

# **NORTHWEST MULTIPLE MYELOMA FIGHTERS!**

## **CANCER TREATMENT/RESEARCH CENTER**

### **Seattle Cancer Care Alliance (SCCA)**

<https://www.seattlecca.org/diseases/multiple-myeloma>

A Seattle based treatment center working with Fred Hutch Cancer Research Institute and University of Washington Medical Center.

### **Swedish Cancer Institute**

<https://www.swedish.org/services/cancer-institute>

A Seattle based cancer treatment center.

### **Fred Hutchinson Cancer Research Center**

<https://www.fredhutch.org/en/treatment.html>

A research institute that is aiming to find new ways to detect cancers earlier, when cure rates are highest; developing effective treatments with fewer side effects; and learning how to prevent cancers from growing in the first place. The institute collaborates with the University of Washington, Seattle Children's and Seattle Cancer Care.

### **International Myeloma Foundation (IMF)**

<https://www.myeloma.org>

The IMF is dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure through our 4 founding principles: research, education, support and advocacy.

### **Multiple Myeloma Research Foundation (MMRF)**

<https://www.themmr.org>

A patient founded organization, the MMRF is focused on speeding the discovery of the cure. A trusted source of information, the MMRF supports patients with information from the time of diagnosis throughout the course of the disease.

### **Leukemia Lymphoma Society (LLS)**

<https://www.lls.org>

World's largest voluntary health organization dedicated to funding blood cancer research, education and patient services.

### **American Cancer Society**

<https://www.cancer.org>

Provides information, day-to-day help and emotional support to people with cancer and their families.

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### **National Cancer Institute**

<https://www.cancer.gov/types/myeloma>

Offers current information and materials on all cancer issues.

### **OTHER SOURCES OF INFORMATION/EDUCATION**

#### **All 4 Cure**

<https://www.all4cure.com>

All4Cure is a knowledge sharing company aimed at improving the lives of patients with cancer by bringing the very latest knowledge and opinions to the problems they face, and then learning from their experiences for the benefit of other patients.

#### **Health Tree**

<https://healthtree.org>

A knowledge sharing platform that is part of the Myeloma Crowd. This site provides information on treatment options, clinical trials and allows you to share your Myeloma story with others.

#### **American Society of Clinical Oncology (ASCO)**

<https://www.asco.org>

<https://www.cancer.net>

Provides timely, comprehensive information to help patients and families make informed health care [decisions](#). [Cancer.Net](#) is supported by the Conquer Cancer Foundation.

#### **Cancer Care**

<https://www.cancercare.org>

Provides free support information and financial assistance.

#### **CancerLifeline**

<https://www.cancerlifeline.org>

Offers a unique array of services to cancer patients, their family members and caregivers based on 4 vital needs: choice in control, information, inclusion rather than isolation, freedom to express feelings. (a Washington state-based organization)

#### **Health Monitor (magazine)**

<https://www.guide2multiplemyeloma.com>

#### **Cure (magazine)**

<https://www.curetoday.com>

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### **Myeloma Beacon**

<https://myelomabeacon.org>

Source of online information regarding multiple myeloma.

### **Myeloma Today (IMF magazine)**

<https://www.myeloma.org/myeloma-today>

### **Patient Power**

<https://www.patientpower.info/multiple-myeloma>

Patient Power is an online source of information on myeloma, treatment, advances and survivorship.

### **SCCA Survivorship Clinic**

<https://www.seattlecca.org/survivorship>

The Seattle Cancer Care Alliance Survivorship Clinic offers treatment, support, and education after cancer treatment is complete.

### **National Bone Marrow Transplant Link (NBMT)**

<https://www.nbmtlink.org>

Help you better understand and deal with the emotional and practical aspects of bone marrow/stem cell transplants and post-transplant concerns. You can download most of their original publications or view informational webcasts.

### **Cancer Pathways“ formerly Gilda’s Club”**

<https://cancerpathways.org/>

Helps cancer patients to discover pathways of support through unique programs to help patients learn to live with cancer.

### **Myeloma Crowd Crowdcare Foundation**

<https://www.myelomacrowd.org>

A source of information and articles on multiple myeloma.

### **Smart Patients**

<https://www.smartpatients.com>

An on-line community for patients and families affected by variety of illnesses, where you can learn about scientific developments related to your condition, share your questions and concerns, and use what you learned in the context of your own life.

### **Definitions of Cancer Drugs & Treatments both experimental & FDA approved**

<https://www.cancer.gov/publications/dictionaries/cancer-drug>

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## **PHARMACEUTICAL RELATED RESOURCES**

**Takeda Oncology (Velcade, Ninlaro)**

<https://www.takedaoncology.com>

**Amgen (Kyprolis/Carfilzomib)**

<https://www.amgen.com/search?q=multiple%20myeloma>

**Celgene (Revlimid)**

<https://www.celgene.com/diseases/multiple---myeloma/>

**Myeloma Central**

<https://www.myelomacentral.com>

Site for myeloma information for patients and caregivers created in cooperation with Celgene.

**Northwest Natural Health Specialty Care Clinic**

<https://www.nwnaturalhealth.com>

Combines traditional natural therapies with the latest nutritional, botanical and health science. They work cooperatively and effectively with oncologists and other medical specialists of your choice.

## **OTHER CARE**

**Evergreen Health Care (home care services)** – hospice and palliative care

<https://www.evergreenhealthcare.org>

**Harmony Hill Cancer, Healing and Survivorship Program (cancer retreat)**

<https://www.harmonyhill.org>

## **AMYLOIDOSIS INFORMATION**

**Amyloidosis Foundation**

<http://amyloidosis.org/>

**Prothena Biosciences Inc.**

<https://www.prothena.com/patients/#amyloidosis>

## **EXERCISE AND SURVIVORSHIP**

**LIVESTRONG at the YMCA**

<https://www.livestrong.org/ymca>

A free exercise programs for cancer survivors taught by specially educated instructors.

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### **Team Survivor Northwest (TSNW)**

<https://www.teamsurvivornw.org/about/>

Provides a broad range of fitness, health and education programs to enable women cancer survivors to take an active role in their ongoing physical and emotional healing.

### **Thrivorship**

<https://www.livethrivorship.com>

A wellness movement helping women recovering from cancer.

## **BOOKS**

### **And Thou Shalt Honor (A caregiver's Companion)**

--- edited by Beth Witrogen McLeod, forward by Rosalynn Carter

### **The Web-Savvy Patient**

---by Andrew Schorr, with Mary Adam Thomas

### **The Helping Hand (The Resource Guide for People with Cancer)**

<https://www.cancercare.org/blog/a-helping-hand-cancercare-s-searchable-cancer-resource-guide>

### **Bone Marrow and Blood Stem Cell Transplants (A Guide for Patients and Their Loved Ones)**

--- by Susan Stewart

### **Autologous Stem Cell Transplants (A Handbook for Patients)**

--- by Susan K. Stewart

### **A Lucky Life Interrupted**

--- by Tom Brokaw

### **Cooking through Cancer Treatment to Recovery ---**

by Lisa A Price, ND and Susan Gins, MA, MS, CN

### **Extraordinary Healers (Readers Honor Oncology Nurses)**

--- <https://www.curetoday.com/extraordinaryhealer>

### **Outside the Box Cancer Therapies**

--- by Dr. Mark Stengler & Dr. Paul Anderson

### **The Metabolic Approach to Cancer**

--- by Dr. Nasha Winters, Jess Higgins Kelley

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### **FINANCIAL ASSISTANCE/CO-PAY ASSISTANCE**

The IMF (International Myeloma Foundation) keeps track of many of the organizations that provide assistance to patients to help cover the drug costs demanded by their treatment. You can visit this site to get the latest updates on the funds that are out of money, etc.

<https://www.myeloma.org/article/co-pay-assistance-programs-update>

### **PHARMACEUTICAL COMPANIES**

**Celgene's** (*Thalomid, Revlimid, & Pomalyst*)

patient support web portal: <https://www.celgenepatientsupport.com/>

**Takeda** Financial Aid

*Ninlaro* 1Point Program: <https://www.ninlaro.com/cost>

*Velcade* Support: <http://www.velcade.com/paying-for-treatment/>

**Amgen** *Kyprolis*

Amgen Assist 360 Program:

<https://www.amgenassist360.com/patient/kyprolis-cost-nurse-ambassador-assistance/>

**Janssen** *Darzalex*

Janssen CarePath Program:

<https://www.janssencarepath.com/hcp/darzalex/affordability>

OR

<https://www.darzalexhcp.com/resources>

### **OTHER ORGANIZATIONS THAT OFFER ASSISTANCE**

Healthwell Foundation

<https://www.healthwellfoundation.org/fund/multiple-myeloma-medicare-access/>  
(800-675-8416)

Leukemia & Lymphoma Society

<https://www.lls.org/support/financial-support/co-pay-assistance-program>  
(800-955-4572)

Patient Advocate Foundation

<https://www.copays.org/>

Patient Access Network Foundation

<https://panfoundation.org/index.php/en/patients/assistance-programs/multiple-myeloma>

CancerCare copay assistance foundation

<https://portal.cancercarecopay.org/Funds-Available/Diagnoses>

Good Days from the Chronic Disease Fund

<https://www.mygooddays.org/patients/diseases-covered>

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National Foundation for Transplants – including stem cell transplants

<https://transplants.org/>

(800-489-3863)

In addition, the American Cancer Society offers assistance in defraying the costs of treatment in a number of ways, including:

### **American Cancer Society**

<https://www.cancer.org> or 1-800-227 2345

#### **-- Road to Recovery**

Program provides rides to patients who have no ways to get to their cancer treatments.

#### **-- Hotel Partners Program**

Providing complimentary lodging for those who live 50 miles or more from their treatment facility.

#### **- Hope Lodge**

A free place to stay when treatment is far away. Over 30 Hope Lodges around the US and Puerto Rico.

### **Other Assistance**

As you can see, insurance is required for most of these funds. If you do not have insurance, I would suggest you call the Patient Advocate Foundation and work with an advocate to make sure all your options are exhausted.

[www.copays.org](http://www.copays.org)

The [Partnership for Prescription Assistance](http://www.pparx.org) brings together America's pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that's right for them. Many will get them free or nearly free. Its mission is to increase awareness of patient assistance programs and boost enrollment of those who are eligible.

[www.pparx.org](http://www.pparx.org)

Cancer Financial Assistance Coalition (CFAC) – Provides directory of associations offering assistance to those facing cancer

[www.cancerfac.org](http://www.cancerfac.org)

## **CLINICAL TRIALS**

Complete listing of all the clinical trial taking place across the US

<https://clinicaltrials.gov/>

## **FACEBOOK GROUPS**

These groups are all closed, which means you must first contact the Administrator, who will ask a few questions before clearing you to join the group.

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These two groups have more than eight thousand members each, and are a good source for drug or treatment questions.

<https://www.facebook.com/groups/57992039445/>

<https://www.facebook.com/groups/108654495840465/>

More of an alternative focused group where any alternative therapy can be discussed without fear of censorship.

<https://www.facebook.com/groups/HealingMyeloma/>

A Darzalex support group

<https://www.facebook.com/groups/217973475357940/>

Facebook support group for spouses/partners of people with MM

<https://www.facebook.com/groups/1547328408718924/>

Beating Multiple Myeloma with a Naturopathic Approach

<https://www.facebook.com/groups/146446022682511/>

### **Shop Amazon and Give to the IMF**

The IMF (International Myeloma Foundation) is one of the important organizations providing patient support and research information. By using a link on Amazon, you can have a donation made to the IMF for your qualified purchases! Sounds like a good deal to us!!

Here is the info:

### **SHOP AMAZON AND GIVE TO THE IMF AT THE SAME TIME (AT NO ADDED COST TO YOU).**

The IMF's partnership with **Amazon** is getting even better! When you shop online .at [smile.amazon.com](https://www.amazon.com) and select IMF as your designated charity, Amazon donates 0.5% of the total of your purchased items to the IMF. For more information:

<https://www.myeloma.org/donation/amazon-smile>