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The Multiple Sclerosis Society:
One Thing People With MS Can Count On

by

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The MS Society.
One Thing People With Ms Can Count On.

This project has been both interesting and beneficial for me. For starters, I was able to continue my interest in nonprofit organizations that was sparked in Leadership in Community Organizations. I was able to see the inner workings of a nonprofit organization and observe how it operated at various levels. Working with the Multiple Sclerosis Society on this project gave me the opportunity to be involved with something that was dear to my heart and interested me. I have a personal interest in the MS Society because my mother was diagnosed with the disease a year ago. My involvement in the organization has helped me to understand some of the issues and intricacies of MS. At the same time that I was learning about the disease and completing my requirements for class, I had the satisfaction of helping people like my mother through volunteering.

MULTIPLE SCLEROSIS

Multiple Sclerosis was first identified as a disease by a French neurologist in 1868. In the more than 100 years since it's discovery, MS has been the focus of many scientific studies. Researchers have made some significant discoveries in regards to how the disease affects the body. Yet, to this day, doctors have not isolated a cure for the disease.
MS is a "chronic disease of the central nervous system," which can make everyday activities a chore.\textsuperscript{1} The disease is brought on by the breakdown of the myelin sheath that surrounds the axons in the central nervous system. Nervous impulses are passed through the axons and the nerve fibers connecting them. When the layer of myelin protection disappears, hard areas of scar tissue form. Extensive demyelination may completely block the conduction of nervous impulses through the bared axon. If the loss of myelin is less severe, then the transmission is slowed and may become severely defective.\textsuperscript{2} This slowing down or destruction of the nervous impulses result in loss of movement or control of certain body parts.

The onset of MS usually occurs between the ages of 20 and 40, with some cases not diagnosed until the age of 60. Women are affected twice as often as men. The disease also seems more prevalent in countries closer to the equator. "There is increasing evidence that MS is more common among close relatives of those with the disease than in the general population."\textsuperscript{3} The disease also seems to be found in brothers and sisters more than in mothers and children. All of this data shows that there is a "genetic predisposition"\textsuperscript{4}, but MS does not follow any of the recognized patterns of other inheritable diseases.\textsuperscript{5}

\textsuperscript{1}National Multiple Sclerosis Society, \textit{What is Multiple Sclerosis}. National Multiple Sclerosis Society.
\textsuperscript{3}Matthews 12.
\textsuperscript{4}NMSS, \textit{Research Directions in Multiple Sclerosis}.
\textsuperscript{5}Matthews 12.
The disease affects people in many different ways, so there is no common set of symptoms. However, there seem to be specific areas that are particularly vulnerable. People with MS often complain of "tingling sensations, numbness, slurred speech, blurred or double vision, muscle weakness, poor coordination, unusual fatigue, muscle cramps, spasms, problem with bladder, bowel and sexual function, and paralysis." Due to the varied symptoms and degree of severity, it is very difficult for doctors to diagnose MS. This variety is the result of the erratic formation of the scar tissue on the central nervous system. The degree of the demyelination affects the severity of the MS. There is no specific test for MS and the cause is unknown. There is a connection between MS and the loss of myelin, but doctors do not know what causes the disappearance of the myelin protection.

It is very difficult to know how many Americans are affected by MS because it is not a reportable disease. It is left up to the clients to register themselves and the disease is often confused for other diseases. The National Multiple Sclerosis Society reports that there are about 1/3 of a million people who have MS.

THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

Sylvia Lawry was disturbed by the lack of information about her brother's illness, so, in 1945, she placed an ad in The New York Times asking anyone who had recovered from MS to contact her. The responses came rolling in. Only one year later, the National

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6NMSS, What is Multiple Sclerosis.
Multiple Sclerosis Society (NMSS) was up and running, spending 100% of it's funding on research.

Currently, there are over 140 chapters and branches in all 50 states that carry out the goals and programs of the national organization. Over the years the amount of funding available to the NMSS has increased dramatically. In 1967, $780,000 was allocated to MS related research. By 1994, the NMSS allocated over $12 million to research on the disease.

The NMSS is the only non-profit health organization in the United States supporting research here and abroad into the cure, prevention, and treatment of MS. In addition, the NMSS provides a wide range of services to clients including: counseling, education, information and referral, public policy development and advocacy, and assistance to clients and their families.

Due to the increased amount of money available, the NMSS has been able to expand the amount of services that it provides. The main events that the NMSS uses to attract donors are the Dinner of Champions, the MS Read-a-Thon, the MS 150 Bike Tour, and the MS Walk. These events have allowed the NMSS to make services much more available to those who need them. In 1967, only 5,000 people received direct services from the NMSS. By 1993 over 500,000 people had been able to utilize the services that are available to them through NMSS.

The International Panel of Corresponding Neurologists was formed through money donated by the NMSS in 1967 (International Federation of Multiple Sclerosis Societies). This organization was formed to keep track of reports for advances in the research of MS.
and has also provided organizational assistance to 34 member countries. Sylvia Lawry, founder of National Multiple Sclerosis Society, is also responsible for the formation of the IFMSS and has continued her involvement by serving as Secretary.\(^7\)

**THE CENTRAL VIRGINIA CHAPTER**

The history of the chapter is unclear because of the high rate of turnover among the staff. The chapter was founded in 1956. In the 1970’s there was a part time staff member. The organization raised money for research only. In the 1980’s a full time staff position was formed. In the mid 80’s the chapter started the special events as a way to raise money; the Dinner of Champions started in 1985, the MS Bike Tour in 1986 and the MS Walk in 1989. In 1990, Jacqui Kozsuch was hired as Executive Director. At the time, there were only six board members and one staff member. By 1995, the Board of Directors consisted of 22 members and the staff had grown to five people. The chapter includes 32 counties and four cities.

**METHODOLOGY**

In order to gain an insight into the organization, I chose to interview a wide variety of people. The groups chosen would have different experiences and opinions of the organization. I chose to do personal interviews with the staff, clients, volunteers, board members, Executive Directors from other chapters, and the Area Director from the National MS Society.

\(^{7}\text{NMSS, Informational Fact Sheet, 1994.}\)
INTRODUCTION

In my study of the Central Virginia Chapter of the National Multiple Sclerosis Society, I have chosen not to focus on the departure of the Executive Director, Jacqui Kozsuch, who is leaving for personal reasons. I have instead focused on the issues that are going to be relevant and important for the growth of the chapter in the future, such as the board involvement, fundraising strategies and meeting the needs of the clients.

BOARD OF DIRECTORS

A nonprofit organization's Board of Directors is responsible for ensuring the success of the organization. It is their duty to determine the organization's purpose and mission, hire the staff, plan for the future, approve and monitor the programs and services, take care of fiscal matters, to represent the organization, and to ensure future success of the organization by continual development.\(^8\)

In order for this to be accomplished, the Board of Directors needs to be made up of active and committed individuals. Bryan O'Connell says, "The board members should represent those individuals who, in the significant majority, have proven their interest in the cause and their ability to help pursue it."\(^9\) The board serves as the guiding force behind the organization and its activities. Without a committed board, the organization is going to struggle.

The board should consist of members from a variety of backgrounds. Recruitment of new board members should be done in such a way that the needs of the board are met by the new member. Everyone on the board should be able to contribute either their time or money. For this reason, a nonprofit board needs members who either have or have access to money or necessary resources, as well as those who are willing to devote their time and expertise. In order to deal with all of the responsibilities of the board, there needs to be personal experience in many of these areas. This brings to mind the saying that a board member should have two of the W’s, either wealth, work or wisdom. If a board is made up of any one group more than the other, then problems will arise.

In a speech to the executive directors of the National Multiple Sclerosis Society chapters, Joan Mason outlined characteristics of the perfect board. She said that every board member should make a donation, the board should have age, gender, and racial diversity, and not more than 1/3 should be personally involved. The Central Virginia Chapter Board of Directors currently has 22 members who serve two year terms, of which there are only three women, no minorities or age diversity and only 17% are personally involved. In addition, only 40% give personal gifts.

The MS board needs to adapt and change from it’s current position in order to continue moving forward. In addition to these facts, there does not seem to be a universal commitment among the board members. Several people referred to the lack of activity and involvement by the board as a whole. There are certain members who take part in the programs or events, but they are few. One
board member said, “Only two or three people do all of the work. The rest come to the meetings and eat dinner, but they don’t do things after that.” Another said that everyone was “on the sideline, they are not rolling up their sleeves and getting it done.” This lack of participation has been noticed at all levels of the organization. A staff member said that most of the board members are there for financial reasons. She feels that if the board members got involved in the projects, they would have a personal reason as well. Another board member said that the wrong people were recruited. Back when the organization was trying to make it, they recruited big name people. He said that they turned out to be only figure head members, not hard workers.

In an effort to change this, the Board of Directors has adopted a change of organizational structure, which will rearrange the committee structure and board/staff involvement. The idea behind the change is to better coordinate the tasks of the chapter and to get more participation out of the board members and volunteers. This change will only work if the board members are ready to accept the responsibility that has been placed on them. This change may also weed out those members who are the “figure heads.” O’Connell says, “Persons who cannot be active should be dropped.”10 If they are not willing to put in the time and effort to help the organization succeed then they should not be on the Board of Directors.11

This past year the first Board of Directors retreat was held to review the performance from the previous year and work on long

10 O’Connell 76.
11 O’Connell 76.
term planning. Every board member who attended the retreat thought that it was a very valuable time. One board member said, "It allowed us four to five hours to discuss some issues thoroughly." This was not something that they usually had time to do during the year. Again, the attendance was poor. Only about half of the board was able to attend the retreat. The same board member thought that it was so worthwhile that they should have a retreat every six months. This is promising to hear considering the implementation of the new structure.

FUNDRAISING

Due to the nature of the organization, fundraising is a crucial part of the MS Society. According to Newton Geurin, the Area Director for the Southeast Region of the National Multiple Sclerosis Society, the Central Virginia chapter ranks among the top four in the southeast region in fundraising performance. The chapter has raised more than 100% of the expected income based on a business purchasing power index. This success has allowed for the expansion of services and programs available to the clients.

The Central Virginia chapter holds several special events in order to raise money. The main events that are held include: the MS Walk, the Dinner of Champions, the Virginia Dare Bike Tour and the UGLY Bartenders Contest. The money raised from these events funds research on the disease and the programs and services that the chapter provides to the clients. Of the total money raised, 40% of it is allocated for research on the disease. A staff member said that is an

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12 Geurin, Newton. Personal Interview.
interesting statistic, because most of it comes back to Richmond. There are currently two doctors at MCV who have grants from the NMSS to do MS related research. The chapter tries to show donors how their money will stay in the Richmond area.

Several people mentioned the fact that the chapter fundraising is very event oriented. This is seen as a weakness, because it is very dependent on external factors that they cannot control, such as the weather and volunteer involvement. The events are often expensive and time consuming as well. Without the commitment and hard work of the volunteers, the chapter would not be able to hold the event.

There are some very important benefits associated with special events. "Without the events the public would not know about the disease," said one staff member. She went on to say, "These events serve as the best way to get our name and cause out to the community." O'Connell states that the "larger the campaign the more public awareness there is of the cause." This awareness is not only beneficial in increasing people's understanding of the disease, but in recruiting volunteers as well. O'Connell sees this as an opportunity to "remind a growing number of people who you are, what you represent, what you can do for them, and what they can do for you."

The board plays a crucial role in getting corporate sponsorship for these events. They have connections around the city and are able to get donations. However, one board member pointed out that they

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13 O'Connell 106.
14 O'Connell 107.
need to work on expanding their list of donors. He said that the same corporations are being asked every year, so the chapter needs to find new sources, in order to sustain the thrust.

There is a national movement to planned giving rather than relying on the special events, according to a staff member. They have realized that the special events are not going to be successful forever. They are going to have to come up with alternative ways of raising money. The problem that arises is the need for the events in order to get the cause in people's minds when it comes time to donate. Without the events, the people don't know about the MS Society and, consequently, don't remember to donate. MS hopes the implementation of planned giving will supplement the events and, therefore, reduce the need to hold them. As a way of addressing this issue, the MS Society is holding a Planned Giving seminar later this year to explain how the process works. The idea is to show people the benefits and have them spread the idea to their friends and neighbors. Through this process, the need for events will decrease. The switch to planned giving is seen as a more traditional form of raising money. Instead of having the overhead costs associated with a special event, there is only the cost of personnel time. This will act as a supplement to the events that have been so successful in the past.

SERVICES

A very strong aspect of the Central Virginia Chapter is the service that it provides to the clients. The commitment of the
organization is evident when the mission is analyzed. The three parts to the Central Virginia chapter’s mission are: 15

- Provide funds for research
- Provide local services to support individuals and families affected by MS
- Educate the general public and health professionals about MS

The emphasis is clear. The MS Society is in existence to serve the clients and their needs.

A client commented, “Recently, the Executive Director and the national headquarters have changed the focus from fundraising and putting the main emphasis on research and the clients with MS.” Another client said, “They used to only care about raising money. They didn’t care about the people. The people are the only reason the organization exists.” This reevaluation of priorities has allowed the chapter to focus on the people with MS. With this refocusing, the number and breadth of services has grown. Part of this is due to the success with the fundraising. Instead of worrying about paying the bills, the chapter is now able to reach out to the clients.

The major programs and services that are offered by the chapter include: 16

- Information and Referral
- Lending Library
- “Multiple Choices” monthly newsletter
- “Inside MS” - NMSS quarterly newsletter
- Advocacy
- Educational Seminars
- Equipment assistance
- Audio Teleconference
- Newly Diagnosed Series

16NMSS, Programs and Services.
With only the Director of Chapter Services responsible for the services that the chapter provides, it would be impossible for her to provide everything herself. The role of the volunteer is a key component to the success of the service programs. Several of the services available are run entirely by the volunteers. In addition, many of the programs were ideas generated by volunteers or clients and then managed by them with assistance provided by the staff. This is an area where the staff is truly serving the function that it should, to assist the volunteers. The services area seems to be the only place that this is the case.

The staff is always looking for new and innovative ideas in order to meet the needs of the clients. The Director of Chapter Services said that she is constantly asking for input about the services and programs that they provide. She said that most of the feedback comes from the calls and questions from the clients. She documents the information that they are looking for and uses this as a basis for the need for new information or services. She is very committed to meeting the needs of the clients and truly values their opinions.

According to a client who has been involved in the chapter for over 15 years, the quality of communication has been very inconsistent. She said that she encouraged the Executive Director to be faithful with the chapter newsletter. This communication serves

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17 O’Connell 27.
many purposes. For many clients this is the only source of information they receive about MS. For one, it is a great method for sharing information about upcoming events. The newsletter serves as the primary source about the programs and services that are available to them. It also serves as a way of informing the clients about new developments in the MS research. The newsletter generally contains news and specific information for living with MS. This type of information follows what O'Connell says is important when sending a newsletter. He said, “Focus on the cause and not the organization.” This information tends to be more interesting and useful for the reader.

STAFF

Like many other nonprofit organizations, the MS Society must rely on a small staff to accomplish it's big tasks. Every one of the staff members is very committed to what they are doing or else they would not still be in their job. One client said that she was amazed at what gets accomplished around the office with such a small staff.

One of the things that several clients and volunteers noted about the staff, as a whole, was their genuine care for everyone who came into the office. This personal interest in the people they work with has some very powerful effects on people. One client said, “Sometimes I'm glad I have MS, so I can experience this.” Another said, “I feel at home when I come here.” These type of feelings seem to be common among those that come in contact with the staff.

18O'Connell 122.
A volunteer said that the staff is very flexible and is willing to work around her schedule or if a client feels tired or fatigued, then the staff tells them to go home and rest. Another client described the staff as “always thankful and grateful.” Through observation and personal interaction, I can agree with this area of thought. The staff has always been willing to work around the schedule of the volunteer and is very appreciative of their time. This is not only one person, but rather, the entire staff. There is a genuine belief that the volunteer is the most important part of the organization. The staff all agrees that without the volunteers, they would not be able to operate.

Based on my observations, this staff is competent in what they do and are able to adapt as new issues arise. This requires coordination and communication among all staff members. When a special event or program is looming, the entire staff joins together to accomplish the necessary tasks. There is a strong sense of a team and empowerment among all members of the staff.

VOLUNTEERS AND CLIENTS

As stated before, volunteers are a very respected part of the organization. Their input and advice are very important to the success of the organization.

In his book, On Leadership, John W. Gardner states that “… the purposes of the group are best served when the leader helps followers to develop their own initiative, strengthens them in the use of their own judgment, enables them to grow, and to become better
contributors." This seems like an ideal description of how a nonprofit organization should treat its volunteers. When an organization is able to develop its volunteers to become better contributors then it is only going to improve the organization as a whole. I see this happening in the service area of the chapter more than any other area. Volunteers are responsible for and run several of the programs offered by the chapter. With these programs, the staff is in a support role and is available for consultation. This allows the volunteers to learn and experience how to carry out the program. Thus, the program will last long after the staff member has left the chapter. This process also empowers the volunteers and, as a result, strengthens the chapter as a whole.

I think that the service area offers many more opportunities for volunteer ideas and involvement because of the large variety of needs. The Self-Help Groups were started by a volunteer because there was a need that was not being addressed. That idea has continued to develop. Recently, another volunteer started a support group for male care givers for women with MS. If the original support groups were not started then this need would most likely not be met today.

A group of dedicated volunteers have headed up a new service, called PAVE (Project Access Visibility Education). The volunteers go to businesses and either praise or instruct the owners on the accessibility of the establishment. These volunteers are completely responsible for all aspects of the program. The Central Virginia chapter sent the volunteers to Denver to attend a NMSS seminar on

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the program. The training is necessary for correct implementation and allows the volunteer to develop their personal skills to the benefit of the chapter.

OTHER CHAPTERS

In order to gain an understanding of how well the Central Virginia Chapter operated, I studied other chapters around the nation. What I found was rather interesting. Other chapters had problems with their board participating in events or programs. For the most part, the services and programs that they provided are similar to the services and programs the Central Virginia chapter offers. In addition, each chapter had its own issues to deal with in regards to volunteer recruitment and fundraising.

Each Executive Director said that they did not have the level of involvement among board members that they wanted and only a small percentage of the members were involved in the special events. They reiterated an idea that I heard among the staff in Richmond, that the board members would have more interest if they were interacting with the participants of the MS Walk or other event.

The availability of volunteers seemed to vary depending on the community and the organizations within it. In Memphis, the local military air base provides them with the support they need for their special events. In contrast, West Virginia has a harder time gathering volunteers for it's events because of the geographical elements. Along these same lines, there is a lack of corporate support, because there are no corporations in the area. This makes fundraising much more difficult. In contrast, the Mid-America
chapter has several corporate sponsors and a large population to recruit volunteers. Each of the chapters has to deal with different issues.

The external environment is an important issue for any nonprofit organization. They need to understand the available resources and special situations that will affect the organization’s activities. By reducing the uncertainty of the external environment, the organization is better able to predict the success or failure of it’s programs.

PROBLEMS WITH THE RESEARCH

The biggest problem I encountered was the lack of access to client names. The names and information are all confidential, so I could not call clients to get a sampling of their perceptions and experiences. As a result, the interviews that I was able to line up were with people who are very active in the chapter. Their continued activity with the chapter shows that they are not displeased by the overall organization. I believe that this is the reason why the results were so positive. The people I had access to saw the effective aspects of the organization. There were a few clients who were not active with the chapter that I was able to interview. These interviews did not prove beneficial to assessing the chapter, because the clients chose not to be associated. They had their own reasons for not participating and these reasons do not relate to the organization itself or it’s performance. In order to get a true assessment of how the organization works, a larger number of non-active clients would have to be interviewed.
I then tried to compare the current status of the chapter to how it had been in years past. With such high turnover rate in the staff and not many clients or volunteers who have been around for a significant amount of time, this proved to be futile. The little information I was able to gather could not provide me with a basis for comparison.

A larger sampling of board members would have provided more insight on why there was such poor attendance and involvement in the programs or events. Newton Geurin pointed out that this may be true according to the staff, but the board may view the situation from a different perspective.

I found it difficult to compare the Central Virginia chapter to other chapters around the nation do. This was because the chapters that I had contact with were not similar in size, location, available resources or needs. A better matching of chapters in regards to these areas would have made the comparison much more effective.

AREAS OF IMPROVEMENT

I think the chapter has made some very positive steps towards changing the role of the board. The members need to understand the reason they are on the board and what is expected of them. In the past, there has been one person who has taken on the task of the organization as a personal mission. This one person has been the force behind the change. The true test for the chapter is going to be how it responds to the loss of the executive director. One board member said, “No one is capable or willing to take on the serious responsibility.” This shows a lack of organizational leadership. The one or two people who are the force behind the organization show
their leadership in getting things accomplished. However, I think another aspect of leadership is empowering others and teaching them to be leaders themselves. This process develops leadership at all levels of the organization in order to keep it going.

Max DePree calls this “Roving Leadership.” He says that there needs to be people at all levels who take control in specific situations where it is appropriate for them. They are not the hierarchical leaders but other members of the organization. This allows for them to take ownership of the issues that face the organization. Volunteers, clients, and staff members need to step up and take charge when it is their turn.

As the “leaders” of the chapter, the board members have the responsibility of making sure that the organization continues to improve. Based on their lack of involvement in the fundraising events or service programs, I don’t think that the members are committed to the organization and its mission. Most of the board members are asked on to the board as representatives of Philip Morris or an associated business. Philip Morris and the tobacco industry have provided the MS Society with thousands of dollars and many volunteers. However, this sort of pressure to become involved in a cause does not bring on true commitment from the people. They need to have a personal belief in the organization and a desire to help that organization in any way that they can.

As was mentioned before, not all of the board members give donations themselves. If the board members, who are responsible for the success of the organization, do not show their commitment,

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then why should anyone else donate? I think that this is an excellent opportunity for these board members to show why they were chosen as representatives of the organization. They should avoid the "do as I say, not as I do" way of thinking and lead by example. If they donate and are committed to what is happening, then that feeling will trickle down and become evident throughout the organization.

Many of the people who volunteer do so for the intrinsic satisfaction. They do not require the monetary compensation or praise that is normally associated with hard work. A leader does not have to stand by the volunteer encouraging and instructing every step of the way. Kouzes and Posner say, "What is rewarding gets done." As long as the chapter is able to match volunteers with tasks involving their interests, the volunteer should not need to have their hand held through each step. The fact that the task is challenging, interesting and necessary should be enough to motivate the volunteer.

A major strength of the Central Virginia chapter is how they show their appreciation for everyone who helps. Most volunteers are not looking for the attention and praise, but they are pleasantly surprised when they receive heartfelt thanks for their time and effort. This may seem like a simple act, but I have observed situations where there was no appreciation shown. The morale and satisfaction were very low among the employees. If this were to happen in a nonprofit organization, the volunteers would not stay

around. So, by the small acts of appreciation, the staff is able to build a strong sense of satisfaction.

"The key success factor, they found, was the development team's interaction with the customer."22 If you apply this same concept to the nonprofit context, then the success of the organization is going to be determined by the interaction with the client (customer). The chapter is very aware of this need and is planning a formal assessment program once a year in each Self-Help group, as well as surveys for everyone who utilizes a particular service or program. This feedback will be used by the chapter as a source of change and improvement.

It is possible to view this relationship as leader/follower rather than provider/customer. In this sense, two-way communication is essential to a healthy leader/follower relationship.23 In this situation, the information that clients have can greatly determine the effectiveness of the organization. The staff does not know what questions or concerns people have, so there needs to be an open channel of communication to all members of the organization.

Along with sharing information, leaders and followers need to be open and willing to innovative ideas. These ideas are necessary for organizational change and adaptation to occur.24 An organization that does not change with the needs of its members will not last very long. I think that new ideas are greatly encouraged in the MS Society in order to continue its success. One staff member said that the staff often brainstorms new ideas during weekly meetings. The

22Kouzes and Posner 57.
24Kouzes and Posner 72.
implementation of volunteer ideas is a great example of how the chapter has utilized these ideas in the past.

CONCLUSION

Based on my research and observation, I think that the chapter has made a turn for the better and has the groundwork laid for future success. All of this is dependent on the commitment and genuine involvement of all members of the chapter. The services and programs will continue to expand, as long as the necessary funds can be obtained either through events or planned giving.

In the past, the responsibilities of the chapter has fallen on the shoulders of a few people. The leadership needs to spread the responsibility among all levels of the chapter in order for the organization to remain successful.
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