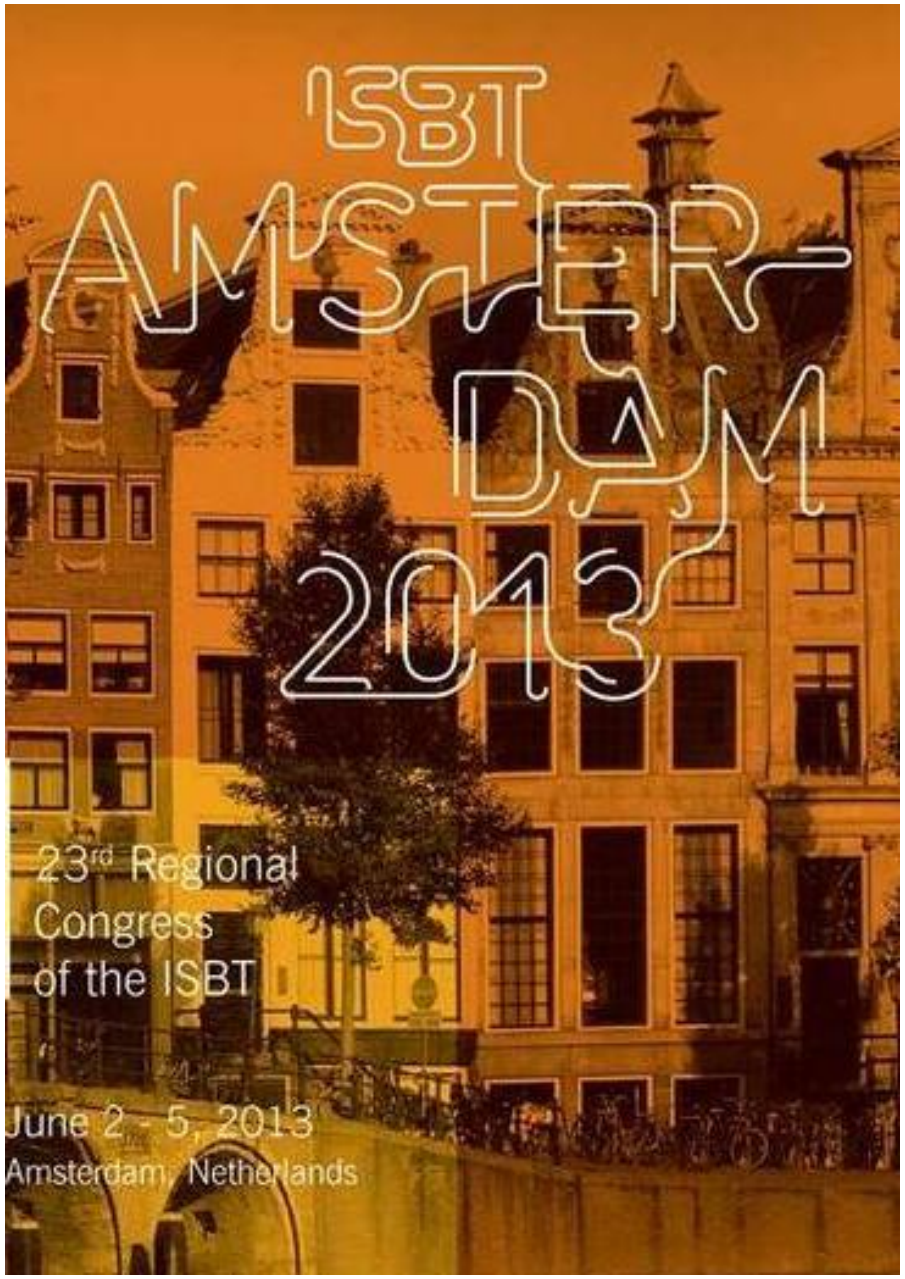

American Red Cross

Global Definitions of Rare Donors

Sandra J Nance, MS, MT(ASCP)SBB

American Red Cross Biomedical Services
Senior Director, IRL
University of Pennsylvania
Adjunct Assistant Professor
American Rare Donor Program
Senior Director
ISBT Working Party on Rare Donors
Chair

Working Party on Rare Donors
Terms of Reference

- To maintain guidelines for standardisation of listing, shipping, testing and re-imbursement for blood from rare donors.
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American Red Cross

Publications

Vox Sanguinis

ISBT Working Party

Vox Sang 1999;77:58–62

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Accepted: December 22, 1998

Rare Blood

An ISBT Working Party Report on Rare Blood Donors

David Anstee Cyril Levene Delores Mallory Marijke Overbeeke
Joyce Poole Marion Reid Elizabeth Smart Yoshihiko Tani
Silvano Wendel Graeme Woodfield (Chairman)
for the ISBT Working Party on Rare Blood Donors

(For affiliations see Appendix.)

American Red Cross

Publications

A review of the ISBT rare blood donor program

G. Woodfield, J. Poole, S.T. Nance, and G. Daniels

IMMUNOHEMATOLOGY, VOLUME 20, NUMBER 4, 2004

American Red Cross

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ISBT Working Party on Rare Donors Webpage

Rare Donors

- Terms of Reference
- Meeting Agendas
- Meeting Minutes
- Meeting Presentations
- Meeting Photos
- Chair's Report to the ISBT Board
- IBGRL Reports on Use of International Donor Panel
- References
- **Management Tools**
- **Members**
- Contact

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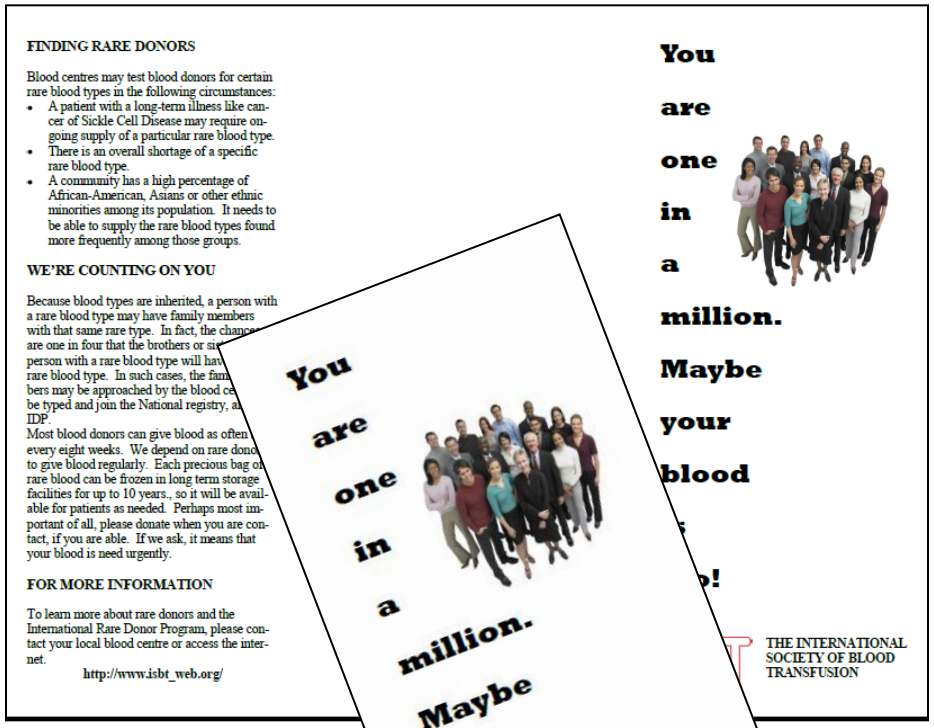
Rare Donor Leaflet for Rare Donor Recruitment



FINDING RARE DONORS

Blood centres may test blood donors for certain rare blood types in the following circumstances:

- A patient with a long-term illness like cancer of Sickle Cell Disease may require ongoing supply of a particular rare blood type.
- There is an overall shortage of a specific rare blood type.
- A community has a high percentage of African-American, Asians or other ethnic minorities among its population. It needs to be able to supply the rare blood types found more frequently among those groups.

WE'RE COUNTING ON YOU

Because blood types are inherited, a person with a rare blood type may have family members with that same rare type. In fact, the chance are one in four that the brothers or sis person with a rare blood type will hav rare blood type. In such cases, the fam bers may be approached by the blood ce be typed and join the National registry, a IDP.

Most blood donors can give blood as often every eight weeks. We depend on rare dono to give blood regularly. Each precious bag o rare blood can be frozen in long term storage facilities for up to 10 years., so it will be available for patients as needed. Perhaps most important of all, please donate when you are contact, if you are able. If we ask, it means that your blood is need urgently.

FOR MORE INFORMATION

To learn more about rare donors and the International Rare Donor Program, please contact your local blood centre or access the internet.

http://www.isbt_web.org/

You are one in a million. Maybe your blood

!

THE INTERNATIONAL SOCIETY OF BLOOD TRANSFUSION

You are one in a million. Maybe your blood is too!

ISBT THE INTERNATIONAL SOCIETY OF BLOOD TRANSFUSION

If the International Rare Donor Program is new to you, please read this brochure. It explains what the Program does and why finding rare donors is such an important mission for all involved with the Program.

The Internal Rare Blood Donor Program assists in finding matching rare blood for patients with specific needs. People with rare blood depend on each other You should be listed in the program.

To understand why rare blood donors are so important, it helps to know why certain blood types are rarer than others.

ABOUT RARE BLOOD

Your blood contains red blood cells, and on the surface of those cells are protein substances called "antigens". Your red blood cells may carry many different antigens that are inherited. Whether you have a certain blood type depends on whether or not your red cells have a particular antigen.

There are more than 600 antigens known today, and more are discovered each year. The familiar antigens are those of the ABO blood type. For example. If you have A blood, your red cells are carrying the A antigen. Likewise, people with the B antigen have type B blood, people with neither the A nor the B antigen have type O blood, and those with both the A and B antigens have type AB blood.

Other antigens are less familiar, because they are found in very few people's blood. Sometimes the reverse is true. There are some antigens that most of us carry on our red cells but that a few people's red cells lack — their blood is said to be "negative" for those antigens.

Your blood type is considered rare if only one person in 500 or more people lacks the same antigens you do. If only one in 1000 or more people lack your antigen, your type is considered very rare.

Obviously, the rarer a person's blood type, the more difficult the circumstances if that person suddenly needs matched rare blood for a transfusion. The Program strives to make sure that rare blood is available for anyone in need. That's why we urge everyone with a rare blood type to join the International Rare Blood Donor Program via your local or national registry.

WHY AN INTERNATIONAL PROGRAM?

When a patient must receive rare blood for a transfusion, time is of the essence., because the blood is usually needed that day or night. Finding rare blood used to be a time-consuming ordeal. At any given hospital or blood centre, requests for rare blood were relatively infrequent, so each facility had to find rare donors on its own when the need arose.

To assist in the supply of rare blood, the International Panel of Rare Blood Donors or International Donor Panel (IDP) was established in 1965 by the ISBT. The day to day running of the IDP is assigned to the WHO International Blood Group Reference Laboratory (IBGRL) in Bristol, UK.

The role of IBGRL is to compile information on rare donors that have been identified at other centres around the world and to make this information available when rare blood is needed. In addition to the donor information the addresses of the centres and telephone, fax and e-mail addresses of contact personnel are kept up to date. Requests for rare blood can be co-ordinated by IBGRL staff when required. As of 2012, there are 5,264 donors from 56 centres in 26 countries on the Rare Donor Panel.

HOW IT WORKS

When a local blood centre or national registry is not able to provide the rare blood required for a patient, the IDP is contacted.

Program personnel search the computer database for rare donors whose blood type matches that of the patient. Once a facility with donors who have that blood type is found, the facility is asked to either send matching rare blood already on hand or to call in rare donors to donate blood. The facility that fulfils this request sends the blood to the centte or hospital that needs it.

Many request are filled within 24 hours, particularly if the blood centres have access to rare blood in frozen storage. If a rare blood donor must be called to come in to donate, time is needed to collect, test and ship the blood.

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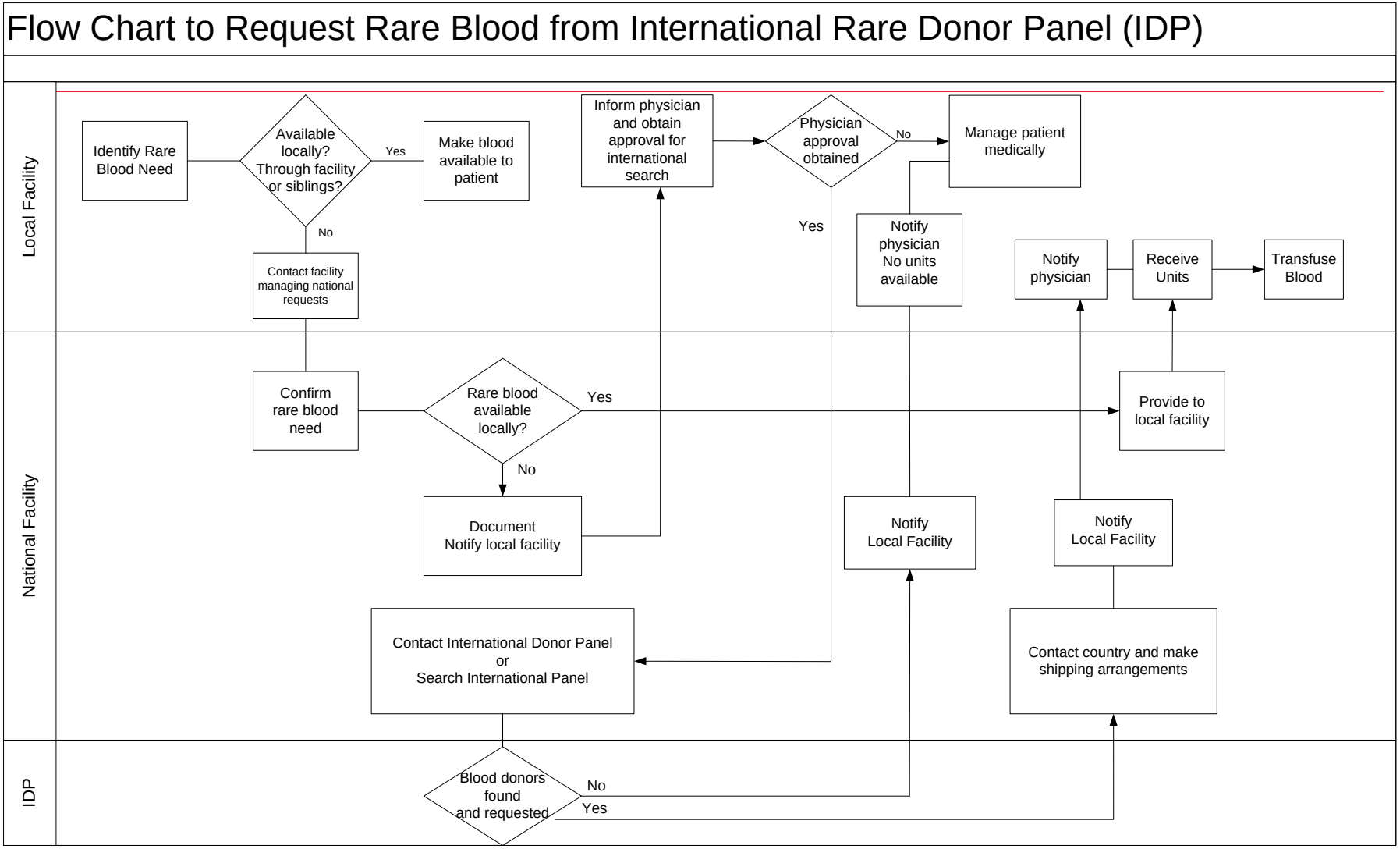
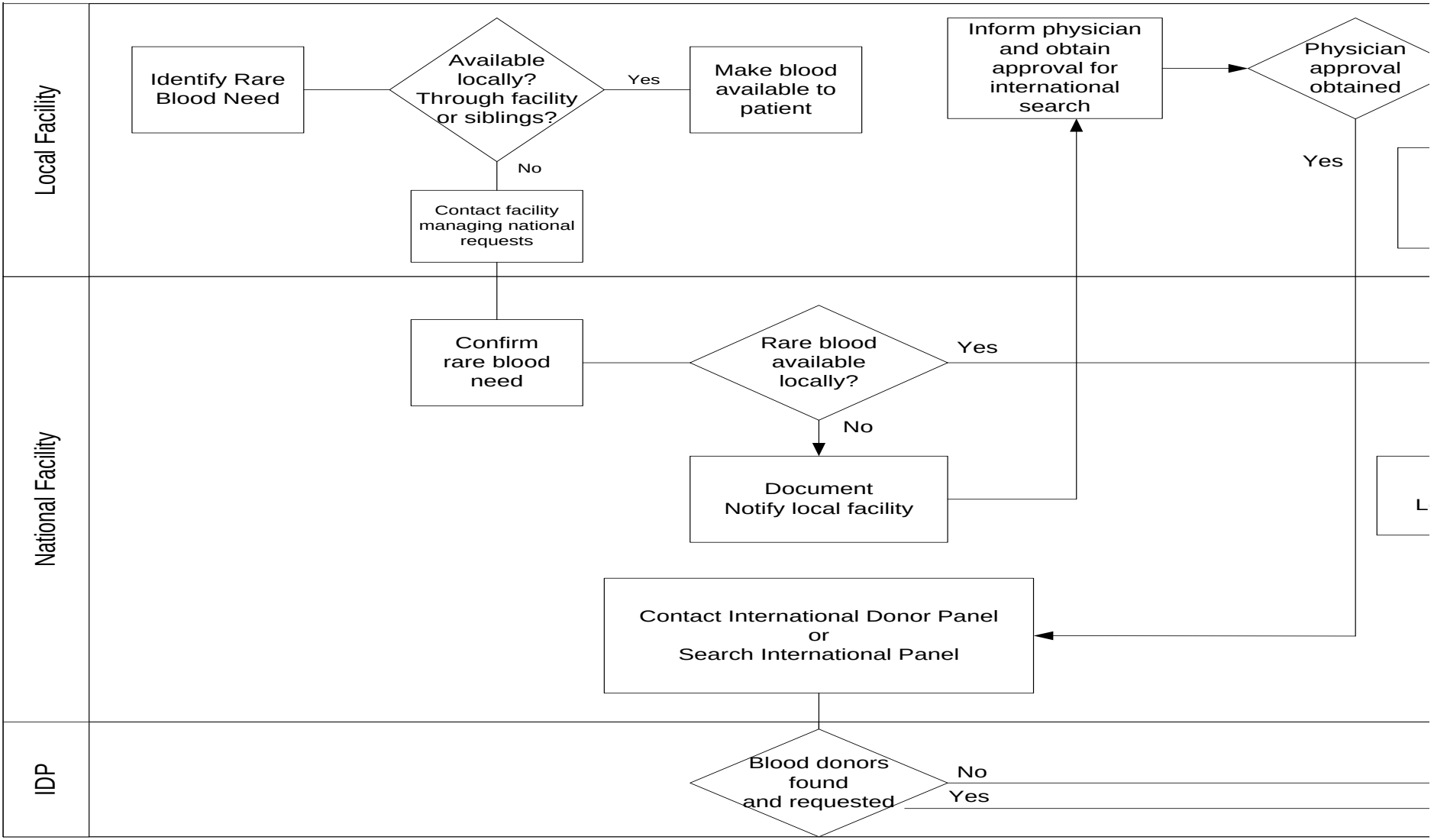
PROCESS FLOW FOR OBTAINING RARE BLOOD



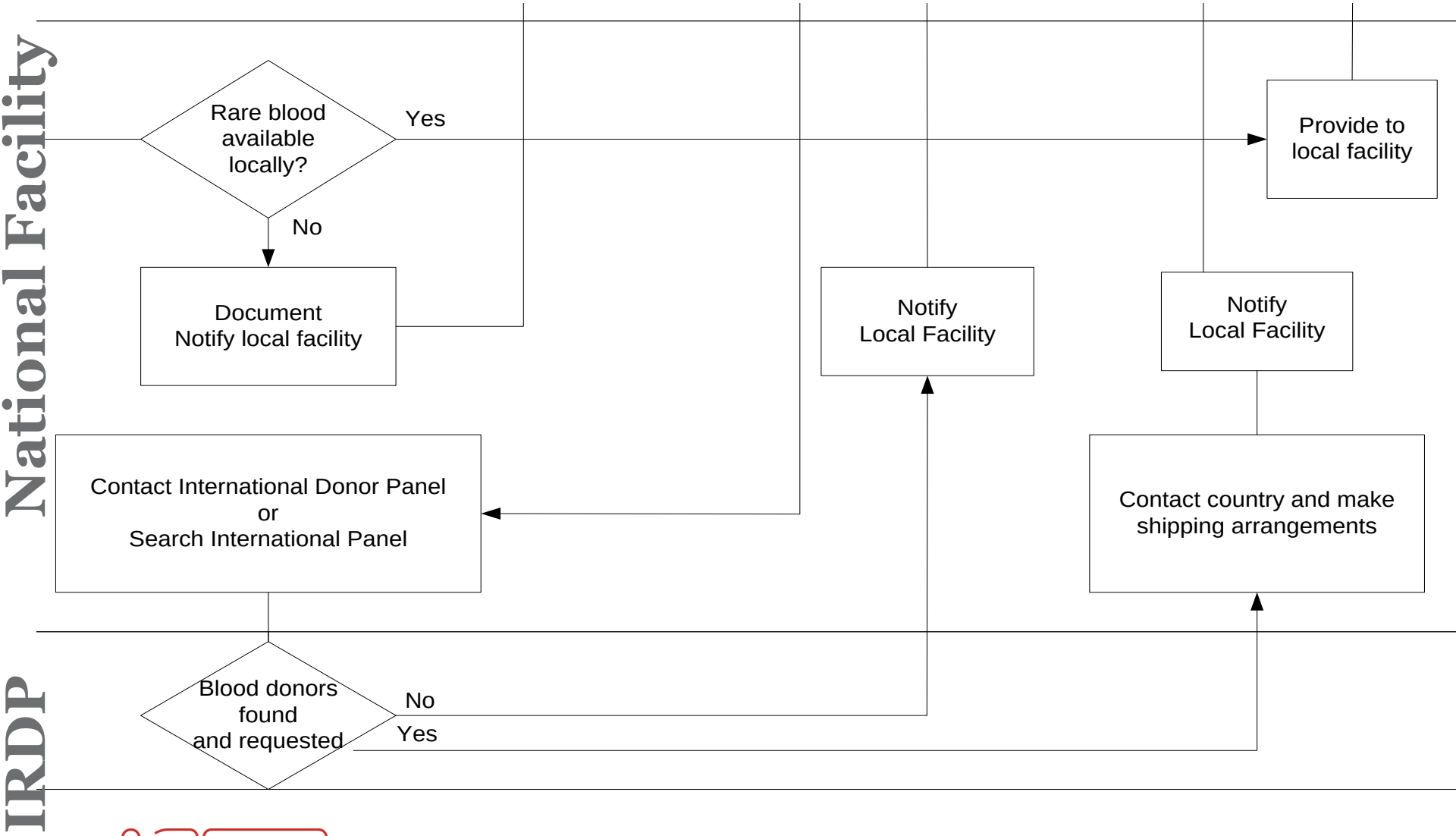
Working Party on Rare Donors

American Red Cross

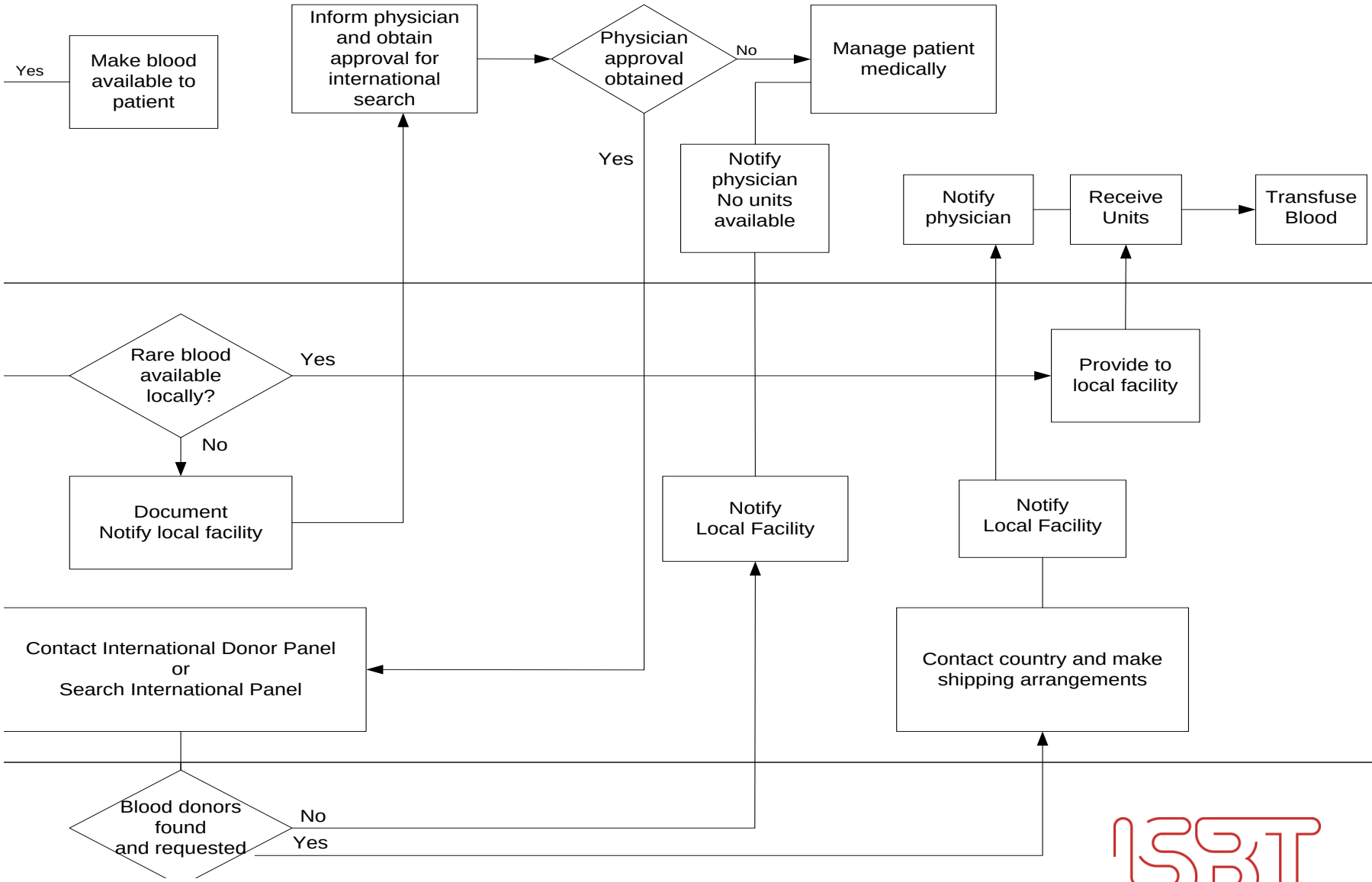
National Facility Role



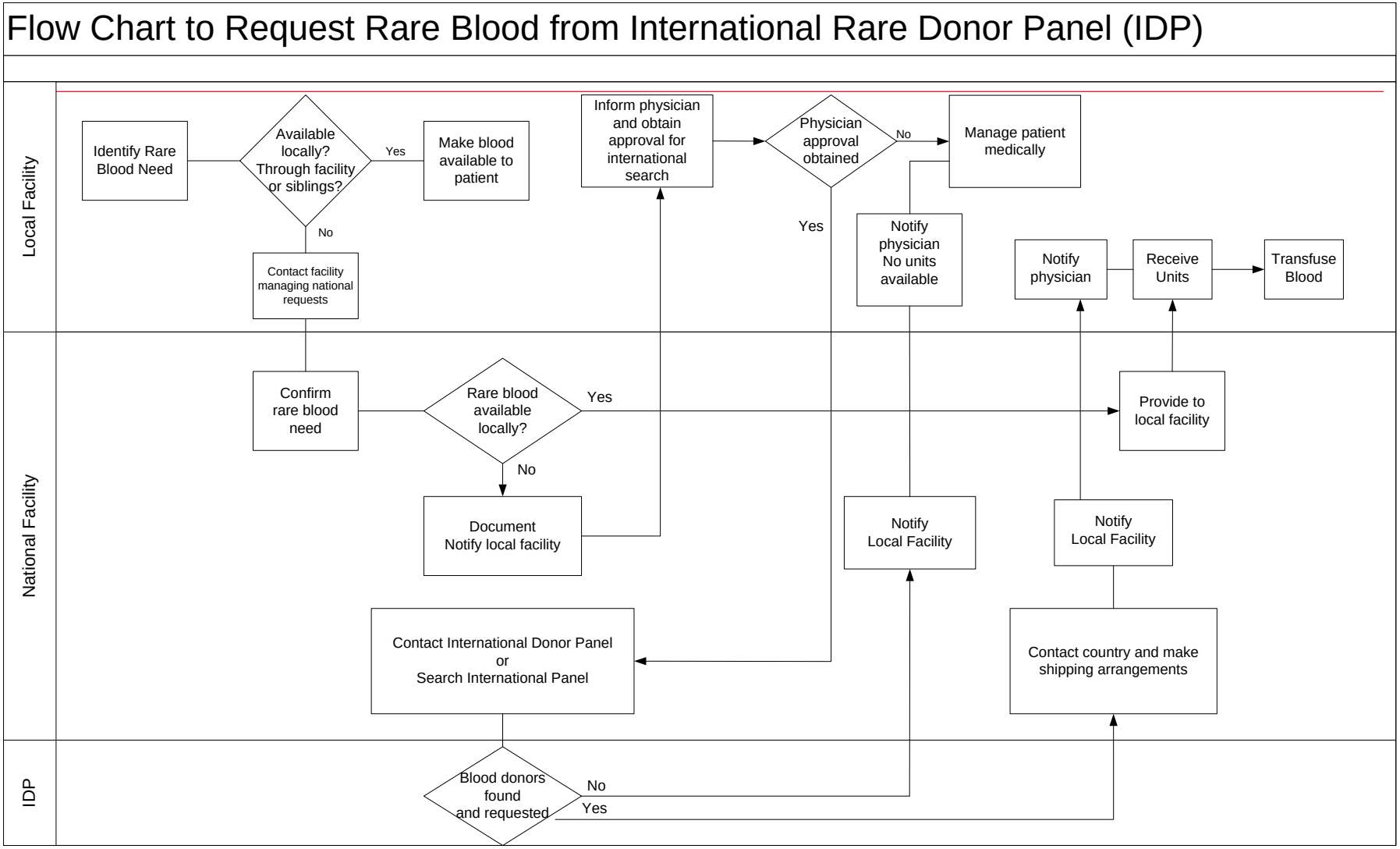
IDP Role


National Facility
IRDP
Rare blood available locally?
Yes
No
Provide to local facility
Document
Notify local facility
Notify
Local Facility
Notify
Local Facility
Contact International Donor Panel
or
Search International Panel
Contact country and make shipping arrangements
Blood donors found and requested
No
Yes

Local/National Facility Role



PROCESS FLOW FOR OBTAINING RARE BLOOD



Working Party on Rare Donors

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Rare Donors Registered

Country	# Donors		Country	#Donors
China	1300		New Zealand	54
Finland	169		Singapore	8
France	1780		South Africa	164
Germany	567		Spain	781
India	0		Switzerland	364
Iran	470		Taiwan	655
Israel	1000		The Netherlands	728
Italy	8333		UK	9000
Japan	600		USA	51,576

International Definitions of Rare Donors

Country	Definition of Rare		Country	Definition of Rare
China	1/1000		New Zealand	1/1000
Finland	Not given		Singapore	1/1000
France	1/250		South Africa	<1/100
Germany	1/1000		Spain	1/1000
India	O^h		Switzerland	Not given
Iran	1/1000, highs and lows		Taiwan	<1/1000
Israel	1/1000		The Netherlands	<1/1000
Italy	<1/1000		UK	IRDP cat +
Japan	1/100 to <1/1000		USA	<1/1000

Most Difficult Types to Source

Country	Most Difficult Types to Obtain
China	Rh_{null},; D - -
FInland	Vel neg; O_h; hr^S–
France	U- ; Fy(a–b–); Vel– ; Rh_{null} ; D - - ; Hr–; Hr^B–
Germany	Fy(a–b–); U–; Gy(a–); Hy–; Jo(a–); Js(b–); O_h, ; D- -; Rh_{null} ; K_0 ; Kx–; Jk(a–b–); Ge–; PP1Pk–; Di(b–)
India	In(a+b–); D--; Rh_{null} ; Co(a–b–)
Iran	D - -; E– c– K- Jk(b–); E–c– K– Jk(b–) Fy(b-); C– E– Jk(b–) S– M–; E– C– c– e– ; I-
Israel	$Rh_{null,}$; Jr(a–); Vel–
Italy	SC:–1; LW(a–b–); K_0; Jk(a–b–); Lan–; I–; P–; P^k–; Jr(a–); S–s–U–; hr^B–; Di(a+b–); Hy–; Jo(a–); Kp(b–); Js(b–)
Japan	D--; $PP1P^k$–; I–; En(a–); Ge–
New Zealand	K_0
Singapore	Di(b–)
South Africa	Ge–; Lan–; Jk(a-b-), Lu:–5; $PP1P^k$–
Spain	K_0; McLeod; Co(a–b–); GE:–2,–3; Rh_{null}; RH:–17; GE:–2; Cr(a–); LW(a–); In(b–); SC:–1; At(a–); Lan-; RH:–46; Jk(a-b-): P–; I– ; U–
Switzerland	Lan–; Jr(a–); U–; Rh_{null}; K_0; O_h
Taiwan	Di(b–); Rh_{null}
The Netherlands	D– U–; K_0; Rh_{null}; Di(b–); Multiple antibodies & rare phenotype{(e.g. Fy(a–b–)}
USA	E– hr^S–; SC:–1,–2; At(a–); Lan–; I–; Jr(a–); $PP1P^k$–; E– hr^B–

Most Difficult Types to Source

Country	Most Difficult Types to Obtain
China	Rh_{null}; D - -
FInland	Vel neg; O_h; hr^S–
France	U- ; Fy(a–b–); Vel– ; Rh_{null} ; D - - ; Hr–; Hr^B–
Germany	Fy(a–b–); U–; Gy(a–); Hy–; Jo(a–); Js(b–); O_h, ; D- -; Rh_{null} ; K_0 ; Kx–; Jk(a–b–); Ge–; PP1Pk–; Di(b–)
India	In(a+b–); D-–; Rh_{null} ; Co(a–b–)
Iran	D - -; E– c– K- Jk(b–); E–c– K– Jk(b–) Fy(b-); C– E– Jk(b–) S– M–; E– C– c– e– ; I-
Israel	$Rh_{null,}$; Jr(a–); Vel–
Italy	SC:–1; LW(a–b–); K_0; Jk(a–b–); Lan–; I–; P–; P^k–; Jr(a–); S–s–U–; hr^B–; Di(a+b–); Hy–; Jo(a–); Kp(b–); Js(b–)
Japan	D--; $PP1P^k$–; I–; En(a–); Ge–
New Zealand	K_0
Singapore	Di(b–)
South Africa	Ge–; Lan–; Jk(a-b-), Lu:–5; $PP1P^k$–
Spain	K_0; McLeod; Co(a–b–); GE:–2,–3; Rh_{null}; RH:–17; GE:–2; Cr(a–); LW(a–); In(b–); SC:–1; At(a–); Lan–; RH:–46; Jk(a-b-): P–; I– ; U–
Switzerland	Lan–; Jr(a–); U–; Rh_{null}; K_0; O_h
Taiwan	Di(b–); Rh_{null}
The Netherlands	D– U–; K_0; Rh_{null}; Di(b–); Multiple antibodies & rare phenotype{(e.g. Fy(a–b–)}
USA	E– hr^S–; SC:–1,–2; At(a–); Lan–; I–; Jr(a–); $PP1P^k$–; E– hr^B–

Rh_{null} listed in 9 countries

American Red Cross

Rh_{null} Donors listed in International Rare Donor Program

- South Africa - 1
- Japan - 2
- France - 2
- Finland - 1
- Australia - 1 (donor difficult to locate when needed)
- America - 1
- Northern Ireland - 1

- Brazil has an Rh_{null} donor who is not currently listed but is being actively recruited

American Red Cross

Most Difficult Types to Source

Country	Most Difficult Types to Obtain
China	Rh_{null}; D - -
FInland	Vel neg; O_h; hr^S–
France	U- ; Fy(a–b–); Vel– ; Rh_{null} ; D - - ; Hr–; Hr^B–
Germany	Fy(a–b–); U–; Gy(a–); Hy–; Jo(a–); Js(b–); O_h ; D- -; Rh_{null} ; K_0 ; Kx–; Jk(a–b–); Ge–; PP1Pk–; Di(b–)
India	In(a+b–); D--; Rh_{null} ; Co(a–b–)
Iran	D - -; E– c– K- Jk(b–); E–c– K– Jk(b–) Fy(b-); C– E– Jk(b–) S– M–; E– C– c– e– ; I-
Israel	$Rh_{null,}$; Jr(a–); Vel–
Italy	SC:–1; LW(a–b–); K_0; Jk(a–b–); Lan–; I–; P–; P^k–; Jr(a–); S–s–U–; hr^B–; Di(a+b–); Hy–; Jo(a–); Kp(b–); Js(b–)
Japan	D--; $PP1P^k$–; I–; En(a–); Ge–
New Zealand	K_0
Singapore	Di(b–)
South Africa	Ge–; Lan–; Jk(a-b-), Lu:–5; $PP1P^k$–
Spain	K_0; McLeod; Co(a–b–); GE:–2,–3; Rh_{null}; RH:–17; GE:–2; Cr(a–); LW(a–); In(b–); SC:–1; At(a–); Lan-; RH:–46; Jk(a-b-): P–; I– ; U–
Switzerland	Lan–; Jr(a–); U–; Rh_{null}; K_0; O_h
Taiwan	Di(b–); Rh_{null}
The Netherlands	D– U–; K_0; Rh_{null}; Di(b–); Multiple antibodies & rare phenotype{(e.g. Fy(a–b–)}
USA	E– hr^S–; SC:–1,–2; At(a–); Lan–; I–; Jr(a–); $PP1P^k$–; E– hr^B–

D - - listed in 6 countries

American Red Cross

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Country	Most Difficult Types to Obtain
China	Rh_{null},; D - -
FInland	Vel neg; O_h; hr^S–
France	U- ; Fy(a–b–); Vel– ; Rh_{null} ; D - - ; Hr–; Hr^B–
Germany	Fy(a–b–); U–; Gy(a–); Hy–; Jo(a–); Js(b–); O_h, ; D- -; Rh_{null} ; K_0 ; Kx–; Jk(a–b–); Ge–; PP1Pk–; Di(b–)
India	In(a+b–); D--; Rh_{null} ; Co(a–b–)
Iran	D - -; E– c– K- Jk(b–); E–c– K– Jk(b–) Fy(b-); C– E– Jk(b–) S– M–; E– C– c– e– ; I-
Israel	$Rh_{null,}$; Jr(a–); Vel–
Italy	SC:–1; LW(a–b–); K_0; Jk(a–b–); Lan–; I–; P–; P^k–; Jr(a–); S–s–U–; hr^B–; Di(a+b–); Hy–; Jo(a–); Kp(b–); Js(b–)
Japan	D--; PP1P^k–; I–; En(a–); Ge–
New Zealand	K_0
Singapore	Di(b–)
South Africa	Ge–; Lan–; Jk(a-b-), Lu:–5; PP1P^k–
Spain	K_0; McLeod; Co(a–b–); GE:–2,–3; Rh_{null}; RH:–17; GE:–2; Cr(a–); LW(a–); In(b–); SC:–1; At(a–); Lan-; RH:–46; Jk(a-b-): P–; I– ; U–
Switzerland	Lan–; Jr(a–); U–; Rh_{null}; K_0; O_h
Taiwan	Di(b–); Rh_{null}
The Netherlands	D– U–; K_0; Rh_{null}; Di(b–); Multiple antibodies & rare phenotype{(e.g. Fy(a–b–)}
USA	E– hr^S–; SC:–1,–2; At(a–); Lan–; I–; Jr(a–); PP1P^k–; E– hr^B–

U- listed in 6 countries

American Red Cross

Most Difficult Types to Source

Country	Most Difficult Types to Obtain
China	Rh_{null},; D - -
FInland	Vel neg; O_h; hr^S–
France	U- ; Fy(a–b–); Vel– ; Rh_{null} ; D - - ; Hr–; Hr^B–
Germany	Fy(a–b–); U–; Gy(a–); Hy–; Jo(a–); Js(b–); O_h, ; D- -; Rh_{null} ; K_0 ; Kx–; Jk(a–b–); Ge–; PP1Pk–; Di(b–)
India	In(a+b–); D--; Rh_{null} ; Co(a–b–)
Iran	D - -; E– c– K- Jk(b–); E–c– K– Jk(b–) Fy(b-); C– E– Jk(b–) S– M–; E– C– c– e– ; I-
Israel	$Rh_{null,}$; Jr(a–); Vel–
Italy	SC:–1; LW(a–b–); K_0; Jk(a–b–); Lan–; I–; P–; P^k–; Jr(a–); S–s–U–; hr^B–; Di(a+b–); Hy–; Jo(a–); Kp(b–); Js(b–)
Japan	D –; $PP1P^k$–; I–; En(a–); Ge–
New Zealand	K_0
Singapore	Di(b–)
South Africa	Ge–; Lan–; Jk(a-b-), Lu:–5; $PP1P^k$–
Spain	K_0; McLeod; Co(a–b–); GE:–2,–3; Rh_{null}; RH:–17; GE:–2; Cr(a–); LW(a–); In(b–); SC:–1; At(a–); Lan-; RH:–46; Jk(a-b-): P–; I– ; U–
Switzerland	Lan–; Jr(a–); U–; Rh_{null}; K_0; O_h
Taiwan	Di(b–); Rh_{null}
The Netherlands	D– J–; K_0; Rh_{null}; Di(b–); Multiple antibodies & rare phenotype{(e.g. Fy(a–b–)}
USA	E– hr^S–; SC:–1,–2; At(a–); Lan–; I–; Jr(a–); $PP1P^k$–; E– hr^B–

K_0 listed in 6 countries

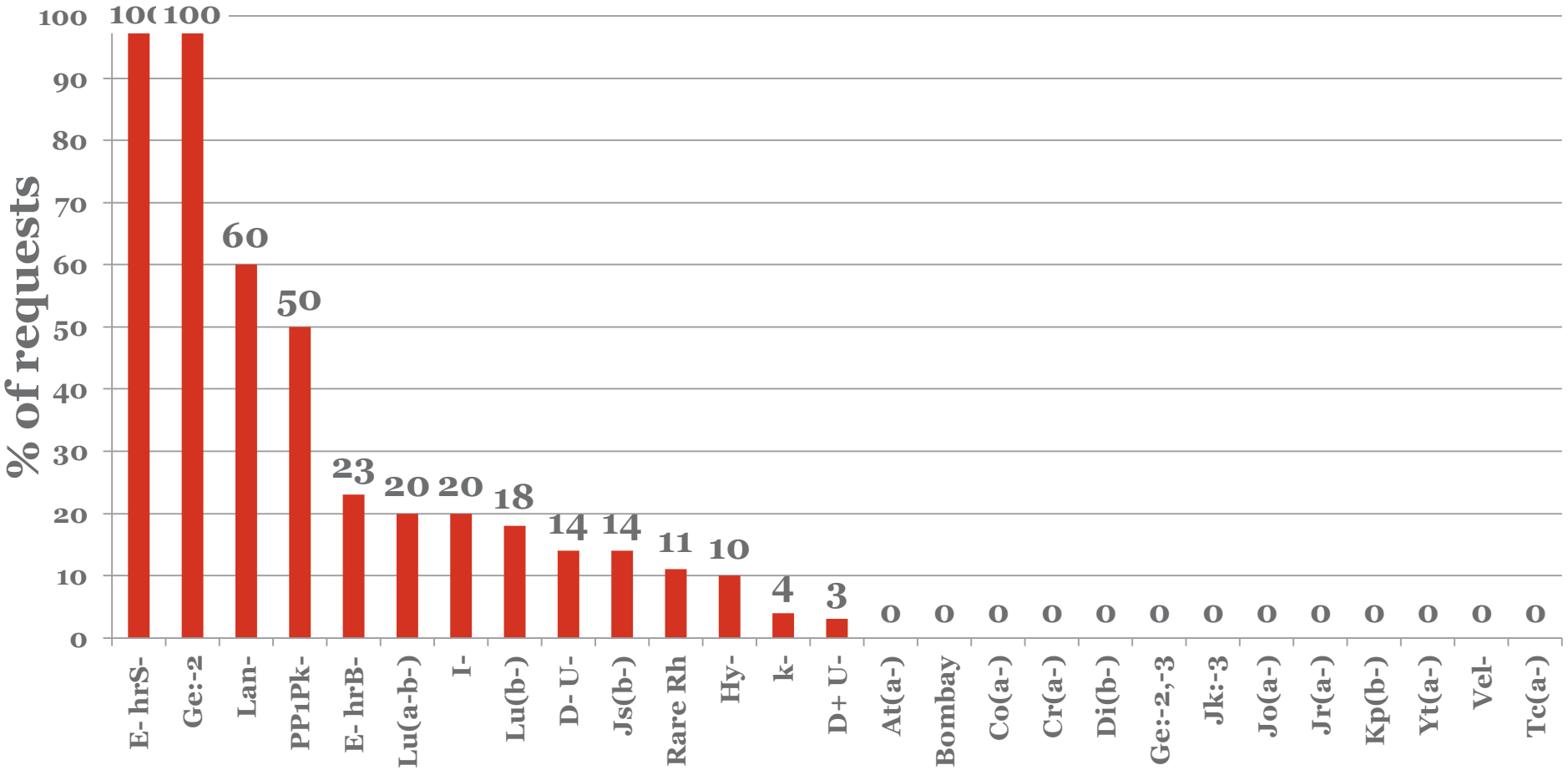
American Red Cross

Table 1 Rare blood types that are challenging to find in different countries

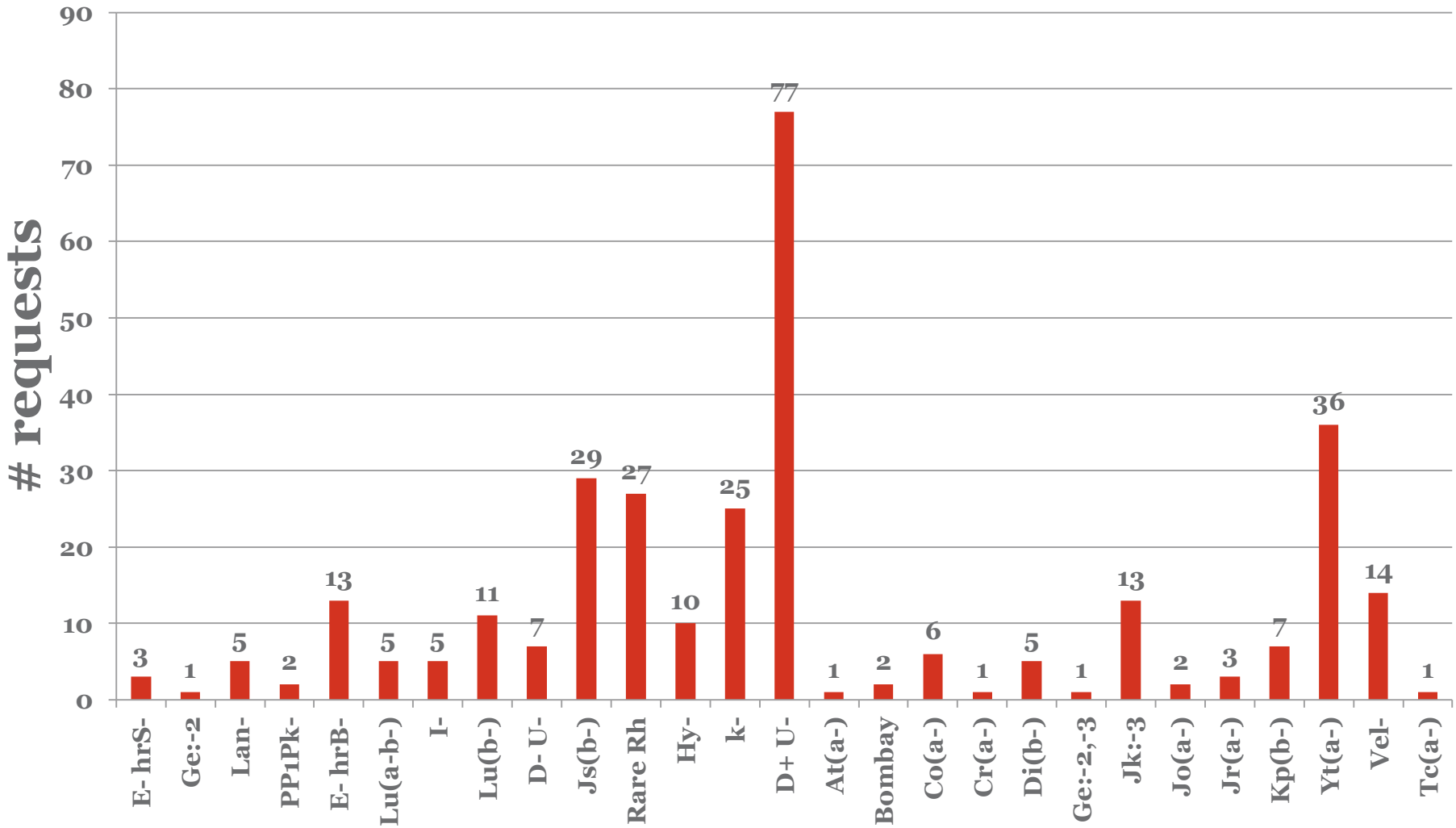
Country	Challenging type to obtain
Austria	Rare Rh phenotypes with antibodies to high-prevalence antigens and other common antibodies
Brazil (Sao Paulo)	McLeod, Ko, Lan−, U−, RH29−, RH17−
Finland	Vel−, Ge: −2
France	U− D−, Hr^S−, Hr^B−, Js(b−), R^N/R^N, Rh_{null}, Jr(a−), Co(a−b−)
Germany	Fy(a−b−), In(b−), Ge:−2, −3, U−
China (Hong Kong)	Di(b−), Fy(a−b−), Jk:−3
Oman and India	D- -, In(b−), Co(a−b−)
Israel	p, Jr(a−), O^h, Ko, U−, Vel− Lan−
Italy (Milan)	Sc:−1, LW(a−), Ko, Jk:−3, U−, Di(b−), I−
Japan	En(a−), M^kM^k, U−, Gy(a−)
The Netherlands	U− D−, Fy(a−b−), Lu(a−b−) D−, At(a−), Cr(a−)
New Zealand	D- -, Ko, McLeod, p, Ge:−2, Js(b−), U−
Spain (Navarra)	Yt(a−), Co(a−), Js(b−), Lan−, Ge−, I−, Jr(a−), Br−
Switzerland	Kp(b−), Vel−, P^k, Jk:−3, D- -, Ko, Lan−
United Kingdom	Rh_{null}, Sc:−1, $P_1{}^k$, Ge:−2, −3, D- -, McLeod, U−
United States	At(a−), En(a−), Hy−, Ko, Cr(a−), Ge:−2, In(b−), Lan−, Di(b−)Ge:−2, Jk:−3, Lu(a−b−), hr^S− E−, Gy−, K:−2 Vel−, Wes(b−), especially when in combination with antibodies to other common antigens

Table from SNance, Vox Sang Science Series 2009

American Rare Donor Program
% Unfilled Requests 2012



American Rare Donor Program
Unfilled Requests 2012



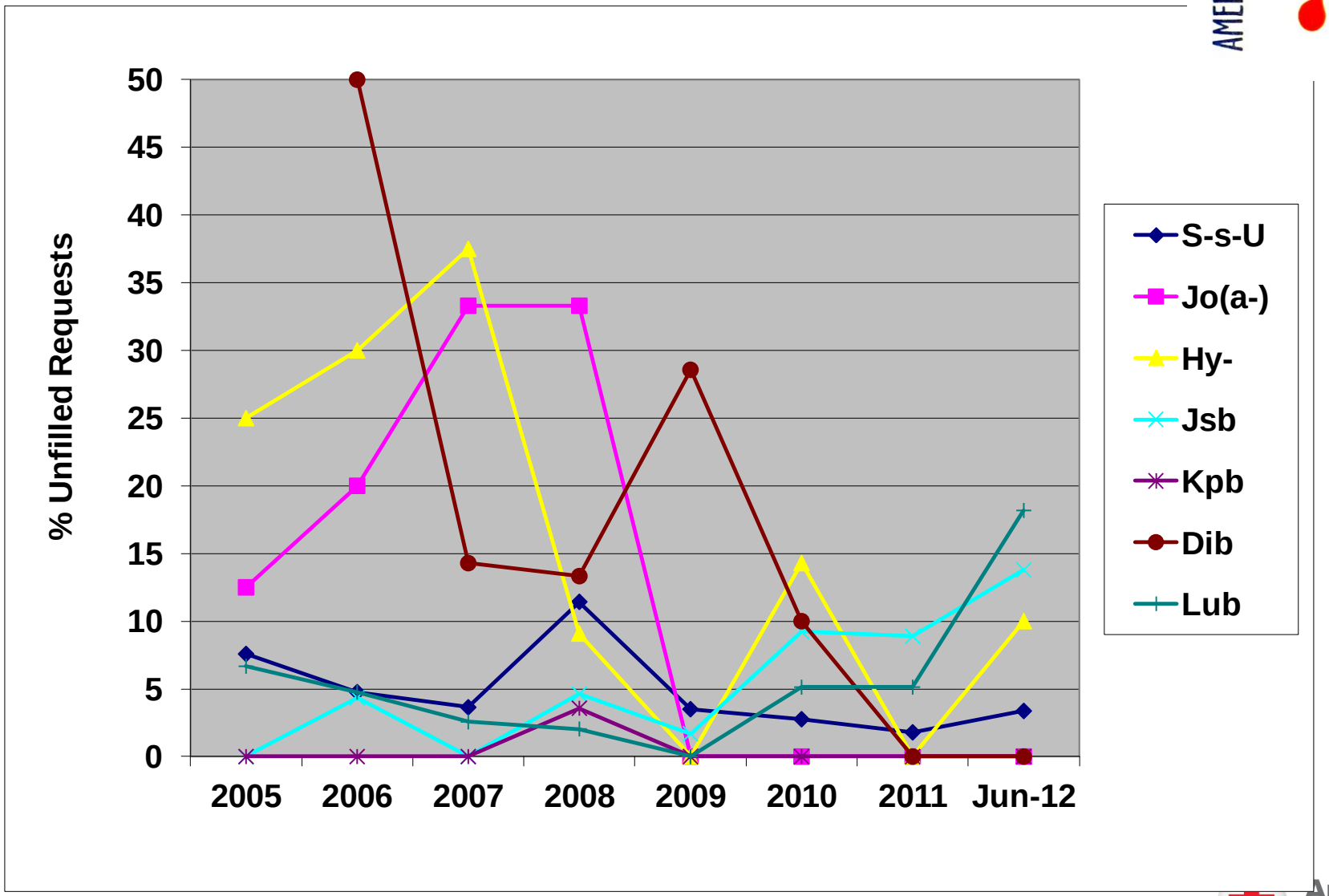
How have Molecular Platforms Helped?

Blood Group	High Prevalence Variant	HEA BeadChip	ProgenikaIDCore XT
Cartwright	Yt^a		1
Colton	Co^a	1	1
Cromer	Cr^a		
Diego	Di^b	1	1
Dombrock	Hy	1	1
	Jo^a	1	1
Scianna	Sc1	1	
Lutheran	Lu^b	1	1
LW	LW^a	1	
MNS	S-s-U-	1	1

American Red Cross

American Rare Donor Program

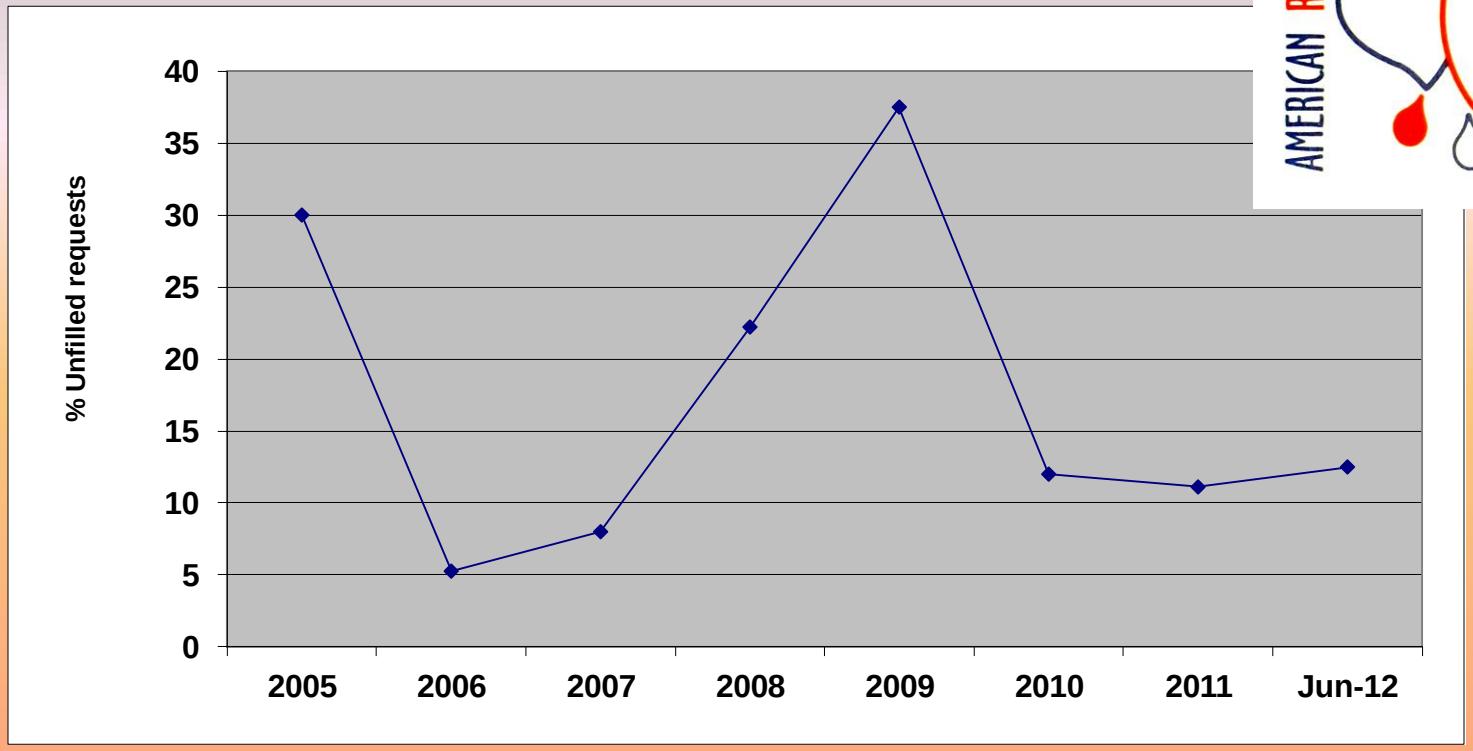
Impact of Molecular Screening Platforms on Filling Rare Requests



Data from Cynthia Flickinger, ARDP

American Red Cross

↓ % Unfilled Requests for hr^{B}-



# unfilled requests	3	1	2	4	9	3	2	1
# requests	10	19	25	18	24	25	18	8

Since 2009, all units provided have been molecularly matched

The need is constant.
The gratification is instant.
Give blood. ™

Slide from Cynthia Flickinger, ARDP

American Red Cross

And its not just an anti-hr^{B}…..

- **Of the 40 patients requiring hr^{B}- units:**

1 required K- Fy(b-) S-	1 required K- Jk(b-) V-	1 required K- Fy(a-b-) s-
5 required D-	1 required K- Jk(b-) S-	2 required K- Fy(a-b-) S-
2 required K-	1 required K- Fy(a-) Jk(b-) s-	1 required Fy(a-b-)
1 required D- S-	1 required K- V-	1 required Fy(a-) Jk(b-) S-
1 required K- Fy(a-)	1 required K- Fy(a-b-) Jk(b-)	1 required K- Jk(b-)
1 required D- K- Fy(a-) S-	1 required K- Fy(a-) S-	1 required K- Fy(a-) S- C^{w}-
1 required Fy(a-)	1 required D- K- Fy(a-b-) Jk(b-) S-	1 required K- Fy(a-) Jk(b-) S- C^{w}- Js(a-)

Working Party on Rare Donors
Terms of Reference

- To maintain guidelines for standardisation of listing, shipping, testing and re-imbursement for blood from rare donors.
- To provide a resource for providing on-going information on matters related to rare blood.
- To develop and extend the liaison with the International Blood Group Reference Laboratory (Bristol, England), and thus assist blood services internationally to be aware of, and contribute to, the International Rare Donor Panel.
- To have broad international representation on the Working Party with regular review of membership on the Working Party.

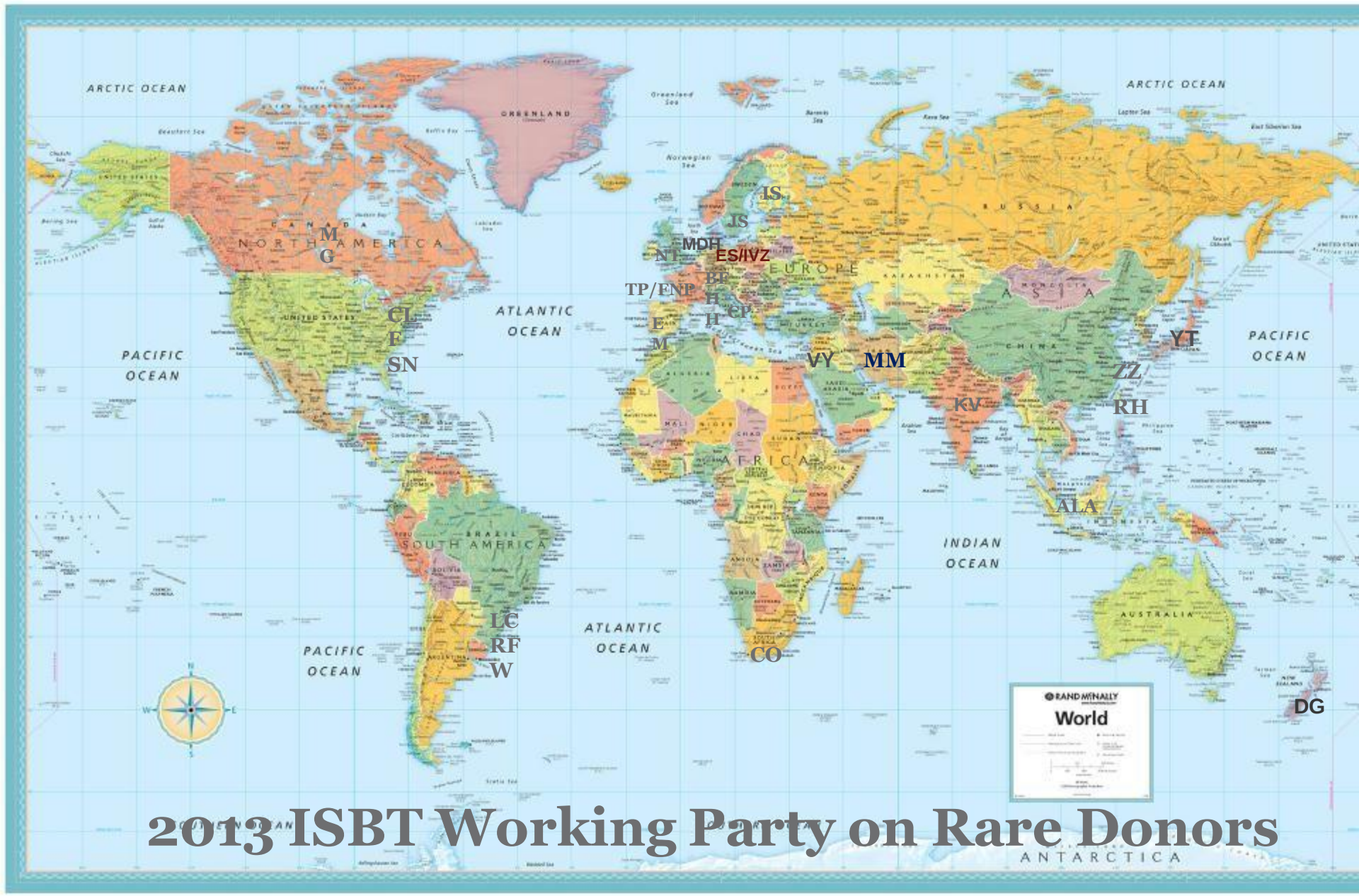
American Red Cross

ISBT Working Party on Rare Donors 2013

Sandra Nance	Chair	USA
Christine Lomas Francis	Vice Chair	USA
Erwin A. Scharberg	Secretary	Germany
Vered Yahalom	Treasurer	Israel
Graeme Woodfield	Past Chr	New Zealand

Members:

Ai Leen Ang	Singapore
Lilian Castilho	Brazil
Masja De Haas	Netherlands
Rita Fontão-Wendel	Brazil
Beat Frey	Switzerland
Mindy Goldman	Canada
Dhana Gounder	New Zealand
Richard Hung	Taiwan
Hein Hustinx	Switzerland
Mostafa Moghaddam	Iran
Eduardo Muniz-Diaz	Spain
France Noizat-Pirenne	France
Coral Olsen	South Africa
Cinzia Paccapelo	Italy
Thierry Peyrard	France
Inna Sareneva	Finland
Jill Storry	Sweden
Yoshihiko Tani	Japan
Nicole Thornton	UK
K Vasantha	India
Inge Von Zabern	Germany
Ziyan Zhu	China



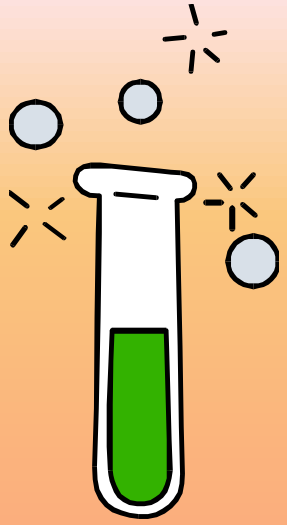
2013 ISBT Working Party on Rare Donors

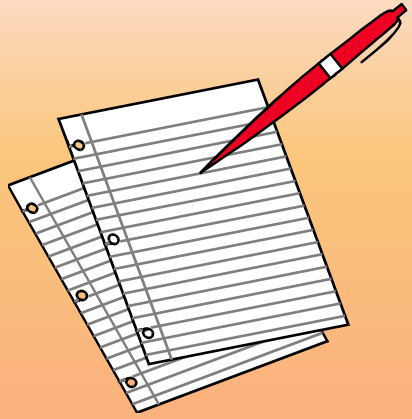
21 Countries - 26 Members

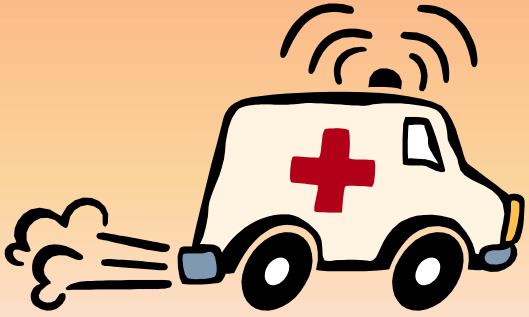
Working Party on Rare Donors

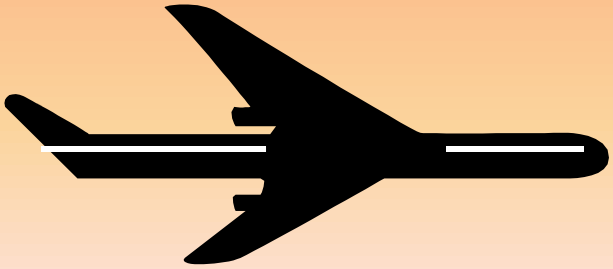
ISBT Working Party on Rare Donors Meeting in Cancun 2012

Rare Donor Working Party









Slide “borrowed” from Joyce Poole

From Joyce Poole and added to by S Nance

Dank Je (Thank You)!!

Thank you to all the wonderful people in centers all over the world who strive to make rare blood available any time of day or night when there is a need and who come in early, stay late, come in on weekends and in the middle of the night to ensure antibody identifications or blood shipments are done effectively and efficiently to get blood to patients all over the globe!!

American Red Cross