



EMBARGO UNTIL PUBLICATION, 00.01 HOURS 12th May 2008 ME AWARENESS DAY

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ESTHER BACKS PEDAL POWER TO HIGHLIGHT PLIGHT OF ISOLATED YOUNG ME SUFFERERS

TV personality, Esther Rantzen CBE, today (*National ME Awareness Day*) put pedal power behind the campaign to improve support and services for children left bed-bound and in excruciating pain by the illness, ME/Chronic Fatigue Syndrome.



Esther Rantzen with recovered ME sufferer Martyn Jones

Esther is backing cyclist Martyn Jones, a former ME sufferer, in his bid to complete the world's toughest endurance sport event, the Tour de France, to raise £30,000 for the UK's children's charity, The Association of Young People with ME and the British Heart Foundation.

Martyn was struck down with the illness for six years at the age of 17. Now aged 33, he is putting his wheels in motion around the gruelling 2,300 mile course to prove he's free of the illness and to highlight the plight of children and young people with ME languishing at home but without support, just as he was for a long time.

Esther Rantzen, whose daughter, Emily suffered for 14 years from ME, said: "It is shocking that so many people still suffer so severely with no treatment or support. It's especially tragic for children and young people since they suffer not only from the illness but from the loneliness and isolation it creates."

"The impact of ME on young people is especially damaging because it hits them at a crucial stage of their lives. Without support the impact can be severe. Martyn's challenging adventure will prove that you can recover excellent health and I am sure it will be an inspiration to the thousands of young people affected by the illness today."

Martyn, who expects his marathon ride around the 2,300 mile route will take three weeks commented:

“Cycling helped me to regain my health after ME and taking on the ultimate challenge is something I could only dream of lying flat on my back for weeks on end when I was younger. It chills me to think that even now the support is just not there for people in the same position today.”

A survey of 2,763 people released today – ME Awareness Day – reveals that no fewer than 40% of people had waited over a year to get a diagnosis.

The survey of members of Action for M.E. and The Association of Young People with M.E (AYME) also reveals that for one in five people (20%), including more than one in four children (25%), it took more than two years to get a diagnosis. Almost 19% of respondents (516 people) said they were simply too ill to seek help for their illness.

Mary-Jane Willows, Chief Executive of AYME, said:

“Children are still waiting too long for a diagnosis. We know if specialist help is given at an early stage, prognosis becomes more optimistic.”

NICE Guidelines say that children severely affected should be offered an assessment by a specialist immediately. Dr Esther Crawley, Consultant Paediatrician said: “In my experience most children don’t have access to a specialist service and this means hundreds of children are housebound without access to specialist help.”

A report of these initial findings, together with a link to a more detailed analysis, is available online through the AYME and Action for M.E. websites, www.ayme.org.uk and www.afme.org.uk.

ENDS

Case Studies of people with M.E throughout the UK are available.

Photos can be downloaded in Hi Resolution from <http://www.flickr.com/photos/26423447@N04/>

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References and notes to editors:

- (1) People wishing to sponsor Martyn Jones can donate at www.justgiving.com/letour4good
- (2) The survey was a postal and online questionnaire of members and non-members with M.E. It was organised by Action for M.E. and the Association of Young People with M.E. in March 2008. 2,763 surveys were completed (1,799 in hard copy and 964 online). The survey reveals 19% of respondents (516 people) were simply too ill to seek help for their illness. Of these, 91 were children and young people. Two were children aged under 11 years, 25 were aged 12-17 and 64 were aged between 18-25 years old.

Initial findings are available in a summary report. Further analysis is available online at:
www.afme.wordpress.com

- (3) National Institute for Health and Clinical Excellence guidelines on the *Diagnosis and Management of CFS/ME in adults and children* was published August 2007. See www.nice.org.uk/guidance/index.jsp?action=download&o=36190
- (4) 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). It affects over 250,000 people in the UK. Common symptoms include persistent exhaustion, un-refreshing sleep, poor concentration and memory, headache, muscle pain and digestive problems.

Patient surveys indicate that 25% of people with the illness are so severely affected that they become housebound or bed-bound, some for many years.

M.E. can affect anyone, at any age and from any ethnic group.

- (5) **AYME** (www.ayme.org.uk) is the largest charity for children and young people with M.E., providing information and support to children and young people with ME/CFS, their families, carers and professionals. AYME raises the awareness and understanding of the impact of this condition on young people. The charity's membership services, run by young people with M.E. aged under 26, focus on reducing the isolation felt by young people.

Action for M.E. (www.afme.org.uk) provides information and support to people affected by M.E. and their carers and campaigns for more research and better treatments and services for them. The charity has a volunteer support line, welfare rights line and a range of helpful booklets and leaflets.

Action for M.E. and the **Association of Young people with M.E.** (AYME) are two of the UK's leading charities dedicated to improving the lives of people with M.E.