

# **POLIO DEJA VIEW**

**Central Virginia Post-Polio Support Group**

**[www.cvppsg.org](http://www.cvppsg.org)**

**June – July 2005**

*Carol T. Ranelli, Editor*

**Saturday, June 4<sup>th</sup> Meeting**

**Annual June Luncheon**

**At Joe's Inn, 6512 Mechanicsville Turnpike**

**Social Hour at 1:00 – Seating at 1:30**

We will have a private room and can order off the menu so you can get whatever tempts your palate! Joe's Inn has a very extensive menu so everyone can find something they like.

Fancy Shirt Day- Prizes will be awarded for the prettiest, the funniest, the wildest, most original, etc.

June 1<sup>st</sup> is the deadline for reservations.

Call Marilyn Decker at 559-0243 or Carol Kennedy at 740-6833

Plan to join us for good food and a chance to visit with friends.

**We will have NO meeting in July.**

**Reminder: If you haven't sent in your annual dues and member up-date form, it isn't too late! Please mail to: Linda VanAken, 14606 Talleywood Ct., Chester, VA 23831**

**If you haven't mailed your Ukrop's Golden Receipt (issued at the stores this year), you may mail it to Easter Seals Virginia, Suite 100, 8003 Franklin Farms Dr, Richmond, VA 23229  
ATTN: CVPPSG**

## Mid-Month Lunch !!

Since we are having our annual luncheon on June 4<sup>th</sup>, we won't have a mid-month lunch in June.

On Wednesday, July 20<sup>th</sup> at 11:30, we will meet at Mandarin Palace Restaurant in Stratford Hills Shopping Center (near The Positive Vibes Café where we met in April)

Take the Forest Hill exit of Powhite Parkway right after you cross the James River Bridge. Turn right onto Forest Hill.

Call Carol Ranelli @ 794-7359 by July 18<sup>th</sup> with your reservation.

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Mark your calendar for **October 1<sup>st</sup>** for our **2005 Post Polio Conference** at Children's Hospital. Our guest speaker will be Dr. Mary Ann Keenan, who will speak on "Saving and Protecting Our Joints", something all PPSers can relate to, regardless of disability. We hope to have a Physical Therapist as our afternoon speaker. Lunch will be provided. The registration cost and times will be presented in the next issue.

*Eighth International Post-Polio and Independent Living Conference  
St. Louis, Missouri, June 8-10, 2000*

## **Coping Styles and Personal Perspectives of Polio Survivors**

Frederick M. Maynard, M.D., Peninsula Medical Center, Marquette MI  
Sunny Roller, M.A., The University of Michigan Health System, Ann Arbor, MI

### **A Review of the Past**

Post-polio patients often experience their new physical symptoms as a recurrence of their original acute illness and many common symptoms are similar. Muscle weakness or the need for adaptive equipment can rekindle old memories of physical helplessness. Because many were young during their acute illness, they may mix age-related dependency issues with those resulting from physical impairments.

Additionally, since most cases of acute polio occurred during epidemics, children were often isolated and separated from their families. Intense feelings of fear, rejection and/or guilt often accompanied and experience of abandonment and entrapment in a hospital. Furthermore, expression of these emotions by children in great distress was actively discouraged by the social pressures of hospital staffs, families and other patients. They were told to be good, to stoically accept whatever was being done to them, and especially not to cry.

The reemergence of intense repressed feelings can come as a surprise to both patient and

professional during re-rehabilitation but must be acknowledged and managed when they occur. One woman reported with some astonishment that during her initial post-polio clinic visit she began to weep uncontrollably the moment she sat on the physician's examining table. Another gentleman revealed his unresolved fear of abandonment that immobilized him whenever his business travel required overnight stays away from his home and family.

During their initial polio rehabilitation, patients were encouraged to fight for recovery from residual weakness. "Use it or lose it" became a household motto for many of these children. They were also encouraged to overcome their disability through hard work and to set high goals for themselves. At the 1985 Conference, "The Post-Polio Experience", for Michigan polio survivors and health care professionals, a former director of the University of Michigan Respiratory Polio Rehabilitation Center reported that the children who did not set personal goals often died. When maximum physical recovery was reached, polio survivors learned to cope in the world with whatever functional capacity was left. Characteristic attitudes and behavior often became part of their personalities as they reached their peak physical capacities by early adulthood. Until the 1980's, few were warned that a loss of functional capacity due to age-related erosion of physical reserves was to be anticipated. The alarm experienced by many post-polio patients who develop new functional limitations can add to their psychological difficulty in adapting again to disability. Since significant change in physical capacity is usually accompanied by strong emotional reaction, it is important that re-rehabilitation professionals do not underestimate the difficulty of rerehabilitation for post-polio patients.

### Three Coping Styles

In the experience of the Post-Polio Program of the University of Michigan Medical Center, distinct patterns for polio survivors' emotional reactions to the need for re-rehabilitation have been recognized. These patterns appear to result from three characteristic styles of living with a chronic disability. A model for categorizing polio survivors has been developed that is based on these observations. Although it is limited by over-generalization, polio survivors have verbally validated the proposed categories at many post-polio conferences. A 1963 study of children with polio and their families also describes early coping behaviors that are compatible with this model. The model designates polio survivors as Passers, Minimizers and Identifiers. These labels characterize typical attitudes and behaviors that were adopted in order to cope with long-term mild, moderate, or severe disability. Passers had a disability that was so mild it could be easily hidden in the normal course of daily social interactions. They could pass for nondisabled. Minimizers had a moderate disability that was readily recognizable by other people. They often used visible adaptive equipment or had to do physical tasks differently in order to optimally function. They typically minimized the importance of their physical differences. Identifiers were severely disabled following acute polio. They generally needed wheelchairs for independent mobility. Some also used respiratory equipment. They needed to incorporate their disability into their identity in order to successfully cope with the major lifestyle adaptations required by their impairments. A close look at each group's coping style will clarify the typical patterns of emotional reaction that occur when polio survivors experience disabling late effects.

## Passers

Passers worked diligently to hide their long-term disability. Many of their acquaintances probably did not know they were disabled in any way. Although intimate family members and friends may have known, on the whole Passers became psychologically invested in hiding their disability from other people. Even today, they may not like to have to explain it or to talk about it. They do not want to think of themselves as having a disability. By using denial, they were able to put their disability out of existence mentally and physically and create an image that completely fooled the casual onlooker. Passers may hide a paralyzed hand by keeping it constantly in a pants pocket or cover slightly imperfect body parts with stylistically camouflaging clothing. Passing is a coping style that requires constant vigilance and attention to the non-disabled disguise. Good Passers believe they cannot “blow their cover” or they might get stigmatized as part of society’s disabled minority.

Based on an attitudes survey given to 100 polio survivors, the mildly disabled Passers were the group who was most distressed in having to adjust to the late effects of polio. They were more likely to be emotionally overwhelmed by the physical changes from the late effects than any of their more disabled post-polio counterparts. It is important for helping professionals to know that among people with a history of polio, it is the Passers who have the greatest resistance to making, and the most emotional difficulty in accepting, some of the relatively minor lifestyle adaptations that are needed to cope with the late effects of polio. Passers who are confronted with post-polio sequelae often have their self-image threatened because they can no longer pass as nondisabled. Their disability has become undeniable and suddenly they must give into it.

They may become frightened because they do not know how far it will progress. Typical thoughts may include: “Wearing a brace could lead to using two crutches, and a year later to a wheelchair, or who knows after that... and now that the disability is obvious, what will other people think...?” When confronted with polio’s late effects, Passers often must alter their self-perceptions and lifestyle in order to continue successful coping. Their former coping style may no longer be effective and new attitudes and behaviors must be learned. Clinically, Passers can often be fully rehabilitated because their new disabilities are less severe. They can often be reassured that modern orthotics, such as plastic braces, can be nicely worn under clothing and completely hidden inside shoes.

Passers may require an unexpected amount of understanding, patience and empathic support from health care professionals because of strong emotional reactions that are not only triggered by the impending public nature of their new disability, but also by memories of past poliorelated experiences. What may appear to be an over-reaction to a minor physical change is founded in years of fearful cover-ups and a longing to be “normal.” When their disability progresses from mild to moderate, they become undeniably disabled for the first time. This can be a harsh reality for them to finally face, accept, and adapt to. Using a new cane or crutch will publicly reveal a disability that can no longer be camouflaged. New coping techniques such as re-evaluating priorities, emphasizing the positive, and setting new goals can be invaluable tactics to employ during the process of re-rehabilitation.

## Minimizers

Minimizers are post-polio people who have had a moderate disability that was always apparent to themselves and to others. They have coped with polio's first effects by minimizing the negative and accentuating the positive. Minimizers may say, "So what if I use braces and crutches and I can't walk in a normal fashion, look at all the other things I can do." Minimizers have adapted by de-emphasizing physical pain, deformity, and functional shortcomings. Many have pursued intellectual vocations and avocations in place of more physical or athletic activities. They often have been high achievers who have pushed themselves to their limits. Minimizers have learned how to tune out their bodies in order to ignore physical imperfections, a process called "devaluing physique". "I was always taught that no one would notice my orthopedic shoes if I wore a pretty smile on my face," reports one Minimizer. This practical approach to living with an obvious physical disability has often been helpful for effective coping in a society that emphasizes physical beauty and prowess. However, Minimizers are often so adept at this form of denial that they recognize polio's late effects only when physical symptoms become unbearable and insurmountable. In order to survive and function at peak capacity they may have learned to use minimizing as a defense mechanism to such an extent that they became quite insensitive to their own pain, sadness, weakness, and anger. This perception can occasionally generalize to become an insensitivity to similar conditions and feelings in other people, including persons with a more severe disability.

When asked to respond to the attitudes survey statement, "I feel uncomfortable around other disabled people," Minimizers endorsed it more than the other post-polio groups. They often had negative attitudes about severely disabled individuals as a group, particularly wheelchair users. Therefore, they may feel that to personally begin using a wheelchair signals joining a social group that they have previously devalued and/or that implies defeat, helplessness, and not fighting vigorously enough against polio's disabling effects. Minimizers sometimes admit to difficulty being socially linked with someone in a wheelchair because the very association might somehow generate their own need to use one. It is useful for professionals to recognize these phobic-like reactions to wheelchair use when they occur and employ techniques for helping Minimizers change their perceptions of wheelchairs and wheelchair users. Indeed, these post-polio patients are the most likely to physically benefit from beginning to use a wheelchair. Minimizers may have difficulty verbally describing new physical symptoms because they are skilled at ignoring and/or denying such problems. They need coaching and encouragement to fully focus on their body sensations and reactions and to become what might be called "wise hypochondriacs." Health care providers must listen closely to Minimizers for the slightest mention of new medical problems and give them permission to elaborate. Minimizers most commonly feel guilty about causing others, including health care professionals, inconvenience related to their new disability. These assumptions can block the progress of thorough and continued re-rehabilitation. Insightful health care professionals can help Minimizers embrace physical and lifestyle changes brought on by polio's late effects by helping the patient re-think and newly experience these disabilities, transforming them from burdensome affronts into simple facts-of-life.

Additionally, Minimizers are likely to have intense angry feelings about having to deal with new disabilities and re-rehabilitation. The classic question is, “do the virtuous fade first?” reflects a justifiable anger at having exercised and strained in daily routines for decades to come back from polio’s acute attack only to become more debilitated later from what authorities call “overuse.” Returning to rehabilitation can feel like an unfair defeat after a hard-fought struggle to overcome impairments and win the promised, sought-after and permanent exit from medical regimens and institutions.

Health care professionals can acknowledge and validate the Minimizer’s anger as logical and can encourage living with that anger in healthy ways. Anger may manifest itself by slowing the re-rehabilitation process temporarily and creating resistance to starting new health care regimens. Alternatively, energy from anger may produce unrealistic expectations and/or impatience with their seemingly slow rehabilitation process. Anger can also give Minimizers the energy to make positive changes. However manifested, it is important that the health care professional not misinterpret anger or hostility as being permanent, personal; or irresponsible. It is a natural reaction to an alarming and serious situation that must be patiently dealt with and for which there is no cure.

In spite of many negative emotional reactions, Minimizers know how to set goals and achieve them with persistence and determination. The astute health care professional will encourage and help empower the Minimizer to use these qualities to re-focus on what is important in life; to take another look at how to be successful; to set new goals and achieve them in new ways. Health care professionals, family and friends must be patient in helping Minimizers work through understandable resistance, fears, and anger with re-rehabilitation. They must respect, remember, and sometimes remind Minimizers that they are experienced copers who have a well-proven capacity to see the positive in adversity and adapt effectively. As some Minimizers become more disabled, they may want to employ the key coping tactics of postpolio Identifiers.

## Identifiers

Identifiers are people who have usually been sufficiently disabled since the onset of their acute polio to require wheelchairs for mobility. They have needed to more fully integrate their disability into their self-image in order to create successful and meaningful lives. Through identifying with others having physical disabilities, they have gained the strength to tolerate social prejudices and architectural barriers. Not surprisingly, many moved beyond their tolerations to become disabled rights activists who inspired environmental change and helped start the independent living movement.

Among the three groups sampled through the attitudes survey, Identifiers most strongly endorsed the statement, “high achievement is a requirement for survival as a disabled person.” They also most intensely believed that taking an active role in the disabled rights movement was necessary to their future well being in society, and that fully acknowledging their disability will help them cope with it more effectively. With the onset of polio’s late effects, many Identifiers confront the loss of their independence. The smallest functional forfeiture can be extremely distressing to a person who has been chronically severely disabled. If breathing function becomes significantly impaired, death may be a realistic threat. For Identifiers who have had to work diligently to learn to feed

themselves and perform other relatively simple self-care activities, independence in daily living activities maybe one of the most important accomplishments of their lives. Therefore, if post-polio sequela threatens a decline in strength, they can be expected to appear extremely distressed. Effective helping professionals need to anticipate the Identifier's concerns and recognize that their intense interest in autonomy and control of their environment is not pathologic. Identifiers have needed to develop a heightened concern about physical independence and about personal choice with how required help is given in order to attain high self-esteem and survive with their severe disability. When their freedom to control personal life activities is threatened by new physical limitation or even by temporary dependency imposed by a hospital setting, Identifiers may experience a threat to their whole life and purpose for living. This reaction often leaves Identifiers vulnerable to other's false perceptions of them as being overly controlling, difficult, and demanding people. In reality, they simply know what they need and are not too timid to ask for it. The informed health care professional will accept this and will do everything possible to let them continue to feel, and actually be, in charge of what happens to them.

## Exceptions to the Models

As previously stated, each of these three coping styles is typically clustered around a mild, moderate or severe disability level. Of course, exceptions are not uncommon. Sometimes, those with severe disability demonstrate Minimizer attitudes. For example, an attorney who had exclusively used a wheelchair for mobility for over 30 years experienced sincere and deep-felt shock at a physician's matter-of-fact reference to his severe disability when explaining the wearing out of his upper extremities, his possible need for electric wheelchair use and the advantages of reducing his work day. The man had de-emphasized his obvious severe disability for years, successfully utilizing the coping style of a Minimizer. Some Passers, likewise, have been highly visible leaders in the post-polio movement, and Minimizers may share the Passer's fear of being stigmatized as part of society's "disabled minority."

Emotional distress is common to all survivors who experience a loss of functional abilities and an uncertain future. However, the greatest distress can be anticipated when a person's current functional capacities cause them to change from being a person with a hidden to a socially obvious disability and from being a walker to a wheelchair user. It must be remembered that each coping style can be successful. Any of them can assist a given individual in maintaining their highest functional level and their optimal social adjustment.

## Successful Re-Rehabilitation

Passers, Minimizers, and Identifiers each adopted a characteristic coping style in the past that worked to create some of our generation's most successful and resilient survivors of physically disabling illness. The onset of new post-polio problems can present a challenge to their previously successful methods of coping and create significant emotional distress and pain. Health care professionals need to be aware of polio survivors' typical past coping styles and of their need to employ different tactics for coping during the re-rehabilitation process. Passers can no longer walk without a cane if

they are now prone to falls. Minimizers cannot continue to ignore new pain and Identifiers may need respiratory aids in order to breath more easily. Helping professionals can point out to polio survivors that it is possible to find opportunity in their time of change. Passers can “come out of the closet” or relax and enjoy a little more freedom with their very acceptable natural physiques and identities. Minimizers can also be empowered to live life with a great sense or wholeness through more fully recognizing, accepting, and integrating all aspects of their bodies. By relinquishing their struggle for physical independence and accepting new personal and technological assistance, Identifiers can gain the time and energy to develop new pursuits and cultivate other realms of interest. In this honest and supportive spirit of healthy transition, successful re-rehabilitation for polio survivors can be fostered.

*Many thanks to the North Central Florida Post-Polio Support Group for permission to reproduce this article.*

## PPS: Is There a Cure?

Just as there is no confirmed etiology, or cause – and thus no definitive laboratory test – there is really no cure at the present time for post-polio syndrome (PPS). There is, however, treatment revolving around a three-pronged rehabilitation approach. Says one expert: “More than 80% of patients with PPS will demonstrate benefit with rehabilitation techniques.”

The three approaches are:

### **Life-style modifications**

1. energy conservation
2. assistive devices
3. non-fatiguing exercise
4. staying warm

### **Medications and supplements**

Though many medications, prescription as well as natural supplements, have been tried, none has been proved to help. There are many anecdotal reports of improvement, but further study is needed. Keep in mind that herbs can interact with prescription medicine, so always let your physician know what you are thinking of taking.

### **Quality of life**

“The strongest medicine that a practitioner can provide to a patient with PPS is education and encouragement... Patients who were better able to make lifestyle modifications (those with better problem-solving skills, more accessible environments, more access to information and support, and a readiness to compensate with assistive devices) adapted better in their daily occupations.” Dr. Susan Perlman.

*From Henry's Desk by Henry Holland*

## My Left Leg

The fiftieth anniversary of the announcement of the successful trials of the Salk vaccine was observed on April 12, 2005. There was considerable media coverage of this historic event as well as an excellent HBO movie on Franklin Roosevelt's connection to Warm Springs, Georgia. Also many survivors of polio are recording some personal memories of their life long experience with polio. When I think of my own fifty-five year experience with polio I somehow feel compelled to remember with kindness and wonder about my left leg.

My acute case of polio affected my body from the neck down and with an asymmetrical degree of involvement. My right leg and right arm were more severely involved than my left leg and left arm. My right arm and hand made a partial recovery. I was able to use my right hand and arm to write again, tie shoes and button clothes. My right leg essentially remained flaccid except for some movement of the hip muscles. Thus, my right leg has been braced for fifty-five years. My left arm made almost a complete recovery and I thought my left leg made a complete recovery.

I cannot begin to estimate the work that my left leg has done in making it possible to lead a very productive life. Because of the strength in my left leg, that leg compensated extremely well for my flaccid right leg. After polio my left leg was not expected to get stronger. I left the Medical College of Virginia Hospital with two long leg braces and wooden crutches on Monday, December 18, 1950. I exercised my legs and arms daily and my left leg and left arm became stronger to where I discarded the left leg brace and the crutches three months later. I never succeeded to any degree of rehabilitation with my right leg despite a major effort over time. Now I know that the damage to the anterior horn cells of the spinal cord was too severe to make a return of function of my right leg possible, but at the time I remember feeling that I had not tried hard enough to "recover" that leg. What did my left leg do over the next twenty years? Maybe some of you can identify with some of these milestones.

My first goal was to be able to master climbing steps in order to return to public school. I did return to the sixth grade of my elementary school a year after contracting polio. I was able to climb steps one step at a time with my left leg doing the work. This school building had two stories with a full basement. My next goal was to regain the ability to ride my Roadmaster bicycle. This was quite dangerous as I could do nothing to prevent falling to the right side of the bicycle when I stopped. I mastered this one leg bicycle riding. All the pedal pumping power was provided by my left leg. Riding a bicycle again was a big step in increasing my mobility and participation in activities with my group of able bodied friends.

My third goal was to play some kind of sports again. I could still throw a ball or bat a ball but I could not run the bases. I could shoot baskets but I could not jump. I became interested in table tennis or ping pong and became rather skilled at this game. Later in my teens my left leg made it possible to walk an eighteen hole golf course and I enjoyed this game during my college years.

I entered junior high school (7th to 9th grade) in February 1952. The school had three stories and no elevator. Classes changed six times a day, much like in high school. The guidance counselor, a survivor of polio, allowed my best friend Harry Lanzillotti and myself to leave each class five minutes early in

order to get to the next class without my being knocked over on the steps because of the rush of students in the hallways and stairwells between classes. Harry also carried my books as we went between classes. He also carried my books home for me as we walked a distance of four blocks. My left leg carried the burden in moving about this school as well as the three story high school that I attended for the 10th through the 12th grades. My left leg made it possible for me to participate and enjoy the many activities of adolescence.

The next challenge in my life was dealing with hills. I received a scholarship to Washington and Lee University. This college is a two hundred and fifty-six year old college located on top of a hill in Lexington, VA. For four years I climbed this hill carrying books at least two to three times a day. My left leg made this hill climbing possible.

Many of you know where the Medical College of Virginia is located in Richmond. It is on top of a hill and most of the parking in the 1960's was at the bottom of the hill. Even the able bodied students called the hill "heart attack hill." The main hospital had seventeen stories. I entered medical school in 1962 and I can remember climbing steps at MCV on many occasions because the elevators were too slow and time was lost waiting. My left leg did all of this climbing.

After graduating from medical school my left leg got me around in hospital parking lots, hospital corridors and in family activities. About a decade ago my left leg began to weaken and gradually pulling up steps became impossible. Now my left leg can still support my weight, but it no longer has the strength for walking or standing for any length of time. When this weakness began ten years ago, it really did not surprise me as I knew that I had Post-Polio Syndrome (PPS) and that "recovered" muscles could weaken as part of PPS. In addition my respiratory muscles have weakened. I am now totally electric. I use a power wheelchair and a ventilator 24/7.

Whatever the real cause of PPS might be I know that the overuse theory makes sense to me, especially when I think about my left leg. I am sure that many of you have similar stories of how stronger muscles did more work over the years to compensate for weaker muscles; and in many cases these previously stronger muscles are now much weaker and can no longer do all the work of the past.

We all have individual stories about our many challenges, triumphs, failures and adjustments made in life because of polio and now we are experiencing similar adjustments because of PPS. The difference with PPS is that we now have each other and we no longer bear our frustrations privately unless we choose to do so.

I watched the HBO movie "Warm Springs" with interest. The film was essentially historical fiction. However, the film did reveal the tremendous effort that Franklin Roosevelt made to help his own rehabilitation. His belief in the warm waters of Warm Springs, Georgia, led to his purchase of the resort. He transformed this old resort into a polio treatment facility. When he went to Warm Springs he would be among other polio patients. This proved to be therapeutic in itself. In the film, Roosevelt addresses the other patients as he leaves to resume his political career. His words were these:

"You will be with me, no question of that. Well I want to say how proud I am to be a part of this community, not based on birthright or privilege, but on compassion and courage. You know I believe the true power of these waters is that they brought us all together and our ability to help one another is what will make our victory over polio endure because what you have done and what we will continue

to do until this disease is defeated is to come together like a family and do what we do best, lift each other up.”

PPS has brought us together. We do help each other and relate to each other as a family. We will continue to lift each other up.