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# CatWalk



THE OFFICIAL MAGAZINE OF
The CatWalk Spinal Cord Injury Trust



Sir Brian Lochore and Richie McCaw escort Toni Street into the CatWalk fold

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### A special thank you to our supporters who help us produce this magazine

PRINT Printcraft MAILHOUSE Western Mailing COVER A handful of CatWalk's National Patrons - Aaron Slight, Dion Nash, Toni Street, Sir Brian Lochore and Richie McCaw.

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### Founder's FOOTNOTE

### Putting my foot in it...yes I can do that well...

You know you are in trouble when you go to a quiz night and the only question you can answer is about Conrad Smith and the birth of his son. Blame Richie and BJ, it's so their fault!

I'd like to say a special thank you to Sam Howard and Ben Petro who have stepped down from the Board after a number of years supporting and guiding CatWalk in their roles as Chair and Deputy. They have not only been fantastic with their prudent financial advice but have stepped up to support at events, run the NYC marathon or encouraged friends (and wife) to run the NYC marathon for us. Sam and Ben have been wonderful assets to the CatWalk team working solidly and quietly behind the scenes.

Filling the shoes at the CatWalk helm are, Australian based kiwi, Scott Malcolm (Chair) and Stephanie Iremonger (Deputy). They have already proven their ability to walk the talk with lots more to come I'm sure.

It's exciting to announce two new Patrons. Toni Street from Seven Sharp

who brings with her a wonderful kiwi down to earth style that we've all grown to love on the screen but also an intense passion to assist CatWalk and our other Patrons in really making an impact on SCI research. And, Dr Rick Acland who switches roles from Trustee to Medical Patron. Rick's ability to advise and guide us on all the technical essentials has been invaluable to our team and with all the exciting breakthroughs to translate, Rick has certainly earned his Patron stripes.

I have been lucky enough to experience the NYC Marathon as a supporter of Team CatWalk 2014. What a week...yes it was



Catriona and Ginny Warby in the 5km dash in New York City



Catriona with CEO of the Christopher and Dana Reeve Foundation, Peter Wilderotter, and daughter Lindsey Wilderotter.

cold but boy was it worth the effort. All the runners completed in excellent times while also enjoying the atmosphere, the entertainment and all that the people of New York City offer. Ginny Warby, my lovely friend, who flew from Brisbane to Auckland to fly with me to New York deserves more than a medal...we did the 5km dash to the finish line on Saturday which ended up being a 5km push for Ginny as it was pouring with rain...wheels and rain don't go together so with slippery hands I just hunkered down for the ride. Thank you Gin for making this trip possible. To all our runners Lee, Anna, John, Rochelle, Patrina, Kim and our top fundraisers Kristy and Charlotte, I absolutely loved meeting you all. THANK YOU from all us wheelies for choosing to run and raise funds for CatWalk.

It's exciting to look forward at all the possibilities ahead. You'll see an update further on what our Auckland based team are up to and the progress they are making, incredible minds achieving incredible things. Also I had the opportunity to discuss the "BIG Idea" with the CEO of the Christopher and Dana Reeve Foundation whilst in NYC. It was spine tingling – excuse the pun! They are raising \$15 million to test the hypothesis on a further 36 patients that epidural stimulation can be used to promote recovery of autonomic control in patients who have been diagnosed as completely paralysed. Why is this exciting? They have already tested four SCI patients at various levels and ALL have made substantial functional gains. Find out more here www.reevebigidea.org. From where

I'm sitting this makes me want to dance.

On a personal note, I'm in the middle of training for the New Plymouth Half Ironman on February 7. This is causing my shoulders to look like Arnold Schwarzenegger. To help with this new look, which is rather becoming for a 49kg female, and if you are not able to join in for the physical challenge please feel free to donate to my fundraising page

http://www.givealittle.co.nz/cause/catrionawilliams1... I promise CatWalk and I appreciate every single penny!



### A MESSAGE FROM OUR InternationalPatron

### Dear CatWalk Friends

014 has been an exciting year for us all, and since my last message it's been the World Equestrian Games in France taking centre stage.

WEG brought together the best from all around the globe and it was a huge excitement to be in the medals with Team GB. It wasn't New Zealand's time to shine but still great news just a few weeks later to see your own Andrew Nicholson in such wonderful form at Burghley.

Also in September, it was a humbling experience to compete in a Wheelchair Rugby clash at the Invictus Games in London. Mike, my cousin Harry and everyone else who took part agreed to tackle an 'exhibition' match. It turned out to be far more than that – it was fun, fast and furious and a reminder of what strength and resilience there is in all top sports people.

With warm regards for a warm and happy New Zealand summer.

Zara Phillips, MBE

#### NATIONAL PATRONS

Sir Brian Lochore, ONZ, KNZM, OBE; Richie McCaw; Dr Rick Acland, Dion Nash; Lance O'Sullivan, ONZM; Aaron Slight MNZM; Toni Street, Sir Mark Todd, CBE; Sarah Walker.

#### TRUSTEES

Scott Malcolm (Chair); Stephanie Iremonger, Derek Lindsay, Pip McCarroll, Rebecca Scott, David Pretorius



Zara Phillips, MBE, at the 2013 Magic Millions Carnival (see more on page 11)

### Street's ahead WELCOME TONI STREET

EVEN RICHIE MCCAW DROPPED BY THE NIGHT BEFORE THE ALL BLACKS FLEW OUT TO ARGENTINA TO HELP WELCOME TONI STREET AS THE NEWEST PATRON OF CATWALK.

He joined fellow patrons Sir Brian Lochore, Dion Nash, Aaron Slight and CatWalk supporters in Auckland to give Toni and hubby Matt France, a warm welcome.

"I was so impressed with the group of incredibly passionate and decent people that support this Trust. says Toni. They're clearly a special bunch."

The top TV presenter, mother and sportswoman is pretty special herself and will be a tremendous asset to CatWalk.

Following her initiation into the CatWalk clan, Toni was singing CatWalk's praises the very next night, to over half a million Seven Sharp viewers, in her role as co-presenter with Mike Hosking.

"The thing I like about CatWalk is that it's about breaking new ground, and getting tangible results. I like that attitude.



Toni Street

No mucking around, just do this" says Toni. "The fabulous thing about Toni is that she doesn't muck around either, she's a doer and she gets us," says Catriona, "Toni is gorgeous on the inside and outside."

For her part Toni is pleased to get behind CatWalk.

"I'm honoured to be involved," says Toni. "From the moment I met Catriona, I knew she was special, she oozes a gritty quality that allows her to get things done and fast. She's the kind of person you certainly wouldn't say no to, and I was honoured that she deemed me worthy enough to be involved with a project so close to her heart".

"As a sporty person myself, I can't imagine how tough it would be to not have the use of my legs

and I want to help in the fight to find a cure so there's hope out there for everyone."



Dr Rick Acland

### Patronstripes

e are delighted that former Board member Dr Rick Acland has taken up a new role with CatWalk as Medical Patron of the Trust.

♥ ♥ "Having stepped down from the Board earlier this year to allow for 'new blood', I was onoured to be asked to become CatWalk's official Medical Patron." says Rick.

A former Director of Burwood and now roving Consultant to both NZ Spinal Units, Rick has been involved with CatWalk since inception, even being at Catriona's bedside in her early recovery days. "The CatWalk family is incredibly unique. Having worked with the team and witnessed first-hand the passion and commitment everyone has for the cause and the difference we're making, signing off completely was and will never be an option. It's an absolute privilege to be part of it." says Rick

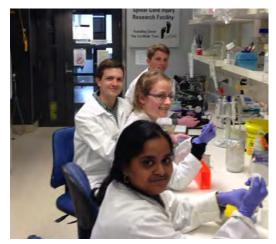
### SPINAL CORD INJURY RESEARCH FACILITY 2014 What CatWalk has been funding

### Gene Therapy Research

ene therapy is a powerful tool that has recently been adapted to alter the function of cells within the brain and spinal cord. This approach has been used successfully to target cells in the brain to develop treatments for a number of neurological disorders and has also shown potential for treatment of spinal cord injury.

The SCIRF approach is to use gene therapy to introduce protective molecules into the spinal cord. The cells in the spinal cord that form a scar after injury are the target. The SCIRF team has demonstrated that they can target these cells successfully. This work was presented at the Australian Neurotrauma Conference in Adelaide in October and received very positive feedback from colleagues.

#### The First PhD Student To Undertake Spinal Cord Injury Research In NZ



The team at the Spinal Cord Injury Research Facility (SCIRF) based in the centre of brain research, University of Auckland Medical School.

The SCIRF is continuing to grow through development of new projects and collaborations. The team have found a particular molecule on these cells that can be targeted with drugs and they are testing whether these drugs are effective for spinal cord injury.

### Protecting Blood Vessels

This project is looking at protecting the blood vessels in the spinal cord, as damage to the blood vessels can lead to increased injury. In the SCIRF, they have identified a number of potential targets that may be of use for treatment.

### The Summer Studentship Programme

The summer studentship programme, funded by CatWalk provides a great opportunity to expose top class students to spinal cord injury research and encourages them to work in this field in their future clinical and/or research careers. This summer three students will be working on a number of different projects.

A PhD student has been recruited and will start in the New Year. The student will test specific proteins that can break down the scar that is formed following injury, as this should assist nerve cell regrowth and result in a functional improvement.

### Prevention of Scar Formation

A project aimed at stopping scar formation is underway. Here the SCIRF are testing whether a drug known to stop production of proteins involved in forming the scar will be protective following injury.

### Immune Cell Damage Prevention

This project is looking at stopping damaging immune cells from entering the cord after injury, thus preventing further damage. Rachael Wiltshire, a year two Biomedical science student and winner of the Brain Bee Challenge (2010) will be working on the project looking at protecting the blood vessels in the spinal cord.

Kate Burgess, also a previous winner of the Brain Bee Challenge (2009), will be doing her third summer studentship through the SCIRF and her project this year takes her to Burwood to the Spinal Unit where she is working with Dr Raj Singhal who has developed a Spinal Traction Unit for use in cervical spinal cord injuries to realign dislocations and reduce compression of the spinal cord so that damage and disability can be minimised.

Quentin Burrell will be working on the project testing the drug to stop scar formation.

# ClassOF2014

NEW YORK MARATHON RUNNER CHARLOTTE GENDALL MUSES ON MONTHS OF TRAINING, WEEKS OF ANXIETY AND ANTICIPATION, SELFLESS DREAMS OF A CURE FOR SPINAL CORD INJURY AND SELFISH LUST FOR A FINISHER'S MEDAL.

I the end though, my own enduring memory of the 26.2 miles of the 2014 TCS New York Marathon will not be of my personal four year journey of blood, sweat and tears, but instead it's of the faces of the hundreds of thousands of people -- supporters, fans, NYPD, officials and volunteers alike -- who lined the streets of the five boroughs on November 2 with their smiles, their signs, their energy and their enthusiasm. None of us



An energetic marathon supporter in New York City

chance to catch up with US based family, it was the perfect time to be a visitor in what I believe to be the world's greatest city, even if there was that nagging 42 kilometres to navigate, now less than a week away. I tried my hardest to remain focused on the task amongst the hoopla but when the opportunity arose to attend a Friday night Waldorf Astoria gala dinner recognising Bette Midler's New York Restoration Project, how could Catriona and I say no? Fellini Hulaweeni was the theme

achieved this run on our own. We may have had the commitment but we needed their belief.

Each member of this year's Team CatWalk has their own story, told here with words and fleshed out with photos. As an overview, it's a privilege to outline a few of the highlights of what it meant to take part in a truly remarkable event. And of course, this year it as NY threw itself at what was - even by NY standards - a party to end all parties. With riotous costuming and a fashion competition judged by Tim Gunn and Michael Kors (Project Runway), dressed for the occasion and spoilt rotten, your Kiwi country mice were living a dream. A Fellini fuelled Bacchanalian dream which seemed a million miles from Masterton.



Team coffee in New York City

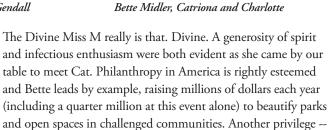
was also a privilege that CatWalk founder Catriona made the trek to support our cohort. We were ready.

Arriving in the Big Apple at the start of Marathon Week, Warwick and I were blessed with unbelievably balmy fall conditions, with Central Park a riot of autumn colour. Ominous signs in the weather forecast for Sunday were put to one side. Wind? What Wellingtonian worth their salt couldn't cope with a gentle breeze? Famous last words, but more on that to come.

Staying apart from the other CatWalkers, but grateful for the

Charlotte and Warwick Gendall

to see giving at its best.



I was also honoured to meet our hostess and took the opportunity to tell her she would be the "wind beneath my wings" during the marathon. Even by my standards it was a pretty lame joke but Bette is nothing if not a good sport and responded with a high five to send me on my way, ecstatic. The night wrapped with a set from R and B legends Earth Wind and Fire. Time for bed -- it was a Halloween after all, and the pumpkin coach (yellow cab) awaited.



Team Reeve!

Saturday brought another momentous event and one which speaks straight to the heart of CatWalk and why we all do this. The Christopher and Dana Reeve Foundation is undoubtedly at the forefront of international awareness and fundraising for a cure. Their most recent "Big Idea" campaign is an exemplar of how to inspire and resonate on SCI. Yet again, it was our privilege, this time invited by Foundation CEO Peter Wilderotter to attend their Team Reeve pre-race lunch and briefing. To be updated on the latest US based and global developments was a unique opportunity for Catriona to network with others who share our ideals.

And then ... no putting it off any longer. The day dawns the moment I and 50,868 others have trained for. The forecasters are, sadly, spot on. It's freezing cold and blowing a gale, in fact the windiest marathon on record, so windy that sectors of the race involving wheelie competitors are rescheduled to start on the far side of the Verrazano Narrows Bridge because of the dangerous conditions.

I put my inner terror to one side, channel the agony of those training runs around the Wellington bays in a northerly, and work on what Catriona and my other mentors have told me. Break it down, keep it simple, breathe. And keep putting one

foot in front of the other. Motivated by my donors, my family and the names on my shirt (recognising Sam Scott and Thomas Russell) the miles slowly tick by as random thoughts flow through my head. Why am I doing this? Is it for them? For me? Fear of not finishing?

On the sidewalks, strangers continually high fiving me, calling my name, telling me "you got this." I don't know if I believe them. Special thanks to the lady who told me 3 miles from the finish that I was stronger than I know. I desperately needed to hear that, just then.

Two targeted screams at me and I see Catriona and crew, once in Brooklyn and again outside the Park. Warwick is there a mile and a half from the finish. I'm tiring but as one sign says "What option do you have? You have to \*\*\*\*\*\* finish now!" And then suddenly it's over. 5.44.59. I'm thrilled. Finished, and in daylight. Across the line and I'm given my medal. Our medal. Satisfyingly heavy and hanging from a handsome ribbon. Wrapped in a warm blanket and race poncho, munching a complimentary apple which tastes as if it came from the Garden of Eden, I stagger in to the family zone to meet Warwick, and my dear cousins Amanda and Amelia. I can't thank them all enough.

Hot bath, team dinner and the greatest sense of physical achievement I've ever known. Perhaps outside 6 February 1996, that is. I reflect on an earlier secret vow that as soon as this torture was over, I'd never run another step again. Now I'm not so sure. Must be the endorphins.

And so as I write this before heading to JFK before the flight home, what's my final marathon message? What was the meaning of the marathon?

He tangata, he tangata, he tangata. It is people, it is people, it is people.

Charlotte Gendall, Class of 2014



Lee, Kristy and Anna before the race



Statue of Liberty Girls!



Charlotte with her medal

### 3. ICC Cricket World Cup 2. IRB Rugby World Cup 1. CatWalk's New York City Marathon



### 2015 IS A YEAR OF WORLD CLASS 'MUST [

n February and March, we'll all become fanatic cricket fans as the Black Caps take on the world - right here at home (and across the ditch). By September / October, we will have switched codes and will be cheering Richie and the ABs on in the UK - bring it home lads! But the true test, the BIG one happens in November. Where will you be? CatWalk are again sending a team to compete in the unforgettable NEW YORK CITY MARATHON. A 42km block party of incomparable proportions. Starting



Rochelle Running



Anna before the run



Kristy with her medal

in Staten Island and finishing in Central Park, runners and walkers pass through all five boroughs of New York City, taking in the inimitable sights and sounds of this remarkable metropolis. We are giving you the opportunity to join us. If you've thought about doing it before and then changed your mind. NOW. IS. THE. TIME. But don't just take our word for it, take theirs...

> The whole trip was been incredible, we feel really proud to have been associated with CatWalk. A highlight was handing over my jacket to an African American man sitting on sidewalk with his two kids supporting us.... I gave it to him as I came off the bridge and he just flipped out!!!! Great feeling. Anna

Thank you to CatWalk Trust for the opportunity, it's something I would never have considered doing otherwise and it was truly the most amazing experience of my life! Rochelle

NYC was absolutely fantastic!!!!! It all seems like a dream now but it was seriously the trip of a lifetime and I feel so privileged to have been part of such an event. I have loved supporting CatWalk and feel very close to the cause as a result. Loved spending time with and getting to know Catriona...such an inspiring lady! Would love to go back and do the run again one day! Might have to drag my husband over next time! Kristy

### Diamonds & CARROTS "I never worry about diets. The only carrots that interest me are the number you get in a diamond." Mae West

gem simply by attending her New York City Marathon **Diamonds** with fabulous prizes far exceeding the value of the bag; raffles and and CatWalk fundraiser.

September to raise money for CatWalk. Presented by high end clothing store in Mount Maunganui, Sisters & Co, with double Commonwealth games champion, Sarah Ulmer hosting the evening. New Zealand fashion designer, Juliette Hogan also made

with a glass of champagne, each glass containing a zirconium diamond however one lucky person out of the 120 guests won a real diamond. Other revenue streams included mystery bags auction prizes including luxury travel. The total fundraising effort



# 21kmsalute HAIF JOIN CATRIONA WILLIAMS IN A WORLD FIRST!



Catriona on the farm

Broken bike in Eketahuna



All fixed!



The beautiful New Plymouth

f all glory is fleeting, you better not miss your chance! We know you're out there and we know you're excited. We've got the celebrities on standby and the electrolytes chilling. The unique and exclusive events are in progress.

All we need now, is the finalised VIP guest list. Is your name on it?

You've already been invited to join us at the Wells New Plymouth Half Ironman on Saturday 7 February 2015. You can either:

- Enter as a team and choose to do one of the following swim like a fish (2km), ride like the wind (90km) or run like Lydiard (21 km). \$300 per team.
- 2. Enter as an individual and do all three. **\$250 per person**.
- 3. AND NOW... we offer a third glorious option.

Be part of another CatWalk milestone as our Founder rolls her way into the history books (again).

If Catriona Williams completes the Half Ironman on February 7, she will be the first tetraplegic in the world to do so. You can run or walk alongside her as she completes the final 21 km leg of her individual Half Ironman effort. **\$100 per person**.

While Catriona pushes herself towards her end goal, you can clip the ticket and bask in the triumph of her world-first achievement - a 21 km SALUTE!

You'll also be able to encourage her along the way and all the while, you'll be supporting CatWalk.

#### The time is nigh.

### world-first triumph

How to be part of this

e've made it super easy for you. To register yourself or your team, email us these details:

- Select one: Individual Entry / Team Entry / 21km Salute
- Competitor's names and discipline (if applicable)
- Primary postal address
- Primary email
- Primary mobile number
- T-shirt size/s

#### Email us here: info@catwalk.org.nz To receive your team t-shirt to wear on the day, we need all details prior to Monday 19 January!

Simple, simple, simple. Even if you've never competed in a race before, now is your chance. This is all about participation and being part of the CatWalk Team.

Glory may be short, but memories are forever.



Thanks to the generosity of Managing Director Vin Cox, CatWalk will benefit from a unique fundraiser held at Brisbane's most prestigious horse sales, Magic Millions, in January 2015.

To kick start the week long Jeep Magic Millions Carnival for 2015, industry leading experts from around the world will assemble on Sunday January 4, 2015 to discuss the economic outlook for the year ahead.

Joining the world-class panel will be special guests, international horse trainer and bloodstock advisor to Her Majesty The Queen, John Warren, Managing Director of Magic Millions, Vin Cox, world leading horse trainer and three time winner of the prestigious Prix de l'Arcs (2014, 2013 and 1979), Christiane 'Criquette' Head-Maarek, News Corp Australia's The Daily Telegraph Editor, Paul Whittaker, and co-owner of The Jeep Magic Millions Carnival and Australia's largest owner-breeder of thoroughbreds, Gerry Harvey. Australian Seven Network sports broadcaster and racing enthusiast, Hamish McLachlan will MC.

The panel will commence at 3.30pm in the Magic Millions Sales Complex and will be open to the public. A gold coin donation will be encouraged with all proceeds going towards The CatWalk Spinal Cord Injury (SCI) Trust and Perry Cross Spinal Research Foundation to help raise funds in support of developing pioneering research for a cure for Spinal Cord Injuries.

#### For the fundraiser CatWalk has joined up with the local Brisbane Perry Cross Foundation which has similar goals to CatWalk and was founded by Perry Cross in 2010 who became a quadriplegic in a Rugby Union accident in 1994.

Magic Millions has partnered with CatWalk and Perry Cross for the 2015 Carnival to join the commitment to a world where spinal cord injury does not mean paralysis for life, a cause they feel passionately about.

There will be a Happy Hour Bar and BBQ at 4.30pm, immediately following the discussion.

The Jeep Magic Millions Carnival spans from Friday 2 to Tuesday 13 January 2015 and includes the richest sales incentive race day in the world, where only graduates of the Magic Millions Sales are eligible to compete for the \$4.7 million prize pool.

Attracting international visitors from all over, Magic Millions is delighted to be welcoming back Patron of Magic Millions Racing Women, British equestrienne and CatWalk Patron, Zara Phillips MBE, for the second time.

Zara's first appearance with be at the Jeep Magic Millions Barrier Draw on the Surfers Paradise Foreshore, Tuesday, 6 January.

For more information go to www.magicmillions.com.au or phone +64 7 5504 1200





AUSTRALIA'S NO.1 SUMMER RACING CARNIVAL



Magic Millions turns up the glamour and excitement of this summer's racing season. You are invited to the spectacular Gold Coast for the 2015 Jeep Magic Millions Carnival, Sales and Raceday.

Revel in 10 magnificent days of Australia's number one summer racing carnival as you gather with friends, don your most fabulous outfits, and toast to the celebrations on and off the track. Experience the energy of Queensland's richest raceday, together with the style and sophistication of the latest trackside fashions. Feel the thrill of the barrier draw, and entertain the dream of owning your very own racehorse at the yearling sales and open day. With visitors coming from all over the world for this flagship event, there are so many magical moments to be a part of! Find out more at www.magicmillions.com.au or call (07) 5504 1200.

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Gold	Coast Jeep				r NAU



Gemma, Amanda, Lola and Ziggy

# IrrepressibleAMANDA

A spinal cord injury can happen to anyone at any time. In just one moment life is changed forever - how you cope with it is what counts according to Amanda and Gemma.

"I look at that girl and thank her for the experiences, memories and physicality that she gave me, but it's not me anymore. I've started a new chapter, a new life."

**C** That girl" that Amanda Lowry is speaking about is herself. She looks at a photo, still on her mobile camera roll, of her looking fit, tanned and bikini-clad, standing on the beach. She stares at the picture with absolute acceptance that that was her, only two years ago.

"I don't miss my legs, my feet or even moving as much as I miss simpler things, like being able to cook, or make Gemma a cup of tea. I miss being able to hold my babies in my arms."

Amanda's life changed forever a mere 18 months ago, on an

ill-fated surfing trip. Amanda is still so new to tetraplegia, you would forgive her for being in denial, raw or even bitter. But speaking with her and partner Gemma Holroyd, these are the furthest descriptions from mind. Amanda's wide smile and chuckle are readily offered and her eyes sparkle as she relays anecdotes about their two daughters.

"Mum, he's a broken-arse too" is one of five year old Lola's most recent declarations. Lola was openly referring to a nearby man (a stranger), also in a wheelchair.

Their humour is infectious and it's clear that laughter is one of their primary means of healing. Stories about catheters and fat thighs are willingly cackled over, nothing is taboo but everything has an underlying significance of reality.

Formerly a passionate kitesurfer and outdoor sports fanatic, on 7 March 2013 Amanda and Lola had taken the family's visiting friend Miguel to the beach for a quick visit while Gemma rested at home with their six day old baby girl, Ziggy. Having just undergone a c-section, Gemma was housebound, unable to drive, stretch or lift any heavy objects. "It was Gemma's turn to take time out; that was the deal. She'd supported me for two years while I completed my Masters."

On that day, 41 year old Amanda, a Sociology Tutor at Waikato University, had finished her surf and dove off the board directly into a sandbar. The resulting trauma severed her neck so badly that x-rays showed what looked like an S-bend. The vertebra was detached to such an extent the doctors called it a 110 per cent dislocation - with the C6 vertebra sitting in front of C7.

Four hours later, Gemma arrived at Tauranga Hospital, with their new baby in her arms and had a desperate wait to find out Amanda's condition.

"I remember a nurse whisking Ziggy out of my arms and thinking 'that nurse has my baby'. Everything else was like

watching a movie. People kept saying 'we don't know yet, we don't know', and then finally, one nurse told me I needed to speak with Amanda."

Amanda's simple words were "They think I might not walk".

After a fleeting visit by anyone's standard - ten days in ICU, one day in the wards, and ten weeks at Auckland Spinal Unit – Amanda, Gemma and their girls were sent home. But where was home?

Their now completely inaccessible Tauranga home had had to be sold and the family needed somewhere to rent. Managing to find

a suitable interim rental property, Amanda and Gemma began creating their new life.

"Unfortunately no one tells you what areas of the country are equipped to look after a certain level of tetraplegia, or what you need to learn to be able to do for yourself," says Amanda.

The duo have navigated their way through the maze of Doctors, Surgeons, Nurses, Occupational Therapists, Physiotherapists, Phycologists, Carers, supported by ACC, and now have a clear goal moving forward. They will finally start progress on building their own home.

Good friend and fellow tetraplegic, Neil Cudby, is assisting them as 'wheelie-consultant-project manager' throughout the building process. "It sounds like a no-brainer, but it is so useful to have someone in a chair involved so that we know to put the cooking extraction controls down low, remove the banister railings out of eye line, where to put the toilet, and to ensure that the entire house has level entry" Amanda says, still smiling.

Everything comes back to living a full and happy life which to these two, is all about family and friends.

"Five year-old Lola and toddler Ziggy bring their challenges but also a balance to our lives," says Amanda.

Every other sentence seems to include mention of another friend who has been there or supported them somehow, and it's not hard to imagine why. Their love and gratitude are palpable and they have a way of making everyone feel very welcome.



"Life is still good, it's just different. Now I have to find new ways to engage in the world, to laugh, to find joy, not only for me but for my family."

> complications. Amanda has a rowing-suit style corset for improved posture and breathing, plus a specialised glove to assist with hand grip and dexterity. Her own car is next on the very simple 'wishlist'.

> "Life is still good, it's just different. Now I have to find new ways to engage in the world, to laugh, to find joy, not only for me but for my family."

She says this with a mighty big smile on her face.

"For someone who really enjoys having some time to myself, I've found only having 16 hours of time alone since my accident quite hard to deal with."

Amanda has had to adjust to her new status at work too. "Apart from the obvious transport and accessibility issues, the invisible affects of reduced respiratory function mean that simple voice projection to a classroom of eager students can cause exhaustion."

But she has already researched techniques and accessories to reduce these and other secondary



### ALL ABOARD the hope, hype and cynicism ride

### THE 2014 SPINAL CORD INJURY ROLLERCOASTER

I could be said that 2014 has been something of a "hopeexpectation" rollercoaster for the paralysis community. A myriad of "breakthroughs" during the last six months have instilled a mixture of hope, cynicism and downright hysteria within the paralysis community and mass media.

Now that the dust has settled, we thought it would be a great opportunity to share our thoughts about what has been a whirlwind year in the field of spinal cord injury research and what we can expect for the future.

It all started in April when we saw some exciting news from Louisville, Kentucky lead by Dr Susan Harkema, whereby four spinally-injured men experienced changes in autonomic and voluntary function after undertaking an epidural stimulation programme that has been championed by the Christopher & Dana Reeve Foundation.

#### Dr Harkema visited New Zealand in late November as part of the Australian and New Zealand Spinal Cord Society Annual Scientific Meeting. We will provide a further update on her progress in our next edition.

#### Working2Walk Symposium – October

The annual Working2Walk Symposium held in Seattle, is run by US non-profit Unite2FightParalysis. The two-day conference showcased some of the most leading edge scientific research into cures for spinal cord injury bringing researchers, clinicians and community members together. Some of the highlights from the symposium included:

Dr Chet Moritz, University of Washington, presented some amazing work with brain-computer-spinal interfaces. By placing hair-like wires below the spinal lesion and stimulating movement through brain-controlled interfaces his team were able to enhance the function of spared spinal circuitry in animals. This could be real possibility for retraining and restoring voluntary hand/grasp function in tetraplegics in the future.

Ida Cahill, CEO of Conquer Paralysis Now, launched a brand new and exciting initiative called The SCI Challenge. This is a multi-million US dollar incentive prize designed to find a cure for chronic paralysis within the next decade. The idea is to incentivise researchers to find a solution to chronic spinal cord injury by offering strategically designed prizes, fostering collaboration through competition and attracting the best scientists and engineers into the field.

Dr Jerry Silver, Case Western, presented more evidence of chronic injury recovery using combinations of peptides, growth factors, peripheral nerve bridges and the chondroitinase enzyme. His work continues to show remarkably consistent recovery of breathing and bladder function in chronically injured rodents. Dr Murray Blackmore, Marquette University, has most recently been leveraging data from the cancer research field and has identified additional gene targets that are responsible for the growth of cortical spinal tract axons – the ones responsible for finer motor movements.

Dr Reggie Edgerton, UCLA, presented some further advancements of neuromodulation – as well as an implanted epidural stimulator he is now working on transcutaneous

(through the surface of the skin) and drug-based ways of stimulating the cord. His lab is developing a new noninvasive stimulator that could be ready for market within the next couple of years.

Dr Wise Young, Rutgers University and SCINetChina, presented some preliminary information from the

Umbilical Cord Blood & Lithium Phase II clinical trial that has taken place in China under his supervision. He explained that although none of the chronic ASIA A participants had improved motor scores, 15 out of the 20 patients were able to take steps with a walker whilst in rehabilitation. This "phenomena" is something that he would like to further study and has not yet been able to explain. Some of the participants also gained multiple levels of sensory function.

#### Nose cell breakthrough

A day after Working2Walk, international news outlets went into a frenzy again claiming that a paralysed man could miraculously walk again thanks to stem cells derived from his nasal cavity. There was an incredible amount of publicity.

Dr Geoffrey Raisman, UCL, has dedicated much of his career to brain and spinal cord injury. His claim to fame until today has been proving that the nervous system is not hard-wired and that it is capable of changing even after injury. He coined the term "plasticity" which is widely used in neuroscience and rehabilitation today to describe the brain and cord's ability to change itself and form new connections. His primary interest over the last decade has been olfactory ensheathing cells (OECs) – cells that assist nerve repair in the sensory system of the nose throughout adult life.

There have been a number of human trials using OECs over the last 10 years. For each trial, the cells were derived from a variety of sources before being transplanted into cord. Such examples include Dr Carlos Lima, Portugal, who transplanted olfactory mucosa from the noses of many patients with SCI and Dr Hongyun Huang, China, used OECs derived from aborted foetuses in over 1600 SCI patients. Both trials produced data showing modest recovery but these results have never really been followed up with further quantitative studies.

In this most recent case, the cells were derived from the olfactory bulb, deep in the brain. The cells were then cultured in a lab prior to being ready for transplantation. In addition to the cell transplant Dr Raisman's Polish collaborator, Dr Pawel Tabakow and his surgical team untethered the cord from its lining, surgically removed some scar tissue from the chronic lesion and took some peripheral nerve tissue from the ankle of the patient for use as a bridge over the lesion.

It is noteworthy that the patient's injury was not a more common contused/bruised cord, but rather a rare knife injury which happens to create a cleaner cut and scar. It's not clear whether removing scar tissue from the lesion would ever be a viable surgical approach in a more common contused injury – especially one that is incomplete. Also, whether the cells or one of the multitude of surgical procedures contributed to the patient's recovery is hard to deduce without there being more participants. We look forward to seeing more data from the

team at UCL and Poland.

Following this, Spinal Research UK has announced £300k of funding to help researchers at Cambridge University, University of London and Kings College London collaborate to develop a human-grade form of chondroitinase – an enzyme that breaks down chronic scar tissue and increases the capacity for

the cord to regenerate and rewire itself.

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With all of these exciting developments, it is important that we as a community manage our expectations of timelines without losing the hope that one day we will all benefit from this great work. Science takes time. However, with more money and more talented people entering the field, we will see these lines of science reach the bedside sooner rather than later. There is a lot to be hopeful for in this field yet a lot of hard work and scientific discovery to come.

#### Rehabilitation is crucial

As with any of the repair strategies on the horizon, rehabilitation will always play a key role in training new functional synapses, rebuilding muscles and co-ordinating new function in order to make use of it in everyday life. If we do want to capitalise on these breakthroughs in the future, it's important that we maintain our muscle mass, bone density and range of motion whilst continuing to stimulate the nervous system in a variety of ways.

Here's hoping the rollercoaster continues into 2015 and beyond and we all get wiser to cutting through the media hype and down to the real scientific facts.

#### Contributed by neurokinex

Neurokinex is the UK's leading provider of neurological activity-based rehabilitation. www.neurokinex.org



# WHAT EVERit takes

CHARMEYNE TE NANA-WILLIAMS CAME TO THE CRUSHING REALISATION THAT SHE, HER HUSBAND PETER AND THEIR EIGHT MONTH OLD TWINS WERE PRETTY MUCH ON THEIR OWN, SOON AFTER AN ACCIDENT LEFT HER CHAMPION BOXER HUSBAND, A QUADRAPLEGIC.

The actions Charmeyne took as a result, has led to her receiving the Queens Service medal in this Years' 2014 Honours. This remarkable woman is making waves in the home care sector.

After finding that services for her quadriplegic and head injured husband, Peter Williams, were woefully inadequate and inflexible, she started a company to change all that.

What Ever It Takes creates a home-based environment completely conducive to care and rehabilitation.

With a background in business management, Charmeyne began accessing ACC funding to build a network of home care support for Peter and her own family and for other vulnerable families in Auckland, Wellington and more recently Whakatane.

Designed to be a wraparound reactive and flexible model for care for the vulnerable, it makes the best use of both willing family members and expert providers. **What Ever It Takes** promotes collaboration with other expert service providers and with ACC to use the best the community has to offer, resulting in an oftentimes common sense approach, rather than a strictly medical framework for care. Sometimes in the care of a loved one, "family really does know best".

Not satisfied with setting up this extraordinary homecare

provision model, Charmeyne has her sights set on putting What Ever It Takes inside a new network of former colleagues who are setting about building social housing in the Pacific.

Several years ago Charmeyne was invited to stand as a Member of Parliament and while she has too much on her plate at present, Charmeyne Te Nana-Williams is not ruling it out in the future. Watch this Space. Go on – change your world view – www.whateverittakes.co.nz.



Catriona and Charmeyne at Government House



### NEW CONNECTIONS

couple of months back, forme Sydenham prop Jase Ryan was sitting having a coffee with good mate Dan Carter when CatWalk's Patron, Richie McCaw, joined therm.

"We got talking about what I've been doing and Richie urged me to hook up with CatWalk." says Jase.

And hook up he has, because Jase's passion is to raise awareness of safe rugby techniques, especially among Front Row forwards. "They're at the greatest risk of injury, especially Spinal Cord Injury," explains Jase, "hence if there's anything we can do for CatWalk and vice versa, we're there."

The Front Row Club is Jase's brainchild and he now coaches front row players from the All Blacks team through to kids' junior rugby teams.



"The key focus of the club is on safety, because "a safe technique is an effective technique"."

After playing more than 180 Senior Division 1 games in the Front Row for Sydenham, plus 1st Class rugby, Jase saw the need for a coaching program dedicated to front rowers.

"We want to equip rugby players from a young age with the resource and skills that will focus on technique and safety. It's great for the clubs, schools

and parents to know that their children are safe and have been taught the right techniques and given the skills to protect themselves in the front row" says Jase.

As for CatWalk; "I'm really inspired by Catriona's story and excited by what we can do together."

Making every rugby player in the country aware of CatWalk and spinal cord injury, seems like an achievable task. www.frontrowclub.co.nz

## MutualAdmiration

t took Victoria Wilson only a few seconds to decide whom she was going to invite when she was given the job of finding an inspirational guest speaker for this year's recent Waikato Diocesan Sports Awards.

"I've known Catriona since I was little and thought she'd be great and of course she was brilliant", says Victoria.

CatWalk Founder Catriona sat in awe during the evening, as student after student received usually multiple awards for representing their school and often their community in their chosen sport.

"It is so impressive how every student is encouraged to use their talents, says Catriona, "I think Waikato Diocesan pretty much must produce every champion from every sport in the region when you see the awards that were handed out!

"I've known Catriona since I was little and thought she'd be great and of course she was brilliant"

Catriona was somewhat over-awed by the time it was her turn to take the stage. She took the audience back to the last minutes she was walking around on the fateful day she fell from a horse during a show jump. She would never walk again.

"Catriona didn't beat around the bush, she didn't leave anything out and told us exactly how it is to lose the use of your legs and body and live life in a wheelchair," says Victoria.

"Everyone listening was so amazed at how successful she's been since her accident. The girls really respected what she's

achieved and beyond that it shows when things don't go your way in life, not to let it worry you too much, because there are so many opportunities you can take that you've never even thought of!"



Guy Irwin, Stewart Hickey, Tiffiney Perry and Chris Harvey Catriona and the girls

Catriona mid-presentation

Victoria Wilson and Catriona

### A CHAMPION OF CatWalk

CATWALK HAS TAKEN THE EXCITING STEP OF OPENING AN OFFICE IN AUCKLAND AND THE BEST NEWS IS, IT IS NOT DIVERTING ANY FUNDS BETTER SPENT ON RESEARCH INTO MAINTAINING IT.

Trowe Horwath is generously sponsoring CatWalk at their Head Office, in Auckland

"We absolutely believe in CatWalk," says Managing Principal, Andrew Sayers.

CatWalk Board member David Pretorius started the ball rolling with Crowe Horwath when he was talking to a colleague, Marnus Beylefeld at the firm.

"We then took our idea to the whole team and everyone was completely in agreement that it is a great charity that we should get behind, says Andrew.

CEO Libby Young will be based in the new Auckland office while Meg Speirs will continue to manage the Masterton office.

"We knew it was crucial to have an Auckland presence, to be able to grow our ability to fund more SCI research", says Libby.

"Now we can do that without having to divert substantial funds into an office structure. We have desks and everything we need all provided by Crowe Horwath in their fantastic downtown location." Crowe Horwath New Zealand is part of an international network of accounting firms ranked in the top ten of global accounting networks, providing practical accounting, audit, tax and business advice to individuals and businesses.

They are specialists in Agriculture, Asia Business, Automotive and Transport, Building and Construction, Franchising, Maori Business, Mergers and Acquisitions, Property, Real Estate the Public Sector and more. They have a practical focus and also offer services such as small business accounting, auditing, risk management, and business advice.

So CatWalkers if you have any accounting needs or business goals, however simple or complex, small or large, Crowe Horwath can offer expert help and are friendly, accessible and easy to do business with. With 23 branches throughout New Zealand and more in Australia there is a good chance there is a branch near all of us.



# Chairman's REPORT

### I AM PLEASED TO PRESENT THE CHAIRMAN'S REPORT FOR THE YEAR ENDED 31 MARCH 2014.

This represents my first report as Chairman of the CatWalk Board of Trustees.

The year to 31 March 2014 was an exciting year for CatWalk. The Trust generated revenue of \$536,566 due to the continued generous contribution and donations from our sponsors. The Trust also continued its strong support of the Spinal Cord Injury Research Facility based at the Centre for Brain Research at the University of Auckland as well as the NZ Brain Bee Challenge.

The highlight of the year was the Big Cycle, which involved a team of 15 cyclists, including three tetraplegics – CatWalk Founder

Catriona Williams, Neil Cudby and Rob Creagh – cycling from Lhasa in Tibet to Kathmandu in Nepal via Everest Base Camp on the Tibetan side of the mountain.

For the fourth year in a row a team of 13 runners represented CatWalk in the New York City Marathon including three keen supporters, Ollie Bradshaw, Dave Copley and Duncan Hawkesby who were part of the CatWalk team in 2012 when the New Year Marathon was cancelled due to Super Storm Sandy.

It was an amazing year for our Founder and very satisfying to see Catriona being publicly recognised for both her commitment



Scott Malcolm at Everest Base Camp in 2013

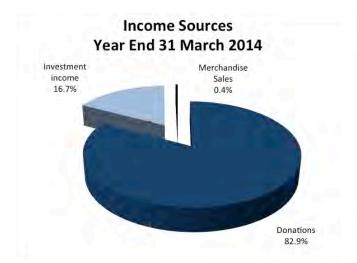
to finding a cure for spinal cord injury and her equestrian talent. In February 2014, Catriona was a finalist in the New Zealander of the Year Awards and in March 2014, she was inducted into the New Zealand Horse of the Year Hall of Fame. Congratulations Catriona.

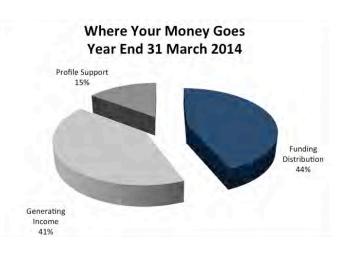
I would like to thank our Board of Trustees and Founder for their support of CatWalk over the year. I would like to make a special mention of my predecessor, Sam Howard, for his significant contribution to CatWalk as Chairman from March 2011 to May 2014. I would also like to thank Rick Acland and Ben Petro, who

resigned from the Board this year, for all their hard work and note that we are delighted that Rick has since accepted the role of Medical Patron. I would also like to mention the CatWalk operational team for their commitment and diligence over the past year.

And finally, thank you to our Patrons and Ambassadors for their continued dedication to, and passion for, all that CatWalk does.

Thank you, Scott Malcolm, Chairman CatWalk Board of Trustees





# Thankyou "We make a living by what we get, but we make a life by what we get, but we make a life by what we give." Sir winston churchill



Sam Howard and family



Ben Petro and family



David Pretorius



The new filly!

### TAKE A BOW

The CatWalk cast is forever changing. Individuals may give us a solo performance, be part of a quartet or join the chorus. Everyone will eventually head into the wings for a brief rest while others take centre stage. For now, we are saying farewell to two very special Prima donnas who are bowing out of the spotlight for a wellearned intermission.

Sam Howard acted as Chairman for three years from 2011 – 2014, while Ben Petro was Deputy Chairman for the same time. What these two gave to CatWalk is a standing ovation worthy performance. Both in the Finance industry by trade, they each contributed to every facet of CatWalk life, from attending and running board meetings, providing astute financial and investment advice, overseeing and guiding operational best practice; through to competing in marathons, securing prizes and sponsorships and even public speaking. For all this and more, we offer our applause.

All members of the CatWalk Board are volunteers and give of their time and expertise freely, willingly and in their case, frequently. Both men are stepping aside to spend time with their expanding families. Thank you Sam and Ben from the full CatWalk ensemble for your many contributions. We look forward to the encore performances in years to come...

### COME ON BOARD

David Pretorius is joining the CatWalk Board of Trustees. David has worked for First NZ Capital since November 2011, and before that Macquarie Private Wealth and BNZ Private Bank. He works as a qualified Authorised Financial Advisor (AFA). David and wife Natasha emigrated to New Zealand from Cape Town in 2004 with their two daughters, Alexandra (13) and Holly (11).

Due to Holly being wheelchair bound since the age of 7, David and Natasha have engaged with several organisations globally that have spinal cord injury rehab and cure as their main objectives. Their greatest desire is to see Holly walk again, which will only happen if this injury is cured completely for all people.

#### A+ FOR ETIQUETTE



Catriona is often approached to speak at schools all over the country to give students motivation and inspiration. While her schedule is pretty tight, Opaki School in Masterton was one she couldn't say no to. Following her question / answer session with a group of Year 7 and 8 students earlier this year, these very special thank you cards were received in the mail.

Cards from Opaki School

Kudos must go to Ali Kersten and the teaching staff at Opaki School for instilling such beautiful manners (and creativity) in their students.

### ON YER FEET

The Ian MacDonald, Peter Hart and CatWalk owned mare had a Per Incanto service fee donated to them by Little Avondale Trust. This has resulted in an athletic filly with a very attractive head (see picture). Currently Per Incanto is the leading First Season Sire with three runners for a winner and two place getters. You can read more about him at www.lastud.co.nz

Good Luck to Ian, Peter and CatWalk for a fast gal!

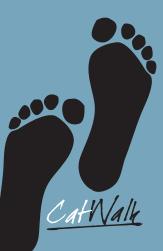
### HONOURS LIST

A very special note of thanks to the Thompson Family Foundation for its generous support of Charlotte Gendall's New York City Marathon fundraising. Thanks to the Foundation, and 92 other amazing individuals, Charlotte was the top fundraiser of 2014, coming in at \$26,259 and helping bring the Class of 2014's combined total to \$65,895. Well done to the whole team and thank you from CatWalk!

And always there to provide CatWalk with cartage and support, DHL Global Forwarding. www.dhl.co.nz



# The only current cure for SCI is <u>prevention</u>



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

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Please return this completed form along with any donations to: The CatWalk Trust 409 Queen Street, PO Box 555, Masterton 5840, New Zealand

### catwalk.org.nz

Thank you for supporting us to get people out of wheelchairs and back on their feet!