

Resources
from 2020 NIH Patient
Advocacy Summit

Patients and Caregivers

Websites with information about GVHD

- Be the Match®, www.bethematch.org/patient
- BMT InfoNet (Blood & Marrow Transplant Information Network), www.bmtinfonet.org
- nbmtLINK (National Bone Marrow Transplant Link), www.nbmttlink.org
- Leukemia & Lymphoma Society, www.lls.org
- Aplastic Anemia and MDS International Foundation, www.aamds.org
- National Cancer Institute, www.cancer.gov
- Post-transplant screening and preventive practices,
<http://www.cibmtr.org/ReferenceCenter/Patient/Guidelines/pages/index.aspx>
- Meredith A Cowden Foundation, <https://cowdenfoundation.org/>
- France Lymphome Espoir, <https://www.francelymphomeespoir.fr>
- Anthony Nolan, <https://www.anthonynolan.org/patients-and-families>
- cGVHD Eurograft, <https://www.gvhd.eu/resources/>

Books about GVHD

- **Graft-versus-Host Disease: What to Know, What to Do**, Susan K. Stewart, BMT InfoNet, ©2020, www.bmtinfonet.org/GVHDbook, Free
- **Enfermedad Injerto contra Huésped: Qué necesita saber. Qué necesita hacer**, Susan K. Stewart, ©2018, www.bmtinfonet.org/Spanish-gvhd-booklet, Free
- **Graft-versus-Host Disease: Living with the After Effects of Bone Marrow/Stem Cell Transplant**, nbmtLINK, www.nbmtlink.org/product/graft-versus-host-disease, \$20
- **nbmtLINK Summit Special for all participants today: FREE** book if you email Peggy Burkhard, peggyburkhard@nbmtlink.org and mention the Summit date. View our book: <https://bit.ly/GVHDBOOK>
- **European Society for Blood and Marrow Transplantation (EBMT) book for nurses**, <https://www.gvhd.eu/wp-content/uploads/2019/03/EBMT-Transplant-Book-for-Nurses-1.pdf>, free

GVHD Videos, Podcasts, and Webinars

- **Graft-versus-Host Disease, Be The Match®**, <https://youtu.be/T5a1MUaKIE>
- **Introduction to Chronic Graft-versus-Host Disease**, Corey Cutler MD, MPH, FRCPC, 2020, www.bmtinfonet.org/intro-GVHD-2020
- **Chronic Graft-versus-Host Disease of Skin and Connective Tissue**, Milan Anadkat MD, 2020, www.bmtinfonet.org/skin-GVHD-2020
- **Your Eyes and Graft-versus-Host Disease**, Zhonghui Katie Luo MD, PhD, 2020, www.bmtinfonet.org/eyes-GVHD-2020
- **Graft-versus-Host Disease of the Gastrointestinal Tract and Liver**, Zachariah DeFilipp MD, 2020, www.bmtinfonet.org/GI-GVHD-2020
- **Breath of Life: Your Lungs after Transplant**, Jane Turner MD, 2020, www.bmtinfonet.org/lungs-GVHD-2020

GVHD Videos, Podcasts, and Webinars

- **Your Mouth and Chronic Graft-versus-Host Disease**, Nathaniel Treister DMD, DMSc, 2020, www.bmtinfonet.org/mouth-GVHD-2020
- **Genital GVHD, Sex and Intimacy**, Pamela Stratton MD, 2019, www.bmtinfonet.org/genital-GVHD-2019
- **Riding the Emotional Roller Coaster of GVHD**, Katie Schoeppner MSW, LICSW, 2019, www.bmtinfonet.org/video/emotionalGVHD
- **GVHD Caregivers: Building Resilience for the Road to Recovery**, Michelle Bishop PhD, 2020, www.bmtinfonet.org/caregivers-GVHD-2020
- **Chronic Graft-versus-Host Disease: Managing Symptoms and Emotional Challenges**, Stephanie Sarantopoulos MD, PhD and Sean Kelley, GVHD Patient, 2019, www.nbmtlink.org/webinars-podcasts/chronic-graft-versus-host-disease-cghvd-webinar-updated-treatment-updates-tips-for-survival-and-support

GVHD Videos, Podcasts, and Webinars

- **Cognition after Transplant: Coping with Attention, Learning and Memory Issues**, Michael Parsons PhD, 2020, www.bmtinfonet.org/video/cognitive2020
- **Fatigue and Transplant: New Insights**, Kenneth Miller MD, 2020, www.bmtinfonet.org/video/fatigue-2020
- **Enfermedad de Injerto Contra Huesped (EICH) Cronica: Diagnostico y Manejo**, Daniel Couriel MS, 2017, www.bmtinfonet.org/intro-GVHD-2017-Spanish
- **Managing Sleep Challenges after Transplant**, Eric Zhou PhD, 2020, <https://www.bmtinfonet.org/video/managing-sleep-problems-after-transplant-3>

GVHD Videos, Podcasts, and Webinars

- **Marrow Masters GVHD Podcasts Series:** There is one whole season dedicated to GVHD and a special Season 2 episode featuring Dr. Steve Pavletic. Visit <https://bit.ly/MarrowMasters>
- **Lunch & Learn with the LINK:** There are several on GVHD and many other topics. They can be accessed here: <https://bit.ly/manyLNLs>
- **How Microbiome and Diet Affect Your GVHD,** Webinar 2020, <https://bit.ly/GVHDSept29webinar>
- **A Virtual Town Hall: Adult Leukemia Care in the Time of COVID-19,** Total Health Conferencing, 2020, <https://www.youtube.com/watch?v=TeykUvjMzdY>
- **How Exercise Can Improve Fatigue, Stamina and Strength,** Scott Capozza, 2020, <https://www.bmtinfonet.org/video/how-exercise-can-improve-fatigue-stamina-and-strength>
- **Exercises for Patients to help manage fatigue,** from Brigham and Women's Hospital, https://partners.medbridgego.com/access_token; access code XA3FFPF8

Emotional Support for GVHD Patients and Family Members

- **Be The Match®**, free professional telephone counseling, one-on-one peer support program, support groups for GVHD patients and caregivers, patientinfo@nmdp.org, phone 888-999-6743 or 763-406-3410
- **BMT InfoNet, Caring Connections** telephone one-on-one peer support for patients and family members, www.bmtinfonet.org/caring-connection, help@bmtinfonet.org, phone 888-597-7674 or 847-433-3313; telephone support groups for GVHD patients and caregivers
- **nbmtLink Peer Support on Call**, telephone one-on-one peer support for patients and family members, info@nbmtlink.org, phone 800-546-5268
- **Leukemia & Lymphoma Society, First Connection** one-on-one peer support program, www.lls.org/support/peer-to-peer-support, 800-955-4572

Emotional Support for GVHD Patients and Family Members

- **AA-MDS International Foundation**, Peer support network, www.aamds.org/support/support-networks, 800-747-2820
- **Cancer Support Community**, Cancer Support Help Line, 888-793-9355; MyLifeLine peer support www.cancersupportcommunity.org/mylifeline
- **CancerCare**, free professional counseling for cancer patients and caregivers in New York and New Jersey; support group for caregivers of transplant patients, 800-813-4673
- **Imerman Angels**, telephone one-on-one peer support, <https://imermanangels.org/contact-us>
- **Patient Advocacy Committee of the European Society for Blood and Marrow Transplantation (EBMT)**, advocacy committee for European patients after stem cell transplantation, <https://www.ebmt.org/patient-advocacy-committee>

Emotional Support for AYA Patients and Family Members

- **Livestrong**, Adolescents and Young Adults, <https://www.livestrong.org/we-can-help/young-adults>, phone 855-220-7777
- **Steven G AYA Cancer Research Fund**, Helping adolescents and young adults with wellness, education, and research, <http://fightconquercure.org/>, phone 216-387-2681
- **Elephants and Tea**, Support for the AYA cancer community, in the form of conversation, webinars, virtual gatherings, and written materials, <https://elephantsandtea.com/>, email info@elephantsandtea.com

Clinical Trials for GVHD Patients

- **Natural History Study of Clinical and Biological Factors Determining Outcomes in Chronic Graft-versus-Host Disease:** free four-day evaluation of your GVHD at the National Cancer Institute. Phone 240-858-3681,
<https://clinicaltrials.gov/ct2/show/NCT00092235?cond=graft-versus-host+disease&lead=National+Cancer+Institute&cntry=US&rank=7>
- **Jason Carter Clinical Trials Program, operated by Be the Match:** helps patients locate and connect with GVHD and other clinical trials. Phone 888-814-8610,
www.ctsearchsupport.org
- **Clinicaltrials.gov:** U.S. federal database of clinical trials for a variety of disorders.

Financial Assistance & Fundraising

- **Be The Match**, financial help for patients who had a transplant facilitated by NMDP/Be The Match. <https://network.bethematchclinical.org/transplant-centers/access-to-transplant/patient-services-and-grants/patient-assistance-grant-program>, email patientgrants@nmdp.org, phone 763-406-8114.
- **BMT InfoNet Patient Assistance Program**, grants to help GVHD patients pay for housing, food, transportation and/or utilities. Email Margaret@bmtinonet.org, phone 888-597-7674 or 847-433-3313.
- **Bone Marrow & Cancer Foundation**, grants to help with transplant-related expenses. <https://bonemarrow.org/support-and-financial-aid/financial-assistance> , phone 800-365-1336
- **Leukemia & Lymphoma Society**, grants for patients with blood cancers to help with treatment- and non-treatment related expenses, lls.org/support/financial-support, phone 800-955-4572

Financial Assistance & Fundraising

- **Lymphoma Research Foundation**, grants for patients lymphoma to help with treatment- and non-treatment related expenses, <https://lymphoma.org/learn/supportservices/financialsupport>, phone 800-500-9976.
- **Children's Organ Transplant Association (COTA)**, fundraising help for families with a child that needs a transplant, <https://cota.org>, phone 800-366-2682
- **Help, Hope, Live**, fundraising help pay for transplant expenses insurance doesn't cover. <https://helphopelive.org>, phone 800-642-6106.
- **National Foundation for Transplants**, fundraising help pay for transplant expenses insurance doesn't cover. <https://transplants.org>, phone 800-489-3863

Financial Assistance & Fundraising

- **National Foundation for Credit Counseling**, free personal counseling to eliminate late fees, consolidate bills into smaller monthly payments, stop collection calls, pay off debt faster, lower interest rates, improve monthly spending habits, www.nfcc.org/about-us or phone 800-388-2227.
- **Pinkyswear Foundation**, grants for housing, car payments, groceries, utility bills and childcare for families with a child undergoing cancer treatment. pinkyswear.org/programs/envelopes, phone 952-974-9600.
- **The National Children's Cancer Society**, grants for travel, meals and lodging while a child with cancer is receiving medical care. thenccs.org/financial-assistance, phone 800-532-6459
- **Triage Cancer**, information about debt management, fundraising, pharmaceutical assistance programs and insurance. <https://trriagecancer.org/financial>