

# PAT DANFORTH

## Who I Am Now



*Because of my disability, I became a whole new person.*

*One who could lift themselves from their chair to a toilet and back,  
who could steer straight, who could dream of a future again.*

**A**ll over my house, I have a lot of pictures and sculptures of mermaids because I think we share a connection. Neither of us can walk on dry land, but we both have adapted to our circumstances.

Everybody remembers their twenty-first birthday. It's a milestone that signals adulthood, and for me, a young woman living in Calgary in 1970, that was even truer because I was finally of legal voting and drinking age. Needless to say, my birthday was a big deal, though, as it turns out, not for those reasons.

I had two invitations for my birthday: dinner out in Calgary or a baseball game in rural Alberta. Thinking I should do something different to mark my special day, I chose the baseball game.

It was a beautiful Sunday in May, and we three girls piled into the front seat of the car, a shiny, white convertible. One friend drove, another sat in the middle, and I was happily by the passenger door. Of course, back then, there were no seatbelts.

We were driving along a gravel road, chatting up a storm, not a care in the world, not another vehicle in sight, when suddenly we began to spin out of control. As we went around and around, I bumped up against the door handle. The door sprang open, and I flew out. Everything happened so fast. I remember hitting the ground hard, then bouncing and rolling. The next thing I knew I was in a ditch.

I don't know how much time passed after that, but I vaguely recall people floating around me, including a woman who assured me that an ambulance was on the way. I tried to move my left arm, but when I couldn't, I thought, "It must be broken." Then I tried to sit up. I couldn't do that either.

"How are my friends?" I asked, hoping they were all right. Fortunately, they were. The driver had some bruises on her thighs, and the girl in the middle didn't have a scratch.

We were about three hours from Calgary, near the town of Taber, when we'd had the accident. The ambulance took me to the Taber hospital, and then I was transferred to the intensive care unit at Foothills Hospital in Calgary. There I was completely immobilized: I was put into a special bed that rotated to turn me upside down from time to time so I wouldn't develop bedsores.

I knew my back was broken, but oddly that prospect wasn't nearly as scary as it should have been. I thought everything broken could be fixed. After all, this wasn't the first time I had seriously hurt myself.

I grew up with my two sisters and brother on the Canadian navy base in Esquimalt, BC, near Victoria. My dad was a navy man, and in 1953, when I was four, he had just come back from the Korean War. I thought the navy would take us to all sorts of places around the world, but we were really settled on the west coast and, to my disappointment, the navy never sent us anywhere.

One late summer day, my mother was busy doing laundry. We had a wringer washing machine, which was state of the art for that time. It had



*Here I am at two and a half years old on the porch of our house on the navy base in BC.*

a tub that cleaned the clothes and at the top was a wringer—two rollers that squeezed the water out of each piece of clothing as they were passed through. Basically, what the spin cycle of a modern washing machine does, so there was a good deal of pressure between the rollers.

After my mother had wrung out the clothes, she went outside to the clothesline. Meanwhile, I decided to help by washing up with a facecloth. When I was done, I started to put it through the wringer. At first, I pushed it toward the rollers with my left hand, but it didn't go through, so I put the cloth in my right hand and tried again. That's when my hand got caught between the rollers.

I pulled furiously to get my hand out. When I finally succeeded, my index finger and the tops of the rest of my fingers were in the washing machine.

The next few hours are a little fuzzy in my memory. Fortunately, our house on the base was pretty much right across from the RCMP detachment. My mother carried me there, and the police drove me to

the hospital. I remember sitting in the back of the police car and being bothered by the loud siren. "Could you turn that off?" I asked. "I don't like that noise."

I was very lucky that Dr. Gordon Grant was at the hospital. He specialized in hand reconstruction. While there was nothing he could do to save the index finger, he did save the rest of my fingers to the first knuckle. The fact that he didn't amputate my whole hand became very important later on after my car accident.

As I got older and my hand grew, I was in and out of the hospital for skin grafting. I was there so often that the nurses extended a real privilege to me and let me see the new babies in the nursery. For two weeks every summer, I went in for surgery and came out with a cast that I would have to keep dry for the rest of my holidays, which meant I had to swim with my right arm out of the water. My mother used to laugh and say that she could always tell it was me in the water—I was the kid with her arm straight up in the air.

She was good at seeing the humour of the situation. The truth was that my hospital bills were taking a financial toll on my parents. There was no Medicare at the time, and we were far from wealthy.

One of my earliest memories is when my dad first came back from Korea and found out that my mother had been buying food on credit. She just didn't have enough money to do it any other way, but my dad was angry. "You should never use credit to pay for food," he said. That stayed with me, and to this day I never have.

By the time I graduated from high school, my hand surgeries were over, but my family still didn't have a lot of money.

My parents told me, "We can't afford to send you to university."

None of my siblings had been able to go to university either, but I was disappointed. I wanted to become a kindergarten teacher. One of my favourite memories was when I was learning how to tie my shoes in kindergarten. I couldn't use the fingers on one hand, but my teacher worked with me until I mastered the task, and I wanted to be like her.

I couldn't find ongoing work in BC, so I decided to move to Calgary, where I could share an apartment with my sister Janice, who already lived there. I got a job as a data clerk processing computer punch cards.

And that's what I was doing when I turned twenty-one, when I made that fateful decision to go to a baseball game.

The first family member to see me in the ICU at Foothills Hospital was my sister Janice. I still don't know how she found out about the accident, but my immediate concern was that she didn't tell our parents. "Don't tell Mother and Dad," I implored her. "They'll just be angry and upset." In order to calm me down, she agreed, but of course she'd already told them, and they arrived soon after, not angry at all. They were half expecting I would be dead, so they were just happy I was still alive.

I had broken my left shoulder as well as that shoulder blade. I couldn't use my left arm at all, but it was nothing they couldn't fix. More concerning was my back. I had broken a lot of vertebrae. The good news was that my spinal cord wasn't damaged above lumbar 1, meaning I had lost most of the function in my hips and legs, but I was okay above that. My back needed to be fused. I hadn't had any feeling in my legs since my accident.

I needed the surgery, but I developed pneumonia, so everything was delayed for two weeks while I recovered. But even after all the surgery, I still had no feeling in my legs and only partial sensation at hip level. I persisted in believing that I'd be walking again once my back healed, until finally a doctor told me, "You're paralyzed. At best you could walk with braces and crutches." He said it just like that. I didn't believe him.

What followed was nine long months of recovery, first in the hospital and then in the rehab centre. I was in pain most of the time and on a lot of medication for that, including Valium, which was prescribed to quiet the muscle spasms that often accompany spinal cord injuries.

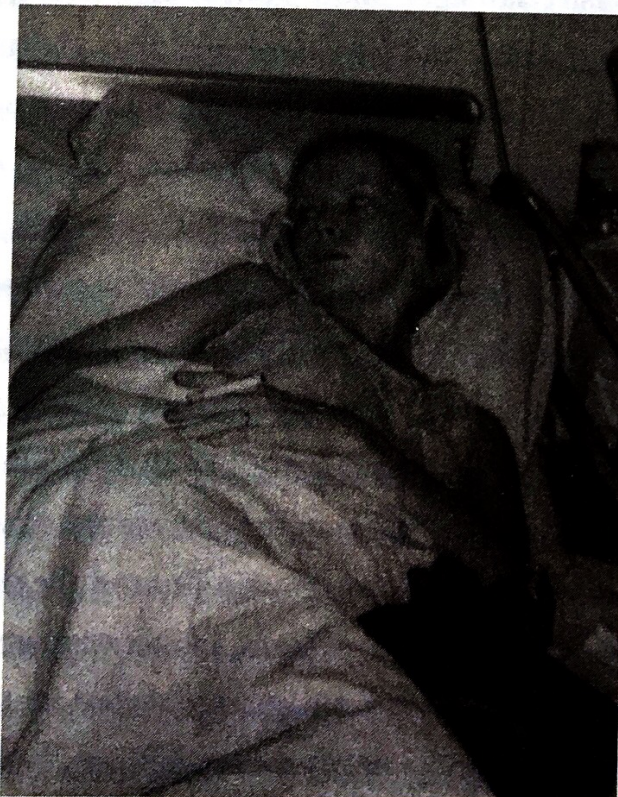
After the first few months of rehab, my left arm had healed enough that I could try using a wheelchair. I remembered a friend of my parents, Helen Austin, who had polio as a child. She had six kids whom I used

to play with at her house. For as long as I had known her, Helen had a wheelchair, which I always thought was completely normal. When the staff helped me into my wheelchair, Helen's image was in my head, and I was confident I was going to be okay because she was okay.

When a representative from the wheelchair company came into my room with the chair, it was a simple manual chair. I was thankful that, years earlier, my doctor had saved the fingers of my right hand. Without them, I wouldn't have been able to steer.

That's not to say it was easy that first day. The hospital hallways were so wide, and I was ping-ponging from one wall to the other wall. I just could not go straight.

The rep watched me and said, "That chair is too big. I'm going to bring you one that will fit you." Sure enough, she came back with a smaller chair, and after that I could navigate much more easily.



*About five months after my accident, in rehab  
at Calgary General Hospital.*

But there was more to life in a wheelchair than just steering. I had to learn how to move from my wheelchair to a toilet and back again. I would practice going into a washroom that had only standard, narrow cubicles because I knew that was what the real world looked like—there weren't as many wheelchair-accessible bathrooms as there are now. It was hard. At first, I didn't have the strength to lift myself from my chair, and so I spent a lot of my time building up my muscles.

I was learning to do everything differently, and nothing was easy or direct. And mentally, I was struggling to adjust to my new reality—life in a wheelchair—in part because the pain medication made me feel numb all the time. I didn't know who I was anymore, and the drugs weren't helping. Eventually, I told the doctors I wanted to stop taking them. They agreed, and very soon the fog I was under began to lift. I realized I would never be the old me again.

Because of my disability, I became a whole new person. One who could lift themselves from their chair to a toilet and back, who could steer straight, who could dream of a future again.

Now when I meet people who have a new spinal cord injury, I tell them, "For the first two years you won't know who you are, but then you will learn about the new version of you."

I knew who I was, but the medical team often seemed to treat me as a case and not as a person. My physiatrist (a doctor in rehab medicine) used to tell me what I could and couldn't do anymore. I remember I could flex a muscle in my left thigh. It didn't do any practical good, but I could do it. One day, I showed the doctor, and his reaction was, "You can't do that."

"But I am doing it," I replied.

"No, you're not. It's a spasm."

"No, it's not. Tell me to do it and I'll do it on command."

But he was insistent. "You can't do that with the level of your injury. You cannot do that."

"What do you know?" I thought.

After that, I decided to do some research on my own and find out as much as I could about paraplegia. There was a library at the rehab centre, and I read a lot of books about people like me. In one, there was a line about a paraplegic woman who had given birth. "Well," I thought, "if you can give birth, you can get pregnant, which I certainly want to do one day, but I don't want to do it just yet."

When I asked the doctor about birth control, he said, "I don't answer those questions. You should go see your general practitioner." So I did.

The summer I left rehab, I went to a camp for people with disabilities in Bragg Creek, just outside Calgary, and there I met Dan. He was one of the counselors, and we ended up dating and eventually getting married.

Just a few years earlier, university hadn't been an option for me, but with the help of what was then called Vocational Rehabilitation for Disabled Persons, a program for people with disabilities that covered the cost of going to university—including tuition, books, and living expenses—I could afford to go to school. I chose to pursue a degree in education at the University of Calgary. Maybe I would become a kindergarten teacher after all.

It was there that I learned a simple lesson that would forever give my life a sense of purpose: Somebody has to be an advocate.

When I went to university, it became apparent very quickly that there were barriers for students with disabilities. There was a small group of us on campus, and we banded together to advocate for changes that would make the school more accessible. For example, the university had one wheelchair-accessible washroom, but it was only for men because apparently only men use wheelchairs or the washroom. I had to laugh at stuff like that or else I'd cry. But we, as disabled people, made our voices heard, and we saw change.

Before my accident, if I wanted to get around, I either walked everywhere or took the bus. After, I had to use a private company that had a vehicle with a wheelchair ramp. They'd take me anywhere I



wanted to go, but a one-way trip cost \$5. That's about \$35 in today's money and it was way more than I could afford. My insurance paid \$120 a month and my rent was \$85. I had to rely on other people to take me places. Dan made sure I got where I needed to go, but it always pissed me off that I couldn't get on the bloody bus.

I encountered barriers all the time. Whenever that happened, I knew I had a choice: I could do nothing, or I could see what I could do to remove the barrier. I never chose to do nothing. I started to talk to other people with disabilities in Calgary and a small action group in Edmonton about the need for greater access to public services. We formed the Alberta Action Group of the Handicapped, now called Voice of Albertans with Disabilities. I served on the board. I was young, and when you're young you can do anything. Dan was very supportive, and he understood how important it was for me to have independence.

Eventually, I did learn how to drive a car—with hand controls instead of pedals. Even before my accident, I had never learned to drive a car, so fortunately I didn't have to unlearn anything, and driving with hand controls came very easily to me. Sometimes I tell able-bodied people, "I don't know what you do with your feet."

Learning to drive wasn't nearly as difficult as getting into the car in the first place. I had to figure out how to move my body into the passenger seat, fold my wheelchair, tuck it into the back seat, close the door, then slide across to the driver's seat. But I became more proficient with practice. I earned my license and got a car, and after that I didn't have to rely on Dan or anyone else to take me to my advocacy meetings.

In 1974, I had a year left at university when my life changed in another big way. I was pregnant and due to give birth in September. Sometimes people with paraplegia can't feel when they're going into labour, so as a precaution, I was put into the hospital in late August, despite me saying I would know when I was in labour. Dan had just gotten a teaching job in Grande Prairie, so he headed out there, intending to race back to Calgary,

a seven-hour drive, at the first sign that I would be giving birth. It was a good plan, but our son, Carl, didn't cooperate. He arrived in the world a couple of hours before Dan arrived at the hospital.

When Carl was two or three weeks old, we joined Dan in Grande Prairie, and I soon continued my advocacy work. I met a woman who was legally blind, and we commiserated on what we needed to change in the city. We knew that two people fighting alone wouldn't get very far, and we looked for who else had disabilities to enlist them in the cause. Grande Prairie is a small city, so we went to the phone book and called each and every number. When someone answered, we simply asked, "Is there anyone in your household with a disability?"

By the end of the phone book, we had a list of about one hundred individuals, which told us that there was a population out there that needed changes. As a group, we attended a couple of city council meetings. The meeting room wasn't accessible, so Dan had to pick me up and carry me up the stairs, but at least they could see that people with disabilities were a part of the community.

We fought for things that would be important for the future. For example, Grande Prairie didn't yet have a bus system, but we got the city to agree that if it ever got a bus system it would be wheelchair accessible. We wanted to ensure that accessibility was integrated from the beginning.

After two years, I was offered an advocacy job in Edmonton. Dan agreed that I should take it, so I never saw the fruits of our labour in Grande Prairie; but today the city has a transit system and every bus is wheelchair accessible.

In Edmonton we found an apartment—though Dan had to build a ramp so I could get into the building—and I began my work. My job was as an information officer with the Alberta Committee Action Group of People with Disabilities, which researched and wrote reports for the government recommending changes in society. For example, integrating accessibility into building codes, including people with disabilities in

human rights legislation, and making it government policy to pay for assisted technology like wheelchairs. I would go down to the legislative building and knock on the doors of elected members to make sure they read our report. Sometimes, I would give them a quick summary of what we were asking for. In other words, it was my job to convince people to enact our changes. I found that most people were willing to listen if I had the right approach and didn't waste their time with other things.

The Alberta attorney general Neil Crawford once said to me, "Pat, every time I see you, you're always friendly and you always stick to what you came to talk about."

I took that as a compliment.

We had some important victories in Alberta. When the province adopted the national building code as their provincial code, we made sure they included the optional provisions for accessibility. The code was rudimentary compared to what we now have, but it provided minimal accessibility and established the principle going forward.

Our next success was addressing the need for equipment for people with disabilities. Saskatchewan had a program for people with a disability to get a wheelchair, crutches, or other mobility aids, and there were similar programs outside of Canada as well. We cited these examples from other jurisdictions—which was important because politicians can be reluctant to try things that have never been done before—and we were able to get that government program in Alberta. It still exists today.

As does a program called Assured Income for the Severely Handicapped. Poverty often goes hand in hand with a disability because many people with disabilities are not able to work full time, and they've often been denied the opportunity to acquire the necessary skills to get a good job. Even for those of us with an education, the unemployment rate is much higher than it is among able-bodied people with the same amount of schooling. Moving from a charity model to more of a social justice model takes a long time, but we fought and secured funding

beyond basic social assistance. Since then, the program has been expanded. Success builds on success, and now almost every province has similar disability assistance programs.

Despite these strides forward, I could never be fooled into believing everything was fine. I had regular and hurtful reminders that I wasn't like everybody else.

In 1977, I went to the airport to fly to Grande Prairie, where I had interviews lined up for some staff jobs with the committee. It was a 45-minute flight from Edmonton that I had taken many times before, but when I went to board this time, I was pulled aside and told I couldn't fly.

"Why not?" I asked.

"You don't have anybody with you to take care of you," said the person from Canadian Pacific Airlines.

I laughed. "Are you kidding? I have flown using a wheelchair for seven or eight years. Mostly alone. I've never had any problems."

In front of everybody else in the boarding area, they asked me a string of personal questions.

"What happens if you have to use the washroom?"

"It's a forty-five-minute flight," I replied. "I'll be fine without using the washroom."

And on it went. I had never been more embarrassed. They even asked, "What happens if the plane crashes?"

"I would probably die," I said, exasperated. "Like everybody else." They didn't like that answer.

This stalemate continued until the airline said that I could fly only if the pilot said so. I spoke to him, and he agreed it was fine. The flight was, of course, uneventful. When I got off I reminded them that I would be back the next day to fly home.

But when I returned to the airport, I went through the same rigmarole. This time it ended with one of their staff flying with me. I couldn't believe it. I had no recourse under the law at the time. The airline could simply

refuse to put a person like me on an airplane if they thought I would be a burden. I was shocked and horrified that this not only happened, but happened to me, somebody who knew my rights as a disabled person.

Earlier that year, Canada had passed the Canadian Human Rights Act. While it prohibited discrimination based on physical disability, it was only in federally regulated employment. I was being denied transportation, a public service, and that too became an ongoing issue.

The mid-1970s was a pivotal time in the development of our voice, and I was proudly part of the birth of the Coalition of Provincial Organizations of the Handicapped, now known as the Council of Canadians with Disabilities. We are a social justice organization of people with all kinds of disabilities that advocates for an inclusive and accessible Canada, where people with disabilities have full realization of their human rights, as described in the UN Convention on the Rights of Persons with Disabilities (CRPD). The CRPD came about in 2006, in part, because people with disabilities spent decades increasing our understanding of human rights—for example, expanding the definition of disability to include persons with mental disabilities.

By the mid-1980s, it was clear to me and to others in my circle that women with disabilities needed a greater voice to fight for their needs. Disabled women tend to be raped and exploited sexually more than other women. Unemployment is higher. Poverty rates are higher. A drunk and abusive father can sometimes be considered a better parent than a disabled mother. Women are generally undervalued in society, and for women with disabilities it's worse, and worse still if they're also Indigenous or gay.

There was no shortage of problems to address. Together with a group of women, we founded the DisAbled Women's Network (DAWN) to combat these problems. As a woman with a disability myself, this was an issue that was near and dear to my heart.

Around this time, my eyes were opened to another harsh truth that many people with disabilities face when it comes to their own medical care.

I heard of a young boy with a significant intellectual disability whose parents had given him to the care of the province of BC. His name was Stephen Dawson, and he had a shunt in his head to drain excessive fluid from his brain; it had become clogged and needed to be replaced. This is a relatively routine procedure for anybody with a shunt, but Stephen's parents suddenly reentered the picture and said they didn't want the shunt replaced. It meant Stephen would die. The B.C. Association for the Mentally Retarded (now Inclusion BC) went to bat for Stephen, arguing that it was wrong to deny him a life-saving procedure just because he had a disability. Thankfully, the judge agreed.

That was the first time I learned that something could go wrong with me and my life could be in the hands of others who could make decisions for me without necessarily knowing all the facts. It was sobering to realize that if you live with a disability, there's a higher chance you will die, not because it's your choice but because somebody else has decided for you. I talked to Dan about my future and made it clear that I did not want my life taken because somebody thought it would be best for me.

That wasn't the case for twelve-year-old Tracy Latimer from Wilkie, Saskatchewan. Born with cerebral palsy, Tracy lived with severe physical and intellectual disabilities and had undergone many operations. In 1993, she was scheduled for another surgery, but two weeks before the surgery, her father, Robert Latimer, killed her. Robert had the sympathy of a great number of Canadians. Even my father told me, "I can see why he did what he did." I thought my dad just didn't understand that his own daughter could be in that precarious position.

For me, this was murder. And anyone who said otherwise had a misguided perception of people with disabilities. Robert Latimer was convicted of murder, but there were allegations of jury tampering. When I heard that a second trial had been ordered, I took some vacation time and attended as a private citizen. I thought it was important

for people—disabled or not—to see someone in a wheelchair. I wanted to be a physical reminder that no one can change the rules because somebody lives with a disability.

It was one of the most important and hardest things I've ever done in my life. As I sat through the trial, I heard about all of Tracy's surgeries. I'd had many of those same operations, but they were just part of who I was. Tracy and I both used wheelchairs, but she had an intellectual disability and was not able to speak for herself. I couldn't help but think that if I had had different parents, things could've ended badly for me.

It kept coming up at the trial that Tracy had Harrington rods implanted in her back for stability, and the rods were always spoken of as if they were torturous medical devices. But I had had them in my back while I healed after the car accident. I knew that what everyone thought was horrific wasn't.

I was sitting next to a reporter, so I leaned over and whispered, "I've had those in my back. It's not a big deal."

He was quite surprised. His normal and my normal were two different things. That was the point I was trying to make. If we look at the world through an ableist lens, we see less value in the life of a disabled person, and suddenly, murder becomes excusable. Regardless of what you think of someone's quality of life, our criminal code says that if you murder somebody, you murder somebody. In the end, the jury saw it the same way, and Robert Latimer was convicted of second-degree murder.

These incidents drove home just how important protection for people with disabilities under the law was. A few years before the Latimer case, I had begun working for the Saskatchewan human rights commission. Initially I was their intake officer, determining whether or not a complainant had enough evidence to move forward. When someone's rights have been violated, they have to substantiate their case and show that it's covered under the law.

I learned that not everything has to be elevated to a government body. Sometimes reasonable people, acting reasonably, can work things out. Eventually I moved from hearing complaints to working with employers and school districts to develop equity programs. It was the kind of work that led to incremental change—slower than I hoped, but it was still change, and that was rewarding for me. I knew the world was not going to be transformed all at once.

It was during this time that I ended up filing a human rights complaint of my own, though not in Saskatchewan.

I took Carl, who was then sixteen, to a Rod Stewart concert at the stadium in Ottawa. When I bought the tickets, I made sure that I would be sitting next to him. It shouldn't have been a big deal. They had wheelchair spaces.

When we arrived at the stadium, the ticket taker said, "You sit there with your wheelchair, and your son sits over there."

"No, no," I said. "I want to sit with my son."

"Sorry, but that's not the way we do it," he told us. "People in wheelchairs go over there, and whoever you came with sits there."

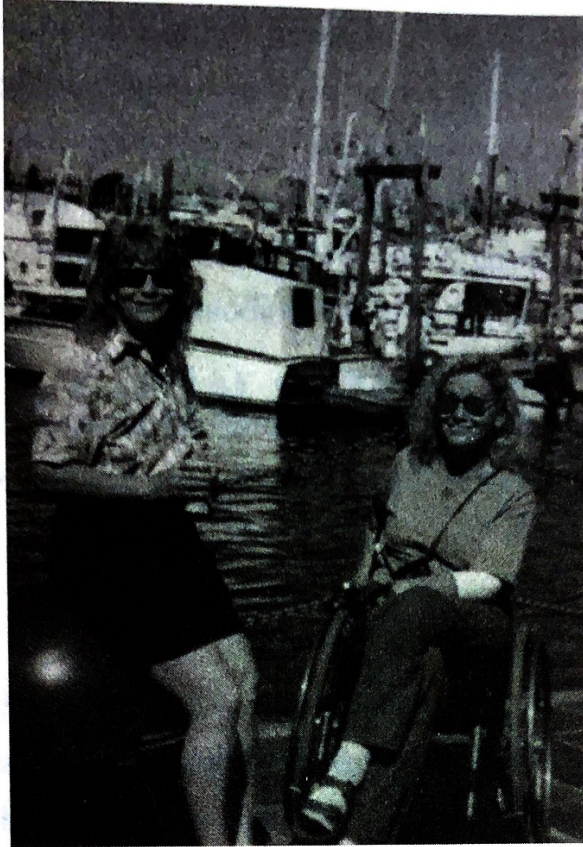
So we were separated. I guess I still enjoyed the concert, but it wasn't the experience it should have been. I wanted to be able to take it all in with my son, feel the exact same vibrations from the music, talk to him while it was happening. Instead, I was surrounded by strangers.

I knew that couldn't have happened in Saskatchewan, where, under human rights law, it had been determined that an accompanying person should be able to sit beside you, not in a separate area.

After I filed a complaint with the human rights commission in Ontario, we negotiated a settlement which included an agreement by the city of Ottawa and the National Capital Commission that any new facilities would be accessible. I felt very good that this solution would benefit others in the future.

At the end of the day, it shouldn't be a battle between the abled and





*With my sister Janice, in 1991, along  
the inner harbour in Victoria.*

the disabled. Or between a person with one type of disability and a person with another type of disability—which sometimes happens. We're all a part of the community. The goal is to design our world so that anybody can move about. We don't want you to notice an accessible entrance. It's just an entrance. As we've made progress, cities and towns have understood that when they build or renovate, accessibility features are just a routine part of the budget. That's what a caring society does.

But the truth is that we're always dealing with preconceptions of what people with disabilities can do. Too many people still see my wheelchair before they see me, and they make assumptions. For example, I often take my older sister shopping for food. Others frequently say to me, "It's so nice that your sister takes you to get groceries." We always laugh and my sister corrects them and tells them it's the reverse.

Fifty years ago, my life completely changed in an instant. With my diagnosis, I became a different person. I found strength that I never knew I had. I went places and accomplished things that I never thought I would. Do I sometimes miss my legs? Yes. Do I get frustrated when I can't do certain things? Yes. But like a mermaid, I've adapted. And over the years, I've stopped thinking about who I might have been and realized who I am.

I'm an advocate, and I'm never going to stop working for disabled Canadians. Because we're not fighting for our privileges; we're fighting for our rights.

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**Pat Danforth** has been advocating for people with a disability for fifty years. A founder of the DisAbled Women's Network, she has also worked for the Saskatchewan Human Rights Commission, the Canadian Labour Congress, and a number of advocacy organizations. She has volunteered for many groups, including the Canadian Union of Public Employees, the Disability Alliance BC, and the Council of Canadians with Disabilities. She lives in Saanich, BC.