

## Working Party On Rare Donors Report April 2013 – March 2014



### 1. Chairperson and committee

The idea for the ISBT Working Party on Rare Donors started in 1984, with the Working Party starting officially in 1985. The first Chairperson was Delores Mallory, MT(ASCP)SBB (1985 to 1994) followed by Graeme Woodfield, MD (1994 to 2004) with the current Chair as Sandra Nance, MS, MT(ASCP)SBB since 2004. The other four members of the Executive Committee are Vice-Chair, Christine Lomas-Francis, MSc, FIBMS, Secretary Erwin A. Scharberg, MD, and Treasurer Vered Yahalom, MD. The Working Party has 26 members representing 21 countries. There were four new Working Party members in 2013, three replacing retiring members and one representing a new joining country (Sweden).

### 2. Membership information

All Working Party members are required to be ISBT members and to share their country's rare donor list (by phenotype) with the International Blood Group Reference Laboratory (IBGRL) who manages the WHO International Rare Donor Panel (IRDP).

### 3. Meetings and Telephone conferences

An informal meeting for the Working Party on Rare Donors was held at the ISBT Regional Congress in Amsterdam in 2013. Eighteen members (or their delegates) and six invited guests attended. The topics included new items on the Working Party webpage, rare donor recruitment leaflet, a report by the IBGRL on the WHO IRDP, discussions with the Wellcome Trust, creating a template for international reporting of outcomes in patients receiving incompatible transfusions, creating an international rare donor card, enlarging the International Rare Donor Panel database by adding new countries to the Working Party, and updating the list by current members. Working Party members reported on their country's Rh<sub>null</sub> donors, the type reported by the most countries as difficult to supply in the 2012 Working Party meeting.

### 4. Activities during the period

Working Party members investigated and reported on the situation in their country regarding Rh<sub>null</sub> donors. Rh<sub>null</sub> donors are in high demand (as are other null phenotypes) because of their compatibility with antibodies to antigens of high prevalence, in the RH system with antibodies made by patients with variant *RHCE* and *RHD* genes that encode partial antigens. All countries prepared reports and there are only 20 known Rh<sub>null</sub> donors! China has the most, with 5 known donors followed by Brazil with four, Germany, South Africa and the USA have two each, and Finland, France, Spain, Switzerland, and the United Kingdom have one each. As this is a critical donor phenotype, a funding request for recruitment of these and other internationally rare donors was recommended and submitted for ISBT funding. It was further recommended to perform absorption/elution and molecular testing on the known Rh<sub>null</sub> donors to determine the genetic background and to ensure that they are not Rh<sub>mod</sub>. Other activities discussed and actions recommended by the Working Party were addition of a description of the Working Party to the webpage, recommendation that it be required to treat rare blood shipments like organ shipments so there are no product-threatening delays, educational program sponsored by the Working Party, development of a reporting template

and webpage on outcomes to incompatible transfusion. The last topic's concept is a way to record transfusion outcomes when incompatible red cells are transfused to assemble anecdotal experiences into a collection. Each Working Party member will make the reporting template known (and it will be posted on webpage), will receive the report, translate, anonymize it, send to the Chair for review and the Chair will arrange posting to the web page.

Respectfully Submitted,

A handwritten signature in cursive script that reads "Sandra Nance".

Sandra J. Nance