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Editor's Notebook -

First of all I extend my apologies for being derelict in my duties of publishing the postbox newsletter. I just didn't have time as the lazy, hazy days of summer challenged me with outdoor activities.

Now, I'm back to near normal and as I scanned my file I didn't find a heck of lot in my postbox file to write about. Such is the dilemma of a burnt out writer even with 41 years of experience working in the craft. However, Blenda has been snipping, sniping, and saving a few items in anticipation of the day that I rise to the occasion.

Think about this for a second...I always consider the postbox as my own publication, but in fact its yours. SO, why don't you send me something to include in the magazine? Write a letter about your activities, a poem, or give your opinion on something. It's not as difficult as you think and you'll get a personal high from the experience.



Congratulations to **Lloyd and Inga MacPherson** who celebrated their 50 years of wedded bliss on October 15. The MacPherson family and friends attended a come and go tea party on October 11 at the Rotary Centre on Elphinstone St.



Our deepest regrets and sympathy to the family of **Carol Biberdorf**, whose father, James Milton Ritchie of Regina, passed away suddenly on

September 13, 1998 at age 83. Carol's mother passed away in January of this year.



Our condolences to the family of **Margaret Jane Mainprize** of Weyburn who died on September 7, 1998. She was 80 years of age. Predeceased by her husband, Herb, she is survived by three daughters, one son and 10 grandchildren.



Many of our members knew Margaret, a polio survivor who was fairly active in promoting various causes to help disabled people. She was a member of Polio Regina but unfortunately wasn't physically able to attend meetings, but she got our information and passed it on to others at every opportunity.



Important changes of address:

Maurice and Virginia Denzin have moved to town, sort of. Although they are still maintaining their farm residence at Craven, the couple now reside at 2836 Rothwell St., Regina. S4N 2E5. The telephone is the same: 775-2821.



Allan and Georgina Heselton have moved to White City and can be reached at the same telephone number: 586-8699. Postal code is SOG 5B0.

Polio Video available

A Paralyzing Fear: “The story of polio in America”

A 90-minute documentary film which was shown in early October on PBS television is available by contacting Fred Ramsay.

The show is 90 minutes followed by a half hour studio discussion with experts on Post Polio Syndrome. It also discusses the on-going plans for world-wide eradication of polio and the future of vaccination for children.

The film tells the story of the disease from the outbreak of the first major epidemic in 1916 through to the discovery of Salk vaccine in 1955 and beyond. Alternating between archival film and interviews with survivors, the movie addresses the affects of the disease which had North America living in terror for years.

The film is about the strength of people who survived polio and how they coped with the disease on their own terms.

One copy is available in our Polio Regina library and additional copies will be made on request for a nominal cost. See Fred.



It's not me... It's my shoes!

By Hilary Hallam

The following excerpt was written by Ms. Hallam of the Lincolnshire post polio network in England. Hilary has found a delightful way to help us accept the nasty affects of post polio syndrome:

It's not me that has the problem...it's my shoes! My walking boots use to do nine miles three years ago, but they tell me now that they only want to keep my feet warm in bad weather.

My dancing pumps are nearly as bad; they should go all night long, discoing the night away. Now after one disco dance, where I barely move my feet, they start complaining and ask me to sit down again.

My flip-flops tell me they get so cold now they want me to wear thick warm socks to help keep them warm.

My flippers and ice skates have left me a note to say they have left home...but I think they are together up in the attic. Goodness knows what they are doing up there.

My trainers, well, they complain and moan if I use them too much, but you should see the smile on their little faces when I get on my scooter...great big grins, they sit up front looking out on the world and smile to all who pass.

Oh, and I forgot my walking boot socks...they seem to be happier now. They tell me they used to hate it inside my boots where it was dark, hot, sweaty and their fluffy bits were squashed. Now they can see the world and keep their fluffy bits fluffed as I wear them to walk around the house. They love keeping my toes warm as toast.

So you see folks...it's not me that can't do what I used to do...it's my shoes...but they do seem happier now that I have understood them.

Vaccine leaves child with polio

Excerpt from Daytona Beach (Fl.) News Journal, July 1998

Michelle Ceballos doesn't hold her daughter like most mothers. The Orlando mother carries 10-month-old Ciara on a pillow rather than in her arms. The braces around Ciara's body and legs make it awkward to carry the infant in a traditional manner.

Ciara wears braces because she contracted paralytic polio from an oral vaccination designed to protect her from the disease. Polio, virtually unknown in North America for two decades, is a viral infection that can produce permanent muscle weakness, paralysis and other symptoms.

The virus, which kept all parents fearful until Dr. Jonas Salk developed an injectable vaccine in 1955, starts in the intestinal tract and travels to the brain and spinal cord.

When Ciara received an oral vaccine in December, the then two month old baby had a one-in-750,000 chance of contracting the debilitating disease. While the injected vaccine developed by Salk carries no risk of infection, oral vaccines are now more popular and commonly used in North America.

Oral vaccines are the only vaccine than can leave a child with severe and permanent neurological defects. They gained favor after their invention in the 1960s because of what doctors call "herd immunity" or the tendency of the vaccine's protection to be passed from child to child. The immunization is spread through local oral contact, a common way for germs to travel.

Ciara's mother said her doctor did not give her information about the difference between the two vaccinations except that one was oral and one was a shot. She was not told about the risk of oral vaccine. "It's kind of like giving Ciara a gun with

749,999 blanks and one bullet," Michelle Ceballos said.

The Ceballos declined to name or comment on the doctor who administered Ciara's vaccine. They have gone public with their story to let other parents know they have a choice. She and her husband want to educate doctors that they must discuss the two vaccine methods thoroughly with parents.

The debate

The oral vaccine that gave Ciara the disease is a pink liquid given to infants through a dropper on four occasions. It contains a weakened live strain of the disease which can mutate and infect the recipient of the vaccine. The risk of contracting polio diminishes after the first dose.

The injectable vaccine, or inactive polio virus, is administered to infants in four shots on different occasions. There is no risk of contracting polio because the shot contains a killed strain of the virus.

So why use the live vaccine?

Each vaccine has its advantages and risks. With the oral dose there's the minute risk of getting polio at the time of vaccination, but it also provides community protection.

When polio was a common disease, doctors embraced oral polio vaccine for its ability to immunize the unvaccinated through contact between children. Makers of the drug still tout the "herd immunity" benefit because it protects many low-income children who have not been vaccinated.

The oral vaccine also reduces the number of injections a frightened and scared infant has to receive; is cheaper than injections and creates less medical waste such as syringes and needles.

Still, some health professionals question using oral vaccine and putting the child at risk when both vaccines prevent wild polio from taking hold in an individual.

When a person swallows the weakened live virus in the oral vaccine, it goes into the intestine - like wild polio. If the person comes in contact with the wild virus, the virus protects the individual in two ways: by stimulating the production of antibodies and by preventing the wild polio from "setting up shop" in the body.

The Centre for Disease Control in Atlanta has recommended that doctors give children two injections followed by two doses of oral vaccine. After two injections, the risk of contracting polio from the oral vaccine is lessened. This recommendation was made after much debate and represents a compromise.

Comments from Barbara Goldstein

Florida East Coast Post-Polio Support Group:

"Well, I've been "preaching" for the past number of years about giving the (injectable) Salk vaccine and **not** the (oral) Sabin vaccine to babies... The doctor told the mother there were two types of vaccines, but **never** told her there was a slight chance that baby Ciara could contract polio."

"I spoke with Ciara's mother today (July 20) who told me that Ciara's bones are so brittle that her left leg was broken during a therapy session and she has to wear a cast on that leg for several months".

"I plead with you: *tell every young mother you know, every grandmother, every pregnant woman, that they must insist their baby be given the Salk (dead) vaccine*".

You're Never Alone

by Margaret Neyton, Angelgate, Dublin

You're never alone, you've an angel
Although it may seem far away
Somewhere up in the sky, above where the clouds fly
But that's where they come from, not where they reside.
You just have to call them to be by your side
'Cos you're never alone, you've an angel.

You're never alone, you've an angel
(At least one, if not two or more)
Just ask them a question, await the reply
Through TV, the post, or in bed where you lie
Asleep, deep in dreaming, and when you awake
Your reasoning, trance-like, your head needs a shake
Make the first thing you do upon waking each day

To record your dream travels and see what they say
They may be a message sent down from above
To help you, to guide you, to fill you with love.
Cos you're never alone, you've an angel.

So if you feel lonely, or if you feel blue
There's an angel beside you to help you, it's true.
Cos you're never alone, you've an angel.
Now open your heart up, it's waiting for you.

Report on Aging Says

Keep the Mind Busy

A report on the Internet by Lucille S. DeView of the *Orange County Register* entitled “Keep mind in shape to age successfully” urges that we should stay mentally alert, to read books and to keep the mind busy. In addition, learn new computer skills. “Don’t merely sit and stare at the TV.

These tips are part of a book called “Successful Aging” that was co-written by Robert L. Kahn, professor of psychology and public health at the University of Michigan, and Dr. John W. Rowe, president of Mt. Sinai Hospital and School of Medicine. Some of the ideas urged by the two are that “regular exercise, weight training in particular, is the most important factor in sustained health for people over 65; and that “Nature is forgiving; it is never too late to benefit from positive changes in your lifestyle and habits.” (from *Polio Epic* newsletter).

The Questioning Mind

- How do you know when it’s time to tune your bagpipes?
- What was the best thing before sliced bread?
- What’s another word for thesaurus?
- Why did they spell phonetic like that?
- Do they have reserved parking for people without disabilities at the Special Olympics?

Post Polio Syndrome: *The Phoenix Affliction*

According to Egyptian mythology, the Phoenix bird rose out of the ashes to live anew. This parallels in some respects the renewed symptoms experienced by former poliomyelitis survivors. From paralytic manifestations that had long been dormant, polio survivors began to experience elapsed symptoms. Not only were there reoccurrences of muscle pain, but some survivors also began to notice limited mobility. Although years had passed since the original paralytic onset, many survivors felt that resurrected symptoms might in some way be attributed to their prior illness.

Although the reoccurrence of weakness symptoms in polio survivors had been under study more than 100 years, it has only lately received medical recognition as a syndrome. The sudden onset of various symptoms seemed at first to have baffled physicians. Some confusion could be attributed to the lack of prior information in medical school curricula on the acute and secondary stages of poliomyelitis. Thus many healthcare providers were unable to correctly diagnose the symptoms.

Polio survivors' complaints received a wide range of misdiagnoses (hypochondria, depressive disorder, arthritis, etc.) to account for the sudden lifestyle changes. This often forced patients to undergo unnecessary testing, and in some instances, incorrect treatment. Some confusion in correctly diagnosing the syndrome may have resulted from the lack of terminology in assessing the wide range of symptoms. Finally, residual complaints by more than 650,000 world-wide polio victims provided the need for further research and analysis.

PPS documented in 1875

Post Polio Syndrome was documented in 1875 by several physicians in Paris. It was reported the new or dormant stage can occur 10-15 years after the acute infectious phase. Early studies of post poliomyelitis deterioration were reported in the *Journal of American Medical Association* (1915) and subsequent studies reported possible fatigue due in part to muscle overuse.

Current research hints that PPS symptoms have also been referred to as post polio muscular atrophy.

Medical research and science has responded by undertaking numerous projects to better understand the syndrome.

Just as important has been the post polio survivors own grass roots effort which has provided support from an advisory network on local national and international levels. The network and support groups give survivors information and provide meetings which often result in opportunities to obtain recommendations and exchange ideas. More importantly, the meetings strengthen their knowledge that they are not alone.

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