

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

**Annual Report and Accounts**

**Year ending  
31<sup>st</sup> December 2005**



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

**Registered Charity No 282732**

# THE TRUSTEES' REPORT

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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 2000) – and charity law.

## **Constitution**

The National Association for Colitis and Crohn's Disease (NACC) is a charitable, unincorporated association registered under charity number 282732.

NACC is governed by a revised constitution adopted on 15th April 2000 and amended at the Annual General Meeting held on 12<sup>th</sup> April 2003. 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 by the annual general meetings of members. 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 is given at the end of this Report.

The Trustees are responsible for determining the policy and budget of NACC. The staff led by the Director report to the Trustees. They are responsible for advising the Trustees and carrying through the policy 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.

## **Policies**

*In relation to the relief of suffering of people who have IBD and the support of those who care for them, NACC's policy is to:*

- publish information in the form of booklets, information sheets, quarterly newsletters, audio visual materials and through a web-site;
- 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;
- maintain volunteer-run groups which provide educational and support meetings, local newsletters, undertake fundraising and maintain a local NACC presence;
- 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;
- raise funds to support these activities.

*In relation to the promotion of the welfare of people who have IBD, NACC's policy is to provide, develop or encourage:*

- membership which is open to patients, their families and friends, health professionals and anyone interested in IBD;
- 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;
- awareness of the value of specialist counselling for people with IBD within NHS services;
- improved awareness and understanding of IBD among the general public through media publicity and the wide dissemination of information about IBD;
- effective representation of the needs and views of people who have IBD within the National Health Service, to public authorities and to relevant commercial and voluntary organisations;
- a partnership approach to working with the health professionals involved with IBD;
- good working relationships with other organisations relevant to IBD.

*In relation to the advancement of education and research, NACC's policy is to:*

- raise funds to provide a minimum of £300,000 annually for research into the medical, social and psychological aspects of IBD and to increase this to £500,000 by 2007;
- 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 award to ensure that there is no financial barrier to its completion;
- ensure the publication of the results of research projects to professional and lay audiences.

## **The NACC Plan for 2005 - 2008**

Following the 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 the actions and objectives that we would aim to achieve in that time period.

### **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.

## **Review of Activities in 2005**

***Activities relating to the relief of suffering of people who have IBD and the support of those who care for them:***

### **Information and Support**

- ◇ The NACC Information Service is staffed by three part-time Information Officers, working an average of 24 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. Over the year the Information Staff responded to 5,000 individual enquiries, 70% by telephone, the remainder by email or letter. Almost two-thirds of those who telephone are patients; just under a third are family members. 40% are NACC members.
- ◇ The DLA Support Line, which was originated through a Community Fund (National Lottery Charities' Board) Grant in 1998-2001, was integrated into the NACC Information Service in 2004. People needing support are able to book a call with a volunteer through the Information Line. 95 people were helped through the appointment service in 2005. The NACC Guide to applying for DLA was first published in 2000 and has been updated when

necessary during the year. A separate Guide is available for children with IBD. A Guide to the Personal Capability Assessment for Incapacity Benefit was completed in 2005.

- ◇ The NACC-in-Contact supportive-listening service is provided by 49 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 2005 the service was extended to cover all weekday evenings from 6.30 – 9.00 pm. The system of publicising Contacts' home telephone numbers for local callers to contact them directly at any time was ended.
- ◇ The NACC web-site receives about 800 user sessions daily, with over 250,000 user sessions through the year.
- ◇ The NACC newsletter was published quarterly, using a professional freelance editor working within guidance set by the Information and Support Services Committee. The Medical Editor for 2005 was Dr Tim Orchard. 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.
- ◇ During 2005 we have created a combined Publications and Information Officer post to ensure that existing publications are regularly updated and new ones progressed. The full range of NACC Publications continued to be available and many were updated during the year. Work continued on a new booklet on Surgery for Ulcerative Colitis and the translation of two NACC booklets into Urdu, Gujarati, Punjabi and Hindi was completed. These texts are available on a CD-ROM which is distributed to hospitals and on the NACC website. A translation into Welsh is nearly complete.
- ◇ 23 Information Sheets were available by post and on the NACC Website and several FAQ sheets have been prepared on various subjects in response to enquiries received through the Information Service.

## **Welfare Fund**

- ◇ 134 individual grants were made to people experiencing financial difficulty as a result of their IBD (*2004: 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.
- ◇ A special Young Persons' Assistance Fund exists to assist with vocational educational needs arising from IBD.
- ◇ Grants do not exceed £500 and applicants can receive no more than three grants in any five-year period.

## **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.
- ◇ As a result NACC is working with CICRA and with the relevant health professional associations to create more awareness in paediatric units of the help that is already available. A joint poster and leaflet was launched in January 2005.
- ◇ A workshop on the transition from paediatric to adult care was held in June 2005 involving health and allied professionals from both paediatric and adult services. The report from the

meeting was published on the web and is leading to the development of guidelines for transition with support from the various professional associations.

- ◇ Within NACC, the 'Smilie's People' Group provides support to families, arranging family meetings twice each year and providing a website. NACC organised a very successful Family Activity Day in September in Avon attended by 30 families.
- ◇ A range of NACC Publications for families continued to be available and are being updated and reviewed.

## **Young people with IBD**

- ◇ The Trustees were committed to review in 2005 how support for Young Adults can be improved throughout NACC and as a first stage a project called IBD and Me was launched. The project is open to members and non-members and involves running a series of one-day meetings to bring young people together to discuss their experience of IBD and what would help them in living with the illness.

## ***Activities relating to the promotion of the welfare of people who have IBD:***

### ***Membership***

- ◇ Membership decreased slightly by 69 in 2005. The figure at the close of the year was 29,643 (2004: 29,712). The number of new members joining during the year was also slightly lower at 3447 (2004: 3,740) and the proportion ceasing membership was 10% (2004: 10.7%). Of those who were members on the 31st December 2005, just over half had joined in connection with Crohn's disease and slightly less than half in connection with Colitis. 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.

### **Increasing awareness**

- ◇ NACC employed a part-time Media Agency (Healthcare Solutions) through 2005 to gain more recognition and awareness of IBD through the lay media.
- ◇ Colitis and Crohn's Week in 2005 saw the launch of NACC's Campaign for specialist nursing for IBD patients. The campaign successfully conveyed the needs of people living with IBD as well as the need for specialist nursing care and significant coverage was obtained in general consumer media as well as health professional media. Carrie Grant, best known from BBC's Fame Academy, again helped the campaign enormously through lending her personal support.
- ◇ The IBD Nurse Campaign invited people affected by IBD to sign up in support via the telephone or web and over 10,000 people had done so by the year end. People were also invited to write to their MP, MSP or AM in support. The campaign will continue into 2006.
- ◇ The difference IBD Nurses make to their patients was highlighted by the first ever NACC Award for IBD Nursing. Members were invited to nominate their nurse and 138 nominations were received. Belle Gregg, IBD Nurse in Liverpool, was selected by the judges as the winner and her prize of a £1,000 bursary for professional development was awarded at the conference of the RCN Gastroenterology and Stoma Care Nursing Forum in Telford in November.

## **Representation, Policy and Campaigns**

- ◇ This area of NACC's work has increased significantly in line with the NACC Plan launched in April 2005. This set out objectives for two major areas of work: *Improving Health Services* and *Influencing the attitudes of society to achieve positive change for those affected by IBD*.
- ◇ NACC responded to various Department of Health, MHRA, NPSA and NICE consultation documents during the year.
- ◇ The difficulties experienced by patients who develop 'radiation colitis' following radiotherapy treatment for cancer came to the attention of the Trustees from calls to NACC's Information Service and from a request from a gastroenterologist for NACC to help this group of isolated patients. A scoping study was commissioned in 2005 and this being undertaken for NACC by Judy Wilson who has great experience of self-help and voluntary sector organisations. The Trustees will consider the report early in 2006.

## **Improving Healthcare Services**

- ◇ As part of the IBD Nursing Campaign, NACC has 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 NACC IBD Nurse Award. This will be available in the summer of 2006.
- ◇ A survey was undertaken of the plans of Primary Care Trusts and Hospital Trusts in respect of specialist nursing for IBD patients. 130 responses were received and in most cases there were no plans to introduce new posts. However, a few expressed interest in future developments.
- ◇ 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.
- ◇ Two one day meetings were held with NACC members to gather views on what would be useful improvements in their IBD care. The report has been very helpful as it has informed NACC's response to various consultations and the IBD Audit.
- ◇ NACC was consulted by the British Society of Gastroenterology in the process of developing a Strategy for Gastroenterology in the UK. This will be published in March 2005 and will address the need for such a document highlighted in the NACC Plan.
- ◇ A programme of pilot Patient Panels has been established to explore how patients and IBD health professionals can interact effectively to assist in the improvement of services and of patients' experience within healthcare. Four pilots were underway as at December 2005 in Carlisle, Bradford, Nottingham and Leicester. A separate IBD Action Group in Brighton is also an active participant in the programme.

## **Influencing the attitudes of society**

- ◇ Several NACC Groups have managed to set up an arrangement with their local police whereby NACC members could park for short periods, without fear of a parking ticket, if they needed to use public toilets in a hurry.
- ◇ NACC members have also made representations to the Government about the eligibility criteria for the blue parking badge scheme and Colitis and Crohn's Disease has been considered in a formal review commissioned by the Office of the Deputy Prime Minister. NACC assisted the consultant carrying out the review, providing the results of a survey of

members, medical information and opinion, and convening a focus group of members in Birmingham to enable personal experiences to be further explored.

### **Links with health professionals**

- ◇ NACC arranged display stands 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 Royal College of Nursing Gastroenterology and Stoma Care Forum. NACC has a representative on the IBD Section Committee of the BSG and continues to have close liaison with the developing group of specialist IBD nurses.
- ◇ 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.
- ◇ NACC staff and members have assisted 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 were included in the NACC web-site and NACC information is regularly being reproduced overseas in newsletters and as translated booklets.
- ◇ NACC has maintained communication with other patients' organisations in the UK, particularly the Crohn's in Childhood Research Appeal (CICRA), IA - The Ileostomy and Pouch Support Group and the IBS Network.
- ◇ Membership or affiliation was also maintained with the Long-term Medical Conditions Alliance, the Association of Medical Research Charities, the Continence Foundation, the UK Continence Alliance, RADAR and the Disability Alliance.

### ***Activities relating to the advancement of education and research:***

#### **Research**

- ◇ Grants are made following nationally-publicised advertisements. Applications are considered by members of either the Medical or Social, Psychological and Health Services Research 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.
- ◇ The costs of administering the research awards are kept to a minimum and are included in the Grant support costs shown on page 3 of the Accounts. In 2005 the administration costs of the NACC Research Awards were 6.6% of grants expenditure.
- ◇ The 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 decided to transfer these funds back into the Research Fund for 2006.

- ◇ 20 applications were received for the annual peer-reviewed Medical Research Awards. Five grants were awarded in March 2005 totalling £277,784.
- ◇ NACC received a Community Fund (previously National Lottery Charities' Board) Award in 2000 to fund research at Newcastle University into 'The effects of patient self-management on the symptoms of ulcerative colitis'. The report from this grant was received in 2004 and in 2005 the Trustees commissioned a Review by University College London of Self-management in Chronic Disease to inform NACC's future policy-making. These will be discussed by the Trustees early in 2006.

## **NACC Groups**

- ◇ NACC Groups are the local face of NACC. The Association maintained 70 active Groups over the year 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 helped enhance local hospital services for IBD. Contributions to local hospitals have usually been to facilitate a new treatment or service, and many of the Groups have provided financial support for nurses to attend recognised IBD training courses.
- ◇ NACC Groups came together for discussion and briefings at the Group Conference in April. In 2005 a new Handbook for Groups was launched setting out a new way of working and identifying possible Group activities as core, optional or nationally supported. The decision was also made to provide all Groups with an 0845 telephone number to avoid the necessity for individual volunteers' home telephone numbers to be published.
- ◇ A framework was developed to encourage more young adults' activities within Groups.
- ◇ 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.
- ◇ The role of Group Development Officer was broadened in 2005 and changed to Group and Volunteer Development Manager. This reflects the importance of volunteers in sustaining all of NACC's activities including Groups. A new post of Group Support Officer was approved at the end of 2005 which will support the development of new Groups and any existing Groups that are 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 2005-2007, NACC has extended the role of the Group and Members Activities Committee and the Group Development Team to include oversight of and support for all volunteering in NACC, co-ordinating overall policies, development and training.
- ◇ 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 55 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 interview 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.
- ◇ In October NACC held four Volunteer Forums in Reading, York, Nottingham and Edinburgh. These were new events open to any existing or potential NACC volunteers and combined briefings, discussion and development sessions.

## **Fundraising activities**

- ◇ NACC has established a Fundraising Strategy Committee and a small fundraising staff team to develop longer term sources of income. The focus for 2005 was on developing individual and community fundraising and activity in this area continued to increase through the year.
- ◇ In November 2005 NACC appointed a Fundraising Manager to lead the development of fundraising throughout NACC and to extend the range of NACC's income.
- ◇ £112,395 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.
- ◇ Income from the NACC affinity Credit Card, which is publicised with support from Sir Steve Redgrave, the Olympic oarsman, provided almost £4,000 to the NACC Research Fund. However, at the end of the year NACC was informed by HBOS that they were terminating their contract with NACC and that the card would cease to benefit NACC early in 2005. A compensation payment for early termination had not been agreed by the year-end.
- ◇ Support was received for national and local NACC activities from several pharmaceutical companies involved in IBD. This most often took the form of reimbursement of the costs of meetings at local or national level. A single donation of £12,000 was received from Procter & Gamble Ltd to support the production of the CD-ROM of translated NACC information and to contribute to the costs of generating media coverage of IBD. The total value of donations in cash or in kind was less than £20,000 in the year.
- ◇ NACC members' subscriptions and donations, together with the funds raised by Groups, provided 39% of the Association's income in 2005 (2004: 33%). The percentage figure is distorted in 2005 because of the exceptionally high legacy income.

## Financial Report

The accounts for 2005 are in the format required by the Charity Commissioners – the Statement of Recommended Practice (SORP 2000). 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 2005 there was an overall surplus of £536,019 (*2004 surplus: £272,838*), which includes an unrealised gain of £94,805 (*2004: unrealised gain of £35,727*) in the value of investments.

The income from legacies was exceptionally high in 2005 and has therefore been shown as a separate item under Incoming Resources on the SOFA. In line with the Trustees' policy the majority of these funds have been placed in the Legacy Holding Fund for future allocation to specific projects or developments.

### Restricted Funds

The figures discussed in the following paragraphs are drawn from Notes 8, 15 and 23 to the accounts.

#### *Research Fund*

The national Research Fund received £243,384 in donations and investment income; in addition NACC Groups transferred £81,192 from their fundraising. The Fund's total income was therefore £324,576 and the total for Resources expended was £249,893, producing a surplus for the year of £74,683 for the year (*2004: £23,409 surplus*).

Resources expended include £277,784 grant expenditure, £18,257 grant support costs less a deduction of £46,148 for the unrealised gain on investments attributable to the Research Fund. The costs of administering the research grants amounted to 6.6% of grant expenditure.

The sum of £766,601 was carried forward for distribution in 2006.

#### *Welfare Fund*

NACC received £33,793 in donations and investment income for Welfare and NACC Groups transferred a further £9,701 from their funds. The Fund's total income was therefore £43,494. Grants awarded and support costs amounted to £42,634 from which were deducted investment

gains of £3,337, producing an overall surplus of £4,197 for the year (2004: £2,177 deficit). The costs of administering the welfare grants amounted to 16.4% of grant expenditure.

£54,826 was carried forward to 2006.

### *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 £1,649,892 (2004: £1,245,056). Expenditure was £1,141,147 resulting in an operating surplus of £508,745 overall. There were net transfers of £60,654 out of Unrestricted funds, mainly Group unrestricted income transferred to the national Research and Welfare Funds, reducing the surplus to £448,091.

There was an additional gain of £35,509 in respect of the unrealised gain on investments attributable to the Unrestricted funds, producing a net surplus of £483,600 on Unrestricted funds across all activities (2004: £254,657 surplus).

### **NACC Groups**

There were accounts from 70 Groups, with two outstanding. In aggregate, their accounts show total income raised as £214,619, local expenditure amounting to £102,788 and transfers to National Funds totalling £114,881. Group transfers to National Funds represented 54% of their total income. Overall the funds held by Groups reduced by £3,050 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 13 weeks' normal running costs. NACC's normal running costs are currently about £1.3 million. At the end of 2005 free reserves were £396,767 representing approximately 16 weeks running costs (*2004: 15 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 fall as additional expenditure is incurred in 2006.

### ***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 1.52 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 2005. Of the balance carried forward the Trustees have allocated £370,000 for medical awards in 2006 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 2005 this was 12.6% (*2004: 10.4%; 2003: 12.2%*).

### **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 2005, 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. The Trustees monitor the income from these investments quarterly and their valuations half-yearly.

The income from the investments has been satisfactory, producing a yield of approximately 3.7% in the year. Following world-wide falls in stock market investments over the last few years, investment values showed a continued recovery in 2005 with unrealised gains of

£94,805 shown in the SOFA. The Trustees do not foresee a need to realise these investments in the near future and are confident that the small amount of remaining unrealised losses will be recovered.

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 the company are the NACC Trustees.

## **NACC Merchandise Ltd**

NACC Merchandise Ltd recorded a net profit of £12,506 in the year (2004: £13,751). 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. NACC wristbands made a significant contribution during 2005. In addition, the company received £11,862 in donations for NACC given with Christmas Card orders which were passed direct to the charity.

## **Risk assessment**

The Council of Trustees, with input from the Director and staff, has conducted a review of the risks to which NACC is exposed 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 have introduced a formal risk management process to assess business risks and implement risk management strategies. Committees and management, when proposing new projects, are required to consider the risks associated with them and 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.

## **Outlook for 2006**

The Trustees are proposing that NACC's constitutional status be changed from that of an Unincorporated Association to a Company Limited by Guarantee on 31<sup>st</sup> December 2006. An Extraordinary General Meeting will be held later in 2006 at which the proposal will be put to members.

Other aims for 2006 are to:

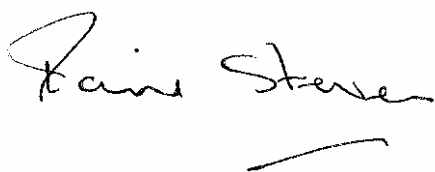
1. Review the principles and effective operation of NACC's membership scheme.
2. Make NACC publications more available as an information resource for IBD patients and their families through hospitals and publish a new booklet on Surgery in Ulcerative Colitis.
3. Create a new section of the NACC website for members offering a discussion board, back copies of NACC News and an e-friends facility.

4. Continue to develop NACC Groups and volunteering within NACC in line with the NACC Plan.
5. Consider how NACC might develop short courses for the education and support of patients and their families.
6. Raise the profile of IBD in Scotland through a special educational meeting at the start of Colitis and Crohn's Week.
7. Continue to develop effective fundraising across a variety of income sources, and, as part of Colitis and Crohn's Week, extend the NACC Millennium Walk from London to two other cities, York and Cardiff.
8. Work with CICRA and other organisations to increase support for and understanding of the needs of families where a child has IBD, including the development of guidelines for transition from paediatric to adult care.
9. Continue to raise awareness of the value of specialist nursing for patients and their families and develop a model business case for local use in supporting existing or new posts.
10. Develop NACC's participation in NHS 'patient involvement' activities and evaluate the programme of pilot patient panels started in 2005.
11. Take an active part in the preparation and implementation of the first UK-wide Audit of IBD services and care in hospitals.
12. Work with other GI patient organisations and professional associations to increase political and public recognition for the burden of gastrointestinal diseases in the United Kingdom through the launch of a strategic framework for gastroenterology services.
13. Review NACC's staffing and infrastructure to ensure there is the capacity to deliver the NACC Plan.

### **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 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  
30<sup>th</sup> March 2006

*The Trustees wish to acknowledge the substantial support for national activities given by the following charitable trusts and companies. (in alphabetical order):*

## **TRUSTS**

The Bernadette Charitable Trust, Bill Browns Charitable Trust, The Elizabeth and Prince Zaiger Charitable Trust, Falk Foundation, The Hulse Charitable Trust, Catherine McKewan Memorial Trust, The G M Morrison Charitable Trust, Pennies from Heaven, Pilkington General Charity, The Saddlers Company Charitable Trust, Wolseley Charitable Trust

## **COMPANIES**

Alstec Limited, Balfour Beatty Rail, Davenport Lions, Domnick Hunter Group, Hampton Allotments & Gardens Limited, Insurance Institute of Reading, Newman Partners Ltd, Procter & Gamble Ltd, V T Merlin Communications, S L A Pharma (UK), Symbol Technologies Inc, Troika

## **Trustees, Officers and Advisers**

From 1<sup>st</sup> January 2005 to the date of signing of this Report and Accounts, the honorary officers, trustees and committee members were as follows:

### ***Life President:***

Professor Lennard-Jones

### ***Vice-Presidents:***

Margaret Chandler

Rod Mitchell

Bradley Brown

### ***NACC Council:***

#### ***Honorary Officers:***

Elaine Steven (*Chairman*)

Susanne Wood (*Vice-Chairman*)

Ray Millar (*Honorary Secretary*)

Peter Barnes (*National Treasurer*)

#### ***Elected Trustees:***

Stuart Berliner

Denise Cann

Jefferson Cann

John Clarke

Gloria Fleming

Dr Martin Gay

Gerald Gregory

Nigel Westwood

#### ***Personal Grants Committee:***

Bradley Brown (*Chairman*)

Dr Martin Gay

Susanne Wood

Julia Devereux

#### ***Advisers Co-opted onto Council:***

Dr Peter McIntyre

Professor David Rampton (*until March 2005*)

Dr Jeremy Sanderson (*from March 2005*)

Dr Simon Travis (*until March 2005*)

Dr Miles Parkes (*from March 2005*)

Kati Maskell

Ben Wilson

#### ***Medical Advisers Committee:***

Dr Peter McIntyre (*Chairman*)

Professor David Rampton  
(*Vice-Chairman until March 2005*)

Dr Jeremy Sanderson  
(*Vice-Chairman from March 2005*)

Dr Simon Travis (*Secretary until March 2005*)

Dr Miles Parkes (*Secretary from March 2005*)

#### ***Group and Membership Activities Committee***

Nigel Westwood (*Chairman*)

Richard Bond

Emma Livesey

Ray Millar

Julie Reynolds

Gail Walford

Ben Wilson

Heather Baumohl

Richard Driscoll

Wendy Childs

#### ***Family Committee:***

Norma Richardson (*Chairwoman*)

Chris Corker

Laura Crawley

Roy Harrison

Diane Ratkovic

Elaine Steven

Richard Driscoll

Stella Leigh

#### ***Information & Support Services Committee***

Susanne Wood (*Chairman*)

Bradley Brown

Deborah Morris

Nigel Westwood

Richard Driscoll

Helen Terry

#### ***Fundraising Strategy Committee***

Jefferson Cann (*Chairman*)

Stuart Berliner

Gerald Gregory

Elizabeth Rex

Elaine Steven

Gerry Thomas

Richard Driscoll

Marie Daley

**Publications Committee:**

*(committee ceased April 2005)*

Bradley Brown (*Chairman*)  
Clare Garcia  
Glenys Davies  
Alan Dinsdale  
Annette Duggan  
Dr Peter McIntyre (*until February 2004*)  
Dr Johann Rademaker (*from February 2004*)  
Richard Driscoll  
Helen Terry

**NACC-in-Contact Committee Managing Team**

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

**Medical Research Awards Committee:**

Professor Michael Langman  
*(Chairman until March 2005)*  
Elaine Steven  
*(ex-officio NACC Chairman 2005)*  
Alan Dearlove  
Professor Subrata Ghosh  
Dr Satish Keshav  
Dr Richard Logan  
Dr John Mansfield  
Dr Peter McIntyre (*until March 2006*)  
Bharat Odedra  
Professor David Rampton  
Jo Spencer  
Dr Simon Travis  
Professor Brendan Whittle  
Richard Driscoll

**Social, Psychological and Health Services Research Awards Committee:**

*(did not meet in 2005)*

John Clarke (*from March 2006*)

Elaine Steven  
*(ex-officio National Chairman 2005)*  
Joanna Brame  
Stephanie Brewster  
Su Hurrell  
Professor Stanton Newman  
Professor Tricia Sloper  
Dr Gillian Thomas  
Susanne Wood  
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*)

**Auditors:**

Kingston Smith  
Devonshire House  
60 Goswell Road  
London EC1M 7AD

**Bankers:**

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

**Solicitors:**

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