Searching for Special Blood

An Inside Look at the American Rare Donor Program and the Importance of Recruiting Unique Donors

By Al Staropoli
AABB CONTRIBUTING WRITER

D.T. has her blood shipped thousands of miles from South Africa all the way to a hospital in Baltimore. Although there are millions of donors for some types of blood, D.T.'s blood type is so rare that there is not a single known donor in the U.S. that can match it. To find a suitable blood donor, D.T.'s physicians turned to the American Rare Donor Program (ARDP).

D.T. is an African-American woman in her 40s with sickle cell disease. She has a long medical history that includes episodes of acute pain and life-threatening anemia requiring chronic red cell transfusions. Over time, she has developed antibodies to red cell antigens that she lacks. And she lacks many antigens — her phenotype is C-, E-, K-, S-, Fy(a-), and hr^B-.

While the ABO and Rh blood group systems are the most well-known, several others exist. Systems such as Duffy, Kidd, Kell, Diego, Colton, P, Xg and Indian are some of the nearly two dozen systems recognized by the International Society of Blood Transfusion, the organization that has helped to standardize them. These systems — which were often named after the patients first discovered to have these rare types of blood — identify nearly 600 red blood cell antigens.

Generally speaking, a person's blood type can be considered rare if it differs from the majority of the population in one of three ways: either the person has red blood cell antigens not commonly found in most of the population, lacks antigens that are common in most of the population, or is deficient in IgA — the immunoglobulin that may help fight infections.

Strictly speaking, a person's blood type is rare if only one of 1,000 people has or lacks the same red blood cell antigens. A blood type is very rare if the match is one in 10,000. D.T. lacks so many antigens that it makes her blood unique even within the rare donor community. For D.T., there simply was not a match in the entire country.

Patients who have sickle cell anemia, like D.T., make up nearly 33 percent of the requests made to ARDP.

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Genesis

In the early 1960s both the American Red Cross (ARC) and AABB realized there was a need to organize information about rare donors. Each organization began compiling a list of donors, thus creating the ARC Rare Donor Registry and the AABB Rare Donor File. In November 1998, these two lists — which by then were in electronic form — were consolidated to create one database of nearly 36,000 active rare blood donors. Today, both organizations provide funding for the program, which currently has 81 reference laboratories as members.

ARDP's "headquarters" is located in Philadelphia at ARC's National Reference Laboratory for Blood Group Serology. All requests for rare blood units are sent to this location, which also is the only site that has access to the database of rare blood donors. Requests can be placed at any time, seven days a week.

A National Search

The search for D.T.'s blood type began within the U.S. With this type of search, the medical facility where the patient is being treated makes the initial request to the local blood establishment. If this blood supplier cannot fill the request but is a member of ARDP, it can extend a search to other members of the network by faxing a request to ARDP.

After the request arrives at ARDP, a database query is performed to produce a list of member facilities that may be able to provide a match and fulfill the request. Once contacted, each facility on the list checks its inventory for the desired rare unit of blood. If a unit is found, ARDP will connect both facilities so that shipping arrangements can be made and the blood can be delivered to the patient.

In the situations when no units can be located, ARDP initiates a nationwide search by broadcasting a request to all 81 member laboratories. The purpose of this broad search is twofold: to identify any units from rare donors that may not yet be registered in the ARDP database and to locate units imported from overseas that were not previously used.

If this search is unsuccessful, the ARDP manager will discuss other alternatives with the requesting facility, such as the possibility of an autologous donation, or locating and testing the patient's siblings. As a last resort, ARDP will launch an international search.

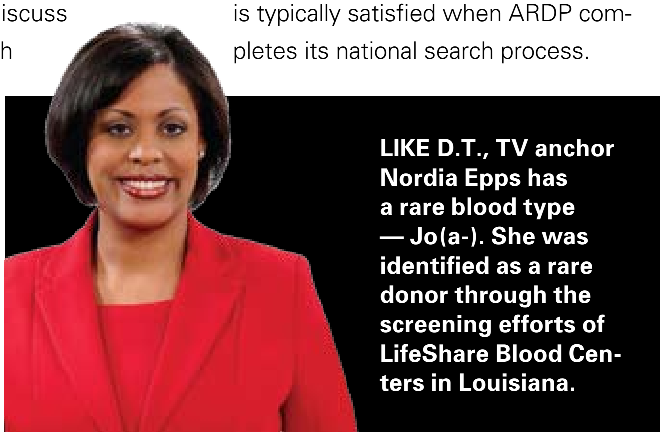
Going Global

An international search is conducted among countries that also have rare donor registries, including Canada, China, Israel, Japan, the Netherlands, South Africa and the United Kingdom. In D.T.'s case, only a few matching units of blood were located in South Africa.

Once the units were found, the blood was shipped by the South African National Blood Service to the facility that initiated the request — in this case, ARC's Greater Chesapeake and Potomac Blood Services Region in Baltimore, which in turn delivered the units to Johns Hopkins Hospital, where D.T. was being treated.

"Searching internationally involves many FDA regulations," said Cindy Flickinger, system manager of the ARDP at ARC in Philadelphia. "Donor blood is certainly tested in other countries but may not be tested by methods licensed by the FDA."

Several criteria mandated by FDA need to be met to allow for the search and shipping of international units of rare blood. For example, a global search can only be initiated once it is confirmed that no available matching units can be found in the U.S. This FDA stipulation is typically satisfied when ARDP completes its national search process.



LIKE D.T., TV anchor Nordia Epps has a rare blood type — Jo(a-). She was identified as a rare donor through the screening efforts of LifeShare Blood Centers in Louisiana.

A second criterion requires that the receiving facility have a procedure to ensure that the imported unit cannot be used except in special circumstances. Imported blood units are considered "unlicensed" by FDA, since they may not meet FDA-mandated testing criteria, and these units cannot be placed into a facility's general inventory.

The physician treating the patient also must sign a letter stating that he or she understands the unlicensed nature of the blood, will notify the recipient that the blood is unlicensed, and will only use the blood for the designated patient.

Once this letter was submitted, D.T.'s blood was transported to the hospital — the successful conclusion to a process that depends on the skills and knowledge of ARDP and its members.

American Rare Donor Program At-a-Glance*

- 36,000 active rare blood donors listed.
- 3,500 new donors added every year.
- 1,500 units shipped per year.
- 93 percent of requests completely or partially filled.
- 81 reference member laboratories.
- 55 monthly requests for rare blood.
- 33 percent of requests are for patients with sickle cell disease.
- 8 countries received or sent blood though the program.

*Approximate figures.

Membership

To become a member of ARDP, a facility must earn immunohematology reference laboratory (IRL) accreditation from AABB and/or be an ARC national testing laboratory. Facilities with pending AABB accreditation status are granted provisional ARDP membership during this two-year process. Non-accredited labs can request rare units of blood from ARDP but must rely on the services of an ARDP member.

Once a facility is accredited, it is automatically considered a member of the ARDP network. This status allows the facility to either send requests directly to ARDP for rare units of blood or directly ship them to other members.

Members also may submit a rare donor’s unique blood type, along with identifying information, to the ARDP headquarters in Philadelphia. There, trained staff enter the data into a secure database that contains multiple verification processes to ensure accuracy. ARDP requires the facilities it works with to confirm the address of every rare donor twice annually to keep the database up-to-date.

Roughly 300 to 400 new rare blood donors are added to the ARDP database every month. Phenotypes found in the African-American population are the hardest to find, perhaps because of the chronic need for blood components for sickle cell anemia patients and the relatively low donation rate in the African-American community.

Still, 94.9 percent of requests for sickle cell patients with rare blood types were completely or partially filled by ARDP from the beginning of 2005 to mid-2006 — a figure slightly higher than the 93.6 percent fill rate for all requests. During this period, a total of 1,070 requests were made to ARDP, of which 351 were destined for patients with sickle cell disease.

Over the last few years, 29 requests have been made for the phenotype O, r”r”, K:-1, Jk(b-). There are only 12 donors of nearly 36,000 in the ARDP database with this phenotype, and three of them are over 75 years old. Although 24 of the 29 requests during this time were filled, a great need remains to identify more donors with rare blood types.

Many labs routinely screen for rare donors as part of the criteria they must meet to retain ARDP membership. To maintain member status, reference laboratories must fulfill at least one of the following criteria every year:

- Registering at least 10 rare blood type donors.
- Shipping at least 15 units to other laboratories through ARDP.
- Performing a family study to identify rare donors.
- Providing antisera for another member to identify rare donors.
- Screening at least 1,000 donors for high-incidence antigens.

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This type of participation increases the total number of rare donors identified, which benefits everyone. “We want reference laboratories to be an active part of the network, thus helping patients in communities throughout the country and, in some cases, around the world,” said AABB’s Jamie Blietz, director of the National Blood Exchange, which records all rare units as part of its blood resource-sharing program. “By performing these functions, reference laboratories contribute significantly to the continuation of the program.”

Identifying Rare Donors

Some facilities identify rare blood type donors by performing mass antigen screening. Typically one or two antigens are tested for in large batches. Detecting the lack of one or more antigens can identify a rare blood donor. Additional testing can reveal if the blood lacks other antigens commonly found, or contains antigens not commonly found, in the general population. Other approaches also exist.

“Different places have their own practices for how they screen and try to find rare donors,” said Flickinger. “It can vary from site to site.” The ARC National Testing Laboratory in Detroit, for example, randomly selects 50 group A and O donors periodically for screening for C, E, c, and e.

LifeShare Blood Centers in Louisiana began screening group O African-American donors for several high-frequency antigens. “Since August 2000 we have identified more than 200 rare donors,” said Trudie Allen, director of business development at LifeShare. “Obviously we can’t use all these units so we freeze them,” she added. Many of these units were eventually shipped to other ARDP members in need.

“The majority of blood centers screen their donors for high-frequency antigens based on the ethnicity of their [collection] population,” said Allen. Screening of all donors, however, is not often performed due to limiting resources such as antisera, staff and costs.

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Special Considerations

“It is important to make rare donors realize that they are very special and that lives truly depend on them donating,” said Flickinger. “Donor center staff need to come up with a way to recognize them and encourage them to donate.” Others seem to agree.

Allen believes that the word “rare” should be used sparingly with donors. “The term ‘rare’ can frighten donors,” she said. “Most will not donate because believing their blood is rare makes them want to keep it for themselves. Instead, we tell them that they are special donors.” At LifeShare, a letter also is sent to all newly identified rare donors explaining what it means to have a special blood type.

Allen also will let some donors know where the blood center is shipping their blood. If donors know their blood is being shipped to a place far away, such as Bermuda, it makes them feel special because they know that they may be one of only a few blood donors in the country that are a match for that patient.

Community Blood Centers of South Florida uses another approach — sending a rare donor T-shirt to newly identified donors to help them understand the importance of their contributions. The center also sends a special mailing to rare donors during the holidays.

Although ARDP can help expedite the search and delivery of units of rare blood, it can only do so when they are found. Although there is a great need to identify and recruit rare blood donors throughout the United States, it also is important to maintain an adequate supply of blood on the shelves, said Flickinger. “The rarest blood is the blood that is not available when it’s needed, no matter what the blood type,” she added.

For more information on ARDP, e-mail ardp@usa.redcross.org.