



The OSTEOGENESIS IMPERFECTA Society of Australia Newsletter

June 2006

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Contents

- 1 President's Report
- 2 The Hermanns
- 2 Jacky Cramb
- 3 Sue & Sophie
- 4 GPs: Valuable Allies
- 5 Web/Sights
- 6 Crossword
- 7 Getting enough sun?
- 8 Board Members
- 8 Noticeboard

N.B.

□ Membership forms due in

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President's Report

Hello Members and Friends,

I hope that you are all well and have recovered from the OI conference.

There is truly only one word to describe our conference this year – 'SUCCESSFUL'. I think that it was definitely our best one yet. Thanks to the hard work that went in behind the scenes by our committee members and the people who came and supported us it was a magical weekend.

We held the conference at the Collaroy Centre at Collaroy from the 31st March – 02 April 2006. Most of us arrived on Friday night where we had a yummy dinner and I had the honour of opening our 9th conference.

We then had a fantastic and inspirational speaker Mr Phil Vardy, who is currently a Vice President of

the International Foundation for the Disabled and was a co-founder of 'Sailability' which is an organisation which helps people with disabilities sail. Phil was injured in a motorcycle accident, but hasn't let that stop him from getting out and enjoying his life to the full. He even bought in one of the boats that he has used to sail on Sydney Harbour. It was certainly a very interesting and uplifting start to our weekend.

Up bright and early the next morning for the start of our day of learning both from our speakers and each other, supporting one other and making new friends. Professor David Silence talked about 'what we need to know about OI in 2006' followed by Associate Professor Professor Hooper and Janine Dawson giving a talk about

'osteoporosis'. Dr Craig Munns then gave a talk on 'Dexa and Comparative Studies of Bisphosphonate in Children' followed by Dr Joanna Walton who talked about 'Hearing loss and the OI person'.

The afternoon was just as informative with Ms Claudine Parr talking to us about 'Centrelink', Dr Angus Gray

—Cont' page 7

Annual General Meeting

RSVP

– Julie Stonestreet –
(02) 9586-4143
or
– Janet Swift –
(02) 9871-8283

Please RSVP for Catering Purposes
by Monday, 10th September

Sunday, 17 September 2006

Anzac Room – Auburn RSL

33 Northumberland Road, Auburn

12 noon – Lunch available at the RSL

1.30-2pm – Speaker, Heidi Forest,
President of People With Disabilities (PWD)

2pm – Annual General Meeting

2 *The Hermanns*



To the OI Committee,

We would like to thank you and all those involved in the recent OI Conference for enabling us to be a part of such an enjoyable and informative event.

We were so excited to be able to attend our first conference and as parents of Morgan (OI Type 3, Age 5) we still had many questions, most of which were answered during the weekend at the Collaroy Centre.

We found that not only did we learn many new things, some good and some not so, but the speakers also refreshed many things we had known but mentally archived over time.

We were very privileged to have one on one time with Prof. Silence who guided us through a difficult and on my part, emotional discussion on Basilar Invagination. We found each speakers' content very informative and relevant to our situation. We were very blessed to meet so many amazing people and their families, and have made

some lifelong friendships because of this.

It was also great to be able to put faces to the members of the OI Committee who work tirelessly to provide us with access to such an informative event, as well as the fantastic website and all the behind the scenes work including fundraising and meetings.

The event was also wonderful for Morgan as even though she knows a few others with OI the conference reinforced to her that there are many people in the world just as wonderful as her. Morgan and Keiley also loved the activities for the kids and the wonderful ladies who kept our little "angels" busy.

The Collaroy Centre was a brilliant venue and the staff made us feel very welcome and accommodated any needs that we had. All in all we found the conference to be a great success and we just want to know "When do we sign up for OI Conferene 2008".

Our kindest regards and warmest wishes to everyone. ☺

Sandy, Jamie, Morgan & Keiley Hermann
Queensland, April 2006

Jacky Cramb

I was looking forward to attending my first national conference and meeting the 'Sydney folk' as they seemed to have such a presence in the osteogenesis imperfecta world in Australia.

The first person I met was Janet who accosted me as I struggled up the hill with my suitcase. I found Phil Vardys's talk inspiring, deciding that I too could sail! To me as an observer, all the participants displayed their unbreakable spirit in their struggles and achievements in life. I particularly found Jules's talk inspiring and will never complain about anything when I travel again.

I wish you all well in your endeavours to support each other and look forward to attending again ☺

Jacky Cramb
Queensland, April 2006



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Sue and Sophie

I feel extremely privileged to have attended the 9th National Conference on Osteogenesis Imperfecta with my daughter, Sophie. Not only were we able to keep abreast of the latest in medical research and rehabilitation relating to OI, but we had the opportunity to meet some of the most positive, caring, compassionate people we are ever likely to meet.

Having attended one previous OI Conference, about 8 years ago, I was looking forward to hearing Professor Sillence and Doctor Ault talk about their specialist areas. We are a lucky group of people to have two experts who care so much about OI individuals and their families. The knowledge they are able to share with us assists immensely by enabling us to become empowered by increasing our own knowledge. I was also very interested in the information shared by Doctor Craig Munns and Doctor Joanna Walton. Again information gained from these talks was able to improve my understanding of OI.

As Jenny Veliscek indicated, it is vitally important to be knowledgeable about OI when dealing with the medical profession about OI related issues and care. The talks given by all from a medical perspective have certainly allowed me to go a long way towards this.

As a parent of a daughter with OI, I worry about the issues she will face as she grows up. What an opportunity the Conference gave me to ease some of these concerns. Thank you to all those who took the time to talk to Sophie on a one to one basis, and shared some of their own experiences with her.

Thanks also to all the other parents and OI people who talked to me and gave me tips and advice. I think



the time we had talking with each other informally was invaluable and I feel heartened by the positive attitude that is so evident in OI sufferers and their families.

Sophie has already started planning for us to attend the next OI conference (in between emailing all her new friends from the conference) and we hope that more of our WA contingent will also be able to come.

Thank you to everyone who worked so hard to put together a fantastic conference and thank you also to all the wonderful people who attended and made our weekend at Collaroy one that we will remember for a long time.

Sue Keay
Perth, Australia



We welcome new members of this email group **from New Zealand and throughout Australia.**


A contact, support and information group for people with Osteogenesis Imperfecta, their families and those who care for them.

<http://groups.yahoo.com/group/OISociety/>

Our email discussion group is

- to offer support and information about living life with Osteogenesis Imperfecta (Brittle Bones);
- to facilitate contact with others who understand your experiences;
- to share links to medical professionals who can care for kids and adults with brittle bones;
- to enable you keep in the loop with state-based OI groups and events;
- and more...

To join, please send a short introduction to the list addressed to craig.andrews@oiaustralia.org

This group is offered by the **OI Society of Australia** and managed by Craig Andrews on behalf of the Board. 



GPs: Valuable Allies

by Dr. Linda Mann MB BS, BSc (Med), FRRACGP

Most of us have a pretty good idea about what we think makes a good GP. Most of us expect good access to a GP when we need it. We also wanted good interaction with our GP. We wanted to be listened to, and to be taken seriously and we also want our doctor to be on time.

There are three main ways to ensure you're on the track to finding a good GP

1. Find someone who is recommended
2. Find someone who is recognised by the profession (on reputation and study)
3. Find someone who is interested in you

Asking friends or family, who they recommend can be one of the most useful ways of finding a good GP. When you find someone who you think you'd like to see, they should have RACGP after their name.

GPs can undertake particular postgraduate study in general practice. These GPs have gained the *Fellowship of the Royal Australian College of General Practitioners* and they will have FRACGP also after their name.

Your GP is a professional, whom you want to be sure is capable of looking after your health. Medical professionals provide an important service within society and have undertaken a significant academic study of health, along with extensive training in health care.

Two remaining points when seeking out a good GP

- * You need someone you can afford to see
- * You need someone who is willing to learn

The best GP is no good if you can't afford them, and the cheapest GP is no good to you, if they are someone you don't want to see.

The GP you're looking for doesn't have to know all about your particular condition, but if they're willing to learn from you and from others, they can be streets ahead already. If money is an issue you should be able to talk to your GP about that.

What to expect when you find your GP?

There are a number of things you can expect the new GP to do for you over the first couple of visits.

You can expect the GP to take your full history as well as your relevant family history. Your GP should also carry out a relevant clinical examination, as well as any routine health checks according to your age and sex. This includes pap smears for sexually active women and prostate checks for men over the age of 50.

Lastly, all good GPs keep one eye on preventive health, such as annual flu injections, risk of heart disease by considering cholesterol, blood sugar, what your mental health is like, how much you smoke, drink and exercise and any other issues considered appropriate because of your particular personal and family history.

Standards in General Practice

GP Standards help guide GPs and their staff. For example, when providing a quality service to you, one example of the standards is practices must provide reminders for patients. Another example is practices must provide facilities for out-of-surgery and after-hours care with tiered options.

A new GP Standard is practices can provide secure electronic communication with patients.

Practices that are willing to measure how well they come up to the standards undergo accreditation. Look for the logo in the practice that says the GP Practice you attend is accredited.

How can you get the most from your GP?

Now that you have found your GP. How do you go about getting the most from the consultation time you have with that GP?

Generally consultation time with GPs are either 20 minutes or 40-45 minutes. You are able to let the office staff or receptionist know if you have time pressures (I have to leave at 2.30 to pick the kids up from school), and they should also do the same (Dr is running 10 minutes late behind today would you like to reschedule?).

As strange as it sounds, one of the best things you can do for yourself and your GP is to make a list. Become a partner in your healthcare, and make a list of the things you need to talk about with your GP. Flag the most important thing on your list with your GP early on in the consultation. If there is insufficient time to address everything on the list, you can decide together what to look out in this consultation and what to leave for later.

Some new initiatives to help patients and GPs

These are referred to as EPC items or enhanced primary care items. These are activities like GP management plans (GPMP), team care arrangements (TCA) and home medication reviews (HMR).

GP management plans offer incentives to GPs to prepare and review patient management plans for patients with chronic medical conditions. For patients

requiring multidisciplinary care from a range of specialists, your GP can also provide you with documents that let you get a Medicare rebate for some allied health attendances. This is recognised by Medicare, as a Team Care Arrangement.

A home medication review assesses a patient's medication management needs and then refers the patient to a community pharmacist for this review. The pharmacist visits the patient at home, where the pharmacist, patient and anyone else the patient desires to be part of the discussion can discuss prescribed medication, over-the-counter medication, and any other drugs or active foods the patient uses for their health. With the patient's consent the GP provides relevant clinical information for the review. The GP then discusses with the reviewing pharmacist, the results of the pharmacist review. The suggested medication management strategies are reviewed by the GP, who develops a written medication management plan following discussion with the patient.


Improved access to allied health practitioners like psychologists have been added to that toolkit for GPs. The allied health professionals that can provide services include psychologists, social workers, mental health nurses, occupational therapists, Aboriginal Torres Strait

Islander health workers dietitians, diabetic educators, podiatrists, exercise physiologists and chiropractors.

On the horizon and mentioned in the 2006 budget, there will be a special Medicare item number, to fund planned annual health reviews for all people, aged 45 with a chronic condition.

Studies have demonstrated that having a regular GP improves an individual's health, decreases the likelihood of hospital admission, decreases the risk of readmission and improves coping skills and mental health.

For GPs, having patients with complex and even rare conditions permits use of skills that distinguish general practice from consultant practice. We get to know you, we age together, and we seek more knowledge to be able to provide the best health-care for you.

Along with gains for the patient there is an increase of professional satisfaction for the doctor as well. We can create a very satisfying and fruitful partnership together. 

Dr Linda Mann MB BS, BSc (Med), FRACGP

Dr Linda Mann is a principal of Inner West General Practice, an award winning general practice (Best practice 1988, Innovation award 2004). Linda practices in Hay with the Royal Flying Doctor Service Women's GP project, and at Balmain General Practice Casualty.

RACGP Standards for General Practice

<http://www.racgp.org.au/standards/>

The RACGP Standards for General Practices are used by general practice accreditation agencies, but the principal aim of the RACGP Standards for General Practices has always been as a tool to assess and improve the care of GP practices.

For more information

Australian General Practice Accreditation
<http://www.qip.com.au/>


Quality Practice Accreditation (GPA Accreditation plus)
<http://www.gpa.net.au/> 




Transition Care Information

www.health.nsw.gov.au/gmct/transition/


- When health professionals in the children's service start discussing "transition" they are talking about getting ready to look for and prepare a young person for adult health services. Transition takes time.

Parents/Caregivers should start to bring up the topic of transition when a young person becomes a teenager. 

Women with Disabilities Online Information


www.wwda.org.au - This directory has recently been developed to help women with disabilities locate information about services and organisations that are available. The information has been organised into various groups and subgroups to enable easy access. 


New online Resources and Services Guide

www.oiaustralia.org/links.html - on the OI Australia website - with links and contact details for a wide range of services and resources for equipment, travel services, support and government services. 

Websites for Siblings

www.siblingsaustralia.org.au - Australian website of Siblings Australia Inc. with information and discussion groups for young children, teenagers and adult siblings as well as resources for service providers. 

www.yourshout.org.au - A website set up as part of the Sibling Project of the Association for Children with a Disability. This website has been created by adolescent siblings to provide a place where young people can express their views and connect with other young people who might share their experiences. 

www.thearc.org/siblingsupport - Website of the Sibling Support Project, a national program for sibling support based in Seattle, Washington. It hosts internet discussion groups for siblings. 

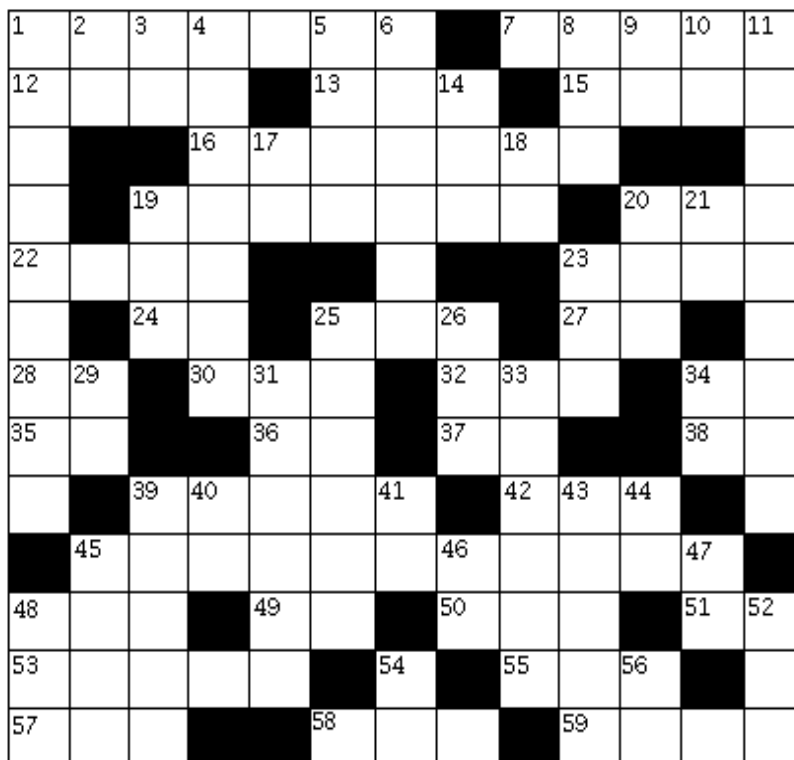
6 Crossword

ACROSS

1. OI is characterised by _____ bones.
7. People with OI have an _____ (mutation) in the genetic instructions on how to make strong bones.
12. OI is a relatively _____ disorder.
13. Containing oxygen or additional oxygen. (**Prefix**).
15. Aviation-related. (**Prefix**).
16. Coming into existence.
19. Bone mineral _____. (BMD).
20. Furnish with support.
22. Obsolete third person singular of *Tread* (from Chaucer).
23. Never pull or push on a _____ of someone with OI.
24. Yes. (**Spanish**)
25. Complex, interconnected structure.
27. Division of the psyche. (**Freud**).
28. Regarding. (**Abbr.**)
30. A signal, such as a word or action, used to prompt.
32. Research has shown that brittle bones is not _____ condition.
34. Move or travel.
35. Former partner. (**Slang**).
36. The symbol for the element *nickel*.
37. 13th letter of the Greek alphabet.
38. Of, relating to, or supporting broad social, political, and educational change. (**Abbr.**)
39. Reminiscent of things past.
42. "Much _____ about nothing."
45. Bisphosphonate used to prevent bone loss, and treat osteoporosis.
48. Young of certain animals.
49. Accomplish.
50. Incoming Call Identification. (**Acronym**).
51. Hewlett-Packard. (**Acronym**).
53. _____ Road: Famous recording studios.
55. Eon.
57. Torres Strait Islander. (**Acronym**).
58. Osteogenesis imperfecta is _____ caused by a lack of calcium.
59. The possessive form of you.

DOWN

1. OI is characterized by frequent bone _____.
2. Ancient Egyptian sun god.
3. Argentina country code.
4. Osteogenesis imperfecta (OI) is a _____ disorder of collagen.
5. Most OI types are said to have an early _____ of hearing.
6. Tariff.
8. Scoundrel.
9. 28 Across.



10. In OI, collagen fibres are either "kinked" _____ broken.
11. Prevents further progress toward an accomplishment.
14. Apart from.
17. Used before words beginning with a vowel or with an unpronounced *h*.
18. New York. (**Abbr.**)
19. Data Encryption Standard. (**Acronym**).
20. Assistance Equipment.
21. Intramuscular. (**Abbr.**)
23. A little white _____.
25. Freak.
26. _____ voyage!
29. From, out of. (**Prefix**).
31. Messy.
33. Subtle shade of meaning.
34. General Practitioner.
39. Scholar qualified to interpret Jewish law.
40. Contraction of *them*.
41. Nearly all cases of OI, mild _____ severe, are caused by a dominant genetic mutation.
43. Milk producer.
44. Occupational therapy. (**Abbr.**)
45. Places of business where alcoholic beverages are sold and drunk.
46. *Hypophosphatasia* is one of several disorders that resembles _____.
47. Used to ascertain or reinforce a listener's interest or agreement.
48. Feline.
52. According to; by.
54. Bone mineral density measurement with DEXA is painless and requires _____ injections or any other advance preparation.
56. Country code for Angola.

Answers in August Newsletter

President's Report Cont'

speaking about 'Scoliosis' and Dr Jenny Ault, Imogen Fisher and Jackie Cramb talking about 'Rehabilitation and Exercise'. I then had the pleasure of doing a talk about 'traveling with a disability'. We were very fortunate to have the best speakers in their field and also that they are so committed to OI.

We all had a wonderful but exhausting day but we all 'glammed' up and headed up to Dee Why RSL for dinner. We enjoyed this free time immensely as we got to wind down from the day but got to know each other better.

Day Two was a slower paced day. Joan Martin from the Northcott society came to talk to us about 'Siblings' and Northcotts services. Ruth Wedd then talked about 'Transitional Care' services and then Dr Linda Mann talked about the 'GP's view of caring of the OI person' (see p. 4). As everyone had such a huge chatting session at lunchtime, we decided instead of breaking into designated groups that we would let groups form on their own so that people could get around and chat with everyone. The conference closed about 2.30pm on Sunday afternoon.

There were months and months of work done behind the scenes before the conference to make it what it was. I would like to thank all those special people for giving up their time to help organise the conference. I especially would like to thank Janet Swift who worked so hard and to Bernard for lending her to us. If you would like to see the photos of the Conference please visit the OI website at <http://www.oiaustralia.org/>.

We normally start organising the next conference about 12months beforehand. If there is something that you



Books/Resources

Busic, V. (2004). *Jason's first day*. Gaithersburg, MD: Osteogenesis Imperfecta Foundation.
(This a good book for introducing the children to brittle bones and has teacher's notes at the back.)

Cintas, H. L., & Gerber, L. H. (2005). *Children with osteogenesis imperfecta: strategies to enhance performance*. Gaithersburg, MD: Osteogenesis Imperfecta Foundation.



particularly liked or would like to have for the next one, please put it in writing to PO Box 401, Epping NSW 1710 or send an email to our secretary Janet Swift at janet.swift@oiaustralia.org

We are very lucky to have Mr Craig Andrews as our web manager as he has done a brilliant job on our website. We have a new look, so if you haven't been on there for a while, please visit us and see what changes we have made. Craig has also set a forum group so that we can chat to each other as a group through the email. You find the information on how you can join by going to <http://www.oiaustralia.org/discussion.html> and follow the links. If you have any questions or concerns you can send your enquiries to Craig Andrews on email craig.andrews@oiaustralia.org

The stork has landed again in the Winters household. Fiona gave birth to Olivia Fiona Winters on the 1st of June 2006 by C-section at 9.30am and weighed 5.7pounds. Olivia has a very excited big sister Annabelle who is now 2 and a half. Fiona and Olivia are now both home and doing great. **Congratulations goes to Fiona and Ross.** We are all very proud of you.

Janet has dusted off her suitcases and has gone overseas with her husband Bernard. I hope that she has a wonderful time and has a well earned rest from all her work as secretary of OI. We look forward to your safe return and all your stories from abroad.

2007 will be the OI Society of Australia's 30th birthday. We are looking at some fundraising ideas for next year. If anyone has any ideas, contacts or wants to be involved, please let us know. We have grown so much in the last 30 years from a small support group to an Australian society. It is because of **the support from YOU** that will keep us going for the next 30 years.

We want to grow stronger and better every year so please continue your support.

Love, Smiles and Sunshine,
Julie Stonestreet
President - OI Society of Australia



Women with Disabilities, Australia (WWDA) is the peak organisation for woman with all types of disabilities in Australia. WWDA is a national voice for the needs and rights of women with disabilities and a national force to improve the lives and life chances of women with disabilities. WWDA addresses disability within a social model, which identifies the barriers and restrictions facing women with disabilities as the focus for reform.

Telephone (02) 6244 8288 Email wwda@ozemail.com.au

Web <http://www.wwda.org.au/> Postal PO Box 605, Rosny Park Tasmania 7018



□ For Your Diary

Christmas Party

Sunday, 3rd December



Annual General Meeting

RSVP
– Julie Stonestreet –
(02) 9586-4143
or
– Janet Swift –
(02) 9871-8283

Please RSVP for Catering Purposes
by Monday, 10th September

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Views expressed in this publication are those of the individual authors and not necessarily those of the *Osteogenesis Imperfecta Society of Australia*. The material supplied is for information purposes only and not to be used for diagnosis/treatment or any other type of advice. The Editor of the *Osteogenesis Imperfecta Society of Australia* Newsletter reserves the right to edit contributed articles for grammar, spelling or space.

OI Australia Board

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– Phone (02) 9871-8283

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Julie Stonestreet – **NEW SOUTH WALES**
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No one at present – **NORTHERN TERRITORY**

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Abby Myer – **SOUTH AUSTRALIA**
– Phone (08) 8367-9787

Sue Cenin – **TASMANIA**
– Phone (03) 6247-3240

No one at present – **VICTORIA**

Hazel Bellman – **WESTERN AUSTRALIA**
– Phone (08) 9249-3069

