MYASTHENIA GRAVIS
TREATMENT & ADVOCACY CENTER

*A program of the Myasthenia Gravis Association
of Western Pennsylvania*

Executive Summary

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Community Partner, Ms. Barbara Lefler
(www.mgawpa.org)

I. Background Information

Myasthenia Gravis Association (MGA) was created in 1955 and has a long history of serving those with myasthenia gravis. **MGA of Western Pennsylvania** organization is located on the campus of Mercy Hospital and provides a variety of services for those affected by MG. Their mission statement is:

> *"Our mission is to address the medial, social and emotional needs of all persons affected by Myasthenia Gravis and to disseminate educational information to persons with Myasthenia Gravis, their families, the medical community and the general public."*

It is one of the worlds' largest and oldest treatment centers for Myasthenia Gravis. The organization works in collaboration of Mercy Hospital and University of Pittsburgh Medical Centre. MGA also provides free brochures which are available regarding some of the basic and imperative topics on *Myasthenia gravis*. It can be also found on the MGA website which is as follows: http://www.mgawpa.org/library/educationpage.html.

II. Consulting Tasks

I provided consulting on two major areas to MGA. The first one was the efficient use of the available software and hardware efficiently and the second was coming up with a user friendly database and coming up with a new format of the form. MGA received the donated laptops from Highmark. They wanted working environment and internet connection set up so that they don't have any place restriction. So, my task was to show them how to set up a working environment and show them how to have internet connection on the laptops.

MGA had problems while working on excel spreadsheets and were not able to retrieve the data from their old Access database files. So, my other task was to come up with user friendly database and also they are able to retrieve the data from the old Access database files.

III. Outcomes Analysis and Recommendations

1. Consulting Task 1: <u>Use of the available software and hardware efficiently</u>

   - <u>Outcomes</u>: The installation of the operating system, necessary software like MS Office and wireless internet facility was done and was shown in a HP and Compaq

Laptop. The installation of the OS, software and connectivity of the internet was later done by the staff member of MGA. They now able to connect to the internet and install the software in other desktops which are available at MGA. This has made them sustainable for the future.

- <u>Recommendations</u>: Wireless Adaptors were recommended as they were inexpensive as compare to the modems. Also, Updating the Laptops/Desktops with Windows Updates regularly and contacting Techsoup for new version of the Software such as Norton Antivirus.

2. Consulting Task 2: <u>User friendly Database and New Format of the Form</u>

- <u>Outcomes</u>: We decided to work on Microsoft Access ver. 2007. They are now able to use the Excel spreadsheets on the Access and are able to retrieve the old information from the database which was in older version of Access and are now able to use Access for database work. They also have now a standard format of the form which is now pretty easy to fill without any editing of the format of the form.

    Sustainability will be an issue here as if they have some problems using the Access Database in the future then they can come back to the same old method of creating database through Excel sheets and not going for Access.

- <u>Recommendations</u>: In order to prevent data being corrupted I will recommend buying a 500 GB mobile USB. This will allow them to back up the files, documents and database in the mobile USB and can update weekly which will be a good option of keeping them secure. Also, to keep their learning in Access, a visual access tutorial and Microsoft Access 2007 book by Lisa Friedrichsen was recommended.

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Final Consulting Report

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I. About the Organization

Organization

Myasthenia gravis (MG) is a neuromuscular disease leading to fluctuating muscle weakness and fatigability. It is an autoimmune disorder, in which weakness is caused by circulating antibodies that block acetylcholine receptors at the post-synaptic neuromuscular junction inhibiting the stimulant effect of the neurotransmitter acetylcholine.

Myasthenia Gravis Association (MGA) was created in 1955 and has a long history of serving those with myasthenia gravis. **MGA of Western Pennsylvania** organization is located on the campus of Mercy Hospital and provides a variety of services for those affected by MG. Their mission statement is:

> *"Our mission is to address the medial, social and emotional
> needs of all persons affected by Myasthenia Gravis and to
> disseminate educational information to persons with Myasthenia
> Gravis, their families, the medical community and the general
> public."*

MGA is a 501(c) 3 non-profit organization and provides a wide variety of services to patients free of charge. The organization is working for more than 50 years in United States. It is one of the worlds' largest and oldest treatment centers. The organization works in collaboration of Mercy Hospital and University of Pittsburgh Medical Centre. Apart from the medical assistance, MGA provides basic information about MG-related topics and co-ordinates with the central MGA, USA. MGA provides free brochures which are available regarding some of the basic and imperative topics. They have a very good and detailed online resource on the website which can be found at http://www.mgawpa.org/library/educationpage.html. Some of the articles have been written by the agency and the representatives of MGA, others have come from outside sources such as other M*yasthenia gravis* associations or physicians of different hospitals like Mayo's Clinic. All articles are only provided for general educational use and are meant to serve as only guidelines.

Facilities

MGA of Western Pennsylvania office in Pittsburgh is located on 1515 Locust Street, Suite 709 at Mercy Hospital. The suite has 5 rooms, one main hall and a kitchen. One of the offices is on the left side of the main hall and other offices is located opposite to Ms. Barbara's office with the room connected with aisle area from the hall to the last room of the office. Four out of five rooms has a desktop PC. They have a storage room where they house some supplies and files and a kitchen for storing the food and other eatables. The Mercy Hospital has decided to shift the MGA office from the current location to some other place at Mercy Hospital.

Programs

One of the main programs of MGA has been **Myasthenia Gravis Treatment and Advocacy Center**, in partnership with Mercy Hospital, Pittsburgh where people have travelled to the center from north as Erie County, Blair County and beyond western and southern borders of Pennsylvania. In rare cases, the patients have been even come from different countries. The program provides best medical care where neurologists who staff in Myasthenia Gravis Treatment and Advocacy Center are experts in MG and guide the patients' treatment which includes in medication, surgery, plasmapheresis, and intravenous immune globulin therapy. The center offers patient-centered care co-ordination through the Nurse.

They have a fundraising program where they contact new and current donors for the fund to support the underprivileged people suffering from *Myasthenia gravis*. One of the programs which is held this year is **14th Annual MGA All-Star Sports Memorabilia Auction** where they invite some of the sports personalities for the donation and create awareness for this disease.

Staff

They have a 2 and a half people working full time at MGA office of Western Pennsylvania.
- **Ms. Barbara Lefler**, Executive Director: The primary representative of the MGA of Western Pennsylvania in Pittsburgh and co-ordinates with the administration for the budget, public relations, and development functions. She look after the technology planning and development at MGA.

- **Ms. Ginny Everard,** Nurse Care Coordinator: The coordinator for the patient's health care, maintains the patient/donor database and assists Executive Director.
- **Ms. Donna Kalisek**: She works part time and three days a week i.e. Monday, Wednesday and Friday. She assists Ms. Ginny and Ms. Barbara in organizing the awareness and fundraising camps.

Technical Environment

Hardware/Equipments:

- 4 HP Compaq NC6000 Laptops: Intel Pentium M, 1.6 Gig RAM, Windows XP with CD/DVD R/RW, Memory 1024 MB, Cache Size (L1/L2): (64/2048) Kb.

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- Dell Photo Printer, Several HP LaserJet Printers, Scanner, FAX Machine and 4 Pen Drives are available.

- They have their own wireless Internet Connection.

- The net connection is done through the Netgear Adaptor- which is connected via USB port.

- The WAN is working with the router for the wireless internet connection in the office.

Software:

- They have a whole software case in which they have a collection of software like Norton Internet Antivirus, Netgear support and installation CDs, Quick books, XP Professional CDs from Version 2000-2005, Microsoft Office 2007 version.

- 4 Monitors with 4 CPUs having XP Platform with Microsoft Office 2007 version.

- 12 Software CDs of Norton Internet ver. 2007.

- Norton Internet version 2007 is installed in all the desktops.

- Microsoft Office 2007 version is installed in two Laptops recently.

Database and Website:

- Prior to the consulting period, the information about the patient's information and donors list are in Access and Excel spreadsheets. The records about patient's information from July 2007 till date are in Excel spreadsheets and before are in Access database. The Access database was not in use because staff members didn't know how to use them. Excel spreadsheets about the patient's information were updated by Ms. Everard and donor's list is updated by Ms. Kalisek and Ms. Lefler.

- They have a website as http://www.mgawpa.org/ and it is regularly updated. The events are posted online in apt format. The entire format of the website is being changed by the **Pittsburgh Technical Institute (PTI)**.

Technical Management

MGA has received the laptops from Highmark and the software like Microsoft XP, Microsoft Office 2007 and Norton Antivirus from Tech Soup. They have hired an IT official who comes and looks after the problems which are encountered by them. Ms. Barbara looks after storing the software and different papers regarding the key number/password, versions and quotations of the software. She communicates with different organizations for the donation and purchase of software and hardware.

The website is updated on a regular basis depending on the programs and different social and awareness programs. The website is being changed by the **Pittsburgh Technical Institute** and they have an email address domain name (@mgawpa.org) and they use it on regular basis.

The patient donor database is managed by Ms. Ginny Everard and it is updated on Excel spreadsheets regularly. The access database is not used as they have problems using them.

Technology Planning

MGA has been doing their technology planning by the help of Tech Soup. They have a good number of Software which they have bought from them. There is no proper and systematic technology planning. The major discrepancy was buying the Windows XP CD pack from year 2000 to 2006 which actually leads to only accumulation of the CDs and wastage of money.

Internal and External Communication

Internal Communication: The internal communication is done majorly through email. The mails regarding the programs and details of different social events are sent between the Board of Directors. Ms. Lefler and Ms. Everard exchange mails back and forth of the updated database of patients and donors as they have problems using the Excel Database and Access Database respectively due to different file extensions and hence are not able to open and read it.

External Communication: The external communication is done via normal mail, electronic mail and by updating the website. They update the information regarding the different Awareness Programs, Newsletters, Treatment Center, Support Groups, Educational Seminar, Hospital Visitation, Educational Materials, and Medication Assistance. The newsletters of the awareness programs are sent both via normal mail and email to the donors and the patients.

Information Management

Most of the information management at MGA is performed electronically. They have maintained the information about the patient and updates all information regarding the patients needed by the organization in the Excel sheets and have used access for the donor list and management people. The patients list has been maintained on Ms. Ginny Everard's computer and details of the donor list have been maintained by Ms. Barbara Lefler. The database contains roughly more than 1000 patient's details and past/current donor list and how much they have donated in the past. The database is also used to inform the patients and donors of different programs which are organized by them. Data is both sent back and forth and saved electronically. They manually compile e-mail addresses from the database if she wishes to send an e-mail out to a specific group of people. This can be a problem because it takes extra time to contact specific people.

Business Systems

The accounting is majorly maintained via the Excel Spreadsheets of the donor lists. They have a database which gives the information about the current/past donors list and the amount they contributed. They have separate files which are manually updated for the same. They have been sometimes loss of data from the database due to the use of the Windows Office Version 2007. The files were saved directly on the .docx file format and not in .doc file format which leads to problems in opening the files for those who uses old versions of MS Office.

II. Scope of Work

Task I: Use of Software/Hardware Resource Efficiently

MGA received donated laptops from Highmark. There are 4 HP Laptop and 1 Compaq Laptop whose configuration has been mentioned above. The Laptops are required so that the staff can work both through office and home leading to easy mobility and fast communication. The staffs required the Internet wireless to be set up on the laptops so that they could use the net and by setting up the network connection within the Laptops and Desktops will hence enhance both the internal and external communication. Also, they required the necessary software to be installed so that there is no difficulty during the work and making the laptop secure too.

Task II: The Database Problem and New Format of the Form

There is entire list of patient's information and donor information on Excel spreadsheets and Access database respectively. They have problems in retrieving the data and updating the data manually in the Excel spreadsheets/Access Database. There has been problem among the staff especially contacting the past/current donors as the data is not systematically arranged leading to external communication problems.

Ms Lefler and I discussed the issues which they had on the donor's and patient's database. We analyzed the situation and then we decided to go for Access. It was seen that all the needs can be easily cater with the Access Ver. 2007. We came up with the new format of the form/Newsletter.

III. Outcomes and Recommendations

Task I: Use of Software/Hardware Resource Efficiently

a. **Outcome and Analysis:**

i) <u>Outcomes:</u> The installation of the operating system, necessary software like MS Office and wireless internet facility was done and was shown in a HP and Compaq Laptop. The installation of the OS, software and connectivity of the internet was later done by the staff member of MGA. They are able to connect the internet on different laptops and install the software in other desktops/laptops which are available at MGA. This has made them sustainable for the future. This has increased their knowledge about different Operating Systems like Windows XP, Vista, Mac and the software which are compatible to different Operating Systems. They got to know about the updates, why they are important and how to do updates of the current software and operating system, which they are using. Also, they have become more aware of the different file extensions and difference between them. For example, they know the difference between the .doc (MS Office 2006) and .docx extension (MS Office 2007). There were cases where they had problems in communicating because of the difference in file extensions and software installed in the desktops. It has increased enhanced communication between the staff members and the data files with proper format are send which was a problem earlier.

ii) <u>Noticeable Changes:</u> It has increased the skill set and knowledge among the staff members. They are now doing the updates of the OS and other software themselves. They were cases when no one used to do the updates on their desktops which actually had lead to getting their desktops infected. It has improved the computing resource at MGA and it has enhanced the internal and external communication between the staff members. They have become more organized. The laptops were used during the event **14th Annual MGA All-Star Sports Memorabilia Auction**. Due to the knowledge, about the formats of the file, they are now able to send the files of correct format which has decreased the data loss and delays which was happening earlier.

iii) <u>Increased Capacity:</u> They got to know more about the modems, network adaptors when we were working on the setting up of the Internet. Hence, it gave a vision to work on better technology planning based on the resources. The knowledge of different formats has improved the documentation work and now they are able to send the files of correct format.

iv) <u>Sustainability:</u> This is sustainable since they had the opportunity to perform them. They did the work and achieved the results, for example they were asked to install operating system and software on their laptops, showed me how to attach and remove the pen drive, showed me as how transfer files from one folder to another. They learn about the updates and how to do the updating of the current software and operating system which they are using. There are few risks involved in the case of sustainability. Since, there are only 3 staff members at MGA so in case they leave, then there will be again the cases of delay in the work and it will be hard for them to properly utilize the software and hardware available at MGA.

v) <u>New Vision:</u> The Executive Director, Ms Barbara Lefler has become more aware of the different hardware as the extra cost for buying the wireless cards was saved and the adaptors are used more efficiently. They got to know more about the equipments which can be used for setting up the internet i.e. wireless cards and wireless adaptors and there market values. It has increased the dependability on the technology since they have to work on the electronic records. As the organization, is growing with number of donors and patients, they will be dependent on technology so knowledge about the technology and its application is an important aspect. Hence, it will improve the technology planning in the organization.

b. <u>Recommendations:</u>

1. <u>Wireless Adaptors:</u>

   a. There were cases in all the current HP Laptops which were donated by Highmark do not have the wireless cards working. Hence, after doing the market analysis, I suggest them to go for the wireless adaptors which were less expensive than the wireless cards/ internal modems and they are also portable enough.

   b. The adaptors can easily be available through Amazon. Also, they can contact any of the hardware shops in Pittsburgh like Target and Circuit City.

      These are pretty inexpensive and easily available and I don't think that there will be any problem. There can be cases where they have to install the software first for accessing the internet through the wireless adaptors which has been showed to them. So, they have to follow the instructions which will be offered in the manual.

2. <u>Updating the Laptops/Desktops with Windows Updates and contacting Techsoup for new version of the Software such as Norton Antivirus:</u>

   a. They have to keep their OS/software updated with the update, whenever they get the message for the update. There were cases when the staff didn't update the Norton Antivirus and that lead to some serious problems and getting their computers infected by the virus. They are already keeping in contact with Techsoup for buying some of the software and they should also go for the Newsletter issued by them. It will hence, keep them updated regarding some new software too.

   b. They should do the update as soon as they get the message or any warning signs for the update of the software or operating systems are flashed. They should contact Techsoup for the new versions or license of the software. This will keep their computer safe and steady.

      Techsoup (www.techsoup.com) is an organization which provides help to the Non Profit Organization by selling the license or new version of the software at a discounted price and provides free newsletter of new software, technology, case studies and reviews of NGO using the software or any new technology.

Task II: The Database Problem and New Format of the Form

a. Outcome and Analysis:

i) Outcomes: I gave them a tutorial on Microsoft Access like building databases by using of the available templates and without using the templates, removing fields form the existing database, adding fields to the existing database etc. They are now able to open the donors and patients records through Microsoft Access and are updating it from the same. They are now able to retrieve data from the previous Access database which they were not using. Now, the insertion of new columns and rows in the database seem easier to implement on Access database. This has also reduced the multiple copies of the documents.

They also have now a standard format of the form which is now pretty easy to fill without any editing of the format of the form. I have displayed them how to make the format on Excel which was later shown by the staff people in case they want to add or delete any of the fields in the form. An entire visual-manual of shortcuts of using Access ver. 2007 was provided to them.

ii) Noticeable Changes: They had problems in working with the Access database and now they are feeling comfortable with the Access. There is a proper format to the database. The retrieving of the data which was a problem is solved. The complexity of using Access has reduced by providing them manuals. Since, nobody at MGA knew to work on Access so they were not using the database which was saved in Access. They are now able to make changes in the current donor and patient databases and previously existing databases which no one was using. Hence, this has solved many of their problems especially getting the data of previous years as they are now able to make the changes in the Access Database. They are now able to import the Excel files via Access database and are making the changes on the files. They are now using the Access database for all the updating of the file as Access has much more features than Excel.

iii) Increased Capacity: They now know about the different features of Access and how to make retrieve the data through the same. It has decreased redundancy and improved the structure of the database and doing the updates with the same. They are able to make the changes and are updating the form with new fields. They are now able to use in case of new donors too.

iv) Sustainability: Sustainability will be an issue here as if they have some problems using the Access Database in the future then they can come back to the same old method of creating database through Excel sheets and not going for Access.

v) New Vision: They are now aware of the Access and while we were making the decision of which database to go for they got to know about some of the database available in the market and there details. This has made them aware of new software and even about the different versions of the software.

b. Recommendations:

1. 500 GB mobile USB:

   a. There were cases where they had their documents getting corrupted. Hence, having back up of the files, documents and database in the mobile USB and updating weekly will be a good option of keeping them secure. It can also act as

an easy resource of transferring the documents and can also act as a shared folder among the staffs at MGA. The USB measures 4.4 x 1.6 x 7.6 inches (WxHxD) and around 1 pound so it can be stored easily in the storage room at MGA.

b. The product name and type was provided. The Amazon link was also provided so that they are able to buy in future if they are considering the same. Some other models and the comparisons of the models were provided through the Amazon website. The Amazon link for the 500 GB mobile USB website is given below. http://www.amazon.com/s/ref=nb_ss_e?url=search-alias%3Delectronics&field-keywords=500+gb+usb+hard+disk&x=0&y=0

Since, it is inexpensive and easily available and I don't think that there will be any problem. Also, the installing and removing of small USB with 2.0 GB space was shown to them, hence it won't be a problem to use them properly.

2. "Visual" Access tutorial CD and Microsoft Access 2007 book by Lisa Friedrichsen:

a. The tutorial is visual and can provide the ongoing learning process for them. It will also tend to solve their problems in case they have in future. The book is cheap and also gives a visual way of learning. Also, many of their problems can be solved via Microsoft Access 2007, hence I think it will be important if they go for the same

b. The Amazon link for the book was provided so that they are able to buy in future if they are considering the same. The link for the website is as follows: http://www.amazon.com/s?ie=UTF8&search-type=ss&index=books&field-author=Lisa%20Friedrichsen&page=1

The book is inexpensive and easily available. There should be weekly meeting among the staffs and should discuss on different problems which they are facing and should solve them together.

1. Recommendations: Google Docs:

a. The Google docs can easily used for sharing of the files among the staff at MGA. Also, Google Docs can be used for the backup of files with private access only.

b. They should make sure that they should make the files as private and should send the invitation in case of sharing the files. It can be accessed, edited and shared by anyone from anywhere. A small visual description of the Google docs on the following website - http://www.youtube.com/watch?v=eRqUE6IHTEA. The tour regarding the Google docs can be viewed through the following website-http://www.google.com/google-d-s/intl/en/tour1.html

c. They should have a Google Account for the Google docs which can be obtained by signing up for the account. The Google Docs can be accessed by website-www.google.com/docs.

2. Recommendations: Google Blog:

a. Blogger is a nice way of informing people about the disease and the help provided by the organization. Hence, it can be used for posting of the newsletters and making people knowledgeable about the same.

b. Annual calendar of events and important summary or information of events can be published via blog. The blog will create awareness among the community and patients. The events and programs can be easily highlighted and hence can be used for creating publicity too.

c. They should have a Google account for the Google blog which can be obtained by signing up for the account. The blog can me updated and published via https://www.blogger.com/start.

3. **Recommendations: Website Design via Joomla:**

a. Suppose in future, the PTI does not provide any technical help then I think they should go for the Joomla. It is a Content Management System (CMS) that will help you build websites and other powerful online applications. Joomla is an open source solution that is freely available to everybody. But, since the PTI is making the website, they insisted on doing on Dreamweaver.

b. Since, the staffs are unaware of Dreamweaver and the tutorial for the same is provided on the web, hence, it will be better way for updating the website rather than not doing it.

c. They have to look for the Joomla which can be accessed by website http://www.joomla.org/ and have to download the same. The online demo of using Joomla is given on the website (http://demo.joomla.org/) and hence can be easily accessed the staff.

d. It will cater the needs such as updating the pages of each link and uploading the documents easily and at the same time this is not as complex as Dreamweaver.

About the Consultant

Ayush Raman is a first year Graduate Student in Computational Biology at Carnegie Mellon University. He will be completing his degree in Dec. 2008.