

open hand

The magazine of Deafblind UK - putting **you** in the picture

Summer 2010



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- Deafblind Awareness Week 2010
- Thanks to our Brighton Marathon runners!
- Focus on communication support



DEAFBLIND
·UK·

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A word from our editor

Welcome to the summer edition of Open Hand. I hope that the cold winter and spring have changed into a warm and sunny summer. It is quite strange that global warming should result in colder weather, but it is supposed to be because of changes in the gulf stream. If this trend continues, I dread to think of the effect on energy prices in the coming years.

Our Chief Executive, Jeff Skipp is writing about the recent election and the potential effects it may have on services. I must admit it was fascinating to follow the changes in government. I am writing this in the first week of the first coalition for sixty five years. It will be intriguing to find out what

happens over the coming months. On the plus side, it took a coalition to get us through the Second World War, and now it has to get us through our massive debt problems – and a another 'small' war.

But on to lighter things, Janice Tillet is reporting on the Boots talking medication labels. The large Boots store in my home town tried something similar some years ago using tape recordings, but few people used it, so it will be interesting to hear what Janice thinks of the new system.

There is an update on our communication support services, and a look at some new technology using a versatile and multi-purpose mobile phone that includes a magnifying lens and CCTV facility.

Some of you may still wish to sponsor people who ran for us in the Brighton marathon, so there is an update on that. We have a poem from John Lee Clark, a deafblind American writer and editor. You might like to check out the website of the e-journal

at www.clercscar.com as it has some interesting articles from people with hearing loss and dual sensory loss.

There is the first part of a short biography on Dr. Robert Smithdas. Dr. Smithdas is a writer, poet and campaigner on behalf of the deafblind, and a powerful force in advocating for the education and employment of deafblind people, not just in his native America, but throughout the world. He is in his eighties, but only retired from work at the Helen Keller National Centre in New York at the end of 2008.

Now that all the Bank Holidays of Easter and May have passed, may I ask you to get your fingers on your keyboards and send us some material for the autumn edition. We want to hear from you, our Members. Do not be afraid of being a little controversial, it makes for good debate on matters important to deafblind people.

Have a great summer,

Rosemary Sandford

Rosemary Sandford.



Chief Executive, Jeff Skipp
updates Members

Talking about savings in the public sector

As I write this article, the week after the general election we are all waiting to see if the Conservative and Liberal Democrat parties can forge a deal which gives the UK a stable government in the coming weeks and months. The press and media are full of speculation as to the possible outcomes and who will be asking for what in order to gain their support. What amazes me is that with all the intrigue and guessing, no political party has told us in any real detail

what we can expect in terms of budget cuts once and if a deal is done.

What concerns me even more is that there is a general consensus that a significant part of any savings will come from savings or cuts in the public sector. This is not to say that efficiency savings are in any way a bad thing, provided they are targeted and do not adversely affect the poorest or most vulnerable people who require support to live

independently and participate within their local community.

However, even though parties have in many ways said they will protect frontline services whilst having to save such mind boggling sums from our schools, Social Services, Police, hospitals and so on, no one has actually told us how this will be achieved. Savings of the size being discussed will inevitably have an impact on charities and other community organisations seeking to support people locally.

Some organisations will merge whilst others will batten down the hatches and protect what they have in order to weather the storm. However, in times of hardship many charities find that demand for their services increases as people turn to trusted voluntary organisations to support them through difficult times.

Deafblind UK is preparing to support more people, and our Information and Advice Line is a key way to achieve this. If you or any Member have any issues or concerns and would like some advice or support then please do

not hesitate to call. There are a number of ways we can help and if, for example, you have requested support from your local council but none is forthcoming then our Information and Advice line will contact our case worker service who can provide advocacy support to help you challenge this decision.

Finally, if after all the electorate talk, discussion and deals are done, many expect there to be another election within 12 months. If this happens and the jolly prospective candidates turn up on your doorstep asking for your vote and telling you why and what they are going to do – take the opportunity to ask them HOW, as this seems to have been the bit they chose to miss out this time round.

Best Wishes

Jeff Skipp



Member, Janice Tillett benefits daily from managing her own personal budget.

Deafblind Awareness Week 2010

21st June to 27th June

Through radical reform, the Government is aiming to personalise adult social care services around individual user's needs. This initiative is outlined in 'Putting people first: a shared vision and commitment to the transformation of adult social care', launched on 10 December 2007.

This approach to service provision means that deafblind people will have much more choice and control over the support they

receive. Depending on each individual's circumstances, support will be paid for via direct payments, personal budgets, self directed support and/or individual budgets.

This year, during Deafblind Awareness Week we will be approaching the media to draw attention to the 'Putting People First' initiative and highlight the choice and control it gives to deafblind people over the support and services they receive.

Warning for Members to be aware of bogus callers

Deafblind UK has been contacted about reports of people trying to trick their way into older residents' homes. Most callers will be genuine and we do not want people to feel anxious in their homes but hope the following advice may be useful:

- Keep your back door locked when there is a knock at your front door. Some bogus callers work in pairs, with one of them entering from the back of the property whilst the resident is distracted at the front door.
- Ask the caller who they are before opening the door, then keep the door on a chain until you have seen their identification and are happy they are genuine callers. Always ask to see their identification and if in doubt do not let them in.
- You can agree a password with your gas, electricity or water company for their staff to repeat to you when they visit your home.



A bogus caller caught by Police

©iStockphoto.com/Tomas Bercic

If you have any concerns about anyone who has called at your home, contact your local Police or call Deafblind UK's Information and Advice Line on **0800 132320** and we will do our best to help you.

Apply for a card from the Cinema Exhibitors' Association

The Cinema Exhibitors' Association has launched a national card that can be used to verify that the holder is entitled to a free ticket for a person accompanying them to the cinema. Terms and condition of use apply.

To apply for the card, you will need to meet one or more of the following criteria:

a) Be in receipt of the disability living allowance or attendance allowance.

b) Be a registered blind person.

The card is valid for 1 year from the date of issue for cards issued since March 2009. Application forms are available from cinemas across the UK supporting this payment card and a £5.50 processing fee is chargeable per card. This is to be sent along with your completed application.



©iStockphoto.com

Download an application form and terms and conditions at: <http://www.ceacard.co.uk/downloads.htm> call: **0845 123 1292**, Minicom / Text phone: **0845 123 1297**, Fax: **0845 123 1296** or if you have any difficulty contact: **The Card Network, Network House, St Ives Way, Sandycroft, CH5 2QS**



A deafblind person cooking dinner

Cooking with confidence

Want to rustle up some tasty recipes in the kitchen but lack the confidence to start? Cooking is great fun, as well as being healthier and cheaper than convenience foods or takeaways.

Maxine Turkington has a condition called Stargardt's

Disease and is partially sighted. Her recipe book, *Cookery for VIPs*, contains over 120 recipes graded according to complexity. Written in large print, it comes with handy hints about how to organise your kitchen if you are partially sighted.

This 160 page book is available for £12.95 plus £2.50 packaging and handling to anywhere in the world. Please contact Maxine direct by emailing her at ssturkington@msn.com or by phoning her on **01223 246712**.

2010 Signature Annual Awards recognises excellence in communication with deaf people

The awards, inaugurated last year to great acclaim, aim to recognise those who have, in their own way, made a significant contribution towards a society in which deaf and deafblind people have full access.

The first ever Signature Annual Awards took place last November in London and saw winners from across the UK scoop a variety of regional and national awards. Those honoured included Hertfordshire Constabulary for its work to support deaf people on its patch; Sara Scanlon, a professional lipspeaker from Reading; and Lynn Delfosse, who has worked wonders for the deaf community in Wales.

The 2010 awards include two brand new categories (Young Learner and Centre of the Year), making seven in all:

- The Joseph Maitland Robinson Award for Outstanding Contribution
- Communication Professional of the Year
- Organisational Achievement

- Teacher of the Year
- Learner of the Year
- Centre of the Year
- Young Learner of the Year (Under 16)

Both Teacher of the Year and Learner of the Year are, initially, awarded on a regional level, with winners progressing to the national awards ceremony, which will take place in November in London.

Jim Edwards, Signature Chief Executive, said: "The quality and diversity of the nominations that we received last year speaks volumes about the amazing work that is undertaken all over the country.

"We are looking forward to hearing about more people and organisations that are really making a difference for deaf people."

Signature
excellence in communication
with deaf people

Touching Art Touching You at Hove Museum & Art Gallery

12th June – 5th September 2010

Touching Art Touching You, a fresh and unique concept in the visual arts comes to Hove Museum & Art Gallery. The exhibition breaks traditional barriers by actively encouraging visitors to experience and explore the art on display through touch and other senses. The experience challenges the notion that sight is essential for creating and enjoying exceptional art.

The exhibition includes paintings, sculptures and installations, including sound, drawn from the permanent collection of BlindArt.

BlindArt is a charity which promotes contemporary works by visually impaired

and sighted artists, showcasing them side by side and challenging the public to tell the difference.

Touching Art Touching You appeals to a wide ranging audience, including visually impaired visitors as well as children and families who can enjoy the freedom to explore the art through touch.

Comments from exhibition visitors:

"Overthrowing years of not being allowed to touch art. Quite mind bending"

"Touching the work added another dimension to the usual event of looking at art".

Attend the free exhibition at: Hove Museum & Art Gallery, 19 New Church Road, Hove, BN3 4AB or contact the museum for information on **03000 290900**, email: visitor.services@brighton-hove.gov.uk or log on to the website: www.brighton-hove-museums.org.uk
Opening Hours: Monday, Tuesday, Thursday – Saturday 10am – 5pm; Sunday 2pm – 5pm. Closed Wednesdays.

Lance Corporal Lundberg tests the BrainPort

Lance Corporal Craig Lundberg, 24, from Walton in Liverpool, has a device to 'see' with his tongue. A soldier who was blinded by a rocket propelled grenade in Iraq three years ago has been fitted with a device that allows him to 'see' with his tongue, enabling him to visualise shapes, read words and walk unaided.

Lance Corporal Lundberg lost his sight while on patrol with the 2nd Battalion Duke of Lancaster's in Basra in 2007. He has been selected by the Ministry of Defence to test the BrainPort miniature video camera and sensory equipment, which could revolutionise treatment for blind patients.

The device works by converting visual images into a series of electrical pulses that are relayed to the tongue. The differing strengths and patterns of the tingles can be interpreted to build up a picture of surroundings and enable users to navigate around objects.

The device consists of a tiny video camera attached to a pair of sunglasses. It is linked by wires to a plastic lollipop-like sensor which users place on their tongue to receive the electrical impulses.

"It feels like licking a nine-volt battery or like popping candy," Lundberg explained. "The camera sends signals down onto the lollipop and onto your tongue, you can then determine what they mean and transfer it to shapes.

"It's only a prototype, but the potential to change my life is massive. It has enabled me to pick up objects straight away. I can reach out and pick them up. Before I would be fumbling around."

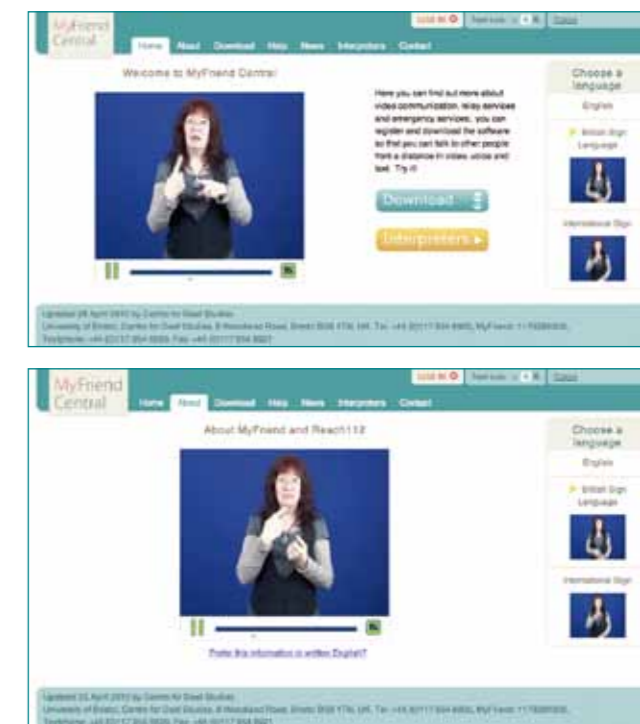
The MoD is paying around £18,000 for the device and training for the trial. BrainPort sends information to 400 points on the tongue connection. Designers plan to upgrade this to 4,000 points, providing a clearer image.

New 999 service

Avon and Somerset Constabulary is going to pilot a project trialling new online video technology called 'MyFriend' for those who use sign language or text communication and need to contact the police in an emergency. Police have signed up to support the REACH112 project, along with some of the fire and rescue services and the Royal National Institute for Deaf People (RNID).

MyFriend is a new video communication tool to keep you in touch with friends and family, to let you catch up on news and information, to send and receive messages, to talk to people through relay services and importantly to report emergencies directly to 999 or 112.

Getting started is easy - just fill in the registration page at: <http://www.myfriendcentral.com/registration/> or call Tel: **0117 954 6900**, Textphone: **0117 954 6920**, Fax: **0117 954 6921** to find out more. Once you



A sample of pages on the 'MyFriend' website

have registered and you have agreed to the code of practice, the software can be downloaded direct to your computer. You can then create your own directory of friends and access the service numbers - all through video, voice and text - the choice is yours.

MyFriend has been developed by the REACH112 project which is supported by the European Commission and is active in five countries in Europe.

New iPad is accessible for blind and partially sighted people

Apple's iPad has caused quite a mixed reaction. Its supporters have labelled it a game changing device that will revolutionise the way we consume media. And its critics have labelled it just a big iPhone.

The RNIB have called the iPad "a revolution in access for blind and partially sighted consumers". RNIB has congratulated Apple for producing a device that blind and partially sighted gadget lovers will be able to engage with. The praise is for the software built into the iPad such as the zoom functionality and the VoiceOver feature. It states that the VoiceOver functionality and the large text available on the iPad could lead to an eBook revolution.

RNIB's principal manager of digital accessibility, Robin Spinks, has called for other tech developers to follow suit. He said: "When it comes to embedding accessibility, Apple has set

the standard in recent years, changing the expectations of blind and partially sighted consumers. The fact that iPad's accessibility features are in-built is a very exciting development. It is now up to other manufacturers to follow the lead set by Apple".



Reading the news using iPad
©iStockphoto.com/David Freund

The Government are encouraging us to recycle batteries

In the UK, only about three to five per cent of all household batteries are recycled. Most old batteries end up in landfill, where they can leak harmful chemicals into the soil. You can help tackle this problem by recycling your batteries where you find the 'Be Positive' signage.

Most supermarkets and shops that sell batteries will have collection bins for used batteries. Some town halls, libraries or schools may also set up collection points. Look out for the Be Positive signs in shop windows and in stores to find these collection points.

Several local councils already collect batteries in the doorstep recycling collection,



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Viacheslav Krisanov

or provide bins at the local waste and recycling centre.

Many of the items you regularly use at home will be run on batteries. Batteries from all of the following items, and many others, can be recycled:

- mobile phones
- laptops
- hearing aids
- watches
- portable cameras
- cordless power tools
- torches
- electric toothbrushes
- razors
- hand-held vacuum cleaners

Check with your local council to find out what battery recycling choices are available in your area. To find more details about battery recycling, visit the websites of the Department for Environment, Food and Rural Affairs (Defra) at: <http://ww2.defra.gov.uk/> or Tel: **08459 33 55 77**

Just Tick It campaign

The Office of Fair Trading (OFT) has published a list of tips in May to help people spot bogus ticket websites as part of its 'Just Tick It' campaign. Make sure you follow the OFT's advice if you or family and friends are looking for tickets to sporting, music or theatre events online.

1. How has the website got tickets to sell? Has the venue released tickets for sale and when will they be sent out?
2. Who is the website registered to and how long has it been registered?
3. What are others saying about the website on the internet?
4. How can you contact the company? Check that you know their full address and that they have a working landline telephone number.
5. Can they provide ticket details? Ensure that the



©iStockphoto.com/Kacey Baxter

face value of the tickets and the seat location are clearly listed.

6. Do they provide refunds? Make sure there is a refund policy in case something goes wrong.

More than 5,000 people were scammed when trying to buy tickets for the UK's top music events last summer, new research from the OFT has found. This is likely to be an under-reported number, as many people do not go to the organisers themselves to complain about the scam. OFT research last year found that one in twelve ticket buyers had admitted to having been caught out by a scam ticket website, with victims losing an average of £80.

Talking Medicine Label from Boots

Awareness Support Officer, Janice Tillett, updates Members about the talking medicine label featured in the Spring issue of Open Hand.

"When I heard about talking medicine labels provided by Boots, the chemist, I felt really excited. Did this mean that for the first time in years my medicine label would be accessible to me? I communicate using clear speech so I do find that the quality of the voice on talking products varies greatly.

My starting point was to contact one of my local Boots stores in Northampton to ask about getting talking medicine labels for my prescription medication.

The process, from flagging up the fact I needed talking labels to having the medication and talking labels delivered to my door took under two weeks. The labels themselves are the size of a credit card.

A member of staff records the name, address of the

patient, the name of the medicine and any directions i.e. dosage onto the label and then a button is pressed to obtain the spoken information.

The quality of the voice on my labels is very good although that may vary depending on the member of staff who records them.

However, thanks to talking medicine labels, I am now enabled to take my prescription medication independently which is a great feeling!"



Talking Medicine Label available at Boots

Technology Today

by Steve Unwin,
Deafblind UK's IT Manager



It really does seem that as far as accessibility options go for the low vision user, there have been some innovative products that have come on the market recently, as my previous articles have shown.

I received an email from Professional Vision Services announcing the release of the Magnilink Go from LVI which transforms a mobile phone with a camera into a portable digital magnifying glass and CCTV.

If your phone already has the Mobile Speaks or Talks screen reading software then you can use Magnilinks OCR capability to convert the text image into speech and the phone can read the captured text in either the Nokia voices supplied with the Magnilink or you can add the high quality Text to Speech

voices from Acapela.

Magnilink Go software can be installed on selected mobile phones utilising the mobile phones camera to give enlarged images which can be captured, saved and viewed later. Simply point the phone at some printed material and use the phones 5 and 6 keys to increase or decrease the magnification, you now have a portable digital magnifier. By pressing another key the phone takes a picture of the page and within seconds displays and reads the text back to you. You can use the 3 key to change text colours to suit you and access the Magnilink menu to customise the display.

The cost of the software is far from cheap, at £695 ex VAT and that is without the

initial cost of the phone. It is an expensive alternative to carrying a magnifying glass with you. If you saw my article in the Autumn 2009 issue about the FarView from Optelec you will remember it was a dedicated portable CCTV machine but at nearly twice the price. It has a larger display than the phone comes but without the reading function.

The software currently only works on the Nokia N82, N86 and 6220 Classic phones and if by chance you already have one of these phones then the software can be downloaded for a free 30 day trial. You can get more information by contacting Professional Vision Services on Tel: 01462 420751. If you want to see it in action then go to YouTube on the internet and type in Magnilink.

Mobile phones are becoming like a Swiss army knife gadget to carry around with you, able to do many applications or apps as the ad men like to call them, way beyond the standard phone call. It is nice to see that the

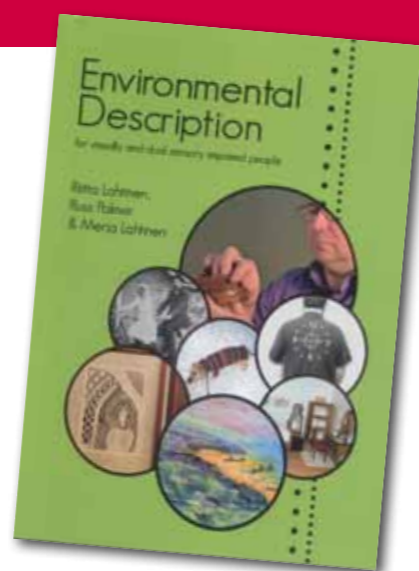
accessibility applications seem to be developing at the same pace rather than as an afterthought. Let's hope this continues in the future and the cost of these products reduces to an affordable level.



Environmental Description for visually and dual sensory impaired people

Environmental Description enables sensory impaired people to perceive spontaneous qualitative information in real time, through everyday life experiences. This type of received information can support a person's own actions and decision-making processes. Environmental Description provides focused sensations and experiences which encourage the visually impaired person to participate more fully and deeply in their environment.

This handbook analyses how we can describe the environment. It presents different methods and techniques which can be developed and applied to each individual user's



Order your copy of this interesting handbook

perspective, ranging from life activities to artistic interpretations. It focuses both on the describer's and the receiver's perspectives; giving practical examples with additional exercises for professionals who work with visually and dual sensory impaired people. It includes ideas for getting started, and practical tips for the basis of various categories of descriptions. The book also includes comments and experiences of describing the environment.

Riitta Lahtinen MEd, PhD. Researcher, Teaching Consultant; Russ Palmer SRAT(M), Music Therapist, Visiting Lecturer and Merja Lahtinen MEd. Special Teacher of the visually impaired. ISBN 978-0-9550323-2-5 / Price: £25.00 (plus p&p) For further information email: rpalmer2@tiscali.co.uk or website: www.russpalmer.com or www.earfoundation.org.uk/shop

News from Deafblind Cymru

Welsh Connections Groups: Helping Our Members in Wales

To date, our Welsh Connections project has enabled us to set up and establish 11 deafblind groups in Wales.

The groups enable deafblind people and companions to meet similar people and to share experiences and information as well as having some fun on social outings.

We have seen a number of success stories where group activities have helped Members to acquire useful information and advice enabling them to remain as independent as possible and to engage more confidently with their own communities.

Members are encouraged to take up voluntary roles and responsibilities within their groups to sustain the groups and shape their future direction.

One of our most recent and notable successes is the case of David Monckton from Rhyl, North Wales. David is blind and deaf. David helps out and takes part in our



deafblind groups and bowling activities. Through his involvement in our project, he has been able to access one to one IT training to help develop his computer skills. Our caseworker acquired a free computer to help him practice his new skills.

With the training he received David was able to achieve skill levels suitable for higher education. He has recently been accepted at Llandrillo College to do an Access to Higher Education course with a view to moving on to study art at University.

If you would like to enjoy the benefits of attending one of our deafblind groups please get in touch with our Project Manager, Martin Griffiths who will put you in touch with your local Group Co-ordinator. His contact details are at the end of this article.

NEW NEW Swansea Deafblind Group

Our new Swansea Deafblind Group launched in April 2010. The first meeting was well attended but there are spaces for new deafblind Members and companions.

The Swansea group meets on the 3rd Tuesday of each month at Swansea Civic Centre, Oystermouth Road, Swansea SA1 3SN from 2pm to 4pm.

NEW Neath Port Talbot

Our new Neath Port Talbot group started in May 2010. New Members and companions welcomed.

The Neath Port Talbot Deafblind Group meets on the 3rd Thursday of each month at Neath PT CVS, Ty Margaret Thorne, 17-19

Alfred Street, Neath SA11 1EF from 2pm to 4pm.

Deafblind Cymru raising awareness of the needs of Members in Wales

We at Deafblind Cymru work closely with a number of influential organisations and groups to ensure that the needs of deafblind people are represented in policy making, strategy development and service delivery in Wales.

We are, for example, members of the All Party Group on Deafness and meet with Welsh Assembly Government members and other leading organisations



Deafblind Cymru Member, Maria Heward who enjoys visits from her volunteer



Enjoying a group lunch

to discuss issues affecting our deafblind Members.

We recently worked with RNIB and other leading organisations to feed into the development of the Wales Vision Loss Strategy. We hope to be involved in a new All Party Group being set up to focus on the needs of blind and partially sighted people.

Deafblind Cymru also works with Age Alliance Wales and other national organisations such as Disability Wales. Our staff attend regional and

local networks ensuring that they too are aware of issues faced by deafblind Members.

To help us, help you, why not write to us and tell us about the issues you face day in day out related to Deafblindness. The more cases we hear the more evidence we can refer to when we work with various influential bodies. We can change your name and location to ensure you cannot be identified if we refer to your case.

If you wish to tell us about issues affecting you contact **Martin Griffiths, Project Manager, Deafblind Cymru, Trident Court, East Moors Road, Cardiff CF24 5TD.** Tel: **02920 601471** Minicom: **02920 495919** or email: **martin.griffiths@deafblind.org.uk**

It's not too late to take a break!

As many of you know, Deafblind UK owns a six berth caravan at Hopton, nr Great Yarmouth. Since our last article about the caravan in the winter edition of Open Hand, we have had a huge response from our Members showing interest and booking holidays for 2010.

The summer months are now fully booked for this year, however we do still have some availability through



Book at stay at the caravan

Autumn and early Winter and we would love it if more of our Members, their families and carers could benefit from a holiday. Whether it's a 7 night stay or a 4 night stay the cost to you is only £30.

Dates available (at time of print)

Sat 10th Oct – Sat 17th Oct
Sat 17th Oct – Sat 23rd Oct
Sat 23rd Oct – Sat 30th Oct

Fri 5th Nov – Mon 8th Nov
Fri 12th Nov – Mon 15th Nov
Fri 19th Nov – Mon 22nd Nov
Fri 26th Nov – Mon 29th Nov

Fri 3rd Dec – Mon 6th Dec
Fri 10th Dec – Mon 13th Dec

From Wednesday 15th December through to 4th January 2011, the caravan is available all the time. There are no services available on site, just caravan hire only.

The caravan will be available to book for holidays in 2011. We will start taking bookings in January 2011.

For more information and to request a booking form, please contact Niki Peacock on Tel: **01733 358100 ext 257.**

Undertaking a fantastic challenge!

My name is Shelly and I have Usher Syndrome Type 1, (deafblind) but can partially see. I am registered with Deafblind UK and have been asked to take part in a fundraising event. I was asked to do a walk up Mount Snowdon in Wales.

The event is on the 22nd June 2010. I am very excited as I have always wanted to do extreme activities, but never actually went with it, due to my condition and

lack of confidence. But, now given the chance with the help of Deafblind UK, I am determined to do it with the help of my carer Leah. I am very confident I will complete this challenge. And in doing something like this I hope it will bring more exciting opportunities for me to do in the future.

I will write into Open Hand again to let you all know how my fantastic challenge went, wish me luck!



Inset: Shelley and Leah,
Main image: Mount Snowdon, ©iStockphoto.com/Rey Rojo

Editor: Good on you Shelly, best of luck and we will ask others let us know of their exciting adventures.

Remembering two lifelong supporters of Deafblind UK

by Rosemary Sandford



Dot as a child
and more
recently

Obituary Dot Wade 1932-2009

Dot Wade, who worked for many years at Rainbow Court, died last year. Although she was born in Scotland, and always retained her love for that country, her family moved to England. First they were at Acton in London, and then moved to Peterborough. She attended St. Mark's School in Peterborough, leaving to begin work in the typing pool at Perkins (not the famous school in the USA).

She then became a nursemaid in Helpston where she met her husband, Eric, and they married in 1952. Thirteen years later her only daughter was born, weighing just 4lbs, and she gave up her job in a home-made cake shop to look after her.

When she returned to work, she went to Rainbow Court, run by the then Deafblind Helpers' League, now Deafblind UK. Over the next

thirty-two years she made friends with both the staff and the residents.

She organised and attended the deafblind rallies that were held twice a year up and down the country, but never ventured abroad. She knew the Deafblind Manual and could read and write Braille, and even write a couple of articles for the magazine, then called Rainbow. One was about a visit to Lancaster House, with the late Patrick Murphy and Ann Barnet, to meet the Princess of Wales. Another was an account of a day trip with her husband to Sandringham House.

Dot also attended two of the Queen's garden parties at Buckingham Palace, and the Young Deaf Achiever Awards in London.

After retiring in 1992, she continued to assist deafblind people, and also took up numerous hobbies involving hand crafts, and loved attending the theatre in London and Peterborough.

©iStockphoto.com/Diane Diederich

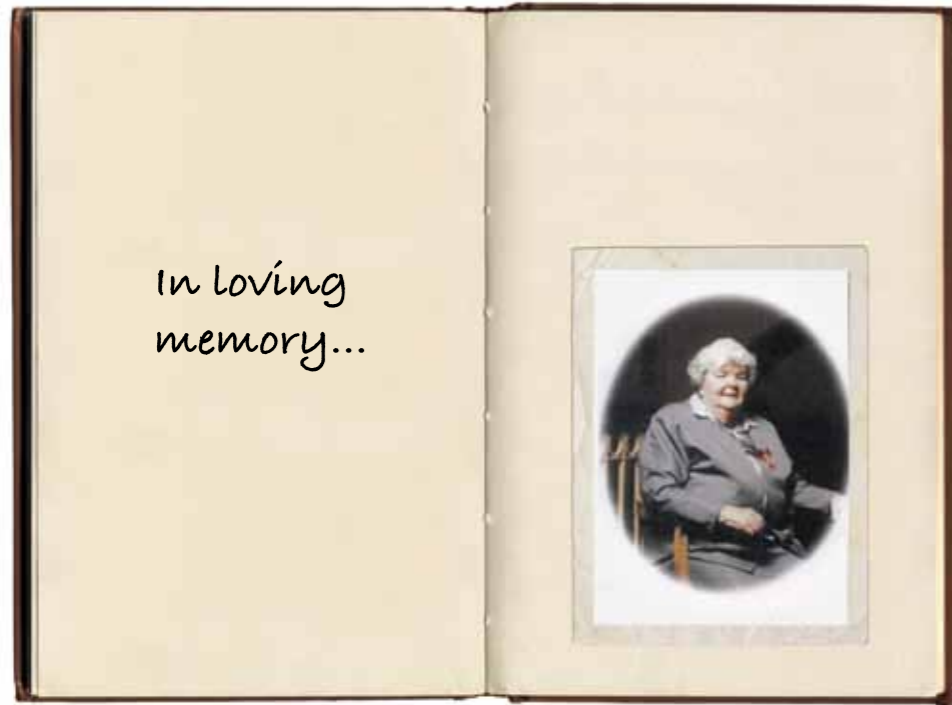
She was widowed in 1994, but continued with her hobbies, particularly cake-making for which she was well known.

Her last holiday in 2008 was to Scotland, staying at Castle Lachlan in Argyle. It was a family event with a party of fifteen, but Dot was probably the only person to take just sandals to wear in Argyle in April.

Dot was much loved by all her family and friends, and a very good friend to many deafblind people.



Obituary Joan Shields 1922-2009



Joan Shields

Joan Shields, who died last year, played an important role in the education of deafblind children in the UK. She began her career in teaching at the East Anglia School for the Deaf and Blind in Gorleston. One of her pupils, Wendy Harden, now 74, remembers her as a much loved but strict teacher. She always encouraged her students to reach out with their hands and minds to grasp learning, ideas and friendship.

In 1951, Joan was seconded by the RNIB to the famous

Perkins School in Boston, in the United States. She spent a year there training as a teacher of the deafblind. On her return to England, she opened a small unit known as High Windows, and later as Pathways, at Conover Hall School, starting with just two children. This grew to thirty children later on, and now there are units throughout the UK.

In recognition of her work and pioneering achievements with children who had been previously excluded from the educational system, she

was presented with the Anne Sullivan Award by the Perkins School in 1966.

In 1980, Joan became the RNIB's Special Advisor for Deafblind People, working with children and adults and travelling the country. She was tireless in her energy as she advised and helped deafblind people, their families, and their service providers.

In 1982, Joan began to consider what could be done to help and inform the families of those who had been diagnosed with Usher's Syndrome. Mary Guest, Principal Research Officer of the Usher Syndrome Project at Sense, remembers Joan for the way she shared her experience and knowledge of families dealing with the condition.

Joan was enthusiastic about the proposal to hold days for families and professionals dealing with Ushers. This took place for the first time at Charing Cross

Hospital, when audiologists, ophthalmologists and voluntary agencies, met the families together.

When she retired in 1987, the IAEDB presented her with the first Distinguished Services Award. She continued to work on a voluntary basis, supporting Sense and the then Deafblind Helpers League, now Deafblind UK. She spoke frequently at seminars, and always carried a bag of toys and gadgets that could stimulate communication with deafblind children.

She was a strong advocate of the use of ordinary items found in the home, and adapting these for the use of children, advising that expensive and specialist toys were not always needed.

In 1992 Joan was awarded the OBE for her services to deafblind children and adults, and many of her friends celebrated the well-deserved honour with her.

Editor's note: I am indebted to Ann Barnett for the information included in this obituary.

My thoughts on politics

by Member, Lizzie Anderson

After a lot of thought I have decided what to do with my newly acquired leisure time, having tried for various jobs such as Samaritans and Mind.

I have finally decided to use my politics A Level.

To give a bit of background, I have always been a Tory



Getting interested in politics, ©iStockphoto.com/Sean Warren

voter, have met one of our former Tory MP's, and now have corresponded with our current Tory MP for Kettering, Philip Hollobone. Never one to miss an opportunity, I have already started to look at issues which affect the disabled, and the lack of services in Northamptonshire. I am now trying to look at a more national issue, exempting all audio recordings from VAT, which is a Europe-wide exemption.

However, Gordon Brown had not decided to put this measure in place for the British visually impaired community, preferring profit to implementing a European directive.

I have previously written to Mr Hollobone on crime and disorder and the funding of specialist college places which have instead of going up over the years, have gone down over the years. My recent course at the Royal National College for the Blind in Hereford should actually have been two years. This means that there is not equality of opportunity for the disabled. Any course should not be compacted into one year and should be delivered

in two, so anyone who is on a lower course has a chance to progress.

This is why I have decided to start at grass-roots level as a canvasser for my local Tory party and then hopefully became a Conservative councillor, as I am the person who has waited 8 hours on that hospital trolley, have not had very satisfactory dealings with the Police – being the victim not the perpetrator – and having had time out from a course which should lead to work; having to have state benefits in an economy where they expect full employment – where are the opportunities?

We will either get more of the same, the Tory administration, a Lib-Lab pact or the Tories and Labour sharing power, not an edifying prospect. By the time you read this no doubt we will know more.

Dr Robert Smithdas - Part 1

by Rosemary Sandford



Dr Smithdas
at an event

Dr Robert Smithdas, now in his eighties, retired from the Helen Keller National Centre in New York in December 2008, after a lifetime of service to the deafblind.

Known as Bob, Dr. Smithdas was born in Pittsburg, PA, to a large family who were Roman Catholic. His early development was normal, but when he was four years old, he fell ill with cerebrospinal meningitis that left him both deaf and blind.

He attended the famous Perkins School, where he later took up wrestling, and began his lifelong love affair with poetry. On leaving school in 1945, he went to the Industrial Homes for the Blind in Brooklyn, New

York, a long way from home. There he learned various skills including rug-making which would provide him with a living, but he had other ambitions. He wanted to go to college. Happily the Home supported and encouraged this ambition, and he attended St. John's University, with funding provided by various sources. He also had the assistance of a high school graduate called Johnny Spainer, who was his guide, communicator and friend for the following nine years.

The two young men had to meet a demanding schedule, meeting in the evenings after work so that Johnny could learn to communicate with Smithdas, and learn how to support him when he started at university in the September. Spainer had to be able to communicate, using the manual fast enough to transcribe lectures, so that Smithdas

could keep up with his class. The Home, and St. John's, arranged for a whole army of voluntary Braille transcribers from across the country to work to ensure that Smithdas had the required reading available for his first year. The American Foundation for the Blind provided him with a new, silent typewriter, so as not to disturb other students.

Saint John's University was under the jurisdiction of the Vincentians, whose patron St. is St. Vincent de Paul, and one of Smithdas's influential teachers was Fr. Docherty, a member of the Order. He impressed on Smithdas the need to keep an open mind and seek the truth in all things. He also emphasised that no-one was entirely free from dependence on someone else.

Smithdas graduated B. A. Cum laude in 1950, and three years later he

became the first deafblind person to receive an M.A. graduating from New York University after specialising in vocational guidance and the rehabilitation of the handicapped.

After leaving university he went to work at the Helen Keller National Centre in New York. There he began his lifelong career as an advocate for the education and employment of the deafblind.



Helen Keller National Centre
for Deafblindness

©www.hknc.org



June Bowden relaxing at home

Simon Said by June Bowden

About fourteen years ago, when I was using an old Braille, I had what silly people may call "Perkins" pals (penpals to you and me and anyone else who wants to treat blind people as normal and hate phrases which set us apart like touch tours and clock face descriptions of food).

In those heady days before the invention of a technology I can barely get to grips with, I established a friendship with Simon, a young man who now lives in Scunthorpe, North Lincolnshire. Through a friend of mine I have now

re-established contact with Simon and this has thrilled both of us for many reasons.

Since age three months I have been blind but Simon, as well as being blind is deaf. Since my days at school and college I have known a few people who suffer this double sensory loss and, knowing how I rely on my hearing to compensate for my lack of sight, I wonder how I would cope were I in their shoes. The eyes and ears are the umbilical cords connecting us to the rest of the world. Without either your eyes or ears you are in an island

state – your body becoming a prison instead of a vehicle for mobility and social communication.

Many people have decided, from their positions of ignorance and stupidity that it is worse to either be blind or deaf. What I say is that it is worse to be both for then you suffer the problems of both and just as the mixing of two colours make a third, so do the mixing of two disabilities make a third one, distinct from either of the other two.

Simon told me he had been in hospital – a scary and unnerving experience for anyone. My first thought was: How did the nurses communicate with you? Or, did they even communicate with you? Hardly anyone knows the manual and the plight of the deafblind is never discussed on radio or TV. Where is Simon's privacy when he needs typetalk to make a phone call?

My last thought as I drifted off to sleep last night was: "How can I make Simon's life better"?

The answer isn't by tut-

tutting and saying it's a shame. The answer isn't to cry into my pillow thousands of sentimental tears of pity. Today, Simon himself provided the answer and suggested I write this article, telling my story or should I say our story. The story of how we re-established contact, thereby publicising the problems of those doubly handicapped in this way.

Words are my business since I am a writer with a blog who has won a short story competition. I love language and words, music and poetry and I cannot imagine life without them so I agreed to do what Simon said. He, from his position of darkness and silence has spoken loudly and clearly to me: "Help me tell it like it is". That was an offer I just could not refuse.

His courage, fortitude and sense of humour, displayed from a position of unrelenting adversity, gives me courage and inspiration of my own so let's all do what Simon says – namely make the world of those without hearing and sight a more bearable and deafblind friendly place.

On My Return from a Business Trip

by John Lee Clark

Let go of my arm. This is the arm
of an Elite Frequent Flyer. I will not wait
until I'm the last person on the plane.
Go away. I never asked for assistance.
What? I don't want that wheelchair.
I'm fine. Let me walk.
Let me feel the spring
of my fibreglass cane off the walls
between my mind's charted waters.
What? I don't want the elevator.
Leave me alone. I don't know what colour
my bag is and I don't care.
No, it won't take me forever to find it.
Go away. I'm fine kneeling here
near the luggage conveyor. No. No.
Yes. See? See? I told you
it wouldn't take forever.
Now will you please go away?
What? I don't want your help.
Let me feel the air sucked away
just before the shuttle pushes it back.
Go away. Let go of my arm.
I'm not going to be your pole.
No need, no need. I can step off
by myself. Let me go. Let me go home.
Go away. Let me walk
with my bag rolling behind me in the sun.
Let me veer off a bit here and step
onto the grass. No, I'm not lost.
Go away. Let me find out that it's spring
in my own way.



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Alexander Selektor



Please address your letters to: **Rosemary Sandford**
or **Jo Johnson, Open Hand Magazine, Deafblind**
UK, National Centre for Deafblindness, John and
Lucille van Geest Place, Cygnet Road, Hampton,
Peterborough, PE7 8FD

Dear Rosemary and
Open Hand

I recently was given a copy
of your article in Open Hand
about Pat Murphy.

I enjoyed reading the article
and being reminded of Pat
and what an amazing man
he was. I first knew him
in the mid 60s when he
lived in Bellingham, near
Catford in London. I think
he would have been in his
early twenties. He was
a proof reader of Braille
books at that time. As a
teenager I used to interpret
the Sunday Service for him

held for the Deaf in Allerford
Chapel.

Sometimes I would go to
his house to walk with him
to the meeting. He was so
easy to interpret for as he
was so in tune with what
was going on and clever to
boot.

He will be missed indeed
and a real loss.

Thank you for the tribute.

Regards

Dorothy Bilton
(nee Barritt)

Dear Ms Sandford

My name is Teresa Buck, I am a communication support worker for Deafblind UK. I have worked here for almost three years. I work with clients in Coventry and Rugby and live in Nuneaton with my husband of ten years David, my stepdaughter Cheryl who attends our local college and our puppy Inca.

On 21st August 2010 one of my clients Phillip King is partaking in a sponsored walk for 'Guide Dogs for the Blind', the event is called "go walkies".

Phillip has been blind since birth; he achieved a degree in music but suffered hearing problems after leaving full time education. He is now living independently in Coventry with support from myself to enable him to go out socially and support from another company to help him cook meals, clean the flat and do his food shopping. Phillip applied for a guide dog last summer after being unsuccessful on previous

occasions. He is currently working on learning routes before he can be successful for this application. Phillip jumped at the chance of participating in this event especially as it meant he gets to see my puppy Inca. He loves animals and misses having one around.

Inca came into our family at Christmas as a tiny puppy, she is a red and white Staffordshire bull terrier and will be just ten months when she goes walkies with us. Inca is such a joy to be with, she is such a cheerful, loving soul, she is currently completing the puppy level of her good citizen dog scheme. She should achieve this in the next few weeks. We hope that when she is older she will be accepted as a PAT dog and will brighten other people's days as much as she does ours.

The dogs are the stars of go walkies, if you do not own a dog or can't borrow one for the day you are encouraged to dress up as one. I am currently trying to get sponsorship from the Sony shop in Coventry, I

have spoken to them and they have requested some information and photos but sounded positive.

I am hopeful that you would be interested in publishing an article in Open Hand about Phillip

I would like to thank you for your time and patience in reading this email and I hope to hear from you soon.

Yours

Teresa Buck, Nuneaton

Dear Editor of Open Hand

News from the Ali Hope Foundation in Israel, we are very grateful for the heavy rainfall on Israel at the moment and it feels like our Seed Foundation is growing to a new level this Spring. Already in 2010, our Board have had a meeting to put forth our goals for this year and write a mission statement.

It is the mission of the Ali Hope Foundation to pursue the empowerment of deafblind people, to promote their independence, to strengthen their confidence and to encourage them to achieve their full potential as members of society.

We want to send you updates every three months to keep you informed of what we are doing in the lives of people who are experiencing positive changes.

Our Foundation is still humming with activities and we have 14 deaf and deafblind people who attend our "dog club" to learn more about their future dogs and also come to ask questions about dogs that we have given to assist them. This is an excellent and encouraging social time together with deaf and deaf blind people and we have seen positive changes in their lives which makes us very happy to know that the Ali Hope Foundation

exists to make a positive impact on peoples lives. The Foundation helps most of these people to meet their needs and to attend the activities and educational programs we hold for them. Some more good news is that our Foundation is just over three years old and very soon we will qualify to issue Tax Deductible Receipts.

We need your support,

like the support the rain is giving to Israel, to raise awareness of the organisation. We appreciate your time and support to enable us to continue to give independence to those who really need it.

Best Regards

Tamara Meirovich
Ali Hope Foundation, Israel.

Dear Rosemary Sandford,
Editor

Thank you so much for the very special magazine. I always find it interesting. I particularly liked the poem 'Small Things'.

I am going to do a pen and ink illustration of it for a

deafblind man I support in a care home.

God Bless, with love,

Susan

Susan Emptage, volunteer,
Portland in Dorset.

Find out more about Deafblind UK's Communication Support Service



Laura Campbell
from Essex

Laura Campbell, a Communicator Guide from Essex, explains her role: 'If I have never met the deafblind person prior to their appointment, I contact them to introduce myself and make the necessary travel arrangements. On the day, I usually arrive about half an hour early to support them in collecting together all the relevant paperwork and equipment they need to take to the appointment.

Deafblind UK's Communication Support Service assists deafblind people to access health services via a Communicator Guide. In turn, this enables and individual to have more control over their lives, by providing clear communication and access to the information necessary to make informed decisions about their healthcare.

All types of health appointments and hospital stays are included, with the funding provided by health and social care.

An important part of my role is to assist the deafblind person to make a list of any questions they want to ask the medical practitioner. This list can then be used as a prompt, or given to the medical practitioner – whatever they prefer.

When we arrive at the medical appointment, I always offer the opportunity of a comfort break before guiding the deafblind person to the right department and enabling them to book in. A huge benefit of having Communicator Guide support

at medical appointments is that when the deafblind person's name is called out, we hear it! So many deafblind people have been left waiting for hours for their name to be called, only to discover that it had been called and they hadn't heard it and consequently missed their appointment.

Once I have guided the deafblind person to the consulting room, it is my job to empower them to fully access all the information at their appointment, using their preferred method of communication. I would then remind them of any questions we had written down, or prompt if preferred. Sometimes, I will have been asked to assist in asking questions if I think anything has been missed and I can also take notes for the deafblind person if required.

Afterwards, I enable the deafblind person to get their prescriptions dispensed and to book any necessary follow-up appointments and ensure that it is written in their diary at home.

Confidentiality is a really important factor in any Communicator Guide's role; medical appointments are never discussed with the deafblind person's relatives or friends without their consent, to ensure they retain their independence and privacy.

Many deafblind people have told me that having a Communicator Guide takes the worry and vulnerability out of their health appointments, enabling them to get the most out of their visit. It's tremendously rewarding to know I'm making a positive difference.'

For further information about the Communication Support Service and to see if this service is operating in your area, please contact Lynn Sargeant or Steph Collier on: **01733 358100**, Tel or text the mobile: **07920 802671** or email: comsupport@deafblind.org.uk

Members' thoughts on Deafblind UK's Communication Support Service



Member, Joseph Ethell and Hazel Lucas

Joseph Ethell, from Northumberland

'I can't walk very far, so I don't go out by myself. Before using the Communication Support Service, I relied on the Ambulance Service to get to medical appointments.

This meant that sometimes I would be waiting for hours to be picked up, then after my appointment had finished, I would wait for ages again before travelling for miles back to my home, while the bus dropped off other patients on the way. Now Hazel, my Communicator Guide, takes me to my appointments, the whole process is a lot less time consuming.'

'Without Hazel to support me, I simply couldn't go to some of my appointments. This is especially true when my hearing aids have to be removed for examination; without them I can't hear anything – so Hazel has to do the talking on my behalf and lets me know afterwards what has been discussed.'

'I would definitely recommend this service, as it takes all the stress out of going to my medical appointments – I have total confidence that Hazel has everything sorted. When I go to medical appointments, it really helps me to have Hazel there to support me. I wouldn't be without her!'



Sarah Arnull-Henry at her recent wedding

Sarah Arnull-Henry, from Peterborough

'I don't have the struggle and anxiety of trying to get to the hospital and to the correct department on time. Previously, the worry of getting to my appointment on time usually meant that I would arrive in worse shape than when I left home. This inevitably affected the results of certain tests as my blood pressure would be much higher than it should have been!'

'The other huge improvement I've experienced relates to my understanding of what is being said. Sometimes it's difficult when the doctor has a strong accent and I feel

embarrassed to keep asking them to repeat what they are saying. Now, after the appointment has finished, I usually talk it through with my Communicator Guide, who is extremely helpful in terms of making sure I have understood exactly what has been discussed.'

'I am extremely grateful this service is available and would definitely recommend the Communication Support Service to other Members. It takes all the worry out of getting to your appointment, leaving you free to think about the questions you want to ask when you get there.'

Well done to all our runners at the Brighton Marathon!



On Sunday 18th April 7,589 runners crossed the start line of the inaugural Brighton Marathon.

The 26 mile Marathon dubbed the 'London Marathon by the seaside' is a reasonably fast and flat course which toured much of the city of Brighton and Hove, taking in the glorious coastal views.

Deafblind UK is sending

a HUGE WELL DONE to our runners Lee Cooper, Sarah James and Andrew Field all from Brighton and Hove who took part in the Marathon in support for Deafblind UK.

All 3 runners completed the race with times ranging from 3 hours 28 to just under 4 hours. A fantastic achievement. They have all done incredibly well hitting their sponsorship target total of £2,500 for Deafblind UK.



The Deafblind UK team in Brighton and Hove



Deafblind UK's Lorraine Densham meets runner Steve Overt

Also, big thanks to the Brighton Deafblind UK team Nikola Fieldhouse, Leila Hughes, Charlotte Oliver, Helen Waite, Richard Spong, Danny Densham, James Carter and his parents Hazel and Len for their help with locating runners, promotion and cheering on the day armed with our Deafblind UK clapping bangers.

You can see how our runners got on at the event including photos from the day itself on our website. And if that inspired you a bit more to get involved then you can also check out our up coming running events and challenges! Visit: www.deafblind.org.uk/fundraising

Feel the fear...and do it anyway!!

Deafblind UK are looking for just 6 brave individuals to dive with sharks in an unusual underwater challenge to raise funds for the charity. Are you brave enough to take up this underwater challenge? This once in a lifetime opportunity

takes place at the Blue Planet Aquarium in Cheshire on Saturday 16th October where participants are guaranteed a close-up encounter with a tank full of Sand Tiger, Lemon, Nurse and Bamboo Sharks, as well as Southern Stingrays and a whole school

of tropical fish found in the Caribbean. And there are no diving cages involved! No previous diving experience is necessary as participants will receive full training and all equipment is provided.

Nina Samson, who took part in a previous dive, says, "I just thought how wonderful, I have always wanted to swim with sharks and this is not in a cage - you are actually swimming with the sharks all around you. It was amazing, it truly was a once in a lifetime experience. I couldn't believe how close they came up to

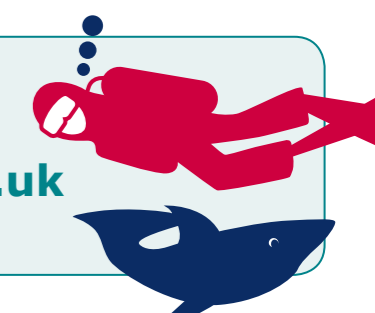
me. It was thrilling".

Deafblind UK would love to hear from anyone feeling brave enough to take up this challenge. It really is an amazing opportunity for anyone with an interest in sharks to get up close and personal with these amazing creatures. Registration fee is £50 and of course anyone raising the minimum amount in sponsorship for the Charity (£350) will, in effect, get basic PADI diving training and certificate plus an amazing shark dive for only £50!



Enjoy the thrill of swimming with sharks!

For more details, or an entry form contact Lorraine Densham on Tel: **01733 358100** or email lorraine.densham@deafblind.org.uk or log onto: www.deafblind.org.uk



About Deafblind UK

Who we are

Deafblind UK is a national charity offering specialist services and human support to deafblind people and those with a progressive sight and hearing loss acquired throughout their lives.

Our aim is to enable people living with this unique disability to maintain their independence, quality of life and reduce the isolation Deafblindness creates.

What we do

We achieve this through campaigning, education, the provision of practical and emotional support via independent living teams and a free information and advice line.

Please send submissions to Open Hand using the contact details on Page 2. Postal submissions can be sent to the address below.

Submissions are required for the Autumn issue by **19th July**.

The views and opinions expressed in Open Hand are not necessarily those of either Deafblind UK or the editor and we reserve the right to edit submissions. Open Hand is available to all Members of Deafblind UK free of charge and to non-Members at £20 a year. Open Hand is available in Braille, large print, tape, audio cd or via email from Deafblind UK and can be downloaded free from www.deafblind.org.uk

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Cover image: Member, Joseph Ethell, tells us
about using the Communication Support Service



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