

# POLIO NETWORK NEWS

## IMPROVING QUALITY OF LIFE: HEALING POLIO MEMORIES

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**AUTHORS' NOTE:** *People who live with the residual effects of polio experience varying levels of fatigue, weakness, and pain. For many, managing these challenges involves re-organizing their lifestyles to adjust to changes in health. Individuals unable to make the necessary lifestyle adjustments usually encounter difficulties in their jobs, recreational activities, daily routines, and/or relationships. In addition, some may experience intense reactions to these difficulties, causing upheaval in their lives and those of loved ones.*

*In this article, we invite polio survivors to consider how polio memories of various types can affect present day responses to changing health needs. We focus on the value of resolving polio memories that may consciously or unconsciously interfere with survivors' ability to make positive life choices.*

*If you find this article unsettling, we encourage you to read it in sections or with the support of a counselor, psychotherapist, or trusted friend.*

While it is common for individuals to experience frustration or discouragement with the loss of physical function, unresolved memories from the original polio experience may amplify the intensity of their emotional responses. Some individuals live with traumatic memories of physical, emotional, or psychological injuries that have impaired their view of the world (Hale, 1996). Others may not have specific polio memories or traumas, but acknowledge the ongoing stress of coping with disability as a child, and now as an adult.

### PROTECTIVE COPING PATTERNS

Over the past decade, health care professionals have studied the coping patterns of individuals with chronic pain and the fears that block their taking steps to manage it (Asmundson, 1999). Such studies may shed light on the coping patterns of polio survivors. Though they report symptoms related to the late

effects of polio, many are reluctant to consult specialists. A post-polio specific study reports that even when they do consult physicians, 50% of surveyed survivors had complied with their doctor's recommendations to use assistive devices (Thoren-Jonsson & Grimby, 2001).

The reasons for avoidance vary and they are important to understand. Some survivors experience anxiety as they approach a medical facility or attempt to wear a nasal mask. Some individuals are unaware of the cause for their feelings of inaction; others are reluctant even to discuss their reactions.

Survivors may cope with past polio experiences by not thinking about that period of their life. Blocking out memories is a common way of protecting against uncomfortable feelings such as sadness, anger, or disappointment. Survivors may unconsciously avoid certain

thoughts, feelings, people, or places through distractions such as:

- Overworking or taking care of others to the detriment of their own health;
- Overeating or unhealthy eating;
- Depending on or overusing alcohol or prescription or non-prescription drugs to reduce pain, relieve anxiety, or to sleep;
- Excessively watching television, spending time on the computer, sleeping, reading, or talking;
- Neglecting responsibilities (e.g., routine health care, medical claims) because these may trigger unconscious painful reactions.

Schiraldi points out that continually blocking out memories requires enormous energy that can leave one fatigued and irritable (Schiraldi, 2000). He adds, "trying to avoid or forget traumatic memories does nothing to neutralize them. In fact, the more we fear and flee them, the more negative energy we give them (Schiraldi, 2000)."

The energy spent avoiding uncomfortable thoughts and feelings

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can strain a person's physiology and immune system, increasing fatigue and susceptibility to other illnesses.

Another reason survivors may avoid questioning the effects of early polio experiences is that they may feel protective of the loved ones who sacrificed a great deal to care for them. The intent of reviewing polio memories is not to criticize or blame others, but to enlighten survivors about how their polio histories affect their present day choices.

Schiraldi says that traumatic memories may continue to pursue us much like a little barking dog chases a person until that person stops, turns, and faces it. "Facing the dog" is often the first step in finding healthier ways to deal with intense reactions and uncomfortable feelings.

"I was in my late 30's when my leg muscles began to weaken and I needed to wear a leg brace again. I remembered that as a child, I disliked wearing a brace because the only shoes that fit it were 'brown boy's shoes.'

"As an adult, I was surprised that I would not wear my new brace in professional and social settings. I was anxious about how management would react to my physical weakness, and how that might affect my job during a period of significant staff reductions. As a single woman, I feared further rejection from men since my disabilities already appeared to be an obstacle. Nevertheless, I was disturbed about my reluctance to wear a brace when it protected me from tripping and helped to conserve my energy. As an advocate for people with disabilities, I was ashamed that I could not easily accept using equipment that identified me more prominently as a person with a disability.

"In psychotherapy, I worked through my grief about losing muscle strength and feelings about cultural attitudes that impacted my self-esteem. I learned how to forgive myself for fearing the reactions of others. I also uncovered valuable memories. I had not realized how hurt I felt when peers avoided or excluded me."

This example illustrates how past experiences contributed to the survivor's feelings of anxiety and shame when she faced the current day decision about wearing a brace.

It also highlights the benefits of personal permission giving – allowing oneself to acknowledge reality, accept one's needs, and take the steps needed to initiate purposeful changes. For polio survivors, personal permission giving is key to making emotionally healthy changes related to the late effects of polio or other chronic health conditions (Kennedy, 1998).

While the idea of permission giving may sound obvious, it acknowledges the complex dilemmas survivors may face in order to:

- accept the reality of their physical condition;
- acknowledge feelings and express them in healthy ways;
- adapt lifestyles to match their abilities and needs;
- use assistive devices and adaptive equipment;
- seek emotional and practical support; and
- consult effective treatment professionals.

Some survivors have benefited from using psychotherapy to explore the impact of their early polio memories.

"I remember painful experiences during puberty that would further explain my 'shame anxiety' (Bieniek, 2001). I realized that when my schoolmates went to the Boys and Girls Club, I felt excluded.

"In the Masters and Johnson's Trauma Program, I learned to value such memories as 'gifts.' Although painful, they explained reasons for my reactions to current day situations and provided me with hope of resolving social inhibitions that still limited my ability to experience deep intimacy (Westbrook, 1996). Resolving other memories has increased my ability to breathe more deeply, concentrate, exercise, and assert myself in social situations."

In her last two explanations, the survivor illustrates "facing the dog." She faced her reactions to present day dilemmas, and the limiting effects from adolescent social situations.

### MEMORIES OF HAVING POLIO

Experiences of having had polio differ. Many survivors experienced supportive responses from their families, medical communities, and school systems. For some, a sense of community developed in hospital units, leading to life-long friendships. For others, new bonds of support have developed over the last 20 years through post-polio support groups and related organizations.

While many people had supportive experiences, others encountered negative situations including bullying, emotional alienation, humiliation, or even physical abuse.

Because polio is a contagious disease, children were usually hospitalized in isolation, some in iron lungs. Often, they endured lengthy hospitalizations

and subsequent surgeries involving further separations from their families.

Until the early 1960s, little was known about the impact of these experiences on child development. The medical field functioned with an authoritarian approach that did not always take into account the emotional and psychological needs of the child. The system had not yet learned about the important support role that family members could play in the hospitalization and medical rehabilitation of young children.

Today, we know that when children are separated from their primary caretakers, they are at risk of developing attachment difficulties that may affect their ability to maintain healthy relationships in adulthood. Some of the factors that may determine the impact of a separation are the age of the child, what is communicated at the time, and the quality of support in the parents' absence (Lieberman, 1987). Attachment difficulties in adulthood relate to problems forming and maintaining long-term intimate relationships as in the following example.

A survivor reported that, as a child, she was hospitalized for polio far away from home. Her parents were unable to travel the distance, so she rarely saw them. When she would cry for her parents, the staff labeled her crying as being "weak." As an adult, she fought similar feelings of intense loneliness. Through psychotherapy, she identified the impact of the staff's mistreatment and the separation from her parents on her present difficulties of consulting health professionals,

expressing emotions, and developing intimate relationships.

Painful medical procedures, unsuccessful surgeries, discrimination, abuse, and the loss of friends who died from polio are all examples of disturbing experiences that may, consciously or unconsciously, deter individuals from pursuing medical and emotional assistance.

Many people have forgotten much of their polio experience; some were too young to remember. When they understand the possible reasons for feeling anxious or avoidant, survivors may find it easier to seek the assistance they need. The following questions may help survivors remember how they perceived what happened to them.

- How did you and your family respond to your having polio?
- Was it openly acknowledged, a "family secret," or avoided?
- How did you and others respond to your physical pain?
- How did others react towards you after your initial recovery?
- Did any event leave you feeling disappointed or abandoned by family, friends, medical professionals, educators, or God?

As individuals deal with the late effects of polio, they may encounter smells, sights, tastes, sounds, or experiences that cause emotional reactions, reminding them of when they had polio. Memories are often repressed until an unconscious trigger takes the survivor back in time. Triggers are cues coming from either the external environment or internal unconscious reactions related to past trauma (Napier, 1993).

For example, an adult survivor recently reacted with pleasure to the smell of the plaster when having a leg brace fitted. It reminded her of when she was eight years old and was able to walk with a leg brace after a successful surgery. For her, the smell of plaster represented a positive association.

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## **International Polio Network**

**Polio Network News** (ISSN 1066-5331)  
Winter 2002 ■ Vol. 18, No. 1

*An international newsletter for polio survivors, health professionals, and resource centers to exchange information, encourage research, and promote networking among the post-polio community.*

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COORDINATED AND PUBLISHED BY:  
Gazette International Networking  
Institute (GINI)

EDITOR: Joan L. Headley, MS,  
Executive Director

GRAPHICS/ASSISTANT TO THE EDITOR:  
Sheryl R. Prater

SPECIAL THANKS TO: Marcia Kaplan, MA

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Triggers, however, are often unconscious cues that can cause intense negative reactions out of proportion to the current reality. The association may be obvious or subtle (Schiraldi, 2000). For example, grief triggers often relate to dates, seasons, holidays, memories relating to the age of a child in one's life, rituals, or music (Dayton, 1997). As the following example illustrates, a trigger may take the form of a bodily reaction, even though the person may not understand the reason (Napier, 1993).

"As an adult, when I would get into a swimming pool or lake, I would tense up, get short of breath, and, at times, have an anxiety attack. In therapy, I began to look at early polio memories and realized that my intense reaction stemmed from a hospital experience. When I was five years old, my polio treatment involved hot baths. One evening, a nurse left me alone in a bathtub, suspended on a net with water up to my chin. I was unable to move and had no way to call for the nurse, who had closed the door. I remember praying that I would not drown.

"Once I worked through the feelings and beliefs associated with that terrifying experience, I was able to get into a pool of water and breathe freely. Since then, exercising in warm water has become my most valuable form of exercise and a great source of comfort and energy."

Triggers are opportunities for survivors to understand the sources of their internal reactions, especially those that create obstacles in their health and relationships. However, even when triggers are not completely resolved, recognizing their sources can help in identifying ways to protect one's vulnerabilities.

## EFFECTS OF TRAUMA

Distressing events or experiences, whether subtle (e.g., a child's interpretation of a parent's facial expression) or blatant (e.g., terrorism that kills thousands), can have traumatic effects when they threaten basic needs to be safe, to trust, to feel some control over one's life, to be valued, and to feel close to others (Saakvitne & Pearlman, 1996).

People react differently to threatening events or experiences. For some individuals, their polio experiences may feel as traumatic as living through a war or natural disaster. The aftereffects can result in clinical conditions. On a continuum, the effects can range from mild anxiety and/or depressive symptoms to panic attacks, obsessive/compulsive behaviors, chronic and/or severe depression, post-traumatic stress disorder, and dissociation. When reactions are severe they can result in feelings of helplessness or being stuck, and an inability to function in certain areas of life.

Post-Traumatic Stress Disorder (PTSD) is a medical condition that can arise immediately after a trauma or perceived threat, or be triggered many years later. PTSD frequently takes the form of intrusive thoughts or memories (e.g., nightmares, recurrent dreams, flashbacks), hypervigilance, isolation and withdrawal, and numbing of feelings (DSM-IV, 1994).

A common example of dissociation is how children block out distressing events from their conscious minds in order to cope. For survivors, dissociation often takes the form of blocking physical pain to avoid overwhelming

feelings such as helplessness and hopelessness.

Stephen Levine recognizes that "... Accidents, falls, illnesses, and surgeries that the body unconsciously perceives as threatening are often not consciously regarded as outside the range of usual experience. However, they are often traumatizing (Levine, 1997)."

In working with a therapy client who suffered from panic attacks, Levine discovered that the cause was a disturbing childhood memory. The experience resurfaced in the form of intense physical and emotional reactions to being in a crowded room while taking a graduate exam.

"When she was three, she was strapped to an operating table for a tonsillectomy ... Unable to move, feeling suffocated (common reactions to ether), she had frightening hallucinations. This early experience had a deep impact on her ... (Levine, 1997)."

Over time, in her therapy sessions, Levine helped this woman to remember and discover the reason for her panic attacks. Gradually, she noticed her anxiety decrease and she was able to learn constructive ways to manage what remained of it.

Each individual will respond uniquely to a traumatic experience based on factors such as personality, self-esteem, level of emotional support, and past experiences of trauma. For this reason, responses to threatening experiences or the perception of a loss of safety can differ, even to the same event. While learning from others' experiences is useful, judging and comparing oneself with others can undermine self-esteem and relationships.

Individuals need to approach themselves compassionately in order to resolve traumatic memories effectively. The very fact that individuals have survived having had polio reflects the depth of their inner strength.

### **MAKING SENSE OF TRAUMA**

Earlier interpretations of events, especially those formulated during childhood, can result in traumatic perceptions. When the facts are explored, some individuals have discovered that their perception of an experience was different from the original intent, as in the following example.

A six-year-old boy who was hospitalized for one year due to polio perceived that his mother had abandoned him and carried this sense of abandonment with him into his adult life. In therapy as an adult, he learned that at the time of his polio his father was serving in the military overseas. His young mother lived six hours from the hospital without a vehicle and was parenting two small children with no family support.

He eventually realized that his mother had, in fact, done the best she could during that difficult time. Through counseling, he was able, over time, to express and process his feelings of grief, hurt, and abandonment. This allowed him to connect with the truth of the original situation and to begin to build trust in intimate relationships.

While previous examples have revealed actual mistreatment and incompetence that have caused great distress to survivors, the above situation points out how even a perceived threat or loss can have a traumatic impact.

“Children can be traumatized by events that might not be overwhelming to an adult because children’s minds, especially in the very young, lack the capability to process the experiences. Many of our traumas remain hidden from us until our minds or bodies give us hints that something is wrong. Scientists have found that we not only store traumatic memories in our minds, but in our bodies as well. As adults, people may have totally forgotten the trauma they experienced as children, and start therapy because they are having nightmares or flashbacks of events they do not recall, or because they are feeling depressed (Finney, 1995).”

From these examples, we can see that even well-intentioned actions can result in harmful long-term consequences. The

goal of exploring past memories is to gain insights that lead to concrete solutions for resolving complex difficulties in life.

### **RECOGNIZING THE NEED TO SEEK PROFESSIONAL ASSISTANCE**

Psychologist Gary Schoener, an international expert on professional boundaries, recommends the use of behavioral health professionals just as we consult specialists in other fields. Schoener suggests seeking professional assistance from a competent, ethical therapist when:

- facing personal difficulties that appear unresolvable;
- feeling emotionally stuck over a long period of time;
- reacting intensely and out of proportion to the reality of present day situations;

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**LINDA L. BIENIEK, CEAP**, is a Certified Employee Assistance Professional, whose knowledge of trauma issues stems from over 15 years of professional training as well as from participating in Master and Johnson's Trauma Programs. As a CEAP, she assesses, counsels, and refers clients with a wide-range of conditions including depression, post-traumatic stress, dissociation, and chemical dependency.

Bieniek previously worked for a major corporation, managing its Employee Assistance Program and often negotiating accommodations for employees with and without disabilities. Bieniek is a polio survivor, ventilator user, and disability advocate who serves on GINI's Board of Directors.

**KAREN KENNEDY, MSW, RSW**, is a registered medical social worker who, for the past nine years, has worked in the Post-Polio Clinic at West Park Healthcare Centre in Toronto, Ontario. West Park Healthcare Centre is a regional rehabilitation centre and offers rehabilitation, complex continuing care and long-term care services.

As a member of the Post-Polio Clinic team, 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.

*The authors recently co-presented at the Ontario March of Dimes Post-Polio Wellness Retreat.*

- having difficulties making changes that would improve an aspect of life such as physical or emotional health, cognitive abilities, relationships, or sexuality;
- becoming aware of unhealthy coping patterns such as compulsive eating, shopping, smoking, gambling, cybersex, or depending on alcohol or medications to relax or to sleep;
- receiving feedback from others that reveals difficulties adjusting to health changes.

Consulting professionals is especially important when a person recognizes any of the following signals:

- increased pain, weakness, and fatigue due to increasing distress (Westbrook, 2000);
- persistent feelings of frustration or irritability;
- isolation and withdrawal;
- loss of interest in pleasurable activities (including sexual intimacy)
- increased difficulty functioning in the workplace;
- feelings of worthlessness or hopelessness (Bieniek, 1999);
- overwhelming feelings of anger, sadness, fear, despair, shame, or guilt;
- nightmares or recurrent distressing dreams;
- anxieties, panic, phobias, and fear responses that interfere with functioning;
- acting or feeling as if a previous disturbing event were recurring (DSM-IV, 1994);
- persistent avoidance of thoughts, feelings, or topics that remind you of a distressing time in your life.

Always obtain regular medical evaluations to rule out the possibility that other medical conditions are causing your symptoms.

### TAKING STOCK

Survivors may want to ask people they trust for their perceptions with questions like these:

- How do you think I am functioning and adapting to my changing physical needs?
- How would you describe my ability to accept assistance from others?
- How do you think I respond to my physician's recommendations?

One essential and healing component of revisiting past memories is that it provides survivors with an opportunity to tell their story, sometimes for the first time.

In *Healing the Blues*, polio survivor Dorothea Nudelman and her therapist described her struggle for wholeness. Dorothea wrote:

"We often resist the pure telling of our story. We want to tell the story as we think it should be and edit out the parts that make us uncomfortable. But this doesn't work. We must be honest and complete. We must acknowledge even the parts we don't like. In fact, where we have the most resistance is exactly where special attention is needed. Our resistance signals where we may discover the most important things about ourselves. There is no part of ourselves we can afford to discard. Every part is crucial for wholeness and has value to us. When we review our life thoroughly, we return to the present

with a renewed sense of meaning and possibility. We catch up with time, as it were, by finishing what is past (Nudelman & Willingham, 1994)."

**AUTHORS' END NOTE:** We have focused on how exploring polio memories may reveal reasons that survivors have avoided seeking help or following up with medical recommendations.

We encourage readers to use the aspects of this article that apply to their lives. We believe that understanding the effects of early experiences can provide insight that offers hope of making positive changes in current life situations. These changes, in turn, may lead to reductions in pain, healthier personal relationships, less stress, and greater ability to experience comfort and joy.

A future *Polio Network News* article will provide suggestions for seeking and evaluating professional assistance to look at and learn from polio experiences. ■

*The authors are grateful to the polio survivors, professionals, and authors who have contributed to this article. Their suggestions and comments have enhanced its value.*

### References

- American Psychiatric Association. (1994). *The diagnostic and statistical manual of mental disorders* (4th ed.), (p. 428).
- Asmundson, G. (1999). Fear and avoidance in dysfunctional pain patients: An overview of fear-avoidance models, emerging evidence and clinical implications. *Pain Research & Management* 4(1).
- Bieniek, L. (1999). Recognizing depression. *Polio Network News* 15(3), 1-2.

## CONFERENCE ON RETHINKING CARE

Joan L. Headley, MS, Executive Director, International Polio Network

- Bieniek, L. (2001). Emotional bridges to wellness. *Polio Network News* 17(4), 1-4.
- Dayton, T. (1997). *Heartwounds: The impact of unresolved trauma and grief on relationships* (p. 26). Deerfield Beach, FL: Health Communications, Inc.
- Finney, L. (1995). *Reach for joy: How to find the right therapist & therapy for you* (p. 17). Freedom, CA: The Crossing Press.
- Hale, T. (1996). Spiritual responses to trauma. *Polio Network News* 12(3), 6-7.
- Kennedy, K. (1998). Permission giving: Emotional adjustment and the late effects of polio. *PoliOntario* 5(2), 5-10.
- Levine, P. (1997). *Waking the tiger: Healing trauma* (pp. 24, 28-32). Berkeley, CA: North Atlantic Books.
- Lieberman, A. (1987). Separation in infancy and early childhood: Contributions of attachment theory and psychoanalysis. In J. Bloom-Feshbach & S. Bloom-Feshbach (Eds.), *The Psychology of Separation and Loss* (p. 118). London, England: Jossey-Bass Publishers.
- Napier, N. (1993). *Getting through the day: Strategies for adults hurt as children* (pp. 44, 73-74). New York, NY: W.W. Norton & Co.
- Nudelman, D. & Willingham, D. (1994). *Healing the blues: Drug-free psychotherapy for depression* (p. 201). Pacific Grove, CA: The Boxwood Press.
- Saakvitne, K., & Pearlman, L. (1996). *Transforming the pain: A workbook on vicarious traumatization* (p. 33). New York, NY: W.W. Norton & Co.
- Schiraldi, G. (2000). *The post-traumatic stress disorder sourcebook: A guide to healing, recovery and growth*. Los Angeles, CA: Lowell House.
- Thoren-Jonsson, A.L., & Grimby, G. (2001). Ability and perceived difficulty in daily activities in people with poliomyelitis sequelae. *Journal of Rehabilitation Medicine*.
- Westbrook, M. (2000). An antidote to post-polio stress: Pleasure seeking." *Polio Network News* 16(2), 1-4.
- Westbrook, M. (1996). Disability as a life course: Implications of early experiences for later coping. *Polio Network News* 12(3), 3-6.

In April 2001, I spent three days in Oslo, Norway, at a conference sponsored by the World Health Organization's Disability and Rehabilitation Team. The Norwegian Ministries of Health and Social Affairs, along with the Norwegian State Council on Disability, the Norwegian Association of the Disabled, and the Norwegian Federation of Disabled People, organized the event.

I struggled with how to report on the experience, and the job was not made easier when I recently received the final report (authored by Professor Colin Barnes, University of Leeds, United Kingdom) of 30 pages with six appendices. I decided to explain why we were there, to extract a few comments in an attempt to portray discussions, and to reflect.

### Why were we there?

The conference – "Rethinking Care from the Perspective of Disabled People" – was convened in recognition of the fact "... that health and disability can no longer be understood in purely medical terms and that a more holistic approach is required." This universal challenge to orthodox thinking about medical, rehabilitative, and support services has its roots in the independent living and self-advocacy movements that emerged in the late 1960s. People with disabilities "... began to demand not only greater participation in the organization and running of disability services, but also to develop their own."

The challenge before the group of 100 from all over the world, both disabled and nondisabled, was to rethink how care for

people with disabilities should be provided.

The background papers stated that the terminology of the conference would be of the social model of disability. In the model, impairment refers to an individual's biological condition. Disability denotes the collective economic, political, cultural, and social disadvantages encountered by people with impairments. In other words, going in we were dumping the "... unhelpful assumption that the only way to overcome the disadvantage of disabled people is to change the individual and not society."

### Excerpts from individual presentations

"The concept of care is changing, from being a matter of charity to one of human rights and equal opportunities for all."

– Guri Ingebrigtsen, Norwegian Minister of Social Affairs

"The magnitude of chronic conditions and injuries has increased in all regions of the world, but at the same time, the old problems of poverty, malnutrition, and wars continue to be an important cause of morbidity and mortality."

– Dr. Ala Alwan, Director, Management of Noncommunicable Diseases, WHO

"The beginning for every disabled person is very much the same. It starts with the emotional shock, together with news about 'the disability.' The way this new life starts will affect the future. The notice may be given by an insensitive professional who is discriminative or may be

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given by a professional with humanism, friendship, and knowledge about disability and about resources available within the community.”

– Dra Gabriella Garé Fabila de Zaldo, Mexico

“The healing for me started from my talks with the nurses who wanted to know me as a real person. However, the caring attitude was limited to pre-discharge. On the day of discharge, I was given a wheelchair, which I had never used before.”

– Marjorie January, South Africa

“Very often, women with learning disabilities are asked to undergo sterilization when they are young. The situation also applies to women with chronic illness, like me. After my first heart operation, my doctor told me that I should not have any children even if I was ‘lucky enough’ to get married.”

– Karen Ling, China

“For example, most parents will spend money on treatment but not for the education of the child or for an assistive device which would make the child able to participate in the community.”

– Anika Rahman Lipy, Bangladesh

“We can legislate the right to relief and support, the right to a home and daily activity, but we can never legislate the right to love. The challenge is to encourage society to welcome people with intellectual disabilities and to facilitate their opportunities for friendship. We must put persons with the most severe and profound disabilities on the agenda.”

– Elaine Johansson, Sweden

“Many times, and during social gatherings in particular, a disabled person is declared persona non grata because most people are of the opinion that impairment is a result of numerous sins against the supernatural. The result is loneliness. How long should or must society carry this misconception?”

– Abdul Salim Usman, Ghana

“A society without care is unthinkable. We all need care. However, the care given does not often empower people. It may be the inverse – it may increase helplessness. The most serious threat against care and social development is implied in the frequent saying of today: ‘I don’t care.’

We are indifferent – too many of us do not care! Indifference never leads to understanding. Lack of understanding creates lack of involvement. Human beings live in poverty, in desolation, without dignity, and without self-respect owing to lack of involvement.”

– Lars Ødegård, Norway

“Care can be rethought. It can be re-oriented and approached from actual, and not perceived, needs. This requires the service provider to surrender control. It also means the user must take on more responsibility. I believe the current situation can be improved with increased dialogue. It is surprising how the ‘monster-providers’ are willing to listen and learn.”

– Alice B. Nganwa, Minister of Health, Uganda

“I hope we are able to discuss the kind of ‘support services’ that are appropriate for disabled people. I see such a service

approach developing within what I will call, an ‘aspirational culture,’ i.e., services that are essentially concerned with supporting disabled people to realize their personal aspirations. This is a ‘recipient requested service,’ i.e., the service users request assistance to meet his or her own aspirations and goals. It contrasts with the ‘care’ services which are ‘deliverer determined,’ i.e., the service provider assesses the needs of the disabled person and then decides which services can be provided.”

– Vic Finkelstein, Centre for Disability Studies, University of Leeds, United Kingdom

“We have heard that there is too much emphasis placed on preventive health care at the expense of long-term care. I believe that the bulk of efforts in preventive health care have been targeted at non-disabled persons, and that persons with disabilities, as a whole, have not received the preventive health care they need. In the words of a disability researcher, ‘to talk about wellness in the context of disability is to break the strangle-hold the medical model has had on disability interventions for far too long.’

“The education of health care providers will be key in addressing the problem. Education should include awareness-raising that challenges the assumptions and stereotypes about persons with disabilities. The curricula should be developed in partnership with persons with disabilities. Finally, persons with disabilities should be recruited into the ranks of nursing and other health care professionals.”

– Dena Hassounah-Phillips, Oregon Health Sciences University, USA



"There are differences in how physiatrists and their interdisciplinary rehabilitation teams accept the active role of the 'patient.' The challenge for our organization is to contribute to making this concept an intrinsic part of rehabilitation medicine practice all over the world."

– William J. Peek, International Society of Physical Medicine and Rehabilitation (ISPRM), Netherlands

"I would like to share the sense of discomfort that I feel at this conference where people from low-income and high-income countries share experiences and ideas. I suspect that historians of the future will say that the most terrible inequality in our current historical era was the enormous gap in wealth between low-income and high-income countries, though I fully acknowledge the terrible inequalities that occur within countries."

– Mary O'Hagan, New Zealand

### Reflections

I, too, was uncomfortable with the disparity of income of the attendees. There are numerous ways to frame it, but since we were talking about health care, I was struck by the fact that our organization pays a monthly fee for private health insurance for a three-person office that is almost four times the annual income of a person living in Bangladesh. It was appropriate that O'Hagan made the comment in the formal meeting, as several of us had discussed it privately. Since I was from the United States, I was in the minority and that was a learning experience for me.

I also was struck by the universality of the points made by

the participants. At times, I felt as if I was back in Missouri at a Governor's Council on Disability meeting, in which a specific disability group would strongly advocate for their special problems, followed by pleas from several other disability-specific groups, followed by a plea from someone that we need to "all stick together." I absolutely concur with the final report and acknowledge our many areas of agreement.

But, the reality is that our solutions can be opposing. The individuals with a psychiatric disability want policies that do not require long hospitalization, particularly without their consent. Individuals with a new spinal cord injury, in many cases, are being sent home without appropriate rehabilitation and support services.

I met very talented people from all regions of the world. It was exciting to make those connections and discuss how we could work together. Since my return to Saint Louis, I have periodically communicated with several of the attendees, but, as so often happens, we become occupied with budgets, editing, speaking, and email viruses – all of those major activities and minor irritations we face in advocating for people with disabilities.

I know there was and will continue to be positive consequences from the meeting, but I am most excited (and consoled) by the memory of those talented people, each doing tremendous work in their part of the world. ■

For a copy of the report, contact Eva Sandborg, Technical Officer, Disability and Rehabilitation Team, World Health Organization (+41 22 791 48 74 fax, sandborge@who.ch).

## POST-POLIO BIBLIOGRAPHY

Chang, C.W., & Huang, S.F. (2001). Varied clinical patterns, physical activities, muscle enzymes, electromyographic and histologic findings in patients with post-polio syndrome in Taiwan. *Spinal Cord* 39(10), 526-531.

Schanke, A.K., & Stanghelle, J.K. (2001). Fatigue in polio survivors. *Spinal Cord* 39(5), 243-251.

Trojan, D.A., Collet, J., Pollak, M.N., Shapiro, S., Jubelt, B., Miller, R.G., Agre, J.C., Munsat, T.L., Hollander, D., Tandan, R., Robinson, A., Finch, L., Ducruet, T., & Cashman, N.R. (2001). Serum insulin-like growth factor-I (IGF-I) does not correlate positively with isometric strength, fatigue, and quality of life in post-polio syndrome. *Journal of the Neurological Sciences* 182(2), 107-115.

Sunnerhagen, K.S., Carlsson, U., Sandberg, A., Stålberg, E., Hedberg, M., & Grimby, G. (2000). Electrophysiologic evaluation of muscle fatigue development and recovery in late polio. *Archives of Physical Medicine & Rehabilitation* 81(6), 770-776.

During the last year, three articles about post-polio problems were published in nursing journals that reach a large percentage of practicing nurses. (See article on page 10.)

### Nursing Journals

Chasens, E.R., et al. (2001). Nocturnal problems in post polio syndrome: Sleep apnea symptoms and nocturia. *Rehabilitation Nursing* 26(2), 66-71.

Chasens, E.R., & Umlauf, M.G. (2000). Post-polio syndrome: Symptoms resurface in polio survivors. *American Journal of Nursing* 100(12), 60-65.

Harrison, T., & Stuifbergen, A. (2001). Barriers that further disablement: A study of survivors of polio. *Journal of Neuroscience Nursing* 33(3), 160-166. ■

## MAXIMIZING HEALTH FOR SURVIVORS OF POLIO – EARLY FINDINGS

Alexa Stuijbergen, PhD, RN, FAAN, The University of Texas at Austin School of Nursing, Austin, Texas

*Dr. Stuijbergen, Professor at The University of Texas at Austin School of Nursing and Associate Dean for Research and Director of the Center for Health Promotion Research in Underserved Populations, has conducted research for about 15 years with persons who have multiple sclerosis. When her new study, funded by the National Institutes of Health, included a study of polio survivors, she contacted International Polio Network (IPN) in 1999 for assistance with locating polio survivors. Stuijbergen mailed questionnaire packets to 2,302 subscribers of Polio Network News and received 2,153 completed questionnaires – a remarkable 93.5% response rate.*

The participants in our study, Maximizing Health for Survivors of Polio, were primarily recruited through IPN, so the findings represent this group of respondents and not a random sample of polio survivors. It is also important to remember that your individual experience can be very different.

The average age was 62 years, approximately half were age 41-60, and half were over age 60. The majority (69%) were female and married (67%). Almost all of the participants had completed high school and 49% had completed at least four years of college. Only 20% of the respondents were still employed full time. Most participants (65%) reported that they had originally had spinal polio involving weakness in the arms, legs, and back; 23% reported both spinal and bulbar polio. Twenty percent of those responding to the questionnaire were under age two when they had polio; 64% were age 10 or younger.

Compared to their own physical best, many reported that during the last five years they had experienced either quite a bit (29%) or a great deal (29%) of a decrease in their ability to carry on their normal activities of daily living. Of those responding, 76% said they had been

diagnosed as experiencing post-polio syndrome and 69% had been diagnosed as having the late effects of polio. Those who had been diagnosed with post-polio syndrome tended to report more barriers to taking care of their health, more depressive symptoms, greater physical impairment, and they perceived their quality of life less positively compared to those who had not been diagnosed with either post-polio syndrome or the late effects of polio. Again, there was a tremendous amount of individual variance.

There were many questions about health practices – nutrition, physical activity, stress management and social support, because the research focuses on how these health behaviors can positively impact a person's quality of life. Overall, the scores on the measures of health promoting behaviors were not very different from the scores of the large samples of persons with MS or other persons residing in the community.

The one major area of difference was in the scores on physical activity. Some individuals wrote on the questionnaire that persons with post-polio syndrome cannot exercise and that these questions should not be asked. I would like

to emphasize that while it is important to not “overdo” and engage in overly strenuous exercise, staying physically active is very important to all persons.

Only 40% of the respondents did stretching exercises, only 16% engaged in light to moderate physical activity, and 15% engaged in leisure-time physical activities. These findings are very important – inactivity can lead to many other problems that are related to deconditioning. If you are experiencing pain or fatigue, you may find that engaging in some type of activity – a stretching program, swimming, gentle exercise, or some type of adaptive activity – may help. You should consult with your physician or a physical therapist to determine what is right for your individual situation.

One of the findings from this study is that the practice of positive health behaviors (stress management, keeping as physically active as possible, engaging in supportive relationships, maintaining a positive attitude, and eating a healthy diet) can mediate the effects of impairment and disability on quality of life. That is, some persons who have more severe impairment and who practice health promoting behaviors more frequently will perceive their overall quality of life more positively and have fewer depressive symptoms than those who do not practice these behaviors.

During the last year, three articles about post-polio problems were published in nursing journals that reach a large percentage of practicing nurses. (See listing on page 9.) ■

# PILOT STUDY ON THE EFFECTS OF CREATINE ON MUSCLE STRENGTH

Sophia Chun, MD, Rancho Los Amigos National Rehabilitation Center, Downey, California

## SUMMARY

The purpose of the study was to analyze the effect of creatine on measured quadriceps strength and endurance, walking velocity and subjective fatigue, and recovery time in symptomatic post-polio syndrome subjects.

## METHOD

Twelve polio survivors were randomly assigned to either the creatine (C) or the placebo (P) group. Seven subjects in the creatine group received 10 grams for 5 days, followed by 5 grams per day of pure creatine. There were 5 subjects in the placebo group. One subject in the creatine group dropped out of the study, with a net of 6 subjects.

The following outcome measures were obtained for each of the subjects at baseline, at 1 week, and at 4 weeks: maximum knee extensor (quadriceps) strength, quadriceps recovery time, 6-minute walk distance, fatigue survey results, and weight.

## RESULTS

*At week one:* There was a measurable decrease in knee extensor strength in both the creatine and the placebo group.

*At week four:* In the creatine group, there was an average increase of 12.25 ft/lb (5-18) absolute knee extension torque in those (N=4) who had 3+ manual muscle grade (about 25% normal muscle strength). Torque to weight ratio was calculated. All subjects that experienced increase in measured muscle strength had an average

of 33.2 (28-37.6) torque to weight ratio (Q/T ratio).

Creatine group subjects with manual muscle test of 4+ and 5 (grade 4 is about 40% normal muscle strength) (N=2) did not show any improvement in maximum knee extensor strength. Both subjects showed decrease in measured knee extension torque at 4 weeks. However, it is noteworthy that both subjects reported subjective improvement in their post-polio syndrome symptoms while on creatine.

In the placebo group, two of the five subjects showed no change in knee extensor strength at four weeks. One subject gained absolute torque of 17 that was negated by another subject that lost an absolute torque value of 17. Unlike the creatine group, there was no correlation of Q/T ratio and strength gained or lost in the placebo group.

There were no significant side effects from a four-week continuous administration of creatine. Two of the six subjects experienced minor GI symptoms.

Fatigue scores did not correlate with gain or loss of knee extensor strength except in the creatine group; the subject with the largest percent gain in knee extensor strength had the greatest increase in fatigue.

Recovery time was not affected by creatine.

## CONCLUSION

Creatine supplement seems to measurably improve the strength of manual muscle grade less than 3+ in post-polio muscles with very minor side effects, which

was measurable at 4 weeks. This improvement in strength may contribute to the subjective feeling of improvement in post-polio syndrome symptoms. However, it is also noted that subjective improvement may lead to increase in physical activity thus resulting in increase in fatigue.

It was also noted that at one week all the subjects had decline in strength, which may be due to the delayed recovery resulting from the baseline testing exertion of the same limb.

## FUTURE STUDIES

Further studies that may be pursued for creatine and post-polio syndrome pending research funding include:

1. Larger study with more subjects with muscle grades of 3 to 3+ (i.e., muscles that are at least able to resist gravity to those muscles that are able to resist two-finger resistance)
2. Long-term study looking at the progression of post-polio syndrome with and without creatine.

## COMMENT

Creatine does appear to provide an "edge" or slight advantage to muscles that under maximum or super maximum demand, such as in the case of weak (e.g., 25% of normal) post-polio affected muscles that are put under maximum demand for activities such as walking. This may be the reason that creatine has shown effectiveness in athletes who are also putting their "normal" muscles under maximum demand for training purposes. ■

GINI appreciates the donations from these support groups ...

... to The GINI Research Fund.

Greater Boston Post-Polio Association

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Sacramento Post-Polio Support Group

... to the Gini Laurie Endowment.

Tri-State Polio Survivors, Inc.  
(Sioux Falls, South Dakota)

Florida East Coast Post-Polio  
Support Group

Post-Polio Resource Group of  
Southeastern Wisconsin

**Deadline for application to  
The GINI Research Fund:**

**March 1, 2002**

[www.post-polio.org/gini/grf-1.html](http://www.post-polio.org/gini/grf-1.html)  
or contact Carol A. Cox at IPN.

## 2002 Calendar

**APRIL 27-28 – 12th Annual Conference of New Jersey Polio Network,** Princeton Marriott Forrester Village, Princeton, New Jersey.

Key speakers are Frederick M. Maynard, MD and Judith E. Heumann. Contact Jean Csaposs (201-845-6860, NJPN10@hotmail.com) or visit <http://community.nj.com/cc/NJPNPolio>.

**MAY 21 (8 am-6 pm) – Post-Polio Syndrome: Improving Quality of Life with Teamwork,** Conference Center at University of Pittsburgh at Johnstown, Pennsylvania.

CEUs available. Contact 814-269-2948, 814-269-2966 fax, or visit [www.pitt.edu~cscoun](http://www.pitt.edu~cscoun).

**JUNE 23 (1-4 pm) – Symposium on Post-Polio Syndrome,** Schaezel Center, Scripps Memorial Hospital, La Jolla, California.

Speakers include Susan Perlman, MD; J. Lindsay Whitton, MD, PhD; and Sam Pfaff, PhD. Contact Mary Clare Schlesinger (760-741-5075, [maryclare@cox.net](mailto:maryclare@cox.net)).

**SEPTEMBER 21 – Post-Polio Conference – 2002: We're All in This Together,** Four Points Sheraton, Milwaukee, Wisconsin.

Speakers include Frederick M. Maynard, MD and Joan L. Headley. Contact Post-Polio Resource Group of Southeastern Wisconsin (414-454-9093, [www.pprg.org](http://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](mailto:mjbarnett@att.net)).

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