

# POLIO DEJA VIEW

February - March 2010

www.cvppsg.org



*A Newsletter for the  
Central Virginia Post-  
Polio  
Support Group*

Mary Ann Haske,  
*Editor*

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## February 6<sup>th</sup> Meeting

2:00 pm at Children's Hospital, 2924 Brook Road, Richmond  
*(Remember to come at 1:30 for refreshments and social time! Cookies provided – bring your own beverage.)*

*An Afternoon of Dialogue with Kenn Shirley*

*Kenn is currently working on his Master's in Rehabilitation Counseling at VCU.  
Kenn will share his personal experience of growing up in a household with an older sister  
who had polio when she was three and he was one. He will then ask you to share with him  
your experiences with your families.*

## March 6<sup>th</sup> Meeting

2:00 pm at Children's Hospital, 2924 Brook Road, Richmond  
*(Remember to come at 1:30 for refreshments and social time! Cookies provided – bring your own beverage.)*

### *General Meeting*

*An Overview of Future Retreats and Membership Involvement In Planning the Retreats*

<b>Mid Month Lunches</b>	<b>Thursday, February 18, 2010</b>
	Mid-Month Lunch at 11:30 Firebirds Wood Fired Grill
	11800 W. Broad Street in the Short Pump Shopping Center, Phone: 364-9744 (Located in the back near Dick's Sporting Goods) For a reservation, call Bev Lordi at 569-4232
	<b>Thursday, March 18, 2010</b>
	Mid-Month Lunch at 11:30 Cheeburger Cheeburger
	11615 Midlothian Turnpike, Phone: 379-0829 (Located at Courthouse Road & Midlothian near Bed, Bath and Beyond) For a reservation, call Bev Lordi at 569-4232

Did you know?...

...Rx Information from Jenny

## ***RUMOR VS. TRUTH***

**RUMOR: Proton pump inhibitors (PPIs-ex: Protonix, Aciphex, Nexium, Prevacid, Prilosec) don't need to be taken before meals after the first few doses.**

**TRUTH:** Some patients are being told that it's not necessary to take PPIs (Prilosec, etc) before meals...after the first few doses. Some believe that the drug reaches an even drug level after a few days...and therefore timing of dosing doesn't matter.

But this isn't true. The half-life (the time it takes for half of the drug to be eliminated or disintegrated) of PPIs is only about 1 or 2 hours...so a steady, even drug level can never be obtained with daily dosing. The drug will have washed out of the body before the next dose is given.

The reason they can be dosed just once daily is because they **IRREVERSIBLY** inhibit the proton pumps (which are responsible for producing stomach acid). Once a proton pump is inactivated, acid inhibition lasts up to 24 hours.

But PPIs only inhibit **ACTIVE** proton pumps, so they work best when acid secretion is being triggered by a meal.\

To summarize, take your PPI on an **EMPTY** stomach...30 to 60 minutes **BEFORE** meals, because it's best if the drug is on board before the acid pumps are activated. This ensures that the drug level is at its highest when acid secretion is maximal

Keep in mind that it can take up to 3 or 4 days of daily medication before you'll have full benefit. This is because not all proton pumps are inactivated with the first dose.

Call me if you have any questions!

Jenny Aveson (804) 730-9498



## Polio Poster Child Memories

About a year ago I wrote an essay encouraging readers to write their stories about their memories of a life with polio. Several readers have undertaken that challenge. Childhood and adolescence were often a difficult time for polio survivors, especially if the survivor had noticeable physical evidence of damage from polio. Obvious examples might be a metal brace on a leg, a limp, the use of crutches, atrophy of muscles of damaged extremities and curvature of the spine. What were the accompanying intra psychic feelings of young and adolescent polio survivors? Being surrounded by able bodied peers, did survivors feel self conscious about their physical handicap? Many consciously denied their physical appearance and attempted to compensate by being up beat, conscientious and develop friendships with able bodied peers

Diane Murphy of Philadelphia contracted polio at age four and was hospitalized for 159 days on the polio isolation ward of the "Hospital for Contagious Disease" in Philadelphia. When Diane became a little older she was selected to be a "poster child" for the National Foundation of Infantile Paralysis in the Philadelphia area. Diane writes informatively.

*The rest of the story is continued on page 4*

## CENTRAL VIRGINIA POST-POLIO SUPPORT GROUP

Carol Kennedy, President	(804) 740-6833	Ckennedy1619@aol.com
Henry Holland, First Vice President	(804) 288-8295	Henry4FDR@aol.com
Frances Thomas, Second Vice President	(804) 550-7590	.CHTSAFETY@aol.com
Linda VanAken, Treasurer	(804) 778-7891	ChatNLinda@aol.com
Judith Moffitt, Secretary	(804) 754-1067	Jmoffitt7114@aol.com
Bev Lordi, Social Committee	(804) 569-4232	.baclordi@aol.com

If you would like to talk with someone about Post-Polio Syndrome, you are welcome to contact the above members. If you send an e-mail, please refer to APPS@ in the subject heading.

We would love to have any of our members write an article for our newsletter. It can be about your lifestyle adjustments, comments on post-polio or any subject, humorous or serious, that we may all benefit from.

**Please send articles for or comments about our newsletter, as well as changes, additions or deletions for the newsletter mailing list to:**

Mary Ann Haske, Newsletter Editor  
2956 Hathaway Rd, Richmond, VA 23225  
or contact me at: (804) 323-9453 or mahaske@hotmail.com

The opinions expressed in this newsletter are those of the individual writers and do not necessarily constitute an endorsement or approval of the Central Virginia Post Polio Support Group.

*Please note: Our articles may be used exactly as written provided credit is given for each article used.*



*Cont'd from page 3*

## Polio Poster Child Memories

“The poster child campaign began in 1946 and was the innovation of Elaine Whitelaw who was appointed by President Roosevelt. A national March of Dimes poster child was chosen to symbolize those afflicted by the disease. The poster child was to be well dressed and meant to look happy and attractive with evidence of leg braces or some other symptom of the disability. The “image” of the vibrant, though “crippled” child, projected hope for recovery and inspired the public to give money to the foundation.

Lucky me!!! I apparently fit the “image” they were looking for the local Philadelphia chapter. It’s a known fact that the media promote images of the helpless, handicapped by reporting on charity drives that feature posters of crippled children. I experienced this media frenzy portrayal as a pitiful and helpless child and was put on public display as a local poster child for the March of Dimes. Being chosen a poster child for Philadelphia was NOT one of the highlights of my childhood; it was not a happy childhood memory for me. I have no idea as to how I was “chosen” or how it all came about. I don’t remember giving my permission to be gawked at and stared at in the public eye. God knows! I was gawked at and stared at in my every day life by the other kids in the neighborhood like I was some freak and was avoided like I had a disease that was still contagious. I was put on public display to promote the fundraising appeals for the March of Dimes to pull at peoples’ heart strings and to play on their pity in an attempt to raise money for the charity. I didn’t enjoy it, nor did I feel like the “happy” child that I was expected to portray. Quite the contrary, I knew I was “different” from the other kids; I didn’t need to be reminded of it. I was told to smile and look pretty; or smile and look like you’re having fun. FUN!!!! What could be fun for a five or six year old who was aware that she was so “different” from other kids and didn’t need to be reminded of it by being in the public eye.

I was frequently taken out of the classroom at school to have my picture taken for various reasons and photo ops for human interest articles for the local newspapers; or for publicity photos for the March of Dimes; or for events going on at the school. There were public appearances with local politicians at ribbon cutting ceremonies; a photo taken with sports figure, Curt Simmons, the left-handed pitcher for the Phillies; photo opportunities for the local newspapers with entertainers like Eddy Arnold, Diahann Carroll, plus other celebrities; a guest appearance on a local popular children’s television show, *The Chief Halftown Show*; numerous publicity photos at various March of Dimes related fundraiser events and an appearance on “This is Your Life.” I have no recollection whose “Life” it was though! There was a bigger than life-size poster of me that hung from the ceiling in the Main Ballroom of the Broadwood Hotel for a March of Dimes fundraiser event. That same picture was printed on the tickets that were sold for the event at the cost of \$1.50. The ticket read, “*Lend a Hand*” to the National Foundation for Infantile Paralysis. **First**

**Annual Dance**, given by Local 2898 - USA-CIO, Saturday, Feb. 13, 1954. Johnny Austin and his Orchestra.

For every publicity photo shoot or public appearance, my mother primed and fussed to make sure my hair was perfectly curled and styled with a matching bow to match my perfectly starched and pressed dress, and my white orthopedic shoes were always clean and polished. Whenever these photo sessions were taken outside in the cold winter weather, I could be seen wearing a matching hat and coat. I was always dressed meticulously, and always “expected” to smile and look “happy” both of which I was mostly defiant about.

As I look back on this period of my life and the media’s tendency to portray people with disabilities in a negative way as pitiful, helpless creatures doomed for hopelessness, I no longer consider this experience as objectionable in the same way as I did when I was a child. I consider it a unique opportunity that I am part of medical history, and have come to realize that it was a unique life experience to have been “chosen” to be a Poster Child for the March of Dimes which is something I am comfortable with and am proud to talk about. It’s a part of what the media portrayed me as; it’s who I thought I was.....NOT who I have become.”

When asked about her adolescence Diane wrote:

“I was very self conscious of my “damaged” body and withered braced legs during my teen years. It was very difficult to hide it or camouflage my braced legs in any way because I always wore dresses or skirts in high school. Pants/slacks were not in vogue for women at that time. Today, however, that’s all I wear.”

This article is an example of how childhood memories of the polio experience can be recalled in vivid detail. I am indebted to Diane Murphy for sharing her memories. I encourage readers to do the same.

## *A Cross Country Adventure*

### *Editor's Note:*

*Two of our Support Group Members, Karen and Jack Wilson, recently spoke to us about a road trip they made from coast to coast. I thought some aspects of their trip might give some of us ideas about similar jaunts. They kindly agreed to share some of their pluses and minuses with our readers.*

We have traveled across the U.S. by plane and train a number of times. We have also gone up and down. We have always wanted to take a leisurely car trip and this had to wait until Karen retired.

On May 16<sup>th</sup>, 2009 we started on our journey. We set the trip meter when we left the driveway. We had a large map of the U.S. and we mapped out a tentative route, which was subject to change day by day.

We stayed in 28 motels. We also stayed with a few friends and relatives along the way. One of our main destinations was San Diego CA so we could attend our grandson's high-school graduation.

After a couple of motels proved inadequate, we realized it is always best to check out the handicapped facilities before checking in. What they tell you they have and what they actually have can be two different things. For the most part we found adequate accommodations. We did encounter a few problems, such as the riser not fitting on the toilet, or the ramps on sidewalks not near the outside rooms.

In one motel the clerk tried to tell us the bed was a queen, not a double. We told her we had slept in a double for 44 years and we knew one when we saw one.

(For 2 yr we have had a queen which has been wonderful.) In Yellowstone it took 3 tries to get the right room. First we could not get into the lodge because of the ice and snow. Then the toilet was very low. After lots of conversation with the clerks and manager, we got what we needed. Another motel was not an option.

Also we learned not to push it, to stop by at least 5PM. If we did not stop, it was very hard to find a handicapped room.

On June 19<sup>th</sup>, coming back across the country, we stopped in Natchez MS. We did not stop soon enough. We encountered our first "flea bag" motel. We really didn't find any fleas but they could have been there. Most of the motels had breakfast, some good some not so good. One place had the breakfast room on a different level from the lobby. There was no elevator, only steps. They said we will bring the food to us. I guess you would get what they thought you needed.

We found most of the places we visited in a book entitled "Off the Beaten Path" by Charles Karult. There were some places Jack could not get into. He was always pretty patient while Karen did the touring and brought back the info and pictures. (We took 1100 pictures). You know Jack never meets a stranger so he had lots of people to converse with. We really did want him to see one of the caves at Mammoth Cave KY. We were told the elevator was broken. I asked

how long it had been out of operation, and they answered 4 years but they were working on getting it repaired..

We did find some of the older town's shops and restaurants always seemed to have at least one step up. Pretty incontinent for us. In Natchez this was a problem. We did find a place, the Pig Out Inn, which was accessible. However, this wasn't Karen's first choice. When we got there and opened the door and saw it was very crowded, we said let's go on. A member of a motorcycle group heard us and said of course you can get in because most of those people are with me and we will make room. Needless to say, we ate at the Pig Out Inn and it was most enjoyable.

Along the way we found people to be very courteous and helpful.

It was a wonderful trip and we have no regrets about going on this adventure. We were gone five and one half weeks. Everybody thought this would be very trying on our marriage. I said, when we got back, that we loved each other when we left and maybe we even love each a little more now. When we pulled into our driveway, the trip meter read 9200 miles. Maybe some of you will be able to make a trip like this. We highly recommend it.

Karen and Jack Wilson

## WINTER MUSINGS .....FROM YOUR EDITOR

Around this time of year, I begin to fantasize about a nice big snow storm. Of course, I have a few parameters. I want a well-stocked pantry, electricity, no theatre tickets that will be wasted, phone service and heat. After the hustle and bustle of the holiday season, I want to experience a few days of being in a cocoon. I want to “hear” the silence that comes with the cessation of traffic. I want to hear the clear calls of children playing in the snow. A big steaming cup of cocoa, a good book or movie, and a warm blanket are also a part of this fantasy. The best part of the fantasy is that everything stops. So what if I was supposed to go to the bank or the dentist. That type of activity can wait. The scene out the window is so indescribably beautiful when the trees, bushes and

roads are coated in white. There is a peace in the air that reaches to the depth of my being.

I have to ask myself why is it necessary to have something as disrupting as a snow storm to cause me to slow down and “veg out”. Can’t I do this simply by waking up, deciding to nest and cancel activities? I am not so sure. There is usually some intrusion which will shatter the peace. I also know that a snow storm does not always bring the quiet that I describe above. When I went to NYC in Dec. of ’03, there was a blizzard. It was exhilarating. I plowed through the drifts and looked at the department store windows, went to a play and Radio City Music Hall. It was exciting and fun. I would not have wanted to stay in and nest or rest!

You, the reader, might be thinking I have lost my mind. Don’t I realize what snow does to those on crutches, canes and other assistive devices? Of course! However, you are a part of this fantasy and you are not supposed to go out either. I wish for you the same calm and peace that I long for. Every now and then, it is good for our spirit to take a deep breath, relax and enjoy this wintry gift. Mary Ann

*(Post Script: This was written before the “Blizzard of ‘09”. I will say that I had enough advance warning to make sure all necessary things were done.....Let’s just say that I was able to relax and nest before the holiday hubbub and I still hope for an encore in a few weeks.)*

## *A Message From Our President*

At the December meeting, the Board of Directors decided not to have a retreat in 2010. We would like to use this time to regroup and get some new ideas on how to improve future retreats. The membership can be of great help in this by answering some of the following questions:

Do you feel the retreats should be continued?

If you don’t come to retreats, what can we do that will make it easier or more interesting?

Is there a better time of year to hold the retreat, other than the fall or a better weekend in the fall?

Would you be willing to serve on a committee to help plan future retreats?

Do you have any thoughts or ideas on how to make retreats new and different?

Please email, call or write me with your ideas.

Thank you and I hope to hear from many of you.

Carol Kennedy

1803 Aston Lane • Richmond, VA 23238

804-740-6833 • Ckennedy1619@aol.com

## The First Step in Treating Pain: Finding the Source

**Amy Clunn, MD, Southeastern Rehabilitation Medicine, Ocala, Florida**

*Dr. Clunn will present the common pain generators in polio patients and help identify ways that the patient can better communicate with his or her physician in regard to symptoms, and outline the process by which the physician should identify the pain generators so that effective treatment can be determined.*

Polio survivors have been found to have multiple potential sources of pain as they age. The pain can interfere with function and add further physical decline, lead to depression, poor sleep and fatigue, which are already problems in most post-polio patients. Therefore it is important to be aggressive in treating pain in order to optimize physical and mental function.

The primary findings on physical exam in polio patients are muscle weakness and atrophy (shrinkage) in the affected limbs. Part of the post-polio syndrome includes progressive weakness with or without atrophy in the limbs that were affected originally, and occasionally in limbs that were not affected originally. The atrophy and weakness occurs because the virus affected the anterior horn cell of the peripheral nervous system in a patchy pattern. This then causes the nerve supply to be poor to the receiving muscle, and it can no longer work fully (the nerve supply is the hard wire that gives the muscle its power and its signal to move). Without actively contracting, the muscle atrophies (shrinks) rapidly. What is left is a muscular system that must struggle to maintain posture, activate joints and work with possibly only 10-80% of its usual power. With this understanding of the disease mechanism, it is easy to see the first reason polio patients often have pain: chronic muscle strain. The muscles in the affected limbs are often overused or strained even in everyday activities such as walking or using arms.

Muscle strain pain presents with aching soreness and soreness in muscles that become tender to touch. The tenderness can be in the belly of the muscle or at its distal, tendinous insertion near the bone (enthesopathy).

Bones and joints are another source of pain in polio. If a bone is not subjected to regular weight-bearing activity, it becomes

osteoporotic (loses its mineral content). This can cause pain and lead to compression or stress fractures that can occur even with normal activity (walking or bending for example). Stress or compression fractures present with acute, focal intense pain, often with swelling, made worse with weight-bearing. It is even more important that post-polio patients undergo bone density studies than the normal population in order to treat osteoporosis if it exists, as it predisposes bones to fractures with falls or even atraumatic activities. Joints can become painful due to arthritis or due to contracture from tightness. Capsulitis (inflammation of the joint capsule) can also occur and presents with very painful and restricted range of motion of a joint.

This is particularly common when weakness has made it difficult to move a joint, and the capsule shrinks or tightens because it is not ranged. Subluxation (slippage of a joint out of position) can be commonly found in feet, sacroiliac (pelvic) joints and shoulders when the surrounding musculature is weak. This presents as pain in range of motion or with weight-bearing, deformity, or crepitation with range of motion.

Nerve pain can present as part of an “overuse “ syndrome when certain activities are overdone, often in response to substituting one function for another where weakness exists. An entrapment of the nerve can occur with the repetitive motion. An example of this is carpal tunnel syndrome, particularly common in manual wheelchair or walker users (repetitive gripping with or without direct compression), or a gluteal nerve injury in response to hip weakness and pelvic instability and strain with walking. Spine pain is also common in polio patients. Spine pain has potential sources such as discs, joints, muscles, ligaments, tendon, bone and nerve roots. Wheelchair users are susceptible to degenerative disc disease (seated position increases intradiscal pressure), atrophy of the paraspinal muscles and scoliosis (curvature).

Sitting also creates tightness in tendons of flexor muscles and can lead to pain when in extension, such as lying down. Joints in spines where weakness is present in a lower limb or in the spine itself are subject to premature and more severe arthritic change than usual. Discs are also subject to more strain injuries such as tears and herniations when gait is unbalanced. They present with intense focal back pain and,

## The First Step in Treating Pain: Finding the Source (cont'd)

if pressure on the nerve root ensues, radiating pain to the abdomen, groin or leg & foot (if lumbar). Osteoporosis also affects the spine commonly with compression fractures.

The circulatory system can also be affected by polio, particularly in limbs that are paretic (weak or paralyzed), and in wheelchair users due to sitting. Venous return of the blood is usually impaired in this instance, and blood can pool in the extremity causing swelling, aching and even ulcerations. Patients can get angina (chest pain due to cardiac ischemia (decreased blood flow) due to cardiac disease hastened by lack of cardiovascular exercise.

If polio survivors are facing any pains that are severe or that last more than a few weeks, they should have an evaluation by a musculoskeletal physician, primarily orthopedists and physiatrists. A careful history should be taken, including information regarding the patient's polio history, other past medical history, functional history and how the pain problem is affecting mobility. The patient should be clear and give an example, such as, "I used to be able to lift a gallon of milk with my right arm and now it is difficult to hold a coffee cup." This tells the examiner the time frame of the problem as well as the severity. After that, a thorough physical examination should follow including gait evaluation, if the patient is able. Strength, range of motion, sensory testing

and inspection/palpation of the affected areas should be evaluated. Subsequent diagnostic testing may be necessary, including x rays, MRIs, bone scans, EMGs and lab work. With this information an appropriate diagnosis can be rendered with treatment to follow.

Beware: One of the worst things a polio survivor can do is feel that all his or her symptoms are part of a post-polio syndrome and think that nothing can be done to help. Hopefully this talk has given polio patients the knowledge to understand some of their unique potential pain generators and what can be done to evaluate them (and formulate a treatment plan).

Dr. Clunn completed medical school at the University of Cincinnati in 1993, followed by internship at Oakwood hospital and an additional 3 year residency in physical medicine & rehabilitation at the University of Michigan in Ann Arbor, where she also served as chief resident. She now practices with Southeastern Integrated Medical, P.L., a multidisciplinary integrated health system in North Central Florida, (in Ocala) full-time. Dr. Clunn is board certified in Physical Medicine & Rehabilitation and also in the subspecialty of Pain Medicine. She is a member of the American Academy of Physical Medicine & Rehabilitation, The American Academy of Pain Medicine & the American Academy of Electrodiagnostic Medicine as well as the Florida Medical Association, Florida Society of PM&R and the Marion County Medical Society. Dr. Clunn is the Physician consultant for the North Central Florida Post-Polio Support Group.

## *In Other News ...*

## *FYI...*

### **SAVE THE DATES**

- Regular Meeting, February 6, 2010
- Mid-Month Lunch, Feb. 18, 2010
- Regular Meeting, March 6, 2010
- Mid-Month Lunch, March 18, 2010
- Board Meeting, March 24, 2010
- Regular Meeting, April 10, 2010; (Note 2<sup>nd</sup>. Sat.)
- Regular Meeting, May 1, 2010

You might be wondering why your Deja View came in an envelope this time. Well, the Post Office will no longer deliver bulk mail that has a staple showing. So, after exploring the situation with the printer, Carol Ranelli came up with the envelope idea. Thanks, Carol, for your ingenious answer.



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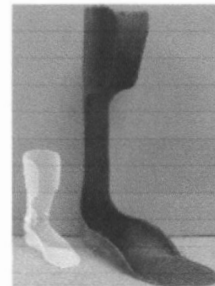
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1803 Aston Lane

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