Understanding the Brain

PHOTO: ‘Sunset of hope’
Liliana Vezetiu (Romania)

“My goal is to travel as much as I can. Even though I have multiple sclerosis and travel difficulties, I like to spend a lot of time in nature, to watch the sunset and to enjoy every moment. I am in this photo and it was made by my husband in Ramnicu Valcea, Romania.”

This photo is from the competition #BrainLifeGoals - Read more on p2

ONE in SIX
people are affected by a neurological disorder.
It’s the challenge of our times.

020 3448 4724 | nationalbrainappeal.org

EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS
“Things many of us take for granted are just dreams for those living with neurological disorders”

MSSOCIETY
We can see a future where nobody needs to worry about MS getting worse.

INTERNATIONAL LEAGUE AGAINST EPILEPSY
Let’s bring epilepsy out of the shadows

"Things many of us take for granted are just dreams for those living with neurological disorders"
#BrainLifeGoals?

Sharing #LifeGoals has become a popular trend in social media. These #LifeGoals are often frivolous wishes like living in a beach hut in the Bahamas, or buying a ridiculously expensive designer handbag! So, what are your #BrainLifeGoals?

The human brain is immensely complex. It is the control centre of our bodies, directly affecting every vital function, ranging from the heartbeat, breathing, food and fluid intake, sleep, emotions and sex.

Research has advanced our understanding of the nervous system as well as the practical and clinical application of this knowledge—how the brain regulates our sleep, appetite, mood and other biological and psychological functions. This understanding is essential to expand and boost brain research in Europe.

The brain mission

To celebrate Brain Awareness Week, why not join the conversation?

The campaign, which has been running for over a year, has also extended its reach beyond medical and research communities, to families and the general public. The #LifeGoals vs. #BRAINLIFE GOALS campaign is an innovative, interactive and engaging platform to improve the quality of life of all those living with a neurological disorder.

The silent emergency of brain disorders

The brain mission

A healthy brain is the ultimate prerequisite for quality of life and sustained social wellbeing. 2014 figures indicate that 270 million Europeans live with disorders of the brain. These include both mental and neurological disorders, such as Alzheimer’s disease, Parkinson’s disease, multiple sclerosis, migraine, depression, schizophrenia, bipolar disorders and anxiety disorders. Every day, two million of these are exacerbations of the brain, these numbers are increasing steadily.

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The silent emergency of brain disorders

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It is evident that understanding the needs of those living with neurological disorders is crucial. The silent emergency of brain disorders is ubiquitous, with 179 million Europeans living with disorders of the brain.

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In recent years, innovative new technologies have emerged that are revolutionizing the way we do healthcare. Research is playing a key role in this process, to usher in which progress would be needed. In business, we look at innovation as a means for future capabilities, such as new products, processes, and services. In health research, research and programmatic support is an important feature for future capabilities of detection, treatment and life-saving, life-changing tools.

It is evident that realisation of change is needed. We need to improve the lives of people living with these life-disrupting diseases. We need research, improved care and a society that prioritises the health of brain disorders in Europe.

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Lack of funding is a huge barrier to innovation. Mental health accounts for 20% of the burden on the NHS, but only 5% of its £134 billion (£112 billion) per annum. Investment in health research is needed to deliver solutions.

The NHS has recognised this with its ambition to improve mental health services, yet these proposals must come with adequate resourcing for them to be delivered.

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**On the cusp of stopping MS**

With 130 people diagnosed in the UK each week, MS remains a devastating blow. But research has got us to a critical point, and the future could look very different.

### Current scientific breakthroughs give us reason to hope, and we now know myelin repair happens naturally in the brain

**Lost myelination**

A debilitating disease can trick older myelin-making cells into behaving like younger, more efficient cells.

**Diabetes drug**

A type 2 diabetes drug can trick older myelin-making cells into behaving like younger, more efficient cells.

**MS SMART trial**

On the back of the latest news from the MS SMART trial, hundreds of people are waking up from sleep attacks on the right track.

### Unlocking existing drugs

Recent scientific breakthroughs give us reason to hope, and we now know myelin repair happens naturally in the brain. In MS, there is a problem with that natural process, so scientists are working to get it working properly again.

### A new type of trial

While progress has been accelerating, MS treatments available for progressive MS are still very limited, and there are still thousands of people – like my sister and me – without any treatment at all.

### What the next decade holds

We can see a future where nobody needs to worry about MS getting worse. By 2050, we plan to be the first in the world to test a range of treatments for people with MS. Some of the biggest challenges we face are how to stop MS from getting worse. It takes many years to take a discovery from the lab to the clinic. There's still a long way to go, but, for the first time, there's genuine hope that we can stop MS.

### MS research could change lives like mine

Jacqueline Krupar is one of over 130,000 people living with MS in the UK. She explains why research is so important to her, and why she believes MS can be stopped.

When I woke up one morning in 2008, with double vision, I brushed it off as a problem with my glasses prescription. But, after a visit to the optician and a referral to a neurologist, I soon realized it was something more serious.

A brain scan revealed areas of scarring on my brain known as lesions – an instantly recognizable feature of MS.

Looking back now, I know I'd experienced my first symptoms almost 20 years before. I'd had problems with my eyesight at school but, at the time, I was working in advertising and didn't really give it much thought.

For the first few years after my diagnosis, I experienced niggling symptoms, but was adamant I was fine. I didn't want to make a fuss. The MS has become harder to ignore.

Worrying for years, I began to have difficulties with my mobility, and cognitive processing. Since then, MS has made me feel less like me, and I don't love being me any more.

Living with my glasses half-fulfilled the criteria I was diagnosed. My sister Yolanda began asking me why I kept shaking my head, and was soon diagnosis with the primary progressive form of MS. What followed was, for her, a very quick downward spiral when she suffered severely with her fatigue and mobility. She lives over 110 miles away, but we talk every day about our MS and how we’re dealing with it, but everything else too! We support each other completely.

Both my sister and I have a problem with that natural process, so scientists are working to get it working properly again.

### Our commitment to finding solutions for people living with multiple sclerosis

In the UK, more than 130,000 people are currently living with multiple sclerosis (MS).1 MS is a potentially disabling disease of the brain and spinal cord (central nervous system): it is three times more common in women than men and it is most commonly diagnosed in people in their 20s and 30s.2

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### Reference


### Jacqueline Krupar and her family

The Krupar family were the first to take part in the MS Society’s Stop MS Appeal in 2008. Today, my son even ran the London Marathon to raise money for MS Society.

### MS Society

Donations to the MS Society can change lives like mine. There are still thousands of people – like my sister and me – without any treatment at all. The future could be very different.
When Nina Mago was a toddler, she would sit silently for minutes on end, unable to communicate what she was feeling. When she was little, her parents and teachers believed she was just shy, but as she grew older, they began to notice a pattern. Nina would have sudden outbursts of aggression, followed by long periods of silence. Her parents and teachers didn’t know what to do, and the situation became more and more difficult as Nina grew older.

When Nina was six years old, her family moved to London for her father’s job. There, she was diagnosed with epilepsy, which meant she had to stop taking the medication she was on. Her parents were devastated, and they didn’t know what to do.

For the next few years, Nina’s seizures were under control, and she was able to go to school and do normal things. However, when she was ten, her seizures started to get worse, and she began to have more and more seizures. Her parents were again at a loss, and they didn’t know what to do.

It wasn’t until she was twelve years old that they found out what was causing Nina’s seizures. They were caused by a birthmark on her skin, which was a sign of a genetic disorder. Nina was diagnosed with Dravet Syndrome, a rare and severe form of epilepsy.

Dravet Syndrome is a genetic disorder that affects the way the brain develops. It is caused by a mutation in a gene called SCN1A, which is responsible for producing a protein that helps to regulate the brain’s electrical activity.

Unfortunately, there is no cure for Dravet Syndrome, and the only way to control the seizures is through medication. Nina’s parents tried many different medications, but none of them worked. They were at their wit’s end, and they didn’t know what to do.

Then, they heard about vagus nerve stimulation (VNS) therapy, which is a non-invasive treatment that can help to control seizures. VNS therapy works by sending low-level electrical signals to the brain, which can help to reduce the frequency and severity of seizures.

Nina’s parents were hesitant at first, but they didn’t have any other options. They decided to try VNS therapy, and it worked. Nina’s seizures started to get better, and she was able to go to school and do normal things again.

VNS therapy is a safe and effective treatment for epilepsy, and it can help to improve the quality of life for people with epilepsy. It is a non-invasive treatment, so it is a good option for people who are not suitable for surgery.

After being diagnosed with Dravet Syndrome, a drug-resistant epilepsy, and being unable to control her seizures, Nina’s parents were at their wit’s end. They were desperate to find a treatment that would help their daughter.

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It is a staggering statistic, that one in six of us suffers from a neurological disorder, such as stroke, brain tumours, multiple sclerosis, Parkinson’s disease, epilepsy and dementia. At The National Brain Appeal we work closely with the world-leading doctors, surgeons and researchers at The National Hospital for Neurology and Neurosurgery and the UCL Queen Square Institute of Neurology, London, to fund their pioneering research, provide access to the best technology for expert diagnosis and treatment for their patients, and train tomorrow’s clinicians.

Since 1984 we have raised more than £45 million that we have invested in major new developments, patient care and research, including the UK’s first dedicated Brain Tumour Unit, the Dementia Research Centre and the MRC Centre for Neuromuscular Diseases.

Our current appeals include:

**Aphasia**
A transformative high dose therapy programme, providing 100 hours of therapy for patients with aphasia – speech and language difficulties following stroke, traumatic brain injury or brain tumours. The programme began in July 2019 with very encouraging results to date.

**Rare Dementia Support**
The world’s first dedicated specialist support service, providing information and guidance for people living with rare dementias, their carers, their families and their friends; support groups that bring people together to share their experiences and access to specialist doctors, nurses and researchers.

**Immunotherapy**
The UK’s first large scale immunotherapy clinical trial for NHS patients recently diagnosed with glioblastoma brain cancer, the most common type of primary, malignant and very aggressive brain tumour. This is currently underway and will be recruiting patients until the end of June 2020.

As well as our big appeals, we have a Small Acorns Fund, where front-line staff have the chance to apply for funding to fast-track smaller scale projects that will have a big impact and benefit to patients, such as mindfulness training to help staff teach their patients how to manage neuropathic pain and mobile arm supports to aid those affected by a stroke.

These might be small changes, but the difference they can make to people’s lives are enormous.

There are many ways that you can support our work: by making a donation, taking on a fundraising challenge, getting your company involved, volunteering for us, becoming one of our Ambassadors for Innovation and leaving a legacy in your Will.

Legacies represent around a third of our annual income. Leaving just 1% of your estate can make a real difference and is an investment in the future. The more money we receive, the more support we can give to The National Hospital, which in turn improves the prospects for those affected by neurological disorders.

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**For more information about our work and how you can get involved**
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Instagram @brain_appeal

**Sponsored by**

The National Brain Appeal helps to provide much-needed funds to support the National Hospital for Neurology & Neurosurgery and the UCL Queen Square Institute of Neurology – together known as Queen Square. This is one of the world’s leading centres for the diagnosis, treatment and care of patients with neurological and neuromuscular conditions.

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