

# Ménière's Society Annual Review and Accounts 2010/11



**Ménière's Society**

helping people with dizziness and balance disorders



## Contents

Society Information	1
Foreword from the Chair of Trustees	2
About the Ménière's Society	3
Review of the Year 2010/11	4
Review of Financial Activities 2010/11	9

### Ménière's Society

The Rookery, Surrey Hills Business Park, Wotton, Surrey RH5 6QT (Registered Address)

Registered Charity Number 297246

### Patrons

Lady Marjorie Clark

Mr Ian Chapman CBE DLitt FRSA

### President and Founder

Mrs Marie Nobbs MBE

### Trustees

Mrs Anne Boënders

Mr Robert Goodier

Mr David Renton *Chair of Trustees (from Oct 2010)*

Dr Humphrey Bowen

Mr Geoffrey Howard

Mr David Riches *Chair of Trustees (until Oct 2010)*

Mr Andrew Clements

Dr Alan Jacques

Mr A Simkins

Mr J Max Coleman

Mr Peter Joiner *Treasurer*

Mr Richard Wheen *Vice-Chairman*

Mrs Carol Evans

### Office Team

Mrs Natasha Harrington-Benton *Director*

Mrs Elaine Fenner *Membership Manager*

### 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

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

## Foreword

### David Renton, Chair of Trustees



The rest of this Annual Report goes into considerable detail about the Society's activities over the past year, but I would like to mention a couple of things that I personally think have been very significant.

We have been having increasing contact with Ménière's Australia, culminating in a visit from, and productive meeting with, their President, John Cook, who came over to the UK to see us recently. As we and they have very similar aims and objectives, it is extremely useful for us both to see how the other is doing things. We hope this will lead to further co-operation, and possibly to joint initiatives, in the future.

Members will no doubt recall that at the last AGM the question was raised, whether the Society's name still best reflected what we were actually about. The consensus over the last year has been that 'The Ménière's Society' was a recognised name, and one that we wanted to keep. After much careful consideration, feedback from members, and not a little debate, we have however made a change to the tagline. We are now known, as readers of Spin will be aware, as: 'The Ménière's Society; helping people with dizziness and balance disorders'. I believe that this new tagline much better reflects what we were already actually doing.

I hope that you find this report interesting and illuminating, and that you will use the AGM as an opportunity to ask any questions you may have about it, and about the Society's activities over the last year. If you are unable to come to the AGM we are of course happy to answer questions at any other time. It's your Society, and the staff and trustees rely on your feedback to do the best job we can.

**David Renton**  
*Chair of Trustees*

# About the Ménière's Society

## *Helping people with dizziness and balance disorders*

The Ménière's Society is the only UK registered charity dedicated solely to supporting those affected by vestibular (inner ear) disorders causing symptoms of 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 currently employs two full time members of staff.

## **Helping patients**

With over 25 years experience providing information to those affected by vestibular disorders, the Ménière's Society helps people source specialists in their local area, publishes a quarterly magazine, Spin, and factsheets on a variety of subjects (e.g. driving, surgery and vestibular rehabilitation) and provides a telephone information line during working hours. Peer support is also encouraged. Members are from all over the UK, with a small number overseas.

## **Working with professionals**

The Ménière's Society maintains an active relationship with interested clinicians and researchers. Authoritative contributions to the Society's publications and magazine, Spin, are welcomed. In return the Ménière's Society provides a valuable source of information and support for their patients.

## **Aims and Objectives**

The aims and objectives of the Ménière's Society are 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 and support vital research into the cause and treatment vestibular conditions
- ◆ 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.

## Review of the Year 2010/11

July 2010 marked 23 years since the Mènière's Society registered with the Charity Commission. There have been a number of changes to the Society's staff, trustees and office location over the years. Membership has grown to almost 5000 and we're delighted that over 200 people who joined when the Mènière's Society continue to support us today. Throughout this time the Society's objectives have remained essentially the same: *"To promote and provide care and relief for sufferers from Mènière's syndrome and related conditions."* We continue to do this through Spin, our information sheets, website, and direct with sufferers via the phone or email. We also encourage members to provide mutual support through local groups and the contact list.

### Balance

Since the Mènière'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 at the Mènière's Society are from those affected by symptoms of vertigo from a wide range of conditions, including BPPV, labyrinthitis, migrainous vertigo and endolymphatic hydrops, as well as Mènière's. Many are still undergoing medical assessment and have not yet had a firm diagnosis of the cause of their symptoms. Patients and carers tell us they're grateful they have an organisation they can contact for support. Health professionals are pleased we are able to take this on and 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 (inner ear) disorders generally and who better to take this on than the Mènière'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. As an organisation we are constantly asking, how can we better reach the people we serve? We want to be able to help more people 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 debilitating conditions.

### Research

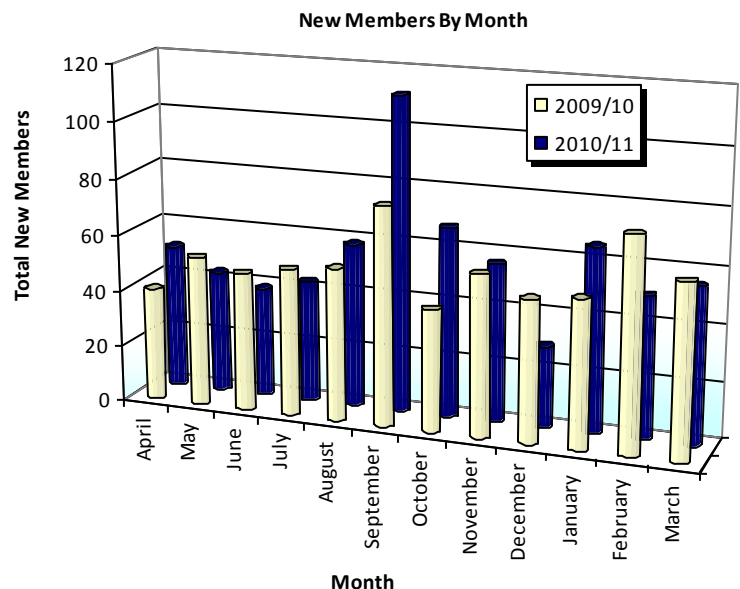
During 2010/11 the Society supported a research *Proposal for a National Study of Balance* (Southampton University), as well as ongoing research: *Clinical Trial: Transtympanic Gentamicin vs Transtympanic Steroids* (Imperial College, London) and *The Use of C-VEMP and O-VEMP Tuning Curves to Predict and Monitor Mènière's Disease* (Leicester Royal Infirmary).

## ENT Aspects of Balance Priority Setting

The Ménière's Society was asked to take part in a priority setting partnership with the James Lind Alliance (JLA). The JLA are pioneering techniques to get the patient's voice heard when setting research priorities. In late May 2010 representatives of the Society attended an inaugural meeting at which the approach sounded exciting: to ask patients what they see as the problems that need a solution; research uncertainties. These are not just medical problems but include, for example, access to information and waiting times - issues which can have a real impact. Once collected, the list of uncertainties is collated and a top ten list is compiled for distribution to highlight the areas which need prioritising, particularly among researchers and funders.

## Membership

Membership numbers in 2010/11 remained consistent with previous years. In addition to existing members, a further 667 people joined the Society this year; slightly higher than 2009/10. A peak in membership figures can be seen in September following a Daily Mail article in August 2010 on BPPV; giving credence to the Society's decision to formalise the inclusion of all vestibular conditions within our support services. Consistent with previous years, the Internet continues to remain the biggest source of new members for the Society, followed by health services/support organisations and the media.



## Raising Awareness

### Ménière's Society Conference & AGM 2010

The Ménière's Society Annual Conference was held on 9 October 2010 at the King's Fund in central London; attended by over 80 people. The Chair of Trustees opened proceedings by reading a message from the Society's President and Founder, Mrs Marie Nobbs MBE. Five speakers presented to conference attendees on a variety of subjects: Andrew Trouton (Hampton Pharmaceuticals) spoke about *Arlevert*, Jenny Dursley (Cochlear Ltd) gave a presentation on *Cochlear Implants*, Dr Jas Sandhu (Leicester Royal Infirmary) spoke about *Testing for Ménière's*, focusing on his research on VEMPS, Andrew Clements (Leicester Royal Infirmary) discussed *Vestibular Rehabilitation after Surgery* and Mr Nitesh Patel (Whipps Cross University Hospital) presented *Ménière's Disease: A Chronological Timeline*. The Ménière's Society AGM took place following the conference at which David Renton was appointed as Chair of Trustees. David was formerly Chair between 1995 and 1998.

## Medicine and Me

In February 2011, the Ménière's Society participated in *Medicine and Me: Tinnitus* at the Royal Society of Medicine (RSM) in central London. Organised by the RSM in association with the Ménière's Society, RNID and British Tinnitus Association, Medicine and Me meetings aim to provide a forum in which patients' concerns about their illness are given top priority. These meetings provide an opportunity for patients and their families to share their experiences, to hear about the latest research and question the experts. The day was split into three sections covering the causes of tinnitus, therapy for tinnitus and patient support. Presentations were given by Dr David Baguley (Addenbrooke's Hospital, Cambridge), Professor David McAlpine (Ear Institute, London), Mr Robin Youngs (Gloucestershire Royal) and Dr Veronica Kennedy (Bolton NHS). In addition there were patients speakers giving their personal experiences, along with representatives from the national charities: Ménière's Society, BTA and RNID. With over 100 attendees, it was an interesting and informative afternoon.

## In the Media

We are encouraged that media coverage of vestibular disorders is gradually increasing. In February 2011 the BBC reported on astronaut, Alan Shepherd, who suffered from Ménière's disease. The Society was pleased to have been involved in a phone in on BBC Radio Devon's 'Interactive Lunch' programme in August 2010, as well as having our details included in two Daily Mail articles in August and November 2010 covering BPPV and Ménière's disease respectively.

## Local Groups

There are currently around 20 local support groups in the UK, supporting sufferers of Ménière's disease, tinnitus and vestibular 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 those affected. During 2010/11 two new groups were formed in Gloucester and East Sussex joining the existing list. We also saw two new group leaders take on groups in Northampton and Hampshire allowing them to continue. Sadly, two groups came to a close during the year: Derby and Somerset. The Derby Ménière's Support Group had been one of the longest running local groups for Ménière's sufferers having run for over 15 years. All those involved in running the groups are thanked for their efforts as well as the members who attend, without whom the groups would not exist.

## Fundraising and 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. All donations, whether large or small, help the Society to continue to provide support to those affected by vestibular disorders and develop our services and research programme.

**Legacies and Donations 'In Memory Of'**

The Ménière's Society was pleased to benefit from five legacies during 2010/11 ranging from £1,000 to just under £39,000; plus a further £6,509 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. Larger legacies enable the Society to support research projects which would not otherwise be possible.

**Sponsored Events**

The Ménière's Society is grateful to everyone who took part in sponsored events during 2010/11 raising over £6,500. Events included the Great North Run, Great Scottish Run and Just Walk 10k as well as the British 10k London Run which the Society entered six places for a second year following the success of this in 2009/10. Sponsorship was also raised by Michael Graham (pictured) who cycled from Lands End to John O' Groats to raise funds for the Ménière's Society. Michael, whose mother suffers from Ménière's disease, completed the distance in 17 days raising over £2,500 for the Society.

**Christmas Raffle and 200+ Club**

The Christmas Raffle and 200+ Club are key fundraising activities for the Ménière's Society during the course of the year; raising around £15,000 for the Society's funds. All proceeds from the 2010/11 Christmas raffle were put towards the Society's research fund. The 200+ Club exceeded all expectations in 2010/11 with over 1000 shares sold for the first time since the Society has held a 200+ Club; not only does this mean an increased income for the Ménière's Society from this source, but also enabled us to increase the value of the prizes too.

**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 confirming their Gift Aid status. In 2010/11 the Society's total Gift Aid claims amounted to over £15,500.



# Review of Financial Activities 2010/11

## Peter Joiner, Honorary Treasurer



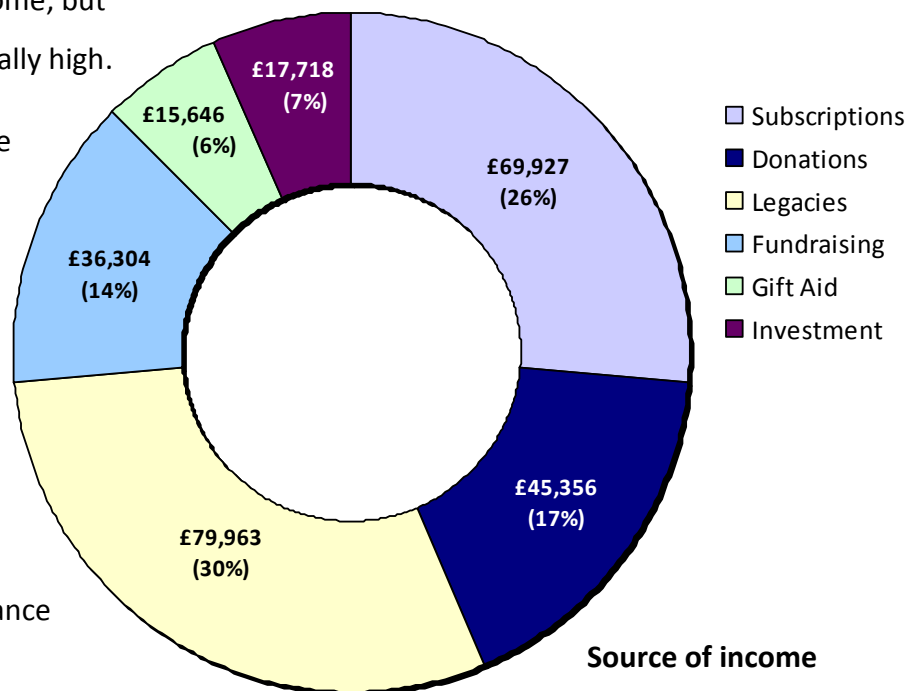
Budgets for both income and expenditure are set each year and performance against these is monitored regularly by the Trustees. Ignoring special factors, the day to day expenditure of the Society was in excess of our income from donations and subscriptions but by a modest £2,671 only. Two special factors outside of this are:

- i) Substantial legacy income of almost £80,000 was received
- ii) Expenditure on research of approximately £10,700 was made which effectively relates to capital expenditure mainly from our restricted funds set aside for that purpose. The amount spent on research for the year was well under the expenditure in the previous year of £63,763 but projects are under review that are likely to involve substantial research expenditure over the course of the next two or three years.

Funds invested by the Society increased in value over the 12 months to March 2011 by approximately £34,000 representing partly accumulated income and partly capital appreciation. The value of the Society's funds overall as at the 31<sup>st</sup> of March 2011 was £644,105 that represent an increase during the year of just over £83,000.

The graph indicates our main sources of income, but for this year the legacy element is exceptionally high.

During the course of the past few months we have been advised that our auditor has discontinued auditing work. In the circumstances we have arranged for a draft audit of our 2010/2011 accounts by another auditor (Chamberlains Chartered Accountants and Registered Auditors). Once a new auditor is appointed at our AGM they will be asked to carry out an audit in accordance with the Society's constitution.



The opportunity is taken to thank all our supporters for their contribution by way of donations, subscriptions and voluntary work, etc which enables the Ménière's Society to support those affected by vestibular conditions and to help finance research.

## Statement of Financial Activities Year End 31 March 2011

	Unrestricted Funds £	Restricted Funds £	Total £	Year Ended 31 Mar 10 £
<b>Income &amp; Expenditure</b>				
Incoming Resources				
Members' Subscriptions	69,927		69,927	77,460
Donations & Gifts	45,356		45,356	36,685
Legacies	79,963		79,963	12,141
Fundraising Activities	26,437	9,867	36,304	36,238
Gift Aid Tax Recovery	15,646		15,646	17,363
Investment Income & Interest Received	17,718		17,718	14,438
<b>Total Incoming Resources</b>	<b>255,047</b>	<b>9,867</b>	<b>264,914</b>	<b>194,598</b>
Resources Expended				
Direct Charitable Expenditure				
Information Services & Helpline	14,322		14,322	20,115
Spin Magazine	26,122		26,122	22,806
Conference	6,851		6,851	3,930
Research	-	10,712	10,712	63,763
<b>Total Charitable Activities</b>	<b>47,295</b>	<b>10,712</b>	<b>58,007</b>	<b>110,614</b>
Indirect Expenditure				
Salaries	95,447		95,447	86,428
Fundraising and Publicity	11,074		11,074	13,412
Management and Administrative	33,506		33,506	34,297
Governance costs (independent examination/audit)	1,300		1,300	764
<b>Total Indirect Expenses</b>	<b>141,327</b>		<b>141,327</b>	<b>134,901</b>
<b>Total Resources Expended</b>	<b>188,622</b>	<b>10,712</b>	<b>199,334</b>	<b>245,515</b>
Net incoming (Outgoing) Resources for Year	66,425	(845)	65,580	(50,917)
Gains on Investments	17,857		17,857	89,379
Net Movement in Funds	84,282	(845)	83,437	
Fund Balances Brought Forward April 1 2010	538,479	22,188	560,667	522,205
<b>Fund Balances Carried Forward March 31 2011</b>	<b>622,761</b>	<b>21,344</b>	<b>644,105</b>	<b>560,667</b>

### Balance Sheet at March 31 2011

	March 31 2011		March 31 2010	
	£	£	£	£
<b>Fixed Assets</b>				
Office Equipment and Computers		2,472		3,279
Investments		444,077		410,449
		<u>446,549</u>		<u>413,728</u>
<b>Current Assets</b>				
Stock of Consumer and Promotional Items	5,835		5,323	
Debtors and Prepayments	19,966		13,223	
Bank Current Accounts and Cash	29,240		29,856	
Bank Deposit Accounts	157,549		106,389	
<b>Total Current Assets</b>	<b>212,590</b>		<b>154,791</b>	
<b>Current Liabilities: Payable in One Year</b>				
Accrued Expenses	14,488		7,852	
HM Revenue and Customs	546		-	
<b>Total Current Liabilities</b>	<b>15,034</b>		<b>7,852</b>	
<b>Net Current Assets</b>		<b>197,556</b>		<b>146,938</b>
<b>Net Assets</b>		<b>644,105</b>		<b>560,667</b>
<b>Funds</b>				
<b>Unrestricted</b>				
General		257,384		227,959
Programme		365,377		310,520
<b>Restricted</b>				
Research		21,344		22,188
<b>Total Funds</b>		<b>644,105</b>		<b>560,667</b>

## Acknowledgements

Our thanks to the following individuals and organisations for your support during 2010/11:

### Our President & Patrons

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

### Health Professionals

Dr David Baguley  
Mr Martin Burton  
Professor Adolfo Bronstein  
Andrew Clements  
Carol Evans  
Professor Joel Goebel  
Mr Ian Johnson  
Dr Sarah Kirby  
Professor Linda Luxon  
Dr Anooj Majithia  
Mr Gavin Morrison  
Mr Nitesh Patel  
Mr Peter Rea  
Professor Shakeel Saeed  
Dr Jas Sandhu  
Dr S S Surenthiran  
Dr Peter West  
Professor Lucy Yardley

### Local Support Group Leaders

Daphne Bromley (Amersham)  
Max Coleman (Bedfordshire)  
Diana Rodda (Canterbury)  
Kay & Roy Smith (Derby)  
Maria Smith (Essex)  
Kirsten Jones (Gloucester)  
Elizabeth Cottingham (Hailsham)  
Sandra Magee (North Hampshire)  
Elaine Watts (London)  
Elaine Hughes (Manchester)  
Valerie Tait (Newcastle)  
Ann Read (Norfolk)  
Kim Wood (Northampton)  
Valerie Moore (Somerset)  
Robin Sharpe (South Wales)  
Angela Fordham (Sussex, East)  
Helen Purdey (Yorkshire)

### Member Support, Contact List and Penpals

Thank you to all our members whose names are on the contact and penpal lists offering support to others. We would particularly like to thank the following people for their regular assistance: Mr K Doidge; Mr R Goodier; Mrs J Hensley; Mr J Hicks; Mrs R Orgill; Mrs M Strong.

### Donors 2010/11

The Ménière's Society is grateful to everyone who has given made a donation to the Society in the last year. Gifts, no matter their size, are vital to sustaining the work of the Society. We would like to thank for following donors for their generous support: Mr S Abdulhadi; Ms C Barnes; Mr & Mrs Clifton; Mr D Ingle; Leicestershire & Rutland Mark Benevolent Fund; London Grand Rank Association (East Sussex); Mr & Mrs Nobbs; Mr J O'Connell; Mr C Searle; Ms L Sharman; Mrs J Shelton; Mr N Smith; Mr H Thompson; Mr R Tinn.

### Fundraisers: Occasions and Sponsored Events 2010/11

Miss L Francis; Mr M Graham; Mrs Y Hanson-Nortey; Mr & Mrs Loane; Mr C Moss; Mrs K Ott; Mr D Paradise; Mr M Paradise; Mr A Simkins; Mr J Simkins; Mr Brian Watts; Mr Ben Watts; Ms D Smith ; Ms E Wheate.

### Volunteers

Rebecca Arnold  
Louise Fenner  
Mark Fenner  
Chris Harrington-Benton  
Mary Hughes

### Organisations

British Tinnitus Association  
East Sussex Hearing Resource Centre  
ENT UK  
James Lind Alliance  
Ménière's Australia  
Migraine Action  
Slaughter and May  
STTRs Direct for Palantype Services

### Print Services

Ashley Forms  
Hobbs The Printers  
Judges Postcards Ltd  
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

**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.**

**Ménière's Society**  
**The Rookery**  
**Surrey Hills Business Park**  
**Wotton**  
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Registered charity number 297246

