps you decipher results.
Website: <http://labtestsonline.org/understanding/>
- **Myeloma Manager**
Free software from the IMF to track and understand lab results. (At present for PC only.)
Website: <http://manager.myeloma.org>
- **National Cancer Institute**
General and treatment information about myeloma and other plasma cell neoplasms.
Websites: <http://cancer.gov/cancertopics/pdq/treatment/myeloma/Patient>
What You Need to Know About Myeloma: <http://cancer.gov/cancertopics/wyntk/myeloma>
- **TRANSPLANT**
 - **Blood & Marrow Transplant Information Network (BMT InfoNet)**
Provide transplant patients, survivors and their loved ones with emotional support, information on financial issues, and high quality, easy-to-understand information about bone marrow, peripheral blood stem cell and cord blood transplants.
Website: <http://bmtinfonet.org/>

- **National Marrow Donor Program**

Provide bone marrow and umbilical cord blood transplants to patients in need. As Be The Match®, they operate a listing of potential marrow donors and donated cord blood units and raise funds to help provide transplants to all patients. They also match patients with donors, educate health care professionals and conduct research.

Website: <http://marrow.org/Home.aspx>

PATIENT RESOURCES: FINANCIAL

Prescription Drug Assistance for the Uninsured and Underinsured

- **Amgen Assist**

Service provides information to get help paying for Amgen medication. Depending on the medication taken and the type of insurance, they may be able to connect to a program or foundation that can help.

Website: <http://www.amgenassist.com/index.jsp>

- **Celgene's Patient Support Coordinator Program**

Patient Support Coordinators assist patients and healthcare providers navigate the challenges of reimbursement, provide information about co-pay assistance, and answer general questions about Revlimid and thalidomide. PSCs can also assist uninsured and underinsured patients with enrollment for Celgene's PAP or free goods.

Phone: 1-800-931-8691

Website: <http://www.celgenepatientsupport.com/>

- **CancerCare Co-Payment Assistance Foundation**

Not-for-profit organization established in 2007 to address the needs of individuals who cannot afford their insurance co-payments to cover the cost of medications for treating cancer.

Phone: 1-866-55-COPAY (1-866-552-6729)

Website: <http://www.cancercarecopay.org/>

- **Center for Medicare and Medicaid Services**

Information on The Affordable Care Act—making sure health insurance plans care for people with higher health costs, making it illegal for a plan to deny someone coverage because they're sick, and lowering the amount people pay for prescription drugs in the "donut hole."

Website: <http://www.cms.gov/index.html>

- **CephalonCares Foundation**

The CephalonCares Foundation Patient Assistance Programs provide Cephalon, Inc. medications at no cost to patients in the United States who meet certain insurance and income criteria.

Phone: 877-CEPH881 (877-237-4881)

Website: <http://www.cephaloncares.com/>

- **Chronic Disease Fund**

The Chronic Disease Fund provides co-payment assistance for pharmaceutical products for patients with private insurance or Medicare part D. Patients who utilize a participating pharmacy can have their out of pocket expenses remitted by the fund directly to the pharmacy. Patients using non-participating pharmacies can submit receipts for reimbursement.

Phone: 877-968-7233

Website: <http://cdfund.org/>

- **DOXILine.com**

Janssen provides assistance to certain eligible DOXIL patients at no charge, based on medical & financial need.

Phone: 1-800-609-1083

Website: <http://www.doxiline.com/pages/doxil/patientassist/intro.jsp>

- **healthinsurance.org**

Information on high-risk pools for the medically uninsurable and state exchanges.

Website: http://www.healthinsurance.org/risk_pools/

- **Healthwell Foundation**

Healthwell helps patients living with chronic and life-altering illnesses pay their share of prescription drug copayments, deductibles, and health insurance premiums.

Website: <http://www.healthwellfoundation.org/>

- **Leukemia and Lymphoma Co-Pay Assistance Program**

The Leukemia & Lymphoma Society Co-Pay Assistance Program helps pay insurance premiums and meet co-pay obligations. They'll also help find additional sources of financial help.

Phone: (800) 955-4572.

Website: <http://www.lls.org/diseaseinformation/getinformationsupport/financialmatters/copayassistance/>

- **NeedyMeds**

The mission of NeedyMeds is to make information about assistance programs available to low-income patients and their advocates at no cost.

Website: <http://www.needymeds.org/>

- **Novartis' Patient Assistance NOW Program**

Quick and easy access to information about the many reimbursement and support programs available.

Phone: 1-800-245-5356

Website: <http://www.patientassistancenow.com/>

- **Partnership for Prescription Assistance (PPA)**

Partnership for Prescription Assistance offers a single point of access to more than 475 public and private patient assistance programs, including more than 150 programs offered by pharmaceutical companies. Includes assistance for the uninsured.

Phone: 1-888-4PPA-NOW (1-888-477-2669)

Website: <http://www.pparx.org/>

- **Patient Access Network (PAN) Foundation**

PAN is an independent non-profit organization that provides assistance to underinsured patients for their out-of-pocket expenses for life-saving medications.

Phone: 1-866-316-7263

Website: <http://www.panfoundation.org/>

- **Patient Advocate Foundation's Co-Pay Relief Program**

Provides direct co-payment assistance for pharmaceutical products to insured patients (including Medicare Part D beneficiaries) who financially and medically qualify.

Phone: 1-866-512-3861

Website: <http://www.copays.org/>

- **Patient Assistance**

Free resource to connect patients who are unable to afford prescription medications with assistance programs.

Website: <http://www.patientassistance.com/>

- **PROCRIline**

Janssen's PROCRIline provides easy access to reimbursement information and support.

Phone: 1-800-553-3851

Website: <http://www.procritline.com/pages/procrit/patientassist/intro.jsp>

- **VELCADE® Reimbursement Assistance Program**

Millennium's VELCADE Reimbursement Assistance Program is available to patients, physicians, and caregivers to provide assistance regarding reimbursement issues related to the use of VELCADE® (bortezomib) for Injection.

Phone: 1-866-VELCADE

Website: <http://www.velcade.com/PayingForTreatment.aspx>

PATIENT RESOURCES: LEGAL

- **Cancer and Careers**

Dedicated to empowering and educating people with cancer to thrive in their workplace, Cancer and Careers strives to eliminate fear and uncertainty for working people with cancer.

Website: <http://www.cancerandcareers.org/>

- **Cancer Legal Resource Center (CLRC)**

The CLRC provides free information and resources on cancer-related legal issues to cancer survivors, caregivers, health care professionals, employers, and others coping with cancer.

Phone: 1-866-843-2572

Website: <http://www.disabilityrightslegalcenter.org/cancer-legal-resource-center>

- **Patient Advocate Foundation**

Mediation and arbitration services to patients to remove obstacles to healthcare including medical debt crisis, insurance issues and employment issues for patients with chronic, debilitating and life-threatening illnesses.

Website: <http://patientadvocate.org/>

PATIENT RESOURCES: SUPPORT SERVICES

- **Association of Oncology Social Work – Tips for Managing Cancer and Caregiving**

Life will never be the same after cancer, but it doesn't mean you stop living. There are many things you can do to handle the emotional impact of cancer.

Website: <http://aosw.org/html/patfam-tips.php>

- **Cancer Hope Network**

Free and confidential one-on-one support to cancer patients and their families. As our core offering, we match cancer patients or family members with trained volunteers who have undergone and recovered from a similar cancer experience.

Website: <http://www.cancerhopenetwork.org/>

- **Cancer Support Community**

July 2009, The Wellness Community and Gilda's Club Worldwide joined forces to become the Cancer Support Community. Services include support groups, counseling, education and healthy lifestyle programs. Today, CSC provides emotional and social support through a network of more than 50 local affiliates, 100 satellite locations and online.

Website: <http://www.cancersupportcommunity.org/>

- **CancerCare**

CancerCare is a national nonprofit organization that provides free, professional support services for anyone affected by cancer. Their programs – including counseling, education, financial assistance and practical help – are provided by trained oncology social workers and are completely free of charge.

Website: <http://www.cancercare.org/>

- **Cancer.net**

Psychosocial issues of cancer from the American Society of Clinical Oncology (ASCO)

Website: <http://www.cancer.net/patient/Coping>

NUTRITION

- Eating Hints: Before, During, & After Cancer Treatment: <http://cancer.gov/cancertopics/coping/eatinghints>

- Memorial Sloan Kettering Nutrition Site: <http://www.mskcc.org/cancer-care/survivorship/nutrition>

PATIENT RESOURCES: CAREGIVERS

- **American Cancer Society – Caregivers**

Learn about what to expect if you become a caregiver for a person with cancer, as well as find suggestions and tips for making sure that you take care of yourself as well.

Website: <http://www.cancer.org/Treatment/Caregivers/index>

- **Association of Oncology Social Work – Tips for Managing Cancer and Caregiving**
 Being a caregiver can be a full time job. Focusing on your own needs is an important part of that job. Here are some ideas on how to cope with the challenges of caring for your loved one as well as yourself.
Website: <http://aosw.org/html/patfam-tips.php>
- **Cancer.net**
 ASCO site provides information on defining the role of caregivers and the potential challenges caregivers face.
Website: <http://www.cancer.net/coping/caregiving>
- **Caregiver Action Network (CAN)**
 CAN (formerly the National Family Caregivers Association) is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge.
Website: <http://caregiveraction.org/>
- **Caringbridge**
 A nonprofit providing free websites that connect family and friends—and ease the burden of keeping family and friends informed—during a serious health event, care and recovery. Authors add health updates and photos to share their story while visitors leave messages of support in the guestbook.
Website: <http://www.caringbridge.org/>
- **Coping with Cancer: For Caregivers, Family, and Friends**
 Information from the National Cancer Institute to help caregivers cope while caring for a loved one with cancer, as well as help someone with cancer talk about and cope with the illness.
Website: <http://www.cancer.gov/cancertopics/coping/familyfriends>
- **Family Caregiving 101**
 The National Family Caregivers Association (NFCA) and the National Alliance for Caregiving (NAC) – leaders in the movement to better understand and assist family caregivers — have joined together to recognize, support and advise this vital group of Americans.
Website: <http://www.familycaregiving101.org/>
- **Family Caregiver Alliance (FCA)**
 FCA is a public voice for caregivers. Their programs support and sustain the important work of families nationwide caring for loved ones with chronic, disabling health conditions.
Website: <http://caregiver.org/caregiver/jsp/home.jsp>
- **For Better *and* For Worse: Impact of Cancer and Transplant on Family Caregivers**
 An audio and slide presentation by psychologist Michelle M. Bishop, PhD, from BMT InfoNet's Survivorship Symposium recorded on September 21, 2008.
Website: <http://www.dcpvidersonline.com/bmtin/af390ee6d177a4c2f404f96167a84c05//player.html>

- **Long Term Care Planning Network (Canada)**

Canada's national resource centre for aging and care planning, education and resources.

Website: <http://www.ltcplanningnetwork.com/index.php>

- **National Alliance for Caregiving**

Established in 1996, The National Alliance for Caregiving is a non-profit coalition of national organizations focusing on issues of family caregiving. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, a government agency, and corporations.

Website: <http://www.caregiving.org/>

- **National Caregivers' Library**

Articles, forms, checklists and links to topic-specific resources.

Website: <http://www.caregiverslibrary.org/home.aspx>

- **Net of Care**

Program of the Department of Pain Medicine and Palliative Care of Beth Israel Medical Center, New York, NY.

Website: <http://netofcare.org/content/default.asp>

- **"Taking Care of Yourself" – An Article from CureToday.com**

In the chaos and intensity that surrounds a new cancer diagnosis, everyone tends to focus all of their care and concern on the patient. Too often, medical staff and relatives forget to stop and ask the family caregiver how they are doing.

Website:

http://www.curetoday.com/index.cfm/fuseaction/journey.showArticle/id/9/enableStageSubMenu/7/article_id/185

- **Today's Caregiver**

Newsletters, magazines and articles offering information, support and guidance for family and professional caregivers.

Website: <http://caregiver.com/>

- **Well Spouse Association**

Offers peer-to-peer support for spousal caregivers of the chronically ill and disabled.

Website: <http://www.wellspouse.org/>

FOR MORE RESOURCES, INCLUDING HOUSING AND TRAVEL ASSISTANCE AND ONLINE INFORMATION RESOURCES, VISIT THE RESOURCES SECTION OF THE INTERNATIONAL MYELOMA FOUNDATION WEBSITE

<http://resources.myeloma.org>

<http://caregivers.myeloma.org>