

# Australian Addison's Disease News

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## 2018 AADAI Annual Seminar: Your invitation to *'Being a WELLbeing'*

Following the success of last year's event, AADAI is excited to confirm details of this year's Annual Seminar, being held in Sydney on Saturday 26 May 2018.

Entitled *Being a WELLbeing*, the seminar will bring 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 the seminar was the Association's key event of 2018.

"Last year, more than 100 people attended the seminar and many described it as life changing," she said.

"People relished the fact they were able to meet and speak with others living with adrenal insufficiency, and they could hear from knowledgeable specialists.

"This year's seminar promises to be even bigger and better as we will have addresses by endocrinologist Professor David Torpy, psychologist Dr Laura Vogl, experienced en-

docrine nurses, and much more."

Professor Torpy said he was looking forward to addressing the Seminar.

"I am delighted to be invited to speak at this year's Seminar," he said.

"There is a lot of important information about this condition and knowledge is very useful in optimising wellbeing and preventing emergencies and long-term problems.

"Bronwyn and the AADAI team have worked hard on organising the meeting and as we all know the work needed is very considerable and should not be underestimated."

**Your invitation to the 2018 AADAI Annual Seminar is on page 6**

# Acting President's Message

It has been a busy start to 2018 with a new Executive Committee settling in.

Many thanks to Michelle Dalton and Desley Rolph for their support and hard work for the Australian Addison's Disease Association since their election as President and Vice-President in November 2016.

Both have made a strong contribution to the Association during their time in office and we wish them all the very best and good health for the future.

Planning for the 2018 AADA Annual Seminar on Saturday 26 May is well underway, and we are delighted that our Medical Advisor, Professor Torpy, has agreed to be the keynote speaker.

He will receive great support from Dr Laura Vogl - a clinical psychologist who happens to be a member. Also on hand

will be our wonderful endocrine nurse team of Julie Hetherington and Klaus Sommer. The whole speaking group will really focus on our theme of "Being a WELLbeing". The Member Survey group will also present further findings from that most impressive member survey.

I continue to be delighted when I get to talk to members - especially the ones who are new to the Association. It is then that I am reminded how important it is to always provide the support that only those living with or alongside the condition can offer.

The Association is always looking for members who would like to lend their assistance. If you'd like to help out, please let me know.



See you at the Seminar—it promises to be the event of the year!

Bronwyn Monro

## Our Valued Patrons

Helen Reddy

*Australian singer, actress & activist*

Geoff Starling

*Australian former professional rugby league footballer*

## Editor's note

You're likely to meet many people in your life, but chances are you won't stumble across many people with Addison's disease / adrenal insufficiency. The 2018 AADA Annual Seminar aims to change that!

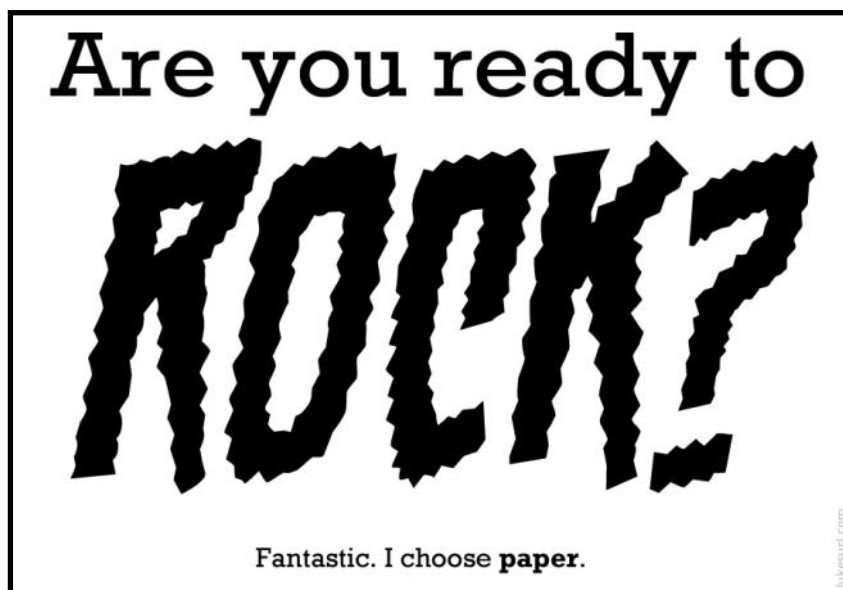
Many tell us their most valuable experience from attending previous seminars was meeting other people with Addison's disease / adrenal insufficiency for the first time.

There's something powerful about talking to others who know exactly what it feels like to have this rare condition.

So clear your calendar and get ready to mingle at this year's seminar!

Matthew Hart

On the lighter side... by [www.lukesurl.com](http://www.lukesurl.com)



**Disclaimer:** The material in this newsletter offers information as unbiased "information only" and is not intended to be complete. The authors of most information in this newsletter do not practice medicine; they are members of a support group. The intention is only to give information to patients and others about these disorders and the support that is available. We urge you to contact your medical practitioner(s) before making any changes to your treatment.

# Making headlines: Addison's in the news

## Research: Your urine could be used to create an artificial adrenal gland

**January 2018:** Scientists have started generating artificial glands using cells derived from urine, which will allow the study of adrenal disorders that affect growth, development, and metabolism.

Researchers at Queen Mary University of London have used cells in urine to begin generating an artificial adrenal gland that could be used to treat adrenal gland disorders.

The study, published in *Cell Reports*, found that steroid-producing cells could be produced by reprogramming cells from the skin, blood, and urine of healthy donors or adrenal disorder patients. These cells were used to model adrenal diseases in a dish and test new personalised treatments and were implanted into mice to check their function.

The adrenal glands are found on top of the kidneys and produce a number of hormones, including adrenaline, and the steroids aldosterone and cortisol. Adrenal disorders, such as Addison's disease, can be caused by genetic mutations, tumours, infections, or problems with other glands, causing the glands to produce too little or too much of a hormone.

Lead author Dr Leonardo Guasti said: "It is a first step in generating an artificial adrenal gland which would benefit all patients with adrenal insufficiency. Regenerative medicine applications for adrenal disorders have been neglected compared to other endocrine fields, such as the world-wide effort to generate functional endocrine pancreas to cure type-I diabetes. This study closes this gap."



In the research, the authors describe for the first time the generation of steroid-producing cells (named human inducible steroidogenic cells, hiSCs) from skin, blood and urine of healthy donors and patients with congenital adrenal disorders. This process is generally called reprogramming.

hiSCs were used to model adrenal diseases in a dish and provided a platform to test interventions for new personalised treatments. The viability of hiSCs living organisms was also tested through implantation experiments in mice.

Reprogramming was achieved by forcing the expression of a single protein (a transcription factor) and the activation of two signalling pathways. The newly generated hiSCs expressed the enzymes responsible for steroid production and crucially were responsive to physiological stimuli, such as the secretion of cortisol upon ACTH stimulation. The steroid profile of hiSCs generated from patients with a monogenic adrenal disorder (congenital adrenal hyperplasia) was altered, in keeping with their profile at diagnosis. When the non-mutated gene was re-introduced into these cells, the steroid profile was back to normal, and similar to that observed in hiSCs obtained from healthy donors.

"It represents an entirely new concept for the study of the adrenal gland as the ability to generate donor-specific and functional adrenal-like cells will facilitate the next generation of cell-based treatments for adrenal insufficiency, the modelling of adrenal specific diseases, and the testing of personalised interventions on cells derived from patients," Dr Leonardo Guasti said.

([https://www.eurekalert.org/pub\\_releases/2018-01/qmuofts013018.php](https://www.eurekalert.org/pub_releases/2018-01/qmuofts013018.php))

### Sponsor a member

Occasionally we encounter someone who wants to join the Association but can't afford to do so. Would you consider donating a membership to another? Let us know if you'd like to help. Donations can be made anonymously.

# Member news

## Treasurer's Report: Renewals, Updating Profiles and Donations

We are now in the midst of our busiest renewal months of this financial year when almost half of our (310+) members will be renewing.

While we continue to send 'reminders' each month, it would help a lot if you proactively renewed without waiting for the reminder.

We are pleased that many have responded to our request to update or fill-in-the-blanks within their member profile, and would encourage everyone to do likewise.

Without pertinent information such as Date of Birth, Year and Type of Diagnosis, we are hamstrung in our ability to provide information that's most useful to all of our members.

We have also received sizeable donations from some of our members and an unexpected one from the staff at Camden Council (NSW).

If you make a donation or encourage an organisation to donate, it will offset annual expenses such as: a) Financial Audit of \$1,000; b) Online Database subscription of \$250; c) HELP Phone Recharge of \$240; or d) Zoom Online Meeting subscription of \$210.



Peter McDonald

## Association extends its congratulations to Professor Eastman AO



AADAI has extended its sincere congratulations to long-time friend and leading Australian endocrinologist Professor Creswell Eastman, who became an Officer of the Order of Australia this year.

Professor Eastman was acknowledged for "distinguished service to medicine, particularly to the discipline of pathology, through leadership roles, medical education, and as a contributor to international public health projects."

Creswell Eastman is the Clinical Professor of Medicine at Sydney University Medical School, Principal of the Sydney Thyroid Clinic and Consultant Emeritus to the Westmead Hospital.

He has also directed or conducted research and public health projects into elimination of iodine deficiency disorders (IDD) in Malaysia, Indonesia, Laos, Cambodia, Thailand, several Pacific Islands, Hong Kong, China and Tibet and Australia. For his work in remote areas of China, he has been dubbed the "man who saved a million brains".

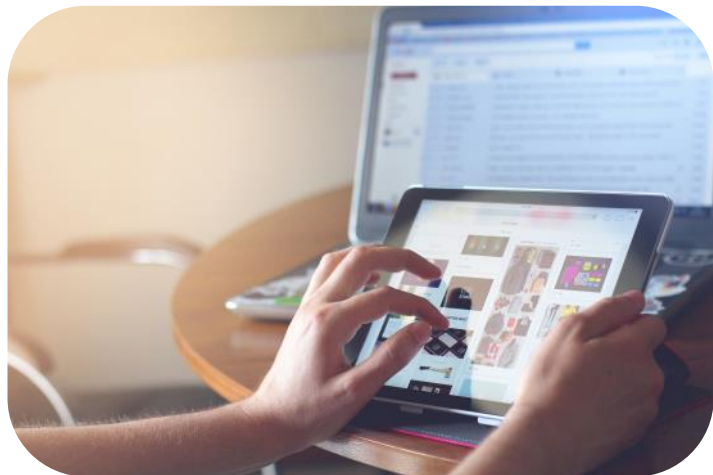
AADAI Secretary Bronwyn Monro said Professor Eastman's role in supporting the Association was also greatly appreciated.

"Many long-term members remember fondly Professor Eastman's encouragement and support from the earliest days, and his direct contributions by way of presentations to gatherings of members. His patients with Addison's disease continue to speak highly of his expertise and care over the years," she said.

The Order of Australia is an order of chivalry to recognise Australian citizens for achievement or meritorious service.

# Member news

## WebGroup Update: Reviewing documents and refreshing the website



The WebGroup is making slow but steady progress on several fronts. I am confident that the planning that has been underway for some time will soon be apparent to those who visit the site. The Committee meets monthly and focuses on three criteria, namely current and new items and closed items.

One of the WebGroup's key areas of attention at present is to improve communication with the Executive. This will ensure that the areas we are working on are in line with the direction set by the Executive. It is all too easy for the specific working groups to get caught up in their own work which may be different from the "big picture".

In recent months, several documents have been prepared and are in the review phase before they can be given approval to be

published. Documents need to be reviewed both for medical accuracy (if applicable) and to ensure that they are free from ambiguity or spelling errors. A new style guide has been approved for all publications to ensure consistency .

A major milestone has been achieved with the handing over of the final draft of "What is Adrenal Insufficiency". Congratulations to Dr Gisela Spallek for her wonderful work in preparing this document and to fellow members who have done "peer reviews" along the way. It is now with Professor Torpy for a final review from his perspective as our advising endocrinologist.

The Website technology requires an update to allow the site to have a more modern look. Several technical issues have become apparent when updates have been attempted and because the current style (known as a theme) does not have any technical support, we will have no choice but to purchase a more modern theme.

This will provide AADA with the opportunity to give visitors to the site with a much fresher look and to realign the topic areas to make things easier to find. The plan is to have the new theme under preparation in parallel with the existing site and when the layout and material have been approved by the Executive and tested for errors, the new site can go live.

In finalising my report, I wanted to thank Michelle Dalton for her contribution whilst being a member of the WebGroup and wish her well in her future endeavours. Feedback and suggestions are always welcome, and they can be sent to: [g.mullins@addisons.org.au](mailto:g.mullins@addisons.org.au).

Geoff Mullins, Website Committee Coordinator

### SA Event: May Addison's Lunch

Members and friends in South Australia are invited to an Addison's Lunch in May.

The guest speaker will be Registered Nurse Carmen Bischoff who will give a talk on how to give yourself an injection. The event promises to be informative as well as a great opportunity for members to get together.

The event continues the series of successful and fun events in South Australia.

**When: Noon, Saturday 19 May 2018**

**Where:** Function room at Goodwood Park Hotel, 75 Goodwood Road, Goodwood

**Cost:** Lunch at own expense

RSVP to [kaye.e@internode.on.net](mailto:kaye.e@internode.on.net) by early May 2018.

### Winter flu jab reminder

A flu jab can help prevent, or minimise the effects of, influenza, which could have serious consequences for members given our immune systems can be compromised.

Annual vaccination is the most important measure to prevent influenza and its complications.

Recent evidence suggests influenza protection may start to decrease from 3 to 4 months following vaccination, so early vaccination needs to be balanced with this. But while influenza continues to circulate, it is never too late to vaccinate.

You may be eligible to receive the influenza vaccine for free under the National Immunisation Program (NIP).

Visit [www.immunise.health.gov.au](http://www.immunise.health.gov.au) for more information and talk to your medical practitioner about what's right for you.

Your invitation...



People with Addison's disease and adrenal insufficiency, along with their supporters, are invited to the Australian Addison's Disease Association Inc. Annual Seminar

**This is a free event** (*donations towards catering welcome*)

**Meet the experts and hear how you can feel and live better.**

**Sessions to feature:**

- Endocrinologist Professor David Torpy (starting at 9am sharp)
- Psychologist Dr Laura Vogl on feeling better within yourself
- Member survey findings presented
- Endocrine nurses on how to manage your condition
- *Much more, including the opportunity to chat with others*



**2018 AADAI Annual Seminar: Saturday 26 May 2018**

*8am: Registration, with tea & coffee*

*9am to 2pm: Seminar, including lunch*

Kerry Packer Auditorium

**Royal Prince Alfred Hospital**

Missenden Road, Camperdown

Sydney

To register or for information:

**M: 0427 601 795**

**E: [Sydney@addisons.org.au](mailto:Sydney@addisons.org.au)**

# Seminar preview with Dr Laura Vogl

*Clinical psychologist Dr Laura Vogl is one of the speakers at this year's AADA Annual Seminar.*

*Here she gives a preview of her address and her tips for "Being a WELLbeing".*

My first knowledge of Addison's disease was thrust on me nearly ten years ago, when I was first diagnosed with Addison's disease.

Despite having worked as a clinical psychologist for nearly 20 years and in mental health research for more than a decade, I found adjusting to this new diagnosis both physically and mentally really challenging.

Like many of us, it took a long time to be diagnosed, with lots of people inferring I was a hypochondriac or suffering from some mental illness, so initially there was a feeling of relief when I was told there really was something wrong with me and it had a name!

The relief was quite short lived as I recognised I was now going to have to adapt to something neither I, nor any of us, planned!

I was really fortunate because I found out about the Australian Addison's Disease Association in the same week I was diagnosed and attended my first seminar in 2007 about a week after my diagnosis was confirmed.

It was really good to be able to talk to lots of other people living with Addison's disease and see that everyone's individual experience had common features, but was also quite different.

I was rapidly educated on the physiology of Addison's disease and how to 'medically manage the condition'. Although this is absolutely vital, as a clinical psychologist it became apparent to me really fast, that no one was speaking about the psychological aspects of Addison's disease and how to cope with this condition to ensure you can feel like a 'WELLbeing' most of the time, which is the theme for this year's seminar!



In the last ten years, the focus of my clinical psychology work has changed. I have become really interested in working with people with chronic health conditions and helping them to adjust and achieve the best out of life.

I am hoping at this year's seminar, I can give you all a few tips and also learn from you to be able to help more people in the future.

**The four main things I am going to talk about are:**

**1. The process of adjusting to being diagnosed with Addison's disease:**

Recognising the challenges and giving yourself time and space to make this adjustment. While it can be a relief initially, it is really important people give themselves time to adjust to the disease. It is important to recognise that there can be a substantial amount of grief. You need to grieve the person you once were, and get used to a new person! It may be that you have been someone who has been energetic and always dived head on into a challenge. You now need to adjust to a body that's often tired and has a lot less energy.

**2. Making friends with your Addison's disease to allow you to live a rewarding life:**

Being friends doesn't mean you are always going to like each other. You will have times you like each other, times you feel indifferent and times where you've just had enough. Just like any friendship you need to manage, you need to manage your disease.

**3. Recognising and seeking help when you need it:**

It is well known that stress can have a causal role in Addison's disease. Likewise, the disease itself can cause stress and impede people's quality of life. Given the association between Addison's disease, stress, anxiety and depression, it is essential that the management of this disease is holistic and doesn't only involve the medical management. This talk will also focus on where you can find help.

*(continued on page 9)*

**Disclaimer:**

These stories reflect the author's personal experience, and as individuals we experience our disease uniquely. Always discuss any thoughts you may feel useful as a result of these articles with your physician.

# Member profile: Meet Dr Michael Lew

*Dr Michael Lew is the Association's pharmaceutical advisor and developed primary Addison's disease last year after starting treatment for Hashimoto's hypothyroid 12 years ago.*

*Dr Lew, 57, is a senior lecturer in the Department of Pharmacology and Therapeutics at Melbourne University.*

*He shares some insights into the medication we rely on for our health and wellbeing.*

I am a pharmacologist at Melbourne University and developed autoimmune Hashimoto's disease (thyroid insufficiency) and later Addison's disease over a decade ago.

I have auto-antibodies against both thyroid and adrenal cells and so I have a polyglandular autoimmune syndrome.

After I was (belatedly) diagnosed and treated, I returned to work and was given responsibility for a few lectures about thyroid and adrenal diseases for the medical students. The rationale was, of course, that I was expert in those areas. At the time I wasn't, but I'm a good learner. My connection to adrenal insufficiency is both personal and professional.

***My Addison's is currently well controlled with 5mg of prednisolone daily, having found that I needed frequent dosing with Cortate to deal with afternoon and evening tiredness.***

Primary Addison's patients should know that there are only a few choices regarding drug treatment.

Cortisol (hydrocortisone) and cortisone (commonly 'Cortate') are the natural glucocorticoids used by the human body. Cortisol is the active substance secreted by the adrenal glands (specifically by the outer layer of the gland), but cortisol is inactivated in the kidneys by conversion into cortisone. However, cortisone is activated in the liver by conversion to cortisol. That means that even though cortisone is inactive, it can be used as a treatment for adrenal insufficiency because it is activated by the liver.

The pattern of cortisol secretion in normal people is that it starts early in the morning prior to awakening and peaks shortly after rising, say 7am.

Thereafter it declines gradually over the day, apart from brief peaks at each meal, and reaches a low level after the person goes to bed.

The usual dosing regimen for Addison's patients is intended to mimic the physiological pattern of cortisol secretion as much as practicable. Take the cortisone or cortisol first thing in the morning. (I usually take mine at around 5 AM and then have a brief snooze before rising.)

Unfortunately for Addisonians, the half-life of cortisone/cortisol in the blood is short and, even though the half-life of its effect is a bit longer, it is often necessary to take more than one dose to make it through the whole day without that foggy-headed fatigue that comes with too little cortisol. Family and friends of Addisonians can experience some of that feeling by getting up at 3 or 4 in the morning!

The sharp peaks of natural cortisol secretion at meals is, presumably, to balance out the glucose lowering actions of insulin and other hormones of digestion, but it does not seem necessary for Addisonians to try to match those peaks for well-being. That's a good thing because it would require small intravenous injections to mimic the brevity of natural secretion.

Of course, we need to be aware that cortisone/cortisol is a stress hormone as well.

Its secretion increases in times of physiological and psychological stress, so Addisonians should take extra doses of glucocorticoid during illness or before surgery.

How much to take is a difficult question. Doubling or trebling of the normal daily dose is the rule of thumb for a viral infection, for example, and the normal dose for gastroenteritis with vomiting is an injection of the whole vial of Solu-Cortef (cortisol), which would be several times the standard daily dose.



## Disclaimer:

These stories reflect the author's personal experience, and as individuals we experience our disease uniquely. Always discuss any thoughts you may feel useful as a result of these articles with your physician.

# Features

*(continued from page 7: Seminar preview with Dr Laura Vogl)*

## **4. Don't be afraid to advocate for yourself:**

Addison's disease is a rare disease, which even many health professionals have never heard of, and if they have heard of it, are unsure how to manage. As patients in the health system we often feel we should be compliant and quietly trust the care we receive. In my experience in many cases this works just fine, but never be afraid to advocate and ask how they plan to take your Addison's disease into account. I will discuss some tips to working with the health system to achieve the best results.

From both my personal and professional experience there is one piece of wisdom I've gained and that is, we all need to 'run our own race'.

No-one knows how you feel better than you do. Addison's disease is a rare disease. Education by medical practitioners almost entirely focuses on blood tests, sick day management and medication regimes.

It is important to recognise the need for holistic care which not only focuses on the essential medical information, but also allows you to be aware of the importance of your mental health and, if you no longer feel you can have a rewarding life, where to seek help.

*(Continued from page 8: Member profile: Meet Dr Michael Lew)*

Dosing during illness has to be done with some care, though, because excessive doses will depress the natural immune response excessively so that recovery might be delayed. How much and how often? You have to read yourself and make your best guesses in consultation with your endocrinologist.

Cortisone/cortisol can be a two-edged sword with regard to sleep. Too much causes alertness and wakefulness, but too little during the night can lead to difficulty staying asleep. For me, I used to partly wake at around 3am with cravings for a 'pill'. I was unable to fix that problem with a larger dose prior to going to bed because it kept me awake, and so I had poor sleep for a long time.

In consultation with my endocrinologist I was able to solve that problem by switching from taking cortisone three times a day to taking one dose of the artificial glucocorticoid prednisolone in the morning. The longer half-life of prednisolone has made a big difference to my quality of life. I sleep better and rarely have the afternoon or evening slump that previously had been so commonplace that my work colleagues would suggest that I needed a 'dose'. Changing from cortisone/cortisol to prednisolone meant that I needed to increase my daily dose of fludrocortisone to make up for the fact that prednisolone has none of the mineralocorticoid activity that is a minor feature of cortisol.

I don't have any real insights into common misconceptions of Addisonians regarding their medications, as the only Addisonian that I have met is me! I do try to ensure that my medical students don't get any misconceptions.

Current and future developments of new treatment of Addison's are likely to be few because of the rarity of the disease. The rapid/slow release formulation of cortisol, called Duocort, does seem to offer some advantage over existing formulations as it may offer single dosing without the afternoon slump, but it seems not (yet?) to be generally available in Australia.

Of course, I have found that a single dose of prednisolone works well and so the improvement offered by Duocort may be minimal. Stem cell technologies may eventually give us the ability to have a functioning replacement for the adrenal cortex, but my personal opinion is that it is too far off to be confident that it will ever come into being. A more promising direction for developments is in the possibility of better diagnosis and treatment of Addison's disease using the existing approaches. The AADAI plays a role in that by promoting education of patients and practitioners.

The 'piece of wisdom' that I would like to impart is that Addison's patients have to become experts in reading their own state of being and in adapting their treatment to the challenges and stresses of life.



# More Member Survey results

## Some more from our Member Survey - Did you know?

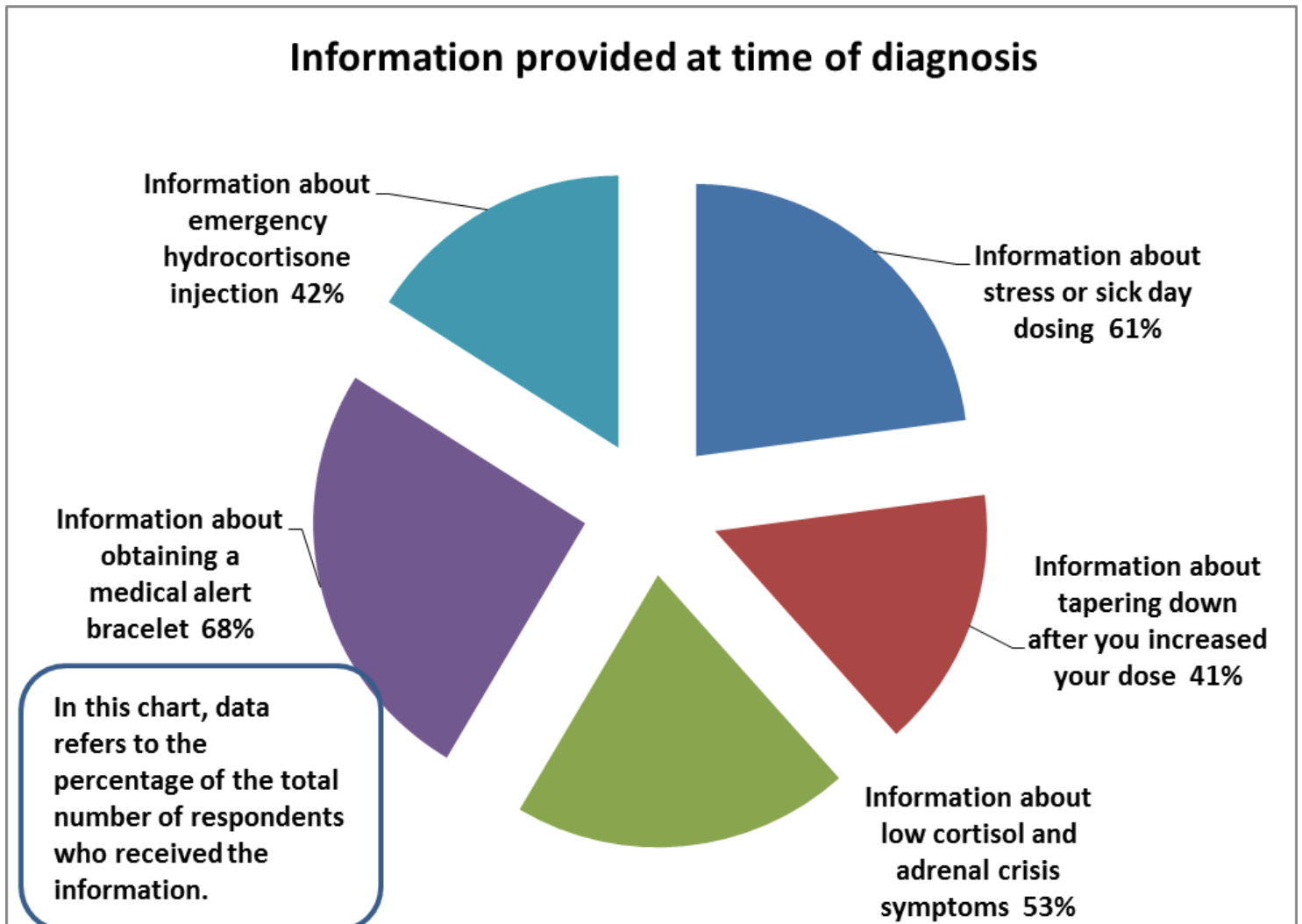
**Did you know** that many of us are well informed about what to do in emergencies at the time of diagnosis? This seems more common for those people who are more recently diagnosed. For example:

*'My diagnosis was a long time ago. Information about stress/sick day dosing and Solu-Cortef was not available.'*

*'My endocrinologist 'is available for questions regarding up-dosing when needed and was the one who informed me that I required an emergency injection kit and that both my husband and I should be trained to do this. She organised the lesson for us with the endocrine nurse at the hospital.'*

*'I learnt this information over the first few years. Doctor did prescribe injectable hydrocortisone but I could not get anyone to teach me how to administer it. So I don't use it.'*

### Information provided at time of diagnosis



Interestingly, for some of the people who completed the survey this Association [AADA] had a role to play in helping to inform them:

*'I found out about Solu-Cortef and medical alert bracelet through AADA.'*

*'As I was diagnosed 30 years ago, I did not get a lot of information at that time. I have worked at my self education over the years and have picked up tips from others and from the newsletter. I now feel I have a lot of information and feel confident overall about how to manage my Addison's condition.'*

Some of us have sought out information from a variety of sources. For example: *'My 'Endocrinologist provided the sick day info. I got medical alert on own, and requested the Solu-Cortef, and needle through the GP.'*

# More Member Survey results

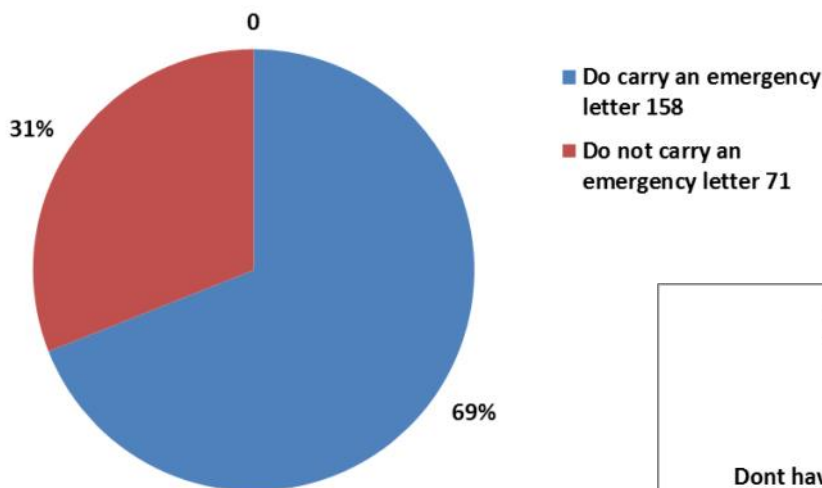
**Did you know** that 31% of us with adrenal insufficiency don't carry an emergency letter? If you are one of the 31%, please talk with your doctor and get a letter as soon as possible.

*'I was given a MedAlert brochure and an up-to-date page about Addison's but no letter.'*

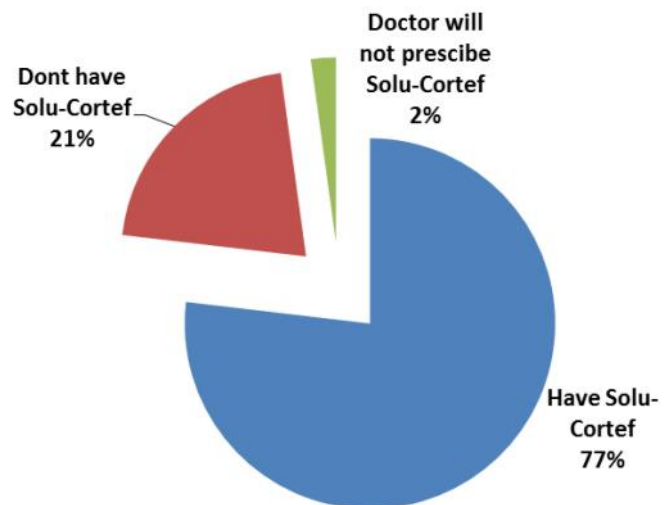
*'I got a letter from my endocrinologist.'*

*'We had to wait 2 hrs in A&E (for the first time in 5 yrs). But now we have a letter & staff were great once we got in.'*

## Respondents who carry an emergency letter



## Is injectable steroid carried for emergencies?



**Did you know** that 77% of us carry an injectable steroid for emergencies? There are lots of varied stories about carrying injectable steroids.

*'My GP refused to prescribe Solu Cortef initially, but I was going overseas so she reluctantly gave me a script. I attended my 1st Addisons meeting in Brisbane this year and a presenter showed us how to draw up and inject the Solu-Ccortef. I have not had to inject myself, but I have presented at a doctors surgery and they have done so.'*

*'My endo says injection Solu-Cortef is just for camping.'*

*'Uncontrollable vomiting and diarrhoea, major fluid loss, low blood pressure, inability to maintain cortisone levels. I was in NZ for work, called the ambulance and was taken to hospital I gave them my letter with the treatment protocol and injectable cortisone. They seemed to think I had some type of infectious disease, isolated me and did not treat me with an antiemetic and cortisone for almost 2 hrs. I yelled the place down and they gave in but kept me in isolation!'*

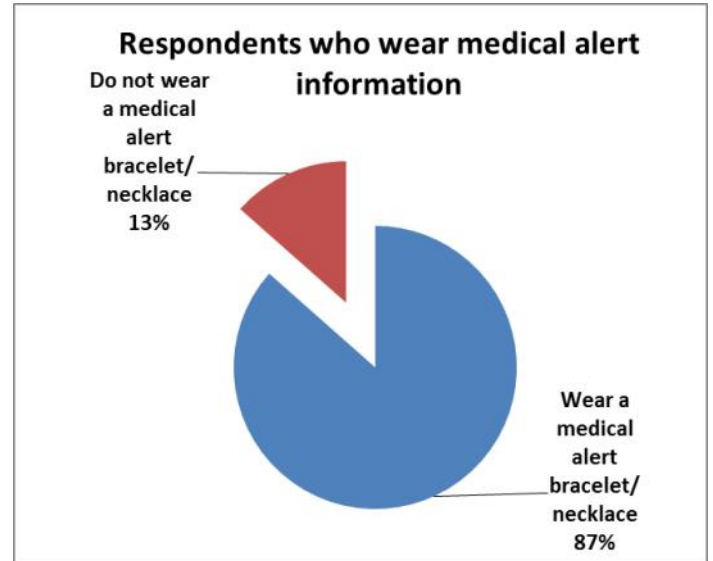
# More Member Survey results

And **did you know** that most of us (87%) wear medical alert jewellery?

It is interesting to compare this result with the number who carry a doctor's letter. People seem more comfortable wearing the jewellery.

*'I wear a medical alert bracelet and necklace.'*

*'I am becoming better at talking about AI. Many people know that I have Coeliac Disease and have had colon cancer and you can almost see them rolling their eyes when I start talking about AI, so I try not to push the issue. But I do mention it in my various recreational/voluntary roles so that people know to check my medical bracelet in an emergency.'*



## Twenty years of the Sydney Chapter of the Addison's Disease Support Group

On the 8 April 1998, we had our first group meeting at Westmead Hospital, set up by Maureen Williams, in a room organised by Prof Eastman AO.

Thirteen people attended this meeting: Janne McDonald, Allen Wonson, Stephen Tiley, Gwen Harragon, Virginia Pena, Leonie McKay, Helen Brown, Margaret Archibald, Marie Maskiell, Geoffrey Mullins, Bronwyn Monro, Judy Mitchell and Maureen Williams.

At the meeting, we introduced ourselves and told a little of our own story, which was usually a harrowing one. We talked about what we would like to achieve as a group, including that we wanted to meet other Addisonians, how we could get A&E departments to recognise an Addisonian crisis and treat it immediately, and how we wanted experts talk to us about a range of health issues, including dental work, depression, DHEA (testosterone), and the role of sugar and salt in managing our condition. From the meeting, we resolved to meet every three months.

After just 18 months, by November 1999, we had 30 members in Sydney, including three boys in one family! We were also now talking about taking extra salt and Florinef on extremely hot days, and drinking more water. We were conscious that ambulance paramedics were not able to give us our emergency injections and started thinking about what we could do to change that. With this in mind, we discussed the importance of taking our medical information when presenting at A&E. Finally, we also looked at fundraising to cover our expenses—our membership fee then was \$20.



We now have support groups across many states in Australia, not just NSW. We have an up-to-date website, brochures, emergency cards and seminars, such as the one in Sydney on 26 May 2018. These achievements are due to the commitment of many people making a contribution in many different ways. These people include Bronwyn Monro, who has been a faithful servant of this Association since 1999, in particular organising the Sydney Seminar at RPA. I know for Bronwyn, the opportunity to make a difference in someone's life is the driving force of her commitment.

In order for us to continue the good work of the Association for another 20 years we need others to help too. What can you do?

Keep well and stay positive.

Janne McDonald

# A member's story

## Beyond diagnosis: How a State Representative supported a member

In December 2013, our family was booked for a holiday to Tasmania to celebrate our eldest daughter's completion of her HSC.

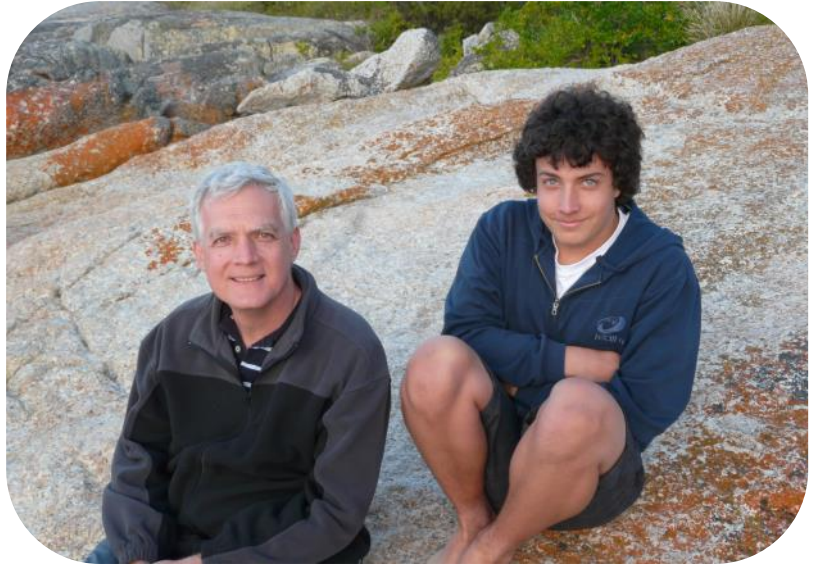
We had begun planning early in the year and it was a motivating event to look forward to during the hard slog of Year 12.

But by July her younger brother had begun experiencing headaches which prevented him from participating in his weekly squad swimming. Then came other unpleasant symptoms of dizziness, fatigue, nausea etc. He himself was scheduled for a school excursion to Tasmania, coincidentally in August/September.

He returned from the excursion exhausted and was scheduled to visit an ENT doctor to investigate the headaches. This was done on Tuesday with no clear reason discovered to explain the headaches. Three days later, he was admitted to emergency and eventually diagnosed with Addison's disease.

When our son faced a couple of complications after the diagnosis we then wondered if our booked holiday would be safe. Thankfully our GP helped allay our fears when our endocrinologist at the time refused to prescribe an emergency injection kit, instead advising for our son to always be within 30 minutes of a hospital.

Our GP clarified that rural GPs will always have hydrocortisone in their equipment. We investigated hospitals and ambulance services in the areas we would be travelling.



Lastly, but certainly not least, we had become members of AADAI in the first week or so of our son's diagnosis and had enjoyed a couple of valuable conversations with Noreen, the then President. This was our first connection with someone with firsthand experience of Addison's disease.

Although my memory is not clear about this, I would not be surprised if my hunch is correct that Noreen suggested I introduce ourselves to the State Representative in Tasmania, Lisa Terry. But no matter how it came about, that is what I did, by email.

Lisa replied in such a friendly manner and was very understanding of what an Addison's diagnosis would be like for a 16 year old. That was a therapy in itself! How reassuring it was to know we had a

friend there who may be able to give some moral support if things went pear shaped.

Thankfully nothing untoward did occur during our 10 day visit, except for the debilitating fatigue, aches and pains of the recovery from years of depleted cortisone and aldosterone production! Which now, years later we are all too familiar with.

Our contact with Lisa gave us all a sense of confidence and connection that enabled a more enjoyable holiday than if we had embarked with this new chronic illness to navigate as well as unfamiliar, even though beautiful, geography solo!

Thanks again Lisa!

Catherine Dyball

# 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*).



## 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.

## 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](mailto:editor@addisons.org.au)
- 0455 534 472

## Keep in touch: we don't want to lose you!

Please let us know if you change your address, phone number or email. There are a few ways you can do this:

- Email: [secretary@addisons.org.au](mailto:secretary@addisons.org.au)
- Text or call: 0455 534 472
- Website: Find 'update member details' under the 'Members' menu on the home page.

## 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!



# Join our Association

## MEMBERSHIP FORM 2018

Please FULLY complete the following in **BLOCK LETTERS** and forward to:

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

I have paid via: Cheque/Money Order  EFT\*  PayPal

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

and an optional donation of \$\_\_\_\_\_

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

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

### OFFICE USE ONLY

Date Rec:

Rec No:

Mem \$      Donation \$

Title:		
Surname:		
Given name(s):		
Date of birth:		
Postal address:		
Town/City:		
Postcode:	State:	Country:
Phone:	(    )	
Mobile:		
Email:		
GP:		Ph No.
Endocrinologist:		Ph No.
<b>Only to be completed by new members or members whose details have changed</b>		
Next of Kin contact details	Name:	Ph:
When were you diagnosed with Addison's disease?	Year:	
I have (tick one)	Primary Addison's <input type="checkbox"/> Secondary Addison's <input type="checkbox"/> Other <input type="checkbox"/>	
Details of Other		
I wish/don't wish to make contact with other members in my area:	By phone <input type="checkbox"/> by email <input type="checkbox"/>	
How would you like to receive your newsletter?	Email <input type="checkbox"/> Post <input type="checkbox"/>	

**Australian Addison's Disease Association Inc.** 48 Glassop Street, Balmain NSW 2041 , ABN: 60 466 289 835  
P: 0455 534 472 E: [info@addisons.org.au](mailto:info@addisons.org.au) W: [www.addisons.org.au](http://www.addisons.org.au)

*The Australian Addison's Disease Association Inc. conforms to the requirements of the Privacy Act in the way it collects, stores & uses the information provided by its members and applicants.*