

Founded in 1989

## Post-Polio Support Group of Orange County Newsletter

Website: [ppsupportoc.org](http://ppsupportoc.org)

15231 Marne Circle Irvine CA 92604

**JULY 2012**

### QUESTIONS AND ANSWERS

#### Dr. Vandenakker's article in our MAY 2012 issue

Now I want to hear about how you feel polio has affected who you are as a person, not just residual problem areas because we all have different problems we grow up with whether it is because of genetics or our childhood environment. Everyone is unique in their challenges. How did you use that polio experience or how do you see that has helped you accomplish something in life or done something with your life that you may not normally have done? The important legacy of polio is how much polio survivors actually accomplished because of their personality.

~ Polio gave me a "damn the torpedoes, full speed ahead" attitude, whether it be "you can't do that". I'll prove you wrong, whatever it is.

~ I was told I would never walk again. [Dr. V – "That was not uncommon."]

~ How you look when you are doing something and it didn't quite fit the norm. The way you pour your coffee or the way you walk. At some point I just decided it is more important to get to that end, to do whatever I want to do in my life than to worry about how it looks in the process. The goal became more important than the comments you get from people. You almost have to be like Teflon to tolerate comments.

~I was from Hawaii, but growing up in United States was very bad for me. When going to school I ate by myself. Nobody played with me. I walked home alone. I didn't know anybody. Other kids didn't want to have anything to do with me. I was so lonely, and it hurt. Once I was chased when leaving school and because I couldn't run well they caught me and set me on fire. My clothes caught fire so fast. They thought I was going to give them the sickness. I am 50 years old and it still hurts. I go shopping and people stare or comment. People are so ignorant. It hurts.

~I would go get jobs and they would call you names. You never know what I've been through. But at least I have a job. At least I go forward. And every time I hear people call me that name I just gasp "whatever. I'm here today. ... I just turn my back on people who say such things."

~I think we all have to understand and really look at ourselves for what we are. We are all very special people. We have gone through experiences that nobody else has gone through. We have come out the other side much better. There is no polio survivor who's going to be standing on the street holding a sign up saying "I will work for food". It's amazing what we have accomplished in life considering what we've gone through. And it's made us stronger.

**Dr. V** – People like you have changed our society. You are very special people. You have gone through things no one else has gone through. It made you stronger. You were the trail blazers as a group and as individuals.

Part of my reason for wanting to talk about this is to emphasize that with all of you because you may not be aware of what polio has done to benefit society or medicine or the disabled population. You were the trail blazers. You have done so much and not just as a group but as individuals. And I think, for anybody, going through difficult experiences make us stronger, make us able to offer things to other people that nobody else

can.

People like you have helped to change our society. Now there are many people who would never do the things that happened when you were young. People are much more aware that disabilities don't change a person. A person is a person. Society has become much more accepting of people who are different in whatever way, which of course is important but doesn't change what has happened to you. Ignorance on any level is a very scary thing.

~One of the biggest things in my early years of post-polio before I even knew about post-polio was the ADA. Sitting at my table at home I could call the United States government and discuss with them a problem I had with someone who was not only ig'-nor-ant but was ig-nor'-ant. There's a big difference between those terms. I had a feeling of power that there were people who were for me, people who had set up an organization and The Americans With Disabilities Act so I could just pick up the phone and talk to the government and get results. That was very significant, very important.

~I agree with everyone here that polio has made me a stronger person. I don't really know what it would be without it. I was 23 months old when it happened. I remember early on that I had to think ahead and plan things through. When you are a child and you are forced to do this because you have limitations I think that helps to make for a wiser person. The second thing I noticed too is that I am goal oriented. I see something and I do what I need to reach that goal.

**Dr. V** - Most of you are goal-oriented people and you need to still have goals. As you get older, even though you can do less, you need those goals, you need something you are working toward. To make life meaningful we all have goals we set for ourselves.

~In a store at checkout people were laughing at me and I asked why and then they stopped. I stared at them for 10 minutes. They wouldn't move because I am staring at them.

**Dr. V** – When people laugh or make fun or torture somebody else it is usually because they are afraid and not necessarily of you but of becoming like you. People do the same thing with people with cancer or who are dying. They are afraid of dying. They don't want to have anything to do with it. I think your action was perfect. Call them on it. "What are you staring at? What are you doing?" When you do that it makes them think about "Why am I doing this?". There is a good chance they will see you as a person. Hopefully it helps to change that behavior.

~I had that a lot, people laughing at me. I fell a lot. But I turned to developing my mind. I read everything I could get my hands on. I became a very good student. Polio became something that happened in the past. "It doesn't affect me now. I'm OK. I'm doing fine." The interesting thing is that my college roommate 50 years ago told me only last year that she also had polio. We both were straight A students, scholarship students. We never told each other that we had polio. It wasn't important at that stage of our life. She's very afflicted with PPS, much more than I.

~I've come to realize is that an advantage of have had some disability for most of my life, I've learned to accommodate that, to deal with it, to find new ways of getting around it so that when a new challenge comes up it's not that hard for me to figure out how to do it and adapt. Somebody who has been able-bodied all their life generally have a disability because they haven't developed those coping skills. So in a way it is an advantage.

**Dr. V** -- Yes, in many ways it is an advantage.

~When I was in Shriner's Hospital I had 8 operations between 5 yrs old and 15 yrs old. I was in there 5 different times. First go in there and stay maybe 3 or 4 months, then I would be in school and then I would come back and finish my rehab, go back to school and life was back to normal again. Then I'd have to be taken back to the hospital again and go through all that stuff again and I'd get back into life again and everything's fine. Then I'd

have to do it again. But you know what? That trains you for real life. Anybody who goes through real life, that's what happens. Things go on fine and then something happens. So you learn how to cope. You learn how to deal with things, how to compensate.

~The thing that changed my life was something my mother said to the neighbor. My mother had 7 children, three of them were sick, two with polio. About a year after I came home I heard my mother tell the neighbor "I pray to God that she would die because I can't handle all these kids and 2 that need so much extra attention and cannot do anything." That changed my life. I could be better than any of them. I was the best student, although at that time I was not allowed to go to high school. Later on I went.

~I had polio in 1952 and was hospitalized in SF. As to personality, I became so feisty. I would not allow anyone to look at me or say anything. There was a boy who taunted me all the time. I think it was fear in him. I couldn't walk too well without my brace. Once I got so mad at him that I took that brace off and I smacked him right across the head. I was feisty and learned to take care of myself.

~Regarding what someone else said about being so able-bodied and then you get something, like my poor husband here, he's been so able-bodied they just don't get it. I tell him, "Hey, work through it. Come on." Yes. I think we've all been blessed. And I feel more like a veteran. I came through a war. And we're just like everybody else.

~I had polio when I was 6 months old. I went to school and worked really hard. They made me go through PT and march with the class even though my doctor wrote a prescription "walks like a duck". When my daughter was a young, she would kiss my left leg and say "Oh I love the polio leg." That cured me of everything. But the first time I used my disability placard for the car, she could not take it. She stayed in the car. She couldn't take having a disabled mom.

~My personality definitely is a polio personality. On top of being a polio survivor in January of this year I was told I had cancer, so I went through chemo and radiation. In the middle of my treatment through fatigue I fell and broke my knee and had to have surgery. So I was pretty sick there for a while. In the midst of all this I would say "I don't know any other way than to be a fighter. That's what I am and that's what I have to do." Because of my polio survivor personality, I just tackle things. I think that's what we do. That's what I did. That's what I am doing right now. I am a double survivor.

**Dr. V** - Cancer survivors do band together as well because that's another one of those diseases where you've gone through a war. You have a lot of things in common because of that. Interesting that if there wasn't the PPS, the polio survivors probably never would have banded together. It is important to talk about not just what's going on now with the new symptoms but those historical things, those things that happened to you as a child. Most polio survivors would never have started to discuss that with someone else. They wouldn't even tell anybody else they had polio, right? So the fact that the PPS became evident and people started banding together I think psychologically had probably been a very good thing for the polio population.

~I think a lot of us have had to grow up because we needed to deal with making decisions about how will I do this and how will I prioritize. I was an elementary teacher for many years. When my fatigue was getting too much I shared a teaching contract with a friend, each of us getting half pay and benefits, for a number of years. Interestingly, a number of people in our school district later started doing job sharing. They didn't have polio. A lot were raising a family and wanted to keep in touch with their teaching. I just think we are doing a whole lot of what other people are doing, only in our particular way.

~I learned recently through a younger sibling the effect my illness had on my parents, their fears and disappointments. They were stoic and not very informed. I felt disappointed and emotional on learning of the profound effect. Had I known, I could have perhaps told them "You know what? It isn't that big a deal."

Sometimes when we look back we didn't really know it was affecting the whole family, siblings, perhaps grandparents too who all were suffering not needlessly completely.

**Dr. V.** -- Typically, siblings who don't have polio feel guilty. It's like, "How did I get away with not having that?" My mother who was from Holland and had 9 or 10 brothers and sisters had a couple of siblings with polio. She did the March of Dimes walk every year. That's what I remember growing up. That my mom was out there every year for the March of Dimes because she had those siblings and that stuck with her.

~ I ask myself what kind of a person I would have been if I didn't have polio. You are so focused. I was a child of the sixties and we all know what went on in the 60s, all the changes being made. I was so focused on my rehab and getting back into school and my lot in life, I wasn't involved in drugs and all that stuff. But I often wonder if I hadn't had polio I may have become a hippie.

~I was more fortunate than many. I was 28 when I got polio in 1952. I was married and had 3 children. I was also well along the way of establishing myself in a medical laboratory. That was probably a plus because I understood what was happening to me and I knew I was going to overcome it. It slowed me down but it didn't stop me.

~I got polio in 1953 and was in the hospital for 3 months. My brother and father were athletic. I was a jock until the middle of college when I realized my body hurt and I was trying to prove there was nothing wrong with me. When I realized what I was doing, I stopped.

~I wanted to mention how wonderful support groups are. The first time I came to this support group, I had the polio personality. I never talked to anyone about it. I don't remember anyone having polio that I knew. Because of the things that were happening to my body, I decided to check it out. I was very apprehensive about coming here. One of the ladies was in a scooter and she asked if I had a scooter. I was insulted because at that time I had no assistive devices. I was just walking around. I changed the subject and didn't say anything about it. After being a part of this group and being educated about PPS and sharing experiences with all the survivors, it changed me completely. Now it is a passion for me to want to help people. I don't mind talking about it to people anymore. I think support groups are the most important thing we can have because we have each other. We're like family. Later I did get 2 scooters, keeping one with me and one at work. Kids love them and want to drive them.

~Being different is cool and I take pride in that.

**Dr. V** -- Yes. You're special.

~ We do feel less vulnerable in a support group. We may now have come to a point where we are able to talk with our family somewhat about this. But our defenses don't all come down. We still keep some of it private. I still hold back. When I got married I never discussed with my husband that I had polio. He brought it up one day because we worked in the same building, and he said his friends wanted to know what was wrong with my leg. I replied "Tell them it is none of their business." I never discussed it with my husband; I wasn't going to discuss it with anyone else. And I never really did until I got with a support group and it got a little easier, but I still didn't talk much. He knows only a tiny bit about my polio experience. My sister recently felt like she needed to tell my son. I still don't spill my guts to my kids. I will not be vulnerable. I will not be needy. I will not whine. That's my motto. She wrote a three page letter to my son explaining what she knew of my early adolescence, my young years of polio. He was stunned. I still can't talk to him about it. I think my kids are in pain to bring it up. I don't know how to explain that except growing up with polio I was one of a large family and I was coddled and kept back and taken care of while everyone else got to go do. I fought that. I was the daredevil. My sisters were taught to ride a bike, but I wasn't. Yet I rode that bike which nearly killed me because I never learned how to brake. I don't know how to explain why I can't be more open about my polio except that I still think I got it.

**Dr. V** - Because there's still so much pain attached to it.

~ I'm the same way. I never talked about it to my siblings, my family. They are all younger than me. I am very short with people asking about polio. It is a very private thing.

**Dr. V** - The ability to talk about your polio depends on who you are and how you like to handle things. For some people it's good to dig down and see why you do not want to talk about it. Often it is the fear of being rejected because back then you were. So you are afraid that by talking about it now or telling people you had polio you are going to be rejected again which is not necessarily true. Obviously this is a safe environment because everybody else had polio. You've already established that. For many people having gone through an intense painful experience like that, sometimes you don't need to talk about it. Sometimes you don't want to drag through those emotions. Sometimes you have to if they are impacting other areas of your life. If it was preventing you from having a good relationship with somebody you would need to work through that. My father was a WWII veteran and he will not talk about it. I have done my best to watch films, read books to have some understanding of what he went through but he won't talk about it. Maybe for your family polio is something you can't discuss. Maybe having a book about polio memories, like one of the historical perspectives on polio, would give them a little understanding without you having to pour out all the personal details. It may be that at some point you need to ask for help.

~I had polio as a child and remember having to prove yourself as a child, prove yourself to your peers. You always had to do this. As I grew up still I had to prove myself to my peers, that I was good, that I was better in whatever I was doing. We all go through this. If we don't, we fall behind. We drive ourselves to excel.

~One very positive thing that has been a help to me is the experience of the man who dropped the plane in the Hudson River. And I say, "You know, I really made some quite extraordinary deposits in my experience bank." And this is true. Those of us who have gone through something like this have made some very significant helpful realistic and habilitating because we are able to understand other people in a way that other people are not. We made these deposits in our experience bank and that's to our credit, that's on the plus side.

**Dr. V.** You have made significant, helpful and realistic deposits in our experience bank.

~ I was 23 with 11 month old twin daughters when I got polio. My arms were affected. I used to carry my babies with my arms straight down and they would crawl up and get on. My only complaint had always been "Who put the salad bowl on top of the refrigerator?" Someone would need to come get the salad bowl down for me. Ten years ago I talked with my children about what it had been like to have polio. They all came and we had a glass of wine and I told them I had made a few notes. I'd cry to begin with, and they said "Well let's not do it then." I said "No, I want to talk about it. I never told you anything about how I felt and what it was like." They said, "Well, do we have to do it today?" I replied "That's why we are here." "Oh, OK." So I got past my emotions and started talking about it, telling them how it felt and how it was having them and how I had gotten along. I thought I had done a really good job and I got through it and they said "What did you want to do this for?" "Because I've never explained anything to you about me having had polio." They said, "Well, so what? You never talked about it so how did we know you ever had it?" "Well, I didn't use my arms very well." Then I remembered I had these braces that came up over my head and my arms hung by rubber bands and I was in the front yard gardening. My little 3 yrs old son was with me. The school kids walking by said "What happened to that lady? What's that thing she's got on?" One little boy said "She got bitten by a tiger." My little 2 yr old said "She did not. She had oleo [sic]." What? Butter? "Yes." {Laughter} Yes, when I had my children all together and told them how it had really been, they were bored silly. They didn't care because I had never complained. It was the way it was. They still feel that way. Now my legs are involved, and that's just not right. I had been to every city in the world. Got a card from my daughter that referenced my slowing down walk as being a drag. The point of this is, how

many people are now having new symptoms that didn't exist when they had polio?

**Dr. V.** - A lot of people now are experiencing new symptoms related to having had polio. Some people are never going to be interested in hearing your polio story until something impacts them. People are all different, and the smart ones want to learn from history and other peoples experiences, and some people are only concerned about themselves.

~There are some PBS videos I got for my daughters because I wanted them to see what I had gone through. Our kids are living the blessings of what we had gone through. So I think it is a wonderful thing to give. Christmas is coming up and PBS has them out there. They should never forget.

~Growing up my brother was asked "What's wrong with your sister?" My brother told everyone I was in a car accident. That's why she walks the way she does. He didn't want people to know I had polio. I stuck with that story when my dates asked me what happened. Even at work when asked, I responded "got in a car accident". I didn't want my boss to know what was wrong with me. "You're limping more." "Oh, it's the weather." For fifteen years my boss never knew. My husband once said "You are limping more. Is the car accident really getting to you?" I sat him down and I told him. He cried. It really got to him. PPS started coming on at work. I would type and get very tired. I would go home and try to make dinner but couldn't. I went to doctors, therapies, and they couldn't find a thing wrong with me. Then finally one doctor said that's what you have. It really gets to me because you have that energy and all of a sudden it is like somebody pulling the plug out. I can't let it get me down. When I come to the support group meeting, you guys really lift me up.

~I read Dr. Bruno's and Dr. Halstead's books about PPS and that helped me a lot to understand what's happening. They give a lot of good advice and even explanation of what exactly polio is.

**Dr. V** – Just because you had the illness doesn't mean you really understand it and what it did to your body if you are seeing it, for many of you, from a child's perspective, not even from a non-medical but a child's perspective.

~I've learned in the last few years that I was a very independent stubborn person and I really didn't ask for help. I've learned to do that because I realized that I was teaching my kids that I didn't need any help from them. I finally had to say "I really do need your help and these are the kinds of things that I need help with." And you know what, they came forth with that. But I had to first admit that I couldn't do it myself. Another thing I've done is write a biography. That's one way of telling others about your experience. You don't have to verbalize it. You can write it down. If you can't write, tell it into a tape recorder. It's helpful to other people that you share that experience.

**Dr. V** -- Don't be discouraged if your kids don't want to hear it. It's still valuable information and there are people who want to hear it and want to know about it.

~I went to Kaiser the other day and got my one arm plopped up on the counter and clerk said "oh, what's wrong with that? Is that why you are here today?" I said "No". He asked what was wrong with the arm. I said "I had polio". He said "What? I never heard of it. What's polio?". He was about 23. I referenced FDR, the President. He was clueless. On the way home I thought "Halleluja. I'm glad he hasn't heard of it because it is passing by and when we're gone that's it."

**Dr. V** – Except for those younger people that have it, when they are your age, everyone is going to go "Huh?" You can't even say "I had polio".

~Same thing. I had a doctor who gave me exercises for the top part of my right lower leg and it really messed me up. She never heard of polio. I told her I had polio and she said "Alright, but this is not going to change that."

~I just had a sleep apnea test and one of the tests I had to have was to get on a treadmill. I told them I can't do that and they said I had to get on it, I'll make it slow. My daughter was with me and she offered to help me,

she put her hand around my back and held onto my one arm. That was Tuesday. I just barely got ready today (Saturday). I haven't been able to walk and I'm mad at myself for letting myself get talked into it and I'm very upset.

**Dr. V** -- You have to have the guts to say "No. that's not appropriate for me." In medicine today, unlike when you were kids and forced to do things, you can't be forced. You always have the right to say "No". Remember that. If it's important enough, make it work or find another doctor.

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<b>How to contact Rancho Support Group</b>	<b>How to Contact OC Support Group</b>
<p>The <b>Rancho Los Amigos Post-Polio</b> Newsletter is published as a joint venture with the Polio Survivor Association.</p> <p>For additional information please call Richard at 562-862-4508.</p> <p>Or email us: <a href="mailto:RanchoPPSG@hotmail.com">RanchoPPSG@hotmail.com</a></p>	<p>Call us for information:</p> <p>Marte Fuller                    562-697-0507</p> <p>Marilyn Andrewws            714-839-3121</p> <p>Newsletter co-editors:</p> <p>Baldwin Keenan    949-857-8828 <a href="mailto:keenanwhelan@cox.net">keenanwhelan@cox.net</a></p> <p>Janet Renison            949-951-8613 <a href="mailto:renison@cox.net">renison@cox.net</a></p> <p>Agenda ideas? Call Aleta at 949-559-7102 or email Priscilla at <a href="mailto:prisofoc@aol.com">prisofoc@aol.com</a></p>

*Special thanks to all those who have made our 2012 Fund drive very successful! Between fund drives we always need funds. Please write your checks to POLIO SURVIVORS ASSOCIATION, 12720 La Reina Ave, Downey CA 90242.*

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# Rancho Los Amigo Meeting

Saturday July 28

## Annual Picnic 2-4 PM

Picnic NOT AT MEETING LOCATION. It is in **ATM Courtyard (600 Bldg)** on the Imperial Hwy side of Rancho. See map in JUNE 2012 RANCHO PPSG Newsletter.

# Orange County Meeting

Saturday July 14

2-4 PM

## Indoor Picnic and Sharing

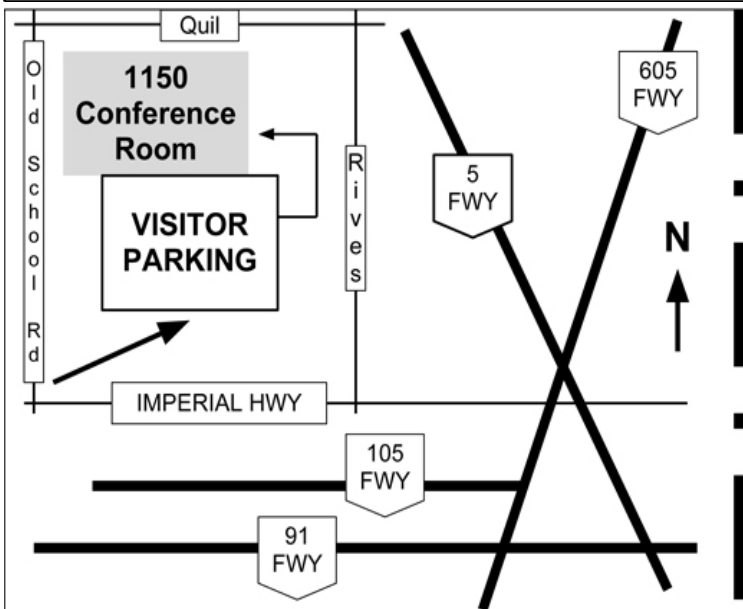
### Future Rancho Meetings

August 25 2 - 4 pm

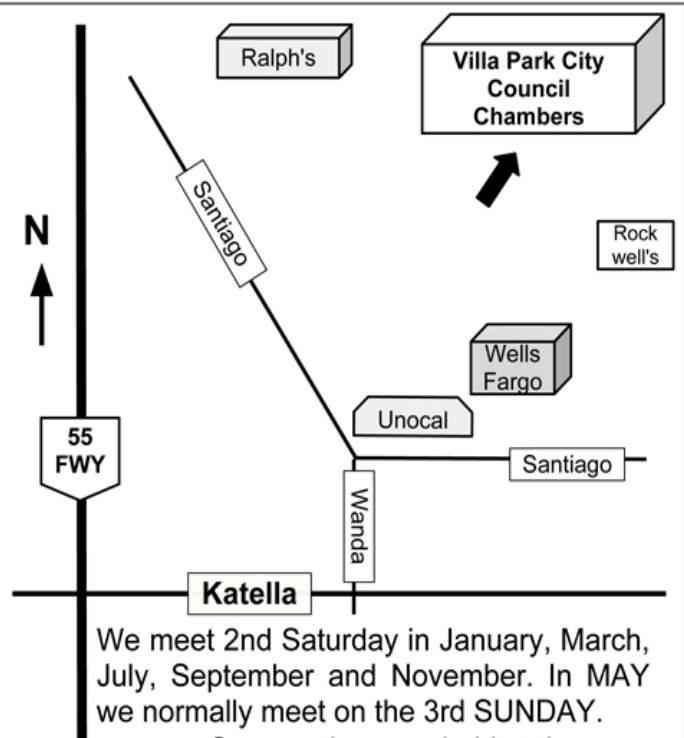
Gadgets, aids, and fun things!

### Future OC Meetings

- No OC meeting in August
- **September 8th HICAP on Medicare changes**
- No OC Meeting in October
- **Sat. Nov 10.** We have invited Dr. Phan from Kaiser, but no confirmation yet.



We meet 4th Saturdays 2-4 PM  
 Rancho Los Amigos  
 National Rehabilitation Center  
 7601 E Imperial Hwy Downey  
 1150 Conference Room  
 Support Service Annex



We meet 2nd Saturday in January, March, July, September and November. In MAY we normally meet on the 3rd SUNDAY.  
 Our meetings are held at the  
 Villa Park City Council Chambers  
 17855 Santiago Blvd. Villa Park  
 2 -4 pm