

# HemetAreaPolioSurvivors

NEWSLETTER

late Feb. Edition

1999

Managing PPS in Southern California

## FROM THE EDITOR

Hello, and welcome to the second year of the HAPS Newsletter.

Although I don't like to make New Year resolutions I do like to set a goal or two. However, with PPS I've learned to always be ready to change plans and modify goals.

For example, in recent years I abandoned the idea of riding a bicycle across America and replaced it with the goal of building a fast, light, long range electric tricycle that's legal to ride on Rails to Trails - to go where bicycles go - maybe across the country? Yeah! Wouldn't it be nice if a few of us could get together, build some super scooters, take a big ride and share the experience? Interested?

The real point of bringing up my personal dream is - not only do we need dreams, but often it takes a joint effort to get it done. As you may have noticed, it takes three of us to add up to one of what we used to be (har, har :-). So, let's stick together for another year of fun while learning to be the best we can be.

We have a lot to look forward to this year. There seems to be more interest in PPS at a national level and science may have a surprise or two for us, so let's keep hoping and...

Have fun....Rick

--∞∞ · ∞∞--

**"Let us go singing as far as we go; the road will be less tedious"**

Virgil (70-19 B.C.)

--∞∞ · ∞∞--

## NORTH COUNTY PPSG MEETING

2-6-98

According to Virginia Burwell the February meeting had a party atmosphere as a result of the birthday celebration for co-facilitator Betty Svare. Happy birthday Betty and happy birthday cake for everybody.

To add to the festive occasion members presented a plaque to Virginia for her fifteen years as facilitator of the San Marcos based group.

Thanks to Marilyn Salisbery's fine work at getting the word out, several new members attended their first meeting and shared their polio/PPS

stories. Discussions included two stories about mis-diagnosis of PPS.

Getting down to business, the group resolved to organize resource management (insurance issues, general PPS information, etc.), and create a document defining the groups goals and structure.

The group was saddened to learn that Mildred Space, wife of long time group member Fred Space passed on unexpectedly the previous week. Our hearts reach out to Fred in this time of sorrow.

-- 0000 • 0000 --

#### **HAPS MEETING REPORT**

2-9-98

At this small self help meeting we discussed family relationships, shoes (what design characteristics work best) and details of the exciting "Super Scooter" project.

As usual it was comforting and informative.

-- 0000 • 0000 --

#### **SD PSG HOLIDAY PARTY**

12-17-98

San Diego Polio Survivors Group's first annual Holiday Party was a great success! Refreshments were served as laughter and live music (provided by "Desert Rain") filled the air.

(CONT.

PAGE 2)

Judy Sander MC'd the White Elephant gift exchange and it was hilarious. I still laugh out loud when I think about it. Eve, who recorded the whole thing for KFMB (see PPS on TV), must have thought PPS causes insanity. (It doesn't, does it? Ha, ha.)

Thanks to all those who brought goodies, and especially to Judy. I can't believe all the work you do for your fellow polio survivors.

-- 0000 • 0000 --

#### **PPS on TV**

12/31/98

On December 31, in her "Health and Fitness" report, Channel 8 News at 4's Sandra Mass presented a three minute film on Post Polio Syndrome. She gave a brief history lesson including film clips from the nineteen fiftys showing children in polio wards, and newspaper headlines declaring, "Salk's Vaccine Works".

Following that were interviews with happy polio survivors (recorded at the December 17 SDPSG Holiday party), and a short interview with U.S.C. Neurologist Dr. Wiederholt.

Thanks you Sandra Mass and KFMB San Diego for helping spread the word that PPS is not a bad dream, but a reality. And, special

thanks to Mary Clare  
Schlesinger for her calls  
and emails encouraging  
Sandra Mass to do the story.

--0000 . 0000--

**SAN DIEGO PSG MEETING**

1-14-99

About forty people  
attended the January SD PSG  
meeting. As usual it was  
very informative and the  
time just flew by.

Myriam Easton told of  
her visit to the Warm  
Springs PPS  
clinic, Marilyn Padowitz  
addressed the group on  
health and nutrition, Rhoda  
Damsky shared her recent  
cruise travel, and Dr. Jim  
Donovan spoke about the  
current state of stem cell  
research and gave a few tips  
on finding a good PPS  
doctor.

**page 2**

Following the main  
meeting seventeen went  
upstairs for lunch and more  
personal discussion about  
the challenges of PPS.

--0000 . 0000--

**EAST SAN DIEGO MEETING**

1/16/99

The first meeting of  
the La Mesa PPS self help  
group took place at the home  
of Betty Svare with 7  
attending. Betty showed a  
video tape of the Ch.8 PPS  
report  
and personal PPS issues were  
discussed.

The next meeting will  
be at Coco's, 1025 Fletcher  
Pkwy. El Cajon on Feb.20, 2-  
4 PM. For more information  
call Betty Svare at  
(619)465-8170.

Thanks, Betty!

--0000 . 0000--

**NEW WEB PAGE**

Judy Sander has built a  
great PPS web page that  
outlines the goals and  
purposes of the SD PSG,  
provides links to many PPS  
related web sites and offers  
other neat stuff. See it at:  
<http://members.aol.com/jsan333/club/index.htm>  
Good job, Judy!

--0000 . 0000--

**NEWSLETTERS HELP YOU**

Newsletters are a very  
good source of management  
information. And, most of  
them are free to polio  
survivors.

Polio Network News (GINI)  
4207 Lindell Blvd. #110  
Saint Louis, MO 63101-2915

PPSG of Orange County  
Newsletter  
18552 Cork St.  
Fountain Valley, CA 92708

Rancho Los Amigos PPSG  
Newsletter  
12720 La Reina Ave.  
Downey, CA 90242

(Cont.

page 3)

The Boomerang c/o Janet  
McMahon  
20559 Palm Way  
Torrance, CA 90503

--0000 • 0000--

### **ASSISTIVE DEVICES, ETC.**

If you need help  
finding assistive devices  
the following may be  
helpful.

Disabled Dealer Magazine  
2006 Latham St.  
Simi Valley, CA 93065  
(800)588-5099  
Subscription rate \$18.00 per  
year.  
or visit [www.blvd.com/DDM](http://www.blvd.com/DDM)

Health & Home:  
UCSD Home Health 543-8255,  
San Diego 452-3210, El  
Cajon 461-1687, Claremont  
Mesa 273-5280

--0000 • 0000--

### **HYPOTHYROIDISM**

An endocrine gland, the  
Thyroid produces the hormone  
Thyroxine which regulates  
the body's rate of  
metabolism. The Pituitary  
gland in the lower part of  
the brain gages the body's  
Thyroxine needs and sends  
out TSH (Thyroid Stimulating  
Hormone) telling the Thyroid  
to get to work.

If your doctor suspects  
a Thyroid problem he may  
order a blood test to  
determine how much TSH is in

the blood - how hard the  
Pituitary is working. A high  
TSH level means a low  
Thyroid output -  
Hypothyroidism.

What's all this got to  
do with PPS? The following  
is a list of some of the  
symptoms of low Thyroid.

Fatigue, cold  
intolerance, infertility,  
heavy menstrual periods,  
muscle aches, depression,  
forgetfulness, dry skin,  
arthritis, weight gain,  
constipation, brittle nails,  
puffy face, enlarged  
thyroid, slow heartbeat, dry  
hair, loss of hair. How many  
of these sound familiar?

There are (as usual) a  
variety of opinions among  
PPS  
professionals. Dr. Bruno  
doesn't

### **page 3**

see the connection but  
stated that Dr. Perry  
believes low thyroid to be  
three times more  
common in PPS patients.

I was tested and found  
TSH to be about three times  
what it should be so my  
primary physician started me  
on Synthroid. Within an hour  
of taking the first pill I  
felt clear headed and  
energetic (in fact, it was a  
struggle to  
avoid overdoing), and it  
became easier to identify  
the PPS symptoms making  
management easier.

Now, a few months  
later, I'm doing more but  
feeling well. I've also lost

five pounds and my memory is working much better.

--∞∞ · ∞∞--

**DEAR BROTHER**

by Rick Van Der Linden

This Thanksgiving I had the rare opportunity to visit with my three closest brothers and I was amazed to discover that there are still uncomfortable feelings that I can't separate from the polio experience as illustrated by the following correspondence.

Brother to me:

... ain't no use in dwelling in the past and there is nothing to gain by placing blame. No use in analyzing it to death. It's done. You are not the only one dealing with an imperfect history. Just look at the results and problems that others are having to deal with. Deal with the present and do not look for blame. I am not particularly proud of the role I have played in your past but we must put it into the perspective of our youth and the time.

My Response:

Sorry that you got the idea that I was laying the blame. What I actually said was that I'm surprised that I don't hold things against my brothers. I agree that we only have control of

the present and therefore to some extent the future.

To properly manage PPS I have to reduce stress by changing my thinking

(Cont.

page 4)

and by gaining a better understanding of myself (Why do I try too hard? Why do I freak out around white coats? What motivates me? What brings me down? Why am I always willing to take the blame?). I have to understand what was hard wired into me back then. There is so much that I've put out of my conscious mind but it's still in my subconscious.

For example: While watching a documentary on PBS called "Paralyzing Fear - the Story of Polio in America" I was reminded of many of the things that struck fear into me. Put yourself in this situation: You're five years old, taken from your family and put alone in a dark room for two weeks, you know you could die, unable to move, might have to be stuck in a big, noisy can and parked in the hallway, nurses threaten if you cry, you're helpless. The scourge that threatens all the healthy children lives in you. Then, weak and facing years of slow recovery to maybe fifty percent of potential strength you're the runt of the litter and picked on by peers.

I'm not whining about it or blaming anyone (I'm sure that if the shoe was on the other foot I would have been as bad), I'm just saying that I have to face up to these things to be able to purge myself of them and take control of myself. You can ignore all that stuff but I can't - it's a management issue.

--0000 • 0000--

**TO THE EDITOR**

Dear Rick,

Thanks for adding me to the mailing list. I thoroughly enjoy the newsletter and the effort you put into its contents that makes it so readable. Keep up the good work... I look forward to subsequent newsletters...

Marcia

Editor's note: Ah, shucks.

--0000 • 0000--

**page 4**

**NEXT ISSUE**

The first of a series on PPS CLINICS. Where to find them, how they can help you.

--0000 • 0000--

**MARK YOUR CALENDAR**

2/6/99 - North County PPSG general meeting- 3 to 5 PM  
Marilyn Salisbury  
(760)738-1177

2/10/99 - HAPS (Hemet) self help group meeting - 10 AM to noon  
Rick Van Der Linden  
(909)929-8208

2/20/99 - East County (El Cajon) self help group - 2-4 PM.  
Betty Svare (619)465-8170.

3/11/99 - San Diego Polio Survivors Group - 10 AM to Noon  
Speakers: Joan Elber and Stan Stein on cruise travel.  
Judy Sander (619)220-2152

Escondido area and small group:  
Mary Clare Schlesinger  
(760)741-5075

--0000 • 0000--

**THANKS**

Thank you for reading the HAPS newsletter. You are a vital part of the ongoing sharing of ideas and finding new hope.

Thank you for the donations and the words of encouragement Marcia, Bob, Phil, Jean, Arnold and Betty, Mike, and Jean.

--0000 • 0000--

**"I've always done all I can  
do. PPS hasn't changed  
that."**

RE

VanDerLinden

-- 00 00 • 00 00 --

The HAPS newsletter is  
published every other month  
by REVanDerLinden and is  
presented as management  
ideas and is not intended as  
a substitute for medical  
care.

To submit ideas, writings or  
commentary, write to:  
HAPS 41348 Plumrose Street  
Hemet, CA 92544 or: E-  
mail HAPSnews@aol.com