



# Newsletter

ISSUE 4 JUNE 2017

## NEWSLETTER OF THE NEW ZEALAND PEDIATRIC TRAUMATIC BRAIN INJURY CONSORTIUM (PTBIC)

While somewhat overdue, welcome to our fourth newsletter! It's been a busy first half of the year. We (NISAN) had a presence at Brain Day held on Saturday 25 March Owen Glen Building at The University of Auckland. This is always a good opportunity to reconnect with other organisations interested in pediatric TBI. In collaboration with ABI Rehabilitation, participant recruitment is now underway for our pilot study of the Teen Online Problem Solving – New Zealand (TOPS-NZ). There has since been interest from additional organisations with another TOPS therapist being trained next month – watch this space! The BIONICAL study, being a 7-year follow-up of children post-TBI is also now well underway, with encouraging responses from those families we have contacted so far (see page 3 for further details). Special thanks to John Hadfield for his contribution to this newsletter by way of reminding us of the impact of pediatric TBI on the wider family (see over page). In addition to our newsletters, there are exciting plans underway to identify opportunities for meeting and collaborating in the future.

For now though, happy reading! Best wishes, Kelly Jones

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SUPPORTED BY:



MIDLAND - TRAUMA SYSTEM -

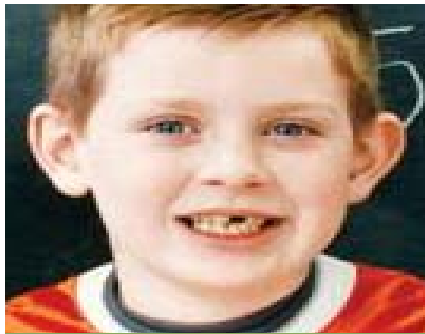


NISAN stand at Brain Day 25 March 2017

### MISSION STATEMENT

Our goals are to 1) expand understanding of TBI during childhood and adolescence and 2) improve outcomes of affected children and their families by promoting a collaborative approach to research.

# A Parent's Perspective on Pediatric TBI



**John Hadfield**

My son Stefan was 24, extremely fit, healthy and at the peak of his powers when he suffered a severe brain injury while skiing in Canada. He was training for a man-powered pole-to-pole expedition to raise environmental awareness. It was for me surreal and traumatic, a nightmare scenario I felt powerless to influence. Surgeons advised he was unlikely to survive or may have little quality of life. After weeks in a coma he started to relearn from scratch – to recognize, to talk, to walk and with no memory. His lower vision was gone but during this miraculous period, we wondered how far rehab could take him. The outpouring of love and support then was awesome and a testament to who he was.

Coming back to NZ was a relief, with our free medical system, familiar surroundings and ACC support. Unfortunately, he contracted an MRSA superbug infection in his brain while in hospital and almost died again. This second trauma was the worst rehab scenario and again very challenging as a parent. After further operations he eventually made it home. He suffered a series of seizures in the first year, which were also difficult to witness. The standard formula of physio, speech therapy and OT swung into action, and was hugely appreciated. Despite the professional involvement, the support initially of family, his girlfriend and friends was critical. With time these fell away though as his new, more constrained, world evolved.

At times there has been frustration when professionals have under-utilized observations and ideas of family who spend most time with Stefan. They have much less interaction with him and he can miss out on assistance by wanting to talk up his capabilities. There are behavioural challenges such as obsessive tendencies which would benefit from therapy. The recovery road is a marathon of little but significant steps and it is important to pace ourselves sustainably and persist. We are very grateful to all those who have helped along the way. - John

If you would like to find out more about John and Stefan's experiences, visit the following link – <https://attitudelive.com/watch/Stefan-Hadfield-Pushing-Too-Far>

## Supporting Organisation Profile **MIDLAND TRAUMA SYSTEM**

Over 5000 people in Midland health region are hospitalised each year due to injury; 300 of whom will sustain severe or life-threatening injuries. While this represents an estimated \$50m in hospital costs alone across the Midland health region, the true burden is many times this for the patients, their families/whanau, and our communities. Established in 2010, Midland Trauma System (MTS) has made significant progress in delivering the critical elements of an efficient trauma system. The registry collects comprehensive data on patients of all age groups and injury severities, allowing detailed analyses of injury events, patient factors, processes in care and outcomes. The ultimate goals are to improve the delivery of clinical care by using collected data to inform the refinement of systems and the delivery of cost-effective services and injury prevention. The aims of MTS align closely with those of the Pediatric TBI consortium and other supporting organisations, being to reduce the burden of trauma in our community. A new project is now underway to examine data from the registry to determine trends in rates of hospitalised pediatric TBI in the region between 2012 and 2016. We look forward to sharing these findings with you. For further information about MTS visit <http://www.midlandtrauma.nz/>

# Brain Injury Outcomes New Zealand in the Community – Adolescence and Late Childhood (BIONICAL)

FUNDED BY WAIKATO MEDICAL RESEARCH FOUNDATION

Following on from the HRC-funded BIONIC study in 2010-2013, and the subsequent BIONIC4you follow-up, a 7-year follow-up of those children identified in the original study is now underway. In addition, a group of parents of children free from TBI of the same age and gender are completing similar assessments. The inclusion of a control group will enable better understanding of the longer-term development effects of mild TBI sustained in childhood. With permission, data are also being collected from children's schoolteachers to inform broader knowledge of children's functioning and performance that may differ across home, school and community settings.

A team of research assistants has been busy since February contacting families and collecting parent's perspectives on their child's development. Data for this study are being collected using online questionnaires, or in-person and phone interviews through until the end of the study in April 2018. Study findings will help researchers, health and educational professionals to better understand a) the impact of brain injury, particularly mild injuries on children's development over time, b) how child factors, injury characteristics and post-injury surroundings are related to long-term recovery; and c) whether those at risk of on-going problems can be identified early to enable the provision of targeted, age-appropriate and effective intervention services.

Ultimately, this research aims to generate new knowledge for service providers, including Accident Compensation Corporation (ACC). This will be achieved by tracking the longer-term recovery pathway, and **identifying key time-points** and high-risk cases where needs assessments and/or services could have the biggest impact on improving child outcomes and the achievement of developmental milestones following injury.


If you'd like to be kept up-to-date on the progress on Bionical and other TBI-related research being undertaken by the NISAN team, feel free to follow us on Twitter - see NISAN? (@AUTNISAN)



*Meet the Bionical team!*



Photos (right) from top to bottom: Moray Carr, Tallulah Harper, Poppy Barran, Kerryn Treanor, and Jenni Slaughter.




**Hey!**  
We are looking for **2000 testers** for a new gratitude app!

Download on the **App Store**

If you are using **iOS 9 or later** on iPad, iPhone or iPod and are keen to give it a try, you can [Click here](#) to register.

**2 Months Free Trial of the app**

For the first 2000 on rating us in the App Store.



**What is 3GoodThings?**

Just 3 steps towards a better life...  
*Recollect → Record → Repeat*

It's proven that when you write 3 good things away night your neural pathways are reinforced, making you notice more and more positive things, this changes the way you think and into the world each day.

*Invest 5mins everyday for at least 21 days in this practice*

It increases self awareness, compassion, emotional resilience, practices being in the present (mindfulness) and with all that gratitude your mental well-being performs at its peak.

*What's the app about?*

If you know any young persons aged 13-18 years with access to an iPhone, iPad, iPod iOS 9 or later, they may wish to consider taking part in The Happiness Experiment. For more details visit <http://www.thehappinessexperiment.co.nz/>

## Upcoming conferences

### BRAIN INJURY – WAIKATO TBI SYMPOSIUM

16 June 2017, Hamilton Gardens, Hamilton (NZ)

<http://braininjurywaikato.org.nz/>

Mark your calendars now and keep an eye on the Brain Injury - Waikato Facebook page for details.

### KIDS TRAUMA CONFERENCE

04 August 2017, Auckland (NZ)

<http://www.trauma.org.nz/kids-trauma-conference>

This year the focus is on spinal trauma – acute care, and rehabilitation.

### SECOND INTERNATIONAL CONFERENCE ON PAEDIATRIC ACQUIRED BRAIN INJURY

20-23 September 2017, Rome (Italy)

*Theme: New strategies to improve outcome and quality of life.*

<http://www.internationalbrain.org/news/second-international-conference-on-paediatric-acquired-brain-injury/>

If you would like to profile your TBI-related research or organisation here email [kelly.jones@aut.ac.nz](mailto:kelly.jones@aut.ac.nz).

## Next Issue:

*Update on 2<sup>nd</sup> International Conference in Pediatric Acquired Brain Injury*

*A summary of pediatric findings from BIONIC4you – a 4-year TBI follow-up study*

