



# ESE News

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THE NEWSLETTER OF **THE EUROPEAN SOCIETY OF ENDOCRINOLOGY** –  
THE EUROPEAN HORMONE SOCIETY

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## European Reference Network

for Rare Endocrine Conditions

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for pheochromocytomas  
and paragangliomas

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This document is available on the ESE website, [www.eese-hormones.org](http://www.eese-hormones.org)

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## Editorial

I hope you enjoyed ECE 2016 in Munich, Germany, as much as I did. I am sure you agree that meeting with fellow endocrinologists, exchanging ideas and learning from one another is an essential, and very enjoyable, part of developing our discipline.

The same principle lies at the heart of the latest exciting initiative in European endocrinology: the development of a European Reference Network (ERN) for Rare Endocrine Conditions. Its purpose will be to share expertise across borders, and further improve patient care.

The European Commission launched the call for ERNs in March, with responses required by June. On pages 6–7, you can read more about the joint proposal coordinated by a dedicated team from ESE and the European Society for Paediatric Endocrinology (ESPE). Our cover image of the legendary Greek figure Europa, after whom our continent is named, marks this exciting European collaboration. We wish the application every success when the results are announced in the autumn.

Ten years have passed since ESE was launched – and what a productive decade we have witnessed! On page 10, Helen



Gregson, Chief Executive Officer of ESE, reminds us not to 'rest on our laurels', but to plan for the future, so that ESE can best support its members and the whole discipline of endocrinology. Please get in touch with your ideas and feedback.

On page 8, Laurence Amar and Pierre-François Plouin highlight the latest ESE guideline to be published, on follow-up after surgery for pheochromocytoma or paraganglioma, adding to ESE's growing list of achievements. On page 9, the Endo Explorer relates the achievements of a European endocrinologist in North America, as Constantine Stratakis gives us an insight into his team's endeavours at NIH in Bethesda, MD, USA.

Finally, you can catch up with some highlights from ECE 2016 on pages 11 and 12. Now's the time to make sure that ECE 2017 on 20–23 May in Lisbon, Portugal, is in your diary for next year.

**AJ van der Lely**  
ESE President  
Co-Editor of *ESE News*

## From the ESE office



It is with great pleasure that I write in *ESE News* as ESE's new (and first!) Chief Executive Officer. I have worked with the Society since its beginning as

an individual membership organisation in 2006, and am very proud to be leading it into a new chapter on its 10th birthday.

Although ESE is young, it has achieved a lot and, with an innovative, positive and future-focused President and Executive Committee, it is in the best possible position to achieve its objectives. These include promoting endocrinology at the European level, improving the quality and accessibility of endocrine education,

working closely with our early career endocrinologists, who will shape the future, and delivering a high quality and expanding European Congress. My personal and professional philosophy is that, where possible, we should work with others where it supports our aims, and we will actively seek partnerships with national, international and specialist societies in order to do so.

Please learn more about ESE's strategic review on page 10, and contact me if you would like to discuss any aspect of ESE activities.

**Helen Gregson**  
Chief Executive Officer, ESE  
[helen.gregson@ese-hormones.org](mailto:helen.gregson@ese-hormones.org)

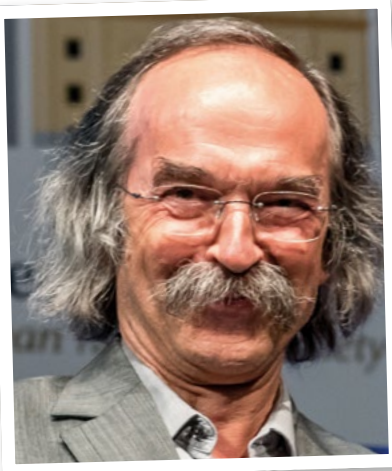
## NEW National Affiliate Membership

ECAS (the ESE Council of Affiliated Societies) meets twice yearly to discuss ways of promoting collaboration across Europe and national issues affecting endocrinologists. Conversations with representatives of ESE's National Affiliated Societies at these meetings result in initiatives to benefit members of the Societies and members of ESE.

One such activity has addressed the distinction between membership of a National Affiliated Society and that of ESE. From 2017, if you are a member of both ESE and one of the Societies, you will benefit from a new, lower price, ESE membership category – 'National Affiliate Membership' – as follows:

- **Ordinary €55** instead of €80
- **Reduced rate (incl. nurses) €20** instead of €35
- **In-training €10** instead of €20

You can find a list of National Affiliated Societies at [www.ese-hormones.org/membership/affiliated/list.aspx](http://www.ese-hormones.org/membership/affiliated/list.aspx).



## New Editor-in-Chief

Josef Köhrle is the new Editor-in-Chief of ESE's open access journal *Endocrine Connections*. Professor Köhrle is Scientific Director of the Charité Centre for Therapeutic Research at Universitätsmedizin Berlin, Germany. His research focuses on thyroid hormones and their metabolites.

## ESE endorses EDM Case Reports

ESE has joined 14 other learned societies across the world to endorse *Endocrinology, Diabetes & Metabolism Case Reports*, an online open access database. ESE members receive a 20% discount on the article publication charge (£280 instead of £350) and are encouraged to contribute their case reports to build this resource for all clinicians working in endocrinology, diabetes and metabolism.



Endocrinology,  
Diabetes & Metabolism  
CASE REPORTS

## Premature ovarian insufficiency

The European Society of Human Reproduction and Embryology (ESHRE) recently published its third guideline on management of premature ovarian insufficiency. You can find all ESHRE guidelines at [www.eshre.eu](http://www.eshre.eu).

## 4th Europit Course

This Postgraduate Course takes place on 14–16 November 2016 in Annecy, France: see [www.europit.org](http://www.europit.org).

# Exercise and sports endocrinology:

## 3rd Combo Endocrinology Course

1–3 October 2015, Athens, Greece

Combo Endocrinology is an annual course to provide trainees, fellows and early career professionals with a comprehensive, in-depth knowledge of specific hot topics in endocrinology, using a combined ('Combo') approach with other medical/surgical specialties.

The meetings cover a different endocrine theme each year, through lectures, 'meet the expert' sessions and case presentations. This year's topic was 'Exercise and sports endocrinology' focusing on physical exercise, hormones, diabetes, nutrition and over-training. It covered exogenous administered substances

(doping), as well as 'prescribing' exercise regimens for treatment of chronic health conditions.

Under the guidance of tutors, participants were encouraged to get involved with exercise techniques and high-tech ergophysiology equipment, and to present clinical scenarios in a 'virtual congress' setting.

We thank Evanthia Diamanti-Kandaraki (who initiated the idea of Combo Endocrinology) and Dimitrios Goulis, as well as the international faculty, for organising this successful course, which was co-organised with the



Book now!

4th Combo Endocrinology Course  
'Ageing and Anti-ageing'

6–9 October 2016 Athens, Greece  
[www.comboendo.gr](http://www.comboendo.gr)

Aristotle University of Thessaloniki, ESE, the Hellenic Society of Endocrinology and the Euroclinic of Athens.

# Jens Sandahl Christiansen

**Jens Sandahl Christiansen, Professor of Internal Medicine at Aarhus University Hospital, has sadly died at the age of 67.**

An old adage says, 'You can take the man out of the country, but you can't take the country out of the man.' Jens was a passionate traveller, but remained faithful to his inner Dane, delighting in educating visitors as to the uniqueness of his 'small Danish kingdom'. As a true Viking, he loved to plunge into the freezing waters of his homeland, preferably accompanied by reluctant and hypothermic foreign visitors.

Jens graduated from medical school in Copenhagen with a gold medal thesis on diabetes. At the Steno Diabetes Center (SDC), he immediately became a valued member of this unique scientific community, and wrote his doctoral thesis on diabetic nephropathy.

Jens completed his postgraduate education in Aarhus. In 1989, he became a consultant in internal medicine and endocrinology at the Aarhus University Hospital, and a clinical professor in 1993. His steadfastness as a clinician resonated well with a local demand for modernisation of diabetes treatment, which he conscientiously met.



He initiated clinical research projects with senior and junior colleagues, resulting in several pivotal discoveries regarding diabetic complications and clinical aspects of growth hormone (GH) research. He was the senior author of the first controlled trial of GH replacement in adult hypopituitary patients, prompting several pioneering papers in that field.

Jens established a strong international network of colleagues and served on boards in several scientific societies. He was a co-founder and later President of the Growth Hormone Research Society (GRS). He was also Editor or an Editorial Board member of several journals. With over 600 publications, his impact on endocrinology is substantial, and he received many awards. Perhaps most importantly, Jens was a treasured physician to his patients and a brilliant teacher of medical and postgraduate students.

He was a bon vivant, famous for his after-dinner speeches with juicy jokes and limericks. But Jens was also a family man; his wife Annette, children and grandchildren were privileged to know and love him best.

His good spirit and humour stayed with him to the end. His many friends and colleagues may not miss the icy waters of Denmark, but they will surely miss Jens.

**Jens Otto Lunde Jørgensen, John J Kopchick, Bengt-Åke Bengtsson, Anne-Marie Kappelgaard**

# Mihail Gr. Coculescu

**Mihail Coculescu, a leader of Romanian endocrinology, has passed away at the age of 72, after a long illness.**

Mihail was Vice President of the Romanian Academy of Medical Sciences, leading the basic and translational section, Corresponding Fellow of the Romanian Academy and Editor-in-Chief of *Acta Endocrinologica – Bucharest*.

He was an important personality in the Romanian endocrine school and a great scientific leader, bringing together successive generations of students and, despite limitations imposed in the early years of his career by the political system, developed international bridges across the endocrine world.

Graduating from the Carol Davila University of Medicine and Pharmacy in Bucharest in 1966, he received his PhD in 1976, under the supervision of Stefan Milcu. He had been a fellow of the Royal College of Physicians (UK) since 1996 and of the American College of Endocrinology since 1997. He was well known

internationally as a neuroendocrinologist; in 1986 he published in *Clinical Neuroendocrinology*, receiving the prize of the Romanian Academy.

His many achievements included synchronisation of the Romanian national professional curricula with European requirements for Romania's entry into the EU in 2007. He was founding President of the Romanian Psychoneuroendocrine Society (RPNES) and Honorary President of the Romanian Society of Endocrinology (RSE). He founded the Romanian Chapter of the American Association of Clinical Endocrinologists, and represented Romania in the UEMS (European Union of Medical Specialists) for endocrinology. He led the Endocrine Committee of the Health Ministry, putting in place guidelines for endocrine disorders in Romania, and launched the international journal *Acta Endocrinologica – Bucharest*.



As a professor and mentor, he showed devotion and compassion to his patients and inspired his students and young co-workers.

Mihail was a family man and will be greatly missed by his wife Lucia, his daughters and his grandchildren.

He will be long remembered by the whole endocrine community.

**Carmen Vulpoi, President, RSE  
Corin Badiu, President, RPNES**

# Sexual health training during residency

Discussions about inclusion of sexual health training in the curricula of various medical residencies are ongoing. Sexuality is an inherent part of being human, and the lack of appropriate formal training across specialties on how to approach sexuality concerns can result in problematic interactions between clinicians and patients.

The European Young Endocrine Scientists (EYES), together with the European Network of Trainees in Obstetrics and Gynaecology (ENTOG), the European Society of Residents in Urology (ESRU) and the European Federation of Psychiatric Trainees (EFPT) agreed to a common initiative to address the problem. Together,



they have designed and conducted a survey on the level of training in sexual health during residency training.

Preliminary results indicate that EYES members think sexual health training during residency is important (49.1%) or very important (37.7%). However, only 41.5% of the responders have received such training. Only 17% of the responders have indicated that sexual health is a compulsory topic in their curriculum, and 19% have said it is an optional topic. Final results will be officially announced after the survey process has been completed.

**Gefsi Mintziori**, EYES co-Chair



EYES Committee at ECE 2016: L-R Anneke van den Beukel, Elahu Sustarsic, Ljiljana Marina, Filip Gabalec, Gesthimani Mintziori, Maxmilian Bielohuby

## Make a date for Moscow: 4th Annual Meeting of EYES

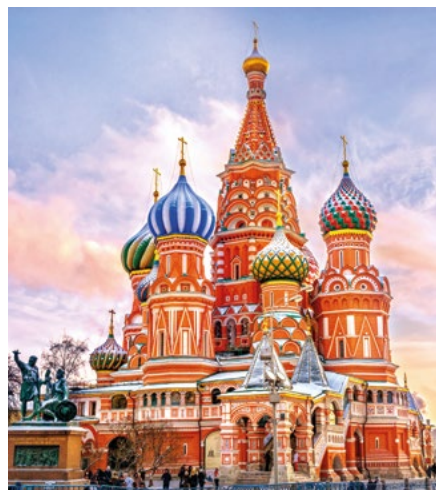
**22–24 September 2016, Moscow, Russia**

The 4th EYES (European Young Endocrine Scientists) Meeting in Moscow, Russia, will bring together young researchers from all areas of endocrinology.

Following previous EYES Meetings in the west (The Netherlands, 2013) and the south (Serbia, 2014, and Italy, 2015), we are carrying the endocrine torch to the eastern part of Europe for 2016.

All aspects of basic and clinical endocrinology will feature (diabetes, obesity, thyroid, reproductive, adrenal and bone disorders, neuroendocrinology and endocrine tumours). For the first time, the EYES meeting will have a separate section for paediatric endocrinology.

The conference takes place in the Endocrinology Research Center – Russia's leading diagnostic, treatment, research and educational institution for endocrinology. It is supported by ESE and the Russian Science Foundation, and is held in collaboration with the Russian Young Endocrinologists' Society (RYES), the Endocrinology Research Center and the Bakoulev Scientific Center for Cardiovascular Surgery.



This unique opportunity for early career endocrinologists to present their results, find new collaborators, enjoy an interesting scientific programme and meet distinguished lecturers has a registration price of just €50; accommodation and an amazing social programme are included!

Register now and submit your abstract at [www.eyes2016.org](http://www.eyes2016.org). We look forward to seeing you all in Moscow.

## Science Committee update

Topics ranging from the future and focus of research funding to establishing the real impact of endocrine-disrupting chemicals are currently under discussion at European Commission level. This means ESE is well placed to provide expert insight into matters of significant importance across Europe, and consequently the Science Committee is reviewing ESE's impact on policymakers.

The Committee is also keen to build on previous success by improving endocrine researchers' access to high quality education programmes. These include the ESE Summer School on Endocrinology, Europit and the ESE Symposium on Hormones and Cell Regulation. ESE will also support researchers to achieve their goals through ESE Short-Term Fellowships and the International Endocrine Scholars' Programme (IESP). You can find out more in the Education and Grants pages at [www.es-hormones.org](http://www.es-hormones.org).

Finally, the scope of the roles of ESE Science Ambassadors is set to broaden, as they continue to promote ESE's activities to basic researchers across Europe. Watch this space for further details!

**Márta Korbonits**  
Science Committee Chair

# European Reference Network for Rare Endocrine Conditions

## On the right track to an important destination

By definition, a rare disease has a low prevalence (specified as  $< 1:2000$  in Europe). But, for a patient with such a disease, it is not a 'rare' situation. The approximately 7000 rare diseases that can be identified affect over 30 million people in Europe.



European  
Reference  
Networks

Diagnosis and management of rare diseases are often challenging for the healthcare system and medical research. For physicians and patients alike, this can lead to difficulties and delays while the appropriate information and expertise are located. It can also be difficult to gather sufficiently large cohorts, or to achieve a critical mass of laboratories and resources, to support medical research. At the European level, the FP7 and H2020 programmes have proved very efficient in developing international networks for research, and some have been specifically devoted to rare diseases. Such successes have indicated that networking at a European level is very beneficial.

At the European level, expertise on rare diseases exists, but is limited to specialised centres, and is not present for a given disease in every region. Furthermore, expert centres are rarely organised into international networks for care (in contrast to existing research networks).

### The call for ERNs

In March 2016, the European Commission launched a call for European Reference Networks (ERNs) for care of rare, or low prevalence, complex diseases. EURORDIS (an alliance representing rare disease patient organisations) has been instrumental in developing this initiative, after a 10-year campaign to promote trans-border care in the EU.

The call aims to 'facilitate access to diagnosis and treatment by centralising knowledge and experience, medical research and training, and resources in the area of rare or low prevalence complex diseases or conditions'. This programme is clearly patient-centred and not primarily aimed at developing research networks



Endo-ERN joint ESE-ESPE 'task force'. L-R: Georg Brabant (ESE), Agnès Linglart (ESPE), Olaf Hiort (ESPE), Faisal Ahmed (ESPE), Jérôme Bertherat (ESE), Alberto Pereira (ESE)

(although, in rare diseases, improvement is usually closely linked to research).

The general scheme of such an ERN is to co-ordinate at least ten centres from more than eight European member states. The ERNs should be large enough for 20–25 ERNs to cover almost all rare diseases. Consequently, the European Commission suggested there should be about 23 ERNs, including one ERN on Rare Endocrine Conditions (Endo-ERN).

### Collaborative approach

ESE, in collaboration with the European Society for Paediatric Endocrinology (ESPE), has promoted the idea of a large ERN, covering all aspects of rare endocrine diseases, from birth to adulthood. Two joint statements were emailed to all members of both societies in February and April, to inform them and promote this initiative.

An adult endocrinologist, Alberto Pereira (Leiden, The Netherlands), and a paediatrician, Olaf Hiort (Lübeck, Germany), are co-ordinating the approach, supported by the two societies. Endocrinologists from more than 15 European countries met to discuss and shape this Endo-ERN in Lübeck and Leiden in March 2016. Discussions were very constructive

and each participant showed great determination to make progress.

However, it was apparent the plans for rare diseases are very heterogeneous among European countries. We can learn by sharing different and complementary experiences from the healthcare systems of member states, but they provide a challenge if we are to move in a co-ordinated fashion.

One important aspect of the ERN programme is that each healthcare provider (HCP) has to be first endorsed by its own Ministry of Health as an expert (or reference) centre, to apply to join the ERN. The arrangements will differ greatly between countries, and an Endo-ERN will have to work hard on these aspects and to promote high levels of participation by centres that have already been recognised internationally for their expertise.

### Embracing all participants

Over 250 groups of rare endocrine diseases could probably be envisaged. One could say that the unifying factor amongst all participants in an Endo-ERN should be that they are hormone specialists. The Endo-ERN will aim to provide a single over-arching 'umbrella' for all.

To this end, eight sub-themes have been identified (see Figure below). Each will be co-ordinated by a paediatrician and an adult endocrinologist. Specific expertise throughout life is important, not only because a disorder might occur more often in childhood or adulthood, but also to provide smooth, efficient patient management for the transition from adolescent to adult.

## Aims and objectives

The general objectives identified by the Endo-ERN initiative to satisfy the requirements of the European Commission are:

- (a) to improve diagnosis and delivery of high quality care in endocrine diseases where expertise is rare, and to promote its mobility;
- (b) to reinforce research and epidemiology;
- (c) to promote training; and
- (d) to spread best practice within and outside the network.

This is clearly a very ambitious programme. To promote synergy among the multiple partners, five large work packages have been defined:

- **Education and teaching**
- **Quality of care and patient view**
- **Research and science**
- **Diagnostics and laboratory analysis**
- **e-Health and ICT.**

The ERN programme is patient-centred. Patients' views will be an important aspect of an Endo-ERN. e-Health will also be important, to exchange expertise across Europe. The idea is that the expertise should travel to the patient, rather than the other way round.

Gathering all the experts and patient associations willing to participate in an Endo-ERN is challenging. The European Commission requested a reply to its call by 21 June 2016. To achieve this, the dedicated team from ESE and ESPE worked extremely hard. Centres from 20 countries were willing to join the effort (see Table).

The results of the call are expected in October. We are all optimistic that the Endo-ERN application will succeed. Then, a long and exciting adventure will begin, as international efforts will result in great progress for the benefit of our patients with rare endocrine conditions.

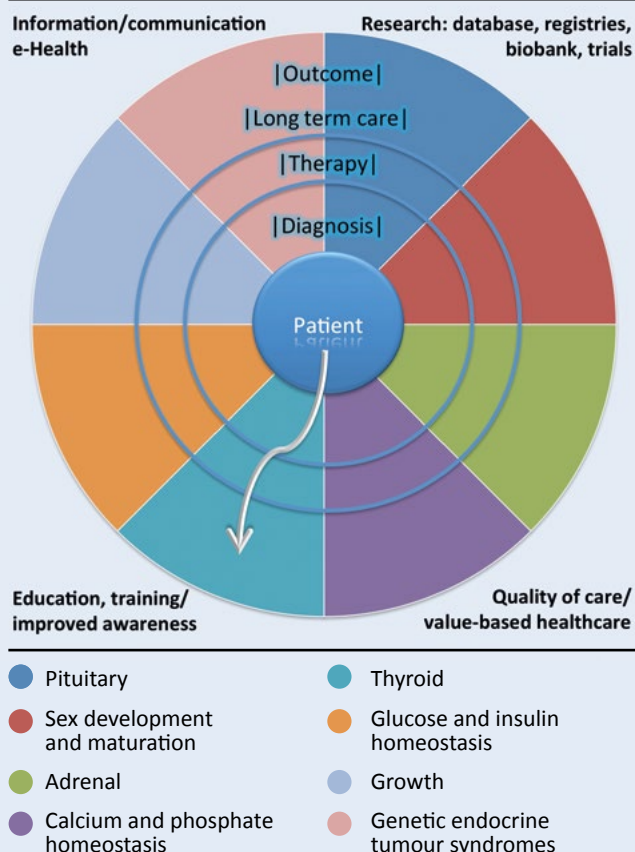
Jérôme Bertherat  
Alberto Pereira

## Distribution of prospective HCPs in the Endo-ERN by country

(as at 17 June; liable to change during the application process)

Country	HCPs
Belgium	6
Bulgaria	2
Czech Republic	2
Denmark	2
Estonia	1
France	8
Germany	12
Hungary	1
Italy	10
Lithuania	1
Luxembourg	1
Malta	1
The Netherlands	8
Poland	2
Portugal	1
Romania	2
Slovenia	1
Spain	3
Sweden	1
UK	8
<b>TOTAL</b>	<b>73</b>

## Endo-ERN: the main thematic groups



~ 31 AUG - 4 SEP ~

**ICE-CSE 2016**  
BEIJING, CHINA

31 AUGUST - 4 SEPTEMBER 2016 | BEIJING, CHINA

#ICECSE2016

**1<sup>st</sup> JOINT GLOBAL SYMPOSIUM ON: OBESITY**

The first in a series of collaborative sessions organised by ISE, ESE & the Endocrine Society, focusing on prominent global endocrine issues.

**YOU MIGHT THINK YOU KNOW, BUT WHY DO WE ACTUALLY HAVE AN OBESITY PANDEMIC?**

FRIDAY, 2 SEPTEMBER 2016 - 10:15 -11:45AM

A COLLABORATIVE SESSION BROUGHT TO YOU BY:

ENDOCRINE SOCIETY      European Society of Endocrinology      ise

[www.icecse2016.org](http://www.icecse2016.org)

# Long term follow-up in patients operated on for a PPGL

## New ESE clinical guideline

The authors of ESE's latest clinical guideline, published in *European Journal of Endocrinology*,<sup>1</sup> recount how they addressed an unmet need for information on patient management.

Phaeochromocytomas and paragangliomas (PPGLs) are rare neuroendocrine tumours. Most PPGLs produce catecholamines that are metabolised into metanephrines. At least 10% of PPGLs are malignant at presentation, as documented by the presence of lymph node or distant metastases. Currently, a genetic germline cause can be identified for around 40% of PPGLs. Standard treatment is surgical resection.

Following resection of the primary tumour, patients with a PPGL are at risk of tumour persistence and of new tumoural events. Tumour persistence is the consequence of incomplete tumour resection, particularly in cases of malignant primary tumour, or of tumour spillage during surgery.

New tumoural events are recurrences, defined as the reappearance of disease after complete tumour eradication, or new tumours. Recurrences may be local, at the site of the primary tumour, or metastatic. New tumours are PPGLs that arise in the contralateral adrenal or in a previously unaffected paraganglion. In addition to new PPGL events, PPGL patients with syndromic diseases such as von Hippel-Lindau disease, multiple endocrine neoplasia type 2, neurofibromatosis 1 or hereditary paragangliomas may develop non-PPGL tumours, including renal cancer and medullary thyroid carcinoma.

A recent Endocrine Society guideline focused on diagnosis and treatment of PPGL, without significant consideration of postoperative long term follow-up.<sup>2</sup> Therefore, there was a need to address the following questions:

- What is the incidence of documented recurrences (local or metastatic) or new tumours in patients operated on for a PPGL with apparently complete tumour resection?

- Which factors are associated with documented recurrences (local or metastatic) or new tumours in such patients?

### Addressing the questions

To provide answers, we searched PubMed and Embase to systematically review all relevant data. The presence or absence of a germline mutation in one of the PPGL susceptibility genes is a candidate predictor of long term outcome. As many such genes have been described only recently, a lot of the published papers do not report the presence or absence of inherited diseases. Most patients in the ENS@T (European Network for the Study of Adrenal Tumours) PPGL database have been screened for the major known inherited diseases involving PPGL. We therefore used the ENS@T database to complement the review of the literature.

In the literature, the 5-year incidence of postoperative new events was 4.9% [95% confidence interval (CI): 3.6, 6.3], distributed as follows: new tumours 22%, local recurrences 23% and metastatic recurrences 55%. The incidence of new events was 0.90 [95% CI: 0.62, 1.19] per 100 person-years in studies involving both syndromic and non-syndromic diseases, and 2.06 [95% CI: 1.37, 2.75] per 100 person-years in studies involving only syndromic diseases ( $P=0.007$  for the difference).

In the ENS@T database, the incidence of new events in the whole population was 10% [95% CI: 8, 14] over the first 5 years of follow-up (new tumours 42%, local recurrences 13% and metastatic recurrences 45%). It was 18%, 27% and 17% respectively in the subgroups of patients with thoraco-abdomino-pelvic paragangliomas, in patients aged less than 20 and in those having a syndromic or genetic disease. The incidence of new



events did not decline after 5 years of follow-up. Estimates after 10 years of follow-up were imprecise due to the small numbers of patients for whom data were available. The most frequent sites for metastases were lymph nodes, the skeleton, liver, and lungs.

### Recommendations

In conclusion, the incidence of new events is lower than previously reported, but more than 40% of new events are malignant recurrences, and new events may occur after a 5-year event-free period. Consequently, we propose the following recommendations and suggestions:<sup>1</sup>

- All patients with PPGL should be considered for genetic testing.
- Metanephrines should be assayed annually to screen for local or metastatic recurrences or new tumours.
- All patients operated on for a PPGL should be followed up for at least 10 years.
- High-risk patients (young patients and those with a genetic disease and/or a paraganglioma) should be offered life-long annual follow-up.

**Laurence Amar & Pierre-François Plouin**, Hôpital Européen G Pompidou, Assistance Publique-Hôpitaux de Paris and Paris-Descartes University, Paris, France

### References

1. Plouin *et al.* 2016 *European Journal of Endocrinology* **174** G1–G10.
2. Lenders *et al.* 2014 *Journal of Clinical Endocrinology & Metabolism* **99** 1915–1942.

### Acknowledgments

We thank OM Dekkers, M Fassnacht, AP Gimenez-Roqueplo, JMW Lenders, C Lussey-Lepoutre and O Steichen who participated in the PPGL Guideline Working Group, and F Beuschlein, Chair of the ENS@T Executive Committee, who allowed us to compile the ENS@T database.





# The Endo Explorer

## Finding genes for pituitary and adrenal tumours

*'Discovery consists of seeing what everyone else has seen and thinking what no one else has thought'*

Albert Szent-Gyorgyi

This is one of my favourite sayings, and was given to me by Aidan Carney when we discovered the gene for Carney complex. The poster with Szent-Gyorgyi's quotation was previously displayed at Dr Carney's office at the Mayo Clinic (Rochester, MN, USA) and now adorns my office at NIH (Bethesda, MD, USA).

My other favourite – *veritas filia temporis* (truth is the daughter of time) – is something that my students and fellows know I repeat time and time again at rounds and lectures; not only is it true for so many aspects of life, but it also reflects well two tenets of science: the search for the truth and the tenacity of research that occasionally has to persist against odds and even disbelief.

Certainly, both these quotes have served my laboratory very well as we investigate the genetic causes of pituitary and adrenal tumours. In some cases, we discovered genetic defects that everybody else had bypassed as the cause of disease and, in other cases, we had to persist for years to prove a hypothesis.

### Early career

During my graduate work, I developed an interest in the genetics of endocrine diseases, especially those that present with a predisposition to endocrine tumours and other neoplasms.<sup>1</sup> My career started in 1985 as a graduate student in the Endocrine Unit of the Medical School of the University

of Athens, under the mentorship of Professor M Batrinos, and as a biochemist (tech) in a radioimmunoassay lab at the Hospital Mitera, Athens, Greece.

In Paris, France, in 1988, I spent time with Jean Pierre Luton and Xavier Bertagna. Then, in 1989–1990, at the lab of George Chrousos at NIH, I was part of the team that identified the first genetic defects in the human glucocorticoid receptor.

I continued with my clinical training at Georgetown University Medical Center (Washington, DC, USA), where I finished a residency and two fellowships in paediatrics, paediatric endocrinology and medical genetics respectively. I was recruited back to NIH, trained in linkage analysis and cancer genetics and, in 1995, started a laboratory studying the genetics of endocrine tumours in the context of a variety of genetic syndromes.

### Carney complex and other discoveries

In 2000, my lab identified the *PRKARIA* gene causing Carney complex; this gene regulates protein kinase A (PKA) and, consequently, cAMP signalling, as we showed in animal models. We then found phosphodiesterase (PDE) genes *PDE11A* and *PDE8B* as potentially being involved in cAMP-related tumour growth. We also identified defects affecting mitochondrial oxidation in endocrine tumours and in paediatric gastrointestinal tumours (GISTs).

In collaboration with the hospital I was trained at in France, we are now working on the *ARMCS* gene in macronodular adrenal hyperplasia, which we are now modelling in mice, flies and fish. Our laboratory identified the *PRKACA* and *PRKACB* genes in micronodular adrenal hyperplasia and Carney complex<sup>2</sup> and, most recently, we described a new condition that we named X-LAG for 'X-linked acrogigantism'.<sup>3</sup>

### Looking forward

Ongoing genome-wide work aims at identifying genetic defects for Carney triad, wild type GISTs, endocrine hypertension (in association with adrenocortical tumours), paediatric gigantism, and other forms of adrenal and pituitary tumours.

Over the years, my laboratory has trained more than 180 students, residents and fellows from all over the world. We are very proud of this extended family that, thankfully, keeps growing. Finally, although my administrative duties have undoubtedly increased over the years, I am still seeing patients and families and teach medical trainees almost daily. I, thus, remain deeply committed to serving the 'academic physician' part of being a physician scientist.

### Constantine A Stratakis

Scientific Director, Eunice Kennedy Shriver National Institute of Child Health & Human Development (NICHD), and Chief, Section on Endocrinology & Genetics (SEGEN), NIH, Bethesda, MD, USA

### References

1. Stratakis 2013 *Endocrine-Related Cancer* **20** P1–P6.
2. Stratakis 2014 *Journal of Clinical Endocrinology & Metabolism* **99** 3629–3633.
3. Trivellin et al. 2014 *New England Journal of Medicine* **371** 2363–2374.

# 10 years on: ESE looks to the future

Our 10th birthday is a good opportunity to reflect on all that ESE has achieved in a relatively short time. We have an ever-growing membership, an increasingly successful and respected Congress, and an established clinical practice guideline programme. *European Journal of Endocrinology* has an excellent impact factor, and our open access journal, *Endocrine Connections*, will be eligible for its first impact factor in 2017.

In addition, we have an expanding range of grants and awards, training courses spanning clinical and basic endocrinology, and an active endorsement programme. We are also working even more closely with our Affiliated Society members, and with our international partners on a range of activities.

However, it is important that, on this milestone birthday, we also look to the future. It is a perfect time to thoroughly review activities, and to ensure ESE is clear about its intrinsic value, essence and purpose, and that we optimally support today's endocrinology and endocrinologists.

## A full review

You may have noticed several activities at ECE 2016 in Munich regarding this full strategic review and the development of a new visual identity. You may have received a communication about involvement in a focus group, been invited to fill out a questionnaire on the ESE stand or by email, or received an invitation to participate in a telephone interview.

In liaison with the various interested parties, the ESE Executive Committee has been working hard to define ESE's strategic priorities for 2017–2021. It has set these out as follows:

- To be at the heart of the endocrine community in Europe, acknowledged as the reference point for endocrine science, knowledge and health
- To provide continuous endocrine-related education and training provision for all career stages in clinical practice and basic research
- To foster early career basic and clinical endocrinologists, creating a dynamic community which will inspire them to become endocrinologists and remain in endocrinology
- To continue to run the leading European endocrine congress

- To ensure that ESE is financially sustainable through excellent management of industry partnerships and a clear business development strategy.

## Eight focus areas

In addition, ESE will create eight focus areas within which to create communities, support research programme collaborations, and categorise content. After considered debate, we have arrived at the following:

- Adrenal and neuroendocrine tumours
- Calcium and bone
- Diabetes, obesity and metabolism
- Environment, society and governance
- Interdisciplinary endocrinology (working title)
- Pituitary and neuroendocrinology
- Reproductive endocrinology
- Thyroid.

Each will be supported by clinical and basic science leads and an advisory group, and will be responsible for implementing activities and devising solutions for issues affecting their area, as well as providing input into the content of ESE's programmes, in particular in relation to ECE.

## An identity for the future

We are reviewing our visual identity, in parallel with our strategy, to ensure we have a strong, contemporary, forward-reaching image that reflects our aspirations. It will help us stand out from the crowd and reach the people and organisations we need to talk to, and will improve recognition of ESE and its activities. It is an investment, but ultimately we are investing in the future of endocrinology and endocrinologists.

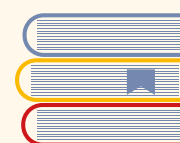
If you would like to discuss any aspect of ESE activities please do contact me. Your feedback and engagement are essential in ESE's continuing success and further development.

**Helen Gregson**  
Chief Executive Officer, ESE  
helen.gregson@ese-hormones.org

## ESE 2006–2016: highlights from the first decade

**€923 936**

in grants  
and awards  
supporting **775**  
endocrinologists

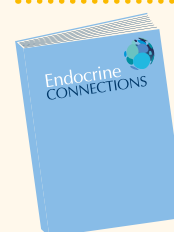


**Clinical  
guidelines  
programme  
established**

...with more in development

**3.892**

high EJE  
Impact  
Factor



**Endocrine  
Connections**  
open access  
journal  
launched

**50%**

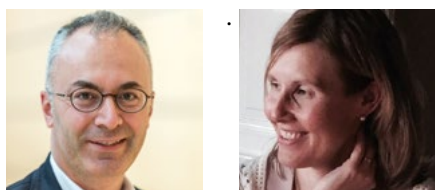
increase in  
ECE attendees



**2422**  
papers  
published  
in EJE

## Executive Committee changes

At the Annual General Meeting during ECE 2016, Bulent Yildiz (Ankara, Turkey) took over as Treasurer of ESE from Richard Ross. In addition, Misa Pfeifer stepped down from the Executive Committee and Camilla Schalin-Jääntti (Helsinki, Finland) was elected. We welcome Bulent and Camilla (pictured) to their new roles, and thank Richard and Misa for their support and hard work.



## Honorary Member & Special Recognition Award winners

Congratulations to Paolo Beck-Peccoz (below top), who was awarded Honorary Membership of ESE, and to Pia Burman (centre) and Josef Köhrle (bottom), who received Special Recognition Awards.



## Prize lecturers at ECE 2016



**Albert Beckers**  
Geoffrey Harris Prize Lecturer  
*'Beyond the Adenoma Valley: from FIPA to gigantism and back'*

Albert Beckers is Chief of the Department of Endocrinology at the University Hospital Centre and Professor at the University of Liège, Belgium. He is well known for characterising familial isolated pituitary adenomas (FIPA) and a newly described paediatric syndrome, X-linked acrogigantism (X-LAG). Professor Beckers describes the exploration of the diseases caused by abnormal neuroendocrine function as his passion, and says being able to work at something that inspires and interests him is one of the great blessings of life.



**Jason Carroll**  
European Journal of Endocrinology Prize Lecturer  
*'Understanding oestrogen receptor gene regulation in breast cancer'*

After embarking on his career in his native Australia, and following a period in the USA, Jason Carroll now runs his own group at Cancer Research UK, the Cambridge Research Institute and the University of Cambridge. He is interested in understanding how the oestrogen receptor causes gene transcription and how this contributes to breast cancer progression, as well as determining how breast cancer therapies work and what happens if they fail. By identifying critical determinants of tumour progression, he aims to develop novel therapies.



**Felipe Casanueva**  
European Hormone Medal Lecturer  
*'Male hypogonadism and obesity: how to differentiate cause and consequence'*

Felipe Casanueva is Professor of Medicine at the University of Santiago de Compostela in Spain. As one of the world leaders in pituitary pathophysiology and diagnosis and medical treatment of pituitary diseases, Professor Casanueva has contributed seminal works in the diagnosis and treatment of hypopituitarism and acromegaly. He is also an internationally recognised authority on clinical practice in obesity, and his fascinating lecture at ECE 2016 examined the links between weight gain and gonadal function in men.



**Wiebke Arlt**  
Clinical Endocrinology Trust Award Lecturer  
*'Steroid metabolomics: principles and application in adrenal disease'*

Wiebke Arlt is the William Withering Chair of Medicine and Director of the Institute of Metabolism and Systems Research at the University of Birmingham. She leads the adrenal and reproductive endocrine specialist services at Birmingham's Queen Elizabeth Hospital. Professor Arlt's research into steroid biology and biochemistry and their translational applications has a special focus on androgens, both in the context of rare adrenal and gonadal disorders and in diseases associated with adverse metabolic risk, such as polycystic ovary syndrome and adrenal incidentaloma.

## Congratulations to all our award winners at ECE 2016



### Young Investigator Award winners

L–R: Katharina Timper (Germany), Nancy Schanze (Germany), Aristides López-Márquez (Spain), Matthias Kroiss (Germany), Tim Korevaar (The Netherlands), Laura Gathercole (UK), Zamira Zuraeva (Russia), Francesca Marta Elli (Italy), Stella Bernardi (Italy), Eylem Cagiltay (Turkey), Katarzyna Siemienowicz (UK), Omeiri Hanin (France).

### Poster Prize winners

Alexandra Bargiota (Greece), Amod Godbole (Germany), Giovanni Lombardi (Italy), Nojan Nejatian (Germany), Marissa Penna-Martinez (Germany), Sonali Shah (Australia), Adriana de Sousa Lages (Portugal), Carles Zafon (Spain).

## ECE 2016 welcomes Syrian specialists



In 2015, the German Society of Endocrinology (DGE) began a successful campaign to collect donations from its members, to support the professional integration of medical specialist refugees into the local healthcare system.

The aim is to organise and fund introductory and medical terminology courses, and to establish a national networking platform to provide contacts, in parallel with the German job centres. The first group of refugees (eight physicians, three nurses and three medical students) was recently invited to the D.A.CH-Tagung (the

joint meeting of German, Austrian and Swiss Societies) as well as ECE 2016 in Munich, Germany.

DGE thanks ESE President AJ van der Lely and ESE CEO Helen Gregson (pictured above with our Syrian guests) for generously supporting the initiative. We encourage ESE's Affiliated Societies to follow suit, and target the needs of their colleagues in the field to promote solidarity.

Further information is available from [info@endoscience.de](mailto:info@endoscience.de) (please write 'network medicine' as the subject).

**Martin Reincke**, President, DGE

## Save the Dates!

ESE Summer School on Endocrinology 2016

**31 July–4 August 2016**

Bregenz, Austria

4th European Young Endocrine Scientists Meeting

**22–24 September 2016**

Moscow, Russia

41st Symposium on Hormones and Cell Regulation (ESE)

**5–8 October 2016**

Mont Ste Odile, France

EndoBridge 2016

**20–23 October 2016**

Antalya, Turkey

4th Europit Postgraduate Course

**14–16 November 2016**

Annecy, France

19th ESE Postgraduate Course on Endocrinology, Diabetes and Metabolism

**17–19 November 2016**

Wrocław, Poland

9th ESE Clinical Update

**13–14 January 2017**

Abu Dhabi, UAE

20th ESE Postgraduate Course on Endocrinology, Diabetes and Metabolism

**20–22 April 2017**

Moscow, Russia



19th European Congress of Endocrinology (ECE 2017)

**20–23 May 2017**

Lisbon, Portugal

20th European Congress of Endocrinology (ECE 2018)

**19–22 May 2018**

Barcelona, Spain

### Deadlines:

**30 September 2016**

**ESE Small Meeting Grant**

– application deadline

**30 November 2016**

**ESE Short-Term Fellowship**

– application deadline