

We're sorry that because of the amount of material we now have, this Table of Contents has become rather clumsy to use. The key material from our newsletters is being compiled by topic into a convenient booklet that will be available on-line.

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NZAN Update Newsletters

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- November 2000 survey, context No.11, p3
- Results of Nov2000 survey No.12- 3 pages attached
- Results of March 2002 survey, 11 pages: No.16 (as separate file on website)
- International Addison's survey – advance notice No.19, p5
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International Connections

- ACIF – website URL change and new bulletin board, No.14, p9;
- North American NADF survey published, No.12, p5
- Addison's disease information on the Internet No.12, p7
- Cushings syndrome book (Dutch Addison's and Cushing Association) No.11, p4; book donation to NZAN No.16, p5
- New UK Addison's Manual No.14, pp4-5
- New UK ADSHG Website, No.17, p10
- International News and Internet forums, No.18,pp11-12
- Newsletters from overseas Addison's groups – strategy for copies, No.19. p14.

IM hydrocortisone injection.

Discussion Draft: Practical Guide for IM hydrocortisone injection. No.18, pp17-20

See standalone publication on “Guidelines” page of the website, posted August 2004.

Members' stories:

Alistair, diagnosed with Addison's in 1957 aged 12 - he has enjoyed a full and happy business and family life, including extensive sport and travel. Adrenoleukodystrophy was diagnosed in his mid-fifties. No.11, Nov00,pp7-12

Anne, diagnosed 1998 with adrenal insufficiency due to long term steroids for eczema, aged 53 – a semi-retired librarian, involved with English as a second language No.12, Mar01,pp7-9

Bob, diagnosed with Addison's in 2000, aged 79 – clarification of the diagnosis enabled him to continue living in his own home No.13, July01,pp13-14

Charlotte went to her GP just for the medical required for a diving course, was referred on to a specialist, and after tests was told the diagnosis, Addison's disease. No.25, pp9-10

Colleen, diagnosed with secondary adrenal insufficiency aged 59, after a lifetime of endocrine problems. No.18, Mar03, pp15-16

Danielle, diagnosed with Addison's in 1992, aged 24 – mother of two, lived in Japan first 3 years after diagnosis No.13, July01,pp12-13

Dyan, born without adrenal glands, tells her story at age 24. No.10, July00,pp8-10

Darren, diagnosed with Addison's aged 20, shares how diagnosis of Addison's was an incentive to make good life choices, sooner rather than later. No.20, Nov03, p17

Gary, diagnosed in 1959 with Addison's probably caused by TB, aged 25. A pharmacist, he considers himself "lucky to be still in business doing what I enjoy, taking part in competitive sport, and travelling extensively. We all must just be aware of our limitations." No.10, July00, pp10-12

Hayley, diagnosed with Cushings syndrome in 2000, aged 37, had her adrenals surgically removed, making her effectively an Addisonian. She lives a full and healthy life. No 16, July02, pp12-15

Jill, diagnosed with Addison's in 1996, aged 49 – lives a full and busy life. No.16, July02, pp10-11.

Joel and Joshua, identical twins, were diagnosed aged 17, Joel first then a Joshua a few months later Joshua. No.25, pp 10-11.

Joy experienced another slow diagnosis of Addison's in 1990, finally made in hospital. Her symptoms seemed to start during her second pregnancy. No.19, July03, pp17-20

Karen, diagnosed with Addison's in 1998, aged 32 – her third pregnancy, after her diagnosis, was 'very uneventful', with the perfect outcome of the birth of Matthew. No.11, Nov00, pp7-12

Kathryn, diagnosed with Addison's in 2000, aged 59 – a keen diver, tramp, international traveller, and helps run the family business No.14, Nov01, pp14-16

Lois, diagnosed with Addison's in 1980, aged 40. She lives in Malaysia, but returns to Christchurch, her original home, for annual medical checks, and to see family. No.10, pp12-14,

Lyn, diagnosed with Addison's in 1995, aged 40 – a keen biker, works in IT industry . No.14, pp16-19

Margaret, diagnosed with Addison's in 1959 aged 35 – a busy life, farming, family, travel, and community service. No.15, pp 9-11

Marianne - her diagnosis of adrenal insufficiency doesn't fit easily into a "classical" category. She also has CMTII, a progressive neurological condition that includes muscle weakness and wasting. That clouded the situation when the new symptoms came along. It continues to be a challenge for Marianne to live with them both. No.20, Nov03, pp18-20

Mary lives in isolated Harihari, population 300, on the West Coast of the South Island, and was finally diagnosed with Addison's disease in 2002, aged 52, by an Iraqi doctor new to Greymouth hospital. . She'd been admitted on four occasions over the previous 10 years, severely dehydrated, with vomiting and diarrhoea and with the classic Addison's symptoms of pronounced tanning and salt craving. IV fluids had perked her up somewhat, and she'd be discharged. Now she lives a busy active life, with few hiccups. No.25, pp11-15

Ngairé, diagnosed with Addison's in 1962, aged 35 – “pregnancy mask” (chloasma) and suspected haemochromatosis (“bronze diabetes”) delayed the appropriate diagnosis. A full life, but coping with diabetes also, for the past 8 years. No.17, Nov02, pp18-19

Ngari was 65 when finally diagnosed with Addison's in 1996, after symptoms worsening over seven years. She tells her story each year to groups of medical students in Dunedin. No.22,pp16-17

Nicole, prompt diagnosis after recognising symptoms in a magazine article - a mum with two young children. No.18,Mar03, pp13-15

Pamela, diagnosed with Addison's in 1984, aged 35 – a slow diagnosis, but a full and busy life since. No.17, Nov02, pp16-17

Robyn, diagnosed with typical tell-tale symptoms aged 43, had a slow recovery after diagnosis, and two years down the track has resigned from full-time teaching in favour of relief teaching, hoping to have a more balanced life and more stable wellness. No 19, July 03, pp14-17

Rosemaree, diagnosed with Addison's disease and Graves' disease aged 27, but continued with plans to go to Thailand the following year as a teacher and paramedic, staying four years. She weathered several adrenal crises, sometimes administering her own IV fluids. Now back in NZ, she has a busy life with her husband and two stepsons. No.21, Mar04, pp14-18

ALSO: Two new members, teenagers with Addison's: James and Richard
No.22, August 04, pp12-13

Contributions from NZAN's medical advisors:

from Professor Ian Holdaway, current medical advisor
(also downloadable as separate pdf files, Nos 13-16 inclusive; Nos 17-19)

NZAN Update Number 13, July 2001

Introducing Professor Holdaway, p4
The value of networks, p5
Adrenal gland hormones – what they do, and how they are regulated, p5
DHEA – worth considering, especially for women, pp6-7
Other comprehensive topics to hear on the tapes, p7

NZAN Update Number 14, November 2001

When the usual daily dose of steroids isn't enough – major illness, moderate illness, anticipating stress and psychological stress, pp6-8
Responding to vomiting and diarrhoea, p7
Tips for getting attention at A&E, p8
Which is more common, primary or secondary adrenal insufficiency? p4
DHEA - a few people may have a confusing “de-energising” response, p4

NZAN Update Number 15, March 2002

Q1. Do people with Addison's ever need adrenaline in emergencies? p12
Q2. What can I do about muscle cramps? p12
Some challenges with cortisol replacement and its monitoring, p13
Optimising fludrocortisone (Florinef), p15
Addison's and bone density, p17

NZAN Update Number 16, July 2002

Q&A: Secondary AI and Solu-Cortef, p9
Comment on Karen's challenges:
Cutting down glucocorticoid doses, p7; Medication delays in hospital, p8.
DHEA and HRT in New Zealand, p11

NZAN Update Number 17, November 2002

Q1: HRT – What are the risks and benefits for Addisonians?, pp14-15
Q2: Is it OK to take Addison's pills on an empty stomach? P16

NZAN Newsletter Number 18, March-April 2003

Comment on Karen's emergency, p3
Responding to vomiting and diarrhoea (reprinted from No.14, Nov01), p6-7
Answers to Joy's questions, p7

NZAN Newsletter Number 19, July-August 2003

From his address at the Auckland Regional Meeting:
Autoimmunity update, p8
Genetics of Addison's disease – update, p9
Checking your medication doses, p10
The effects of adrenal hormones on the body, p11
Comment on Joy's speculation about blood groups, p20

NZAN Newsletter Number 20, November 2003

From his address at the Auckland Regional Meeting, May 2003:

- Addison's crisis p4
 - Addison's disease and other meds p5
- Comment about salt intakes p13
Comment about fluid intakes p14

NZAN Newsletter Number 21, March-April 2004

From his address at the Auckland Regional Meeting, May 2003:

- Addison's Disease and Other Medications – interactions, p8
- Q&A from the Open Forum session at the Second Northern Regional Meeting in Auckland, May 2003: pages 9-13

NZAN Newsletter Number 22, August 2004:

Q&A: pp 18-19
1. Does Addison's contribute to anaemia?
2. Under what circumstances should people with Addison's disease also have their blood glucose checked?
Reminder: monitoring thyroid function

from Dr Geoff Braatvedt, medical advisor 1998-2000
(page numbers refer to separate downloadable pdf file)

pages 1-3: from NZAN Update Number 5, November 1998

Overview - Hormones and the adrenal gland

- Q1. Getting the medication right, so that you feel well
- Q2. About the renin test

pages 4-5: from NZAN Update Number 6, March 1998

- Q1. Do patients with Addison's disease produce adrenaline? Can they get a 'high' from bungy-jumping?
- Q2. Should people with Addison's disease take more vitamin C than usual?
- Q3. Lidy asks "*I have been prescribed Serzone as an anti-depressive which works via adrenaline activation. Will I get the full benefit of this, being an Addison's patient?*"
- Q4. Which steroid replacement is best?
- Q5. What about bone density in Addison's disease? Should I take more calcium?

pages 5-8: from NZAN Update Number 7, July 1999

- Q1. What is the difference between an adrenaline response and cortisol response in people with normal adrenal glands?.
- Q2. Does the normal adrenaline response decline with age?
- Q3. What is an ACTH test? What controls ACTH?
- Q4. Should cortisol in the blood or urine be measured as a test of replacement dosage?
- Q5. Does the calcium intake of patients with Addison's disease matter?
- Q6. What happens to the adrenal gland in Addison's?

pages 8-10: from NZAN Update Number 8, November 1999

- Q1. Can patients with Addison's disease avoid jet lag on long distance, cross time zone travel by giving extra Hydrocortisone?
- Q2. Does the dose of hydrocortisone change with age?
- Q3. Does Addison's disease affect your ability to cope when sleep deprived? Q4. Do patients with Addison's cope less well with night shift work?
- Q5. My bone density is low and my GP has started me on Rocaltrol and calcium tablets. I take 10 mg of prednisone for my Addison's disease. Are there any problems with this?

pages 10-11: from NZAN Update Number 9, March 2000

- Q1. Prednisone or Hydrocortisone?
- Q2. Alcohol and Addison's
- Q3. Faulty 'Thermostats' and Addison's
- Q4. Emergency Hydrocortisone by Injection
- Q5. Emergency Treatment of Addison's – How Good is the Ambulance Service?
- Q6. Lisa Laments About Weight Gain. She takes 25mg of Hydrocortisone and 50ug of Fludrocortisone