



HUNTINGTON'S DISEASE ASSOCIATION

ANNUAL REPORT

AND SUMMARY ACCOUNTS

MARCH 2015

CARE FOR FAMILIES NOW...



A CURE FOR FUTURE GENERATIONS.



**Winner of
2013 GSK
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:

PATRICIA 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 MRCP (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:

Duncan Sheard Glass

Castle Chambers

43 Castle Street

Liverpool L2 9TL

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.

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.

MISSION STATEMENT

- 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 families affected by Huntington's disease
- to create public awareness of Huntington's disease in order to eradicate ignorance
- to raise funds in order to accomplish these aims

Aims AND OBJECTIVES



ANNUAL REVIEW FROM THE CHAIR



Since being elected as the Chair of your Trustees back in June 2011, it has been a very interesting and rewarding journey.

I have attended many national and international events and the highlight must be when Robin and I attended The World Congress in Rio. What a marvelous opportunity to travel to Brazil with Cath Stanley and Bill Crowder, but also meeting families from South America whose stories will stay with me always.

The Huntington's Disease Association of England and Wales is not only highly respected in the UK but throughout the world. We should all be extremely proud of what our marvelous team have achieved, not only whilst I have been Chair, but for the last 40+ years.

Without our very persuasive Fundraisers, we would not be able to fund our wonderful team of Specialist HD Advisers. On a personal note, having a partner with HD, I know I would have been totally lost when Robin was diagnosed in 2007, without the support of our Specialist HD Adviser.

The money raised to run the HDA comes from many sources, including; the Big Lottery Fund, grants from trusts and foundations, local authorities and CCGs, plus our branch and support group donations. In this time of austerity it is not always easy to raise funds and we are incredibly grateful for all the support we receive.

Back in 2011 we had 31 members of staff. We have gone through a period of steady growth since then and we now have two additional Specialist HD Advisers, plus a Youth Worker as well as a Head Office team which is second to none. We now have 37 team members.

So, to the future. We need to develop new income streams in order to further develop the services that we offer, the demand on our services has seen a 51% increase in referrals to the SHDA service.

Finally, I would take this opportunity to thank Carol Carruthers, our ex-Chair, who supported me when I was first appointed; Cath Stanley and every one of the extraordinary individuals who care for our families across England and Wales; the Executive Officers: Nick Heath, Peter Morse and all Trustees; and not forgetting all those scientists working so very hard to find solutions to help life become a little easier.

And finally, finally, all of you; our members. You are why these wonderful people work so hard to support those of us who are living with HD.

Heather Thomas
Chair of the Huntington's Disease Association

"THE HUNTINGTON'S
DISEASE
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TREASURER'S REPORT



The results for the year show an overall deficit of £154,682. Income was stable with the anticipated decline in funding from Statutory Bodies being covered by a substantial increase in branch income. Volunteers have been active not only in their branches but also in campaigns through internet giving, which is budgeted to show continuing growth in future years.

The strategic plan as implemented in 2014/15 resulted in a substantial increase in salary costs which were covered by funds held in the Designated Fund as explained in Note 20. The Association has also improved the support network for our Specialist Huntington's Disease Advisers in order to maintain the quality of our services.

The Trustees are confident that the reserves available, although reduced below target as a result of the 2015 deficit, are sufficient to sustain current activities. However additional fund raising will be required if the Association is to continue with its support of major research projects.

Nick Heath
Treasurer

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ANNUAL REVIEW FROM THE Chief Executive



2014/15 has been a busy and exciting year. We have been able to develop the Specialist HD Advisory service (formally known as Regional Care Advisory Service) and appointed some new recruits. This was much needed as we have seen a steady increase in demand for this service. At the end of March we also said goodbye to Ayla Besser, who had been Head of Fundraising for some time. Ayla worked hard to develop a fundraising model for the HDA which enabled us to see a steady growth in income. Looking forward, we will need to explore and develop new income streams, to be able to continue to grow.

Our Patron, Tony Hadley, kindly donated a special CD which we were able to raffle and the lucky winner got to do a meet and greet with Tony and the band.

Supporting families to improve quality of life remains our core aim. Working directly with families at home, in nursing homes, working with other professionals to support families and individuals remains the core purpose of our work. During Awareness Week we had a big push to improve the knowledge and understanding of HD amongst mental health teams; the focus came as a direct result of feedback from families. The SHDAs delivered training up and down England and Wales to mental health teams and mental health in-patient units. We also produced a specific booklet that the HDA and families were able to distribute. In addition we were able to work with specialist providers to develop some specific standards of care for nursing homes, linked closely to Care Quality Commission (CQC) guidelines.

As part of our AGM/Family Conference weekend we were able to invite Jim Pollard, esteemed speaker, over to the UK from the USA. Jim spoke at the Family Conference, but also spoke at events organised up and down the country to enable a range of families and professionals in different areas to hear him speak. The end result will be better informed care.

In preparation for a meeting of the All Party Parliamentary Group (APPG) on HD, we undertook a mapping exercise to identify where specialist HD services exist, and the gaps in service provision. This led to a really interesting meeting of the APPG. Unfortunately due to lack of support this group has now folded.

Finally, I will leave you with some quotes from families; it is them that provide the inspiration for our work:

"She sat with me and offered advice on various issues, especially about meeting new friends and trying to get back into work. Gave good help to me about how best to try and move on with my life."

"He put us in touch with people who can help us. We felt we had support from him. It was good to talk about Dad because we have found that nobody has heard of this horrific disease"

"Very informative, very knowledgeable, very supportive, obviously has a people personality and cares for clients. Excellent for the job she does."

"The HD association has been friendly, supportive, sensitive and informative - all that other professionals should be but were not!"

"Some of the 'fear' element was removed, certainly diminished. The knowledge that we had someone concerned with my case was helpful."

"A lifeline"

"She is very good at her job and has such a calming manner and makes me feel that everything will be fine in the end."

**Cath Stanley
Chief Executive**

The Specialist HD Advisory Service



First of all I would like to welcome Lee Martin and John Gregor as the latest additions to our growing SHDA team. Both have written a paragraph about what they have been up to in the past few months and I am pleased to say that they have settled

in very well indeed. This year's Awareness Week actually became an extended version of the norm, stretching from May to July and most SHDAs gave training to mental health professionals during that time. All training is vitally important for improving quality of care and enhancing services for people with HD and their families, including carers. This is a huge focus on the support provided by the SHDAs.

I am pleased to welcome yet another member of staff to the fold. Sue Tompkins has commenced as SHDA for Northants, Oxfordshire and Warwickshire. She took up post in November.

As you will read, the network of branches and support groups is expanding and each has a role to play in the local HD community, often supported by the local Specialist HD Adviser. There have been many activities on offer across the country both on land, above ground and on water, so it's not all serious stuff. Nevertheless, it is important to raise awareness in whatever takes your fancy, whether that be a Gong Bath or a zip wire!

Bill Crowder - Head of Advisory Service



Youth Service Update

To say that the last six months have been busy would be an understatement. As well as continuing to contact and visit the 151 children and young people that I support, August saw a few new activities that I would like to tell you about and also take the opportunity to thank a few people along the way.



At the beginning of August we held our second young person's residential for 16-18 year olds. This year we had nine young people from

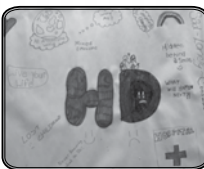
around the country meet up in Lichfield and spent the weekend literally hanging around (we did high ropes and climbing), set fire to things (we also did bush craft) and complain (the weekend included a workshop on stress). Feedback from the young people was great and we have already booked the venue for next year (1st to 2nd August just in case you're interested).

From Lichfield it was then on to Southend where the branch had very kindly agreed to let me pilot an arts workshop in one of their rooms while the branch meeting was going on



in the main room next door. The idea was to invite any young people connected to the branch to come along and express their thoughts about HD on a big piece of flip chart, they could either draw or write on it with no boundaries. It just had to be true for them. We had two young women come along and as we talked through the piece they had produced I personally found it very thought provoking.

After Southend I travelled down to Plymouth, this was the first time I had visited the area and I have to say it is a lovely part of the country. We had organised an activity day for young people from the Devon and Cornwall branches that consisted of a first aid session and an afternoon of sailing on the River Tamar. Five young people along with their families came along and spent the day taking part and for some of them



facing their fears, after all being on the open water can be just as scary as being high up for some people. Again the feedback we received was really good and an excellent day was had by all of the young people.

While we only had what could be counted as small numbers for each of these activities I think it is important to have them. One of the biggest concerns for young people living in families affected by HD is the feeling of isolation. It doesn't matter if they live in the centre of London surrounded by thousands of people or the middle of a forest surrounded by nothing but trees. If they don't know or have never met another person who shares something as monumental as coming from a HD family the sense of isolation can be daunting. By giving these young people the opportunity to meet others their own age who they have this in common with it can only be of benefit.

Finally I would like to take this opportunity to say a big THANK YOU to; Ruth Abuzaid and Theresa Westhead for supporting the 16 to 18 residential; Alison Heavey, David McDonagh and the Southend Branch for their help and support with the Arts Workshop; Charles Whaley, John Crosswaite, the Tamar River Sailing Club and the Devon and Cornwall Branches for their support and generosity on the Activity Sailing Day.

If you would like further information about my role or the support that I am able to provide please feel free to contact me, I can be contacted on 0151 705 3460 or adam.cho@hda.org.uk.

Adam Cho – Specialist Youth Worker



"ONE of the
biggest CONCERNS
for young people
living in families
affected by HD
is the feeling of
isolation.....
.....By giving
THESE YOUNG
people the
opportunity
TO MEET OTHERS
THEIR OWN AGE
who they HAVE
THIS IN COMMON
with it CAN ONLY
be of benefit."



The Specialist HD Advisory Service

"All TRAINING
is vitally
important
for
improving
quality of
care and
enhancing
services
for people
with HD
and their
families,
including
carers."



I have continued to be busy supporting families and the branches across Essex. New referrals come my way every month and I am pleased to report that awareness of HD is better than ever in Essex. I was able to give training to many Community Mental Health Teams across Essex

as part of our Awareness Week campaign and this has led to better team working. I have also been working closely with Community Matrons and the hospice services in Essex, giving training and raising awareness of the needs of those with HD and their families. I have been able to work with and give specialist knowledge to those assessing for Continuing Healthcare funding.

I visit care homes that care for those with HD and always offer training to staff, which is most usually keenly accepted. I really enjoy these training sessions and know that it leads to better understanding of HD and therefore better care for your family members. The West Essex Family Carer Course was successful with 8 carers having a day of learning, sharing problems and making friends. Following on from this day, I am trying to start a regular meeting for family carers in Harlow every month. So far we have had one daytime meeting and one evening meeting, both of which were poorly attended, but I hope it will improve with the lighter evenings and better weather to come. We meet at the Park Inn hotel in Southern Way, Harlow. For details of the dates and times of meetings, please contact me. It would be great to see you!

I also continue to organise the Young Adult Weekend for those at risk/tested positive/partners aged 18 to 35.

Please contact me if you have any ideas for raising awareness of HD in Essex or areas that require support and training;

alison.heavey@hda.org.uk, 01255 823088.

Alison Heavey – SHDA for Essex, Southend, Thurrock, Barking and Dagenham, Havering and Redbridge



This has been another action packed six months for Dorset and Wiltshire, with a well attended Family Information Day held in June, which was well evaluated.

Among other activities, I have undertaken training in nursing and care homes, for agencies providing care at home; worked with employers to enable

symptomatic individuals to continue to work for longer with an agreed plan of action of support within the workplace; worked with multi-disciplinary professionals to ensure appropriate packages of care are in place for those who need them, with regular reviews. I have visited people at a place to suit them and supported many others by telephone and/or email.

The Swindon HD Forum continues to facilitate professionals working with those with HD to access other members of the team to ensure best practice in meeting the needs of those with HD. The Dorset Advisory Group meeting has changed its format slightly and now focusses on Multidisciplinary Case Reviews to work towards improved outcomes. We had the kind offer of Gong Baths for those on low income in Dorset. As I had never heard of them,

I went along to try one for myself one evening! Although I have no scientific proof that this is beneficial, the anecdotal evidence is very positive. I certainly found it very pleasant and could see how it could benefit others, especially stressed carers. I found a brief description of this as follows: "The gong bath is a one hour immersion in sacred and healing sound wherein the gong master activates the full sonic potential of the gong and bathes the listener with sustained waves of primordial sound." Several people tell me they have taken up the offer and benefitted. I think this sums up just how very varied and interesting the role of an SHDA is and how important it is to have an open mind. You never know what will happen next and that is never boring!

Ann Pathmanaban – SHDA – Dorset & Wiltshire



The last six months have had a strong commitment to training and increasing awareness. In July, I organised a conference at Wrexham Medical Institute, which was predominantly about Mental Health and HD. This was well attended, with over 75 delegates. No sooner had

one conference finished, than the preparation for the next one began. This time a joint venture with colleagues, which has already reached its maximum capacity and has attracted a good balance of families and professionals.

The Wrexham Branch is now well established and although has only a small group of members, it has been very effective in supporting many HD families. A recent joint venture with Mountain Lane CP Golf Committee raised an astonishing £6500, not to mention awareness!

The North-Wales HD Clinic continues to flourish. Dr Raj Sambhi and Dr Alberto Salmoiraghi are committed to working with the HDA and seeing the clinic develop further. It is on target for becoming registered as an Enroll HD site. Exciting times ahead, which should lead to better services for North Wales patients and their families.

Diane Lyes – SHDA - Flintshire, Wrexham, Powys and Shropshire



My first five months in my post have been an enlightening experience. Every day with the HDA, you learn something you did not know before and this makes for an interesting and challenging environment.

I have met and continue to meet some amazing people, those who have HD, those living with relatives or spouses

with HD and those who provide care and services. Attending the AGM also offered me the opportunity to meet people from a variety of different areas, and listen to some incredibly inspirational speakers with their own unique involvement with Huntington's disease. I can now say my new professional crush for motivational speaking is Dr Ed Wild; an incredibly effervescent speaker who is so intelligent and articulate, he even made having a lumbar puncture sound attractive!

I am lucky to have had some great teachers and a fantastic mentor who have shown patience and

The Specialist HD Advisory Service



kindness to a new starter. My background in care management has been a great apprenticeship, for what is now, the best job in the world.

Lee Martin – SHDA – North East Yorkshire



I have been in post as the Regional Care Adviser for the North East since Dee Boyd retired in May. I have heard some wonderful things about how much Dee's support has meant to people over the years, and have come to realise that I have some very big shoes to fill!

It has been an intense few months trying to deepen my understanding of Huntington's disease and the complex issues that surround it. I was fortunate to be able to attend the HD Course in Liverpool in May. I have also had the opportunity to meet some wonderful and inspiring people as I have travelled around the North East introducing myself to the families affected by HD and the professionals supporting them. I have tried to get out to meet as many people as possible and will continue to do so over the coming months. If you would like me to visit please get in touch.

I would like to say thank you to the Branches and the Support Group in the North East who have given me very warm welcomes, which have been invaluable in helping me settle into my new role.

John Gregor – SHDA – North East



Having been in post since November 2014, I am learning more every day from the inspirational people who live with HD, their families and those who support them.

Taking over areas from three very experienced advisers has had many benefits in that I have had lots of help and advice in my new role from them. I know from conversations with

families what a difference they have made to many lives - the challenge is to continue their good work! Having attended the HD professionals course in Liverpool back in November, I have spent my time since meeting as many of the families in all three regions as possible, or at least make contact where this was not possible. I have visited care homes and agencies, provided training for staff, attended clinics and professional meetings, establishing positive relationships in order to provide the best support possible for those in our area. I have also established a DWP partnership in order to effectively work my way through the benefit maze.

I have been made very welcome at support group and branch meetings in Northampton and Oxfordshire. The January trip to the panto in Oxford was a great success; it was wonderful to see people of such a variety of ages having fun together - oh yes it was!!

Sue Tompkins – SHDA - Warwickshire, Oxfordshire and Northamptonshire



I was lucky enough to attend the AGM and Family Conference in Telford last October and also assist with a small 'relaxation' and complimentary therapy workshop with Alison Heavey. As many commented, it really was a special AGM, further enhanced by Jimmy Pollards attendance and amazing input.

Thanks to funding from the

West Midlands Branch, I was able to run a Men's Family Carers Day in November. I was struck by the honesty and support that everyone who attended showed towards each other. As I purposely kept the group small, there were a number of gentlemen who couldn't attend. Therefore my plan is to run a similar group for carers later in the year.

With regards to HD services in the West Midlands, you will be pleased to hear that Maricia Robinson has joined Sandwell and West Birmingham district as a clinical nurse specialist in neurology, focusing on rare conditions like HD. In the short time that she has been in post she has really enhanced service provision, joining me on home visits and providing excellent support, advice and medical assessment for families. Dr Rickards has also been looking for a specialist neuro nurse to join the Barberry team. Currently this role is in the process of development and I hope that with joint working this will, in time, enhance service provision in the West Midlands.

Coventry's Support Group and the West Midlands Branch continue to thrive and grow. I hear that Coventry's Christmas meal and Birmingham's panto trip were enjoyed by many and there are plans in the pipeline for other entertaining outings.

Additional events for the next quarter's agenda is of course the wonderful 'Decisions, Dilemmas and Discussions' weekend, followed by a talk on Occupational Therapy, the HDA professional course and then it will be time for the JHD weekend - crossing fingers and toes for good weather there!

Poppy Hill – SHDA – Birmingham & West Midlands

In summary...

The emphasis this year has been training professionals to understand HD and mental health, but we have run many successful conferences and training days with hugely inspirational speakers. Jimmy Pollard has been a great hit at conferences in the north, south and at the AGM/Family Conference in Telford. I had the job of chairing this conference as Cath was nursing broken bones at the time. I was rewarded with a pie in the face for my efforts, as a line of us did a version of the Mexican wave. It's put me off squirty cream for life.

Adam continues to work with young people individually and in small groups which work well. He is always looking for new ideas so bring them on and contact our Youth Worker.

Don't forget to make contact with your local SHDA if you need advice, support or help in any way. We have experienced staff in all parts of England and Wales who are happy to assist wherever they can.

Bill Crowder
Head of Care Services

“My
background
in care
management has
been a great
apprenticeship,
for what is
now, the best
job in the
world.”



FUNDRAISING EVENTS AND ACTIVITIES

GRAFHAM WATER CENTRE CAMP 2014

This year's camp was held from 8th-10th August, we had 14 children between the ages of 9-15 plus 5 adult leaders.

As everyone arrived and met up with old friends or began to make new ones, there was craft work in progress in the form of decorating ceramic mugs using acrylic paints—there was some attractive and interesting work produced. After the evening meal we enjoyed archery, always a popular activity, and on to the 'Grafham challenge' where we were blindfolded and encouraged not to peep as we walked, climbed and crawled around a very muddy course. (Not all adults felt it necessary to participate in all parts of this challenge!!).

Saturday brought fine weather and after breakfast we donned wet suits and buoyancy aids and went sailing and kayaking. As if these activities weren't wet enough, in the evening we put on warmer clothing and taking gear to make hot chocolate and lots of marshmallows, some children bringing some with them in case I forgot - as if!! We clambered into canoes and rowed round part of the lake looking at wildlife as we went. Having reached the appointed beach we went ashore, learned how to make fires - a very popular activity, while a couple of the leaders supervised the fires and heated hot water in cans suspended over it, the children divided into 2 teams and constructed camp shelters using materials they found nearby. As we finished the hot chocolate and toasted marshmallows in the distance there was the rumble of a storm. Packing up was done very quickly and we climbed back into the canoes to get back before the storm hit us.

Heavy rain greeted us the following morning and despite the rain, children and some leaders enjoyed the high ropes. In the afternoon a decision was made by centre staff that mountain biking was too dangerous and so as an alternative fun was had on the climbing wall.

From the feedback forms it was apparent that the children had a good time and all want to come again next year. At this point I must thank the team who helped make the camp a success; that is Kevin, Jill, Catherine, Becki and Tim and also the staff in Head Office who deal with all the administration that is involved with running all the camps - a big thank you.

Sue Hill

SHDA – East Anglia and Lincolnshire

GREAT NORTH RUN 2014

The Huntington's Disease Association would like to thank everyone who took part in the 2014 Great North Run on our behalf.



Anna Talbot and Zoe Campbell



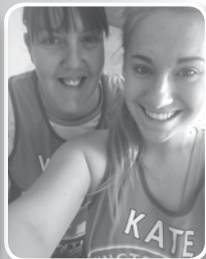
Ellis, Eb, Stewart Kerton

We had 5 Gold Bond places and 14 ballot places in this year's Great North Run. The total raised was £7532.33

Congratulations one and all!



Manpreet Varraich



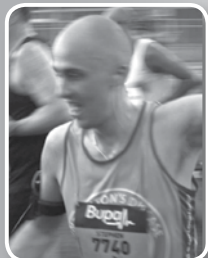
Kate and Wendy Brown



Kelly Tomlinson



Kate and Wendy Brown



Stephen Cooper



Stephen Cooper



Vicki Finnegan and Daniel Watson



Dale Joint

Below is a list of our runners and their finishing times.

Ellis Kerton	2:11:30
Edwin Kerton	2:37:57
Stewart Kerton	2:11:29
Vicki Finnegan	2:50:13
Kelly Tomlinson	2:16:03
Dale Joint	2:43:24
Daniel Watson	2:50:14
Nick Parry	2:24:47
Barry Crowe	2:31:38
Stephen Cooper	1:50:26
Anna Talbot	3:04:00
Wendy Brown	3:23:43
Kate Brown	3:11:53
Manpreet Varraich	3:12:54
Paul Reed	2:30:34
Zoe Campbell	2:45:06

Saturday night saw the room dressed up to reflect WW1, as well as the bunting, pictures, ration boxes, planes, hats etc all served to set the scene. From the first to the last record the dance floor was full, a special evening had by all.

Sunday morning saw the opportunity to see the DVD again, or attend workshops on EHDN update, complementary therapies and relaxation, and a small group session with Jimmy.

I would like to thank the HDA staff team for their hard work over the weekend, and to our Head Office staff for all the preparation of materials. A big thanks to Karen, Mark and Chris for looking after the children, and a huge thank you to the hotel staff for their exceptional service. A personal thank you to Bill and Ruth for stepping in to carry out the majority of my role, but most of all thank you to the families and people who attended and made the weekend special and memorable.

Cath Stanley
Chief Executive





FAMILY DAY AT BROCKENHURST

The Family Day at Brockenhurst started with rain and thunder, with everyone struggling through the elements to get there.

Carol Thorpe-Tracey was there to welcome everyone, give them their conference packs and sell raffle tickets. By lunch time the sun was out making the journey home later on a different story altogether!

Excellent presentations, proficiently choreographed by Alan Shelley, were given by Rosy Williams, Specialist Genetic Nurse, Elspeth Watson of the DWP Partnership Team, Nikki Haswell of Diverse Abilities Plus and Russell Bloor, Manager of Kennet Unit, Glenside, Salisbury.

Gino Cirelli presented two sessions of relaxation running concurrently, with one gentleman saying he should have waited until the last workshop as he now had to try to stay awake for the next! Another dreamy comment was "That was awesome". Eve Payler's sharing tips workshop was so successful it was difficult to pry everyone away at the end!

A delicious welcome of tea/coffee/cold drinks with various croissants started the day. A buffet lunch was provided by Hussen and his team which kept everyone topped up until tea time. That was the time that the cake makers of our families showed the results of their expertise and came into their own! Yum!! Thank you to Carol and Eve for making sure everyone had plenty of everything. The raffle, gratitude expressed to all involved, a brief chat about Branches and Support groups ended the day and everyone left to make their way home.

All in all a productive but relaxed day. Thank you to everyone for making it a great team effort!

Ann Pathmanaban

SHDA – Dorset & Wiltshire



TRISHA HODDINOT'S FAMILY FUN NIGHT



After several years of appointments with the GP and persistence to find out what was wrong with my mum, at the age of 77 she was diagnosed with HD. Being the first recognised case within the family, it came as a shock for the whole family.

Just one year after diagnosis and now understanding more about the condition, my nieces and I decided to organise a family fun night to raise money for the HDA.

With just 5 weeks planning, on 14th November we held our charity night with raffles, auction, disco and lots more fun and games. We had a visit from Mickey and Minnie Mouse to present the children with raffle prizes and also provided a buffet.

We have raised a huge £1,360. We are now hoping to do another event in the summer and create a summer fayre, hopefully raising even more!!

Trisha Hoddinot



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.

Hampshire Branch

The Hampshire Branch have been busy since our last report.

In addition to the bimonthly Branch meeting and the monthly carers meetings we have had several social events. We had two barbeques over the summer; one on the Isle of Wight and one on the mainland.

We had two boat trips, one was a thrilling trip with 'Wetwheels' who specialised in taking disabled people out on the water in a small catamaran with the passengers being encouraged to take the tiller; the other was a more sedate cream tea cruise to the island and back. We also enjoyed a buffet and skittles afternoon.

We are looking forward to more events and activities over the coming months.

Anne Stephenson
Branch Secretary



Local Branches of the Huntington's Disease Association

- Bristol
- 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
- Southend
- South Wales
- South Yorkshire
- Sussex
- West Midlands
- West Yorkshire
- Wrexham & District

NORTH KENT Support Group



Our monthly meetings continue to be held at Sidcup Baptist Church Hall and this year we've had a varied programme with speakers on Stress Management, Tai Chi, Qigong and Meditation and the Charity 'Education for the Children' (in Guatemala).

A member, Sue and her twin sister entertained us with a presentation about tracing their ancestors. No skeletons in their cupboard but on delving into my family history, Sue came upon a distant relative who was a horse thief!!!!!! Our final speaker this year was a freelance photographer who talked to us about his Remembrance Image Project in connection with the centenary commemorations for the First World War.

We've started to hold Carers' Meetings and will soon have our 4th. This has been well received and the numbers increase each time.

Last year's popular 3 hour boat trip on the River Medway was repeated on a perfect summer's day with 34 of us on board the Kentish Lady. Another boat trip at the end of September was enjoyed by 12 members. A smaller boat this time available specifically for people with disabilities and run by The Kingfisher Trust.

We've been chosen as the Charity of the Year by the Bexley Homebrew Club and I attended their main event in October. The last event of the year was our annual Christmas Buffet.

Cream teas (twice a year) and coffee meets in between meetings are still popular and 35 people attended our annual Summer Barbecue in August.

We've fundraised at two local Tabletop Sales and our Star Fundraiser, Maura, deserves a mention. When she opened her

lovely garden in mid July, served coffee, tea and luscious cakes, then provided a wonderful barbecue the next day, she raised the amazing sum of £3,500 for the HDA. Such a lot of hard work went into that weekend and after some wet, miserable days preceding the event, the sun shone for Maura and brought the crowds out.

Sandra Abbott
Support Group Leader



Support Groups

- Berkshire
- Cambridge
- Carmarthenshire
- Conwy & Denbighshire
- County Durham & Cleveland
- Coventry and Warwick
- Great Yarmouth
- Harrow
- Herefordshire
- Jersey
- Lancashire
- Lowestoft
- 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



SOUTHEND BRANCH

Hello to all our lovely extended HD family.

Well... what a great year we have had again at our Southend Branch (which covers Southend and South East Essex). Our meetings are weekly every Thursday from 10.30am until 1pm without fail. Also, of course, Wednesday every week at our fantastic allotment.

We have had lots more of our group who had a lumbar puncture for research. Some of them for the second time; very brave they are too. Dr Salman Haider came to the group in May and members who wanted to take part gave blood for research. Adam Cho came to see us in August and organised a separate support group for young members at risk.

Alison Heavey, our RCA, continues to visit us once a month for the carers meeting. The meetings are valuable to all our members who come from all over South Essex. Alison, please keep them up; where would we be without you?

The group has had some great days out. We went to the cockle sheds at Old Leigh on a lovely summer's day, for a pint or cup of tea and cockles, prawns and whelks; smashing. We also went to the Cliffs Pavilion to see La Cage aux Folles, and the Alan Titchmarsh show again organised by Pete, we always have a good time there. There was a very lively charity night out at a Mexican restaurant set up by Carol which raised a lot of money.

Our variety music night in December was a stupendous hit with some enthralling and talented turns. Paul's son Oliver took part in a boxing match; what an unusual way to raise lots of money for us, and huge awareness. A pamper and physic evening was also a great success. Our pantomime of Snow White and the Seven Dwarfs was hysterical, with mostly members with HD taking part. They were absolutely fantastic, I am so proud of each and every one of them. Roll on this year's epic production. Our Christmas meal was just as lovely as the year before.

Steve Saunders' brainwave of HD fridge magnets was also a hit, as were the two days spent in the foyer of Morrison's, raising great awareness for us. Also the huge advert that Steve's son put in the Financial Times for us in several editions, well done.

We were happy to welcome some new members to our group this year.

Our magnificent allotment

We didn't start off the year very well with our greenhouse being completely shattered in the terrible winds. But on a good note the men built a new wheelchair friendly one that is so strong that it could take a nuclear explosion. We accepted a donation from Leigh Horticultural Society who made us their charity of the year. We had a Christmas party for all allotmenters in December. We also had another Easter family and barbecue day. Our annual scarecrow making day went well with paella and barbecue in August. We had another very welcome visit from three members of the London Branch in August. Last November our firework and bonfire night was a great success with 100 + turning up for a brilliant night out. We hope to see as many people this November.

I am sorry to say that our phenomenally unique chairman David McDonagh has had to stand down as Chairman of our Branch. He has not been in good health for a long time and has kept battling on regardless. We have not lost him completely as he will still be on our Committee as a valued member of our group. You can't keep a good man down. Our group is so strong and successful all due to this lovely man who has put his heart and soul into it. Thank you David.

Pat Nelson

Branch Secretary and Allotment Manager

CAMBRIDGE SUPPORT GROUP

The Cambridge Support Group is a small, friendly group who meet in the afternoon on the third Tuesday of the month.

Our informal meetings are usually held at Buchan Street Neighbourhood Centre in Cambridge and involve tea, coffee, cake and chat.

Over the last year our meetings have included playing variations of the game Mancala, visiting the University Botanical Gardens and welcoming a student genetic counsellor who kept us updated on recent research.

We have also continued to enjoy afternoon tea and cakes at local garden centres and National Trust properties.

Last October two members attended the AGM and Family Conference in Telford for the first time where we made many friends within the HD community.

In December we had our first festive lunch out. We were lucky to have the use of a private dining room in a local village pub. The food was delicious and thoroughly enjoyed by all. It was a great end to 2014.

We are planning a few social events in the forthcoming months as well as our regular meetings.

If you would like to meet others affected by Huntington's disease and share your experiences please do get in touch, we would love to meet you!

Nikki Pilsworth

Support Group Leader

hdacambridge@aol.co.uk

www.facebook.com/HDACambridge

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 2014/15, including those who have chosen to remain anonymous:

	Sunderland LA, Garfield Weston Foundation, Sir James Knott Charity
	Blackburn & Darwen CCG, The Lynn Foundation
	Sir James Reckitt, The February Foundation, Sovereign Healthcare Charitable Trust, Garfield Weston Foundation, D'Oyly Carte Charitable Trust, The Mollie Croysdale Charitable Trust, George A Moore Foundation, Sylvia & Colin Shepherd Charitable Trust
	Big Lottery Fund
	Salford CCG, Green and Lilian F M Ainsworth and Family Benevolent Fund, The Freemasons' Grand Charity, The Ursula Keyes Trust, Miss J K Stirrup Charitable Trust (North West)
	Big Lottery Fund
	Big Lottery Fund Wales
	Telford & Wrekin Council, Telford & Wrekin CCG
	Derby CCG, Simplyhealth, Edith Murphy Foundation, Staffordshire and Lancashire CCG, Trustees of the Thomas Farr Charity, The Frederick & Phyllis Cann Reg. Charity
	Cambridge CCG, The Jarrod Trust
	Kirby Laing Foundation
	Birmingham LA, Dudley LA, Birmingham and District Nursing Charitable Trust, The Eveson Charitable Trust
	William and Christine Eyenon Charity, Hoover Foundation
	Bartlett Taylor Charitable Trust, PF Charitable Trust, Barnwood Trust, John James Bristol Foundation, Zurich Community Trust
	No funding received
	NHS Northern, Eastern and Devon CCG, The Norman Family Trust
	Dorset CCG, AE Cooper Dean Charitable Trust, The Valentine Charitable Trust
	Southern Central CCG, Hampshire LA, The Dyers' Company Charitable Trust,
	Bedfordshire Community Chest, Buckinghamshire Community Foundation, The Steel Charitable Trust, The Roger Vere Foundation, The Wixamtree Trust
	N.E. Essex CCG, Essex Community Fund, Walter Farthing Trust
	The Roger Raymond Trust
	Big Lottery Fund
	The Tory Family Foundation, Ian Askew Charitable Trust, Raymond and Blanche Lawson CT, Sandra Charitable Trust, Pannett Charitable Trust, Swale Charitable Trust



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

Bothwell Charitable Trust, Simon and Philip Cohen Charitable Trust, Chapman Charitable Trust, The Michael and Anna Wix CT, The Albert Hunt Trust, The Orr Mackintosh Foundation, Donald Forrester Trust, The Bernard Lewis CT, Cecile Baines Charitable Trust, Johnson Wax Ltd.

Thank you to the following organisations who have supported our wider work and events during 2014/15, including:

Juvenile Huntington's Disease Family Weekend

Sylvia Adams Charitable Trust

Welfare Fund

Francis Winham Foundation

Company Sponsors

Bartrams Associates, Exemplar Health Care, Kirton Healthcare Ltd., PJ Care, St. Andrew's Healthcare, Stanley House Ltd, St. John's Waterbeach Wives, Moor Park Golf Club, Square One Resources, IAC Group.

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

STATEMENT OF FINANCIAL ACTIVITIES
YEAR ENDED 31 MARCH 2015

Income and Expenditure

	Unrestricted funds	Restricted funds	Total funds 2015	Total funds 2014
	£	£	£	£
Incoming resources				
Incoming resources from generated funds:				
Voluntary income	294,636	2,357	296,993	376,116
Activities for generating funds	378,222	13,351	391,573	386,528
Investment income	16,987	-	16,987	13,047
Incoming resources from charitable activities	252,770	430,145	682,915	616,069
Other incoming resources	1,665	-	1,665	2,179
Total incoming resources	<u>944,280</u>	<u>445,853</u>	<u>1,390,133</u>	<u>1,393,939</u>
Resources expended				
Cost of generating funds:				
Fundraising costs	150,152	-	150,152	125,264
Charitable activities	960,795	452,622	1,413,417	1,255,888
Governance costs	10,320	-	10,320	9,148
Total resources expended	<u>1,121,267</u>	<u>452,622</u>	<u>1,573,889</u>	<u>1,390,300</u>
Net (outgoing)/incoming resources before other recognised gains and losses	(176,987)	(6,769)	(183,756)	3,639
Realised gains on investments	3,481	-	3,481	63
Unrealised gains on investments	37,593	-	37,593	15,004
Net movement in funds	(135,913)	(6,769)	(142,682)	18,706
Balance at 1 April 2014	<u>990,320</u>	<u>24,692</u>	<u>1,015,012</u>	<u>996,306</u>
Balance at 31 March 2015	<u><u>854,407</u></u>	<u><u>17,923</u></u>	<u><u>872,330</u></u>	<u><u>1,015,012</u></u>

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.

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

Company No. - 2021975

BALANCE SHEET
As at 31 MARCH 2015

	2015		2014	
	£	£	£	£
FIXED ASSETS				
Tangible assets	8,682		12,772	
Investments	<u>543,011</u>		<u>566,304</u>	
		551,693		579,076
CURRENT ASSETS				
Stocks	8,957		6,157	
Debtors	73,161		109,090	
Cash at bank and on short term deposits	<u>344,747</u>		<u>426,542</u>	
	426,865		541,789	
CREDITORS – Amounts falling due within one year	<u>(106,228)</u>		<u>(105,853)</u>	
Net current assets		<u>320,637</u>		<u>435,936</u>
		-		
Total assets less current liabilities		872,330		1,015,012
CREDITORS – Amounts falling due in greater than one year		-		-
Net assets		<u>872,330</u>		<u>1,015,012</u>
Reserves				
Restricted funds		17,923		24,692
Unrestricted funds				
General Funds		410,569		500,028
Branch Funds		103,838		90,292
Designated Funds		<u>340,000</u>		<u>400,000</u>
		<u>872,330</u>		<u>1,015,012</u>

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 14 August 2015

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

BRANCH FUNDS

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

	£	2015 £	£	2014 £
Cash balances at 1 April 2014		90,292		99,621
Receipts in year		166,256		110,931
Expenditure				
Local welfare grants	29,615		29,803	
Sent to head office	54,665		42,073	
Branch activities, local newsletters, equipment, research, etc.	68,430		48,384	
		(152,710)		(120,260)
Cash balances at 31 March 2015		103,838		90,292

We have examined the Statement of Financial Activities, Balance Sheet and Accounting Policies for the year ended 31 March 2015. 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 14 August 2015. 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 2015.

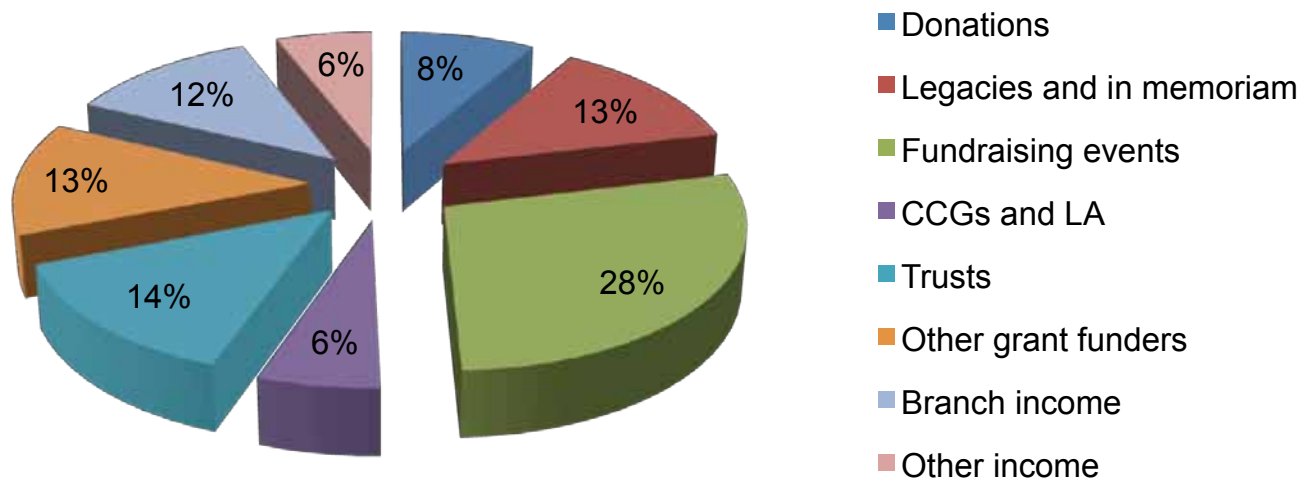
Andrew Moss BA FCA (Senior Statutory Auditor)
for and on behalf of Duncan Sheard Glass

Castle Chambers
43 Castle Street
Liverpool
L2 9TL

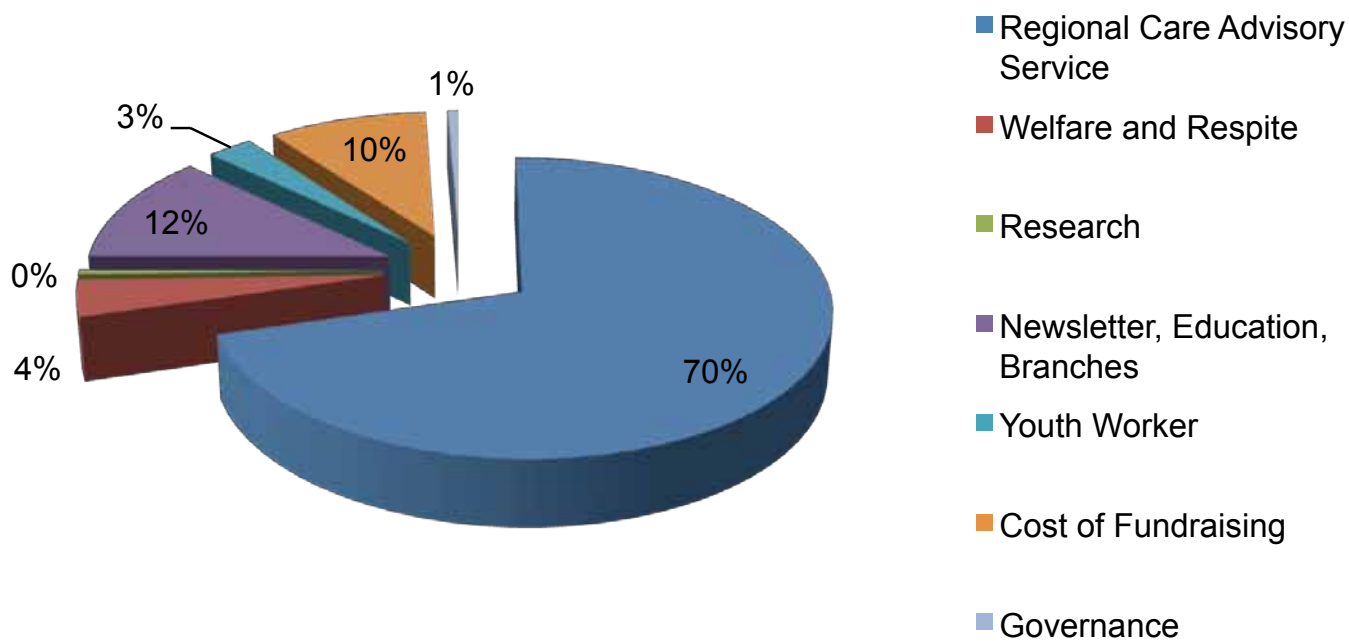
These summarised accounts, which have been extracted from the audited accounts approved by the trustees on 14 August 2015, may not contain certain information for a full understanding of the financial affairs of the Charity. For further information, the full annual accounts, the auditors' report on those 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.

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

WHERE OUR FUNDS CAME FROM



HOW THEY WERE SPENT





HUNTINGTON'S DISEASE ASSOCIATION

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 131 Mount Pleasant, Liverpool L3 5TF
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