Public & Intergovernmental Affairs Committee

Councillor David Courtemanche, Chair
Councillor Ron Bradley, Vice-Chair

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MS Sudbury Chapter of the
Multiple Sclerosis Society

SP Société de la sclérose en plaques
section Sudbury

2002 Super Cities Walk
Toute la ville est en marche

CHARITABLE ORGANISATION NO. 88968 7646RR0001
REGISTRATION NO. 0187690-11

August 12, 2002

Mr. Thom Mowry
Clerk
City of Greater Sudbury
Phone: 671-city Fax: 671-8118

Dear Mr. Mowry,

The Sudbury Multiple Sclerosis Society is gearing up for the 9th Annual Super Cities Walk.. **The event will take place on Sunday, September 15, 2002 at Science North.**

This letter will serve as an official request to make a brief presentation to City Council on behalf of the Multiple Sclerosis Society, Sudbury chapter at the first September meeting of Council on September 12th, 2002 at 7 30 PM.

The presentation will be made by board Chair Joanne Nother who will bring greetings, new information and treats. The amount of time requested is five minutes. Please contact me at 524-do-it (3648) to confirm.

We look forward to a positive response.

Sincerely,

Rachel E Proulx

Rachel E. Proulx, Chair

Super Cities Walk 2002

1188 St. Jerome Street, Suite

SUNDAY NEWSMAKER

Rachel Proulx

Rachel Proulx, past president of the Canadian Federation of Business and Professional Women's Club and the first chair of College Boreal's board of governors, was diagnosed with Multiple Sclerosis in 1996.

Since then she's become actively involved in the Sudbury Chapter of the Multiple Sclerosis Society including her position as chair of the Super Cities Walk on Sept. 15.

The Sudbury's Star Laura Stradiotto joined Proulx in her office at the MS Society to discuss how the disease has altered her life.

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At the time you were diagnosed with MS, where were you in your career?

I was right smack in the middle of my career. Things were really going well and I was quite involved in starting up one of the colleges here in Sudbury (College Boreal) and things were happening. And raising kids, and everything at the same time — juggling a career and volunteering.

Right as I turned 40, I was diagnosed.

What is interesting though, is it affects young adults right in between the ages of 20 and 40, right when you're in the midst of things.

It's important to realize that children are now being diagnosed — children as young as two years of age. We have some cases at Sick Children's Hospital in Toronto with a number of young children who've been diagnosed.

How would a child's symptoms differ from an adult, or from what your symptoms were?

Symptoms are similar and that's perhaps why it's sometimes difficult to diagnose. One year I was diagnosed with chronic arthritis, the next year I was diagnosed with fibro myalgia and the following year I was diagnosed with MS. So, there are a number of things that you will feel and sometimes it's difficult for the medical community to pin point exactly what the problem is.

The ultimate tool is the MRI. And with the new technology that's why they are now able to identity in younger people what exactly they do have, which is the myelin that has broken down.

If they're able to diagnose that in a two-year-old, perhaps it was there all along in younger people and we never really knew because they weren't able to diagnose MS that early back then.

John E. Lightfoot Jr./THE SUDBURY STAR

Local business women Rachel Proulx has led a full life since being diagnosed was diagnosed with multiple sclerosis in 1996. Now, she's the chair of the Super Cities Walk, the Multiple Sclerosis Society's largest fund-raiser, on Sept. 15.

Fully

Even some of the buildings I try to get in have a six-inch stoop. I can't get in there with my chair.

I think that a lot of businesses are now looking at yes, maybe they do need to do something. I think there's an awareness that has to be created. But I also think there needs to be occupational therapists who can go into a location and look at what's required to make the building accessible.

It's not like putting a bar behind a toilet and thinking your washroom is accessible because that's not the definition of accessibility. It's where are those strategically located for that person. You need to work hand in hand with the builder and the occupational therapist to deal with the disabled and allow them to go onto your premise.

> **"And the lack of accessibility, not only into buildings and activities, into employers. For some people with disabilities, it is very difficult to find employment because, unfortunately, some cannot see past that chair."**

Have your symptoms changed over time?

Oh, definitely. They have changed and they've reoccurred. Some of them are on and off. It's something that you deal with as it happens. I don't really dwell on what my symptoms could be, I just deal with them as I have them and find ways of coping and hopefully, if they're too severe, they'll go away at some point. But you never know. Symptoms do change.

What activities are planned for the Super Cities Walk for MS on Sept. 15?

It's people who've had MS, their friends, families and colleagues and the business community realizing that MS is the most common and severe nervous system disorder that you can have, and it's growing. It used to be one in every 750 people had MS. Now, it's one in every 500. Now, we're seeing more and more younger people.

The people who support the cause for MS are going to walk for the cause. It could be people individually, or a team. They will walk eight kilometres and there's also a scenic walk, or a shorter walk on the boardwalk for those who are with wheelchairs. But still people in wheelchairs and scooters will do the eight kilometres. It takes them anywhere from an hour to two hours to do that eight-kilometre trek.

They come back to Science North and we feed them to a barbecue, and there's some prizes. It's a social event as well — people meeting people, people talking about different issues.

enabled

The hardest part of dealing with MS is overcoming perceptions

What type of MS do you have?

Remissive-progressive, which means that sometimes, if I have an attack, it's a setback.

If it's progressive, it will cease and then continue. If you have an attack and can't move something, your arms or fingers, and if you're progressive, you probably won't be able to move again.

If you're remissive, it means that maybe you can get your brain to think about moving your fingers or moving that limb. And depending on the severity of the attack, you may or may not be able to do the things you were able to do before.

So, I am remissive-progressive, which means I may have an attack and may have some symptoms, but after my attack I'm fine and back to the way I was.

As you see I'm in a wheelchair so, unfortunately I haven't been able to (walk). But I have in the past been able to rewalk after I wasn't able to walk for a bit.

Now, I've been in a chair for a couple of years, so it doesn't look too good.

What treatment or therapy have you received?

I'm not taking any treatment as it is now. There is medication that helps with spasms, for lack of control. So I am taking that medication.

I'm really cautious about any medication and the side effects that are associated with it. I believe in the healthy kind of things that I've always done in the past, you know, the vitamins that you continue with.

Life goes on after MS. MS is a reality so, life goes on. So, to remain healthy, I have to make sure I take my vitamins as anybody else would. My spasm pills are for that particular situation I have to deal with. I don't take anything else.

At the moment there are treatments and medications to help you deal with and cope with the reality of the illness and give you the best quality of life that you possibly can have. And there is always the way of thinking — that's positive.

And life's greatest thrill is tomorrow, so, who knows what else is going to happen. So, it's always thinking positive and working that way because you have to make a choice. You really have to work with your psyche. It's difficult sometimes to accept you have an illness. Once you decide you're going to deal with it, you decide how you're going to deal with it.

What adjustments have you made since 1996?

In every facet of my life I've had to make adjustments. Starting with physical changes, which is the modification of my home. Getting in and out of the house was a number one priority.

Some people have ramps, others modify doors, so you can get into the washroom, or bedroom. Also, setting up my office in my own home, so that it would be easier for me to work from my home, when I was working a lot.

That allowed me to organize things so that I was able to work with my computer and with the equipment that I have.

The other adjustments are your social life. You know, sometimes you think about wanting to go somewhere, a restaurant, a play. You just hop in your car and go. I can't do that. I have to call ahead and find out if I can get in because not all locations, businesses and government offices are accessible. So I have to find out beforehand will I be able to get into the door. And then, if so, if it's on the third floor, do they have an elevator? Because if is on the third floor and there's no elevator, I'm not going up there.

So, it's always thinking ahead for the day-to-day things. Travel is the same thing. If you're wanting to go away with your family, it's very nice to say, we'll go here or we'll go there. But not all hotels are accommodating or have the proper equipment.

So, all of those things we take for granted as an able-bodied person, when you have a disability you have to think twice about everything. Because in your mind, you're not disabled. In your mind, you're still functioning. I could talk to you on the phone and you can't tell that I'm in a wheelchair.

But when you're not in that situation, you don't think of the things that it entails.

And the lack of accessibility, not only into buildings and activities, into employers. For some people with disabilities, it is very difficult to find employment because, unfortunately, some cannot see past that chair. You have a thinking brain, however some people are disabled in their mind because they can't get past that visual image. Look at people in their eyes and in their faces and you'll see that they're people just like you.

In Sudbury, do you find that the majority of public facilities like restaurants are wheelchair accessible?

Not the majority. Many try to accommodate someway or somehow. Unfortunately some people's idea of a ramp is not the safest ideas of a ramp. And I'm thinking of one local facility that the ramp is so steep that I had to have somebody in the back hang onto my shoulder because I kept feeling like I was going to fall off. The ramp was too steep.

So, unfortunately we have a long ways to go.

A lot of business people meet there as well, because they also have their team. It gives the business community an opportunity to have a social event, help the community and work towards a good cause and common goal: to support MS and find a cure.

What is the financial goal for the Sudbury Super Cities walk for MS?

I would like us to at least meet and beat last year's total which was $36,000. So, certainly we hope we will be able to meet that and I think we can go a little over that. Sudbury is an excellent community. People care. It's a good way to go out and get some exercise. Rain or shine we're walking. We're walking and rolling and wheeling.

But, in order to walk, you have to be registered. Walkers that collect $25 or more get a T-shirt. There are opportunities to get all sorts of prizes.

What does the MS Society do for those diagnosed with MS in the city?

The Sudbury chapter is extremely important to the community because they will assist with education and information for those who have MS and their families who have questions.

One of the reasons I became involved was that the staff person that came to see me was so caring and so wanting to help not only with information and resources, but was also there when I needed equipment. They lend me some equipment from what they call the loan cupboard where people donate equipment who no longer have use for it.

They can also assist you in buying some equipment, like an air conditioner or wheelchair. So although they may not buy it outright, they might assist and pay a portion. So, that's where the MS Society is so important, and why we need to raise a lot of money, because we can only help people with the funds we do have locally. We don't get the dollars from the other levels of organizations.

So, how we help people locally, must be raised locally. That's why we depend on the community to help us raise money. The Walk is the key fund-raiser for the year.