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Please make cheque payable to: **Polio Regina Inc.** and mail this application form and cheque to:

Polio Regina Inc.
825 McDonald Street, Regina, Sk. S4N 2X5

(Official receipt of donation for income tax purposes will be mailed.)



Editors: Blenda &
Fred Ramsay
Phone: 543-6380

September 2002

Polio Regina Incorporated 825 McDonald Street, Regina, Sask. S4N 2X5

When Blenda and I sat at the kitchen table planning this issue of Post Box we realized there were a lot of things happening in Polio Regina this summer. We held our annual picnic at the Rotary Senior Centre in June; had a special visitor from the Ontario March of Dimes organization; sent flowers, fruit baskets and cards to several members and made personal contact with members. Some of that information is contained in this edition of Post Box.

The bulk of the information in this issue of Post Box comes from material forwarded to us by Dr. Mavis Matheson, our librarian and from Internet websites (just click on "Polio"). The struggle for us was to edit and reduce the information to fit into our booklet. The interview with Dr. Richard Bruno, for example was cut in half. We could have easily filled 100 pages with internet stuff.

Just before this publication went to print, we learned from Dr. Mavis Matheson that Dr. Bruno will be featured on **Canada AM** on September 30 or October 01 and will tape a documentary for a **Discovery Canada** program to be shown this Fall. Watch for these programs. Have a great day! *F & B*



March of Dimes visitor to Regina

Kim Dowds, Ontario March of Dimes, Manager of Post Polio and Conductive Education Programs, was in Regina last month and met with 15 members of Polio Regina. at the Ramsay's backyard. It was an informal

The goal of educating every polio survivor and doctor may be ambitious but it is doable with the help of the media, governments throughout the world and polio survivors mailing The Post-Polio Letter to their doctors. But all of this must happen now. Since research has shown that motor neurons are actually dying in polio survivors who have increasing muscle weakness, polio survivors have no time to waste!

Dr. Bruno's book, *The Polio Paradox* was published in June 2002 by AOL Time Warner, costs \$25.95.

Conserving Energy: *Your key to better health*

It takes time and effort in order to use energy conservation to your greatest advantage. It is important to have the right attitude. There are times for different kinds of tasks to be done, and other times when you have to be willing to do a job less thoroughly than usual in order to have the energy to spend on your family or friends.

Try to accept the things you can't change and minimize the frustrations you face. Don't expect the impossible because even with a good plan, there will be setbacks. Work-simplification is an important tool to use in reaching your daily and long-term goals in life.

Remember: *using your energy to best advantage* will allow you to do more and better.

Upcoming Events:

Our next meeting will be held on Thursday, **October 31 @ 7:00 in** Salon A & B on second floor of the Wascana Hospital.

November meeting will be November 28.

Annual Christmas Banquet will be December 7 at the Eagles Club.(Same place as last year.)

Paradox Lost

*Dr. Richard Bruno, Director, Post-Polio Rehabilitation and Research Service
at the Kessler Institute for Rehabilitation, New Jersey*

Patty slowly limped into my office leaning heavily on a walker and collapsed into a chair. Small and slender, black hair framing a pale face showing fatigue, pain, fear and anger, she looked much younger than her 58 years. She fixed me with her dark eyes which filled with tears as she said, "I don't want surgery, again!"

She explained that during two long years she had had the proverbial "million-dollar work-up." Her family doctor started with the standard blood tests. When all results came back negative, Patty was shipped off to local specialists where the exotic testing began. The new test battery read like a Wall Street ticker: ACE, ANA, ANCA, MMA, PE, RPR, SPEP. When these results, too, revealed no physical illness, Patty was asked the inevitable question:

"Do you think you're depressed?"

"Of course I'm depressed," she told the doctors. "I'm exhausted all the time. I can't stay awake during the day, but I can't sleep at night. I have trouble swallowing. My legs burn and aren't strong enough to take me from one end of the house to the other. And my low back always hurts."

Ah! Low back pain. Now that was something the doctors could deal with. So Patty began a new round of studies with a new batch of specialists and — Eureka — they found something! Patty had a herniated disc in her neck. Excited by finally finding something abnormal the doctors sent Patty to the most prestigious university teaching hospital in Manhattan. There she underwent painful studies reminiscent of tests performed on her when she had polio: a spinal tap and a myelogram. A neurosurgeon suggested removing the disc, in spite of the fact he stated that it did not explain her exhaustion, trouble sleeping, swallowing and walking — or even her low back pain.

Not one of nearly a dozen doctors took into account the simple fact that Patty had had polio. "I told them all," she said. And, sure enough, in each and every doctor's

Q. Why is it that doctors today don't know the facts about polio?

A. Actually, lots of doctors during the epidemics didn't know the facts about polio. There is a very painful paradox that frightened parents and polio patients: Polio survivors were often told when they first entered the hospital that they would die, but they didn't; they were told they would need an iron lung, but they didn't; they were told they would never walk again, but they did.

Q. Why would doctors have told parents their children would die and not walk?

A. There's a question I can't answer. Maybe in the 1940s doctors hadn't seen enough polio survivors to know what the outcomes were going to be. But by 1950 they should have known better and not predicted such a frightening future. At worst about 15% of polio patients died, while most recovered significantly and many walked within a year of leaving the hospital.

Q. You said there is another paradox about predicting polio survivors' futures.

A. Again, there are several. The first is that The March of Dimes and their "Poster Children" created its own paradox. The very campaign that raised money to pay for polio survivors' treatment caused them to become social pariahs, made people fear and sometimes hate anyone who looked like they'd had polio. Another paradox is that polio survivors who were told they would never go to college or get a job went on to college and became the world's best and brightest. And, of course, there is the ultimate paradox: The super Type A lifestyle that was so well taught and so well learned — the very way of life that polio survivors believed allowed them to escape being pariahs, appear "normal" and re-enter society — is itself the cause of the overuse/abuse that has beaten up polio-damaged bodies and triggers PPS.

Q. Why is it so hard for polio survivors to be less Type A, to take care of themselves and to treat their PPS?

A. Our clinical experience and research says it's because polio survivors are scared to change. Polio survivors discuss in the book their belief that Type A behavior prevented further abuse. But our research and clinical experience at The Post-Polio Institute show that fear of changing Type A behavior prevents polio survivors from moving from the "use it or lose it" lifestyle that they were taught to the "conserve to preserve" mode that is required to treat PPS. A related paradox is that polio survivors — whose abuse by the medical establishment caused a lifelong aversion to

There is no question that the PPS are real and that there's no more time to waste in treating them. At least half of North America's estimated 1.8 million polio survivors are in their 40's, 50's and 60's, at the peak of their careers, the apogee of their lives and are watching as new symptoms cause their ability to work and function ebb away. This need not happen! After two decades of research we know why polio survivors are having new problems and we know how to manage them.

Did You Know?

Although Rotary clubs develop autonomous service programs, all Rotarians worldwide are united in a campaign for the global eradication of polio. In the 1980s, Rotarians raised \$240 million to immunize the children of the world; by 2005, Rotary's centenary year and the target date for the certification of a polio-free world, the **Polio Plus** program will have contributed \$500 million to this cause. In addition, Rotary has provided an army of volunteers to promote and assist at national immunization days in polio-endemic countries around the world.

Hello letter from Maple Ridge, BC:

I just received your newsletter and was delighted to find PPASS' 8-page insert/handout enclosed. You are welcome to reprint articles from PPASS News, provided that their source; i.e., PPASS News, is acknowledged. Our 8-page insert was put together by PPASS members and, as you can see, there is no mention of PPASS anywhere in your copy so their effort goes unrecognized. When we use someone else's article(s), we always include recognition of their source. I would appreciate it if you would recognize PPASS News as the original source of this handout in your next newsletter. Many thanks, Jennie Bedford, PPASS News Editor. P.S. Keep up the good work. The colour photographs are excellent.

Our profound apologies to the Post Polio Awareness & Support Society of British Columbia for our failure to mention them as the source of an eight page handout which we distributed to our members with our last Post Box Newsletter. We thank the members that were involved in putting together such a well-written and informative article. Our members appreciated the information.

the cause and treatment of PPS. And, maybe most importantly, I could tell polio survivors' stories — from the day they got polio to the moment they recognized they had PPS and realized that they needed to change their lives because of new symptoms.

Q. That sounds like a tall order. So what is the book? A history of polio? An explanation of PPS? A memoir of your 20 years of studying and treating PPS?

A. Well, I think the book is all those things. It has always amazed me that polio survivors know nothing about what the poliovirus did to their bodies to cause their initial symptoms, or what's happening inside now to cause PPS. To tell about all that, I went back and reread everything I'd read about polio and PPS. Then I read everything I hadn't read.

Q. How much reading was that?

A. More than 1,200 books, scientific and medical journal articles, symposia and discussions, personal documents, laboratory notes and letters. I wanted the book to be an "owner's and operator's manual" for the post-polio body. But the book isn't just the body's nuts and bolts. It's also an exploration of the psychology and sociology of America's — the world's — response to polio and polio survivors. It's an expose' about the institutionalized abuse of children with polio by the medical profession. And it's a medical mystery.

Q. What do you mean by an expose' of institutionalized abuse?

A. I think most polio survivors know that in our five International Surveys of over 3,500 people, polio survivors on average report 30% more Type A behavior — being hard-driving, time-conscious, driven, self-denying, perfectionistic and overachieving — than do individuals of similar age, gender and income who do not have disabilities. Since we thought early experience might have made polio survivors more Type A, our 1995 Survey asked what happened to people after they had polio, how they were treated by medical professionals, family, and members of the community. We found that polio survivors experienced 34% more physical abuse and 94% more emotional abuse than their non-disabled peers; all of that additional abuse was the result of being disabled by polio. In the book, polio survivors describe their experiences of abuse, both in the hospital and when they returned home.

Medical Clinic:

We understand there is a medical clinic that has opened up in Regina at 1689 Dewdney Ave. E. and they are receiving new clients They are open Monday-Friday 9-7 pm; Saturday and Sunday from 12-5 pm. Phone 789-8816 for an appointment. Thank you to Verna Copeland for giving us this information.

Benefits from the Canadian Paraplegic Association (Saskatchewan) Inc. include:

- * Vehicle Registration Rebate Program
- * SaskTel Mobility Cellular Phone Benefits
- * Lottie V.M. Teale Scholarship/Bursary

Contact Regina Branch Office, 210-4401 Albert St., Regina Phone (306) 584-0101

Saskatoon Head Office, 3-3012 Louise St. Saskatoon Phone (306) 652-9644

Items for Sale:

* One 4-wheel walker in new condition with bicycle brakes, a basket, a tray and seat. Price \$300.00.

* One 4-wheel walker in new condition, with pressure brakes, a basket, and a seat. Price \$300.00

* One four wheel walker in very good condition, with pressure brakes, a basket and a seat. Price \$200.00. Please phone Ed at 761-0853, Regina.



“Winning the Prairie Gamble” The Saskatchewan Story 1905-2005:

The museums are searching for artifacts such as crutches, artificial limbs, Emerson Iron Lung or any symbols of the devastation caused by Polio. Janet Mackenzie, Project Manager, Western Development Museum, Saskatoon is looking for anything that would tell the polio story. New permanent exhibits will be created at Moose Jaw, North Battleford, Saskatoon and Yorkton. If you have anything to contribute, please call Blenda (543-6380) and I will pass on your information.

visit and she talked about trying to organize the National Post Polio Network that is funded by the Ontario March of Dimes. One of the things they would like to establish is National Polio Awareness month or week, which would happen



annually. They plan to set up a web page with links to different groups. Polio Regina could be linked if we wanted. Someone would have to be in charge of keeping it up-dated. General communication will involve a member from each support group across

Canada, communicating through a “chat line” two or three times a year.

Some services the National Network would provide include:

Polio Survivors Registry - Polio survivors who join the Polio Survivors Registry receive a comprehensive information package on Post Polio Syndrome, along with a free subscription to Ontario March of Dimes newsletter, local chapter newsletters and bulletins on news and events.

Health Care Professionals Registry - Education to the health care community is a very important part of the program. You can ask Ontario March of Dimes to send an information package to your doctor and other health care professionals.

Education and Information - Education is the core function of the program. In addition to distributing information to people who join the registry, Ontario March of Dimes also offers a full library of information on the Late Effects of Polio and Post Polio Syndrome.

Conferences - Ontario March of Dimes organizes conferences, seminars and workshops on the Late Effects of Polio and Post Polio Syndrome.

Please let your Polio Regina executive know if we should become involved.



Saskatchewan Drug Plan Changes:

Changes to the Saskatchewan Drug Plan took effect on July 1st:

The semi-annual deductible of \$850 will be eliminated. The Drug Plan coverage is being changed to provide a consistent level of benefits to all families. This means assistance for prescription drug costs in excess of 3.4 per cent of total family income.



Generally, families with incomes of less than \$50,000 will not have to pay more.

Approximately 100,000 families who currently receive Drug Plan benefits will not be affected by the change. About 11,000 families with higher incomes may pay more for prescription drugs.

Families who are affected by this change and whose family prescription drug costs are greater than 3.4 per cent of total annual family income, are encouraged to apply for financial assistance through the Drug Plan Special Support Program.

Special Support applications are available at pharmacies across the province or on-line at <http://formulary.drugplan.health.gov.sk.ca>.

The public may also contact the Drug Plan toll free at 1-800-667-7581 or, in Regina, at 787-3317. For more information, contact: Myrna Stark Leader, Saskatchewan Health, Regina. Phone: (306) 787-4083

report was the same sentence: “History of childhood polio.”

Even if Patty hadn’t told them about the polio it was obvious. Just by watching her walk it was clear that her left leg was much shorter, smaller and weaker than her right. I asked how her odyssey of doctor visits and medical tests had begun. Patty sighed and said, “I told the doctor my legs felt weak.”

Leg weakness and burning muscles. Exhaustion. Trouble sleeping and swallowing. and, of course, back pain.

How many polio survivors like Patty have I seen during the past 20 years? How many patients have come to The Post-Polio Institute after having the million-dollar work-up that found “no medical cause” for their symptoms? How many polio survivors around the world had been turned away by doctor after doctor, being told that their symptoms were the result of depression or “all in their heads?” The answer is tens of thousands.

Patty’s experience made me realize that polio survivors are caught in a paradox:

Polio was thought to be a “stable disease.” Once polio survivors recovered muscle strength after the polio attack their physical abilities were supposed to remain for the rest of their lives. Now, polio survivors’ strength and abilities were ebbing away.

Patty’s exasperating, exhausting and hurtful experiences with doctors revealed a second painful paradox:

In the 1980’s, doctors were ignoring and rejecting the same polio survivors whose plight had riveted the attention of the world’s medical community and spurred it to action just 30 years before.

It’s unacceptable in the year 2002 that polio survivors like Patty are being forced to run such expensive, painful and unproductive medical gauntlets. With 20 years of medical journal articles describing new symptoms called Post-Polio Sequelae, no polio survivor should be told by doctors that overwhelming fatigue is “just a symptom of depression,” that muscle weakness is “all in your head,” or that they don’t “believe in” PPS.

doctors — must now return to hospitals and put themselves in the hands of medical professionals to help treat and manage their new symptoms.

Q. This must be terrifying for polio survivors, especially those who have been abused.

A. It is terrifying. That’s why nearly 20% of polio survivors who come to The Post-Polio Institute refuse treatment or quit. It’s too frightening for many polio survivors to be in the hospital again, or to do for themselves and say no to others — and especially to appear more disabled by using crutches or a brace and especially a wheelchair.

And this fear uncovers what I think is the greatest polio paradox of all. Polio survivors cheated death, conquered disability and dealt with years of severe physical and emotional pain to become “the best and the brightest,” not just surviving polio but thriving and creating extraordinary personal and professional lives. Yet, polio survivors believe that have no survival skills at all, no courage, imagination or internal resources to build a new life — let alone a better one — and survive and thrive with PPS.

Q. I imagine the psychological effects of polio and PPS fill a lot of space in your book.

A. They do. Of all of the many facets polio survivors Nancy Frick and I have studied, this is ultimately the most important. If polio survivors can’t get their heads around dealing with the old polio fears and the new PPS issues, their bodies don’t have a chance. There are separate chapters on the psychological toll of polio — the initial hospital experience, being in a rehab hospital and having surgery and then going home again to have even more therapy and more surgery.

Q. These are incredibly ambitious goal. It’s as if you’re trying to treat 20 million patients.

A. Well, that’s how I feel, not to mention the 10 million people with CFS and ME. But we can’t treat everyone at The Post-Polio Institute. We can only evaluate or treat less than 200 polio survivors a year.

Polio survivors need to take treatment into their own hands and teach interested doctor how to help them.

News About This and That:



Please let us know if you would like any special items or announcements to put in the Post Box.

Polio Regina offers our condolences to Joan McIver on the passing of her brother Allan on May 4, 2002; also to Keith and Jackie Ball on the death of his mother on July 29, 2002 and to Grace and Don Lekivetz on the death of her sister on August 28, 2002.

Blenda spoke with Marion Kenney of Moose Jaw recently and found that they are planning a trip to visit families in Indiana this fall. She also mentioned that her husband, Carl is waiting to have hip surgery. Marion and Carl are long time members of Polio Regina.

Congratulations to proud grandparents Barry & Betty Williams on the arrival of a new granddaughter, Sophia Jane Williams born May 22, 2002.

Annual Christmas Banquet to be held at Eagles Club on Sat., Dec. 7th. Tickets will be on sale at October Meeting.

Thanks! We thank Barry & Betty Williams for sending us a report on their fabulous trip to Australia. A fascinating travelogue but we couldn't publish it this time because of space limitations. We would also suggest their story might be a topic for a presentation at one of our meetings.

Laugh & Splash Swimming classes resume at Wascana Hospital pool starting September. 28 to November 30, from 2-4 pm. Cost is only \$10 for ten weeks for an individual with a disability and **free** for family members and assistants. To register call the Playline at 777-7529 (City of Regina) or drop by to register at North West Leisure Centre, Sandra Schmirler Leisure Centre or the Lawson Sportsplex Centre.

Lindsay Chamberlin from South Sask. Independent Living Centre informed us that the Western College of Remedial Massage Therapy will **not** be able to offer free massages to SSILC members any more. Although it may not be an option, the College will offer massages by students for \$12/hr from Monday-Thursday in the evenings 5-9 pm. To book appointments, call 757-2242.

Q. And how is the book a medical mystery?

A. There are many mysteries surrounding polio and PPS. Why do polio survivors get PPS is the mystery that usually comes to mind first. But there are many other mysteries that people may not even think to ask. Why had there never been polio epidemics until the 20th Century? Why was polio "Infantile Paralysis" in the 1930s and then older children and teens were primarily affected by the 50's. Why were Northern states first hit by polio? Why did so few African-Americans get polio? Why did adults hardly ever get polio? How could someone be totally paralyzed by polio — maybe even be in an iron lung — and then walk out of the hospital and go back to school weeks later? All of the answers to these questions are pieces of the puzzle that helped us explain the cause and find treatments for PPS.

Q. Those are mysteries. But what is the "Polio Paradox?"

A. Again, there isn't one paradox but many, having to do both with polio and PPS. The first paradox is that polio was thought to be a stable disease. Once you recovered muscle strength and physical abilities they remained for the rest of your life.

Q. But we all know now that polio is not stable, that polio survivors develop PPS about 35 years after having polio.

A. Do we ever! And that's the first paradox. What was thought to be stable isn't! Another paradox has to do with the fact that polio riveted the attention and spurred to action the world's medical and scientific community during the 1940s and 1950s. Then, not even 30 years after the polio epidemics, the world's physicians ignored and even rejected polio survivors, refusing to believe their new symptoms were "real."

Q. And this is a terrible problem for polio survivors, that doctors know nothing about polio or about PPS.

A. And what doctors do know is often wrong. How about this paradox? Doctors believe that the poliovirus damaged only motor neurons in the spinal cord, when the poliovirus actually entered and damaged the brain stem first, whether or not it entered the spinal cord. So every polio survivors had "bulbar" polio! And it's brain stem damage that our research has found causes post-polio fatigue, as well as the new problems with swallowing, sleeping and low blood pressure.

The doctor with 30 million patients



*An interview with **Dr. Richard Bruno**
Director, Post-Polio Rehabilitation and Research
Service, the Kessler Institute for Rehabilitation,
New Jersey*

*Written by Vicki McKenna
Excerpt from *A Balanced Way Of Living*
Newsletter 4 April 2002*

A couple of years ago I wrote a book about PPS called “A Balanced Way of Living.” The second half of the book was relatively easy for me to write as it deals with ways of coping

with PPS which include holistic healing strategies very familiar to me as an acupuncturist. The first section of the book however explains in mainstream medical terms what PPS is and discusses ways to obtain a diagnosis and here I felt very much in need of input from someone with an orthodox medical background.

I had read many articles written by different PPS experts and contacted some of these people—most of whom didn’t bother replying. I then came across Dr. Bruno’s web site and e mailed him with some queries. Within a couple of hours I had a cheery e-mail in reply that answered my questions clearly and knowledgeably—obviously from an in-depth background of research into and care of those who had contracted polio.

Over the following weeks and months, as I researched and wrote my book, Dr. Bruno was immensely helpful and to this day whenever I have a query I know that I can happily approach Dick with it and that he will do his best to give me as much help as he can. He also very kindly agreed to become the patron of the Scottish Post Polio Network which I helped to co-found.

I am only one among many, many Bruno fans! There is a whole body of people grateful to Dick who have been helped by his articles, his lecture tours and the

hands-on service he provides those with PPS at his hospital in Englewood New Jersey. In this clinic he offers a comprehensive diagnosis and treatment plan for those experiencing the long term effects of polio.

Many of us would like to know more about this doctor who has done so much for us forgotten survivors of the so called “summer plague” and that thought inspired me to contact the man himself and find out about his new book: *The Polio Paradox*, in which Dick describes his 20-year journey studying the cause and finding treatments for Post Polio Sequelae.

Q. The first question is why you have written a book when you said you never would?

A. Truth be told my agreeing to write a book was a surprise even to me. When Time Warner came to me almost two years ago and asked me to do a book, I said no. I have never had any intention of writing a PPS textbook that no doctor was going to read. And I certainly didn’t want to write a “cookbook” on how to treat PPS.

Q. Then how did the *Polio Paradox* come about?

A. I told a friend that Warner Books wanted me to write a book and that I had said no. She said I was crazy to turn them down. The media power of AOL Time Warner would finally bring PPS worldwide attention. So she asked me two fundamental questions:

“What’s important to you about PPS?”

That answer was simple: my patients.

Then she asked, “What don’t polio survivors know —what haven’t they been told — about polio and PPS that they need to know?”

And I swear I said, “What polio survivors haven’t been told and need to know would fill a book!”

She smiled and shrugged and *The Polio Paradox* was born. I realized, too, that a book would allow me to answer all of the questions my patients ask me about polio. I could summarize in clear terms all the research that we and others have done on