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EDITORIAL

Dear All

The year has once again whizzed by at a great rate of knots! I hope families have enjoyed the school holidays and the kids are geared up for a busy last term.

I have included a variety of bits and pieces in this newsletter. Kit has written about her investiture for the Queen's Service Medal and has included a couple of great photos.

Also there is a request from Jessica Reeve (supervised by Assoc Prof Melanie Porter, the Australian Researcher on WS) asking NZ families with a WS child between the ages

of 18 months to 7 years to take part in her research into neuropsychological functioning in preschool WS children. They will carry out the research in NZ. Families should contact her directly if you wish to take part. This would be a great opportunity to have your child assessed and have data to backup applications for educational resourcing. (See Page 5)

Disability Connect (Parent & Family Resource Centre Inc.) have given a very thorough report on "Living Options" in their December 2014 "Networker" magazine which I have copied and attached separately. I know that this is Auckland focused but does apply to the rest of NZ.

Coincidentally, also included is a "blog" from David Slone about Matthew's flattening experience. David has set up a blog on disability issues, which is well worth a look. The link is An Optimistic Cynic <http://the-optimistic-cynic.my-free.website/>

Our sympathy is extended to Gareth and the Praat family on the loss of Adrian. A truly lovely man who sadly passed away in August after a brave battle.

I'm sure you'll find something of interest to read.

Regards,
Sandra Paterson

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2015 WORLD SPECIAL OLYMPICS

Matthew Slone attended the 2015 World Special Olympics in Los Angeles in August where he competed in three swimming categories and won a Gold medal in the 50m Butterfly.

Matthew came 6th in the 100m Freestyle and his team

came 4th in the 4x50m Relay. He also beat four of his Personal Bests and his Relay team completed their final race 16 seconds faster than during the heats.

What a wonderful achievement Matthew. Congratulations!

Matthew's father David has written an inspirational account on "The Road To The World Games" included on Pages 6-9.

David and Judith also travelled to Los Angeles to support Matthew and I quote "it was an unbelievable trip for him and us".



Gold Medalist - Matthew Slone



Official Investiture photo of Kit with the *Governor General* kindly supplied by Woolf Photography, Wellington.



A delighted Kit after the Investiture

QUEEN'S SERVICE MEDAL

In early April I found a letter in my letterbox with an imposing golden coat of arms from the office of the Governor General informing me that I had been recommended for a Queen's Service Medal for "Services to Williams Syndrome" in this year's Birthday Honours.

No one could have been more surprised than I was! Certainly most unexpected, but a great thrill to both my family and me. Undoubtedly I would have had a "High Five" from Gordon were he still alive, and I feel it is a tribute to him as well as he got me into the intricacies of Williams Syndrome in the first place!

I greatly enjoyed the years in which I was involved and I've learnt a lot along the way. How meetings work for one thing and how to give talks to interested groups such as Plunkett Nurses and School Teachers informing them about a little known syndrome and the problems likely to be encountered. With the development of computers I taught myself to type, though too late to help with the newsletters I put out in the early years. I also learnt a bit about such things as balancing the books and preparing the accounts for auditing and indexing our collection of information about WS when forming our small library in the days while we gradually set up the NZWSA.

But the greatest pleasure has been how over the years I have met so many lovely families with whom as a group we share so much. Not only the anxieties but we also discover the many joys that our person with Williams Syndrome brings to us and the communities in which we live.

Thank you to everyone and especially those wonderful people who from the beginning have put their name forward to set up the Association we have today.

With best wishes,

Kit

CONDOLENCES



Gareth & Adrian - WS Camp 2015

It was with great sadness we learnt of the passing of Adrian Praat in August.

Adrian always attended our WS Camps with Gareth along with his late wife Lynda in earlier years. He was a gentle, kind man with a lovely dry sense of humour. He loved music, and I remember he used to play the guitar at our camps encouraging everybody to sing along. Gareth also loves music and Adrian was so proud of him at the Williams' Got Talent night in January.

We extend our sincere condolences to Gareth and family.

September 2015

Dear Parents,

INVITATION FOR RESEARCH PARTICIPATION

My name is Jessica Reeve. I am currently completing my PhD project entitled "*Neuropsychological Functioning in Preschool Children with Williams syndrome: A Longitudinal Study*", supervised by Associate Professor Melanie Porter, Senior Lecturer and Senior Clinical Neuropsychologist, Psychology Department, Macquarie University.

I would like to invite you and your son/daughter with Williams syndrome (WS) to participate in our research, which aims to look at the early neuropsychological profiles and learning processes that contribute to the intellectual, adaptive, academic and mental health outcomes in children with WS. We are currently seeking the participation of children with WS aged 18 months to 7 years.

There are 3 components to the research project, **and you can choose to participate in as little or as much as you like.** Testing of the various components can be done in one session, or across multiple sessions. Most components can be done in your home or at a location convenient to you. The components include:

- 1. Neuropsychological Component:** Participation in this study would require parents to complete a 1-hour interview (which can be completed either in person or by phone), as well as some brief questionnaires on behavioural and social skills taking approximately 30 minutes in total. Participation also requires up to 2 hours (including breaks) of cognitive testing with your son/daughter with Williams syndrome. This testing will look at aspects such as attention, verbal abilities, pre-academic skills, motor abilities, and social problem-solving.
- 2. Social and Eye-Tracking Component:** Participation in this component would involve your child looking at a series of videos and photos of faces whilst we record their eye movements, imitating the actions of actors, and participating in different types of play activities – all whilst having fun with the many different types of toys we have! This component will take approximately 1 hour to complete. Participation in this study would also require parents to complete a short questionnaire on social abilities, taking approximately 10 minutes in total.
- 3. Hormone Component:** If you choose to participate in this component we would collect 4 x 1 ml saliva samples from the person in your family with Williams syndrome at different time points during the day. Saliva is then used to determine levels of oxytocin, a prosocial hormone produced in the brain that plays a crucial role in social behaviour and social affiliation and anxiety, as well as levels of cortisol and vasopressin, other related hormones. Saliva collection should take approximately 5 mins.

We can also provide you with feedback (including a written cognitive report) on your child and participants will go in the draw to win one of two \$100 Coles/Myer vouchers for participating. A detailed information and consent form is available upon request.

There is also an opportunity of participating in follow-up studies in approximately eighteen months, five years, ten years, and then twenty years to track your child's development over time. These are, of course, optional.

If you are interested in participating or if you would like further information please contact:

Jessica Reeve

Mobile 0402 288 411

E-mail: jessica.reeve@students.mq.edu.au

Postal Address: PO Box 1183, Crows Nest NSW, 1585, AUSTRALIA

I look forward to hearing from you!

Yours sincerely,

Jessica Reeve

(PhD/Masters of Clinical Neuropsychology Candidate)



Matthew Slone - Gold Medal Winner - World Special Olympics 2015

A Golden Journey

Matthew Slone's trip to the World Games

When Sandra asked me to write something about Matthew's journey to the Special Olympics World Games, it made me think a little bit differently about what it could really mean. For this reason, I've tried to tell the whole story.....

It was an incredible occasion and what parent wouldn't be so proud of a kid who had won a gold medal representing their country at the biggest sporting event in 2015. The medal race though was only the final step of a journey that started when Matthew was eight years old. It is this journey that I hope can help inspire people with Williams Syndrome to achieve their goals and to give hope and aspirations to those parents just starting out on the Williams road trip.

First a little bit about the World Games. These are held every four years and this year Los Angeles was the host city. With 7,000 athletes from 170 countries this was the largest sporting and humanitarian event in the world in 2015. It was also the largest sporting event in Los Angeles since the 1984 Olympics. The opening ceremony was at the LA Coliseum in front of 80,000 people – including Michele Obama.

Due to the numbers involved, countries could only enter a set number of athletes based on their overall registrations. In the case of swimming, we could only enter a maximum of six athletes. It isn't just the fastest swimmer selected, it also came down to other factors such length of time in Special Olympics, dedication, ability to fit into a team and how they would be as an ambassador for the country. To put it another way, it wasn't just Matthew the swimmer selected – it was also Matthew the person.

We found out that Matthew was selected in about June last year. Sue Wood a magnificent professional coach with Waikato offered to manage his training regime. This meant he started two additional training sessions per week with Sue. Another of the Waikato team offered to training with him to offer support – and Kym stuck with him through all his training.

Labour weekend 2014 saw the first official team camp in Wellington, with lots of information around training, diet plus what to expect. Matthew wasn't a good technical swimmer, his speed was generated through strength and desire. Sue worked hard on his stroke and Matthew really listened. Sure people with Williams might be easily distracted but I've noticed that when they really need to, they can be the picture of concentration. Training was hard – even pauses between routines were timed to the second. In addition to the pool work, Matthew also went to a gym twice per week and he followed the diet advice (pies and bread were rationed – that in itself was quite an achievement).

Shortly before the big trip, the team received their uniform. The two athletes from Waikato had theirs presented to them by Sir John Gallagher (our patron). I saw uniform but we're talking a full kit – from shoes and socks right through to the suitcase. I must say, it was a really smart uniform as well.

Thursday 16 July and the team met in Auckland ready to fly out. There was an official send-off first, including each athlete being awarded their individually numbered cap. We all then went to the departure gate and said our good byes. Like every parent, we had the normal emotions seeing our child head off overseas without us, it was going to be a huge trip to a foreign land – scary enough for every parent let alone one with a Williams child. This was coupled however with such pride – seeing him part of a New Zealand team, resplended in

his formal uniform and knowing that this was a once in a life time opportunity, one most of us simply don't get.

Once in LA, the team immediately got stuck into training. The first few days was at Long Beach followed by a few days in a host town called Camillo (pronounced Camarro). In between they had their one day off so took the opportunity to visit Disneyland. Yes parents – someone with Williams Syndrome can go to Disneyland and not get lost! They then went to the games village at the University of Southern California (USC) – with a nine car police escort on the freeway, lights flashing.

I've said a bit about the opening ceremony earlier. When you see your son march into a stadium like that, it's hard to describe how you feel. Obviously we were so very proud but also very aware that this was his moment to shine. He was doing something that we could never do – and no one in our family had ever done. Matthew was an Olympian, making so many people proud.

Day one of competition was the 100m freestyle heat. This was the moment – how would he fare against some very quick opposition? Would he swim correctly or would the occasion be too much and he'd just go hell for leather, all splash and no technique? Would his dive be up to this standard of competition? Well straight away he set the scene for the week. A personal best time and a perfect stroke. After this race was also the first time we managed to talk to him since he left NZ almost two weeks earlier. Fair to say, it relieved a lot of anxiety all around.

The next day he recorded another personal best time in the final of the 100m free. He didn't get a medal but in swimming no one can ask more of you than swimming faster than you ever have before.

Over the next two days he competed in the 4 by 50 medley relay. The team didn't quite get into the medals (4th) but Matthew was certainly quick in his stroke (butterfly).

Onto his specialist event – the 50m butterfly. It was a tough heat with some exceptional swimmers – but again, a personal best time was recorded. The next day was the final – and his last swim of the Games. Slow off the blocks, he was well behind the other swimmers for most of the first length but had managed to claw it back at the turn. He hit the front and simply powered away. Gold medal in another personal best time!!!

I think you can all guess how we felt seeing him on the podium getting his medal.

I'm glad he got a gold medal – so he could see for himself the reward for the effort he put in. It also means that other people takes his achievement seriously. Personal best times prove to those in the sport that he did the best he could but the medal is something everyone can understand.

Best of all – while the training has eased back, he is still doing additional sessions to stay in shape and to make the most of what he did before the games.

When we first joined the Williams Syndrome Association, seeing the adults who were around at that time gave us huge encouragement for the future. I just hope that people can now look at what Matthew has achieved and view a future filled with optimism and go forward looking for, and meeting, challenges.

David Slone.

Gold at Special Olympics

Cambridge News

One Cambridge athlete has swum his way to the top at this year's 2015 Special Olympics, winning a gold medal in the 50m butterfly heat.

21-year-old former Cambridge High School student Matthew Slone, who has Williams Syndrome, travelled to Los Angeles to compete in three swimming categories at the games.

Matthew said he really enjoyed taking part in the 100m freestyle and the 50m butterfly, as well as in the 4x50 relay as part of a team. "It was really fun," Matthew said.

Matthew made Cambridge proud winning a Gold medal in the 50m butterfly, he also came 6th in the 100m freestyle and his team came 4th in the 4x50m relay.

"I was absolutely stoked, I was really pushing my limits for the butterfly," Matthew explained. "I wanted to feel like I was swimming for everyone, like my supporters and coaches."

"I was pushing everything that I had inside of me just to go a little bit faster. It was emotional, a good blessing that I've done something well for my country."

"Mum and dad were shouting out and cheering me on," Matthew added. "Dad even lost his voice, he was shouting that loud."

Since September last year Matthew has trained 3 times a week for the Special Olympics. That hard work and training paid off when Matthew beat four of his personal-best swimming times (PBs) during his various races at the games

"I got four of my personal best times which was unbelievable," Matthew said. His relay team also completed their final race 16 seconds faster than during the heats.

37 New Zealand athletes were at the competition competing against over 7000 athletes from a total of 177 countries.

Matthew was coached by Sue Wood, alongside his father David Slone who is a Waikato swimming manager.

And it wasn't just showing off his gold medal that Matthew had to look forward to when he got home, but also a "winners birthday cake" from Grandma. "I got my cake from my grandma the other day, it was great and she was stoked too."

Matthew says he hopes to compete at the pan pacific games which will be held in New Zealand in 2 years.

HAPPY 90th BIRTHDAY TIL

On the 21st of July Til Carati celebrated her 90th birthday with family and friends.

Instead of receiving presents she asked for donations to the Williams Association in memory of Eveline. Til received \$200.00 which she has kindly forwarded to us.

Thank you Til and congratulations on your 90th birthday!



Roland Pauline Kit Till Yel Susan Kim Colin Fern Mary

David Slone has written about Matthew's move away from home.

This appears on his blog about disability,

[An Optimistic Cynic](http://the-optimistic-cynic.my-free.website/)

David Slone

021 208 6270

Here is the link <http://the-optimistic-cynic.my-free.website/>

Flatting - the new adventure: Part 1

19 Oct, 2015

David Slone

When your child leaves home - there is a never ending story to be told

Matthew moved out of home in July 2014, one month before his 21st birthday, to go flatting with two friends in Hamilton. His flat mates were already flatting together and there was an empty room in their flat. They are supported by Community Living under the Choices in Community Living funding.

We spend so much time fighting for our children, overcoming challenges and just doing whatever it takes to give them opportunities that the thought that they will leave home one day and enjoy their independence doesn't always come automatically. It's more a long term goal – what we strive for but never knowing for sure that it will be achieved. Scary and exciting, it's something that needs to be done – something that will leave an empty feeling in your stomach but also immense pride.

After Matthew left school we wanted him to start thinking about the day he will go flatting. This was so that he was prepared mentally and also took more interest in learning the necessary skills (cooking, cleaning, public transport etc).

Matthew initially wasn't keen at all but we kept at it. Over time he started to think more about it, planning firstly to do it in a fairly long timeframe ("I'll move out when I'm 33") and then suddenly one day he decided it was time. He then went a step further and put paid to all of our thinking. We were thinking a managed transition period of a year or two and then him moving into a flat in Cambridge. Matthew however decided that he not only wanted to move out straight away, he also wanted to live in Hamilton.

We knew that moving to Hamilton would present challenges – for him and us. All of his activities and interests were in Cambridge, he didn't know Hamilton at all and had never used the bus system over there. Truth be told, we had never even considered him not living in Cambridge. Like most parents I guess, we wanted to be there if necessary and if he could just pop around for a visit, it enable us still to have lots of contact with our boy. Having said all that – it also made sense to us that any young man would want to move to "a big smoke". In fact, that is what we both did when we left home. His friends from Special Olympics live in Hamilton and there would be more opportunities for work etc in a city than a small town like Cambridge.

So Hamilton it would be.

Going into the process, we knew that Residential Services were simply not an option and asking around, we were warned about this new funding model being trialled that Disability Support Links (DSL) was pushing. Like many parents, we didn't have a lot of faith in the system so it was in a cynical mood that we approached DSL.

On the back of the needs assessment, we were visited by DSL to discuss Choices In Community Living. This is where we came across two remarkable opportunities. The story of two young men was part of the

information provided – and we knew one set of parents through Special Olympics. The first opportunity was to talk to another parent about how the system really worked in practice. All of the various organisations may have their hearts in the right place but at the end of the day, parents of children with a disability tend to look after each other and we really value each other's opinions and experiences.

Funding model sorted.

While we did the formal approaches to organisations, and had their 'sales pitches', the second remarkable opportunity is what drove us forward. The two young men mentioned above had a vacancy in their flat. Matthew knew both of them and they got on really well together at a sports programme and through Special Olympics. We didn't want to press things too hard in case they weren't keen but Matthew was positive that he wanted to go flatting with these guys. A few meetings, some discussions, visits to the flat and all parties were keen to go ahead with Matthew moving in with Glen and Alex.

Flat found.

We met with two different service providers and both met our requirements while past experience/knowledge meant that several others were ruled out immediately. Knowing the flatmates and their parents, having met the staff, learning first-hand about how the flat operated and was supported were the key things for us. Who the organisation behind it all was almost secondary (as long as it was one of the two we decided were appropriate). One area that pleased us with Community Living was the fact that the house was managed by someone who knew the flatmates really well, not by someone who just happened to be in charge of that area but didn't know the guys. That sort of flexibility gave us a lot of confidence.

Service provided agreed.

Stage one complete – we hired a trailer and packed up our son to begin his new life in Hamilton. Some of the key things we learnt from those process were:

Things don't always go the way we think they will – and that's completely OK

Things often happen when they're meant to happen

The opinions and experiences of fellow parents are gold

When your first child leaves home it's usually a big thing, but when it's also a child with a disability it's a huge thing. Yes it was hard, yes tears were shed but the staff and the other parents understood this. The empathy definitely made things easier. The biggest thing though was seeing how happy Matthew was, and seeing the genuine friendship all three flatmates had for each other.

Our flatting experience has been relatively easy up to this point but we know there will be hiccups ahead – there always is. We also understand that no two journeys are the same and some people will encounter many more issues than we have. Choices in Community Living may also not be the best option for you at this point in time. All we can say is that it's working for us, we're so happy that Matthew is enjoying flatting and if you're in the flatting process or ready to start – we wish you all the very best.



This information was kindly sent via Jude Sonneland - some very useful products



Solutions

Resources and solutions
that make life easier for people
with special needs.

We are having a bit of a clear out of Sensory Products

Featured Products



Funny Faces Stress Reliever

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28)

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and
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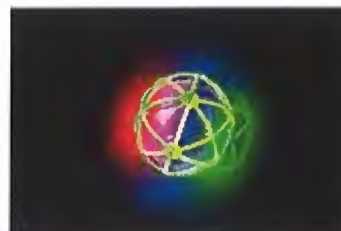
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Stress reducers are a necessary
tool for people with special
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Stellar
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emanate
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Super Chew - Green

The Green Super Chew offers a solid and smooth surface for practicing biting and chewing skills.

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space ball.
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Flashing Spikey Ball

Flashing Lights are activated for 10-15 seconds with each bounce or shake.

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P's & Q's -

P's & Q's are fun new exercisers for practicing biting and chewing skills!

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Tangle Toy



Textured Twistable therapy device which instantly calms sensory seekers.

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Shake Loose a Memory is a friendly, fun and easy game especially for elderly people who are memory impaired.

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[m](#)

Please forward on to others who have an interest in supporting people with Special Needs

New Products

We are constantly sourcing new products to enhance the lives of those less able. If there is a products you would like please feel free to [contact us](#)

The following information was in the December 2014 "The Networker". It is on Living Options for a person with a disability. While it is focused on Auckland many of the options are available throughout the country.

disability
connect.
helping families

NETWORKER

Supporting parents and families of disabled children and young people

There are some current options and some emerging options which are based on the Ministry of Health (MoH) New Model for supporting people with disabilities. We will look at four options: Community Residential Care, Supported Living, Choice in Community Living (CiCL) and Family Governed Models.

Families can work through these options and we hope that by putting this information in the Networker it will help their understanding. This overview is of living options in Auckland at present – it is important to note that not all options are available everywhere in New Zealand at this time (eg: CiCL).

And we come to a point, often at the end of schooling or just before, when we start thinking "where to from here?" What kind of a life do we visualise for our children? How much support do they need (or we for that matter)? What decisions can they make? How much of a role do we want in their lives and how much do they want us in their lives? Most of these questions are typical ones in any family no matter what ability their child has - some of them are special questions and probably the most important question is "are WE ready to let go?"

It is a normal transition for young people to move out of the family home. This is the same for young disabled people. Young adulthood is a time of many 'transitions' – leaving school, sometimes leaving home and leaving childhood behind – and parents transition also within this process.

Some parents may well decide that the best option is to keep their child at home and care for them until they can't do it any more, believing that they can provide the best care. No doubt every parent believes they know their child best and can provide the best care. But other options could be considered too.

- Community Residential Care offers fulltime support with aspects of household and personal cares. The house and care is provided – this option is generally suitable for more severely physically and/or intellectually disabled people.
- Supported Living has more of a facilitation component. A house or flat is rented or owned by the disabled person (sometimes with Work and Income support). The person receives support to facilitate independent living.
- Choice in Community Living (CiCL) is an alternative to residential services for those with significant disabilities. This offers more choice over where and how people live and how they can be supported to facilitate this.
- Finally there are Family Governed Models which allows the person to own or rent their own place, using Individualised Funding and Work and Income benefits to buy the support they need.

At a quick glance each service offers a greater/lesser degree and type of support. With that also comes more/less choice and control and also more/less self-responsibility.