

CatWalk

Your pathway to information and support for a cure



The official magazine of
The CatWalk Spinal Cord
Injury Trust



This issue May 2013

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Founder's Footnote

Dear CatWalk Supporters,

We are in full training mode at present. Most will find it hard to track us down due to the kilometres we're doing on the handcycle so eyes up if you're driving around the Wairarapa we may be down your road soon.

The BIG Cycle team are a dynamic and dedicated bunch of individuals who, despite not knowing each other, are about to put themselves through a cultural challenge like no other. By the end of our cycling road trip from Lhasa to Kathmandu, we will either be bonded for life or very pleased to be dispersing to the various corners of the world. I can't wait, and I know the rest of the team are feeling the same.

I would like to make a special mention of the sponsors and supporters thus far - Platinum Primary Producers, Greenstone Partners, Kathmandu, House of Travel, Faith Taylor and Peter Halkett - you are the ones helping us on this adventure to make a real difference to SCI research.

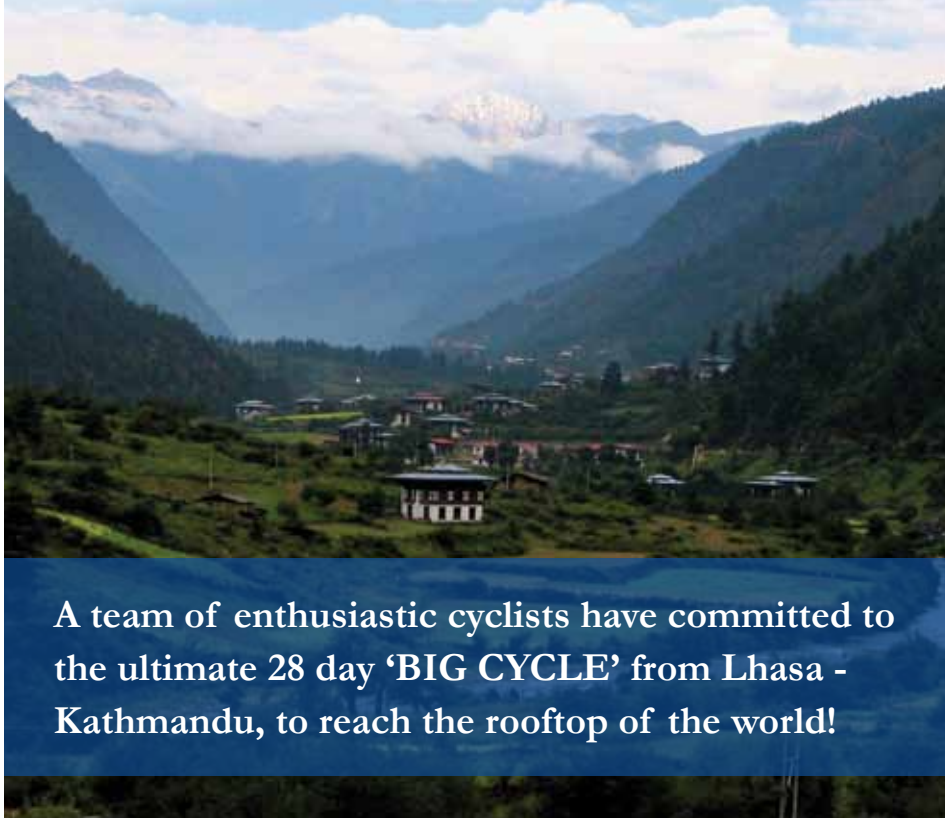
CatWalk Trustees Scott Malcolm & Stephanie Iremonger along with CatWalk friend Charles Bachelor and I recently visited the Spinal Cord Injury Research Facility at Auckland University to get a progress update from the scientists that we have committed \$500,000 to over the next few years. Professor Richard Faull and Dr Simon O'Carroll presented to us and showed us around. It's incredibly exciting to see and hear about the work that is being done. If any of our supporters are keen to do this too please contact the CatWalk office and a tour can be arranged.



Absolute best research into SCI repair. All research applications presented go through a thorough process with the Neurological Foundation of NZ that includes international peer review and a Scientific Advisory assessment. This is so we can guarantee that those with the expert knowledge are the ones making the decisions and we can confidently say YOUR support money is absolutely going in the BEST possible direction.

Remember I'm in a chair, if it was my decision I'd support anything presented... just in case! My request is small - a boogie on the dance floor please... on my feet. While we're waiting... let's go cycling!

Catrina



A team of enthusiastic cyclists have committed to the ultimate 28 day 'BIG CYCLE' from Lhasa - Kathmandu, to reach the rooftop of the world!

“...clearly they're not only physically challenged to take on this adventure!!! But like a cure for SCI, with a great team, the impossible becomes possible.”

Richie McCaw, CatWalk National Patron



From 14 June – 11 July 2013, the BIG CYCLE team will undertake the gruelling challenge of climbing ten Himalayan Mountain Passes (of which five are over 5,000 metres in height); all in the name of cycling so others can walk.

Three hand cyclists, Catriona Williams, Neil Cudby and Rob Creagh (all Tetraplegics); have stepped up to the challenge. Flanked by friends, including CatWalk Ambassador - Penny Barnett, CatWalk Trustee - Scott Malcolm, Catriona's husband Sam, SCIN CEO Dr Stephanie Williams, CatWalk supporters - Stuart Laughton and Mike Weston, team doctor, Piotr Szawarski, plus three carers; the BIG Cycle team is not to be underestimated.

While The BIG Cycle trip will be an unforgettable experience, the physical toll on the team will be enormous. This will be most severely felt by the three tetraplegics, who have been told by a number of doctors not to underestimate the risks to their bodies.

Wheelchairs and camping are not a natural combination and our wheelies will experience all the discomfort of their abled bodied colleagues and so much more. To complete the daily basics, each of

the tetraplegics has recruited an able bodied carer, plus they have to travel with their own pop up showers and purpose made tents among other necessities.

Altitude sickness is a likely complication. Thanks to support from the Royal New Zealand Air Force (RNZAF), team members have been put through their paces in a decompression chamber. Much to the relief of the team and doctors, all the results have been good.

This trip will be an incomparable test of patience, character and determination.

As if the physical challenge isn't enough for the team, they have set themselves the goal to raise \$1 million for CatWalk and spinal cord research. Our motivated BIG Cycle team is passionate and dedicated – they are fully funding their own flights, accommodation and all costs associated with this trip in addition to fundraising. The team are proof that if you DARE TO DREAM...YOU WILL SUCCEED!!

The BIG Cycle is part of an international collaboration between The CatWalk Trust and The Spinal Cord Injury Network Australia (SCIN).



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We are proud to introduce The BIG Cycle Team.....

Catriona Williams

Catriona Williams' equestrian career saw her represent New Zealand on the international stage. After a devastating horse-riding accident in November 2002, Catriona was left a C6/C7 tetraplegic. In 2005, she founded The CatWalk Spinal Cord Injury Trust and in 2010 Catriona led a group of 25 CatWalk supporters to compete in the New York City Marathon.

Sam Williams

Sam is the proprietor of Little Avondale Stud and has been running it with his wife, Catriona, for about 15 years. A keen hockey player, Sam has recently taken up cross fit training. Until recently Sam's bike riding experience had been limited to getting him around the farm but he was delighted to recently complete the South Island Rail Trail.

Anita Pomare

Anita Pomare will be Catriona's main carer on this amazing bike adventure. Anita has been working as a carer for a couple of years, for McIsaacs which specialises in Spinal/Brain injury clients only. She says, "I have met absolutely fabulous people and clients during this time and have thoroughly enjoyed the experience. I enjoy socializing, meeting and greeting new faces, places and challenges which this trip is sure to provide in abundance"

Neil Cudby

Neil is, in his own words, "a 39-year-old, originally hailing from the central North Island where mountains, rivers and lakes were integral in my upbringing. I now live the dream of wife, kids and a house near the beach in Papamoa. In life I like balance of the heart, head and body. How about a Tibetan handcycle tour to the top of the world to lift the balance bar?! A lot of people ask me how I ended up like this when I first meet them - I broke my neck playing rugby when I was 17. The label reads C5 Tetra."

Nicki Everton

Nicki is joining this trip with Neil Cudby as his carer. "When Neil phoned up out of the blue saying he was going on another adventure and was I interested, I immediately said yes! The fact that it involves Catwalk and the Himalayas is just a huge bonus!" Nicki lives in Nelson and works at the local hospital as an occupational therapist in an acute orthopaedic ward. She is involved in planning people's discharge from hospital with the view to them making a successful transition from hospital to home after trauma interrupted their lives.

Penny Barnett

Gorgeous Penny has been a wonderful CatWalk supporter since day one. When we are looking for volunteers, Penny is always the first to offer. Penny is the proud owner of Trelise Cooper Wellington Flagship Store and Designer Clothing Gallery in Greytown. When Catriona mentioned The BIG Cycle, Penny immediately put her hand up to join the team... no surprise that she is one of CatWalk's 'official' Ambassadors. Penny is a fantastic team player and a HUGE asset to the team.

Stephanie Williams

"As the Chief Executive of the Sydney-based Spinal Cord Injury Network, I am thrilled to join CatWalk on The BIG Cycle! I sustained a serious spinal injury in a horse-riding accident as a university student. At the time it was devastating. Now I know and appreciate just how fortunate I was to eventually make a full recovery... thanks to a bit of luck, some good medical care and excellent rehab. We are joining forces across the Tasman in the true spirit of collaboration to raise funds for spinal cord injury research."

Rob Creagh

"Breaking my neck under a friend's car in my teens should have dampened my enthusiasm for foolhardy and risky adventures...but happily it hasn't. The BIG Cycle sounds a little insane but a lot of fun, and I signed up with little time for proper consideration. Hell, what could go wrong...! I still remember doing a school project of the first summiting of Everest and I'm particularly excited with the prospect of a visit to Base Camp. When not hand-cycling, I'm either working from my home office or attending to our 6 year old's demanding schedule."

Amy Shaw

Amy is joining the team as Rob's carer. "I'll never forget the day my older brother taught me how to ride a bike. I am the middle child of seven kids & grew up in Kaikohe. We always had at least one bike in the house. After leaving Northland I got a degree in art whilst doing support work and I've been living abroad since. No matter where I am, I've always got a bike. It's such a huge privilege for me to join this team for The Big Cycle and I am so excited about seeing Tibet and the Himalayas."

Michael Weston

Michael comes from a farming family and has been involved with the equestrian world from a young age. He show jumped throughout Europe and the States. "Currently I hold a position with the ASB Bank but I still ride horses. Catriona and her family have been sound friends to me and my family. An opportunity to support her and her quest to help find a cure for spinal cord damage was too good to miss."

Scott Malcom

Scott became a Trustee for CatWalk in 2011 and is based in Sydney. Scott founded Greenstone Partners in 2003 - an independent corporate advisory firm focused on middle market mergers, acquisitions and divestments. Scott is married to Jane and has two daughters. He enjoys running and was part of CatWalk's 2010 NYC Marathon team. Despite his geographical position, Scott is a keen supporter of the All Blacks. When the concept of The BIG Cycle came up, Scott jumped at the opportunity to be part of the team.

Stuart Laughton

Stuart has been in the Australian Army for over 30 years. *"I am a Physical Training Instructor so I love physical challenges. My wife is a Speech Therapist and I am a father of 3. I have always had a love of the outdoors and those sports aligned to it; kayaking/canoeing, climbing, abseiling, fishing etc. It was through Scott Malcolm that I got into this adventure and after meeting Cat my mind was made up to assist in any way possible. This trip will be life changing and I look forward to it with unbridled enthusiasm."*

Piotr Szawarski - Team Doctor

Dr Piotr Szawarski was born and brought up in Poland. He graduated from Southampton University, UK in 1999. Having gained MRCP and MSc in Infectious Diseases, he then moved on to train in Anaesthesia and Intensive Care. He is a Fellow of the Royal College of Anaesthetists by examination (FRCA) and holds a European Diploma in Intensive Care. In 2003 his interest in the great outdoors caught up with him on a professional level. He joined a Medex Himalayan research expedition as a medical officer. During that time an opportunity had arisen to join the faculty of a newly formed Diploma in Mountain Medicine. An expedition to climb Cho Oyu followed in 2005 and a chance to work for the Himalayan Rescue Association in Pheriche, Khumbu in 2007. He is married and has a two year old daughter.

Kris Male

Accountant turned Financial Investor might be what pays the bills, but with a love of living life and energy to burn it doesn't take much of an excuse to leave the computer behind.

"I'm passionate about health and fitness and happiest when working towards achieving goals. While more of a weekend warrior than an elite athlete, I do like to take on challenges outside my comfort zone. My support team; amazing husband Simon (who's put up with me for 25 years) and two awesome sons, Mike (23) and Steven (21) are always encouraging me to step up to new challenges.

With the belief that growth and contribution is what drives us to be better humans, when the opportunity to support such a worthy cause and be part of the team arose, I didn't need any convincing..... I was in!

I look forward to supporting and being part of Catwalk and the Big Cycle Team as we embark on this extraordinary journey together..... I'm sure there will be many challenges to overcome but am very excited and honoured to be part of this once in a life time opportunity."

Jack Holmes

I am an Auckland University graduate personal trainer who has worked in Beachlands, a beautiful part of the world for the past decade with my wife, Sara (5 months pregnant). We are fortunate to have created and own our own gym – Perform Fitness. I personally believe real life exists and should be pursued outdoors, with the gym being your perfect tool to enable you to specifically develop your body so that you can enjoy life to its max! Working with people in the health sector has taught me so much about the body and the mind that I am committed to learning and contributing as much as I can. I first became aware of Catwalk and their epic excursion when my client Michael Weston told me he was going and wanted to be trained for it. With boat loads of envy from my side we focused on the goal. To now be on the team it still feels surreal – just two years ago I decided I wanted to visit Mt Everest and the chance to embark on that journey with the Catwalk team is simply a once in a lifetime opportunity.

For me I can't wait to get this adventure started, I know it's going to be testing for us all, but the benefits to follow of personal growth and inspiration to others will make us succeed and enjoy this moment to its fullest.



The CatWalk Spinal Cord Injury Trust would like to take this opportunity to thank Faith Taylor for her incredibly generous and ongoing support of the Trust.

Faith Taylor and her family have been committed supporters of the Trust for several years, attending events, donating auction prizes and spreading the word about CatWalk to their friends, family and contacts. Recently Faith has once again stepped up to show her support by providing sponsorship for a doctor to travel to the Himalayas with The BIG Cycle team.

We were lucky enough to find Piotr Szawarski. His experience and expertise is a huge reassurance and his presence could quite possibly make the difference between the success or failure of the trip. Without Faith Taylor's generous sponsorship Piotr would not be making the trip. On behalf of Piotr, the rest of the team, their friends and families and everyone in a wheelchair who stands to benefit from our fundraising, we thank you Faith!



CatWalk does Top Gun!

The BIG Cycle team conducted a hypobaric chamber run on Sunday February 2nd in preparation for a high altitude 1000 km cycling fundraiser across the Himalayas, with the assistance of the Royal New Zealand Air Force (RNZAF).

The CatWalk Trust's Catriona Williams will hand cycle with two fellow tetraplegics, Neil Cudby and Rob Creagh, from Lhasa in Tibet to Kathmandu in Nepal, to raise \$1 million for spinal cord injury research in June 2013.

Catriona Williams said a number of doctors had expressed concern about people with spinal cord injury and decreased lung function going to high altitude.

"We stepped up to the altitude challenge with thanks to the support from the RNZAF and their hypobaric chamber. It was a real confidence booster that means with good guidance on ascent we might just make it!" Catriona Williams said.

RNZAF Aerospace Physiologist Flight Lieutenant Gareth Iremonger assisted the team with the testing and explained the hypobaric chamber could be used to demonstrate the physiological effect altitude has on exercise performance.

"Tests were performed at easy, moderate and hard intensities at ground level, 5,000, 10,000 and 15,000 feet

tomimic expedition conditions," he said.

The team, their doctors and all their supporters were delighted with how the team's time in the chamber went. It was a fantastic day and, while it does not offer any guarantees that altitude sickness will not strike, knowing how well they coped is a huge reassurance.

We would like to sincerely thank the Royal New Zealand Air Force for their support of The BIG Cycle by offering the hypobaric chamber for our use and assisting the team throughout their day. What an unexpected, hugely beneficial day.



Pen & Cat's South Island Adventure



As preparation for The BIG Cycle, Penny and I was decided that it would be good idea to do a summer cycling adventure around the South island. It seemed like a good idea over a wine in the middle of winter! The aim was to test bikes, bodies and minds.

Wendy - Catriona's carer - and her husband David set off with the car all loaded up with the bikes and necessities. We started the adventure in Blenheim with Gretchen and Dick Bristed who looked after the team like rock stars for two days. A Friday night dinner with a number of the Blenheim locals announced the North Islander's arrival and set the scene for the trip.

A 25km jaunt with the Marlborough Bunch Riders, organised by Jon Cunliffe and Grant Baxter, around some of the vineyards was a stunning beginning to a day that just happened to coincide with the Marlborough Wine and Food Festival. Never ones miss a good opportunity, CatWalk supporters including Fleur Hansby, her husband Nick and son Luke did a little bucket collecting and raised just under \$700. Meeting up with old friends Roddy and Emma Bremer and others made it special and the Festival has since been put on the 'must do' list for anyone that likes good food and wine!

The following day the hard core cyclists drove to picturesque Lake Rototoi. It was absolutely worth the drive and the intended 100km cycle back to base. The heat got to the team a little and, after 60km on a wine and food recovery day, it was decided that it was a pretty good effort. A late night drive to Hanmer to excellent Indian food at Malabar (www.malabar.co.nz) and good accommodation at The Hanmer Inn ensured a good nights sleep for the adventure cyclists. The Power House Café had the best breakfast selection for hungry cyclists and was followed by a scrummy lunch in Geraldine with Sarah Wilson, Fra Mills, Kevin and Robbie Moline, Peg Wood and Suze Wyborn.

A fun night in Tekapo was highlighted by Sam thinking the chef had left part of his tooth in the pizza only to find out the next day he had part of his missing. Quick apologies were made!!! Twizel and cycling the canals was the next big day. Impeccably organised by Jill from Cycle Journeys (www.cyclejourneys.co.nz), the team thoroughly recommends booking any cycling adventure with them. Cycling with the team was Shelley Spry an inspirational amputee, Wally, Lek Jocelyn and Kevin Moore. A visit to Twizel school to talk a little 'CatWalk' and catching up with CatWalk supporters Ron, Jen, Kirsty and Simon Williamson wound up a magic day.

It was then onto Middlemarch and The Otago Rail Trail. Excellent wheelie and ablebodied accommodation at 'The Lodge' only metres away from the trail enabled a good start to the first day. It was a bonus that it was owned and managed by Helen the local policewomen because a phone charger that got left behind managed to miraculously appear at the next nights accommodation! 50kms later and a test of

character in Ranfurly with "glamping" (glam camping!) had at least one team member very apprehensive about 28 days in the Himalayas. The realisation of the amount of patience one is going to have to have when camping for such a long period meant a huge appreciation for any level ground and good beds.

Middle day cycling from Ranfury to Ophir was outstanding. Despite battery troubles with the power assist (on the handcycle that MacGyver Sam sorted) it was the views, the big sky, the tunnels and the terrain straight from the art of Grahame Sydney, that remain vivid memories. The day was capped off with a beautiful night at Pitches in Ophir (www.pitches-store.com) where hostess Colleen Hurd made everyone feel like they were the most important group in New Zealand. Pitches was the old general store and butcher during the gold rush and has been done up very stylishly without destroying the feeling of its history.

A good start enabled a catch up with North Island friends in Alexandra. Annabel and Nick Whisker, Barney Pike and Kate Irvine and Melissa and Willie Duncan were all just starting their Rail Trail and after 12 km only Mr Whisker had blood on his knee. The team had picked up the Wilson family, Sarah, Rob, Catriona's goddaughter Anna, Sam and Phoebe back in Twizel. Anna, aged 10, cycled all day in Twizel and the whole Rail Trail totalling in excess of 200km. GREAT effort Anna!

Photos were taken in Clyde just to prove the trail had been completed. A wave to new Australian friends who had kindly made an online donation to CatWalk after hearing about the charity from our cycling PR machine Penny and then it was onto Queenstown. Novotel is great central accommodation for those wanting to avoid taxis and enjoy all the best parts of the town centre. A morning cycle with CatWalk ambassador Anna Hiatt and Andrew Town around the lake front to Jacks Point finished off a magic eight days.

A special thank-you to everyone involved in this trip...after this success there'll definitely be more.



SCI ACHIEVER ROB CREAGH

is a member of our BIG Cycle team and has recently completed the Tour of Northland as part of his training. He currently lives in Auckland with his wife and son.

What has caused you to be in a chair and when did it happen? On a Friday night in 1984 I squeezed into a small car with 8 friends. After getting up to a wee bit of mischief we parked up at Takapuna beach. I was climbing out of the rear hatch but slipped and ended up with my head and shoulders lying on the road, and with my legs hanging over the lip of the hatch. Unfortunately the driver picked that exact moment to reverse. I was rolled over under the back of the car where I stayed until my friends lifted it off me. The exhaust gave me third degree burns on my back and the roll dislocated my neck.

Are you a paraplegic or tetraplegic? I'm a C6 tetraplegic.

Tell us about any surgery that you have had since your accident. Nothing too exciting – the tendons of my toes released, removal of a bursa and screws inserted into both big toes. I'm planning to undergo tendon transfer surgery on my right hand but life keeps getting in the way.

Tell us about your fitness regime. I cycle three to four times a week and wrestle a six year old boy regularly. It would be great to get some time in for strength training but it's just not happening.

Tell us about your support network, especially family, friends, medical. I've got a good network of friends and helpers and the line between the two blurs more often than not. Having been fiercely independent in my younger days I've finally learned how much easier life can be with good support and now wouldn't be without it. Almost thirty years of experience has also taught me the importance of having good medical people to consult. Getting a second opinion on any significant health issues is always a good idea. And of course, when everything else fails, family are only a call away.

Are you currently employed, or how do you spend your days? I work as a self-employed contractor from my home office. For the last five years my work has been focused on the development and rollout of the Individualised Funding scheme. Other work has involved work-force training and health sector contracts. For the past two years I've been working part time, which allows me to have a significant role with our son and maintain my fitness.

Tell us about any specific modifications to your home or place of work, especially those beneficial to others in chairs. I'm about to trial dictation software to see if it will increase my productivity. I last tried this software approximately 20 years ago but found it clumsy. There have been major improvements since then and I'm feeling fairly optimistic I'll find the software useful this time around. My general philosophy is to take advantage of mobile technology such as ultra-books and smart phones, and utilise tools that enable me to work effectively with geographically remote clients, such as Skype.

What are your goals for the future? I'm terrible with deliberate goal setting. I think it's counted as one of the "Seven habits



of Successful People" but there you have it. Here's a few I carry in my head at present: gain a qualification in mediation, be a good husband and father, plan some more exciting cycling expeditions (assuming I make it back from the Himalayas in fair condition), visit my wife Karen's homeland Norway, import an adapted kayak (with hand-crank propulsion), dedicate some time to writing, and learn to swim.

What is the one piece of equipment that you just couldn't do without? Too hard! There are a number of things I couldn't do without: a 1970s Campomatic (trailer tent with an elevated bed) that we take family holidays in; a 6X6 Explorer all-terrain powerchair for exploring rockpools, hanging at the beach, and going bush; a standard powerchair for walking the dog, and getting across playgrounds and soccer fields; a recumbent power-assisted hand-cycle for fitness and fun (oh, and for taking part in insane Himalayan adventures); and a self-drive Kia Carnival.

What has been one of your most satisfying achievements since being in a chair? Playing a lead role in the development and national roll-out of the Individualised Funding (IF) scheme. Basically, it gives people living with disability control and flexibility over their support needs. IF enables people to employ their own support staff rather than receive services from bulk-contracted care agencies. There are now over 1,500 individuals using the scheme and growing.

Who inspires you and why? My boyhood hero was David Attenborough because what he did looked like the best fun in the Whole World. I had his book 'Life on Earth' and desperately wanted to be a zoologist ranging the plains of Africa and braving the rainforests of Brazil. I'm pretty sure he's the reason I completed a science degree in biology...and he was on TV again this evening!

When a cure for SCI is found, what will be the first thing you will do? After sending a thank you note to the genius who made it possible I wouldn't mind heading to Murawai beach with my wife and kids for a swim and stroll around the rocks. Then maybe I'll find something useful to do...I owe a lot of favours.



“to be part of any sort of change you have to be in there boots ‘n all”

I was so fortunate to represent CatWalk in my ambassador role at the Attitude Awards on the 29th November. What an inspirational, motivating and entertaining event! There are certainly a variety of challenges that people face in life which can lead to certain difficulties in day-to-day life.

There were seven categories of award with 22 nominees overall - this group of people are testament to how determination, focus, good support and overall, a great attitude, can help to cope with, and overcome these difficulties leading to amazing results and fantastic achievements in life. The award categories and winners were: Attitude Youth Award - Erin Gough (Canturbury law student), Attitude Sport Performer of the Year Award - Adam Hall (snow skier), Attitude Artistic Achievement Award - Andrew Blythe (painter), Attitude Courage In Sport Award - Neelusha Memon (coast-to-coast athlete), Attitude ACC Employer Award - Invacare NZ (mobility equipment company), Spirit of Attitude Award - Sharon Davies (national organisation and council worker), Attitude Making a Difference Award - Nola Burgess (blind foundation and riding for the disabled supporter) .

One of these seven winners was then selected for the overall ACC Attitude Supreme Award. This year's winner was Sharon Davies - what an inspiring and down to earth lady. A staunch advocate for disabled access and equal opportunity she practices what she preaches and abides the motto “to be part of any sort of change you have to be in there boots ‘n all”.

A further award was given to recognise outstanding lifelong service and contribution to the disability community by induction into the Attitude Hall of Fame. This year's recipient was Sir Murray Halberg (athlete and disabled sport supporter) and his story was told by the governor general Sir Jerry Mataperae.

In addition to the inspiring award nominee stories the evening was hot on entertainment - Dave Dobbyn sang 'Loyal' to open the evening and The Navy brass band and other musicians and singers including Blake Leitch and Natalie Te Paa continued the entertainment between the award presentations. Some of the 2012 Paralympic athletes were also present at the award ceremony and their achievements were acknowledged on the night.

Last year's Supreme Award winner Robbie Francis spoke and summed up what I think was the overarching theme of the award ceremony and the Attitude programme - “Guys, you may be able to see our disability, we may look different, we may have different needs from other people but the fact is that we are NO different from anyone else. I am not defined by my disability but it inspires me to do more than society tells me that I can. So keep going guys, the world needs us”.

Photo caption: Along with the award ceremony I took the opportunity to go to the Auckland Zoo and wore my CatWalk t-shirt... rather appropriately, right at the time Doug was taking this picture the lioness decided to finish her nap and go off for a stroll!

From one of our collaborative partners -
the Burwood Academy for Independent Living
in Christchurch we are pleased to introduce

the BAIL Bulletin

Kia Ora from the team at BAIL

We are thrilled to have been offered an opportunity to make regular contributions to the CatWalk magazine and plan to highlight important matters within our research environment and inform you of things that you might not otherwise hear about. In our first offering, we want to give you a little background to BAIL. As the brainchild of the late Professor Alan Clarke we emerged from the NZ Spinal Trust in 2005 with a focus on building a vibrant culture of research focusing on issues relevant for people who live with acquired impairments such as spinal cord injury and traumatic brain injury. Our dynamic organisation is committed to improving the life experience of people recovering from serious injury and illness by amassing research evidence to support changes in health services for the better. Based in the beautiful Allan Bean Centre at Burwood Hospital in Christchurch, the Academy is working to establish strong links to consumer organisations, national and international universities and rehabilitation professionals. As an Academy we also foster students living with impairments to develop research career pathways to ensure the perspective of the lived experience is nurtured. We have a small but talented core team led by Dr Debbie Snell (Academic and Research Director), Anne Sinnott (Lead Researcher), Hans Wouters (Project Manager) and Brian Laurie our Administrator (the man that keeps everything going!).

We are passionate about ensuring our research becomes a catalyst for growth and have numerous successful outcomes to demonstrate how we have been achieving this goal. In particular we want to make sure results of research actually make their way back to benefit users of health services (or End Users as we say at BAIL). To facilitate this we have established an End User Research Consultation Committee



which will provide a resource for researchers to better understand the needs of those they wish to research. We have had excellent support internationally for this initiative and it seems we are leading the way around the world with this approach. If you are interested in finding out more about the Committee's activities and membership, check out our End User page on our website (www.burwood.org.nz). Thanks for reading and watch this space because we have some exciting research projects underway which we are keen to tell you about in the coming BAIL instalments.

Kia Kaha, stay strong, from Debbie, Hans, Anne and Brian.

New Trustee

We are delighted to announce that we have a new Board member. **Stephanie Iremonger** has kindly agreed to join the Board. A long time supporter and formerly a CatWalk Ambassador, Steph is a management consultant based in Auckland. In her spare time she owns and rides horses and so understands that accidents can happen to any of us which is why finding a cure for spinal cord injuries is so important. Steph has assisted CatWalk in many guises over the years, and even ran the New York Marathon in 2010 as part of the inaugural Team CatWalk, an experience she thoroughly enjoyed!

Merchandise

Cycle shirts, caps and socks: Stock up on socks for school before the weather turns and catch our special offer. **\$5 per pair** or get a week's worth (5 pairs) for \$20! (normal RRP \$6 each). A fee of \$6 for postage and packaging applies per order.



Thank yous

Jean Campbell is a philanthropist in the making. She made a collection of her pocket money in the run up to Christmas which she generously donated to CatWalk. What a generous girl – and what a great example she sets. Thank you Jean! We treasure your note.

Jackie Harrington works as CMS Cameron Mckenna LLP - a law firm in London - and hosted a “Dress Down Day” in February which raised an incredible \$1187! Thank you to everyone who participated - we hope you enjoyed dressing down!

Kim Allan set herself the phenomenal challenge in November of walking 500km around the Auckland Domain with no sleep! She walked for an incredible 376km, setting the record for the longest nonstop/without sleep distance by a Kiwi and **raising an amazing \$4585!!** We cannot thank you enough for what you put yourself through on CatWalk's behalf Kim!

The Young Event Horse competition run in the UK by Judy Styles has always supported CatWalk. They recently donated a fantastic \$2400!! Thank you so much to Judy and all involved.

A huge thank you to **Pinfolds Transport (2008) Ltd** based in the Wairarapa. They kindly supported Johnny Griffith in his New York marathon Effort in 2010 but have continued to make annual donations to CatWalk since then of \$1500 each year. We really appreciate this ongoing support.

Katie Treadaway is tackling the Rotorua Half Marathon on 4th May in aid of CatWalk. Good luck and thank you for choosing to support CatWalk! We look forward to hearing how you get on. If you would like to support Katie's efforts, please donate to www.fundraiseonline.co.nz/KatieTreadaway/

We would like to especially thank **UBS** and **Vodafone** for the very generous way in which they match staff donations. Between them they had three employees who were part of Team CatWalk 2012 - **Ollie Bradshaw, Nick Ross** and **Mark Jones** - and they matched every dollar that these guys raised! An amazing and extremely generous level of support. Thank you.

Gifts in kind are also incredibly helpful to CatWalk as they enable us to spend an even higher percentage of our income on research. We are lucky enough to be supported by **Computer Partners** in Masterton who donate all of their time and considerable expertise to offer us free computer servicing.

Techsoup provides donated and discounted technology products and services from companies to eligible New Zealand Charities, through their program CatWalk has recently upgraded to the latest software at a massively discounted rate. An enormous help, thank you.

A big thank you to our **Ambassador Kate Lambie** for her amazing support of CatWalk. Through the sale of her Hit-Air safety vests, she is not only promoting safety in equestrianism and preventing spinal cord injuries from occurring but she has also **donated \$1320** from the sales of them to CatWalk for research into a cure as well. Amazing! See www.hitair.co.nz for more details.

Research Spotlight

Can TNF inhibitors be used to treat spinal cord injury?

Spinal cord injury (SCI) is often the result of a sudden, traumatic blow that fractures the spine and causes damage to the spinal cord. This primary damage is followed by a complex biological response. In the first 24 hours after injury, there is a second phase of damage caused to the spinal cord after a traumatic blow where the body releases powerful proinflammatory mediators.

Scientists are exploring potential treatment options, which aim to slow down or stop the effect of these proinflammatory mediators in the second phase of damage. Evidence is mounting that blocking a key proinflammatory mediator known as Tumour Necrosis Factor-alpha (TNF- α) is a promising target for treating SCI. Earlier this year, Bayrakli and colleagues reported the effect of administering a drug that blocks TNF- α in rabbits in the European Spine Journal. Rabbits with a partial SCI were treated with an anti-TNF- α agent “etanercept,” which appeared to enhance their clinical and electrophysiological recovery. Whilst the results were seen as preliminary, they were clearly a foundation for further studies. More data on different drug doses and investigation in a range of animal models is needed.

Amazingly, TNF- α was discovered more than a century ago, its importance in SCI has come to light in recent years. Levels of TNF- α go up after a SCI, reaching a peak within one hour of the initial trauma. At the same time, many neurons start to die. By blocking TNF- α , scientists hope they might be able to slow down or potentially stop the process of the neurons dying.

A number of drugs block TNF- α activity. A study in Turkey using rats has shown an anti-TNF drug used in rheumatoid arthritis has some effect on the spine of rats. Recently, scientists have used a mouse model of SCI to show the effect of thalidomide in reducing the development of inflammation and tissue-injury events associated with trauma to the spinal cord. Thalidomide reduces TNF- α production, although the scientific jury is out on how much of it is needed to work as a TNF- α inhibitor in living organisms.

There is no doubt blocking the activity of proinflammatory mediators as a therapy for SCI is of interest and should be further investigated. A range of issues is taken into account when considering the development of new treatments. It is vital the treatment is safe. The cost, timing and effectiveness of the treatment also come into play. Many scientists hope TNF- α is a good therapeutic target for SCI. We hope they are right.

Scientist Update

“Things are moving ahead at a fast pace in the CatWalk funded Spinal Cord Injury Research Facility in the Centre for Brain Research at the University of Auckland. We have just purchased a new microscope to add to its arsenal of high tech equipment to support the research being



undertaken in the facility. This microscope will be used for our spinal cord surgeries. It has state of the art optics and is ergonomically designed which will allow the surgeries to be carried out more easily and quickly. Our work using the mimetic peptide to regulate gap junction channels for spinal cord injury repair has recently been published in the peer-reviewed international journal Neuroscience Research. This work demonstrated that even when delivery of the peptide was delayed after the injury, there was reduced inflammation, reduced scarring, improved cell nerve cell survival and behavioural improvement was seen in the treated animals. This is an important finding in developing the peptide as a treatment for spinal cord injury as it demonstrates that there is a “window of opportunity” for treatment after an injury has occurred.

Over the summer one of our past Brain Bee Champions, Kate Burgess who is now in second year of the Biomedical Science programme at the University of Auckland undertook a 10 week Summer Studentship funded by the CatWalk Trust to carry out gap junction mimetic peptide “site of action” studies. This work is part of a wider study to understand the pharmacodynamics of the peptides we use to regulate gap junction channels for spinal cord injury treatments as a basis for future clinical trials. Kate worked with Dr Jie Zhang (with support from Dr Simon O’Carroll), and Yeri Kim, a PhD student in Ophthalmology. Yeri, who will be working on peptide site of action and mode of action during her PhD in order to understand mechanisms of action, has been accepted to attend the 2013 Australian Course for Advanced Neuroscience (run by the Australasian Neuroscience Society). Only small numbers are able to attend this course, and Yeri will bring back significant new physiology skills to the spinal injury research team at the Auckland University. And the end of January both the North Island and South Island Round 2 Brain Bee winners (sponsored by the CatWalk Trust), Jiantao Shen and Jawon Kim, headed for the Australian Neuroscience Society annual conference and scientific meeting to compete in the National Finals held in conjunction with the conference that was in Melbourne this year. It was a very closely fought battle but once again it is the North Island contestant who will head off to the International Brain Challenge, this time in Vienna, to represent New Zealand later this year. You can read more about this exciting final on the New Zealand Brain Bee web site; www.nzbbc.ac.nz/media_1.html www.nzbbc.ac.nz/media_1.html



The “Believe” Black Friday Trust Dinner and Charity Auction held in August 2011 raised significant funds to support Get Black On Your Feet - a collaborative campaign between three New Zealand charities representing the prevention, rehabilitation and cure of spinal cord injuries. The NZ Rugby Foundation, the NZ Spinal Trust and CatWalk all benefited from the wonderful event held at the Langham Hotel in Auckland.



The funds donated to CatWalk helped to establish the dedicated spinal cord injury research facility which has been established within the Centre for Brain Research at the University of Auckland.

On March 18th, CatWalk Founder Catriona Williams, CatWalk Trustees Scott Malcolm and Stephanie Iremonger and CatWalk supporter Charles Batchelor toured the research facility, hearing first hand about the progress being made from research scientist Dr Simon O’Carroll and Professor Richard Faull and meeting some of the PhD students who work at the facility.

The NZ Spinal Trust and NZ Rugby Foundation donated their share to the Auckland Spinal Rehabilitation Unit where it was decided that a

deck would be built off the dining room. On March 19th, the official opening took place with 50 guests including NZ Spinal Trust Patron, Sir Tim Wallis, NZ Rugby Foundation Patron Sir Colin Meads and Mark O’Donnell of the Black Friday Trust as well as many other notable rugby legends.

The deck is a magnificent piece of work, providing a large outdoor area for the patients, their families and friends to enjoy. The nature of spinal injuries often necessitates lengthy stays at the Unit and the therapeutic benefits of being able to enjoy some time outdoors cannot be underestimated. The deck is strong enough for powerchairs and beds, and half of it is shaded to protect users from the fierce Auckland sun. The NZ Spinal Trust is very proud of this deck. It is a welcome addition to the infrastructure of the Auckland Spinal Rehabilitation Unit, and will allow families to have their space whilst staying near the relative safety of the ward.



The only current cure for SCI is prevention

Our vision is a world where spinal cord injury does not mean a lifetime of paralysis



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