

Polio Outreach Of Washington

State of Washington, Non-profit Corporation

"Our Mission Statement"

To minimize the impact and increase awareness of Polio/Post-Polio Syndrome by providing education and support to Polio Survivors, their families and healthcare providers.

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POOW



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COUNT THAT DAY LOST

If you sit down at set of sun
And count the acts that you have done
And counting, find
One self-denying deed, one work
That eased the heart of him that heard,
One glance most kind
That fell like sunshine where it went --
If, through it all
You've nothing done that you can trace
No act most small
That helped some soul and nothing cost --
Then count that day as worse than lost.

---GEORGE ELIOT Voice for Health

'MY LEFT LEG'

From Henry's Desk by Henry Holland
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Permission to Reprint from: POLIO DEJA VIEW
Central Virginia Post-Polio Support Group
Newsletter June - July 2005

The 50th Anniversary of the announcement of the successful trials of the Salk vaccine was observed on April 12, 2005. There was considerable media coverage of this historic event as well as an excellent HBO movie on Franklin Roosevelt's connection to Warm Springs, Georgia. Also many survivors of polio are recording some personal memories of their life long experience with polio. When I think of my own fifty-five year experience with polio I somehow feel compelled to remember with kindness and wonder about my left leg.

My acute case of polio affected my body from the neck down and with an asymmetrical degree of involvement. My right leg and right arm were more severely involved than my left leg and left arm. My right arm and hand made partial recovery.

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

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

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'MY LEFT LEG'

From Henry's Desk by Henry Holland

(Continued From Page 1)

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

I entered junior high school (7th to 9th grade) in February 1952. The school had three stories and no elevator. Classes changed six times a day, much like in high school. The guidance counselors, a survivor of polio, allowed my best friends Harry Lanzillotti and myself to leave each class five minutes early in order to get to the next class without my being knocked over on the steps because of the rush of students in the hallways and stairwells between classes. Harry also carried my books as we went between classes. He also carried my books home for me as we walked a distance of four blocks. My left leg carried the burden in moving about this school as well as the three story high school that I attended for the 10th through the 12th grades. My left leg made it possible for me to participate and enjoy the many activities of adolescence.

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

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

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

Whatever the real cause of PPS might be, I know that the overuse theory makes sense to me, especially when I think about my left leg.

I am sure that many of you have similar stories of how stronger muscles did more work over the years to compensate for weaker muscles; and in many cases these previously stronger muscles are now much weaker and can no longer do all the work of the past.

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

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

PRESIDENT FRANKLIN D. ROOSEVELT'S REMARKS

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

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



Today's mighty OAK
is just yesterday's nut
that held its ground!

" POST-POLIO SYNDROME CLINICAL EVALUATION PART 1 "

The proper Evaluation, Treatment, and Management of PPS

By Carol Vandenakkers, MD

Director, University of California Davis Medical Center Post-Polio
Clinic, Sacramento, CA

Presentation at SFBAPS May 15, 2004 Meeting. Transcribed
and edited by Phyllis Hartke, SFBAPS President, and approved
by Dr. Carol Vandenakker.

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OVERVIEW

AGING WITH A DISABILITY

Survivors of acute polio with neurologic deficits have a 40% risk of developing new progressive muscle weakness (Sorenson et al, 2002. Similar delayed decline is seen in survivors of other conditions (myelopathy) that injure anterior horn cells (Narayanaswami et al., J. Neurol Sci 184:11, 2001).

As you know there is a difference between post-polio syndrome and just aging with polio. If you do not meet the diagnostic criteria of full blown PPS, being seen in the PP Clinic or by somebody who knows about polio may be helpful. In the PP Clinic I do not make a differentiation. I see anybody who has had polio. Many times the problems that present are problems that we can do something about and are really very similar to those two populations. For instance, polios not experiencing PP fatigue might be having joint pain, more walking difficulty, or certain other parts of the syndrome. Instead of labeling someone post-polio syndrome, I explore the patient's problem and what we are going to do about it.

According to the studies that have been done, 40% of polio survivors who have neurologic deficits develop what we define as PPS. We also see similar symptoms in some other neurologic disease groups as they are aging and being studied. There is some cross-over in symptoms, not exactly the same, but certainly some similarities.

Everyone is different. In some patients we have optimized everything we can, and the patient has done everything right, and they're still slowly losing ground. I just do not have all the answers. Some of it is a combination of aging plus the PPS. I hate to say that because too many doctors say, "oh, it's just aging." But the truth is that aging in general compounds the whole PPS problem. It is like you age twice as fast. At this point in time, you just do not have anything extra to lose.

SYMPTOMS OF PPS

- o Excessive fatigue (>80%)
- o Muscle/joint pain (60-80%)
- o New weakness/atrophy (40-50%)
- o Cold intolerance (25%)
- o Dysphagia/breathing changes (10-20%)

You all know the symptoms of PP, the fatigue, muscles or joint pain, new weakness, new atrophy, cold intolerance, and then there are swallowing and breathing difficulties...also cognitive issues. Often these symptoms are not as much present in people who are well rested or employ simple compensatory techniques.

(Continued on Page 4)

INTRODUCTORY REMARKS

When I talked to Phyllis about various topics that I could present to the group, she suggested SFBAPS member might be interested in how we do our Post Polio Clinic assessments. This will give you an idea of what sorts of things I see as particularly important. You may recognize certain problem areas that you will want to report to your doctor. To accomplish this I will examine Phyllis in front of the group today, trying not to get too personal.

I will also be presenting for the CA Society of PMR tomorrow morning about PPS, and hope some of the PMR physicians around the state will know a little more about postpolio after my presentation. Part of what we cover today will be in that talk, but I will give them more background because they do not have as much knowledge about PPS as you folks do.

PMR stands for "Physical Medicine & Rehabilitation," also known as "physiatry." It is often the medical specialty with the most knowledge about PP. Orthopedic surgeons no longer do surgeries on PP children, and seem to have lost interest in polio. There are also neurologists who follow PP, so that would be the other group that might have some familiarity.

I do not know how many physicians do extensive assessments the way I do. Assessments are very time-consuming. Most physicians who are in private practice cannot afford to do them, and this may be one reason why polio survivors have difficulty finding a polio-experienced doctor who can give a thorough, good post-polio evaluation. I do train residents, so more are learning. Also, in Sacramento our department is developing a program at the local Veterans Administration Medical Center. Probably I will be able to set up a PP Clinic there maybe once a month or so. Those of you who have VA benefits will be able to see me there when that is established.

How do you get a post-polio evaluation once you find a polio-knowledgeable physician? There is no specific terminology you need to use when scheduling the appointment or asking for a referral from your primary care doctor. The diagnosis code is "postpolio" and "possible PPS."

(Continued next column.)

DIAGNOSTIC CRITERIA FOR PPS

o Prior episode of acute polio.

The actual strict diagnostic criteria for PPS includes a definite history of acute polio. I have seen people in the Clinic who have had other neurologic diseases and were not sure if they had polio, or they thought they had polio and it wasn't.

o Period of neurologic recovery, followed by at least 15 years of functional stability.

A period of neurologic recovery with stability for at least 15 years is part of the definition that really differentiates some of the neurologic diseases.

o Onset of new weakness or muscle fatigability, with or without generalized fatigue, muscle atrophy, or pain. Exclusion of other medical, orthopedic, or neurologic conditions.

This aspect makes it tough to put this diagnosis on a lot of people.

In someone who has many medical problems, it is very hard to tease out the symptoms. For instance, if you are getting weaker, is this due to heart disease, cardiovascular disease, diabetes, etc.? Is it PPS? Is it a combination or something else? So the strict criteria says we have to rule out those other things as etiology. That can be a gray area in some cases.

DIAGNOSIS OF PPS

Statistics show that for polio survivors coming into our Polio Clinic,

- o one-third with new symptoms will have an unrelated medical, orthopedic, or neurologic condition that is not strictly polio related.
- o one-third will be experiencing deterioration of previously stable orthopedic problems, like arthritis joint issues related to the polio.
- o one-third will actually have true new progression of motor unit dysfunction (PPS and the clinical loss of motor unit function).

As I said earlier, we address all three of these groups and try to identify what is going on and how we can intervene.

EVIDENCE-BASED MEDICINE

The types of interventions we make are based on what the literature has shown up to this point. What helps the most is rehabilitation. Many studies show that rehabilitation interventions (therapeutic exercise, conditioning, energy conservation, adaptive devices, and bracing) are able to stop the progression of symptoms and improve function and quality of life in patients with PPS. Improving some factors can result in overall improvement (pain management, pulmonary or sleep interventions, weight loss, treatment of depression) and is better than no improvement.

We do different types of therapeutic conditioning exercises that are very individual depending on the person and what muscles have what strength. We work on energy conservation, pacing, and using adaptive devices and bracing. If medical examination and tests reveal something else is going on, that is addressed.

ASSESSMENT, DIAGNOSIS, & TREATMENT

- o Complete medical assessment essential and (time consuming)
- o Diagnosis and treatment of medical, neurologic, or musculoskeletal conditions
- o Optimize body mechanics/protect weak or painful joints with assisted devices and bracing
- o Limited, specific exercise is recommended for conditioning and maintaining functional range of motion
- o Medications should be used with caution
- o Define each presenting symptom
- o Design diagnostic plan
- o Follow up on testing
- o Make recommendations
- o Follow up to assess effectiveness of interventions

BODY MECHANICS

- o Careful assessment of body mechanics and gait are essential.
- o Correlate to manual muscle test
- o Evaluate current, previous, and possible need for orthotics and assistive devices
- o Consider pros and cons of any changes
- o Discuss with patient

EXERCISE

- o Exercise recommendations based on individual needs and capabilities
- o If therapist is used, be certain there is a basic understanding of polio and post-polio syndrome
- o Patient must know how to identify overuse symptoms

MEDICATION

- o Review patient's current medication list for potential problems
- o Treat post-polio symptoms with modalities other than medication if possible
- o Use medication cautiously

PATIENT EDUCATION

- o Pace activities to avoid fatigue
- o Recognize signs of muscle fatigue and overuse
- o Improve factors that can be controlled
- o Symptoms must be evaluated, not every symptom is polio-related
- o Education

PHYSICIAN/PATIENT PARTNERSHIP

- o Ongoing communication is essential
- o Patients must take ownership of their health
- o Make decisions with your patients

EDITOR'S NOTE: I am reprinting this article from the previous 2nd Quarter newsletter issue. I apologize for the mistake of leaving a word out. The last line is underscored and the word is BOLDED. *Sincerely, Vivian J. Clark, Editor*



POOW
Trading Post
available

DR. JULIE K. SILVER, MD
REVIEW OF HER BOOK
[CHRONIC PAIN AND THE FAMILY]
 A New Guide
 Reviewed By: **Audrey H. Baugh, April 15, 2005**
 South King County, Support Group Member

The following information is available by contacting the person's phone number. We can't note any prices.

This is an economically sensible book covering the causes and characteristics of chronic pain, exploring the impact on families or that pain. Acute Pain and Chronic pain are examined and defined in understandable terms.

WHEELCHAIR LIBRARY - Wheelchairs, Canes, Walkers, Crutches, Braces, Hospital Beds, Scooters, Craftmatic beds.
Contact: Chuck Morris - 360-479-4535 Bremerton WA

The chapter topics include the Effect on The Couple; Intimacy; Work Issues; Childbearing and Inheritance; Growing Up with a Parent in Pain; Chronic pain in Children; The Extended Family; Emotional Changes and Depression; Medication Dependence and Addiction; then finishes up with Diagnosing Chronic Pain Conditions; Traditional Treatment Options and Complementary and Alternative Medicine.

NEEDED: INVACARE RECLINING LIFT CHAIR
Contact: Darlene Jones, 206-783-3091 Seattle WA

REST, PACING AND TIMING
 By Grace R. Young, MA, OTR

Fatigue and pain must be respected. Overuse to muscles is not always apparent while it is occurring. Muscle pain is a warning signal that the muscles have been overused. The damage accumulates over a period of time and may not become obvious until you lose the ability to do an activity which was previously possible.

REST - Try to rest at least one hour during the day. If you work and resting at lunchtime is not possible, take a one-hour rest immediately after work. This will make your evening activities more productive and enjoyable.

Lie down to rest so your back doesn't have to support your body weight. Sitting takes 1/3 more energy than reclining. If you want to read, use an overhead book holder so your hand and arm muscles won't stay tense. You can listen to music, practice visualization or meditate; the point is to allow all the muscles in your body to relax.

PACING - Have you had days when you felt so good that you took on an ambitious project and kept pushing yourself so you wouldn't lose momentum? Were you incapacitated for a few days after that? It is tempting to overdo on your good days. However, you'll be more productive over all if you plan your activities for a balanced lifestyle. Prolonged activities such as cleaning house or gardening can leave you exhausted for the rest of the day unless you break them into short segments with rest breaks in between.

(Continued in next column.)

Sidebars throughout the book enlighten the reader in many areas, including very complete listings of alternative therapies; Commonly Used Medications and their possible side effects; and non pharmacologic treatments, i.e., assistive devices, exercise, massage and ultrasound to mention just a few. This is a book that could be comfortably used as an ongoing reference, but it reads very well in a straight forward manner. While it is **not** totally projected toward the person with a polio history, many of the subjects are of vital importance to the polio/post-polio population.

The price of this book is reasonable about \$10.95, not including Tax. You can order it through B & N or Borders. It is also referred to local book sellers. You can ask for it by the author's name, Julie K. Silver M.D.

PACING (Continued)

Before starting an extended activity, decide how long you will work at it and allow a 15 minute rest break every 30 minutes. Use a kitchen timer to let you know when to stop working and when to start up again.

Alternate light and heavy tasks throughout the week. Split your ambitious projects into daily segments throughout the week and stick to your plan no matter how good you feel on any particular day. Plan fewer activities for the days when evening activities are on the agenda.

TIMING - You may have different levels of pain and fatigue at various times of the day. Activities which are simple to perform in the morning may be difficult later in the day or vice versa.

(Continued on Page 6)

PPS Fo-

Early brain trauma due to polio, combined with the death of remaining neurons as you get older, reveal attention

Q: *An article in the New York Times Magazine describe me to a tee. I can't remember peoples' names and forget what I want to do when I go from one room to another. The article says that early brain trauma can cause middle-aged memory loss. I remember polio as a kid but I don't remember hitting my head. Did I forget that, too?*

Maybe you never hit your head, but you do remember early brain trauma.

That trauma was Polio. The poliovirus damaged neurons in your brain stem responsible for activating your brain and focusing attention whether or not it damaged your spinal cord motor neurons. But the poliovirus neither damaged neurons in the hippocampus, which is responsible for storing memories, nor in the cortex, the thinking "computer" of your brain. So why, in our 1990 International Post-Polio Survey, did nearly 85 percent of polio survivors report memory problems, 70 percent report difficulty "thinking of words I want to say"?

First, it makes sense that the more fatigue polio survivors report, the more memory and thinking problems they have. But even our most severely fatigued polio survivors had no trouble when we gave them tests of memory and thinking. However, severely fatigued polio survivors took up to two-thirds more time to complete attention tests, and had more errors, than did polio survivors without fatigue. All of the fatigued polio survivors' scores on these tests were abnormally low.

Second, word-finding difficulty isn't a memory problem. Trouble with word finding happens when the part of your brain that "thinks" of a word has difficulty talking to the part of the brain that says the words. Our studies found that word-finding difficulty is related to both fatigue and trouble with attention. We found word-finding difficulty, fatigue severity and attention problems were all related to polio survivors' brains making less dopamine. Dopamine is the brain-activating neurochemical. You may know that low levels of dopamine cause Parkinson's disease. We found that polio survivors and people with Parkinson's had identical levels of word-finding difficulty -- no surprise since it is dopamine that connects the word "thinking" and word "saying" parts of the brain.

So, it's early brain trauma, due to the poliovirus killing dopamine-producing and brain-activating neurons, combined with the natural death of remaining neurons with age, that reveal attention and word-finding problems in midlife.

This is the same process that is thought to be responsible for midlife attention and word-finding problems in individuals who had an early brain injury: The normal age-related loss of neurons reveals that they already have a reduced number of brain neurons.

(Continued in next column.)

It will be a relief to know that polio survivors don't develop Parkinson's disease any more frequently than do other individuals. What's more, polio survivors may actually be protected against getting Alzheimer's disease. The gene that makes the poliovirus receptor -- which grabs the poliovirus and pulls it inside neurons, where it does its dirty deeds--is found on chromosome 19. The poliovirus receptor gene shares space on chromosome 19 with another gene, the one that makes a protein called APOE-4, which is thought to damage the brain in ways that cause Alzheimer's disease. But the two genes have an "either/or" relationship: You can't have one with the other. If you have the APOE-4 gene, you can't make poliovirus receptors, and vice versa.

With the APOE-4 gene a person would be less susceptible to polio but more likely to get Alzheimer's. **Without the gene** you would make poliovirus receptors and be susceptible to polio, but be less likely to get Alzheimer's disease.

Shanda Davis surveyed polio survivors and older Drew University alumni, asking if they had Alzheimer's. Remarkably, 3.6 percent of the Drew Alumni had Alzheimer's but only 0.3 percent of polio survivors did. Polio survivors had 12 times less Alzheimer's disease than those who didn't have polio. Of Post-Polio Institute patients, only 0.4 percent had Alzheimer's. So maybe even the dark cloud of polio has a silver lining that becomes evident decades down life's road

Permission to Reprint this article from New Mobility Magazine; www.newmobility.com; and PPS FORUM - by Richard L. Bruno, E-mail: PostPolioinfo@aol.com

REST, PACING AND TIMING

TIMING - (Continued from Page 5)

For example, if cooking supper in the later afternoon is too stressful, prepare most of it in the morning, to be reheated later.

HOW CAN YOU JUDGE IF AN ACTIVITY IS TOO STRESSFUL? The easiest sign is a feeling of fatigue while you are in the midst of the activity. This seems obvious but many of us do not pay attention to our body.

If the level of fatigue is out of proportion to the level of activity, the activity may be too stressful even if your mind says it shouldn't be.

If there is a change in the quality of movement. For example, you develop a tremor or "jerkiness" in your motions while performing the activity.

(Continued on Page 10)

THINGS TO CONSIDER



Eating Well ! High-fructose Corn Syrup

High fructose corn syrup (HFCS) is a form of sugar used to sweeten

hundreds of products found on grocers' shelves -- from soft drinks, to breads, to cereals, to ketchup and more.

HFCS isn't so bad if you consume it in moderation. But because it's so pervasive in our food supply, you may be eating more of it than you realize.

Why you don't want to over-consume HFCS:

- 1. Fructose -- in any form (except in fruit) --** can boost blood triglycerides. High triglyceride levels are linked to heart disease.
- 2. Sometime fructose is not well absorbed** and it becomes fuel for undesirable intestinal bacteria. This can cause bloating, diarrhea, and other intestinal problems.
- 3. Fructose may interfere** with calcium, copper, and chromium absorption.
- 4. Most of the foods that contain HFCS** are goods we should limit anyway because they are usually highly processed, high in calories and dangerous hydrogenated fats, and low in nutrients.

Hope/Health-Source: *Environmental Nutrition*, Vol. 26, No. 2

The Polio Vaccine: 50 Years & Beyond...

Reprinted from: Post Polio Awareness & Support Society,
March-April 2005 Vol. 20 No. 2 -
PPASS of BRITISH COLUMBIA

Many doctors in the 40's and 50's cautioned that undue concern was being raised about the incidents of polio. They pointed to the fact that the rate of death by accident was much higher than the rate of death by polio. However, for Canadian mothers and fathers – polio was a dreaded disease that could steal away a child's life or leave them permanently paralyzed. Death by accident could be avoided, but the medical community had no answers for the public regarding how to prevent polio. The unknown of polio – who would get it, when an epidemic would happen or where it would strike next, even how it was transmitted, increased that fear. In 1947, an epidemic in the Arctic increased those fears as polio had been previously associated with the summer time and that children were relatively safe in the winter months.

In addition, more public attention and government attention was given to polio as the number of middle class children stricken with polio continued to rise.

(Continued in next Column)

50 YEARS AND BEYOND (Continued)

Prominent adult members of society were stricken with polio – from Franklin Delano Roosevelt to Hugh MacMillan and Paul Martin Sr. and his son (now our Prime Minister) Paul Martin Jr.

Very few Canadians were not touched in some way by polio – most knew a neighbor, schoolmate, friend or relative that contracted polio. Because of this, Canadians were driven by fear and also compassion to “get up and do something” about this disease that disabled so many.

Very few know that Canadian scientists played an integral part in the development of a polio vaccine. Without their ground-breaking work, the SALK vaccine would have taken years longer to develop and would have been extremely expensive to produce.

It was in the University of Toronto's Connaught Medical Research laboratories that the miracle of the polio vaccine came to fruition. The key to Dr. Jonas SALK being able to produce enough polio vaccine were two innovations of Connaught scientists: “*Medium 199* and “*Toronto Method*”. Medium 199 was critical as it was the only known medium that could grow large volumes of poliovirus fluid. The “Toronto Method” rocking bottles were invented by Dr. Leone Norwood Farrell and were crucial in speeding up the process of virus growth.

Another little known fact is that the SALK vaccine TRIALS in 1954 happened not only in the United States, but also in 46 health districts in Canada. Salk needed a large sample of population and did not have enough children available in the United States and so he turned to Canada and Finland to assist.

On April 12, 1955 the announcement finally came from Ann Arbor, Michigan that the vaccine trials had been a success. Immediately vaccine manufacturers in the United States began distributing the SALK vaccine.

Unfortunately, the United States government did little to control and monitor the manufacturers of polio vaccine. On April 24, 1955, only 12 days after the announcement, disaster struck. Six cases of polio were reported to children who had received the vaccine. There was public fear that the vaccine was not safe. Three days later it was determined that the vaccines in question had all come from one source, Cutter Laboratories. All vaccines from Cutter were immediately pulled. However, the damage had been done and government and public confidence in the vaccine had dropped.

(Continued on Page 9)

Designate Your Donation
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WASHINGTON
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Combined Federal Funds

Polio Outreach wants to take this opportunity to thank all of you who gave to any of these funds and designated it to Polio Outreach Of Washington. Your generosity has been a great help this past year (2004 - 2005). During this time, 10-01-2004 through 08-04-05 (with only two months to go) we have added 119 new Polio/Post-Polio survivors to our database.

The 2005-2006 Combined Fund Drives begin in October 2005. Please consider again designating your contribution to Polio Outreach Of Washington. Also, ask your family and friends to consider donating to POOW through their employer.

Even though Polio Outreach of Washington is not a member of your local United Way you may designate through donor choice: **Note: All Donations to POOW are Tax Deductible.**

"Good Company In A
Journey Makes The
Way To Seem The

"My Story About Joint Replacements"

By: Kathleen Ryan (polio 1952)
kathy_patryan@msn.com

Thank you so much for all the wonderful articles in our "new" quarterly newsletter. I have been enjoying your newsletters for so many years and always find something new which helps me in dealing with Post-polio.

I noticed the article on joint replacement (which was excellent) was written 1992. So many advances have been made over the past 13 years that this information was somewhat passe. A year ago I underwent a total ankle replacement at University of Washington/Harborview. This particular joint replacement has been done for nearly 20 years now and is certified by the FDA. After many years of suffering incredible pain from degenerative arthritis, caused by a misaligned ankle fusion done 45 years ago, I was referred to The Foot and Ankle Clinic at Harborview in Seattle, part of the University of Washington Medical School. Two years ago I underwent a realignment of my right foot. Last year this two part surgery, for me, was completed with a total ankle replacement. This surgery was done on my most severely affected foot/leg with wonderful results. I must admit, I still have some occasional discomfort but it is minimal compared to what I went through for a number of years prior to this joint replacement.

I would hope that anyone who is suffering from severe pain for similar reasons to find the most qualified orthopedic surgeon for knee, hip, ankle/foot, back that there is and talk to the surgeon regarding the procedure needed. There are many new surgeries available for spines now also, that weren't being done when Dr. Eulberg wrote her article. One new surgical procedure which will be coming up in the near future is replacement disks for the upper back, a surgery which has been in Europe for the past 17 years and will hopefully be available in the USA within the next 5 years.

I do agree that the best treatment for post-polios is learning how to readapt our lifestyles to our bodies as post-polio gradually saps us of our strength. It takes a lot of mental adjustment to get the past the "use it or lose it" concept which we were all taught when we first experienced polio. And even more adjustment for our families to realize that Mom or Dad/husband or wife can't do all those things which we have done in the past.

Also, The University of Washington offers a post-polio evaluation clinic (or did) which I went through about 12 years ago. The evaluation included a lengthy questionnaire plus physical testing and exam. I had spent years trying to find out what was causing all of my problems. I had discovered Gazette Internal Network and had been following the guidelines set forth in the "[Handbook on the Late Effects of Poliomyelitis](#)" prior to actually being diagnosed with post-polio.

(Continued on Page 9)

MY STORY ABOUT JOINT REPLACEMENTS

(Continued from Page 8)

I was thankful to finally be able to find a physician who was familiar with post polio and who could actually put a name to my significantly increasing symptoms of fatigue, pain and muscle weakness. Sometimes as patients, we have to insist on referrals for this type of evaluation because our own physicians may or may not be familiar with the availability of such a clinic.

Thanks again for this wonderful forum to express ideas, medical advances etc. I look forward to receiving each and every newsletter and have also introduced so many friends who are post-polio to POOW also.

Editor's Note Re: JOINT REPLACEMENTS

Thanks for your nice notes and for writing about Joint Replacements. I fall into that same category. I have had two Knee Replacements. My first one was December 1987 and my second one was January of 1989. Seventeen years later on June 27, 2005 I had a revision on one of my knees. They changed the plates and cleaned up the hardware and did a bone graft on my knee. Mine is due to Heredity-degenerative Arthritis. When I called my identical twin sister and told her I was having it done, she said, "I can't believe you are telling me this, I'm having mine done in January." She had revisions on her two knees two years ago.

Yes, many new things are happening in the world of Joint Replacements. I am still doing Physical Therapy and Water Therapy which helps a lot. My knee now bends to 125 degrees. I have one more month of therapy.

Vivian J. Clark, Editor

50 YEARS AND BEYOND

(Continued from Page)

On May 7th 1955 the US government stopped all vaccine programs and a ban was put on all polio vaccine manufacturing.

In Canada there was public and political pressure to do the same. Prime Minister Louis St. Laurent, looking ahead to a federal election was reticent to continue the vaccinations in Canada with the cloud of the Cutter incident looming. He urged his Minister of National Health & Welfare, Paul Martin Sr. to issue a halt to vaccinations in Canada.

Unlike the US, however, the Canadian government had kept a watchful eye on the vaccine manufacturing process and had limited production to one manufacturer – Connaught.

A GRANDMOTHER'S WISH

(Grandparents day is September 11)

If I were granted any wish,
I'll tell you what I'd do...
I'd wish my kids were small again, for just a
Month or two; to hear their squeals of laughter,
To watch them while they play,
And when they asked me to join in,
I'd NOT say, "Not Today".

To hug again their chubby frame,
To kiss away their tears,
And cherished childhood innocence
That's washed away the years;
Then when it's story time again,
I'd stay a little longer;
To answer questions, sing the songs,
So memories would be stronger.

But time is callous, wishes myths,
Yet God in His wisdom,
Has given me another chance before
I join his Kingdom;
The face may not be just the same,
The name is change, 'tis true,
But yet the smile that radiates
Reminds me so of you.

God must have known that Grandma
Would need a chance or two,
For many little happy things
She hadn't time to do;
So God gave love to Grandmas
To equal that before,
That in effect, embraces those
Little lives she bore. -Unknown

Voice for Health May-June 2005

GREAT BOOKS FOR SALE!

Over of two books we previously advertised in January 2004. The Polio Outreach Of Washington has several copies left

**Understanding and Treating
"Post-Polio Syndrome" and
Chronic Fatigue. "The Polio Paradox"
By-Richard L. Bruno, H.D., Ph.d.**

A copy of this paperback book can be obtain by a donation of \$17.50 which includes shipping and handling.

**Post-Polio Sydrome, by - Julie K. Silver, MD and
Anne C. Gawne, MD.** A copy of this book can be obtained from Polio Outreach of Washington for a donation of \$27.50, which includes shipping and handling.

To reserve a copy of the above books call the
Polio Outreach Of Washington Office
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Polio/Post-Polio Syndrome Support Groups

Please contact the leaders of the PPS Support Groups for further details. **1-800-609-5538 or 253-847-811.** Revised: ++

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Bremerton & Kitsap County LouAnn Miller--360-692-1381, rmiller@wavecable.com

Clarkston, Idaho: Tri-State Polio Pals - Jim Hueston, 208-790-3805, rockinnj@clarkston.com

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REST, PACING AND TIMING (Continued from Page 6)

If there is a change in the quantity of movement, that is, decreased range of motion. For example, you can usually lift your arm to a certain height but that height lessens as you continue the activity.

If you start to use compensatory movement. For example, you "hunch" your shoulder in order to raise your arm or you swing your leg out to the side instead of flexing at the hip.

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SECRET BOX - There was once a man and woman who had been married for more than 60 years. They had shared everything. They had talked about everything. They had kept no secrets from each other -- except that little old woman had a shoe box in the top of her closet that she had cautioned her husband never to open or ask her about the box. For all of these years, he had never thought about the box. One day the little old woman got very sick and the doctor said she would not recover. In trying to sort out their affairs, the little old man took down the shoe box and took it to his wife's bedside. She agreed that it was time that he should know what was in the box. When he opened it, he found two crocheted dolls and a stack of money totaling \$25,000. He asked her about the contents. "When we were to be married," she said, "my grandmother told me the secret of a happy marriage was to never argue. She told me that if I ever go angry with you, I should just keep quiet and crochet a doll." The little man was so moved; he had to fight back tears. Only two precious dolls were in the box. She had only been angry with him two times in all those years of living and loving... He almost burst with happiness. "Honey," he said, "that explains the dolls, but what about all of this money? Where did it come from?" "Oh," she said, "that's the money I made from selling the dolls."

Polio Outreach Of Washington

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