COVID-19 Updates
Quick Links
Patient Resources
Publication List
Newsletters
News Releases
Slides and Reports
Statistical Resources
CIBMTR 50th Anniversary
Get Involved

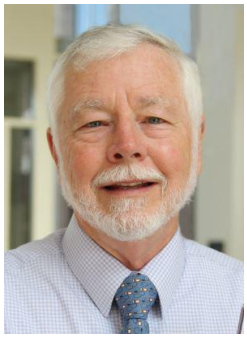
August 2021 Newsletter

Volume 27, Issue 3

Table of Contents:

Perspectives: Unintended Consequences of a Life-Saving Gift

By John Wingard, MD



More than two decades ago, Robin Cook wrote a medical thriller titled, "Chromosome Six." The premise was that mad scientists mastered a way to take chromosome six of a person in need of an organ transplant and insert it into a primate; their goal was to produce an engineered animal that could serve as the personalized organ donor for the person who needed a transplant. Of course, they thumbed their nose at a few ethical constraints, and naturally, these humanized donors were not intended to become universal donors to address the worldwide shortage of suitable donors but were to be sold to the wealthy few who could afford the exorbitant price. What could go wrong? Naturally, there were unintended consequences. Besides the HLA molecule, other genetic traits were residing on chromosome six that govern behavior and those engineered traits caused extreme aggressiveness; not surprisingly, the primates turned on their caretakers and others, wreaking havoc.

Although the hematopoietic cell graft is lifesaving for the recipient and offers a second chance for a life without leukemia or some other dreadful disease,

hematopoietic cell donation can sometimes be associated with unintended consequences for the recipient. A 2020 CIBMTR study expands on earlier observations that subtle genetic variants in the donor can be associated with adverse outcomes for the recipient.

Clonal hematopoiesis of indeterminate potential (CHIP) has been increasingly recognized as an entity found in older individuals. It has been associated with both malignant and non-malignant sequelae and shortened longevity. Uncommon before the age of 50, the occurrence increases with age and affects 10-20% of individuals over the age of 70. CHIP has been notably associated with increased risks for hematologic malignancy and cardiovascular disease. With the adoption of better-tolerated "reduced intensity" conditioning regimens, older patients are undergoing transplants at greater rates in recent years. That means more older siblings are also being used for donors.

Earlier studies showed that CHIP in donors can engraft in recipients, expand over time, and undergo clonal evolution. In some recipients, these changes can result in donor leukemia, unexplained cytopenias, chronic GVHD, and perhaps altered immune function. Such observations have raised concerns about the use of older donors and sparked debates about whether an unrelated younger donor might be more desirable than an older sibling donor.

As more sensitive assays to detect CHIP have been developed, this issue has become more complicated. Very sensitive sequencing techniques have shown that most adults over the age of 50 harbor rare hematopoietic clones, not detected by less sensitive techniques.

Using ultrasensitive sequencing techniques, Wong and colleagues found that in a small group of 25 younger donors (median age 26, range 20-58), more than 40% harbored clones with potential pathogenicity in low frequency (1). Serial testing of recipient blood samples showed these clones engrafted and persisted through the first year after transplant. In some cases, they expanded over time, with some clones exhibiting additional de novo mutations gained after transplant.

What does this mean? While it is unclear at this time, as the authors remind us, there is the possibility that in some instances this may be a ticking bomb with the downstream clinical relevance becoming manifest only years later. Are there factors related to the transplant experience that govern the fate of such clones, and could they be manipulated? Given two prospective donors to choose from, should we test for and select the one without a rare clone? If all the prospective donor choices have clones, will we be tempted to purge the clones from the graft, perhaps by some modern version of genetic manipulation envisioned by Robin Cook? What do we say to the donor about his / her health?

This is no Robin Cook intrigue. It is simply new findings that expand our understanding of hematopoiesis and aging. It certainly makes donor selection a bit more challenging.

Reference:

Wong WH, Bhatt S, Trinkaus K, et al. Engraftment of rare, pathogenic donor hematopoietic mutations in unrelated hematopoietic stem cell transplantation. Science Translational Medicine. 2020 Jan 15;12(526):eaax6249. doi: 10.1126/scitranslmed.aax6249. PMID: 31941826; PMCID: PMC7521140.

Return to Top

Health Services and International Studies Working Committee

Committee Leadership

Co-Chairs:

- Shahrukh K. Hashmi, MD, MPH, King Faisal Specialist Hospital, Riyadh, Saudi Arabia
- Leslie Lehmann, MD, Dana Farber Cancer Institute, Boston, MA
- William Wood, MD, MPH, University of North Carolina, Chapel Hill, NC

Scientific Director:

- Wael Saber, MD, MS, CIBMTR MCW

Statistical Director:

- Ruta Brazauskas, PhD, CIBMTR MCW

Statistician:

- Naya He, MPH, MS, CIBMTR MCW

In 2013, the CIBMTR's Health Policy / Psychosocial Issues Working Committee and the International Studies Working Committee merged to form the Health Services

and International Studies Working Committee. This Working Committee aims to improve the practice and outcomes of HCT through health services research worldwide. The committee brings together a global, enthusiastic, and diverse group of HCT investigators who represent varied clinical and research backgrounds. One of the current co-chairs is the director of an international transplant center and this experience is invaluable in evaluating studies from low- and middle-income countries.

The study portfolio in this committee includes population-based studies to advance understanding of health disparities in access and outcomes of HCT. These studies address practice patterns in HCT and the impact of HCT-related variables and social determinants not only on survival but also on other outcomes such as cost and health care utilization. To complete some of these studies, investigators not only query the CIBMTR Research Database but also link it to other large databases both within and outside the US. In addition, the committee strives to improve the overall quality of registry data by understanding gaps in follow-up and leading efforts dedicated to improving international data collection. If you want to tackle an important issue of outcomes, healthcare delivery, or global health research within the HCT arena, join us at the 2022 Tandem Meetings | Transplantation & Cellular Therapy Meetings of ASTCT and CIBMTR to see our committee in action.

In the past five years, the Health Services and International Studies Working Committee published 10 papers, including the following:

- Bona K, Brazauskas R, He N, et al. **Neighborhood poverty and pediatric allogeneic hematopoietic cell transplantation outcomes: A CIBMTR analysis.** Blood. 2021 Jan 28; 137(4):556-568. doi:10.1182/blood.2020006252. Epub 2020 Oct 26. PMC7845011.
- Tay J, Beattie S, Bredeson C, et al. **Pre-transplant marital status and hematopoietic cell transplantation outcomes.** Current Oncology. 2020 Dec 1; 27(6):e596-e606. doi:10.3747/co.27.6327. Epub 2020 Dec 1. PMC7755447.
- Hong S, Brazauskas R, Hebert KM, et al. **Community health status and outcomes after allogeneic hematopoietic cell transplantation in the United States.** Cancer. 2021 Feb 15; 127(4):609-618. doi:10.1002/cncr.33232. Epub 2020 Oct 21. PMC7855526.
- Arnold SD, Brazauskas R, He N, et al. **The impact of donor type on outcomes and cost of allogeneic hematopoietic cell transplantation for pediatric leukemia: A merged Center for International Blood and Marrow Transplant Research and Pediatric Health Information System analysis.** Biology of Blood and Marrow Transplantation. 2020 Sep 1; 26(9):1747-1756. doi:10.1016/j.bbmt.2020.05.016. Epub 2020 May 25. PMC7518194.
- Buchbinder D, Brazauskas R, Bo-Subait K, et al. **Predictors of loss to follow-up among pediatric and adult hematopoietic cell transplantation survivors: A report from the Center for International Blood and Marrow Transplant Research**. Biology of Blood and Marrow Transplantation. 2020 Mar 1; 26(3):553-561. doi:10.1016/j.bbmt.2019.11.003. Epub 2019 Nov 11. PMC7367505.
- Paulson K, Brazauskas R, Khera N, et al. **Inferior access to allogeneic transplant in disadvantaged populations: A CIBMTR analysis.** Biology of Blood and Marrow Transplantation. 2019 10; 25(10): 2086-2090.
- El-Jawahri A, Chen Y-B, Brazauskas R, et al. **Impact of pre-transplant depression on outcomes of allogeneic and autologous hematopoietic stem cell transplantation.** Cancer. 2017 May 15; 123(10):1828-1838. doi:10.1002/cncr.30546. Epub 2017 Jan 19. PMC5419891.
- Arnold SD, Brazauskas R, He N, et al. **Clinical risks and healthcare utilization of haematopoietic cell transplantation for sickle cell disease in the U.S. using merged databases.** Haematologica. 2017 Nov 1; 102(11):1823-1832. doi:10.3324/haematol.2017.169581. Epub 2017 Aug 17. PMC5664386.
- Wood WA, Brazauskas R, Hu ZH, et al. **Country-level macroeconomic indicators predict early post-allogeneic hematopoietic cell transplantation survival in acute lymphoblastic leukemia: A CIBMTR analysis.** Biology of Blood and Marrow Transplantation. 2018 Sep 1; 24(9):1928-1935. doi:10.1016/j.bbmt.2018.03.016. Epub 2018 Mar 19. PMC6146070.
- Kanda J, Brazauskas R, Hu ZH, et al. **GVHD after HLA-matched sibling BMT or PBSCT: Comparison of North American Caucasian and Japanese populations.** Biology of Blood and Marrow Transplantation. 2016 Apr 1; 22(4):744-751. doi:10.1016/j.bbmt.2015.12.027. Epub 2016 Jan 4. PMC4801761.

The committee's current portfolio contains 7 studies in progress:

- HS16-01: Trends in utilization and outcomes of autologous and allogeneic hematopoietic cell transplantation in racial and ethnic minorities
- HS16-03: Relationship of race / ethnicity and survival after single and double umbilical cord blood transplantation

- HS18-01: International collaborative study to compare the prognosis for acute leukemia patients transplanted with intensified myeloablative regimens
- HS18-02: Racial differences in long term survivor outcomes after allogeneic hematopoietic cell transplantation
- HS19-01: Factors associated with clinical trial participation among HSCT patients: A CIBMTR analysis
- HS19-03: Haploidentical stem cell transplantation for malignant and non-malignant hematological diseases in patients without sibling donor: A multicenter prospective longitudinal study of the Brazilian bone marrow transplantation study group
- HS19-04: Outcomes after allogeneic stem cell transplants performed in Brazil from HLA-matched siblings, unrelated and mismatched related donors. Retrospective study on behalf of the Brazilian Bone Marrow Transplantation Society (SBTMO), GEDECo (Brazil-Seattle)

The unique strength of the Health Services and International Studies Working Committee is its collaboration with many societies / organizations in areas of health policy, health care delivery, and global health to answer questions not often addressed by other committees. The committee works closely with the CIBMTR Health Services Research Program operated by NMDP/Be The Match's Patient and Health Professional Services department. The Health Services Research Program facilitates investigator-initiated studies that require expertise and resources beyond those typically needed in CIBMTR studies. Recently the Working Committee partnered with the Brazilian Society of Stem Cell Transplantation to perform joint studies of HCT-related health services in Brazil, and other international collaborations are ongoing. We encourage investigators from both within the US and globally to bring forth innovative studies to our committee. Our mission is to foster and support studies that achieve worldwide impact.

Return to Top

Regimen-Related Toxicity and Supportive Care Working Committee

Top row left to right: Edward Stadtmauer, Bipin Savani, Mohamed Sorror

Bottom row left to right: Saurabh Chhabra, Kwang Woo Ahn, Mariam Allbee-Johnson

Committee Leadership

Co-Chairs:

- Edward Stadtmauer, MD, University of Pennsylvania Medical Center, Philadelphia, PA
- Bipin Savani, MD, Vanderbilt University Medical Center, Nashville, TN Boston, MA
- Mohamed Sorror, MD, MSc, Fred Hutchinson Cancer Research Center, Seattle, WA

Scientific Director:

- Saurabh Chhabra, MD, MS, CIBMTR MCW

Statistical Director:

- Kwang Woo Ahn, PhD, CIBMTR MCW

Statistician:

- Mariam Allbee-Johnson, MPH, CIBMTR MCW

The Regimen-Related Toxicity and Supportive Care Working Committee works with investigators worldwide to mitigate treatment-related morbidity and mortality after HCT, with an overarching mission to improve transplant outcomes. The committee takes advantage of the CIBMTR's large and representative clinical database to study various toxicities after HCT and the supportive care needed for such toxicities. This includes characterizing toxicities associated with specific conditioning regimens and understanding which HCT patients are at greatest risk for developing these complications. A better understanding of HCT- and other cellular therapy-related toxicity is not only important for surveillance in clinical practice but also for the development of new strategies to improve supportive care in vulnerable populations.

The committee meets annually in person during the Tandem Meetings of ASTCT & CIBMTR. The Co-Chairs, along with the Scientific Director, Statistical Director, and MS Statistician, meet quarterly through teleconference to ensure the timely completion of projects, reassess priority areas, and promote and develop the committee's scientific agenda. The 2021 Working Committee meeting occurred virtually and enjoyed continued strong participation! Moreover, the productivity and enthusiasm of the committee have resulted in positive evaluations by both meeting attendees and the CIBMTR Advisory Committee, which conducts ongoing reviews of the individual committee meetings.

A list of the committee's studies, including recent publications, is provided on the Regimen-Related Toxicity and Supportive Care Working Committee webpage. Participant engagement in committee activities is essential to the committee's accomplishments. The committee has collaborated with other registries, both nationally and internationally, with the resulting publications leading to practice changes. Specifically, the committee prospectively validated the HCT-comorbidity index and further advanced the field through developing a modified HCT-comorbidity index for pediatric and young adult recipients of allogeneic transplantation. The committee's portfolio comprises 6 protocols in development, analysis, or manuscripts in preparation. These cover a wide range of topics pertinent to the care of HCT survivors for benign and malignant disorders.

The Regimen-Related Toxicity and Supportive Care Working Committee provides a platform for consolidating ideas from members across the globe to study the HCT-related toxicity, biology, and management of varied complications. By serving as a partner for researchers, we leverage the power of big data to undertake projects and answer questions that are difficult for a single institution to accomplish. Through this collaborative process, the CIBMTR develops stronger connections and fosters a continued commitment to the overall mission of the organization. The vision of our committee is to keep this loop alive so that we can achieve greater national and international recognition for HCT-related research. We aim to accelerate the discovery of cures for patients afflicted by these diseases and highlight existing disparities in access to HCT and other cellular therapies to rectify these disparities.

The success of the committee depends on new ideas, testable hypotheses, and participation from individuals with different perspectives and scientific backgrounds. The Regimen-Related Toxicity and Supportive Care Working Committee encourages investigators with an interest in our committee arena to propose a study. We seek novel ideas and encourage the involvement of junior investigators interested in outcomes research. We believe early involvement encourages the long-term participation of junior investigators in committee activities.

Our tips for writing / submitting proposals:

Please submit your proposals any time of the year! Writing a study proposal should not take more than 2-3 hours. Please follow the study proposal template, which is available online. In brief, you need to answer the following questions:

1. What do you want to study?
2. How do you want to study?
3. Why is it important?
4. How will the results of this study change the way we practice today? (We want to publish high-impact factor studies!)

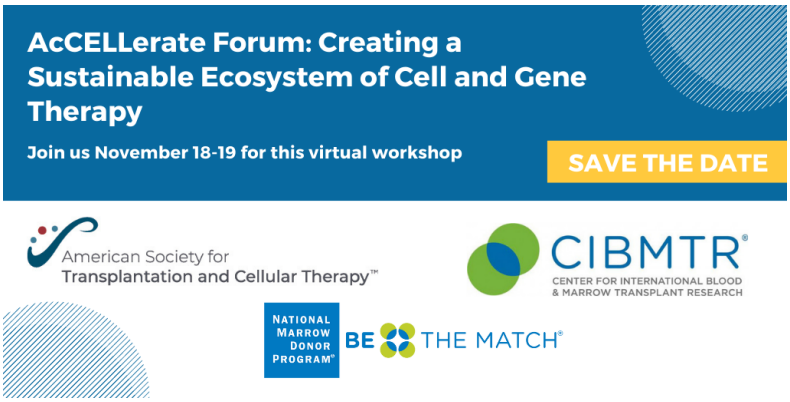
Before you propose a study, please review the CIBMTR inventory—data forms submitted to CIBMTR and available information in the registry data. Collection of supplementary data depends on the scientific impact of the study. This is a red flag as it takes time and money! Please view planned, in-progress, and completed studies and publications on the Regimen-Related Toxicity and Supportive Care Working Committee webpage. Our committee encourages participation by

clinicians and scientists early in their careers, and many of our studies are led by senior fellows and junior faculty with Working Committee mentorship.

To learn more about the committee or to discuss your research ideas and proposals, contact one of the members of the Working Committee leadership team (listed above). We strongly encourage our Working Committee members to actively participate in the committee activities and look forward to everyone's participation at the 2022 Tandem Meetings of ASTCT & CIBMTR!

Return to Top

AcCELLerate Forum of ASTCT, CIBMTR, and the NMDP/Be The Match



Save the date for the AcCELLerate Forum of ASTCT®, CIBMTR® and the National Marrow Donor Program®/(NMDP)/Be The Match®

Join us November 18-19 for this new, virtual workshop

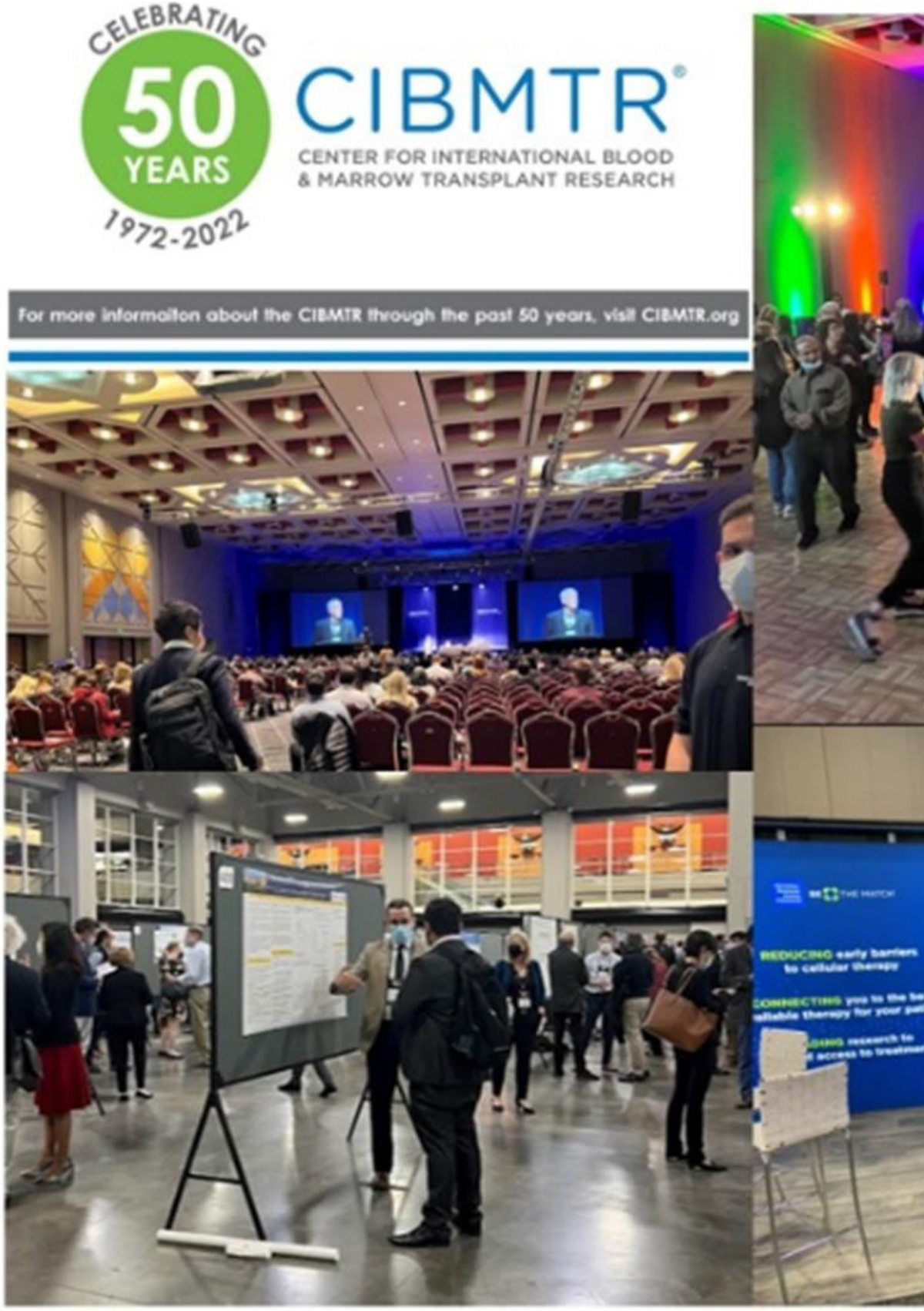
ASTCT, CIBMTR and the NMDP/Be The Match are excited to present the *AcCELLerate Forum: Creating a Sustainable Ecosystem of Cell and Gene Therapy* —a two-day, virtual workshop that will offer providers, payers, government agencies, and industry involved in the field of cell and gene therapy increased educational and advocacy opportunities. This new event, scheduled for November 18-19, 2021, features educational sessions that will bridge the gap among stakeholders, and identify ongoing needs and opportunities in the field for advocacy, measurement of value and impact, and sustainability.

Stay tuned for additional information, including registration, in the coming weeks.

Return to Top

2022 Tandem Meetings

By Tia Houseman



The Tandem Meetings | Transplantation & Cellular Therapy Meetings of ASTCT and CIBMTR (Tandem Meetings) are the combined annual meetings of the American Society for Transplantation and Cellular Therapy (ASTCT) and the Center for International Blood & Marrow Transplant Research (CIBMTR). Administrators, clinicians, data managers / clinical research professionals, fellows-in-training, investigators, laboratory technicians, MDs / PhDs, nurses, nurse practitioners, pharmacists, physician assistants, and other allied health professional attendees benefit from a full scientific program that addresses the current issues in HCT and cellular therapy.

Celebrating Our History, Looking Forward to the Future

In preparing for the 2022 meetings, ASTCT® and CIBMTR® are gearing up to safely welcome people back in person and commemorate five decades of CIBMTR history. To help celebrate the CIBMTR's 50th Anniversary, and the rich history of our meetings, our organizations renamed our meetings to **Tandem Meetings | Transplantation & Cellular Therapy Meetings of ASTCT and CIBMTR**.

In 1995, ASTCT and CIBMTR combined their annual meetings, holding the inaugural BMT Tandem Meetings. Today, the meetings draw together more than 4,000 individuals in the HCT and cellular therapy field. Attendees benefit from a scientific program focused on the latest scientific updates, new technologies, and innovative products to help healthcare professionals save and improve life for patients with blood-related disorders.

We look forward to safely bringing our communities together in Salt Lake City, Utah, February 2-6, 2022. Stay tuned for additional details in the coming months.

Scientific Program Topics

- 50th anniversary of the CIBMTR: Building on the past to address the challenges of the future
- CAR-T and beyond
- Cell and gene therapy - HCT for sickle cell anemia: Donor selection, peritransplant management, and long-term follow-up - safety focus
- The challenge of translating evidence into action in HCT
- Clonal hematopoiesis
- Disparities in cellular therapy
- Donor optimization
- GVHD
- How to prevent GVHD
- Innate immunity: Friend or foe?
- Measurable residual disease and mechanisms of relapse / genetic manipulation to enhance immunotherapeutic response against myeloid malignancy
- Role of autotransplant vs CAR T (lymphoma and myeloma)
- Statistical issues in transplant and cellular therapy studies
- Treatment of respiratory viruses in HCT / cell therapy recipients
- Worldwide equity in 15 years?

Plus: Mortimer M. Bortin Lecture, E. Donnall Thomas Lecture, late-breaking abstracts, CIBMTR Working Committee meetings, ASTCT spotlight sessions, and Meet-the-Professor sessions. Along with these state-of-the-art educational offerings, industry-supported satellite symposia, product theaters, and exhibits will further broaden the spectrum of presentations.

Tracks

Confirmed tracks: Administrative directors, advanced practice providers, BMT CTN coordinators, clinical research professionals / data management, IT and informatics, nursing, pediatric, and pharmacists.

Abstracts, Registration, and Housing

The abstract submission site will open in August with a late September deadline. Online registration and housing will open in September.

Support Opportunities and Additional Information

Please direct questions regarding support opportunities at the 2022 Tandem Meetings of ASTCT & CIBMTR to the Tandem Meetings Conference Office: TandemMeetings@mcw.edu.

We look forward to seeing you!

Follow ASTCT and CIBMTR on social media, as well as the official hashtag **#TandemMeetings22** for updates.

Return to Top

Updated CPI Program Begins Fall 2021

By Jenni Bloomquist, MS

Beginning in September 2021 and continuing through the end of 2022, the CIBMTR will phase in a newly structured CPI program to track form submission requirements. These enhancements will better align the requirements with the data needs of the transplant community while simplifying the metrics tracked to improve the quality and availability of research data.

Requirement categories:

- On-time critical forms submission
- Overall critical forms submission

- Study supplemental forms submission
- Other forms submission
- Data query resolution

Access the CIBMTR Data Management Guide for details about the requirements and the target percentages.

Return to Top

HCT Data Centralization

Late in 2020, the CIBMTR launched an initiative to consolidate and centralize HCT data curated from a legacy system that has stored data since 1980 to a new and more integrated system. Today, this legacy system provides centers access to these data within the DBtC, DBtC-Download, and Data for RFI, using the CIBMTR Portal. However, the new integrated system is better designed to accommodate data more flexibly from new therapies, new indications, and novel data types. The CIBMTR will apply this new infrastructure to more efficiently integrate and deliver all data to DBtC, DBtC-Download, and Data for RFI.

What this means for you

Until the new system can support the full scope of HCT data, the legacy system will remain the source of HCT data in DBtC, with temporary limitations in the availability of new data. During this transition, Centers can expect the following:

- **DBtC & DBtC-Download**
  - HCT data submitted on form versions published in FormsNet3 before October 2020 are continually available in DBtC, and DBtC-Download.
  - HCT data submitted on forms versions published in FormsNet3 after October 2020 will not initially appear in DBtC, DBtC-Download, or Data for RFI. However, the CIBMTR will incrementally add these data to DBtC before the end of 2021.
  - More HCT data from new form versions published in FormsNet3 after October 2020 are expected by mid-2022.
  - During this transition, you may notice the suspension of some filters and visualization in the DBtC application, based on the limited availability of data.
- **Data For RFI**
  - This transition will largely not affect Data for RFI (built upon the ASTCT template), which locks data prior to October 1, 2020.
  - For the Data for RFI in 2021, stakeholders should be aware of potential gaps in the last months of RFI depending on when the center submitted their data.
  - The goal is to restore Data for RFI in 2022

There will be no loss of data submitted to CIBMTR; the impacts above are limited ONLY to the presentation of these data in tools on the CIBMTR Portal. We appreciate your patience as we work toward this objective.

Looking to the future

As we move forward with the HCT centralization project, our stakeholders can expect to receive regular communication at periodic intervals with updates on the project's progress and its impacts on our community. The CIBMTR will also begin to reimagine novel ways to package, present, and enable access to the data.

Return to Top

Prognostic Indicator of Post-HCT MDS Relapse Risk

By Yung-Tsi Bolon, PhD

Prior studies uncovered several genetic indicators where mutations in key genes were observed to associate with poor transplant outcomes in patients with MDS. In a major study, Lindsley et al. (*The New England Journal of Medicine*, 2017) highlighted that mutations in TP53, JAK2, and RAS pathway genes were prognostic for outcomes after HCT among patients with MDS. To determine whether epigenomic factors, characterized by assessing genome-wide methylation, also play a prognostic role, and to facilitate the detection of novel determinants, the CIBMTR MDS Omics study group recently completed and published a pilot study: Wei Wang, Paul Auer, Tao Zhang, et al. **Impact of epigenomic hypermethylation at TP53 on allogeneic HCT outcomes for MDS.** Transplantation and Cellular Therapy. *doi:10.1016/j.jtct.2021.04.027. Epub 2021 May 13.*

We hypothesized that epigenomic signatures in MDS patients before undergoing HCT serve as a novel prognostic indicator of post-HCT MDS relapse risk. Pre-HCT whole blood samples were obtained from the CIBMTR repository. In a matched case-control study design on 94 patients with MDS where 47 patients relapsed post-HCT and 47 did not relapse, we analyzed reduced representation bisulfite sequencing profiles to evaluate whole-genome epigenetic profiles. We then tested these epigenomic signatures for association with post-HCT outcomes. Cohort inclusion criteria specified patients with MDS that underwent HCT were wild-type for TP53, RAS pathway, and JAK2 mutations to promote the discovery of novel factors. Case-control matching was based on conditioning regimen intensity, age, sex, Revised International Prognostic Scoring System, Karnofsky Performance Status, graft, and donor types.

Through this study, we mapped epigenomic profiles for patients with MDS and found that cases displayed more hyper-differentially methylated regions pre-HCT than controls, even after adjusting for pre-HCT use of hypomethylating agents. In addition, the hyper-differentially methylated regions specific to cases mapped to the transcription start site of 218 unique genes enriched in five different signaling pathways. Strikingly, although the patients selected for this cohort were wild-type for the TP53 gene, cases showed significantly greater levels of methylation at TP53 than controls. Our findings suggest that previously identified prognostic genes for MDS such as TP53 may affect disease relapse not only through genetic mutation but also through epigenetic methylation mechanisms (Figure 1, see below). Further study and validation are currently underway.

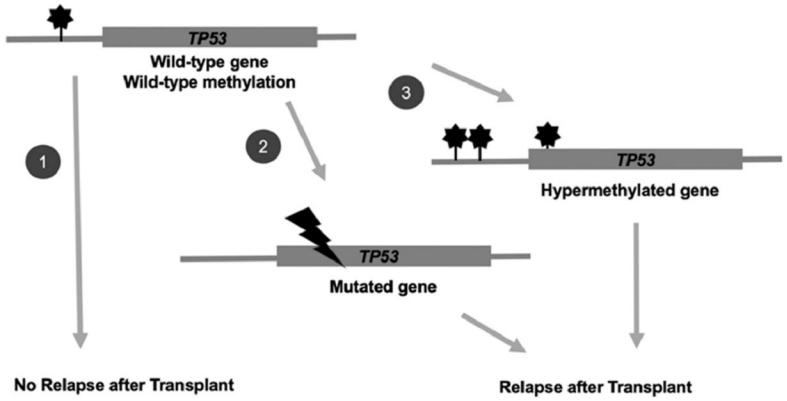


Figure 1: Post-HCT outcomes in patients with MDS associate with the presence of genetic mutations or epigenetic hypermethylation in *TP53*.

In the first pathway (1), patients with the wild-type *TP53* gene at wild-type methylation levels pre-HCT do not experience relapse post-HCT. However, those patients with (2) genetic mutations at *TP53* or (3) hypermethylation at *TP53* pre-HCT are at increased risk of MDS disease relapse post-HCT.
https://doi.org/10.1016/j.jtct.2021.04.027

Return to Top

New Data Manager Onboarding

By Eileen Tuschl, DNP, RN, ACNS-BC, APNP

CIBMTR Data Operations offers new data manager onboarding twice per year: In-person each February at the Tandem Meetings of ASTCT & CIBMTR and virtually each September.

New data manager onboarding is for individuals with 6 months or less experience at their center. The classes include interactive training in our FormsNet3 training environment and CIBMTR Portal as well as topics pertinent to new data managers to submit quality data.

The September virtual onboarding cost is $125 while the February in-person onboarding at the 2022 Tandem Meetings is $200. Centers who have joined the CIBMTR in the previous 6 months attend new data manager onboarding free of cost. Click HERE for more information.

Return to Top

Data Transformation Initiative Update

As summer sizzles, so does the Data Transformation Initiative (DTI). Buoyed by successes with early partner organizations, we are conversing with more than 60 centers interested in using DTI's customized solution to flow data to the CIBMTR.

DTI achieved a major milestone in late July – a software update ensures that partner centers' data submitted via the CIBMTR Reporting App will pre-populate in FormsNet3. This improvement saves time for partners, time savings that will increase exponentially as more data variables are added to the DTI solution.

The updated CIBMTR Reporting App (via the EPIC App Orchard) is the result of Herculean efforts put forth by the DTI, Data Operations, and the CIBMTR Information Technology Group Quality Assurance and Development teams. It is a learning process for all, as the CIBMTR works to create the best experience for our center network partners. These early milestones are just the beginning ... Stay tuned. Please email DT@nmdp.org if you would like to learn more about the Data Transformation Initiative.

Return to Top

Sharing Your Research with the Public

By Jennifer Motl

Four new plain-language summaries for CIBMTR research may help your patients:

Lower income children with blood cancers are less likely to survive after blood and marrow transplantation

More support and resources are needed for children and families

Read more: accessible or 1-page version

Care guides can help you manage your health in the months and years after blood and marrow transplant

Read more: accessible or 1-page version

Half-matched donors help more people with MDS get transplants

Both matched, unrelated people and half-matched relatives can donate

Read more: accessible or 1-page version

Medicaid does not cover many costs of transplant for people with sickle cell disease

Survey shows more coverage needed for life-saving treatment

Read more: accessible or 1-page version

On the Study Summaries for Patients webpage, you will find even more summaries.

Return to Top

Additional Research Datasets Available for Secondary Analysis

By Liz Siepmann

In accordance with the NIH Data Sharing Policy and NCI Cancer Moonshot℠ Public Access and Data Sharing Policy, the CIBMTR is making publication analysis datasets publicly available on the CIBMTR Research Datasets for Secondary Analysis webpage.

These publication analysis datasets are freely available to the public for secondary analysis. While providing these data, the CIBMTR is committed to safeguarding the privacy of participants and protecting confidential and proprietary data.

NEW datasets are now available online.

Return to Top

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Return to Top

Abbreviations

Need an acronym defined? Review our list of common abbreviations.

Return to Top

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Last Updated: 9/22/2021 11:48 AM

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