Welcome to our first edition of Kia Maro for 2016.

In this issue, we focus on International Rare Diseases Day being celebrated on 29 February. The feature article tells of Melissa’s story, which I found to be a heartfelt and compelling journey highlighting the challenges of living with a rare condition.

As we look ahead, the year brings exciting times with the opening of our new flagship EASIE Living Centre at 585 Main Street, Palmerston North, on 22 February. We hope to see you all there.

Enjoy our newsletter, it’s a great read.

Scott Ambridge, General Manager, Enable New Zealand

If you have any comments regarding this newsletter, please send an email to info@enable.co.nz

Do you want to go on the mailing list for this newsletter, or know somebody who would like to receive it? Please send an email to info@enable.co.nz

Enable New Zealand provides: Equipment, Housing & Vehicle Modification Services, Disability Information & Advisory Services, Needs Assessment Service Co-ordination, Spectacles Subsidy, Short Term Loan Equipment, Wheelchair & Seating Outreach Services, Housing Outreach Clinic and Palliative Equipment.
WHAT'S ON

RARE DISEASE DAY 2016
29 FEBRUARY
JOIN US IN MAKING THE VOICE OF RARE DISEASES HEARD

LIKE US ON FACEBOOK
About the day

Rare Disease Day takes place on the last day of February around the world and is an annual celebration and fundraiser for those rare germs in our community. Here in New Zealand we are lucky to be the first to kick off the celebrations worldwide.

Rare Disease Day 2016 is an important opportunity to raise funds for those support groups in the community whose hard work often goes unnoticed. Supporters all around the country will be organising fundraising events. If you are keen to get involved, check the NZ Rare Disease Day Facebook page www.facebook.com/groups/179489492086837/ for details of events that you can contribute to. Or you can organise your own event www.rarediseaseday.org.nz/how_to_get_involved_od and don’t forget to share your event www.rarediseaseday.org.nz/home with us so we can list it on this website. There are spot prizes up for grabs for those that share their event.

And, find out how other countries are celebrating their rare germs.

Why is Rare Disease Day important?

- They are more than 7000 different rare diseases affecting eight percent of the population. If evenly spread, one in 12 households would be affected by a rare disease.
- A day focused on rare diseases can bring hope and information to people living with rare diseases, their carers and their families.
- Rare disease patients are often the orphan of the health system, sometimes without diagnosis, without effective treatment or without research.
- Diagnosis, treatment and cure of rare diseases are major public health problems for society.
- Rare diseases are often life-threatening with a high level of complexity. Patients and their families are often isolated and vulnerable. Life expectancy for many rare disease patients is significantly reduced.
- Rare disease patients often have difficulty accessing appropriate health and disability services – they are too often put in the “too hard” box.
- Holding a national awareness day is a great way to inform and remind people that rare diseases need attention in research and health services.
On Wednesday 27 January at 6am, we participated in the Karakia Whakawātea, blessing and opening of the EASIE Living Centre at 585 Main St, Palmerston North. The early start symbolises a new day; bringing a new beginning for the whare (building), its new purpose and new occupants.

The karakia is believed to introduce positive spiritual energy to the building and dispel any negative forces. CEO Kathryn Cook and GM Māori and Disability, Stephanie Turner, attended alongside Enable New Zealand staff and two Māori Advisors from the Central PHO next door. The ceremony itself was officiated by Rangitāne kaumātua Manu Kawana who took time to explain the meaning and importance of the blessing. A significant part of the ceremony was “te tuku taonga” wherein a tokotoko (carved walking stick) was accepted as a cultural reminder that the users of our service are mainly the elderly and people with a disability. It was carved especially for the EASIE Living Centre and will be on permanent display once the building is opened officially on 17 February 2016.

By Hare Arapere, Kaupapa Manager, Enable New Zealand
Every New Zealander deserves to live the most productive and fulfilling life they can. Families living with disability or with an ageing family member are looking for more information, advice and products to assist their loved ones to make more of each day.

Our EASIE Living & Demonstration Centre delivers just that. Working together with our support partners, our flagship centre offers an exciting and innovative accessible home with smart features alongside a learning and demonstration centre, and brings together a range of possibilities and opportunities in a ‘one stop shop’ that the community can share.

The centre is built around five foundation pillars – Equipment, Advice, Services, Information and Education (EASIE).

EASIE Living will change how people with disabilities can live in their own homes. We are open six days a week at 585 Main Street, Palmerston North and admission is free. Our accessible home will provide you with a kinesthetic and tactile experience, where you can test our low and hi-tech living options. It will comprise living room, study, bedrooms, kitchen and bathroom, and will feature the latest innovations. The EASIE Living & Demonstration Centre team will coordinate a variety of education and training programmes and workshops to allied health professional and other professional groups.

At our retail space within the Centre you will find a large selection of mobility equipment and aids for daily living to help you in your everyday life. Our staff will be available to assist you with the many choices available, without the need to make an appointment.

The EASIE Living & Demonstration is open from the 22nd of February.
As part of recognising Rare Disease Day, we have included Melissa's story. Melissa was diagnosed with having a rare disorder called Dandy-Walker syndrome as a baby. Her story however is not about the rare disorder she was born with, but about a medical condition that she developed as an adult. A condition that is so rare the doctors are still confounded by it and there is no name or diagnosis for it.

Melissa, born in 1970, is the older of two children born to a farming family in a small Manawatu rural community. An observant Plunket nurse noticed Melissa's unusual head shape and recommended to her parents that they seek further medical advice, which they did and Melissa was subsequently diagnosed with Dandy-Walker Syndrome. This is a congenital brain malformation involving the cerebellum (an area at the back of the brain that controls movement) and the fluid filled spaces around it. Melissa has been told she was the second child to undergo shunt surgery in New Zealand. In 1976, a shunt was inserted into the lower part of the internal part of her skull to relieve the fluid buildup. Her shunt was last replaced in December 1994. Melissa believes Dandy-Walker syndrome has had very little impact on her life over all. Melissa had a typical rural up bringing for the times. After leaving school she worked in the service industry. Melissa started dating John when she was 18 years old. They married in 2000 and their first child Zach was born in 2003 and their second child Charlie in 2005. Melissa was content in her role of being an at-home mum and wife. One of her favorite pastimes was going for walks with her children – her youngest in the pushchair, her oldest beside her, chatting away, offering up his insights of the world to her.

In 2008, Melissa started to notice subtle changes with her arms; she developed pins and needles in her right arm and weakness in her left arm. Her then five-year-old Zach told Melissa her walk was different and that she was walking like a crab. Initially, Melissa thought she was simply stressed from having two active children to look after as well as running the home. John worked long hours all week, which resulted in Melissa caring for the children alone for most of the time. Once Charlie no longer needed a pushchair Melissa realized she had been using this to support her mobility. Melissa's gait was slightly stiffer, her walking balance was just a little off and she was consciously having to correct her balance at times. This was something she had never done before in her life. Sitting and playing with her sons on the floor became more problematic as the arm weakness and the feeling of having pins and needles became all pervasive. General fatigue started to set in after playing with her sons for shorter and shorter periods of time. Melissa experienced further muscle deterioration particularly in her legs. Eventually in Easter 2009, she sought out medical advice and this led to her undergoing a battery of tests. All the results came back negative. The medical advice she received at that time excluded Dandy-Walker syndrome as causing the muscle weakness. After further tests and consultations with an array of specialists, it was decided surgery would be Melissa's best option. Melissa was confident that her muscle weakness, the constant feeling of pins and needles could be explained and resolved medically after having surgery in Wellington hospital.

The neurosurgeon thought that it could be a buildup of unwanted pressure in her spinal column and he wanted to operate to widen her spinal column. The neurosurgeon opened her spinal column in her neck between the C2 and C8 vertebra and inserted metal bolts to widen the spinal column and to release the built up of pressure in the spinal column (this surgery is called a Laminoplasty). Post surgery, the surgeon was confident it had been a success and Melissa would eventually have near to, or full function of her hands, arms and legs.

After surgery Melissa became an inpatient at the Star 2 Unit of Palmerston North Hospital. However soon after her return, it became apparent to Melissa and the medical staff that her condition was not stabilising and improving, but deteriorating further. Melissa continued to attend physio sessions at the STAR unit gym in an attempt to stop the muscle weakness. These attempts were unsuccessful and Melissa started to use a manual wheelchair to get around the ward. Several weeks later Melissa could not use the manual wheelchair.
any longer as her muscle strength in her arms and hands had deteriorated to the point that her left hand was left without any meaningful function, propelling a manual wheelchair was out the question.

Again Melissa was sent down to Wellington for surgery. This time round the surgeon removed all but one of the bolts he put in between the C2 and C8 vertebrae. He then performed a laminectomy operation; surgery that creates space by removing the lamina — the back part of the vertebra that covers your spinal canal. This was done to enlarge Melissa’s spinal canal to relieve pressure on the spinal cord or nerves.

Post recovery, the neurosurgeon, was optimistic that this would at the very least give back her function in her hands and enable Melissa to propel a manual wheelchair and in time walk short distances. Melissa was also optimistic that the second surgery would restore her hand and arm function to at least what she had when she was admitted to hospital. Melissa then went back to the Palmerston North STAR unit and again went to physio sessions in the gym.

But the longed for post surgery recovery never happened. Other non-surgical options were tried and nothing made any difference. By this time, Melissa had spent several months in the STAR unit and as there were no further treatment options that required her to remain in hospital, planning for discharge started. Melissa was going to leave hospital without answers to why events unfolded in the way they did. As part of the planning for discharge, Melissa reluctantly learnt to use a power chair as this was the only way she could mobilize. Melissa also started using a catheter to assist with maintaining personal hygiene. Melissa’s greatest fear was that she would not be able to return home, but instead end up going to a residential facility and continue to be separated from John, Zach and Charlie. Enable New Zealand NASC modifications were undertaken to ensure Melissa’s personal hygiene was maintained. Melissa and John were not eligible for Ministry of Health funded home help support, so John continued to complete the household tasks on top of working long hours and having to transport the children places. At times John struggled with the extra responsibility of household management on top of everything else.

In 2011, Melissa was given the opportunity to go to the Burwood Spinal Unit for further rehabilitation for two months. This rehab gave her more confidence but ultimately did not see any improvement in her function. It was then Melissa and John realised this was going to be her permanent reality. While this was difficult to come to terms with, she felt she must continue raising the children as best she could. Melissa reasoned that though there were some practical tasks she was unable to support her children with; she was able to support her children emotionally. Melissa accompanied the children to and from school in the power chair most non-rainy days. Melissa started going to as many school events as she could to encourage them.

In 2014, after being together for 26 years Melissa and John separated. As with any break up of a long term relationship, there were many reasons which contributed to the break-down. Melissa believes that while her disability was a significant reason for the break up, it was not the only reason. Melissa and John agreed on 50-50 shared custody of Zach and Charlie. This means they live

Continued on next page...
with each parent week about. Melissa agreed to move out of the house she had shared with John. However this brought unexpected ramifications for Melissa, as she was unable to find a house to rent that met her requirements of safe access for her powerchair, wet floor shower and three bedrooms. As Melissa's moving out date loomed, she was forced to face the reality that she was going to have to move out without having found a suitable house for her and the children. With local social housing agencies having long wait lists, a one bedroom motel unit with a wet floor shower was the only option available to her. Ironically even sourcing such a motel unit was difficult, due to the high demand of accessible motel units and low turnover of these units in Palmerston North. Melissa put her belongings in storage. Due to the lack of space in the motel unit she was unable to see Zach and Charlie while living in at the motel. Melissa was at her lowest point during this time, as it was very upsetting that she could not have her children living with her.

Palmerston North CCS (A Supported Living Agency) advocated on her behalf and Melissa was fast-tracked through the New Zealand Housing waiting list and she was given the opportunity to rent a suitable home, it had already been adapted and had three bedrooms. Melissa moved into the house in October 2015.

Support workers from the Lavender Blue agency continue to visit four times a day and complete personal care tasks. Staff from the same agency also completes the home management tasks for her. A support worker from CCS takes her grocery shopping to enable Melissa to choose what items she wants.

Melissa is comfortable about the 50-50 shared custody arrangement of the children. Zach and Charlie live with each parent one week about. Melissa reflects now they are older it’s easier to manage things. Her older son can put food in the microwave with supervision, both children are old enough to shower and dress themselves, with only the usual prompts around personal hygiene needed from a parent. Melissa is steadfast in the conviction that her main role as a parent is to raise her children to become independent adults who will contribute to society. Melissa mused that she feels her disability has not hampered her in any way around teaching the children the life skills required to become independent adults.

The location of Melissa's new home is about 20 minutes by power chair from where she had previously lived and allows Melissa to continue to accompany her youngest child to his primary school on non rainy days. If it is raining Melissa's son is taken by a taxi to school (and back home if the rain is still falling at 3pm). Melissa has to strictly ration the trips she and her sons make in a mobility van. Currently there is a Manawatu Regional Council discount given to disabled people via the Pink Ticket scheme. This scheme pays up to $10 of a one way trip. While Melissa appreciates this discount it still means she usually pays between $10 and $15 a taxi ride. As Melissa is on a benefit, frequent use of a mobility transport is beyond her financial means. So, if they are going to the movies, they may walk to the cinema and take a mobility van home afterwards. Melissa does her best to ensure her sons participate in community activities; the walking to or from an event is simply factored in.

Melissa is relishing the opportunities to make her own decisions around her life. She is starting to tentatively enjoy venturing out into the wide community and is exploring different interests with encouragement with facilitators from CCS.

Nearly seven years later there is still no explanation as to what happened to Melissa to cause her to lose so many of her core functions. Melissa chooses not to dwell on having an undiagnosed condition; instead she takes one day at a time focusing instead on living her life with Zach and Charlie. Melissa has hopes to own a house and finding employment. Melissa wants to be able to contribute and give back to society. Melissa wants to have an ordinary life like other people in her community.

What is Dandy-Walker?

Dandy-Walker Syndrome is a congenital brain malformation involving the cerebellum (an area at the back of the brain that controls movement) and the fluid filled spaces around it. The key features of this syndrome are an enlargement of the fourth ventricle (a small channel that allows fluid to flow freely between the upper and lower areas of the brain and spinal cord), a partial or complete absence of the cerebellar vermis (the area between the two cerebellar hemispheres), and cyst formation near the internal base of the skull.

An increase in the size of the fluid spaces surrounding the brain as well as an increase in pressure may also be present. The syndrome can appear dramatically or develop unnoticed. Symptoms, which often occur in early infancy, include slow motor development and progressive enlargement of the skull. In older children, symptoms of increased intracranial pressure such as irritability, vomiting, and convulsions, and signs of cerebellar dysfunction such as unsteadiness, lack of muscle coordination, or jerky movements of the eyes may occur.

Other symptoms include increased head circumference, bulging at the back of the skull, problems with the nerves that control the eyes, face and neck, and abnormal breathing patterns. Dandy-Walker Syndrome is frequently associated with disorders of other areas of the central nervous system including absence of the corpus callosum and malformations of the heart, face, limbs, fingers and toes.

How did you become an Assistant?

My journey started in 2006 when I was working in the farming industry as a Senior Administrator, and my supervisor approached me with a brochure she had received in the post. It was advertising an Administrative Professionals’ Day event hosted by the Association of Administrative Professionals NZ Inc. (AAPNZ), so we decided to attend to learn more about it.

I can safely say that this introduction to AAPNZ single-handedly turned my job into a career, and suddenly I was no longer “just” an administrator. At only 20 years old I felt out of place being around such capable administrators, but I was welcomed with professional and personal development through guest speakers and mentoring.

Two years into my membership, I was awarded a scholarship towards a Diploma in Business Administration. This qualification gave me the skills and confidence I needed to pursue an Assistant role, and by 2010 I was employed by Enable New Zealand as a Personal Assistant.

You are known as New Zealand’s new PA of the Year. How did this come about and how has it changed your working life?

I have been inspired by previous winners of the award for nearly 10 years; however, it wasn’t until I attended my first national AAPNZ Conference in 2012 that I realised I shared many of the same attributes as the finalists. My confidence though was severely lacking, so I concentrated on upskilling as well as starting a family. Two years into my membership, I was awarded a scholarship towards a Diploma in Business Administration. This qualification gave me the skills and confidence I needed to pursue an Assistant role, and by 2010 I was employed by Enable New Zealand as a Personal Assistant.

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I finally applied for the Award in 2015 and was stunned when I became one of the finalists, but felt completely intimidated when I learnt about the amazing women I was up against. They had more experience than I had, but I couldn’t allow that to affect my mindset.
It was a nerve-racking few months, but being forced to take stock of my skill set and achievements boosted my confidence like no other experience has before. That is until I won, of course!

Being announced the winner of the 2015 AAPNZ Administrative Professional Award was an extraordinary achievement and one of which I am incredibly proud. The ways it has changed my working life have been numerous.

For a start, I now voice my professional opinions or concerns with conviction instead of uncertainty. I still have self-doubt, but this award has given me confidence in my own abilities and knowledge. I am now more critical of my work, but this helps me strive to find continuous improvements.

I have been assigned a mentor who helps untangle my thoughts, provides valuable feedback, and is an excellent sounding board for my ideas.

The award has also encouraged me to create an online presence, which has allowed me to take advantage of opportunities on a global scale and connect with many industry leaders. I was recently invited to write a guest blog for the Global PA Association that I will be writing soon.

What inspires and motivates you?

I am inspired to help others so I try to carry this through all aspects of my life. I’m a “big picture” type of person; I see my role within the Health and Disability Sector as having a ripple effect. When my Managers, teams and networks are well supported, they have a greater ability to provide the services that are integral to the lives of others. In my opinion, behind the scenes is just as important as the front line.

I am also motivated to be a good role model for my son. It is important for me to show him the value of education, the importance of following your dreams, and the significance of helping others with no expectation of reward.

You have managed to juggle a young family with your studies and career very successfully – how have you managed this and what advice would you give to others in the same position?

It hasn’t been easy. I’ve needed to keep a clear vision in my mind of what I hoped to achieve in order to stay on track, and I couldn’t have achieved what I have without my husband believing in my vision as well. Chris has always supported my endeavours and keeps our life ticking when my head is stuck in the books. It is imperative to have family support.

There have certainly been trade-offs though, and anyone considering an acrobatic lifestyle needs to be willing to accept these. The last time I worked fulltime and studied extramurally, I sacrificed a large portion of my personal life to study. This time, my personal life has had to come first as I don’t want to miss spending quality time with my family. This has meant less time for study, and subsequently I received my first C on an assignment. Normally I am an A student, so this grade was difficult to accept, but I am proud that I was still able to pass with the limited time I had.

I encourage those willing to take on this lifestyle to inform your employer. I have had great experience with two employers supporting my education; from decoding financial jargon, offering advice, and by providing study time away from the office.

Many employers will consider financial support, especially if there is strong evidence that the study will enhance your capabilities in the workplace. Don’t be afraid to start the conversation; you may be pleasantly surprised where it leads.

What advice would you give someone just starting out as an Assistant?

Join and be active within a professional association. You will learn how to network with peers in your industry, receive mentoring and professional development, and there will be opportunities to practice new skills within a safe environment that are directly transferable to your role.

Within nearly 10 years, my AAPNZ membership has helped me achieve:

- Web and social media experience
- Confidence with public speaking
- Improving my project management abilities
- Two scholarships
- Certification status, which means I have been nationally benchmarked against industry standards

And lastly, the opportunity to be New Zealand’s ambassador for the administrative profession through the Administrative Professional Award.

Joining a professional association has been the best investment I have ever made, and I look forward to continuing my relationship with AAPNZ.

So what’s next for Rebeka Adamson? Where do you want to be in five years’ time?

In February 2016 I will be a guest speaker at the Aspire Conference being held in Auckland, New Zealand, where I will share my top efficiency tips with fellow administrators. I have always enjoyed sharing my knowledge with others, so this has been an exciting development in my career.

Within the next five years I hope to engage in many more training and public speaking opportunities, as I want to be part of the rapidly evolving global move towards the professionalisation of administrators.

Of course some of this starts at a local level in giving back to those who helped me start my career. Within the Manawatu sector of AAPNZ, I plan to volunteer for the Vice President role before finally taking on the role of Group President. I hope to be as strong a leader as the women before me.

Article used with permission.

UNIVERSITY OF AUCKLAND STUDY – RARE DISORDERS

Researchers at the University of Auckland are leading a study to uncover DNA changes responsible for rare neurodevelopmental disorders that have not been explained through standard tests. They plan to apply revolutionary new DNA sequencing technologies to obtain a genetic diagnosis for participating families and demonstrate the benefits of routine clinical use of this technology in New Zealand.

They are currently looking for families who have a child (or children) with an undiagnosed neurodevelopmental condition with an accompanying intellectual disability. Participants need to provide a DNA sample (saliva or blood). This study is approved by the Northern B Health and Disability Ethics Committee, reference 12/NTB/59 and is part of a larger project investigating the genetic underpinnings of neurodevelopmental disorders in New Zealand. More information about the wider research programme can be found at: www.mindsforminds.org.nz or by way of the contact below.

If you are interested in participating in this research project please contact the research team directly – Whitney Whitford at: arnnz@auckland.ac.nz

PARENT MANAWATU SIB DAY

When: Sunday, 20 March 2016
Where: YMCA, 148 Park Road, Palmerston North

Open to all children who have siblings with a disability, special need or health impairment.

The day is a busy interactive day for siblings. Games and activities are interspersed with time for discussion and sharing.

SibmDays are a great way for siblings to learn new techniques, discuss issues and meet new friends.

The day is FREE and is open to all siblings aged 8–18 years.

Morning tea, lunch etc are provided.

If you would like further details or to register your interest please contact Debra Broughton Regional Coordinator (06) 355 0787 or 0508 236 236
Victoria Esplanade is a real asset to our community. It is enjoyed by children, the elderly and the disabled. It comprises 19 hectares of stunning gardens and features, including fernery and conservatory, bird aviaries, nature trails with a number of accessible walkways, a large duck pond, free barbeque facilities and children’s paddling pool and playgrounds. The onsite café offers tasty treats, icecream and drinks, while an extensive miniature railway offers rides on weekends and holidays for a small fee. Within the esplanade is the Dugald McKenzie rose garden, which is home to over 5,500 varieties.

Location

You can access this park from Manawaroa Street, which is off Fitzherbert Ave, as well as from Park Road, next to the Lido Aquatic Centre. Open all year from dawn to dusk.

Begonia House

The main Begonia House was built in 1951 and has recently been refurbished. The beautiful Begonia’s, ferns, tropical plants, waterfall and fishpond with accessible walkways are a must to see when visiting the Esplanade.
Esplanade Cafe
Esplanade Cafe offers tasty morning tea and light lunches, also a wide choice of ice creams and drinks in a lovely setting.

Miniature Railway
Enjoy the scenic railway which travels through native bush, gardens and secluded areas of the Esplanade.

Concerts
Victoria Esplanade hosts annual summer concerts. These concerts are very popular with young and old alike.

Walkways and Gardens
Mrs Virginia Money and Mr Merle Bell (pictured) often visit the Victoria Esplanade Gardens when they come over from Levin for the day. They enjoy the beautiful gardens with accessible walkways including the Rose garden and fern lined paths, which cater for a wide range of age groups, from children to the elderly and disabled. Taking a rest to enjoy the view in front of the Little Library which one can take time out to read a book, provided by the City Council.
WEKA WEBSITE GIVES DISABILITY-RELATED INFORMATION
"WHAT EVERYONE KEEPS ASKING"

WEKA is funded by the Ministry of Health and is New Zealand’s premier website for delivering national disability information.

The website includes:

• Contact details for disability information centres around New Zealand
• Suppliers of various items of disability equipment (including their contact details and links to their websites)
• Support services for disabled people, with the ability to break it down by region and/or service provided
• Resources available to disabled Maori
• A free DVD Library where you can borrow disability-related DVDs with the only cost being for their return
• Disability-related news and events of interest to disabled people
• Disability-related information and assistance – including information sheets on specific disabilities, information for people new to disability, education, funding, transport, and information giving disabled people advice on personal security.

Come and check us out.

Navigating Your Future Disability Expo

30th March 2016
11am—6pm

@ The Convention Centre—Elwood Room

Palmerston

Sponsored by: Palmerston North City Council
Proudly brought to you by: Phoenix Supported Employment