NEWSLETTER N°12, November 2009

EuroMyasthenia

Summary

Dear Colleagues and Friends,
I am sure that you will enjoy this newsletter with a lot of information and interesting interviews giving viewpoints from both a specialist and a patient. I am aware of the concern felt by Veronika Sumpichova and other members of patients' associations with regard to the continuity of the Euromyasthenia network. During our network's final meeting, to be held on November 30 prior to the International Conference on Myasthenia, we shall not only report on the activities of the network during the four past years, but, most importantly, we shall discuss its future. I am convinced that the role of patient's associations is very important, and I invite them to take part in the future discussions and actions. For those of you who would like to participate to the network's meeting, please contact Nicole (nicole.kerlero-de-rosbo@u-psud.fr). I would also like to take this opportunity to thank again and again Nicole for her wonderful job and her efficiency and involvement in the activities of the Euromyasthenia Network and particularly, in the organization of the International Conference.

As you know, the International Conference on Myasthenia Gravis will be held in a few days (December 1-2), right in the heart of Paris. Researchers, medical doctors, and members of patients' associations, from more than 30 countries will attend. A video of the whole conference will be available on the www.euromyasthenia.org website a few days after the meeting.

Finally, I would like to inform you that the 2009 campaign of donation for the AFM, the French association against Myopathies, is now open through the Telethon, a 30-hour long broadcast, that aims at collecting funds for scientific and clinical research as well as public health aspects. The AFM is briefly described in this Newsletter. Based on competitive calls, this association supports research on all MG topics, regardless of the nationality of the research teams. To help AFM help you, you can make an online donation (http://donate.telethon.fr/) and spread this message to your relatives.

We look forward to seeing you soon in Paris
Sonia Berrih-Aknin, Coordinator

To get info on the project please contact: Nicole Kerlero de Rosbo (nicole.kerlero-de-rosbo@u-psud.fr)

Presentation of the Euromyasthenia Network Partners

The French Muscular Dystrophy Association (AFM) and The Myasthenia Gravis Group (www.afm-france.org/myasthenie@afm.genethon.fr)

History of the Association: Created in 1958 by a group of patients and their families and recognized as a non-profit association, AFM (the French Muscular Dystrophy Association) has one clear objective: to win the fight against neuromuscular diseases. It has set itself two missions: curing neuromuscular diseases and reducing the serious disabilities they cause.

The members of the board. They are either parents of patients or patients themselves. Laurence TIENNOT HERMENT (President of AFM), Marguerite FRICONNEAU (responsible for the MG group), Annie ARCHER, Sylviane RENEVEY and Colette VANDAMME (members of the MG group).

Activities and goals: The Association is financially supported by the French Telethon. During 30 hours of a show on the public TV channel, Telethon organises 20000 local events in the whole of France, 5 million people are mobilized during two days, 200000 volunteers organize local events, more than 1 million of donors and 80 national partners, for the longest TV show in the world.

AFM finances:

1) More than 350 fundamental and clinical research programs per year: independent groups and public research laboratories, equipment
2) 130 specific research projects for rare diseases (2005-2008)
3) 34 clinical trials in 2008 for 30 different diseases
4) 3 "research centres " (*Genethon*, a gene therapy laboratory, *Institute of Myology*, a centre for muscle expertise, unique in Europe, *I-Stem*, a research institute for stem cells).

The MG group of AFM. From left: Annie Archer,Colette Vandamme and Marguerite Friconneau

While waiting for a cure, AFM fights and acts to help the patients to confront the evolution of the disease: appropriate treatment, correct and precise diagnosis, development of innovative technical aids, defence of patient rights, citizenship matters. Today, patients' quality of life has improved and, for many, life expectancy has increased considerably.

The Myasthenia gravis patient group is one of the groups created by AFM and is taking a very active part in the global work. Several patients have already become experts in their disease and often help the MG group in supporting new patients and their families. The group was initiated in 1985, after the American model of the MGFA; the mother of a young teenage patient saw the improvement of the quality of life of her child due to information and experience sharing with other patients and families, and therefore decided to start the group in order to promote this sharing of information.

More than 1400 MG patients are known by AFM. The MG group is ruled by a team of 3 persons under the direction of a person in charge. This team is in close cooperation with the medical, social and scientific services of AFM, as well as with the other patient groups. The role of the group is to listen and to answer the questions of patients in various fields such as the way to deal with everyday life, with work, how to take the medicines properly and why one has to take them.

Presentation of the Euromyasthenia Network Partners - continued

Neuromuscular Research Group, Maastricht University, Faculty of Health Medicine and Life Sciences, Maastricht University Medical Center, Maastricht, The Netherlands

(www.unimaas.nl/mhens)

Head of the MG team: Prof. Marc De Baets MD PhD, Professor of Neuroimmunology, Head Division Neuroscience in The School for Mental Health and Neuroscience

Members of the clinical group: PI: Dr Catharina Faber **PhD:** Dr.Mayienne Bakker, Dr.Mieke Hermans, Dr.Els Vanhoutte, Dr.Brigitte Brouwer, Dr. Ingemar Merkies MD PhD (left photograph).

Members of the research group: PI: Dr. Mario Losen, PhD, assistant professor, Dr. Pilar Martinez, PhD, assistant professor, Dr. Peter Molenaar, PhD, senior lecturer **PhD:** Dr. Marko Phernambucq, Dr. Kathleen Vrolix, Dr. Alejandro Gomez, Dr. Chiara Mencarelli, Dr. Joost van den Broek, Dr. Caroline Hammels, Dr Gerard Bode **Other:** Jorike Endert, technician, Eline van der Esch, technician, Ralf Schneider, technician (right photograph).

MG Team: At the outpatient department of the Maastricht University Hospital MG patients visits are planned once a week. We mainly operate as a secondary and tertiary referral center for patients on immunosuppressive treatment and Da Vinci Robot thymectomy. A nurse is present at all visits and is also available via telephone for specific questions. The MG team is part of the neuromuscular group, which is especially involved in patient care and research on myotonic dystrophy, small fiber neuropathy and peripheral neuropathies.

Da Vinci Robot thymectomy: Via 3 small incisions a 3D camera and 2 robotic arms are introduced in the chest of the MG patient and thymus or thymoma is removed into a small basket. After a 2 to 3 day hospital stay the patient can go home and resume his or her normal activities within one week. The operation is performed by Prof J Maessen and Dr L Van Garse. They have already performed 70 thymectomies for follicular hyperplasia or thymoma in MG patients with no complications and a very short in hospital stay.

MG research: *New targets for the antibody response in MG*. We are investigating the pathogenic mechanisms of anti MuSK antibodies. We are also investigating other antibody targets at the neuromuscular junction using B cell immortalization.
Gene therapy of experimental autoimmune receptor diseases. We found that the molecular composition of the postsynaptic membrane influences the effect of the antibodies. By using gene therapy to change the molecular composition, we can protect muscles against the antibody attack. Currently, we investigate the therapeutic potential of this gene therapy in an experimental autoimmune MG model.
Specific immunotherapy by recombinant human antibodies. We and others have shown that antigen-binding antibody fragments (fragments that are able to bind to a target, but cannot trigger an immune response); directed against the AChR, block the binding of pathogenic anti-AChR antibodies. The drawbacks of antibody fragments are quick serum clearance and, in many cases, immunogenicity, because of their non-human origin. We are optimizing a human anti-AChR antibody by recombinant DNA technology to create a stable therapeutic agent. This technology will also be applicable in other neuroinflammatory diseases.

Other involvement in the MG community: We have a good co-operation with the Dutch association for Muscle Disorders (VSN) and the two other centres in the Netherlands specialist in MG treatment. Dr Jan Verschuuren (Leiden) and Prof Dr Jan Kuks (Groningen). We are also a member of the Dutch-Belgian neuromuscular study club.

MG research networks: We are a partner in the EuroMyasthenia Network. Recently we established a joint Serbian Dutch MG project with Prof S Apostolski and Dr. Dragana Lavrnic (Beograd, Serbia) on anti MuSK antibody positive MG patients and Robot Thymectomy.

Relevant recent publications:

- Van der Neut Kolfschoten, M., Schuurman, J., Losen, M., Bleeker, W. K., Martinez-Martinez, P., Vermeulen, E., den Bleker, T. H., Wiegman, L., Vink, T., Aarden, L. A., De Baets, M. H., van de Winkel, J. G., Aalberse, R. C., Parren, P. W., 2007. Anti-inflammatory activity of human IgG4 antibodies by dynamic Fab arm exchange. Science. 317, 1554-7
- Bakkers, M, Merkies, IS, Lauria, G, Devigili, G, Penza, P, Lombardi, R, Hermans, MC, vanNes, SI, De Baets, MH, Faber, C G, Intra-epidermal nerve fiber density normative values and its application in sarcoidosis. Neurology 2009;**73**:1142-1148.
- Faber, C. G., Molenaar, P. C., Vles, J. S., Bonifati, D. M., Verschuuren, J. J., van Doorn, P. A., Kuks, J. B., Wokke, J. H., Beeson, D., De Baets, M., AChR deficiency due to epsilon-subunit mutations: two common mutations in the Netherlands. J Neurol. 2009; in press
- Martínez-Martínez P, Phernambucq M, Steinbusch L, Schaeffer L, Berrih-Aknin S, Duimel H, Frederik P, Molenaar P, De Baets MH, Losen M. Silencing rapsyn in vivo decreases acetylcholine receptors and augments sodium channels and secondary postsynaptic membrane folding. Neurobiol Dis. 2009 35:14-23
- ter Beek WP, Martínez-Martínez P, Losen M, de Baets MH, Wintzen AR, Verschuuren JJ, Niks EH, van Duinen SG, Vincent A, Molenaar PC. The effect of plasma from muscle-specific tyrosine kinase myasthenia patients on regenerating endplates. Am J Pathol. 2009 Oct;175(4):1536-44

Interviews with specialists and patients

Starting from this issue, we will be presenting two interviews from persons involved with Myasthenia Gravis: Clinicians, Researchers, Patients and representatives of Patient Associations. In this issue, we are pleased to host Professor Nick Willcox of the UK and Veronika Sumpichova of the Czech Republic.

Professor Nick Willcox

Professor Willcox has been a major contributor to MG research. He has been investigating the immunogenetics and cellular immunology of autoimmune MG patients since 1979 with his colleagues at the Royal Free Hospital and subsequently at Oxford University, contributing in several seminal findings on MG. Prior to this, he qualified as a doctor in 1968 and spent several years in basic immunology research. Despite his recent retirement (end of 2008), he keeps an avid interest in MG developments and is always available to help anyone who needs his vast experience.

Q. ***For how long did you perform research on MG?***
NW: I joined our multi-disciplinary group in 1979, ~3 years after John Newsom-Davis and Angela Vincent started to assemble it in London, where we worked for 10-12 years, before moving here to Oxford in 1988.

Q. ***Over those years, have you seen any progress/ improvement in the understanding/ treatment of the disease? Any examples?***
NW: The autoimmune basis of MG was first shown in the 1970s, and the main background facts established by ~1980. Since then, there has been a lot of incremental progress in basic understanding of:- the autoantibodies, their targets, their diversity and their pathogenicity; the cells producing them; the T cells that control these responses; genetic risk factors; possible scenarios of autoimmunisation in the hyperplastic and neoplastic thymus.
From the patients' point of view:- use of more aggressive immuno-suppression (often including steroid-sparing drugs) is now on the increase at the expense of symptomatic treatment with anti-cholinesterases; thanks to better awareness/ diagnosis, many more patients – whether with autoimmune or inherited myasthenias – are now being managed better/ earlier by neurologists with more relevant expertise.

Q. ***What were your lab's main discoveries related to MG?***
NW: Thanks to many excellent colleagues, we have:- (**a**) implicated thymic epithelial and myoid cells – and complement attack on them – in initiating/ diversifying anti-AChR autoantibody responses; (**b**) identified novel autoantibodies against type I IFNs, IL-12, and now Th17 cytokines, in patients with late-onset and thymoma-associated MG; (**c**) helped to locate one MG-susceptibility locus closer to the HLA-class I than its class III region; (**d**) cloned helper T cells truly specific for naturally processed AChR epitopes, one of them potentially dominant, and most of them presented by such 'minority' class II molecules as HLA-DR52a (DRB3*-0101) rather than DR3 (DRB1*0301); (**e**) shown that they are susceptible to selective targeting *in vivo*; (**f**) identified combinations of cortical and medullary markers on the neoplastic cells in thymomas, and proposed their common ancestry, which is now widely accepted; (**g**) collected a bank of plasma, DNA and cell samples (still available) from many patients.

Q. ***Were you satisfied with the support (financial or other) MG research is getting in your country?***
NW: Thanks to the high profile of MG – which John and Angela did so much to maintain – we were very lucky with funding until ~1995, though it became **much harder** after John retired. We have always been blessed with extremely loyal support from both the patients and the neurologists who referred so many of them to John; also with the wealth of clinical detail that he recorded so systematically on them, and the popularity of thymectomy (and the larger samples allowed) then.

Q. ***Where do you see MG research/ treatment/ understanding 10 years from now?***
NW: Ongoing genome-wide association studies should identify novel pathogenetic pathways/ targets for therapies in MG; multi-centre trials and/ or animal models should help to establish the relative merits of various immuno-suppressants (incl methotrexate and mycophenolate) in different MG subgroups, and/ or of the several neuromuscular transmission-enhancers in the various congenital myasthenias; complement inhibitors may prove useful in acute/ intractable MG; serological screening may identify patients with extra autoantibodies, eg against Aquaporin 4, that might give early warning of associated syndromes like neuromyelitis optica or even limbic encephalitis, and thus allow earlier treatment before neurons are killed. As always, however, the unexpected will probably prove the most significant.

Interviews - continued

Q. (a) ***How do you think we can improve research on MG?***
NW: I am still optimistic about:- more selective immunotherapies in MG; learning how to predict which patients need immuno-suppressive drugs, and who will respond well or adversely to which of them; clues to aetiology and therapy emerging from gene-screening; defining key loci in the HLA region.
(b) ***Where do you expect the gaps to be greatest?***
I long for more progress on:- the aetiology of late-onset MG; how steroids and IvIg act in MG; how to stop long-lived plasma cells from making their autoantibodies; single-cell cloning of panels of Ig heavy/ light chain pairs in their natural combinations from panels of patients so as to define AChR epitopes recognised by low affinity, pathogenic and possibly even protective antibodies; environmental risk factors; the remarkably higher prevalence of very early-onset MG in the Far East; a trial on the possible steroid-sparing effects of thymectomy in early-onset patients, including those with low affinity antibodies.

Q. ***To what extent did you interact with MG patients and/or Doctors?***
NW: A great deal, especially in the last ~20 years, when I started by giving talks at local, regional and then national meetings of our Myasthenia Gravis (Patients') Association (MGA). I then became one of its Trustees/ editors of its publications. I now know many of the MG specialists in the UK who have done PhDs in our group.

Q. ***Did this interaction affect your research plans?***
NW: It has affected my research dreams greatly, but their fulfilment much less, alas (see **6b** above). I particularly wish I could see where to make a start in late-onset MG.

Q. ***What is your opinion about the "EuroMyasthenia" network?***
NW: It should play an important part in levelling-up standards of diagnosis and management both within the UK and across Europe. It has greatly helped our own group to collect serum and thymus samples from uncommon MG subgroups (eg with anti-MuSK antibodies), and DNAs for gene-screening.

Q. ***As an experienced researcher, what would you say to MG patients about the future of their disease?***
NW: "The future seems bright (as outlined above), but don't expect instant break-throughs. **You** can play **your** part in the progress we all hope to make, eg by noticing unusual connections, by kindly answering questionnaires or by providing samples. Above all, keep fighting your MG and don't let it take over your life."

Q. ***What have you most enjoyed in your work?***
NW: The dual challenges of working on humans (where, like astronomers, we can only watch things happening) and of explaining our findings to non-specialist patients; having my limited abilities stretched beyond capacity; the excitement of the unexpected (eg, finding anti-cytokine autoantibodies in 100% of patients with *AIRE* mutations); above all, the **camaraderie** it has brought – in what other field could one collect such a delightful bank of friends around the world??

Veronika Sumpichova

Veronika was born in 1981, studied at the Charles University, Faculty of Pharmacy 2003-2008 (Master's degree), and is currently studying towards a Ph.D. at the same faculty and working as community pharmacist. She is a founding member of the Czech MG Association (MYGRA-CZ, www.myastheniagravis.cz). She is an MG patient herself.

Q. Can you please give us a brief description of your Association?
VS: 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 has so far reached one hundred. It was founded in June, 2009 when around 70 patients and friends met to elect the Executive Board and agree on domestic rules.

Interviews - continued

Q. In what ways your Association helps its members?

VS: 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.

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

VS: The association is currently working on a few 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 November 14, 2009 we had a national meeting of the members where they gathered to discuss the latest issues, socialize and learn.

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

VS: Our members get all the possible information via our two major contacts that work closely together. Dr. Jiri Pitha from the myasthenic clinic in Prague spreads the information about latest trends in diagnosis, clinical research, surgery etc. As a pharmacist and a 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.

Q. Do you believe there is enough research performed on MG?

VS: Well this question is hard to answer. Since MG is a rare disease, it is clear why this disease is not of so much common interest by research groups. Of course there could be more research, clinical studies, etc performed.

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

VS: One of the main reasons for founding the association of MG patients in the Czech Republic was that there were plenty of cases when patients were misdiagnosed for many years. As a new practicing pharmacist working in a community pharmacy, I saw, within a period of only six months, three patients who did not receive appropriate treatment. As my intention was to help them, I contacted Dr. Pitha, who has very long experience in treating myasthenia. He saw the 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 a network of physicians and pharmacists, who would be communicating together for the patients' benefit. The other issue is the healthcare system in the Czech Republic that needs updating and patient's cards or database of patients would make our work more efficient. So far we are distributing MG patients' cards. Their content is the necessary information about the patient to ease the steps for the doctor when the patient is in need.

Q. What are your expectations from the Government?

VS: We hope they will implement the diagnosis and treatment schemes for the GPs regarding MG, e.g. the "step-by-step plan" how to diagnose or exclude the disease in the patient.

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

VS: Of course! While discussing with Prof. Smat when I underwent thymectomy myself, we talked about how MG 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 to 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 have been possible 50 years ago!

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

VS: Yes we do. We put the information we find on EuroMyasthenia website in the "news" section of our magazine. Dr. Pitha also frequently updates the myastheniagravis.cz web pages and he includes new information 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.

Q. What is your opinion about the "EuroMyasthenia" project?

VS: It is very sad that 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 a Czech proverb says: "there are no cookies with no hard work done"! So on behalf of Czech patients and healthcare professionals, I would like to thank all participants in the EuroMyasthenia project for what they have done. Because it does make a difference!

For Patients and Doctors

Lifestyle and home remedies for MG patients

(by: the Mayo Clinic Staff; http://www.mayoclinic.com/health/myasthenia-gravis/DS00375)

Supplementing your medical care with the following approaches may help you make the most of your energy and cope with the symptoms of myasthenia gravis:

Adjust your eating routine. Try to eat when you have good muscle strength. Take your time eating and rest between bites. More frequent, smaller meals may be easier to handle. Also, try soft foods and avoid sticky foods that require lots of chewing.

Use safety precautions at home. Install grab bars or railings in places where you may need support, such as next to the bathtub. Keep the floors and halls in your house clear of clutter, cords and loose rugs. Outside your home, keep the steps, sidewalk and path to your car clear.

Use electric appliances and power tools. Save your energy in the bathroom, in the kitchen or at the workbench by using electric appliances, such as toothbrushes, can openers and screwdrivers.

Wear an eye patch. If you have double vision, using an eye patch can help relieve this problem. Wear the patch while you read or watch television. To avoid eyestrain, periodically switch the patch from one eye to the other.

Plan. If you have a chore to do around the house, shopping to do or an errand to run, plan the activity to coincide with the time at which your medication provides your peak energy level. If you are working on a project at home, gather everything you need for the job at one time, to eliminate extra trips that may drain your energy.

Ask for help. Depending on your energy level, you may not be able to do everything you have planned around the house or run every errand that you need to. Ask family members and friends to lend a hand.

Can taking showers make you ill?

Following similar earlier studies, a new report has arisen from US scientists that states that showering may be bad for your health. They have shown that dirty shower heads can deliver a face full of harmful bacteria.

Tests revealed nearly a third of shower devices harbour significant levels of a bug that causes lung disease. Levels of *Mycobacterium avium* were 100 times higher than those found in typical household water supplies. *M. avium* forms a biofilm that clings to the inside of the shower head, reports the National Academy of Sciences (Feazel *et al*, 2009, PNAS, Vol106, N38, pp16393-99).

The study authors say their findings might explain why there have been more cases of these lung infections in recent years, linked with people tending to take more showers and fewer baths. Water spurting from shower heads can distribute bacteria-filled droplets that suspend themselves in the air and can easily be inhaled into the deepest parts of the lungs.

While it is rarely a problem for most healthy people, those with weakened immune systems, like the elderly, pregnant women or those who are fighting off other diseases, can be susceptible to infection. They may develop lung infection with *M. avium* and experience symptoms including tiredness, a persistent, dry cough, shortness of breath and weakness, and generally feel unwell.

When the researchers swabbed and tested 50 shower heads from nine cities in seven different states in the US, including New York City and Denver, they found 30% of the devices posed a potential risk. Since plastic shower heads appear to "load up" with more bacteria-rich biofilms, metal shower heads may be a good alternative.

Safety of influenza vaccination in patients with MG

Because the safety of influenza vaccination in patients with MG has not been established, some clinicians discourage vaccination for these patients. However, a recent study (Zinman *et al,* 2009, Muscle Nerve, Vol. 40(6), pp947-951) has shown that vaccination of patients with MG against influenza was not found to be associated with exacerbations of the disease. Their findings do not support the practice of withholding influenza vaccination in patients with MG.

EuroMyasthenia Questionnaire analysis (part I)

The EuroMyasthenia network was created by several European countries with the aim of helping to establish the necessary background for developing a sustainable coordination in the area of health information, collection of epidemiological data, exchange of data, and information about MG within and between Member States. In this context, among several other activities, two questionnaires were created and distributed to MG patients and to neurologists treating MG patients.

The main aims of these questionnaires were two. Firstly, to determine the degree of MG knowledge of the patients and the clinicians and through their responses improve communication between them and the researchers in order to improve overall awareness, understanding and treatment of the disease. Secondly, to identify their expectations from a network like EuroMyasthenia and thus make that network better.

During the first phase, more than 500 questionnaires were delivered to patients and almost 100 to neurologists from nine countries. Of these, 497 questionnaires were returned completed by the patients and 43 from the doctors. Below we summarise the results from the questionnaires received by patients and in the next issue of the Newsletter we will present those from the Doctors. This effort was coordinated by the Athens partner and received the invaluable contribution of several EuroMyasthenia partners.

It has to be stated that the results are indicative of the people who answered the questions and may not reflect the opinions of the entirety of the MG patients.

Patients' questionnaires:

The first observation that can be made is that the number of patients that returned a completed questionnaire varies greatly among countries and that it is not proportional to the population of each country. This may have to do with the unit that delivered and collected the questionnaires; doctors to their patients and local MG Associations to their members: how well organized they may be and how much they can motivate, encourage and inform the patients to participate in such activities.

Secondly, there is a prevalence of female patients, among those who responded, in all countries. Specifically, in Romania, France and Croatia more than 75% of patients that responded are females. This can be a combination of the fact that there is a prevalence of female patients in MG and that women are more sensitive towards social issues and therefore were more willing to complete the questionnaires. The mean age of the patients in all countries is between 40 and 60.

Table 1. Demographic aspects of the patients and effect of MG on daily life.

Country	Number of patients	Sex (%)		Age	Has MG affected your work or other daily activities? (%)			
		Male	Female		No	Little	Moderately	A lot
Greece	48	27	73	41	17	23	27	33
Romania	62	15	85	40	2	8	19	68
Sweden	103	37	63	57	13	28	25	34
Cyprus	9	33	67	48	0	22	11	67
Croatia	129	22	78	45	6	43	43	9
Scotland	35	46	54	58	6	9	31	54
Oxford	50	38	62	52	18	18	34	30
Holland	14	43	57	47	14	21	0	64
France	47	21	79	57	4	11	23	60
Average	**(Total 497)**	**31**	**69**	**50**	**9**	**20**	**24**	**46**

EuroMyasthenia Questionnaire analysis (part I, continued)

The way by which MG is diagnosed varies from country to country. Some countries almost exclusively use antibody based assays and no electromyograph (EMG) (Greece, Croatia), whereas others, base their diagnosis mainly on clinical observations and EMG (Cyprus). It is also noted that the percentage of MuSK-positive patients is around 5%, a value close to the one cited in the literature. Almost all patients are confident that the diagnosis of their disease is definite. Most people with MG state that their disease has affected their work and their daily activities at least to some extent. About 30% indicate weakness (generalized or limb) as their main problem, while another 20% report breathing problems. A large proportion had to quit their jobs. This stresses the need for more efficient treatments for MG.

There is a varying degree of satisfaction from the offered healthcare. This is probably due mostly to the varying healthcare systems that exist in the different countries. It could also be due to the difference in character of people leaving in different countries: some people are satisfied for less, some always want more. Patients from Western Europe (Sweden, Scotland, England and Holland) seem to be overall more satisfied by the offered healthcare. They provide suggestions on issues where their healthcare can be improved. One of the suggestions that comes up very often from every country is better communication between patient and doctor and more information about the disease. People from some countries also ask for better overall treatment; more specialists and readily available medications. A large number of patients (~ 20%) also ask for specific medical exams and treatments to be free of charge.

There is a great difference among the countries in the field of sickness/disability benefits. This is again due to the different healthcare and social policies of every country. However, some patients have stated that “it is too complicated” to claim such benefits.

Most patients recognize the fact that there is progress over the years in the diagnosis and clinical management of the disease. With better communication between researchers, clinicians and the patients, the number of patients recognizing this progress would be even higher.

The majority of MG patients keep themselves informed about their disease through their doctor, followed by the Internet and the patient associations. Since the Internet is also their preferred means of information, it is very important to direct them to “verified” websites where they can find reliable information about MG.

The need for more information on MG that patients expect from EuroMyasthenia focuses mainly on two aspects: “practical advice” and “regular updates”. The former has mainly to do with how to cope with the symptoms of MG, whereas the latter, shows the importance of the EuroMyasthenia newsletter.

The vast majority of MG patients are willing to help with research on their disease by either giving blood samples, or by answering more questionnaires.

Table 2. Expectations of MG patients from the EuroMyasthenia Network

Country	What are your expectations from EuroMyasthenia?(%)						
	Better communication	More info. on MG	List of neurologists	Info. on associations	Practical advice	Regular updates	Others
Greece	38	69	54	38	58	73	5
Romania	47	84	50	39	81	85	15
Sweden	22	63	33	20	50	70	2
Cyprus	78	89	11	33	89	89	11
Croatia	12	86	7	5	64	4	0
Scotland	20	43	20	26	43	63	0
Oxford	20	42	28	22	52	48	0
Holland	50	64	43	29	57	79	0
France	34	70	51	19	57	79	4
Average	**36**	**68**	**33**	**26**	**61**	**65**	**4**

MG News and Events

International Conference on Myasthenia, Paris, France

Session dedicated to patients (December 2, 2009)

A reminder about the International Conference on Myasthenia organised by the EuroMyasthenia Network in Paris on December 1-2, 2009. Many international specialists in MG, clinicians and researchers will participate. At the end of the second day of the conference, a session will be dedicated to answering questions from patients with MG. There are no registration fees for MG patients to attend this session. We shall post a video of the session on the EuroMyasthenia website after the conference so that all patients with MG can benefit from the answer(s) to the question(s) they will have submitted through the website, and the possible ensuing discussions.

Czech MG Association

In May 2009, Dr. Pitha, 50 MG patients and two nurses founded the Czech MG association. Their name is MYGRA-CZ and their website is www.myastheniagravis.cz. They are currently working on a patient's card, a first Czech weekend meeting of MG patients and much more. The association publishes the newsletter that is sent to everyone who has registered. One of the founding members, Veronika Sumpichova, is interviewed on page 4 of this issue.

Volunteers needed in Clinical trials for MG treatments

At present, several drugs and treatments for MG are undergoing Clinical Trials. There is a dedicated website where hospitals, research institutes and pharmaceutical companies are posting their needs for volunteers to participate in such clinical trials:
http://clinicaltrials.gov/ct2/results?term=Myasthenia+Gravis&recr=Open

Forthcoming meetings

- International Conference on Myasthenia Gravis, 1-2 December 2009, Paris, France (info: www.euromyasthenia.org; nicole.kerlero-de-rosbo@u-psud.fr)
- 2010 MGFA National Conference, 5 – 7 May 2010, St. Louis, MO, USA
- 3rd European Neurological Conference on Clinical Practices Neurovascular and Neurodegenerative Diseases, 22 January 2010, Bucharest, Romania

EUROMYASTHENIA WEBSITE

Visit the **EuroMyasthenia Website** (www.euromyasthenia.org) to see its new postings and add your contributions

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