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LYME DISEASE
ASSOCIATION OF AUSTRALIA
For Lyme Disease Awareness & Action

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LDAA Newsflash

Dear Lymelighter,

Welcome to the August 2013 Edition of Newsflash.

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What's Happening with the CACLD???:

First up, what IS the CMO's CACLD??? (and why is it so important) – the letters CMO's CACLD stands for the Chief Medical Officer of Australia's Clinical Advisory

Committee on Lyme Disease (which is a bit of a mouthful, hence why we use the term CACLD). This committee is made up of people from the following groups...

- Australian Government Department of Health and Ageing
- Lyme Disease Association of Australia (patient representative, Nikki Coleman)
- Karl McManus Foundation
- An Australian and International Expert
- Public Health Laboratory Network
- Communicable Diseases Network Australia
- NSW Health
- Royal College of Pathologists of Australasia
- Royal Australian College of General Practitioners
- National Health and Medical Research Council
- Australian Society for Infectious Diseases

This committee was formed this year by Professor Chris Baggoley in order to look at the extent of the evidence of Lyme disease in Australia; to report to the CMO on the most appropriate testing and treatment for people with suspected Lyme disease in Australia; to explore the best way to distribute information about Lyme disease to the medical community and the wider public; to encourage research on Lyme disease in Australia and to look at other questions raised by Lyme disease in Australia.

So what's the big deal? It's just a committee, there are thousands of those around Australia? Yep, you are right, it is just a committee making recommendations to the CMO – BUT previous policy discussions on Lyme disease in Australia have NEVER included a patient representative or even researchers who argue that Lyme disease IS in Australia - so previous committees on Lyme disease met in secret (members of the Lyme community only found out about them later & the LDAA had to go through 12 months of FOI requests in order to see the deliberations of that committee) and came with the perception that it had an agenda to deny treatment of Lyme disease in Australia. This time around, the committee is a lot more balanced, with a wide range of views on Lyme disease in Australia AND it is a federal committee (previous policy groups have been instigated by various state health departments). Also, Professor Baggoley seems very open to the idea of Lyme being in Australia AND is very concerned by the plight of Australian Lyme disease sufferers (particularly the discrimination they face in order to get treatment). This gives us great hope that there may be policy change – after 20 years of denying the science that Lyme disease is in Australia, there is hope that we may have some positive movement for lymies and their families!!

Finding the organism that causes Lyme disease in Australia is the top priority for the CMO & the CACLD. With this in mind, a scoping study is currently being done to work out the best way to find the organism, and how to fund this research. The next step (after the scoping study) will be the actual research to find the causative agent that is causing Lyme disease in Australia. Exciting announcements about how this research

will be done and where are expected by the end of the year – it seems likely that it will be a multi-disciplinary and multi-centre study in order to find the organism causing Lyme disease in Australia.

This process is slower than we like (the committee and the CMO are very aware of the current suffering of Lyme patients in Australia), but it is important to get this right, given that previous attempts around Lyme disease in the 1990's have been so disastrous for Lyme patients since that time.

The CACLD next meets in early September, so keep an eye on our website and facebook group for announcements of latest developments.

In order to give information to the CMO about discrimination faced by Lyme patients and their families, particularly around the issue of being denied medical treatment, the LDAA is collating stories to give to the CMO in October (as a part of limelight month). If you have been denied treatment for Lyme disease by your local doctor, specialist, hospital or allied health professional, PLEASE send us your story. Lyme disease sufferers often have a hard time finding medical practitioners who will treat their Lyme disease, and quite simply this is unjust and MUST STOP. Please send your story to myself or Sharon Whiteman at the LDAA (if you wish your story to remain anonymous, we can do that, just let us know in your email).

The LDAA is here to represent your views and to work with the government and other NGO's to bring about positive change for Lyme disease sufferers in Australia – together we WILL win against Lyme disease. If you have any questions about the CMO's CACLD or other issues around advocacy & lobbying for Lyme disease, feel free to email Nikki Coleman through the LDAA – info@lymedisease.org.au

The World Wide Lyme Protest (WWLP): Amazing Awareness.

The Lyme Disease Association of Australia sponsored the first ever World Wide Lyme Protest in May and what an amazing awareness campaign this was!

Twenty nine countries held over fifty events to raise awareness for Lyme disease during 11-12 May 2013. In Australia, the WWLP Awareness & Protest campaign masterminds were International Co-ordinator, Karen Smith and her WWLP partner and fellow Australian Co-ordinator, Janice Foster. Events were held in Brisbane, Cairns, Canberra, Sydney, Coffs Harbour, Melbourne, Hobart, Adelaide and Perth and each one was made possible by some very dedicated local co-ordinators - our hats off to each of them! The work and effort that went into each of these was truly amazing and inspirational. The achievements and turn-out to each was nothing short of sensational. People were clearly motivated, keen and dedicated to making each of these events a success and it was inspiring to experience this across the nation and across the globe!

One of the obvious successes of the WWLP was seeing so many iconic buildings and public spaces lit up green for Lyme Disease Awareness. The lighting up of these places was a fun but sure way to gain public attention and we are sure this will now be a WWLP tradition. It is with hope that the lighting up green will get bigger and better and this will ultimately see our messages about Lyme disease reach more people.

Another major success of the WWLP was that it brought the Lyme community together. Not only did it provide a often very isolated group of people with a chance to meet, it also gave them the chance to work together on a project that was aimed at achieving something very close to their hearts. A great many friendships and networks were developed. Some groups have reported to have met since the WWLP and email and phone contact occurs between many people from the events now too!

Thirdly, the WWLP supported the Lyme community in connecting with the general public. Speaking to people in person does seem to have a powerful effect and I guess that's because it connects a face and a story – it simply makes a topic much more personal and real. So if we just think for a minute about how many of these conversations would have occurred around the world during the WWLP, we do get a sense for just how powerful an event like this can really be. It would be safe to say that Lyme disease is now on so many more people's radar!

The final achievement of the WWLP we'd like to highlight was the amount of media attention it gained. Groups and individuals were able to attract incredible attention both in the lead up to and following the WWLP. There were newspaper articles, TV news and current affair programs, magazine articles, medical journals, radio interviews and talk back segments. News items are still appearing today! Each of these has undoubtedly raised public discussion which is exactly how disability will be avoided and lives will be saved. Discussion amongst friends and communities is a powerful way in which Australian's will be made aware of Lyme disease. So... a very BIG thank you to all the brave people who shared their stories in any way for this cause. We fully understand it can be quite daunting to do this and your efforts have been very much appreciated.

So when we we take a minute to think about all of these successes together, it really does make for an extraordinary achievement! The inaugural WWLP was a valuable learning experience, was much bigger and more successful than anyone imagined, and will help us all to achieve more for Lyme Disease Awareness in the future.

Our deepest appreciation and congratulations are extended to Karen, Janice and all of the motivated and passionate event co-ordinators, team and local community who made the 2013 WWLP such an amazing event!

For more information and photos from these events go to <http://worldwidelymeprotestaustralia.weebly.com/> click on "Around Australia" and select each of the state events - thank you to Karen Smith for this professional online pictorial diary.

Shine your #Lymelight October 2013.

Planning is underway for the next exciting LDAA Lyme event.....

Shine Your #Lymelight

Will be held across Australia and New Zealand in October 2013.

Lyme Awareness Saves Lives... We invite you to get your thinking caps on, grab a few people to help you (it might be those new friends you met at the WWLP) and create an event in your local area.

Again it's all about fundraising and awareness for Lyme disease. This time the focus is about people participating in whatever way they feel they can and in their own communities or circles. It can be as little or as big as you like but please just remember only do what is manageable!

SO HOW DO YOU SHINE YOUR #LYMELIGHT?

You might like to

- Create an idea for a fundraising/ awareness event
- Organize an event with family/friends/work colleagues to raise money for LD
- Help others with an event in your local area
- Sell some Lyme Merchandise (on your own or with others) to raise money for LD.
- Ask a familiar local business to display & sell some merchandise items for you.

To get your creative juices flowing we have provided some examples of what you might like to do:

- A boys/girls night in.
- A boys/girls night out.
- A movie night,
- A public/community or group screening of UOS.
- An information / fundraising stall in your local shopping center/community hub.
- A market stall.
- A public BBQ (market, Bunnings, community hub).
- A private BBQ/Party/Gathering.
- A work place or community Lime Green Morning/afternoon tea.

- A "Lunch for Lyme"
- A Pj party

Or you might have another great idea!

Whatever you do choose to do though.....Register your interest and/or event at:
www.facebook.com/LymeDiseaseAustralia or via info@lymedisease.org.au

We can help you connect with other events in your area, organise your LDAA event pack to get you underway or assist and help along the way.

If you just wish to attend an event visit us at:
www.facebook.com/LymeDiseaseAustralia or via info@lymedisease.org.au
& follow the event posts or ask us about events near you.

LDAA is working on getting access to ILADS training for Australian doctors & you can help this project by Shining Your Lymelight in October! It WILL make a difference!

Support Gladiolus Day for Lyme Research and Awareness.

MONDAY 16TH SEPTEMBER IS LYME GLADIOLUS DAY!

Did you that the Gladiolus is the favorite flower of Dame Edna?

Did you know that Barry Humphries is a patron of the Karl McManus Foundation?

And

Did you know that along with many other projects, the Karl McManus Foundation is funding Lyme Disease research

at the Tick Borne Diseases Unit, School of Medical Sciences at the University of Sydney?

By getting involved you can help raise awareness and the lives of people suffering from Lyme Disease.

There will be a range of Lyme Disease, KMMF & special Lyme gladiolus merchandise available for purchase.

For more Information on Lyme Gladiolus Day,
visit the KMMF website: at www.karlmcmmanusfoundation.org.au

Lyme Disease, Relationships and the Family: Lets Stop and Think About Carers for a Minute

Lyme disease can have an enormous impact on a person's life but it also impacts the

people around that person too. There is often loss for the person who has Lyme but there is loss for the family too. Family members lose the partner/the parent/the daughter/the son they had before, they also lose the lifestyle that was lost due to illness and on top of this they watch their loved one suffer. The strain of all this is quite enormous. Caring is a major job that has both physical and emotional impacts on a person. It is often something easily overlooked, because the focus naturally goes on the essential care and support that is needed.

The Lyme journey can take a person through a mountain of difficult feelings (especially in their relationships). There are often feelings of guilt, being a burden on loved ones, difficulties with facing challenges on a daily basis and enduring loss and grief too. Because the person is ill, the guilt, challenges and feelings of a carer are often put on the back burner – not intentionally but more because the carer naturally feels like they cannot complain to the person they care for – this would only cause more guilt and burden. How can a carer say I am sick of doing everything when they know their loved one can't help being sick? How can a carer say I want this nightmare to stop – when they know that the person they care for wants this more than anybody - and besides, this would only make them feel worse right? While nobody is at fault, a carer is forced suddenly into a role where they need to hold things together and they are forced to do it silently because simply: there is enough suffering going on in front of them. As we all know, Lyme Disease is often a long road. So for this reason, Lyme patients, practitioners and carers all have to try to remember another important thing in this Lyme journey – To look after our Lyme carers!

Unfortunately carers, just like Lyme patients, are often overlooked in the system. There are quite a few social support initiatives for carers of people who have cancer or dementia or who care for an aged parent right?.... So where can a carer go to talk to someone who understands about caring for someone with Lyme disease?

There is an incredible Lyme Carer support group that has just been founded on facebook, you can visit it here: <https://www.facebook.com/groups/481811915227599/?ref=ts&fref=ts>

The Commonwealth Carer Respite Center (CRCC) is a national service for all people in a caring role. Caring for an aged person, someone who has a disability or who has a long term illness. You do not need to be a centerlink carer to be registered with the CCRC , you can be working, you can be a close friend, neighbor or family member - you can be a child/teenager looking after a parent (a young carer). While they may not know much about Lyme disease, they do recognize long term illness and the impacts this has on a carer. The CCRC may be able to offer information to link up to support services, may help you explore some respite options (can be residential, can be some in-home help while your carer goes out for a while to take a break, but it can also be recreational respite for you and your family). The CCRC may be able help you

organize emergency in home support or some once-off support for a special occasion or they can help you look at your eligibility (and costs) for longer term services that you might be able to access. Each of these can help relieve some of the burdens carers of people with Lyme disease can feel over time.

We all know that once we take a break and do something nice for ourselves (this doesn't have to be any more than seeing a movie or going on an outing knowing that the person at home is being cared for and is safe) we can come back a bit fresher and ready to tackle things again.

More information on CCRC including contact details and links to location details to all centers can be found here.

<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-carers-respcent.htm>

Please note CCRC eligibility and service provision criteria may differ slightly across regions and states. Please check these with your local office.

Giving up things when you are sick is heartbreaking

Giving up things when you are well but your family member is ill, is just as heartbreaking!

Thinking about how everyone can help each other to do anything positive in your Lyme Journey

will improve your relationships and your journey. Giving thanks to a carer by helping them to take time out

can also be rewarding for everyone.

Thoughts from the LDAA Committee

As you can see we've been having a busy few months - our team is aligning and implementing the necessary foundational systems to support our growing Lyme community. We'd like to welcome Michelle Kelly as a new member of the committee and who is working diligently and professionally behind the scenes supporting our email and communications.

Supporting the Lyme community is a very mixed experience - we go from mourning the tragedy of lost lives, to empathising with the grief of lost quality of life to, celebrating health improvements, to receiving the gratitude so many people have to finally find 'an answer'. There are more and more doctors who have been added to our list - doctors who are Lyme-aware, cognisant that it's illogical to deny the existence of Lyme in Australian and who are doing the right thing. We say thank you! Sadly, we also have many closing their books due to the incredible demands - let us know if your doctor is

willing to see Lyme patients, we depend on your referrals!

The preparations are underway to extend and continue the benefits that were gained with the data from our first patient experience survey in 2012. Stay tuned for notification of another survey coming soon - we'll be calling on you!

We'd like to strongly encourage you to participate in what ever way you can, go where your heart leads you in spreading Lyme Disease Awareness education - we assure you it saves lives. If you have an idea you'd like to brainstorm or a connection that would be of assistance - feel free to contact Jennifer Sherer or Sharon Whiteman at info@lymedisease.org.au.

Would you like to Volunteer Your Time? Or, Know Someone Who Does?

We have MANY projects to implement - let us know if you can donate some time or expertise, or know someone who will!

We'd like to say a **BIG thank you** to Steven Doig of [Doig Website Technologies](#) who's been updating our website 'behind the scenes'. So very much appreciated!

Have you got something you would like to share or? see in the LDAA Newsletter

- Are you doing or have you done something for the good of Lyme disease?
- Have you got an event or program coming up in the near future that you would like others to know about?
- Have you got an idea for a topic you would like to suggest we try to cover?
- Do you have a Lyme success story to share?

If so...

Then we would like to hear from you!

If we can, we will follow up with your suggestions.

Email your story, event details or suggestion to Michelle Kelly at info@lymedisease.org.au

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Michelle Kelly  
on behalf of  
Lyme Disease Association of Australia  
Newsflash Editor

~~~~~  
Contributing Editors
Rev. Nikki Coleman
Sharon Whiteman

Tweet for Lyme

Join us in tweeting for Lyme Awareness,
follow [@lymediseaseaus](#)

Random Acts of Lymeness

Coming soon - Grass Roots community
action list. Watch [this page](#) over the coming
months & there will be something you can
do!

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