

Questions to an MG Association Representative (interview Veronica with representative of Euromyasthenia)

Please give us a brief description of your Association (history, number of members etc).

The association's name is Czech myasthenic association, MYGRA-CZ. This association connects patients diagnosed with MG as well as their family members and friends and healthcare professionals. Currently, the number of the members is raising everyday and it is so far reaching a hundred. Founded in June, 2009 when around 70 patients and their friends have met to elect the Executive and agree on domestic rules.

In what ways your Association helps its members?

By publishing the magazine, we try to spread the latest information on myasthenia gravis, pharmacotherapy, diagnosis and treatment not only between the association's members, but also between healthcare professionals. We advice patients online and let them share their life-stories.

What are the activities you have planned for the near future?

The association is currently working on couple of new projects, one of these is focused on implementing the diagnostic strategies into the GPs' guidelines, spreading more information among them and developing communication between physicians and pharmacists. On 14th November, 2009 there will be the country meeting of the members where they will gather to discuss the latest issues, socialize and learn.

Are you satisfied with the amount of information about MG available to your members?

Our members get all the possible information via our two major contacts that work closely together. Dr. Jiri Pitha from myasthenic clinic in Prague spreads the information about latest trends in diagnosis, clinical researches, surgery etc. As the pharmacist and pharmacy PhD student, I am passing all the important information on pharmacotherapy, drug effectiveness and nutrition. There is plenty of information out there when one speaks English, so we translate a lot because not so many patients speak English.

Do you believe there is enough research performed on MG?

Well this question is hard to answer. Since MG is very rare disease, it is certain why this disease is not that common interest of research groups. Of course there could be more research, clinical studies etc more performed.

Do you think Doctors in your country/region are well informed about MG? Is your Association doing anything to help them?

One of main reasons of founding the association on MG in the Czech Republic were plenty of cases when patients were misdiagnosed for even many years. As shortly practicing pharmacist working in community pharmacy, I have seen in six months three patients who were not treated well. As my intention was to help them fast, I contacted Dr. Pitha, who has the longest

experience in treating myasthenia and he had seen patients, changed the pharmacotherapy and these patients are now stable or in remission. However, this is not the solution. This is not how things should be running. So what we are trying to achieve is creating the network of physicians and pharmacists, who would be communicating together for patients` good. The other issue is the healthcare system in the Czech Republic that needs restoration and patient`s cards or database of patients would make our work more efficient. So far we are distributing MG patients` cards. The content is the necessary information about the patient to ease the steps for the doctor when patient is in need.

What are your expectations from the Government?

We hope they will implement the treatment schemes for the GPs regarding myasthenia gravis, e.g. the “step-by-step plan” how to uncover or exclude the disease in the patient.

Have you seen any improvements on the treatment of MG over the years?

Of course! Having the discussion with Prof. Smat when having thymectomy myself, we talked about how it used to be treated without the thymectomy. I think with modern technology the science is now running so fast! Also thanks to the internet we can search for plenty of solutions of our problems with just one click of the hand and have the information right on spot when we need it. This is a fantastic improvement which would not be possible 50 years ago!

Do you keep your members up to date with the research accomplishments on MG?

Yes we do. We put the information we find on EuroMyasthenia website in “news” section in our magazine. Dr. Pitha also frequently refreshes myastheniagravis.cz web pages and he puts the new information whenever it comes online for everyone to know as soon as possible. So yes, information is flowing to the Czech myasthenic patients and families as well as to professionals.

What is your opinion about the “EuroMyasthenia” project?

It is very sad this project is about to end. We find all about this project very valuable and helpful for everyone. Thanks to EuroMyasthenia, more professionals get in the action and the impact of the group then of the individual is much stronger. The essential information has been spread among the professionals and now we can build up on these. It is sad that money issue is the limitation. However, as one of Czech proverbs say: there are no cookies with no hard work done! So on behalf of Czech patients and healthcare professionals, I would like to thank to all included in EuroMyasthenia project for what they have done. Because it makes difference!