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Scourge of Infantile Paralysis Stamped Out

A Brief History of Polio – 1916 - 1999

By Larry Kohout

Polio was a little known disease until the middle of the 20th Century. Then it became well known mostly because of the efforts of Franklin Delano Roosevelt, 32nd President of the United States. As almost every school child knows, Roosevelt was a polio survivor himself. What few realized was the extent of his disability. He kept that hidden through hard work and what Hugh Gregory Gallagher called FDR's Splendid Deception. Roosevelt, raised as a Hudson River patrician, knew that the country would not accept a person with a disability as their political leader, so he simply deceived everyone into believing his disability was minor at most. He never denied his disability; he talked about it quite openly in fact. But like the magician, he turned people's attention to other things and worked

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Polio Eradication Efforts

By Larry Kohout

This article, written in late 2004 and early 2005, is a review of the available information in the world's press to determine the state of the efforts to eradicate polio. The Nigerian boycott of immunization efforts set the program back, and it the year ended with a higher number of cases of polio than had been reported in 2003. This was the first reversal the program had seen since its inception. Heretofore, even warring parties had laid down arms for a brief period in order to allow health workers access to the world's children.

In late June, 2004 the World Health Organization (WHO) was announcing that Africa was on the brink of a major polio outbreak¹. Nigeria, where political leaders had refused to participate with the immunization efforts, reported 257 cases or 77% of the 333 cases reported globally at

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From Where I Sit

By Gary Dunn, Chair

It seems like only a short time ago I was able to sit back and enjoy the articles written by Jane St Onge, the past PPASS MN Chair. It never crossed my mind that I would be writing an article as the new Chair.

My first thought was what to write about, so I reviewed previous articles written by Jane to get a flavor of what you enjoyed. Rather than find a flavor of what to write about, I realized that this petite lady who has been so active in PPASS MN has left me some pretty big shoes to fill. She has served as Chair of the West Metro Chapter and for the last two years serving as Chair for the State organization. I had known Jane prior to joining the organization. I was impressed with how

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Scourge of Infantile Paralysis Stamped Out

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exceptionally hard to develop a walking style that, for the most part, concealed the fact that he was totally supported on bilateral long leg braces.

Roosevelt knew the problems of living with a disability and so made it his personal mission to do everything in his power to relieve the suffering of polio. In the same way that Jack Kennedy set the course for human kind's venture into space, FDR set the course to rid the world of polio. In his radio address on the occasion of the Sixth Birthday Ball for Crippled Children on January 30, 1939 he said, "I emphasize the importance of a nationwide, continuous campaign because experience tells us that epidemic diseases can be stamped out only through carefully directed work on a nationwide scale. We need, therefore, the cooperation of every state and county, every city and town, every hamlet and crossroads community in this work. Only by such cooperation has tuberculosis been brought under control in our lifetime. Only by the same concerted action will the scourge of infantile paralysis be stamped out."¹

He spent two thirds of his personal inheritance² to acquire the decrepit and failing resort, the Meriwether Inn, at Warm

Springs, Georgia which he then turned into a treatment center for polio. While President he was speaking to a group of surgeons visiting Warm Springs in 1935 and said, "My whole objective was to make the country as conscious about polio as it is about TB³."

The beginning of the end for polio was announced on the tenth anniversary of Roosevelt's death, April 12, 1955 with the announcement of a safe and effective Salk polio vaccine. We are approaching the 50th anniversary of that event and we are within a hair's breadth of achieving the goal that was one of Roosevelt's fondest wishes, world-wide eradication of polio. But I have started my story in the middle.

Polio has been around since prehistoric times as evidenced by the Egyptian stele dating from the eighteenth dynasty that now resides in the Carlsberg Glyptothek, Copenhagen (see figure 1). This stone carving shows the gate keeper, Ruma, at the temple of Astarte in Egypt. Some thought that the work



Figure 1 – Egyptian stele dating from the eighteenth dynasty (1590 – 1350 BCE) now in the Carlsberg Glyptothek, Copenhagen, Kindness of the National

was just badly drawn, but the work tells the story of Ruma's bout with childhood polio⁴. He carries a stick to use as a crutch and his right leg is flail and atrophied with tell-tail drop foot.

So if polio was known that far back why was it so little known in the early part of the 20th century? The answer is simple, polio, prior to the 20th century, never reached epidemic proportions. What usually happened is that an infant was born, and during the nursing process picked up a temporary immunity through the co-

lostrum, based on its mother's immunity. Then, while the child still had a temporary immunity to the disease, she or he was exposed to the live virus that circulated freely throughout the world and was passed through food or drink contaminated by fecal matter⁵. While this exposure may have caused a slight illness, it also built a number of antibodies in the individual's bloodstream to that particular virus strain and a life long immunity to it.

So it was that throughout most of history, most people developed their protective immunities and only a few unlucky human beings actually contracted polio and developed the residual disability that we associate with the disease. So what changed? One of those ironies of history is that while the germ theory rose in popularity and societies developed more advanced methods of sanitation, fewer people were exposed to the wild virus during their periods of natural immunity. Therefore, they emerged from that period without developing a natural immunity of their own. By the late 1800s, the people of Western Europe and America are beginning to build large populations who have no natural immunity to polio.

Like the little ripples that precede the tidal wave, there were small epidemics in the US prior to 1916. Then "In the summer of 1916, while European armies bat-

tered each other senseless, New Yorkers were engaged in a very different kind of struggle. An invisible enemy was killing and crippling children, in particular, quite as effectively as bullets and shrapnel killed and maimed the infantrymen stumbling through the wire and mire of the Somme⁶." Suddenly the western world, and soon all the world, was facing epidemic polio. In that year of 1916, there were 9,000 cases of polio in New York City alone, with 2,343 deaths. Nationwide there were 27,000 cases with 6,000 deaths⁷.

Epidemics waxed and waned through the teens, the 20s, and 30s, but with the population spurt of the early 1940s and the movement of our troops from the US to Europe and Asia came an increase in the size of the epidemics. Throughout the '30s and '40s, the size of the epidemics continued to build (see figure 2⁸) but for the most part had stayed below 10,000 nation-wide. In 1943, we suddenly went from 4,167 the previous year to 12,450 and it never dropped beneath 10,000 again until after the vaccines were introduced.

But we have managed to gloss over an important event that occurred on August 9, 1921⁹. On that date, a young man who was then a recently defeated US Vice Presidential Candidate was vacationing with his family at their Campobello Island, New Brun-

wick summer home. He had exercised hard, swimming, sailing (even fallen overboard), and fought a small forest fire with his children that day. In the evening, he sat exhausted in his wet swimming suit before getting changed. The next morning he was ill with flu like symptoms which in time were diagnosed as infantile paralysis, today known as poliomyelitis or polio. That young man, of course was Franklin Delano Roosevelt.

As mentioned earlier, FDR spent his own money in the purchase of the resort at Warm Springs. Later, as president, he twisted the arm of his law partner, Basil O'Conner, and got him to take over the management of the Warm Springs Foundation¹⁰.

FDR continued to lend his name and fame to the cause of raising money for polio. He clearly had a vision of what needed to be done. The Thanksgiving Dinner was always the Social event of the Warm Springs year. During Thanksgiving in 1934, he told those in attendance "You must always remember, that you who are here . . . only represent a tiny fraction of the people throughout the land . . . who have infantile paralysis . . . Even if we were to double in size or quadruple in size, we could treat only a small fraction in this country of the people who need treatment¹¹."

At first funds were raised with an

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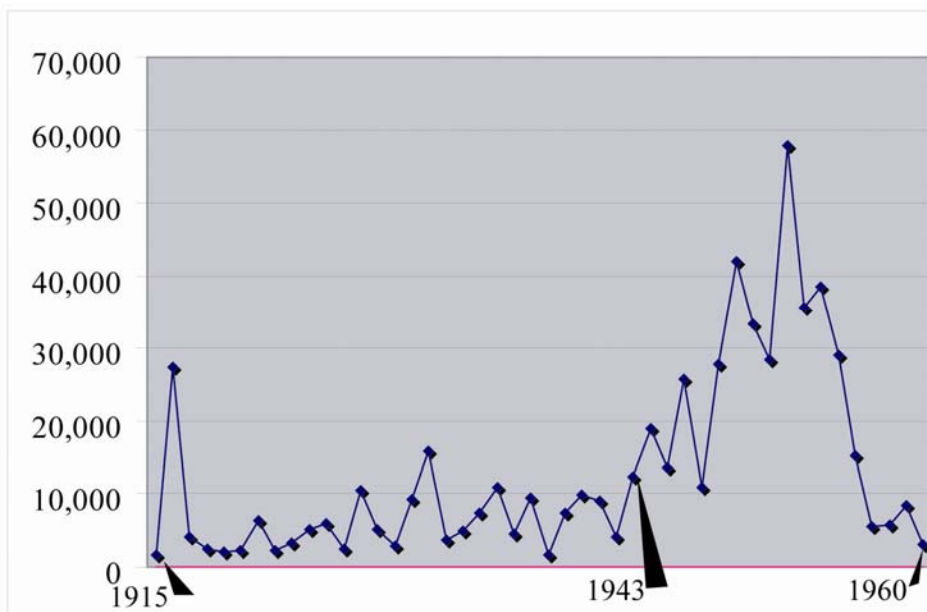


Figure 2 – Incidence of Paralytic Polio in the US Between 1915 and 1960

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annual President’s Birthday Ball. These were held in cities across the country beginning on January 30, 1934. The first ball raised over a million dollars for Warm Springs. But as the balls grew year by year and Roosevelt’s political enemies began to take shots at him and at the Warm Springs Foundation, it became clear it was time to separate the Foundation from Roosevelt. So on September 23, 1937 the National Foundation for Infantile Paralysis was created¹². In setting up the National Foundation Roosevelt outlined an ambitious program, “The general purpose of the new Foundation will be to lead, direct, and unify the fight on every phase of this sickness¹³.”

The Foundation was to cover the cost of treatment and care of patients, of research into new treatments, and cure or prevention.

Up until this time, many cases of polio had gone undiagnosed or unreported. Hospitals were not set up to treat the disease and many would not admit polio patients. With the Foundation announcing that it would bear the cost of treatment without a means test the number of diagnosed cases began to swell. Basil O’Conner recognized that the million dollars a year raised by the Birthday Balls was not going to do the job, they would need millions of dollars. When Franklin and Eleanor agreed to lend their names to the effort, Eddie Cantor, the vaudeville and radio entertainer came up with the idea of calling it the March of Dimes¹⁴, a play on the then-popular movie news-reel called the March of Time.

Ultimately, the National Foundation changed its name to the March of Dimes, the name it is

known by today. It funded patient care to the maximum possible under available funds within each community and at the same time, it invested in research. This was a highly risky project as research provides no guarantees. But FDR had said he wanted the scourge of infantile paralysis stamped out. Therefore, money was put into funding research. One of the first things the research identified was the total number of virus types that transmitted polio (three). This was a critical step in developing a vaccine because in order to have a vaccine against the disease you have to know all the causes of the disease. Today both vaccines – the live attenuated vaccine being used in Asia and Africa and the dead vaccine now used again in the Americas and in Europe – are called trivalent vaccines because they carry the immunity to all three of these virus types.

So the efforts that FDR set in motion in 1934 and 1937 and that he pushed his whole life long finally came to fruition ten years after his death and was announced on the anniversary of his death, April 12, 1955, when Dr. Thomas Francis Jr. announced “Safe, effective, and potent.” Dr. Francis, who was the director of the Poliomyelitis Vaccine Evaluation Center at the University Of Michigan School Of Public Health, announced to the world that the Salk polio vaccine was up to 90% effective in preventing

paralytic polio¹⁵.

Basil O'Conner was ready for the announcement; he had taken a risk and given the go ahead to manufacture twenty seven million doses of vaccine at a cost of \$9,000,000 with the Foundations money¹⁶. The evening of the announcement, April 12th, President Eisenhower's Secretary of the brand new Health, Education, and Welfare Department, Oveta Culp Hobby released the new vaccine. Senator Alexander Smith of New Jersey noted, "Refusing to be precipitated into a hasty program of federal regimentation, Mrs. Hobby, her advisors with the full cooperation of the doctors, vaccine manufacturers, and distributors, worked out a program of voluntary distribution which promises maximum effectiveness and retains our basic American principle of non-federal control of the doctor-patient relationship.¹⁷" The very next day the vaccine was being distributed to doctors around the country.

Polio, that had hit an all time epidemic high point in 1952 with 57,829 cases, began to be brought under control. With the introduction of the vaccine in 1955 cases dropped to 28,985, in 1956 they were down to 15,140, in 1957 they were finally under the 10,000 mark again, down to 5,485. The next few years showed a little bumping up as people began to get complacent.

You may remember Elvis Presley was pulled into the fight in 1958 to try to get people to pay attention to their vaccinations.

In 1961, the oral "Sabin" vaccine with the attenuated virus was introduced in the US. It had already been tested on 80 million people in Russia. By 1961 wild polio in the US had dropped to only 998 cases, never in the short history of epidemic polio had there been that few cases. But there was also a new number that year; there were 2 cases of vaccine-induced polio.

The oral polio vaccine is an attenuated virus, which means it is a weakened virus but it is still alive. People with compromised immune systems did not have the wherewithal to fight off the weakened virus and ended up with a case of infectious polio. As the cases of wild polio dropped the cases of vaccine-induced polio climbed for a time. In 1973, there were 8 cases of wild polio and 8 cases of vaccine-induced polio in the US. Then wild polio disappeared except for an outbreak in an Amish community in 1979 which produced 12 new cases. Those were the last cases of wild polio in the US. We continued to have vaccine-induced polio until 1998. That year a parent's organization petitioned the Centers for Disease Control and made a strong case for switching from the attenuated vaccine back to the original, so

called Salk vaccine. That ended polio in the US and in this Hemisphere. FDR would have been very pleased.

But the disease still persists in the world. In 1985, the service organization, Rotary International, made a commitment to immunize all of the world's children against polio. They have been working in conjunction with the World Health Organization (WHO), United Nations International Children's Emergency Fund (UNICEF), the Centers for Disease Control (CDC) in Atlanta, Georgia, and with local governments around the world. By 2005, the revised target date set for the eradication of polio, Rotary International has raised in excess of 1.5 billion dollars in support of this project. When WHO joined the Rotary effort in 1988 there were an estimated 350,000 cases of polio worldwide and polio was freely circulating in 125 countries¹⁸. At the end of 2003, there were a total of 784 cases of polio¹⁹ in only seven countries. However, in August of 2003 political forces in the northern regions of Nigeria lead a boycott against the immunization program, claiming it was a plot on the part of the US to sterilize Africans and to infect them with the AIDS virus. By the time the boycott was resolved in July of 2004, the polio virus had once again gained ground. Polio was

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active now in 12 countries in Africa as well as in India. The year 2004 ended with a total of 1,185 cases of polio.

See the accompanying article Polio Eradication Efforts for an update on the world situation today. Once again, Rotary International, Who, UNICEF, CDC, and the local governments have set their sites on eradicating polio by the end of 2005. As this is the 50th anniversary of the introduction of the first polio vaccine, it seems a fitting year to eradicate polio. It will be only the second disease eradicated in the whole of human history. Smallpox was declared eradicated on May 8, 1980. Now this second epidemic-disease is being wiped out through – to borrow someone else’s words - careful directed work on a world-wide scale. The scourge of infantile paralysis is nearly stamped out.

REFERENCES:

- 1 “Radio address, Sixth Birthday Ball for Crippled Children” January 30, 1939 <<http://www.fdrlibrary.marist.edu/index/html>> (February 28, 2005)
- 2 Hugh Gregory Gallagher, *FDR’s Splendid Deception*, (New York, New York: Dodd Mead & Company 1985) p 43.
- 3 *Ibid* p 146
- 4 “Famous People Who Had Polio” <<http://www.geocities.com/Heartland/Ranch/5212/poliopeople.html>> (February 20, 2005) Note: The web site references the sources “Never to Die: the Egyptians in their own words,” by Josephine Mayer and Tom

- Prideaux, p. 80 and "Polio Pioneers, The Story of the Fight Against Polio" by Dorothy and Philip Sterling, 1955, p. 9-12
- 5 John R. Paul, *A History of Poliomyelitis*, (New Haven, Conn.: Yale University Press, 1971) p 2, 10-12
- 6 Tony Gould, *A Summer Plague - Polio and its Survivors*, (New Haven & London: Yale University Press 1995) p 3 – 4.
- 7 *Ibid* p 28.
- 8 From data in authors collection, compiled from March of Dimes Statistics.
- 9 Hugh Gregory Gallagher, *op. cit.*, p 1
- 10 Tony Gould, *op. cit.*, p 45-46
- 11 Hugh Gregory Gallagher, *op. cit.*, p 145
- 12 *Ibid* p 147
- 13 *Ibid* p 148
- 14 *Ibid* p 150
- 15 “1955 Polio Vaccine Trial Announcement” N.D. <<http://www.sph.umich.edu/about/polioannouncement.html>> (February 28, 2005)
- 16 Tony Gould, *op. cit.*, p 148
- 17 “Oveta Culp Hobby and the Women’s Army Corps, Biographical Sketch” N.D. <<http://www.rice.edu/fondren/woodson/exhibits/wac/hobby.html>> (February 27, 2005)
- 18 “Polio Cases From High to Low” 12/9/2004, <www.Boston.com/News/BostonGlobe/Health/> (December 10, 2004)
- 19 “West African leaders redouble polio fight” 2/20/2005 <http://seattlepi.nwsource.com/national/apscience_story.asp?category=1500&slug=Africa%20Polio> (February 28, 2005)



Polio Eradication Efforts

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that time.

According to an article in the Boston Globe, “The introduction of two vaccines in the mid-20th century swiftly led to eradication of polio in wealthier countries and eventually inspired the global eradication movement because one of the vaccines, delivered orally, was so simple to give. In 1988, when the campaign started, polio was transmitted in 125 countries, with an estimated 350,000 cases. At the end of last year [2003], the virus resided in just six countries, accounting for 784 cases.”²

By November 18th WHO confirmed that 682 Nigerian children had been paralyzed by polio this year [2004], accounting for 74% of the global polio. In Lagos, Nigeria, past District Governor of Rotary international, Ade Adefoso, disclosed that at least \$1.5 billion dollars would be saved annually from polio vaccination if polio were eradicated worldwide.³

The outbreak of polio in Nigeria and Niger this year caused the disease to overflow the borders and turn up in 12 countries that had been polio free for the past four years. On November 19th, Dr. Mafany Njie Martin, Cameroon’s Provincial dele-

gate for public health, was quoted in the Cameroon Tribune "has advised inhabitants of the Province to scrupulously respect normal routine Polio vaccination schedules to avoid spending hundreds of FCFA for emergency treatment of the disease. If the vaccination programme were respected by 100 per cent, he noted, the more than CFA fifty million in cash and huge sums in support activities would not be spent." However, to succeed in the total elimination of polio, the delegate explained, neighboring countries must be committed. They must in common manage their border populations in order to ensure success, which can only come "when all living forces in every society have all hands on deck, adding that polio knows neither hierarchy nor borders.⁴"

On Sunday November 21st, India entered into the final round of inoculations with Congress president Sonia Gandhi even getting into the act and administering vaccine. According to the internet site Health India, over 168 million children received the polio drops on that day. One hundred thousand volunteers spread out over the country to find every child five years old and younger for the inoculations (which works out to an amazing 1680 children per volunteer). This year, India re-

ported 85 cases of polio, the lowest count ever in the country. Of these, 58 were reported from Uttar Pradesh and 20 from Bihar. The other cases were reported from Maharashtra, West Bengal, Karnataka, Andhra Pradesh, Tamil Nadu and Delhi⁵.

On November 24th, the Press Trust of India reported that following Sunday vaccine administration four infants in Khammam district of Andhra Pradesh died. Parents of the four children alleged that they died due to complications a day after being administered polio drops. District Collector Rajendra Narendra Nimje categorically denied the charge and attributed the deaths to "other health problems". On the 25th two more children also died. A postmortem on the exhumed bodies of four children who had died over the weekend showed that they had succumbed to neonatal complications. Health officials said none of the deaths could be attributed to the oral polio vaccine drops. Nevertheless, the incident is being "critically viewed" and samples of the vaccine given to the children were sent to the Central Drug Research Institute at Kasauli.⁶

On December 1st the Canadian Press, under the headline "WHO Aims To Eradicate Polio By 2005" announced that

through heroic efforts of millions around the globe, the world is poised within the next year to eradicate a disease - polio - for only the second time in history. Canada has been a major player in the program, which dates back to 1988. In addition to providing significant funding, personnel and expertise, the country's political leadership has been instrumental in putting - and keeping - polio eradication on the agenda of key groups. Some suggest a key contribution Canada has made is Dr. Bruce Aylward, a passionately committed physician from St. John's, Nfld., who has spent a dozen years working for the WHO around the globe⁷.

On December 5th, in an Opinion piece in the Daily Champion (Lagos, Nigeria), the editors heaped great praise on the political leadership and skill of Vice-President Atiku Abubakar for his orchestration of the end of the boycott of the polio vaccinations. "As a key figure in the [President] Obasanjo administration, which has been ardently pursuing immunization programme across the country, including the north where polio is ravaging the future of our innocent children, the Vice-President could not have found himself in a more embarrassed situation as a result of the knotty issue of polio vaccines safety. . . . The rap-

idly changing attitude towards the safety of polio vaccines, in spite of negligible pockets of resistance to immunization in certain areas of the north, arising from deep-seated prejudice, is a tribute to the Vice-President's political sagacity in defusing a medical time bomb, ticking slowly but dangerously, threatening to blow up our children!⁸”

On December 6th, in a story on Yahoo News the head of the United Nations Children's Fund praised the "exceptional" progress towards eradicating polio in Pakistan, one of only six countries where the disease is still endemic. “A major vaccination programme with health workers hiking to remote regions has cut the number of cases in the South Asian nation by 50 percent.” UNICEF executive director Carol Bellamy said Monday.

"That is exceptional," she told a news conference in Islamabad after meeting with prime minister Shaukat Aziz to discuss the organisation's work in Pakistan. Cases in Pakistan fell from 88 last year to 40 this year, according to UNICEF⁹.

Also on December 6th and closer to home, the Minneapolis Star Tribune reported that Charlie Cogan, a member of the Northfield Rotary Club, would lead a group of 16 Rotarians on a trip to Togo, Benin

and Burkina Faso to immunize children against polio. Cogan, who recruits international students for Carleton College in Northfield, has strong ties to the West African nation of Togo. He lived there as a Peace Corps volunteer and Fulbright scholar, and he met his wife, Nalongue, there¹⁰.

On December 9th, the news is very mixed. In Cote D Ivoire (the Ivory Coast) Reuters News is reporting that there is no school and no vaccinations for millions of children because of on-going civil war¹¹. War continues in the Sudan. Yet Kathy and Dennis Crawford of the McCandless, PA Rotary Club were leading a group of 13 volunteers to Niger to participate in polio eradication efforts. Please note that when these people make these trips they do so at their own expense¹².

In a January 27, 2005 Associated Press article in the Kansas City Star “The United Nations said Thursday that it has received grants of \$10 million from the Bill & Melinda Gates Foundation to help develop and introduce a more effective new vaccine for polio. Developing a new polio vaccine is a key part of the World Health Organization's strategy to eradicate the crippling disease by the end of 2005. ‘Epidemiologists believe the new vaccine could help to bring a swift end to po-

lio through mass immunization campaigns,’ WHO and the U.N. children's agency said in a joint statement.¹³”

On February 11, 2005 in an Eric Green, article in the Patriot News¹⁴, he said “Millions of children in the Americas, especially those ‘normally left behind,’ are the focus of a large immunization drive that will be conducted April 23-30, the Pan American Health Organization (PAHO) has announced. PAHO, which is coordinating the effort, said in a February 11 statement that ‘Vaccination Week in the Americas’ will also target the region's population who live in rural border areas, indigenous people, and vulnerable groups, including women of childbearing age and the elderly. The vaccinations are to protect people against measles, polio, rubella, and other diseases.”

The article continued “In the 2004 Vaccination Week campaign, some 43.7 million people, mostly children, were vaccinated in South and Central America, said PAHO. The United States and Canada participated in that effort by promoting the benefits of immunization, especially among children. In 2004, the campaign theme for that year's Vaccination Week was the CDC-inspired motto of ‘Love Them,

Protect Them, Immunize Them.”

The CDC says immunizations protect the entire community by preventing the spread of disease and providing protection for those who cannot be vaccinated. The agency said that measles, whooping cough, diphtheria, rubella, and polio -- diseases that just a few years ago caused tremendous suffering and death -- still circulate in the United States and in many other parts of the world. The CDC says these diseases can return with devastating consequences if immunization coverage rates are allowed to fall.”

In an article in *Medical News Today* on February 26¹⁵ they reported “22-nation synchronized immunization campaign to reach 100 million children as virus spreads to Ethiopia - A mass polio immunization drive starting today across Africa gained greater urgency from reports that a child has contracted polio in Ethiopia, the first case there in four years.” The cross-continental drive - spanning 22 countries and reaching 100 million children - is the first in a series of 2005 campaigns to stamp out polio in Africa, which saw a fierce resurgence last year endangering global eradication efforts. With polio now in its low-

transmission season, the next few months are critical to stopping the virus.

The article went on, “By reaching children cut off from the eradication effort by insecurity and the threat of violence African leaders have a real opportunity to halt polio's advance,” said Dr. Ezio Murzi, UNICEF Regional Director for West and Central Africa.”

Commentary: A close reading of the above excerpts reveals a number of minor errors that will creep into stories no matter how hard the writer and editor try to screen them out. But what is most obvious to this reader is a halting, jerking, lunging attempt on the part of the peoples of the world to rid us of this disease. As happened last year in Sudan, opposing sides in the civil war in Cote D Ivoire have agreed to a truce to allow health workers access to the children. There have been very positive moves on the part of the political leadership in northern Nigeria, and slowly but surely the Sudan is beginning to get its arms around the vaccination problem. I know I'm an optimist, but it might just be possible that there is enough good will in our collected humanity to put an end to the poliomyelitis virus.

REFERENCES:

- 1 “WHO: Africa on Brink of Polio Outbreak” 6/22/2004 <<http://www.healthy.net/library/news/index.asp>> (December 9, 2004)
- 2 “Polio Cases From High to Low” 12/9/2004, <www.Boston.com/News/BostonGlobe/Health/> (December 10, 2004)
- 3 “\$1.5bn to Be Saved From Polio Eradication” 11/18/2004 <http://allafrica.com/publishers.html?passed_name=This%20Day&passed_location=Lagos> (December 9, 2004)
- 4 “South West : Polio, A Cross-Border Disease” 11/19/2004 <<http://allafrica.com/cameroon/>> (December 9, 2004)
- 5 “India inches closer to eradicating polio:” 11/21/2004 , <<http://www.newkerala.com/news-daily/news/features.php?action=fullnews&id=77740>> (December 9, 2004)
- 6 “Polio scare in Andhra after four infants die” 11/24/2004 <http://www.hindustantimes.com/2004/Nov/24/181/_1259318,001301480000.htm> (December 9, 2004)
- 7 “WHO aims to eradicate polio by 2005” 12/1/2004 <<http://www.cp.org/english/hp.htm>> (December 9, 2004)
- 8 “Polio Crisis: The Wisdom of Atiku's Leadership” 12/5/2004 <<http://www.champion-newspapers.com/>> (December 9, 2004)
- 9 “UNICEF chief hails polio elimination efforts in Pakistan” 12/6/2004 <<http://>>

story.news.yahoo.com/news?
tmpl=story&cid=1508&ncid=751
&e=9&u=/afp/20041206/hl>
(December 9, 2004)

10 “Northfield Rotarian leads Africa polio effort” 12/6/2004
<<http://www.startribune.com/stories/587/5265826.html>>
(December 9, 2004)

11 “COTE D IVOIRE: Civil war means no school, no shots for millions of children” 12/9/2004
<<http://www.alertnet.org/thenews/newsdesk/IRIN/6c35fa697162fa3244ac2d89b680654a.htm>> (December 9, 2004)

12 “Mars residents part of polio eradication effort” 12/9/2004
<http://pittsburghlive.com/x/tribune-review/trib/tribnorth/s_280716.html> (December 9, 2004)

13 “Gates Foundation Gives \$10M for Polio” 1/27/2005
<<http://www.kansascity.com/mld/kansascity/news/world/10749356.htm?1c>>
(January 27, 2005)

14 “Millions of Children Focus of Vaccination Week in the Americas” 2/11/2005
<<http://www.allamericanpatriots.com/m-news+article+storyid-6108-PHPSESSID-c80f599795ea727669d8a48fa676ce5c.html>> (February 12, 2005)

15 “Coast-to-coast polio drive to counter epidemic in Africa” 2/26/2005 <<http://www.medicalnewstoday.com/medicalnews.php?newsid=20403>> (3/5/2005)

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professionally she handled the PPASS MN Chair position. I think it appropriate to use part of this article to say a big THANK YOU for all her efforts and the contributions she has made to the organization. I am glad she will be helping PPASS MN in an advisory capacity this next year.

I have been a member for two years. I had polio in 1949 at the age of 7 and spent the next 40 years denying that I had polio. I have found PPASS to be a refuge where others can understand what you are talking about when you relate your polio experiences. I am glad to be part of the organization and have found a wealth of talent in its Officers and Board members. I see many good things happening in the future.

As your new Chair, I would like to hear from you. What would you like to see in these articles? Give me ideas. You can e-mail me at dollkin@pressenter.com. Until next time, may all your dreams be beautiful.

Chapter Happenings

Owatonna

By Dick Baumer

Due to the cold weather, the January meeting was lightly attended so the meeting turned out to be more of a social gathering. I spoke about the status of global polio as the situation in Africa was of interest to the group. I was searching the internet for news regarding the 2004 polio outbreak in certain African states when I came across a chart that very nicely summarized the status of polio world-wide. Unfortunately, I didn't bookmark that site but I think it was the World Health Organization (www.who.int) I will continue to search for that information and pass it on in a future news letter because the information is updated monthly. The remainder of the January meeting centered on what we want to do and accomplish this year. The agendas for the West Metro group were passed out and members were asked to study them and present their ideas at the February meeting.

At our February meeting two new members were introduced so the time was spent telling our polio sto-



ries and explaining the ins and outs of PPASS MN. I passed on pertinent information from the Board of Directors meeting. We've received word from several of our members that winter in warmer parts of the country that they will rejoin the group at the March meeting and we welcome them back to the tundra.

West Metro

By Larry Kohout

January 10th – We started our meeting with the usual check in. We found out the Mary Rongey's husband, Jack, is a pharmacist and he volunteered to assist any of us that my need help in understanding our medications. Our January meeting was devoted to the showing of the video *A Paralyzing Fear – The Story of Polio in America*. The film was made by Nina Gildea Seavey, who was given heretofore unheard of access to the March of Dimes archives in doing her research. Up until this time, the March of Dimes has been very protective of the people and information contained in their archives, but when Seavey presented her plan for the research and the subsequent film, she was granted access.

PPASS has both the film (video tape) and its companion book in our library and they are available to both chapters and individual members. The film, as might be gathered by its title, focuses on the fear that the disease polio generated during the 20th century. Because the mechanism of transmission was not at all understood by the public, the disease appeared to be very random and therefore even more fearful.

There are a number of Minnesota connections shown in the film. Among them, Dave Kangas who used to belong to the group that was in St. Paul and has subsequently moved to Duluth, Dr. Richard Owen, and Marilyn Rogers. There were also several other Minnesota people interviewed.

The film also highlighted all those polio associations of the '30s, '40s, and '50s like closed summer swimming pools, closed schools and fairs, March of Dimes collections canisters in the theaters, and the ever present polio poster child. It also detailed the development of the two polio vaccines and the near hysteria when the announcement was made that the Salk vaccine was safe and effective.

However, immediately after the announcement and the beginning of the inoculations a horror story broke. Kids were contracting polio from the vaccine.

Cutter laboratories in California were doing an inadequate job of "inactivating" the virus and people were being inoculated with a virulent form of the virus. The incident caused 10 deaths and 192 cases of paralytic polio. Supposedly, the incident was the result of not following the vaccine protocol.

Following the introduction of the so-called Salk vaccine there was a real push to get everyone vaccinated in the 1956 to 1960 time frame. In 1961, the Sabine oral polio vaccine was introduced making vaccination much easier, no one had to endure the needle. However, because so many in the US had already received the inactivated Salk vaccine, Dr. Sabine had to go to Russia in order to conduct the double-blind, placebo controlled studies on his vaccine. But with its introduction here, once again, people lined up and vaccinations commenced.

February 14th – Since our regular meeting fell on Val-

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Chapter Happenings

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entine's Day we were treated to a big heart shaped cherry chocolate cake and apple cider. During our meeting check-in one of the members brought up a new food preparation method he'd found.

There are a couple of different places like this in the Twin Cities, this writer mentioned going to Let's Dish (<http://www.letsdish.net/>). These places do all the grocery shopping, initial food preparation, and have things set up at industrial kitchen food preparation stations with a recipe mounted in a prominent place on the station. You go to the station line a crock with a plastic bag and proceed to follow the recipe, putting one item after another into the plastic bag. Sometimes a recipe will require food to be put into two or even three bags and then the whole is sealed and the pre printed cooking instructions are affixed to the outside of the bag. Each entrée feeds six people. They allow you to divide an entrée in two (or even into three if you can re-portion a recipe in your head). Be-

fore you arrive, you choose a time and select between 8 and 12 entrees so that they have the required quantities of food ready when people get there. The beauty is that you can adjust each recipe to your own tastes with the spices and seasonings as you prepare it. When you are finished, you take everything home and put it in the freezer. Our trip yielded 24 entrées from the basic 8 entrées we chose for \$125. We found it a lot better than TV dinners and every bit as easy to put on the table.

The focus for our February meeting was the "Emotional Fallout of Polio." We had a group discussion focusing on some of the things we remembered about emotional impact of having had polio. One of the most telling comments of the meeting came at the beginning when one of the members told of going to the doctor and being told that s/he had PPS. No, s/he replied, you're wrong, I don't have that. Members that were very young at the time of being hospitalized talk about an on-going feeling of abandonment and a fear of being left alone. Someone talked about not wanting to go off

to school and realizing it was because s/he was afraid that the family might not be there when s/he returned.

There was also, once again, a clear realization that there is a difference in the way that people experienced things, based on their residual disability. Those that were left with significant disabilities at the outset, who had little significant recovery, mourned their losses at that time. As a result, PPS has been less of an adjustment for them but rather a matter of more of the same. While people who experienced significant recovery after their acute polio more or less walked away and forgot about it. This has made the adjustment to the losses they have experienced with PPS much more difficult.

One person talked about spending most of her/his life literally running from the polio experience, always having to move as fast as possible to prove something. While another person talked about refusing invitations to join in parties rather than submit to the humiliation of having to be carried into and out of people's homes.



Coming Meeting Dates

By Larry Kohout with Input from chapter Leaders

Brainerd/Baxter

March – Closed for the season, reason, freezin’

April 4th – In the Brainerd public library at 416 South Fifth Street. Meeting is from 10:30 until noon, and anyone that wants to can go to lunch afterwards.

Owatonna

March 17th – in the Library at the senior high rise complex at 2211 Hartle Avenue on the south side of Owatonna – 7:00 to 8:30 -

April 21st - in the Library at the senior high rise complex at 2211 Hartle Avenue on the south side of Owatonna – 7:00 to 8:30 -

St. Cloud

March – Closed for the season, reason, freezin’

April 8th -

Twin Ports

March 21st -

April 18th -

West Metro

March 14th – A panel discussion on Assembling your Medical Team led by Margy Hull and Larry Kohout.

April 11th – Group discussion on the theme – “A Memorable Polio Experience.” This theme has been used before and proven to be very popular. We’ve had many a good laugh as well as shed a tear or two.

One Psychologists Perspective on the Polio Experience:

Part 17

Mindfulness – Patience

By Margy Hull, Ph.D

Editor’s Note – The first 12 essays in this series were originally published in the *Atlantic Tide* Newsletter of the Atlantic County New Jersey Post Polio Support Group. The 13th and subsequent essays were written specifically for *PPASS Times*.

For the last few times, we have been looking at six different aspects of mindfulness, as described by Jon Kabat-Zinn in his book, *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness*. Again, he describes mindfulness as both a kind of meditation and a way of living our lives. He has learned that the discipline of this way of being has been very helpful for people suffering from chronic pain and disability.

This time we will be considering the aspect of patience. My computer gives this definition: “the capacity to tolerate delay, trouble, or suffering without becoming angry or upset”. My first thought was that this is something we polio survivors have learned the hard way during our initial recovery from acute polio, and we ought to be pretty good at it. (The anger and upset may have been there,

but often underground.) My pastor back then told me to say over and over “Every day in every way, I am getting better and better”. I did that, when my Dad reminded me, and damned if it didn’t work. Time alone, and the miracle of the body’s immune system and other restorative mechanisms, did a lot to help us recover. Add to that our hard work, various therapies, and in some cases, surgical intervention and significant improvement occurred for almost all of us. So we know firsthand the value of patience.

But with our new post polio symptoms, will that kind of patience be helpful? They’re telling us hard work is no longer in vogue for us; and we can “conserve to preserve”, but “getting better and better” is not what it’s all about these days. So what’s the payoff now? What should we be patient for?

There is a dimension of patience that makes sense as being essential for learning to live mindfully. To practice mindfulness meditation, you must be prepared for the intrusion of extraneous thoughts and feelings, and the more you fight against them, the more insistent and intrusive they become. It is only through thinking of meditation as a process that unfolds

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One Psychologists Perspective

(Continued from page 13)

over time that you can relax into it and learn to focus on the present moment. I realize now that an important part of patience is that awareness of being in time, and that our experience is continuously in a state of flow with twists and turns and ups and downs.

When living mindfully, moments of pain are moments of pain. There may be moments of pain that seems unbearable, followed by moments where it's nagging in the background, followed by moments where pain is hardly discernible.

These moments are mixed up with other moments of beautiful music and laughter and worry about the bills. They "capacity to tolerate trouble or suffering" comes at least in part from experiencing it as one thread in the fabric of our lives.

The other area where patience is called for, "to tolerate delay", comes often for us as polio survivors. Here again the dimension of time seems relevant. A line from a hymn, "God gives us his fruit in due season," has kept popping into my mind as I have been preparing this article. Knowing the seeds have been planted, waiting for the fruit to become ripe, having a mindful awareness of the processes that

are taking place beneath the surface: this works for me when I think about that wait for pain medication to kick in, Metromobility to arrive, or retirement or other benefits to come through.

Another metaphor about time comes from cooking. Putting our cooking pot to simmer on the back burner as we wait for the flavors to mix: this works for me in waiting for assistive devices to fit and work right, especially if I can add a spice here and there or drain off some of the fat. That patience to let the pot simmer comes in even more when it comes to finding a new way of life after post polio symptoms surface or in retirement. Those we love need time to get used to the changes in us, and figure out what changes they need to make in adjustment. And we need the patience to give them and ourselves that time. It takes time to find the right pace, the right combination of activities, the right shifting of gears from "what I'm gonna do next" to "what does life have to offer me today".

So just as our patience saw us through all that hard work in our initial recovery, may it now lead us to a way of living where time is of a different essence, one of mindfulness.



2005 Membership Forms

By Larry Kohout

While I was very delinquent in getting this years membership forms to the printer, the printer and the post office managed to hang on to most of the forms for the better part of February. However, they should all now be printed and mailed. If you have not seen your 2005 membership form something has gone wrong. Do not wait, get it figured out. Get in touch with the PPASS MN office and let us know you did not receive a membership form in the mail.

Also, get the form signed and sent in. In the past you secretary has played Mr. Nice Guy and carried people all the way to the end of the year even if they had not sent in that years membership form. At the last Board of Director's meeting, it was decided that members must have their forms completed by mid year. So PLEASE complete your form and send it in now while you

are thinking about it or you may find yourself swept off the membership rolls. Remember you must complete a membership form each year.

If you are a current member (and you are if you are getting this newsletter) and there are no address or phone number changes, **all you have to do is sign the form and send it back to us.** It is also perfectly acceptable to have someone else sign the form for you, as long as the form gets signed and sent back indicating your intentions.

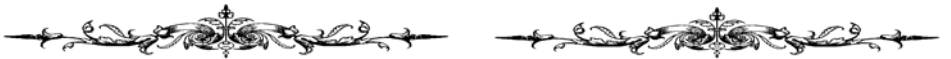
Those of you who have already sent in your forms will see "Member" printed next to your name on your mailing label. I have processed all forms received through March 8 and that is reflected in the address label.

PS – This isn't to say that we wouldn't like your membership dues. Your editor seems to fill up pages with ever issue and that costs money to print and mail, to say nothing of the other programs your organization is trying to run in your behalf.

PHI Awards Research Grant To Johns Hopkins

On January 27, 2005, Post-Polio Health International awarded a research grant of \$25,000 to a team from Johns Hopkins University. The researchers propose to determine whether early use of noninvasive positive pressure ventilation (NIPPV) prolongs survival in patients with amyotrophic lateral sclerosis (ALS) and to relate their findings to other neuromuscular diseases including polio and its late effects.

Unfortunately, do to lack of space we couldn't get the whole article in this issue but will cover it in full in the next issue



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PPASS Times

Newsletter of the Post Polio Awareness & Support Society of Minnesota

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