

PARADIGMS: A NEW INITIATIVE TO CUT THROUGH THE NOISE ON MULTIPLE SCLEROSIS

A CONVERSATION WITH DR ANDREAS LYSANDROPOULOS

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Disclosure: The project is sponsored by Genzyme EMEA for logistic and organisational purposes.

Received: 23.04.14 **Accepted:** 22.05.14

Citation: EMJ Neurol. 2014;1:44-48.

About Dr Andreas Lysandropoulos

- Andreas Lysandropoulos is a neurologist specialised in multiple sclerosis and neuroimmunology working at the University Hospital Erasme in Brussels, Belgium.
- He received his M.D. in Greece and completed his internship in Neuroimmunology in Lausanne, Switzerland.
- He is actively involved as a principal investigator in major clinical studies and has published many peer-reviewed articles.



INTRODUCTION

ParadigMS is a new, independent peer-group of multiple sclerosis (MS) experts, aiming to provide a high level of science and insight to healthcare practitioners (Table 1). The project is sponsored by Genzyme EMEA for logistic and organisational purposes.

During one or two international meetings a year, the experts will discuss between six and nine topics, and identify evidence-based approaches and strategies, but always in interactive and pragmatic ways. Then, each participant will disseminate the information through national symposia in order to reach out to neurologists and healthcare practitioners in their own language and with information tailored to each country's characteristics.

One of the members of ParadigMS, Dr Andreas Lysandropoulos, tells us more about this exciting new venture and the topic he presented at the second meeting - quality of life (QoL) - and the general wellbeing of patients living with MS.

You are part of ParadigMS, and it seems that this programme comes at a time when we know so much about MS, yet many questions remain unanswered and some paradigms have shifted, disrupting in the process some certainties. What are the main challenges physicians are facing today regarding MS?

MS is a topic that is currently 'exploding' because a lot of new data are constantly flowing in from everywhere and new products are regularly added to the therapeutic armamentarium. Our peer-group recognised the need to review this amount of data in an objective way and with a high scientific level. Thus, we will be able to focus on evidence-based knowledge that we can summarise then disseminate to our colleagues also working with MS patients. We are aiming to provide a collection of scientific data they can actually use and broadcast to others. Hopefully, we will help physicians position themselves in this rapidly changing environment.

You are then aiming to address one of the main weaknesses of congresses and medical education:

Table 1: The members of ParadigMS.

Position	Name	Country
Chair	Otto Van Eikema Hommes	the Netherlands
Co-Chair	Bernd Kieseier	Germany
Member	Paolo Gallo	Italy
Member	Nikolaos Grigoriadis	Greece
Member	Eva Havrdova	Czech Republic
Member	Raymond Hupperts	the Netherlands
Member	Ralf Linker	Germany
Member	Andreas Lysandropoulos	Belgium
Member	Celia Oreja Guevara	Spain
Member	Carlo Pozzilli	Italy
Member	Maura Pugliatti	Italy
Member	Sven Schippling	Switzerland
Member	Vincent Van Pesch	Belgium
Member	Bart Van Wijmeersch	Belgium

sometimes the information can be impractical or impossible to implement locally.

Yes, some physicians who are not specialised in certain areas may feel drowned by the information provided at congresses, sometimes after only 15 minutes. Our objective here is to provide practical knowledge without getting lost in incomprehensive and complicated algorithms. That said, our goal is to always give information that everyone will be able to select and use: our documents will be developed at different levels so that each doctor can decide whether he/she is interested in basic or advanced information.

The ParadigMS project thus acts as a filter?

Sometimes the word 'filter' can imply negative aspects: we do not pretend to know or choose what information is useful or not, we will simply offer core evidence-based medicine. We will not present scientific hypotheses that have not yet been confirmed, we will only focus on evidence, and we will provide it in a structured and practical way, so that doctors will be able to use it.

What sets your programme apart is the extremely pragmatic approach.

Yes, in most areas, including MS, treatment algorithms are developed, but this is not real medicine. Instead of this, our ambition is to deliver a framework and a philosophy so that physicians

can 'feel' how to treat a patient with MS. Certainly, we will present information related to the disease, its evolution, and hands-on aspects ('how to evaluate a patient', 'how long should we wait between two magnetic resonance imaging (MRI) scans', 'which clinical scales should we use'), but we will never introduce information rigidly.

How many meetings are scheduled per year?

At least once or twice a year; this year, we had two meetings. The current project is to create an online Cloud where we can share our presentations at two levels: one for members of ParadigMS, so we can collaborate all year long and suggest some changes along with new research developments, and the other level for healthcare practitioners as a learning platform. We had a very nice experience during both meetings, our approach is very modern, and we have a very relaxed atmosphere. By including experts who still practice and see patients every day, we continue to have a feeling of 'everyday life' while discussing at a very high scientific level.

How do you ensure impartiality throughout the process as a pharmaceutical company is sponsoring the project?

It is clear that we need organisational support for several reasons; it is an international project, MS specialists are coming from everywhere, and it is obvious that this kind of project is difficult to

organise by the academy or by an independent team. The pharmaceutical company supports us in terms of logistics, organising our meetings, and our presentations, but it was very clear from the start that the firm is not involved at any stage of production, maintenance or evaluation of what we provide. The presence of the pharmaceutical company is very restrained, and the proof is that during the first two meetings, we did not speak at any time about specific products from Genzyme or another company.

The topic that you presented at the first meeting focused on QoL for MS patients, could you provide a brief overview of what was discussed?

QoL should be the main focus when evaluating a patient and the main objective of MS management. Clinical studies on new drugs or new therapeutic approaches usually rely on clinical aspects or MRI results, but this is not reality. Some patients can be stable when you consider these criteria, yet their QoL scores are catastrophic and the patient can be in a lot of pain, psychologically speaking. On the other hand, a patient can present disastrous clinical results but his/her QoL can be close to normal. As you can see, there is a discrepancy between what is objectively measured and what happens in real life. QoL can comprise fatigue, sexual dysfunction (for psychological or physical reasons), and cognitive impairment. Public perception of MS is often linked to the wheelchair stigma. At the time of diagnosis, many patients feel lost and betrayed by their bodies; they isolate themselves and abandon professional or personal projects.

Furthermore, QoL must be measured. We have scales at our disposal but there is no consensus on which scale can perfectly assess QoL. We have to work on this by applying scales, collecting data, and evaluating them in cohort studies.

On another level, to detect issues related to QoL, physicians must have sufficient time to spend with their patients. This is crucial and this belief is shared by all of my colleagues from ParadigMS. Nowadays, time is consumed for very practical aspects of disease management; we miss things that are much more crucial to our patients, things that they do not usually admit to right away, so we have to work with them and discuss sensitive issues.

This is extremely relevant since some studies have shown that QoL can directly influence clinical aspects of MS and be a prognostic tool for the evolution of the disease.

There are even studies that are very impressive and discuss the effect of the psychological state of mind of patients, and how they see themselves in our society and in the lives of others. Some other results show that psychological support may have a direct influence on the brain's inflammatory lesions, and it shows on MRI readings. This is the proof that psychological care is not just theoretical; it has a direct impact on the biology at the core of the disease.

Additionally, cognitive impairment is more and more recognised as it is an issue from disease onset and mainly concerns rapid processing of complex information. We know that cognitive reserve is not only influenced by genetics, but also by cognitive leisure activities and life experiences. This is very important with respect to QoL; we must encourage patients to remain active on a cognitive level.

These are topics that seem very basic but are quite new to MS. 10 years ago, people with MS were people with physical disabilities. Now we know that MS patients experience fatigue and cognitive impairment, but we can implement useful approaches and they do not necessarily have to be pharmacologic strategies.

Could you give us some principles to further close the gap between medical rationalism and patient insight?

I would advise to spend more time with patients, apply scales, and take advantage of the internet. If you ask your patient to fill a scale on QoL for 10 minutes, you lose valuable time. It does not help either to ask a patient to fill the scale at home and return it for next time because the patient might forget. Now, if the patient prints a scale at home and fills the information in real-time, the results will be much more accurate and closer to the historical reality than to ask a patient to recall the last 3 months during a consultation. MS patients are connected - there are a lot of discussion forums and patient associations - and we can turn this into a very useful tool.

How can multidisciplinary care help with issues related to QoL such as sexual dysfunction?

Many problems of this disease should be managed by a multidisciplinary approach. As an example, dynamic physiotherapy has a beneficial effect; exercise with a physiotherapist influences brain plasticity and helps to create new networks. Psychological care, alone or in working groups, is essential. Studies also have shown benefits for

patients who are part of a group who meet along with healthcare practitioners to discuss together many aspects of the disease.

How do you address these sensitive issues?

These issues should be discussed privately with the patient by taking the time to let the patient confide in us during a consultation; we should not take our patient by surprise. At first, it is important to find the root of the problem. Sexual dysfunction may be related to self-image, psychological or organic issues, directly or indirectly related to MS. A good patient-doctor relationship built on trust is of crucial importance to ensure good communication and proper care. While we may have psychologists in our multidisciplinary teams in hospitals, private care neurologists should not hesitate to address a patient to a psychologist if they feel the issue requires further help.

What about pregnancy? How can we manage female patients before, during, and after pregnancy, and ensure acceptable QoL?

In the last decades, pregnancy was believed to have a negative effect on MS because in the first 3-6 months after delivery, the patient might present resurgence of inflammatory disease activity, even if the third trimester was quiet. We must not avert our patients from becoming pregnant as pregnancy is only contraindicated in extremely severe cases. Pregnancy is a project that is important in the life of a woman so we must benevolently assist, advise, and manage our patients during this important stage of their lives.

We know now that the idea to stop any treatment for 3 months before a pregnancy is questionable for interferons and glatiramer acetate, which are traditional treatments of MS, so we can tell our patients to continue therapy until pregnancy is confirmed. This is an important development for QoL because patients who interrupt their treatment in order to attempt a pregnancy are often anxious. With anxiety, pregnancy will not happen right away and sometimes patients will experience a slight relapse, which will discourage them and make them give up their plans for pregnancy.

We have a supportive role to play in collaboration with the obstetrician/gynaecologist. The latter do not often see MS patients and may have questions on whether these patients can deliver vaginally or receive anaesthesia; the answer to both is: Yes!

Breastfeeding is important for the mother-child relationship, but as MS drugs are not recommended during lactation, we may - with the help of clinical evaluation and MRI results - determine the ideal timeframe and ask the patient to stop breastfeeding earlier or later than anticipated.

Let's go back to ParadigMS - what are the next steps?

Currently, we are finalising the presentations of the second meeting and uploading them online on our Cloud. Then we will go to the local level; each member of ParadigMS, with support from Genzyme, will organise a national meeting in his/her country in order to disseminate the information and share our thoughts with healthcare professionals.

The next meeting in 2015 will review failures and successes of our national meetings; we will share the feedback we received and address things that need to be improved. This project is not an autistic project and we will listen to what our colleagues suggest. To date, there are no specific topics defined for the next meeting as this collaborative approach will actually use the feedback from the last, and we are waiting to see which topics our colleagues want us to refine or address.

We want to be useful above and beyond theoretical aspects, so then we will move on to more practical things such as building tools to evaluate QoL.

What are the long-term ambitions of this programme?

All the participants were very enthusiastic during both meetings and ideas are flowing in! We shall discuss the possibility of developing online learning platforms and tools for physicians alongside mobile educational solutions for patients, although we must work step-by-step in this direction and not go too fast.

I would like to highlight the participation of Prof Van Eikema Hommes in this project; he has been intensely involved with MS for a very long time, despite his career level and age, and has retained a very modern and pragmatic vision for MS management. He is very charismatic and inspires us a lot, and we believe this is crucial to the project. He is the best example of a doctor who, through all the years, has kept the patient at the core of his interest. That is actually the first thing he insisted on when we started working together; before us, as physicians, we have a human being and we must consider the patient as a whole.

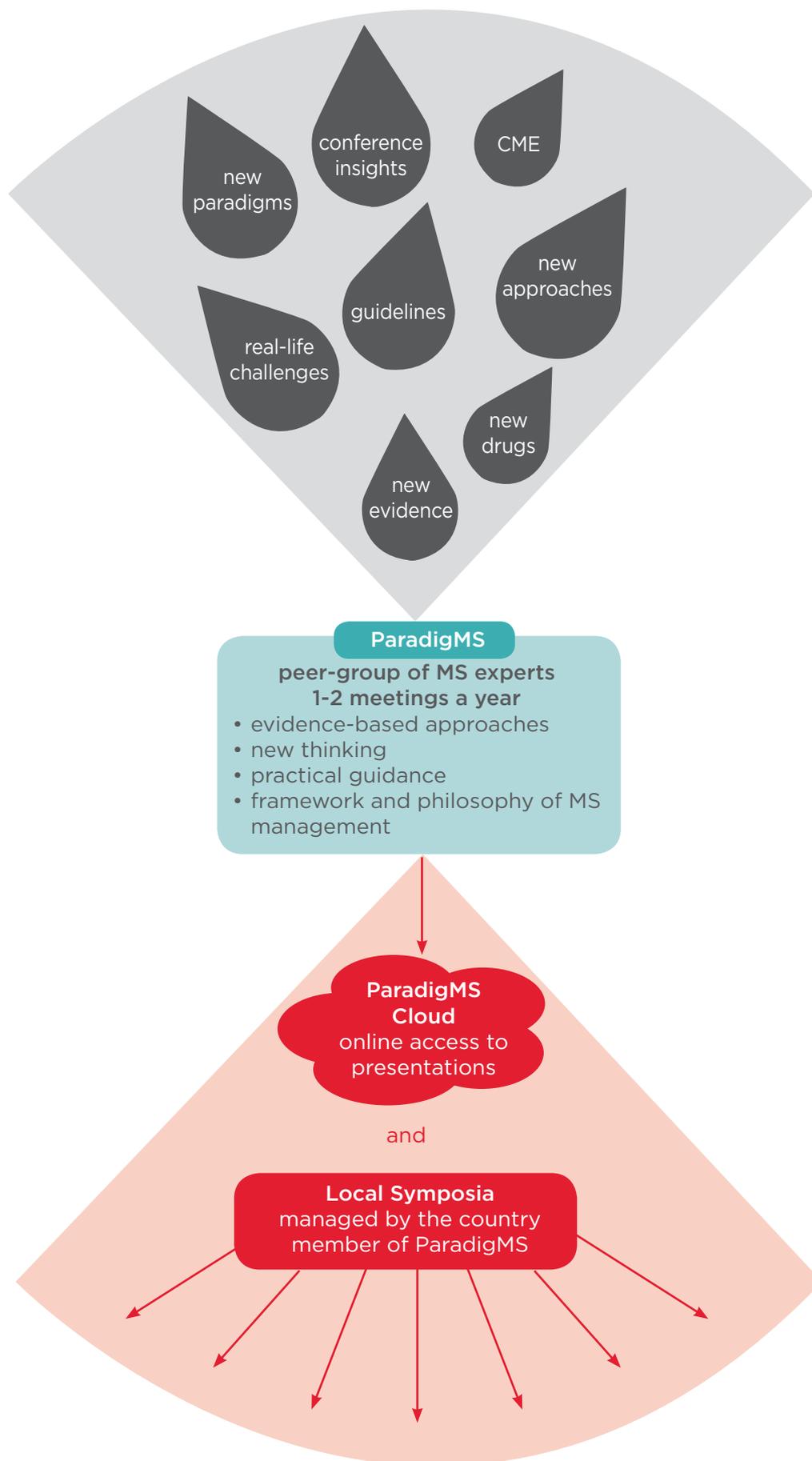


Figure 1: ParadigMS, a new independent peer-group of multiple sclerosis (MS) experts.