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Thank you to Allianz for their support for the production of this edition of Transform.

WHO IS BACK UP FOR?

Back Up is for everyone affected by spinal cord injury and their family members, regardless of age, level of injury or background. Our services aim to build confidence and independence and include:

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

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



Welcome to Transform's latest edition. Our 30th anniversary is almost over, so I want to thank everyone who's been involved in Back Up since 1986. As our founder, Mike, savs on page 6, we're only here today because thousands of people, like Katie, and Tracv and her family (pages 5 and 14) have supported us. You have all transformed the lives of people affected by spinal cord injury.

Back Up continues to evolve and change - with a growing international influence (page 10) and new support for families (page 23). But despite all we've achieved, the need is greater than ever. Many newly injured people are coming home just as they are starting to adjust, often without the right support or housing. They may feel isolated and lack confidence. Thanks to you, Back Up will be there to help everyone affected by spinal cord injury. both now and in the future.

Best wishes for a great Christmas and New Year

Rest wishes

Louise

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

LATEST NEWS

London2Paris ride raises over £50.000



Our first ever joint fundraising challenge with ASPIRE raised almost £52,000 as 27 cyclists and hand cyclists completed the three-day ride from London to Paris. This was also our first ever overseas challenge - a great way to celebrate our 30th Anniversary! "Everyone had a great time," said community fundraiser Kat Espiritu. "We had perfect weather for cycling and passed through wonderful scenery. At the end, we had a day exploring Paris which made the trip complete. The money raised from this event has helped fund services. like

our dedicated support for children with spinal cord injury, enabling us to train 100 young volunteers and build their skills and confidence. Thanks to everyone who took part and donated. Keep an eve out for our next big challenge!"

#BackUp4Paralympians



Back Up was proud to count 28 members of the 2016 British Paralympics team as former service users. For many people, we offer the first opportunity to get back to being active following a spinal cord injury.

Alex Rickham, Lauren Rowles, Lucy Shuker, Karen Darke, and Tom Aggar all took home medals from the games. "We're thrilled that Back Up's services have helped so many to go on to successful sporting careers. It can be difficult adjusting to life after a spinal cord injury but we

believe it shouldn't stop anyone getting the most out of life," said Louise Wright, Back Up's CEO.

Snowdon Push; people coming together -



The Snowdon Push is Back Up's toughest, most exhilarating fundraising event and in 2017 we need you to make this our biggest vet. In 2016, 11 intrepid teams. each including a wheelchair user, took on the tallest peak in England and Wales in the race for the Fastest Team award. Jason Miller was one of those who took part, helping to raise an incredible £57,000 for people affected by spinal cord injury. He was keen to tackle Mount Snowdon again after his injury, and was delighted to join the team organised by one of our corporate

partners, RBS. Jason, his daughter and the RBS team sped up the mountain in a record 3 hours, 32 minutes. Already preparing for next year's Push, Jason says, "I can't wait to come back again - I am amazed at just how many people came together to support those with a spinal cord injury." If you want to take part in the Push in 2017, please email katherine@ backuptrust.org.uk



Back Up youth advisor and young group leader, Katie Krzyzanowski, has won the prestigious Diana Award for her work inspiring others with spinal cord injury to go out and "live the life they want".

The 17-year-old won in the Courageous Citizen category of the Awards, which recognise the social action of young people.

Katie first came to us aged 12 for help to rebuild her independence after her spinal cord was damaged by scoliosis. She then started volunteering on youth courses. before becoming a youth advisor herself. Now she plays a key role in shaping our services and supporting new youth advisors. She's been described as an inspiration and a 'great leader' by her colleagues.

66 On my first Back Up course, I relied on my parents for everything, >> she says. 66 I didn't do anything on my own. Within the week, I learned to do more by myself. When I came home my parents were amazed at

the change in me. Since then, I have gone on weekends away, volunteered and staved in places on my own. Without Back Up, I wouldn't have done any of that >>.

About her role as a youth advisor she said: 66 I learnt more about spinal injuries and how they affect people individually. Through working with Back Up. I've learnt more about myself and I think my perception of what I can achieve has changed. >>.

A fantastic role model, she has demonstrated a real dedication to educating people about spinal cord injury and taken part in several films to raise awareness. She's also attended the Nordic Camp for spinal injury in Oslo, travelling independently for the first time. This summer she was the young group leader for our first ever Youth City Skills Course.

From everyone at Back Up, congratulations and well done Katie!

66 A WORD FROM MIKE

Mike Nemesvary, our founder, set up Back Up in 1986 after his spinal cord injury. Mike who joined us recently from Canada to celebrate our anniversary, tells us about the early days and what makes him most proud.

Tell us about your life before your spinal cord injury

My life was all about sport. After winning my 1st Canadian National Freestyle skiing Championship at age 15, I spent 10 years representing Canada and Great Britain. I won the first ever World Cup for Britain and have 40 titles in my sport. In the 1980s, I was also establishing myself in numerous film and commercial roles. I was approached by the James Bond film producers, Albert "Cubby" and Barbara Broccoli and Tom Pevsner to help to choreograph and perform the stunts for the opening sequences of "A View to a Kill". Sadly, this was the last film I worked on prior to my spinal cord injury on May 18th, 1985.

What motivated you to set up Back Up?

After my very first sit skiing trip to Switzerland just seven months after my injury. I was filled with a sense of accomplishment. adventure and optimism that I wanted to share with others whose lives were affected. by spinal cord injury. Then, there were virtually no other organisations set up to offer similar opportunities.

Who else was involved in setting up the charity?

From my bedside at the Royal National Orthopaedic Hospital in London, my friends, Barbara Broccoli and Jess Stock supported



the concept of Back Up and used their vast influence within the film and ski industries to garner support. Konrad Bartelski was also one of the notable figures who jumped on board to build up the charity.

The commitment of volunteers cannot be stressed enough - from Board and Committee members to carers and buddies on courses and our many fundraisers and supporters. Back Up would not be in existence today without the literally thousands of individuals who believed in our mission.

What was life like for people with spinal cord injury when you set up Back Up?

Once you've left rehabilitation, you often feel like you're living in a "vacuum" cut off from the supportive community you relied on. I guess I was fortunate that I had some resources, a strong support network of family and friends and a zest to carry on and redefine my purpose in life, albeit from a sitting position.

How do you think things have changed?

Originally we found our niche in offering adventure pursuits which helped people see their lives from a new perspective. Now, we've expanded to helping all age groups through our mentoring, wheelchair skills, support back to work and school and influencing which I think is fantastic. I'm so pleased to know that we are sharing our "best practice" with the international community.

I've been a very strong public advocate for the rights of disabled people. While some things have changed our quality of life is often dictated by people still seeing our disabilities before our abilities.

What are you most proud of?

I'm most proud of how Back Up has grown into a mature and successful organisation effecting change on the international platform. I'm proud that I had the opportunity to represent two countries and achieve most of my competitive sporting objectives. I'm proud of becoming the first quadriplegic to independently circumnavigate the globe in my modified vehicle. I'm proud to be with my partner Mary Anne and assistance dog Jigger!

What were you most looking forward to about coming over to the UK?

A good glass of premium Scotch! I was particularly looking forward to visiting our offices and meeting the many new individuals who are now "running the show". It was fun reacquainting myself with some old friends who were pivotal in the early days.

What would you like to see Back Up achieve in the next 30 years?

Keep following the same path of steady growth and become "a force to be reckoned with" both in the UK and across the globe!



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GET INVOLVED IN 2017

During our anniversary year, we've been amazed by your support and we're so grateful for all you've done. From sharing your stories to volunteering and taking on fundraising challenges, your contributions have helped improve the lives of the people we support. Here's just some of the exciting ways you can support us in 2017:

JANUARY-

New year, new you

Make your new year's resolution whilst raising money for Back Up.

FEBRUARY -

Back Up Bake Off

Hold a bake sale or party using our new fundraising pack.

MARCH-

Skydive

Free fall at over 120mph through the air and raise funds for Back Up!

APRIL.

Spring Cycle

Choose your own distance on your bike or hand cycle.

Supernova Night run - 1st

Join us at this exciting night run at the Olympic Park.

London 2 Brighton - 27th - 28th

Test your endurance and walk 100km.

Kavak the Great Glen - 4th - 9th

Kayaking is back! Join the team on this beautiful paddle in Scotland.

Snowdon Push - 30th June - 2nd July

Sign up today for our toughest challenge.

Ride 100 - 30th July

Register now for the UK's biggest cycling event from Surrey to London.

AUGUST -

Back Up Fest - TBC

Join us at our first Back Up Festival, run by our amazing youth advisors.

SEPTEMBER -

Parallel London - 3rd

Join thousands of people to run, push, or walk around the Olympic Park in London.

Dragon Boat Race - 7th

Sign up your company to battle it out at the Docklands.

OCTOBER -

Back Up Booo-gie

Hold a Halloween themed party for Back Up.

NOVEMBER -

Back Up Ball - 11th

Early bird tickets available now for the biggest party of 2017!

DECEMBER -

Christmas Collection

Volunteer at one of our Christmas Carol collections, or hold your own festive fun!

Contact our fundraising team

fundraising@backuptrust.org.uk or 020 8875 1805 for more information.

For details of Back Up's courses in 2017, visit www.backuptrust.org.uk/ coursecalendar or call on 020 8875 1805



After 30 years helping people with a spinal cord injury rebuild their lives, we've learned a lot. Now we're sharing our knowledge with others in the UK and Europe to promote understanding and help improve services internationally.

66 Some of what we do at Back Up is unique, >> explains Head of People Development, Stef Cormack. 66 For example, we're the only organisation that offers family mentoring. We decided to share some of the knowledge we've built up so it can benefit others - and in the process of sharing, we can learn more ourselves. > Back Up presents at conferences on areas where we have special expertise. In 2015, Stef spoke at the European Spinal Psychologists Association on the great results we've achieved using mentoring to help people adjust after their injury.

Sharing our expertise

Our presentations reflect the broad, inclusive nature of our services - and often draw on personal experience. Two Back Up volunteer school advocates, Holly and Kevin, presented at the RI World Congress in October on our work on schools inclusion. This event brings together the world's leading disability experts to discuss a more inclusive and accessible world for all.

The International Spinal Cord Society (ISCoS) annual meeting in September was attended by Back Up volunteers, Lucy Robinson and Will Clark (both pictured). Will wrote about his experience of presenting as a powerchair user at the event:



Will Clark:

66 I was invited to deliver a presentation about the peer support I am involved with and have benefited from and how this relates to all those with a high level injury.

Following my injury in 2012 I received mentoring from Andy who had sustained a similar injury. A powerchair skills trainer also visited the centre which helped me to develop my skills before leaving hospital. I have since become a mentor myself, and volunteered as a schools advocate to include children with spinal cord injury in the school environment. I hope to also become a powerchair trainer.

At this summer's City Skills Course in Belfast, I had the highest level of injury. However I was fully included and didn't hold back the rest of the group.

Back Up love to challenge an individual to fulfil their true potential. Not only did I have to overcome the fears and preconceptions around my first flight. I was also representing the charity and all those with a high level spinal injury on an international stage. To add to this, my talk was straight after the keynote speaker on the first day! It was only when I arrived at The Hofberg Palace (the former imperial palace in Vienna) I realised the scale of the task I had taken on.

The audience of 300 professionals enjoyed hearing about the initial development of Back Up's mentoring service, our research and the expansion into family support. They also heard about the coping mechanisms we use to both talk with a mentee about their wellbeing and also to examine the impact of a mentoring relationship.

The value of support from people with a similar experience really hit home. Many overseas organisations who don't provide peer support for those with a high level injury voiced an interest. It's great that I may have motivated others to consider expanding their services. This is a positive step towards ensuring peer support is available to all and to help anyone - irrespective of age, injury level or background - come to terms with their injury. >>

Reaching out internationally

Since this presentation, we've been in touch with organisations in Germany, Sweden. Norway and Greece. The connections we've made at previous conferences have led to exciting partnerships with sister organisations in other countries. Back Up has supported Dutch and German spinal cord charities to develop their mentoring work, based on our model. And in September, Mentoring Coordinator Andrew Dickinson travelled to meet Alli Opsi, the Greek spinal injury charity, to explore possible mentoring services.

We're looking forward to developing more partnerships like these in the future - so that all people affected by spinal cord injury and their families are included by the organisations that are best placed to support them.

GIVE THE GIFT OF INDEPENDENCE



Ste is one of our dedicated wheelchair skills trainers, who travels the length and breadth of the country, sharing his expertise.

Our Christmas campaign this year focuses on how Back Up helped transform Ste's life. Initially he struggled to get out of the house after his injury but this changed after he received support from Back Up and became a volunteer.

Ste was inspired by his experience on a Back Up multi-activity course. He said: 66 I found myself in Keswick doing amazing things I had never thought possible again. The course totally changed my life and my perception of what I was capable of doing as a wheelchair user. I went home a transformed person to the point where it changed my lifestyle completely. >>

66 There is no better feeling than being able to pass on my knowledge to someone who is in the same position as I used to be. If I can help to make one person's life that little bit better it makes everything worthwhile. The feeling I get from helping others is priceless. >>

Support our work

During the 12 days of Christmas, 36 people and their families will have their lives changed forever by a spinal cord injury.

You can help now by donating to our Christmas appeal - visit

www.backupteam.org.uk/xmas







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GETTING INVOLVED — HAS MADE MY — **FAMILY STRONGER**

Getting involved with Back Up was not only a milestone in Tracy Watson's journey to rebuild her life - it's brought her family closer together too.

As her son Harry, niece Amie and sister-inlaw Lisa lined up at Parallel London, the new accessible challenge event at the Olympic park. Tracy reflected on the progress she and her family have made since she sustained a high level spinal cord injury.

66 I cried when I left the spinal injury centre, >> she says. 661 found it quite hard to adjust to the outside world. I was really feeling flat and finding things like showering and going to the loo very difficult. >>

Her injury was also a challenge for Harry, 18. 66 He's been great but it was hard for him understanding what it's like to be in a power chair and knowing what kind of help to give. >>

Things started to change when Tracy volunteered. 66 I knew about Back Up because I'd done a wheelchair skills course at Stanmore. It was brilliant - and gave me hope about what's possible with my level of injury. >>

Getting back to my life

66 I kept in touch but I had no idea of getting involved. Then, I saw something about Back Up's fashion show on Facebook and that looked like fun. I spoke to someone about it and she suggested I volunteer in the office or support the events team in the office in the lead up to the event.

I hadn't worked in a while, so the idea made me nervous. But actually, it was the best thing for me. It's given me structure and helped me get back into the world of work. I can use my skills in a safe environment, surrounded by supportive people, many of them with injuries like mine. >>

Tracy has been volunteering with Back Up since February. Merryn Thomas, Courses Co-ordinator says: 66 Not only has Tracy done so much to help support the team, but it's great having her and her support dog, Ruby, brighten up the office every Friday. >>

By the time Tracy established herself as a volunteer, Harry had shown a keen interest in the charity seeing what Tracy was able to do. 66 I suggested he get involved too. He volunteered as a buddy on a multi-activity course and loved it. >>

Time for a challenge?

If Tracy's story has inspired you, why not apply to become a volunteer - and get your family involved too. We've got lots of opportunities from mentoring and wheelchair skills training to office work and buddy roles.

We've also got lots of fundraising challenges open to people of all abilities, ages and levels of injury see page 9 for more details.

Contact Kat on 020 8875 1805, email: katherine@backuptrust.org.uk

Helping my family understand

66 It helped him understand my needs - like when to offer help and when to wait until asked. And it was also great for him. He's never been very confident in groups and the course changed that. It really brought him out of himself. He was buzzing when he came back and wanting to do more. 99

Harry says: 66 Going away to help the fantastic group of participants on their multi-activity week was very eye opening about what support is required for people in wheelchairs, which has given me a deeper understanding and has brought me closer to my mum.

After the course I have sought out more ways to contribute to Back Up and am now starting to volunteer in their office based in London. >>



Bringing us all together

When Parallel London came along, Tracy spotted an opportunity to get the whole family involved. including her niece and sister-in-law. They raised funds for Back Up and had a fantastic time on the push, with other family members there to cheer them on.

66 It's been amazing, 99 said Tracy. 66 It's really pulled us all together and made us stronger and more united. 99

Tracy has now trained to become a mentor, deepening her links with Back Up.

66 I feel like I'm doing something positive with my life - not only helping other people with spinal cord injury but giving something back to my family at the same time. >>



In the last 30 years, Back Up has grown from a great idea to a major charity that has changed thousands of lives. Will you help us continue our work by leaving a legacy to Back Up?

We want to help more people with spinal cord injury to reach their potential long into the future. Making a donation in your will is one of the best ways you can help.

It's a way to make a lasting difference to the lives of the people we support even if you can't commit money today. We recognise that your loved ones come first, but anything you leave will help to ensure Back Up's work continues into the future.

It's a common myth that only the rich and famous leave money to charity in their will. In fact, increasing numbers of people are choosing to support a charity in this way. Leaving just 1% of your estate could make a huge difference for someone with spinal cord injury. Another option is to leave items such as furniture or jewellery which could be sold to raise funds.

To find out more about leaving a legacy for Back Up, call Janet on 020 8875 1805 or look at our guide www. backupteam.org.uk/remember-backup

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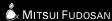




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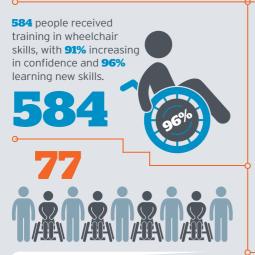
Your support changes people's lives.



Over 1000 people were newly injured last year. We registered 825 new people with spinal cord injury to

receive our services and 662 people were provided with telephone support. We're reaching more people partly due to a 45% increase in registrations from general hospitals and to our continuing partnership with Aspire.





100% of people attending our Back Up to Work course achieved their personal goals.

77 people took part in a Back Up course, with 100% saying they would recommend our courses to a friend. All under 13s on our courses improved their wheelchair skills, confidence making friends and independence.

ACT IN 2015/16



138 people were matched with volunteer mentors. 44 of these were family members and 90 were adults with spinal cord injury. 97% of people who were mentored felt more able to cope with their situation.



34 children and young people were supported back to school. 100% of those who received intensive face-to-face support were happier at school. 34's of school advocates felt they had made a difference.

40-50 children sustain a spinal cord injury each year. In 2015/16 we registered 42 new young people with spinal cord injury.



30% of adults on our courses and 35% of people matched with a mentor were aged over 50.

> For more information about the difference Back Up made to people's lives last year, visit www.backuptrust.org.uk/about-us/ reports-and-accounts to read our full Annual Report and Accounts 2016.



Back Up carried out research in 2015 into the experiences and issues of people with a spinal cord injury who can walk. In June this year Jacques Liebenberg, one of our Mentoring Coordinators, spoke at the annual Guttmann conference about the results of our research. He believes that we often have a very fixed idea of what it means to have a spinal cord injury, and people who can walk don't fit that image. Jacques can walk with crutches for two to five minutes, and then feels incredibly exhausted.

Even if walking is possible it doesn't mean it's easy - far from it. During his rehabilitation (outside of the UK) Jacques had his wheelchair taken from him for over a week to effectively force him to walk. The support from the hospital staff, while second to none. didn't always take Jacques's needs into consideration.

Jacques says: 66 [During rehab] therapists spent all their time trying to get me to walk again. I didn't know how much freedom and independence being in a wheelchair could give me. >>

SUPPORTING PEOPLE WITH A SPINAL CORD INJURY WHO CAN WALK

Jacques chooses to use a wheelchair because he believes that he has a better quality of life this way. However, other people find this choice hard to understand. And people with a spinal cord injury who can walk often feel that way too.

So there's a stigma attached if you choose to use a wheelchair, and there's a lack of understanding if you choose to walk. This can leave people feeling a bit stuck in the middle and not guite sure where they 'fit in'.

One of our research participants told us: 66 What really stood out for me during rehab was feeling out of place - it's escalated in the 15 months since. This bothers me more than the injury. >>

This feeling of being excluded can be caused by many things. Spinal cord injury is not always a visible disability. And if the injury can't be seen, then people assume you must be happy and healthy. But people who can walk can still have problems with bladder and bowel control, neuropathic pain and fatigue.

66 You get a lot of the same issues that a full-time wheelchair user would have but feel unable to verbalise your thoughts, feelings, especially around pain. There were days when I wanted to say to people 'yes I can walk, but it is painful too'. "

As a result people with a spinal cord injury who can walk often feel like they are not entitled to access services that should be reserved for people with a 'proper' disability. This is reflected in the way spinal cord injury is often represented. Back Up now has specific page on its website for people who can walk and includes stories on social media and our blog.

"I have the luxury of walking around, but bloody hell it comes at a cost, to you and those around you."

Dan spotted this online and contacted us: 66 Since my accident this is the first time I have seen anything to do with spinal cord injury and still being able to walk, even if this walking is not far, everything always seems to



To find out more about our Next Steps Courses in 2017, contact karim@backuptrust.org.uk or call



be directed to wheelchair users. Maybe I have been looking in the wrong places. Thanks so much for sharing this content. >>

So where can we go from here? Jacques believes that raising more awareness is key, and that's why his keynote presentation at the conference was so important. We need to change people's perceptions to ensure that people who can walk receive the support they need.

That's why we introduced our new course -Next Steps - specifically designed by and for people with a spinal cord injury who can walk. Participants on the first course in September had varying levels of injury but they all had one thing in common. They were delighted to have a chance to speak to other people in a similar situation because there was so little out there in terms of research or support.

Acknowledging that these issues exist is the beginning of making support and services more inclusive for this group. People felt so positive during the course because it was often the first time that they had shared their experience with people who understood - and they had a lot of fun!



NEW SUPPORT FOR FAMILIES



When someone has a spinal cord injury, the impact is felt not just by the individual but by their family and friends. At Back Up we already offer support to some family members through our family mentoring and under 18s services - but we know we could do a lot more. We are now expanding our support for families by introducing a new outreach role who will be focused on their needs.

The new Families Outreach and Support Coordinator will be part of our outreach team and will themselves be a family member of a person with spinal cord injury. They will be a first point of contact for family members, providing much needed peer support and advice. This, in turn, will enable families to better support their injured partner, sibling, or child. Often, many family members feel guilty about asking for help because they feel the focus should be on their loved one. This role will take the initiative, and working with volunteers, will reach out to families on visits to wards and at information sessions. They'll be there to offer telephone support and link people into mentoring and other services.

This role has been made possible thanks to a two-year grant from the Baxter International

Foundation, 66 We're very excited this grant will increase the support we offer the family members of people with spinal cord injury throughout the country, >> said Andy Masters, Outreach and Support manager. 66 Many people experience feelings of depression and isolation after the injury of a loved one. By supporting these family members, we're also indirectly supporting the rehabilitation of the injured person. This new service will make a real difference to the lives of everyone affected by spinal cord injury. >>

Baxter Healthcare staff, Nicky Sturt, Market Access Director and Andy Goldney, General Manager, UK, Ireland and Nordic visited Back Up's offices in November (pictured above) to meet staff involved in the new service. Andv said: 66 Baxter has a long history of providing essential healthcare products for patients in hospitals, clinics and homes across the world, ensuring everyone gets the care they need. This is reflected in our commitment to improve access to healthcare for all, and we strongly believe that should extend to family members too. We look forward to seeing the difference this role will make to the lives of families throughout England. >>



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