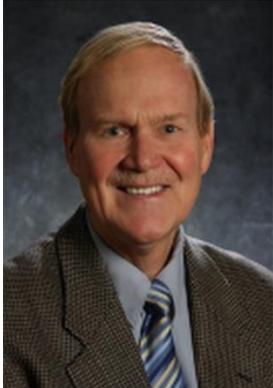


A Personal Reflection on the Early Years of MPN: Insight, Then Action Emerged from Dissent

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I remember the first meetings in 1984. People from around the state had by some means found each other and started attending an ad hoc coalition to address unexpected changes in the health and functioning of Michigan polio survivors. Members were expressing a lot of distress, even desperation, about what was occurring, why it was happening and what could, or should, be done about it. There was concern that the polio virus was re-emerging from dormancy which drew the attention of alarmed public health officials who quickly joined the coalition.

After just a few meetings, participants rapidly united around the need to organize a statewide conference on the Late Effects of Polio (LEoP) to alert and educate polio survivors about what was becoming known about the LEoP. The second goal of the state conference was to raise public awareness about this problem in order to create funding and resources for helping survivors receive needed services. This became Michigan's first post-polio conference in 1985 and was modeled around several ground-breaking national conferences organized by Gini Laurie's Rehabilitation Gazette, a magazine for and about polio survivors that soon expanded its mission and eventually became today's Post-Polio Health International (PHI).

After the highly successful State Conference in Lansing and the legal incorporation of the coalition into MPN, its principal members continued to meet bimonthly. Participants at the meetings were high-spirited and often contentious -- with passionate opinions expressed about what actions the MPN should take. Two women at these meetings stand out in my memory. One is Jo Strauss, whom many consider to be the founder of MPN. She was a severely disabled polio survivor who used a wheelchair, respiratory aides and needed a personal attendant. She was a knowledgeable and energetic woman who was a fierce

advocate for greater funding of services for people with disabilities. She also was a politically savvy woman and personal friend of an up-and-coming politician from her hometown of Mt. Pleasant named John Engler. Through her persistent and fiery demands for programs and services to meet survivors' medical needs, MPN was able to secure some annual funding from the Michigan Department of Public Health (MDPH).

The second memorable woman is Charlene Bozarth who became the first elected chairperson of the MPN. She was a polio survivor who had made a nearly complete recovery from childhood polio, but who was then experiencing severe fatigue and a new mild foot drop. Charlene was a gentle and soft-spoken person with a great deal of insight about and compassion for the physical and emotional changes being experienced by polio survivors. Her priority for the organization was sharing information about the LEOp, talking about methods for helpful treatment of symptoms and promoting the formation of self-help peer support groups throughout the State. She also started the first post-polio support group in Michigan.

There were other regular attendees at the early MPN board meetings and as a rule, they tended to be split—supporting either the Strauss perspective or the Bozarth point of view. They also seemed to be either survivors with a modest extent of chronic physical disability who experienced distressing new physical limitations from pain, fatigue and/or new weakness (a symptom complex that became widely known as Post-Polio Syndrome) or were among those with a more severe degree of chronic disability that made them very aware of handicappers' rights issues. Those in the second group were often experiencing new health problems that threatened not only their independent lifestyles, but often for them, life itself.

After attending a number of early board meetings at which there seemed to be a lot of argument and 'talking over each other' discussion, I began trying to understand why there was so much apparent division and dissension among board members. I shared my thoughts and frustrations about this with my polio survivor friend and associate, Sunny Roller, as we drove to and from Ann Arbor to Lansing meetings.

Based on insights gained from reflecting on the people and their passions at MPN board meetings, we realized that there were indeed several good reasons for having different viewpoints and priorities on the needs of polio survivors. Differences seemed to roughly correlate with the severity of residual motor weakness after initial polio recovery and the degree to which disability was socially obvious. Out of struggling to understand why these differences may have developed, we began characterizing polio survivors as Passers, Minimizers or Identifiers. Each group appeared to have adopted a typical style of coping with disability which seemed to predict how they would react to the LEOp and resulting changes in functional capacities.

Sunny and I conducted some survey research on this topic among MPN support groups which seemed to support our theories and led to a medical journal publication, “Recognizing Typical Coping Styles of Polio Survivors Can Improve Rehabilitation”. To read it: <http://www.sunnyrollerblog.com/wp-content/uploads/2014/08/Coping-Styles.pdf>

It also led to our collaboration with MPN to produce a 20-minute video on “Coping with the LEOp”. To view it: <http://www.polioplace.org/resources/coping-successfully-polios-late-effects>

Both of these educational resources were well-received as helpful by the wider community of polio survivors and health care professionals in the US and worldwide.

In reflecting on the dissension I saw among early MPN members, I can now appreciate that a strength of the organization has been its full embrace and inclusion of all polio survivors. By listening to the diverse concerns and needs of survivors with different backgrounds, experiences and needs, MPN achieved a wide range of unique and notable accomplishments during its 33 years of existence. I believe that some of the most important ones are listed as follows.

Outstanding Accomplishments of MPN

- Received several years of funding from MDPH
- Supported post-polio medical research and established a statewide registry of polio survivors

- Created a Post-Polio Library Collection available to all statewide survivors through inter-library loaning
- Helped fund original educational resources, such as the *Stay Well* manual and the video on coping with polio's late effects
- Organized many educational conferences for polio survivors and health care professionals throughout Michigan and the Midwest
- Facilitated creation of several Post-Polio Clinics at hospitals in Michigan
- Published an educational newsletter, *Perspectives*, quarterly for over 30 years
- Promoted local support groups in Michigan for over 30 years
- Promoted the development of health & wellness programs for polio survivors in Michigan including the Bay Cliff Post-Polio Wellness Retreat

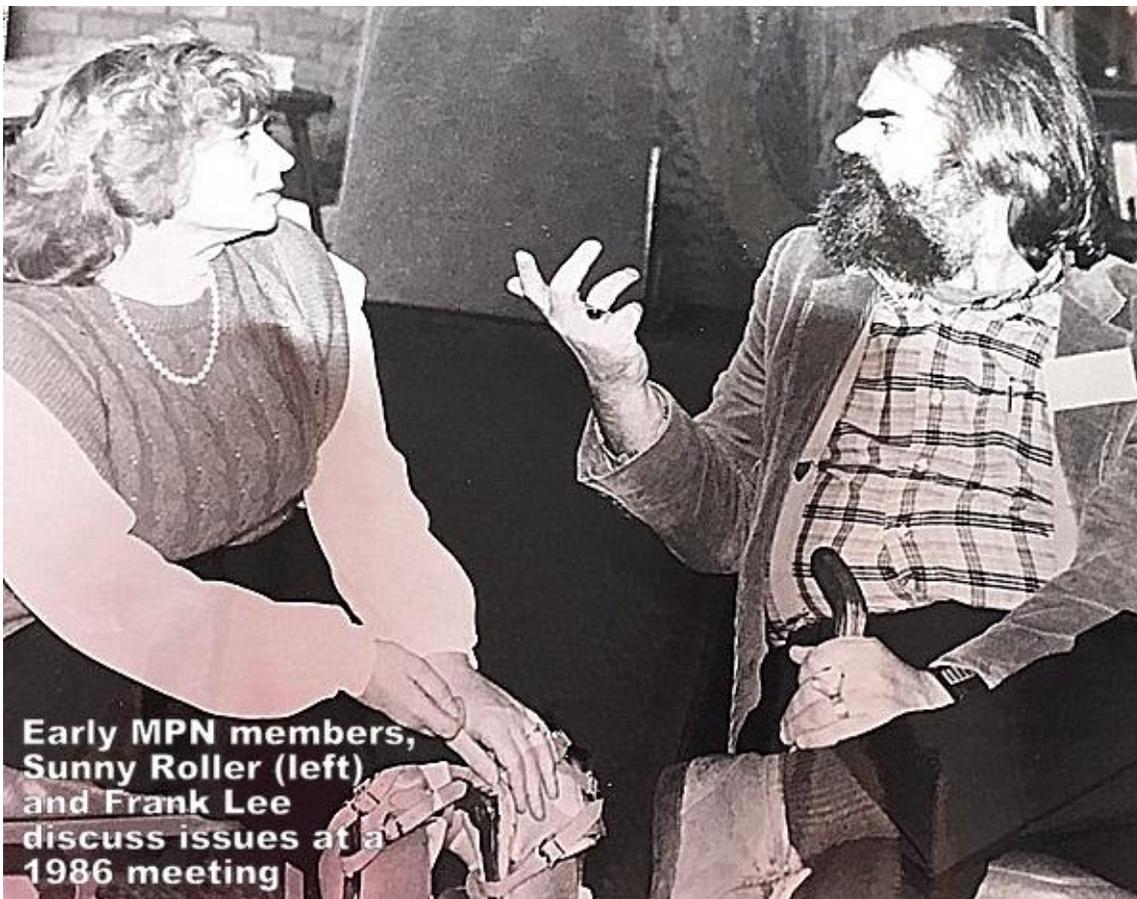


Photo by Janice Gross