SUMMARY OF ACCOMPLISHMENTS

MISSION
The CIBMTR® (Center for International Blood and Marrow Transplant Research®) collaborates with the global scientific community to advance hematopoietic cell transplantation (HCT) and cellular therapy worldwide to increase survival and enrich quality of life for patients. A research collaboration between the National Marrow Donor Program® (NMDP)/Be The Match® and the Medical College of Wisconsin (MCW), the CIBMTR facilitates critical observational and interventional research through scientific and statistical expertise, a large network of transplant centers, and a unique and extensive clinical database.

VALUE TO THE COMMUNITY
The CIBMTR represents an international network of approximately 400 participating transplant centers that submit transplant-related data for patients. CIBMTR research involves 6 major programs:
- Clinical Outcomes
- Health Services
- Immunobiology
- Bioinformatics
- Clinical Trials
- Statistical Methodology

The CIBMTR has been collecting HCT outcomes data worldwide for >40 years, resulting in a Research Database with information on >440,000 patients. These data are freely available to investigators with interest in HCT and treatments for cancer and other life-threatening diseases. The CIBMTR has become a respected leader in HCT research by providing a unique resource of information and expertise to the medical and scientific communities.

IMPROVING PATIENTS’ LIVES
The CIBMTR is dedicated to improving survival, treatment, and quality of life for transplant patients. With >1,100 publications, the CIBMTR conducts practice-changing research that helps patients and physicians:

SELECT DONORS AND GRAFTS
CIBMTR studies have established the paradigm for selecting the best donor and graft:
- Optimal human leukocyte antigen (HLA) matching
- Impact of donor characteristics
- Cord blood vs bone marrow vs peripheral blood

EVALUATE PATIENT RISK
CIBMTR studies have shown which patients:
- Have the highest risk of graft-vs-host disease (GVHD) and other complications
- Are most likely to benefit from transplant

IDENTIFY LONG-TERM EFFECTS OF TRANSPLANTATION
CIBMTR studies provide insight into:
- Long-term impact of transplant on patients and their families, including risk of second cancers and other late complications
- Survivors' quality of life

PROVIDE MEDICAL CARE GUIDANCE FOR SURVIVORS
The CIBMTR has worked with the medical community to develop guidelines for optimal long-term care of transplant survivors to:
- Decrease the rate of late complications
- Preserve patients’ fertility as much as possible
- Identify post-transplant best practice preventive health behaviors

ADDRESS ACCESS TO CARE AND FUTURE WORKFORCE NEEDS
CIBMTR studies address the broad range of issues that influence access to transplant and long-term care after transplantation, including:
- Disparities in access and outcomes of specific populations
- Costs of care
- Future work force capacity

Publications establishing the CIBMTR's research in each of these areas are listed at www.cibmtr.org/About/ProceduresProgress/Pages/SummaryPubs.aspx
Fifteen Scientific Working Committees oversee most of the CIBMTR’s clinical outcomes research. Their accomplishments this year include:

- Administered the committees on which >2,300 worldwide researchers participate
- Collaborated with the 48 global experts in the HCT field who voluntarily chair the committees
- Conducted >180 ongoing studies
- Reviewed almost 200 new study proposals, >90 of which were presented and 38 of which were approved at the BMT Tandem Meetings
- Supported >500 scientific authors at >250 institutions worldwide to publish research findings
- Published 42 manuscripts and 2 letters to the editor in peer-reviewed journals, including The New England Journal of Medicine, JAMA, and the Journal of Clinical Oncology
- Presented 33 abstracts (20 oral and 13 poster) at national and international conferences, including:
  - 19 (11 oral and 8 poster) at the American Society of Hematology Annual Meeting
  - 10 (8 oral and 2 poster) at the BMT Tandem Meetings

This year the program’s accomplishments include:

- Published 7 manuscripts and 2 letters to the editor in peer-reviewed journals
- Presented 9 abstracts at national and international conferences
- Reviewed and accepted 3 new project proposals
- Distributed 15,919 research samples to investigators
- Completed HLA and killer-cell immunoglobulin-like receptor (KIR) typing on >3,000 donor / recipient research sample pairs
- Curated samples from 12,731 participants in the Research Repository (137,044 overall)

Research Repository:

- Added 4,255 unrelated recipient samples (54,437 overall)
- Added 1,295 related recipient samples (6,159 overall)
- Added 4,815 adult unrelated donor samples (60,094 overall)
- Added 1,303 related donor samples (5,900 overall)
- Added 1,063 unrelated cord blood samples (10,453 overall)
This year the program’s accomplishments include:
- Awarded a 2 year grant from the Patient-Centered Outcomes Research Institute (PCORI) to develop a patient-centered HCT outcomes research agenda; the first symposium, Setting the Stage for Engagement in PCOR, was highly successful and led to the formation of 6 Working Groups to develop and prioritize research questions.
- Completed enrollment of 495 HCT survivors on a multi-center randomized controlled study to evaluate the effectiveness of an individualized survivorship care plan template (funded by PCORI).
- Surveyed US transplant physicians to understand the impact of published findings from BMT CTN 0201 on peripheral blood vs bone marrow graft from unrelated donors; this study is in the data analysis phase.
- Based on results from a needs assessment, developed a 3 part educational webinar series to increase early referrals for HCT consultation targeting community hematologist / oncologist physicians who treat patients diagnosed with acute myeloid leukemia (funded in part by the National Comprehensive Cancer Network and Pfizer).
- Provided technical plain language writing consultation; developed 10 easy-to-read consent forms and 1 patient information sheet for 4 BMT CTN protocols.
- Published 3 manuscripts in peer-reviewed journals.
- Presented 8 abstracts at scientific meetings.
HCT is a complex process with multiple competing risks and dramatic changes in the risks of specific events over time. The CIBMTR has developed and evaluated many of the statistical models used in HCT research and works to provide guidance for appropriate application and interpretation of these sophisticated models.

Biostatisticians with the Statistical Methodology Research Program ensure the statistical integrity of CIBMTR scientific activities, contribute to results in articles on HCT-related statistical issues for clinical audiences, and support Working Committee study investigators in developing scientific study protocols using CIBMTR data. This year biostatisticians published 1 peer-reviewed manuscript comparing matching and regression for observational studies. An additional 4 manuscripts are in press.

This year investigators with the Bioinformatics Research Program presented 14 abstracts at national and international conferences and published 18 peer-reviewed manuscripts and 2 other articles in scientific journals.

**BIOINFORMATICS RESEARCH PROGRAM**

The Bioinformatics Research Program provides expertise in and conducts research on translational and operational bioinformatics.

**STATISTICAL METHODOLOGY RESEARCH PROGRAM**

The Statistical Methodology Research Program’s goals are two-fold: Develop statistical models to use in HCT research, and compare new models with existing solutions using the Research Database.

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**PATIENTS IN THE CIBMTR RESEARCH DATABASE BY DISEASE**

- **Allogeneic Transplants**
- **Autologous Transplants**

- **Lymphoma**
- **Plasma cell disorders**
- **Acute myelogenous leukemia**
- **Acute lymphoblastic leukemia**
- **Chronic myelogenous leukemia**
- **Aplastic anemia / PNH**
- **Immune disorders**
- **Inherited bone marrow failure**
- **Inborn errors of metabolism**
- **Hemoglobinopathy**
- **Other nonmalignant disorders**
- **Other diseases**
In addition to its Research Programs, the CIBMTR is committed to sharing the data we collect as well as the information and knowledge produced from our data and our extensive collaborations with investigators in the HCT field. The CIBMTR shares information, data, tools, and biospecimens in various ways.

**INFORMATION REQUEST SERVICE**
The CIBMTR provides timely access to transplantation data to patients, physicians, hospitals, pharmaceutical companies, insurance companies, and others involved in healthcare. This year the CIBMTR fulfilled 474 requests for information and data. For questions about requesting CIBMTR data, contact inforequest@mcw.edu.

**PUBLIC WEBSITE**
The CIBMTR public website (cibmtr.org) provides visitors with information about the CIBMTR and its research, including standard reports, publication and study lists, annual meeting information, and data management training materials. This year visitors accessed pages on the CIBMTR public website approximately 566,080 times.

**DATA SHARING APPLICATIONS**
- **AGNIS** - AGNIS allows participating centers to electronically collect and share data with the CIBMTR. This year 20,637 forms for 14,928 patients were submitted through AGNIS by 21 US transplant centers and by the European Society for Blood and Marrow Transplantation for 48 of their affiliated centers.
- **Qlikview** - The CIBMTR launched 2 Qlikview applications at the end of April. eDBtC, which provides centers with their data and a variety of analytic tools, was accessed by transplant personnel 467 times in the first two months, and Center Performance Analytics, which provides centers with their SCTOD database data, was accessed 183 times.

**BMT TANDEM MEETINGS**
The CIBMTR and American Society for Blood and Marrow Transplantation host the BMT Tandem Meetings annually in February. With 3,221 attendees from 48 countries, the 2016 BMT Tandem Meetings included 5 plenary sessions, 9 concurrent sessions, 133 oral abstracts, 2 poster sessions, 5 corporate-sponsored symposia, and 5 product theaters.

**DATA MANAGEMENT TRAINING**
The CIBMTR provides detailed information and training to help centers submit high quality data in an efficient manner. Examples on the CIBMTR Training and Reference webpage include the Forms Instruction Manual, FormsNet and AGNIS trainings, and Clinical Research Professional / Data Manager Conference materials. Online courses are also available; this year the CIBMTR added 5 new courses, so a total of 19 courses are now available.
The CIBMTR published 85 peer-reviewed manuscripts and 13 other articles in scientific journals and books this year. Some of the CIBMTR’s key findings were published in the following articles:


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