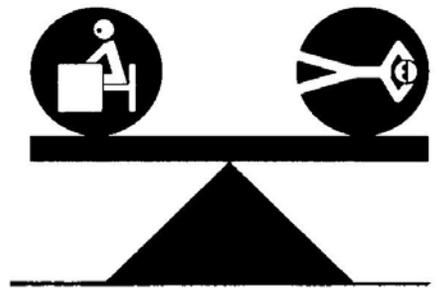


POST POLIO PACER



Conserving Strength and Energy through Pacing
January 2007 — Madison, Wisconsin
Madison Area Post Polio Support Group Newsletter

The Latest Facts about the Diaphragm Pacing Stimulation (DPS) System

Sandra Stuban, RN, Fairfax, Virginia,
stubanrn@aol.com

Most of us who use ventilators are aware that the late Christopher Reeve had some kind of experimental diaphragmatic stimulator implanted in 2003 to help decrease his dependence on his ventilator. Many folks may think this technology is only available for the rich and famous. Not true!

It is true, though, that Reeve was one of Dr. Raymond P Onders's first success stories. Having completed 38 of these procedures to date - 27 in people with spinal cord injury (SCI), 11 in people with ALS - Dr. Onders is now performing one or two every month with a 96% success rate in people with SCI (an intact phrenic nerve is key), enabling them to breathe with an adequate tidal volume without a ventilator. He has performed the procedure both soon after an injury and up to 25 years post-injury.

For about two decades, Onders and his colleagues, Anthony DiMarco, MD, and J. Thomas Mortimer, PhD, pondered the issue of some kind of implanted device to improve the quality of life for ventilator users. Today, as the Director of Minimally Invasive Surgery at University Hospitals of Cleveland in Ohio and Associate Professor of Surgery at Case Western Reserve University, Dr. Onders is making this dream a reality.

The device is called the NeuRx Diaphragm Pacing Stimulation (DPS) System. Its goal is to free a person's dependence on a ventilator over time by stimulating the diaphragm with intermittent electric impulses. They cause the diaphragm, the primary muscle for breathing in, to contract, thus enabling air to enter the lungs as in normal respiration. The impulse sensation has been described as similar to a flick of the finger.

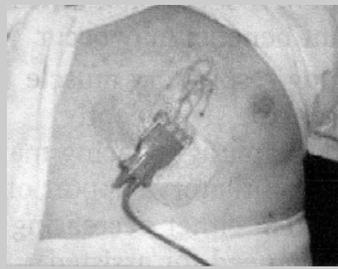
In a two-hour outpatient procedure, electrodes are placed directly on the diaphragm near the phrenic nerves using a laparoscope. The wires from the electrodes are attached to an external battery pack about the size of a remote control and set at a determined rate, usually 10 to 14 discharges per minute. Because the procedure is still considered investigational by the FDA, potential candidates* and dedicated caregivers must follow precise postoperative instructions and return for all scheduled follow-up appointments.

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MEETING DATE CHANGE!

Our luncheon meetings will be on the 2nd Saturday of March, May, July, Sept., and Nov. to allow members to attend the Milwaukee P-P meetings on the 3rd Saturday of the months above if they wish, without missing the Madison Support Group meetings and hopefully, allow Milwaukee members to attend our meetings.

*The clinical trial is currently recruiting patients at the University Hospitals of Cleveland and the Shepherd Center in Atlanta. A third site is planned for the West coast. Detailed information is online at www.clinicaltrials.gov/ct/show.



Contact Mary Jo Elmo, NP, University Hospitals of Cleveland, 216-844-8594, maryjo.elmo@uhhs.com or Michelle E. Nemeth, PT, The Shepherd Center, 404-3507688, Michelle.Nemeth@shepherd.org.

Full FDA approval is expected in about one year for people with SCI to receive the DPS System. Its protocol has been designated "category B" by the FDA, making it eligible for Medicare billing.

All the people who have had the procedure so far were covered by Medicare, Medicaid or private insurance with the usual copay. For non-US citizens paying cash, the bill includes device cost, surgery, anesthesia, professional fees and x-rays for a total cost of approximately \$20,000. Transportation costs are the patient's responsibility.

I had an opportunity to ask Dr. Onders and Nurse Practitioner Elmo questions about this important work.

Synapse Biomedical Inc. is the company that Drs. Onders and DiMarco formed to manufacture the DPS System. www.snyapsebiomedical.com

Q: How do you measure success?

A: In our ongoing studies, 27 SCI patients using mechanical ventilation via tracheostomy were implanted with the DPS System. All procedures were performed on an outpatient basis with no intra-operative complications. One

patient had a false positive preoperative phrenic nerve conduction study, and therefore was never able to pace. The remaining 26 patients (96%) achieved greater than their predicted tidal volume during stimulation; 24 patients underwent weaning from the ventilator at home by capping the trach while the DPS System stimulated their diaphragm. Fifteen patients now use the device fulltime, and eight use it 12-24 hours a day resulting in more than 40 years of cumulative active implantation time. The home-based weaning protocol allows patients to maintain caregiver support, work and significantly lower expenses.

Diaphragm or Phrenic Nerve Pacers

Diaphragm pacing via phrenic nerve stimulation is not new. William Dobbelle, of the Dobbelle Institute (now Avery Biomedical Devices, Inc.), began developing it in 1971. The current Avery model is the Mark IV Breathing Pacemaker and the only phrenic nerve pacing system that has full FDA approval for implantation in the USA. The Avery system requires surgical, rather than laparoscopic, implantation of electrodes directly on the phrenic nerve and utilizes an antenna. www.breathingpacemakers.com

A Finnish company, Atrotech Ltd., uses a quadripolar electrode system for their device, the Atrostim® Phrenic Nerve Stimulator V2.0, which must be surgically implanted. Like the DPS System, it is classified as only an investigational device by the FDA for use in the USA. www.atrotech.com

Q: How does this work for people with ALS?

A: The objective of our study in people with ALS was to use diaphragm pacing technology to maintain respiratory muscle function. If successful, at least two significant benefits may occur. Life threatening respiratory muscle dysfunction may be significantly delayed. And, diaphragm pacing may be effective in ventilatory support of patients with ALS, either decreasing or obviating the need for assisted mechanical ventilation.

We have now implanted 11 ALS patients with the DPS System. These patients had a forced

vital capacity (FVC) of at least 50% at the initial screening and had not yet required invasive mechanical ventilation. The first four patients have used the system for more than one year. The results to date have confirmed that there is a sound scientific rationale for electrical stimulation of the diaphragm in ALS, especially in this group of patients whose FVC at implantation was 53% or lower.

In our first four patients who have surpassed the one-year mark, we have shown a 65% decrease in the rate of respiratory decline. The pre-implant rate of decline was 4.1 % per month, while the post-implant rate after conditioning with DPS was 1.4% per month. This corresponds to more than an additional 20 months of survival without a ventilator.

Q: What is the goal of DPS?

A: Our goal with people with SCI is to replace the ventilator. The longest-term patient was implanted March 6, 2000 and has been using the DPS System as his sole means of respiratory support for more than six years. With the ALS population, we are evaluating whether electrical stimulation of the diaphragm will slow the rate of progression and delay the need for a ventilator.

Q: Is the DPS System less expensive than a ventilator?

A: Economically, when balanced against the long-term costs of ventilator equipment, supplies and care, the DPS System is far less costly. After the cost of the procedure itself, there are minor costs for battery and external cable replacements. Our data show that savings for one patient who uses the DPS System fulltime are \$13,000 per month for Ohio Medicaid.

Q: Are there other benefits to using DPS?

A: Physically, individuals with the DPS System are able to smell, eat and talk more "normally." They also report less need for suctioning and fewer hospitalizations.

During hurricanes and other natural disasters, the widespread loss of electricity can cause significant and life-threatening problems for



Laszlo Nagy (laszlon@adelphia.net) became a C3 quadriplegic as a result of a motorcycle accident in June 2002. Nagy says, "I was implanted with the DPS System exactly one year later. Seven weeks after the surgery, I was ventilator free for 24 hours a day, seven days a week. Since then, I have never needed to use a ventilator, and I have been infection free. I have also developed the ability to breathe on my own for up to several hours, turning off the DPS System. I use this as my 'backup,' although I keep an Ambu bag on my wheelchair."

Nagy retained his tracheostomy for suctioning, usually only once a day. He continues, "I am able to live in my own home. On August 12, I got married. The DPS System allows me to travel and to leave my home virtually worry free. It has made my life much easier."



Tom Davis (tomdavisfl@cox.net), a C1/C2 quadriplegic, had the DPS System procedure in May 2004. One month later he was completely "freed from the ventilator" and remains so. Davis says, "The DPS System has revolutionized my lifestyle. I no longer have to lug around that heavy ventilator on the back of my chair. Instead, I have a small box that is tucked in the waistband of my pants. Without the ventilator, the length of my wheelchair has been shortened by nearly two feet and has given me much more maneuverability in tight spaces."

"When they turned the pacer on for the first time, I could smell everything in the room. This of course has made food taste much better, which has caused me to gain a little weight. The procedure has cut in half the amount of times I need suctioning."

Also, I no longer have those long pauses between breaths from the ventilator. When people talk to me on the phone, they have no idea that I use an assisted breathing device. I love it!"

anyone who uses a ventilator more than a few hours per day. Ventilator batteries last from only one to eight hours before requiring electricity for recharging. The DPS System uses a standard disposable 12V external bat-

tery that lasts 500 hours, and patients are supplied with a stock of batteries. The DPS System improves the quality of life during these events by decreasing anxiety, easing evacuation if necessary, and simplifying temporary housing until power is restored.

Q: Who are other potential candidates for DP'S?

A: We expect to branch into the muscular dystrophies, post-polio and hypoventilation syndromes, such as CCHS, within a year.

References

DiMarco AF. Onders RP, Ignagni A, Kowalski KE. Inspiratory muscle pacing in spinal cord injury: case report and clinical commentary. *Journal of Spinal Cord Medicine* 2006; 29(2): 95-108.

Office of Public Affairs. Christopher Reeve Receives New Implantable Breathing Device Developed by Faculty. School of Medicine Case Western Reserve University.

Passion S. Breathing Easier. *Spinal Column*, the magazine of Shepherd Center. Spring 2006; 16-17.

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Editor's note: Although the preceding article does not pertain directly to post-polio survivors now, it provides important background information that may be pertinent when DPS is developed for polio survivors, possibly within a year or two.

DR. LAURO HALSTEAD'S NEW BOOK NOW AVAILABLE

MANAGING POST POLIO: A Guide to Living and Aging Well with Post-Polio Syndrome, edited by Lauro S. Halstead, M. D., Director of the Post-Polio Program at the National Rehabilitation Hospital in Washington, D.C. is now for sale. This excellent collec-

tion of polio information and suggestions features fifteen chapters by "a cadre of experts from NRH and elsewhere," as well as six "insightful polio survivors who 'tell their stories' and provide personal perspectives on living with polio and PPS."

Nebraska Polio Survivors Association's Nancy Baldwin Carter's personal story, "Making Peace with My Aging Disability" appears in the 250 page soft-cover book, as well as a chapter she co-wrote with Joan L. Headley, "Support Groups: Keeping Them Active and Useful". Headley is Executive Director of Post-Polio Health International (formerly called GINI) in St. Louis, Missouri.

Cost for one copy is \$13.95 + \$4.25 shipping. Two to five copies: \$13.95 + \$7.50 shipping. For those wanting to place larger orders, discounts are available-call (202) 877-1776.

Order from: NRH Press, National Rehabilitation Hospital, Publications Office, 102 Irving Street, N.W., Washington, D.C. 20010-2949.

This article was reprinted from the January/ February 2007 issue of GLEANINGS, Nebraska Polio Survivors Association, P.O. Box 45139, Omaha, NE 68145-0139.

THE BOOK SHELF

Information about the following books about the Polio Experience are found at Post Polio Health's website <<http://www.post-polio.org/ipn/books.html>>

Mason, Martha. (2003). **Breath: Life in the Rhythm of an Iron Lung**. Asheboro, North Carolina: Down Home Press (PO Box 4126, Asheboro, NC 27204). (ISBN 1-878086-95-2) You can read a review on the website above.

Malizia, Alan M. (2004). **The Little Red Chair**. AuthorHouse, 1663 Liberty Drive, Ste. 200, Bloomington, IN 47403, 800-839-8640. www.authorhouse.com (ISBN 1-4140-2837-7, \$12.50 USD).

If anyone has read either of these books, please share your thoughts about the book and send it to the Editor for publication in the next issue of the *Post-Polio Pacer*.

Please let us know promptly when you change your e-mail address so our list can be accurate.

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The following names have been removed from the above list because their addresses "bounced": **Dennis Gremminger & Tom Comeford**. Please let us know your correct address and we'll restore you to the list.

Reader input is needed for each issue. Here are some suggestions for topics you, the reader, might share for the April issue:

- Your "polio story"
- A brief review of a book about polio
- A favorite easy recipe (including nutritional information if possible)
- Tips for making activities of daily living easier



Send a whole article or just a couple of paragraphs; they may be handwritten, typed, or by e-mail, but do it now, before you forget! Your contribution will be used in the next or a future issue depending on space available.

F.Y.I.

Did you know that there is an exhibit about "Whatever Happened to Polio?" Take a virtual tour of the Smithsonian Museum's exhibit at <www.americanhistory.si.edu/polio>.

Copies of the Medicare Medical Health Account Fact Sheet will be available at the March meeting. Janet Niedfeldt talked briefly about this health account at the November meeting.

The Overture Center for the Arts in Madison has a "guide to patron services & information" available at <www.overturecenter.com> or by phone 608-258-4177. Large print programs, transportation wheelchairs and assistive listening headsets may be obtained at the Information Desk. All restrooms are accessible. Ramp, metered, and accessible parking is located within one block of the Overture Center. Accessibility information is also available at <www.overturecenter.com/accessibility.htm>.

T'N'T: Tips and Techniques for Polio Survivors by Dr. Richard L. Bruno

Not from Tennessee? You may not know the name Steve Cohen. If you don't, write it down. Because, if you're a polio survivor anywhere in these, the United States, freshman Democratic Representative and polio survivor Stephen Cohen has just become your Congressman.



"Delayed gratification", was Cohen's reply when I asked how he felt about winning. "I'm excited about going to Washington, where I've wanted to be my entire life."

Cohen has been trying to get to DC for forty years. At sixteen, he applied to be a Congressional page. "Over the years, I applied to be a Congressional intern, a government lawyer, and for jobs in Democratic administrations." Cohen was never hired. He also lost a 1996 Congressional bid.

But, although Washington was always on his mind, Cohen was working hard in Tennessee. A practicing lawyer, Cohen was elected to serve as a Shelby County commissioner, where he helped to create The Med, a community-funded regional hospital. Cohen was elected to the Tennessee State Senate in 1982, where he served for twenty-four years and supported expanding healthcare access, voting rights and the medical use of marijuana.

Some of Cohen's passion for public service and health care can be related to polio, which he had at age five in under particularly disturbing circumstances. "My father was a pediatrician, participating in the 1954 Salk vaccine trials. The protocol was to give vaccine to second graders, like my brother Martin, who got the shot. My father thought about taking some vaccine home to give to me. He didn't do it."

Cohen isn't sure why his father withheld the vaccine. One notion is that his father thought there was a small chance Cohen could get polio from the vaccine. "The other story is that my father didn't give me the vaccine because it wasn't right, my not being in the study group. I got polio in fall of '54, an ironic situation."

Cohen was hospitalized in isolation and then in a rehabilitation facility for about 3 months. "My left leg and back were affected." He got the usual treatment -- hot packs, water therapy and PT—and used crutches for all of first grade. "I wore a cast sophomore year in high school to stretch my Achilles tendon, which didn't work. So, I had tendon lengthening surgery my junior year."

Cohen is one of not even a handful of polio survivors in the public eye who admits to having Post-Polio Sequelae. "I limp more than I used to. The past year, when I'm standing, I feel like I'm going to lose my balance."

Cohen also says he gets more tired than he used to. "But, I drive myself. I go way beyond warp, and I always have." Based on the theory of conserving to preserve poliovirus-damaged neurons, Cohen says, "I probably took five to seven years off my leg during the campaign, because I was going every minute. I was hustling like when I was 20 year-old!"

But, Cohen knows what he has to do now. "Take two rest periods, sit when you can and save your neurons ...which is the opposite of what I've always been thinking: Exercise, Exercise, Exercise." A PT had given Cohen exercises -- muscle resistance, quad strengthening by squatting and balancing on one foot -- which he hasn't done.

What's more, Cohen was planning to manage his PPS even before he was sworn in. He asked for a ground floor suite in the House office building closest to the Capitol, right next to the escalator going to the subway that travels to the Capitol building. Cohen is also thinking of getting a Segway.

Cohen is already planning to help polio survivors and promote polio vaccination during 2007, declared by Congress as The Year of Polio Awareness. He has already talked to Rhode Island Representative and quad Jim Langevin, who asked Cohen to join the Disability Caucus with another polio survivor, Missouri Congressman Ike Skelton.

"Polio is part of my life. I want to do whatever I can to help polio survivors and encourage vaccination in Africa and in America. I am a testimonial to what vaccination could do."

Delayed gratification and persistence. A winning combination for one polio survivor from Tennessee and 1.63 million polio survivors across the US.

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We **need** people to bring new ideas for speakers, topics, books to read and discuss, etc. Call or e-mail (see e-mail list) one of the people listed above to suggest program topics or speakers, volunteer to organize one meeting program, share your knowledge (or find an expert) about becoming a non-profit organization or volunteer your talents (financial, organizing, etc.) as a committee member.

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Golden Rule of Post Polio Syndrome

"If something you do causes you fatigue, weakness or pain, you shouldn't be doing it!"

Dr. Richard Bruno is Chairperson of the International Post-Polio Task Force and Director of The Post-Polio Institute and International Centre for Post-Polio Education and Research at Englewood (NJ) Hospital and Medical Center. Phone Toll Free: 1-877-POST-POLIO

Thank you

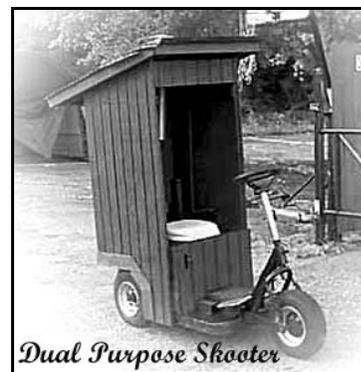
Like all my post-polio friends who warm my heart, the bread tray (shown at right) presented to me at the November meeting will not only keep the bread warm, but make me think of each of you every time it is used. The comments on the cards to Carole and to me also relay your appreciation for the effort put into the Pacer.



Being Editor of the Post-Polio Pacer is a learning experience with each issue. This is truly a "labor of love". I appreciate the articles, recipes, "helpful hints for living", and requests for information on specific topics that I have received in the past. Together we can continue to have an informative newsletter.

Marcia

A little humor...



Dual Purpose Skooter

POST POLIO PACER is a quarterly newsletter for polio survivors, the Madison Area Post Polio Support Group, health care professionals and interested persons to share information and to promote friendships. Articles in this newsletter are for information; medical advice is always necessary.

Disclaimer: The opinions expressed in this publication are those of the individual writers & do not imply endorsement by Easter Seals Wisconsin or the Madison Area Post Polio Support Group.



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See meeting date change on page 1

A NEWSLETTER FROM THE MADISON-AREA POST POLIO SUPPORT GROUP

Mark your calendars!

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Noon to 2:30

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Saturday, March 10, 2007
Holly Jellinek, Ph.D, Licensed Psychologist
Her topic is
"Understanding Depression
& What You Can Do"

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