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 350 participating transplant centers that submit transplant-related data for patients. CIBMTR research involves 6 major programs:
- Clinical Outcomes Research
- Immunobiology Research
- Clinical Trials Support
- Bioinformatics Research
- Health Services Research
- Statistical Methodology Research

The CIBMTR has been collecting HCT outcomes data worldwide for >40 years, resulting in a Research Database with information on >415,000 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.

SUMMARY OF ACCOMPLISHMENTS

July 1, 2014 – June 30, 2015

IMPROVING PATIENTS’ LIVES

The CIBMTR is dedicated to improving survival, treatment, and quality of life for transplant patients. With >1,000 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 1,700 worldwide researchers participate
- Collaborated with the 54 global experts in the HCT field who voluntarily chair the committees
- Conducted 197 ongoing studies
- Reviewed 157 new study proposals, 73 of which were presented and 35 of which were approved at the BMT Tandem Meetings
- Supported 445 scientific authors at 227 institutions worldwide to publish research findings
- Published 47 manuscripts in peer-reviewed journals, including the New England Journal of Medicine, JAMA, and the Journal of Clinical Oncology
- Presented 36 abstracts (25 oral and 11 poster), including:
  - 16 (9 oral and 7 poster) at the American Society of Hematology Annual Meeting
  - 10 (9 oral and 1 poster) at the BMT Tandem Meetings

This year the program’s accomplishments include:

- Published 9 manuscripts in peer-reviewed journals
- Presented 7 abstracts at scientific meetings
- Reviewed and accepted 8 new project proposals
- Distributed 13,012 research samples to investigators
- Completed HLA and killer-cell immunoglobulin-like receptor (KIR) typing on >3,400 donor / recipient research sample pairs
- Curated 11,776 samples in the Research Repository (129,981 overall)

Research Repository:
- Added 4,408 unrelated recipient samples (55,153 overall)
- Added 1,259 related recipient samples (4,855 overall)
- Added 3,946 adult unrelated donor samples (56,971 overall)
- Added 1,236 related donor samples (4,595 overall)
- Added 916 unrelated cord blood samples (8,406 overall)

Numbers of Patients Registered with the CIBMTR Continue to Grow

(Data are incomplete for 2015)
The program is currently engaged in projects to:

- Develop pipelines to analyze next generation sequencing typing data, including full-gene HLA, KIR, and genome-wide sequencing, to refine our understanding of genetic matching
- Investigate the role of genetic ancestry in transplantation, including the best way to match individuals with multiple races in their family tree
- Develop data standards and tools for making immunogenetic data portable for research and clinical use
- Investigate HLA data from other countries to better understand global frequencies and improve matching
- Develop methods for HLA association studies

This year investigators with the Bioinformatics Research Program presented 11 abstracts at national and international conferences and published 9 manuscripts in peer-reviewed journals, including:

- HLA match likelihoods for hematopoietic stem-cell grafts in the US registry
- HLA match likelihoods for Indian patients seeking unrelated donor transplantation grafts
- Fine-mapping of HLA associations with chronic lymphocytic leukemia in US populations
This year the program’s accomplishments include:

- Established the HCT Health Economics Interest Group, which held its first meeting at the 2015 BMT Tandem Meetings
- Completed 50 semi-structured interviews as part of the evaluation phase of the Easy-to-Read Informed Consent for HCT Clinical Trials study
- Opened a multi-center randomized controlled study to evaluate the effectiveness of an individualized survivorship care plan template; 17 centers will participate in this study
- Conducted a national survey of community hematologists / oncologists on referral practices, perceptions of HCT, and education preferences
- Provided technical plain language writing consultation; developed 3 easy-to-read consent forms and 5 patient information sheets for 3 BMT CTN protocols
- Published 3 manuscripts in peer-reviewed journals
- Presented 14 abstracts at national conferences

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 while also acknowledging that it is important to guide the research community in 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 6 peer-reviewed manuscripts and 1 editorial, including:

- Proportional odds cumulative incidence model for competing risks
- Proportional hazards regression model for the subdistribution with covariates-adjusted censoring weight for competing risks data
DATA MANAGEMENT

The CIBMTR collects data for approximately 21,000 patients annually as well as follow-up data on previously reported transplants. To collect and share data in an efficient manner while ensuring data quality, this year the CIBMTR:

• Performed on-site audits of 57 transplant centers (45 in the US and 12 internationally)
• Added autologous HCTs to the Continuous Process Improvement program; as of the May 2015 report, 96% of US centers met program standards for allogeneic HCTs and 89% for autologous HCTs
• Added 11 new eLearning modules for a total of 19 modules available in the Learning Center

INFORMATION TECHNOLOGY (IT) SERVICES

The CIBMTR IT team manages CIBMTR data and information, adapts commercial software products, develops custom software, and provides technical support.

FormsNet
More than 95% of data collected by the CIBMTR are submitted electronically via FormsNetSM, which contains >240 forms to capture HCT outcomes for donors and recipients. This year the IT team received 236,350 HCT recipient forms and implemented numerous enhancements, including a flexible CIBMTR patient identification number (CRID) to support the long-term strategic goal of supporting data collection for non-transplant therapies.

Research Database
The IT team upgraded the technical infrastructure that supports the CIBMTR Research Database and completed integration of >2,800 revisions to data collection forms.

Data Sharing
The CIBMTR is committed to sharing data as well as the information and knowledge produced from data. This year the IT team completed a data sharing assessment and created a roadmap and plan to implement data sharing in an Integrated Data Warehouse.

AGNIS
AGNIS allows electronic data transmission between FormsNet and transplant centers. This functionality allows centers to submit data from a local database without manual re-entry. This year the IT team increased the number of AGNIS production users from 9 to 14 and collected >26,000 forms from the European Group for Blood and Marrow Transplantation.
The CIBMTR published 79 manuscripts and 7 other articles in peer-reviewed journals this year. Some of the CIBMTR’s key findings were published in the following articles:


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