

The Spanish program for rare blood donors

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The Spanish program for rare blood donors was created in 2005. Before that year, no official program existed and no government measure had been taken to create a program for providing rare blood for patients in need. To better understand the origin, history, and outcome of our program, it is necessary to understand how Spain is organized from a political and administrative point of view. Spain is divided into 17 autonomous regions, each with its own government and health care, making health care in Spain highly decentralized. The regional governments are in charge of managing their own health services and work as competent authorities as part of the National Network of Blood Establishments and Hospital Transfusion Services. The Ministry of Health, in Madrid, coordinates the functions of the whole health care structure and works as the competent authority for many responsibilities, including managing the relationship with the European Union. About 2 million blood components were transfused in Spain in 2014. All these units were collected, processed, and distributed by 24 blood transfusion centers (BTCs) and were transfused at 400 hospitals throughout the country.

For several years, four BTCs, each from a different region, had been working on the collection and the cryopreservation of red blood cells (RBCs) with rare phenotypes (Catalonia, Galicia, Madrid, and Valencia), and a fifth center (Navarra) participated by providing a list of donors with rare phenotypes. All this work was undertaken on the initiative of these BTCs, given the absence of a national policy concerning the collection, maintenance, and provision of rare blood. At that time, each center knew what units it had at its disposal, but this information was not available to the public. No one in the country knew the total number of cryopreserved units, the total number of rare blood donors, or the antigenic profiles of these units and donors. Finally, at the end of 2005, the Spanish program for rare blood donors was established, consisting of the five BTCs involved in the management of rare blood phenotypes. Additionally, the group requested the support of the Spanish Society of Blood Transfusion (SETS), who agreed

and suggested that the cooperative group should be constituted as a Working Party of SETS.

A year later, the national stock of cryopreserved units with rare blood types (consisting of 658 units) was published for the first time. Since then, this information has been updated and published every year in the SETS journal and on the Web site of our Society. The list and the phenotype profile of the 766 cryopreserved rare units of blood currently available are shown in Table 1. In addition, the program has a list of 900 rare blood donors willing to give blood in emergency cases. This list needs to be upgraded, however, to distinguish between two types of donors: (1) donors willing to give blood after being informed about their rare phenotype and (2) donors with a rare phenotype but who have not yet been informed. In practice, only the first group of donors should be included in our reports.

To make the service more workable and more uniform, a protocol for requesting rare blood units was established. This protocol includes the Requesting Form and the Receiving Form; both forms are available from the Web site of our Society. The Requesting Form consists of two parts: one part concerns the details of the requesting center and the other part deals with the details of the patient (e.g., phenotype of the RBCs requested, number of units, and the preferred mode of units requested [cryopreserved, thawed, or fresh]). The Receiving Form, inspired by the form originally designed by the Working Party on Rare Donors of the International Society of Blood Transfusion (ISBT), also consists of two parts: one concerns the shipping center and the other concerns the patient (e.g., whether or not the units arrived in perfect condition [state of the bag, temperature, etc.]). Moreover, to provide a more efficient service, each BTC is responsible for the rare RBC units requested from a certain number of autonomous regions. The BTC of reference may request a sample from the hospital whenever it considers this to be necessary. If the units are not available in Spain, the BTC of Catalonia is responsible for obtaining the units from the International Rare Donor Panel (IRDP) in Bristol, United Kingdom. Our rare units of blood

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Table 1. Inventory of cryopreserved units of rare blood in the Spanish program for rare blood donors, 2015

Phenotype	A+	A-	O+	O-	AB+	AB-	B+	B-	Total
k-	25	18	86	60	0	0	0	0	189
Lu(a+b-)	12	2	38	43	1	0	0	0	96
Fy(a-b-)	8	1	32	38	0	0	0	0	79
PP1P ^k -	17	0	32	5	1	0	19	0	74
Kp(a+b-)	12	0	15	38	0	1	0	3	69
Vel-	4	10	21	15	1	0	0	0	51
Co(a-)	5	0	25	4	0	0	0	0	34
Yt(a-)	6	3	17	6	0	0	0	0	32
r'r'	0	9	0	19	0	0	0	0	28
Jr(a-)	5	0	8	9	0	0	0	0	22
Di(b-)	0	0	16	0	0	0	2	0	18
D--	12	0	0	0	0	0	0	0	12
r''r''	0	3	0	7	0	0	0	0	10
Lan-	0	0	6	2	0	0	0	0	8
U-	0	0	6	1	0	0	0	0	7
Jk(a-b-)	0	3	0	3	1	0	0	0	7
JMH-	0	0	5	1	0	0	0	0	6
S-s-	0	0	5	0	0	1	0	0	6
R ₂ R ₂	0	0	6	0	0	0	0	0	6
Lu(a-b-)	0	0	4	0	0	0	0	0	4
O _n (Bombay)	0	0	4	0	0	0	0	0	4
r'r''	0	0	0	2	0	0	0	0	2
K ₀	0	0	0	2	0	0	0	0	2
									766

were integrated into the IRDP in 2009 when the Spanish Working Party on Rare Donors became an official member.

Regarding the activity of our program, 246 rare units of blood were supplied in the period from 2010 to 2014: 122 of these units were thawed and 124 were fresh (Table 2). Twelve of these units were distributed in response to international requests: 1 Vel- (Israel), 5 Di(b-) (Sweden), 5 Jr(a-) (4 UK and 1 Sweden), and 1 D-- (Portugal).

In the last 10 years, all requests but one were filled. The only exception was the case of a woman with an antibody directed against a high-prevalence antigen for which the specificity had not been identified before transfusion. She was transfused with RBCs from her son and suffered from a moderate hemolytic transfusion reaction. Some months later, the International Blood Group Reference Laboratory (IBGRL) of Bristol (UK) identified a new specificity directed to a new antigen termed DOLC in her blood. This antigen belongs to the Dombrock system.

At present, we have no active Rh_{null} donors, but one donor and two patients had been identified in the past as carriers of this rare phenotype. The molecular background was

investigated in one of the patients in whom a complete deletion of the *RHAG* gene was found. There are other phenotypes that are also very difficult to find in our country, such as K₀, McLeod, Co(a-b-), GE:-2, GE:-2,-3, Rh17-, Rh29-, Cr(a-), In(b-), SC:-1, and At(a-).

In summary, the creation of this Working Party on Rare Donors in Spain has led to major improvements in recent years. In the last 2 years, two new BTCs (Aragon and Basque Country) have been incorporated into the Working Party, also providing a list of blood donors with rare phenotypes. Our panel of cryopreserved units currently includes 766 units, and the list of donors with rare blood types includes 900 blood donors.

This impressive list of units and donors with rare phenotypes is the result of the great effort made by the different BTCs in the years before the creation of the Spanish Working Party. The union of all these efforts, together with the creation of the Spanish program for rare blood donors, allowed us to optimize the list of donors and units to improve the service we offer to hospitals and to patients. In recent years, our donors have shown a high level of commitment without any incentive

Table 2. Rare units of blood supplied by the Spanish program for rare blood donors, 2010–2014.

Phenotype	Cryopreserved	Fresh	Total
Kp(a+b-)	48	23	71
k-	19	25	44
Vel-	5	22*	27
Lu(a+b-)	6	15	21
Fy(a-b-)	4	13	17
Yt(a-)	4	8	12
PP1P ^k -	6	2	8
Jr(a-)	8 [†]	0	8
U-	7	1	8
Co(a-)	2	5	7
Di(b-)	2	5 [‡]	7
R ₂ R ₂	4	1	5
O _h (Bombay)	4	0	4
r'r'	2	2	4
D--	1 [§]	1	2
r''r''	0	1	1
	122	124	246

*1 Israel.

†4 UK, 1 Sweden.

‡5 Sweden.

§1 Portugal.

other than the satisfaction of altruistically helping the patients needing a transfusion from a rare blood donor. We believe that the best way to achieve this level of commitment is to provide the donors with the most complete information possible about the significance of being a carrier of a rare blood group.

To determine the efficient use of these special units of blood, further work is needed to reinforce the habit of reporting the final destination and outcome of the units supplied. Although our panel covers most of the phenotypes that are clinically important, we continue searching for others that are extremely rare due to their low prevalence. The ISBT Working Party should play a central role in coordinating the search for these very rare phenotypes with the different members.

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