

Now called
Post-Polio Health

POLIO NETWORK NEWS

"Many of the popular claims made for the power of the mind to alter the health of the body are based on speculation, but a growing body of science-based research is now establishing the role that the brain plays in health and disease. The findings of this new field of study have the potential to revolutionize our understanding of the brain and the body as an interconnected whole."

Brain-Body Science: A Progress Report, The Charles A. Dana Foundation, Brain-Body Institute, December 1999

Stress

Stress begins in the brain and is expressed in the body as well as in the state of our minds. When we find ourselves in a situation that challenges us emotionally or physically, we react with the classic "fight or flight" stress response. The brain sends out chemical messengers in the form of stress hormones to almost every system and organ of the body, setting off a cascade of physiological changes.

Heart rate, blood pressure, and muscle tension rise sharply, the stomach and intestines become less active, and the blood level of glucose (blood sugar) rises for quick energy. The brain arms the body

for battle or escape. Stress hormones activate immune cells that rush to the battlefield to protect the body from whatever is threatening its stability. When the stressful event is over, the body returns to normal functioning.

Understanding both the social conditions that trigger this response, as well as the psychological states that may buffer or protect us from stress, is critical.

The Toll of Chronic Stress

Chronic stress creates a different scenario. For example, if you are under constant pressure at work, or having difficulties with a spouse or loved one, the body reacts with the stress response. But if the stressful situation continues over days, weeks,

or months, the stress response may not turn off. If it doesn't, protective hormones shut down the regular repair and maintenance functions of our bodies. The result can be a suppressed immune system, prone to infection.

The cumulative toll of stress can affect the body in a number of ways. Scientists have observed bone loss, muscular weakening, hardening of the arteries, and increased insulin levels that cause greater levels of fat deposition in the body, especially around the abdomen. Some people end up with the "apple" body shape that researchers have shown predisposes some individuals to heart disease.

Stress and Natural Killer Cells

Many researchers have focused on the activity of natural killer (NK) cells – specialized immune cells that protect the body from health threats by seeking out and destroying abnormal or virus-infected cells

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An Antidote to Post-Polio Stress: Pleasure Seeking

Mary Westbrook, PhD, Sydney, Australia

When talking about stress, we must distinguish between stressful events (stressors) and a person's reactions, both physiological and psychological, to such events (stress responses). There are some events that almost everyone would experience as very stressful: consider the late effects of polio. Lightning has struck us twice; the physical gains we achieved melt away and the lives we built are threatened on every side by ongoing losses such as forced early retirement or the inability to continue favourite social and leisure activities. How will it all end?

Post-polio is a chronic stressor in response to which our stress levels fluctuate. Such changes may be caused by happenings (a fall, a new symptom, lack of access, being dropped from a friend's social calendar) and/or by our state of mind and body (tiredness, pain level, other worries). When we feel stressed our post-polio symptoms get worse¹. So life often becomes a vicious circle. We receive much advice on techniques to reduce both stress levels and symptoms of fatigue, pain, and increasing weakness. So we learn to pace ourselves, slow down, delegate, have

rests during which we do absolutely nothing, give ourselves permission to say 'No' (to all the nice things we want to do), meditate, do relaxation and stretching exercises, purchase aids and special equipment, and try

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– as physiological “markers” of immunity. Changes in the number or responsiveness of NK cells have been linked to a number of diseases, and they seem to be critical to the body’s defense against viral infections and cancer. Stress, even the stress of loneliness, can lower NK cell activity in normal populations. Stress can also depress the ability of NK cells to wipe out tumor or viral-infected cells.

Stress, Cancer, and Social Support

If stress can suppress immune function, it then makes sense that psychosocial interventions designed to reduce stress – such as support groups, medication, relaxation therapy, or other stress reduction techniques – might have a positive effect on immune function.

Nowhere is this more obvious than in studies that have looked at cancer survivors. There are more

than eight million cancer survivors in America today. With new treatments, advances in surgery and drug therapy, as well as earlier awareness and detection of the disease, more people are discovering that a diagnosis of cancer is not a death sentence. They survive. But the stresses of chemotherapy, unsettled family relationships, and interruptions in the regular schedule of work and leisure time, can create what the National Cancer Institute calls “survivor stress,” a state of mind that can have serious health consequences.

Many researchers believe that handling stress successfully plays a prominent role in the ability of a cancer patient to survive and avoid recurrence. Evidence exists to show that stress alters immune function, and may weaken the ability of the immune system to play its critical “surveillance role” in controlling some cancers.

What the Studies Show

◆ Chronic stress lasting a month or more doubled the incidence and severity of the common cold. (Cohen, S. et al., 1998)

◆ “Lonely” medical students have lower levels of NK cell activity than those who have friends they care about. (Kiecolt-Glaser, J.K. et al., 1987)

◆ Stress can be measured in the body. Eight physical indicators – from blood pressure to cortisol levels to abdominal fat – can be measured to give a tangible indication of an individual’s stress load. (McEwen, B.S., 1998)

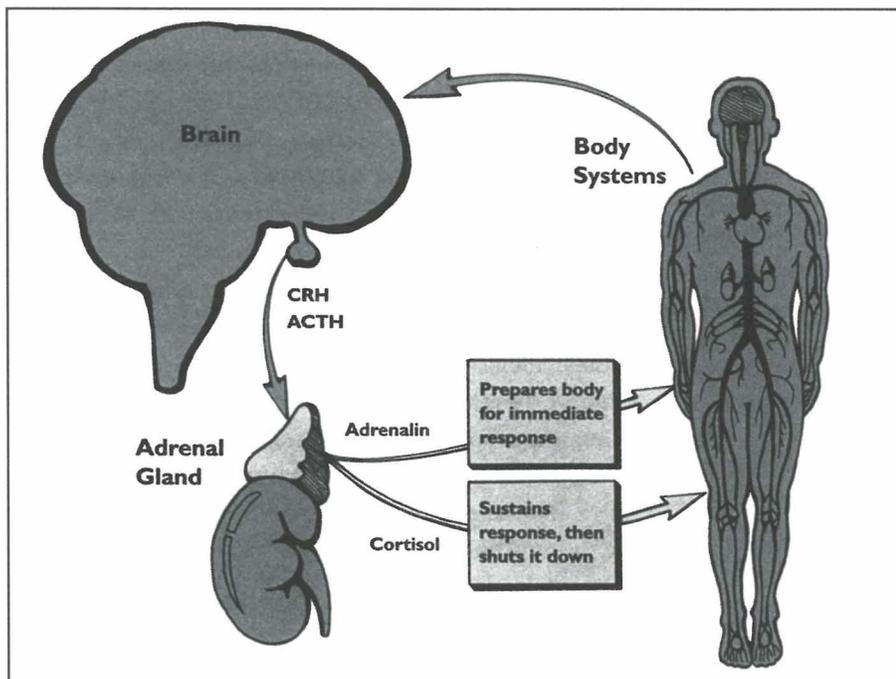
Ongoing research continues to look at the positive effects of psychosocial support. It isn’t clear yet that the beneficial effect on survival rates is the direct result of improvement in the immune response. Psychosocial interventions may also work by helping patients increase their adherence to medications or by improving their nutrition. In addition, not all cancers are responsive to psychosocial interventions and their effectiveness may also be directly tied to the stage of cancer at which they are introduced. But there is solid evidence that providing some cancer survivors with social support increases the likelihood of recovery and lengthens their survival time. ■

Extracted from *Brain-Body Science: A Progress Report*, The Charles A. Dana Foundation, Brain-Body Institute, December 1999

Want to know more about the brain and brain-body science?

Publications of The Charles A. Dana Foundation include *Brain Work: The Neuroscience Newsletter*, a bi-monthly newsletter for the general public on recent advances in brain research; *The Brain in the News*, a bi-weekly compilation of articles from the popular press on brain-related research; and *Brain-Body Health*, a quarterly newsletter for the general public on brain-body science and health.

To be added to the mailing list for The Charles A. Dana Foundation, contact The Dana Press, 1001 G Street NW, Suite 1025, Washington, DC 20001 (202-737-9200, 202-737-9204 fax, danainfo@dana.org).



The Stress Response

When the brain perceives stress, it immediately releases adrenalin from the adrenal glands and corticotrophin-releasing hormone (CRH) from nerve cells in the hypothalamus. CRH travels to the pituitary gland, where it triggers the release of adrenocorticotrophin hormone (ACTH), which then stimulates the production of cortisol in the adrenal glands. Cortisol sustains energy, but it also curbs the surge of adrenalin and turns off CRH.

massage and body therapies. Yes, many of these strategies do provide some relief, but they are also frequently sources of irritation, boredom, frustration, and regrets that we are not otherwise engaged. Post-polio seems to have taken over our lives. While some of us manage to achieve Buddha-like serenity, many of us, I suspect, do these things in the hope that we will feel well enough to do a little bit of busy living again.

Polio survivors' reactions to our ongoing stressors are often accompanied by the shame that Kitty Stein², who has MS, describes. This shame response tells us, "I'm bad; it's me; I'm not dealing with it well," whereas the healthy response is, "Yes, I am having a hard time. How can I get help or help myself?" Stein goes on to advocate that people with chronic health conditions acquire a "nurturant" voice, and enter into a mutual, loving relationship with themselves. Unfortunately, self-nurturance is foreign to most polio survivors who are characterised by their self-criticism and their compassion for others but not themselves.³

In his research investigating factors related to Americans' feelings of well-being or happiness, Bradburn⁴ found that neither the number of positive nor negative events that people were experiencing in their present lives predicted their ratings of their overall happiness. However, the discrepancy between these two types of events was an excellent predictor. The greater the excess of positive over negative experiences, the higher a person's rating of happiness.

Mary Westbrook, PhD is a psychologist who conducted the first Australian research into post-polio. She spoke at the GINI conference in 1994 and contributed to the recently revised *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*. In 1998 she was made a Member of the Order of Australia for her service to people with disabilities through research into post-polio, physical disability, and education in the health professions.

When I taught psychology to health professionals involved in rehabilitation, I suggested this equation had important implications both for them and their clients. When a person becomes disabled, there are usually deficits and losses that can never be cured or replaced. However, if we consider the person's overall life situation, there are often changes and additions that can be made that will increase the person's positive experiences and their overall well-being. Sad to say, rehabilitation programs concentrate more on providing vocational skills than the social and recreational skills that would serve disabled people well in their changed lives. Bradburn's model is a useful one for health practitioners in that it focuses their attention on what they can achieve for their clients and lessens feelings of helplessness or inadequacy that may develop if they concentrate only on the problems that cannot be solved.

Several psychologists have provided tips for the seeker of pleasure. In her recent book, polio survivor Rhoda Olkin writes of the importance of having something to look forward to and suggests this is especially important for people with disabilities because the effects of pain, fatigue, and weakness can occupy a large portion of time and erode our ability to find pleasure⁵. Olkin says that we need "four levels of positive future events: 1) small pleasures that occur at least once a day, e.g., reading in bed and eating two stale marshmallows; 2) slightly larger events that occur at least once a week, e.g., listening to the *Prairie Home Companion*; 3) monthly events, e.g., visiting with a good

friend and going out for a nice dinner; and 4) larger events that occur maybe once a year, e.g., family vacation and a favourite holiday."

Having to retire early from my university position led to a drastic reduction in my daily social contacts and particularly the interchange of stimulating ideas. A daily treat that substituted for this was joining mailing lists on the Internet. I belong to a number of post-polio lists and have joined many others related to my interests such as disability studies, L M Montgomery, mysticism, and women's issues. Most mornings I receive about a hundred e-mails, some fascinating and maybe demanding a reply, and others quickly deleted. I read them with a cup of coffee much as I had a cup of coffee in the staff room at work. The Internet provides treats that are readily available when I feel low. At such times nothing beats a visit to Amazon.com or Barnesandnoble.com, a wander through their aisles, and maybe the purchase of a book online. Art galleries on the net are a means to pursue another interest.

Many polio survivors recognise that gaining pleasure from having interests is a survival strategy. In a survey of Australian polio survivors⁶ I asked, "What advice would you give to someone who developed post-polio symptoms?" The fifth most common recommendation was "Develop new interests" and "Maintain those interests that you can." The most frequent advice was, "Talk with other post-polio survivors" or "Join a support group." When I attended GINI's Sixth International Post-Polio and Independent Living Conference in 1994, I remember initially feeling confused because I felt so comfortable and relaxed. Then I realised that it was because everyone had had polio, so the "disability factor" that must be dealt with in other social encounters did not exist.

One of my new pleasures, my commonplace books, began about seven years ago, almost by accident. One day I was given an art diary that seemed too beautiful to be used for scribbles about my daily appointments. Then I realised it was just the place for the quotations that I like to keep. My books contain extracts from articles, poetry, letters from polio mailing lists, photographs of special happenings (my recently built wheelchair-accessible courtyard garden that substitutes for the large garden I can no longer tend, my baby granddaughter, Marilla), cards from friends that were particularly moving, advertisements for a film

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International Polio Network (IPN)
4207 Lindell Boulevard, #110
Saint Louis, MO (Missouri)
63108-2915 USA
314-534-0475 ■ 314-534-5070 fax
Relay MO: 800-735-2966 TDD, 2466 V
gini_intl@msn.com, www.post-polio.org

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GRAPHICS/ASSISTANT TO THE EDITOR:
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or art exhibition that I enjoyed, and a few cartoons. The contents consist of writings that "speak to my condition."

Pleasures can slip by without our extracting much of their joy. An exercise entitled, "First the good news; then stop!," is surprisingly effective in counterbalancing a focus on the negatives in our lives. At the end of each day, I review the day's happenings and single out those personal activities that were enjoyable. Recalling a phone call from a friend and the enjoyment of reading a thriller reminds me that life can still be good.

How does pleasure affect our bodies? According to neuroscientist Candace Pert, "Our new understanding of neuropeptides and receptors has enabled us to see more of what is going on in conditions of stress. When stress prevents the molecules of emotion from flowing freely where needed, the largely autonomic processes that are regulated by peptide flow, such as breathing, blood flow, immunity, digestion, and elimination collapse down to a few simple feedback loops and upset the normal healing response."

Experiencing pleasure or "having fun is the cheapest, easiest, and most effective way I know to instantly reduce stress and rejuvenate mind, body, and spirit – it gets our emotions flowing, and our emotions are what connect us, give us a sense of unity, a feeling that we are part of something greater than our small and separate egos," says Pert⁷.

I open my commonplace book and Nancy Mairs⁸ tells me of her visit to Knole, an English stately home with 365 rooms. "Only the oak-paneled Great Hall can be reached by wheelchair. I can huddle in it grieving over the rare and fabulous silver furniture the others will see upstairs in the King's room without me. Or I can contemplate the ancestral portraits all around me, the elaborately ornamental oak screen at one end, and, when I've

What Psychotherapists Should Know About Disability (ISBN 1-57230-227-5) by Rhoda Olkin, PhD, professor in the clinical psychology program at the California School of Professional Psychology in Alameda, California; \$35, hardback; 368 pages, August 1999; Guilford Publications Inc., 72 Spring Street, New York, NY (New York) 10012 (800-365-7006, 212-966-6708, info@guilford.com; www.guilford.com).

looked deeply enough, wheel out in the rare bit of English sun, dreaming that Vita Sackville-West and Virginia Woolf once walked by this very spot, heads together, arms entwined, their laughter fluttering through the gate and into the deer park beyond. Only one of the options will give me joy. I choose joy."

My pleasures may not please you, but I encourage you to explore the treats and small adventures lurking around corners in every day. ■

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No Mountain Too High

Nancy L. Caverly, OTR/L, Bland, Missouri

These words are embroidered on the jacket patch of every instructor at Winter Park Ski Resort in Winter Park, Colorado. They embody the hope of many skiers who come to enjoy the alpine beauty and the thrill of skiing down slopes of the Rockies. For many years I have dreamed of skiing, but thought that I could not due to the weakness of my legs and lower back. As a polio survivor, I remembered the golf and skating I had enjoyed before polio came into my life just after my graduation from high school. But to ski – wow – it seemed like a dream.

Then my son, John, who lives in Colorado, sent me a brochure that discussed “sit-ski, bi-ski, and mono-skiing for individuals who need to ski in a seated position.”

Last January, I polled the family members about a ski trip to celebrate the end of the century. “How would you all like to meet in Winter Park the week after Christmas?” With a vote of confidence, I made reservations in an accessible condo which would sleep our seven adults and three grandsons and had elevator access from the third floor to an indoor garage below. Catalog orders provided the extra clothing needed for the adventure – ski pants, warm gloves, a soft hat, and metal cleats to attach to my Walk-Easy crutches. We all gathered in Winter Park the 28th of December in three vans full of food, clothing, and excited family members.

The Sports Center was founded in 1970 when Denver Children’s Hospital asked the resort to teach 23 amputees to ski. Now, there are 12 certified instructors, 23 full-time employees, and over 1000 trained volunteer skiers.

My instructors on the first morning were a couple who were long-time

skiers. They share their lives and skills with people in Austria and Colorado. In a room with a variety of skis, boots, walkers, wheelchairs, and individuals with disabilities, I was informed of my options for



skiing. I could be in a sit-ski with either one or two skis under me. If I chose the latter, the two skiers behind me would move the skis and I would go along for the ride. If I chose one ski, I could ski independently (sure!) after I learned how to keep my balance and operate the outrigger skis attached to crutches like mine, though much shorter. Knowing that I had come to ski and not ride, I chose the mono sit-ski. I was fitted in the seat, a tight bucket, with my legs in front and my boots on a bar. Then, I was velcroed into the ski from my waist to my ankles.

My patient instructors worked with me on the snow to gain my balance, learn how to use the outriggers, and go down a gentle slope near the children’s ski area. Falling,

which I did several times, was not painful. It was a short distance to the ground and I landed on my shoulder. The instructors’ job was to right the sit-ski with me in it each time. In the afternoon of the first day, we moved up on the Gemini lift (a great ride) to Discovery Park, an area where neophytes were everywhere, skiing and snowboarding. Practice, practice, practice, and then descending the “Turnpike” slope to end the day. I kept both instructors very close to me when going down the slopes, not at all confident of my ability to guide, turn, and stop the sit-ski.

Days two and three brought me to a new level of confidence with the director of the program as a consultant and my new skills acquired. The director uses a sit-ski as a result of paraplegia, and I was able to see what I had been hearing about from my instructors – what a difference that made!

On New Year’s Day, with my Colorado son on his skis, I skied with three other sit-skiers who were very good. John used the video camera and caught me in my new-found independence on the slopes and a couple of “wipe-outs,” too. To say the day was exhilarating would be a mild statement – it was a real high for me. Dreams really do come true! ■

For more information, contact:

Sports Center for the Disabled,
P.O. Box 36, Winter Park, CO (Colorado)
(907-726-5514).

National Center on Physical Activity and Disability (NCPAD), headquartered in the Department of Disability and Human Development at the University of Illinois at Chicago, MC 626, 1640 West Roosevelt Road, Chicago, IL (Illinois) 60608-6904 (800-900-8086 voice/TTY, ncpad@uic.edu, or www.ncpad.org). (NCPAD is funded by the Centers for Disease Control and Prevention’s Disability and Health Branch.)

Air Travel with Mobility Aids

Grace R. Young, MA, OTR, Fresno, California

Excerpted from her forthcoming book, *Help Yourself! Living Well with a Chronic Condition*

Travel within the USA has become much easier for a person with a disability. Most hotels and motels, even in smaller cities, have at least one or two wheelchair-accessible rooms. The major auto rental companies have vehicles with hand controls and there are lift- or ramp-equipped vans available to rent at most destinations. Cities are more likely to have curb cuts and you should not have to look far to find restaurants without steps at the entrance.

Travel outside the USA is more challenging. The ADA-mandated changes that we take for granted have not made the leap to Europe, Asia, or the Middle East. But if you are flexible, resourceful, and have a sense of humor, experiencing the charm and beauty of other countries and cultures is well worth the effort.

When making travel plans, consider the availability of ground transportation at your destination. A folding manual chair will fit into the trunk of most cars, so transportation problems will be minimal inside and outside the USA. Although scooters can be disassembled, the largest component may not fit into the trunk of small foreign cars. Power chairs and scooters require a van with a lift or ramp and are available for rent in cities throughout the USA but are less common in other parts of the world.

MAKING AIRLINE RESERVATIONS

If possible, take a flight that is either nonstop or direct (where you can stay on the plane at intermediate stops). If it is necessary to change planes, ask your travel agent or the airline reservation agent to put "MAAS" (meet and assist) into your reservation record to help you get to your connecting flight. It is best to use the same airline for all flights, if possible; then one airline has the responsibility of getting you to your next flight on time.

If you are ambulatory but will need wheelchair assistance to get to the boarding area, ask for this information to be put into the computer. Let the airline know exactly what equipment you will be bringing on board – manual wheelchair, power chair, or power scooter, and have the dimensions ready to give them if they ask. Tell them whether you need an aisle or bulkhead seat; however, people with disabilities are not allowed to sit in exit rows due to safety reasons. For ease in transferring, ask if any aisle seats are available with lift-up arms.

Tell the airline agent whether you can walk short distances or if you will need an onboard wheelchair for boarding and using the restroom. While regulations vary, most airlines require at least 48 hours' advance notice if you will need the use of an onboard wheelchair, will need to use oxygen during the

flight, will require ventilator hook-up to an aircraft's electrical power, or will require the packaging of a wheelchair battery for shipment as checked baggage. If you need oxygen during the flight, the airline will supply it and will charge you for onboard oxygen service. For safety reasons, you cannot use your own oxygen unit or the aircraft's built-in oxygen.

Keep reconfirming your seat arrangements until the time you leave. Sometimes airlines have to substitute an aircraft with a different seat configuration and the computer changes the original seating plan.

For overseas flights, arrive at the airport three hours early. Larger aircraft can store one folding wheelchair in the passenger area, but if you are not the first person to check in with a wheelchair, yours will go into the baggage compartment. Power chairs and scooters always go into baggage.

BEFORE YOU LEAVE

Write to the tourist offices of every country you will be visiting to request information on travel for the disabled. Be sure your equipment has gel batteries. Acid batteries will be taken off the chair or scooter and packed in a separate box before being loaded into the baggage compartment. This is a time-consuming stressor that will not add to the enjoyment of your trip. If possible, carry printed information that confirms that your batteries are the gel type. Also, carry a copy of the USA government's publication, "New Horizons: Information for the Air Traveler with Disability."

Put identification tags on any parts that could become separated from your chair or scooter. Have bungee cords ready for strapping loose parts to your equipment after you reach the boarding area. Make two copies of your travel documents, credit cards, passport, and traveler's check numbers; carry one set in a separate place from the originals and leave one set at home.

Grace R. Young, MA, OTR is an occupational therapist who works part-time for San Joaquin Valley Rehabilitation Hospital in Fresno, California. Grace has published and lectured extensively on subjects relating to lifestyle modification for polio survivors. She shares information gleaned from her trips abroad using her power scooter and manual wheelchair.

For more information on energy conservation from Grace, check her Web site at www.geocities.com/HotSprings/4713.

At The Airport

When you check in at the airport, have baggage tags placed on your equipment stating that it should be delivered to the arrival gate.

Now here is the most important travel tip I can give you. Do not surrender your chair or scooter at check-in. Stay in it until you are ready to board the plane. This is not usually a problem, but occasionally the check-in person will want you to check your equipment along with your luggage and then have airport personnel push you to the boarding area in a manual wheelchair. Do not do it! This will only increase the chances of your equipment being misdirected, mishandled, or damaged, and if you use a power chair or scooter you will not have the independence to move around while you are waiting to board your flight.

If you use crutches or canes, they can be placed in an overhead compartment after you board the plane. If you use special cushions, take them on the plane with you.

When you get to the boarding area, remind the personnel that you need to board first and estimate how much extra time it will take you to do it. Early boarding for people with disabilities and parents with small children is supposed to be done automatically, but sometimes this rule is forgotten or not enough time is allowed. On one of my recent flights, the call for early boarding was announced, but before I was halfway down the jetway the regular passengers were allowed to proceed and I was soon engulfed by people. Sit close to the door so you can begin as soon as early boarding is announced.

Have clear instructions for disassembling and assembling the equipment attached to the chair. When you are ready to board the aircraft, supervise whatever dismantling is necessary before you get on the plane. Remember that the crew at the arrival airport has not witnessed

this process, so providing clear instructions with diagrams are crucial.

At your destination it is difficult to predict whether your power chair or scooter will be brought to the arrival gate (even though it is tagged) or will be taken to the baggage claim. I have seen it done both ways. If it goes to the baggage claim area, airline personnel will bring a wheelchair to the plane and push you to baggage claim and stay with you until you find your chair.

Make a thorough inspection of your equipment. Document any damage in writing and do not use the word "minor" on your report. Obtain a claim number and a phone number to call for follow-up on having your chair repaired. Do not leave the airport until this is done. Every USA airline is required by Federal law to always have a designated Conflict Resolution Officer (CRO) available, by phone

or in person. If you cannot settle a difference, you have the right to discuss the problem with the CRO. Ask for a copy of the outcome in writing in case you need it for future reference.

With advance planning, you can enjoy the rewards of new sights, new friends made, and new experiences. Bon Voyage! ■

Horizons: Information for the Air Traveler with a Disability. Published by U.S. Department of Transportation. Topics include accessibility of airports and aircraft; requirements for advance notice, attendants, and medical certificates; handling of mobility aids and assistive devices; and much more, including how to file a complaint. Order from Consumer Information Center 2-D, P.O. Box 100, Pueblo, CO (Colorado) 81009.

Accessible Car and Van Rentals

UNITED STATES

Adapted Car Rentals. Rental cars with hand controls are available at most airports and major cities. To reserve ahead, call: Alamo (800-327-9623), Avis (800-331-1212), Budget (800-527-0700), Dollar (800-421-6868), Enterprise (800-736-8222), Hertz (800-654-3131), National (800-328-4567), Rent-A-Wreck (800-944-7501), or Thrifty (800-367-2277). Call ahead to make arrangements for hand controls to be installed in the car you plan to rent. If you load your wheelchair into the back seat, specify that you need a two-door car.

Wheelchair Getaways, Inc. is a national network of franchises providing wheelchair accessible van rentals throughout the United States and Puerto Rico (www.wheelchair-getaways.com).

Scoot-Around North America will locate a scooter to meet your specific needs and deliver it directly to the location of your choice (888-441-7575, 204-772-6499 fax, info@scootaround.com, www.scootaround.com).

Accessible Vans of America. Nationwide provider of accessible vehicles for rent or sale (888-AVA-VANS; www.accessiblevans.com).

Wheelers Accessible Vans. Serving 120 cities and 35 major airports across the United States, including Hawaii (800-456-1371; www.wheelerz.com).

OUTSIDE THE UNITED STATES

Wheelabout Van Rentals Pty. Ltd. Wheelchair accessible van rentals in Australia (www.wheelabout.com).

Wheelchair Travel. Rental of self-driven, lift-equipped minivans, hand-controlled cars, and accessible cars in the United Kingdom (+44 1483 233640, info@wheelchair-travel.co.uk, www.wheelchair-travel.co.uk).

POST-POLIO RESEARCH

STUDY AT THE UNIVERSITY OF TEXAS AT AUSTIN

Thank you for your overwhelming response to participate in the survey "Maximizing Health for Polio Survivors." Principal Investigator, Alexa K. Stuijbergen, PhD, RN, FAAN, reports a 73% response rate. The large sample will allow her to look at the experiences of several different sub-groups. We received several comments about the payment of \$10 for filling out the survey. It is a standard practice for researchers to pay individuals to participate in a study. In many instances, researchers are required or encouraged to provide payment. It shows respect and acknowledges that your contributions are of value.

SURVEY FROM RANCHO LOS AMIGOS NATIONAL REHABILITATION CENTER

As the result of an abstract in *Neurology* 1999; 52:854-857 by Mark Tarnopolsky, MD, PhD and

Joan Martin, MSc entitled *Creatine monohydrate increases strength in patients with neuromuscular disease*, Jacquelin Perry, MD, DSc (Hon) and Sophia Chun, MD have sent out a survey to polio survivors in their area to ascertain if they have used or are using creatine and what has been their experience. While the reports are encouraging, Dr. Perry would caution polio survivors not to take a higher dosage than recommended.

NIDRR FUNDING EARMARKED FOR POST-POLIO RESEARCH

The National Institute on Disability and Rehabilitation Research (NIDRR) received \$462,500 earmarked for post-polio syndrome research at Albert Einstein Healthcare Network in Philadelphia, Pennsylvania. A panel of experts will review the proposed research plan and provide feedback to the researchers. ■

Update on Global Polio Eradication

The world is about to witness another public health victory with the achievement of the global poliomyelitis eradication. Since the launch of the global polio eradication campaign at the World Health Assembly in 1998, countries have continued to make steady progress towards successfully interrupting the circulation of wild poliovirus. The number of polio cases has decreased from an estimated 350,000 in 1988, to some 5,200 reported cases in 1999. The proportion of the world's children living in polio-infected areas has dropped from 90% to less than 50 percent. The disease has already been eradicated from Europe, the countries of the Western Pacific, and large portion of the Middle East and Northern and Southern Africa. In 1991, the Americas became the first region in the world to eradicate polio.

At this point, the conclusion of the global eradication initiative depends on the efforts carried out by 30 countries in sub-Saharan Africa and South Asia. Many of these have either been affected by civil conflict or remain reservoirs of poliovirus. India, with 70% of the world's remaining polio cases, holds the key to the success of global eradication. WHO plans to accelerate its eradication and surveillance efforts in the endemic countries. Extra rounds of National Immunization Days (NIDs) in 2000 and 2001 will be conducted in Afghanistan, Angola, Bangladesh, Democratic Republic of the Congo, Ethiopia, India, Nigeria, Pakistan, Somalia, and Sudan. ■

SOURCE: *EPI Newsletter, Expanded Program on Immunization in the Americas*, Volume XXI, Number 6, December 1999.

News From the Czech Republic

Best wishes to all of you from the Czech Polio Association. Many thanks for sending us your publications. It is my pleasure to tell you that we have found on its pages not only interesting news from the polio-world, but also inspiration for our work.

Polio Association in Czech Republic will be ten years old this year and we have almost 2,000 members. Our members receive our quarterly magazine. We also have succeeded in organizing many activities for our members. Members in Prague and Ostrava have the opportunity to swim once a week. We have organized a boat trip on the Vltava, a tour of the wine country in Moravia, and a visit to Novy Bor to see Czech glass being made. About 100 members spent 14 days in rehabilitation at the warm springs of Janské Lázně and Krnov. Our three-day annual meeting included lectures on post-polio, dancing, theatre, and exhibitions of paintings and photographs by our members. Creating opportunities for our members to get together is the most pleasant part of our work. ■

To communicate with our group, contact Vera Novotná, Secretary, or Vladimír Vonrejs, Vice-President, Czech Polio Association, Zvánovická 2505/9, 141 00 Prague 4, Czech Republic.

Post-Polio Bibliography

Post-polio related poster sessions at the American Academy of Physical Medicine and Rehabilitation (AAPM&R) 61st Annual Assembly and Technical Exhibition in conjunction with 13th World Congress of the International Federation of Physical Medicine and Rehabilitation, Washington, DC, November 1999:

"Lumbar spinal stenosis presenting as the postpolio syndrome: An increased incidence in a postpolio population?" Myron M. LaBan, MD (William Beaumont Hospital, Royal Oak, MI); John A. Szajenko, MD.

The diagnosis of post-polio syndrome (PPS) continues to rely on the exclusion of other pathologic conditions that may also present with the symptoms of progressive pain and/or weakness in patients with a previous history of polio. To date, the pathophysiology of PPS remains speculative and its histopathologic features, nonspecific. Nine post-polio patients presenting with pain and progressive weakness, initially suspected of having PPS, were instead found to have spinal stenosis (SS). This diagnosis was subsequently confirmed by imaging and electrodiagnostic studies. These patients ranged in age from 48 to 78 years and included only two men. Six had moderate to severe SS with the three remaining patients having only mild stenosis. Although there is no typical pattern of residual paresis in post-polio, nor a singular syndrome of SS, a prospective study of a larger population of symptomatic post-polio patients might well give credence to a heretofore unrecognized increased association between post-polio and SS.

Carod-Artal, F.J., Vargas, A.P., del Negro, M.C., & Lima, G.A. (1999). Magnetic resonance findings of the anterior horns of the spinal cord in a patient with post-polio syndrome. *Revista de Neurologia*, 29(8), 789.

Baydur, A., Layne, E., Aral, H., Krishnareddy, N., Topacio, R., Frederick, G., & Bodden, W. (2000). Long term non-invasive ventilation in the community for patients with musculoskeletal disorders: 46 year experience and review. *Thorax*, 55(1), 4-11.

Conclusions of this study by members of the Chest Medicine Service of Rancho Los Amigos Medical Center, Downey, California, USA: Non-invasive ventilation (NIV) in the community over prolonged periods is a feasible although variably tolerated form of management in patients with neuromuscular disorders. While patients who received body ventilation were followed the longest (mean 24 years), the need for tracheostomy and deaths occurred more often in this group (most commonly in the poliomyelitis patients). Despite a number of discomforts associated with M/NIPPV (mouth/nasal intermittent positive pressure ventilation), a larger proportion of patients experienced improved well-being, independence, and ability to perform daily activities.

Wenneberg, S., & Ahlstrom, G. (2000). Illness narratives of persons with post-polio syndrome. *Journal of Advanced Nursing*, 31(2), 354-361.

This qualitative study by the Department of Caring Sciences, University of Orebro, Sweden, investigated the lifetime illness experience of individuals with the 'late effects' of polio or post-polio syndrome. Fifteen individuals were interviewed twice about their illness experience and the interviews were transcribed verbatim. The empirical material first underwent a categorization process. The preliminary categories generated through this analysis were then condensed into broader categories which in the final analysis gave rise to the following temporal pattern or stages of the illness experience: (1) the acute phase of polio and subsequent treatment and care; (2) rehabilitation and care at institutions for the disabled; (3) adaptation to a new life; (4) living with the post-polio syndrome today, and finally, (5) memories of the past and apprehensions concerning the future. In spite of the difficult experiences of falling ill and slowly recovering from a life-threatening disease, these individuals have had a good life and accomplished most of their ambitions in the areas of work and family life. Their present psychosocial situation is complicated by the symptoms of the post-polio syndrome that make them more vulnerable to stress, but they are able to handle this burden except when any added strain makes it overwhelming. This potential vulnerability may sometimes express itself as a sudden flashback to traumatic polio experiences and it is therefore important that nurses are aware of the illness history of this patient group. ■

Gazette International Networking Institute (GINI), with the talented and dedicated assistance of a friend who wishes to remain anonymous, continues to add to its Web site.

The site is organized in four sections:

◆ **Gazette International Networking Institute** contains information about GINI's mission and history, its services, and its publications. Select articles from past issues of *Rehabilitation Gazette* are online. (We will be adding more and more.) "Networking – Can You Help?" is a page within this section on which GINI will post your non-medical questions (and the answers as they are received) to facilitate networking.

◆ **International Polio Network** contains post-polio information including our popular brochures, "The Late Effects of Polio: An Overview" and "Polio & Post-Polio Fact Sheet," select articles from the last 16 years of *Polio Network News*, a listing of books about the polio experience, select listings from our *Post-Polio Directory-2000*, and ordering information for the recently revised *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*, *Polio Network News*, the complete *Post-Polio Directory-2000*, and other materials.

◆ **International Ventilator Users Network** includes select articles from the last 13 years of *IVUN News*, *IVUN Resource Directory 1999/2000*, and ordering information.

◆ The fourth section, **Post-Polio Task Force**, contains the material developed by the Post-Polio Task Force that was funded by ICN Pharmaceuticals including the contents of the CD-ROM (Post-Polio Syndrome: A New Challenge for the Survivors of Polio) and much more. ■

Readers Write

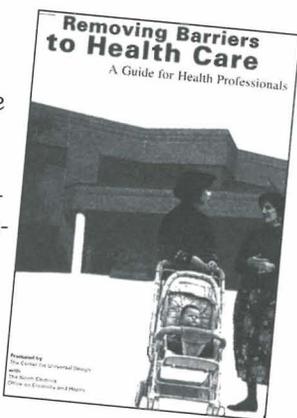
"As I age and as I have more difficulty in getting around, I notice that many of the places I frequented in the past are now inaccessible to me. I find myself most irritated by the inaccessibility of my physician's office. Any suggestions?"

JANE, CALIFORNIA

Removing Barriers to Health Care: A Guide for Health Professionals

is a new publication from The Center for Universal Design. The 17-page booklet is comprehensive (discusses vision, hearing, speech, cognitive, and mobility disabilities) and easy to read. Several pages feature sketches of accessible parking, entrances, lobby and reception area, toilets, dressing rooms, and examination rooms. For more information about the center, visit www.design.ncsu.edu/cud. To request your free copy, call 800-647-6777 or e-mail Cindy_Crouse_Martin@ncsu.edu and leave your name and address.

Hausmann Industries, Inc., 130 Union Street, Northvale, NJ (New Jersey) 07647 (888-428-7626, www.hausmann.com) manufactures a patented wheelchair accessible Powermatic® examination table that is designed to accommodate people with disabilities. Features include a motorized lift from 20 inches to 30 inches; a pneumatic backrest with dual adjustment for 0 to 75 degrees; and pop-up elevating leg rest, etc.



"My 't score' from the bone densitometry of my right hip was -2.34. My 't score' for my lower spine was -2.67. What do these numbers mean?"

JOSEPH, INDIANA

The World Health Organization (WHO) recently published a document that attempted to clarify definitions ... a normal value for bone mineral content is within 1 standard deviation (SD) of the mean value for young adults of the same age and sex (that is, the *t* score is more than -1). Osteopenia is considered to be present when the value for bone mineral content is more than 1 SD but not more than 2.5 SDs below the mean for young adults (that is, the *t* score is less than -1 and more than -2.5). Osteoporosis is considered to be present when the value is more than 2.5 SDs below the mean bone mineral content for young adults (that is, the *t* score is less than -2.5). Severe osteoporosis is considered to be present when the value for bone mineral content is more than 2.5 SDs below the mean for young adults and there is at least one so-called fragility fracture (a fracture assumed to be associated with osteoporosis because it occurred as a result of slight trauma).

Physicians should initiate therapy to reduce the patient's risk of fracture on the basis of the presence or absence of risk factors for osteoporosis. Therapy should be initiated to reduce the risk of fracture in women who have a bone mineral density *t* score of less than -2 in the absence of risk factors and in those who have a *t* score of less than -1.5 if other risk factors are present.

In other words, your right hip meets the criteria for osteopenia, your lower spine *t* score indicates osteoporosis. If you have not begun some therapy, consult your physician.

The above information is extracted from a comprehensive article, Osteoporosis: Epidemiology,

Diagnosis, and Treatment, published in *Southern Medical Journal* 93(1): 2-18, 2000, by Southern Medical Association. Send your reprint requests to the author, Mohammad Masud Iqbal, MD, MPH, MSPH, University of Alabama at Birmingham School of Medicine, Department of Psychiatry, 1001 Sparks Center, 1720 7th Avenue South, Birmingham, AL (Alabama) 35294-0017.

Another resource is the National Women's Health Information Center (www.4woman.gov; 800-994-9662 voice, 888-220-5446 TTY) which operates from 9 am to 6 pm, eastern standard time.



"In celebration of its Centennial, Helen Hayes Hospital in West Haverstraw, New York will be hosting a Patient Reunion on Saturday, June 24, 2000. The physical rehabilitation facility is currently trying to locate patients who were treated at the hospital at any time during its one hundred-year history.

"The hospital was originally a pediatric facility that treated children and young adults with tuberculosis of the bone, polio, cerebral palsy, and other disabling conditions. In more recent years, Helen Hayes Hospital has cared for adults with stroke, traumatic brain and spinal cord injuries, orthopedic disorders, and other disabilities.

"Patients may remember the hospital by one of its former names, including the New York Rehabilitation and Research Hospital, the New York State Reconstruction Home, or the New York State Orthopedic Hospital for Children.

"Former patients can contact Helen Hayes Hospital Public Relations Department at RT 9W, West Haverstraw, NY (New York) 10993 (888-70-REHAB, extension 4225, or visit the Web site at www.helenhayeshospital.org." ■

Spirit of ADA Torch Relay

The Spirit of ADA Torch Relay marks the 10th anniversary of the American with Disabilities Act (ADA) and the 25th anniversary of the Individuals with Disabilities Education Act (IDEA) with a call for individuals, communities, and leaders to renew their commitment to an America that works for everyone.

Join the celebration in your city. You can locate the organizing committee in your area by logging on to www.spiritofada.org/ or by calling the American Association of People with Disabilities (AAPD) at 800-840-8844. The AAPD is the national host organization for the Torch Relay. Volkswagen of America is the relay title sponsor.

Renew the Pledge.

You can join other people with disabilities and the country in renewing your commitment to the Spirit of ADA by signing the pledge below.

Spirit of ADA Petition for Private Individuals

I do hereby pledge my strong support for the goals of equality of opportunity, full participation, independent living, and economic self-sufficiency for all people with disabilities, and pledge to honor the 10th anniversary of the Americans with Disabilities Act (ADA) and the 25th anniversary of the Individuals with Disabilities Education Act (IDEA) by calling on the President, the Congress, my Governor, other elected officials, candidates, and policy makers to work for the following:

Full implementation of and compliance with the federal civil rights laws ADA and IDEA;

Increased outreach and technical assistance so that people with disabilities and families are educated on their rights under ADA and IDEA;

Adequate funding for monitoring, oversight, and enforcement of ADA and IDEA;

Universal access to affordable, quality health care and integrated, affordable, and accessible transportation for children and adults with disabilities and their families;

Removal of barriers to employment for adults with disabilities, including the elimination of ongoing work disincentives in our public income maintenance and health care programs;

Greater choices for people who need long-term services and supports so that they can get the services they need in integrated settings and pursue full and satisfying lives;

Greater investment in affordable, integrated housing options and expanded use of universal design concepts so that access for all is built in as we modernize the infrastructure of our towns and communities, including the technological and telecommunications infrastructures that are transforming the ways we live, learn, communicate, and do business.

By promoting the goals of ADA and IDEA, I hereby reaffirm my commitment to an America that lives up to the promise of liberty and justice for all.

Signed _____ Date _____

Address _____

E-Mail _____

Torch Relay Route

June 11	Houston, Texas
June 13	Austin, Texas
June 17	San Francisco Bay Area, California
June 19	Los Angeles, California
June 21	Phoenix, Arizona
June 24	Salt Lake City, Utah
June 27	Denver, Colorado
June 30	Topeka, Kansas
July 4	Saint Louis, Missouri
July 7	Madison, Wisconsin
July 9	Chicago, Illinois
July 11	Memphis, Tennessee
July 13	Jackson, Mississippi
July 15	Montgomery, Alabama
July 17	Tallahassee, Florida
July 19	Warm Springs, Georgia
July 20-21	Atlanta, Georgia
July 22	Columbia, South Carolina
July 25	Arlington, Virginia
July 26	Washington, DC
July 29	Philadelphia, Pennsylvania
July 31	Auburn Hills/ Detroit, Michigan
August 3	Boston, Massachusetts
August 6-7	New York, New York

Please mail your signed pledge to Spirit of ADA Campaign, AAPD, 1819 H Street NW, Suite 330, Washington, DC 20006-3603. If you renew the pledge by e-mail, please send it to aapd@aol.com.

For more information, contact the AAPD at 800-840-8844, 202-457-0046 voice/TTY, 202-457-0473 fax, or www.aapd-dc.org.

EIGHTH INTERNATIONAL
Post-Polio AND
Independent
Living
Conference

SAINT LOUIS, MISSOURI

JUNE 8-10, 2000

Opening Luncheon -- 11:30 am, Thursday, June 8
Closing Session -- 3:30-4:30 pm, Saturday, June 10

Saint Louis Marriott Pavilion Downtown
1 Broadway, Saint Louis, Missouri 63102

Join other polio survivors, ventilator users, their families, and knowledgeable health professionals for three days of (40+) informative, interactive sessions, including ...

... **Opening Thursday luncheon** honoring Dr. Augusta Alba, Coler/Goldwater Memorial Hospital, Roosevelt Island, New York, and Dr. Jacquelin Perry, Rancho Los Amigos National Rehabilitation Center, Downey, California.

... **Thursday Evening Twilight Sessions** that will offer you an opportunity to explore writing, music, and art. In addition, you can participate in a discussion of sexuality and intimacy or participate in a session about partnership with your spouse or significant other.

... **Friday evening dinner presentation by The Dis-Ability Project** under the direction of Joan Lipkin of That Uppity Theatre Company, Saint Louis, Missouri. Enjoy thought-provoking original theatre created and presented by disabled and non-disabled individuals.

... **Lighting of a Spirit of ADA Torch** on Saturday at the luncheon by guest speaker Robert J. Provan. Mr. Provan, polio survivor, was featured on the front page of the Wednesday, January 26, 2000 issue of the *Wall Street Journal* acknowledging his commitment to revolutionizing the health care industry. Provan's chief attack has been his work in *Zamora, et al. v. Humana, et al*, a lawsuit set to go to trial in November that challenges the practices of HMOs based on the Americans with Disabilities Act.

Learning About and From Post-Poliomyelitis: A Seminar for Physical and Occupational Therapists and Physical and Occupational Therapist Assistants

is scheduled for Friday, June 9 (7:45 am - 4:45 pm) and Saturday morning, June 10 (7:45 am - 11:45 am). Attendees will be awarded a certificate of attendance for 9 1/2 contact hours.

Check GINI's Web site

www.post-polio.org/conf2000/ for more details.

For a registration form, contact Carol A. Cox at GINI or check pages 9-11 of *Rehabilitation Gazette*, Vol. 40, No. 1.

Call the Saint Louis Marriott Pavilion Downtown to reserve your room (314-421-1776, ask for the "GINI post-polio meeting")

NOTE: A **Program/Abstract book** will be compiled of material contributed by the presenters at the Eighth International Post-Polio and Independent Living Conference. Additionally, some of the sessions will be audiotaped. The book and the tapes will be available after the June 8-10 meeting. Ordering information will be published in the Summer 2000 issue of *Rehabilitation Gazette* and will be put on www.post-polio.org - GINI's Web site.

 **Gazette
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