Braces and More for Polio Survivors in the Democratic Republic of Congo

Jane Atkey, Toronto, Canada, JaneAtkey@cs.com

Tay Nash worked as a Peace Corps volunteer in the 1970s in what was then Zaire and is now the Democratic Republic of the Congo (DRC). That was when he first encountered many people crawling on the ground or limping around on paralyzed legs—as well as a few who had braces and crutches—and learned that polio was the cause.

There has not been a confirmed case of acute poliomyelitis in the DRC since the year 2000, according to the Global Polio Initiative. The country remains vigilant though, as there are still polio outbreaks in neighbouring countries.

Africa presents unique obstacles for those who can't walk. In the DRC, streets are usually unpaved, muddy and full of people's rubbish and sew-

age, so just staying clean is a con-

tinual challenge.

There are many children, youth and some adults living with varying degrees of paralysis. Parents of children with disabilities are rarely able to pay for the extra treatment and equipment their children require to achieve maximum mobility.

Over the years and while working for the US Agency for International Development (USAID) in Lubumbashi, DRC, Nash assisted a few young people to obtain the equipment they needed, but there was so much more to be done.

On a visit to the capitol of the DRC, Kinshasa, he encountered a friend with a disability who had just completed formal training in brace making but who remained without a job. Nash opened a brace shop in his garage in Lubumbashi, and his friend began to craft new braces and to train new apprentices/assistants from those with disabilities. A second brace shop followed at a friend's house in Kinshasa in 1999.

Soon, more and more kids with polio began showing up and staying at the two houses during their pre-bracing treatment, brace-fitting and physical rehabilitation, or just hanging around on weekends to help out. The housesturned-brace-shops provided an important opportunity for the children to give each other moral support, gain confidence and reduce self-consciousness.

The two facilities were officially linked in 2000 and organized as a registered NGO (non-governmental organization) named the Congolese Association for Orthopedic Assistance to Young Persons with Disabilities (Association

continued, page 2

The DRC has a population of over 60 million in an area of slightly less than one-fourth the size of the US. Straddling the equator, it is mainly landlocked with a 24-mile stretch on the Atlantic Ocean which contains the mouth of the Congo River. The DRC is a former Belgian colony and the official language is French. It is sometimes confused with the Congo (Brazzaville is its capitol), a former French colony that lies just west of the DRC.

Networking

Braces and More for Polio Survivors in the DRC

continued from page 1



Congolaise pour l'Assistance Orthopédique aux Jeunes Handicapés— ACAOJH).

In 1999, Nash, along with friends and family, founded the International Polio Victims Response Committee

(IPVRC) as a not-for-profit organization in the United States to raise additional funds to assist ACAOJH. It covers virtually all costs for orthopedic equipment, pre-bracing treatment or surgery, and physical rehabilitation for poor families. Almost all of ACAOJH's staff is made up of former beneficiaries.

Does your group provide assistance to polio survivors in the developing world? PHI is dedicating a section of its website to highlight programs that are directed by, or for, polio survivors. The goal is to facilitate networking among these groups and to encourage others to start similar programs.

To its credit, IPVRC/ACAOJH supplements its brace-provision service with a program designed to promote the mainstreaming of the children. Many children with disabilities are never encouraged to attend school or are shunted off at an early age to special segregated schools to learn vocational skills such as tailoring, shoe-making and ceramics. The program counsels parents to send their children to regular neighbourhood schools and helps

them to cover school fees, as well as uniforms and books.

Today, brace-crafting facilities are maintained in Kinshasa, Lubumbashi and Butembo, cities located in the west, southeast and northeast corners of the country, each about 1000 miles away from the next. And, the two rehabilitation houses continue to operate. In his current capacity as senior program officer for USAID's Office of Foreign Disaster Assistance in DRC, Nash continues to advise the Congolese organization and serves as its liaison with IPVRC.

Want to help buy a brace for a polio child (\$150.00)? Support the education of a polio child for a trimester or a year? (\$0.70 per day for one non-boarding student or \$1.00 per day for one boarding student)?

Contact IPVRC, 10250 Harrison Road, Loveland, OH 45140 www.ipvrc.org, info@ipvrc.org

ANESTHESIA NEWS

Guidelines for Obstructive Sleep Apnea Patients Established

Selma Harrison Calmes, MD, Olive View/UCLA Medical Center, Sylmar, California

bstructive sleep apnea (OSA), a relatively common disorder in post-polio people, is now recognized to be associated with increased morbidity and mortality during and after anesthesia and surgery. The American Society of Anesthesiologists (ASA), the national organization for anesthesiologists, approved consensus guidelines on management of OSA patients at its annual 2005 meeting. Although the guidelines' purpose is to focus on which OSA patients might be safely done in an outpatient facility, they are also helpful in planning for OSA patients having surgery in a hospital.

The new guidelines rate a particular OSA patient's risk using a numeric score. A patient with a high score should be treated in a hospital. Rated are the severity of the OSA as determined on a sleep study (or the clinical history if a sleep study is not available), coexisting diseases, invasiveness of the operation, the type of anesthesia needed, anticipated postoperative narcotic requirements and how the patient would be observed post-operatively. The guidelines also define requirements for the facility, such as on-site radiology service for chest X-rays and the ability to do arterial blood gases.

The guidelines also discuss use of CPAP intraoperatively and postoperatively. The need to measure adequacy of ventilation during sedation by continually measuring expired CO2 (the waste respiratory gas) is emphasized; continuous monitoring of CO2 is always done during general anesthesia.

The important postoperative period is also discussed. In addition to use of CPAP, especially for those on it preoperatively, OSA patients should be monitored for at least 3 hours longer than non-OSA patients. Monitoring should continue for about 7 hours after the last episode of airway obstruction or hypoxemia while the

patient is breathing room air and is not stimulated.

Discharge guidelines are also defined. The oxygen saturation on room air should return to baseline, and the patient should not become hypoxic or obstructed when left undisturbed. CPAP use should continue at home for those who used it preoperatively.

The guidelines were developed by a consensus process, using experts in this area and careful analysis of the medical literature. They are not practice standards, do not guarantee a successful outcome and are not vet validated.

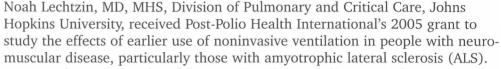
Over time, we will learn more about how satisfactory they are and perhaps change them, again using the expert consensus process. However, their development is of great help for those who might be pushed into a procedure at an outpatient facility (a freestanding outsurgery center or even a physician's office) by their insurance company. The guidelines can be "ammunition" when fighting the insurance company about where an operation will be done. They are also helpful to anesthesiologists because they help organize thinking about a difficult problem, defining the many factors to consider.

The September 2005 issue of Anesthesiology (Vol. 103, No. 3, pp. 638-644) featured "Postpolio Syndrome and Anesthesia" by David A. Lambert, MD, Elenis Giannouli, MD, and Brian J. Schmidt, MD, from The University of Manitoba, Winnipeg, Canada.

The guidelines are available at www.asahq.org/ publicationsandservices/ sleepapnea103105.pdf.

Preliminary Report from The Research Fund Recipient

Exploring Early Use of Noninvasive Ventilation



The study results of the question, "Does earlier use prolong survival?" may be applicable to people with other neuromuscular conditions, including post-polio syndrome and muscular dystrophy.

Noninvasive positive pressure ventilation (NPPV) has been shown to prolong survival when used with advanced respiratory muscle weakness. Experts now recommend NPPV when an individual's forced vital capacity (FVC) is below 50% of predicted, but a study found people who started using NPPV when their FVC was greater than 65% of predicted survived approximately one year longer than those who started NPPV with lower FVCs. This suggests that NPPV use may have effects on the respiratory system beyond simply supporting failed muscles. NPPV may result in benefits by resting fatigued respiratory muscles, improving lung compliance, or reducing the hypercarbia/acidosis which can impair muscle contractility.

Dr. Lechtzin's (nlechtz@jhmi.edu) final report will be released by Post-Polio Health International in mid-2006.



Screening Recommended for Male Polio Survivors

A poster presented during the annual meeting of American Academy for Physical Medicine and Rehabilitation last October in Philadelphia recommends the screening of male polio for bone mineral density (BMD) to prescribe appropriate treatment and to decrease fracture risks.

Julie K. Silver, MD, and Dorothy D. Aiello, PT, Harvard Medical School/Spaulding Rehabilitation Hospital, Boston, tested the hypothesis that male polio survivors are at risk for low bone mineral density. The authors compared polio men who ranged in age from 38-81 to age-matched normative data. The polio men were 12 years old or older when they had polio (85%); currently are ambulatory in the home (75% of the time with or without assistive devices); and currently use some assistive device (82.5%). Some had both hips tested; some just one.

All the hip scores bilaterally for the polio men had a lower BMD than the age-matched data. The lumbar BMD data was within normal limits in the same comparison.

While further research is needed, the authors recommend screening polio men for osteopenia/osteoporosis, because they are at high risks for falls with subsequent fractures.

PHI's Fourth Award:

Wednesday, March 1, 2006 was the deadline for proposals vying for \$25,000 to be given in 2007. The recipient will be announced in the fall of 2006.

Post-Polio Health International Awarded Health Promotion Grant from Christopher Reeve Foundation

A \$20,000 Health Promotion grant awarded by the Christopher Reeve Foundation (CRF) to Post-Polio Health International will explore and address the problem of inadequate or inappropriate treatment of adult users of home mechanical ventilation in emergency situations.

The outcome will be guidelines for use by ventilator users, their families and advocates, and their health care team to improve the consequences and decisions made during emergency situations.

To date, PHI has developed a project plan, begun collection of all possible persons to be contacted for their experiences relative to this issue, and has planned a February face-to-face session in the Chicago area.

Project leader Virginia Brickley will conduct this meeting with polio survivors who also use a ventilator and their spouses. Linda Bieniek, Mary Ann and Bill Buckingham, and Val and Rick Brew-Parrish will participate in a brainstorming session to assist with the development of the questionnaires designed to capture past experiences, both good and bad.

Members who receive *Ventilator-Assisted Living*, the quarterly newsletter of International Ventilator Users Network, and names or groups listed in the *Resource Directory for Ventilator-*

Assisted Living will be invited to participate in the collection of experiences via the Internet and mail.

Polio survivors who use a ventilator, their families and/or medical professionals should begin making note of things to share about their experiences in emergency situations. Also, the project will be seeking ideas about what could and should be done differently and where specific change is needed.

The Health Promotion grant, a special category of the CRF Quality of Life grants, is funded through a cooperative agreement with the Centers for Disease Control and Prevention.

If you are a polio survivor who uses a ventilator and does not receive Ventilator-Assisted Living, contact PHI to be involved in this very important work.



Christopher Reeve Foundation

The Quality of Life grants program was conceived by Dana Reeve, Chairman of the Christopher Reeve Foundation and Co-Founder of the Christopher and Dana Reeve Paralysis Resource Center, to help people with living with paralysis in the "here and now."

PHI's grant was just one of 86 awards given in this cycle totaling \$581,034. The CRF also recently gave \$100,000 to five Gulf Coast charities in the immediate wake of Hurricane Katrina.

Applications are now being accepted for the 2006 Quality of Life Grants. Deadlines are March 1 and September 1. (www.christopherreeve.org)

Check out www.paralysis.org, the Christopher & Dana Reeve Paralysis Resource Center redesigned Internet site.

Therapeutic Use of Music

Janalea Hoffman, PMT, MA, Rhythmic Medicine, Olathe, Kansas music@rhythmicmedicine.com

In a study done at St. Agnes Hospital in Baltimore, patients in critical care units listened to classical music. They found that half an hour of music produced the same effect as 10 mg of Valium. This study proved that music can be as powerful as a drug to help calm individuals who are very stressed. It changed many medical professionals' opinions about the value of music.

People have stereotypical ideas when they hear the words "music therapy." One is "rhythm bands and sing-a-longs" and another is "background music." People tend to think, "Yeah, I know. Put on some background music and it calms you down." I have been a music therapist since 1977 and I promote and create "music with a purpose." There is a difference between recreational music and therapeutic music, even though recreational music can be therapeutic.

Dr. Oliver Sacks, a neurologist who wrote the book *Awakenings* has said, "The power of music to integrate and cure is quite fundamental. It is the profoundest non-chemical medication."

Whatever you concentrate on, you become.

Our minds easily become absorbed in sound. We all, even infants and animals, enjoy listening to music. When the mind is fully concentrating on anything, there can arise a feeling of inner bliss.

Even plants are affected by music. Sunflowers are known to follow the sun's rays. When loud rock music was played around sunflowers, they turned away. Soft music did not disturb the flowers' natural inclination to look to the sun. Imagine then what sounds could do to us as humans.

High frequency sounds energize the brain. Low frequency sounds drain energy away. To give you an example: Humming sounds of electrical appliances, computers and printers cause

a tiring, irritating effect. Any machine sound, even if it is subtle, has a tiring effect on the body. Watching television for several hours can make you feel really exhausted. Part of the cause is the low-frequency hum.

It is very important to be cognizant of your sound environment, because it really does affect your body. You need to feed your ears the proper sounds, just like your brain needs proper oxygen and nutrition.

The rhythm of music and the phenomenon called entrainment.

There is a lot of debate about what it is about music that is healing. One of my interests has been rhythm because of the natural phenomenon of entrainment. A Dutch scientist Huygens was also a clockmaker and had a room full of grandfather clocks. He noticed that when two clocks with pendulums were very close to each other, they synchronized, and he called this *entrainment*.

Humans are always entraining or synchronizing with each other, sometimes in real positive ways and, sometimes, in not quite as positive ways.



Janalea Hoffman, PMT, MA, at PHI's Strategies for Living Well Conference in June 2005, where she presented sessions on Therapeutic Use of Music and Therapeutic Uses of the Native American Cedar Flute. If you are sitting next to somebody who is really agitated, you might find yourself becoming agitated. Or, if you are a little agitated and someone beside you is very, very calm, you might entrain with the calm rhythm.

When we hear something, it is not just through the ears.

Most people have heard about an opera singer who can sing a high note and break glass. That is an example of sound energy moving matter. One experiment used vats of thick liquid that were absolutely smooth on the top. With sound vibrations, the liquid moved, creating patterns. The patterns for the base notes looked like water waves and when the higher pitches occurred, the patterns looked like little drips of water dancing above the lower water waves.

Experiments such as this prove that sound touches matter. When you hear something, it is not just through the ears. It literally touches your body, so it is important to pay attention to the music and sounds in your world, because they have an effect on the immune system and brain.

Music has a unique ability to quickly change our mood from one to another. When I hear the hymn "In the Garden," I'm instantly taken back 40 years to my grandmother's funeral.

Music with a purpose.

People say to me, "There is so much music out there. How do you find healing music?"

When I first started this work, I used a lot of classical music until I realized the great masters did not write music for relaxation. Bach, Beethoven and Brahms were writing for the court and for the emotional side. They weren't thinking, "I need to relax somebody."

A piece by Rachmaninoff has been used in two research studies. In one study, people who heard the music said, "It relaxed me and it soothed me." But, they were also hooked up to monitors checking heart rates and blood pressure which went up. The researchers scratched their heads, saying, "What's happening here? People are saying they are relaxed, but their heart rates and blood pressures went up. Their minds are giving one answer and their bodies another."

The reason for this discrepancy has to do with entrainment. The classical music made them feel good emotionally but the rhythm of the music was unpredictable and up and down. Their bodies could not entrain with the music. The emotional response to music is different than the physiological response.

If you want to do something to feel emotional, to bring up imagery or to feel inspiration, listen to classical music. If you want to do something more on a physiological level, you should use music with slower rhythms.

This is one of the reasons I have experimented with writing my own music for therapeutic purposes—music with a purpose.

For example, I created a CD called "Musical Acupuncture" which is music at exactly 50 beats per minute. The listener imagines the tones coming into their body, similar to needles with acupuncture. The sound has the ability to energize the body.

Musical acupuncture is a way of interacting with the music and doing something proactive with pain or discomfort. In so many cases the only solution for pain is pharmaceutical, but musical solutions are pleasant and have no side effects.

Techniques to Help Us Make Changes

Mavis Matheson, MD, Regina, Saskatchewan, Canada



In 1995, I wrote an article called "Changing Your Life by Conserving Energy." In it, I listed three techniques from an article by Sybil Kohl. Her techniques have helped me to make healthy choices and prevent further pain and weakness. Kohl¹ suggests three techniques that we could use to help ourselves make changes. These are push to avoid pain, blank pad and plain talk.

The **push to avoid pain** system acknowledges the amount of energy that we must generate in order to reduce our activity level. It is a statement of action, not of failure or backing down. It means that we are dedicated to taking care of ourselves. To use respiratory equipment is an action with enormous consequences; to retain authority in a seated position requires great assertiveness. Other people, obligations and commitments will be prioritized according to pain thresholds and those actions that reduce pain. Taking care of ourselves is not giving in, but rather a restatement of control. The pain will not control us; we will control the pain.

The **blank pad** method of documenting accomplishments during the day reinforces a sense of purpose. Instead of making lists of things to be done and then crossing off what has been completed, use a blank pad to record all you have done. It is a great training exercise for developing awareness of the energy expenditure that does occur. It also saves us from devaluing ourselves for that which was not done. The goal is to avoid negative feedback at the end of the day and replace it with positive feedback.

Plain talk was developed in response to people asking how to keep from feeling manipulated. If someone does not respect a simple "No" in response to a request, we may have to ask ourselves, "Why do you want me to be in pain, more tired, overextended, not able to enjoy our time together, etc.?" We need to practice simply worded responses that will increase the other person's awareness

of the impact of their requests without creating defensiveness.

In addition, I have discovered the following three techniques that have proven to be beneficial to me in managing my health. These are meditation, working to time and taking care of myself first.

Meditation helps you to rest regularly. While setting aside a few 15or 20-minute breaks to do nothing but rest each day made me feel as if I was giving in, meditating during those times makes me feel as if I am doing something positive for myself. It is possible to meditate in any position, and if I fall asleep while meditating lying down, I realize that my body probably needed the rest. I found it best to start with concentration mediation and work up to insight meditation. In addition to taking the rest breaks that you need, you will add a new facet to your life.

Mavis Matheson, MD, had polio in 1952. She led a full and busy life until she developed post-polio weakness and fatigue 40 years later. She practiced medicine until 1993, and designed and maintains the Polio Regina website (http://nonprofits.accesscomm.ca/polio) and library, and is involved with Regina Insight Meditation.

Working to time helps me to feel a sense of accomplishment even if I'm unable to complete the entire task. How often do you find yourself worn out before a job is done but push ahead to finish it? The technique of working to time helps me feel a sense of completeness even if I am unable to finish the entire project. When first practicing this technique, I find it helps to set an alarm to keep track of the time while you are working. If you start an activity with a plan to work for 20 minutes, you can feel you've accomplished what you set out to do when you've worked for 20 minutes. After a while, you'll be able to judge your fatigue level and determine approximately how long to stay at an activity.

Take care of myself first.

At first glance this may sound selfish. Although, it is our nature to care for

others, first we must care for ourselves. On an airplane, when the oxygen masks drop down, we are told to secure our own masks before trying to help the child traveling with us. In stressful situations, I try to stop, identify and manage my needs. When I am able to do this, my family appreciates not having to guess what I require. By taking care of my own needs first, it helps to eliminate worry, stress and anxiety.

Energy conservation helps us feel better and do more with less. As we continue to change physically, our old coping strategies may not work and we must make adjustments to fit our needs. We are responsible for what we do. Only we can make the decision to take control and take care of ourselves.

Reference

1. Kohl SJ. Emotional Responses to the late effects of poliomyelitis. In Halstead LS, Weichers DO, eds. Research and Clinical Aspects of the Late Effects of Poliomyelitis. White Plains, NY: March of Dimes Birth Defects Foundation; 1987: 135-143

Try a Cane

Did the article, "Fear of Falls, Risks and Practical Strategies" in the last issue of *Post-Polio Health* ring true? If so, here are a few tips on selecting and using a cane, which you can purchase at a local drug store or a medical supply store. Some insurance plans will cover the cost of a cane.

What is the proper length of a cane?

You should be fitted for your cane in your walking shoes. The general guideline for adjusting or cutting the length is that your elbow should be at a comfortable 20-30 degree angle with the cane in your hand. Or, with your arm hanging straight down at your side, the top of your cane should come up to the crease in your wrist.

Which hand do I carry the cane in when I walk?

Generally, a cane is carried in the hand opposite the weakened or painful leg. This position widens your base of support, giving you greater stability, and should help you to walk more naturally and be less tiring. However, if the opposite arm is also weak or painful, you may need to use the cane with the same-sided hand. \triangle

For Canes and Cane Accessories, visit www.abledata.com > products > walking. Select "canes accessories" and/or "canes general."



Maria Gray

Welcome!

PHI welcomed **Maria Gray** to its staff in November 2005. Gray has over 20 years of experience working as an assistant within disability and medical-oriented organizations.

Thank You and Best Wishes!

Justine Craig-Meyer is now Executive Director of Lemay Housing Partnership, a not-for-profit in the Saint Louis region. Craig-Meyer contributed her talents as a staff person from June 1997-December 1999 and from May 2002-January 2006. She and her husband, Jeff, are the

proud parents of Mitchell.



Mary Stephen, Belleville, Illinois, very ably fulfilled the multi-faceted position of administrative assistant from March 2005-September 2005.

PHI is indebted to both Justine and Mary for their dedication to our mission.



Mary Stephen

Justine Craig-Meyer with her son. Mitchell.

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

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INSIDE THIS ISSUE

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POLIO HISTORY

Prominent Figure in Physical Therapy Dies

Florence Peterson Kendall, Physical Therapist, of Severna Park, Maryland, died on January 28, 2006 at the age of 95. The eleventh child of Swedish immigrants, she became one of the world's most celebrated physical therapists.

In 1938, she and her late husband, Henry O. Kendall, wrote a US Public Health Bulletin on the aftercare of polio. They also authored "Orthopedic and Physical Therapy Objectives in Poliomyelitis Treatment" published in *The Physiotherapy Review*, Vol. 27, No. 3, May-June 1947. Members who would like a copy of this article should contact PHI.

Polio Vaccine Developers Honored

Stamps honoring Jonas Salk and Albert Sabin are scheduled to be released by the United States Postal Service on March 8, 2006.







In August 2005, the Canada Post released a new stamp to mark the 50th anniversary of universal polio vaccination program.



POST-POLIO HEALTH INTERNATIONAL INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

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