LICANSIO III

For everyone affected by spinal cord injury

Autumn 2015

Up course has changed the way I see myself

MENTORING FOR FAMILIES: SANDY'S STORY

BECOME A CORPORATE PARTNER

INSIDE: BACK UP BALL

BBC LIFELINE

LATEST NEWS



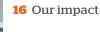
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Back Up is for everyone affected by spinal cord injury, regardless of age, level of injury or background. We are here for family members too. Our services include:

- Mentorina
- Wheelchair skills training
- Residential activity courses
- Support to make sure children are included at school
- Support with going back to work

All our services aim to build confidence and independence.

We understand a spinal cord injury can be devastating, but we believe it shouldn't prevent anyone from getting the most out of life.

To find out more call us on **020 8875 1805** or visit backuptrust.org.uk



The Back Up Trust, Jessica House, 191 Wandsworth High Street, London SW18 4LS. Reg Charity Numbers 1072216 and SC040577. Company No 3596996 Registered in England and Wales



NEARLY THE BIG 3-0

It's important for Back Up to let you know how our services make a difference. I'm pleased to report that we have exceeded last year's target of reaching 600 service users; signing up almost 700. But people's needs are increasing more quickly than we thought. The challenge now will be to stay in touch with more and more people as they return home from hospital, and to continue to meet their needs.

2016 will see Back Up celebrate our 30th anniversary. We've come a long way since Mike Nemesvary founded the charity in 1986 and want to invite all of our supporters, volunteers, service users and partners to help us mark the occasion! You can read more about how to get involved on page 13.

Best wishes.

Louise

Chief Executive, Back Up louise@backuptrust.org.uk or **020 8875 1805**.

LATEST NEWS

Back Up awarded over £400k by Big Lottery

Back Up is thrilled to have been awarded £404,884 by the Big Lottery Fund's Reaching Communities programme. The five year grant will help us reach more than 500 people a year in England through our Join the Dots Outreach and Support project, which includes telephone support, residential courses and community-based wheelchair skills training. The funding means we'll be able to equip even more people with the practical and emotional tools to make the transition from hospital to home.

Registrations are up!

Record numbers of people with spinal cord injury have signed up to receive our help for the first time in 2014/15. This is partly thanks to our new joint registration process with Aspire, which gives people the option to sign up to receive help from both organisations at the same time. This collaboration has helped us to register a record 694 people with Back Up in 2014/15, so that we can keep in regular contact with them when they return home.

Join Back Up and Aspire's joint London to Paris cycling challenge

Our first ever joint challenge event with Aspire is taking place from 3rd to 6th June 2016, We're looking for cyclists and hand cyclists to take part in the ride from London to Paris, which will cover 300 km in three days. All the money raised will be split equally between Back Up and Aspire. It's a great way to mark Back Up's 30th anniversary. To sign up visit www.backuptrust.org.uk/london2paris

Back Up's drive to raise awareness of employment

This year on Spinal Cord Injury Awareness Day, Back Up called for a greater focus on employment and increased support for the 1,000+ people who are paralysed every year. Our survey of the experiences of people with spinal cord injury in finding and keeping employment was reported in the Independent on Sunday and showed 82% of people who were not currently working did not feel confident about getting a job, 44% were not encouraged to consider work as an option while they were in hospital and 33% didn't receive any support to help them into work. We explore the issue of employment on pages 6 and 10 of this Transform. To find out more about our survey, visit www. backuptrust.org.uk/worksurvey











GAINING SKILLS FOR INDEPENDENCE

Our Skills for Independence course takes place once a year at Zinc Arts Centre in Chipping Ongar, Essex. The next one will take place in Autumn 2016. What does this course offer and could it be right for you?

Skills for Independence helps you feel more positive about your future, boost your confidence, develop new skills and achieve personal goals.

The course focuses on the skills that will improve your independence; whether it's having a bath, using public transport or getting dressed. The aim is to give you the confidence you need to lead a more independent and active life.

The group leaders and trainers work with you before the course to establish what you want to achieve, as well as suggesting some new ideas. With Back Up's support, we aim for everyone to amaze themselves at what can be achieved!

Here's what two recent course participants had to sav:

66 Attending the course has made a massive difference to my confidence and being able to get out and about in the real world. All of the skills I learnt were invaluable and I am now living my life again. >>

66 I will always be in debt to you for helping me turn my life around. >>

For more information, contact the courses team on 020 8875 1805 or visit www.backuptrust.org.uk/courses

This course is generously supported by The Big Lottery Fund

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THE IMPORTANCE OF **VOCATIONAL REHAB**

Since 2007, Back Up has provided residential Back Up to Work courses which help people reveal their talents, enhance their CVs, receive advice on job hunting, practise interviews with recruiters and rebuild their confidence. Read about lan's experience of attending this course on page 10. We have also started to offer one-to-one support after the courses to ensure people achieve their aspirations. Evidence shows that early intervention is key to helping people back to work, starting in hospital.

We hear the views of three people working in vocational rehabilitation about its importance for people adjusting to life with a spinal cord injury.

Kathleen Kelly, Senior Social Worker at Dublin Spinal Unit, says:

66 Vocational rehab is crucial and should be factored in early on for everyone with a spinal cord injury. The evidence is clear - if people are working and doing activities they're less likely to get ill or suffer from mental health issues. And let's not forget important factors like the financial independence, self confidence and social interaction it provides. >>

Fiona Ryan, Senior Occupational Therapist,

66 It's about 'vocation' in the broadest sense, so it can include voluntary work, childcare and leisure activities. On our rehab programme here in Dublin we liaise with people's employers to help facilitate their return to work, or help people look at possible new career paths, sometimes years after their injury. Peer support is a fundamental part, which is why Back Up's work is so vital. There's no substitute for hearing someone's real, lived experience and we know Back Up provides that crucial supportive network for people in the UK. >>

Peter Davies has run his own vocational rehabilitation consultancy based in Scotland since 1993. He says:

66 Vocational rehabilitation focuses on having a place in the world that's defined by ability, not disability. It should be integral to rehabilitation through hospital and into the community. In our society we're defined by our occupation and we can lose our place in the world if we aren't able to work. People need to be aware of services that are there to help, such as Back Up's vocational courses, which help people consider career opportunities, prepare for going to university, or learn to be more independent. >>

To find out about Back Up to Work and our other courses, visit www.backuptrust.org.uk/courses

If you're a health professional and would like to share your views in a future issue, call us on 020 8875 1805

neurokinex is the UK's leading provider of activity-based rehabilitation programmes for spinal cord injury.

Activity-based rehabilitation programmes consist of carefully crafted activities that target the body and nervous system above and below the level of injury in order to maximise physiological and neurological potential.



"The specialised equipment is amazing and the support and motivation from the team of trainers is outstanding, helping me improve both physically and mentally. Taking part in the programme is the best decision I have made since my injury"

Lucky Phull (T6 incomplete SCI)

neuro

REDEFINING POSSIBILITIES

Unlike other traditional rehabilitation providers, neurokinex:

- uses a multi-disciplined team from a variety of health and fitness backgrounds providing a dynamic, innovative and fun approach to rehabilitation
- is inclusive of all types of spinal injury and levels of paralysis
- is a not-for-profit committed to delivering the best rehabilitation solutions to the Community

Facilities based in:

- Watford
- Antrim
- Bristol

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- eneuroki<u>nex</u>
- neurokinex.org
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c 0300 77 77 188

Fundraising ADVERTISEMENT

BACK UP'S BBC LIFELINE APPEAL

Many of you will have watched Back Up's BBC Lifeline appeal in June. We want to thank all our supporters for helping spread the word about the appeal and make it a huge success. So what has been the outcome of the appeal for Back Up? We peek behind the scenes and take a look at the results...

Back Up's appeal was presented by Olivia Colman, star of TV's Broadchurch, Rev and Peepshow, and told the stories of two people affected by spinal cord injury. Clair Turnbull and Joe Lockington. It also featured one of our mentors, Matt King, who also appeared in Back Up's 2012 BBC Lifeline appeal and Tim Scott, who teaches vital wheelchair skills to people affected by spinal cord injury. Our appeal aimed to raise awareness among as many people as possible, showing viewers both the physical and psychological impact of spinal cord injury for the injured person and their family.

THE RESULTS



Over **800,000** viewers watched across BBC One and BBC Two



3,367 people watched our appeal on YouTube



We tweeted 488 times. got 608 mentions and 10.2k profile visits



We've received over £18,000 in donations

You can still donate and transform the lives of people with spinal cord injury like Clair and Joe. Text BACK22 to 700 give £5 or you can donate via our website.







You can watch the appeal on YouTube by searching for







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On Facebook.

- the day the

broadcast on

BBC One

appeal was first

we reached **13,795** people on 14th June

Ian Hetherington, aged 54, sustained an incomplete injury at C4 during a bike race in Snowdonia in 2012. He tells us how the Back Up to Work course has helped him consider his next career move.

lan says:

66 I've been in full time rehabilitation since my injury and it's only recently that I have felt strong enough to think about returning to work. I don't use a wheelchair, but I'm not able to go back to my former job as an architect due to my limited mobility and hand function. I can walk independently indoors but outdoors I use elbow crutches. My Occupational Therapist told me Back Up had a course to help people prepare for going back to work taking place the following week. So I didn't really have time to think about it - I just went for it.

Just getting to the course was a revelation in itself for me, as it was my first train journey alone since my injury. It pushed me out of my comfort zone and I felt I'd already achieved something before I even got there! It was also the first time I had interacted with other people with spinal cord injury and I found it interesting to hear how others

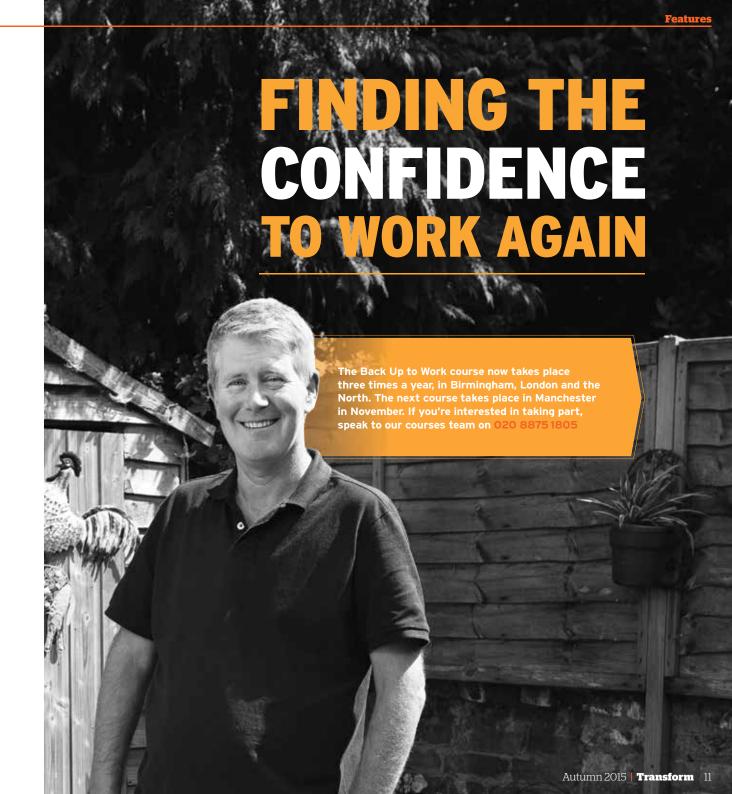
"Back Up to Work has changed the way I see myself."

cope. The course was held in the Allianz office and I found being back in a work environment for the first time since my injury very helpful it restored a lot of lost confidence.

I would wholeheartedly recommend Back Up to Work because it has changed the way I see myself. I now realise that just because I have a spinal cord injury doesn't mean I have nothing to offer - in fact I've done a whole lot of things which are relevant to an employer. The practical side of the course was very helpful - we discussed how and when we should disclose our injury when applying for a job and how to explore the accessibility requirements for an interview. We learnt how to get our CVs in order and we had live interviews with senior Allianz staff which were invaluable. Receiving real feedback about my performance has given me so much self-belief.

Since the course, I've started contacting employment agencies. I've also met with an architecture acquaintance that might be able to offer me some consultancy work. Without a doubt, the Back Up to Work course has given me the confidence to follow up these opportunities.

I've decided to get more involved with Back Up in other ways too -I'm already speaking to them about volunteering as an ambassador. The Back Up to Work course was just the start of my journey. >>





IT'S BACK UP'S BIRTHDAY IN 2016 -**HELP US UNLOCK POTENTIAL**



Back Up's founder, Mike Nemesvary, was a stunt skier who broke his neck whilst training. In 1986 he set up the charity to help other people in his situation to get back to ski-ing post-injury.

30 years on, our services have expanded and changed to meet the needs of people affected by spinal cord injury. Our wheelchair skills training, mentoring, outreach and support and residential courses help people of all ages, injury levels and their families regain confidence, and independence.

There lots to celebrate in 2016, thanks to you and all our service users, supporters and volunteers. There's a growing demand for our services. But while we've come so far there is much more to be done. Despite huge advances in medical care and research, improvements to the day-to-day lives of people with spinal cord injury haven't kept pace. Some groups find it especially hard to access support. We want this to change.

This is the year we set ourselves a challenge - to reach a wider group of people affected by spinal cord injury, raise awareness of the issues they face and bring people together for change. Our aim is for everyone affected by spinal cord injury to live the life they want to lead and to fulfil their potential.

Get involved:

- Share your memories, personal aspirations and experiences
- · Invite our volunteers to raise awareness or funds in your school, workplace or community
- Take part in a fundraising event or challenge
- · Become a volunteer buddy, mentor or wheelchair skills trainer
- · Follow and like us on social media

What's happening?

Each month we will focus on a theme - an issue, an aspect of our work or a specific group of people affected by spinal cord injury. We will be turning the spotlight on the fantastic volunteers who deliver our services and sharing the stories of individuals and families we support.

2016 Monthly themes

FEBRUARY J JANUARY J MARCH U Challenge Celebration **Families** MAY APRIL JUNE **Partnership Diversity Volunteers** AUGUST SEPTEMBER JULY Children and Independence Champions

OCTOBER 1 **Employment**

I NOVEMBER U Fun

f J december f J

Future

young people

Keep in touch by contacting us on 0208 875 6727; visit our web site, www.backuptrust.org,uk/anniversary, email anniversary@backuptrust.org.uk.



We will be using the hashtag #BackUp30 throughout the year so why not join the conversation?

GIVING BACK TO BACK UP

Stephanie Benac, aged 23, from Stoke-on-Trent, sustained a spinal cord injury at T9 following surgery to remove a bone tumour. However, she hasn't let this stop her from leading a very active life since her injury and we caught up with her about her latest fantastic accomplishment - a kayaking £1,100 for Back Up.



Impact Impact

BACK UP'S IMPACT IN 2014/15



694

Last year, we registered a record 694 new people with spinal cord injury with Back Up. This increase is thanks to close working with the spinal cord injury centres and with Aspire.



550

We trained 550 people in wheelchair skills, with 91% of them increasing in confidence and 89% learning new skills.



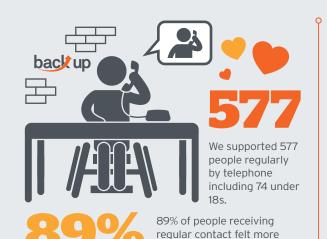
We matched 118 people with a mentor including 80 adults, 2 under 18s with SCI and 36

100%

family members.

100% of people who were mentored achieved their goals.





supported.



100% of our young wheelchair skills trainers are more confident teaching wheelchair skills and talking about spinal cord injury.



100%

100% of course participants would recommend us to a friend.

98%

98% of people on our courses achieved their personal aims.



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Features Features

BACK UP HAS QUITE LITERALLY SAVED ME

When someone is spinal cord injured, their family members often need support to adjust. Sandy Shaw shares her experiences of Back Up's family mentoring service, which matches family members with other people who have been through a similar experience.

broke his neck in a swimming pool accident in Africa four years ago, our lives changed irrevocably. Like most mothers thrown into this situation, I knew nothing of spinal cord injury. After being flown home from Ghana, Tom was admitted to Stoke Mandeville Hospital where he spent almost a year. Apart from a broken neck, he had also developed pneumonia and a huge pressure sore on his back which required extensive skin grafting. He had to have two major operations on his back and neck and spent four months in traction, only able to move his face.

poor shape emotionally. Eventually I plucked up the courage to call Back Up and I will never forget that moment. I hadn't realised how far I was sinking until at least an hour of sobbing and listening to the kind, warm, beautiful voice on the end of the phone. She understood! It was a defining moment for me because suddenly I did not feel totally on my own. I had finally met someone who knew about my alien planet and knew people that lived there!

Back Up put me in touch with mentors: the parents of young people with a similar injury

to Tom's, who helped me to begin to come to terms with what had happened to my beautiful boy and to

"I plucked up the courage to call Back Up and I will never forget that moment"

After Tom's injury I was in denial and ignorant of what spinal cord injury really meant. It was when Tom was eventually discharged and we were out in the world that I realised we had landed on a new planet called spinal cord injury. We had no map, we did not speak the language and we didn't know any of its inhabitants outside of the hospital.

As a mother, I felt the need to be insanely positive, encouraging, entertaining and empowering. But reality hit me some time in the second year and I found myself in very

our family. They had had similar practical and emotional experiences. They still help me and I learn so much from them. Back Up has, quite literally, saved me and continues to do so.

Tom took part this year in a Back Up ski karting course in Sweden. Not only did Back Up provide a personal assistant for each of the five participants, but they helped with the equipment and everything was meticulously organised.

I recently spent five months working for a charity called VSO in Papua New Guinea, training student teachers and their lecturers, which was wonderful. I can honestly say that without Back Up, I would not have had the courage to leave Tom and pursue my own dream. I am now counting the weeks until I can train as a mentor for Back Up and start to give back, by supporting other mothers and parents of children who have suffered spinal cord injury.



Back Up provides trained mentors for people with spinal cord injury, as well as their partners, parents, siblings and other family members. If you feel you would benefit from Back Up mentoring, or if you would like to become a mentor call the team now on 020 8875 1805 or email polly@backuptrust.org.uk

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REMEMBERING **JAMIE**



When Jamie Hay sadly passed away last vear aged just 20 due to complications from his spinal cord injury, his family generously chose to hold a collection at his funeral which raised funds for Back Up. His mother, Linda, tells us why this tribute was so important to them.

66 Jamie was 16 when he was injured at C6/7 in a road traffic accident in 2010. Back Up supported us right from the start, both in the hospital and by staying in regular contact after he came home. The next year he went on a Back Up course in the Lake District and he was a different boy by the end of the trip. He pushed himself to try all the activities and he thoroughly enjoyed it.

Next he wanted to go on a skiing course with Back Up but unfortunately he never got the chance. Jamie was a very unusual case and kept on having one major setback after another following his injury. He sadly died last year from sepsis.

The fact Jamie achieved so much during his short life was down to his grit and determination. He got two Scottish Highers even though he was constantly in and out of hospital. He flew to London to watch football and boxing matches and went on holiday to Magaluf with a group of friends and two carers. I couldn't hold him back.

Jamie got so much out of the Back Up course that it felt right to raise some money for them at his funeral. We collected £800 for Back Up and £800 for a charity called Options, which was run by the physiotherapists who helped him. I hope this means other people with spinal cord injury can be supported in the way that Jamie was, 🥦

A gift to Back Up in memory of a loved one, whatever the size, would help us to support even more people with spinal cord injury in their darkest hours. To find out more, speak to Melissa on 020 8875 1805 or visit



In a galaxy far far away

Every year, you have the chance to make your way to the largest and best fully accessible party in the UK. This November, we welcomed 400 quests at a superb space-themed event including a fantastic awards ceremony, auctions and dancing. Thanks to everyone who helped make it such a great night.



2016's 30th Anniversary Ball will be even bigger and better:

Where: Hilton Birmingham Metropole Hotel

When: Saturday 5th November 2016

How: Early bird discounts are available in November - contact Leigh Anne on **020 8875 1805** or visit backupteam.org.uk/back-up-ball to find out more.



Marta Vernau, regular Back Up Ball attendee, says:

66 The Ball is the party of the year! It's when those of us who have become friends through Back Up get to catch up, let our hair down and make new friends. Planning our outfits and travel all builds up to the excitement, resulting in a fun evening in lovely surroundings, celebrating everyone's achievements and raising much needed funds! >>

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For further information call Peter Henry (C5/6) or Linda Adamsen on 01524 34100 or visit www.origincare.com

COULD YOU BE A CORPORATE PARTNER FOR BACK UP?



Whether you are looking for team building, staff development opportunities, a strategic partnership or just a little fun, Back Up can help you achieve your goals. Natalie Lipscombe, Market Manager at our partner Coloplast tells us more.

66 We work with Back Up because we believe there is a lot of synergy between our two organisations in terms of mission and values. Back Up's work is all about helping people get their lives back after a spinal cord injury and that's very close to our hearts - we want to ensure people are able to get on with their lives with dignity and a high quality of life. We provide a range of products to make life easier for people's intimate healthcare needs, such

as bladder and bowel management, which is obviously a huge part of adjusting to life with a spinal cord injury.

Coloplast have been the headline sponsor for Back Up's wheelchair skills training programme since 2008. We provide volunteers to help run the training sessions and refreshments for participants. By supporting Back Up in this way, we are able to see firsthand the challenges people with spinal cord injury face. This insight is invaluable - both in terms of better meeting our customers' needs, and also broadening our teams' awareness and understanding of disability.

We've also entered teams for the Snowdon Push and attended the Back Up Ball - events like these encourage a greater diversity of our employees to interact with Back Up and understand their work. It's also really important to us to raise money and give back to the community. We see our work with Back Up as a partnership and not just a marketing opportunity, so we're always looking for ways we can work together on shared goals. >>

Sean McCallion, Corporate Partnership Manager at Back Up says:

66 It's really important to us to work with organisations who share our vision and values, like Coloplast, so that we can create partnerships that are mutually beneficial. Partnership working is a big part of our ethos at Back Up and we're always on the lookout for new, innovative ideas which can help us better support people affected by spinal cord injury. 🥦

Do you work for a company who might consider working with Back Up as a corporate partner? If so speak to Sean on 020 8875 1805 or email seanm@backuptrust.org.uk. We are looking for new partners to work with us on our under 18s services and there are plenty of opportunities to get involved at our events.



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