

PPASS MN (Post Polio Awareness & Support Society)

EIN: 22-3881312

Form 1023 Part II, Question 1.

“Past Activity History”

PPASS MN (Post Polio Awareness & Support Society of Minnesota) was founded in 1999, by a few polio survivors who gathered monthly to offer each other mutual support and exchange medical information on the late effects of polio, also known as Post Polio Syndrome (PPS). During the fall of 1999, one of those members succeeded in convincing a television network to air a special during the local evening news being broadcast within the Minneapolis/St. Paul, MN area. This television special described the progressing difficulties that polio survivors were experiencing due to the late effects of polio. Other polio survivors who viewed this television special were also having those same problems such as new and progressive weakness, pain, fatigue, swallowing, and breathing problems. Many of these viewers joined this initial group of polio survivors, marking the beginnings of our growth.

Members of the support group decided there was a need for structure and organization. Accordingly we incorporated on July 29, 2002. The members determined the offices of chair, vice chair and secretary/treasurer would be needed. Those elected positions were to be filled by non-paid volunteers who are polio survivors. The officers composed a Mission Statement, Philosophy Statement, and an Organizational Statement. All three of those statements are enclosed.

“Ongoing Activities”

Support for our members is garnered through our monthly meeting and is equal to 60% of PPASS MN activities. During the first two years, our support meetings were held in the Goodwill Industries Building, located in St. Paul, MN. Currently we are meeting in a public library, selected for its central location between Minneapolis and St. Paul. Since 1999, our meetings have been held the 2nd Monday of every month, from 1:00 PM until 2:30 PM. There is also a half hour, both before and after each meeting, set aside for support and socializing among our members. The total time for our meetings and socializing is 2 ½ hours every month. Our support group meetings encompass the exchange of information, knowledge, ideas, and resources, from and to fellow members, about the late effects of polio and the needs of polio survivors. We have, on occasion, invited health professionals as guest speakers to further educate our members. They have provided us with this service, free of charge, so far. The process of securing a medical professional as a guest speaker, in lieu of a fee, is understandably difficult. We need funds to pay future guest speakers, especially for doctors who are recognized nationally as specialists in the treatment of the late effects of polio. We have a professional facilitator who leads us through group discussion. This facilitator is provided by Independence Crossroads, a Section 501(c)(3) tax-exempt organization funded by Hennepin County, Minnesota. This service is free of charge to PPASS MN as long as we continue to hold our meetings within Hennepin County.

Currently, and in years past, we have provided post polio **Education** to our members in several ways. Past and present educational activities represent 30% of PPASS MN activities. Our secretary produces a bi-monthly newsletter entitled, “PPASS Times.” Our newsletter is mailed to all of the members on our roster, regardless of whether or not they are able to attend our monthly support group meetings on a regular basis. Our newsletter consists of at least 10 pages of fact filled articles concerning post polio syndrome, up-dates on our last support group meeting to address those members who were not able to attend and announcements concerning future support group meetings.

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Articles that appear in our newsletter usually are written by medical professionals and reprinted with the author's permission. In order to cover the minimum costs of essential materials, along with the printing service used in producing our newsletters, our members are asked to make an annual \$20.00 donation. Members, who are financially unable to afford a donation, continue to receive our newsletter. Our organization qualifies for free mailing through the US Postal Service, making it financially possible for our secretary to mail newsletters to our members. See our enclosed newsletter. Again, our secretary is a volunteer and receives no salary. He spends an enormous amount of time in putting together this newsletter, to further post polio awareness and education.

Our secretary personally owns an extensive library, made up of books and articles pertaining to polio and post polio syndrome. He has thoroughly catalogued everything in his collection and generously lends them out, free of charge, to any member who is interested. He has compiled this library over a period of many years, even before our organization was formed and has done this at his own expense. We need funds to supply a library of our own to further our member's knowledge of post polio syndrome, in order for them to become better health care consumers.

All members of our group have participated in compiling a list of doctors and other medical professional that they deemed knowledgeable and helpful in the treatment of post polio syndrome. Due to the polio vaccine, polio has become an antiquated virus that has been eradicated in most countries. Many doctors are sorely lacking in their knowledge of polio and the late effects that polio survivors are currently dealing with. This list has enabled our members to become better health care consumers.

Our **Post Polio Awareness** activity is very important to us. Post polio awareness represents 10% of PPASS MN activities to date, due to our very limited funds.

The officers of PPASS MN have designed a brochure that contains a brief history of the poliovirus, describing the symptoms of post polio syndrome, along with information on our organization, such as where and when we meet, including phone numbers to call for additional information concerning our support group meetings. The brochures have been distributed by our members, to doctor's offices with the intent and hope they will be displayed and read by their polio patients. The brochures have also been circulated to church bulletin boards and other public areas. See the enclosed pamphlet.

This past year our organization put together a medical packet and mailed it to our medical professionals in order to keep them up to date on any new treatment advances used in helping those who are experiencing the late effects of polio. The packets contain articles, published by doctors who are recognized nationally for their knowledge in the treatment of post polio syndrome.

Our organization is very fragile. The main reason for this is the fact that all of the work that makes our organization successful is currently being completed by member volunteers who are experiencing post polio syndrome. Most of our members are no longer employed due to their disabilities from the late effects of polio. We have very limited energy supplies. In order to stabilize our organization, we need to begin fundraising in the hope that we will be able to raise the funds needed to continue moving our organization forward, to a growing, statewide organization. To accomplish this we need money for supplies and occasional secretarial assistance provided through a temporary employment agency. Without those funds, our group could very well fall apart, as our physical disabilities continue to progress, making us less able to complete the work of PPASS MN. Since we have no product or service of monetary value, we do

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not intend to ever become an organization for profit. We are a group of polio survivors who are experiencing post polio syndrome and simply want to help others who share this medical condition, by supplying them with support and information. We are polio survivors, helping polio survivors. Presently, we need to succeed in obtaining a determination from the Internal Revenue Service as a tax-exempt organization under Section 501(c)(3). This status will enable our organization to be considered for and receive grants and other fundraising contributions made by various corporations, non-profit organizations, and individuals.

For those reasons we have decided to proceed with the process of incorporating our organization as tax-exempt under Section 501(c)(3) of the Internal Revenue Code. To economize on legal fees, we have opted for a committee, made up of volunteer polio survivors who are members of our organization. Together, they will complete the required forms. Our attorney will then check those forms for accuracy and advise us from there.

Enclosures:

- Mission Statement
- Philosophy Statement
- Organizational Statement (of original group - see draft By Laws for new structure)
- PPASS Times
- PPASS MN Pamphlet

"Planned Activities"

As we look to the future of PPASS MN, our planned activities can be grouped into three categories, **Education, Chapter Organization, and Fund Raising.**

The first category, **Education**, will account for 60% of our time. We want to continue providing information on Post Polio Syndrome to Polio Survivors, the medical community, and the general public. We will do this by continuing to print and distribute our bi-monthly newsletter, PPASS TIMES, and PPASS MN Information Pamphlets. We will continue to provide the medical community with PPASS MN Physician Packets, and update these medical professionals on a regular basis. We will continue to share with our members, polio and post polio articles, books, video, and audiotapes through our PPASS MN Information Library. We will expand our current Medical Resource List to include doctors and other professionals throughout the state who specialize in the treatment of Post Polio Syndrome beginning the 1st Quarter, 2003. Monies needed to print the above information will come from membership dues and fundraising.

PPASS MN needs a computer and the necessary software to publish the newsletter and run the organization. We also may need temporary secretarial help. We are using our annual membership dues of \$20.00 a person to defray the cost of the newsletter. The costs for the computer, software, and part-time staff would come from fundraising. Anticipated time to initiate this would be the 1st Quarter, 2005.

To reach out to other people around the state who are looking for information on Post Polio Syndrome, to notify them of the time and location of future support group meetings and to display our newsletters, PPASS MN will establish an Internet web site. This requires raising funds to cover the costs of creating the web site and paying the Internet service provider. The Board of Directors of PPASS MN will appoint the person (s) to

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organize this. They will initiate this activity, after funds are raised, in the 1st Quarter, 2003.

We will increase awareness of Post Polio Syndrome (PPS) within the medical community by sponsoring seminars during which recognized experts will present their latest findings to the doctors, physical therapists, and orthotists. Our plan is to offer these as all day seminars with morning and afternoon sessions. We will serve a midday meal, during which the expert presenters will be placed around the room to give as many people as possible an opportunity to converse with them. We plan to do one of these seminars in the Twin Cities in 3rd quarter 2003 and two more in the out-state area, one in the 2nd quarter and one in the 3rd quarter of 2004. The seminars will be presented free of charge to the medical professionals. Costs for sponsoring the seminars will be covered by fundraising.

Education of the community of polio survivors will be address in the 3rd quarter of 2005 with a three-day symposium open to polio survivors, their families, care givers, and the medical community from around the state and the country. The symposium will open with a welcoming dinner the night before its sessions begin. The first two days will start with a breakfast followed by two one and a half hour sessions, lunch, two one and a half hour sessions, and an evening meal. The third and final day will start with breakfast followed by a panel discussion and a question and answer period. The sessions during the first two days will be restricted to smaller audiences with several sessions running concurrently while the panel discussion and Q&A will be open to the entire symposium audience.

The Symposium will address such subjects as (but not be limited to) muscle fatigue, central fatigue, post polio pain, exercise, orthotics, the etiology of PPS, respiratory problems, stress, and coping. We will be seeking to bring in experts from around the country such as Dr. Stanley Yarnell from San Francisco to speak on exercise, and Dr. Dawn Ehde, a Clinical Psychologist from Seattle to speak on Stress and Coping. Some of the costs of the Symposium will be offset by charges to the individuals in attendance. Fundraising will cover the remaining costs.

The second category of activities is **Chapter Organization** and accounts for 30% of our time. Using the Twin Cities-PPASS MN Support group as a model, we will seek out others who wish to start a support group. We will help them organize and train their leaders. We will also identify existing Post Polio support organizations around the state. We will determine how we can be of assistance to them and invite them to join our statewide umbrella organization. A committee formed by the Board of Directors of PPASS MN will direct this activity. They will formulate a plan and begin implementing it in the 1st and 2nd Quarters of 2003. Any costs involved will need to be covered by funds generated by PPASS MN fundraising activities.

The third category is **Fund Raising** activities. These will make up 10% of our time. We will solicit contributions from individuals, groups, foundations, and corporations. The Board of Directors of PPASS MN will form a committee to be in charge of fundraising. They will begin raising funds in the 2nd Quarter, 2003.