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 practise 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.
FROM THE PRESIDENT

We are just about up to the Christmas celebrations. This year seems to have gone so fast, it is hard to keep up with it.

It has been a very busy year, which is good. It shows we are at last getting through to the doctors, they seem to be diagnosing quickly and their patients are becoming members much quicker than they used to. We have had more members join since the AGM.

We have some exciting things happening. Pfizer Australia is donating some Solu-Cortef cases to keep your injections in. They will be sent to you all early next year. I’d like to thank Ashok Dixit, from Pfizer, for organising this for us. The cases will be greatly appreciated by our members.

Our pre- and post-operative brochure is still in the hands of the Ethics Board. You will receive it when it has been approved and printed.

I feel this year has gone so well, we have covered so much. My phone calls are going well, I am making new friends all the time. My husband can't understand how I can talk to the same person for so long and not repeat myself.

We have two new state representatives. Julia Kelly from Victoria and Leanne Osmond from South Australia resigned. Our thanks go to both of you for all the good work you both did for your states.

They have been replaced by Stephen Thom in Victoria and Kaye Toshach in South Australia. I hope you will both be very happy working with us.

The Awareness Month went off really well this year and now the Christmas parties are starting to happen so it is all go all the time.

I would like to thank Associate Professor David Torpy for all he has done this year. We don't hear much from him but he is working behind the scenes all the time.

Thank you to Kerry for writing the newsletters, Terrence for being the webmaster and our hard working committee for everything they have done throughout the year.

To all the representatives in each state, we appreciate all the work you do.

I would like to thank anyone who has helped us this year, whether it be medical professionals, members or others. Your help is always appreciated.

Also to all the people who have given us donations, a big thank you to you all. It has been a great year. Some of your donations will soon be used to fund information on Addison’s disease and adrenal crises. More information later.

On behalf of the committee and myself I would like to extend our best wishes to you all and hope you all have a very Merry Christmas and a Happy New Year.

Noreen Secomb
President
AADA
Welcome to the December newsletter.

I hope that this busy time leading up to Christmas finds you well. I am trying to pace myself with the necessary preparations. I try to do a little at a time, although the days seem to be flying by!

This newsletter has some articles I hope you will find interesting as well as informative. It would be so good if there were no stories about members receiving poor treatment at hospitals but, unfortunately, there is another one of these stories on page 7.

The former AADA webmaster, Peter Stewart, has been investigating how Addison’s disease has been portrayed on TV programs. Peter has reviewed three programs and explained how the diagnosis of Addison’s was reached in these programs. His article is on page 5. I also remember seeing an episode of Doc Martin (Remember Me, Season 5, Episode 5) where one of the characters treated already had Addison’s disease.

Helen Reddy has announced an Australian tour which starts in April. Helen, as you may know, has been touring in the United States to rave reviews. If you are interested in going to one of Helen’s shows the details are on page 6.

It is 50 years since the assassination of John F Kennedy, who was President of the United States at the time. There are some new reports that have recently been released that describe JFK’s medical conditions and medications. I have summarised some of the information in the reports on page 7. There are some websites included if you are interested in reading the reports in more detail.

My best wishes to you all for Christmas. I hope that the New Year brings you happiness and good health.

Please send me any stories or articles you think would be of interest to members. I am happy to talk to any of you about including these in the newsletter.

Kerry Wheeler
AADA Editor
PO Box 7212
Baulkham Hills NSW 2153
Email: editor@addisons.org.au
HAVE YOU CHANGED YOUR CONTACT DETAILS?
Please let us know if you change your address, phone number or email. There are a few ways you can do this:
- go to the website and click on Association, then Update Your Details on the left hand side. You can enter your new details here.
- contact Noreen on 02 6652 4761.

COMMITTEE NEWS
The last committee meeting was held on Sunday, 1st December. Present were Noreen, Sylvia and Yvonne in Coffs Harbour. Apologies from Suzanne.

Issues discussed included:
- Website updates
- Medication survey
- Updates to Emergency letter
- Cases for Solu-Cortef donated by Pfizer for members
- Addison’s information to be updated & reprinted
- Noreen’s fax machine will no longer be used
- AADA letterhead updated
- A new member is interested in promoting Addison’s to medical professionals.

COMPLIMENTARY INFORMATION
The AADAI sends complimentary newsletters and information to GPs, endocrinologists and other medical practitioners.

If you would like your medical or healthcare practitioner to receive the newsletters please advise a committee member or a state rep.

You can also tell your medical professional to go to the AADAI website and click on Medical Professionals. All details are checked to ensure that only genuine medical professionals are requesting this information.

LOGON DETAILS
HOW TO LOG ON TO THE MEMBERS ONLY AREA OF THE WEBSITE
Go to the website www.addisons.org.au and click Enter.

Find the Members Only Area by clicking on Association on the left hand side. Click on Members Only Area then on Click Here to Enter.

OR
Click on the information you want under the Latest News on the right hand side and then on Click Here to Enter.

You then need to type in the box:
- **** where it says User name
- **** where it says Password
Click on OK.

MEMBERSHIP PAYMENT BY EFT
Please be aware that you MUST include your FULL NAME on the description, otherwise we cannot be held responsible if your membership is not renewed as we may have no idea who the payment came from. We also ask that members complete the renewal form and include payment details.

Bank: Westpac
BSB: 032 576
Account: 269471
Account name: Aust Addison’s Disease Association Inc

HELPLINE
Many of us take advantage of the Helpline where we can ring Noreen for advice or just a reassuring chat.

Please be advised that the Helpline is open every day from 9am - 9pm EST. Making your calls within these times would be appreciated.
Addison’s disease is something of a rare condition, so it’s not likely to be found often on television. Surprisingly though, I’ve now seen it on two top rating medical dramas, *House MD* and *Grey’s Anatomy* as well as the comedy series *Becker*. Even more surprising, if not disappointing, is that the program which appears to give the more realistic portrayal of an Addison’s case is the comedy series *Becker*!

Here are my synopses/reviews of all three episodes.

**Grey’s Anatomy – Season 10, Episode 7 (2013)**

A girl presents to hospital, appearing alert and whose only symptom appears to have been vomiting after eating candy the night before. After no more than a 20 second consult, the senior doctor orders tests and, as a result, diagnoses the girl with enlarged adrenals with no sign of tumour, indicating adrenal insufficiency where “her body’s not producing enough adrenalin”. The doctors panic when the girl wanders off around the hospital, sparking a race to find her in case she has a sudden life-threatening shock, since she doesn't produce enough adrenalin! This sudden shock of course happens and she immediately collapses. Clearly they subscribe to the well-used principle of never let the facts get in the way of a good story! At least on discovering the girl, fortunately in the nick of time, they order saline and IV hydrocortisone – the only saving factor in what otherwise is an unrealistic and inaccurate portrayal of an undiagnosed Addisonian.

**House MD – Season 3, Episode 1 (2006)**

For a genius diagnostician, House treats his patients for a dictionary full of conditions before finally arriving at the right diagnosis and almost killing them in the process. In this episode a patient unable to speak and severely disabled since brain surgery for cancer eight years prior, manages to drive his wheelchair into a swimming pool. After several dangerous tests and scans, House decides the patient drove into the pool as scarring from a previous surgery on his hypothalamus was affecting his ability to cool down and pressuring his pituitary, causing his adrenals to shut down – Addison’s disease!

This diagnosis seems to have no evidence or apparent symptoms of Addison’s, nor was it tested for. He decides that jabbing him with a dose of cortisol will cure him. Confusingly, of all the nasty and dangerous tests and surgery he is allowed to subject this patient to, a less harmful injection of cortisone isn’t allowed by his superior. However a last minute change of heart sees the injection given right at the elevator just as he is being taken home. Miraculously and within seconds, this man who had been wheelchair bound and virtually comatose for eight years begins to regain movement and stands up, hugging his family - apparently cured. A miracle usually only reserved for the Bible! I doubt if the producers actually used a medical advisor, or perhaps in this case the facts simply got in the way of an “unbelievable” story.

**Becker – Season 1, Episode 9 (1999)**

Dr John Becker struggles to diagnose a male patient whose declining health shows symptoms including lethargy, weakness and a stomach complaint, all making it difficult for him to work or even get out of bed. Becker runs numerous tests, with no abnormal results. Despite trawling through medical books and seeking an opinion from a colleague, he seems no closer to a diagnosis until the incompetent assistant remarks on how strange it was that the patient still had such a great tan so long after his holiday, given that he worked in an office all day. Becker concludes it could be hyperpigmentation and raises the likelihood of Addison’s disease while ordering tests for cortisol and electrolytes. This comedy of a grumpy doctor in a small practice, who keeps getting into all sorts of situations, showed the most accurate depiction of Addison’s disease of all! Despite being a comedy, the episode showed a concerned doctor’s struggle to discover his patient’s illness.

How a comedy can realistically portray a case of Addison’s disease when two well-known medical dramas can fail so miserably, truly disappoints and frustrates me. Although these programs are unlikely to raise awareness or improve the diagnosis and treatment of Addison’s disease, it is annoying that script writers don’t research their work a little better. Clearly these programs are only for entertainment and can’t be taken seriously, but if they wish to use real illnesses, perhaps accurate diagnoses may help give a degree of credibility which is clearly lacking. Those of us who suffered a drawn out and debilitating diagnosis can’t get much enjoyment to see such ludicrous examples of our condition.

*Peter Stewart*
HELEN REDDY UPDATE

Helen Reddy will commence a tour of Australia in April, 2014.

If you are interested, the dates and venues for the tour are:

MELBOURNE
THE ARTS CENTRE HAMER HALL
5th APRIL
8PM

SYDNEY
THE CONCOURSE CHATSWOOD CONCERT HALL
7th APRIL
8PM

SYDNEY
THE ENMORE THEATRE
11th APRIL
8PM

BRISBANE
QPAC CONCERT HALL
13th APRIL
7PM

ADELAIDE
FESTIVAL THEATRE
15th APRIL
8PM

PERTH
CROWN THEATRE
17th APRIL
8PM

For more information: http://helenreddy.com/personal-appearances/
JOHN F KENNEDY

With the recent 50 year anniversary of the assassination of John F Kennedy, President of the United States, some new reports have been published or released that focus on JFK’s health issues during his time in office. These new insights into JFK’s health were made possible when documents from 1955-1966 were released earlier this year.

The reports highlight the fact that, had JFK’s health issues been known, he may not have been elected as president. During the 1960 presidential campaign, questions were asked about Kennedy’s Addison’s disease by aides of his rival, Lyndon Johnson. A carefully worded answer claimed that Kennedy did not have classical Addison’s disease where the adrenal glands are destroyed by tuberculosis. In fact his doctor issued a statement saying that JFK’s health was excellent.

The reports detail JFK’s various medical conditions as well as the range of medications he had to take. Some of the medical conditions listed in the reports show that, as well as Addison’s disease, JFK had colitis, prostatitis, atrophic gastritis, hypergonadotropic hypogonadism, coeliac disease and hypothyroidism. He took up to 12 medications a day, and took more during times of stress.

There is also speculation that JFK’s medical conditions contributed to his death. He wore a brace to keep his back straight (osteoporosis of the back from steroid treatment is also a suggestion). If JFK was not wearing the brace he would have slumped over when struck by the first gunshot. However, as he was held upright by the brace, his head was a perfect target for the second, fatal, bullet.

Editor

A MEMBER’S STORY

After contracting gastro and diarrhoea, an ambulance was called to my home and I was taken to a small country hospital. The doctor refused to attend at night, although he was on call. I didn't see him until 10 am Monday morning. By this time I was very ill. I requested Solu-Cortef (hydrocortisone) and he refused. I was on a saline drip, but that was all. As I became worse, he eventually sent me by ambulance to a larger regional hospital.

The doctors were astounded at my lack of treatment. Of course, hydrocortisone was administered immediately as well as saline and antibiotics.

In telling this story, it would be good if information on Addison's and the treatment of it could be sent to all small hospitals, doctors and paramedics.

June
NEWS from WESTERN AUSTRALIA

Best wishes for Christmas and the New Year.

Joyce
WA Rep

NEWS from ACT

Season’s Greetings to all AADA Inc members and family, as we would like to wish everyone a safe and happy Christmas Season, and all the very best for a happy and healthy 2014.

To celebrate the festive season it is with pleasure that we invite you and your significant other to join with local members of the Australian Addison’s Disease Association Inc. for a Christmas Dinner in the home of a member.

Sunday 8th December 2013 at
34 Croton Street
Rivett
ACT 2611

Commencing 6:30pm

Cost of $10 per head and bring your own drink

RSVP by Thursday 5th December 2013
Ross: croton@webone.com.au
Robin: nhart@netspeed.com.au

We would be honoured if you could join us.

Ross
ACT and Region Area Representative
NEWS FROM SOUTH AUSTRALIA

Leanne, the rep for South Australia, has resigned from the position.

On behalf of the Australian Addison’s Disease Association, and particularly the members in South Australia, we thank Leanne for the work she had done for the Association and wish her all the best for the future.

We welcome a new rep for South Australia, Kaye Toshach, who has agreed to take on the role.

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NEWS FROM VICTORIA

Awareness Month 2014
Victorian county Meeting

I have made some enquiries about having a meeting in country Victoria and the suggestion has been on the weekends of either 17 or 24 May 2014.

Leonie and Wayne Clayton (the owners of Comfort Inn Goldfields) son Bryce is an Addisonian. Understandably they find it difficult to get to Melbourne for meetings and have generously offered to provide a package for members to spend the weekend or just a night at the motel in Stawell, giving the opportunity to visit Halls Gap, the Grampians and many interesting sites.

It’s not limited to country members only. All are welcome.

We would try to have a meeting on the Saturday and see if we can attract some local health professionals and possibly the local media. Any ideas of what you would like information about would be great. And possibly have dinner together on that night, leaving Sunday for sightseeing etc.

Stawell may be in the north of Victoria, but it gives you the opportunity to come to a meeting and avoid the City Traffic.

Ideally we would like to have about 10 or more members (and carers) coming and I ask that you let me know your expressions of interest by the end of January.

Please reply: Stephen@thomco.com.au

We will also look at having a meeting in Melbourne.

Many thanks
Best regards
Stephen
Hi Queenslanders,

We held our Christmas meeting on the 23rd November at the Aspley Hornet’s Club.

First of all I have to start by thanking a few people for their help and commitment to helping our members.

Dr Rick Sapsford has made a special effort to attend our last three meetings. Thank you Rick, it is most appreciated. Our members really appreciate your input. Rick gave a talk on patient care management. This was very interesting to listen to and I hope we all learnt something to take away with us.

Secondly I would like to say a very big thank you to Endocrinologist Dr Monica Wagenaar who gave a wonderful talk and PowerPoint presentation on Addison’s disease and secondary adrenal insufficiency. She also talked about the statistics for getting thyroid problems and diabetes. Dr Monica Wagenaar had also been in contact with Professor David Torpy to discuss the hydrocortisone pump that is being trialled at present. Many of us were unaware that this was also being trialled in the P.A hospital in Brisbane as well as Adelaide. So if anyone does attend the P.A. and would like to trial the pump make sure you ask your doctor.

Thirdly I would like to thank Mr Bob Wybourne for giving a talk on Adrenoleukodystrophy. Bob has done a lot of work for this awful condition. He is currently trying to get the heel prick test on new born babies in Australia to detect Addison’s disease at birth. Bob has been working with a drug company in the USA where a drug has been developed and they are willing to fly a family to the USA with accommodation included free of charge. So if you hear of a baby with Addison’s disease and Adrenoleukodystrophy are linked, especially in males. So males if you haven’t been tested for Adrenoleukodystrophy now may be a good time.

I had a very positive reply back from Queensland Ambulance Services regarding cortisone being carried in ALL ambulances. This is going ahead and should be implemented in the very near future.

Thank you to our members who attend the meetings. It’s great to get to meet you all.

I would like to wish our members a very Happy Christmas and a Healthy Happy New Year.

Anita
QLD Rep
SYDNEY NEWS

Addisons Spring Picnic

Sydney Harbour sparkled in the bright morning sun where our picnic group gathered above Dawn Fraser Pool in Balmain.

The small and very happy gathering was delighted to meet Geoff Starling, a patron of the Association, and his partner.

The picnic gave us a chance to exchange positive experiences and share our Addison’s story with others in a most fantastic environment.

It is very reassuring to put our difficult patches into perspective!

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SYDNEY CHAPTER NEWS

CLAIMING THE DATE!

2014 SEMINAR

Date: May 24th, 2014
Where: Kerry Packer Auditorium
      Royal Prince Alfred Hospital, Camperdown
Guest speaker: Professor Mark Cooper (endocrinologist from Concord Hospital)

Everyone is welcome. Hope to see you there!

Bronwyn and the organising committee
Regional Representatives

Victoria
Leanne Lynch
Stephen Thom

Queensland
Anita Bird

Toowoomba
Barbara Cossart

South Australia
Kaye Toshach

Western Australia
Joyce Sangston
and
Bob Craig

ACT
Ross Wilson

NSW (Sydney)
Bronwyn Monro

NSW (Newcastle)
Pam McCrindle
and
Gillian Nicholas

Tasmania
Lisa Terry

Northern Territory
Vacant