



# Outcomes Database Discussion: Development of the LABMT Transplant Registry

**WBMT/WHO Workshop  
Salvador, Bahia  
October, 2013**



# Discussion: Importance, Development and Participation in Transplant Outcomes Databases and Transplant Registries.

Panelists	Country
Gregorio Jaimovich	Argentina
Luis Bouzas	Brazil
Willem Bujan	Costa Rica
Ritsuro Suzuki	Japan
Dietger Niederwieser	Germany
Helen Baldomero	Switzerland
Vanderson Rocha	UK



Moderator:  
Marcelo Pasquini

# Panel Discussion

- **What** data to collect?
  - **Levels** of transplant data collection
- **How** data is currently collected in Latin America?
  - Activity survey - Activity Registry
  - Outcomes Database – follow up, survival...
- **How** this data can be utilized by Latin American centers?



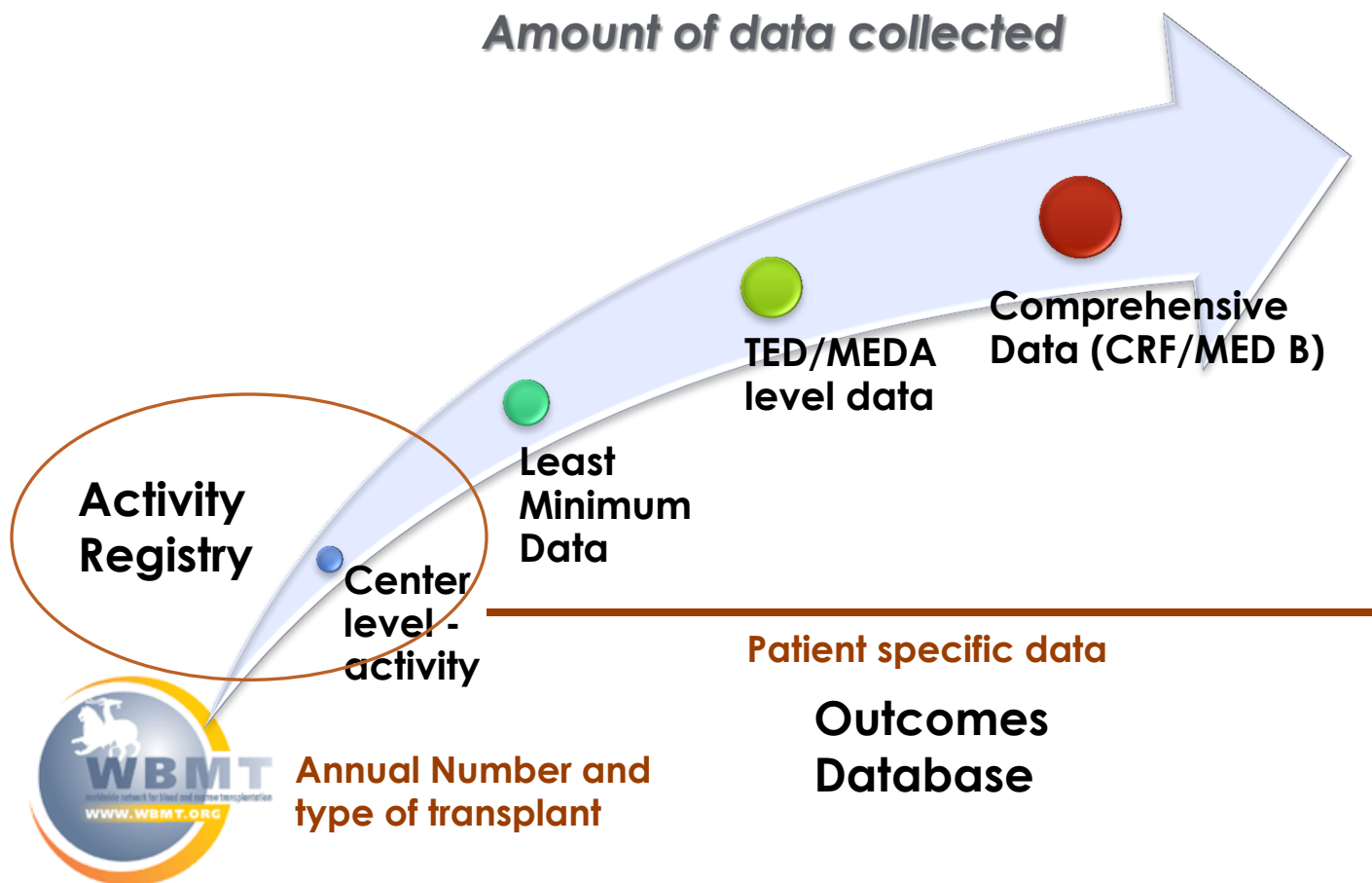
# What data to collect?

- Center vs. patient level data
- Registry vs. outcome databases
- Limited, minimal and comprehensive level data.
- Importance of utilizing the same data elements.



# Levels of data collection

*Amount of data collected*



**Annual Number and type of transplant**

# Is there a value of collecting data?



- Identifying population
- Understanding outcomes
- Collaboration to study important regional issues.
- Integration across registries.



## APBMT Least Minimum Data Items

Characteristics	Fields
Identification	Center and patient numbers
Patient	age, gender
Disease	disease status and subtype
Transplant	Date, graft type, conditioning regimen (intensity, agents, irradiation),GVHD prophylaxis
Donor type	Donor type, multiple donors, HLA match, donor gender and relation
<b>Outcome</b>	
Engraftment	Date, graft failure
GVHD	Acute, date of maximum grade, date of chronic
Disease status post transplant	Response, relapse and date
Survival	Status at last f/u, cause of death
<b>Follow up</b>	
Data collection calendar	100 days, 6 months, 1 year and yearly thereafter.

# Current Data Collection

- How's done at your center?
- Is there any mechanism at you country for general data collection?
- Participation in international registries
  - Unrelated donor and cord blood units
  - Local logistics

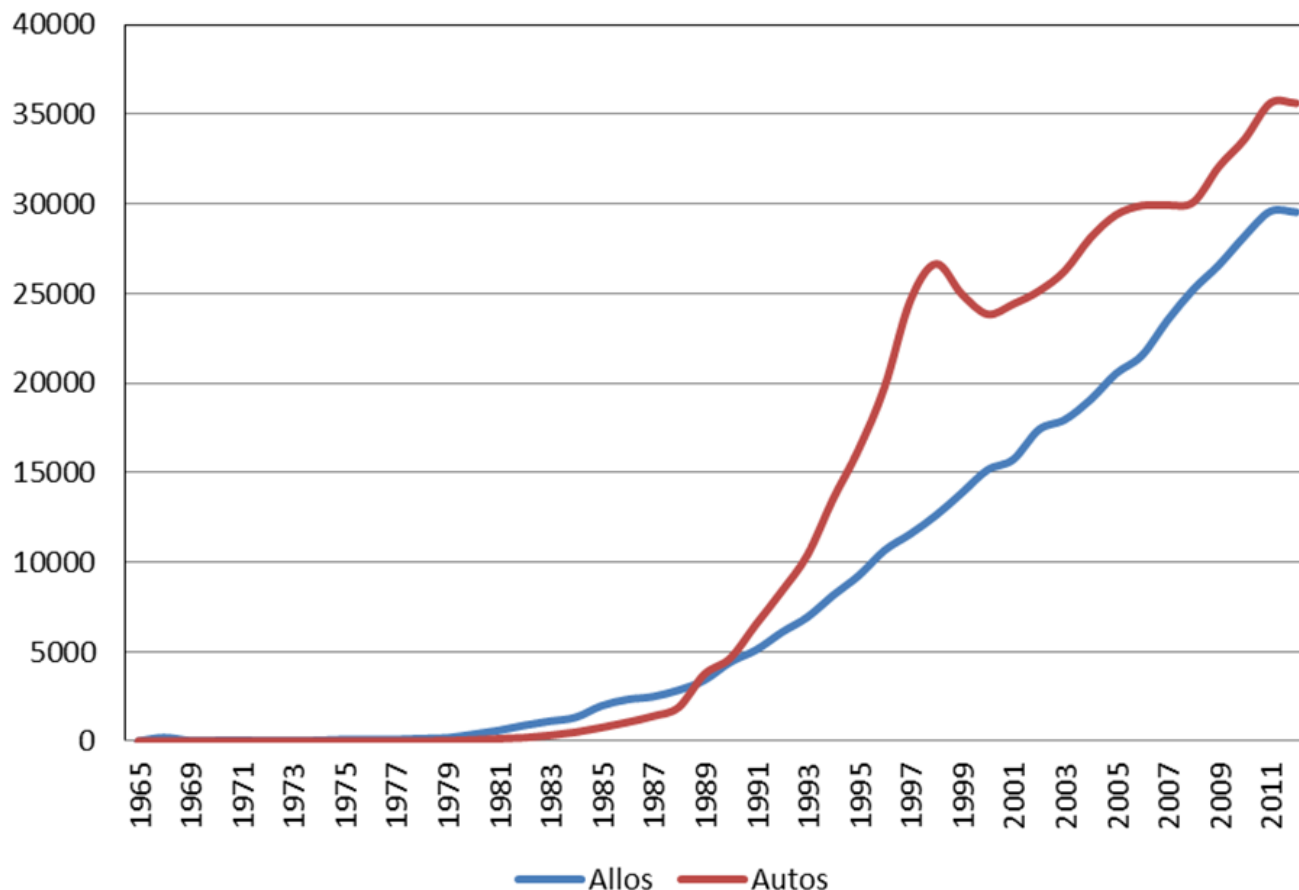






# Estimation of Global Transplant Numbers

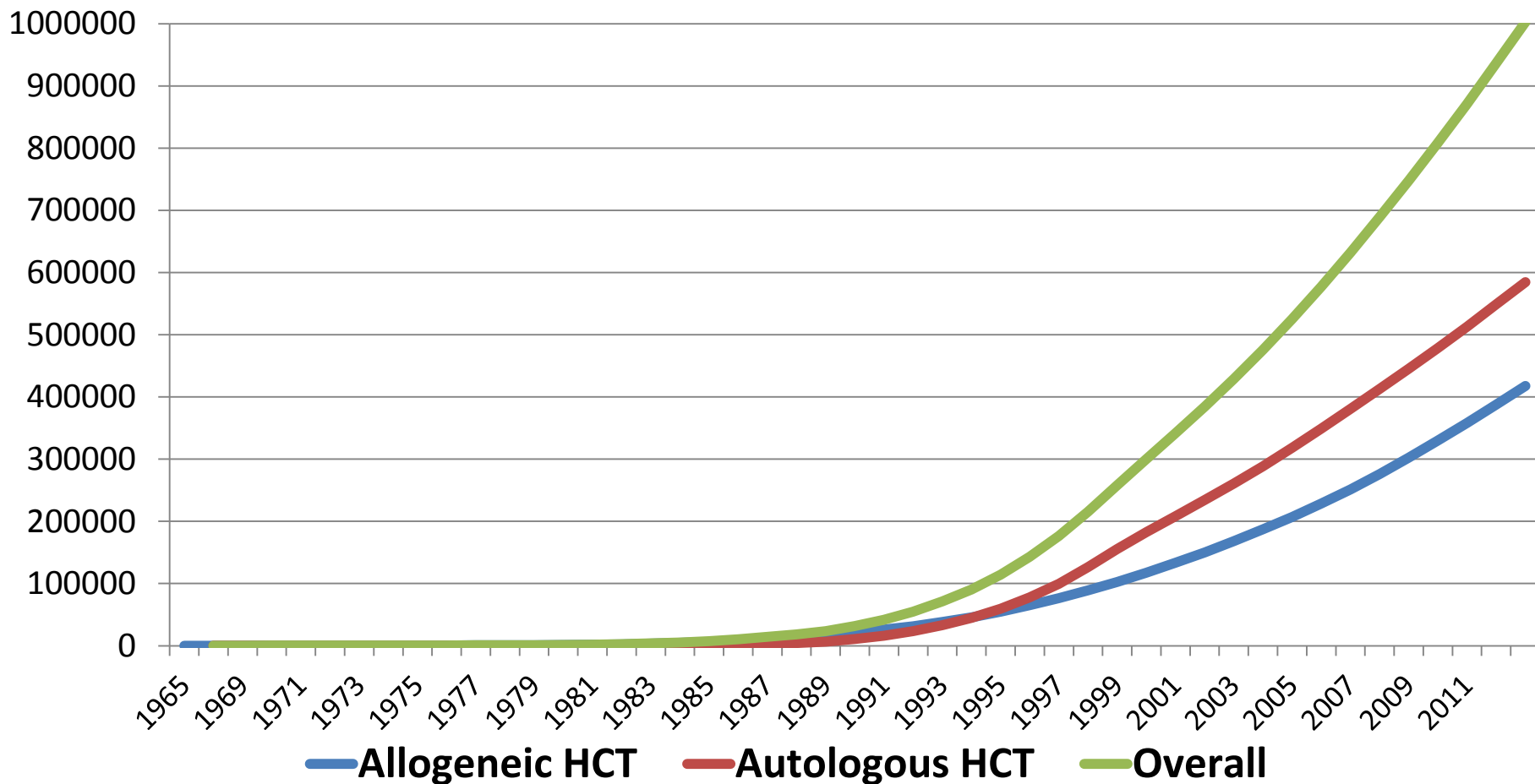
## Allogeneic and autologous





# Estimation of Global Transplant Numbers

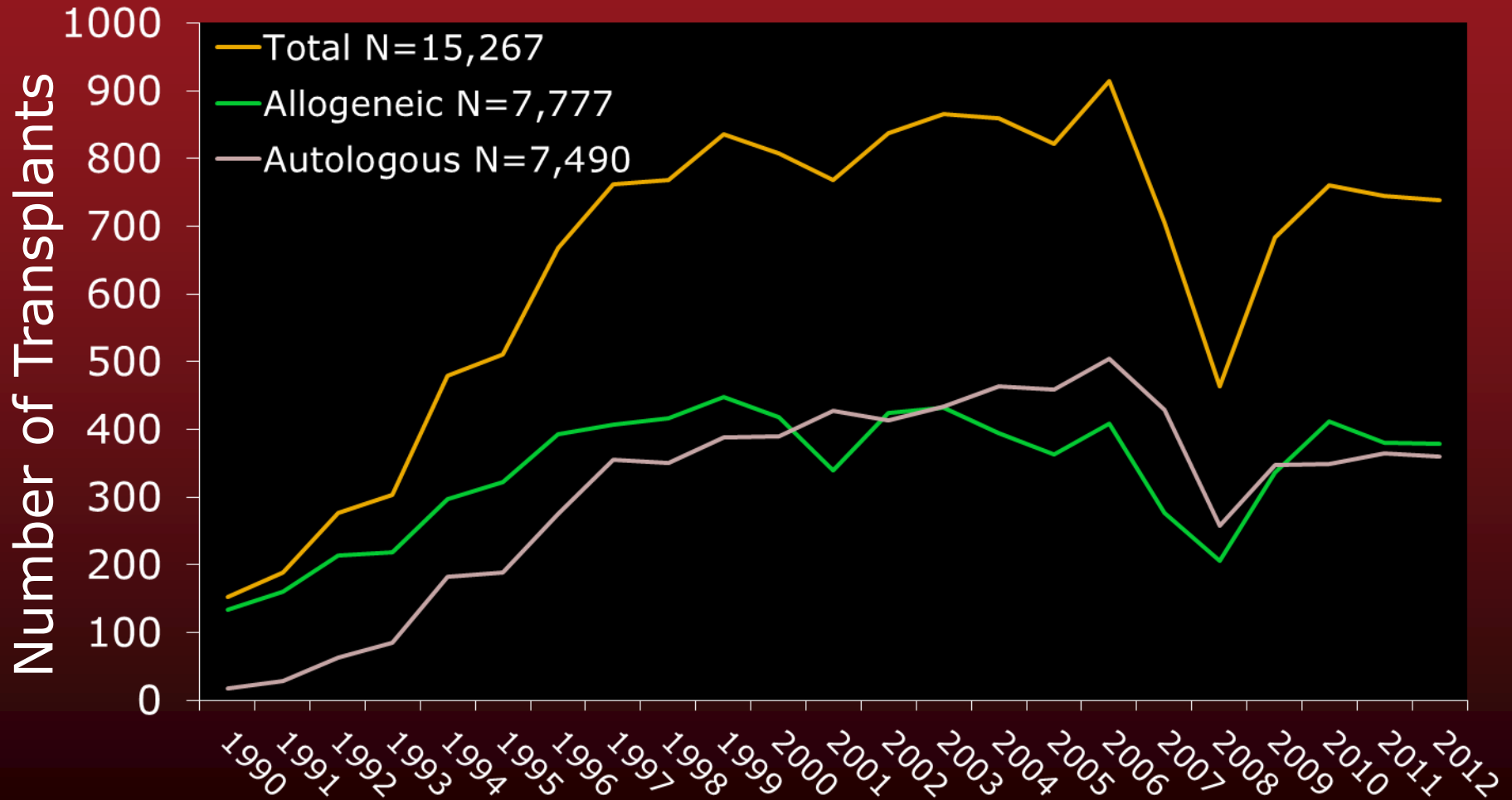
## Allogeneic and autologous



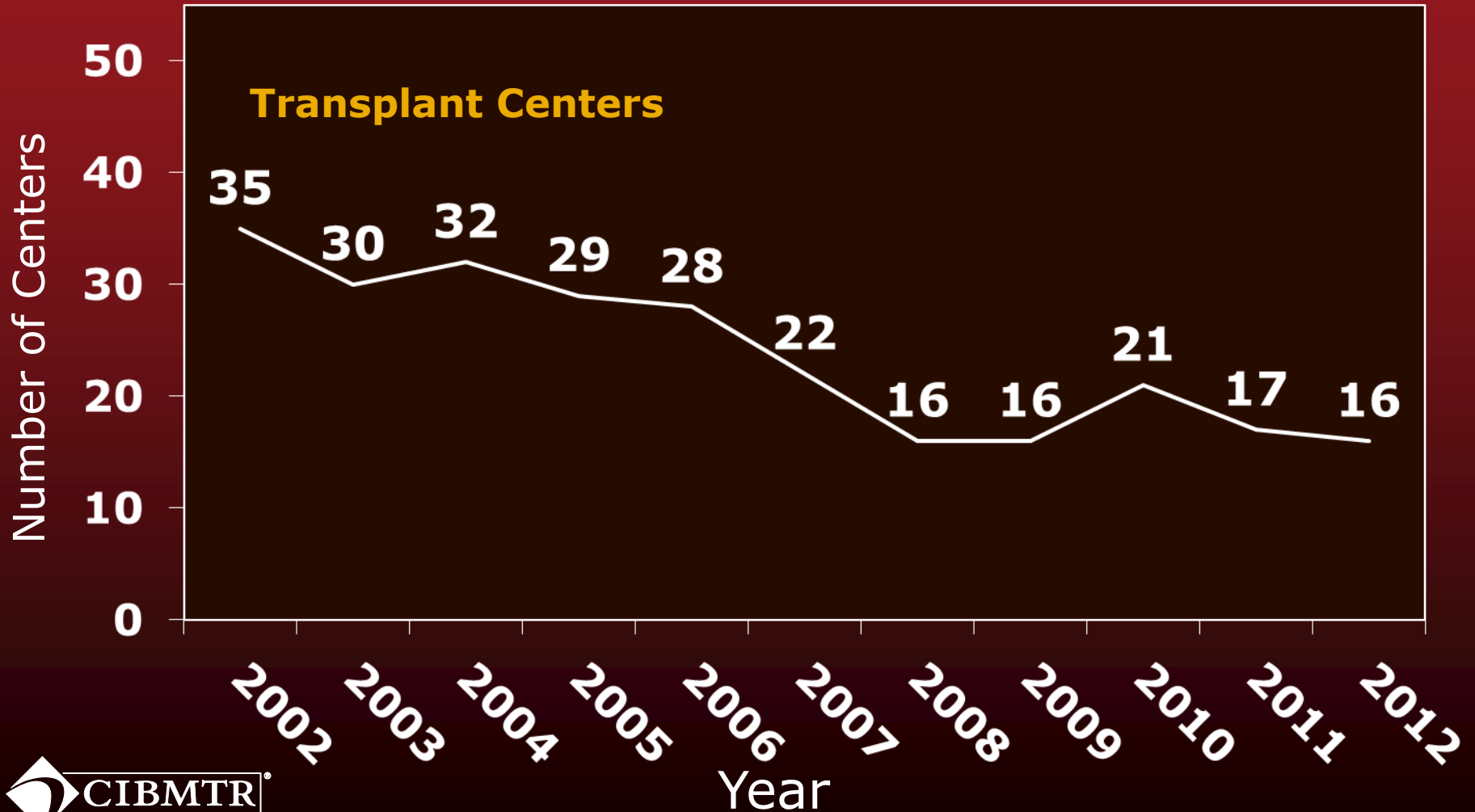
*Worldwide Network for Blood and Marrow Transplantation*

# Annual Numbers of Blood and Marrow Transplantations Reported to the CIBMTR, 1990-2012

## - Latin America -



# Annual Number of Latin American Transplant Centers Reporting to the CIBMTR, 2002-2012



# Centers in Latin America with Continuing Reporting to CIBMTR from 2008 to 2012

Center	Country
British Hospital	Uruguay
Clinica RUIZ de Puebla	Mexico
<b>Ct de Transp del Servicio Medico Integral</b>	Uruguay
<b>Ciudad Hospi Dr. Enrique Tejera</b>	Venezuela
Clinica Marly	Colombia
<b>Fundaleu</b>	Argentina
<b>Hospital Amaral Carvalho</b>	Brazil
<b>UFPR - Curitiba</b>	Brazil
<b>Hospital Rebagliati</b>	Peru
<b>Hospital Privado de Cordoba</b>	Argentina
Inst. Onc. Pediatrica	Brazil
<b>INCA</b>	Brazil
<b>UNICAMP</b>	Brazil
<b>Inst. De TMO de la Costa Caribe</b>	Colombia



# WBMT/WHO Workshop Salvador, Brazil October 2013

## HCT in Argentina 2009-2012

# ARGENTINA

Inhabitants: 41.000.000

HCT centers: 28

Location: 4 provinces

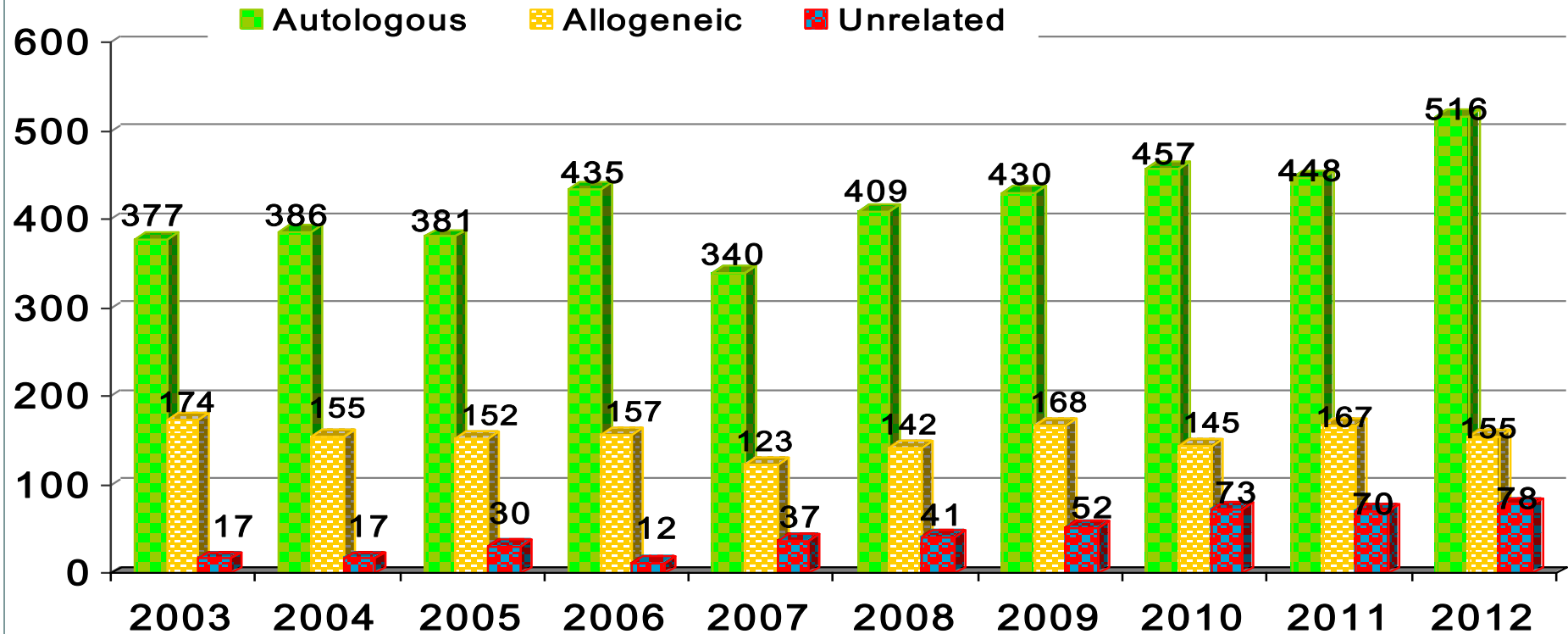
HCT beds: 100

HCT per year: 750

Country distance north to south km:  
5.700

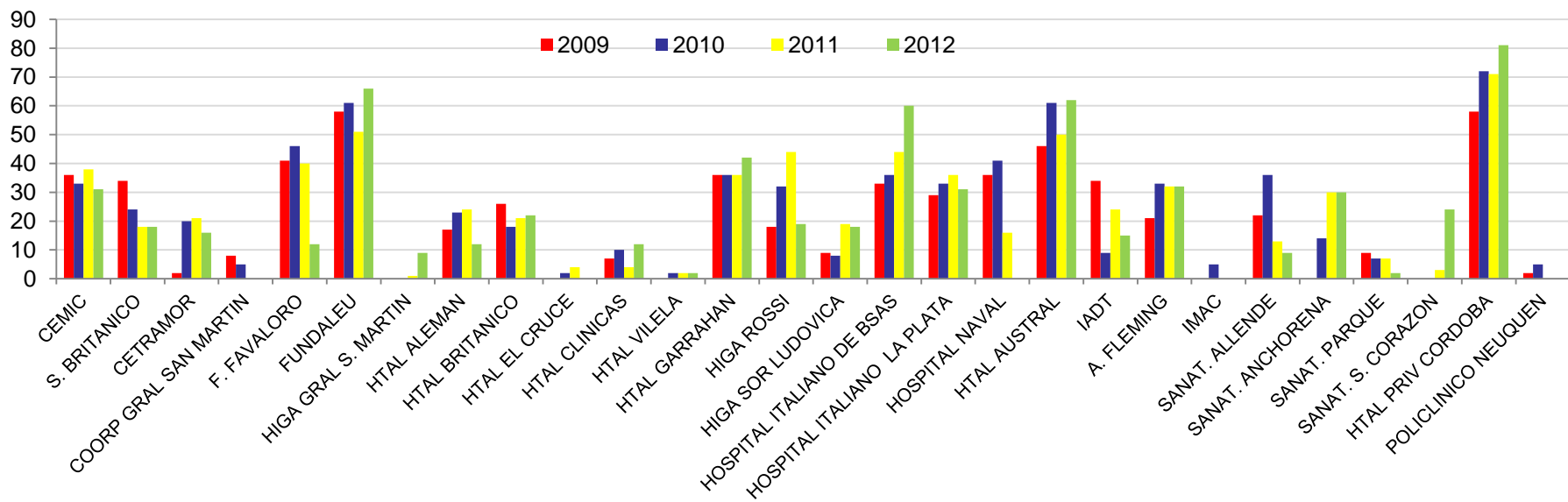


# Types of HCT per year

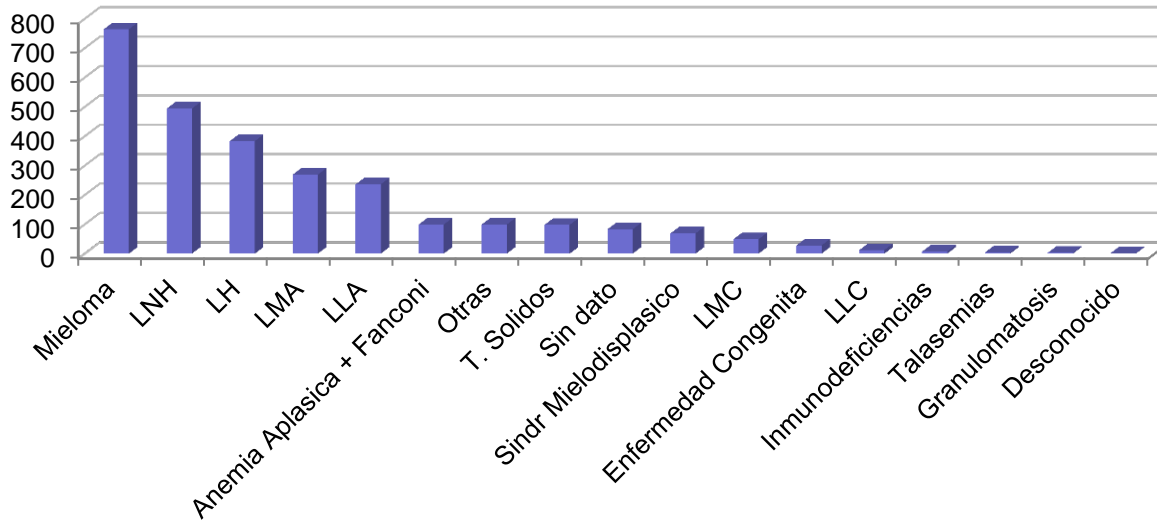




# HCT per center 2009 - 2012

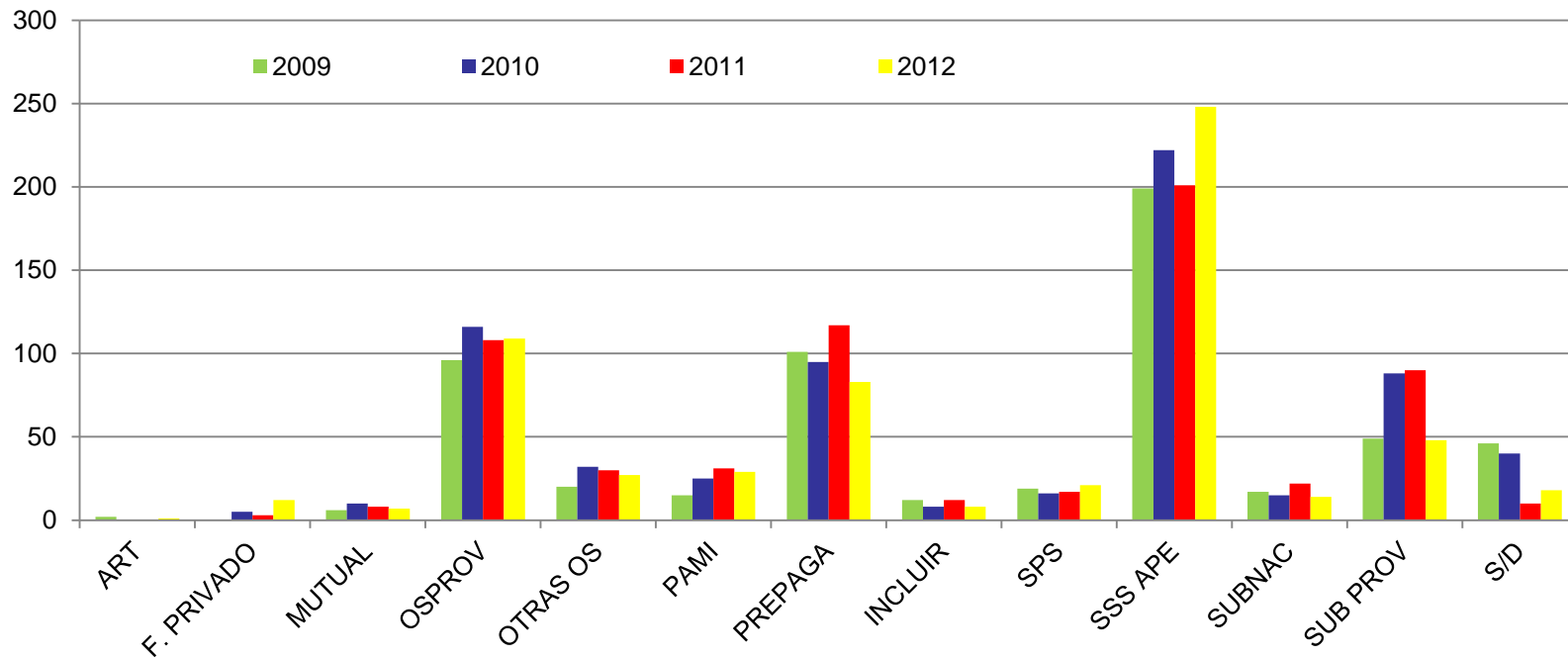


# HCT by diseases

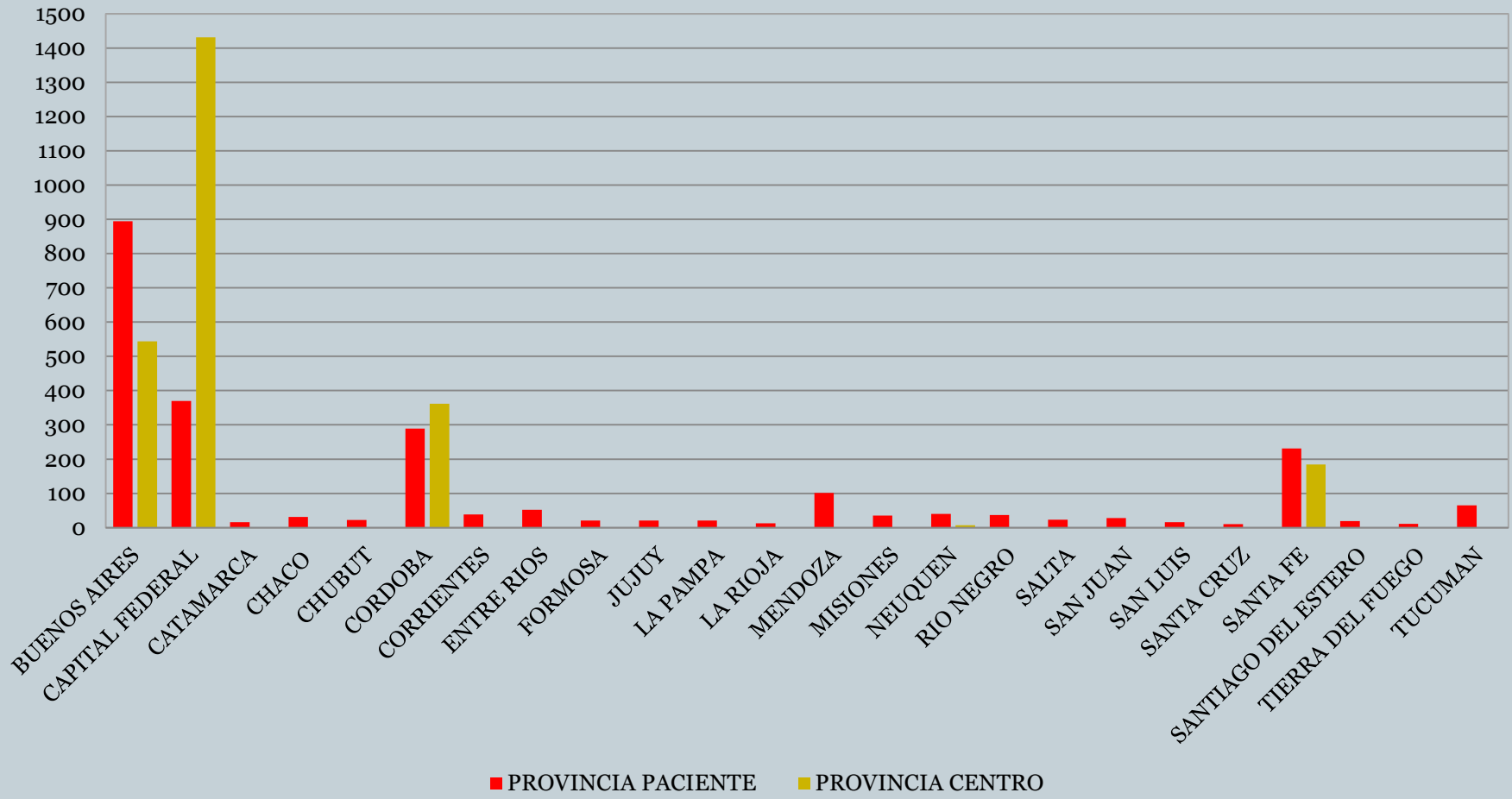


DIAGNOSTICO	TOTAL
Mieloma	764
LNH	494
LH	383
LMA	269
LLA	236
Anemia Aplasica + Fanconi	99
Otras	99
T. Solidos	98
Sin dato	83
Sindr Mielodisplasico	69
LMC	49
Enfermedad Congenita	28
LLC	12
Inmunodeficiencias	7
Talasemias	4
Granulomatosis	3
Desconocido	2
<b>TOTAL</b>	<b>2699</b>

# HCT by source of financial support



# Patient origin and transplant site 2009-2012



# Development of Regional Registry

- APBMT development
- What would be the model for development of a Latin America Registry?

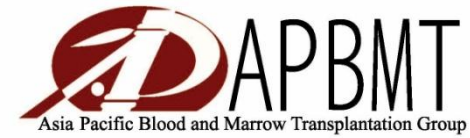
Data collection → Storage → Utilization  
Data Use Agreement



Oct. 4, 2013

WBMT 2<sup>nd</sup> Workshop

Grand Hotel Stella Maris, Salvador



# HSCT Outcome Database: Experience in Japan and APBMT

Ritsuro Suzuki

Nagoya University, Japan

# HSCT Database in Japan



平成6年度

## 骨髓移植患者新規登録票

秘

患者氏名：  
施設名：

性：男・女      生年月日：19 年 月 日  
記入者名：

移植実施日    199 年 月 日

1. 診断名（下記から1つ選択。該当診断名がない場合には記載して下さい）

1) 白血病 FAB M1 M2 M3 M4 M5 M6 M7 その他（  
急性骨髄性白血病 FAB L1 L2 L3 その他（  
慢性骨髄性白血病 成人型 若年型  
その他の白血病 病型（  
2) MDS の病型：RA RAEB RAEB-T その他（  
3) その他の悪性疾患 病名（  
4) 再生不良性貧血 病名（  
5) 先天性代謝異常 病名（  
6) その他疾患  
診断年月日 19 年 月 日

2. 移植の種類      M L C    R → D (+ · -)    D → R (+ · -)

1) 一卵性  
2) 血縁者間同種：  
HLA適合同胞      HLA不適合同胞（不一致抗原数 1 2 3）  
HLA適合非同種 Donorの統制は？（  
HLA不適合非同種（不一致抗原数 1 2 3）  
3) 非血縁者間：  
HLA適合      HLA不適合（不一致抗原数 1 2 3）  
4) 自家骨髄移植：purging なし      あり（種類）  
5) 末梢血幹細胞移植  
6) 末梢血幹細胞移植 + 自家骨髄移植  
7) その他

3. 移植実施時期（悪性腫瘍の場合）

1) 悪性腫瘍 初回寛解（慢性期）    2回目寛解（慢性期）    3回目以降の寛解  
初回寛解不能    再発中    end stage, accelerated, blastic  
2) その他の疾患（

4. 移植前処置（実施したものに○印を付けて下さい）

1) 放射線照射 無    有（TBI TAI TLI その他（  
2) 化学療法剤 大量Ex 大量CA 大量VP-16 大量busulfan 大量L-PAW  
その他（  
3) その他（

5. GVHDの予防法（実施したものに○印を付けて下さい）

1) MTX 2) CyA 3) PSL 4) ATG 5) その他（

6. GVHDの程度

1) 急性： 0    1    2    3    4    2) 慢性： 無    有（199 年 月 日頃）

7. 転帰

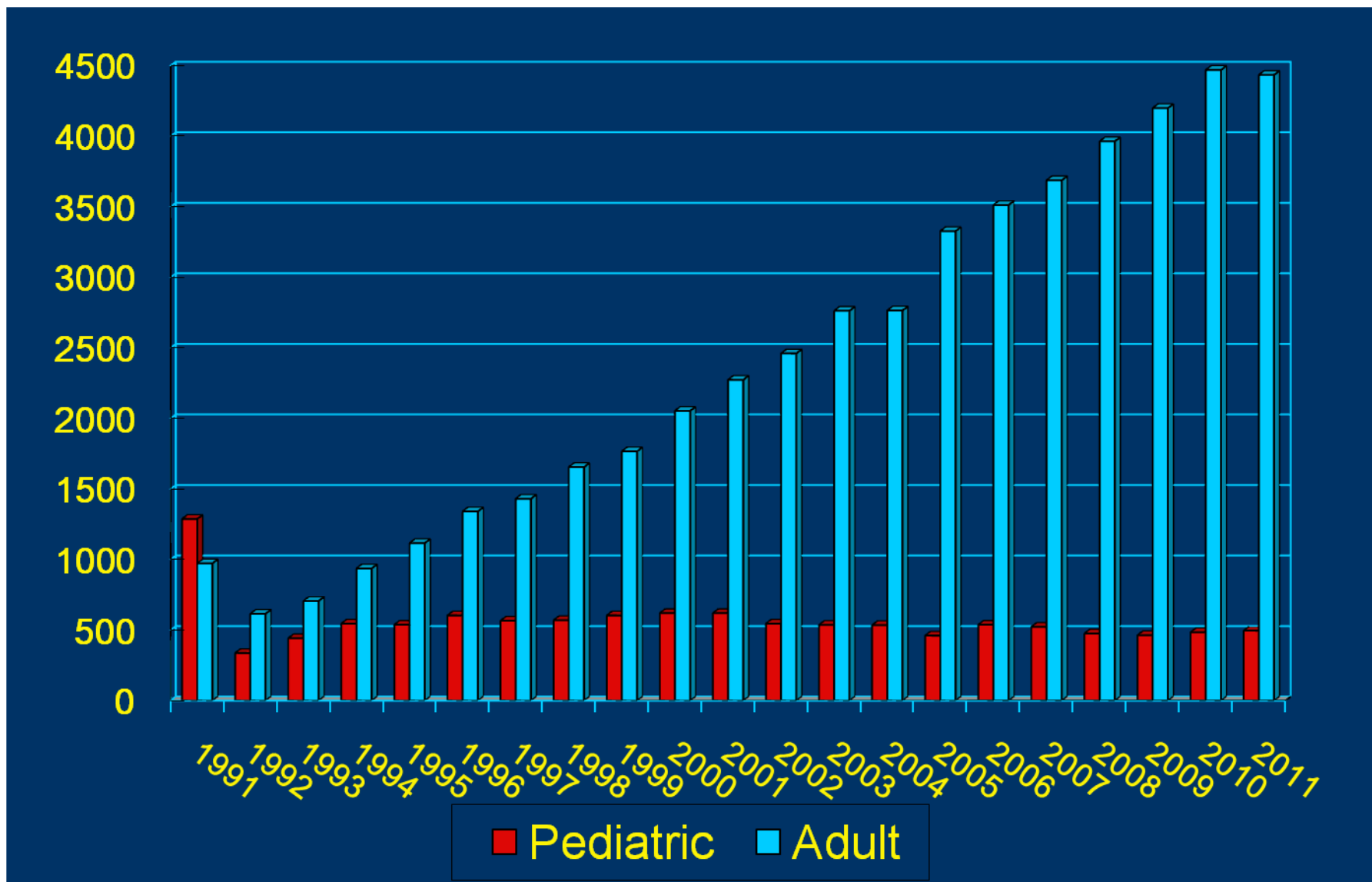
1) 移植後の再発： 無・有      再発年月日：199 年 月 日  
2) 生死      生存・死亡      死亡年月日：199 年 月 日  
死因（  
3) 生存の場合の最終確認日：199 年 月 日

Started in 1993 (paper CRF)

- Only included **23 items**

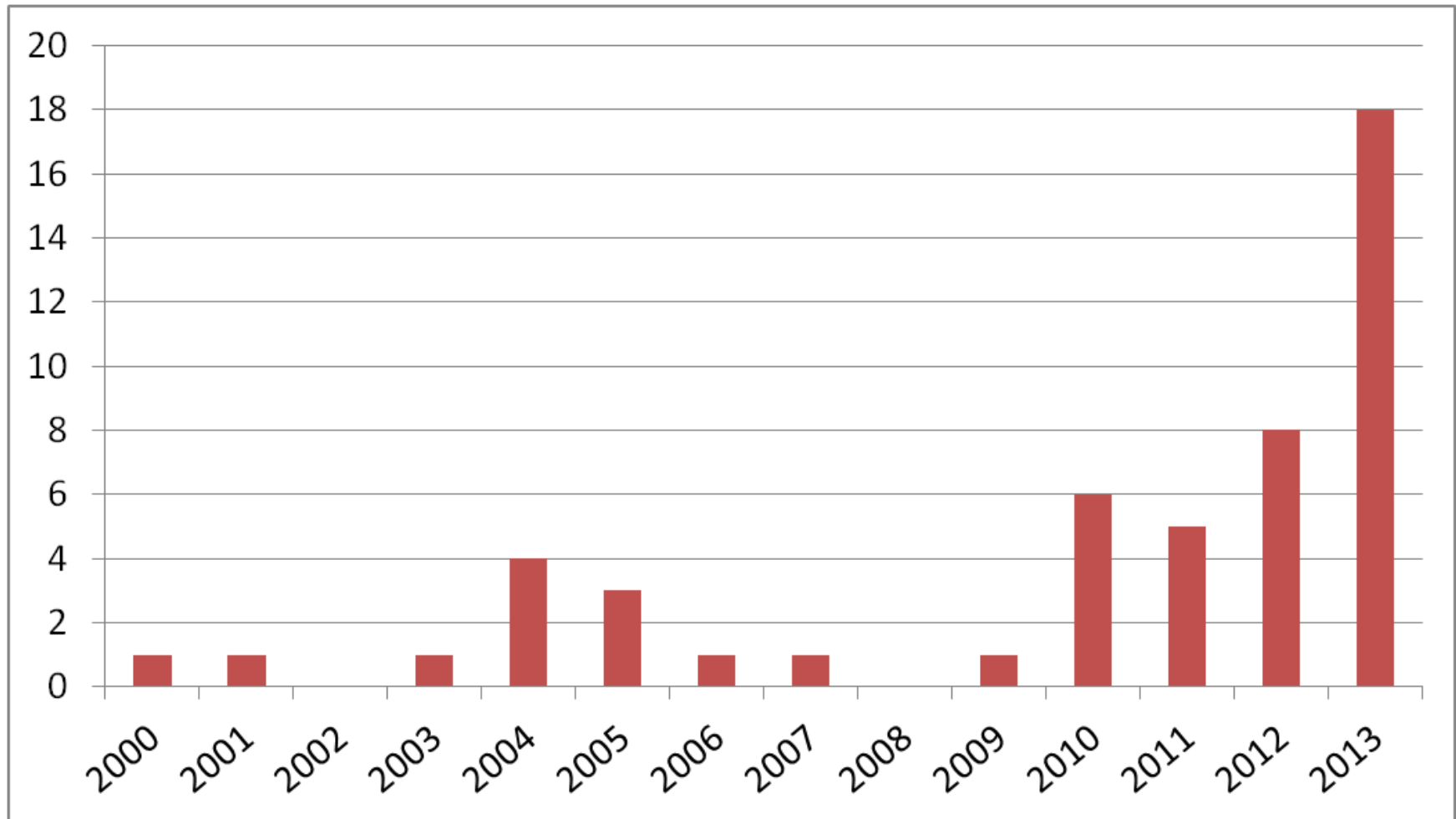
Patient name & sex  
Institution  
Date of birth & BMT  
Diagnosis & date  
Donor (including auto)  
MLC (both direction)  
Disease status at BMT  
Preconditioning  
(radiation & chemo)  
GVHD prophylaxis  
aGVHD grade  
cGVHD & onset  
Disease recurrence & date  
Survival & last follow-up  
Cause & date of death  
(if dead)

# Numbers of HSCT in Japan



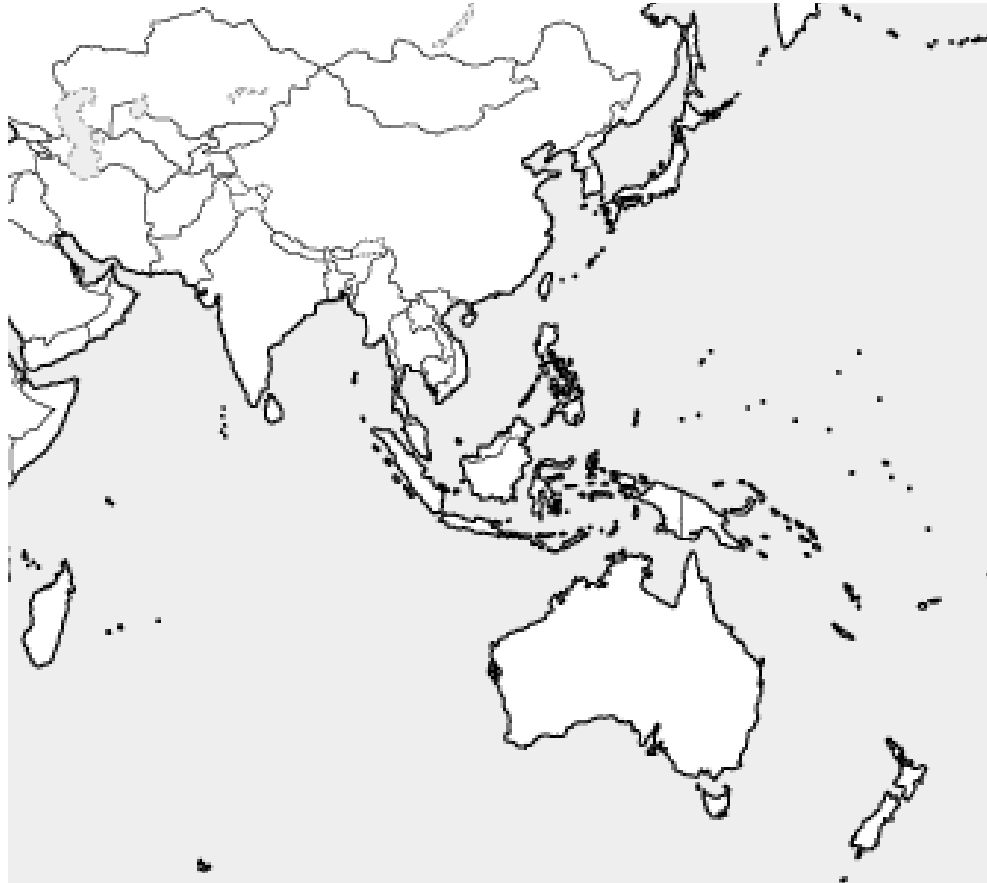


# Scientific papers using JSHCT database



**Total : 50 papers**

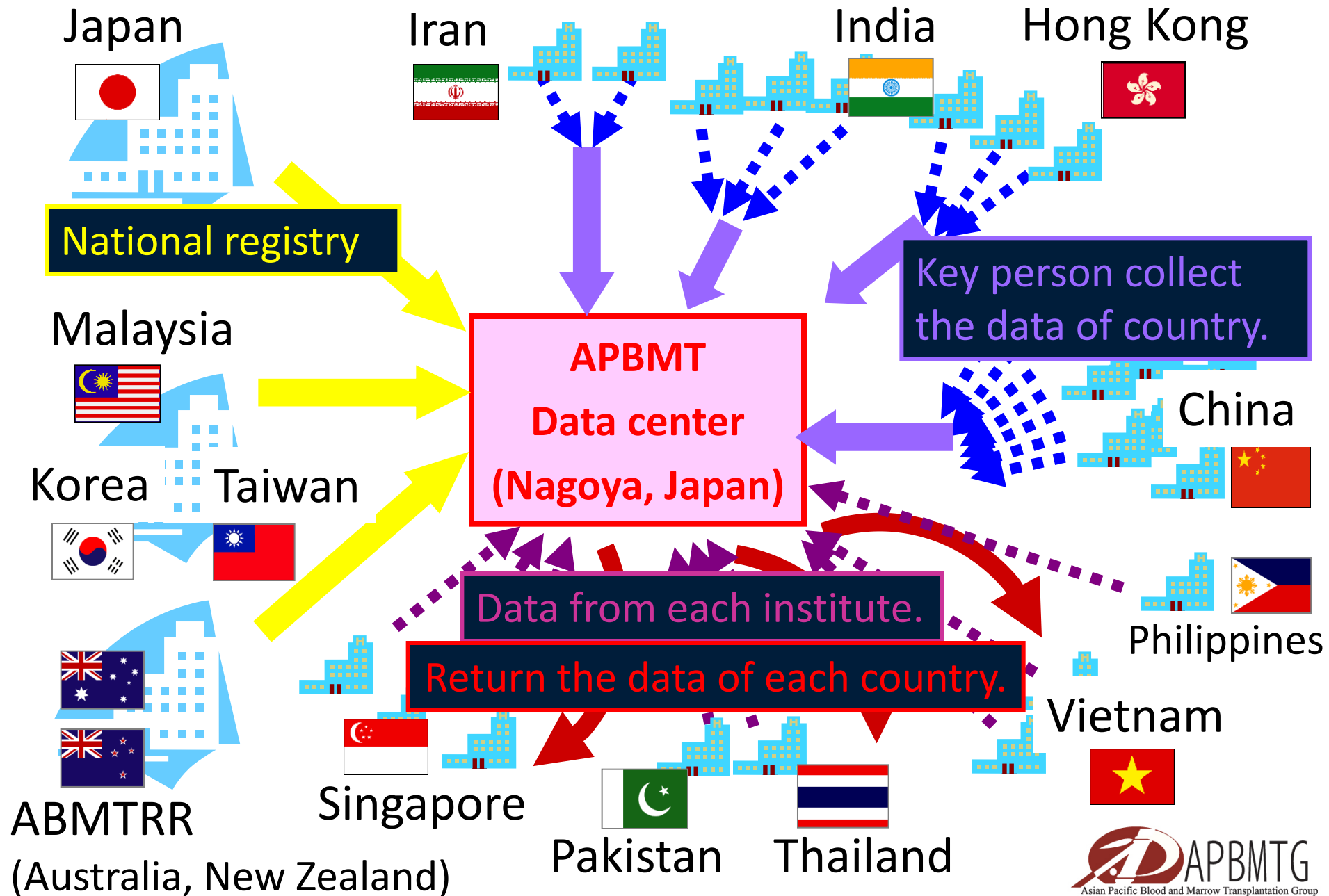
## Asia-Pacific Blood and Marrow Transplantation Group



- Australia
- Bangladesh
- China
- Hong Kong
- India
- Indonesia
- Iran
- Japan
- Korea
- Malaysia
- Mongolia
- Myanmar
- New Zealand
- Pakistan
- Philippines
- Taiwan
- Thailand
- Singapore
- Vietnam



# APBMT data collection

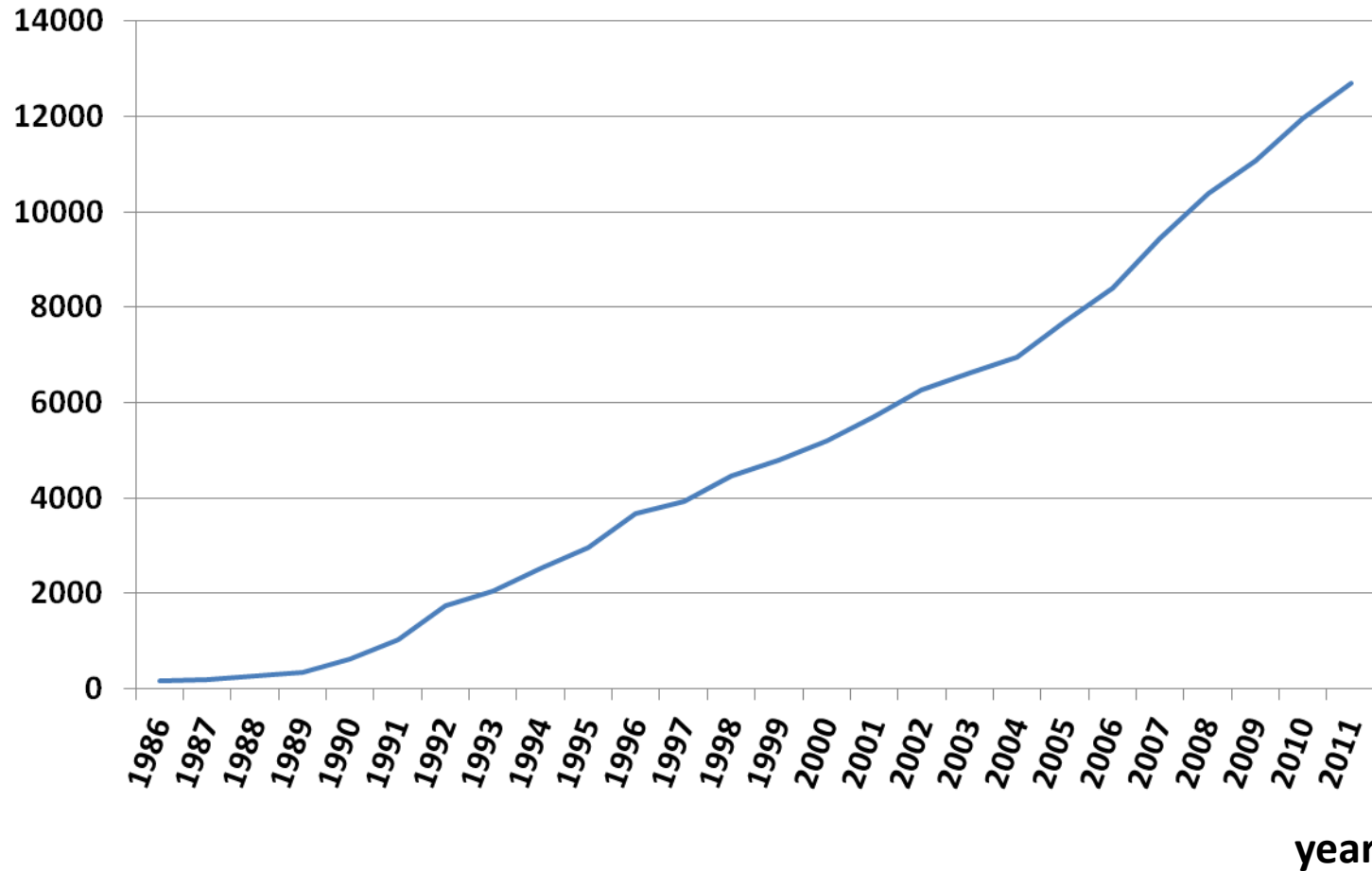


## No. of centers and HSCTs in APBMT countries























































































	Centers in 2011	HSCTs in 2011	Total HSCTs from 1986 to 2011
Australia	41	1,450	20,371
China	34	1,910	10,270
Hong Kong	2	176	2,471
India	29	877	3,008
Iran	8	451	3,754
<b>Japan</b>	<b>373</b>	<b>4,924</b>	<b>61,592</b>
Korea	43	1,900	17,733
Malaysia	-	-	1,703
New Zealand	6	201	2,281
Pakistan	2	55	367
Philippines	1	7	40
Singapore	4	164	1,560
Taiwan	18	492	4,300
Thailand	7	72	1,589
Vietnam	3	6	102
<b>Total</b>	<b>571</b>	<b>12,685</b>	<b>131,141</b>

# Total Number of HSCT in APBMT

No. of HSCTs



# HSCT Activity Report in APBMT

	2005	2006	2007	2008	2009	2010	2011
<b>Australia</b>							
<b>China</b>							
<b>Hong Kong</b>							
<b>India</b>							
<b>Iran</b>							
<b>Japan</b>							
<b>Korea</b>							
<b>Malaysia</b>							
<b>New Zealand</b>							
<b>Pakistan</b>							
<b>Philippines</b>							
<b>Singapore</b>							
<b>Taiwan</b>							
<b>Thailand</b>							
<b>Vietnam</b>							
	7	9	14	15	15	14	14

## 5<sup>th</sup> option for APBMT Outcome Registry

1. Minimum data-set                      273 items  
    Same as the CIBMTR/EBMT consensus (TED/MED-A)
  2. Small data-set                              400 to 600 items
  3. TRUMP (Japan)                              700 to 800 items
  4. Mega data-set                              ~ 1000 items  
    Same size with the full-set of CIBMTR/EBMT
- However, no countries sent the data in 2009 !
5. Least minimum data-set (LMD)      100 items  
    The most essential items.

# Least Minimum Dataset of APBMT

APBMT Center#: \_\_\_\_\_ Unique Patient Number (UPN): \_\_\_\_\_ HSCT Date: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
**APBMT Registry**  
Day 100 report sheet

**CENTRE IDENTIFICATION**  
APBMT Center #: \_\_\_\_\_  
Hospital: \_\_\_\_\_ Unit: \_\_\_\_\_  
Contact person: \_\_\_\_\_  
Country:  Australia  China  Hong Kong  India  Indonesia  Iran  Japan  Korea  Malaysia  New Zealand  Pakistan  Philippines  Singapore  Taiwan  Thailand  Vietnam

**PATIENT IDENTIFICATION**  
Unique Patient Number or Code: \_\_\_\_\_  
Date of Birth: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (yyyy-mm-dd)  
Sex:  Male  Female

**Disease**  
 AML  ALL  CML  MDG  CLL In situ  PLL  MDS/MPD  
 ATL  NHL  Hodgkin  PCID/MM  BM aplasia/other  
 SAA  Hemopoietopathy  Solid tumor  Other \_\_\_\_\_

**HSCT**  
Type of HSCT:  
 Autologous  
 Allogeneic  
Source of Stem Cells (check all that apply):  
 Bone Marrow  Peripheral Blood  Cord Blood  Other \_\_\_\_\_  
Date of 1<sup>st</sup> HSCT: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (yyyy-mm-dd)  
Chronological no. of HSCT for this patient \_\_\_\_\_  
Was this intended to be myeloablative? (allo only)  
 Yes  No

**DONOR**  
HLA match type  
 Syngeneic (monozygotic twin)  
 HLA-identical sibling (may include non-monozygotic twin)  
 HLA-matched other relative  
 HLA-mismatched relative:  
Degree of allele mismatch: \_\_\_\_\_ HLA code to 4 digits  
 1 HLA antigen mismatch  
 2 HLA antigen mismatch  
 Unrelated donor  
Complete number of mismatches inside each box:  
A B C DRB1 DQB1 DPB1 Antigenic  
          
HLA code to 2 digits  
       
Allelic  
       
HLA code to 4 digits  
Mismatch: #None mismatch; 2-2 mismatches; #A=not done  
Donor Sex:  Male  Female

**Preparative regimen**  
(Check all that apply) \_\_\_\_\_ Gy  
 TBI  
 TLI, TBI, TAI \_\_\_\_\_  
 ALG, ALG, ATG, ATG (before/d) \_\_\_\_\_ Horse  Rabbit  
antithyrotine  
 daunorubicin  doxorubicin  idarubicin  
 bleomycin  
 busulfan \_\_\_\_\_ Oral  IV  Both  
 carboplatin  
 carmustine (BCNU)  
 cisplatin  
 cytarabine  
 cyclophosphamide  
 cytarabine (Ara-C)  
 etoposide (VP16)  
 fludarabine  
 flutamide  
 imatinib mesylate (Gleevec, Glivec)  
 lomustine(CNU)

meiphamin(L-PAM)  
 mitoxantrone  
 monoclonal antibody(MAb)  
 Camptan  
 Rituximab (Rituxan, anti-CD20)  
 Gemtuzumab (Mylotarg, anti-CD33)  
paclitaxel (Taxol, Xyotax)  
teniposide (VM26)  
trastuzumab  
other, specify: \_\_\_\_\_  
radiolabeled MAb  
 Toxifumomab(Bexxar)  Iortumomab(Zevalin)

GVHD prophylaxis given (Allografts only)  
 No  Yes:  immunosuppressive chemotherapy  
 ALG, ALG, ATG, ATG (after/d)  
 FK 506 (Tacrolimus, Prograf)  
 Cyclosporine (CSA)  
 ECP (extra-corporeal photopheresis)  
 Flx 526 (Tacrolimus, Prograf)  
 Methotrexate (MTX)  
 In vivo monoclonal antibody (MAb)  
 Ant CD25 (Zenapax, Dacizumab, AmTAC)  
 Camptan  
 Etanercept (Enbrel)  
 Infliximab (Remicade)  
 Other \_\_\_\_\_  
Mycophenolate (MMF, Cellcept)  
cyclosporin Rapamycin, Rapamune  
Other drug, specify \_\_\_\_\_  
Absolute neutrophil count (ANC) recovery (engraftment)  
(Neutrophils  $\geq 0.5 \times 10^9/L$ )  
 No, Date of last assessment: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (yyyy-mm-dd)  
 Yes: Date of ANC recovery: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (yyyy-mm-dd)  
 Lost graft  
 Never below  
 Unknown  
Acute Graft Versus Host Disease (Allografts only)  
Maximum Grade:  
 None  I  II  III  IV  Not applicable  
Present but grade unknown  Not applicable  
Best disease status (response) after HSCT (prior to treatment modification in response to a post HSCT disease assessment)  
 Continued complete remission (CR)  
 CR achieved: Date achieved: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (yyyy-mm-dd)  
 Never in CR: Date assessed: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (yyyy-mm-dd)  
 Not evaluated  
First relapse or progression after HSCT (Not persistent disease)  
Relapse/progression detected by clinical/haematological method:  
 No, Date assessed: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (yyyy-mm-dd)  
 Yes: Date first seen: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (yyyy-mm-dd)  
 Not evaluated  
Survival Status:  
 Alive  Dead  Died before HSCT  
Date of last contact: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (yyyy-mm-dd)  
Date of last follow up or death: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (yyyy-mm-dd)  
Main Cause of Death (check only one main cause):  
 HSCT Related Cause  
 Relapse or Progression/Persistent disease  
(check as many as appropriate):  
 GVHD  Cardiac Toxicity  
 Rejection/Poor graft function  Infection  
 Pulmonary toxicity  Veno occlusive disorder  
 Other \_\_\_\_\_  
 Unknown  
 Other \_\_\_\_\_

One page for day 100 report

APBMT Center#: \_\_\_\_\_ Unique Patient Number (UPN): \_\_\_\_\_ HSCT Date: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
**APBMT Registry**  
Disease classification sheet

**AML** **ALL** **Other Acute Leukemias**

**ACUTE LEUKEMIAS**

**Classification:**  
AML with recurrent genetic abnormalities  
 AML with t(8;21)(q22;q22), (AML1/ETO)  
 AML with abnormal bone marrow eosinophils and Inv(16)(p13;q22) or t(16;16)(p13;q22) CBFS9/11x11  
 AML with t(15;17)(q22;q12), (PLM/RARα) and variants (FAB M3)  
 AML with t(11;22), (MLL) abnormalities  
 AML with multilineage dysplasia (w/o MDG or MDS/MDG antecedents)  
AML not otherwise categorized  
 AML, minimally differentiated (FAB M0)  
 AML without maturation (FAB M1)  
 AML with maturation (FAB M2)  
 Acute myelomonocytic leukemia (FAB M4)  
 Acute monoblastic/acute monocytic leukemia (FAB M5)  
 Acute erythroid leukemia (erythroid/myeloid and pure erythroleukemia) (FAB M6)  
 Acute megakaryoblastic leukemia (FAB M7)  
 Acute basophilic leukemia  
 Acute panmyelosis with myelofibrosis  
 Myeloid sarcoma  
 ALL, not otherwise specified  
 Transformed from MDG - Complete MDG section on Disease Classification Sheet 3. Do not complete the remainder of AML

**Secondary origin**  
 Yes: Disease related to prior exposure to therapeutic drugs or radiation  
 No  
 Unknown

**Status at HSCT:**

STATUS	NUMBER	FOR COMPLETE REMISSION ONLY, TYPE OF REMISSION
<input type="checkbox"/> Primary induction failure	(complete only for CR or relapse)	No Yes Not evaluated Unknown
<input type="checkbox"/> Complete haematological remission (CR)	<input type="checkbox"/> 1st <input type="checkbox"/> 2nd <input type="checkbox"/> 3rd or higher	Cytogenetic Molecular <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<input type="checkbox"/> Relapse		
<input type="checkbox"/> Never treated		
<input type="checkbox"/> Not evaluated		

One page for disease items

APBMT Center#: \_\_\_\_\_ Unique Patient Number (UPN): \_\_\_\_\_ HSCT Date: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
**APBMT Registry**  
Follow up sheet 1<sup>st</sup> year post transplant and yearly follow-up

**CENTRE IDENTIFICATION**  
APBMT Center #: \_\_\_\_\_  
Hospital: \_\_\_\_\_ Unit: \_\_\_\_\_  
Contact person: \_\_\_\_\_  
Country:  Australia  China  Hong Kong  India  Indonesia  Iran  Japan  Korea  Malaysia  New Zealand  Pakistan  Philippines  Singapore  Taiwan  Thailand  Vietnam

**PATIENT IDENTIFICATION**  
Unique Patient Number or Code: \_\_\_\_\_  
Date of transplant: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (yyyy-mm-dd)

**DISEASE STATUS**  
Best disease status (response) after transplant (prior to treatment modification in response to a post transplant disease assessment)  
 Continued complete remission (CR)  
 CR achieved: Date achieved: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (yyyy-mm-dd)  
 Never in CR: Date assessed: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (yyyy-mm-dd)  
 Previously reported

**DATE OF LAST CONTACT**  
Date of last follow up or death: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (yyyy-mm-dd)

**COMPLICATIONS OF TRANSPLANT**  
Chronic Graft Versus Host Disease present during this period  
 No (never)  Limited  Extensive  Unknown










**FIRST RELAPSE OR PROGRESSION**  
First Relapse or Progression after HSCT  
Relapse/progression detected by clinical/haematological method:  
 No: Date assessed: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (yyyy-mm-dd)  
 Yes: Date first seen: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (yyyy-mm-dd)  
 Previously reported  
 Continuous progression since HSCT  
 Not evaluated

**PATIENT STATUS**  
Survival Status:  
 Alive  Dead  
Check here if patient lost to follow up:   
Main Cause of Death (check only one main cause):  
 Relapse or Progression/Persistent disease  
 Secondary malignancy  
 HSCT Related Cause  
 GVHD (check as may as appropriate):  
 Rejection/Poor graft function  Cardiac Toxicity  
 Infection  
 Pulmonary toxicity  Veno occlusive disorder  
 Post transplant lymphoproliferative disorder  
 Other \_\_\_\_\_  
 Unknown  
 Other \_\_\_\_\_

One page for follow-up



# APBMT Outcome Database

	2010	2011
<b>Australia</b>		
<b>China</b>		
<b>Hong Kong</b>	(N=991)	
<b>India</b>		
<b>Iran</b>		
<b>Japan</b>		
<b>Korea</b>	(N=4,438)	
<b>Malaysia</b>		
<b>New Zealand</b>	(N=23)	
<b>Pakistan</b>		
<b>Philippines</b>		
<b>Singapore</b>	(N=3)	
<b>Taiwan</b>		
<b>Thailand</b>	(N=106)	
<b>Vietnam</b>		

Total N=5,561

- Still there are obstacles.
- 2011 data were not sent from Philippines at the moment.
- From China and Taiwan, the number of centers decreased. (at the moment)

## Good news

- Pakistan & Singapore data were sent from CIBMTR based on the agreement of data transmission.
- This agreement project was originally planned in 2008. (product of struggle)

# Agreement Form



## Data Transmission Agreement



This Data Transmission Agreement, effective September 16, 2010, is entered into by and between the Asia-Pacific Blood and Marrow Transplantation (“APBMT”), an international organization whose office and data center in Aichi Medical University School of Medicine and Nagoya University Graduate School of Medicine, and Singapore General Hospital (“Transplant Center”).

The APBMT is an international organization to share information and promote collaboration in basic and clinical research of hematopoietic cell transplantation in Asia-Pacific countries. The APBMT Data Center in campuses at Nagakute, Japan (Aichi Medical University School of Medicine) and Nagoya, Japan (Nagoya University Graduate School of Medicine) facilitates submission of outcome data from transplant centers or national transplant outcome registries for the purpose of clinical research. The purpose of this Agreement is to set forth terms by which the APBMT will facilitate Transplant Center’s participation in data submission for research activities of the APBMT.

### Section 1. Data Collection and Records

#### (a) Types of Data

i. APBMT Outcome Registry Data. Transplant Center shall participate as a APBMT Outcome Registry Registration Center, and shall submit the initial baseline and

**This form can be applied to the agreement between CIBMTR and societies other than APBMT.**

Center may submit TED data equivalent to APBMT Outcome Registry Data directly to CIBMTR. CIBMTR may provide such TED data to the APBMT. Similarly, centers submitting data to APBMT agree to allow APBMT to share these with CIBMTR.

# Conclusion

- Successful data collection is usually started from the small size.
- Any system based on “single person” is not a real system.
- Language, budget and labor are the major obstacles for data collection.
- Merits of data collection should be shared with participants, but it requires rather long time for data accumulation and usage.

# Acknowledgement

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# Development of Regional Registry

- APBMT development
- What would be the model for development of a Latin America Registry?

Data collection → Storage → Utilization  
Data Use Agreement



# Data Use Agreement

- Who owns and authorization to share the data.
- Sharing at what level?
- Who will oversee it?



# Model for implementation

- How to utilize the infrastructure that is available?
- Improvement in local databases?
  - Activity Registry
  - Outcomes Database
- Data Utilization



# Data collection: overcoming challenges

- Mandatory vs. Voluntary data collection.
- Trained personnel for data collection.
- Ongoing training.
- Incorporation of data collection in daily transplant related activities.
- Frequent interaction between transplant center and registry.

