



Donor Registries and Cord Blood Banks: Challenges

Dennis L. Confer, MD
National Marrow Donor Program
2nd Workshop of WBMT
2013 October 4

The Worldwide Picture Today

- More than 22 million registered adult donors in more than 75 registries
- Nearly 640,000 publically available cord blood units in 160 cord blood banks
- World Marrow Donor Association, founded in 1994, provides a structure for international collaboration and standardization
 - www.worldmarrow.org

What are the Challenges?

- Data management
- Regulatory issues
- Quality and consistency
- Donor attrition and retention
- Emerging registries

Data Management

- HLA Data: Managing serology, low resolution DNA-based, high-resolution and next generation sequencing
- Emerging loci of interest with unclear importance: NIMA, KIR, HLA-DP, SNPs
- Multiple matching algorithms
- No “single solution”: www.bmdw.org consolidates much of the donor data, but there is no workflow
- EMDIS supports search and workflow, but is variably available and variably implemented

Regulatory Issues

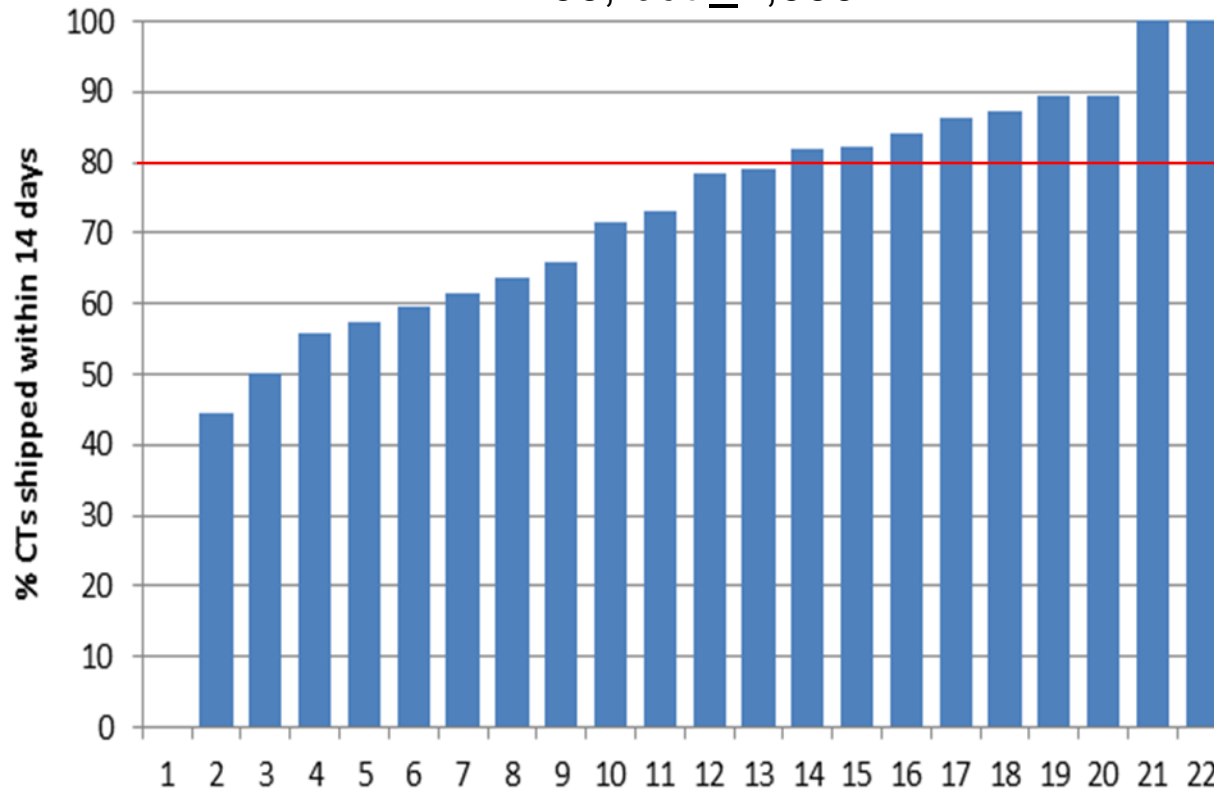
- Regulatory requirements continue to emerge without consistency or international reciprocity
 - E.g., US regulations apply to registries outside the US
- Import/export regulations, which are also inconsistent, threaten to increase complexity and cost
- Vigilance and surveillance is a global concern actively being pursued

Quality and Consistency

- WMDA promotes Standards for registry operations
- WMDA has established a registry accreditation program with on-site inspections
- WMDA is introducing a new program for “Key Performance Indicators”

Quality and Consistency

Confirmatory Testing Samples Shipped
within 14 days
>100, but $\leq 1,000$



Quality and Consistency

- WMDA promotes Standards for registry operations
- WMDA has established a registry accreditation program with on-site inspections
- WMDA is introducing a new program for “Key Performance Indicators”
- All positive steps, but –
Few standards for product manufacture or product quality exist

Donor Attrition: “Unavailable Donors”

- Attrition is a major challenge for all registries
 - Donor cannot be located
 - Is no longer interested in donation
 - Is medically unable to donate
 - Has a temporary issue, e.g., schedule conflicts
- Loss of interest is a complex problem
 - Absent commitment at recruitment
 - Incomplete education at recruitment
 - Cultural influences
 - Influence from family and friends

Retention: Reducing “Unavailable Donors”

- Recruitment without coercion or inducements
- Clear and appropriate education at recruitment
- “Two-step” recruitment: register, then activate
- Continuing engagement of registry members
- Competent reengagement during search process
- Active assessments of ambivalence, gaps in donor understanding, extent of family/friend pressure, etc.

Emerging Registries

New registries are needed to meet the diversity of HLA in worldwide populations

- Starting a new registry is expensive
 - Usually lack adequate financial support
 - Low volume HLA typing is expensive
- Must be a “comprehensive” build to succeed
 - Donor recruitment is not enough
- Success is also dependent upon medical need
 - The medical community needs to recognize and support

What are the Solutions?

- Professional Societies: WMDA and WBMT
- Collaborating and sharing information
- Establishing best practices and benchmarks
- Research to advance understanding
- Recognizing and accepting limitations