



The Polio Post

Ohio Polio Network Newsletter

Fall 2013 Issue

LAUGHTER YOGA

Laughter Yoga is a simple yet profound technique based on the philosophy of "acting happiness" and is a physically oriented technique, not a mental practice. In Laughter Yoga, you do not need to be happy, have a sense of humor, or even have a reason in order to laugh. Laughter is a tremendously efficient way to express and release tension in a positive manner, and is proven to relieve stress, improve blood flow and digestion, and strengthen the immune system.

We all need to laugh more!

Laughter Yoga was developed by an Indian medical doctor, Dr. Madan Kataria in 1995 with just five people. There are now 6,000 yoga clubs in sixty countries.

Dr. Kataria discovered that the body cannot tell the difference between fake and real laughter. Incorporating laughter, be it fake or real, as part of an individual's wellness routine has enormous physical, mental, and emotional benefits including decreased symptoms of depression and anxiety, while boosting an individual's capacity to effectively manage their own moods, deal with uncomfortable feelings, and generally strengthen the ability to cope with life.

What are some of the benefits of laughter?

- Is a stress buster. It reduces the levels of stress hormones epinephrine and cortisol.
- Strengthens the immune system.
- Is anti-aging. It increases blood supply to the face, nourishing the skin and making it glow.
- Is an aerobic exercise.
- Increases levels of endorphins - the body's natural painkillers. Helps control high blood pressure by reducing the release of stress-related hormones.
- Helps dump depression, anxiety and psychosomatic disorders.
- Makes us more creative and imaginative.
- Shrinks the hurts of everyday life.
- Defuses anger.
- Helps individuals be more self-confident and self-expressive.

The world needs more laughter!

For more information, go to laughteryoga.org.

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Editor: Alice Sporar

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IT'S THAT TIME OF YEAR AGAIN TO RENEW YOUR OPN MEMBERSHIP

(see form on page 10)



Oxygen is NOT for Hypoventilation in Neuromuscular Disease

E.A. Oppenheimer MD, FCCP

Editor's Note: Dr. Oppenheimer has been gone quite a while, but this article is the one that current pulmonologists and groups have referenced for years. The PHI/IVUN (Post Polio Health International and International Ventilators User Network) office continually hears from people with post-polio or other neuromuscular diseases and conditions being inappropriately prescribed O₂ therapy. This anecdotal evidence (confirmed by the Mayo Clinic case series) supports the need for accurate information from the physicians most expert in the pulmonary aspects of neuromuscular disease to be disseminated more widely to alert people to the reasons why they should be wary of O₂ therapy.

If progressive respiratory failure occurs in people with neuromuscular disease, an abnormal nocturnal oximetry study is often an early indication that hypoventilation is occurring. There are significant periods of decreased oxygen levels in the blood or hypoxemia during sleep when lying flat in addition to decreases in vital capacity (VC), maximum inspiratory force (MIF), and maximum expiratory force (ME F). Decreased oxygen saturation (SaO₂) combined with increasing carbon dioxide (CO₂) retention or hypercapnia are the hallmarks of hypoventilation. This is sometimes called ventilatory pump failure, due to the weakened respiratory muscles.

Patients with neuromuscular diseases who are developing progressive respiratory failure due to respiratory muscle weakness will die unless mechanical ventilation is used. The rate of progression is often hard to predict. Some patients seem suddenly to experience life-threatening hypercapnic respiratory failure. They may not have been aware of gradually increasing symptoms and signs, particularly since they are often not physically active and are often not being regularly monitored with simple pulmonary function tests,

Administering oxygen does not provide assistance to the weakening respiratory muscles, but gives both the patient and the doctor the false impression that appropriate treatment is being provided. While in fact hypoventilation is mistaken for an oxygen transfer problem. Indeed, administering oxygen can mask the problem. Also there is a danger of causing respiratory depression by giving oxygen; Oxygen is NOT the treatment for hypoventilation. It will improve the SaO₂, but not the hypoventilation and may increase the danger of dying of sudden respiratory failure. In hypercapnic respiratory failure due to hypoventilation, the SaO₂ falls due to the rise of the CO₂. The alveoli in the lungs (tiny gas exchange units) should clear most of the CO₂ out with each breath. Instead, with hypoventilation, CO₂ accumulates and thus there is decreased room in the alveoli for oxygen. When mechanical ventilation using room air is provided, it lowers the CO₂ in the alveoli, corrects the SaO₂, and rests the respiratory muscles. The ventilator should be adjusted to achieve a normal SaO₂ on room air. If oxygen is being administered, one cannot use noninvasive oximetry to tell whether enough assisted ventilation is being provided: repeated arterial blood gas specimens (ABGs) would be needed.

- When there is respiratory failure in neuromuscular patients (ALS, post-polio, muscular dystrophy, etc.) who have no additional pulmonary disease that impairs oxygen transfer, the ventilator set-up is adjusted to: be comfortable for the patient;
- achieve SaO₂ of 95% or higher on room air (this can be measured with a finger-sensor oximeter)
- assist the patient to effectively cough and clear secretions;
- provide improved oral communication (if vocal communication is possible).

It has been common for people using noninvasive nasal ventilation (NPPV) with a bi-level positive pressure unit to use inadequate settings; frequently, they are not monitored with dinkal evaluation and oximetry, The EPAP is often set too high = usually it should not be higher than 3-4 EM H₂O; the IPAP is set too low ~

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usually it needs to be 12-16 EM H2O and adjusted to achieve an oxygen saturation of 95% or higher. Some situations may require administering oxygen, such as pneumonia due to infection or aspiration. If this occurs in patients with respiratory muscle weakness and hypoventilation, then it is important to provide both assisted ventilation and supplemental oxygen, and use ABGs to monitor them.

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POST-POLIO AND PHYSICAL THERAPY by Kat Wollam, PT

Why do patients seek out physical therapy? Some answers are: pain - biomechanical changes can cause joint and muscle pain, weakness, overuse vs. aging, loss of mobility or function, decreased energy/ endurance.

Physical therapy evaluation consists of: interview, patient goals, physical exam and muscle test, gait evaluation, home ergonomics and/or adaptive equipment.

Exercise prescription: land-based exercise, aquatic exercise, exercise guidelines, postural instruction, breathing techniques.

1. Do not use muscles with strength of less than 3/5 for conditioning or strengthening exercise. These muscles must work all day to fight gravity and basic activities of daily living. Attempting to strengthen these muscles can cause overuse and increased weakness.

2. Start a conditioning program slowly. Often 3-5 minutes of conditioning exercise is all that can initially be tolerated. If needed, start with one minute intervals with rest periods and slowly build up endurance.

3. Strengthening exercise can be done with muscles of strength greater than

3/5. Remember to start with a minimum number of repetitions (5-7) within tolerance.

4. Aquatic exercise is very beneficial as the buoyancy of the water will support weak muscles and decrease joint stress while providing resistance to strong muscles. Remember to start slowly in the pool. It is easy to overdo in the pool, because it is so much easier to move. (PHTN note: Pool should be 90-94 degrees temperature).

Patient education: Energy conservation. Signs of overuse: muscle cramps or spasms, muscle twitching, muscle pain, extreme fatigue.

Practice: pacing activities, daily rest, weight control, listening to your body, and communication with your physical therapist.

Remember that you can safely exercise and will reap the benefits of your improved condition with less fatigue; improve endurance and functional improvement if your program is approached with patience and consistency.

Reprinted from Polio Heroes News, Polio Heroes of Tennessee, Spring 2013. Reprinted from Second Time Around, presentation Oct. 2012, Boca Area Post-Polio Group.

HIDDEN IN PLAIN VIEW - The Hidden Threat That Could Prevent Polio's Global Eradication

In the August 2013 issue of Scientific American, Helen Branswell, writes that global eradication of polio has been the ultimate game of Whack-a-Mole for the past decade; when it seems the virus has been beaten into submission in a final refuge, up it pops in a new region. Now, as vanquishing polio worldwide appears again within reach, another insidious threat may be in store from infection sources hidden in plain view.

Polio's latest redoubts are "chronic excreters," people with compromised immune systems who, having swallowed weakened polioviruses in an oral vaccine as children, generate and shed live viruses from their intestines and upper respiratory tracts for years. Healthy children react to the vaccine by developing antibodies that shut down viral replication, thus gaining immunity to infection. But chronic excreters cannot quite complete that process and instead churn out a steady supply of viruses. The oral vaccine's weakened viruses can mutate and regain wild polio's hallmark ability to paralyze the people it infects. After coming into wider awareness in the mid-1990s, the condition shocked researchers.

Philip Minor, deputy director of the UK's National Institute for Biological Standards and Control, describes the biomedical nightmare: wild polioviruses stop circulating. Countries cut back on vaccination efforts. A chronic excreter kisses an unvaccinated baby, and the baby goes to day care. "And zappo," he adds, "it's all over the place, with babies drooling all over each other. So you could see a scenario where polio would come back from a developed country."

It could happen in the developing world as well. Although it was once thought that immunocompromised individuals could not survive for long in lower-income countries, circumstances are changing as those countries improve their health care systems. In 2009 an immunodeficient 11-year old Indian boy was paralyzed by polio, five years after swallowing a dose of oral vaccine. It was only then that researchers recognized him as a chronic excreter.

Reprinted from The Polio Sentinel, The Polio Outreach of Connecticut, August 2012.

News from the Mid-Ohio Valley

The Mid-Ohio Valley Post-Polio Support Group of the Wood County Society (MOVPPSG) has had a busy year.

This is the twenty-fifth anniversary of its founding. Becky White arranged for its first meeting to be in the Marietta Ohio Easter Seals Building in 1988. Both Wood County, West Virginia and Washington County, Ohio were in the same Easter Seal district. In 1994, Easter Seals consolidated its operations in Chicago and eliminated most local groups. The Post-Polio Support Group moved to HealthSouth Western Hills (then Nova Care) in West Virginia, acquired Dr. Michael Shramowiat as its medical advisor, became an affiliate of the Wood County Society and changed its name to the Mid-Ohio Valley Post-Polio Support Group. The group has held regular meetings and planned or contributed to four conferences. It has also retained its association with the Ohio Polio Network.

In May, Bob Baumann, physical therapist from Health South gave an excellent talk on exercise for post-polio survivors. The rest of the early portion of the year was consumed with planning the twenty-fifth anniversary celebration.

Most members contributed stories and pictures to a memory book distributed to group members and contributors thanks to the generosity of the Wood County Society. The Society was also generous in its assistance of the anniversary lunch was held in the tent of the Blennerhassett Hotel on June 17. Fifty survivors, family members and friends attended. The mayors of Marietta, Ohio; and Parkersburg, Vienna, and Williamstown,

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West Virginia attended and presented the group with Post-Polio Awareness Week proclamations. Slide shows of the pictures in the memory book were played. We were fortunate that two of the four surviving founding members of the group, Kayleen Andersen and Larry Young, were able to attend. Warren Peascoe took short excerpts from many of the stories and made a moving oral collage of them which he read at the luncheon. We spent several hours visiting each other and renewing friendships.



In July, eighteen of us gathered over pizza at the Vienna Public Library and watched the DVD--"A Life Worth Living" about the enactment of the ADA. We held a Dutch treat luncheon and gab fest at the Golden Corral in August.



Warren Reading Oral Collage



Desiree Kurucz, Food and Nutrition Services Manager at Health South will speak to us on "Nutrition Matters" on September 16 at the Golden Corral. A games meeting at which we will also plan for 2014 is scheduled for October. Our year will end with a Thanksgiving-Christmas party the third Monday in November. Leaders will be chosen or conscripted for 2014 in November Polio Survivors at anniversary luncheon.



Bob Baumann, Physical Therapist at Health South Receives "The Late Effects of Polio: Introduction to Clinical Practice" from Warren Peascoe after May meeting of Mid-Ohio Valley Post-Polio Group of the Wood County Society

**You Rock
Mid-Ohio**

MEDIA RELEASE

Yellow Cab of Columbus Unveils Columbus' First Wheelchair Accessible Taxi Cabs

Those Who Use Wheelchairs, Physically Challenged and Senior Citizens Will Benefit from Service (Columbus, OH) On Wednesday, July 24, Yellow Cab of Columbus President Jeff Kates unveiled the city's first wheelchair accessible taxi cabs during a news conference at Columbus City Hall Parking Plaza.

Yellow Cab of Columbus' recent investment in the new vehicles and expected future investment for additional vehicles initiated earlier this year when the moratorium on taxi licenses was lifted specifically to add wheelchair accessible cabs to Columbus. Yellow Cab received 10 of the 30 taxi licenses.



"We knew this was a prime opportunity to better serve our current customers," said Kates. "We knew what it would mean to the quality of life for so many citizens in our community throughout the city and Franklin County.

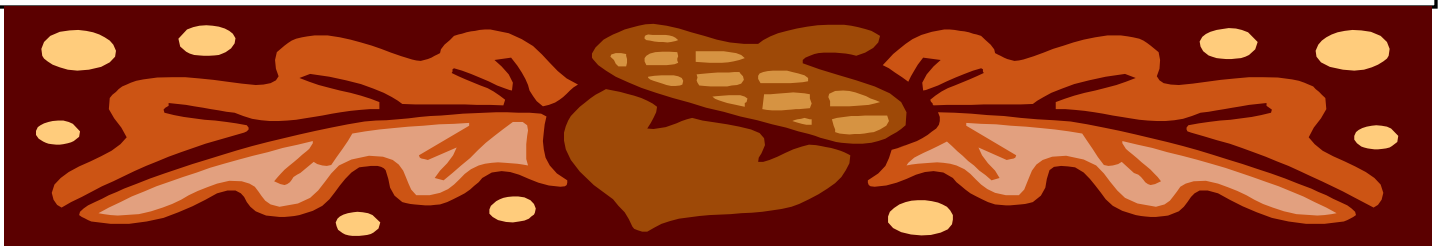
Councilwoman Michelle Mills discussed the process that was required, at both the local and state levels, to apply for and receive a license to operate handicapped accessible taxi cabs and how these recent changes will have a positive impact on the lives of Columbus residents.

"This is an important and exciting day for the City of Columbus, as well as our residents and visitors," said Councilmember Michelle M. Mills, chair of the Public Safety and Judiciary Committee. "These wheelchair accessible cabs are a less expensive way for those with limited mobility to travel and highlight how Columbus is working to be the most inclusive community possible."

Jennifer Flynn, a member of the Columbus Committee on Disability Issues, also spoke about what this change means to her personally as well as for the community.

"This has been a long awaited mode of transportation reform," said Flynn. "We can be out in the community with our families and have last minute transportation available to us as well as visitors who come to our city." The new taxi cabs will not only benefit the citizens of Columbus, but thousands of visitors to the capital city each year. Reliable "on demand" transportation that meets the needs of citizens throughout our community and beyond is important for truly offering ease of access to mobility for all individuals.

"Building our hospitality system for visitors means taking steps to be accessible for all," said Mike Brown, Director of Public Affairs and Development for Experience Columbus. "We are proud to work with Yellow Cab and local transportation companies to make sure it is safe and easy to travel between Columbus' many attractions, districts and neighborhoods." Citizens who wish to request a wheelchair accessible cab can do so by calling Yellow Cab of Columbus at 614-444-4444 or visiting its website at www.yellowcabofcolumbus.com. The cabs will be available 24/7.



HB84 HOME ACCESSIBILITY TAX CREDIT (Stinziano M) To authorize a nonrefundable income tax credit for the purchase or construction of an accessible home or for the renovation of a home to improve its accessibility.

Reps. Stinziano and Grossman presented the bill, which would create the Livable Homes Tax Credit. According to Stinziano, the credit would encourage improving the accessibility of Ohio's homes by providing state tax credits for building, purchasing, or remodeling homes that incorporate accessibility features.

The representatives urged that this was important for the health and safety of Ohio's aging population.

"The need to address falls among older Ohioans will continue to grow as the number of Americans aged 65 and older is expected to double in the next 25 years due to increased life expectancy and aging of the baby boomers," said Stinziano.

"With Ohio's aging population and more individuals with disabilities seeking to live independent lives in the community, HB84 is a step in the right direction to ensure that accessible housing is available in future years," said Grossman.

Rep. Terhar asked if there were any federal programs similar to this proposal, to which the sponsors said that they have not discovered any yet. Rep. Scherer asked if the credit required an income-based evaluation of need, to which the sponsors said no.

Chair Beck asked if this credit could change the valuation of a home. Stinziano said he would look into that and get back to the chair.

"Of all the forms of inequality, injustice in health care is the most shocking and inhumane"

– Dr. Martin Luther King, Jr.

Our lives begin to end the day we become silent about things that matter.

--Martin Luther King Jr

"A small group of thoughtful people could change the world. Indeed, it's the only thing that ever has."

-- Margaret Mead

Mary M. Butler, Systems Change Coordinator
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THE KILLING WILL

A fashionable, widely practiced notion is the execution (double entendre) of a "living will." The document projects and exodus from the terminal sickness or injury...such permission given ahead of time to relatives or physicians to detach or otherwise disable life-extending devices.

In other words, it suggests that spouse or physician murder someone. Or alternately, a planned suicide with or without assistance from family, or friends, or health professionals. Witness the controversial recent book, Last Wish, in which Betty Rollin describes how she helped her 76-year-old mother with cancer to die prematurely.

The term "living will" is an oxymoron – an intrinsic contradiction akin to calling the MX missile a "peacekeeper." Perhaps it is appropriate to label it a euphemism – like "revenue enhancement" for "taxes."

The notion of a "living will" has been in the headlines recently as a "mercy" killing when a retired Floridian shot his wife who had advanced Alzheimer disease. As the facts were revealed, it seemed that the husband was more concerned about terminating his own suffering than his wife's. The court suggested that other options existed and that the act was clearly homicide.

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Curiously, the defense attorney pointed out that she also was suffering from “extraordinarily painful osteoporosis – an incurable disease”: a characterization which is an inappropriate hyperbole at best.

My inclination as a physician is to approach these situations with flexibility and tolerance.

Technology is changing our practice but we shouldn't be stampeded into supporting legal solutions for defining death. Judges can't practice medicine.

A past example of ludicrous jurisprudence was a judge ruling that a male tennis player could put on a dress and undergo a sex transfer operation, then play in a women's tennis tournament. With that absurd ruling, this man raised his ranking from an average regional player in the men's to a “top 20” in the women's. The issue wasn't a civil rights issue – it was a medical one! Any physician knows that this tennis player's reach, strength and size weren't changed by the lipstick and earrings.

Brain death is human death. Determination of the brain death is more accurate now but we still should exercise caution in shutting off the life-support systems. Examples abound, even today, of individuals existing in “irreversible” coma for several months who then recover to have useful lives.

A recent TV segment presented an elderly man with ALS and a tracheostomy and ventilator whose wife wanted to end his (her?) suffering. As the video interview continued, it seemed clear to many of the viewers that he didn't want to die in spite of his previous “living will”.

Also, we have ways of breathing (without compromising communication) for patients who need ventilation assistance. Ask the thousands of post-polio people who have been on ventilators for 30 years or more.

Only our brain make us human, and technologies to keep the brain viable and thinking ARE rational and appropriate!

If we need to use kidney dialysis, a heart pacemaker, a ventilator – hats off to technology. Maybe in the future even an artificial heart that's cost-effective.

All of these life extenders are, in principle, no different than giving insulin to a diabetic or penicillin to a patient with pneumonia.

The Living Will: it's a license for murder or suicide.

Or, more accurately, it can be described as a technique to minimize the suffering of the relatives and health professionals caring for the patient. William Osler, our honored forebear, reportedly philosophized that the most uncomfortable people in a terminal saturation were the relatives, physicians and nurses – NOT the patients. Intractable and unbearable pain is almost always in the eyes of the beholder – either the health professional or the family member.

A “living will” is – as we used to say in the Army – “anticipating the command”.

Our will to live is strong and over-riding: “don't hasten death” is sound advice in most situations.

A “living will,” on the other hand, is permission for killing.

Another contradiction occurs to me – many people who promote the “living will” are adamantly opposed to capital punishment!

DNR (do not resuscitate) is a difficult decision and in my judgment, should not be prescribed by law. It must be a medical decision! It is not a circumstance to unload guilt to survivors! Or a debate on who pays the bill.

Many years ago a baby was brought into a local ER dying of pneumonia. The baby died but was resuscitated with open-heart massage by a surgical resident. With tubes and ventilators the baby's heart was kept beating for one week when, by horrible coincidence, the baby died with the same resident in attendance. He opened the chest through the same incision and attempted resuscitation again – and many of us learned a lesson not to deny the grim reaper when he has already arrived.

Death is inescapable but in the living is too remote to fear of appreciate truly the signing away of the right to live.

A “living will” is a “lethal legacy.”

Reactive depression at these difficult times clouds clear thinking, fosters irrationality and may result in a wrong decision of KILLING someone. Programming death is murder (if done by others) or suicide if unassisted.

Life is priceless! and should not be “willed away.”

As Yogi Berra so inaptly phrased it: “it's not over 'til it's over.”

Mithridatically yours,
Ernest W Johnson, MD
Editor

*as always, this is solely the editor's opinion!

Fall 1985

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