

PPASS Times

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From Where I Sit

By Jane St. Onge, Chair

Craniosacral Therapy -

Like Post Polio Syndrome, craniosacral Therapy isn't a familiar term. My understanding is the craniosacral system involves the bones of the skull, mouth and face (the cranium) and extends down the spine to the tailbone area (the sacrum). Cerebrospinal fluid that surrounds and protects the brain and spinal cord is enclosed in membranes that are attached to these bones. In Craniosacral Therapy, the therapist uses a light touch at the skull and tailbone area to monitor the rhythm of this fluid as it flows through the system. The therapist then uses gentle manipulation to correct any imbalance or restrictions.

I first learned about this from a friend of mine who is a physical therapist. About 10 years ago he was trained in Craniosacral Therapy. He then added these methods to his practice and was so pleased with the results, he has continued to explore al-

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In Search of an Iron Lung

By Larry Kohout

The following is the unexpurgated opinion of the author and does not reflect on the corporation or its other officers or board members.

Ilost my ability to breathe on my own 50 years ago. I also got it back nearly immediately. Whether due to the fever and the illness or my own inability to deal with the trauma of that time I have spent the past 50 years believing that the iron lung I was in had not been turned on. A few months ago, I finally came to the realization that it had been turned on, and that the disease had actually taken away my ability to breathe for one short week.

As it turns out, the after affects of that disease have once again taken away my ability to breathe on my own, and I have been using a ventilator for the past three years. For me the iron lung has been a symbol of fear. But for several of my friends, people who were not as lucky as I was, the iron lung has not been a symbol of fear, but a friend. For these people the disease took and kept their ability to breathe as

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Group Happenings

By Larry Kohout

Well I'm not sure what happened in the groups this past two month period. I sent out a note in March letting everyone know what the deadline for this issue would be and I **assumed** that everyone knew and would comply with the deadline. The operative word in that sentence is assume. Do you know how to spell assume? The old saw is that every time you assume you make an ASS of U and ME and I think that's exactly what I did. Mostly the egg ends up on my face. Apparently, no one got the note and I got the input from no one. Electronic communication is not as reliable as we'd like to believe it is.

As it turns out, I had everything ready to go for this issue and was ready to start working on why the Group Happenings columns weren't coming in when I got word that my mother (who has been in a nursing home with Alzheimer's disease) was rapidly failing. Therein lays the reason that PPASS Times is so late this issue. Mother passed away on the 13th of April, was cremated and for reasons of scattered fam-

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From Where I Sit

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ternative treatments for his patients. When my post polio symptoms were at their worst, my friend asked if he could treat me with some of his new approaches. I was hesitant. This new therapy sounded a bit strange, a little "out there." So I stalled, for quite awhile. Thank goodness, my friend persisted and I decided to give it a try.

I barely had enough energy for my first appointment. My craniosacral rhythm was 27. A reading of 6 was normal. My treatment lasted over an hour and during this time, using very gentle manipulations; my friend was able to release many restrictions to my craniosacral system. I left feeling much better and instead of going home for a nap, I went out for lunch. I continued getting treatments two to three times a week for a month, and then I was able to taper off. My body was functioning better and because I had more energy and less pain, I was moving more. My good muscles were getting some exercise and my balance improved. My PPS symptoms didn't go away, but they were more manageable.

I still have Craniosacral Therapy, usually every 6 weeks. I think of it as my "tune up." By then my pain and fatigue have increased, my chest and neck muscles have tightened making my breathing shallower and my

right hip has slipped down so that my leg drags. I know I need a treatment. After an hour of therapy, my hip is back where it belongs; I can breathe better and move my neck. I have more energy and my pain is less.

As I've been traveling, I've found other craniosacral therapists to treat me by looking in the yellow pages under physical or massage therapy. All the therapists I have found have been trained by the Upledger Institute. You can get a list of therapists from their website www.upledger.com. These treatments, not always covered by insurance, average \$60-70 for an hour's therapy.



Group Happenings

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ily, we didn't have the memorial service until May 1st. Thanks to all of you who send me expressions of sympathy, and to those of you who didn't know, thanks now for your thoughts. I'm now finishing the newsletter during my annual sojourn to the North Shore of Lake Superior. So believe me it will be relaxed.

We'll see if we can't work out a better communication mechanism with the Chapters so that we get input from each of them as to what has happened during the past period. Those of you in the Chapters, think about taking your turn at reporting for your Chapter.



In Search of an Iron Lung

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well as most of their other voluntary muscle functions. For these people the iron lung has been a safe and comfortable home that has allowed them to breathe freely and comfortably as though they were breathing on their own.

There aren't many of these people left, something less than 50 in the whole country and this includes people other than just the polio survivors who have been using the iron lungs the longest. There are also people who have spinal muscular atrophy and similar diseases that have chosen the iron lung as the safest and most reliable form of ventilation available.

And what is happening to all these iron lung users? Respironics, the company that has been maintaining the iron lung for these past years, has decided that the iron lung is not commercially viable. Therefore, they have told the users to work with their doctors to find another form of ventilation that will sustain them. If the users so choose, the company will give them the iron lungs that they are using and it then becomes the users' problem to maintain the machines themselves.

Shame on you Dr. Salk. Shame on you Dr. Sabin. How could you eradicate a disease in this hemisphere and make this product "not commercially viable?" Now this poor company must rely on other diseases and accidents to create the clientele to use their ventilators, their masks, their Continuous Positive Airway Pressure (CPAP) machines. Because there are hun-

dreds of thousands of us who use these various machines, **they** are all “commercially viable.”

And what is happening to all these iron lung users? Well, one I know of has transitioned to a Port A-Lung. Another has accepted the iron lung and is going it on her own. Another intends to accept the offer when it comes time and is looking for another machine to use as spare parts. Do you know of an unused iron lung that is lying around somewhere? If so, please do let us know so we can do something to help these people.

Do these people have another choice? Yes, they could change from the positive/negative pressure ventilation of the iron lung that they have been using for the last 45 to 55 years and move to positive pressure ventilation. Of course this would probably require that they also undergo tracheotomies as it is rare for someone who uses ventilation 24/7 to be able to use it through non-invasive means especially if they also lack arm and hand function. Arm and hand function would allow them to reposition a mask if it begins to rub or to pick up a mouth tube if it is dropped. But without arm and hand function these things aren't possible and the likelihood is that they will end up undergoing tracheotomies.

Of course, Respironics will then be able to rent them another ventilator, one of their many commercially viable ventilators that work in conjunction with masks or tracheostomies. The cost of these ventilators may even be slightly less than the cost they are currently charging for the iron

lung.

But then there are the costs associated with maintaining the trach. The trach tube itself has to be replaced every six to ten weeks, the inner cannulas must be purchased, cleaned, and ultimately replaced. There are drain sponges and collars needed daily to say nothing of the necessary daily cleaning supplies: peroxide, saline, and single tipped cotton swabs. Oh yes, there is also a breathing circuit (a fancy name for the hose that hooks the person to the ventilator) that is replaced twice each week otherwise nasty little bugs begin to grow in them and eventually invade the lungs.

I've forgotten to mention another issue, smelling. That's out. You don't get to use your nose anymore as all your air is now supplied through a hole in your trachea and that bypasses your nose. But the nose has another function; it maintains the humidity level within our lungs. When our nose is taken out of the breathing loop, we have to compensate for it by adding humidity to the air we breathe. Guess what, Respironics just happens to manufacture a number of different models of humidifiers.

And what is happening to all these iron lung users? Some are transitioning to a device called a Port A-Lung. This modern reincarnation of the iron lung seems to be commercially viable, probably because someone holds a patent on some little part allowing them to charge six prices for it. Some are sticking with their iron lungs and betting their lives that it won't fail. Some are still hoping Respironics will change their corporate mind.

All the people I know who use iron lungs are total quads, they have no ability to make any, but the smallest of movements on their own: shift a head, wiggle a finger. For these people being moved is difficult, even painful, so, unlike me, mobility is not a priority for them. Their preference is to stay put because staying put doesn't hurt as much as moving does. I finally got the nerve to ask Carol Purington, one of my iron lung using friends, to discuss the psychological aspects of using an iron lung. She responded, “The lung has always provided the most effective and most comfortable breathing for me. It has always been where I rested when I was tired or sick. It was, during hospital days, where I felt safest from painful treatments. It is, I suppose, both physically and psychologically a combination of security blanket, comfortable old chair, and very private space.”

And what is happening to all these iron lung users? Do they have a choice? Yes, they do, they can leave their security blankets that they have depended on for 45 plus years and try something new. That alternative works for me. However, I'll tell you this, I sure wouldn't want to be forced to give up the ventilator that I've come to trust and depend on these last three years.

When I first started having breathing problems, six or seven years ago, my doctor prescribed a Bi-level Positive Airway Pressure machine for me (BiPAP). The machine I got was from Respironics. I have thought highly of the company as I have had to

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In Search of an Iron Lung

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learn more about the ins-and-outs of breathing problems. It is funny how quickly you change your opinion of a bully, isn't it.

Please look around, and ask around, and if there is anyone you know that has an iron lung, we have someone that very much wants access to that machine. All my contact information is on page 16. As I started this article there were two people that were looking for spare iron lungs but luckily our Marilyn Rogers has found one. Now we need to find one for Martha Mason, author of *Breathe, Life in the Rhythm of an Iron Lung*.



Coming Meeting Dates

By Larry Kohout with input from Chapter Leaders

Brainerd/Baxter

Monday, May 3rd – to be announced.

Monday, June 7th – to be announced.

Owatonna

Wednesday, May 19th – View the video *A Paralyzing Fear, - The Story of Polio in America*

Wednesday, June 16th – View the video *Modern Marvels - Polio Vaccine*

St. Cloud

Friday May 7th – to be announced.

Friday, June 4th – to be announced.

Twin Ports

Monday, May 17th – Physical therapist students from Lake Superior College are scheduled to come for a discussion with polio survivors on how PT can help with PPS and why it often is harmful.

Monday, June 21st – to be announced.

West Metro

Monday, May 15th – ATTENTION! This was **not** a Monday meeting. This was one of our two parties a year. This was our Saturday Spring picnic.

Monday, June 14th – Since June begins the travel season, we are going to have a group discussion focusing on travel experiences. Dig back into those memory cells and bring both your successes and your failures to share with the group.



Late Breaking News

By Larry Kohout

You may remember that in the January/February issue we presented a proclamation that we had sent to the Governor asking him to declare 2004 the Year of Polio Awareness. We got a call this morning, May 27th, from the Governor's office (an administrative assistant actually) telling us that the proclamation is signed.

Now we need to find ways to make use of the proclamation to spread the word and the work of PPASS MN. It is unfortunate that we missed the April 12th anniversary of the start of the largest placebo-controlled, double-blind study ever undertaken by the scientific community, the field trials of the so-called Salk polio vaccine. However, the trial did continue on throughout the year so maybe we can use it that way.

Next Issue — Those of you with Internet access received an E-Mail message from me a while ago letting you know that the public television stations in Duluth and Rochester were carrying a new documentary put together by KERA TV in Dallas, Texas called *A Fight to the Finish: Stories of Polio*. We subsequently wrote to public television in the Twin Cities and are now happy to announce that this program is scheduled to be shown on TPT channel 2 on Sunday June 20th at 4:00 P.M. and again on TPT channel 17 on Tuesday June 22nd at 9:00 P.M. PPASS MN has volunteered to assist with publicity.



Supporting PPASS MN

By Dick Baumer - Treasurer

After the title of this article caught your eye, you are probably thinking PPASS MN is looking for money again! Although financial support is essential for PPASS MN or any charity to continue providing its services, there are other non-financial ways to support PPASS MN and its Chapters. It is important to note that PPASS MN Officers, Directors, and Chapter Leaders are volunteers. PPASS MN has no salaried employees and it owns no property.

Financial Support

Let's get the financial support out of the way first. PPASS MN is a 501(c)(3) tax exempt charity as defined by the United States Internal Revenue Service. This status means that contributions to PPASS MN are tax deductible.

What is often overlooked is that many corporations have community and state charitable support programs, in which you, as an employee, may be eligible to participate. For example, your employer may award a charity of your choice a matching contribution based on a contribution you made. They may also have a program that simply grants a specific amount of money to a charity of your choice whether or not you made a contribution.

Your employer may also contribute to a charity for which you personally volunteer a specific amount of time each year. Of course you, a group of your friends, or a club that you may belong to may make a contribution to PPASS MN.

Check with your company human resources department to learn about their community relations programs and to make them aware of PPASS MN and our mission.

In-Kind Support

Although not often thought about, "in-kind" contributions are another way of supporting PPASS MN. In-kind con-

tributions are things like securities, property, buildings, vehicles, services, and labor.

Volunteer Opportunities

"How can I help" is all too often presented as an excuse rather than being stated as a question. Everyone has something they contribute to PPASS MN whether it's making phone calls, arranging meeting space, working on projects, joining committees, etc. As PPASS MN grows, there is an every increasing list of things to do. Here is a list of a few things with which we need help. You may not be able to help with any of them, but there may be chance you know someone who can and that person does not have to be a member of PPASS MN.

Grant Writer: We need someone experienced in writing Grant Requests. This is not a job for the faint of heart. This job requires someone who understands the mission of PPASS MN, can interpret the requirements of a corporation or other entity regarding their grant process, and then tell the PPASS MN story in a way that fits those requirements.

Newsletter: Whether or not you are an accomplished writer, you can contribute to the publication of the PPASS Times newsletter. Larry is always looking for relevant articles to publish. Whether you write them yourself or whether you see an article published elsewhere, bring it to Larry's attention. Remember, copyright law prevent publication of certain material without permission of the author or publisher. Polio, Post Polio Syndrome, and related health issues are always of interest to the membership. Coping with disability, family issues, travel, and a host of other topics are also worthy of space in the newsletter.

Committees: There are a couple of active committees at this time. Committees working on the election of officers and the Annual Meeting could use your help.

So you see, there is a great deal of opportunity for you to put your talent to good use. Step up to the plate and lend a helping hand.



One Psychologist's Perspective on the Polio Experience

Part 12

By Margy Hull, Ph.D.

I used to think that I had given more thought about our topic for this month--- asking for help--- than about anybody I know because I have to ask for so many things in the course of a day. Then I read the psychologist Marsha Linehan's ideas about asking for help in her book about treatment suggestions for people with personality disorder. Her pointers are really about

For those of us with the late effects of polio, asking for help is one of those arenas where our most deeply held values clash with what we are being told we must do to preserve our strength and well being.

emotionally healthy living and I thought it might be helpful to see how they relate to our issues. For those of us with the late effects of polio, asking for help is one of those arenas where our most deeply held values clash with what we are being told we must do to preserve our strength and well being. It has been so important to us to look and act like everyone else and not draw attention to our differentness. We are as American as the next

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One Psychologist's Perspective

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guy so self reliance is right at the top of the list of desirable qualities. Above all we do not want to be a burden, so what do you mean we need to learn to get help rather than wear ourselves out?

In order to do this thing that is so hard for us it may be helpful to have a frame of reference for thinking about whether to ask for help in any particular instance and if so, how intense to make the request. Linehan says that first we have to think about our priorities: how important is the thing that we are asking for help with? What effect will the request have on our relationship with the person asked? And what effect will the request have on our self-respect? Linehan's shorthand for these three dimensions of priorities is objectives, relationship, and self-respect.

Because of our rumored tendency to be perfectionistic, we need to take some time for Linehan's first question about objectives. Do the folds of the drapes really need to be rearranged? It's bad enough that we do this to ourselves and only right that we shield our families from our excesses in this area. For Linehan's other two questions about relationship and self-respect we need to stretch a bit in our conception of what is allowable and acceptable. Is our marriage really going to be jeopardized by asking our spouse to take over our task of putting away the dishes? (Whether or not it is will have more to do with how we ask rather than if we ask.) And is it

really true that having someone else wash your car is evidence of wimphood and wussdom for men everywhere?

Linehan goes on to consider other factors by presenting a series of questions to ask oneself about the making and intensity of a request in any given instance.

Capability: Can the person give me what I want? Whether we ask and how insistent we are should depend on to what extent the other person has the ability to grant our request. Insisting that our spouse put up the drapes when he doesn't have a clue on how, is a guaranteed miserable afternoon.

Timeliness: Good time for me to ask? In the middle of the baseball game is not it. Springing a request at the last minute is also dirty pool.

Homework: Am I prepared? Am I ready to be clear about what it is I want? Don't insist on immediate help with the drapes before you've decided where they go.

Authority: Is what the person does my business? Instructing the sales clerk on how to rearrange shelves to make them handier for the disabled is probably not my role as a customer. If I feel moved to make suggestions, I should diplomatically direct it to the manager.

Rights: Do I have a right to what I'm asking for, either because of law or established custom? Access to a public restaurant is my right. Ramps at my friend's house is, alas, another matter.

Relationship: Is the request appropriate to the relationship? This can be the most difficult to

answer but it boils down to figuring out whether either of us will end up feeling awkward later when we have to relate in a different manner. (The prosecutor asking the defendant to the door?)

Reciprocity: Am I asking more than I give? If our powers to give wane in some areas, we may need to think about other contributions we can make so we feel balanced in the exchange of favors.

Goals: Is asking important for long term goals? If I neglect to ask for help now will I be buying short term peace at the cost of feeling angry and alienated in the long run? I could take out the trash myself perhaps, but am I risking re-injuring my ankle right before our upcoming trip?

Respect: Am I acting competent? Am I too quickly asking for help when I could think up an easier way to do something myself thus saving my requests for the stuff I really need? (I think I have just revealed a silly unconscious idea I have that we are allotted a certain number of requests per day and we must learn to live within our means. It feels like that sometimes, but I think for most of us there is a liberal credit policy.)

Next month we go on to saying "no" when we're asked to do too much.

Margy Hull Ph.D. is a Psychologist who formerly worked in a community mental health center in Atlantic County, New Jersey.



Polio Biology XI

The Biology of Fatigue

By Eddie Bollenbach

Editor's Note - This Series was originally written for, and published in, the Lincolnshire Post Polio Library. It is republished here by Eddie's kind permission. This is the eleventh in the series

William Shakespeare, Sonnet XXVII: 'Weary with toil, I haste me to my bed.'

Everyone has experienced fatigue, even Shakespeare. It is a reaction the body has evolved to maintain a healthy steady-state. It is a countermeasure to overuse and acts to avoid damage to muscles and nerves. If our bodies, sculpted through millions of years of evolution, had no way to tell us that it is time to shut down, we wouldn't have gotten this far. So my first point in this essay is to emphasize that fatigue is not just the province of people living with post-polio syndrome. Everyone in the human family has experienced fatigue.

One area of the biomedical literature which has examined fatigue, and its components, is the discipline of sports medicine. The 2000 Sydney Olympics is on the docket and you can be sure that trainers and sport's physicians are studying every aspect of fatigue that can effect their athletes. Why? Fatigue degrades performance. An understanding of all of its manifestations allows athletes to take steps to avoid and minimize the likelihood

of a poor performance.

Of course we with post-polio syndrome live with fatigue. It is a much more common state for us and does not abate easily and normally as it does for an athlete. We have to be especially careful about it and also knowledgeable about it if we are to improve our lives.

Elite athletes know about fatigue to win medals, we must know about fatigue to improve our lives. Who knows more about the biology of fatigue, the elite athlete or the post-polio survivor? I hope this essay can help improve our general knowledge, from the biological perspective, and allow us to intelligently use this information to improve our lives.

Biology of Fatigue.

Throughout this series we have mentioned the motor unit. This is the nerve/voluntary muscle unit of contraction. The nerve depolarizes (that means the charge on the outside of the cell membrane (+) rushes inside (-) resulting in the charge on either side canceling). This depolarization moves along the nerve away from the Central Nervous System eventually to a voluntary muscle. When an activity requiring muscle contraction begins (running is a good example) the rate of depolarization and re-polarization (which requires energy) is rapid in the motor unit. The nerve cell depolarization triggers depolarization in the muscle cell membrane. The muscle cell depolarizes and the muscle fiber contracts

(shortens) due to the activity of proteins inside the muscle fiber. The muscle and nerve quickly recover and re-polarize. This uses nutrient energy. Then they fire again. If this rapid firing is not interrupted, either by other motor units taking over (which we lack- see [Polio Biology X](#)), or because of maximum intensity exercise over a long period, the nerve, nerve/muscle junction, and/or the muscle fiber itself will fatigue.

Inside the nerve the energy used to re-polarize the membrane is derived from specialized molecules, nutrients, and enzymes. As they become depleted waste products accumulate. If the waste products interfere with normal energy production and utilization we have metabolic fatigue inside the cell. The same can happen in the muscle fiber where chemicals like lactic acid, ammonia, and creatine build up faster than they can be excreted. All of this biochemistry, which may manifest as a feeling of burning inside a muscle, cramping, weakness, pain, or creepy crawly feelings are the result of fatigue, specifically **localized fatigue**. Any fatigue in the nerve, muscle fiber, or entire motor unit (muscle and nerve) constitutes localized fatigue.

If fatigue occurs in any nerves above the motor unit it is called **Central Fatigue**. It too is a common protective mechanism for the muscles and nerves below it and athletes experience it mostly as a

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Polio Biology

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consequence of over training. I get the sense that many polio survivors think that Central Fatigue is reserved for them and is a unique and disturbing symptom not known to others. This is not so.

There is a way to measure the magnitude of subtypes of Central fatigue. If you use a small electric shock to stimulate a muscle and measure the maximum force of contraction you can use this as a baseline of strength of contraction. If you then prompt a person to contract the same muscle as vigorously as possible you can measure the difference between tetanic contraction (of the unit with the electric pulse) and the maximum **voluntary** force possible. This is one measure of one subtype of Central Fatigue. We don't know a lot about Central Fatigue at the molecular level but it manifests itself, often, as a loss of drive or motivation to perform. Again, one can appreciate the role of Central Fatigue in protecting the nerves and muscles by inhibiting their over work at the level of the Central Nervous System.

There is a part of the human brain you may have heard about: **The Reticular Formation**. Nerve cell firing there keeps us awake. Some say, or have said, that polio damage has affected the reticular formation and that this is why some of us sleep so much and cannot easily rouse. I think

this would be a very difficult idea to prove because of the complexity of the arousal system and the role of Central Fatigue in overwork, blood gases, and other factors. If you experience a blow to the head the neurons of the Reticular Formation can all depolarize and you will be rendered unconscious. If re-polarization occurs (hopefully in a short while) you will awaken. Anyway, this depolarization and re-polarization is how all neurons work.

Let's get back to Central Fatigue. Any negative effect on muscular performance, which is generated above the motor unit, is Central Fatigue. This includes inhibitory processes arising in the brain. We know less about this but we do know that it occurs in athletes as well as in polio survivors. The Central Nervous System is involved to a large extent in the regulation of muscular activity. (Bompa 1990)[[1](#)]. Elements within the Central Nervous System result in a number of psychological factors, and emotions, which can degrade muscle performance and result in a loss of drive due to Central Fatigue. (McComas 1996)[[3](#)].

During prolonged exercise in an athlete, or during any activity which exceeds the fatigue point for a polio survivor, the blood chemistry changes. Amino acids, which make up proteins, change with respect to their relative abundances. Those amino acids with branched chains decrease and fatty acids increase. Ex-

amples of branched chain amino acids are leucine, isoleucine, and valine. Tryptophan is an amino acid but is not a branched chain amino acid. The ratio of Tryptophan/BCAA rises during fatigue, which results in a biochemical alteration of tryptophan to 5-hydroxytryptamine (5-HT) in the brain. You may know (5-HT) by its more commonly used name of serotonin.

To make a very complicated story short serotonin can act on serotonin receptors in the brain to cause sleep and also increase the mental effort (motivation) needed to maintain muscular activity. It's all rather complicated chemically, and this is but one theoretical biochemical pathway of many that helps explain Central Fatigue.

We've also heard of dysfunction of the hypothalamus and pituitary to explain Central Fatigue in post-polio syndrome. As is to be expected, these areas are implicated in Central Fatigue for elite athletes too. Possible indicators of Central Fatigue, cited by Lehman et.al. (1993)[[2](#)] include an impaired neurotransmitter metabolism, with increased cerebral 5-hydroxytryptamine (5-HT) concentration, partial hypothalamic and pituitary dysfunction, with resultant dysfunction of the neuroendocrine axes.

It has been observed that over-training in athletes (which happens often for our normal activities) results in faulty prolactin metabolism as

well as adrenocortical insufficiency. Well, enough of the biochemistry.

Suffice it to say that fatigue is a complicated phenomenon which involves motor units and the CNS and regulates the body by preventing overuse on many levels. There is not much difference in the CNS aspects of fatigue comparing elite athletes and polio survivors in my opinion. We just must do more with less and get to fatigue sooner.

I've never heard of anyone trying Branched Chain Amino Acids to help with Central Fatigue but I believe they are available at health food stores. To do any good (and they may not) you probably need 10 to 20 grams. Ask a physician before you try this. The fatigue is there for a purpose. If you reduce it without addressing the root of it you could hurt yourself.

References.

1. Bompa TO (1990): Theory and methodology of training: The key to athletic performance. (2nd ed.) Dubuque: Kendall/Hunt Publishing Company.
2. Lehmann, M., C. Foster, and J. Keul. Overtraining in Endurance Athletes: A Brief Review. *Medicine and Science in Sports and Exercise*. 25(7):854-862, 1993.
3. McComas AJ, Stuart DG, Thomas CK and Pierce PA (Eds) (1996): Fatigue: Neural and muscular mechanisms. New York: Plenum Press, pp. 457-469.



Book Review - Epidemics - Deadly Diseases Throughout History - POLIO

by Dick Baumer

I recently read a book titled *Epidemics - Deadly Diseases Throughout History* and subtitled *POLIO*. This is a hard cover but just a short read (60 pages or so) covering the polio story from early times to Post Polio Syndrome in a simple, very easy to read style. No new revelations or theories however. The book is written by Allison Stark Draper and was published in 2001 (ISBN 0-8239-3348-2). If any of you are looking for "polio basics" and don't want to spend several days reading consider this book. It's short, concise, and generally non-technical.

The introduction mentions a stone plaque displayed in the Carlsberg Museum in Copenhagen, Denmark which depicts a man with a withered right leg and a dangling foot. The plaque is from the Kingdom Period of Egypt circa 1300 B.C. and the man very likely was a polio survivor. A fairly detailed chart is included covering significant events, people and epidemics from 1771 through 2005 which is the tentative date for eradication of polio world wide.

Of particular interest is the early research on how polio was spread, how it was determined whether polio was a virus or a bacterial infection,

and of course, the Sister Kenny vs the medical community story. There are a few black & white photos of an iron lung ward, early braces, and some other treatment related photos.

This would be an ideal read for a middle school age or older student who needs to do a class project or simply wants to know about grandma or grandpa's bout with polio. At the back of the book is a Further Reading page. Here is a list of those books

- In the Shadow of Polio* -- Kathryn Black (1997)
A summer Plague - Polio and its Survivors -- Tony Gould (1997)
Small Steps: The Year I Got Polio -- Peg Kehret
A Nearly Normal Life: A Memoir -- Charles L. Mee (1999)
A Paralyzing Fear: The Triumph over Polio in America -- Nina Gilden Seavey, Jane S. Smith & Paul Wagner (1998)
Franklin D. Roosevelt -- Karen Bornemann Spies (1999)

Editor's Note

All of the books listed in Further Reading, above, are in the PPASS MN Library. In order to make use of a book in our library, call, write, or E-Mail the secretary (contact details in the disclaimer on page 16), with the name of the book or video you would like to borrow. It will be mailed to you free of charge, along with a return mailer, also free of charge. Make use of your library.



Doubles

By Landon Lockett

Editor's Note: Although Landon wrote this several years ago, this is the first time it has been published. It is published now with Landon's kind permission.

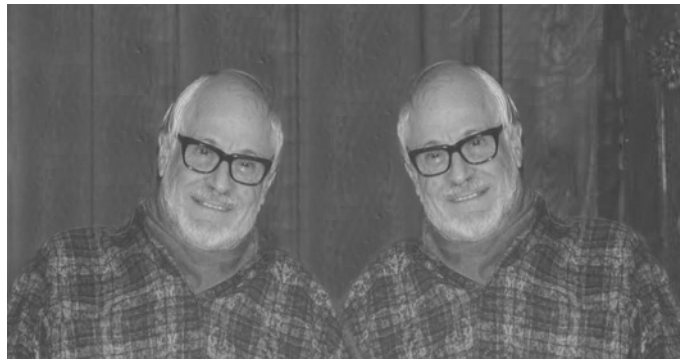
Who's your double? What? You don't have any? Are you sure? Yes, I know we physically challenged like to think of ourselves as unique, at least as to the particular constellation of disabilities with which each of us is endowed. You may still, however, have a double--or even several doubles. Have you met them yet? If not, do you know who they are? Whether you realize it or not, your double is probably out there, and could even bring to your life a touch of notoriety you never thought you deserved.

I am a post-polio, in a wheelchair, and have lived or spent some time in a number of places, primarily in Texas and Brazil. And I have two known doubles in Texas and three in Brazil.

What is a double? Well, haven't you ever been sitting in your wheelchair on a street corner and had a stranger come up and say, "Hi, Bill, how are you? Haven't seen you in months. How have you been?" The problem is your name isn't Bill. You can be sure, however, that Bill is someone, at least of the same sex as yourself, who also

uses a wheelchair. If this sounds familiar, then you too have a double, and if you live in a place for a while you may even get to know your double personally and be taken for him frequently. Even if you don't know him personally you may know who he is. You might have even, as I have, seen your double on national television. This is due to the mechanics of the situation. For a stranger to assume you are some other individual who also uses a wheelchair, and who may even bear some slight resemblance to you, it helps if this other individual is well-known. He

may even be a public figure. When I lived in



Landon Lockett and his double

Houston my double was a prominent lawyer. Although I won't mention his name, I happened to know this particular double personally, and was mistaken for him often. The more prominent your double is, the more people will have met him, and the more prestigious he is the more they will want to enhance their status by reminding him--or who they think is him--of the acquaintance. In Austin, the state capital, my double was a member of the legislature.

Having doubles is not too extraordinary in my home country. But, because of changed circumstances in my life, I came to live in Brazil. And what did I find? I also had doubles there, even more than back home. Only one of these did I know personally. He was the son of a prominent businessman in a small town in southern Brazil, and one day while I was sunning myself in the plaza there someone came up and asked, "Aren't you Osvaldinho, the son of Dr. Afonso Pinheiro?"

The second Brazilian double was too prominent for me to

know personally. I first heard of him when with some friends at a bar in

Olinda, a city not far from Natal, where I was working. As we sat there, a man who was apparently several drinks ahead of us came up and started talking to me in an excited and almost threatening way. I had no idea what was happening until a Brazilian with us jumped up and persuaded the man to leave, then explained to me that this person had thought I was a certain Brazilian senator from that area, a man who, of course, also uses a wheelchair. Once aware of this senator I began to look

for him on television and saw that he appeared often, was no more than ten years my senior and, like me, would not have suffered unduly from the loss of a few pounds.

While living in Natal I once went, with some friends, to Caico, a town deep in the arid interior of northeastern Brazil, one of the poorest and least-developed areas of South America. It was Saturday and Caico swarmed with country people, many of them wearing the leather hats that are the trademark of the rural nordestino. Wanting to visit the open market, I drove as close to it as I could, parked, and proceeded to transfer to my wheelchair, immediately attracting a small crowd of onlookers--people who had apparently never even heard of, much less seen, someone in my shape driving a car. But since the market turned out to be not exactly barrier-free, with everything from sacks of manioc flour to bundles of medicinal herbs cluttering the aisles, I decided to just sit on the sidewalk (one of my favorite sports, as you know by now) while my friends went ahead. As I sat there the small crowd slowly expanded to thirty or forty people, all staring at me. Not saying a word, just staring, and staring, until, even though I have a long experience of being stared at, I began to feel uncomfortable. From the awestruck attention I was getting I could have

been a paraplegic ET who had just rolled out of a flying saucer. Finally, as I was beginning to wonder what I might do to break the spell (I hate being conspicuous) an old man in a leather hat separated himself from the crowd and approached me.

"Excuse me, sir," he said. "Aren't you the nephew of Sr. Deolindo Carvalho?"

Editor's Note: The following was a private e-mail but Landon has agreed to allow it to be added to the story.

Larry,

I just got a phone call from my wife Carol saying she had just returned from a funeral service for a fellow librarian where she encountered Jim Fowler, a fellow wheelchair user who, like me, has a beard. While he and Carol were chatting Tom Moriarty, my foot doctor, walked up, saw Carol and Jim together, and said to Jim "Hi, Landon." Although I've often been thought to be someone else, this is the first time I know of in which someone else in a wheelchair has been thought to be me.

Landon



PPASS MN and Your Privacy

By Dick Baumer & Larry Kohout

Hardly a day passes without us hearing about identity theft, or an unauthorized person or group obtaining and misusing an individual's personal information, or marketing firms plugging your mail box with junk mail. While some of these activities can be considered a nuisance, others can be financially and emotionally devastating. Most of us have taken the warnings to heart and take measures to protect personal information.

The Secretary and Treasurer of PPASS MN are required legally and by our By Laws to maintain certain records. These records contain names, addresses, phone numbers, and e-mail addresses of the membership. Financial records include the transaction date, name, address, city, state, zip code, phone number, amount paid, and every transaction has a receipt number associated with it that is also recorded.

In the past, we published membership lists with people's addresses and phone numbers. We have ceased that practice altogether and now only share your personal information with those people inside the group who have a legitimate need to know. Within the West Metro Chapter, we have a system of callers who remind people of upcoming meetings. Those people receive the phone numbers and only the phone numbers of members who do not have another means of being contacted, namely e-mail.

Likewise, the West Metro Chapter as a Sunshine Lady who sends out get

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Your Privacy

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well cards and others such tokens to members who had experienced illness or tragedy in their family. The Sunshine Lady receives the information she needs to do her job on an as needed basis. Occasionally a member will call and ask for another members phone number. Unless I have absolute first-hand knowledge of the relationship between the two members I do not give out the information but call the second person and ask permission or give the name and number of the first person to allow the call to be returned.

While we have absolute faith and complete trust in both our chair and vice chair, they do not have a need to know and therefore do not have access to any personal information. Recently we have become aware that there is good reason to put all e-mail addresses in the blind copy area rather than send them in the open. This makes it more difficult if not impossible for spammers to harvest e-mail addresses. Therefore, in the future e-mails that amount from PPASS MN will have the addresses in the blind but a notice in the message as to which of the chapters have received that particular e-mail message.

We do indeed take seriously our responsibility to protect your privacy. Be assured that your personal information is not shared with anyone. Notes that accompany dues payments and even the mailing envelopes are fed through a crosscut shredder. If you have any concerns or questions about PPASS MN records feel free to call, write, or e-mail PPASS MN.



Owatonna Chapter off the Ground

by Dick Baumer

Thanks to Mr. Todd Hale, a Columnist for the Owatonna People's Press and Host of the Owatonna Today Show, word was spread about a PPASS MN informational session being held in Owatonna. Mr. Hale interviewed Dick Baumer (PPASS MN Treasurer) for his TV show which aired on local cable channel 14 on February 20th and again on the 23rd. In addition, Mr. Hale included an article about the meeting in his column in the Sunday, February 22 edition of the People's Press. As a direct result of Mr. Hales interest and involvement in this effort, steps are well under way to bring the Owatonna chapter under the PPASS MN umbrella.

Pat & Dick Baumer and Cathy and Larry Kohout hosted the PPASS MN informational session Monday evening, February 23 at Senior Place in the scenic West Hills complex in Owatonna, MN. Seven polio survivors and a couple of spouses from Owatonna and Medford were in attendance. Several others were unable to attend because of work schedule conflicts. Dick and Larry provided their personal polio stories followed by a detailed background of PPASS MN, its mission, philosophy, and near term plans.

Following the PPASS MN story, everyone told their personal story. In three instances, multiple siblings were stricken. About half of the group was hospital-

ized for treatment while the other half had physician visits with recovery at home. It was observed that although most of the people knew something unusual was going on with their bodies and suspected that it might be polio related, few realized that many of their symptoms were also being experienced by others. Swallowing, fatigue, and muscle problems seemed to be the three most significant symptoms.

The group indicated they would continue to come to meetings if a group was organized. Dick agreed to arrange a meeting room for another meeting in April. Membership details were distributed and described, and a very successful meeting ended at 8:40 PM.

Look for more news from Owatonna in the future.



Impact of PPS on a Polio Partner

By Dave Van Aken

Editor's Note: This article was originally published in the *Polio Deja View*, the Newsletter of the Central Virginia Post Polio Support Group. I read the article in the February 2004 issue of the Auckland Polio HAPPENINGS, the Newsletter of the New Zealand Post Polio Support Group. I'd like to thank both Ramon Wilton, the editor of Auckland Polio HAPPENINGS, and Dave Van Aken for permission to publish this article.

I am not an expert. I am a husband and spouse. I am a Polio Partner, not a caregiver. There is a difference. A Partner is anyone who works to better someone's PPS situation. They can be a spouse, a brother/sister, a child, or a friend. And I am a survivor. If necessary, I will

adapt every day to our changing situation. When PPS came into our lives, we Partners faced a choice – fight or flight. We chose to stay and fight. But what are we fighting for? I am fighting to maintain my wife’s quality of life, as well as our collective quality of life. My guess is we are each trying to accomplish the same thing.

The one thing I have found that is true about PPS is each survivor is different. And as each survivor is different, then each of our situations is different. We do, however, face one common theme – coping with PPS involves a series of compromises. We must remain flexible and tolerant, as we must adjust to our Partner’s ever-changing condition.

So, how are the Polio Partners impacted by PPS? I believe there are three main impacts on the Polio family – Financial, Physical, and Emotional.

Financial Impact

It simply costs more to be disabled. Your family may have a loss in income. You may become the primary income producer for the family. Adaptive devices become necessary or required. Braces, scooters, or power chairs. Modifications to your home could include ramps, grab bars, higher toilets, or even a new home. All create extra expense.

Traveling requires more forethought and planning. Depending on your situation, the impromptu “escape” trips may be a thing of the past. We trade in our sports cars for minivans to accommodate scooters or electric chairs. Public transportation offers even more challenges. Trains and plane service has come a ways in dealing with the handicapped, but often have a ways to go to become trouble-free.

Physical Impact

We have all heard “Conserve to Preserve.” Most Polio Survivors have had this preached to them repeatedly. We need to pay attention to this as well. We try to have our Partners conserve their muscles and adapt to new methods and devices. We should listen to our own advice and use technology, children, or friends to help share our increased load. We are aging as well and our own aches and pains will affect our ability to provide care for our Partners.

Emotional Impact

Early on – when we are naïve or unknowledgeable - our expectations can be unrealistic. “If you do all of this, then you’ll get better.” “When you get better, we’ll do this and that.” We (some older Partners in one of our discussions) scared the “hell” out of a new Partner. As she admitted later, she expected her husband to beat this and they would carry on with the plans

they had envisioned for themselves.

Anger, depression, anxiety. Our Partners thought they beat polio over 30 years ago, and now it has come back to haunt them. Their bodies are giving out, betraying them, and losing functionality. They lose “face” as they succumb to the adaptive devices in an effort to save what is left. Is it any wonder, they get angry at the world, and we, sometimes, bear the brunt of it?

We hurt as we watch our Spouse’s hurt both emotionally and physically. At times, they lose their sense of self. As a culture, what we do for a living or where we volunteer often defines us. As our Spouses curtail this type activity, there is a sense of loss. This can trigger a sense of depression, which we, as Partners, try to cope with and ease our Partner out of it.

There is the physical side, or pain we watch our loved ones endure. We ache to be able to ease some of the pain they suffer. In most cases, we pick up extra chores so they don’t have to do it.

We grieve over our futures. We – as couples or as individuals – had dreams and desires. While they do not have

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Impact of PPS on a Polio Partner

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to be abandoned, they must be reevaluated.

Mid to Late Stages - As we grow older and more experienced with PPS, continual adjustments have become the norm. We must accept each situational change and move forward.

Fatigue periods can become common. These can add more anxiety, anger, or depression for our Type A spouses. Polio fatigue crashes are real. Linda “crashed” in October of last year. For seven weeks, she was flat on her back. I adjusted. I did the housework, the laundry, and the cooking. Before October, my repartee in the kitchen was scrambled eggs or waffles. But, I provided Linda with hours of entertainment as she directed my efforts in the kitchen. We didn’t starve, and weren’t poisoned, so I guess we did ok. [Guys – spend some time in the kitchen before you have to. It’s a survival skill!]

The hardest part I find in being a Partner is watching the sometimes rapid decline of one of our Polio friends. We all know it may come. We hope and pray it won’t. So, we nag and cajole our Partners and friends into behaving and conserving their abilities.

A Partner friend confided that their biggest fear was not being physically able to care for their spouse. On the other side, their Survivor’s biggest fear was becoming a burden on the Partner. Our fears are so much the same.

Friends and Family

Unfortunately, family and friends often judge our Partners by their appearance. What does fatigue and muscle weakness look like? Part, if not most, of the problem is that they look so normal. There is no disfigurement.

Friends and family do not understand the Survivor must make choices each and every day about the most mundane things.

They may have a slight limp, which has become more pronounced now, and they should always use their canes or crutches. Friends can’t understand why they can’t do this activity or that. They see them in their scooters, or using their canes doing the activities they choose. Why can’t they do it all (just like they used to)?

Friends and family do not understand the Survivor must make choices each and every day about the most mundane things. My wife has a system

she calls “energy presents.” Every activity uses some energy presents. She has about 10 presents each day. So she monitors what she does, and tries not to exceed her 10 presents/day. But, sometimes she does, and she must take extra rest. And if she really blows it out, we both may enjoy the short term, but both of us will suffer the consequences.

What Can We, as Partners, Do?

Communicate, communicate, and communicate! You and your Partner must communicate on your fears, your concerns, and your plans on how to move forward. Sometimes these discussions can become heated – I prefer to think of them as passionate discussions (I think every relationship needs passion). The more emotional and honest, the better the understanding between both of you.

Educate yourself – Knowledge is Power. Find out as much as you can about Polio and PPS. Apply what you learn to your situation.

Educate your family and friends. You need the help, and your Partner needs the support. If your family and friends don’t get it, you have a choice – either continue to educate or drop off (another loss). It’s your energy you are using, thus your choice.

Take Care of Yourself. Take charge of your life; do not let your Partner's disability or illness always take center stage. Be good to yourself, you deserve it. You are doing a very hard job. When people offer to help, let them. The task may not be done "the way you would," but it will be done. Grieve for your losses, and then begin dreaming new dreams. Trust your instincts. They will be right most of the time.

Seek support from other Partners. There is strength in knowing you are not alone. Many of the Survivors belong to a PPS support group. Do you, as a Partner, attend these meetings? Do other Partners attend? Grab some of the other Partners and go get some coffee while the PPSers

meet. Encourage your support group to give you an opportunity to meet separately. Often a general discussion all the agenda needed.

Central VA PPS group discovered this at our annual retreat about 4 years ago. We had a Partners forum where we openly discussed our concerns, fear, and things that worked. We invited a minister to come and facilitate our first meeting. Since that meeting, I have been facilitating meetings for Partners about 2 times each year. Our discussions are usually about what is going on in our lives at that moment, and we share what works for us and what didn't.

There are some online support groups, but mostly they deal with PPS. There are some

Care Giving web pages, which provide some good information, but not strictly on PPS. I don't have a lot of experience with these, because like most of us, we Partners don't have a lot of free time anyway.

As I said in the beginning, I am not an expert. If you have questions about a Partner's session, I would be happy to help. If you have specific questions about Partnering, I would be glad to help. I have some special Partner friends who have more experience than I do, so maybe we can provide an answer. I can be reached at DvanAken@aol.com but be certain to mention PPS in the subject title, or I might not open your message.



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PPASS Times

Newsletter of the Post Polio Awareness & Support Society of Minnesota

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