

POLIO NETWORK NEWS

WHAT IS CRAMPING YOUR STYLE? Straight Answers to Your "Cramped" Questions

Holly H. Wise, PT, PhD, and Kerri A. Kolehna, MS, MD, Coastal Post-Polio Clinic, Charleston, South Carolina

Tired in the morning? Is it difficult to get comfortable for a good night of sleep? A complaint often reported at the Coastal Post-Polio Clinic in Charleston, South Carolina, is the inability to get to sleep at night due to leg pain, twitching, or cramping.

Muscle cramping is a relatively common, painful, and bothersome complaint among generally healthy adults, and is more common in women than men. Some studies estimate as many as 50-70% of older adults may experience nocturnal leg and foot cramps (Abdulla, et. al., 1999). Although, leg cramps are a common complaint in older adults, they must be taken seriously when the individual is a polio survivor.

What is a muscle cramp?

AKA "stitch," "spasm," "knot," "Charley-horse," or "twitch."

Muscle cramping involves a physiological disturbance of muscle that produces an involuntary and painful contraction. Cramps typically occur in the calf muscle and are accompanied by sudden excruciating pain and persistent muscle contraction. Occasionally, both legs may be affected by cramping simultaneously. Although cramps often resolve spontaneously within minutes of onset, the episodes may continue for hours or days with no apparent pattern of frequency or duration.

Cramps can occur throughout the day but more often occur at night or when a person is resting. Although it is not known exactly why cramps happen mostly at these times, it is thought that the resting muscle is not being stretched and is therefore more easily excited.

The basis for the theory that cramps occur more at rest, due to the muscle not being stretched, is that passive stretching can relieve muscle cramping. Pain associated with cramping is likely caused by the demand of the overactive muscle exceeding its metabolic supply. This excessive demand results in ischemia, or diminished blood flow, to the muscles, and the accumulation of metabolites (waste products).

Causes of Leg Cramps

Twitching and cramping can be caused by over-activity of nerves and muscles from faulty posture, shortened muscle length, and excessive activity or exercise.

Other known causes of muscle cramping include diabetes mellitus, kidney failure, thyroid or neurological disorders, and poor blood flow or peripheral vascular disease. In addition, certain medications and occupational routines can precipitate muscle cramping.

Recurrent cramps without a known cause are called *idiopathic cramps*. These cramps are suspected to be the result of disruptions or imbalances of unknown

origins anywhere in the central and peripheral nervous systems and may explain the wide range of conditions in which the cramping occurs (Bentley, 1996).

Seeking Answers

A thorough history and possibly a referral for screening labs will help determine the causes for leg pain and cramping. Polio survivors can provide a description of their muscle cramps, identification of the time and place when they occur, and an activity log of the 24-48 hours preceding the episode(s). For example, if after a vigorous exercise session or a particularly long walk, a polio survivor's muscles are noticeably twitching, aching, or painful, then the activity probably exceeded the strength of the muscle.

In addition, the physical examination should include:

- ◆ Observation of edema, or swelling in the legs, and an examination of the circulation, or vascular supply, to the legs. Occasionally, a diagnostic ultrasound test (a Doppler) will also

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be performed to determine the adequacy of blood flow in the legs.

♦ Baseline measurements of joint and muscle range of motion to establish if there are shortened muscle lengths and limited motion contributing to the cramping.

♦ Manual muscle tests (MMT) of the arms, legs, and trunk muscles to identify which muscles, if any, are at risk for overuse and subsequent cramping. In general, muscles with a strength grade less than a 3 on a 5-point scale are at risk for overuse.

♦ Posture, gait, and/or a mobility assessment complements the information gathered from the MMT. Faulty posture is associated with cramping and particular attention should be given to inefficient patterns of movement due to muscle weakness.

Prevention and Treatment of Leg Cramps

The treatment approach for non-idiopathic cramps – cramps in which the underlying cause is known – is to treat the underlying cause. The only proven strategy for the prevention and treatment of *exercise-induced muscle cramps* is the avoidance or reduction of activities that cause cramping.

Strategies to reduce muscle overuse may include lifestyle changes, such as weight reduction, use of assistive and orthotic devices, and the adoption of energy conservation techniques. Other strategies include advice from a physical therapist to create efficient mobility patterns and to intentionally pace day-to-day physical activities. These approaches are designed to allow for sufficient rest of overused muscles and to eliminate

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Dr. Kolehma is a physiatrist who is board-certified by the American Academy of Physical Medicine and Rehabilitation. In addition to her private practice, Coastal Pain & Rehabilitation Center, PA, Dr. Kolehma is also Clinical Associate Professor of Neurology at the Medical University of South Carolina.

Dr. Wise is a physical therapist and has worked with polio survivors since 1984. In 1994, she co-founded the University of Miami Post-Polio clinic with Carol Vandenakker, MD, where she worked until 1997 when she relocated to Charleston. Dr. Wise is currently an Assistant Professor in the Physical Therapy Educational Program, Department of Rehabilitation Sciences, College of Health Professions, Medical University of South Carolina.

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muscle twitching, cramping, and pain.

As with the general population, nocturnal muscle cramping in polio survivors may also be *idiopathic* in nature and not just related to overuse of muscles affected by polio or the other known causes listed above. The first line of treatment is to stretch the leg muscles before sleep, avoid caffeine in the evening, and eat foods high in potassium (bananas, orange juice, etc.).

To accomplish self-stretching, polio survivors can put their foot flat on the floor and slowly put weight on the foot. This action stretches out the calf muscle, which can also be done in bed by “pointing your toes towards your nose” until the cramping stops. Applying heat and massaging the cramped muscles can provide relief, as can wearing night splints that help prevent muscle shortening. Individualized intervention sessions with a physical therapist and/or referral to a certified orthotist are usually required to correct muscle imbalance and faulty posture.

Although no treatment is conclusively effective, many people achieve temporary relief of symptoms with one or more of these treatments. Success would

include the reduction in the intensity of cramping episodes, number of cramps per episode, and/or in the number of nights free of cramps.

What about quinine? Any new treatments?

The standard pharmacological treatment that has been used for over 50 years is 300 mg quinine taken at night. The outcomes are substandard with about 40% of individuals getting relief (Diener, et. al., 2002). The medicine must be taken for one month to truly tell if it is going to work, and does have side effects: ringing in the ear (tinnitus), dizziness, blurry vision, and headaches.

Newer treatments include vitamin E or calcium gluconate, both of which are available over the counter. The beneficial effects of these non-prescription treatments on nocturnal cramping have not been studied in detail. ■

REFERENCES AND RESOURCES

- Abdulla, A.I.J., Jones, P.W., & Pearce, V.R. (1999). Leg cramps in the elderly: Prevalence, drug and disease associations. *International Journal of Clinical Practice*, 53, 494-496.
- Bentley, S. (1996). Exercise induced muscle cramp – Proposed mechanisms and management. *Sports Medicine*, 21(6), 409-420.

EDITOR'S COMMENTS

GRANT AWARDED FOR SCOOTERS

International Polio Network (IPN), coordinated by Gazette International Networking Institute (GINI), has received a grant from SPIN, a charitable organization in Chicago, Illinois. The grant for \$3,000 was awarded to help individuals purchase a scooter.

In order to assist the greatest number of individuals, IPN will provide up to \$500 per applicant. If you are a polio survivor or you use a ventilator, and you and/or your insurance are unable to meet the complete cost of the scooter you plan to purchase in 2003, please contact Justine Craig-Meyer at IPN for an application. There is no deadline for applying and the payments will be disbursed as eligible and qualified individuals apply. ■

Diener, H.C., Dethlefsen, U., Dethlefsen-Gruber, S., & Verbeek, P. (2002). Effectiveness of quinine in treating muscle cramps: A double-blind, placebo-controlled, parallel-group, multicentre trial. *International Journal of Clinical Practice*, 56(4), 243-246.

Drug Information Handbook. (1999). Hudson, OH: Lexi-comp Inc., 875-876.

Guide to Physical Therapist Practice. 2nd edition. (2001). Alexandria, VA: American Physical Therapy Association.

Kanaan, N., & Sawaya, R. (2001). Nocturnal leg cramps – clinically mysterious and painful – but manageable. *Geriatrics*, 56, 34-42.

Principles of Ambulatory Medicine. 4th edition. (1995). Baltimore, MD: Williams & Wilkins, 1255-1256.

Riley, J.D., & Antony, S.J. (1995). Leg cramps: Differential diagnosis and management. *American Family Physician*, 52, 1794-1798.

Yunus, M.B., & Aldag, J.C. (1996). Restless legs syndrome and leg cramps in Fibromyalgia syndrome: A controlled study. *British Medical Journal*, 312, 1339.

It happened again. I received another phone call from a reporter who wanted to know “what polio survivors think.” He wanted to know what polio survivors thought about the creation of the poliovirus at SUNY at Stony Brook last year. I held that some polio survivors were surprised, a few were angry, but that the majority was silent on the topic. I further explained that in my experience, polio survivors and their opinions are representative of the population in general.

How do I know? I hear from you. So, let me assure you that the lead article on cramping and overuse is intended to caution polio survivors. I am not saying we should stop “living life.”

The articles about bracing are meant to inform you of current options. They are not advertisements and the companies did not pay us to print the information.

I have printed the article about “Disability and Wellness,” to reinforce the message that people with disabilities can experience good health. Our organization encourages us, as polio survivors, to focus our energies on what we can do, in conjunction with societal attitudes, our health professionals, families, and friends, to be healthy – physically, emotionally, mentally, socially, and spiritually.

We offer three pages of Treatment Approach Options for dealing with stress, change, memories, etc. We did not include them because we think post-polio problems are “all in your head.” As many of you know, we have committed the last two decades to combating that incorrect message.

We want you to continue living life, and our mission is to offer you information and options.

As an organization, we consider the generous contributions you sent as a stamp of approval for the work we are doing. Although you are not listed on page 8, those you chose to honor are. We thank you for your financial support and for letting us know “what you think.”

–Joan L. Headley, MS
Executive Director, GINI

International Polio Network

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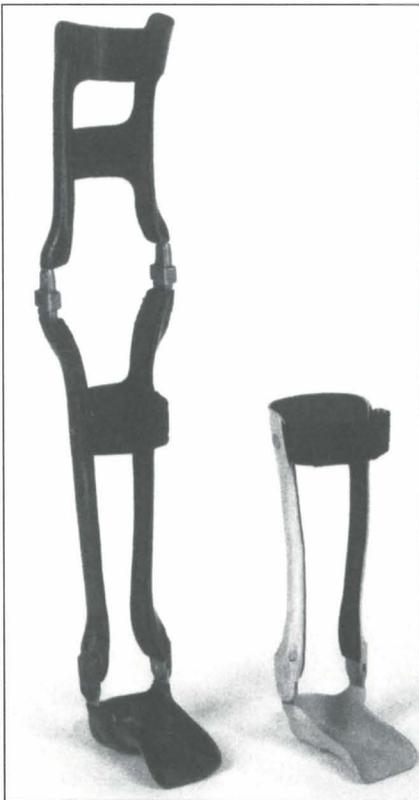
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BRACING OPTIONS: SHADOW BRACING SYSTEM

Kyle Scott, CO, a certified orthotist for over 15 years, has been confronted with the same question from hundreds of polio survivors – “Where’s the new technology in orthotics?”

“I find everyone wants to see the newest gizmos, but really wants someone else to try them,” says Scott. In his experience, polio survivors fall into three main orthotic groups: those who have worn braces since contracting polio; survivors who wore braces after the acute disease, but who learned compensation techniques to overcome their weaknesses and, in turn, discontinued wearing braces; and those who had a less severe case of polio or those who had a full return to function and never had to wear



Any trim configuration is possible as long as the brace is structurally sound. Almost any color or skin tone can be reproduced and personalized fabrics (Spandex™) can also be laminated into the brace.

braces, but now are experiencing new weakness.

Each group now has unique needs, both physically and psychologically, and each polio survivor’s needs must be addressed individually.

Metal and leather (M&L) braces were the primary orthotic treatment in the early years. “My polio patients who wear M&L braces have a love/hate relationship with them,” Scott reports. “They love the comfort, durability, and very positive structural support, but hate the excessive weight, bulk, and odor that is sometimes associated with the leather, and the limited footwear choices, as the M&L braces have to be attached to the outside of the shoe.”

With the development of thermoplastics over the past 20 years, the orthotics and prosthetics industry responded to these complaints with the next advancement in orthotics. Thermoplastic braces are lighter, less bulky, washable, more appealing, and fit inside shoes, so polio survivors can wear different styles of shoes.

Scott continues, “However, experience has taught orthotists that all thermoplastics have an elastic property to them, so even when the brace looked to be structurally equal to M&L, the plastic material couldn’t duplicate the structural support of metal.”

Scott pondered his patients’ comments that they didn’t feel their brace was as supportive, would bend under their body weight, and that their brace had a “rubbery feel.” What material could be used that would be structurally as strong as metal, but lightweight, less bulky, and

fit into shoes easily as the plastic braces do?

After joining Oregon Orthotic System, the industry leader in laminated orthotic braces in 1990, Scott realized that lamination provided all the benefits of M&L combined with all of the benefits of thermoplastic.

The Shadow Bracing System combines time-tested (M&L) engineering, with today’s cutting edge carbon-graphite lamination technology to keep it lightweight. Stainless steel knee and ankle joints are standard, with titanium ankle joints a popular option. A standard long leg brace with stainless steel components weighs between 2.75 and 3 pounds, while a short leg brace can weigh as little as a pound when titanium components are used.

Oregon Orthotic System, based in Albany, Oregon, knows no bracing system can meet every need, but offers the The Shadow Bracing System as newer technology that can address many of the concerns of polio survivors. ■

Give Oregon Orthotic System, Inc. a call at 800-866-7522 or 541-967-1821 to see if a laminated brace is for you and to find a skilled orthotist in your area.

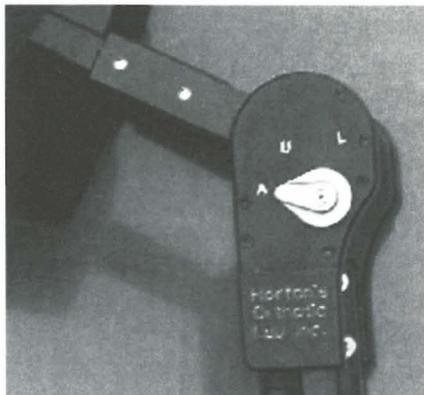
RESOURCES

The American Board for Certification in Orthotics and Prosthetics (ABC) sets standards for quality. Find a certified orthotist in your area at www.abcop.org.

International Society for Prosthetics and Orthotics’ aim is to promote high quality of care. Review their specific activities at www.ispo.ws.

THE STANCE CONTROL ORTHOTIC KNEE™

The mechanically-actuated Stance Control Orthotic Knee™ joint is the latest innovation from Horton Technology, a private laboratory headquartered in Little Rock, Arkansas. Horton's



Stance Control Orthotic Knee™ joint

knee joints have been incorporated into custom-made leg braces and can prevent the knee from collapsing as polio survivors walk, automatically releasing to permit unimpeded knee flexing during the swing phase of gait.

Preliminary scientific studies from the University of Central Arkansas (UCA) suggest that these braces provide a more



Stance Control KAFO

normal gait pattern and reduce the effort required for people with lower limb weakness and paralysis to walk.

The mechanically-actuated version has been commercially available since January 2002. More than 400 orthotists in North America have successfully completed the advanced training course in the application of this innovative rehabilitation technology.

At the annual meeting of the American Orthotic & Prosthetic

Association (www.aopanet.org) in the fall of last year, Horton Technology, Inc. unveiled an electronic version of the Stance Control Orthotic Knee™ joint. Polio survivor Paul Ellis demonstrated how the Smart Knee™, which can be powered for several days by ordinary AA batteries, enables him to walk safely up and down ramps despite knee muscle paralysis and weakness in both legs.

Horton's electronic Smart Knee™ is currently undergoing final clinical trials in the United States and will be commercially available in early 2003. ■



Smart Knee™

Call Horton Technology at 866-663-3970 or visit their website at www.stancecontrol.com for more information.

Potpourri

GUIDE FOR EMERGENCY PERSONNEL

The National Organization on Disability (NOD) has released the first edition of its "Guide on the Special Needs of People with Disabilities for Emergency Managers, Planners, and Responders." The guide is designed to acquaint front-line emergency personnel with specific issues that impact people who have disabilities.

The 28-page guide highlights key disability concerns to emergency managers, planners, and responders so their emergency

plans include the needs and insights of people with disabilities before, during, and after a crisis. It is designed to help professionals make the best use of budgets and resources as they strive to include all community members in emergency preparedness. The guide is relevant to diverse emergency situations, from fires to natural disasters to man-made catastrophes.

Emergency management professionals may request up to three free copies from epi@nod.org or 202-530-0727 fax. The guide can be downloaded at no charge from www.nod.org.

COMPUTER/ELECTRONIC ACCOMMODATION PROGRAM (CAP)

CAP, established by the Department of Defense (DoD), is the federal government's centrally funded accommodations program, providing assistive technology solutions to the 53 federal agencies that have joined the CAP initiative. The DoD pays the bill to improve federal employment opportunities for people with disabilities in each agency.

For more information about the CAP initiative, visit www.tricare.osd.mil/cap/captec/captec. ■

OCULAR HEALTH AND PULMONARY ASSIST MACHINES

Richard E. Hector, MD, FACS, Bradenton, Florida (www.DrHector.medem.com)

Maintaining good ocular health and comfort is a challenge even under “ordinary” conditions. It is especially difficult when you use a pulmonary assist machine, such as C-PAP, BiPAP, etc., with a face mask, because such use can affect the stability of your tear film. A stable protective three-layer tear film is partially responsible for good vision and comfortable, healthy eyes.

We are most familiar with reflex tears, those watery tears you experience while watching a sad movie or cutting onions. If these reflex tears are present for no particular reason, the culprit is usually a dry eye condition. This exists when the other, more protective, and less familiar “tear” is absent, either due to reduced production or increased evaporation.

Numerous small glands in your eyelids produce the protective three-layer tear film that is

necessary for the health of the external surface of your eyes. If the tear film is absent, the external surface breaks down, which can be very painful and can increase the risk of severe infection, scarring, and loss of vision.

Using a pulmonary assist machine with a face mask can increase the rate of evaporation of your natural tear film, and will, at first, stimulate your reflex tears, causing your eyes to tear inappropriately. If other conditions are present that reduce the production of this valuable tear layer, an advanced dry eye condition can develop to the point that your eyes will not tear or water at all. The use of hormone replacement therapy that includes estrogen, allergy medications such as antihistamines and diuretics, and Rheumatoid arthritis and Parkinson’s disease are all associated with an advanced dry eye condition.

The treatment is similar in most cases. Over-the-counter artificial tear solutions of various compositions and thickness need to be used. The frequency of applying these solutions depends on the severity of the dry eye condition. Avoid those that “take the red out” and look for a bland lubricating product such as Refresh Tears/Gel or Thera Tears/Gel; Bion Tears or Tears Naturel Forte; Hypotears or Tears Naturel Free; Genteal Tears/Gel; and Refresh Endura. If artificial tears are needed more than five times a day, preservative-free solutions should be used.

In very severe conditions of dry eye, the tear drainage system can be modified, either temporarily or permanently, by using small plugs that fit inside the eyelids and/or the eyelids themselves can be sutured partially closed to further protect the surface of the eye from exposure and drying. ■

Readers Write

My polio story has a very typical beginning, but a very different ending. As a child, I was diagnosed with polio and had two orthopedic surgeries on a “polio foot.”

I was active, even a bit athletic, in my 20s and 30s, but got lazy in my 40s. I noticed that my polio leg was slightly weaker, but I ignored the signs, planning to “get back into shape soon.”

At age 50, I finally decided to get into shape, trying to bike and jog short distances at first. It kept getting more difficult until I could not raise my right leg sideways at all! I had always assumed that polio had affected me only

below my knee. I turned to the Internet to learn about post-polio syndrome. I was careful to refrain from overuse, but noticed my arms becoming weaker, too.

Realizing that I might need to go on Social Security Disability eventually, I started doctoring to get a diagnosis of post-polio onto my medical records. Tests ruled out other problems until the MRI discovered lipomyelomeningocele, a congenital neural tube defect related to spina bifida, correctable with surgery! I turned to the Internet again and discovered that it causes orthopedic deformity just like mine – and just like polio. It took a few minutes to really sink in – I never had polio at all.

According to my neurosurgeon, overuse is not an issue; what I need to avoid until I have surgery is any jolting or bouncing moves, or stretching.

How could I have been so misdiagnosed? My mother was alone during a polio epidemic of the early ‘50s and she had no transportation to a hospital. I had become very sick with a fever, so she called the hospital and nurses told her to keep my legs in very hot water. At age five, the doctors, looking at my “polio foot,” pronounced that it had indeed been polio.

– Doris, Oceanside, California
ncumc@earthlink.net

WELLNESS AND DISABILITY

"Nobody would be sitting here unless we accommodated what we're not able to do. We're not able to get up to this floor unless we build stairs, and when we – society – put(s) out those efforts to sort of assist, then disability doesn't exist."

In this era of New Age ideas where organic food stores and yoga studios can be found in busy street corners and in office buildings, there seems to be a focus on health and wellness. Our Rehabilitation Research and Training Center on Health and Wellness Consortium at Oregon Health & Science University is studying what *health and wellness* means to people with disabilities.

We have found that for people with disabilities, health and wellness presents a compounded challenge. When asked to define health and wellness, people in our study, all of whom are living with long-term disabilities such as cerebral palsy, post-polio, multiple sclerosis, amputation, and spinal cord injury, noted that it meant several things.

Health and wellness means being able to function and being given the chance to do what one wants to do; being independent; having self-determination regarding choices, opportunities, and activities; having physical and emotional states of well-being; and not being held back by pain.

When asked about wellness, one participant stated, *"At the end of the day, if I feel like I've accomplished something and been able to meet – not necessarily set goals – but things I felt were important to accomplish, then I feel like I had a well day."*

Our RRTC found that polio survivors, as well as other people living with disabilities, face not only the health and wellness issues that everyone faces but also some unique challenges that fluctuate based on individual abilities and the societal structure around them. One participant stated, *"...you still have to cope with health and wellness issues that you would if you're able-bodied. I still have periodontal disease. I still have a heart problem ... and (it's) in conjunction with other problems that are normally associated with spinal cord injury, you know, pain, infection, ability to do things."*

The participants identified personal attitudes and overall mental outlook as one of the key factors that deeply affects overall quality of health. Another individual noted, *"I think it (having a disability) does affect your self-image. It almost always starts out to be a negative experience. But, I think it can evolve into something that you're proud of – proud of your ability."* They also identified coping strategies, interacting with others with disabilities, participating in physical activity and exercise, working for pay or volunteering, and achieving personal goals as ways to promote and maintain personal wellness.

People in the study also stressed that community support and societal attitudes were vital to their health and wellness. These society-based, external factors

range from being able to enter a downtown bookstore or stay at a nice hotel to receiving financial relief for the added cost of living with a disability, such as tax credits for personal assistance services and equipment and improving insurance coverage for alternative medicine, specialists, and assistive technology.

Like most people, the persons in the study noted a desire to feel like they are valued and supported by family, friends, and health care providers.

Our RRTC on Health and Wellness recommends several strategies for meeting the health and wellness needs of polio survivors, as well as many other people living with disabilities. They include providing access to public facilities, expanding the definition of health for persons with disabilities, creating materials that would educate people with disabilities on how to maintain a healthy lifestyle, and providing training to health care providers about how to meet the needs of people with disabilities.

By taking these first steps, society can move forward in meeting the needs of *all* of its members. ■

POST-POLIO DIRECTORY-2003 will be available after March 1, 2003. The *Directory* lists comprehensive clinics, knowledgeable health professionals, and support groups and is available online at www.post-polio.org/ipn/locate.html.

Print copies are available for **\$8.00 USD** from International Polio Network. Individuals who have prepaid will receive their copies soon after March 1st.

Our Appreciation

Numerous individuals support our mission to enhance the lives and independence of polio survivors and home mechanical ventilator users by promoting education, networking, and advocacy among these individuals and health care providers.

Many choose to recognize important people, past and present, in their lives. Those honored individuals are listed below.

To The GINI Laurie Endowment in memory of ...

Eugene Bieniek	Robert V. Lohse
Bud Blitzer	Thomas S. Marshall Jr.
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To The GINI Laurie Endowment in honor of ...

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Jim and Judy Headley	The St. John Family
Joan Headley	Judy Whitehead
Linda Hilton	Sally Williamson
Anne Horvath	

To The GINI Laurie Endowment from Support Groups ...

Delaware Valley Polio Survivors (New Britain, Pennsylvania)
In memory of Shirley Linfield

Nebraska Polio Survivors Association (Omaha, Nebraska)

Polio Survivors Association (Downey, California)

Polio Survivors Foundation (Reseda, California)

Polio Survivors of Stark County (Hartville, Ohio)
In memory of Marianne Weiss

Post-Polio Resource Group of Southeastern Wisconsin (Milwaukee, Wisconsin)

The Polio Connection (Cincinnati, Ohio)

To The GINI Research Fund in memory of ...

Clarence Astling	Elizabeth & Hugh Jeffery
Mary Lou Burkhart	Bertha Kossman
Mickie Cammerer	William A. Lang
Andrew H. Chudy, Jr.	Gini Laurie
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John G. Griffin	Lawrence William Trotter
Kathy Gustafson	Max Weinstein
Ethel Haft	Marianne Weiss
Kaye Harding	
Harold Horsley	

To The GINI Research Fund in honor of ...

All polio survivors	Frederick M. Maynard, MD
Milan "Doc" Barto	Mrs. Donald (Pat) Miller
Linda Bieniek	Linda Nyhart
Richard Bruno, PhD	Philip Perrine
James DePreist	Jacqueline Perry, MD
Nancy Frick, MDiv, LhD	D. Virginia Roberts
Phyllis Gayman	Gene Santeusano
Kay Gilley	Ed & Karen Slawin
Faye Greenwood	Beverly Smith
Paul Harber	Bill Standrich
Nancy Heiskell	Jean Stephens
Carolyn Jones	Lynne Billiard Warnke
Sister Ann Martin Klee	Emily Wegusen
Roseanne Lasater	Sally Williamson
Donald Peck Leslie, MD	

EDITOR'S NOTE: In the last newsletter, we concluded our series of four articles about polio memories and we have placed them online (www.post-polio.org/ipn/pnn18-4B.html#fin). We also posted on the Internet, the extensive chart – Treatment Approach Options – compiled by one of the authors, Linda L, Bieniek, CEAP. Because the response to the chart was so positive, we decided to publish it for all of our readers. Our goal is not only to explore the problems polio survivors are facing, but also to provide solutions. Our hope is that within these pages you will find interesting and compatible options to explore.

TREATMENT APPROACH OPTIONS

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STRESS MANAGEMENT	BENEFITS	METHOD	GOOD FOR PEOPLE WHO ...	RESOURCES	COMMENTS
Relaxation Techniques -Progressive Muscle -Diaphragmatic Breathing	Improves energy, sleep, breathing, circulation; reduces pain.	Focusing, breathing, stretching, imaging.	... respond well to structure; want to increase their physical energy, feel calm, or reduce their pain; are busy, have active minds, or are sensitive to feelings of others.	Audio/videotapes, books, classes at medical, community, & wellness centers	Research-based health benefits. Can do alone or with others.
Journaling	Clarifies thinking; helps to solve problems & make decisions.	Writing about thoughts, feelings, desires, needs, & experiences.	... like to write or read; are list-makers; are shy, reserved, imaginative, perceptive, or dreamers; need private time to sort out decisions.	Books, workshops, specialty journals www.tcm.com/hr-books/journaling.htm Cameron: <i>The Artist's Way</i>	Private, can do alone or in groups. Person controls depth of subject matter.
Biofeedback	Reduces pain; improves breathing, heart rate, blood pressure.	Focusing, breathing, & visualizing, monitoring changes with machine.	... need structure; are good at following instructions; prefer concrete & logical approaches; or who like technology & visual results.	http://aapb.org www.aabt.org Assn for Applied Psychophysiology & Biofeedback (303-422-8436)	Research-based. Offered at rehab & pain centers. Covered by some health insurance policies.
HeartMath	Improves blood pressure, heart rate, cholesterol levels.	Breathing, visualizing, shifting focus; monitoring progress with computer.	... are active or need immediate relief; seek structured approaches to increase their energy or reduce stress-related medical problems.	www.heartmath.com (800-450-9111) Books, workshops, training, & computer programs Childre & Martin: <i>The HeartMath Solution</i>	Research-based. Used in hospitals & corporations.
Guided Imagery	Strengthens immune system; reduces tension, pain; improves respiration & heart rates.	Visualizing while listening to music or narration; interpreting images.	... are visually-oriented; enjoy movies & plays; are energized by nature; dream or are imaginative; want to develop their intuition.	www.nancyjnapier.com www.healthjourneys.com/guidedimagery.asp www.healthroads.com/gi (877-330-2746)	Research: effective for immune-related conditions. Useful for stress, decision-making, health.
SOLUTION-FOCUSED THERAPIES	BENEFITS	METHOD	GOOD FOR PEOPLE WHO ...	RESOURCES	COMMENTS
Dialectical Behavior Therapy (DBT) Created by Marsha Linehan, PhD	Regulates emotions; reduces distress & therapy-interfering behaviors. Increases self-responsibility, relationship skills.	Training in mindfulness & interpersonal effectiveness skills.	... have had difficulty being in therapy or with interpersonal relationships; are judgmental or emotionally reactive; need structure.	www.phoenixinflight.homestead.com/Linehan.html www.priory.com/dbt.htm (Professional)	Research-based results. Useful approaches & skills for traits that interfere with developing & maintaining healthy relationships.
Hypnotherapy	Shifts beliefs & perceptions; identifies options; builds self-esteem & resources to take action & make positive changes.	Exploring sensory images & affirming language; using symbolic language to engage client; focusing on intentions & positive outcomes.	... have difficulty making changes; value humor, lightheartedness, & playfulness; are sensual or sensitive to external environments. Caution: Useful for trauma work ONLY when client knows how to pace the work, contain overwhelming feelings, & stay grounded in reality.	www.stephengilligan.com www.erickson-foundation.org www.hypnosiscanada.com	Post-polio research: useful results. Clinician needs to be well-trained & integrate into therapy.
Neuro-Linguistic Programming (NLP)	Identifies goals & strategies; improves communications, learning, performance, resourcefulness.	Using sensory observations, language, cognitive-behavioral & hypnotherapy techniques.	... want to achieve results & learn how to improve their work performance, health, & relationships; teaching, training, & interpersonal effectiveness.	Books, tapes, training programs www.nlpanchorpoint.com (800-544-6480) O'Connor: <i>Introducing NLP</i>	Very useful. Does not probe deep feelings; not a "quick fix" for trauma issues.

SOLUTION-FOCUSED THERAPIES, CONT.

BENEFITS	METHOD	GOOD FOR PEOPLE WHO ...	RESOURCES	COMMENTS
Helps in shifting negative thoughts, limiting beliefs, & unhealthy coping behaviors.	Identifying aspects of problems; challenging negative thinking; creating action plans; offering problem-solving skills.	... are "thinkers" and "doers"; tend to see the world in opposites; are cynical & critical or stuck in problematic behavior patterns; want to focus on present-day issues; are emotionally reactive.	Workbooks, workshops, counseling National Assn of Cognitive Behavioral Therapy http://iacp.asu.edu/links.htm	Focuses on thinking, social interactions, & behaviors. Limited in affecting deep feelings; useful with other approaches.

INSIGHT-ORIENTED THERAPIES

BENEFITS	METHOD	GOOD FOR PEOPLE WHO ...	RESOURCES	COMMENTS
Improves self-esteem, communication, & relationship skills; reduces interpersonal conflicts, loneliness.	Discussing issues; strengthening awareness of self & others; setting goals; learning skills; resolving conflicting needs.	... are couples/partners with interpersonal conflicts or sexuality problems; are individuals seeking a life partner or greater satisfaction with their relationships; are willing to learn about themselves & others.	Books, workshops, video/audiotapes www.mastersandjohnson.com www.imagotherapy.com www.aamft.org	Learn skills & insight for health, self-esteem, & relationships. Affects medical, disability, or trauma issues.
Develops insight into behaviors & decisions; resolves inner conflicts; builds self-esteem; improves relationships & health.	Exploring needs, desires. Discussing unconscious motivations & impact of family of origin issues on present-day situation; discovering healthy coping options.	... are curious and want to make positive changes; are insightful or sensitive to others' reactions; are "thinkers" and "doers" wanting to strengthen their ability to be intimate; have difficulty expressing feelings and ideas; value relationships.	www.mental-health-matters.com/treatments/trt_details.php?trtID=54	Important to improve relationships & satisfaction with life. Useful for understanding attitudes.

EXPRESSIVE THERAPIES

BENEFITS	METHOD	GOOD FOR PEOPLE WHO ...	RESOURCES	COMMENTS
Releases feelings & physical tension; improves body awareness & self-esteem; empowers client, increases energy, playfulness.	Expressing spontaneous physical movement with or without sound; connecting to body; reflecting on, discussing, & learning from experiences.	... value dance or music; are affected by sounds; busy "doers" who do not pay attention to their bodies or their feelings; individuals who tend to be compulsive or obsessive; those who want to have fun; have difficulty expressing feelings.	www.adta.org (USA/International) Levy: <i>Dance Movement Therapy: A Healing Art</i> Needham-Constonis: <i>Therapy in Motion</i> Chodorow: <i>Dance Therapy & Depth Psychology</i>	Research: very effective for people with trauma, medical, or disability issues. Can be done in a sitting or lying position; client can use imagination.
Improves self-awareness, cognitive abilities, intuition, safe expression of emotions.	Using art materials; creating spontaneous expressions; interpreting meaning from visual images.	... learn visually and tactilely; enjoy working with their hands or concrete objects; value art, spontaneity, & playfulness; have difficulty expressing feelings.	www.arttherapyincanada.ca Malchiodi: <i>The Art Therapy Sourcebook</i> Allen: <i>Art is a Way of Knowing</i>	Research: increases self-esteem; useful for people with health problems, disabilities, or trauma.
Shifts moods; reduces tension; improves heart rate, breathing, releases endorphins.	Using sounds to evoke feelings, soothe, support, & comfort.	... enjoy or find sounds stimulating, uplifting, or comforting; are private, reserved, shy, or outgoing & active; need control over their environment & support in releasing feelings.	www.musictherapy.org Bruscia: <i>Defining Music Therapy</i> Gaynor: <i>The Healing Power of Sound</i>	Research: good results; useful for people with medical, disability, or trauma issues.
Identify & resolve conflicting needs; strengthens awareness, acceptance, decision-making, & ability to take action. -Gestalt -Parts Work -Internal Family Systems (IFS)	Journaling, drawing, or dialoguing about self: personality characteristics.	... are expressive; value plays, movies, books, character development; are private about their feelings; are very busy or over-committed; have strong, forceful personalities; are sensitive or creative; have conflicting priorities or needs; want to understand reasons for unhealthy coping behaviors.	info@gestalttherapy.org www.selfleadership.org/ifsmode1.htm Stone & Stone: <i>Embracing Our Selves: The Voice Dialogue</i> Cappacchione: <i>Healing the Inner Child & The Well-Being Journal</i> Schwartz: <i>Internal Family Systems Therapy</i>	Parts exercises reveal positive reasons for unhealthy traits. Valuable alternative to worrying & obsessing.

ENERGY-FOCUSED THERAPIES	BENEFITS	METHOD	GOOD FOR PEOPLE WHO ...	RESOURCES	COMMENTS
Focusing <i>Developed by E. Gendlin, PhD</i>	Gain awareness of intuition & body's messages.	Noticing & interpreting sensations, feelings, thoughts, & dreams.	... want to develop their intuition; need to respect their health conditions; discount their physical or emotional needs; have difficulty making decisions; are unaware of their feelings.	Gendlin: <i>Focusing</i> Gendlin: <i>Focusing-Oriented Psychotherapy</i> www.focusing.org (845-362-5222)	Extremely useful self-awareness skills. Serves many purposes.
EMDR: Eye Movement Desensitization and Reprocessing <i>Originated by Francine Shapiro, PhD</i>	Identifies & resolves anxieties, phobias, distress, traumatic memories in contained way.	Visualizing images & moving eyes; expressing feelings; discussing meaning.	... have problems stemming from one incident; have a history of trauma & have a trusting relationship with an ethical, well-trained therapist; know how to use grounding, pacing, & containment skills.	www.emdria.org www.emdr.com Shapiro: <i>EMDR: The Breakthrough Therapy for Overcoming Anxiety, Stress, and Trauma</i> Parnell: <i>Transforming Trauma: EMDR</i>	Research: useful for trauma issues. Health cautions with certain cardiac, respiratory, or neurological conditions.
Energy Therapies <i>Emotional Freedom Technique (EFT) or Thought Field Therapy (TFT)</i>	Reduces distress, anxiety, phobias, physical tension; improves cognitive functioning, stabilizes emotions.	Using fingers to tap or press Chinese medicine points on the body; stating positive intentions; measuring distress levels.	... need immediate relief from distress; are open to exploring different approaches & have a trusting relationship with well-trained, ethical therapists.	www.tftrx.com www.energypsycho.org http://emotionalrelief.org www.meridianpsych.com/methods.htm Gallo: <i>Energy Psychology in Psychotherapy</i>	Clinician needs high level of experience to integrate with content. Can be adapted without tapping for clients who cannot use their hands.
Somatic Trauma Therapy	Reduces highly aroused "fight, flight, & freezing" impulses to trauma triggers.	Employing body awareness, expression of feelings, use of images.	... have endured traumas, surgeries, accidents, medical complications, or diseases; are unaware of body sensations; want to reduce the distress of physical symptoms/pain; need to release blocked feelings.	www.traumahealing.com www.fsu.edu/~trauma/v6i3a3.html www.nwc.net/personal/babette/somatic.htm Rothschild: <i>The Body Remembers</i>	Harvard University research finds effective for treating trauma. Clinicians must be well-trained & support client before & after processing.
TREATMENT PROGRAMS	BENEFITS	METHOD	GOOD FOR PEOPLE WHO ...	RESOURCES	COMMENTS
Trauma Resolution Programs <i>Affiliated with behavioral health or major medical centers or universities. Available in some nations.</i>	Stabilizes & strengthens client's ability to function; provides structure, expertise to resolve unhealthy responses to traumas; builds responsibility.	Assessing effects & triggers of traumas; developing healthy coping skills; creating plans to prevent relapses; using multiple treatment approaches.	... have a history of intense or ongoing neglect or abuse; are at risk medically; are potentially harmful to self or others; are unable to function adequately or to process traumas in outpatient setting; are highly emotional or have difficulties expressing emotions safely.	www.trauma-pages.com www.sidran.org/traumabr.html www.issd.org (Internat'l) www.estss.org (Europe) www.isst.org (Internat'l) www.mastersandjohnson.com http://traumacenter.org www.rossinst.com	High quality programs are extremely valuable. Clinicians need to be well-trained, ethical, & able to understand how emotional & psychological traumas can get replayed in treatment.
Chemical Dependency Programs	Stabilize & manage client's compulsive behavior; increase self-awareness & healthy coping skills.	Teach skills to intervene; learn about underlying needs & how to respond to emotions.	... use alcohol, medication, or illegal drugs to numb their feelings; depend on substances to function, relax, sleep; or cannot function or react harmfully because of usage.	http://helping.apa.org/therapy/alcohol.html (Professional)	Quality of program, staff's boundaries, & training critical to prevent emotional trauma to client.
Chemical Interventions	Relieve emotional pain & cognitive distress; improve mood, functioning, sleep, appetite; increases physical & mental energy & emotional resilience; reduces pain, obsessiveness, & emotional reactivity.	Using drugs prescribed by MD/DOs; taking medication to stimulate & balance the brain's chemistry, replenishing its neuro-transmitters depleted from trauma or accumulated stress.	... have difficulty sleeping, eating, remembering, concentrating, managing emotions, or lacking energy, and/or feeling hopeless for extended period of time; whose anxiety, depression, or dissociation interferes with daily functioning or responsibilities; or whose mood changes frequently and/or rapidly.	www.mental-health-matters.com/medication/index.php	Avoid addictive medications & using them to mask feelings. Post-polio research showed that polio survivors with depressive symptoms were under-diagnosed & under-treated for depression.

PARTICIPANTS NEEDED

Fear of falling in older adults has been an area of interest for Kristine Legters, PT, DSc, NCS, for several years and is reflected in a review she wrote in the March 2002 *Physical Therapy Journal* (Vol. 82, No. 3, pp. 264-272) titled "Fear of Falling."

Under her direction, a group of physical therapy students at Gannon University in Erie, Pennsylvania, is doing a study on the fear of falling and health-related quality of life (HRQOL) as they relate to post-polio syndrome.

The fear of falling has not been researched before in polio survivors. The goal of the study is to provide valuable information to health care professionals to help decrease the fear of falling and to improve treatment options for polio survivors.

The survey that will take less than 15 minutes to complete and will be administered via email through the Gannon University website or through the mail. All responses will be strictly confidential. The results of the study will be available to all participants either by email or mail.

To participate in this study, contact Kristine Legters, PT, DSc, NCS, at Gannon University, 109 University Square, PAC 3023, Erie, PA 16541 or legters001@mail1.gannon.edu. ■

2003 CALENDAR

APRIL 26-27 – 13th Annual New Jersey Polio Network Conference, Lafayette Yard Marriott Hotel, Trenton, New Jersey. Featuring John R. Bach, MD, and a selection of workshops. Contact NJ Polio Network, P.O. Box 537, Martinsville, NJ 08836 (201-845-6860, NJPN10@hotmail.com, <http://community.nj.com/cc/NJPNPolio>).

MAY 16-17 – Third Post-Polio Conference: You Can Choose How You Feel, Embassy Suites, Greensboro, North Carolina. Featuring Julie K. Silver, MD. Contact Triad Post-Polio Support Group, 600 Savannah Street, Greensboro, NC 27406 (336-373-1122, Azvvis@aol.com).

AUGUST 22-23 – Michigan Polio Network's 18th Annual Conference, Best Western Midway Hotel, Lansing, Michigan. For polio survivors and caregivers; a special caregiver segment will be offered. For registration forms or further information, call 313-885-7855.

OCTOBER 23-26 – Ninth International Conference on Home Ventilation. "Noninvasive Ventilation: From the ICU to Home." Caribe Royale Resort Suites, Orlando, Florida. Contact IVUN (314-534-0475, www.post-polio.org/ivun) OR the American College of Chest Physicians (847-498-1400, www.chestnut.org).

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