

Celebrating Our Heroes

3,685 days with Frank

By Josh Martin

Kumiko Forsyth was apprehensive the first time she walked into the Vancouver Island care facility to see Frank. A senior leader in her Buddhist community suggested visiting Frank to practise giving joy and taking away the suffering of others. And although she agreed, she had some nagging concerns.

What would it be like interacting with someone with a fatal, degenerative disease? How would she fit these volunteer hours into her already busy work schedule? Was she really up for the challenge?

Turns out she was. And then some.

With the exception of brief breaks after giving birth to her two children, Kumiko visited Frank every day for 10 years. More than 3,600 visits later, she wonders what life will be like without their daily chanting sessions.

During that time, Kumiko's life has seen a lot of changes: she beefed up her education, got married and started a family. But through it all, she found time to hop on her bicycle and pedal over to see Frank, who had no family of his own in the area.

Frank had Huntington disease (HD): a genetic disease that causes the progressive breakdown of cells in the brain. And although HD had become a big part of Frank's life, Kumiko quickly found out that it did not define him.

She got to know about Frank's past as a talented artist and graphic designer and about his love of nature. When they weren't chanting together by his bedside shrine, they would go outside for walks. And when Frank could no longer walk, Kumiko pushed him in his wheelchair. Frank helped Kumiko too, opening her eyes to the everyday beauty around them. "He often stopped and gazed intently at individual flowers, trees or houses," she says. "I'd never really paid attention to those things before."

Frank also showed her how someone can grow stronger as a person, even as they became weaker physically. In the early days, their chanting focused on Frank and his health. In time though, the tone shifted, with Frank suggesting they chant for others, from world peace to finding a husband for Kumiko. She marvels at the gratitude he was able to express, even in the midst of suffering. "The



last words he spoke were 'thank you,'" she recalls.

Their visits didn't just benefit Frank and Kumiko. Wendy Margetts, the care manager at Aberdeen Care Home, remembers the effects Kumiko's joyful presence had on the entire facility. "It was like a trail of positive energy following on behind her," she says.

Frank passed away peacefully last November. On the day of his memorial service, Kumiko took a page out of the Book of Frank and chanted "thank you" to the man that had such a profound impact on her. "At the beginning of my visits, I could not imagine how Frank would affect my life," she says. "I thought that it would be a challenge to visit him every day, but it became part of my life and a joy."

"I realized that volunteering is not only giving but also receiving a gift from others," she concludes.

In May, HSC recognized Kumiko with an award for her years of devoted service. "I am humbled to receive such an honour from your society," she says.

Thank you Kumiko, we could never achieve what we do without the incredible support from volunteers like you.

If you are interested in learning more about volunteering please contact us at 1-800-998-7398 or at info@huntingtonsociety.ca, there are many ways to give back and make a difference.

Emily Neuman's speech

Emily Neuman spoke at the 2013 Walk to Cure Huntington Disease on May 25th in Peterborough. Her speech captured the challenges that those who know Huntington disease face every day. We wanted to share it with you. Emily Neuman is an active member of the Peterborough Chapter as the YPAHD representative.

I'm sure that most of us volunteers have to pause briefly when asked the question "what exactly is Huntington disease?" How do we explain such a complicated and difficult disease in a mere sentence? No matter how hard we try, we just can't seem to cram that much emotion into a simple short reply. Because of this, people often brush it off, and forget about it. Yet when we're given the time to open up and tell our stories, we often leave people at a loss for words.

Because only then can they understand why HD is often described as a roller coaster, or a nightmare, and even one of our volunteers who's had a double lung transplant due to cancer says that HD is the worst disease she's ever seen – there's nothing else quite like it. It is a ticking time bomb, a race against the clock. It starts off slowly, and then picks up speed as the disease spreads through the brain, and before you know it, it's like a locomotive, changing and worsening faster and faster until you can no longer keep up with it.

Most of us here have been affected by Huntington's in one way or another, so we all know how terrible it is, but every once in a while we need to be able to look on the bright side of things. Each and every person who has acted as a caregiver for someone with HD, grew up surrounded by the disease, is at risk, or has the disease; these are without a doubt the strongest and most resilient people I have ever met.

Today we are fighting not only for a cure, but for awareness and understanding within our community. A huge thank you goes out to all of you who have told your stories time and time again. And to those of you who are dedicated supporters, thank you for coming out and showing that you care. It means more to us than you will ever know.

Let's hope that the 2013 Walk to Cure Huntington Disease is an outstanding success!

Thank you,

Emily Neuman