



The Second Wave

Newsletter Of The Ocean County
Post Polio Support Group

WINTER 2012

OCPPSG Message From The Chair January 2012

Susan P. Gato, RN, OCPPSG Chair

Winter is here along with its beauty and wild life and thoughts of 2011. January 31 will mark one year since we lost our beloved Addie Del Priore. She is greatly missed and remembered with love and laughter for her strength and many contributions to OCPPSG.

Last year OCPPSG again enjoyed good food and warm company at our four (4) general membership meetings at Health South in Toms River, we thank them for continuing to provide us with such a wonderful space to meet and conduct our programs. Our July Day at the Races with Monmouth County PPSG was another winner for awareness with the Polio Network of NJ up in lights on the billboard, sponsoring one of the 11 races. Our Holiday Party at the Quality Inn in Toms River was well attended including guests from New York City who shared in the good times and related their Polio life experiences. They are still trying to find a PPSG in NYC.

OCPPSG continues to attract new members through our newsletter, website, community notices, word of mouth and social media such as our Facebook page. www.facebook.com/ocppsg. If you have not visited our page, please have a look or get someone, perhaps a teenager :) to help you visit and "Like" us on Facebook. The Polio Network of New Jersey has a page on Facebook as well.

There are also other Polio related pages on Facebook that you may find very interesting such as the harvest center's Post-Polio "COFFEE HOUSE" where you can post a question and get many replies and answers. Social media such as Facebook is also a wonderful way to connect to other Polio Survivors from the comfort and protection of your own home especially when bad weather keeps you in.

I continue to volunteer as recording secretary on the Executive Board of the Polio Network of New Jersey with our next meeting taking place at the Manville Library, Jan. 23, at 11 am. The date for the next Polio Network Conference, again held at the beautiful Bridgewater Marriott is Sunday, April 22, 2012, at 11 am. The conference has been a wonderful event in the past where you can meet Polio Survivors from all over New Jersey and the United States. I can't wait to attend and I encourage you and family & friends to attend. For more information or to register visit: www.pnnj.org.

OCPPSG members are linked to many other helpful organizations and friends. ADAOCAN (ADA Ocean County Action Network) is one such group with our own Dorothy McDowell as the President. The website is up – check it out at www.adaocan.org. Lots of info about accessibility concerns, a topic that relates to all Polio survivors and consciousness raised adults. For our members with Food Allergies, allergy news from FAAN has been very encouraging, visit www.foodallergy.org or 800-929-4040.

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OCPPSG CALENDAR OF EVENTS 2012

GENERAL MEMBERSHIP MEETINGS

Saturday, April 14, 2012
 Saturday, June 16, 2012
 Saturday, September 9, 2012
 Saturday, November 10, 2012

Meetings start at 10 AM with a welcome brunch followed by a program at 11 AM.

General membership meetings are held at:

HealthSouth Rehabilitation Hospital of
 Toms River ,
 14 Hospital Drive,
 Toms River, NJ 08755

BOARD MEETING DATES

Thursday, January 12, 2012-Elections
 Thursday, March 1, 2012
 Thursday, May 10, 2012
 Thursday, August 9, 2012
 Thursday, October 18, 2012

SOCIAL EVENTS

Thursday, March 8, 2012
 Social Luncheon
 Thursday, May 17, 2012
 Laurita Winery
 August 2012 — To Be Announced
 Day at the Races
 Saturday, Dec 15, 2012
 Holiday Social Luncheon

✓ *Mark Your Calendar*

FROM THE CHAIR

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Life in Action magazine, the official publication of NSCIA (National Spinal Cord Injury Association), a program of United Spinal Association, is a real treasure. It is packed with so much helpful information, such as, information & referral, wheelchair medic, congressional liaison office, Able to travel and Veterans Service officers and more. Individual membership to NSCIA is free to those with spinal cord injury (including Polio survivors). Learn more or join at www.spinalcord.org or call 800-962-9629.

The American Legion Post 129 at 2025 Church Road, Toms River is accessible and has hosted ADAOCAN celebrating the Anniversary of the passage of the *Americans with Disability Act* in their rental hall that is open to the public. Check out www.alpost129.com. Several of our OCPPSG members are also Veterans and members of the Post and I thank them for their service. Our "*Second Wave*" Editor Al is one such person.

Over the last 8 years, living with PPS and OCPPSG, I have learned a lot of things about myself, human abilities, possibilities and change. PPS (*Post Polio Syndrome or the Late Effects of Polio*) sent me through an unwanted transition. Resistant at first, I am steadily adapting to a different life and work and discovering more satisfying possibilities. Our group works on awareness and helps each other find answers and enjoy life. Together we learn the latest social happenings, helpful connections, scientific information and research from throughout the world. It's all about networking and caring

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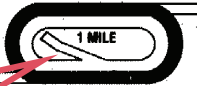
WIN, PLACE AND SHOW
EXACTA, TRIFECTA AND 10-CENT SUPERFECTA
DAILY DOUBLE (RACES 5-6)/PICK 3 (RACES 5-6-7)

Approx Post 2:45PM



5

CLAIMING
Purse \$32,000



WIN	PLACE	SHOW

Polio Network Of New Jersey

(Plus 40% for N.J. Breds)

FOR THREE-YEAR OLDS AND UPWARD WHICH HAVE NEVER WON TWO RACES. Three Year Olds, 110 Lbs. Older, 122 Lbs. Non-winners of races since June 13 Allowed 3 Lbs. Claiming Price \$30,000, For Each \$2,000 To \$25,000 1 lb. (Races where entered for \$22,000 or less not considered in allowances). One Mile.

Track Record: FORTY NINER (3), 114 lbs; 1:33.80 (7-16-88)

	OWNER	TRAINER	JOCKEY	MORNING LINE
1	ROBERT REIDY White, Green Shamrock and Orange RR, Green Bars on Sleeves, White Cap	MARIO SEREY, JR. (L) **112	RAMON MOYA	12
Red	CORAL KEY B.g.4 Awesome Again - Coral Necklace by Conquistador Cleo (FL)			\$30,000
2	RHR STABLES Royal Blue, Red and White Hoops, Red and White Bars on Sleeves, Royal Blue Cap	JOSEPH ZOPPI (L) 116	PEDRO L. COTTO, JR.	6
White	SAMMY'S TRIP Ch.g.3 Trippi - Queen Debby by Notebook (FL)			\$30,000
3	CASNER RACING, LP White, Green Diamond, White Cap	SHANNON RITTER 119	EDGAR PEREZ	4
Blue	ELKHORN CREEK B.g.4 Distorted Humor - Settling Mist by Pleasant Colony (KY)			\$30,000
4	ROLANDO J. LIMA White, Red Collar and Blocks, Red Stripes and Cuffs on Sleeves, White Cap	OWNER (L) 119	JOSE FERRER	5
Yellow	ELIDEFEATSPEYTON Ch.g.3 Limehouse - Propeller by Lear Fan (FL)			\$30,000
5	LEE LEWIS Turquoise, Blue Belt, Turquoise Bars on Blue Sleeves, Turquoise Cap	MARK A. HENNIG (L) 119	PACO LOPEZ	5/2
Green	FRAMED B.c.4 Tale of the Cat - Deb's Honor by Affirmed (KY)			\$30,000
6	PTJ STABLE Yellow, Red Collar, Multi-Colored Pinwheel, Green Band on Red Sleeves, Yellow Cap	JAMES T. RYERSON (L) 116	ELVIS TRUJILLO	3
Black	OH SO DEBONAIRE Dk B/ Br.g.3 Regent - Impress the Lady by Native Regent (FL)			\$30,000
7	BRIER CREEK FARM & J.F. YOUNG Teal, Black Diamond Belt, Black Cap	ANTHONY R. MARGOTTA, JR. (L) 114	CARLOS MARQUEZ, JR.	7/2
Orange	ROCKY START Ch.c.3 First Samurai - Deb's Honor by Affirmed (KY)			\$25,000

CORAL KEY Returns to conditioned claiming company for his sixth career start. Four-year-old tries this distance for the initial time and may show speed on the stretchout.

SAMMY'S TRIP Shortens up to a mile and heads into this race off a solid third-place finish. This gelding will likely flash early foot and is a contender.

ELKHORN CREEK Exits allowance/optional claiming company for his first start off the bench. He sports a steady worktab for his return to the races and may be found sitting midpack throughout the early stages of the race.

ELIDEFEATSPEYTON Goes turf-to-dirt for his second start against winners and exits allowance company. He tries this distance for the initial time and may head toward the early lead from the break.

FRAMED Exits starter allowance company for his return off the layoff and goes out for a jockey/trainer combo that is 2-for-4. He boasts a solid record at this distance and is a contender.

OH SO DEBONAIRE Makes his first start for new connections and shortens up to a mile. Three-year-old may settle in behind the early leaders and would be no surprise.

ROCKY START Makes his first start off the claim this afternoon and sports a 3-furlong breeze for this event. This colt draws the outside post for his second start off the layoff and could be charging hard late if there is a fast early pace. Top choice.

Brad Thomas
Elkhorn Creek
Rocky Start
Framed

Thomas Cassidy
Rocky Start
Framed
Sammy's Trip

PROBABLE FAVORITES: 5 - 6 - 7

FROM THE CHAIR

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for each other. For international information visit: www.post-polio.org.

Thank you to all Board members and Committee Chairs for their work and commitment throughout the year. Thank you to all our loved ones & friends, for their support and understanding in 2011.

I wish you a healthy & Happy New Year.

Susan P. Gato, RN, OCPPSG Chair

DAY AT THE RACES

Kitty Reams

On Friday, August 12, 2011 a group of twenty people from **Monmouth** and **Ocean County Post Polio Support Groups** met at Monmouth Park Raceway for a day of fun.

Everyone enjoyed a delightful à la carte luncheon and drinks on the dining terrace while we watched the races.

The **Polio Network of New Jersey** was highlighted as a sponsor of one of the races.

After the race some of our group was invited to join the owner, trainer and jockey in the winner's circle.

FRIENDS AND PARTNERS: THE LEGACY OF FRANKLIN ROOSEVELT AND BASIL O'CONNOR IN THE HISTORY OF POLIO

By David W. Rose, March of Dimes Archivist

Among the multitude of Franklin Delano Roosevelt's enduring accomplishments is his creation of the March of Dimes, founded as the National Foundation for Infantile Paralysis (NFIP) in 1938, FDR created the NFIP by presidential proclamation on September 23, 1937 to "lead, direct and unify" the fight against polio. The new foundation quickly became a beloved institution through its popular March of Dimes fund-raising campaigns through which it claimed the conquest of polio with the Salk vaccine licensed on the tenth anniversary of FDR's death, April 12, 1955. In 1958, with polio on the wane, the foundation re-invented itself by launching an adventurous program directed at birth defects. As the birth defects programs developed through the 1960s, the foundation's mission expanded through the burgeoning fields of genetics and perinatology, evolving into its present mission, strongly characterized by a campaign against premature birth launched in 2003. These later developments, which FDR could not have foreseen, continue and thrive as part of his permanent legacy.

While the story of FDR's creation of the NFIP and the first March of Dimes radio campaign in 1938 that deluged the White House in dime donations has often been told, the person who orchestrated these campaigns that revolutionized vol-

unteerism and fundraising in the United States has been nearly lost to history. Basil O'Connor (1892-1972), FDR's former law partner, who also played key roles in the Georgia Warm Springs Foundation and the President's "Brains Trust" in the 1930s, led the NFIP as president for over three decades, from 1938 to 1972. During that period he served, simultaneously, as head of the American National Red Cross (1944-1949) and was instrumental in creating the Salk Institute for Biological Studies in 1960. Roosevelt and O'Connor are the only two non-medical honorees in the Polio Hall of Fame at Warm Springs, Georgia; and yet there is no complete biographical treatment of Mr. O'Connor's life that can validate his historical importance as "the architect in the fight against polio."

In actuality, Roosevelt and O'Connor together set the groundwork for the massive campaign to end the polio epidemics in the United States through the Georgia Warm Springs Foundation and the NFIP. Well-known is O'Connor's initial reluctance to spearhead the efforts to create the Georgia Warm Springs Foundation, but his loyalty to FDR superseded any initial hesitation he may have had. O'Connor eventually supported FDR's interest in Warm Springs wholeheartedly, and he became a passionate spokesman for the polio cause. Their relationship matured not only through their mutual interest in Warm Springs, but through myriad channels of advice that O'Connor provided for FDR after he became President of the foundation until his death in 1945, often spending time at his home there, the "Little White House," it was O'Connor who directed the foundation
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ROOSEVELT

(continued from page 4)

during the Roosevelt years, serving as treasurer and chairman of its Executive Committee and ultimately succeeding FDR as president.

The NFIP was founded in 1938 in part to establish a non-partisan basis for polio fund-raising and research beyond the confines of Warm Springs. Realizing that the problem of polio could not be effectively addressed by a local institution like the Georgia Warm Springs Foundation, FDR issued a proclamation on September 23, 1937 to create the NFIP. In his proclamation, FDR focused on the need to create a national organization to approach the problem of polio in a holistic fashion. He stated that the Georgia Warm Springs Foundation had devoted its efforts "almost entirely to the study of improved treatment of the after effects of the illness" whereas the new foundation would attack "every phase of this sickness." Of course, O'Connor assumed responsibility for leading the NFIP even though he continued to manage the program at Warm Springs.

The formative years of the NFIP coincided with a period of global war, and raising funds for polio in a wartime economy found stiff competition from war bond drives. Yet, in the patriotic climate of support for the President and American armed forces, Hollywood favored the March of Dimes. MGM mogul Nicholas Schenk chaired the Motion Pictures National Committee March of Dimes Drive, ensuring industry support from the highest level. As a result, the March of Dimes had a monopoly on movie theater fund-raising during the war as thousands of theaters were authorized to permit collec-

tions that preceded a film. Popular movie stars like Judy Garland, Mickey Rooney and Greer Garson appeared in March of Dimes trailers and films. Patriotism, the global war, the fight against polio and the dominance of the film medium at the time all converged to make the March of Dimes extremely popular and successful despite the war. As an ending to the war began to emerge as a real possibility, FDR appointed O'Connor as President of the American Red Cross in 1944. O'Connor's visits to the Pacific and European theatres of the war for the Red Cross provided critical experience to him for the logistical complexities of the Salk polio vaccine field trial to come.

After President Roosevelt's death on April 12, 1945, Basil O'Connor succeeded Roosevelt as president of the Georgia Warm Springs Foundation, headed the Roosevelt Memorial Commission, and continued to lead both the NFIP and the American Red Cross (until 1949). O'Connor led the Roosevelt Memorial Postage Stamp Ceremonies at Warm Springs in August 1945 with a speech, "Nothing Could Conquer Him," a title which summarized O'Connor's admiration of FDR as president, commander-in-chief and fighter against polio. O'Connor promoted FDR's legacy at every opportunity. FDR's influence on the history of disability, ~polio and the independent living movement has been repeatedly demonstrated.

Through O'Connor, the March of Dimes willingly accepted FDR's legacy and actively promoted its mission in the aura of FDR's colossal reputation as the first and only disabled president. The foundation steadfastly and symbolically
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ROOSEVELT

(continued from page 5)

honored the memory of FDR in traditions such as the annual visit to FDR's gravesite in Hyde Park by each new national March of Dimes poster child. This practice endured at least until Eleanor Roosevelt's death.

Historian Saul Benison has commented on the historical significance of the NFIP which illustrates the role of ordinary Americans in the fight against polio. Benison said: "in 1937 . . . President Roosevelt became convinced that polio could only be conquered through a broad and sustained program of scientific education and research. The organization of the NFIP was in essence the first step toward the realization of that goal. It was also something more. At a time when deadly assaults had already been launched against the human spirit and life itself in Europe, the new Foundation . . . stood as an affirmation of the value of conserving human life and dignity. Ordinary people everywhere recognized this quality and quietly and emphatically made its cause their own." However, behind this realization lay the spirit of Warm Springs and the March of Dimes, and the two men - friends and partners - who were most responsible for formulating their vision and realizing their success.

David Rose has been Archivist of the March of Dimes since 2001. He is a Certified Archivist, and he oversees the preservation and organization of the documents, photographs and films of the March of Dimes Archives in its national office in White Plains, New York. He is author of the first photographic history of the March of Dimes in the

Arcadia Images of America series published in 2003. He is also an advisor to the Jonas Salk Legacy Foundation. David holds a Masters degree in Anthropology from the New School for Social Research (New York, NY) and a Bachelor's degree in Anthropology and Philosophy from Case Western Reserve University (Cleveland, Ohio).

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FYI



I am a Polio Survivor with Post-Polio Sequelae (PPS) unexpected midlife symptoms:

- Overwhelming Fatigue
- Muscle Weakness
- Muscle and Joint Pain
- Sleep Disorders and Cold Intolerance
- Difficulty Swallowing and Breathing
- Heightened Sensitivity to Anesthesia

(over)

These wallet size cards issued by the State Of New Jersey Health Department are available from the ocean County Post Polio Support Group. Contact Susan Gato for your card.

ANESTHESIA WARNING!

I am a Polio Survivor...

- **EASILY SEDATED**, difficult to wake;
- **Difficulty BREATHING** and **SWALLOWING** with anesthesia;
- **HYPERSENSITIVE** to **PAIN** and **COLD**. Need heated blanket and increased pain medication post-op.

For more information, visit:

www.nj.gov/health/cd/postpolio/index.shtml

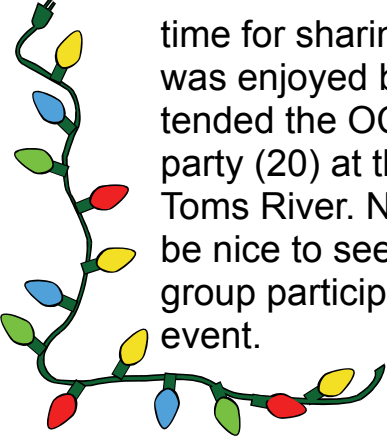
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HOLIDAY CELEBRATION

Ruth Fiedler

Our joyous Holiday Celebration took place Saturday afternoon, December 17. A delicious meal and a



time for sharing our histories was enjoyed by all who attended the OCPPSG Holiday party (20) at the Quality Inn in Toms River. Next year it would be nice to see more of our group participating in this event.

Study: Bullying More Common Among Students with Disabilities

by Michelle Diamant

From Disability Scoop July 29, 2011

(Ed Note; Thanks to Kathy Roberson, People & Families Editorial Board member)

Kids with disabilities and other special health care needs are at increased risk for bullying and generally show less motivation to succeed in school, new research indicates.

The findings come from a study published this week in the journal *Pediatrics* that looked at more than 1,450 students in fourth through sixth grade attending three rural school districts in Maryland and West Virginia,

Through surveys of the students and

their parents, researchers found that about 1 in 3 kids in mainstream classrooms at the schools had some type of special health care need ranging from asthma and attention deficit hyperactivity disorder to emotional and behavioral disorders.

When the survey responses were matched up with school records, it became clear that children with disabilities missed more days of school and had lower grades, according to the research team from the University of Pennsylvania, Johns Hopkins and Marshall University.

These kids also reported higher levels of bullying and were less likely to feel safe in school, the study found.

Moreover, when it came to academics, students with special health care needs were less likely to report that getting good grades mattered to them.

"These problems threaten both their wellbeing as youth and their future flourishing as adults," the study authors write. "Health and school professionals will need to work together to identify these children much earlier, ensure that they receive appropriate supports and services and monitor the effectiveness of services."

Of the students surveyed, boys were twice as likely as girls to have special health care needs. Children from lower income households were also at increased risk for falling into this category, which could explain the high rate of the conditions among students in the study sample.

(from: *PEOPLE & FAMILIES – FALL 2011 – submitted by Jerry Bojko – thanks*)

VIRUS MAY AFFECT MEMORY LOSS YEARS LATER

Infections linked to colds, diarrhea or polio can damage the brain

Washington - Forget where you left your glasses? Did those keys go missing again? Now you do not have to blame your spouse - a virus may be to blame. A family of viruses that cause a range of ills from the common cold to polio may be able to infect the brain and cause steady damage, a team at the Mayo Clinic in Minnesota reported.

"Our study suggests that virus-induced memory loss could accumulate over the lifetime of an individual and eventually lead to clinical cognitive memory deficits," said Charles Howe, who reported the findings in the journal, *Neurobiology of Disease*. The viruses are called picornaviruses and infect more than 1 billion people worldwide each year. They include the virus that causes polio, as well as colds and diarrhea. People contract two or three such infections a year on average. "We think picornavirus family members cross into the brain and cause a variety of brain injuries. For example, the polio virus can cause paralysis," Howe said.

"It can injure the spinal cord and different parts of the brain responsible for motor function. In the murine (mouse) virus we studied, it did the same thing and also injured parts of the brain responsible for memory." The Mayo Clinic infected mice with a virus called Theiler's murine encephalomyelitis virus, which is similar to human poliovirus. Infected mice later had difficulty learning to navigate a maze. Some were barely affected, while

others were completely unable to manage, and when the mice were killed and their brains examined, a correlating amount of damage was seen in the hippocampus region, related to learning and memory.

One virus particularly likely to cause brain damage is enterovirus 71, which is common in Asia, the researchers said. It can cross over into the brain and cause encephalitis, a brain inflammation that can lead to coma and death. "Our findings suggest that picornavirus infections throughout the lifetime of an individual may chip away at the cognitive reserve, increasing the likelihood of detectable cognitive impairment as the individual

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The Second Wave

Newsletter Of The Ocean County Post Polio Support Group

Please copy and share the information contained in this newsletter

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Articles and ideas welcome.

Information in the Second Wave newsletter is for educational purposes only and is not intended to diagnose or prescribe. We encourage you to educate your health care providers by sharing information with them on Post Polio Syndrome. Prior to beginning any new medications, nutritional plans, exercise or any other health related issue, consult your health care provider. The OCPPSG does not assume any responsibility for individual member's actions.

Ocean County Post Polio Support Group logo
created by Webmaster

Jerry Russell.

www.tomsrivernjpolio.org

Ocean County Post Polio Support Group

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or find us on FACEBOOK



A 501(C)3 ORGANIZATION

THE SECOND WAVE

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TOMS RIVER, NJ 08754-4515

FREE
MATERIAL FOR THE BLIND
OR HANDICAPPED

VIRUS *(continued from page 9)*

ages," the researchers wrote in their report.

"We hypothesize that mild memory and cognitive impairments of unknown etiology may, in fact, be due to accumulative loss of hippocampus function caused by repeated infection with common and widespread neurovirulent picornaviruses." Other viruses are known to kill brain cells, including the herpes virus and human immunodeficiency virus or HIV.

(Reprinted from Polio Epic, Inc, AZ, Aug/Spt 2010. Via SECOND TIME AROUND, January 2012 – PUBLICATION OF BOCA AREA PORT POLIO GROUP, BOCA RATON, FL – submitted by Jerry Bojko – thanks)

"GO GREEN"

If you would like to receive this newsletter via e-mail please contact Ruth Fiedler [rabfiedler@comcast.net] and help us save paper and money.

