

POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

www.cvppsg.org

April – May 2004

Carol T. Ranelli, Editor

April 3rd Meeting

2:00 pm at Children's Hospital, 2924 Brook Road, Richmond

General Discussion and Brown Bag Auction

Twice a year we have a brown bag auction where the proceeds go toward our social committee's expenses. The social committee pays for the extras needed for the June and Christmas luncheon, as well for many "extras" involved in our Annual Retreat in September. We ask each member to bring a small gift or white elephant item in a brown bag. Attached should be a clue as to the contents. These auctions are always fun and bring in much needed funds.

May 1st Meeting

2:00 pm at Children's Hospital, 2924 Brook Road, Richmond

Our speaker will be **Mr. Gray Corbett,**
Safety and Security Coordinator for Retreat Hospital

Mr. Corbett will speak on "How to Make Your Home Safe"
with guidelines and ideas for keeping us injury-free.

Sixth Annual PPS Support Group Retreat will be September 17th – 19th !!!!

Complete information and registration form inside this issue!

Rooms are available on a first come - first serve basis.

Deposits are due no later than July 1st.

Mark Your Calendars for Our Mid-Monthly Lunch

Our members are taking turns arranging each mid-monthly lunch get-together. If you have a suggestion for a future restaurant that is accessible, please let a board member know! We love trying new places.

Wednesday, April 14th – 11:30 Virginia Museum of Fine Arts Members Dining Room. Call Mary Ann Haske at 323-9453 or e-mail at: mahaske@hotmail.com by April 9th to reserve a place.

Wednesday, May 12th – 11:30 Hill City Chop House, 10099 Brook Road at Virginia Center Commons. The Chop House is located in a separate building within the Mall parking area.
Call Frances Thomas at 550-7590 by May 7th to reserve a place.

FYI: Dr. Courtney Goodman, Pharmacist, who spoke to our support group in November, has graciously offered to be our "Pharmacist-in-Residence". If anyone has questions concerning prescriptions, drug interaction, drug alternatives, etc., they can write Courtney with their question and their phone number and she will get back to them. We are lucky to have a medical professional take such an interest in our group and thank Dr. Goodman for her friendship and help.

Dr. Courtney Goodman, 7407 Hillview Dr., Mechanicsville, VA 23111

Our new website!!

We finally have our new website up and running!! Many thanks to Eric Johnson, our esteemed Webmaster, for his patience and hard work during this process. We still have a few adjustments and additions to make, but come visit us at: www.cvppsg.org. We have an archive of past articles, links to other PPS groups, helpful services, and information about the PPS Clinic at Sheltering Arms, etc. You may also contact us through e-mail with any questions you might have.

- Carol R.

SIXTH Annual Fall Retreat!!!

It's time to reserve a room for our SIXTH Annual Fall Retreat at Camp Easter Seal-East from 3 pm, Sept. 17th until noon, Sunday, Sept. 19th.

The camp is situated in Caroline County, VA, about an hour drive from central Richmond.

Our speaker will be **Dr. Lauro Halstead**, noted author and Director of the PPS Clinic at National Rehabilitation Hospital in Washington, DC.

We were honored to have Dr. Halstead speak at one of our PPS Conferences and look forward to hearing him speak on the latest post-polio issues and answer our questions. Dr. Halstead and his wife, Jessica Scheer, will be our guests for the weekend.

We MUST have 50 people attending this year as Easter Seals Virginia is strictly imposing their requirement of a 50 person minimum due to increased operational costs. If we do not meet this quota, our support group will have to make up the difference from our treasury. We have subsidized the individual cost in past years to keep member's costs down.

As in previous years, we will be housed in the Federation Lodge, which has meeting rooms, lounge, dining room and bedrooms all in one building. Camp Easter Seal-East is totally handicapped accessible. Each bedroom has an accessible bathroom. This is a totally NON-smoking facility. Linens are provided. We recommend that you bring an egg-crate mattress pad for your bed.

The camp is refurbishing the bedrooms and rearranging the bed set-ups, but we will make every effort to accommodate any special needs. **The bedrooms will be on a first come – first serve basis.** We can also use the dormitory building which is a very nice facility and adjacent to the Lodge and good for all the "single" members who attend.

We have again arranged to have two massage therapists join us on Saturday from 9 until 4. They will charge \$20 for a 20-minute session. You may schedule a double session if you desire. Sign up for the massage schedule will be during registration on Friday afternoon...or upon arrival on Saturday if time slots are still available. We need to know ahead of time how many people will be interested in this service. Please respond on your registration form.

The indoor accessible pool will be available on Saturday afternoon.

We are including an application form in this newsletter for those who already know they will be attending. We are also requesting a \$30 per person deposit by July 1st. This will give us a better idea of what this year's attendance will be.

Final reservations and complete payment MUST be received by Linda VanAken by Sept. 1st. For those who sent in an early deposit – the remainder is due by Sept. 1st.

The cost of the entire weekend is \$125 per person, which includes 2 nights and 5 meals. If you are only able to come for the day on Saturday, the cost will be \$40 per person for the use of the facility, lunch and dinner.

Registration Form for September Retreat

Friday, September 17th until Sunday, September 19th

Please mail to: Linda VanAken, 14606 Talleywood Ct., Chester, VA 23831

WITH check made out to: **“Camp Easter Seals”**

Final payment has to be received by **Sept. 1st**.

Name: _____

Address: _____

Phone: _____ Number of Persons attending: _____

Type of Room accommodation: _____ (single or double)
If you have special needs for bedroom or bathing facilities, let us know.

Are you interested in scheduling a massage therapy session? _____

Will you be attending just for the day on Saturday? _____

Number attending: _____

Do you have any special dietary requirements? _____
(We cannot change the pre-set menu unless there are specific needs)

Price for the weekend (2 nights and 5 meals) \$125 per person

Price for Saturday only (includes lunch and dinner) \$40 per person

Amount of check sent: _____

PAIN RELIEF

Some tips from the collected wisdom of the Internet Polio Mail List

Assembled by Tom Walter

Tom Walter is a Polio Survivor. Up until a few years ago, 30 years or so on from recovering from Polio, he walked unaided with only a slight limp, working and living a normal life. He didn't even know any other people with Polio. He now has difficulty swallowing and breathing and spends most of his days in a wheelchair or propped up in bed. With his laptop computer he collects and dispenses advice and information on post-polio syndrome. Tom, or TominCal as he is known by his email name, is highly regarded and respected as a source of reliable information by the online post-polio community worldwide. In 1997 he was interviewed by Susan Kelleher of the Orange County Register for an article "Polio strikes back".

NUMERO UNO -- "*Lifestyle Adjustment*" -- The "sine qua non" without which none of the other tips or aids seem to do much good.

That means reducing physical exertion / activity AND mental stress to the level of one's current capabilities.

Dr. Perry, over 40 years at the polio clinic in Rancho Los Amigos Medical Center in Downey CA USA, says we should exercise normal (if any) muscles normally but not do anything that causes PPS-affected muscles pain, weakness or fatigue that lasts more than 10 minutes.

Assuming the person has been thoroughly checked for any other conditions that could mimic PPS symptoms and be treated -- and that any orthopedic anomalies that could be causing pain have been treated -- here's a partial list of some tips that PPSers have reported seem to work for them, alone or in combination:

1. Moist heat applied to the painful area.
2. Light massage to the painful area.
3. Ice packs applied to the painful area.
4. Chiropractic or osteopathic "adjustment" of neck / back / joints.
5. Acupuncture; and electro-acupuncture to the ear lobe.
6. Herbal dietary supplements such as ginger, pycnogenol, cayenne pepper.
7. Treatment of sleeping difficulties, i.e., insufficient amount of Stage IV sleep.
8. Treatment of breathing difficulties, i.e., insufficient amount of oxygen and or too much carbon dioxide, especially during sleep.
9. Use of assistive and adaptive aids, as necessary, to reduce stress and strain to muscles and joints; assuring that all body parts that require it, e.g., neck, head, back, shoulders, are properly supported at all times.
10. For inflammation of muscles / joints -- use of arthritis-type drugs: NSAIDs (Non-Steroidal Anti-Inflammatory Drugs). Over-the-counter types like Aspirin, Ketoprofen or prescription types like Relafen, Voltaren, Naprosyn.

11. For "nerve" pain -- use of anti-depressant prescription drugs --
 - Elavil (amitriptyline) -- an anti-depressant of the tricyclic type -- is the first choice in drug therapy by some PPS specialist docs for those with PPS pain AND trouble sleeping, at dosages less than would be used for clinical depression. But a lot of us don't tolerate it well.
 - And for those (and also those who DON'T have sleeping problems), one of the SRUB class of anti-depressants (Serotonin ReUptake Blockers) such as Zoloft or Paxil -- also in smaller doses than would be used for clinical depression -- may be of help.
12. Occasional and/or careful use of muscle relaxants such as Quinine or Methocarbamol.
13. Hormone Replacement Therapy, especially for post-menopausal, post-hysterectomy women and others with lower than normal levels of estrogen, testosterone, thyroid. DHEA, Melatonin.

From Henry's Desk by Henry Holland

Abuse and Polio Patients

Over the years some have written that polio patients encountered significant abuse from medical and nursing staff members, physical therapists and even family members during the time of acute polio and during the months and years of rehabilitation. I will attempt to write about this sensitive topic and my opinions will be just that, opinions. First I will define abuse as found in the Merriam Webster Dictionary:

abuse

Pronunciation: &-'byūs

Function: *noun*

Etymology: Middle English, from Middle French *abus*, from Latin *abusus*, from *abuti* to consume, from *ab-* + *uti* to use

Date: 15th century

1 : a corrupt practice or custom

2 : improper or excessive use or treatment : **MISUSE**

3 *obsolete* : a deceitful act : **DECEPTION**

4 : language that condemns or vilifies usually unjustly, intemperately, and angrily

5 : physical maltreatment

In regard to polio patients, some have written about improper or excessive use of treatment or physical maltreatment. Also these writers have written about sexual and psychological abuse or trauma to polio patients. The most prolific writers about this abuse have been Drs. Nancy Frick and Richard Bruno. These writers are not medical doctors themselves, but hold doctorates in other areas. Their conclusions are based on surveys and some personal testimonies from polio survivors. The reader can find one of their articles on the Internet at:

<http://members.aol.com/harvestctr/Library/frick.html>

This particular article alleges that polio patients developed so called "Type A" personalities and were overachievers in trying to be normal. There may be some truth to these theories, but I feel that some understanding of the historical times and some psychodynamic considerations have to be considered before projecting so much of this alleged abuse on physicians, nurses, physical therapists, and family members. My own memory and many polio survivors with whom I have talked, do not feel that they were abused, but are grateful for the care they received. Historically polio was feared by the parental generation because polio was indiscriminate in it's random selection of victims and there was no absolute protection. During the summer months, polio compared to other serious infectious diseases, received an inordinate amount of attention from public health departments, the medical community, the national and local press and from public service clubs. The reason for this concern and attention was largely due to the reality that the majority of polio patients were children and this disease could be both fatal and crippling. The greatest national epidemic of polio occurred in 1952 with nearly 60,000 reported cases and the greatest epidemic in Virginia was in 1950 with 1200 reported cases.

I think one has to consider the immediate treatments for acute polio and the rehab treatments administered for years after polio. The usual acute treatments involved the Kenny hot packs which

when initially applied to the involved parts of the body might illicit some short term pain because of the heat. After a few minutes the hot packs were usually soothing. More painful was the vigorous application of physical therapy. This therapy was intended to prevent contractures in the joints of the extremities and to help retrain weakened muscles. The stretching necessary to achieve the desired results was usually very painful and would often evoke cries of pain or simple weeping. Most polio patients would try to endure this "treatment" in a stoical manner because this therapy often seemed to bring about the desired results.

Depending on one's age this physical therapy treatment might be perceived as abuse because it was painful. A child who could understand the purpose of the physical therapy would probably be better able to accept this treatment than a child much younger. The ordeal of isolation might be perceived as abuse because of the separation from loved ones and the care being provided by total strangers who might be perceived as aloof and uncaring. Once out of isolation most polio survivors that I have interviewed remember caring and empathic nurses and staff. In my memory most of the nursing staff were relatively young, encouraging, optimistic and upbeat. While on the polio ward at MCV I kept an autograph book as most of the other patients did. Below are a few entries. These entries communicate encouragement, optimism and some humor.

Keep looking forward Henry, you'll soon be up walking again
Ann Harrell

Richmond, Va, October 15, 1950

Dear Henry,

It was just you to be so pleasant at all times. Keep on keeping on.

Mrs. Therla Hall P.N. (This nurse was African American)

11/16/50, Medical College of Virginia

To Henry

One of the nicest and sweetest patients I've ever had.

Keep your chin up and "Enjoy yourself, it's later than you think!"

Marian Brantley (signed with stick figure with red hair)

11/16/50

Dear Henry, (This nurse was African American)

Hope you will get "Well Soon."

Miss B. V. Taylor P.N.

M.C.V. 5th floor

Remember me well

Remember me long

Remember when

You are well & strong

P.S. Don't be too long

Josephine Marie Murphy

Lynchburg, Va.

Nurse figure to the right wearing glasses with
caption saying, "Hey Henry – How about eating
that egg?"

Dec 6, 1950

12/6/50

I like you so much – I hope the best things in life happen to you – You sure have been a lovely patient. Best wishes for a speedy recovery the rest of the way.

Mary Tomlin

M.C.V., Oct. 17, 1950

To a very sweet and wonderful patient, I wish all the luck in the world:
Here's hoping your stay here will be a very short one.

Your nurse

Mrs. Bryant R.N.

Dec. 12, 1950

Dear Henry,

It's been grand knowing you, even though you are kind'a mean. Hope I see you soon in something besides striped pajamas!

Best of luck always. You deserve it. Don't forget me.

Love, Gertie

Gertie Blow, Goldsboro, N.C.

It is interesting to note that nurses were recruited from other parts of Virginia or surrounding states as indicated by two of the autographs above. There was a nursing shortage in many locations where epidemics occurred. 1950 was an epidemic year for Virginia and newspaper articles report that nurses were recruited from surrounding states. In 1950 the MCV hospitals were racially segregated, but African-American nurses, graduates of the St. Philip Nursing School, were working on all white polio wards as evidenced by two of the autographs above.

I am of the opinion that the vast majority of nursing personnel on polio wards wanted to be there and provided compassionate care. Many misperceptions probably occurred, often the result of simple personality factors and differences. Also the patients were congregated in wards where there was some community spirit and identity. Intentional individual abuse would have been difficult to accomplish unobserved. I am aware that there were exceptions and I have interviewed a few female polio survivors who were sexually abused as adolescent girls. They felt helpless against sexual abuse. Sexual abuse of female children and adolescents was under reported in the polio years, but there was also a different moral tone in the nation at that time. Issues of right and wrong were more clearly defined in the mores of our culture.

The philosophy of "no pain, no gain" was an often spoken and/or unspoken motivating resolve that many polio patients of reason could adopt. The desire to get back on one's feet was also a strong motivator. Accomplishing this goal often meant that the polio survivor would be able to return to school and participate in the world beyond the front door steps. Those who tried steadfastly to get out of wheel chairs and ultimately failed were at a distinct disadvantage in the culture of the mid twentieth century. Some of these polio survivors had to overcome some feelings of guilt and failure. They wondered whether they had tried hard enough to "overcome" polio. Fortunately, most of them in time were able to enter the world again in their wheel chairs. In retrospect I was fortunate. I walked out of MCV Hospital with two braces and crutches and re entered public school a year later.

Some of you reading this may feel that you were victims of abuse during your younger polio years, but I am more hopeful that most of you recall doctors, nurses, physical therapists, family members and friends who were positive, encouraging, supportive and loving.