

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.

From Around the Network

Judith R. Fischer, MSLS, IVUN Information Specialist, info@ventusers.org

International Ventilator Users Network's mission is to enhance the lives and independence of home mechanical ventilator users and polio survivors through education, advocacy, research and networking.

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Special thanks ...
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To be sure you receive email updates from PHI and IVUN, set your spam filters to allow messages from info@post-polio.org and info@ventusers.org.

Product News

Pixi™ is a new nasal mask from ResMed for children over 2 years of age or weighing more than 13 kg (28.6 lbs). A soft silicone cushion minimizes pressure on the face, tubing has two positions for sleeping, and headgear has flexible stabilizers and quick release latch. Available worldwide. www.resmed.com



ResMed's Pixi™

HT®70S from Newport Medical Instruments is similar to the HT®70 ventilator but it does not provide pressure support or trends. For equipment specifications, visit www.ventilators.com.



Pepper Medical's Vent-Strap®

Vent-Strap®, from Pepper Medical, is used with the Trach-Tie® to provide extra security for the T-piece. www.peppermedical.com

Trilogy100, the Philips Respironics ventilator replacing the PLV®-100 series, is comprehensively reviewed by vent user John Gugie, who has Duchenne muscular dystrophy. Go to www.associatedcontent.com/article/6073240/trilogy_100_ventilator_from_philips.html?cat=5.



Philips Respironics' Trilogy100

NeuRx Diaphragm Pacing System (DPS)™ from Synapse Biomedical, Inc., recently received "Humanitarian Device Exemption" approval from the FDA for use in select patients with ALS. These individuals must have a stimulatable diaphragm, and their hypoventilation cannot have progressed to a forced vital capacity less than 45 percent of predicted. For a clear explanation of how ALS affects breathing and how the system works, go to www.synapsebiomedical.com/als/als-patientInfo.shtml.

MORE on www.ventusers.org

See "Update: NeuRx Diaphragm Pacing System (DPS)."

www.ventusers.org/edu/valnews/val_24-1Feb10p4.pdf

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Ask The Experts

QUESTION: *Individuals with high-level (C1-C3) spinal cord injuries need to use ventilators full time to assist their breathing. However, I know several people with a spinal cord injury at a lower level who were weaned from the ventilator but now, decades later, seem to be having more trouble breathing. What kinds of tests should be conducted to evaluate their breathing? Would a bilevel device with a nasal or face mask be prescribed to use at night?*



ANSWER: *Franz Michel, MD, FCCP, Swiss Paraplegic Centre, Outpatient Care Unit, Nottwil, Switzerland, www.paranet.ch*

Decades after incurring a spinal cord injury, you will lose the ability to breathe adequately due to several reasons. Depending on your lesion level, your inspiratory muscles weaken. Your thoracic (rib) cage stiffens and becomes narrower, trapping your initially normal lung so that it cannot expand fully. Due to the autonomic dysfunction of your intestinal contents, you become more obstipated (severely constipated), and the intra-abdominal pressure rises, causing the intestinal contents to press against the diaphragm, further diminishing your ability to breathe in. With aging, there is often a rise in the use of anti-spastic and pain medications, which will weaken the inspiratory muscles and the central control of breathing, especially during the night. Breathing patterns become irregular and insufficient to the needs of your body. Obesity is also a concern, because most patients gain weight while aging.

What you can do: obtain your maximal inspiratory capacity (MIC), which should be measured at the end of your first rehabilitation. This is done by inspiring as deeply as possible, and then trying, with the aid of the air stacking technique or an Ambu® resuscitation bag, to expand your thoracic cage and lungs as much as possible. The amount of air you are able to exhale is measured and becomes your personal MIC. Once you know this value, try to stabilize or even expand it during the following decades with the aid of a specially designed inspiratory muscle training device and daily efforts to expand your lungs.

Keep your lungs healthy, don't smoke and keep your airways clear with an efficient cough (either through special cough training or manually-assisted cough techniques or mechanically-assisted techniques, such as the CoughAssist®). Your lung function should be tested at regular visits (once a year or every two years), particularly if you are tetraplegic. These tests include body plethysmography to measure the volume of gas in the lungs, maximum inspiratory and expiratory pressure (MIP and MEP), maximum inspiratory capacity and peak cough flow. If you are very sleepy during the day, first obtain an overnight screening with oximetry, and if in doubt, a sleep study.

For those with insufficient breathing and symptoms (initially most often during the night), I prescribe noninvasive ventilation with a nasal or nasal-oral mask and initiate this therapy during a short hospital stay or in an outpatient setting if appropriate.

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Carrie Lucas Fights for the Rights of Disabled Parents

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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.



ANSWER: Steven Kirshblum, MD, Medical Director, Director of Spinal Cord Injury Services, Kessler Institute for Rehabilitation, and Professor, UMDNJ-New Jersey

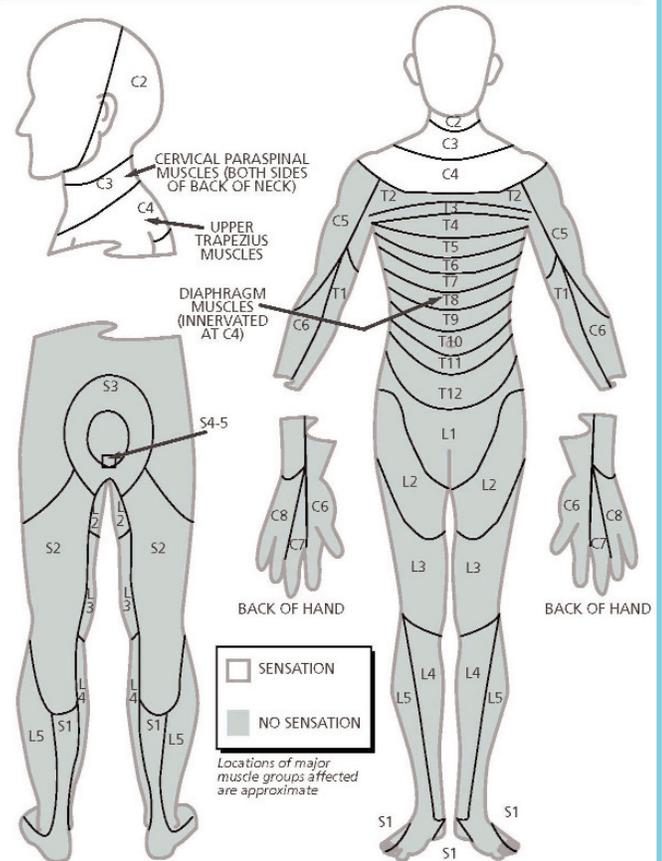
Medical School, www.kessler-rehab.com;
<http://kesslerfoundation.org/researchcenter/sci>

Most people who initially require a ventilator after their spinal cord injury (SCI) are able to be weaned from the ventilator, unless it is a high level SCI (C1-3). However, as persons with a spinal cord injury age, their ability to remain off the ventilator full time may be affected. (In fact, respiratory issues are the leading cause of death in all persons with SCI, especially patients with high level injuries.)

The need for some assisted ventilation may arise from the development of sleep apnea and/or underventilation or from other changes associated with aging. People with tetraplegia are at higher risk for sleep apnea and underventilation, and those with injuries C4 and above are at highest risk. This is an extremely important issue and should be part of the routine follow up for all patients with chronic injuries. This includes evaluation for symptoms of sleep apnea (i.e. snoring, daytime sleepiness and morning headaches) and testing for the ability to cough and take deep breaths (i.e. peak cough flow, forced vital capacity). Formal sleep testing may be required.

Treatment of sleep apnea and/or underventilation includes traditional measures such as nasal continuous positive airway pressure (CPAP), nasal bi-level positive airway pressure (BiPAP) and supplemental oxygen if needed. Weight reduction is also helpful if this is a problem. ▲

FIGURE 1—LEVEL C4 SENSATION DIAGRAM



Reprinted with permission from the Paralyzed Veterans of America (PVA) Consortium for Spinal Cord Medicine Clinical Practice Guidelines Consumer Guide: "Expected Outcomes: What You Should Know A Guide for People with C4 Spinal Cord Injury" Washington, DC: ©2002 Paralyzed Veterans of America

Copies of the PVA's Guidelines are available at www.pva.org or through the PVA Distribution Center (toll-free 888-860-7244).

Are you a ventilator user or health professional with a question about home mechanical ventilation?

Send it to info@ventusers.org, and IVUN will find experts to answer it.

"Postrehabilitative Health Care for Individuals with SCI: Extending Health Care into the Community" and other articles about health and health care disparity in people with SCI appeared in *Topics in Spinal Cord Injury Rehabilitation*, 17(2), Fall 2011, 1-58. <http://thomasland.metapress.com/content/x59825564807/?p=0fe7d9085fde46df8eef8ca57fc84ddc&pi=0>

Muscular Dystrophy

Presentations from the Parent Project for Muscular Dystrophy's Connect Conference in July are available for downloading from PPMD's website. Several sessions were also streamed live, and those broadcasts are also available to view. Visit www.parentprojectmd.org and click on Connect, then Annual Conference.

Chronic Conditions in Young Adults

Physician-Parent Caregivers (PPC) is a nonprofit organization dedicated to advancing the independence and quality of life of young adults with chronic conditions and disabilities. Many people are not aware that these conditions are controlled, rather than cured, or that when children turn 18, they often fall through the patchy safety net of social and medical services. Recently PPC launched "Campaign Emerge" to increase the public's understanding of the "lived experience" and needs of these emerging adults. The campaign also calls for a conference to be convened to develop a system to address the healthcare needs of these young adults. <http://physicianparent.org>

Emergency Personnel: Responding to Vent Users

"Ventilator Emergencies in the Home" is the title of an article in the journal *Fire Engineering*. Author Francis Califano, an emergency management coordinator in New York, does an excellent job of presenting what emergency medical personnel need to know when called to the home of a ventilator user. An article by vent user Sandy Stuban, RN, is cited as a reference. www.fireengineering.com/articles/print/volume-164/issue-9/departments/fire-service_ems/ventilator-emergencies-in-the-home.html ▲

Join IVUN! ...and receive Ventilator-Assisted Living, IVUN's bi-monthly newsletter.

The eight-page newsletter will be sent electronically in February, April, June, August, October and December. (IVUN Members without email access may request print copies by contacting IVUN). Members will also receive an electronic *IVUN Membership Memo* in alternate months. To become a Member, complete this form. *Memberships are 100 percent tax-deductible.*

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Philips Respironics' Trilogy100

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