



Farewell to Sue Pinkerton P7

Knowledge Gained P9

> A Positive Outlook P13-14

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 medical, caring and education fields.

Our Vision:

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;

Need more information about living with TSC?

The ATSS website: www.atss.org.au

throughout Australia and New Zealand that can help you with the challenges of living with TSC and

1300 733 435 or info@atss.org.au

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

President Debbie Crosby

Vice President Vacant

Treasurer Hauley Hill Membership Secretary Hayley Hill

Minutes Secretary David Matheson

Committee Members Mary Beijerinck-Gooley

Kate Green

Narelle Kerr

Sally Nicholson

Kate Norris

Janiffer Reynolds

Life Members Lynn Wilson OAM JP

Andrew McKinnon JP

Public Officer David Matheson

Medical Advisory Board Dr David Mowat,

Dr John Lawson, Paediatric Neurologist

Project Manager Clare Stuart



Editorial

David Matheson - Editor

ife has a way of bringing the unexpected to us. If we sat down as a young adult and listed the things we expected to do in our lives for the next, say, twenty years, then wrote a list twenty years later of the things we actually did do, for most people there would be some things the same, but also quite a few differences. We reach some goals, but things that we had never imagined happening end up being part of our lives. The differences can be experiences we treasure, but also significant challenges.

Unexpected events happen to everyone, but are a particular part of the lives of families affected by Tuberous Sclerosis Complex. The vast majority of those receiving a diagnosis of TSC have never heard of it before. They may be an individual whose life has suddenly taken a strange twist involving possible health problems and genetic complications, or parents of a newly diagnosed child who now face an uncertain future with a whole range of potential medical issues. Negotiating life with TSC is not what we expected to be doing. It is tempting to think, "This is not what I signed up for."

Yet, despite living with Tuberous Sclerosis Complex not being what we planned, most people manage to successfully adapt their lives to whatever it brings. It can be quite traumatic initially, but after some time life falls into a new rhythm. TSC was not what we imagined, yet somehow we find a way to live in a different way and meet the challenges with our best efforts.

The Australasian Tuberous Sclerosis Society has provided support to people affected by TSC for many years. A large number of these people find the support invaluable in the early stages soon after a diagnosis as they adjust to their unexpected life. Often there is less need for support as time goes on and they have adapted to living with Tuberous Sclerosis. It still continues to present challenges, but it is not as overwhelming as the initial stages.

ATSS also has to adjust to new challenges. Sue Pinkerton, who led and guided the Society for nearly two decades, is no longer President. Sue helped the Society to grow and has enabled it to provide a wide range of services to meet the needs of

those living with TSC. She will be missed by all those who have been supported by her work for ATSS. But the Society will now continue under the leadership of incoming President Debbie Crosby. Fortunately Sue has provided a sound basis for the Society to move forward. ATSS will continue to support families as it moves in new directions.

This issue of *Reach Out* contains the annual reports of ATSS. They show the many and diverse activities of the Society over the last twelve months. Also in this edition are three different personal experience stories that show how different families have adapted to the life that TSC has brought them. I hope that in the pages of Reach Out you find something that will help you deal with the unexpected challenges of living with Tuberous Sclerosis Complex.

TSC was not what we imagined, yet somehow we find a way to live in a different way and meet the challenges with our best efforts.



Tuberous Sclerosis Complex

A Worldwide Organization

of Tuberous Sclerosis Complex Associations

Reach Out: Official journal of the Australasian Tuberous

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President's Report

Report presented to the Annual General Meeting, 12 August 2012

Sue Pinkerton - President

It is with both pleasure and pride that I present the President's Report to the 31st Annual General Meeting of the Australasian Tuberous Sclerosis Society.

This past year has witnessed the most extraordinary developments in the ATSS. Following a very busy and successful year in 2011 when over \$200,000 was raised for the Topical Rapa TREATMENT Trials, this past year has seen the inclusion of the Sydney Children's Hospital as a research site for the international study into topical Rapamycin. Many generous donors contributed to this ongoing project which will eventually improve the lives of so many TSC affected people.

The 5-year strategic plan was revisited and has informed this year's ATSS activities.

Fulfilling the ATSS vision that TSC families are empowered, through access to information and support has been a goal of the year's activities.

The very successful and well attended "Riding the TSC Wave" family and medical conference was held in Sydney in October 2011. This was the first event of a year focused on providing opportunities for Australian and New Zealand families to hear international and local TSC experts, to meet other families and be empowered through increased knowledge and understanding of TSC. This event was made accessible to families via travel grants funded by the Federal Department of Families, Housing, Community Services and Indigenous Affairs.

This popular event was followed by a Top of Mind Meeting in collaboration with Epilepsy Action in Brisbane in November.

ATSS also held a meeting for Queensland families in Brisbane in May during the International Neurology Conference. This was followed by a conference called "Making the Puzzle Easier, Together" in Melbourne in June. This meeting, held at the new Royal Children's Hospital was well attended by TSC families and created opportunities for Victorian professionals to present with the two international Polish experts, Dr Sergiusz Jóźwiak and Dr Katarzyna Kotulska.



The annual Seminar Day held at Sydney Children's Hospital, Randwick, continues the provision of TSC related information for parents and people affected by TSC. Planning is underway for a conference in Perth in 2013.

In last year's Annual Report I highlighted the need for ATSS to respond to the ever increasing opportunities for growth. For many years I had hoped that one day ATSS would be in a position to employ a part-time worker. The major response of ATSS to the opportunities for development was the employment of a Project Manager. Clare Stuart was employed in this role for 10 hours per week from November 2011. This role would relieve the dependency for the growth of ATSS on the small voluntary committee. The position was possible due to a grant from Novartis Pharmaceuticals Australia, who funded the Resource Directory Project which culminated in the recently launched new ATSS website. This project was delivered by the Project Manager and my thanks are extended to Clare Stuart for her professionalism, initiative and drive in fulfilling so many activities in only 10 hours of paid employment. Clare has also driven the abovementioned interstate family conferences; organising, facilitating and bringing them to fruition. Now is also an appropriate time to thank Clare for her many years of voluntary work as a Committee Member with particular responsibilities for IT development.

During the past 12 months, stronger networks with other professional organisations have been developed, raising the profile and professional recognition of ATSS. Clare, as Project Manager, has developed strong links with other organisations, collaborating with a range of government and NGOs as listed in the Project Manager's Report. Included is her work with TS Alliance to shape the TSC International agenda aiming to involve other member groups in activities.

Clare collaborated with the Centre for Genetics Education to write their first fact

sheet on Tuberous Sclerosis. The Centre for Genetics Education is funded by New South Wales Health and is the key organisation in Australia providing information on various aspects of genetics and genetic diseases to health professionals and the public.

With the employment of a Project Manager, ATSS infrastructure has been strengthened with a number of policies written and approved by the Committee. The future for ATSS is exciting. This is a dynamic and vibrant group with clear directions for growth in services for all families living with TSC.

This positive future is due to a number of people whom I would like to acknowledge:

I would like to thank Hayley Hill, for her tireless and generous work as the ATSS Treasurer and Membership Secretary. Working closely with the Project Manager, Hayley has brought the ATSS into the financial technical age, learning and establishing new processes to benefit members and donors. Hayley is also the ATSS Facebook Administrator.

I also acknowledge the long-term commitment of David Matheson in editing the bi-annual ATSS journal *Reach Out*. May was the first edition with a fresh new look, and a change of designer and printer to align with the new website. This valuable resource is always highly anticipated by members. David also keeps the accurate and detailed minutes of all meetings.

I would also like to thank every member of the committee who has given of their time and skills, some for many years despite difficult personal circumstances. In particular I would like to acknowledge the work of Deb Duffy, who was a valued member of the committee and held the position of Vice-President for part of this year. I would also like to thank the families of all Committee Members and regional contacts whose support is essential.

...Continued on page 6



Treasurer's Report

Report presented to the Annual General Meeting, 12 August 2012

Hayley Hill - Treasurer

A TSS financial accounts of 2011-2012 were audited by Rachel Goddard (ACA). ATSS would like to thank Rachel for volunteering her time once again to audit the accounts. A copy of the financial accounts follows this report.

This financial year has resulted in a loss for ATSS of -\$51,690.73. This is caused by the first payment, of approximately \$97,000, for the clinical trial for topical use of Rapamycin being due this year. This money was raised in prior financial years.

ATSS received many generous donations over the past year. The breakup of the donations received for this financial year 2011-2012 are:

- General Donations \$ 29,932.52
- Donations to Rapamycin Topical
 Cream Research Fund \$ 3,358.00

General donations are up by approximately \$20,000. This is a fantastic result that was triggered in part by the introduction of gold, silver and bronze supporter levels in place of the flat membership fee. Thank you to the many donors who have generously become supporters and provided this additional funding to ATSS.

ATSS expenses increased this year due to increased activities. ATSS plans for new projects and activities to be funded through various grants to ensure that cash reserves are maintained. Expenses related to the Family Conference in October 2011 were covered by a grant from the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and from an educational grant from Novartis Pharmaceuticals (\$30,000). Expenses relating to the Resource Directory and the Brisbane and Melbourne conferences were covered by educational grants from Novartis Pharmaceuticals (\$40,000 and \$8,000 respectively).

The employment of Clare Stuart as ATSS Project Manager in November 2011 was a milestone for ATSS. Clare's wages are built into project budgets and are funded by the grants obtained to deliver these projects. I'd like to thank Clare for all the hard work she has put into getting the new website up and running, organising the Brisbane & Melbourne Conferences and also obtaining grants for these and future projects.

Most of the general expenses were less than the previous year. The telephone expenses are up due to having more teleconferences with different states over the year. Travel costs have increased primarily due to ATSS staff and volunteers travelling to the Brisbane and Melbourne ATSS events.

ATSS currently holds the following term deposits:

- CBA Elizabeth Pinkerton Memorial \$5,000.00
- CBA Term Deposit maturing 19/8/12 \$109,197.54
- Macquarie Term Deposit maturing 12/10/12 \$ 29,966.89

The Commonwealth Bank Cash Investment Account is currently \$126,385.31; this is high due to one of the CBA term deposits closing, is receiving interest at a rate of 3.25%, and is working similar to a normal cheque account.

The balance sheet shows assets of over \$280,000. A large proportion of this is allocated to in-progress projects, including more than \$100,000 still to be contributed to the clinical trial for Topical Rapamycin and \$20,000 still to be spent on the Resource Directory setup and running costs. Excluding these allocated amounts, ATSS reserves are over \$100,000 which is in line with our goal to have sufficient cash in reserve to run ATSS for three years.

ATSS funds could not grow without the continuous help and support from its generous members and their friends. On behalf of the hundreds of TSC affected families that benefit from the work of ATSS, I thank you.



ATSS Supporter Renewals

ATSS Supporter Renewals were due on 1 July 2012. Thank you to all who have renewed since the last issue of Reach Out in May 2012. If you have not paid your renewal you will find a reminder insert in your 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 Secretary's Report

Report presented to the Annual General Meeting, 12 August 2012

Hayley Hill

As of 30th June 2011 the ATSS Membership Database held a total of 564 details of past and present Members.

250 of these are active financial members. 314 are inactive, meaning their contact details are unknown or they have not renewed their membership.

The active members are comprised of:

- Families 131
- Honorary 23
- Organisations 12
- Professionals 84

The introduction of gold, silver and bronze supporter levels was well received by current members. This programme offers three levels of support to choose from: Bronze \$25, Silver \$50 and Gold \$100. From each of these \$5 is a membership fee and the remaining amount a donation. For the 2011-2012 financial year, there were: – Gold Supporters 58

- Silver Supporters 23
- Bronze Supporters 66

As at 30th June, a total of 83 Supporters have prepaid for 2012-2013 financial year. This includes 29 Gold, 21 Silver and 33 Bronze Supporters. It is expected that approximately 50 more will renew over the next year. Reminder notices for ATSS Supporters for 2012-2013 will be included in the next issue of *Reach Out* in November.

ATSS is grateful to those members who have renewed membership promptly for this year and welcomes new supporters.

Active members are posted a copy of *Reach Out*, the ATSS journal that is published twice a year. Members may also opt to receive *Reach Out* electronically.

In response to the evolving use of Facebook, the ATSS Facebook Group recently changed names from Australasian Tuberous Sclerosis Society to Discussions of Australasian Tuberous Sclerosis Society. This group currently has 216 members. This year

has seen many great discussions on various aspects of life with TSC. The members of this group have told us it is a fantastic way to meet other people who are either affected personally or have a family member who is affected by TSC from all over Australia and New Zealand.

Clare Stuart, the ATSS Project
Manager, assists me in managing the
Facebook Group. Clare also manages
the official ATSS Facebook Page called
Australasian Tuberous Sclerosis Society. This
is another way for ATSS to share up to date
information and fantastic events that ATSS
are holding. This page has a timeline focus
whereby people can look at the past and see
the wonderful things ATSS have achieved
over the years.

On behalf of the ATSS Committee, I hope that you and your families find Reach Out, the ATSS website and our Facebook group and page informative. You feedback and suggestions are always welcomed.

President's Report

...Continued from page 4

I extend appreciation and gratitude to the growing number of ATSS Medical Advisors, particularly Drs David Mowat, John Lawson and Orli Wargon, who have supported the goals of ATSS in developing best practice models of care, actively participated in research projects, and encouraged medical expertise in TSC.

The 2012 Annual Report will be my last, as I am not standing for re-election and I am resigning from the Committee. Before I conclude this report I would like to acknowledge the people who made it possible for me to be in this role for the past 19 years: my family. When I became a Committee Member some 25 years ago little did we know the commitment the whole family would make to ATSS. It is only fair to recognise the contribution they have made which made it possible for me to accomplish what has been achieved for ATSS and every TSC affected family in Australia. So, I thank Nick, Clare, Sam and Tom

for giving up their time with Mum, and to Ross for giving up his time with his wife. Instead she took phone calls from families at all hours of the day and night, edited and compiled quarterly editions of *Reach Out*, developed the tradition of the annual Seminar Day and Family Conferences, established professional relationships with medical professionals, and worked with the committee to raise funds to grow the work of ATSS for all TSC affected families.

I know it has been worthwhile as ATSS is a thriving organisation with many remarkable achievements to be proud of for such a small voluntary group. I have tried to make a positive difference during my involvement with ATSS and it has been a privilege to serve and be a part of the history of this genetic support group.

Receiving a diagnosis of TSC can cause the whole family to live a different life to the one they imagined. As Robert Frost says in the poem The Road Not Taken: Somewhere ages and ages hence: Two roads diverged in a wood, and I I took the one less travelled by, and that has made all the difference.

Like many of you, the Pinkerton family took the road less travelled when our Lizzie was born. It is a journey I would take again because it made such a difference to our lives. It was Lizzie who was the reason for my passion and commitment to improving our lives and the lives of so many others.

Everything has a season and my season as President of ATSS is over. I am confident that the future for TSC families and ATSS in particular is secure as the people, internal structure and finances are in place, and support from families and professionals is strong. I know the legacy I leave is in good hands with dedicated, committed people to take this remarkable organisation into the next stage of its service to TSC families.

This concludes the 31st President's report to the Annual General Meeting.



Farewell to Sue Pinkerton

Sue Pinkerton has completed her final term as President of the Australasian Tuberous Sclerosis Society. ATSS will continue as a vibrant organisation under new President, Debbie Crosby, while Sue moves on to new challenges in other areas.

As President of ATSS, Sue Pinkerton dedicated countless hours of work to improving the lives of families affected by Tuberous Sclerosis Complex. She has guided the growth and development of ATSS to ensure that it continues to be of support for families in new ways.

Sue joined ATSS in 1985 after the birth of her daughter Lizzie, who was diagnosed with TSC at seven months; in 1986 she joined the ATSS Committee. Sue became the President of ATSS at the Annual General Meeting in 1994 and served as President until 2001. She remained as a member of the Committee until 2003 when she became President again, continuing in that role until this year.

Sue has overseen and been the driving force of numerous major achievements of ATSS over many years. These include:

- The introduction of family conferences, one of the Society's major activities.
 These conferences provide the opportunity for families affected by Tuberous Sclerosis to hear professional speakers present on a range of topics. Sue organized and arranged many conferences, and facilitated their smooth running.
- As President, Sue established and maintained connections between ATSS and a number medical and other professionals. This has enabled members of ATSS to have up to date information regarding research and treatment of the symptoms of Tuberous Sclerosis Complex.
- Sue gave numerous presentations regarding Tuberous Sclerosis Complex. These have included speaking to medical students about TSC, and presenting at meetings of service clubs such as Rotary.
- Sue assisted with the establishment of the Association of Genetic Support Australia, an umbrella group for support groups for those affected by genetic disorders, and was a member of its inaugural committee.
- Sue answered many telephone calls from families and individuals affected by TSC, and responded to correspondence from families, medical professionals and



Debbie Crosby and Sue Pinkerton

other interested people.

- ATSS receives no ongoing Government funding. Sue actively sought funds for ATSS through writing submissions for special projects, encouraging donations, and the development of other fundraising initiatives. A partnership has been established with Novartis Pharmaceuticals
- The establishment of a genetic testing laboratory in Sydney for Tuberous Sclerosis. This laboratory is the first in Australia to offer gene testing for Tuberous Sclerosis, and is also the first non-profit genetic testing facility for TSC in the world.
- Production of an Australian DVD about Tuberous Sclerosis Complex, 'You Are Not Alone'.
- The ATSS 2007 Medical and Family Conference. This was the first time in Australia that international experts and Australian medical professionals and families affected by TSC were brought together. The conference was held at the Sydney Children's Hospital in November 2007 and was officially opened by Her Excellency Marie Bashir, Governor of New South Wales.
- Sue worked in conjunction with staff at Sydney Children's Hospital to establish

- the TREATMENT trial. This trial is part of international research
- Establishment of the annual Elizabeth Pinkerton Memorial Award for a health professional in Australasia who has made a significant contribution to the management and treatment of TSC affected people.
- It was one of Sue's hopes for many years that ATSS would be in a position to have a paid employee. This was achieved in 2011 with the employment of a parttime Project Manager.

Sue has encouraged and inspired others by her energy and commitment. She has devoted her time to the work to ATSS in a purely voluntary capacity. Over the years she has been a vital contact for many families affected by Tuberous Sclerosis and has provided valuable information and support. Sue's leadership has ensured that ATSS will continue to meet the needs of families affected by Tuberous Sclerosis Complex.

As a wife and mother, as well as working full-time as a teacher of hearing impaired children, Sue has been able to balance care for her family and a professional career with dedication to the work of ATSS. A remarkable achievement.

Elizabeth Pinkerton Memorial Award

A t the Australasian Tuberous Sclerosis Society's Annual General Meeting in August, the annual Elizabeth Pinkerton Memorial Award was presented to Dr John Lawson. Elizabeth lived with Tuberous Sclerosis and Polycystic Kidney Disease. She was the inspiration for the Pinkerton Family's dedication to the work of ATSS.

Dr John Lawson is a Paediatric Neurologist and Epileptologist at the Sydney Children's Hospital, Randwick, and Conjoint Senior Lecturer at the University of New South Wales. He completed his medical degree at the University of Newcastle and Diploma of Paediatrics at the University of New South Wales. In 2003 Dr Lawson was conferred his PhD from the University of New South Wales in "Quantitative MRI Studies in Childhood Epilepsy". He completed his Neurology Fellowship training at the Sydney Children's Hospital, Randwick, and the Miami Children's Hospital, a Centre of Excellence for epilepsy surgery in the United States of America.

Dr Lawson is a Fellow of the Royal Australasian College of Physicians, and a professional member of the Australian Association of Neurology, Australian Child Neurology Study Group and Epilepsy Society of Australia.

Dr Lawson has an extensive portfolio of research into paediatric epilepsy and neurology. His interests include enhancing the diagnosis and management of children with epilepsy and Tuberous Sclerosis Complex. Publications have focussed on new imaging techniques in childhood epilepsy, as well as the effect of epilepsy on quality of life and cognition. Current projects include epidemiology of TSC, out-of-hospital use of midazolam for emergency management of seizures, and efficacy of the ketogenic diet for intractable epilepsy. In addition, Dr Lawson is also an Investigator on a George Institute led study investigating the incidence of epilepsy and illness consequences in metropolitan Sydney, and a Novartis sponsored multi-centred international trial investigating the use of Everolimus for treatment of SEGA in TSC.

Dr Lawson is a highly respected Paediatric Neurologist and much loved by his patients. His dedication to enhancing the diagnosis and medical management of epilepsy is evident in his commitment to patients and indeed is reflected in his role as Medical Advisor to the Australian Tuberous Sclerosis Society.



Elizabeth Pinkerton



Dr Lawson (second from right) with Ross & Sue Pinkerton (parents of Elizabeth Pinkerton) and Clare Stuart (sister of Elizabeth Pinkerton)

Knowledge Gained and Connections Made in Melbourne

The 2012 ATSS Family Conference

June saw the biggest Tuberous Sclerosis event ever held in Melbourne. An enthusiastic group of families and health professionals gathered at Royal Children's Hospital for the ATSS conference.

The conference provided different perspectives from different speakers: three neurologists, an epilepsy nurse, a neuropsychiatrist, a kidney specialist, a support organisation manager and a geneticist all addressed different aspects of TSC.

Leading TSC researchers from Poland, Professor Sergiusz Józwiak and Dr Katarzyna Kotulska, shared the latest results from international research studies into epilepsy treatment, SEGA surgery and new medicines for TSC. This included the effectiveness and side effects seen in clinical trials of mTOR inhibitors (these include Sirolimus/Rapamycin and Everolimus/Afinitor) as well as novel treatment approaches for epilepsy in infants diagnosed with TSC. Other highlights included a summary of epilepsy surgery, a great discussion about treatment approaches for kidney involvement in TSC, and advice on accessing services in Victoria for children with a disability. Many of the slides are available on the ATSS website.

As with most ATSS events, the day was an opportunity for families to connect with each other. Stories were shared formally and informally. Our thanks to Narelle Kerr and Adam and Les Cope who shared TSC stories.

This event was made possible by the support of many people. Dr Simon Harvey, in addition to being a fantastic speaker, assisted in organizing the meeting and securing the fantastic venue within the newly renovated Royal Children's Hospital. The event was funded by an unrestricted educational grant from Novartis Pharmaceuticals and the generosity of ATSS's supporters. And of course, many thanks to the dedicated speakers who volunteered their time on a weekend to speak with families and attend conference sessions.

The 2013 family conference will be held in Perth in March and a Seminar Day will be held in Sydney in August. Both events will be opportunities to refresh information and renew connections.



Dr Katarzyna Kotulska and Prof Sergiusz Jozwiak in Brisbane

Brisbane 'Meet the Expert' Evening

Prof Sergiusz Jóźwiak and Dr Katarzyna Kotulska, who spoke at Melbourne Conference, travelled to Australia for the International Child Neurology Congress which was being held in Brisbane.

During the congress, ATSS hosted a 'Meet the expert' evening. Several families from around Brisbane heard from Sergiusz and Katarzyna as well as Dr David Mowat.



Dr Simon Harvey speaking to conference participants in Melbourne

Sydney Seminar Day

The ATSS Seminar Day was held on Sunday, 12 August at Sydney Children's Hospital, Randwick. Speakers and their topics were:

Associate Professor Ernie Somerville, Neurologist, 'When medication doesn't help';

David Mowat, Clinical Geneticist, 'Outcomes of the 2012

TSC Consensus Meeting';

Dr Vanessa Sarkozy, Developmental Paediatrician, 'Assessment and Beyond'.

ATSS thanks all speakers for their time and to all families who participated in the day.

Committee Changes

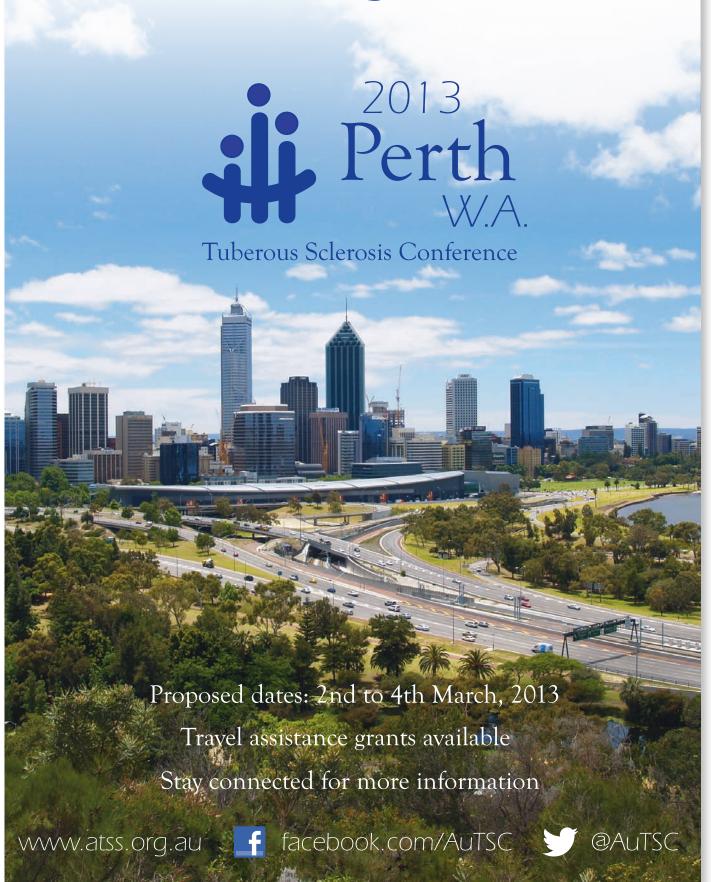
a new Committee was elected. Debbie Crosby was elected President. As mentioned elsewhere in *Reach Out*, Sue Pinkerton decided not to stand for re-election after many years as President and Committee Member. The position of Vice-President remains vacant. Hayley Hill will continue as Treasurer and Membership Secretary, while David Matheson remains Minutes Secretary. Newley elected Committee Members are Mary Beijerinck-Gooley and Kate Norris. Congratulations to all on the Committee, especially the new Committee Members, for volunteering your time to assist the work of ATSS



Plans are underway for the second Tuberous Sclerosis Complex Global Awareness Day on 15 May, 2013. Celebrations will include the ATSS National Picnic Day on 19 May. Subscribe to our e-Newletter to find out more.



Next year, the ATSS Conference is heading west...



Hope for the Future

Joy McArthur

over the many years that the ATSS magazine has been published I have read the heartbreaking stories of things that have happened to all of you and the story I am going to tell you should give everyone a lift and hope for the future. This will be a short potted version so there will be some aspects such as trauma, anger, fights, frustration and tears left out.

My daughter Anne was born 48 years ago; our third child, and right from the beginning I felt there was something wrong with her. She cried nonstop and took petit mal fits from nine months of age. Doctors told me I was neurotic and not to worry: she would be fine.

From age one to eight the fits continued and eventually we found a doctor who gave her Dilantin which fixed the fits and they ceased.

When she was due to go to high school the doctors found that she had an enlarged left kidney and removed it, saying that she had polycystic kidneys. Anne did all right at school but was not allowed to play contact sport.

Anne obtained a secretarial position but before she was 20 both her lungs burst, which meant that the plural cavity had to be filled with talc to stop further bursting.

At 21 years of age Anne took herself off to Melbourne to live and work as far away from her family as she could. Life was fairly normal for her until when she was 28 and was having a check-up at the kidney specialist, she was told that she had Tuberous Sclerosis. At last we knew, but after searching through both families we could find no one else with it.

In 1991, aged 26, Anne had to have a calcification removed from her brain, from which she made a full recovery. We were told at this time that ten years would be the longest she would live.

Anne continued to work and enjoy life. That was until about five years ago when her remaining kidney started to deteriorate and her lungs started playing a part as well.

About two years ago she was told that she had LAM and the only solution was a transplant. But the snag was she had to have the lungs and kidneys transplanted at the same time because rejection drugs would kill her if done singly. What a



Doctors told me I was neurotic and not to worry: she would be fine.

decision to have to make knowing that you could die any time.

In December 2011 Anne was put on the list and on 28 December she had a massive 15-hour operation where they gave her two new lungs and a new kidney from the same donor. I cannot tell you what is has done to the family, especially her father and I, as neither of us are very young. But at last she looks like going to rehabilitation in a few days time and God willing she will live to a ripe old age.

For months she had not eaten a thing through the mouth, or spoken a word or walked, and has been totally reliant on the nurses for her every need. They are miracle workers as far as I am concerned.

Both my husband and I hope that this small contribution will give others hope where there doesn't seem to be much.

They know so much more now than they did when Anne was born into this world.

Post Script:

At the end of April Anne started to show signs of recovery and since then has slow-

ly got on her feet, learned to walk, talk, eat and take notice of her surroundings again. In June she made it out of hospital and into rehab and is now nearing the end of her time there. It has been slow and tedious at times, but apart from a couple of hiccups she has made a remarkable recovery.

My husband and I and her siblings will always be eternally grateful to the donor and the team at the Alfred Hospital in Melbourne for all they have done for our daughter when there was no solution. She will always have to be careful and take great care of herself but knows she will now lead a full life again.

It has been slow and tedious at times, but apart from a couple of hiccups she has made a remarkable recovery. A Positive Outlook

Debbie Crosby

My husband Anthony and I have two beautiful daughters, Alana and Sophie. Alana, who is eight years old, has TSC, and Sophie is five years-old. I know I am biased but they are beautiful, funny, sweet and caring girls. I wanted to tell our story in the hope that it may help other families, especially newly diagnosed, and share the difficulties we have experienced.

When we first bought Alana home and settled in for a couple of weeks, I kept on thinking that I was the luckiest mum in the world. She ate very well, slept very well and was a calm and content baby. At the age of 6 months-old I noticed Alana started to have these jerking kind of movements and then she would fall asleep after them. It looked like she had reflux or a very bad case of the hiccups. She was also very unsettled and would cry for hours at a time, which was not like her at all. After I noticed this a few more times, I took her to the GP and she was diagnosed with reflux and given some medication. After a week or two I didn't think it was reflux and our GP suggested I take her to a paediatrician. He examined her and saw the large white ash leaf on her tummy, which we thought was a birth mark, and he looked quite concerned and ordered a CT scan. At that appointment he told me that he thought Alana was having infantile spasms and that they could be caused by Tuberous Sclerosis. Although doctors tell you not to do this, every parent rushes home and looks up Dr Google. That to say the least was not a very good idea. My husband and I were shocked, confused and became very worried about Alana's future. I think we both knew at the time that Alana did have TSC.

After the CT scan, which showed many tubers in her little brain, our paediatrician diagnosed TSC. We were devastated.

At this time Alana was still having infantile spasms, but by the time we saw our neurologist, which was 6 weeks after the first seizure, they had stopped. He told us this was quite rare for them to stop without medication, and we were quite relieved. However, we had to face



everything else that comes with a diagnosis of TSC. The doctors' appointments, ultrasounds, blood tests and all of the emotional upheaval. Anthony and I also had tests and it was very overwhelming. We had so many questions: Was our daughter going to be okay? Would the seizures come back? Would she have autism or a developmental delay? Looking back it now feels like a big dream. We were very lucky that we found a wonderful neurologist and he tried to answer all of our questions and we felt very supported.

After the diagnosis you have your good days and bad days, but we tried to take one day at a time. Alana wasn't having any seizures, but I was always looking for signs. She did take longer to reach the normal milestones, but by the age of 18 months old she was walking and started to babble and was a very happy smiley baby. However she also began showing the early signs of autism and we felt like we were starting all over again with another diagnosis.

We began early intervention and although she had a noticeable developmental delay and some autistic behaviour, Alana was a very happy child who loved to play and laugh. At the age of two and a half years the seizures came back. She was given medication and this helped for a while but she had absence seizures nearly every day. They would last for 10 seconds or up to 2 minutes and she would be very sleepy afterwards. Some days she would have one seizure and other days there would be multiples. They would come on more strongly after she woke in

the morning or if she was very tired. Even though this sounded terrible to people who don't know about TSC, most days we considered ourselves lucky, as she never had to be hospitalised because of a seizure.

At this time she also became very whingey and irritated and she would cry for hours at a time. Because Alana couldn't talk or communicate with us we became very frustrated and didn't know what she was feeling and what she wanted. We tried so many different medications and combinations of these, and some would help for a short while, but then the seizures would come back. We even tried the modified Atkins diet for ten weeks, which made her feel very sick but we persevered hoping the seizures would stop. They didn't.

We were also dealing with autism. She didn't like loud noises, and she would sit in the corner and rock back and forth. Because of the seizures and the autism Alana would progress developmentally for a while and then a few months later regress. We would wake up every morning and we didn't know if we were going to have a good day or bad day. We felt like we didn't have any control and it felt like things were never going to get better. However we persisted with therapy and she attended a fantastic inclusive preschool. We tried to lead as normal life as possible and we decided to have our second child.

This was not an easy decision and any family would tell you the same thing. We received genetic counselling before we went ahead, and then decided to have genetic testing when we got pregnant. We are very grateful that Sophie is a very



healthy and happy child. She is a very caring, empathetic and fun sister to Alana, and she asks many questions about Alana and has some understanding of her condition

I knew having a second baby and looking after Alana was going to be difficult, but I wasn't prepared for what was to come. The first year after Alana was born was the hardest year of mine and Anthony's life. Alana's seizures became more frequent and none of the medications were working. We had tried eight different medications and several combinations of these. Some made her very sleepy and others gave her terrible tantrums and behaviour. We had tests to see if the seizures could be stopped with surgery, but she was not a good candidate because the seizures were being caused by different tubers in her brain. She even began to have drop seizures where she would lean so far down she would drop onto her knees. They were very scary.

She would also wake up at two or three in the morning and not go back to sleep. This would go on for months and months and it was exhausting. As a mum I also felt very isolated as it was difficult taking both Alana and Sophie out together and we could not do the normal things families do.

Finally after three and a half years we found a drug combination that worked. At first I was very sceptical and thought that it wouldn't last, but for two years she was seizure free. When the seizures stopped, Alana became much happier and she made

small improvements. However ten months ago we changed one of the medications because it was causing side effects and the seizures came back. I think that like many other families seizure control is so frustrating and we struggle with this all the time. Luckily at the moment the seizures have stopped again and we are hoping it stays this way for a while.

TSC and autism cause many challenges for Alana and our family. She doesn't talk, but does say the important words like "Mum", "Dad" and "Yum". She attends a special needs school and loves it, and last year she began attending vacation care in the school holidays for the first time. She loves music and dancing, especially the Wiggles, and she gives the best cuddles. Even though she has a severe developmental delay and autism we are very lucky that Alana is quite a social child who loves to play with her sister, she loves going out, she doesn't have any problems with changes to her routine, and she loves to eat and try new foods. We also began a new type of autism therapy 18 months ago and her nonverbal communication has really improved. This has made a big difference to our family life as we are able to understand what she needs and wants.

Although our story sounds challenging and at times very sad, Alana is one of the strongest and happiest children you will ever meet. We are very lucky that for most of the time she is a calm and playful child who always has a smile on her face, even when she is going through many tests and

procedures in hospital. We try and celebrate every day that she is able to run, laugh and play. We never forget that some children are not able to do these simple things.

While I was writing this I thought about what is the hardest thing to deal with TSC. There are so many things but for us it is the lack of control over this disease. I can't control the seizures, and when we watch her have them we feel so helpless. I can't switch off the autism either. But the few things we have learned from having a child with TSC are going to sound like clichés, but they are true. The most important things in life are family, friends and compassion for others. It teaches us patience, perseverance and we now take one day at a time. We appreciate and celebrate the little things in life, and we tell our girls we love them and hug them way more times than they would probably like us to.

Even though we are dealing with epilepsy, autism, AMLs in her kidneys, and all the other things that go along with TSC, compared to where we were five years ago, we are a stronger, happier family and we have a positive outlook for Alana's future.

Eighteen months ago I decided to join the ATSS Committee because I felt I wanted to give something back and help other TSC affected families. In August I took on the role of President and it feels very rewarding being part of a Committee that helps ATSS empower families and individuals through access to the most up to date information and support.

Still My Darling Julia

By her grandmother Berice after the death of Julia's great grandmother, Edna.



ulia, my granddaughter and Edna's great granddaughter, was loved very much by Edna always, but especially during the frequent visits she paid to Edna in the nursing home. Many children do not like visiting nursing homes, but Julia, because of her TSC, plodded in and checked the tables of the four residents in Edna's room. Eventually she sat on a chair eating a lolly or two and she would also lie on one of the beds watching a lady's TV. When she thought we had visited long enough she would come over to me and very seriously bow her head for Mum to give her a kiss goodbye. (This sometimes happened more than once.)

All the dear old ladies became quite attached to Julia and they would always ask me when "the girl" was coming again. She caused great concern twice over the years. Once when the community radio was fiddled with and their music disappeared until someone knew how to fix it, and another time when it became too hard to resist plunging her hand into the tank of fish. The residents were mortified at the time but eventually, or really quickly I suppose, depending on their varying degrees of dementia, they forgot about it.

I wrote to ATSS years ago under the title of "My Darling Julia". She is still "My Darling Julia". My dear 13 year-old grand-daughter is very special to me. My other five grandchildren kindly accept that I have a special love for her because she is different.

Julia lives at Windsor and I drive over to bring her to my place at Greystanes for the weekend sometimes and she also stays



People must be stunned as the car goes by or stops at lights with loud music with a thumping beat and a grandma at the wheel.

for a bit longer during school holidays. Of course I am super lenient! The discipline comes from her dad and her school. They do it brilliantly but we all need some times to be stress free so Julia and I make the most of our time together!

People must be stunned as the car goes by or stops at lights with loud music with a thumping beat and a grandma at the wheel. Julia would be seen doing her strange hand signals and wild thrust to the left or towards the windscreen repeatedly pressing some control to give us a rendition of a few seconds worth of something "really good" during our 40 minute trip. We hear a repeat of this part all the way home.

When Julia arrives she checks all the special places in my house: her musical toy collection in a box on the verandah; the fridge, and she tastes contents; the

lounge room and her DVDs and CDs; the bathroom and bath; my bedroom, which is excellent to spend time in after an organised routine - close the blinds, switch off the light, close the door with a bang, climb under the bed covers together and sing.

Sometimes I look across in the car or during a trip to the shops to see Julia's beautiful brown eyes gazing steadily at me. They are the same depth of feeling I have only seen in her dear dad's eyes when I had to break terrible news to him once long ago.

Julia doesn't speak but seems wise in many ways – unwise in many too, I must admit. She is never conscious of how old or ugly anyone is or how hard or cruel things can be at times. Life is just accepted and her hand is always ready to hold mine and always will be.

Research News Update On The Treatment Trial

This trial is being funded by your generous donations to the Topical Rapamycin Cream fund.

Sydney Children's Hospital, Randwick, NSW is participating in an international research study of a new treatment for facial angiofibromas associated with Tuberous Sclerosis Complex (TSC) in children and adolescents aged 17 years and younger.

The treatment is an ointment which contains a medication called Rapamycin.

Rapamycin is approved in Australia to prevent organ rejection in people who have had a kidney transplant. However, it is not approved to treat facial angiofibromas.

The study aims to learn more about how safe and effective Rapamycin is when used in an ointment and applied to the face over a six month period. If you would like more information, please speak with your treating physician who will be able to discuss this treatment with you, or contact the Study Coordinators at Sydney Children's Hospital on 02 9382 1757

Other Research News

The first medicine to treat kidney symptoms of TSC has been approved by the Food and Drug Administration (FDA) in the United States. The approval of Afinitor (Everolimus), an mTOR inhibitor, for the treatment of renal angiomyolipomas (AMLs), occurred in April 2012. Applications for approval in Australia and New Zealand will be made in 2013. It is important to remember that many kidney AMLs do not require treatment and that this medicine is only one treatment option. A specialist kidney doctor can provide more information on the treatment of kidney AMLs.

This is an exciting development that follows the approval of the same medicine for the treatment of subpendymal giant cell astrocytomas (SEGAs), a type of fast growing brain tumour that affects up to 20% of people with TSC.

A clinical trial into a new treatment for epilepsy in TSC is in the early stages of planning. Centres in Sydney, Brisbane, Melbourne and Perth are all being considered. More information will be provided on the ATSS website and in our e-newsletter when it becomes available.

A LAM Genome Wide Association Study is seeking participants with a confirmed

diagnosis of LAM from around the world. Drs David Kwiatkowski, Lisa Henske and Frank McCormack are initiating a genome wide association study in LAM. Genome wide association studies (GWAS) are done to try to identify genes that predispose to disease development. Sometimes GWAS lead to identification of genes that were completely unexpected from prior knowledge. These doctors hope that this will be the case in LAM, pointing to the importance of a new research direction and possibly even a new therapy for LAM.

Participating involves completing a questionnaire and a saliva sample. More information about the study is available on the ATSS website.

The 2012 International TSC Research Meeting was held in Naples in September. Research presented covered a range of topics including the latest clinical trials into mTOR inhibitors, SEGA surgery case reports, epilepsy management and quality of life studies.

Recently published articles on Tuberous Sclerosis include:

- A summary of TSC written for nurses in The Journal of the American Academy of Nurse Practitioners
- Guidelines from Europe for the treatment of Epilepsy in TSC
- A study into the use of mTOR inhibitors to prevent recurrence of a SEGA after surgical resection
- Numerous publications of work that furthers our understand of the underlying causes of TSC tumours

More information about these articles and other research news is available on the ATSS website.



2012 TSC Clinical Consensus Conference

Held in Washington, DC

They selected eight additional experts to lead working groups focused on key aspects of TSC

n June 14 & 15, 2012, more than 60 health care professionals, each having expertise treating one or more aspects of Tuberous Sclerosis Complex (TSC), met in Washington, DC, to update consensus recommendations for the diagnosis, surveillance, and management of TSC. The prior guidelines were based on a 1998 consensus conference, and the TSC field has made tremendous advancements in the meantime. The need for updated guidelines for diagnosis, surveillance and treatment was raised at the 2011 meeting of Tuberous Sclerosis Complex International (TSCi) at which there were three ATSS representatives. To ensure the resulting recommendations would benefit from diverse perspectives and be internationally applicable, experts from 14 different countries were included.

Drs Hope Northrup and Darcy Krueger co-chaired this important effort. Together with the TS Alliance, they selected eight additional experts to lead working groups focused on key aspects of TSC: brain tumours, dermatology and dental, epilepsy, genetics, neuropsychiatry, pulmonary, renal, and a collection of additional manifestations including cardiac, endocrine, gastrointestinal, and retinal. These group leaders, in turn, selected representative experts to participate in the effort. David Mowat, ATSS Medical Advisor, was selected to participate in the Genetics working group.

Specific recommendations for the surveillance or monitoring of individuals with TSC were developed

Beginning months prior to the conference, these groups communicated by phone and email to prepare questions, review the scientific literature, and set priorities. This pre-work ensured the face-to-face discussions were efficient and productive.

Indeed, consensus was reached during the intense day-and-a-half meeting based on evaluation of data in the scientific literature and expert opinion. The most significant change to the diagnostic criteria was to enable diagnosis based on genetic testing alone if an individual has a mutation in TSC1 or TSC2 that is known to cause TSC in other individuals or that produces a non-functional TSC1 or TSC2 protein. Recommendations for diagnosis of TSC based on clinical criteria, including major and minor features of TSC, remain similar to the previous criteria, but the guidelines are simplified. Specific recommendations for the surveillance or monitoring of individuals with TSC were developed by each working group.

Similarly, recommendations for treatment of the various manifestations were updated based on the latest data. For each feature of TSC, the recommended treatment approach, such as surgery vs. drug therapy, differed depending on the relative risks, benefits, and state of knowledge. Of course, every individual's specific situation will influence choices of treatment, but the consensus recommendations will help improve the quality of care to everyone affected by TSC by providing state-of-the-art guidance to physicians around the world who are less familiar with TSC.

Drs Northrup and Krueger are working on first drafts of the two overarching manuscripts – one for diagnostic criteria and one for recommendations for surveillance and management of TSC.

These articles will describe the overall consensus and highlight the importance of comprehensive and co-ordinated care in this disease that involves so many different medical specialists. The manuscripts will be submitted to an appropriate scientific journal that will provide open access to everyone worldwide. The working groups will also produce discipline-specific manuscripts to provide more detailed guidance in journals that are frequently read by specialists in the area.

Together with our Medical Advisors, ATSS will publish a summary of the recommendations that can be used a reference by families and health professionals. We will also promote the guidelines in Australia to clinicians and other health professionals. A future issue of *Reach Out* will contain a summary of the guidelines and these will be posted on the ATSS website and on social media.

The conference could not have happened without the hard work of the TS Alliance staff and the generous support of sponsors who donated funds without playing a role in the planning or having a presence at the conference: the Rothberg Institute for Childhood Diseases, Novartis, Sandra and Brian O'Brien, and Questcor. We are also grateful for the time and energy invested in this important effort by compassionate international experts to help improve the lives of those affected by TSC around the world.

Adapted with permission from TS Alliance *Perspective*, Summer 2012.

So much more than a facelift

Have you seen our new website? Go to www.atss.org.au and explore:





I need to know more

for brand new information on the signs and symptoms of TSC, reviewed by ATSS medical advisors

Newly Diagnosed

for a series of guides to our new information tailored to prenatal, child and adult new diagnosis

Living with TSC

to explore the ATSS Resource Directory, a growing list of organisations, publications and websites to help families with TSC

Ways I can help

to make a donation, renew your support or sign up as a monthly donor

There's also personal stories, events and our news blog. Sign up for the new ATSS eNewsletter to stay up to date between issues of Reach Out.

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For ATSS March 2012 - September 2012

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A new way to support ATSS is to become a monthly champion.

If you, or someone you know, would like to donate to ATSS on a monthly basis, this facility is now available. Simply click on the 'Champion' tab on the ATSS webpage and we can process your donation monthly. A receipt will be emailed to you.

Calendar of events

3 November 2012
2-4 March 2013
15 May 2013
19 May 2013
20-23 June 2013

ATSS Committee Meeting, Sydney

Tuberous Sclerosis Conference, Perth

Global TSC Awareness Day

ATSS National Picnic Day

International Research Conference on Tuberous Sclerosis Complex and Related Disorders, Washington DC, USA

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