WELCOME HOME - A REUNION
Children’s Free Hospital
Farmington, Michigan
On the Campus of
Botsford Commons Senior Community
Saturday, September 13th
10:00am to 2:00pm

We have a story to tell... And you may be part of it!
The former Children’s Free Hospital, on the site of the current Botsford Commons Senior Community, was once a jewel in the treatment of polio and other childhood illnesses and disabilities. The original large red brick buildings remain preserved on the campus, and serve today as a Senior living Center and Clinical Services Building.
In the early 2000's, we’ll be celebrating the 100th anniversary of these Albert Kahn designed facilities! In preparation for that event, and realizing that none of us is getting any younger, we invite former patients, nurses, physicians, volunteers and others involved in the Children’s Free Hospital to return to the campus September 13th to tell their story!

Our special “Welcome Home” day is Saturday, September 13th, from 10:00am - 2:00pm. We invite you to come and explore. Albert Kahn Associates has graciously shared a set of the buildings' architectural drawings. You’ll be able to find the library, the operating room, the dentist office, and the ramp. And we’ve graciously preserved the playroom and dining room fireplaces. Two of the hospital’s original wooden wheelchairs have remained on site. Won’t you come and explore?
Bring your photographs, your movies, and most of all, your personal recollections. We’ll have volunteer historians from the Farmington Community Library’s Heritage Room and the Farmington Historical Society available to hear and record your story. You might even find an old friend!
Help us preserve an important part of Farmington area history! It was also called The Sister Kenny Hospital. After 1955, the buildings were no longer used to serve crippled children.

Reservations encouraged.
Contact Kimberly Gimmarro at
(248) 426-6951

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FROM THE CHAIR
Bruce Sachs, Chairman

Now that the days are warmer and the snow is finally gone we can get out and enjoy meeting with family and friends, do a little shopping or just sit outside. At the Annual Board of Directors meeting in May we elected officers for this year. A complete list of Board members and office holders can be found on the back of this newsletter. Dianne and I represented the MPN with a table at the Elder Expo on Tuesday July 8th at the Soaring Eagle Casino and Conference Center in Mt Pleasant. For those that would like to meet other polio survivors, I will extend an invitation to check out the following.

The Third Annual “Wellness Week” being held at Bay Cliff Health Camp, Big Bay, Michigan, September 22 - 27. For more information: contact Christy at Bay Cliff by calling 906-345-9314 or emailing baycliffhc@aol.com. Post-Polio Health’s 10th International Conference, “Living with Polio in the 21st Century” will be held April 23 - 25, 2009 at the Roosevelt Rehabilitation Institute in Warm Springs, Georgia Hotel accommodations will vary in cost and luxury. Watch www.post-polio.org for details.

Interested in a pre-conference retreat that will go one-step beyond re-rehabilitation and focus on health and wellness? A Post-Polio Wellness Retreat is being planned for Sunday, April 18, 2009 – Thursday, April 23, 2009. It will be modeled after the popular retreats held at Bay Cliff Health Camp in Big Bay, Michigan. Want to know more? Watch the 10-minute DVD "Holistic Health and Wellness Retreat for Polio Survivors." at www.post-polio.org At this time there are no details on either the Conference at Warm Springs or the Wellness Retreat. Keep checking www.post-polio.org for details. I was informed that details would be available in September. While we are enjoying the summer weather, take a few minutes and contact your local newspaper and see if they are interested in interviewing you about your polio experience. Also, if you would like to comment on the following, contact the President and your people in Washington before September. Plan Seeks More Access for Disabled

WASHINGTON — The Bush administration is about to propose far-reaching new rules that would give people with disabilities greater access to tens of thousands of courtrooms, swimming pools, golf courses, stadiums, theaters, hotels and retail stores.

Have a great summer. Bruce
STATE OF THE NETWORK
As part of the Annual Meeting on May 17th, Chairman Bruce Sachs presented the following summary of the Michigan Polio Network.

Financially: The Network is a non-profit organization and depends upon paid memberships and donations to provide the "Perspectives" newsletter, conferences, the Polio Library and other services to polio survivors. None of the Board members are paid for their involvement with Board activities and are only reimbursed for materials needed. As Chairman, although I attend conferences, support group meetings, Elder Expos, etc. I consider my expenses as a donation to the network.

We would encourage everyone to consider donations to the Michigan Polio Network when making charitable donations and when making your final plans.

Membership: Although we have lost some members, there are still thousands of polio survivors, in Michigan, that are not members. If you know of any non-members, encourage them to join.

The MPN Library: The library continues to provide information to polio survivors, medical people and others interested in learning about polio, post-polio. The library has continued to purchase new books and materials as they become available. Books and tapes may be borrowed from the library.

Board of Directors: The Board is the policy making part of the Network and helps plan conferences and oversees the working of the network. Presently, we have room for 1 Board member. If you know of anyone interested, have them submit a brief biography to the chairman.

Bruce and I were married in Boca Raton, Florida on April 2, 2008 with our Cruising friends present. Our Southeast Post-Polio Support Group surprised us with a pre-wedding reception held at the 1st Presbyterian Church in Troy, Michigan held on March 22, 2008. Bonnie and Dick Levitan, along with our Southeast Post Polio Support Group surprised us with a wonderful luncheon and darling gifts.

It was amazing walking into our support meeting and seeing wedding decorations. Rick and Gwen Schwendenmann brought a beautiful wedding cake and champagne. Rick was also our official photographer.

We are so blessed and grateful to have these wonderful friends to share our special day. We thank Joel and Maureen Sinkule from Boca Raton, Florida so very much for the surprise wedding reception in their home and for being our witnesses. Sandra Santa Maria performed a beautiful ceremony, while husband Tony played the keyboard. Martin Goldstein walked me down the hall and gave me to Bruce. Matthew Henriksen, Maureen's son, was the official photographer, head waiter, and all around helper. Other "Cruising" guests included Danny Kasper, Walter and Ruthie Olsen and Lee Rosen. Ruthie sang "Wind Beneath My Wings" that brought tears to our eyes.

Thank you everyone for making our wedding memorable. We will never forget this day--------Apr12, 2008.
FOR YOUR INFORMATION

American Disability Association
Synopsis by MobiLife, Power Wheel Chairs

The American Disability Association came to existence in 1990 along with the Americans Disabilities Act which has served the disability community by enforcing their civil rights, decreasing discrimination, and increasing the standard of living for them. The Association also supports and creates high standards for disability devices such as mobility and handicap equipment so people with disabilities are able to get around easier, as well as, improving the environment and public areas. They are dedicated to helping disabled people, through the American Disabilities Act, by stopping discrimination through employment opportunities, developing better transportation systems and providing better accommodations in public areas.

There are five Titles that the ADA is built upon: Employment, Public Services, Public Accommodations, Telecommunications, and Miscellaneous Provisions. Title I Employment, was developed basically so that people with disabilities are offered an equal opportunity for employment and cannot be discriminated against if they are considered a "qualified" candidate. Public Services are Title II and built up of two sections; one includes government buildings in local, county, and state areas, and the other covers public transportation. Section 1 was developed so that there are specific areas and devices such as handicap parking and entrances, as well as, elevators so power wheel chair users have easier access at these facilities. Section 2 makes sure there is public transportation such as buses. Public Accommodations, which is Title III, basically states that all public facilities such as hotels, restaurants, stores, and pretty much anywhere, have handicap access and accommodations. The third Title protects those with a hearing or speech impairment disability. They have developed a system called Teletypewriter, (TTY), that allows them to communicate to others over the phone. Title V protects all Miscellaneous Provisions. It states that the ADA cannot amend, override, or cancel anything in Section 504. By improving and enforcing these Titles, people with disabilities will be able to live a tremendous life.

Contact: Civil Rights Division
U.S. Department of Justice
Disability Rights Section- NYA
Address 950 Pennsylvania Avenue, NW
Washington, D.C. 20530
Phone: (800) 514-0301
TTY: (800) 514-0383

Disabled Americans still facing obstacles 18 years after federal act passed

Disabilities Act is 18 years old today
Saturday, July 26, 2008
Sabrina Eaton, Plain Dealer Bureau
Washington -- Getting around Cleveland by public transit was a nightmare for 50-year-old Donna Prease in the years before the Americans with Disabilities Act passed.
"There were no accessible buses," recalls Prease, who was born with a bone disease that requires her to use a wheelchair.
The situation has improved greatly in the 18 years since the act, known as the ADA, required that businesses, employers and the government provide ramps, lifts or elevators, and other accommodations to give people with disabilities the same access as everyone else. The law, which President George H. W. Bush signed 18 years ago today, required modifications to buses, stores, restaurants, theaters, even telephones for people whose hearing is impaired. It also continued next page...
required accommodations in the workplace. But as advocates celebrate today at a National Forum on Disability Issues in Columbus, the focus is expected to turn to what remains to be done to fulfill the ADA's goals. Employment discrimination still hasn't ended, say Prease and hundreds of other disability-rights activists who gathered in Washington this week in an effort to update the act.

"What do we want? Freedom!" they shouted as they marched toward Capitol Hill to meet with members of Congress.

Eugene Leber, 49, of Bellbrook, near Dayton, who has used a wheelchair since he was injured in a 1979 shooting accident, says that the ADA has made it easier for him to get into stores, restaurants and other facilities but that the law still needs to be tweaked.

A Proclamation by the President of the United States of America:
Anniversary of the Americans with Disabilities Act, 2008

Last update: 10:13 a.m. EDT July 25, 2008
WASHINGTON, Jul 25, 2008 (BUSINESS WIRE) -- The Americans with Disabilities Act (ADA) has helped tear down barriers for millions of people living with disabilities. On the anniversary of this important legislation, our Nation underscores our commitment to ensuring that all individuals have an equal opportunity to realize their full potential.

On July 26, 1990, President George H. W. Bush signed this groundbreaking Act into law, better enabling citizens with disabilities to participate fully in all aspects of life. Over the course of nearly two decades, this Act has made our schools and workplaces more welcoming, helped change attitudes that once seemed unchangeable, and expanded opportunity for many exceptional Americans. The ADA is one of the most successful civil rights laws in our history and has been an essential part of countless American lives.

My Administration is committed to working to empower those with disabilities so that all our people can achieve the American dream.

Building on the success of the ADA, the New Freedom Initiative of 2001 has had a positive impact for many of our citizens. Technological advances have helped individuals gain greater access to everyday life. Students with disabilities are given the tools they need to succeed, and in the workplace, innovative hiring and employment practices are helping to integrate Americans with disabilities into the workforce. The Ticket to Work and AbilityOne programs have helped them become more self-sufficient by expanding access to employment. Our Nation has benefited from the progress we have made since the enactment of the ADA, and it is our responsibility to continue working toward a country where all people are treated with the respect and dignity they deserve.

On this anniversary, we highlight our commitment to the ADA and celebrate the progress that has been made toward full participation of people with disabilities in our society.

NOW, THEREFORE, I, GEORGE W. BUSH, President of the United States of America, by virtue of the authority vested in me by the Constitution and laws of the United States, do hereby proclaim July 26, 2008, as a day in celebration of the 18th Anniversary of the Americans with Disabilities Act. I call on all Americans to celebrate the vital contributions of individuals with disabilities as we work towards fulfilling the promise of the ADA to give all our citizens the opportunity to live with dignity, work productively, and achieve their dreams.

IN WITNESS WHEREOF, I have hereunto set my hand this twenty-fourth day of July, in the year of our Lord two thousand eight, and of the Independence of the United States of America the two hundred and thirty-third.

GEORGE W. BUSH
SOURCE: White House Press Office

*****
Five Things You Never Knew Your Cell Phone Could Do

For all the folks with cell phones. (This should be printed and kept in your car, purse, and wallet. Good information to have with you.)

There are a few things that can be done in times of grave emergencies.

Your mobile phone can actually be a life saver or an emergency tool for survival. Check out the things that you can do with it:

FIRST
Emergency
The Emergency Number worldwide for Mobile is 112. If you find yourself out of the coverage area of your mobile network and there is an emergency, dial 112 and the mobile will search any existing network to establish the emergency number for you, and interestingly, this number 112 can be dialed even if the keypad is locked. Try it out.

SECOND
Have you locked your keys in the car?
Does your car have remote keyless entry? This may come in handy someday. Good reason to own a cell phone: If you lock your keys in the car and the spare keys are at home, call someone at home on their cell phone from your cell phone. Hold your cell phone about a foot from your car door and have the person at your home press the unlock button, holding it near the mobile phone on their end. Your car will unlock. Saves someone from having to drive your keys to you.

Distance is no object. You could be hundreds of miles away, and if you can reach someone who has the other 'remote' for your car, you can unlock the doors (or the trunk).

Editor's Note: It works fine! We tried it out and it unlocked our car over a cell phone!

THIRD Hidden Battery Power
Imagine your cell battery is very low. To activate, press the keys *3370#. Your cell phone will restart with this reserve and the instrument will show a 50% increase in battery. This reserve will get charged when you charge your cell phone next time.

FOURTH
How to disable a STOLEN mobile phone?
To check your Mobile phone's serial number, key in the following Digits on your phone: *#06#. A 15-digit code will appear on the screen. This number is unique to your handset. Write it down and keep it somewhere safe.

When your phone gets stolen, you can phone your service provider and give them this code. They will then be able to block your handset so even if the thief changes the SIM card, your phone will be totally useless. You probably won't get your phone back, but at least you know that whoever stole it can't use/sell it either. If everybody does this, there would be no point in people stealing mobile phones.

And Finally....

FIFTH
Free Directory Service for Cells
Cell phone companies are charging us $1.00 to $1.75 or more for 411 information calls when they don't have to. Most of us do not carry a telephone directory in our vehicle, which makes this situation even more of a problem.

When you need to use the 411 information option, simply dial: (800)FREE411, or (800) 373-3411 without incurring any charge at all.

Program this into your cell phone now.

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Michigan Polio Network
ANNUAL ELECTION RESULTS:
Ballots sent out 630 (apx)
Ballots returned 307
Results:

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<th>Votes</th>
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<td>Don Pixley</td>
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<td>Jane Evans</td>
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<td>Carl Fenner</td>
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<td>Paula Lemieux</td>
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<td>Rick Kugel</td>
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<td>Sharon Kugel</td>
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<td>Rick Schwendenmann</td>
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Write Ins: Betty Combs 1, Dianne Dych 1
Mohammed Yust 1

**********
ARE YOU AT A LOSS AS TO WHAT IS HAPPENING TO YOUR HEALTH?
DO YOU NEED SOME ANSWERS TO UNDERSTAND WHAT TO DO KNOWING YOU MAY HAVE POST-POLIO SYNDROME?
WE HAVE SOME HELP FOR YOU!!

Make an appointment with Michigan's Post-Polio Clinic. They are very helpful the minute you arrive for your appointment. You will find out a lot about yourself, your problems, and guidance as to what doctors you need to see. So take the first step to some of the answers. CALL:

The Post-Polio Clinic
Center for Physical Medicine and Rehabilitation
13850 East 12 Mile Road
Warren, MI 48088
Phone (586) 778-4505

FALLING UP "I TRIPPED ON MY SHOELACE AND I FELL UP" These are the opening words in a children's poem by Shel Silverstein. If only we would "fall up" when we lose our balance, we would be a lot better off. I am using the following personal experience as a reminder to all of us that have a balance problem to be aware of our limitations. Diane and I had returned from Florida a few days earlier and I was still in the process of cleaning up things in my Livonia house before I completed my move to Mt. Clemens. While working in the laundry room I lost my balance, fell over backwards and hit my head on the edge of the shower door. I must have passed out because the next thing I remember is being on the floor with blood oozing from my head. After moving around the room trying to find a way to get up, I realized that I needed to call for help. Although I usually have my cell phone with me when I leave the house I don't always carry it when I am around the house. That night I had it on my belt and was able to call my sister, who is a nurse and lived about 10 minutes away, she also had a house key. With the help of my sister and 2 neighbors they were able to get me to the hospital. Meanwhile, Dianne was in Mt. Clemens, about 45 minutes away, when she was called. With me being at the hospital, she went to the Livonia house to clean-up. She knew there would be blood, but was not prepared to see what she called a "crime scene". She met us at the hospital where I received 14 staples to close the large cut in my head. I have used this experience to remind everyone to be aware of your surroundings and be prepared for the worst. Many of us can not get up when we fall, either carry a cell phone or get an alert device to place around your neck. I hope the next time I fall I "FALL-UP", Bruce

*****

Some helpful hints how you can get help.

*Have your cell phone with you as Bruce did.
*Keep your car keys by you at night and carry them around with you in the day. If you need help just hit the car alarm button. This will alert neighbors that something is wrong and will come to you. It is helpful to let the neighbors know your idea.
*Get The Nationwide Medical Alert / Medical Alarm System With Interactive "2-Way" Personal Medical Emergency Monitoring. A 24/7 Monitored Medical Alarm System from Connect America® provides peace of mind because, if ever needed, live help is just the push of a button away.

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MPN Board of Directors Meetings
Oct. 18, 2008

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THE MICHIGAN POLIO NETWORK, INC
MAILING ADDRESS
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Polio Perspectives

Polio Perspectives is published four (4) times a year by the Michigan Polio Network, Inc. (January, April, July, and October). We encourage our readers to send in articles, information, personal accounts, humor, helpful hints, and anything you find useful and interesting to polio survivors. We give our readers the right to publish anonymously.

All material in Polio Perspectives is that of the individual writers. Articles do not constitute an endorsement or approval of the MP Network Inc Directors or the Polio Perspectives Staff.

June 19, 2008

Just passing along some information that might be of interest to your readers.

This past winter I found these boots that fit over my orthopedic shoes and braces that are attached. They are not “fashion designer” attractive but they help keep me from slipping in the ice and snow. -Virginia Ford

NEOS OVERSHOE

Since 1994, NEOS has brought about a surge in the popularity of the overshoe. Gone are the days of having awkward pack boots or rubber galoshes. You can wear NEOS--super lightweight, durable and waterproof - right over your everyday, comfortable footwear.

All NEOS performance overshoes are designed with a large gusset opening from the toe of the boot for easy on-and-off convenience. This opening fits over every shoe, from running shoes or hiking boots, to clogs or even sandals.

Whatever your footwear, NEOS overshoes provide protection from all weather conditions. NEOS performance overshoes are made with genuine Vibram performance outsoles. These lugged soles employ an aggressive tread with high traction for cold, icy conditions. A specially formulated rubber keeps NEOS flexible even at sub-zero temperatures. The overshoes are equipped with an adjustable instep strap for a secure, quick fit.

NEOS has many different models to choose from. Perfect for commuting, travel, biking or snowshoeing. NEOS offers a performance overshoe with functioned features for your specific needs. Now you can wear your favorite footwear year-round.

Arthur C. Clarke


Mr. Clarke contracted polio in 1962. His apparent complete recovery allowed him to return to his favorite sport, table tennis. However, in 1984 he, like so many of us, developed post-polio syndrome, and due to progressive muscle weakness, extreme fatigue and breathing difficulties spent the last years of his life in a wheelchair.

Leave Your Legacy

You can help the Michigan Polio Network, Inc. continue its vision and its goal to help all those who had polio. How can you do this? By remembering the Michigan Polio Network in your Will, your Estate Plan, or in your final wishes.

Like so many nonprofit groups, the Michigan Polio Network runs on a shoestring budget. Any bequests or charitable gifts are most earnestly appreciated.

Thank you for your support!
POLIO SURVIVORS SHARING

This is a one-on-one e-mail list so you can mail only to the selected name; an e-mail list of Polio Survivors who wish to communicate with other Polio Survivors and discuss your concerns, ideas, fun, jokes, as well as sharing information of what is happening to each other. I would like your permission to add you on this list. Please email to vhazel38@comcast.net to get on the list! Also include your city and state. Happy Sharing!!  

Vera Hazel, Editor

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Sanibel Island, FL
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susanvrm@clear.net.nz - Susan Kerr New Zealand

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**WEB SITES**

Michigan Polio Network, Inc--
www.geocities.com/mi_polio_net.

Lincolnshire PP Network--
http://www.zynet.co.uk/ott/polio/
lincolnshire/directory.html

Post-Polio Health International (PHI)
4207 Lindell Blvd #110, Saint Louis, MO 63108
info@post-polio.org - www.post-polio.org

Harvest Center's Post-Polio Library--
http://members.aol.com/harvestctr/
pps/polio.html

New Mobility's Post-Polio Forum --
http://newmobility.com/polio.ctm

International Post-Polio Task Force
at Englewood Hospital and Medical Center
Englewood, New Jersey USA 07631
201-894-3724 877-POSTPOLIO
postpolioinfo@aol.com
PostPolioInfo.com/post polio

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**MICHIGAN POLIO NETWORK, INC. MEMBERSHIP FORM**

The Michigan Polio Network, Inc. is a tax exempt non-profit organization with 501 (c) (3) status. Your contribution is tax deductible as allowed by law. Membership includes our newsletter Polio Perspectives. To join it is not necessary to be a resident of Michigan or be a Polio Survivor.

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**PRINT:**

Name ____________________________
Address ____________________________
City ____________________________
State: ______ Zip: __________
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1156 Avon Manor Rd
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AN APPROACH TO THE PATIENT WITH SUSPECTED POST POLIO SYNDROME

Polio survivors are at risk for the occurrence of certain physiologic changes in the nervous system which result in a characteristic set of symptoms now known as Post Polio Syndrome. In addition to these unexpected physiological changes there are anticipated complications such as arthritis, scoliosis, and entrapment syndromes that frequently accompany paralytic conditions. These anticipated complications are not the problems that distinguish PPS from other diseases of the nervous system. Post Polio Syndrome (PPS) is a major chronic illness and one which poses unique problems to its survivors and their physicians.

No Diagnostic test exists for PPS, so clinical criteria must be used to establish the diagnosis. Many Physicians lack training in the diagnosis and management of a syndrome only recently acknowledged as existing. Patients are often uncomfortable with physicians they feel do not understand their problems. They also fear increased disability, often at the same time they are coping with limitations of aging. Patients are often trapped in a "conquer the disease" mentality derived from the experience of recovering from the acute episode an average of 25 years earlier. This is incompatible with the lifestyle adjustments necessary for optimal results in PPS rehabilitation.

I. INTRODUCTION

A. DEFINITION OF POST POLIO SYNDROME

An otherwise unexplained constellation of symptoms which may include weakness, fatigue, pain, heat or cold intolerance, and swallowing, breathing, or sleep disturbance developing in a patient who had paralytic polio. Post Polio Muscle Atrophy (PPMA) has been used as the label for the above symptoms when they include progressive muscle atrophy.

B. SCOPE OF THE PROBLEM

1987 National Health Interview Survey estimated 1.63 million American polio survivors (= 0.625% of population). 50% with some Post Polio Syndrome symptoms.

C. DIAGNOSTIC CRITERIA

1. PPS is a diagnosis of exclusion and should be based on a thorough history and physical exam.
2. Evidence of prior paralytic polio: via EMG, an appropriate history, or characteristic residual atrophy.
3. Period of apparent stability before any new symptoms. New symptoms may often be seen after an illness or injury.
4. Exclusion of other conditions (especially motor neuron diseases and overuse syndromes).

II. PATHOLOGY: PHYSIOLOGIC AND CLINICAL CONSEQUENCES

A. EXTENSIVE NEURONAL INVOLVEMENT IN THE ACUTE POLIO INFECTION

1. The extent of central nervous system infection by polio virus is not well appreciated. Infection is far more widespread than anterior horn cells alone.
   Often anterior horn cell infection is largely subclinical due to residual capacity of uninfected and surviving neurons. Infection outside the anterior horns is likely to be largely subclinical also, but may help to explain the disabling symptoms of fatigue and pain which are subjective and controversial (because the physiologic basis is uncertain).
2. Ninety-five percent (95%) of motor neurons are infected in an average acute infection, with a 50% neuronal fatality rate.
3. There is frequent segmental involvement, accounting for the lack of symmetry of weakness.
4. In addition to the anterior horns in the spinal cord, infection involves intermediolateral horns and dorsal root ganglia.
5. Infection also involves motor cortex, hypothalamus, and globus pallidus, brainstem nuclei, reticular formation, cerebellar roof nuclei, and vermis.

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B. MOTOR UNIT REMODELING IN THE POST RECOVERY PHASE
1. A normal quadriceps has, on average, 200 muscle fibers/anterior horn cell and a normal anterior horn cell can adopt as many as 1,000 orphaned muscle fibers.
2. Over 50% of motor units may be lost without symptoms. (Normal walking uses only 15-20% of maximum muscle strength.)
3. Clinical improvement occurs acutely through recovery of mildly affected neurons, collateral sprouting, and strengthening (hypertrophy) of intact musculature.
4. Increased demand on surviving motor units results in increased firing frequency which in turn produces a change in fiber type to predominantly aerobic "slow twitch" fibers with increased vascularity.

C. DECOMPENSATION THEN PRODUCES POST POLIO SYNDROME
While a single underlying etiology for PPS has not been proven, several theories exist:
1. There is an increased metabolic burden on surviving anterior horn cells (even in asymptomatic muscles) as they direct more muscle fibers to contract, more often, to achieve the same force of contraction. This leads to anterior horn cell fatigue and can lead to premature metabolic injury, perhaps even cell loss. Fatigued neurons may be unable to continue to trophically support as many muscle fibers. The collateral sprouts to some muscle fibers will degenerate. The strength of these muscle fibers will be lost to the motor unit, and a spiral of decline may set in. This mode of decompensation augured by fatigue, may be anterior horn cell based. This appears not to be a static process and there may be dynamic denervation and reinervation.
2. Another mode of decompensation is muscle fiber based: Rapidly firing muscle fibers produce more lactic acid which may not be adequately dissipated. This is especially true with any degree of isometric contraction. Muscle fiber fatigue may lead to muscle fiber injury, lost function, and a spiral of decline.

3. Any increase in mechanical load (such as would result from increased weight or increased physical activity) or decrease in force generating capacity (such as would result from inactivity following illness or injury) may trigger metabolic failure in motor units or in muscle fibers functioning close to their capacity.
4. The resulting relative weakness may lead to joint and muscle misuse and overuse. This may lead in turn to both arthritis and overuse syndromes.
5. In addition to anterior horn cell and muscle fiber modes of fatigue, central fatigue may also be a factor. Polio virus infection of the motor strip and the reticular activating system is well described. A working definition for central fatigue is: "Increased mental effort necessary to perform a fixed amount of muscle contraction". This is very much how Post Polio Syndrome patients describe their feelings of fatigue, many report hitting a "post polio wall".

III. PATIENT PRESENTATION
A. PRIME SYMPTOMS
A common presentation is a polio survivor who previously had lower extremity involvement in a well defined polio episode. The patient may have restricted ambulation from hiking or jogging, lived a sedentary life, and did not feel disabled. After a period of relatively stability he or she may begin to notice unusual fatigue and discomfort and may further restrict activity. Denial of decreased functional capacity may lead to a crisis as the patient can no longer can meet occupational, social, and family commitments. Persistence and attempts to continue at a previous activity level may lead to a downward spiral of decreasing functional capacity with resulting depression and despair. On examination, relative obesity may be present and weakness is easily demonstrated, often in the "good" leg; limbs considered unaffected are often subclinically affected with polio and may present with "new" polio. A statistical summary of the clinical characteristics of several series of PPS patients is as follows:

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1. Fatigue, Pain, and Weakness are almost always present. Fatigue (89%); Pain in Muscle or Joint (86%); New weakness (83%) in previously symptomatic (69%) or asymptomatic (50%) muscles.

2. New Atrophy (28%); This equates to Post Polio Muscular Atrophy (PPMA).

3. Activities of daily living difficulties (78%) =
   Functional loss. Walking (64%); Climbing Stairs (61%); Dressing (17%).

B. ADDITIONAL PRESENTING PROBLEMS

1. Pulmonary dysfunction:
   Patients with Post Polio Syndrome may suffer from weakness of the breathing muscles, namely the diaphragm and rib cage. Occasionally, this can be severe enough to cause symptoms of dyspnea on exertion and even at rest, poor clearance of respiratory secretions increasing the risk of pneumonia, and elevations in the resting arterial CO2 level. Measurement of pulmonary function tests in these patients usually shows a significant restrictive pattern (small lung volumes) on the basis on neuromuscular weakness.
   If respiratory muscle weakness is severe enough mechanical ventilation may be required. Small mechanical ventilators have been developed which deliver breaths through a comfortable plastic nose mask. This is often performed while the patient is asleep at night and results in improved daytime function.

2. Sleep Disorders:
   Patients with Post Polio Syndrome have a high incidence of sleep disturbances with poor sleep quality and frequent awakenings which may be due to several factors. However, the most important etiology to rule out is central, obstructive and mixed sleep apneas. Nocturnal hypoxemia and hypercapnia can lead to worsening of daytime function of the breathing muscles. Nocturnal non-invasive ventilation can be used in these patients to improve sleep quality and reduce symptoms of daytime sleepiness, and perhaps improve daytime respiratory muscle function.

3. Dysphagia:
   Many PPS patients reported some new difficulty with eating or swallowing more commonly in those with bulbar polio. Video fluoroscopy has been used for evaluation and has frequently revealed pharyngeal constrictor weakness. Laryngeal penetration and loss of the cough reflex may occur without symptoms, suggesting an underestimation of the presence and severity of dysphagia in this population. Many patients have already employed compensation such as altering diet, cutting solids into small pieces, chewing it thoroughly, taking small sips of liquids, eating slowly, and using postural maneuvers. Most patients with dysphagia had also experienced some progressive speech difficulty such as increased hoarseness, weakness, or slurring.

4. Cold intolerance (29%):
   Limbs may be cold and cold exposure produces weakness. This is thought to be due to intermolecular column involvement resulting is vasoparesis, venous pooling, and excessive heat loss.

5. Degenerative arthritis:
   A joint that is biomechanically disadvantaged may develop degenerative arthritis.

6. Social and psychological problems:
   Long term disability and denial may result in social and psychological problems.

C. PAST HISTORY

1. Average age of polio onset is 7 years. Median time to maximum recovery is 8 years. Median period of stable neurologic and functional status is 25 years. Median post polio symptom duration before patient presents for evaluation is 5 years.

2. Variables associated with shorter interval to PPS: greater severity and greater age.

3. Initial symptoms are most frequent in the lower limb most affected in the acute illness. (Upper extremity weakness is easier to compensate for without overuse resulting.)

4. The onset is usually insidious but is frequently precipitated by injury, illness, bed rest, or weight gain.

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IV. EVALUATION PROCESS
A. IDENTIFY AREAS OF DYSFUNCTION
1. The history is especially useful in identifying fatigue, dysphagia, sleep disorders, and alteration in activities of daily living.
2. The Neurologic exam will identify atrophy or weakness and verify that reflexes are not increased. Pay special attention to the "good" limb as significant weakness may be present of which the patient has never been aware. With leg muscles, functional tests must be used because manual testing may not detect quadriceps weakened to 30% of normal even though this is sufficient strength for routine daily activities. Seek a mechanical advantage in manual muscle testing: Test the triceps or quadriceps with the elbow or knee flexed more than 90 degrees. Test the psoas in the supine position.
3. The general physical and biomechanical exam note obesity, joint deformity, overuse syndromes, and scoliosis.
4. Electromyography may be requested when needed to document previous anterior horn cell disease (especially when the previous history of polio is in doubt). EMG can also be used to rule out other neuromuscular pathologies or to identify subclinically involved muscles.
5. CK elevation may be seen in patients but may not correlate with progressive weakness.

B. FORMALIZE TREATMENT GOALS
After the diagnosis of PPS is established, a patient conference is a convenient way to formalize treatment goals and begin patient education. These areas should be addressed:

1. Lifestyle Modifications:
This item is the "sine qua non" of all attempts at successful management of PPS. At the time of formal diagnosis, patients are often desperate, yet imbued with a belief in their own ability to overcome their disability through the "no pain, no gain" approach. This approach may have served them very well after their acute attack of polio many years ago but is now actually self-destructive.

Persistence in this approach of "overcoming" illness has led to a spiral of deteriorating function and frequently a parallel decline in self worth. Patients must understand the concept of "living with" PPS in order to lead the fullest life possible. An understanding of the need for lifestyle modification is rarely achieved at the first visit and is often best reintroduced by a knowledgeable Occupational or Physical Therapist and reinforced and monitored at subsequent physician office visits.

2. Increase Muscle Capacity:
a. Muscular capacity can be increased by achieving increased strength or endurance. Strength can be increased through isometric exercise. However, muscles must be carefully selected for isometric exercises. Some muscles will already be functioning at their maximum. Exercise may actually have a deleterious effect by forcing these muscles beyond their metabolic capacity and producing injury.
b. Endurance may be increased, susceptibility to fatigue decreased, and long term deterioration minimized through appropriate exercise supervised by a physical therapist experienced with post polio patients. Almost all patients have initial difficulties with exercise programs resulting from overdoing. They may also equate fatiguing daily activities (which challenge the weakest musculature and do not provide an effective aerobic training level) to exercise. This can be an instructive opportunity for the patient in understanding the "Lifestyle modification" and to experience its benefits. Goals in aerobic exercise are:
(1) Educate the patient to avoid potentially harmful exercise-induced fatigue. A reasonable approach would be to establish the level of peak performance by patient history. Then start at 50% of peak performance and slowly increase performance as tolerated.
(2) Select exercises which can create a training effect in the patient with weakened, atrophic musculature and overuse syndromes. Exercise intervals with intervening rests are necessary, just as is pacing of daily activities. A knowledgeable Physical Therapist can be crucial to this aspect of management.

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c. Muscle capacity can also be increased by bracing,orthotics, or other aids which extend, amplify or substitute for muscles.
d. Pharmacologic treatment of fatigue: Some medications seem to raise the threshold for fatigue. These observations are, as yet, anecdotal and await confirmation from clinical trials.
(1) Amantadine: up to 100 mg BID as tolerated.
(2) Deprenyl: up to 5 mg BID as tolerated.
(3) Mestinon: up to 60 mg TID when careful monitoring is available.
Medications for the amelioration of fatigue must be understood as aids which can give a running start to the rehabilitation process. However, if they are perceived by the patient as a form of curative treatment, they will only forestall the day of reckoning.
3. Decrease Muscle Load To Less Than Muscle Capacity:
a. PACING of activity is the logical consequence of a successful LIFESTYLE MODIFICATION. Implementing of PACING requires that patients identify for each of the activities of daily living the length of time they may participate before experiencing fatigue. They must then break up their activities into smaller modules of time, each of which is of less duration than the time required to produce fatigue. A corollary concept to PACING is ENERGY BUDGETING which imagines that one has a fixed expenditure of energy for each day and that this sum should be "spent" on activities of the highest personal priority. (Exceeding this daily limit may be conceptualized as spending principle or acquiring debt but probably correlates to metabolic injury of the motor unit through overuse.)
b. Other means of decreasing muscle load are diet when overweight, use of orthotics to improve mechanical efficiency, use of wheelchairs or scooters to save energy expenditure, and treatment of chronic overuse syndromes.
4. Treat Specific Complications:
a. Attention to specific complications such as dysphagia, pulmonary dysfunction and sleep disturbances may require specific referrals. The goals of these referrals can be addressed with the patient at this first conference.
b. Functional consequences also result from overuse syndromes which can lead to joint deformity. Physiatry consultation can be helpful here and orthopedic intervention is occasionally required. Evaluate need for orthotic prescriptions (i.e., splints, braces, AFO's)
c. Somatization, depression, anxiety, and self worth problems may occur as capacity decreases. Referral for counseling should be considered (MSW, psychologist) or polio support group (see reference section).
d. Evaluate and/or modify work duties through referral to occupational therapist or vocational counselor.

C. PROGNOSIS
Patients often present during a period of decompensation. Decompensation may be caused by even slight embarrassment in strength due to inactivity or injury superimposed upon aging. It may also result from slight increase in muscular work resulting from weight gain or increase in activities. In either case, a spiral of deterioration may result from potential overuse injury to the motor unit and subsequent decrease in functional capacity can result. Patients may easily become fearful and depressed at this ominous decline in their previously stable, if compromised, neuromuscular status. It is important to clarify for the patient the difference between deterioration in function and deterioration from disease progression. In fact, there is little evidence that any loss of function experienced by PPS patients is due to progression or recurrence of polio virus infection. If patients can understand that opposing forces of muscle strength versus muscle load are acting near a capacity threshold, they will be quicker to accept PACING concepts, to employ an appropriate exercise program, and to utilize other elements of rehabilitation. In most cases, this will allow the patient to return to or approach the previous functional baseline. It is not difficult for patients to then minimize deterioration in function over the years by:

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1. Achieving an optimal balance between muscle strength and endurance (achieved and maintained by exercise) versus muscle burden (resulting from body weight, mechanical inefficiencies, and activity level).
2. Utilizing PACING and restriction of activities after the point of fatigue so that muscle work is kept within the limits of muscle capacity and decompensation does not occur.
3. Gradually decreasing total daily energy expenditure over the years much as a non PPS individual might do. This rarely results in much loss of individual activities or functions, only in the amount of each that is performed each day.

V. RESOURCES IN PATIENT MANAGEMENT
The patient with PPS is best served by having a physician who has experience evaluating post polio symptoms, formalizing treatment goals, and making the appropriate referrals such as those listed below:

A. NEUROLOGY CONSULTATION
When the Diagnosis is in question.

B. PHYSIATRY (PHYSICAL MEDICINE AND REHABILITATION)
A Physiatrist is a physician with expertise in the orchestration of the rehabilitation process. Especially when disability is severe, complex, or when biomechanical problems are prominent, physiatry consultation can help with the initial planning and selection of specific exercise programs, physical therapy, orthotics, and adaptive equipment.

C. PHYSICAL THERAPY
A Physical Therapist who is experienced regarding PPS will be of tremendous value in introducing and customizing the lifestyle modifications and in introducing the useful concepts of pacing and energy budgeting. Physical Therapists can also screen for inefficiency in movement resulting from deformity or weakness, assist in establishing your patient on a safe exercise program, and monitor for the almost inevitable initial over indulgence in that program.

D. OCCUPATIONAL THERAPY
Occupational Therapists are trained to assess the home environment and the patient's daily activities in order to restructure tasks, introduce mechanical aids like grab bars, and provide devices such as sock lifters which make possible physical activities otherwise compromised by disability. Instruction in PACING of routine daily activities and associated lifestyle modification can also be provided by an Occupational Therapist.

E. SPEECH PATHOLOGY
A speech pathologist can help in the evaluation and treatment of swallowing and speech problems.

F. PULMONOLOGY
A Pulmonologist can evaluate and manage respiratory dysfunction and sleep dysfunction.

G. PSYCHOLOGY
A psychologist or MSW can evaluate and counsel regarding reactive depression, coping strategies, pain management and life style adjustment. This is especially important to help the post-polio survivor deal with the "reemergence" of a neuromuscular disorder they thought had been previously conquered.

H. SUPPORT GROUPS
Local education/support groups meet on a monthly basis in various locales, offering education, support, and social opportunities for polio survivors and their families.

I. OTHER
Orthopedics, nutrition, and social work referrals for evaluation will occasionally be useful in specific circumstances.

VI. BIBLIOGRAPHY
Sones and Dalakas. Dysphagia in Patients with the Post-Polio Syndrome. NEJM 1991;324:1162-7.
SUPPORT GROUPS
AND
INFORMATION CONTACTS

ANN ARBOR (PPSG)
Liina Paasuke (734)332-1715
Sunny Roller (734)971-1335
Meetings 3rd Tues. of August and December.

Thumb Area PP Support Group
Rita Wall (989) 673-3678
Blue Water Center for Independent Living
1184 Cleaver Rd Suite 1000
Caro, MI
Meets last Tuesday of each month 2:30pm

MID-MICHIGAN (PPSG)
Jean Lutzi, Harrison, MI
(989)339-3781
Group info. 1-800-999-3199
Meeting twice a year. June and Nov.

LANING AREA SUPPORT GROUP
Bill Messeroll
13350 Chandler Rd
Bath, MI 48808
(517)641-6398
Meet 1st Wed of Month (except July & August?)

SOUTHEAST MICHIGAN (PPSG)
Bonnie Levitan 313-885-7855
co-facilitated by Bruce Sachs 248-476-2477
Dianne Dych 586-465-3104
Bobbi Stevens 248-549-2149
Meets 4th Sat. of the month
March thru October 10am-Noon

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MILESTONES of Southwest Michigan
(616)983-3981
Ken Sipress after 5:00 (616)925-2498

WEST MICHIGAN PPSG
Jim Huttenga -Grandville (616)538-3472
George Waddell-Comstock Park and North
(616)785-9440
Michael Balcerzak -Wyoming (616)531-1634
Lynette Acosta -Grand Rapids/E (616)455-5748
Scheduled meetings: Apr, June, Sept, Nov
For time/place email: bigsteelhead@earthlink.net

Clio Area Polio Survivors' Support Group
C/o The Clio Area Senior Center
2136 W. Vienna Rd.
Clio, MI 48420
810-687-7260
Contact person for information:
Jill V. Hastings
810-687-1931
Meets third Friday of every month at 2 P.M.

HARTFORD, MICHIGAN - PPSG
Jeannie Wessendorf
Support group meetings at Hartford Federated Church, Hartford Michigan for meeting times please call Jeannie at 269-621-2059 or email jeanniew@provide.net

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Our Michigan Polio Collection Library is proud and happy to be able to serve Post-Polio People everywhere in their quest for information about the late effects of polio. Our library offers books, periodicals, pamphlets, articles, video tapes, and audio cassettes, all pertaining to Polio and Post-Polio Syndrome (PPS). We also have a Post-Polio Informational Packet.

Laura Barbour

LIBRARY CORNER
Summer greetings to you all! Since it is the season to be working outside when I can, I have to say that the book orders are a little slow in going to Amazon or Barnes and Noble. There should be a greater number of books when the season changes. Meanwhile, I weed the garden (the weeds are winning, by the way) and try to sort out the house when the humidity tells me to stay indoors.

We were given a donation of the HBO special, "Warm Springs," by Bernadette Oleksa, a member of the Southeast Michigan Post-Polio Support Group. It stars Kenneth Branagh and Jane Alexander, among others, and looks quite interesting. This is on a disc which should work if you have a DVD player. Many thanks to Bernie, who made the copy for the MPN Library!! Bruce Sachs suggested that I order a book called Love, War & Polio: The Life and Times of Young Bill Porteous, which was authored by Timothy James Bazzett and published by Reed City's Rathole Books. This volume is described as "a slice of history, filled with authentic details...Bazzett captures perfectly the ideals of the 1940s (in) this life story of a remarkable man who lives with honor, courage, and love...A pleasure to read (Peg Kehret, author of Small Steps: The Year I got Polio)."

To continue with the description on the book jacket: "Combining copious and meticulous research with original letters, interviews, personal recollections and anecdotes, Tim Bazzett tells Bill Porteous's story with compassion, insight and humor. His narrative conveys a contagious and obvious delight in discovering how we are all connected. Here is a homespun history lesson about the nearly forgotten polio plague years and our fathers' and grandfathers' war, presented in a way that manages to bridge the gap between generations and even allows us to laugh a little as we learn of such serious matters. "Perhaps in the end, however, Love, War & Polio is a simple and universal tale--one of faith, hope, and the healing power of love."

Sounds like a winner! If you would like to read this book so you can make up your own mind about it, please let me know.

Jill Hastings, a Clio polio survivor, is working hard to help get a support group in that area "off the ground" and doing a fine job, in my humble opinion. She asked to borrow one of our videotapes, "Post-Polio Experience, Pts. I and II," and made the following comments about it: "The explanation of how the nerve/muscle bundles are affected by the polio virus, the importance of exercise but not too much and why, the chronic pain, emotional problems, all the adjustments that may be needed in time, the need to plan ahead for activities, how important talking with other polio survivors is--and so much more--caused me to view the video twice and decide what part could be shown at the second meeting of the support group I'm helping to establish. In fact, I took notes for future reference and may borrow that video again. The information is timeless!"

Books, videos, CDs, and other information you may need can be sent to you for your perusal. Contact me at 989-739-4065 or at denilaur@sbcglobal.net. I hope that you will enjoy the rest of this beautiful summer season! Till next time, take care.

Laura Barbour
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