

WESTSIDE WEEKLY - August 3, 2005



Graduation walk first of many big steps

By Dorothy Brotherton

When Paul Thomas got up from his wheelchair and walked across the platform to receive his graduation diploma, students and guests at the Mount Boucherie Secondary grad ceremonies gave him a standing ovation.

The laborious walk was a result of an agreement Paul had made with MLA Rick Thorpe.

“I made a deal with him. I was to graduate with my Dogwood and walk across the stage. He’s going to take me to Victoria and introduce me in front of the caucus,” explained Paul.

He said it wasn’t really so hard, after he had trained and taken physiotherapy for about four years.

“I set a goal and I achieved it,” said Paul, adding that he felt “really good that it was over and really good that I could--can--walk.”

The ovation was “really loud,” he said with a grin, but it didn’t break his concentration.

Thorpe called it a “terrific achievement” and said he’d make good on his promise to fly Paul to Victoria for the September legislative session.

He and Paul became connected through the Adopt An MLA program, explained Paul’s mother, Christina.

The program, started by parents, aims to connect decision-makers and politicians with people living with disabilities and foster understanding.

“Rick came and had coffee with us and Paul. The Rick picked up on it and has become part of Paul’s network,” Christina explained.

The network is a product of Okanagan Lifetime Networks Association, associated with Planned Lifetime Advocacy Networks that works from Vancouver. Without government funding, the group sets up networks of caring people, friends and advocates for people with disabilities, as well as giving instruction in financial security and trust funds.

It means that a person with a disability is tied into a network of people who can offer support throughout life, first in a formal way, which usually becomes an informal and growing network.

“We told Rick we’d send him Paul’s newsletter and keep him informed but he said he’d like to be part of Paul’s life. He comes for coffee and he’s an official part of Paul’s network,” said Christina. Yasmin John-Thorpe, wife of the Okanagan-Westside MLA, is also involved by writing parts of the newsletter.

Paul’s rare disability is called Glutaric Aciduria Type 1, a genetic and degenerative disorder in which a person is missing an enzyme. Paul is probably the only person in B.C. with the disorder, said his father, Evan.

Evan has become a bit of an expert at working through government agencies and ministries for people living with disabilities. Physiotherapy has been helping Paul, and Randy Goodman of Pinnacle Sport Physiotherapy in Westbank, helped them get into a program that paid for the physiotherapy, but it was cut off when Paul turned 18 last fall.

“That’s when Rick stepped in to try to help. He ended up hitting every wall that we had hit. But he’s not giving up. He said it’s an area the government needs to take another look at,” said Evan. Paul said, “Without physiotherapy I start to feel less in control of my body.”

The next step for Paul is a big one. He hopes to move out of the family home in Peachland, probably into Kelowna.

“I’d like to move by Actors’ Studio. I’m an actor and I’d like to get more included in acting roles,” said Paul.

He has acted in school plays and with a Shakespearean production in the park. He also is starting a business, making DVDs of home movies for people. He calls himself “The Digitizer,” and for now can be reached at 767-9422.

Realizing the goals gets complicated. Vela Microboard, based in Surrey, is helping the Thomas’ develop an individualized plan for Paul. They assist the family in putting together a budget that is presented to Community Living B.C., under the Ministry of Children and Families. Part of disability funding is handled by the Ministry of Health. Most of Paul’s disability cheque must be contributed to the budget. He is only allowed to make about \$500 a month more than his disability and have a small amount in a savings account.

“We don’t say Paul should not contribute, but when it comes to him having a good life, that’s not much,” said Evan. “So between the two ministries we are negotiating a budget that will include a caregiver.” Paul requires 24-hour care.

He explained that many parents of people with disabilities are in their 70s and 80s and are “getting desperate” about how to care for adult children with disabilities.

“That’s why a network and independence are so important, without relying on government.”

Paul is excited about moving out and being on his own. He feels ready to take this important step, in fact, “I can’t wait.”

