



Crohn's and Colitis UK
Annual Report and Accounts
Year ending
31st December 2011

Crohn's and Colitis UK
is the working name for
The National Association for Colitis and Crohn's Disease

**Crohn's and Colitis UK, 4 Beaumont House, Sutton Road,
St Albans, Herts, AL1 5HH.**

**Charity registered in England and Wales No.1117148 and Scotland No. SC038632
A company limited by guarantee in England: company number 5973370**

Crohn's and Colitis UK

Trustees Report 2011

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The Trustees of Crohn's and Colitis UK have pleasure in presenting their report and financial statements for the year ending 31 December 2011. The charity is registered with the Charity Commission under registration number 1117148 and with the Office of the Scottish Charity Regulator under number SC038632. It is a company limited by guarantee. Crohn's and Colitis UK operates in England, Northern Ireland, Scotland and Wales. Details of Trustees, Officers, senior staff and committee members who served in 2011 are set out on page 20.

Strategic Plan 2010 - 2012

The strategic plan for 2010-2012 entitled 'Meeting the Challenge of Colitis and Crohn's Disease' was published in December 2009. The aim, vision and principles stated in the charity's previous strategic plan were largely unchanged and many services and activities continued unaltered. However, new strategic priorities and objectives were identified together with a number of key cross-cutting themes to be addressed over the three years. This report is presented to match the structure of the Strategic Plan, which sets out the Challenge, Vision and Objectives for 2010 – 2012.

Crohn's and Colitis UK Aim

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

Crohn's and Colitis UK's Vision

Crohn's and Colitis UK should be a well-known and active organisation recognised for excellence in:

- Providing support & information for patients & their families who are affected by Inflammatory Bowel Diseases (IBD).
- Raising public & political awareness of 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 Crohn's and Colitis UK's Vision

Crohn's and Colitis UK will be an *active organisation* both in the sense that members and volunteers will take an active role in achieving the objectives that have been agreed and in the sense that NACC will take a leading role in championing the needs and concerns of people affected by Inflammatory Bowel Diseases.

Crohn's and Colitis UK will aim 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.

Crohn's and Colitis UK will expect 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 will forward Crohn's and Colitis UK 's objectives through research, development and service activities in partnership with health service, professional and other patient organisations and with the pharmaceutical industry.

Overview 2011 and 2012

As part of the NACC Plan 2010 – 2012 a major PR theme was agreed for each of the three years which would act as a focus for development across all areas of the charity's work. In 2011 the theme chosen was IBD and Employment, recognising the impact of Inflammatory Bowel Disease on people's career opportunities and working lives. Identifying the theme well in advance enabled the project to be developed beyond a PR campaign and to become an integrated part of all of the charity's activities and services. The research undertaken with generous support from Abbott has made a major contribution to the understanding of the experience of IBD patients of all ages in relation to work. The Report provided clear evidence of the impact of IBD on employment to underpin the campaign for better awareness and support from both employers and health professionals, as well as policy messages for government.

Adopting this planned approach meant that the focus on employment could extend across the different areas of the charity's work, for example updating the relevant publications, conveying the key learning points to members through NACC News, presenting the findings to health professionals at their conferences and meetings, and providing the focus for raising political and public awareness of IBD. The Trustees have already agreed to maintain this approach and themes will continue to be set three years ahead. In 2012 the focus is on IBD, Sport and Fitness, the intended impact being to encourage patients to recognise the importance of maintaining exercise and fitness where possible within the constraints of their illness, and in 2013 will be on Young People Living with IBD, the intended impacts being to lessen their isolation by providing more opportunities for interaction, and to increase awareness and understanding of IBD among young people and in educational institutions.

Alongside this major theme, as the report above demonstrates, the regular services and activities of the charity have been maintained and continually developed. Each of the information and support services saw an increase in demand over the previous year. Membership levels were maintained, and our capacity to support local Groups and volunteers was increased by establishing an extra post covering Scotland and Northern Ireland. Ensuring that our services can demonstrate that they are working to a high standard is important. In 2011, the charity's accreditation under the Department of Health's Information Standard was confirmed for a third year and an application for accreditation with the Telephone Helplines Association will be made in 2012.

The charity has continued to develop its Public Affairs work seeking to influence government policy and services. There are a wide range of issues affecting IBD patients' lives and it has proved necessary to decide on which to prioritise in 2011/12. The two areas chosen were welfare reform and NHS services, both areas where there are major policy changes taking place which will impact on IBD patients. The focus in welfare reform has been to secure recognition for the fluctuating nature of

IBD and proper assessment of fatigue and continence and the charity has participated in a government advisory group looking at these issues. This will remain the priority focus for 2012.

Within the NHS the challenge is to promote better quality services in the context of significantly reduced funding and across the four nations which each have different organisational systems. The charity works closely with the relevant health professional organisations and plays a major role in the national IBD Audit and Quality Improvement Projects. There remain significant policy and organisational barriers to the redesign of traditional IBD services to a more patient-centred approach. In 2012, the development focus will be on supporting the integration of the national IBD projects, the renewal of funding for the national Audit, how best to influence commissioners in England and how to obtain national support in Scotland and Wales for improving IBD Services.

The Trustees approved significant improvements to the office facilities in 2011, taking additional office space to enable more effective working and upgrading the charity's IT and telephone systems. These should now be adequate for the next five years apart from routine equipment replacements.

At the beginning of 2011 there was considerable concern about future income in the light of the country's economic circumstances. Voluntary donations have continued to fall, but our greater emphasis on promoting fundraising and on marketing has successfully generated additional income. However, the most significant factor leading to a surplus in 2011 has been the exceptional level of legacies. This possibly reflects a benefit from the regular promotion of legacy-giving to members and supporters, but a direct link cannot be shown. The increased legacy income has maintained the charity's general reserve and enabled the Trustees to compensate for the drop in donations for research and personal grants in 2011 by allocating additional funds to maintain current grant levels through 2012.

The Trustees' current policy for legacy funds is to budget on the basis of £200,000 unrestricted legacy income each year and to maintain a holding fund of any additional legacy funds and carry them forward as a contingency against a low level of legacy receipts. When safe to do so, these funds are then released for investment in new projects. On this basis, the Trustees have been able to allocate £150,000 as a legacy project to develop additional support for young people during 2012.

In 2012, the Trustees and staff will work on developing a strategic plan for the next three years, reviewing progress against the objectives set for 2010/12 and considering whether current services and activities should be continued or changed to meet new challenges.

Raising Awareness of IBD

- **Overview** - During 2011, a range of existing communications' channels were developed, using the media, existing local Groups, Ambassadors – to help raise awareness of the specific conditions of Crohn's Disease and Colitis, and their umbrella term of IBD (Inflammatory Bowel Disease). Some of these channels produce measurable outputs, whereas others – such as PR activity - rely largely on anecdotal evidence to show benefit.
- **Marketing** – during 2011, the charity updated its Membership Application forms and distributed these for the first time to GPs surgeries across the UK. This initiative was coupled with a push to advertise the charity in six hospitals across the UK in areas where there are no active local Groups. The charity continued to approach its members to encourage them to give e-mail details, in order to support regular e-comms in future. Development work on the first monthly e-zine to fundraising supporters was finalised and the first opt-in email sent to 3,000 existing supporters at the start of 2012. The first in-depth article on Groups' fundraising in Action!, the fundraising quarterly mailed to members, was included in March 2011 and was warmly welcomed – this will now become an annual feature. Groups were supported in the purchase of pull-up banners for exhibitions and talks – aligning the brand look with local Groups.
- **Media** – Overall media reach (online and offline) in 2011 amounted to 658,684,851 – 42% up on the 2010 total of 379,907,791. Half this coverage was due to the Darren Fletcher/ulcerative colitis disclosure which, while not generated by the charity, offered numerous opportunities for professional medical comment from its medical advisors and media supporters. Significant coverage of the Rick Parfitt Jnr 2nd Rock Ball, featuring Rick Parfitt Snr and Status Quo, also boosted media coverage. Groups online coverage was up 57% and Crohn's and Colitis Month coverage in May was up 66% on the previous year, thanks to successful selling in of media volunteers' stories to support the launch of the IBD and Employment research on World IBD Day 19th May 2011.
- **PR** –The launch event for the IBD and Employment research, funded by Abbott and hosted by Lord Prescott at the House of Commons, was well attended and reported. The microsite "Good Desk, Bad Desk" developed with Healthcare Solutions, the charity's PR agency, proved popular and has been kept online as a result. In October, the charity also held its first 'Red Hot' Business Breakfast for the local business community of south west Herts at its newly-developed downstairs premises. This was attended by its Ambassador, Carrie Grant, and received local press coverage. The staff team also entered the St Albans' community Pancake Race for the first time, scooping first place and media exposure. Developing relations led to the election of the charity for the first time as the beneficiary of the St Albans Chamber of Commerce annual ball.
- **Groups** – The charity's 70 Groups held over 200 specific awareness raising events and distributed over 7000 Crohn's and Colitis UK leaflets locally. The Groups had around 85,000 individual visits to their websites and this is increasing year on year. Group publicity is estimated to have reached 22,203,600 people in 2011, which is a 48% increase on the previous year.
- **Volunteering** - In 2011 14 speaker/cheque receivers represented Crohn's and Colitis UK at 14 events and collected approximately £50,000 for the Charity, raised by individual fundraising supporters in aid of its work.
- **External events and conferences** – Staff and members have taken part in various training courses for health professionals during the year, both locally and nationally, in line with our objective of raising awareness of the charity, the condition and the impact on people's lives. There were information displays at the national meetings of BSPGHAN (British Society of Gastroenterology, Hepatology and Nutrition) and the BSG (British Society of Gastroenterology) as well as at many regional or local meetings organised by health professional groups or pharmaceutical companies.

- **New ambassadors: the Prescotts** – during 2011 relations were developed with Roz Prescott, Lord Prescott and the rest of the family, culminating in their acceptance of the charity's invitation to become the latest Ambassadors.
- **New champions for 2012** – several potential Champions were approached towards the end of the year, in preparation for posters and filming to be rolled out in 2012 to support the PR theme of IBD: Sport and Fitness. This work included negotiation with the international Olympic Office and the London Office for the Olympics, over logo development.
- **IBD Nurse Awards** – The Crohn's and Colitis UK award scheme was developed to raise awareness of the value of specialist IBD nursing to patients. Additional funding was secured from Abbott in 2011 to support the rolling out of the charity's first IBD Specialist Nurse Awards since 2005. Members were canvassed for nominations during September, resulting in 435 nominations of 183 individual nurses. All nominated nurses received a letter of congratulations, giving individual anonymous feedback from their nominators.
- **Communicating the value of IBD specialist nursing** – The letters to IBD Nurses were copied to the CEO's of their Hospital Trusts, to underline the high value place on these members of the IBD team by their patients and a number of hospitals assisted by rolling out the press coverage internally and in their local press. Filming of shortlisted nurses and their nominators was started at the end of 2011.
- **IBD and Employment Report dissemination** – in addition to the 500 copies distributed at the launch and in answer to postal requests, over 7,000 copies of the report have been downloaded from the main website and/or the microsite, as well as downloads of the charity's associated information sheets for Employees, Employers, Schools and Universities.
- **Website** – Although long overdue for re-design, the charity's website continued to provide the public and its members with a valued source of information about the conditions, the charity's services and forthcoming events, attracting more visitors than the previous year. Overall there were 456,147 visitors in 2011 (386,164 - 2010).

Meeting needs for information and support

- **Groups' education and support meetings** - In 2011 Groups held over 300 meetings, reaching 6,000 people affected by IBD. These meetings may follow the traditional educational meeting format, but also more informal and support style of meetings.
- **Groups keep in touch** by sending regular local Newsletters to members and at the end of 2011 over half the Groups had set up a Face Book page and 5 were using Twitter accounts to help reach more people living with IBD.
- **Crohn's and Colitis UK Publications** are available as Information Sheets or Booklets and are offered to individuals free of charge. 10,151 Information Sheets and 3,500 Booklets were distributed from the Crohn's and Colitis UK office in 2011. All publications are now available as downloads from the Crohn's and Colitis UK website. In 2011, a total of 206,033 publications were downloaded.
- **Editorial Board** - Crohn's and Colitis UK publications are supported by Medical Advisers who sit on an editorial board. This board held its first meeting at the BSG in April 2011.
- **Information Accreditation** - Membership of the Information Standard was confirmed for the third consecutive year following a surveillance visit, which confirmed our continuing compliance with the requirements for accreditation.
- **NACC News** is the quarterly newsletter for members of Crohn's and Colitis UK. This provides members with information and comment on developments in research and treatment, and Tariq Ahmad, Consultant Gastroenterologist, served as Medical Editor for the year.

"Thank you for continuing to send me your excellent quarterly newsletter. I have been on your mailing list for quite a few years and have always been extremely impressed with the high quality of this publication."

- **Information Packs** – 7,250 Information Packs and 1,400 Family Packs were distributed by UK hospitals to newly diagnosed patients. In November 2011, short questionnaires were sent to 50 new members who had recently been given a Crohn's and Colitis UK (NACC) Information Pack by their hospital. All the respondents commented positively on the usefulness of the pack – and all added a comment about what they had found most useful, for example:

"Very useful to be able to refer to information in print"

"... having knowledge about my condition and treatment options"

"... Advice on learning to live with the problems"

"... Everything was helpful. I refer back to things in the information pack regularly."

- **Information Officers** responded to 4,639 individual enquiries in 2011: 3671 by phone, 909 by email and 59 by post. Positive feedback from service users included:

"I have gained more information in the last 20 mins, than I have over the past 5 yrs with the NHS."

"It is nice to know I can contact you if I ever need to. It's been quite a journey for me these last few years, and isolating. You make that better, and must for many people, thank you."

- **NACC-in-Contact** changed its name to **Crohn's and Colitis Support** in 2011, and provided 'a safe place to talk' for 752 people who called this confidential, volunteer-led helpline for emotional support in 2011.
- **Benefits** - 98 people were supported in their claims for Disability Living Allowance or Attendance Allowance by **Disability Benefit Service** volunteers, including one member who wrote:

"This has been a long and stressful process, and without the help and support from your volunteer and the excellent guide, I don't think I would have been awarded DLA. Thank you so much for your help."

- **Parent Support** - A small but very dedicated group of parent volunteers continued to offer support by telephone appointment to other parents of children with IBD. 25 parents received support from the **Parent to Parent** service in 2011.
- **Personal Grants** - 237 people experiencing financial difficulty as a result of their IBD benefitted from a Personal Grant in 2011. Of these, 5 were awarded to young people to support their education or training.
- **Online Forum** - The number of young people registered to use the **IBD and Me** Online discussion forum increased by 509, to 2761, in 2011, with 342 new discussion threads started and 3869 messages posted.
- **Social Media** - During 2011 the **Facebook** page increased from 355 to 3,228 'Likes' and was viewed 676,703 times. Facebook has been used to increase participation in surveys, direct people with questions to the information team/website downloads, provide information about local Groups, and encourage fundraisers. By providing a (deliberately) limited and fully moderated forum for discussion, the online Facebook community provides a place to share common concerns (postings about fatigue were particularly popular), applaud examples of positive coverage (the IBD nursing winners received many positive comments), debate key issues

and reach out to groups of people who don't engage with other mainstream services (the gay/lesbian research, funded by Crohn's and Colitis UK provoked many comments but remained civil at all times).

Campaigning for better provision for people living with IBD

- **IBD and Employment** – This was a major focus for the charity in 2011 generously supported by Abbott. An expert Steering Group was recruited by the charity comprising representatives from The Work Foundation, the TUC, the Institute of Work, Health and Organisations at the University of Nottingham, the charity and the company. This group, chaired by the Vice-Chairman Crohn's and Colitis UK, oversaw the research which was conducted among IBD patients and employers, reviewed the findings and produced the Report 'IBD and Employment: from Career Aspirations to Reality'. The Report was launched at the House of Commons in May 2011 and formed the basis of our primary media campaign, additional support for people with IBD, and dissemination to policy makers, health professionals and employers. The impact of these elements is described in the relevant sections of this report.
- **Meetings and discussions** with The Employers' Forum on Disability, Tesco's team of occupational therapists, and the British Chambers of Commerce, all raised awareness of the workplace needs of employees and how these can be met by employers, using the findings from the research project. The findings have been presented to health professional meetings nationally and internationally.
- **Party Conferences** - Crohn's and Colitis UK had representatives at the Liberal Democrat, Labour and Conservative Party Conferences for the first time in 2011. Each Party Conference provided an opportunity for networking. Representatives of Crohn's and Colitis UK were able to take advantage of the occasion to speak to policy-makers about the major issues of relevance, and gather intelligence about key policy areas to enable us to exert maximum influence when decisions are taken which impact on people living with IBD.
- **Work Capability Assessment** - Crohn's and Colitis UK were one of five charities invited by Professor Harrington to form a working group, to make recommendations to the Department for Work and Pensions on improving the Work Capability Assessment for people with fluctuating health conditions.
- **Disability Living Allowance** - Crohn's and Colitis UK were represented at a meeting with Maria Miller, Minister for the Disabled, to discuss the proposal to replace Disability Living Allowance with a new benefit (PIP). Face to face meetings with three MP's were held to raise awareness of the impact of proposed welfare reform on people living with IBD.
- **Policy Position Statements** – these were fully developed for the first time, including 'key asks' for three key policy areas, namely welfare reform, parking concessions and access to public toilets.

Improving IBD healthcare services

- **Policy on NHS Services for IBD** - Implementation of the IBD Standards produced in 2009 continues to be the primary focus of the charity's work in this area. Position statements were prepared for development of IBD healthcare in each devolved administration and the key messages have been promoted in each UK nation through political contacts, presentations at health professional meetings, visits to individual hospital teams and through the national IBD projects described below.
- **IBD Standards Group** - In 2011 the IBD Standards Group chaired by the charity's Chief Executive was reconvened to review the IBD Standards' document, assess progress and undertake work on

key development areas where it is important to develop a consensus view. The two key areas for 2011/12 were identified as agreeing specific outcome and process measures that could be presented to governments as reliable and collectable indicators of quality and development of agreed methods for routinely capturing IBD patients' experience of their health services.

- **National IBD Projects** - Crohn's and Colitis UK is a leading partner in three UK-wide projects relating to Quality Improvement and Assurance. These are the IBD Audit, IBDQIP (Quality Improvement Programme) and IBD Registry. The charity takes an active role in each project, fosters communication and coordination between them and is promoting future convergence of the projects into an integrated IBD Quality Assurance and Improvement Programme. An important objective for this work is to support equal standards of IBD care and equal access to high-quality clinical care across the UK even though the four nations now have distinctly different NHS organisations.
- **Audit of IBD Care** - In 2011, the first results from the 2010 Organisational IBD Audit were published and Crohn's and Colitis UK has worked to ensure that the results of key indicators for individual hospitals are made publicly available through NHS Choices with supportive explanations to aid interpretation of the information.
- **Quality Improvement Visits** - Crohn's and Colitis UK staff took part in several pilot visits from the IBDQIP team to individual hospitals as part of the IBDQIP programme. They contributed a patients' perspective to the discussions and this is now established as a core component in the peer-to-peer visits being developed as phase 2 of IBDQIP.
- **Commissioning** - The charity is also part of a collaborative group with the British Society of Gastroenterology and other professional and patient organisations developing a Guide to Commissioning Gastroenterology Services. This is in response to the reorganisation of the NHS in England and will be published in June 2012.
- **Research projects** - The charity is funding a number of research projects relevant to improved IBD Services. The project to develop a Patient Reported and Outcome Measure for Crohn's Disease (PROM) has made good progress through 2011 and will be delivered in November 2012. Other projects are developing patient access to hospital records and an 'app' to assist patients in self-managing remotely from their hospital.
- **Patient Panels** - At the end of 2011 there were 39 Patient Panels. Crohn's and Colitis UK support IBD Health Services to set up and run Patient Panels. Patient Panels are made up of patients, carers and staff in the local hospital IBD Service. 2011 saw the development of the first Paediatric Patient Panel model; a conference for Patient Panel members to attend; the first e-newsletter which shares good practice and what patient Panels are achieving. The IBD Patient Panel based at Ipswich Hospital lent its support to and helped secure a pilot specialist IBD nursing post initially for 12 months.

Supporting IBD Research

- **Medical Research Programme** – Five awards were made in 2011, the total cost of the five projects being £187,949.
 - **Dr Felix Randow**, MRC Laboratory of Molecular Biology: How do cells defend their cytosol against invading bacteria and could failure cause inflammatory bowel disease. (£73,110)
 - **Dr. David Wilson**, University of Edinburgh: Establishment of UK & Irish IBD Genetics Group. (£50,000)
 - **Dr Miles Parkes**, Addenbrookes Hospital: UK IBD Genetics Consortium study of anti-TNF pharmacogenomics and IBD genetics in the UK South Asian population. (£30,000)

Dr Stuart Taylor: University College Hospital: Magnetic Resonance Imaging derived mural perfusion dynamics in Crohn's Disease: Pathophysiology and prediction of disease relapse. (£28,999)

Dr Andrew Stagg, Barts and The London School of Medicine and Dentistry: PhosphoFlow analysis of gut-homing blood cells in Crohn's Disease activity. (£5,840)

- **Living with IBD Research Programme** - Three awards were made in 2011, the total cost of the three projects being £209,949.

Dr Chris Calvert, Salford Royal Hospital Foundation Trust: A randomised control trial to assess the impact of an interactive electronic record 'IBD Patient View'. (£107,974)

Prof. Angus Watson, Raigmore Hospital, NHS Highland: Personalised care with 'Smart Phones' for patients with IBD in the Highlands and Islands of Scotland. (£75,257)

Lesley Dibley, Buckinghamshire New University: Adaption of the ICIQ-B questionnaire for assessing incontinence, quality of life and psychosocial impact in people with IBD. (£26,718)

- **Health Services Research** – No new grants were made in 2011. Research continued on the two currently funded projects: Integrated Care for IBD in Stockton-on-Tees and Development of a PROM for Crohn's Disease in Liverpool.
- **IBD and Fatigue Big Lottery Grant** – This four year project is managed by Crohn's and Colitis UK and carried out with delivery partners at Kings College London, University College London, Buckinghamshire New University and Addenbrookes NHS Trust. All partner organisations worked very effectively with Crohn's and Colitis UK to achieve the milestones in year one, with all work being submitted to agreed deadlines by July 2011. Twenty in-depth interviews were carried out across the UK, and data analysed to help inform the development of a fatigue measurement scale in year two. A literature review of fatigue in IBD was also completed in year one, which has further elaborated the need for this research. A microsite dedicated to the project was commissioned and launched in 2011.
- **Supporting external applications** – The charity is regularly asked to review and support applications for research funding being submitted by health professionals and academics. This provides useful opportunities to give a patient viewpoint on the research objectives and protocols.
- **Representing patients' perspectives** – Several members of the charity have been appointed to Steering Groups for IBD-related research projects contributing a patient perspective on issues of ethics, methodology, involvement of patients in the research activities.
- **Assisting the delivery of research** – The charity regularly assists researchers by recruiting participants for surveys through the website or mailings. In some instances this assistance and the willingness of IBD patients to respond has made the difference between success or failure of the project.

Involving members and volunteers

- **Volunteer activities** - Crohn's and Colitis UK have over 14 separate volunteer activities with approximately 1000 volunteers supporting our work. Volunteers are involved with all levels of our work e.g. Trustees; Committee Members; Helpline Services; Local Groups. Our volunteers work alongside the staff and enable the Charity to meet its aims and objects. We held our annual Volunteer Conference which over 100 volunteers attended. Members are made aware of Volunteering opportunities through NACC News.
- **Group development and new Groups** - During 2011 we have been working to support our Local Groups to carry out their four main activities: Raising Awareness, Fundraising, sending out a Local Newsletter to members and to deliver educational meetings. We hold development days and in 2011 carried out research and development of distance training approaches.

- **Health Professional Advisers** – 23 Medical Advisers support the production of Crohn's and Colitis UK publications by being part of the Editorial Board, commenting on draft documents and signing-off publications in terms of their medical content. Approximately 200 Health Professionals support the Charities Local Groups as health professional advisors. They support the organising teams of the Groups by speaking at educational meetings, finding speakers, checking IBD related articles for the Group's local newsletter. Health professionals also helped us to review the Groups Local Grant Policy and provide guidance for what Local Grant money should be spent on.
- **Family Days** - In 2011 we held 5 events aimed specifically for families – 3 run by Smilie's network; one Family day held in Scotland and one event put on by a Local Group. Approximately 500 people benefitted by meeting others in a similar situation and sharing experiences.
- **Trustees** – The Trustees support the charity not just in their governance role, but also by taking part in many of the various activities of the charity, attending Group meetings, awareness and fundraising events, supporting our Public Affairs work and representing the charity on external groups and events.
- **Crohn's and Colitis Support** recruited and trained 11 new volunteer 'Contacts' in 2011
- **National Walks** - During 2011 National Walks took place in London, York, and Rutland. The walks raise awareness and funds for the Charity. They also enable members, friends and families to get involved as either as walkers or volunteers. The London Walk saw 385 participants walking with 61 volunteers supporting the walk; York Walk had 338 participants and 45 volunteers supporting and Rutland Walk and Cycle Ride saw 228 participants and 33 volunteers supporting the walk. The Rutland Walk was delivered by local Groups (Leicester and Rutland; Nottinghamshire and Northamptonshire) volunteering alongside the charities staff. The outcomes of the walk have helped define what in future will be a national walk.

Raising Funds

- **Local Groups** - help raise funds by putting on events e.g. walks; balls; collecting funds at Supermarkets; holding raffles. In 2011 Groups raised £97,464, very slightly down on the 2010 figure of £98,228.
- **2011 Annual Appeal for the helplines** – A disappointing return on the appeal to Membership fronted by Jeff Hordley, the charity's Ambassador, resulted in under £5,000 income.
- **Challenges and runs** - Despite the recession affecting the ability of individuals to raise sponsorship from family and friends, the Fundraising team worked hard to maintain and develop levels of individual fundraising supporter participation and promote sponsorship generation in national challenge events:
 - the London Triathlon (£14,490 an increase of 122% on 2010 revenue)
 - the Edinburgh Festival (£17,066 an increase of 97.8% on 2010 revenue)
 - the London 10K (£18,670 an increase of 7% on 2010 revenue)
 - the Virgin London Marathon (£53,599 an increase of 3% on 2010 revenue)
- Organisers of major events are increasing their "package" charges for places year on year. For example the Great North Run package now costs £16,575, against the income raised by participants of £61,258 in 2011. The fundraising team constantly reviews charges, searches for new challenges and runs, and in 2011 successfully applied for status as an affiliated charity for the 2012 Brighton Marathon.
- **Christmas cards** - Christmas card sales were very similar to 2010 (2,526 orders in 2011 compared to 2,573 in 2010) but the average sale was £15.81 compared to £8.85 in 2010. Sales income, excluding donations and postage, was up by 81% against 2010. The ALMS.net database software enabled us for the first time to remind previous Xmas card purchasers of deadlines.

- **Corporate Supporters** – Abbott, Dr Falk Pharma, Warner Chilcott and Ferring Pharmaceuticals all confirmed renewal of their corporate support during the year. The charity continued to work with other companies to secure corporate support and Olympus Medical agreed to join as new corporate supporters just before the end of the year. An application was put to Network Rail to be considered as their charity for 2013, but no reply has been received to date. Individual relationships continue to be developed. Abbott, in particular, worked closely with the charity during 2011, and hosted a Lunch and Learn at their premises, as well as funding charity representatives to attend the 2011 patient association IMID conference in Stockholm, providing a pilot for mutual communications and benefits which it is hoped can be rolled out to other corporate supporters during 2012.
- **In Memoriam and Legacies** – Regular mentions were made throughout the year of the importance of legacies and in-memoriam gifts. Legacies received in 2011 totalled £474,117 a significant increase over previous years. A new legacy brochure was produced for distribution at the beginning on 2012. In memoriam gifts continued to be an important source of income, contributing £77,869. The charity's policy is that such gifts are put to Research unless otherwise requested.
- **Red Hot Day, Balls and It's a Knockout** – Rick Parfitt Jnr's annual Rock Ball exceeded all expectations in 2011, bringing in £50,000. Various events in aid of the charity were run through the Catherine McEwan Foundation and income will be received in 2012. Derek McEwan separately raised £ 7,000 for the charity through the Square to Square Project – a relay run by Derek and his friends from Trafalgar Square to George Square in Glasgow. It's a Knockout raised over £17,000 in its second year, showing a profit of £10,000. Red Hot Day raised £7,000 and fewer packs were requested (2011: 136 packs sent; 2010 166 packs). It is hoped that in 2012 Red Hot fundraising will go up as a result of the first National Raffle – being branded "Red Hot 4 Research."
- **National Walks** - The charity's national Walks continued to attract interest in terms of participation, but income was drastically reduced, particularly for the **London Walk**, which took place on Saturday 7 May. A total of 490 adults and 104 children were registered, however there was a significant downturn of attendance on the day and donations will be solicited at the time of registration to protect the charity in 2012.
- The **York Walk** took place on Sunday 22nd May 2011 – a total of 266 adults and 72 children were registered, and excellent media coverage was achieved by the new local Walks' coordinator and team. The new **Bluebell Walk and Cycle Ride** was held at Rutland on Sunday 1st May 2011. A total of 131 adults, 44 children and 53 cyclists attended and profits of £3,000 were passed to the local group who will take the project on in 2012, with registration and marketing support from the Crohn's and colitis UK Office.
- The new **City Stroll** raised over £3,000 in sponsorship, working with Davy's Fine Wines who donated the venue, St Albans fundraising staff and volunteers guided groups of walkers around the Bankside and City, providing a Sunday opportunity in autumn as a successful pilot event.
- **Walks Handbook** - To encourage more individuals and Groups to pilot Walks in their areas, a new handbook was produced by the independent Walks Consultant, Hannah Simpson.

Increasing the membership and expanding volunteering

- **Newly diagnosed patients' folders** – These are distributed free to hospitals so that newly-diagnosed patients have important basic information about their condition and some of the practical help that is available (e.g. the Disabled Toilets National Key Scheme). The costs of the packs are partially met through educational grants from some pharmaceutical companies. There is a separate version of the pack for families where a child has been diagnosed with IBD. 8,650 packs were distributed in 2011.
- **Promoting membership through hospitals** - Groups distribute approximately 5000 leaflets about Crohn's and Colitis UK and IBD to hospitals throughout the UK encouraging people to attend Local Group meetings and become members and volunteers of the Charity.

- **New members in 2011** – 3425 new members joined, including 238 aged 16-18 who benefited from our free membership scheme for young people. The charity offers free or reduced-rate membership to people who request this because of their personal circumstances and 493 benefited from this scheme in 2011.
- **Overall membership in 2011** – 22,832 members renewed, 4,445 allowed their membership to lapse and 713 ex-members rejoined. Taking into account new members, at the end of 2011 membership of the charity stood at 29,242.
- **Introductory free membership** – A scheme to enable pharmaceutical companies to offer a 6-month trial of membership to patients using their medicines was introduced in September 2011. The objective is to ensure more patients hear about the charity and have an opportunity to experience membership at no cost for 6 months. Two companies have shown interest in the scheme and the companies will meet the costs of the subscription for any patients who take up the offer. There will be an evaluation of whether patients subsequently renew the membership in their own right.
- **Membership Management** – in September 2011 the membership database was upgraded to a new system 'ALMS.net' designed to improve the efficiency of administering subscriptions, financial processing and mailings for our 30,000 members. This was the second phase of development towards one integrated contact and financial management system for all the charity's activities and was a major milestone towards this goal.
- **Volunteer associate trainers** - In 2011 we increased our number of Volunteer Associate Trainers to 11. This enabled us to plan different methods of training for 2012. Providing relevant training ensures that our volunteers feel supported and appreciated and that we are delivering up-to-date and high quality services to members and the public.
- **Office volunteers** - We also increased our office Volunteers to 17 which enables us to provide more administrative support to the office staff to deliver support and information to our members and the public.

Financial Report

The accounts for 2011 are in the format required by the Charity Commissioners – the Statement of Recommended Practice (SORP 2005). This calls for the classification of Crohn's and Colitis UK funds using the following terms:

Restricted funds – refer to income that has been specified for a particular purpose by the donor, e.g. Research and Personal Grant Funds;

Unrestricted funds – refer to donations, grants or other income that has not been specified for a particular purpose by the donor;

Designated funds – refer to unrestricted income that the Trustees have decided to allocate for specific purposes; such funds may subsequently be reallocated by the Trustees.

The figures in the following paragraphs are taken from the Consolidated Statement of Financial Activities ('the SOFA') and from the Notes to the Accounts.

Overall position

The financial result for the year is shown in the Consolidated Statement of Financial Activities and represents the total income, expenditure and resources relating to all activities in the year, being the work of the charity at national level, local groups and the contribution from the trading company, NACC Merchandise Ltd.

In 2011 there was an overall surplus of £171,868 (2010: Deficit £214,697) due largely to the exceptionally high legacy income received in 2011.

Funds

Restricted Funds

These funds have been given for specific aspects of Crohn's and Colitis UK work and cannot be utilised to respond to a shortfall in operating income. The figures discussed in the following paragraphs are drawn from Notes 11 and 23 to the accounts.

Research Fund

Donations and investment income received were £236,627 for the year. Groups fundraising activities raised an additional £23,668. The Fund's total income was £260,295. (2010: £307,306). Resources expended were £432,474. The total carried forward to 2012 was £199,225. Grants awarded in 2011 for Medical Research amounted to £187,939 and Living with IBD Research totalled £209,949.

The Trustees have designated £100,000 of unrestricted funds to be available to maintain levels of research grants in 2012 if required.

Welfare Fund for Personal Grants

Grants are made by the Personal Grants Panel to individuals who have a particular need arising as a result of their inflammatory bowel disease. The maximum level of grant in 2011 was £500. xxx grants were made during the year amounting to £65,896 (2010: 245 grants, total £70,613).

Crohn's and Colitis UK received £36,352 in donations and investment income for the Personal Grants Fund (2010: £63,864). Grants awarded and support costs amounted to £65,896 resulting in an overall deficit of £29,544 after transfers for the year (2010: £12,767 deficit).

The Trustees have transferred the sum of £101,996 from unrestricted funds to ensure that personal grants can continue at the same level in 2012. The fund carried forward to 2012 is therefore £80,000.

Unrestricted and designated funds

The figures discussed in the following paragraphs are drawn from the SOFA and Notes 15 and 22 to the accounts.

Designated funds have been created to hold money set aside by the Trustees for particular purposes. These are to support projects or developments not included within the Association's normal annual budget, to cover any potential liabilities arising from the office lease, to meet the annual depreciation costs of the capital expenditure on premises and equipment, and to hold unrestricted legacy funds. (See Reserves Policy.)

The Trustees' policy is to maintain a clear distinction between ongoing expenditure, which they aim to cover from dependable sources of income, and 'one-off' projects or new developments, which are funded from special fundraising or from legacy income that may vary unpredictably from year to year.

Total unrestricted income from the combined national and Group activities was £2,112,876 (2010: £1,802,656).

Expenditure was £1,914,255 (2010: £1,804,349) resulting in an operating surplus of £198,621 (2010: deficit £1,694) overall.

The total of unrestricted funds carried forward to 2012 is £1,739,887. Of this some £820,000 is held in the General Reserve Fund to cover 26 weeks operating costs.

Cost of generating funds.

One indicator of a charity's efficiency is seen as the cost of generating funds as a percentage of total incoming resources. In 2011 this was 12.89 (2010: 21.40%)

Reserves Policy

Until 2009 the Trustees' policy was to carry forward sufficient unrestricted reserves to cover 20 weeks of the charity's general operating costs. With the economic difficulties facing the country and the potential for reduced levels of donations and fundraising the Trustees decided to increase the levels of reserves to 26 weeks. They are continuing this policy into 2012.

The charity benefits from legacies from members and supporters. These can be restricted or unrestricted and the amounts to be received in any one year are very unpredictable. The Trustees budget for £200,000 in unrestricted legacy income each year but, if possible, set aside that amount into a designated legacy holding fund at the end of each year to cover the risk that legacy income in the following year will be lower than budgeted. Once the legacy target has been reached the funds in the legacy reserve are released for investment in new projects or the development of the charity's existing activities.

Gift Aid

The Trustees review each year how the Gift Aid reclaimed from the Inland Revenue should be allocated to the various aspects of the charities work and base their decision on what they believe to be the best interests of people living with IBD at the time. For 2011, the Trustees allocated the Gift Aid claimed from subscriptions and donations to the General, Research and Welfare Funds in the same proportion as the funds to which members directed their donations.

Investments and property

Some £2.7m is placed in high-interest-bearing Deposit Accounts with the Bank of Scotland, Clydesdale Bank and Santander.

Crohn's and Colitis UK has a 15-year lease, ending September 2015, on its first floor accommodation in St Albans, which is held in the name of NACC Nominees Ltd. The Directors of NACC Nominees Ltd are the Trustees of Crohn's and Colitis UK. In 2011, the charity took additional premises on the ground floor which will be held on an 8-year lease with a break option in 2015. An option to extend the first floor lease by an additional three years has been confirmed.

Grant-making Policies

Research Grants

Grants for Medical and 'Living with IBD' Research are made following nationally-publicised advertisements. Applications are considered by members of the Awards Committees, comprising academic and medical specialists as well as lay representatives. External specialist referees are asked to comment confidentially on applications. Crohn's and Colitis UK has been awarded a Certificate of Good Practice for its peer-review procedures by the Association of Medical Charities. Grants are normally made for periods of up to three years, with reports required at annual intervals. Funds are normally set aside for the total cost of the project in the year of award. Health services Research is normally commissioned taking advice from relevant academic and health professional experts to provide peer review.

Personal Grants

Personal grants are made from the Welfare Fund and are decided by a small committee of members including two Trustees. Grants are made to people on low incomes and with specific needs arising from IBD. The normal maximum grants are £300 under the general scheme and £500 under the Young Persons' Assistance scheme.

Local Grants

Local Groups sometimes make grants to their local hospitals to support or enhance aspects of their provision for IBD patients. Grants have to be made according to the policy guidelines approved by the Trustees and cannot be made for items that should be NHS funded. Group grants have to be specifically approved and a matching amount given to national funds.

NACC Merchandise Ltd

NACC Merchandise Ltd recorded a net operating profit for the year of £8,492 (2010: deficit £8,474) after a gift aid donation of £9,108 to Crohn's and Colitis UK. The main activity of the company continues to be the sale of Christmas Cards to members through mail order although additional merchandise items are being made available.

Risk Assessment

The Trustees, with input from the Chief Executive and staff, have conducted a review of the risks to which NACC is exposed in its ongoing activities and, in particular, the Trustees considered:

- the type of risks the charity faces;
- the level of risks which they regard as acceptable;
- the likelihood of the risks concerned materialising;
- the charity's ability to reduce the incidence and impact of risks that have been identified, and
- the costs of operating particular controls relative to the benefit obtained.

The Trustees review risks in relation to any new developments proposed and Committees and management are required to conduct at least annual reviews of the areas for which they are responsible.

Governance

Constitution

From 1979 to 2006 The National Association for Colitis and Crohn's Disease (NACC) was a charitable, unincorporated association registered in England and Wales under charity number 282732. The Association was governed by a revised constitution adopted on 15th April 2000 and amended at the Annual General Meeting held on 12th April 2003. In 2006 the members voted to change the constitutional status of NACC to a charitable company limited by guarantee and this came into effect at midnight on 31st December 2006. (At that time the Unincorporated Association transferred all its assets and activities to the new charity registered under the same name as charity number 1117148 and as a company registered in England number 5973370. The Unincorporated Association remained in being under the new name of the National Association for Colitis and Crohn's Disease 1979-2006 until it was removed from the Charity Commission register on 29 October 2008.) In 2009, the Articles of the Charitable Company were altered by resolution at the AGM renaming the Council of Trustees as the Board of Trustees and increasing the permissible number of co-opted advisers.

The newly incorporated charity is also registered with the Office of the Scottish Charity Regulator under Scottish charity number SC038362. In May 2010, the working name of Crohn's and Colitis UK was adopted by resolution at the AGM.

Trustees

The constitution provides for a Board of Trustees consisting of four executive honorary officers plus not less than three and not more than eight ordinary trustees, elected at the annual general meetings of members. Members who express an interest in being nominated for election as a Trustee have a meeting with the Trustees to ensure they are aware of the responsibilities and requirements of the role before nomination takes place. Once elected individual induction is arranged according to the Trustee's experience. The Trustees have power to co-opt Advisers as non-voting members of the Council and to appoint a number of committees. A full list of Trustees and Committees is given at the end of this Report.

The Trustees are responsible for determining the aims, policies, activities and budget of NACC. The staff led by the Chief Executive report to the Trustees. The staff are responsible for advising the Trustees and carrying through the policies and activities in accordance with the approach and budget determined by the Trustees.

Objects

The charity's objects, as set out in its constitution, are:

- the relief of those suffering from Ulcerative Colitis, Crohn's Disease or related inflammatory bowel diseases (together generally referred to as IBD) including the support of those who care for them;
- the promotion of the welfare of those suffering from IBD;
- the advancement of education and research into the causes, prevention, treatment and cure of IBD and improvements in the management of the conditions, and the publication of the results of such research.

The objects are fulfilled through the aims, strategies and activities expressed in the 'NACC Plan 2010-2012' and, in the furtherance of these objects, the Directors, as the charity trustees, have complied with the Charities Act 2011 to have due regard to the Charity Commission's published general and relevant sub-sector guidance concerning the operation of the public benefit requirement under that Act. It should be noted that all of the charity's services are open to non-members to use as well as members.

Acknowledgements

The Trustees would like to record their thanks and appreciation to all those who continue to make the charity's work possible - the many people who individually or in Groups who have raised funds for Crohn's and Colitis UK, the charitable trusts and companies who have given their support, the volunteers in our Groups and support services, those who support the charity's activities or serve on our committees, our medical advisers and, not least, the Chief Executive, Senior Managers and staff at the Office in St Albans.

Approved by the Trustees and authorised to be signed by the Chairman on their behalf.



Keith Stewart, Chairman

29th March 2012

Board of Trustees, Officers, Senior Management Team and Committees

From 1st January 2011 to the date of signing of this Report and Accounts, the Honorary Officers, Trustees, Senior Management Team and committee members were as follows:

Life President

Professor John Lennard-Jones

Vice-Presidents

Margaret Chandler

Rod Mitchell

Bradley Brown

Elaine Steven

Senior Management Team

Richard Driscoll Chief Executive

Heather Baumohl Dir. of Member Involvement & Volunteering

Suzi Clark Director of Marketing & Fundraising

Helen Terry Director of Information and Support

Caroline Hardy Dir. of Finance & Administration

(from March 2011)

Board of Trustees - Honorary Officers

Keith Stewart (Chairman)

Dr Martin Gay (Vice-Chairman)

Tim Mutum (National Secretary)

Alan Thackrey (National Treasurer)

Board of Trustees - Elected Trustees

Stuart Berliner

Denise Cann

John Clarke

Gerald Gregory (until October 2011)

Mike Hilton

Deborah Hodges

Kati Simpson

John Stanley

Board of Trustees – Co-opted Advisers

Professor Christine Norton

Professor David Rampton

Julie Reynolds (until October 2011)

Dr Jeremy Sanderson

Dr Ian Shaw (until March 2011)

Professor Chris Probert (from March 2011)

Member Involvement and Volunteering Committee

Mike Hilton (Chairman from December 2011)

Barbara Harvey (Vice-Chairman)

Julie Reynolds (Chairman until December 2011)

Nancy Greig

Gail Walford (until October 2011)

Heather Baumohl

Bev Loczy (from January 2012)

Arron Gill (from March 2011)

Information and Support Committee

Tim Mutum (Chairman)

Bradley Brown

Denise Cann

Rebecca Fisher

Charlotte Gosden

Gerald Gregory (until October 2011)

Deborah Hodges

Judy Murphy

Dr Tim Orchard

Deirdre Choo (until February 2011)

Richard Driscoll

Public Affairs Committee

Dr Martin Gay (Chairman, from February 2011)

David Barr

Mike Hilton

Kiron Kurien

Azmina Verjee

Heather Baumohl

Peter Canham

Richard Driscoll

Alison Orlandi (until December 2011)

Helen Terry

Personal Grants Panel

Bradley Brown (Chairman)

Denise Cann

Melissa Fletcher

Dr Martin Gay

Stella Leigh

Julia Devereux (Secretary)

Helen Terry

Crohn's and Colitis Support Managing Team

Deborah Hodges (*Chairman from January 2011*)
 Lynne Bird
 Bruce Boyd
 Denise Cann
 Peri Gillespie
 Laura Hawes
 Emma Livesey (*until September 2011*)
 Elina Bloomfield
 Helen Terry
 Samantha Edmundson (*from March 2011*)

Marketing and Fundraising Committee

John Stanley (*Chairman*)
 Stuart Berliner
 Jonathan Edwards
 Peter Foy
 Berkeley Greenwood
 Gerald Gregory (*until August 2011*)
 Sandra Oldfield (*from August 2011*)
 Carolyn Smith (*from November 2011*)
 Liz Smith
 Suzi Clark
 Richard Driscoll

NACC Merchandise Ltd

Alan Thackrey (*Director*)

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 Beauclerc House
 3 Queens Road
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Clydsdale Bank
 4th Floor
 Verulam Point
 Station Way
 St Albans
 AL1 5HE

Health Professional Advisers Panel

Dr Jeremy Sanderson (*Chairman*)
 Professor David Rampton (*Vice-Chairman*)
 Dr Ian Shaw (*Secretary until March 2011*)
 Prof. Chris Probert (*Secretary from March 2011*)

Medical Research Awards Panel

Professor David Rampton (*Chairman*)
 Dr Tim Card
 Professor John Cummings
 Alan Dearlove
 Dr Martin Gay
 Dr Barney Hawthorne
 Professor Yash Mahida
 Bharat Odedra
 Dr Jeremy Sanderson
 Dr Ian Shaw (*until March 2011*)
 Douglas Smallwood
 Dr. Alison Simmons
 Dr Andrew Stagg
 Richard Driscoll

Living with IBD Research Awards Panel

John Clarke (*Chairman*)
 Denise Cann
 Dr Peter Irving
 Dr Anna Madill
 Lynne Marriott
 Professor Susan McLaren
 Professor Christine Norton
 Dr.Sneh Shah
 Professor Tricia Sloper
 Dr Gillian Thomas
 Helen Terry

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