

FROM THE EDITOR

Hi Fellow PPS Managers.

I read the letter from Easter Seals - "Regretfully..." After a week of pleading from myself and others, an e-mail from Debbie Ball at Easter Seals let us know that this was their final decision - Easter Seals could no longer afford to support the PPS community.

A series of thoughts hit me: Now what? Will the September issue be the final issue? How will we remain connected? We can't all go to meetings. We're not all on the internet. After four years the newsletter can't just disappear without a word! There has to be at least one more issue!

And, if this is to be the last issue, what would be the parting words? The final bit of advice that could carry you through? (Read "The Final Word?")

Well, there are a lot of bright, hard working polio survivors out there who are intent on making this thing continue. Offers of financial help, organizational ideas...

Between the larger print and the coverage of the above mentioned hot topic, (and, of course, the important selected e-mails) two articles I had started before the bad news - Escape Velocity and Is it PPS? - will have to wait until next time. That's positive thinking for you.

Have fun....Rick

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IN THIS ISSUE:

The Letter from Easter Seals.

How to Rescue Your Newsletter.

The Final Word.

A whole bunch of e-mail and more.

The Letter from Easter Seals

On August 30, 2002 I and the other Southern California PPS newsletters who were dependent upon Easter Seals to print and mail their newsletters received a version of the following letter:

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Dear Rick,

Regretfully, Easter Seals has had to make the difficult decision to withdraw support for your Post-Polio Syndrome group as of September 1, 2002. We will also

no longer be able to help with the mailing of the newsletter. Due to escalating business costs, a slow economy and fundraising challenges since September 11, it is not possible for Easter Seals to continue to support the service.

...

Easter Seals has enjoyed providing support to your Post-Polio group and working with you on getting your newsletter out to hundreds of people. We deeply regret the inconvenience this program closure will cause.

Sincerely, Debbie Ball, Regional Director. >>

From the Editor:

On behalf of all the Polio Survivors who have benefited from your help, I would like to thank the good people at Easter Seals. You have been very encouraging and helpful, and I wish you the best.

For our readers who have contributed to Easter Seals in the past, I hope this won't change anything. Their many great programs are of life changing help to many disabled people. Easter Seals deserves to prosper in spite of the temporarily negative economy.

Rick Van Der Linden

How to Rescue your newsletter.

The United States Postal Service to the Rescue!

Having seen "Free Matter for the Blind or Disabled" in the upper right hand corner of letters, I thought it worth a try to see if we can take advantage of the USPS service.

After a half day of phone calls - getting passed around like a hot potato - I finally got through to the right person and found that we can very easily use this free service. All I have to do is follow a few simple rules.

Those of you who have been reading this newsletter since the beginning might remember that four years ago I used larger print to make it easier for you to read your newsletter. A few years ago I reduced the print size for economic reasons - with all the information available since the late 1990's it became necessary to either increase the cost to Easter Seals by printing more pages, or get more out of the same number of pages.

According to USPS regulations one of the requirements is that the printed material be 14 point font. Better, eh?

At the current postal rate of 37 cents we are saving over \$1300.00 per year. And, since I can print "Free Matter for the Blind and Handicapped" in place of a stamp, we save the labor of attaching a stamp to each of 600 letters!

Thank you USPS!

Readers to the Rescue!

Another regulation imposed by the USPS is that we can't sell advertising. We are not allowed to profit from, or promote any business or individual who may profit from the newsletter.

This is not a problem. The PPS Manager Newsletter has been running in the red since the beginning. I prefer it that way.

Since attempts to find a benefactor have, so far, have been unsuccessful, it's an excellent opportunity for you to do some altruistic activity yourself.

It's up to you.

Up until now my expenses have only been for ink, paper and mailing of the originals to Easter Seals. From now on we have to pay for printing and labels and shipping bulk newsletters to individual groups.

I don't know what the total cost is going to be yet, but I do know I need your help. If enough of you can afford to contribute five or ten dollars each, that should take care of it for the next year. If this is a hardship for you, don't worry about it. Nobody will be dropped from the mailing list unless you contact me personally by phone, mail, or e-mail. You'll find my address, phone and e-mail address at the end of the newsletter.

Even if response to this plea for help results in a ton of money, it won't be spent on administration, a coffee fund, compensation for my time, or anything other than what you see when your newsletter arrives in the mail. (Heck, it's even posted free on the internet.) I plan to keep track of everything just to be sure. If funds get too low or there are excess funds I'll let you know.

This is a volunteer venture for me. Volunteering my time is good for me. That's my profit, and it can be yours, too.

In the meantime, write me.

Your humble servant,
Rick Van Der Linden

[If this were to be the last PPS Manager newsletter I write, what would be:]

The Final Word.

Polio survivors have learned that the two biggest triggers for PPS symptoms are physical stress and emotional stress. Manage both and you'll have a better life.

Careful management significantly reduces fatigue and pain.

Learn to conserve energy. If it hurts, don't do it. Don't let your pride or past fears prevent your using braces, wheels - whatever helps you get around with as little effort as possible.

Your muscles are weak. Besides loss of muscle mass and the possible breaking down of nerve/muscle connections, overuse can and often does result in a reduction of nutrients reaching the brain. The resulting "central fatigue" reduces memory function, concentration, and the ability to focus your energy (assuming you have some). It can cause depression and increase pain.

Don't feel like a wimp just because you need to relax your body and mind more often.

Diligently pursue comfort.

Understanding reduces emotional stress. Read a book or two.

Dr. Halstead, Dr. Julie Silver, and Richard Bruno have written about their research and clinical experience with PPS. Read. Skip a chapter if it makes you feel uncomfortable, but keep trying to learn.

If you have trouble holding a book, get someone to read for you or find a better way to hold the book. I read laying down, head slightly elevated, elbows resting on the bed, book balance above elbows. To be able to do this properly, I had to get reading glasses with just the right focal distance. Forget the fine print.

You are not alone.

Some of the most successful PPS managers are those who have a spiritual connection. Organized religion, PPS group spirit, reaching out

by charitable contributions and/or volunteer work, music... try it all if you can. And keep learning.

Your doctor can help...

...if you have the right doctor, that is. If you don't have the right doctor, try a new one. Your local PPS clinic is a good place to start.

Start your day with a song.

The poliovirus went where the action was. It stunned the body's movement, breathing, emotional response... but fortunately it left the mind and heart alone. Sometimes they are all you've got - use them. Enjoy life any way you can.

Reduce frustration.

Don't feel responsible for the problems of the world. News stories and TV drama are mostly tales of the unusual, not every day stuff. Don't forget that there's more good than bad in the world and choose to take part in the good stuff. If this means not watching the news, or not reading the newspaper, or turning off the TV, so be it.

Good music, prayer, positive affirmations, humor, self improvement, volunteerism, and love are just some of the antidotes to frustration. Find one or more that work for you and keep up the good work.

Rick Van Der Linden

From the (e-)mail bag

Hi Rick--Our little book, Snapshots: Polio Survivors Remember, is finally completed, and I think folks are going to be very pleased with it. I hope YOU will be! Many thanks to you and fifty-seven other polio survivors, caregivers, and medical professionals who provided us with such wonderful stories! The book looks good, too--108 pages of text, soft cover, coil bound. Nice.

A number of people asked me to notify them when the books were available, so I'll pass this information on, in case you or others are interested in ordering information:

IN THE USA:

All copies of Snapshots are \$10 each, plus postage as designated below:

1-4 books--\$2 postage and handling each book.

FOR A LIMITED TIME ONLY!

The following shipping and handling charges are good only until December 1, 2002:

5-19 books--add \$6 shipping and handling.

20+ books--FREE shipping and handling

To order, send the following information along with a check or money order made out to Nebraska Polio Survivors Association (NPSA) to:

NPSA

P.O. Box 45139

Omaha, NE 68145

Subj: RE: HMO / Medicare conflict

Date: 9/24/2002

From: helpline@dmhc.ca.gov

To: PPSRiverside@aol.com

Thank you for contacting the Department of Managed Health Care (DMHC), California HMO Help Center. This Department regulates health care service plans under California's Knox-Keene Act of 1975.

"What can this woman do to follow up on this situation? Should she file an appeal with her HMO?"

Yes, her first step would be to file the appeal with the HMO regarding the denial. We recommend a written letter to the HMO. She may also want to request a copy of her Evidence of Coverage (EOC) to understand what benefits she is entitled to receive. She may obtain this information from her health plan. For more information on her rights, contact HICAP(see next paragraph).

"Should she drop her HMO and go just with Medicare?"

Unfortunately we cannot advise whether someone should drop their HMO and go with straight Medicare. However, we do recommend she contact the Health Insurance Counseling and

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Advocacy Program (HICAP) 800-434-0222 or www.cahealthadvocates.org. HICAP provides information through community forums about the myths and realities of Medicare and private health insurance, counseling and advocacy to assist individuals with long-term care planning and insurance policies/billing/claims, and legal representation and advise when necessary and appropriate.

HICAP will help an individual file Medicare or other health insurance claims, understand his or her coverage and consumer rights, assist with managed care issues, and long-term care planning and evaluate his or her insurance or health care needs.

HICAP serves current and future Medicare beneficiaries or those planning for retirement and future health and long term care needs. HICAP counseling is confidential and free of charge.

“Does Medi-Cal have any part in this? What are her options?”

If she is on Medi-Cal she should contact them to see if this is a covered benefit. If she does not have Medi-Cal she should call Medi-Cal to see if she qualifies for the program. Medi-Cal www.dhs.ca.gov or general information 916-636-1980 or call her county social services agency office.

We hope this assists you with your questions. If it does not please let us know.

Sincerely,
Consumer Assistance Technician
HMO Help Center
1-888-466-2219

Hello; I came across your web site and I want to share a story with you.

I have a friend who has PPS. She has written a children's book on some of the symptoms of PPS. It is very well done and I would love for you to visit her web site nananeedsanap.com. Please forward this information on to people who will benefit from this book.

Thank You Dee

Dear Post-Polio Support Group Leader:

On November 2, 2002, Dr. John Bach, the proponent of noninvasive ventilation for people with neuromuscular disease, will be featured at a day long conference in San Diego. The target audience is comprised of polio survivors, and people with ALS, muscular dystrophy, and SMA.

In the morning, Dr. Ian Morales, a trainee of Dr. Peter Gay, will speak on "Breathing and Sleep in Post-Polio." There will hands-on w/ masks and ventilatory equipment. The link to the complete program is:

<http://www.doctorbach.com/sandiego/program.htm>

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Thank you.

Judith R. Fischer, Editor IVUN News

714-761-4503 714-761-3980 fax

JFisc48232@aol.com www.post-polio.org/ivun

Dear Rick,

Great letter--good content and presentation!! Your comments on fatigue are right on the button as are care in position changes and balance.

I have trouble with the comments on MDs and their charging attitudes in regards to really "easy money". I never thought of any Patients problems in a monetary sense at any time!! I can only say they must come out of med. schools with a different venue now. I will admit I have found only total frustration in the lack of PPS being in the med. school curriculum but that may be as much a fault of PPS on a national basis as it is for those who belittle MDs for lack of knowledge about PPS.

Books are great but most of those on PPS are read by those with [PPS] or close associates of those with PPS. I really hope that the forth coming radio/TV programs with the notables will help!!! I am working with children with severe mental&physical disability and I can only say it is equally frustrating.

Caring/God Bless, Dr. JIM Donovan MD

[Excerpt from my reply to Dr. D:
What I had hoped to convey is that doctors have a helpful and valuable service to offer and deserve to be paid for their years of training and caring.]

[After the word spread that Easter Seals dropped us I received a boat load of letters. The following which was sent directly to Easter Seals says it all. Ed.]

September 7, 2002

San Diego County-- Easter Seals
1035 E. Valley Parkway
Escondido, CA 92025

Attention: Debbie Ball & Laura Noell
RE: Easter Seals withdrawal of support for the Post-Polio Newsletter on September 28, 2002

I am a polio survivor! I can't tell you how it pains me to say those words. After contracting polio in 1951 I fell sick, was hospitalized, went home still partially paralyzed, worked to rehab my muscles...then I went on with my life *almost* like normal, ignoring the lingering affects as I went on to run, play, hike, backpack and enjoy life almost as fully as those not afflicted.

Two years ago all that changed, and my life, as I knew it, ended quite abruptly with a diagnosis of Post Polio Sequelae. The muscle fasciculations, fatigue and pain were finally explained after much work to isolate the cause, and the final tests, EMGs, found old polio in muscles in my legs and left arm. At the time I *heard* the diagnosis of Post Polio Syndrome, but it has taken me two full years to completely *understand* the ramifications of the diagnosis; it is a mixed bag of emotional ups and downs and physical limitations of gigantic proportions.

After receiving an email two days ago from one of the members of the La Jolla Post

Polio group, I found that funding for a newsletter that services my area has been withdrawn and eliminated from your budget. In this time of limited resources, the loss of your support has been one more misery for those of us suffering from the late affects of polio to deal with. I believe that at 54 I am just the tip of the "old polio iceberg;" there will be many, many more from the 1951 epidemic that will be surfacing in the next decade. My extreme exercise level over the years just took me to this place in life sooner than it has the others that will be following me, and more and more people will be affected by your decision than the present numbers that you are counting as perhaps too small to be of help by your funding.

My note to a friend after being notified of your withdrawal of financial support for Post Polio survivors was, "...when the skies are the darkest, another door closes. How sad!" The words were heartfelt as I see myself failing bit by bit physically, and I know that there are those out there that feel alone and are dependent upon the communication of the Post Polio Newsletter to stay connected. I hope that you will reconsider your decision, and continue to support those still in need of your assistance, now for the *second time* in their lives.

Sincerely, Gladys Swensrud

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Thank you for reading the PPS Manager Newsletter. And, thanks for your help and your words of encouragement. Special thanks to Marion, Rick K, Judy S, Judy M, Bob H, Lois

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

To offer financial help mail to address below (make check payable to RE VanDerLinden)

To submit ideas, writings, or commentary, write to: PPS Manager, 34711 Lyn Ave, Hemet, CA 92545 or E-mail PPSman@aol.com or call Rick at (951)926-5492