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Connecting for change

Building connections with friends, neighbors and lawmakers is a powerful way to positively affect people’s lives.

by Matt Alderton

A connection is a powerful thing. Like a bridge that spans a wide river or a deep valley, connections can remove obstacles and close gaps. But the most powerful connections aren’t between places or things—they’re between people.

People with multiple sclerosis often find that sharing information, experiences and emotions with others helps them live more powerfully. But that’s just the start of it. When connections happen within a community, they can drive concrete and positive change, such as more accessible places to live, better access to care and greater impact.

Three people—including 14-year-old Taylor Prather, diagnosed with MS when she was 10; Bill Luria, diagnosed in 2007; and Ralph Montefusco, whose wife was diagnosed in 2006—share their stories about how, as MS activists, they catalyze change through connection, across the country, throughout a state and in a local community.



Taylor Prather

Age: 14

Location:
Bakersfield, Calif.

Advice for connecting: Talk about your MS. “There has to be someone out there going through the same situation I went through. By talking about it, maybe I can help them.”

The power of story

In many ways, Taylor Prather is a typical teenager. A freshman in high school, she’s a junior varsity cheerleader who likes to dance and listen to music. In fact, she likes dancing so much that she started doing it competitively when she was 7 years old. However, that’s also when she began seeing doctors for symptoms such as joint pain, headaches and vision loss—which eventually got so bad, she had to stop dancing altogether.

“She had an MRI and was diagnosed with a tumor in her optic nerve,” recalls Taylor’s dad, Brett Prather. Doctors began radiation therapy immediately but stopped four days into the 28-day treatment when Taylor’s parents consulted a second specialist, who diagnosed Taylor’s condition as optic neuritis, an inflammation of the optic nerve that is often the first symptom of MS. Taylor’s other symptoms progressed until she was hospitalized at age 10, unable to walk, let alone pirouette or chassé. A couple of months later, doctors finally diagnosed her with MS.

Now 14, Taylor feels more like herself again, thanks to her disease-modifying treatment. She still has vision problems, however, and often reports numbness in her arms and legs, not to mention occasional fatigue, headaches and tingling, especially in warm weather when the heat triggers her symptoms.

It’s not easy, but it’s manageable, says Taylor, who finds that talking with others about her disease helps her cope. Since being diagnosed in 2010, she’s actively shared the story of her diagnosis and symptoms—some, like bladder problems, not so comfortable to disclose—with friends, classmates, media and community members, including her congressman, Rep. Kevin McCarthy, whom she first met at Walk MS in Bakersfield, Calif., in 2012.

“One of the reasons I’m so open about my MS is because people get misdiagnosed,” Taylor says. “There has to be someone out there going through the same situation I went through. By talking about it, maybe I can help them.”

While advocacy takes many forms, Taylor’s willingness to speak up and raise awareness of MS has made her an ideal champion for the cause. In fact, when the Society secured a meeting with a field representative from Congressman McCarthy’s office to discuss increasing federal funding for MS research and drug trials, Taylor and her parents were invited to attend. While MS research relies on critical government funding, the Society often acts as a co-financer of government-funded research and in 2013, invested more than \$48 million in MS research.

During the meeting, Taylor told her story again. She presented a letter she’d written to McCarthy. “[His staffer] seemed pretty interested and said he’d make sure the congressman got our note,” Brett says. Although the question of increased funding for MS research remains unanswered for now, the congressman contacted the Society shortly after their meeting to express his continued interest in MS advocacy. What affected the congressman’s staff most, Taylor recalls, was the fact that she is the youngest-ever person in her county to be diagnosed with MS, and that her symptoms make adolescence—already difficult for the typical teenager—that much more challenging.

“Taylor still has her whole life ahead of her,” Brett says. “MS research gives her hope that she’ll be able to live her life and manage this illness.” Taylor didn’t set out to connect with Congress. The fact that she did, however, demonstrates the power of communication: When you talk, you might be surprised by who listens.

That’s why Taylor’s future plans involve even more storytelling and more MS activism. She hopes this will lead to more connections and, eventually, positive change for those with MS. “I’ve talked to my dad about it, and we might write a book,” Taylor says. “It’s just an idea, but I think it would be pretty cool.”



Bill Luria

Age: 71

Location:
Bainbridge Island, Wash.

Advice for connecting: Treat elected officials like your neighbors, because oftentimes they are. “These are ordinary people who care about their community. They’re very anxious to meet with their constituents.”

The power of friendship

Bainbridge Island, Wash., is a close-knit community of approximately 23,000 people. A 35-minute ferry ride from downtown Seattle, it’s the kind of place where everyone knows everyone. When he was diagnosed with MS in 2007, longtime resident Bill Luria felt he had a choice: He could withdraw from that community, or he could use his diagnosis to effect change for others living with MS.

“I was diagnosed with MS when I was 65 years old,” says Luria, now 71, who has nearly 40 years of experience in public policy and community development, and worked previously in both municipal and state government. “I could have just crawled back into my little hole and felt sorry for myself.”

But for Luria, MS wasn’t just a diagnosis; it also was an opportunity. “It’s strange, but I feel there was a benefit to being diagnosed with MS,” he says. “It’s opened up a whole new world of people and networks where I can actually get involved and have some impact. That’s really important for me personally; now that I’m in my 70s, I want to use my experience to try to make a difference.”

After being diagnosed, Luria reached out to the Society to express his interest in being an MS activist. He now serves on the Society’s Government Relations Committee in his area, which advocates for people with MS across the Pacific Northwest, focusing in particular on accessible housing, transportation and employment.

Along with his experience, his friendships have helped him make a difference—not only in Bainbridge, but throughout the state of Washington. He personally knows Washington State Rep. Sherry Appleton and Washington State Sen. Christine Rolfes, both of whom represent his district.

The relationships aren’t exclusive. They’re authentic, established during years Luria spent volunteering on public committees, nonprofit boards and political campaigns. “We’ve been working hard to significantly increase funding for accessible transportation in the state,” says Luria, who serves on the Washington State Council on Independent Living—and Sen. Rolfes happens to serve on the Washington State Senate Transportation Committee. “I said, ‘Christine, I want to get together to talk about accessible transportation.’ She said, ‘Let’s do it, Bill,’ and we did. She’s been pretty receptive.”

You don’t have to personally know state officials to establish connections with them, Luria says. You just have to treat them like they’re neighbors—because oftentimes they are. And it’s never too late to start building relationships. “These are ordinary people who care about their community,” Luria says. “As long as you don’t feel intimidated by their position, it’s easy to make contact and connect with them. They’re very anxious to meet with their constituents.”

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Connecting for change

The power of awareness



Ralph Montefusco

Age: 63

Location:
Burlington, Vt.

Advice for connecting: Stay engaged in your community. “The key to being an effective activist is building and maintaining personal relationships.”

When his wife, Michele, was diagnosed with MS in 2006, Ralph Montefusco dealt with the news the best way he knew how: He joined a Society committee in his area.

“I’m not a particularly warm, fuzzy type of guy—support groups aren’t really my thing,” says Ralph. “What I am, however, and what I’ve always been, is a political activist. When Michele was diagnosed, we started going to Society events, and by 2007 I was working as a volunteer on the Government Relations Committee.”

For Ralph, who became chair of the committee in 2008, it was a natural fit. Although he’d spent the first 18 years of his career as a technician at IBM, he spent the last 10 in more political endeavors, first as a labor organizer, then as a political director for the 2012 campaign of Vermont State Treasurer Beth Pearce. Before retiring in 2012, he ran his own political consultancy, leveraging his lifelong experience as a volunteer for political campaigns, commissions and committees. “Advocacy is what I naturally go toward, so I decided to use my personal network here in Vermont to advocate for people with MS,” says Ralph, who’s now retired.

Ralph’s network—which includes elected officials from Vermont, whom he met during his political organizing days—has helped the Society make state-level progress on important issues such as health care. What Ralph’s most proud of, however, is the local change he’s effected in Burlington, where accessibility is a major priority.

“People with MS have mobility issues,” Ralph explains. “Because they can’t always get into buildings and don’t always have access to restrooms, they tend to stay home. That means they’re not going to events or participating in elections and community forums. It means they’re not enjoying life like the rest of us.”

In a place like Burlington, known for its progressive culture, vibrant downtown and lush outdoors—that’s a travesty, says Ralph, who recently helped revive a defunct city group known as the Burlington Accessibility Advisory Committee (BAAC), which is dedicated to making Burlington more accessible to people with disabilities. The committee includes a representative from the Department of Parks and Recreation, which recently installed a special ramp and mat that make a local beach on Lake Champlain wheelchair-accessible. Likewise, the city’s zoning administrator and building inspector serve on the BAAC and are actively encouraging accessibility among local businesses that apply for building permits.

“We’re also partnering with the Vermont Statewide Independent Living Council, which has a website called [Accessible Adventures](#),” Ralph says. “You can go online and rate your experience with Burlington. Whether it’s a restaurant, a public building or a park, you can write a review so people with disabilities who visit from Boston or Montreal know where they can have dinner or see a show. We see it as economic development.” While Accessible Adventures is exclusive to Vermont, many state and local tourism bureaus publish Web pages dedicated to accessible travel.

Although Ralph’s connections were with government officials, they don’t have to be. A connection with a local business—a café, grocery store, movie theatre or boutique—can have just as much of an impact. When they know their customers and the challenges they face, businesses are more likely to accommodate them.

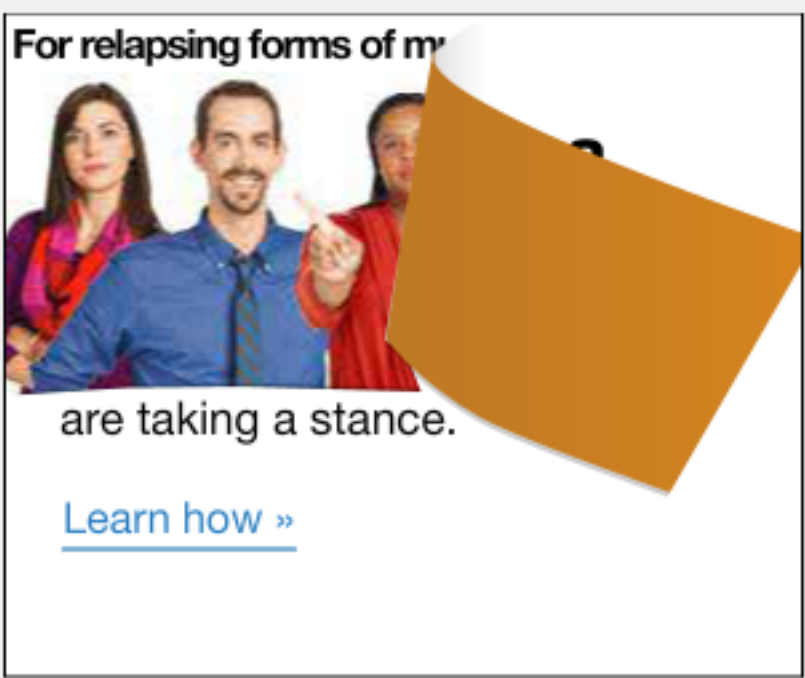
“A local restaurant that didn’t have an access ramp just put one in,” Ralph says. “The next week, four of us [from the BAAC] went there for dinner and said, ‘We’re from the committee, and we’re here specifically because you did this. Thanks a lot.’ ”

It all boils down to awareness: The best way to improve your community is to be in it, asking for help from those who can give it. “The key to being an effective MS activist is building and maintaining personal relationships,” Ralph says. “You have to be visible in your community and let people know you’re there.”

Matt Alderton is a Chicago-based freelance writer and editor.

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