



# Pediatric Endocrinology Nursing Society 2019 National Conference

April 25-28, 2019

Hyatt Regency Long Beach • Long Beach, California

## Program

### Target Audience

The conference is designed for nurses and other health care professionals interested in recent developments in the field of pediatric endocrinology nursing, including pediatric diabetes.

### Program Goals

It is PENS' goal to promote high quality endocrinology nursing practice through this educational offering. Conference participants receive the latest information in basic to advanced practice, experience and research as demonstrated by pediatric endocrinologists and pediatric endocrinology nurses.

### Program Objectives

- Develop new skills to improve educational and patient outcomes
- Provide educational opportunities in pediatric endocrinology for nurses and others with expertise in the area
- Promote the pursuit of nursing practice and research through a research presentation and poster session
- Provide educational opportunities in the management and treatment of selected endocrine disorders
- Provide direction for understanding health care changes
- Objectives for each session are listed within the schedule

### PENS Conference Planning Committee

Kelly D. DeGrote, RN, BSN, Chair

Sheri L. Luke, MSN, FNP-C, Co-Chair

Mary Burr, DNP, CPNP-PC

Karen Engel, RNC

Jane Torkelson, MS, RN

Leigh Pughe, RN, MS, CPNP

Cheryl Switzer, MSN, RN, CPNP, CDE, Board Liaison

### Accreditation

Application has been made to the Greater Kansas City Chapter of the American Society for Pain Management Nursing, an approved provider of continuing nursing education by the Kansas State Board of Nursing. Kansas State Board of Nursing provider number LT0279-0412.

The above application will include approval of Advanced Pharmacology contact hours for APNs. To receive contact hours for this conference, participants must complete the online evaluation.

### **Networking**

The opportunity to develop and continue relationships with your colleagues through networking is one of the key benefits of attending the PENS Conference. Networking offers many tangible benefits to conference participants, including, but not limited to, validating your experience in providing nursing care and developing a better understanding of your practice and your role in care delivery by learning from others who are dealing with similar circumstances, solving the same problems and confronting the same issues. Take advantage of this national gathering of pediatric endocrinology nurses to learn more about national issues and trends.

### **Posters**

PENS is providing a venue for meeting attendees to view and discuss participants' poster presentations on Thursday evening. Visit with the poster presenters and learn about current research that will affect your clinical practice!

# Thursday, April 25, 2019

## Time

12:30 p.m. - 4:30 p.m.

4.5 Contact Hours\*

## Presentation/Event

### Pre-Conference Workshop:

#### ***Mastering the Skills of Appraising Research Evidence: What Do We Know about Transitioning Our Endocrinology Patients from Pediatric to Adult Care?***

During this workshop, we will identify and discuss real, everyday clinical problems for pediatric endocrine patients and nurses. To take on these problems, we will practice hands-on skills in evidence based practice, learning how to locate, evaluate, and bring best practices to your patients. Use this opportunity to become a leader in your institution! Re-visit or expand your EBP skills to excel in your annual evaluation criteria and to help your organization meet the Magnet goal of transformational leadership.

## Presenter(s)

Terri Lipman, PhD, CRNP, FAAN  
Sharron Close, PhD, MS, CPNP-PC, FAAN  
Carol Howe, PhD, RN, CDE

12:30 p.m. - 4:30 p.m.

4.5 Contact Hours\*

### Pre-Conference Workshop:

#### ***T1D & Me Program: Learn about an Educational Resource for Children with T1 and Their Caregivers***

Being diagnosed with type 1 diabetes may be overwhelming at times. Even when providers do their best to explain the diagnosis and treatments, many young patients and their parents are left wondering how they will be able to successfully manage living with the disease. Families of recently diagnosed children are mindful of keeping blood sugar levels in range, coping with blood testing and injections, deciding on which foods to eat, and just managing everyday life. In many cases, the learning curve can feel overwhelming and leave the families with "information overload".

To help with this problem, the T1D and Me Program has been developed by Novo Nordisk in partnership with JDRF. Using the proven Conversation Map® model, the program aims to find new and better ways to impart knowledge and build confidence in the early stages of life after diagnosis. Designed with group facilitation in mind, the program has been granted a favorable review by the AADE and can be customized to work in any pediatric diabetes treatment setting. Join this workshop to be trained on implementation for your center, and to order your free facilitation kit.

4:30 p.m. - 5:30 p.m.

### **New Member/First Time Attendee Orientation & Past Presidents Reception**

5:30 p.m. - 7:30 p.m.

**Welcome Reception in Exhibit Hall**  
*Beverages and Appetizers Provided*

## Friday, April 26, 2019

**Time** **Presentation/Event** **Presenter(s)**

7:30 a.m. - 8:00 a.m.

Breakfast  
*Breakfast Buffet Provided*

8:00 a.m. - 9:00 a.m.  
*1.2 Contact Hours\**

**Keynote Address**  
***Sugar Surfing Concepts (Part 1)***

Stephen Ponder, MD, FAAP, CDE

This presentation will cover the following:

- Compare and contrast static versus dynamic diabetes self care decision making
- Visual interpretation of trending BG data: the six basic features of a CGM trendline
- How to assign significance to trending BG data
- How to perform, practice, and refine basic Sugar Surfing models

9:00 a.m. - 10:00 a.m.  
*1.2 Contact Hours\**

**General Session 1**  
***Differences in Sexual Development: Physical, Psychosocial, and Ethical Issues***

Terri Lipman, PhD, CRNP, FAAN

The study of sexual differentiation has undergone dramatic changes. Advances in knowledge of genetics and hormonal regulation have expanded the understanding of Differences in Sexual Differentiation (DSD). More importantly, societal perspectives have markedly altered, (1) the perception of DSD (from a DISORDER to a DIFFERENCE), and, (2) the decision making power related to sex assignment, surgery etc. from the medical team to the parent/patient. The purpose of this presentation is to update PENS nurses on research related to DSD and give them the opportunity to ponder ethical decisions from the perspective of the patient and parent. This interactive session will present a complex, fascinating topic, discuss the controversies, and provide PENS nurses with the tools to advocate for patients and parents.

10:00 a.m. - 10:30 a.m.

**Refreshment Break in Exhibit Hall**  
*Coffee, Tea, Water and Soft Drinks Provided*

# Friday, April 26, 2019

Time	Presentation/Event	Presenter(s)
10:30 a.m. - 11:30 a.m. <i>1.2 Contact Hours*</i>	<b>General Session 2</b> <b><i>Using the Clinical Lab: Practical Pearls for the Pediatric Practitioner</i></b> In this presentation by a pediatric endocrinologist who now works as a clinical laboratory director, attendees will learn practical tips on how to work with their clinical lab to ensure the best possible outcome for their patients. Interesting, true-life cases will be used to illustrate some of the key clinical learning points. We'll answer questions such as, "How do I make sure the right test gets done for my patient?", "What are my options if the lab says there's not enough sample to do the test?", or "What can I do if the results don't seem to fit my patient's clinical picture?". We'll also discuss special considerations for those involved in clinical research, and what changes in the regulatory environment may affect clinical and research practice.	Jon Nakamoto, MD, PhD
11:30 a.m. - 12:30 p.m. <i>1.2 Contact Hours*</i>	<b>General Session 3</b> <b><i>Basics of Genetics</i></b> The presenter will provide an overview of the basics of genetics, which will include the difference between DNA, genes, and chromosomes. We will cover various types of mutations, such as deletions, duplications, missense and nonsense mutations, as well as the five types of classifications, from Pathogenic to Benign. We will also cover various types of popular technology used to detect different types of mutations. Other topics will include inheritance patterns, such as autosomal dominant and recessive, and X-linked and how it relates to diseases. The presenter will also discuss the difference between clinical testing and consumer genetic testing such as through companies like 23andMe.	Mingshu Dong, MS, LCGC
12:30 p.m. - 2:00 p.m.	<b>Lunch with Exhibitors</b> <b><i>Boxed Lunches Provided</i></b>	

# Friday, April 26, 2019

## Time

2:00 p.m. - 3:00 p.m.

**1.2 Contact Hours\***

## Presentation/Event

### Concurrent Session 1

#### **1A: ENDO Case Studies**

Case Study 1: Not Your Average Turners

Discuss case, presentation, evaluation, and treatment options. This is not your typical Turner Syndrome. How AND when should this patient be treated? Should we treat with growth hormone, hormone replacement, or pubertal suppression? Participants will have the opportunity to weigh in!

Case Study 2: Exploring the Mystery of 22q Deletion Syndrome

The presenter will discuss the case of a young girl diagnosed with 22q Deletion Syndrome and many of the common issues seen in this syndrome. With more affordable and accessible genetic testing, we are seeing more individuals diagnosed with 22q Deletion syndrome. Without more knowledge about the diagnosis and the co-morbidities associated with it, it may be difficult to manage affected patients.

#### **1B: (ALL) Advanced Sugar Surfing (Part 2)**

This presentation will cover the following:

- How to apply dynamic management principles to real-life situations
- How to learn effective diabetes self-management from problem-based examples (e.g., food, activity, stress)

## Presenter(s)

Barb Lightner, APRN-CNP, CDE  
Terri Luetjen, MS, RN, CPNP, CCRC

Stephen Ponder, MD, FAAP, CDE

3:00 p.m. - 3:30 p.m.

### Refreshment Break in Exhibit Hall

*Coffee, Tea, Water and Soft Drinks Provided*

# Friday, April 26, 2019

Time	Presentation/Event	Presenter(s)
3:30 p.m. - 4:30 p.m. 1.2 Contact Hours*	<b>Concurrent Session 2</b>  <b>2A: Insights into McCune Albright Syndrome: A Complex, Rare Disease with Individual Presentations</b> The presenter will provide an overview of McCune Albright Syndrome. Since MAS is a rare disease, it is important to be knowledgeable about this disease and its management, as any given practice is likely to encounter at least a few patients (perhaps more!) with this disease.  <b>2B: Coding and Billing: The Link between Documentation and Reimbursement Potential</b> In the presence of rising health care costs, it is critical for Advanced Practice Providers (APP) to be able to describe the financial impact of their role. Documentation of the patient care provided has been a long-standing component of communication among the healthcare team. With the expansion of APPs billing for the care they provide, it is essential to have an understanding of the impact this documentation of patient care has on billing and reimbursement. This presenter will provide an overview of the components in documentation that are used to determine the level of service for care provided. This content will assist APPs in accurately matching documentation with the level of service, allowing them to maximize billing and potentially reimbursement for the care they provide.  <b>2C: Managing Type 1 Diabetes in the Young Child: Using Tools New and Old</b> As the incidence of type 1 diabetes in young children is increasing in the United States, diabetes providers are faced with management of these young children in larger numbers. Younger children need more daily care, and management is challenging. Diabetes providers must quickly educate families after diagnosis and then help them as they re-enter the home, work, and daycare environments while safely managing blood sugars. The presenters will provide diabetes practitioners with many cases and examples of creative solutions that can be used in the management of young children with diabetes.	Lori Guthrie, RN-C, BSN, CCRC Jamie Streit, RN, BSN  Marianne Buzby, MSN, CPNP-PC  Melissa Andrews Rearson, MSN, CRNP Meredith Allen, RD, CDE

# Friday, April 26, 2019

Time	Presentation/Event	Presenter(s)
<b>4:40 p.m. - 5:40 p.m.</b> <i>1.2 Contact Hours*</i>	<b>Concurrent Session 3</b>  <b>3A: (ENDO/ADV) <i>The Treatment of Pediatric Obesity: Beyond Lifestyle Modifications</i></b> We will first review the etiologies underlying obesity and how treatment should be tailored based upon the causes. We will then discuss the use of anti-obesity pharmacotherapy (including medication options, off-label use, practical considerations, and costs) and metabolic/bariatric surgery for the treatment of pediatric severe obesity.  <b>3B: <i>How to Deliver a Successful Presentation</i></b>  <b>3C: <i>The Evolution of Diabetes Management: Where We've Been, Where We Are, and Where We Are Going</i></b> This presentation is for anyone from novice to advanced learners interested in diabetes management. The goal of the presentation is to educate the audience about current and future technology to manage insulin-dependent diabetes. In order to understand our current and future management choices, there will be a brief discussion about our past diabetes management options.	<b>Eric Bomberg, MD</b>  <b>Craig Alter, MD</b> <b>Terri Lipman, PhD, CRNP, FAAN</b>  <b>Rebecca Crespi, BA, RN, MSN, CPNP, CDE</b>
<b>5:45 p.m. - 7:15 p.m.</b> <i>1.8 Contact Hours*</i>	<b>Poster Reception</b> <b>Research Posters Presented by Authors</b> <i>Refreshments and Appetizers Provided</i>	
<b>7:30 p.m. - 10:00 p.m.</b>	<b>Networking Night - On Your Own</b>	

# Saturday, April 27, 2019

Time	Presentation/Event	Presenter(s)
8:00 a.m. - 9:00 a.m.	<b>Awards Breakfast</b> <i>Breakfast Buffet Provided</i>	
9:00 a.m. - 10:00 a.m. <b>1.2 Contact Hours*</b>	<b>General Session 4</b> <b><i>The Politics that Influence Pediatric Endocrine Care</i></b> The presenter will include an overview of national trends and federal legislation that impact pediatric endocrine care. Additionally, session attendees will be provided guidance on ways to get involved in grassroots advocacy.	Mandi Cafasso, DNP, RN, CNP
10:00 a.m. - 10:15 a.m.	<b>Refreshment Break</b> <i>Coffee, Tea, Water and Soft Drinks Provided</i>	
10:15 a.m. - 11:15 a.m. <b>1.2 Contact Hours*</b>	<b>General Session 5</b> <b><i>Mystery Cases</i></b>	Craig Alter, MD
11:25 a.m. - 12:25 p.m. <b>1.2 Contact Hours*</b>	<b>Concurrent Session 4</b>  <b>4A: <i>Research Visits with the Prader-Willi Population</i></b> The presenters aim to provide insight into completing research visits with Prader-Willi patients by highlighting the unique characteristics of this population, providing examples of scenarios from previous and current studies, common barriers and challenges, and solutions and recommendations based on this information. The audience may have clinical experience with this population or research with other populations, but have not yet run PWS studies. Recently, numerous PWS studies have started with more in the pipeline, and there is a strong interest from the PWS community. As this area of research continues to expand, clinical staff who are inexperienced with PWS-specific research and are seeking to learn more can benefit from this presentation and become better prepared for studies with this population. The presenters will also leave time for questions and open discussion to further engage participants and provide additional input on this exciting topic.	Brittany Machus, MA, CCRP Sue Kearns, RN, MN

# Saturday, April 27, 2019

Time	Presentation/Event	Presenter(s)
<b>11:25 a.m. - 12:25 p.m.</b> <i>1.2 Contact Hours*</i>	<b>Concurrent Session 4</b>	
	<b>4B: <i>Pediatric Diabetes through a Developmental Lens</i></b> The diagnosis of Type 1 Diabetes is often unexpected and brings change and challenge to the individual and family. It is important to have a developmental approach to care. Case studies will be used to explore challenges to care through the lens of developmental expectations. After presentation of case study(s) participants will explore strategies to assist with improving care. Discussion will focus on lived experience and support of the individual.	<b>Shari Liesch, APNP</b>
	<b>4C: <i>Obesity and Type 2 Diabetes in Youth: How Did We Get Here and What Can We Do about It?</i></b> The presenter will review the prevalence and trends in pediatric obesity and type 2 diabetes, highlighting the growth of these disorders and the potential future impact on the healthcare system. Dr. Bomberg will discuss the multi-factorial causes of obesity and type 2 diabetes in youth, and review how to diagnose these conditions. Finally, Dr. Bomberg will discuss treatment options for obesity and type 2 diabetes in youth (including evidence-based recommendations, the benefits of dietary modification and exercise, and medication options).	<b>Eric Bomberg, MD</b>
<b>12:30 p.m. - 1:45 p.m.</b>	<b>Membership Meeting/Lunch</b> <i>Lunch Buffet Provided</i>	

# Saturday, April 27, 2019

## Time

1:45 p.m. - 2:45 p.m.

1.2 Contact Hours\*

## Presentation/Event

### General Session 6

#### ***Mind the Gap: Transition from Pediatric to Adult Care for Those with Multiple Pituitary Hormone Deficiencies***

Twelve percent of all young people in Australia have chronic health issues, and 90% of these young people are now living into adulthood. Patients with what were once thought of as “pediatric diseases” now live into adulthood. This means that children with complex endocrine conditions such as multiple pituitary hormone deficiency (MPHD) will eventually grow out of a pediatric service and require ongoing care as adults. The presenter will describe transition issues, identify the follow-up required, who will coordinate care, and when it should happen. The presenter will also discuss the challenges regarding different models of care, the difficulties of parents “letting go” and the timing of the move to adult health care services. Transition planning is a challenge for all nurses working with children with complex ongoing health care needs, and the opportunity to share expertise will allow further discussion with participants. The presenter will provide an opportunity for those with experience to share “tips of the trade” that have worked for them, and for all of us to consider the issues that need addressing for a successful transition of care to the adult medical team.

## Presenter(s)

Bin Moore, RN, CNC

2:45 p.m. - 3:00 p.m.

### Refreshment Break

***Coffee, Tea, Water and Soft Drinks Provided***



## Saturday, April 27, 2019

Time	Presentation/Event	Presenter(s)
<b>3:00 p.m. - 4:00 p.m.</b> <b>1.2 Contact Hours*</b>	<b>Concurrent Session 5</b>  <b>5B: <i>Diabetes Case Studies (contd.)</i></b> <i>Case Study 2: From Pakistan to Philadelphia: Managing Newly Diagnosed Diabetes in a Toddler</i> Managing newly diagnosed diabetes in a young toddler is tricky, and when coupled with cultural health perspective differences and behavior challenges, the journey through the first year of diabetes must be guided by a team heralded by patience and creativity.  <b>5C: <i>Writing for Publication</i></b> This presentation will focus on the following objectives: <ul style="list-style-type: none"><li>• Discuss the knowledge and skills necessary for writing for newsletters, journals, and other nursing related publications.</li><li>• Identify a potential topic for publication based on your area of clinical expertise.</li><li>• Identify potential organizational resources within the work setting that can be accessed to achieve your publication goal.</li></ul>	<b>Melissa Andrews Rearson, MSN, CRNP</b> <b>Meredith Allen, RD, CDE</b>          <b>Cecily Betz, PhD, RN, FAAN</b> <b>Maureen Dever, MSN, CRNP, PPCNP-BC, CDE</b>
<b>4:10 p.m. - 5:10 p.m.</b> <b>1.2 Contact Hours*</b>	<b>Concurrent Session 6</b>  <b>6A: (ENDO) <i>Endocrine Case Studies</i></b> <i>Case Study 1: Water, Water, Everywhere, and Not ENOUGH to Drink: A Case of Isolated Diabetes Insipidus then Evolving Pituitary Dysfunction</i> This presentation will include the evaluation of polyuria/polydipsia to lead to a diagnosis of central diabetes insidious, endocrine treatment of diabetes insidious, and then additional evaluation as to the cause of central diabetes insidious. This patient's differential diagnosis includes Langerhans Cell Histiocytosis (LCH), so the	<b>Leigh Pughe, RN, CPNP</b>



# Saturday, April 27, 2019

Time	Presentation/Event	Presenter(s)
	<p><b>6B: Screening for Depression and Eating Disorders in Youth with Diabetes (contd.)</b></p> <p>involves intentional insulin restriction for the purpose of weight loss. Insulin omission is associated with increased risk of ketoacidosis and long-term complications and mortality occurring at younger ages. including retinopathy, nephropathy, vascular disorders and premature death. Early intervention improves prognosis for those with co-occurring eating disorders and type 1 diabetes. Raising awareness among healthcare professionals and utilizing screening tools in practice is crucial for providing appropriate medical, nutritional and psychological care.</p>	
	<p><b>6C: Prader-Willi Syndrome Choking Prevention and Education: A Practice Change</b></p> <p>The presenters will educate participants regarding the risk of choking in the Prader-Willi Syndrome (PWS) population. They will discuss how a quality improvement program can help lead to improving patient outcomes and safety. The presenters will inspire participants to take the information presented back to their own practices while imparting new knowledge and changing current practice.</p>	<p>Amy Moffett, MSN, RN, CPNP Kathryn Anglin, MSN, BSN, RN</p>
5:15 p.m. - 6:15 p.m.	<b>Committee Meetings: Education, Research, Nominations, Conference Planning</b>	
7:00 p.m. - 10:00 p.m.	<b>Evening Event</b>	

# Sunday, April 28, 2019

Time	Presentation/Event	Presenter(s)
7:45 a.m. – 8:00 a.m.	<b>New Member/First-Time Attendee Feedback Session</b> Be first in line for breakfast and provide some feedback to the PENS leadership about your first impressions of the PENS National Conference. This is a roundtable discussion to gather data from new members and first-time attendees.	Board of Directors and Conference Planning Committee
8:00 a.m. - 9:00 a.m. <i>1.2 Contact Hours*</i>	<b>General Session 7 and Breakfast</b> <b><i>Resiliency in Nursing: Exploring Intimate Spaces of Caring</i></b> In the ever changing matrix of health care, the health care provider continually needs to adapt. In helping others, stress may occur. Stress may impact our physical, emotional or spiritual realm. Personal concerns (ailing family members or personal illness) may shadow our ability to provide care. When the joys or storms of life strike, how does one navigate all the emotions attached to care, to not only survive, but thrive? Resiliency, the ability to bounce back despite adversity, is a dynamic process. Resiliency is “individual” and can be fostered. The ability to access resilient-reflective strengths is invaluable, as resiliency and personal health are interconnected. The goal of this session is to explore resiliency, both personally and professionally: Individual resiliency through the 7C’s (Frankowski, et al.) as promoted by the American Academy of Pediatrics through the lens of Adverse Childhood Experiences (ACEs) (Murphy, et al. and Boullier & Blair, 2018). Next, resiliency in nurse leadership will be discussed through exploration of its parts: equanimity (conveying a sense of calm in crisis), optimism (viewing situation with positivity), and perseverance (ability to move forward with courage and energy) (Stagman-Tyrer, D.). Relationships are important in resiliency support and are often forged through caring. Reflecting on individual and collective nurse journeys will encourage participants to embrace the spirit of being an endocrine nurse (Baikie, K. & Wilhelm, K. and Liesch, S.). The oak fought the wind and was broken, the willow bent when it must, and it survived. (Robert Jordan in The Fires of Heaven).	Shari Liesch, APNP

# Sunday, April 28, 2019

Time	Presentation/Event	Presenter(s)
<b>9:00 a.m. - 10:00 a.m.</b> <b>1.2 Contact Hours*</b>	<b>General Session 8</b> <b>Research Oral Presentations</b> <ul style="list-style-type: none"><li>• The Influence of Social Determinants of Health on Family and Self-Management of Type 1 Diabetes in Black Single Parent Families</li><li>• The Impact of Change in Neighborhood Poverty on BMI Trajectory</li><li>• National Survey of Neonatal Growth Measurement Practices</li></ul>	<b>Jennifer Morone, MA-ATR, BS-RN</b> <b>Krista Schroeder, PhD, RN</b> <b>Jan Foote, DNP, ARNP, CPNP</b>
<b>10:00 a.m. - 10:15 a.m.</b>	<b>President's Address</b>	<b>Catherine Flynn, RN, MSN, APRN, CDE</b>
<b>10:15 a.m. - 10:30 a.m.</b>	<b>Refreshment Break</b> <i>Coffee, Tea, Water and Soft Drinks Provided</i>	
<b>10:30 a.m. - 11:30 a.m.</b> <b>1.2 Contact Hours*</b>	<b>General Session 9</b> <b>Osteoporosis in Children: Cases, Workup, and Treatment</b>	<b>Kevin Lewis, DNP, ARNP</b>
<b>11:30 a.m.</b>	<b>Conference Concludes</b>	

*\* Subject to change based upon approval*

*Total number of contact hours applied for is 25.5 (21 for the regular conference plus 4.5 for the pre-conference workshop)*