



2020 NIH Chronic GvHD Patient Advocacy Summit

November 20, 2020



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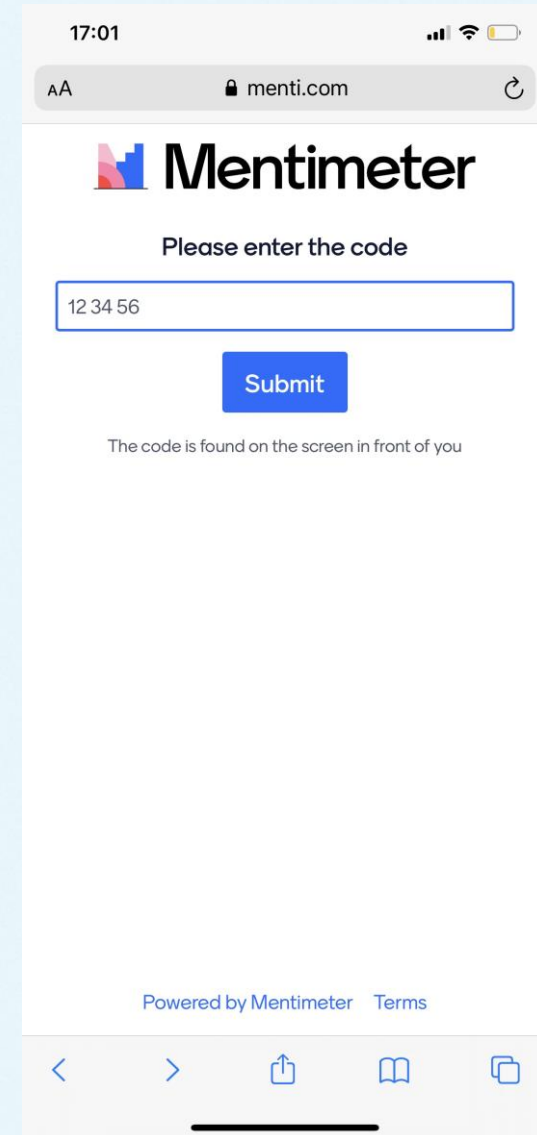
Presentation Agenda



- Review of NIH Chronic GVHD Consensus working group manuscripts
- Support and Education for Patients and Caregivers
- Psychosocial and Neurocognitive Impact of CGVHD
- Survivorship and Long-term Care
- Q & A Session

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Etiology and Prevention

Katie Schoeppner, LICSW & Michelle M. Bishop, PhD





Etiology and Prevention: Synopsis of Manuscript



- Moderate to severe cGVHD can be debilitating & deadly, needs to be prevented
- We have some effective prevention strategies, but further research is needed
- We need to find balance between decreasing cGVHD while maintaining the GVT effect to prevent relapse
- Goal is to achieve the highest GVT effect with the minimum cGVHD



Etiology and Prevention: Synopsis of Manuscript


- The causes of cGVHD are multifactorial
 - Primary and secondary insults
 - Donor, graft, recipient factors
 - Tissue damage and dysfunction from pre-HCT conditioning, post-HCT infections, immunosuppressive medications, changes in microbiome and mucosal integrity
 - Multiple immune populations are important
- Where, when, and how to intervene
 - Different targets – donor selection, graft engineering, t-cell depletion, balance of immune effector & regulatory cells, infection & tissue damage prevention, etc.
 - cGVHD risk assessment and stratification tools
 - Prevention trial design



Etiology and Prevention: Key Points For Patients and Caregivers



- Patients are benefiting from what we already know (e.g., type of donor, T-cell & B-cell depletion) and will presumably benefit from further research
- It is critical to the prevention of relapse that cGVHD is not eradicated completely – important for patients to understand this
- There are important considerations to balance the benefit and risks of interventions at different timepoints along HCT experience



Etiology and Prevention: Additional Comments/Questions



- Could patients positively impact their own health/recovery/cGVHD prevention?
 - Can patient health practices help to reduce certain secondary insults (e.g., oral care and sun exposure)? If, yes...
 - Are recommendations standardized?
 - Do patients understand and engage in these behaviors?
 - Are community physicians aware of health practice recommendations?
 - Are there barriers to compliance? (e.g. health literacy, finances, insurance, systemic issues)
 - Would creating patient/provider fact sheets be useful? Improve health behaviors?
 - Do patients understand how to assess their own cGVHD symptoms?
 - How do we best educate and empower patients, caregivers, and community physicians?



Etiology and Prevention: Beyond Clinical Outcomes - Quality of Life Matters



- Other health sequelae, such as infections and side effects of immunosuppressants, may negatively impact QOL even if cGVHD grade is reduced – this matters immensely to patients
- QOL assessment should be included in research and prevention trials



Clinical Implementation and Early Diagnosis

Meredith Cowden, LPCC-S





Clinical Implementation and Early Diagnosis



Goals of Clinical Implementation and Early Diagnosis manuscript:

- Provide updated recommendations for implementation of diagnostic criteria to prevent late recognition of cGVHD
- Outline future research to help identify cGVHD sooner, both systemically and with highly morbid manifestations of cGVHD
- Specific organs discussed in the paper are: skin/fascia, eyes, and lungs, as these have the highest incidence of irreversibility and morbidity
- Guidelines are outlined for additional organs, including mouth, liver, GI tract and genitalia



Clinical Implementation and Early Diagnosis



- Overall improvement in early diagnostic efficacy is possible by:
 - Better education for healthcare providers regarding diagnosis of cGVHD, using shorter, targeted training sessions, online platforms, teleconferencing, and e-tools (apps)
 - Routine evaluation for cGVHD beyond clinical trials and more within clinical practice, including baseline status of patient pre-transplant, at Day 100, and at follow-up visits every 1 to 3 months
 - Empowering patients to learn about, monitor, and report signs and symptoms of cGVHD to provider
 - Telehealth tools may assist with this, but physical evaluation is necessary as well



Clinical Implementation and Early Diagnosis



What does this mean for patients and caregivers?

- Currently, many patients do not meet NIH Consensus diagnostic criteria until the cGVHD manifestations are irreversible, even though there are concerning signs and symptoms before this
- Earlier diagnosis may lead to better management and treatment of cGVHD, reducing negative impact on patients and their caregivers (reduced symptom burden, improved QOL, reduced strain on caregivers)
- Patients are the experts of themselves! The guidelines encourage patients to participate in their own evaluation and treatment, facilitating a collaborative approach between patient and provider



Clinical Implementation and Early Diagnosis



- Recommendations include observational studies of patients over at least 1 to 2 years post-transplant
 - It may be valuable to extend the timeframe of observational studies, as there are very few studies that focus on patients more than 10 years post-transplant
- Technology allows for increased communication between patient and provider and opportunities for self-evaluation of patients at home
 - Apps could be created to facilitate self-evaluation and remind patients and caregivers of what to look for, as well as how to tell if a change is related to cGVHD or not, using Lee Symptom Scale, P-ROM, etc.



Clinical Implementation and Early Diagnosis



- Potentially increasing the participation of patients and/or caregivers in the follow-up evaluation of symptoms empowers patients and facilitates more collaborative relationship with care team
- Challenges potentially around presentation of cGVHD symptoms, as they may appear as other conditions, or be related to HCT, pre-transplant and/or unassociated condition, etc. rather than cGVHD
 - Biomarker identification may assist with this
- Key factor: ongoing education for patients and providers or more readily available access to transplant team
 - Patients/caregivers often reach out to community supports and peers (i.e., online support forums) for assistance in identification of cGVHD
- Involvement of patients, advocates, and caregivers in design of research studies and/or app development may increase successful outcomes for both



Pre-Emptive Therapy

Susan Stewart





Pre-Emptive Therapy: An Overview of the Manuscript



- General risk factors for cGVHD are **known**.
- Predicting who has a **high risk** of developing **moderate/severe** cases of cGVHD requires identifying predictive biomarkers.
- Severity of disease in **high-risk patients** might be reduced with pre-emptive therapy, given before symptoms of cGVHD appear.
- Giving pre-emptive therapy to all patients after transplant could increase side effects in patients who would not benefit from the therapy.
- Trials to identify biomarkers and test pre-emptive therapies are expected to take 6-10 years.



Pre-Emptive Therapy: What this means for patients and caregivers



- In the future, we may be able to personalize treatment plans for each cGVHD patient
- Offering personalized cGVHD treatment plans will require:
 - identifying biomarkers that accurately predict a patient's risk of developing moderate/severe cGVHD
 - clinical trials to test whether early treatment in high-risk patients actually reduces the severity of cGVHD
 - identifying which agents, if any, given before symptoms of cGVHD appear are most effective
 - ensuring all transplant centers are capable of offering personalized therapy to their patients



Pre-Emptive Therapy: Some Things to Consider

- Can we shorten the timeline?
 - Biomarkers 3 years + clinical trials 3-7 years + integration into standard practice = ??? years
 - Concurrent trials? Is testing currently available therapies prophylactically really more dangerous to patients than allowing moderate/severe cases of cGVHD to develop?
- What can be done while we wait to reduce incidence of cGVHD?
 - bone marrow vs. PBSC?
 - expand use of therapies like post-transplant cyclophosphamide?
- Regional GVHD Multidisciplinary clinics



Treatment of Established cGVHD

Guy Bouguet and Peggy Burkhard





Treatment of Established Chronic GvHD



- Corticosteroids are toxic for patients and unfortunately still the front line therapy
- Chronic GVHD is a heterogeneous disease and is the leading cause of morbidity in allogeneic transplantation
- Corticosteroids are still the systematic first line but with heavy side effects
- Despite numerous new therapeutic treatments (immuno-targeted), the clinical and biological markers relevant for better success are not always clear.
- If we want to change practice, it's important to better design single innovative therapy trials compared to steroids.
- Systematic sample (e.g., biopsies) collection at all phases of the patient journey is key to better understand and address GVHD and design trials.
- Better coordination between center and industry in clinical trial design
- Large randomized clinical trials for new agents should be promoted



Treatment of Established Chronic GvHD

- What does this mean for patients and caregivers?
 - Better management for cGVHD by optimized clinical trial designs
 - A more personalized approach to treatments through newly designed algorithms
 - More sampling interventions (biopsies...)
 - Better outcome with less invalidating/disabling side effects
 - Better QOL
 - Potential corticosteroid-free treatment of cGVHD



Treatment of Established Chronic GvHD

- Additional commentary and perspective
 - What will it take to get trials progressing faster?
 - What are the barriers to clinical trials and progress in research/practice?
- Because.....
- GVHD has a multi-dimensional impact on patient's QOL
 - cGVHD can become a heavier burden than the original disease
 - Patients should be better educated in recognizing first potential GVHD symptoms
 - The goal of future clinical trials is for treatments to be prescribed in a more effective manner with a more personalized approach, either based on clinical phenotype or biological profile.
 - Patient Advocacy Groups can help promote and educate re: trials



Highly Morbid Forms of cGVHD

Chiara DeBiase, MCSP and Christina Ferraro, CNP





Highly Morbid Forms of chronic GvHD

- While progress had been made in early treatment of cGVHD late forms of cGVHD with fibrosing changes remain challenging and are often permanent
- Most frequent organs affected that impact quality of life the most:
 - skin (physical function)
 - eyes (vision)
 - lung (physical functioning and survival)
 - intestines (survival)
- The current strategy steroids +/- other agents primarily evaluated in early forms fails frequently and results in significant side effects (changes of mood, muscle loss, bone loss, diabetes)



Highly Morbid Forms of chronic GvHD

- Significant burden (QoL, social and occupational rehab, financial)
- Both – prevention of highly morbid forms by early intervention and treatment of established “non-reversible” forms is important (need for new steroid free interventions since muscle loss is increased by steroids)
- Development of predictive marker for response (*trial and error* approach goes on the expense of the patient)
- Survival endpoints or complete/partial remission concepts do not reflect the symptom burden of patients – need for relevant endpoints in clinical trials (QoL, symptom burden, physical functioning)



Highly Morbid Forms of chronic GvHD

- Provide access to trials/research targeting “non-reversible” late manifestations
- Establish evidence and subsequent guidelines for supportive care also (i.e. topical treatment of cutaneous GVHD, autologous serum eye drops).
- Toxicity (side effects) of treatment in case of prolonged exposure is relevant – currently not captured well
- Disseminate/spread the knowledge on treatment incl. supportive care



Highly Morbid Forms of chronic GvHD

What does this mean for patients and caregivers?

- Ideally more patients will participate in trials to help increase knowledge and treatment options
 - Small samples sizes can make it hard to form conclusions in trials
 - More patients involved the more impactful the data
- This includes many samples of blood, tissue (skin biopsies), tears, stools, etc.
- Frequent testing like PFT's or bone density
- Frequent patient reported outcomes (surveys)

But:

- Can lead to sample/survey fatigue
- Can increase trips to clinic which can be costly and time consuming



Highly Morbid Forms of chronic GvHD

- Consider:
 - Incentives/reimbursement to patients and caregivers to help offset out of pocket expenses when enrolling in studies
 - Researchers should be thoughtful about samples required and needed for studies

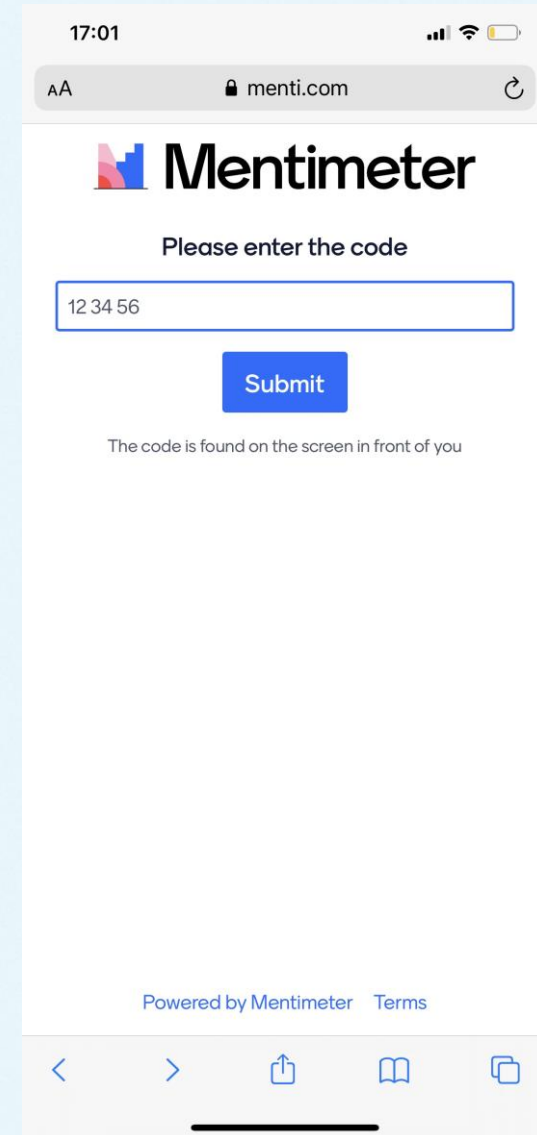


Menti Introduction



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Education and Support for Patients and Caregivers

Guy Bouguet, Peggy Burkhard, and Katie Schoeppner, MSW, LICSW

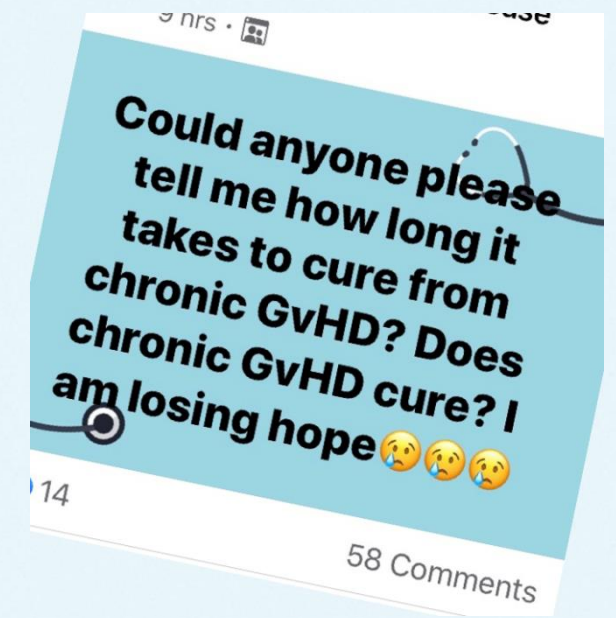
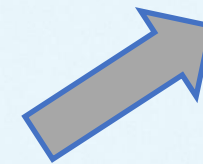


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Major Issues

- There are significant barriers to getting patients and their loved ones information about GVHD before, during and immediately after transplant
- Today we will scratch the surface. This actual social media post speaks volumes:



What gets in the way of patients and caregivers receiving support and education about cGVHD?

- Lack of internet or technology expertise prohibits access to education
- Lack of understanding of what is available through reputable patient advocacy groups. Patients don't always know where to get information they can trust.
- Beware of Dr. Google!
- Patients may not have been informed pre-transplant about the realities of GVHD: Need more from transplant staff and physicians. Getting the right information at the right time!
- Lack of unified approach within the center among all specialties required for GVHD follow up (cardio, dermatology, liver, eye, lung, etc.....)
- Local family doctors who resume care and do not know enough about cGVHD

Current Standard of Care

Who?	Transplant Center: Once a patient is referred and upon discharge from the hospital.
What?	Varies by Center: Sometimes a binder and long-term follow-up clinics
Where?	Transplant Centers – in hospital or clinic
How?	Information at the Medical Center, usually written and some verbal education. Reality of GVHD mostly ignored in pre-transplant discussions
When?	Varies by Center: Sometimes pre-transplant information, less post-transplant
What works and what does not?	People learn many different ways: offering a variety as one size does NOT fit all.



Gaps and Unmet Needs

What do providers, researchers, clinicians, etc. need to know to improve this?

- For providers/clinicians – There is an abundance of reputable education out there (BMT InfoNet, NMDP, nbmtLINK, Triage Cancer, Cancer Care, etc.). Encourage patients to seek it out.
- Need to focus on how and when patients need cGVHD education.
- Information needs to be repeatedly provided to patients and caregivers.
- Information sharing between patients and providers.



Solutions and Suggestions

- **Magic Wand Question?**
 - Ideal if patients had access to ALL the information about GVHD in one place
 - A vetted National Directory: Perhaps a Patient Nationwide Reference Guide/package portal within FACT/JACIE accreditation
- **Five Year Plan.**
 - Determine the landscape right now.
 - Who is using patient portals to share info?
 - Determine where patients get their education/information?
 - Elevate the importance of education!
- **How to Create This and What is Needed?**
 - Consider a multi-pronged approach.
 - Peer Support is also really important
 - Advocate like crazy.



Psychosocial and Neurocognitive Impact of cGvHD

Michelle Bishop, PhD, Meredith Cowden, LPCC-S, Susan Stewart, and Daniel Wolff, MD



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HCT Survival Comes with a Price

Psychosocial challenges:

(Barata, et al, 2016 – review paper)

- depression: 13-27%
- anxiety: 14-27%
- fear of progression: 23-29%
- PTSD: 15-28%
- Only 39% are on meds and 22% are in therapy (Hefner, et al., 2014)

Other challenges:

- 70% of HCT patients report neurocognitive problems (Scherwath, 2013)
- 27-39% of cGVHD patients can't return to work due to health reasons
- Self-esteem, body image, and relationships are altered due to illness, treatment, and cGVHD (Eeltink, 2019)



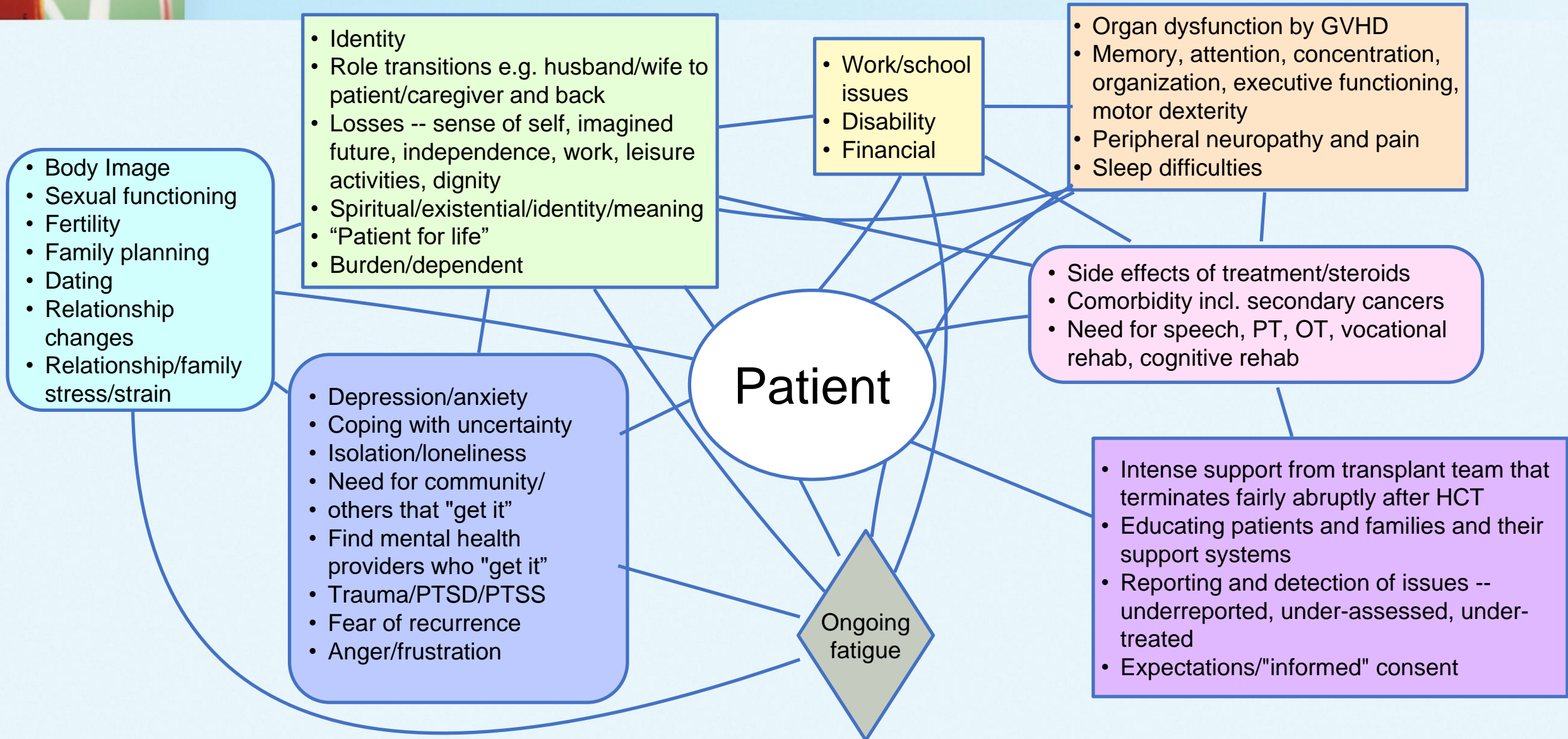
Family Caregivers Impacted, Too

- **Caregiving is a long-term responsibility:**

- 68% still provide care to recipient six years after HCT (Jamani et al, 2018)
 - 20% report poor QOL
 - Greater depression and sleep problems than general population

- **Spouse-caregivers** (average of 7 years after transplant) (Bishop, et al, 2007)
 - Greater fatigue, cognitive, sleep and sexual problems than peers
 - Less social support, more loneliness than HCT survivors
 - Odds of depression 3.5 X higher than peers
 - Less likely to get psychosocial help than HCT survivors

Patients Need a Holistic Approach





Psychosocial Needs: Poorly Understood, Inadequately Addressed



- **Complex psychosocial needs** of cGVHD patients and caregivers is **poorly understood** and under-studied
- Patients **under-report symptoms**, providers **under-assess**
- **Disparity between patient and provider perception** of patients' psychosocial well-being
- **Psychosocial counseling at transplant centers often not available** beyond peri-transplant and/or for caregivers
- **Community-based psychosocial support** with HCT or GVHD experience is **sparse**.
- **Unmet mental health needs** can result in (Barata et al, 2016)
 - poor QOL, increased symptom burden, decreased physical and social functioning
 - social isolation, non-adherence to post-HCT regimen, greater mortality, increased suicidal ideation



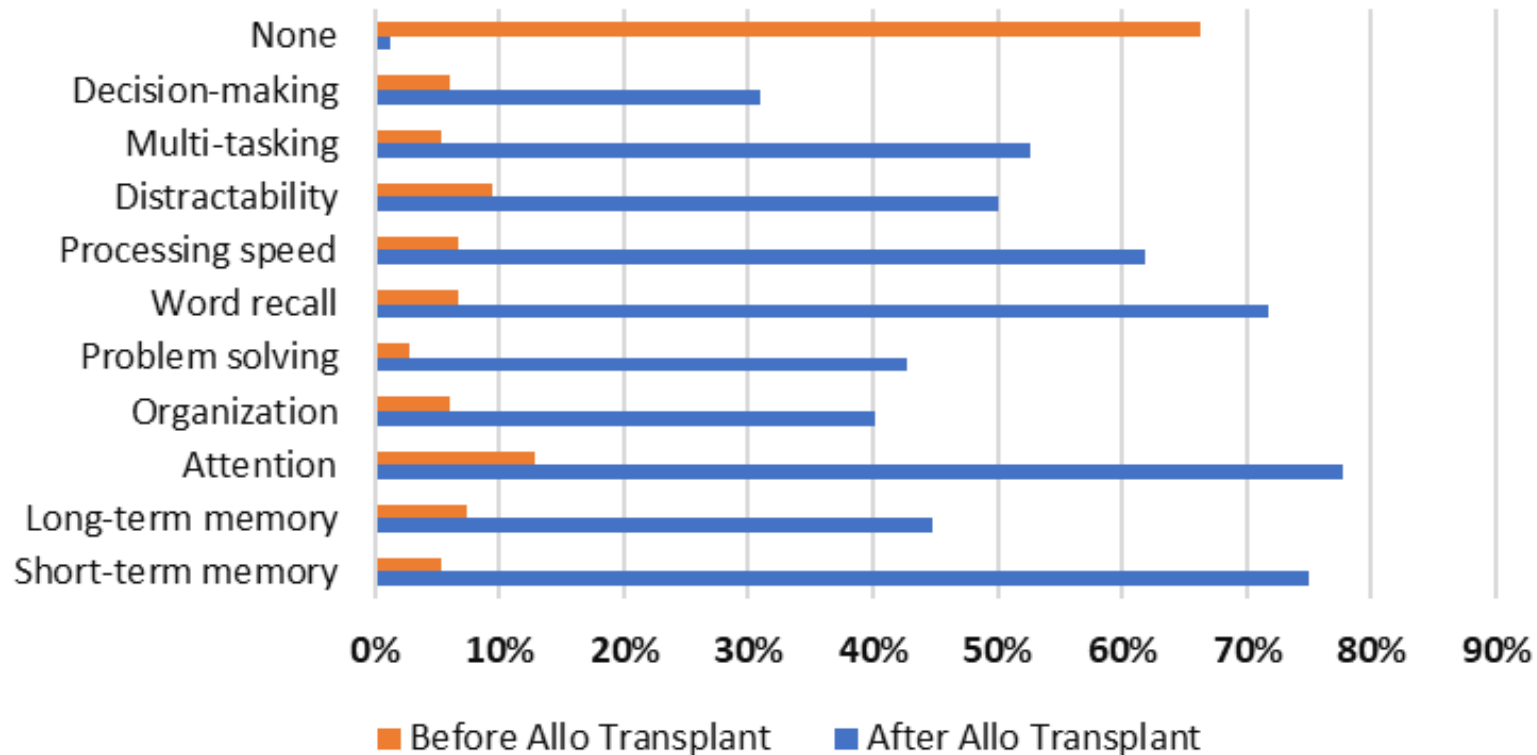
Improving Psychosocial Health



- **Develop a holistic, collaborative approach** to care for cGVHD patients including mental health professionals, occupational therapists, and advocacy organizations during and after HCT
- **Develop fact sheets** for patients, caregivers and physicians on how to address depression, anxiety, neurocognitive issues (Eeltink, et al, 2019)
- **Integrate technology to assist** - apps, portals, webinars, Telehealth
- **Include positive psychology constructs in research and interventions:**
 - gratitude, perseverance, resilience, optimism, hope, purpose in life, meaning (Amonoo, 2019)
- Longitudinal natural history **trials to study cGVHD symptoms AND psychosocial issues**
- **Identify interventions:** modulators, preventive measures and treatment

Neurocognitive Problems after HCT

Allogeneic Transplant



- Can affect ability to manage GVHD medications/regimens
- Adverse impact on QOL
- Increases caregiver burden
- May persist for a long time
- HCPs don't ask, patients don't tell = unresolved problem
- Less than 50% said HCP suggested remedies
- cGVHD features impair neurocognitive function in mice (K. MacDonald 2020)

Potential Strategies to Manage/Research Neurocognitive Issues



- **Neuropsych consult** to identify specific deficits
- **Referrals to rehabilitation specialists** (speech therapist, occupational therapist)
- **Organizational/technology aids** eg. medication organizers, phone reminders, calendars, memory stations (all important things in one place)
- **Environmental changes** to reduce distraction, eg. noise cancelling headphones
- **Physical exercise:** promote nerve cell growth, blood supply to brain, reduce inflammation

- **Educational resources from patient advocacy groups, eg.**

Cognition after Transplant (Michael Parsons) bmtinfonet.org/video/cognitive2020

Coping with Learning, Memory and Attention Problems after Transplant (Margaret Booth-Jones)

bmtinfonet.org/video/cognitive2019

- **Identify contributing factors for neurocognitive impairment** within clinical trials and experimental settings (Jim 2012)



Survivorship and Long-Term Care

Chiara DeBiase, MCSP, Christina Ferraro, CNP, and Naomi Pineda



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Major Issues

- Unique and highly complex patients
- Long term follow up screening and prevention
 - Recommended screening and preventive practices for long-term survivors after hematopoietic cell transplantation, (Majhail, et al., 2012)
- Partnerships and responsibilities
 - Providers and patients
- Survivorship care clinic models
 - Integrated, consultative, shared, transitional
- Mental health care



Barriers

- # of providers who are knowledgeable
- # of collaborating specialist
- Defining responsibility
- Ancillary/administrative services
- Starting up a clinic specific for BMT patients
- Distance from clinic
- Support for caregivers



Current Standard of Care

- Recommendations for screening, surveillance and follow up
- Survivorship care clinic models
 - Integrated, consultative, shared, transitional
- Team approaches
 - Utilize all resources, RN, SW, APP, MD, psych, pharmD
- Treatment summary and care plans
 - Review past and current treatment, establish plan for surveillance and monitoring for late effects
- Standard GVHD assessments



Gaps and Unmet Needs

- Outside providers need to be comfortable with BMT survivors
 - Increase educate, establish teams/relationships
- Fertility prior to transplant and post transplant
- Sexual health care
- Mental health support before, during and after transplant
 - Depression
 - Anxiety
 - PTSD
 - Grief



Solutions and Suggestions

- More mental health care support prior, during and post transplant
 - Long term follow up care with mental health providers
- More fertility and mental health counseling prior to transplant
- Increase education for PCP, ED and other community providers on GVHD and late effects of treatment
- Financial assistance for patients and caregivers
- More effective side effect management including pain control
- Improve GVHD treatments and identifying those patients with increase
- Establish a minimal required survivorship plan for all centers
- Integrate virtual/telemedicine into long term care



Menti Discussion





Open Discussion

Question and Answer Session





Q & A Session



For additional and/or personal questions regarding yourself or a loved one, please email:

CGVHD2020@mail.nih.gov



Thank you!



Please consider joining the
International GVHD Patient and
Caregiver Network by sending your
contact information to:

meredith@cowdenfoundation.org



Resources

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/gential-GVHD-2019
- **Riding the Emotional Roller Coaster of GVHD**, Katie Schoepner 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@bmtinfonet.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>