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Post-Polio Health

POLIO NETWORK NEWS

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FATIGUE RESEARCH: TWO PROTOCOL OPTIONS

MODAFINIL OPTION: William Campbell, MD, Walter Reed Army Medical Center (WRAMC), Washington, DC, announced new pharmacological fatigue research at the May conference – “Post-Polio Syndrome: Improving Quality of Life with Teamwork” – in Johnstown, Pennsylvania.

Fatigue is a prominent and common symptom of post-polio syndrome, and there is no satisfactory therapy. Modafinil, a drug approved by the Food and Drug Administration (FDA) for use in narcolepsy, will be used in this study. Modafinil, however, has not been approved for use for fatigue associated with post-polio syndrome.

The purpose of the study is to see if modafinil will decrease fatigue. The study will compare two different doses of modafinil and placebo (“sugar pill”) to see what effects they may have on fatigue. Patients will be randomized, chosen by chance, to take either modafinil or placebo for the first six weeks. There will then be two weeks in which no study drugs are taken (“washout phase”). For the last six weeks each patient will “cross over.” The patients who took placebo for the first six weeks will take modafinil for the last six weeks and those that took modafinil for the first six weeks will take placebo for the last six weeks. The study is “double blind,” which means that neither the patient nor the doctor will know whether modafinil or placebo is being taken.

Modafinil, or Provigil, has been tried in treating fatigue from multiple sclerosis,¹ Parkinson’s disease,² and sleep apnea.³ Modafinil is classified as an analeptic drug and its precise mechanism of action is unknown. It is a nonamphetamine drug that enhances wakefulness and vigilance. Modafinil is described as being “well-tolerated, with few adverse reactions.” Reported side effects include headaches, and less often, nausea, infection, nervousness, anxiety, and insomnia.

Polio survivors in the States who have served in the military may be eligible for the modafinil study being conducted at WRAMC. Marinos Dalakas, MD, National Institutes of Health, Bethesda, Maryland, and Lauro Halstead, MD, National Rehabilitation Hospital, Washington, DC, are conducting the study for civilians in the States. For more details, call the Post-Polio Syndrome Program information number – 301-295-0231.

In his presentation, Dr. Campbell noted that there are many causes of fatigue, such as sleep disturbances, depression, chronic debilitation, fibromyalgia, and abnormalities of muscle fibers, neurons, the immune system, etc. Consequently, finding a solution for fatigue is not easy and the modafinil study is examining just one option.

NON-DRUG OPTION: David Riley, MD, of the Integrative Medicine Institute of Santa Fe, New Mexico, also presented

an overview of a non-drug option for fatigue research in Johnstown. The protocol involves nonfatiguing intermittent isometric exercises and stress management techniques. Preliminary observations indicate that fatigue, pain, and weakness are reduced. Riley notes that the more an individual can strengthen their internal reserves, the more likely they are to activate their own self-healing process.⁴

Barbara J. Duryea, Project Coordinator of the Post-Polio Program at Conemaugh Health System, Johnstown, Pennsylvania, reports that one goal of the research is to provide an option that avoids potential drug side effects and interactions. William DeMayo, MD, of the Conemaugh Health System is working in conjunction with Riley and Duryea to develop and evaluate a lifestyle intervention for fatigue.

In an effort to offer the protocol to polio survivors and health professionals in diverse geographic locations, the Conemaugh Health System has developed a 30-minute instruction video. All polio survivors in the States are eligible to apply for this study and can learn about the protocol and the tape by calling 800-587-5875 or Duryea at 814-534-5741.

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POST-POLIO SYNDROME PROGRAM (PPSP) The Uniformed Services University of the Health Services and the Henry M. Jackson Foundation are collaborating in medical research efforts with WRAMC, National Institutes of Health, National Rehabilitation Hospital, and Conemaugh Health System focusing on post-polio syndrome. The Post-Polio Syndrome

Program is funded by the Department of Defense. ■

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EDITOR'S COMMENTS

This issue includes another article related to the memories of having had polio, specifically the benefits of therapy. The inclusion of this article does not imply that all polio survivors need therapy, just as an article about anesthesia does not imply that anesthesia should be avoided. (See Editor's Comments, *Polio Network News*, Vol. 18, No. 2).

Two research studies are briefly described in the front-page article. Be aware, when you call, that there are "inclusion criteria" which you may not meet, and that there may be other requests made of you during the course of the research – none without your permission, of course.

Readers Write offers some personal ideas as to "What Works" for polio survivors. You are invited to send a description of your specific solution to a problem for future publication and/or to be added to "What Works" at our website, www.post-polio.org. (To find us, you must type in the hyphen.)

Our site lists books about the polio experience over the decades (www.post-polio.org/ipn/books.html). Younger

physicians have expressed an interest in the earlier treatments survivors received, and it is information that should be recorded from polio survivors who have not written or cannot write a book. We will be placing online individual stories about the early polio experience (not the late effects of polio). You may choose to send us your story, making sure that you include the year and where you lived, because these two factors certainly influenced the treatment you received. Please send your story via email to gini_intl@msn.com with "My story" in the memo line, or mail it to our Lindell Boulevard address.

International Polio Network has just published a new brochure, with three sections, entitled "The late effects of polio for polio survivors, for families and friends, and for health professionals." The informational piece will be translated into four other languages that will be placed online. To receive 1-3 copies in English, please send a self-addressed #10 envelope with 37 cents postage.

– Joan L. Headley, MS
Executive Director, GINI

A Guide for Exploring Polio Memories

Linda L. Bieniek, CEAP, La Grange, Illinois, and Karen Kennedy, MSW, RSW, Toronto, Canada

“History, despite its wrenching pain, cannot be unlived, but, if faced with courage, need not be lived again.”
– Maya Angelou (1993) *On the pulse of morning*.

In this and the upcoming article (*Polio Network News*, Vol. 18, No. 4), we focus on psychotherapy as a way to heal traumatic memories that interfere with a person’s functioning, health, relationships, or responsibilities. Survivors – whether they were children, adolescents, or adults when they contracted polio – experienced losses as a result of contracting the disease. In order to survive painful experiences, individuals adapted to the overwhelming feelings caused by separations from their families, long hospitalizations and rehabilitation, and disruptions in activities that stemmed from the disease. How did they do this? Their minds creatively protected them from dealing with the distress by blocking it out of their conscious memory. This is a common coping response to trauma.

What differs for polio survivors? In addition to dealing with the impact of past memories, many are contending with the late effects of polio – a physical condition that affects their energy levels, mobility, endurance, and daily functioning. Many report that their physical conditions have disrupted their relationships, careers, and financial security. For some, current circumstances are traumatic and can unconsciously remind them of earlier polio experiences.

Our previous article (*Improving Quality of Life: Healing Polio Memories*, *Polio Network News*, Vol. 18, No. 1) illustrated how unresolved issues from early polio experiences can limit survivors’ abilities to make changes that would improve their health and outlined how survivors can determine if they need therapeutic assistance. This article offers readers options of what they can do to reduce the distressing effects of their polio memories. We focus on psychotherapy as an effective option and highlight benefits that survivors have reported. Recognizing that effective psychotherapy requires a partnership, we begin by identifying responsibilities of the person seeking care and will address those of the therapist in the next issue of *Polio Network News*.

Psychiatrist and polio survivor Milton Erickson, MD, was considered a genius at helping clients make difficult changes. His success stemmed from his belief that problems are “gifts” that offer us valuable learning experiences, and his use of metaphors – symbolic language – which provided clients with an appealing perspective of their problems. In other words, he restated what felt like heavy problems into understandable, manageable, and, often, playful terms.

Likewise, we encourage survivors to consider the symptoms of their problems as a wake-up call for finding ways to experience healing power and the energy to stay healthy (Gilligan, 1997).

The Benefits of Psychotherapy

The good news is that research continues to present evidence that effective psychotherapy, using certain approaches, can result in positive changes for trauma survivors (van der Kolk, 1996). In *Healing the Blues*, author and polio survivor Dorothea Nudelman described how she has benefited from working through depression in psychotherapy (Nudelman, 1994). Other individuals who have benefited from their therapeutic experiences have reported the following improvements:

Emotionally feeling better

- ◆ calmer and hopeful for longer periods of time after a therapy session
- ◆ grateful for what is of value in one’s life
- ◆ relief in understanding the reasons for unhealthy coping patterns
- ◆ feeling compassionate towards oneself and others

Physically feeling better

- ◆ having less pain
- ◆ being able to breathe more deeply
- ◆ sleeping more soundly
- ◆ gaining energy
- ◆ having fewer headaches, less digestive distress
- ◆ being aware of one’s body messages

Acquired insights and improved understanding

- ◆ thinking more clearly and rationally

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- ◆ improving one's ability to concentrate
- ◆ accepting one's limits
- ◆ distinguishing what is and what is not his/her responsibility

Ability to take action

- ◆ speaking up in useful, respectful ways
- ◆ making healthy decisions and choices
- ◆ letting go of efforts to control the reactions and behaviors of others
- ◆ saying "no" without feeling guilty or obsessing
- ◆ setting appropriate limits
- ◆ focusing on the present, rather than daydreaming or worrying

Survivors are encouraged to ask themselves what changes they want if they choose to invest in healing their polio memories. Those already in therapy may want to use this article as a tool to assess how their therapy is helping them make positive changes and what additional assistance they may need.

Individual Choice and Self-Responsibility

Not all polio survivors are in need of deep intensive healing work, and others have already resolved these issues. Some survivors use psychotherapy to learn better coping skills and to reduce the impact of depression and anxiety. Others choose to make improvements in their lives on their own by exploring self-help resources. Still others cope with what they know and do not want to look at any issues related to the subjects of feelings, distress, or their

pasts. Some individuals may choose not to read this article because they do not want to venture into uncomfortable territory or may not possess the energy required.

Each polio survivor has the right to choose what fits with his/her values, priorities, and interests. Each option has its advantages and risks. We encourage survivors to approach these issues with an open mind, and to ask themselves what they need in order to take care of their health and fulfill their goals, regardless of the stage of their lives.

Those survivors who choose psychotherapy will need to:

- ◆ display the commitment and self-responsibility to make changes by attending sessions regularly and investing time and energy outside the sessions to improve their lives (Finney, 1995);
- ◆ select an ethical, competent therapist with expertise in healing memories;
- ◆ gain access to affordable services;
- ◆ use the therapy process as a practice ground, disclosing honest reactions during sessions; and
- ◆ risk experiencing difficult feelings.

Not every survivor will want or can afford to deal with these issues in therapy. Individuals who do not have access to adequate mental health services, financial or physical resources, or who do not want to do this work, are advised not to pursue memory work. Instead, we recommend they use available resources to manage the distress of symptoms. A list of possible

resources will be published in the Fall issue of *Polio Network News*.

Goals of Psychotherapy

Depending on an individual's circumstances and what the person wants from therapy, treatment plans and approaches will vary. Goal setting is an essential part of any therapy experience. What does one want to change? What specific and positive results do they want to achieve and experience from investing in therapy? Therapists need to ask their clients these direct questions, gain agreement on treatment goals, and tailor the therapy process to meet the client's needs.

For example, people who have frequent nightmares may identify sleeping soundly as an ultimate goal. Trauma survivors, such as veterans or people who live in war zones, often have related sleep disturbances.

Polio survivors have reported having anxiety attacks before going to medical appointments. These individuals may want to feel calm and confident when dealing with health care issues. Learning how to communicate assertively may help them grow in confidence. However, if their anxiety continues, they may need to consider what causes the anxiety attacks. Unresolved memories may be affecting their unconscious minds.

In successful therapeutic relationships, clients will learn how to express their thoughts and feelings, and how to set healthy limits. Talking about the therapy process and reactions to the therapist typically offers another

very useful learning experience (van der Kolk, 1996).

A respectful and nonjudgmental therapist can use these opportunities to build trust and safety with their client. On the other hand, one who does not openly disclose disappointment or anger with a therapist may add to "unresolved issues." These, in turn, may consume mental and emotional energy that can affect a polio survivor's fatigue level.

Another important goal of therapy is to use issues that arise in the therapeutic relationship as a way to uncover unresolved issues. For example, a person who had difficulty speaking up to authority figures expressed disappointment to her therapist and was relieved by the therapist's accepting and validating responses. In talking about her fears, the client uncovered an unconscious belief from her childhood that was limiting her ability to communicate her disappointments and concerns to health care professionals. She came to realize that, as a young child, she had believed that if her doctors became angry at her, they would not take care of her, and she would die.

People who are afraid to talk with a therapist or who find fault with every suggestion a therapist offers, may choose to set a goal of building trust with the therapist. Otherwise, their fear or fault-finding may interfere with their ability to address core issues, such as their feelings about their pasts. Marsha Linehan has created a process known as Dialectical Behavior Therapy (DBT) that can help in reducing "therapy-interfering behaviors" of this nature (Treigle, 2001).

Another goal of therapy is to learn skills that will help the therapeutic process progress towards the client's desired outcomes. For example, one who wants to improve his/her relationship may benefit from learning interpersonal skills. The therapist and client need to identify the particular skills that would help the individual reach his/her goals and make the therapy process productive.

Because working through traumas can trigger thoughts and feelings that may leave one overwhelmed, it is essential that therapists teach their clients skills that will help them learn how to stay focused on the present reality (van der Kolk, 1996). Nancy Napier offers useful techniques that can help clients learn how to cope with the potential dis-

tress of working through traumatic memories (Napier, 1993). Normally, treatment programs teach participants how to stay connected to their bodies (rather than being distracted by overwhelming thoughts or feelings), pace the release of feelings and memories, and contain them when they are too overwhelming or inappropriate to deal with at the moment.

Dealing with Feelings

People learn many ways to protect themselves from experiencing their feelings. Since working through memories brings uncomfortable feelings and anxieties to the surface, a person may feel worse before feeling better. Realizing that facing hurt

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Linda L. Bieniek, CEAP, is a Certified Employee Assistance Professional with knowledge of trauma issues from over 16 years of professional training and from participating in Master and Johnson's Trauma Programs. She has assessed, counseled, and referred clients with anxiety, depression, post-traumatic stress, dissociation, and addictive behaviors. As the manager of a corporate Employee Assistance Program, she worked extensively with employees who have had chronic medical conditions and negotiated accommodations for them.

Bieniek is a polio survivor, ventilator user, and disability advocate who serves on GINI's Board of Directors. She previously chaired the Board of Directors of Chicago's independent living center. Recently, she presented a professional workshop for psychotherapists and counselors at Abilities Expo in Metro Chicago on working with clients who have chronic medical conditions or physical disabilities.

Karen Kennedy, MSW, RSW, a registered medical social worker, has worked for the past ten years in the Post-Polio Clinic at West Park Healthcare Centre in Toronto, Ontario, a regional rehabilitation centre offering rehabilitation, complex continuing care, and long-term care services. Kennedy provides assessment, counseling, education, management recommendations, and referral for individuals and families of those who have previously contracted poliomyelitis. Kennedy holds a Masters of Social Work degree from the University of Toronto. Kennedy also meets with younger immigrants who have more recently contracted polio. Some have faced traumatic effects due to cultural superstitions, civil wars, and/or poverty.

and anger are part of grieving can support a client in recognizing the benefits of committing to the healing process.

In his article, "The Lessons and Legacies of Polio," Lauro Halstead, MD, illustrates how aging adults may need to grieve polio-related losses that they, as younger people, were unable to express emotionally.

"It wasn't until several years after that, when I joined a support group and began talking with other polios about my new loss and new pain, that I began to grieve for the body I had lost thirty years earlier (Halstead, 1995)."

Traumatic events can involve a sense of loss – of safety, childhood activities, career opportunities, or trust in self or others. Therapy needs to create safe opportunities for expressing reactions to these events from the past – the "sad, mad, glad, scared" feelings (Glaser, 2001). The healing process requires releasing feelings, understanding the effects of a loss, and discovering ways to find meaning and growth from the experience (Schiraldi, 2000).

Treatment for Trauma

Most individuals who want to resolve the impact of their polio memories enter therapy on an outpatient basis. However, individuals who have experienced ongoing, intense traumas (e.g., abuse) may require clinical programs that offer the needed level of assistance and expertise to reduce their distressful symptoms and safely support them through the process of working through memories.

When a survivor's symptoms interfere with their ability to function and/or to process memories on an outpatient basis, and, if a client's physical reactions to the distress of the process present a risk to the individual (e.g., some physical health conditions may require monitoring of cardiac and respiratory function), then an intensive outpatient or inpatient program is medically necessary to prevent the development of further symptoms.

Structured Trauma Programs are usually affiliated with major medical centers or universities or are a service offered by select behavioral health treatment centers. They are available in some countries, but not all. Effective, ethical programs can help stabilize disruptive symptoms such as compulsive eating, excessive sleeping, flooding of feelings, and prepare a client for continuing therapy with an outpatient therapist.

For those who choose to address their polio memories, trauma specialists agree that treatment needs to be approached in phases. The International Society of Stress Studies recommends that treatment focus on:

- ◆ stabilizing and reducing distressful symptoms;
- ◆ managing unhealthy, harmful behaviors;
- ◆ improving functioning and the ability to concentrate, assert needs, set limits, communicate effectively, make healthy decisions; and
- ◆ building healthy, respectful relationships with self and others (ISSD, 2000).

Harvard University Professor Bessel van der Kolk and other

trauma specialists state that processing trauma information involves identifying, exploring, and modifying the effects of memories. In addition, they emphasize the need to teach survivors how to create and use plans that can prevent them from slipping back into unhealthy coping behaviors such as self-neglect, gambling and other addictions, and neglect of responsibilities (Glaser, 2000).

During this process, individuals need to learn how to listen to their bodies' messages ("gut feelings") and to respect their intuition. The success of their recovery involves learning how to nurture and fulfill their present-day physical, emotional, relational, and intellectual needs to counter the effects of traumatic situations from their pasts. This requires a compassionate approach, being responsible for their behaviors and treatment, and developing internal and external support. ■

The Fall 2002 issue of *Polio Network News* will explore the process of locating and selecting a therapist and additional treatment approach options.

The authors are grateful to individuals who have contributed to this article, especially to Marcia Kaplan, MA, for her editing assistance.

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Many people claim that "the past is past." While that is true, researchers have found physical evidence in brain scans indicating that trauma physically affects the brain and neurobiology of a trauma survivor (Bremner, 2002).

Research continues to reveal that traumatic experiences affect the body, the mind, and a person's neurology, and that these are interconnected. For example, trauma affects the mind when it results in a person developing limiting beliefs about self or the world. One illustration is a child, who was emotionally injured by a caretaker, thinking that she is bad and the world is not safe; another is a young adult, who contracted polio in a country where the disease is considered an evil curse, believing that he is unworthy to succeed in marriage or a career.

Trauma can leave long-lasting effects including low self-esteem or depression, blocked energy in the form of fatigue or decreased motivation, and physical symptoms ranging from digestive trouble to pain similar to that experienced during the original traumatic incident (Bieniek & Kennedy, 2002).

In recent years, psychiatry has rediscovered that dissociation plays a critical role in the development of trauma-related symptoms and conditions. "Dissociation" occurs when a person is overwhelmed by an experience and puts the experience out of his/her conscious mind because it is too difficult to integrate. In other words, the reality of what happened is too much for the person to deal with at that time. This happens not only at the time of the traumatic event, but also can continue as a long-term consequence of the trauma (van der Kolk, 1996).

Clinically, dissociation occurs in a variety of ways on a continuum of related psychological conditions. For example, in veterans who have post-traumatic memories of military scenes, symptoms may include intrusive recollections, nightmares, and flashbacks that can limit their concentration and functioning (van der Kolk, 1996).

For example, some individuals who lost a parent as a child may numb their feelings of grief by reading excessively or overusing alcohol. They may distract themselves from their feelings by taking care of others or talking compulsively. Extreme forms of dissociation can develop from chronic or intense neglect, or from physical, sexual, or psychological abuse that often occurred at an early age (van der Kolk, 1996).

The good news is that even if a person has had such a painful life history, treatment can effectively resolve or reduce the impact of these experiences. Trauma programs are especially useful for survivors of severe and ongoing trauma. One client who had problems functioning because of frequent shifts in his mood, energy, and ability to concentrate reports, "I was relieved to find professionals who understood the reasons for my intense distress. They helped me learn what I needed to get my life back."

Although trauma issues are difficult to face, there is hope. Skilled professionals who understand can help trauma survivors free themselves from the long-lasting effects of the painful experiences in their pasts.

Yoga Benefits Polio Survivor

Alan Fiala, PhD, Falls Church, Virginia (fialaalan@earthlink.net)

Yoga has provided benefits to me in improving breathing, maintaining flexibility, improving balance, and reducing stress. I have post-polio syndrome with loss of muscle strength, and I do not seek to gain strength from yoga. I do have pulmonary problems, and the development of good breathing habits from yoga practice has noticeably improved my performance on pulmonary function tests. A stretching routine works off "morning stiffness" more rapidly and keeps lower back pain and sciatica away. Habits developed from both yoga and Alexander Technique make me much more aware of my body and how it is functioning.

Yoga is very popular these days, and it has developed many forms. The yoga I practice is the so-called gentle version of hatha yoga. I discovered it by accident about six years ago (1996). To my great good fortune, my first instructor had studied some anatomy and physiology as part of her yoga training, and she had a great interest in helping those with disabilities to

Alan Fiala, PhD, is an astronomer, who retired from the Naval Observatory in June 2000, after 38 years of service, specializing in eclipses and navigational almanacs. Fiala had polio in 1952 and began to experience the late effects of polio in 1984, when he started using the PLV®-100 while sleeping. He is also now using the Pulmonetics LTV800™. Although he has one fused ankle and a partially fused spine, he is ambulatory, but uses a scooter to conserve energy.

find alternate ways to perform poses made difficult by the disability. (Explore her website at www.yoga4u2.com for more on her style of practice.)

As you are taking classes, you should strive to develop your own daily practice at home with advice from the instructor. Some may offer an individual development session for a fee. While the cost of yoga classes (in the Washington, DC, area) typically run \$13-17 per session, an individual session can run \$50 or more. If you have severe disability, a few private sessions to find adaptations for your particular body may be of more benefit than a group session that tries to help all and hurt none.

The typical yoga class lasts 60-90 minutes. Within this time, you may do some warm-ups, some breathing exercises, some meditation, some eye exercises. You mostly do "poses," aimed at flexing and stretching all parts of the body. Emphasis is on flexing the spine in all directions – forward, backwards, and sideways. Poses are done lying down, sitting on the floor (or a chair), on hands and knees, and standing.

Balance poses involve standing on one leg at a time. There may also be inverted poses. In a gentle class, inverted poses are limited to lying down and having your legs up on the wall or a chair. The class always ends with 10-15 minutes of complete relaxation.

Is it for you? The first requirement for most yoga classes is the ability to get down onto the floor and get up by yourself. Occasionally a class is offered for people who cannot do this, but can sit



in a chair. Such classes are perhaps offered in assisted-living homes, hospitals, etc. Otherwise look in recreational centers, adult education programs, YMCAs, yoga studios, and, maybe, health clubs.

In all instances, if the class is called "gentle yoga," interview the instructor for certification by a yoga organization, and experience in working with individuals with disabilities. Does the instructor know what each pose is meant to do for your body, and know alternative poses that might be easier for you? An unqualified or inexperienced instructor can lead you to hurt yourself.

You might also check with your physician or other health care professional for advice. In my experience, health professionals who do not have firsthand knowledge of yoga may tend to be negative. If so, ask for specifics, as it applies to you, and take that advice with you to class.

There are also books and videos on yoga, and even a few aimed at rehabilitation. There may be some on "gentle" yoga, but I have not seen them. I personally doubt that you could develop a practice for yourself this way, without personal instruction, and suspect that you might hurt yourself, if not be outright discouraged. ■

Readers Write

"My swallowing and voice are doing much better in the long run. I had expected a quicker deterioration, but that is not the case. My gastrostomy tube is working out fine; I use it for the bulk of my nutrition and liquids and do some 'recreational eating' on the side of soft and moist foods to keep things working in my throat. I will gladly communicate through email with anyone who has similar problems. Maybe we can start our own electronic support group."

– Pat, Oak Harbor, Ohio
(patngene@nwonline.net)

"Two pieces of equipment have helped me cope with my decreased ability to speak loud enough for others to hear me or for any length of time.

"I use the ZaVox Speech Amplifier, a small portable aid that is powered with a 9V battery and simply attaches to my belt. I only need an outgoing breath, such as a whisper, to enable ZaVox to provide amplification.

"My doctor also recommended ZYGO LightWRITERS®, small portable text-to-speech communication aides that can accommodate people with a wide range of disabilities. The speech synthesizer is available in several languages as well as English, which I use. There are a wide variety of features and options as well as a free videotape that demonstrates the LightWRITER in use by a number of different people in real-life situations.

Both speech aides are available from ZYGO Industries, Inc. (800-234-6006) or visit www.zygo-usa.com."

– Name withheld by request

"Thanks for *Polio Network News* (Vol. 18, No. 1), 'Healing Polio Memories.' After years in hospitals, I have many negative memories, including sexual abuse. I have yet to consider these issues, finding myself shocked that I utilize all the protective coping patterns on your list. Thanks for helping me understand this."

– Cathleen, Cottage Grove, Oregon
(ccasey@epud.net)

"I cannot thank you enough for suggesting that my comments be put in *Polio Network News*. These contacts are bringing me wonderful people to correspond with regarding common feelings. You gave me a gift."

– Judy, Wichita, Kansas

"Back in 1985, my pulmonologist, Oscar Schwartz, MD, Saint Louis, Missouri, sent me to a respiratory therapist who instructed me in using an Ambu bag. He knew it would help maintain the elasticity of my lungs as well as stretch my chest muscles and chest cavity. The trick is to allow the air to go into your lungs and not let it escape out your nose.



I usually pump in three or four compressions of the bladder and hold the air in my lungs for about 30 seconds. I repeat this at least three times in succession.

"I do this 'exercise' each night while in bed after I remove my back brace, which I started wearing in 1991, and before using my Bi-PAP® S/T, which I started using in 1999. If I have a cough, which I rarely do, I use the 'bag' more frequently during the day."

– Doris, Dellwood, Missouri

"Dr. Silver's Myth # 3 – 'Swimming is good for you' from the Spring issue of *Polio Network News* (Vol. 18, No. 2) confirms what I have experienced. The pool here in my retirement community opened two weeks ago, and the energy required to get there had made the exercise a losing deal. My walker, my scooter, and my clothing are all factors. Thank goodness I had learned enough from IPN to know what to do about it.

"I began by just 'water walking' around the edge of the pool, which made me aware of the balance and energy I had to rebuild. I am now up to four rounds of walking and several rounds of floating on my back. Each day I'm getting a little steadier."

– Bill, Saint Louis, Missouri

We welcome your ideas that will help someone else.

Send them to International Polio Network (IPN), 4207 Lindell Blvd., #110, Saint Louis, MO 63108-2915 USA, 314-534-5070 fax, or email to gini_intl@msn.com.

Certification of Poliomyelitis Eradication – European Region, June 2002

On June 21, 2002, the Regional Commission for the Certification of Poliomyelitis Eradication certified that the European Region (EUR) of the World Health Organization (WHO) is free of indigenous wild poliovirus transmission. The last known case in EUR of polio caused by indigenous wild poliovirus transmission occurred in southeast Turkey in November 1998. EUR comprises 51 countries with an estimated population of 873 million and is the third of the six WHO regions to be certified as polio-free, following the Americas Region in 1994 and the Western Pacific Region in 2000. An estimated 3.4 billion persons (55% of the world's population) live in countries and territories certified free of endemic polio. ■

SOURCE: CDC's *Morbidity and Mortality Weekly Report (MMWR)*, July 5, 2002, 51(26), pp. 572-573. Waltham, MA: Massachusetts Medical Society.

Poliomyelitis – Madagascar, 2002

Surveillance for acute flaccid paralysis (AFP) in Madagascar has detected a cluster of four cases of paralytic poliomyelitis from which type-2 vaccine-derived polioviruses have been isolated. Preliminary data indicate that these patients, residing in the Tolagnaro district of Toliara province in southeastern Madagascar, had onset of paralysis during March 20–April 12, 2002. None of the children affected was vaccinated fully. During March–April 2002, provincial authorities conducted a small-scale house-to-house vaccination response. Genetic sequencing studies of these vaccine-derived viruses indicate substantial genetic drift and recombination with nonpolio enteroviruses. These findings are compatible with an outbreak of paralytic polio associated with a circulating vaccine-derived poliovirus (cVDPV); however, further investigation is required. ■

SOURCE: CDC's *Morbidity and Mortality Weekly Report (MMWR)*, July 19, 2002, 51(28), p. 622. Waltham, MA: Massachusetts Medical Society.

On the Internet ... The Disability History Museum has placed excerpts from GINI's early newsletters in its "Library." Check them out at www.disabilitymuseum.org. Search for "Toomey." GINI has been publishing information for polio survivors since the late 1950s and the earlier newsletters were called *Toomeyville Gazette*, *Toomey Jr. Gazette*, and *Toomey j Gazette*, after Dr. John Toomey, a physician in the respiratory ward in Cleveland, Ohio.

The End of Acute Polio ... Photographs by Sebastião Salgado

A photographic exhibition depicting the story behind the largest public health initiative in history – the bid to eradicate polio globally by 2005 – can be found on the Internet (www.endofpolio.org). The images, captured by the world-acclaimed Brazilian photographer, document the ravages of acute poliomyelitis on children to the heroic efforts to deliver vaccine in conflict-ridden countries. UNICEF Special Representative Salgado worked with the Global Polio Eradication Initiative (GPEI) lead agencies: WHO, Rotary International, CDC, and UNICEF to document the world-wide campaign to end acute poliomyelitis.

Medicare Savings Programs ... You May Qualify

Studies have shown that millions of Americans may be eligible for programs called "Medicare Savings Programs" but are not taking advantage of them.

"Medicare Savings Programs" is an umbrella name given to the Qualified Medicare Beneficiary (QMB), Specified Low-Income Medicare Beneficiary (SLMB), Qualifying Individual (QI), and Qualified Disabled and Working Individual (QDWI) programs. These state-administered Medicaid programs subsidize certain Medicare expenses for beneficiaries with limited means. Under the authority of a recently enacted provision of the Social Security Act, SSA is identifying potential Medicare Savings Program eligible individuals.

The SSA will be sending letters to individuals from May to November alerting them of their potential eligibility for QMB/SLMB/QI benefits. These programs pay the Medicare Part B premium, now usually \$54 per month. The QMB program also pays other Medicare-related expenses. The QDWI program pays the Medicare Part A premium. The monthly premium is either \$175 or \$310 per month. The premium amount depends on the work history.

The letters vary from state to state because each has different eligibility rules. If you receive one of the letters, act on it. You may be eligible for savings. ■

LIVING WITH PAIN

Penney Cowan, Executive Director, American Chronic Pain Association

Managing life today can be difficult. Managing life with pain is even more challenging, but it is possible. There are ways to balance your life so that you can live the way you choose, rather than allowing your illness to dictate your life. The key is for you to become an active member of the treatment team. It is important to understand what your responsibilities are to ensure a quality lifestyle. Your health care team will do all they can to provide the necessary medical care, but you are responsible for much of the day-to-day routine.

First, you must clearly understand what your needs are. Personal needs can range from finding a balance between getting proper rest and physical exercise to taking medications and reducing stress. While managing illness and pain involves complex issues, the majority of the components are simple common sense, good living skills. Things such as good nutrition, open communication with family, asserting yourself so that your needs are met, and finding a balance between activity and rest are all keys to successfully managing pain.

It is important to recognize your limitations to prevent becoming overly tired or risking increased pain levels. Staying within your limits can enhance your ability to think clearly and concentrate on important tasks. Understanding your personal needs will provide a means to develop a workable plan so that you can incorporate daily tasks into your daily routine.

An excellent way to ensure that necessary tasks are completed while bringing you one step closer to independence is to journalize. Balancing daily activities with necessary rest periods is easier when you have a written record of your endurance while accomplishing everyday tasks.

Your journal can also provide you with insight into daily stressors. Reducing stress is vital in the fight against pain. Muscles that are already painful will experience increased pain as your stress level increases and your muscles tighten.

Recognizing and understanding feelings are another important component to successful pain management. When you ignore feelings, they do not go away, but show up as increased tension, feeling out-of-sorts, or even anger. Dealing with feelings as they occur can greatly reduce both stress and pain levels. Your journal, with its daily entries, can become your roadmap to wellness and provide you with a sense of empowerment.

Daily exercise should also become a routine activity. Simple stretches can strengthen muscles, improve circulation, and maintain energy levels. Ask your doctor about an exercise program designed to fit your ability.

When you plan your day, keep in mind your need to pace activities according to your ability for that particular day. A simple way to remember the importance of pacing is found in the letters of the word PACE.

P ... is for *prioritizing* your tasks to ensure that the most important ones are done first.

A ... is for *planning your actions* to ensure the best use of your time.

C ... is to remind yourself that your physical *comfort* is important. If a task creates increased pain levels, then perhaps you need to ask for help.

E ... is for *energy*. Energy levels are never the same from day to day.

You need to consider how much energy you have at the beginning of each day to ensure you are working and playing within your ability.

By combining PACE – priorities, action, comfort, and energy – with your personal commitment to a “near-normal” life, you can begin to feel like a person rather than a patient. ■

Penny Cowan is the founder and executive director of the American Chronic Pain Association (ACPA). The ACPA is spear-heading *Partners for Understanding Pain*, a campaign to elevate the awareness of chronic and acute pain and pain caused by cancer, and to facilitate a whole-person approach to pain management. (800-533-2075, www.theacpa.org).

GINI appreciates the donations from these support groups ...

... to The Gini Laurie Endowment

First Coast Post-Polio Support Group, Jacksonville, Florida
Greater Boston Post-Polio Association, Wellesley, Massachusetts
In memory of Jack Ahern
In memory of William Hoyt
Pasadena Post-Polio Support Group, Montrose, California
Polio Survivors of Central Montana, Great Falls, Montana
Polio Survivors Organization, Inc., Louisville, Kentucky

... to The GINI Research Fund

Central Virginia Post-Polio Support Group, Richmond, Virginia
Florida East Coast Post-Polio Support Group, Ormond Beach, Florida
New Jersey Polio Network, Martinsville, New Jersey
In honor of Jean Fox Csaposs
North Central Florida Post-Polio Support Group, Dunnellon, Florida
Polio/Post-Polio Resource Group, Fern Park, Florida
Polio Survivors Foundation, Reseda, California
Post-Polio Association of South Florida, North Miami Beach, Florida
The Post-Polio Support Group for Southern Hillsborough County,
Sun City Center, Florida
In memory of Paul Elrod
In memory of Marian Swing
Sacramento Post-Polio Support Group, Rocklin, California

2002 Calendar

SEPTEMBER 21 – Post-Polio Conference – 2002: We're All in This Together, Four Points Sheraton, Milwaukee, Wisconsin. Speakers include Frederick M. Maynard, MD, William Waring, MD, Paul Barkhaus, MD, and James Agre, MD, PhD. Contact Post-Polio Resource Group of Southeastern Wisconsin (414-454-9093, www.pprg.org).

OCTOBER 19 – Post-Polio Conference honoring Nancy and Bill Carter with Joan L. Headley, Nebraska Polio Survivors Association, First United Methodist Church, Omaha, Nebraska. Contact Marian Barnett (402-341-0710, mjbarnett@att.net).

NOVEMBER 2, 2002 – PPS into the 21st Century, The Shepherd Center, Atlanta, Georgia. Lauro Halstead, MD, will be the guest speaker. Contact Linda Priest (P.O. Box 250566, Atlanta, GA (Georgia) 30325; lindaleepriest@earthlink.net).

**Gazette
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