



# THE OSTEOGENESIS IMPERFECTA SOCIETY OF AUSTRALIA

## NEWSLETTER

ISSUE No: 5

WINTER JUNE/JULY 2005

### PRESIDENT'S MESSAGE

Hello Members and Friends,

I hope everyone is well and isn't freezing to death with the latest cold snap. I am definitely not a winter person. The oi' bones don't like it either and we both will be looking forward to Spring!

The OI Board have been extremely busy. Recently we held a very successful Trivia night, where we raised approximately \$3500.00 for our kitty. Chris Taig has written an article in this newsletter, so please check it out for the ins and outs of the night.

We are also busy organising our 2<sup>nd</sup> OI Adults Information Day. We would love to see all of our OI Adults there along with parents of OI teenagers who are about to enter "Adulthood". The day will be held at the Wesley Lodge Westmead. You will be receiving an invitation soon, so please keep the day free. To cover the costs of catering on the day a fee of \$30 per person will be charged. However for OI members the cost has been reduced to \$15.00. Some of the topics to be covered on the day will be Health Issues, Osteoporosis, Pregnancy, and Transition from paediatrics to adults. Speakers confirmed at this stage are Professor David Sillence, Dr Michael Hooper and Dr Craig Munns. The 2005 AGM will also be held at 2pm during the day. I am looking forward to catching up with you all!

Can you believe it is Conference time coming again? Get out your diaries and write down the dates. We have already booked the Collaroy Centre and will send out registration forms as soon as speakers and the programme have been confirmed. Our board members are working extremely hard for you and we would appreciate your support towards the OI Society by coming along to our Events.

A special mention to thank Janet Swift our secretary, who has been extremely busy keeping the running of the Society smooth and efficient. Janet, as all of our board members does this on a voluntary basis and I thank them for their dedication and hard work

Love, Smiles and Sunshine

Julie Stonestreet  
President  
OI Society of Australia

<b>WHAT'S IN THIS ISSUE</b> Presidents Message From the Editor For your Diary State Representatives Items of Interest Latest News Updates Membership renewal
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## FROM THE EDITOR

Hello Everyone!! Well winter is now upon us and those early mornings and evenings are seemingly somewhat chilly. It's hard to believe we have actually been hearing the sound of rain on our roofs – something that most of us are sadly forgetting the sound of!!

I hope you are all well and ready to read our latest newsletter. The Board is very pleased to announce that the OI Australia webpage is finally up and running – you will find details in this newsletter.

I would also like to remind our members and friends, that we love to hear from you – so if you have some news or a story to tell, email me, or one of the board members so we can publish your story in the newsletter. We try our very hardest each issue to provide you all with new and informative topics, however we do need a little help from our friends (so to speak) with feedback on what information that you would like to see in the newsletters. It is often hard to please every reader, so a little feedback would be appreciated.

Fiona Winters  
Board Member

*“For poise, walk with the knowledge that you will never walk alone” Audrey Hepburn*

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### THE OI BOARD 2004/2005

<b>President:</b>	Julie Stonestreet	Ph: 02 9586 4143	Email: jstonest@bigpond.net.au
	Lynne Foxall	Ph: 02 9869 1486	Email: petlyn@hotmail.com
	Peter Foxall	Ph: 02 9869 1486	Email: petlyn@hotmail.com
	Mike Kendall	Ph: 02 9624 5719	Email: mike.kendall@bigpond.com
	Janet Swift	Ph: 02 9871 8283	Email: b_jswift@optusnet.com.au
	Suzy Winch	Ph: 02 9440 3895	Email: swinch@bigpond.net.au
	Chris Taig	Ph: 02 9626 8417	Email: pa_ma_taig@hotmail.com
	Sue Chamberlain	Ph: 02 9621 6269	Email: <a href="mailto:djchambo@optushome.com.au">djchambo@optushome.com.au</a>
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NB. The Osteogenesis Imperfecta Society of Australia is affiliated with the OI Foundation (USA), and the Osteogenesis Imperfecta Federation – OIFE (Europe). Their websites are: [www.oif.org](http://www.oif.org) and [www.oife.org](http://www.oife.org)*

### FOR YOUR DIARY

- Splash (Swim-a-thon) ConnecTed. Saturday 10<sup>th</sup> September 2005. Sydney Aquatic Centre, Homebush Bay. 9am – 12.00 noon.
- OI Adult Day – Saturday 17<sup>th</sup> September 2005. Venue: Wesley Lodge Westmead
- OI Society AGM – Saturday 17<sup>th</sup> September 2005 at 2pm. The AGM will be held during the OI Adults seminar day.

## STATE REPRESENTATIVES

*Please find below a list of our state representatives.*

### STATE REPRESENTATIVES 2004/2005

- ACT: Christine Martin (02) 6291 9969
- NSW: Julie Stonestreet (02) 9586 4143
- QLD: Rachael Richards (07) 3841 4057
- SA: Therese Lampe (08) 8362 7011
- TAS: Sue Cenin (03) 6247 3240
- WA: Hazel Bellman (08) 9250 3737

## ITEMS OF INTEREST

### Trivia Night

On Saturday May 7<sup>th</sup> 2005, we held our trivia night at St Bernadette's Parish Hall, Lalor Park.

About 115 people were in attendance, all excited and filled with a wealth of knowledge. There were a few OI families that arrived with friends and family. We also had a couple of 'kids' tables and even a table of teachers. The local community supported us by supplying trivia enthusiasts and some great donations of prizes.

The fun began about 8pm, and Sue Babb (our Trivia buff) had organised some very interesting questions that kept us all thinking. Muriel Mastrippolito was our MC for the night and added to the fun atmosphere. We started with 3 rounds of 10 questions before we had our first heads and tails contest. This was followed by two more rounds of questions before having a break to devour some delicious supper, which included Krispy Kreme donuts and Michel's Patisserie goodies from Michel's Patisserie at Marayong. Yummmmmmy!!!!

During our supper break, there was some contesting going on for the items in the silent auction. We had electrical appliances, movie tickets, a car service and a Bridge Climb for 2, just to name a few. There was also tickets to buy for the raffle that include baskets of goodies, sports clothes and videos. It was during this break that we drew the lucky door prize of a meat tray!

It was now time to get back to another 5 rounds of questions with another heads and tails contest in between. Just after 11pm we announced the winners of the auction, drew the raffle and awarded the prizes for 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup>, last and the best kids table.

The organisers went home exhausted but very pleased that so many people had had such a great night and raised \$3,500 for the OI Society. What a wonderful way to raise money and have a fabulous time in the process!!

## ITEMS OF INTEREST – CONT'D

### *OI Website*

We are pleased to announce that our Web page is finally up and running. The website address is: [www.oiaustralia.org](http://www.oiaustralia.org).

Listed below are a few contact email addresses.

- Julie Stonestreet [Julie@oiaustralia.org](mailto:Julie@oiaustralia.org)
- Lynne Foxall [lynne@oiaustralia.org](mailto:lynne@oiaustralia.org)
- President [president@oiaustralia.org](mailto:president@oiaustralia.org)
- Fiona Winters [newsletter-editor@oiaustralia.org](mailto:newsletter-editor@oiaustralia.org)

### *Genetics Service*

The Greater Southern Area Health Service – facilitating Goulburn, Cooma, Yass, Queanbeyan, South Coast and Far South Coast.

Matthew Burgess had recently started as the new genetic counsellor based in Goulburn. He joins Christine Ward, the genetic counsellor in Wagga. Together they make up the Genetics Service for the Greater Southern Area Health in NSW.

This service provides individuals, couples and families with up-to-date information about genetic conditions. Information can be provided regarding testing, diagnosis, counselling and support to people who have concerns about conditions which may have a genetic component.

The service is covered by Medicare, and a referral letter from a local doctor is required to see the Geneticist.

- For more information, contact:  
Matthew Burgess (Associate Genetic Counsellor)  
Child, Infant and Family Tertiary Service  
195 Faithful St  
(Locked Bag 15)  
Goulburn, NSW, 2580  
Ph: 02 4827 3950  
Mon – Fri 8.30am to 5.00pm

## ITEMS OF INTEREST – CONT'D

### *Disability Housing*

Northcott Housing Links (part of The Northcott Society) have several houses/units available for short term accommodation. The accommodation is provided for people with disabilities.

For further information regarding accommodation, please contact Jenny Sanders, who is the independent living co-ordinator at Northcott.

Email address: [JenniferS@northcott.com.au](mailto:JenniferS@northcott.com.au)

Phone: 02 9890 0902

### *Low Cost Internet Services For People With Disabilities*

About 250,000 aged, Veterans and people with disabilities throughout Australia will have access to a low cost Internet service thanks to a partnership arrangement negotiated by Technical Aid to the Disabled Australia. Details of the partnership between TADAust and the internet services provider ISPOne were announced on Friday, 20 May in a joint statement by the ACT Minister for Disability, Housing and Community Services, John Hargreaves and ACT Liberal senator, Gary Humphries.

The partnership will enable the aged, veterans and people with disabilities to go online at the vastly cheaper rate of only \$5.50 a month. Such internet services usually cost \$30 to \$40 a month. Normally the cost of such access is beyond the reach of many of people with disabilities, Veterans and the aged and their carers. However, this agreement will provide a wonderful new range of opportunities for people to improve their quality of life and their independence,

The dial-up service to be provided by ISPOne includes no setup fee, unlimited downloads and flexible contract arrangements. It will be fully supported and available to people with a Disability Support Pension, a DVA Entitlement Pension and an Aged Pension Card, and also to TAD clients.

Technical Aid to the Disabled is a national not-for-profit organisation that aims to improve the quality of life, and independence of people with disabilities and the aged, through the application of technology, and the work of volunteers.

For more information and to register please contact TadACT on 02 6287 4290 or visit the website at [www.tadaustconnect.org.au](http://www.tadaustconnect.org.au)

### *For Sale*

Apartment for sale, fully designed for wheelchair access. If anyone is interested please contact Century 21, Beecroft.

For further details on description of apartment, location and cost, please phone:

- Office phone: 02 9484 3330
- Or Contact Matthew 0404 045 461

## LATEST NEWS UPDATES

### *Clinical Trials and Bisphosphonates*

The OI Society of Australia and OI Foundation (USA) has linked WebPages on important information concerning **CLINICAL TRIALS & BISPSPHONATES**.

**The OIFoundation's webpage address is: [www.oif.org](http://www.oif.org)**

Under Medical Treatment: On-Going Studies: Bisphosphonate Studies.....  
Is an excellent source of information about the Treatment and Trials of Bisphosphonates.

**POISE (Paediatric Osteogenesis Imperfecta Safety and Efficacy) study sponsored by Proctor & Gamble Pharmaceuticals and Sanofi-Aventis, is currently recruiting children with Osteogenesis Imperfecta (OI).**

**The study is a three-year study of an oral bisphosphonate, Residronate, for the treatment of the OI Child.**

This study is being conducted on an international level with three current Australian sites:

- The Children's Hospital at Westmead,  
Professor David Sillence, Clinical Geneticist  
Dr. Craig Munns, Endocrinologist  
Contact No. (02) 98450000
- The Princess Margaret Children's Hospital, Western Australia.  
Dr. Elizabeth Davis, Endocrinologist  
Contact No. (08) 93408222
- The Royal Children's Hospital, Brisbane.  
Dr. James McGill, Metabolic Paediatrician  
Contact No. (07) 3636 3777

For more information or if you think your child would qualify for the study please contact the nearest site to you.

**MEMBERSHIP RENEWAL FOR THE FINANCIAL YEAR**  
**1<sup>ST</sup> JULY 2005 TO 30<sup>TH</sup> JUNE 2006**

**The Society was formed in 1977 by parent and friends of those with O.I. and is a Voluntary organisation with no paid staff or Government funding.**  
**THE SOCIETY IS REGISTERED AS A COMPANY LIMITED BY GUARANTEE UNDER THE COMPANIES (NSW) CODE.**

To enable us to continue our work of supporting vital Medical Research and passing on important information to people with O.I. their families and other interested people, we need your support.

Membership is \$10.00 (includes GST) per person per year.  
 Payment can now be made by cheque, Money Order, Bankcard, Mastercard or Visa and any donation over \$2.00 is tax deductible, **Credit Card payment minimum \$10.00**

TITLE	FIRST NAME	SURNAME	
ADDRESS:			
SUBURB / TOWN		STATE	POSTCODE
Telephone No's:			
EMAIL:			
Membership 2005-2006 - \$10.00 per person (incl. GST)			\$
Donation (Tax Deductable)			\$
<b>TOTAL</b>			\$

I submit the above payment for the Total of \$.....

By  Cheque,  Money Order  
 or please debit my  Bankcard,  Mastercard,  Visa Card

Cardholder Name \_\_\_\_\_

Card Number     →     →     →     →     →

Expiry Date   → /   →

**Cardholder Signature** \_\_\_\_\_