

Ménière's Society

helping people with vertigo, tinnitus and deafness



Annual Report and Accounts 2009/10

The Ménière's Society is the only registered charity in the UK dedicated solely to supporting people with Ménière's disease and related disorders causing dizziness and balance problems for sufferers.

Registered Charity No.: 297246

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About the Ménière's Society

The Ménière's Society is the only UK registered charity dedicated solely to supporting those affected by Ménière's disease and related disorders causing dizziness and imbalance. The Society is run on behalf of members by a Board of Trustees who control the activities of the Society and meet as an Executive Committee at least four times a year. Day-to-day management of the Ménière's Society is the responsibility of the Director. The Ménière's Society employs three paid members of staff.

Our Aims and Objectives

The Ménière's Society aims to:

- Support members, their families and carers to help improve their quality of life
- Provide information to members, health professionals and the public
- Raise awareness of Ménière's disease and related vestibular disorders
- Encourage research into the cause and treatment of Ménière's disease and vestibular disorders
- Monitor world-wide developments
- Provide a resource for members on related subjects e.g. services, alternative therapy and publications
- Encourage members to lend each other help and mutual support
- Co-operate with other organisations having similar objectives to those of the Society.

Who's Who

Patrons:	Lady Marjorie Clark	Mr Ian Chapman CBE, D.Litt, FRSA	
President:	Mrs Marie Nobbs MBE		
Trustees:	Mr David Riches <i>Chair</i>	Mr Richard Wheen <i>Vice-Chair</i>	Mr Peter Joiner <i>Treasurer</i>
	Mrs P Anne Boënders	Dr Humphrey Bowen	Mr Andrew Clements
	Mr J Max Coleman	Mrs Carol Evans	Mr Robert Goodier
	Mr Geoffrey Howard	Dr Alan Jacques	Mr Andrew Simkins
Office Team:	Mrs Natasha Harrington-Benton <i>Director</i>		
	Mrs Elaine Fenner <i>Membership Manager</i>		
	Mrs Sarah Trezise <i>Administrator</i> (until June 2010)		

Registered Office: The Rookery, Surrey Hills Business Park, Wotton, Surrey RH5 6QT

Foreword

David Riches, Honorary Chair



In my Foreword to the Annual Report for 2008/09 I wrote 'I am optimistic for the Future'. This report shows my optimism to have been justified. Membership support has been maintained despite the difficult global conditions and a fine team of trustees has been strengthened. The review of Financial Activities shows increased spending on research and a substantial recovery of investment losses made in the previous year, evidence of the Society's prudence in financial matters.

The AGM and Conference held in 2009 took place the day following the meeting of the British Society of Neuro-Otology in Leicester. The BSNO meeting, sponsored by the Society, was heavily weighted toward aspects of research into Ménière's disease and participants in Leicester gave presentations at the Society's Conference. There can be little doubt that the Society's activities have resulted in a better appreciation of the condition and a better informed clinical base from which to expand. The stamina of the Society's three representatives and those speaking at the Conference was also observed!

It has been part of the Society's key function to increase knowledge within the medical field. A pharmacist recently observed that the Society knows more about Ménière's disease than the doctors do; as it should. However, the Society will continue to press hard for a better understanding and acceptance of its constitutional remit to 'promote and provide care and relief for sufferers from Ménière's Syndrome and related conditions'. It is a fact that research into Ménière's disease designed to assist sufferers and alleviate symptoms must have a beneficial spin-off by helping those who, not having Ménière's disease, nonetheless suffer from some of its symptoms, e.g. balance problems. The Society, I believe, gives excellent value for money in this way, comparing well in the charity area with larger and wealthier organizations and encouraging increased membership as this becomes better known.

I approach the end of three years as Honorary Chairman of the Society (for those who would prefer Honorary Chair, I am not to be sat upon!) and have been impressed by the level of member support, the help of volunteers and the unstinting commitment of the Staff and Trustees. The Society's progress during this time has been entirely due to this commitment and future plans will pursue this course. The help of members to this end should not be underestimated. Keep the suggestions coming; telling us what you think might assist expansion and further increase the Society's value to you, our members. Thank you for your support; I wish you well.

A handwritten signature in black ink, appearing to read 'David Riches', with a long horizontal flourish extending to the right.

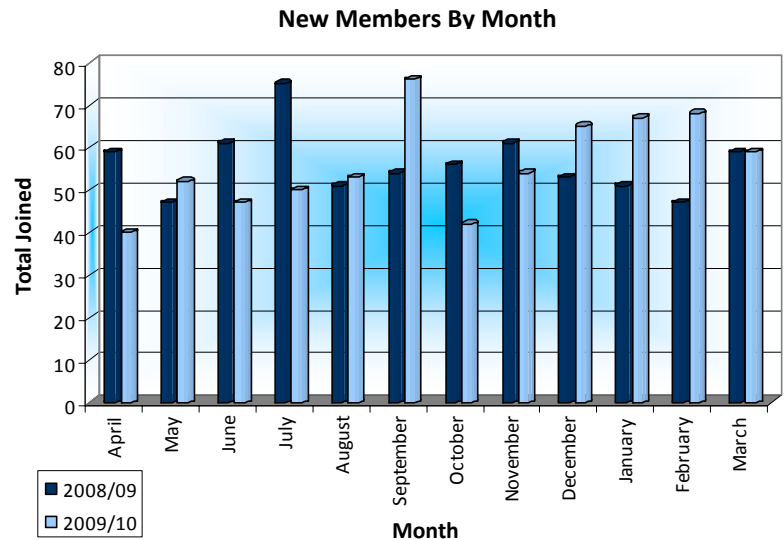
Overview of Society Activity 2009/10

Membership

In 2009/10 membership of the Ménière's Society remained steady in comparison with the previous year. A further 700 people subscribed to the Society during the year keeping the total membership at around 5,000. A peak in membership figures can be seen in September 2009 following a Daily Mail article in August on the Clinical Trial in Refractory Ménière's Disease at Imperial College, London (see Research Review page 6).

In 2008/09 the annual membership subscription was increased to £16 for UK members and £24 for international members and organisations. These rates were maintained in 2009/10.

The Internet continues to remain the biggest source of new members for the Society, closely followed by health professional and/or support group recommendation. Increased media publicity has made this the third highest source of new members for the Ménière's Society in 2009/10.



As well as supporting people affected by Ménière's disease, there has been an increase in the number of enquiries from people suffering from related conditions with symptoms of dizziness and imbalance; such as labyrinthitis, benign paroxysmal positional vertigo (BPPV) and other conditions where there is a vestibular dysfunction. Many of the Society's existing members have symptoms of vertigo from conditions other than Ménière's disease and, as a result, the Society has been reviewing and developing the information available as well as looking at the future role of the Society (page 10).

AGM and Conference 2009

The 2009 conference took place at The King's Fund in central London on Saturday 16 October. This was the fifth year the Ménière's Society had chosen this venue to host the annual conference and, as in previous years, it met the high standards expected for this event.

At the AGM four further trustees were appointed: Anne Boënders, Andrew Simkins and Alan Jacques, along with Andrew Clements who returned to the trustee board after stepping down due to constitutional requirements. The Society was delighted to welcome Andrew Clements back to the Board, along with the three new trustees and looks forward to working with them over the coming years.

Publications

Spin

The Society's quarterly magazine, Spin, continues to go from strength to strength. During the year articles have been included on Migraine Associated Vertigo by Robert Baloh MD; Advances in Understanding the Pathological Basis of Ménière's disease by Professor Leslie Michaels and Dr Sava Soucek and Benign

Paroxysmal Positional Vertigo (BPPV) by Dr Peter West. The regular features - Dear Spin, Penpals, Groups and In the Media remain popular, along with the A-Z of Ménière's glossary which is drawing to an end for Spin, but is currently being reproduced by Ménière's Australia in their quarterly publication, *Equilibrium*.

Balance Retraining and Controlling Your Symptoms

The Ménière's Society regularly receives requests for these two publications which were produced by Professor Lucy Yardley following research funded by the Ménière's Society in 2004. As well as receiving requests from individuals affected by balance problems and dizziness, health professionals also request copies of the booklets; often in large quantities. In 2009/10 we distributed over 1200 copies as a result of requests from health professionals.

Information

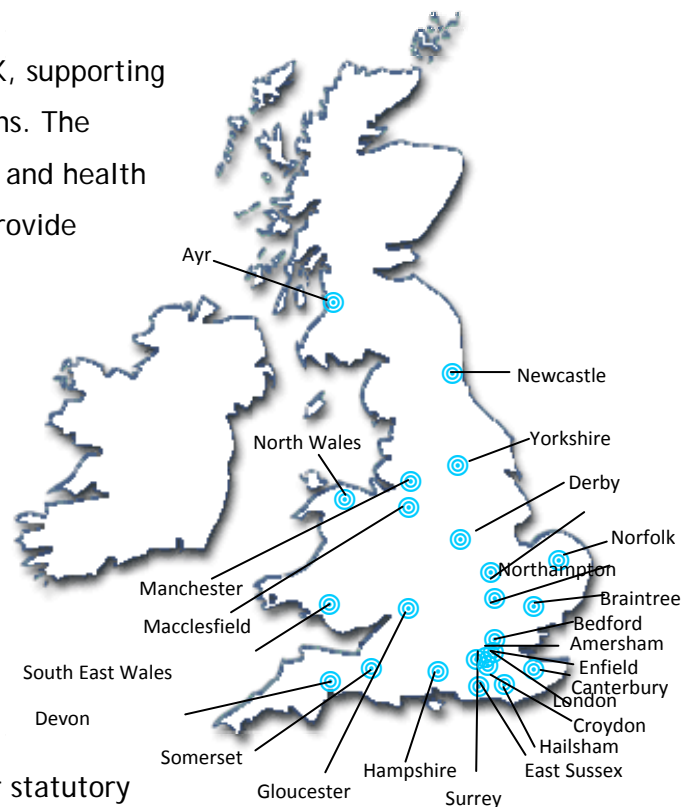
The Ménière's Society now produces over 60 information sheets on a variety of subjects to support those suffering from Ménière's disease and related conditions. In addition to information for general enquirers and the membership pack, since December 2009 the Ménière's Society also offers additional information sheets as a bound booklet for members' reference.

Local Support Groups

There are currently around 20 local support groups in the UK, supporting sufferers of Ménière's disease, tinnitus and related conditions. The groups are set up by both members of the Ménière's Society and health professionals working in the field, on a voluntary basis, to provide support and information to sufferers and their families.

During 2009/10 we were delighted to see the formation of New groups in Essex, Norfolk, Surrey and Yorkshire. Sadly, groups in Enfield and Somerset have closed this year.

In November 2009, the Ménière's Society attended a balance awareness day hosted by the Newcastle Group, NE1 Dizzy, at the Freeman Hospital in Newcastle.



Fundraising

Donations

The Ménière's Society is not currently in receipt of grants or statutory funding and relies on the generosity of donors to grow its financial resources. In 2009/10 donations ranged from £1 to £1000 and, whether large or small, all donations received help the Society to continue to provide support to those affected by Ménière's disease and related conditions, develop the services provided and fund research.

Legacies and Donations In Memory

The Ménière's Society was pleased to benefit during the year from two legacies totalling £12,000; plus a further £2,000 donations in memory. Not only do these gifts enable the Society to carry out its day to day

work, but they also contribute to the future plans of the Society. In the past larger legacies have enabled the Society to support research projects which would not have been possible otherwise.

200+ Club and Christmas Raffle

The 200+ Club is a key fundraising activity for the Ménière's Society. There has been steady growth in the number of people participating in the 200+ Club and the total shares purchased. This year exceeded all expectations with 477 participants and 970 shares sold – the largest amount for this fundraising activity since it commenced.

All proceeds from the 2009/10 Christmas Raffle were put towards the Ménière's Society Research Fund. The Society raised just under £12,000 (see Financial Statement p 8) from ticket sales.

Gift Aid

The Ménière's Society is proactive in encouraging members to participate in the Gift Aid Scheme. Around three quarters of members have completed a declaration to confirm whether or not Gift Aid can be claimed on their donations. In 2009/10 the Society's total Gift Aid claims amounted to over £17,000.

Sponsored Events

A number of supporters chose to raise funds for the Society taking part in sponsored events this year. The Ménière's Society also signed up for six places in the British 10k London Run through to 2012 as part of our fundraising and awareness programme. Over £4,000 was raised for the Society from this one event.

Publicity and Awareness

British Society of Neuro-Otology

The British Society of Neuro-Otology (BSNO) bi-annual meeting was held in October 2009. The Ménière's Society sponsored this event which was held at the Leicester Tigers Rugby Stadium on behalf of the Leicester Royal Infirmary and Balance Centre.

In the Media

The Society was delighted to have received a number of media opportunities during 2009/10. The most positive of these was an article in the Daily Mail in August 2009 which highlighted the Clinical Trial in Refractory Ménière's disease taking place at Imperial College, London. The article "*Dizzy Spells? Noises in your ear? At last there's an end to your torment*", caused a great deal of interest and the Society received around 200 enquiries as a result. The Ménière's Society also received further mentions during the year in a variety of publications, including ENT News, My Weekly Magazine and www.bbc.co.uk.

National Salt Awareness Week 2010

The Ménière's Society attended a reception at the House of Commons in February 2010 as part of National Salt Awareness Week run by Campaign for Action on Salt & Health (CASH). The reception was hosted by Mary Creagh MP and guests included retailers, food manufacturers, caterers, major supermarkets and non-government organisations, MPs and Peers, Department of Health, Food Standards Agency and the media.

Research Review 2009/10

Dr Humphrey Bowen, Trustee (Research)

Progress has been made on several research projects which are expected to produce results during 2010/11.



The *Clinical Trial in Refractory Ménière's Disease: Transtympanic Gentamicin vs. Transtympanic Steroids* at Imperial College, London being conducted by Dr Agarwal, Professor Bronstein and Mr Harcourt has a further year to run. We await the results of this study with interest which should provide solid information on the effects of these treatments for Ménière's sufferers.

An article in the Daily Mail in August 2009 raised the profile of this study and Dr Agarwal and the team at Imperial College were inundated with enquiries. The Ménière's Society also benefitted from this publicity to increase awareness of Ménière's disease and the work of the Society. Around 200 calls were received by the Society's office for further information and details of the treatment mistakenly reported by the Daily Mail as a *cure* for Ménière's disease.

The work on *The use of Cervical Vestibular Evoked Myogenic Potential (C-VEMP) and Ocular Vestibular Evoked Myogenic Potential (O-VEMP) Frequency Tuning Curves to Predict and Monitor Meniere's Disease* is ongoing. The principal investigator, Dr Sandhu, has now moved to Balance Centre at Leicester Royal Infirmary from the Royal Sussex County Hospital and is continuing the study in Leicester. Published results are expected late 2010.

One of the difficulties of obtaining funding for research into Ménière's disease and support for sufferers is that its prevalence across the UK is not well quantified. Balance problems like Ménière's disease caused by a vestibular (inner ear) dysfunction have been estimated as affecting around one in 10 of the population. The Ménière's Society has funded the preparation of a proposal for a *National Study of Balance and Dizziness* led by Professor Lutman of Southampton University and coordinated by Dr Anna Morris. The proposal has been submitted to the Medical Research Council with a decision expected late 2010.

The Ménière's Society has continuing involvement with the NIHR funded *Trial on the Self Management of Dizziness With or Without Therapist Support* led by Professor Lucy Yardley and Dr Sarah Kirby at Southampton University. Published results for this study are expected 2010/2011.

Although other proposals have been received by the Society this year, for various reasons they have not led to any new research. The Ménière's Society continues to seek further high quality research and is in discussion with a number of universities with ideas for future proposals.

Review of Financial Activities 2009/10

Peter Joiner, Honorary Treasurer



The 2009/10 financial results indicate three positive factors that arose in the year;

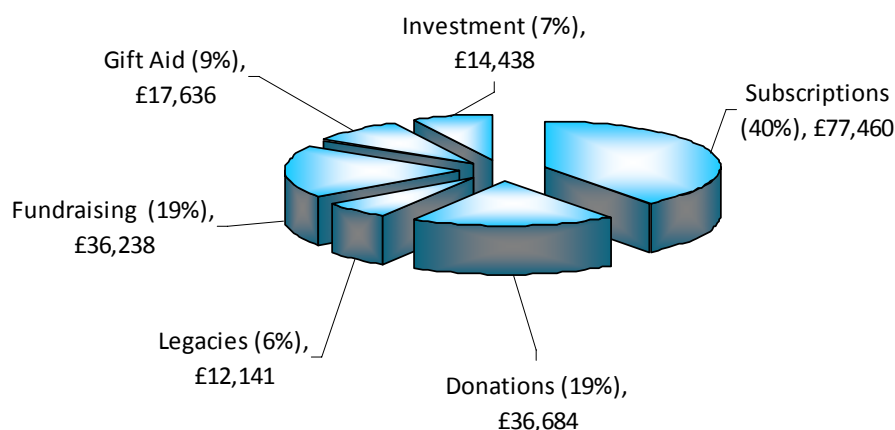
- i. Almost £64,000 of research expenditure was made which represents the highest ever figure spent in one year on this key activity of the Society.
- ii. The invested funds of the Society increased in value by almost £90,000. This reflects the recovery in Stock Markets around the World following a very poor year in 2008/2009. In fact most of the loss sustained in the former year was recovered in the 12 months to the end of March 2010.
- iii. Income from members' subscriptions showed a modest improvement even though membership numbers didn't increase. This is because of the increase agreed at the 2008 AGM that began to take effect from April 2009.

The overall funds of the Society increased in value over the 12 month period to March 2010 by approximately £38,000.

Ignoring expenditure on research the income of the Society showed a modest surplus over expenditure in the year. The Trustees and staff continue to work to a disciplined regime reviewing financial data and performance against budgets on a regular basis.

The three main sources of our income continue to be members' subscriptions, donations and fundraising activity as shown in the following graph;

Source of Income 2009/10



The work of the Ménière's Society would not be possible without the support provided in various ways such as subscriptions, fund raising and voluntary work etc and the opportunity is taken to thank all our supporters. It is hoped that such support will continue to help those affected by the condition.

Statement of Financial Activities Year End 31 March 2010

	Unrestricted Funds	Restricted Funds	Total	Budget (All Funds)	Variance from Budget (under) over	Year Ended 31 Mar 09
	£	£	£	£	£	£
Income & Expenditure						
Incoming Resources						
Members' Subscriptions	77,460		77,460	80,000	(2,540)	72,974
Donations & Gifts	36,684		36,684	42,500	(5,816)	37,513
Legacies	12,141		12,141	8,000	4,141	1,000
Fundraising Activities	24,273	11,965	36,238	50,000	(13,762)	37,449
Gift Aid Tax Recovery	17,636		17,636	15,000	2,636	27,123
Investment Income & Interest Received	14,438		14,438	6,000	8,438	23,772
Total Incoming Resources	182,633	11,965	194,598	201,500	(6,002)	199,831
Resources Expended						
Direct Charitable Expenditure						
Information Services & Helpline	20,115		20,115	19,325	790	15,489
Spin Magazine	22,806		22,806	24,000	(1,194)	23,773
Research		63,763	63,763	64,474	(711)	42,993
Total Direct Expenses	42,921	63,763	106,684	107,799	(1,115)	82,255
Indirect Expenditure						
Salaries	86,428		86,428	99,655	(13,227)	96,003
Fundraising and Publicity	13,412		13,412	16,250	(2,838)	11,675
Management and Administrative	38,990		38,990	45,830	(6,840)	44,091
Web Site Development	-		-	5,000	(5,000)	-
Total Indirect Expenses	138,831	-	138,831	166,735	(27,904)	151,769
Total Resources Expended	181,751	63,763	245,515	274,534	(29,019)	234,024
Net Outgoing Resources for Year	882	(51,799)	(50,917)	(73,034)	(35,922)	(34,193)
Capital Increase/(Reduction) in Investments	89,379		89,379			(90,695)
Net Movement in Funds						
Fund Balances Brought Forward April 1 2009	448,218	73,987	522,205			647,093
Fund Balances Carried Forward March 31 2010	538,479	22,188	560,667			522,205

	March 31 2010		March 31 2009	
	£	£	£	£
Balance Sheet				
Fixed Assets				
Office Equipment and Computers		3,279		6,414
Current Assets				
Stock of Consumer and Promotional Items	5,323		7,843	
Debtors and Prepayments	13,223		29,500	
Bank Current Accounts and Cash	29,856		29,877	
Bank Deposit Accounts	106,389		160,919	
Investments	410,449		307,134	
Total Current Assets	565,240		535,273	
Current Liabilities: Payable in One Year				
Subscriptions Received in Advance	-		5,165	
Accrued Expenses	7,852		11,902	
HM Revenue and Customs	-		2,415	
Total Current Liabilities	7,852		19,482	
Net Current Assets		557,388		515,971
Net Assets		560,667		522,205
Funds				
Unrestricted				
General		227,959		227,077
Programme		310,520		221,141
Restricted				
Research		22,188		73,987
Total Funds		560,667		522,205

Ménière's Society - The Future

Balance and Dizziness

Since the Ménière's Society was founded by Mrs Marie Nobbs MBE in the 1980s it has evolved from a small support group to the UK's largest national charity solely supporting those with dizziness and balance problems. In Marie's address at the Society's 2009 Conference she said: "*We can look back on all our endeavours and feel proud of what we have achieved.*" The enquiries received by the Ménière's Society are from people suffering from vertigo due to a number of conditions. Some have Ménière's disease, others have a related disorder such as BPPV, labyrinthitis, migraine associated vertigo, endolymphatic hydrops or other vestibular dysfunction. Many are still undergoing medical assessment and have not yet had a firm diagnosis. Patients and carers tell us they're grateful they have an organisation they can contact for support. Health professionals support us in providing helpful information to those affected by these conditions, as well as putting their patients in contact with the Society. They argue that there is a great need for an organisation to provide support to people suffering from vestibular disorders and who better to take this on than the Ménière's Society who already has the skills and resources in place? It is also timely with the current NHS initiatives and the Government's 'Big Society' agenda to make it clearer that we support this wider patient group. We want to be able to help more people affected by these debilitating symptoms and are doing all we can to raise awareness among patients, health professionals and the general public, as well as seeking opportunities for more research into these conditions.

Research 2010/11

The British Society for Academic Otolaryngology in partnership with the James Lind Alliance and supported by ENT UK and members of several other professional organisations, have set up a Priority Setting Partnership. The James Lind Alliance is funded by NIHR and MRC to support the partnership between patients and clinicians on priority setting. This partnership aims to identify unanswered questions about the treatment of balance disorders from the perspective of both patients and clinicians and then prioritise those that both groups agree are the most important. The Ménière's Society is contributing to this project the results of which are expected late 2011.

The Chartered Society of Physiotherapy has invited the Ménière's Society to contribute to a group setting research priorities in physiotherapy. This project is being carried out by the well tried Delphi and the results of this work are expected mid-2011.

Working With Others

The Ménière's Society is pleased to have met with a number of organisations to discuss opportunities for working together during the coming year. The Ménière's Society, along with the BTA and RNID are participating in the Medicine and Me: Tinnitus event, hosted by the Royal Society of Medicine in February 2011. The Ménière's Society has also collaborated with Migraine Action on a poster distributed to neurology departments around the UK and hopes to participate in further joint events during the coming year.

Acknowledgements

Our thanks to the following individuals and organisations for your support during the year:

Our President & Patrons

Mrs Marie Nobbs MBE and Mr Gordon Nobbs
Mr Ian Chapman
Sir Robert & Lady Marjorie Clark

Health Professionals

Dr David Baguley
Professor Adolfo Bronstein
Andrew Clements
Carol Evans
Professor Joel Goebel
Mr Ian Johnson
Dr Sarah Kirby
Professor Linda Luxon
Mr Gavin Morrison
Dr Danuta Orłowska
Mr Peter Rea
Eloise Scholtz
Professor Shakeel Saeed
Mr David Selvadurai
Dr S S Surethiran
Dr Peter West
Professor Lucy Yardley

Local Support Group Leaders

Daphne Bromley (Amersham)
Eleanor Given (Ayr)
Max Coleman (Bedfordshire)
Diana Rodda (Canterbury)
Janet Dicker (Devon)
Maria Smith (Essex)
Elizabeth Cottingham (Hailsham)
Marie Quinn (North Hampshire)
Elaine Watts (London)
Phillip Gilchrist (Macclesfield)
Elaine Hughes (Manchester)
Valerie Tait (Newcastle)
Ann Read (Norfolk)
Liz Papps (Northampton)
Ian Winter (North Wales)
Valerie Moore (Somerset)
Robin Sharpe (South Wales)
Helen Purdey (Yorkshire)

Fundraisers - General & Regular Donors 09/10

Mr D Campbell; Mr & Mrs Clifton; Mrs S Cook;
Dr S Dahl; Mr R Cowan; Mr G Edwards; Mr D Ingle;
Miss Maylen; Mr Magee; Mr & Mrs Nobbs and
residents of Buxted Court

Fundraisers - Sponsored Events 09/10

Sadhana Ali *Charity Yoga Day*
Myra Barnes *Sponsored Swim*
Lisa Benson *Various Running Events*
Andrew Spence *Great North & Scottish Runs*
Alex Tye *Reading Half Marathon*
Chris Harrington-Benton; Michael Jaye;
Monique Maw; James Norden, Antony Sloan and
Declan Trezise *British 10k London Run*

Volunteers

Rebecca Arnold
Louise Fenner
Mark Fenner
Yvonne Harrington
Chris Harrington-Benton
Mary Hughes
Jonathan Maxted
Declan Trezise

Organisations

British Tinnitus Association
Deafness Research UK
East Sussex Hearing Resource Centre
King's Fund
Medtronic
Ménière's Australia
Migraine Action
Royal National Institute for Deaf People (RNID)
Slaughter and May
STTRs Direct for Palantype Services

Print Services

Ashley Forms
Hobbs The Printers
Quick Print (UK) Ltd
Red Eye Display and Graphics

IT, Website and Office Services

Blackbaud
Craig Grannell, Snub Communications
E D G Matthews and Sons
Principal I Ltd
Shredder Waste Paper

Accountant

Mr Michael Harlow FCA, Acquis
The Bell House, 57 West Street, Dorking, Surrey RH4 1BS

External Auditors

Crilly & Co Chartered Accountants
Wyvern House, 1 Church Road, Great Bookham KT23 3PD

Bankers

CAF Bank Limited (*from February 2009*)
25 Kings Hill Avenue, Kings Hill, West Malling ME19 4JQ
Lloyds Bank Plc
12 High Street, Haslemere GU27 2JG

Investment Funds

CCLA Investment Management Ltd
COIF Charity Funds, 80 Cheapside, London EC2V 6DZ
Sarasin Investment Management Ltd
Juxon House, 100 St Paul's Churchyard, London EC4M 8BU

The Ménière's Society is extremely grateful for all the support we receive. Our thanks to all members for your continued support. Your membership fees, donations and fundraising efforts allow us to continue supporting those diagnosed with Ménière's disease and related disorders; as well as enabling us to fund vital research.

Contact us:

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www.menieres.org.uk

Registered charity number 297246

Ménière's Society

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