

Carrie Lucas Fights for the Rights of Disabled Parents

“My basketball coach told me I was just lazy,” Carrie Ann Lucas says in recalling her teen years. In fact, she was not lazy; her movement difficulties were a harbinger of serious problems ahead. It wasn’t until her mid-20s that she “hit the genetic jackpot” and was diagnosed with central core disease.

Central core disease is a rare genetic muscle disorder that takes its name from structures in the center of many muscle fibers that appear empty, or “cored.” The age at onset of symptoms and the affects of the disease vary widely.

“I went from using braces and crutches to a wheelchair (currently a Quantum 6000 power chair) at age 25. I started using a BiPAP ventilator at night at 29, and five years ago, I started using the LTV® 800 ventilator full time. Two years ago, I was trached,” she says. Carrie also lost her hearing and is legally blind.

Now 39, Carrie is a successful lawyer in her native Colorado and nationally recognized advocate for people with disabilities. She is also mother to three adopted daughters with disabilities, 12½, 16 and 21, all of whom experienced abuse and neglect in their birth families and in the foster care system.

She adopted her biological niece in 2000 from foster care in Tennessee. “I battled 14 months to get her from Tennessee,” she says. “The first adoption from a foster system is hard. The kids have suffered so much trauma. But I was actually recruited to adopt my third daughter, and I’m in the process of adopting a 10-year-old boy with developmental disabilities.”

After graduating from Whitworth College in Spokane, Washington, Carrie taught at a junior high school in the Northern Mariana Islands. “I would have loved to live there, but I was using braces and crutches, and it was an eight-hour flight to Honolulu to see a doctor.” Returning to Denver, she earned a Master of Divinity at Iliff School of Theology. In 2005, she graduated from the University of Denver College of Law, combining Braille and sign language classes with law classes as her sight failed.

An internship at the Colorado Cross-Disability Coalition led to full-time employment and the founding of the Center for the Rights of Parents with Disabilities, dedicated to combating discrimination that impacts parenting for parents with disabilities. Since April 2011, the Center (www.disabledparentrights.org) has been an independent nonprofit organization, based in Windsor, Colorado, with Carrie as executive director.

“We handle primarily juvenile law and social services cases. I try to focus on cases where I can create change,” she says. “We turn away an average of 10 cases a week.”

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In 2010, Carrie Lucas was named a Fellow by the Petra Foundation, which seeks out and champions unsung heroes who deserve recognition for their distinctive contributions to the rights, autonomy and dignity of others.

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Carrie with daughters Asiza (standing) and Adrienne (sitting).



A “Typical” Day

My attendant gets me up and into the shower at 5:30 a.m. Shower, dressing and nebulizer takes about an hour, and then I get the kids up,” Carrie says. “Two are in wheelchairs and fed through feeding tubes. The youngest

is out by 7:10 a.m. to catch the bus, and my middle daughter, who dawdles, walks to school. My 21-year-old daughter has recently moved to a carriage house apartment behind ours. Windsor is a small town, so we are within wheelchair distance of school, church and stores.

Carrie has been working from her home for the last six months but recently obtained office space that is within wheelchair distance. She uses ZoomText software on the computer, a captioned telephone and innate screen magnifiers for the phone and iPad.

An attendant drives Carrie to Denver when she has to go to court. In the courtroom (her attendant remains with her), she uses either sign language interpreters or CART (Communication Access Realtime Translation) that instantly translates the spoken word into text using a stenotype machine, notebook computer and realtime software, mandated as part of the Americans with Disabilities Act.

“Judges are pretty darned patient about my need for suctioning and when my vent battery alarm starts going off,” she says. “I never know if the battery is going to last one hour or three hours.”

Carrie uses a cuffed trach at night but is able to speak without a speaking valve during the day, although “I can’t get out my entire email address without running out of breath.” She says

Center Provides Support to Parents with Disabilities

The Center for Rights of Parents with Disabilities started as a program of the Colorado Cross-Disability Coalition (www.ccdconline.org/crpd/crpd.htm) in 2004. While at the Coalition, Carrie Ann Lucas was the program director, and it provided support in developing the program. The program was initially funded by an Equal Justice Works fellowship which provided funding for the first two years, and later funded through legal fees and grants. Since April 2011, the Center has been an independent nonprofit organization and has applied for IRS 501(c)(3) status. Carrie Lucas is its executive director.

“We are a committed group of volunteers dedicated to combating discrimination that impacts parenting for parents with disabilities,” she says. “Disabled parents experience discrimination in a variety of arenas. From a subsidized housing provider that refuses to allow a child to live with her parent, to a court that refuses custody due to a parent’s disability, disabled parents frequently experience insidious discrimination. This discrimination has a detrimental affect on families, ultimately victimizing both parents and their children.”

The Center helps parents with disabilities in several areas. The Center provides direct representation to a limited number of cases within Colorado to parents who meet the State of Colorado’s indigency guidelines. It also provides technical assistance to attorneys representing parents with disabilities and information and referral services to parents with disabilities.

“Education is the best way a parent with a disability can avoid involvement with the legal system or ensure a positive outcome,” says Carrie. “We operate from the assumption that there are no perfect parents. We can always learn and improve our parenting skills. Part of being a good parent is knowing your rights as a parent, knowing your children’s rights, advocating for yourself, and advocating for your children.”

- ▷ she has struggled with humidification post-trach because of the altitude in Colorado and because she has had asthma since infancy.

Colorado has consumer-directed attendant support paid for through Medicaid. “I don’t use nurses; I prefer to hire and train people to do what I need done. I have seven to eight



Carrie and Adrianne on a camping trip.



Carrie and daughters Adrienne, Asiza and Heather (in front).

attendants on a regular basis, and some also work for my daughter. I hire and schedule them and set their wages. I don’t get funding for 24-hour attendant care, but I can make the budget stretch,” Carrie says. “Funding is not available for children on vents, so a good many are warehoused in hospitals. I am waiting to get my 21-year-old daughter’s situation reassessed.”

“It’s a gift to raise children in the disability culture,” she says. “I want to be their role model and raise them to be proud of who they are.” ▲

Conference Calendar 2011-12

OCTOBER 29, 2011. 9:00 am-2:30 pm. Breathing and Sleep Symposium III.
Salk Institute for Biological Studies, La Jolla, California. FREE.
<http://poliotoday.org/breathingandsleep2011>

NOVEMBER 5-8, 2011. AARC International Respiratory Congress.
Tampa Convention Center, Tampa, Florida. www.aarc.org

NOVEMBER 27-DECEMBER 2, 2011. International Alliance of ALS/MND Associations Annual Meeting and International Symposium on ALS/MND.
Sydney Hilton, Sydney, New South Wales, Australia. www.alsmndalliance.org

MARCH 15-17, 2012. International Conference on Home Mechanical Ventilation,
Barcelona, Spain. Sponsored by Journées Internationales de Ventilation à Domicile (JIVD) and European Respiratory Care Association (ERCA). Abstracts due January 15, 2012. Contact Brigitte Hautier, JIVD, +33 (0)4 78 39 08 43; brigitte.hautier@free.fr; www.jivd-france.com.