

# POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

October - November 2006

*Carol T. Ranelli, Editor*

visit our website at [www.cvppsg.org](http://www.cvppsg.org)

## **October 7<sup>th</sup> Meeting**

2:00 pm at Children's Hospital, 2924 Brook Road, Richmond

Our speaker will be **Mr. Warren Rice**,

President of the Hanover Rotary Club

who will speak on "

**"Rotary International's Quest to Eradicate Polio  
World-Wide"**

## **November 11<sup>th</sup> Meeting**

**PLEASE NOTE: This is the second Saturday in November due to the  
Teddy Bear Run at Children's Hospital on Nov. 4th**

2:00 pm at Children's Hospital, 2924 Brook Road, Richmond

Our speaker will be **Ms. Maria Fakhoury**,

Certified NeuroMuscular Massage Therapist

who will speak on

**"Dealing with Post Polio's BIG FOUR Painful Body  
Parts: Shoulders, Neck, Wrists and Hips"**

**Make a note on your social calendar!! Our annual  
Christmas luncheon will be held on December 2<sup>nd</sup>. Details in  
the next newsletter.**

## Mid-Month Lunch

**Wednesday, October 18<sup>th</sup> 11:30 at Joe's Inn,**  
6512 Mechanicsville Turnpike

Call Bev Lordi by October 16<sup>th</sup> with your reservation - 746-3864

**Wednesday, November 15<sup>th</sup> at 11:30 at Azzurro Restaurant**  
6221 River Rd. at River Road Shopping Center at the end of Huguenot Bridge  
Call Bev Lordi by Nov. 13<sup>th</sup> with your reservation

Please join us for a relaxed, social time with other PPS members

## Talk to Me, Doctor!

*Information from June Isaacson Kailes' book Be a Savvy Health Care Consumer, Your Life May Depend on It!*

Finding your way safely through the increasingly complex health care jungle is never easy, especially if you are sick. It can be a tricky and pressure-filled business, but there are ways to protect yourself. The most important thing to be recognized is that ultimately you alone are responsible for managing your own health. June Kailes, a Disability Policy Consultant, points out that consumers, especially disabled consumers, have to stand up for themselves, treating health professionals as consultants rather than as gods.

Passive consumers want providers to take charge of their health, rely totally on providers' advice, do not ask questions, offer information only when asked, are complacent and have a fatalistic "what will be, will be" attitude, are not interested in thinking about options, are hesitant to disagree with or confront their providers, often feel helpless and lost in the health care system, and worry that their health care will be compromised if they ask questions or disagree. In fact, research confirms that people who are more active in their relationships with their physicians have more positive results. As providers get to know you, they're able to see you as an individual rather than a textbook or theoretical case. Visiting a provider can be highly stressful. Being partially or completely undressed and addressing the doctor in a white coat can be intimidating. Some advice for getting over the "white coat" syndrome:

1. Consider bringing an advocate/friend who can listen, take notes, and help ask questions. Choose a support person who has the skill to think objectively and is able to listen and remember accurately. Ask them to assist but not take over.
2. Take notes. "The faintest ink is more accurate than the strongest memory."

3. Ask open-ended questions. Avoid leading questions. Leading questions can force providers to give the answer you want even if it's not true. Wrong or leading question: "I'm going to be okay, aren't I?" (This implies you may not want to know any bad news.) Right or open-ended questions: What are the chances of my recovery? What's the outlook? My prognosis? What are the implications of the treatment?
4. Never be afraid to say, "I'm having trouble understanding. Could you describe the problem in plain terms?"
5. Sometimes what you hear may surprise, shock or upset you. Ask how much time you can take for making a decision without endangering effective treatment.
6. Always consider getting a second opinion. When the second opinion differs from the first, you may feel justifiably confused and decide you want a third opinion. Get one or use a trusted provider to review the differing recommendations.
7. If you have a disability, be sure to find doctors who are "disability-aware." Being a savvy health care consumer does take time and planning. If you do not follow any of these visit strategies, at least remember this: you have the right and responsibility to ask: Why? Why not? What? How? When?

### ***Book News:***

Margaret Backman, Ph.D., a Clinical Psychologist who has written numerous articles and given presentations on the psychological aspects of post-polio, has just published the book:

#### **The Post-Polio Experience: Psychological Insights and Coping Strategies for Polio Survivors and Their Families.**

The book is based on her experience over 25 years working with those who have had polio.

Today many polio survivors find them-selves with new symptoms reminiscent of the earlier days when they first had polio- these new symptoms trigger frightening memories that had long been repressed, along with anxieties about what the future holds.

In ***The Post-Polio Experience*** Dr. Backman, examines polio survivors' psychological reactions to their earlier experiences and to their current struggles with the late effects of polio.

The book also includes practical guidelines for polio survivors on:

- Coping with the emotional and interpersonal aspects of Post-Polio Syndrome
- Managing stress and depression
- Negotiating relationships with family and friends
- Developing a positive self-concept
- Improving doctor-patient communication

Family and friends will also find the **The Post-Polio Experience** of interest, as they learn to deal with the changing roles that they and the survivor now face and gain insight into their own needs, which interact and sometimes conflict

with the polio survivor's needs.

Mental health providers and physicians will find insights that help them gain a better understanding of their patients' psychological reactions to Post-Polio Syndrome-paving the way for more effective treatment.

**The Post-Polio Experience** can be purchased online through the publisher: [www.iuniverse.com](http://www.iuniverse.com), or it can be ordered at Barnes & Noble bookstores. You can also place your order by telephone through the publisher at: 1-800-288-4677, Ext. 501. The cost is \$18.95, plus shipping and sales tax, where applicable.

*Dr. Backman, who specializes in Health Psychology, is also the author of The Psychology of the Physically Ill Patient: A Clinician's Guide (Plenum Press/Kluwer) and is in private practice in New York City.*

## Polio Survivors' Painful Body Parts: The Big Four

By Dr. Richard Bruno

**Polio Shoulder:** Because polio survivors usually have more leg than arm muscle weakness, they use their relatively stronger uppers to compensate for weaker lowers. So, when getting up out of a chair, climbing out of the bath or walking using crutches, the arms take the freight. The joint that complains most is usually the shoulder, the pain typically caused by bursitis or tendonitis. Sometimes, shoulder pain and an inability to lift your arm directly upward in front of you may be signs of a rotator cuff tear that could require physical therapy or, possibly, surgery.

**Polio Neck:** "Polio shoulder" can also be a part of "polio neck," when the muscles that move the head and those that "shrug" the shoulders upward, go into spasm due to overuse weakness and poor posture. Polio neck is also the number one cause of headaches in polio survivors.

**Polio Wrist:** "Polio wrist" is usually caused by carpal tunnel syndrome, the squishing of the nerves that pass across the wrist. Polio survivors have much more carpal tunnel syndrome than the general population because pain in the wrists develops in the same way as polio shoulder – from overuse of joints- and in the case of the wrist, with repeated hyperextension (bending backward) as you push yourself upward from sitting to standing or walk using crutches.

**Polio Hip:** Pain in the hips also is often the result of bursitis or tendonitis caused by weak hip muscles trying to keep you from wobbling back and forth. Polio survivors and many doctors immediately assume that all hip pain is due to arthritis. Polio survivors can have arthritis, but hip pain is almost never caused by arthritis. Again, it is irritated tendons and ligaments that are making you hurt. What's more, what you call hip pain may actually be caused by low back or butt muscles going into spasm as they try to compensate for weak leg muscles.

What do you do about the big four? Since pain is triggered by overuse, you need to take the load off of angry joints, their weakened muscles and nerves and their abused ligaments and tendons. Raising the height of chairs, using a toilet booster seat with arm/hand grips to help you stand and using a wide tub bench instead of standing in the shower or hauling yourself in and out of the tub will take the load off your upper body.

Once you are up, using light-weight Lofstrand crutches is better than using nothing or even a cane. If you have "polio wrist" crutches that have foam covered hand grips or grips that are ergonomically designed could be a big help. (See [www.walkeasy.com](http://www.walkeasy.com)) Crutches are also helpful for polio hip since they balance you from front to back and side to side, taking the load off of strained tendons and ligaments and weak hip, back and butt muscles. Of course, rolling in a power wheelchair is better than walking to ease all post-polio pains.

If taking the load off isn't helping enough, bursitis, tendonitis and muscle spasm can be treated by a physical or occupational therapist with ultrasound, heat (and sometimes, ice) and deep tissue massage. Your doctor may want to try a non-steroidal anti-inflammatory drug, like ibuprofen or Celebrex. However, oral steroids should almost never be used to treat bursitis and tendonitis since their side effects are very unhelpful for most polio survivors. However, a few injections of cortisone and a local anesthetic into a joint or a muscle, followed by the above therapies, can knock down inflammation and prevent spasm. Local injections of cortisone in the wrist can also help reduce inflammation and swelling in those with carpal tunnel syndrome.

Sometimes, surgery may be required to treat CTS when the nerves are being pinched and damaged – and to repair a rotator cuff. For some rotator cuff tears, therapy is recommended to increase muscle strength. Strengthening should be done without causing fatigue, muscle weakness or pain and only after pain is gone. Asking a polio survivor to strengthen an overworked joint or muscle is like trying to put out a fire with gasoline.

*Reprinted from "The Seagull" July, 2006 issue, Triad Post Polio Support Group, Greensboro, NC*

## **Improving Quality of Life: Healing Polio Memories**

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

*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.*

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 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 re-actions 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 lifelong 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.

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;
- 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.

Reprinted from IPN Polio Network News, Winter 2002, Vol. 18, No. 1

*From Henry's Desk by Henry Holland*

## Polio, the First Twenty-four Hours

Recently I have noticed that the days of this September fall exactly as the dates fell in September 1950. The day I contracted polio was Sunday, September 17, 2006 and the day that I was admitted to the polio isolation ward at the Medical College of Virginia Hospital was Saturday, September 23, 1950. The dates and days this year are exactly the same as then. As many of you I have been trying to record some memories of my life with polio. For this newsletter I thought I would share my account of my first twenty-hours after the invasion of the polio virus into my body. I am sharing more detail than may be of interest to the reader. For me, remembering the details helps me to interpret the greater event. Here goes:

"Son, you have polio" expressed Dr. Robert Morton on Saturday morning, September 23, 1950. These words were terrifying to me at age 11 and they still convey a haunting anxiety when I think of them today. I remember every detail of that awful Saturday and what a permanent impact the poliovirus made on my life. Many times over the years I have wondered and asked myself, "Why me?" The impact of crippling polio affected my self-esteem, my self-image, my goals in life, my personality defenses, my religious pilgrimage, and my understanding of others.

Let me start with the invasion of my body by the poliovirus. I had returned to school entering the

5H grade on Thursday, September 7th. I had attended James Ewell Brown Stuart Elementary School in the north side of Richmond, Virginia since beginning public school in January 1945. The school system in the Richmond Public Schools at that time required a child to be 5 ½ years old to begin school. As a result I began school in the middle of the school year and my grade promotions were always during the middle of the regular school year. I entered the second semester of the fifth (5H or high) grade on that September 7th. . Meeting my classmates after a long summer was a good feeling. I got my books for the new school year, put on book covers and got my supplies after school that first day. My school attendance and performance had been excellent. School was beginning that year as it had for previous years. After completing the first full week of school, I was looking forward to the weekend and riding my Roadmaster bicycle.

On Saturday morning, September 16th, I awakened and sat up on the side of my bed. I proceeded to get dressed with underwear, short pants, and a T-shirt. I leaned over to tie my sneakers and I immediately felt a stiffness or pain in the back of my neck. It hurt to touch my chin to my chest. I immediately thought that a stiff neck was an early warning sign of polio. This may sound hard to believe, but I distinctly remember this thought passing through my mind.

Every year at the local neighborhood theater, the Brookland Theater, a short movie clip would be shown during the annual March of Dimes polio drive. The warning signs of polio would be mentioned and I remembered the one about the stiff neck. After the movie clip, cardboard canisters were passed along the aisles and folks dropped their dimes and dollars into the canisters. I recall the smiling appearance of the March of Dimes poster child. The child's smile persisted despite the braces that were strapped to the child's legs.

My polio thought on that Saturday morning quickly vanished and I went about my day as planned. I went on a lengthy bicycle ride near a ravine in my neighborhood. I also attended the Saturday afternoon matinee of a double feature western at the Brookland Theater. Admission was only eleven cents. That night was spent with no sign of illness. The next morning I experienced the same painful stiffness in my neck as I dressed in preparation to attend Sunday school. While in the bathroom that morning, I began to feel some nausea and had a headache. As I began to descend the steps, my grandmother noticed that I was not feeling well. She took my temperature and I had a fever. She ordered me to stay home and to return to bed. My grandmother was a practitioner of many 19th century medical treatments. Whenever I got sick, no matter how mild or severe the disorder, bed rest was mandatory. Her treatments involved the abundant and vigorous application of Vicks vapor rub all over the nasal passages and chest, and the hanging of a turpentine rag on the bedpost for any type of upper respiratory disorder. For gastrointestinal disorders, her remedies involved various broth and laxatives. If the symptoms were not quickly resolved, the application of a warm water enema was often the next treatment alternative. I had been subject to these treatments in the past for measles, chicken pox, mumps, and scarlet fever. Despite these treatments, I had always recovered completely. I remember feeling sad that I could not go to Sunday school. I did feel poorly and accepted the bed rest sick role, but I had every confidence that I would recover.

The next morning, the family doctor, Dr. Robert Morton, was summoned. Dr. Morton was a

general practitioner who lived only two blocks away. He made house calls and had treated me during my usual childhood illnesses. Somehow, he had injured his right hand and his finger movements were affected. He held his pen between the ring and little finger of his right hand whenever he wrote a prescription. His pen made a noticeable scratching sound as he wrote. In my mind when he went to write a prescription, I would usually feel better as I would know that some medicine would soon be available that must have magic potency to cure my ailment. He examined me on that Monday morning. I was already upset about missing a school day. He took my temperature with his pocket thermometer and proceeded to examine me. His examination involved a rather gagging look down my throat and a rigorous palpation of my abdomen. My grandmother was also in the bedroom. He turned to her and announced his diagnostic impression. Dr. Morton had one of those loud voices that could be easily heard from upstairs when he entered the front door downstairs. "He's got Devil's Grippe." In retrospect, this diagnosis was valid. The force of the devil had a grip on my body, more specifically my stomach and intestines. I immediately felt some relief as the thought of polio had entered my mind again. I knew that I should recover from the Devil's Grippe and be back in school in a few days. Thus, my first twenty-four hours with polio ended.