



Rare blood  
An international kaleidoscope.

Peter J.M. van den Burg, MD, PhD.

*Vilnius, 14 May 2026.*

**For Life.**

# Disclosure

## Affiliations:

- Sanquin blood supply, transfusion medicine and education,
- The University of Groningen, Management in Transfusion Medicine (MTM),
- The Netherlands School of Public and Occupational Health (NSPOH), Donor medicine,
- EBA, chair WG 'Rare blood provision'.

I have no financial disclosure or conflict of interest with the presented material in this presentation.

# Outline

- 🔴 Rare blood, a case repost
- 🔴 Rare blood from an international perspective
- 🔴 About rare blood and disasters
- 🔴 Conclusions.

## Case:

A patient with African ancestry in The Netherlands.



# Case



## Patient:

- ◆ A 26 years old male patient, with African ancestry, suffering from sickle cell disease.
- ◆ Admitted to the hospital with sickle cell crises.

## History:

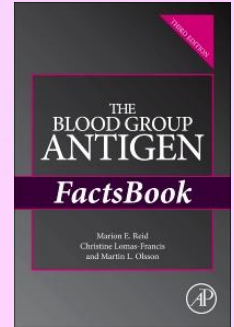
- ◆ Multiple sickle cell crises & anaemia (2.4-3.2 (mmol/L)/(3.9 – 5.5 g/dL).
- ◆ Chronic kidney disease (creatinine > 300  $\mu$ mol/L) on dialysis for 2 years.

## Compatibility testing:

- ◆ ABO-Rhesus: A, Rh- (ccdee), Fy(a-b-), Lu(b)-.
- ◆ Antibodies: clinically significant anti-C and anti-Lutheran B (Lu(b)).
- ◆ Transfusion advise: A/O, C-, D-, E-, Fy(a)-, Lu(b)- and S-.



Phenotype	White	Black
Lu(a+b-)	< 1	< 1
Lu(a+b+)	7	7
Lu(a-b+)	93	93
Lu(a-b-)	Very rare	Very rare



### Occurrence Lu(b)

- 🔥 All population 99,8%.

### Clinical significance of allo anti-Lu(b)

- 🔥 IgG IAT
- 🔥 Transfusion reaction: mild to moderate.

### Available donors?

- 🔥 Only 0.001% compatible donors in The Netherlands.



Search for donors: Sanquin, family and international.

Explore stem cell transplantation.

Make a transfusion-transplantation plan.



### Search for donors:

- 🔴 Plan A: A/0, C-, D-, E-, Fy(a)-, Lu(b)- and S- : 4 available!
- 🔴 Plan B: A/0, C-, D-, E-, Fy(a)-, Lu(b)- and S+ : 9 available!

### Search in family:

- 🔴 1 Lu(b)-.

### Explore stem cell transplantation with HLA-identical sister:

- 🔴 Desired 15 units RBC for exchange prior to SCT & transfusion.

Start international search.

# International search



International Rare Donor Panel

The International Rare Donor Panel (IRDP) was conceived under a joint World Health Organisation (WHO) and ISBT initiative in 1965 to facilitate the rapid location and exchange of rare blood between countries.

The panel currently contains details of rare donors from 27 contributing countries and also frozen unit inventories from frozen blood banks around the world. The compilation and maintenance of the IRDP is carried out by the Red Cell Reference department of the IBGRL in Bristol, UK.



## Units collected, imported and cryopreserved:

- 🔴 10 RBC: A/O, C- D- E- K- Lu(b)- Fy(a)- en S- from England and France.
- 🔴 10 RBC: A/O en C- D- E- K- Lu(b)- Fy(a)- en S+ for plan B.

# Cryopreservation Sanquin





# Rare blood type requests in the Netherlands 2015-2024:

## Data from our rare donor program

C.M. Canté, M. Grootveld, F. Danovic, C. Folman, C. Derichs, J. Luken, M. de Haas, Sanquin bloodbank The Netherlands

11-4-2025					
Phenotype	O-	O+	A-	A+	Total
ccdEE	11	NVT	5	NVT	16
CCdee	8	NVT	4	NVT	10
Co <sup>a-</sup>	9	4	0	0	13
Dj <sup>b-</sup>	3	1	0	0	4
Ge2-	8	2	2	0	12
H-	0	12	0	0	12
Jk(a-b-)	0	21	0	6	27
Jr <sup>a-</sup>	2	5	12	0	19
cellano-	5	8	0	8	21
Kp <sup>b-</sup>	9	9	10	7	35

11-4-2025D		SBFB			
Phenotype	O-	O+	A-	A+	Total
Lan -	2	1	0	1	4
Ko	0	1	0	2	3
Lu <sup>b-</sup>	17	8	14	7	46
InLu	2	1	2	8	13
PP1Pk-	2	9	0	0	11
U-	3	11	0	0	14
Vel-	4	12	4	9	29
Yt <sup>a-</sup>	2	7	2	8	19
Fy(a-b-)	9	35	2	4	50
I-	0	2	5	6	19
Sc1-	0	5	0	12	17
P-	2	10	0	0	12
D--	0	4	0	1	5
Rhnull	0	3	0	0	3

## The treatment:

- ◆ RBC exchange with compatible 6 units before transplantation.
- ◆ Successful SCT with stem cells from sister.
- ◆ 6 additional compatible RBC transfusions.

Successful treatment, recovery and discharged with haemoglobin 6.8 mmol/L (11.0 g/dL).

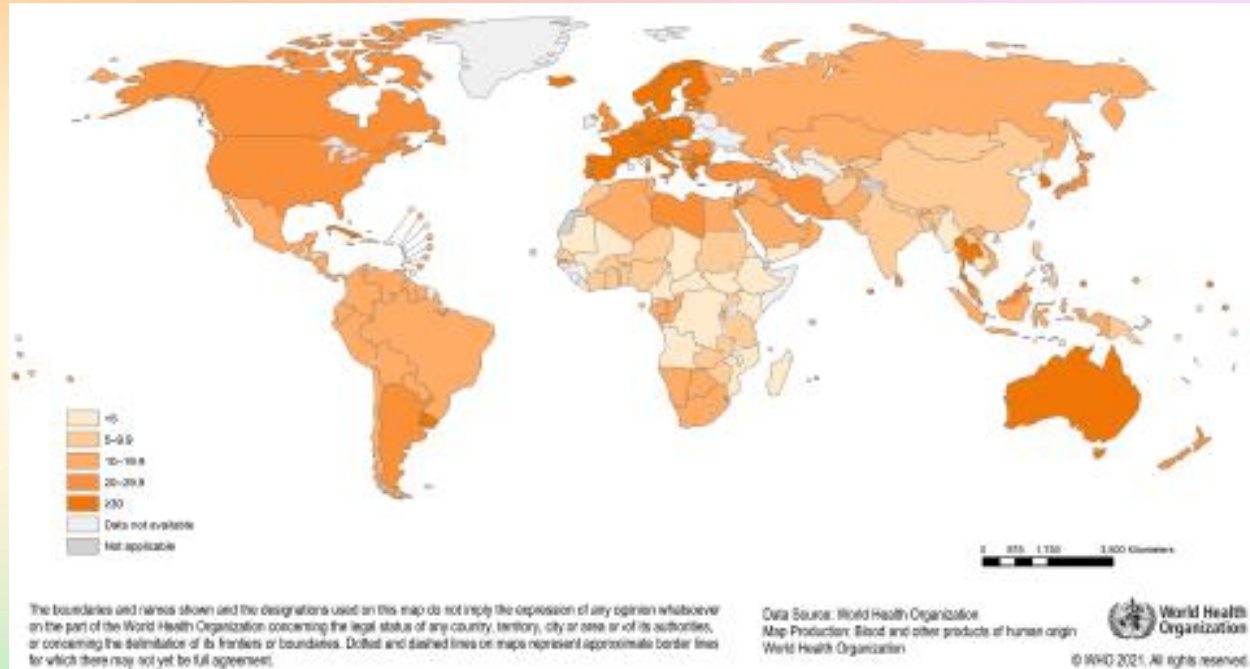


**Yes, BUT...**

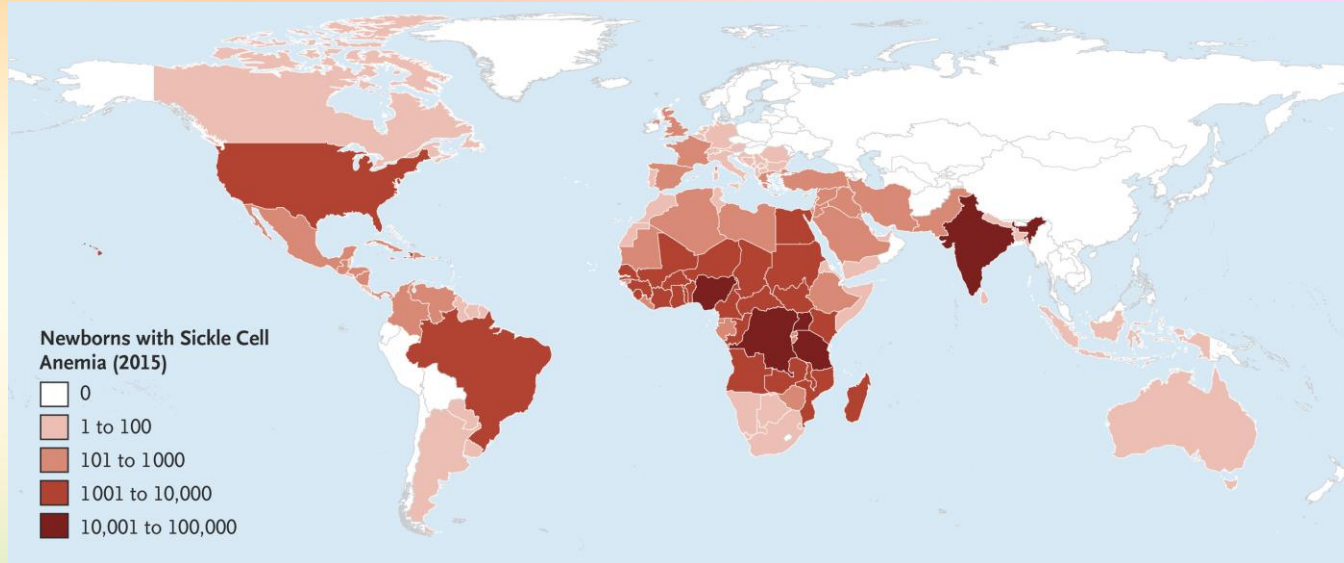
# Outline

- Rare blood, a case report
- **Rare blood from an international perspective**
- About rare blood and disasters
- Conclusions.

# Figure 5. Whole blood donations per 1000 population.

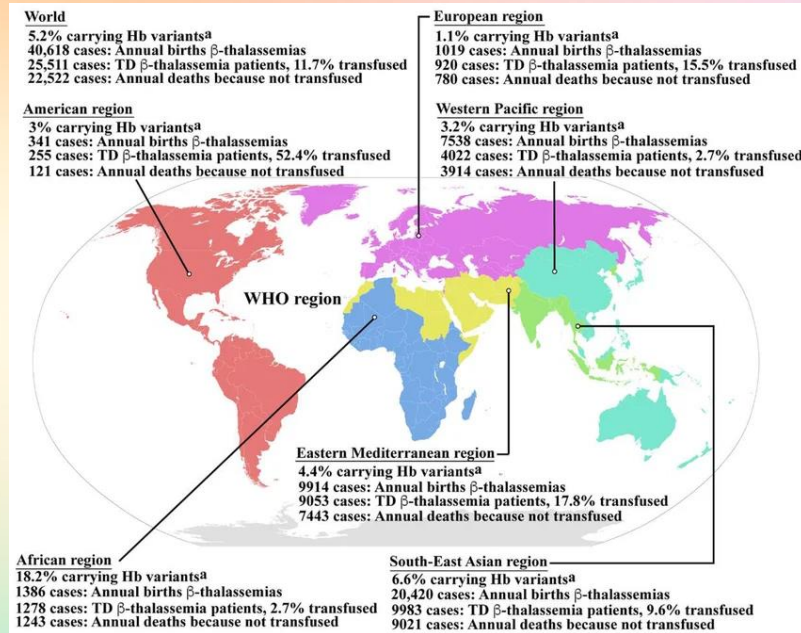


# Sickle cell worldwide

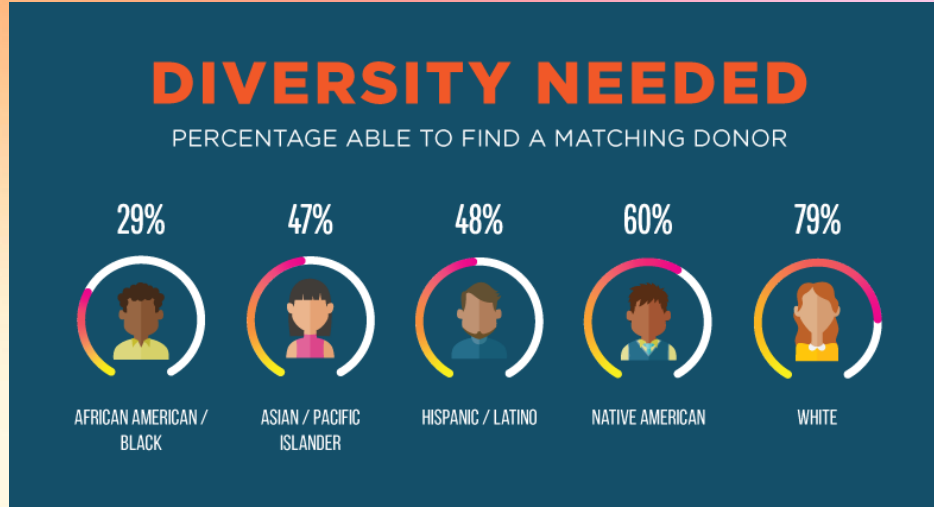


Authors: Frédéric B. Piel et al, N Engl J Med 2017;376:1561-1573. DOI: 10.1056/NEJMra1510865. VOL. 376 NO. 16. Copyright © 2017

# Thalassemia worldwide



The Roles of Mitophagy and Autophagy in Ineffective Erythropoiesis in  $\beta$ -Thalassemia - Scientific Figure on ResearchGate.  
[https://www.researchgate.net/figure/Epidemiology-of-b-thalassemia-Global-epidemiological-data-including-the-percentages-of\\_fig1\\_363817357](https://www.researchgate.net/figure/Epidemiology-of-b-thalassemia-Global-epidemiological-data-including-the-percentages-of_fig1_363817357) [accessed 3 Mar 2026]



Human Leukocyte Antigen (HLA) matching in organ and stem cell transplantation—while medically aimed at reducing rejection—functions as a form of **institutional discrimination** that results in significant racial and ethnic disparities in access to care. **Because** HLA types are inherited and vary by ancestry, minorities often have harder-to-match profiles, leading to longer wait times, fewer suitable donor offers, and higher rates of transplantation failure compared to white patients!

# Segregation in past

O'Hara Denies Prejudice In Policy Numbers Trial

14 PAGES FULL OF NEWS

**Detroit Tribune**

LEADING NEGRO WEEKLY OF MICHIGAN

5¢ IN MICHIGAN  
7 CENTS ELSEWHERE

VOL. XIX--NO. 40 2146 St. Antoine

DETROIT, MICHIGAN, SATURDAY, DECEMBER 26, 1951

CLIFFORD 2324--PRICE 5 CENTS PER COPY

## RED CROSS SAYS REFUSAL OF NEGRO BLOOD IS U. S. ORDER

BLOOD DONORS CONFER ON RED CROSS REJECTION

**Mrs. Bethune To Open Confab; Deltas Launch Defense Drive**

**Rejected Donors Hold Protest Meeting**

**Sorors Plan To Feature Stamp Rally**

**Soldiers Will be Special Guests At Open Ball**

**NAACP CALLS HOUSING MEET**

**Educator Will Speak At Public Meeting**

**Local Chapter Awaits Coming Of Renowned Sorors**

**Reading, Watson,**



AMERICAN RED CROSS

The group above led the meeting at the Red Cross headquarters at 400 and Adams streets.

The group above led the meeting at the Red Cross headquarters at 400 and Adams streets.

## Government Impact on Hospital Practice

### Segregated Blood: A Backlash Backfires

In 1958 the Louisiana legislature, spurred on by White Citizens Councils, passed an act requiring the racial labeling of human blood for transfusion as "Caucasian," "Negroid," "Mongoloid," or equivalent designation. The law specified that a recipient must be informed whenever blood from a racially different donor was to be used. Only in an emergency, certified by a physician, could interracial transfusions be given without patient consent. Violation carried a penalty of \$100 per instance, 30 days in jail, or both.

Similar legislation was introduced in other Southern legislatures but enacted generally was prevented. Only Arkansas, in April 1959, joined Louisiana. The Arkansas General Assembly "found and declared . . . that such law is necessary to protect the health and welfare of the citizens of this state. Therefore, an emergency is hereby declared to exist and this act, being necessary for the immediate preservation of the public peace, health, and safety, shall be in full force and effect from and after its passage and approval." The Arkansas law was quickly repealed this January.

The repeal removed a dilemma that had confronted Arkansas hospitals and still confronts those in Louisiana. If they obeyed state law, they faced loss of Medicare, Medicaid, Hill-Burton, and other federal money. Title VI of the 1964 federal Civil Rights Act explicitly forbids federal assistance to institutions that discriminate by race, color, or national origin. According to the Department of Health, Education, and Welfare, "any separation or identification of blood or blood derivatives based upon race, color, or national origin, or any racial distinction in the source of blood used for transfusions, constitutes discrimi-

nation prohibited by Title VI. . . . Louisiana's status as the only state with a blood segregation statute still on the books may not last long. During a recent HOSPITAL PRACTICE investigation that put questions about the law to federal, state, hospital, and other organizations, Louisiana officials said they would instruct hospitals that the law would not be enforced and that the federal Civil Rights Act superseded the state law. A special assistant to Gov. John McKeithen told this magazine that it was too late this year to ask the legislature to repeal the law but that next year the governor would work for repeal.

Meanwhile HEW's Office for Civil Rights, after a special investigation

that showed some Louisiana hospitals did label blood racially, wrote to the governor to advise him that this practice violated Title VI. Leon Panetta, O.C.R. director and special assistant on civil rights to HEW Secretary Robert H. Finch, said he hoped Louisiana could resolve the problem promptly. HEW began exploring with the U.S. Department of Justice the possibility of a federal suit against a state-run or other hospital found complying with state law. Such a suit would involve a judicial determination on the constitutionality of the state law.

Whether the governor's nullification instructions will satisfy HEW, which at this writing had not received copies, is not yet known. The American Public Health Association, which has condemned the Louisiana statute, said it will not be satisfied until the statute is off the books and until there is clear evidence that blood segregation is no longer practiced.

During the HOSPITAL PRACTICE study, the American Red Cross, which has a national policy of nondiscrimination in blood banking, ended a small, exceptional traffic in segregated blood. To satisfy the replacement needs of out-of-state patients with blood credits, ARC — which has no blood bank (continued on page 24)

**CPD WHOLE BLOOD (HUMAN)**

Contains 450 ml. Human Blood Plus 63 ml. Citrate Phosphate Dextrose Anticoagulant Solution (CPDS Formula)

**ISO-SOLUPLASMA TYPE**

NOT DETERMINED

**CAUTION**

1. See container for full labeling instructions of use and storage.
2. Before use, check expiration date.
3. Do not use if expiration date has passed.
4. Check appearance of container seal.
5. Inspect for any leakage or damage.
6. Do not use if container is damaged.
7. Do not use if container is damaged.
8. Do not use if container is damaged.
9. Do not use if container is damaged.
10. Do not use if container is damaged.

**NO IRRREGULAR ANTIBODIES DETECTED**

Tested with Rapid Red Blood Cells Test by Multiple Technicians

**NEW ORLEANS BLOOD BANK**

New Orleans, Louisiana 70119

U. S. Government License No. 354

**NEGROID**

**DONOR NO. N 7835 H**

**CPD WHOLE BLOOD (HUMAN)**

Contains 450 ml. Human Blood Plus 63 ml. Citrate Phosphate Dextrose Anticoagulant Solution (CPDS Formula)

**ISO-SOLUPLASMA TYPE**

NOT DETERMINED

**CAUTION**

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**NEW ORLEANS BLOOD BANK**

New Orleans, Louisiana 70119

U. S. Government License No. 354

**(HUMAN)**

**DONOR NO. N 7684 H**

**CPD WHOLE BLOOD (HUMAN)**

Contains 450 ml. Human Blood Plus 63 ml. Citrate Phosphate Dextrose Anticoagulant Solution (CPDS Formula)

**ISO-SOLUPLASMA TYPE**

NOT DETERMINED

**CAUTION**

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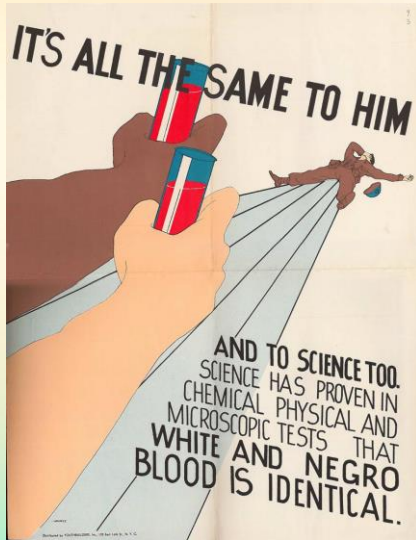
**NEW ORLEANS BLOOD BANK**

New Orleans, Louisiana 70119

U. S. Government License No. 354

As recently as April of this year, the New Orleans Blood Bank was designating the racial origin of its blood stores, as these labels show. They, together with much additional information contained in the accompanying article, were supplied to HOSPITAL PRACTICE by a physician who has asked that his name not be disclosed.

# Missing minorities today



Without A, B & O, we can't save anybody. You are the #MissingType we need.



## Help us fill the missing blood types.

You might not realize how important certain letters are until they're gone. A, B and O are the main blood types and when not enough people donate blood, A's, B's and O's may be missing from hospital shelves when a critical patient arrives.

Every two seconds, someone in the U. S. needs blood. But for the past four years, new Red Cross blood donors have declined by about 80,000 each year. We need your help to fill in the missing blood types so patients can receive the lifesaving care they need.

You are the **#MissingType**.

Visit [redcrossblood.org/missingtypes](https://redcrossblood.org/missingtypes) to schedule your blood donation appointment today.

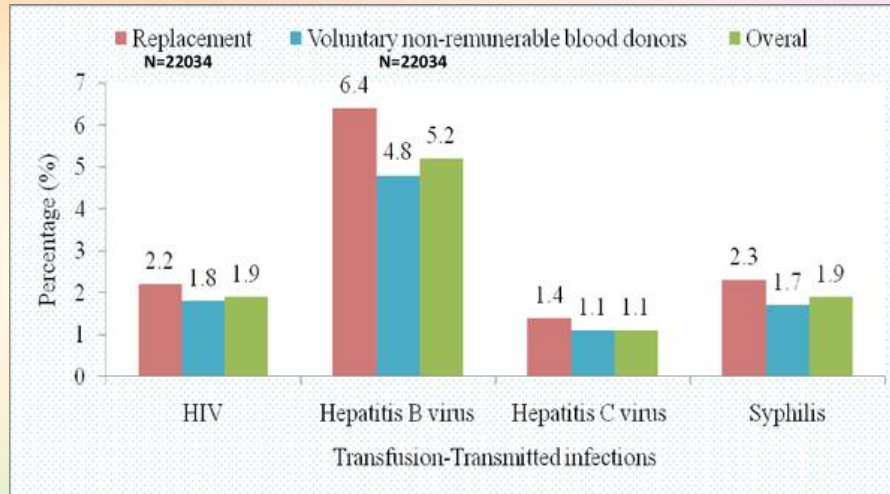
#MissingType | [redcrossblood.org/missingtypes](https://redcrossblood.org/missingtypes) | 1-800-RED CROSS

© 2018 The American National Red Cross | 171901

# **Directed/replacement versus anonymous donation.**



# Prevalence of HIV, Hepatitis B, Hepatitis C and syphilis among replacement blood donors and voluntary non-remunerable blood donors at the NZBTC.



**Yes, BUT...**

Mremi A, Yahaya JJ, Nyindo M, Mollel E (2021) Transfusion-Transmitted Infections and associated risk factors at the Northern Zone Blood Transfusion Center in Tanzania: A study of blood donors between 2017 and 2019. PLOS ONE 16(3): e0249061. <https://doi.org/10.1371/journal.pone.0249061>  
<https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0249061>

# Case:

A patient with African ancestry in The Netherlands,  
A Kaleidoscope.



## Search in **family**:

- 1 Lu(b)-.

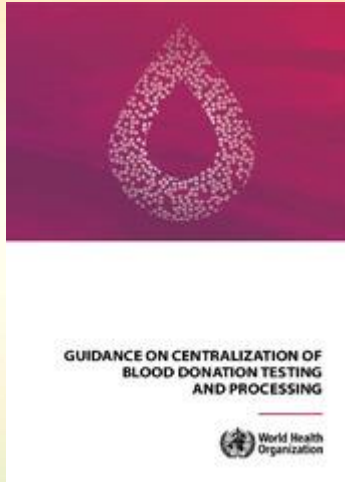
## Explore stem cell transplantation with HLA-identical **sister**:

- Desired 15 units RBC for exchange prior to SCT & transfusion.

# Outline

- Rare blood, a case repost
- Rare blood from an international perspective
- **About rare blood and disasters**
- Conclusions.

# Centralisation versus decentralisation.



## Overview

Multiple barriers to the safety and availability of blood components for transfusion were identified in the 2015 Global Database on Blood Safety, many of which derive from weak regulatory oversight, insufficient financing, and fragmentation of the national blood system. Centralization of key functions of the blood service within a limited number of blood establishments, particularly testing and processing of blood donations, can overcome several shortcomings that often exist in decentralized blood systems that are highly fragmented.

Guidance in this area contributes to meeting a strategic objective of the World Health Organization (WHO) *Action framework to advance universal access to safe, effective and quality-assured blood products 2020–2023* to promote functioning and efficiently managed blood services. Supporting access to quality and safe blood and blood components at global level aligns with the objectives of World Health Assembly (WHA) resolution 63.12 (2010) on availability, safety and quality of blood products.

This guidance provides decision-makers, particularly in low- and middle-income countries, a roadmap for consideration of whether to centralize blood donation testing and processing and the steps needed to implement these functions in selected blood establishments. Centralization of blood donation testing and processing in designated blood establishments (BEs) is one strategy to improve the overall function and efficiency of the national blood system. Practical advice on the creation of such BEs is provided.





<https://www.abc.net.au/news/2023-08-07/russia-missiles-hit-ukraine-blood-bank-and-airbase/102695552>

# Disasters in The Netherlands



Airplane crash, Amsterdam 1992, 43 dead/26 injuries  
Fireworks explosion, Enschede 2000, 23 dead/950 injuries  
Fire in bar, Volendam 2001, 14 dead/200 injuries  
Airplane crash, Amsterdam 2009, 9 dead/86 injuries

**Hardly any extra (emergency stock) blood transfusions needed!!!**

# The Netherlands and contingency.



Within 30 minutes > 200 beds, IC and OK.

# The Netherlands and contingency, UN aid.

WEEK	PACKING DATE	DESTINATION	MISSION
28	Friday, 04 July, 2025	Bangui, CAR	MINUSCA
28	Monday, 07 July, 2025	Mogadishu, SOMALIA	UNSOS
28	Thursday, 10 July, 2025	Entebbe	MONUSCO
28	Thursday, 10 July, 2025	Kigali (Goma)	MONUSCO
29	Friday, 11 July, 2025	Juba, SOUTH SUDAN	UNMISS
29	Friday, 11 July, 2025	Abyei, SOUTH SUDAN	UNISFA
29	Monday, 14 July, 2025	Nairobi, KENYA	UNON
30	Friday, 18 July, 2025	Bangui, CAR	MINUSCA
30	Monday, 21 July, 2025	Beirut, LEBANON	UNIFIL
30	Monday, 21 July, 2025	Mogadishu, SOMALIA	UNSOS
30	Thursday, 24 July, 2025	Entebbe	MONUSCO
30	Thursday, 24 July, 2025	Kigali (Goma)	MONUSCO
31	Friday, 25 July, 2025	Juba, SOUTH SUDAN	UNMISS
31	Friday, 25 July, 2025	Abyei, SOUTH SUDAN	UNISFA

More than 2000 units red cells/year to more than 10 regions/countries.

# Rare blood and disasters



## **Challenges rare blood and disasters:**

- 🔥 Finding and maintaining minorities.
- 🔥 'Smart' test algorithms, genotyping and stock management.
- 🔥 International collaboration e.g. EBA & ISBT.
- 🔥 Make the chain of donation and transfusion less vulnerable.

*Thank  
you!*