



INCA International
Neuroendocrine
Cancer Alliance

International Neuroendocrine Cancer Alliance

NET Patient Advocate Summit 2014

May 27th –28th, 2014

Hotel Carlotta

Belgirate, Italy





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Dear Friends,

Let me thank you for the great pleasure and honor of spending the two days of the Second INCA NET Patient Summit with you – two days that made me feel empowered by a sense of belonging to such a remarkable community of passionate NET patient advocates.



It is very rewarding, indeed, that the International Neuroendocrine Cancer Alliance managed to bring together 17 very dedicated NET patient advocates from around the globe for this significant event. Our target has been to put in place a Summit programme to hopefully serve everyone's needs and expectations, and also be interactive and dynamic, so as to facilitate networking and multi-level exchange among the participants.

The main aim of the Summit is to enable NET patient advocates from around the world to share best practices and learn from each other, and finally return them to their own countries, recharged with new motivation and equipped with innovative approaches to their work. We were happy to have succeeded in attracting keynote speakers whose valuable contributions helped bring in new insight to important developments on the NET and patient advocacy arena.

I'd like to specially acknowledge the extraordinary commitment of the INCA Summit Committee, led by Pierrette Breton, and comprised of Grace Goldstein, Jo Grey, and Yoshi Majima, who have invested a lot of thought, time and effort into making this Summit happen. We very much hope that the Second Global Summit of NET Patient Advocates was beneficial to you, helping you obtain new knowledge and skills to support your work, as well as gain a greater understanding of what other groups around the world are doing to face their challenges.

I must once again thank you all for taking time out of your busy schedules to join us for this event, and I hope to see you at the next INCA NET Patient Summit.

With all best wishes,

Teodora Kolarova
INCA President

INCA NET Patient Advocate Summit 2014



Meeting Location

Hotel Villa Carlotta
Via Mazzini 121-125
28838 Belgirate/Baveno
Italy
Phone: +39 0322 76461



Meeting Participants:

INCA Board Members:

- | | |
|---------------------|--|
| 1. Tore Aasbu | CarciNor, Norway |
| 2. William Claxton | CNETS Singapore, INCA Treasurer |
| 3. Jo Grey | AMEND, UK, INCA Secretary |
| 4. Grace Goldstein | Carcinoid Cancer Foundation, USA |
| 5. Ron Hollander | Caring for Carcinoid, USA |
| 6. Teodora Kolarova | APOZ & Friends, Bulgaria, INCA President |
| 7. Maia Sissons | NET Patients Foundation UK INCA President-elect |

INCA Full Members:

- | | |
|------------------------|--------------------------------------|
| 8. Pierrette Breton | CNETS Canada |
| 9. Siobhan Conroy | New Zealand – The Unicorn Foundation |
| 10. Véronique De Grave | VZW NET & MEN Kanker |
| 11. Simone Leyden | The Unicorn Foundation |
| 12. Pascal Louw | APTED, France |
| 13. Yoshi Majima | PANCAN Japan |
| 14. Allen Wilson | Pheo Paratroopers |

INCA Guests:

- | | |
|-------------------------------|----------------------------------|
| 15. Sugandha Dureja | CNETS India |
| 16. Carmen-miranda Kleinegris | Stichting NET-groep, Netherlands |
| 17. Adele Santini | AI NET |

Speakers

- | | |
|--------------------------|---|
| 18. Erik Briers | Europa Uomo, Belgium |
| 19. Karen Facey | Evidence Based Health Policy Consultant, Scotland |
| 20. Piero Ferolla MD PhD | Cancer Network Umbria Region |
| 21. Karen Hamel | Novartis |
| 22. Ken Paterson | University of Glasgow, Scotland |

Sponsors

- | | |
|-----------------|-------------------|
| 23. Seiko Asai | Novartis Oncology |
| 24. Karen Hamel | Novartis Oncology |



- Front row, left to right – Yoshi Majima, Grace Goldstein, Pascal Louw, Allen Wilson, Tore Asbu
- Second row, left to right – Sugandha Dureja, Teodora Kolarova, Ron Hollander, Simone Leyden, Maia Sissons, Siobhan Conroy
- Last row, left to right – Adele Santini, Dr. Piero Ferolla, Pierrette Breton, Karen Hamel, Jo Grey, Bill Claxton, Véronique De Grave



International
**Neuroendocrine
Cancer Alliance**

Acknowledgements

**INCA would like to recognize our meeting sponsors,
who made this valuable exchange of
NET patient knowledge and inspiration possible:**





INCA NET Patient Advocate Summit 2014

Uniting NET patient advocates from around the world

Agenda



2014 SUMMIT PROGRAMME

(may be subject to change without notice)

Monday 26 th May	Tuesday 27 th May	Wednesday 28 th May
	08:30 – 09:15 Arrival/registration	08:30 – 09:15 Arrival/refreshments
	09:15 – 09:30 Welcome and plan for the day (Teodora Kolarova, INCA President)	09:15 – 09:30 Welcome and plan for the day (Teodora Kolarova, INCA President)
	Session 1: Running a Successful Organisation	Session 5: Medical Update
	09:30 – 10:15 Managing risk in small organisations (Erik Briers, Europa Uomo)	09:30 – 10:20 Current and future medical therapies for NET (Dr Piero Ferolla MD, PhD, Coordinator Multidisciplinary Group for Diagnosis and Treatment of NETs Umbria Region Cancer Network)
	10:15 – 10:30 Succession Planning (Pierrette Breton, CNETS Canada)	10:20 – 10:30 Q&A
	10:30–10:50 Q&A	10:30 – 11:00 Coffee Break
	10:50 – 11:20 Coffee Break	
	Session 2: Patient Advocacy	Session 6: Influencing Healthcare Policy
	11:20 – 12:10 Building evidence about patient experience to support advocacy positions (Ken Paterson, University of Glasgow, Scotland)	11:00 – 11:30 Having a voice in the development of healthcare policy (Karen Facey, Scotland)
	12:10 – 12:30 Q&A	11:30 – 12:00 Japanese experience in the development of rare cancers healthcare policy (Yoshiyuki Majima, PanCan Japan)
		12:00 – 12:30 Q&A
	12:30 – 14:00 Lunch Break	12:30 – 14:00 Lunch Break
	Session 3: Raising Awareness	Session 7: NET Cancer Day 2014
	14:00 – 14:30 Raising awareness of the disease (Teodora Kolarova, APOZ)	14:00 – 15:00 Brainstorming ideas for NET Cancer Day 2014 and summary
	14:30 – 15:00 Reaching out to NET patients (Grace Goldstein, Carcinoid Cancer Foundation)	15:00 – 15:30 Brainstorming ideas for the next INCA Summit and summary
	15:00 – 15:30 Raising awareness of your organisation (Simone Leyden, Unicorn Foundation)	
	15:30 – 16:00 Coffee Break	15:30 – 16:00 Coffee Break
	Session 4: Funding for Your Organisation	Session 8: Farewells
	16:00–16:30 Preparing a pharma funding proposal (Karen Hamel, Novartis)	16:00 – 16:30 Feedback exchange
	16:30–17:20 Raising funds from sources other than pharma: (Jo Grey, AMEND and Ron Hollander, Caring for Carcinoid)	16:30 – 16:45 Finish
	17:20–17:30 Round-up of Day 1 & Finish	
19:00 Welcome Drink and Dinner (Hotel Carlotta)	18:00 Meet in lobby of Hotel Carlotta for short walk to dinner	18:00 Meet in lobby of Hotel Carlotta for boat transfer to dinner
	19:00 Dinner (Hotel Milano Lago Maggiore)	19:00 Dinner (Trattoria Imbarcadere)

Session 1 – Running a Successful Organization

Managing risk in small organizations

Erik Briers – Europa Uomo

Since 1990 Briers is CEO of Beta Ventures, a company founded to serve the in vitro diagnostics industry as a consultant and publisher of specialised media. As such he is chief editor and founder of the magazine “Focus Diagnostica”, which is specialised in laboratory medicine.

Today, Erik Briers is a guest lecturer for the subject “Trends and Innovations in the Biomedical Sector” within the Master study programme Bio-Engineering at University of Leuven Faculty of Engineering Technology since 2009.

Doctor Briers strong social involvement within patient organisations began after his own prostate cancer diagnosis in 2001 and successful radical prostatectomy treatment with no signs of recurrences until today.

He joined the Belgian patient support group “Us Too Belgium” and acted as representative of this group as one of the founders of the European umbrella organisation EUROPA UOMO. Today he is the Ex Officio Board Member of EUROPA UOMO and board member of “Us Too Belgium”. For this organisation he is also the editor of the magazine “PROSTAATinfo”.

He was the Executive Director of the European Cancer Patient Coalition organisation (ECPC) (2012-2013). Today he is Executive Director ad interim of EPPOSI a multi-stakeholder think tank in health policy-making.



Keys Points

- Identify risks before event happens
- Evaluate each risk
 - Impact
 - Exposure
 - Possibility to avoid
- Prioritize/Weigh each risk
- Implement avoidance



For more information access the full presentation [here](#)

Succession planning

Pierrette Breton – INCA Member Representative since 2011

- INCA Past-Treasurer
- CNETS Canada Board member



- **Practical example – The late Maureen Coleman, founder and Past-President, CNETS Canada**
 - Persistence is key
 - Start before it is critical
 - Hand over key responsibilities
 - Provide challenges to potential replacements
 - Introduce to key sponsors

For more information access the full presentation [here](#)



From left to right: Bill Claxton, Allen Wilson, Ron Hollander

Session 2 – Patient Advocacy

Building evidence about patient experience to support advocacy positions

Prof Kenneth Paterson – FRCP(Glas, Edin, Lond) FFPM, University of Glasgow, Scotland

Ken Paterson was appointed consultant physician with interest in diabetes mellitus at Glasgow Royal Infirmary in 1986. In addition to his clinical work in a busy city-centre diabetes service, he was actively involved in the wider world of diabetes, forming the Glasgow Local Diabetes Services Advisory Group and chairing a SIGN guideline development group looking at diabetic renal disease.



He has also worked for the British Diabetic Association (now Diabetes UK), chairing both its Professional Advisory Committee and Project Grant Committee, and served on the Council of the European Association for the Study of Diabetes (EASD). He was Honorary Secretary of the Royal College of Physicians & Surgeons of Glasgow from 2001 – 2004 and was a Member of the Board of the Faculty of Pharmaceutical Medicine until 2013. He was also Clinical Director of Medicine for North-East Glasgow (Glasgow Royal Infirmary and Stobhill Hospital) from 2006 - 2008.

His other interests include clinical pharmacology and therapeutics and, after many years as Vice-Chair of his local Area Drug and Therapeutics Committee, became Chair of the New Drugs Committee of the Scottish Medicines Consortium (SMC) in 2004 and held the Chair of SMC from 2008 to 2011.

Ken recently stepped down from his full-time clinical post but is continuing his interests in health technology assessment of medicines and medicines management as well as clinical diabetes and internal medicine.

Key Points

- The Journey of a Medicine
 - Pre-discovery/discovery
 - Medicine optimization
 - Clinical trials
 - Registration/licensing
 - Health technology assessment
- Health Technology Assessment
 - How does the medicine benefit the patient?
 - Comparison to current therapy
 - Current unmet patient needs
 - Can any metric of the benefit be derived?
- Patient Advocacy Input
 - Describe current unmet needs
 - Describe current therapy limitations
 - Understand “real world” treatment and access



For more information access the full presentation [here](#)

Session 3 – Raising Awareness

Raising awareness of the disease

Teodora Kolarova – INCA President

- INCA Member Representative since 2011
- APOZ and Friends, Bulgaria

NET Zebra

The zebra has become the international symbol of neuroendocrine cancers with the creative potential to turn a rare cancer into an engaging story. Born in the International Neuroendocrine Cancer Alliance, the NET zebra inspired its members to be “the hero” of their NET Cancer Awareness Day campaigns.



In Bulgaria, APOZ and Friends marked November 10th by creating a special event on Facebook to summon participants for a flash mob in support of the Worldwide NET Cancer Awareness Day.



An impressive group of young people, summoned only via Facebook communication, followed the zebra with a flash mob-dance in the underpass of Sofia University. Before the eyes of the surprised passersby, they danced to the fascinating rhythm of the live performance by Oratnitza band, who complement the traditional Bulgarian folklore drum, flute and vocals, with Australian didgeridoo and Peruvian cajon.

Over 2,000 brochures containing the zebra cartoon sequel and useful facts about the disease were disseminated at the venue of the activation. The Bulgarian Association of Medical Students partnered the initiative.

For more information access the full presentation [here](#)



Circle of communication

Grace Goldstein – INCA Board Member and Past-President

- INCA Member Representative since 2010
- Carcinoid Cancer Foundation, USA



Key Points

- Use all of an organization’s digital and social media platforms to reach out to and communicate with the carcinoid/neuroendocrine tumor community
- As different audiences are reached with different forms of communication, there is value in sharing the same information through all of an organization’s communications
- Social media is of extraordinary value to nonprofits – it helps expose new audiences to your cause, raises awareness of your cause, strengthens relationships with your organization and your community, connects members of a rare disease community for information sharing and support, and provides potential supporters of your organization.

For more information access the full presentation [here](#)



How to build your brand

Simone Leyden – Unicorn Foundation, Australia

Key Points

- building your brand awareness should be pivotal in all activities
- brand values such as credibility, reliability and so on are crucial to your success in gaining respect and buy in from patients, clinicians etc
- use your contacts or make contacts in media to build awareness (send out media releases with newsworthy stories)
- look for innovative ways to capture interest in your message



For more information access the full presentation [here](#)



Adele Santini & Dr. Piero Ferolla



Session 4 – Funding Your Organization

Lottery funding

Jo Grey – INCA Secretary

- INCA Member Representative since 2013
- AMEND, UK



Key Points

- Grasp opportunities and ideas
- Build your evidence of need (e.g. user surveys)
- Research your idea further (e.g. research articles)
- Research and think about innovative non-pharma funding opportunities (e.g. lotteries)
- Be prepared for organizational changes due to success (e.g. policies)!

For more information access the full presentation [here](#)



Preparing a pharma funding proposal

Karen Hamel – Director, Global and US Public Relations, Novartis Oncology

Karen Hamel is a Director of Public Relations for the Oncology division of Novartis Pharmaceuticals, with a focus on neuroendocrine tumors and kidney cancer. In her previous role, she served as Director of Global Patient Relations for Novartis Oncology and worked closely with NET patient groups from around the world. Karen has more than 20 years of experience in healthcare communications and patient advocacy relations.



Key Points

- Plan in advance
- Submit funding request early to allow sufficient time (3-6 months) for review
- Submit requests in writing on your organizational letterhead
- Provide sufficient detail on the budget and purpose of project
- Provide follow up after the event or activity
- When looking for who to contact at a company look for a “patient group contact”, or alternatively the “public relations person” or the “brand manager”
- It is important to remember that to get funding from pharma the requesting organization must be a “legal entity”, for example, needs to be incorporated and cannot be a person
- At Novartis the main relationship holder is the local person – local to your organization
- Novartis encourages multi-sponsored funding over the long term so ask for ideas for or connections to other sources of funding – such as introductions to other pharma reps
- Consider other types of support and ask for it
 - Printing & document production
 - introduction to pro-bono services; etc.
- Novartis and other pharmaceutical companies are governed by various rules and guidelines, including country laws and regulations, industry codes of conduct and their own internal guidelines. All of these can impact how a company approaches patient group funding and it can vary country by country.



Session 5 – Medical Update

Current and future medical therapies for NET

Dr Piero Ferolla MD, PhD,

Coordinator Multidisciplinary Group for Diagnosis and Treatment of NET, Umbria Region Cancer Network, Italy



Source: www.enets.org/d.n.14.pdf

Key Points

- More incidence of NETs likely due to awareness and better imaging
- Previous overall 5 year survival rate at 50%
- Today well differentiated is at 64%
- PNET survival rate now at 9 years
- Unfortunately not much new for poorly differentiated – no change since 1993
- Lanreotide autogel works best in mid-gut tumors but still improvement in PNETS grade 1 and 2 tumors
- While tumor is stable better to leave the patient alone - “do more” is not better
- Important to keep the cancer and immune system in equilibrium

What physicians need from Patient Advocates

- Diffusion of information
- Role in clinical trial awareness
- Help with health authorities
- Availability of research grants
- Interchange of information country to country
- Inform patients on what to expect in treatment & diagnostics



Session 6 – Influencing Healthcare Policy

Having a voice in the development of healthcare policy

Karen Facey, Scotland

Karen Facey is medical statistician who has worked in the pharmaceutical industry and medicines regulation. Twelve years ago she went to Scotland to setup the first national health technology assessment (HTA) Agency, which sought to engage patients throughout the HTA process. She is now an independent HTA and health policy consultant working with all stakeholders including policy makers and patient organisations. She was Chair of the HTAi Interest Group on Patient/Citizen Involvement in HTA for seven years and is now undertaking two research projects for them – developing values and standards for patient involvement in HTA and developing submissions templates for patients to contribute to HTA. Karen acted as a senior PPI advisor to NETSCC until 2012, when the PPI framework was developed. She was guest editor on a special themed edition of the International Journal of Technology Assessment in Health Care about patient issues and she is currently co-editing a special edition of The Patient journal about rare diseases



Key Points

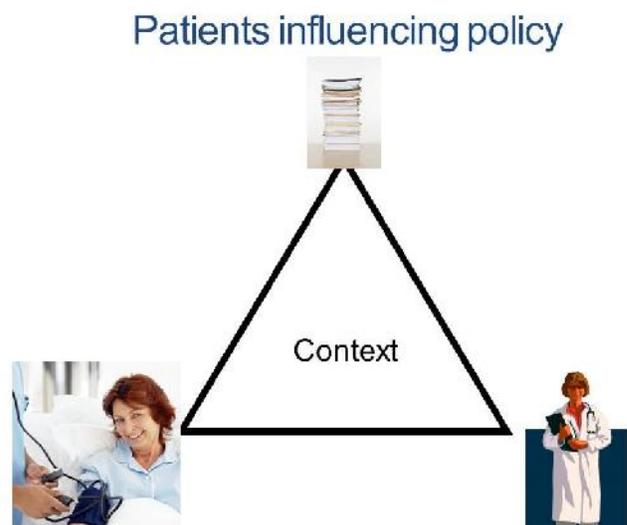
Empowering the Patient

- Work with clinicians for evidence and submissions – more accepted than pharma
- Audit your helpline – gather statistics
- Need a range of patient input
- International template for submissions provided
- Risk:benefit assessment of clinical trials is seen differently by the clinician vs the patient

Patient Research Partners - FIRST

- Facilitate: inclusive attitudes, accessible
- Identify: patients with relevant experience/time
- Respect: patient’s experience
- Support: one-to-one meetings, feedback, partner network
- Train: research processes

For more information access the full presentation [here](#)



Japanese experience in the development of rare cancers

Yoshiyuki Majima - INCA Member Representative since 2013
- PANCAN Japan



Key Points

- Japan is a small country with large aging population
- National health insurance with universal coverage
- Medical expenditure as percentage of GDP is 21st among OECD nations
- Cancer is No1 killer in Japan
- Gap between needs of aging population and health care delivery system
- Slow drug approval process and severe drug approval lag
- Rare cancer initiative needs to be included in next 5 year anti-cancer control plan



For more information access the full presentation [here](#)



Session 7

Brainstorming ideas for NET Cancer Day 2014

The mission is to get patients a timely diagnosis, the best care and a cure.

It was noted that the Summit's tag line was good and on target:

'Uniting NET patient advocates from around the world'

1. Leverage data/information from global survey

- Common challenges and common goals for NET cancer patients around the world
 - Highlight progress made (data, trials etc.)



Discussion:

For the next NET Cancer Day INCA will have results from the survey and a new understanding of the experiences patients are having. Progress has been seen in clinical, research, advocacy and other areas. Results from the survey would be a good place to start.

The message can be shared via a press release to reach a global, regional and country wide audience. We could go further and use the message for lobbying, and also networking with medical professionals.

2. Utilize patient stories

- String together international stories/footage; use film; agree format/criteria

Discussion:

It was suggested that we gather patient stories – at least one from each group. Video the patient's story focusing on a specific aspect of the disease. Post on each group's website. The short videos could be cut into an international one with the underlying message "we come from all over the place but we all have common problems". The link could be emailed along with the press release to maximize the impact. It could go to various online video channels and also get exposed in the media.



3. Need to focus on NEC as well as NET as it is all part of the same family.

- We could explore the differences of NEC vs. NET. Video could segment the focus on each. A to Z of NET/NEC

4. Trailers leading up to NET Cancer Day

- 10 day buildup of 'myth-busters'; commonalities, short subjects/topics; start with basic info (biology); leverage film on NET cancer treatments from NET Patient Foundation; align around commonality (hormones, neuroendocrine)

Discussion:

We could include FAQs to help in differentiating NEC & NET.

What is the neuroendocrine system? Use and explain ‘hormones’

- Tumors arise from the neuroendocrine system
- Neuroendocrine system includes cells with
 - Regulatory role
 - Secreting local “messages”
 - Providing hormonal action etc



Be sure to think about whom the audience is – physicians, patients, and journalists – segment messages tailored to the different audiences.

5. **Staging events around the world**

Flash mobs, zebra parties, etc. would produce significant impact.

6. **Zebras worldwide or selfies**

INCA and members could encourage people to take pictures with our Netty zebra in cool places around the world and post these on the website.

7. **Body art**

- Painting our organs as zebras

8. **Using “net”**

- Fishing net
- Fishnet stockings
- Butterfly nets

Put up something easy-to-do and visual: single-minded call for action; use Instagram, leverage social media altogether – think about how to use the zebra to unify the message



Brainstorming ideas for next INCA Summit

- This year had good practical speakers and would like to see more of that
- PR/Communications workshop to create a communications strategy, plan and messaging media outreach and how to reach the target audience
- How to reach out to GPs to deliver the message
 - Noting that campaigns are hard to measure and there is a huge cost range
- Invite ENETS to discuss centers of excellence
- Take a field trip to a NET center.
- MDs to talk to the groups to educate on the wide variety of NEC and NET cancer
- Each member organization should have an opportunity to share their activities
 - Each member organization could bring a poster presentation.
- An overview of NET and NECs



Looking forward to our next Summit!



List of Participants – Contact Information

NAME	INCA MEMBERS	COUNTRY	EMAIL
Tore Asbu	CarciNor	Norway	asbu@broadpark.no
Pierrette Breton	CNETS Canada	Canada	pmbreton@bell.net
William Claxton	CNETS Singapore	Singapore	williamc@cnets.org
Siobhan Conroy	New Zealand - The Unicorn Foundation	New Zealand	siobhan@unicornfoundation.org.nz
Véronique De Grave	VZW NET & MEN Kanker	Belgium	veroniquedegraeve@hotmail.com
Grace Goldstein	Carcinoid Cancer Foundation	USA	ggoldstein@carcinoid.org
Joanna Grey	AMEND	UK	jo.grey@amend.org.uk
Ronald Hollander	Caring for Carcinoid Foundation	USA	ron.hollander@caringforcarcinoid.org
Teodora Kolarova	APOZ	Bulgaria	teodora.kolarova@gmail.com
Simone Leyden	The Unicorn Foundation	Australia	sleyden@unicornfoundation.org.au
Pascal Louw	APTED	France	pascallouw-toutvabien@yahoo.fr
Yoshi Majima	PANCAN Japan	Japan	ymajima@pancan.jp
Maia Sissons	NET Patient Foundation	UK	maiasissons@me.com
Allen Wilson	Pheo Paratroopers	USA	paratrooperallen@googlemail.com
NAME	GUESTS	COUNTRY	EMAIL
Carmen-miranda Kleinegris	Stichting NET Groep	Netherlands	carmenmiranda.kleinegris@yahoo.com
Adele Santini	AI NET	Italy	adelesantini@gmail.com
Dr Sugandha Dureja	Carcinoid and Neuroendocrine Tumor Society-CNETS India	India	sugandhadureja@gmail.com
NAME	SPEAKERS	COUNTRY	EMAIL
Erik Briers	Europa Uomo	Europe	dolf.das@gmail.com betaventures@telenet.be
Karen Facey	Evidence Based Health Policy Consultant	Scotland	k.facey@btinternet.com
Dr Piero Ferolla	AI NET	Italy	pferolla@alice.it
Ken Paterson	University of Glasgow, Scotland	Scotland	ken.paterson@dsl.pipex.com
NAME	Sponsor	COUNTRY	EMAIL
Seiko Asai	Novartis Oncology	USA	seiko.asai@novartis.com
Karen Hamel	Novartis Oncology	USA	karen.hamel@novartis.com



Beautiful peacock of Lago Maggiore, on Isola Madre, Italy