

23rd Regional Congress of the ISBT
Amsterdam, The Netherlands

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2013

ISBT Informal Meeting of the Working Party on Rare Donors

Rh_{null} Donors

Very Rare Donors



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Lilian Castilho

Hemocentro-UNICAMP,
Campinas-SP, Brazil

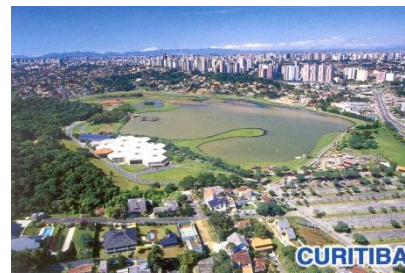




BRAZIL



- ❖ How many Rhnull donors are known in your country? 4 (2 sisters in Curitiba (South of Brazil) group A and 2 donors in Rio de Janeiro group O)
- ❖ Are these donors in a national registry or database? No, as Brazil doesn't have a national registry yet. So, we believe that we probably have more Rhnull not known in the country.





BRAZIL



- ❖ What special work is done to retain these donors or recruit them for continued donations?
- ❖ Education focusing in how rare and important they are
- ❖ Sensitization of the families. One donor in Rio donated blood to a baby of the family in Curitiba and all of them became very sensitized and realized how important is the donation.

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Mindy Goldman

CANADA

Canadian Blood
Services





CANADA

- ❖ How many Rhnul donors are known in your country? None active at present
- ❖ Are these donors in a national registry or database? They would be if we had any identified



CANADA

❖ What special work is done to retain these donors or recruit them for continued donations?

We are working on developing tools for this, at present, there is an initial letter, but not a lot of follow-up with rare donors to improve retention.

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Ziyan Zhu, MD

China

Shanghai Blood Center





China

- ❖ How many Rhnull donors are known in your country? 5
- ❖ Are these donors in a national registry or database? yes



China

❖ What special work is done to retain these donors or recruit them for continued donations? At present, the recruitment of these donors has difficulty. 2 donor always work in different provinces ,and the another one just have his heart operation 2 years before.

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Inna Sareneva

Finland

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FINLAND

❖ How many Rhnull donors are known in your country?

- ❖ One Rhnull (possible regulator) with no antibodies
 - ❖ she has donated once in 1988
 - ❖ not eligible for donation anymore

❖ Are these donors in a national registry or database?

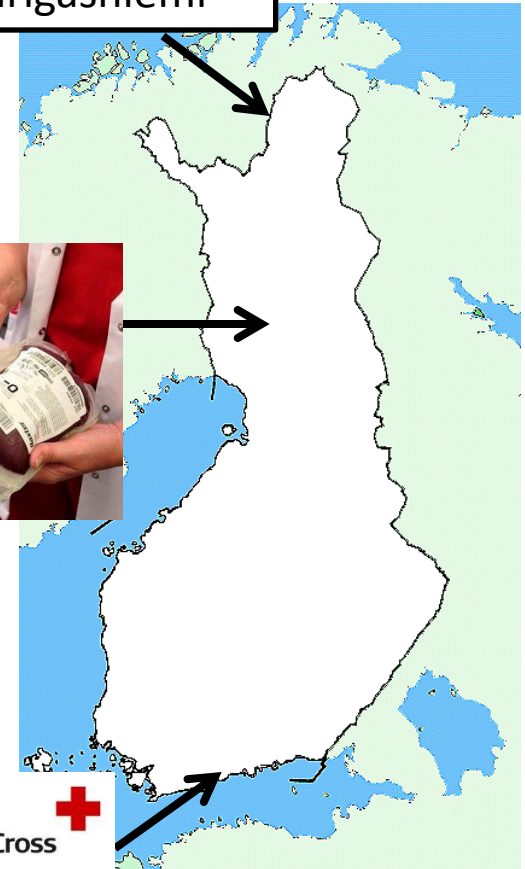
- ❖ We don't have a national registry but all data from rare donors are in our database

FINLAND

❖ What special work is done to retain these donors or recruit them for continued donations?

- ❖ She has been previously contacted many times, but donated only once
- ❖ She has a twin sister, also Rhnull phenotype, who has been eligible for donation

Karigasniemi



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Thierry PEYRARD

FRANCE

National Institute of
Blood Transfusion





FRANCE

❖ **How many Rh_{null} donors are known in your country?**

5 Rh_{null} subjects have been registered in France: 4 patients (only 2 are still alive) and 1 repeat donor.

❖ **Are these donors in a national registry or database?**

Our single Rh_{null} active donor (group A) is included in our national registry of people with a rare blood type.



FRANCE

❖ **What special work is done to retain these donors or recruit them for continued donations?**

Our single Rh_{null} donor gives blood about once a year. Since he lives in Switzerland and due to difficulties to import rare RBC units in France, we have convinced him to donate in a French city close to the Swiss borderline.



FRANCE

❖ **What special work is done to retain these donors or recruit them for continued donations?**

In France, 100% of blood donors are typed for D, C, E, c, e. This has been the case for more than 20 years, with about 400 000 new donors /year.

Despite this mass screening, no new Rh_{null} donor could be found.

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I. von Zabern¹ and A. Scharberg²

Germany

¹Institute for Clinical Transfusion
Medicine and Immunogenetics Ulm,
University of Ulm, ²German Red Cross
Blood Transfusion Service Baden-
Württemberg-Hessen, Institute Baden-
Baden





Germany

❖ How many Rhnull donors are known in your country? 2

1. A Rh_{null} by routine serological methods, by adsorption/elution DEL and c positive, by PCR positive for alleles D, C, c, e; compound heterozygous for 2 different RhAG alleles (splice site mutation and amino acid substitution at transmembraneous /intracellular border); 11 units cryopreserved



Germany

❖ How many Rhnull donors are known in your country? 2

2. A Rh_{null} by routine serological methods including indirect antiglobulin test (adsorption/elution not performed); compound heterozygous for 2 different RhAG alleles (splice site mutation and amino acid substitution at transmembraneous/intracellular border); 8 units cryopreserved



Germany

❖ Are these donors in a national registry database?

❖ No. 1 Registration

- ❖ in DGTI registry of cryopreserved units (Berne registry)
- ❖ probably in donor DGTI and IBGRL Registry in the future if donor agrees and can continue to accumulate cryopreserved units; several units have to be stored for homologous use (clinical indication)

❖ No. 2 Registration

- ❖ In DGTI registry of cryopreserved units (Berne registry)
- ❖ in donor database of Red Cross Blood Transfusion Service NSTOB



Germany

- ❖ What special work is done to retain these donors or recruit them for continued donations?
 - ❖ No 1: Donor is informed about his rare blood group and donates regularly
 - ❖ No 2: Encouragement to donate will be continued

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Mostafa Moghaddam

MA, CLS(ASCP) BB

IRAN

Iranian Blood

Transfusion Organization





Iran

❖ How many Rhnul donors are known in your country?

So far no Rhnul individual has been identified .

But there are five individuals identified as D - - Phenotype registered in the National Rare blood database

Next slide shows a table with related information

Rare Blood donor/patient identified in Iran D- - phenotype



Type of individual	ABO& Rh	Male	Female	Geographic area	Age (years)	# of frozen units	Misc
Patient /Donor	O Rh+		1	South West of Iran (City of Brojerd)	30	2	Anti-Rh 17(Hr _o) Abortion
Patient /Donor	AB Rh+		1	South East of Iran (City of Zabol)	36	0	Anti-Rh 17(Hr _o) Abortion
Patient /Donor	A Rh+		1	North West of Iran (City of Uromieh)	30	1	Anti-Rh 17(Hr _o) Abortion
Female teenager (daughter)	A Rh+		1	North East of Iran (City of Mashad)	15	0	Antibody screen test Negative
Patient (father)	O Rh+	1		North East of Iran (City of Mashad)	49	1	Kidney Transplant Candidate History of blood transfusion

Iran



❖ What special work is done to retain these donors or recruit them for continued donations?

1- Providing educational information by discussing their rare blood type and the importance of continuous donation for their own use and the patient they would be helping

2- Occasional telephone contact to remind them to donate as member of National Rare Donor Program .

As a member of National Rare Donor Program, each Rare Donor is given a personalized wooden and metal plate with their name , rare blood type and pertaining information carved on it. (sample on next slide)

3- Facilitating transportation to the blood center for blood donation. The rare donor would be taking care of as a special individual at the donor center

4- Storing frozen autologous rare blood free of charge for possible future use by the donor

5- Occasionally after several donations, the rare donor is provided with a gift card with a minimal monetary value to cover for the time off from work or any expenses (Taxi charges) he/she had to pay for meeting the appointment to donate.

Members of Iranian National Rare Donor Program receive a personalized wooden and metal plate plus a platinum necklace

Information carved on Rare Donor necklace:

Donor name – Rare blood type - Donor Center 24 hr telephone number to call during Emergency

Personalized wooden and metal plate, following information carved on it :

Rare Donor name – Rare blood type and brief information about rare blood and how to prepare for blood need before emergency situation.



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Cinzia Paccapelo

Italy

Centro Trasfusionale e
di Immunoematologia





ITALY

❖ How many Rhnull donors are known in your country?

According to a recent survey, no Rhnull active donors are known in Italy

❖ Are these donors in a national registry or database?

No



ITALY

❖ What special work is done to retain these donors or recruit them for continued donations?

Actually no special work or policy is carried out to retain or recruit these donors in Italy

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DHANA GOUNDER

New Zealand

New Zealand Blood Service





New Zealand

❖ How many Rhnull donors are known in your country? **None**

❖ Are these donors in a national registry or database? **N/A**



New Zealand

❖ What special work is done to retain these donors or recruit them for continued donations? **No active recruitment is being done**

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Dr Ang Ai Leen

Singapore

Michael Ng, presenting on
behalf of Dr Ang Ai Leen





SINGAPORE

- ❖ How many Rhnul donors are known in your country? **NIL**
- ❖ Are these donors in a national registry or database? **Not Applicable**

SINGAPORE

❖ What special work is done to retain these donors or recruit them for continued donations? **Not Applicable**



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Coral Olsen

South Africa

South African National
Blood Service





SOUTH AFRICA

- ❖ How many Rhnull donors are known in your country?
 - ❖ Currently two known donors – one Group O and one Group A.
- ❖ Are these donors in a national registry or database?
 - ❖ Yes but originate from the Western Cape of Southern Africa.



SOUTH AFRICA

- ❖ What special work is done to retain these donors or recruit them for continued donations?
- ❖ The donors are maintained by the Western Province Blood Transfusion Service. Gifts of thanks are provided in the form of one of the following:
 - ❖ Care hampers
 - ❖ Fuel reimbursement
 - ❖ Grocery vouchers

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Dr Eduardo Muñiz-Diaz

Spain

Head of the
Immunohaematology
Department
Banc de Sang i Teixits





SPAIN

❖ How many Rhnull donors are known in your country? **1**

This donor has an Rh-deficiency of the regulator type, and an antiRh29 in his plasma.

❖ Are these donors in a national registry or database?

NO.

He has a mild hemolytic anemia very well compensated, but because of the anemia he only wants to give blood in case of an urgent situation.



SPAIN

❖ What special work is done to retain these donors or recruit them for continued donations?

This donor perfectly knows about the interest of his blood and the problems we have to obtain blood with the same phenotype. However, he prefers only to be contacted when there is a patient who needs to be transfused with this kind of blood. He was contacted twice in the past with an excellent response.

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Jill Storry

Sweden

R&D Coordinator, Blood Group
Immunology, Clinical
Immunology & Transfusion
Medicine, Labmedicin Skåne





Sweden

❖ How many Rhnull donors are known in your country?

❖ None

❖ Are these donors in a national registry or database?



Sweden

- ❖ What special work is done to retain these donors or recruit them for continued donations?
 - ❖ No program

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Hein Hustinx

Switzerland





Switzerland

❖ How many Rhnull donors are known in your country?

Only one

We have about 365.000 donations a year. This means 200.000 regular donors and 35.000-40.000 new donors a year. The most of these donors are phenotyped.

Till now we have only found one -D-/-D-



Switzerland

❖ What special work is done to retain these donors or recruit them for continued donations?

I do not know. This donor donates in France.

Also our -D-/-D- donor donates in France.

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Dr. Rianne Koopman

Dr. Masja de Haas

The Netherlands

Sanquin Blood Supply





The Netherlands

- ❖ How many Rhnull donors are known in your country?
 - ❖ No Rhnull donors are known

- ❖ Are these donors in a national registry or database?
 - ❖ Not applicable



The Netherlands

- ❖ What special work is done to retain these donors or recruit them for continued donations?
 - ❖ When a patient / person comes to our attention, the person will be invited to become a donor.
 - ❖ The donor will be registered in our National Database.
 - ❖ The donors will be asked to donate at a regularly base for the Sanquin Bank of Frozen Blood.
 - ❖ Consent will be asked to approach family members for testing RhD phenotype.

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Nicole Thornton

United Kingdom

IBGRL, NHSBT





United Kingdom

- ❖ How many Rhnull donors are known in your country? 1
- ❖ Are these donors in a national registry or database? Yes (National & International Rare Donor Panel)



United Kingdom

❖ What special work is done to retain these donors or recruit them for continued donations?

❖ When a rare donor is identified they are assigned a VIP flag code in the donor database to ensure their donations are removed from the general donation pool and treated as a rare unit for freezing.

❖ The donors receive a letter explaining how unique and important they are and also given instruction about how they may be called upon in special situations to donate for particular patients, they are also asked about any possible family members who may be willing to become donors.

❖ Donors may be invited to an award ceremony as a special donor

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Sandra Nance

Christine Lomas-Francis

United States of America

American Rare Donor
Program





United States of America

- ❖ How many Rh_{null} donors are known in your country?
 - ❖ 1 group A
 - ❖ 1 group O
- ❖ Are these donors in a national registry or database?
 - ❖ Group A---ARDP
 - ❖ Group O—not registered



United States of America

❖ What special work is done to retain these donors or recruit them for continued donations?

❖ Group A donor

❖ very aware of her rare status as per her conversations with her blood collection center (Alabama ARC)

❖ donated numerous units over the years—some were autologous; some were homologous;

❖ she asked to be contacted (for permission to use her homologous units) when there were requests so that she would know the number of her available units and she would donate more; she always gave permission to use them.

❖ now rather elderly but with 3 autologous units although they are likely >10 years old. Whenever she came to the blood center to donate, the IRL manager met her personally and rolled out the red carpet—complete with lunch and special attention.



United States of America

❖ What special work is done to retain these donors or recruit them for continued donations?

❖ Group O donor

❖ aware of her own hematological condition associated with the Rh_{null} state.

❖ Donor contacted a hematologist for treatment but found that she knew more than he did about her rare condition.