



**Colitis and Crohn's Week
16-24th June 2007**

“First survey of Young People with Colitis & Crohn's Disease reveals huge need for better support and information”

16th June, 2007. St Albans, Herts. The first major survey of nearly 1,000 young people with Colitis and Crohn's Disease reveals that these life-long Inflammatory Bowel Diseases (IBD) have a dramatic impact on their lives. Carried out by NSM Research for the National Association for Colitis and Crohn's Disease (NACC), the survey highlights a huge need for improved support and information for young people aged between 16-29 years to help them better understand and manage their conditions.

With an average age of diagnosis of just 20 years, over 80% of the 974 responders reported their most serious symptoms as being diarrhoea, pain and severe tiredness. Disease flare-ups were reported as occurring at least once in the previous year by 75% of the young responders and 24% had suffered more than four flares in the last year. These serious levels of illness resulted in 33% of responders being admitted to hospital and a similar proportion undergoing major surgery.

Not surprisingly the survey underlines the profound effects that Colitis and Crohn's Disease can have on the education, careers, social lives and relationships of young people. More than 20% stated that their disease impacted negatively on their education; 35% reported that it seriously affected their career; 51% their social life and 17% of responders felt that it seriously affected their ability to find a partner.

A less obvious consequence of Colitis and Crohn's Disease is the isolation brought about by needing to be near a toilet combined with the symptoms of pain and tiredness. 43% of young people reported feeling seriously isolated at the time of their diagnosis and 20% said they are still affected by isolation today.

As a result of these survey findings and further research NACC has carried out amongst young Colitis and Crohn's patients, the medical charity is responding to young people's particular needs for information and improved support by launching a new out-reach campaign – **“IBD and Me”**.

Designed to inform and help young people who are often isolated by their disease, “IBD and Me” takes the form of a new website area with links to helpful information from NACC, and a discussion board

that enables young people to share feelings and experiences with others of their own age. The web address is www.nacc.org.uk/ibdandme

NACC is aiming to reach as many young people as possible, starting in Colitis and Crohn's Week (16th-24th June) with free membership for 16-18 year olds and the launch of "IBD and Me" posters in hospitals and pharmacies nationwide and media campaign. In September the campaign will be extended to schools, colleges and universities. The charity aims to increase awareness and understanding of the extreme difficulties faced by young people, not only in coming to terms with their adolescence, but also learning to cope with the distressing day-to day symptoms of IBD and the unpredictable disease flare-ups that can occur.

Richard Driscoll, NACC Director, explains, "Many young people haven't had the chance to meet others who have the same illness and we can see from the survey that they often feel very isolated in their experience of IBD. NACC can reassure them they are not alone and provide the means for them to be in touch with other young people. The information and contacts they find through NACC can help greatly in adapting to life with Colitis or Crohn's Disease."

NACC's aim is to improve life for as many young people as possible. The hospitals, pharmacies, schools, colleges and universities are all being asked to place the NACC Campaign posters in prominent positions, and, says Richard, "The support of everyone in spreading awareness of our campaign will be really important in helping us reach the thousands of young people who are coping with IBD on their own."

Young people can log onto www.nacc.org.uk/ibdandme or call the Information Line: 0845 130 2233 (daytime) or NACC-in-Contact Line: 0845 130 3344 (afternoons and evenings). **ENDS**

Editor's Notes

Background notes on Colitis, Crohn's Disease, NACC and IBD and Me are available on www.nacc.org.uk in the media section

Crohn's Disease and Ulcerative Colitis affect more than 1 in 400 of the UK population and approximately 13,500 new cases are diagnosed annually.

NACC provides a valuable support network and information resource for people and families affected by Colitis and Crohn's Disease as well as raising significant funds for research. The 70 local **NACC Groups** across the UK enable members to meet other people who have these illnesses and share information and experiences.

The **NACC Information Line** (daytime) is available to members and non-members alike who have queries about all aspects of their disease. The **NACC-in-Contact Line** (afternoons and evenings) offers people a chance to speak to a trained volunteer who has Colitis or Crohn's Disease.

Membership of NACC is open to anyone who has Colitis or Crohn's Disease, their friends and families, health professionals and anyone who wishes to support the charity. Membership costs £12 in the first year, £10 thereafter. NACC is now offering free membership to 16-18 year olds.

NACC – Improving life for people affected by Colitis and Crohn's Disease

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