

# Patient Inspired Innovation

Welcome to the issue 6 of the NIHR Brain Injury MedTech Co-operative newsletter.

In this edition, find out more about an initiative you can be involved in, our Regenerative Neuroscience Theme Leader, and a project to get involved young people to research.

## About us

The MIC is one of eleven national Med-tech and In vitro diagnostic Co-operatives (MICs) funded by the National Institute for Health Research (NIHR).



The MIC works with patients, carers, academics, clinicians and industry to develop new medical devices, healthcare technologies and technology-dependent interventions to improve treatment and quality of life for patients with brain injuries.

## Get Involved!

The MIC has developed a volunteer register for patients, carers and whoever has an interest in the advancement of healthcare technologies. For more information on the Register for Healthcare Involvement and Technology Evaluation (RHITE), please visit our website: <http://www.brainmic.nihr.ac.uk/rhite>

## Important:

To unsubscribe from RHITE and this newsletter please send an email to: [involve@brainmic.org](mailto:involve@brainmic.org)

## The NIHR Be Part of Research campaign begins!

To mark International Clinical Trials Day (ICTD) 2019, which took place on 20 May 2019, the NIHR launched the Be Part of Research campaign to encourage patients, carers and the public to get involved in research. The campaign was launched to coincide with Be Part of Research website, the public opportunity to find out about clinical trials that are relevant to them. This is a platform that gives the opportunity for patients, carers and the public to speak to healthcare professionals about research and how they can get involved to help improve healthcare for the future. In addition, the NIHR's social media channels will be highlighting the stories behind the research, hearing from researchers, healthcare professionals, patients and their families on an ongoing basis. The campaign is a chance for everyone to 'pledge' to be part of research on the NIHR website - whether you're taking part in a trial or simply telling friends and family about the importance of research.

**NIHR** National Institute for Health Research **NHS**

**BE PART OF RESEARCH**

Be Part Of Research

**I'M PART OF RESEARCH BECAUSE...**  
"I believe that there are gaps in the system following childhood traumatic brain injury. Patients and their families have a valuable knowledge base that can help to close those gaps."  
Ms Kate Gravett, parent  
BE A RESEARCH VOLUNTEER.

**NIHR** National Institute for Health Research

**870,250** participants took part in clinical research across England. This is the equivalent of **2,383** per day!

**In the last 12 months!**

## How to Pledge to Be Part of Research

We want patients, carers and the public to pledge their support for health and care research.

Take part, tell others about opportunities, and spread the word!

To find out how you can pledge this campaign, click this link: <https://www.nihr.ac.uk/news/nihrs-be-part-of-research-campaign-begins/11207>

Series; The Brain Injury MIC presents its Theme Leads

## Regenerative Neuroscience: Dr Mark Kotter

As you may be aware, the work of the NIHR Brain Injury MIC is divided into eleven themes led by internationally renowned experts in their respective field. This month we are delighted to introduce to you our Regenerative Neuroscience Theme Lead: Dr Mark Kotter.



Mark Kotter is an academic Neurosurgeon and Honorary Consultant at the University of Cambridge specialising in complex spinal surgery.

He graduated with distinction from the University of Graz, and obtained MPhil/PhD degrees studying neural regeneration at the University of Cambridge. He received neurosurgery training at the Medical University, Vienna, and the University of Cambridge, and sub-specialist training in complex spinal surgery at the University of Toronto.

His research focus is regenerative medicine and spinal cord injury with a particular interest in degenerative cervical myelopathy, the most common form of spinal cord dysfunction of adulthood.

He is Chief Investigator of the first ever regenerative medicine trial Cervical Spondylotic Myelopathy (RECEDE Myelopathy) and is the founder and a Trustee of Myelopathy.org, the first charity dedicated to Degenerative Cervical Myelopathy (DCM), which was launched on 7 May 2019 at the House of Lords.

Mark Kotter is also founder, Chief Executive Officer, and Director of Elpis Biomed Ltd, which won the Cambridge Start-up of the Year in 2018. To find out more about Dr Mark Kotter and his projects, please visit the website <http://www.brainmic.nihr.ac.uk/regenerative-neuroscience>

## What is Degenerative Cervical Myelopathy?

Degenerative Cervical Myelopathy (DCM) results from arthritic, congenital and degenerative changes to the spine and surrounding soft tissues causing progressive compression of the cervical spinal cord. Its onset may often be gradual, with limited symptoms such as numbness and tingling in the hands, imbalance, and increased urinary urgency.

It is a common but often overlooked neurological condition, affecting up to 5 per cent of people over the age of 40. However, it is underrecognized as patients and primary care practitioners often fail to appreciate the common early symptoms of gait dysfunction, hand impairment and neck/arm pain.

Surgical treatment is a highly cost-effective intervention which prevents progression of DCM and reverse many but not all of the symptoms. Early detection by clinical examination and magnetic resonance imaging is key. But too often DCM becomes progressive and as result has devastating impact on quality of life.

Most will never get a diagnosis, and those that do wait on average three to five years before getting appropriate treatment. This contributes to poorer outcomes, and most people with myelopathy are left with life long disability. Only around half are able to return to work. This leads to unnecessary suffering, and in addition burden on carers, families, health care systems.

In order to find out how improve recognition and diagnosis to prevent suffering, among health professionals and the lay public, Dr Kotter founded the initiative Myelopathy.org which was officially launched as a Charity last 7th May at the House of Lords.

to continue...at Myelopathy.org Launch Event!

**VISIT THE WEBSITE!**  
<https://myelopathy.org/>

**Myelopathy.org Launch**  
**Tuesday 7th May 2019**  
**House of Lords**



**Dr Mark Kotter,  
Founder and Trustee**

***“Myelopathy.org is here to give patients a voice, to ask questions, to effect change and to support research”***

On 7th May 2019, in the scenic venue of Cholmondeley Room and Terrace at the House of Lords, the BrainMIC attended the Launch of Myelopathy.org, the first charity dedicated to Degenerative Cervical Myelopathy (DCM). The special event was hosted by Lord Patrick and Lady Julia Carter of Coles and it featured talks from many speakers, including patients, clinicians, and industry representatives, all working together to improve the lives of those affected by this neurological condition.

Founded by Dr Mark Kotter, Dr Ben Davies with Mr Iwan Sadler, Myelopathy.org is now the first global scientific and clinical organisation dedicated to changing outcomes in cervical myelopathy through research, education, and collaboration.



**Mr Iwan Sadler,  
Patient and  
Founder**

*“I was 44 yrs old when i was diagnosed with cervical spondylotic myelopathy. I knew no one with DCM and I felt isolated and increasingly frustrated at the lack of information and awareness about this life changing condition”.*

**Prof Michael Fehlings,  
University of Toronto**

*“Future research will be directed at improve clinical assessment and imaging protocols, development of biomarkers and genetic tests, and translation of novel regenerative and neuroprotective strategies.”*



**Founder Dr Kotter with Simon Stevens,  
CEO of NHS England**



**Ms Shirely Widdop, Patient**

*“I was diagnosed with classical DCM in 2012 and underwent surgical decompression and fusion surgery that year, but have been left permanently disabled. I am a volunteer for Myelopathy.org, helping them spread the word at national neurosurgical & neurology conferences.”*





Take Part to Research...

## Designing the study protocol for Cortirio: Portable brain imaging for point-of-care diagnosis of traumatic brain injury

Last 10 May, the BrainMIC hosted a patients focus group at the Cambridge Professional Development Centre (CPDC) aimed at supporting Cortirio's in the development of a novel technology for brain imaging.

Cortirio team, led by Dr Patrick Beldon, has been funded by the NIHR i4i SME (Small Medium Enterprises) Connect to develop low-cost portable brain imaging to be used at the bedside of the roadside following traumatic brain injury. The initial concept is a headband that will wrap around a patient's head and allow clinicians to detect, image and monitor bleeding within the head through functional near infrared spectroscopy (fNIRS).



Different digital prototypes of the portable device were showcased by Dr Beldon and received real-time feedback by the focus group. The discussion with patients helped Cortirio to identify and clarify views on various aspects of the product and its development process, including the shapes, materials, composition and the consent procedures to use the device.

The group agreed to engage again with further workshops for the Cortirio project to assess and give feedback on the next prototyping phase.

**If you want to be involved in the focus group or have further info, please contact us at [involve@brainmic.org](mailto:involve@brainmic.org)**

**For info on CORTIRIO, please visit the website:  
<https://cortirio.com/>**



An update on...

## Reaching Out North Essex: "Young Minds Inspiring Health & Wellbeing Research" Event in Colchester

On 12 June 2019 the East of England NIHR Public Involvement Collaborative hosted a public engagement evening in Colchester, funded by NIHR Involve and the Research Design Centre (RDS).

Around 80 people - from local health, social care, council, voluntary sector, research organisations and young people - took part to the event aimed at developing projects to empower and giving a voice about community needs to local children and persons.

The creative thinking of this group of diverse adults and young people was facilitated by Mr Tom Mellor, an experienced and charismatic workshop practitioner, performer, sound recordist and teacher with a Masters in Education from Cambridge University, who energised the meeting and broke any potential barriers by involving people in shouting welcomes to each other across the room.



After welcome drinks, the launch evening got into full swing.

A group of young people who have attended every Reaching Out North Essex project partnership meeting, presented their ideas and creative projects leading the way in teaching the adult audience how to involve young people in research as equal partners.

Four were the projects presented with the help of mentors from:

- Firstsite Young Art Kommunity (YAK)
- Refugee Action Colchester
- Junior Ambassador Scheme
- Essex Council for Voluntary Youth Services (ECVYS)

The collaboration with community partners for community engagement demonstrated the layers of cultural and social nuances that are sometimes missed



The Reaching Out project is coming to an end in the next couple of months and we will keep you up to date with the projects and sustainable pathways developed to carve our future!



***This project is funded by a grant from NIHR INVOLVE and Research Design Service for one year from September 2018 until August 2019. It is one of four Reaching Out projects funded across England.***

***Please, visit the website: <https://www.invo.org.uk/current-work/reaching-out/>***

For further information

Tracey Johns Project Lead  
NIHR Research Design Service East of England  
Website: <https://rds-ee.nihr.ac.uk/>

School for Health & Social Care  
University of Essex, CO4 3SQ  
Email: [tracey.johns@essex.ac.uk](mailto:tracey.johns@essex.ac.uk)  
Mobile: 07557 939045

NIHR Brain Injury MedTech Co-operative  
Dept. of Clinical Neurosciences  
University of Cambridge  
Box 167 - Cambridge Biomedical Campus

T: 01223 336 944  
W: [www.brainmic.nihr.ac.uk](http://www.brainmic.nihr.ac.uk)  
Twitter: NIHRBrainMIC