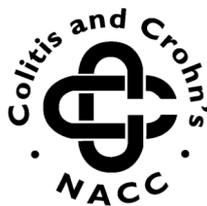


**National Association  
for  
Colitis and Crohn's Disease**

**Annual Report and Accounts**

**Year ending  
31<sup>st</sup> December 2008**



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

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

# 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 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 12<sup>th</sup> 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 31<sup>st</sup> December 2006. (At that time the Unincorporated Association transferred all its assets and activities to the new charity registered under the same name as charity number 1117148 and as a company registered in England number 5973370. The Unincorporated Association remained in being under the new name of the National Association for Colitis and Crohn's Disease 1979-2006, until it was removed from the Charity Commission register on 29 October 2008.)

NACC, the newly incorporated charity, is also registered with the Office of the Scottish Charity Regulator under Scottish charity number SC038362.

## 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 trustees, elected at the annual general meetings of members. Members who express an interest in being nominated for election as a Trustee have a meeting with the Trustees to ensure they are aware of the responsibilities and requirements of the role before nomination takes place. Once elected individual induction is

arranged according to the Trustee's experience. The Trustees have power to co-opt 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 Chief Executive report to the Trustees. The staff are responsible for advising the Trustees and carrying through the policies and activities in accordance with the approach and budget determined by the Trustees.

## **Objects**

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**

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 and their families who are affected by Inflammatory Bowel Disease (IBD) to enable them to manage their IBD and to live their lives as effectively as possible within the constraints of their illness.**

### **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 accurate and reliable information in the form of booklets, information sheets, a quarterly newsletter, audio visual materials and through the NACC website;*
- *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 2008:**

- ◇ The NACC Information Service staff responded to 5,000 individual enquiries. Most enquiries were by telephone (81%). 50% of those who telephone are patients; 20% are family members, of which 4% are parents of children under 18. 25% are NACC members. The Service is staffed by three part-time Information Officers and one Publications and Information Officer, 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, with an answerphone and ring back service outside these times.

- ◇ The DLA Support Service helped 57 people through its appointment service in 2008. People needing support are able to book a call with a volunteer through the Information Line. Eleven Guides to Benefits relevant to IBD are available on the NACC website and by post.
- ◇ 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 days. The service is available on weekday afternoons and evenings.
- ◇ NACC has been chosen by the Department of Health from over 120 applications to participate in the testing phase of a new scheme to ensure good quality information across the health and social care sector. NACC is testing the scheme alongside others from the commercial, public and voluntary sectors. Subject to achieving certification through this testing phase, NACC will become one of the first scheme members when it launches in 2009.
- ◇ NACC publications are reviewed and updated in a planned programme. 31 Information Sheets are available by post and on the NACC Website. Over 12,000 of these were sent out by post in 2008. 9 Information Sheets were updated in 2008 and 4 new titles introduced: Travel and IBD; Talking to my Child about IBD; Staying Well with IBD; and Ulcerative Colitis and Crohn's Disease: a guide for employers.
- ◇ A new title 'Adalimumab' was added to the set of Drug Treatment Information Sheets, which describe individual immunomodulator and biologic therapies prescribed for IBD. These Sheets have been produced in parallel with guidance for professionals provided by the BSG (British Society of Gastroenterology) and cover Azathioprine/6MP, Ciclosporin, Infliximab and Methotrexate.
- ◇ 9 booklets are available free of charge to individuals. During 2008, all booklets were also made available for hospitals to order in bulk. Two booklets, Living with IBD and Understanding Colitis and Crohn's Disease continue to be offered free of charge to hospitals in multiples of 20, and a charge of £10 per 20 copies is made for all other booklets. One booklet was updated in 2008 and another completely rewritten. Seven booklets have been reprinted in the new design for the booklets agreed in 2006.
- ◇ Over 8,000 copies of the NACC Information Pack for newly-diagnosed patients were distributed to hospitals during the year. These packs are provided free-of-charge to hospitals with the aid of support grants from eight pharmaceutical companies.
- ◇ 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 2008 was Dr Cathryn Edwards. 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 website receives an average of 21,031 unique visitors per month and the annual total of user sessions exceeds 366,792
- ◇ NACC has 70 active Groups which arrange regular meetings open to anyone who is affected by IBD.
- ◇ 169 individual Personal Grants were made to people experiencing financial difficulty as a result of their IBD (2007: 124). 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. Applicants can receive no more than three grants in any five-year period and the average grant is just over £300.

### *Young people with IBD*

- ◇ In 2007 NACC developed the IBD and Me web pages and discussion board as a support service for young people. 550 new members registered on the board in 2008.
- ◇ A special Young Persons' Assistance Scheme exists to help meet vocational and educational needs arising from IBD and 12 grants were made in 2008 (9: 2007).

### *Families with children who have IBD*

- ◇ 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 Family Information Pack was introduced in 2008 for families of children newly-diagnosed with IBD. 1,500 copies were provided free of charge to paediatric units with the aid of a support grant from the fundraising group 'Pennies from Heaven'.
- ◇ Guidelines on the transition from paediatric to adult care were published in January 2008 and made available free of charge to health professionals, parents and young people. with support from four companies. 1190 Young People's Guides have been distributed, 1130 Parents Guides and 504 Guides for Health Professionals.
- ◇ Within NACC, the 'Smilie's People' Group changed its name to 'Smilie's network' and continued to provide support to families throughout the UK. Two Family Days were run in 2008 Bristol and at the York Hill Hospital in Glasgow and a residential family weekend in Ironbridge.
- ◇ A college and university project looked at what young adults and their parents may want to know when starting college and university.
- ◇ The Parent to Parent Telephone Support Service was launched in 2008. Parents needing support are able to book a call with a volunteer through the Information Line. 24 appointments were made during the year.

#### **Key objectives for 2009:**

- Provide new audio-visual materials about living with IBD on DVD and the NACC website.
- Introduce an interactive members' area on the website.
- Publish three new Information Sheets on Complementary and Alternative Therapy; Nutritional Treatment for IBD and Fistulae.
- Publish an additional Drug Treatment Information Sheet on Steroids.
- Explore the possibility of publishing a book for children with IBD.
- Adopt the Information Accreditation Scheme standard and demonstrate a level of excellence by achieving certification as an accredited information provider.
- Appoint a Helplines Development Manager and a second part-time Publications Officer.
- Agree a plan for involving and supporting young people more effectively and begin to implement this.
- Plan how NACC can develop a programme of 'Living with IBD' workshops to be launched in 2009, if funding can be secured.

## 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 speak publicly about their experiences at relevant events and in the media.*
- *ensure that health professionals have a good understanding of NACC's services*

### **Achievements in 2008:**

- ◇ NACC continued to employ a media agency (Healthcare Solutions) to gain more recognition and awareness of IBD by promoting features in health professional and consumer media. The total number of reader or listener impressions in 2008 exceeded 44 million.
- ◇ For the second time in three years, NACC was awarded the PR Communiqué Award as Patient Association of the Year.
- ◇ Colitis and Crohn's Week in 2008 focused on the needs of families affected by IBD and the launch of the Parent to Parent Service.
- ◇ NACC continued its programme of raising political awareness of IBD with the support of Portcullis Public Affairs. Briefing sessions were arranged for politicians at Westminster, the Scottish Parliament and the Welsh Assembly with a very positive response. These have prepared the ground for the launch of the IBD Standards in 2009.
- ◇ 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 to 460.
- ◇ NACC continued developing a specific programme of raising awareness among health professionals in Scotland where in the past the number of NACC members and Groups has been proportionally lower than the rest of the UK. A number of units were visited individually, four meetings for IBD Nurses were arranged and NACC was represented at all the major Scottish Gastroenterology meetings.

### **Key objectives for 2009:**

- Plan and begin to implement a more extensive awareness strategy for all audiences, general public, health professionals and managers, patients and their families and key groups such as employers, schools and universities.
- Raise awareness of NACC and IBD through events and the media by holding a Colitis and Crohn's Awareness Week in June.
- Continue to develop the political awareness programme in Westminster, in Scotland and in Wales to support NACC's work on improving healthcare services and other issues affecting people who have IBD and to extend this into Northern Ireland.
- Recruit additional volunteers to speak about their personal experiences to the media.
- Appoint several NACC Ambassadors and Celebrity Supporters to assist NACC in raising awareness of Inflammatory Bowel Diseases and of NACC's work.

### 3. Improving healthcare services & provision for IBD.

#### **Strategies:**

- *support the publication, promotion and implementation of UK-wide Standards for the healthcare of people who have Inflammatory Bowel Disease;*
- *promote the development of a strategic partnership between IBD organisations to support improvement of health services for IBD patients across the UK;*
- *campaign for more specialist nursing for people affected by colitis or Crohn's Disease;*
- *promote awareness of the value of specialist counselling and psychological support for people with IBD within NHS services;*
- *engage with partners to undertake projects or research that will inform future strategy for IBD services;*
- *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;*
- *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 and Patient Involvement opportunities within the NHS and related bodies.*

#### **Achievements in 2008:**

- ◇ The Chief Executive of NACC chaired the ongoing working group to agree national standards for healthcare services for IBD patients. The working group involved the major gastroenterology health professional associations.
- ◇ NACC is one of four organisations jointly managing the 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 second round of the Audit, which was extended to include paediatric services, was undertaken in the autumn of 2008.
- ◇ NACC responded to various Department of Health and NICE consultation documents during the year, in particular the NICE appraisals on antiTNF treatments for IBD.
- ◇ NACC is a partner in the IMAGE Project which is exploring how the care provided by GPs for gastrointestinal conditions can be improved. The project focuses on IBD, Coeliac disease, Irritable Bowel Syndrome and Reflux disease. The project is managed by the department of General Practice and Primary Care of Kings College London School of Medicine and is funded by a £500,000 Health Foundation grant.
- ◇ Additional NACC Patient Panels were formed following the successful pilot programme in 2005/6. By the end of the year there were 15 Panels in place and several more under development. A poster describing the evaluation of the pilot Panels was presented at the March 2008 British Society of Gastroenterology conference and an article was published in the Health Service Journal.

**Key objectives for 2009:**

- Support the launch and implementation of agreed standards of care for IBD within the National Health Service.
- Produce guidance for those who commission IBD health services.
- Explore how primary care services for IBD patients can most effectively be involved in healthcare services for IBD patients.
- Assist in promoting the UK IBD Audit and in securing funding for further IBD Audits.
- Work with the Crohn's and Colitis Special Interest Group in the Royal College of Nursing to undertake further research into the roles and value of specialist nurses in IBD.
- Consider whether NACC should undertake some specific research into PROMs (Patient reported outcome measures) for IBD.
- Represent the interests of patients with Crohn's Disease in the ongoing NICE appraisal considering availability in the NHS of antiTNF treatment.
- Recruit a panel of members who can take up opportunities for patient representation in the NHS.
- 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 Living with IBD (Social and Psychological) research projects;*
- *identify members who are willing to work as individual volunteers or in teams on specific projects or campaigns.*

**Achievements in 2008:**

- ◇ NACC took part in the various national debates about Prescription Charges, submitting evidence to consultations where appropriate.
- ◇ NACC continued to make representations to the Department of Transport about how the needs of people with IBD for urgent parking could be met.

**Key objectives for 2009:**

- Seek the support of the Department of Transport for a scheme which adequately meets the needs of people living with IBD for urgent parking.
- Support campaigns for better access to public toilets.
- Appoint a Policy Officer to further these areas of work.

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

### **Strategies:**

- *raise funds to provide a minimum of £350,000 annually for research into the medical, social and psychological aspects of IBD and how health services for IBD can be improved and seek to increase this annual sum to £500,000;*
- *make awards for research projects through an annual peer-reviewed application 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;*
- *seek opportunities for bringing external research funds into IBD research;*
- *ensure the publication of the results of research projects to professional and lay audiences.*

### **Achievements in 2008:**

- ◇ The amount raised for research in 2008 was £292,169.
- ◇ £292,792 was awarded for medical research in 2008 enabling 4 projects to proceed.
- ◇ The NACC Social and Psychological Awards Committee was re-formed under the title 'Living with IBD' Research and awarded £234,784 for two projects.

### **Key objectives for 2009:**

- Establish a Research Strategy Committee and publish a formal NACC research strategy.
- Award funds of at least £500,000 for research into the medical scientific aspects of IBD and into the social and psychological impact of IBD on people's lives.
- Consider what Health Services Research needs to be undertaken to provide better evidence for IBD healthcare and define how NACC should approach this.
- Consider opportunities for collaborative IBD applications between NACC and other partners to external research funding bodies.

## **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 involved in the activities necessary to achieve NACC's objectives;*
- *encourage young people diagnosed with IBD to become involved in NACC;*
- *ensure NACC's volunteer policies and practices meet good practice standards;*
- *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 2008:**

### **Membership**

- ◇ Overall membership increased by 1.2% (334 members) in 2008, mainly due to the additional young people taking advantage of the free membership for 16-18 year olds. The figure at the close of the year was 30,537 (2007: 30,203). The number of new members joining during the year was virtually the same as the year before at 3,840 (2007: 3,838) and the proportion ceasing membership was 11.5% (2007: 11%). The number of new members joining on-line on the NACC website in the year was 2,471 (2007: 2,190), 64% of the total.
- ◇ The proportion of young people (under 30) joining NACC increased from 33% in 2007 to 35% in 2008.
- ◇ NACC introduced free membership for 16 and 17 year olds in September 2007. 331 (2007:23) took advantage of this in 2008.
- ◇ A reduced subscription is made 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 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 to support 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.
- ◇ All NACC Groups have been provided with an 0845 telephone number to avoid the necessity for individual volunteers' home telephone numbers to be published and up to 3 volunteers in each Group have been trained to take these calls.
- ◇ 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.
- ◇ Co-ordinated Groups have taken their place alongside the more traditional style of NACC Group and are working well. It is hoped that this style of Group will meet the needs of members by being less formal. In 2008, 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, the Disability Living Allowance Support Service and the Parent to Parent Support Service. These 70 volunteers have undergone selection and training for their roles, work to

defined policies and procedures and receive regular support. NACC uses 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 indicate 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.
- ◇ NACC supported its Volunteer Associate Trainers during 2008 to help deliver the development days which are open to all NACC volunteers to attend. The development days enable the volunteers to feel confident and have the skills to better serve the NACC members.
- ◇ NACC held its first 2 day Volunteer Conference in 2008, which enabled volunteers carrying out different volunteer activities to be trained, share experiences and meet each other.
- ◇ NACC recruited volunteers to act as NACC Speakers, and Cheque Receivers and also to staff Exhibition Stands. These volunteers were trained and started delivering during 2008.

### *Leadership*

- ◇ NACC will take a leadership role whenever this seems to be helpful to the interests of IBD patients and their families, for example in the development of national standards for IBD health services and support of local IBD Patient Panels.

### **Key objectives for 2009:**

- Promote membership more actively by publicity within hospitals and GP surgeries and increase the overall number of members of NACC.
- Clarify and promote the categories and benefits of NACC Membership.
- Strengthen the NACC Group Network.
- Appoint a Volunteer Development Manager and a Group and Volunteer Development Officer for Scotland and Northern Ireland if funding is available.
- Hold a combined Volunteer Conference for NACC volunteers and Groups.

## **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 National Health Service both 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;*
- *seek opportunities for effective collaboration with relevant pharmaceutical companies within the ethical framework set out in NACC's pharmaceutical relations policy.*

### **Achievements in 2008:**

#### *Links with health professionals*

- ◇ NACC had information displays at the annual meetings of BSPGHAN (British Society of Gastroenterology, Hepatology and Nutrition), the BSG (British Society of Gastroenterology), the ACPGBI (Association of Coloproctology) and the Colitis and Crohn's Nurses' Group within the Royal College of Nursing.
- ◇ NACC has formal representation on the IBD Section Committee of the BSG.
- ◇ NACC is playing a leading role in the development of national standards for IBD Healthcare through a multi-organisation working group chaired by the Chief Executive of NACC.
- ◇ 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.
- ◇ NACC has undertaken a survey and individual visits to hospitals in Scotland to establish how NACC can best support health professionals in Scotland in providing for the needs of IBD patients.

#### *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 on the NACC web-site and NACC information is regularly being reproduced overseas.
- ◇ NACC has maintained communication and worked in partnership 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 Gut Trust (formerly the IBS Network).
- ◇ Membership or affiliation was also maintained with National Voices in England, the Long-term Conditions Alliance for Scotland, the Association of Medical Research Charities, the UK Continence Alliance and the Disability Alliance.

### *Links with pharmaceutical companies*

- ◇ NACC has a policy for relations with pharmaceutical companies. This sets out the positive benefits of good working relationships with the industry, encourages multi-company support for NACC and states that financial support from pharmaceutical companies should not be greater than 10% of NACC's income in any year.
- ◇ NACC has produced a Corporate Supporter Framework with three levels at which companies can provide support for the general work of NACC, with up to half of the funds being designated for specific projects and half unrestricted. There were three Gold and one Bronze level members in 2008.
- ◇ From 2008 all pharmaceutical support is being published on the NACC website.

### **Key objectives for 2009:**

- Maintain and develop existing links with Health Professional Associations and strengthen the links to paediatric gastroenterology and the Primary Care Society of Gastroenterology.
- Continue raising awareness of NACC among health professionals in all UK countries.
- Encourage additional support for NACC from pharmaceutical companies within the Corporate Supporter Framework.

## **8. Fundraising activities**

### **Strategies:**

- ◇ *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.*

### **Achievements in 2008:**

- ◇ NACC increased its fundraising staff team to four. They provide advice to individuals and groups fundraising for NACC and are developing NACC's national fundraising initiatives.
- ◇ The team's work is supported by office volunteers and the Fundraising Committee.
- ◇ The NACC Walks for Colitis and Crohn's were held in three cities during Colitis and Crohn's Week in June – London, Cardiff and York. 812 people took part in the walks raising awareness and donations of £58,890 including Gift Aid.
- ◇ £17,000 was raised through Red Hot Day activities.
- ◇ A new leaflet on leaving a legacy to NACC was made available on the NACC website and sent to all members.
- ◇ A catalogue of NACC merchandise was produced to raise both awareness and funds.
- ◇ The main area of income growth in 2008 continued to be in fundraising activities by individual supporters through events, sponsored runs and walks, and challenge activities and treks.
- ◇ £134,096 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 31% of the Association's income in 2008 (2007: 32%).

### **Key objectives for 2009:**

- Increase the funds raised through marathons, runs and challenge events.
- Review fundraising support materials and fundraising web pages to suggest new ideas, encourage more participation, and promote more effective fundraising.
- Implement a new fundraising database to support all fundraising activities.
- Hold national NACC walks in York and Cardiff in June.
- Encourage more participation in Red Hot Day.
- Encourage greater participation in the Gift Aid scheme.
- Continue to promote legacy giving to members and supporters.
- Seek greater support from charitable trusts and companies
- Revise the remit for the responsible committee from Fundraising Strategy to Marketing and Fundraising.

## **Financial Report**

The accounts for 2008 are in the format required by the Charity Commissioners – the Statement of Recommended Practice (SORP 2005). This calls for the classification of NACC funds using the following terms:

**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 24 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, its Groups at the local level and the contribution from its trading company, NACC Merchandise Ltd.

In 2008 there was an overall surplus of £58,387 (2007: Deficit £79,817).

### **Restricted Funds**

The figures discussed in the following paragraphs are drawn from Notes 2 and 23 to the accounts.

#### ***Research Fund***

The national Research Fund received £260,158 in donations and investment income; in addition NACC Groups transferred £32,011 from their fundraising. The Fund's total income was therefore £292,169 plus net transfers of £55,450. The total for Resources expended was £474,589 producing a deficit for the year of £126,970 (2007: £35,438 surplus).

Resources expended include £451,268 grant expenditure and £32,010 grant support costs. The sum of £881,173 was carried forward for distribution in 2009.

## ***Welfare Fund***

NACC received £33,978 in donations and investment income for the Welfare Fund. Grants awarded and support costs amounted to £59,660 producing an overall deficit of £25,682 for the year (2007: £4,509 deficit). The cost of administering the Personal Grants & Welfare Fund was higher this year due to additional staff support and equipment requirements and the total amounted to £10,340.

The sum of £22,846 was carried forward to 2009.

## **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 the combined national and Group activities was £1,776,303 (2007: £1,356,663). Expenditure was £1,526,935 (2007: £1,461,217) resulting in an operating surplus of £249,368 (2007: Deficit £104,554) overall. There were net transfers of £46,883 out of unrestricted funds, mainly Group unrestricted income transferred to the national Research and Welfare Funds, decreasing the surplus to £202,485.

## **NACC Groups**

There were accounts from 63 Groups. In aggregate, their accounts show total income raised as £196,645 (2007: £153,884), local expenditure amounting to £85,552 and net transfers to National Funds totalling £86,010. Group transfers to National Funds represented 44% of their total income. Overall the funds held by Groups increased by £25,083 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. These are currently about £1.7 million. At the end of 2008 free reserves were £647,529 representing approximately 20 weeks running costs (2007: 20 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 2009.

### ***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 funds held in the Research Fund at the year-end have been earmarked for grant awards to 'Living in IBD' (Social and Psychological) Research Awards, £250,000, Medical Research Grant awards £330,000 and £20,000 to IBD Health Services Research.

The Welfare Fund had insufficient reserves at the year end to ensure that the level of Personal Grants could be maintained in 2009. The Trustees have made a transfer of £10,000 from General Reserves into the Welfare Fund in early 2009 and will review the fund status again later in 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 2008 this was 18.8% (2007: 20.5%)

### **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 the best interests of people living with IBD at the time. For 2008, 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**

NACC Funds are placed in high-interest-bearing Deposit Accounts with Birmingham Midshires via the Charities Aid Foundation and the Bank of Scotland so that NACC has no investments subject to the vagaries of the stock market.

NACC has a 15-year lease, ending September 2015, 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**

#### ***Research Grants***

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

Research is normally commissioned taking advice from relevant academic and health professional experts to provide peer review.

### **Personal Grants**

Personal grants are made from the Welfare Fund and are decided by a small committee of members including two Trustees. 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 normal maximum grants are £300 under the general scheme and £500 under the Young Persons' Assistance scheme.

### **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 £15,515, before making a gift aided donation of £15,463 to the Charity (*2007 £27,110, gift aid £27,092*). 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 £12,064 in donations for NACC given with Christmas Card orders which were passed direct to the charity. The donations in turn generated an extra £2,423 in gift aid. The costs of administering the Christmas Card orders have been kept very low for the last 10 years by the dedicated work of two NACC volunteers.

## **Risk Assessment**

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

- the type of risks the charity faces;
  - the level of risks which they regard as acceptable;
  - the likelihood of the risks concerned materialising;
  - 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 2008 and Direction for 2009

### Review of 2008

2008 marked the end of the period covered by the first NACC Strategic Plan and, overall, the Trustees are very pleased with what has been achieved over the four years. NACC has significantly developed its work and influence in all the areas set out in the plan, but particularly in Information and Support, Raising Awareness, Improving Healthcare Services and the active involvement of members and volunteers. NACC's work across all areas was recognised by winning the PR Communiqué Award for Patient Association of the Year for the second time in three years.

The next strategic plan will set out how NACC can continue and build upon the successes of the current areas of work, but also begin to address some new areas. A major objective will be to raise public awareness and understanding of Inflammatory Bowel Disease since this underpins all aspects of the association's activities and will directly help everyone who is living with the condition.

The Review in the 2007 Report highlighted the challenge of developing the capacity and effectiveness of NACC to keep pace with the extending scope and complexity of our work without diminishing the personal 'feel' of NACC's origins as a self-help and mutual aid association. Formal internal reviews have taken place through 2008 covering staffing and management, governance and fundraising. The Trustees have approved proposals to increase our staffing resources in all the front-line areas of NACC's work, to support the Senior Management Team in their roles and to adjust the governance arrangements to match NACC's current activities and needs. The approach taken recognises that maintaining the quality of personal relationships and communication between members, volunteers and staff underpins the feeling of involvement in NACC and that this is time-intensive to develop and sustain.

Given the current economic recession the Trustees considered NACC's financial situation very carefully before authorising continued growth in activities. They have committed to support this growth from reserves if necessary over 2009/10 and the surplus achieved in 2008 has helped. However, a significant increase in income will be required to ensure that the increased level of activities can be sustained into 2010 and beyond. This applies to all three NACC Funds – Research, Welfare and the General Fund that supports all support, awareness, member involvement and campaigning.

Looking forward to 2009 the key strategic issues for NACC are:

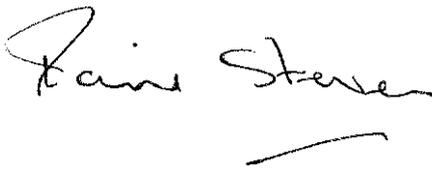
- Increasing public and political awareness as this underpins the understanding of the needs of IBD patients individually and collectively;
- Supporting the implementation of the national Standards for Healthcare services for Inflammatory Bowel Disease;
- Ensuring that NACC maintains high quality standards in the information it produces;
- 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;
- Improving our support for people who wish to be involved in NACC as volunteers;
- Deciding how far NACC needs to respond differently in the four UK countries to their potentially different environments and needs;
- Identifying how NACC can promote or support more research into all aspects of IBD;

- Completing the implementation of the internal reviews of NACC's staffing, governance and fundraising;
- Identifying sources of new or additional income to support our work – at current levels of activity we have to raise over £250,000 in extra funds to fulfil our plans for 2009 – and this higher level then needs to be sustained;
- Finalising NACC's strategic plan for 2009-2012.

### **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, DLA and Parent to Parent Support Services, those who support NACC activities or serve on our committees, our medical advisers and, not least, the Chief Executive, 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.

A handwritten signature in black ink, appearing to read 'Elaine Steven', with a horizontal line underneath.

Elaine Steven, Chairman  
28<sup>th</sup> April 2009

## **Trustees, Officers and Advisers**

From 1<sup>st</sup> January 2008 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 John Lennard-Jones

### **Vice-Presidents:**

Margaret Chandler

Rod Mitchell

Bradley Brown

### **NACC Council:**

#### **Honorary Officers:**

Elaine Steven (*Chairman*)

Nigel Westwood (*Vice-Chairman*)

\*Ray Millar (*Council Secretary, until April 2008*)

Tim Mutum (*Council Secretary, from May 2008*)

\*Stella Donoghue (*National Treasurer, until November 2008*)

\*Allan Hood (*National Treasurer, until March 2009*)

#### **Elected Trustees:**

Stuart Berliner

Denise Cann

John Clarke

Dr Martin Gay

Gerald Gregory

Kati Simpson

John Stanley

#### **Personal Grants:**

Bradley Brown (*Chairman*)

Dr Martin Gay

Denise Cann

Helen Terry

Julia Devereux

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

\*Professor Subrata Ghosh (*until February 2009*)

Dr Jeremy Sanderson

\*Dr Miles Parkes (*until March 2008*)

Dr Ian Shaw (*from March 2008*)

Professor Christine Norton

Ben Wilson

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

\*Professor Subrata Ghosh (*Chairman, until February 2009*)

Dr Jeremy Sanderson (*Vice-Chairman*)

\*Dr Miles Parkes (*Secretary, until March 2008*)

Dr Ian Shaw (*Secretary, from March 2008*)

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

Nigel Westwood (*Chairman*)

Richard Bond (*until February 2008*)

Tim Mutum

Julie Reynolds

Gail Walford

Ben Wilson

Heather Baumohl

Richard Driscoll

Wendy Childs

#### **IBD Health Services Committee**

Elaine Steven (*Chairman*)

David Barr

Peter Canham

Mike Hilton

Margaret Hughes

Martin Gay

Kiron Kurien

Andy Player

Richard Driscoll

Helen Terry

Heather Baumohl

**Information & Support Services Committee**

\*Elaine Steven (*Chairman, until July 2008*)  
Tim Mutum (*Chairman, from February 2008*)  
Bradley Brown  
Denise Cann  
Glenys Davies  
Charlotte Gasden  
Gerald Gregory  
Dr Tim Orchard  
Deirdre Choo  
Richard Driscoll  
Helen Terry

**Fundraising Strategy Committee**

Elaine Steven (*Chairman*)  
Stuart Berliner  
Gerald Gregory  
Gerry Thomas  
Richard Driscoll  
Heather Baumohl

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

Dawn Carter (*Chairman*)  
Emma Livesey (*Vice-Chairman*)  
Lynn Bird  
Bruce Boyd  
Denise Cann  
Tania Clarke  
Peri Gillespie  
Deborah Hodges  
Clair McNamara  
Rachel Wright  
Elina Bloomfield  
Helen Terry

**Medical Research Awards Committee:**

Professor Derek Jewell (*Chairman*)  
Dr Tim Card  
Professor John Cummings  
Alan Dearlove  
Dr Martin Gay  
\*Professor Subrata Ghosh (*until February 2009*)  
Dr John Mansfield  
Bharat Odedra  
Dr Jeremy Sanderson  
Dr Ian Shaw  
Douglas Smallwood  
Jo Spencer  
Professor Brendan Whittle  
Richard Driscoll

**Living with IBD Research Awards Committee**

John Clarke (*Chairman*)  
  
Professor Julie Barlow  
Denise Cann  
Dr Anna Madill  
Lynne Marriott  
Sneh Shah  
Professor Tricia Sloper  
Elaine Steven  
Dr Gillian Thomas  
Richard Driscoll

**NACC Merchandise Ltd:**

Rodney Mitchell (*Chairman*)  
Elaine Steven

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