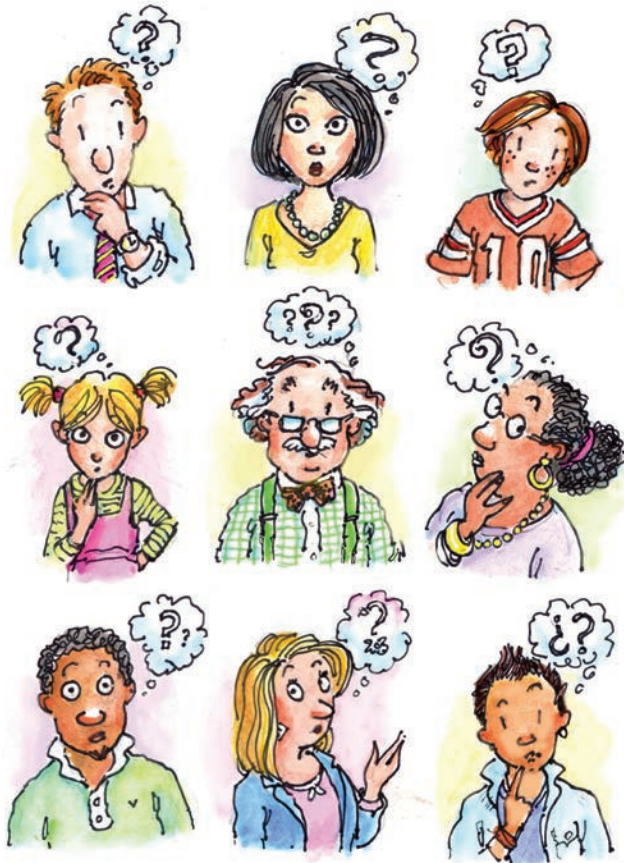


# Resource Directory for Transplant and CAR T-cell Recipients



BMT INFONET

### **BMT InfoNet**

is a non-profit organization that supports transplant and CAR T-cell recipients before, during, and after treatment.

Since 1990, our network of medical experts and survivors has helped over 300,00 patients navigate a transplant or CAR T-cell therapy.

Our goal is to empower patients with credible information and support so that they can take a more active role in decisions affecting their health and treatment options.

### **Let us know how we can help you!**

**Email [help@bmtinfonet.org](mailto:help@bmtinfonet.org)  
Phone 888-597-7674 or 847-433-3313.**

### **Follow us on social media:**

[facebook.com/bonemarrowstemcelltransplantclub](https://facebook.com/bonemarrowstemcelltransplantclub)

[linkedin.com/company/bmt-infonet](https://linkedin.com/company/bmt-infonet)

[youtube.com/user/BMTinfonet](https://youtube.com/user/BMTinfonet)

[bsky.app/profile/bmtinfonet.bsky.social](https://bsky.app/profile/bmtinfonet.bsky.social)

[instagram.com/bmtinfonet](https://instagram.com/bmtinfonet)

**1548 Old Skokie Road, Highland Park, IL 60035  
847-433-3313 888-597-7674 fax 847-433-4599  
[help@bmtinfonet.org](mailto:help@bmtinfonet.org) [bmtinfonet.org](http://bmtinfonet.org)**



**BMT INFONET**

# **Resource Directory for Transplant and CAR T-cell Therapy Recipients**

**Published by  
BMT InfoNet**

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**Visit [BMTInfonet.org](https://www.BMTInfonet.org)**



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**Go to Transplant Basics**

# PREPARING FOR TRANSPLANT

## TRANSPLANT BASICS

### BMT InfoNet

[bmtinfonet.org/transplant-basics](http://bmtinfonet.org/transplant-basics)

(847) 433-3313

(888) 597-7674

[help@bmtinfonet.org](mailto:help@bmtinfonet.org)

Information in English and Spanish about:

- preparing for transplant
- transplant process and possible complications
- post-transplant challenges
- resources for caregivers
- U.S. transplant centers
- financial assistance

Telephone counseling, video learning library and peer support program for patients and caregivers.

### Center for International Blood and Marrow Transplant Research

[bit.ly/cibmtr-slides](http://bit.ly/cibmtr-slides)

(414) 805-0700

[contactus@cibmtr.org](mailto:contactus@cibmtr.org)

Slides about transplant trends and survival data at [bit.ly/cibmtr-slides](http://bit.ly/cibmtr-slides)

## Transplant Handbooks for Patients

Learn what you need to know about bone marrow, stem cell and cord blood transplants in these easy-to-read handbooks, called the “transplant bible” by many patients. Order online at [bmtinfonet.org/products](http://bmtinfonet.org/products) or phone 888-597-7674.

*Available in English and Spanish.*





## NMDP®

[nmdp.org/patients-and-families](https://nmdp.org/patients-and-families)

(612) 362-3410

(888) 999-6743

[patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)

Information about:

- finding a donor
- diseases treated by transplant
- U.S. transplant centers
- transplant process
- survivorship issues
- clinical trials

## nbmtLINK

[nbmtlink.org](https://nbmtlink.org)

(800) 546-5268

[info@nbmtlink.org](mailto:info@nbmtlink.org)

Booklet and podcasts about stem cell transplants.

## Learn about U.S. Transplant Centers

BMT InfoNet's Transplant Center Directory at [bmtinfonet.org/transplantcenters](https://bmtinfonet.org/transplantcenters) provides data on

- number of transplants performed at each center
- diseases treated
- pediatric or adult program
- key personnel

NMDP's Transplant Center Directory at [bit.ly/NMDP-Transplant-Centers](https://bit.ly/NMDP-Transplant-Centers) provides historical data (2020-2022) including the one-year survival rate for patients transplanted with donor cells (allogeneic transplant) at each center.





# FINDING OR BEING A STEM CELL DONOR

## BMT InfoNet

[bmtinfonet.org](http://bmtinfonet.org)

(847) 433-3313

(888) 597-7674

[help@bmtinfonet.org](mailto:help@bmtinfonet.org)

Information about:

- finding a donor at [bmtinfonet.org/find-donor](http://bmtinfonet.org/find-donor)
- being related donor at [bmtinfonet.org/be-related-donor](http://bmtinfonet.org/be-related-donor)
- being an unrelated donor at [bmtinfonet.org/being-unrelated-donor](http://bmtinfonet.org/being-unrelated-donor)
- collecting donor cells for transplant at [bmtinfonet.org/harvest-cells](http://bmtinfonet.org/harvest-cells)

## NMDP®

[bit.ly/NMDP-Find-Donor](http://bit.ly/NMDP-Find-Donor)

(763) 406-3410

(888) 999-6743

[patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)

Information about finding and becoming an unrelated donor.



## PRESERVING FERTILITY

### BMT InfoNet

[bmtinfonet.org/preserve-fertility](http://bmtinfonet.org/preserve-fertility)

(847) 433-3313

(888) 597-7674

[help@bmtinfonet.org](mailto:help@bmtinfonet.org)

Online information and videos about preserving fertility before transplant and options for creating a family after transplant.

### Expect Miracles Foundation Family Building Grant

[bit.ly/EMF-fertility-grant](http://bit.ly/EMF-fertility-grant)

617.938.3484

[info@expectmiraclesfoundation.org](mailto:info@expectmiraclesfoundation.org)

Grants for cancer survivors age 21-39 for fertility preservation, assisted reproduction, gestation carrier or surrogacy fees, fertility testing and adoption.

### Oncofertility Consortium

[oncofertility.msu.edu](http://oncofertility.msu.edu)

(517) 884 6434

[oncofert@msu.edu](mailto:oncofert@msu.edu)

Information about fertility preservation before cancer treatment for both children and adults.

### LIVESTRONG

[livestrong.org/fertility](http://livestrong.org/fertility)

(855) 220-7777

[livestrong@livestrong.org](mailto:livestrong@livestrong.org)

Information about preserving fertility before treatment, fertility clinics, financial aid for sperm, embryo and egg freezing services.

## GVHD Support Groups

BMT InfoNet's GVHD Support Groups provide patients and their care partners a welcoming, safe, online space to connect with others who are living with chronic GVHD. Each group is led by a licensed mental health provider who has extensive experience helping patients and their loved ones cope with GVHD.

To learn more go to at [bmtinfonet.org/gvhd-support-group](http://bmtinfonet.org/gvhd-support-group), email [michala@bmtinfonet.org](mailto:michala@bmtinfonet.org), or phone 847-433-3313.



# GRAFT-VERSUS-HOST DISEASE

## BMT InfoNet

[bmtinfonet.org/gvhd-basics](http://bmtinfonet.org/gvhd-basics)  
(847) 433-3313  
(888) 597-7674  
[help@bmtinfonet.org](mailto:help@bmtinfonet.org)

- Extensive online information about GVHD.
- Free Booklet: *Graft-versus-Host Disease: What to Know, What to Do*
- Online directory of GVHD Clinics and specialists.
- Videos about GVHD at [bmtinfonet.org/videos](http://bmtinfonet.org/videos)
- Online support groups for GVHD patients and caregivers

## NMDP®

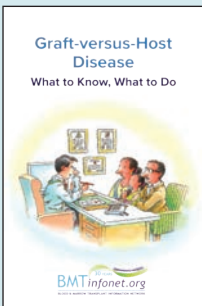
[nmdp.org/PatientGVHD](http://nmdp.org/PatientGVHD)  
(612) 362-3410  
(888) 999-6743  
[patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)

Online information about GVHD symptoms and treatment.

## GVHD Alliance [gvhdalliance.org](http://gvhdalliance.org)

Information hub listing GVHD resources provided by various advocacy groups.

### *Graft-versus-Host Disease: What to Know, What to Do*



Take charge of your GVHD with this free booklet from BMT InfoNet. Learn the symptoms of GVHD, treatment options, side effects of treatment, and steps you can take to control your GVHD. Order online at [bmtinfonet.org/GVHDbook](http://bmtinfonet.org/GVHDbook) or phone 888-597-7674.

*Available in English and Spanish.*



## nbmtLINK

[nbmtlink.org/marrow-masters-podcast](http://nbmtlink.org/marrow-masters-podcast)  
(248) 358-1886  
(800) 546-5268  
[info@nbmtlink.org](mailto:info@nbmtlink.org)

Podcasts about graft-versus-host-disease.

## BostonSight

[bostonsight.org](http://bostonsight.org)  
(781) 726-7337

Information about PROSE lenses for patients with severe ocular GVHD.

## National Cancer Institute GVHD Study

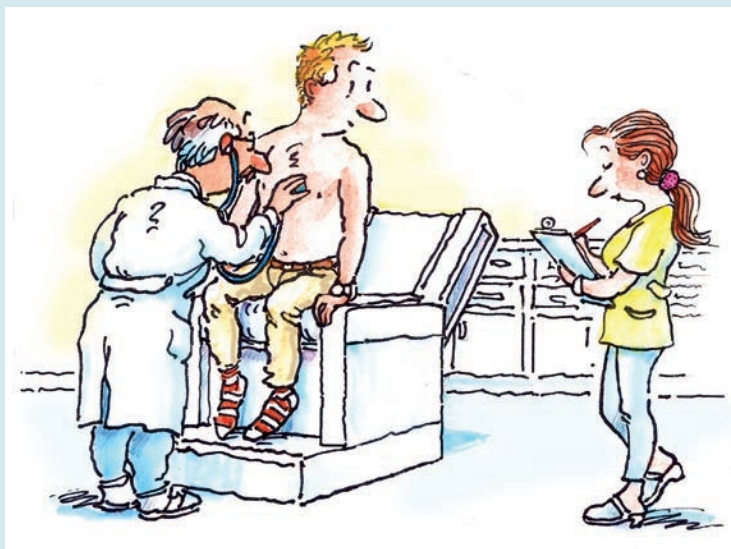
[bit.ly/ncigvhd](http://bit.ly/ncigvhd)  
(240) 858-3681  
[pavletis@mail.nih.gov](mailto:pavletis@mail.nih.gov)

Free, comprehensive medical evaluation by GVHD experts and follow-up care recommendations.

## BMT InfoNet Directory of GVHD Providers

This helpful directory lists GVHD clinics, specialists, and subspecialists who can help you manage your GVHD.

If you no longer have access to GVHD care at your transplant center, check this directory at [bmtinfonet.org/gvhd-directory](http://bmtinfonet.org/gvhd-directory) for a provider near you.



# PREPARING FOR CAR T-CELL THERAPY

## BMT InfoNet

[bmtinfonet.org/car-t-cell](http://bmtinfonet.org/car-t-cell)

(847) 433 3313

(888) 597-7674

[help@bmtinfonet.org](mailto:help@bmtinfonet.org)

- Online information and videos about CAR T-cell therapy
- Directory of CAR T-cell Centers
- Free patient booklet about CAR T-cell therapy
- Videos about CAR T-cell therapy

## Leukemia & Lymphoma Society

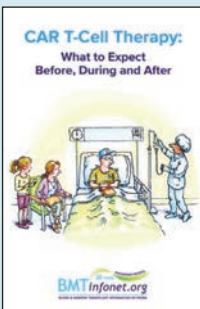
[lls.org/CARTtherapy](http://lls.org/CARTtherapy)

(800) 955-4572

[infocenter@lls.org](mailto:infocenter@lls.org)

Online information and videos about CAR-T cell therapies approved for patients with leukemia, lymphoma, and multiple myeloma.

## *CAR T-cell Therapy: What to Expect Before, During, and After*



Get up-to-date information with this FREE booklet from BMT InfoNet. Learn who can receive CAR T-cell therapy, the steps involved, potential side effects, and managing life after CART. Order online at [bmtinfonet.org/car-t-cell-booklet](http://bmtinfonet.org/car-t-cell-booklet) or phone 888-597-7674.

*Available in English and Spanish.*



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## Lymphoma Research Foundation

[bit.ly/LRF-CAR-T](https://bit.ly/LRF-CAR-T)

(310) 204-7040

(800 ) 500-9976

[Helpline@lymphoma.org](mailto:Helpline@lymphoma.org)

Online fact sheets about CAR-T cell therapies approved for patients with lymphoma.

## nbmtLINK

[nbmtlink.org/marrow-masters-podcast](https://nbmtlink.org/marrow-masters-podcast)

(248) 358-1886

(800) 546-5268

[info@nbmtlink.org](mailto:info@nbmtlink.org)

Podcasts about CAR T-cell therapy.

## Learn about CAR T-cell Centers

BMT InfoNet's Directory of CAR T-cell Centers at [bmtinfonet.org/car-t-cell-centers](https://bmtinfonet.org/car-t-cell-centers) provides details about:

- the number of CAR T-cell therapies done annually at each center
- CAR T-cell products used
- diseases treated
- patients accepted (adult and/or pediatric)
- key personnel
- accreditation status
- link to each center's website.



## CAR T-cell Support Groups

BMT InfoNet's CAR T-cell Support Groups provide patients with a welcoming, safe, online space to connect with others who have been through CAR T-cell therapy. Each group is led by a licensed mental health provider who has extensive experience helping CAR T-cell patients.

To learn more go to at [bmtinfonet.org/support-groups](https://bmtinfonet.org/support-groups), email [michala@bmtinfonet.org](mailto:michala@bmtinfonet.org), or phone 847-433-3313.



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# FINANCIAL SUPPORT

## **BMT InfoNet Patient Assistance Fund**

**[bmtinfonet.org/PAF](http://bmtinfonet.org/PAF)**

**(847) 433-3313**

**(888) 597-7674**

**[help@bmtinfonet.org](mailto:help@bmtinfonet.org)**

- Grants for living expenses during first 12 months after a transplant using your own cells or cells from a related donor.
- Grants for patients who have graft-versus-host disease (GVHD).

## **NMDP®**

**[nmdp.org/grants](http://nmdp.org/grants)**

**(612) 362-3410**

**(888) 999-6743**

**[patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)**

Financial help for:

- donor search and costs
- housing costs
- travel to clinical trial

## **Leukemia & Lymphoma Society**

**[lls.org/financial-support](http://lls.org/financial-support)**

**(800) 955-4572**

**[infocenter@lls.org](mailto:infocenter@lls.org)**

Financial aid for treatment-related expenses, travel, lodging and insurance co-pays.

## **Lymphoma Research Foundation**

**[lymphoma.org/financialsupport](http://lymphoma.org/financialsupport)**

**(800) 500-9976**

**[Helpline@lymphoma.org](mailto:Helpline@lymphoma.org)**

Financial aid for patients with lymphoma or Hodgkin lymphoma and chronic lymphocytic leukemia.

## **Air Charity Network**

**[aircharitynetwork.org](http://aircharitynetwork.org)**

**(877) 621-7177**

Free air transport for patients who must travel for medical treatment.

---

## Alex's Lemonade Stand

[alexlemonade.org/travel-for-care](http://alexlemonade.org/travel-for-care)  
(866) 333-1213

Assistance with travel and hotel bills while child is undergoing treatment.

## American Cancer Society

[cancer.org/support](http://cancer.org/support)  
(800) 227-2345

Free car rides to medical care. Access to low cost lodging.

## CancerCare, Inc.

[cancercare.org/copayfoundation](http://cancercare.org/copayfoundation)  
(800) 813-4673  
[information@cancercarecopay.org](mailto:information@cancercarecopay.org)

Co-pay assistance for cancer patients with certain diseases.

## Children's Organ Transplant Association

[cota.org](http://cota.org)  
(800) 366-2682  
[cota@cota.org](mailto:cota@cota.org)

Fundraising help for a child who needs a transplant.

## Dollar For

[dollarfor.org](http://dollarfor.org)

Help for qualified patients to access discounts on hospital bills.

## Expect Miracles Foundation

[expectmiraclesfoundation.org/samfund](http://expectmiraclesfoundation.org/samfund)  
(617) 938-3484  
(866) 439-9365  
[programs@expectmiraclesfoundation.org](mailto:programs@expectmiraclesfoundation.org)

Financial aid for young adults ages 21-39 after cancer treatment. Grants for fertility treatments or adoption.

## Healthcare Hospitality Network

[hhnetwork.org/directories](http://hhnetwork.org/directories)  
800-318-8861

Referrals to free or low-cost lodging near medical facilities.

## HelpHOPELive

[helphopelive.org](http://helphopelive.org)  
(800) 642-8399

Fundraising help for patients with a catastrophic illness.

## Joe's House

[joeshouse.org](http://joeshouse.org)  
(877) 563-7468  
[info@joeshouse.org](mailto:info@joeshouse.org)

Directory of lodging near medical centers with patient discount rates.

## The National Children's Cancer Society

[thenccs.org/financial-assistance](http://thenccs.org/financial-assistance)  
(314) 241-1600  
(800) 532-6459  
[communications@thenccs.org](mailto:communications@thenccs.org)

Help with travel, meals, and lodging while a child is receiving medical care.

## National Foundation for Credit Counseling

[nfcc.org](http://nfcc.org)  
(800) 388-2227

Network of credit counseling agencies that help people facing bankruptcy or overwhelming debt.





### **National Institutes of Health Center for Cancer Research**

[bit.ly/NIH-clinical-trials](http://bit.ly/NIH-clinical-trials)  
(888) 624-1937

Free stem cell transplants for patients who qualify for one of the agency's clinical trials.

### **National Organization for Rare Disorders**

[rarediseases.org/patient-assistance](http://rarediseases.org/patient-assistance)  
(203) 744-0100  
(800) 469-0283  
[orphan@rarediseases.org](mailto:orphan@rarediseases.org)

Financial aid for patients with certain rare diseases.

### **Patient Access Network Foundation**

[panfoundation.org](http://panfoundation.org)  
(866) 316-7263  
[info@panfoundation.org](mailto:info@panfoundation.org)

Help with co-pays for medicines to treat certain diseases.

### **Patient Advocate Foundation Co-Pay Program**

[copays.org](http://copays.org)  
(757) 952-0118  
(866) 512-3861

Grants to qualified patients to help with prescription co-pays and insurance co-pays and deductibles.

### **Pinkyswear Foundation**

[bit.ly/pinkyswear-financial-help](http://bit.ly/pinkyswear-financial-help)  
(952) 974-9600

Financial assistance for families with a child undergoing cancer treatment.

### **UnitedHealthcare Children's Foundation**

[uhccf.org](http://uhccf.org)  
(855) 698-4223

Help with medical expenses not covered by insurance for patients up to age 16 who have health insurance.

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## What to Know about Health Insurance

### Maximize Your Benefits

Most transplant centers have a financial coordinator who will work with you and your insurance company.

It is important to tell your financial coordinator upfront about all of your insurance policies so that he or she can maximize your benefits and minimize your out-of-pocket expenses.



### Cancer Insurance Policies

Some patients have a cancer policy and expect the policy to cover the full cost of treatment. Cancer policies do not replace full insurance plans or provide sufficient benefits to cover the cost of a transplant or CART-cell therapy. Rather, they help cover things like deductibles and co-pays on your main health insurance policy and lost income.

### Health Insurance Cost-Sharing Ministries

Some patients belong to a health insurance cost-sharing ministry. These arrangements are not considered insurance by most transplant and CAR T-cell centers because there is no guarantee that the fund will pay your medical bills.

Consequently, most centers will require a significant deposit from you up-front before beginning treatment.

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# HEALTH INSURANCE

## **BMT InfoNet**

**[bmtinfonet.org/insurance](http://bmtinfonet.org/insurance)**

**(847) 433-3313**

**(888) 597-7674**

**[help@bmtinfonet.org](mailto:help@bmtinfonet.org)**

Online information and videos about selecting a health insurance plan that will suit your needs and appealing a denial of coverage.

## **HealthCare.gov**

**[healthcare.gov](http://healthcare.gov)**

**(800) 318-2596**

Federal website that offers health insurance plans for people not covered by employer or private health insurance. Discounts available based on income.



## NMDP®

[bit.ly/NMDP-Insurance](https://bit.ly/NMDP-Insurance)

(612) 362-3410

(888) 999-6743

[patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)

Tips for talking to your insurance company about what your plan covers. Options for getting health insurance if you have none.

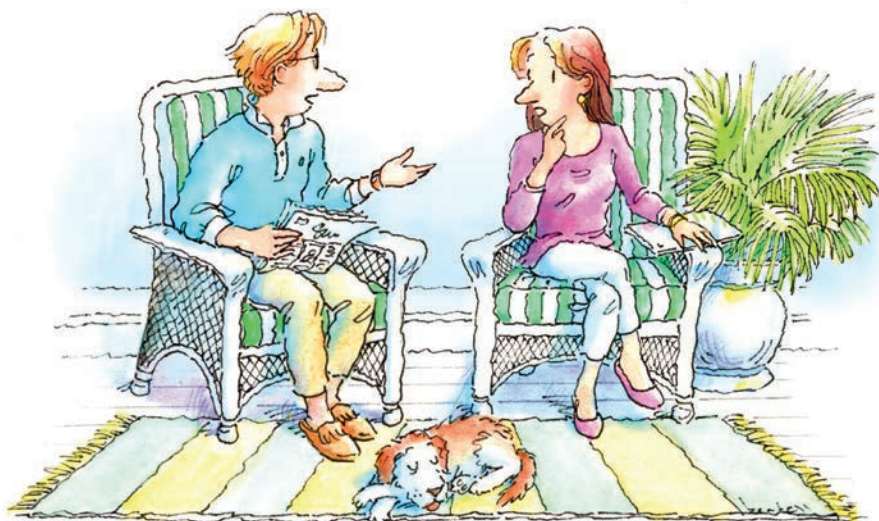
## Triage Cancer

[Triagecancer.org](https://Triagecancer.org)

(424) 258-4628

[triacancer.org/gethelp](https://triacancer.org/gethelp)

Information about health insurance options, disability insurance, the Americans with Disabilities Act, and the Family and Medical Leave Act.



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## RESOURCES FOR CAREGIVERS

### **BMT InfoNet**

**bmtinfonet.org**  
**(847) 433-3313**  
**(888) 597-7674**  
**help@bmtinfonet.org**

Detailed information about caring for a transplant recipient at [\*\*bmtinfonet.org/caregivers\*\*](https://bmtinfonet.org/caregivers).

Information about caring for a CAR-T-cell recipient at [\*\*bmtinfonet.org/CAR-T-Caregiver\*\*](https://bmtinfonet.org/CAR-T-Caregiver).

Peer support through Caring Connections program. (see next page)

Support groups for caregivers of GVHD patients at [\*\*bmtinfonet.org/support-groups\*\*](https://bmtinfonet.org/support-groups).

### **NMDP®**

**NMDP.org/Caregiver**  
**(612) 362-3410**  
**(888) 999-6743**  
**patientinfo@nmdp.org**

Information about caregiving for a patient going through transplant.

### **CaringBridge**

**caringbridge.org**  
**(651) 789-2300**  
**customercare@caringbridge.org**

Website to organize volunteers and allow patients to keep in touch with family and friends during treatment.

### **Lotsa Helping Hands**

**lotsahelpinghands.com**

Website to organize volunteers during and after treatment.

### **Meal Train**

**mealtrain.com**

Website to recruit volunteers to provide meals and raise funds to help the patient.

### **nbmtLINK**

**nbmtlink.org/caregivers-guide**  
**(800) 546-5268**  
**info@nbmtlink.org**

Booklet: *Caregiver's Guide for Bone Marrow/Stem Cell Transplant*

## Caring Connections Peer Support

If you or a loved one is going to have a transplant or CAR T-cell therapy, chances are you're feeling scared and overwhelmed. BMT InfoNet's Caring Connections Program can help!

Talk with someone who has been through transplant or CAR T-cell therapy and understands how you feel. Our volunteers can:

- share their experience
- answer your questions
- provide emotional support
- offer tips for coping with household and job responsibilities, the needs of other family members, and more



To learn more go to [bmtinfonet.org/caring-connection](https://bmtinfonet.org/caring-connection) or phone 847-433-3313.



Want to become a Caring Connections volunteer? Go to [bmtinfonet.org/volunteer](https://bmtinfonet.org/volunteer) for details.



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# EMOTIONAL SUPPORT

## BMT InfoNet

[bmtinfonet.org](http://bmtinfonet.org)

(847) 433-3313

(888) 597-7674

[support@bmtinfonet.org](mailto:support@bmtinfonet.org)

Caring Connections one-on-one peer support (see page 16).

Online support groups for patients and caregivers living with graft-versus-host disease and CAR T-cell recipients at [bmtinfonet.org/support-groups](http://bmtinfonet.org/support-groups).

Online Directory of Mental Health Providers.

## NMDP®

[nmdp.org](http://nmdp.org)

(612) 362-3410

(888) 999-6743

[patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)

Individual telephone counseling for patients and caregivers.

Monthly virtual support groups and one-on-one peer support.

## Find a Mental Health Provider

BMT InfoNet's Directory of Mental Health Providers lists licensed therapists who have experience working with transplant and CAR T-cell recipients, people living with graft-versus-host disease, and their caregivers.

To search the director go to [bmtinfonet.org/mh-directory](http://bmtinfonet.org/mh-directory).









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# PLANNING FOR SURVIVORSHIP

## MANAGING LATE EFFECTS

### BMT InfoNet

[bmtinfonet.org/late-effects](https://bmtinfonet.org/late-effects)

(847) 433-3313

(888) 597-7674

[help@bmtinfonet.org](mailto:help@bmtinfonet.org)

Online information and videos about managing medical, psychosocial and financial challenges after transplant and CAR T-cell therapy.

Annual online Celebrating a Second Chance at Life Survivorship Symposium at [symposium.bmtinfonet.org](https://symposium.bmtinfonet.org).

### NMDP®

[bit.ly/NMDP-After-Transplant](https://bit.ly/NMDP-After-Transplant)

(763) 362-3410

(888) 999-6743

[patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)

Care guidelines for patients six- and twelve-months post-transplant.

### Children's Oncology Group [survivorshipguidelines.org](https://survivorshipguidelines.org)

Long-term follow-up guidelines for children who underwent cancer treatment.

Planning for Survivorship

## Video Learning Library

Unlock a wealth of easy-to-understand information about how to live well after transplant and CAR T-cell therapy at [bmtinfonet.org/videos](https://bmtinfonet.org/videos). Choose videos from these categories:

- Transplant Basics
- CAR T-cell Therapy
- Graft-versus-Host Disease
- Other Transplant Complications
- Caregivers
- Exercise and Rehabilitation
- Nutrition, Herbs, and Supplements
- Employment and Insurance
- Patient Stories

A transcript and the speaker's slides accompany each video.



## NUTRITION

### BMT InfoNet

[bmtinfonet.org/nutrition](http://bmtinfonet.org/nutrition)

(847) 433-3313

(888) 597-7674

[help@bmtinfonet.org](mailto:help@bmtinfonet.org)

Online information and free pamphlet on managing various eating challenges at [bmtinfonet.org/eat-well](http://bmtinfonet.org/eat-well).

Videos about nutrition and eating challenges after transplant.

### NMDP®

[nmdp.org/FoodSafety](http://nmdp.org/FoodSafety)

(612) 362-3410

(888) 999-6743

[patientinfo@nmdp.org](mailto:patientinfo@nmdp.org)

Food safety guidelines after transplant.



### *Eating Well, Living Well after Transplant*

This free pamphlet explains how to manage the many eating challenges that can occur after transplant such as dry mouth, mouth sores, lack of appetite, nausea, changes in food taste and more.

Order online at [bmtinfonet.org/eatingwell](http://bmtinfonet.org/eatingwell) or by phoning 888-597-7674.

*Available in English and Spanish.*

### CancerDietitian

[cancerdietitian.com](http://cancerdietitian.com)

Website with information on diets for cancer survivors, food safety and menu planning.

## CHRONIC FATIGUE AND SLEEP PROBLEMS

### BMT InfoNet

[bmtinfonet.org/fatigue-and-sleep](http://bmtinfonet.org/fatigue-and-sleep)

(847) 433-3313

(888) 597-7674

[help@bmtinfonet.org](mailto:help@bmtinfonet.org)

Online information and videos about managing fatigue and insomnia.

### Society of Behavioral Sleep Medicine

[bit.ly/sleep-therapists](http://bit.ly/sleep-therapists)

(859)312-8880

Directory of therapists trained in cognitive behavioral therapy for insomnia.

### Books

#### **The Insomnia Workbook: A Comprehensive Guide to Getting the Sleep You Need**

Stephanie Silberman

ISBN-13: 978-1572246355

#### **Say Good Night to Insomnia**

Gregg D. Jacobs

ISBN-13: 978-0805089585

#### **Overcoming Insomnia**

Jack D. Edinger and Colleen E. Carney

ISBN:978-0199339402

## SEXUAL HEALTH

### American Association of Sex Educators, Counselors and Therapists

**aasect.org**  
**(202) 449-1099**  
**info@aasect.org**

Offers a directory of certified sex therapists in the U.S.

### BMT InfoNet

**bmtinfonet.org/sexualhealth**  
**(847) 433-3313**  
**(888) 597-7674**  
**help@bmtinfonet.org**

Online information about sexual problems after transplant and strategies to manage them.

View videos about sexual health after treatment at **[bmtinfonet.org/videos](https://bmtinfonet.org/videos)**.

## Free Online Survivorship Symposium

The Celebrating a Second Chance at Life Survivorship Symposium is a wonderful opportunity to learn from transplant and CAR T-cell experts how to manage the many challenges that can arise after transplant or CAR T-cell therapy. It's also an opportunity to connect online with other survivors and caregivers.

### Workshop topics include:

- Protect Your Health after Transplant
- CAR T-cell Therapy
- Graft-versus-Host Disease
- Coping with Emotional Challenges
- Attention, Organization, and Memory Problems
- Managing Fatigue
- Other late effects of treatment
- Caregiver Challenges.

Join us at our next symposium and take charge of living!

For more information go to **[symposium.bmtinfonet.org](https://symposium.bmtinfonet.org)** or phone 888-597-7674.



# BMT INFONET





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# ADOLESCENT AND YOUNG ADULT RESOURCES

## Elephants and Tea

[elephantsandtea.org](http://elephantsandtea.org)  
[info@elephantsandtea.com](mailto:info@elephantsandtea.com)

Online magazine for adolescents and young adults (AYA) with cancer. Schedule of events of interest to AYA cancer survivors.

## Expect Miracles Foundation

[expectmiraclesfoundation.org/samfund](http://expectmiraclesfoundation.org/samfund)  
(617) 938-3484  
(866) 439-9365  
[programs@expectmiraclesfoundation.org](mailto:programs@expectmiraclesfoundation.org)

Financial aid for young adults ages 21-39 after cancer treatment.

Grants for fertility preservation and infertility treatment after transplant.

## First Descents

[firstdescents.org](http://firstdescents.org)  
(303) 945-2490  
[info@firstdescents.org](mailto:info@firstdescents.org)

Free local, national and international outdoor adventures for young adult cancer survivors.

## LIVESTRONG

[livestrong.org/we-can-help/young-adults](http://livestrong.org/we-can-help/young-adults)  
(855) 220-7777  
[livestrong@livestrong.org](mailto:livestrong@livestrong.org)

Information about issues of concern to adolescents and young adults after cancer treatment including fertility and family planning.

## Stupid Cancer

[stupidcancer.org](http://stupidcancer.org)  
212-619-1040  
[support@stupidcancer.org](mailto:support@stupidcancer.org)

Resources for adolescents and young adults (AYAs) during and after treatment.

## Ulman Foundation

[ulmanfoundation.org](http://ulmanfoundation.org)  
(410)-964-0202  
(888) 393-3863  
[info@ulmanfoundation.org](mailto:info@ulmanfoundation.org)

Information for young adults about navigating cancer treatment and survivorship.



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## PEDIATRIC RESOURCES

### **BMT InfoNet**

**bmtinfonet.org/pediatric-transplants**  
**(847) 433-3313**  
**(888) 597-7674**  
**help@bmtinfonet.org**

Information on when and how to talk to your child about transplant, and how to help siblings cope.

### **NMDP®**

**bit.ly/NMDP-children-teens**  
**(612) 362-3410**  
**(888) 999-6743**  
**patientinfo@nmdp.org**

Video for children about what to expect during and after a bone marrow transplant. Tips for back-to-school issues and helping siblings cope.

### **Children's Oncology Group**

**childrensoncologygroup.org**

Detailed medical information about childhood cancers, treatment options, side effects, and long-term follow-up survivorship guidelines.

### **Cure Search for Children's Cancer**

**curesearch.org**  
**(800) 458-6223**  
**info@curesearch.org**

Information about pediatric cancers, treatment options, and side effects.

### **Leukemia & Lymphoma Society**

**lls.org/children-and-young-adults**  
**(800) 955-4572**  
**infocenter@lls.org**

Information about childhood blood cancers, managing school issues, helping siblings cope, and coping tips for parents.

### **Alex's Lemonade Stand**

**alexslemonade.org**  
**(610) 649-3034**  
**(866) 333-1213**  
**resources@alexslemonade.org**

Information and support for children diagnosed with cancer and their siblings.

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## American Childhood Cancer Organization

**acco.org**

**staff@acco.org**

Information about pediatric cancers, treatment options, and long-term complications. Resources for parents, children, and teens.

## Books

### **Neutrophil's Guide to Stem Cell Transplants for Kids**

Robert Henslin

ISBN 978085373641

Book about transplant for children ages 9-12 and parents about blood cells and transplant.



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# CLINICAL TRIALS

**NMDP® Jason Carter  
Clinical Trials Search and  
Support Program**  
[ctsearchsupport.org](http://ctsearchsupport.org)  
(888) 814-8610  
[contact@ctsearchsupport.org](mailto:contact@ctsearchsupport.org)

Online information and telephone support to identify clinical trials open to patients with a blood cancer or other blood disorder.

**Leukemia & Lymphoma  
Society**  
[lls.org/treatment/types-treatment-clinical-trials](http://lls.org/treatment/types-treatment-clinical-trials)  
(800) 955-4572  
[infocenter@lls.org](mailto:infocenter@lls.org)

Find clinical trials open to blood cancer patients with the help of a patient navigator.



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## **International Myeloma Foundation**

**[myeloma.org/sparkcures](https://myeloma.org/sparkcures)**

Information about myeloma clinical trials in the U.S.

## **Lymphoma Research Foundation**

**<https://lymphoma.org/resources/supportservices/ctis>**

**800-500-9976**

**[helpline@lymphoma.org](mailto:helpline@lymphoma.org)**

Information about clinical trials for lymphoma patients in the U.S.

## **National Institutes of Health Center for Cancer Research**

**[ccr.cancer.gov/clinical-trials/patients](https://ccr.cancer.gov/clinical-trials/patients)**  
**(888) 624-1937**

Free stem cell transplants for patients who qualify for one of the agency's clinical trials.

## **National Institutes of Health clinicaltrials.gov**

Information about clinical trials at medical facilities world-wide.

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## MORE HELPFUL RESOURCES

### Autologous Stem Cell Transplants: A Handbook for Patients

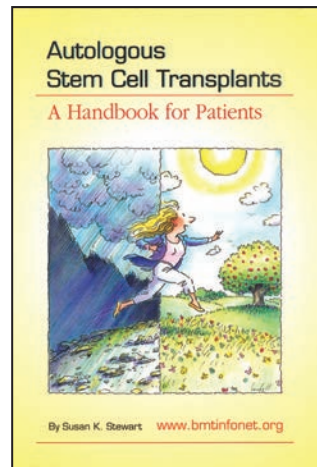
by Susan K. Stewart  
with Anna Schaal, RN, BSN, MS, ARNP  
Illustrations by Norm Bendell  
©2024

Price: \$12.95 (bulk discounts available)

A comprehensive easy-to-read book for patients undergoing a stem cell transplant using their own stem cells.

Chapters include:

- History of Transplantation
- An Introduction to Transplant
- Choosing a Transplant Center
- Insurance and Financial Help
- Emotional Challenges
- When Your Child Needs a Transplant
- Conditioning/Preparative Regimen and Side Effects
- Infection
- Nutrition and Eating Difficulties
- Relieving Pain
- Caregiving
- Planning for Survivorship
- Late and Long-Term Effects of Transplant



Available in English and Spanish

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## Bone Marrow and Blood Stem Cell Transplants: A Guide for Patients and Their Loved Ones

by Susan K. Stewart

Illustrations by Norm Bendell

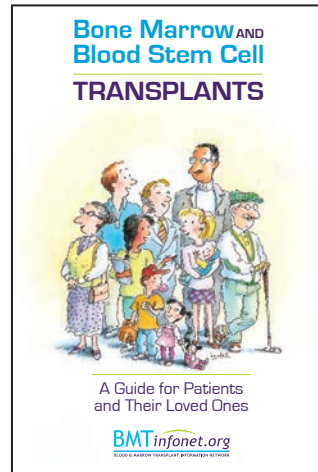
©2024

Price: \$12.95 (bulk discounts available)

A comprehensive easy-to-read book for patients undergoing a transplant using donor cells (allogeneic transplant).

Chapters include:

- History of Bone Marrow/Stem Cell Transplantation
- Steps Involved in an Allogeneic Transplant
- Choosing a Transplant Center
- Finding a Donor
- Being a Donor
- Insurance and Financial Help
- Emotional Challenges
- Conditioning/Preparative Regimen
- Graft-versus-Host Disease
- Infection
- Nutrition
- Relieving Pain
- When Your Child Needs a Transplant



- Caregiving
- Planning for Survivorship
- Late and Long-Term Effects of Transplant



Available in English and Spanish



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## Graft-versus-Host Disease: What to Know, What to Do

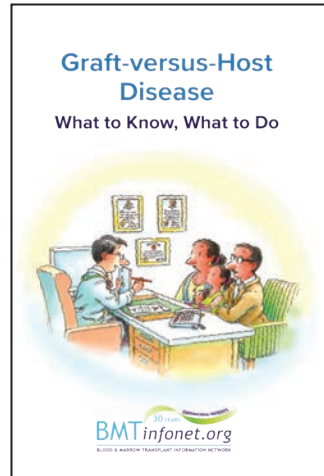
by Susan K. Stewart  
with Anna Schaal, RN, BSN, MS, ARNP  
Illustrations by Norm Bendell  
© 2024

Price: Free

Graft-versus-host disease (GVHD) is a complication that often occurs after a transplant using cells from a donor (an allogeneic transplant). This booklet will help you understand the symptoms of GVHD, organs it can affect, and treatment options.

Chapters include:

- What is graft-versus-host disease?
- Acute graft-versus-host disease
  - Prevention
  - Symptoms
  - Treatment
- Chronic graft-versus-host disease
  - How chronic GVHD is managed
  - Monitor yourself for symptoms
  - Find a GVHD specialist
- Infection
- Clinical trials
- Coping with the stress of GVHD
- The role of the caregiver



- Steroids and their side effects
- Drugs used to prevent and treat GVHD



Available in English and Spanish

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## CAR T-Cell Therapy: What to Expect Before, During and After

by Susan K. Stewart  
with Anna Schaal, RN, BSN, MS, ARNP  
Illustrations by Norm Bendell

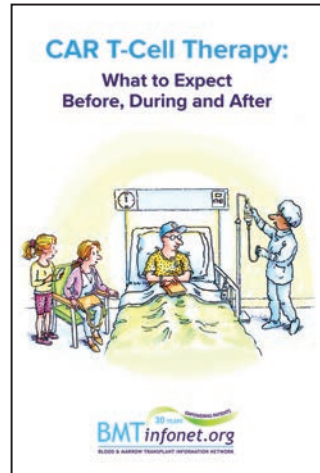
© 2024

Price: Free

If you are considering CAR T-cell therapy, this easy-to-read booklet will help you understand what to expect before, during, and after treatment.

Topics include:

- What is CAR T-cell therapy?
- What's involved in undergoing CAR T-cell therapy?
- What are the side effects?
- Follow-up care
- Coping with the stress
- The role of the caregiver
- Financial considerations
- Medical centers that offer CAR T-cell therapy
- Does CAR T-cell therapy cure cancer?
- Helpful resources



Available in English and Spanish





## Join Us on Social Media

Join our growing community of patients, caregivers, and healthcare professionals to access timely information, connect with others who understand your experience, and stay informed about upcoming events and support groups.

### **BMT InfoNet Facebook Club**

[facebook.com/bonemarrowstemcelltransplantclub](https://facebook.com/bonemarrowstemcelltransplantclub)

### **Linked In**

[linkedin.com/company/bmt-infonet](https://linkedin.com/company/bmt-infonet)

### **YouTube**

[youtube.com/user/BMTinfonet](https://youtube.com/user/BMTinfonet)

### **BLUE SKY**

[bsky.app/profile/bmtinfonet.bsky.social](https://bsky.app/profile/bmtinfonet.bsky.social)

### **INSTAGRAM**

[instagram.com/bmtinfonet](https://instagram.com/bmtinfonet)



# BMT INFONET

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