PA Polio Survivors Network

Information and Inspiration
for All Polio Survivors and Their Families

Serving the Keystone State and Beyond

www.polionetwork.org

August 2018

Our Mission:

To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups, Survivor's Families and their Caregivers.

There's a lot happening and we have so much to share.

Join us on September 15th.

Join the fun as we team up with Richard L. Bruno, HD, PhD for a live webcast "The Best of PPS" *and* something completely new. This opportunity is available in the US and Abroad.

Registration Details are on Page 6 and on our website. Register early. We will be posting a "link" ahead of time, so you can make sure your device has the correct software downloaded.

Do you struggle with Arthritis?

Dr. DeMayo answered a question from a survivor, and wrote a fascinating article about this issue. We do have care options. Thank you Dr. DeMayo for introducing a complex topic and explaining it in a way we can all understand.

Unfortunately, Polio Has Really Been In The News Recently.

On the other hand, it is a reminder that this disease we are all so tired of, has NOT been eradicated. Last month, we started a series explaining the differences in the IPV (injectable) and OPV (oral) Polio vaccines. This month, we are explaining the Polio virus(es). So many Polio survivors are unaware that there are more than one. This is a huge part of the reason the eradication effort has been so complex.

And speaking of the eradication effort, Team Survivor 2018 is a marvelous way for us to become part of the solution. Yes, we are survivors of this terrible disease.

Now, we are working together to help end it once and for all.

Team Survivor 2018 has already donated enough funds to vaccinate 1,300 children in the most difficult to reach parts of the world !

We are happy to announce two exciting new ways you can become a part of this fun effort. Your contribution to any of these means that the Gates Foundation additional gift will result in your donation being *tripled*. (Details on page 8).

1. Make a donation to the Rotary Foundation for Polio Plus and you've joined ! Just mail us the check (made out to them). Did you donate through Rotary ? Send us the confirmation.
2. Do you love to cook or purchase gifts for someone who does? For anyone who makes a purchase through a special "link", Pampered Chef will make a 14% donation to the Rotary Foundation for Polio Plus – in YOUR name. This is available until World Polio Day, Oct. 24th.
3. Do you love documentaries? Dare to Dream is the story of how Rotarians had the enormous vision to become the heart and soul of Polio Eradication. When you use the promo code "Team Survivor", you can purchase this film (for a significant discount by download only) for $10.00. For every Team Survivor purchase, with the Gates Foundation additional gift, approx. 34 children will be vaccinated against this crippling disease.

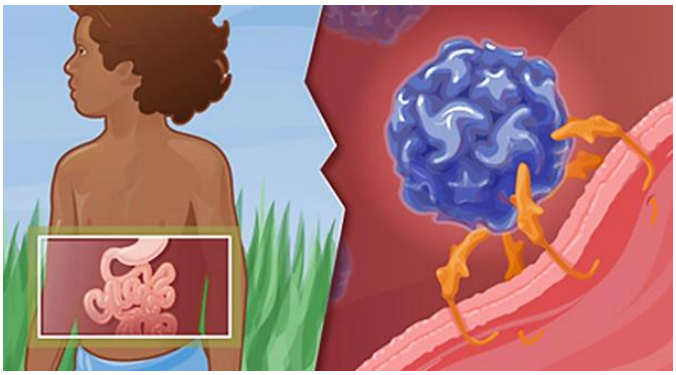
We always love to end our newsletters on a positive note.

Thank you Post-Polio Health International

The Polio Virus(es). What's the Difference between them?

(The OPV and IPV vaccines were covered in our July, 2018 issue)

Polio Is Caused By A Human Enterovirus Called The Poliovirus.

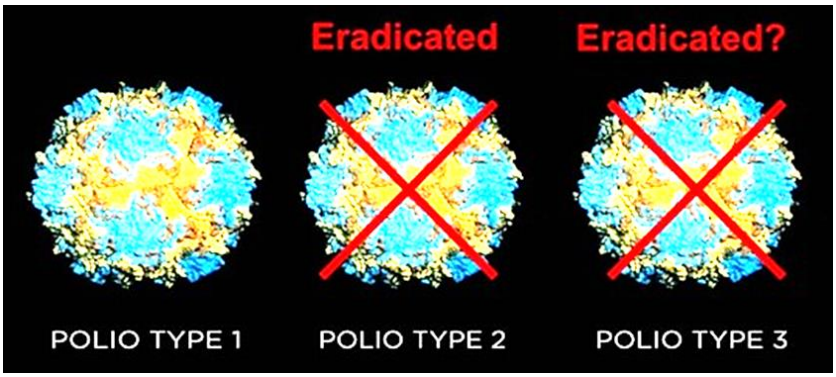


Polio can interact in its host in two ways:

- Infection not including the central nervous system, which causes a minor illness with mild symptoms
- Infection including the central nervous system, which may cause paralysis

Less than 1% of poliovirus infections result in paralysis. The virus is most often spread by the fecal-oral route. Poliovirus enters through the mouth and multiplies in the intestine. Infected individuals shed poliovirus into the environment for several weeks, where it can spread rapidly through a community, especially in areas of poor sanitation.

The poliovirus consists of an RNA genome enclosed in a protein shell called a capsid. There are three serotypes of wild poliovirus type 1, type 2, and type 3 each with a slightly different capsid protein. Immunity to one serotype does not give confer immunity to the other two. Outbreaks of poliovirus were largely unknown prior to the 20th century. However, with improved sanitation in the 20th century, the average age at which individuals were exposed to poliovirus increased. With progressively declining protection from maternal antibodies, poliovirus infection increasingly resulted in paralysis.



Type 2 poliovirus was declared eradicated in September 2015, with the last virus detected in India in 1999. Type 3 wild poliovirus has not been detected here in the world since November 2012.

Vaccine-derived Polioviruses (VDPVS)

VDPVs are rare strains of poliovirus that have genetically mutated from the strain contained in the oral polio vaccine. The oral polio vaccine contains a live, attenuated(weakened) vaccine-virus. When a child is vaccinated, the weakened vaccine-virus replicates in the intestine and enters into the bloodstream, triggering a protective immune response in the child. Like wild poliovirus, the child excretes the vaccine-virus for a period of six to eight weeks. Importantly, as it is excreted, some of the vaccine-virus may no longer be the same as the original vaccine-virus as it has genetically altered during replication. This is called a VDPV.

Circulating Vaccine-derived Poliovirus (cVDPV)

On very rare occasions, if a population is seriously under-immunized, there are enough susceptible children for the excreted vaccine-derived polioviruses to begin circulating in the community. If the vaccine-virus is able to circulate for a prolonged period of time uninterrupted, it can mutate and, over the course of 12-18 months, reacquire neurovirulence. These viruses are called circulating vaccine-derived polioviruses (cVDPV).

The lower the population immunity, the longer these viruses survive. The longer they survive, the more they replicate, change, and exchange genetic material with other enteroviruses as they spread through a community. If a population is fully immunized against polio, it will be protected against the spread of both wild and vaccine strains of poliovirus.

Episodes of circulating vaccine-derived poliovirus are rare. Between 2000 and 2011 – a period

in which more than 10 billion doses of oral polio vaccine were given worldwide – 20 cVDPV outbreaks occurred, resulting in 580 polio cases. In the same period, in the absence of vaccination with OPV, around 6 million children would have been paralyzed by poliovirus.

Immunodeficiency-related Vaccine-derived Poliovirus (iVDPV)
Prolonged replication of VDPVs has been observed in a small number of people with rare immune deficiency disorders. Because they are not able to mount an immune response, these people are not able to clear the intestinal vaccine virus infection, which is usually cleared within six to eight weeks. They therefore excrete iVDPVs for prolonged periods.

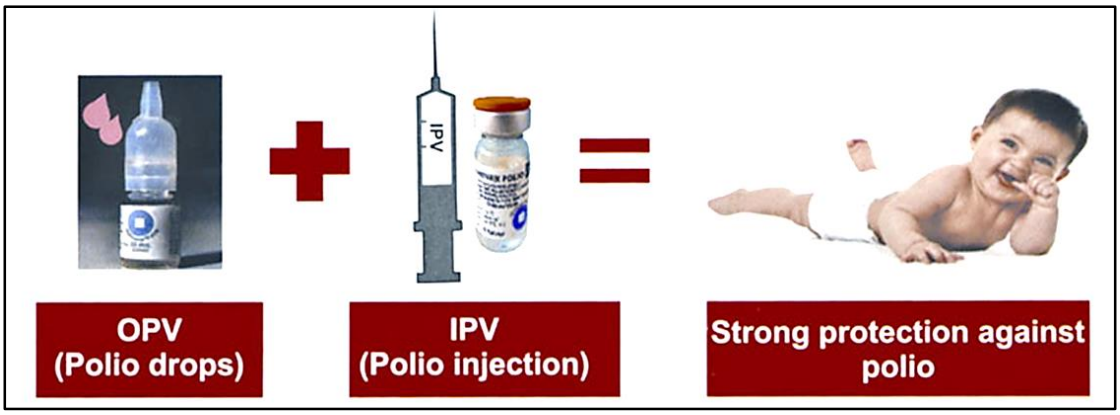
The occurrence of iVDPVs is very rare. Only 111 cases have been documented worldwide since 1962. Of these, most stopped excretion within six months or died.

Ambiguous Vaccine-derived Poliovirus (aVDPV)
aVDPVs are VDPVs that are either isolated from people with no known immunodeficiency, or isolated from sewage whose ultimate source is unknown. Very little is known about them.

Management Of Vaccine-derived Polioviruses
Circulating vaccine-derived polioviruses must be managed in the same way as wild poliovirus outbreaks. The solution is the same for all polio outbreaks: vaccinate every child several times with oral polio vaccine to stop polio transmission, regardless of whether the virus is wild or vaccine-derived.

Vaccine-derived polioviruses appear to be less transmissible than wild poliovirus. Outbreaks are usually self-limiting or rapidly stopped with 2–3 rounds of high-quality supplementary immunization activities.

Stopping the Virus
Once wild poliovirus transmission has been stopped globally, the vaccine-viruses will be the only source of live polioviruses in the community and could potentially lead to the re-emergence of polio. *Use of the oral polio vaccine in routine immunization programs will therefore be phased out to eliminate the rare risks posed by vaccine-derived polioviruses.*



Testing For Polioviruses
All cases of acute flaccid paralysis (AFP) among children under fifteen years of age are reported and tested for wild poliovirus or vaccine-derived polioviruses within 48 hours of onset. AFP is caused by a range of factors. The Global Polio Laboratory Network tests upwards of 100,000 AFP samples a year, of which a very small portion are positive for poliovirus.

Ref: http://polioeradication.org/polio-today/polio-prevention/the-virus/

Thank you for your kind words and generous donations.
We genuinely appreciate your help.

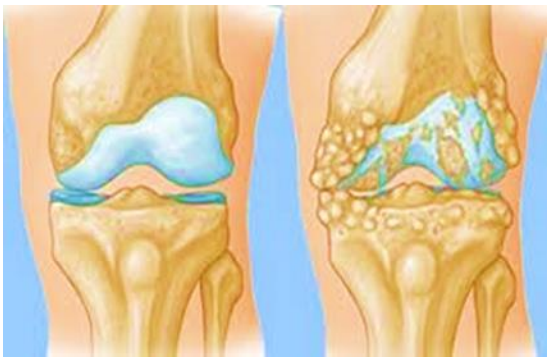
Arthritis and the Knee – What are my Options?

William M. DeMayo, MD
DeMayo's Q & A Clinic

Question: I have arthritis and some bone spurring in my weak left leg. The pain has been unbearable. I had a cortisone shot in my knee, which helped with the pain. How does or will it, affect my polio leg? What are your thoughts on orthoscopic surgery or replacement of the knee.

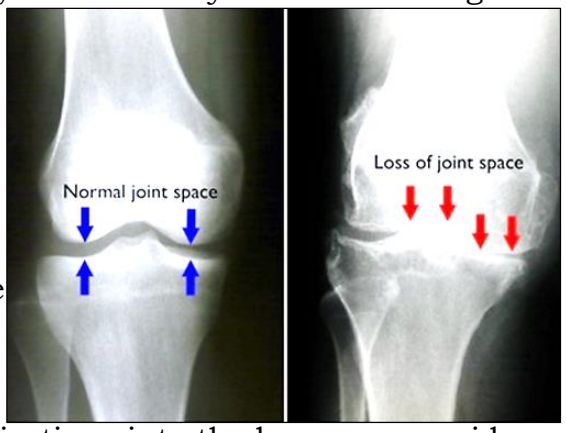
Answer: Your question is a common one and is a good example of how a typical problem (arthritis) can be much more problematic for a Polio survivor.

First off, we should define arthritis. Any word beginning with any version of "arthro" refers to a joint. The end of the term, "itis" means inflammation. So, arthritis is literally joint inflammation. The inflammation can be due to many causes and include immune diseases such as rheumatoid arthritis. The most common cause is osteoarthritis, also called degenerative arthritis, in which joint wear and tear is the focus. In degenerative arthritis the normal smooth surfaces of the joint have become worn and expose rough bone. The rough surfaces rubbing on each other create an inflammatory cascade that can cause further joint destruction and lead to abnormal bone growth such as bone spurs. A healthy joint resembles the joint you would see in carving a chicken or turkey with white/smooth surfaces that fit together nicely.

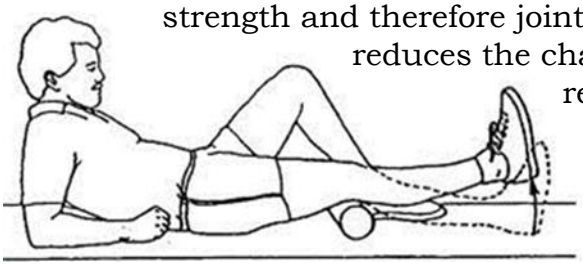


A severely arthritic joint can have a dramatically different appearance and loose the biomechanical effect it was originally designed to have. As a result, there can be pain from the inflammation and a level of instability that results in functional impairment. In the case of the knee, this often leads to a decrease in ambulation. Unfortunately, decreased activity leads to deconditioning and the loss of muscle strength leads to abnormal movements of the joint and more instability. A cycle is established where inflammation causes pain. Pain causes reduced activity. Reduced activity causes weakness. Weakness causes instability and then more inflammation.

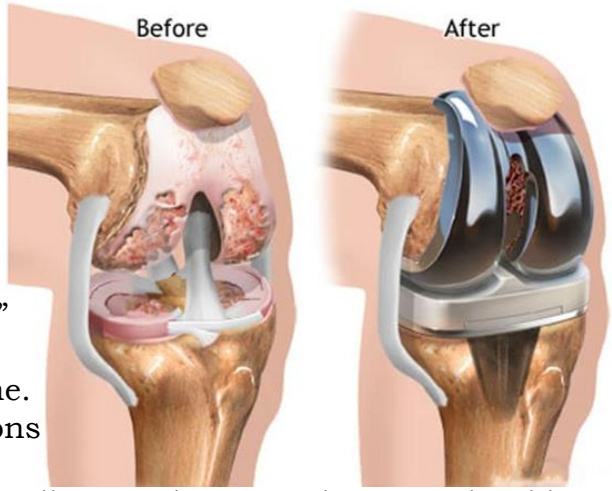
Whenever possible, it is important to try to interrupt this cycle. This may include learning exercises that strengthen the knee muscles with out causing pain (e.g. isometric "Quad Sets") or using non-steroidal anti-inflammatory medications (NSAIDS). Anti-inflammatory medications have gotten a bad rap in recent years due to potential adverse effects. This should be discussed with your doctor. I generally recommend against long term NSAIDS in favor of taking them at full dose for 10 to 14 days then stopping. This minimizes the chances of adverse effects while maximizing the potential benefit. Another option is an oral steroid as an anti-inflammatory, but this should be used very sparingly and rarely repeated due to multiple potential problems highly correlating with long term steroids. Steroid injections into the knee can provide the benefit with some reduction in the long term risks. In my opinion, injections should always be done in conjunction with Physical Therapy or a regular home exercise program. As one weighs risks and benefits of oral or injected anti-inflammatory medications, it is important to weigh the risk of not treating and having disease progression as well as the potential benefit that



short term treatment to control inflammation can allow therapy or home exercises to rebuild strength and therefore joint stability. Improved joint stability and biomechanics then reduces the chance of inflammation reoccurring. It is important to remember that permanent destructive changes do occur in the joint, but many other factors are at play. It is not uncommon for someone to have no pain one week and start with significant arthritis pain the next. Typically, the joint did not deteriorate overnight. Rather, the other factors including reduced muscle stabilization led to a point where a relatively mild trauma, such as overuse, kicked off the above cascade. In some cases, this can be undone and years of relatively pain free function can follow.



While the above is true, it is a very big challenge in an individual with Polio to improve muscle stabilization in a knee on their weak leg. Sometimes appropriate bracing of the foot and ankle can dramatically change the stress on the knee and thereby reduce knee pain. Bracing of the knee itself is less helpful but can provide some short term relief for some individuals. While bracing the foot and ankle can provide long term improvements in biomechanics for some individuals, bracing of the knee itself does not really alter the underlying biomechanics.

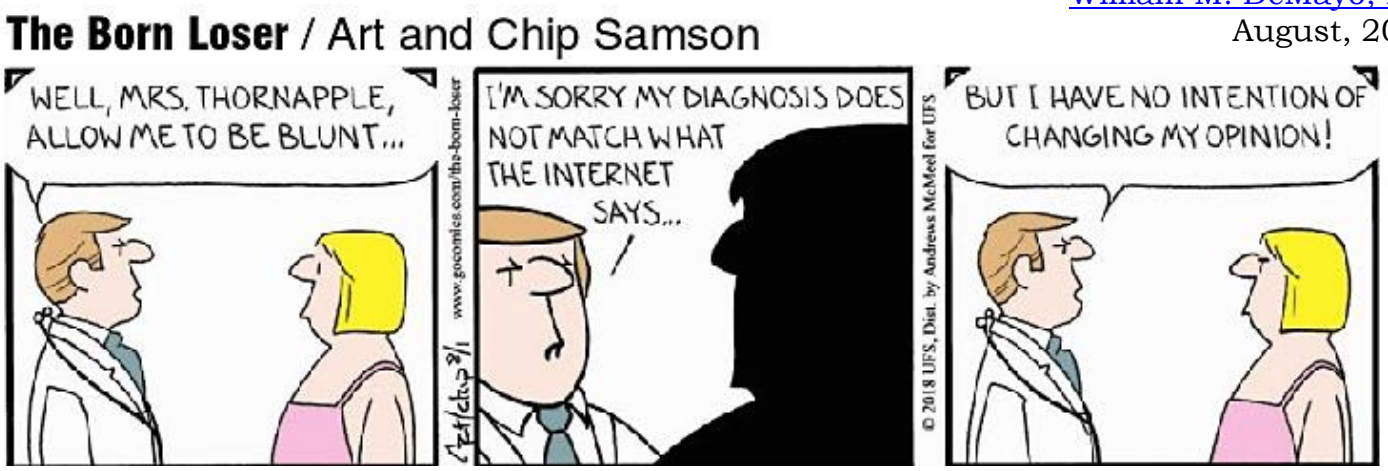


If therapy/home exercises, bracing and anti-inflammatory medications do not work, surgical intervention is reasonable to consider. Arthroscopic surgery had been very common in years past to "clean out" degenerative tissue in an arthritic knee. Studies have shown that most of those surgeries did not change outcome. Still, there is a role for arthroscopic surgery if specific lesions are present and pain reduction can be dramatic in these cases. This is an option to consider if offered by the orthopedist. At the same time one should carefully discuss the "down time" post operatively and resultant problems that may create for the Polio survivor. Similarly, total knee replacement surgery can have profound benefits for some but needs to be planned carefully and specific individualized risks discussed with the surgeon.

Typically, joint deformity in a severely effected Polio knee is significant and I would suggest having a couple of opinions to discuss options. Usually, a prosthetic knee that has more than the usual internal stability is selected. A detailed discussion of Total Knee Replacement in Polio is beyond the scope of this short article. My overall recommendation would be to proceed slowly, don't be afraid, but be wise and ask lots of questions. Joint replacement can be life changing, it can also backfire and worsen disability.

William M. DeMayo, MD
August, 2018

And just for fun . . .



Bruno Bytes

Richard L. Bruno, H.D, PhD
Chairperson, International Centre for Polio Education

On the topic of understanding the limitations of PPS

Original Post: Well, I did a lot today. I went to the library for Dr. Bruno's book, pharmacy for an anniversary card, made my puppy a raincoat, made my awesome breakfast muffins. I made supper and I am finally sitting down . . . . Mind you I made all of this in stages while sitting down for long periods in between. I'm tired but happy with my day. This means I'll be pooped for the next few days so I'll rest, rest, rest.

Dr. Bruno's Response: You should have read the book first so you wouldn't have done so much! Polio survivors only have so much energy. It's like money. On days when you have cash (energy) you can't spend it all on shopping and cooking and then be poor (pooped) for days! Being totally "pooped" is your body saying "TOO MUCH!!!!" Damn the muffins and full nap ahead!

On the topic of "Pushing" Yourself too Far

Original Post: I've noticed for a few years now, that when I pushed myself either because I just want to, or because I need to. At the end of the day, maybe even 1 to 2 days later, I experience shivers or fever like symptoms. I've always concluded it was due to me pushing myself beyond my limits. Could that be true?

Dr. Bruno's Response: At the Post-Polio Institute we call it the "48 hour lag." You beat yourself up on Monday, are surprised you feel good on Tuesday and then crash on Wednesday. Back in the early 80s people talked about PPS symptoms and described flu – like symptoms similar to those survivors had with polio originally. In the thousands of patients we've studied and treated, very few talk about shivers and fever – like symptoms. That being said, especially as the weather gets colder, the more fatigued you are the harder it is to control your body temperature and the more likely it is you are to feel cold inside when you overexert yourself. It's always good to remember that

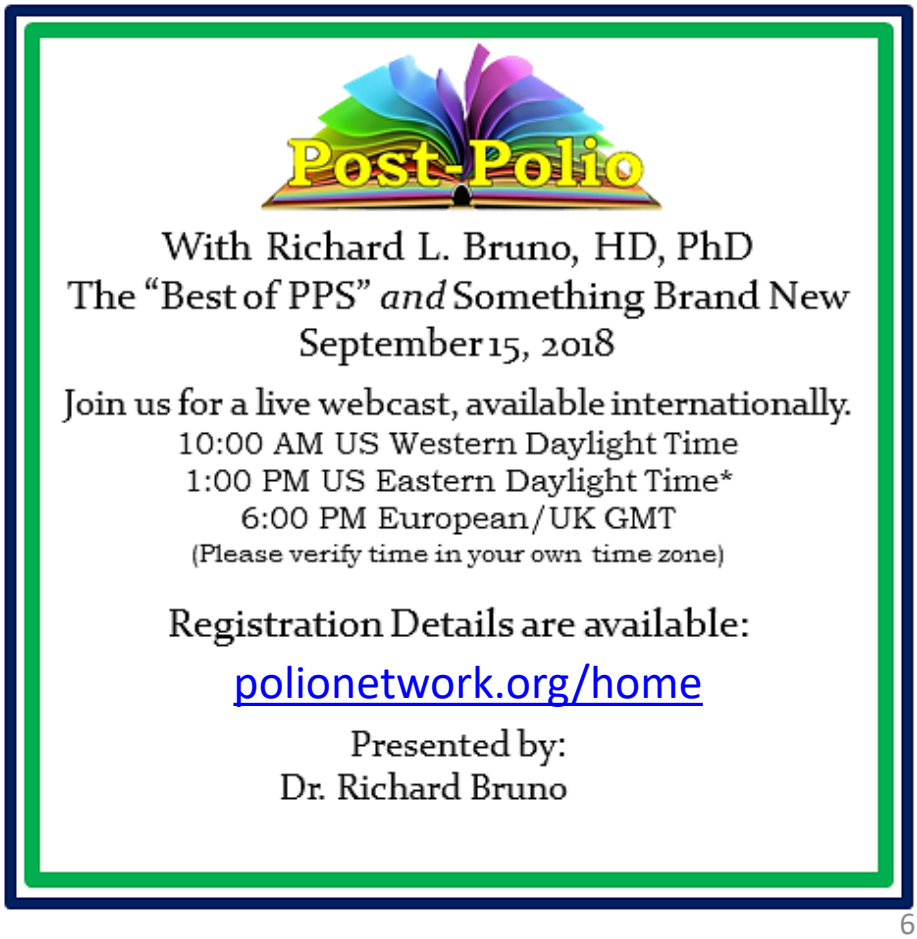
PPS IS A DIAGNOSIS OF EXCLUSION

Your doctor may want to get general bloodwork and check your thyroid levels.

These two "Bruno Bytes" are just a sample of what Dr. Bruno will be discussing live on September 15th.

Were you in the DT Watson Home for Children? There is going to be a special event for the webcast that day. Join us !

ALL the details are on our Website- www.polionetwork.org



A positive attitude about health and wellness is maintained by becoming an active participant in one's health care, planning an individualized program, accepting the fact that some aspects of life will change with age, and believing one can control one's health.

Attributes relevant in maintaining a positive mental attitude include:

•Optimism and hope. Believe that things can be better and hope for relief or improvement in the future.

•Control and self-direction. Take control over the disability experience and willingly direct one's life. Plan ahead for the future.

•Commitment. Commit to something, such as religious groups, civic duties, hobbies, family, work. Stay involved and curious.

•Closeness or intimacy. Engage in personal and group relationships.

•Good health. Tend to a proper diet, appropriate exercise, and rest. Avoid excessive drinking, smoking, and other potentially dangerous social habits.

•Feelings and perceptions. Avoid guilt, anger, hostility, fear, anxiety, and feelings of low self-esteem. Perceive life and life events as challenges rather than threats.

•Flexibility and adaptability. Be willing to reorder priorities.

•Humor. Look for humor, especially in one's own situation.

•Openness. Accept whatever comes along in life without blame and by forgiving people and oneself.

Excerpt from PHI's "Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors."

http://www.polioplace.org/living-with-polio/positive-attitudes

Polio Survivors Becoming Part of the Solution.

Join Team Survivor and help eradicate this terrible disease . . . . once and for all.

Pampered Chef Purchase

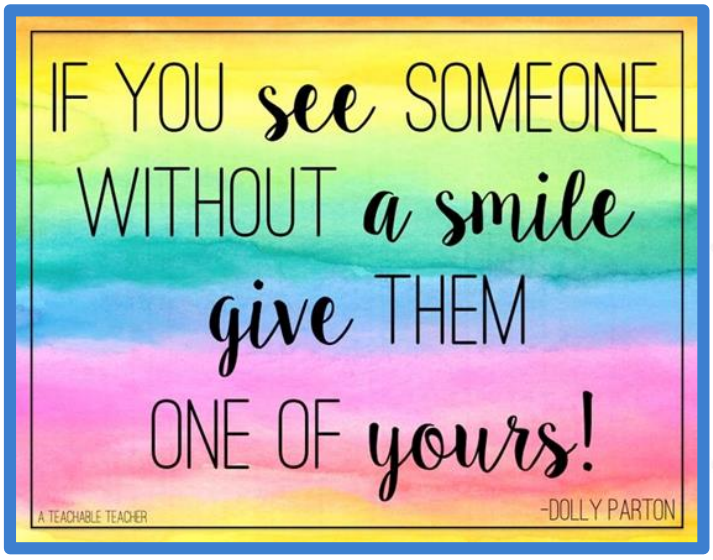
Dare to Dream Purchase

Your Donation by Check (US Mail) or Online Donation.

Simple Donation

In October, we will be publishing a list (with everyone's permission) of all contributors to this fun project.

August



Do you have a topic you would like us to cover? Please let us know.
Always feel free to contact us.
The Polio Network Team

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