

PPASS Times

Newsletter of Post Polio Awareness & Support Society of MN

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On the Web at [Http://www.ppassmn.org](http://www.ppassmn.org)

Vol. 6, Number 5

From Where I Sit

By Nancy Gosz, Chair

There are undoubtedly many readers of this Newsletter who were not at the October 8, 2005 PPASS Annual General Meeting (AGM) to hear my opening remarks and some who have not had the opportunity to read the Chair's Report in the AGM booklet. To those readers, I will explain my presence in this column. At the 2004 AGM my friend Gary Dunn was elected by PPASS members to the Chair position of PPASS MN. At the same time I had the honor of being elected Vice Chair. Who am I kidding? There's little honor in an election where one runs unopposed! Anyway, I felt honored to have been nominated and to have the opportunity to serve PPASS MN in a new role. Gary and I took office January 1, 2005. Together we had plans to visit each chapter throughout our two year term. Unfortunately, ongoing health problems prevented Gary from being actively involved as an officer for many months. We emailed and phoned, gaining his input throughout the months. Being unable to drive distances and having lost Gary as my driver those chapter visits did not happen.

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Annual General Meeting Report

By Larry Kohout

This year's Annual General Meeting (AGM) was held at the Faith United Methodist Church in West St. Paul, MN on Saturday October 8th. This year the Advisory Committee wanted a theme for our meeting - something that would hold things together and provide a focus. They tossed around ideas and words to fit with their idea of learning to enjoy life after polio and post polio syndrome. But it wasn't until Keenan McIntyre-Talbott, who as a polio survivor's grandson knew full well that polio survivors can go and do and have as good a time as any able bodied person, said "Grandma: Let the Good Times Roll" that we had our theme. With that as a focus, they asked all the presenters to introduce humor into their presentations and booked Charlie Wittwer, a comic who bills himself as a Sit-Com (Charlie's another wheelchair user) to provide us with some post lunch laughs.

Things kicked off with a 9:00 a.m. registration, cups of hot coffee, and muffins. Each registrant received a package containing a list of the day's activities, their conference

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We've Got Advertising

By Larry Kohout

If you thumb our pages a bit you will see something new. PPASS Times is now carrying advertising. From our inception we have been prohibited from advertising by the fact that we were being distributed under the Free Matter For the Blind and Handicapped. Now that we no longer have that prohibition we have reached out to the business community and begun to find those that are willing to underwrite our endeavors. We encourage you to patronize these advertisers.

There is something else new at the same time. We are opening a classified ad section. Those of you who have E-mail have already heard about this and we already have one ad in this section. Classified ads are free to all our members.

So if you have something you want to buy or sell, think about placing an ad. Our deadlines are the 15th of the month in February, April, June, August, October, and December. You must have either E-mailed or snail mailed your material to the offices of PPASS Times

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From Where I Sit

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This past September, after trying his best to become more active with the organization, Gary, strong in his belief that PPASS MN needed consistent leadership, made a tough decision and submitted his resignation to the PPASS MN Board of Directors. In accordance with the PPASS MN Bylaws we needed to act quickly to assure continued leadership. The Board of Directors sadly accepted Gary's resignation, and following the guidelines provided by the Bylaws we moved quickly to provide new officers for the interim, which is until the Chair and Vice Chair position are again on the election ballot in 2006. Through a nominating and voting process, I was elected to the position of Chair and Lois McIntyre to the Vice Chair position.

As I noted in the AGM booklet Chair's Report, Lois is a member of the West Metro Chapter and has served on the Advisory Committee for several years. If you don't already know her, you may be familiar with her name as the author of the West Metro column in the Newsletter's Group Happenings column. Lois has worked hard for PPASS MN, especially with her huge efforts in the organization of our AGMs. Lois is my good friend and I am thrilled to have her, with her many skills and talents, join the Executive Committee.

The West Metro chapter and PPASS in general became a bright spot in my life; a place where I found just what my life was missing; peers! Polio peers! PPS peers! I felt like a kid visit-

ing an amusement park for the first time when I went to my first meeting 3 ½ years ago. I truly love being a member of this fantastic organization, and I am surprised by the speed with which I found myself becoming ever increasingly involved with PPASS. In future columns I will share with you the behind the scenes organizing of PPASS MN, many areas of which were quite surprising to me.

Gary Dunn is a very good friend to PPASS MN and so along with all of you, I wish him the very best in his health struggles. Get better soon, Gary!



AGM Report

(Continued from page 1)

book, ballot, trivia contest form, and an evaluation form.

At 9:30 our Chair, Nancy Gosz called the meeting to order. After explaining how she had become Chair and Lois McIntyre Vice Chair (see the From Where I Sit column) there were a few other announcements and she called for the report of the Nominating Committee. The Nominating Committee, represented by its chair, Judy Wuollet, recommended Larry Kohout for another term as secretary and Judy Baxley for a term as treasurer. There were no further nominations from the floor and both these candidates were elected.

At the conclusion of the business meeting Nancy gave away the first of over 40 door prizes. With business concluded, we turn to our featured speaker Dr. Frederick Maynard for his key-

note address. Dr. Frederick Maynard is a physiatrist working for the Upper Peninsula Rehabilitation Medicine Associates in Marquette, Michigan. Dr. Maynard is also the current President of the granddaddy of all post polio support organizations, Postpolio Health International or PHI. Dr. Maynard's association with the post polio movement dates back to the very first conference on post polio, organized by PHI, or as it was then known Gazette International Networking Institute. As he tells the story he was in the hotel when Sonny Roller stopped by looking for help on something to do with the upcoming conference. She asked an older colleague of Dr. Maynard's who turned her down but pointed her at Dr. Maynard. The rest is history. Obviously it has been a rough ride for him as he is still there 24 years later. Dr. Maynard used that quarter-century of knowledge and experience as he framed the current state of research and the best practices in the treatment of post polio syndrome today with what has been learned over the last two and a half decades.

Following the keynote address, we stayed right at our tables and were served lunch by the many fine volunteers recruited by Jim and Jane St. Onge. Other volunteers helped with registration, worked in the kitchen, setup, and served as guides. Once we were settled into lunch, our Sit-Com provided entertainment.

From 11:45 until 1:00 p.m. there was free time to visit the

four vendors that were on hand to demonstrate their wares: 4-Day Medical Stores, Aagaesen Chiropractic Clinic, Aihu – a comfort products vendor, and Cummings Mobility Conversion & Supply Inc., who brought along a converted van but didn't volunteer to give it as one of the many door prizes.

Breakout sessions filled the rest of the day. Five breakout sessions were offered in all. Attendees could choose to sessions from the following list: Easy Access Adventures Travel with presenter Karen Kolodziejczyk, Insurance Issues with presenter Anne Kennedy, Polio Partners Encore with presenters Robin McIntyre & Gene Sauter (this session was only for the spouses, family or care givers of polio survivors), Puppy Love Caring Canines with presenter Maureen Leach, and State Disability Coordinator with presenter Margot Cross. Each session lasted 45 minutes and was repeated after a 15 minute break.

The day wrapped up back in the main room with the announcement of the trivia contest winners, the election results and a few last minute announcements and door prizes. The polio and post polio trivia contests were won by Judy Wuollet and Inez Gaudet. The 85 people in attendance seemed to express a genuine appreciation and joy with the event. For those of you that missed it, we're sorry we didn't see you there.

We've Got Advertising

(Continued from page 1)

and the material must be received on or before those deadlines. Space may be limited, in which case material will be put in on a first come basis. One last thought we will be increasing the page count commensurate with the amount of advertising we take on so that we do not short you on the amount of information we are providing.



Do You Have A Suggestion?

From the Board of Directors

- Do you have something to say about how PPASS MN is being run?
- About how PPASS Times is published or edited?
- About how your local chapter is being operated?
- Do you have either a gripe or some praise for anyone or anything?

Well your Board wants to hear from you. You can send it in either anonymously or under the cover of your name as you wish.

If you E-mail it you will automatically identify yourself but you may E-mail it to lko-hout@mn.rr.com.

By phone you can call (952) 835-9714 but be sure to say that this is a suggestion for PPASS MN or PPASS Times.

By Mail send it to PPASS MN
7220 York Ave. So. #520, Edina,
MN 55435

Chapter Happenings

Owatonna

by Dick Baumer

At the September meeting we discussed at length the polio outbreak in the Amish community in central Minnesota. Since it had just been reported little detail was known at the time so there was a fair amount of concern about how it was contracted and if it would spread. We also discussed the upcoming Annual General Meeting -- specifically the importance of registering and getting the proxy material turned in. Four people from the Owatonna Chapter attended the session.

At the October meeting Barb Jacobson from Flying Wheels Travel visited the group to discuss how Flying Wheels Travel could help with arrangements for disabled travelers. Flying Wheels Travel, a Division of Travel Headquarters, Inc., is located in Owatonna, and has been in this business since 1970. Their web site is www.flyingwheelstravel.com and their phone number is (507) 451-5005.

Barb pointed out that while disability travel poses obvious challenges there are many options if you have the desire to travel. For air travel especially, she indicated that disabled travelers should avoid peak travel times such as holidays and daily peaks which are normally early morning and mid to late afternoon as airline

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Classifieds

Classified ads are now being placed in *PPASS Times*. The fee is free for a member. Call the PPASS MN offices for Commercial Advertising rates.

For Sale: Bruno Curb Sider scooter lift, \$850. (new \$2155) / Versa-Haul folding scooter/wheelchair carrier, \$375. (new \$650) Call Jane St. Onge at 651-213-6598.

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Chapter Happenings Owatonna

(Continued from page 3)

staff are less busy and you will be less stressed since the gate areas are less crowded. Arrive at the airport at least two hours before flight time to ensure sufficient time to clear security and take care of check in and boarding needs.

Barb touched on the Americans with Disabilities Act (ADA) and how transportation companies must make arrangements for you provided you make arrangements early enough. She pointed out that she has noticed two distinctly different attitudes in travelers with disabilities. Those who were disabled prior to the ADA seem to be far less familiar with what they are entitled to in this regard than those who were disabled after the ADA. Having said that, it is apparent that we need to get the State Disability Coordinator to visit us in Owatonna.

Following the Flying Wheels presentation we discussed the AGM, attendance, vendors, and response to breakout sessions. A couple of weeks ago it was announced that one of our members, Marlene Nelson was running for City Councilperson at Large. We wish Marlene all the best in her run for this important role.

I announced to the group that as of January 1, 2006 Judy Baxley would be taking over duties as PPASS MN Treasurer and that this would free me to pursue grants and other sources of funding for PPASS MN. Thanks for stepping up Judy.

The agenda for November is open at this point. The meeting for December will be our Holiday Party. That event will start at 5:30 so it becomes more of an "evening meal". Details for this event will be worked out at the November meeting.



Chapter Happenings West Metro

By Lois McIntyre

September 12th, 2005

A meeting was scheduled for October 10th at the Library at 12:00 to plan the meetings for the year 2006. We also set a date for our annual Holiday outing, it will be on November 12th at the Timberlodge Steakhouse in Bloomington. A sign up sheet was passed around.

Our regular meeting started at 1:00 with two former nurses who worked at Sister Kenny in 1952 and 1953 joining us to talk about the years they worked with polio patients. Jan had volunteered to go to Harlingen, TX to work with patients there and then returned to Minneapolis to work at Sister Kenny. She worked nights and had several children in iron lungs that she cared for. She remembered being very busy and how lonely the children were for their parents. She married a man who had polio and had been a farmer.

Lucille was an LPN and also worked with the children. She told of one family that sold their farm so they could move to Minneapolis to be near their son at Sister Kenny. She also remarked about the children crying and how she would console them.

It reminded the group members of their days in the hospital and the hot packs, short visiting hours, pain, crowded rooms, exercising sore muscles and yearning to return home. We discovered that several in the group had never had the vaccine, which was created after their initial bout.

We were reminded of the upcoming AGM on October 8th.

October 10th, 2005

The planning committee met before our meeting to brainstorm on topics for meetings in 2006. Since this meeting followed the AGM, we had a small attendance, due, I am sure, to many being tired out from all of the activity on Saturday. It was a great AGM and went well and all enjoyed it.

Our meeting today was conducted by Margy Hull and dealt with the problem of us needing help from people, whether it might be family, hired help or friends and how it makes us feel. Excerpts were taken from a book "Counting on Kindness: The Dilemmas of Dependency." We divided into small groups and discussed the issues, such as, how do we feel when we have to wait for people to help us, does it make us feel inferior because we need help? Do you feel like you have to keep

track of how much people are doing for you? Do the small things bother you more because you are not able to do them and have to wait for help? It might make you feel better if you can exchange favors with a person that is helping you. The discussions gave us a chance to express how we feel about needing and requiring help and what we can do to alleviate some of the guilt we might feel. It is usually quite easy for us to tell whether a non disabled person actually understands the position we are in and how they respond to our needs. I do my own grocery shopping etc. and find that most people really like to be helpful in reaching a can or box of cereal up on that top shelf, even bagging for me, which I could do on my own. Thanks Margy for a very interesting meeting.



West Metro Chapter Holiday Party

Saturday

November 12th

12:30 P.M.

At the Timberlodge
Steakhouse in the
Southtown Mall

Southeast of intersection of
I494 and Penn Ave. So.
Restaurant is midway along
the businesses on south side of
Mall

Coming Meeting Dates

By Larry Kohout with Input from chapter Leaders

Brainerd/Baxter

Closed for the season, reason, freezin'

Owatonna

November 17th – Meeting in the Library at the senior high rise complex at 2211 Hartle Avenue on the south side of Owatonna – 6:30 to 8:00 – Meeting agenda is open.

December 15th - Meeting in the Library at the senior high rise complex at 2211 Hartle Avenue on the south side of Owatonna – 5:30 to:?? – Holiday Party - Details for this event will be worked out at the November meeting.

St. Cloud

November 11th –

December 9th –

Twin Ports

November 21st –

December 19th –

West Metro

November 12th – This is our annual holiday party being held once again at the Timber Lodge Steak House 7989 Southtown Center Bloomington. Lunch starts at 12:30 P.M. Note – NO MEETING on 2nd Monday.

December 12th – The meeting is at the Edina Library 5280 Grandview Square Edina, MN from 1:00 p.m. until 2:30 p.m. with a half hour social time both before and after that meeting time. Caring – the care we get and the care we give to our caregivers.

Trivia Contest

The trivia contest at the AGM was divided into two halves, the polio trivia, which most people found the easier, and post polio trivia. Answers to these questions are found on page 12.



Polio Trivia

1. What is the earliest know evidence associated with polio?
2. Who developed the most widely used polio vaccine?
3. Who developed the first polio vaccine?
4. What did Sister Kenny's title of "Sister" signify?
5. The word polio is a shortened form of what word? **Bonus:** What does it mean?
6. What politician was most influential in the irradiation of polio?
7. On what date was the Salk vaccine declared Safe & Effective? **Bonus:** Was there any other significance to this date?

8. What entertainer coined the term "March of Dimes?"
9. Prior to 1945, what was the typical treatment for polio?
10. Who revolutionized the treatment of polio at the beginning of the 1940's?

Post-Polio Trivia

1. In what year was the first conference addressing what came to be known as PPS? **Bonus:** In what City was it held?
2. What organization sponsored this conference and why?
3. What are the three most frequently described symptoms of PPS in any order?
4. When PPS is miss-diagnosed what disease is it most frequently diagnosed as?
5. Why is it that muscles thought to not be affected by polio show weakness in PPS?
6. What are the 4 preconditions that may signal PPS?
7. In treating PPS what is one of the primary concerns?
8. PPS severity can vary widely. What 3 pre-conditions are associated with the more extensive involvement?
9. What percentage of a muscle's motor neurons must be destroyed before it is possible to notice any weakness of that muscle on a manual muscle test?
10. In what year were the symptoms of PPS first recorded in medical literature?

One Psychologists Perspective on the Polio Experience: Some Thoughts about Memory

By Margy Hull, Ph.D

I have been thinking lately about the important role that memory has played in my experience of acute polio, and later in post polio. I would like for the next few articles to explore some of the ideas from psychology that might help us to use memory as a positive force for our well-being. This time I'm thinking about the way memory helped me in three different stages.

The first stage occurred during those first months in the hospital. In the beginning, at age eight, when I was in solitary confinement—excuse me, *isolation* -- in an iron long, unable to visit my brothers and baby sister and seeing my parents only for brief visits, I found myself with long stretches of time to think. Without TV, even radio, certainly not laptops, I learned to recognize every swirl in the ceiling that might be recognized as a horse, cat or person's face. But I also spent a lot of time recalling many scenes and events from my childhood. Later when I was moved to another respiratory center many miles from my home, and then to another hospital just as far, going over and over these memories became an important bridge to those people that I loved and just as importantly, to the child I had been. That child had the name of Margy (with a hard g), while all these new peo-

ple in my life called me Maggie, Peggy, Margie, Margaret, Madge, *ad infinitum*. It was only relatively late in adulthood that I realized that I could insist that people call me that name from the past, and that became important to me as a symbol of the continuity I sought.

I had a very frightening dream in those early months about going across a very high bridge that suddenly broke off in the middle. In later life I thought the dream had been about fear of death, but I think now, at another level, it was also about being cut off from my former life and my former identity. My family was fortunately very good about keeping

...when I was finally discharged from the hospital and returned to a new home in a new city. I found myself compulsively remembering many details of my experiences in the hospital,

in touch with me with wonderful letters, and visits, but the memories served a central function in keeping me connected. I wonder if others of you found that your memories of life before polio became highlighted and valued for that sense of continuity. For some, of course, they were too young to have such memories, and for others perhaps it was too painful to think about.

The next stage occurred when I was finally discharged from the hospital and returned to a new home in a new city. I found myself compulsively remembering

many details of my experiences in the hospital, sharing them with my family and my friends who came to visit. I wonder now if it was *ad nauseam*, but I don't recall anyone complaining. Some of the stories were memories of suffering, but many of them were about funny things that happened with friends on the wards, interchanges with therapists, times that I was clever or brave. I think in this period, my memories served the purpose of helping me to integrate the entire experience in my mind, to build a solid base from which to move on with my life. Freud talked about repetitive dreams of trauma experiences that seemed to go against his theory about dreams representing the pleasure principle. He used the term *retroactive mastery of stress* as an explanation of why we both dream about and mull over negative or painful life events. Going over and over those events helped me to feel less a victim, and more as someone who had surmounted difficulties and thrived. Did others of you also find yourselves dwelling on those early experiences of acute polio?

Later in my life, in fact more frequently now in retirement when I again have more time to think, I find a new stage of memory occurring. I find myself noticing things about myself now or at other times in my adult life, and wondering if that quality was part of the Essential Margy (as I now say, "with a hard g, because I'm tough"), or if it was something that developed as a consequence of coping with disability.

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One Psychologists Perspective

(Continued from page 7)

This process involves searching for times in that early life when I was stubborn, or persistent as I prefer to call it, when I was obsessed with learning new things (the dinosaurs and the caveman), when I was daring (climbing trees), when I was focused on the practical (watching with envy when my mother slipped on a pillowcase with such ease).

When I was in graduate school, I was criticized by one of my first professors for being too caught up in the details of the life of the person I was interviewing instead

Would I have been that way if I hadn't had polio and learned to become obsessed with adaptation

of going for the underlying feelings, attitudes and so forth. I learned to respect the latter, but I never lost my interest in the circumstances in which my clients lived, believing that the risk of homelessness, for example, took priority over low self esteem as something to be addressed first. When it was my turn to be the supervisor, I made sure that my students paid attention to the gritty details of daily life problems. Would I have been that way if I hadn't had polio and learned to become obsessed with adaptation, or would the little girl Margy have been that way too if she grew up as a therapist without having had polio? This line of thinking has been encouraged by the fascinating studies of

identical twins raised apart, who often end up having amazing similarities such as loving to collect fine china, which one would never have thought as being genetically rather than environmentally determined.

Of course, there are no answers to these questions, and if I overdid it, it would be perhaps a bit unhealthy. There is the danger of slipping into a version of Marlon Brando *On the Waterfront* saying "I coulda been somebody, I coulda been a *contender*". But I seem to find myself enjoying such memories, and finding them meaningful. Have others of you polio survivors found yourselves thinking about the kind of person you might have become and how different, if at all, you would have been without the polio experience? If so, do you see it as healthy or not so much? If such uses of memory seem to conflict with my earlier emphasis on being in the here and now, considering that forays into the past are also *experience* in the moment and as such we can choose to bring to them the same nonjudgmental open-mindedness, trust in self, and all the other qualities of mindfulness.

In each of these three stages of using memory in slightly different ways, there was the common thread of seeking a coherent, positive sense of identity for my life. Next time we will consider more about how memory is important in creating identity.

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



Six New Books about Polio

Reviewed By Mary Westbrook, Ph.D

EDITORS NOTE - Mary Westbrook writes the Syndicated column Polio Particles published first in the newsletter of Post - Polio Network (NSW) INC. (in New South Wales, Australia). We have the privilege of carrying her column in our newsletter when we have the space. After a bit of arm twisting, she consented to allow us to publish these reviews. The prices given in square brackets at the end of some reviews are prices in have found when double checking her prices on Amazon dot com. Unless otherwise noted the prices she quotes have not changed.

Here are brief reviews of six recently published books about the polio epidemics, the development of the vaccine, and the aftermath of the epidemics. Most have been published by university publishing presses and this is reflected in the quality of the writing. With the exception of Marc Shell and Patrick Cockburn the authors are Americans and their focus is almost exclusively on the American polio experience. Shell, who is a Canadian by birth, knows there is a wider world out there where people lived and still live with polio. It's nice to see references in his book to many other countries including Australia eg the Tasmanian polio epidemic and its survivors and Carol Mara's book *Iron Cradles*. Anglo-Irishman Cockburn contracted polio as a six year old child in Cork. Wilson, Shell, Cockburn and Irvin are identified as polio survivors. Probably for the polio survivor Wilson's book is the most tempting to buy as it is entirely devoted to what con-

cerns us most, polio survivors' life experiences. Encourage your local library to order books that appeal to you. I have given the Amazon.com prices. Amazon also sells second hand books via their website so you may pick up a cheaper copy. My experiences of this facility have worked out satisfactorily to date although some second-hand booksellers on the Amazon lists do not send books to Australia.

Polio: An American

Story by David Oshinsky

The author, a professional historian, gives a detailed, very interesting, accurate 'warts and all' description of the American polio epidemics and the protagonists in the race for a polio vaccine. The focus is unrelentingly American. The author writes: *Americans were primed to see polio as an indigenous plague... Why did it [polio] thrive in the United States?* (No mention that there were worse epidemics elsewhere eg Iceland, Tasmania had higher per capita rates). It was the *good old Yankee virtues of know-how and can-do* that resulted in the conquest of polio and even though the main players, Salk, Sabin, Koprowski and Basil O'Connor were not *genetically* American, as they were all the children of migrants, that is *all the more reason to view the conquest of polio as truly an American story.* (How does one become genetically American I wonder?). The heroes have feet of clay. Oshinsky says that Sabin's *best friends described him as arrogant, egotistical... 'Smart. But a brainsucker' who took too much credit for a collective dis-*

covery. Salk was accused of similar behaviour. *Not everyone applauded Salk's announcement about the development of the vaccine. His co-workers were angry as no mention was made of their contribution.* Some saw Salk as *a man who cultivated the press with the same care he cultivated viruses. This damaged Salk's standing among scientific researchers.* Oshinsky says: *It is revealing that while Salk was awarded his country's Two highest honours—the Congressional Gold Medal in 1955 and the Presidential Medal of Freedom in 1977—he was denied admission to the elite National Academy of Sciences for the reason, it was said, that he had made no 'basic scientific discovery'. As Albert Sabin, a long-time academy member sneered: 'You could go into the kitchen and do what he did'. The feud between Salk and Sabin would outlive them both. There is still ongoing debate about which man produced the better vaccine.* Oshinsky concludes that there is much about polio that *remains a mystery. One of the ironies of the great polio crusade is....that the successful vaccines helped close the door to future research.*

Published by Oxford University Press, 2005, Amazon price \$US19.80

Living with Polio: The Epidemic and its

Survivors by Daniel Wilson

The chapters in Wilson's book cover the various stages of life with polio from the diagnosis (titled *I'm afraid it's polio*), through life in hospital, going home, living with polio to *An old*

foe returns: Post-polio syndrome. The story is developed from quotations from biographies written by over 150 polio survivors and these are of considerable interest. The experiences of these survivors resemble those of their Australian counterparts: long periods in hospital with limited visiting hours, staff coldness and at times cruelty. Wilson has used a somewhat biased sample of polios as he acknowledges. Survivors who write biographies are usually coping well with their disabilities. Wilson refers to a study of polio patients discharged from the Seattle Respiratory Center during the epidemics. About 10% died within two years. These patients *didn't necessarily have different physical problems...from those who 'succeeded', but rather seemed 'to lack the initiative, drive, imagination and support systems to achieve what the more successful patients had'.* In the conclusion Wilson writes: *One didn't so much overcome polio as learn to live with its legacies and compensate for its losses. Polio survivors have endured and have succeeded in many things...but no one who had paralytic polio truly overcame the disease.* Wilson speaks of how polio survivors helped break down social barriers for people with disability and were among leaders in the disability rights movement. Reading this book will bring back many memories and give you new perspectives on some aspects of your polio past. Published by Chicago University Press, 2005, Amazon price \$US19.14

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Six New Books about Polio

(Continued from page 9)

Splendid Solution:

Jonas Salk and the

Conquest of Polio by Jeffrey Kluger

This book concentrates on Salk's role in the conquest of polio.

Kluger, a writer for *Time* magazine, has the journalist's knack of telling a good story and he gives a lively account of the research and politics behind the development of the Salk vaccine. The book begins in early April 1954 when a rumour spread through the US that its government had stashed tens of thousands of little white coffins in depots around the country. *The location of these coffins was never specified, and that was just as well. If you knew where the coffins were kept, you'd know where the government expected the people to start dying...Jonas Salk would be the person responsible for the deaths* Journalist Walter Winchell, whose popularity was failing, was responsible for broadcasting and writing this story that the Salk vaccine could be a killer. In the storm of anxiety that followed, 150,000 individual children and some areas of the US that had been going to participate in the vaccine trials were withdrawn from the trials. Despite this setback the Salk vaccine trials commenced on April 26th, 1954 and were successful. The book presents a more generous and heroic portrait of Salk than does Oshinsky's book.

Published by Putnam, 2005, Amazon price \$US17.13

Polio and its Aftermath: The Paralysis of Culture

by Marc Shell

This was the book I found most stimulating of the six because Shell goes beyond the medical history and the biographies of polio survivors and talks about some of the broader cultural and political implications of the epidemics and the drive to eliminate polio. Shell writes that: *No study yet written attempts in any way to take in the whole world of the polio pandemics or allows us to see the universal in the particular.* The effects of race, social class, religion, time have been ignored eg the different experiences of black and white Americans. He notes the placing of black and white children in the same polio wards in a few hospitals was an early landmark in racial integration. The polio epidemics coincided with the development of movies and the cold war and influenced attitudes toward these events. Shell's own story is woven through the book, often in the form of imagined conversations with his parents. When he was a child they denied he had been left with any after effects of polio, never spoke of his polio, insisted he take part in activities that were dangerous because of his polio weaknesses and punished him by strapping his polio affected leg. The book is a fascinating meditative ramble about numerous ways in which polio left its mark. Shell discusses a relationship between polio and stuttering. He compares the approach of orthopaedic specialists who put polios on *the rack of perfection* with their surgeries (which seem to have

been much commoner in the US than here) and physiatrists (rehabilitation specialists). The former *seem to convey to polios the message, 'This is not the way to be'* while the counterstatement from physiatrists is *'Learn to be the way you are'*. Ultimately Shell says, *most people with long-term disabilities learn none too soon that there is a limit to what medical science can do to understand and treat us...so we are often, in the last analysis, probably less dependent on doctors for the way we 'get along' than we are on...architects, urban planners, and legislators—those who build the city and interpret its books of justice—and engineers, who make devices like telephones, stair-climbing wheelchairs, hearing aids, talking crosswalks, portable respirators, and voice recognition machines.* There are many ideas to ponder in this book. This is not everyone's book and some readers may agree with the reviewer in *The Economist* (16/6/05) that, *Alas, his [Shell's] own interesting story and that of other famous 'polios' are lost in a mess of literary analysis. The result is as wet and woolly as one of Sister Kenny's treatments.* Published by Harvard University Press, 2005, Amazon price \$US35.00

Home bound: Growing up with a disability in America

by Cass Irvin

The author contracted polio, aged 9, in 1954. After six months in hospital Cass returned home to spend most of the rest of her childhood in bed. As a member of a dysfunctional family, *it was*

*just easier on my mom if I didn't get in my wheelchair. Cass's only times of liberation were periods spent receiving treatment at Warm Springs. As an adult Cass gradually took control of her life, moved out of home with attendant care and in the process came to see disability as a social and political issue. *The only difference between Roosevelt and most disabled people was power and money. Our degree of living a 'normal' life has more to do with resources than with disability... Roosevelt's message—that you cannot let them see how disabled you are, not if you want to succeed—is the message today's 'successful' disabled person has internalized. This belief has kept most of us from joining activist groups to change society.* The book is full of vivid, oh so true, examples of life with disability eg asking whether you can get into a venue. *People usually do not know whether their buildings are accessible or not. And, even when they think they know [you] cannot rely on them. This time the school was ramped and he insisted I would have no trouble getting into the building. He forgot about the four inch curb before I ever got to the ramp. Or when Cass was looking for a job; finally a few encouraging words: 'You know dear, I know if God wants you to have this job, He will provide you with a driver'. I wanted so badly to reply, 'He told me to call you' but I didn't have the guts. Ironically most of what Cass learned about disability issues and the connections she made enabled her to organise good care for her father when he became disabled in old age.* Published by Temple University*

Press, 2004. Amazon price \$US19.95. [Paperback – Hardcover US \$61.50]

The Broken Boy by Patrick Coburn

Patrick Cockburn contracted polio during the Cork epidemic in 1956. Peter Preston who reviewed the book in the Guardian (12/6/05) wrote: *Patrick is six, a cheerful cosseted lad.... Suddenly he has a fever. Suddenly his whole life turns on its head. He is alone, utterly alone... He'll be a cripple forever... He remembers the thin grey, hospital slop of minced meat and potato; the fear of tyrant nurses snapping his head off., the ward tours by lordly consultants brooking no questions nor arguments.* It sounds like Children's Hospital. I remember that when I was at the Collaroy annexe and finally got callipers, one of my first walking activities was to wrap up my bed-bound friends' and my mince and slop, walk to the end of the grounds and throw it over the fence where fortuitously there was a public litter bin. Very few polio memoirs express the anger that Cockburn does. I suspect many of us buried our anger deep because to show it was so dangerous. Cockburn is angry with his parents for moving the family back to Ireland when there was an epidemic and at the way the authorities handled the epidemic. The book also recounts the goings on of his Anglo Irish ancestors and his research into the epidemic but we are told almost nothing of his own life as a polio survivor once he returned to school. Cockburn says he carries *a lot of emotional scar tissue from polio. But I also thought—*

probably rightly-- there was not much I could do about it. He mentions having a severe limp and worrying about post-polio syndrome. From the cover and book's acknowledgements I learnt he is a foreign correspondent in the UK and is married. Cockburn's final words are: *Polio inflicted and continues to inflict great suffering among its surviving victims. Very occasionally well-meaning people suggested to me as a child that sufferings built character and endurance. Even at the age of seven or eight I suspected I had acquired those supposed benefits at an excessive price.*

Published by Jonathon Cape, 2005, £11.19 at Amazon.co.uk [7 new & used from \$US \$26.96 on Amazon]



New Additions to PPASS MN Library

The following new books have recently been added to the PPASS MN library. They may be withdrawn for your reading pleasure by a call to the office (952) 835-9714, an E-mail to the office, or a note to the office, address is on back cover. Remember, let us know what book you want and where to send it.

Chronic Pain and the Family – A New Guide by Julie K. Silver, M.D;
 Living with Polio: The Epidemic and its Survivors by Daniel Wilson;
 Polio and its Aftermath: The Paralysis of Culture by Marc Shell;
 Polio: An American Story by David Oshinsky ;
 Splendid Solution: Jonas Salk and the Conquest of Polio by Jeffrey Kluger



Book Review – Chronic Pain and the Family

Reviewed by Larry Kohout

Chronic Pain and the Family is a new Guide in a series of health guides published by the Harvard University Press Family Health Guides and written by Julie K. Silver, M.D., the doctor who has written so much on post polio syndrome. This guide covers the gamut with chapters on “What is Chronic Pain?” through “Intimacy and Sexual Activity” to “Complementary and Alternative Medicine.”

For those with young children there is a chapter on “Growing Up with a Parent in Pain” which is aimed at the parent. This chapter gives advice on how to recognize the impact your pain is having on your child and how and when to seek help for you child. Of course there is also advice for the “Effect on the Couple” which is where many of us are.

The chapter on “The Extended Family” is probably the most applicable to those of us with PPS. With or without chronic pain the words of wisdom that Dr. Silver dispenses in this chapter apply equally. Whether it is the pain of PPS or the

other symptoms, the words in this chapter seem to apply. Things like “Family relationships can also be strained when members yearn for the way the person in pain ‘used to be’ rather than accepting him as he is now.” Seem to apply equally to chronic pain and all the symptoms of PPS.

Chronic Pain and the Family –
A New Guide by Julie K. Silver, M.D. 166 pages Harvard University Press, Cambridge Massachusetts, London, England.

ISBN 0-674-01666-1
\$31.50 Hard Cover,
\$12.60 Trade Covers.



Trivia Contest

Answers

The polio and post polio trivia contests are on page 6. If you haven't taken the test yet, don't be looking at the answers. If you have taken the test you can be gentle with yourself in scoring.

Polio Trivia Answers

1. An Egyptian stele dating to the 18th dynasty (1580 - 1350 BCE) is generally accepted as showing a priest with a flail leg typical of poliomyelitis. Acceptable: Egyptian stone carving or similar. Or you can even give yourself credit if you answered Egypt.
2. Albert Sabin
3. Jonas Salk
4. “Sister” was an honorary title

- given to nurses in Australia. In reality, Kenny was not a nurse.
5. Poliomyelitis Give yourself credit if the spelling is close. - **Bonus:** Inflammation of the gray matter.
6. Franklin D. Roosevelt
7. April 12, 1955 **Bonus:** Tenth anniversary of FDR's death.
8. Eddie Cantor
9. Place the affected limb in a cast.
10. Sister Elizabeth Kenny or any recognizable variant

Post-Polio Trivia

Answers

1. 1981 **Bonus:** In Chicago.
2. Rehabilitation Gazette Incorporated. They had published a letter in 1979 from a polio survivor describing these new symptoms and they were deluged with letters saying “me too.”
3. a. Fatigue b. Pain c. New weakness
4. ALS
5. Because some of the anterior horn cells for those muscles were damaged or destroyed by polio.
6. a. A history of polio b. A period of recovery. c. A long stable period. d. New symptoms not attributable to any other medical conditions.
7. Improving the efficiency and safety of a polio survivor's mobility.
8. a. Older when polio was originally contracted. b. More extensive original paralysis. c. Greater degree of recovery.
9. 60%
10. 1897



Two Survival Tips

By Dick Baumer

Emergency Service Entry to Your Home

If you live alone, give some thought to how someone could come to your aid if you found yourself unable to move to answer the door. Recently, a family friend suffered a stroke but felt it coming on and was able to dial 911. However, when the Ambulance and Police arrived, they couldn't get into the locked house.

The door was eventually broken down and obviously a considerable amount of damage was done. If you have an attached garage with a door opener, purchase a second opener and keep it by your bed. Some are even small enough to wear as a pendant. Should you need help but are otherwise able to use the phone, you can direct emergency personnel to enter through the garage as you will open it for them. Obviously if you have a detached garage this won't work.

Locating You In An Emergency

With all of the natural disasters as of late, here is another tip for survival should you be trapped in your home. Most stores that sell boating equipment and supplies stock a

device that serves as an "air horn". It is a small canister like the small cans of mosquito spray and attached to it is a funnel shaped affair. There is enough propellant in the can for several blasts on the horn. Larger versions are also available. Placing a couple of the small versions at strategic spots in your home would let you alert rescue personnel of your whereabouts. I think this would be especially valuable in the event of fire. Granted, this is not a device you would have on your person at all times, but if you have a few in the house, it gives you one more survival tool.



Polio Found in

Minnesota -

What's all the Fuss?

By Cathy & Larry Kohout

Local newspapers and television stations are raising quite a ruckus in their attempts to sensationalize the discovery of several cases of polio within Minnesota's Amish community. The event that sparked this brouhaha was the unfortunate union of an unvaccinated child and the Vaccine Derived Polio Virus (VDPV) type one. That is to say, some recently

vaccinated person passed through this child's world and left behind a "gift" of attenuated (weakened) vaccine derived virus.

...some recently vaccinated person passed through this child's world and left behind a "gift" of attenuated (weakened) vaccine derived virus.

We can surmise that the "gift giver" was from Africa or India since these are the only two places in the world using the live virus oral vaccine (OPV). Details are scanty, but it appears that this chance encounter caused no permanent damage and did, in fact, do exactly what oral polio vaccine was meant to do.

The oral polio vaccine being an attenuated form of the live polio virus will cause the body to produce antibodies to the polio virus, but it is not strong enough to actually invade the body and cause the same damage as the wild polio virus – with one proviso. That proviso is that a person receiving the vaccine must have a healthy immune system.

From the time of the last case of naturally occurring wild polio in this

(Continued on page 14)

Polio Found in Minnesota

(Continued from page 13)

country in 1979 (which also occurred in an Amish community, by the way) we continued to have, on average, eight case of Vaccine Associated Polio (VAP) every year. These occurred in

From the time of the last case of naturally occurring wild polio in this country in 1979 we continued to have, on average, eight case of Vaccine Associated Polio every

people with compromised immune systems who didn't have what it takes to fight off the virus. In 1998 an association of parents representing children who had contracted polio in this manner petitioned the Centers for Disease Control in Atlanta, Georgia asking that they stop using the OPV.

Now you need to understand something about the oral polio vaccine. It behaves in the same manner as the wild polio virus does. That is it goes in through your mouth (many of you remember that you were given drops on a sugar cube or

had it dropped on your tongue from a dropper), replicates in your intestines, and excretes in your feces. Sorry if you are a bit squeamish but this is an important point. Both the wild polio virus and the oral polio vaccine go back into the environment where they get picked up by other people. In the case of wild polio it may cause one of three things: a case of abortive polio, a case of non paralytic polio, or a case of paralytic polio. In the case of the oral polio vaccine it does exactly what the drops on the sugar cube did. It vaccinates the people that come in contact with it. This is called "herd immunity." It was known about from the beginning and was thought to be one of the great side benefits of the oral polio vaccine.

However, by 1997 there hadn't been a case of wild polio since 1979. The only ones that were coming down with polio were a few people who happen to have compromised immune systems. Their parents reasoned that this "herd immunity" thing really wasn't important to the general health of our population any longer and felt we should stop using the oral polio vaccine. They suggested switching back to the Inactivated Polio Vaccine (IPV), the original and so

called Salk vaccine, since it contained dead and harmless virus.

From an article in the Journal of the American Medical Association on October 13, 2004 "To reduce the [Vaccine Associated Paralytic Polio] VAPP burden, national vaccination policy changed in 1997 from reliance on OPV to options for a schedule of inactivated poliovirus vaccine (IPV) followed by OPV. In 2000, an exclusive IPV schedule was adopted." {Didn't you just know there had to be yet another acronym in this article?}

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So what does all this tell us about those Amish children in central Minnesota? We know for sure that they hadn't been vaccinated, because, if they had, it wouldn't have mattered what kind of polio virus they encountered. A vaccinated child would be immune.

We also know that these Amish children and all other unvaccinated people, are at increased risk in our ever-growing bor-

derless, boundaryless, world. The person who carried the oral polio vaccine virus to these kids could just as easily have been carrying the wild polio virus, whooping cough, diphtheria, or some other preventable

disease.

Just how many people are at risk? The Minnesota Department of Health reports that we have a vaccination rate of 98% - an impressive statistic until you realize that it means 102,019 people are not vaccinated. If we use the Census Bureau's ratio of 6.7% of those being children under five years of age then we have 6,835 of those who are in the prime target age for paralytic polio.

Apparently there is some substance to this story, even if our news providers aren't telling it. All it takes is one traveler, with a bug replicating in her/his gut, to stop at a rest-

room, use the toilet, and neglect to wash his/her hands. The virus that never gets washed off might be passed with a handshake, an exchange of money, or any other innocent contact. In a blink of an eye the passing is complete. Had it been wild polio, it could have been catastrophic.

There is an excellent Q&A on line at the Post-Polio Health International (PHI) Web Site. If you go to <http://www.post-polio.org/> there is a "Connect Here" in a box right under their banner. It lists a number of good questions and answers about this whole situation.



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Our support group feels an exchange of information between groups is important, and it is our hope for the future that all groups will join those of us who take the time and effort to research, contribute, and educate responsibly



Newsletter of the Post Polio Awareness & Support Society of Minnesota

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