

Rare Donor Program in Spain: experience and challenges



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Political and administrative organization of Spain

Spain is divided into
17
autonomous regions



The central government
has transferred all competence
in health matters
related to blood transfusion
to the autonomous regions

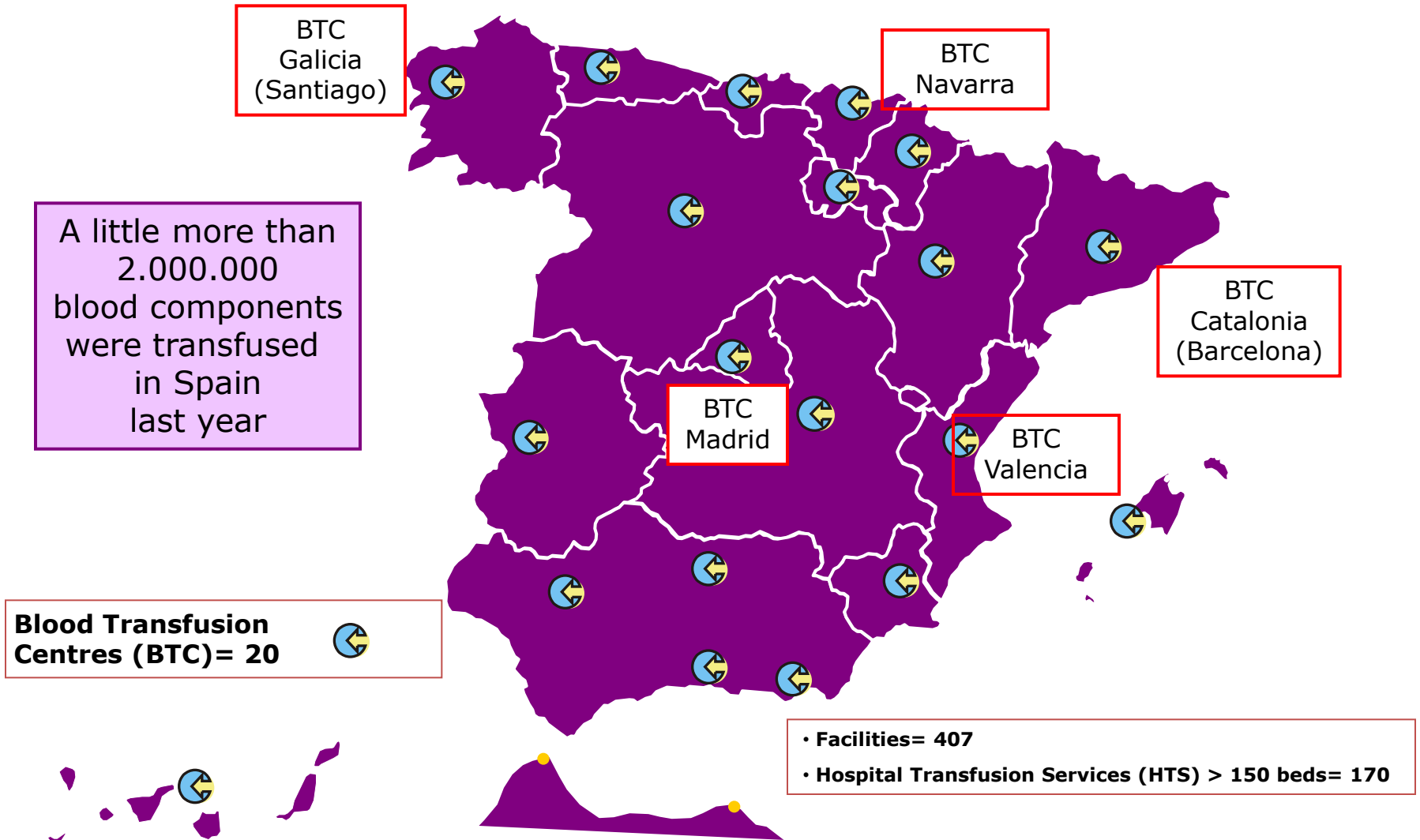


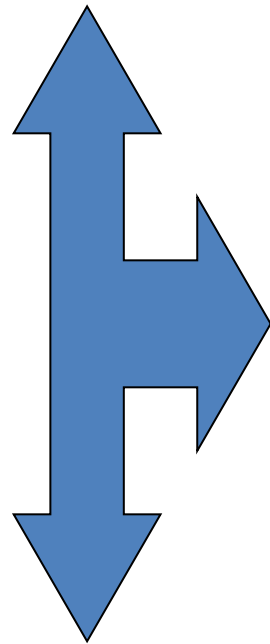
Each regional
government
is in charge of
health surveillance



The health authority of each region is the
"competent authority" as described in the
EU Blood Transfusion Directives

The Blood Transfusion Network in Spain (2012)





BTC of Catalonia

BTC of Galicia

BTC of Madrid

BTC of Valencia

BTC of Navarra

Nobody in the country knew:

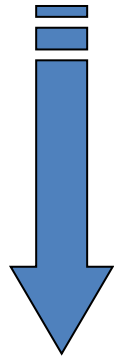
- The total number of cryopreserved units
- The total number of donors with rare blood groups
- The antigenic profile of these units and/or of these donors



Spanish Blood Transfusion Society (SETS)



Sociedad Española de Transfusión Sanguínea y Terapia Celular



Spanish Working Party On Rare Blood Groups

Blood Transfusion Centre (BTC)	Contact person
BST (Cataluña)	Dr. Eduardo Muñiz-Díaz
CTG (Galicia)	Dra. Ana Castro
CTCAM (Madrid)	Dr. Alberto Richard
BSN (Navarra)	Dra Marisa Ayape
CTCV (Valencia)	Dr. Luís Larrea

Working Party on Rare Blood Groups in Spain

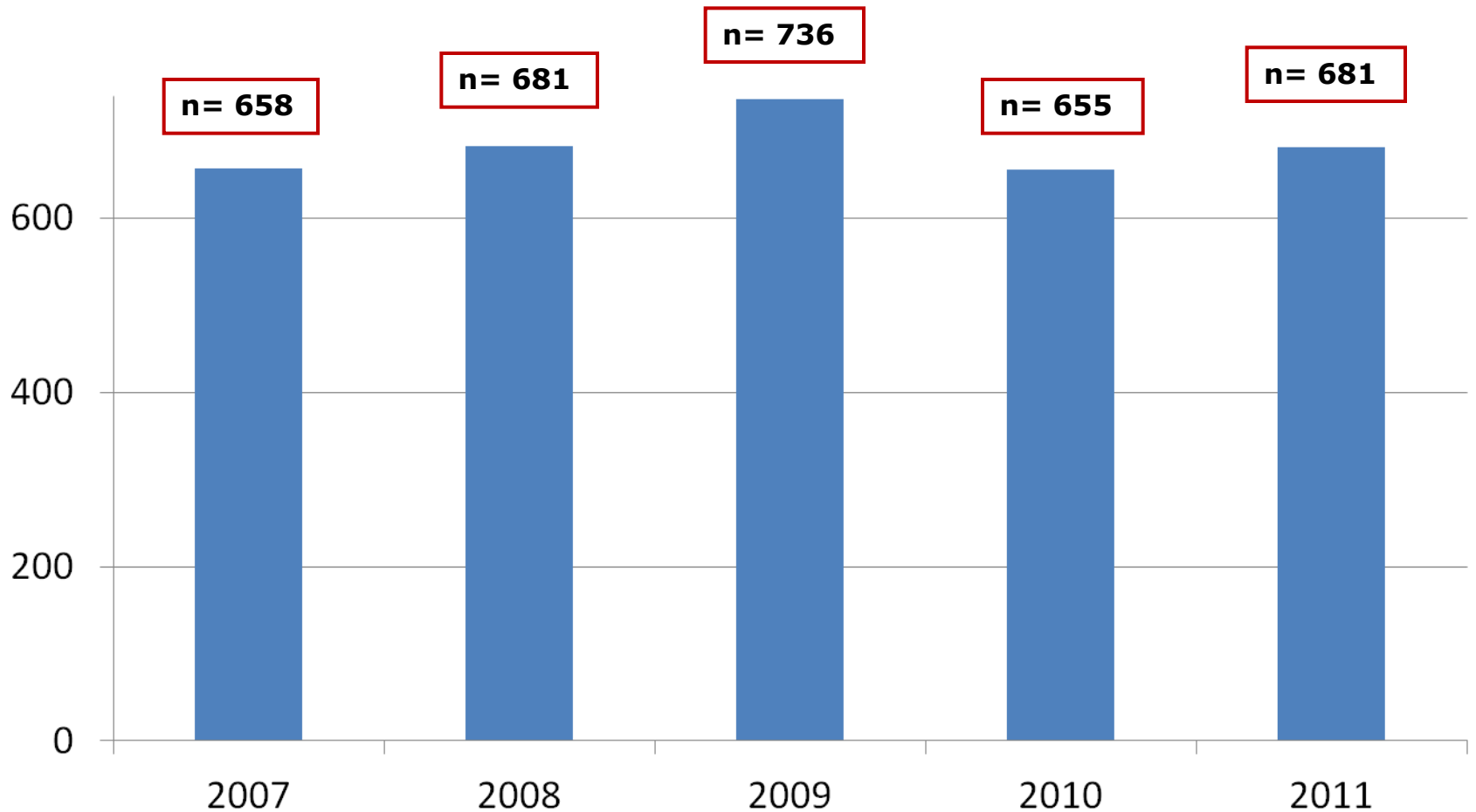
Aims

1. To share the information concerning cryopreserved units and the list of donors with rare blood groups.
2. To publish the composition of this stock regularly in the Journal of SETS and on the Web page.
3. To offer these special units to all BTC and Hospital Blood Transfusion Services in Spain.
4. To set up a protocol to request these units as well as the conditions for their use.



In 2007 the “national stock” of cryopreserved units with rare blood groups was published for the first time: 658 blood units

Evolution of the number of cryopreserved units with rare blood groups over the last five years



Rare Blood Groups in Spain

ISBT	Name	A+	A-	O+	O-	AB+	AB-	B+	B-	Total
KEL:-2	KK	15	19	60	46			3		143
KEL:-4	Kp(a+b-)	18	2	20	29				1	70
KEL	Kp(a-b-)	2								2
KEL:-1,-2,-3,-4	Ko				1					1
LU:-2	Lu(a+b-)	8	6	32	26	1				73
LU:-1,-2	Lu(a-b-)			8	1					9
PP1Pk	Tj(a-)	13		27	3			14		67
Vel neg	Vel -	4	7	23	23	1		1		59
FY:-1, -2	Fy(a-b-)	5		32	31					68
JK:-1, -2	Jk(a-b-)		3	2	1					6
CO: -1	Co(a-)	1		7	4					12
DI:-2	Di(b-)			8	1			2		11
YT:-1	Yt(a-)	5	3	14	5					27
Jra neg	Jr(a-)	3		10	9					22
JMH-	JMH-			5	1					6
Lan neg	Lan (-)			6	2					8
MNS:-3,-4	S(-) s(-)						1			1
MNS:-5	U-			11						11
GLOB	P-	7	3							10
	Bombay(Oh)			13	14					27
	r'r'			1	4					5
	r''r''		9		8					17
	Rz Rz	3		4						7
	-D-/-D-	11		6						17
RH 46 neg	Sec neg			1						1
	I neg							1		1

CRYOPRESERVED UNITS, June 2012

681

ISBT	Name	A+	A-	O+	O-	AB+	AB-	B+	B-	Total
KEL:-2	KK	142	67	180	39	11	4	21	1	465
KEL:-4	Kp(a+b-)	8		14	18				1	40
LU:-2	Lu(a+b-)	14	7	23	12	1		5		62
LU:-1,-2	Lu(a-b-)			4	1					5
PP1Pk	Tj(a-)	11		5	1					17
Vel neg	Vel -	2	1	22	33	1				59
CO:-1	Co(a-)	1		6	4					11
Lan neg	Lan -			6	6					12
FY:-1,-2	Fy(a-b-)	6	2	30	16			2		56
JK:-1,-2	Jk(a-b-)			1	2					3
MNS:-5	U-			7						7
JMH-	JMH-			3						3
Jra neg	Jr(a-)	1		6						7
YT:-1	Yt(a-)		3	8	8					19
DI:-2	Di(b-)			12						12
	-D-			1						1
	Bombay (Oh)			2						2

Donors with rare blood groups in Spain

781

CENTRO SOLICITANTE

Médico (persona de contacto):

Teléfono/FAX:

Dirección:

Horario posible para la entrega:

DATOS DEL PACIENTE

Requesting Center

- Doctor's name
- FAX
- (or name of the contact person)
- E mail
- Address
- Telephone
- Time of Delivery

Patient

- Name and surname
- Date of birth
- Gender
- ID number
- Name of Hospital
- Diagnosis
- Transfusion antecedents
- Gestational antecedents
- Previously identified antibodies
- Phenotype of cells requested
- Number of units
- Mode of units requested: (cryopreserved, unfrozen, fresh).

CENTRO REMITENTE

Médico (persona de contacto):

Teléfono/FAX:

Dirección:

Fecha y Hora de Envío:

DATOS DEL PACIENTE

- Name and surname
- Date of birth
- Gender
- ID number
- Mode of presentation matches the requested units

Shipping Center

- Doctor's Name
(or name of the contact person)
- Telephone
- FAX
- Date
- Address
- Time of Shipment

Patient

- The ID number of each unit
- The time and date of reception
- Whether the units arrived in perfect conditions
- The person in charge of the reception sign for the shipment

**ISBT RARE DONOR WORKING PARTY - INTERNATIONAL
SHIPMENT OF RARE BLOOD RESPONSE FORM
RECEIVING/REQUESTING CENTRE REMARKS**

Institution Information:

Receiving Institution: Facility Name: _____ City: _____ Country: _____ Date Received: _____	Sending Institution: Facility Name: _____ City: _____ Country: _____
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Please provide answers to the following:

1. Number of RBC units received: _____ Were the units received in acceptable condition? If no, what was the problem? Broken: _____ # _____ Thawed: _____ # _____ Other: _____	<input type="checkbox"/> Yes <input type="checkbox"/> No
2. Were the units received at the expected time? If no, what was the problem? _____	<input type="checkbox"/> Yes <input type="checkbox"/> No
3a. Were the infectious disease tests performed and documented?	<input type="checkbox"/> Yes <input type="checkbox"/> No
3b. Were they sufficient to allow transfusion?	<input type="checkbox"/> Yes <input type="checkbox"/> No
4. Were the billing documents in order? If no, what was the problem? _____	<input type="checkbox"/> Yes <input type="checkbox"/> No
5. What was the transfusion outcome? a. Patient received units? If no, please give reason: _____	<input type="checkbox"/> Yes <input type="checkbox"/> No
b. Please describe outcome of patient. _____ _____	
6. Phenotype of Units: _____ # received: _____	

Name of individual completing form _____ Date: ____/____/____
(day/month/year)

Fax:
IBGRL FAX: 44 117 959 1660
Shipping Center FAX: _____
Country of Receipt _____

**WORKING PARTY EN DONANTES CON GRUPOS RAROS DE LA ISBT -
REGISTRO INTERNACIONAL DE RESPUESTA AL ENVIO DE UNIDADES DE
FENOTIPO RARO
OBSERVACIONES DEL CENTRO SOLICITANTE/RECEPTOR**

Información de la Institución:

Institución receptora: Nombre: _____ Ciudad: _____ País: _____ Fecha recepción: _____	Institución suministradora: Nombre: _____ Ciudad: _____ País: _____
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Por favor, responda a las siguientes preguntas:

1. Número de unidades recibidas: _____ ¿Han llegado en condiciones aceptables? En caso negativo, ¿cuál es el problema? Rotas: _____ # _____ Descongeladas: _____ # _____ Otros: _____	<input type="checkbox"/> Si <input type="checkbox"/> No
2. ¿Han llegado dentro del tiempo esperado? En caso negativo, ¿cuál ha sido la razón? _____	<input type="checkbox"/> Si <input type="checkbox"/> No
3a. ¿Se han realizado y se documentan los resultados de las pruebas para el cribado de agentes infecciosos transmisibles?	<input type="checkbox"/> Si <input type="checkbox"/> No
3b. ¿La información es suficiente para permitir la transfusión?	<input type="checkbox"/> Si <input type="checkbox"/> No
4. ¿Han llegado en orden todos los documentos esperados? En caso negativo, ¿cuál ha sido el problema? _____	<input type="checkbox"/> Si <input type="checkbox"/> No
5. ¿Qué ha sucedido finalmente con las unidades? a. ¿Ha sido transfundido el paciente? En caso negativo, ¿cuál ha sido la razón? _____	<input type="checkbox"/> Si <input type="checkbox"/> No
b. Por favor, explique cómo ha evolucionado el paciente. _____ _____	
6. Fenotipo de las unidades: _____	
# recibido: _____	

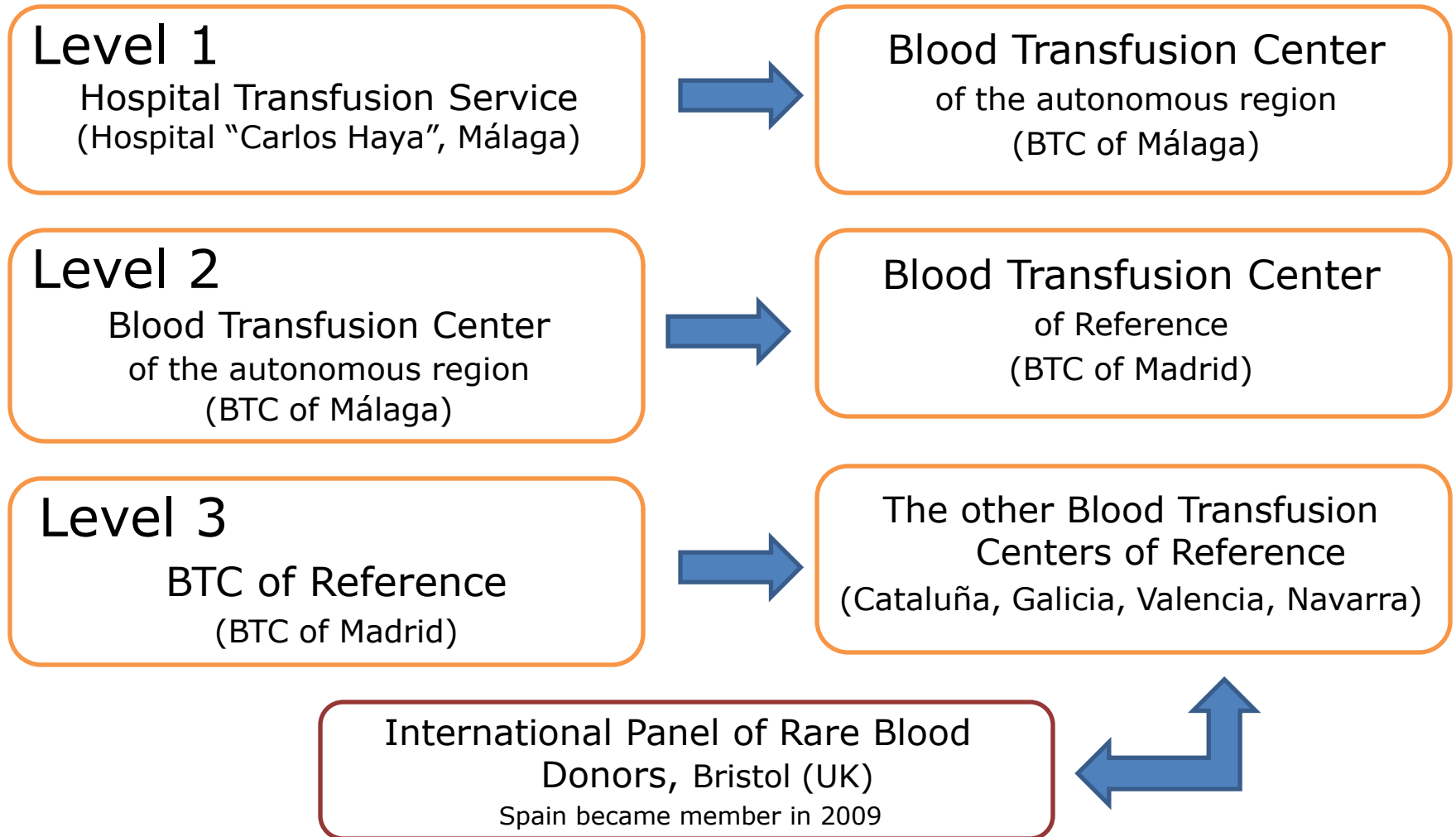
Nombre de la persona que cumplimenta el registro _____
Fecha: ____/____/____

(día/mes/año)

Each of the 4 BTC of the Working Party is responsible for a group of regions



Functional Algorithm



The BTC of reference can demand a sample from the requested hospital whenever it considers this to be necessary

Provision of rare blood in the year 2010

ISBT	Name	Cryopreserved Units	Fresh Units	TOTAL
KEL:-2	KK	8	10	18
KEL:-4	Kp(a+b-)	3	1	4
LU:-2	Lu(a+b-)	2		2
Vel neg	Vel neg	2	3	5
CO:-1	Co(a-)	2	2	4
DI:-2	Di(b-)	2		2
	r''r''		1	1
	RzRz	4	1	5
	-D-	1*		1
		28	20	48

94% of the units were efficiently employed

*1 unit was sent to Portugal through the IBRGL International Panel

- 25 out of the 28 cryopreserved units were transfused to the intended patients.
- 18 out of the 20 fresh units were transfused to the intended patients and the remaining 2 were cryopreserved.

Provision of rare blood in the year 2011

ISBT	Name	Cryopreserved Units	Fresh Units	TOTAL
KEL:-2	KK		4	4
KEL:-4	Kp(a+b-)	8	3	11
LU:-2	Lu(a+b-)		1	1
Vel negative	Vel negative		2	2
89% of the units were efficiently employed				
	Bombay (O _n)	3		3
FY: -1, -2	Fy(a-b-)		2	2
PP ₁ Pk neg	Tj(a-)	3		3
		14	14	28

- 11 out of the 14 cryopreserved units were transfused to the intended patients.
- The 14 fresh units were also transfused to the intended patients.

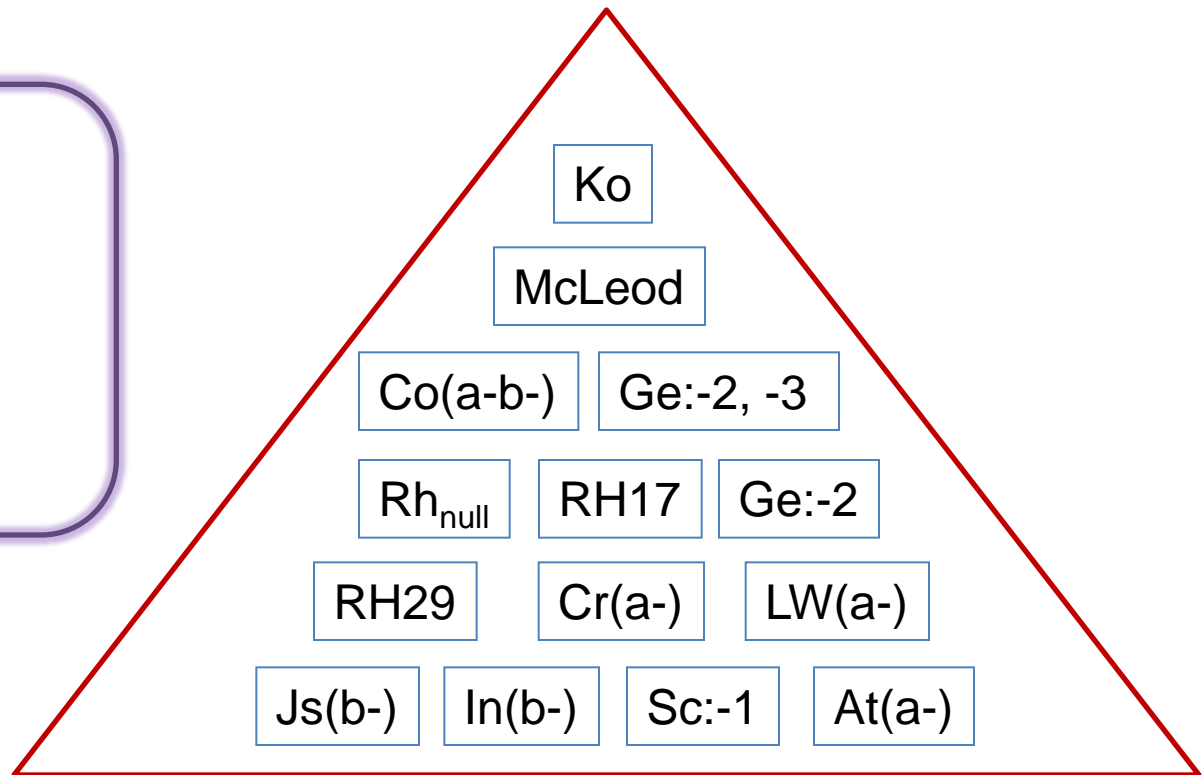
Provision of rare blood in the year 2012 (January-June)

ISBT	Name	Cryopreserved Units	Fresh Units	TOTAL
KELL:-2	KK	4	2	6
KELL:-4	Kp(a+b-)	6	3	9
PP ₁ Pk neg	Tj(a-)	1		1
DI:-2	Di(a+b-)		6*	6
83% of the units were efficiently employed				
FY:-1,-2	Fy(a-b-)	1	2	3
YT:-1	Yt(a-)		4	4
		12	18	30

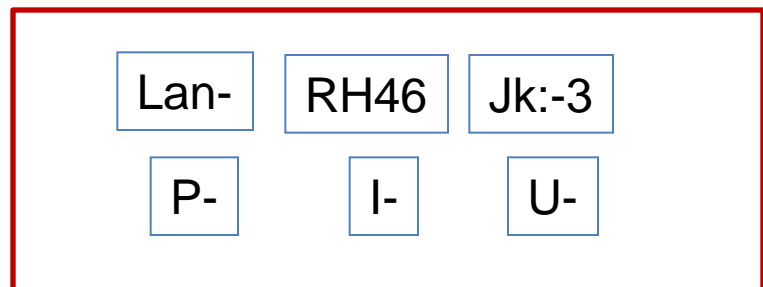
*6 units were sent to Sweden through the IBRGL

- 11 out of the 12 cryopreserved units were transfused to the intended patients.
- 9 out of the 18 fresh units were transfused to the intended patients, 5 were cryopreserved and 4 expired.

What phenotypes are the most difficult to find?

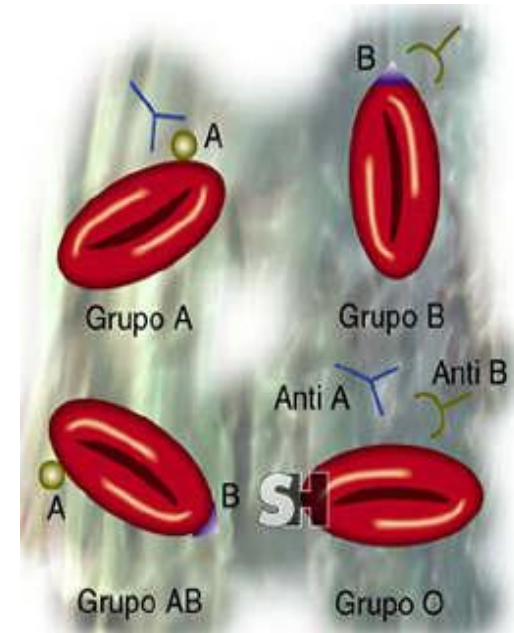


Limited number of units to provide



Conclusions

1. The creation of this Working Party on Rare Blood Groups in Spain has resulted in major improvements in recent years.
2. Our Panel of cryopreserved units is constituted by 681 units, and the list of donors with rare blood groups includes 781 blood donors.
3. We have reached an acceptable level of traceability in the units provided as well as in the level of efficiency in recent years (88%) .
4. Nevertheless, further work is necessary to reinforce the habit of reporting the final destiny of the provided units.
5. Although our Panel covers most phenotypes that are clinically important, it has not been possible to include others that have a very low frequency.
6. The ISBT Working Party must play a central role in coordinating the search for these very rare phenotypes with the different members of the WP.



Immunohematology Laboratory.

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Thank you for your attention!