

POST POLIO MATTERS

Polio Survivors Network Newsletter - Volume 8, Issue 4/12
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**June
2014**
Vol 8, Issue 4



Enter 100+ articles



**POLIO
TOTALS**
2011 - 650
2012 - 223
2013 - 400
>14.6.2014
Pakistan 75
Afghanistan 4
Nigeria 3
Equatorial Guinea 4
Cameroon 3
Iraq 2
Ethiopia 1
Somalia 1
Syria 1
Total 94



We met in St. Louis!

Report starts page 5
www.post-polio.org



POST POLIO SYNDROME
A Condition Without Boundaries

25th to 27th June 2014
Amsterdam, The Netherlands
www.polioconference.com

**PICTURES
ON
FRONT PAGE**

**Top Right
The St. Louis Arch**

**Top Left
Watching a
Presentation
about
Post Polio
Symptoms.**

**Watching
“One World”
performed by the
DisAbility Project
of the
Uppity Theatre
Company and
Common Threads
Dance Company.**

**Hilary Boone
with Polly O’Lyffe
and
Dr. Carol
Vandenakker**

**Presentation
‘Effective
Communication
between Patient and
Practitioner Provides
Better Outcomes’
Based on
Polio Survivors
Network
‘My Polio Life’**

Facebook Friends

**Frank Frisina,
Donna Kidner,
Hilary Boone,
Polly O’Lyffe,
Millie Lill,
Jeanne Houghton,
Dave Marsh,
Micki Minner
and
Jann Hartman.**

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New Members and Donations received.

Thank you to all members who have recently renewed.

Thank you to the following for donations given towards our work
up to the end of May 2014.

Shirley Bingham, Christine Darlington, Yvonne Grosse,
Dianna Nash, Shirley Rose, Lynn Hobday, Dinah King,
Ruth Bridgens, Susan Freeman, John Ward, Ann Stone,
Margaret Edmunds, Carol Murray, Lesley Forsyth,
Michael Farkinder-Walker, Barry & Olivia Branson
Dave Marris, Tony Scrace-Walters, Hilary Boone,
Jennifer Jones + Mum, Jann Hartmann and Janice Whitworth

Member donations £ 832.00
Annual General Meeting donations £123.00
Donations towards Conference £ 225.00
plus in cash at the PHI Conference £ 260.00
Val Scriveners Cards £ 55.80

Thank you very much - Grand Total of £ 1,495.80

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Editorial by Hilary Boone

Richard and I are in Canada with our daughter, son in law and grandson aged 3 and we have just come back from the Zoo. I saw my first porcupine and elk, but there was no Moose which I really wanted to see. What made us laugh was that as Richard moved along the front of the cheetahs cage one got up and followed him backwards and forwards for about two minutes. Meals on Wheels maybe? We also saw a very large golden coloured bear swimming and throwing rocks up in the air and batting them away as if they were tennis balls. The sky here in Alberta today is so blue and the clouds seem suspended in mid air, the temperature is 22 [73] and the air so fresh.

The four day PHI conference in St. Louis finished on June 3rd 2014 and polio survivor attendees in touch on Facebook agree it was great to learn new information and share experiences with other polio survivors and pps professionals old and new. We now have even more folks to share information with to pass on to you all. There were multi sessions every part of the day so it was not possible to attend all sessions. We hope to have more articles from other attendees in later issues. Reports start on page 5. Did we pace and rest... we tried to and having wheels made a difference to how much we could do but nothing would stop us meeting for a few drinks and lots of laughs in the evenings till 9.30 pm. [honest]

The biggest issue mentioned by polio survivors seems to be the lack of knowledge and experience by almost all health professionals dealing with issues and symptoms being experienced by polio survivors across the world. This includes symptoms that are polio or post polio related but also those that have nothing to do with polio but because you are a polio survivor there are extra facts to take into consideration.

The main reason that no or far too few facts are taught, or will be taught in the future by Colleges of Medicine, I was told is because 'you are all dying off so there is no need.' However, whilst the three polio viruses may be close to eradication there are still other enteroviruses and West Nile Virus that cause acute flaccid paralysis which is the main symptom of polio. In addition to that there are many neurological conditions that have similar symptoms, issues and problems. There are a few excellent PPS clinics and health professionals but most too far to travel.

I wish more neurological alliances could be formed where our symptoms and issues were mapped so that more professionals in the disability field would see that the 'not enough of you' is probably incorrect. In fact considerable money could be saved helping us manage the massive overlap of symptoms and issues we experience in every day life. We may start at a different place with a congenital or acquired brain injury or neurological diagnosis and the path may be short or long but if we can't get out of the bath, are having swallowing difficulties, need some equipment to make us more mobile, etc. then the condition name is almost irrelevant.

To all of you reading this there is a lot of information and excerpts with more information to come in later newsletters. We are indebted to the hard work of Joan Headley Executive Director, the Board of Directors and all the team who worked so hard to produce a great Conference. Thanks also to the Polio Survivors who so willingly share information and experiences.

I hope you will find the items included in this newsletter of interest and please if you have a question, no matter how small, call, write or email us. We know from past experience that you wont be the only one who has asked/is asking.

Do you have a few hours now and then and would like to help please get in touch. Do you take a regular magazine, (specially one relating to age, medical condition, disability, mobility equipment, driving for the disabled, etc. How about dropping us a line with any items that you think might interest other members.

Polio Survivors Network - Meetings

If you have any matters you would like us to discuss at our meetings please get in touch via
hilary.boone@poliosurvivorsnetwork.org.uk
or Tel: 01522 888601 or write to us at Polio Survivors Network PO Box 954, Lincoln LN5 5ER

MESSAGE FROM OUR CHAIRMAN - Simon Parritt

Muscle is something we as post polio people think a lot about. The truth is that as we fall under the influence of diminishing muscle power, for whatever reason, we can begin to feel not just the loss of power in terms of lifting, walking, wheeling but the loss of independence. Essentially we become more reliant on those people around us and the adaptations that help us to live in a non-disabled world as we would choose. But muscle also implies power to do something.

For me at least, I find this challenging, despite years of dealing with it in myself and others it never gets any easier especially as denial, a cherished coping method of many of us, becomes less and less possible. I freely admit that I struggle at times to stay calm and feel positive in the face of the extra irritations and barriers that the non-disabled world places in my path. I have been a disabled person since the age of 5 and to constantly re-iterate, explain, filter my feelings and justify myself to another person, social worker, organisation or even family member can be very emotionally and physically taxing.

This often comes to mind when I occasionally look at polio postings on Facebook and see how people have adapted over the years to fit in with a non-disabled world and yet not recognise this as a form oppression and discrimination. Whilst I understand the 'must not grumble' / 'others have had it worse' / 'I do my best to manage' approach, it doesn't sit well with me at times. I was once in a meeting where I mentioned my disability and someone said in response that they didn't see me as disabled but only as a colleague and Simon. A black woman responded, 'if someone told me that they didn't see me as black but only as a colleague and Maria I would feel unseen and offended as it is one important part of who I am'. Good point I thought!

In PSN we strive, as equals, to explain, work with and educate others including professionals. But, I note that it seems hard to recruit actual members and maybe this is because there is a denial that we are disabled not just by our impairments but by our lack of power as disabled people and polio survivors because we are not loud enough or pushy enough to be heard. Maybe we are still trying to 'pretend' that we are, in spite of our impairment, just like any non-disabled person. By joining and campaigning we acknowledge we are seen as disabled and different, the very thing we have been fighting against all these years.

Simon Parritt, C.Psychol, AFBPsS, MSc, BSc(Hon), BA, CPsSC, MBACP

Chartered Psychologist

HCPC Registered Counselling Psychologist

www.sp-psychology.com

Simon Parritt <simon.parritt@poliosurvivorsnetwork.org.uk>

REMEMBER

No two Polio Survivors are identical - what a nightmare for health professionals we must be!
As Polio Survivors we have developed totally unexpected methods of performing actions often using muscles not normally expected by health professionals to be involved in that action.

If asked by a health professional "Can you do this action"

Remember you may be perfectly correct in answering "Yes" because you can do it... BUT

1. Is your way the normal able bodied accepted way.
2. If it is different then is it the same way you have always done it or
3. Have you had to change the way you do this now because of new weakness...

Always answer as if you have been asked "How do you do this action?"

**It is not easy admitting things have changed but
assessing you will be much easier if you 'tell it like it really is'**



11th International Conference

May 31st to June 3rd 2014

Hyatt Regency St. Louis at the Arch
St. Louis, Missouri, USA.

Information from the Conference.

Starts here..

PHI has served the community for 55 years and coordinated 11 educational conferences for the post-polio community over 33 years. Joan Headley, Executive Director and Polio Survivor writes "Our theme, Promoting Healthy Ideas, asserts PHI's view that we individually can, and must, be part of the solution as we age with a disability. For this reason, PHI's goal at this conference is to arm each participant, including survivors, family members and health professionals with information and connections." Lastly she gives a message from the Board of Directors asking what does the future hold? Asking all to come forward with ideas and comments as to what kind of programs we would find most helpful.

The first day started at 12.00 with registration and a chance to meet and chat with others. Followed by a Pre-Conference Orientation session for participants attending their first PHI conference. The evening started with a half hour in the bar followed by Dinner and an excellent 75 minute presentation "One World" performed by the DisAbility Project of the Uppity Theatre Company and Common Threads Dance Company. The theme was how the participants had experienced issues in their disabled lives and many a comment triggered a memory from the past for the polio survivors in attendance. Three people were given a chance to comment about the presentation and each persons voice broke as they were speaking. It was a very emotional, thought provoking, excellently acted performance.

Sunday, Monday and Tuesday there were multi choice sessions. I had to pick which I thought would be of greatest benefit to our members. All presentations and supplementary material will be made available over the next few weeks and we will let you know how you can obtain a copy if you wish.

Dr. John R Bach [www.doctorbach.com] gave a presentation on Polio's effects of breathing which included many photos of polio survivors and others with respiratory issues that he had helped, including Christopher Reeve. His research is written up in many medical articles and his three books were mentioned

1999 - Guide to Evaluation and Management of NMD {Neuromuscular Disease}

2002 - Non-invasive Mechanical Ventilation

2004 - Management of Patients with Neuromuscular Disease.

EXCERPTED SLIDES FROM PRESENTATION. [Editors note:- I appreciate some of the terms will not be understood but if you have respiratory issues your health professional may benefit from the information]

How to avoid Respiratory Failure and Tracheotomies.

- Maintain Oxygen saturation >94% without Oxygen especially during colds.
- How? By using Mechanical insufflation exsufflator (MIE) and non invasive intermittent positive pressure ventilation.
- If Spo2 <95%, you have either hypoventilation, mucus or pneumonia.
- Since ventilator drive prevents asphyxia avoid sedatives and oxygen.

Most Common Errors are

- Misinterpretation of symptoms
- Inadequate Pulmonary Function Tests
- Failure to monitor sleep
- Over reliance on Arterial Blood Gases.

- Over reliance on Tracheostomy
- Over reliance on suctioning
- Oxygen therapy.

Outcomes of Oxygen Therapy are worse than NO THERAPY.

BachJR, Rajaraman R, Ballanger F, Tzang AC, Ishikawa Y, Kulesa R, Bansal T. Neuromuscular ventilator insufficiency: the effect of home mechanical ventilator use vs oxygen therapy on pneumonia and hospitalization rates. Am.J.Phys.Med Rehabil. 1998,77(1),8-19

Supplemental Oxygen Impairs Detection of Hypoventilation by Pulse Oximetry and it also “covers up” airway secretions.

Fu ES, Downs JB, Schweiger JW, Miguel RV, Smith RA. Chest 2004;126:1552-1558

Treatment Goals

- Optimize chest wall/lung ROM and Growth.
- Optimize cough flows
- Maintain normal ventilation.

Indications for Tracheostomy

When the Spo2 decreases below 95% and can not be normalized by NIV [Non Invasive Ventilation] or MAC [Mechanically Assisted Coughing]

[Editors Note:- Cough Assist Machine. The Cough Assist Machine helps to clear secretions from the lungs by helping you with your breathing. When you breathe in (inspiration), the machine gives you air (positive pressure) to help expand your lungs. When you blow out (expiration), the machine creates a sucking force (negative pressure) that pulls the air out of your lungs. This rapid change in pressure during the different phases of breathing (inspiration and expiration) helps make your cough stronger and more effective. This was demonstrated to me and I can see that it would be extremely helpful if we had a cold and have contacted our respiratory therapist to discuss this.]

PROVEN ENERGY BOOSTS.

Presentation by Betsy Thomason RRT - See Flyer

I attended this presentation and was a bit taken aback by the information. I wonder how many other Polio Survivors reading this will have, like me, held their breath to perform an action. I thought it gave me more stability and oomph to do things, like get up out of a chair.

Betsy Thomason told us that what we should be doing is to gently blow as if we were blowing a child’s pinwheel. This takes little effort and when you finish the in-breath is automatic and for me (and I expect all of us) larger than normal. Betsy told us that instead of holding our breath to perform an action try blowing out gently and amazingly it is easier.

Betsy is going to write us an article for the newsletter but pressure of work meant that she could not manage our deadline. More information next newsletter. In the meantime you can read the first chapter of her book - see next page. If you do not have access to the internet drop us a line and we will print and post you a copy.

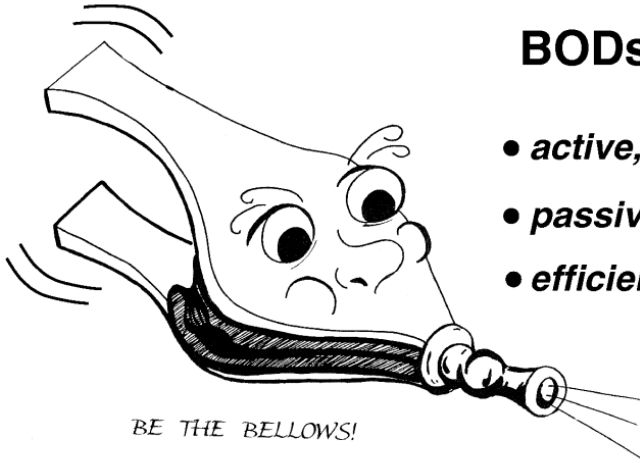
A personal word of caution. I found that whilst I could do this that repeating it more than a couple of times, because it increases the depth of breathing, made me a little dizzy. So as normal I have started slow using one slow breath out to get up out of chairs, and doing two BODs a few times a day, stretching intercostal muscles.

BREATHING TRAINING: DEVELOPING A USER - FRIENDLY BODY

Featuring

the BreatheOutDynamic system

BODs



- *active, spine-stretching outbreath*
- *passive, relaxed inbreath*
- *efficiency for energy and relaxation*

- Purse lips / pull in belly
- Focus on exhalation
- Relax for inbreath
- Use images / imagination
- Exhale on exertion
- Think Positive: I CAN DO THIS
- Be patient - You are changing habit patterns. Muscles are slow learners.
- Use BODs every day
- When in DOUBT, blow OUT!



Betsy Thomason, BA, RRT

36 Mountain Ave., Park Ridge, NJ 07656 • 201-930-0557

BT Breathing Training, LLC offers individual and group BODs instruction for people who want to improve—even maximize—their physical ability, experience increased energy, and manage stress. **For more information, visit the website www.btbreathingtraining.com.**

If you would like to read the first chapter of Betsy's soon-to-be-published book

Just Breathe Out: Developing a User-Friendly Body,
featuring the BreatheOutDynamic system,

e-mail Betsy at betsy@btbreathingtraining.com with the words

Just Breathe Out Chapter 1 in the subject line.

Glossary of some of the terms used.

Please note there are USA spellings and UK spellings of words. E.g. apnea and apnoea.

Obstructive sleep apnea/apnoea [OSA] is a condition in which the flow of air pauses or decreases during breathing while you are asleep because the airway has become narrowed, blocked, or floppy. A pause in breathing is called an apnea episode. A decrease in airflow during breathing is called a hypopnea episode

Central sleep apnea/apnoea [CSA] occurs because your brain doesn't send proper signals to the muscles that control your breathing.

Mixed sleep apnea/apnoea is where both obstructive and central sleep apnoea is present. .

Restless legs syndrome (RLS) is a condition in which your legs feel extremely uncomfortable, typically in the evenings while you're sitting or lying down. It makes you feel like getting up and moving around. When you do so, the unpleasant feeling of restless legs syndrome temporarily goes away.

Non Invasive Positive Pressure Ventilation [NIPPV - sometimes referred to as Nippy] or Non Invasive Ventilation [NIV] is the term most commonly used now for

Continuous Positive Airway Pressure [CPAP] is a treatment that uses mild air pressure to keep the airways open. A constant pressure for both in and out breath. This is delivered by a machine through a face mask.

Bi-level Positive Airway Pressure [BiPAP or Bi-level] is a similar treatment that uses mild air pressure to keep the airways open. The machine has two level settings, a higher level for the in breath and a lower level for the outbreath. This type of machine is needed by people who have a neuromuscular disease and do not have the muscle power to breathe out at the same pressure as a CPAP machine.

Sleep priming. The following impact on sleep. Watching a horror movie or the news, spending time on the computer or iPad, thinking about the days bad stuff. Instead try sleep priming, e.g. a tape of peaceful music or prayer anything that is calming.

ROM - Range of Movement.

Beyond Eradication: The Forgotten Polio Survivors of India.

Neena Bhandari

India, which has been certified polio-free by the World Health Organisation on 27th March 2014, was the epicentre of polio with nearly 200,000 reported cases a year until 1978. While data abounds on number of children vaccinated and the number of reported cases, there is no count of polio survivors, many of whom are battling with PPS. There are few doctors, who recognise and understand PPS, and there are no polio support groups. Despite the odds, stories of endurance and resilience unfold as I meet polio patients in villages, towns and bustling cities. The Government, NGO's and the larger community now needs to invest in polio survivors facing new physical, social, cultural and economic challenges.

My New Reality Session.

I contracted polio in India soon after receiving the oral polio vaccine, a month short of my third birthday. Since then, I have lived and worked in three continents as a journalist and foreign correspondent, reporting on issues ranging from environment and development, human rights and gender, education and health to crime and law. Many by-lines and many callipers on, as PPS poses new challenges each day. I am constantly evolving ways to live life to its fullest as a mother, a wife and above all a professional in the fast-paced, highly competitive media industry.

SLEEP AFFECTS THE WHOLE PERSON AND THE WHOLE PERSON AFFECTS SLEEP

Report from Dr. William M. DeMayo presentation A Good Night's Sleep

There are many things that affect sleep and are interlinked. Emotional issues such as job and other stress and frustration. Pain from fibromyalgia, neurologic and muscular pain can lead to depression and/or insomnia. Fatigue which can come from a variety of causes including but not exclusive to Post Polio Syndrome. Then there are underlying sleep disorders.

Obstructive Sleep Apnea [OSA] can now be diagnosed by a Home Sleep Study and treated with CPAP or BiPap whichever is appropriate. Remember there are multiple masks available.

Central Sleep Apnea [CSA] treated by BiPap.

Restless Leg Syndrome or Periodic Leg Movement Disorder can be treated by Mirapex, Requip Neurontin, Lyrica.

We can improve on our quality of sleep if we get enough good quality hours of sleep a night. [A study on weight gain and sleep demonstrated that the group that cut back an hour on sleep gained 20lbs in weight.] Try keeping a log of what you did during the day up to going to bed. How many hours sleep did you get. Did anything keep you awake? Also we need to take note of the Don'ts and Do's.

The DON'T list

1. Alcohol although it promotes sleep onset, alcohol leads to shallow, fragmented sleep.
2. Caffeine can stay in our system for 14 hours.
3. Nicotine - at low doses, tends to act as a sedative
 - at high doses it causes arousals during sleep.
4. Daytime Napping can be ok if sleeping well at night.
5. Exercise Lack of exercise during day
 Too much exercise at night.

Frequent factors disturbing sleep

6. Poor Sleep Environment noise, distractions, other stressors associated with that space, temperature and positioning.
7. Medications review with your physician and pharmacist
8. Other distractions Television, Computers, Reading, DVD's, C.D's [exception items manufactured for sleep, e.g. White noise applications like Sleep Pillow]
9. Pets Care of pets at night and sleeping with pets.

The Good Sleep Hygiene List [The DO List]

- A. Set specific bedtime and wake time with enough hours sleep and stick to it.
- B. Establish a Bedtime Routine, maybe a warm bath. [Sleep Priming]
- C. Consider adapting environment
 Body Pillow (especially for sacroiliac back pain)
 Sound Machine (Ear Plugs, Aromatherapy, etc)
 Dimmed lights.
- D. Get out of bed if unable to sleep for 15 to 30 minutes and leave bedroom if possible. Sit quietly. Do nothing stimulating other than a relaxation tape or App which is ok)

Monday, June 2, 9:00 – 10:15 am
Let's Talk About the Spine: Medical Overview
Carol Vandenakker-Albanese, MD

The spine: supports the trunk, stabilizes the limbs, protects the spinal cord and nerve roots, and allows multidirectional movement

Effect of Paralytic Polio on the Spine

The polio virus attacks the cell body of motor nerves in the spinal cord, resulting in paralysis or partial paralysis of muscles. This causes asymmetry of skeletal or spine support and spine bone growth may be affected.

These changes result in loss of bone strength, altered body mechanics, secondary deformity, increased stress on spine segments, and increased stress on supporting soft tissue. Related spinal problems in the polio survivor include: spinal deformity, osteoporosis, accelerated degeneration, and symptoms related to nerve impingement secondary to spine degeneration can mimic post-polio syndrome.

Spinal deformity/ Scoliosis

Risk of scoliosis in a polio survivor is 30%, Results from: asymmetric weakness of trunk muscles (intercostal, abdominal, paraspinal), pelvic weakness, tilt and/or leg length difference. The progression of curve correlated to degree of weakness and age at onset of curve. Bracing is often not successful in preventing progression and surgical fusion often recommended.

Risk of dramatic increase during adolescent growth spurt, however progression can continue after skeletal maturity due to degenerative changes: asymmetrical disk degeneration, vertebral compression fractures, lateral slippage of vertebrae (spondylolisthesis). Progression can cause: pain, nerve impingement, an unbalanced spine, bony pressure points, reduced lung function.

Osteoporosis

Polio survivors are at increased risk of osteoporosis based on: reduced peak mass, reduced muscle action on bone, and reduced mobility.

Spine (vertebral) fractures may occur with falls / trauma or spontaneously if bone is very weak.

Vertebral compression fractures may contribute to progression of spinal curves

Spine Degeneration

Spine degeneration is common in the general population. Polio survivors often have increased stress on the spine related to loss or asymmetry of muscle support and altered mechanics of movement. Spinal curves often progress with degenerative changes. Degeneration in the spine can start with disc degeneration or arthritis in the facet joints. Degeneration in one area puts increased stress on the other structures and eventually degeneration occurs in both. Slippage of vertebrae, enlargement of joints and ligaments, and bulging discs all reduce the space around nerves (stenosis) and can result in nerve compression. Single level nerve compression can cause pain, weakness and/or loss of sensation in specific pattern in a limb. Pain may be constant or intermittent. Pain may be related to position or activity.

Spinal stenosis refers to narrowing of the spinal canal. It is commonly a result of degenerative changes including disc bulging, facet and ligament hypertrophy and osteophytes. Onset of symptoms is often gradual with progressive increase but may be acute. Symptoms can include: loss of balance, pain in buttocks or legs, deep ache in the legs that increases over time while standing or walking. Pain is usually relieved with sitting, less when walking with shopping cart or walker (forward flexed position), and may confused with symptoms of post-polio syndrome.

Symptoms related to spine degeneration include: back pain, leg pain and/ or weakness, loss of sensation, change in bowel/ bladder control, difficulty breathing, increased fatigue, increased loss of balance, increased frequency of falls. Problems related to the spine may be confused with the symptoms of post-polio syndrome: new weakness, increased fatigue, leg pain with

walking/ relieved with rest, increased difficulty breathing.

Treatment of Spinal Disorders

Medical evaluation is important to identify cause of symptoms and focus treatment (Spine specialist). Treatment options for spine conditions include: physical therapy, medications for pain control, bracing, injection procedures, and surgical intervention for nerve impingements and unstable spine.

The pain medications commonly used include: acetaminophen (used in moderation – least side effects), anti-inflammatories (may cause gastritis/ ulcers), narcotics (cause drowsiness, fatigue, constipation, and tolerance) and neuroleptics (also cause drowsiness, “spacey” feeling)

Spine bracing is safe but not always tolerated. Braces may be semi-rigid or rigid. They reduce motion and provide support. They can be custom molded, semi-custom, or off-the-shelf. They may be uncomfortable, especially with sitting, but they do not cause harm.

Spinal injection procedures may be very helpful for inflamed nerves or joints. Nerve blocks can help alleviate pain from joint degeneration, but relief is usually temporary. If pain is severe surgical intervention may be considered. Surgery is also indicated when there is nerve compression with loss of function or an unstable spine. Spine surgery is often major surgery with significant risk involved.

Preferred management of spine conditions is conservative. A conservative program may include topical medications and modalities, change in lifestyle, activity modification and an exercise program that includes strengthening, stretching and cardiovascular conditioning . This treatment is usually taught through physical therapy.

Summary

Spine problems in polio survivors are common. Common problems include:

- Scoliosis or other spinal deformity
- Osteoporosis
- Degenerative changes
- Nerve compression

Problems related to the spine may be confused with symptoms of post-polio syndrome:

- New weakness
- Increased fatigue
- Leg pain with walking/ relieved with rest
- Increased difficulty breathing

Treatment options include:

- Pain medications
- Bracing
- Injections
- Surgery
- Physical therapy

Advice on Solo Aging - Sunday June 1st 2014.

Member Jann Hartman. - Restructuring my life after my husband's premature death continues to be a challenge, but the transition has brought with it the realization that I am not truly alone. Faith, friends and family are what get me through one day to the next.

Susy Stark, PhD, OTR/L, FAOTA - Aging in a place alone with a disability can be easier with “environmental support”. Support can be formal or informal personal support or changes to the physical environment. Strategies to enhance daily activity performance and community participation will be discussed.

Editors Note: If you are managing alone and would like to share information and ideas with Member Jann Hartman please get in touch with PSN and I will pass on your details.

Introduction

Physical therapy treatment for spinal pain and dysfunction requires a multifaceted approach. Treatment follows a detailed evaluation and is specific to the needs of each patient. Not two backs are the same even with the same diagnosis.

Modalities [variety of treatment tools]

Modalities are often utilized in the physical therapy treatment of spinal pain. Following an evaluation, a physical therapist will determine the appropriate modality for each patient situation.

The therapeutic application of heat and cold has long been utilized for pain control. Heat accelerates the metabolic process of increasing circulation. This helps flush out the waste products of a muscle spasm and reduces pain. Local cooling decreases the metabolic process thereby decreasing the inflammatory response. It offers an analgesic effect by decreasing nerve conduction and muscle contractibility. People with a history of polio are often less tolerant to the application of cold. Using moist heat adjacent to the cold usually makes it tolerable.

Myofascial release and soft tissue mobilisation have been found to be effective in the treatment of back pain. Massage brings increased circulation to the area, aids in the release of muscle spasm; allows stretching of abnormal fibrous tissue; and increases extensibility [capability of being stretched] of the soft tissues.

Ultrasound is a modality that uses sound waves to treat pain and promote healing. The thermal effects of continuous ultrasound cause increased friction and heat on a molecular level. This promotes healing by increasing the metabolism of the cells in the soft tissue.

Electrical stimulation can reduce pain by sending small electrical impulses through electrodes placed on the skin to underlying nerve fibres. Pain reduction can occur by blocking the pain signals to the brain or by causing a release of endorphins, natural chemicals in the brain which act as an analgesic.

This form of electrical stimulation is commonly known as TENS [transcutaneous electrical nerve stimulation]. TENS should not be confused with EMS [electrical muscle stimulation] which can be used to stimulate a muscle contraction.

Therapeutic Exercise

Therapeutic exercise refers to physical activities prescribed to improve function, correct an impairment or obtain a state of well-being by restoring strength, endurance, flexibility, stability and balance.

The first objective of the therapeutic exercise is to assist the body in reducing pain and inflammation. Once that is achieved, often in conjunction with modalities, the exercise focuses on improving range of motion, increasing muscle strength and endurance.

With polio affected muscles, if an exercise is too strenuous, certain signs of overuse may occur within 24 to 48 hours. These signs include muscle cramps or spasms, muscle twitching, moderate to severe muscle pain and extreme fatigue. This needs to be reported to your physical therapist so that the exercise program can be modified.

Stretching, Strengthening, Conditioning: Muscle flexibility and joint range of motion are achieved through stretching and movement. The stretching helps lubricate the joints and prepare the nervous system.

Hold a stretch position for 20 to 30 seconds. Don't bounce into the stretch. People with spinal

issues often have tightness in their lower back and hamstring muscles. However, if paresis of the hamstring occurred with polio, these muscles are often overly flexible. Do not overstretch weak flexible muscles.

Strengthening exercises are performed with resistance using weights, stretch bands, or your own body. Often the core muscles are weak with spinal issues. However, when complicated by a battery of polio, the exercise guidelines must be observed. Increase resistance and number of repetitions cautiously. Watch for signs of overuse.

Endurance exercises engage large muscle groups over a longer period of time. When the muscles have good endurance, they will support the spine and provide postural stability throughout the day. When early fatigued, the spine is subject to more biomechanical stress.

Aquatic Exercise: An excellent way of achieve improved flexibility, strength and general conditions is with aquatic exercise. Aquatic exercise is very beneficial, as the buoyancy of the water will help support weak muscles and decrease joint stress while it can also provide resistance to strong muscles. Exercises are modified in the water and core muscles can be strengthened by using the resistance of moving both arms at one time.

Body Mechanics.

Body mechanics refers to the way we move during daily activities. Good body mechanics may protect the back from pain and injury. Adjustments during daily activities may be required to accommodate body changes related to aging, spinal dysfunction and polio related issues. Movement methods used in the past may not be safe and effective with the physical changes.

Good body mechanics and proper positioning can help protect your spine and may help alleviate some associated problems with digestion, swallowing and breathing. Following are some basic guidelines to help you with good body mechanics. Of course, this can be difficult depending on your physical limitations. Supports, braces and positioning devises can help with proper body mechanics.

When lifting an object: Stand with feet apart, back straight. Bend from knees, not the waist. Get close to the object. Lift the object using your arm and leg muscles. Do not use your back muscles. Pivot to turn, do not twist. Ask for help is you are unable to lift the object.

When carrying an object: Hold the object close to your body. Do not carry things that are too heavy for you. The seat of a rolling walker can carry your lunch tray, a laundry basket or groceries and take the strain off your spine.

Sitting: Sit on a supportive chair with armrests. Use a small pillow, rolled towel or lumbar roll to support your lower back. Sit on a wedge shaped cushion if there is significant atrophy of one buttock in comparison to the other. Do not sit for long periods of time. Get up and change position.

Conclusion.

Physical therapy evaluation and treatment of spinal dysfunction provides intervention and guidelines for the long term management of symptoms. To maintain the results achieved in physical therapy, compliance with a **realistic** exercise program, simple lifestyle modifications and small adjustments to movement is essential. Improvements in spinal health and a general sense of wellbeing can be attained.

Active and Passive Isolated Stretching. www.stretchingusa.com

Editors note:- Some years ago I was asked by a post polio support group in central Florida if I could visit Aaron Mattes to learn more about the treatment he offered. This method of stretching increases range of movement in a very short time. Each stretch can be done by you [Active] or to you [Passive] Aaron presented and demonstrated at our Annual General Meeting in 2004 and at personal sessions later that day. He also did a days taster course the day before for 20 local therapists. His well known method of stretching is used by many medical, sports and alternative health professionals as part of their treatment packages. Available on the website are manuals and DVD's that demonstrate each stretch which can be done by you or to you by a therapist or taught to a family member.

Ten Instant Stressbusters
from Why Worry? Stop Coping and Start Living
Kathryn Tristan, Washington University School of Medicine.

1. **BREATHE, BREATHE, BREATHE.** The amazing power of feeling more relaxed begins with taking three deep breaths and slowly exhaling. Stop stressed out shallow breathing.
2. **MOVE, WIGGLE, STRETCH.** To dissipate anxious feelings loosen up taut muscles and move around.
3. **FOCUS ON NOW.** Although you have to plan for the future and take care of responsibilities, don't forget to enjoy the present moment.
4. **SAY A CALMING PHRASE.** Develop a phrase that helps you such as "all is well" or "This, too, shall pass." Keep repeating it.
5. **FOCUS ON POSITIVE POSSIBILITIES.** Stop terrorizing and assuming the worst may happen. Visualize things going the way you want and feeling happy about it. POSSIBILIZE!
6. **EMBARGO JUNK FOOD.** What you eat affects your mood. Reduce sugary, caffeinated, or non-nutritious food. Try eating a banana, some turkey or drink chamomile tea. All contain natural relaxants.
7. **TAKE A HIKE.** Get out or connect with Mother Nature in some way. Touch your feet to the ground to literally 'get grounded.'
8. **DO SOMETHING ENJOYABLE.** Whether it's gardening, organizing, or engaging in a special hobby, etc., build in some fun time.
9. **SMILE.** Studies show whether you mean it or not, smiling releases mood-enhancing endorphins.
10. **TAKE A MENTAL HEALTH DAY.** Sometimes you just need a break to rebalance. You deserve it.

THE FIVE MINUTE MENTAL MARINADE

To quickly reset and rebalance both psychologically and physiologically, do the following exercise. It should take about five minutes or longer if you wish. It's a great "bad-biochemistry" buster and something especially to do before bedtime!

- ◆ **CROSS** your hands over your heart.
- ◆ **CLOSE** your eyes and take 5 deep, slow breaths.
- ◆ **RECALL** five positive things about your life.
- ◆ **FOCUS** on a beautiful scene, someone you love, or something you love to do.
- ◆ **TAKE** five deep, slow breaths.
- ◆ **RELAX** and marinate the feeling!

For more free tips, tools and strategies see www.whyworrybook.com

Your Newsletter needs your stories, hints, tips and bits

A way of doing something, or aid, that helps you might help someone else. Tell us.

How about a recipe that tastes great on the lips but not on the hips.

CARERS - Are you a Carer and would like to write and tell us how we might help Carers understand what you go through helping us manage our lives.

Articles and items for Post Polio Matters

are always welcome, by post, by email and by phone if writing is not easy for you.

Deadline date for next issue is July 30th 2014

Sunday June 1st 2014.

Advice on Solo Aging.

Member Jann Hartman. - Restructuring my life after my husband's premature death continues to be a challenge, but the transition has brought with it the realization that I am not truly alone. Faith, friends and family are what get me through one day to the next.

Susy Stark, PhD, OTR/L, FAOTA - Aging in a place alone with a disability can be easier with "environmental support". Support can be formal or informal personal support or changes to the physical environment. Strategies to enhance daily activity performance and community participation will be discussed.

Editors Note: If you are managing alone and would like to share information and ideas with Member Jann Hartman please get in touch with PSN and I will pass on your details.

Relatives of Survivors ; Three Perspectives.

Stephanie T. Machell, PsyD, Mary Navarre, OP EdD, Willard (Bill) Smith PhD.

It has been observed that when one member of a family has a disability the entire family is affected. In this presentation family members of polio survivors will speak about their experiences as spouse, sibling, and child of a polio survivor. The diversity of our experiences and those of all who have lived in polio-affected families is reflected in the different styles that will be used by each presenter, including storytelling, a meditation on marriage vows, and a consideration of how personal experience can create and be integrated into professional life. At the end of the presentation the moderator will engage the audience in dialog with the presenters about how what we have presented might help polio survivors and their families better support one another by opening up communication and sharing our experiences.

Editors Note:- It was not possible to attend this session but I hope to get a report from another polio survivor who attended for the next issue.

Late Effects of Polio and Your Health

Frederick M. Maynard MD.

This talk explores concepts of holistic health and categories of changes resulting from aging with paralytic polio sequelae that affect health and function. One change is loss of muscle strength resulting from motor nerve losses that defines post-polio syndrome, a late complication of polio. Other common complications result from years of living with initial polio sequelae (weakness and deformities). Most relate to accelerated age-related "wearing out" of joints, ligaments, muscles and tendons, resulting in musculoskeletal pain problems. Also, many common medical conditions known as co-morbidities of aging" may develop at increased frequency. These include heart disease, diabetes and obesity and commonly produce fatigue and weakness. Other changes occur in the psychosocial and environmental dimensions of health.

Five key strategies for achieving lifetime wellness as a polio survivor will be discussed at length:

- 1) optimize activity and exercise;**
- 2) optimize nutrition, sleep and reduce stress;**
- 3) prevent complications and/or recognize and treat early;**
- 4) educate yourself, family and friends;**
- 5) empower yourself by taking control and involving others.**

Editors Note:-

Anyone who attended this Conference is welcome to send in articles for future issues.

11/6/2014 Global Polio Eradication Initiative via ReliefWeb

Independent Monitoring Board of the Global Polio Eradication Initiative Ninth Report. - May 2014.

Extract:- EXECUTIVE SUMMARY

Eighteen months ago as 2012 drew to a close optimism was running high for the Global Polio Eradication Initiative. Polio transmission in India had been interrupted. The three remaining endemic countries (Pakistan, Nigeria, Afghanistan) had made significant programmatic improvements. Some believed that success was imminent, that polio would soon be history. Within a matter of months, the optimism quickly unwound.

Targeted killing of polio vaccinators in Pakistan shocked the world and created major operational constraints.

Polio virus entered Waziristan, a part of Pakistan in which polio vaccination had been - and remains - banned by Taliban commanders.

The national structure for managing polio eradication in Pakistan was dismantled at a time when it needed to be strengthened.

Nigeria's security situation deteriorated. Here too vaccinators tragically lost their lives and the program's operations were severely impaired.

Nigeria polio virus was exported to southern Somalia where it infected a population unprotected against polio because of an al-Shabab ban on vaccination that remains in place.

Pakistan polio virus spread to Syria, causing a major outbreak amidst the country's civil war.

Pakistan polio virus spread also to Israel, West Bank and Gaza and Iraq, and Nigeria polio virus to Cameroon and Equatorial Guinea - each outbreak over-stretching the global program's resources and credibility.

In 2012 there were 233 polio cases in five countries. In 2013 there were 407 cases in eight countries. During last year and first few months of this year much hard work has been undertaken by infected countries and their global partners to try to reverse the negative eradication trend that became established in 2013.

Nigeria has markedly improved vaccination coverage in many areas, most notably in Kano and in the highest risk Local Government Areas, and has been rewarded with a substantial decrease in polio transmission.

Afghanistan has maintained strong performance and is on track to stop endemic transmission before the end of 2014, although importation of Pakistan polio virus will continue to pose a threat.

In Somalia, the program responded strongly to the outbreak of Nigeria polio virus and transmission has now been substantially quelled as a result. Responding quickly to the IMB's [Independent Monitoring Board] criticism in October 2013, the program also strengthened its coordination across the Horn of Africa.

In Pakistan, Peshawar and Karachi mounted innovative and determined campaigns to reach children with polio vaccine in a manner that maximises the safety of the polio vaccinators - bright spots in an otherwise gloomy program.

When Pakistan polio virus was detected in Syria, novel challenges mixed with some controversy over the program's approach in a complex conflict-affected environment. Despite this, in the IMB's view, the program responded well - in Syria and across the region.

The global community, recognising the importance of polio eradication, requested WHO [World Health Organisation] to convene an emergency committee under the International Health Regulations, as the IMB had recommended. On this committee's advice, WHO has recommended mandatory travel vaccination for residents and long-term visitors travelling internationally from countries exporting polio (currently Pakistan,

Cameroon and Syria), but the recommendation would also immediately apply to Nigeria or any other country in the event of a future export.

Source article http://reliefweb.int/sites/reliefweb.int/files/resources/10IMB_Report_EN.pdf

14th June 2014 - USA: Travelers Headed to 10 Countries in Africa, Middle East Urged to Get Polio Vaccine Booster. - ArkansasMatters.

Extract LITTLE ROCK, AR [News release] - The Arkansas Department of Health cautions people and groups traveling to Afghanistan, Cameroon, Equatorial Guinea, Ethiopia, Iraq, Israel, Nigeria, Pakistan, Somalia and Syria. The World Health Organisation [WHO] declared the international spread of wild poliovirus [WPV] also known as polio, a Public Health Emergency of International Concern. As a result of that declaration, the Centers for Disease Control and Prevention [CDC] has issued new polio vaccine recommendations for travellers to these countries.

The United States has been polio-free since 1979 however, there are countries in the world where the virus is still a serious problem. Those traveling to these countries for business, pleasure or a mission trip should make sure they review the new guidelines to protect their health.

The CDC now recommends an adult inactivated poliovirus [IPV] booster dose for travellers to the 10 countries listed above. Countries are considered to have active WPV circulation in they have ongoing endemic circulation, active polio outbreaks, or environmental evidence of active WPV circulation. Travelers working in health care settings, refugee camps, or other humanitarian aid settings in these countries may be at particular risk.

Source article - <http://www.arkansasmatters.com/story/d/story/travelers-headed-to-10-countries-in-africa-middle/11942/S0Twb8DI0arYik7mNdwcQ>

14th June 2014 Mosquito-borne virus shows polio-like symptoms. - The Times of India.

Extract. PUNE. Two months after the country earned its polio-free tag, a mosquito has emerged as a fresh concern. Mosquito-borne West Nile virus has been found to be causing acute flaccid paralysis [AFP], the main symptoms of poliomyelitis, for the first time in India. The symptom is the most common sign of acute polio and is used for surveillance during polio outbreaks.

However, unlike polio which is a childhood disease, West Nile Induced AFP is seen in adults. So the finding is not going to undermine the success of polio free certification, say researchers, but is still reason for concern. Nationwide AFP surveillance is the gold standard to detect polio cases.

Neurologists from hospitals in Kochi, Kerala along with virologists from Indian Council of Medical Research [ICMR] designated virology laboratory Manipal Centre for Virus Research [MCVR]. Manipal University have reported three laboratory confirmed cases of West Nile virus induced AFP, a syndrome historically associate with infection by polio virus.

The findings are bewildering. While polio virus is a member of enterovirus family transmitted by water, the WNV is an arthropod borne virus from the arbovirus family, which is transmitted by mosquitos. However, the devastating effects are found to be the same", said virologists G. Arunkumar, professor and head. Manipal Centre for Virus Research and one of the main researchers who reported the first three cases of West Nile virus induced AFP.

The emerging threat from the West Nile Virus is being looked at with concern given that the country earned it polio free certification from wild polio virus transmission only in March this year.

The case reports of three patients, all in the age bracket of 42 to 55 years, have the doctors flummoxed. The three patients were suffering from extreme muscle weakness of limbs, reduced muscle tone, impaired breathing and fever which are primarily the characteristics of polio.

Only after running blood tests and performing a battery of radiology tests that record activity in the nerves and in spinal cord cells, did the doctor reach their diagnosis AFP caused by West Nile Virus.

"Previously, severe cases of West Nile had been characterised by meningitis and encephalitis, the brain swelling that is regarded as the most serious consequence of the virus. But the muscle weakness and other problems associated with AFP were not evident said Arunkumar

Source article

<http://timesofindia.indiatimes.com/City/Pune/Mosquito-borne-virus-shows-polio-like-symptoms/articleshow/36517803.cms>

Editors Note:-

I have included the following letter written by someone with Parkinson's because I think you will find some similarities with how he feels. Maybe it will help you write something for your family and friends. Richard has both PPS and Parkinson's as do a few other Polio Survivors we know in the States. There are other Polio Survivors with PPS who also have MS, or Cancer, Diabetes, Heart problems, Arthritis, Fibromyalgia etc. Life is what we make of it. Share how you feel about what is happening to you with others and **listen and allow them to tell you how they feel** about seeing this change in your life. I suggest that this should also include your health professionals especially those that you have seen for quite a few years.

This letter has been reproduced from Parkinson's UK Lincoln Branch Newsletter with permission.

I have Parkinson's. It is not catching or hereditary. No one knows what causes it, but some of the dopamine cells in the brain begin to die at an accelerated rate. Everyone slowly loses some dopamine cells as they grow older. If the cells suddenly begin to die at a faster rate Parkinson's develops. It is slowly progressive and usually occurs as people get older. Medicine can help. I'll take newer, stronger kinds over the years. Some make me sick and need lots of adjustment. Stick with me. I have good days and bad days.

Tremors - You are expecting me to shake. Maybe I will, maybe I won't. Medicine today takes care of some of the tremors. If my hands, feet or head are shaky, ignore it. I will sit on my hand or put it in my pocket. Treat me as you always have. What's a little shakiness between friends.

My Face - You think you don't entertain me anymore because I am not grinning or laughing. If I appear to stare at you, or have a wooden expression, that's the Parkinson's. I hear you. I have the same intelligence. It just isn't easy to show facial expression. If swallowing is a problem I may drool. This bothers me, so we'll mop up.

Stiffness - We are ready to go somewhere and as I get up I can hardly move. Maybe my medicine is wearing off. This stiffness or rigidity is part of the Parkinson's. Let me take my time. Keep talking. I'll get there eventually. Trying to hurry me up won't help. I can't hurry. I must take my time. If I seem jerky as I start out, that's normal. It will lessen as I get moving.

Exercise - I need to walk every day. I will do as much as I can. Encourage me to do a little more each day. Walk with me. Company makes walking fun. It may be a slow walk but I will get there. Remind me if I slump or stoop. I don't always know I am doing this. My stretching, bending, pushing exercises must be done every day. Help with them if you can.

My voice - As my deeper tones disappear, you will notice my voice is getting higher and wispy. That's the Parkinson's. Listen to me. I know you can talk louder, faster and finish my sentences for me. I hate that! Let me talk, get my thoughts together and speak for myself. I'm still there. My mind is OK - because I am slow in movement, I talk more slowly too. I want to be part of the conversation. Let me speak.

Sleepiness - I may complain that I can't sleep. If I wake in the middle of the night, that's the Parkinson's. It has nothing to do with what I ate or how early I went to bed. I may nap during the day. Let me sleep when I can. I can't always control when I am tired or feel like sleeping.

Emotions - Sometimes I cry and appear to be upset and you think you have done something to hurt my feelings. Probably not. It is the Parkinson's. Keep talking to me, ignore my tears. I'll be OK in a few minutes.

Patience my friend - I need you. I'm the same person. I've just slowed down. It's not easy to talk about Parkinson's but I'll try if you want me to. I need my friends. I want to continue to be part of life. Please remain my friend. ANON.

Genuine comments to Councils.

I am writing on behalf of my sink which is coming away from the wall. My lavatory seat is cracked, where do I stand.
The toilet is broken and we can't bathe the kids till it's fixed. It's the dog mess that I find so hard to swallow.

Management Committee [Trustees] and Operations Team

Management Committee [Trustees]

Chair - Simon Parritt - simon.parritt@poliosurvivorsnetwork.org.uk

Secretary - Hilary Boone - hilary.boone@poliosurvivorsnetwork.org.uk

Treasurer - Gillian Bryan - gillian.bryan@poliosurvivorsnetwork.org.uk

Trustee - Chris Salter - chris.salter@post-polio.org.uk

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Administrative Support - Gillian Bryan - gillian.bryan@poliosurvivorsnetwork.org.uk

Printing and Website - Elpeeeko Ltd, Lincoln.

 Please contact us if you would like to help with our work 

Membership

Full membership includes voting rights and is available to polio survivors, their partners, families and friends.

Associate membership, no voting rights, is available to patient organisations, health and social care professionals working in the interests of polio survivors £10.00 per year

Membership Fees

UK Individual - £ 12.50 per year

Associate Membership - £ 10.00 per year

Yearly fees can be paid by Standing Order.

Life membership - £ 150.00 or pay by Standing Order £ 5.00 x 30 mo.

We welcome members living in other countries and details will be sent upon request.

Please note the majority of information will be sent via the Internet.

Email:- membership@poliosurvivorsnetwork.org.uk

All Forms are available on our Website, by phoning our helpline or writing to us.

<http://www.poliosurvivorsnetwork.org.uk/joinus.html>

Donations

giftaid it

Donations, small or large, towards our work will always be gratefully received.

SEE BACK PAGE - Val Scrivener is making and selling brilliant photo greetings cards

- Some members send us a few postage stamps
- Some members take their newsletter via the internet saving us printing and posting costs.
 - Others add a donation amount to their yearly cheque, or Standing Order amount.
- Some members send us a donation with some specifying, e.g. for AGM, for Conference.Fund
 - UK Taxpayers can Gift Aid their subscription and donated amounts.
- **NEW CONFERENCE & MEETING FUND - See Editorial**

The Gift Aid scheme. Charities can reclaim an extra 25% in tax on every eligible donation by a UK taxpayer. This 'transitional relief' does not affect your personal tax position. You must pay tax at least equal to the amount reclaimed on your donations in the current tax year.

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Polio Survivors Network

Lincolnshire Post Polio Network - Registered Charity No. 1064177

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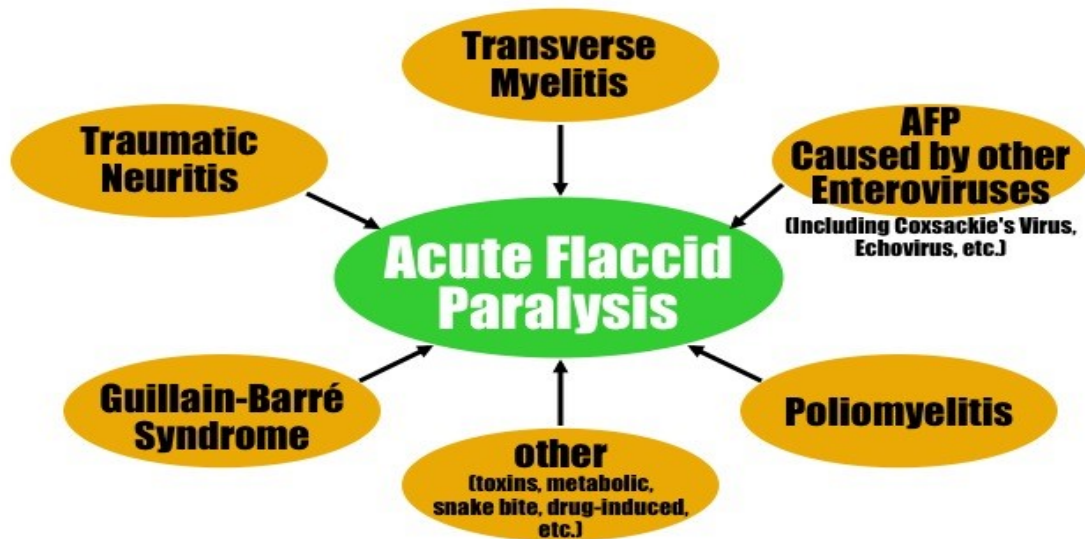
POLIO SURVIVORS ARE BEING TOLD 'BECAUSE YOU ARE ALL DYING OFF'

there is no need to teach more facts

about the symptoms and problems you are experiencing,
do more research or provide specialist health professionals and clinics

What about the other diagnoses who have Acute Flaccid Paralysis?

Partial Differential Diagnosis of AFP



POLIO

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