

NEBRASKA POLIO SURVIVORS ASSOCIATION

THE EARLY YEARS

It was the summer of 1984. Searching for answers to the mysterious pain and exhaustion she had experienced for years, Nancy Baldwin Carter telephoned Gazette International's Gini Laurie in St. Louis after seeing her name in a *Newsweek* article about post-polio. Gini suggested Nancy start a support group in Nebraska. And thus began Nebraska Polio Survivors Association.

FIRSTS

Nancy started calling Nebraskans she knew with polio. These people gave her more names, and she called them, too. Nancy's husband, Bill, always helping, became our number one volunteer. Marlene Orton took a large role from the start. Her daughter, Alison, at age 13, became our official photographer. Organizational meetings that summer led to the beginnings of structure for NPSA when we decided:



- This would be a statewide independent all-volunteer association.
- We would finance the organization through donations and fundraisers, never charging fees or dues.
- We would hold monthly support group meetings.
- NPSA would provide a packet of information for anyone asking for post-polio help.
- The home office would exist in the director's house in Omaha.
- The mailing list would never be sold or given out.

Over sixty polio survivors showed up at the first NPSA support group meeting in Omaha in the fall of 1984. Rejoice Lutheran church offered us whatever free space and equipment we needed for our meetings there.

Our initial publicity came through an article in the *Omaha World-Herald*. Nancy phoned their medical writer and told her about the late effects of polio and our organization. We begged her to do a story letting polio survivors know what was happening to them and to tell them about our support meetings. She was intrigued and said she'd do some research and get back to us. A few days later she called back to say she couldn't do the story. She had checked with several local neurologists, she said, and they told her this was all nonsense. "That's exactly the point," we argued. "This is the very reason for our Association." We asked if she might change her mind if we supplied reputable medical journal articles about the condition. She said she'd take a look. Before long she wrote the story, listing the name and address of our organization as reference.

The response was overwhelming. Letters and phone calls poured in from everywhere. People had clipped the *World-Herald* article and sent it to relatives and friends all over the country who were experiencing symptoms of polio's late effects. Everyone we heard from told the same story. Everyone wanted help. We answered each request.

Individuals contacted us from **Hastings** (Erma Ocker) and **Grand Island** (Nancy Murray, Kathleen Buechler, and Kathleen Hendrickson) wanting to start groups in their cities. Then came **Lincoln** (Diane McEntee, Nancy Erickson, and Lois Bergin) and **Norfolk** (Donna Mavis) and **Holdrege** (Delores Bray). Polio survivors responded robustly to these support group meetings.

We wanted NPSA to be easily accessible from any point in Nebraska. Nancy spoke all over the state, answering questions, encouraging participation in NPSA support groups. Marlene took a slide show to many towns throughout Nebraska, doing the same. Everywhere we went, the rooms were packed. The organization was expanding quickly.



People participated enthusiastically. They volunteered for jobs at meetings—setting up, providing goodies, making name tags, serving on committees. Early on, the Grand Island and Hastings groups held a joint speaker’s banquet attended by many polio survivors in central Nebraska and a good number of individuals from the medical community. The Omaha group had its First Annual Jubilee Festival and Down-Home Picnic.

By 1986 **St. Paul** (Richard Hanisch, M.D.) and **Chadron** (Cheryl Marchant) had their first NPSA meetings. NPSA kept *happening!*

MEETINGS

Our support group meetings were meant to fulfill many needs of polio survivors. All were directed at providing an understanding of post-polio and how each of us can benefit from an awareness of the changes we must make to find our way down the unfamiliar path we were finding ourselves on.

A detailed “How to Organize a Successful Meeting” list was provided to each group leader:

- Make each member feel welcome and comfortable. Assign greeters to meet everyone as they enter the meeting room and introduce newcomers to others individually, as friend to friend.
- Assign volunteers to set up a name tag table near the entrance and give one to each individual. Other volunteers come early to make coffee and set out goodies on a side table.
- Leaders begin the meeting with a short update of post-polio happenings—such as items from journal articles, newspapers, TV “breaking news” types of information.
- Make meetings friendly, fun, informal—and perpetually informational. Don’t waste people’s time.
- Leaders ask for members to volunteer for the next month’s meeting tasks.
- Let everyone help. There is *always* something a member can do to volunteer. Leaders assist others in finding ways appropriate to their abilities and physical condition.
- Offer variety in the theme of each meeting, with topics picked by a committee of members. All meetings must relate to some aspect of dealing with late effects of polio. They might be informational in an assortment of ways: lecture, demonstration, entertaining, or something else.
- Alternate between Speaker Meetings (wherein a speaker addresses the group, as with a lecture or a demonstration) AND Sharing Meetings (wherein members respond to a particular theme chosen as that day’s topic, such as “The lifestyle change that has helped me the most”—or wherein members might tell their stories or express themselves in other ways).
- NPSA offers support, not group therapy. We do not give “professional” advice.
- Leaders encourage appropriate interaction at meetings, fostering communication among members as well as with speakers. Promote respectful Q&A sessions after speakers complete their presentations.
- Be *consistent*—always hold meetings at the same time period (third Sunday of the month?), at the same hour (2 p.m.?), and at the same location (the public library at 4th & Z?).
- Certain Speaker Meetings in Omaha will be videotaped, with these tapes distributed to meetings in smaller towns in Nebraska where it may be impossible for them to engage such a speaker. Specific

other videotapes might be available for showing at NPSA meetings statewide. Group discussion would follow any such presentation.

- Volunteers arrange seating in circles to accommodate discussion at Sharing Meetings and use theater-style seating for Speaker Meetings if this is what the speaker wants.
- Members encourage family members and close friends to attend and participate in NPSA meetings to help them voice their own concerns and play an active role in unlocking the late-effects puzzles their loved ones go through.



Here are a few topics from early NPSA meetings:

- MDs: Orthopedist reviews and discusses articles in *Orthopedics* medical journals; pulmonologist discusses polio and breathing; psychiatrist talks about dealing with emotional aspects of late effects of polio; Chairman of Neuromuscular Clinic comes several times to discuss making plans to start a post-polio clinic
- Specialists: Director of pain management clinic; Stress Management expert; Physical Therapists; Occupational Therapists; Director of Vocational Rehabilitation; Director of Social Work tells us How to Talk With Your Doctor; Med Center Fitness Director discusses fitness for those with disabilities; Mobility expert demonstrates chairs and carts, equipping cars and vans; Security Expert discusses enhancing security for those with disabilities
- Panel discussion made up of representatives from March of Dimes, Easter Seal, Paralyzed Veterans of America, and the Governor's Commission to Hire the Handicapped—NPSA members invited to ask questions
- Social Security: Information Director—SSA benefits and how to get them; Disability Examiner—SSA disability claims from the Government's perspective
- Wellbeing: Massage Therapist gives a demonstration in meeting and conducts drawing for free massages later; Yoga instructor gives demonstration; Endorsed Trainer of Windmills project—How We Think and Act About Disability; Inspirational speaker—Making the Most of What We Have
- Report from eight members who attended GINI Conference
- Videotapes from Gazette International and other sources
- BC/BS—new health insurance for those with disabilities

INCORPORATING

NPSA needed to become a 501(c)(3) non-profit corporation in order to legitimize ourselves and give donors more incentive, so the long incorporation process began. Aside from NPSA's director, Nancy Baldwin Carter, and assistant director, Marlene Orton, board members were Charles Mackenzie, PhD; William Berton, MD; Marcia Bredar, JD; Jack McGrath, JD; Robert Allington, PhD; Shirley Marsh, state legislator; and Patsy Kravchuk, IBM—all NPSA members.

The Board gathered monthly in open meetings. All NPSA members were welcome to attend, though only Board members had voice and vote unless otherwise specified.



ADVOCATING

Getting help for the good of NPSA members was paramount. A few examples: When an insurance company refused to pay for a cart, arguing that a cart was not a wheelchair, we sought help from the state Department of Insurance, which taught us to look at the definition of each—and we learned how to convince such companies to ante up. AND We'd find sources for members with special needs, at times employing the help of Gazette International. AND Years before the ADA, members implored the powers that be in towns throughout Nebraska to remove physical barriers—with great success.

NEWSLETTER

Gleanings

had its debut in April 1985. NPSA needed a newsletter, and *Gleanings* was just the ticket. At first we typed our newsletters using a typewriter and ran off copies on the copy machine our friends at the Paralyzed Veterans of America allowed us to use free.

One day each month, volunteers came to the NPSA office in the home of the director to collate, staple, fold, stamp (until we got our non-profit stamp), label, and bundle the growing number of newsletters we sent out. Eventually Chip Mackenzie produced them on computer. Finally we were able to afford to have the newsletters printed.

When The Millard Foundation learned we were desperate for a copy machine of our own, they came through with grant money for us.

These are the standards we tried to stick by:

- Be consistent.
- *Gleanings* would be a monthly three-column newsletter in which every item must relate in some way to polio.
- Check facts, do research, use direct interviews.
- Write original articles rather than copy from other sources, usually keeping articles to 500 words. Give proper credit when credit is due.
- Always have at least two articles on page one. Always place the editorial on the last page. Put upcoming meeting information as well as all other regular features in the same spot each issue so that readers will get used to seeing it there and can quickly turn to it.
- Use material written by members; strive for variety; publish disability cartoons; highlight abstracts of journal articles written especially for us by our friend Ted Vergith, MD; include medical reminders, such as getting shots, for instance.
- Emphasize articles on equipment, products, gadgets helpful for those with disabilities; include pieces on travel and recreation; put the “spotlight” on group leaders, board members; profile special active members, people in the community helping NPSA; report on the business of NPSA; make good use of photos.



We wanted a newsletter filled with information—post-polio facts and tips, ways to live more fully, links to helpful books, journals, and catalogs; “who to call” or “where to find” guides; personal experience articles and a way to honor volunteers. We wanted to help educate survivors about their conditions in every way—physically, emotionally, spiritually—and to do it with a certain amount of lightheartedness when possible. Importantly, everything that happened at NPSA was shared with members through the newsletter.



Gleanings was mailed free to everyone who asked to be on our mailing list (well over 3,000 after some years, in every state and a few foreign countries). We paid the post office for “Return Service Requested” so we would not be dead-ending mail if we could help it, and volunteers updated the mailing list monthly. Many volunteered for newsletter duty, but nobody could ever approach the number of hours Lyle and Virginia Walker dedicated to preparing *Gleanings* for the mail.

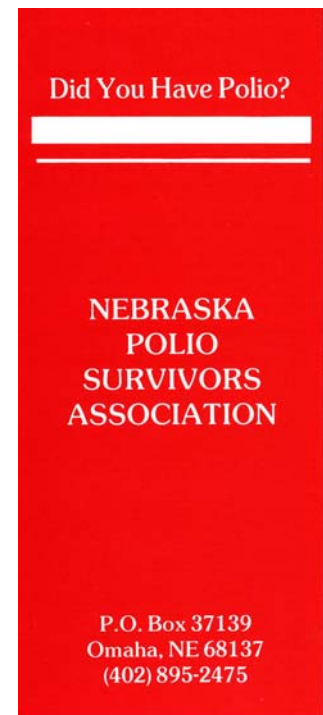
SPREADING THE WORD

We did what we could to keep NPSA before the public. We worked at being interviewed for TV spots and newspaper articles, statewide. Local TV did two thirty-minute programs about NPSA and the late effects of polio. We responded to any newspaper reference to polio by writing letters to the editor and longer “Another Point of View” op ed pieces. The public library provided a mailing list of all newspapers in the state, and we periodically mailed them press releases, knowing small-town papers are likely to print such articles, which they did. Our director wrote full columns as a “pinch hitter” for the Lincoln paper. Every effort we made contained information regarding how to reach NPSA.

NPSA’s earliest large outreach project involved having a three-fold heavy-paper pamphlet (with photos) made to acquaint the public with late effects of polio and with the availability of help from NPSA. Aside from the cover, one panel contained a polio update, one the symptoms of the condition, and one introduced NPSA and what we offered. The entire third fold was a perforated postcard, to be torn off and stuck in the mail by those wanting more information. The front of the postcard was addressed to NPSA, and the back was designed to hold details on how to reach the sender, as well as to identify this person’s relationship to polio (survivor, relative, doctor).

The cover was made so that the title of the pamphlet, “Did You Have Polio?,” would easily attract the attention of those who might have need of its information. Members all over the state placed these pamphlets in medical offices, hospitals, banks, libraries, grocery stores—anyplace that had bins meant to hold this kind of material, so that the top part of the pamphlet stuck up to catch the eye of polio survivors. We always asked for permission—and we were never turned down. The return was enormous and we contacted each person who asked us to.

We spoke wherever we were invited—doctor groups, nurse associations, therapist groups, church groups—if there was an interested audience, we went. We manned NPSA booths at health fairs. We wrote public service blurbs for civic-minded opportunities like utility company newsletters that went out with bills. We placed meeting notices in newspapers and church bulletins and on TV bulletin boards, as well as those in grocery stores. And everything emphasized NPSA’s name, address, and phone number.



GETTING INVOLVED

Being active players in the disability community helped NPSA in many ways. Networking. Give and take. Knowing. Becoming known. We became participants, active members of the President's Committee on Employing the Handicapped, the Governor's Committee, the Mayor's Commission, the League of Human Dignity Organizational Committee. We attended GINI conferences, taking part as speakers and moderating a newsletter workshop. We were part of a Tilting at Windmills Conference, and a Conference on Technologies for the Physically Challenged. We distributed questionnaires for a physical therapy association learning about late effects of polio, as well as for the University of Nebraska Medical Center when they considered starting a polio clinic.

FUNDING

DONATIONS: Everything we did was paid for with donated money and fundraisers. We operated by the "If you build it, they will come" theory. We had the idea that if we did significantly important work, people with money would help us pay for it, and they did. We appealed to the membership through *Gleanings* for funds, and those who could give, gave. If we had a particular project in the works and needed cash, often we mentioned it in a meeting and had a check from a member to pay for it by the time we went home. Friends with money seemed to seek us out, and as we explained NPSA's need to them, they donated large sums. Bequests were always in the picture. Finally, members were instructed in the way to have their United Way donations transferred to NPSA. We were convinced we took in much more money through donations than we ever would have by charging dues or fees. And everyone got help free.

FUNDRAISERS: NPSA had some magnificent fundraisers, and 100% of the profit from each of them went to NPSA. Volunteers sold coupon books as an annual event. Many people were interested in purchasing books with tear-out coupons that allowed them to eat at favorite restaurants or shop at favorite stores at a discount. We were ready to help. We stuck a label containing NPSA's name, address, and phone number on each cover so our salespersons could combine PR with fundraising, and they sold hundreds of them. On the phone. Took a stack to a friendly barkeep or beautician who would place them on a counter and sell them for us. Whatever worked. It became a contest with lots of publicity and nice gifts for the volunteers who sold the most.



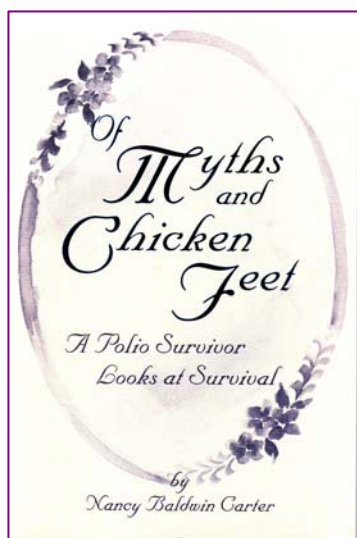
All of our groups came up with excellent fundraisers:

- For years one group collected aluminum cans and turned them in for cash for NPSA
- A friend held Tupperware parties and donated profits to NPSA
- Boy Scouts took us under their wings and had paper drives for NPSA
- One civic organization adopted NPSA and donated proceeds of their efforts to us
- Groups held garage sales, yard sales, craft sales for NPSA

We knew that people cannot resist buying cookbooks, so publishing an NPSA cookbook became our first truly major fundraiser. So many members were anxious to see their family gems in print that we had to limit the number of recipes each could submit for our 170-page tabbed book. We devoted the opening pages to a description of NPSA, the late effects of polio, and post-polio symptoms to watch for. The

cover, of course, displayed our name, address, and phone number. A professional cookbook company did the printing, and our members found ingenious ways to market the product throughout the state.

Some of our particularly clever volunteers set up tables in a mall and had a bake sale of goodies made from recipes in the book. As they sold the books along with their sweets, they had also gift-wrapped a number of them so that buyers would think to take one book for themselves and buy a second (or third or fourth) as gifts. The books were a hit—we sold 1500 of them to satisfied customers.



But they were not our largest-selling publication. That honor goes to a pretty little book of Nancy Baldwin Carter's essays called *Of Myths and Chicken Feet: A Polio Survivor Looks at Survival*. With the title in aqua foil, the cover design appealed to many, and certain polio survivors were anxious to take a look.

Once again, NPSA members revved up to the challenge. The books were marketed all over the state (placed in bookstores, jewelry stores, pharmacies—anywhere that would take a stack and sell them for us) and even at a few polio conferences around the country and in Canada. Church groups bought them for use in book study sessions. Volunteers peddled them among friends and relatives. We sold 2,000. All profits went to NPSA, and as a pleasant bonus, many customers left us with generous donations as well.

INVOLVING THE COMMUNITY

In the beginning, almost no one had heard of post-polio syndrome or the late effects of polio. A goal was to get out into the community to spread the word by involving others in NPSA. We told our story and sought help. If we needed something specific, we *asked*—and while we were at it, we explained about post-polio issues and why this was important. Publicity was a part of all of this; being turned down was rare. Some examples:

- Two medical facilities and one university made their indoor heated pools available, free, for member use.
- A copy service donated personalized badges for NPSA members to wear at the GINI conference.
- A realtor became a “disability specialist,” finding homes that fit the needs of those who are disabled.
- A shoe store specializing in shoes for those who wear mismatched sizes became knowledgeable in our cause and catered to members.
- A shoe repairman became expert at repairing braces.
- Organizations throughout the state gave use of meeting rooms and equipment for our meetings.
- Doctors read and discussed journal articles brought to them by their NPSA patients.
- The governor and legislature celebrated Nebraska Polio Survivors Association week.

KEEPING MEMBERS UPDATED

A primary function of NPSA was to inform members and others. This was a part of every NPSA activity. We had a library of books and articles and video and audio tapes from Gazette International and other sources for member use. We distributed packets of current information, updated regularly. With the help of a Social Security examiner, we wrote a comprehensive pamphlet describing how to apply for Social Security Disability Insurance, which we disseminated throughout the country. Our newsletter was a constant source of important post-polio news and happenings. All of this was free to those in need.



CONFERENCE



On April 1, 1989, NPSA funded and facilitated (through the work of all our volunteers) a major one-day conference, with the backing of the University of Nebraska Medical Center College of Medicine and in cooperation with the UNMC Center for Continuing Education (to encourage attendance by those in the medical community and allow them to receive credit.) Polio survivors and their families were also target attendees. Headliners were Augusta Alba, MD from New York (Post-Polio Breathing Problems), Neil Cashman, MD from Quebec (Post-Polio Syndrome: The Neurology), Sybil Kohl, CSW-ACP, ACSW from Texas (Coping with Post-Polio Changes), and Jacquelin Perry, MD, from California (Orthopedic Programs for Post Polio). A panel discussion and informal Q&A rounded out the program. We cut off registration at 300 (and somehow registered 301) for this special day at the Red Lion Inn in Omaha.

NPSA arranged for Dr. Cashman to come early to present grand rounds at several local hospitals at this time, as we did our best to interest local doctors in our condition and the possibility of starting a post-polio clinic here.

WHY?

Why did we do it? It certainly wasn't for money—nobody ever got a paycheck. Getting NPSA off the ground those early years took an enormous amount of work and dedication. But members seemed willing. Communities seemed willing. We believed in the cause. Everyone seemed to feel a great sense of urgency and excitement and fulfillment. Finally somebody was doing something about our problem, and that somebody was *US!* Our participation gave us a feeling of ownership. NPSA was *ours!* We were *YES* people, all the way. Anticipation. Possibility. We were making it happen.

