

POLIO NETWORK NEWS

STANFORD'S PROGRAM: AN OPPORTUNITY FOR SURVIVORS

THE OPPORTUNITY: International Polio Network (IPN) is collaborating with Conemaugh's Regional Neuroscience Center in offering a five-day "train the trainer" workshop August 12-16, 2002 in Johnstown, Pennsylvania, the home of Conemaugh's Health System. The course will train individuals to be leaders of the Chronic Disease Self-Management Program (CDSMP).

WHAT IS THE CDSMP? The program was developed at Stanford University over twenty years ago. The aim of the program is to assist people with chronic conditions to self-manage their health. The program teaches participants the practical skills for making decisions, communicating needs, and taking action to improve their physical, mental, and emotional health. For details about the program, visit www.stanford.edu/group/perc/programs.html.

IPN and Conemaugh are looking for applicants (preferably in pairs) to receive the training to be leaders of the CDSMP.

WHO SHOULD APPLY? Candidates may be a polio survivor, ventilator user, or a health professional; a part of a support group, a post-polio clinic, a pain clinic, an HMO, etc. The course is designed to be taught by two people, so we will offer the training to pairs of individuals who are committed to teaching the course together. Individuals (polio survivors, ventilator users, health professionals) are encour-

aged to apply if they live in area where another person is already qualified to teach the course. To determine if this is so, contact Stanford University's CDSMP at www.stanford.edu/group/perc/cdsites.html.

IS THIS TRAINING FREE? Selected participants will receive the five-day training, training materials, onsite lodging and meals, and material to provide the program free of charge in their own communities. Participants will be responsible for their own transportation costs to Johnstown, Pennsylvania, USA. Pittsburgh is the closest major city.

WHO WILL TRAIN THE SELECTED PARTICIPANTS? Carol Yoder, Barbara Duryea, and Joan Headley, all individuals who have been trained as "master trainers" and individuals who have a chronic condition will teach the August training.

HAVE POLIO SURVIVORS PARTICIPATED IN THIS TRAINING OR TAKEN THE COURSE? Yes, polio survivor Peter Jay of the British Polio Fellowship reported on the United Kingdom's experiences with the CDSMP in the Summer 2001 *Polio Network News* (Vol. 17, No. 3). Jay will present at the May 21, 2002 conference – "Post-Polio Syndrome: Improving Quality of Life with Teamwork" – in Johnstown.

Barbara Duryea, Project Coordinator of the Regional Neuroscience Center, will host the training and reports that Stanford's

research demonstrates that participants have experienced significant improvements in their health behaviors, health status, reductions in hospitalizations, visits to health providers, and days in the hospital.

WILL THIS REPLACE SUPPORT GROUPS? No, the class meets for 2½ hours for six weeks, i.e., it has a beginning and an end. This approach appeals to some survivors. They want to attend a structured class that will assist them in managing their late effects of polio.

COULD OUR SUPPORT GROUP OFFER THE CLASS? Yes. It can be offered as an alternative to the typical support group meeting, but remember it only last six weeks.

WHAT IS MY OBLIGATION ONCE I RECEIVE THE TRAINING? You will be asked to teach the CDSMP at least one time during the next year. You will need to find a place to hold the class and advertise, so polio survivors who want to take advantage of the class can attend and learn ways to self-manage their life as they age with polio. You will also receive the necessary materials to teach a class of twenty.

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HOW DO I APPLY? Contact IPN at 314-534-0475 or at gini_intl@msn.com.

I WOULD LIKE TO TAKE THE COURSE BUT NOT TEACH IT. HOW CAN I FIND OUT IF IT IS OFFERED IN MY AREA? Contact Stanford University's CDSMP at www.stanford.edu/group/perc/cdsites.html or call Carol Cox at IPN (314-534-0475).

If it is not offered in your area, we ask you to encourage your rehabilitation center, post-polio clinic, older citizen centers/organizations/facilities, independent living centers, etc. to send a pair to the training. They will be required to advertise the course for polio survivors, but they can offer the class to anyone with a chronic condition.

GINI will publish the dates of any course that is offered by these newly trained leaders in *Polio Network News* and on our website – www.post-polio.org.

If you have any questions about this opportunity, call Joan Headley at 314-534-0475 or Barbara Duryea at 814-534-5741. ■

International Polio Network

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International Polio Network (IPN)
4207 Lindell Boulevard, #110
Saint Louis, MO (Missouri) 63108 USA
314-534-0475 ■ 314-534-5070 fax
Relay MO: 800-735-2966 TDD, 2466 V
gini_intl@msn.com, www.post-polio.org

COORDINATED AND PUBLISHED BY:
Gazette International Networking
Institute (GINI)

EDITOR: Joan L. Headley, MS,
Executive Director

GRAPHICS/ASSISTANT TO THE EDITOR:
Sheryl R. Prater

SPECIAL THANKS TO: Judith R. Fischer, MSLS

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EDITOR'S COMMENTS

I am told that sometimes my comments hint at my frustration. This time I am not hinting. I am frustrated! For the last 15 years, my job has been to educate polio survivors and health professionals about the late effects of polio – to alert them about the potential problems and to assist in finding solutions. I never anticipated that I would spend so much time clarifying misinformation that results from simplifications or overgeneralizations.

A daughter of a polio survivor called last week and was distressed because her mother had refused surgery that she needed (a 2% chance of living without it) "*because polio survivors should not have anesthesia!*" While we encourage polio survivors to discuss anesthesia issues with their physicians, we never have stated that they cannot tolerate it. We receive calls and questions from polio survivors and health professionals (albeit in a skeptical tone) asking for the "list of medications that all polio survivors should avoid" and for the information that

"supports that all polio survivors should not exercise."

Needless to say, I was pleased when Julie Silver, MD, sent an article about three ideas that are "polio myths," or at best, "half-truths." I have included several "Letters to the Editor" that demonstrate the variety of issues facing polio survivors and their proactive methods of addressing them. We both hope that we can prevent some unnecessary hysteria and guilt.

We must continue to share information and ideas, but also question the soundness of post-polio information, particularly as it relates to each of us as individuals. I challenge you to do your "homework" and determine your own path to optimum health and independence, in conjunction with a caring physician who thinks critically.

Perhaps, you, too, are frustrated by awareness efforts that have gone awry or have resulted in counterproductive responses. I invite you to send your concerns to me.

– Joan L. Headley, MS
Executive Director, GINI