Australian Addison's Disease News
Issue 124
October 2018

Join us at this year's AGM: Your invitation is inside!

New health initiatives due to begin

From the implementation of the Australian Government's *My Health Record* to moves to protect the supply of life-saving medicines, there are a number of changes afoot members need to be aware of.

My Health Record, which brings together health information from you, your healthcare providers and Medicare, has received widespread attention and the opt-out date is fast approaching. (*More information on this health initiative is on page 7)*

Meanwhile, the Australian Government is introducing measures to make manufacturers report shortages of important medicines as soon as they occur.

On behalf of members, the AADAI has written to the Health Minister to ensure the medications required by people with adrenal insufficiency are included. *(More information on this reform is on page 5)*

In this edition…

Acting President's Message

As I consider the approaching AGM, to be held at Club Ashfield on Sunday 28 October at 11am, I have been reflecting on the past year and the progress we have made.

As the Executive Committee will have to step aside from their roles at the AGM before renominating, we wonder if you too would like to join the Executive running the Association? Please do ask me or other committee members if you want more information about what is involved. I have learnt it is such a rewarding opportunity.

We welcome new ideas and suggestions, so send them to us or come to the meeting. You can use Zoom technology to participate online if you can't make it to the venue.

The committee meetings are also run by Zoom and generally go for an hour every six weeks.

Our advocacy teams, led by Grahame Collier, are working on developing up-to-date publications that are available to members on our website.

Geoff Mullins leads the website team. They meet regularly and are creating a new look website. Thanks to all of you.

A warm welcome is extended to our new members too. Janne McDonald is trying to set up local coffee groups, starting with Central Coast and possibly the Blue Mountains. Sorry we haven't got a plan for other areas yet, do you have a suggestion?

We hope you find the information in the new member kits helpful. Don't forget you can ask for a complimentary kit for your doctor if you think it would be helpful. If you need more of any item in the kit we can send it to you, just ask us. Love to hear from you, your feedback is helpful.

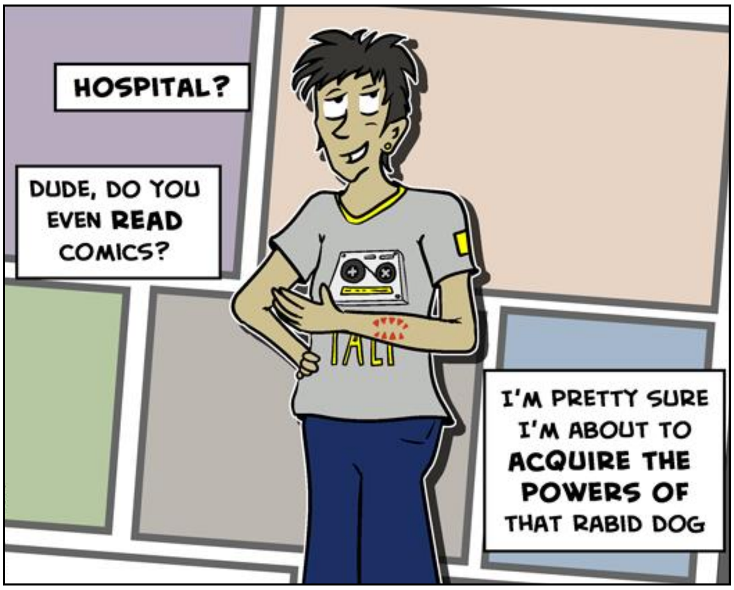
Our 2018 Sydney seminar brought together many new people, from the country and interstate as well as Sydneysiders, and old hands. We are all trying to live as well as possible with primary (Addison's disease) and secondary AI and sometimes with other medical issues. Thanks for joining us on that day.

Dr Teresa Anderson spoke about Area Health issues and *My Health Record* (see article on *My Health Record* in this newsletter), she welcomed Professor Torpy to Royal Prince Alfred hospital, and opened our seminar. We are very pleased she is supportive of groups such as ours.

Planning is underway for 2019 seminar, to be held at the end of May, 2019. We plan to use the same venue. The recordings of the 2018 seminar proceedings are being checked and we will advise you how you can access them when they are ready. Thank you, Peter McDonald, for this work.

Bronwyn Monro

On the lighter side by 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 explores if stress disorders are linked to autoimmune diseases

July 2018: Autoimmune disease has been linked to stress disorders in animals, but the evidence in humans is limited.

Researchers from Iceland, Sweden, and the United States have collaborated in a study to determine the association between stress disorders and the risk of autoimmune disease. Their findings, recently published in the journal JAMA, show some interesting results.

The researchers used a nationwide Swedish registry that followed individuals from 1981 to 2013 who had received a stress disorder diagnosis during this time. The researchers were able to control family factors by using a sibling based comparison approach. The average age of the diagnosis of a stress disorder was 41 years.

They found that compared to individuals who had not been exposed to stress, those who had been exposed and developed stress disorders were at a higher risk for developing autoimmune diseases. This association also held true in the comparison with siblings who had not been exposed to stress.

The team looked up cases of 41 different autoimmune diseases, including Addison's disease, type 1 diabetes, lupus, psoriasis, multiple sclerosis, inflammatory bowel disease and celiac disease.

The results showed that people with stress-related disorders were at greater risk for autoimmune diseases than both their siblings and other healthy participants. Among the participants with stress disorders, researchers found autoimmune disease in 9.1 cases per 1000 person-years. Among siblings the rate was 6.5 per 1000 person-years, and the group of other healthy individuals had 6.0 cases per 1000 person-years.

What these results show is that not everyone with an autoimmune disease had stress disorders, but that such illnesses were somewhat more common among people with stress disorders.

Interestingly, the use of drugs that help with stress disorders, such as serotonin reuptake inhibitors, especially during the first year following the diagnosis of stress disorder showed a decreased risk of autoimmune disease.

(www.ncbi.nlm.nih.gov/pubmed/29922828)

Study explores everyday managing and living with Addison's disease

October 2018: People with rare diseases are a minority group that faces risks for healthcare and work inequities because knowledge and resources on how to systematically support health or working life are limited. Integrating voices of persons living with rare diseases are an important aspect in inclusive and relevant healthcare practices.

A Swedish study published in the Scandinavian Journal of Occupational Therapy, called *Everyday managing and living with autoimmune Addison's disease: Exploring experiences using photovoice methods*, sought to actively involve persons with autoimmune Addison's disease in exploring challenges and possibilities situated in everyday life.

Photovoice methods were used to incorporate experiences through photographic documentation and group discussions with five persons over seven weeks. Data generated from group sessions were visually analysed or transcribed and analysed with thematic analysis.

Five themes emerged: Individual and fine tuning in everyday life; It is not how it was; The power of knowledge and support; Becoming the expert in an uncertain context; and, Finding balance and paving new ways.

The findings showed that everyday life with Addison's disease was more complex than earlier portrayed and entailed several barriers and negotiations. In order to meet the needs of persons with Addison's disease, more extensive and relevant information, support and self-management education is needed. Moreover, a complementary focus on everyday life to promote their health and wellbeing is also important. *(www.tandfonline.com/doi/full/10.1080/11038128.2018.1502351)*
)

Your Invitation: 2018 AADAI AGM

Join us at this year's Association Annual General Meeting

Sunday 28 October 2018

The AADAI exists to inform and support you.

Support your Association by joining the Annual General Meeting along with your fellow members. Have your say about your Association's future direction.

This year, you can join us in person at the live meeting, or join us online via Zoom.com—an online conferencing portal.

For more information and to RSVP:

Phone: 0427 601 795

E-mail: secretary@addisons.org.au

This year, the AADAI 2018 Annual General Meeting starts promptly at:

- NSW, ACT, VIC & TAS: 11am AEDT
- SA: 10:30am ACDT
- QLD: 10am AEST
- NT: 9.30am ACST
- WA: 8.00am AWST

SUNDAY 28 OCTOBER 2018

Join us at the live meeting

New Board Room
Club Ashfield
1-11 Charlotte Street
Ashfield, Sydney
New South Wales
www.clubashfield.com.au

Stay on for lunch at the bistro (at own cost)

Join us online via Zoom

The live meeting will be transmitted via **Zoom.com**—an online conferencing portal.

The use of Zoom allows members from Cairns in Queensland to Albany in Western Australia to take part in the AGM.

You can only join the meeting via an INVITATION CODE so please RSVP before the day to receive it via email.

This amendment will be moved at the 2018 AADAI AGM. It is proposed that an additional Clause (7) is added to Section 14 of the AADAI Constitution as adopted in 2017: 14 Composition and membership of Executive Committee. The proposed additional clause is:

(7) 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.

Member news

Australian Government moves to protect supply of life-saving medicines

On 11 July 2018, the Federal Minister for Health Greg Hunt announced the supply of critical and life-saving medicine would now be protected. Under the new law, medicine companies will now have to report shortages of important medicines as soon as they occur.

"In addition, if a critical drug is being removed from the market, my Department must be notified by the manufacturer at least 12 months in advance, or as soon as possible. This new law protects patients who rely on vital medicines. They also give the community, medicine company and patients the opportunity to take action to mitigate against a medicine shortage," Minister Hunt said.

Mandatory reporting will apply to all prescription medicines as well as other medicines which are vital for public health. Under the new law, a critical medicine is deemed to be in shortage if there is not enough, or likely will not be enough, for all patients in Australia who take it or may need to take it, at any time in the next six months.

In response to this media release, the AADAI has written to the Minister for Health, on behalf of members, to ask that the medications used by people with adrenal insufficiency be recognised as both vital and critical. There have been issues with supply of some medications, especially Hysone, over the past 12 months. Manufacturers are not always aware of the medical conditions that their medications treat.

The AADAI is hopeful the new legislation, due to become law from 1 January, 2019, will make sure that we have a good supply of our medications with more time to organise if medications are going to be in short supply.

Emergency+ - an App that could save your life

The Emergency+ app is a free app developed by Australia's emergency services and their Government and industry partners.

The app uses GPS functionality built into smart phones to help a Triple Zero (000) caller provide critical location details required to mobilise emergency services.

Emergency+ is a national app developed by Australia's emergency services and their Government and industry partners, helping people to call the right number at the right time, anywhere in Australia.

'Emergency+' also includes SES and Police Assistance Line numbers as options, so non-emergency calls are made to the most appropriate number.

The App is available for both the iPhone and for Android devices and is highly recommended for use by sufferers of Addison's disease and adrenal insufficiency.

https://emergencyapp.triplezero.gov.au

SA Event: Spring Picnic

Members and friends in South Australia are invited to an upcoming Spring Picnic.

It will be a great opportunity to catch-up with others. Please bring your picnic lunch and a chair.

Date: Midday, Saturday 3 November 2018

Where: Mitcham Reserve, Norman Walk, Mitcham.

For more information, contact SA Representative Kaye Toshach on kaye.e@internode.on.net.

Coffee Catch-Ups

Would you like to meet other Addisonians?

We have had feedback from the Sydney Seminar that some of you would like to meet other Addisonians for a chat and to share information, but are not able to attend a meeting organised in the larger centres.

If you would like to organise or attend a coffee catch up near you anywhere in Australia, contact Janne McDonald, Seminar Organiser, at home on 02 9979 5570 (you can leave a message).

Web Group Update: Lots of good work done and great changes to the site

I am pleased to report that the Web Group is working well and has achieved a considerable amount since the last report. The group works closely with the Executive to ensure the work we undertake is in line with the strategic direction that they have set.

We have welcomed Layla Homewood who has replaced Gisela Spallek. We publicly thank Gisela for her valuable contribution.

The wonderful work of the Advocacy Group is now coming to fruition with a number of new documents recently placed in the Members area of the current web site. This material will be able to be taken to the new website when the site is ready.

The task of providing regular updates to the existing site and planning the style and technical capability of the new site is challenging and for that reason, it was felt that weekly group meetings was required.

Our aim with the new site is to ensure that it provides an excellent source of information in a modern, professional way for both members and visitors. A critical need is for people needing to find emergency information to find it immediately without having to search through complex menu structures.

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.

Recent changes that have been released have included a new menu structure to allow items to be placed under their different subject areas. These are available for Medical FAQs, Pharmacy FAQs and Ambulance Protocols.

The Links page under Information has also been reviewed and made much neater. Redundant and irrelevant links have been removed.

The Web Group are members of the Association and like you, we want our organisation to be the best it can be.   We always want to receive your suggestions on what you expect from the new site and any difficulties you have with the existing site. This information is important so that we can meet your expectations as we work towards the launch of the new site.

Please send your suggestions to **g.mullins@addisons.org.au**

Geoff Mullins, Website Committee Coordinator

Treasurer’s Update: Strong finish for FY18

Due to the large donations that have been made and re-growth of the membership, the profit in the past financial year was exceptionally good, leaving the Association in a very strong position to continue its Advocacy and Awareness programs.

More will be said about the Association's overall financial position at the upcoming AGM and in the newsletter thereafter.

Peter McDonald, Treasurer

My Health Record

Details about the Australian Government's *My Health Record* explained

There has been much publicity about the new Australian Government initiative *My Health Record,* which provides an online summary of your health information. Some people are comfortable with this, others would rather opt out of having their details included on this online system. The final date to opt out has been extended until **15 November, 2018.**

To help you make the decision that is best for you here is some more information.

What is *My Health Record?*

My Health Record is an online summary of your key health information.

When you have a *My Health Record*, your health information can be viewed securely online, from anywhere, at any time – even if you move or travel interstate. You can access your health information from any computer or device that's connected to the internet.

Information you can add to your record

You, or someone authorised to represent you, can share additional information in your record that may be important for your healthcare providers to know about you.

This can include information such as: contact numbers, emergency contact details, current medications and allergy information.

What information is used?

Information from healthcare professionals

Healthcare providers such as GPs, specialists and pharmacists can add information about your health to your record, including:

- an overview of your health uploaded by your doctor
- hospital discharge summaries
- reports from test and scans, like blood tests
- medications that your doctor has prescribed to you
- referral letters from your doctor(s).

Information from Medicare

Up to two years of past Medicare data may be added to your record when you first get one, including:

- Medicare and Pharmaceutical Benefits Scheme (PBS) information held by the Department of Human Services
- Medicare and Repatriation Schedule of Pharmaceutical Benefits (RPBS) information stored by the Department of Veterans' Affairs (DVA)
- organ donation decisions
- immunisations that are included in the Australian Immunisation Register, including childhood immunisations and other immunisations received.

More details are available from: www.myhealthrecord.gov.au

Australian Government
Australian Digital Health Agency

My Health Record

The Help Desk

Your adrenal insufficiency questions answered by Professor David Torpy

Q: When I fast (for blood tests etc) I get hypoglycaemia symptoms even though my blood sugar reading is not actually low. I've talked to a few other Addisonians about this and found that I'm not alone. Do we know what causes this?

Symptoms on fasting are common and diverse, only rarely do they represent true hypoglycaemia. Measuring glucose with symptoms requires proper blood glucose testing in the lab. The typical error of home glucose monitors is around 20% so it can be difficult to ascertain the difference between the 3s and 2s which is where hypos genuinely arise. I have found some Addison's patients do have low glucose after fasting and this may occur when the amount of glucocorticoid in the blood is low while fasting as glucocorticoids help us access stored glucose in the liver. This often occurs at night. The issue is pretty complex and it is hard to generalise, but for most people concern should only occur when brain function is clearly disturbed with confusion or loss of consciousness. For patients with actual hypoglycaemia this is usually follows "adrenaline rush" type symptoms – tremor, palpitations, sweating, hunger, anxiety and so on.

Q: Since I've been diagnosed with Addison's disease, I've started to get eczema on my legs. It comes and goes, but seems to be coincide with times when I'm really busy and run down. Is this related to Addison's at all or more something else with the immune system?

Eczema is not caused by Addison's but is a feature of atopy, or allergy. Both allergy and autoimmunity such as that which causes common adult onset Addison's are associated with overactivity of the immune system, but direct connections/associations are limited in practical terms.

Professor Torpy, Deputy Director, Endocrine and Metabolic Unit, Royal Adelaide Hospital

Your pharmacy-related questions answered by Dr Michael Lew

Q: I have a Magnapool Filtering system in my pool . The minerals used are magnesium and potassium, and it appears potassium makes up 70% . My son has Addison's disease and has been advised swimming in the pool will harm him.

It is sensible for many Addisonians to be a little cautious regarding potassium intake because many of them lack the ability to secrete aldosterone, a 'mineralocorticoid' that is one of the physiological hormones involved in the regulation of potassium. However, after some quick calculations, it doesn't seem to me that the amount of potassium in the Magnapool system is so high that swimming in it would present a substantial danger to an Addisonian (beyond the normal risk of drowning!). Not every Addisonian or person with adrenal insufficiency lacks aldosterone: if you do not need to take fludrocortisone then your adrenal glands probably secrete aldosterone normally.

The Magnapool minerals safety datasheet indicates that potassium chloride (KCl) makes up more than 60% of the minerals, and potassium makes up 68% of the mass of KCl. That means that there is between 0.31 and 0.52 grams of potassium per gram of mineral powder. The online advice on Magnapool mineral dosing says that 1 to 1.3 grams of the minerals should be added for each litre of water in the pool (30–40 kg per 30,000 litres of water), and that would give a potassium concentration of about 0.4 to 0.7 grams per litre, or 400 to 700 milligrams per litre.

It is convenient to use a banana as a familiar unit of potassium. According to the USA Department of Agriculture, a medium banana contains about 420 milligrams of potassium. That means that a person would have to swallow more than half a litre of pool water to obtain the same dose of potassium as a banana. There is a second type of salt in the Magnapool system, magnesium chloride (MgCl), but the concentration of magnesium in the body is regulated by mechanisms that appear to be unaltered by Addison's disease. All in all, it seems that swimming in a Magnapool system swimming pool is likely to be quite safe for an Addisonian.

Dr Lew, Department of Pharmacology & Therapeutics, The University of Melbourne

Advice: Living alone with adrenal insufficiency

One of our members shares their advice on looking after themselves

This year, for the first time in my life, I have found myself living alone. Like most of you I have always lived with others – parents, husband, children, elderly parents. Suddenly they are all gone and no longer rely on me to help them and they are not around to help me.

While this comes either as a shock or relief when it finally happens to us, it made me stop and think about how to set myself up if an emergency arises at home.

I keep reading about the importance of having an advocate in case you need to call an ambulance or go to hospital. I don't have one of these. I could call on one of my married children, who don't live too far away. I have friends I could ask.

However, I am reluctant to do this. I then realised after dealing with my late father's many hospital admissions that no one has the knowledge to tell medical personnel about my condition or how to monitor treatment.

With this in mind I have set up folders with the following:

- a page with my medical information that includes my medical conditions, medications and when to take them, allergies, Medicare number, GP and endocrinologist contact details, Health Fund details and MedicAlert number
- information about treating an Adrenal Crisis (available from the AADAI)
- the NSW Ambulance protocol for treating an adrenal crisis (available from the AADAI)
- results of recent blood tests – I ask my GP to give me a copy of these
- Patient Health Summary – from my GP

I keep one folder in a prominent position in my house, with my Solu-Cortef injection, so it can be seen easily. I also have a folder in my car and one in my handbag. **In addition:**

- I have told my children that if I ring them and sound confused or not well that they should hang up and ring an ambulance immediately.
- I have a Vital Call system where you have a pendant or bracelet to push in an emergency. This connects you to a person who asks if you need help. This alarm works from anywhere in my house or in the garden. There are many similar systems available, some that call you every day, some that monitor for falls and some that give GPS map locations.

I stay as healthy as possible:

- I try to organise my life so that I am not too busy for days at a time as I know this can cause problems for me. I am getting better at saying "no" if it is something I really don't want to do.
- I have a good routine for taking my tablets three times a day and rarely forget them.
- I monitor how I feel, especially at night. Most times I feel ok. Sometimes, I may need to take a small extra dose if I feel I need it.
- I eat regular meals

It is important for everyone with adrenal insufficiency to have a plan for an emergency but it's even more important if you live alone. Do you have any other ideas to help you live independently?

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*).

The Australian Addison's Di

Educate the medical profession to have

Make the general public a

Supply up to date information tc

Supply a caring network to give support for people with Addison's

Membership Profile

Hello Matthew Hart, your mer bership is current and you have f ll access to the website.
Your Membership will expire n Thursday August 31st, 2017

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
- 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
- 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!

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
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Webmaster
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webmaster@addisons.org.au

Medical Advisor
Professor David Torpy
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Pharmaceutical Advisor
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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 *your name / member's name* 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 area:	By phone: ☐	By email: ☐
How would you like to receive your newsletter?	Email: ☐	Post: ☐
Next of Kin contact details	Name:	Ph:

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.