



## Collaborative Conference on CFS/ME 2007

AYME and Action for ME in collaboration with the National Network for CFS/ME Therapists and the National NHS Collaboration

**Milton Keynes 4th - 5th October**

### Invitation and Registration Programme

You are invited to attend the first Collaborative Conference on CFS/ME, which has been developed with a broad base of support and is intended to interest a wide audience. Many of you will know that the National Network of therapists has met in October for many years, and this conference stands in the place of the meeting this year.

The National NHS Collaboration grew from the national meetings of the Clinical Network and Coordinating Centres representatives, and continues to coordinate the development of effective NHS services for people with CFS/ME. There is of course an overlap in membership between the Network and the Collaboration. The programme was developed in collaboration with Ayme and AfME, and we hope that the learning and networking opportunities at the conference will be stronger as a result.

### Programme Outline

The programme will be divided into three sections. The first, on Thursday morning, involves a choice of meetings. The second, on Thursday afternoon, involves a choice of workshops. Plenary sessions and the Keynote Speaker, Professor Gijs Bleijenbergh, will take place during the day on Friday. In addition, there will be a poster presentation throughout the conference, and a conference dinner on Thursday evening.

## Registration and registration fees

You will find a registration form at the end of this document: please complete this, and return it before the first of August for an "Early Bird" discount.

Registration Fees are:

- Early registration (until 1st August) £100 for one day, £180 for both
- Late registration £125 for one day, £200 for both days
- Paediatric Special Interest Group alone: £50
- Conference Dinner: £25 plus wine

*Accommodation is not included within these costs (see below for accommodation details).*

CME approval is pending: attendance certificates will be supplied.

## Invitation To Submit Abstracts For Posters

The CFS Network is inviting delegates to submit posters about their work. We would like particularly to attract work from health professionals at the grassroots level of CFS (clinical and research) and encourage those who may not have published previously in this field.

The conference programme will include an "interactive" poster session when authors can give a 3-minute talk summarising their poster and answer questions. Delegates will also have the opportunity to view posters before the conference and during the breaks.

The subject matter for posters should fall into one or more of the following categories:

- 1. Reports of evidence based practice with patients with CFS**
- 2. Original research (which may be ongoing) which advances our theoretical understanding of CFS or its treatment**
- 3. Issues affecting the provision of services for patients with CFS**
- 4. CFS Service Audits**

Members of the executive committee will review abstract submissions. Successful submissions will be invited to display the poster at the Conference, where invited judges will choose the best poster.

*We are hoping to be able to offer a prize for the best poster and presentation*

Please submit your poster **abstract** in MS Word as an email attachment, by **Friday 3 August 2007** to:

[Gabrielle.murphy@royalfree.nhs.uk](mailto:Gabrielle.murphy@royalfree.nhs.uk)

Your abstract should contain the following information:

- **Title**
- **Authors**
- **Affiliation**
- **Email address of contact author**
- **Body of abstract** – no more than 200 words. Please structure this as appropriate for the subject material, e.g. for research reports, use the following headings: Background/objectives; design/methods; results; discussion/conclusions/clinical implications. Case studies or reports of qualitative work may vary from this format.

You will be informed by **Friday 17<sup>th</sup> August** whether your abstract has been accepted for a poster at the conference. At this time you will be sent more advice on formatting your poster. The maximum size for posters is likely to be B1 (100cm x 70cm).

## Conference Meetings: Thursday Morning

There will be three meetings held at the same time, which are:



### **1. Paediatric Special Interest Group Inaugural Meeting**

The Royal College of Paediatrics and Child Health Paediatric CFS/ME Special Interest Group will have its inaugural meeting at the conference, chaired by Dr Tim Chambers. This will include a mixture of research and clinical practice sessions. All are welcome to join.



### **2. National Network for CFS/ME Therapists AGM**

The network membership includes general practitioners, occupational therapists, physicians, physiotherapists, psychiatrists, nurses and psychologists. The Network functions across the Primary/Secondary Care boundary, and across the Paediatric/Adult boundary. The Network is also a stakeholder group in the development of the NICE guidelines for CFS/ME. The network has met once a year for an annual autumn multiprofessional study and information day for several years, and it's meeting this year is combined with the Collaborative Conference. All are welcome.



### **3. CFS/ME Champions and Co-ordinators Meeting**

This is a closed meeting for the current clinical champions and network coordinators, scheduled following our last meeting in May 2007.

## Workshops: Thursday Afternoon

Delegates can choose to attend two out of the following workshops:

- ★ **Vincent Deary:** Using CBT with adults
- ★ **Dr Esther Crawley:** collecting data to understand CFS/ME
- ★ **Facilitator tbc:** implementation of the NICE Guidelines
- ★ **Dr Hugh Rickards:** Depression, anxiety and the problems with differential diagnosis
- ★ **Chris Daniels/Rosanne Walton:** Innovations in service delivery for severely affected users
- ★ **Professor Trudie Chalder and Dr Mary Burgess:** Working with adolescents

## Friday: Keynote Speaker and Plenary Sessions

- ★ **Keynote Speaker: Professor Gijs Bleijenberg**  
Head of the Nijmegen Expert Centre for Chronic Fatigue, Netherlands  
*Cognitive behavioural therapy for chronic fatigue syndrome: the role of pain and the effects of guided self-management.*
- ★ **Dr Brian Marien**  
*The evidence supporting an integrated (mind/body) explanatory model for CFS/ME.*
- ★ **Professor George Davey-Smith**  
*The future of genetic research and CFS/ME*
- ★ **Dr Manny Bagary**  
*Sleep and CFS/ME research*
- ★ **Dr Julia Newton**  
*'Standing up for Fatigue': Autonomic Nervous System Dysfunction in CFS/ME*

## Speaker Information and Biographies

### **Keynote speaker: Professor Gijs Bleijenberg**

Clinical psychologist and Head of the Nijmegen Expert Centre for Chronic Fatigue, Radboud University Nijmegen Medical Centre in the Netherlands. The Expert Centre for Chronic Fatigue is a multidisciplinary collaboration focussing on the study of chronic fatigue. Furthermore, the ECCF is also a national referral centre for patients with chronic fatigue. About 300 patients a year can be seen for fatigue diagnostics, not only CFS patients but also patients with cancer related fatigue or with fatigue and a chronic disease. About 200 of them are treated with diverse forms of cognitive behavioural therapy.

### **Professor George Davey-Smith**

Professor of Clinical Epidemiology and head of the new MRC centre for genetic research in Bristol University, Director of ALSPAC, and Honorary Consultant with North Bristol NHS Trust, from October 1994. A world leader in epidemiology and genetic epidemiology, George Davey Smith has led the way in discovering which genes are important in traits such as obesity and height. He thinks we can do the same for fatigue and discover some of the important biological pathways for CFS/ME. Come and find out if this is true!

### **Dr Julia Newton**

Senior Lecturer in the Institute for Cellular Medicine, Newcastle University. She is the academic lead of the internationally renowned Cardiovascular Investigation Unit (Falls and Syncope Unit), which is arguably the largest autonomic nervous system testing laboratory in Europe. She has a reputation in the investigation of autonomic function in the pathogenesis of fatigue with a research programme funded by the MRC, ME Research UK, and Liver North. She founded and chairs the local multidisciplinary Fatigue Interest Group. The talk will focus on the physiological changes that occur when humans stand, and how autonomic nervous system responses to assuming the upright position may be impaired in those with CFS/ME.

### **Professor Trudie Chalder**

Professor of Cognitive Behavioural Psychotherapy in the Dept. of Psychological Medicine at King's College London. She has worked as a clinician and a researcher in the area of chronic fatigue syndrome for about 18 years and has in the last decade turned her attention to the needs of adolescents.

### **Dr Mary Burgess**

Works in the Chronic Fatigue Syndrome Research and Treatment Unit at King's. She is specifically interested in the needs of the severely affected and is currently piloting and evaluating a home based treatment for this group.

**Vincent Deary**

Is currently MRC Research Fellow at the University of Newcastle conducting research into medically unexplained dysphonia (hoarseness and voice the loss). He has been researching and treating (so called) medically unexplained symptoms for 12 years and, with Trudie Chalder, has pioneered the use of cognitive behavioural therapy to treat children and adolescents with chronic fatigue syndrome.

**Rosanne Walton**

Acting Head OT with the chronic pain and fatigue management team based at Rayners Hedge in Aylesbury. She was involved in setting up the fatigue component of the team in 1998 and has worked in it since. They run interdisciplinary chronic fatigue management programmes using a cognitive behavioural therapy approach with graded exercise therapy. They also offer a limited amount of individual outpatient fatigue management. She initially trained as a biologist, then did an OT degree and has since done a postgraduate diploma in psychology. Rosanna is currently trialling the use of Videophone with people at home. This means the client has a hands-free videophone at their house connected to one in the hospital.

**Chris Daniels**

A qualified counsellor and previously the Clinical service Manager for Action for ME, Chris now manages the NHS counselling and information telephone service for Avon Gloucester Wiltshire, and more recently Greater Manchester. This telephone service is targeted at the severely affected. Chris also works as a counsellor in the Bristol CFS/NHS Adult team.

**Dr Hugh Rickards**

Dr Rickards is a Consultant in Neuropsychiatry who is part of an interdisciplinary neuropsychiatry team based in Birmingham and in the West Midlands. He leads the CFS/ME Service in this region.

## Accommodation

The link below (which you need to click on to open) will take you to a Milton Keynes website which lists various hotels in Milton Keynes. Jurys Hotel (the conference venue) is listed/flagged as 'B'.

<http://maps.google.co.uk/maps?hl=en&q=hotels&near=Milton+Keynes,+UK&ie=UTF8&z=13&ll=52.032746,-0.738659&spsn=0.076883,0.159645&om=1>

Registration Form: Collaborative Conference on CFS/ME 2007

Jurys Hotel, Milton Keynes, Bucks  
Thursday 4<sup>th</sup> and Friday 5<sup>th</sup> October 2007

Please print clearly in block capitals. Your name, place of work and Profession/position held: these will be used for your name badge, the attendance list and your certificate of attendance.

Full name and title.....

Place of employment.....  
.....

Profession/Position held.....

Postal address.....

County .....

Postcode..... Tel No.....

Email.....

Special dietary requirements or other special needs.....

*Please tick the boxes as appropriate.*

- I have enclosed a cheque for: Until 1<sup>st</sup> August 07 £100 for one day, £180 for both days. After 1<sup>st</sup> August 07 (late registration) £125 for one day, £200 for both days. This does not include your hotel accommodation which you need to book independently. Paediatric SIG only £50  
*(Please note that this is the only form of payment we are able to accept and cheques must be made payable to **North Bristol NHS Trust budget code B09052**)*
- I would like attend the conference dinner at £25 per head plus wine
- I would like to be sent directions and/or a map.

Please return your completed form to:

Sue Webb  
9 Osterley Close  
Newport Pagnell  
Bucks  
MK16 0EZ

For further information please email:  
mecfsnetwork@fsmail.net

Reservation is a contract.  
Cancellations must be made in writing and will be subject to a 10% administration charge. No refunds will be made for cancellations notified within fourteen days of the event, but substitute delegates will be accepted at any time.