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CHILDHOOD POLIO INFECTION MAY CAUSE CHRONIC FATIGUE SYNDROME IN BABY- BOOMERS

The Post-Polio Institute
ENGLEWOOD HOSPITAL and MEDICAL CENTER

For Immediate Release . . .
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Englewood, NJ, January 11, 2000 -- A childhood poliovirus infection may cause chronic fatigue in baby-boomers concludes a paper published in the January, 11, 2000, issue of the American Journal of Physical Medicine and Rehabilitation "Paralytic Versus 'Non-Paralytic' Polio: A Distinction without a Difference," by Dr. Richard L. Bruno, director of The Post-Polio Institute at New Jersey's Englewood Hospital and Medical Center and chairperson of the International Post-Polio Task Force.

Bruno reviewed the personal laboratory notebooks, publications and private correspondence of Dr. Albert Sabin, developer of the oral polio vaccine, regarding a 1947, Cincinnati, Ohio outbreak of the "Summer Grippe," a flu-like disease that affected more than 10,000 children. Because Summer Grippe was associated with a stiff neck-- a hallmark symptom of polio-- Sabin hospitalized and studied a dozen children. "Sabin concluded that Summer Grippe was caused by a mild form of the Type 2 poliovirus which caused a flu-like illness even though it did not cause paralysis," said Bruno. However, when Sabin infected monkeys with poliovirus from the Summer Grippe children, spinal cord and brain stem neurons were killed just as they would have been by a paralytic poliovirus. "Both the Summer Grippe and paralytic polioviruses damage the brain stem," Bruno continued. "Sabin showed us that even a 'mild' poliovirus infection could cause neuron damage that, although not apparent in

terms of causing polio-like symptoms, was very real."

However, Bruno reports that another "mild" poliovirus outbreak did cause symptoms. In the very next year, 1948, over 1,000 Icelanders became ill with a flu-like illness causing stiff neck, some muscle weakness, and fatigue. While many of those with "Iceland Disease" recovered, some who became ill in 1948 still have fatigue today. "Iceland Disease was also apparently caused by a relatively mild Type 2 poliovirus," said Bruno, "but one that did more severe and therefore more apparent damage to the brain stem -- damage that caused chronic fatigue." Fifteen years of research at The Post-Polio Institute treats many middle-aged adults with fatigue who had non-paralytic polio as children. "Albert Sabin showed us that even a mild poliovirus infection can damage the brain activating system setting the stage for fatigue to develop later in life," said Bruno. The Post-Polio Institute's experience is supported by the 1987 U.S. National Health Interview Survey which found that 21% of those who had had non-paralytic polio report fatigue in mid-life. "The one million North Americans who had non-paralytic polio must be assertive," said Bruno, "telling their doctors that both paralytic and non-paralytic polio survivors develop late-onset fatigue."

An epidemiological study by Dr. Leonard Jason, published in the October 11, 1999, issue of the Archives of Internal Medicine, found that half of the estimated 836,000 Americans with CFS are at least 40 years old. Jason concluded that baby-boomers may be at greater risk for CFS. "Potentially half of those diagnosed today with CFS may in fact have had Summer Grippe or undiagnosed non-paralytic polio as children in the years before the polio vaccine became available," said Bruno. "They may also have brain activating system damage that causes chronic fatigue."

"There is no question that neither the naturally-occurring poliovirus nor the Sabin oral polio vaccine causes CFS today," said Bruno. "But the

possibility of a non-paralytic poliovirus infection in childhood causing chronic fatigue in middle-aged baby-boomers is a reason for hope." The Post-Polio Institute's research has found that conserving energy, daytime rests breaks, stopping activities before fatigue starts, and a higher-protein diet significantly reduce symptoms of fatigue."

"Paralytic Versus 'Non-Paralytic' Polio: A Distinction without a Difference" can be found at <http://members.aol.com/ppseng/NPP.html>. Dr. Bruno's article on the Summer Grippe can be found at <http://members.aol.com/ppseng/Stealth.html> and on Parallels Between PPS and CFS at <http://members.aol.com/ppseng/Parallels.html>.



Post-Polio Rx: Seek Harmony, Conserve Energy By Vicki McKenna

The following is excerpted from the book "A Balanced Way of Living: Practical and Holistic Strategies for Coping with Post Polio Syndrome," by Vicki McKenna. See below for information on ordering.

We may not choose to have post-polio syndrome (PPS) but we can choose how to cope with it. By seeing PPS as an opportunity for change and growth we learn to come to terms with it and find ourselves in control of our lives once more.

We have seen how we can build energy by practicing certain techniques and watching what we eat. In this way we protect ourselves from becoming stressed and damaging our sensitive nervous systems. Finally we need to focus on our outer environment and start to make changes in our homes and at work that will also help the process of sustaining and conserving energy.

If we pay attention to intuition, the teacher within, we will find ways of doing this. Always ask your inner wisdom for guidance; through prayer, meditation, dreams, we can find solutions that prompt easier, more harmonious ways of doing the things that presently drain us. What follows are merely suggestions. If you feel uncomfortable with them put them aside. Always, always listen to your own heart -- be guided by its wisdom.

The model of Chinese philosophy provides us with a path that shows us the basic foundations we need in order to live a life of balance and harmony, including the practice of breathing exercises

and meditation; the need to let go and flow with the energy of life. It remains to be said that the wise man in Chinese philosophy traditionally cultivates a lifestyle that teaches us the following three things.

Firstly, we need to understand that although we seemingly lead separate lives, we are all linked and we all affect each other. Because of this we need to care for our fellows and be cared for by them. In other words, we need to feel supported. In this way the human heart and spirit are fed and nourished.

Secondly, we need to live lives of simplicity and make our environment easy and stress-free to live and work in. We do this by careful planning and organizing.

Thirdly, we need to ground ourselves in a calming sense of routine, which brings rhythm and stability to our days. In this way we can feel energized and uplifted, able to live our lives fully. Let us look more closely at each of these areas.

Support: As polio survivors we need to be supported in many ways. Crucially we need the emotional support of those around us but practically speaking we also need financial and physical support to assist us in our lives.

Marjorie often feels despair now that PPS has limited her mobility and finds it hard to ask for help. She has written a piece called *Isolation* which she has kindly allowed me to quote from: "It's a lonely word, isolation; on bad days it seems to envelop me like a smothering blanket cutting off sustaining air. Once I liked to be alone with my books and music, then, private time away from people and pressures provided nourishment for my soul... Solitude was precious because it balanced the pressures of days spent dealing with people ... At times I feel imprisoned, like Rapunzel in the castle tower, without the advantage of long hair to slide down. It is difficult obtaining help when one is proud and independent." Marjorie feels excluded and lonely and is finding it hard to tackle life without a support network.

Stressors can be endured more easily when you have a strong supportive network of family and friends. Research shows that good health depends on a support system. Ethnic communities often do not have the same stress-related diseases that the rest of us do simply because they are composed of close-knit communities.

As polio survivors we need to learn that it is OK to ask for help and accept the support and en-

couragement that others can give. We all taught ourselves to push on independently of others -- we can manage fine on our own. We do not need to be ultra brave and strong -- just realistic. We need to accept our disability pragmatically and trust others to help us. Many of us have support networks set up, others need to construct them. The key to support is communication -- we need to be able to clearly express what help we need. In this way we will not feel that we have lost control of our independence.

Dorothea Nudelman, polio survivor, mother and author of "Healing the Blues" (a very moving account of Dorothea's experience of psychotherapy, which I highly recommend -- especially for anyone thinking of going through the therapy process) found that PPS allowed her to make many changes in her life. She writes, "The most complex and far-reaching changes I need to make lie in communication with my spouse, my daughter and my close friends -- people I interact with on a daily basis and who are closest to me. I think that for polio veterans to move forward in developing significant relationships with children, spouses and friends, we must abandon our silences and voice our needs more openly and directly. While the need to 'ask for help' seems self-evident, it is difficult to do when the lessons of silence were tied to independence and self-reliance throughout our recovery years. Though silence served as strong motivation in our initial recovery, it is futile and destructive when used inappropriately. If we now need to rely somewhat on others for the full enjoyment of our lives, not to ask for help exhibits false pride and recklessness."

Dorothea describes a conversation with her daughter that reveals clearly how communication is indeed the key. "Offhandedly I asked her, 'What memories about my coping with polio are vivid for you now as you look back?' Without hesitation she answered, 'Your never relaxing, never stopping when you worked at something until it was done. I always knew when the end came when you'd say, 'Okay. Now I've got to go and put my feet up.' It wasn't until recently that I knew your legs hurt you. It was that, knowing about the pain, that got my attention. I felt bad when I learned it hurt. I understood 'hurt.' Had I understood earlier, I think I'd have been a lot quicker to do things, to help. At first it made me angry that I didn't know. Now it just makes me sad. You never said anything.'"

Dorothea was amazed that her daughter saw her mother's silence from this perspective. "I'd never seen it this way. Silence was the very thing I'd practiced so as not to leave her burdened. But this 'protection' didn't serve her well any more than it had served me. Once I realized that, the flood-gates of conversation opened easily. Since then, I have been entirely honest and direct with her. And she has said it's so helpful, all the time, to know what's going on with me. Speaking for herself and her dad she said, 'That's the best way for us to help you. The best, the easiest, the fastest way for us to know where you're at -- open communication without demanding.'"

We polio survivors need to realize that asking for help does not constitute 100 percent dependence. As we reach out to others, we find we can still be in the driving seat. Taking the decision to clearly ask for help will improve the quality of our lives rather than trying to do everything alone and getting exhausted in the bargain.

Asking for help is hard but one way of doing this is to gather together all those who are connected with you -- family and friends -- and explain to them how PPS is affecting you and what your needs are now. You may need more help with getting out and about shopping and socializing or with housework. If everyone is put in the picture they will be more able to help you.

Do not expect others to anticipate your needs -- you need to ask. Allow others to help and give them recognition and thanks for doing so. Often people want to help but are often put off by the feisty, determined attitude of a polio survivor. Instead of wasting energy pushing support away and coping in type-A style, we need to learn to ask for help and welcome it when it is given. We needed to be type-As in the past in order to survive with our disabilities; now we need to give ourselves permission to relax and reach out to others whom we trust to help us.

A trained counselor can also be part of a support network. Marjorie found counseling very helpful, "because many of us don't want to burden friends and family with our worries." Since the stressful period when she wrote *Isolation*, Marjorie has come a long way towards accepting her limitations and allowing others to help.

I experienced several months of therapy and it helped me enormously to know that there was someone I could offload to and who would lis-

ten as I voiced my fears. With my therapist's support I learned to cope better with the changes in my life. If you see a councilor try to find someone who is not inclined to take a "psychosomatic" view. Your therapist needs to be informed that PPS is a real organic illness and not the result of a depression.

Giving Support: We need to be aware that as much as we need to be supported we are also capable of giving support. The stress pioneer, Hans Selye, found that the best way to be loved was to act lovingly towards others. He described this as "altruistic egoism." Whatever we put out is mirrored back to us; when we extend love and care we will receive the same in return. Often it helps to focus on others' problems rather than our own. This can be done by campaigning for civil rights, by being involved in a support group or in any number of ways.

Marjorie has set up a small maternity agency that she runs part time from home -- providing a service for others helps her feel good. Jennifer finds it hard to do the things she previously took for granted but manages to find the time to be a volunteer caregiver at a local nursery for children from deprived backgrounds. We can all do something, in our own way, to reach out and make a difference to the world. Taking the focus off ourselves and spending time loving others helps us to feel valued and included.

Supportive Equipment: Our bodies now tire more easily and our limbs are weaker than they were. We may need to use equipment such as canes and wheelchairs where previously we managed without. Giving ourselves permission to appear disabled by using such equipment is hard for those of us who passed for able-bodied but it is crucial that we let go of pride and denial if we are to help ourselves and move forward.

It is hard to admit that we may now need more help -- we fought the battles of polio and felt we had conquered the affects of the disease forever. For many of us it feels almost like a backward step into failure to start having to use assistive aids.

Those who have already relied on equipment such as this may now find that using a wheelchair for long distances can make mobility less of a problem. Jim, on first using a ventilator, says he felt "as if I have been given a new start to life". He feels that the machine is well worth the hassles involved in learning to use it and of upkeeping and maintaining it for with it he has his life back.

To push on without the right kind of help can mean wearing out weak and vulnerable muscles -- particularly those that were not obviously damaged by polio but were nonetheless affected. Once we let go of pride we can start to enjoy life as we zip along on our electric scooters. Adapting to change is never an easy process but as we have seen earlier -- we need to let go of struggling and focus on whatever it takes to help us cope more effectively so that we may move on in our lives and start to enjoy ourselves again.

Financial Support: Developing PPS may mean an end to stable employment and being forced onto benefits. Most people I spoke to have had to take early retirement or revert to part-time work. This may mean a decrease in their standard of living and a precarious financial future. Clare found she had to sell her flat and move out of London to live somewhere cheaper. She realized she would not be able to continue to pay her mortgage after having to stop work due to PPS. I found myself in a similar situation and moved cities to make our financial situation easier. Changes such as these are never easy but neither is living with the stress of a demanding job and PPS. Try to sort out your financial situation before you work yourself into the ground and are forced to retire.

Sharron denied her symptoms of PPS for a long time before she realized; "I couldn't cope. I ended up going on sick leave and couldn't handle the thought of going back to any of my jobs mentally or physically." With the help of a councilor, Sharron began to make the changes necessary to lead a more relaxed lifestyle and now reports that her life is manageable once more.

Stability: We need to see energy as a bank account -- if you keep drawing on your energy without replenishing it you will wind up with an empty account. We need to live lives where we give equal weight to rest and activity for in this way we keep the bank account balanced and in the black. PPS is an opportunity to let go of lifestyles that exhaust us so that we can start to live on more of an even and balanced keel.

Chinese medicine always stresses the importance of a lifestyle that adapts to life's changing circumstances and often refers to the changing seasons as the best teacher on how to "go with the flow." When it is winter we all need to accept a reduction in activity and take more rest, as plant life does.

With PPS we may have to encourage ourselves to be more often in "winter mode" and take plenty of rest. We need to learn to value this time and see purpose in it. Just as seeds need to be dormant before developing into shoots so the daydreams and reveries of our resting time can allow us to develop helpful insights. In this way we connect with the deep wisdom of our inner selves and build energy so that we can be more active when necessary. Here are some of the ways that we can pace ourselves and lead more harmonious and enjoyable lives.

Always plan at least two rest periods per day. I do meditation, chi-gung and breathing exercises in the morning for an hour and have a one-hour nap in the afternoon. Resting must mean a total break from all distraction and noise. I turn off the phone and tell everyone not to play music or disturb me. Call me an old grouch if you like but I know what helps me to feel better.

Alternate periods of activity with breaks. Break activities up into chunks and do a little at a time. If I work on the word processor for an hour I will then take 15 minutes to recover the energy expended.

"Have to" and "should" need to be used rarely. In this way we cut back on tasks involving duty and increase on the level of pleasure. I now avoid loading myself with situations that I used to push myself through. If they cannot be avoided then I get on with the task in hand but I focus on the fact that this stressful activity will soon be over and meantime it is an opportunity for growth -- a chance to practice mindfulness, going with the flow and breathing techniques.

A stable life is one that has clear boundaries. I have routines that enable me to choose how and when I expend and conserve energy. Sometimes this means that I have to say "no" or "maybe" to friends. I have planned my life to enable me to do the things I want to do, when I want to do them. That may sound selfish but it is actually a matter of survival. If I were to live a life of abandoned spontaneity, I would be exhausted and of no use to myself or anyone else. The crucial element here is to have a balance of work and play.

Some time needs to be spent in pursuit of hobbies and other leisure activities. Creative expression can release frustration and through activities such as painting or writing we can let go of our feelings. Include time with friends and family shar-

ing how the day/week has been. Periods of relaxation are the foundations of a balanced day. We need to be alone with ourselves to contemplate and regenerate. This is the time to do gentle exercise and practice meditation, to take a nap or simply sit in the garden or local park and absorb the pleasures of nature.

Vicki McKenna was born in 1951 and contracted polio the following year. She spent her childhood years in Pakistan, a background which led her to a BA degree in history and religious studies. She had four daughters and then trained as an acupuncturist. She is now based with her family in Glasgow.

She can be contacted via e-mail at Vicki@share.force9.co.uk.

To order her book "A Balanced Way of Living: Practical and Holistic Strategies for Coping with Post Polio Syndrome," send a check or money order for £10 (UK) or \$25 (US) to Vicki McKenna, 42 Regent Park Square, Glasgow G41 2AG, UK.