

Catching up with... Susan Lindsay

Former Acton resident continues struggle with rare brain disease

Although her life is still full of many challenges, compared to six years ago, things have definitely improved for former Acton resident Susan Lindsay.

In 2000 the now-36-year-old woman was featured in *The Independent & Free Press* for her determination in trying to regain her life while battling an extremely rare inherited disease—Chronic Granulomatous Disease (CGD)—which caused fungus to grow in her body.

Back then she spent six months in Maryland's National Institutes of Health undergoing several operations to remove fungus lesions that had invaded her brain, hips and lungs. She was on strong doses of antibiotics, anti-fungal medication and steroids and had white blood cell transfu-

sions to kick-start her immune system.

Today Lindsay, who lives in an assisted living apartment in Guelph, says things have improved, and for the past year her condition has been considered stable.

It took some time to get to that state, however, as she had to endure several other operations following her diagnosis in 1990, including operations to remove parts of her scalp bone and lung.

She also had to have both of her hips replaced, which has made her much more mobile, but the vision loss she suffered from the fungal infection in her brain has remained, so she can't drive. She can't work and battles depression.

But, she continues to do things she enjoys like volunteering with an adult litera-

cy program in Guelph, and playing flute with the Guelph Concert Band.

She's looking forward to performing in the band's *Lights, Camera, Action* show at Guelph's River Run Centre at 3 p.m., this Sunday. The show features musical excerpts from such films as *Chicago*, *Chicken Run* and the *Wizard of Oz*. Tickets (\$20 for adults \$15 for seniors, children and students are \$5) are available at the River Run box office.

Lindsay, an English major, who used to manage the Olde Bookhouse in Acton, also enjoys reading.

"If I couldn't read I would be devastated," said Lindsay.

Now separated from her husband, Lindsay, also loves spending time with her dog and cat.



SUSAN LINDSAY

Lindsay doesn't know if or when the virus or fungus will come back, but she does all she can to keep them at bay. She continues to take extensive medication and checks in the Maryland hospital every three months for a check-up.

"For the most part I just take everything in stride now," said Lindsay.

(Lisa Tallyn can be reached at ltallyn@independentfreepress.com)

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