



Endocrine Nurses' Society of Australasia Inc.

ENSA News

December 2018

2018-2020 Committee

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The Endocrine Nurses' Society of Australasia incorporated, (ENSA Inc.) is a professional organisation which provides a forum for continuing education and professional development for nurses working in the field of endocrinology.

The Society promotes collaboration between health professionals. It is committed to the advancement of the art and science of endocrine nursing as a specialty field, through the development of standards of practice, enhancing clinical expertise and promoting and encouraging nursing research.

www.ensa.org.au



<https://www.facebook.com/groups/1715617448664910/>

Comments due now

Harmonisation of Endocrine Dynamic Testing (HEDT)

Dear Members

We have an opportunity to feedback our expertise in the development of guidelines for the Harmonisation of Endocrine Dynamic Testing – copy sent by separate email.

We have 90 days to provide our expert feedback so please offer your comments (due December).

Please clearly identify the test you are responding to and return all comments to

Josephine.Green@monashhealth.org

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2018 President's Report –

<http://www.ensa.org.au/presidents-report/>

Chris Yedinak, President ENS and Assistant Professor, Oregon Health & Sciences University is pleased to announce the upcoming publication of the **Advanced Practice in Endocrinology Nursing** which represents the culmination of work by 114 authors from 15 countries and includes 69 chapters.

“Many ENS and ES members contributed to this effort which is edited by Sofia Llahana, Cecilia Follin, Chris Yedinak and Ashley Grossman. This was initiated with Springer UK over 2 years ago. It has been an exciting and immense project and would have not have been achieved without the excellent collaboration between nurses and endocrinologists from ENSA, ES, ENS and the European Society of Endocrinology (ESE).”

The projected publication date is December 2018.

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SECTION 1: Growth and Development: Kate Davies & Meg Keil

SECTION 2: Endocrine disorders & genetics in childhood: Kate Davies & Meg Keil

SECTION 3 – Hypothalamus & Pituitary – Chris Yedinak and Judith van Eck

SECTION 4 – The thyroid gland – Violet Sanderson

SECTION 5 – The adrenal gland – Sofia Llahana

SECTION 6 – Female endocrinology and reproduction – Sofia Llahana & Gerard Conway

SECTION 7 – Male endocrinology and reproduction – Andrew Dwyer & Sofia Llahana

SECTION 8 – Parathyroid, calcium and bone disorders – **Ann Robinson** & Cecilia Follin

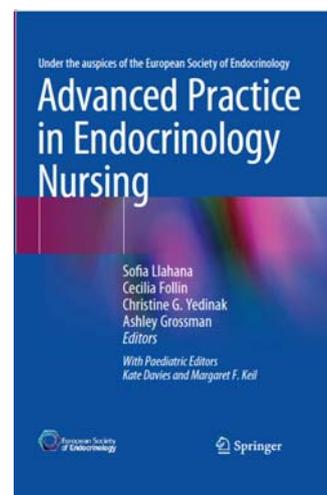
SECTION 9 – Obesity and disorders of lipid metabolism - Cecilia Follin

SECTION 10 - Late effects of cancer treatment in relation to endocrinology – Cecilia Follin

SECTION 11 – Endocrine emergencies – Philip Yeoh & Anne Marland

SECTION 12 – Neuroendocrine tumours and multiple endocrine neoplasia: Mike Tadman

SECTION 13 – Advanced practice nursing in endocrinology – Sofia Llahana



Checkpoint inhibitors

Seery, V. (2017). Interprofessional collaboration with immune checkpoint inhibitor therapy: the roles of gastroenterology, endocrinology and neurology. *Seminars in Oncology Nursing*, 33(4), 402-414. <https://doi.org/10.1016/j.soncn.2017.08.002>

Clinical Guidance for the Diagnosis and Management of Osteoporosis in New Zealand

PHARMC's decision on June 8th to fund denosumab (Prolia) for the treatment of severe, established osteoporosis. <https://www.pharmac.govt.nz/news/notification-2018-06-08-denosumab/>

Diagnostic approach to low renin hypertension – Review article

Monticone, S., Losano, I., Tetti, M., Buffolo, F., Veglio, F., & Mulatero, P. (2018). Diagnostic approach to low renin hypertension. *Clinical Endocrinology*, 89(4):385-396. <https://doi.org/10.1111/cen.13741>

Osteoanabolic Agents for Osteoporosis

Haas AV, LeBoff MS. (2018). Osteoanabolic Agents for Osteoporosis. *J Endocr Soc*, 2(8):922-932. <https://doi.org/10.1210/js.2018-00118>

Polycystic Ovarian Syndrome Clinical Practice Guidelines (2018)

Teede HJ, Misso ML, Costello MF, et al.; On behalf of the International PCOS Network (2018). Recommendations from the international evidence-based guideline for the assessment and management of polycystic ovary syndrome. *Clinical Endocrinology*, 89:251–268. <https://doi.org/10.1111/cen.13795>

In mid-2017, the Alliance began work with the Sax Institute to survey secondary fracture prevention practice in Australia, with the view of developing a proposal of how both the effectiveness and efficiency of secondary fracture prevention might be improved across the Nation. As this work is now nearing completion, we would like to update you on our progress with the attached report.

As always, we welcome your comments and suggestions. Please email James Ansell at james.ansell@sosfracturealliance.org.au if you'd like to know more or get involved in the Alliance's future work.



**Fracture
Alliance**

Making the first break the last

November 2018

Towards an integrated Australian program for the prevention of secondary osteoporotic fractures – An update for our members.

In mid-2017, the Alliance began work with the Sax Institute (www.saxinstitute.org.au) to develop a proposal for a survey of secondary fracture prevention practice in Australia's fracture liaison services (FLSs) and ways in which practice might be improved. The survey was designed to also cover FLSs' engagement with primary care and their use of routinely collected health data.

Experts were consulted on the potential of primary care engagement and use of routine data to enhance the operation of FLSs. This work was funded by a grant to the Sax Institute from Amgen, a pharmaceutical manufacture, and is now nearing completion.

On the basis of the survey, the Sax Institute has outlined best practice for an Australian Secondary Fracture Prevention Program. It is developing a plan for a new, 2.5 to 3-year project in which a number of Australian FLSs, as best practice demonstrations sites, collaboratively and innovatively increase their effectiveness and efficiency. The demonstration sites will have a particular focus on greater use of routinely collected health data in several models entailing greater engagement with primary care. Their performance will be rigorously monitored and evaluated, and cost-effectiveness will be carefully assessed.

The results of these demonstration site evaluations will be projected nationally to estimate the impact on secondary fracture prevention and cost effectiveness of an Australian secondary osteoporotic fracture prevention program that is based on the learnings from this work, integrated across tertiary, secondary and primary care and robust to health service variation among states and territories.

The project plan will be finalised following a half-day meeting with representatives of prospective FLS demonstration sites on 23rd November. The next step will be to seek funds for its implementation.

The Sax Institute project is guided by an Expert Advisory Group with representation from the Australian National SOS Fracture Alliance, Consumers (Osteoporosis Australia), Primary Health Networks, Industry and the NSW Agency for Clinical Innovation.

As a member of the SOS Fracture Alliance, we welcome your comments and suggestions. Please email James Ansell at james.ansell@sosfracturealliance.org.au.

FINE PRESIDENT:	Chris Yedinak (USA)
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WEBMASTER/MEDIA	Sofia Llahana (UK)

“Thanks and congratulations to all for your responses and support. We now have our first ‘official’ FINE Board of Directors. I appreciate the votes for President and will commit to taking this position for the next 2 years and helping out with the following 2 years. We are planning much FINE fun over the next years! Our goal is to keep up to date with endocrine care, promoting endocrine nurse and nursing research and enjoy working together.

We now have enough board positions filled so that we can move forward with establishing ourselves as a tax exempt/ nonprofit entity. Please see Bio’s for those members who have volunteered for board membership (sent via email). It is fabulous that we will have such an accomplished board. We will keep you posted as to the next steps in the formation of FINE as a non-profit/charitable organization.

We are still in need of volunteers for a development chair to help with finding funding for future projects. Please help!”

Chris Yedinak, President FINE

Membership

Go to <https://members.asnevents.com.au/register/organisation/91?SubsiteID=67> for all membership updates and renewal.

Contact the Secretariat – Shona and Daniela
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Facebook posts and enquiries - Contact maresa.derbyshire@svha.org.au



Newsletter enquiries / contributions – Contact carol.jarvis@waikatodhb.health.nz

Next newsletter – websites update/ ICE reports / patient resources / ENSA2019



Wishing you all a restful and rejuvenating holiday, and a joyful New Year

16th US SIXTEENTH INTERNATIONAL PITUITARY CONGRESS
MARCH 20 - 22, 2019
 New Orleans, Louisiana

ENDO2019
 MARCH 23-26, 2019
 NEW ORLEANS, LA

Access only through www.endocrine.org/endo2019 as there are multiple bogus sites.

ENS 29th Annual Symposium
Saturday March 23, 2019
 New Orleans, Louisiana, USA

ECE 2019
 21st European Congress of Endocrinology
 18 - 21 May 2019, Lyon, France
 For more information contact ece2019@endocrinology.org

ESA CLINICAL WEEKEND
 16 - 18 AUGUST 2019
 Intercontinental Double Bay, NSW
www.esaclinicalweekend.org.au

ESA-SRB-AOTA 2019
 International Convention Centre, Sydney
 18 - 21 AUGUST
WWW.ESA-SRB-AOTA.ORG

Endocrine Nurses' Society of Australasia Inc.
 International Convention Centre, Sydney - 19 August, 2019

29th Australian and New Zealand Bone and Mineral Society Annual Scientific Meeting
27th - 30th October, 2019 Darwin Convention Centre
www.anzbmsconference.org



I had the wonderful opportunity to attend the ENSA 2018 Annual symposium which was held at the Adelaide Convention Centre.

As usual the Symposium organising committee together with ASN had put in a lot of effort in organising a specialised program for the ENSA annual Symposium. This year it was themed as “The Evolving World of Endocrinology-from Testing to Transgender” and it also featured captivating lectures, abstracts, presentations and posters.

During the sessions it was enthralling to hear about the varied expertise and knowledge in the field of Endocrinology from prominent International and National speakers.

The Endocrine Society of Australia and Society of Reproductive Biology (ESA-SRB) conference started off with presentations from excellent speakers like Prof. Duncan Topliss and our well known and popular speakers from Royal North Shore Hospital, Professor Bruce Robinson and Liza Nery. The welcome address by the lovely ENSA President Yuk Fun Chan was very inviting which was followed by a presentation from the vibrant Kate Davies all the way from the United Kingdom where she enlightened us about the career pathways for nurses in the U.K

Another interesting presentation by Dr Cherie Chiang on Harmonisation of Endocrine Dynamic Testing (HEDT) provided a clarification on the necessities of having standardised and updated evidence-based protocols for Endocrine dynamic testing within Australia and New Zealand. I found this information very captivating since it would enable a good standard of structured practice in Endocrine Dynamic Testing.

Post lunch we had the Jenny Nairn ‘NURSES IN ACTION’ session where our celebrated speakers Julie Hetherington, Carmen Bischoff, Yuk Fun Chan and Venecia Willenberg presented on excellent topics and shared their expertise as Endocrine nurses. There was a lot of knowledge that I could relate to as an Endocrine nurse from these presentations.



However, the one topic that I was drawn to was the presentation by **Julie Hetherington** on “**Addison’s Angle: A ten-minute tool to avoid Adrenal crisis**”. Julie, as always with her expertise, skills and wealth of knowledge in Endocrinology, has provided us with a great tool in educating patients on avoiding Adrenal Crisis.

I work as an Endocrine Clinical Nurse Specialist at Sydney’s Royal North Shore Hospital in the Outpatient Clinical setting. My role involves a lot of patient teaching apart from conducting and assisting with Endocrine Diagnostic testing. I often have to teach patients self-injection of Hydrocortisone during Addison’s crisis. Quite often patients appear confused and overwhelmed with all the medical information and the complexities involved in self-injection of Hydrocortisone during Addison’s Crisis. This invariably causes confusion and lack of awareness in the management of their symptoms.

The delay in seeking timely medical treatment during Addison’s crisis can be potentially life threatening. Therefore, we as Endocrine nurses should be able to educate the patients and their families in detecting early signs and management of Addison’s crisis. Prior to this, but I was not very sure about advising the patients when to inject Hydrocortisone. I would give them general advice to contact their Endocrinologist or their local General Practitioner or present themselves to an Emergency Department of the Hospital.

Julie Hetherington's ten-minute tool has given me insight to provide quality education to patients with Addison's disease. Here is a picture of the ten-minute tool.

"Addison's Angle: A ten-minute tool to avoid Adrenal crisis"

Developed by Julie Hetherington, Endorsed Nurse Practitioner in Endocrinology & Metabolism, 2018.

Later that evening at the ENSA Dinner at the Adelaide Oval, I had the privilege to be seated next to Julie Hetherington where she further enlightened me with her expert knowledge on educating patients with Addison's disease from Non-English speaking background. She was also kind enough to give me permission to give copies of her educational tool to the patients with Addison's crisis.



The ENSA dinner was an occasion that allowed me to socialise with other fellow Endocrine nurses from within Australia and New Zealand. It was an amazing night with some video presentations from the Washington Conference and Award presentations supporting the phenomenal work of Endocrine Nurses. Another highlight of the ENSA dinner was the launching of Ann Robinson's 2nd edition of 'The Hand-Held Health Care Record for People with Acromegaly'.



I wish to thank ENSA and the Australian Pituitary Foundation for all the support in bestowing me with the Travel Grant Award. I would like to thank Ray Bissett and Rob McGregor from IPSEN who are always supportive, allowing me the opportunity to attend this conference. Most importantly, my profound thanks to Liza Nery, Malu Alvarez, and the Head of Department of Endocrinology, Associate Professor Dr. Roderick Clifton – Bligh, for the support and assistance in my career progression as an Endocrine Nurse for the last few years. Lastly, I would like to thank ENSA committee and ASN for their collaborative effort in organising ENSA 2018 Symposium.

Reflecting back, this Conference has been a very rich experience for me where I have gained a lot of knowledge from distinguished Endocrinologists, Endocrine nurses and other speakers. I have returned back home with a wealth of knowledge which would enable me to share my experiences of the ENSA 2018 conference with my fellow colleagues at the Royal North Shore Hospital.

Thank you once again for this incredible opportunity. See you all again next year in Sydney.



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"THE EVOLVING WORLD OF ENDOCRINOLOGY – What's new?"



The ENSA 2018 Annual symposium was held at the Convention Centre in Adelaide. As always, it offered Endocrine nurses from Australasia the chance to network with new and longstanding colleagues... The theme of this year's meeting was "The Evolving World of Endocrinology-from Testing to Transgender". It covered a variety of paediatric, adolescent and adult issues ensuring that the day was filled with renowned speakers and stimulating topics.

The morning commenced early with a combined ESA-SRB symposium on 'what's new in 2018 - A practical guide to prescribing Tyrosine Kinase Inhibitors (TKIs)' chaired by **Prof Bruce Robinson**, and presented by **Prof Duncan Topliss** and **Liza Nery**, a foundation member of ENSA. The symposium noted and encouraged the involvement of an endocrine nurse, an essential member of the multidisciplinary team, in the care of a thyroid cancer patient prior to their commencement of a TKI.

The first presentation of the combined ESA-SRB meeting for the day was the Harrison Lecture given by **Prof Peter Fuller** and was on the "Actions and interactions of aldosterone and the mineralocorticoid receptor". This basic science lecture was, perhaps for many, a bit difficult to follow but was interesting nonetheless.

The ENSA meeting started off with a presentation by **Dr David Torpy** who gave us an update on Primary Aldosteronism as well as sharing their site's tips on performing a successful adrenal vein sampling procedure. **Kate Davies**, a Senior Lecturer and Course Director of the Advanced Nurse Practitioner programme for paediatric endocrine nurses in the UK, presented informative session on the Endocrine Nurses Career Pathways and UK career progression. Endocrine nurse competencies, courses available and further tertiary education were highlighted during her motivating presentation. Something to think about for the Endocrine nurses here in Australasia.

Other sessions included **Dr Jui Ho's** presentation highlighted the challenges of pituitary disorders, diagnosis and its management during critical illness; and **Dr Thomas Chesterman's** and **Dr Elaine Pretorius'** presentations on gender dysphoria and LGBTQI made us realise that we have much to learn about the "people behind the alphabet".

The '**Nurses in Action**' session, as always, was informative and interesting with our colleagues sharing the expertise of their knowledge and skills. The session never fails to live up to what our colleague, Jenny Nairn, would have expected from her fellow Endocrine nurses

The highlight of the day for me was **Dr Cherie Chiang's** presentation on the Harmonisation of Endocrine Dynamic Testing (HEDT) project. Endocrine dynamic testing is not only the cornerstone of practice; it also plays a vital role in clinical practice in decision making. However, different sites have different protocols and reference ranges often making it difficult to compare results. The HEDT promotes the standardization of well-structured endocrine testing protocols with the aim that it will be used by all Endocrine clinicians, making it easier for endocrine nurses performing the tests.



The ENSA dinner was held at the Premiership Suite at the Adelaide Oval. Amidst drinks, wonderful table settings and a delicious dinner, it was easy to talk and network with each other during the evening. I was fortunate enough to be seated next to and get to know **Janet Gilbert**, an endocrine nurse from New Zealand. The dinner as a great way to end what had been an interesting, stimulating but tiring the day. There was much to celebrate and a number of ENSA awards for handed on the night. I was lucky enough to be one of the recipients of a travel grant. The travel grants, supporting nurses' travel to the annual symposium, were generously sponsored Ipsen and the Australian Pituitary Foundation.

The ENSA Symposium 2018, as always, was a very fruitful experience; a chance to catch up with new and "old" Endocrine nurse friends, an opportunity to learn, advance and share our knowledge and skill amongst colleagues. The real accomplishment of this year's annual meeting is I can't wait to return to next year's symposium!

Thank you to ENSA for its generous travel sponsorship.

Malu Alvarez

Endocrine Clinical Nurse Specialist | Endocrinology Department, Royal North Shore Hospital



A workshop of the International Conference on Cancer Nursing (ICCN) 2018

Nursing NET patients

September 23rd, 2018 - Auckland

An introduction to NETs –Philippa Davies (Keynote Speaker) - Vice Chair ENETS UK

A senior Matron at the Royal Free Hospital in London and an experienced oncology nurse, Philippa lay the foundations for the workshop by giving an overview of Neuroendocrine Tumour's (NETs) in the United Kingdom, including the estimated incidence there of 4500 new diagnoses per year. She outlined the clinical presentation and secretory syndromes associated with this “best cancer to have” and described the common theme of diagnosis delay that NET patients experience worldwide. Using a prognostic indicator algorithm, Philippa detailed the biochemical and histological testing that underpins the World Health Organisation 2017 NET classification system and staging modalities that lead to treatment decisions. This comprehensive synopsis provided an excellent framework for the day's other presentations.

Genetics of NETs – Dr Richard Carroll, Endocrinologist, Wellington DHB

Richard described the hereditary NET syndromes of Multiple Endocrine Neoplasia's (MEN) arising from autosomal dominant genetic mutations. He went on to explain the syndromes associated with succinate dehydrogenase (SDH) gene mutations and again the common theme of delay to diagnosis arose as a major factor in survivorship. Early detection, genetic screening, and ongoing surveillance make a difference for these patients.

A nurse's perspective of treatment – Philippa Davies

Following on from her first presentation, Philippa spoke about treatment modalities for NET patients. This included surgery, local-regional ablation therapies such as radiofrequency, cryo or ethanol, and embolisation treatment. Drawing on work by Pavel et al (2016) in the ENETS Consensus Guidelines update on metastatic NETs, Philippa described the use of somatostatin analogues to manage functional syndromes and avoid carcinoid crisis during surgery and anaesthetic. Other treatments she outlined included Interferon alpha, Telotristat etiprate (a serotonin synthesis inhibitor), chemotherapy, targeted agents such as everolimus and sunitinib, and new immunotherapy such as Avelumab (an anti-PD-L1 monoclonal antibody) for use with Merkel Cell Carcinoma, along with Peptide-Receptor Radionuclide therapy (PRRT). These treatments, while not all available in New Zealand, offer hope of successful disease management for NET patients and those who care for them.

Unmet needs of NET patients – Simone Leyden, CEO Unicorn Foundation, Australia

Simone spoke about the survey of NET patients to identify quality of life outcomes and unmet needs within this community. Access to allied health providers for psychological, diet, exercise, and symptom control support was flagged as unmet needs for a large number of patients. Themes of access to optimum care and treatments and the differences in priorities between patients and healthcare providers highlighted the need for strong patient advocacy organisations and collective action. The World NET Cancer Awareness Day on 10th November aims to focus attention on empowering patients and raising the NET profile.

Patient perspectives

This particularly powerful session enabled those present to hear the very personal stories of the NET patient journey, where chance often plays a part and patients are sometimes expected to be an expert on their disease.

Nutrition in NETs – Erin Laing / Nutrition in NZ project – Olivia Cochrane & Kelsey Paterson

The importance of nutrition to NET patient wellbeing was discussed in two presentations, the first being presented by Erin Laing. She reviewed the literature around malnutrition screening tools and the impact NET disease has on quality of life (QOL). Strategies to improve QOL and response to treatment, minimise weight loss and symptom burden, while treating vitamin and fat malabsorption, were examined in the context of carcinoid diarrhoea. Following on from this, Dietician Masters students Olivia Cochrane and Kelsey Paterson detailed the research they are undertaking about the nutritional needs of NET patients in New Zealand. This stunning piece of work will provide valuable information to guide best practice in this area.

Psychological support for NET patients – Juliet Ireland, Auckland DHB

From her perspective as a psychologist, Juliet Ireland expanded on the topic of the wider needs of NET patients. Again the unique features of an often tortuous route to diagnosis, uncertainty and misunderstanding of NETs, chronicity, and issues of access to treatment arose. Juliet described aspects of psychological and social support that can assist patients on their NET journey and allow health care providers to detect distress and improve survivorship QOL. She also reminded us about self-care!

Survivorship care planning in NETs – Kate Wakelin – NETs Nurse Specialist, Unicorn Foundation, Australia.

Kate eloquently illustrated the use of Survivorship plans and collaborative care models of treatment and support that can be utilised by NET patients and their carers.

Genomics research – Dr Ben Lawrence – Oncologist, Auckland DHB

At the final session of the day, Ben Lawrence detailed some of the data emerging from the NETWork! Study in the area of genomics and how this is adding to the body of knowledge around treatment modalities such as immunotherapy. The ability to target oncogenic single nucleotide variants (SNVs) and determining the tumour mutational burden are among the approaches being utilised to develop novel treatments.

Workshop supported by Novartis, Unicorn Foundation NZ, and Cancer Research Trust NZ

Carol Jarvis

Endocrine/Research Nurse | Waikato DHB, Hamilton, NZ