

Gutsy Yvonne Battles Debilitating Illness

Yvonne Foong, 21, author of "I'm Not Sick, Just a Bit Unwell", has her own newspaper column, is a public speaker, and was voted as the Asian Youth Ambassador's "Most Outstanding Youth of the Year 2005". She has achieved all this despite battling a rare chronic condition known as Neurofibromatosis (NF), which among other things, has caused her to lose her hearing. Here, the petite and gutsy lass shares her story and hopes with **Noelle Lim**.

PHOTOS COURTESY OF CHERYL LEONG PEI LI



Life Before NF

As a child I was active, I learned ballet since 7 years old up to grade 6 when I had to stop due to my worsening sense of balance. I learned to play the piano too. In secondary school, I took up karate and earned myself a brown belt. I played squash and sang as a Soprano in the school choir.

I lost my hearing in the right ear in 1999 but my parents did not take my complaints seriously even though I demanded for medical attention. My balance deteriorated since age 13, and by age 16, my parents had to put me in a wheelchair as we finally made our way to the Kuala Lumpur General Hospital. I could barely walk then. I was diagnosed with NF, a rare chronic condition known as Neurofibromatosis, that year.

MRI scans revealed multiple tumours along my spinal cord and a few in my brain - one of which damaged the hearing nerve. I was diagnosed with NF2 and a surgery was immediately scheduled and classified as an emergency.

I became totally deaf at age 19. I

pursued a music diploma after school while I could still hear. But soon, I had to give up that as well. Now, I am studying Psychology in the same college where I used to study music. It sure was memorable meeting my ex-lecturer in music studies.

Change As A Person

I was your average teenager, who did not do well in her studies. I lived everyday without meaning. Sure, there was homework to do, ambitions to hope for, but it was my diagnosis that gave my life a purpose to live by.

I often feel sad for not being able to hear well and actively participate in conversations. I often feel left out in crowds and would remember how I used to be with perfect hearing. I miss singing, dancing, and figure skating. But the fact is that although there are many things I lost, but I gained ten fold. A lot of things I have today would not be mine otherwise. That includes real friendship, experiences dealing with people from all walks of life, giving speeches and inspiring people through writing, traveling to the US

for medical treatments also exposed me to many life lessons. My condition is also causing people to grow up and learn.

Purpose In Life

As a child, I wanted to become a psychologist and serve mankind. But due to limited resources, I at first could not pursue psychology. Little known, God already had a plan. Today I helped more people than I could only imagine. I don't need a PhD and a million dollars to help people. I just need a bit of tribulations, pain and tears, and viola! I have a true story. I am always thankful to God for giving me such a great purpose to live by.

Help From Kind Doctors

Dr Friedman in Los Angeles did my third surgery for free. He did my fourth surgery at a discounted price. My neurosurgeon at St. Vincent Medical Center in Los Angeles also charged me a lower rate. Whenever I went there for medical appointments, they gave me a discount. Dr Friedman did not charge me consultation fees.

When raising funds for surgery, many said it is too expensive and far-fetched. But they failed to see the long-term benefit of having caring doctors.

Cost Of Medical Treatments

NF is a life long illness and the health costs are sure to escalate. I may need around RM4,000-RM5,000 every 6 months for brain and spine MRIs, visual field tests and other tests.

Presently, tumours along my spinal cord have grown back to double the original amount. They affect my cervical spine, all the way down to the lumbar spine. There are several tumours in the brain, at least 2 of them I know are worrisome at the moment. I also have a lot of tumours along my peripheral nerves that can be felt under the skin. Most of them cannot be removed without severing the affected nerve - some involve morbidity risks.

So we are closely monitoring the tumours through periodic MRI scans, noting every millimeter of growth and deteriorations. When necessary, surgery would be done to either debulk the tumours or remove them entirely, depending on many factors.

Raising Funds

My friend, James Tan designed a t-shirt and now a cap. My friend April Yim made earrings and mobile phone straps that matched James Tan's design. She occasionally sponsors me other items too. Other people also contribute in their own ways. One example is blogger, Yue Chin, who sponsored 4 dresses in March 2007 for an auction.

I support myself by writing a weekly column in the YellowPost.

People also donate to my medical fund without purchasing anything. I currently have about RM50,000. This pool of money I use for medical treatments such as MRI scans, visual field tests and medicines whenever necessary. RM50,000 may sound like a big sum, but NF is unpredictable, I may suddenly be hospitalised. Remember, I cannot depend on my parents and I am uninsured. So I just do my part and trust in God to provide for my healthcare.



Writing The Book "I'm Not Sick, Just A Bit Unwell"

My friend, Cordelia Lee who was touched by my life encouraged me to write a book. She told me not to worry about publishing as that would come later. She told me to focus on writing and I did just that, I wrote without any expectations. It was a milestone, as I told my story for the very first time. I cried a lot writing the book. It may seem simple to many, but it was the

WHAT IS NEUROFIBROMATOSIS (NF)?

"There are three distinct types, classified as NF1, NF2, and the newly discovered Schwannomatosis. I am suffering from NF2, which mainly involves the auditory nerves - the brain and spinal cord. It is considered the more severe form of NF," says Yvonne.

"Unfortunately, or maybe fortunately, my condition appears to be more complicated than the average NF2 patient. Because I am developing a lot of rare tumours that do not normally affect NF2 patients. One example is optic nerve tumours that should be prevalent in NF1 patients, but I got it."

"NF is genetic. It could be hereditary, and it could be a spontaneous mutation. I am a case of spontaneous mutation. Neither of my parents have NF."

"There is presently no cure. Research is underway worldwide to find better treatment and a possible cure for NF. Researchers are looking into replacing the missing tumour suppressor gene, which should be present in every healthy person."

"But the more urgent question is not a cure, but rather a better quality of healthcare, which I fervently champion for the betterment of all who require healthcare in Malaysia."

best I could do at that time. It was an emotional release through words.

Helping Others

I am quite transparent in my writings online and that helps people relate with me. An ex-hostess now suffering from Clinical Depression became a constant reader of my blog. So I made a very simple post on my blog, putting up her photographs that generated some responses from my readers. That post is still up today, and people suffering Depression often stumble upon it and decide to e-mail me and share their story.

By my writing about Psychology and my own problems, I have received numerous e-mails from people enduring such problems themselves. I do try to help people in other ways, like donating to charity (from the money I earn through writing) which is nothing to shout about knowing many others do that. But ultimately, writing is my calling.

Life Philosophy

We often hear about living one day at a time. I thought I knew what it means, but I did not. I am still learning about it now. Living one day at a time means today is too tiring and painful that you cannot muster the strength to think of tomorrow's events. I am always out of energy, my back gets tired after 2 hours in college and all I want to do is lay down flat. I used to have big dreams, about spreading awareness about NF, writing a best-selling book, touching lives and what not. Now I just want to live a Godly life everyday, treating those around me well everyday, doing good at my allotted work everyday. Because today's events itself requires more energy that I can muster.

My last surgery was in October 2006. Before that, I was stronger. I could travel and sell shirts everyday. Look how much my body changed in a year.

Helping Yvonne

My book "I'm Not Sick, Just a Bit Unwell" is on sale at MPH, Popular, Kinokuniya and Borders bookstores. You can also buy fashionable accessories, caps and T-shirts from my online store at www.yvonnefoong.com. ■