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February 2018 Newsletter

Volume 24, Issue 1

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Perspectives

By Robert Siffer, MD

Understanding and manipulating donor immune responses has been the cornerstone of translational research in allogeneic HCT for nearly half a century. Through analysis of human samples and by developing experimental models, investigators have tried to link elements of immunogenetics, donor graft composition, proteomics, tumor genomics, and immune reconstitution in the hopes of predicting who will develop the often unpredictable and devastating consequences of GVHD, microbial susceptibility, and inadequate control of the underlying malignancy. We, as a community, have largely relied on analysis of blood or graft cellular components to arrive at some predictive associations, many of which have prompted interventional strategies that, in some circumstances, have been successful in addressing these life-threatening complications. To do so, we have frequently banded together to pool samples of cells and plasma from multiple centers to arrive at definitive correlations, which would be largely impossible from single center analyses. By



leveraging its comprehensive and well annotated clinical database, the CIBMTR has played a critical role in these efforts.

Historically, much of our attention has focused on correlating donor cell immune reconstitution with transplant outcomes and much less on host factors that might influence immune recovery and function. However, in the past 5 years, the availability of high-throughput sequencing technology for microbiome characterization has led to convincing data from single centers correlating perturbations in the gut microbiome with GVHD, tumor relapse, and transplant survival. These observations may be startling for some, but those of us who are AARP members remember data from the 1970s that demonstrated that mice undergoing transplant in germ-free environments experienced less GVHD and better survival. This led to the use of protective environments with laminar air flow rooms, low bacteria diets, gut decontamination, and assiduous skin cleaning. The goal of these interventions was not only to reduce infectious complications but also to reduce microbial initiated inflammatory responses resulting in GVHD. Many of these precautions have been abandoned over the years because small studies supporting their use yielded conflicting results. However, most of us have witnessed clinical scenarios where infectious episodes have appeared to trigger GVHD in patients.

The impact of the microbiome on health and disease reaches far beyond HCT with correlations reported in multiple medical conditions. The development of powerful new tools such as high-throughput molecular methods including 16S ribosomal RNA gene sequencing, metabolomics, and shotgun metagenomic sequencing have opened the door for comprehensive investigation. The integrative Human Microbiome Project (IHMP) from the NIH focuses on creating integrated datasets of multiple biological properties from both the microbiome and the host over time in specific microbiome-associated diseases, specifically inflammatory bowel disease, Type 2 diabetes, and pregnancy.

There is probably no clinical scenario where shifts in the microbiome are so dramatic and likely to impact an inflammatory milieu as in HCT. Our patients receive high dose chemotherapy or radiotherapy that dramatically alters their ability to eat and disrupts mucosal barriers promoting microbial translocation. They are also exposed to both prophylactic and therapeutic antibiotics altering gut flora and immune suppressive medications compromising immune competence. Given that the risk / benefit divide is uncomfortably narrow in transplantation, it is imperative that we accelerate our understanding of the impact of shifts in the microbiome as expeditiously as possible.

To accomplish this task will take an extensive, coordinated effort. The variability in dietary, environmental, conditioning, GVHD prophylactic, and antibiotic-prescribing practices creates quite a challenge as do inconsistencies of antibiotic- and infection-reporting. Moreover, uniformity of stool collection techniques, storage, and analysis need to be established. Several groups-including teams from New York, Stanford, Houston, Regensburg, Boston, Seattle, and elsewhere - are trying to spearhead this effort, and the CIBMTR should be poised to assist. To accomplish our goals of truly understanding how diet, antibiotics, chemotherapy, immune suppression, and donor / host genetic polymorphisms impact the microbiome - and, in turn, how the microbiome influences immune reconstitution and transplant outcomes - will undoubtedly be a resource-intensive undertaking. It is time to move beyond the seemingly unavoidable junior high school commentary about stool and think creatively how to marshal the support to create such a vibrant, comprehensive annotated sample repository and get going.

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[2018 BMT Tandem Meetings](#)

By Tia Houseman

The BMT Tandem Meetings - the combined annual meetings of the CIBMTR and ASBMT - are North America's largest international gathering of BMT clinicians and investigators, laboratory technicians, advanced practice professionals, transplant nurses, pharmacists, administrators, and clinical research associates since 1999.

More than 3,300 leading worldwide authorities will convene in Salt Lake City, Utah, to present the latest developments in blood and marrow transplantation at the Salt Palace Convention Center February 21-25.

More than 700 abstracts from more than 30 countries were submitted to this year's meeting. We invite you to join us for the Best Oral Abstract Session on Friday, February 23, in Hall C, and on Sunday, February 25, as we close the meeting with Late Breaking Abstracts.

In addition to an outstanding scientific program, the 2018 meetings offer peripheral sessions for BMT pharmacists, BMT center administrators, coordinators, investigators, medical directors, clinical research professionals / data managers,

transplant nurses, and advanced practice professionals. Along with state-of-the-art educational offerings, industry-supported satellite sessions and product theaters will broaden the spectrum of presentations.

Please join us after the Best Abstracts Session on Friday afternoon as the CIBMTR Distinguished Service Award is presented to Mahmoud D. Aljurf, MD, MPH. This award is presented to Dr. Aljurf for his service and commitment to the CIBMTR and its missions. Following the awards on Friday, we invite you to attend the Mortimer M. Bortin Lecture, presented by Eliane Gluckman, MD, PhD, FRCP and the E. Donnall Thomas Lecture, presented by Robert S. Negrin, MD.

Visit the [2018 BMT Tandem Meetings webpage](#) to create your own personal agenda, register and view additional details. As of early January, more than 2,400 attendees were registered. On-site registration rates went into effect on January 24. After registering, take advantage of special conference guest room rates at a wide variety of hotels within the BMT Tandem room block.

Remember to reserve your ticket to the BMT Tandem Reception on Saturday, February 24, at the Salt Palace Convention Center, South Foyer.

Tandem Goes Mobile!

Attendees may now download the official BMT Tandem Meetings app for quick and easy access to the most current version of the meeting schedule, attendee list, venue information and more! Watch for additional details in your email. The app is free for all attendees and with wi-fi available throughout all BMT Tandem meeting rooms, users can:

- View and search meeting program schedules
- Vote / participate in interactive sessions
- Complete session surveys
- Search for speakers
- View exhibitor map and booth locations
- Create personal schedules
- Message other attendees
- Access other meeting information

Questions regarding support opportunities at the 2018 BMT Tandem Meetings may be directed to [Sherry Fisher](#), Director of Advancement for the CIBMTR. For general information, email bmttandem@mcw.edu.

We look forward to seeing you in Salt Lake City!

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2017 CIBMTR Annual Report

We recently published the CIBMTR 2017 Annual Report. This report focuses on information most important to transplant center personnel and other partners. We explain who we are, what we do, how we share knowledge, how we collect and manage data, and what we will do next. Review the [electronic version](#) to access links directly, or pick up a hard copy at the CIBMTR booth at the BMT Tandem Meetings.



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[Graft-vs- Host Disease Working Committee](#)

Committee Leadership

Co-Chairs:

- [Daniel Couriel, MD](#), Utah Blood and Marrow Transplant Program, Salt Lake City, UT
- [Amin Alousi, MD](#), M.D. Anderson Cancer Center, Houston, TX
- [Joseph Pidala, MD](#), PhD, H. Lee Moffitt Cancer Center and Research Institute, Tampa, FL

Scientific Directors:

- [Mukta Arora, MD, MS](#), University of Minnesota Blood and Marrow Transplant Program, CIBMTR Minneapolis
- [Stephen Spellman, MS](#), CIBMTR Minneapolis

Statistical Directors:

- [Tao Wang, PhD](#), CIBMTR Milwaukee
- [Ying Liu, PhD](#), CIBMTR Milwaukee

Consumer Advocacy Representatives:

- Kristin Scheeler, Leukemia & Lymphoma Society, White Plains, NY
- Jennifer Wilder, BSN, RN, National Institutes of Health, Bethesda, MD

Statistician:

- [Michael Hemmer, MS](#), CIBMTR Milwaukee

GVHD is the most critical complication of allogeneic HCT, and its occurrence prevents favorable outcomes in a large proportion of affected patients. GVHD is an entirely iatrogenic complication of allogeneic HCT, and its prevention and treatment are of paramount importance to the transplantation community. In the last few years, increased attention has been paid to the prevention and treatment of GVHD as alternative and mismatched donors have been increasingly used in transplantation and as novel immunosuppressive agents have been developed for the treatment of the autoimmune and rheumatologic conditions. The GVHD Working Committee examines both acute and chronic GVHD outcomes across all diseases treated by allogeneic HCT.

Under the committee leadership (listed above), the GVHD Working Committee has focused on:

- Comparisons of GVHD incidence, GVHD-free and relapse-free survival (GRFS), and other outcomes of different GVHD prophylaxis regimens and stem cell sources, including UCBT and HLA haploidentical donors;
- Evaluating the influence of age on GVHD in children;
- Examining the impact of donor parity on transplant-related outcomes.

The GVHD Working Committee has 11 ongoing studies with plans to complete at least 3 studies each academic year, making it one of the most productive committees. This committee benefits from broad enrollment to the CIBMTR Research Database. The number of allogeneic HCTs in 2001-2016 total >44,000 for leukemic diseases (AML, ALL, MDS, CML, and other leukemia) and >18,000 for non-leukemia malignancies.

The GVHD Working Committee is always seeking interesting and novel ideas for study as well as encouraging the involvement of junior investigators and those wanting to break into the field of BMT and outcomes research. Join the GVHD Working Committee for their annual in-person meeting during the BMT Tandem Meetings on Friday, February 23, 12:15 to 2:15 p.m. in the Salt Palace Convention Center, Room 355 BC.

View planned, in-progress, and completed studies and publications on the [GVHD Working Committee webpage](#).

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[Lymphoma Working Committee](#)

Committee Leadership

Co-Chairs:

- [Sonali Smith, MD](#), University of Chicago Medicine, Chicago, IL
- [Anna Sureda, MD](#), Institut Catala d'Oncologia, Spain
- [Timothy Fenske, MD, MS](#), Froedtert Memorial Lutheran Hospital, Medical College of Wisconsin, CIBMTR Milwaukee

Scientific Directors:

- [Mehdi Hamadani, MD](#), CIBMTR Milwaukee

Statistical Director:

- [Kwang Woo Ahn, PhD](#), CIBMTR Milwaukee

Statistician:

- [Carlos Litovich, MPH](#), CIBMTR Milwaukee

The Lymphoma Working Committee, one of the first established within the CIBMTR, focuses on cellular therapy for both Hodgkin lymphoma (HL) and NHL patients and has conducted numerous studies addressing a wide range of issues in the field of HCT for patients with these diseases. Although the number of autologous and allogeneic HCTs have been steadily increasing over time for both HL and NHL, the role and optimal timing of HCT is evolving in light of ever-increasing numbers of new pharmacologic and immunologic therapies. In addition, advances in molecular profiling / subtyping and the discovery of new biologic risk factors, combined with the increasing utilization of metabolic imaging in lymphomas, have led to the identification of multiple subsets and heterogeneity in lymphoma in general. Even within specific lymphoma subtypes, there is substantial heterogeneity, which requires continuous re-evaluation of the role and timing of HCT for these patients.

Since 2008, the disease-specific research-level forms have collected basic PET scan information, such as whether a PET scan was performed or not and whether it was positive at any site prior to the start of the conditioning regimen. Since 2013, the updated forms collect additional PET information, such as whether there was nodal versus organ involvement, and not just pre-transplant but also at the time of transformation. In 2018, an updated version of lymphoma disease-specific forms will be implemented to capture molecular testing information, such as whether certain chromosomal translocations were identified in the lymphoma, and other molecular subtyping information, such as germinal center versus non-germinal center "cell of origin" for diffuse large B-cell lymphoma (DLBCL). This additional information will allow the Lymphoma Working Committee to conduct more up-to-

date and clinically relevant analyses in the future. At the same time, the increasing use of new transplantation and cellular therapy strategies (e.g. the use of haploidentical donors for allogeneic HCT and the use of CAR T cell therapies) will result in additional important data for the Lymphoma Working Committee to capture and analyze.

Thanks to the considerable number of lymphoma patients treated with HCT whose data are in the CIBMTR Research Database, the Lymphoma Working Committee is able to provide information with the capacity to change clinical practice in many transplant related issues.

The Lymphoma Working Committee has been extremely active over the last few years, in large part due to the extensive data available in the CIBMTR Research Database. The number of transplants for lymphoma added to the Research Database from 2000 through 2017 are listed in the table below. During the annual committee meeting at the 2017 BMT Tandem Meetings, 8 new proposals were presented, and 3 were approved to be further developed and analyzed. In 2016, 8 proposals were presented, and 3 studies were approved. Join the Lymphoma Working Committee at their annual in-person meeting at the 2018 BMT Tandem Meetings on Wednesday, February 21, 2:45 - 4:45 p.m. in the Salt Palace Convention Center, Room 355 E.

The Lymphoma Working Committee was also quite productive with presentations and publications in 2017. Committee investigators presented five oral abstracts at national and international conferences, including one at the ASCO Annual Meeting and three at the BMT Tandem Meetings. They published seven manuscripts in peer-reviewed journals, including Journal of Clinical Oncology, Cancer, and Biology of Blood and Marrow Transplantation. There is also an important ongoing Clinical Practice Guideline collaboration between CIBMTR, EBMT, and ASBMT for post-autologous HCT maintenance strategies as well as regarding conditioning regimens for allogeneic HCT in lymphoma.

Several of the Lymphoma Working Committee publications in recent years are of particularly high impact, including the demonstration that chemosensitivity to salvage regimens may overcome the adverse prognosis associated with early relapse in DLBCL patients undergoing autologous HCT (Hamadani et al, Biol Blood Marrow Transpl, 2013) and two studies indicating comparable outcomes - in terms of treatment-related mortality, relapse / progression, and overall survival - using haploidentical donors versus matched sibling donors (Ghosh et al, J Clin Onc, 2016) or matched unrelated donors (Kanate et al, Blood, 2016).

Going forward, there are a number of clinically relevant questions yet to be addressed that can only be studied in a large registry dataset. Examples include the role of HCT in rare types of lymphomas, comparative analyses between “experimental” stem cell sources and more “standard” sources, prognostic factors modifying the long-term outcome of HCT in different histologies and disease situations, and comparisons between allogeneic and autologous HCT in specific clinical scenarios. The Lymphoma Working Committee is also in the position to be a major player in joint studies with other scientific transplant societies, such as the EBMT.

Number of Cases Added to the CIBMTR Research Database 2000 - 2017		
	TED-Level Data	CRF-Level Data
NHL		
Allogeneic HCT	13,080	4,282
Autologous HCT	41,541	4,869
Hodgkin's Lymphoma		
Allogeneic HCT	3,210	534
Autologous HCT	15,712	1,466

View planned, in-progress, and completed studies and publications on the [Lymphoma Working Committee webpage](#).

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CIBMTR Trivia

How many abstracts were submitted for presentation at the 2018 BMT Tandem Meetings this year?

- A. 575
- B. 615
- C. 685
- D. 705

[Enter your answer online.](#) If you answer correctly, you will be entered into a drawing to win a CIBMTR prize.

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[Team Spotlight: CIBMTR Information Technology Team](#)



Left top corner to right: Tom Moerke, Tim Skowronski, Josh Gier, Carolina Espinoza, Tad Degen, Charles Zhang, Xiaolan Zhang, Barbara Liu, Erik Bergman, Tian Hongu, Mita Desai; Not pictured: Paul Gengler and Angela Kummerow

The CIBMTR Information Technology (CIT) Team includes >60 personnel on the Minneapolis and Milwaukee campuses. CIT supports a diversified continuum of IT and informatics solutions that serve the CIBMTR and its stakeholders. Both campuses share the same, unified commitment to the CIBMTR mission and work together in an integrated fashion to achieve strategic and operational goals. CIT is organized according to specialization, expertise, and the capabilities required of the products and services supported. That support extends along the life cycle of data from capture to validation, extraction, and use in research.

Three teams of CIT professionals are dedicated to enhance, maintain, and support CIBMTR electronic data capture solutions, including FormsNet and AGNIS (A Growable Network Information System). The primary channel for centers to contribute their data to CIBMTR is FormsNet. Now in its third generation, FormsNet is regularly enhanced, requiring coordination not only within CIT or even CIBMTR but throughout the scientific community. Metadata analysts uphold the CIBMTR commitment to facilitate data interoperability by curating common data elements and linking these to industry standard terms. Business analysts, software developers, and other IT professionals identify and transform functional requirements into system features to create new forms, validate user responses within acceptable ranges, hide or expose questions based on user response, make other forms come due, and much more. Since form changes in AGNIS follow closely on the heels of those implemented in FormsNet, the AGNIS team is engaged in very similar activities, with the added challenge of facilitating system to system data exchange.

Another group of IT specialists maintain and enhance the process by which data is extracted from our data capture systems and loaded into our analytical systems. This process, known as data extraction, transformation, and load (ETL), is integral in moving data between systems in a controlled fashion. It also is essential for validating data for consistency, completeness, and accuracy within and across data capture forms. CIT programmers, business systems analysts, and data analysts work closely with a cross-functional Data Quality Team and with CIBMTR Scientific Directors to embed in logic the collective knowledge of the scientific community and to continuously measure the quality of data against this logic.

Data that pass these quality criteria are loaded into the CIBMTR Research Database, which is used for research and sharing data. The Research Database team consists of database analysts and a database administrator, all with extensive experience. They harmonize changes to the Research Database resulting from form revisions and continuous improvements. CIT also loads data into the CIBMTR Integrated Data Warehouse (IDW). The IDW touches virtually every facet of CIBMTR,

and CIT holds a key role in its design, development, and implementation. Data architects, business systems analysts, and programmers work side by side with CIBMTR Scientific Directors, statisticians, and other subject matter experts to build and enhance the IDW.

CIT team members who focus on the CIBMTR data sharing mission extract data from CIBMTR analytical systems and present these data to meet stakeholder needs. To do so, CIT team members maintain and enhance data extracts, which statisticians use to create study data sets. These data are also shared with centers and other stakeholders through applications in Qlikview and applications custom-built to meet the community's needs. Each of these applications were designed to fulfill specific data and information purposes. CIBMTR gathered stakeholder input in the design and update of these applications via in-person site visits and annual meetings and forums.

Throughout the data lifecycle, CIT project managers and AGILE ScrumMasters coordinate, remove obstacles, allocate resources to fulfill demand, manage risk, and escalate issues to leadership. Programmers and system administrators maintain and enhance the CIBMTR web presence and its interfaces with other core systems. Information security personnel ensure that CIBMTR maintains the most current practices and systems that provide data privacy and cybersecurity.

CIT professionals enhance and maintain operational systems that enable the CIBMTR to function on a daily basis. They are the backbone that allows centers to submit and retrieve high-quality data as efficiently as possible. Their work allows statisticians to create accurate and complete data sets that drive practice-changing research. They ensure CIBMTR data are secure. They support every facet of the CIBMTR organization.

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[2017 Center-Specific Outcomes Report](#)

By Carol Doleysh

The SCTOD is part of the US Health Resources and Services Administration-funded C.W. Bill Young Cell Transplantation Program that collects data on all allogeneic HCT performed in the US and on transplants done elsewhere using cellular products that originated in the US.

Center Outcomes

Outcomes reporting in allogeneic HCT is necessary to provide information requested by patients, insurers, and government agencies and to comply with current laws. The SCTOD contract requires the CIBMTR to conduct an analysis of one-year survival rates at each transplant center in the US annually. The report generated by the CIBMTR is meant to be useful as a quality improvement tool for transplant centers. [View data](#) made available to the public online.

The 2017 Center-Specific Outcomes Report, which includes first allogeneic HCT performed between 2013 and 2015 in the US, was distributed in December to Center Directors and Payors. The data was also updated on the Be the Match website. Additional tools accessible to transplant centers for quality improvement work include Center Performance Analytics and the Survival Calculator. Access to these is through the secure CIBMTR Portal. For additional information, contact cibmtr-portalhelp@mcw.edu.

To be included in the analysis, transplant centers were required to have at least one year of follow-up on >90% of related and unrelated HCT recipients. A [description of the methodology used in generating this report](#) can be found on the CIBMTR website.

In late 2013, incorporating feedback from the HCT community, the CIBMTR began collecting additional variables on the pre-TED form. These variables, particularly, the disease-related items, will be evaluated for use in risk adjustment in the Center-Specific Survival Analysis. The CIBMTR has worked with the ASBMT Committee on Quality Outcomes and other stakeholders to incorporate these variables in the analysis plan for 2018.

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[BMT CTN Accrual Tops 10,000 Patients](#)

By Amy Foley, MA

BMT CTN Accrual Tops 10,000 Patients

More than 10,000 patients have been enrolled on BMT CTN trials since 2003! The BMT CTN and its network of Core and Affiliate Centers play a critical role in improving patient outcomes and advancing the science of HCT. This accrual milestone represents an example of the BMT CTN's many scientific achievements. Thank you to all of the BMT CTN investigators, coordinators, and regulatory, laboratory and clinical staff who helped us reach this milestone! A special thank you to all the patients who participated.

New BMT CTN Leadership

The BMT CTN Steering Committee is now under the leadership of Richard Jones, MD (Johns Hopkins), who started his two-year Chair term on January 1. Helen Heslop, MD, DSc(Hon) (Baylor College of Medicine) is Chair-Elect, and Steven Devine, MD (Ohio State University) is now Immediate Past-Chair.

See you at the BMT Tandem Meetings

Mark your meeting calendars for the **BMT CTN Investigators Meeting**: Wednesday, Feb. 21, 3:15-4:30 pm MT, Room 251 AB. Dr. Richard Jones will showcase upcoming BMT CTN studies:

- 1702: Donor Source Cohort Study
- 1703: PROGRESS III PTCy vs. Tac/Mtx as GVHD Prophylaxis
- 1704: Prognostic Assessment in Older Adults
- 1705: Treatment for High-Risk Acute GVHD
- 1706/SWOG S1803: Myeloma Maintenance Therapy.

In the Maximizing BMT CTN Biorepository Samples session, Steven Spellman, Director of Immunobiology & Observational Research, NMDP/Be The Match, will share what samples and resources are available to interested investigators. Dr. Shernan Holtan, University of Minnesota Blood and Marrow Transplant Program, will provide results of her ancillary studies conducted using BMT CTN samples. There will also be a BMT CTN 1506 (AML Maintenance Therapy) study update presented by Dr. Yi-Bin Chen, Massachusetts General Hospital. We hope you can join us!

The **BMT CTN Coordinators Meeting** will be held Wednesday, February 21, 7:30 am – 3:00 pm MT, in Room 251 DEF. The meeting will cover BMT CTN processes and study overviews, and it will feature presentations from several BMT CTN Investigators. We hope to see all the BMT CTN study coordinators there.

Don't miss the BMT CTN 1203 (PROGRESS I; GVHD Prophylaxis) study results presented in the **Late Breaking Abstracts** session on Sunday, February 25, at 12:30 pm MT, presented by Javier Bolaños-Meade, MD, The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins: Novel Approaches for Graft-Versus-Host Disease (GvHD) Prophylaxis: Primary Results of Progress I Multicenter Trial of Matched Allogeneic Hematopoietic Cell Transplantation (alloHCT) Using Reduced Intensity Conditioning (RIC) BMT CTN 1203.

Also, please stop by the **BMT CTN booth**. BMT CTN Investigators and Data and Coordinating Center staff will be there during breaks to answer your questions and provide ideas for how your center can get involved.

About the BMT CTN

The CIBMTR shares administration of the BMT CTN Data and Coordinating Center with National Marrow Donor Program/Be The Match® and The Emmes Corporation®. Together, these three organizations support all BMT CTN activities.

To get up-to-date information about BMT CTN studies, meetings, and news:



facebook.com/bmtctn



[@BMTCTN](https://twitter.com/bmtctn)

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Electronic Patient Reported Outcomes

By Erin Leckrone

Within RCI BMT, the Survey Research Group operates as a stand-alone team to assist researchers in developing and conducting research involving questionnaires, direct subject interviews and patient-reported outcomes. The group handles collecting high quality, scientifically valid data from donors, patients and their families. The Survey Research Group currently utilizes standardized and semi-structured telephone interviews as well as self-administered questionnaires.

In 2017, the CIBMTR began planning and developing an electronic Patient Reported Outcomes (ePRO) system. Within an ePRO, patients can access and complete the

questionnaires from a link sent by SRG. The system integrates Qualtrics as a patient-facing interface with Salesforce as the client relationship management system. It delivers PROMIS (Patient-Reported Outcomes Measurement Information System) measures using computer adaptive testing (CAT) technology. PROMIS are person-centered measures that evaluate physical, mental, and social health and are supported by a NIH initiative. The CAT technology presents a respondent with items from an item bank. As a patient completes the initial question in an item bank, the CAT algorithm selects only those next items that sharpen estimation of the patient's score in the domain. This technology decreases respondent burden as patients only see questions that are relevant to them. During 2017, the CIBMTR selected vendors, secured internal resources, and reviewed the system design with the Architecture Review Board, information security team, and enterprise project management office. The team is on track to complete the initial build phase of the ePRO system in time to enroll patients in a pilot study in spring 2018.

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[Health Services Research Update](#)

By Linda Burns, MD; Ellen Denzen, MS; and Beth Murphy, EdD, RN

Survivorship

- The HSR Program, in partnership with Fred Hutchinson Cancer Research Center, held 3 patient and caregiver focus groups as part of the NIH funded study, **INSPIRE: A Multicenter Randomized Controlled Trial integrating health informatics in a scalable stepped care self-management program for survivors after HCT**. Participants provided feedback on print and web-based interventions to address late effects of HCT (e.g., cardiovascular and mental health, and screening for secondary cancers). This feedback will be analyzed for saturation of themes and used to optimize the interventional tools for the randomized, controlled study.
- **Patient-Centered Outcomes Research (PCOR) in HCT webinars** are now available online (funded in part by PCORI). Visit bethematchclinical.org to view the webinars, learn about recommended research questions, and earn continuing medical or nursing education credits. Also, a manuscript describing the recommendations has been submitted for peer-review publication.
- Results from the PCORI-funded project, **Individualized Care Plans for HCT Survivors (HSR/RCI BMT study SCP-13)**, were presented by study Co-PI, Navneet Majhail, MD, MS, at the December ASH Annual Meeting. The randomized study showed that the care plan and treatment summary populated with CIBMTR data decreases treatment-related distress, especially among younger adult patients. A manuscript is undergoing peer review for publication.

HCT Workforce Capacity

- The **HCT Multidisciplinary Care Teams: Burnout, Moral Distress, and Career Satisfaction** study (HSR 14-02) results showed a prevalence of burnout across transplant disciplines, despite high career satisfaction. Moral distress was found to be a significant contributing factor. [Read full publication](#).

2018 BMT Tandem Meeting Activities

- **ASBMT Health Economics and Value Special Interest Group (SIG) meeting will be held Thursday, February 22, 1:15 - 4:30 pm MT** featuring:
 - David Vanness, PhD: *Roadmap to Assessing Value of T-Cell Therapies*
 - Mark Juckett, MD: *Patient-Centered Outcomes Research in HCT: Models of Care Delivery and Financial Burden –*
 - Staci Arnold MD, MBA, MPH: *Patient-Centered Outcomes Research in HCT: Financial Burden*
 - William Pierce, MD, PhD: *Delivery of Care to the Patient with Suboptimal Payer Support*.
- **Join the ASBMT Survivorship SIG for breakfast on Wednesday, February 21, 7:00–8:30 am MT** The agenda will include updates on the work of the Palliative Care SIG, next steps for the NIH Late Effects Initiative, and presentation of investigators' research proposals.
- **A National Survey Study of Transplant Physicians' Attitudes about Palliative Care (HSR 16-03)** presented by Areej El-Jawahri, MD, Oral Abstract Session D, February 22, 4:45 pm MT.
- **Estimating Propensity Scores for the Receipt of Allogeneic Hematopoietic Cell Transplantation (AlloHCT) in Outcomes Research Using Claims Data: A Machine Learning Approach (HSR 16-05)** presented by David Vanness, PhD, Poster Session I, February 21 6:45-7:45 pm MT.

For questions about the Health Services Research Program, contact [Ellen Denzen, MS](#), Senior Manager, Health Services Research, or visit the [Health Services Research webpage](#).

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[Physicians and Search Coordinators Survey](#)

In early February, physicians and search coordinators will receive an invitation to participate in the Unrelated Donor Search and Selection Survey.

The goals of this research survey are to better understand standard practices for unrelated donor searches at transplant centers in the US and to identify potential solutions to facilitate urgent transplants for eligible patients. Your responses will inform services and programs offered to centers by NMDP/Be The Match. This online survey will take about 15 minutes to complete. Our goal is to receive an 80% response rate. Your participation is voluntary, and your responses are confidential.

To thank you for your time, you may elect to be entered in a drawing to win a \$100 Visa gift card. One hundred Visa gift cards will be distributed. Check your email for this survey as it will be closing on **March 12**.

For questions about the study, contact Tatenda Mupfudze, PhD, tmupfudz@nmdp.org or (763) 406-5128.

We appreciate your consideration of this important study.

Sincerely,
Joseph Pidala, MD, PhD
Chair, NMDP/Be The Match Histocompatibility Advisory Group
H. Lee Moffitt Cancer Center & Research Institute

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[Data Management Workshop held in Sydney, Australia](#)

In late fall 2017, Janet Brunner-Grady, Program Director of CIBMTR Data Operations, and Leigh Ann Laczkowski, CIBMTR Clinical Research Coordinator, coordinated a Data Management Workshop in Sydney, Australia, with the help of Gemma White, Data Manager in Perth, Australia. The day-long workshop accommodated ~25 data managers from Australia and New Zealand as well as staff from the Australian Bone Marrow Donor Registry. The workshop covered topics such as:

- Overview of AML, MDS / MPN, and Multiple Myeloma
- Disease Assessment Pre- and Post-HCT
- Interpreting Cytogenetics and Molecular Reports
- Common Data Entry Errors
- Understanding HPC Product Summaries
- Acute and Chronic GVHD Reporting
- Post-HCT Complications

Presentations were met with great enthusiasm from the participants with talk of convening another workshop in 2019.

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[Instructions for Gaining Portal Access](#)

The CIBMTR Audit Team launched a new SharePoint website that allows transplant centers to easily access their CIBMTR audit documents.

To access the CIBMTR Portal ("Portal"), follow the instructions below. Please note: Only Medical Directors and Primary Contacts listed in Salesforce are allowed access to audit data through the Portal. For others who desire access, please reach out to your center's Primary Contact.

Instructions for Gaining Portal Access:

1. Go to <https://portal.cibmtr.org>
2. If you don't have a Gmail account that's been authenticated for Portal access, follow the instructions on the Portal homepage, near the bottom. They begin with "To access the Portal and its applications...". If you already have access to the Portal to view Data Back to Centers (DBtC), Center Performance Analytics (CPA), etc., skip this step and proceed to step 3.
3. Click on Sign-in with Google, the red button to the right of the screen
4. Click on Audit Data at the top of the page
5. Click on your center folder (this should be the only folder you see)

6. Click on the audit year from which you wish to view documents
7. Click on the document you wish to view

From this point, you may view your chosen document online, download it, or print it.

For questions or issues related to Portal access, contact cibmtr-portalhelp@mcw.edu.

For questions related to audit folder contents (e.g. missing documents, etc.), contact Jenna Umar, Clinical Trials Assistant, at jhullerm@nmdp.org.

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[Be The Match Bio Therapies launches Cell Lines Blog](#)

Be The Match BioTherapies®, a subsidiary of the National Marrow Donor Program® (NMDP)/Be The Match®, recently launched a blog sharing advancements and expert insights in the cell and gene therapy industry.

To stay up-to-date on this rapidly advancing field, browse new articles on the [Cell Lines Blog](#), and subscribe to be notified when new articles are posted on topics like cell sourcing, research and outcomes reporting, cell supply chain complexities, and clinical development.

Connect with Be The Match BioTherapies on [Twitter](#) and [LinkedIn](#) for cell therapy industry updates and links to new blog posts.

[Be The Match BioTherapies](#) leverages the experience of both the NMDP/Be The Match and the CIBMTR to connect organizations developing cell and gene therapies with customizable solutions, such as outcomes data collection and analysis through the CIBMTR Cellular Therapy Outcomes Registry.

To learn more about Be The Match BioTherapies visit us online at bethematchbiotherapies.com.

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[Five New Patient Summaries of CIBMTR Research](#)

By Jessica Gillis-Smith, MPH

Five new patient summaries of CIBMTR publication were recently posted on the [CIBMTR Patient Resources webpage](#).

- [Common late effects after transplant in very young children](#)
 - 30% of very young BMT recipients have organ damage or other late effects.
 - Common late effects are delayed growth, cataracts, and hypothyroidism.
 - Full-body radiation increases the chance of getting these late effects.
- [Auto transplant helps some people with multiple sclerosis](#)
 - For almost half of people who got auto transplant, their MS didn't get worse for 5 years after transplant
- [Better transplant results with rituximab for people with B cell non-Hodgkin lymphoma](#)
 - Rituximab helped patients live a little longer without the NHL getting worse.
 - Rituximab made no difference in rates of overall survival, GVHD, and relapse.
- [Better survival over time for patients with acute GVHD](#)
 - Treatments for patients with moderate to severe acute GVHD have gotten better over time.
 - Tacrolimus helped patients with moderate acute GVHD live longer.
- [Cytogenetics predict transplant results in older patients with acute myeloid leukemia](#)
 - Cytogenetic testing can predict BMT outcomes in older patients with AML.
 - Transplant works for about 1 of every 3 older patients with AML.

Summaries are created through a collaborative process involving CIBMTR Consumer Advocacy Committee members; CIBMTR and NMDP/Be The Match Medical Writers, Communications Specialists, and Patient Education Specialists; and CIBMTR Scientific Directors. Developing these summaries is one of the main initiatives of the Consumer Advocacy Committee.

The [Consumer Advocacy Committee](#) was created in 2005 as a subcommittee of the Advisory Committee to communicate CIBMTR research results and data to the non-medical community and to provide patient and donor perspectives during the development of the CIBMTR research agenda. Many members have personal experience as a donor, recipient, or family member.

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[Abbreviations](#)

Need an acronym defined? Review our [list of common abbreviations](#).

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CIBMTR® (Center for International Blood and Marrow Transplant Research®) is a research collaboration between the National Marrow Donor Program®/Be The Match® and the Medical College of Wisconsin

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