



# The Road to Change

## JUDITH SNOW'S WORLD PEACE THROUGH INCLUSION TOUR

By Erin Socall

It is 8 a.m., and the sun filters into the trailer as if to say “Good morning, sunshine!” As usual, Gabor gently wakes Judith and prepares her for the day. She awakens with anxiety most days. At the moment, it’s because our schedules are off. Judith, so used to being on time, has no choice but to go with the flow. Eating, cleaning, bathing; everything needs careful preparation and time management. The simple task of making a meal takes twice as long as it would at home.

We’re in the fifth week of a road trip across North America. The three of us – Gabor, Judith and me – have been living in and driving a toy hauler hitched to a van since November 2, 2008. We started off in Toronto, and now, more than 1,600 kilometres later, we’re on Tybee Island, Georgia. Judith’s goal is to teach and talk about how inclusion creates peace within a community. The tour is a dream of hers that became a reality, and it is now changing lives, not least of all our own.

From the age of eight, Judith has used

a wheelchair. She lives with a condition called Spinal Muscular Atrophy, associated with an absence of Survival Motor Neuron Gene (SMN1) proteins. Without adequate SMN1 proteins, the spinal-cord neurons responsible for motor activity do not react appropriately. This leads to loss of muscle control and, eventually, muscular deterioration.

In the early 1950s, when Judith was six years old, she was told by her father that children in North America like herself, and others with Down Syndrome, were being



**Clockwise from top left: Judith meets a sheriff in Cambridge, Ohio; Judith and Erin Socall on Tybee Island, Georgia; Judith with (from left) Gabor Podor, Erin, and hosts Kristin Russell and Brad Baugh in Savannah, Georgia; Gabor with the team's toy hauler at a Tybee Island trailer park. (Beach and group photos by Gabor Podor; sheriff and toy hauler photos by Erin Socall.)**



**From top: Judith on Thanksgiving Day, 2008, visiting Camphill Sophia Creek, a "life-sharing" community in downtown Barrie, Ont., that includes adults with developmental disabilities; a look inside the group's toy hauler, which they are driving and living in for the duration of the tour. (Photos by Erin Socall.)**

killed because society felt the responsibility of care was too much and that it didn't have adequate resources to support them. Judith made a commitment to support and advocate for people who are labelled with a disability.

She was one of the first students to attend York University in Toronto, back in the late 1960s. (At the time, it had one accessible washroom for the entire campus, and lacked accessible housing and automatic doors.) Judith studied for her Honours B.A. in mathematics and psychology. She also received the Murray G. Ross Award for Outstanding Contribution to Vanier College. She went on to earn a Master's degree in clinical and counselling psychology, graduating in 1976.

Judith was the founder and coordinator of York University's Centre for Special Services for Handicapped Students, started in 1977 and funded through the Atkinson Charitable Foundation. (Today, York has a Disability Services office for its students.)

In her second year working at York, Judith, then 27, and others who were labelled as having a disability were required to live in institutions in order to receive federal benefits. She was not prepared for this experience. In October of her 29th year, she was malnourished and near death. Her physician granted her some time away from the institution (permission required even though she spent more than four days a week offsite, working on campus). She never went back. Instead, she lived in the hallway of a friend's apartment, with no money. She implored people to provide financing while she fought for individualized funding.

This is when Judith's Support Circle

was created. A Support Circle is a group of people who meet regularly to help somebody accomplish their goals in life. The Circle acts as a community for that person and his or her family. In turn, Person Centered Planning (PCP), for people with cognitive disabilities, was born. A group of committed individuals helps the person with a disability achieve goals and plan for the future. People involved with PCP and Support Circles are generally friends, family, support workers and advocates. Among the members of Judith's Circle was Jack Pearpoint, founder of Inclusion Press, who helped her write letters to the government.

After her brush with death, Judith realized she had to make major changes. What did she need in her life to live independently? Which dream would she start with? Who could provide support? As a trail-blazing self-advocate, she set out to dismantle preconceptions about disability. She planned to show the world that people like her could live in the community – just differently. Although the use of her own limbs is limited, this simply means that she can gain assistance from someone who is more mobile. In some respects, this provides her with unrestricted mobility. With adequate support, she has few boundaries.

About four years ago, a dream sparked inside of Judith – a journey across North America to spread her message. At the time, she had no way of knowing how this dream would come to fruition, but she always strives for what seems, at first, like the impossible. She didn't have any money or support staff, but what she did have were connections and her Circle.

In January of 2008, she travelled south to Georgia to visit her long-time friend Tom Kohler, who heads up Chatham-Savannah Citizen Advocacy. While in town, Judith started talking. People in the community voiced their concerns regarding the school system and violence in town. She talked to them about the concept of inclusion, and they felt that was the way to peace within their troubled community. By working with support staff, churches and other organizations, the citizens of Savannah started the Southern Collective for Inclusive Citizenship (SCIC) to make changes in the community and educational system and lower the rate of violence. This provided a foundation to get Judith on board with her own dream of effecting change.

In the summer of 2008, Judith met a person who would help take her dream a little farther. She was searching for a personal assistant, and Gabor Podor

was introduced to her by way of a family friend. Gabor showed up at her door burdened by apprehension and self-doubt. He and Judith hit it off immediately. As fate would have it, he was the person who would take the plunge and help Judith make her dream a reality. Whether they knew it or not, their acquaintance would change their lives forever.

Over the course of a few weeks, Judith told Gabor about her dream. He was inspired, and without hesitation, he was on board. Things happened quickly shortly thereafter. Judith sold her house in Toronto and bought the toy hauler, which is an accessible vehicle that did not require too many modifications to accommodate our needs. It had enough room for a bed, a desk with computer equipment and a drop-down ramp in the back. Even though the quarters are cramped, there is still some semblance of normalcy as we have meals and follow Judith's daily routine.

Gabor, whom I had been dating for quite some time, introduced me to Judith shortly after he became her personal assistant. He told me about her dream, and the force she carries within herself. When I met her on Cherry Beach one Sunday afternoon, we hit it off. The next week, she asked if I would join them on the inclusion tour. With me being a writer and publicist, she saw the team as complete and ready to make accommodations for the tour to become a reality.

I was excited, but Gabor had reservations. Being as I am a single mother of two pre-teens, how was I going to make this fly? Would we bring the kids? If we kept them home, who would be their caregiver? All valid questions, which in time would work themselves out. First, we started a Support Circle with the help of Judith. Second, we let nature take its course, and slowly, opportunities arose. We found a caregiver for the kids – and as I always say, everything is possible.

After months of struggle and disappointments ranging from organization of familial concerns to lack of funding, it was time to leave. We set sail on November 2, 2008. Onward and upward! Challenges await! New lives to unfold before us all!

The first stop was Detroit, Michigan. Judith had been asked to speak on behalf of her long-time friend Micah Fialka-Feldman at a Board of Trustees meeting at Oakland University. Micah was petitioning for the right to live in residence, and over 20 people came to speak in his defense. As more than 150 people from all over North America listened, Judith spoke about an age when dinosaurs refuse to make policy revisions according to student

needs. Unfortunately, Micah is still working on getting into residence.

After our amazing stay with the Fialka-Feldmans, it was time to make some headway. We stopped in Mouth of Wilson, Virginia, home of my alma mater, Oak Hill Academy. We spoke with administrators about the tour and the possibility of talking to the students. The next day, each of us gave a short speech, which the students received warmly. We hope that many of them have a new perspective on inclusion.

After many more hours on the road and a few stops along the way, we finally made it to Georgia. As we pulled into our space on the beach at 3 a.m., Judith took off down the street to look at the stars and the moon and all the glorious waters that surrounded us. It had been a long time since she had visited her favourite place on earth. We could hear the ocean.

It took quite some time to get settled into a routine in Savannah. Things weren't as we'd expected – many of the people who had been gung-ho about getting together for change seemed to have disbanded. Slowly, we reconnected with members of SCIC and found new people with the same ideals. We attended dinners at the Presbyterian church, where Judith had met some young, community-active people, and just started talking again. She also reconnected with Citizen Advocacy and was invited to a brainstorming session. Soon after, we met with a young teacher at Savannah Country Day School to talk about our team being the first Resident Activist of the school's new diversity program.

For now, it looks as though the tour will stay on in Savannah until the end of March, seeing as people want us to remain active in the community and become more active themselves. Just recently, we attended an event called Sounds of Civil Rights, a presentation of songs and stories that originated with the slaves who landed at St. Simons Island, put on by the Savannah Telfair Museum. It was an amazing kick-off to what it is we came to Savannah to achieve: developing a sense of connected community, and bringing together those who have differences and utilizing the abilities every person can bring to the table. Events like Sounds of Civil Rights show that people who are labelled – no matter what label – have a position in their community. They are contributors in ways most people have never conceived of.

While we are making progress, we continue to learn, day by day, how to make things work. We continue to rely on Judith's savings for financing. We are grateful to our supporters for their

donations, but they do not cover all of our expenses. Continuing with the tour has meant making major adjustments to Judith's life. Not only has she left the comforts of her life back in Toronto, but the struggles of having only one person to assist her creates barriers of their own. Back home, she could create a daily/weekly schedule with her full- and part-time assistants, and she usually had more than five people on her roster. Contact with her closest friends and Support Circle members, formerly a daily occurrence, is now limited. Everyone seems to be at arm's length. Loneliness is palpable.

There are times when the three of us feel the strain of being away from home, as well as the difficulty of being together all the time, and trying to work together. At times, communication between us breaks down; we feel weak, lost and emotionally drained. But we wouldn't have been able to do this without each other. We all knew that this initiative would be our teacher, but we have yet to realize what and how much it is teaching us. We must stand strong in the face of our own adversities and help create stronger ties with each other, the community and the world.

*Erin Socall is a freelance writer who is working on her first book. Since writing this article, she has returned to Toronto, but continues to work as the tour's fundraiser/journalist/publicist. For more information about Erin, visit <http://blog.erinsocall.com> or email [info@erinsocall.com](mailto:info@erinsocall.com).*

## LEARN MORE

Check out these websites to learn more about Judith's work, her tour for world peace through inclusion, and some of the people she has met along the way.

Judith's blog ([www.peaceforinclusion.blogspot.com](http://www.peaceforinclusion.blogspot.com)) has the latest news.

Community Cave ([www.communitycave.com](http://www.communitycave.com)) is an organization that's dedicated to community-building in Toronto.

On the tour, Judith connected with Chatham-Savannah Citizen Advocacy ([www.savannahcitizenadvocacy.org](http://www.savannahcitizenadvocacy.org)).

Read Judith's articles and find out about her book, *What's Really Worth Doing and How to Do It*, at [www.ancilla.tv](http://www.ancilla.tv).

Micah Fialka-Feldman ([www.throughthesamedoor.com](http://www.throughthesamedoor.com)) is fighting for the right to live on his school's campus.