Media release

iPhone app launched to help people manage chronic condition

ActiveME®, a new iPhone application, has been launched to help patients with Chronic Fatigue Syndrome/ME (CFS/ME).

Developed by experts in the field of CFS/ME, and tested by people with the condition, this new app is designed to assist patients in keeping track of their activity levels, a key part of rehabilitation and self-managing this chronic condition.

CFS/ME affects approximately four in every 1000 people in the UK. The condition is common in children affecting at least 1% of teenagers, and is arguably the most common cause of long-term absence from school.

The Royal National Hospital for Rheumatic Diseases (RNHRD) NHS Foundation Trust, the Northern CFS/ME Clinical Network and Indigo Multimedia have teamed up to utilise modern technology as a tool to help these patients, who often find themselves in ‘boom and bust’ energy cycles.

Dr Esther Crawley, consultant paediatrician and service lead for the children and young peoples CFS/ME service at the RNHRD explains;

“Patients with CFS/ME suffer from chronic exhaustion that is not helped by sleep or rest. This affects all aspects of their lives, and on a bad day, even tasks that you or I might take for granted such as brushing our hair or watching TV can be extremely difficult. The flip side of this is that on a good day a person will do too much and then pay for it for the next few days. We call this ‘boom and bust’ energy cycles.

“Energy is anything that stimulates the brain or body. The evidence-based treatment that we use at the RNHRD involves patients monitoring their energy usage on day-to-day activities so that we can see when these cycles occur, prevent them from happening in the future, and help the patient to maintain balance and improve their condition.”

ActiveME® takes this premise and provides an innovative, interactive patient-centred tool designed to help patients monitor and track their activity and energy levels, show energy patterns and help to plan activities on an hourly basis. This data can then be recorded within the application and provide the person with a visual representation of their information.

Louise Wilson, programme manager for the Northern CFS Clinical Network adds;

“The app is a fantastic way for people to feel in control in managing their condition. Having the app on their iPhone makes their charts and monitoring information more portable and accessible which we hope will encourage more meticulous use of this self-monitoring tool.”

Dr Crawley goes on to say;

“The information recorded can then be discussed with their clinical teams and the data used to inform treatment plans. This makes each patients treatment highly individualised and patients can really feel that they are taking charge of their care.
“This is a really exciting development and provides us with another tool to help people with this complex condition to maximise their independence.”

The application is available to download from the Apple App store under utilities.

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Press contacts:

Royal National Hospital for Rheumatic Diseases NHS FT:
Caroline Kenny, Marketing and Communications Officer, caroline.kenny@rnhrd.nhs.uk
01225 465 941 ext 278

Northern CFS Clinical Network:
Samantha Start, Communications Officer, sam.start@northoftyne.nhs.uk
0191 217 2852

Notes to Editors

- Screen shot images of the ActiveME® app are available on request
- It is important that ActiveME® is used in partnership and rehabilitation planning with a patients specialist CFS/ME clinical team.
- Patients who do not have access to a smart phone will still be able to utilise exactly the same charts and information that is available on the app.
- The application will work on all types of iPhone running version 4.0 software and above. It will also work on iPods and iPads.
- The app is predominantly aimed at young people aged up to 25. However, patients over this age can also use the app.
- The app could also be used in other areas where fatigue management is part of a rehabilitation programme.
- The RNHRD NHS FT is a national specialist rehabilitation and rheumatology hospital based in Bath. Offering services to adults, children and young people, the trust has expertise in general and complex:
  - Rheumatological and musculoskeletal conditions
  - Neurological rehabilitation
  - Chronic pain management
  - Chronic Fatigue Syndrome/ME
  - www.rnhrd.nhs.uk
- The Northern CFS/ME clinical network aims to promote and support the delivery of evidence-based care for CFS/ME in the North East and North Cumbria
  www.cfsmenorth.nhs.uk
- Indigo Multimedia is an award winning digital agency offering solutions in web design, video production and e-marketing for a large portfolio of clients.
  www.indigomultimedia.com