

JUN
2011

Thinking Differently

The quarterly newsletter of *Autism New Zealand Inc.*



It's Appeal Week! We need your help.

As you are receiving this newsletter we will be launching into Autism New Zealand Annual Appeal Week.

We have high hopes that the 2011 campaign will be very successful.

We need your support to make sure this happens. Keep an eye out for our street collectors in your area – they should be easy to spot with their bright yellow bibs.

If you want to give but can't find a collector, you can easily donate through our website at www.autismnz.org.nz.



Give a dollar, change a life.

This year we are very pleased to have Whitcoulls on board with the 'Give a Dollar, Change a Life' campaign.

Staff at all 63 Whitcoulls stores throughout New Zealand will be asking customers to add a dollar to their purchase during Appeal Week and all of the money collected will be donated to Autism New Zealand. We cannot thank the staff and management of Whitcoulls enough for offering to support our Appeal in this way.

Autism New Zealand is dedicated to doing all we can to help and support individuals with ASD and their families. As readers of this newsletter you will know that the financial and emotional impact of ASD is huge, which is why we are asking you to please give generously this year, and help us make a difference for New Zealanders affected by ASD.



Autism New Zealand Inc.
Including Asperger Syndrome and Related Disorders

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Welcome

I would like to welcome you to the June issue of *Thinking Differently* – the newsletter for members of Autism New Zealand.

As you read this we will be in the middle of Autism New Zealand's Annual Appeal (1-7 June). I would like to give a special thank you to all of those members who have given up your time to help with the street collection in your area. Without your help we would not be able to do it. Every year when I am standing with a bucket and a bright yellow vest collecting from the public I wonder why we decided to have our Appeal Week in the middle of winter! This is our main fundraiser for the year so it is very important to the organisation and a great opportunity for us to meet and talk to the general public about autism and the effect it has on our community. If you see our collectors on the street please say hello and tell them you are a member.

In April, to commemorate World Autism Awareness Day, we held a breakfast at Parliament, hosted by Catherine Delahunty MP. We were pleasantly surprised that 20 MPs accepted our invitation and many of them commented that it was the best turnout of MPs they had seen to such an event. They listened to several speakers including Lachlan MacKay, who gave a personal insight into life with Asperger Syndrome.

As well as the MPs, representatives from 17 other organisations that work with ASD in New Zealand attended the breakfast. Afterwards a symposium was held where all of these groups agreed three key messages that we are all going to promote in this election year. I would like to share these with you:

'A right to my own life, my own way'

- Are my rights the same as yours?
- Access to support is not there
- Living my life may not be the same as you living yours and that's OK
- Respect for diversity
- ASD has a culture of its own that is diverse and unique
- My needs cross all areas of life.

'A simple pathway'

- Provision of service that is accessed simply
- A single point of contact
- Intervention, investment and inclusion
- Support as required across life to enhance quality
- Development of services a person can choose from.

'Support today equals success tomorrow'

- Enough trial, assessment, review
- We will work together to make it happen
- Investing in ASD now will have payback for the community in economic and social terms
- Being proactive means action
- Let's get on and do.

I think these are messages we can all support, and I invite you to take the opportunity to make your voice heard during this election year. Let's make sure the voices of the 40,000 New Zealanders with ASD and their families and friends are heard.

Oh, and if you are in Wellington this week and see a chilly looking lady in a bright yellow vest holding a bucket, please come and say hello to me!

– Alison Molloy, CE Autism NZ

Multicoloured Mayhem!

To celebrate World Autism Awareness Day this year, schools around New Zealand were invited to wear their support for autism loud and proud, by having a Multi Coloured Mayhem Day.

The day gives students an opportunity to reflect on how the autism spectrum affects some of their friends' lives. By wearing their brightest, most colourful clothes, students can celebrate the unique talents and skills of those with ASD.

During the Mayhem, Emma Cutts and Jo Lloyd from the Auckland Branch visited Gulf Harbour Primary School to give the students there a bit of insight into autism.

Matakana Primary School saw a very special spectacle, with one of their students, Kip Simpson, going all out for autism.

Kip's new 'do.

This Autism Awareness Day 10-year-old Kip Simpson decided he wanted to do something special to raise both awareness of and funds for Autism New Zealand, so he took a bold step and shaved off all his hair!

With twin brothers on the spectrum, Kip wanted to help other kids with ASD by raising money for early intervention training and programmes in New Zealand.

Starting up a fundraiseronline.co.nz page, Kip managed to raise over \$1,500 by the time 2 April rolled around, which we think is a very impressive effort! Good on ya Kip, you've done Autism New Zealand proud.



Constitution review

Last November the branch committees and the Board agreed to an expansive review of our constitution. A small subcommittee working with our Chief Executive, Alison Molloy, and the law firm Simpson Grierson, who generously took on the work pro bono, has conducted the review and is in the process of writing a new draft constitution.

The new constitution will be significantly different from the existing one and once a draft is agreed upon it will be posted on our website for wider feedback. We are aiming for this to happen in mid to late June. The proposal to amend the constitution will be put to a vote at the AGM in November.

Nominations for Board Elections 2011.

Nominations for Board Elections 2011

This year three positions on the Board will become vacant when the incumbents end their term. Nominations are invited from members of Autism New Zealand Inc to fill these positions.

A nomination form can be downloaded from the Autism New Zealand website www.autismnz.org.nz or by emailing Kate.Walsh@autismnz.org.nz. Nominations close on 30 June 2011. If an election is required, voting papers will be available from September 2011 and voting will take place by postal vote. The AGM is on Sunday 6 November 2011 in Wellington.

Meet our Patron: Sir Wilson Whineray

We are incredibly pleased to introduce you to Autism New Zealand's Patron, Sir Wilson Whineray.

The Board had been considering for some time the idea of appointing a Patron to help raise our profile and support us publicly as a figurehead and we are very grateful Sir Wilson agreed to support us.

Sir Wilson's name is legendary, both here in New Zealand and internationally. He first came to public attention back in the 1950s and 1960s as an All Black, and to this day many argue he was one of the greatest All Black captains ever.

After retiring from rugby in 1965, Sir Wilson went on to build an impressive career in business, most notably as Chairman of Carter Holt Harvey, a major New Zealand company.

Sir Wilson is very involved in a number of charities and has been patron of the New Zealand Rugby Union since 2003. He is a passionate supporter of Starship Children's Hospital and all royalties for his recent

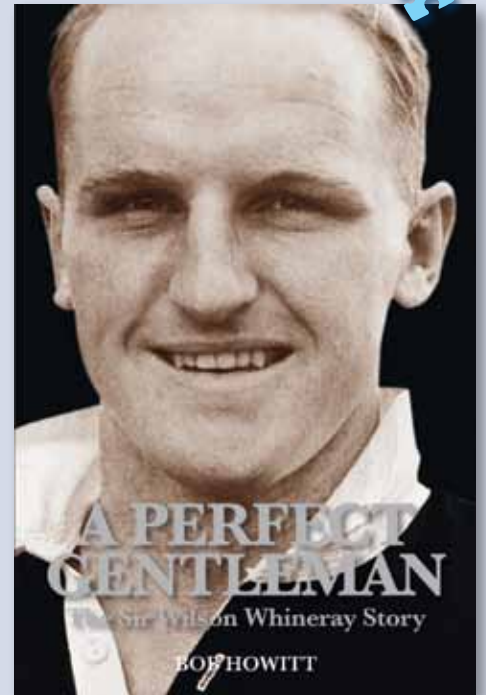
biography, *A Perfect Gentleman*, are going to the Starship Foundation.

Delighted to be able to lend his name to Autism New Zealand, Sir Wilson and his wife, Elizabeth, have a personal connection to ASD through an old friend (and bridesmaid) of Elizabeth. Her friend's granddaughter has been diagnosed with autism and they're happy to be able to help.

"The role of Patron is really quite a simple one," explains Sir Wilson. "I'm lending my name to the cause, because I'm no longer in a position to attend lots of meetings and events. But it's good to know I can help by being Patron and I plan on being Autism New Zealand's patron for many years to come."

"I believe that Autism New Zealand is doing excellent work to support families and individuals affected by ASD, and I'm a big fan of supporting the people who roll up their sleeves to make the lives of others easier. That's a great thing to be a part of."

Welcome to Autism New Zealand, Sir Wilson. We're very happy to have you on board.



Sir Wilson Whineray, as All Black Captain on the cover of his biography.

Move over Valentino, Torenzo's taking over.

Stand aside, Valentino and Versace, Torenzo Monopoli is about to explode onto the fashion world as a leading designer – well, in a few years' time, anyway.

At just six years old, Torenzo is an impressive budding fashion designer, and has already seen one of his creations displayed on the catwalk at Nelson's Nouveau Design Awards in February this year.

Torenzo created the ensemble, shown here in a newspaper article about his success, but the rules of the competition allowed for parental help in constructing the outfit, so long as it was to his original specifications. Actually creating the dress became a fun family activity in the Monopoli household.

"It's not immediately obvious, but Torenzo has autism and we think this might have contributed to his interest in design. He can certainly be quite focused on some things and he definitely thinks differently," explains Jason, Torenzo's father.

Torenzo's passion for fashion emerged after a family visit to Spotlight (a large fabric and craft shop). "He was almost overwhelmed by

all the bright, interesting things in the shop. He was deliriously happy and at one point even lay down on his back on the floor in an attempt to take it all in," says Jason.

After this visit, and a serious heart-to-heart between father and son about Torenzo's desire to be a girl, it emerged that he really just wanted to be around "beautiful things". Jason explained to Torenzo that a boy could be around beautiful things without having to act like a girl, and introduced him to the idea of being a fashion designer. Torenzo loved the idea and promptly went back to his boyish ways, but with a desire to grow up to be a fashion designer (and a peacock farmer!).

Jason hunted down some mannequin underlays on the internet for Torenzo to get started on and now he can often be found with coloured pens and pencils in hand, creating some new and often impressive outfit.

"He's got a great imagination and, who knows, he might just grow up to be a great designer. We're just happy that he's found something that interests him and makes him happy."



We're delighted to be able to report that Torenzo won the 6-10 year-old children's section of the award. Good on you, Torenzo! We look forward to seeing what you create in the future!

Respite Survey Report: The Results

Over 40,000 New Zealanders have an Autism Spectrum Disorder (ASD). While it affects people differently, there are many individuals whose ASD causes them serious disability requiring intensive respite care. For the families of these individuals, respite care is an important support network and provides an invaluable opportunity to take a break from full-time care.

Released in 2008, the New Zealand Autism Spectrum Disorder Guideline provides guidance on ASD individuals. It conveys evidence-based information and advice for decision-making to help improve the health, educational and social outcome for those with ASD.

While the Guideline recognises the benefit of respite services, it doesn't explore the characteristics of good respite care and what makes it work successfully for individuals, families and whānau affected by ASD. It also limits the value of respite care to children, even though there are many ASD adults and adolescents living with their families.

To help fill the knowledge gaps, Autism New Zealand surveyed its members to gather their views on respite care. The responses of 339 New Zealand families confirmed that our members value respite care when it is provided. While some families are receiving good respite care funded by the Ministry of Health, others are not, often because they may not be aware of the services and support available to them. These families either do without respite care or rely on friends and extended family to help out.

A lack of options is the second most common reason some families are not getting respite care. There are several reasons for this, including lack of local availability, respite care being unable to meet the behavioural need of the individual, and the ASD individual being high functioning and respite care not providing the right sort of care and stimulation. Others are simply not eligible for funding because their child isn't 'bad enough' or is too old.

Through this survey our members have told us the many ways that respite care services can be improved, and the role



they would like to see Autism New Zealand play in the respite care services.

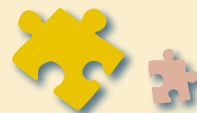
This includes Autism New Zealand partnering with other providers, because the organisation understands both ASD and the needs of respite care. The most common suggestion was for Autism New Zealand to increase its involvement in holiday, weekend, after school and other activity programmes. Families see these programmes as offering both a break for them and a way for ASD individuals to enjoy positive experiences and opportunities to socialise.

Other ideas include Autism New Zealand providing residential and overnight services to address the gaps currently offered by respite care. Some families thought rather than take a hands-on role with service delivery, Autism New Zealand could provide families with information and advice on support services available to them and work with providers to improve the quality of their respite care services.

Autism New Zealand will consider all of these ideas and suggestions as we plan our next steps in contributing to the improvement of respite care. To read the full report on our respite care survey, please visit <http://www.autismnz.org.nz/Autism-New-Zealand/Respite-Survey-Results.php>



Meet the team



Luminita-Lucia Sprague



"It's hard to believe I've been here over four months – time really has been flying," says Luminita-Lucia Sprague, the new Information Coordinator for the Auckland Branch.

People say that "time flies when you're having fun", so Luminita must be enjoying her position with the Auckland Branch; she's certainly taken to the task with gusto.

"As the Information Coordinator, I'm the link between Autism New Zealand on the one hand and caregivers, professionals, schools, the public and families/whānau with a loved one on the spectrum on the other. I also provide and disseminate information, generate our monthly newspaper and manage the library."

"I've really enjoyed the job so far. I'm so lucky to work with a team of passionate people – it gives me a good reason to beat the morning traffic jams each day!"

With an Aspie son herself, Luminita is dedicated to Autism New Zealand and the work we do for our members.

"My son is brilliant and has definitely been the catalyst in my decision to strive for improvement in the quality of life for people on the spectrum. I also know what people are going through and how tough a time it can be – so when I manage to help someone in a

bad situation, I find it really rewarding."

An all-round passionate person, Luminita's other big cause is conservation.

"Last year I went with my son and some friends to Motuihe Island in the Hauraki Gulf and planted trees – it was a highlight for me. In the past I have also been involved with charities such as the aid and development organisation Tear Fund."

Outside of these pursuits Luminita-Lucia is a bit of a fitness fanatic, which she says "helps keep me sane".

"Sport is my drug of choice. I take every opportunity to run, cycle with my son, train at the gym or do Pilates. Next on my list is synchronised swimming – just kidding!"

Pat Gluck

For the last two years Pat Gluck has been lighting up Head Office in Wellington with her very unique spark.

"I may be 51 and sensible on the outside, but on the inside I am Katy Perry and I live with Russell Brand in Hollywood. It keeps me on my toes, I tell you!"

Moving to New Zealand with her family 10 years ago, Pat originally came from the UK, which is where she first became aware of autism.

"My best friend from England, Kelly, has a profoundly autistic son," says Pat. "We had our children around the same time, so I saw the process of Kelly beginning to suspect there was something different about her second child, right up to when he was diagnosed with classic autism."



Before joining Autism New Zealand, Pat had previously worked with our Chief Executive, Alison Molloy, which prompted her move to our organisation.

"When Alison was appointed at Autism New Zealand, I knew she was going to really make something out of it, and I very much wanted to be part of that," explains Pat. "So I stalked her until she gave me a job!"

In her role as National Programme Manager, Pat works in conjunction with the regional branches to organise all the national training and seminars we offer to our members.

"I keep details of all the families waiting for parent education programmes, organise the locations, trainers and venues, and then try to make sure everything runs as smoothly as possible."

"For seminars I look for speakers who will make a difference for our members, pass on useful information and hopefully motivate them. I'm always on the lookout for speakers, so if anyone has any ideas, please pass them on!"

As you can see, Pat is dedicated to her job, even managing to work a plug for speakers into her own profile!

"I really enjoy working at Autism New Zealand. I get to make a difference to people in crisis, which I find really rewarding, but also humbling."

When Pat manages to escape from her desk, you will most likely find her chasing after her teenage kids.

"I have three boys, one at university in Dunedin and two in college in Wellington, which pretty much means I don't have spare time. But if I manage to grab some moments, I really enjoy reading my Kindle (e-book reader)."

Tips from those in the know...

Here are some great tips from Luminita-Lucia Sprague, our Auckland Information Coordinator (we introduced her in the story above).

If you are asking a question or trying to give some instructions to a child on the spectrum, follow the five-second, five-word rule.

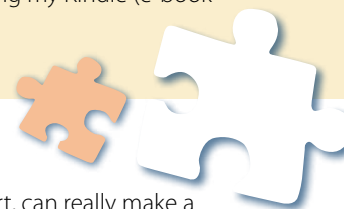
Wait for five seconds after you have asked your child to do something – this should give them enough time to process the information and make a response. If they don't respond, repeat your request. Try not to use more than five words in a sentence; otherwise they might lose you.

Don't say "don't"! Instead of telling your child what you do not want them to do, say what you want them to do instead. This is more

positive and, combined with a rewards chart, can really make a difference in behaviour.

Reminders, cues and routines are things that people on the spectrum find reassuring, so setting them up is always a good idea. If you are having trouble getting your child in the car and off to school in the morning, try setting an alarm on your cellphone to go off as a reminder that it's time to get in the car.

Luminita has some wise words from ancient Rome to share with you – "I cannot stress enough the importance of sport for children/people on the autism spectrum, so I make sure my son is exposed to some form of physical activity every single day. Mens sana in corpore sano (a sane mind in a sane body) – the Romans nailed this one!"



Meet the team

Jo Lloyd

Starting in her role of Programme Coordinator in January, Jo Lloyd is a great addition to our Auckland Branch and it's clear she's been enjoying her new-ish job.

"At the moment, my job primarily revolves around implementing and coordinating our school holiday programme. We are trying to get it up and running in more than one location to make it more geographically accessible to our members," explains Jo.

"I'm also involved with the branch in a variety of really interesting ways ranging from organising appeal weeks to assisting Emma, our training specialist, on some of her school talks and visits."

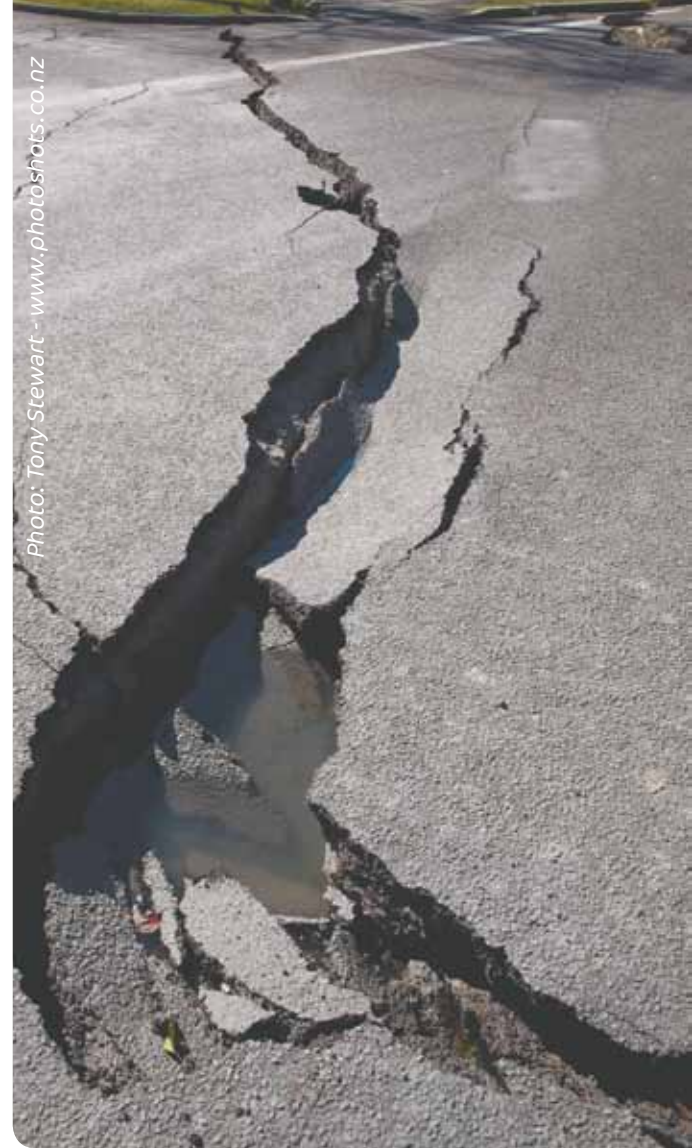
"Working at Autism New Zealand is a total change in direction career-wise for me. My background until recently has been in media, acting and recruitment. I became interested in autism when my youngest son, Elliot, was diagnosed with Asperger's four years ago. I took an active interest in finding out all I could about the subject for my own interest and also to learn how best I could help my son."

"When this job came up at Autism New Zealand, I immediately registered my interest and was lucky enough to be the successful candidate. I really enjoy my work. It's very rewarding to hear the good news stories that come through the office as a direct result of something we've done or when we've assisted with making a positive impact on someone's life."

"I'm very privileged to work with some very knowledgeable, clever people who help these changes come about, and I'm excited to be learning so much from them every day."

Living on Auckland's North Shore with her two sons, Jo is always busy trying to keep up with their school, sporting and musical activities.

"I really enjoy (when I get the chance to get out) going to the movies and to the theatre. I am also a marriage celebrant, mainly over summertime, and try to keep my hand in the acting world with the odd bit of work here and there. All this, combined with my job at Autism New Zealand and taking care of my beautiful kids, keeps me one very busy, but happy, woman!"



Parliamentary breakfast for autism awareness

On 6 April, Catherine Delahunty MP hosted a breakfast reception at the Beehive in Wellington to celebrate World Autism Awareness Day. We were very proud to be associated with this event, which included a wide range of guests from across the political and social sectors. Lachlan McKay spoke beautifully about the gift of Aspergers in his life.



Lachlan McKay and Catherine Delahunty MP at the breakfast

AUTISM SPECTRUM QUARTERLY

The Autism Spectrum Quarterly is a professional journal aimed at parents and professionals which provides well written, practical articles on everyday issues.

- Articles by, for, and about individuals with ASD
- Focus on families and family issues
- A spotlight on best practices: Each issue will feature an educator, clinician, or paraprofessional whose work on behalf of those with ASD has been exemplary
- Tips and practical strategies for dealing with a variety of situations • Internationally renowned advisory board (including Dr Tony Attwood and Carol Gray) ensures that the information conveyed is of the highest quality

Subscription includes 4 quarterly issues. Four Issues - \$85.00 pa (including postage & GST).

To subscribe go to the bookstore at www.autismnz.org.nz or call us on 0800 AUTISM (0800 288476)



The Christchurch earthquakes:

Sparing a thought for people with ASD



Almost without exception, Cantabrians have suffered enormously in the traumatic events of February's devastating earthquake. While everyone's lives have been disrupted, it is easy to forget that those with ASD have found the disaster especially hard.

With their routines and environments shattered, families and individuals affected by ASD have had to make the hard choice between coping with their new way of life, and getting away for a well-deserved break from it all.

For those who got away for a bit of a break, setting up in a new city can also be a difficult task, especially for an ASD child who is already anxious from the quake and now has to settle in a strange, new city.

One such family who went through these difficulties was the Callaghans. After living in Christchurch with no sewerage, the family decided to escape to Auckland for a while and live with relatives. When they arrived

in Auckland, the Callaghans' son found it difficult to settle, so they turned to Autism New Zealand for help.

"Jane Callaghan rang the office one day rather distressed and wanting to know if we had any resources she could borrow," explains Emma Cutts, Auckland Team Leader Service Delivery. "She was having a very difficult time occupying Frazer as she had very few toys and games with her. I offered to visit and see how we might be able to help out."

The Callaghans' other child had been placed in an Auckland school, but the school was unable to accommodate Frazer because of his behavioural issues. This left Jane to take care of him at her mother's retirement home, where they were staying.

"When I went around, I gave her some strategies for helping Frazer cope with living at a new place. He was obviously quite anxious after the earthquake and was convinced another one would hit, so we wrote him a social story to explain the situation. As his usual routine had completely disappeared I also gave them some visual

strategies to use in the home to provide new structure."

"We talked about ways to structure his days so that they followed more of a routine. After this I put Jane in touch with a local support group on the North Shore, who set up some play dates and offered other support as well as lending much-needed toys and games. A highlight was being able to offer the family free tickets to the Southern Stars Big Kids Day Out and both Frazer and the rest of the family had a fantastic day."

Autism New Zealand is very proud to have been able to help the Callaghans. We are here to support our members and Emma did a fantastic job of helping out a family in a bad situation.

"Jane recently sent me a thank-you card. She was very appreciative and said that Autism New Zealand offered her a lifeline when she was having a difficult time."



Canterbury Branch Update

Our doors are open and we're up and running!

After the February earthquake, we were closed for a couple of weeks to allow everyone to sort their personal affairs. Once that was done, we moved straight back into our usual building in Riccarton and got everything back up and running as fast as we could.

Recently during the school holidays we ran our usual holiday programmes, although we did see reduced numbers in the badly hit eastern suburbs. In other areas, everything went ahead uninterrupted, but we did need to combine some groups because a number of our regular halls are out of action.

There has been an increase in school issues for our families post-February. School closures and site sharing, combined with the personal upheaval of families having to either change schools or move away, have caused a lot of anxiety for our families. We have been doing our best to liaise with various schools and families to try and find the best way

forward to cause as little distress to everyone as possible.

This year, the Canterbury Branch will probably not be taking part in the street appeal during the Autism New Zealand Annual Appeal week. Life has changed so much down here, and we do not want to have unrealistic hopes or burden our members with demands for volunteer work. We will, however, press ahead with the fun run in October, which will now be our main fundraising event.

As for looking ahead, we are re-prioritising everything and will continue to focus on the essential services for our members. Remember that we are still here and don't hesitate to call if you need us!

Our branches have a lot more information to share than we are able to include in this newsletter, so please visit www.autismnz.org.nz to find out what is happening in your region.

Our Supporters

We are forever grateful to our supporters and funders, whose contributions go a long way towards making a difference to our members.

We'd like to say a special thanks to **Pub Charity**, the **Lottery Grants Board** and **Lion Foundation** for your funding support; and to **Y&R**, **Footprint Books**, **Simpson Grierson**, **Springfree Trampolines**, **MedicAlert**, **Haven Licensing**, **Angels for Children Charitable Trust**, **Sovereign Sunshine** and **IHC** for your ongoing assistance.



Sling Shot is 'Raising the Flag' for autism

Raising the Flag empowers Slingshot customers to choose to have a portion of their monthly bill donated to an Autism NZ Branch. Then each month, Slingshot will send us a cheque to help those affected by an Autism Spectrum Disorder.

To join Slingshot for internet and tolls, visit www.slingshot.co.nz/autismnz or phone **0800 89 2000**.

If you are already a Slingshot customer, simply let them know you want to be part of this programme and they'll link your account.



Shine a light for autism

The official Autism Candle is made with 100% natural soy wax, a pure cotton wick and is infused with coconut and lime. It comes in a specially designed tin which is easy to post and makes for a great gift.

Created by the award-winning Candles of New Zealand and available from Stevens stores nationwide or Flicker Candle Emporium's boutique website: www.flickercandles.co.nz



\$8 from each candle sold is donated to Autism NZ

This newsletter was brought to you by:

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Our Branch information

Our branches have a lot more information to share than we are able to include in this newsletter, so please visit www.autismnz.org.nz to find out what is happening in your region.

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