POLIO DEJA VIEW

Central Virginia Post-Polio Support Group

WWW.CVPPSG.Org

June – July 2008

Carol T. Ranelli, Editor

ANNUAL JUNE LUNCHEON

June 7th is the date of the Annual Luncheon which will be held at the Expressions Restaurant at The Cultural Arts Center at Glen Allen, 2880 Mountain Road. Take 295 West toward Charlottesville, take Exit 45 – Woodman Road South Go to the light, turn right onto Mountain Road. Go ¾ mile and the Cultural Arts Center is on your right – turn right at the sign. This facility has ample handicapped parking and is easy to find.

Please review the menu on the next page and make your selection prior to calling Bev Lordi or Barbara Bancroft to make your reservation. They will note that you are coming and what you are ordering for lunch. We will bring the list with us as a reminder in case people forget their menu choice.

<u>NOTE</u>: If a person selects a dinner item, then this item choice cannot be changed the day of the luncheon. Normally dinner items are not available at noon and must be special ordered by the restaurant staff.

We look forward to the luncheon which is taking place in a spacious room with windows to an open courtyard and feel that all will have a good time.

The deadline for contacting Bev Lordi 569-4232 or Barbara Bancroft 204-1688 is Saturday May 24th.

There will be no July Meeting

In this issue: Information about our NINTH ANNUAL FALL RETREAT

Expressions Restaurant Menu

Chef's Salad – Mixed lettuce, grape tomatoes, cucumbers, carrots, croutons, julienne of ham, turkey, provolone, cheddar, egg slices and your choice of dressing

\$8.00

Expressions Classic House Salad – Mixed lettuce, grape tomatoes, cucumbers, carrots, mixed shredded cheese, croutons and your choice of dressing

\$6.00

Add: Chicken Tenders, grilled or blackened

\$2.50

Add Salmon:

\$4.00

Turkey MeIt – Sliced turkey, melted swiss and dijonaise on grilled rye toast with choice of French fries, chips or fresh fruit cup

\$8.00

Burger – Half pound certified Angus beef patty cooked to your liking with lettuce and tomatoe on a Kaiser roll; add cheese for 50 cents

\$6.50

Sesame Ginger Chicken over rice with baked potato and choice of grilled mixed vegetables or side salad

\$17.00

Crab cake with baked potato and choice of grilled mixed vegetables or side salad

\$19.00

Filet of beef, cooked to order with baked potato and choice of grilled mixed vegetables or side salad

\$20.00

Freshly baked rolls and butter

Desserts from \$4 to \$6

Full bar available: Beer \$3-\$4, Wine \$4.50-\$7.00, Cocktails \$5.00-\$7.00

Soda, coffee, tea: \$1.50

Mid-Month Lunch

There will be no mid-month lunch in June.

Thursday, July 17th we will take a road trip to

Pomme, (540) 832-0130. A true French Restaurant with a talented chef. Entrees \$19 to \$30. 115 S. Main Street, Gordonsville. (out 64 West)

Please call Bev Lordi at 569-4232 by July 14th if you are going.

We will make arrangements to carpool after we get the final reservations of those who'll be going.

Did you know?...... PX Information from Jenny

PROPER DISPOSAL OF PRESCRIPTION DRUGS

Reports of trace amounts of pharmaceuticals in our water supply are getting a lot of press. Investigators are finding hormones, antibiotics, heart medicines, antidepressants and others in our drinking water. There's a lot of discussion about whether this is hazardous to humans and wildlife, or if the amounts are not enough for concern. Some authorities are reassuring the public that the amounts are miniscule and not enough to have any effects on health. But, some toxicologists say these contaminants could affect fish and wildlife and contribute to antibiotic resistance. These medicines get into the water supply either as human waste or when drugs are flushed directly down the toilet. As a reminder, you do NOT want to flush MOST unwanted medications. An exception is controlled substances. Some of these should be flushed to avoid diversion.

Here are some guidelines regarding disposal of prescription drugs:

- Take unused, unneeded or expired prescription drugs out of their original containers. Mix them with an undesirable substance, such as used coffee grounds or kitty litter, and put them in impermeable, non-descript containers, such as empty cans or sealable bags. Then, throw them in the trash. This will further ensure the drugs are not diverted.
- Flush prescription drugs down the toilet *only* if the label or accompanying patient information specifically instructs doing so. The following drugs SHOULD be flushed: Actiq, Daytrana, Duragesic, Oxycontin, Avinza, Tequin, Zerit, Meperidine and Percocet
- Take advantage of community pharmaceutical take-back programs or solid-waste programs that allow the public to bring unused drugs to a central location for proper disposal.
- Most local pharmacies will also take back unused drugs and dispose of them properly.

Please feel free to call me with questions anytime!

Jenny Aveson (804) 730-9498

FYI: Useful Information

Scholarship Fund: This is just a reminder that the Central Virginia Post Polio Support Group has a Charlie Brower Scholarship Fund. This money is available to members for use at group events (Retreats, etc.), or to subsidize newsletter dues. Should you be unable to afford either an event or the donation requests please contact either Linda Van Aken or Carol Kennedy to make use of this scholarship fund.

This information is from the Chesterfield Disabilitie Service Board:

This article was in yesterday's Daily Press. The web site is <u>virginiadrugcard.com. or call</u> 1-877-321-6755

A new prescription drug card coming out April 16 for Virginia residents has helped residents in other states save an average of 32 percent on their doctor-prescribed medicines.

The free card is available to any state resident, regardless of age or income. It's provided through the United Networks of America, a Louisiana-based company that offers identical drug-card programs in 25 states, said Francesco Ciccone, program director for the Virginia Drug Card.

"The discount is given at the pharmacy so the pharmacy takes less of the profit from the prescription being sold and the pharmaceutical company gives money back to the pharmacy," Ciccone said.

Any Virginia resident can go online to virginiadrugcard.com to download a card. Savings can be as high as 75 percent on some drugs, according to United Networks of America

Please be on the lookout, in the mail, for your Ukrop's Golden Gift Certificates, which are being mailed now. If (and we understand you may have other causes you want to donate to) you are planning to give them to our group, please bring them to the May meeting or mail them to me by the end of May. I <u>must</u> turn them in by June 14. Thank you.

Carol Kennedy 1803 Aston Lane Richmond, VA 23238-3066

The Polio Personality: DOES IT EXIST?

People often ask if there is a "Polio Personality". My simple answer is: "Not that I've seen."

Those with polio come in all stripes, as they say. Some are ambitious, others more laid back, some have up-beat personalities, and some are depressed.

Polio affected people in different ways, physically, psychologically, and socially. Those who got polio came from different home environments. They went to different institutions for treatment and had different treatments. And they also had different educational and social opportunities and experiences. The list goes on and on, with each factor interacting with the others, shaping the person.

That said – the more complex answer recognizes that there is still some common ground that polio survivors share. Although there may not be a specific polio personality or a specific polio self-concept, the stories of others may sound familiar, and you may find yourself reacting in a similar way.

Let us look at one personality type that is common, though not universal.

THE DOER

Many polio survivors describe them-selves as Doers. They are the ones that spend a lot of time taking care of others – family and friends. (At this point you may be smiling and shaking your head in recognition.)

The need to take care of others may come from guilt felt over the years, for having relied on others so much. "Doing" may be a defense that is intended to lessen the sense of guilt and help you feel accepted. In moderation "doing" can be a good

thing, but when it takes on a life of its own and becomes "over-doing", it can become a problem unto itself.

Maria, a self-reported Doer, says that even when she gets tired, she is not able to stop herself:

"I just keep on "doing", until I'm fatigued – and then I become resentful."

"I do too much for people and come on too strong."

"I try to fix others. If I can fix others, I don't have to focus on myself."

HELPING THE DOER NOT TO OVER-DO

Take a piece of paper and write down the WHYS and WHATS:

- 1. Why do you feel you have to keep going?
- 2. What are you afraid of?
- What do you think others will think of you if you don't keep going and "doing" more?
- 4. Why do you care?
- 5. What would happen if you weren't so helpful anymore, if you just stopped?
- 6. What may you be avoiding in looking at yourself?

THE TYPE A PERSONALITY AND PPS: FACT OR WHAT?

Let us not confuse the Doer with the Type A personality. Do polio survivors have Type A personalities? Some seem to think so, since many of those who survived polio are real strivers and doers – so to speak. But before we reach any conclusions we need to understand what is meant by Type A.

Type A and Type B Personalities

People typically think of those with Type A personalities, as very active, ambitious, hardworking, and successful. But this is not the whole story.

The Type A personality is characterized by

- aggressiveness,
- competitiveness, and
- impatience. It has been described as the "hurry sickness." Those so classified are easily moved to
- anger

And show frequent displays of

- irritation, and
- hostility,

Particularly when things are not moving fast enough nor going as they would like.

This is in contrast to the Type B personality, which is more relaxed and more accepting of life and of others.

RESEARCH FINDINGS

Early studies of Type A personality looked at the relationship of this personality syndrome to heart attacks. The implication of the findings was that a person's Type A personality caused the heart attacks. That is still the idea in the popular press, even though more recent research is showing the issue to be much more complex.

Results are mixed and seem to depend upon the different questionnaires and interview techniques used to assess Type A traits. It does appear, however, that certain traits, such as *anger*, *hostility*, *cynicism*, *and suspiciousness* affect a person's tendency to succumb to some illnesses.

The polio literature often refers to those with post-polio syndrome (PPS) as having Type A personalities. If we accent this, we are then saying that those who had polio are typically hostile and angry, cynical and suspicious? I think not. Some may be, but is this the rule? Having a little bit or some of the traits does not mean one is Type A.

Amongst those who had the gumption to try psychotherapy with me, some survivors did exhibit Type A traits. But I cannot say that this was in greater proportion than in the general population. And there were certainly those with more "laid back" attitudes and behaviors, typical of the Type B personality.

More research needs to be done before one can make statements with confidence about the relationship between personality and PPS. In so doing, we must be careful that our surveys are not biased.

Those who participate in research studies are quite possibly a select group. Because of their character traits, survivors with Type A traits are the ones most likely to turn up at support groups or to seek help from clinics and physicians. They are more assertive, for example, than those who stay home and do not seek help for their problems. They are also more likely to answer questionnaires in greater numbers than their Type B counterparts, who are, thus, not well represented in our data.

Why is This Important?

One reason is the common belief that over-doing it physically may have contributed to post-polio symptoms. After all, the treatment early on was to exercise, exercise, exercise, and exercise. And throughout life for many there was the continued pressure to be like others, to succeed, if not excel, in the mainstream. Do; do more; do more and more.

Still some hearing about the possible association between Type A and polio may worry: Did I cause my post-polio symptoms? Did all that exercise and activity throughout my life lead to PPS?

A BAD RAP

The Type A personality has been given a bad rap. It is not something to be ashamed of, not is it necessarily something to be changed. In some cases, it may be a very good type of personality to have, as long as certain traits, such as hostility and anger, are kept under control.

Persons with Type A are often very successful in their lives, and in terms of heart attacks do much better than their counterpart Type B's when it comes to surviving a second heart attack. Some think it is the very Type A traits that enable people to take better care of their health following the first attack. Thus, it may be a good thing that some survivors of polio have the assertiveness and energy so common to the Type A; this may be what makes them seek better medical care and be active in keeping the medical profession on its toes.

PPS AND TYPE A

So what does this mean in terms of the person who has had polio? Did the earlier efforts in treatment cause people to become Type A's? Certainly there was pressure to exercise and to be reintegrated into society at large. Yet in my clinical experience I cannot say that all those who had polio or have PPS fit the classic Type A description. Indeed, many lead successful busy lives, but others were not so fortunate. Those who were successful may have been ambitious, but not necessarily hostile or angry.

Having polio or developing new symptoms can made one angry at times. Being frustrated by physicians who do not understand can bring out hostile feelings, even in the most even-tempered. But these feelings or behaviors alone do not make a Type A. In fact it may be the keeping in of hostile feelings that compromise one's health. The issue is very complex. As we've said before.

Labeling may be useful in research when one is grouping large numbers of people for studies. But labeling individuals can be misleading, inaccurate and possibly harmful. If people who had polio – or for that matter, cancer, MS, or other diseases – are made to feel that their personalities are the cause of their physical problems, that is another burden put upon them.

By overusing the term Type A, we obscure what the experience and behavior of those with PPS is really about – interfering with our deeper understanding of the late effects of polio.

Reprinted from The Post-Polio Experience by Margaret E. Backman, Ph.D. Published by iUniverse, Inc., website (<u>www.iuniverse.com</u>)

It is with great sadness that we acknowledge the death of long time member Linda Wyand on April 12th. Linda's sweetness and friendly demeanor was always welcomed at meetings, social events and our Annual Retreats. The group's sympathy goes out to her family.

Gift of Gab:

If you've ever been told you talk too much, keep this comeback in mind: Chatting with relatives or friends (either in person or on the phone) can boost your brainpower, a new study has found. Plus, discussing a social issue for only ten minutes improves your memory just as much as more traditional intellectual activities, like doing crossword puzzles.

Source: University of Michigan Institute for Social Research in "Arthritis Today".

Two Redheads & A Blonde Tour - Part Two by Dave VanAken

The last cruise was perfect, but maybe we should have been forewarned, as we left on the Ides of March. All kidding aside, this cruise scored an 8 to 8.5. We just had a few minor bumps in the road.

We left Richmond very early (probably a bit too early for a couple in our troupe). The flight left on time, but we experienced our first bump in the air somewhere around Charlotte, North Carolina. The Captain came on the speakers and warned us about the ground fog in Charlotte. We could possibly be diverted to Greensboro, and we wondered about the flights to San Juan from there. Not to worry, it was early in the morning; the ship did not leave until 10:00 that night, so plenty of time to make the sailing.

We did land in Charlotte and scootered to the next gate. We rented travel scooters in Richmond to use on the ship and in the five (5) ports we were scheduled to see. The plane left on time and we were that much closer to blue skies, warm breezes and blue seas. We stumbled a bit in San Juan airport. After the ground crew delivered our two scooters to the gate area, we discovered one of them had issues and would not run. I worked feverously trying to get it working in the middle of the departure gate area with hundreds of people watching and some trying to be helpful. Frustrated, I eventually gave up and dragged it to the baggage and transportation area.

I let the baggage handlers at the ship terminal cart the dead scooter to our room. I figured I could call on the legendary maintenance teams on the ships. But gone are the days when the industrious ship maintenance team would swarm over your assistive device, take it apart and repair it. One of the maintenance guys did come up to our cabin, and he ssisted me in trying to repair the scooter. Alas, it was not meant to be. So, rather than the burial at sea the dang thing deserved, we parked it on the balcony for the week. A couple of days later, we eventually got a manual wheelchair from the ship, which we used on board and in port for the remainder of the cruise.

We were scheduled to visit St. Thomas, St. Martin, Antigua, St. Lucia, and Barbados. Five islands in as many days might be a bit much for able bodied travelers. The ladies decided to

skip St. Martin, but shop in St Thomas. St. Thomas is the most accessible island. We didn't have any problem getting around in town; cutouts and ramps were prevalent. However, some shops in the downtown area were not what we would consider accessible. The thresholds were about 3-4 inches high, which did restrict wandering into the shops for those on wheels. Interestingly, the shops at the cruise ship piers were accessible and the deals were almost identical to those downtown. So the ladies got their shopping therapy session completed.

There are many cruise land excursions to choose from. However, St. Thomas has the only truly accessible tour. A handicap bus, which accommodates your scooter or power chair, tours you around this beautiful island. Other island tours may indicate they are accessible, but none would carry or stow an electric scooter. We used the manual wheelchair from the ship on Antigua and St. Lucia, folding it and carry it on the bus. Our tour companions were generally very accommodating on this. The steps into the bus can be steep and the guides are willing to offer a helping hand or a boost up. It is best to ask questions before booking. We found the tour information on-line and in brochures was not informative enough to make a decision. We requested additional accessibility information from the cruise line and received some more information, but nothing beats the experience of a knowledgeable cruise staff.

So, what did we learn from this Caribbean adventure?

- 1. A good plan can be trashed within minutes of executing it. But, it is good to have a plan; otherwise you can become a frenzied and crazed traveler.
- 2. Do not, repeat **do not**, book your relaxing cruise during Spring Break. We had 400 children with us on the cruise (20% of the passengers). We "enjoyed" stopping at each floor on our elevator rides and dodging running children in the eating areas.
- 3. A little alcohol goes a long way with Polios (and others). Watch your intake if you are experiencing turbulent seas. However, a three-point head stance can help you get into your room.
- 4. On some of the new ships, the doors to your (accessible) room may be automatic. Insert your card key and the door opens, sometimes. Do not get in its way as it closes, for it is heavy and can leave a mark (if it doesn knock you aside). If you are sharing a room, be sure to knock before barging in, as the door does stay open for about 20 seconds.
- 5. Be patient with the cruise staff. They are here to help you, but may not fully understand you or your needs. Keep trying and one of them will finally get it.
- 6. Order as many desserts as you want. It is all inclusive; same goes for lobster, steaks or any portion of the meal.

7. We should attach some form of instructions on how to maneuver your scooter or power chair. Airline folks do not understand how they work and left to their own devices will make up instructions that will truly amaze you and hopefully not break your ride. I thinking of a brightly colored holder with bold large type indicating how best to handle your equipment. Even then, it may be ignored.

One final learning - Travel with people who make you laugh and can make you laugh at yourself. The three I traveled with did make me laugh and helped me enjoy my vacation even with the bumps in the road. All I can say is where are we going next time?

Editor note: As I was one of the Redheads in this article, I have to add: There were many aspects of this Royal Caribbean cruise that were better than the first. Many of our staff were exceptional and a pleasure to work with. We had charming dinner companions (we love having a large table to share with others for dinner). Traveling with a disability isn't easy, takes planning, patience and fortitude, but the joys of creating memories with friends is certainly worth the effort!

-C.T.R.

From Henry's Desk by Henry Holland

Three Gone Running

"Linda Wyand went to run with the Lord on Saturday, April 12, 2008." This is how Linda's obituary began when it appeared in the Richmond Times Dispatch a month ago. Linda had been a long time member of our Post-Polio support group. At the age of 10 in 1946, Linda contracted paralytic polio. As so many of that time period she regained some strength, but still bore the mark of polio for the rest of her life. She did what people of our generation often did. She finished high school and junior college, married, had four children and raised them and worked for twenty-five years in the circulation department of Richmond Newspapers. In her latter years she adapted to a van and a wheelchair. She had rallied from near death a few years ago when congestive heart failure slowed her down even more. The family had a photo of Linda on her new bicycle shortly before she had polio. Now Linda is not only running but riding her bike with other polio survivors who have gone before.

On January 29, 2008, Dr. William M. Lordi began practicing psychiatry in the Kingdom of God. Bill died in his sleep on January 29, 2008. Bill had polio as a 31 year old adult in 1954. He did not have much residual effect except for a weakness and limp in his right leg. He had many falls after polio and his wife Beverly stated that "Bill fell well." Bill graduated from the State University of New York College of Medicine in Brooklyn, NY in 1949. He went on to achieve specialty training in general psychiatry and child psychiatry. Bill had a full and successful career. He was a leader in opening a psychiatric children and adolescent hospital in Richmond.

Bill and his wife Beverly were both polio survivors and active members of our support group. Bill was always cheerful and uplifting. During the last year he had gotten a power wheelchair. Fortunately his wheelchair had a back up warning horn. This was a blessing because the horn gave some warning to those nearby that Bill was moving and was close by.

Woodrow "Woody" Morris is cutting hair in the Kingdom of Heaven. Woody had been an active member of our support group for many years. He had polio when he was five years old and was initially in a coma. He spent some time in an iron lung and gradually improved with the aid of a brace. He eventually got rid of the brace. With the onset of PPS, he began using a brace again. Woody was a barber as was his father in the suburban village of Sandston, VA. Woody died on August 7, 2007 from cancer. Woody loved our group's brown bag auctions. These auctions were to raise a little money for our social committee. On almost every item auctioned Woody would make the opening bid and often made repeated bids until he often won. If the item was something that was not particularly interesting to Woody, he would simple give it away to another member of the group. Recently our group had the first of what will be many Woody Morris Memorial Auctions.

Linda, Bill and Woody are probably running together in the hereafter. All three had fulfilling lives despite polio and all three were active and positive members of our Post-Polio support group. Their love of life and exemplary lives will be long remembered. What can one say at such a disheartening time? The words of the Apostle Paul to his younger friend Timothy say it well.

"As for me the hour has come for me to be sacrificed; the tune is near for me to leave this life. I have done my best in the race. I have run the full distance and I have kept the faith. And now there is waiting for me the victory prize of being put right with God, which the Lord, the righteous Judge, will give me on that Day - and not only to me, but to all those who wait with love for him to appear." (II Timothy 4: 6-8)

Ninth Annual Fall Retreat !!!

The Annual Fall Retreat will be Friday, September 19th until Sunday,the 21st at the Holiday Inn Express Hotel & Suites in Ashland, VA (www.hiexpress.com/ashlandva). This is located right off Rt. 95, just north of Richmond and will be convenient for everyone. We have tentatively reserved 15 guest rooms and all six handicapped accessible rooms. If you need a handicapped room, please let us know what your exact needs are; you may only need a bath bench or raised toilet seat. If you can supply your own, it would benefit those of us organizing the Retreat.

The hotel serves a multi-coarse breakfast and we have arranged to have two dinners and a lunch catered by a local caterer. We will have the use of the conference rooms, heated indoor swimming pool, hot tub and exercise facility.

The rooms have microwaves and refrigerators, TV, coffee makers and hair dryers. Those who attended in previous years gave rave reviews to the facility.

We will offer this for \$120.00 per person based on double occupancy for the entire weekend, including all meals. This is \$10 less than last year, as the support group is still subsidizing part of the total expense.

If you want to come just for the day on Saturday, the 22nd, the cost will be \$50 a person which includes lunch and dinner.

Our speaker for Saturday morning will be Dr. Albert Jones, who has been the Director of the Post Polio Clinic at Sheltering Arms for several years. Dr. Jones is also the Medical Director of Sheltering Arms. We will announce his topic in the next newsletter.

We have arranged to have one massage therapist join us on Saturday from 9 until 4. She 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.

Dave Van Aken will again conduct a "Partners Session" on Saturday afternoon for those interested.

It is imperative that you make your reservations as soon as possible!!! We are working with a busy hotel and they need to know the exact number of guests by September 1st!!!

Final reservations and complete payment should be received by Linda VanAken by August 31st. For those who send in an early deposit – the remainder is due by August 31st.

We welcome all who have attended in years past and any new members who would like to share their polio stories, ask questions and generally have a rewarding and FUN weekend!

See the next page for the registration form.

Registration Form for September Retreat

Friday, September 19th until Sunday, September 21st

Please mail to: Linda VanAken, 14606 Talleywood Ct., Chester, VA 23831 with check made out to: "CVPPSG"

Final payment has to be received by **August 31**st.

Name:	
Address:	
Phone:	Number of Persons attending:
Type of Room accommodation:	(single or double) Handicap accessible?
If you are single and sharing a room, who will be your roommate?	
Are you interested in scheduling a massage therapy session?	
Will you be attending just for the day on Sa	aturday? 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) \$120 per person based on double occupancy	
Price for Saturday only (includes lunch and dinner) \$50 per person	
Amount of check sent:	

Remember, all rooms, including the handicap accessible rooms, are on a first come-first serve basis. Your registration form, with a \$30 deposit, guarantees your room.

If you know you will be attending, please send your registration in early. Thank you.