Insights into MAnaging Growth for Endocrine Nurses

18-19 October 2018, Marseille, France
An Independent Medical Education Event for Paediatric Nurses
Welcome to IMAGE 2018

Dear Delegate,

Bienvenue à Marseille!

The Insights into MAnaging Growth for Endocrine nurses (IMAGE) 2018 Symposium, organised by Springer HealthcareME and EXCEMED, provides high-quality, practical clinical training for nurses involved in paediatric endocrinology practice.

This year’s symposium focuses on paediatric thyroid disorders, examining the role of the specialist nurse from presentation to acute and chronic management of these disorders.

Some of the highlights include learning about causes, detection and treatment of hypothyroidism and hyperthyroidism, developing practical strategies to manage challenging situations, and looking at the transition from paediatric to adult endocrine care.

There will be plenary lectures and case studies, followed by plenty of time for discussion, as well as parallel break-out sessions to encourage and facilitate lively debates, with an emphasis on informality, discussion, and exchange of views, with interaction between delegates and faculty.

The IMAGE symposium offers an important opportunity for nurses to be updated on new developments in the field and to share experiences with nurses working in a similar field in different parts of the world. We are delighted to welcome you all here today.

We hope that you enjoy this symposium.

Kate Davies

Chair
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Educational grant

This independent programme is made possible thanks to an educational grant received from Merck KGaA, Darmstadt, Germany.

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Continuing Medical Education

This continuing education activity has been approved by the International Council of Nurses (ICN) for the award of 8.5 International Continuing Nursing Education Credits (ICNECs).

As a member of the Good CME Practice Group, Springer Healthcare IME and EXCEMED create and deliver truly independent and well-respected education in compliance with European CME standards and codes of practice.
Programme

WEDNESDAY 17 OCTOBER

19:30 – 22:30 Welcome dinner

THURSDAY 18 OCTOBER

UPDATE IN PAEDIATRIC THYROID DISEASE, ADHERENCE TO HORMONE THERAPY AND TRANSITIONAL CARE OF GROWTH HORMONE DEFICIENCY

08:55–09:10 Welcome introduction and objectives
Kate Davies and Rachel Reynaud

Session 1: Thyroid disorders

Chairs: Stephen Shalet and Kate Davies

09:10–09:25 Plenary 1 Why children need a thyroid gland
Juliane Léger

09:25–10:05 Plenary 2 Paediatric hypothyroidism
Tim Cheetham

10:05–10:45 Plenary 3 Paediatric hyperthyroidism
Juliane Léger

10:45–11:05 Coffee break
Session 2: Thyroid disorders in practice

11:05–11:45  Breakout group 1
Chairs: Tim Cheetham and Susan Sparrow

i) Nurse case presentation
Lee Martin

ii) Nurse case presentation
Christine Davies

11:45–11:50  Presenters change rooms

11:50–12:30  Breakout group 2
Chairs: Juliane Léger and Martin Savage

i) Nurse case presentation
Kate Davies

ii) Nurse case presentation
Bailie Tabak

12:30–13:30  Lunch
Session 3: Managing challenging situations (I)

Chairs: Rachel Reynaud and Bailie Tabak

13:30–14:10  New techniques to address adherence
John Weinman

14:10–15:00  Challenging situations: planning for the expected
Katie Frost

15:00–15:20  Coffee break

Session 4: Managing challenging situations (II)

Chairs: John Weinman and Kate Davies

15:20–16:20  Challenging situations: preparing for the unexpected
Katie Frost

Overview of day 1

16:20–16:30  Kate Davies
FRIDAY 19 OCTOBER

Session 5: Paediatric and adult thyroid practice

Chairs: Tim Cheetham and Lee Martin

09:10–09:50  A nurse-led thyroid clinic
Susan Sparrow

09:50–10:40  Adult consequences of paediatric thyroid disease
Stephen Shalet

10:40–11:00  Coffee Break

Session 6: Update on transitional care

Chairs: Juliane Léger and Christine Davies

11:00–11:40  Update on transitional care of patients with growth hormone deficiency: reality and challenges
Martin Savage and Stephen Shalet

11:40–11:55  Case presentation
Christelle Tressens

11:55–12:15  Case presentation
Lee Martin

12:15–12:45  Endocrinology quiz
Martin Savage

Overview and closing remarks

12:45–12:55  Kate Davies

12:55  Lunch and close
Venue and location

Conference venue

The meeting and delegate accommodation are at the **RADISSON BLU HOTEL, MARSEILLE VIEUX PORT**.

Radisson Blu Hotel address: **38-40 Quai de Rive Neuve, 13007 Marseille, France**.

Plenary room: **“Thym Romarine”** located on the first floor of the Radisson Blu Hotel.

Airport transfers

Transfers from/to the airport will be provided for all delegates.

Upon arrival at the airport, after passing through luggage claim and customs area, our transfer assistant will be holding a signboard with IMAGE and your name.
Information for delegates

Registration
The registration desk is located in the Thym Romarine meeting room foyer, on the first floor.
The hospitality desk is located in the main hall of the Radisson Blu Hotel, on the ground floor.
Registration will be open from 8.30 to 8.55 on Thursday, 18 October. Pre-registration will also be available on Wednesday, 17 October from 16.30 to 18.30.

Welcome dinner
The welcome dinner will take place on Wednesday, 17 October from 19:30 to 22.30 at Le Quai du 7ème located on the ground floor of the Radisson Blu Hotel.

Conference dinner
The conference dinner will take place on Thursday, 18 October at 20:30 at La Nautique (20 Quai de Rive Neuve, pavillon Flottant de la SNM, 13007 Marseille). Delegates are asked to gather in the hotel lobby at 20:15. The restaurant is 5 minutes walk from the hotel (please see the map for details).

Lunches
Lunch will be served at Le Quai du 7ème restaurant located on the ground floor of the Radisson Blu Hotel. Dedicated signs will direct you to the restaurant.

Luggage
Check-out time is at 12:00. Delegates have the option of storing luggage at the reception following check-out. Please ask at the front desk of the hotel to make arrangements.

Who to contact
If you have any problems or questions during the meeting, please contact valeria.frazzini@meridiano.it (mobile: +39-380 7427269)

CNE Certificate
This continuing education activity has been approved by the International Council of Nurses (ICN) for the award of 8.5 International Continuing Nursing Education Credits (ICNECs). Delegates will receive certificates by post after the symposium.
Organising Committee

Kate Davies

Senior Lecturer in Children’s Nursing, London Southbank University, London, UK

Kate Davies has been a qualified children’s nurse since 1994, working in general paediatrics, paediatric ICU and neuroscience before specialising in paediatric endocrinology in 2000. During this time she has focused on advancing her education by studying for a BSc (Hons) in Psychology, an MSc in Occupational Psychology and an MSc in Professional Healthcare Research and, building on her clinical skills, including Non-Medical Prescribing. She is also a qualified children’s advanced nurse practitioner, and a nurse teacher.

Davies has become well-known internationally in the paediatric endocrinology field, having presented and published widely. Her experience as a clinical nurse specialist in paediatric endocrinology has led her to work with some of the world’s leading experts across several London NHS Trusts. She has sub-specialised in growth and puberty, neuroendocrine late effects of childhood brain tumours, adrenal disorders and disorders of sex development.

Davies has always been passionate about educating staff and students and in 2015 joined London South Bank University, London, UK, the leading University in the UK for training children’s nurses, as a senior lecturer in Children’s Nursing. She launched a new BSc/MSc module, ‘Principles of care for the child and young person in endocrinology’ in 2017, and has run two successful intakes. She is also the course director for the MSc/PGDip Children’s Advanced Nurse Practitioner programme.

Martin Savage

Emeritus Professor of Paediatric Endocrinology at William Harvey Research Institute, Barts and the London School of Medicine & Dentistry, London, UK

Martin Savage is emeritus professor of paediatric endocrinology at Barts and the London School of Medicine & Dentistry in London. He was head of the Paediatric Endocrine Unit at Barts and the London School of Medicine from 1982 to 2007. He is a clinician, with both clinical and research interests in growth disorders, specifically those with abnormalities in the growth hormone (GH)-IGF-1 axis. His main research field has been the phenotypetypegenotype relationships of GH-IGF-1 axis defects, and he published the first human case of an IGF-1 gene defect in the New England Journal of Medicine in 1996. Other clinical interests are Cushing’s syndrome and growth in chronic inflammatory diseases.

Professor Savage was general secretary of the European Society for Paediatric Endocrinology (ESPE) from 1997 to 2004. He has lectured in 59 countries worldwide and has published over 440 original articles, reviews, textbook chapters and books. In 2007, he was awarded the ESPE Andrea Prader Prize for contributions to paediatric endocrinology, and in 2018 he received a Visionary Award from the American Human Growth Foundation. He continues to lecture nationally and internationally.
Speaker Biographies

Rachel Reynaud

Professor of Paediatrics, Aix Marseille Université; Head of the Paediatric Endocrinology and Diabetology Unit, APHM Hôpital de la Timone, Marseille.

Rachel Reynaud trained at the Jean Monnet Medical School, Saint-Étienne. She then specialised in paediatrics at the Marseille Medical School where she obtained her MD degree. Professor Reynaud completed her PhD in Neurosciences at the Université de la Méditerranée and then went on to train with the group of Jean Jacque Lebrun at McGill University, Quebec, Canada.

She is currently professor of paediatrics at Aix Marseille Université Diabetes CA, Marseille; head of the Paediatric Endocrinology and Diabetology Unit at the Timone University Children's Hospital, Marseille; and paediatric coordinator at the Rare Disease Reference Center for Pituitary Diseases (HYPO) and the Center for Severe Child Obesity Diseases (CSO PACA). In her department of paediatric endocrinology and diabetology, their interdisciplinary education team includes paediatric diabetologists, diabetes specialist nurse educators, dieticians, a psychologist and a social worker, and they care for more than 400 children with type 1 diabetes. They provide both conventional diabetes treatment and advances in diabetes management and technology, as well as hospital-based home care.

Professor Reynaud's clinical research interests focus on endocrine disorders, diabetes and educational methods, and she is a member of a clinical research network on genetically determined pituitary hormone deficiency (GENHYPOPIT). She has contributed to over 130 publications as an author including the Journal of Health Psychology, Recherche en soins infirmiers, The Diabetes Educator, Archives de Pédiatrie, Diabetes Care and The Lancet Diabetes & Endocrinology.

Juliane Léger

Professor, Department of Paediatric Endocrinology and Diabetes and Head, Reference Centre for Rare Endocrine Growth Diseases, Robert Debré University Hospital, Paris, France.

Juliane Léger is head of the French National Reference Centre of Growth and Development Endocrine Disorders, Department of Paediatric Endocrinology and Diabetes at Robert Debré University Hospital in Paris, France.

Professor Léger has been, and continues to be, an active member of both the European Society of Paediatric Endocrinology and the Endocrine Society, and is on the Editorial Board for the European Journal of Endocrinology. Her research interests include thyroid, pituitary and pubertal diseases, and the management and epidemiology of rare growth endocrine disorders.
Tim Cheetham

Paediatric Consultant, The Newcastle-upon-Tyne Hospitals, UK

Tim Cheetham is a paediatric consultant and university reader based in Newcastle-upon-Tyne, UK, with a particular interest in paediatric thyroid disease, and is a member of the National Institute for Health and Care Excellence (NICE) thyroid guideline committee. He had a major role in the British Paediatric Surveillance Unit (BPSU) congenital hypothyroidism (CHT) study, contributed to the European Society for Paediatric Endocrinology (ESPE) congenital hypothyroidism consensus document and is chair of the UK Advisory Committee for congenital hypothyroidism.

Cheetham is chief investigator for two UK multicentre therapeutic trials in paediatric thyrotoxicosis, one of which is funded by the Medical Research Council. He has a broad clinical practice and is involved in a range of other trials and studies in areas that include Duchenne muscular dystrophy, growth in preterm infants, growth in young people with mitochondrial disease, diabetes and transition. Cheetham was formerly BSPED chair (until 2016) and is an associate Editor of Archives of Disease in Childhood.

Lee Martin

Clinical Nurse Specialist in Paediatric Endocrinology, Barts Health NHS Trust, London, UK

Lee Martin qualified in nursing at Monash University, Melbourne, Australia in 1995 and completed his post-graduate Diploma in Children’s Nursing at London’s City University in 2001. He has been with the Department of Paediatric Endocrinology at Barts Health NHS Trust since 2004 and completed both a Degree and Masters level course in the field of Paediatric Endocrinology at Keele University in 2006, and 2013, respectively.

Martin is also a Non-Medical Prescriber. He is an active member of the national paediatric endocrine nursing community, as both a member of the Royal College of Nursing (RCN) Children and Young People’s (CYP) Specialist Care forum, and the British Society of Paediatric Endocrinology (BSPED).
Christine Davies

Paediatric Endocrine Specialist Nurse, Children's Hospital, Cardiff, Wales, UK

Christine Davies completed her general and then children's nurse training at the University Hospital of Wales in Cardiff in 1985, and 1989, respectively. Davies worked for 12 years in the acute paediatric sector as a senior staff nurse. She made the move into the community setting firstly as a district nurse, followed by a school health nurse and later as a nurse educator. Davies completed her first degree in specialist community public health nursing in 2004, taking up the role as senior school health practice teacher, with lead responsibility for growth in the community.

Davies completed her PGCE in 2008 and became an associate lecturer in specialist community public health nursing at the University of Glamorgan. She returned to the hospital setting to take up the position of paediatric endocrine specialist nurse in 2010 and also obtained an MSc in Child Health. Davies is currently the lead paediatric endocrine specialist nurse at the Children's Hospital for Wales.

Bailie Tabak

Clinical Research Nurse, Endocrine Clinic, The Hospital for Sick Children, Toronto, Ontario, Canada

Bailie Tabak graduated with a Bachelor of Nursing degree in 1996 from the University of Manitoba, Winnipeg, Canada. Throughout her career she has specialised in paediatrics working as a travel nurse in the USA and Canada with children in the following areas: multi-organ transplant, medical/surgical, general paediatrics and endocrinology. For the last five and a half years she has worked in the endocrinology clinic at The Hospital for Sick Children. She is the working case manager coordinating care within the multidisciplinary team for patients with growth hormone disorders and thyroid carcinomas. Her passion is educating patients and families. Tabak is an active member, and is the current treasurer of the Canadian Paediatric Endocrine Nurses group (CPEN/ICEP).
John Weinman

Professor of Psychology, Kings College London, London, UK

John Weinman is professor of psychology as applied to medicines in the School of Cancer & Pharmaceutical Sciences, and emeritus professor at the Institute of Psychiatry, Psychology & Neuroscience in King’s College London.

The main focus of his research has been on the ways in which patients’ beliefs about their illness and treatment affect self-regulation and self-management across a wide range of physical health problems. Increasingly, part of this work is concerned with understanding the reasons underlying non-adherence to treatment, and in developing effective interventions for improving use of medicines and other recommended treatments. This has also resulted in the development of widely-used measures and cognitively-based interventions, which have been shown to be effective in improving adherence to treatment, recovery and quality of life.

Weinman has taught undergraduate and postgraduate medical, pharmacy and psychology students, and is the author of many books and papers in peer review journals. He has been instrumental in developing health psychology as a discipline and a profession in the UK and Europe, and was the founding editor of international journal Psychology & Health. He currently holds visiting professorships in UCL, Denmark and Ireland, and was awarded a lifetime achievement award and an honorary fellowship by the British Psychological Society. Weinman is a fellow of the European Health Psychology Society, the American Academy of Behavioral Medicine Research and the Academy of Social Sciences.

Katie Frost

Learning and Professional Development Coach

Katie is a professional coach and workshop facilitator. She specialises in helping people work with assertive communication skills in the workplace and manage conflict situations with confidence.

Taking a psychologically informed approach, she enjoys working with hard to reach young people to support them achieve their goals and potential. Katie is interested in addressing the emotional barriers that can get in the way of people making positive changes in their lives.

Katie is passionate about learning and currently completing her Diploma in Coaching at the University of Cambridge. Trained in motivational interviewing she practices these techniques within her coaching practice and is qualified in a range of psychometric tools.
Susan Sparrow
Paediatric Endocrine Clinical Nurse Specialist, Cambridge University NHS Foundation Trust, Cambridge, UK

Susan Sparrow is a paediatric endocrine clinical nurse specialist at Cambridge University NHS Foundation Trust. She completed her training as a sick children’s nurse in 1994, and gained a degree in children’s nursing in 2002. Having worked as a staff nurse in a range of diverse roles, including specialised paediatric surgery, neuroscience and paediatric intensive care, in 2002 she became a paediatric endocrine nurse. She is part of a team of four paediatric endocrine nurses caring for children with endocrine disorders across East Anglia in England, providing specialised care for children and their families.

Sparrow has helped develop the service in Cambridge and has implemented a nurse-led Thyroid Clinic, where she, and other nurses, play an important role in the endocrine clinics, and other specialised services, such as oncology, congenital adrenal hyperplasia, genetics, disorders of sex development and transition. In her role she also performs dynamic testing, initiates growth hormone treatment, provides sick day rule training for adrenal insufficiency and does bone age reporting.

Stephen Shalet
Emeritus Professor of Endocrinology, Christie Hospital, and University of Manchester, Manchester, UK

Stephen Shalet completed a BSc in Physiology at the University of London and qualified in medicine at the Royal London Hospital. Hospital medical training posts in London and Bristol were followed by an appointment as research fellow in endocrinology at the Christie Hospital, Manchester.

His extensive research interests include the late endocrine effects following treatment of cancer, pituitary disorders and abnormalities of growth hormone secretion. He is the author or co-author of over 500 articles and more than 200 of these are related to clinical disorders of the growth hormone (GH)-IGF-1 axis and therapeutic use of GH therapy.

Previous positions and professional activities include chairman of the Strategic Planning Committee of the European Society of Paediatric Endocrinology, co-editor of the first edition of the Oxford Textbook of Endocrinology, and member of the Council of the Society for Endocrinology and the Specialist Advisory Committee in Endocrinology and Diabetes. Professor Shalet has served as president of the Endocrine Section of the Royal Society of Medicine, and as member of the Council of the European Society of Paediatric Endocrinology, and of the Clinical Practice Committee of the Society for Endocrinology. Previously he was the chairman of the Specialist Training Committee in Diabetes and Endocrinology for the North West Region.
Christelle Tressens

Pediatric Nurse, Hôpital des Enfants, Toulouse, France

Christelle Tressens is a paediatric nurse working in the Consultations Department at Toulouse Children's Hospital. She has been a qualified nurse for 16 years; six as a paediatric nurse, in addition to specialising in growth hormones for over four years.

For the past four years, with a team of paediatrician endocrinologists and nurses, Tressens and her group have set up a paediatric therapeutic educational project. In 2017, they studied approximately 1250 children and teenagers treated with growth hormone. The objective of the study and her work is to improve the care of children treated with growth hormone and to facilitate better adherence to treatment.
Aims and learning objectives

Session 1: Thyroid disorders

Session overview

The function of the thyroid gland is of key importance for the normal pre-natal and post-natal growth of the child and for intellectual development. For this reason, hypothyroidism is detected at birth by national neonatal screening programmes in most countries. The physiology of the thyroid gland will be explained in terms relevant to clinical practice. The causes and effects of paediatric hypothyroidism, both congenital and acquired, will be clearly explained by Dr Tim Cheetham, Associate Professor of paediatric endocrinology in Newcastle, UK, who is highly experienced in this field. Dr Cheetham will discuss diagnosis and the importance of treatment, which needs to be started as early as possible in congenital hypothyroidism.

Professor Juliane Léger, from the Hôpital Robert Debré in Paris, will discuss the causes and presentations of hyperthyroidism. Prof Léger has lectured internationally on this topic and will explain the importance of early recognition of hyperthyroidism, which is relatively rare in children compared with adolescents and adults, and discuss its diagnosis, prognosis and treatment. Early treatment is essential to prevent weight loss and hyperactivity, and to maintain good academic progress at school.

Learning objectives

At the end of the session the delegates will understand:

- Pre-natal thyroid function
- Post-natal thyroid function
- Diagnosis of congenital hypothyroidism
- Diagnosis of acquired autoimmune hypothyroidism
- Treatment strategy of hypothyroidism
- Causes of hyperthyroidism
- Presentations of hyperthyroidism
- Treatment strategy and therapeutic options in hyperthyroidism
Session 2. Thyroid disorders in practice

Session overview
In these parallel breakout sessions, cases of hypothyroidism and hyperthyroidism will be presented by both nurses and endocrinologists. This will provide the opportunity for nurses to share their personal experience in the presentation, diagnosis and management of these important paediatric disorders.

Learning objectives
At the end of the session the delegates will understand:

- Challenges for nurses in the diagnosis and management of thyroid disorders
- Treatment of thyroid disorders
- Different clinical presentations of hypo- and hyperthyroidism
- Questions they can expect from families and patients about thyroid disorders in children

Session 3: Managing challenging situations (I)

Session overview
Paediatric endocrinology nurses are frequently put in difficult situations regarding patient care and their interaction with patients and families. In this session, the first topic will be adherence to growth hormone (GH) therapy. There is overwhelming evidence that poor adherence is common, i.e., patients frequently miss injections. There are also strong data linking poor GH adherence with poor clinical response to GH therapy. Patients with poor adherence grow more slowly than those with good adherence and have worse long-term outcome from GH therapy. Professor John Weinman, a psychologist from King's College London, will discuss new ways of looking at adherence that are relevant to the roles of specialist nurses.

In the second part of the session, Katie Frost, an experienced professional coach, will discuss how nurses can develop and learn techniques to deal with difficult situations that may occur, and they may be faced with, in their contact with families, particularly related to poor adherence to GH therapy.

Learning objectives
At the end of the session the delegates will understand:

- Why adherence to GH therapy is a problem
- Why patients adhere poorly
- How nurses can address this problem effectively
- How adherence can be improved
- How to prepare for difficult and potentially confrontational issues
- How to act professionally if provoked
Session 4: Managing challenging situations (II)

Session overview
Katie Frost will explain and discuss techniques for coping with unexpected situations that may occur. Difficult patient contact may be threatening and potentially confrontational, and nurses in a specialist role need to be equipped to predict these situations and to act professionally and effectively to defuse them and reach a positive outcome, maintaining good professional relations with the family and patients.

Learning objectives
At the end of the session the delegates will understand:

- How to prepare for difficult situations that may occur related to GH therapy
- How to defuse a challenging situation with an angry patient or family
- How to remain calm and professional when provoked
- How to make use of motivational interviewing techniques
- How to avoid threatening and judgemental responses in challenging situations

Session 5: Paediatric and adult thyroid practice

Session overview
This session consists of a presentation by a specialist nurse in Cambridge, UK, on her experience of running a nurse-led thyroid clinic for children. The role of the nurse will be described in the context of the increased responsibilities given to nurses, and the breadth of these responsibilities will be discussed. Challenges will be debated and the application of these roles to nurses in different countries and cultures will be discussed. In the second talk, Professor Stephen Shalet, an adult endocrinologist from the University of Manchester, UK, will describe the adult outcomes of paediatric thyroid disorders. This will include both hypo- and hyperthyroidism. The patients and diagnoses that will require adult endocrine care will be identified, and the complications of thyroid disease presenting in childhood that persist into adult life will be discussed.

Learning objectives
At the end of the session the delegates will understand:

- How a nurse-led clinic can work
- Shortcomings and advantages of such a clinic
- Nurse prescribing
- Decisions related to changes of therapy
- Organisation and frequency of appointments, etc.
- Key messages about long-standing thyroid disease starting in the paediatric age range
- Transitional strategy for chronic thyroid patients
- Hospital surveillance or GP referral
- Age and organisation of transitional care
Session 6: Update on transitional care for patients with GH deficiency

Session overview

Transitional care of GH deficient patients as they reach the end of adolescence is a highly challenging topic. Transition from paediatric to adult care should be straightforward, but is in reality full of difficulties, to the extent that it is only practised successfully in a small number of university centres. Paediatric and adult endocrinologists need to collaborate and respect each other in order for transitional care to be successful for the family and the patients. Professors Savage and Shalet will discuss the paediatric and adult perspectives on transitional care of the patient with ongoing severe GH deficiency. Case presentations from nurses sharing their experience of transitional care will complement the discussion. The session will finish with a general multiple-choice quiz covering all the topics in the symposium.

Learning objectives

At the end of the session the delegates will understand:

- Which patients need transitional care
- When and how they should be transitioned
- When and how their GH secretion should be retested
- How a joint paediatric–adult transitional service can be run effectively
- The main reasons that patients are often poorly rather than well transitioned
- The roles and responsibilities of nurses in the transitional process