



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

NACC Review of 2005





On behalf of the Trustees, I am delighted to introduce the NACC Annual Review for 2005. This, the first new-style review, highlights the main achievements over the year and tells you, our members and supporters, how we are meeting the needs, wishes and concerns of IBD patients and their families. The back pages give you an insight into how our funds are raised and allocated, and explain how you can support and be involved in the ongoing work of the Association.

The Review demonstrates the importance of members and volunteers in every aspect of NACC's services and activities, from NACC-in-Contact and NACC Groups through to the families from all over the UK who joined in the fun at the Millennium Walk. All of this is underpinned by our hardworking team of staff at St Albans.

As Chairman for the last two years, I have been proud to see the growth and development of NACC as an active and caring community and as a professional and responsible organisation helping many thousands of people to live with IBD.

Elaine Steven, Chairman, NACC

NACC's Aim

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

NACC's Vision

NACC should be a well-known and active organisation recognised for excellence in:

- providing support & information for IBD patients & their families
- raising public & political awareness of Inflammatory Bowel Diseases (IBD)
- striving to improve healthcare services & provision for IBD
- influencing the attitudes of society to achieve positive change for those affected by Inflammatory Bowel Diseases.
- promoting research into all aspects of Inflammatory Bowel Diseases & how they affect people's lives.

The principles underpinning NACC's Vision

NACC is an active organisation with both members and volunteers taking an active role in achieving the objectives that have been agreed and with NACC taking a leading role in championing the needs and concerns of people affected by Inflammatory Bowel Diseases.

NACC aims for excellence by basing its policies and plans on objective evidence wherever possible and by adopting recognised standards of quality in its services and practices.

NACC expects Trustees, members, volunteers and staff to observe the principles of compassion, equality and inclusion and to act with respect and integrity in their work for the Association.

Whenever possible the Trustees forward NACC's objectives through research, development and service activities in partnership with Health Service, Professional and other patient organisations and with the pharmaceutical industry.

How we work to improve life for people affected by Colitis and Crohn's Disease



Information Services

In 2005 our information service fielded nearly 5,000 individual enquiries. Almost three-quarters of these came by telephone, just over a quarter by email and a small percentage by letter. Interestingly, the number of people choosing to contact us by emails rose significantly over the year while the number of telephone calls fell.

Information Line 0845 130 2233

This is one of the most important contact points for people seeking details about IBD, especially for those making their first contact with NACC. 60% of people using the line for the first time are non-members.

Queries are wide-ranging, covering topics such as employment, insurance and complementary therapies. The most common issues are:

- drugs (particularly side effects) accounting for a third of calls
- Disability Living Allowance (DLA)
- symptoms
- diet

The line is open weekdays from 10am to 1pm. An answer phone service is available outside these hours where messages can be left for an Information Officer to call back.

Disability Living Allowance

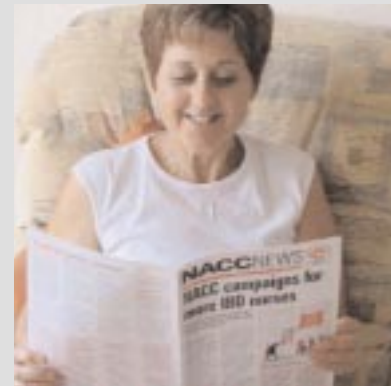
Support and the opportunity to talk about claiming DLA was given by telephone appointment with a trained NACC volunteer to a total of 95 people in 2005. NACC's series of seven written guides to inform and help people claiming DLA have been updated during the year.

NACC-in-Contact 0845 130 3344

This service provides the opportunity for people to talk to a trained NACC volunteer who has also had personal experience of living with IBD. As patients or relatives of patients, contacts can offer a very personal quality of understanding, giving people the chance to talk confidentially and, if they prefer, anonymously to someone outside their immediate circle of family, friends and health professionals. The service hours were extended in 2005 so that Contacts are now available every weekday evening from 6.30pm to 9pm.

Publications

In 2005 the post of Publications and Information Officer was created to make sure that regular updates are made to NACC's 43 current publications and that new ones are produced effectively. A CD Rom containing translations of two NACC booklets into Urdu, Gujarati, Punjabi and Hindi was produced and a Welsh translation is also close to completion.



NACC News

The NACC newsletter received many plaudits during the year and continues to be published quarterly. As it is nearing five years in its present format, we are planning to consult members on possible design and content changes to the format over the coming year.

Website

There were more than 6,000 separate user sessions every week on the NACC website in 2005. The most frequently accessed pages were IBD Basics, NACC Services, NACC Information Sheets, the Disability Living Allowance Guide and the Research information. The web pages on NACC Groups and fundraising were also regularly used. The website has played a key part in the NACC campaign for specialist nursing and the development of the IBD and Me Project for 16-29-year-olds. Forthcoming plans include the addition of discussion forums to improve communication between members and the inclusion of back issues of NACC News.

Personal grants

In 2005, grants were made to 134 people in financial difficulty or on low incomes as result of their IBD. Most grants were for replacement washing machines, bedding or clothing and sometimes for recuperative breaks. People obtain forms from the NACC website or office and a committee of volunteers

considers applications confidentially. Grants can be up to £300. There is also a Young Person's Assistance Fund which makes grants up to £500 for young people with vocational educational needs arising from IBD. This has helped students with additional costs such as special equipment needs or having en-suite facilities in their hall of residence.

Family support

Often families with young children who have IBD have found it difficult to obtain information and support. So NACC has joined with CICRA – the Crohn's in Childhood Research Association – to produce a joint poster and leaflet for paediatric units in the UK. The two charities also held a joint workshop on the transition from paediatric to adult care, with health professionals from both services. This is leading to the development of guidelines for improving support and services.

Several meetings for families were held in 2005. The Smilie's People Group, open to UK families with a child who has IBD, provides support through meetings and a website, and celebrated their tenth anniversary with a day of fun and activities in Sheffield. NACC also held a Family Day at the Avon Ski Centre hosted by the local NACC Group and volunteers. Thirty families took part, the children enjoying the activities and the parents sharing experiences and talking with health professionals.



'Thank you' for your really helpful information. I'm so grateful that you took the time to find just the information I was after, and even photocopied me relevant articles. You run a great service.



Specialist Nursing Campaign

NACC's major campaign to improve specialist nursing for IBD patients was launched in June 2005. The need for more specialist nursing for IBD came out strongly in the market research among patients and health professionals upon which the NACC Plan for 2005-2008 was based. The need was reinforced by two focus groups on Improving Healthcare that were held in 2005.

The campaign has several elements:

- NACC commissioned the University of the South Bank to review all published evidence for specialist nursing in IBD (the results will be available in summer 2006)
- a national petition was launched and by the end of the year more than 10,000 people had signed up to support the campaign by telephone or on the website
- 430 members wrote to their MPs, MSPs or Members of the Welsh Assembly
- a survey of Primary Care and Hospital Trusts raised their awareness of the importance of these specialist posts and established a baseline for future activities
- a media campaign was launched, supported by the Royal College of Nursing Gastroenterology and Stoma Care Forum. Thirty-one feature articles were secured plus an interview with Carrie Grant and IBD specialist nurse Allison Nightingale on BBC Breakfast TV.

To underline the importance of this work, the NACC Award for IBD Nursing was launched. Members made over 130 nominations and the winner was Belle Gregg from Liverpool who won a £1,000 bursary for professional development.

National IBD Audit

2005 saw the start of the first UK-wide audit of hospital services and care for IBD patients. NACC has joined with the Gastroenterology and Colorectal Surgeons organisations in managing the project. The audit is being run from the Royal College of Physicians Clinical Effectiveness Unit thanks to a grant of £500,000 from the Health Foundation.

The web-based audit will look at the care of 40 patients in each UK hospital and how IBD services are resourced and organised. The report in 2007 will help to establish consistent and good quality care across the UK and may provide evidence to argue for more resources for IBD services in some areas. The audit ties in with other collaborative work to develop and improve Gastroenterology Services as a whole.

Patient Panels

NACC set up a programme of pilot Patient Panels to explore how patients and IBD health professionals can work together to improve services and patients' experiences of healthcare.

Being nominated for the NACC IBD Nurse Award by one of my patients and reading how much she appreciated my role as her IBD Nurse was so encouraging.



I have found the whole experience of patient panels to be very interesting and good fun. I have learned a lot and it has also helped me further my career at work and given me more confidence.

Pilots are underway in Carlisle, Bradford, Nottingham and Leicester. Results have already been seen: in Nottingham the Paediatric Gastroenterology Service has been allocated more staff for 2006 and in Carlisle there is now an allocation of dedicated dietician time for IBD patients.

Raising awareness

Increasing the awareness of Colitis and Crohn's Disease and the impact they have on people's lives is a central part of NACC's Plan.

In Colitis & Crohn's week 2005, we launched our nursing campaign, achieving coverage in regional newspapers, interviews on local radio and BBC Breakfast TV, plus major articles on IBD nursing in the professional nursing journals. In total there were 57 million opportunities to read or hear about the campaign.

Members and volunteers play a key part in raising awareness. Following an appeal in NACC News, more than 300 members offered to tell their stories of living with IBD to the media, providing the personal interest that encourages journalists to devote a feature to IBD. This approach enables us to convey a true picture of living with these illnesses. Public events also help to boost awareness. About 800 people took

part in the 5th Millennium Walk in London, raising over £40,000 and catching everyone's attention as they carried our red and white balloons along the Thames.

Campaigning

Employment, insurance, prescription charges, public toilets and parking are all regularly discussed in members' meetings and correspondence. NACC encourages members to tackle these issues by individual lobbying and by coming together in small campaign teams supported by the Trustees and NACC staff.

The Blue Badge campaign shows that members' action can make a difference. Several NACC Groups liaised with local police to set up schemes so that NACC members could park in restricted areas for short periods to use public toilets without worrying about parking tickets. Members wrote to MPs who raised the issue with Ministers, and one member, Gail Walford from Leicester, led the lobbying of the Government department responsible for Blue Badge eligibility rules.

As a result, Colitis and Crohn's Disease has been considered in a formal review commissioned by the Office of the Deputy Prime Minister. NACC supplied a survey of members and medical information to the review and organised a focus group which provided personal testimonies.

The patient panel with NACC has been very enjoyable, a change too. I feel I am helping other people in a small way. I have gained new friends and taken part in activities that I previously would not have done.



Research

Research is a very important activity for NACC members who want to see improvements in our understanding of IBD. The importance was recognised in the NACC Plan in which the Trustees set an objective to increase our annual research fundraising to £500,000 by the end of 2007.

Medical Research

20 applications were received in 2005 and five grants totalling £277,784 were awarded. These were:

- Guy's Hospital, London, £89,946: Genetic investigation of NF-kB pathway in susceptibility to inflammatory bowel disease
- Addenbrooke's Hospital, Cambridge, £25,501: Expanding the Cambridge and Eastern England IBD genetics project.
- University of Bristol, £5,756: The role of Fascin in IBD-related cancer risk
- University of Manchester, £67,339: P-glycoprotein and the interaction between colonic epithelium and gut bacteria
- St George's Hospital, London, £89,242: Progress towards the development of a vaccine against MAP

A review of the research funded by NACC in 2000-2005 has been commissioned and will be published later in 2006.

Social and Psychological Research

No new awards were made in 2005. Several ongoing projects were completed. These were:

- Loughborough University with Leicester General Hospital, £68,200: The integration of patients' concerns into treatments for IBD: a qualitative study of opportunity and understanding
- Institute of Work, Health and Organisation, Nottingham, £44,785: Managing Inflammatory Bowel Disease at work: employee needs and employer awareness
- Loughborough University, £45,000: IBD in Adolescence: using life stories to investigate and support everyday living

Health Services Research

NACC commissioned two research reviews, one into Specialist Nursing for IBD patients by the University of the South Bank and one into Self-Management of Long-term Medical Conditions by University College London. The need for more Health Services Research in Gastroenterology was highlighted in the recent strategy document on the Care of Patients with GI Disorders in the UK published by the British Society of Gastroenterology .

Reports of NACC-funded research are made available on the NACC website as soon as they can be published.



It's so frustrating when you have good research ideas and can't get the funding to investigate them. Knowing that NACC makes more funds available every year without fail is really important to maintain progress in IBD.

Volunteers

Being a member of NACC is not just about receiving information and support, it's also about meeting other people living with IBD. For many people it's also about taking an active part in the work of the Association.

Many of NACC's services and activities rely on members volunteering their help either in a continuing role or in one-off projects including:

- the NACC in Contact and Disability Living Allowance Support Services, provided by trained volunteers
- the 70 local NACC Groups, run by volunteer Organising Teams and individual members who help in many ways, by fundraising, offering to talk to the media or taking part in one of NACC's campaigns or projects
- the Blue Badge Campaign (see page 7), which illustrates how members' involvement can make a real difference
- the Millennium Walk where more than 50 volunteers came together to make sure the event ran smoothly
- selling our Christmas Cards, which raised over £4,700

Improving the support we offer to volunteers is an integral part of NACC's approach. In 2005, a series of induction opportunities, development days, conferences and volunteer forums were held for existing and potential volunteers.

Groups

Groups are the local face of NACC, offering a local point of contact and support for members and health professionals, raising awareness and funds and arranging opportunities for members to meet.

There were 70 NACC Groups active in the UK. Groups aim to:

- provide links with local health professionals and meetings where people can find out more about Colitis and Crohn's Disease and chat about practical aspects of living with IBD
- raise local awareness, taking an active part for example in our specialist nursing campaign
- fundraise (£214,000 in 2005) to cover running costs, help local hospital services with equipment, pay for the training of specialist nurses and support NACC's national activities

To help Group Organising Team members develop their plans, a new Group Handbook was introduced. This informs new Organising Team members on how to set up a new NACC Group and sets out how to run an existing Group. The Core, Optional and Joint National/Local activities are explained and greater involvement of young adults encouraged. The Group Handbook is easy to navigate and full of relevant information, while still allowing each NACC Group to develop its own local approach within the NACC framework.

I feel I have got more out of being a volunteer than I have actually given. The training and support given by NACC to its volunteers has improved tremendously over the last 10 years and I feel proud to tell people that I am a NACC volunteer.



Volunteering with NACC generates benefits and satisfaction beyond just those of helping a worthwhile cause. Skills are learnt and friendships forged that can make a difference to the life of a volunteer throughout the rest of their life.

Fundraising: every pound counted

A huge thank you to each and every one of you who made a donation or fundraised in 2005. Only with your support were we able to achieve so much over the year.

How you supported NACC financially in 2005



Bowling £2,090
 Concerts £2,500
 Skydiving £6,106
 Cycling £6,118
 Walks £9,742
 Anniversaries/birthdays £10,500
 Triathlons £12,182
 NACC merchandise £18,565
 Trusts £20,008
 Treks/challenges £21,036
 Pyramid Box Appeal £36,000
 In Memoriam £72,472
 Marathons/runs £109,209
 Groups £125,162
 Donations £151,847
 Other events £183,931
 Legacies £452,291

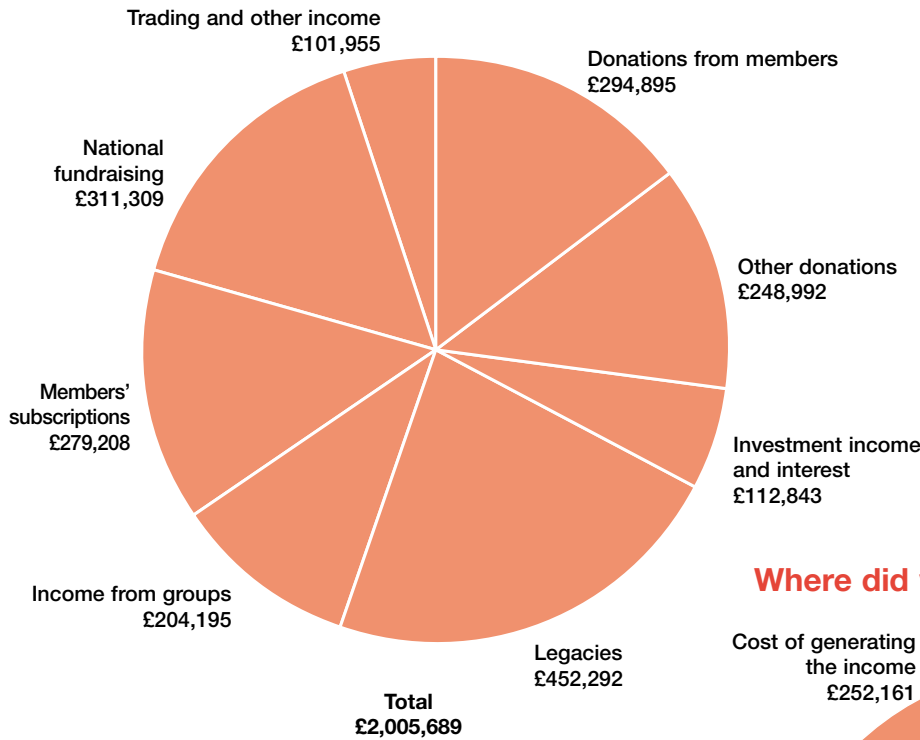


Adventurous NACC supporters walked, ran, sang, danced, swam, cycled, trekked, jumped out of planes and generally had a good time raising funds. Others donated either on their own behalf or in memory of someone else. Legacies bequeathed to help future generations of people affected by Colitis or Crohn's Disease were also a vital source of income.

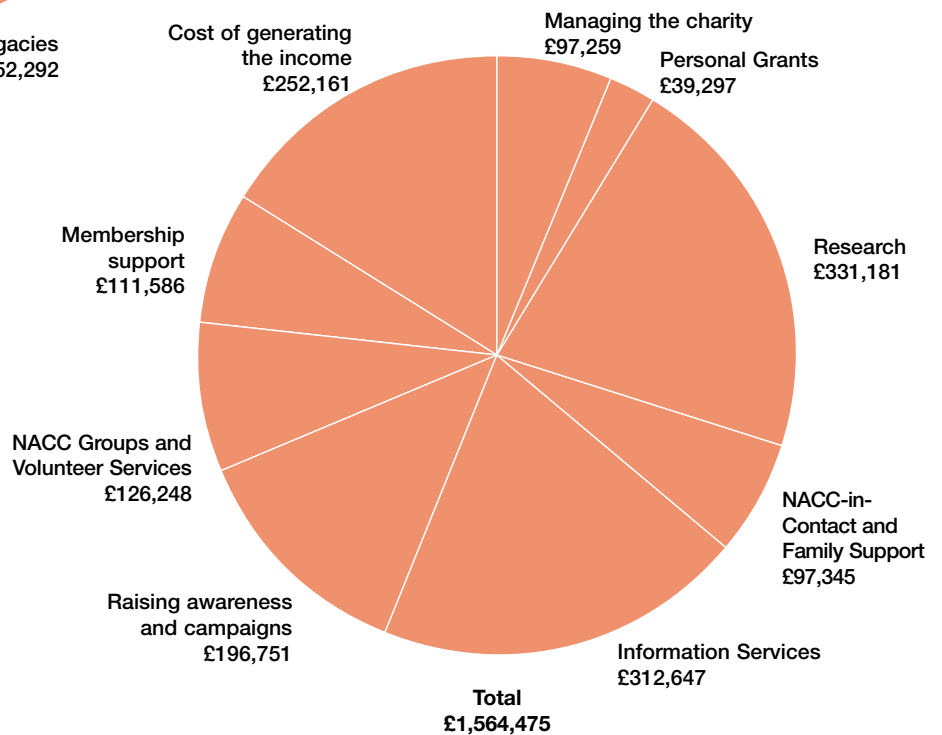
Together, the £s you gave added up to a massive £1,239,759

However you supported NACC in 2005 - THANK YOU

Where did our funds come from in 2005?



Where did we spend the money in 2005?



This summarised financial information for the year ending 31st December 2005 is extracted from the full annual report and accounts which were approved by the Trustees and signed on their behalf on the 31st March 2006. If you would like to see a detailed version of this summary, then you can obtain a copy of the full audited and unqualified Trustee Report and Accounts by requesting a copy from the NACC Office or from the About NACC page on our website www.nacc.org.uk.

How to get involved

Whether you have IBD yourself or know someone who has, please do get involved in NACC – together we really can improve life for people affected by Colitis and Crohn's Disease.

Volunteer

There are many ways to volunteer with NACC either at local or national level:

Locally

- Support your local NACC group by attending events or joining the local Organising Team – they are all ordinary people, some who have IBD and some who don't – they will welcome your support
- Raise awareness by becoming a patient panel representative or get involved in Colitis & Crohn's Week
- Fundraise for your local Group and/or NACC nationally
- Sell Christmas cards on behalf of NACC

Nationally

- Offer to tell your story to the media and help raise awareness
- Be a project volunteer – the Blue Parking Badge, Prescription Charges, the Nursing Campaign
- Volunteer for our telephone support services – NACC-in-Contact or the DLA Support

For further information about making a difference by becoming a NACC volunteer, please contact Heather Baumohl, Group and Volunteer Development Manager, at the NACC Office.

Fundraise for NACC

By raising funds for NACC you will help us to:

- Provide independent high quality information and support
- Represent the views and concerns of IBD patients locally and nationally
- Research and advise on how best to minimise the impact of IBD on people's lives
- Fund the best research into the causes of and treatments for Colitis & Crohn's Disease

For further details contact the fundraising team on 01727 734485. Our website at www.nacc.org.uk contains details of events you can take part in as well as ideas for holding your own event.

Make a donation

Every pound counts. You can donate by sending a cheque to NACC at the address below, or see the coupon attached.



The National Association for Colitis and Crohn's Disease (NACC)

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Website: www.nacc.org.uk Information Service: 0845 130 2233
NACC-in-Contact Support Line: 0845 130 3344

Registered Charity 282732

Front cover:

Carrie Grant starts
NACC's Millennium
Walk in London in
June 2005