

Founded in 1989

The Post-Polio Support Group of Orange County

NEWSletter

18552 Cork Street
Fountain Valley CA 92708

SEPT. 2014

FUTURE MEETINGS

In the coming months, we have scheduled three areas we hope will be of interest to our fellow PPS-ers. The first on September 13, on BRACING, is thanks to Aliene Spence, whose article on her own bracing experience at Kaiser is inside this issue. She has worked closely with the Hanger Orthotics people on meeting her own bracing needs and felt there was sufficient interest within the group to bring one of their reps to a meeting to explain their offerings and their protocols.

In November we will once again have a representative here from the HICAP department to explain in detail what next year's insurance offerings will be through Medicare, Medicaid, The Affordable Care Act and the latest pricing options as of that date. As you plan your healthcare for next year, you will have the latest updates on plans available. It will be in the midst of the Open Enrollment period so if you have specific queries on the plans you are considering, be sure to bring those questions

Inside this Issue

Future Mtgs	Pg 1
Mobility Ctr.	Pgs 1-2
Bracing	Pgs 2-3
Debbie's Story	Pgs 3-5
World Polio Program	Pgs 4-6
Wilderness on Wheels	Pg 6
Meetings	Pg 7

so that you can get them answered. It is suggested that you bring your Medicare or other information booklets to the meeting so that you can jot down the answers.

In January, we have generally begun each year with a finger food POTLUCK. We will be continuing with that tradition but instead of the purely social interaction of the past, we have asked the folks at The MOBILITY CENTER who have presented in the past to give us information on the safety and awareness items which can be attached to our low-riding power chairs and wheelchairs to make us more easily seen and heard.

Mark your calendars for these three important meetings, each on the SECOND SATURDAY of the month, 2-4 PM in the Villa Park City Hall Council Chambers near the corner of Santiago and Wanda in the Ralphs Shopping Center lot at the rear.

###

MOBILITY CENTER HELPS

In the past four months, I have had several near misses while traversing behind cars in parking lots. It is not helpful that I have lost the sight in my right eye which makes catching the reverse lights on parked cars as soon as the driver puts his car in reverse to exit his spot. In addition, my situation is not aided by lots near freeways which generate so much noise, hearing the cars

Continued on Page 2

is very difficult. And with the number of hybrids and all electric vehicles to be found today, this problem is a growing one. As a result of my own difficulties, I thought others of you would be interested in the offerings to be found at the Mobility Center which, as you may recall I mentioned in a prior issue, has moved their facility to a much larger showroom and workshops in the Business Center at the end of Granite Way located adjacent to the intersection of Mouton Parkway and Lake Forest in Laguna Hills.

They have, in addition to Omar, Ali and their sister, Summer, expanded their staff to include another couple of employees who are there to help you find the products you need or to deliver services there at their facilities or through their Mobile Repair truck fleet. They will go to your home for in-house repairs, or pick up and deliver equipment to their shop if necessary. These folks are a wonderful family of concerned and service oriented experts and they have expanded the offerings in their showrooms in addition to acquiring certification from a number of equipment providers so you know you have the best possible information on sources for your mobility needs.

Come listen to what Omar has to say at our Finger Food Potluck meeting in January or, if you need the information sooner than that, stop by and talk to them personally in their Facility.

BRACES—NECESSARY EVIL,

submitted by Alliene Spence

As a polio survivor since the age of five, I have worn more than 15 long leg braces. My last experience has been the most

difficult both in terms of adjusting to the brace and navigating my way through the Kaiser Health system to obtain it.

I joined the Kaiser Health System in the 90's and was unaware of their orthotics processes and procedures necessary to get braces. Initially, I purchased a brace with my own funds. That first brace was not satisfactory and I applied for a new brace using Kaiser's medical benefits which proved to be a very frustrating experience but I did manage to get new braces a couple of times. With Kaiser, a brace is expected to last for a minimum of five years before replacement. However, I found I needed a replacement before that time period was complete. I made my request initially to my Primary Care Physician who was not familiar with the required steps to obtain replacements. I have since learned that the doctor I needed to work with was in the Physical Medicine and Rehabilitation Group. Getting to those doctors is step one. The next step is attending a clinic consisting of medical professionals who can and will evaluate client needs and make recommendations.

During that process, I requested several names of available orthotists in order to determine who would most effectively meet my needs and with whom I could establish the type of relationship I feel is essential. First and foremost, I wanted someone who would listen to my concerns and who also has the medical expertise for making a long leg brace for a Post Polio patient.

I also learned that there is a long period of adjustment for a new brace, particularly due to aging and other physical discriminators inherent to PPS-ers. All in all, I have learned that it is important to be persistent

in seeking information and finding the “right” orthotist for YOU. One who will work closely with you to make sure the brace is a proper fit. Adjusting to a new brace, which can take months, can be a very frustrating experience. But one must also keep in mind the ultimate goal of mobility which makes the entire effort worthwhile.

###

This Is My Story

By Debbie Hardy

Sixty years ago, I made my entrance into this world. I was so anxious to get here that I arrived three months early and weighed less than two pounds. In the days before NICUs, just surviving was a feat in itself. When the doctors told my parents to go home and forget about this child because she will never survive, they had no idea of the force they were reckoning with. I persevered and soon gained enough weight to come home to my parents and four siblings.

Polio has always been a part of my life. Having contracted the disease when I was 15 months old, I have never known my body to be any different. There is no story to tell about suffering through the actual disease because, thankfully, I was too young to remember any of it. Growing up, I faced the same problems that all of you have faced (surgeries, braces, physical therapy and accessibility problems prior to the ADA) and I struggled through them the same way all of you have – putting one foot in front of the other and just doing the best I could. But, growing up I had wonderful experiences too. In grade school, I might not have been able to ride a bike or jump rope, but I had best friends, sleepovers,

choir and Girl Scouts. High School experiences included glee club, dances, proms, and honor societies, dating and having fun with friends. There were a lot of things that I missed because of my physical limitations, but as I look back, the majority of my memories are filled with good times and great friends.

I married a wonderful man, raised an amazing daughter and had a successful career. I also found time to do the things that I felt were important to my child. Because there were many things that I couldn't do with my daughter physically, I resolved to be there in other ways. I was the room mother, the Girl Scout Leader and the first to volunteer if help was needed at school. Like all of you, I had to work harder to do any job, but I was determined that I could and would do it all. At the time, I had never heard of PPS and didn't know that my physical ability and energy would run out as quickly as it happened. But I must confess, even if I had known, I would not have changed a thing.

Time marches on and just having celebrated a “big” birthday a few months ago, I find that my legs (even the good one that I've always been able to count on) sometimes don't want to cooperate. I fall more, don't get up as easily and find sitting in a chair without arms is almost impossible to rise from because of my diminished leg strength. I know the time has come that I might occasionally need to use a wheelchair or a scooter, but I worry that using them will make my legs even weaker. I've had numerous surgeries on my leg and foot, but as I age, I find that my back (because of the way I walk) is giving me the most problems. I've had two back surgeries and a third has

Continued on page 4

been advised. But, because my bones heal so slowly, I'm hoping that will not happen. For now, I just try to slow down and take things a little easier and, if I'm having a good day, I still tend to pull out the vacuum and clean the house or tackle that closet that I've been meaning to get to for months. It's hard to change old habits.

When I was growing up, the fact that I had polio was never mentioned or discussed in our home. It was the unspoken elephant in the room. Even as I grew older and my parents aged, I was hesitant to ask them questions about the illness. I know that I was paralyzed from the neck down on both sides of my body and that I had treatment at Children's Hospital in Los Angeles. Growing up I wore leg and back braces and had many surgeries. I also know, in my heart, the fact that I had a disease that left me with a visible handicap was something they felt so badly about they couldn't discuss it. They have since passed, so the answers to my questions are buried with them. I regret the fact that I didn't have the courage to bring up the subject when my questions might have been answered. This regret is not only for myself, but also for them. My older siblings tell me that my mother was worried about having me vaccinated because people were getting polio from the vaccinations and having been more prematurely, she was too afraid to take that chance. I would have liked to tell them that I was ok with their decision and they should be too. They were good parents, did the best they could and the fact that I had polio was no one's fault – just the luck of the draw.

Regardless of the differences in our lives and the uniqueness of our physical abilities,

we all share a chapter in the polio story. We all deal with it in different ways and come to terms with it in our own time. Nevertheless, it runs through each of us and binds us to the other. We are its offspring. We all carry its battle scars in one way or another and we should all be proud of those scars. They have helped make us what we are today – courageous, brave and stronger than anyone would ever imagine.

I would like to thank those of you who have volunteered to be the subject of this column. Your stories have taught me so much and have given me insight and courage. If you would like to volunteer to be the next subject of this column, please contact me at dhardy828@earthlink.net or (562) 693-6265. ###

Worldwide Polio – What is Happening?

The global effort to eradicate poliomyelitis has been spectacularly successful, eliminating 99% of cases in its 25 year history. But that progress has begun to unravel in the past 18 months, with outbreaks in east and west Africa and in the Middle East. The lesson is clear; as long as the virus is allowed to persist in the three countries in which it remains endemic --- Pakistan, Afghanistan and Nigeria --- exports of the disease will continue to affect other countries as well. A determined effort is needed to eradicate the virus from these endemic countries, and FAST!

The worsening situation meant that in May, the World Health Organization (WHO) declared polio a public health emergency of international concern. This allowed it to impose a requirement that all travelers

entering or leaving Pakistan, Cameroon, Syria and Equatorial Guinea --- the countries currently exporting polio --- MUST have up-to-date polio vaccinations. And it strongly recommended the same for other nations with ongoing polio outbreaks. The WHO also requires the governments of affected countries to declare that polio constitutes a national public health emergency. It is too soon to tell how all countries will enforce the travel restrictions or how effective they will be, but the WHO's declaration has another and arguably more important potential impact. It has greatly heightened public and political awareness of the global polio threat. The move could yet shame those nations with weak control efforts into doing better. Ultimately, political will, through every level of government right down to the local level, is crucial if eradication efforts are to succeed. The setbacks have reignited skepticism among some critics of the multibillion-dollar global effort which has repeatedly missed its own deadlines for worldwide eradication. The first such deadline was set for 2000. But this must not obscure the fact that impressive gains have been made, so much so that at the end of 2012, global polio eradication truly seemed within reach. It is important to turn the current situation around quickly, consolidate those gains, and condemn polio to the history books.

There is cause for optimism. In Afghanistan, the virus has been wiped out from many areas where it was previously rampant, with cases now restricted mostly to the northeast, where polio is imported from across the border with Pakistan. Afghanistan is expected to become polio-free perhaps as soon as year's end.

Nigeria has also improved its eradication efforts resulting in a sharp drop in case numbers. Eradication there is in sight, although a current worsening of the country's political and security tensions risks undoing their progress.

Pakistan, despite a lack-luster control effort, has also shrunk the geographical range of the virus. "Ultimate responsibility for Pakistan's bungled polio efforts lies with its authorities". The global eradication effort -- despite some shortcomings --- has a good track record of successfully fighting sporadic flare-ups. There is every reason to believe that the current spate of outbreaks will be contained (although war torn Syria could remain problematic). The big challenge is to conquer the virus in the endemic countries that are fueling exports of the disease are above all in Pakistan. A report released in May by the independent Monitoring Board of the Global Polio Eradication Initiative puts it bluntly: "Pakistan's situation is dire. It's program is years behind the other endemic countries." Unless matters change, the report concludes, the country is "firmly on the track to be the last polio-endemic country in the world". That damning indictment needs to be heard and responded to at every level of Pakistan society. The country faces many obstacles, but so, too, the other countries that nonetheless have succeeded in eradicating polio. There is no excuse for Pakistan not to do so. Its government must pull out all the stops to act swiftly and decisively. As the report rightfully argues, ultimate responsibility for Pakistan's bungled polio efforts lies with its authorities. "If the country's leaders were to truly and wholly take on the mission of wiping polio from their borders, what now

seems to some an impossible dream would fast become reality.”

Another barrier to eradication is societal resistance to vaccination, rooted for example, in local distrust of immunization campaigns and unfounded concerns that it conflicts with religious beliefs. Polio has spread to Waziristan in northern Pakistan, a stronghold of the Taliban who have banned vaccinations. Vaccinators have also been murdered.

In the past few months, international Islamic scholars and bodies --- including the newly formed Islamic Advisory Group for Polio Eradication --- have to their credit, spoken out to condemn attacks on polio workers, and to emphasize that polio vaccination is compatible with Islam, denouncing those who claim otherwise. Resistance and suspicion of vaccines will always be present, but religious leaders can help by reiterating these messages to local populations.

Pakistan’s situation is exacerbated by the Taliban’s stubborn blocking of polio vaccinations, ostensibly in opposition to US drone strikes. But polio has no religion. It respects no political affiliation. For the benefit of all, every effort must be made to overcome residual resistance to vaccination and to root out the virus from its last strongholds. ###

WILDERNESS ON WHEELS –

An Accesible Taste of the Wild

This company offers camping, hiking, fishing and picnicking to those with disabilities and has done so for over 26 years. Twenty-nine acres of forest beckon you to the base of Kenosha Pass, 65 miles

west of Denver on Highway 285. You could spot deer, including fauns meandering through meadows of colorful wild flowers or roll along an 8-foot wide boardwalk by a meandering river, all the way to the top of a 9500 foot mountain. EVERYTHING is completely accessible to those using wheelchairs.

WOW is a non-profit organization relying strictly on donations. One or two annual major fundraisers allow WOW use of the facilities for free. They do, however, accept donations from anyone for daily or overnight use. Some people can while others cannot donate. WOW does not discriminate.

WOW supplies all the firewood, but you must bring your own charcoal to the 10 picnic sites, each of which has both cooker and fire pit. A pond, stocked three times per season provides anglers with a chance to fish in a beautiful environment that is accessible to all. Ten tent sites, two cabins (one rustic with an outhouse, and the other modern). In addition, there are five Huts and two accessible public restrooms provide comfort for family camping. There are USUALLY openings but reservations are suggested/encouraged.

Check out the website at www.windernessonwheels.org for further information. Board member, Barbara Cramer, is a Post Polio Survivor and can be reached at (720) 308-2239 or at bcandthewheel@q.com for a PPS friendly discussion of the facilities. Now is your chance to experience the great outdoors in a way seldom available to those of us in chairs. ###

DONATIONS STILL ACCEPTED

Future Rancho SG Meetings



Saturday, Sept.27
2 -4 PM
Historic Videos

Orange County Meeting

September 13, 2014
2 - 4 PM
BRACING- Hanger Orthotics

November 11, 2014
2 - 4 PM
HICAP

How to contact Rancho Support Group

The Rancho Los Amigos Post-Polio Newsletter is published as a joint venture with the Polio Survivors Association.

For additional information please call Richard at **562-862-4508**

Or email us:

Rancho PPSG@hotmail.com

How to contact OC Support Group:

Call us for information:

Marilyn Andrews **714-839-3121**

Newsletter editor:

Janet Renison 949-951-8613

renison@lagunawoodsvillagenet

Agenda ideas for PPSG of OC?

Please call Aleta at 949-559-7102 or email

Priscilla at *prisofof@aol.com*

Special thanks to the following donors: All donations received during our Fund Drive are gratefully appreciated. Thanks to all who contributed .All donations make our support group possible. Please write checks to **Polio Survivors Association**. Please **mail checks to** Priscilla Hiers, Treasurer PPSG of OC, 18552 Cork Street, Fountain Valley, CA, 92708.

Disclaimer: Information provided in our newsletters and at our meetings is provided by the PPSG of OC and the Rancho Los Amigos Support Group solely as information. It is not to be taken as an endorsement of any product, individual, medication, or treatment. If you have personal medical problems, please consult a physician knowledgeable in the late effects of Polio. Unless otherwise stated, the articles in this newsletter may be reprinted, provided that they are reproduced in their entirety and that the author, the original source, and the PPSG of OC and/or the Rancho Los Amigos Support Group are acknowledged in full. Copyrighted articles require prior approval before re-printing. No article may be edited.

POST POLIO SUPPORT GROUP
 OF ORANGE COUNTY
 18552 Cork Street
 Fountain Valley, CA 92708

**FREE POSTAGE FOR
 THE BLIND AND
 PHYSICALLY DISABLED**

RETURN SERVICE REQUESTED

