HUNTINGTON'S DISEASE ASSOCIATION

ANNUAL REPORT AND SUMMARY ACCOUNTS

MARCH 2014

CARE FOR FAMILIES NOW...

A CURE FOR FUTURE GENERATIONS.

science communication awards amrc
Winner

Winner of 2013GSK IMPACT Award
Recognising outstanding work in community healthcare

Policy

The Association is governed by an Executive Council, a management body elected by democratic vote at the Annual General Meeting.

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Overall policy is made at the Annual General Meeting, managed by the Executive Council and implemented by the Association's staff.

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Priorities set at the Annual General Meeting are reflected in the work of the Association.

Patrons:

Countess of Harewood
Tony Hadley & Shane Richie

Members of the Executive Council

Chairperson: Heather Thomas
Honorary Treasurer: Nicholas Heath
Company Secretary: Peter Morse

Mr Ken Taylor
Dr Elizabeth Howard
Mrs Sandra Abbott
Mr Matthew Ellison
Mr Ben Tindel
Mr Andrew Bickerdike
Dr George El-Nimr

Medical Advisory Panel

Dr Elizabeth Howard BSc MBChB MRCGP (Chair)
Dr David Craufurd MB.BS., MSc., FRCPsych
Mrs Cath Stanley RGN BSc (Hons)
Professor Nicholas W Wood PhD FRCP FMedSci
Professor Gillian Bates FRS FMedSci DSc PhD
Professor Sarah J Tabrizi BSc (Hons) MBChB (Hons) FRCP PhD
Dr Monica Busse PhD MSc (Med) BSc (Med) Hons BSc (Physio)
Dr Edward Wild MB BChir MA MRCP PhD
Ms Rachel Taylor RN BSc(Hons) MSc
Bill Crowder Reg. SW CSS

Affiliations

The United Kingdom and Ireland Huntington's Alliance
International Huntington Association
National Council for Palliative Care
Association of Medical Research Charities
Genetic Alliance UK
Neurological Alliance

Bankers:

National Westminster Bank Plc
66-68 St John's Road
Clapham Junction
London SW11 1PB

Auditors:

Lescott Limited
10 Station Court
Station Approach
Wickford, Essex SS11 7AT

Huntington's Disease Association

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Registered Charity No. 296453 Registered in England No. 2021975

Huntington’s Disease

Huntington’s disease is a degenerative neurological disorder that causes progressive mental deterioration, behavioural changes and severe physical incapacity.

It is hereditary, with each child of an affected parent at 50% risk of inheriting the condition.

The duration of the disease varies between 10 and 25 years. The age of onset is typically between 30 and 50 but Huntington’s disease can affect either sex at any age.

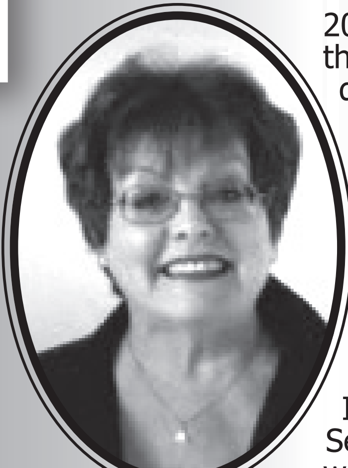
Mission Statement

Pioneers in the field of specialist care in all aspects of Huntington’s disease, the Huntington’s Disease Association is a national charity committed to supporting people affected directly or indirectly by Huntington’s disease. It pursues the best possible care; provides training and advice to families and professionals; raises awareness; and promotes research towards better treatment and the ultimate aim of a cure for Huntington’s disease.

Aims and Objectives

- to provide support to people affected by Huntington’s disease, carers and those at risk of Huntington’s disease
- to promote and support medical and social research
- to promote and secure effective care facilities
- to develop local facilities to meet local needs
- to provide specialised advice
- to develop and support Branches and Groups throughout England and Wales
- to provide literature on all aspects of the disease
- to educate other service providers as to the needs of Huntington’s disease families
- to create public awareness of Huntington’s disease in order to eradicate ignorance
- to raise funds in order to accomplish these aims

Annual Review from the Chair



2013 – 2014 has been a yet another extremely successful period for the HDA. Not only were we recognised again as an outstanding charity devoted to supporting families affected by HD, but also we were awarded the prestigious ARMC award.

As the HDA grows it is important to expand the infrastructure to enable us to continue to grow. To that end we intend to appoint a Personal Assistant to Cath Stanley CEO, the Executive Council and myself. This new post will release both Cath and myself from certain administrative duties which take time, but do not promote the Association nationally and internationally.

In September I accompanied Cath and Bill Crowder, Head of Care Services, to the World Congress of Huntington's Disease in Brazil. This was an event which again highlighted the exemplary work we carry out in England and Wales.

It also highlighted how lucky we are to have Dr Ed Wild working alongside us with research into the disease and his management of the research website HDBUZZ.

Whilst in Rio I was elected onto the International Huntington's Association Board and have taken up the role of Treasurer. This I could not have agreed to undertake without the support of Sharon Bakewell, our Financial Accountant.

Fundraising has been an area we have been reviewing and in 2014 we intend to appoint a Corporate Fundraiser. We are able to establish this role from the £400,000 we had put to one side for specific projects, as we felt this appointment would, in time, compliment the already excellent work carried out by Ayla Besser, Head of Fundraising.

As in previous years, the Branches and Support Groups have been busy raising funds, and on behalf of us all, I thank you. Without these monies we could not offer the services that we do.

In September the EHDA will be taking place in Barcelona, which I will be attending and will be reporting back in our newsletter.

We have now reached a point within the HDA where it is necessary to consolidate our activities and, with the new appointments, evaluate how we move forward as a charity.

With the above in mind I will be holding a follow-up session with your Trustees at the end of this year to review how, as a group, we have developed over the last two years since I last carried out a Skills Audit.

Finally, I would like to thank Cath Stanley and the team for their continued excellent work and the HDA's Executive Officers; Nick Heath, Peter Morse and the whole of the Trustee group for their support, enthusiasm and dedication.

Heather Thomas
Chair of the Huntington's Disease Association

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TREASURER'S REPORT

The accounts for 2014 show a small overall surplus after the record-breaking 2013 results. Income fell to just under £1.4m with legacies amounting to £215,000 which is more in line with the average in recent years. The General Reserves now amount to just over £590,000 with £90,000 of this being held by 34 branches. Our target for general reserves held centrally is six months' salary and running costs which amounts to £583,000 based on 2014 figures. This is an achievable aim which will provide resources to cover costs during any downturn and also enable improvements to our services to be made which can be sustained over a period of time even if income falls.

Within the Restricted Funds, we have some resources available to carry forward but we may have to support the next major projects from other resources. This could be the General Fund or the Designated Fund which was established from the legacies received in 2013. The £400,000 in this Fund has been invested separately from the General Funds of the Charity. It was not utilised in 2013/14 but in 2014/15 the costs associated with a newly appointed Corporate Fundraiser have been covered from this Fund.

The Association has for many years been committed to expanding the Regional Care Advisory Service. We should be able to continue to do this in 2014/15 based on a balanced budget and the knowledge that any shortfall can be covered by reserves. We shall also be able to assess the results of the programme of Corporate Fundraising and other continuing fundraising activities nationally and within our branch community and develop the Strategic Plan to maximise the use of our resources.

Nick Heath
Treasurer

The Association has for many years been committed to expanding the Regional Care Advisory Service. We should be able to continue to do this in 2014/15

Annual Review from the Chief Executive

It has been a busy, exciting and challenging twelve months. As always the main focus of our work remains working with families. In the last year our RCA service has supported 4370 people with HD, 4634 carers, 3266 adults at risk, and our RCA and youth service supported 2539 children and young people. The work done has been varied including working with people within their own homes, meeting carers in neutral places, visiting nursing homes, day centres and prisons, visiting young people in schools and many more.

In addition to direct work, the RCA service has also worked hard to raise awareness of HD, as well as understanding of this complex illness. To that end they have carried out 172 training sessions and 292 information sharing sessions in the last 12 months. In addition to this we have been able to continue to offer a residential three day course, twice a year, to professionals working in the field of HD.

> the amazing network of volunteers that we have doing just incredible and wide ranging events for us has brought in an incredible amount of money; a heartfelt thanks to each and every one of you.

We continue to hold family information days and a big focus this year has been training events for family carers. We held a residential carers course and then this has been rolled out to carers courses throughout the country. We have also held three summer camps for children between the ages of 9 and 15; these are informal fun activity weekends. We held a young people's weekend for children/young adults between the ages of 16 to 19, which was a mixture of fun and support, plus a weekend for families affected by juvenile HD; a unique opportunity for families affected by this rare but devastating form of the illness to meet with other families, plus a young person's conference for those aged 18 to 30 ish, which provided a mixture of information and peer support. All of these events offer the opportunity to support people in an additional way. Perhaps, however the best weekend of all was our family conference. We had a fantastic range of speakers and we held our own Oscars…celebrating some of the amazing organisations such as HDBuzz and HDYO as well as individual achievements within the HD community.

I would like to recognise the enormous loss of Mary Howlett, Merseyside Branch Chair, and former Trustee of the Association. Mary was an incredible lady; wise and reflective, loved with a big heart, and could not do enough for anyone. On the other side, fun loving and the life and soul of any event. She sadly passed away on 12th March 2014 and will be greatly missed by us all.

It has been a year of change from an income point of view. The well-publicised statutory funding cuts have inevitably had an effect on that income stream, however the amazing network of volunteers that we have doing just incredible and wide ranging events for us has brought in an incredible amount of money; a heartfelt thanks to each and every one of you. In addition, our branch network are so supportive, both doing interesting fundraising and supporting local families with that all important peer support.

Attending the World Congress in Brazil brought home the importance of supporting the wider HD community. Many families don't have access to clean water, never mind the healthcare resources that we have available to us. However, inevitably we still have a lot of work to do. One of our key aims for the forthcoming year is to raise awareness of the complex mental health and cognitive symptoms that some people with HD display, and to provide training and educational materials to mental health teams.

Cath Stanley
Chief Executive

THE REGIONAL CARE ADVISORY SERVICE

It's really good to see the clinics developing in Wales and the three RCA's are involved in each of them in North and South Wales. The clinics in England are also extremely important and most have RCA's working alongside the consultants and their teams. Most are well established and there are a few new developments happening which will make life easier for families.

The RCA's are always looking to enhance and develop new services across England and Wales through networking and seizing opportunities to raise awareness of HD and the work of the HDA. Many of the reports you will read below show how Branch and Support Groups play a pivotal role in the lives of local people and although it may not be for everyone, take a look at what these support networks get up to and do consider popping along to the one closest to you.

Bill Crowder - *Head of Care Services*

ARIENNIR GAN Y LOTERI
LOTTERY FUNDED

I have been in post for 3 years and I believe I continue to raise the profile of Huntington's disease in North Wales.

I have increased awareness amongst Health and Social care professionals through delivering training/information sessions and one to one personal contact with senior medical and nursing staff.

During the last six months our HD Clinic at Colwyn Bay has gone from strength to strength. I am now working with a new consultant Dr Raj Sambhi. I am in the process of collaborating with Health professionals to form Multi-Disciplinary teams to be linked to the clinic.

I continue to assist our Mon & Gwynedd Branch in fundraising and other issues.

During our Awareness Week in June I involved the young Carers in a fun Zumbathon event which was thoroughly enjoyed by all. We raised £1.088. Other events I assisted in were a Charity Golf Day and Sponsored Walk. An amazing £3.500 has been raised in total and this money will provide a substantial amount of support for people with Huntington's disease in North Wales.

We also established a website for the Mon & Gwynedd Branch (North Wales HD Branch). This can be viewed at: www.hdanorthwalesbranch.org.uk.

We held our first North Wales HD Branch Day in March 2014 and established a new support Group for Conwy & Denbighshire.

I have been successful in a number of cases in supporting my clients and their families in achieving financial stability through applications and appeals with various statutory organisations. My external networking with various organisations has extended, giving me more opportunities in developing future improvements for the HD families in North Wales.

Alwena Potter, RCA - Anglesey, Gwynedd, Conwy & Denbighshire

ARIENNIR GAN Y LOTERI
LOTTERY FUNDED

This year I have been actively involved in supporting and advising our families on a monthly basis in clinics at the Walton Centre. I am so delighted to say that the HD and research clinics at the Walton Centre are going from strength to strength.

It gives me great pleasure to be working alongside our families, consultants and the nurses within the units. The consultants and nursing staff are very warm and welcoming. As a team, it has been a great success and it enables me to provide information, support and advice to our families who are attending the clinics.

We are all working hard to ensure that we continue to grow, contributing all that we can to further develop these valuable services.

Additionally I am visiting and liaising regularly with care homes and specialist units, providing them with information, advice and training.

On the 8th September 2013 I arranged a family day in collaboration with the Merseyside Branch. The day was a great success, and was enjoyed by all who attended. We had some new family members who came along too which was great to see and they were warmly welcomed as always. I would like to say a big thank you to our families, guest speakers who presented on the day, the local community who donated prizes and the Halewood Town Council who provided the venue free of charge.

I would also like to thank Adam Cho, our Youth Worker, Head Office and my family and friends who helped out on the day and donated prizes. We are already busy planning our family day for next year; please see our branch newsletter, or you can contact Head Office or me for further details of our up-coming events.

The Merseyside Branch, as always, continues to be a valuable network of support for our families old and new. They are all very welcoming and dedicated to providing advice and support in whatever way they can.

Anita Daly, *RCA - Merseyside and IOM*

The last 6 months has been packed with educating professionals, supporting families and awareness raising. I continue to develop the RCA service in West Yorkshire above the M62, and hope that many have felt the benefit from this. I can honestly say that families are reaching out and learning that they are not alone and have support around the corner.

Events such as Disability Awareness Day in Warrington in July has helped raise the knowledge of Huntington's disease due to a staggering estimated attendance of 29,000 visitors. That is a lot of people to talk to. I would also like to thank Hannah Longworth for her support with the event and during the months before.

Requests for training have increased by over 100% and the need to educate services such as the Department of Work and Pensions and ATOS has dominated a huge proportion of my working week. Since all the changes to the benefits and the health care system have started in the Greater

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THE REGIONAL CARE ADVISORY SERVICE

> "I was privileged to be able to attend the AGM and Family Conference in Telford ... this was a humbling experience and a reminder as to why I love my role with the HDA."

Manchester and Cheshire areas first, we have been very much the trial for the rest of the country. For this reason working closely with Commissioners of health has also been vital in ensuring knowledge is passed on so that services are in place and the effects of changes mean minimal disruption to all families.

My aim for the coming six months is to spend more time supporting you all, and continuing to develop existing links with health and financial services, and to introduce myself to others who have yet to hear about us.

My dedication and support to families and professionals is my main aim, I look forward to the coming months and remind you all that I am just a phone call away.

Debra Robinson, RCA – *Greater Manchester, Cheshire and West Yorkshire (North of M62)*

I returned to work from my maternity leave in May, and I have to say my feet haven't touched the ground since. It has been great to get back to work and getting involved in supporting the families. Sadly I was not able to join those at camp this year. I will be there next summer so please do come along and join us.

I have been involved in a number of things alongside supporting the families in the area. I have been in a number of care settings advising and training staff over the summer.

I have run the first of two carers courses in the Hampshire area.

I am also planning a professionals' day on the Isle of Wight at the end of the year. To support the variety of professionals involved in the care for the families there.

I continue to work alongside Dr Christopher Kipps and Dr William Gibb at Wessex Neurological Centre. It is hoped that in 2014 the HD clinics held there will be increased from 3 times a year to 6 times a year. A number of clinics will also be held at Royal Hampshire County Hospital (Winchester). Work is still in progress with the clinic at Royal Berkshire Hospital and I know Dr Richard Armstrong is very keen to get this off the ground.

The Hampshire Branch has had a busy summer with Segway Racing, cruises on the river and theatre trips planned, amongst other things. New and old faces are always very welcome to join in any of the events.

Eve Payler, RCA – Hampshire & Berkshire

During June I had the opportunity to run the JHD Weekend in the Lake District. We had fantastic weather, not a spot of rain and everyone had a great time doing a variety of activities from cycling to zip wire!

I have also attended Avon Tyrell Summer Camp where the weather was not quite so kind – very enjoyable despite the downpours.

In the last six months I have given training sessions to a variety of professional groups including carers, nurses and occupational therapists – further raising awareness of HD. I continue to attend the HD clinic at Guys' Hospital on a monthly basis and enjoy attending Branch meetings.

The main part of my work is providing advice and support to families and individuals; either visiting them, speaking on the phone or meeting them in clinic and at support group meetings. I am always pleased to hear from you so do get in touch.

Fiona Sturrock, RCA - Kent and Sussex

I was privileged to be able to attend the AGM and Family Conference in Telford this year. As ever this was a humbling experience and a reminder as to why I love my role with the HDA. It was lovely to see so many people from my area and meet new people as well. I hope people left feeling positive about the future and all the research that is being undertaken.

I was able to deliver two successful Carers Courses and I'm planning more this year and into next year as well. With one of my colleagues, I supported the Children's Activity Camp in the North of England from 30th May to 1st June, it was a fun weekend.

As ever I continue to support families across the East Midlands and beyond. I have continued to provide training to care establishments and have worked alongside health and social care professionals to increase their knowledge and understanding of Huntington's.

Helen James, RCA - Northants, Derbyshire, Leicestershire, Nottingham & Staffordshire

I'm now twelve months into my new role and I can honestly say it's one of my best jobs ever!

The support that I've received from people within the HDA organisation itself has been great and I'm very proud to be working here.

London North and South East is a big area to cover so I've spent a good deal of time on trains and buses to get to families, professionals and groups - but it has been worth it! I've had the pleasure of meeting and working with some truly inspirational doctors, nurses and other allied professionals, who are doing an excellent job of supporting our families.

Attending the HD National Clinic at Queen's Square every 2 weeks is fantastic and I'm very proud to be part of that dedicated team.

I've delivered quite a few training/information sessions - which are always very well received and I helped out at a kids camp back in August, which was great fun so I've signed up for two kids camps next year.

I seem to be learning something new every working day which is great and I attended my first HDA AGM in October and the HD course for professionals in November.

Every day is different - that's what makes the RCA role so good.

Most of all, I'm enjoying getting to know my London clients and their families and doing my best to support them in any way I can. They are the people who inspire me the most.

Jeanette McMullen, RCA - North & South East London

ARIENNIR GAN Y LOTERI
LOTTERY FUNDED

Thanks to continued support from the lottery I have been as busy as ever - I'm not sure where the time goes. There are so many people wanting advice, ranging from Young Carers to people at risk, relatives and friends who are concerned about the people they care about.

We have had an active year in Surrey & South West London. The South London Support group continues to meet at the Royal Hospital for Neurodisability on a monthly basis (every second Wednesday). We are a small but enthusiastic group who enjoy having a cuppa and a chat. The West Surrey Branch also continues to blossom providing members with a variety of informative & social events throughout the year.

Once again I helped my colleagues with the Youth Forum which is a very popular event and very well attended. It's such a valuable forum for young people to meet and find mutual support discussing topics that are important to them. I am also delighted that the Young Persons meetings are now up and running regularly in London where they meet in a pub near Euston Station and details can be found on our website.

I continue to visit families in their homes and try to support them through what is often proving to be a very challenging time for them. I continue to give training & information sessions to increase and raise awareness of HD to anyone who will have me. Together with my colleague who covers Sussex & Kent, we hosted a Carer's course on 6th November 2013 at a venue located on the Surrey/Sussex Borders.

Once again I would like to thank all the families I meet and speak to in the course of my job. You all inspire me with your courage and strength and it is a privilege to work with you all.

Mandy Ledbury – RCA, Surrey & South West London

I can't believe where the last six months have gone! As usual the past few months have been very busy but very exciting. After much preparation the first meeting of the Darwen Support Group in Lancashire took place in June. This was very well attended by people who were familiar with the RCA service and some people who were unaware that the HDA existed. The group has continued to thrive over the past couple of months. My thanks go to Jantina and Becky for making this happen.

I have continued to raise awareness about HD and the RCA service by undertaking numerous training and information sessions in nursing homes. (I even gave a brief information session whilst I was on Jury Service).

I continue to be involved in attending the MDT clinics, Case Reviews, Funding Meetings etc.

As always the main focus of work remains with supporting my families where ever they may be and ensuring they receive the correct service and support.

Theresa E. Westhead, RCA - Lancashire & Cumbria – including Wigan & Bolton

Youth Service Update

In August we ran our first Young People's residential for 16-19 year olds, it took place in the Midlands and although we only had a small group it was a really good weekend.

All of the young people who attended enjoyed themselves and got something out of the weekend. One of the key issues that many young people mention to me is that they feel isolated so it was nice for them to meet other young people in a similar situation and have the confidence to talk about their experiences.

We were also asked to collaborate with HDYO on a video project to explain the work that HDYO does and how it can help young people. The group fully engaged with the filming process and I have a feeling that we may have seen some of the budding stars of tomorrow make their first appearance on film.

After the success of the pilot it has been agreed that we can run the weekend again and hopefully it will become a regular part of the HDA activities calendar.

The last six months hasn't all been zip wires and raft building though, I've been invited into more schools to meet more young people and I am glad to say that the schools are asking questions about how they can support these young people. This is one of the areas that I have been hoping would develop. While I can see a young person for an hour every eight to twelve weeks, they spend more time at school and can receive more support in between visits if the school are willing to work with us.

This doesn't have to be a training or information session for the school although I'm more than happy to do this, but it can be a conversation over the phone or an exchange of emails. It can even be a ten minute chat before or after I visit the young person, I'm more than happy to fit in with whatever the school needs to support the young person so they can get the best out of their time at school.

As always if you would like to contact me to speak more about my role and the support that I can offer, or would like me to attend a Branch or Support Group meeting I can be contacted on 0151 705 3460 or adam.cho@hda.org.uk.

Adam Cho – Specialist Youth Worker

In summary…

Providing advice, support and education is a large part of the RCA role and as you can see, Adam is featuring quite a bit as he travels the country. It's worth pointing out though that you can obtain support through other ways instead of waiting for a visit. All staff have email addresses and much of their work is done over the telephone so don't hesitate if you need to speak to someone. The HDA provides a telephone duty system Monday to Friday from 9.00 to 17.00 so if you can't reach your local RCA, ring Head Office and you will be put in touch with another experienced member of the RCA team.

Bill Crowder
Head of Care Services

"Once again I would like to thank all the families I meet and speak to in the course of my job. You all inspire me with your courage and strength and it is a privilege to work with you all."

Fundraising Events and Activities

JHD Family Weekend 2013



The JHD Family Weekend was held at the Calvert Trust in the Lake District in June. The weekend is for young people with Juvenile Huntington's Disease and their families, giving them an opportunity to meet other people in a similar situation and to try some exciting activities and let their hair down.

The weather was truly fantastic; blue skies and hot sunshine throughout the weekend, we really were lucky. As usual the Calvert Trust had organised a great programme of activities from cycling, canoeing, swimming and – a new one this year – a zip wire!

On Saturday night we had a Hollywood theme to the evening and everyone joined in with great enthusiasm. Batman and James Bond attended to name but a few and most people became unrecognisable in wigs and feather boas. A themed treasure hunt and picture quizzes added to the entertainment and it really is amazing how some balloons and red carpets can transform a venue.

This year we also filmed activities and parents spoke to the camera to make a DVD for training purposes. I would very much like to thank everyone who allowed us to film them.

Thank you to all who came; families, volunteers and speakers – you make the weekend such fun. I would also like to thank our sponsors Genetic Disorders UK and the Sylvia Adams Charitable Trust.

Fiona Sturrock

Regional Care Adviser for Kent and Sussex






Virgin London Marathon 2013

The Huntington's Disease Association would like to thank all of our runners who took part in the 2013 Virgin London Marathon. Thank you so much for all the hard work and dedication you have put into training and fundraising. We are so grateful to each and every one of you for your support.

If you wish to take part in the next Virgin London Marathon we ask that you please enter the public ballot before applying for one of our Gold Bond Places.



AWARENESS WEEK 2013

Our annual Awareness Week took place during 10th to 16th June 2013 and many events were organised by our Regional Care Advisers, Branches and Support Groups around England and Wales.

The focus this year was on the important work of our carers and ensuring that they are properly supported.

A selection of photos can be seen here from some of our carer events which took place in Devon, Cornwall, Wiltshire, Gloucestershire, London, North Wales, South Wales, Hertfordshire, Sandwell, Merseyside, and Staffordshire.

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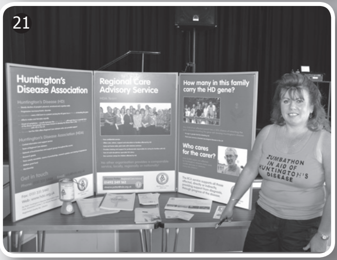

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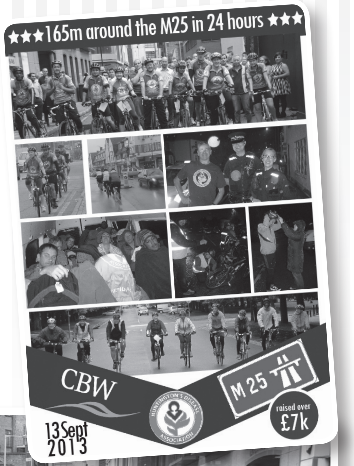
1/2/3/4: Carers Course, Wiltshire. 5: Devon and Cornwall.
6: Hertfordshire Locality Conversation Cafe.
7/8: Merseyside. 9: Sandwell.
10: South Wales. 11/12/13/14/15: Staffordshire.
16/17/18/19: Putney. 20: Glocestershire. 21/22: North Wales.

CBW V THE M25 CHARITY BIKE RIDE



It was billed as the "greatest fight in history" with 14 riders and 5 support crew from CBW endeavouring to cycle around the M25 within 24 hours.

It did actually turn into a battle – but it was more against the weather than the distance. The heavens opened up...and stayed open for the entire 165 miles!

However, the team is now delighted to report that after...

- **2 encounters with the local constabulary**
- **1 significant wrong turn**
- **85 cups of tea**
- **12 cans of red bull**
- **16 packets of biscuits**
- **0 casualties**
- **195 miles by the support vehicles**
- **169 miles by bike (yes, there was an unintentional "detour")**
- **60 al fresco pee stops**
- **15 bacon butties**
- **6 veggie sausage butties**
- **14 riders**
- **1 midnight guest rider**
- **5 support crew**
- **14 bikes and 2 support vehicles**
- **1 surprise box of Krispy Kreme doughnuts**
- **Too many hills to mention**
- **1 send-off lunch from CBW**
- **1 brilliant brunch to finish**

.......they arrived back safely in Greenwich Park with 1.5 hours to spare.

The team raised over £7,500 for the Huntington's Disease Association. More photos are on the CBW facebook page:
https://www.facebook.com/carterbackerwinter

The CBW Team

Charity fancy dress walk from Johnstown to Llangollen

We al**l met up at the New Inn at Johnstown at 10.30am. A few laughs were exchanged on what we were all wearing by many passers-by, so without any more embarrassment we dished out badges and buckets, and then set off 30 minutes later.**

As we walked through Johnstown with our heads held high, we reached Ruabon and stopped off at the Wynn Stay for a small drink. Following that we marched through the rest of Ruabon and onto Cefn Mawr, many people stopped in their cars and donated money to our fund.

When we reached Cefn Mawr we all decided to call in at the Jolly Masons to quench our thirst and cheer up the locals.

After that we called into the Queens Hotel in Cefn Mawr, where the landlord kindly put on a vast array of sandwiches and nibbles for everyone free of charge. When we were all full up we gathered everyone together and ploughed on to the Telford Inn, in Trevor. We were all still in great morale at this time, after another 30 minute break in all we finished our drinks and set off along the canal for 2.2 miles walk to The Sun in Trevor, the surprised look on many holiday makers in their narrow boats were a picture and couldn't believe where we had come from and going to in one day.

After that we continued back along the canal for another 2 miles until we reached Llangollen. When we reached Llangollen we all went different ways still dressed up in super hero, cowboy and Smurf outfits, so we could cover all of Llangollen and not miss anything out.

The whole day was a great success, everyone really enjoyed themselves, and we raised a grand total of £320 in the buckets.

I would like to say a big thank you to all the kind support and donations from all the pubs, shops and the general public.

All proceeds will go to Huntington Disease Association Wrexham Branch.

Sion Davis

BRANCH NEWS

We are incredibly grateful to all of our Branches and Support Groups for their tremendous support, both to the Association and to local people in their regions. We could not operate as efficiently without their commitment and hard work.

CUMBRIA BRANCH

At last a Cumbrian summer with a fair bit of sunshine. This has made our social activities that bit better.

We must congratulate Jill Thomson for yet another London Marathon under her belt.

In June, the Sunday before Awareness Week we held our annual cruise on the Steam Yacht Gondola. This gives our members an evening relaxing while Gondola silently glides around Coniston Water. We take the opportunity to invite some of our supporters to join us so we can let them know what the Branch tries to do for local people affected by HD and their families. We were pleased to welcome the president and members of the Keswick to Barrow Walk Committee who have been awarding the Branch grants for many years.

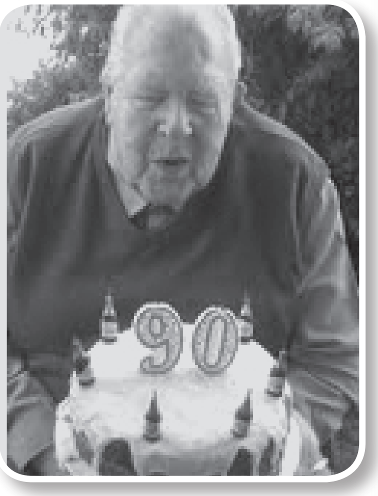
In September our stalwart members from the north of our area gathered at the immediate past Branch Secretary's house for a barbeque and chance to catch up on each other's news.

We have held two support meetings in Barrow for informal exchanges of their experiences; Theresa Westhead our RCA was able to attend one of these.

Two local Rotary Clubs welcomed our Chair to give them a talk on living with HD. Theresa Westhead was able to accompany him to one of the Clubs and as a result of an IT failure was dropped into the deep end and gave an off the cuff explanation of the disease.

Dennis Whittaker
Branch Chair

DORSET BRANCH



Our branch is happily thriving at the moment! We have several new members and meetings are a real buzz. We are not doing anything special just being there consistently when people want to dip in and out.

We have informal meetings in a church hall and then pub lunches and social events on the alternate months. We have had several donations recently from members fundraising and in memory of two members who sadly passed away. We have been able to help many local families with welfare grants. Gaynor and I and four friends are swimming in the sea on Christmas day (without wetsuits) to raise funds for our branch. http://uk.virginmoneygiving.com/HDADorsetbranch

Our Facebook page is proving to be a great way of keeping in touch and we would recommend other branches setting one up. **https://www.facebook.com/HuntingtonsDiseaseAssociationDorsetBranch**

My advice to any branches struggling is hang on in there and keep doing what you are doing. We had 2 years + of meetings where sometimes no one turned up but it's normal to have peaks and troughs and it does get better!

A big thank you to our RCA Ann Pathmanaban who works so hard to support our local families.

The highlight of our year was Hedley Thomas 90th birthday party. He founded the branch after losing his wife to HD and he was an inspiration to us all. Sadly, Hedley passed away on 19th November at home. He will be greatly missed and our thoughts are with his family.

Emma Devekey
Secretary

Local Branches of the Huntington's Disease Association

- Bristol
- Chelmsford & District
- Colchester & District
- Cornwall
- Cumbria
- Devon
- Dorset
- Easington & District
- Gloucestershire
- Hampshire
- Herts, Beds & Bucks
- Hull and East Riding
- London
- Merseyside
- Newcastle
- North Staffordshire
- North Wales
- North Yorkshire
- Norwich
- Nottinghamshire
- Oxfordshire
- Shropshire & Mid Wales
- Somerset
- Southend
- South Wales
- South Yorkshire
- Sussex
- West Midlands
- West Surrey
- West Yorkshire
- Wrexham & District

Support Groups

- Cambridgeshire
- Conwy & Denbighshire
- County Durham & Cleveland
- Coventry and Warwick
- Great Yarmouth
- Harrow
- Jersey
- Lancashire
- Manchester
- Milton Keynes
- Northamptonshire
- North Kent
- North Lincolnshire
- Nottingham Carers Group
- Orchard House Herne Bay
- Peterborough
- Plymouth
- Pontypool
- Preston
- South London
- St. Andrew's Healthcare
- Suffolk
- Wiltshire

Contact details available from
Head Office
Tel: 0151 331 5444

Lancashire Support Group

The HDA Lancashire Support Group was set up by Jantina after attending the HD Awareness Course in Liverpool for families and carers of people affected by HD.

The Lancashire Support Group had their first meeting in June 2013 and meet up once a month in Darwen on a Monday evening from 7pm to 9pm. The Support Group is for anyone affected by HD directly or indirectly.

The Group is well attended and new members are always made very welcome. Some people may think that a support group is not really for them and are often surprised that they themselves actually have a lot to offer by sharing their experiences with others in the group. The Group is hoping to organize social activities over the coming year in addition to the informal support group meetings. Please email or call to check dates and venue of our next meeting.

Jantina Etezadi

Chair

North Kent Support Group

We continue to meet on the second Thursday of each month at Sidcup Baptist Church Hall and have welcomed more new members this year.

So far we've had very interesting speakers on reflexology (with a demonstration) and speech and language therapy as well as an entertaining and fascinating review by two members of our group plus the twin of one of them, on their "Experiences at the Paralympics 2012".

Twenty of us enjoyed our spring cream tea at a local Garden Centre and we'll be at a new venue for our autumn cream tea. We had a stall in Awareness Week, at a Community Fun Day event, raising funds for the HDA and one of our energetic members raised an amazing £2,200 at a cream tea she organised in her lovely garden on the first day of real summer weather. (She truly deserved this perfect day as the fundraising Jubilee Tea she organized last year, took place on the day of the Jubilee River Pageant and I'm sure most people can recall how cold and wet that was!!).

We met at a local pub in July and 31 people attended our annual summer barbecue in August. At the end of September in beautiful autumn sunshine, 40 of us boarded the "Kentish Lady" for a 3 hour boat trip on the River Medway (plus onboard picnic) and this was much enjoyed by all.

We have been given an account of the World HD Congress which took place in September in Rio de Janeiro, a talk by a Welfare Benefits Advisor and held our annual Christmas get-together. We've also discussed possible subject matter for our meetings in 2014 with some excellent ideas being put forward.

Our occasional daytime coffee meets continue to be popular and enable those who can't attend the monthly meetings to get out and have a chat with their HD friends.

I've received many phone calls and emails over the last year and our mailing list gets ever longer which at least means more and more people are becoming aware of the existence of the HDA and their local Support Group.

Sandra Abbott
Chair

North Staffordshire Branch

The North Staffordshire Branch continues to be active in 3 main fields; providing mutual support to its members, fundraising and promoting awareness to the community and professionals.

We continue to meet monthly and are now firmly established in our new venue at Hanley Community Fire Station which has excellent facilities for all our members and visitors.

Fundraising is going well. We continue to hold our 6 monthly coffee mornings at Leek and the table top sales at Biddulph and in addition to raising funds these also raise the profile of the HDA and local Branch. We also attended the annual Midsummer Mayhem - an event at which a number of charities have stalls to raise funds and promote their work. Unfortunately, despite the promising title of the event we again had heavy showers in the afternoon but we did not let this dampen our spirits and there was a great sense of camaraderie. We are wondering next year whether to video some participants putting up their gazebo - we are sure we could submit it to You've Been Framed to try to win £250!

In addition Darren Wallace again ran in the Potter's Arf Marathon beating his last years time and funds raised, all his sponsorship will be matched pound for pound by his employers NPower. We are thrilled also to thank Gordon Brough who, although no stranger to the triathlon circuit, this year took part in the Hay Ironman Triathlon to raise funds for the first time for the HDA. Whilst he awaits final sponsorship totals his tremendous effort has raised over £1000. A big congratulations to both and thanks to all the sponsors.

In addition to raising awareness in communities the group is currently involved with the local Clinical Commissioning Group (CCG) in evaluating tenders for the proposed revised Community Neurology Service Tender. We are really pleased that the CCG seeks our views and allows us to keep Huntington's disease on the agenda.

It is with sadness that we report the loss of Brenda Sekorson in May last year. Her husband Barry fought hard to care for Brenda at home and has, on many occasions, brought the struggle to the attention of the local media and politicians. Our thoughts are with Barry at this time.

Glenys White
Secretary

The Huntington's Disease Association would like to thank...

We are extremely grateful for all the support we receive. In particular, the HDA would like to thank the following supporters for their donations during 2013/14, including those who have chosen to remain anonymous:

Local Authorities & CCG's: Salford LA, Cheshire East LA
Trusts and Foundations: Big Lottery Fund, Marjory Boddy Charitable Trust, Pennycress Trust

Local Authorities & CCG's: Sunderland LA
Trusts and Foundations: Sir James Reckitt Charity, Big Lottery Fund, Liz and Terry Bramall Charitable Trust, Joseph and Annie Cattle Trust, Sylvia and Colin Shepherd Charitable Trust, Sir James Knott Trust, Hadrian Trust, Catherine Cookson Trust, Chrysalis Trust

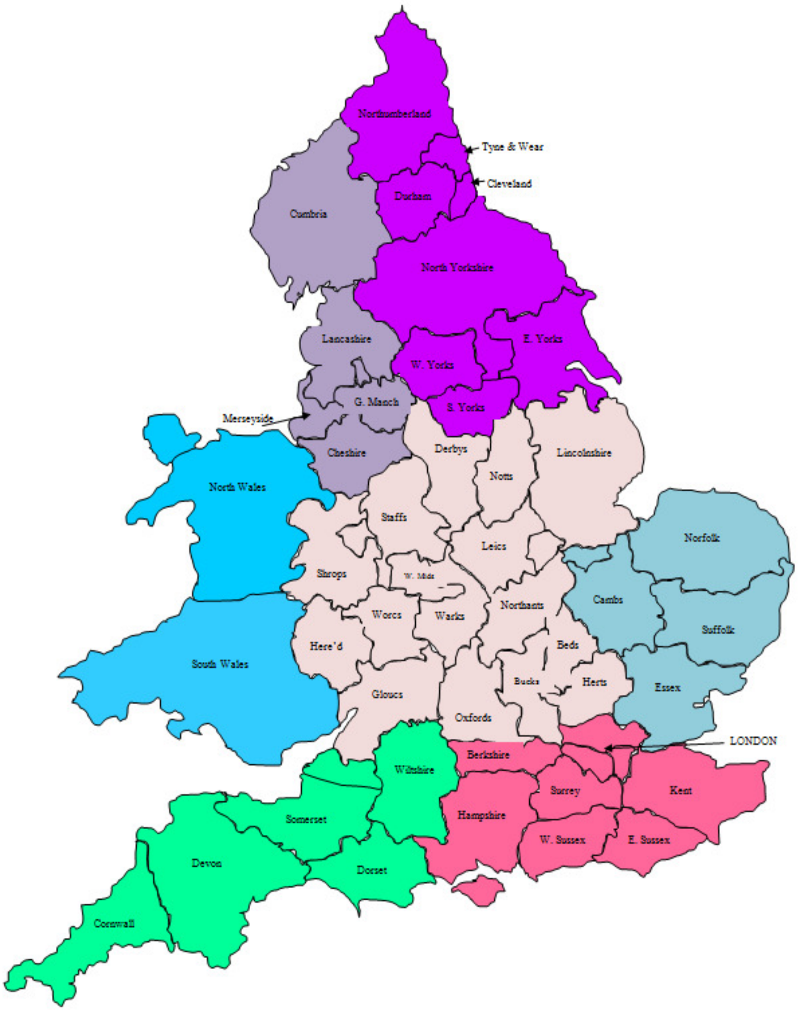
Trusts and Foundations: Big Lottery Fund - Wales, Sobell Foundation

Local Authorities & CCG's: Birmingham LA, Derby County CCG, Dudley LA, Lincolnshire LA, Telford & Wrekin LA, Staffordshire & Lancashire CCG, Southern Central CCG
Trusts and Foundations: The 29th May 1961 Charitable Trust, Zurich Community Trust, Douglas Arter Foundation, Birmingham and District Nursing Charitable Trust, Strangeward Trust, Sir John Eastwood Foundation, Jones 1986 Trust, Lady Hind Trust, Benham Charity Settlement

Local Authorities & CCG's: Essex LA, N.E Essex CCG, Cambridgeshire & Peterborough CCG
Trusts and Foundations: Charles S. French Charitable Trust, Childwick Trust

Local Authorities & CCG's: Dorset CCG, New Devon CCG
Trusts and Foundations: Alice Ellen Cooper Dean Foundation, Kirby Laing Foundation, John James Bristol Foundation, The Leach Trust

Local Authorities & CCG's: Hampshire LA
Trusts and Foundations: The Order of Women Freemasons, The Adint Trust, The Ernest Kleinwort Charitable Trust, The Pannett Charitable Trust, West End Office Agents Society, The Roger Raymond Charitable Trust, Sir Jules Thorne Charitable Trust, Gerald Micklem Charitable Trust, Ardwick Trust, Big Lottery Fund, Childwick Trust, The Dyers' Company Charitable Trust, Sandra Trust



Thank you to those who have supported us on a national scale:

Simon and Philip Cohen Charitable Trust, Chapman Charitable Trust, Bothwell Charitable Trust, Coutts Charitable Trust, Edmundson Shaw Cran Charitable Trust, Phoenix International Charity, The Albert Hunt Trust, The Hospital Saturday Fund, Tanner Trust, Fitton Trust, Gwyneth Forrester Trust

Thank you to the following organisations who have supported our wider work and events during 2013/14, including:

Juvenile Huntington's Disease Family Weekend
Sylvia Adams Charitable Trust, Genetic Disorders UK

Welfare Fund
The Hedley Foundation

Young People's Conference
The Schuh Trust

Summer Camps
BBC Children in Need

Company Sponsors
Allsorts Design & Print, Barchester Heath Care, Bartrams Associates Ltd, CareFlex, Exemplar, ILG Ltd, Kirton Healthcare, PJ Care Ltd, Royal Hospital for Neurodisability, St Andrews Healthcare, Stanley House Ltd

HUNTINGTON'S DISEASE ASSOCIATION
(A company limited by guarantee)

STATEMENT OF FINANCIAL ACTIVITIES
YEAR ENDED 31 MARCH 2014

Income and Expenditure

	Unrestricted funds	Restricted funds	Total funds 2014	Total funds 2013
	£	£	£	£
Incoming resources				
Incoming resources from generated funds:				
Voluntary income	349,921	26,195	376,116	794,317
Activities for generating funds	378,274	8,254	386,528	345,890
Investment income	13,047	-	13,047	7,588
Incoming resources from charitable activities	192,279	423,790	616,069	630,508
Other incoming resources	2,179	-	2,179	1,135
Total incoming resources	935,700	458,239	1,393,939	1,779,438
Resources expended				
Cost of generating funds:				
Fundraising costs	125,264	-	125,264	99,900
Charitable activities	781,571	474,317	1,255,888	1,232,581
Governance costs	9,148	-	9,148	9,122
Total resources expended	915,983	474,317	1,390,300	1,341,603
Net incoming resources before other recognised gains and losses	19,717	(16,078)	3,639	437,835
Realised gain/(loss) on investments	63	-	63	(132)
Unrealised gains on investments	15,004	-	15,004	11,223
Net movement in funds	34,784	(16,078)	18,706	448,926
Balance at 1 April 2013	955,536	40,770	996,306	547,380
Balance at 31 March 2014	990,320	24,692	1,015,012	996,306

The Statement of Financial Activities includes the income and expenditure account and all gains and losses recognised in the year.

All incoming resources and resources expended derive from continuing activities.

Company No. - 2021975

BALANCE SHEET
As at 31 MARCH 2014

	2014		2013	
	£	£	£	£
FIXED ASSETS				
Tangible assets	12,772		17,693	
Investments	566,304		157,208	
		579,076		174,901
CURRENT ASSETS				
Stocks	6,157		2,209	
Debtors	109,090		62,046	
Cash at bank and on short term deposits	426,542		942,489	
	541,789		1,006,744	
CREDITORS – Amounts falling due within one year	(105,853)		(185,339)	
Net current assets		435,936		821,405
Total assets less current liabilities		1,015,012		996,306
CREDITORS – Amounts falling due in greater than one year		-		-
Net assets		1,015,012		996,306
Reserves				
Restricted funds		24,692		40,770
Unrestricted funds				
General Funds		500,028		455,915
Branch Funds		90,292		99,621
Designated Funds		400,000		400,000
		1,015,012		996,306

The accounts have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

N.M. HEATH)
) TRUSTEES
MRS. H THOMAS)

Approved by the Trustees on 8 August 2014

BRANCH FUNDS

Reports received from branches are set out below and incorporated in the accounts.

		2014		2013
	£	£	£	£
Cash balances at 1 April 2013		99,621		95,362
Receipts in year		110,931		149,196
Expenditure				
Local welfare grants	29,803		32,383	
Sent to head office	42,073		53,127	
Branch activities, local newsletters, equipment, research, etc.	48,384		59,427	
		(120,260)		(144,937)
Cash balances at 31 March 2014		90,292		99,621

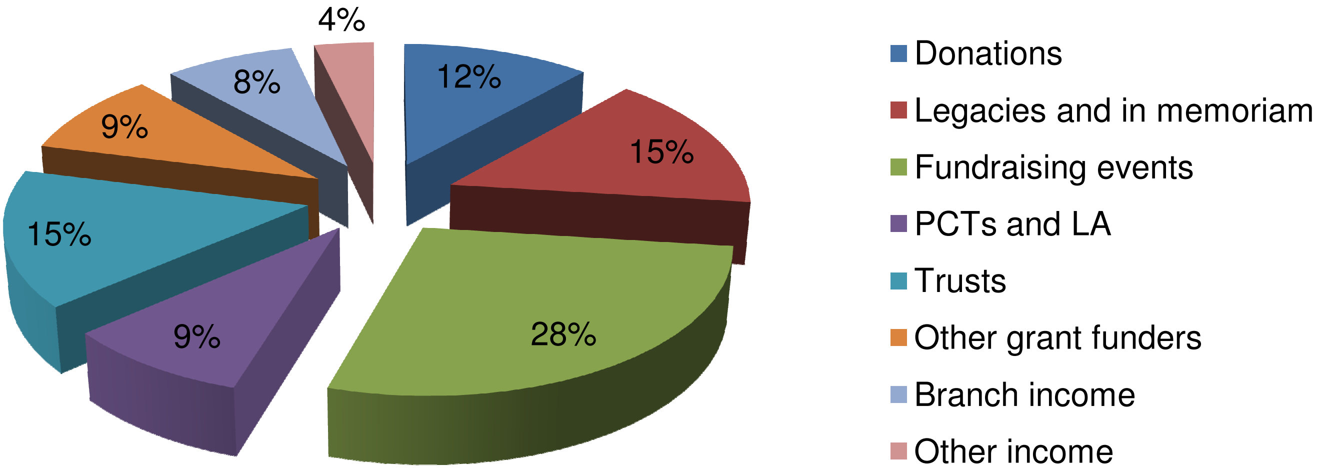
We have examined the Statement of Financial Activities, Balance Sheet and Accounting Policies for the year ended 31 March 2014. You are responsible for the preparation of the Summary Financial Statements. We have agreed to report to you our opinion on the Summarised Statements consistency with the Full Financial Statements on which we report to you on 8 August 2014. We carried out the procedures we consider necessary to ascertain whether the Summarised Financial Statements are consistent with the Full Financial Statements from which they are prepared. In our opinion, the summarised Financial Statements are consistent with the Full Financial Statements for the year ended 31 March 2014.

10 Station Court
Station Approach
Wickford
Essex SS11 7AT

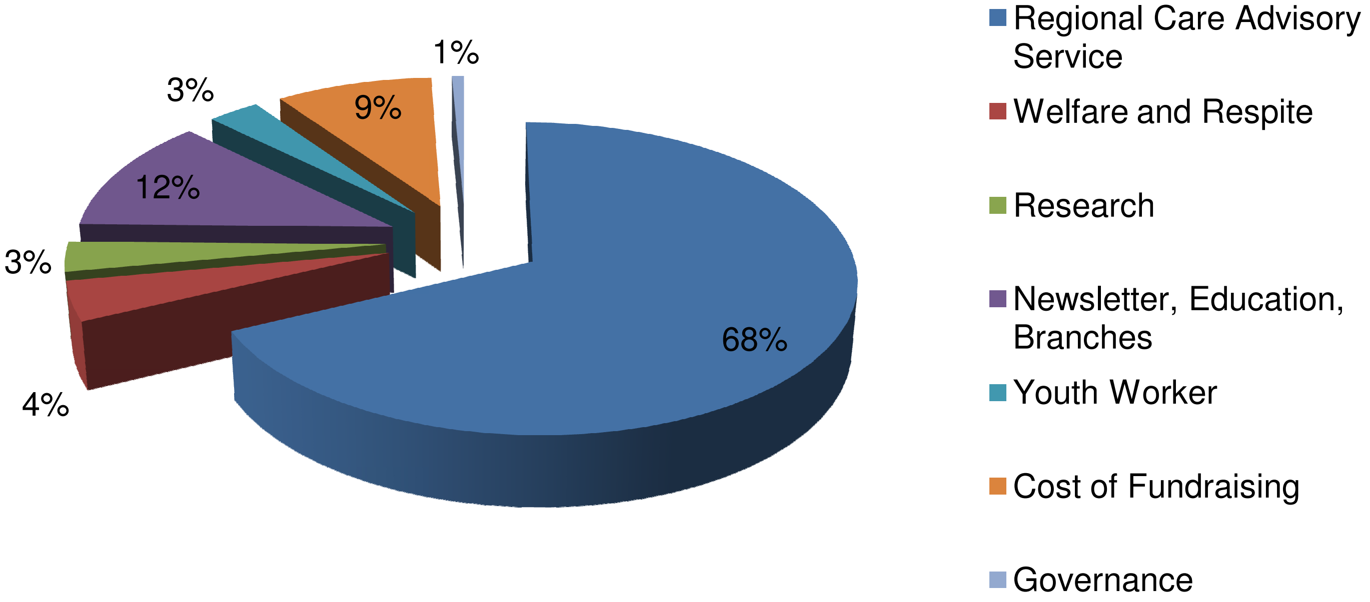
Steven Lescott
LESCOTT LIMITED
Registered Auditors
Chartered Certified Accountant

These summarised accounts, which have been extracted from the audited accounts approved by the trustees on 8 August 2014, may not contain certain information for a full understanding of the financial affairs of the Charity. For further information, the full annual accounts, the auditors' report on those accounts and the trustees annual report may be obtained from the Huntington's Disease Association, Suite 24, Liverpool Science Park, Innovation Centre 1, 131 Mount Pleasant, Liverpool L3 5TF.

WHERE OUR FUNDS CAME FROM



HOW THEY WERE SPENT



HUNTINGTON'S DISEASE ASSOCIATION

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