

## **Headache Research in the UK**

A summary of the meeting of the All-Party Parliamentary Group on Primary Headache Disorders  
12<sup>th</sup> March 2013

**Ministers in attendance:** Jim Fitzpatrick MP (chair)

**Members of the Lords in attendance:** Lord Walton of Detchant, Lord Collywn

**Apologies:** Pauline Latham MP, Lord Luce

**Speakers:** Becky Purvis, AMRC (in place of Sharmila Nebhrajana), Dr Phillip Holland, University of Edinburgh, Dr Joanna Zakrewska, Dr Anna Andreou, Imperial College London, Dr Zameel Cader, University of Oxford

### **Introduction:**

Jim Fitzpatrick MP welcomed the speakers and attendees. He introduced the topic of headache research in the UK which was last discussed by the APPG in 2010.

### **Perspectives on Medical Research in the UK**

#### **Becky Purvis, Head of Policy, Association of Medical Research Charities (AMRC)**

Becky explained the large role medical research charities play in funding medical research in the UK equating to £1,137m a year. The majority of this (excluding the Wellcome Trust) is raised by individuals. She outlined the disparity between funds raised for health conditions and charities of various sizes. Generating research funds for less common or well recognised conditions or by small charities with limited resources presents significant challenge. Of the annual figure raised from health charities only 2% was allocated to neurological conditions. Becky outlined some of the key issues facing the UK research environment. Engagement of the NHS in research is expected to improve following the duty under the Health and Social Care Act for the promotion of research and the use of research evidence. This recognises research as a priority and marks a move towards research recognised as a part of good care. Becky stressed the importance of supporting the meaningful involvement of patients in medical research and ensuring that data is shared safely. Becky highlighted the importance of government and pharma investment to match charity funding of medical research.

### **Challenges to establishing research on primary headache disorders in the UK**

#### **Dr Phillip Holland, University of Edinburgh**

Dr Holland explained that he studied at the Institute of Neurology and completed his PHD before moving to San Francisco to undertake headache research. When he returned to London he was unable to obtain funding for headache research and therefore changed his research focus. He explained that these are the problems facing scientist working in the headache field in the UK.

Dr Holland explained that historically the UK has been at the forefront of research into migraine and headache. However we are now failing to hold that position, falling behind America and Europe. He demonstrated the prevalence of the condition in comparison to other neurological conditions and said that despite this it remains underestimated, under-recognised, under-treated and under funded. He explained that if the UK put more money into research to advance treatments this could significantly reduce the burden and save vast amounts of money for the economy.

Dr Holland outlined the key challenges facing independent researchers applying for funding. He explained that funding must become available to address the declining research base. Currently not enough universities in the UK have specialists who can support young headache researchers. He recommended establishing regional centres of excellence to train the next generation of headache

specialists. Dr Holland stressed the need for the priority of headache to be recognised by research journals. Currently headache is seen as a specialist area and therefore researchers frequently fail to be published in high impact journals which in turn make them less valuable to the universities and unlikely to achieve recognition of excellence. This impedes the ability of independent, non-clinical researchers to obtain funding. Finally Dr Holland stressed that greater scientific and public awareness of the seriousness of this neurological condition and work to challenge misconceptions

### **Trigeminal Neuralgia - Research**

#### **Professor Joanna Zakrzewska, University of Central London**

Professor Zakrzewska began by describing the symptoms and the impact of trigeminal neuralgia on patients and their families. She explained that whilst treatment options do exist, these come with drawbacks and side effects; there is currently no cure. Research is needed to support patients and clinicians to treat this disabling condition.

Professor Zakrzewska shared data from the National Institute for Health Research demonstrating the disparity between the low number of open studies for anaesthesia and pain compared to other health conditions. She outlined the requirements to conduct effective research into trigeminal neuralgia. These include epidemiology of the condition, an understanding of the genetics, information from patients, diagnostic tests and an understanding of the basic science causes and mechanisms involved. Professor Zakrzewska explained the challenges that mis-diagnosis can present for trying to find suitable patients to take part in clinical trials. She stressed the need to educate at primary care level and use support groups to help tackle this. The UK's clinical practice research datalink was cited as a valuable resource to unlock the potential of patient data in research. She highlighted the advancements that can be made when patient data is made available, allowing scientist to make predications and recommendations. Recent data collected on patients with TN and MS from America was used as an example.

Professor Zakrzewska concluded that more available grants from NIHR and similar bodies, national collaborations to strengthen scientific research, increased public engagement and patient involvement in research is needed to move this area of work forward.

### **Present and Future of Headache research in the UK**

#### **Dr Anna Andreou, Imperial College London & Chelsea and Westminster Hospital**

Dr Andreou outlined the prevalence of headache disorders that cost the UK £7billion per year. She explained that despite the problem being recognised and reported by the World Health Organisation, The Global Campaign against headache and the APPG on primary headache disorder there has been little change to relieve the burden. She identified that although there are some UK headache experts, the UK is now losing its' position at the forefront of the research field.

Dr Andreou outlined the knock on effect of the diminishing research base. The lack of knowledge means that there is insufficient education for health professionals and as a result patients are poorly managed which puts further strain on the NHS and UK economy. She demonstrated the lack of headache education in undergraduate medical school: 21 of the 34 medical schools do not teach on headache. Dr Andreou explained that this is not different from data collected from low-income and poor-resource countries in Africa. She explained that the lack of interest in this area is leading to a lack of investment and causing the UK to lose researchers.

Dr Andreou spoke about the difficulties that are faced by The Migraine Trust in raising funds for research and the challenges of conducting her research in an academic institute with no headache mentors. Dr Andreou outlined her current work investigating hypothalamic-thalamic interactions in migraine pathophysiology. She noted that parts of the study have been awarded from the International Association

for the Study of Pain which shows a positive step towards recognition of the importance of this area of research.

Dr Andreou concluded that moving forward research councils must acknowledge the importance of funding headache, there is a current misunderstanding by the MRC that funding is received from the London Pain consortium, and for headache specific grants to generate more research. She highlighted the role of the DoH and NIHR to fund research for better clinical provision and patient education. She called on academic institutions to accept international mentors not based in the UK to enable researchers to work here and to strive for excellence by increasing headache teaching. Finally she recommended that headache experts in the UK work collaboratively to apply for consortium grants and adopt multi-discipline research approaches to maximise opportunities for obtaining funding.

### **'The Headache in a Dish'. Perspectives on Headache Services and Research in the UK**

#### **Dr Zameel Cader Oxford University Hospital Trust & Oxford University**

Dr Cader introduced himself and his professional background as a consultant neurologist and lead of a research group investigating neuroregeneration in migraine. Dr Cader outlined the major burden that headache presents the UK. He explained that headache is in the top 3 reasons for A&E admissions and, despite being predominantly treated in primary care, accounts for 1 in 4 neurology outpatient referrals. Dr Cader stated that neurological clinical services in the UK are a disgrace. The UK falls behind Europe in the ratio of neurologist to population at an average of 1 neurologist serving ~110,000 people. Less than 1 in 30 Neurologists are headache specialists. Dr Cader stressed that specialist systems mentioned earlier to the APPG must be complimented by greater education at primary care level.

Dr Cader explained that despite investment by pharmas the number of successful efficacious drugs is falling and therefore companies are as a result not investing. This presents a problem for headache disorders as the nature of pain and headache disorders makes standard techniques and clinical trials very challenging; as a result many pharmas are not investing in headache research. Dr Cader emphasised some of the key UK led discoveries in migraine, namely the development of the triptan and discovery of the first gene linked to a typical form of migraine. However he explained that the latter only occurred through a side funding because the MRC would not fund a primary project in migraine.

Dr Cader outlined the approach to research developments that his group is currently undertaking. He described the Stem BANCC Consortium, an EU funded programme, which develops stem cells for drug discovery. The programme focuses on 8 major disorders, one of which is migraine. He emphasised that the inclusion of migraine was a result of developments made in his side-projects into the condition rather than being sought out as an area of priority need by investors. Dr Cader explained the on-going challenges of persuading pharmas of the benefits in investing in this work for headache disorders. Dr Cader summarised that building a strong research base in headache will improve clinical services and re-invigorate industry for drug discovery.

### **Questions and Comments**

Jim Fitzpatrick invited questions from the floor and asked speakers to summarise responses. These covered the following topics: engaging with Clinical Commissioning Groups to advance service provision, the need for research and the use of non-drug treatment including acupuncture, physiotherapy and psychiatry, the opportunities to submit funding proposals to cardiovascular charities, the need for the social and physical impact of pain to be recognised to underpin advancements in headache education and the use of GPs with special interest to provide education.

**Dr Cader:** He stressed that progress is being made in the headache research field. He encouraged the involvement of psychology and the positive effects of adapting a collaborative approach. He encouraged the headache community to lobby loudly on clinical provision to ensure that headache disorders remain on the radar. He stressed the need to pair up excellent clinical research with excellent basic research, involving GP interest groups and neurologists to establish a network across the UK that will invigorate scientist.

**Dr Andreou:** She recognised that although the MRC have funded some research into the history of headache funding must become available to investigate and develop therapies for patients. She reported her experience of being unable to secure interest from cardiovascular charities to jointly fund research and attributed this to a lack of acknowledgement of the problem. She welcomed multi-disciplinary approaches and the cost savings of training GPs with special interest.

**Professor Zakrewska:** She encouraged collaboration between headache groups and the pain groups who now have more access to funding. She highlighted the need to harness the number of patients to contribute to research to enable quality data for researchers. She also said that the lack of education problem applies to pain as well as headache.

**Dr Holland:** He confirmed that whilst collaborative approaches to funding were a good idea this was problematic with cardiovascular diseases as the relevant bodies have not expressed interest. He welcomed the opportunities that alternative therapies present for headache disorder sufferers.

**Becky Purvis:** She emphasised the benefits of collaborative working and highlighted the UK Clinical Research Collaboration which recognised a big gap in preventative research. The issue of co-morbidities could lead to joint funding calls which bring vital funds.

**Close**

Jim Fitzpatrick thanked the speakers and the attendees. The meeting was closed.