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STEP UP AND BE COUNTED

www.nacc.org.uk
Information Support Research
for **CROHN'S and COLITIS**
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YOU STEPPED UP TO BE COUNTED ... AND GOT THE BALL ROLLING

On 10th March 2010, former Deputy Prime Minister, the Rt Hon John Prescott MP and his daughter-in-law Roz Prescott, who has a serious form of the inflammatory bowel disease Ulcerative Colitis, were supported by a host of other leaders in the fields of politics, the health sector industry, commerce and the arts – all of whose lives have been touched in some way by inflammatory bowel disease – to launch the “Step Up and Be Counted” campaign at 11 Downing Street for the registered medical charity and patient association, The National Association for Colitis and Crohn’s Disease (NACC).

The charity was seeking to gain wide public support for a national IBD Patient Register as at the time of the launch, only 39% of UK hospitals held a database of their Colitis and Crohn’s Disease patients and the total numbers of patients have been merely estimates.

The aim of the IBD Patient Register is to ensure quality care for all patients, gather data for research into a cure and identify patients who are not in a follow-up system and may be at risk of complications. It is thought that approximately 240,000 people in the UK have the life-long conditions, Ulcerative Colitis or Crohn’s Disease (known jointly as IBD or Inflammatory Bowel Disease) which are typified by symptoms of relentless diarrhoea, bleeding, pain, profound fatigue, eye, skin and joint problems, and impaired growth in childhood. At the launch, the charity appealed to the public through its own membership of 31,000 and through Emmerdale actor Jeff Hordley; singer Rick Parfitt Jnr and TV personality Carrie Grant. Roz Prescott explained, “This campaign is all about seeking out and knowing rather than guessing how many individuals in the country have Colitis and Crohn’s. From my personal experience, I feel strongly that a Patient Register is long overdue and that other well known individuals should speak up about their Colitis or Crohn’s to raise much-needed awareness.

“This charity asks everyone to add their voices and their votes for an IBD Register by visiting www.stepupandbecounted.org.uk” Roz and her family know just how challenging these lifelong conditions can be. Roz herself has recovered from two life-threatening complications of her Colitis and was forced to part with her one-week old daughter in order to have surgery. Roz’s husband David and her supportive in-laws played a vital role in her 6 week hospital recovery, looking after baby Ava Grace Prescott. The charity’s CEO Richard Driscoll added, “NACC will be emphasising to Government, policy makers, NHS managers and doctors that Colitis and Crohn’s disease are serious life-long and sometimes life-threatening conditions affecting about 1 in 250 of the population.

“Very close to my heart as I have had Crohn’s Disease for 16 years. It nearly killed me at university but I fought back and now I have two gorgeous children.”

“IBD needs support and exposure. Why should those of us that have IBD be the poor relatives of the health world?”

The provision of an IBD Register will significantly improve patient care and research in the long term, by providing a definitive resource for auditing patients and their ongoing care.” Richard continued, “We also know from our IPSOS Mori Poll in 2009 that public awareness of Crohn’s and Colitis is so much lower than that of other less prevalent illnesses such as Parkinson’s Disease or Multiple Sclerosis, particularly in young adults, which is when IBD is most likely to be diagnosed. Our celebrity supporters make all the difference when it comes to increasing awareness of these often hidden and distressing conditions. We ask anyone in the public eye with IBD to please contact us at NACC (01727 830038) and offer their support for this year’s campaign.”

The “Step Up and Be Counted” launch marked the beginning of a programme of awareness and fund-raising events which culminated in Colitis and Crohn’s Month in May and World IBD Day on 19th May 2010. Shortly afterwards, the charity successfully steered through its first rebrand in 30 years, launching its new working name of Crohn’s and Colitis UK, whilst preserving its registered charity name of the National Association for Colitis and Crohn’s Disease (NACC) as a legal entity and to retain its established brand with its membership and within the health sector. The Step Up and Be Counted campaign and the huge support demonstrated by the 7,412 online signatures and comments have been a significant catalyst to the creation of the National IBD Registry.

By the end of the year, the newly-formed Registry Board, made up of representatives from relevant professional and patient organisations and with Richard Driscoll, Crohn’s and Colitis UK’s Chief Executive as Vice-Chair, will move towards launching the Registry.

The Registry Board has raised an initial £200,000 to fund the project through 2011 and 2012. In June this year, a call for tenders will go out to select the software company that will develop the database which will underpin the new National IBD Register. The aim is for the Registry to start collecting data at the beginning of 2012.

“To have moved from the launch of the campaign to first data collection in less than two years is a fantastic achievement,” said Richard Driscoll, “and this summary report of the campaign with a selection of the inspiring comments will form part of our bid for much-needed national support from the Department of Health.”

“Very helpful information pack and regular updates from your charity help make living with IBD more bearable.”

“NACC was an invaluable source of help and support when I was first diagnosed. Since then I have made some very good friends since joining NACC and subsequently joining the local committee.”