

**National Association
for
Colitis and Crohn's Disease**

Annual Report and Accounts

**Year ending
31st December 2006**



**NACC, 4 Beaumont House, Sutton Road,
St Albans, Herts, AL1 5HH.**

Registered Charity No 282732

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This report and the attached statement of accounts comply with current statutory requirements and the Constitution of NACC and are in the format required by the Charity Commissioners - the Statement of Recommended Practice (SORP 2005) – and charity law.

Constitution

From 1979 to 2006 The National Association for Colitis and Crohn's Disease (NACC) was a charitable, unincorporated association registered 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 remains in being under the new name of the National Association for Colitis and Crohn's Disease 1979-2006.)

Trustees

The constitution provides for a Council of Trustees consisting of four executive honorary officers plus not less than three and not more than eight ordinary members, elected at the annual general meetings of members. Members are advised of the procedure to be nominated for election in the notice of AGMs each year and those interested meet with the Trustees to ensure they are aware of the responsibilities and requirements of the role. Individual induction is arranged according to the Trustees' experience. The Trustees have power to co-opt not more

than six 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 Director 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

NACC'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.

The NACC Plan for 2005 - 2008

Following market research undertaken by NOP World for NACC in 2004, the Trustees agreed an overall plan for NACC for 2005 – 2008, which was launched at the AGM in April 2005. The Plan set out NACC's Aim, Vision and Principles, and set the objectives for NACC in that time period and the strategies intended to meet them.

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 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 NACC's Vision

NACC 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.

NACC 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.

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

Our objectives and how well we are achieving them.

1. Providing support & information for patients & their families who are affected by Inflammatory Bowel Diseases (IBD).

Strategies:

- *respond to individual enquiries for information;*
- *provide information and support relating to Disability Benefits;*
- *offer support over the telephone through the 'NACC-in-Contact' scheme;*
- *publish information in the form of booklets, information sheets, quarterly newsletters, audio visual materials and through a web-site;*
- *provide opportunities for interaction and mutual support between members through the NACC website.*
- *maintain volunteer-run groups which provide educational and support meetings,*
- *provide a support network for families with children and for young people who have IBD;*
- *offer individual grants to people who have financial needs arising from their IBD;*
- *provide members with a 'Can't Wait' card which can be shown to retailers when asking for urgent use of private toilet facilities where no public facilities are available;*
- *ensure that health professionals have access to information materials from NACC for their patients*

Achievements in 2006:

- ◇ The NACC Information Service staff responded to 6,618 individual enquiries, an increase of 17% on 2005. Most enquiries were by telephone (80%). Almost two-thirds of those who telephone are patients; just under a third are family members. 40% are NACC members: The Service is staffed by three part-time Information Officers, working an average of 27 hours per week each. The telephone service is provided on an 0845 (local call rate) number and is available five days per week, from 10.00 am to 1.00 pm.
- ◇ The DLA Support Service helped 92 people through its appointment service in 2006 (2005:92). The Service was originated through a Community Fund (National Lottery

Charities' Board) Grant in 1998-2001 and people needing support are able to book a call with a volunteer through the Information Line. Seven Guides to Benefits relevant to IBD are available on the NACC website and by post. These are updated each year.

- ◇ The NACC-in-Contact supportive-listening service is provided by 56 trained volunteers from their homes. Calls on the NACC-in-Contact Support Line are routed to them via an 0845 number and 3 or 4 calls are taken on most evenings. During 2006 a pilot project was started extending the service to weekday afternoons. This has increased the overall number of people helped and was made possible by training 12 additional contacts in 2006.
- ◇ During 2006, many of the publications were updated and a new booklet Surgery for Ulcerative Colitis was published. 23 Information Sheets were available by post and on the NACC Website and new FAQ sheets were prepared in response to enquiries received through the Information Service = these were Managing Diarrhoea and Microscopic Colitis.. A new design for the booklets and Information Sheets was developed and will be implemented in 2007.
- ◇ The NACC newsletter was published quarterly, using a new professional freelance editor working within guidance set by the Information and Support Services Committee. The Medical Editor for 2006 was Dr Ian Arnott. NACC News provides members with information on developments in research and treatment, the opportunity to share experiences of living with IBD and news about NACC activities.
- ◇ The NACC web-site receives an average of 25,000 unique visitors per month and the annual total of user sessions exceeds 350,000.
- ◇ NACC has 70 active Groups which arrange regular meetings open to anyone who is affected by IBD
- ◇ 144 individual Personal Grants were made to people experiencing financial difficulty as a result of their IBD (2005: 134). Most grants were for washing machines, bedding, clothing or recuperative holidays. Applicants must provide supporting evidence of their diagnosis of IBD from a doctor or nurse, of their need for assistance from a social worker or similar professional and must complete a statement of family income and expenses. Applications are considered in confidence by the Personal Grants Committee. Grants do not exceed £500 and applicants can receive no more than three grants in any five-year period.
- ◇ A special Young Persons' Assistance Scheme exists to help meet vocational and educational needs arising from IBD and 17 grants were made in 2006.
- ◇ Colitis and Crohn's Week in 2006 focused on publicising the Can't Wait Card scheme and its importance to NACC members
- ◇ Two significant information projects were undertaken in 2006 to improve the information available to patients in hospitals at critical moments in their treatment for IBD. These were an Information Pack for newly-diagnosed patients and a consultation aid to be used when surgery is being discussed. The latter includes a CD with seven patients speaking about their experiences. Both projects were funded with support from pharmaceutical companies.

Young people with IBD

- ◇ The Trustees commissioned in 2005 a project called IBD and Me to gather the views of young people on their experience and needs related to their IBD and their views on how NACC might be better able to offer support. The project involved focus groups and a dedicated discussion board on the NACC website. The Report was presented to Trustees in September 2006 and each area of NACC's work is now being reviewed in relation to the information and recommendations in the Report.

Families with children who have IBD

- ◇ In 2003 the Family Committee of NACC identified the main needs of families where a child has IBD as being information, support and having opportunities to meet; it also identified the need for further research into the impact of IBD on teenagers. These priorities were accepted by the Trustees.
- ◇ NACC continues to work with CICRA and with the relevant health professional associations to create more awareness in paediatric units of the information and support that is available. A joint poster and leaflet launched in 2005 continues to be distributed.
- ◇ NACC and CICRA held a workshop on the transition from paediatric to adult care in June 2005 which involved health and allied professionals from both paediatric and adult services. A working group was formed in 2006 to develop guidelines for transition with support from the various professional associations and the guidelines will be available in 2007.
- ◇ Within NACC, the 'Smilie's People' Group continued to provide support to families throughout the UK, arranging two family events and running a residential weekend for families in September. Two NACC Groups were assisted in planning for Family Days to take place in 2007.
- ◇ The Information Sheets on IBD in Children and Coping with IBD for Parents were both updated in 2006.

Key objectives for 2007:

- Undertake a formal evaluation of the experience and satisfaction of people using the Information Line, DLA Support Service and NACC-in-Contact and consider what changes or developments might be needed.
- Introduce an interactive members' area on the website.
- Agree a plan for involving and supporting young people more effectively and begin to implement this.
- Publish and promote the guidelines on Transition from paediatric to adult care in IBD.
- Promote the use of the NACC Information Pack for newly-diagnosed patients in hospitals as widely as possible.

2. Raising public & political awareness of IBD.

Strategies:

- *improve awareness and understanding of IBD among the general public through media publicity and the wide dissemination of information about IBD;*
- *increase awareness of IBD among politicians and those responsible for managing health services;*
- *encourage and support patients who have Colitis or Crohn's Disease to become patient representatives at national or local level in response to the Public Involvement opportunities within the NHS and related bodies.*
- *ensure that health professionals have a good understanding of NACC's services*

Achievements in 2006:

- ◇ NACC was chosen as the PR Communiqué Patient Association of the Year for the Campaign for Specialist Nursing which was launched in 2005.

- ◇ NACC continued to employ a part-time Media Agency (Healthcare Solutions) through 2006 to gain more recognition and awareness of IBD through the professional and lay media. The total number of reader or listener impressions in 2006 exceeded 25 million.
- ◇ Colitis and Crohn's Week in 2006 focused on the Can't Wait Card. The campaign successfully conveyed the needs of people living with IBD by explaining why the Card is needed. The campaign was run in collaboration with CICRA (the Crohn's in Childhood Research Association). Carrie Grant, best known from BBC's Fame Academy, again helped the campaign enormously through lending her personal support.
- ◇ The campaign for specialist nursing care was continued throughout the year and significant coverage was obtained in the professional nursing journals.
- ◇ NACC began a programme of raising political awareness of IBD with the support of a professional company Portcullis Public Affairs. Preparatory work in identifying key opinion leaders in Westminster and in Scotland was undertaken, which will lead to a programme of individual contacts in 2007.
- ◇ In October 2006 a reception was held at the House of Lords with the kind support of Lord Newton to raise awareness of the impact of IBD on young people and to launch the new NACC Information Pack.
- ◇ The NACC 360° E-newsletter was sent monthly to subscribing health professionals. The newsletter provides summary reports from gastroenterology meetings and journals, pharmaceutical news, health policy developments and key messages about NACC. The number of professionals subscribing rose by 40% in the year to 350.

Key objectives for 2007:

- To continue the Specialist Nursing Campaign through the media and by running the NACC IBD Nurse Award for the second time.
- To develop the political awareness programme in Westminster and in Scotland to a much higher level to support NACC's work on improving healthcare services and other issues affecting people who have IBD.
- To recruit a panel of members who can take up opportunities for patient representation in the NHS and to support NACC Groups and Patient Panels in representing the needs of IBD patients within their local health organisations.

3. Striving to improve healthcare services & provision for IBD.

Strategies:

- *undertake a campaign for more specialist nursing for people affected by colitis or Crohn's Disease.*
- *seek to establish a strategic framework for the future funding and development of services for gastroenterology patients across the UK;*
- *assist in developing an independent document outlining good practice in the care of patients who have colitis or Crohn's Disease.*
- *encourage the inclusion of patients' experiences of living with IBD in health professionals' training;*
- *support the development of patient panels or other initiatives through which people affected by Colitis or Crohn's Disease and the professionals involved in their care can exchange ideas on how local services for IBD can best be developed;*
- *promote awareness of the value of specialist counselling for people with IBD within NHS services;*

Achievements in 2006:

- ◇ NACC commissioned the University of the South Bank to undertake a systematic review of the published evidence for specialist nursing in IBD and a thematic analysis of the nominations for the 2005 NACC IBD Nurse Award. This was published in December 2006.
- ◇ NACC is one of four organisations jointly managing the first UK-wide audit of hospital services and care for IBD patients. The audit is being run from the Royal College of Physicians Clinical Effectiveness Unit and has been made possible through a £500,000 grant from the Health Foundation. The first round of audit will report in early 2007.
- ◇ NACC has developed a statement of IBD Patients' Expectations and our Vision for an IBD Service based on the focus groups and other consultations on quality of services. This will be publicised in 2007 and forms the basis of NACC's contribution to the development of a national strategy for IBD services. This work is taking place in collaboration with all the professional associations.
- ◇ NACC responded to various Department of Health, MHRA, NPSA and NICE consultation documents during the year.
- ◇ The Trustees received a report on the pilot IBD Patient Panels which NACC had established to explore how patients and IBD health professionals could interact effectively for the improvement of services and of IBD patients' experience within healthcare. It was apparent that these were, in their different ways, making an effective contribution to local developments and the Trustees approved the mainstreaming of this work as a valuable contribution to patient involvement in the NHS.

Key objectives for 2007:

- To work with the professional associations to develop agreed standards of care for IBD and promote these within the National Health Service.
- To produce a briefing document for those who commission IBD health services.
- To explore how primary care services for IBD patients can be improved.
- To help publicise the findings from the first round of the UK IBD Audit and support actions to improve the quality of services.
- To work with the RCN Gastroenterology and Stoma Care Forum to increase the published evidence for the roles and value of specialist nurses in IBD.
- To represent the interests of IBD patients in the forthcoming NICE appraisals of new treatments for IBD.
- To increase the number of IBD Patient Panels and extend these to include paediatric care.

4. Influencing the attitudes of society to achieve positive change for those affected by Inflammatory Bowel Diseases.

Strategies:

- *represent the needs and views of people who have IBD to public authorities and relevant commercial and voluntary organisations;*
- *develop actions based on the findings of our Social and Psychological Research projects,*
- *identify members who are willing to work as individuals or in teams on specific projects or campaigns.*

Achievements in 2006:

- ◇ The Can't Wait Card was the theme for Colitis and Crohn's Week in 20 highlighting the needs of members and the assistance that retailers could provide. The information gathered in a 2005 survey of NACC members underpinned the message. The publicity achieved was substantial, particularly in the regional and local press, but the formal response from retailers was disappointing.
- ◇ The research funded by NACC into the experience of IBD patients at work was reported at the NACC AGM and published during the year. The report will help to inform NACC's future work in this area.
- ◇ Some preparatory work was undertaken on the travel insurance available to IBD patients. This will be continued into 2007.
- ◇ Members and young people were invited to come forward and take part in a project team to explore how NACC can provide more support to young people attending further education.

Key objectives for 2007:

- To develop the student project.
- To review how work on these areas of non-healthcare needs can be taken forward more effectively within NACC.

5. Promoting research into all aspects of Inflammatory Bowel Diseases & how they affect people's lives.

Strategies:

- *raise funds to provide a minimum of £300,000 annually for research into the medical, social and psychological aspects of IBD and seek to increase this to £500,000;*
- *make awards for research projects through a peer-review process;*
- *set aside the full amount of funds required for NACC-funded research at the time of the awards to ensure that there are no financial barriers to their completion;*
- *ensure the publication of the results of research projects to professional and lay audiences.*

Achievements in 2006:

- ◇ The amount raised for research in 2006 was £344,739. Some additional fundraising was undertaken seeking support for a major project into the Genetics of Ulcerative Colitis, but with limited success. However, NACC was a co-applicant in a major research application to the Health Foundation which has resulted in a grant of £500,000 to explore how the quality of Primary Care Services for Gastroenterology can be improved. NACC is not the grant-holder by 25% of the project relates to IBD.
- ◇ £354,466 was awarded for medical research in 2006 enabling six projects to proceed including NACC's largest ever single grant for a multi-centre collaboration for Genetics Research in Ulcerative Colitis. 30 applications were received.
- ◇ Funds had previously been set aside for a Patient-Professional Partnership Project, which was intended to gather evidence of the views of patients and health professionals on what improvements in health services would make most difference to the care of IBD patients. This project has been superseded by work on Improving Health Services described above and accordingly the Trustees have transferred these funds back into the Research Fund.

Key objectives for 2007:

- To consider opportunities for collaborative IBD applications between NACC and other partners to external research funding bodies.
- To review the output of NACC's previous Social & Psychological research awards and identify what has been learned and what further research needs undertaking.
- To publish a review of the last five years of NACC Research Awards.

6. Being an active organisation both in the sense that NACC 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.

Strategies:

- *promote membership to patients, their families and friends, health professionals and anyone interested in IBD;*
- *maintain volunteer-run groups which provide educational and support meetings, local newsletters, undertake fundraising and ensure a local NACC presence;*
- *encourage and support people to become active volunteers in support of the activities necessary to achieving NACC's objectives;*
- *encourage young people diagnosed with IBD to join NACC and become more involved;*
- *ensure that NACC is properly governed;*
- *ensure NACC's volunteer policies and practices meet commonly accepted good practice standards.*
- *raise the funds necessary to sustain the work envisaged, without the essential nature of NACC changing so that it comes to be perceived as primarily a fundraising charity.*
- *encourage fundraising by groups and individuals that raises funds and awareness, but also provides opportunities for mutual support in an informal and enjoyable context.*
- *represent the needs of everyone affected by Inflammatory bowel diseases;*

Achievements in 2006:

Membership

- ◇ Overall membership decreased slightly in 2006. The figure at the close of the year was 29,445 (2004: 29,643). The number of new members joining during the year was also lower at 3186 (2004: 3,447) and the proportion ceasing membership was 11.4% (2005: 10%). However, an analysis of the figures showed that the rate of new members joining has increased by almost 20% over the last six months of the year. This may in part be due to the introduction of a facility for on-line joining on the NACC website in September 2006, which 830 people had used by the end of the year.
- ◇ A reduced subscription is available on request to anyone who cannot afford the normal subscription because they are on a low income.
- ◇ New members were each provided with a pack of information booklets and all members received their annually-renewed 'Can't Wait' card, quarterly newsletters and the opportunity to be in touch with a NACC Group if they wished.

NACC Groups

- ◇ There are 70 active NACC Groups covering most parts of the United Kingdom and providing invaluable opportunities for patients and their families to find out more about IBD and to meet each other informally.
- ◇ The Groups continued to increase the profile of the Association through local publicity and events. They raised significant funds for national activities, particularly for research, but also supporting local hospital services for IBD. Contributions to local hospitals have usually been to enhance some aspect of service or equipment, and many of the Groups have provided financial support for nurses to attend recognised IBD training courses.
- ◇ A successful Group conference was held in April 2006.
- ◇ Progress was made both in training Group volunteers in responding to calls they receive locally and in providing all Groups with an 0845 telephone number to avoid the necessity for individual volunteers' home telephone numbers to be published.
- ◇ The effectiveness of Groups has often depended on the commitment of relatively few long-serving volunteers, many of whom have IBD themselves. Identifying and developing sufficient new volunteers to maintain continuity can prove difficult and a number of Groups have ceased to function when existing Organising Team volunteers decided to retire.
- ◇ A new post of Group Support Officer was created during the year to support the development of new Groups and any existing Groups going through a process of change.
- ◇ In 2005, the programme of induction and development days was continued to help local volunteers work effectively within their Groups.

NACC Volunteers

- ◇ NACC encourages the active involvement of members as volunteers in all of its activities. As part of NACC's plan for 2005-2008, NACC is developing support for all volunteering in NACC, co-ordinating overall policies, development and training, and seeking to maximise the opportunities for active participation in all aspects of NACC. We estimate there are 1,000 people currently active as volunteers within NACC.
- ◇ At Group level, several hundred members undertake support, publicity and fundraising as part of NACC's network of 70 Groups throughout the United Kingdom.
- ◇ At national level, NACC provides some national services through volunteers, notably NACC-in-Contact and the Disability Living Allowance Support Service. These 60 volunteers have undergone selection and training for their roles, work to defined policies and procedures and receive regular support. NACC has developed an innovative use of the Public Service Telephone Network using 0845 technology to present a national service number whilst enabling volunteers to provide the service from their own homes.
- ◇ An increasing number of volunteers assist NACC through participation in managing and advisory committees, and in ad hoc working groups. Wherever practicable, the Trustees advertise these opportunities in the NACC newsletter and invite members to apply with a CV. Candidates are then invited for selection before appointment to a committee. This process has enabled the Association to benefit more effectively from the pool of knowledge and expertise that exists within the membership.
- ◇ Over 300 members help directly by offering to tell their stories to the media to assist in raising awareness and understanding of IBD among the public. These members are recruited through the NACC newsletter, using a questionnaire that enables them to outline their 'story' and set limits on the types of media that they are willing to participate in.

- ◇ Many members also give generously of their time to respond to questionnaires which assist IBD research projects, inform NACC's submissions to consultations and underpin the planning of NACC services.

Leadership;

- ◇ NACC is willing to take a leadership role whenever this seems to be helpful to the interests of IBD patients and their families. This is most clearly demonstrated in 2006 through our work on Improving Health Services, particularly the Campaign for Specialist Nurses.
- ◇ A further example of NACC's leadership role is the action taken to assist patients who develop 'radiation colitis' following radiotherapy treatment for cancer. This came to the attention of the Trustees from calls to NACC's Information Service and from a request in 2005 from a gastroenterologist for NACC to help this group of isolated patients. A scoping study was commissioned and was published in 2006. A workshop was held by NACC to bring together patients, other voluntary organisations from the cancer field and health professionals from gastroenterology and oncology. As a consequence, a new booklet is now being made available through cancer units alerting patients to the possibility of late effects from radiation treatment and guiding them to sources of help. A major research grant has also been secured to explore the treatment and care issues further. Although his work has not been led by NACC, it has been stimulated by NACC's initiative.

Key objectives for 2007:

- To promote membership more actively by publicity within hospitals and increase the overall number of members of NACC.
- To review the categories and benefits of NACC Membership.
- To strengthen the NACC Group Network.
- To complete the introduction of Group 0845 numbers and to provide a facility for NACC Groups to develop their own website linked to the main NACC site.
- To hold a combined Volunteer Conference for key NACC volunteers, not just Groups.
- To recruit a Volunteer Support Officer to improve the effectiveness of our working relationships with volunteers.

7. Working in partnership with Health Service, professional and other patient organisations and with the pharmaceutical industry

Strategies:

- *take a collaborative approach to working with the Health Service nationally and locally throughout the UK;*
- *maintain close links with medical, surgical, nursing and allied health professional associations*
- *seek opportunities for effective partnership with other patient organisations;*
- *be an active member of the European Federation of Crohn's Disease and Ulcerative Colitis Associations and maintain links with other IBD associations around the world;*
- *be an active member of relevant umbrella organisations, particularly the Long-term Conditions Alliance and the Association of Medical Research Charities and their equivalent bodies in each UK country;*
- *seek opportunities for effective collaboration with relevant pharmaceutical companies within the ethical framework set out in NACC's pharmaceutical relations policy.*

Achievements in 2006:

Links with health professionals

- ◇ NACC had information displays at the annual meetings of BSPGHAN – the British Society of Gastroenterology, Hepatology and Nutrition, the BSG - the British Society of Gastroenterology, the Association of Coloproctology and the IBD Nursing Group within the Royal College of Nursing Gastroenterology and Stoma Care Forum.
- ◇ NACC has formal representation on the IBD Section Committee of the BSG and has played an active role in a National IBD Workshop – a project that may lead to service improvements in the NHS.
- ◇ The number of gastroenterologists and surgeons formally linked to NACC as Medical Advisers is about 120. Each NACC Group has at least one appointed Medical Adviser and many advisers also assist with the NACC Publications and with media enquiries.
- ◇ NACC staff and members have taken part in various training courses for health professionals during the year, both locally and nationally.

Links with IBD and voluntary sector organisations

- ◇ NACC has continued to be closely involved with EFCCA - the European Federation of Crohn's and Ulcerative Colitis Associations - and regularly exchanges information with other overseas IBD organisations. Links to these are included in the NACC web-site and NACC information is regularly being reproduced overseas.
- ◇ NACC has maintained communication with other gastroenterology patients' organisations in the UK, particularly the Crohn's in Childhood Research Appeal (CICRA), IA - The Ileostomy and Pouch Support Group, Coeliac UK and the IBS Network.
- ◇ Membership or affiliation was also maintained with the Long-term Conditions Alliance, the Association of Medical Research Charities, the Continence Foundation, the UK Continence Alliance, RADAR and the Disability Alliance.

Links with pharmaceutical companies

- ◇ NACC received a £10,000 educational grant from Procter & Gamble Pharmaceuticals (UK) Ltd. to meet the costs of the NACC Medical Advisers Meeting at the BSG Conference and as a donation towards the costs of NACC's Colitis and Crohn's Week.
- ◇ NACC Merchandise received payments totalling £9,900 from SHS Nutricia Ltd, Schering H
- ◇ NACC received educational support grants of £4,000 from each of the following companies towards the costs of the House of Lords Publicity Event and the NACC Information Pack for newly-diagnosed patients – Abbott, Otsuka Pharmaceuticals (UK) Ltd., Procter & Gamble Pharmaceuticals (UK) Ltd., Schering Healthcare Ltd., Schering-Plough, Shire Pharmaceuticals Ltd., SHS Nutricia Ltd., UCB Pharma Ltd.
- ◇ NACC collaborated with Oyster Healthcare Communications and Procter & Gamble Pharmaceuticals (UK) Ltd. to produce a consultation aid for IBD Surgery that was endorsed by the Association of Coloproctology.

Key objectives for 2007:

- To maintain existing links with Health Professional Associations and strengthen the links to paediatric gastroenterology.
- To increase awareness of NACC in Scotland and establish better communication with health professionals in that country.
- To establish closer links with the Scottish Long-term Conditions Alliance.
- To publish guidelines for NACC's relationships with pharmaceutical companies to make clear that financial support from the companies does not involve ethical compromise.

8. Fundraising activities

- ◇ NACC has a small fundraising staff team (led by the Fundraising Manager appointed towards the end of 2005) who provide advice to individuals and groups fundraising for NACC and who are developing NACC's fundraising initiatives at a national level.
- ◇ The team's work is supported by office volunteers and the Fundraising Strategy Committee.
- ◇ Through the contacts of our Fundraising Strategy Committee NACC was able to host the awareness-raising event at the House of Lords which launched the NACC Information Pack for newly-diagnosed patients.
- ◇ The Millennium Walk was extended to three cities during Colitis and Crohn's Week in June – London, Cardiff and York. About 850 people took part in the walks raising awareness and nearly £65,000.
- ◇ The main area of income growth in 2006 was in fundraising activities by individual supporters through events, sponsored runs and walks, and challenge activities and treks.
- ◇ £117,090 was claimed during the year under Gift Aid as a result of a continuing drive to inform members of the scheme. Almost two-thirds of NACC's members have now signed ongoing Gift Aid declarations or informed us that they are not taxpayers.
- ◇ NACC members' subscriptions and donations, together with the funds raised by Groups, provided 35% of the Association's income in 2006 (2005: 39%).

Key objectives for 2007:

- To increase the funds raised through individual and community activities by providing improved support and guidance to supporters and encouraging more people to fundraise in aid of NACC.
- To implement a new fundraising database to support all fundraising activities.
- To involve more supporters in the Millennium Walks and to develop a national fundraising day for NACC later in the year.
- To seek greater support from charitable trusts and companies.
- To encourage members to consider making a legacy to NACC in their will.
- To assess the potential for new income sources to meet NACC's future development needs.

Financial Report

The accounts for 2006 are in the format required by the Charity Commissioners – the Statement of Recommended Practice (SORP 2005). This calls for the use of certain terms that require clarification:

Restricted funds – refer to income that has been specified for a particular purpose by the donor, e.g. NACC's Research and Welfare 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 overall financial result for the year is shown in the SOFA on page 3 of the accounts. This reports the total income, expenditure and resources relating to all aspects of NACC's activities in the year: including the work of the charity at national level, of its Groups at the local level and the contribution from its trading company, NACC Merchandise Ltd.

In 2006 there was an overall surplus of £9,617 (2005 surplus: £536,019), which includes a realised loss of £17,230 (2005: unrealised gain of £94,805) in the value of investments.

Restricted Funds

The figures discussed in the following paragraphs are drawn from Notes 5 and 23 to the accounts.

Research Fund

The national Research Fund received £302,990 in donations and investment income; in addition NACC Groups transferred £86,281 from their fundraising. The Fund's total income was therefore £389,271 and the total for Resources expended was £382,497 producing a surplus for the year of £49,352 (2005: £74,683 surplus).

Resources expended include £354,466 grant expenditure, £19,466 grant support costs plus £8,565 for the realised loss on investments attributable to the Research Fund. The costs of administering the research grants amounted to 5.5% of grant expenditure.

The Research Funds previously held in a separate fund for the Patient and Professional Partnership Project were transferred back into the Research Fund as the Trustees decided not to pursue this project as a research activity.

The sum of £945,677 was carried forward for distribution in 2007.

Welfare Fund

NACC received £30,717 in donations and investment income for Welfare and NACC Groups transferred a further £6,850 from their funds. The Fund's total income was therefore £37,567. Grants awarded and support costs amounted to £39,293 to which was added an investment loss of £597, producing an overall deficit of £2,920 for the year (2005: £4,197 surplus). The costs of administering the welfare grants amounted to 7.2% of grant expenditure.

£52,503 was carried forward to 2007.

National projects

The 'Self-management' research project was undertaken within the University of Newcastle and the Northumbria Healthcare Trust. It was funded through a Community Fund grant managed by NACC.

Other project 'funds' relate to the receipt and application of specific restricted grants or donations.

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 for future allocation to specific projects.

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 national and Group activities was £1,320,438 (2005: £1,649,892). Expenditure was £1,229,755 resulting in an operating surplus of £90,683 overall. There were net transfers of £66,184 out of unrestricted funds, mainly Group unrestricted income transferred to the national Research and Welfare Funds, reducing the surplus to £24,499.

There was a loss of £6,218 in respect of the realised loss on investments attributable to the unrestricted funds, producing a net surplus of £18,281 on unrestricted funds across all activities (2005: £483,600 surplus).

NACC Groups

There were accounts from 65 Groups. In aggregate, their accounts show total income raised as £187,941, local expenditure, amounting to £89,648 and net transfers to National Funds totalling £116,391. Group transfers to National Funds represented 62% of their total income. Overall the funds held by Groups reduced by £18,098 in the year.

Reserves

Unrestricted Funds

The General Reserve Fund exists to safeguard and underwrite NACC's continuing activities in the event of a temporary reduction in income. The Trustees' policy is to maintain uncommitted reserves in the national General Reserve Fund to a level equivalent to 20 weeks' normal running costs. NACC's normal running costs are currently about £1.5 million. At the end of 2006 free reserves were £570,811 representing approximately 20 weeks running costs (2005: 16 weeks). With the growing scope and extent of NACC activities to meet the objectives set out in the NACC Plan the Trustees anticipate that the reserves figure will have to be enhanced by a transfer of funds from Designated Funds (Legacies) to maintain the 20 week level in 2007.

Restricted Funds.

These funds have been given for specific aspects of NACC's work and cannot be utilised to respond to a shortfall in NACC's General Income. The reserves of the Welfare Fund equate to

1.4 times current annual expenditure on individual grants due to a significant legacy received some years ago.

The funds held in the Research Fund reflect the fact that there was no Grant Programme for Social and Psychological Research in 2006. Of the balance carried forward the Trustees have allocated £354,466 for medical awards in 2007 and £250,000 for Social and Psychological Research. Further allocations may be made during the year.

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 2006 this was 12.8% (2005: 12.6%; 2004: 10.4%).

Gift Aid

The Trustees review each year how the Gift aid reclaimed from the Inland Revenue should be allocated to the various aspects of NACC's work and base their decision on what they believe to be in the best interests of people living with IBD at the time. For 2006, 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

The Trustees have power to invest and deal with NACC's funds. Some years ago they agreed a policy to maximise the return on those funds and, in order to achieve this, to invest long-term funds in two Charities Aid Foundation unit trusts, one geared towards income and the other geared towards capital growth. In 2006, the Trustees decided to withdraw these funds to protect the capital value and place them in high-interest banking accounts.

The realised value of the investments reflected a loss of £17,230 on the original investments. This was a substantial improvement on the losses experienced in the world-wide falls in stock market investments over the previous years.

NACC has a 15-year lease on its office accommodation in St Albans, which is held in the name of NACC Nominees Ltd. The Directors of NACC Nominees Ltd are the NACC Trustees.

Grant-making Policies

Personal Grants

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

Research Grants

Grants are made following nationally-publicised advertisements. Applications are considered by members of the Awards Committees, comprising academic and medical specialists as well as lay NACC representatives. External specialist referees are asked to comment confidentially on applications. Grants are made for periods of up to three years, with reports normally required at annual intervals. Funds are normally set aside for the total cost of the project in the year of award.

Local Grants

NACC 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 has to be given by the Group to NACC's national funds.

NACC Merchandise Ltd

NACC Merchandise Ltd recorded a net profit in the year of £13,032, before making a gift aided donation of £13,190 to the Charity (2005: £12,506, gift aid £7,657). The main activity of the company continues to be the sale of NACC Christmas Cards to members through mail order although additional merchandise items are being made available. In addition, the company received £11,118 in donations for NACC given with Christmas Card orders which were passed direct to the charity.

Risk Assessment

The Trustees, with input from the Director and staff, has 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;
 - NACC'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. NACC's Committees and management have also been made aware of the need to communicate quickly to the Trustees any significant new or increased risks as and when they arise together with proposals as to how the Trustees can respond to them.

Strategic Overview 2006 and Direction for 2007

Review of 2006

The Trustees are satisfied with the progress made towards achieving the objectives set out in NACC's Plan for 2005-2008. Considerable progress was made in all areas in 2006 as described in detail above and there has been sustained internal development in terms of evaluating services and activities, additional and changing staff roles, greater support for and

flexibility in Group activities and increasing emphasis on active volunteer recruitment and participation. These developments are continuing and essential to the delivery of the Plan.

The area of greatest demand on NACC in 2006 was probably our increasing involvement, both in response to requests and from our own initiatives, in all aspects of healthcare services. NACC is seen as the voice of IBD patients and their families and we feel an obligation to fulfil this role nationally and locally. To do so requires both staff and volunteer capacity, continual liaison with professional and other voluntary organisations, maintaining an understanding of the diverging health systems in the four UK countries and a commitment to seeking the views and experiences of people with IBD to inform our representation.

As the scope and complexity of our work grows, probably the biggest challenge we face is to develop the capacity and effectiveness of our organisation in every way – staff, volunteers and sustainable funding – without diminishing the personal ‘feel’ of NACC’s origins as a self-help and mutual aid association.

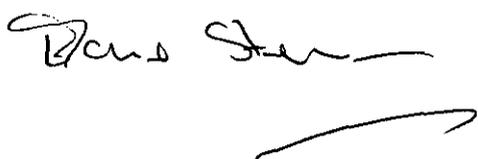
Looking forward to 2007 the other key strategic issues for NACC are:

- Increasing public and political awareness as this underpins the understanding of the needs of IBD patients individually and collectively;
- Establishing a national consensus and statement that sets out the quality of the healthcare services that should be available to people who have IBD;
- Finding ways to involve more young people with IBD in NACC so that they can benefit earlier in their lives from the support, knowledge and experience that people can offer to each other;
- Identifying new ways for people who have IBD to come together and help each other in living with IBD;
- Deciding how far NACC needs to respond differently in the four UK countries to the potentially different environments and needs;
- Identifying significant sources of new income to support our work – at current levels of activity we have to raise over £350,000 in extra funds to fulfil our plans for 2007;
- Reviewing NACC’s current position and beginning to plan the way forward for 2008-2011.

Acknowledgements

The Trustees would like to record their thanks and appreciation to all those who continue to make NACC’s work possible - the many people who individually or in Groups have raised funds for NACC, the charitable trusts and companies who have given their support, the volunteers in our NACC Groups, NACC-in-Contact and DLA Support Services, those who support NACC activities or serve on our committees, our medical advisers and, not least, the Director, Senior Managers and staff at the NACC Office in St Albans.

Approved by the Trustees at a Council meeting and authorised to be signed by the Chairman on their behalf.



Elaine Steven, Chairman
15th April 2007

Trustees, Officers and Advisers

From 1st January 2006 to the date of signing of this Report and Accounts, the honorary officers, trustees and committee members were as follows (* indicates no longer serving):

Life President:

Professor Lennard-Jones

Vice-Presidents:

Margaret Chandler

Rod Mitchell

Bradley Brown

NACC Council:

Honorary Officers:

Elaine Steven (*Chairman*)

*Susanne Wood

(*Vice-Chairman, until April 2006*)

Nigel Westwood

(*Vice-Chairman, from April 2006*)

*Peter Barnes

(*National Treasurer, until March 2006*)

Stella Donoghue

(*National Treasurer, from April 2006*)

Ray Miller (*Honorary Secretary*)

Senior Staff:

Richard Driscoll (*Director*)

Helen Terry

(*Information and Support Services Manager*)

Heather Baumohl

(*Group and Volunteer Development Manager*)

Andrew Shanks

(*Finance and Administration Manager*)

Eleanor Shearns

(*Fundraising Manager*)

Elected Trustees:

Stuart Berliner

Denise Cann

Jefferson Cann

John Clarke

Gloria Fleming

Dr Martin Gay

Gerald Gregory

Tim Mutum (*from October 2006*)

Nigel Westwood (*until April 2006*)

Group and Membership Activities Committee

Nigel Westwood (*Chairman*)

Richard Bond

Emma Livesey

Ray Millar

Tim Mutum

Julie Reynolds

Gail Walford

Ben Wilson

Heather Baumohl

Richard Driscoll

Wendy Childs

Advisers Co-opted onto Council:

*Dr Peter McIntyre (*until April 2006*)

Professor Subrata Ghosh (*from April 2006*)

Dr Jeremy Sanderson

Dr Miles Parkes

Kati Maskell

Ben Wilson

Professor Christine Norton

(*from November 2006*)

Family Committee:

Norma Richardson (*Chairwoman*)

Denise Cann

Chris Corker

Roy Harrison

Kate Piggott

Diane Ratkovic

Elaine Steven

Helen Thomas

Heather Baumohl

Stella Leigh

Richard Driscoll

Personal Grants Committee:

Bradley Brown (*Chairman*)

Dr Martin Gay

Ray Millar

Helen Terry

Julia Devereux

Medical Advisers Committee:

*Dr Peter McIntyre (*Chairman, until March 2006*)

Professor Subrata Ghosh

(*Chairman, from March 2006*)

Dr Jeremy Sanderson (*Vice-Chairman*)

Dr Miles Parkes (*Secretary*)

Information & Support Services Committee

*Susanne Wood (*Chairman, until March 2006*)
 Elaine Steven (*Chairman, from March, 2006*)
 Bradley Brown
 Denise Cann
 Dawn Carter
 Glenys Davies
 Clare Garcia
 Charlotte Gosden
 Gerald Gregory
 Tessa Lees
 Judy Murphy
 Dr Tim Orchard
 Richard Driscoll
 Helen Terry

Fundraising Strategy Committee

Jefferson Cann (*Chairman*)
 Stuart Berliner
 Gerald Gregory
 Elizabeth Rex
 Elaine Steven
 Gerry Thomas
 Richard Driscoll
 Heather Baumohl
 Eleanor Shearn
 Marie Daley
 Geraldine Tunnicliffe

NACC-in-Contact Committee Managing Team

Dawn Carter (*Chairman*)
 Emma Livesey (*Vice-Chairman*)
 Denise Cann
 Tania Clarke
 *Gloria Fleming
 Zoe Grainge
 Tessa Lees
 Clair McNamara
 Charles Melean
 Elina Bloomfield
 Stella Leigh
 Helen Terry

IBD Health Services Committee

Elaine Steven (*Chairman*)
 David Barr
 Peter Canham
 Mike Hilton
 Margaret Hughes
 Martin Gay
 Andy Player
 Richard Driscoll
 Helen Terry
 Heather Baumohl

Medical Research Awards Committee:

Professor Derek Jewell (Chairman)

Alan Dearlove
 Professor Subrata Ghosh
 Dr Satish Keshav
 Dr Richard Logan
 Dr John Mansfield
 *Dr Peter McIntyre (*until March 2006*)
 Bharat Odedra
 Dr Miles Parkes
 Dr Jeremy Sanderson
 Jo Spencer
 Elaine Steven
 Professor Brendan Whittle
 Richard Driscoll

**Directors of trading subsidiary,
NACC Merchandise Ltd:**

Rodney Mitchell (*Chairman*)
 Peter Barnes (*Company Secretary*)
 Bradley Brown (*until January 2005*)
 Elaine Steven (*from January 2005*)

Bankers:

Lloyds TSB plc
 36 Chequer Street
 St Albans
 Herts AL1 3YQ

Auditors:

Kingston Smith LLP
 Devonshire House
 60 Goswell Road
 London EC1M 7AD

Solicitors:

Bates, Wells & Braithwaite
 2-6 Cannon Street
 London EC4M 6YH