



action for **M·E**

**MRC** | Medical  
Research  
Council

Conference report  
M.E./CFS research summit workshop  
8–9 November 2006  
Executive summary

# Foreword

Over 30 research scientists and clinicians joined representatives of the Medical Research Council (MRC) and Action for M.E., 8-9 November 2006, at Latimer conference centre, Chesham, to identify opportunities for biomedical research into M.E./CFS.

Introduced by Dr Trish Taylor, Co-chair of Action for M.E. and chaired by Professor William C Reeves, Principal Investigator for the CDC CFS Research Program, Atlanta, the event included presentations on:

- *The funder's perspective* by Professor Colin Blakemore, Chief Executive, Medical Research Council
- *The PRIME project: patient experiences in research* by Sally Crowe, Douglas Badenoch and Dr Kirstie Haywood, PRIME
- *An overview of UK research to date* by Professor Peter White, Professor of Psychological Medicine, Barts & the London Queen Mary School of Medicine, Wolfson Institute of Preventative Medicine
- *Interdisciplinary studies of M.E./CFS – an international perspective* by Professor Nancy Klimas, Professor of Medicine, Psychology, Microbiology and Immunology, University of Miami.

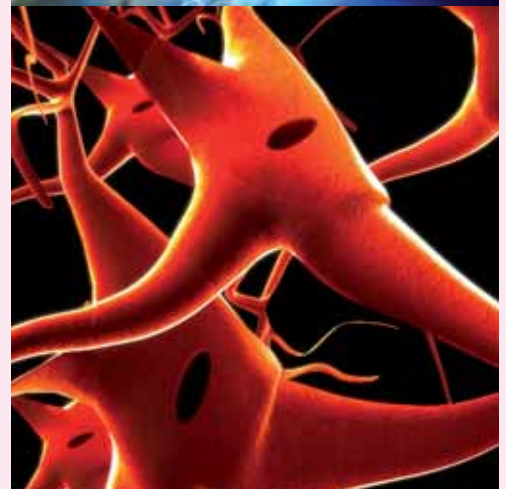
A panel discussion was then followed by a brainstorming session in breakout groups, which aimed to identify possible avenues of research.

This executive summary includes an overview of the presentations and outcomes of the event.

**M.E. (Myalgic Encephalomyelitis/Encephalopathy) is a chronic, fluctuating illness, also known as Chronic Fatigue Syndrome (CFS) and sometimes diagnosed as Post Viral Fatigue Syndrome (PVFS). The illness will be referred to as M.E./CFS for the purposes of this report.**

**M.E./CFS has been classified as a neurological illness by the World Health Organisation and Chief Medical Officer. The most common symptoms include severe fatigue, poor concentration and memory loss, unrefreshing sleep, headache, muscle pain, problems with digestion.**

**It is estimated that there are at least 250,000 people with M.E./CFS in the UK. Patient surveys lead Action for M.E. to believe that about 25% of its members are bedbound or housebound. M.E. can affect men, women and children from all social and ethnic groups. It appears most commonly in women.**



# Introduction

*Professor William C Reeves, Principal Investigator for the CDC (Centers for Disease Control) CFS Research Program, Atlanta.*

The M.E./CFS Research Summit organised by Action for M.E. and the MRC was the first MRC/patient advocacy group collaboration on an event for researchers and clinicians about the M.E./CFS research agenda.

Personally I think it is extremely important to have an active collaboration of the key stakeholders in M.E./CFS – patients, clinicians and the scientists who provide the evidence-based research on which the treatment depends. In the United States, the Department of Health and Human Services which includes the CDC, works very closely with the CFIDS (Chronic Fatigue and Immune Dysfunction Syndrome) Association of America, providing about \$6 million a year to educate health providers in the most up-to-date scientific knowledge and to conduct a public awareness campaign to educate the public.

**“This is your chance to think strategically about research agendas and what needs to be done in the field. How has what you have done complemented others? Where is it going? What needs to be achieved? This is the time to think outside the box.”**

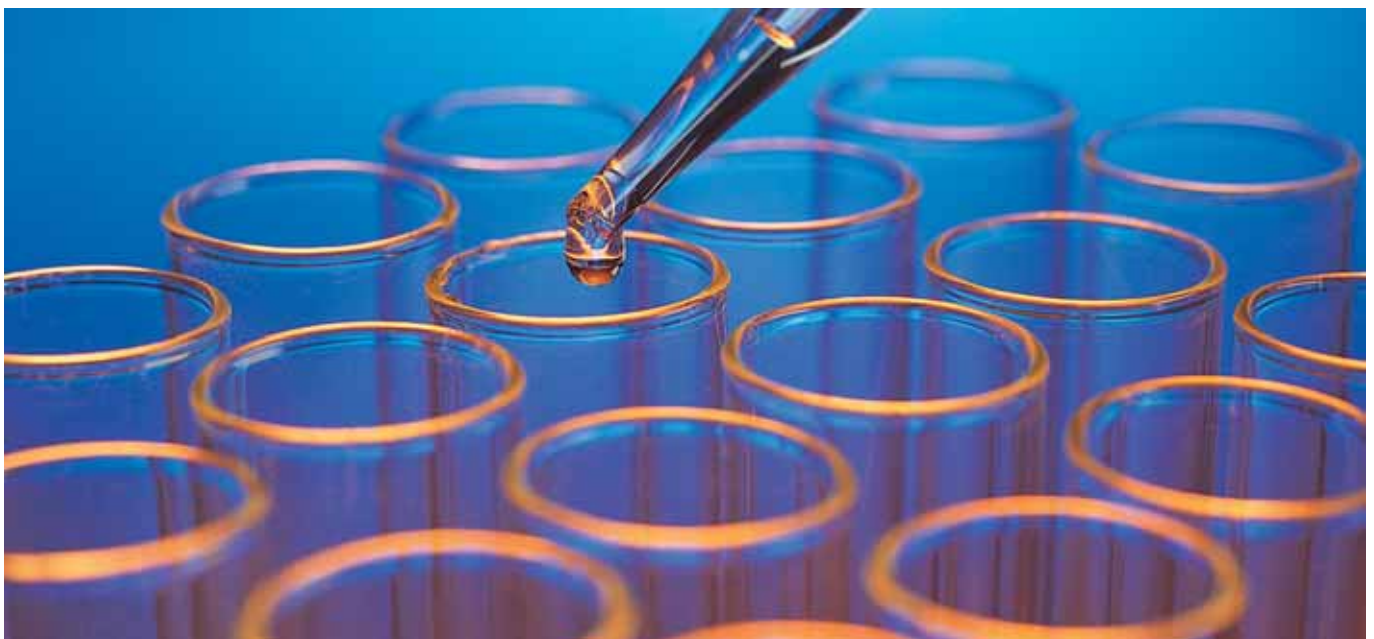
*Professor William C Reeves, CDC*

This event aimed to encourage more grant-supported research into M.E./CFS by identifying feasible goals for research based on current knowledge. To achieve this, it brought together investigators and clinicians to:

- identify opportunities for biomedical research
- develop networks for sharing information
- identify strengths, weaknesses and gaps in research
- facilitate capacity building
- assist the MRC and other funders in developing strategy.

The programme included an introductory session with four presentations which provided a context for discussing future research proposals. The speakers described funding opportunities and constraints, patient-experiences, UK research so far and the latest research from the USA.

This session was followed by a panel discussion and brainstorming in break-out groups to identify ideas for research.



# Summary of presentations

## The funder's perspective

*Extracted from the presentation by Professor Colin Blakemore, MRC*

The MRC does not commission research but can award funds for high quality research proposals which meet certain criteria. Grant applications are scored by referees drawn from the UK's College of Experts together with specialist reviewers from Britain and overseas. Short-listed applications are then assessed and scored by a Research Board.

Further information about grant assessment may be found on the MRC's website at [www.mrc.ac.uk](http://www.mrc.ac.uk)

Core assessment criteria are:

- how important are the gaps in knowledge that are being addressed?
- what are the prospects for good scientific progress?
- do the importance and scientific potential justify funding on the scale requested?
- are there ethical issues or risks to human participants?

Different funding schemes have additional criteria eg. the Research Grant Scheme favours innovative research plans but they must be realistic in aims and resources.

In 2003 the MRC issued a 'highlight notice' for M.E./CFS, to flag up that it would welcome high quality, investigator-initiated research proposals in the field. However, there is a need for more high quality proposals in the area.

## The PRIME project: patient experiences in research

*Extracted from the presentation by Sally Crowe, Crowe Associates, Douglas Badenoch, Minervation Ltd and Dr Kirstie Haywood, Royal College of Nursing Institute*

The PRIME (Partnership for Research in CFS and M.E.) website and database ([www.prime-cfs.org](http://www.prime-cfs.org)) is a searchable collection of anonymised, validated extracts from patient experiences, derived from interviews and literature search.

People with M.E./CFS are very willing to share their experiences but their accounts are often seen as 'soft' evidence, anecdotal and difficult to access/interpret, yet patient 'acceptability' and experience are important determinants of effective treatment.

The PRIME database presents this information differently, in a format which can be searched by theme (eg. coping strategies), age, sex, severity of illness and time diagnosed. The database currently includes 1,320 extract experiences.

Another area of work is a structured review of patient/person reported outcome measures (PROMs) used in the assessment of people with M.E./CFS. Well developed PROMs, usually in the form of questionnaires, can play an important role in healthcare assessment, providing information specific to the patient experience of ill-health and healthcare. This form of assessment may have greater relevance to patients, enhancing involvement in the consultation and evaluation process.

Well-developed PROMs are a powerful, quantifiable and standardised research tool, providing complimentary information to more traditional methods of health assessment. However, evidence suggests that there is little guidance and standardisation with regards to the appropriate assessment of health-related quality of life in M.E./CFS. Moreover, initial evidence suggests that assessment in M.E./CFS currently lacks an appropriate, scientifically rigorous, patient-reported assessment that adequately reflects patients' concerns and experience.

## Research in the UK

*Extracted from the presentation by Professor Peter White, Professor of Psychological Medicine, Barts & the London Queen Mary School of Medicine, Wolfson Institute of Preventative Medicine*

The main focus of treatment research in the UK has been to test two therapies: Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT). While some research indicates that a percentage of people with M.E./CFS improve with GET and/or CBT, some patient groups report deterioration and question the effects on children and the severely affected. There is dispute about how many people recover, whether pacing is as effective and what constitutes the essential process of improvement.

In the UK, the MRC has invested in two large-scale trials (PACE and FINE), an epidemiological feasibility study of chronic fatigue, irritable bowel syndrome and chronic widespread pain and a study which looked at chronic fatigue and ethnicity. The PACE trial (Pacing, Activity, Cognitive behaviour therapy; a randomised Evaluation) is looking at the effects of Standardised Specialist Medical Care (SSMC), and SSMD when supplemented by CBT, GET and pacing amongst 600 people attending hospital



outpatients in England and Scotland. The research is supported by the MRC, Department of Health (DH), Department for Work and Pensions and the Scottish Office. (See [www.pacetril.org](http://www.pacetril.org)).

The FINE trial is a nurse-led rehabilitation programme, compared to supportive listening and usual GP care, involving 360 primary care patients, based at home in the North West of England. It has the major advantage of the treatment being delivered in the patient's home, so severely disabled patients are eligible. It is MRC and DH funded. (See [www.fine-trial.net](http://www.fine-trial.net)).

Other current UK research includes genomics and proteomics, neuro-imaging, biochemical labelling, pharmacological treatments, behavioural aspects, secondary fatigue, the immune system and hormones. Some people are working with adolescents and the National M.E. Research Observatory will investigate the epidemiology of M.E./CFS.

Many research opportunities exist, eg. to collect data from the clinical network of multi-disciplinary services in England. Barriers to success include insufficient inter-disciplinary collaboration and insufficient funding for pilot study work.

There is much to learn from overseas, eg. from the Wichita study (see the main conference report or the CDC website at [www.cdc.gov](http://www.cdc.gov) for more information).

## Interdisciplinary studies of M.E./CFS – an international perspective

*Extracted from the presentation by Professor Nancy Klimas, Professor of Medicine, Psychology, Microbiology and Immunology, University of Miami*

Multi-disciplinary research teams add significantly to the scientific knowledge base. Professor Klimas said that her team at the University of Miami includes experts in immunology, autistics, endocrinology, behavioural medicine, nutrition, epidemiology, genomics, cognitive assessment, clinical assessment and neuroimaging. Studies have looked at a range of aspects of M.E./CFS, such as genetic predisposition, triggering event/infection, immune, endocrine, neuroendocrine and psychosocial mediators and health outcomes/persistence.

A number of events in America have resulted in research proposals. The CFIDS Association set up four Think Tanks on different aspects of M.E./CFS. Experts from related fields were formed into panels, and evaluated the state of the science after presentations from M.E./CFS investigators, then made recommendations. An additional day was spent in a methodology workshop, sharpening research plans and developing collaborative relationships. The experts on the panel became interested in the field and 35 new applications were received by the CFIDS Association Grants program. Unfortunately, they only had funding for four!

The National Institutes of Health (NIH) organised a more formal two-day workshop with an integrated multi-disciplinary intent. The event was open to the public and investigators in the field were encouraged to attend. The workshop had a number of invited speakers who have since gone on to find funding. The published proceedings provided valuable reading for would-be funding applicants. The resultant research programme announcement strongly endorsed multi-disciplinary research and attracted a number of applications.

The NIH agreed to sponsor another workshop on 17 September 2007 and welcomed both US and non-US proposals. For information on the workshop see <http://orwh.od.nih.gov/cfs.html>

The challenges of M.E./CFS research are: drawing new experienced investigators into the field; developing young investigators able to work in interdisciplinary teams; establishing a critical mass of investigators in the field across basic and clinical sciences to bring laboratory findings to the bedside; having a well defined patient base.

Private funding allows targeting of areas of research and can also be very successful in developing individual centres of excellence.

**“The challenges are drawing new experienced investigators into the field; developing young investigators able to work in interdisciplinary teams.”**

*Professor Nancy Klimas*

# Findings

The key findings were that there were opportunities for multi-disciplinary work and areas of potential research which could be developed into proposals (see below). As well as the challenge of attracting funding for their work, some researchers had found patients' "hunger" for answers or opposition to the nature of their research discouraging.

## Key outcomes – research proposals

Twenty research ideas and proposals were put forward as a result of the Summit. Topics included:

- pathophysiological studies to understand the disturbance of normal mechanical, physical and biochemical functions in individuals with M.E./CFS
- health outcomes research to understand the end results for particular healthcare practices and interventions and underpinning resources
- intervention studies including complementary medicine studies and feasibility studies for clinical trials
- observational studies of individuals with M.E./CFS.

**"An invigorating and productive day – helped break down barriers."**

*Anon evaluation form feedback*

**"A very interesting and thought-provoking workshop."**

*Dr Stephen Reid,  
St Mary's Hospital*

## Other outcomes

With agreement from participants, Action for M.E. established an e-network of researchers and clinicians, to encourage multi-disciplinary collaboration.

Researchers at the Summit agreed to circulate its findings at UK, regional and international meetings.

Evaluation forms described the event as innovative and called for the networks and ideas which were established to be taken forward. Suggestions for the future included:

- the organisation of further events such as an international conference
- production of an overview of what research is being conducted and what is needed
- increased communication between M.E. charities and funding bodies.

## Acknowledgements

Action for M.E. is indebted to Robert and Lizzie Cathery for their support, without which the Summit would not have been possible.

The charity would also like to thank the MRC for its contribution to the event.

Particular thanks go to Dr Sarah Perkins, MRC, for her invaluable help in planning the Summit workshop, to Professor William C Reeves, Principal Investigator for the CDC CFS Research Program, Atlanta, for chairing, to all our speakers for their presentations, to the researchers and clinicians who gave up their time to attend the Summit, not least those who have submitted proposals and to Dr Jane Turner for facilitating the event.

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