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General Information Letter for Polio Survivors

Why are "old polios" who were stable for years now losing function? What should they do about it?

Jacquelin Perry, MD, DSc (Hon), Rancho Los Amigos National Rehabilitation Center, Downey, California

The basic problem is that polio destroyed some of the nerve cells that activate the muscles. To the extent possible, the neurological system responded by having the remaining nerves adopt the muscle fibers that had lost their original nerve supply. This meant that nerve cells now had a demand much greater than normal. While this was an effective solution initially, the passage of time (30+ years, usually) has taught us that overuse can be destructive. As a result, these secondary nerves are wearing out with resulting muscle loss, i.e., post-polio syndrome.

Post-polio muscle strength is commonly over estimated as the usual test depends on manual resistance by the examiner. In addition, polio survivors mask their disability by clever use of their normal control and normal position sense to substitute for missing musculature. The post-polio muscle graded "normal" (5) averages 25% less than "true" normal (only 50% normal for the quadriceps). Similarly, the muscle graded "good" (4) is only 40% of normal strength. These strengths are adequate for a person to carry on customary activities in a typical manner, but at a demand that is 2-2$^1/_2$ times the usual intensity; hence, the muscle nerves have been experiencing strain for years.

The apparent abrupt loss in function relates to two functions. One is the buffer zone present in all of our physiological systems which enables them to accept strain for a considerable time, but once the buffer limits are exceeded, the loss is very prominent. Secondly, activities such as walking or lifting objects present fixed mechanical demands. As long as the person's muscle strength exceeds that demand, he/she can continue to perform as usual but with earlier fatigue. When the strength goes below the essential limit, suddenly that function is lost.

The answer is redesigning your lifestyle to avoid those activities that cause muscle strain, cramping, persistent fatigue, and, consequently, weakening. This means to very carefully look at how you are using your arms, legs, and back, and to avoid those tasks that cause the symptoms of persistent fatigue, muscle soreness, and/or a sense of weakness after use. At times, this requires the employment of special devices to take the load off of the arms. If the changes are made early, strength can be recovered. It will not be sufficient to prepare the muscles for excessive strain again, but it does bring the muscles up to a more useful level. Other ways of reducing strain is by using self-care devices, walking aids, braces, and corrective surgery to lessen the stress.

Once the strain has been reduced, then cautious exercise may be of value. We have been using short duration (5 repetitions) or moderate intensity (50-70% of one's maximum capability). Let me caution you not to take on the exercises, however, until you have worked out a lifestyle that avoids the strain. Also, if the exercises cause any pain, persistent fatigue, or increased weakness, STOP! This means just the mechanics/activities of daily living (ADL) are sufficient exercise for your muscles.

Recent research on the course of muscle strength over time in persons over age 50 years showed a normal average decline of 1% per year, but for post-polio survivors the rate was 2% per year. The rate of change is so subtle that a four-year study was needed for a measurable change. Also, the weaker "polios" experienced greater functional loss. This latter

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fact *appeared* to indicate strength training by exercise would deter the process. However, retesting this group of polio survivors at eight years and adding muscle analysis told a different story. The muscle fibers were hypertrophied, twice normal size, not atrophic. The person with the greatest strength loss also had the greatest hypertrophy.* MRI recordings showed areas of muscle loss and fatty replacement. The source of the visible muscle atrophy is muscle fiber loss secondary to nerve fiber overuse failure. These findings confirm the need for a saving program rather than challenging exercise.

The advantage of having had polio rather than another disability is that it allowed one to resume a very active and profitable life for many years. Now it is necessary to recognize that excessive strain was being experienced and that lifestyles must be changed to accommodate this situation.

Be an "Intelligent Hypochondriac" – Listen to your body and adopt a program that avoids the strain. ■

Jacquelin Perry, MD, DSc (Hon), was certified by the American Board of Orthopedic Surgery – one of the first women to be certified – in 1958. Immediately after her residency in orthopedic surgery, she was invited by Dr. Vernon Nichol (Chief of Surgical Services) to join his staff at Rancho Los Amigos in the Los Angeles area. She has been involved in the management of the problems of polio survivors since that time. She is Professor Emeritus Orthopaedics, University of Southern California.

Starting New Study ...

Sophia Chun, MD, works with Dr. Perry at the Post-Polio Service, Rancho Los Amigos National Rehabilitation Center, Downey, California (www.rancho.org), and reports that they will be studying the effects of creatine monohydrate on strength, endurance, and fatigue level in symptomatic post-polio patients (in Southern California) starting in late October or November 2000.

* "Several histologic studies have shown that the myofibers of polio survivors can be twice the size of those found in other persons. A few studies have provided indirect evidence for a possible transformation of some of the surviving type II (fast-twitch fibers) to type I (slow-twitch fibers). The few studies performed have shown a preponderance of type I muscle fibers in very weak muscles that were constantly being used in daily activities. It has been postulated that a person would have to utilize all motor units in these very weak muscles to perform all daily activities and that, over time, the type II fibers are transformed to type I fibers."

Source: Agre, J.C., Sliwa, J.A. (2000). Neuromuscular rehabilitation and electrodiagnosis. *Archives of Physical Medicine & Rehabilitation* 81(3), Suppl S27-31.

Selected Post-Polio Bibliography

❑ Agre, J.C., & Sliwa, J.A. (2000). Neuromuscular rehabilitation and electrodiagnosis. *Archives of Physical Medicine & Rehabilitation* 81(3), Suppl S27-31.

This self-directed learning module briefly highlights the differential diagnosis for acute weakness in patients with acute respiratory failure requiring prolonged mechanical ventilation.

❑ Bartholdi, D., Gonzalez, H., Borg, K., & Melki, J. (2000). Absence of SMN gene deletion in post-polio syndrome. *Neuromuscular Disorders* 99(10).

❑ Burger, H., & Marincek, C. (2000). The influence of post-polio syndrome on independence and life satisfaction. *Disability Rehabilitation* 22(7), 318-322.

This study from Slovenia found that the new symptoms in post-polio survivors, which may be classified as post-polio syndrome, increased their walking and climbing stairs disability, increased their disability to perform daily activities, and also decreased their satisfaction with life.

❑ Gandevia, S.C., Allen, G.M., & Middleton, J. (2000). Post-polio syndrome: Assessments, pathophysiology and progression. *Journal of Disability and Rehabilitation* 22(1/2), 38-42.

This paper describes the establishment of a post-polio clinic and the principles adopted in quantitative muscle testing using twitch interpolation. Peripheral endurance and/or voluntary drive to muscles is impaired in about 30% of prior-polio patients attending the clinic. Progression of these deficits is slow and not easily predicted by factors associated with the original illness.

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Editor's Comments

Dr. Perry's article (page 1) covers the basics and defines post-polio syndrome right up front. Definition continues to be a problem. The medical literature more narrowly defines post-polio syndrome; some lay literature equates post-polio syndrome and the late effects of polio. International Polio Network does not. When reading any information, including the articles cited in "Post-Polio Bibliography (page 2)," it is always wise to first establish how the author defines post-polio syndrome.

Definition was briefly discussed at the recent March of Dimes/ Warm Springs meeting (May 2000). The experts still need to reach a consensus. The information that was presented by the health professionals (listed in the last issue of *Polio Network News*) is now being edited. The Executive Steering Committee hopes to have the final product available by early 2001.

International Polio Network will begin updating the *Post-Polio Directory–2001* in late December. Please watch for your entry via mail or e-mail, carefully check the information, and return it to us immediately. The "Post-Polio Clinics" will receive a survey to complete which will clarify their services for evaluating and managing the late effects of polio. If you know of knowledgeable, caring health care providers who should be listed, please send their information to us. We will contact them.

Many of you participated in the "Mobility, Disabilities, Participation, and Environment" study by the Program in Occupational Therapy at Washington University. David Gray, PhD, reports that the project received additional funding. A future issue of *Polio Network News* will include conclusions and insights from the research.

Several of you have asked about the benefits of human growth hormone (hGH). Human growth hormone is produced by the pituitary gland at the base of the brain and is responsible for our growth spurts as children. Its production tapers off as we age (beginning in our 30s). A few small studies have shown that hGH supplementation may increase muscle mass. A study published in 1995 by K.R. Shetty, et al., gave hGH to six individuals meeting the criteria for post-polio syndrome and measured their before and after muscle strength and endurance. The majority of the muscle function tests showed little or no improvement or change after three months of hGH treatment. The possibility of benefit from treatments longer than three months remains.

The Mayo Clinic Health Newsletter (June 2000) reminds us that there are side effects to this prescription drug taken by injection and that it is costly (a year's supply can be $10,000). If you have seen the full page advertisement in the newspaper reporting the benefits of hGH, read carefully because what is being sold is not hGH but "growth hormone releasing" nutrient, a specific combination of amino acids that is said to release our hGH from its "sequestered state." We will keep you posted on any research being done specifically for the survivors of polio.

Polio survivor and friend, Ellen Fay Peak died of cancer in August. Ellen helped me immensely with editing over the last four years. She and I were both ex-teachers, and we had a similar outlook on many aspects of life. The last time I spoke with Ellen, she was calling to tell me that she was now "taking medication for her medication." Her polio experience was much more complex than mine, and she freely shared her thoughts. I will miss her.

– Joan L. Headley, MS
Executive Director, GINI

International Polio Network

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Antidotes to Stress

Polio survivor Mary Westbrook, PhD, from Sydney, Australia, author of "An Antidote to Post-Polio Stress: Pleasure Seeking," *Polio Network News*, Volume 16, Number 2, shares her personal antidotes. They are followed by the experiences of other survivors.

Pleasure Seeking Ideas

Mary Westbrook, PhD
(MTWestbrook@bigpond.com)

Friends and interests, including work, have always been major sources of pleasure in my life. As these have been eroded by post-polio, I have tried to preserve what I could, often by modifying activities. When I could no longer garden, I had a small wheelchair-accessible garden with containers and raised beds constructed. But some activities and friendships cannot be preserved.

I have learned to let go and be open to new possibilities. The smartest thing I did when I had to retire was get on the Internet. The support, understanding, sharing of knowledge, and laughter on the Internet polio mailing lists provides one of my lifelines. One of the happy surprises of post-polio is that it has brought me so many new friends, albeit I rarely meet them face-to-face.

When I retired, I rejoined the Post-Polio Network of New South Wales (www.post-polionetwork.org.au). We receive numerous queries from our 800 members as well as from survivors all over the world. It is enormously interesting to talk with survivors who live in other countries and rewarding to be able to pass on information.

Frequently, when I am resting or feeling low, I leaf through one of the commonplace books in which I record happy memories and quotations of friends, some I have met only through their publications. One is Nancy Mairs who has MS and has taught me the art of having small adventures. "I have a low adventure threshold," she wrote[1], "rather like having a low pain threshold .... The trouble with having a low adventure threshold is that everything that crosses it may be an adventure, and thus you may be inundated and swept away by the events of a life that seems to others as still as a stagnant pond. I'll never make it to Tibet. Maybe not even to Albuquerque. Some days I don't even make it to the back yard .... I refine adventure, make it smaller and smaller."

My three-year-old grandson and I have adventures searching for small lizards in my garden. Little happenings are heightened to moments of joy. Yesterday evening, the sun reached a dark corner of the garden and sent reflections through large leaves creating splotches of living, vibrating, emerald fire such as I had never seen before.

[1]Mairs, N. (1986) *Plaintext*. New York: Harper Row.

Dolls!!!

Nickie Lancaster, RN, Hermitage, Tennessee (smlphtn@bellsouth.net)

When I had polio in 1950 at age 8 1/2, many people gave me dolls. I could not play with them due to total paralysis. My Dad took an entire wall and hung the dolls with elastic so I could see them. Four years later, when my parents divorced, my mother emptied her belongings from her cedar chest and put in my dolls. There they stayed for 40 years. One day I decided I was old enough to play with my dolls. Over 100 dolls were just as they were in 1955. Wow!!! Now they were "collectibles."

Stress relief is a new doll magazine or catalogue. I save all year to attend the big doll collectors' show in Nashville each winter. I have added many new dolls to my collection, and I also love to give dolls away to friends.

Caroleanne Green, a polio friend, also enjoys collecting dolls. When Caroleanne and I get on the phone, our conversation is 20% polio and 80% dolls.

Contract Bridge

Philippe Galaski, Amherst, Massachusetts (phgalaski@aol.com)

I totally agree with Mary as to the importance of finding something pleasurable to decrease stress. I have done this and found that my stress and fatigue levels have decreased. I decided to join the American Contract Bridge League. I currently go to a club to play bridge once a week, and sometimes I may go to a tournament over a weekend. It gives me pleasure to play bridge. I am pretty good at it, and it improves my self-esteem when the PPS blues creep up. It allows me to have social contact, meet people, and enjoy their company. It also makes my brain work and this type of activity is very important. Finally, it is a hobby that does not involve physical stress, as I sit most of the time.

Save Your Sanity through Poetry

LaVonne Schoneman, Seattle, Washington (vonnejo@aol.com)

Save your sanity through poetry? This may sound strange, but it works for me and my friends.

A friend, who is experiencing the late effects of polio, designed his own advanced college degree program. He called it "Creating Wellness through Poetry." The act of writing out his feelings by focusing on God and His creation helped him achieve better mental health.

Another friend wrote a poem called "Saved by a Gibson" about a discarded guitar later found by a streetperson whose life was restored.

Saving sanity through poetry sounds like a motto from an old 1950s TV program. Nevertheless, I believe it has often saved me. Reading beautiful thoughts of another poet or jotting down my own, even during pain, helps me. Reading about someone else who had the same feelings helps me realize I am not alone.

Others may get this same release through a cherished hobby. Gardening is my husband's choice. Before anyone says, "I can't do that anymore," let me hasten to assure you we all lose bits and pieces of ourselves along the way from youth to age.

Making a hoop shot, dancing 'til dawn, or climbing a mountain may beyond your scope today, but so many other things are not.

I call them my "free fixes."

We can find magic in cobwebs, intricate weavings, more delicate than handmade lace. Hidden in the beauty of growing things – an Amaryllis started from a bulb in winter keeps our spirits up as we watch it push up through the soil day by day. The silly song of a grandchild can sound more lovely than an aria by a world famous tenor. A dandelion can mean more than a dozen hothouse roses when delivered by a loving child. Music really does have the power to charm and soothe. Petting the cat, grooming the dog, feeding the fish ... choose your pleasure. Admire the wrinkles in someone's face, spouse, stranger, or yourself.

Look deep into the eyes of your family members or friends as you converse. DO take time daily to really converse. If you live alone, you can still get that connection through telephone or e-mail. The post-polio support group I check in with on the World Wide Web offers a caring group of people with like problems and readily shared solutions twenty-four hours a day.

Concentrating one's flagging energy on uplifting things is so beneficial. In this season of political hammering we need to limit the amount of time we allow such assaults. When you find yourself reading a story or watching a movie that makes your stomach churn or gives you the feeling you need to wash your mind out with Grandma's lye soap and hot water, S-T-O-P! Give yourself permission to do something else – something aesthetically pleasing (uplifting, fun, silly). Read the comics, watch a happy video, appreciate the rain or snow or sunshine ... listen to the wind blow.

A positive attitude is all it takes – and that costs nothing.

Haiku

Carol Purington, Woodslawn Farm, Massachusetts (CARPUR@aol.com)

Carol writes poetry from her farm where she has slept in an iron lung for the last 41 years. She switched to the smaller Porta-Lung four years ago. Carol has published four books of her poetry.

A stone for birth a stone for death
We hand them to the Maidens –
we,
the women of the People,
who know the weight of birth of death

The Trees Bleed Sweetness

Ramp Safety

Nancy A. Heiskell, Indianapolis, Indiana (shh-nah@worldnet.att.net)

I recently bought a lowered floor conversion van. Because the ramp is just a little wider than my chair, it is difficult to judge exactly where I am, causing me to worry about driving over the side of the ramp.

After a couple of days of precariously going in and out of the van, I asked my husband to apply a 1/2" wide strip of red reflective tape in the "center of the traveling path" of the ramp from one end to the other. Next, I had him apply a short piece of tape in the center of my chair's footrest.

Here is how I use it: I visually line up the tape on the footrest with the tape on the ramp and I keep the two aligned as I travel up or down the ramp. I feel it is better and safer than trying to judge where I am on the ramp. We then applied the tape in the center of my portable ramp. Maybe the van conversion companies and ramp manufacturers will incorporate a ramp guideline feature in their future products. ■

Frequently Asked Questions

My physician has suggested I consider Social Security Disability Insurance (SSDI). Can you provide some details about this program?

Two Social Security programs provide benefits based on disability. Both programs define disability as the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) which can be expected to last at least a year or to result in death.

Title II Social Security Disability Insurance (SSDI) covers three categories of disabled workers and their dependents who are insured under the Social Security Act after having contributed FICA (Federal Insurance Contributions Act) tax from their earnings to the Social Security trust fund. The categories are: a disabled insured worker under 65; a disabled widow or widower age 50-60 if the deceased spouse was insured under Social Security; and a person disabled since childhood (before age 22) who is a dependent of a deceased insured parent or a parent entitled to Title II disability benefits.

Under SSDI, disability benefits start six months after Social Security decides the disability began. After 24 months of SSDI payments, recipients are automatically enrolled, premium free, in Medicare Part A, hospital benefits. The other part of Medicare, Part B, which helps pay doctors' bills and other services, is available upon payment of a monthly premium.

Title XVI Supplemental Security Income (SSI) provides payments for individuals (including children under age 18) who are disabled and have limited income and resources. Under SSI, disability payments may begin as early as the date the individual files an application. In most states, individuals who qualify for SSI disability payments also receive Medicaid health care benefits.

Anyone fitting the above description(s) may apply for Social Security disability benefits any time after the onset of disability by phone, mail, or in person at any local Social Security office. The initial claims process requires Social Security number; proof of age; names, addresses, and phone numbers of doctors, hospitals, clinics, and institutions with dates of treatment; a summary of jobs held and employers in the past 15 years; and a copy of the most recent W-2 form or federal tax return.

The Social Security office collects medical evidence from licensed providers and health care facilities regarding medical diagnoses, pain, and other symptoms; physical examination findings; results of x-rays and tests; medications; past medical and surgical treatments; and functional activities which are affected by the disease process, such as grooming, dressing, walking, bathing, toileting, and homemaking.

Other relevant information may include: work limitations involving concentration; pace in completing tasks; and limitations in standing, sitting, lifting, climbing, stooping, kneeling, and manipulating items.

When the evidence from the survivor's own medical sources is inadequate, the review panel may require additional medical information from the treating professional(s) or an independent examiner, or non-medical evidence from social welfare agencies, employers, teachers, and other practitioners. Ultimately, a team, consisting of a physician or psychologist, depending on the nature of the disabling condition, and a disability evaluation specialist from a state's Office of Disability Determination Services (DDS), makes decisions regarding disability.

If an individual is denied disability benefits (which is often the case), the person has 60 days to initiate an appeal. Appeals must be filed in writing and may be submitted by mail or in person to any Social Security office. The appeals process consists of four levels: reconsideration by another physician/administrator panel; hearing before an administrative law judge; review by an appeals council; and finally, an appeal to the US federal district court, a complex and expensive process. The whole process may take a year or more and may necessitate updated medical evaluations and resubmission of medical evidence forms.

Benefits continue as long as an individual remains disabled. Periodic case reviews are done to verify ongoing disability. The frequency of reviews ranges from every six months to once in seven years, depending on the expectation of recovery. Benefits will stop if the individual returns to work at a "substantial" level, defined as average earnings of $700 or more per month (July, 1999). Benefits also will stop if Social Security decides that a person's medical condition

has improved to the point that the individual is no longer disabled.

In 1987, the Social Security Administration acknowledged the late effects of poliomyelitis and issued criteria for the evaluation of the ability of survivors to continue employment in its Program Operations Manual System (POMS). The listing number for Evaluation of the Late Effects of Poliomyelitis is DI 24580.010E.3. The Evaluation includes a definition, the signs and symptoms, how to document and evaluate, in addition to descriptions of fatigue and loss of endurance, weakness, pain, cold intolerance, etc.

Survivors are advised to take an active role in the process by assisting with the collection of medical evidence and relevant information, following the claim from step to step, making copies of important documentation, meeting all deadlines, and appealing, if necessary.

For more information, call Social Security (800-772-1213). The National Organization of Social Security Claimants' Representatives (800-431-2804) can suggest an experienced disability lawyer.

Excerpt from *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors,* Revised 1999.
(See page 11 for ordering information.)

Should adults be vaccinated for polio?

RECOMMENDATIONS FOR IPV VACCINATION OF ADULTS: Routine poliovirus vaccination of adults (i.e., persons aged ≥18 years) residing in the United States is not necessary. Most adults have a minimal risk for exposure to polioviruses in the United States and most are immune as a result of vaccination during childhood. Vaccination is recommended for certain adults who are at greater risk for exposure to polioviruses than the general population, including the following persons:

- Travelers to areas or countries where polio is epidemic or endemic.*
- Members of communities or specific population groups with disease caused by wild polioviruses.
- Laboratory workers who handle specimens that might contain polioviruses.
- Health care workers who have close contact with patients who might be excreting wild polioviruses.
- Unvaccinated adults whose children will be receiving oral poliovirus vaccine.

Unvaccinated adults who are at increased risk should receive a primary vaccination series with IPV. Adults without documentation of vaccination status should be considered unvaccinated. Two doses of IPV should be administered at intervals of 4-8 weeks; a third dose should be administered 6-12 months after the second. If three doses of IPV cannot be administered within the recommended intervals before protection is needed, the following alternatives are recommended:

- If more than 8 weeks are available before protection is needed, three doses of IPV should be administered at least 4 weeks apart.
- If fewer than 8 weeks but more than 4 weeks are available before protection is needed, two doses of IPV should be administered at least 4 weeks apart.
- If fewer than 4 weeks are available before protection is needed, a single dose of IPV is recommended.

The remaining doses of vaccine should be administered later, at the recommended intervals, if the person remains at increased risk for exposure to poliovirus. Adults who have had a primary series of OPV or IPV and who are at increased risk can receive another dose of IPV. Available data do not indicate the need for more than a single lifetime booster dose with IPV for adults.

Source: "Poliomyelitis Prevention in the United States: Updated Recommendations of the Advisory Committee on Immunization Practices (ACIP)," supplement to *Morbidity and Mortality Weekly Report* Recommendations and Reports, May 19, 2000, Volume 49, Number RR-5.

*The Centers for Disease Control and Prevention (CDC) recommends that travelers to countries where polio is epidemic or endemic receive the IPV before departure. For an up-to-date listing of the countries in question, call the CDC's automated vaccine information line at 888-232-3228 or the autofax line at 888-232-3299 or log on to www.cdc.gov and choose Traveler's Health.

Did a contaminated polio vaccine cause the AIDS epidemic?

Like gossip, a juicy scientific hypothesis doesn't die easy. There has been a dilly percolating through the scientific community this last year, a suggestion at once horrifying and plausable. It has been suggested that a vaccine caused AIDS.

This is not as silly an idea as it might at first appear. To under-

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stand its peculiar force, let us quickly review what science knows about the origin of AIDS.

1. Despite loud claims to the contrary made by the lunatic fringe, the evidence is absolutely solid that AIDS is caused by a virus, human immunodeficiency virus, HIV for short.

2. When scientists analyzed the DNA sequence of HIV, it turned out to be quite similar to the DNA sequences of viruses found in African monkeys and chimpanzees, the so-called simian immunodeficiency viruses (SIV). The most common human AIDS virus, HIV-1, is so startlingly similar to the chimpanzee version of SIV that essentially all researchers agree the human virus must have arisen from the ape one.

3. While the AIDS epidemic began in this country in 1981, the earliest known AIDS cases – a Manchester seaman who had worked in Central Africa and a Bantu man from the Congo – date back to 1959.

From these three facts we can reasonably conclude that HIV passed from chimpanzees to humans in Africa sometime prior to 1959.

Now comes the outrageous suggestion. Extensive oral polio virus trials were carried out in Central Africa (the old Belgian Congo) between 1957 and 1960. Polio was a big killer and crippler then, producing the same level of concern that AIDS does now, and the pressure to find a reliable vaccine was intense. While small trials were carried out in America, the bulk of the vaccine trials took place in Central Africa.

The CHAT polio vaccine tested in Central Africa was developed in the 1950s at the Wistar Institute in Philadelphia. The CHAT vaccine consisted of polioviruses grown in tissue culture, then weakened – the weakened virus could not cause disease, but could evoke a strong immune response, protecting the vaccinated person from any future polio infection.

Most batches of CHAT were grown on tissue taken from monkeys. Importantly, however, a small number of batches were grown on chimpanzee kidneys. What if these chimpanzees had been infected with SIV? If they were, the CHAT vaccine prepared from their kidneys might have been rich with SIV virus. With only a few quick mutations the CHAT polio vaccine would have become a reservoir of HIV. Immunizing thousands with the polio vaccine would unknowingly have started an epidemic of HIV among humans, igniting the pandemic that grips the world today.

You've got to admit, that's a pretty juicy hypothesis.

Most researchers have resisted taking this hypothesis very seriously. Only a small number of chimpanzee kidneys were ever used in preparing the polio vaccine, and SIV is quite rare among chimpanzees. Still, the suggestion would not go away. Even if a stretch, it might be true. It had to be tested.

Now it has been.

In research reported this summer in the journal *SCIENCE,* a team of medical researchers led by B. Korber and T. Bhattacharya of the Los Alamos National Laboratory, New Mexico, has used parallel supercomputers to examine complete DNA sequences from the env gene collected from several hundred HIV-1 infected AIDS patients.

The env gene encodes the protein gp160 which makes up the virus coat. The HIV virus undergoes many mutations as it passes from one person to the next – its DNA copying machinery is pretty sloppy – so HIV samples collected later in the epidemic will have accumulated more changes in the env gene than samples collected earlier. By extrapolating back, it is possible to estimate the date when the last common ancestor to HIV-1 came into being – that is, when HIV-1 first originated from SIV.

When this is done, the researchers obtain a date of 1931. Because they employed so much data in their analysis (hence the supercomputers), they are able to put 95% confidence intervals of 1915 to 1941 on their estimate. Furthermore, a sample known to have originated in 1959 gave an accurate estimate for the date of its origin.

It thus seems very clear that the HIV-1 virus responsible for most of the AIDS pandemic originated far earlier than the late 1950s when the polio vaccine was being tested in Central Africa. There is no reasonable way the AIDS epidemic could have been caused by a polio vaccine thirty years before the vaccine was made.

The suggestion that a vaccine caused AIDS was a horrible possibility, but wrong.

Source: On Science, *Saint Louis Post-Dispatch,* Friday, August 25, 2000 (www.txtwriter.com). On Science is a

weekly column by George Johnson, PhD, professor of biology for the past 28 years at Washington University in Saint Louis, Missouri, who is increasingly involved in public science education. Johnson pursued an active research career from 1972-1982, and, since1983, has authored eight biology texts, served on a National Research Council task force to improve high school biology teaching, and is working to incorporate interactive learning into USA classrooms.

Because of my medical history, I would consider donating my body to science. Is there a place conducting research on post-polio problems that accepts body donations?

No. However, the National Neurological Research Specimen Bank is a donor program of pre- and postmortem tissues and cerebrospinal fluid/blood and a collection of cryopreserved human neurological specimens for neuroscientists. Located in the Los Angeles, California area, the "Gift of Hope" donor program generally involves no expense at all to the donor family. The Specimen Bank Representative will assist in arrangements for the brain tissue donation. For more information and for "Gift of Hope" Donor Enrollment Forms, contact W.W. Tourtellotte, MD, PhD, National Neurological Research Specimen Bank (127A), West Los Angeles Healthcare Center, 11301 Wilshire Boulevard, Los Angeles, CA (California) 90073 (310-268-3536, brainbnk@ucla.edu). Most medical schools do not accept body donations from persons who have donated any type of tissue. One usually must make a choice between donating their organ(s) versus donating one's entire body to a medical school. ■

The National Institute of Neurological Disorders and Stroke (NINDS) has launched a redesigned version of its website at www.ninds.nih.gov. New features include:

- An alphabetical disorder index page: www.ninds.nih.gov/health_and_medical/disorder_index.htm.
- A listing of addresses and websites for national non-profit organizations: http://ninds.nih.gov/find_people/organizations_index.htm.
- A listing of professional societies with an interest in neurology or related fields: http://ninds.nih.gov/find_people/professional_societies.htm.
- Links to disorder-specific clinical trials from the new http://clinicaltrials.gov website: www.ninds.nih.gov/health_and_medical/studies.htm.
- Pre-formatted disorder-specific searches of PubMed (Medline). These searches were created with the assistance of NIH librarians to provide access to the most recent biomedical research publications concerning human subjects: www.ninds.nih.gov/health_and_medical/research.htm.

www.FinancialAssistanceNetwork.org offers a booklet "Free & Low Cost Medical Care" published by the Financial Assistance Network in Washington, DC. The booklet contains information on how and where to get free and low-cost medical care under the Federal Hill-Burton program.

Currently 656 facilities nationwide provide free or low-cost medical care and over 1,100 prescription drugs are available free or at very low cost to qualified individuals.

Consumers can receive a copy by sending $5 to cover the cost of printing, postage, and handling to: Financial Assistance Network, Free & Low Cost Medical Care Booklet, Dept. MCB-0801, POB 60848, Washington, DC 20039-0848.

The Social Security Administration has launched a new website that offers information aimed at helping people with disabilities enter the workforce. The site can be accessed from the main Social Security Administration's website at www.ssa.gov/work or at this link: ww.ssa.gov/work/index2.html.

Medicare & You 2001, the reference book for the Americans covered by Medicare, highlights preventive screenings as well as information on Medicare Parts A and B. To request a copy of the guide, phone 800-633-4227. *Medicare & You 2001* is also available at www.medicare.gov/publications/overview.asp.

WeMedia (www.wemedia.com) is a sponsor of eBay's "Disability Resources" section, a theme page that promotes listings of new, pre-owned, and one-of-a-kind merchandise that people with disabilities may find useful. (http://pages.ebay.com/theme/disability.html).

Robbie Leonard, listed in the last issue of *Polio Network News* as a participant in the OT/PT Seminar at the Eighth International Post-Polio and Independent Living Conference, has a new address: Robbie B. Leonard, MS, PT, St. Francis Women's and Family Hospital, Rehab Services, Medical Office Building 131, Suite 200, 131 Commonwealth Drive, Greenville, SC (South Carolina) 29615 (864-675-4654, rleonard@stfrancishealth.org). ■

Flu Update

What is the flu? The flu, or influenza, is a respiratory infection caused by type A and type B influenza viruses. It is most common in the fall and winter.

The flu is highly contagious; the virus usually enters the body through mucous membranes in the mouth, nose, or eyes. When a person with the flu coughs or sneezes, the virus becomes airborne and can be inhaled by anyone nearby.

In a mild flu season, about 10% to 15% of the population becomes infected. In a more severe flu season, 20% or more of the population can suffer from the flu.

How do I know if I have the flu? Flu generally strikes 1 to 3 days after exposure to the virus. The onset of flu often seems sudden: people describe feeling "like they've been hit by a truck." Common flu symptoms include sudden onset, fever and chills, cough, muscle and joint pain, headache, fatigue, and weakness. Some people also get a stuffy nose and sore throat.

What's the difference between the flu and a cold? Both the flu and a cold are viral infections and can cause symptoms such as coughing and sore throat. A cold is a minor viral infection of the nose and throat. The flu, however, is usually more severe, with higher fevers and the addition of aches and pains.

Is the flu dangerous? A bad case of the flu will probably send a healthy adult or child to bed for 3 to 5 days. Afterwards, the person will recover fully, but cough and tiredness may persist for days or weeks.

Signs & Symptoms	Flu	Cold
Onset	Sudden	Gradual
Fever	Characteristic, high (over 101° F); and lasting 3-4 days	Rare
Cough	Dry; can become severe	Hacking
Headache	Prominent	Rare
Myalgia (muscle aches and pains)	Usual and often severe	Slight
Tiredness and weakness	Can last up to 2 to 3 weeks	Very mild
Extreme Exhaustion	Early and prominent	Never
Chest Discomfort	Common	Mild to moderate
Stuffy nose	Sometimes	Common
Sneezing	Sometimes	Usual
Sore throat	Sometimes	Common

Nonetheless, the flu can be a serious illness. Each year, up to 40 million Americans develop the flu, and about 150,000 are hospitalized. During past epidemics in the United States, influenza and its complications have caused between 10,000 and 40,000 deaths.

People over the age of 50 and those of all ages with chronic illnesses (such as diabetes, heart disease, asthma, and HIV) are more likely to become seriously ill with the flu. These people are also more likely to go on to develop other serious infections such as pneumonia. If you are elderly or have a chronic disease, you should call your doctor at the first sign of flu symptoms.

Can the flu be cured with antiobiotics? No. Because the flu is a viral infection, it cannot be treated with antibiotics. Antibiotics are medicines that kill bacteria and are, therefore, only useful for treating bacterial infections.

If your doctor does not think that you need antibiotics to treat your infection, do not insist. Inappropriate use of antibiotics contributes to the development of antibiotic-resistant strains of bacteria, which is a major public health problem.

Is there anything I can do to avoid getting the flu? To prevent getting the flu, or to lessen the severity of the flu, you should get a flu shot each fall — particularly if you are over the age of 50 or have a chronic health problem.

*A flu vaccination is your best chance to protect yourself against the flu.** However, the vaccine is not always effective because the flu strains it protects against may not be the same as the ones that are going around in your area. So even if you have received a flu shot, you could still get the flu.

If you are pregnant or if you are allergic to eggs, you should ask your doctor about whether or not you should get a flu shot.

There are also simple common sense things you can do to try to protect yourself from the flu:

- Keep your distance, if possible, from people who have the flu since the virus is spread when a person with the flu coughs or sneezes.
- Wash your hands frequently to reduce your risk of catching a cold or the flu.
- Avoid second-hand cigarette smoke; if you smoke, try to quit.
- Try to maintain a healthy lifestyle: follow a good diet, get enough sleep, keep stress levels low, and drink lots of water. ■

Source: Roche Pharmaceuticals, www.igotflu.com/

*Medicare Part B covers an annual flu shot (in fall or winter). You pay nothing if your healthcare provider accepts "assignment" (the Medicare-approved amount).

❑ Hazendonk, K.M., & Crowe, S.F. (2000). A neuropsychological study of the postpolio syndrome: Support for depression without neuropsychological impairment. *Neuropsychiatry, Neuropsychology, and Behavioral Neurology* 13(2), 112-118.

These results indicate that the attention and memory difficulties reported by symptomatic polio survivors may be linked to the physical or psychological manifestations of the illness rather than to objective decrements in cognitive performance.

❑ Kling, C., Persson, A., & Gardulf, A. (2000). The health-related quality of life of patients suffering from the late effects of polio (post-polio). *Journal of Advanced Nursing* 32(1), 164-173.

This Swedish study showed that the patients mainly reported that their physical, functional status was affected by their post-polio condition. Factors found to be associated with the physical, functional status were age and the number of parts of the body affected by polio. The women with post-polio reported more pain, as compared with both the men with post-polio and the women in the general population sample. The family life of the patients – in contrast to their physical abilities – did not seem to be affected by the new deteriorating condition.

❑ Nielsen, N.M., Wohlfahrt, J., Melbye, M., Rasmussen, S., Molbak, K., Askgaard, D.S., & Aaby, P. (2000). Multiple sclerosis and poliomyelitis: A Danish historical cohort study. *Acta Neurologica Scandinavica* 101(6), 384-387.

During 149,364 years of follow-up, 19 cases of multiple sclerosis were observed among 5,652 polio patients compared with 11.0 expected (SIR = 1.75 [1.04-2.74]). The results are based on small numbers of events, however the findings suggest that the polio patients might be at an increased risk of MS.

❑ Rekand, T., Albrektsen, G., Langeland, N., & Aarli, J.A. (2000). Risk of symptoms, related to late effects of poliomyelitis. *Acta Neurologica Scandinavica* 101(3), 153-158.

Although symptoms defined in PPS are unspecific and may occur in the general population, the risk for developing such symptoms are higher among the polio survivors. The difference in risk among nonparalytic and paralytic patients may depend on the extent of motor neuron damage in the acute stage.

❑ Campbell, M.L., Sheets, D., & Strong, P.S. (1999). Secondary health conditions among middle-aged individuals with chronic physical disabilities: Implications for unmet needs for services. *Assistive Technology* 11(2), 105-122.

Data from the Aging with Disability Study are used to examine variations in the types and frequency of secondary conditions. Results reveal significant differences in the types of new health problems reported by persons living with polio, rheumatoid arthritis, and stroke and document marked disparities, or accelerated aging, between disabled and nondisabled adults.

❑ McNeal, D.R., Somerville, N.J., & Wilson, D.J. (1999). Work problems and accommodations reported by persons who are postpolio or have a spinal cord injury. *Assistive Technology* 11(2), 137-157.

Ninety-six individuals with a disability (50 who are postpolio and 46 who had a spinal cord injury) were interviewed by phone. 90.9% of the work problems of polio survivors were new and would not have been significant problems for them when they first began working. Three out of every eight problems did not have an accommodation satisfactory to the employee. The primary reason why a satisfactory solution was not provided was that no accommodation had been identified. Employers were generally supportive of the employee's need for accommodation; they paid for 59.1% of the accommodations that had a cost and refused to provide an accommodation for only 18 of the 480 problems.

❑ Sandberg, A., Hansson, B., & Stålberg, E. (1999). Comparison between concentric needle EMG and macro EMG in patients with a history of polio. *Clinical Neurophysiology* 110(11), 1900-1908.

In conclusion, macro EMG better reflects the size of the motor unit than the Concentric Needle EMG. ■

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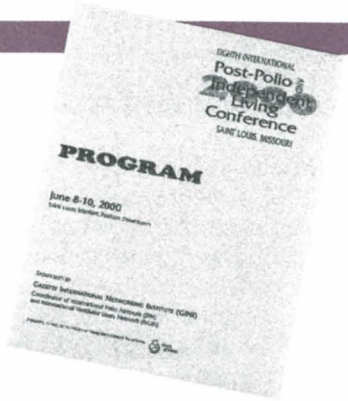

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