ISBT Working Party for Rare Donors:
24 years of International Collaboration

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Working Party on Rare Donors

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- Joyce Poole, UK
- Elizabeth Smart, SOUTH AFRICA
- Marcia Novaretti, BRAZIL
- Graeme Woodfield, NEW ZEALAND

Members:
- Beat Frey, SWITZERLAND
- Christine Lomba-Francis, USA
- Cyril Lavone, UK
- Marie Overbooke, Martin Reid, NETHERLANDS, USA
- Pauline Fogg, SOUTH AFRICA
- Sannmah Joss, SULTANATE OF OMAN
- Silvano Wendel, BRAZIL
- Vered Yahalom, ISRAEL
- Tani Yoshitaka, JAPAN
- Ziyan Zhu, CHINA

Working Party Terms of Reference

- Develop guidelines for standardization of listing, labeling, shipping, testing and reimbursement for rare donor blood
- Provide a centralized international web resource for providing ongoing information on matters related to rare donors.
- Develop and extend the liaison with the International Blood Group Reference Laboratory (IBGRL in Bristol, UK) and thus assist blood service internationally to support and contribute to the WHO International Rare Donor Panel.

Develop guidelines for standardization of listing, labeling, shipping, testing and reimbursement for rare donor blood

White Paper: An Updated Report from the Working Party on the Use of Rare Blood for non-members and physicians who rarely request blood internationally

On ISBT Website under Working Parties, 2004

Policies for importing Rare Blood

2004 Working Party Report

Flowchart on process for requesting Rare Blood


The Problem Statement:
Patients need transfusion with rare blood products that are not available locally

The Solution:
International collaboration to supply rare products

S Nance 16 Sept 2008 Düsseldorf
Where do they come from?
1. Local Facility
2. Regional Facility
3. National Facility
4. International Facility

How does that happen?
Summary Points on Process Flow

- Multiple contact points for Local Facility with National Facility
- Information critical regarding treatment in the absence of blood product availability
- Immediate shipment critical
- Patient/Physician understanding of untested nature of the blood

Provide a centralized international web resource for providing ongoing information on matters related to rare donors

Working Party posts all relevant materials on the Working Party section of the ISBT website

2004 White Paper
2007 Flowchart
2007 Shipping Outcome Form
2007 Working Party picture from formal meeting of the Working Party in South Africa at the ISBT Congress
2007 Transfusion Today article on the Working Party and its purpose

Provide a centralized international web resource for providing ongoing information on matters related to rare donors

Publications/Postings

An Updated Report of the ISBT Working Party on Rare Blood Donors, December 2004 (PDF, 109 Kb)

Transfusion Today #71, June 2007 (1.5 Mb)

Utilisation of Rare Blood, Vox Sang Science Series. November 2007

Transfusion Today #75, June 2008 (1.23Mb)

Shipping Outcome Form

International Shipment of Rare Blood Response Form
The ISBT Rare Donor Working Party is concerned about the effectiveness of the transport and use of rare blood products shipped internationally. The committee has developed a form which relates the critical information about the shipment. This form is to be packed by the shipper when rare blood is shipped and completed by the receiving facility. This form will then be sent by FAX or email to International Blood Group Reference Laboratory (IBGRL) for monitoring purposes. The country of origin can also monitor the forms if desired. The form is a template that can be translated into the host county language if used only within the country. When used internationally, the language should be English.

Rare blood shipment form (PDF, 29 Kb)
Develop and extend the liaison with the International Blood Group Reference Laboratory (IBGRL) in Bristol

Working Party numbers 19 members from 14 countries 1984-2008

Working Party surveyed and established that 118 centers have rare donor capacity. Contacts were determined for each facility 2006

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### Requests via IBGRL August 2004 to August 2006

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### IBGRL Requests August 2004 to August 2006 Internet access

| Australia   | 4 | Portugal | 2 |
| Canada      | 3 | Scotland | 8 |
| Czech Rep   | 18| Sweden   | 13|
| Denmark     | 12| Switzerland | 30|
| France      | 6 | The Netherlands | 25|
| Germany     | 34| Philippines | 30|
| Israel      | 27| UK       | 351|
| Norway      | 2 | USA      | 20 |
| Poland      | 11| TOTAL    | 596|
Question 1. What is your definition of a rare donor?

Question 2. Do you, in your country, have a national panel of rare donors and/or a national bank of frozen red cell units from such donors? If so what percentage of cases do you find compatible red cells for the above patients? Which of the relevant phenotypes are lacking in your panel/bank?

Question 3. If no compatible donors/units are available from your national panel/bank, or if no such panel/bank exists, do you appeal to the WHO IDP and or the European Bank of Frozen Red Cell or national panels in other countries. If you do, could you indicate how many times you have appealed to those institutions in the past 5 years and what % of cases were compatible donors obtained. Donors of which phenotype were most difficult to find?

Question 4. Were there any problems encountered in finding compatible units for your patients?

Question 5. Are there restrictions in your country for the use of units that were frozen at a time that not all tests required at present were performed and when no blood sample is available to do those tests?

Responses from 16 countries

Rare donor definition –
Vast majority of countries those donors with red cells lacking antigens of high-prevalence are considered rare
varies from 1:1000 to 4:1000 (France) to 1:100 – 1:1000 (Japan)
Second category: negative for combination of common antigens, varies from 1:200 to 1:1000

National panel of donors –
Nearly all respondents have national center
Some have several panels
One country has panel of patients requiring rare types (France)

Percentage of cases that compatible red cells can be provided is as high as 100%

Difficult types to find are:
K
f, McLeod, U-, Vel-, Lan-, O\h, p

No compatible products:
WHO International Panel of Rare Donors in Bristol, UK
Sanguin Bank of Frozen Blood in Amsterdam (previously the Bank of Frozen Red Cells)

Problems encountered:
- Logistics – transit time longer than cells remain frozen
  Different freezing methods may necessitate that the blood is thawed in country of origin
- Very rare types are difficult to find
- Eligibility criteria reduces numbers of donors eligible
- Differences in testing between countries makes importing a medical challenge

Case Study
- This case report shows the value of international collaboration
- It is all about lifesaving transfusions for patients with rare blood needs
- We are stewards of this rare resource
- Continued efforts are needed globally to identify and collect rare donors for transfusion to any patient in need.