

President's Final Report

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Introduction

As I look back on my Presidency of this wonderful organization over the last two years, and leading into as President Elect in 2017, I am overcome with pride and possibly a bit of exhaustion! Despite the endless conference calls, meetings, development of materials and reviews, and sleep lost due to time zones, this role and organization is truly a labor of love.

Since the group's inception at a dinner in New York in 2009 of the founding members to come up with an awareness day (World NET Cancer Day), to today a fully registered and truly global Alliance organization, we have achieved so much together.

INCA today is a collective of 26 patient organizations from 6 continents, all with the shared vision:

A world where all patients with neuroendocrine cancer (NETs), get a timely diagnosis, optimal treatment, support and care and ultimately a cure. of improving outcomes for Neuroendocrine cancer patients.

I hope you will allow me the privilege of highlighting some of the key achievements and events over the past years.

Key Achievements and Events

2017

ENETs/INCA Symposium



In 2017 at our first INCA/ENETs symposium in Barcelona, I had the honor of presenting as President Elect, the first released data of the Unmet Needs study. I thank Ron Hollander my predecessor and Teodora who initiated and have continued to drive this work, with the aim of looking at the different perceptions of need from the patient, advocate and healthcare professional perspective.

As I sat putting together the presentation slides, one of the key discrepancies that immediately jumped out at me was the huge gap in perception around meeting the **needs of adequate information**.

While HCPs felt they provided patients with sufficient information (59%), informational needs were mostly or fully met for only 30% of patients and 18% of advocates.

The results of this survey were well received at this meeting in 2017 and formed the foundations for our projects going forward including work under the Research Committee, Awareness Committee and Access Committee.

Projects such as “Closing the Information Gap” and “SCAN” are just some of the work which have resulted from the study that we work on today.

2018

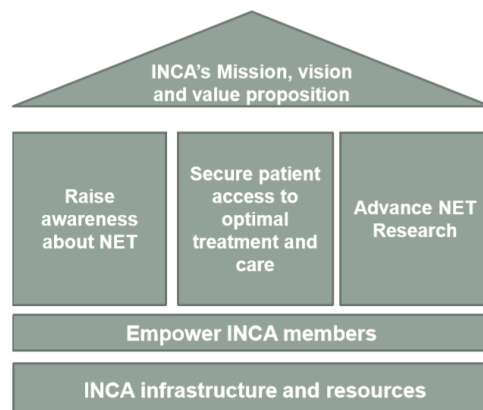
March - ENETS & INCA Summit



March 2019 ENETs and INCA Summit saw us participate in an intense workshop with Kathy Redmond steering our strategic goals. Here we worked as a collective group to define our vision, mission and prioritize our objectives into our core strategic pillars. It was wonderful to watch all the members contribute and have a voice in the direction of the organization.

Each member presented a poster on their World NET Cancer Day activities from the year before and it was fantastic to see all the different events from around the globe with the common goal of raising awareness about NETs.

INCA's strategic pillars 2018-22



April - Peter MacCallum Cancer Centre ENETs COE – First outside Europe



Closer to home we welcomed the decision to have Peter MacCallum accredited the first ENETs COE outside of Europe. To be part of the process as a patient organization, we saw

firsthand the tireless work and effort of our specialists in achieving such a certification and we are proud of all those involved.

August – “Lets Talk About NETs” Campaign – Development of 1st Member Toolkit



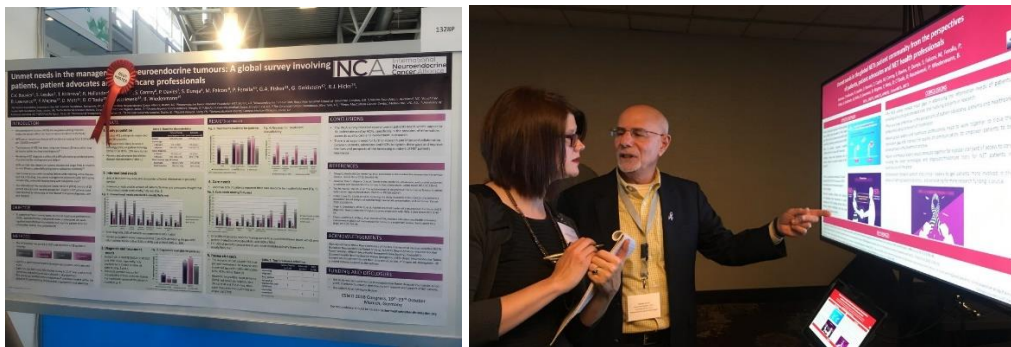
Many hours of review and design went into the final product, with much effort going into finalizing key messages. We hope you agree the final product produced by Megan of Huckster PR was well worth it.

August - Presentation on INCA to the Union of International Cancer Control in Geneva



Whilst in Switzerland for my brother's wedding, I took the opportunity to present our organisation to the team at UICC. It was fantastic to showcase all our work to a full room and thank them for listening and now working with us as we took up membership in 2019.

Unmet Needs wins “Best Poster” at ESMO



Starting off what was going to be a busy time for our “Unmet Needs” research, we were thrilled to win best poster at the esteemed European Society of Medical Oncology meeting in Munich, Germany.

This was followed by the North American Neuroendocrine Tumour Society (NANETS) meeting in October and the Asia Pacific Neuroendocrine Tumour Society (APNETs) in November

October – Launch of New Look Website



This was a fantastic achievement, but we know that it is always a work in progress, and we have much more to do. Watch this space as we build our patient resources under the “Information Pack” project and also build up our research and clinical trials pages.

November - APNETS 2018



It was a huge honor to co-convene with my esteemed and NET colleagues Prof Rod Hicks and Dr Grace Kong, the 6th Asia Pacific Neuroendocrine Tumor Society (APNETs) meeting in Melbourne Australia. It was a truly global meeting with NET experts from around the world including Dr James Yao (USA), Dr Simona Glasberg (Israel), Prof Dermott O'Toole (Ireland), Dr Ben Lawrence (NZ), Prof Halvdan Sorbye (Norway), Dr Jien Chen (China) and leading experts from the Asia Pacific Area. The high-quality scientific program was followed

by the experts giving up their time to present a multi-disciplinary meeting to over 250 NET patients.

Once again the “Unmet Needs” research featured as an oral presentation.

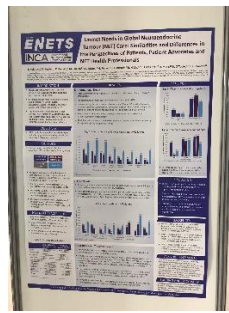
November - First World NET Leadership Summit – Palma Mallorca Spain



It was amazing to be represent INCA at the first World NET Leadership summit in 2018, to where amongst other things we spoke about the possibility of a World NET Summit, and also how we could work together on the “Information Gap” project. All the President’s from the organisations around the world supported both projects and we are so thrilled to see that they will come to fruition in 2020.

2019

March - ENETs – Best Poster



ENETs 2019 was a busy meeting indeed! Once again, the “Unmet Needs” research was front and centre winning Best Poster.

ENETs - IPSEN Symposium “Living with NETs An Open Conversation on the Real Patient Experience”



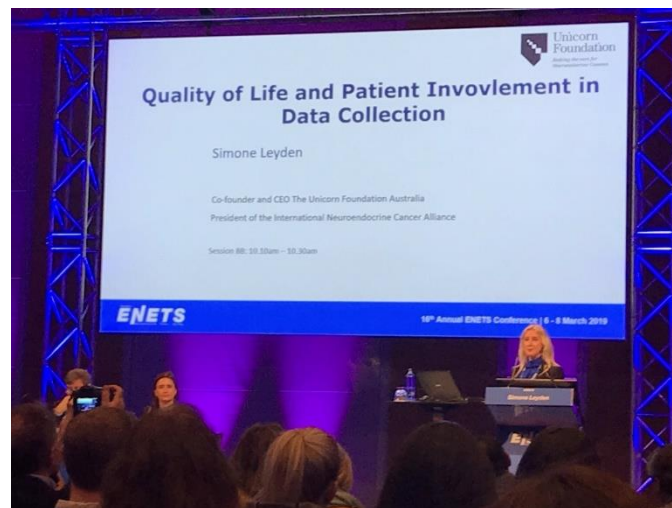
With over 850 people attending the lunchtime IPSEN Symposium, having the patient at the centre of care was able to be communicated far and wide.

March - INCA Showcase



In the absence of a stand-alone INCA/ENETS symposium, we decided to run an INCA showcase on the last morning of the meeting. To a crowded room we were able to display our work under our three pillars and interact with specialists on their involvement in us achieving our goals. All attendees filled out a questionnaire prior, so we were able to clearly communicate our messages and make sure we were aligned with our partners.

March ENETs – Innovations in Measuring Outcomes



It was fantastic to be able to present the work we are doing in Australia with our electronic Patient Reported outcome App and how it interacts with the clinical registry with the ENET COEs.

June - INCA Summit – Plovdiv



Getting the “family” together in such a beautiful location always motivates and stimulates the best in all of us. Many laughs and a lot of hard work was achieved over those days, and we are so grateful for all our members, industry partners and NET specialists’ contributions.



October – ASCO Breakthrough, Bangkok Thailand



Grateful to Yoshi for representing us at this meeting and presenting our poster, “Access to diagnostics and treatment of neuroendocrine tumors (NETs): The difference between patient perception and reality”. From our “Unmet Needs” research the issue around Access formed the basis for our next research piece “SCAN”.

November – International Journal of Cancer Publishes our “Unmet Needs” research



After months and years of hard work, we were finally validated with the publication of the “Unmet needs” research in the esteemed International Journal of Cancer. We stand beside NET leaders from around the globe bringing this important information to the forefront, to demand change for our patients and carers.

December COMMNETS – Tokyo Japan



Last year finished with the annual COMMNETS meeting, a collaboration between Australia, New Zealand and Canada. Like any developing group revisiting strategic planning and goals is important and it was great to be able to contribute to this from a NET advocate perspective. Thank you to all the organisers for once again such a successful meeting.

2020



As I pass the baton over to my friend and colleague Cathy Bouvier, I would like to thank everyone for their support, enthusiasm, patience and hard work to what is such a vital cause. Thank you to the INCA board, Teodora and Kristina and to my organization the Unicorn Foundation for your endless dedication.

I also thank our industry partners, Novartis, IPSEN, ITM, AAA, Pfizer and Lexicon Pharmaceuticals for their support of our important projects.

Thank you to the support of my fellow Presidents of ENETs, NANETS, APNETS, COMMNETS, CHINETs, JNETs, CSNET and Argentum for working together to achieve some pretty fantastic ambitions in particular the 1st World NET Forum.

I look forward in 2020, to putting all my effort into my position as Chair of the Research Committee, remaining an active member of the INCA board and driving our projects to success.

Closer to home we look forward to the rebrand of our 10 year old organization in March, to NeuroEndocrine Cancer Australia, as we look to confirm our place as the peak body in our region and work within our global community.