Session dedicated to patients

Medical Panel: Prof. A. Evoli (Italy), Dr. A. Kostera-Pruszczyk (Poland), Prof. D. Sanders (USA), and Prof. C. Tallaksen (Norway)

The medical panel will answer questions submitted by patients prior to the meeting through the conference website

Sport and MG

Dr. A. Kostera-Pruszczyk

I'd like to know something more about sport in myasthenia. In general doctors say that a little physical exercise is useful for myasthenic people. But what about a more strong training? Is it useful or damaging for myasthenia, going farther the first feeling of fatigue, when possible ? Which is the scientific explanation ?

Cristina Vatteroni, Italy

Vaccination and MG

What about the Swine Influenza ? Should myasthenic people get vaccinated, or better not ?

Vaccination of patients with autoimmune diseases remains controversial and many neurologists are unsure how to advise patients.
However, inactivated flu vaccines should be considered safe in MG patients. There is always the possibility that patients under immunosuppressive therapy will not be immunized, but otherwise they do not face other risks. On the other hand, it should be considered that flu respiratory complications may precipitate a myasthenic crisis. Then, all considered, flu vaccination should be encouraged in MG patients. In agreement with this view is a recent study showing no association between flu vaccination and hospitalization for MG (Zinman L. et al. 2009).
An increased risk of developing Guillain-Barré syndrome has been reported after A(Swine flu) vaccines in adults (Haber et al,. 2004). The injection vaccine for H1N1 flu is an inactivated vaccine and on this respect it can be considered safe in MG. The multi-dose preparation contains thimerosal to prevent growth of bacteria (single-dose versions do not contain it) and some vaccine preparations used in Europe and Canada include an adjuvant containing a fish oil called squalene.
Swine flu vaccination appears to be associated with the same rate of side effects as other seasonal vaccinations. A 2009 review of oil-based adjuvants in influenza vaccines reached the conclusion that this type of adjuvant does not raise any safety concerns (Vogel F, 2009) and according to the W.H.O. there is "no evidence of toxicity in infants, children or adults exposed to thiomersal in vaccines“.

Vaccination and MG

Prof. D. Sanders

My daughter was diagnosed with myasthenia when she was 18 years old. Her first symptoms appeared a few months after she was vaccinated against hepatitis B. There is a strong suspicion of a link between multiple sclerosis and vaccination against hepatitis B. What is known on such a link with MG? My daughter is now 31 years-old; she has two children. The question now arises: should her children be vaccinated? What are the real risks? Have researchers considered a possible relationship between vaccination against hepatitis B and MG? For my part, I believe there is indeed a causal relationship, but I am not a specialist in this matter.

Dominique, France

Unusual symptoms

Prof. D. Sanders

I first presented to my GP with double vision and tingling in the face. I was lucky in that my GP made a quick diagnosis of MG. Can the tingling in the face be alligned with MG or is this something different. I have never been able to get a response or resolved this issue with my neurologist. The tingling in the face was initially constant. It is now more irregular but it still keeps returning on a regular basis.

Gordon Radcliffe,
Australia

Diagnostic issues

Prof. D. Sanders
Dr. A. Kostera-Pruszczyk

Most leading neurologists are certain that a normal SFEMG done in a weak muscle (eg-one that is clearly involved in the disease) will rule out MG. Can it be that some of the Sero-Neg (AChR-Neg & MuSK-Neg) patients do have MG in spite of normal SFEMG ?

Moshe Pick, Israel

Unusual symptoms

I was orignally diagnosed with Chronic Fatigue Sydrome 14 years ago when my problems started with weak legs and drooping eyes. Last year I was diagnosed Occular MG through an EMG but with a negative antibody. I do have a positive Anti Striated Muscle Antibody. I was told I did not have Genralised MG even though my problems are with my facial muscles and limbs etc. I also have episodes of breathing difficulties.I have now recently been told that I do not have MG Occular even though these symptoms are still causing me a great deal of weakness. I have neen told that I cannot have MG as it starts with the eyes and works it's way downwards but my problem started with the legs and worked upwards. The Doctors have basically refused to look into it any further and have basically left me to get on with it. Bearing in mind the positive EMG and the positive anti striated muscle Tests. Could this still be MG and if so how can I obtain the right help.I first presented to my GP with double vision and tingling in the face. I was lucky in that my GP made a quick diagnosis of MG. Can the tingling in the face be alligned with MG or is this something different. I have never been able to get a response or resolved this issue with my neurologist. The tingling in the face was initially constant. It is now more irregular but it still keeps returning on a regular basis.

Andreafm, UK

Apparently ocular myasthenia was diagnosed on the basis of EMG. It would be very helpful to have more details about this exam (was it RNS or SF-EMG?) and its results. A diagnosis of MG is still possible in this case, as MG weakness can spread from limb to ocular districts, but it seems that the disease presentation was with double vision and tingling in the face, so the clinical history should be more clear. Tingling can not considered a MG symptom.

Diagnostic issues

Prof. D. Sanders
Prof. C. Tallaksen

Subject: Limb girdle pseudomyopathic MG

I am 52 years old patient, with moderate generalised MG since 1987, predominantly affecting my legs. I am on methylprednisolone (medrol) 6mg/day for 10 years, and mestinon 180mg/day.
With time, I noticed a new different type of weakness in my proximal limb girdle muscles causing me a specific, almost permanent, waddle.
The weakness occurs mostly in the morning and improves during the day, and doesn't dissapear totally with higher doses of Medrol or mestinon (as the other myasthenic muscular involvments).
My doctor told me I may have "cortisonic myopathy".
In my patient support group I met 2 other colleagues with the similar problem who don't take cortisone at all.
The doctor told them they may have a limb girdle pseudomyopathic MG (?)
Questions:
Is this myopathic form a specific form of MG? Is there a specific treatment and is it possible to prevent permanent limb girdle muscular damage?

Nadia Radulescu, Romania

Imuran treatment

Under Imurel (Imuran) treatment, after several months of treatment, I had severe muscles pain all over my body except my head. With my neurologist, we stopped and tried again several times to see wether it was caused by Imurel (Imuran). We both had to come to the conclusion that this awful pain was due to Imurel (Imuran). My neurologist told me it is very unusual to have this kind of problem. Has any of the scientist an idea what could be the cause of such pain ?

Josselyne Goodley, France

Imuran treatment

Prof. D. Sanders
Prof. C. Tallaksen

I have MG for 29 yrs (I am 49rs old) I'm on 4 Mestinon daily and 20mg Deltacortril on alt. days. I was on Imuran (125mg daily) for 12 years approx. I have just had 2 Basal cell carcinomas removed, and the Dermatologist recommended my Neurologist to stop the Imuran immediately. I also have almost 100 small warts on my body (mainly on legs & arms) and lots of small lumps beneath my skin (legs and arms mainly). I have 2 questions

1. I stopped taking Imuran in March '09, and I feel no difference in my MG, is this likely to continue, or has my body not been cleared of Imuran yet?
2. Now that I have stopped Imuran, will the warts and lumps go, or will I continue to make them?

Thank you.

Angela, Ireland

Imuran treatment

Can Imurel draw away the appearance of certain forms of cancer ?
How long they can take it without danger ?
Why do certain neurologists prescribe it for a maximum length of 3 years while others make it for 10 years or more ? Is it a question of age of the patient ?
Thank you.

ZANETTACCI, France

A case-control study on the risk of cancer in MS patients treated with azathioprine (Confavreux et al, 1996) showed a dose-response relationship with no significant risk during the first years of treatment and a possible increased risk after about 10 years of continuous therapy.
An increased incidence of non-melanoma skin cancer has been reported and subjects taking azathioprine should be advised to limit sun exposure.
The patient age is important owing to the increase of cancer frequency, especially skin cancer, with aging.

Treatment for Helicobacter pylori

I have MG and H.Py positive. I am 32 years old.I have taken one month ospamox 7 days and ibutin and nexium. The pain in the left part of my body under my last rib and nausea did not dissappear.I went to the doctor again, did an endoscopy and the result was H.Pylori gastritis, which confirmed again the diagnostic.The doctor put me on another scheme for another one month: amoxicillin 2 gr/day, Clarithromycin 1 gr/day for 7 days and continue with sucralfate 4 gr/day and Omeprazolum 20 mg/day. I have started this scheme and I am very weak, with very hard pains in the left side oof my stomach, under my ribs, nausea and queasiness feeling. For MG I take 5mg of prednisone and 360 mg of mestinon.What is your advice?I desperately need help and guidance.

Mihaela C, Romania

Symptoms are very probably due to the fact that Helicobacter pylori infection is still active. Your treatment scheme is correct but alternative treatment may be needed for H. pylori eradication (Ables et al, 2007).
Moreover, chronic prednisone treatment may favor H. pylori infection and high doses of Mestinon can increase gastrointestinal symptoms. If possible, Mestinon dosage should be reduced and prednisone suspended.

Influence of psychologic state on prognosis

Prof. C. Tallaksen

Can the patient's psychologic state modify the MG-prognosis ? Is a correct antidepressant therapy useful also for MG prognosis in depressed or little-depressed patients ?Most leading neurologists are certain that a normal SFEMG done in a weak muscle (eg-one that is clearly involved in the disease) will rule out MG. Can it be that some of the Sero-Neg (AChR-Neg & MuSK-Neg) patients do have MG in spite of normal SFEMG ?

Cristina Vatteroni, Italy

Childhood onset and clinical severity and response to treatment

Dr. A. Kostera-Pruszczyk

My MG started when I was 13 years old. I am now 20 years old and, despite treatment, I suffer from severe muscle weakness and use a wheelchair. I would like to know if the severity of my MG is related to the fact that I developed the disease as a child, i.e. are there differences in clinical symptoms and reaction to treatment between early and late onset MG.

Rehan, Argentina

Steroid treatments

Dr. A. Kostera-Pruszczyk

Thank you for this conference. In spite of a severe myasthenia, I refuse treatments by cortisones because I know the damages. In France, the proposed treatments are or dangerous or ineffective.
The myasthenia cause me intense muscular pains and invalidating. What is your opinion? Did the research at the level international evolve in a positive way for this disease? What hope for the future?

Lou, France

Steroid treatments

Prof. C. Tallaksen

For 30 years I have been taking high doses of cortisone (from 100 tapered to 25 mg). My skin has thinned down and become brittle. It peels when touched and becomes infected because I also have healing problems. All dermatologists give me the same answer: it is a result of the cortisone treatment. Is there no remedy?

An984, Italy

Steroid treatments

May an earlier treatment with cortisone or immunosuppressive drugs prevent the loss of ACh-receptors? Would it be better to take cortisone from the beginning even in the lighter forms of generalized MG than taking only anticholinesterase medication (Mestinon)? Are there any studies or some evidence (even experimental) upon this subject (which shows that the loss is greater when the patient doesn`t take cortisone).

Camelia, Romania

There are experimental data that anti-acetylcholine receptor antibodies cause receptor loss. Corticosteroids and immunosuppressants reduce anti-AChR antibody level and, by this way, prevent the loss of AChRs.
However, it is fairly clear that not all anti-AChR antibodies are pathogenic as shown by the lack of correlation between antibody titer and clinical status and by the evidence of serum antibodies in patients who are in clinical remission.
There are no studies showing that – irrespectively of disease severity – the loss of acetylcholine receptor is greater in patients not taking prednisone. So, in mild forms of MG the use of anticholinesterase medication as only treatment appears to be justified.

Other treatments

Prof. D. Sanders

Where are we with the MONARSEN ?
Will it be marketed some day ?

Domenech, France

Other treatments

Prof. D. Sanders

The patients of more than 60 years, treated for a long time by Cortisone, can they benefit from trials of, and possibly from treatment with RITUXIMAB ?
Can we hope for future use of this treatment in all forms of myasthenia, in particular in non-refractory autoimmune myasthenia instead of the classic treatments with cortisone or immuno-suppressors ?
What is the schedule of the injections of RITUXIMAB ?

Domenech, France

Other treatments

Dr. A. Kostera-Pruszczyk

How are congenital myasthenic syndromes treated, since they have a limited reaction to Mestinon and neither thymectomy nor treatment with steroids and immunosuppressive drugs are recommended?What about vaccines for MG?

Silvia Curubeto, Argentina

Other treatments

Prof. D. Sanders

What about vaccines for MG?

Silvia Curubeto, Argentina

Influence of infections on MG

Prof. C. Tallaksen

I was diagnosed with MG 11 ears ago.I am on chronic therapy with oral Methylprednisolone(Medrol) 8mg/day and Mestinon 60mg, 2tablets/day.
I am also diagnosed with B Hepatits since 2007.My concerns are if the chronic presence of the HBV virus in my body may interfere with Myasthenia Gravis and make my MG simpthoms worse or the chronic corticotherapy may favorize the virus activity.My doctor recomanded me an antiviral medication with lamivudine or entecavir.I would also like to know if those antiviral drugs may worsen MG.
Thank you very much.

Ionna N, Romania

MG "heredity"

Prof. D. Sanders
Dr. A. Kostera-Pruszczyk

Is it true that the child of a mother or father with MG has a greater probability to develop an autoimmune disease during the course of his/her life?

Stefania, Italy

MG "heredity"

Prof. D. Sanders
Dr. A. Kostera-Pruszczyk

I would like to know what are the experiences in pregnancy of women with MG abroad? What per cent children of women with MG will get MG after their birth or during their life?

Hana, Czech Republic

Pregnancy, delivery, and MG

Prof. D. Sanders
Dr. A. Kostera-Pruszczyk

I would like to know what risk myasthenia represents for pregnancy. Can a myasthenic woman give birth naturally? Can she normally nurse his/her children? Should Mestinon treatment be suspended during the pregnancy?

Leila80, Italy

Diet issues

Prof. C. Tallaksen

Before my onset of MG 17 years ago I had to change diet due to hypercholesterolemia and lost a lot of weight. Could this have had an impact on the disease start, i.e. an imbalance in the immune response due to cholesterol changes?
I have noticed that my fatigue increases when I eat "more healthy food", ie less carbohydrates and fat. For example, if I ingest high energy food/drinks my muscle power improves immediately on a temporary basis. What is known about the importance of diet for MG?
What is the mechanism behind the severe exacerbation of myasthenic fatigue with mental stress?

Margaretha Rostedt,
Sweden

Diet issues

Prof. C. Tallaksen

Can a gluten-free diet have any bad or good influence on MG?

Goodley, France

Cognitive impairment

Where neurologists have measured cognitive impairment in MG patients who are in an active myasthenic state, their conclusions have been broadly along these lines.

1. Yes cognitive impairment does exist. (Iwasaki 1990)

2. Some impairment was found but the experiments were faulty (PR Bartel 1994; Robert H Paul 2000)

3. It's there but it must be related to an existing psychological disorder.(Fotiou and Konstantinos 2000; SJ Ruegg 2007)

4. It's there but it must be a lifestyle problem. (Henry J Kaminski 2002)

5. It's more pronounced in visual tasks. (E Sitek 200

If there is a true acetylcholine disorder in the CNS of MG patients, as data does tend to suggest, and this disorder is accompanied by psychiatric symptomatology and higher cognitive- function deficit, then a significant question concerning the need for treatment emerges.

Has there been any move internationally to treat patients who exhibit these problems and if not, why not.

Maria Teanby, UK

The possibility of central nerve system (CNS) involvement in MG has long been debated and clinical studies have produced conflicting results. A recent study has investigated cognitive function in 100 patients older than 60, with different disease severity, in comparison with matched healthy controls (Marra et al., 2009). In agreement with previous reports, the authors did not confirm the hypothesis of CNS cholinergic involvement in MG. No significant differences were found between patients and controls. A trend towards worse performances in MG subjects on tasks exploring psychomotor and attentional abilities was observed in severely affected patients and was related to general visual motor slowness and to the concomitant presence of other diseases. Furthermore, the rate of overt dementia in the study sample was lower than that observed in the general population of the same age.

Medication abuse and onset

Prof. C. Tallaksen

Is there some correlation between the abuse of antibiotics and outbreaks of myasthenia?

Halenka, Slovakia

Natural product treatments for MG

Subject: Natural products with immunoregulatory effects and MG

It's a very popular subject on our patients' forum an any patient`s desire to find a medication that will help myasthenia without side effects.
Many romanian MG-ers use the oil from Nigella sativa seeds (black cumen) as natural adjuvant therapy and reported good effects, such as improved strenght, and increased resistance to respiratory infections.
Other MG-ers used dietary supplements recommended as immunoregulatories ,such as: colostrum, schizandra or reishi.

Question: Are there any medical rewiews about natural immunereglatory products benefits, besides the placebo effect ?
Do you think it will be interesting to run larger studies in MG patients? Is there some correlation between the abuse of antibiotics and outbreaks of myasthenia?

Romanian, MG association

Myasthenic crisis

Dr. A. Kostera-Pruszczyk

Is it possible to avoid the “Myasthenic crisis”? If it does occur, is it possible to prevent it from occurring again?

Silvia Curubeto, Argentina

Myasthenic crisis

Is there a possibility to monitor a myasthenic crisis? It is difficult for a patient to know when hospitalisation is necessary and for a clinican to decipher a patient's clinical signs. At what time would a simple rest suffice and when is a more stringent treatment necessary?
It is very stressing not toknow where one stands in a myasthenic crisis as fear sets in as soon as some breathing difficulty appears.

Katy, France

In most cases an impending respiratory crisis is characterized by the association of dyspnea with increasing weakness of bulbar muscles responsible for difficulties in swallowing, speaking, chewing and more generalized weakness. So it is very uncommon that respiratory failure is as an isolated symptom.
Every MG patient with breathing difficulties should seek medical advice without delay. The patient history and clinical signs, and arterial blood gas will help to decide if emergency treatment is necessary.

Miscellaneous

Is there any connection between using contact lenses and ocular myasthenia? Can wearing contact lenses make eyes more tired?

Sonia, Czech Republic

No, there is no connection between the use of contact lenses and ocular myasthenia. Wearing contact lenses makes eyes more tired, but this has nothing to do with myasthenic weakness of ocular muscles. Old-style "hard" contact lenses, which are now obsolete, could rarely cause mild “traumatic” ptosis, that could theoretically aggravate an MG ptosis, but with no pathogenic connection with MG.

The following slides are of questions not validated on the website, to be answered if there is time

In february 2009, after several weeks of Cellcept treatment, I developed two types
of allergies:
- skin allergy : my face was burnt and needed treatement for several weeks
- other allergy: I am affected by cluster headache (treatement and follow up by Hôpital Lariboisière) and my cluster headache crisis became unbearable.
According to Roche laboratories, Cellcept could not have been the problem.
But after several trials with Cellcept, my two neurologists (one for mg and one for cluster headache) came to the conclusion that Cellcept was the problem.
Every time I stopped cellcept, after a few days, cluster headache crisis (awful pain) stopped.
Is this problem known when you have mg and cluster headache ?
Treatment for cluster headache (Oxygen, Imiject and Verapamil).

I can answer this - Don

We hear (and I am here speaking on behalf of many mgers) very often :
mgers live a normal life or a nearly normal life. But we all know that despite medication, many, not to say most, mgers do not live a normal life.
Living a normal life means you can work, you can do all the things you want without feeling tired, without restraining yourself, etc....
My own neurologist (one of the top men in France) says
he knows that most mgers do not live a normal and that it is wrong to say so.
One top neurologist (retired now) used to say (even publicly) :
Il vous faut faire le deuil ce que vous étiez auparavant (you have to give up the life you used to lead).
Can we really discuss this problem and ask the few mgers who do not have any sign of mg anymore to accept that this is not the case for most of us.
This illness is an invisible illness (or almost invisible).
All the literature we find always says : mgers live a normal life.
But what is a normal life ?

What anti-pain can they take without risk, notably in cas of rheumatic pain ? Thank you.

What is now the view of therapy of MG patients through thymectomy.
Have all the patients get a disability pension? Is the pension a life or terminable annuity.
Could we have a special MG card, like MGA card in USA, with some important data in two languages (english and native)? This could help us to travel to other countries and explaining the help we need in emergency.
Are all the MG patients need to be treated immunoglobulins?
Could we, MG patients, get, as MG patients in USA, a list of medications forbidden for MG patients or such that could worsen myasthenia weakness, especially when new drugs are introduced for sale.
What physical therapy we can use for therapy MG and other disorder? What we have to consider with such therapy?
Is it possible to make an internet forum for patients, which could be moderated by a physician to help with answer the questions we have? This should not be a forum for therapy.
Could be make also such a forum or place for professional question

A year ago I was diagnose to be positive to Acetylcholine Receptor Antibodies. I'm using Corticosteroids (prednisone) for a treatment and it works. I want to learn if Thymectomy is the correct treatment for remission? If yes please advice the best method and point me to the right medical center. I'm from Cyprus and the option I have here is to open my stern?

- Can regular (monthly or bimonthly) and long term (years) IgG cures help patients keep a certain "level" of "normal life"? Could we use this alternative on the long term, and are there any risks of resistance?

- What is your opinion about the "Revimune" (clinical trials in the John Hopkins Hospital) Therapy, wich could "reboost" an immune systeme wrecked by myasthenia?

- Does the constant subjective mental fatigue due to myasthenia have a significant effect on the cognitive performance of the patients suffering from myasthenia gravis?
  And, how to cope with this constant mental fatigue?

What are the results of the FORCE trial (I'm one of the patient)?

Is there anybody who may have experience with NEXAVAR, sorafenib, medicament which is used in the treatment of the hepatocellular carcinoma. Please if somebody would be so kind and tel us as fast as possible if Nexavar may have negative side-effect to myasthenia gravis signs and symptoms. Thank you very much.