Center for International Blood and Marrow Transplant Research

The Year in Review –
Or, What Your Data Makes Possible
CIBMTR Number of Patients Registered, 1970-2016

Data are incomplete for 2016.
## CIBMTR Research Database
### Number of Patients

<table>
<thead>
<tr>
<th>Year</th>
<th>Transplant Essential Data (TED)</th>
<th>Comprehensive Report Forms (CRF)</th>
</tr>
</thead>
<tbody>
<tr>
<td>TOTAL</td>
<td>63,821</td>
<td>12,716</td>
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<tr>
<td>2014</td>
<td>21,851</td>
<td>5,167</td>
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<tr>
<td>2015</td>
<td>22,791</td>
<td>5,095</td>
</tr>
<tr>
<td>2016*</td>
<td>19,179</td>
<td>2,454</td>
</tr>
</tbody>
</table>

* Transplants continue to be registered for 2016; Data are incomplete
Geographic Distribution of All Patients Registered in 2016*

**Allogeneic Transplants**
N = 7,988

**Autologous Transplants**
N = 9,418

*Transplants continue to be registered for 2016; Data are incomplete
We Have Enhanced Our Infrastructure for Collecting Cellular Therapy Data

Cellular Therapy

- Pre-CTED
- Post CTED

Hematopoietic Cell Transplantation

- Pre-TED
- Post-TED

Form 2804/2814

Unique ID Assignment

Comprehensive Data

Basic Level Of Data Collection

CRF
CTED Level Data – Applies to all Cellular Therapies

• Pre-CTED: demographic, indications, disease status and therapy prior to CT (if applicable)
• Infusion form: description of product and manufacturing, product analysis and infusion details.
• Post-CTED: follow-up infusions, survival and disease status, cause of death, new malignancies, persistence of the product, major complications
First 70 Patients Reported on New Cellular Therapy Forms

<table>
<thead>
<tr>
<th>Indication</th>
<th>Number of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hematologic malignancy</td>
<td>18</td>
</tr>
<tr>
<td>Neurologic disease</td>
<td>17</td>
</tr>
<tr>
<td>Relapse posttransplant</td>
<td>13</td>
</tr>
<tr>
<td>Infection/PTLD</td>
<td>7</td>
</tr>
<tr>
<td>Immune reconstitution</td>
<td>6</td>
</tr>
<tr>
<td>Other</td>
<td>9</td>
</tr>
</tbody>
</table>
Information Resources

For Life.
Sharing knowledge.
Sharing hope.
Learn more

For Life.
Sharing knowledge.
Sharing hope.
Learn more

Help shape the future of transplantation outcomes
See how you can make a difference in research by getting involved in CIBMTR
Learn how

News & Events
2015 BMT Tenders Meetings
New Association Created for Cord Blood Banking

Key Resources
- Summary Slides - Trends & Survival
- CIBMTR Publication List
- Data Collection Forms
- Patients Transplant Guidelines
- Patient Resources

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

322,154 page views in 2016
## Utilization of CIBMTR Web Presence and Other Information Resources, 2016

<table>
<thead>
<tr>
<th>Total</th>
<th>251,506</th>
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<tbody>
<tr>
<td>CIBMTR Webpage Totals</td>
<td>251,066</td>
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<tr>
<td>Data Management Materials and Tools</td>
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<tr>
<td>Web-Based HRSA US Transplant Reports</td>
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<td>Resources for Patients</td>
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<td>Statistical Resources for Researchers</td>
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<td>Administrative Reports and Newsletters</td>
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<tr>
<td>CIBMTR Information Services Custom-Analyses Totals</td>
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<tr>
<td>CIBMTR Information Services Custom-Analyses Totals</td>
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<tr>
<td>Physician / Researcher</td>
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<tr>
<td>Patient / Relative</td>
<td>46</td>
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<tr>
<td>Pharmaceutical / Biotech Company</td>
<td>39</td>
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<tr>
<td>Student</td>
<td>19</td>
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<tr>
<td>Federal Government Agency</td>
<td>4</td>
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<tr>
<td>Market Research Firm</td>
<td>3</td>
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<tr>
<td>News Media</td>
<td>3</td>
</tr>
<tr>
<td>Cord Blood Bank</td>
<td>2</td>
</tr>
<tr>
<td>Insurance Company</td>
<td>1</td>
</tr>
</tbody>
</table>

Total: 251,506
CIBMTR >450,000 of Patients Registered, 1970-2016, >1100 Publications

Cumulative Patients Registered

- Allogeneic = 236,892
- Autologous = 226,364

Health Services, Cost-effectiveness

QOL, Survivorship

Immunobiology*

Multicenter Clinical Trials

Technology Assessment

Prognostic factors

Descriptive

*NMDP Repository - Specimens for >40,000 donor-recipient pairs.

Data are incomplete for 2016
CIBMTR Research Programs

- Observational Research
- Prospective Clinical Trial Support
  - Clinical Outcomes
  - Immunobiology
  - Health Services
  - Bioinformatics
  - RCI BMT
  - BMT CTN

- Statistical Methodology
CIBMTR Research Programs

Observational Research
- Clinical Outcomes
- Immunobiology
- Health Services
- Bioinformatics

Prospective Clinical Trial Support
- RCI BMT
- BMT CTN

Statistical Methodology
Working Committee Structure

- Acute Leukemia
- Autoimmune Diseases and Cellular Therapies
- Chronic Leukemia
- Donor Health and Safety
- Graft Sources and Manipulation
- Graft-vs-Host Disease
- Health Services and International Studies
- Immunobiology

- Infection and Immune Reconstitution
- Late Effects and Quality of Life
- Lymphoma
- Non-Malignant Marrow Disorders and Inborn Errors of Metabolism
- Pediatric Cancer
- Plasma Cell Disorders and Adult Solid Tumors
- Regimen-Related Toxicity and Supportive Care
Working Committee Studies

- >2,600 researchers participate in WCs
- 193 proposals submitted, 92 presented, and 39 accepted at 2016 WC meetings
- 204 proposals submitted for the 2017 WC meetings; 77 to be presented
- 67 ongoing collaborative studies with numerous organizations, including international and US-based hospitals, research centers, universities, and other registries
Donor-Recipient Research Repository – 2016

• Unrelated Donor Repository
  – 36,796 Adult Recipient / Donor pairs
  – 3,811 Recipient / Cord pairs
  – 11,769 samples distributed to investigators in 2016

• Related Donor Repository
  – 66 centers participated in 2016
  – 5,705 Adult Recipient / Donor pairs

• More than 2.3 million aliquots stored
CIBMTR Research Programs

- Observational Research
  - Clinical Outcomes
  - Immunobiology
  - Health Services
- Prospective Clinical Trial Support
  - RCI BMT
  - BMT CTN

Statistical Methodology
HSR Program Focus

• Center and physician practice patterns; quality of care
• Disparities in access and outcomes
• Health economics research
• Survivorship
  – Current study explores use of CIBMTR data to create individualized survivorship plans
• Patient engagement
  – Symposium on Saturday
Patient-Centered HCT Outcomes Research Symposium

February 25th: You’re invited!

NMDP/Be the Match is in receipt of a Patient-Centered Outcomes Research Institute (PCORI) Award: *Engaging Patients in Developing a Patient-Centered HCT Research Agenda.*

We invite you to attend the symposium during the 2017 BMT Tandem meetings.

This is an invitation only meeting for anyone with an interest in patient-centered outcomes, including clinicians, patients/caregivers, patient advocates, pharmacists, social workers, program directors, administrators, and payers.

Symposium Details:

- **Title:** Building a Patient-Centered Outcomes Research (PCOR) Collaborative Community
- **Date/time:** Saturday, February 25th, 2017, 12:15 pm – 4:45 pm
- **Location:** Gaylord Convention Center, Orlando, FL. Room Sun A
- **Format:** Interactive discussion presented by patients, caregivers and the co-chairs of the six working groups: physical health and fatigue, emotional, cognitive and social health, financial burden, models of care delivery-survivorship and late effects, patient, caregiver and family education and support, and sexual health and relationships. Following the working group reports, additional research opportunities within PCORI, BMT CTN, and CIBMTR will be presented, and we will discuss next steps in building a collaborative research community.
CIBMTR Research Programs

- Observational Research
- Prospective Clinical Trial Support
- Clinical Outcomes
- Immunobiology
- Health Services
- Bioinformatics
- RCI BMT
- BMT CTN

Statistical Methodology
Bioinformatics Research Goals

• Develop pipelines to analyze Next Generation Sequencing data and immune genes (HLA, KIR) and whole genomes

• Investigate the role of genetic ancestry in transplantation

• Develop data standards and tools for making data portable

• Investigate HLA data from other countries

• Develop methods for HLA association studies
RCI BMT

• Study infrastructure in place for multicenter prospective Phase I/II trials and other studies requiring statistical and/or logistical support

• Offers statistical consultation, study, data and sample management, and regulatory expertise

• Not a funding mechanism
  – Provides multicenter infrastructure for PIs
  – Will assist PI seeking third party funding
Protocols Opened in 2016

• Mismatched unrelated donor (MMUD) protocol sponsored by BeTheMatch
  • Protocol released to sites May
  • First site activated August
  • First subject enrolled December (3 of 80 enrolled)

• Clinical Evaluation of the MSD® Point of Care Biodosimetry Test (Mesoscale):
  • First site activated in June
  • First subject enrolled in August
  • 16 of 20 enrolled
Ongoing RCI BMT Studies

NMDP-sponsored IND studies

• Access and distribution of cord blood units by (10-CBA)
  – Opened to accrual October 2010
  – 3,251 enrolled
  – Open indefinitely to allow distribution and access to unlicensed cord units

• Filgrastim-mobilized PBSC for unrelated allogeneic transplant
  – Opened to accrual April 1996
  – Just over 27,000 URDs enrolled
  – Will close to accrual upon FDA licensure; another protocol will be opened to maintain access to unlicensed products
Ongoing RCI BMT Studies

Coverage with Evidence Development for Medicare; Allows for reimbursement for BMT in Medicare patients

- MDS (10 CMS-MDS-1)
  - Opened to accrual Dec 2010
  - 1697 patients enrolled

- Myelofibrosis (16 CMS-MF)
  - Received protocol approval October 2016
  - Opened to accrual December 2016
Ongoing RCI BMT Studies

Donor Studies

• Related donor safety and QOL (RDSafe)
  – 1,812 donors enrolled
  – Two manuscripts published
  – Primary manuscript near completion

• Long-term follow-up of unrelated donors after BM vs PBSC harvest (LTDFU)
  – 21,568 donors enrolled; closed to accrual October 2015
  – Follow-up continues through 2020
  – Interim analysis completed November

Accrual numbers as of Dec 2016
CIBMTR Research Programs

Observational Research

Prospective Clinical Trial Support

Clinical Outcomes

Immunobiology

Health Services

Bioinformatics

RCI BMT

BMT CTN

Statistical Methodology
BMT CTN Centers

>125 centers have enrolled >9,300 patients since 2003

= Core Centers
= PBMTC Centers
= Affiliate Centers
**BMT CTN Trials Developed in Years 1-10**

**Total Subjects =**
- 1,050 2003
- 1,600 2004
- 2,150 2005
- 2,600 2006
- 3,050 2007
- 3,460 2008
- 4,450 2009
- 5,250 2010
- 6,000 2011
- 7,400 2012
- 8,600 2013

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**SWOG**

**COG**

**ECOG**

**CALBG**

**BMT CTN Steering Committee**

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**BMT CTN Trials Developed in Years 1-10**

- **2001 2002**
  - Developed Infrastructure

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**Enrollment/follow-up complete**

**Enrollment complete; ongoing F/U**

**Enrollment on-going**

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**PUBLICATIONS**

- **Primary Outcome**
- **Safety, Secondary Outcome, or Design**

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**BMT CTN Trials Developed in Years 1-10**

- 2003: 0701 PII NST for NHL
- 2004: 0604 PII DCB-Adult
- 2005: 0603 PII Haplo-Adult
- 2006: 0601 PII Sickle Cell INST
- 2007: 0603 PII T-depleted HCT for AML
- 2008: 0601 PII Unrelated Tx for aplastic anemia
- 2009: 0501 III Single vs. Double CBT
- 2010: 0502 PII NST for AML >60y
- 2011: 0503 PIII MM maintenance
- 2012: 0402 PII GVHD prophylaxis
- 2013: 0401 PII BEAM vs BEAM-Bexar for Lymphoma
- 2014: 0301 PII Unrelated Tx for aplastic anemia
- 2015: 0403 PII Etanercept for IPS
- 2016: 0404 High Risk CLL

---

**BMT CTN Trials Developed in Years 1-10**

- 2003: 0703 PII HD
- 2004: 0704 PIII MM maintenance
- 2005: 0503 PII T-depleted HCT for AML
- 2006: 0501 III Single vs. Double CBT
- 2007: 0402 PII GVHD prophylaxis
- 2008: 0401 PII BEAM vs BEAM-Bexar for Lymphoma
- 2009: 0302 PII AGVHD therapy
- 2010: 0303 PII T-depleted HCT for AML
- 2011: 0301 PII Unrelated Tx for aplastic anemia
- 2012: 0403 PII Etanercept for IPS
- 2013: 0404 High Risk CLL
- 2014: 0503 PII T-depleted HCT for AML
- 2015: 0501 III Single vs. Double CBT
- 2016: 0404 High Risk CLL

---

**BMT CTN Trials Developed in Years 1-10**

- 2003: 0703 PII HD
- 2004: 0704 PIII MM maintenance
- 2005: 0503 PII T-depleted HCT for AML
- 2006: 0501 III Single vs. Double CBT
- 2007: 0402 PII GVHD prophylaxis
- 2008: 0401 PII BEAM vs BEAM-Bexar for Lymphoma
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- 2011: 0301 PII Unrelated Tx for aplastic anemia
- 2012: 0403 PII Etanercept for IPS
- 2013: 0404 High Risk CLL
- 2014: 0503 PII T-depleted HCT for AML
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**BMT CTN Trials Developed in Years 1-10**

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**BMT CTN Trials Developed in Years 1-10**

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- 2012: 0403 PII Etanercept for IPS
- 2013: 0404 High Risk CLL
- 2014: 0503 PII T-depleted HCT for AML
- 2015: 0501 III Single vs. Double CBT
- 2016: 0404 High Risk CLL
- 42 Trials Opened; 11 currently open
- 32 BMT CTN-led
- 8 NCI Group/PI-led (+)
- 1 open soon (1502)
- 4 in development (1506, 1507, 1601, 1602)
Publications Summary

• 2016
  – 15 papers published
  – 2 other primary results submitted:
    • 0703/SWOG S0410, 0901 (accepted 1/6/17)

• 72 total:
  – 20 primary results papers
  – 30 other protocol-related papers
  – 6 methodology papers
  – 16 other Network publications
CIBMTR Data and Clinical Trials

• Helps inform trial design, including likely accrual time frames
  – Almost all BMT CTN trials have met targeted accrual

• Complements clinical trial data

• Provides infrastructure for long-term follow-up

• Helps assess generalizability of clinical trial findings
CIBMTR Research Programs

Observational Research

Prospective Clinical Trial Support

Clinical Outcomes
Immunobiology
Health Services
Bioinformatics
RCI BMT
BMT CTN

Statistical Methodology
Biostatistics Faculty

• Director of MCW Division of Biostatistics
  – Brent Logan, PhD

• CIBMTR Chief Statistical Director
  – Mei-Jie Zhang, PhD

• PhD Statistical Directors

Soyoung Kim
Raphael Fraser
Ying Liu
Kwang Woo Ahn
Ruta Brazauskas
Tao Wang
2017 BMT Tandem Meetings

• 19 Abstracts (13 oral and 6 poster)
  – 6 Working Committees
    • 3 Lymphoma
    • 3 Regimen-Related Toxicity and Supportive Care
    • 2 Immunobiology
    • 2 Late Effects and Quality of Life
    • 1 Infection and Immune Reconstitution
    • 1 Plasma Cells Disorders and Adult Solid Tumors
  – 3 BMT CTN
  – 2 Statistical Center
  – 1 Health Services Research Program
  – 1 RCI BMT
# It Takes a Village

**CIBMTR PUBLICATIONS by Federal U24 Grant Periods**

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<td>98</td>
<td>158</td>
<td>211</td>
<td>339</td>
<td>542</td>
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</table>

~40% of studies led by junior investigators (paired with senior investigators)

* First 4 years of grant period 2013-2017
Peer-Reviewed Publications 2004-2016
Have These Studies Made A Difference?
The Value of CIBMTR: Identifying patients most likely to benefit from BMT

Probability of Overall Survival after HCT for AML not in Remission by CIBMTR Risk Score

Risk score = 0, N = 148, 42% (39-50)
Risk score = 1, N = 326, 27% (23-33%)
Risk score = 2, N = 342, 15% (11-19%)
Risk score = 3, N = 321, 6% (3-9%)

Duval, JCO, 2010
Outcomes after Transplantation of Cord Blood or Bone Marrow from Unrelated Donors in Adults with Leukemia

Mary J. Laughlin, M.D., Mary Eapen, M.B., B.S., Pablo Rubinstein, M.D., John E. Wagner, M.D., Mei-Jei Zhang, Ph.D., Richard E. Champlin, M.D., Cladd Stevens, M.D., Juliet N. Barker, M.D., Robert P. Gale, M.D., Ph.D., Hillard M. Lazarus, M.D., David I. Marks, M.D., Ph.D., Jon J. van Rood, M.D., Andromachi Scaradavou, M.D., and Mary M. Horowitz, M.D.

Number of transplants

- Adults
- Children

Year:
- 1992
- 1993
- 1994
- 1995
- 1996
- 1997
- 1998
- 1999
- 2000
- 2001
- 2002
- 2003
- 2004
- 2005
- 2006
- 2007
- 2008
- 2009
- 2010
- 2011

Number of transplants:
- 0
- 50
- 100
- 150
- 200
- 250
- 300
- 350
- 400
- 450
- 500

Note: The graph shows the number of adult and children cord blood transplants from 1990 to 2011 in the United States. The number of transplants has increased over time, with a significant increase starting around 2005.
The Value of CIBMTR: Understanding the Influence of HLA

S. Lee, et al. Blood 2007 Showed impact of single allele mismatch at A, B, C and DRB1: *changed the paradigm for selecting adult donors*
Survival After Unrelated Donor Transplantation
Age <50 years, myeloablative conditioning, acute leukemia in remission or MDS

Odds of 1-year survival increased by 8% per year (95% CI, 7-9%) on average between 1990 and 2011
Adjusted Probability of After Transplantation for AML, 2002-2006

- HLA-id Sib (N=624)
- 7/8 MUD (N=406)
- 8/8 MUD (N=1,193)

Probability of Survival, %

Months
Haploidentical Transplant Recipients in the US, by Graft Type

Year 0603/0604 paper was published

*2015 Data incomplete
Haplo-Identical Transplantations
Hematologic Malignancy

Years of 0603/0604 trial

Year 0603/0604 paper was published

Other centers
CTN 0603 centers

Number of Transplants

2008 2009 2010 2011 2012 2013
CIBMTR Data Facilitated Medicare Coverage for HCT for Myelodysplastic Syndromes

- Assessment of allogeneic HCT in Medicare beneficiaries with MDS (10 CMS-MDS-1)
  - Opened to accrual Dec 2010
  - 1294 patients enrolled
  - **Allows reimbursement for BMT in Medicare patients**

US Allogeneic Transplants for MDS in patients older than 65, 2005 - 2014
People Turn to CIBMTR to…

Get support when planning research
  - Summarized data, statistical expertise, protocol development

Participate in CIBMTR research
  - Propose a study, join a working committee, enroll patients

Access data & tissue samples for research
  - Conduct research external to CIBMTR

Access reference materials
  - Slides, guidelines, publications, education
What Makes Us So Valuable to the Transplant Community?

High quality, comprehensive data on hundreds of thousands of patients
DATA DOESN’T JUST HAPPEN

• Providing the data needed to do good clinical research is hard work
IBMTR – 1985
(year of first major NIH funding)

1970 - 1985
• 200 centers
• 1,000 transplants
• 35 publications

Mortimer M. Bortin, MD
Scientific Director

Al Rimm, PhD
Statistician

D’Etta Waldoch
Sharon Nell (now Meier)
Diane Knudsen
Data Management

Karen Witkowskki
Admin. Assistant
Paper Forms

RECIPIENT INFORMATION

7. Name: ________________________________

8. Male □ Female □

9. Date of Birth: ___/___/___
10. Height: __________

Weight: 55.2 kg

11. Race: Caucasian □ Negro □ Oriental □ Other □ specify

CIBMTR
CENTER FOR INTERNATIONAL BLOOD & MARROW TRANSPLANT RESEARCH
The Exception in 1985: Forms Completed by a Data Professional!
What Is a Professional?

1. Person formally certified by a professional body of belonging to a specific profession by virtue of having completed a required course of studies and/or practice. And whose competence can usually be measured against an established set of standards

2. Person who has achieved an acclaimed level of proficiency in a calling or trade.
What is a Data Professional?

Someone

• Who understands the importance of accurate, complete data and
  – Knows how to get it
  – Is committed to getting it (including developing the skills necessary to deal with recalcitrant clinicians)

• Who takes the time to understand the data because understanding increases accuracy

• Who understands that nature did not take our forms into account and that sometimes……
What is a Data Professional?

• We must squeeze square pegs into round holes – with our best judgment
What is a CIBMTR Data Professional?

• Someone committed to improving the lives of transplant patients through research and dissemination of knowledge
Thank you!
........Is Not Enough
We Want to Support You

• By providing the training and information you need
  – Committed to expanding on line training modules

• By making data entry easier
  – Clearer forms
  – Continuous enhancements to FormsNet to improve user experience
  – Working with Epic to help capture information in a useful way
  – Exploring ways for electronic transfer of data
We Want to Support You

- By giving you tools to take advantage of the data you have submitted to CIBMTR
  - Principle of “Enter Once, Use Often”
- eDBTC
  - Analyze data
  - Download data
  - Center performance analytics
  - ASBMT RFI
Data Back to Centers (DBtC)

• Originally introduced in 2009 to provide validated data to centers from CIBMTR Research Database
• Includes Pre-TED (2400) and Post-TED (2450) data or equivalents from CRF forms:
  – FormsNet as well as legacy IBMTR & NMDP data (pre-December 2007)
  – Allogeneic and autologous transplant data
• Accessible on the CIBMTR Portal; refreshed quarterly
• Downloadable file in comma separated values (.csv) file
• >400 data downloads by 113 centers
• 1,376 unique visits by non-CIBMTR users
eDBtC (enhanced DBtC) using Qlikview

- Launched in April 2016
- Dramatically improved user interface
- Visualization of center analytics and descriptive statistics
  - ~60 selectable data dimensions, TED and CRF variables
  - ~30 predefined filters
- Logical organization of data in tabs
- Ad Hoc analysis – explore your data, including outcomes
- Data refreshed monthly
- Ability to export application source data to excel
- Historic DBtC data download capability retained
Center Performance Analytics using Qlikview

• Launched in April of 2016
• On-demand access to the same center specific analysis data set used to prepare your annual Center Specific Survival Analysis report
• Provides analytics features to support quality and performance management
• Updated annually (currently updated for 2014)
Qlikview Apps 2016 Activity

• eDBtC
  – Since launch in April, 217 unique users have accessed 1,169 eDBtC sessions; and
  – 82 unique users have performed 218 eDBtC data downloads

• Center Performance Analytics
  – Since launch in April, 126 unique users have accessed 338 CPA sessions
eDBtC: Planned this year

• Data for RFI – To be demonstrated at Tandem
  – A tool for centers to support completion of their ASBMT RFI
  – Leverages eDBtC data
  – Support for clinical and survival statistics

• Enhanced features & more data New filters and data to Ad Hoc query tab
  – Add Sub-disease groups to Disease tab
  – Cytogenetics
  – GVHD Prophylaxis – common drug combinations
  – HLA match information for unrelated donors
We Want to Support You

• By listening to you - *really*
• What do you like and not like about
  – Our training resources
  – FormsNet
  – DBTC
  – This meeting
  – Anything else
• We take your feedback seriously
Thank you!
Center for International Blood and Marrow Transplant Research

Together, we are........

.........Sharing Knowledge
Sharing Hope............