

Acton women battles rare disease in top U.S. hospital

Only one of handful of cases recorded

By FRANCES NIBLOCK
The New Tanner

There will be no finger pointing, no assigning blame and no unproductive what-ifs.

Those are the ground rules as Acton native Susan Lindsay begins a long recovery from an extremely rare brain infection in an American research hospital and the Acton community offers it help with a fundraiser for the family.

While it will take an MRI scan to say for sure, it looks like Susan, 30, is beginning to recover from a deadly fungal disease, a nasty consequence of a rare inherited genetic disorder - Chronic Granulomatous disease (CGD) an immune system deficiency. There are approximately 400 cases of CGD worldwide and no more than five cases where the fungal disease has attacked the brain.

Last week, Susan was moved out of ICU at a National Institutes of Hospital infectious disease facility in Bethesda, Maryland, where she's been since mid-February, and into a ward. She's been upgraded to serious from critical condition following three brain operations totalling 27 hours of surgery.

While her parents, Jim and MaryAnn, brother Ted and sister Sara, and her newlywed husband Mark Verspagen, are cautiously optimistic - there have been many setbacks since Susan became ill - there is also real progress.

"She's improving and we're probably looking at bringing Susan home late spring or early summer," dad Jim Lindsay said on Saturday.

"Things are looking better, but we'll know for sure when we get the MRI results back early next week. Susan is getting dressed each day and we were out in the courtyard feeding the squirrels."

Medical nightmare

Susan's medical nightmare began in earnest last March when she, then manager of the olde Book Shoppe in Acton, felt ill, was losing

weight and having difficulty walking.

Several doctors and many tests later it was determined that she had an infection in her hip - a determined Susan used a cane to walk up the isle to be married in June - but her health continued to deteriorate.

In August, her hip was operated on in Toronto and the fungal infection was identified. Susan spent the next few weeks in several hospitals suffering from severe headaches and scans found the fungal disease had spread to her brain.

For several months, drug therapy appeared to be reducing the size of the brain lesions and Susan walked out of the hospital Christmas Eve on a new medication. By New Year's Susan couldn't walk and was readmitted to hospital in January.

Though her doctor in Peel and the Internet, the National Institutes of Health - a government-run research facility in the U.S.A., became aware of the case and took Susan as a patient mid-February because of the rarity of the disease.

It's a comfort to her family to know she's getting the very best care available in the world for CGD patients. Susan is not charged for any treatment or experimental drugs and the American government allows one family member to fly half-price and receive a hotel discount.

Enormous toll

The toll on the family - emotionally, physically and financially - has been enormous and during all this, Susan's maternal grandfather died.

"You don't know how scary it is, but it is also comforting to have all these doctors and staff at this world renowned hospital caring for Susan," Jim Lindsay said, his tired face brightening when he recount what a doctor said about his daughter.

"He said she's truly a amazing person. He said he'd never seen anybody as strong as Susan for what

she's been through and anyone else probably wouldn't make it."

Susan's mother Mary Ann is a part-time nurse at the Georgetown hospital and says going to work gives her a sense of control while the rest of her life seems out of her control. The ordeal sent her racing to the medical library and while her medical background gives her a better understanding of what's happening to her daughter, it's also "scary" to know what can go wrong.

Jim Lindsay's employer was not accommodating to his need to be at Susan's bedside on a regular basis and wouldn't give him a leave. Susan's employer, olde Hide House president Steve Dawkins, is holding her job for her and has encouraged employees to be tested for the bone marrow registry. The Lindsay family has become advocates for the non-related bone marrow registry - Susan may need a marrow transplant at some point.

No blame

Looking back, her parents say Susan was always slow to heal and now know why she had slow-healing abscesses in her 20s and pneumonia that left some scar tissue. Mom Mary Ann said it's hard not to want to blame somebody.

"As Susan said, you can't point fingers, and you try not to and now that she's getting better, it's easier, but it's hard because Susan manages the book store, lives to read and plays the piano - suddenly her sight is affected and if it doesn't come back, Susan's life will change drastically," Mary Ann Lindsay said, adding her peripheral vision was affected by one of the brain operations.

Despite the vision and short term memory problems, a stress fracture in her lower back, last Wednesday, a surprisingly chipper sounding Susan said she feels "considerably better" and is starting rehabilitation.

"I'm on my way back. I'm relearning how to walk. That's a very weird thing but once you get the strength back in the muscle the muscle memory will come back," Susan said, adding she can't wait to be discharged and return to her home in Guelph.

"Thank you for all the thoughts and well wishes from Acton people who've sent them. I'll be home as soon as I can." Her husband Mark, started to grow a beard, which Susan doesn't like, and vowed not to shave it off until she comes home.

Susan has an e-mail address - susanl81@hotmail.com - and would like to hear more news from home.



Susan Lindsay at graduation

Community rallies help

For all of the people who have asked the Lindsay family what they can do - there now is a way to help.

On June 9, at the Acton Legion, family and friends are holding a benefit dance to help defray the enormous expenses of being at Susan's bedside in the American research hospital.

"Everyone says, 'What can we do to help?' Well, now they can contribute what they really need, money, to help pay for the hotels and airfare to Maryland, for the long distance phone calls and all of the other expenses," Susan's aunt, Doreen

Lindsay said.

"We're hoping for 500 people and if half the people who ask me regularly how Susan is, come to the dance, it will be a great success. We're planning to set up a video camera so people can record messages for Susan."

The fundraiser will feature live entertainment, dancing and a silent auction and a number of local businesses have come forward to offer goods and services for a silent auction. Three major prizes, including airfare and a week at a beachfront condo in Madeira Beach, Florida, courtesy of Ted Tyler Travel

and Canada 3000, a gas barbecue from Home Hardware and goods or a shopping spree at the olde Hide House, will also be raffled.

There are plans to set up a video camera so people can tape a message for Susan to view later. There's also talk of setting up a real-time video link with Susan in her Bethesda, Maryland hospital.

Tickets to the dance are \$20 each and are available at Home Hardware, Blooms Away, the olde Book House and olde Hide House. For more information call Don or Doreen Lindsay at 853-2057.

Susan is an old school chum

By ANGELA TYLER

A few weeks ago, an old friend's father passed away. Although I haven't seen or talked to her in years, I still felt sad for her and called another friend who I thought would want to know.

Near the end of the conversation, I asked my friend Megan, "Did you hear about Susan Lindsay?" Megan and Susan were good friends in school and a group of us always seemed to be around each other. She said she had but neither of us had much information. We only knew from our parents that she was very ill.

We had both saw her working at the olde Book House in the past year and we both had a tale of how she just didn't look like how we remembered. Then again, all of us change with age. At that time I didn't realize she was ill. Later that week, I found out how sick Susan really was and I was devastated.

I have this picture of Susan in my head. An extremely petite young girl, smart with brown chin length hair and always smiling. That was Susan. This past week I rummaged through my old high school year books and from grade nine to grade 13

every picture I found of Susan, she was smiling. Some people may have had that teenage attitude look going, but not her. There were pictures of Susan with the band, hanging out in the cafeteria, dressed as a green Crayola crayon for Hallowe'en and in numerous school events. A girl who's graduation picture included her favourite saying of "hey man" and her pet peeve was the "wallies of Acton High".

Of course, the thing that sticks in my head the most were the three of us on Commencement night. We were the three in the group that were dateless. All glammed up, Megan, Susan and I, dined in formal wear, at McDonalds in Milton before partying the night away as graduates do.

I really haven't had much to do with Susan since that night. However, in a small town like Acton, especially when you grew up here, parents know what is going on with other families and keep their children informed. I heard different things about Susan over the years, about her job at the book house, her brother's children and Susan's marriage.

The other great thing about Acton is when some-

one needs help, the people of Acton do what they can to help. I remember a few years back the townspeople went upon a fundraising venture to purchase a van for Matthew Fleet, a then young Acton boy who was paralyzed while swimming on vacation. Even though I never bowled, I did that night to help raise money for him.

Now it's time again for people in Acton to help. Even though Susan's home is in Guelph now, she is an Acton girl. She was raised here, went to school here and her family is still here.

Susan is suffering from a rare disease that only 400 people worldwide are known to have. It is Chronic Granulomatous Disease. It's a disease that causes a fungus to grow inside her body.

Now, the young woman who should be enjoying a wonderful career, the honeymoon time of her marriage and all life has to offer is in the Isolation Unit of the Maryland National Institute of Health in Washington. She is being cared for by her mother, to weak to move, is being fed by a feeding tube, separated from her home, her husband, her family and her life.

Her treatment is experi-
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Susan and Mark Verspagen were married last June in Guelph