



Newsletter of the

**AUSTRALIAN
LEUKODYSTROPHY
SUPPORT GROUP INC.**

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Ambassador - John Olsen

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Office Hours

Office hours are 10.00am to 5.00pm.
Many of you know there is the answering machine and you are always welcome and encouraged to leave a message. Sr. Julie will reply as soon as possible.

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Mission Statement of the Australian Leukodystrophy Support Group

To provide assistance and information to those affected by Leukodystrophy and to support research into Leukodystrophy.

From the President

I hope all are able to enjoy some of the spring sunshine and of course more than welcome is the rain in many States.

Since our June newsletter we have had a couple of families make contact with us and I have been able to link a few families; this is a good chance for parents to talk and share their worries and anxieties and of course compare how they are receiving necessary help particularly via a Case Manager.

I am aware there are many children and a few adult sufferers who have been and are unwell, making hospital a necessary place to be for brief stays and some much longer stays. This is a trying and tiring time and we all know; there is no place like home.

Joshua Quinsey died at home in Hamilton Victoria on Sunday evening August 30th. Josh was 15 years old and was beautifully cared for by his devoted and loving mother **Deirdre** and his two older sisters **Samantha** and **Ashley**. Josh had an undiagnosed Leukodystrophy, but despite his disability he was a happy boy who had a delightful smile and enjoyed so much, special people and activities that filled his life. Even though Josh is now at peace, he has left a big space in the lives of his mother, sisters, grandparents and all who loved and cared for him for so long. Our thoughts and prayers are with you Deirdre, Samantha and Ashley.



DVD. Thanks to Michael Long from Mobile Multimedia we have a new supply of our DVD which was prepared and launched in October last year. If anyone would like a copy please contact the office as soon as possible and you will have one sent to you.

Carers Week: Sunday October 18th – Saturday October 25th.

This is a week time when we recognize and acknowledge carers throughout Australia. In Victoria we are having a Social Gathering at Banksia Park in Heidelberg on Sunday October 18th. (Invitation enclosed for families in Vic) If however, anyone from other States is visiting Melbourne that week end you would be most welcome to join us. You will see in S.A. news what Sally has arranged through Haigh's Chocolates. Thank you Sally.

A big thank you to **Marie Grafen**, who once again arranged and organized a Luncheon at the Caulfield Race Course in the Elms Function Room.

John Olsen was the guest speaker who spoke about many of the highlights of his 7 months walk across Australia. It was great to see so many there, including some who will read this newsletter. I wish to say a sincere thank you and Marie presented us with the proceeds of \$2,000.00.

Two surveys will be enclosed in this newsletter:

1. Family Needs Survey (i.e. for those who have a Leukodystrophy)
2. "A Day to Remember" for families who has lost a special one/s – the result of this will be on the web site.

From the President/cont.....

Christine Morton who has been a committee member for approximately 6 years has cancer. As a result she has no choice but to resign from the ALDS committee in order to undergo treatment which we all hope and pray will be most successful. Christine has been a quiet, but pro active member and it goes without saying she will be missed by many for her optimistic attitude and ever ready willingness to work for the good and promotion of the Group. I thank you Christine for so much and hope to hear positive news about your health in the near future.

Geelong Lions Club. On Monday October 5th the District Governor of Geelong will be present at a special dinner where **John Olsen** and six members of the Club will be present. These men supported and assisted John during his walk. Bede Dempsey (V.P) and I have been invited to join them and we will present each with a Certificate of Appreciation.

I will conclude my report by informing everyone that as a result of much thought and consideration and after 17 years as President I am resigning at the 2010 February AGM. You will hear more about this in the next newsletter.

Thank you and best wishes to all.

Julie Thomas

Treasurer's Report

Financial Summary - January to August 09

This year ALDS continues to benefit from the terrific generosity of many people and organisations.

Over \$43,000 this year was raised by John Olsen's Longest Walk for an Aussie Kid a member of the Geelong Lions Club a further \$18,200 had already been received last financial year from this great initiative.

Over \$34,000 in donations was received for a NSW family. Many other donations received total nearly \$17,500.

Fundraising total is \$19,500 with \$14,000 from Sponsor a Triathlete. Elms Luncheon raised \$2000. Other fundraising includes WA Raffle at \$540 and Jewellery Sales at \$750.

Grants received are \$20,000 from the St George Foundation and \$2,500 from Camberwell Rotary.

Other income includes Members Subs at \$1,700 and Interest from Term Deposits at nearly \$4,000.

Total Income for the year to August 09 is \$143,230. This year's income may even exceed the \$155,000 of last financial year.

As a consequence, this has allowed a year to date distribution to Parents of sick children of \$75,000.

Over \$30,000 of expenditure has been incurred in Insurance, administration and maintaining the support services Australia wide to the ALDS community. The surplus of \$37,600 will ensure that ALDS meets its ongoing and future commitments, provides funds for the replacement of depreciating assets, plus ensures that the ALDS organisation remains financially sound.

Once again your continued support is greatly appreciated and thanks to those members who have paid their annual membership subs.

Tony Laragy - Aug 09



Sister's Care Continues



Sister Julie Thomas

A MENTONE woman has vowed to continue her work caring for those affected by a rare genetic disorder.

Brigidine sister **Julie Thomas**, who founded the Australian Leukodystrophy Support Group 17 years ago today and remains its president, said the disorder was devastating for families. "Hearing the news they just can't believe it " Sister Thomas said. "They are in a state of shock, sometimes denial." Leukodystrophy is a group of inherited, progressive genetic disorders affecting about one in 5000 people worldwide. Featured in the film *Lorenzo's Oil*, it has no cure and many children with the condition die at an early age. Sister Thomas was diagnosed with X-linked Leukodystrophy when she was 38 and now uses a wheelchair. Her two brothers died from Leukodystrophy aged 17 and 11. Sister Thomas, who was awarded the Medal (OAM) of the Order of Australia in 2001, said her group relied on volunteers and received little government funding, making donations vital. For more information phone 9584 7070 or go to alds.org.au

Published in Mordialloc/Chelsea Leader Newspaper August 17th 2009.

The Companion Card allows people with a profound disability, who require attendant care for the rest of their lives, to participate in community activities and events without discrimination. Companion Cards can be presented at participating organisations where cardholders will not be required to pay an admission fee for their companion who is providing attendant care. Participating organisations (affiliates) will recognise all Companion Cards, which share common visual identity and security features. The Companion Card operates throughout Australia and more information is available on their website www.companioncard.org.au

Make-A-Wish Foundation of Australia

All Leukodystrophy families are eligible for assistance from the Make-A-Wish Foundation. Make-A-Wish Foundation of Australia is a not for profit charitable organisation that grants wishes to children with life-threatening illnesses. Children up to the age of 4 can receive a Wish Gift Package which is personalised for the child's special needs and interests and siblings are also eligible for a personalised Wish Gift Package. Children between the ages of 4 and 18 are eligible for a full wish which can vary from family holidays, computers, cubby houses or meeting a favourite celebrity.

STATE NEWS

New South Wales

ALDS Fundraising GOLF Day – NSW

We have a handful of teams confirmed for the Leukodystrophy Golf Day and Lunch at Northbridge Golf Club in Sydney on the 23rd October 2009, but we need the support of our members (particularly those from NSW) to help make this event a fundraising success.. We ask if you have any friends or corporates in Sydney who may be interested in participating in this special ALDS fundraiser to contact us for registration procedure by visiting our website at www.alds.or.au

Another request is whether anyone has any tangible items that we can add to our prize list, so please contact the office for more information.

Earl Schonberger - NSW

South Australia

Alister Haigh the CEO of Haigh's Chocolate Factory with regard to sponsorship as previously discussed with the committee. I have organised a Factory Tour and afternoon tea at Haigh's for 1.30pm Saturday afternoon 17th October, to celebrate 'Carer's week'.

I have arranged with Muscular Dystrophy Association to have a family luncheon on Saturday 7th November at the association rooms similar to the one previously organised by Leanne Longfellow. This will be funded by Haigh's. Haigh's will forward a cheque for \$500.00 to cover the luncheon.

Sally McDonald – S.A.

Western Australia

All Western Australian families have been contacted either by email or by letter regarding the Christmas event. This promises to be great fun for all.

Date chosen is the 12th December.

I have made contact with Erin Dickman, the OT at Bentley Hospital. She is giving some great support to a man who is great need. She is also in close contact with Jan de Frank, Dr Phillipa Lamont's assistant. I have supplied the DVD to Erin and she will forward that to Jan.

Bethanie is supporting this man well with home showering and visiting three times a week. He received his Sunbeam electric rug from ALDS and is finding it a great comfort. It has been unseasonably cold here.

A family from Merredin is receiving more assistance now, making things a little better for them. They will relocate in January and hope for a purpose built home through the Education Department to be ready the next year. Our other families seem to be managing right now and Josh Yates is achieving great results in a range of sporting events.

A sister of one of our sufferers continues to fund raise through her meat raffles, in spite of a house and career moving taking a lot of her time.

Veronica Seeber – W.A.

MAKE MY DAY - “Family’s Heartbreak – Please give our sick boy a home”

The following is part of the story of the Groves family that was published in a June 2009 edition of Woman’s Day. . .

“Aron now 7 had always been a happy little boy who loved nothing more than playing outdoors and wrestling with his dad.....

After several tests, the paediatrician noticed Aron’s behaviour was becoming erratic and suspecting he had small blockage in his brain, recommended an MRI scan. But the results were worse than Suean and Daniel could ever have imagined. Suean remembers “I knew something was very wrong. They showed me Aron’s MRI scan and I could see a white cloud over half of his brain. Then they told me he had a degenerative brain disease and he probably had about a year and nine months to live.

After lots of research, Suean learnt ALD is a genetic disease that occurs in boys, usually between the ages of 4 and 10. The gene is carried by women, so she had unknowingly passed it on to Aron. “All the women in my family have had daughters” Suean says, “So there was no way any of us knew we were carrying the gene. Aron was the first boy” Sadly since the New Year Aron has deteriorated and has now lost his vision and needs a wheelchair to get around. Desperate for help, Suean turned to the “Make My Day” team.

Woman’s Day was more than happy to donate \$8000 to help Suean and Daniel get a foot in on the property ladder, and create a home where they can make lasting memories of their time as a family.



Suean, Aron, Daniel and Melanie Groves

WE WOULD LIKE TO HEAR FROM YOU

If you are a new family to the ALDS or an existing family or member and have a story to tell we are interested in hearing from you. Even if your story is in the current Story Book, there may have been changes in your life that you can share with us.

These stories can range from

- Caring for the older or younger siblings and how it has affected them. They may like to write their own story for us.
- How to cope going on holidays.
- Deciding on having more children.
- What sort of respite services you may use to “Have a Break”, in your State/City.
- Sharing your web site. The Links Category of the ALDS mc2 web site has a link which can allow you to publish the address of your personal web site. <http://mc2.vicnet.net.au/home/alds/index.html>

Well done Josh!

The World Transplant Games are held every other year, are open to participants who have had any life-saving organ transplant and are on a regime of immunosuppressant medication. Up to 2000 participants from 50 countries competed in 14 sports between August 22nd and 30th, and this included 300 Australians, one of them being Josh Yates. Jane Yates was pleased to announce the “Great News” that her son Josh won a bronze medal in the 5000m walk, did the 5km road race (7th), ten pin bowling (10th), 1500m (5th), 800m (8th), the 4 x 400m relay, and last but not least – he also had the time of his life.

The Busselton Newspaper in WA published an editorial about the 17th World Transplant Games – Queensland.



Josh Yates and pictured with another local athlete who took part in the 17th World Transplant Games

Josh had a bone marrow transplant for treatment of Adrenoleukodystrophy in August, 2004.

Contacting the Editor

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Please send articles for the next newsletter by the 7th December, 2009. Articles can be posted or faxed. For all emails could they please be sent as a word document attachment?

Thank you

DISCLAIMER

The Australian Leukodystrophy Support Group Inc. (ARBN 091 020 021) is proud to be a source of information about the Leukodystrophies. Our comments are based on professional advice, published experience and expert opinion, but do not represent therapeutic recommendation or prescription. For specific information and advice, consult your doctor.

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