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He's only four, but Alexander has a big need

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Alexander Phan, 4, reads with his father Steve Phan. The youngster is suffering from a rare disease and needs a bone marrow transplant. A donor drive is set for this Saturday at St. Mark's Church. Photo by Rochelle Ballin.

For a four year old, Alexander Phan is extremely intelligent. When he isn't playing with his 19-month old sister Kayla or his six-year-old brother Peter, he is sitting at the wooden table by the door of his family's apartment, writing.

He has a notebook and his own pen. He uses them to write words and not just the words that a four year old would usually write, like "cat" or "dog" or "ball." Those words are in there, too. But so are "watermelon" and "strawberry" and "family."

"He sits and writes on his own," said Alexander's father, Steve Phan. "We don't make him do it. He is very smart."

The day before Alexander became sick last June, he won the reading award at the Ellison-Parks Early Education Center. He was running a 99 degree fever and his father rushed him to the hospital right away.

"The doctor sent us home," said Steve. "Because I'm the father I know something better than the doctor. He sent us home and I sent him back right away another day."

Steve's intuition kicked into overdrive and insisted that what the doctors originally diagnosed as pneumonia was much more than that. A few weeks later, Alexander was diagnosed with hemophagocytic lymphohistiocytosis or

HLH, a rare disease that attacks 1 in 200,000 children born every year.

According to the Histiocytosis Association of America's website, HLH occurs when the body produces an overabundance of histiocyte, which are cells created by the bone marrow, and lymphocytes. The cells travel to different parts of the body to help fight infection. When too many of these cells are produced, they attack the good tissue and can cause organ damage.

The actual cause of HLH is unknown. The primary form is inherited, while the secondary form develops from atypical activity in the immune system. While doctors do have an understanding of the disease now, it is still a life threatening disease and is very difficult to treat.

Alexander has spent the better part of the last six months or so, in and out of the hospital and on and off of chemotherapy. All the activity has taken an emotional toll on the Phan family.

"He cries because they are so many tests and his hands are blue because they use the medicine to find his veins," said Steve Phan, who works at Dorchester's Richard J. Murphy School. "He understands that something is wrong and Peter understands because we spend a lot of time in the hospital."

Because of Alexander's illness the Phans have moved from their home on Talbot Avenue in Dorchester to Cambridge, to be closer to Steve's mother and sister, who help his wife care for Alexander and Kayla during the day, while dad works as a para-professional in the special needs class at the Murphy School.

Since Alexander has been sick, his father's colleagues have gone above and beyond to do what they can for the family. Rosemary Connors, the school nurse at Ellison-Parks, is spearheading a Bone Marrow Donor Drive that is being held this Saturday, Dec. 20 in an effort to find a donor for Alexander.

"I am very thankful for anyone to help me at this time," said Steve Phan. "The Murphy school is very good to me. When I need to leave and when I want to stay home, they understand."

The disease has progressed to the point where he needs a bone marrow transplant. The entire Phan family has been tested, but no one is a match for this quietly curious little boy.

Mr. Phan called Rosemary about a month ago asking for her help because Alexander was very sick and in need of a transplant. She was very familiar with Alexander and older brother Peter.

"Dad would always drop the children off and pick them up like clockwork," said Rosemary. "I would always know what time of day it was when I saw him."

The first call Rosemary made was to the National Marrow Program Registry, where she spoke with Chris Mulcahy, who is in charge of community outreach and setting up donor drive for people who are in need. The second call she made was over to St. Mark's Church on Dorchester Avenue which has a very large Vietnamese congregation. In Alexander's case, it is preferable that the donor be of Asian descent.

If the donor and the recipient are of the same ethnic background, the match works better. Unfortunately for Alexander, there is a severe shortage of Asian donors.

"Asians in general only have a 25 percent chance of finding a match," said Chris. "There are not enough in the registry. About 64 percent of Caucasian, 45 percent of Hispanics and only 17 percent of Black and African Americans find a match."

Because Alexander's case call for a bigger issue than just finding him a donor, the federal government is covering the cost of typing anyone who goes out to the drive to get tested.

"Donors need to be 18 to 60," said Chris. "They need to be in good health and they need to be willing to donate to any patient that they match."

Steve Phan is hoping for a miracle for his son, whose favorite book is Goldie Locks and the Three Bears, and who has "the same sweater and pants as Peter."

Steve Phan and his family has traveled to New York's Memorial Sloan-Kettering Cancer Center in order to get more concrete help for Alexander than the have been able to get at Children's Hospital in Boston.

"If the bone marrow fits together, he'll be just fine," said Mr. Phan. "That, they just found out last week at the hospital in New York."

For Alexander, being sick has left him with a little less energy than he had before, but the same things that make any little boy happy still work for him. He recently got a letter from Santa Claus. His favorite movie is The Polar Express. He enjoys playing in catch with Peter and Monkey in the Middle, where, according to Peter, Kayla is usually the monkey.

What he seems to miss most is going to school and interacting with his classmates.

"They welcome him, but they worry about him," said Mr. Phan.

He was supposed to start school in September, but the reoccurrence of his 105 degree fever every time he stops chemo has forced his parents to keep him home for fear of him become sicker. He is now on his third round of chemo.

"He asked me, he wants to see his friends from school," said Mr. Phan. "His teacher [from last year] called him last week and wants to give him a present for the holiday."

Rosemary is doing her best to get help for Alexander. She and some Boston area teachers have made it their mission to help him. The Boston teacher's union has also been understanding of Phan's situation, allowing him to take the time off that he needs to care for his son and distributing information is an effort to get help for Alexander.

"When a child is sick, it is not just the family's problem," said Rosemary. "It becomes a community problem as well."

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