



Happy New Year!

Medication availability protection

AADAI has taken action on behalf of members to ensure the medications used by people with adrenal insufficiency are included on the list of mandatory reporting medicines.

This follows an announcement by Australian Health Minister Greg Hunt in September last year that a new scheme would be launched to ensure the supply of vital medications.

Under this scheme, medicine companies will have to report shortages of important medicines as soon as they occur.

AADAI lodged a formal submission to the Health Minister, who responded with reassurance that all shortages of prescription medicines would be reported to the Therapeutic Goods Administration.

(More information on page 5)

In this edition...

- Making headlines: Addison's in the news
- Latest Association updates
- Your invitation to the AADAI 2019 Seminar
 - Save the date!
- Actions to ensure medication availability
- Meet member Phillipa Morris
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 - FY18 Financial Statement

President's Message

Happy New Year everyone! Greetings to all at this busy time of the year. Remember, it is supposed to be a happy time too. However, I am aware that some members are not travelling so well with their adrenal insufficiency, and may find the busy days quite stressful. Don't overcommit and keep things simple would be some good tips!

I had a three-day stay in hospital recently, suffering from gastro and pneumonia together. I had excellent care, but it was a stark reminder that I am vulnerable to infection.

The AGM on Sunday 28 October went smoothly, thanks to a lot of preparation in advance. Eight people attended the live meeting and 8 more Zoomed in, one from Western Australia and one from New Zealand, framed by stunning views of Lake Wakatipu as she trekked above Queenstown.



I love the way Zoom allows us to stay in touch. The Treasurer's Report was very positive and was able to point towards future directions of the Association.

Congratulations to the new committee, who were elected and have volunteered to serve the Association for the coming 12 months. The members include Grahame Collier as Vice President, Kerry Wheeler as Secretary, Peter McDonald as Treasurer, and Phillipa Morris, Catherine Dyball, Tammy McLandsborough, Janne McDonald and Linda Hobbs as Committee Members. We have had two committee meetings since the AGM to progress our work.

The next seminar details are also listed in this newsletter. Please think about joining us on

May 25 in Sydney.

Bronwyn Monro

Catch-ups

Three of our Western Australian members caught up recently. Dianne and Stan Steber from Manjimup went to Albany and caught up with AADAI WA State Representative Felicity Tadj (*see photo below*).

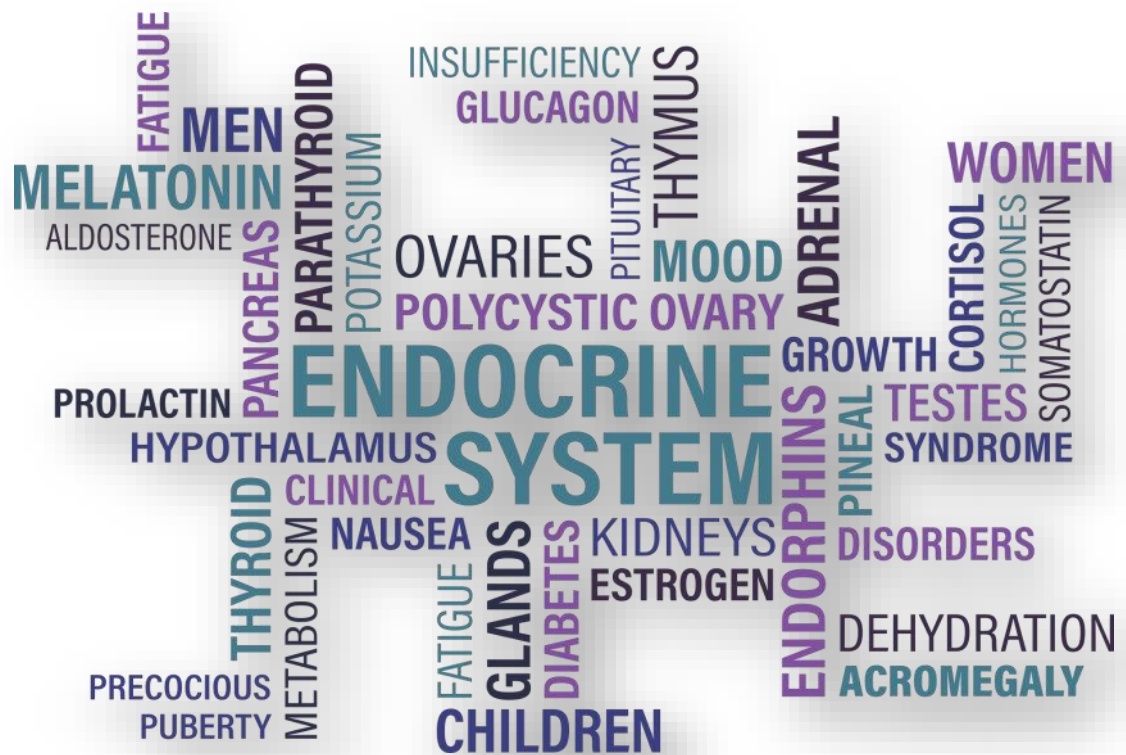
As Felicity said: "it was lovely to spend time and talk all about Addison's and just know each experience without having to try and explain in detail!".



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.

Risk of Addison's disease in patients with type 1 diabetes

(<https://www.healio.com/endocrinology/adrenal/news/in-the-journals/%7B0bf88fe5-62f4-401e-930c-dbc11e383ae%7D/autoimmune-thyroid-disease-retinopathy-may-signal-addisons-disease-in-type-1-diabetes>)



Save the date

Join us
at the
AADAI Seminar

25 May 2019
Sydney



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 Dr Bronwyn Crawford
- Pharmacy advisor Dr Michael Lew
- Endocrine nurses on how to manage your condition
- *Much more, including the opportunity to chat with others*



2019 AADAI Annual Seminar: Saturday 25 May 2019

8am: Registration, with tea & coffee

9am to 2pm: Seminar, including lunch

Kerry Packer Auditorium

To register or for information:

Royal Prince Alfred Hospital

M: 0427 601 795

Missenden Road, Camperdown

E: Bronwyn@addisons.org.au

Member news

Actions to ensure the availability of adrenal insufficiency medications

On the 11 September 2018, the Minister for Health, the Hon Greg Hunt MP, issued a press release about a new scheme to ensure availability of supply of vital medications. In this press release Minister Hunt said [extracts only]:

'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.

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.

Mandatory reporting will apply to all prescription medicines as well as other medicines which are vital for public health, such as EpiPens and inhalers.'

In response to this, AADAI acted swiftly on behalf of its members by writing to the Minister. In essence, this formal submission strongly requested that all medications used by people with adrenal insufficiency for cortisone replacement be included in the list of mandatory reporting medicines. A copy of our Fact Sheet - Medications for adrenal insufficiency was provided. Please see this in the members area of our website.

It should be noted that Professor Torpy, the AADAI Medical Advisor supported this approach, in writing.

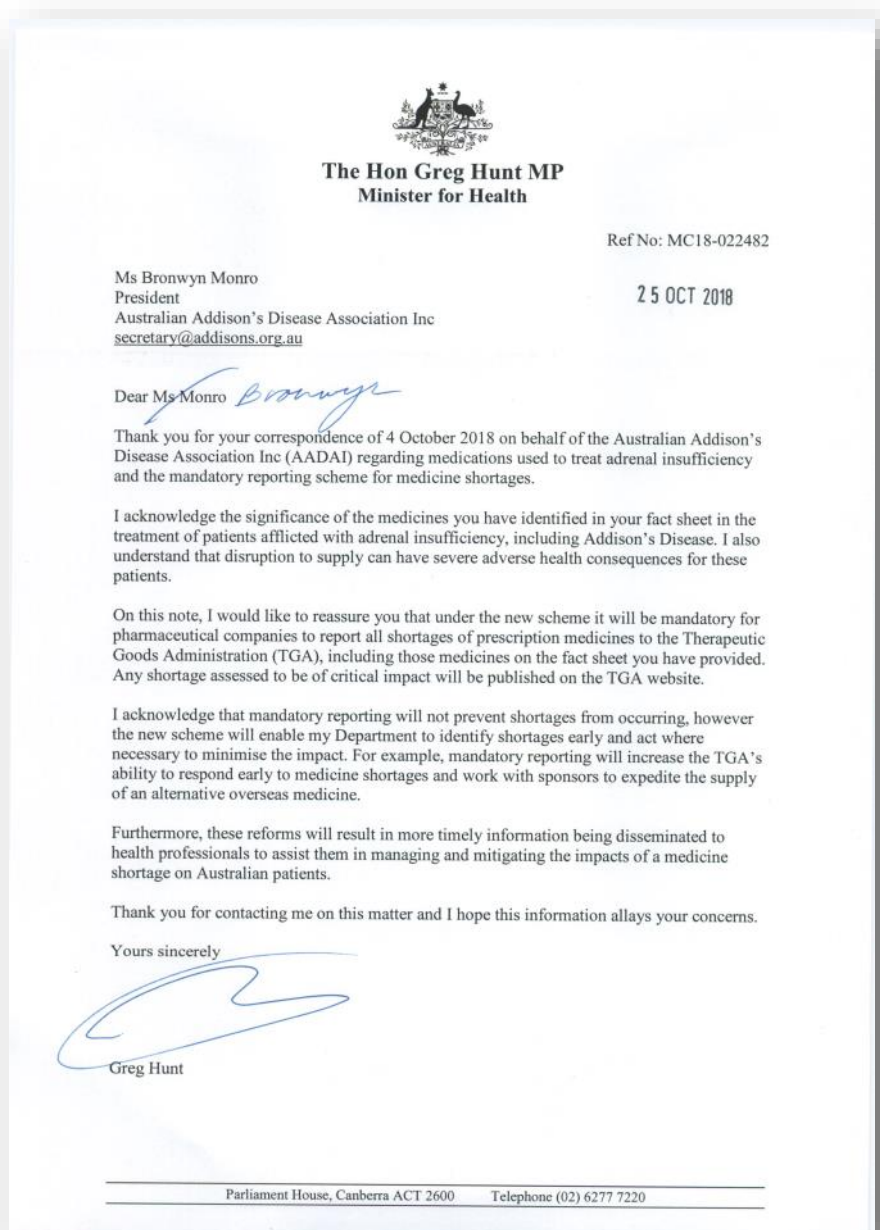
The Minister responded to our President on the 25 October 2018 saying that:

'I acknowledge the significance of the medicines you have identified in your fact sheet in the treatment of patients afflicted with adrenal insufficiency, including Addison's disease. I also understand that disruption to supply can have severe adverse health consequences for these patients.'

On this note, I would like to reassure you that under the new scheme it will be mandatory for pharmaceutical companies to report all shortages of prescription medicines to the Therapeutic Goods Administration (TGA), including those medicines on the fact sheet you have provided. Any shortage assessed to be of critical impact will be published on the TGA website.'

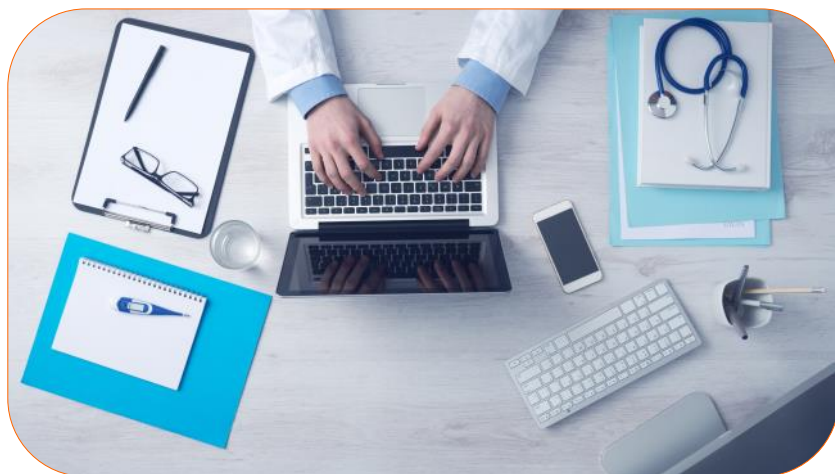
The Minister did acknowledge that mandatory reporting will not prevent shortages from occurring but it will increase the TGA's ability to respond quickly to medicine shortages.

AADAI is very pleased with this outcome and the Executive believes that it will be of benefit to all members, when and if shortages occur.



Member news

More than an ID: Take your health into your own hands with MedicAlert



MedicAlert is more than just protection in an emergency. It gives you peace of mind that your doctor, pharmacist or other health professionals can cross-check treatments with your secure electronic health record – which, as a member, you can personally update and know is professionally-verified.

Given that adrenal insufficiency is a hormonal disorder, living with this condition means managing physical weakness, fatigue and low blood pressure as well as muscle and joint pain. Our busy lifestyles can exacerbate these symptoms and lead to emergency treatment.

No matter where they are, first responders and health professionals can access a member's health and medical information by calling the 24/7 Emergency Response Service and speaking to their trained response team.

When you're unable to communicate your condition and medications to paramedics, the MedicAlert ID will 'speak' for you, when seconds matter.

MedicAlert is a globally recognised not-for-profit organisation that has supported for their members for almost 50 years.

A wide range of stylish bracelets, necklaces and ID accessories are available to choose from ensuring there is an ID to suit your style.

The nature of adrenal insufficiency symptoms requires immediate medical care and, a MedicAlert membership will protect you if they arise.

Take your health into your own hands... with a MedicAlert ID. For more information visit www.medicalert.org.au.

SA Event: Spring Picnic

Members and friends in South Australia gathered on Saturday 3 November last year for a Spring Picnic.

As AADAI State Representative Kaye Toshach reported, it was a great opportunity to informally catch-up with everyone.

Nine people, including five Addisonians, attended the event at Mitcham Reserve

"We all learnt something new, while talking with each other," Kaye said.

The next lunch will be held on Saturday 4 May.

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



LtoR: John, Rick, Peter, Kaye, John, Bruce, Sharyn, Maryanne

Condolences

The AADAI would like to extend its condolences to the family and friends of the following members who are sadly no longer with us: Patricia Chapman, Don Vergers and Elizabeth Walters.

Member Profile

Meet Phillipa Morris

My name is Phillipa Morris, I am 60 years old and although I have worked in many admin jobs and also spent 25 years on and off in the mining industry, I am currently in my fourth year working full time in retail.

I manage a very popular and busy olive oil body care/ gourmet food shop in Margaret River Western Australia.

I have three daughters, two granddaughters and one grandson.

I love living in Margaret River, which has been my home for over six years, as the cool climate suits my health needs and the town has such a wonderful energy of beautiful trees, beaches and always something interesting to see and do. I enjoy going for walks and am a passionate gardener.

My diagnosis

In October 2008 I was working 12-hour day/nightshifts operating heavy earthmoving equipment in a gold mine where I had been really struggling with extreme fatigue, depression, anxiety, very low blood pressure and had an insatiable appetite for salt.

My skin was so dark all over. I had a distinct white patch of skin under my chin and a doctor referred me to a dermatologist.

As soon as I walked in the door and she saw my skin, looked at the dark creases of pigmentation on the palms of my hands and checked in my mouth, she immediately said it looked like I had Addison's disease!

The white patch of skin is vitiligo. Bingo! Blood tests confirmed primary Addison's disease and Hashimoto's thyroid disease. I feel she saved my life.

Hashimoto's turned into Graves Disease a few years ago and after a year on medication my thyroid is sort of normal now.

I was relieved at the diagnosis of Addison's disease as I thought I was going mad.

My biggest concern was that I have always hated and had difficulty swallowing tablets so to have to take medication for the rest of my life to stay alive was very confronting. Now I look forward to every dose to feel better!

Also I was told I would put on weight due to the steroid treatment. I sure did - 20kg quick smart and in a hurry!!! I was extremely thin at 48kg though so definitely needed more meat on my bones.

Now I roll with the fact that the extra weight is protection for my bones in case I have a fall!

After 10 years I still have difficulty explaining my condition to others and most people just don't understand it as I look well - how could I feel unwell? Very frustrating.

So until very recently I have just pushed and pushed myself to be normal like everyone else but I just can't keep up the pace any more. So from now on I am honouring and being kinder to myself. No more pretending.

Living with Addison's disease

For the past year, I have been taking 8mg Hysone and 100mcg Florinef in the morning, 4mg Hysone at midday and 4mg Hysone at 4pm. This works better for me than the first nine years when I was taking 10mg Hysone morning and noon. My original endocrinologist retired and my new one prefers to work out the medication by formula of height/weight ratio and over three daily doses.

I have a wonderful GP who is very caring and thorough and she told me about a monthly visiting endocrinologist to Margaret River, who I now see. I am much happier with the care I receive now and don't have to drive the three hours to Perth any more.

For me the most challenging thing about living with Addison's disease is still my inability to cope with stress in the various jobs I have had and normal family problems.

(Continued on page 8)



Member Profile

Meet Phillipa Morris (*continued*)

I find when I am under stress I don't make very good decisions.

My GP advised me to take antidepressants as one of the common side effects of taking steroids is depression. It was a good thing and helped me cope better with the day-to-day stressors of life.

However, I mistakenly tried reducing the dose when I reduced Hysone from 20mg to 16mg but soon found myself down in the dumps again so quickly put myself back on original dose of antidepressant.

My main goal for myself is to try and secure a better paying and less stressful job in Margaret River to support myself, my mortgage and two Siamese cats.

I am aiming to come over to the seminar in May this year to meet as many people with Addison's disease as I can.

It has always been a dream of mine to go for a holiday on the Ghan from Darwin to Adelaide so I'm saving every spare cent to achieve that in late 2020.

Reflections

I would advise others living with Addison's disease to definitely join the Australian Addison's Disease Association.

I Googled and found the Australian Addison's Disease Association immediately after diagnosis as I was hungry for information to learn how others coped. It was one of the best decisions I ever made.

The most valuable aspect of being a member has been the constant support by telephone and also the newsletters which I always look forward to so very much to see if there are any new tips to help me on my journey.

Honour themselves and not push through life to keep up with family and friends.

Be open and honest with people when feeling unwell and rest up.

Reach out for support from others living with the disease as it really helps.

I only just recently learned about having a mantra of "having an Addie day" when not feeling that great, so am using it from now on!

Being able to help others in a similar situation to mine would be a great upside and positive from having Addison's disease. I am very grateful that with the help of medication I can still live a relatively full life.

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!

Treasurer's Update

Strong finish for FY18: Reminder to members to renew their memberships

Although the Association's AGM was a little while ago, it is pleasing to share the very positive FY18 Financial result with you (refer to the *Income & Expenses statement below*).

Due to a re-growth of membership and a windfall of corporate donations, on top of a steady annual flow of member donations, we recorded a strong profit for the fiscal year. However, given the current softening of membership, **we would ask those who have put aside their 'renewal reminder' to arrange payment in the next month or two.**

Wishing you all a healthy and positive year.

Peter McDonald, Treasurer

Australian Addisons Disease Association Incorporated

ABN: 60 466 289 835

Income Statement

For the year ended 30 June 2018

	2018 \$	2017 \$
Income		
Membership Fees	9,636.85	6,786.29
Donations - Seminar	904.40	394.80
Donations - Other	9,805.98	2,608.57
Interest income	645.95	163.19
Other income	-	170.00
	<u>20,993.18</u>	<u>10,122.85</u>
Expenses		
Accounting fees	1,430.00	2,090.00
Advocacy expenses	1,862.68	-
Awareness expenses	1,081.85	-
Bank charges	147.78	117.56
Computer expenses	431.29	147.60
Insurance	330.00	318.94
Meeting costs	249.85	2,920.51
Postage & courier	1,570.35	1,078.80
Printing & stationery	1,555.46	566.89
Research funding	-	2,000.00
Seminar costs	2,420.73	1,211.60
Subscriptions	1,008.31	538.43
Telephone	60.00	60.00
	<u>12,148.30</u>	<u>11,050.33</u>
Other income		
Net profit (loss)	<u>8,844.88</u>	<u>(927.48)</u>
Retained earnings at the beginning of the financial year	39,446.17	40,373.65
Retained earnings at the end of the financial year	<u>48,291.05</u>	<u>39,446.17</u>
Number of paid up members (Est.)	<u>312</u>	<u>277</u>

[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

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Bronwyn Monroe

Vice President
Grahame Collier

Secretary
(all general enquiries)
Kerry Wheeler
secretary@addisons.org.au

Treasurer
Peter McDonald
treasurer@addisons.org.au

Committee members
Phillipa Morris
Catherine Dyball
Tammy McLandsborough
Janne McDonald
Linda Hobbs

We're always on the look out for people to assist the Association, including those keen to 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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Tasmania
Lisa Terry
P: 0428 218 268
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 2019

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

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:		
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) <input type="checkbox"/> Secondary adrenal insufficiency <input type="checkbox"/> Other <input type="checkbox"/>		
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: <input type="checkbox"/>	By email: <input type="checkbox"/>
How would you like to receive your newsletter?	Email: <input type="checkbox"/>	Post: <input type="checkbox"/>
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.