

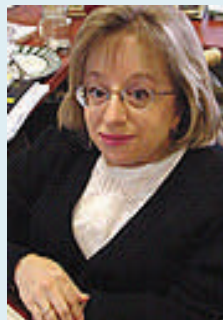


2009 Newsletter Winter Edition

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PRESIDENT'S REPORT – JULIE HARAKSIN



Hello everyone!

We are so glad to get this newsletter out! A lot is happening with your OI Society of Australia Board and we are keen to pass it on!

Society AGM

The Society's AGM for this year will be 27 September 2009 at the Auburn RSL from 2.00pm - 4.00pm. We are working on the agenda and are open to suggestions.

Society Living in the Community Survey

Another important initiative underway is a joint survey between the OI Society and Ability First. Ability first is a national body of leading disability organisations working to achieve a fair go for Australians living with a disability. Member organisations were

originally the State Based Crippled Children Societies that now include:

- Cootharinga Society (North QLD),
- Montrose Access (QLD),
- Northcott Society (NSW),
- Novita (SA),
- Rocky Bay (WA), and
- St Giles (Tas).

The survey will provide the Society and the service providers with a picture of what you and your families need from us to be informed about OI and participate fully in the community. We may also use it to lobby the government for more services or research in response to the issues raised. We appreciate the time you take to answer the survey and will report on it at the National Conference. Your input can be provided anonymously and will not be associated with you. In fact you may receive the survey more than once, since each organisation will post a copy to all on its mailing list.

Information resources

We are working with Professor Silence to

publish several booklets, the first is a reprint of How To Care For A Child With OI. He and the Board are also interested in one on the medical issues for adults with OI. This would bring together much of the research and experience of adults with OI and practitioners who may not be aware of the many medical and allied health issues we may encounter. I think these booklets would be very helpful for all of us including our State Representatives who are the front line with new families across Australia.

In the meantime, we have had several contacts from Australia and overseas of people recently diagnosed with OI. Some have access to reasonable care, while others have not been told of the many options such as surgery and Bisphosphonates. Our reach can be far and wide and yet even locally we have people who need our help. Please continue to join us in supporting one another and looking toward the future.

Julie Haraksin

OI Society President

02 9418 7795

9th—11th April 2110



OI Society of Australia Biannual Conference

In 2010 we will be holding our National Biannual OI Society of Australia Conference from 9 - 11 April 2010.

We have scheduled it over the Easter Break so it would be warm and would allow families to combine their travel to the conference with possibly an Easter holiday or

clinic appointments (or both!)

Speaker options and possible activities are under consideration now, so if you have any requests, please contact us ASAP.

oiaustralia@westnet.com.au or ring Chris on (02) 9626-8417

Please let us know if your contact details have changed as we

will be sending registrations out at the end of the year

For more information about the Collaroy Centre please check out their website

<http://www.collaroycentre.org.au/>

Facebook is a fantastic way for you to put your thoughts feelings or ideas and let us know what YOU want!



OI Society of Australia is on FACEBOOK

We have set up a Facebook page for the OI Society of Australia where you can catch up on events, issues and discussions.

It is an easy way we can all keep in touch.

To join all you have to do is type in OI Society of Australia in the search box and you should bring up our page. You just click to join.

If you have any problems in finding us please contact Julie Stonestreet and she will send you an invitation.

Please note that wall posts do not go into your inbox so please check the site to see any messages or updated information.

Any special information will be sent out to members in a separate email

Thanks to the people that have already joined. Please feel free to write your thoughts or ideas on our page.

The Yahoo OI Society Group is still open too and if you are part of that group you have probably seen mine and others' postings.

ConnectED Fun Day– 30 August 2009 11am

The Society is joining ConnectED in a fun get together on 30 August 2009. The day will include all of the organisations and families with connective tissue dysplasia disorders.

The Connective Tissue Dysplasia (CTD) Clinic at Westmead have been tirelessly responding to the needs of children with over 600 connective tissue dysplasia disorders for

over 27 years and now it is our turn to thank them for all their work, while having fun.

Come join us for an interactive, fun-filled day at the "Let's get ConnectED" Picnic in the Park.

Admission is free! and each family will receive a free show bag!

The event is on Sunday 30th August 2009, from

11 - 3pm, at Egret & Heron Picnic (SITES 3 & 5) Bi-Centennial Park, HOMEBUSH NSW.

To register your interest please email Lynne Foxall of lynnef@chw.edu.au or check their website

<http://www.connectedforkids.org.au/>

ConnectED



A little birdie told me it is Professor David Sillence's birthday and we will be having a cake for him

Are you a Webmaster or Journo?

The Society is looking for a member who can provide webmaster assistance for our website.

Do you have some experience with websites, know 'html' and are interested in volunteering your

assistance to the Society?

You don't even have to live in NSW as we are happy to email or post the information to you and all you have to do is type it up for us.

We are also looking for a new newsletter editor! If

you are interested, please ring Chris Taig for more information

Chris Taig
(02) 9626-8417



Corrimal Beach Tourist Park–Wheelchair Accessible

Corrimal Beach Tourist Park is located on picturesque Corrimal Beach, approximately an hour's drive south of Sydney airport and just 5kms north of the vibrant and beautiful city of Wollongong with cycle way access all the way to the CBD. The region and local area offers many attractions including sightseeing, arts, entertainment and

recreation facilities, shopping and a selection of excellent restaurants, cafes and clubs.

The park has a 3 bedroom wheelchair accessible cabin (mountain view room) which sleeps up to six people.

The cabin has a fully equipped kitchen with bench height adjusters. There is a pullout pantry/ cupboard.

The bathroom is fully accessible although you will need to provide your own shower chair.

The property also has a washer/dryer, LCD TV, DVD, mini stereo and gas bbq

For more information and prices please contact

Lake Parade, Corrimal NSW 2518. 4285 5688

Great travel idea from \$145 per night

Do you have any other great accessible travel ideas

OI Xmas Party–29th November 2009

A DATE FOR YOUR DIARY

The OI Society of Australia Xmas party will be held at Auburn Community Picnic Centre.

Invitations will be sent out closer to the

date but we wanted to let you know to keep it free for your diary.

REASONS TO COME TO THIS YEAR'S XMAS PARTY

- Connect with old friends
- Make new friends

- Find out what is happening with the OI Society
- Talk to other people with OI and share ideas
- See Santa



OI XMAS PARTY

Preparing for Natural Disaster Emergencies with a Disability

The recent bushfires in Victoria and floods in Queensland, highlighted the need to be prepared in case of emergency. This is important for everyone in the wider community, particularly if you live in an area prone to fire, flood or other natural disasters.

What kinds of plans do you need to put in place if you are living with OI or live with others with OI? It's important to think about what steps you might need to take to be prepared particularly any extra preparation that might be needed.

It is recommended that a person with a disability have a personal support network of people who will check in on them to see that they are ok. This includes at one's workplace or school.

It is also important to plan where to go in an evacuation and how you will get there. If you have a disability, you might need to be evacuated earlier. Become familiar with two travel routes.

They also recommend you set up a family communication plan. Have extra food and water supplies available and make sure you become informed about local emergency services in your local area and state. Keep a list of emergency telephone numbers on your fridge (and stored on your mobile perhaps?) Prepare an emergency kit:

- A waterproof container with copies of important documents
- A summary of basic medical information and medications.
- Medical kit – first aid and splinting materials.
- Equipment like a flashlight, batteries, portable radio, sturdy gloves, solar or battery re-charger.

Do you have a battery operated torch/ radio?

The NSW Government State Emergency Service or SES has a list of suggested Home

Emergency Kit. This can be found at www.ses.nsw.gov.au Check your state emergency service for information relevant to your state or territory.

Some of the suggestions they make for an emergency kit include: equipping yourself with a portable radio, spare batteries, torch, first aid kit, gloves, important documents and emergency contact numbers. Often its recommended to keep a home emergency kit in a waterproof storage container, but depending on your mobility needs a waterproof backpack or satchel might be a better option.

If you have to leave your home it's important to take any medications or medical documents you might need.

Remember everyone's needs are different but its a good idea to do some of your own research and preparation 'just in case'.

TAFE Disability Services - Are you ready to study after school?

There are disabilities services available to both enrolled and prospective TAFE NSW students who have a disability.

TAFE NSW employs specialist Teacher/Consultants for Students with Disabilities to ensure that people with a disability have equal access to education and training at TAFE NSW campuses. Teacher/Consultants provide a range of services to assist students. These include pre-course counselling and assistance with the enrolment process, as well as determining the most appropriate classroom support and assessment

modifications. A range of strategies can be employed and may involve tutorial support, the use of adaptive technology, a sign language interpreter, note-taker or disability assistant. These adjustments may also apply to students who have a temporary disability.

Different Teacher/Consultants have specialist disability areas – contact a Teacher/Consultant relevant to your disability to discuss any assistance you may need, or just to find out about campus facilities or course requirements.

Different Teacher/Consultants

have specialist disability areas – contact a Teacher/Consultant relevant to your disability to discuss any assistance you may need, or just to find out about campus facilities or course requirements.

People with a disability may be eligible for a fee exemption or concession fee.

Please ring your local TAFE in your state to find out who the Teacher consultants are in your area

A good website to start to find information is below

Notice of Annual General Meeting 2009

Members are hereby notified that the Annual General Meeting of the Osteogenesis Imperfecta Society of Australia will be held in the Anzac Room at Auburn RSL Club, 33 Northumberland Road Auburn, Sunday 27th September 2009, at 2pm. Please join us for lunch at the RSL's buffet at 12.30pm

AGENDA:

Apologies

Minutes from 2008 AGM to be circulated and adopted as a true record.

President's Report

Treasurer's Report

Election of President, Vice President(s), Secretary, Board Members.

General Business.

Notes:

Members are reminded that only financial members are allowed to vote or stand for nomination.

Financial members are also reminded that each member is entitled to one vote, either personally if present or by proxy. Forms of proxy may be obtained from: -

The Secretary

OI Society of Australia

PO Box 401

Epping NSW 1710

oiaustralia@westnet.com.au

Secretary: Mrs Christine Taig

Phone: (02) 9626 8417

Mobile: 0412 390 472

**OI SOCIETY OF AUSTRALIA
BOARD OF DIRECTORS**

Julie Haraksin – **PRESIDENT**

Julie Stonestreet – **VICE-PRESIDENT**

Arthur Szeto – **VICE-PRESIDENT**

Chris Taig – **SECRETARY**

Mike Kendall – **TREASURER**

BOARD MEMBERS

Suzan Mehmet

Andrew Longhurst

Gail Peacock

Ian Irwin

**HAVE YOU MOVED OR CHANGED EMAIL
ADDRESS**

Please let us know if you have moved as we try to keep our database as current as possible. To try and cut costs we would prefer to email you any correspondence so if you have an email address instead of a postal one please let Chris Taig know

oiaustralia@westnet.com.au

Phone: 02 9626 8417

www.oiaustralia.org

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 serves the right to edit contributed articles for grammar, spelling or space.

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OI SOCIETY OF AUSTRALIA AIMS AND OBJECTIVES

1. To offer information and support to individuals and families affected by O.I.
2. To encourage and support research
3. To provide public and professional education and create awareness.

The OI Society of Australia would like to acknowledge the continued support of Servier Australia for our education and information awareness



Like to share your ideas or information with the OI community? Send your submissions to the OI society newsletter. **Email** oiaustralia@westnet.com.au **Postal** PO Box 401 Epping NSW1710

STATE REPRESENTATIVES

Christine Martin – **AUST. CAPITAL TERRITORY**

– Phone (02) 6291-9969

Julie Stonestreet – **NEW SOUTH WALES**

– Phone (02) 87356698

No one at present – **NORTHERN TERRITORY**

Raechel Richards – **QUEENSLAND**

– Phone (07) 3841-4057

Abby Myer – **SOUTH AUSTRALIA**

– Phone (08) 8367-9783

Sue Cenin – **TASMANIA**

– Phone (03) 6247-3240

Hazel Bellman – **WESTERN AUSTRALIA**

– Phone (08) 9296 3008

No one at present—**VICTORIA**