

North and West Yorkshire ASBAH



**CONNECTING THE SPINA BIFIDA AND
HYDROCEPHALUS COMMUNITY**

Sponsored by Sovereign
Health

SUMMER NEWSLINK

Letter from the editor.

Hello! How are you all? Its such a shame that we haven't been able to run our activities for over four months now. I hope that the extra edition's of the Newslink have helped in keeping you connected to your ASBAH family in these unusual times. The Newslink has always been a great way to share our news and resources with our members, particularly with those who haven't felt able to actively participate in our activities. More recently we have used it as a space to welcome the news, experiences, and stories of our members, and this edition is no exception. By offering you this space to share, my hope is to re-engage with those I have yet to meet, to learn from your lives, inspire others, and to positively impact our work as a charity going forward.

OUR BIG NEWS

Finally, before I leave you to enjoy the delights of this edition, I'd like to let you know this very exciting news- We have been awarded money from the National Lottery Community Fund to support our new Befriending Scheme!! (see inside for details)

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*'There's a crack in
everything; that's
how the light gets
in'*
- Leonard Cohen

A HIDDEN DISABILITY - THE CHALLENGES

Written by Oliver Loudon

Me and my health

I am 36. I have Hydrocephalus only, diagnosed shortly after birth. It was acquired through a genetic liver condition, present at birth. Due to complications with Hydrocephalus when I was 6, I had 4 operations in a week. I was on a ventilator, and thus asleep for that whole week. The pressure on my brain kept increasing, which affected the electronic signals from my brain to my eyes. I was left with a vertical nystagmus. (eye wobble) and a palsy on my left side. I am also epileptic.

The reason for writing this article

I have experienced numerous issues in employment and education. I wish to recount these for the benefit of those who read this, as some of the issues I cover may strike a chord. Hydrocephalus cannot be seen. I have undergone an array of challenges of living with a 'hidden disability'. These have been no more prevalent than during my education and employment.

I graduated with a degree in Law, from Northumbria University which I started in 2009. In reality, this was far from easy, and my mental health was seriously impacted. It took 6 years, but I qualified as a Solicitor in 2015.

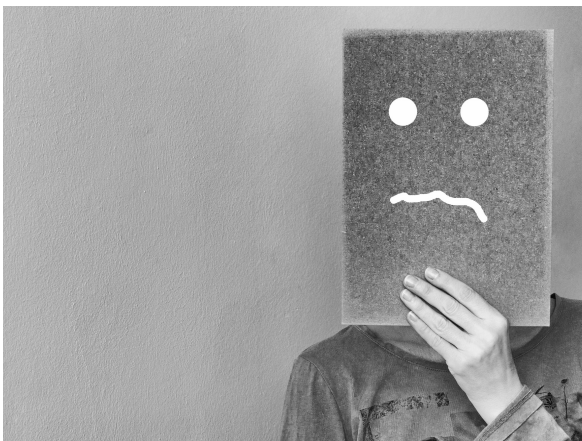
I never thought of myself as being disabled, until I was asked the direct question in March 2018. Whilst I said I did not want to think of myself like that, the honest answer I gave was yes. I was asked this by the new Managing Partner at my former firm following my father's retirement from the same very role at the firm in October 2017. At this point things started to change. They had the information about my medical issues, which I gave to them directly. I was micro-managed to within an inch of my life and my anxiety and stress levels increased. I had very long periods where I was not sleeping well. All of this I felt was because my disabilities could not be seen.

Where I am at now

I gave my all to that firm following my father's retirement. I was regularly in the office at 6am; my record was 5.15am! In short, I worked under these conditions until I resigned in November 2019. It was not an easy decision. One thing that Hydrocephalus has given me is perseverance, resilience and determination and that is why I lasted as long as I did. However, all of this happened basically, I believe, because what I have is unseen. My confidence was, and is, still shattered.

Historical challenges

I had a similar experience with an employer before starting my legal Training Contract. I was advised not to say anything about my medical issues, unless, and until, an issue arose. When I did raise it, they looked at me as if to say 'nothing is wrong with you; yet you are asking for reasonable adjustments?'. I highlight this as a contrast. I was not upfront about my medical issues, yet they found it difficult to comprehend when I brought it up. In my latest role, my employer was aware, yet following my father's retirement this was forgotten. I repeatedly reminded them. Hidden disabilities make you feel that the odds are stacked against you. I have chosen to look at this as being their issue. I am who I am. I come what I come with. The way you are, whilst it can appear personally demoralising and make you self-aware, should not be a barrier.



I have been unemployed since November 2019. Granted, the current pandemic has not helped. I am now back to square one. I was once told 'ability, not disability'. I fear this will happen again, but I must focus on my strengths and the positives. Perseverance. Resilience. Determination. If there is something you want in the employment world, then go for it. You are who you are. Make it the problem of your employer. I experienced similar issues at University.

Finally, I attended a Hydrocephalus and Spina Bifida Workshop, for adults, in Headingley, in February 2012. Even though it was with some people in a similar position to me, I was very apprehensive to attend. That was because I felt I would be received in the same way. I was wrong to think this, but the anxiety was there.

The message

Whatever condition you may have, should not hold you back. On face value, you may see it as having a stigma attached to it. Look past this..

Perseverance.

Resilience.

Determination.

You will get where you want to be.



PAUL CARTWRIGHT

No Limitations.

Growing up as a spina bifida child, I was brought up as close as possible as an able bodied child. Having had a sister who sadly passed just before I was born with spina bifida, my mum & dad had it tough. The operation to close the hole in the back had not been perfected in my sister's time plus she had hydrocephalus so sadly she lost the fight at 2yrs old.

On growing up I played in the street with my mates and did the things they did, making dens, chumping at bonfire time etc like any other child of my time. Even after having 18 major surgeries by the age of 7, I had really no inkling that I might be different to anyone else.

On starting school I was shepherded to a special school, where things began to change. I was lumped in with not only physically disabled children but mentally disabled children also. I learned at an early age that the books (children) where all been judged by the cover, not something I was used to. I grew up being told you can't, shouldn't , or won't be doing something. Thing is, most things I was told I wouldn't be doing, I'd probably all ready done, and couldn't understand stand why not.

This set me on a path to prove that you really shouldn't judge the book by its cover.



At the age of about ten it was seen that I should go into mainstream education as my (book) cover seemed to be somewhat brighter than they were used to, a very new thing at the time. So, the next year I started at mainstream school that had facilities for disabled people. This brought good and bad things, I was bullied for being different but was getting a better education than I could ever have expected at the special school. The sad thing was, that although I had an uncle who was a doctor of education, academical I was not (lol), but I always believe that everyone has a key to unlock what they are good at in life, it's just about finding the key to fit the lock, mine, was sport.

I was made to sit on side-lines of any class P.E lesson, and couldn't really understand why, I also could never understand the kids who hated P.E, after all, it was just games, they played cricket I played at home with my mates, but not at school in a gym. They played football I was always the goalkeeper with my pals on the street, but not allowed at school, the list goes on. Anyway I took it into my own hands and started to join in, much to the shock of the teachers. This was to be the turning point, I was sometime later asked if I would like to make up a team to represent the school at the Yorkshire school disability championships, after giving it some thought and realising it meant a day off school, I agreed!

The day of the event came and I did very well winning 5 gold medals & a silver in wheelchair racing, I was devastated with the silver as I liked that the most, so went home and did sit-ups and push ups for a year, I had no idea about training but was determined to be the ready for the next championship. The next year I did a clean sweep of all the events I was entered in.

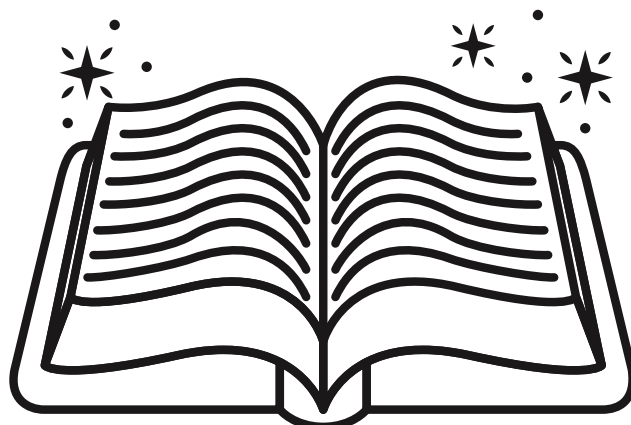
I had a friend in my class who's dad was an amputee and ran a disabled sports club, he came to school to recruit me into it, I was, and still am, a keen angler, and asked if they did fishing, he lied, and said yes just to get me involved! Things then started to really move for me, and it turned out, without flying the flag too much, I was a prodigy of my time. I was entered into senior competitions when I was still a junior and was wiping the floor with them all!

Before I knew where I was, I had a coach and was being invited to train with the GB squad, I got my first call up to to the GB team in 1981 and never looked back, I'd been all over the world by 25.

Being invited to represent your country in anything is a big thing and a feeling you never forget.

The reason I wanted to share my experience is:

1. To prove the book & cover theory as rubbish.
2. Never give up on your dreams you can be who you want to be.
3. Never accepted the words can't, won't, shouldn't.
4. Don't let anyone put you down.





**COMMUNITY
FUND**

**NORTH AND WEST YORKSHIRE
ASSOCIATION FOR SPINA
BIFIDA AND HYDROCEPHALUS**

PEER SUPPORT & BE-FRIENDING

**CONNECTING, SUPPORTING AND
CELEBRATING OUR COMMUNITY.**

A REGISTERED CHARITY SINCE 1967

Do you need someone to talk to? Want to meet others who share the same diagnosis and their families? Take control and thrive by getting in touch with us on 07966161299 or katyravenasbah@gmail.com



WE CAN BE HERE FOR YOU

For one to one support or peer led group support, we can help.

This service is for anyone new to a diagnosis or who is living with Spina Bifida and/or Hydrocephalus. This includes:

- Expectant Families
- Families
- Children and Teens
- Adults
- Parents and Carers.

MEMBERSHIP NEWS



IMPORTANT CHANGES TO YOUR MEMBERSHIP

If you can, then we would really appreciate a donation to help keep this service supporting the Spina Bifida and Hydrocephalus community.

You can do this via a bank transfer stating 'donation' at:

*Yorkshire Bank
Account Number*

35052510

Sort Code

05 05 30

*Or by sending a cheque to: 25 Hornbeam Court,
Oxford Ave, Guiseley,
Leeds, LS20 9BW*

With Thanks



What do you get from being a member of the NWY ASBAH community?

- Regular news and updates via the Newslink and email
- Peer support activity groups
- A be-friending scheme for when you need that extra bit of connection from people who understand
- The opportunity to volunteer, contribute and give back to the local association that have supported you.
- Educational workshops
- Conferences
- Residentials
- Signposting to other services.

ALL OF THIS IS NOW FREE TO YOU!!

If you are reading this online please click this [link](#) to confirm your details.

If you have received a hard copy of the Newslink, then fill out the form and send it back to us. If you are having difficulty with this then please be in contact and we can help you!

If we do not hear from you by 15th of August, you will receive a curtesy call confirming that you wish to be removed from the membership.

Incredible Lennie



Our well loved member Lennie, raises over £9k for his school over lockdown!

Lennie has been using his love of music and lockdown to help raise funds for his school in Sheffield - Paces, who are hoping to open a new facility at the school.

Sharing his incredible talent of being able to learn music by ear, Lennie has been taking peoples request's of their favorite songs, learning to play them, and sharing them on social media. He even made the BBC news where he was quoted as saying "What a huge amount of money, I never dreamed I would be able to raise so much just by playing the piano. Thank you to everyone who has supported me." His mother, Sally, who filmed the performances, said: "I am so proud of Lennie. His efforts and the amount he's raised are staggering and he amazes me every day"

Lennie has Cerebral Palsy and Hydrocephalus, this boy really is an utter inspiration! check him out at his Facebook page his mum set up for his music - Look up Lennie's Tunes.

If you would like to donate to Lennie and help support his very special school, Paces, in Sheffield, then head to his Just Giving page:

www.justgiving.com/campaign/Lennies_tunes



What have our friends at Irwin Mitchell been up to over lockdown?

Through Lockdown we have been hosting a huge number of webinars such as:
Summer Survival Guide – coping strategies for parents of disabled children, Friday 10 July 2020, 1:00pm - 2:00pm **or**
The impact of COVID-19 on special education needs (SEN) provision, 09/04/2020 **and**
Changes to the Care Act and how they could affect you, 28/05/2020 - **to name but a few!**

If you are able to follow the link below you can catch up on topics of interest that you have missed, and also get a look at what they are programming in the future! There is some really helpful and relevant information there so do investigate should you wish.

If you are keen to find out more, or are unable to use the computer/internet and would like some advice, please contact :

Sarah Coles

DDI: 0113 3946894

Mobile: 07423430280

Phone: 0370 1500 100 Extension: 6894

www.IrwinMitchell.com

<https://www.irwinmitchell.com/news-and-insights/events>

ASBAH AND WYCANN HAVE JUST MADE FRIENDS!

This is a fabulous resource for families to connect with others who face similar challenges. We hope to share lots of advice and activities in the future! check out their Facebook and Twitter pages.

FB: <https://www.facebook.com/westyorkshirecann>

Twitter: <https://twitter.com/CannWest>



LOCKDOWN GALLERY

So what have you been up to then?



SHINE NEWS



Shine have recently ran a Hydrocephalus and Learning (one hour) Webinar aimed at the parents/ carers, Senco and support staff of 3 to 13 year olds. We ran this with the support of the Witherslack Group and have a recording available.

Presented by Jan Tippet, former national educational officer for Shine Charity You are invited to learn more about hydrocephalus, a little-known brain condition, and its effects on learning. Around 1 in 1000 children are born with or acquire hydrocephalus per year, a condition where there is excessive pressure on the brain by cerebrospinal fluid (CSF). Hydrocephalus is the most common reason for a child to have a brain operation in the developed world.

In this webinar Jan will -examine the possible effects of hydrocephalus on learning raise awareness about the difficulties children and young people may face in schools find out about useful learning strategies.

This webinar is part of our Shine's Little Stars programme, brought to you by funding from The Community Fund, which supports our 0 to 10 year old members and their families to get the best start in life.

If you are interested in receiving a copy of the Webinar, and Hydrocephalus support resources i.e. What is Hydrocephalus booklet, please do get in touch with :-

Denise Deakin Shine Little Stars Early Intervention Project Worker

Email :- denise.deakin@shinecharity.org.uk

Mobile :- 07824464266

You may also wish to get in contact with your regional Support and Development Worker:-

Saima Khalil

Mobile: 07917402926

Email: saima.khalil@shinecharity.org.uk

Other useful addresses and telephone numbers:

Shunt pathway scheme

Call the shunt pathway scheme if you have a concern about your child's, or your own, shunt. and you Ring the following ward number direct for advice: **Children (under 16 years) 0113 392 7452**

Adults (female) 0113 392 7424 Adults (male) 0113 392 7425

William Merritt

Disabled Living Centre & Mobility Service **Aire House Town Street, Rodley LS13 1HP Tel. 0113 350 8989 Email: info@wmdlc.org Web site: www.wmdlc.org**

The Centre is a registered charity and provides impartial information, advice and assessment on equipment and practical aspects of daily living for disabled people of all ages, their carers, professionals and older people.

Bradford Disability Services

103 Dockfield Rd, Shipley BD17 7AR tel DeB: 01274 589162 email: equipment@disabilityadvice.org.uk

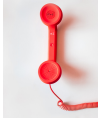
DaB: 01274 594173 email: enquiries@disabilityadvice.org.uk DeB and DaB give a similar service to the William Merritt DLC and they sell RADAR keys for the national key scheme (for toilets).

Family Fund

08449 744 099

www.familyfund.org.uk.

Keep in touch with us and follow our social media pages...



Tel: 07966161299



Email: katyravenasbah@gmail.com



Facebook: NWY ASBAH @ASBAHNWY



Instagram: ASBAHCHARITY



Try Fundraising

The benefits of fundraising:

- Getting to educate and raise awareness to your community on your condition
- Meeting new people and sharing stories
- Being an ambassador for your local association
- Raising money to continue supporting others
- Gaining entrepreneurial and volunteering skills - which look great on CV's, records of achievement, Brownies, Cubs and Scouts awards, Duke of Edinburgh's etc.
- Most of all, getting that great feeling of accomplishment and a warm and fuzzy glow from knowing you've done good!!

If you would like to fundraise for NWY ASBAH we would very much appreciate your time and efforts. Please be in touch for help and marketing materials should you need them!

