



## ISBT Working Party on Rare Donors

The ISBT Working Party on Rare Donors has 22 members from 18 countries. The members are their country's representatives and they have active Rare Donor Programs. The overall objective of the Working Party is to provide a mechanism for collaboration between countries to enable provision of rare blood products to the patients who need them. The Specific Terms of Reference are:

- To maintain guidelines for standardisation of listing, shipping, testing and re-imburement 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.

The membership composition is as follows:

- Membership is open to any ISBT member who has a particular interest in rare blood matters and has demonstrated expertise or special experience in the subject.
- Nominations for membership will be made from two W/P members, and confirmed at a formal meeting of the Working Party by majority vote or by email vote.
- Before nomination of a new member, nominators should discuss the nomination with the Chairman of the Working Party who has a responsibility to ensure that as many areas of the world are represented as possible and to avoid over representation from any country or continent.
- Member shall represent their country and be employed in a centre with an active Rare Donor Program

The International Rare Donor Panel database is primarily made up of donors from the countries represented on the Working Party. Thus, it is important that countries with active Rare Donor Programs are members of the Working Party. The focus of the last few years was to include such countries so that several new countries were added recently (Canada, Finland, India, Iran, Italy, Singapore and Spain). Another recent action has been to include members whose country is striving to locate and store blood from Rare Donors. This was encouraged by the past Chair of the Working Party, Dr Graeme Woodfield,

and taken to heart by the Executive Committee of the Working Party. The current members are listed in Table 1. And by initials, these members are represented on the map in Figure 1.

The Working Party on Rare Donors met at the 2012 ISBT Congress. The normal business agenda was discussed and in addition all attending members presented information on their countries' Rare Donor Programs and activities. The full presentations from each country are posted on the Rare Donor Working Party page of the ISBT website. Table 2 summarizes the number of rare donors reported for each country in the presentations.

The most important activity of the International Rare Donor Panel is to make rare donors available for patients who need them. Even the best inventories may lack certain types, especially if ABO types are different from those of the available donors and if antibodies to other common antigens are present. The countries reported that the types listed in Table 3 are most difficult to find.

The Working Party also made the most of the Program that was presented in the main Congress session in showing the activities of a national program (South Africa), regionally organized programs working together to provide rare donor blood for the country (Spain), a Rare Donor program just starting (Iran) and a review of the International Rare Donor Panel activities for 2011 and 2012. The program was well received and a number of people from countries initiating Rare Donor Program were in attendance and asked questions.

The ISBT Working Party on Rare Donors is a vibrant group, as seen in Figure 2, eager to assure that each patient who needs rare blood is able to receive it. This activity recognizes no political boundaries and thus is all for the common good of patients around the world. The Working Party would like to honour the dedication of Ms Joyce Poole who has worked tirelessly in the administration of the International Rare Donor Panel on behalf of WHO. Ms Poole retired in July 2012 after nearly 50 years of dedicated service to patients. The Working Party would also like to thank all those centres and their staff who make differences every day in the lives of patients!!

Sandra J Nance, Chair, Working Party on Rare Donors

Christine Lomas Francis, Secretary, Working Party on Rare Donors

Table 1 – Working Party on Rare Donors Members

Sandra Nance	Chair	USA	Mostafa Moghaddam	Iran
Vacant	Vice Chair	TBD	Eduardo Muniz-Diaz	Spain
Christine Lomas Francis	Secretary	USA	France Noizat-Pirenne	France
Vacant	Treasurer	TBD	Coral Olsen	South Africa
Members:			Cinzia Paccapelo	Italy
Ai Leen Ang		Singapore	Philippe Rouger	France
Masja De Haas		Netherlands	Inna Sareneva	Finland
Rita Fontão-Wendel		Brazil	Erwin Andreas Scharberg	Germany
Beat Frey		Switzerland	Yoshihiko Tani	Japan
Mindy Goldman		Canada	K Vasantha	India
Dhana Gounder		New Zealand	Inge Von Zabern	Germany
Richard Hung		Taiwan	Vered Yahalom	Israel
Hein Hustinx		Switzerland	Ziyang Zhu	China

Table 2 Number of rare donors registered per country.

<b>Country</b>	<b># Donors</b>		<b>Country</b>	<b>#Donors</b>
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

Table 3 Most difficult types to find per country

Country	Most Difficult Types to Obtain
China	Rh <sub>null</sub> , D - -
Finland	Vel neg; O <sub>h</sub> ; hr <sup>S</sup> -
France	U- ; Fy(a-b-); Vel- ; Rh <sub>null</sub> ; D - - ; Hr-; Hr <sup>B</sup> -
Germany	Fy(a-b-), U-, Gy(a-), Hy-, Jo(a-), Js(b-), O <sub>h</sub> , D- -, Rh <sub>null</sub> , K <sub>null</sub> , Kx-, Jk(a-b-), Ge-, PP1Pk-, Di(b-)
India	In(a+b-), D--/D--; Rh <sub>null</sub> ; Co(a-b-)
Iran	E- c- Jk(b-); E-c- K- Jk(b-); C- E- Jk(b-) S- M-; E- C- c- e-
Israel	Rh <sub>null</sub> , Jr(a-), Vel-
Italy	SC:-1; LW(a-b-); K <sub>0</sub> ; Jk(a-b-); Lan-; I-; P-; P <sup>k</sup> -; Jr(a-); S-s-U-; hr <sup>B</sup> -; Di(a+b-); Hy-; Jo(a-); Kp(b-); Js(b-)
Japan	D-; PP1P <sup>k</sup> -; I-; En(a-); Ge-
New Zealand	K <sub>0</sub>
Singapore	Di(b-)
South Africa	Ge-, Lan-, JK:-3, Lu:-5, PP1P <sup>k</sup> -
Spain	K <sub>0</sub> ; McLeod; Co(a-b-); GE:-2, -3; Rh <sub>null</sub> ; RH:-17; GE:-2; ; Cr(a-); LW(a-); In(b-); SC:-1; At(a-); Lan-; RH:-46; JK:-3; P-; I- ; U-
Switzerland	Lan-; Jr(a-); U-; Rh <sub>null</sub> ; K <sub>0</sub> ; O <sub>h</sub>
Taiwan	Di(b-); Rh <sub>null</sub>
The Netherlands	D- U-; K <sub>0</sub> ; Rh <sub>null</sub> ; Di(b-); Multiple antibodies & rare phenotype{(e.g. Fy(a-b-))}
USA	E- hr <sup>S</sup> -; SC:-1, -2; At(a-); Lan-; I-; Jr(a-); PP1P <sup>k</sup> -; E- hr <sup>B</sup> -

Figure 1 – Map representing the countries represented.



Figure 2 Photo from the 2012 ISBT International Congress Working Party on Rare Donors Meeting.

