# Leading Transplant Organizations Unite as GVHD Alliance, Announce Inaugural GVHD Day on February 17, 2023

- *Graft-Versus-Host Disease (GVHD) is a rare disease that commonly impacts allogeneic blood and marrow transplant recipients*[1]
- *New GVHD Alliance aims to bridge existing gaps in unmet needs of the GVHD community and launch new dedicated awareness day*

**Orlando, Fla., February 17, 2023** – A newly formed Alliance is bringing together leading transplant organizations to improve access to resources and support for people living with graft-versus-host disease (GVHD) and the GVHD community. This new alliance, the GVHD Alliance, also has designated February 17 as GVHD Day to elevate voices in support of people impacted by this condition. Current GVHD Alliance member organizations include American Society for Transplantation and Cellular Therapy (ASTCT), Be The Match-operated by the National Marrow Donor Program (NMDP), Blood & Marrow Transplant Information Network (BMT InfoNet), Meredith A. Cowden Foundation, and National Bone Marrow Transplant Link (nbmtLINK). The GVHD Alliance and GVHD Day are supported by Sanofi.

"GVHD has been part of my daily life for over two decades, so I know first-hand the impact this disease can bring to both patients and their families," said Meredith Cowden of the Meredith A. Cowden Foundation. "This is an isolating and debilitating condition; raising awareness through the Alliance is one way to empower and connect this community with resources and assistance."

GVHD has a consequential and far-reaching impact on allogeneic (meaning cells come from a donor) blood and marrow transplant recipients. While not all patients will develop GVHD, depending on the severity of the symptoms and the number of organs affected, the condition can impair a person's ability to engage in usual daily activities and, in severe cases, be life-threatening.[2]

"NMDP is proud to work with the Alliance to reach patients with information they need to recognize and treat symptoms earlier. This collaboration will help connect patients to support groups, and access resources like social workers and patient navigators who can help them advocate for treatment, while addressing their fears and concerns," said Jeffery Auletta, MD, Senior Vice President of Patient Outcomes and Experience, Be The Match and Chief Scientific Director, Center for International Blood and Marrow Transplant Research at NMDP. "Be The Match/NMDP brings a wealth of knowledge to these efforts based on our joint investigation with the transplant community of the safety and efficacy of GvHD prophylaxis regimens and treatments, and our initiatives to alleviate the psychosocial burden associated with a patient experiencing GvHD."

The inaugural GVHD Day will be held on February 17, 2023, at The Tandem Meetings | Transplantation & Cellular Therapy Meetings of the American Society for Transplantation and Cellular Therapy (ASTCT) and the Center for International Blood and Marrow Transplant Research (CIBMTR) in Orlando, Florida, February 15-19, 2023.

"Ten years ago, we were limited in our ability to help GVHD patients. Thanks to increases in advocacy, research and funding, we've made advances that help this unique population," said Corey Cutler, MD, MPH, FRCPC, Medical Director, Stem Cell Transplant Program, Dana-Farber Cancer Institute and Vice President, ASTCT. "When we unite on behalf of the GVHD community, our collective efforts can make an even bigger impact. That's why we're proud to be part of the GVHD Alliance and GVHD Day."

GVHD creates many challenges which can adversely affect physical functioning, bodily pain, chronic fatigue, general health, vitality, and social functioning, among other things.[2] Symptoms vary and can include a distinctive rash, persistent nausea, vomiting, change in skin texture and painful dry mouth and eyes.[2,3]

"There are significant barriers to reaching patients and caregivers with information about GVHD before, during, and after an allogeneic blood or marrow transplant," said Susan Stewart, 33-year transplant survivor and Founder and Executive Director of BMT Infonet. "The Alliance website is a repository of timely, actionable information designed to help patients and their family members throughout their journey."

People living with this condition can also face physical, functional, and psychosocial deficits that result in the inability to return to work or school and poor quality of life.[2] These include, but are not limited to, fibrosis in organs, depression, anxiety, impaired vision, and more.[4-9]

"As the GVHD Alliance, our mission is to address the needs of people living with this condition," said Peggy Burkhard, Executive Director of National Bone Marrow Transplant Link (nbmtLINK). "It can be overwhelming and frustrating for patients, as well as their caregivers and family. We want to better educate them and help them live their best lives."

Learn more on the Alliance website, www.GVHDAlliance.org, a unified platform where the GVHD community can access a variety of educational resources and support tools.

## About Graft-versus-Host Disease (GVHD)[1]

Graft-versus-host disease, or GVHD, is a complication that can happen after an allogeneic blood and marrow transplant, meaning the cells came from a donor. In GVHD, donor cells (the graft) attack the patient's (the host's) organs and/or tissues. GVHD is characterized as acute GVHD (aGVHD) or chronic GVHD (cGVHD); allogeneic blood and marrow transplant recipients can develop one, both, or neither form of GVHD.

## About the GVHD Alliance

The GVHD Alliance is empowering voices in the GVHD community to increase awareness and help improve the lives of people living with GVHD. The GVHD Alliance has developed a unified platform that facilitates a nurturing community for people living with GVHD, connecting resources, education, and support. Current GVHD Alliance member organizations include: American Society for Transplantation and Cellular Therapy (ASTCT), Be The Match, Blood & Marrow Transplant Information Network (BMT InfoNet), Meredith A. Cowden Foundation and National Bone Marrow Transplant Link (nbmtLINK).

## About the American Society for Transplantation and Cellular Therapy (ASTCT)

The American Society for Transplantation and Cellular Therapy™ is an international professional membership association of more than 3,000 physicians, investigators, and other health care professionals from more than 45 countries. ASTCT's mission is dedicated to improving the application and success of blood and marrow transplantation and related cellular therapies. We strive to be the leading organization promoting research, education, and clinical practice in the field. For more information, visit http://www.astct.org.

## About Be The Match

Be The Match® is a global leader working every day to save lives through cellular therapy. For people with life-threatening blood cancers—like leukemia and lymphoma—or other blood disorders like sickle cell, a cure exists. Be The Match connects patients with a matching donor for a life-saving blood stem cell transplant. The Be The Match Registry® is the most diverse registry in the world and includes both adult donors willing to donate to a stranger in need and stored cord blood units. In addition, Be The Match provides patients and their families one-on-one support, education, and guidance before, during and after transplant. Be The Match is also a global leader in research through the CIBMTR®(Center for International Blood and Marrow Transplant Research®)—a collaboration with Medical College of Wisconsin, investing in and managing research studies that improve patient outcomes and advance the future of care. For more information, visit http://www.bethematch.org.

## About Blood & Marrow Transplant Information Network (BMT InfoNet)

Blood & Marrow Transplant Information Network (BMT InfoNet) is a leading advocacy organization for bone marrow, stem cell and cord blood transplant recipients. Founded in 1990, BMT InfoNet has pioneered a vast array of services to help transplant patients make critical decisions throughout their transplant journey. For more information, visit http://www.bmtinfonet.org.

## About Meredith A. Cowden Foundation

The mission of the Meredith A. Cowden Foundation is to increase the number of blood and marrow transplant survivors, to raise awareness of transplant complications and late effects, and to reduce their impact. The Meredith A. Cowden Foundation is committed to: Providing funding for research to prevent, treat and cure Graft vs. Host Disease (GVHD); educating physicians, researchers, patients, and the general public concerning GVHD and late effects of transplants, their prevention, treatment and cure; providing general information concerning the blood cancers and their treatment, with a special emphasis on the treatment of leukemia and bone marrow and stem cell transplantation; and providing resources to support programs designed to enhance the quality of life of patients and their families during treatment. For over a decade, the Foundation has hosted a unique conference where physicians, mid-level medical personnel, patients, and their caregivers and family come together to receive the best current information concerning the treatment of GVHD and late effects. For more information, visit http://www.cowdenfoundation.org.

## About National Bone Marrow Transplant Link (nbmtLINK)

Established in 1992, the National Bone Marrow Transplant Link (nbmtLINK) is a 501(c)(3) nonprofit organization dedicated to serving individuals before, during, and after a bone marrow or stem cell transplant. Myra Jacobs founded the nbmtLINK and its mission is to help patients, caregivers, and families cope with the social and emotional challenges of bone marrow/stem cell transplant from diagnosis through survivorship by providing vital information and personalized support services. For more information, visit http://www.nbmtlink.org.

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