

# THE BRAIN AND MULTIPLE SCLEROSIS

<http://www.euractiv.com/specialreport-brain-multiple-sclerosis>

## Contents

Researchers look to improve understanding of complex brain.....	p.1	Data shows treatment inequalities for EU's multiple sclerosis patients.....	p.7
Small workplace changes help people with multiple sclerosis keep their job.....	p.3	Neurologist: 'The brain is running all other illnesses and must be preserved with special care'....	p.8
MS expert: Lawmakers must put disability higher on the agenda.....	p.4	Public-private partnerships point way forward for brain research.....	p.10

## Researchers look to improve understanding of complex brain

Understanding the human brain could provide the foundation to explore new ways to treat and eventually prevent diseases such as multiple sclerosis, Parkinson's or Alzheimer's disease, according to the European Brain Council (EBC).

The brain is at the centre of exciting but challenging new times in neuroscience research.

"We have already identified a lot of gaps in knowledge about treatments of brain diseases," said Gordon Francis, head of the NeuroInflammation Clinical Science Unit within the Neuroscience Franchise at the Swiss pharmaceutical company Novartis.

Francis was addressing a conference on Friday (14 February) focusing on brain-related issues in Barcelona, Spain, which advocated for a "brain-political road map" under the motto 'Understanding the brain: Where are we in 2014?'

Among the challenges that scientists are looking into are the loss of brain tissues which for example occur at very early stages



Photo: gpointstudio / Shutterstock

of multiple sclerosis and dealing with the changes of brain volume, said Frederik Barkhof, professor of Neuroradiology at the VU University Medical Centre in Amsterdam.

### The case of multiple sclerosis

According to data by the European Multiple Sclerosis Platform (EMSP), at least 600,000 people in Europe are affected by multiple sclerosis, an autoimmune disease of the central nervous system.

The potentially disabling disease, which strikes the white matter of the brain and spinal cord and affects the rest of the nervous system, has far-reaching consequences for society as more than one million people are affected indirectly through their role as carers and family members, the EMSP said.

However, despite its importance, knowledge on how the brain works is still very limited. According to researchers,

**Continued on Page 2**

### Continued from Page 1

understanding the complex brain could provide the foundation to explore new ways to treat, cure and eventually prevent brain diseases such as multiple sclerosis, Parkinson's or Alzheimer's disease.

"We don't want this to be a race or competition against cancer, cardiovascular diseases or diabetes," Mary Baker, president of the European Brain Council, told EurActiv.

"But it is the brain that manages cancer, cardiovascular diseases and diabetes. The brain is a very special organ, we must take care of it," Baker added.

A disease like multiple sclerosis significantly impacts on the quality of life of patients and their families. For example, less than 50% of people with multiple sclerosis will be employed 10 years after receiving their diagnosis. About one-third of people will also need a wheelchair within 20 years of developing multiple sclerosis, according to data published by the Multiple Sclerosis Foundation.

"We try to mobilise the key actors, among them the European Commission's DG Research, on the need for innovation (with new drugs), but also on the social impact of multiple sclerosis," Baker stressed.

### Economic and social costs of brain diseases

According to the EBC, the direct cost of healthcare related to brain diseases has increased from €386 billion in 2004 to €798 billion in 2010, measured across 30 European countries.

This means "more money is spent into brain diseases than cancer or cardiovascular diseases", according to Baker.

The EBC wants to put the emphasis on the economic burden of brain diseases, in particular on multiple sclerosis. Up to 2.5 million people worldwide are affected by multiple sclerosis. It's more often younger people between 20 and 40 who are diagnosed with multiple sclerosis, and women are diagnosed twice as often as men.

In the UK alone, the direct healthcare costs of brain diseases are estimated at 37% of the overall health budget which Baker called "an enormous amount of money, simply not sustainable".

A part from the economic burden on society, a multiple sclerosis diagnosis can be devastating for the individual young adult who may be starting careers and making plans for the future. Early adulthood is also a time when young people may be pursuing higher education, making new relationships or considering starting a family.

"They are the brains of the future," Baker said.

### More attention to research

The EBC advocates for more and better funding for brain research, for example a combination of public and private sector resources. The EBC is currently working with the Commission's DG Research and the Innovative Medicines Initiative (IMI) on one of Europe's largest public-private initiatives aiming at speeding up the development of better and safer medicines.

The second project, IMI2, has a budget of €3.45 billion.

"The attention paid to brain diseases is still relatively low when you compare it to cancer or diabetes. In order to raise awareness on multiple sclerosis, you need to make clear what the implications of the conditions are, what the impact they have for a condition like multiple sclerosis which hits people in their 20s. It has a huge impact," Alan Thompson, chair of the International Progressive MS Alliance, told EurActiv.

"The problem with the pharmaceutical industry is that people think they are just raising the profile in order to sell more drugs, but a combined approach should be better," he said.

According to the Atlas of MS survey conducted in 124 countries by the Multiple Sclerosis International Federation (MSIF), access to drugs (Disease-Modifying Therapies, DMTs, or Symptomatic treatments) is very limited in low or medium-income parts of the world. Only 40% in developing countries have access as opposed to 90% in high-income countries.

"Unfortunately, inequalities remain," Thompson stated.



# Small workplace changes help people with multiple sclerosis keep their job

While many people who suffer from multiple sclerosis are highly skilled, 50-60% can expect to be unemployed after receiving their diagnosis despite the fact that only little adaptation in the workplace is needed to keep them employed, experts say.

The economic burden of healthcare costs related to brain diseases such as multiple sclerosis has increased from €386 billion in 2004 to €798 billion in 2010 across 30 European countries, according to the European Brain Council (EBC).

Aside from the drastic increase in healthcare costs, Europe is also losing a highly-educated group of young workers as many lose their jobs shortly after being diagnosed. This happens although employers only need to make small adjustments in the workplace to hold on to a young employee with multiple sclerosis. Around 70% of Europe's 600,000 people with multiple sclerosis are diagnosed with the disease in their 20s and 30s.

Shoshana Pezaro, who was diagnosed with multiple sclerosis at the age of 28, though she had lived with the symptoms of the disease for years, has a university degree in theatre and film and landed a job in television immediately after graduating. As a production coordinator, she sometimes worked two days without stopping though she would lose the feeling in her arms and would need help to get dressed in the morning and be taken to work.



Photo: pinkypills / Shutterstock

Eventually, Pezaro decided it would be better to become self-employed in Brighton, England, and set up her own business with 13 employees teaching piano, singing, dancing and drama, to control her working hours.

However, Emma Rogan, who works as a project coordinator at the European Multiple Sclerosis Platform (EMSP) in Ireland, said that people living with the condition have different symptoms that vary in type as well as severity.

This means that some might be able to work full-time with only small adaptations at work.

"Fatigue is a symptom for many people with multiple sclerosis, me included," Rogan said in an interview. "However, a planned rest period during the day means I continue my work and complete tasks. To facilitate this my employer last year put a reclining chair in the building. For others it's about having their lunch hours extended so they go home and take a rest," she said.

Multiple sclerosis is a potentially disabling disease, which strikes the white matter of the brain and spinal cord and affects the rest of the nervous system. It has

great consequences for society as more than one million people are affected indirectly through their role as carers and family members, according to the EMSP.

Younger people between 20 and 40 are the ones who are the most often diagnosed with multiple sclerosis, and women are diagnosed twice as often as men. Both Pezaro and Rogan were diagnosed in their 20s.

## Focus on SMEs and self-employment

Pezaro cited the example of a friend with multiple sclerosis who was able to keep her job at a large energy company because the firm had been "fantastically supportive". For example, the company has ensured flexible working hours for her and has made sure she could sit close to the toilet and a window to prevent her from overheating.

"She doesn't need physical adaptation, but she knows that if she did need a large screen that they understand her needs and are willing to talk about it. She doesn't even

Continued on Page 4

### Continued from Page 3

fear of losing her job. She feels like her work is valued,” Pezaro stressed.

Rogan added that keeping an employee with multiple sclerosis isn't only good for the person concerned.

“When word gets out that you are an employer who takes such considerations, it's great for business and it opens up a whole new market,” she said.

But while a large energy company in Britain was able to keep an employee with multiple sclerosis, Pezaro said that the real issue in the EU is the lack of government support for SMEs which employ around 80% of the EU's workforce.

While the EU has also established a youth unemployment scheme where national governments can apply for funding, it remains to be seen how much money trickles down to young people with disabilities.

“If one of the people working for me had multiple sclerosis and was suddenly off, I would have really struggled financially to keep the business running. There's no financial support in place for small businesses if someone is off,” Pezaro stated.

Self-employment is another way for people with multiple sclerosis to get to do what they are passionate about, according to Pezaro. But had she been diagnosed with the disease before she set up her business, she wouldn't have succeeded to get business insurance, loans or overdraft.

“The banks would just have said 'no',” she said. “So I think to support people to be able to work independently and set up their own enterprises, we really need to look at how that can be funded and where the grants could come from so that people could have equal opportunities.”

### The question of quotas

While other disability groups have called for quotas to force companies to hire people with disabilities and to make sure that job centres keep them as a priority, Pezaro said that idea would make her “fearful”.

“I could imagine that I could be forced into a job that was not appropriate for me. It would be demoralising and awful. A non-recognition of my skills and talent. That's what I fear. On the other hand, I can see

how that could be positive in making people make an effort with disabled people finding employment. I would just be concerned that it wouldn't be appropriate employment,” she emphasised.

Concerning quotas, Rogan referred to the example of the number of women in politics and the under-representation of half the population.

“As long as there isn't an equal playing field, there needs to be quotas. When it comes to people with disabilities and quotas for employment, I think in general terms they are useful. However, there must be processes in place to follow through. If someone with a disability has specific experience, qualifications and skills in one area but is offered a job which is a complete mismatch no-one is going to benefit,” the EMSP's Irish project coordinator stated.

EurActiv has asked several members of the European Parliament who have dealt with issues related to multiple sclerosis and employment in the past, what more could be done in the EU to keep young people with multiple sclerosis employed in the EU. They all declined to comment.

## MS expert: Lawmakers must put disability higher on the agenda

Every single person in the EU will have a friend, a relative, a neighbour, an employer or employee who will be affected by a disability at some point in their lifetime. Therefore, EU politicians need to put disability higher on the agenda, says Emma Rogan.



*Emma Rogan is project coordinator for the European Multiple Sclerosis Platform (EMSP) which represents 600,000 people with multiple sclerosis in Europe. She spoke to EurActiv's Henriette Jacobsen.*

**What are some of the things you need to change as an employer if you have someone with multiple sclerosis working for you or if you are considering hiring a person with multiple sclerosis?**

People who are diagnosed with multiple sclerosis have different symptoms that vary in type as well as severity (physical and cognitive). The fluctuating nature of the condition can be a challenge but it can be managed. Fatigue is a symptom for many people with multiple sclerosis, me included. However, a planned rest period during the day means I continue my work and complete tasks.

To facilitate this, my employer last year, MS Ireland, put a reclining chair in the building. For others it's about having their lunch hours extended so they go home and

Continued on Page 5

Continued from Page 4

take a rest. Many businesses are providing quiet spaces for employees to take time out from their schedule and to regenerate. It makes business sense to have well-rested, energetic employees.

#### **What about the option of working from home once in a while?**

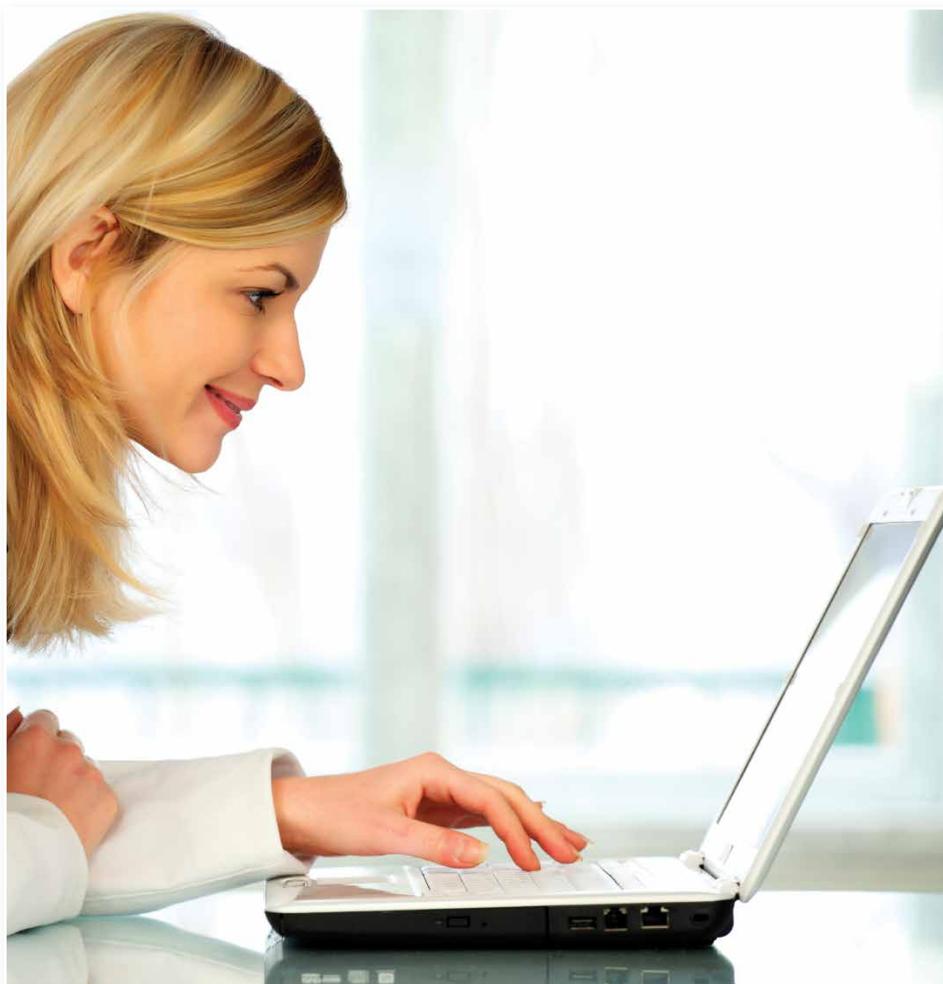
With modern technology, working from home has become more of an option for businesses. Where possible, flexibility has the potential to affect a person's workday for the better. Innovation and creativity applies to every aspect of life and yet when it comes to someone having a different need, for some reason it is not considered. However, working from home is an approach for many, particularly for people with multiple sclerosis to manage their work.

Where relevant, it makes sense to apply the same innovation to the working lives of people with disabilities. Restoring confidence by adapting to circumstances empowers people to rebuild and/or maintain their work life for longer. People don't want charity, they want opportunity to work.

#### **Do you have the impression that it's difficult for people with multiple sclerosis to negotiate these changes with their employer?**

It can be very difficult. Negotiations are about working things out and bringing about a win/win situation for all parties involved. If there is a change in the person's circumstance, knowing the employer is open to listen, to discuss options, will make all the difference. Being diagnosed with a chronic neurological condition such as multiple sclerosis can have serious implications for a person's mental health as they process the change in life. This can be very difficult to deal with.

Difficulties arise when people are working and then diagnosed with multiple sclerosis. They may have to hide their symptoms for fear of losing



their job. This has happened where the employer jumps to a conclusion without ever finding out how multiple sclerosis is affecting their employee. Decisions are then based on prejudice and are, quite often, not lawful. Most people with multiple sclerosis remain capable in terms of work and most adaptations don't cost anything financially.

However, when employers and employees talk through the changing needs, it is then they can figure out a solution that keeps the person with multiple sclerosis employed and the business retains a competent member of staff. It's a success on all fronts.

#### **How should it be communicated to an employer that maybe hiring someone with a disability, for example multiple sclerosis wouldn't mean changing many things in the workplace?**

Awareness and information are fundamental to understanding the needs

of people with disabilities. Support is available from different multiple sclerosis organisation in every country.

The EMSP is currently developing a project, Believe and Achieve, to provide young adults with multiple sclerosis with the opportunity for internships with partnering businesses and organisations. EMSP will provide support and information to ensure success for all involved. There are thousands of young, well-educated adults who have the passion and capabilities to work; all they need is the purpose, an opportunity to become great employees. Their symptoms might need some adaptations but with the right opportunities and guidance, together you make the most of their skills.

A business owner will give someone the opportunity to get work, helping them learn new skills and they give back in the work they do. When word gets out that you are an employer who takes such

Continued on Page 6

### Continued from Page 5

considerations, it's great for business and it opens up a whole new market.

Perhaps I won't convince someone who does not see the possibilities. However, by giving people the chance to show what they can do is life changing for all involved. I never imagined that aged 27 I would be diagnosed with multiple sclerosis nor need the support to get back to my life and fulfilling my ambitions. It was only when I saw an opportunity and had the chance to make the most of my education and skills, that I re-discovered my potential.

When an organisation gives someone an opportunity and adds to the diversity and skill-set of the workplace, everyone benefits. Diversity brings creativity and a new perspective that enhances the workplace. It's about seeing the advantages of holding on to a member of staff or employing someone who is passionate and capable.

**There have been other disability groups who have called for quotas for companies or targets for job centres when it comes to employment of people with disabilities. What is your opinion on this?**

When it comes to quotas I refer to the example of the number of women in politics and the under-representation of half the population. As long as there isn't an equal playing field, there needs to be quotas.

When it comes to people with disabilities and quotas for employment, I think in general terms they are useful. However, there must be processes in place to follow through. If someone with a disability has specific experience, qualifications and skills in one area but is offered a job which is a complete mismatch no-one is going to benefit. There has to be something in the process that equips the staff in job centres to follow through a process with the person, it has to be a conversation. It can't just be "Here's a company with a position for a person with a disability and here's the person with

the disability." Everything needs to be discussed to ensure respect and dignity for the person and there needs to be a match.

With the job centres, yes, I think targets for employing people with disabilities are a good idea, but the processes and evaluation need to be there to match. People are always saying to be that I don't look sick or disabled. Just because we have a label for my chronic condition, doesn't mean that I'm going to fit in with someone's idea of what I should be doing. I remain a woman with strong career ambitions; multiple sclerosis doesn't mean giving up on my ambitions, just rethinking how I can achieve them.

**If you were an EU politician, let's say a member of the European Parliament, what would be the first thing you would do or change for people living with multiple sclerosis in the EU?**

What a wonderful ambition! The first thing I would change would be to open up the conversation and involve everyone. We don't talk openly about disability or the discussions are limited to a certain group of people with disabilities and a certain number of people who focus on the disability issues. This is a subject for every person reading this.

Every single one of us in the EU will have a friend, a relative, a neighbour, an employer or employee who will be affected by a disability. It is part of life yet we treat it as though it was an exception. The only exception is the old-fashioned attitudes that are formed when people don't have information or are dismissive. When we talk about chronic illness and disability people living with the conditions need to be at every stage.

It absolutely needs to be higher on the agenda. More than one in four people will be affected by a disability in their lifetime. We have millions of people in the EU with neurological conditions such as multiple sclerosis, Alzheimer's and Parkinson's disease and the numbers are growing. The medical expenses and our pharmaceutical costs are getting higher. What is the one

thing we all have that makes us capable taking part in this process? Our brains. Yet, we still don't place enough on the importance of taking care of our brain, the neurological side of our life and have to be jolted into reacting.

But one thing I love about being part of the EU is the idea that we can get everyone together and we can talk, discuss, plan, be creative and innovative and bring about social change.

**At the moment, many policies are also short-term, especially right now when everyone is afraid of taking risks. What impact does this have?**

I think it's always like that. If you are an elected representative then you have people who have voted for you and you are going to make sure that you keep them happy. This is of course, how the system works. But in the EU Parliament, the horizon is bigger and the possibilities endless. I think the idea of the EU community is to take the local issues to the international level, collaborate with others working on the same issues and implement changes together to benefit the whole of the EU population.

There are all these wonderful strategies and targets such as Europe 2020. By taking a reasoned approach it is possible that we will have a sustainable and inclusive economy and community. While we might have different cultures, most people want to work, to have family and friends, to be safe, to have their voices heard and to live a life of health, wealth and happiness. Much of these are an adult's responsibility but it is the policy and decision makers who can ensure the right environment for their people to have these outcomes.

**The European Parliament elections are coming up in May. Thinking in a cynical way, could it be about somehow letting politicians know that there are a huge number of voters with disabilities that they can appeal to, and letting the people**

Continued on Page 7

Continued from Page 6

**with disabilities know that they need to vote because they will be heard?**

Absolutely, they will be heard. If you're going to ignore a large percentage of the population by only including them when you want their vote, people are going to respond in the same way and ignore MEPs

at election time. It's part of democracy to listen to your voters, but what's happening is that democracy seems to only matter when a politician wants a vote.

For me, it's not just about politicians announcing and deciding. When people with expert experience, people who live with conditions such as multiple sclerosis are involved at every level in working

out policy, the results will be relevant and more sustainable. We need people with disabilities to speak out and take part and we need the others at the table to make room. This is not only possible, it is necessary for the sustainability of the Union. It is this that will make the difference to all of us, whether we're living with a disability or not.

## Data shows treatment inequalities for EU's multiple sclerosis patients

Access to treatment and services varies remarkably for EU citizens diagnosed with multiple sclerosis, depending on which country they live in, according to a survey by the European Multiple Sclerosis Platform (EMSP).

The MS Barometer 2011, which has measured and compared wellbeing and quality of life for people living with multiple sclerosis in 33 European countries, including 26 EU member states, shows huge disparities in terms of access to treatment, therapies and employment.

While Germany overall came on top as the best country for people with multiple sclerosis in the EU, scoring 207 points, ahead of Sweden (184 points) and Austria (178), Bulgaria scored the fewest points (62 points), followed by Poland and Lithuania with 87 and 88 points, respectively.

Maggie Alexander, CEO of the EMSP, told EurActiv that the impact of having a condition such as multiple sclerosis is much more severe in countries that fail to



Photo: Adam Gregor / Shutterstock

provide the optimal treatment and services to help people maintain control of their disease, including remaining economically independent and fully participate in society.

"The EMSP will continue to drive forward effective collaborations with EU institutions and all those that share our commitment to escalate progress in the vital areas of research, healthcare and employment," Alexander said.

"This will help to reduce the health inequalities that are faced by far too many of the nine million people in Europe living with neurodegenerative conditions," EMSP's CEO continued.

Multiple sclerosis is a potentially disabling disease. It strikes the white matter of the brain and spinal cord and affects the rest of the nervous system. According

Continued on Page 8

### Continued from Page 7

to the EMSP, multiple sclerosis has great consequences for society as more than one million people in Europe are affected indirectly through their role as carers and family members.

Younger people between 20 and 40 are the ones who are the most often diagnosed with multiple sclerosis. Women are diagnosed twice as often as men.

### Strong protection

More than 120,000 people with multiple sclerosis live in Germany. This is more than in most other European countries. The EMSP said that Germany, with its long tradition of universal healthcare, provides strong protection for all disabled people.

When it comes to multiple sclerosis, the treatment in Germany is carried out by inter-disciplinary teams. The full cost of disease-modifying drugs is reimbursed by government without limits on duration of treatment and the treatment of symptoms is also fully covered. People also have unlimited access to rehabilitation.

Another positive fact about Germany is that good access to new medication and that specialised palliative care are offered while the country also scores high on research.

Germany also scores best in employment and job retention for people with multiple sclerosis, the barometer confirmed. This is due to protective legislation and flexible working conditions. 32% of people with MS are employed full time and 13% part time. An early retirement pension fund also exists.

### Restricted access to care

At the same time, an EU country with low government spending on healthcare, like Poland, provides poorer treatment and quality of life for people with multiple sclerosis.

Poland has a very high ratio of people with multiple sclerosis, 120 in 100,000 people affected. Around 500 people are

newly diagnosed each year. However, access to disease-modifying treatment provided is restricted. For example, after five years, access is transferred to the next person on the waiting list.

And though access to therapy for treating symptoms is relatively high, state reimbursement is modest with less than one-third of people having access to rehabilitation services.

Concerning employment, Poland fairs well due to strong laws against discrimination in the workplace. The country also scores well on empowerment of people with multiple sclerosis.

### Lacking EU response

In September 2012, the European Parliament passed a written declaration initiated by the Romanian MEP Petru Luhan from the European People's Party (EPP) on tackling multiple sclerosis in the EU, endorsed by more than 400 MEPs, calling for the European Commission and member states to enhance equal access to quality care.

But this commitment was not followed up with any concrete measures to reduce the inequalities for people with multiple sclerosis across the EU.

The EMSP said that the EU should live up to its declaration by addressing four major problems. First of all, the EU needs a closer scientific collaboration and comparative research on multiple sclerosis.

Secondly, there should be equal access to treatment and flexible employment policies for people with chronic neurological disorders such as multiple sclerosis.

Thirdly, there should be equal access to quality care, the EMSP said, for example by using certified educational training tools and lastly, collection of patient data at national level is encouraged in order to compare best practices.

EurActiv has asked Luhan as well as other MEPs, who have previously been involved with issues related to multiple sclerosis, for an interview. Unfortunately, they all declined.

## Neurologist: 'The brain is running all other illnesses and must be preserved with special care'

More research on the brain could help tackle diseases of all sorts but there shouldn't be a funding race between brain conditions and other diseases, says Mary Baker.



*Dr Mary Baker is the President of the European Brain Council (EBC). She spoke to EurActiv Spain's Fernando Heller at the conference 'Understanding the brain: Where are we in 2014?' in Barcelona, Spain.*

**You said during the conference that you don't want there to be a race or competition between brain diseases and cancer, cardiovascular disease and diabetes. Do you feel there is a "competition" around diseases?**

Continued on Page 9

Continued from Page 8

Health is a very competitive market. There are so many patient organisations, so many organisations in general... and all speaking with passion! What we are trying to do in the European Brain Council space is to let them all speak with one voice.

And I really want to make it very clear: I don't want to see brain dominating over cancer or diabetes. The difference about the brain is that it is running all other illnesses and it must be preserved with special care.

#### **What can -and should- politicians do at EU and national level?**

They need to do something because the cost is running away it's very high for the European economy. And I put it very cruelly: Cancer patients are usually cured... or they die. Brain patients are continuously deteriorating. So the social costs can't be sustained. How can we do things better? Perhaps with better management and early diagnosis.

#### **Do pharmaceutical companies invest enough in brain research and multiple sclerosis?**

I think for big companies, multiple sclerosis is relevant, but it's much more difficult to deal with. I was told not long ago by a representative of a big pharmaceutical company: "You know Mary, in cancer we can take a tumor into laboratory look at it, cut it out and understand it. But we can't look in the brain until someone is dead."

The brain is not as easy to understand. And we also have other problems: The brain is very affected by the environment. It's such an important organ to try to keep going because that's highly cost-effective for yourself, your family and your health system.

#### **A combination of public and private sector resources could be the right answer?**



Photo: Tyler Olson / Shutterstock

Certainly, a private-public combination could be one way to go. I think they (politicians at EU level) need to support research on the brain, more than they do because, frankly, it will be the brain that will get us out of the present troubles. It won't be the kidney or the liver. We really need to invest in this. If we don't do it, it's going to really hurt GDP in the whole of Europe.

#### **You put the emphasis on the economic impact of multiple sclerosis and brain diseases... What about the patients?**

Of course, this is about distress, of course both for patients, to families, but it's also a very big economic question. There is an economic formula to explain

this: It takes six tax-paying working people to sustain one elderly pensioner and the birth rate is falling all across Europe!

#### **Is this also about raising awareness among politicians?**

The message we have for the European Commission is that we need more research to try to have better understanding of the challenges, but it's also the society that plays a role in prevention. What can we do to improve our own health? We should do more, for instance, to prevent stroke, as this consumes an enormous amount of money.

Certainly, we could do much more on alcohol and tobacco prevention. Lifestyle is still important for brain diseases. And, don't forget, also for the taxpayer's money.

# Public-private partnerships point way forward for brain research

Pharmaceutical companies hesitate before investing in brain research, as it is seen as an overly complex area, but a European Commission initiative is a step in the right direction, according to the European Brain Council (EBC).

The direct cost of healthcare in Europe related to brain diseases has soared from €386 billion in 2004 to to €798 billion in 2010, according to data from 30 European countries, highlighting the need for research in that area.

But as the brain is a difficult organ to deal with for researchers, pharmaceutical companies hesitate before making the investment, especially during times of austerity.

This is where public funding can make a difference. A public-private partnership between the European Commission and the European Federation of Pharmaceutical Industries and Associations (EFPIA) could provide a way forward. The programme, called the the Innovative Medicines Initiative (IMI), aims at speeding up the development of better and safer medicines.

The IMI is strongly endorsed by the European Brain Council's president, Mary Baker.

"Certainly, a private-public combination could be one way to go," Baker told EurActiv in an interview. "I think they [politicians at EU level] need to support research on the brain, more



than they do because, frankly, it will be the brain that will get us out of the present troubles. It won't be the kidney or the liver. We really need to invest in this. If we don't do it, it's going to really hurt GDP in the whole of Europe," she said.

The first IMI, which took place between 2007-2013, funded 40 projects and developed new therapies for patients while creating nearly 1,500 jobs for a budget of €2 billion, with half of the funding coming from the Commission and the other half from the pharmaceuticals industry.

The second initiative, spanning the period 2014-2024, has seen its budget rise to approximately €3 billion. It will focus on the development of treatments that contribute to lifelong health and well-being, which are expected to gain in importance due to the aging population and rising levels of chronic and degenerative diseases.

At the same time, the Commission has launched the Future and Emerging Technologies (FET) initiative which includes the Human Brain Project. This project aims to contribute to neuroscience, medicine and future technology via modern information technologies, based on the principle that "understanding the human brain is one of the greatest challenges facing 21st century science".

But while the EU is making the right steps in terms of treatment, Baker said that policies also need to focus on

prevention as the brain is an organ which is highly affected by the environment.

"What can we do to improve our own health?," Baker asked. "We should do more, for instance, to prevent stroke, as this consumes an enormous amount of money. Certainly, we could do much more on alcohol and tobacco prevention. Lifestyle is still important for brain diseases. And, don't forget, also for the taxpayer's money," the EBC president stated.

## For information on EurActiv Special Reports...

### Contact us

**Delia Nicolaescu**

[events@euractiv.com](mailto:events@euractiv.com)

tel. +32(0)2 788 36 72

**Arnaud Sonnet**

[publicaffairs@euractiv.com](mailto:publicaffairs@euractiv.com)

tel. +32(0)2 226 58 17

### Other relevant contacts:

**Rick Zednik**

[ceo@euractiv.com](mailto:ceo@euractiv.com)

tel. +32(0)2 226 58 12

**Frédéric Simon**

[executiveeditor@euractiv.com](mailto:executiveeditor@euractiv.com)

tel. +32(0)2 788 36 78

**Henriette Jacobsen**

[henriette.jacobsen@euractiv.com](mailto:henriette.jacobsen@euractiv.com)

tel. +32(0)2 226 58 15



# EU NEWS & POLICY DEBATES - ACROSS LANGUAGES -

## THE EUROPEAN MEDIA NETWORK FROM 12 EU CAPITALS



### EurActiv network

- Core network members
- ▲ Network members
- Associate network members
- Syndication partner

[www.euractiv.com](http://www.euractiv.com)

*“Efficacité et Transparence des Acteurs Européens”*



# Raising the voice of people with MS in Europe

The European Multiple Sclerosis Platform (EMSP) represents more than 600,000 people living with multiple sclerosis (MS) in Europe. Their needs are the main focus of our advocacy and awareness-raising campaigns. Our flagship projects aim to improve quality of life as well as access to treatment, care and employment. En route to its ultimate vision of a world without multiple sclerosis, EMSP works to ensure that people with MS have a real voice in determining their own priorities.

Photographs from the multi-media **Under Pressure** project  
[www.underpressureproject.eu](http://www.underpressureproject.eu)



## Flagship projects

- **European MS Barometer** – a bi-annual collection of comparative MS data provided by national MS societies;
- **Under Pressure** – a multimedia project involving renowned photographers, illustrating the healthcare inequalities captured in the MS Barometer;
- **EUREMS** – a data-registration initiative aimed at building a cross-border MS-information infrastructure which combines knowledge from specialists, researchers and patients;
- **MS Nurse Pro** – an accredited online education programme, promoting the role of MS nurses and the provision of care across Europe;
- **Believe and Achieve** – an awareness-raising campaign to improve access to employment and training for young people with MS in Europe.

## Call to action

MS continues to pose important challenges for individuals and society. The current total cost of dealing with multiple sclerosis in Europe has been estimated at 15 billion euros per year. This problem will not simply go away with time.

Therefore it is up to organisations such as EMSP, together with people affected by MS, policy-makers, specialists and researchers, to work with urgency towards a world without MS. We are at a tipping point and we cannot afford to move backwards now.

## Support EMSP

Those who believe in our mission can support us by making a donation or by promoting our messages and projects. Information on ways to support our work is available on the 'Get Involved' section of the Under Pressure website: [www.underpressureproject.eu](http://www.underpressureproject.eu)

**European Multiple Sclerosis Platform**  
 Rue Auguste Lambiotte 144/8  
 1030 Brussels | Belgium  
 telephone +32 2 304 5015  
 fax +32 2 305 8011  
[secretariat@emsp.org](mailto:secretariat@emsp.org) | [www.emsp.org](http://www.emsp.org)

# European Multiple Sclerosis Platform