Australian Addison's Disease News
Issue 123
July 2018

Our biggest Annual Seminar yet!

The AADAI Annual Seminar attracted 180 attendees—its largest ever crowd—when it was held in Sydney on Saturday 26 May 2018.

Entitled *Being a WELLbeing*, the seminar brought together experts and people with Addison's disease and secondary adrenal insufficiency to share tips and insights on living better with the condition.

Seminar organiser Bronwyn Monro said she was overwhelmed by the record attendance.

"Last year, more than 100 people attended the seminar, and to see such a jump in the number of attendees is exceptional," she said.

"We had people attend from all over Australia, which goes to show how people with adrenal insufficiency are wanting more information, and to meet and speak with others living with their condition."

Plans are already underway for the AADAI Annual Seminar in 2019.

(More from the Seminar starting page 9)

In this edition…

Main photo (LtoR): Professor David Torpy (endocrinologist), Dr Teresa Anderson (Sydney Local Health District Chief Executive), Julie Hetherington (endocrine nurse)

Inset top: seminar audience

Inset bottom (LtoR): Emily Malouf, Bronwyn Monro, Noreen Secomb, Jack Malouf

Acting President’s Message

Winter greetings! Keep warm and well through this season.

The seminar planning committee was delighted to see so many people on Saturday 26 May in the Kerry Packer Auditorium at Royal Prince Alfred Hospital for the AADAI Annual Seminar.

The Seminar’s sessions were inspiring and informative, as well as confronting at times. At the same time, many ideas were keenly discussed by attendees in the tea breaks. New members were shown how to prepare the Solu-Cortef vial to inject hydrocortisone.

It was a pleasure to welcome the Association founder, Noreen Secomb, to the Seminar. Thanks for coming Noreen, with your lovely grandchildren, both of whom are medical students.

Some statistics from the this year’s Seminar: a total of 180 people attended, with 45% of these having Addison’s disease, and 10% having secondary adrenal insufficiency. The remaining 45% of attendees were family members or friends, which is a fantastic show of support.

Of the 100 attendees with adrenal insufficiency, 45% were from Sydney, and 55% were from regional New South Wales, Queensland, Victoria and one grateful member from Western Australia.

Remarkably, attendees told us their diagnossis times ranged from a few weeks to 46 years!

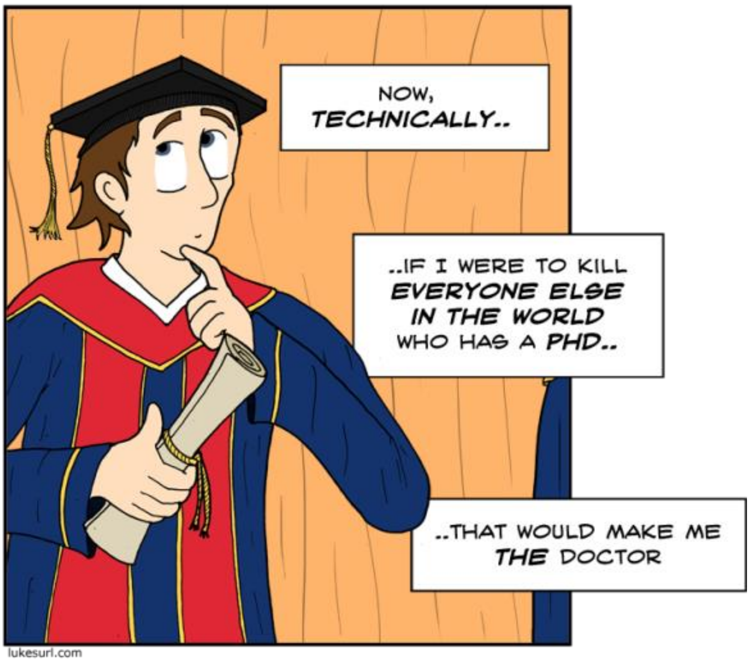
Thanks to all presenters and those who worked hard to make the day such a success. Plans are underway to hold the event again in 2019. Hope to see you there!

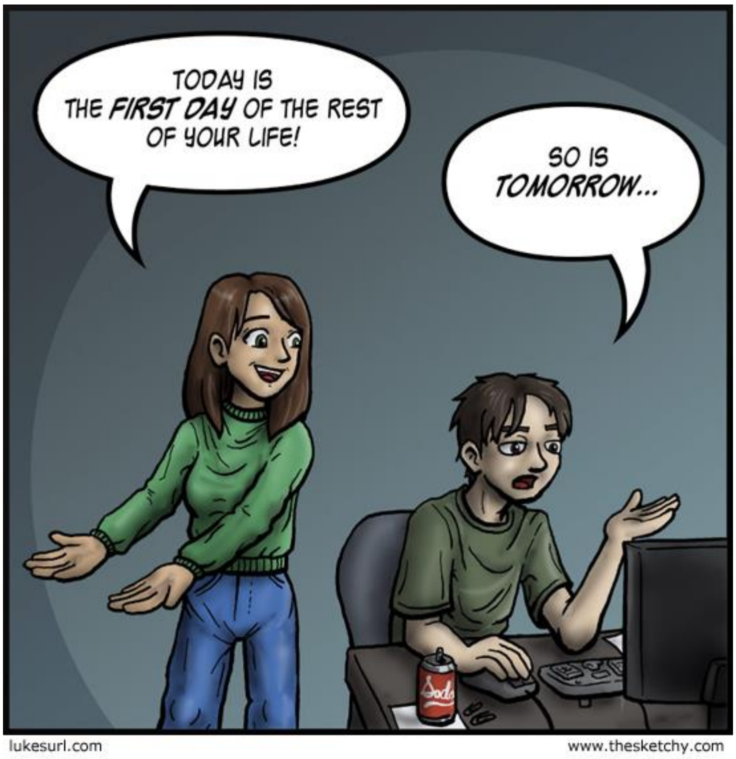
Condolences from the Executive Committee on behalf of the Association are extended to our past President Michelle Dalton and her family on the recent death of her mother, Beatrice. We are thinking of you Michelle.

The Advocacy committee is gradually working through many set tasks, thanks to all on those teams. The website is our “face“ to the community, and Geoff Mullins and his crew are lifting the website profile on our behalf.

Bronwyn Monro

On the lighter side by www.lukesurl.com





Making headlines: Addison's in the news

Diurnal selects company to conduct adrenal insufficiency drug trials

March 2018: Worldwide Clinical Trials has announced that it has been appointed by Diurnal, a specialty pharmaceutical company targeting patient needs in chronic endocrine diseases, as its preferred provider of clinical trial services.

It said it would initially support the US clinical development of its Chronocort product in both congenital adrenal hyperplasia (CAH) and adrenal insufficiency (AI). Chronocort provides a drug release profile that Diurnal believes mimics the body's natural cortisol circadian rhythm, which current therapy is unable to replicate, and is designed to improve disease control for adults with CAH and AI.

Worldwide said it was selected by Diurnal because of its experience in rare and orphan disease clinical research. Demand is rapidly growing for trials in rare and orphan diseases – rare is defined as a disease that affects a very small percentage of the population, while orphan diseases have no definitive, convincing treatment.

The US remains an important market for Diurnal's late-stage pipeline focused on cortisol deficiency, with a market size for the treatment of CAH estimated at $110 million. The AI market is a much larger opportunity, with the US market estimated at $880 million.

Diurnal CEO Martin Whitaker said the US represented an estimated total market opportunity of approximately $1 billion for Chronocort in these two disorders.

Diurnal expects to initiate the Phase III study around the middle of 2018. The Phase III study will recruit up to 150 patients with CAH, who will be randomized to either receive Chronocort twice daily or immediate-release hydrocortisone thrice daily. Patients in the study will be treated for 12 months, with the primary endpoint of the study being the proportion of patients achieving biochemical control with Chronocort or standard of care.

In addition, Diurnal is seeking to pave the way for future indication expansion opportunities with Chronocort through the initiation of a Phase II proof-of-concept study in AI patients. Worldwide will also conduct this Phase II study, which is expected to commence around the end of 2018.

(www.businesswire.com/news/home/20180312005642/en/Diurnal-Selects-Worldwide-Clinical-Trials-Preferred-CRO)

New device helps patients access life-saving treatment for rare diseases

April 2018: Patients with rare medical conditions can receive life-saving treatment at the touch of a button thanks to a new device developed by scientists.

Researchers at Newcastle University, UK, have devised a way for patients and healthcare professionals to access web-based emergency clinical management information for Addison's disease.

A team of experts have now developed a Quick Response (QR) code which may be carried by patients and scanned to access vital medical support. The QR code is printed on bracelets and plastic cards, and, when scanned using a smartphone, links to the Addison's Disease Information System (ADIS), which provides comprehensive clinical management advice specific to the patient.

(www.eurekalert.org/pub_releases/2018-04/nu-ndt041918.php)

The Last Remaining Light documentary launched

July 2018: Swedish Addison Association founder Martin Norrman, along with filmmaker Martin Wallgren, have completed their short documentary *The Last Remaining Light*.

The documentary is billed as a true and honest life story about Addison's disease, biking and Norwegian landscapes.

"Our one goal is to raise global awareness about this rare and life-threatening disease," Mr Norrman said.

The film can be viewed online at:

vimeo.com/martinwallgren/thelastremaininglight

Member news

Treasurer's Report: Surge in donations, membership steady

As we end the financial year, I am pleased to report that there has been a surge in donations, with in excess of $3,200 donated over the past two months. Most notably was $1400 received from family-owned Australian tour company APT – www.aptouring.com.au. One of our youthful members arranged a zany fund-raising in-company event, APT then unexpectedly matched the dollar amount donated by their staff.

Additionally, attendees at the Sydney Seminar generously filled the buckets with over $900. The Helen Brown memorial, whereby this longstanding member directed donations to the Association, and personal donations (large and small) from lots of individual members make up the difference – so our sincere thanks to you all!

Finally, monthly member renewals remain steady and new members are joining at the usual rate. Hence, we should at least reach our ongoing target of 310+ members. However, if you have not responded to a renewal reminder in the January to May 2018 period (or earlier), we would be grateful if you did.

Peter McDonald

SA Event: May Addison's Lunch

Members and friends in South Australia gathered in May for an Addison's Lunch.

Held at Goodwood Park Hotel, the guest speaker was Registered Nurse Carmen Bischoff who demonstrated how to give yourself an injection in the event of a crisis.

A group of 11 people attended the lunch, which continues the series of successful and fun events in South Australia. Among the group were Kaye, Peter and Marianne (LtoR below).

The next gathering will be a Spring Picnic, to be held in the Mitcham Reserve. For more information, contact SA Representative Kaye Toshach on kaye.e@internode.on.net.

Thank you to APT

As a not-for-profit association, AADAI relies on the support of its members and others in the community to continue its operations and deliver key initiatives to benefit members.

Recently we were heartened to receive several donations, including a large contribution from Australian touring company APT.

Today APT is known for its range of travel experiences, from river and ocean cruises to air, land and rail tours.

Visit www.aptouring.com.au

Proposed Constitution Change

An amendment to the current constitution is proposed for approval at the **2018 Annual General Meeting on Sunday 28 October 2018**.

This amendment asks that, in as far as is possible, members of the Executive Committee should give a minimum of one month's notice in writing if they wish to resign mid-term.

More information on the AGM and the proposed change will be made available on our website.

Member news

Web Group Update: Plans for the new Association website

The pace of activity has increased for the Web Group recently. To accelerate plans for the launch of the new site, the Web Group is meeting fortnightly now.

Our aim is to ensure that the new site provides an excellent source of information in a modern, professional way for both members and visitors. The existing site has been a wonderful resource for many years and we want to include all that it offers now and more. The new technology makes this possible.

The new Website software (known as the theme) has been chosen that will allow us to present the site with a fresh look with menus that are much easier to navigate. The aim is that people should be able to locate the required information much more quickly. A critical consideration is for people needing to find emergency information to find it immediately without having to search through complex menu structures.

The supplier of the new theme, WPLook has also provided AADAI with a test area on their system where we are working on the new layout. Ultimately, they will host the site as well as providing technical support when we need it. I wish to thank Peter Stewart for the wonderful support and hosting service he has provided over many years.

All documents currently on the website and those recently prepared are being checked for both medical accuracy and to ensure that they are consistent in term of layout and style. We are working closely with the Executive on this process and I wish to thank Grahame Collier for his advice in this regard.

Thanks to the Executive, the Web Group will be building up a graphics library to make available images, photographs etc. that can be used in all material produced by AADAI, including the Website, educational material and our quarterly newsletter.

Members are our lifeblood and without them, we would not have an Association. We would love to hear your suggestions on what you want from the site and any difficulties you have with the existing site. This information is great as we can include it when we are working on the establishment of the new site. Please send your suggestions to g.mullins@addisons.org.au.

In finalising my report, I wanted to thank Desley Rolph for her contribution whilst being a member of the Web Group and my colleagues on the Web Group, Gisela Spallek and Matthew Dyball for their support and good humour.

Geoff Mullins, Website Committee Coordinator

Condolences to the families of:

***Beatrice Dalton** – our sympathy to Michelle and your family on the passing of your mother, Beatrice. You were a wonderful carer to her.*

***Helen Brown** – a long-time member of the AADAI, Helen was a founding member of the Sydney Chapter of the Association. Helen was an enthusiastic supporter of the AADAI and will be greatly missed.*

***Lyn Buxton** – a caring and passionate advocate for her son, Blake, who lives well with Addison's disease. Lyn and Peter were keen fundraisers for the Association.*

***Sam Harrison** – a nurse and great Queensland supporter, she sadly passed away recently after a battle with secondary adrenal insufficiency and other debilitating illnesses.*

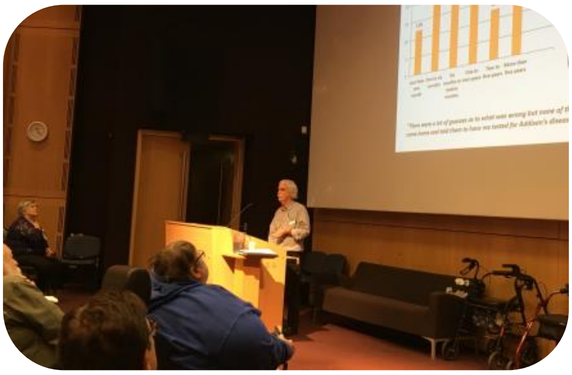
AADAI Annual Seminar 2018

Seminar success: Members and friends gather for the AADAI annual event

Professor David Torpy receives a "rockstar" reception at the Seminar

What a magnificent roll up for our seminar at the Kerry Packer Education Centre at Sydney's RPA this year.

All up, 180 people heard our medical advisor, endocrinologist Professor David Torpy, an authority on adrenal matters, share his experience and wisdom. He provided valuable information on the causes of adrenal insufficiency and various treatments available. He also spoke about the rise in secondary adrenal insufficiency due to the use of steroids for other conditions. Questions that had been submitted before the seminar were answered during the presentation. People enjoyed Professor Torpy's good humour.



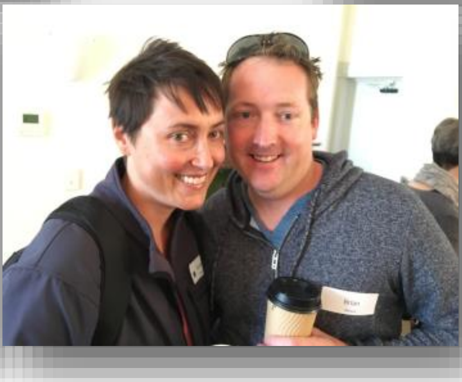
The seminar was opened by Dr Teresa Anderson, Chief Executive of Sydney Local Health District, who welcomed us to RPA and said that it was good to see the refurbished Kerry Packer auditorium being well used for seminars such as ours. She also spoke about the benefits of support groups and electronic health records.

Dr Laura Vogl, a clinical psychologist with a PhD in Public Health and Community Medicine who also has Addison's disease, works to help people adjust to living with a chronic disease and she shared her experience in this area. She had some constructive suggestions and practical strategies for managing our ongoing medical condition as well as coming to terms with the loss of good health. Laura also spoke about her involvement with the development of an app "to help people who suffer from Addison's disease to gain the information/ skills and contacts to better manage their illness and associated lives".

Left: Kim Fouracre & Frankie Tatar

Right: Noreen, Secomb, Professor David Torpy & Bronwyn Monro

Above (LtoR): Trisinta, Simon, Kyshea, Heidi & Jasmin



Above (LtoR): Karen & Brian Mexon

Above (LtoR): Cathi & Kevin Thomas

Being a WELLbeing

Grahame Collier presented the results of the member survey in a very accessible format. We gained so much information from this survey and it is underpinning our planning and future directions.

Julie Hetherington and Klaus Sommer, both Clinical Nurse Consultants of many years experience, demonstrated the drawing up of the Solu-Cortef injection and talked many participants through the process as they practised. People from regional areas commented that this part of the day was most helpful for them as they don't have access to this type of service in the country.

The key seminar sessions have been recorded, Peter McDonald was instrumental in organising this process. The KPEC technology has been upgraded since last year. We are working on how to best share the recordings with you.

The Harris room was a welcoming space for the "early birds" who enjoyed refreshments set up by keen volunteers. Having a coffee and chat before proceedings commenced set the Harris room buzzing! It was exciting to see people from different states and towns meeting up, sharing tips and asking questions.

Morning tea featured delicious homemade slices, thanks to the volunteers who made these and to people who helped prepare and serve morning tea. Lunch was again catered for by the RPA catering department and we are grateful to them for their generous assistance on the day. The breaks are opportunities for members and families to ask questions and reflect on talks. Many people find this a most valuable part of the day.

The seminar organising committee, Janne, Kerry and Bronwyn, were delighted with the day and thank participants and committee members for their enthusiasm. Plans are underway for 2019. Will you join us again? Do you have any issues you would like to see addressed? We are always open to new ideas.

Left: Matthew, Robert & Catherine Dyball

Right: Michael Whitbread, Geoff Mullins & Janne McDonald

Below: Gisela Spallek & Tammy McLandsborough

Left: Michelle Clubberham & Robynne West

Right: Kerrie Hartin & Vicki Hall

Left: Alistair Dolk, Erin Garrity & Maxine Garrity

Right: Joanne Long & Michael Whitbread

Professor Torpy's Insights

Endocrinologist Professor David Torpy is the Deputy Director of the Endocrine and Metabolic Unit at Royal Adelaide Hospital.

A long-time medical advisor for AADAI, he presented the keynote address at this year's Seminar.

Watch his full address when available on the Association website. Below are some of the highlights.

On the three layers of the adrenal cortex...

"So we've inherited these adrenals from millions of years back and they're absolutely essential for survival.

Now the glomerulosa is the one that makes the aldersterone – so salt. The fasciculata is involved in cortisol, which produces sugar. Reticularis makes the sex steroid.

So you could say — salt, sugar, sex, the deeper you go, the sweeter it gets!"

On why the autoimmune system attacks the adrenal glands...

"In essence, when we're in utero, our body, the T cells, learn what is us. It teaches the immune system not to attack any bits that are us.

Unfortunately, there are faults in that sometimes. There are things that go through to the keeper and the T cells don't properly learn, it seems, that some parts of the body are us.

Autoimmune diseases affect about 20% of the population. It's common. So not learning what parts of the body are us and the immune system having a go is quite common and the most common target overwhelming is the thyroid.

So quite a lot of people with Addison's have other autoimmune diseases."

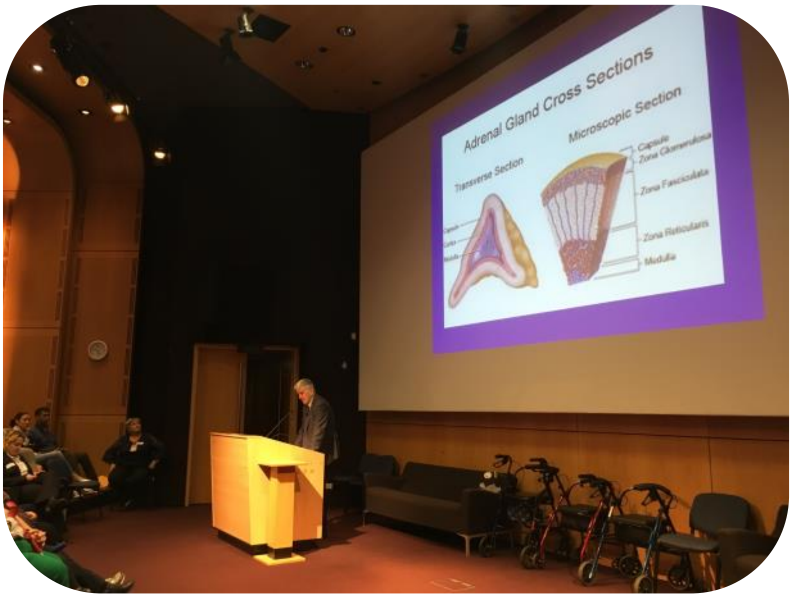
On having Addison's disease...

"It's not good to get a disease, there's no question about that, especially a chronic disease that will last for rest of your life. But perhaps the substantial compensation is when it is treatable.

And the good thing with Addison's is it is treatable and it's only been treatable for about 70 years. Before that, everybody who got this died.

There's a good news / bad news story there.

Yep, it's bad to get a disease, but it's good to get one that's treatable. And the treatment is not too horrible."



On developing Addison's disease...

"You get antibodies, indicating the immune system has launched an attack on the adrenal gland. That person is well. The renin level goes up, but you're still well.

The next thing that happens is the aldosterone drops away and ACTH rises. During all of this, most people are pretty good. They might be a bit flat, but they're ok.

Finally the cortisol drops to low levels and then they have symptoms of adrenal insufficiency.

This is very, very similar to diabetes, and the process really takes about four to seven years. So it's a long time."

On the story behind the discovery of steroids...

"It was in the 1950s we started to use steriods. It was an amazing invention, and we have to thank the US military for that.

They had in the war, they had a coming together of ideas, but I think it's an amazing story.

They believed the Germans were taking adrenal extracts to help them do dive bombing. That this somehow gave them magic powers to avoid decompression sickness or sickness form the pressure changes.

They thought we'll get someone to find out what's in the adrenal glands and they paid $1 million to some chemists as a grant to find out what was in the adrenal glands.

Hydrocortisone is one of the things they found.

That really changed the world. Steroids are remarkable treatments for all sorts of diseases because they are the body's natural anti-inflammatory and a lot of diseases have inflammation as part of their repertoire.

About 3% of the population are taking steroids at any one time for a whole myriad of conditions."

Professor Torpy's Insights

On the long-term prospects...

"The mortality of Addison people compared with the general population is only very, very slightly higher than the general population, and a fair bit of that relates to adrenal crisis.

So if we can beat adrenal crisis, basically you have a normal life span and with the treatment you have, if you get the dose right, you should enjoy good wellbeing and you should be nice and safe, and you should be able to whatever it is you were otherwise planning to do in life."

On pregnancy...

"(For people without adrenal insufficiency) As the weeks of pregnancy pass, by 16 weeks you can see cortisol levels rise really substantially—about two or three times. Pregnancy is a time, we don't really think of it as stress, but it is a time of sustained excess cortisol compared to normal.

(For people with adrenal insufficiency) In pregnancy, we think we need more cortisol, but we don't need to increase it by that much... and usually increase the dose by about 30-40% later in pregnancy."

Living with adrenal insufficiency and managing the world around you

Clinical psychologist and Addisonian Dr Laura Vogl shared with the Seminar attendees valuable tips on living well with adrenal insufficiency.

Watch her full address when available on the Association website. Below are some of the highlights.

Managing the world around you...

Big things, like losing a job, the death of a partner, a serious car accident or approaching deadlines lead to stress.

Daily hassles, such as being tired and managing work, family and social demands, heavy traffic on the way to work, unpleasant work colleagues etc, add up and are often a greater source of stress.

Think about changing your environment and changing the sources of stress.

- **Work**
    - Change from full-time to part-time (financial constraints), job closer to home etc
- **Family responsibilities**
    - Reach out for help, childcare, ask family to cook frozen meals, a cleaner (if possible)
- **Social events**
    - Space them more, leave earlier, have a "not on a school night" policy, ensure they're with people you truly value
- **School & university**
    - Arrange special consideration, pathways can be spread over several years, disability provisions, educate young people there are 'many ways to skin a cat' - it's important to for them to learn they're not in a hurry

Learn to relax...

- Progressive muscle relaxation
- Yoga and meditation
- Massages, bubble baths etc
- Manage your time
    - Timetables
    - SMART goals (Specific, Measurable, Achievable, Relevant, Time-bound)
- Problem solve
- Reach out for help!

Tips to help cope with grief and adjustment...

- Acknowledge and express how you feel (there can be personality, cultural and societal issues)
- Getting sad is NOT bad for you
- Talk to people you can trust
- Ask for help if you need it—admit you are struggling
- Be honest with family and friends
- The intensity and duration of grief varies from person to person
- Talk with others who share the same experience (but be careful)
- Take care of your physical health with regular exercise, eating healthy meals and limiting alcohol use
- Participate in enjoyable activities, hobbies and interests
- Do your best to get enough sleep, but accept that this may not be perfect for a while given medication impacts sleep.

Housekeeping

How to check your membership expiry

We're calling on members to keep an eye on their membership and remember to renew it before it expires. Your membership expiry date is shown under "My Profile" once you've logged onto the Association website (*see below*).

Your membership runs for 12 months from the date that you joined the Association.

Individual reminders are also sent out via email or post. Contact the Treasurer for any assistance (*see next page*).

Membership Profile

Hello Matthew Hart, your membership is current and you have full access to the website.
Your Membership will expire on Thursday August 31st, 2017

Do you have a burning question?

Did you know that you can email or text us a general Addison's disease-related question to be answered by our medical advisor Professor David Torpy or pharmaceutical advisor Dr Michael Lew?

Of course, questions of a personal, case-specific nature are best directed to your personal health care providers. Send your questions via email or text message:

- editor@addisons.org.au
- 0455 534 472

2018 AADAI AGM

The Association's Annual General Meeting will be held on Sunday 28 October 2018 at 11am (Australian Daylight Saving Time).

It will be held in the New Board Room at Club Ashfield, 1-11 Charlotte Street, Ashfield (next to Ashfield Station) in Sydney. Video conferencing will also be made available for non-Sydney residents.

More details will be available on the website and in the next newsletter. If you would like to nominate for one of the formal Association roles, or lend a hand in other ways, let us know!

Tip for making EFT payments

If you are paying for your membership via electronic funds transfer (EFT), please be aware that you must include your FULL NAME in the description. Otherwise we may have no idea who the payment came from.

Bank: Westpac
BSB: 032 576
Account: 269471
Account name:
Australian Addison's Disease Association Inc.

If you are not renewing online, we ask that members complete the renewal form found on the website.

Would you like to help us?

Perhaps you have a good idea for fundraising?

Can you spare the time to be a State or Regional Representative?

Would you like to share your Addison's story?

Have you discovered a product that could benefit all Addisonians?

How ever you might be able to help, please contact the committee to discuss your idea.

We'd love to hear from you!

Get in touch

Phone: 0455 534 472

Please call between 8am and 9 pm

If your call is unanswered, send a text so we can call you back as soon as possible or try again at a later time.

Post: Australian Addison's Disease
Association Inc.
48 Glassop Street
Balmain NSW 2041

Website: addisons.org.au *includes contact request form*

Association Committee

President (Acting)
Bronwyn Monro

Vice President (Acting)
Peter McDonald

Committee Members
Grahame Collier
Catherine Dyball
Tammy McLandsborough
Kerry Wheeler

Secretary
(all general enquiries)
Bronwyn Monro
secretary@addisons.org.au

Treasurer
Peter McDonald
treasurer@addisons.org.au

As you will notice we are currently searching for people to solely be support representatives in most parts of Australia. Let Bronwyn or Peter know if you are keen to assist and we can then give you a call to discuss how to make the role work for you.

With assistance from:

Newsletter Editor
Matthew Hart
editor@addisons.org.au

Webmaster
Matthew Dyball
webmaster@addisons.org.au

Medical Advisor
Professor David Torpy
Adelaide, South Australia

Pharmaceutical Advisor
Dr Michael Lew
Melbourne, Victoria

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E: kaye.e@internode.on.net

Tasmania
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E: lterry@jmg.net.au

Western Australia (Albany)
Felicity Tadj
P: 0417 181 004
E: felicity@dftadj.com

State representative vacancies

- ACT
- New South Wales
- Queensland
- Victoria

Join our Association

MEMBERSHIP FORM 2018

Complete this form in full if you have primary or secondary adrenal insufficiency.

Family members should cross out the details below your own email address and guardians should attach a second copy of the form with their child's details.

Alternatively, consider using the online version at addisons.org.au/payments/membership-au-12months/

Post to:

The Treasurer, Australian Addison's Disease
Association Inc., 48 Glassop Street, Balmain,
NSW 2041 Australia

I have paid via: (please circle)
Cheque / Money Order / EFT* / PayPal

$35 for membership within Australia
$40 for membership outside Australia

and an optional donation of $________

Tick if you are a:

- Guardian ☐
- Supporter ☐

(Complete details for child on another copy)

OFFICE USE ONLY

Date Rec:

Rec No:

Mem $ Donation $

**EFT - please make sure you put <u>your name / member's name</u> in the reference*

Bank:	Westpac
BSB:	032 576
Account:	269471

Acc. Name:
Australian Addison's Disease Association Inc.

Title:	**USE BLOCK LETTERS IN THESE BOXES**	
Surname:		
Given name(s):		
Date of birth:		
Postal address:		
Town/City:		
Postcode:	State:	Country:
Phone:	( )	
Mobile:		
Email:		
Endocrinologist:		Ph No.
Endo's email:		
GP name/practice:		Ph No.
GP email:		
Only to be completed for new members or members whose details have changed		
I have (tick one): Primary adrenal insufficiency (Addison's disease) ☐ Secondary adrenal insufficiency ☐ Other ☐		
Details of Other		
When were you diagnosed with adrenal insufficiency?	Year:	
I wish/don't wish to make contact with other members in my	By phone: ☐	By email: ☐
How would you like to receive your newsletter?	Email: ☐	Post: ☐
Next of Kin contact details	Name:	Ph:

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