

www.williams-syndrome.org.nz

EDITORIAL

Dear All



I hope you have all had a great summer and managed to have a break over the holiday period. We have just come back from two weeks in Wanaka where the weather was fantastic, even too hot some days!

I have included the brilliant article on education for special needs students which appeared in the December 2015 issue of "The Networker" - Disability Connect's newsletter.

Denise Bray, together with volunteer help from the Rare Disorder Group has revamped our website and

this will be launched shortly. I've had a sneak peak at it and I'm sure you will agree it is very good and is much easier to navigate. Also, it now clarifies that you are only a member of the NZ WSA by being a paid up member, rather than being a member of the website, which was very confusing before. Unfortunately we have lost touch with some people because of this ambiguity.

Which leads me to request that if you have changed your email address please advise me, Denise or Tasha. We hope to cut down the cost of producing the newsletter by emailing it to the majority of members, but we will still post out a hard copy

to those who prefer that option or for those who do not have email.

The next WS Camp has been confirmed as being in Rotorua. Further information is overleaf. The organising committee has met recently and we will let you know more details as they come to hand.

Also, 2016 membership subs are now due, please see the form attached.

Happy reading, and enjoy the rest of the summer!

Regards
Sandra Paterson.



SPECIAL EDUCATION

As mentioned above, at the rear of the newsletter you will find a complete copy of the Special Education article from the latest "The Networker" - Disability Connect's newsletter.

It takes a comprehensive look at the New Zealand Education

System for special needs students. It is recommended by the authors that you keep this handy as it will be very useful to you while you and your child are navigating the education system.

I wish this was available when our boy was at school, alt-

hough we were lucky compared to many other families we heard about. Please read it thoroughly and put it away safely, because you may never know when you may need to refer to it!

Sandra Paterson.

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WS Camp 2015

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NEXT WS CAMP



2015 WS Camp

Organisation is already underway for the next camp.

It's to be held in Rotorua at the Keswick Christian Camp from Friday the 20th January 2017 to Monday 23rd January 2017.

So mark that in your diaries and start saving for the next great NZ WS Camp.



Wai-O-Tapu Geothermal Area, Rotorua



WS Camp 2015

These upcoming seminars are hosted by Disability Connect and are based in Auckland. Please check in your area for your local seminars/information.

Individualised Funding including Respite Seminars

Central Auckland – 23rd February 7 – 9pm Disability Connect premises, 3b Olive Road, Penrose

Central Auckland – 15th March 7 – 9pm Disability Connect premises, 3b Olive Road, Penrose

Central/South – 7th April 7 – 9pm Mt Richmond School, 30 Albion Rd, Otahuhu

Central Auckland – 14th April 12.30 – 2.30pm Disability Connect premises, 3b Olive Road, Penrose

Central Auckland – 31st May 7 – 9pm Disability Connect premises, 3b Olive Road, Penrose

Central Auckland – 14th June 7 – 9pm Disability Connect premises, 3b Olive Road, Penrose

Trust and Welfare Guardianship Seminars

Central Auckland – 24th February 6.30 – 9.30pm Disability Connect premises, 3b Olive Road, Penrose

South Auckland – 22nd March 6.30 – 9.30pm Rosehill Special School, 48 Rosehill Drive, Papakura

West Auckland – 12th April 6.30 – 9.30pm Westwave Pool and Leisure Centre, 20 Alderman Drive, Henderson

Central/South – 19th May 6.30 – 9.30pm Mt Richmond School, 30 Albion Rd, Otahuhu

North Auckland – 24th May 6.30 – 9.30pm Yes Disability Resource Centre, 3 William Laurie Place, Albany

Central Auckland – 8th June 12 – 3pm Disability Connect premises, 3b Olive Road, Penrose

Education Legal Issues Seminars

Central Auckland – 16th February 7 – 9pm Disability Connect premises, 3b Olive Road, Penrose

West Auckland – 1st March 7 – 9pm Westwave Pool and Leisure Centre, 20 Alderman Drive, Henderson

Central Auckland – 8th March 12.30pm – 2.30pm Disability Connect premises, 3b Olive Road, Penrose

South Auckland – 5th April 7 – 9pm Rosehill Special School, 48 Rosehill Drive, Papakura

Central Auckland – 10th May 12.30pm – 2.30pm Disability Connect premises, 3b Olive Road, Penrose

Central Auckland – 17th May 7 – 9pm Disability Connect premises, 3b Olive Road, Penrose

North Auckland – 7th June 7 – 9pm Yes Disability Resource Centre, 3 William Laurie Place, Albany

Work and Income Supports in Disability Seminars

South Auckland – 17th February 7 – 9pm Rosehill Special School, 48 Rosehill Drive, Papakura

Central/South – 3rd March 7 – 9pm Mt Richmond School, 30 Albion Rd, Otahuhu

North Auckland – 16th March 7 – 9pm Yes Disability Resource Centre, 3 William Laurie Place, Albany

Central Auckland – 6th April 7 – 9pm Disability Connect premises, 3b Olive Road, Penrose

West Auckland – 3rd May 7 – 9pm Westwave Pool and Leisure Centre, 20 Alderman Drive, Henderson

Central Auckland – 21st June 7 – 9pm Disability Connect premises, 3b Olive Road, Penrose

Living Options Seminars

Central Auckland 2nd March 12.30 – 2.30pm Disability Connect premises, 3b Olive Road, Penrose

Central Auckland 30th March 7 – 9pm Disability Connect premises, 3b Olive Road, Penrose

Transition Seminar

Central/South – 5th July 7 – 9pm Mt Richmond School, 30 Albion Rd, Otahuhu

Planning for Adulthood - The Legal Framework around Disability and Disability Rights Seminar

This seminar was previously called 'Trusts and Welfare Guardianship, planning for when we are no longer here'

This seminar will be of interest to you if: You worry about the long term welfare of your young person with a disability when you die – who will support them to make decisions about their personal care and welfare? And who will understand their needs and make decisions about their personal and physical welfare on their behalf if they are unable to do so?

You need to understand the difference amongst welfare guardianship, power of attorney, property management and how a Trust may be useful for managing property

You need information about the relevance of a Will and Letter of Wishes and how these might be useful

You are concerned about managing and protecting assets or income of your young disabled person

You are considering a family trust or sole beneficiary trust for management of assets

2016 - Education Legal Issues

A presentation by Nan Jensen, Quinlaw

This seminar will be of interest to all families raising a child with a disability, whether in mainstream or special school environments. Come along and learn about enrolment rights, decision processes around special education, processes around an ORS funding decline, requests to parents for teacher aide funding contributions, requests to parents for funding for student support at extra-curricular camps and activities, stand-downs, use of restraint, and much more.

Nan Jensen – Barrister and Solicitor, Quinlaw

Nan has been involved in the disability sector since 1998, in governance, advisory, support parent, advocacy and employee capacities. Two of her four children are on the autism spectrum, and she decided to study law after taking a successful arbitration case against the Ministry of Education to retain ORRS funding for her son. She was admitted to the bar in 2012 and specialises in disability law. She lives in Te Kowhai near Hamilton with her husband, Søren, their children and their dog.

MEDICAL RESEARCH & UPDATES

BIRMINGHAM UNIVERSITY

PROFESSOR CHRIS OLIVER AND PROFESSOR PATRICIA HOWLIN

We have an ongoing research project, taking place jointly at Birmingham University's Cerebra Centre and Kings College London into a very significant issue for people with WS – **Anxiety and Mood Difficulties**. Over the last few months, the team led by Professor Chris Oliver, Professor Patricia Howlin, Dr Jane Waite and Rachel Royston have carried out a preliminary interview study with parents and carers, to explore the emotional difficulties faced by people with WS.

Although only a small sample, it has already provided crucial information about how anxiety and mood difficulties are shown, and the types of triggers and behaviours associated with them, as well as the impact these difficulties have on individuals and their families. The project (funded by WSF and the charity Cerebra) now moves into its second research phase, with much larger numbers of individuals. Its aim is to find out whether specific factors increase or decrease the risk of anxiety in WS individuals (particularly environmental factors and health/well-being) and examine how anxiety affects their quality of life. The final phase of the project will involve very detailed assessments of selected individuals – and, hopefully, will lead to the future development of potential intervention strategies.

Information for Phase 2 will be collected through an online survey, which will take around 45 minutes to complete and is open to parents and carers of individuals over the age of 12, regardless of whether the WS person experiences anxiety or not.

To ensure that the information reflects the experiences of as wide a range of individuals as possible, we are hoping for responses from more than 150 participants.

Anyone members wishing to take part should email Rachel Royston: rxr180@bham.ac.uk (or telephone 0121 414 2855).

DURHAM UNIVERSITY

DR. DEBBIE RIBY

Staying on the subject of **Anxiety in WS individuals**, Dr Debbie Riby's North East Williams Syndrome Research Group has now published its Anxiety Booklet for all parents and schools, receiving fantastic feedback from both teachers and parents – and, we hope, opening a gateway for discussion about anxiety with teachers and schools. The booklet, based on extensive interviews and focus groups with WS individuals and parents, has also been translated and distributed throughout France, thanks to funding from our counterpart charity there, Autour des Williams. Dr Riby's research group has also recently secured just over £7,500 funding from Durham University to produce an adult version of the anxiety booklet (at the request of parents), to host an anxiety workshop in Dublin in 2016 and to distribute the anxiety booklet throughout Ireland and to the US. Furthermore, as part of a £17,000 grant from the Pfizer Foundation with colleagues in Tokyo, the anxiety booklet will be translated and distributed in Japan, with Drs Riby and Hanley presenting this to the Japanese Williams syndrome Associated in Tokyo in 2016.

In September, WS families, practitioners and teachers from all over the UK travelled to the research group's one-day workshop (funded by the British Psychological Society) on Anxiety in Neurodevelopmental Disorders, focusing on Autism and WS. One adult with WS (Jarleth Tynan) was confident enough to address the workshop audience of 90 delegates, talking about his experiences of anxiety, while the parents of another WS adult (Jacqueline Dolan) spoke of how anxiety affects the whole family in all aspects of their daily life. In October, Dr Riby also presented her anxiety work to a meeting of our Italian counterparts and FEWS at a conference in Rome aimed at Harmonising Williams Syndrome in Europe – see a report on that event in the next magazine.

The group's research focuses largely on social-cognitive functioning, and the mental health needs of people with WS. Their work explores social vulnerability (ie. Interacting with unfamiliar people) and understanding how others may be feeling in order to judge how to interact with them socially. Dr Riby explains: "The issues that we explore in our research have everyday significance for individuals with WS and their families. We have been focusing on social behaviours where we know that parents have significant concerns about social approach and vulnerabilities, especially during adolescence and adulthood as independence may increase. Furthermore, the widespread impact of anxiety cannot be underestimated and, therefore, this research is crucial for intervention design to meet the specific needs of those who have WS."

Dr Riby is currently working on more papers on anxiety in WS and, over the next year, her PhD student Emma Lough will be publishing a number of articles around trust behaviours and social approach in everyday situations. They are currently recruiting for several studies on social vulnerabilities (including approach behaviours to strangers and social trust decisions), as well as anxiety and sensory processing. Members wishing to take part or know more can contact the team as follows:

**Social Vulnerabilities Projects –
Emma Lough**
e.f.lough@durham.ac.uk
or **Amanda Gillooly**
Amanda.gillooly@strath.ac.uk

**Sensory Processing in Children –
Magda Glod**
m.glod@newcastle.ac.uk

**For copies of academic publications –
Debbie Riby**
deborah.riby@durham.ac.uk



WS Camp 2015





Membership Form

for the year to 30 September 2016

Membership Details:

Name of WS Member	
Date of Birth	
Current Address	
Telephone Number	
Mobile Number	
Email Address	
Name of Parents / Caregiver	

Membership Fees

2016 Subscription Fees (\$20)	
Donation to NZWSA	
TOTAL	\$

Payment Options (please tick)

Internet Banking Cheque

A receipt will be issued for all monies received.

Internet Option Account number: 020184 0316244 00

Please include the WS member's name as the reference.

Please return this form and cheque if applicable to:

Denise Bray
97A Wheturangi Road,
Greenlane 1051
Auckland



WS Camp 2015

USEFUL WEBSITES

- education.govt.nz
- nzcurriculum.tki.org.nz
- ccsdisabilityaction.org.nz
- kdec.school.nz - **Kelston Deaf Education Center**
- spectrumimages.co.nz
- kiwifamilies.co.nz
- inclusive.tki.org.nz
- kidshealth.org.nz
- up2date.co.nz
- cpag.org.nz - **Child Poverty Action Group**
- parents.education.govt.nz
- ero.govt.nz/Early-Childhood-School-Reports - **Education Review Office**
- educationcounts.govt.nz
- nzcurriculum.tki.org.nz/
- seonline.tki.org.nz/
- youthlaw.co.nz/information/school/special-needs/
- weka.net.nz/ - **What everybody keeps asking**
- ieag.org.nz/home - **inclusive education action group**
- nchenz.org.nz/special-education-needs/
- clickspednz.com/home
- health.govt.nz/your-health/pregnancy-and-kids/services-and-support-you-and-your-child/children-serious-conditions-and-special-needs

INTRODUCTION

The education of your child is one of the most important decisions a parent will make. For parents of a child with a disability these decisions are even more momentous with consideration given to the different educational environments, and the various supports/funding which may be available. This edition of the Networker aims to provide parents and professionals with important information and perspective of the factors involved to enable informed decision making.

Whether parents choose a mainstream or a special school there are policy and legislative requirements guiding education including the following:

- The Treaty of Waitangi
- The Education Act 1989
- The Human Rights Act 1993
- The Health and Disability Commissioner Act 1994 (amended 2003)
- The New Zealand Disability Strategy 2001
- National Education Guidelines - Ministry of Education
- New Zealand Curriculum Framework 2004

The information presented here is up to date at time of publication (December 2015). Please refer to the Ministry of Education website for more detailed or updated information.

We also wish to thank Oaklynn Special School and their families for some of the fabulous photos in this publication.

WHICH SCHOOL IS RIGHT FOR MY CHILD?



For students with a disability there are a variety of environments to choose from – Mainstream (local school), Mainstream with independent Special Unit attached (not part of a Special School), Special School (including Satellite classes), Home schooling and Correspondence School. It is advisable for parents of a child with a disability to start the decision making process early and allow plenty of time to look at all the options to see what suits your child/family best.

Mainstream schools are also commonly referred to as 'local schools', so throughout this publication "mainstream" and "local" are interchangeable terms.

The Education Act 1989 states that every child from the age of five has the right to go to their local (mainstream) school and this right applies equally to children with special education needs. The New Zealand Disability Strategy and United Nations Convention on the Rights of Persons with Disabilities also supports inclusion of children with special education needs at their local mainstream school.

Government is currently reviewing the Education Act.

For example, choosing a mainstream school may offer the advantages of inclusive education (refer Inclusion

Principals later in this publication) at a school nearby and the possibility of socialising with children during (and outside) school hours. There is also generally less travel if your other children are at the same school. This may be an ideal option for some families.

If a student is eligible to attend a special school and parents wish to pursue this option, the benefits may include smaller class sizes and lower student vs staff ratio. Access to specialists, services, therapies and intensive programmes are also available. Generally most students who attend a special school will have ORS funding.

A useful (but not the only) way to gain insight to how a school operates, its policies and the school culture is to seek Education Review Office (ERO) reports. Most schools post their reports on their school website. All schools in New Zealand (including Special Schools) are reviewed by ERO at least once every three years.

MAINSTREAM / LOCAL SCHOOLS

Most children with special education needs will be in regular classes and have extra help provided by the school. An advantage of mainstreaming children with special needs is that it

is a naturally inclusive environment, reflective of the community. Being in the mainstream offers opportunities for children with special needs to learn important life skills, especially socialisation. Mainstream expectations are consistent across the school population which may encourage children with special needs to achieve academically by providing challenges and benchmarks.

The level of experience and professional knowledge of teachers is also a major consideration. Disability awareness and education is a very small component of New Zealand teacher training. Therefore some mainstream teachers may have little experience of disability which could be reflected in teaching and assessment methods, goals and demands on students with a disability.

www.inclusive.tki.org.nz contains useful inclusive practice information for parents, teachers and educational professionals including information on 'Universal Design for Learning'.

Having students with a disability in mainstream can be beneficial to the broader school community in many ways. Statistics reveal one in four New Zealanders have a disability, a large component of which are students at school. Disability informs everyone about diversity. A buddy system can be provided in some schools to teach skills and provide exposure to different learning and social experiences.

Schools must make sure children have a safe physical and emotional environment. If this involves making changes to buildings, the school will work with your local Ministry of Education office to provide this support.

Some parents of non-disabled students report concerns that mainstreaming could lead to children developing negative attitudes about peers with special needs, especially if they feel they are receiving more attention from the teacher and other students. It is expected that all children are included in their school of choice regardless of their needs. Refer to 'What an Inclusive School Looks Like' Ministry of Education document (available online).

Most parents of young children with a disability envisage their child will