

Parkinson's advocate **JACKIE HUNT CHRISTENSEN** makes sure to get her message across—even while driving.



The Patient Revolution

Becoming a patient advocate empowers you to help others, and yourself.

BY STEPHANIE CAJIGAL

PHOTO BY DAVID ELLIS

Jackie Hunt Christensen, 43, a lifelong environmental activist, believes that her efforts to make the world a greener place may have inadvertently caused her to develop Parkinson's disease.

When Christensen was in her mid-20s, she and fellow activists did a boat tour to call attention to pollution that chemical plants and other sources were dumping into the Mississippi River. "The waste runoff from the St. Louis wastewater treatment plant looked like Mountain Dew instead of what one expects sewage to look like," says Christensen, who lives in Minneapolis, MN.

Afterwards, she had flu-like symptoms for about a week.

"Now I know those symptoms are similar to that of acute pesticide poisoning," she says. "I certainly can't prove that's what happened, and I'll never know, but I think it definitely played a role."

Some people might understandably have withdrawn into their own pain at this point. Not Christensen. Facing a future with Parkinson's only motivated her to explore and expose environmental links to the disease, which she's been doing since her diagnosis in 1998.

She's worked with Greenpeace, the Institute for Agriculture and Trade Policy, Health Care Without Harm, and the Collaborative on Health and the Environment. Christensen is also

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vice-president of the Parkinson's Association of Minnesota, state coordinator for the Parkinson's Action Network, and the author of *The First Year: Parkinson's Disease, An Essential Guide for the Newly Diagnosed* (Marlowe & Co, 2005).

Being an advocate, she says, is one way to cope with a progressively debilitating disease. “A cure would be nice, but what I really am working toward is preventing other people from getting the disease,” she says. “It may be a way to try and control the situation or give myself the illusion of that—I'm not sure. But at least for me it's something I can't not do.”

Some of the things she can't not do include lobbying lawmakers about increasing funding for Parkinson's research and improving services for people with the disease; writing press releases, letters to the editor, and op-eds about the environmental links to Parkinson's; and talking to scientists about the need to study environmental triggers.

“It keeps you engaged in life,” Christensen says of advocacy work. “If you focus only on your own Parkinson's and sit at home and go ‘poor me’ all day, it's not positive and it's not going to be good for the way your body copes with the disease. I'm not saying I never do that. I'm saying I try not to do that.”

LENDING A HELPING HAND

You too can become part of a cause you care about. To start, research the different national organizations that represent people with your condition. “Shop around to see what feels right,” Christensen recommends.

Speaking publicly isn't a requirement for being an advocate, she emphasizes. In fact, nonprofit organizations offer a myriad of ways to get involved: you can join their support groups, write for their newsletters, or help out with chapter fundraising. Christensen also suggests sending letters to the editor and opinion pieces to your local newspaper or any publication where you'd like your voice heard.

“Everybody has an amazing, powerful personal story to tell,” she says. “It's not just the story of one person; it's the story of their whole family, because chronic diseases don't affect just the person who is sick—they impact everybody.”

Another way to get involved is to call or send letters and e-mails to Congressional representatives, either through an organization or on your own. Educate them about your disease and let them know if there's legislation that should be passed or issues that need public support, Christensen says.

If the idea of talking to elected officials seems intimidating, just remember that for the most part, “they're just like we are,” she adds.

“Just be yourself. If you don't know something, don't pretend that you do. Speak about how you've been affected by the disease, and nobody can dispute that,” she says.

FINDING TIME

As the mother of two boys, ages 10 and 16, Christensen acknowledges that finding the time to do these things can be a challenge, especially when Parkinson's drains her energy. When worsening symptoms forced her to quit her full-time job with the Institute for Agriculture and Trade Policy, she volunteered with environmental and Parkinson's organizations. She currently devotes about two hours a week to advocacy work, she says.

Denise L. Pease, 54, of Queens, NY, understands the challenges of managing a disease while also balancing a full-time job and volunteer activities. Pease suffered a traumatic brain injury in 1995 as a result of a car accident and later developed epilepsy. She spent six-and-a-half years relearning how to read, write, and speak. Because of her brain damage, she could no longer perform in her job as Deputy Superintendent of Banking for New York State and had to resign.

But Pease returned to work in 2000 and has since been promoted to assistant comptroller for commercial banking in New York City. She also started volunteering with the Epilepsy Foundation and currently serves as a member of its Board of Directors, through which she regularly contacts elected officials about the need to establish programs for people with epilepsy and other disabilities. In March, she spoke at a National Institutes of Health epilepsy conference about her experience with the disease.

CHANGE THE WORLD IN 5 MINUTES OR LESS

E-MAIL: Some group Web sites, such as that of the Alzheimer's Association (alz.org), have a section where all you have to do is insert your contact information, and a letter urging action on an issue is automatically e-mailed to your local Congressional representatives.

DONATE: Mailing in a check—even if it's for only a dollar—helps with funding research. You can also donate through many organizations' Web sites.

TALK: Simply talking to other people about your condition helps to spread awareness.



ADVOCATES Pease speaks to the NIH about living with epilepsy (left); Billauer's organization provides surfing lessons for people with paralysis (right).

"I think that since I've been blessed to be able to come back to work and have a very responsible job, I should do whatever I can to open that door and keep that door open for other people," she says.

Having an understanding and flexible boss, such as New York City Comptroller William C. Thompson, Jr., also helps, she says. "Does it mean that I sometimes work Saturdays and Sundays because I had to attend a meeting on Monday or Tuesday? Yes, it does."

But Pease, like Christensen, says that just talking to people about your disease is a form of advocacy. She recalled how during a plane ride from New York City to Rome, she sat next to a couple who noticed her epilepsy advocacy bracelet and asked her what it represented. After hearing about Pease's work with the Epilepsy Foundation, the couple—who had a family member with the disease—said they were motivated to learn more about the disease and to join an organization.

"Everyone needs to evaluate their time commitment individually," Pease says. "Recently, someone told me 'Oh, Denise, you need to slow down, you need to not let people push you so much.' But one of the things I've realized is that though part of this is helping others, I'm also helping myself. Just realizing that there are other people who may benefit from your advocacy makes this world a better place and easier for us all to live together and prosper."

Her proudest accomplishment? Helping to organize the Epilepsy Foundation's first annual walk in Washington, D.C. last March. "When I looked up Constitution Avenue I saw thousands of people coming out of the shadows; it wasn't just

the families and those of us who have epilepsy, but also people who care about us. I thought that maybe someone's child who has epilepsy will not suffer the stigma of epilepsy that I've gone through."

SPEAK UP, CAREGIVERS

Caregivers should make themselves heard too, says Bob Marino, 52, of Lafayette Hill, PA. While assisting his dad in the care of his mother, who died of Alzheimer's disease in 2000, Marino felt "desperate to get help" and sought caregiving advice from the Alzheimer's Association. Afterwards, he wanted to give back to the organization and began serving as a volunteer family caregiver trainer with its (then) Southeastern PA chapter (now known as the Delaware Valley Chapter, where he sits on the board). The program offers advice on taking care of people with Alzheimer's, including how to communicate with them and how to handle legal issues such as durable power of attorney. The chapter also runs a 24-hour caregiver help line.

Marino continues to volunteer, even though he now coordinates care for his 87-year-old father, who recently developed Alzheimer's. Every year, Marino and other volunteers visit Capitol Hill, where they lobby representatives about the need to increase funding for Alzheimer's research. In 2006, he received the Alzheimer's Association's Maureen Reagan Outstanding Advocate Award.

"Sometimes I have to resist going into a legislator's office and pounding the table and saying 'Don't you get it, don't you understand this is going to be the next plague, especially for baby boomers?'" he says. "I try to snap myself out of it by

“Just realizing that there are other people who may benefit from your advocacy makes this world a better place.”

remembering all the things that we’ve done that have been meaningful.” Marino says he’s optimistic that pouring money into research will lead to a cure or at least treatments to halt Alzheimer’s by the time Generations X and Y become old enough to develop the disease.

Since Marino runs his own consulting business, his schedule is flexible. This, combined with the fact that he can afford an in-home aide to care for his father, allows Marino to spend more time on advocacy work than the average caregiver could, he says. Nevertheless, people can be effective advocates from their own home by calling or e-mailing their elected officials. For example, the Alzheimer’s Association Web site (alz.org) provides an advocacy link where caregivers can find out who their Congressional representatives are and how to contact them. The site even includes a form letter that the user can personalize and e-mail to their representative. The entire process takes a half hour or less, Marino says.

STARTING YOUR OWN ORGANIZATION

But what if you want to do something that none of the organizations are doing? Why not start your own organization?

That’s what Jesse Billauer had in mind in 2002 when he formed Life Rolls On, a nonprofit that organizes surfing lessons for people with spinal cord injury.

At 17, Jesse was an aspiring professional surfer. Then one day in 1996, while surfing off a Southern California beach, a wave knocked him into a sandbar and broke his neck, leaving him quadriplegic. Friends and neighbors raised money for Jesse’s medical expenses. After a few years, when Jesse’s medical bills were paid, Jesse and his brother Josh decided to use the money to start an organization that would raise awareness about spinal cord injury as well as money for research.

“After my injury everyone kept saying ‘well, life goes on,’ and I thought no, ‘life rolls on,’” Jesse says.

So far, Life Rolls On has raised between \$1 and \$1.5 million, says Josh, who serves as chairman of the board.

But before deciding to start your own organization, Josh advises that you do your research to make sure your mission doesn’t overlap with that of other organizations’. If you do find that your cause is unique and want to go ahead with starting a new organization, you need to hire a lawyer who is familiar with the state and IRS filings required for nonprofit status. Or you can do what the Billauer brothers did: Find a lawyer willing to donate legal services.

Be prepared for a lot of work. Just obtaining nonprofit status takes six months to one year and filing fees cost about \$1,000, Josh says.

Another crucial step is to set up a professional-looking Web site through which people can make donations and find out about events, he says. Life Rolls On (liferollson.org) uses Kintera Sphere software that processes e-mails and membership databases. “You need to map out the technology side so that two or three years after, when you are a success, you don’t get burdened with hundreds of e-mails a day that you can’t manage,” Josh says.

Finally, define your organization’s mission, and target people whom you think will believe in and donate to it, he adds.

For Josh, who also has a full-time job as a money manager with Wachovia Securities, it was time well spent. “When you’ve put all the effort in and see the smiling faces of people surfing who never thought they could even get into the ocean, you tend not to dwell on how much time and energy went into everything,” he says.

“ME” TIME

And while getting involved can be empowering, Christensen, the Parkinson’s advocate, offers this caveat: Make time for hobbies and friends and family, because living a disease 24/7 isn’t healthy. “It may sound like that’s the main focus of my life,” she says, “and it does take up a lot of it, but it’s not who I am.” **NN**

Stephanie Cajigal is the associate editor of Neurology Now. For the July/August issue she wrote about journalist Richard Cohen’s life with multiple sclerosis.

A 3-STEP PLAN FOR BECOMING AN ADVOCATE

► **DEFINE YOUR CAUSE:** What issues affect you on a day-to-day basis? What are you passionate about?

► **JOIN AN ORGANIZATION:** Use the Internet to find an organization that represents people with your condition. One option is to visit google.com/Top/Health/Organizations/Conditions_and_Diseases for a listing of disease organizations. Idealist.org is a good place to search for volunteer and paid positions. You can also see Resource Central on page 30 for a listing of a few advocacy groups.

► **GET ACTIVE:** Attend your organization’s local chapter meetings, help organize a fundraising bake sale, start a letter-writing campaign—anything you think helps.