

# Partners for Life: the transfusion program for patients with sickle cell disease offered at the American Red Cross Blood Services, Southern Region, Atlanta, Georgia

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The American Red Cross Blood Services (ARCBS), Southern Region, located in Atlanta, Georgia, currently serves 128 hospitals, primarily in the state of Georgia, with a service area of 60,000 square miles. The region distributed approximately 350,000 units of RBCs to its customers in 2005. Georgia has a population of 8.2 million, with 4.5 million residing in the metropolitan Atlanta area. Of the four major counties encompassing this metro area, African Americans make up the majority of the population in two of these (DeKalb and Fulton Counties). In metropolitan Atlanta and throughout Georgia, there are many patients, mostly African Americans, with sickle cell disease (SCD), who are in need of RBC transfusions.

Since January 1993, the ARCBS Southern Region has offered a phenotype-matching transfusion program for patients with SCD called Partners for Life (PFL). The physicians and staff at the ARCBS Southern Region Immunohematology Reference Laboratory (IRL) have worked closely with the faculty of the Departments of Adult and Pediatric Hematology and Oncology at the Emory University School of Medicine as well as at the Morehouse School of Medicine to develop and further refine the PFL program. Most of the patients with SCD enrolled in the PFL program are treated by these same faculty physicians at the Georgia Comprehensive Sickle Cell Center, consisting of three major children's hospitals in Atlanta: Children's Healthcare of Atlanta at Egleston Hospital, Children's Healthcare of Atlanta at

Scottish Rite Hospital, and the Hughes Spalding Hospital of the Grady Health System.

In February 2006, Children's Healthcare of Atlanta also assumed responsibility for the management of services at Hughes Spalding Hospital. Today, Children's Healthcare of Atlanta is the second largest pediatric healthcare system in the United States. The Children's Healthcare of Atlanta system comprises 430 licensed beds, 63 of which are dedicated to hematology and oncology. Each year, Children's Healthcare of Atlanta manages approximately 450,000 patient visits, 21,400 hospital admissions, 33,800 surgical procedures, 211,300 emergency department visits, and 8900 specialty clinic visits.

The American Family Life Assurance Company of Columbus (AFLAC) Cancer Center and Blood Disorders Service of Children's Healthcare of Atlanta treats approximately 1000 pediatric patients per year who have a diagnosis of SCD. Approximately 300 of the Children's Healthcare of Atlanta patients with SCD are enrolled in the PFL program, and of these, nearly 175 are chronically transfused, using the simple transfusion, phenotype-matching protocol of the PFL program. Many of these pediatric patients also require one or more acute RBC exchange procedures each year, due to various complications of SCD.

The PFL phenotype-matching protocol has been essentially identical since its inception in 1993. Patients with SCD are extensively phenotyped by the

ARCBS Southern Region IRL upon entry into the PFL program, before their first transfusion. Patients are separated into two categories: Category I patients have no history of prior antibody formation; Category II patients have already made one or more antibodies when they enter the PFL program.

Category I patients receive RBCs that are phenotypically matched for C, E, c, e, and K. Category II patients receive RBCs that are phenotypically matched for C, E, c, e, K, Fy<sup>a</sup>, Jk<sup>a</sup>, and Jk<sup>b</sup>, as well as for any other RBC antigens to which the patients have already made antibodies.

All PFL patients receiving simple transfusions are provided with RBCs that are HbS negative, leukocyte-reduced, and (if at all possible) less than 14 days old. For patients with SCD undergoing acute RBC exchange, every attempt is made to procure the appropriate phenotypically matched RBCs that are less than 10 days old.

RBCs that are CMV negative or irradiated are not routinely provided to PFL patients. On rare occasions, such as for transfusion of those patients preparing for or undergoing marrow or stem cell transplants for SCD, irradiated or CMV-negative components may be requested and provided.

From 1993 until 2000, the PFL program was a limited-donor, phenotype-matching program, with each PFL patient being assigned between eight and ten partially phenotypically matched blood donors. PFL blood donors would commit to donating RBCs for their “partner” patients with SCD, according to the chronic simple transfusion schedule set for each of the patients.

Although the PFL program was successful in reducing the alloimmunization rate in this group of children during that 7-year period to less than 7 percent, down from the previous rate of more than 20 percent, only 6 percent of PFL patients received all of their RBC transfusions exclusively from their PFL donors. The vast majority of PFL patients received a combination of RBCs from their PFL donors and RBCs from phenotypically matched units (using PFL Category protocols) from the general blood donor pool. The reasons for this lack of adherence to protocol are many, and have to do with the complicated logistics of matching a specific donor’s blood unit with a specific patient’s transfusion schedule.

Another component of the difficulty in having only PFL units go to each PFL patient is caused when PFL

patients present to nonparticipating hospitals in (typically) emergent situations. Although the patients’ guardians have always been given PFL cards stating their children’s RBC phenotypes and any RBC antibodies already made, many of these children received RBC units at nonparticipating hospitals that were not phenotypically matched, contributing to the 7 percent alloimmunization rate observed in PFL patients.

Given the complicated logistics and higher costs associated with the special recruitment of partner donors, the constant and often confusing communication with hospitals about each PFL patient’s transfusion schedule, the difficulties in scheduling partner donors’ collections to meet each separate patient’s transfusion schedule, the “no-show” rate for donors and patients, and the time-sensitive shipping of the PFL donor units, the ARCBS Southern Region converted, in 2000, to the use of phenotypically matched RBCs from the general donor pool for its PFL program patients. This change instantly created a larger pool of donors from which to screen units for rapid provision to SCD patients.

This change also made the logistics of the PFL program more efficient, especially as regards effective communication between the blood center and its partner hospitals. Each week, the hospitals now electronically send the ARCBS Southern Region IRL a list of all PFL patients who are scheduled for chronic transfusion during the following week. The IRL then tests for and determines the appropriate RBCs needed for each patient scheduled for transfusion, and ships the freshest units possible prior to the anticipated date of transfusion.

The alloimmunization rate in the PFL program is currently around 5 percent. It is believed that the rate has not dropped closer to 0 because many PFL patients continue to present to nonparticipating hospitals for emergency transfusions and often receive non-phenotypically matched RBC units at those hospitals.

There is currently no specific telerecruitment strategy for recruiting blood donors into the PFL program. The ARCBS Southern Region does have an active African American blood donor recruitment campaign; the donor recruiters are knowledgeable about SCD and the importance of African American donations to the care and well-being of patients with SCD.

A unique and special contribution to the success of the PFL program in building an appropriate blood inventory has been the region’s nationally recognized

Minority Donor Recruitment Advisory Board, comprising African American leaders in government, business, nonprofit, religious, and other organizations throughout the State of Georgia. These board members have truly embraced the cause of increasing blood donations by African Americans; they emphasize the importance of blood donation daily within their places of business, their communities, their churches, and in other settings as well. They personally host or support blood drives at churches, businesses, and other organizations comprising primarily African Americans, including the Historically Black Colleges and Universities of the Atlanta University Complex. These college campuses have strongly supported the ARCBS Southern Region in holding successful blood drives on several occasions each year.

The success of this recruitment campaign in raising awareness about the importance of blood transfusion within the large African American population in Georgia has greatly contributed to the region's ability to maintain the appropriate inventory with which to supply partially phenotypically matched RBCs to all patients with SCD in the region's service area.

A special communication process occurs daily among the collections staff, the donor information databases, the data entry employees, the manufacturing laboratory personnel, and the IRL staff within the region, to identify appropriate units for testing and phenotype matching. Approximately 13 percent of all donors in the ARCBS Southern Region self-identify as African American on their blood donation records. RBCs from these donors are initially screened by the IRL for C and E, using automated RBC typing equipment. When additional serologic testing identifies a donor with the correct phenotype for a PFL patient, a "flag" is entered by IRL staff into the computer system, so that any future donations from that donor will be sent directly to the IRL after RBC processing and testing.

After initial identification, donors are informed of their special RBC phenotype status via a letter, explaining the importance of their donations to patients with SCD; a special PFL wallet-size card is included in the letter. This card may be presented by the donor to collections staff members at blood collection sites, to further identify these special units

for patients with SCD. Of note, approximately 400 PFL donors from the former limited-donor pool program remain actively involved in the "new" PFL program, and they donate at regular intervals to provide RBCs for any PFL (or SCD) patient in need.

Approximately 5500 phenotypically matched RBCs were distributed last year for acute and chronic transfusions from the ARCBS Southern Region to patients with SCD who were actively enrolled in the PFL program. It is estimated that at least 4000 blood donors with the correct phenotypes are needed each year to support the ARCBS Southern Region's PFL phenotype-matching program. This estimate includes many variables, such as the predicted number of units to be distributed for PFL patients during the year, the rate of unsuccessful donations (as a result of "quantity not sufficient," donor deferrals, etc.), the RBC discard and donor "no-show" rates, and the number of times each year each donor gives blood. Of note, the majority of PFL donors donate more than once per year.

It is important to note that many phenotypically matched RBCs are supplied by the ARCBS Southern Region to patients with SCD who are not officially enrolled in the PFL program; most adults at the academic center's hospitals (as well as at other large hospitals throughout the state) who require transfusion for SCD receive phenotypically matched units from the ARCBS Southern Region, most often using the same phenotype-matching protocol as for PFL. Many of these adults are on chronic transfusion protocols; many often require acute RBC exchange transfusion (erythrocytapheresis) as a result of acute chest syndrome, cerebrovascular accidents, multisystem organ failure, and other complications of their disease.

Each year, approximately 12,000 phenotypically matched RBCs are distributed to meet the transfusion needs of all adult and pediatric patients treated for SCD within the 60,000 square-mile service area for which the ARCBS Southern Region is the primary blood supplier. Using the same variables as were considered above (discard rate, no-show rate, etc.), it is roughly estimated that at least 10,000 blood donors with the appropriate phenotypes are needed each year to support the transfusion needs of all patients with SCD in the State of Georgia.

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