

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

Annual Report and Accounts

**Year ending
31st December 2004**



**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 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 12th 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, videos 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 and 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 a project 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.

Review of Activities in 2004

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

Support and information

- ◇ 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 7,356 individual enquiries, two-thirds by telephone, the remainder by email or letter.
- ◇ 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. The Tuesday evening service in which an 0845 number was routed to the homes of trained volunteers was closed and instead people needing support were able to book a call with a volunteer through the Information Line. 89 people were helped through the appointment service in 2004.. 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. Work has begun on a comparable Guide to Incapacity Benefit.

- ◇ The NACC-in-Contact supportive-listening service is provided by 50 trained volunteers from their home telephones. Their numbers are publicised through a national list and local publicity. Over 30 of these volunteers also worked on the NACC-in-Contact Support Line through the year, which was available on an 0845 number on Monday, Tuesday, Wednesday and Thursday evenings each week. 3 or 4 calls were taken on most evenings. From early in 2004 some contacts were also available during daytime hours.
- ◇ The NACC web-site now receives about 800 user sessions daily, with over 250,000 user sessions through the year (*2003:135,000*).
- ◇ The same range of NACC Publications continued to be available and some were updated during the year. Work continued on a new booklet on Surgery for Ulcerative Colitis and started on the translation of two NACC booklets into Urdu, Gujarati, Punjabi and Hindi. These texts will be published on a CD Rom and distributed to hospitals in 2005.
- ◇ Managing Pain and IBD was highlighted during the year with a major feature in consecutive issues of NACC News covering both the experience of members and approaches to the management of Pain.
- ◇ The NACC newsletter was published quarterly, using a professional freelance editor working within guidance set by the Publications Committee. The Medical Editor for 2004 was Dr Miles Parkes.
- ◇ 23 Information Sheets were available by post and on the NACC Website.
- ◇ The difficulties experienced by IBD patients and their families through the reality or fear of faecal incontinence was the subject for NACC's national lecture in April 2004. Professor Christine Norton identified a variety of ways in which people could be helped or could help themselves to limit the impact of this problem on their day-to-day lives.

Welfare Fund

- ◇ 134 individual grants were made to people experiencing financial difficulty as a result of their IBD (*2003: 145*). 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 Welfare Committee. Grants do not exceed £300 and applicants can receive no more than three grants in any five-year period.
- ◇ A special Young Persons' Assistance Fund exists to assist with vocational educational needs arising from IBD. Grants under this scheme may be up to £500.

NACC Groups

- ◇ The Association maintained about 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 Forum in April.
- ◇ 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 committee volunteers decided to retire.
- ◇ NACC has a full-time Group Development Officer who supports the development of a stronger Group network throughout the country, providing ongoing support for existing groups as well as helping new ones get started. In 2004, the programme of induction and development days was continued to help local volunteers work effectively within their Groups. Several experienced Group members have taken on the role of volunteer Group Support Workers.

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 was prepared in 2004 ready for launch in January 2005.
- ◇ A workshop on the transition from paediatric to adult care has been planned for June 2005. The meeting is being run jointly by NACC and CICRA with support from the various professional associations.
- ◇ A questionnaire on support and information needs was circulated among families within NACC and this will help with planning further developments.
- ◇ Within NACC, the 'Smilie's People' Group provides support to families, arranging family meetings twice each year and providing a website. They also arranged a residential activity weekend for families in September 2005.
- ◇ A range of NACC Publications for families continued to be available and are being reviewed.

Young people with IBD

- ◇ A review of how best to support Young Adults Groups was undertaken and the Group and Members' Activities Committee produced a framework document outlining how such groups could operate within the existing NACC group structure.
- ◇ The Trustees have committed to review in 2005 how support for Young Adults can be improved throughout NACC.

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

Membership

- ◇ Membership increased from 2003. The figure at the close of the year was 29,712 (2003: 29,088). The number of new members joining during the year was also slightly higher at 3,740 (2003: 3,576) and the proportion ceasing membership was 10.7% (2003: 13.3%). Of those who were members on the 31st December 2004, 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 2004 to gain more recognition and awareness of IBD through the lay media.
- ◇ Colitis and Crohn's Week in 2004 focused on Pain and IBD. Following a survey of members' experiences, significant media coverage was obtained in general consumer media as well as health professional media.

Representation

- ◇ 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 have received a commitment that Colitis and Crohn's Disease will be considered in the forthcoming review.

Links with health professionals

- ◇ NACC arranged display stands at the annual meetings of the British Society of Gastroenterology, the Association of Colo-proctology and the Royal College of Nursing Gastroenterology 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 close to 100. Each NACC Group has at least one appointed Medical Adviser.

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 Contenance Foundation, the UK Contenance 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 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 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 2004 the administration costs of the NACC Research Awards were 3.5% of grants expenditure.
- ◇ £120,000 was set aside in a previous year as a separate fund for a research project entitled the 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 was deferred during 2004 and will be reviewed in 2005.
- ◇ 26 applications were received for the annual peer-reviewed Medical Research Awards. Six grants were awarded in March 2004 totalling £367,721.
- ◇ An expert group undertook a review of the evidence connecting MAP and Crohn's Disease and their report was published early in 2004. The report is available from the NACC website and copies were sent to DEFRA and the Department of Health.
- ◇ 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 formed the basis for a presentation at the NACC AGM in April. The research will inform NACC's future developments in this area.

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 2004 was on developing individual and community fundraising and income from this area was more than doubled through the year.
- ◇ £105,170 was claimed during the year under Gift Aid as a result of a continuing drive to inform members of the scheme. Half of the NACC membership have now signed ongoing Gift Aid declarations and this is contributing over £70,000 annually to NACC's income.
- ◇ 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.
- ◇ Support was received for national and local NACC activities from the majority of the pharmaceutical companies involved in IBD. In most cases this represented reimbursement of the costs of meetings or printing of publications. 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 51% of the Association's income in 2004 (2003: 50%).

Contribution of 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 Officer to include all volunteering in NACC and to co-ordinate overall policies, development and training.
- ◇ At Group level several hundred members undertake support, publicity and fundraising as well as the necessary organisation for a voluntary network of about 70 Groups throughout the United Kingdom.
- ◇ NACC is committed to providing some national services through volunteers, notably NACC-in-Contact and the Disability Living Allowance Support Service. These volunteers, about 65, 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 also 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 2004 NACC held four Volunteer Forums in Bristol, Birmingham, Bradford and Glasgow. These were new events open to any existing or potential NACC volunteers and combined briefings, discussion and development sessions.

Market Research and Developing a Strategic Plan for NACC:

Market Research

- ◇ In late 2003 NACC commissioned NOP Healthcare to undertake independent market research on perceptions of NACC among members, lapsed members, patients in hospital clinics and health professionals.
- ◇ The findings showed that:
 - People generally had a good understanding of what NACC offered.
 - They valued **all** the existing services.
 - They wanted NACC to do more in some areas, but not risk current services.
 - People who left and responded were **not** dissatisfied with NACC.
 - Health professionals wanted to know more about NACC and hear from NACC more often.

Areas in which people wished NACC to do more.

- Creating more awareness of Colitis and Crohn's Disease and of NACC
- Undertaking more campaigning on issues that affected the lives of patients and their families
- Enabling more research – raising more money
- Campaigning for more Specialist Nursing for people who have Colitis or Crohn's Disease

Developing a Strategic Plan for NACC

- ◇ In July 2004 the Trustees held a Planning Day at which they identified the strategic priorities for NACC in 2005-2007 taking account of the market research findings.
- ◇ The elements of the plan covered:

The Information Service and Publications

- Continuing to develop the Information Service, recruiting a Benefits Specialist and producing a Guide to Incapacity Benefit.
- Continuing to develop NACC Publications, including a process for reviewing all publications regularly, producing a booklet on Surgery and Ulcerative Colitis, and information in Ethnic Minority Languages.
- Continuing to develop the website with a members' discussion board/interactive area.
- Considering the development of short courses in IBD.

Raising Awareness of IBD and NACC

- Ensuring hospitals have information about NACC for new patients and their families.
- Ensuring families that have a child who has IBD know there is information and support.
- Increasing media publicity: the aim being to convey that Colitis and Crohn's are serious illnesses.
- Creating a major awareness campaign in 2005/6 to focus on the need for specialist nursing.

Improving Health services

- Encouraging members to become involved in the NHS *Public & Patient Involvement opportunities*.
- Piloting a number of IBD 'patient panels' through which patients and professionals can share ideas on improving local services.
- Taking a leading role in getting the need for and value of specialist nurses recognised.
- Developing partnerships with all the professional associations to establish guidelines and standards for IBD services.

Influencing attitudes to achieve change

- Identifying members who will work in teams on specific projects and campaigns, for example the Blue Parking Badge and prescription charges (focusing on Scotland first).
- Developing work based on the findings of our Social & Psychological Research projects, for example the research on managing IBD at work.

Developing research

- Raising our yearly fundraising target to £500,000 by 2007.
- Providing 50% of funds to Medical and 50% to Social and Psychological Research.

- Undertaking a formal review of how best to apply NACC's Research funds and NACC's overall role in IBD and Gastroenterology Research.

Fundraising

- Aiming to raise more funds to support NACC's activities, but not being seen as primarily a fundraising charity.
- Encouraging more member and volunteer fundraising recognising that this also provides opportunities for mutual support, sharing of experiences and fun!

Groups and Volunteers

- Developing the roles of NACC Groups and volunteers at the local level.
- Introducing a framework for Young Adults to work within NACC Groups.
- Introducing a framework for volunteers to work in Campaign and Project Teams.
- Encouraging more members to support NACC's work through active volunteer involvement.

A new vision for NACC:

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.

Financial results

The accounts for 2004 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 the national level, of its Groups at the local level and the contribution from its trading company, NACC Merchandise Ltd.

In 2004 there was an overall surplus of £272,838 (2003 surplus: £251,744), which includes an unrealised gain of £35,727 (2003: unrealised gain of £31,493) in the value of investments.

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 £262,699 in donations and investment income; in addition NACC Groups transferred £125,387 from their fundraising. The Fund's total income was therefore £388,086 and the total for Resources expended was £364,677, producing a surplus for the year of £23,409 for the year (2003: £177,726 surplus).

Resources expended include £367,721 grant expenditure, £13,492 grant support costs less a deduction of £16,536 for the unrealised gain on investments attributable to the Research Fund. The costs of administering the research grants amounted to 3.7% of grant expenditure.

The sum of £691,918 was carried forward for distribution in 2005.

Welfare Fund

NACC received £25,999 in donations and investment income for Welfare and NACC Groups transferred a further £5,795 from their funds. The Fund's total income was therefore £31,794. Grants awarded and support costs mounted to £33,971, producing an overall deficit of £2,177 for the year (2003: 722 deficit). The costs of administering the welfare grants amounted to 5% of grant expenditure.

£50,629 was carried forward to 2005.

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 £1,245,056 (2003: £969,130). Expenditure was £906,157 resulting in an operating surplus of £338,899 overall. There were net transfers of £98,733 out of Unrestricted funds, mainly Group unrestricted income transferred to the national Research and Welfare Funds, reducing the surplus to £240,166.

There was an additional gain of £14,491 in respect of the unrealised gain on investments attributable to the Unrestricted funds, producing a net surplus of £254,657 on Unrestricted funds across all activities (2003: £68,516 surplus).

NACC Groups

There were accounts from over 70 Groups, with two outstanding. In aggregate, their accounts show total income raised as £259,156, local expenditure amounting to £109,694 and transfers to National Funds totalling £185,073. Group transfers to National Funds represented 71% of their total income. Overall the funds held by Groups reduced by £35,611 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 changed their policy in 2003 and aim to build up uncommitted reserves in the national General Reserve Fund to a level equivalent to 13 weeks' normal running costs (previously 26 weeks). NACC's normal running costs are currently about £1 million. At the end of 2004 free reserves were £290,543, representing approximately 15 weeks running costs (2003: 11 weeks).

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 1.33 times current annual expenditure on individual grants due to a significant legacy received some years ago. The funds held in the Research Fund will enable NACC to increase the number of awards made in 2005/6.

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 2004 this reduced to 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 2004, the Trustees allocated the Gift Aid claimed from 2003 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 4.2% in the year. Following world-wide falls in stock market investments over the last few years, investment values showed a partial recovery with unrealised gains of £35,727 shown in the SOFA. The Trustees do not foresee a need to realise these investments in the near future and are confident that the remaining unrealised losses will be recovered once the stock market itself fully recovers.

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 £13,751 in the year (2003: £2,286). The main activity of the company continues to be the sale of NACC Christmas Cards to members through mail order. In addition, the company received £11,456 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 2005

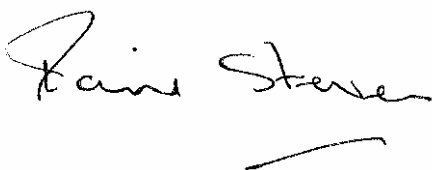
In 2004 the Trustees developed the Strategic Plan for NACC which has been outlined above. In line with this plan key objectives agreed by the Trustees for 2005 are to

1. Reorganise NACC's internal committee structure to meet the new priorities, merging the Information Service and Publications Committees and creating a Health Services Committee.
2. Review the principles and effective operation of NACC's membership scheme.
3. Review and clarify the purpose of Groups in support of the NACC Plan.
4. Review the place of NACC publications as an information resource for IBD patients and their families.
5. Develop more co-ordinated and consistent policies for involving volunteers within all areas of NACC.
6. Continue to develop effective fundraising across all possible income sources.
7. Produce information about IBD in Urdu, Gujarati, Punjabi and Hindi as a first step towards meeting the needs of people from ethnic minorities.
8. Develop the NACC website to offer more opportunities for interaction for users.
9. Develop understanding of the need for and value of specialist nursing for patients with colitis and Crohn's Disease and to undertake a major awareness campaign to support this objective.
10. Work with CICRA and other organisations to increase support for and understanding of the needs of families where a child has IBD.
11. Develop NACC's participation in NHS 'patient involvement' activities particularly through a number of pilot patient panels.
12. Seek political and public recognition for the burden of gastrointestinal diseases in the United Kingdom and contribute to the development of a strategic framework for gastroenterology services.

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 serve on our committees, our medical advisers and, not least, Richard Driscoll and the 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
31st March 2005

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

AMEC Group, The Bernadette Charitable Trust, British Airways Regional Cargo, Castell Alun High School, The Catherine McKewan Memorial Trust, Chapman Charitable Trust, The Coulthurst Trust, Cranfield Software Co., Denstone, Diamond Holidays, The Elizabeth and Prince Zaiger Charitable Trust, Ferring Pharmaceuticals Ltd., Fluor Ltd., The Hawthorne Charitable Trust, The Hulse Charitable Trust, Ihsan Yousaf Textiles, J A Harris Ltd, The Madeleine Maby Charitable Trust, The G M Morrison Charitable Trust, Murco Petroleum Ltd., Pennies from Heaven, Procter & Gamble Pharmaceuticals Ltd, Schroder Charity Trust, St James' Church, St Bernadette Catholic Secondary School (Bristol), Shell Egypt, The Souter Charitable Trust, Troika, Twycross House School, The David Uri Charitable Trust, USB Celltech Ltd., The Weinstock Fund.

Trustees, Officers and Advisers

From 1st January 2004 to the date of signing of this Report and Accounts, the honorary officers, trustees and committee members were as follows:

Life Presidents:

Professor Lennard-Jones
Lady Bingley (who sadly died in January 2005)

Vice-Presidents:

Margaret Chandler
Rod Mitchell
Bradley Brown (*from April 2004*)

NACC Council:

Honorary Officers:

Bradley Brown (*Chairman until April 2004*)
Elaine Steven (*Chairman from April 2004*)
Elaine Steven (*Vice-Chairman until April 2004*)
Susanne Wood (*Vice-Chairman from April 2004*)
Ray Miller (*Honorary Secretary from April 2004*)
Peter Barnes (*National Treasurer*)

Elected Trustees:

Stuart Berliner (*from April 2004*)
Denise Cann
Jefferson Cann
John Clarke (*from February 2004*)
Gloria Fleming (*from April 2004*)
Dr Martin Gay
Gerald Gregory
Ray Millar (*until April 2004*)
Nigel Westwood
Susanne Wood (*until April 2004*)

Advisers Co-opted onto Council:

Dr Peter McIntyre
Professor David Rampton (*until March 2005*)

Dr Simon Travis (*until March 2005*)

Group and Membership Activities Committee

Nigel Westwood (*Chairman*)
Richard Bond
Gerald Gregory (*until March 2005*)
Sarah Longes (*until March 2005*)
Ray Millar
Ben Wilson
Heather Baumohl

Welfare Committee:

Bradley Brown (*Chairman*)
Dr Martin Gay
Jacqueline Hockey
Susanne Wood

Medical Advisers Committee:

Dr Peter McIntyre (*Chairman*)
Professor David Rampton
(*Vice-Chairman until March 2005*)
Dr Simon Travis (*Secretary until March 2005*)

Family and Young People's Committee:

Norma Richardson (*Chairwoman*)
Bradley Brown (*until April 2004*)
Chris Corker
Laura Crawley
Gillian Hamer-Hodges (*until October 2004*)
Elaine Steven (*from April 2004*)
Ruth Tilley (*until March 2004*)
Richard Driscoll
Stella Leigh

Information Services Committee

(committee changing April 2005)

Susanne Wood *(Chairman)*

Bradley Brown
Deborah Morris
Nigel Westwood
Richard Driscoll
Helen Terry

Publications Committee:

(committee changing 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

Medical Research Awards Committee:

Professor Michael Langman
(Chairman until March 2005)
Bradley Brown
(ex-officio NACC Chairman 2004)
Elaine Steven
(ex-officio NACC Chairman 2005)
Alan Dearlove
Dr Alastair Forbes *(until September 2004)*
Professor Subrata Ghosh
Dr Satish Keshav
Dr Richard Logan
Dr John Mansfield *(from September 2004)*
Dr Peter McIntyre
Bharat Odedra
Professor David Rampton
Dr Simon Travis
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)*

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

Fundraising Strategy Committee

Jefferson Cann *(Chairman)*
Stuart Berliner *(from November 2004)*
Sheila Edwards *(until March 2005)*
Elizabeth Rex
Elaine Steven *(from April 2003)*
Gerry Thomas *(from November 2004)*
Richard Driscoll
Marie Daley
NACC-in-Contact Committee: *(from January 2005 the NACC-in-Contact Managing Team)*
Elaine Steven *(Chairman until June 2004)*
Dawn Carter *(Chairman from June 2004)*
Denise Cann *(Vice-Chairman until June 2004)*
Emma Livesey *(Vice-Chairman from June 2004)*
Gloria Fleming *(Contact Organiser)*
Zoe Grainge *(from June 2004)*
Tessa Lees
Charles Melean *(from October 2004)*
Roger Moulton *(from January –September 2004)*
Stella Leigh *(Training Organiser)*

Social, Psychological and Health Services Research Awards Committee:

Lady Bingley
(Chairwoman until September 2004)
Bradley Brown
(ex officio National Chairman 2004)
Elaine Steven
(ex-officio National Chairman 2005)
Joanna Brame
Stephanie Brewster
Su Hurrell
Professor Stanton Newman
Dr Lynne Quine
Professor Ian Robinson
Dr Jon Shaffer *(until September 2004)*
Professor Tricia Sloper
Dr Gillian Thomas
Susanne Wood
Richard Driscoll

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