*<WRWeb 16.3 Reading File ***>*

The Most Precious Blood on Earth

For people with very rare types, obtaining lifesaving blood can involve a complex network of donors and doctors that stretches across the globe

By Penny Bailey
The Atlantic

His doctor drove him over the border. It was quicker that way: If the man donated in Switzerland, his blood would be delayed while paperwork was filled out and authorizations sought.

The nurse in Annemasse, France, could tell from the label on the blood bag destined for Paris that this blood was pretty unusual. But when she read the details closely, her eyes widened. Surely it was impossible for this man seated beside her to be alive, let alone apparently healthy?

Thomas smiled to himself. Very few people in the world knew his blood type did—could—exist. And even fewer shared it. In 50 years, researchers have turned up only 40 or so other people on the planet with the same precious, life-saving blood in their veins.

Red blood cells carry oxygen to all the cells and tissues in our body. If we lose a lot of blood in surgery or an accident, we need more of it—fast. Hence the hundreds of millions of people flowing through blood donation centers across the world, and the thousands of vehicles transporting bags of blood to processing centers and hospitals.

It would be straightforward if we all had the same blood. But we don't. On the surface of every one of our red blood cells, we have up to 342 antigens—molecules capable of triggering the production of specialized proteins called antibodies. It is the presence or absence of particular antigens that determines someone's blood type.

Some 160 of the 342 blood group antigens are "high-prevalence," which means that they are found on the red blood cells of most people. If you lack an antigen that 99 percent of people in the world are positive for, then your blood is considered rare. If you lack one that 99.99 percent of people are positive for, then you have very rare blood.

photo: Malota / Shutterstock.com

If a particular high-prevalence antigen is missing from your red blood cells, then you are "negative" for that blood group. If you receive blood from a "positive" donor, then your own antibodies may react with the incompatible donor blood cells, triggering a further response from the immune system. These transfusion reactions can be lethal. Because so few people have it, by definition, rare blood is hardly ever needed. But when it is, finding a donor and getting the blood to a

patient in crisis can become a desperate race against the clock. It will almost certainly involve a convoluted international network of people working invisibly behind the bustle of "ordinary" blood donation to track down a donor in one country and fly a bag of their blood to another.

* * *

Forty years ago, when 10-year-old Thomas went into the University Hospital of Geneva with a routine childhood infection, his blood test revealed something very curious: He appeared to be missing an entire blood-group system.

There are 35 blood-group systems, organized according to the genes that carry the information to produce the antigens within each system. The majority of the 342 blood-group antigens belong to one of these systems. The Rh system (formerly known as "Rhesus") is the largest, containing 61 antigens.

The most important of these Rh antigens, the D antigen, is quite often missing in Caucasians, of whom around 15 percent are Rh D-negative (more commonly, though inaccurately, known as Rh-negative blood). But Thomas seemed to be lacking all the Rh antigens. If this suspicion proved correct, it would make his blood type Rh_{null}—one of the rarest in the world, and a phenomenal discovery for the hospital haematologists.

Rh_{null} blood was first described in 1961, in an Aboriginal Australian woman. Until then, doctors had assumed that an embryo missing all Rh blood-cell antigens would not survive, let alone grow into a normal, thriving adult. By 2010, nearly five decades later, some 43 people with Rh_{null} blood had been reported worldwide.

Hardly able to believe what she was seeing, Dr Marie-José Stelling, then head of the hematology and immunohematology laboratory at the University Hospital of Geneva, sent Thomas' blood for analysis in Amsterdam and then in Paris. The results confirmed her findings: Thomas had Rh_{null} blood. And with that, he had instantly become infinitely precious to medicine and science.

Researchers seeking to unravel the mysteries of the physiological role of the intriguingly complex Rh system are keen to get hold of Rh_{null} blood, as it offers the perfect "knockout" system. Rare negative blood is so sought after for research that even though all samples stored in blood banks are anonymized, there have been cases where scientists have tried to track down and approach individual donors directly to ask for blood.

And because Rh_{null} blood can be considered "universal" blood for anyone with rare blood types within the Rh system, its life-saving capability is enormous. As such, it's also highly prized by doctors—although it will be given to patients only in extreme circumstances, and after very careful consideration, because it may be nigh on impossible to replace. "It's the golden blood," says Dr. Thierry Peyrard, the current Director of the National Immunohematology Reference Laboratory in Paris.

Blood groups are inherited, and Rh_{null} is known to run in families. So the next step for the haematologists in Geneva was to test Thomas' family in the hope of finding another source, particularly as Thomas wouldn't be able to donate until he turned 18. Things looked even more hopeful when it turned out Thomas' grandfathers were third-degree cousins. But the tests showed Thomas' Rh_{null} blood was due to two completely different random mutations on both sides. Pure chance, twice over, in the face of vanishingly small odds.

When he turned 18, Thomas was encouraged to donate blood for himself. There is now no frozen-blood bank in Switzerland, so his blood is stored in the rare-blood banks in Paris and Amsterdam. He travels to France to donate,

avoiding the bureaucratic machinery that would grind into action if his blood had to be sent over the Swiss border to Paris.

The first urgent request came a few years after Thomas began donating, when he got a phone call asking if he would mind taking, and paying for, a taxi to the blood center in Geneva to donate for a newborn baby. That moment brought it starkly home to him how valuable his blood was. It was perhaps also the first intimation that the costs of donating would ultimately be his. Some countries do pay donors (and some pay more for rare blood) to encourage donations. But the majority of national blood services don't pay, to deter donors with infections such as HIV. The altruistic ethos of the blood services in western Europe means that they also don't cover donors' travel costs or time off work, both of which would constitute payment for blood. They can't even send a taxi to take a rare donor to a blood center, although the blood itself can travel by taxi from the center to a patient.

It's something that can become a frustrating and potentially fatal problem. Thierry Peyrard told me that he was recently contacted by a doctor in Zurich asking for blood with another rare combination of negatives, for a patient about to undergo surgery. There were only four compatible donors in France, and Peyrard could only contact two by phone. One of them was a 64-year-old lady living in a village near Toulouse. Although she was more than willing to go to the blood center in the city and donate, since she can't drive, she simply couldn't get there.

So unless his doctor drives him over the border again—a courtesy going far beyond the call of duty between a doctor and patient—Thomas will take a day's holiday from work, twice a year, and travel to Annemasse in France to donate, paying his own travel costs there and back.

Since his blood can be given to anyone with a negative Rh blood type, Thomas could save countless lives. But if he ever needs blood himself, he can receive only Rh_{null}blood. If he donates a unit for himself, he has to permit it to be used by anyone else who might need it. This leaves Thomas dependent on other Rh_{null} donors. But of the other 40-odd people known worldwide with Rh_{null} blood, only six or so besides Thomas are thought to donate. And they're all a long way away: Their locations include Brazil, Japan, China, the U.S., and Ireland. The reluctance to donate is perhaps understandable, but it places an added burden on the people who do give their blood. It's also probably why Thomas, when Peyrard and I met him in Lausanne, greeted us with mild amusement. "Is it interesting to put a face to the bag of blood?"

Over tea, he described the impact of his blood on his life. As a child he couldn't go to summer camp because his parents feared he might have an accident. As an adult he takes reasonable precautions: He drives carefully and doesn't travel to countries without modern hospitals. He keeps a card from the French National Immunohematology Reference Laboratory in Paris, confirming his Rh_{null} blood type, in his wallet in case he is ever hospitalized. But one thing that is in his blood—and that of almost everyone growing up in the shadow of the Alps—is skiing. Abstaining seems to have been an option he never even considered.

The only apparent health effect he experiences is mild anemia, which is why he was advised to donate twice a year instead of four times. Intriguingly, one doctor once asked whether he has a quick temper. In fact, the opposite is the case: "I am very calm. If it's just my personality or if my blood has an impact or not, I don't know."

On the whole, Thomas is laid back about his "condition." "I don't have a problem like

hemophilia that has an impact on daily life. In that sense, I'm lucky. I'm glad also that when I was told I had this special blood, they told me it's okay to have children. I was allowed to have a family, so I'm happy."

Donors like Thomas never learn what has happened to their blood—and hematologists don't fly across borders to express their appreciation. But on this day, as we sat in a room full of spring sunlight looking out at the hazy white-flecked peaks, Peyrard told Thomas that his blood had saved lives. Just recently, a unit was sent back from France to Switzerland for a young child who would otherwise have died.

On one level, Thomas' blood does divide him from the rest of us. On another, as the French philosopher Simone Weil observed, every separation is a link.

And Thomas' different blood has given him the odd unexpected perk. When he was due for conscription, the doctor who first told him about his blood—Dr. Marie-José Stelling—wrote to the army saying it was too dangerous for him to do military service, so he was exempted. Over the course of the past 40-odd years, Thomas and Stelling have developed a particularly close relationship. Last year, she joined him and his family and friends to celebrate his 50th birthday party on a boat on Lake Geneva. "She was very kind," Thomas says. "She saw the human aspect of being Rh_{null}—not just a bag of blood."