A Patient's Story

A Brave Child's Dream for Cancer Research

Alexandra "Alex" Scott was an upbeat, spirited little girl who developed cancer before her first birthday.

Alex's cancer treatments began when she developed neuroblastoma as a baby. Doctors removed most of her tumor, but more grew back. Over the next three years, Alex had chemotherapy and more surgery.

When the chemotherapy no longer worked, parents Liz and Jay Scott brought Alex to the Children's Hospital in Philadelphia for experimental treatments, which included stem cell treatments.

"We were told by several hospitals that there were no more treatment options and we should just enjoy her last days," says Jay. "But the experimental treatments gave her 4-1/2 more years with us."

Those precious years enabled Alex to be a kid and to revel in the love of her parents and brothers.

"Experimental treatment is a different decision for every parent," says Liz. "In the back of your mind you're always hoping for a cure, but in Alex's case, the chances of a cure were small. The treatments gave Alex a lot more time. Even if you don't feel hope for a cure, there are ways to extend life and quality of life."

During the extra few years that the experimental therapy bought her, Alex was an inspiration not only to her family, friends and research team, but to people around the country.

Three years after she began experimental treatments, Alex asked her parents if she could set up a lemonade stand by their house in Manchester, Conn.

"We kind of laughed," says Jay. "We thought she was going to use the money to buy a toy."

But Alex surprised everyone. Her lemonade stand raised $2,000, which she donated to 'her doctors.'

"All kids want their tumors to go away," she explained.

Word of Alex's annual lemonade stand spread. Everyone wanted to support the brave girl who raised money to help others. People flocked to the stand, which she set up annually and set up stands of their own.

Eight-year-old Alex lost her battle with cancer in 2004. She died at home, surrounded by her family. But even by that tender age, she had realized her dream. She had raised more than $1 million for childhood cancer research and volunteers in every state had joined her cause by setting up annual lemonade stands.

In 2005 Liz and Jay established the Alex's Lemonade Stand Foundation to carry on Alex's work. The foundation has raised more than $40 million for childhood cancer research.

"Any strength and heroism we may have shown was coming from Alex, and seeing how she dealt with things," says Liz.

How can I weigh the risks of participating in a clinical trial?

Participating in a clinical trial is an intensely personal decision, and the stakes differ for each person.

For those with a serious, advanced stage disease, even a slight chance of getting a more effective treatment makes the decision easy. For healthy volunteers or people with less critical conditions, however, the risks of participating need to be balanced against the possible rewards.

Most people who consider participating in a trial do some soul searching. Some people choose to participate:

- **To gain access to new treatments.**
- **To advance science and help others.**
- **To earn extra money.**
- **To receive free medical care.**

Many volunteers are searching for a cure for themselves or for others who suffer from their condition. They want to make a healthier world for their children and grandchildren. Others are attracted by the financial compensation that some trials offer or the lure of free medical care: In a clinical trial, the experimental treatment is typically free to the participant and researchers usually monitor volunteers' vital signs and pay attention to their symptoms and overall health while they are participating in a trial.

While many volunteers benefit from participating in a trial, as a potential volunteer you need to consider the risks you might face:

- **You might get a placebo instead of the test drug.** Placebos are inactive treatments or "fake" drugs. Some trials include placebos so researchers can see whether the experimental treatment works better than no treatment at all. If you receive a placebo, you will not receive an active treatment for at least part of the test period. As a result, your condition may worsen.

- **You may be exposed to harmful side effects.** Although many volunteers experience only minor side effects or none at all, serious side effects are not uncommon.

- **A standard treatment is already available.** If your current treatment is helping, you may prefer to stick with it, rather than try a new treatment that might not work.

- **Taking part in a trial may be inconvenient.** When you participate in a trial you agree to do everything that's spelled out in the informed consent document. That might include frequent clinic visits, uncomfortable procedures or "homework" like keeping a journal.

- **You may incur unexpected costs.** Although the study sponsor pays for the study drug and direct medical care in most clinical trials, you might have to pay other costs, such as parking, transportation or lodging, associated with the visits.

In the end, your decision about whether or not to participate really depends on your answers to two questions: Do I have all of the information that I need to make an informed choice? And: How far am I willing to go?

While the answer to the second question may be subjective and personal, having a clear understanding of the trial can ease the decision making process and help you feel more confident about your choice.