back up | Compared to the content of the content o

SAMUEL

to see Lucy explain to my classmates what my injury is.

YOUNG PEOPLE INSPIRE COURSE

JOIN THE DOTS

INSIDE: SUPPORTING FAMILIES 30 FOR 30 CHALLENGE | 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:

- Mentoring
- 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 rebuild 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



CELEBRATING **30 YEARS**

Welcome to our 30th anniversary edition. Thanks to supporters like Sophie (page 19) and to our dedicated staff and volunteers, Back Up has grown dramatically since our first ski course in 1986. Over 700 people now receive our support. We are here for everyone affected by spinal cord injury, including people who are able to walk (page 4). We also offer unique services with and for under 18s. A spinal injury in childhood can damage your chances of a job or getting married. But with the right support and opportunities to meet others and to participate. voung people like Sam and Yasmin (pages 10 and 14) can enjoy full lives now and in the future. That's definitely something to celebrate!

Best wishes.

Louise

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

LATEST NEWS

New Next Steps course

Our new Next Steps course is for people with an incomplete spinal cord injury who are able to walk, who may use a wheelchair some of the time, or not at all, and want to rebuild their confidence and independence. The three day course will cover skills such as using public transport, making a meal and getting around a busy city. Developed by and with people who are able to walk, this course is planned for September 2016 and is likely to take place in Bath or Liverpool, subject to confirmation.

Find out more at: www.backuptrust.org.uk/nextsteps

Back Up takes wheelchair skills to Dublin

We have close links with the National Rehabilitation Hospital in Dublin, so we were delighted when they recently asked to sample our wheelchair skills training. During our visit in January, our team led three wheelchair sessions for inpatients. We're now exploring how we can work together to offer sessions more regularly. Dr Eimear Smith, consultant in rehabilitation medicine, said: "There was great enthusiasm from both patients and staff about the sessions. The support provided by the team from Back Up was invaluable."

Spotlight on a Youth Advisor

Congratulations and thanks to Ashleigh Harris, who is a youth advisor, young group leader and wheelchair skills trainer. Ashleigh won a "Children of Courage" award for her efforts in overcoming her disability and for her volunteer work with Back Up. Ashleigh also recently shared her story as part of November's BBC Children in Need appeal. In the film, she explained how attending a Back Up multi activity course transformed her life: "I genuinely don't think I would be here without the support they gave me." To see the film, search for BBC Children in Need on YouTube.

Back Up Ball 2015

Back Up's Galactic Ball in November was a massive success, raising a total of £27.000. During the event, we recognised our volunteers and supporters by giving out nine awards. Winners included Julie Hill, who received the Volunteer of the Year award. Joe Lockington, our Young Person of the Year and Malene Sweeney who received our Special Recognition award. We also presented awards to Joe Gadd, Michele Beckwith, Helen Cooke, Veronika Capova, Leigh Day and Stewarts Law. See page 5 for details of this year's Ball.











A special night to celebrate 30 years of supporting people affected by spinal cord injury

Since our very first Back Up Snow Ball in 1986, we have always known how to throw a great party. For anyone who has ever come along to one of our balls, you will know it is always a night to remember.

In our 30th anniversary year, it seems fitting to bring back the theme of our first ever Ball in 1986 - so we are delighted to invite you to the Back Up Snow Ball 2016! This will be the most glamorous and dazzling event vet - and vou can help us make it happen by joining us, letting your hair down and sharing in the festivities.

Following a year of anniversary activities, in which many of you will have been involved, this will be a fantastic opportunity to celebrate what we have achieved together and to look to the future - with plenty of fancy dress, fundraising and dancing.

"What didn't I enjoy?! The people, the meal, the fancy dress and the atmosphere - fantastic."

Where: Hilton Birmingham Metropole Hotel

When: Saturday 5th November 2016

Dress: Winter themed fancy dress or Black Tie

How: Tickets are £80. Book now by calling 020 8875 1805 or visit

Quick before they all sell out!

2016 **EVENTS CALENDAR**



To find out more about our courses and activities, call us on 020 8875 1805

Visit our anniversary blog to find out how we're marking our 30th year - backup30.wordpress.com.

MAY

Back Up city dinner, London 5th

Over 50s Edinburgh city skills 19th - 24th

Edinburgh Marathon Festival 28th - 29th

5 day multi activity course, Exmoor 30th May - 3rd June

JUNE

London to Paris cycle ride 3rd - 6th

Back up to work course, Birmingham 5th - 7th

7 day multi activity course, Lake District

18th - 25th



JULY

AUGUST

NEW!13-17s youth city skills, Bristol 5th - 8th

18-25s moving forwards course, Leeds 16th - 20th

Snowdon Push, Wales 1st - 3rd

Under 13s multi activity course, Exmoor 25th - 29th

> City skills course, Belfast 28th July - 2nd August

Prudential Ride London-Surrey, 100, London 31st



NEW! Next Steps course Venue & date tbc

Dragon Boat Race, London 8th

Great North Run, Newcastle 11th

Over 60s multi activity course. Lake District 12th - 16th



OCTOBER

Skills for independence course Date & venue tbc

Royal Parks Half Marathon, London 9th

NOVEMBER

Back Up Ball, Birmingham 5th

Back up to work course Date & venue tbc

Run in the Dark, London and Manchester

16th

J ALL YEAR

Zipline - Nationwide venues Throughout the year (restrictions may apply)

Skydive - Nationwide locations Throughout the year (restrictions may apply)





Coloplast







For information on the SpeediCath range and other continence solutions for both men and women, go to www.coloplast.co.uk/backup, where you can also request free samples.

Neil Malcolm is a keen hand cyclist and wheelchair racer. He competes nationally in Paratriathlon. After a skiing accident left Neil permanently paralysed, he was determined not to let his injury hold him back. He struggled with intermittent selfcatheterisation until he found a product that met his needs.

Neil says: 66 In 2012, a skiing accident resulted in damage to my spinal cord. I had to start adjusting to a new life. I had been a very active person before and I decided never to let my spinal cord injury hold me back. The London Paralympics had only been a few months before and I was not going to let this slow me down.

During my rehabilitation in Pinderfields spinal cord injury centre, I was determined to get the most out of my time there. I engaged with the staff and pushed myself hard. The thing that never got easier was coming to terms with intermittent self-catheterisation (ISC).

Whilst ISC seemed like a great solution at the time, the whole process was like trying to thread a needle with cooked spaghetti. I used to limit where I would go purely on how many catheters I could carry and hide away, to avoid intrique from friends.

A Back Up wheelchair skills course sponsored by Coloplast helped give me back some of my lost freedom. That is when I discovered SpeediCath Compact, and took some samples from Karen, the Coloplast representative helping out at the training. Until then I had thought that all catheters were the same but it was a revelation trying it for the first time. I had finally found a product that fits me, and my lifestyle.

SpeediCath Compact is easy to use, convenient and discreet. It goes with me wherever I go and I feel it allows me to get on with my life. >>



Back Up's core focus is providing direct support to people with spinal cord injuries and their families. However we recognise that in order to continue to improve people's lives we need to influence and change the systems and services which other organisations provide, for example the NHS.

A key part of Back Up's influencing work focuses on ensuring under 18s get access to good quality specialist rehabilitation and ongoing care after their injury.

Stef Cormack, Back Up's Head of Services. says: 66 A few years ago we became aware that a lot of children were not getting specialist spinal rehab, which is considered essential for adults. Many children are in a general hospital on the children's ward, where there is a lack of specialist knowledge. If a child misses out on specialist help it can have a long term detrimental impact on their development. They may never realise their true potential. >>

At Back Up we're determined to ensure children get access to specialist rehabilitation after injury, and as part of the NHS spinal cord injury clinical reference group, we're

working with spinal centres across the UK to develop pathways for children's care and rehab after injury. The process is part way through, with a draft document that is currently in the consultation phase. Some new approaches will be tested this year and should be improving children's lives by 2017 or 2018.

Stef says: 66 Rehabilitation for children and young people with spinal cord injury lasts much longer than just the initial post-injury phase. As they grow they need to learn to manage their condition, become independent and participate fully in all aspects of normal life; education, social and recreational activities, and career planning. They need vital specialist and peer support. It's critical to get things right from the start. So they can build their confidence and skills and live life to the full, both now and in the future. >>

To find out more about Back Up's influencing work, or to read more about the consultation process on our work with the NHS spinal cord injury clinical reference group, speak to Stef on 020 8875 1805.

Back Up is proud to introduce a new Youth City Skills course for 13 to 17 year olds - planned and developed by our team of Youth Advisors.

The course will be held in Bristol in August and will include everyday activities such as using public transport, visiting a museum and the theatre, and a treasure hunt around the city. Similar to the adult city skills course, it will last three days and promote the young people's independence, along with the new element of bringing a sibling or friend.

This course was the brainchild of Back Up's Youth Advisory Group, which explores how to improve Back Up's services for children and young people. The Group for young people has been running since 2012.

Yasmin Attisha, 16, one of the Youth Advisors involved in planning the course, says:

66 We picked Bristol as the venue because it's a cool city with some great places to practise your wheelchair skills. Getting around town is very important. And if a friend who doesn't have a spinal cord injury is interested in learning we want them to come along. We want them to see what we do. >>

Yasmin says the Youth Advisory Group helped her meet young people in a similar situation.

66 When you're away for a weekend with people with similar problems you can just laugh about it. They're going through what vou are. Often we just have a lot of fun. The Youth Advisory Group has given me a lot of confidence. I'm thinking of new ideas and things to do. I feel I'm making a difference to other people. >>

Beth Scrimshaw, Under 18s Service Manager, says: 66 We really believe in young people being able to volunteer and participate in Back Up. We depend on young people for strategic guidance. >>

This is the second new Back Up course developed by the Youth Advisors. In 2013, they came up with the idea for the Moving Forwards course for 18 - 25 year olds, which bridges the gap between the courses for under 18s and adults. Based at the Leeds University campus, it helps young adults



deal with issues around their increasing independence such as travelling and moving away from home. This year the Group is holding a second training weekend in Coventry to further develop their plans.

Beth says: 66 Youth Advisors give us the ideas and we help them to become a reality. It's an exciting partnership - it's not just lip service and ticking the box. We encourage them to lead and run services. >>

The Youth Advisors are active on social media





and have a closed Facebook group for young people with spinal cord injuries where they can communicate with others throughout the UK and post practical information, such as choosing which cars are good when learning to drive. Meeting other young people with a spinal cord injury is very important.

Beth says: 66 Get them together and it's amazing the ideas they come up with. In the space of two days there's a big change. At first the group can be guiet but by the end strong friendships have formed and opinions voiced! >>





LOTTERY FUNDED

This course is funded by the **National Lottery** through the Big Lottery Fund.

There are a few places on our August City Skills course still available. We're also looking for new Youth Advisors for our training in July. Speak to Beth on 020 8875 1805 to find out more.

THE IMPORTANCE **OF SUPPORTING FAMILIES**

When someone is going through rehabilitation after a spinal cord injury, their families often need support. Sarah Standish is Family Counsellor at the National Spinal Injuries Centre at Stoke Mandeville. She shares her views and experience with us.

66 The most common issue I deal with is emotional trauma during the 'crisis' phase immediately after the injury. Then there are the practical considerations when someone has to be in a rehab centre for a long time - things like who's looking after the kids and the house: these are big concerns for people. Anxiety and sleep deprivation are very common - there is endless worrying for the injured person. Am I doing enough? Am I doing too much?

As well as offering counselling for families whilst their loved one is in a rehabilitation centre. I also offer a follow up service 6-8 weeks post discharge - this can often be the most challenging time as families make the transition home after months away.

It doesn't really matter what the level of injury is, or its cause - adjusting to spinal cord injury is tough whatever the circumstances. However, there are things that people find helpful across the board, such as accurate information, being able to ask questions, meeting other families in a similar situation and most importantly - hearing the real, lived experience of other people who are further along in their journeys with spinal cord injury. These are the things which make a difference.

That last one is obviously where Back Up has a huge role to play. My experience of Back Up's family mentoring service is that speaking to someone who has been there



really does help. There are things people can ask a mentor that they can't ask me because I wouldn't have the answers. People have told me it feels different than getting medical advice - it has more meaning to hear it from someone with personal experience. It helps people to translate the advice they have heard in hospital into real life. I tell everyone I work with about Back Up's family mentoring service and I always emphasise the value of giving it a go. 🤧

If you are the family member of someone with a spinal cord injury and would like to talk to a mentor, call our mentoring team on 020 8875 1805 or visit www.backuptrust.org.uk/ familymentoring. We'd also love to hear from you if you are a health professional and would like to share your views in our next issue.

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After ten weeks in hospital Samuel Appleton, aged nine, was ready to come home. A spinal infarction during a rugby match had left him with minimal feeling and movement in his legs and needing to use a wheelchair.

Ali, Samuel's mum says: 66 The injury turned our lives upside down. You think when you've got him home from hospital you've achieved something, but some of the hardest times were ahead: getting all the services lined up and getting him back to school. >>

Samuel's school, Stonefield Primary near Woodstock in Oxfordshire, was very supportive, helping him keep up with his studies whilst in hospital and encouraging him to return one morning a week as his condition improved. The school has two other wheelchair users, but it had no experience with spinal cord injury. Samuel had always been very sporty and active but now couldn't easily take part in PE lessons or playtime games.

Ali says: 66 The school was asking questions we didn't have the answers for. There was so much to do we didn't have the time to research things. The school has been brilliant, and our relationship with them was very positive, but they wanted more information and help so they could do their best for Samuel. 99

Ali had met Back Up when Samuel was in Stoke Mandeville, so she contacted our school inclusion service for help. She says: 66 They were on it right away. Within half an hour of speaking to us, Back Up got on the phone to the school arranging when to come in and see them. >>

Lucy Robinson is one of Back Up's 25-strong team of volunteer school advocates and has a spinal cord injury herself. She came to speak to the children and to answer any questions they might have about Samuel's injury.

Ali says: 66 Kids want it straight and Lucy was very honest and open and talked about her own injury. She really put them at ease. >>

Lucy also met staff and helped them to make Samuel feel included in school activities. By fully involving all the children in activities, it means Samuel doesn't feel as if things have changed just because of his injury.

Samuel, now ten, says: 66 Lucy told the class to ask before helping me, which is great because I would rather be independent. Before they would open doors for me, but I can open them myself. It's helpful but I don't want people doing stuff for me.

66 It felt good to see Lucy explain to my friends and classmates what my injury is. It's difficult for me to explain - it's new to me too. I'm not being asked as many questions as I was. I'm still asked some, but I can answer them because Lucy's answered all the hard ones. >>



We wouldn't be able to deliver this service without the support of The Freemasons' Grand Charity, The John Horniman's Children's Trust and Evan Cornish Foundation.





LET BACK UP HELP YOU

We wouldn't be able to delivery this service without the support of The Motability **Tenth Anniversary Trust**



Going from the smooth surfaces and wellordered surroundings of a spinal centre to the bumpy roads and wonky cambers of the average British town or city is a big leap for newly injured people who are still uncertain of their skills.

That's why we developed Join the Dots, a community-based wheelchair skills course which takes the skills learned at the spinal centres and transfers them to the real world of a local town centre.

It's an expansion of the original wheelchair skills programmes which we have been running since 2001, where experienced wheelchair users have given thousands of people life-enhancing confidence.

Andy Masters, Back Up's Outreach and Support Manager says:

66 We are always relating what we do in skills sessions to real life but it's hard to practise pavements and cambers in a sports hall. >>

Join the Dots is all about using your wheelchair in everyday places and situations. Participants have the chance to leave hospital premises and tackle challenges such as using cash points, going round shops and dealing with high shelves.

It's an opportunity to perfect your pushing technique, and tackle going backwards, turning, and flicking the front castors to get over small bumps. You'll also learn the back wheel balance for getting up kerbs and going down slopes. Power wheelchairs are big, heavy and hard to manoeuvre, and you'll learn better spatial awareness and control in tight environments.

As well as technical skills, there's also a psychological element. For many people Join the Dots is the first time they have left the spinal injury centre and been in a wheelchair in public.

Andy says: 66Part of the course is getting over the initial perception of what it's like to be in a chair. We understand that it can be guite daunting and easy to think 'people are staring at me' but that's not the case. The course helps people learn that. >>



Join the Dots is sponsored by Irwin Mitchell Solicitors and Gerald Simonds Healthcare, a wheelchair supplier. Irwin Mitchell volunteers attend sessions, providing practical help and an extra pair of hands, which means more people can get involved. The programme runs at eight of UK's spinal centres, and we are hoping to expand it to cover all centres in the future.

So what do recent participants say?

- out into the local community and speaking with people in the same position as myself. Little tips on how to get around different areas, as well as relaxed time to be able to chat to others about everyday life difficulties.
- 66 I enjoyed being introduced to the real world in a wheelchair: hills, cambers, uneven pavements. Thank you for putting me through it!
- 66 As a volunteer I enjoyed spending time with the patients who had not been out of the unit since their accidents or had a pint. A funday.

For more information about our Join the Dots programme, call Andy on 020 8875 1805 or visit backuptrust.org.uk/ jointhedots.

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SOPHIE'S 30 230 FUNDRAISING CHALLENGE

Back Up volunteer, Sophie Tandy, who works at Wellspect Healthcare, spent 30 hours in a wheelchair in February to celebrate our 30th anniversary. She raised an amazing £1,100 for Back Up.

Sophie found the 30 hours a lot more challenging than she had expected:

66 The experience was eye-opening and humbling. Throughout both days there were things that happened that surprised me. On my first day I found not being at other people's eye level the strangest. You seem to become invisible and then when people do see you they can't help but stare. I never found it to be malicious but it was still not a nice feeling.

The second day of my challenge was my biggest struggle. Using a wheelchair put a big strain on my body - my arms, hands, shoulders and hips all began to ache. But it also gave me

a whole new perspective on the challenges faced by wheelchair users every day.

Selec

She first volunteered at Back Up city skills course in September 2015, where she supported people with spinal cord injury as they improved their everyday skills, such as getting around the city and using public transport. After her experience on the course Sophie wanted to do more. Sophie says:

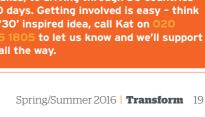
66 I thought it would be a great way to fundraise and raise awareness for Back Up. I was interviewed on my local radio station and my story featured in the local paper so hopefully I've also helped to educate people about spinal cord injury.

Since Sophie took on her challenge, other Back Up supporters have also made the commitment to spend 30 hours in a wheelchair to raise funds and awareness.

Thanks to everyone who's got involved.

Issue Mado Gloucester and top

Can you take on your own fundraising challenge to support our 30th anniversary? Our incredible supporters are doing everything from baking and selling 30 cakes, to driving through 30 countries in 30 days. Getting involved is easy - think of a '30' inspired idea, call Kat on 020 8875 1805 to let us know and we'll support you all the way.



30 YEARS OF TRAI

Thanks to your support, Back Up has helped thousands of people of



We ran our first course in **1986**, taking four people skiing, 30 years on, we run 17 different courses a vear. helping over 100 people to transform their lives.

In 1989, we offered our first outdoor activity course for people with spinal cord injury.



skills. Last year, we trained

increasing in confidence.

550 people, with 91% of them

1986

1991

Could you spare something each month?

Just £10 a month will provide a crucial lifeline to newly injured people. Call us on 020 8875 1805 to make a regular donation to Back Up by direct debit

By **1991**, we were making regular visits to several spinal centres to meet patients, family and staff. Now we reach patients in all 11 centres and offer telephone support as they move from hospital to home.

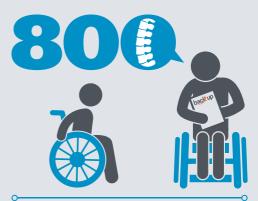


ISFORMINGLIVES

ver the last 30 years. We couldn't have come this far without you.



In 2009, we introduced dedicated support to ensure young people get the best chances at school and helped 17 children and their families. In 2015 100% of the 33 children we supported were happier at school.



In our **30th year**, we are reaching out to over **800** newly injured people in spinal centres and hospitals, more than ever before.

2006

2012

2016

In 2006, we launched our mentoring service and helped 8 people who needed support. This year we will help over 150 people through our accredited mentoring service.



In 2012 we launched a multi activity course dedicated to older people. It was so popular that we now run 2 over 50s

courses each

year.



HOW YOU CAN HELP

WHERE THERE'S A WILL, THERE'S A WAY

Have you ever thought about leaving a legacy? Simply, it's a donation you leave in your will and is one way you can continue to help others in the future.

For further details on leaving a legacy to Back Up contact Alex on 020 8875 6749 or visit our web site: backupteam.org.uk/

We understand that a spinal cord injury can be devastating but we believe that it shouldn't stop anyone from getting the most out of life. Leaving a gift in your will to Back Up would make a lasting difference to the lives of those we support. We recognise that your loved ones come first, but if the time is ever right to include Back Up in your will, your gift would mean a great deal to us. Even just a small amount can help change lives.

PAYROLL GIVING

Payroll Giving is an easy and tax effective way to give regularly to Back Up. Your donation is taken from your pre-tax salary, meaning that for a £10 donation it will only cost you £8 (or £6 if you're a higher rate taxpayer). The extra £2 comes from tax that would otherwise go to HMRC. Some companies even match your donation through payroll giving, making your donation go even further. Back Up receives no government funding and your donation will allow Back Up to continue supporting those affected by spinal cord injury.

To find out more, contact Alex on 020 8875 1805 or visit backupteam.org.

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