



Polio Outreach Of Washington

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Polio Outreach of Washington

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A quarterly publication

Mission Statement:

To help minimize the impact of Post-Polio Syndrome by providing education and support to polio survivors, their families and healthcare providers.



Polio Survivors and Supporters Picnic Welcomes Newcomers

The 13th annual Polio Survivors and Supporters picnic on August 23 in Auburn was blessed with perfect picnic weather for the 74 people who attended. Finding the park was a bit of a challenge for us, being new to the area. It was nice to find ample, close-in handicapped parking arranged by our gracious hosts, the Renton Support group

John and I, fairly new to the Everett group, thought it would be fun to attend the picnic and indeed it was. An impressive array of door prizes and game awards took awhile to check out. Picnics, by definition, should feature good food and sure enough there was enough chicken, ribs, baked beans, potato salad, rolls and fruit to fill up our plates and then some.

The Modern Woodmen singers from Modern Woodmen of America provided delightful golden oldies music and was very well received. John Clark served as host/announcer and his capable team organized some fun games including a timed scooter challenge race course and balloon toss. Winners received prizes, along with wet clothes when the balloons finally burst. The Renton group won the attendance prize with 17 members in attendance.

One of the most valuable aspects of attending the monthly meetings of our respective Support Groups is the companionship and sharing of information that takes place. This picnic had that in abundance as small groups gathered for animated chatting throughout the afternoon. Old friends connected and new friendships were begun.

It seems that polio survivors and their 'caregivers' share a friendly and eager-to-help attitude. Many thanks to all who made the 2009 picnic a success and when the 2010 picnic is announced, you can be sure we'll sign up!

by Lee Sanne Buchanan

All POOW personnel are polio survivors or supporters and are non-paid volunteers.

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q3suz@embarqmail.com

VICE PRESIDENT - Jim Fry
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425-883-7951
rsstahr@raincity.com

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Lauris Whitehead, Rhonda Whitehead

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Outreach: Rhonda Whitehead, Chair and Support Group Assistance, Bill Veters – Website, Suzanne Limric – Medical Referral List, Linda Fry – Newsletter

Events: Vacant

SUE SAYS...

Sue Warren, President



I'd like to thank all who attended and participated in our Fall Business and Membership Meeting.

A huge 'THANKS!' goes to our Kitsap Support Group, chaired by LouAnn and Bob Miller. Their facility at the Central Kitsap Fire and Rescue Station #56 is very nice - spacious and accessible. Everyone was very gracious and the refreshments were delicious.

Of course, one of the main topics on the agenda was the election of Board members and officers. Up for re-election were Jim Fry, Linda Fry, Bob Miller, & Bill Veters. We accepted the resignations of Larry Christensen and John Clark. Additional nominees were Scott Stahr from the Everett group, Lois Barber from the Kitsap group and Jan Stahr was nominated from the floor. The slate was accepted and officers selected. Our sitting Board is as follows:

Sue Warren - President Jim Fry - Vice President
Scott Stahr - Secretary Members-at-Large: Linda Fry, Suzanne Limric, Jim Limric, Bob Miller, Jan Stahr, Bill Veters, Rhonda Whitehead, & Lauris Whitehead

Lois Barber was appointed Office Manager, Linda Fry will continue as newsletter editor.

The Board would like to fill the position of Treasurer, which has been vacant for a couple of years. Members with accounting experience may submit a letter of interest to me, or any Board member.

The Treasurer must be a member of the Board, be bondable, and pass a background check, and be able to coordinate with our CPA service. A job description is available.

Bill Veters, has volunteered to be our web master. Jarrod Williams has done such a fabulous job of creating the new website and has agreed to train Bill and put together a training manual. Bill gave us a computer presentation of how some of this done, and all I can say is "I'm glad HE understands it!" ;-) Thanks Bill!

FYI - from our website, you are able to email the President, Vice-President, Secretary, Editor, and Office Manager. We welcome your comments and suggestions!

Rhonda Whitehead gave a report on supporting Support Groups, and mentioned one of the difficulties is when leaders forget to update e-mail address and phone numbers. These contacts are SO important, because what we have listed is what we give to new members that need a referral. If it's not current, it can be very discouraging.

SUPPORT GROUP LEADERS! PLEASE NOTIFY US OF PHONE AND E-MAIL CHANGES!! WE NEED YOU!! ;-)

Though we've made some office changes, our 800# will stay the same. 1-800-609-5538.

Another area of discussion was the 2010 Picnic and Fall Business meeting. A suggestion had been made about the possibility of combining them as a two day event, perhaps at the Embassy Suites Hotel in Yakima [one suggestion]. Apparently this space has been used in years past with good success. This would allow more latitude in perhaps obtaining speakers, have break-out groups on different topics, having more opportunity to rest, and of course more time to visit! **BUT, alternative site suggestions are also welcome!** Our goal is to make our meetings as convenient and accessible to as many members as we can.

We would need volunteers to plan and host the picnic. Suggestions for speakers or agenda items are also sought. A decision needs to be made no later than December 1st. If we don't use Yakima, the Tacoma Support Group has volunteered to chair the picnic, and it would be held at the Auburn Game Farm.

Our next Business meeting is scheduled for Tuesday, April 13, 2010. Please reserve this day on your calendar ;-) We are hoping to meet at the Paralyzed Veterans of America office in Burien, but this needs to be confirmed.

My wishes for a safe and healthy fall and winter for you all!
Sue Warren



We would like to recognize the retiring Board Directors for faithfully giving their time, talents and energy to promote the mission of Polio Outreach of Washington. They are Larry Christensen, Secretary, and John Clark, Office Manager. We appreciate your efforts and passion to support the polio survivors of Washington State in such a meaningful way.

2009-2010 Board of Directors

Polio Outreach of Washington Post-Polio Support Groups

Please contact the group leaders for further information.

Benton County

3rd Saturday 1:00pm Neurological Resource Center 712 Swift Blvd, Richland, Norma Peters, 509-946-5485, norevepet@gmail.com

Clallam County

4th Friday of every odd number month Sequim Library 630 N Sequim Ave 10:30 to 12:30 Paul Tucker 360-452-6487, paulaver@olympus.net

Clark County

Susie Koeser 360-574-4523 vipsusie@msn.com or Stan Nelson 360-892-5314 stanor@juno.com

Douglas County

3rd Monday 5:00 - 7:00 pm City Side Cafe in Red Lion, Wenatchee Sandee and Jim Thornton 509-884-8856, smt1107@charter.net

Kitsap County

3rd Saturday of every odd month 1:00 - 3:00 pm Bob and LouAnn Miller, 360-692-1381 rmiller@wavecable.com

Pierce County

1st Monday 1:00-3:00 pm TACID Bldg-Tacoma
No meeting January or July.
Apr., Aug., Dec. potlucks 11:00 am
Marlys Tron, 253-863-9556
Sandra Morley 253-752-6176

Snohomish & North King County

2nd Saturday of each month 1:00 - 3:00 pm, Everett Providence Hospital - Pacific Campus No meeting in August. Rhonda Whitehead 425-488-0219 laurishw@comcast.net

South King County: website:renton-postpolio.info

3rd Saturday of each month noon to 2:00 pm - potluck Mimi Sangder 206-725-8937, fuzzface7@juno.com

Spokane County

1st Tuesday of every third month at 6:30 pm. Shriners Hospital in the 5th floor auditorium, Sharman Collins 509-448-8517 or sharmancollins@msn.com

Whatcom County

Last Saturday of odd-numbered months Noon to 2:00 pm. Bellingham St. Joseph Hospital. Patrick Ewing 360-966-4253 pre47airstream@aol.com

Asotin County: Tri-State Polio Pals

4th Saturday, 1:00 PM to 3:00 PM Tri-State Hospital. Jim Hueston, 509-758-2187, rockinnj@cableone.net

Note to support group leaders: Please notify the newsletter editor of any contact information or meeting changes for you. Thanks!

PIERCE COUNTY POLIO SUPPORT GROUP NEWS



Please join us for our holiday event on Dec. 7 at TACID, 6315 S 19th St, Tacoma (253-565-9000). The late morning begins with musical entertainment, followed by a pot luck meal and a large raffle. A fun time is to be had; people are urged to come from 10:30-10:45 for visiting as the program begins at 11:00.

For additional information call Marylys Tron 253-863-9556 or Sandra Morley 253-752-6176.

We have been contacted by a polio survivor who lives in the Hoquiam area. She is having trouble finding a doctor who will listen about her PPS symptoms. If anyone has a possible referral within her travel radius, preferably less than an hour, please send the information to Sue Warren at q3suz@embarqmail.com

Polio Survivors Go Surfing!

Here are the featured Websites for this quarter:

Breathing & Sleep - a free symposium - Solutions for people with neuromuscular disorders such as Post-Polio Syndrome, ALS, MS, and Muscular Dystrophy

Sunday, November 1, 2009 - Noon to 5:00 p.m.
Salk Institute for Biological Studies Auditorium
10010 North Torrey Pines Road, La Jolla, CA USA
92037

People with neuromuscular conditions often encounter difficulties seeking and obtaining proper respiratory care. Too often, primary care physicians, neurologists, and respiratory care professionals treat their respiratory problems as a lung issue, rather than as a muscle/nerve problem. And too often, sleep labs look only for obstructive sleep apnea and miss under ventilation.

To find out more information and to register by October 28, 2009, go to:

<http://www.salk.edu/breathingandsleep/>

Websites in Washington State by polio survivors:

www.danmillerspeaker.com Based in Yakima, Dan Miller is a former educator, full time speaker and author. He has a powerful message of overcoming polio to reach impossible dreams.

www.just2drops.com Denny Wilford lives on the Kitsap Peninsula and has established The Denny Wilford Foundation. Its mission is "to support the rehabilitation of persons affected by polio by raising funds for equipment, facilities and procedures for the treatment of disabled children and adults."

www.renton-postpolio.info The place to learn about what the post-polio support group has been up to and is planning. Dozens of picnic pictures can be viewed here. Links to other websites.



WE ARE GOING GREEN...

Reading the newsletter on the website, www.poliooutreach.com saves Polio Outreach the cost of printing and mailing it to you. If you would be interested in not receiving the newsletter by mail, simply call the office manager, Lois, at 1-800-609-5538 and let her know!



www.poliooutreach.com The place to find medical information, resources, support groups and more...

Supporters



And

Survivors

More of the Right Tools

I gained many new tools from the *Powerful Tools for Caregivers* 6-week series for unpaid family Caregivers.

A Caregiver's Tool Bag is never complete. The more tools one has, the better they will be able to handle the ever changing challenges that arise for both the Caregiver and the Care Receiver. For Polio survivors, Change or *Transition*, as it is referred to in the Handbook, is constant.

The Caregiver and the Care Receiver experience the 3 Phases of Transition together. Both must accept the end of what was, and the beginning of what is or may be.

An adult child with a life of their own suddenly becoming a Caregiver, either by choice or necessity, to their parent or spouse is overwhelming and difficult for both. There is fear of being entirely responsible for the well being of a parent or spouse. There are mixed emotions about their new roles. Neither person wants to give up the life they had, the things they did. Both have feelings of sadness, loss, resentment, anger and resistance mixed with caring, compassion, love, and concern. They mourn the life that was, the life that could have been.

Now the child feels like they are the parent. They are uncomfortable making decisions for the parent that has always been in control of their own needs. The parent or spouse resents giving up or sharing that control. Understanding these 3 Phases; The Ending, The Wilderness, The New Beginning, and the emotions that go with them will make working through the phases a positive learning experience.

There are 3 Transition Phases:

1 - **The Ending Phase** for the Polio survivor usually starts as a noticeable decline in their physical capabilities. There may be increased fatigue when walking, more frequent stumbling or falls, or difficulty getting out of a chair or bed. The Caregiver may be the first one to realize that the status quo must change. Ever increasing physical demands on the Caregiver may now necessitate the introduction of a walker, bracing, a power scooter, handicapped equipped vehicle, hiring extra help, or other types of aid that contribute to maximizing the Care Receiver's independence while striving to minimize the physical and emotional demands on the Caregiver.

An Ending Phase for the Caregiver may be signaled by increased fatigue, stress, frustration, feeling overwhelmed, inadequate, or pushed beyond their ability to cope with a new situation. The Caregiver should approach the Ending Phase with a positive attitude. Encourage open and honest dialogue with the Care Receiver about the transition that is occurring or that may occur in the near future. Involve the Care Receiver in planning for potential changes rather than ignoring them

until a crisis occurs. Care Receivers may not willingly accept the fact that the manner in which care has been given is no longer effective. **Focus on the benefits to both of you by implementing changes.** Accepting the end of old roles will make it easier to see the good in new ones.

2 - **The Wilderness Phase** is adjusting to the new roles and changes in caregiving requirements. This is usually the longest phase. It is a time when each must come to terms with how their routine will be adapted to meet their new needs. They are in uncharted territory. Feelings of inadequacy, confusion, anxiety, fear of the unknown, or of doing something wrong may undermine the Caregiver's confidence in making good decisions for the Care Receiver. This is a time when the Care Receiver may resist giving up the security blanket of the way things had been done in the past. They too fear the unknown, the un-tried. This may lead the Caregiver to have feelings of failure. The Caregiver may also feel they are providing un-necessary care that allows the Care Receiver to increase their dependency. **Discuss various ways to achieve the needed caregiving changes.** Be flexible. Test ideas out to see if they are workable before making them a permanent part of the New Beginning Phase.

3 - **The New Beginning Phase** is moving forward with confidence that both can be comfortable in their new roles. The Caregiver may need to acknowledge that they have reached their caregiving limits. Implementing plans made during the Wilderness Phase, accepting help, either volunteered or hired should be viewed as positive steps forward in providing the best care for their loved one and themselves.

Both the Caregiver and Care Receiver deal with a succession of Ending Phases, Wilderness Phases followed by New Beginning Phases. At times there is very little opportunity to experience the Wilderness Phase.

We all spend our lives going through some type of transition. For the Polio Survivor it is the Ending of being a healthy active person, through the struggle in the Wilderness to accept the person Polio has created, to dealing with the New Beginning of life as a Polio Survivor. Transition phases come in all sizes. It may be as minor as using a drinking straw because weakening respiratory or swallowing muscles has increased the chance of choking. It may be as major as moving from one's home to a care facility. **Unfortunately, transitioning from one level of caregiving to the next is seldom openly discussed between those impacted by it.** It is a Caregiver's responsibility to themselves and to their own well being to make frequent use of the powerful tools in their Caregiver Tool Bag.

Take care of yourself so you thrive, not just survive.

~Lynne Hollister, Everett Polio Support Group member

Editor's note: This is the second in a three part series with Lynne sharing the rest of this class in our next issue.

For more information on **Powerful Tools for Caregivers** and other Support Programs provided, contact:

Stefanie Bonigut, MSW, Caregiver Specialist

10201 E. Riverside Drive, Bothell, WA 98011

stefanieb@seniorservices.org, 425-286-1047, www.northshoreseniorcenter.org

ROOSEVELT WARM SPRINGS REVIEWED

On my “bucket list” of things to do before I die was to see Warm Springs, GA, and the pools where FDR spent a lot of time after he had Polio. It is located about an hour and half from Atlanta, GA, so it is not that easy a place to just stop by. So, when Post Polio Health International in St. Louis decided to hold their 10th conference there, I knew I had to try and attend. It was well worth the effort to go back to the east coast to hear the presentations of a variety of wonderful speakers.

This conference was unique as it was held in a rural area with a variety of available lodging rather than the usual big city hotel. Each has its advantages, but I was glad to have rented a scooter as it was necessary for me, especially in such a spread out area. There were handicapped accessible mini-busses that worked very well, too. The staff at Warm Springs did all they could to accommodate us. While they are used to working with individual with various disabilities, I don't think even they were quite prepared for the numbers who showed up. They were probably stretched to their limits, but I was impressed with how they went above all expectations to help as needed.

I always enjoy time to meet with old friends, and make new ones, too. I was lucky to have 2 roommates (one gal was from GA and the other one was from CA). We shared a room in one of the 2 lodges at Camp Dream on the WS campus overlooking the lake. The camp was built in the 1990s to allow handicapped kids to fully enjoy the camping experience. The accessibility was outstanding both inside and outside.

The theme of the conference was “Living with Polio in the 21st Century.” Roosevelt Warm Springs Institute for Rehabilitation (RWSIR) has been providing rehabilitation for a variety of conditions for the past 81 years, starting with FDR and Infantile Paralysis. The Executive Director, Greg Schmieg, welcomed us all to WS. He spoke about the “Spirit of Warm Springs” and the caring and compassion, that we saw everywhere. He noted that, “Franklin D. Roosevelt never learned to walk by coming here, but I believe it made him a better man and a much better President.” From what I have read, Eleanor, his wife, would have agreed with him.

The idea for the conference at WS came from a former patient, and founder of the North Central Florida Post Polio Support Group, Carolyn Raville. She wrote about her experiences at Warm Springs and it is on their website: <http://www.postpoliosupport.com/goingback.html>

At the Opening Session (“Polio: The Legacy of Warm Springs”), Edith Powell, Ed.D, spoke about the Tuskegee Institute and the Fight Against Infantile Paralysis, 1941-1965. Dr. Booker T. Washington founded the Institute to serve the needs of the rural south during a time of segregation. It was made possible by an early grant from the National Foundation for Infantile Paralysis (NFIP). FDR founded the NFIP which later became the “March of Dimes.” Dr. George Washington Carver, a world-famous scientist, was working on “peanut oil” to relieve sore muscles (wrongly promoted as an early “cure” by a reporter, not by Dr. Carver).

We also heard from several authors, including Naomi Rogers, Ph.D, who spoke on “The Polio Crusaders: Disability Activism at Warm Springs in the 1930s. At WS, the patients had a newsletter, The Polio Chronicle, which had the slogan: “Every Patient, a Polio Crusader.” Ms. Rogers is the author of the book: “Dirt and Disease: Polio Before FDR.”

Daniel J Wilson, PhD, who wrote the book, "Living With Polio," discussed "The Legacy of Warm Springs." As a history professor, he noted that most of his students today have no idea what Warm Springs was. We don't want this part of our history to be lost. Many at the conference had been patients at WS, and many were back for the first time. Others of us saw similarities in the old pools and exercise areas and even the rural setting. The grounds at Warm Springs were patterned after the campus at the University of Virginia, and are exceedingly beautiful, especially in spring.

There were so many interesting topics, as usual. But, there is a program booklet (actually one each day) given to all those attending which is a wonderful take home of all the handouts. Post Polio Health International also has a CD of all this that can be ordered from their website.

One of the most interesting sessions I attended was the "Anesthesia Update: Separating Fact from Fear." Dr. Selma Calmes is a polio survivor and an anesthesiologist (retired). Anesthesia, like any medical specialty, is changing rapidly. So, it is futile for us to try and keep up with drugs and practices. Instead, Dr. Calmes emphasizes proper pre-operative planning and communication with your pre-op team, including the anesthesiologist. Anesthesia today is safer and more effective than ever before. But, no one type of anesthesia is best for all because it depends on what is best for you and your type of operation. Dr. Calmes reports her clinical impression is that, "if a good pre-op evaluation is done and if surgical, anesthesia, and hospital care are competent, PPS patients can have surgery without problems." Right now, the Mayo Clinic is assessing data from 1986-2008 (including effects of anesthesia on people who had polio/PPS). More information by Dr. Calmes is available on the PHI website: <http://www.post-polio.org/ipn/anes.html>

Dr. Calmes also urged us to carry a card in our wallets with emergency info on it, or better yet to get a Medic Alert bracelet. In ER situations, it could save your life.

Another session dealt with, "Regulatory T cells as a Biomarker of Post-Polio Syndrome." According to researcher Rahnuma Wahid, "No biomarker(s) has been identified for PPS as yet that could assist in providing a definitive, easy, and rapid diagnosis." Researchers at the University of Arkansas are looking at signs or changes in the immune system that can be linked to PPS. "The observations from this study do, however, suggest that there is a problem with the immune responses in polio survivors, which could contribute to PPS." She also said that it is unclear at this time "whether immune components have a direct role in the initiation and progression of PPS or merely indicate the presence of a problem with the immune system..."

In the session, "Finding Causes of and Monitoring Fatigue," none of these drugs have been found to be effective in reducing fatigue:

Modafinil, Pyridostigmine, Prednisone (high doses), Amantadine, or Coenzyme Q-10.

Intravenous Immunoglobulins have not been found effective for fatigue, but they are still looking into IVIG for pain management, muscle strength, and vitality.

Barbara Duryea, MSN, RN, discussed Complementary and Alternative Medicine (CAM), which includes

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things like Hatha Yoga and acupuncture. The FDA advises caution with claims of a cure for diseases like diabetes, cancer, or AIDS. It is wise to be suspicious of infomercials where people make claims such as the government is trying to suppress the information they have. More can be found on the website: National Center for Complementary and Alternative Medicine: <http://nccam.nih.gov>

Kathryn Bussey, RD, LD, spoke on “Feel Good Food: Boosting Energy, Maintaining Weight.” She reiterated that there is no “magical diet” for us or anyone else. She had an excellent presentation on Nutrition 101, as well as lots of practical information. But, it is worth repeating that our dietary choices need to be nutritious foods in the proper amounts.

The conference closed with “Polio: A Look Back at the Public Health Crusade that Mobilized a Nation.” David Oshinsky spoke to a packed house in Roosevelt Hall. “The battle against polio mobilized an entire nation against the 20th century’s most feared disease. He is the author of “Polio: An American Story.”

Just outside Roosevelt Hall is the display of Polio Information and Memorabilia, including an iron lung. It first appeared at the Smithsonian Institute in Washington, DC. I missed it there, so I was glad to see it in Georgia, and visited it several times during the conference.

If anyone wants to visit Warm Springs, give them a call. There is plenty to see and do in the area including the Little White House, and the historic pools.

*Janice Knight Hartman
Burlington, WA*

Have One? Want One?



Pride Revo power scooter with basket, in wonderful condition, includes instruction booklet. Free to polio survivor, offered by polio survivor, Rita Anderson. Phone number is 206-525-3335. Located near Green Lake area of Seattle. Must provide your own means of transporting the scooter.

If you would like to place your items available or request for items on this page, please submit your information to Linda Fry by the newsletter deadline at frydaze3@comcast.net.

Polio Outreach Of Washington

Please use this form when you are submitting any information. Include your name, address, phone number and e-mail address. When you go on vacation or move, please submit an address change to us and also another address change when you return! Thank you.

As an independent, 501(c)(3) non-profit organization we rely on our readers and membership for support. Your donations are appreciated. The date next to your name on the label is one year from the date of your last donation for the newsletter.

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UPSET

About 30 years ago when the late effects of having polio (PPS) began to kick in, I started using a cane for added walking stability. Over the years I've had a number of falls probably typical of weakening leg muscles and cane slipping on wet floors.

About 15 years ago I tried out a wheelchair and quickly discovered a more stable means of transport. Upsets in wheelchairs and scooters may be more infrequent, but can be dangerous particularly if you tip backwards.

Several years ago we traveled to Alaska on the ferry named Klondike on a route between Bellingham and Seward. On route the public address system announced an unscheduled stop at Yakutat. I decided to be on deck when the ship docked. I overslept and didn't realize the vessel had arrived until I heard the ship's engines back-down. I hurriedly dressed and transferred into my chair then raced down the corridor to the open deck. The door to the deck was protected by a high threshold. As I rushed across the threshold my chair went over backwards! Fortunately my backpack was filled with a heavy coat, so I wasn't hurt and no one was around to witness my fall.

I will always remember the tipping point, when you no longer have control but your whole life seems to appear before you and you vow to be more careful in the future!

Still rolling, *Carl Larson Snohomish, South King County Support Group member*

Newsletter Deadline:

The deadline for the next issue of POOW newsletter is December 1.

If you have any articles, information or suggestions for items you would like to see printed in this publication, please send an e-mail with that information to me at: frydaze3@comcast.net

Thank you to all who have contributed to this issue of our newsletter! Linda Fry, Editor

Polio Outreach Of Washington, a 501(c)(3) Non-Profit Corporation



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Calendar

*Our website is now ready for you !
www.poliooutreach.com*

October

- ~ begins new term of officers*
- ~ new office manager*
- ~ new office address*
- ~ fundraising letters mailed*

November

~Happy Thanksgiving

December

*~Enjoy the
Holidays!*

