

"THE FACEBOOK EFFECT leaves you with a deep understanding of Facebook, its philosophies and, most startlingly, its power."
—David Pogue, The New York Times Book Review

The
Real Story
Behind
THE SOCIAL
NETWORK

the Facebook effect

THE INSIDE STORY OF THE COMPANY
THAT IS CONNECTING THE WORLD

DAVID KIRKPATRICK



Sparr0w82 Todd Sparrow
on branch with @bluebird!



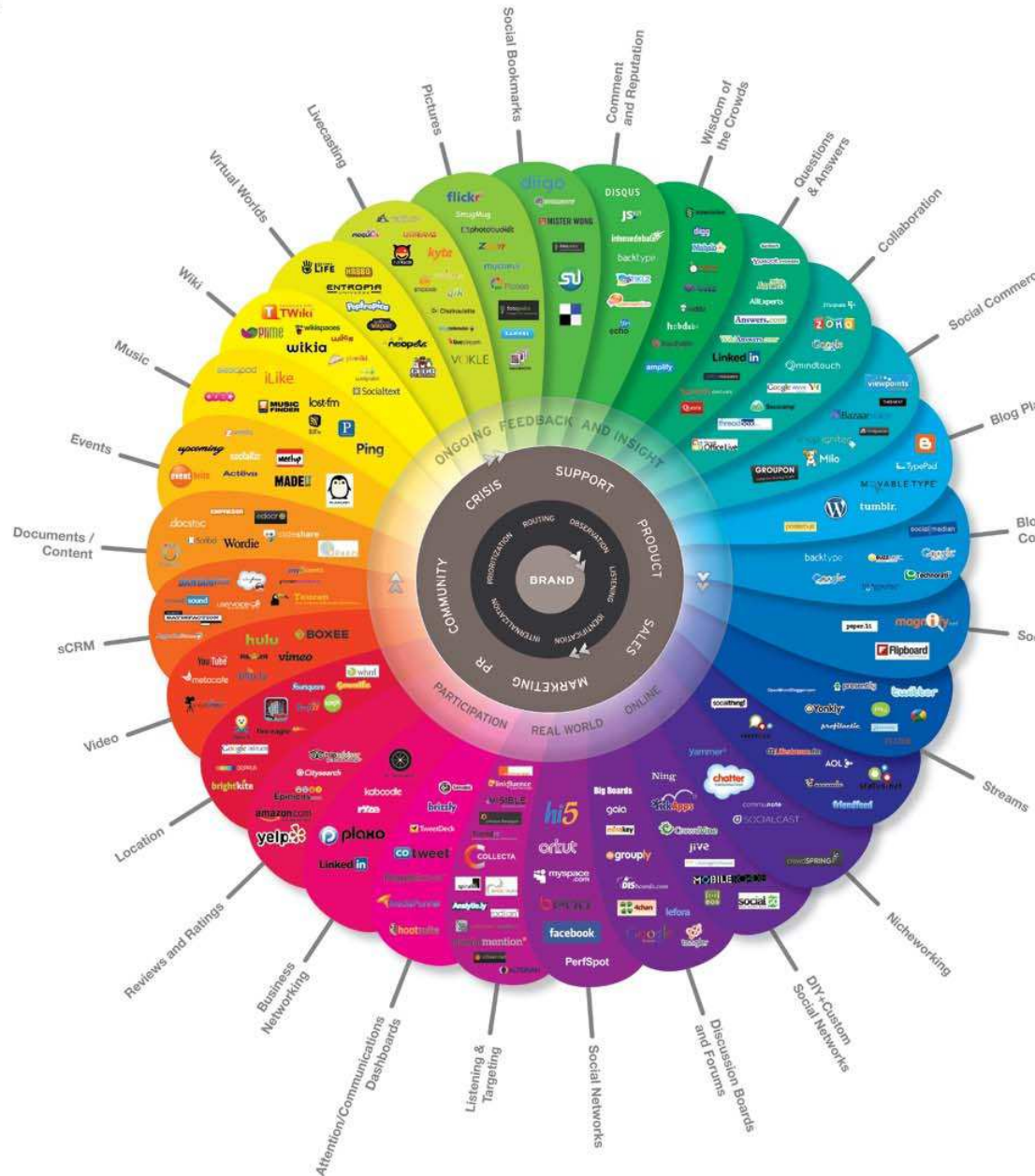
Twitter

THE CONVERSATION PRISM

Brought to you by Brian Solis & JESS3

Social Media and HSCT

- Pros:
1. Connection with the new generation
 2. Immediate feedback
 3. 3rd party supporters
 4. Multiple platform
 5. Crisis management



- Cons:
1. Disconnect with the paper generation
 2. Uncontrolled feedback
 3. Potential loss of confidentiality
 4. By-the-way marketers

Adapted from Kari Bailey et al, NMDP

For more information check out theconversationprism.com



- Wall
- Info
- Friend Activity
- Photos
- Links
- Notes
- Discussions
- Events
- Welcome

About
Our mission - to provide cord blood units of high safety and quality, throu...
More

622 like this
10

Singapore Cord Blood Bank Like

Non-Profit Organization · Singapore, Singapore



Wall Singapore Cord Blood Bank · Everyone (Top Posts)

Share: Post Photo

Write something...

Singapore Cord Blood Bank
Happy Children's Day to all SCBB Infant Donor and Beneficiaries!



Wall Photos

Like Comment Share October 7 at 10:39am

You and Singapore Co



3 friends like this.

This group is scheduled to be archived

Over the next few months, Facebook will be archiving all groups created using the old groups format. Would you like to continue being a member of this group?

[Learn More](#)



Bone Marrow Donor Programme (Singapore)

Wall Info Discussions

Share: Post Photo Link Video

Write something...

Information

Category:
Organizations - Non-Profit
Organizations

Description:
This group is for all supporters and partners of the Bone Marrow Donor Programme (Singapore).

WHO ARE WE?
BMDP is a Singapore-based non-profit organization dedicated to building and managing a register of volunteers who are willing to donate their bone marrow to patients of Leukaemia and other blood disorders.

[... See More](#)

Privacy Type:

Open: All content is public.



Rylan Mitchell Digital Marketing Agency - Online Profit Strategist specialize in designing marketing strategies for search engines, social media and online branding. <http://www.facebook.com/DigitalMarketingAgencyAsia>



Digital Marketing Agency - Online Profit Strategist

We are the founders and guardians of the Asia's premier Web Development, Digital Marketing and Social Media community. We help businesses to create a web business that sell by riding on the Internet wave with our brand expertise in business oriented web development, digital marketing and E-business consulting.

Page: 727 like this

July 27 at 2:00pm · Like · Comment · Share



Angelina Low how can i confirm if i am already confirmed as a potential donor?

March 19 at 8:16pm · Like · Comment



Dissemination of Information

Practice guidelines for registries & donor centers

Dissemination of adverse event information

Volunteer Donor Recruitment Strategies



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WMDA cares for donors to save patients' life

WMDA:

- Developed template forms to use for an unrelated search
- Published white papers explaining all aspects for unrelated stem cell donation
- Analyzes trends in unrelated stem cell donation
- Registry Handbook Project



About WMDA

WMDA Recommendations

The Working Groups of the WMDA have developed guidelines for registries working through the WMDA to facilitate hematopoietic stem cell transplants. Below you will find each section of the WMDA recommendations on many aspects of registry operations.

GENERAL ORGANISATION OF THE REGISTRY

- [Recommendations and Requirements for a Standardized Practice](#) - J. Goldman
- [International Standards for Unrelated Stem Cell Registries](#) - C. Hurley
- [Improvement and Assurance of Stem Cell Accessibility](#) - T. Egeland
- [Combined Private And Public Banking of Cord Blood and Other Related Products](#) - M. Boo

DONOR RECRUITMENT

- [Informed Consent - Suggested Procedures](#) - A. Rosenmayr
- [Donor Commitment & Patient Needs](#) - R. Bakken
- [WMDA Recommendations for Evaluation of Donor Health](#) - N. Sacchi
- [Hematopoietic Stem Cell Registries: WMDA Definitions of a Donor Center](#) - N. Sacchi
- [Foreign Recruitment](#) - T. Egeland
- [Confidentiality Donor - Patient](#) - M. Duffy/K. Coffey
- Donor as Research Subject (published, Bone Marrow Transplantation)

DONOR CHARACTERIZATION

- [HLA Dictionary 2010](#)
- [Search Algorithm](#)
- [Hematopoietic Stem Cell Donor Registry Strategies for Assigning Search Determinants and Matching Relationships](#) - C. Hurley
- [A special Report: Histocompatibility Testing Guidelines for Hematopoietic Stem Cell Transplantation Using Volunteer Donors](#) - C. Hurley
- [WMDA Guidelines for use of HLA Nomenclature](#) - W. Bochtler

SEARCH REQUESTS

www.worldmarrow.org



Google



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- [A special Report: Histocompatibility Testing Guidelines for Hematopoietic Stem Cell Transplantation Using Volunteer Donors](#) - C. Hurley
- [WMDA Guidelines for use of HLA Nomenclature](#) - W. Bochtler

SEARCH REQUESTS

- [Donor Work Up and Transport](#) - S. Cleaver
- [Suggested Procedures for International Donor Search](#) - T. Wiegand
- [Forms for each step of the Search Process](#) - T. Wiegand
- [Patient Consent to Donor Terms and Transplant Centre Expectations](#) - P. Heard

SECOND AND SUBSEQUENT DONATIONS

- Guidelines for Subsequent Donation (submitted for publication)

COLLECTION, PROCESSING AND TRANSPORT

- [Donor Work Up and Transport](#) - S. Cleaver
- [World Marrow Donor Association \(WMDA\) Guidelines for Couriers and the Transportation of Haemopoietic Progenitor Cells \(HPC-BM, Apheresis and Therapeutic Cells- T Cells\)](#) - S. Gordon
- Validation of HSC Products - M. McGregor (submitted for publication)
- [Recommendations for labeling](#)

PATIENT AND DONOR FOLLOW-UP

- [WMDA recommendations concerning G-CSF](#)

FINANCIAL AND LEGAL LIABILITIES



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Adverse Events

SEAR and SPEAR

The Serious (Product) Events and Adverse Reactions of WMDA or "SEAR" and SPEAR" are a central reporting system of the WMDA member organizations to the WMDA Clinical Working Group. SEAR's goal is to obtain insight in the occurrence of serious events and adverse effects in relation to stem cell donation by unrelated donors while SPEAR's goal is to obtain insight into the occurrence of serious events and adverse effects in relation to stem cell harvest and processing from unrelated donors.

All participating member organizations receive a reminder by e-mail every three months. Participating is compulsory for accredited registries.

To relate the total number of serious events to the total harvests of each type from participating registries, relevant general information will be extracted from the annual report and reported as total accumulated data of the donor registries.

The chair of the **Clinical Working Group** annually reports the number of reported incidents. The Annual Report of the WMDA also contains lists of participating registries and detailed information about the number of incidents.

Below these links to the online reporting system, the forms and the manuals, you will find more information about SEAR and SPEAR.

- [SEAR Standard Operating Procedure \(SOP\)](#)
- [SPEAR Examples of what to report and what not to report](#)
- [Link to the Online Survey System](#)
- [SEAR FORM \(v3 2007\)](#)
- [SPEAR FORM \(v2 2007\)](#)
- [SEAR Summary from 2003 to 2010](#)

Tips & Tricks for the Online Reporting System:

- Make sure your browser has enabled JavaScript. all scripts from sgizmo.com, surveygizmo.com and cloudfront.net should not be blocked.
- There is a possibility to save your survey at any time by clicking "Save and continue survey later" on top of the screen. Please bear in mind that only the entered data on previous pages will be saved. In order to save the data on the page you are at that moment, continue to the next page and save there.
- On the last page there is a special field where files (documents, pictures, PDF, etc.) can be uploaded.

SPEAR Serious (Product) Events and Adverse Reactions

Firefox WMDA SEAR and SPEAR 2011

AntiPhishing

www.surveygizmo.com/s3/483024/SEAR-and-SPEAR-2011

SEAR and SPEAR 2011

General Questions 1

This online questionnaire requires javascript to work properly. Please make sure your browser has javascript enabled before continuing this questionnaire.

- 1. Name Registry: ***
- 2. Name person completing this survey: ***
- 3. Email address: ***
A copy of the completed survey will be emailed to this address and will be used for further contact.
- 4. If this is a follow up report of a previously reported case, please enter date of the previous report here in YYYY/MM/DD:**
- 5. Your personal identifier:**
You can enter here a personal identifier (e.g. a date or donor ID) for this report for your own records. The WMDA does not require this field.
- 6. Date donation in YYYY/MM/DD:**
- 7. Date serious adverse event/reaction reported to/discovered by the registry in YYYY/MM/DD:**
- 8. Do you want to report a SEAR or a SPEAR? ***

Windows taskbar: SEAR and SPEAR 20..., Microsoft PowerPoi...

SEAR and SPEAR 2011

General Questions 2

9. What type of donation/transplant?

- Cord blood
- G-CSF Stimulated PBSC
- Marrow
- Unstimulated aphaeresis
- Whole blood

- First
- 2nd or consecutive

10. Did the selection criteria or the medical examination for this donor differ in any way from your normal selection criteria?

- Yes
- No

11. Did the donor have any previous medical history or medical condition prior to donation that might has influenced the occurrence of the event notified?

- Yes
- No

12. Did the donor use any medication previous to the donation?

- Yes
- No



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Volunteer Donor Recruitment Strategies

**What do you do if you would like to
recruit volunteer donors
in your country?**

www.worldmarrow.org
wmda@europdonor.nl



Get in touch - three international initiatives for donor registries

- Bone Marrow Donors Worldwide (BMDW)
- European Marrow Donor Information System (EMDIS)
- World Marrow Donor Association (WMDA)





BMDW

- International database
- Stem Cell Donors listed from 47 countries
- Cord Blood Units listed from 28 countries
- 18,110,332 donors and 496,732 CBU's
- On-line match programs


➔ Telephone book to find your donor





EMDIS

- Is a standard platform for computer based donor registry communication
- Covers all aspects of an unrelated donor search
- Connects 86% of the donors listed in BMDW


 Protocol for electronic communication between registries





WMDA stands for

- Standards
- Education
- Donor Safety
- Globalization
- Accreditation

 International recommendations
for unrelated stem cell donation





World Marrow Donor Association

- Established in 1989 as an international collaborative effort of organizations and individuals involved in hematopoietic stem cell (HSC) donation and transplantation
- First President - Dr E. Donnall Thomas,
- Current President - Professor Eliane Gluckman
- Mission to foster international collaboration to facilitate the exchange of high quality HSC for clinical transplantation worldwide and to promote the interests of unrelated donors..



World Marrow Donor Association

■ Recognition.

- *de facto* society that oversees the international exchange of HSC products and promotes the interest of unrelated donors
- grant legitimacy with local governmental bodies as well as international organizations

■ Participation

- participate in the crafting of international policies and decisions
- differences in needs that may be important to take into account

■ Accreditation

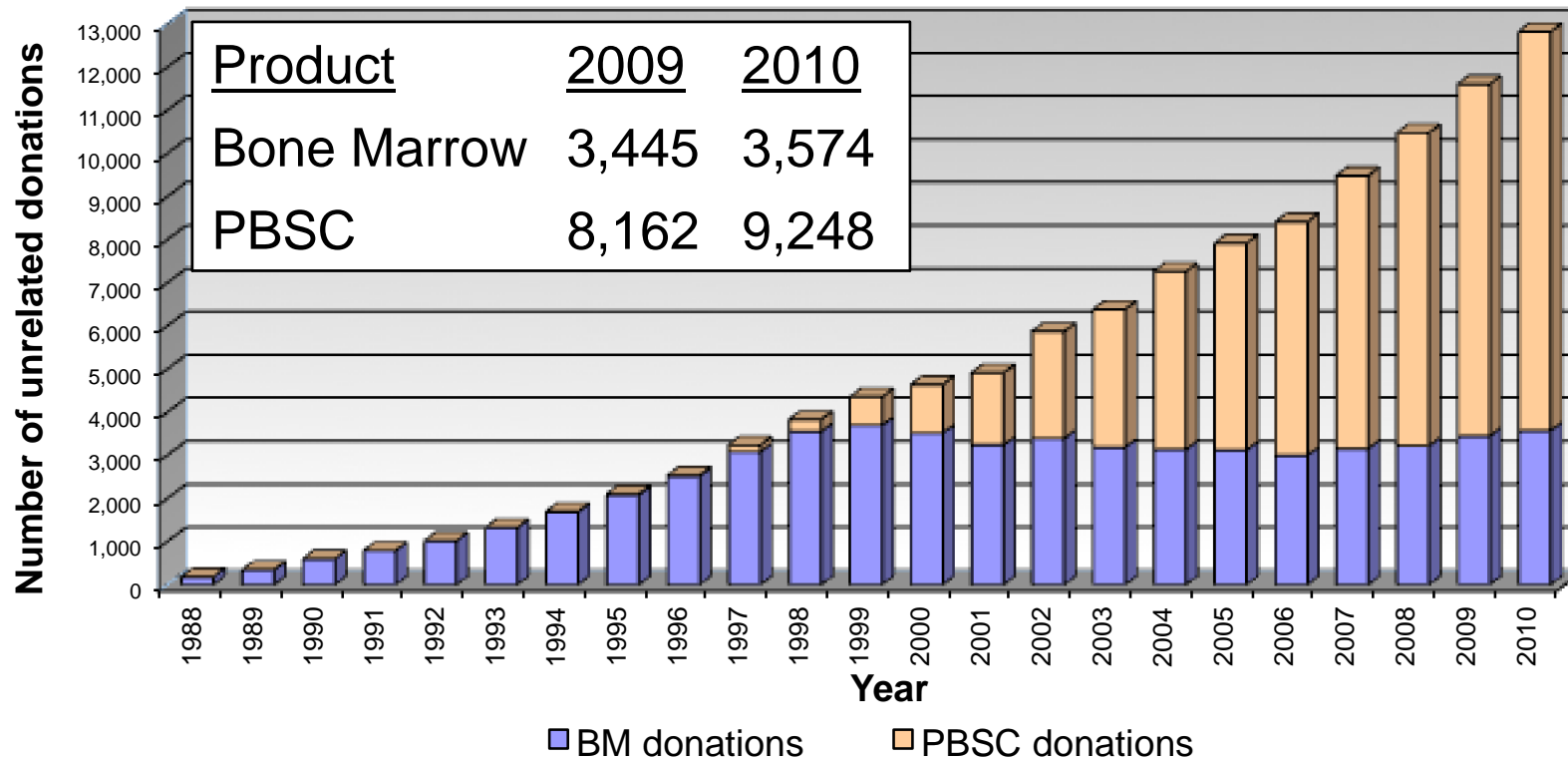
■ Leadership

- Clinical, Cord Blood, Donor Registries, Ethics, Information Technology, and Quality Assurance Working Groups as well as key office holders.



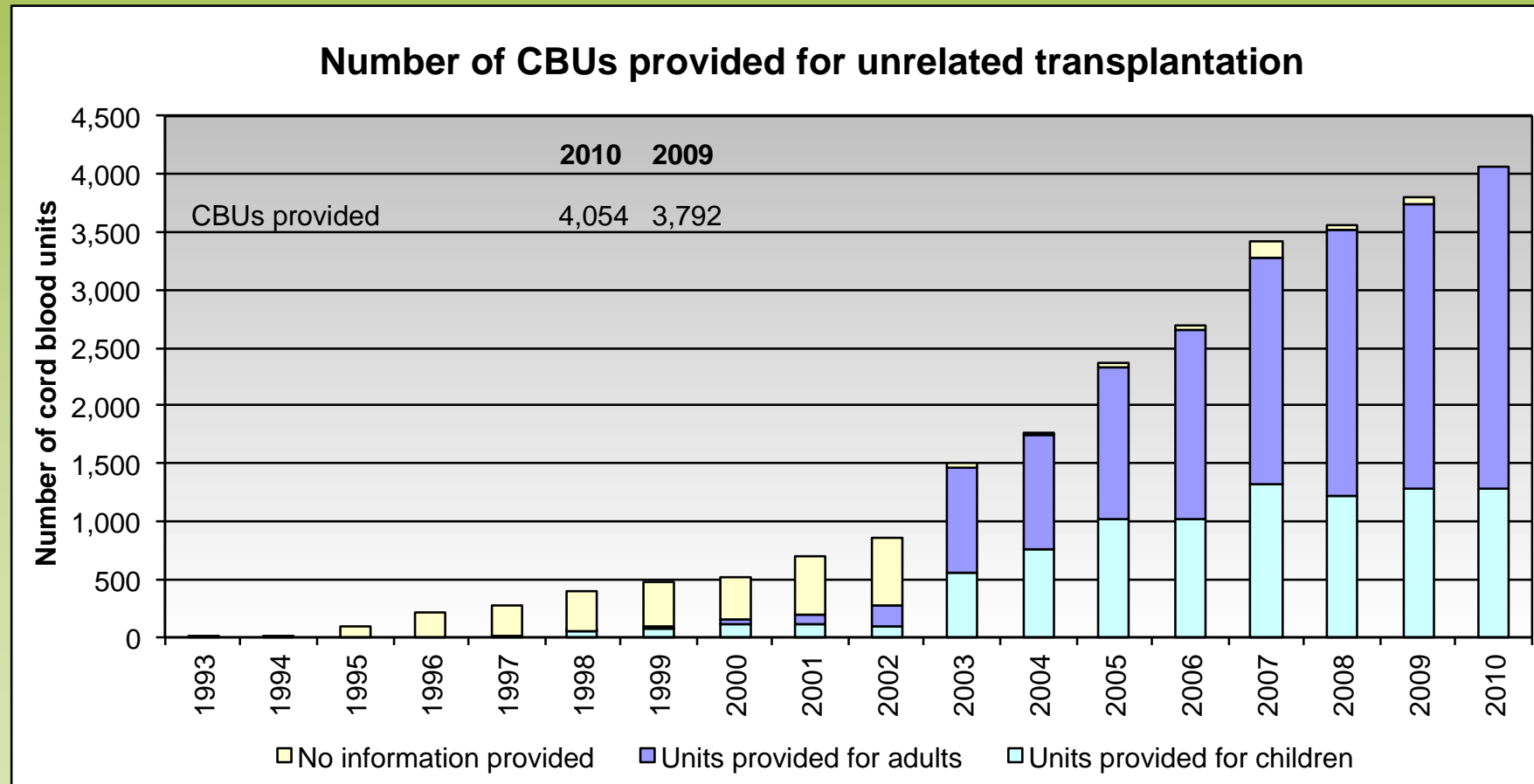
In 2010 79 Stem Cell Donor Registries worldwide participated

Number of unrelated stem cell donations (BM/PBSC)





In 2010, 149 Cord Blood Banks worldwide participated





Share Information

Get in touch with the WMDA, BMDW, EMDIS

- IDRC and WMDA Working Group meetings
Sydney, Australia: 1 – 5 May 2012
www.wmdasydney2012.com



- WMDA Fall Meeting and NMDP Council Meeting,
Minneapolis, USA:
7 – 10 November, 2012