

# POLIO NETWORK NEWS

## MOUSE MODEL DEVELOPED FOR POST-POLIO RESEARCH

In the winter of 2001, Burk Jubelt, MD, and Jeremy Shefner, MD, of Upstate Medical University, Syracuse, New York, and Rob Morris, who had polio as an infant, sat down to discuss the existing therapeutic alternatives for the array of symptoms seen in post-polio syndrome.

(See box, page 2.)

It was clear that the current therapies are supportive and decrease weakness, pain, and fatigue, etc., rather than halt or reverse the underlying pathology, or the cause.

Eventually, the conversation turned to the relatively recent developments in regenerative and neuro-protectant medical research. The obvious question was whether or not some of that work might be applicable to post-polio syndrome. The conclusion was that, in theory, certain combinations of pharmaceuticals, nerve growth factors,

and cellular therapies might result in useful therapies. However, in order to test any of the new therapies a reliable animal model of post-polio syndrome would have to be created, as trying such therapies first on human subjects would be unethical.

Morris agreed to provide funding for a research proposal crafted by Jubelt, Rapka, and Shefner to develop a post-polio mouse model. A group of mice were infected with the polio-virus and then the researchers compared their neurological development with that of a group of mice that were not similarly infected with the poliovirus (a control).

The plan was to follow the mice for over a year and measure both their level of nerve damage and muscle function. Then, other studies would be performed on the mice to examine the three principal theories of the pathology of post-polio syndrome.

*Degenerative theory*, the most widely held theory, postulates that the new sprouts which grew to substitute for the sprouts killed by the original infection are dying back due to exhaustion from increased metabolic demand over years of use.

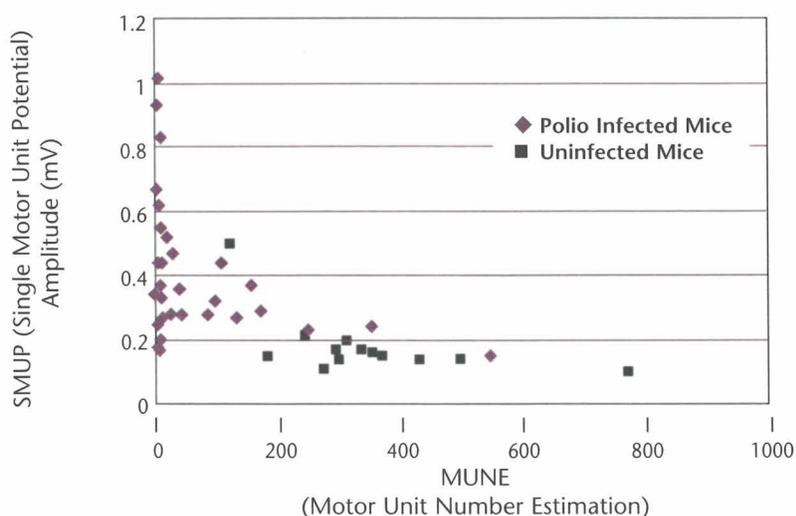
*Viral theory* hypothesizes that the old poliovirus has either lain dormant in the central nervous system or mutated into a form that is slowly destroying nerve tissue. No conclusive evidence for this theory has ever been established.

*Immune mediated theory* implies that inflammation or an auto-immune mechanism has led to the symptoms. Empirical evidence for this theory has been contradictory.<sup>2</sup>

An abstract published by Drs. Jubelt, Rapka, and Shefner in *Neurology* (Apr. 1, 2002, Suppl. 3) indicates that the mice exhibited electromyographic patterns similar to that seen in individuals with post-polio syndrome. (See figure 1.) The mice had a decreased number of motor units (*MUNE* in Figure 1), and the remaining units were enlarged (*SMUP Amplitude* in Figure 1). Additionally, degenerative neurologic changes were seen

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Figure 1: MUNE vs SMUP Amplitude



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in both symptomatic and asymptomatic mice.

During the summer of 2002, the mice were sacrificed and analyzed for inflammatory and viral evidence. The results of this work and the final EMG studies are expected to be

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Research Program. Dr. Jubelt has researched post-polio syndrome for 18 years.

### **The criteria for the diagnosis of post-polio syndrome (PPS) include:**

- ◆ A prior episode of poliomyelitis with residual motor neuron loss (can be confirmed by typical history, neurological examination, or electromyography);
- ◆ A period (usually  $\geq 15$  years) of neurologic and functional stability after recovery from the acute illness;
- ◆ The gradual or rarely abrupt onset of new weakness or abnormal muscle fatigue, muscle atrophy, or generalized fatigue; and
- ◆ Exclusion of other conditions that could cause similar manifestations.

completed and submitted for publication this fall.

Additional funding allowed the researchers to inoculate more mice to create a population of mature mice, analogous to a 40-year or older human experiencing post-polio syndrome. These mice will ready for further testing after additional funding for test materials is raised.

Dr. Jubelt commented, "We are very excited about the potential for the mouse model. We should be able to sort out

the cause of the late weakness seen in post-polio syndrome. Once the cause is sorted out, many options are available for possible therapeutic benefit. The model will allow us to test these different therapies." ■

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2. Jubelt, B., & Cashman, N.R. (1987). "Neurological manifestations of the post polio syndrome" *Crit. Rev. Neurobiol.* 3, 199-220.

## **EDITOR'S COMMENTS**

Were you confused by the West Nile Virus headlines? In late September, the headlines reported that individuals diagnosed with West Nile Virus (WNV) infection demonstrated poliomyelitis symptoms. Why "poliomyelitis?" Because WNV attacks the anterior horn cells of the spinal cord, the same nerve cells attacked by the polio-virus – different virus, same nerve cells – thus a "poliomyelitis."

While the complete picture is not known, the WNV is transmitted through blood and public health officials recommend that we, specifically polio survivors, remain personally vigilant by wearing DEET-containing

mosquito repellent and in clearing containers of water around our homes during mosquito season in whatever part of the world we live.

The Social Security Administration (SSA) in the States reviewed a number of claims for SSDI (social security disability insurance) by polio survivors and found that further training of its adjudicators was needed. The training has been given and SSA is now working on a ruling addressing post-polio sequelae. The ruling, which has the power of a regulation, and, therefore, must be followed by everyone, should be completed within a couple of months. The neurological listings are also being reviewed and revisions are to be expected.

At the moment, refer to the SSA's Program Operations Manual System (POMS) for Evaluation of the Late Effects of Poliomyelitis [DI 24580.010E.3].

The Chronic Disease Self-Management Program lay leader training session in August of 2002 was a huge success. Check out [www.post-polio/calendar](http://www.post-polio/calendar) for the dates of future classes to be taught by the newly trained leaders or call Justine at 314-534-0475 to receive a copy of the list.

I trust you have gotten your flu shots.

— Joan L. Headley, MS  
Executive Director, GINI

# PURSuing THERAPEUTIC RESOURCES TO IMPROVE YOUR HEALTH

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

Leaders in the post-polio community point to critical factors that can empower polio survivors to manage the effects of their polio and optimize their health. They recommend obtaining reliable information; cultivating strong support systems, including partnerships with health professionals; and developing positive attitudes, new skills, and an ability to enjoy the present (Maynard, Headley, 2002).

Even when following these recommendations, people sometimes continue making choices that are harmful to their health and relationships (Thoren-Jonsson, & Grimby, 2001). Why? Research has revealed that unresolved polio memories can interfere with the ability to make changes – physical, emotional, cognitive, and even spiritual – that contribute to health and well-being (Westbrook, 1996). Survivors have reported improvements in their health and relationships following successful experiences in therapy.

This is the last in a series of articles in *Polio Network News* exploring this phenomenon and the value of psychotherapy as an option for resolving the impact of polio memories. This article is designed to assist in the following ways:

**For individuals interested in pursuing psychotherapy**, this article recommends four steps for identifying and selecting qualified professionals.

**For individuals currently working with a therapist**, these same guidelines can help in assessing the effectiveness of their own therapy.

**For survivors with limited financial resources**, a separate section (page 9) contains suggestions about other resources to pursue, including publicly and privately funded services.

Bieniek has created a 3-page “**Treatment Approach Options**” chart that describes various styles of treatment, the benefits and methods of each, characteristics of people who may find a particular approach appealing, and available resources. The chart offers useful suggestions on ways to reduce the stress of physical symptoms and present-day problems. It is available on [www.post-polio/ipn](http://www.post-polio/ipn) or upon request from those who send a self-addressed, stamped (37¢ USA), business-sized envelope to International Polio Network (IPN).

## UNDERSTANDING THE ROLE OF A PSYCHOTHERAPIST

Individuals who choose to explore psychotherapy as a treatment option need to understand the role of the psychotherapist and the importance of the psychotherapist’s training, knowledge,

experience, and personality in contributing to productive results.

Individuals previously in therapy may have had a disappointing or unproductive experience. As in any profession, the skill level and integrity of therapists varies. Also, a client’s own readiness and willingness to deal with

uncomfortable issues can affect the results of the process.

However, when a therapist’s expertise and personality match a client’s needs, the therapy process and relationship can produce extremely beneficial insights and behavior changes for the client (Roberts, 1998).

Therapy is a blend of art and science. The therapist’s job is to help the client make healthy changes to achieve his/her goals. A therapist is a guide and mentor, responsible for interacting with a client in ways that provide a healthy, safe, professional relationship. For people who have had traumatic experiences, this is especially critical. The understanding insights of the therapist’s responses can help transform the client’s limiting beliefs about self, others, and the world that may have been formed in response to traumatic events in the past (Napier, 1993).

A therapist’s role also includes matching the client’s needs and ways of learning with appropriate responses, interventions, and available resources. For clients who have had hurtful and harmful life experiences, research offers a number of effective approaches that therapists can use.

Clients are not responsible for trying to make their therapists feel good. Reading about professional boundaries is especially advisable for those who have a tendency to feel responsible for another person’s feelings (*Polio Network News*, Summer 2001, Vol. 17, No. 3, p. 5).

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## RECOGNIZING A QUALIFIED THERAPIST

*Look for a therapist who possesses appropriate knowledge, skill, and experience.*

Therapists demonstrate their knowledge and skills when they:

- ◆ Use strategies that help clients make positive changes.
- ◆ Present insights and options for responding to current life situations.
- ◆ Explain the reasons for using certain approaches and offering specific advice.
- ◆ Ensure that clients do not spend their therapy sessions simply reporting current events in their lives – often a way people avoid dealing with uncomfortable issues. Instead, the therapist can ask questions to help the client gradually confront issues.
- ◆ Identify unhealthy, self-protective coping skills in non-judgmental ways, uncover the positive underlying needs, and offer healthy options for meeting those needs.
- ◆ Teach clients how to recognize characteristics of trustworthy people and how to develop relationships with them.

For example, when a client slips into an unhealthy coping pattern (e.g., overeating, overworking, etc.), the therapist's job is to teach the client how to respond compassionately rather than critically (Amada, 1995). A therapist can remind the client to reward him/herself for the smallest changes in thinking, communicating, or responding to a situation. Practicing ways to ask for support with the therapist also can help a client gain

confidence needed to support and share his/her progress with others.

When therapy involves resolving traumatic memories, it is critical that the therapist possesses the specialized training and experience to do memory work safely and effectively. This means that the therapist must understand the effects of traumas – including how psychological or emotional issues have impacted their client's life – and how to use research-based interventions that can improve clients' responses to present-day situations that unconsciously remind them of the past (van der Kolk, 1996). Therapists who intervene inappropriately, or fail to intervene when needed, may actually cause further distress.

### *Look for a therapist who thoroughly assesses the client's needs.*

The therapist and client need to agree on specific changes the client wants to make and to review the treatment progress on an ongoing basis. A therapist displays respect for the client's intelligence and intuition by seeking feedback, inviting the client to participate in the creation of treatment plans, and by integrating the client's needs in the next step of the process (Williams, 1994).

It is important for clients to know that therapists often approach the assessment process in different ways. Some may spend the first few sessions asking questions and having the client tell his/her history. Others will address an immediate need and gradually obtain information throughout the sessions.

Each approach has advantages and disadvantages. What is important is that the therapist asks questions in a respectful and paced way to help the client voice what is troubling and explore the possible causes of these difficulties. The therapist needs this information to determine how to intervene and help the client. Steps of this process include:

- ◆ Asking questions to understand the client: *What do you think ... How do you feel about ... What do you wish had happened ... What do you consider your options?*
- ◆ Gathering adequate information before drawing conclusions or making recommendations.
- ◆ Asking questions to discover unhealthy coping patterns.
- ◆ Identifying problems and diagnosis/conditions accurately.

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*Linda: As an Employee Assistance Professional, I have assessed clients who have been in therapy for years and yet their therapists had not identified their unhealthy coping patterns. Employees reported routinely overspending, exploring cybersex, or having a few drinks each night when I asked them what they do when they feel anxious, overwhelmed, or lonely. One employee remarked, "No one has ever asked me those questions."*

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For therapy to be effective, a polio survivor typically needs to work with a therapist who understands and can *integrate the impact of a client's disability on his/her life*. This means learning how polio has affected the client's past and also how physical adjustments and emotional losses in the present

impact the person's relationships and life. Understanding the causes of the client's new weakness, fatigue, and physical pain, and the need for pain management and energy conservation, is important for determining treatment strategies and the client's tolerance levels.

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**Karen:** *As a social worker counseling individuals who have had polio, I often indicate to clients that they are welcome to stand, walk, or take a short break if that will help them manage their pain and physically pace the session. Upon hearing this, one individual stated, "Thank you for acknowledging that my pain is a daily reality."*

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Experts stress that a thorough assessment includes an understanding of a person's family system and the family's attitudes toward the person's disability: differing roles, relationships in terms of power issues, and communication dynamics (Olkin, 1999).

Questions about a client's family history should address the possibility of chemical dependency and other addictions. The prevalence of addictions is higher in families with a child who has a physical disability. This is important because individuals who grew up with chemically dependent parents or elders are more likely to have experienced physical or emotional neglect or abuse, to have witnessed domestic violence, and to be at increased risk of sexual abuse (Olkin, 1999).

Since studies have repeatedly found the rates of substance use (e.g., alcohol, prescription drugs, or illegal drugs) in persons with

disabilities substantially higher than in the general population, it is important that a therapist screen for this possibility. Olkin explains that the higher rates stem from chronic pain, social isolation, and increased incidence of sexual abuse (Olkin, 1999).

Without this screening, a person may be in therapy struggling with depression and/or anxiety, not knowing that one of the obstacles to progress may be dependency on using alcohol or drugs. If a therapist does not ask questions at a deeper level or if the client withholds the truth, the therapist will be missing vital information that is needed to accurately assess and address the client's treatment needs.

#### ***Look for a therapist who creates a safe environment.***

Creating safety is one of the primary responsibilities of a therapist who helps clients resolve traumatic memories (van der Kolk, 1996). Van der Kolk warns that the failure to approach trauma-related material gradually, with safety measures in place, may intensify trauma symptoms, such as sleep disturbances, digestive problems, and anxiety attacks. For this reason, therapists need to teach clients skills that will enable them to stay present to reality while managing their reactions to their memories. Preparing clients, before exploring memories, will help prevent them from relapsing into unhealthy coping patterns when they begin to deal with their stories (Napier, 1993).

An important part of healing from polio memories takes place when a client tells his/her stories and the therapist responds with empathy and understanding.

A therapist conveys compassion through tone of voice, facial expressions, body posture, and comments. These characteristics, combined with strong listening skills, helps to create a safe setting that encourages the client to tell his/her truths.

When a client experiences emotion such as fear, shame, guilt, anger, or sadness, feeling safe, understood, and accepted is need-

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## **International Polio Network**

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ISSUED QUARTERLY

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ed in order to openly express and discuss these feelings. The therapist is responsible for encouraging healthy expressions of feelings and for suggesting safe ways to release them (e.g., art therapy, letter writing). By contrast, if the therapist changes the subject when a client begins to cry, the client may interpret the therapist's response as disapproval or discomfort, and may shut down his/her emotions – replaying an unhealthy and even traumatizing coping pattern.

***Look for a therapist who tailors the process to the client's needs.***

Therapists should explain available treatment options, including their intended purpose, benefits, and limitations. This information will empower the client to collaborate with the therapist in tailoring the process to his/her specific needs.

Experts say that therapists need additional skills to understand and work through the complexi-

ty of issues related to a client's disability and need to know how to modify the diagnosis and treatment depending on the disability (Olkin, 1999). Clients need to pay attention to how a therapist responds to their disability. If a therapist focuses solely on the client's disability or ignores it, this can be detrimental to the therapy process.

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*Karen: When I meet with individuals who have respiratory problems, I sometimes initiate relocating the session to a spacious office with a window in order to accommodate the client's need for "breathing space."*

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***Look for a therapist who develops a trusting partnership.***

From the very first interaction and throughout the therapy process, a therapist builds trust by communicating empathy, compassion, and integrity. Examples include:

- ◆ Sitting across from the client (not behind a desk).
- ◆ Making direct eye contact.
- ◆ Acknowledging the client's comments and feelings.
- ◆ Pausing during sessions to allow time for reflection.
- ◆ Being warm and approachable.
- ◆ Communicating honestly, clearly, and consistently.
- ◆ Being punctual for appointments, except in emergencies.
- ◆ Acknowledging reasons for becoming defensive or critical and apologizing for these reactions if they occur (Roberts, 1998).
- ◆ Remembering key information.
- ◆ Holding the client responsible without shaming the person.
- ◆ Explaining the need to refer to another professional or to seek consultation about complex issues.

***Look for a therapist who empowers the client.***

Therapists can empower clients by affirming their strengths. For example, many survivors have deep reservoirs of spiritual strength that their therapists can highlight and nurture. Therapists can encourage clients to apply their own strengths to the therapeutic process.

Other ways that therapists can empower their clients include:

- ◆ Affirming the important issues that the client raises, identifying issues as they emerge, and integrating them into the sessions.
- ◆ Supporting the exploration and use of other resources.
- ◆ Encouraging the client to consider the therapy relationship as a "practice ground" for managing other relationships,

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**KAREN KENNEDY, MSW, RSW**, is a registered medical social worker who, for the past ten 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.

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*The authors welcome your comments. Send them to IPN (4207 Lindell Boulevard, #110, Saint Louis, MO 63108-2915 USA, gini\_intl@msn.com).*

inviting the client's honest reactions to the therapy and the therapist, and learning to resolve differences in healthy ways.

- ◆ Providing feedback that increases a client's self-awareness and ability to listen to self and others.

Therapists can *promote self-care* by helping clients develop the skills to:

- ◆ Assert their needs.
- ◆ Practice positive self-talk.
- ◆ Set limits and say "no" when necessary.
- ◆ Make time and space for pleasure.
- ◆ Use relaxation strategies and/or affirming materials.

People with disabilities need to pay attention to how a therapist talks about their physical and medical conditions. It is important for a therapist to use *empowering language that shows respect for the whole person* and recognizes that one's physical condition is not the sole basis for one's identity. Disability organizations have identified empowering, respectful words, and also those considered demeaning.

Individuals need to understand that statements that glorify them as heroic or refer to them with pity are potentially harmful. The polio survivor who needs to accept physical limitations yet is glorified for excessive performance, may strive to overachieve in order to gain recognition from the therapist. On the other hand, an attitude of pity can easily contribute to promoting a victimized rather than resilient self-image.

In addition, when a client talks about his/her disability in negative terms, the therapist has the opportunity, and responsibility, to make the client aware of the potential effect of using such references and to offer alternative words that promote a positive self-image.

### ***Look for a therapist who demonstrates integrity and ethical boundaries.***

An ethical therapist will:

- ◆ Display healthy boundaries. Therapists should *not* barter services, have a personal or dual relationship with the client, or have any sexual contact with a client (Napier, 1993).
- ◆ Maintain confidentiality and obtain informed consent except as required by law.
- ◆ Hold sessions in a private setting.
- ◆ Follow through with policies such as canceling appointments.
- ◆ Communicate consistently and clearly about policies.
- ◆ Seek supervision and consultation about therapeutic issues as needed.
- ◆ Encourage the client to seek medical assessment and treatment as needed.

### **IDENTIFYING QUALIFIED THERAPISTS**

Qualified professionals may include psychologists, psychiatrists, clinical social workers, psychiatric nurses, clinical mental health counselors, and marriage and family therapists. However, their level of training, roles, experience, and fees vary widely (Sherman, 2001).

For this reason, individuals seeking psychotherapists are encour-

aged to approach the selection process as *consumers searching for a professional* who is accessible, affordable, and well-suited to help them achieve their goals. Survivors can identify potentially qualified professionals by obtaining recommendations from trustworthy sources. They can ask, "What therapist would you go to or refer a family member to if they had similar issues?" when they contact the following resources for referrals (Finney, 1995):

#### **Personal contacts/resources**

- ◆ Well-informed colleagues or friends
- ◆ Physician or clergy member
- ◆ Employee assistance programs
- ◆ Reputable mental health professionals

#### **Professional organizations**

- ◆ Trauma experts who train therapists (e.g., International Society for Stress Studies, authors, trauma programs)
- ◆ Professional licensing or certifying associations (e.g., National Association of Social Workers, American Psychological Association)

#### **Health/medical, social services resources**

- ◆ Pain or rehabilitation clinics
- ◆ Psychology, psychiatry, or social work departments in medical centers or universities
- ◆ Mental health associations
- ◆ Local family or disability services

When calling for referrals, it is important to keep organized notes that identify the person who offers the referral and their feedback.

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## CHOOSING A THERAPIST

Since most referral services do not rate the competency of their members, it is important to research and interview several potential therapists. If an introductory session cannot take place in person, interviews can take place on the phone. Potential clients can learn a lot from the way a therapist responds to questions. "Each interview will provide valuable information and give you more experience about therapists so you will become more confident about your ability to make a wise choice. Do not hire a therapist you do not like (Finney, 1995)."

In selecting a therapist, individuals are encouraged to analyze their options and trust their intuition. Consumers may gain insight about each therapist they interview from:

- ◆ How they feel while interviewing the therapist, e.g., comfort level (Sherman, 2001).
- ◆ How the therapist communicates.
- ◆ What they understand about the person's experience, training, treatment approaches, and attitudes.
- ◆ What, if anything, they learn about themselves from talking with that therapist.

The questions below can be used as guidelines for interviewing therapists (Bruckner-Gordon, et al, 1988). However, what is most important is for a person to ask questions that will help in making a satisfying decision (Striano, 1987).

### Background

What do you specialize in?  
What is your experience work-

ing with traumatic memories?  
What is your experience working with persons with disabilities or chronic health conditions?  
What is your educational background? What kind of license or certification do you have?

### Policies and practices

Do you set treatment goals? How do you determine if a client is making progress? What are your fees? Are you covered by my insurance? Do you offer a sliding scale? What are your policies regarding emergency phone consultations and cancellations of appointments (Finney, 1995)?

## IN CONCLUSION

Each survivor needs to decide whether exploring past memories fits with his/her priorities, life choices, and capabilities. Some people cannot afford to work in depth, and others may choose not to. Still, others may opt to explore psychotherapy or the alternative approaches outlined on page 9. Whatever a person's choice, individuals who are interested in resolving the impact of their polio memories are encouraged to:

- ◆ Clarify their priorities and the benefits they want to gain from this "learning experience."
- ◆ Approach themselves compassionately and patiently.
- ◆ Research and analyze their options.
- ◆ Focus and build on their strengths while being realistic and accepting of their physical needs.
- ◆ Identify trustworthy people they can turn to for encouragement.
- ◆ Ask questions to gain the information they need and

trust their intuition about the responses they receive.

- ◆ Select an ethical, qualified clinician with whom they feel safe.

Whatever avenues individuals choose, this information provides useful guidelines for obtaining support as they consider ways to understand and manage the impact of polio memories on their present-day lives. ■

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## SUGGESTIONS FOR PEOPLE WITH LIMITED RESOURCES

Individuals with limited financial resources, who are interested in reducing their symptoms and pursuing a level of healing from their polio memories, are encouraged to consider the following options:

### RECOMMENDED READINGS

The reference books listed in the "Treatment Approach Options" chart (available from IPN, [gini\\_intl@msn.com](mailto:gini_intl@msn.com)) and the references (on page 8) are available through many libraries and can be ordered at bookstores. Carefully selected reading materials can guide survivors through varying levels of emotional healing. For example, *The Post-Traumatic Stress Disorder Sourcebook: A Guide to Healing, Recovery and Growth* by Glenn Schiraldi is a useful self-help tool. While this option is not a replacement for therapy, a person can gain insights and ideas that can help in managing problems and reacting to stressful situations.

### HEALTHY SUPPORT GROUPS

Support groups can offer sources of support and healing for individuals who have lived their polio experience in isolation. A healthy support group will provide a safe place for people to be heard and understood by others who live with a similar challenge; focus on wellness by providing speakers, workshops, and balanced input from the healthcare community; explore healthy wellness alternatives; avoid negativity and encourage participants to move forward in their coping; and spin off into small networks of people who meet or call one another.

### PERSONAL DEVELOPMENT WORKSHOPS

Medical centers, mental health clinics, family service associations, and other non-profit organizations may offer workshops and talks on topics such as anxiety management, pain management, and coping with depression. By attending these workshops, survivors can gain self-awareness and learn about strategies that can help them with everyday coping.

### HEALTHY RELATIONSHIPS

The section on "Recognizing a Qualified Therapist" discusses healthy principles that individuals may apply to their daily lives. Survivors can use this information to recognize those relationships that have healthy characteristics versus those that are damaging or re-traumatizing (Whitfield, 1993). Part of the healing process involves making choices about the kind of friendships and relationships they will pursue. For the good of their own health, they may need to gradually set limits and boundaries with people who are draining or distressful to be around or are unwilling to take responsibility for their own welfare.

### TREATMENT APPROACH OPTIONS CHART

Individuals with limited resources may select one area that they can afford to gain assistance. The chart, available online ([www.post-polio.org/ipn](http://www.post-polio.org/ipn)) or via mail from IPN (see box on page 3), lists various therapeutic approaches that are effective in reducing stress, anxiety, and physical symptoms.

### PUBLICLY-FUNDED MENTAL HEALTH SERVICES OR NON-PROFIT PROGRAMS

Individuals may qualify for these services or programs, which often offer sliding-scale fees based on the client's ability to pay. The availability, cost, and expertise of community services vary greatly, yet are worth pursuing when funds are limited. Clients typically are assigned a therapist in an agency – they may not have a voice in choosing one. However, consumers have the right to ask questions to determine if a therapist is qualified to help them. Most organizations will respect a client's need to work with a person with whom he/she feels comfortable and who has expertise in treating the client's specific problem.

Also, consumers are encouraged to thoroughly investigate the reputation of an agency or program by checking with other organizations and professionals about their experiences with that agency, and if possible, with clients who have used the agency's services (Finney, 1995). ■

**EDITOR'S NOTE:** This concludes our series of articles in *Polio Network News* exploring the emotional issues that can co-exist with physical problems in the survivors of polio. The previous articles (listed below) are available at [www.post-polio.org/ipn](http://www.post-polio.org/ipn) or for \$1 each from IPN.

**Emotional Bridges to Wellness**  
(Fall 2001, Vol.17, No.4)  
by Linda L. Bieniek, CEAP

**Improving Quality of Life:  
Healing Polio Memories**  
(Winter 2002, Vol. 18, No. 1)  
by Linda L. Bieniek, CEAP, and  
Karen Kennedy, MSW, RSW

**A Guide for Exploring Polio  
Memories** (Summer 2002, Vol. 18,  
No. 3) by Linda L. Bieniek, CEAP,  
and Karen Kennedy, MSW, RSW

**"Women with Polio: Menopause, Late Effects, Quality of Life, and Psychological Well Being"** has been selected as the recipient of 2003 GINI Research Fund grant.

Denise G. Tate, PhD, Professor, Department of Physical Medicine and Rehabilitation, is the Co-Principal Investigator. Claire Z. Kalpakjian, PhD, Research Fellow, Department of Physical Medicine and Rehabilitation, is the Co-Principal Investigator and Project Director, and Elisabeth H. Quint, MD, Department of Obstetrics and Gynecology is Co-Investigator. All are from the University of Michigan, Ann Arbor, Michigan.

The study is an expansion of the *Wellness for women with polio: A holistic program model* funded by the National Institutes of Health in 1996-1999. A pilot study conducted this summer at the University of Michigan by Drs. Kalpakjian and Quint collected information on the menopausal experience, the use of hormone replacement therapy (HRT), and the late effects of polio of 103 women. Nearly 50% of these women were using some form of HRT with 64% using estrogen-only therapy. For those who had a natural menopause, use of HRT was statistically and significantly higher than estimates for non-disabled woman in the US (41% vs. 20% respectively). Additionally, a significant association was found between severity of late effects and menopausal symptom severity.

The GINI Research Fund award will provide funds for a nationwide study of women and men with polio. The study will not involve any interventions, but will be a retrospective, descriptive study of the menopausal experience of women polio survivors including HRT use as well as an extensive study of aspects of the polio survivor's current health.

In attempting to understand the unique contribution of menopause for women with polio, men with a history of polio will serve as a control group.

Using men as controls will help clarify the findings by using them as an age-matched comparison group. This will also allow for an in-depth exploration of differences between women and men in terms of late effects and other health problems. No other studies to date have directly compared late effects severity and symptoms between women and men to the extent that is planned with this study.

A greater understanding of the differences between women and men in their experience can help influence treatment and management approaches to late effects for both women and men. Additionally, this balance of men and women subjects is important as most polio studies typically report on a greater number of females.

Kalpakjian feels that this study is even more relevant in light of the findings of the Women's Health Initiative findings published this summer in the *Journal of the American Medical Association* (JAMA, 2002: 288 (3): 321-33) that found that women taking

combined estrogen-progestin therapy were more at risk for invasive breast cancer, stroke, and coronary heart disease (CHD). The well-publicized findings have caused a 632,000 drop in prescriptions for all brands of HRT.

Many women with disabilities, because of their limited mobility, may be at a higher risk for problems when taking HRT, however, very few studies have addressed the particular risks of women with disabilities. As such, Kalpakjian is confident that the data gathered from this study will help to begin to clarify the risks for people with limited mobility and the relationship between a higher risk for CHD and the use of combination therapy for protection.

Women with disabilities, primarily because of reduced mobility compromising cardiac and bone health, may be at particular risk for problems associated both with the onset of menopause as well as taking HRT. However, much research is still needed to better understand the interaction of menopause and HRT and these risk factors that are more prevalent in women with disabilities. In light of the HRT findings this summer and these potential risks, Drs. Quint and Kalpakjian suggest that, like with any medication or treatment regime, women should discuss their own unique risks and the potential to benefit from HRT with their physicians. ■

## THE GINI RESEARCH FUND FIRST AWARD RECIPIENT RELEASES FINAL REPORT

*Ventilator Users' Perspectives on the Important Elements of Health-Related Quality of Life* the final, informative report from the Toronto-based research team has been released.

The 115-page report analyzes the data from interviews of 26 individuals who are experienced with using mechanical ventilation for 12 to 24 hours a day via noninvasive modes or tracheostomy. The ventilator users live in the Toronto and Edmonton areas. Ages range from 23 to 66 years: 16 males and 10 females. Diagnoses included polio, Duchenne muscular dystrophy, spinal muscular atrophy, spinal cord injury, ALS, transverse myelitis, and cerebral palsy.

Polio survivor and ventilator user, Audrey King, MA (Psych), one of the authors of the report explains, "This study was qualitative in nature, rather than quantitative. Qualitative data is derived from personal interviews and involves textual analyses. Qualitative research seeks to establish a picture of how a specific population lives and how it perceives itself in terms of problems, solutions, and determinants. This information

is useful in providing professional education, and in changing or improving programs, services, technologies, and protocols."

The ventilator users who were interviewed perceived mechanical ventilation as a positive benefit rather than an intrusive burden that the general public and health care providers assume it to be.

Gender and age did not appear to influence perspectives on quality of life, but the nature of the introduction to mechanical ventilation (critical vs. non-critical) and the presence or absence of a tracheotomy did produce differences.

In addition, the following issue-specific subcategories emerged: transportation, personal support workers (personal assistant services), advocacy, funding for mechanical ventilation equipment, and experiences with the health care system.

The final report expands on these key findings and includes numerous, enlightening quotations from ventilator users. The report is available at [www.post-polio.org](http://www.post-polio.org) or by contacting Justine at 314-534-0475. ■

The GINI Research Fund, a separate, special fund for research, was established in 1995 with a bequest from Thomas Wallace Rogers from Moline, Illinois. Today the corpus of the fund is \$250,000. GINI's goal is to continually increase the fund, so we can increase the size and the number of grants made available.

Donations are welcomed and can be sent to 4207 Lindell Boulevard, #110, Saint Louis, MO (Missouri) 63018. Please make the checks payable to The GINI Research Fund.

Readers of *Polio Network News* are also invited to send ideas for future research to the address above or to Joan L. Headley at [gini\\_intl@msn.com](mailto:gini_intl@msn.com).

*GINI appreciates the donations from these support groups to ...*

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First Coast Post-Polio Support Group  
(Jacksonville, Florida)

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Central Indiana Post-Polio  
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*In memory of William Hoyt  
and Jack Ahern*

The Greater Boston Post-Polio  
Association

### DO YOU USE A VENTILATOR? BI-PAP? DO YOU SUBSCRIBE TO *IVUN NEWS*?

*IVUN News* (ISSN 1066-534X), the networking newsletter of our International Ventilator Users Network (IVUN), is published quarterly in March, June, September, and December. Edited by Judith Raymond Fischer, it links ventilator users, their families, and peers with each other and with health professionals committed to home mechanical ventilation.

The subscription rates for this 8-page periodical are:

USA \$18

Canada, Mexico, and

Overseas surface \$23

Overseas air \$28

### International Ventilator Users Network (IVUN)

4207 Lindell Boulevard, #110

Saint Louis, MO 63108-2915 USA

[www.post-polio.org/ivun](http://www.post-polio.org/ivun)

## POST-POLIO DIRECTORY-2003

**REMINDER:** *Post-Polio Directory-2003*, which lists self-reported clinics, health professionals, and support groups with post-polio experience, is scheduled to be released March 1, 2003. The print copy is available from IPN for \$8 USA; \$10 Canada, Mexico, Overseas surface; or \$12 Overseas air. It is also available at [www.postpolio.org/ipn/locate.html](http://www.postpolio.org/ipn/locate.html).

We need your help in updating *Post-Polio Directory-2003*. IPN will send a reminder to those currently listed after the holiday rush and request that you immediately and carefully review your information.

Post-polio clinics, knowledgeable health professionals, and support groups who would like to be added to the *Directory* should send their information to [gini\\_intl@msn.com](mailto:gini_intl@msn.com), Attn: Sheryl, Directory.

**INVITATION:** IPN welcomes support groups who are subscribers and who are listed in our

*Post-Polio Directory* and who do not have their own websites to send their meeting information for the coming year – location, dates, and information about speakers and/or activities – to [gini\\_intl@msn.com](mailto:gini_intl@msn.com), Attn: Sheryl, Directory. We will create a web page for each group that will be linked from their entry in our *Directory*. See the entry for Northwestern University Post-Polio Clinic Support Group at [www.post-polio.org/ipn/sg-usa.html#il](http://www.post-polio.org/ipn/sg-usa.html#il) for an example. ■

**IVUN RESOURCE DIRECTORY 2003**, a resource for users of home mechanical ventilation and health professionals who treat them, is now available at [www.post-polio.org/ivun/d.html](http://www.post-polio.org/ivun/d.html). A print copy can be purchased from IPN for \$8 USA; \$10 Canada, Mexico, Overseas surface; or \$12 Overseas air. ■

## FOR THE GRANDCHILDREN

Polio survivor Beryl K. Baker from Barrie, Ontario, Canada, has written *Nana Needs a Nap* (ISBN 0-9731136-0-X), a children's book explaining classic post-polio syndrome to her grandchildren. Complete with colorful, descriptive illustrations by Chris Barry, the book is available for \$14.95 CDN (Canada), \$9.95 USD (Outside Canada) plus \$5 shipping & handling (Shipping and handling charges are in Canadian funds for Canadian orders or USD for orders outside of Canada), from Computer Elite, 3105 Highway 11 East, RR 2, Oro Station, Ontario, Canada L0L 2E0, Attention: Nana Needs A Nap or log on to [www.nananeedsanap.com](http://www.nananeedsanap.com). ■



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