

Reach Out

November 2013 Issue 98



Positive
Hope for
Ellyse P9



Elizabeth
Pinkerton
Memorial
Award P7



Happy Tenth
Birthday
Bradley P12

www.atss.org.au

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Australasian Tuberous Sclerosis Society Inc.

Who are we?

The Australasian Tuberous Sclerosis Society is a voluntary organization established in 1981 to connect families affected by Tuberous Sclerosis Complex. There are hundreds of members around Australia, New Zealand and internationally, including families living with TSC and professionals from the medical, caring and education fields.

Our Vision:

That TSC families are empowered through access to information and support.

Our Mission:

As the only Tuberous Sclerosis organization in Australia and New Zealand, we:

- Provide access to current information and resources;
- Help TSC families build relationships and support networks;
- Ensure best practice management and care for TSC affected people in Australia and New Zealand.

Need more information about living with TSC?

More information about Tuberous Sclerosis Complex is available at:

The ATSS website: www.atss.org.au

Tuberous Sclerosis Alliance, USA: www.tsalliance.org

Tuberous Sclerosis Association, UK: www.tuberous-sclerosis.org

Email or call us to get in touch with a volunteer in your area. ATSS has regional contacts throughout Australia and New Zealand that can help you with the challenges of living with TSC and connect you with services and other families in your local area:

1300 733 435 or info@atss.org.au

Not in Australia or New Zealand?

ATSS is a founding member of Tuberous Sclerosis Complex International, a worldwide association of Tuberous Sclerosis Complex organizations.

Tuberous Sclerosis Complex international, www.tscinternational.org

President	Debbie Crosby
Vice President	Kate Norris
Treasurer	Hayley Hill
Membership Secretary	Hayley Hill
Minutes Secretary	David Matheson
Committee Members	Kate Green Janiffer Reynolds
Life Members	Lynn Wilson OAM JP Andrew McKinnon JP
Public Officer	David Matheson
Medical Advisory Board	Dr David Mowat, Clinical Geneticist Dr John Lawson, Paediatric Neurologist
Project Manager	Clare Stuart

Editorial

David Matheson – Editor

One of the most important aims of the Australasian Tuberous Sclerosis Society is to raise awareness about Tuberous Sclerosis Complex. Most individuals and families receiving a diagnosis of TSC have never heard of it and are amazed to discover its wide range of symptoms. Even many medical general practice doctors are unfamiliar with TSC. There is clearly much more work to do in raising awareness about TSC, both in the general community and among the medical profession.

“ATSS aims to inform people of the existence of Tuberous Sclerosis Complex, but also to develop better understanding of the condition within the community”

ATSS is part of Tuberous Sclerosis Complex International (TSCi), a world-wide group of Tuberous Sclerosis Complex organizations. Each year TSCi promotes TSC Awareness Day on 15 May. This year's TSC Awareness Day included the focus 'Where in the world is TSC?' which involved TSC affected people around the globe posting a photo online of themselves or a family member with a sign showing their location in the world. It was a simple but effective way of demonstrating that TSC can affect people from all walks of life and in any part of the world. Many people from Australia and New Zealand posted photographs in the online gallery. A sample of these photos can be seen on page 8 of this edition of *Reach Out*. ATSS also held picnics in a range of locations around Australia and New Zealand on the weekend following TSC Awareness Day. Through these activities ATSS helps to develop connections between people and



also to promote awareness of TSC.

Awareness raising is, however, not an end in itself. ATSS aims to inform people of the existence of Tuberous Sclerosis Complex, but also to develop better understanding of the condition within the community. For families directly affected, it is hoped that they can be educated about the genetics of TSC, as well as the symptoms and treatments. When people are informed about TSC they are empowered to take action to improve the lives of people in their care that are affected by TSC. ATSS also works towards educating medical professionals about TSC, and through this aims to develop better care of affected patients.

Enclosed in this edition of *Reach Out* is the Annual Report of ATSS. This is the first time that the Annual Report has been published separately, with reports previously being printed within the pages of *Reach Out* itself. The Annual Report allows us to communicate with both TSC families and donors about our many activities in 2012-13. We hope that you appreciate this new format and can see the wide-range of achievements of ATSS, and our future goals.

Readers are encouraged to consider contributing to *Reach Out*. All contributions, however big or small, are welcome. It could be a personal experience story, a celebration, a recommendation, or anything that is worth sharing with other readers. Your experiences and insights can be helpful for others in developing their own understanding of TSC. Contributions can be emailed to reachout@atss.org.au or posted to 17 Linksvie Rd, Springwood NSW 2777. If there is a particular topic or theme that you would like to see covered in *Reach Out*, you are also welcome to contact the Editor about your ideas.



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President's Report

Debbie Crosby - President

Welcome to another issue of *Reach Out*. Firstly I would like to congratulate our Project Manager, Clare Stuart, and her family on the birth of their second child, Julian Corry Stuart, who was born on 31st August. Both mum and baby are doing well; Clare will be taking some well deserved leave and returning to work for ATSS in the near future. Clare's leave has placed a few of our activities on hold, including our monthly email newsletter.

The past six months has been very busy and most of our work has been focused on our goal to employ a TSC advisor. A TSC advisor will be there to offer immediate support to families and individuals when they receive a TSC diagnosis. They will be able to provide up to date and accurate information and help direct people to other support services they need. To achieve this goal we are focusing on identifying and planning on how we will attract donations to raise the money needed to employ an additional person to our organisation.

“Your generosity allows our small organisation to support families, provide up to date information and fund medical research.”

Our Annual General Meeting was held in August and it was great to meet some new families and catch up with some of our regulars. Our Annual Report, which is included in this issue of *Reach Out*, is presented in a new easy to read format. The report highlights our achievements for the past financial year, and clearly illustrates how many individuals and families we have supported and the different ways in which we have supported them. It is not until you see these numbers that you realise what a wonderful job our Project Manager and volunteers do. I would also like to thank our donors. Your generosity allows our small organisation to support families, provide up to date information and fund medical research.

Also at our Annual General Meeting the Elizabeth Pinkerton Memorial Award was given to Dr Kate Riney from the Mater Children's Hospital in Brisbane. Kate was able to join us in Sydney to receive the award and it was wonderful to see her dedication in helping children with TSC recognised. Included in the issue of *Reach Out* is one family's story about how Dr Riney and her team have helped their daughter and their family navigate the world of TSC.

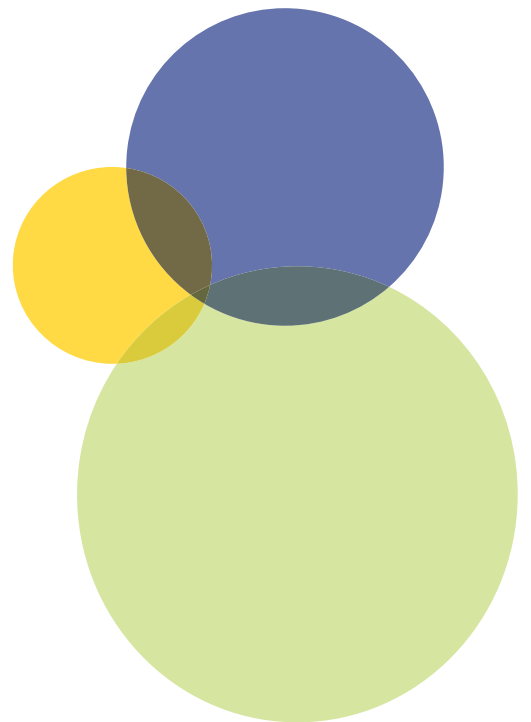
As some of you know from reading our website and receiving our monthly newsletter, ATSS and individual families made



submissions to the Pharmaceutical Benefits Advisory Committee (PBAC) asking them to consider listing Everolimus on the Pharmaceutical Benefits Scheme (PBS), and afterwards Everolimus was recommended for listing. We are now waiting to hear from the newly elected Government on when it will be listed; we will keep you posted.

Finally, I would like to acknowledge and thank the Committee Members and Regional Contacts who have put their hands up once again to volunteer for ATSS for another year. Without them we would not be able to achieve our goals in supporting families and providing information and access to resources. I'd like to acknowledge Sally Nicholson who has stepped down from the ATSS Committee after many years. Sally continues answering the 1300 number and looks forward to contributing to ATSS in the future. I am also grateful for the skills and time of Tania Colman and Dianne Cini, who are helping ATSS with various projects. We are always looking for new volunteers and if you would like to help us even for a short time please contact ATSS through our website.

I hope you enjoy this issue of *Reach Out* and that you can take something from it that helps you face the challenges of living with TSC.



Treasurer's Report



Hayley Hill - Treasurer

ATSS financial accounts of 2012-2013 were audited by Rachel Goddard (ACA). ATSS would like to thank Rachel for volunteering her time once again to audit the accounts. Copies of the financial accounts are published in the Annual report.

This financial year has resulted in a loss for ATSS of \$41,679.94. This is due to progressive payments of funds raised in 2010 and 2011 for the Clinical trial into Topical Rapamycin. This year ATSS paid more than \$60,000 of accumulated funds to support the trial. The last of the significant payments for the trial will occur in 2013-2014 financial year, after which we anticipate the operating profit of ATSS to become positive.

ATSS currently holds the following term deposits:

- CBA - Elizabeth Pinkerton Memorial \$5,000.00
- CBA Term Deposit maturing 19/8/13 \$114,169.18
- Macquarie Term Deposit maturing 8/10/13 \$32,370.71

ATSS held a conference in Western Australia in 2013. Grants were received for this conference that covered all expenses and travel reimbursements.

ATSS had a new website built during 2012 that included a computer program, CIVICRM, that helps with the accounting, membership, emails and event registrations. A grant was received to fully cover the initial costs of this new system. ATSS incurs a yearly fee for keeping this new system secure and up to date.

Travel and accommodation costs are up from previous year due to sending President of ATSS, Deb Crosby, to Naples in Italy for the Tuberous Sclerosis Conference.

Publishing of *Reach Out* has risen slightly due to normal inflation costs of printing and postage.

Donations received during 2012-2013 were from general donors, additional donations made with renewals, as well as proceeds from community fundraising activities that were held throughout the year.

The major fundraising activities that were organised by people throughout the year were:

- Elliott Cunnew, husband to our committee member Sally Nicholson, received \$1,100 in donations from family and friends for competing in a triathlon in Forster, New South Wales.
- A Charity Golf Day was held in January by ATSS Members Caroline Cox and Catherine Catlow with Riversdale Golf Club in Victoria, with over \$6,925 being raised on the day.
- Chris and Julie Graham from Maitland, New South Wales, who are friends of Committee Member Janiffer Reynolds, received \$316 in donations for their Christmas lights display.
- A dance fundraiser was held in Victoria at a dance studio which is owned by a friend of Regional Co-ordinator and Committee Member Narelle Kerr, with donations over \$300 being raised at the event.
- ATSS was lucky to be a one of three winners in the Coles Click for Com-

munity on Facebook this year and received \$1000.

- In May, around the time of TSC Global Awareness Day, I, Hayley Hill, ran a charity day at my local gym with a few of the personal trainers with \$2,500 raised on the day.
- Cassie Ashdown also promoted ATSS within her company's newsletter by making awareness of Tuberous Sclerosis and donations were received.
- On behalf of the Chigioni Family – Intimo Lingerie donated a percentage of sales from a Lingerie party to ATSS.

As you can see from small fundraisers that were held throughout the year, ATSS generously received more than \$13,000 in donations.

The 2013-2014 financial year is off to a great start. During the City2Surf 2013 fun run in August over \$6000 was raised by the friends and families of ATSS team that consisted of Committee Member Kate Norris, Elliott Cunnew, Kate Robinson and Tom Magann.

The money from these fundraising activities and other donations are used to provide the support and information services provided by ATSS to families living with Tuberous Sclerosis throughout Australia and New Zealand. I would like to thank the generous ATSS members and their friends, as without their support ATSS could not continue to grow these services.

I have enjoyed being volunteer Treasurer for another year. Thank You.

ATSS Supporter Renewals

ATSS Supporter Renewals were due on 1 July 2013.

Thank you to all who have renewed since the last issue of Reach Out in May 2013. If you have not paid your renewal you will find a reminder insert in this issue of Reach Out.

Please take the time to update your details, including your email address, on the renewal form. This helps us to inform you of upcoming events and other news in between editions of Reach Out.

You can also renew your support online at www.atss.org.au. Other ways to keep up to date are by regularly checking the ATSS website and by finding us on Facebook.

Membership Report

Hayley Hill - Membership Secretary

ATSS implemented a new website during 2012-2013; this included a computer program CIVICRM, which holds all of the ATSS information on members, professionals and organisations. This program has great benefits for ATSS. It is easy to use with all information stored in one place so that those volunteers and staff who require it can have direct access to all the information.

One of the extra benefits which Clare Stuart, our Project Manager, has been able to use, is creating and emailing our monthly email newsletter to all of our contacts who have provided us with their email address. We hope that you all have liked the new addition of the monthly e-newsletter that keeps you informed of what is happening of late with ATSS news and research.

ATSS continues to produce the newsletter *Reach Out* in May and November of each year. We encourage you to share a story with the TSC Community about your journey with Tuberous Sclerosis.

The ATSS has a Facebook Page that has 217 likes. This page is another way that ATSS can keep people informed with news,

research and information on fantastic events and raise awareness of TSC and ATSS to a wider audience.

Discussions of Australasian Tuberous Sclerosis Society is our peer support Facebook Group that has 251 members. This group is a place where people can share ideas, as well as ask about other people's experiences and advice on issues like sleep and medications. There are always a lot of people sharing and ATSS has had positive feedback that this is a fantastic group so that people all over Australia and New Zealand can say that they are not alone when dealing with TSC themselves, or that of a family member or friend.

Both these pages in Facebook are administrated by Clare Stuart and myself.

The ATSS Committee strives to provide information that is informative and up to date. Feedback and suggestions are always welcomed. If you need any further information please do not hesitate to contact myself or any of the ATSS staff or volunteers.

It has been a pleasure once again to be the volunteer Membership Secretary for ATSS. Thank You.

Committee Changes

At the ATSS Annual General Meeting in August a new Committee was elected. Debbie Crosby was re-elected President. Kate Norris has taken on the position of Vice-President. Hayley Hill will continue as Treasurer and Membership Secretary, while David Matheson remains Minutes Secretary. Thanks to Sally Nicholson, Mary Beijerinck-Gooley and Narelle Kerr who decided not to stand for the Committee this year.

Sally had been a member of the Committee for fifteen years and previously held the position of Membership Secretary. She will continue to support the work of ATSS by answering calls to the 1300 number. Narelle will continue her work as a Regional Contact in Victoria. Congratulations and thanks to all on the Committee for volunteering your time to assist the work of ATSS.



ATSS Seminar Day

What a difference early intervention can make in TSC. At the ATSS Seminar Day held in Sydney on 18 August, Dr Kate Riney gave a touching, inspiring and challenging presentation. She described cases she's managed in which anti-epileptic treatment was given prior to onset of visible seizures, using EEG monitoring, with better outcomes for mental impairment and management plans for her patients.

For TSC patients and families who are older, it was a hard message to receive – what could have been was heavy in the air. Yet it's such a positive message for the future.

Dr Riney is a passionate and caring provider who's proud to have smiling pictures around her of her TSC patients that remind her of what's at stake. ATSS was delighted to award her the third Elizabeth Pinkerton award for her services to TSC in Australasia.

Claire Jennings from Epilepsy Action Australia emphasised the importance of accurate and up to date information to be given to care givers in an Action Plan. It's best if this includes what your seizures look like, and what actions should be taken during and after the seizure. You can create your own Action Plan using the form at <http://www.epilepsyaustralia.net/pdf/Epilepsy%20Management%20Plan.pdf>.

The question to ask when faced with challenging behaviour is not "How do I stop it?" but "What do I want them to do instead?" Autism Spectrum Australia's (ASPECT) worksheet reads like a masterclass good parenting! It was part of Tom Tutton and Anne Joukhadar's presentation designed to help care givers

understand behaviours, their purpose, and then plan interventions that teach new skills and rewards their use. Please contact ATSS if you would like a copy of the materials discussed in the ASPECT presentation.

Feedback for the Seminar Day showed those who attended found it very helpful. We'd love to reach more people. What keeps you from making it to ATSS events? Would on-site experienced childcare assist you to attend? Please email your feedback or comments to: info@atss.org.au



Elizabeth Pinkerton Memorial Award

This award is given annually by ATSS to a health professional to recognise their efforts to improve the lives of TSC affected families in Australasia. Elizabeth (Lizzie) Pinkerton (1984 – 2010) had Tuberous Sclerosis Complex and Polycystic Kidney disease. Lizzie lived a life full of friends, dancing and laughter. She provided inspiration for her family's involvement in ATSS for over 25 years, particularly her mother Sue as President of ATSS.

At the Australasian Tuberous Sclerosis Society's Annual General Meeting in August, the annual Elizabeth Pinkerton Memorial Award was presented to Dr Kate Riney.

Dr Kate Riney is a Consultant Paediatric Neurologist and Epileptologist, Chair of the Queensland Paediatric Epilepsy Network, and Senior Lecturer at the University of Queensland Mater Children's Hospital.

Dr Riney undertook undergraduate medical studies at University College, Dublin, before qualifying as a doctor. She completed her pre-registration house officer post in the Ulster Hospital, Dun Donald, Belfast, before moving to Australia for her first Senior House Officer post. This post involved working for four years in Queensland, with the last two years spent at the Royal Children's Hospital in Brisbane. She joined the Royal Australian College of Physicians as a Paediatric Trainee and completed the FRACP examination in July 2000. At this time she returned to Dublin where she worked at the Children's Hospital, Temple Street, Dublin, in the specialties of Accident and Emergency and Paediatric Neurology.

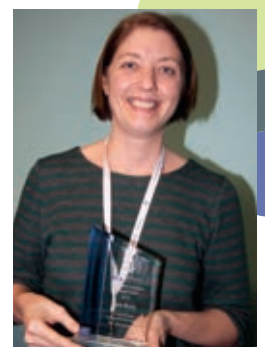
Dr Riney moved to the United Kingdom in 2001, initially working in the Bradford Royal Infirmary, before moving to Great Ormond Street Hospital for Sick Children, London, where she worked in the

Paediatric Neurology Department. She returned to Australia and became a Fellow the Royal Australian College of Physicians in March 2003, but continued post-FRACP training in Paediatric Neurology. Her area of particular interest is epilepsy, and in September 2003 she joined the Institute of Child Health as a Clinical Research Fellow and began a three year PhD research project entitled 'Improving the detection of focal brain abnormality in children with intractable extratemporal epilepsy'.

Dr Riney started the Tuberous Sclerosis Complex clinic at Brisbane's Mater Children's Hospital in recognition of the co-ordination of care required for children significantly affected by TSC. The aim of this clinic is to assist with the diagnosis of Tuberous Sclerosis Complex and to provide and advisory for children affected by complex issues related to TSC.

Dr Riney is highly regarded by her patients, some of whom travel long distances to see her. Besides her busy professional life, Dr Riney is also the mother of two boys.

ATSS congratulates Dr Kate Riney as the recipient of the 2013 Elizabeth Pinkerton Memorial Award.



TSC Global Awareness Day - 15 May



On May 15, ATSS and Tuberos Sclerosis Complex (TSC) organizations around the world to observe the second annual TSC Global Awareness Day. On this day, thousands of individuals and families affected by TSC joined together to increase public awareness of the rare disease and share their stories of hope for the future.

TSC Global Awareness Day is sponsored internationally by Tuberos Sclerosis Complex International (TSCi), a worldwide consortium of TSC organizations of which ATSS is a member.

Part of TSC Awareness Day this year involved Where in the

World is TSC? People around the world uploaded photos to a gallery. Some of the Australian contributions can be seen on this page. To view the gallery go to <http://www.tscglobalday.org/gallery.aspx>

ATSS hosted picnics in a range of locations throughout Australia and New Zealand on the weekend following TSC Global Awareness Day. Picnics were held in Hamilton (New Zealand), Brisbane and Cairns (Queensland), Sydney (New South Wales), Launceston (Tasmania), Melbourne (Victoria) and Adelaide (South Australia). These picnics provided the opportunity to meet and share experiences with other TSC affected families.



Positive Hope For Ellyse

Simon Ludvigh

The way Kate Riney and her team at the Mater Hospital in Brisbane have helped us and our daughter Ellyse is far too hard to put into a few sentences. They have become like a family to us and have done everything they could to ensure our daughter was given the right care at the right time. We travel four hours return trip every month to see Kate and sometimes it has been every couple of weeks; when our daughter was admitted to hospital this trip was daily. At times Kate has realised we have been booked in for certain appointments on different days and she has made sure we got all of them out of the way in the one day although we were not booked in for them. Once when we were at the Mater to see the paediatrician, Kate saw us there and realised we were back in a week for an EEG so she booked us in straight away for the EEG and made room in her busy day to see us while we were there.

“Having a child with TSC can be overwhelming enough, but with the help of Kate and her team we are left with only positive hope for Ellyse.”

Our journey that brought Kate to us was started before Ellyse was even born. From 18 weeks into the pregnancy there was found an unusual measurement in her heart. At 25 weeks Dr Alex Gooi found rhabdomyomas in her heart and told us of Tuberous Sclerosis Complex. At 32 weeks into the pregnancy Ellyse had an MRI and was diagnosed with Tuberous Sclerosis.

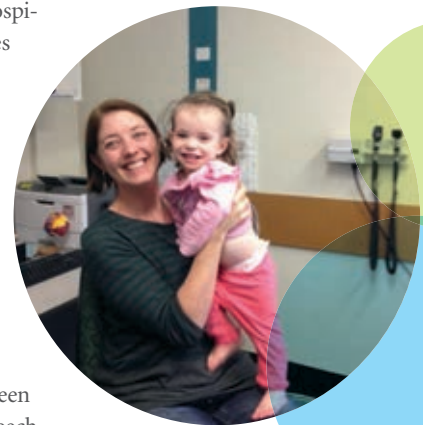
The day Ellyse was born Dr Glenn Gardner performed the procedure and assured us that he would introduce us to Dr Kate Riney. The communication between Drs Alex Gooi, Glenn Gardner and Kate Riney when it comes to TSC would have to be the best in Queensland, and if I may be biased, I would say in Australia. The Mater even set up an outreach program to save distant patients the travel time and allow us to have an appointment at our local hospital, of which we were told Ellyse was the first patient.

The first day we met Dr Kate Riney she assured us that Ellyse had been born at the right time as there was a new program that could possibly help Ellyse and aid in the prediction of any possible seizures. So from day two of Ellyse's life she had her first EEG and then had another every two weeks, which would soon become once a month. At three months-old Ellyse started to



show strange movement in her leg. Gemma used her phone to video the movement and emailed it to the Mater where we were booked in first thing the following morning for an EEG. Ellyse was started on Sabril, and again the frequency of EEGs was increased to monitor Ellyse's brain activity.

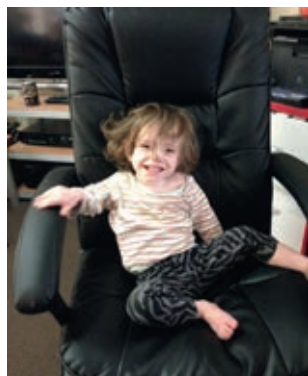
At around seven months-old our visits with Kate after the EEG were not so positive. Ellyse had stopped reaching milestones in her development and we could see a definite change in her usually happy friendly nature; something was not right and we are sure Kate could tell. In late August last year, at seven and a half months, Ellyse had her first infantile spasm. As a parent this was the hardest moment I've ever had to deal with. Within a matter of hours Kate and her team organised a hospital bed for Ellyse and we found ourselves sitting in a hospital room. Once again Kate explained to us what our options were at this stage and started Ellyse on Topamax as well as Sabril. So far to date Ellyse is now 19 months-old and has had no more seizures. There have been issues with her weight; she took a long time to start eating solids, and went for about three months without putting any weight on at all. Thanks to recommendations from Kate we have been able to get Ellyse into physiotherapy, speech therapy and occupational therapy.



Dr Kate Riney with Ellyse

Regular EEG's, I believe, have definitely aided in the treatment and protection of Ellyse's development to allow her the opportunity to have the most positive outlook to her future. Having a child with TSC can be overwhelming enough, but with the help of Kate and her team we are left with only positive hope for Ellyse. I only wish that every parent of children with TSC could be in Kate's care.

Kate definitely shows that the most important thing in your child's life is their health and wellbeing. Kate and her team have definitely become like a family to us, and we are more than happy with the help, care and the attention to detail that this extended family has offered us along our journey, sometimes an emotional journey with Ellyse and her condition Tuberous Sclerosis Complex. Ellyse makes it easy for us as she is the happiest child you have ever met.



Just Between Us

Receiving a diagnosis of autism for your child who already has Tuberous Sclerosis was probably the biggest challenge we faced when our daughter Alana was four years of age. For a child who already had severe seizures and a severe intellectual disability, adding autism to this list was very overwhelming for our family. Autism presents many challenges on a daily basis and although these have lessened as Alana has got older, it still affects our child and our family on a daily basis.

The biggest challenge we face is communication as Alana is nonverbal and is not always able to show us what she wants. With the help of early intervention and ongoing therapy she has improved; however, we have learned that this progress is very slow and many small steps are needed to achieve a goal. We found showing photos to her when she needs to make a choice has helped her communication, and the teachers at her special needs school have played a major role in supporting us with this type of communication.

We always consider ourselves lucky that Alana's behaviour is very good and she is a calm and happy child who likes to socialise with others. This was not always the case and it was very difficult when she was younger to have a "normal" day out. Although things have improved, we always have to plan ahead before we go out and ensure that she will be able to cope with where we are going and what we will be doing. Again, we have learned strategies through a specialist autism therapist to help us, giving us the confidence to try new things and give Alana the same experiences other children have.

Finding information on autism and how to help your child is very difficult as there are so many different points of view and conflicting research. One book that did help was the Australian Autism Handbook by Benison O'Reilly and Seanna Smith. This book was very easy to read and provided really use-

ful information that was relevant to Australia.

Alana will be turning ten years old next month. Looking back from where we are now, it has been a long and challenging journey. The biggest lesson we have learned from our experience with autism is to take one day at a time and celebrate the small achievements.

Deb, Sydney

Normal is Boring - Life with Hamish. Last Sunday morning I woke up with my son Hamish, Spike the cat and a broom in my bed. This was not entirely unusual. Welcome to my world.

Hamish is eight and has Tuberous Sclerosis Complex, which was diagnosed when he was two days old. He has global developmental delays, no formal language yet, and is intellectually somewhere in the region of a two year-old. He also has the face of an angel, an array of very effective communication and charm techniques, and is endlessly funny. While Hamish is not technically autistic as such, he has what are termed "autistic tendencies". These include the lack of speech, lots of happy flapping and a tendency to wander off if given half a chance. Fortunately he is never presented with that chance. Life with Hamish can be challenging at times and not always predictable. I've found that maintaining an open mind and trying to see the humour in situations is essential. His schooling is a great example.

“Hamish's achievements will be different and at his own pace, but no less meaningful.”

Hamish is in his third year at the Port Phillip Specialist School in Port Melbourne. During the term, the school bus arrives to collect him at 8.35 each morning. Hamish loves catching the bus and is loudly greeted by the other kids when he hops on. On his birthday recently the whole bus sang Happy Birthday to him before they set off. They certainly got the attention and a few smiles from the people walking past our house.

At school Hamish is in a class of five children, with a special needs teacher and two assistant teachers. His curriculum consists of art, music, drama, dancing, literacy, numeracy and swimming. In Hamish's class, it also includes Swahili as a second language! Peter the assistant teacher is from Kenya and is teaching Swahili words to Hamish and his classmates. I'm not sure how much Swahili is sinking in with Hamish, but given that his other teacher



...Autism

is from the USA, I'm half expecting him to start speaking Swahili with an American accent.

PPSS is a lovely school and the care and dedication shown by the staff is amazing. Hamish is thriving in this environment. His sense of humour and love of silliness is encouraged, even if it involves him throwing all of the class teddy bears out the window or getting soaked in water during sensory play. When I arrive to collect him in the afternoon he is always happy and draws out the leaving process as long as possible. This routine includes giving each of his teachers a good bye pat on the face and trying to sneak out the door with whichever toy he happens to be playing with. By the time I've chatted to his teachers, extracted Hamish and said hello to the other parents, it is often a case of the long good bye.

Schooling is the area where I find the greatest contrast between Hamish and his fifteen year old brother Alex. Alex is in Year Ten at an all boys school where he has recently discovered a passion for mathematics and sciences. He has just chosen his Year 11 VCE subjects and is hoping to do astrophysics at university. Whilst Hamish and I both love his school, it saddens me sometimes that he will never have the same sort of experiences that Alex is enjoying. On the other hand, Hamish will never have the sort of pressures that his brother is facing, such as exams, entrance scores, and many of the other tribulations of being a teenage boy. On a purely selfish level, I will only have to go through the drama of a son doing VCE once. Hamish's achievements will be different and at his own pace, but no less meaningful.

At home Hamish loves to potter in the garden, sort through his toys, play on the iPad and snuggle. The obedience he shows to his teachers usually magically disappears at home, where it is replaced by what I call selective deafness. Which is not to say he is naughty. He's a very chilled little boy, but has plenty of attitude and is very good at getting his own way. He's also a master of passive resistance. When bedtime rolls around he won't kick and scream if he's not tired. Instead he will walk with me to bed, but gradually sink to his knees, then onto his hands and knees, then finally onto his tummy in the manner of a reluctant snake. Hamish thinks this is hilarious. Once he's finally slithered into bed he usually goes to sleep pretty quickly. The nights when he decides he doesn't want to sleep can be interesting. He will either very calmly come out of the bedroom again and again to show me that he's still awake, or he'll quietly and efficiently pull everything out of the cupboard and scatter it across the room. I personally prefer the first option.

Like many developmentally delayed children, Hamish goes through phases of being fixated on a particular toy or domestic item. The egg whisk is a perennial favourite and the dish brush also frequently goes missing. He also has a number of locations around the house where he "posts" items. Fortunately he realises that car keys, mobile phones and sunglasses are off limits. Luckily, Hamish also loves food and will try almost anything. His tastes actually run to the quite exotic. He prefers camembert and quince



paste on water crackers to Twisties and loves anything spicy. However, chocolate and ice cream are his first loves, so in that respect he's much like all eight year old boys.

Which brings me back to waking up with Hamish, a broom and a cat. The broom is his latest fixation. He drags it across the floor, swings it around and takes it with him to his thinking spot on top of the step ladder, where he sings to it. He loves it so much at the moment that he brought it into bed for a cuddle. Along with his opportunistic cat Spike. Which pretty much sums up life with a child such as Hamish. It's nothing if not interesting. Sometimes frustrating and occasionally sad, but over-all funny and very happy, in a slightly demented sort of way.

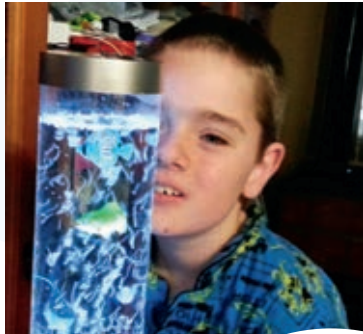
Kate, Melbourne

Just Between Us: Next Issue

The next issue of *Reach Out* will include a feature on genetic testing. We would welcome your comments and experiences, however short or long. You can email reachout@atss.org.au or visit the Discussions of Australasian Tuberous Sclerosis Society Facebook page.

Celebrations

Want to share your family's news, milestones or triumphs? We'd love to hear your stories and share them with others on this page. Email info@atss.org.au, write to us or call us on 1300 733 435.



Bradley with his sensory tube



Happy Tenth Birthday Bradley

Bradley hit the double digits on 7th August this year. His tenth birthday was stretched with three birthday parties. Brad enjoyed all the celebrations with two cakes on his actual birthday, one at school with his class and teachers, followed by a family birthday dinner at McDonalds, and then a barbecue/party at Nurranginy Reserve on the weekend with family and friends. He had a fantastic time playing bubbles, going on the play equipment, riding his scooter and hitting the pirate ship piñata. Bradley enjoyed clapping to Happy Birthday and of course eating his cakes and lollies.

Bradley is now is Year 4 at William Rose School at Seven Hills, which is a special school. He loves school and is learning to count to ten with cards and objects. Brad loves to use the iPad and interactive whiteboard for many activities, like matching and learning the alphabet. He loves the gym and sports activities as well.

One of the birthday presents Brad received was a sensory tube. He absolutely loves it as you can see from his picture.

Bradley has small daily seizures which are still uncontrolled although he is on medication. He is non-verbal, developmentally delayed, has autistic tendencies and some minor behaviour problems, but among the challenges that he faces Brad always seems to put a smile on our faces with his energy and smile.

Glad you enjoyed your tenth birthday Bradley.
David & Hayley Hill

Amelia's 17th Birthday

On Anzac Day this year, Amelia turned 17. Time flies and while those 17 years haven't all been easy, the last seven have definitely been easier than the first ten.

Amelia's speech is far more developed than I guess we ever thought it would be; this and vastly improved seizure control has made life easier over the past years. Amelia is a delightful girl with a winning personality who seems to enjoy every day of her life.

While she sounds perfect, she could definitely work on improving her independence skills! It's a dream of mine that one day she will be able to dress herself, wash, dry and brush her own hair, and tie shoelaces but I guess in the overall scheme of a child with TSC, we also have a lot to be grateful for.

Amelia is in Year 10 of an IO class for students with moderate intellectual disabilities at Cromer High School and finishes there this year. She is moving to Freshwater Campus for Years 11 and 12 where they will work on life-skills and getting her ready for an appropriate TAFE program.

She is very excited about the change to a more adult environment and she will be making the move with three good friends from her class, which should make the transition less stressful and hopefully a positive experience. I would love it if she could be travel trained and catch the bus to school but will take things one step at a time. She loves a bus trip so I fear she'd just stay on the bus to the end of the line.

Amelia celebrated her birthday with family and some close friends. The girls played laser tag against Dad and Lachie, and then back to our place for some musical chairs, games and cake.

Sally Nicholson



Amelia and Stanley



Research News

Clare Stuart

Research continues into the use of mTOR inhibitor medicines to treat Epilepsy in TSC

A recently published study by researchers at Texas Children's Hospital, Baylor College of Medicine and Cincinnati Children's Hospital has shown promising results in a small number of TSC patients being treated with Everolimus for epilepsy. Everolimus is an mTOR inhibitor medicine and is also known as Afinitor. The publication of this paper resulted in some positive media coverage, especially in social media.

Krueger, D.A., et al., Everolimus treatment of refractory epilepsy in tuberous sclerosis complex. *Annals of Neurology*, June 24, 2013.

This study only included 20 patients and did not include a comparison group; that is, all 20 patients were treated with Everolimus. The next step is a larger, worldwide clinical trial called EXIST-3. Four Australian neurologists are involved in the study and we expect there to be study sites in Sydney, Melbourne and Perth. If you would like more information about this study you can speak to your neurologist or contact ATSS.

If this larger study shows positive results, this new medicine may be approved in the future to treat epilepsy associated with Tuberous Sclerosis Complex in Australia and New Zealand.

ATSS welcomes PBAC recommendation for Everolimus

The first ever medicine specifically for Tuberous Sclerosis Complex (TSC) has recently been recommended for inclusion on the Pharmaceutical Benefits Scheme (PBS), making it accessible to TSC affected individuals.

One of the difficult to manage symptoms of TSC is a type of brain tumour called a subependymal giant cell astrocytoma (SEGA). Up to 15% of individuals with TSC will develop a SEGA. SEGAs mostly grow from late childhood and the chance for growth greatly decreases after the mid-20s. Although they are not cancerous, SEGAs can be problematic because they may grow sufficiently large to block the flow of fluid within the brain, causing an increase in the pressure within the

head and enlargement of the fluid-filled ventricles (a process known as hydrocephalus). This build-up of pressure can result in symptoms such as vomiting, nausea, headache, and changes in appetite, behavior and mood. If left untreated, hydrocephalus can lead to death. You can read more about SEGAs on the ATSS website: www.atss.org.au/i-need-to-know-more/signs/brain/

Up until the approval of Everolimus by the Therapeutic Goods Administration (TGA) in early 2012, brain surgery was the only treatment option for large SEGAs. Listing of Everolimus on the PBS will make this much needed second option affordable for those patients and their families that require this treatment.

ATSS welcomes the decision by the Pharmaceutical Benefits Advisory Committee (PBAC). We have written to the Federal Minister for Health to encourage him to authorise the listing as soon as possible. We thank the many families who contributed to this success by participating in clinical trials of this medicine, by making submissions to the PBAC, and by supporting ATSS in our advocacy work on this issue. We also continue to monitor the accessibility of mTOR inhibitors in New Zealand and would welcome contact from any families in New Zealand who may be experiencing difficulties accessing these medicines.

Publication of newly updated clinical consensus guidelines for the diagnosis, surveillance and management of TSC

The newly updated clinical consensus guidelines for the diagnosis, surveillance and management of tuberous sclerosis complex (TSC) have been published. This major revision reflects the significant medical advances since the first guidelines were published in 1998.

To communicate the recommendations to healthcare professionals, the October issue of *Pediatric Neurology* includes two peer-reviewed papers detailing the new guidelines – one entitled, "Tuberous Sclerosis Complex Diagnostic Criteria Update: Recommendations of the 2012 International Tuberous Sclerosis Complex Consensus Conference" and the other, "Tuberous

Sclerosis Complex Surveillance and Management: Recommendations of the 2012 International Tuberous Sclerosis Complex Consensus Conference."

Darcy A. Krueger, MD, PhD, of Cincinnati Children's Hospital Medical Center, and Hope Northrup, MD, of The University of Texas Medical School at Houston, wrote both papers in *Pediatric Neurology*. Drs Krueger and Northrup served as co-chairs of the 2012 International TSC Consensus Conference, which involved 79 TSC experts from 14 countries to develop the new guidelines. Dr David Mowat, ATSS Medical Advisor, was selected to participate in the genetics committee.

An article published in *Reach Out* in May 2013 describes the changes made to the diagnostic criteria for TSC. The surveillance and management guidelines include recommendations applicable at the time of initial diagnosis and also for follow up care. You can find detailed information about the guidelines, including links to the journal articles, on the ATSS website. ATSS is working with other TSC organisations around the world to promote these guidelines to health professionals, and to provide easy to understand information for TSC families about the guidelines.

Northrup, H., et al., Tuberous sclerosis complex diagnostic criteria update: recommendations of the 2012 international tuberous sclerosis complex consensus conference. *Pediatric Neurology*, October 2013.

Krueger, D.A., et al., Tuberous sclerosis complex surveillance and management: recommendations of the 2012 international tuberous sclerosis complex consensus conference. *Pediatric Neurology*, October 2013.

Research webinar recordings now available

If you would like to keep up to date with the latest TSC research news and hear directly from leading clinicians and researchers, the TS Alliance's research webinar series is a great resource.

Recordings are available at: www.tscinternational.org/pages.aspx?content=13

Researchers Share Cutting Edge Data at International Research Conference on TSC and Related Disorders

This article was written by Steven L Roberts, PhD, Chief Scientific Officer for the TS Alliance in the United States of America. It has been adapted with permission by Clare Stuart, ATSS Project Manager.

The Rothberg Institute for Childhood Diseases, in collaboration with the TS Alliance, presented the 2013 International Research Conference on TSC and Related Disorders: Molecules to Medicines, on June 20-23, 2013, at the Omni Shoreham Hotel in Washington, DC. Clare Stuart, ATSS Project Manager, was funded by Tuberous Sclerosis International (TSCi) to attend the conference and to co-chair the adjoining TSCi meeting.

Nearly 200 researchers, clinicians and other professionals attended this successful and productive conference. Feedback from attendees included, "One of the best meetings for my professional development," "Excellent opportunity for networking," and, "It was my first TS Alliance conference, and I felt very, very welcomed." The conference demonstrated that TSC research benefits from a passionate and collaborative research community that is excited about working towards better treatment and, one day, a cure for TSC.

The program featured oral presentations covering a variety of basic and clinical research, along with a poster session and working groups. The conference's opening session revealed new data on multiple cellular mechanisms that impact mTOR activity, which is elevated in TSC. Some of these mechanisms are associated with drugs being tested in animal models of TSC. The conference's keynote address by Dr Mustafa Sahin of Boston Children's Hospital discussed how alterations in connections between neurons in the brain of individuals with TSC may be responsible for the neurological and neuropsychiatric problems that so frequently occur in TSC. A session on clinical studies covered lessons learned from past clinical trials in TSC and ideas for future clinical trials in TSC. The session on genetics revealed that no third gene has yet been identified to cause TSC and that many individuals in whom mutations could not be identified are now

being found to be mosaic for TSC1 or TSC2 mutations, meaning only some of those persons' cells carry mutations. The final two sessions of the conference discussed both animal models and clinical data, from which we are learning more about the TSC disease process and how we might identify new treatments or how we might more effectively deliver care using existing treatments. Working groups held during the conference enabled attendees from all different backgrounds to tackle specific questions or problems, including how to achieve the best comprehensive clinical care for individuals with TSC, and how to utilise and develop a biobank of tissue and blood or urine samples from people with TSC. The conference also included time for interactive panel discussions on ways to approach and interact with industry and on services

available from the National Center for Advancing Translational Sciences, the newest division of the National Institutes of Health, USA. Most participants reported in a survey following the conference that they envision new collaborations arising because they attended this meeting. In this and many other ways, the conference was a big success for TSC research efforts.

ATSS would like to recognise the ongoing work of the TS Alliance in driving the international TSC research programme. We thank them and other conference sponsors for organising this conference.

Clare Stuart has written about some of the interesting themes emerging in the conference presentations at www.atss.org.au/news. Clare also presented on this topic to the 2013 Seminar Day held in August in Sydney.

Tuberous Sclerosis

International (TSCi) is the worldwide association of Tuberous Sclerosis Complex organisations. A face to face meeting of TSCi

delegates was held in Washington in June, immediately prior to the research conference. Clare Stuart, a member of the TSCi working group, worked closely with Katie Smith from TS Alliance to co-chair this meeting of over 20 delegates.

The meeting included a discussion of the best ways to promote the International TSC Clinical Consensus Conference Recommendations. Several projects, including a series of webinars, have been identified and will be worked on over the coming year. Ideas for 2014 TSC Global Awareness Day were shared – keep an eye out for more details of this annual event via ATSS's email newsletter and facebook over the coming months. Other areas that TSCi members will collaborate on in 2014 include access to topical mTOR inhibitors for angiofibromas and the promotion of co-ordinated clinic care of individuals with TSC.

ATSS was a founding member of TSCi and we work closely with other members of TSCi, with whom we share many of the same goals and challenges. You can find out more about Tuberous Sclerosis International at www.tscinternational.org.

Changes to the Diagnostic Criteria for Autism Spectrum Disorder

With the recent arrival of the DSM–5, there have been changes to the way that Autism Spectrum Disorder is being diagnosed. Below is a summary of the changes and the potential effects of these changes.

How is Autism Spectrum Disorder Diagnosed?

When diagnosing Autism Spectrum Disorders, clinicians and diagnosticians use a number of measures to determine whether or not an individual meets the criteria for a diagnosis. They may conduct observations, take a developmental history, and assess the individual's communication skills, social and play skills, adaptive behaviour, and cognitive skills. Usually a number of professionals are involved in the diagnosis, including a paediatrician or psychiatrist, a psychologist, and a speech pathologist, and all come together to make a diagnosis based on their individual areas of expertise.

One of the items in a diagnostician's tool kit is called the Diagnostic and Statistical Manual of Mental Disorders (or DSM for short). The DSM is a publication published by the American Psychiatric Association, and includes the diagnostic criteria for many different conditions, including those on the autism spectrum. In May 2013, the fifth edition of the DSM was published, and in it there have been some changes to the diagnostic criteria for ASD.

Why have the criteria in the DSM changed?

The DSM is revised periodically to bring it more into line with current research and practice. As new evidence about a condition comes to light, the manual needs to change so that the criteria in it more closely reflect new understanding of the condition, in line with how clinicians in the field are currently diagnosing individuals with various conditions. The fourth edition of the DSM (the DSM–IV) was published in 1994, and since this time there have been many studies conducted and thousands of articles published to give us a greater understanding of the disorder.

The changes that have been made to the diagnostic criteria in the fifth edition were based on expert advice from clinicians and researchers in the field. The proposed criteria were open for public discussion and underwent a number of revisions before the final criteria were settled. The criteria as they appear in the new edition are thought to better capture how we currently conceptualise Autism Spectrum Disorder.

What are the changes?

The first and most important change is that the discrete (separate) disorders that were introduced in DSM–IV under the category of 'Pervasive Developmental Disorder', or PDD (ie Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder – Not Otherwise Specified) will now be replaced by a single diagnostic term: Autism Spectrum Disorder.

The individual's *current* level of symptom severity also forms part of the diagnosis, and the new criteria bring a recognition that this can change over time, or in different contexts. These are:

Level 1	Requiring support
Level 2	Requiring substantial support
Level 3	Requiring very substantial support

This brings us to the other significant change to the criteria. The traditional 'triad of impairments' (impaired social reciprocity, impaired language/communication, and restricted and repetitive patterns of interests/activities) has been collapsed into two 'domains':

1. Social communication deficits
2. Restricted interests and repetitive behaviours

Social and communication deficits have been merged into a single category to reflect their interrelatedness.

The changes are depicted in the figures below.

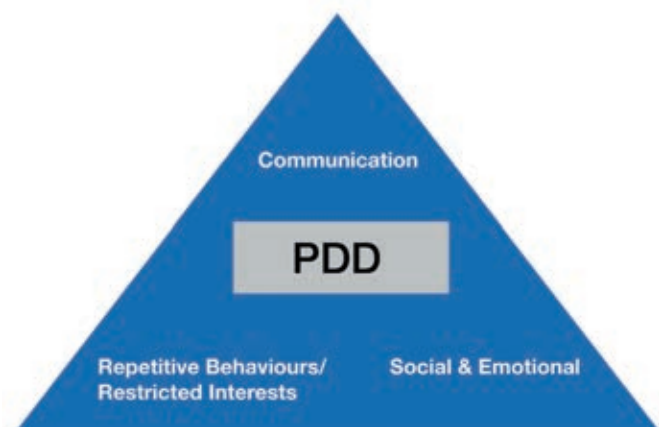
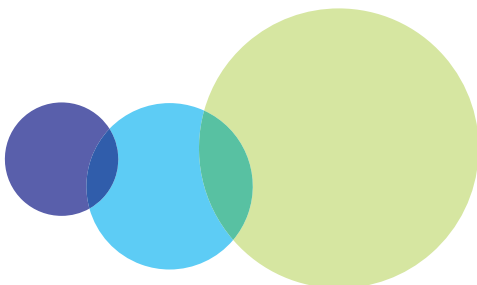


Figure 1—Pervasive Developmental Disorder (DSM–IV)



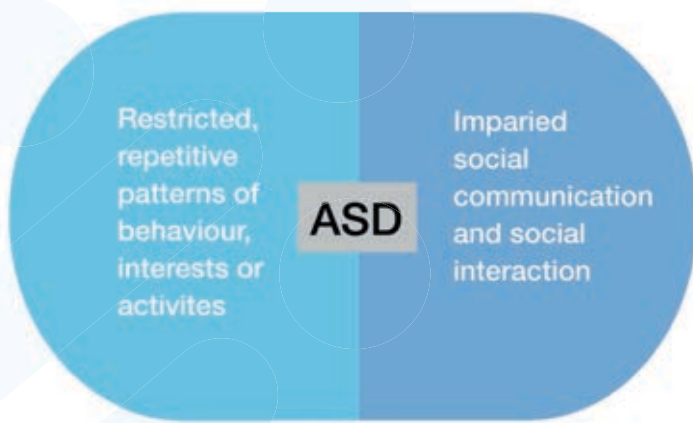


Figure 2— Autism Spectrum Disorder (DSM-5)

There are severity descriptors for both domains for each of the 3 levels.

The new criteria acknowledge that while symptoms must be present in the early years of life, they may not become fully evident until the individual is faced with social demands that exceed their coping capacities (such as when they start school and need to work with peers).

Other changes include recognition of the sensory difficulties and differences experienced by many individuals with ASD, the removal of a delay in language development as a factor in diagnosis, and an ability to officially diagnose another disorder (such as Attention Deficit Hyperactivity Disorder) in addition to ASD.

What do the changes mean?

There is much debate about what these changes will mean for individuals with ASD. A number of studies were conducted in the lead up to the release of the new criteria, to see if people who met criteria under DSM-IV would still receive a diagnosis under the new criteria. Results varied considerably with some studies suggesting around 40% of people would no longer meet criteria, and others estimating a much more conservative figure of around 5–10%. The studies varied widely in their estimates, partly due to the fact that they used different methods to come to their conclusions.

“The changes that have been made to the diagnostic criteria in the fifth edition were based on expert advice from clinicians and researchers in the field.”

It is unlikely that we will know the real extent of the changes until we see how diagnosticians in Australia start using this tool. It is expected that some people with less severe symptoms, such as some people with PDD-NOS or Asperger Syndrome (referred to in DSM IV as Asperger’s Disorder) who met criteria under DSM-IV might not receive a diagnosis of ASD under the new criteria. This could have implications for service delivery.

Generally, people with a DSM-IV diagnosis will not need to be reassessed. Similarly, individuals with a diagnosis of Asperger Syndrome don’t need to give up their ‘label’ if it is something they identify with.

“It is unlikely that we will know the real extent of the changes until we see how diagnosticians in Australia start using this tool.”

Some people who don’t meet the new criteria for ASD may meet criteria for a new diagnosis – Social Communication Disorder. Social Communication Disorder is not an ASD, but it does include some of those social communication difficulties that are common in ASD, such as impairments in the social use of verbal and nonverbal communication, and difficulties with the pragmatics (practical use) of language. Social Communication Disorder is distinct from ASD as there is an absence of the required number of fixated interests and repetitive behaviours to meet criteria for ASD.

It is as yet unknown whether individuals who meet criteria for Social Communication Disorder will be eligible for funding assistance and support.

DSM-5: The final word?

The DSM is a living document that reflects current knowledge and understanding. Current thinking has moved a long way from the diagnoses of ‘childhood schizophrenia’ or ‘infantile autism’ that were described in previous editions, and as we learn more about Autism Spectrum Disorder, future editions of the DSM will continue to adapt to meet our ever increasing knowledge of the condition.

More information:

Olga Tennison Autism Research Centre (OTARC):
<http://www.latrobe.edu.au/otarc/info/dsm-changes>

Positive Partnerships:

http://www.autismtraining.com.au/orionfiles/upload/public/files/Fact%20Sheet%2010_DSM-5_04_07_12.pdf

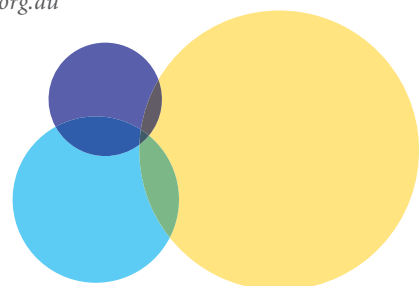
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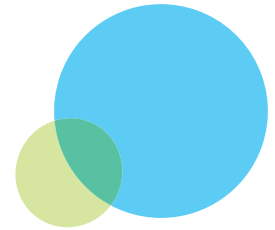
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Huerta, M., Bishop, S. L., Duncan, A., Hus, V. & Lord, C. (2012). Application of DSM-5 criteria for autism Spectrum Disorder to three samples of children with DSM-IV diagnoses of Pervasive Developmental Disorders. *American Journal of Psychiatry*, 169, 1056–1064.

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www.amaze.org.au



Autism Resources



Tips to use with children

Be consistent

Children with autism have a hard time adapting what they've learned in one setting (such as school) to others, including the home. For example, your child may use sign language at school to communicate, but never think to do so at home. Creating consistency in your child's environment is the best way to reinforce learning.

Stick to a schedule

Children with autism tend to do best when they have a highly-structured schedule or routine. Again, this goes back to the consistency they both need and crave. Set up a schedule for your child, with regular times for meals, therapy, school, and bedtime. Try to keep disruptions to this routine to a minimum. If there is an unavoidable schedule change, prepare your child for it in advance.

Use Visual Strategies

Children with autism are often visual learners and thinkers. Develop a visual schedule, review it throughout the day and mark off activities as they are completed. Use words, pictures, symbols, or a combination to get your message across.

Catch Them Being Good

Provide praise and/or rewards when you see good behaviour. This is one of the best ways to motivate your child to repeat the desired behaviour. Provide the positive reinforcement as soon as possible after they complete the activity. Be specific when praising your child; tell them exactly what they did well. For example "Great job putting your toys away!" or, "I like the way you're staying with me."

Know Your Environment

Children with autism spectrum disorders may have very little awareness of common danger. Watch out for excessively noisy or crowded environments that could overstimulate your child and cause unwanted behaviour. Be attentive to your child's behaviour and tendencies that may be dangerous.

Use Your Child's Special Interests

Allow for special interests, such as: trains, cars, movies, dinosaurs, etc. These can be used as motivators/reinforcers for positive behaviour. Let them know that after they pick up their toys, they can watch their favourite show. If you are working on conversational skills, use their favourite area of interest as the topic of conversation.

Use social stories

Social Stories explain what will happen in different situations. Write a social story about a new situation coming up soon, such as going to a different place, and read this with your child over a few nights and weeks. Pictures can also be used to illustrate social stories.

Websites to Explore

Autism Spectrum Australia (Aspect)

- www.aspect.org.au

Amaze (Autism Victoria)

- www.amaze.org.au/

Department of Families, Housing, Community Services and Indigenous Affairs - Helping Children with Autism

- www.fahcsia.gov.au/autism

Autism Noticeboard

- www.autismnoticeboard.com.au/

Autism Awareness

- www.autismawareness.com.au/
- www.facebook.com/AutismAwarenessAustralia

Australian Advisory Board on Autism Spectrum Disorders

- www.autismadvisoryboard.org.au/

Australian Autism Aspergers Network

- www.aaanetwork.com.au/

Raising Children Network

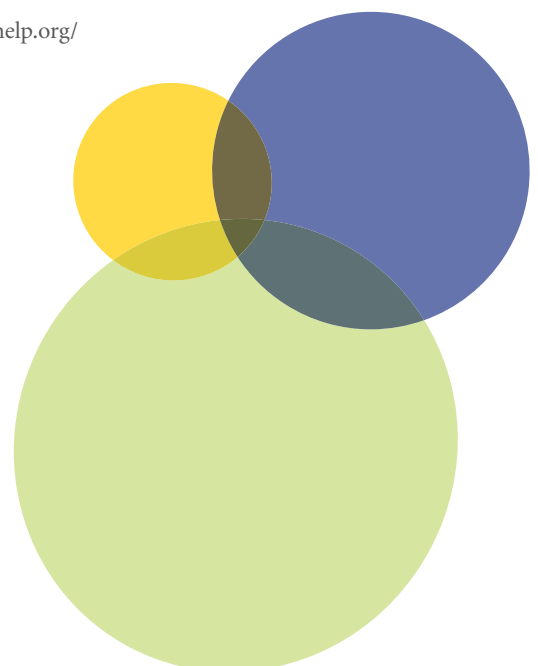
- www.raisingchildren.net.au/autism

Positive Partnerships

- www.positivepartnerships.com.au

Autism Help

- www.autism-help.org/



Fundraising Thank You

Romios Family Raises over \$25,000 for Tuberous Sclerosis Research

Kristian Romios was diagnosed with TSC in 2012 when he was seven weeks old. His family and friends were inspired by his fighting spirit to raise more than \$25,000 to fund a TSC research project at Royal Children's Hospital in Melbourne. The fundraising included online donations, an auction, and Kristian's dad, Kon, shaving his head.

The funds will continue the work of Dr Simon Harvey and his team in understanding which parts of the brain cause a seizure to start. This knowledge helps to refine the approaches used in brain surgery for infants and children with TSC and epilepsy that cannot be controlled by medication.

There is some debate between researchers over which parts of the brain cause a seizure to start. The RCH team's previous work has highlighted the role that cortical tubers play in starting seizures; other groups suggest that surrounding brain tissue may also play a role.



Kristian Romios

With this funding, and in conjunction with their neuroscientist colleagues at the Florey Neurosciences Institute in Melbourne, the RCH team will examine resected tuber tissue to better understand how they cause seizures. This will include in vitro electrophysiological studies and ultrastructural imaging studies. Work to date suggests that seizures arise from the centre of some tubers, and this may allow surgery to be focused to a smaller part of the brain.

Joanne and Kon Romios would like to say thank you to everyone who supported the cause- family, friends, and even complete strangers who donated and shared their message around Facebook, helping to raise further awareness about TSC. They would also like to acknowledge the Neurology, Neurosurgery and nursing teams at the Royal Children's Hospital for their fantastic care.

Congratulations to Joanne, Kon, your family and friends for this amazing effort.

Sydney Gym Raises More Than \$2,500 for ATSS

The brainchild of Hayley Hill, ATSS Treasurer, Genesis Gym in Blacktown, New South Wales, held a fundraising event on 23rd May. The event included personal training sessions offered for a donation, a fantastic raffle and sponsorship of some of the trainers to do their first ever Zumba class.

The day was made possible by:

- Genesis Gym, who hosted the event;
- Personal Trainers Kevin Bartley, Rebecca Napier and Navid Alaei, who gave up their day to train people in exchange for a donation;
- Zumba Instructor, Elena Macnamara, from Macs Fitness, who hosted a Zumba class for the personal trainers and others who made a donation;



Hayley and trainers

- The many companies who donated raffle prizes: Genesis Gym Blacktown, Star Shots at Caringbah, Caltex Energy NSW, Playtime Blacktown, Napoleon Blacktown, Imax Theatre, Outback Steakhouse Parklea, Hoyts Blacktown, AMF Bowling Blacktown, Sharon Sparks, Glow Meat – Arncliffe Park, and Gloria Jeans Coffee Blacktown.

Thank you to all of these people and companies who got behind this local event. And a big thank you to Hayley Hill for your passion and commitment to ATSS. Both Hayley and her son Brad have Tuberous Sclerosis.

The event raised \$2,668 – a wonderful result!

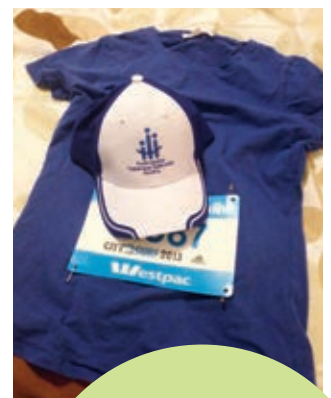
ATSS City2Surf Team Raises \$6,500

Sunday, 11 August dawned sunny and the crowd was bouncing to the start. The Sydney City2Surf 2013 was a first go for ATSS using the EverydayHero online fundraising interface. It was a great success, with the small team raising around \$6,500 in donations for their run. Kate Robinson ran the 14km from Hyde Park to Bondi Beach in 80 minutes, Tom Magann in 82 minutes and Kate Norris in 88 minutes.

A big thank you to our ATSS team of runners and to our wonderful donors!

Our EverydayHero account enables ATSS to fundraise easily through a variety of fun runs and events around Australia.

<http://www.everydayhero.com.au/home/events>



We'd love to support your fundraising effort for ATSS. Contact ATSS well ahead of your event so that we can ensure the event is not only successful and fun, but also legal and safe.

Supporters and Donations

1st October 2012-14th April 2013

ATSS Champions	Silver Supporters & Donations	Bronze Supporters & Donations	General Donations
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Calendar of events

2 November 2013	ATSS Committee Meeting
23 November 2013	Seminar with Dr Chris Kingswood, Melbourne
18 May 2014	ATSS National Picnic Day
Late 2014	ATSS Family Conference, New Zealand
August 2014	ATSS Seminar Day, Sydney

To find out about upcoming ATSS events, sign up to our monthly email newsletter at www.atss.org.au

ATSS Brochure

We're increasing awareness of TSC and ATSS with a new brochure. The brochure has been printed at a discount by SGK Print, a Queensland based printing business run by a TSC family <http://www.sgkprint.com.au/>. We thank them for their ongoing support. If you would like some brochures to distribute in your area, please contact ATSS.