

# PPASS Times

Newsletter of Post Polio Awareness & Support Society of MN

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## From Where I Sit

By Jane St. Onge, Chair

**S**cootin' Around - Conserve to preserve is the mantra of polio survivors with Post Polio Syndrome. And we all have a variety of ways we do that, besides naps, naps and more naps. The best energy saver I have is my scooter.

It wasn't love at first sight. And I certainly wasn't ready to commit. But like most lasting relationships, my scooter kind of grew on me. At first I had mixed feelings. Up until then, my disability hadn't been very obvious. Using a scooter would definitely be a "coming out" for me. I felt pretty self-conscious and worried about unwanted attention or stares from passersby. What I found is that people pretty much ignored me and my confidence got stronger.

Some close calls with pedestrians taught me easy does it and to look both ways before rounding the aisles at the grocery store. I also learned about corners and cutting them too close. Of course that was only after taking out a display rack of underwear at Marshall Field's.

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## Confessions Of An Editor

By Larry Kohout

**O**kay, your newsletter is late. I have been extraordinarily stupid and now I am having to learn to do things differently. I suppose you want me to explain? Well, it all started when I returned from my vacation on the North Shore at the end of May. I came home to 247 e-mails in my inbox. Okay, I admit it, I am a compulsive letter writer -- big deal!

My left hand has been weak for some time and I have been using a program called Dragon NaturallySpeaking to do my typing for me - most of the time. Well, most of the time when I have one or two e-mails to write at a time. When I would work on the newsletter I would usually do the typing manually. I always seem to think better with my fingers on the keyboard. Since I would work on the newsletter one article at a time, the typing was never excessive.

After I got through reading my 247 e-mails there were about half of them that needed a response. Here is where the stupidity comes in. I sat down and started banging away on all of the replies manually. As I said I seem to think better with my fingers on the keyboard and it was

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## Group Happenings

By Larry Kohout

**W**ith this issue we once again see an expanded Group Happenings column. As PPASS MN has now gone state wide we have had two other organizations join our fold. The existing groups in Brainerd and Twin Ports (Duluth/Superior) have each decided to become a Chapter of PPASS MN. As the organization grows we will be able to watch what each chapter is doing as it reports on its happenings in this column.

## Brainerd Chapter

by Mary Kay Keithley

The Brainerd chapter is now glad to have our snow birds back with us, and glad that they got home safe. Since the snow birds returned we have had two meetings. We really miss them when they fly south.

We lost our usual meeting place so we decided to take the first Monday of the month and go out for lunch. We have been talking about what is happening to us. Bob Loucks, one of our group members, has found some great material that he has copied for us and handed out at the meetings. We need more information on

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## From Where I Sit

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The payoff for me has been greater mobility and less energy drain. My first big trip with my scooter was to Toys R Us to buy my grandkids' Christmas presents. I was able to take my time and really look without getting all worn out. I love being able to shop for myself now, too, instead of depending on family or friends.

Maybe you've been considering a scooter and wondering how it might change your life. From where I sit, it's changed my life and I'm thankful for that.

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## Confessions Of An Editor

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always much faster than dictation. The first two and one half days went just fine but by the end of the third day my left hand was misbehaving a good deal. By the end of the fourth day it simply quit working. The three small fingers on that hand curled up into my palm in what at first appeared to be a gigantic muscle cramp.

However, by the next day the muscle cramp was gone and the fingers were still moving. A discussion with my doctor two days later put a name on it - severe overuse syndrome. "Put those fingers in a splint for the next three weeks and do not use them at all. They may come back, but they also might not. You have severely overused an inherently weak hand." I've had

better news.

Why do I tell you this? Because we all have an inherently weak "something or other." I used to have a choice about what I typed and what I used my magic dicta-

Because we all have an inherently weak "something or other."

tion program on. I tell you this so that you can maintain your choices. I may again have a choice, as I have heard of others severely overusing something and it taking two years to recover. I always look on the bright side.

In the meantime I am learning to think with my fingers in my lap. There are also all kinds of opportunities to figure out how to get other things done. By the July/August issue I may even figure out how to get the newsletter done on time.

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## Group Happenings

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what is going to happen to us later. Bob has had some very nice handouts and we thank him for that.

We are looking forward to getting to know the Twin Cities Chapter. It's nice to meet other people that are in the same boat that we are.

## Twin Cities Chapter

by Larry Kohout

The May meeting featured a talk by our own member Dr. Margy Hull. Margie is a psychologist who was formerly employed with a community mental health center in Atlantic County New Jersey. Titled, Tend and Befriend: The Other Stress Response, the talk was based on Shelley Taylor's book, The Tending Instinct: How Nurturing is Essential To Who We Are and How We Live.

Margy pointed out how research has shown that human beings have a natural tending instinct. This is in addition to the "fight or flight" response that we have known about for years, and that is so prevalent in the male of the species. The tending instinct is more prevalent in the female of the species; however, both sexes have and use both responses.

Why is tending important? Because it is an essential part of who we are as human beings, but more so because of how it makes us feel either as the tender or the tendee. Whether it is you meet-

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## Group Happenings

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ing the needs of someone else, or someone else is tending to some of your needs, when this is done in a caring manner the result is that both people feel good. For those of us in the disability community the tend and befriend response just might have some special significance

Beyond simply feeling good, research has shown that our tending instinct can lead to some actual improvements in our physical health. It is not only the quality of our life that has improved but there are measurable improvements in our cardiovascular systems, immunological systems, and evidence indicates that we actually have prolonged life as a result of our tending instincts. I think that is worth tending to.

The June meeting was our annual "picnic meeting" and was held at the Sydney's in Eagan. Our original destination was The Two Guys From Italy restaurant at Centennial Lakes in Edina, which unfortunately went out of business just a week before the picnic. Therefore we ended up doing some quick scrambling to locate an alternative destination. Because this is Minnesota we needed a place that could handle our crowd either indoors or more preferably on an outdoor patio. The Sydney's in Edina had the outdoor patio but not sufficient room for our crowd inside. They suggested we try the Eagan store and they were most accommodating. It was fortunate we did as the weather drove us inside.

While all of our snow birds were back some of them had hit the

road again before it was picnic time. Nevertheless we had a wonderful turnout, with nearly 30 people altogether in attendance. It is always fun to see the spouses that we only get to meet at the two parties that we have each year. Spouses, we look forward to seeing you again in November.

## Twin Ports Chapter

by Larry Kohout

On May 19 Chair, Jane St. Onge and I made the trip north to Duluth to meet the members of the Twin Ports Chapter. The group meets at a local senior citizen's Center where lunch is served each day. This allows the group to have lunch together prior to their meeting, a practice we found to be most agreeable. The group is led by Leo Plewa and his wife, and they have had a functioning group in the Twin Ports area for a whole lot longer than PPASS MN has been around.

The purpose of the May meeting was to meet with PPASS MN officers and ask questions about the state organization. We presented how and why it was that we had decided to form a state organization, how the organization was set up, and what our initial plans were. After a few questions about PPASS MN we got down to talking about everyone's favorite subject -- Post Polio Syndrome.

The Twin Ports Minnesota Chapter is a lively group of well-informed medical consumers.

## Twin Cities Chapter Future Meetings Agendas

By Larry Kohout

**W**ant to know what the future holds for PPASS meetings in the Twin cities?

July Meeting - July 14<sup>th</sup> - We will be back at the library for a support meeting. The first portion of this meeting will be a discussion of the reorganization and renaming of the Twin cities Chapter of PPASS MN. The second portion of the meeting will be a discussion focusing on "Exercise and the Polio Survivor."

August Meeting - August 11<sup>th</sup> - Sharing A Memorable Polio Experience. This meeting will dovetail with topics highlighted elsewhere in this issue on telling your polio story. Whether it be a hospital story, a rehab story, or something that has happened later in your life, members will be encouraged to share with the group a memorable polio experience.

September Meeting - September 8<sup>th</sup> - Margot Imdieke from the Minnesota State Council on Disability will join us to talk about the disability parking law, access requirements and so on. Margot has a wealth of experience in this area as she works for the State Council on Disability and specializes in the "Rights of Persons with Disabilities."

October Meeting - October 13<sup>th</sup> - Our perennial favorite subject "Whatever Works." This is the meeting where you get to bring along any pieces of durable medical equipment or other gadgets, either purchased or homemade, that aid your life and your life style. You get to show off Whatever Works.

# Book Review – England On A Roll

Reviewed by Larry Kohout

I just finished “England On A Roll” by Carole Carsey. It is sub titled “A Wheelchair Adventure in London and the West Country.” Very interesting! Carole is a vent dependant polio quad who has but a small amount of function in her left hand and shoulder. However, she and her husband, Willy, planned and executed a two week visit to England in May of 1999. I’m always interested in how others fair in their travel experiences, and was especially interested in how someone with a significant disability would be able to handle things.

Carole is very forthright and honest in telling the story and manages to weave a bit of suspense into the tale as well. As when her husband needs to find a public loo (rest room) and they have 45 minutes in which to catch the last accessible bus back to their hotel. Willy tells Carole to “wait here” and dashes off to the loo. Carole, in the fashion typical of polio survivors, decides to “help” things along by going off towards their bus stop where she’ll surely run into Willy.

I’ll tell you this much, Carole got back here to write the book. If I were Willy I might have killed her but I’m not. I do very much agree with her now deceased father, Carole needs to keep writing books. As is typical of new authors, she is a bit stingy with some of the details that could really flesh out the story but I’ll bet a buck she’ll learn if she’ll just keep at it. For my money

“England On A Roll” is a darn good read. Available in paperback or Electronic Book (PDF) format, both are available from 1<sup>st</sup> Books <http://www.1stbooks.com/cgi-bin/1st?partner%7E1st|type%7E6|Data1%7E7913>. In Trade Covers it is \$15.50 and the Electronic Book format is \$3.95 The Trade Cover format is also available from any book store and most of the dot com book stores.

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## One Psychologist’s Perspective on the Polio Experience

### Part 7

By Margy Hull Ph.D.

This time we look again at how we use defense mechanisms to protect us from conflict within and stress without. Some have compared defense mechanisms to a medieval coat of armor. It can save your life and limb from lance and sword while in the midst of battle, but you can’t see or hear very well, and it sure does limit your range of motion. (How on earth did they ever go to the bathroom? Somehow I always seem to think of that!)

Some of the ways we protect our self-concept when we deal with others can seriously distort our view of reality and prevent us from taking constructive action. The three defense mechanisms for this time are displacement, help-rejecting complaining, and projective identification.

We’ve all heard *displacement* described as kicking the dog

when you’re mad at the boss. The idea is that we redirect our negative emotions when it seems too difficult or costly to direct it where it truly belongs. It is all too easy when we find things harder to do because of post-polio symptoms to curse at our mate for putting the damned lids on too tight. How can you curse at polio and get a satisfactory response? Our worry about our difficulties getting our job done might get displaced onto preoccupation with our child’s problems understanding math. Instead of thinking of solutions for simplifying our work, we nag and hover over our child increasing his anxiety and interfering with his ability to learn.

*Help-rejecting complaining* was described by Eric Berne in his book *The Games People Play* as the game of “yes, but”. This defense is used by people who complain loudly of some problem and make unending demands for aid, but then have some excuse why they can’t or won’t use the aid that is proffered. It is one of the more infuriating habits human beings are prone to and hard to understand on the face of it. However, if you see it in its defensive function, it begins to make more sense. We do so hate to change our ways, yet we want to see ourselves as trying to improve our lot in life. We also want to have someone “feel our pain.” So we go on wailing about being so tired, while pushing ourselves to work harder and leaving our crutches at home.

The final defense mechanism for this time is *projective identification*, which is a tad more compli-

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cated than its cousin projection, with which you may be more familiar. In projection we act as if our own unacceptable negative emotions are coming from the other person. ("You're angry at me, aren't you?") In the case of projective identification, we let ourselves feel the negative emotions, but we make them justified by getting the other person to treat us in a corresponding way.

Let's say we are feeling a sense of shame and defeat that we need to go back to the assistive devices we thought we had left behind when we first recovered from polio. When challenged on our attitudes, we say it's not us, but people are just turned off by disability. We then hide our devices, are conspicuously silent in explaining their presence, and avoid using them whenever possible. People respond to our obvious discomfort by averted gazes and a studied disinterest in our health status. We say to ourselves "See? People think I'm a pitiful cripple," never seeing the connection between their response and our own projected emotions. This is an example of a "self-fulfilling prophecy."

This time I've focused on warnings about defenses that can damage our relationships with others. In the next set of articles we'll look at the defense mechanisms of self-observation, anticipation, and humor, which can protect us from inner pain while also strengthening our effective coping.

Margy Hull, Ph.D. is a Psychologist who formerly worked in a community mental health center in Atlantic County, New Jersey.

## **Polio Biology**

### **Part VI**

### **The Polio War and Vaccine Strategy**

By Eddie Bollenbach M.S.

Editor's Note—This Series was originally written for and published in the Lincolnshire Post Polio Library. It is republished here by Eddie's kind permission. This is the sixth in the series.

**T**he beginning of the end for polio arrived in 1955 when the Salk vaccine was released for general use. The Salk vaccine is a concoction comprised of killed polio virus yet it still retains the capacity to stimulate the immune system to produce humoral immunity to live polio virus. Humoral immunity means that the immunity is restricted to the blood. A person with humoral immunity is protected from live polio virus migrating from the intestine, where it begins multiplying, to the Central Nervous System, where it does lasting damage. The Salk vaccine is produced by subjecting live virus to formaldehyde until it is damaged enough to prevent it from causing a polio infection but not damaged enough to prevent it from stimulating an antibody response in the blood. It is delivered by injection intramuscularly. During those early years of Salk, from 1955-1961, there were many cases of polio, a significant number of which occurred in individuals who had already been vaccinated with the Salk vaccine. Like all vaccines, it wasn't 100% effective, and in the midst of an epidemic it slowed the rate of infection somewhat but didn't eliminate new cases of polio as quickly as we would have liked.

The only other way to produce immunity in 1955 was to become in-

fectured with polio and recover from it. This produces a stronger and longer lasting "active" immunity. The body responds with a potent immune response if it is infected with a live polio virus. But even if you became infected naturally and recovered, you would have strong immunity to only one of the three strains of polio, the strain you were infected with. The Salk vaccine would give you a weaker but effective "active" immunity and it would work against all three polio strains because the vaccine is trivalent (which means it contains all three strains).

The use of vaccines like the polio Salk vaccine to immunize an "individual" against a polio infection is only one of the considerations of an epidemiologist trying to eliminate the disease from a "population". The Salk vaccine produces humoral immunity so it protects the inoculated individual, but how well does it protect the "population"? How well and how fast can it diminish the prevalence of polio? During an epidemic the virus is entering and exiting hosts. Some individuals have "silent" infections and never show symptoms. Some have mild symptoms that abort and resolve quickly while others have muscular symptoms without paralysis.

Of course, in an epidemic, many develop lasting symptoms of paralysis. The common thread that runs through all of these categories of polio is that in each type the virus enters the body orally, grows in the small intestine, and exits in fecal material. In order to stop an epidemic you must concentrate on interrupting this virus life cycle. You must stop the virus from multiply-

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## Polio Biology

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ing and exiting the body. This reproductive process is the mindless engine of a polio epidemic. This is also what epidemiologists think about when they want to stop an epidemic. It is interesting to note that the epidemiologist is thinking about prevalence in populations while most of us are thinking about infected individuals.

In 1961 Albert Sabin's live polio vaccine was introduced in the United States. This vaccine is different than the Salk vaccine in that the polio virus is alive, can infect individuals, but is attenuated (weakened) so that the virus becomes impotent to harming the Central Nervous System, except in extremely rare cases. There is a low, but finite chance of contracting paralytic polio from Sabin live virus vaccine. The chance of infection is in the vicinity of 1 in a million or so vaccinations. This past year<sup>1</sup> the Centers for Disease Control in Atlanta recommended that all new vaccinations in the United States be done with the Salk vaccine since there have been no cases of natural polio in the Western Hemisphere in years. The CDC recognized that Sabin vaccine associated cases of polio were the only cases that had occurred. It made more sense to avoid vaccine related cases and to use the dead virus Salk vaccine which produces good blood (humoral) immunity to protect individuals. The epidemics of the past were gone.

Editor's Note:

<sup>1</sup> that was in 1999.

## Telling Your Story

By Larry Kohout

Off and on over the history of PPASS MN we have had discussions about people telling their polio stories and getting them written down. A month or two ago at a meeting of the Twin Cities group, this subject came up again. At the time I said I had just read an article on how to go about writing your story. That article was "How to Record an Oral History of Your Experiences and Your Thoughts About Polio" by Mary Le Clair. I read the article in the newsletter of POST-POLIO NETWORK (NSW) INC., NETWORK NEWS. I have subsequently gotten permission to reprint the article, which you will find elsewhere in this issue.

There are a couple of important points about getting your story told. First, as Mary points out in her article, it is your story and your piece of history and it should not go untold. Your family will be interested even if no one else is. But believe me, there are many others who will be interested. I am an inveterate reader of polio memoirs.

The second point, and in my opinion by far the more important, is that the telling of your story will help you clarify and understand a portion of your life. This is the portion of your life that you may have shielded from scrutiny or hidden from altogether.

Because I have spent most of my career as a writer, I was fortunate to learn years ago that when I am in an emotional tur-

moil I need to write about it. Whether I do journaling and throw it away or do something like I did when I wrote "The Fine Art of Breathing," the initial point of the whole thing is for me to get my arms around the emotion of that all. I cannot guarantee that you'll have the same results that I do, however, I can guarantee that if you don't bother to look at it at all you will never come to grips with an emotional subject.

The process of writing your polio story is not concerned with writing about the emotions, although they should not be ignored. Rather, it is to get as much factual information recorded as possible. I was hospitalized on the first of September 1953, and it was a very hot evening as I made the ambulance ride to Sister Kenny Institute. It came on the heels of a very hot last week of August in which I had been playing football with some of my neighborhood friends. On the second of September it turned rainy and it cooled markedly. What has all this to do with my polio story? I have always thought the weather was a mirror to my emotions at the time. I have vivid memories of the rain streaking down the window outside my hospital room.

A few years ago I learned that on that same September 1<sup>st</sup> Dr. Jonas Salk inoculated his wife and children with what he then knew to be a safe and effective polio vaccine. This is a detail that has been added into my polio story from the historical timeline. If you read Mary's article and try the techniques that she

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recommends I think you'll find that you are able to unearth memories and details that will help you piece together your own polio story.

We would love to print your stories in the newsletter and there is talk of publishing this collection of polio stories as a book and selling that book as a fundraiser for the organization. This is a technique that the Nebraska Polio Survivors Association has used very successfully. There are several of us around who would be very willing to help you flesh out and edit your stories. But, whether or not you share your stories with the rest of us isn't nearly as important as it is for you to share your story with yourself and with your family.

The Ontario March of Dimes was collecting polio stories in 2001. In their circular asking people to contribute their stories they published a list of suggestions on how people could stimulate their memories. Here is that list:

- ◆ In what year and at what age did you acquire polio? What do you remember about that day?
- ◆ Where were you hospitalized and what was your rehabilitation experience like? Were you rehabilitated far from home?
- ◆ What assistive devices (braces, wheelchairs etc) were prescribed? How were they made or paid for?
- ◆ Did getting polio cause financial or other hardship for you or your family? Who or what

organization covered your hospital stay?

- ◆ What was it like coming home again and being accepted back into your family, your school and your community?
- ◆ Was returning to school and getting educated a problem?
- ◆ How were (are) your physical needs accommodated?
- ◆ What were your experiences with being a teenager, with dating, getting married and raising children?
- ◆ How did polio affect your relationships? (romantic or otherwise)
- ◆ What kind of jobs did you hold before and after having had polio? How did polio shape the vocation you chose to pursue?
- ◆ How did you get around, do your shopping or travel?
- ◆ What kinds of problems did you or have you encountered over the years?
- ◆ What solutions did you, your family or your community find?
- ◆ Did you invent gadgets, devices or other innovative homemade solutions?
- ◆ What were some of the memorable times, both dreadful and joyous?
- ◆ What enabled you to cope?
- ◆ All of us have experienced hilarious incidents because of our disability. What ones do YOU remember?

## How to Record an Oral History of Your Experiences and Your Thoughts about Polio

By Mary Le Clair

Editor's note: The following article is reprinted with permission of the editor from the newsletter of POST-POLIO NETWORK (NSW) INC., NETWORK NEWS. The editor, Gillian Thomas, can be reached at [gillian@post-polionetwork.org.au](mailto:gillian@post-polionetwork.org.au). The following note appeared at the beginning of the original article.

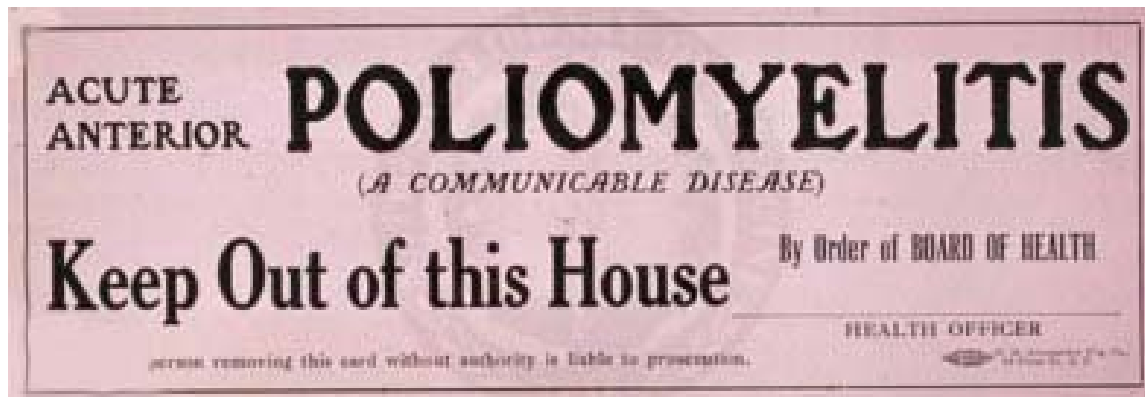
Member Mary Le Clair arrived in Australia from Canada in 1973 and formed a public relations business where she designed and presented segments of public platform speaking and other aspects of communication. Due to the late effects of polio Mary has now retired and uses a scooter to get around.

Mary presented this "fun and cathartic" workshop at our 1996 International Conference "Living with the Late Effects of Polio". Considering our call for members to tell their polio stories, I thought Mary's article might help those who "don't know how or where to start".

Many people have urged me over the past few years to relate the story of my life. The idea walled in my mind until I met Janet Simpson, the perfect person to do the writing! She was an English teacher for many years before becoming a lawyer thus bringing the perfect skills to the job ... writing, attention to detail, and the ability to seek out details.

My main reason for beginning the project was to give my own children some detail of their life in Canada and some background

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Does this look familiar? A poster very similar to the one above was placed on both the front and back door of the editor's home and kept there for two weeks when he was first diagnosed with polio.

## How to Record an Oral History . . .

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of their ancestry. I also think it is imperative for each of us to preserve some snapshots of life as it was when we lived. Unless we contribute to history, our own contribution, however small it may be, is lost forever.

For polios it is particularly important that our stories be told. It is inconceivable to most people that children could be snatched from all they know and love to be "abandoned" for not days but years! This experience colours all our actions and reactions. It is also possible that our contributions will keep alive the debate about vaccinating children. Young parents today just have no idea of the devastation of polio. Young doctors aren't even studying the disease in medical schools.

So for these reasons over the period of a year Janet and I worked on my memories.

The exercise has given my children some snapshots of their past and talking about the project has kept the vaccination issue up-front. It has also been a cathartic

experience. At the end of the book I liked myself better... the most unexpected result.

But the most valuable and unexpected result was that the polio experience was put into perspective. Let me explain. We are often urged to write about our fears or demons. One problem about that for polios is that most of us had it as children and the memories are buried so far into our psyches they can never be retrieved. Even those of us who had it as adults have buried many of the terrible memories so deep that we must dig long and hard to get them up to our consciousness. Another problem with writing only about the polio experience in isolation is that we can to often lose sight of the fact that it is only a part - however traumatic a part - of a WHOLE LIFE.

Everyone, when reaching middle age and beyond, feels the urge to look back on their lives and this is an excellent way to do it for everyone.

Consequently I strongly recommend that you stop worrying about what you can't remember and concentrate on what you CAN. It is amazing how those

memories will trigger others ... unbidden.

This paper is written to encourage you to consider writing your stories and memories down, and to give you some tips and tools to help you do it.

There are a variety of ways to retrieved memories and some of them may help you.

### 1 TIME LINE

Take a notepad preferably with lines and record every year from the year of your birth down the pages. Then enter significant dates from your own life.

For example, your birthday, family members birthdays, weddings, graduations, deaths etc.

Then enter major events that you remember or can research, such as the opening of the Harbor Bridge, Kennedy's assassination, the Queens first visit to Australia, the Stock Market crash, the Darwin cyclone.

Each of these entries may spur a tiny, tiny memory ... jot down key words about that memory onto the back of the paper to be expanded later

### 2 FAMOUS PEOPLE

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Make a list of famous people. Sister Kenny, Menzies, Gandhi, Sinatra. What made you think of them ... a dress? Another person? Remember, key words on the other side of the paper for later then forge ahead with ...

### 3 SONGS

What were you doing when ...? Who did you know?

### 4 PHOTOGRAPHS

Try to look at the clothes and the surrounds of the picture. Try to remember one characteristic of some of the people in the pictures.

### 5 OLD BOOKS AND MAGAZINES

If you have none, spend some time in the local library. Sometimes the model of the car you see, the different artefacts [sic] or the price of something may twig a memory. Jot it down. Try not to fill in any in depth [sic] memories while you are doing any of these things.

### 6 DRAW A PICTURE OF THE HOME/HOMES YOU LIVED IN

When you do this put into the rooms the furnishings you remember ... the colour of the walls, the carpet ... the paintings on the wall. Maybe you can remember the hospital ... draw the floor plan ... see the people in your mind's eye.

### 7 TAPE RECORDER'S

If possible keep a tape recorder handy. As you think of something as you go about your daily chores, mentioned them into the tape for writing about later.

### 8 PETS AND TOYS

### 9 SCHOOL DAYS

### 10 SMELLS

Interestingly, few people realize that smells are the most potent memory enhancers.

### 11 OTHER PEOPLE

I put this near the end because sometimes others will remember something differently. This can influence your recording of your own memories.

### 12 HOLDING NICK-KNACKS IN YOUR HANDS

### 13 HOLIDAYS

### 14 MODES OF TRANSPORT

As you begin to fill in the blanks you will find that you will have to move things around on the time line because it will be difficult at first to get things in the right order. Do not worry about that.

### RESULTS

You will remember more than you think! Some of the later memories will take on new meaning when they are seen in relation to all the things that have happened in your life. Even though you still may not be able to record the "polio experience" in detail many of the things you do remember will help you fill in missing pieces.

You will be amazed at how many happy memories will be intertwined with the sad ones giving you a balanced look at your life. Hopefully you too will like yourself better at the end of the exercise!

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**Postscript.** During the workshop at the Post-Polio Conference people who were convinced that they could not remember things surprised themselves! Almost at the beginning of the time we had together one-man insisted he could not retrieve ANY memories. How surprised we both were when he was the first one who had a flashback when someone mentioned cod liver oil!

Another lady had visions of some tiny chicks she found at home when she was released. Others told of favourite toys being whisked away when they fell on the floor in the hospital.

I was gratified when many people told me they were really enthused about giving the project a try. I hope they let me see, hear or read some of the results!



## The Mark of Polio

By Henery Holland

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### SCRIBBLE

**To be crippled  
To sit in a twist  
Unable to be straight.**

**To reach out and topple over  
into the bend.  
No balance at all.**

**Scoliosis  
The Mark of polio  
Uneven as a scribble  
No way to unwind and rest.**

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## The Mark of Polio

*(Continued from page 9)*

An American female polio survivor wrote the (preceding) poem. The author prefers to remain anonymous. She had polio at age two and she suffered significant paralytic damage from the neck down. Like so many severely damaged polios, she spent much of her childhood trying to walk with two braces and crutches. She was unable to attend school away from home until her high school years. She eventually earned an undergraduate and master's degrees and worked until Post-Polio Syndrome (PPS) ended her career. She had no choice but to commit to a wheelchair as a teenager and a power chair as an adult woman. For years she drove her own van equipped with hand controls. Like many confined to wheelchairs, she drank almost no fluids during the day in order to avoid using non-handicapped restrooms while at work. PPS has taken its toll on her. She is essentially quadriplegic. She has a lifting apparatus to lift her from her bed to her wheelchair and back as well as to lift her from her wheelchair to the toilet seat and back. As a result of polio, she has scoliosis. Recently when she was sitting in her bed, she fell over because of her weakened back muscles and could not get up right again. During this time of helplessness, she thought of the words for her poem. She was successful in getting one of the lift straps under her chin and with some struggle, was able to return to a sitting position. In regard to the poem, she explained,

"The poem poured out of me because the minutes before I was unable to sit up - I kept falling over to the right. I felt like a corkscrew. The left side of my back has no muscles, so those on the right, when used, pull me over."

Much has been written about the pain, new weakness, and fatigue of PPS. Much has been written about the changes in lifestyle that PPS demands and much has been written about the various modalities of treatment and recommendations to help PPSers. I have written my share of articles on these topics. Many polio survivors, who were fortunate to achieve good recoveries, now have to deal with PPS. Many writers refer to these PPSers as "passers" because for so many years they "passed as normal." From my perspective the "passers" conquered polio, but were caught off guard by PPS and were often misjudged by medical professionals because they had no visible marks of polio.

I would like to write a few words about the many polio survivors who were left with some mark of polio. They were left with a deformity as a result of acute polio. "Scribble's" author is one of them. I am one of them. I use the word deformity because that word captures the shame, the horror and the emotional pain of a perception that is real. There are countless deformed polio survivors around the world. Many are too disabled to attend support group meetings. Many do not have computers. I know that these people are out there and hopefully are on the mailing list of some Post-Polio support

group's mailing list. If you are on this group's mailing list, then hopefully you are reading this newsletter. This group of survivors has overcome incredible obstacles at a time when most cripples were kept out of the public eye. And even when one managed to achieve an entrance to the public eye, one can never forget the stares, the reactive expressions of fear, and the desire to avoid such encounters. Most of us learned the almost automatic reflex to present an outer expression of contentment and joy. Many of us developed wit and humor to distract others. One had to smile because tears were not a possibility. Tears invited pity and being crippled was bad enough. The author of "Scribble" wrote the following to me:

"Yes, you must write about deformity. It makes no sense to me, but he withered arm or leg is enough to crush some people. The deformed face is the worst of deformities and number two is the back. Both are impossible to hide. I am not consoled to understand it is inborn, a survival mechanisms that keeps others away from the sick and possibly harmful. I couldn't have married the elephant man, and for that I sit judged and condemned. Maybe I could have married the elephant man, but it would have taken years to see the beauty in his eyes. But he wouldn't have had beauty in his eyes because he would have been defensive and frightened. He would anticipate the gasps - involuntary gasps - from those who saw him without extensive preparation and maybe a good shot of whiskey. I understand this, and when I got out in the world, I realized I had to be personable, funny, smart, kind and funny again. I had to be on, all the time. It was my part of the social contract. It was exhausting, especially in the early years

when I was scared to death of people's reactions to me. These reactions were uniformly negative. I got it together in the seventies, but that was my hippie time, but also was the times, as the times - in they were a-changing."

We have all benefited from "the times a-changing." But most of us with the mark of polio had adapted to an unchanged world long before the social revolution of the late sixties and seventies. The ADA law of 1990 found most of us in middle age. We can now go in many restaurants, hotels, concerts, plays, parks, malls, and even airplanes because of the ADA and greater accessibility. Modern technology has made life easier for us. Mobile power chairs, scooters, vans with lifts, and hand-controlled vehicles give us greater mobility and freedom. Ventilators have both prolonged lives and retained some quality of life. The ventilator has prolonged my life for thirty-five years. Many PPSers are now using C-pap, BiPAP and volume ventilators and these machines are prolonging livable lives. Many of us have bolstered the business of powered wheelchair and scooter manufacturers. We often can use the help of advocates in finding ways to financially afford necessary modern technology.

And the Lord put a mark on Cain, so that no one who came upon him would kill him. Then Cain went away from the presence of the Lord, and settled in the land of Nod, East of Eden. (Genesis 4: 15b - 16)

As children or young adults many of us found our own inner lands of Nod. Nod was an inner lonely world where total under-

standing was absent and an explanation for the "why me's" was silence. Many of us may have sought and found spiritual comfort where others perhaps felt unnoticed and forgotten by God. I do not believe that God is responsible for the Mark of polio nor do I believe that God has abandoned the deformed. The Ministry of Jesus of Nazareth included much healing, including the healing of the deformed. Two verses in Matthew address and summarize his healing ministry:

Great crowds came to him, bringing with them the lame, the maimed, the blind, the mute, and many others. They put them at his feet, and he cured them, so that the crowd was amazed when they saw the mute speaking, the maimed whole, the lame walking, and the blind seeing. And they praised the God of Israel. (Matthew 15: 30 - 31)

For so many with the deformities of polio, polio is a lifelong process. We are older, weaker, tired, hurting and less defended. We benefit from the understanding of our loved ones and each other. I encourage you to share your story with your family, the younger generation, and with us.

Before I conclude that these thoughts, I often think about, remember, and hope I never forget those many polio victims who have already died from polio. There were many who died from the acute disease. They never had a life beyond polio. There were others who died from complications of polio in the early decades after polio. Their lives were shortened and often incomplete. If you have a mark of polio, try to move away from your inner land of Nod and return to

Eden, but be sure to tell the people in Eden about your experience in Nod. Otherwise they will never know.

References:

1. On "Scribble," author anonymous and excerpts from e-mail. May 2002
2. Meeks, Wayne A., Harper Collins Study Bible, New Revised Standard Version, Harper Collins Publishers, New York, 1993.

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## PPASS MN Annual Meeting Announced

By Larry Kohout

Jane St. Onge, chair of PPASS MN announced on Friday, June 27 that the organization would hold its first annual meeting on Saturday October 18, 2003. The meeting will be held at Christ the King Lutheran Church in White Bear Lake, MN and is tentatively scheduled to run from 1 pm to 3 pm of that afternoon. Additional details will be forthcoming over the next few months

In addition to the normal business of the organization we are looking for a speaker to make a medical presentation at this meeting. Further, there will be the opportunity to meet members of other chapters from throughout the state.

Anyone with ideas or concerns regarding the annual meeting may address these to me, at the phone, address, or e-mail address in the disclaimer on the back cover.

## Disclaimer—

The information presented at the PPASS MN meetings and in its newsletter are not endorsements of any product, medication, or individual. It is solely for information. Please consult your own physician, knowledgeable about post polio syndrome, regarding your personal health care.

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## *PPASS Times*

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