

ISBT Working Party for Rare Donors :

24 years of International Collaboration

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Working Party on Rare Donors

| | | | |
|---|--------------|------------------------------|-------------------|
| In the Chair: Sandra Nance | USA | Members: Beat Frey | SWITZERLAND |
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| | | Tani Yoshihiko | 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

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|---|---|
| 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 | On ISBT Website under Working party and published in Transfusion Today, June 2007. In Science Series of Vox Sang Nov 2007 |



The Problem Statement:

Patients need transfusion with rare blood products that are not available locally



The Solution

International collaboration to supply rare products



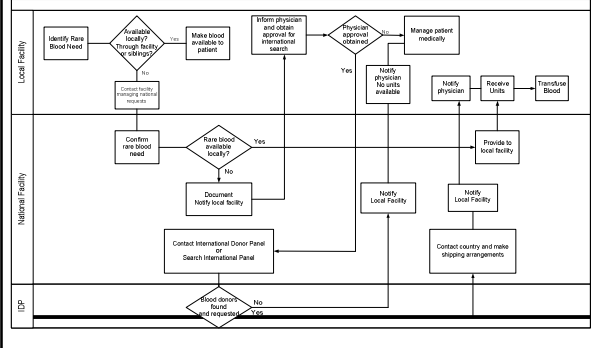
Where do they come from?

1. Local Facility
2. Regional Facility
3. National Facility
4. International Facility

How does that happen?

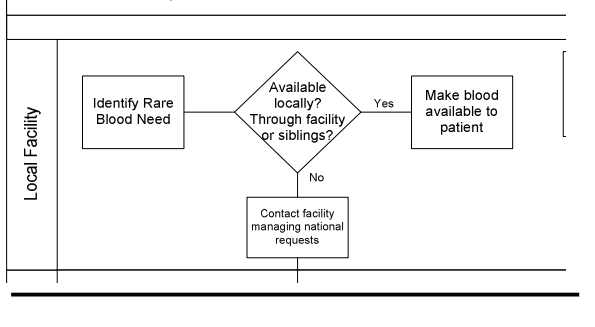
PROCESS FLOW FOR OBTAINING RARE BLOOD

Flow Chart to Request Rare Blood from International Rare Donor Panel (IDP)

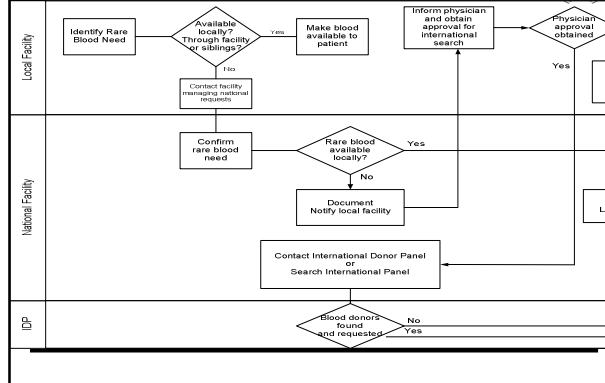


Local Facility Role

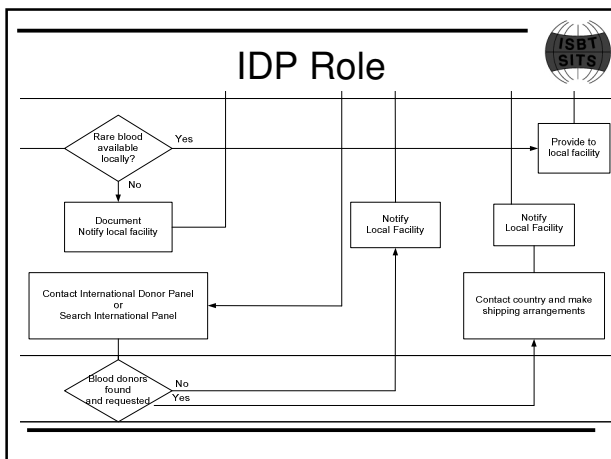
Flow Chart to Request Rare Blood from International Rare Donor Panel



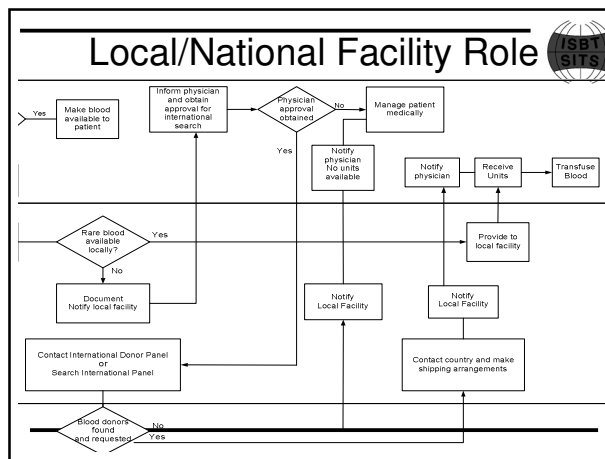
National Facility Role

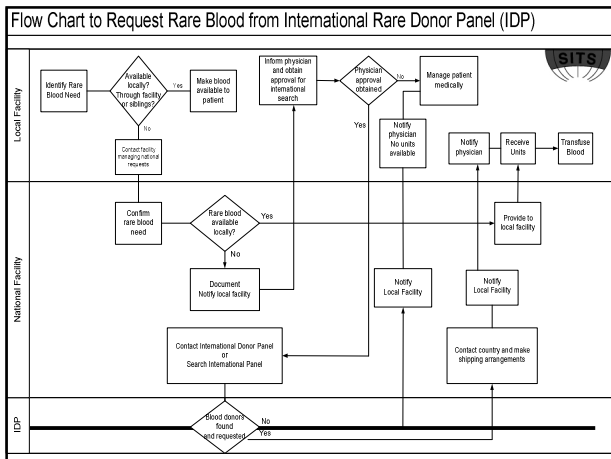


IDP Role



Local/National Facility Role





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 critical

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)

Shipping Outcome Form

ISBT RARE DONOR WORKING PARTY - INTERNATIONAL SHIPMENT OF RARE BLOOD RESPONSE FORM
RECEIVING/REQUESTING CENTRE REMARKS

Instructions for Review and Use of Receiving/Requesting Centre Remarks Form (for Internationally Shipped Rare Blood Units)

- Review template for ISBT Rare Donor Working Party - International Shipment of Rare Blood Response Form Receiving/Requesting Centre Remarks
 - a. Translate into host country's language, if desired.
 - b. Add appropriate host country I.F.A.S. number, if desired.
 - c. Approve through appropriate local channels change control system.
 - d. Notify shipping/receiving facilities of new numbering process.
 - e. Checkbook forms according to local process.
- Instructions for using the ISBT Rare Donor Working Party - International Shipment of Rare Blood Response Form Receiving/Requesting Centre Remarks
 - a. Shipping facility includes form with units to be shipped.
 - b. Receiving facility completes form answering all questions and initials.
 - c. Receiving facility form on a weekly basis to:
 - i. IBGRL
 - ii. National Organization of Country
 - iii. Shipping facility
 - d. File form with shipment paperwork, as desired.

1. Number of RBC units received: _____
 Were the units received in acceptable condition?
 If no, what was the problem?
 Broken: _____ # _____
 Thawed: _____ # _____
 Other: _____

2. Were the units received at the expected time?
 If no, what was the problem?

3a. Were the infectious disease tests performed and documented?
 3b. Were they sufficient to allow transfusion?

4. Were the billing documents in order?
 If no, what was the problem?

5. What was the transfusion outcome?
 a. Patient received units?
 If no, please give reason: _____
 b. Please describe outcome of patient.

6. Phenotype of Units:
 # received: _____




Develop and extend the liaison with the International Blood Group Reference Laboratory (IBGRL) in Bristol



Working Party numbers 19 1984-2008
 members from 14 countries

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

Requests via IBGRL August 2004 to August 2006



| Request | Group | Supplied |
|-------------|----------------|---------------|
| Switzerland | Yt(a-) | UK |
| Israel | pp | Sweden |
| Thailand | Jk(a-b-) | ? |
| Netherlands | At(a-) | USA |
| Spain | Wr(b-) | Not available |
| Austria | Jk(a-b-) | ? |
| Thailand | pp | ? |
| USA | rr Gy(a-) | Not available |
| India | O ^h | ? |
| Israel | ii | ? |
| USA | G-U- | ?UK |

Requests via IBGRL August 2004 to August 2006




| Request | Group | Supplied |
|-----------|----------------------------------|---------------|
| Germany | C-E-Fy(a-b-)Jk(b-)M-Le- | ? |
| USA | Sc:-1,-2,-3 | Not available |
| Brazil | D-/-D-- | ?Japan |
| Israel | R2R2 Jk(a-)Fy(a-) | UK |
| USA | C-E-K-S-Fy(a-) hr ^B - | S Africa |
| Czech Rep | D-/-D-- | USA |
| Brazil | Rh _{null} | ? |
| Germany | U- | ? |
| Australia | C-Fy(a-b-)Jk(b-)Do(a-) | ? |
| USA | hr ^B - | S Africa |
| USA | Vel- | USA |
| China | C-Fy(a-) | Japan |

Kell Requests via IBGRL August 2004 to August 2006



| Request | Group | Supplied |
|-------------|---------------------|------------|
| USA | McLeod | UK frozen |
| USA | Ko E-S-Fy(a-)Jk(a-) | ? |
| Spain | Js(b-) | ? |
| Netherlands | KK Fy(a-) Jk(a-) | ?UK |
| Germany | Ko | ? |
| Brazil | McLeod | UK frozen |
| S Ireland | KK | USA |
| Germany | Ko | not needed |
| Thailand | Ko | Japan |
| Israel | KK R1R1 Jk(b-) | UK |

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 |

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- 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?

Vox Sang 2008;94:1-16

Vox Sanguinis International Forum July 2008



- 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?

Vox Sang 2008;94:1-16

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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)

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

Difficult types to find are:

K_o, McLeod, U-, Vel-, Lan-, O^b, 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)

Vox Sang 2008;94:1-16

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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

Vox Sang 2008;94:1-16

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.