

# Lists of Honorary Officers, Trustees, Staff, Committees and Corporate Supporters

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Allan Hood (National Treasurer to March 2009)

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Sneh Shah  
Professor Tricia Sloper  
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*Helen Terry*  
Dr Gillian Thomas

## NACC Merchandise Ltd

Rod Mitchell (Chairman)  
Elaine Steven

## Auditors

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London EC1M 7AD

## Bankers

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36 Chequer Street  
St Albans  
Herts AL1 3YQ

## Corporate Supporters

Abbott  
(Gold)  
Dr Falk Pharma UK Ltd  
(Silver)  
Schering-Plough Ltd  
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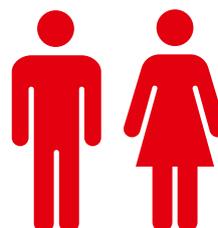
## Solicitors

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London EC4M 6YH

## Staff

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*Heather Baumohl*  
*Hilary Beattie*  
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*Jenny Wilson*

*New Staff joining in 2009*  
*Staff who left in 2009*



Front cover statistics are from a range of sources including NACC's own database

# 2009 – a year of transition and development

During 2009 NACC's internal governance, management and staffing structures were reshaped to encourage continued improvement across the charity's activities.

A Strategic Plan for 2010 – 2012 was formed and distributed to members.

*(Copies available from the NACC Office)*

The following areas were progressed:

## **Awareness of Inflammatory Bowel Disease (IBD)**

In May 2009 the NACC Trustees commissioned Ipsos Mori to undertake a survey of public awareness of IBD (the full report can be found at [www.nacc.org.uk/reports](http://www.nacc.org.uk/reports)) - as a result, increasing awareness is a main objective throughout the NACC Plan for 2010-2012.

## **Young People who have IBD**

Half of the people diagnosed with IBD are under 29 years old; many are in their teens and early twenties – and they form about a third of new NACC members. NACC's 'IBD and Me' Project, which targets this age range, continued during 2009.

## **A focus on 'Living with IBD'**

In 2009 NACC funded research into how young people use on-line forums for support and how people who have IBD cope with the very urgent need for a toilet that is one of the main consequences of having IBD. NACC's Information Service frequently responds to enquiries about the practical issues of daily living - the financial impact of having IBD, access to benefits and to the Blue Parking Badge – and these problems are also addressed in NACC's awareness and campaigning work.

## **Meeting everyone's needs – developing inclusiveness in NACC**

While NACC continued to develop its range of generic support and information for people living with IBD, a focus on groups of people who have specific needs is planned for 2010-2012.

## **'Empowering' people who have IBD**

Most of NACC's services and activities in effect 'empower' people who have IBD; however, 'empowerment' as a concept is not one that NACC had formally adopted prior to this year. NACC's IBD Patient Panel Programme is a good

example of this approach and in 2009 NACC applied for funding from the Dept of Health to expand the programme to more hospitals.

## **iNACC**

More people of all ages use the internet. In 2009 NACC established its first Facebook page and moved closer towards getting all of its services and communications to members and supporters online.

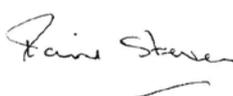
## **Adapting to the impact of devolved government in the UK**

Particularly in NHS services, there is a growing divergence as a result of government being devolved within the four UK countries. During 2009, NACC worked closely with organisations in Scotland, Northern Ireland and Wales to raise awareness of the need for quality standards of healthcare for IBD patients.

## **Raising funds to maintain and develop NACC's work**

NACC cannot sustain and improve its range of activities and support without increasing its income. Traditionally, the charity has relied almost entirely on voluntary income and in 2009 to support all activities NACC needed to raise about £35,000 every week (£5,000 every day).

NACC's income was lower overall in 2009, but the excellent efforts of our volunteer and staff fundraisers have in some areas increased income despite the recession. At present voluntary donations, membership subscriptions, merchandising and fundraising do not fully meet our ongoing expenditure, but, as the Financial Report on page 9 explains, the Trustees have felt able to reaffirm their commitment to developing NACC's services and activities by continuing with the establishment of an enhanced staff team.



Elaine Steven  
Chairman



Richard Driscoll  
Chief Executive

# Contents

<b>Lists of Honorary Officers, Trustees, Staff, Committees and Corporate Supporters</b>	2
<b>2009 – a year of transition and development</b>	3
A report by Elaine Steven, Chairman and Richard Driscoll, CEO	
<b>Information and support services</b>	4
Recognising the quality of NACC's publications and the ever-growing call for its services	
<b>Public and political awareness</b>	5
From Stormont to the Scottish Assembly – the growing recognition of NACC's work	
<b>Improving healthcare services and provision for IBD</b>	6
Patient Panels and campaigning, NACC's fight to gain better services	
<b>Local and global</b>	7
NACC's organisational relationships extend from its doorstep outwards	
<b>The accounts</b>	8/9
<b>Personal grants and personal giving</b>	10
From washing machines to legacies, ways in which we helped you in 2009 and you helped NACC to help others	
<b>Research</b>	11
Research grants we awarded in 2009 and the Big Lottery grant we won	
<b>Member involvement and volunteering</b>	12
What volunteering means for NACC and for the individual	
<b>NACC Groups</b>	13
There's strength in numbers – how joining a local NACC Group can help	
<b>Marketing and fundraising</b>	14
The critical mix and how it worked	
<b>What is NACC and what does it aim to do?</b>	15
<b>Get involved in 2010</b>	16
Crohn's and Colitis Month, May 2010	

## Information and support services

NACC continues to provide high-quality one-to-one information and support services to anyone affected by Crohn's or Colitis, with 2009 seeing an increase in demand across all of NACC's helpline services.

Information Officers have responded with empathy to 5,000 queries from people affected by IBD, from straightforward questions about travel insurance to complex medical information or research.

NACC-in-Contact celebrated its 20th year anniversary at the NACC Volunteer Conference in October 2009. Set up to provide a sympathetic ear at the end of a telephone for people to talk to, NACC-in-Contact has evolved into a highly effective supportive listening service offering patient-centred support from skilled volunteers who, through their own experience of IBD, offer a very personal level of understanding.

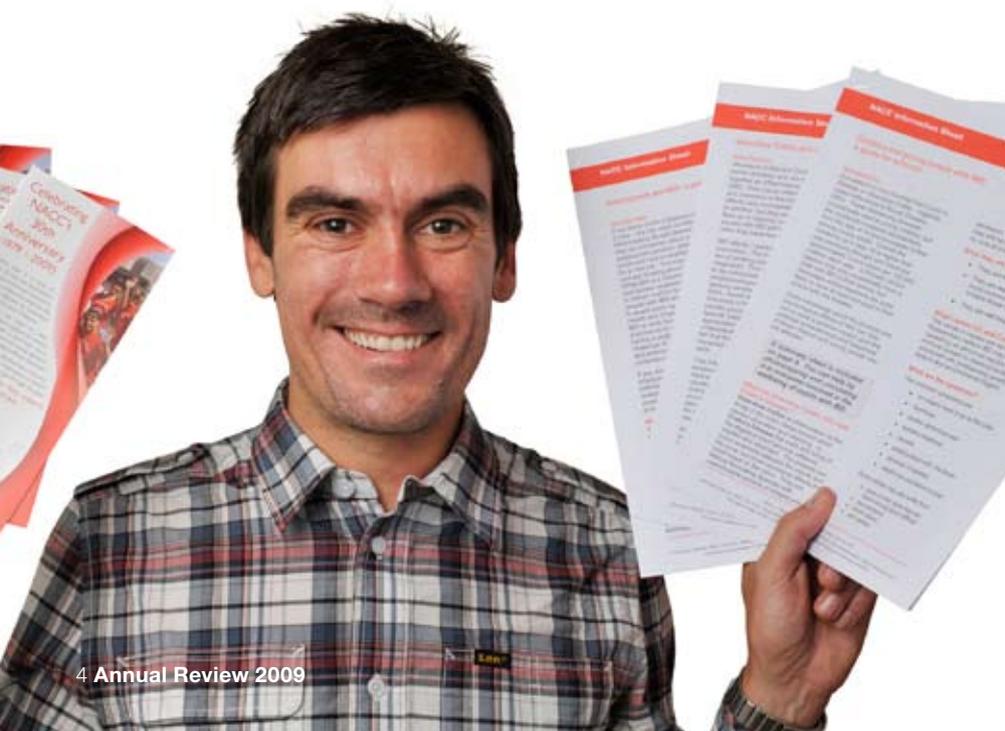
Likewise, NACC volunteers offering telephone support to people claiming Disability Living Allowance or Attendance Allowance have seen a 50% increase in the number of people using their service. Parent to Parent has also seen a steady rise in demand, as awareness of this latest addition to NACC's information and support services increases.

NACC was one of the first organisations to achieve Department of Health Information Standard accreditation in 2009.

1,836 young people contributed to discussions on the on-line forum IBD & Me - covering a broad range of topics including fertility, diet, education, employment and relationships.

A total of 206 personal grants were made to help people cope with the financial burden of living with IBD. Of these, 18 were awarded to support young people in furthering their education or training.

As a newly certified member of The Information Standard, NACC became one of the first organisations to have this endorsement of their high-quality publications, covering both the medical and non-medical aspects of living with IBD - a success for NACC and reassurance for readers that their information comes from a reliable, trustworthy source.



*Celebrating 20 years of NACC's volunteer-run supportive listening telephone service NACC-In-Contact*

*Ambassador Jeff Hordley (left) with the NACC 30th Anniversary brochure and a small selection of the many fact-sheets and information booklets (over 50 in total) that NACC provides*

## Public and political awareness

Raising political and public awareness is key to successful campaigning for improved services.

The Ipsos Mori survey commissioned in 2009 confirmed that Ulcerative Colitis and the term Inflammatory Bowel Disease, or IBD, are not well-known. Compared with diabetes at 95% and Multiple Sclerosis at 84%, only 41% of the public are aware of Ulcerative Colitis, while awareness of IBD stands at 64%. Crohn's Disease was better known at 74%, perhaps due to controversy over the MMR vaccine and the MAP bacteria as possible causes, leading to widespread media coverage.

NACC surveyed members to ask about their experience of people's awareness in their daily lives and also how willing they were to talk about having IBD. Over 3,000 members replied and 70% said their teachers, lecturers and employers do not appreciate the true impact of their Crohn's and Colitis symptoms. 70% admitted that they were embarrassed to talk about it, with 34% saying that they chose to hide it.

Based on this information, NACC launched a media campaign called Rising to the Challenge of Colitis and Crohn's Disease which aimed to encourage NACC members to talk about their experience of living with the conditions.

NACC Ambassador Jeff Hordley played a significant part in raising awareness through media interviews, reflected in the highest number of online and print media mentions of NACC in its history.



*Launch of the IBD Standards at the Scottish Assembly (above) and the Northern Ireland Assembly (below)*

To raise political awareness, receptions were held in the Parliaments and Assemblies of each of the four UK countries. The focus of these events was to launch the IBD Standards for Healthcare Services, but they also raised awareness amongst MPs, leading to Parliamentary Questions being asked and Early Day Motions being tabled, which helped to keep IBD alongside other, better-known and funded health conditions.

NACC responds regularly to government consultation documents on behalf of its membership. In 2009 NACC and IBD were specifically mentioned in the Select Committee Report on Public Toilets and the Report which proposed changing the eligibility for Blue Parking Permits. Unfortunately, Department of Transport officials refused to make IBD patients automatically eligible for emergency parking permits. NACC is pursuing this campaign.

One of the challenges of devolved government is the difference in public policy and provision. Prescription charges are just one example of differential treatment and campaigning to address inequalities is a key part of NACC's work.



## Improving healthcare services and provision for IBD



Patients discussing hospital changes including improvements to toilets on the Gastroenterology ward

Healthcare services for IBD have not been included in any national plans or priorities in the NHS and do not yet have a NICE guideline.

NACC's 2009 key objectives were to achieve formal recognition of the IBD Standards by government and to secure onward funding for the two-yearly national IBD Audit.

The charity has also worked to try and ensure that the IBD Standards are used to benchmark quality IBD care by the Care Quality Commission in England and equivalent bodies and also to argue the case for the national development of integrated IBD care services at local level, in order better to support people living with IBD.

Working with health professional organisations to communicate these messages to managers at national, regional and local level, NACC has helped to support the case for additional funding for improvement by local health trusts and boards.

In 2009 the Action Plan for Long-term Conditions in Scotland referred to IBD in the introductory paragraph as an example of a long-term condition – a small but significant step towards recognition.

Other successes are reflected in the inclusion of the IBD Audit in the National Programme of NHS Audit in England and Wales and, more recently, in Scotland. National funding has been secured for the next three years, making it more likely that the results of the Audit will be embraced as part of the NHS Quality Performance systems.

Whilst working with politicians and government officials to adopt quality standards of care is a key weapon in the fight for improved health services, NACC has also invested significant resources in helping health professionals to improve local services. This has involved regular participation and presentations at conferences and educational meetings, and continuing development of the IBD Patient Panels in hospitals.

- Carlisle Panel – worked with IBD dietician to improve access to support
- Leeds, West Herts and Leicester Panels – contributed to strategic review of IBD services across the community
- Leicester Panel – conducted micro-study regarding levels of access to information and services by patients of South East Asian origin to investigate their experience when seeking to access clinical and information services
- Nottingham Panel – representations led to the re-opening of paediatric gastroenterology services to new patients
- Wigan Panel – worked with IBD consultant to make business case for appointment of IBD specialist nurse
- East Kent Panel – worked with PCT to look at the provision of care 'closer to home' for IBD patients

We developed two excellent applications for Dept of Health Funding in 2009/10 – the Integrated IBD Care Project in Stockton-on-Tees and establishing IBD Patient Panels in more hospitals. These both reached the final round but, disappointingly, were then not funded.

"From a patient's perspective, being able to talk openly about what works and doesn't work with their IBD service is a very empowering feeling."  
**Carlisle member**

"It's a huge leap forward for a patient group to have a meaningful voice in our Trust that can only improve the services offered to people who have IBD."  
**Cheltenham and Gloucester IBD NURSE**

NACC is building links locally, in Europe and across the world – online and face-to-face.

As a national charity, the NACC has had a relatively low profile in its local community. This all changed in 2009.

Autumn 2009 saw a push to raise awareness in the local Community. NACC's Chief Executive, Richard Driscoll, won the Herts Business Person of the Year Award. NACC has benefited from local business support through its Chamber of Commerce and other business networks, as well as being featured in the local media. Working alongside its Hertfordshire Groups, NACC is also developing community relations with a wider network, including the University of Hertfordshire which has received recent research funding from NACC.

### **NACC in Europe**

NACC is a founder member of the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) and joins with the other IBD patient organisations to establish Europe-wide awareness of IBD and share information and good

practice. In 2009, NACC presented its work on Improving Health Services to the Annual EFCCA Meeting. EFCCA is running several exciting projects including a Summer Camp for young people in 2010.

### **NACC links across the world**

NACC has always shared publications and research information with the IBD patient organisations in other countries. In 2009, six major IBD patient organisations including NACC met in Chicago to further these relationships. The idea of holding a World IBD Day on 19th May 2010 was agreed and NACC has participated in its development to raise online awareness among the public and politicians in every country - (visit [www.worldibdday.org](http://www.worldibdday.org)).



NACC Ambassador Carrie Grant with local dignitaries and NACC supporters at the first St Albans Red Hot Community Breakfast, October 2009

# Consolidated Accounts 2009

National Association for Colitis and Crohn's Disease

Extract from the Consolidated Statement of Financial Activities for 2009

Income & Expenditure Account (including NACC Merchandise Ltd and NACC Group Accounts)

	Unrestricted funds (inc. designated funds) £	Restricted funds £	Total funds 2009 £
<b>Incoming resources</b>			
Incoming resources from generated funds			
Voluntary income:			
Donations and similar income	338,743	279,384	618,127
Legacies	166,690	-	166,690
Activities for generating funds	628,823	134,415	763,238
Investment income and interest	119,525	27,113	146,638
Incoming resources from charitable activities	398,280	-	398,280
<b>Total incoming resources</b>	<b>1,652,061</b>	<b>440,912</b>	<b>2,092,973</b>
<b>Resources Expended</b>			
Cost of generating funds	394,772	8,088	402,860
Charitable activities			
Grantmaking	6,888	596,620	603,508
Information line, booklets and newsletters	430,052	21,637	451,689
Raising awareness	135,955	-	135,955
Policy & Campaigns	184,543	-	184,543
NACC Groups	275,685	-	275,685
NACC in Contact	41,227	-	41,227
Membership costs	152,135	-	152,135
Governance	74,428	-	74,428
<b>Total resources expended</b>	<b>1,695,685</b>	<b>626,345</b>	<b>2,322,030</b>
<b>Net income/ (expenditure)</b>	<b>(43,624)</b>	<b>(185,433)</b>	<b>(229,057)</b>

## Notes to the Accounts

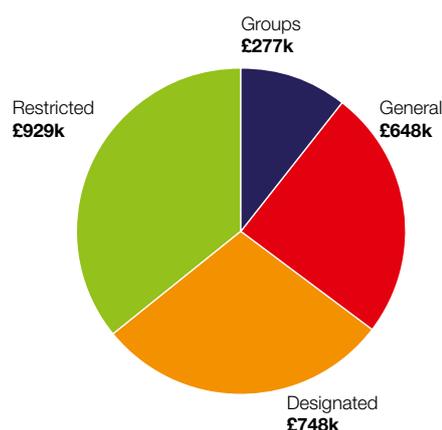
**Unrestricted general funds** - can be used in accordance with the charitable objects at the Trustees' discretion.

**Designated funds** - are set aside by the Trustees out of unrestricted general funds for specific purposes in accordance with the development plans of the organisation.

**Restricted funds** - can only be used for particular restricted purposes within the objects of the charity.

For a full set of the 2009 Audited Accounts and Report, please send a stamped, addressed A4 envelope (stamps to the value of £1) to the NACC Office (address on back cover).

## Reserves at the end of 2009



# Financial Report

Although the Trustees have always maintained a prudent level of reserve funds, a major concern entering 2009 was the uncertain impact of the recession on NACC's income. Many charities have reported a significant reduction in income, in the region of 10-15%. NACC's income for the year has fallen by about 5% overall - 2009: £2,092,973 (2008 £2,181,151), the reduction being mainly in voluntary donations. Our fundraisers – staff and volunteers – have done really well to keep income at these levels.

Subscription income increased due to the small rise in the annual fee from £10 to £12, though NACC continues to reduce or waive this for people on very low incomes. Legacies – a very important part of our income – also increased slightly in 2009. Our trading company, NACC Merchandise was able to Gift Aid £27,000 in profit to the charity. It is also important to note that forward planning by Andrew Shanks, NACC's Director of Finance and Administration, secured NACC a very good rate of interest on our reserve funds that continued through most of 2009.

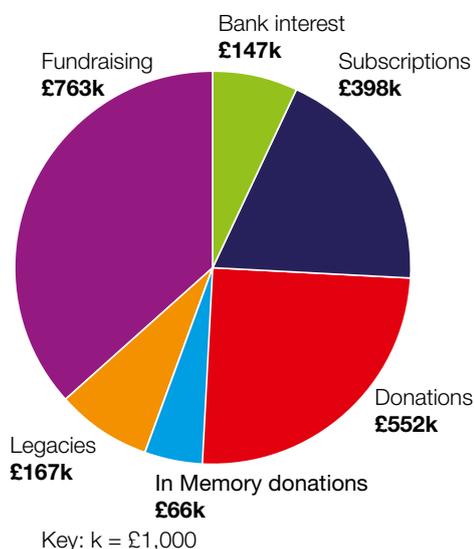
NACC's areas of expenditure are illustrated below. Total expenditure was increased by £200,000 spread across all aspects of NACC charitable activities, except for fundraising and membership administration costs which were both held at or below 2008 levels. Only 16p in every £1 donated is spent on governance and general administration. NACC increased its research grants to over £500,000 in 2009. This reduced the Research Fund reserve significantly as income was only £360,000. The level of Personal Grants was maintained by a transfer of money from the Unrestricted funds. At the end of the year NACC's Unrestricted funds were £86,000 lower and Restricted funds £143,000 lower.

Looking ahead to 2010, NACC carries forward a sensible level of General Fund Reserves and a reduced reserve in the Research Fund. We face a significant challenge in 2010 and beyond to raise the additional funds needed to enable the charity to fulfil the objectives set out in the NACC Plan for 2010-2012.

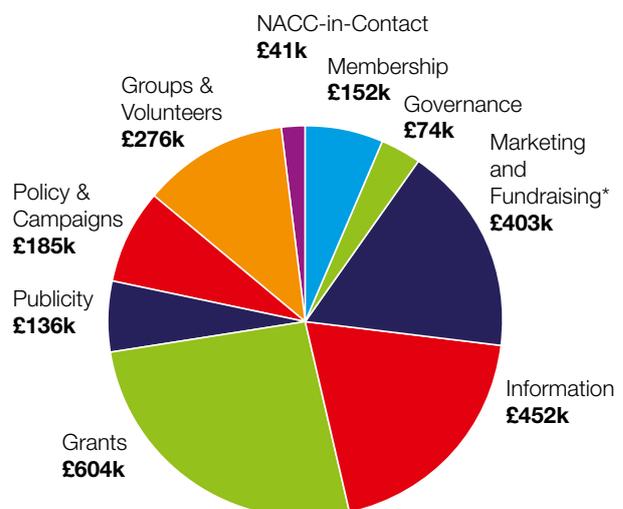


**Richard Driscoll**  
Chief Executive

## Where did our money come from in 2009



## Where did we spend the money in 2009



\* Marketing and Fundraising costs include the full cost of any national or Group fundraising events as these have to be shown in full. They also include marketing, promotion and processing costs for legacies, in memory donations and all forms of income except membership subscriptions and investment income.

## Personal grants and personal giving



*Every cheque and gift received is carefully recorded and the funding put to good use*

### NACC makes over two hundred personal grants annually in the case of financial hardship.

NACC's confidential personal grants range from as little as £25 to £300 (personal grant) or £500 (educational or vocational grant) but the difference they can make is incredible.

Imagine you are losing bowel control several times a week and you have no washing machine to wash your bedsheets and clothes in. Or you have managed to wash them but you have no way of getting them dry.

Imagine suddenly losing several stones in weight because of sickness and diarrhoea. Or suddenly gaining several stones in weight because of your medication.

Imagine the strain of looking after a sick child when you are trying to juggle the needs of your healthy children too.

Then imagine the sheer relief of a personal grant from NACC for a washing machine, a drier, some clothes that actually fit or a short break which will help you to re-connect as a family.

NACC also offers grants in Educational and Vocational Support. In 2009, 18 such personal grants were awarded to support young people in progressing their education or training.

During 2009 the calls on NACC's support services increased in every area ... more booklets required, more people asking to waive their membership fee, more calls to our Parent to Parent line, our NACC-in-Contact volunteer helpline and our Information Line.

The message for NACC members and everyone affected by IBD is .... "you are not alone".

**Information line 0845 130 2233**

"We only found out about NACC two weeks before Mum died. You were so helpful. We only wish we'd found out earlier."

### Personal Giving

#### There are many ways to support NACC

■ If you are a member, you are already helping us – we put a lot of your membership fee back into keeping you informed through your quarterly mailings – but there is a bit left over to go towards administration.

■ If you are a volunteer, you are already helping us – we also invest in you through training, the volunteer conference and other activities.

■ If you are a fundraising or corporate supporter – you help to bring in the funds that keep us going.

#### Do you Gift Aid your gift to us?

Gift Aid was worth £119,000 in 2009 (less than the whopping £134,000 Gift Aid in 2008, but still a lot to claw back from the Treasury).

Finally, if you are going to make a will, please remember NACC once you have looked after your loved ones. Legacy giving is growing and now represents an important part of the income which funds NACC's services and activities.

In 2009, legacy funding was worth over £166,000.

All In Memoriam gifts go towards NACC's Research Fund and enable us to make more grants towards vital scientific and social science research work across the UK.

NACC research grants are given to projects seeking to further our understanding of the causes and possible cure for IBD and also for the issues faced by people in living with IBD.

In 2009, NACC awarded half a million pounds in research grants and secured a further half a million from the National Lottery through the Big Lottery Fund.

### NACC has three programmes of research:

- Medical awards focusing on 'cause, treatments and finding a cure'
- Living with IBD awards which aim to further our understanding of the issues faced by people in living with IBD
- Health Services Research evaluating how the quality of IBD care and services can be improved

### News from a past award

In November 2009 the results of NACC's largest ever research grant were announced – three new genes were found linked to Ulcerative Colitis. These are the first genes linked specifically to Ulcerative Colitis and they play a role in how the lining of the gut (the epithelium) works as a barrier to the bacteria in the gut.

### Medical awards 2009

Three new grants totalling £320,000 were made and these will investigate:

- Professor Ilyas: The role of the stem cell marker CD24 during the healing phase of inflammatory bowel disease (Nottingham)
- Dr Lee: The application of gene expression profiling in inflammatory bowel disease to predict disease behaviour (Cambridge)
- Professor Pirmohamed: Investigation of the role of ABCB5 in corticosteroid transport and response in IBD (Liverpool)

### Living with IBD awards 2009

Two awards totalling £143,000 were made in 2009.

- Professor Christine Norton from Buckingham New University will lead a study into continence issues in IBD and
- Dr Neil Coulson from the University of Nottingham is looking at social support in cyberspace: The role of online support communities for individuals living with IBD.

### Health Services Research Award 2009

The Trustees approved a grant of £30,000 to evaluate the Integrated IBD Care Project in Stockton-on-Tees.

### £500,000 Big Lottery grant awarded to NACC and its partners for a four-year project investigating Fatigue in IBD

As well as giving out research grants, NACC also receives research funding. In collaboration with University College and King's College, London, and Addenbrooke's Hospital, Cambridge, NACC has won major funding to investigate severe fatigue.

Severe fatigue is a serious problem reported by people with IBD, but awareness of its effects is low and treatment often lacking. Thanks to a grant from the National Lottery through the Big Lottery Fund, NACC will be leading a four year project to improve understanding and develop effective treatment options.

Even during remission, around 40% of IBD sufferers report this particular symptom as having greatest impact on their daily lives.



## Member involvement and volunteering



Volunteers staff the Walks Registration desk

NACC could not achieve all that it does without the fantastic support of its 1,000 active volunteers. Every one of them plays a part in NACC's success.

So much of what is sent out from the national office is packed by our highly valued office volunteers, including but not limited to information such as Red Hot Day packs, Group Matters, Essentially NACC and letters to members of NACC Groups. This added up to approximately 10,000 letters in 2009. These volunteers also support the staff team by carrying out research, doing data entry, processing Gift Aid and packing merchandise. Volunteers have played a vital role in the ordering and sales of Christmas cards.

Other volunteers help NACC to thank our supporters who raise funds by attending events, collecting cheques and saying 'thank you' as well as talking to people about NACC. In 2009 volunteers collected cheques amounting to over £13,000 from all around the UK.



In Autumn 2009 Smilie's Network held a picture competition for children and teenagers who have IBD themselves or know someone affected by IBD. Almost 200 children sent in entries in 3 categories - Winter, Nature and Family Celebrations. The winning pictures have been made into cards and are being sold to raise money for NACC.

"Developing skills with NACC as a volunteer has helped me to feel confident and to find a job."

Volunteers also raise the profile of NACC and awareness of IBD by taking stands at exhibitions and giving talks in places such as schools, workplaces, local clubs and associations. Several hundred members are on NACC's list of people affected by IBD who are willing to tell their story on the radio or in newspapers and magazines.

Over 100 volunteers were responsible for making the NACC Walks a success in 2009, working with staff and consultants to plan the events and ensure that everything ran smoothly in both London and York.

NACC supports its volunteers by holding training and development days as well as bringing volunteers together for the annual volunteer conference which our Volunteer Associate Trainers play an important role in designing and delivering.

There are hundreds of quotes from volunteers which show just what helping NACC means to them – here are a few:

- The nicest part is making so many friends over the years.
- I've really valued meeting different people with similar health concerns and learning from them.
- I feel I have gained a huge amount of insight into myself as well as IBD and the services NACC offers. It really feels like NACC has been prepared to invest a lot of time and energy in me and I really hope I can repay that by being a good volunteer.

Smilie's Network holds family fun days and enables parents of children with IBD to share their experiences, whilst offering a chance for the children to have a lot of fun. Other family days are put on by volunteers, health professionals and NACC, working all together.

NACC local Groups enable members, their families and their friends to become involved in support, publicity and fundraising activities in their local community. They also offer people affected by IBD the opportunity to meet others and share their experiences, as well as meeting informally with health professionals. There are around 70 Groups nationwide, each run by an 'Organising Team' of volunteers.

NACC Groups have helped to raise NACC's local profile during 2009 by:

- Holding local events and meetings, including educational meetings; quiz nights; 'meet and chat' social meetings; small support style meetings; meetings aimed at specific interests such as parents or young adults (16-29 years of age).
- Holding fundraising activities, including sponsored events such as swims, walks and cycle rides; collections at football grounds, racetracks, theatres and other locations; holding Red Hot Day events; contacting local societies and clubs including Lions and Rotary for support; auctions, golf tournaments & other activity based events. In 2009, Group fundraising achieved £207,000 – of this, £117,585 was given to NACC towards its various funds and £37,135 was allocated by Groups locally towards the needs of their IBD communities.
- Raising awareness of NACC and IBD, including activities for Red Hot Day and Colitis and Crohn's week – from June to September 2009 Group coverage in the local press reached a readership 4,711,467 nationwide; awarding Local Grants to hospitals for nurse training, capsule endoscopy tablets and other purposes; selling NACC merchandise; engaging local councillors, MPs and Euro MPs; information stalls at out-patients clinics, fetes, shopping centres, holiday locations and festivals.
- Support to people affected by IBD, including; local Group newsletters and MacNACC (in Scotland); helping to set up Patient Panels; organising Family Fun Days; campaigning for local issues such as the provision of IBD nurses and being able to park for a short time whilst visiting a public toilet; setting up and maintaining NACC Group websites, which are accessible day and night; and not forgetting the chance to meet others who are affected by IBD.



Members from North Dorset Group

“ I now feel that there are other people with this dreadful disease and I am not alone and there are friends out there who will help me through my bad times, and I hope I can help someone else and make them feel as special as the Group have made me feel. ”

# Marketing and fundraising



Christmas Day dip in the North Sea off Lowestoft to raise funds



The continuing need to raise awareness of NACC and its work is critical to the successful development of fundraising. Already the impact of improved marketing is reflected in growing participation levels across various challenges. Golf Day income alone leapt from £4K in 2008 to £18K in 2009.

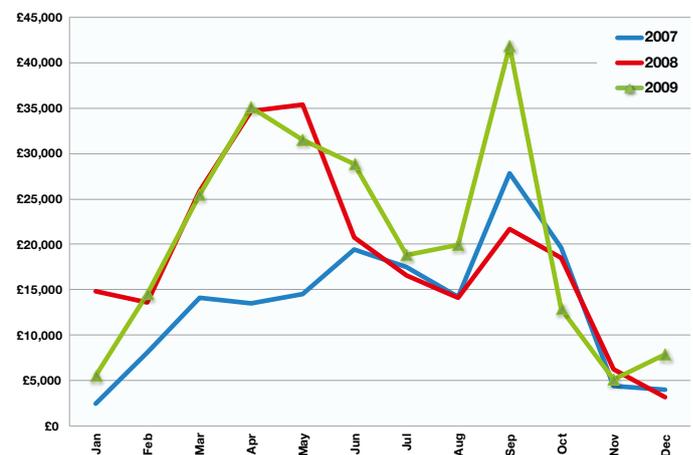
## Main achievements in 2009:

- Implementation of the new Alms database allowing new online sales and registration processes to be introduced
- Christmas card income only experienced a small drop, thanks to online sales and great volunteer support
- Walks registration worked well online for the first time
- The 2009 Great North Run was the biggest and best yet for NACC, and exceeded its fundraising targets
- Although the Edinburgh Marathon income dropped from £13K in 2008 to £6K in 2009 there were higher levels of participation thanks to improved marketing
- The London Marathon is both an achievement and a disappointment. Significant funds have been raised by 'own-place runners', but NACC does not receive any allocation of guaranteed 'Bond' places
- NACC had its first team for the New York 2009 Marathon
- Action! fundraising marketing magazine, started in 2004, is developing into a vital quarterly marketing tool
- Merchandise sales stayed fairly buoyant despite the recession and new lines are being launched in 2010
- Successful first Charity/Community breakfasts for St Albans
- Red Hot Day has never hit its first year levels of £30K fundraising income, but matched the £17K income of 2008 again in 2009 – an achievement in view of the recession

- Following NACC's first Legacy leaflet, there has been increased legacy giving for the charity
- In 2009 the team made a successful BBC Radio 4 application which won a charity appeal slot for May 2010
- A £250K bid to the Department of Health for Patient Panels was rejected at final round
- Successful bids resulted in 50% funding for the new Children's Booklet in 2009
- New print during 2009 included the Strategic Plan, a new Fundraising Pack, NACC in a Nutshell, a first Corporate Giving Brochure, celebrity posters and much, much more!

Suzi Clark started as NACC's first Director of Marketing and Fundraising at the end of July, 2009. The team of three Officers was supplemented in late October to include a Fundraising Administration Assistant and a Marketing and Media Assistant.

Reviewing the 'NACC brand' and producing quality fundraising and awareness raising materials, as well as relaunching the website, should further support fundraising efforts. Engaging even more people in fundraising and encouraging them to spread the word is critical to NACC's success.



NACC's Just Giving pages are growing in number and effective fundraising every year. (figures courtesy of Justgiving.com 2009)

## What is NACC and what does it aim to do?



NACC 2009 staff at their 30th Anniversary Away-Day

In 2009 NACC spent just 16p in every £1 on administration and governance.

The National Association for Colitis and Crohn's Disease (NACC) is made up of 31,000 members, volunteers, trustees, fundraisers, a small professional staff and a wider network of supporters who together aim to improve life for people affected by Ulcerative Colitis, Crohn's Disease and all forms of Inflammatory Bowel Disease or IBD.

NACC's principles are based on active support and engagement, championing the needs and concerns of its members and the wider community of people affected by IBD in a way that meets quality standards for excellence across all of its services. Basing its policies and plans on objective evidence wherever possible, the charity expects all its representatives to observe its principles of compassion, equality, inclusion, respect and integrity.

NACC progresses research, development and service activities in partnership with the health service, health professional and patient organisations, and also with the pharmaceutical industry, it does so in line with the charity's own policies, aiming to inform, support and raise awareness to help all those in the UK struggling to cope with the symptoms and effects of IBD, whether they are themselves patients, or the family, friends or colleagues of patients.

NACC continues to campaign with, and on behalf of, people living with IBD, in order to win them better support, such as improved access to toilets, parking concessions and the introduction of free prescriptions for people with long-term conditions living in England.



From left CEO Richard Driscoll, Suzi Clark (Director of Marketing and Fundraising), Heather Baumohl (Director of Member Involvement and Volunteering), Andrew Shanks (Director of Finance and Administration) and Helen Terry (Director of Information and Support) – senior management team days are held free of charge at the offices of a local corporate supporter, Clydesdale Bank PLC.

Membership and involvement in all NACC's activities is open to all with an interest in promoting these aims and principles.



# May 2010 Crohn's and Colitis Month

People think of me as bubbly, bouncy Carrie - the motivational vocal coach on Fame Academy working with stars like Lemar, Will Young and Melanie C. But life is not always bright for me. I have my moments of struggle. Moments when my IBD (inflammatory bowel disease - in my case Crohn's, but IBD also includes Ulcerative Colitis) gets me down. When I can't eat with the kids because I'm on the

elemental diet, moments when slapping on the facepaint is a struggle because I'm so exhausted or in constant pain, moments when my husband takes me out for a romantic dinner and eats alone whilst I'm stuck on the restaurant loo.

Times like that, I'm glad I'm able to talk to someone at the National Association for Colitis and Crohn's (NACC) - it helps to know that together we can work to

make a difference and help others to find their inner strength to face the future - it isn't always easy.

If you have IBD or know someone who has - tell them to contact NACC - there's friendly help and support available for all ages, with understanding people at the other end of the telephone line ... just call!

Carrie Grant, NACC Ambassador

## Ways that you can lend your support

Listen to Carrie Grant's Radio 4 Charity Appeal in aid of NACC on 23 May 2010

Run the Great North Run for NACC on 19 September 2010 - now one of the world's biggest half Marathons

Trek the Andes, the Himalayas or Hadrian's Wall for NACC ... call us for the challenge of a lifetime

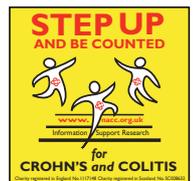
Take Manhattan ... New York, the city that never sleeps - but you will, after running around Manhattan for NACC on 7 November 2010

Are you a tri-athlete? Would you like to be? We still have NACC places in the 2010 London Triathlon 7-8 August - the largest Triathlon in the world

Red Hot Day - fundraising fun with NACC on 15 October ... what can you and your friends or colleagues do that is RED HOT and raises money? No ideas? Call us and we'll start you off!

It's a Knockout with NACC in St Albans on 25 July ... imagine your work colleagues in penguin suits juggling a giant doughnut over a gunge pool ... what a team-building opportunity!

Support our call for a national patient register for people suffering with IBD (inflammatory bowel disease) **click to vote!**  
[www.stepupandbecounted.org.uk](http://www.stepupandbecounted.org.uk)



Join the hundreds of people on our two national Walks for Colitis and Crohn's (London Saturday 8th May and York Sunday 23rd May)

Join us in Newcastle on 22 May for the NACC National Meeting and AGM - excellent speakers about living with IBD, research and treatments, and a chance to have your say.

### 19 May is World IBD Day, Step Up and be Counted for IBD!

**National Association for Colitis and Crohn's Disease (NACC)**

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