



Newsletter

A QUARTERLY UPDATE FOR NEW JERSEY POLIO SURVIVORS

Summer/Fall 2012 / Vol 23. No. 1

Dr Bach: Non-Invasive Respiratory Therapy A Must to Treat Post-Polio Breathing and Sleep Problems

by Jean Csaposs

One of the world's leading specialists in non-invasive respiratory therapy and support, Dr John R Bach, delivered a comprehensive, lively, and illuminating presentation of critical importance to polio survivors at PNNJ's 22nd annual conference in April.

Dr Bach, Professor of Physical Medicine and Rehabilitation as well as Professor of Neuroscience at the UMDNJ Medical School, is a longtime friend of our Network, and a third-time speaker at our conferences. Each of his presentations has explored territory related to breathing difficulties encountered by many polio survivors, particularly those whose initial polio was of the bulbar type, but extending also to other aging men and women who are experiencing post-polio effects.

The main thrust of Dr Bach's presentation was his unequivocal condemnation of tracheostomy for polio survivors. "No one with polio has ever needed a tube in the neck," he declared at the beginning of his talk, an admonition he returned to repeatedly, citing case studies to illustrate his thesis, and elaborating in detail on less dangerous and more efficient alternatives.

He urged his audience not to rely on doctors to make decisions about a tracheostomy. "You need to know all about it," he insisted. "Very few doctors in the United States will agree to depart from standard practice."

The unwillingness of the medical profession and most healthcare providers to explore alternatives to the surgical insertion of breathing tubes and in many cases maintenance on them for life is "paradigm paralysis," according to Dr Bach. In addition to their general resistance to abandoning long-held practices, he also blamed the lack of "financial incentives" to adopt less expensive alternatives. "Tracheostomy and stomach tubes are big moneymakers," he said. As for nursing homes, the profit motive is clearly a factor in keeping people institutionalized who could very successfully live at home with self-controlled, simple breathing devices.

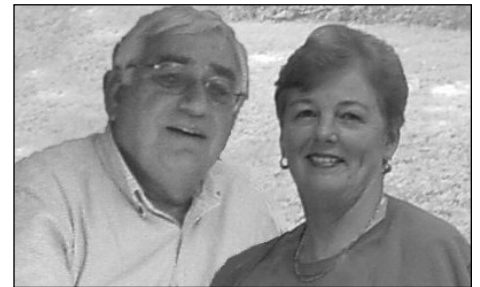


(l to r) Lee Bekir, President, Polio Network of New Jersey; John Bach, MD, who gave the keynote address; and Patrick Bird, PhD, author of *A Rough Road*, who read from his book at the conference, pause for a photo.

Dr Bach traced the history of respiratory management of polio patients from the days of the Iron Lung and the rocking bed through portable ventilators with trach tubes, up to "mouthpiece ventilation," the alternative he prescribes, a concept first introduced in 1953 at

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Announcing the Formation of the Joyce & Arthur Siegfried Memorial Fund



Joyce and Arthur Siegfried.

Post-Polio Health International (PHI) has named a special fund to underwrite its program that supplies braces and custom-made shoes to eligible individuals as the Joyce and Arthur Siegfried Memorial Fund. Established with a generous contribution from PNNJ, the fund honors our late PNNJ leaders who were pioneer advocates for polio survivors.

Joyce, a co-founder of the Network in 1991 and its treasurer for many years, had attended the 1987 international meeting of PHI (then known as GINI), where she took "pages and pages of notes" back to New Jersey, determined to share the information she had received at the landmark St. Louis conference. She founded the Raritan Valley Post-Polio Support Group that year and led it until her death in 2004. Joyce was an organizer of the first New Jersey Conference on the Late Effects of Polio and other activities that first brought awareness of post-polio syndrome to the public.

Arthur was our longtime Board attorney and president for five years,

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Respiratory Therapy *(continued from page 1)*

Rancho Los Amigos in California. He gave examples of polio survivors who have been using mouthpiece devices, as needed, for up to 55 years, some of whom have had trach tubes removed, without weaning and without adverse complications, at University Hospital in Newark, where he currently has about 30 post-polio patients.

The subject of sleep apnea, its causes and effects, and the pros and cons of such devices as C-PAPs and Bi-PAPs, were reviewed. Many polio survivors who experience “anxiety and shortness of breath” are actually afraid of what will happen if they fail to breathe while sleeping. This is a genuine concern, Dr Bach agreed, and he strongly advised against anyone with weak respiratory muscles taking sleeping pills. But the remedies for sleep apnea unrelated to polio are not a substitute for solving the breathing problems of post-polio sleep-deprived patients. The mouthpiece device has worked successfully for such patients.

The necessary balance of oxygen intake and carbon dioxide expulsion formed a detailed part of Dr Bach’s presentation. Normal blood gases can be provided by providing noninvasive (mouth piece/nasal) ventilation and, when airway congestion is a problem, by helping people cough effectively to expel sputum and prevent pneumonia. “The most important part of coughing is getting a deep breath.” Various devices to assist coughing have come onto the market over the years; *Cough-Assist* was approved by the FDA in 1992. Unlike airway suctioning, it helps to clear the left lung as well as the right, an important step forward. But the overriding concern is to maintain a proper balance of muscles that control breathing, and according to Dr Bach, “no one with polio should *ever* use oxygen at home.” Those who have special interest in exploring the more technical aspects of inspiratory and expiratory muscle function may want to consult one of Dr Bach’s books, *Noninvasive Mechanical Ventilation or Management of Patients with Neuromuscular Disease* (see column 3, this page, for details).

Frog breathing, an entirely non-mechanical form of breathing, came in for an explanation and a demonstration that caused some amusement on the part of the audience, but which has actually been a “life-saver” for some patients with very weak respiratory muscles. It consists of pistoning a series of gulps of air into the lungs to maintain normal ventilation and get deep breaths for coughing. Those interested in learning more about frog-breathing should consult Dr Bach’s books.

Dr Bach concluded with an impassioned plea to his post-polio audience to refuse to sign an Advance Directive in a medical emergency – but even more, to instruct one’s closest advocates to refuse to allow a tracheostomy under any circumstances, even though temporary intubation may be required. “If you insist on this – no tracheostomy! – and even more importantly, if the one closest to you insists – they will have to relent and send you to us at University Hospital!”

More about Dr Bach

At University Hospital, Newark, Dr Bach is Director of Research and Associate Chief of Service of the Department of Physical Medicine and Rehabilitation. He also serves as Medical Director of the Center for Ventilator Management Alternatives. Rehabilitation of patients with neuromuscular disease, pulmonary disease, and home mechanical ventilation are his primary clinical focus. He has authored more than 250 publications including seven books on neuromuscular pulmonary rehabilitation, and noninvasive mechanical ventilation, and has lectured widely in the U.S. and in international symposia.



Coco and Leila Bach, who attended our April conference, are world travelers with their parents, Dr John Bach and his wife Anne-Marie. The twins conduct brisk sales of their colorful handmade “frog” bookmarks to highlight the importance of “frog breathing,” a non-invasive breathing method for many people with severe respiratory problems. This and other non-invasive breathing methods are central to Dr Bach’s clinical practice of respiratory therapy.

Two Relevant Books by Dr Bach:

MANAGEMENT OF PATIENTS WITH NEUROMUSCULAR DISEASES

A great majority of people with neuromuscular diseases including post-poliomyelitis continue to be told that they have “terminal illnesses” and are not offered management options that can spare them of cardiopulmonary morbidity and mortality. This book is unique in offering viable management alternatives that result in a patient’s prolonged survival and enhanced quality of life.

PHILADELPHIA: HANLEY & BELFUS 2004, 350 PAGES, ILLUSTRATED. ISBN 1-56053-604-7

Key features

Unique because it offers descriptions of how to eliminate the respiratory or cardiac causes of complications and death for neuromuscular diseases.

Emphasizes the home care/management of severe disabled individuals with neuromuscular disorders and those who require ventilator use.

Describes inexpensive methods of clearing airway secretions and preventing episodes of respiratory failure that would otherwise necessitate hospitalizations and expensive, invasive interventions like tracheotomy or result in the patient’s death. Important in the third world where this could prevent many deaths.

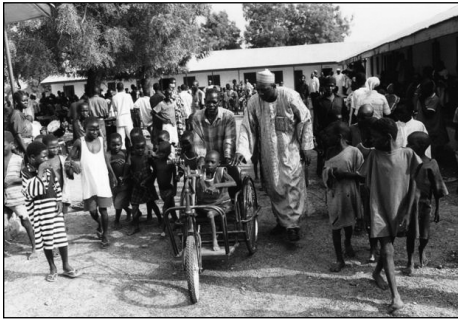
NONINVASIVE MECHANICAL VENTILATION

This book describes the use of inspiratory and expiratory muscle aids to prevent the pulmonary complications of lung disease and conditions of muscle weakness. It also describes treatment and rehabilitation interventions specific for patients with these conditions. This book is unique in presenting the use of entirely noninvasive management alternatives to eliminate respiratory morbidity and mortality and avoid the need to resort to tracheostomy for the majority of patients with lung or neuromuscular disease.

PHILADELPHIA: HANLEY & BELFUS 2002, 600 PAGES, 200+ ILLUSTRATIONS. ISBN 1-56053-549-0

Both books are available on Amazon.com

PNNJ Donates Tricycles to Polio Survivors in Nigeria



Through a contribution of \$1,500, the Polio Network of New Jersey is providing 10 tricycles to polio survivors in Nigeria, which still experiences more polio than any other country in the world. In this African nation, tens of thousands of children and adults spend their lives crawling on the ground. The rough terrain and scarcity of paved sidewalks and roads make conventional wheelchairs virtually useless. Tragically, no significant efforts had been made until recently to do anything to improve the sad lives of these victims. But there is a glimmer of hope. *Wheelchairs for Nigeria* is a project sponsored by the West Side Presbyterian Church, Seattle, Washington.

Tricycles from bike parts

Dr Ron Rice, a retired Presbyterian pastor, and his Nigerian partner, Ayuba Gufwan, who walks on his hands from polio, have built and donated almost 5,000 wheelchairs to Nigeria's polio survivors. They have their own shop in Jos, Nigeria, with 25 employees, where they build these 3-wheeled, self-pedaled "tricycles" out of bicycle parts for \$150 each. Five of the employees are handicapped themselves. This is by far the largest wheelchair ministry in all of Nigeria, a country that is half the population of the U.S.

Transforming lives

For \$150, a child's life is absolutely transformed. Now they can go to school. Now they have hope and a future. Adults can now get vocational training or an apprenticeship, become self-supporting, and not have to resort to begging. Wheelchairs are given to

both Christians and Muslims. In a country frequently torn by tribal and religious violence, Christians giving wheelchairs to Muslims is looked upon as a symbol of peace and reconciliation. Even employees in the shop are both Christian and Muslim.

PNNJ learned about the Nigeria Wheelchair Fund through the Naples, Florida post-polio support group. Members of the Network's Board explored the possibility of participating in the program by directly contacting Dr Rice, who spends much time each year working with the tricycle builders in their Nigerian workshop. Contributions to the fund are tax-deductible. Those who wish more information can visit the website: www.wheelchairsfornigeria.org, and can send e-mail to the program's sponsors at info@wheelchairsfornigeria.org.

Joyce and Arthur

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retiring in 2010. The couple were both energized Board members, acting as liaison with New Jersey support groups affiliated with PNNJ. An attorney with a law practice in Red Bank, Arthur wrote the *LegalEase* column in the *Network Newsletter* for many years.

Upon Joyce's death in 2004, Arthur assumed the leadership of the Raritan Valley Support Group. He had previously been a member of the Shore Group and founded and led the Monmouth County Group. During Arthur's presidency of PNNJ, the Network added a new support group, Essex-Union County Area, held annual conferences, and expanded our outreach into nearby states.

"This generous gift assures that PHI can continue to assist polio survivors in living independently by granting funds for shoes and bracing," said PHI executive director Joan L Headley. "We are grateful to PNNJ, and excited about the collaboration that helps both of our organizations fulfill their missions."

PNNJ president Veliko "Lee" Bekir said, "This gives us the opportunity to bring the names of our friends, Joyce and Arthur, into a larger sphere of philanthropy and service, thus helping many polio survivors and at the same time honoring this outstanding couple in a more permanent way."

New on the PNNJ Website

If you haven't been on the PNNJ website in a while, you're in for some surprises. First there is the User Forum Area. This is a place where you can discuss a topic with other polio survivors, locally or across the world. You can reach the User Forum from the website, www.pnnj.org, or directly at www.pnnj.org/forum.

The 2012 edition of the *NJ Resources* manual produced by the New Jersey Department of Human Services, Division of Disability Services, is now available on our website.

There's even a page on our website devoted to the 23rd PNNJ Annual Conference scheduled for Saturday, April 20, 2013. The Multimedia page will soon be updated to include Dr John Bach's presentation at the 22nd Annual Conference.

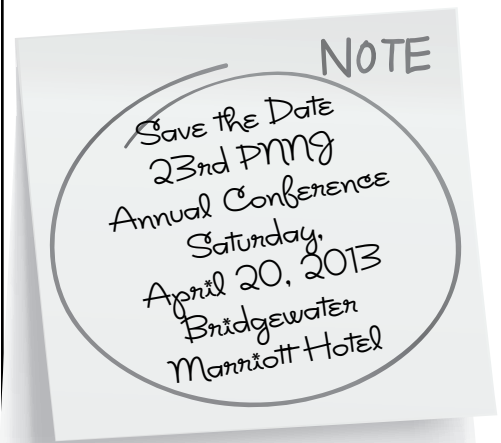
Webmaster Lee Bekir has also added a Quick Links feature that highlights new information on the website which you can quickly access with a click of your mouse.

So visit the website soon, and check back often.

Some Helpful Websites

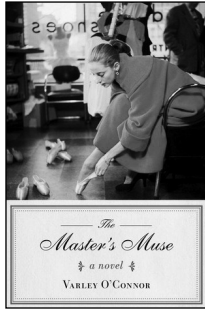
www.abledata.com: Information about assistive technology products and rehabilitation equipment. Almost 40,000 product listings in 20 categories.

www.homefreehome.org: Free architectural design for individuals who require plans to reconfigure their living quarters to accommodate changes in their lives. 516-883-0403.



SUGGESTED READING

The Master's Muse



By Varley O'Connor
Hard Cover, \$25
Scribners, 2012

Review by Joan Swain

Tanaquil LeClercq was a brilliant twenty-seven-year-old ballerina married to the legendary choreographer George Balanchine when she was struck by polio while on a European tour with the New York City Ballet in 1952. She would never walk, or dance, again.

Varley O'Connor begins her novel about this fascinating power couple at the point when their lives are changed by polio. In an online interview accompanying the *Reading Group Guide* for the book, the following exchange takes place:

Interviewer: How did you decide where to begin and end Tanny's story?

Varley O'Connor: "I knew very early in the process where it would begin and end. For me, the polio was a sort of refining fire for both LeClercq and Balanchine. It reshaped them in many ways, as individuals and as a couple. And it had a huge impact on Balanchine's work. So I knew I'd start with the polio, that great terrible challenge. As for the end, I saw Balanchine's final illness as in some ways parallel to LeClercq's polio. He helped her through her illness, and she helped him through his."

I'm confident that many of us who had polio would agree with O'Connor's

description of it as a "great terrible challenge." And it is interesting to observe the manner in which the couple, together and separately, address this challenge. Polio readers will undoubtedly see parallels to their own situations.

(O'Connor's interest in polio stems from her father, who had polio as a child and later started the Michigan Polio Network. She includes a young boy with polio in an earlier novel, *The Cure*.)

By assigning Tanaquil LeClercq the role of narrator of this novel, O'Connor provides an intimate point of view of the dancer's relationship with her creative but difficult husband. And there are insights as well into her relationships with other dancers of the era – Jerome Robbins, Diana Adams, Maria Tallchief, Allegra Kent, Jacques d'Amboise, and Balanchine's final muse, Suzanne Farrell.

In *The Master's Muse*, Varley O'Connor has portrayed a woman of great strength and integrity who continued to live in the world of ballet after meeting her "great terrible challenge."

PNNJ's Ruprecht Fund May Meet Your Need

For information about
limited funding for
polio-related needs,
see our website
www.pnnj.org or call
Marie Perez at
201-996-9100.

Polio Network of New Jersey NEWSLETTER

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Tuning in on the Polio Network of NJ

ATLANTIC COUNTY AREA

Ye Olde Mill Street Pub
6033 Main St, Mays Landing
3rd Wednesday at 12 noon
Contact: Marge or Steve Disbrow
For directions and to confirm date
609-909-1518
kittystamp@comcast.net

BERGEN COUNTY

Maywood Senior Center
Duvier Place, Maywood
1st Saturday, 11:30 am-1:30 pm
Contact: Heather Broad 201-845-6317
hbroad@netzero.net

ESSEX-UNION AREA

80 South Munn Avenue, East Orange
2nd Saturday, 12 noon to 2 pm
March, June, September, December
Contact: Edwina Jackson 973-699-1564 or
Thelma Van Liew, 908-753-6514
nubianqueen8@aol.com

MONMOUTH COUNTY AREA

Seabrook Village
300 Essex Road, Tinton Falls
3rd Monday at 2 pm
Contact: Toni Wilczewski 732-229-9343
skywash01@aol.com

MORRIS COUNTY AREA

Denville Municipal Building
1 St. Mary's Place, Denville
3rd Saturday, 11 am
April, May, June, September,
October, November
Il Villaggio Restaurant
22 Gibraltar Drive, Parsippany
973-644-4888
Dinner meeting, 3rd Wednesday evening
March, July, December
Vince Avantagiato 973-769-0075
drvince@njpolio.org

OCEAN COUNTY AREA

Health South Rehabilitation Hospital
of Toms River
14 Hospital Drive, Toms River, NJ 08755
Four (4) times a year on Saturdays
April, June, September, and November
Contact and confirm date and time with:
Jerry Bojko 732-505-0151 or
Susan Payne Gato 732-864-0998
Website: www.tomsrivernjpolio.org

RARITAN VALLEY– Somerset/Hunterdon Counties

Manville Library, Manville, 908-722-9722
1st Saturday, 10 am-12 noon
Oct, Nov, Dec, March, April
Contact: Ray Jajko 609-531-6595
flyguyray@comcast.net

SOUTHWEST JERSEY AREA

New Seasons at Voorhees
501 Laurel Oak Road, Voorhees
4th Saturday, 10:30 am-12 noon
Contact: Anna Nasuti 856-740-1106
amn46@comcast.net

As meeting locations, days, and times may change, it is advisable for those who are not in frequent touch with support groups to call the contact persons in advance of your planned attendance.

You Can Copy Us!

You are welcome to copy material from this newsletter. We ask that you credit the Polio Network of New Jersey Newsletter.