

Pediatric Endocrinology Nursing Society

Advancing Endocrine and Diabetes Care November 2-5, 2020

# 2020 Virtual Conference

# **Program**

Save the Date

# **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.

# **PENS Conference Planning Committee**

Sheri L. Luke, MSN, FNP-C, Chair Leigh Pughe, RN, MS, CPNP, Vice Chair Jane Torkelson, MS, RN Josie Hong, BSN, RN Christin Morell, RN, BSN Amanda Patterson, BSN, RN Catherine Flynn, RN, MSN, APRN, CDCES, Board Liaison

# Accreditation

This activity was submitted to the Ohio Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation. (OBN-001-91).

# Networking

The opportunity to develop and continue relationships with your colleagues through networking is one of the key benefits of participating in 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. The Conference Planning Committee is working on ways to make this virtual experience as equally as interactive as an in-person event to learn more about national issues and trends.

#### **Posters**

PENS is providing a venue for conference attendees to view and discuss participants' poster presentations. Visit with the poster presenters and learn about current research that will affect your clinical practice during the live sessions!

# Tuesday, November 3, 2020

Time (ALL TIMES ARE EASTERN)

12:00 p.m. – 12:15 p.m.

# 12:15 p.m. – 1:15 p.m. 1.0 Contact Hour\*

# **Presentation/Event**

## Welcome & Opening Remarks

# Keynote Address

## *Laugh to the Top – A Hilarious Guide to Achieving Your Goals*



This highly entertaining, thought-provoking presentation is packed with practical, proven techniques for setting, pursuing, and achieving both professional and personal goals, and will inspire attendees to attack their objectives with renewed vigor, determination, and focus. In his Seven-Step Guide--from Controlling Stress to Identifying a Specific Target to Taking Bold Action--Mack dramatically demonstrates how far diligent baby steps can take you, how to maintain a positive attitude and sense of humor during the direst of circumstances, and how to dissolve that knot of fear when you're venturing into unknown and frightening new territory. The

audience will listen, mesmerized by the message and Mack's magical stage presence, they'll laugh, and they'll learn that nothing can prevent them from making themselves and their organizations the very best that they can be.

# Newborn Screening for Adrenoleukodystrophy: Monitoring for and Treatment of Adrenal Insufficiency

Adrenoleukodystrophy is a peroxisomal disorder with varying clinical presentations, variably affecting the adrenal glands, nervous system, and testicular function. New York State started screening for adrenoleukodystrophy (ALD) on the newborn screening panel on December 30, 2013. Since that time, it has expanded to 14 states, with many states mobilizing efforts to add it to their screening panels after ALD was added to the Recommended Uniform Screening Panel in 2016. Initial experience with early onset adrenal insufficiency led the Pediatric Endocrine Society to publish guidance for monitoring newborn males with ALD, and recent publications have suggested adrenal insufficiency is present in the vast majority of males with ALD.

2:15 p.m. – 2:45 p.m.

1:15 p.m. – 2:15 p.m.

1.0 Contact Hour\*

# **Break/Visit Exhibits**

# **Presenter(s)**

Catherine Flynn, RN, MSN, APRN, CDCES

**Mack Dryden** 

Molly O. Regelmann, MD

# Tuesday, November 3, 2020

Time	Presentation/Event	Presenter(s)
2:45 p.m. – 3:45 p.m. 1.0 Contact Hour*	TransCon Technology: The New Paradigm Shift for the Treatment of Unmet Medical Need – TransCon hGH, TransCon PTH, and TransCon CNP TransCon technology provides the paradigm shift of long-acting medication to achieve unmet medical need. The Phase 3 heiGHt trial demonstrated TransCon hGH had superior efficacy, as well as comparable safety and tolerability to daily growth hormone. It is believed that these results provide a validation of the TransCon technology platform, which forms the basis of the endocrinology pipeline, which includes TransCon PTH for hypoparathyroidism and TransCon CNP for achondroplasia. This presentation will be helpful for practitioners in the field of pediatric endocrinology.	Pisit Pitukcheewanont (Dr. Duke), MD, FAAP
3:45 p.m. – 4:55 p.m.	<ul> <li>Product Theaters</li> <li>3:45 - 4:05 p.m Arbor Pharmaceuticals: Title TBA</li> <li>4:10 - 4:30 p.m Zeris Pharmaceuticals: Title TBA</li> <li>4:35 - 4:55 p.m Companion Medical: Data-Driven MDI Therapy with Smart Insulin Pens for All Ages</li> </ul>	
5:00 p.m. – 6:00 p.m.	New Member/First-Time Attendee Networking	
Wednesday, November 4, 2020		
Time	Presentation/Event	Presenter(s)
2:30 p.m. – 3:30 p.m. 1.0 Contact Hour*	Oral Abstract Presentations Understanding Parental Beliefs and Practices toward Sugar-Sweetened Beverage Consumption in Their Young Children The Influence of Social Determinants of Health on Family and Self-management of Type 1 Diabetes in Black, Single-Parent Families	Angela Northrup, PhD, RN, FNP; Christen Cupples Cooper, EdD, RDN Jennifer Morone, MA-ATR, BS-RN
3:30 p.m. – 4:30 p.m.	Ultragenyx Symposium: Whole Body, Whole Life, Whole Family: X- Linked Hypophosphatemia (XLH), The Effects of a Genetic Bone Disease	Marian Hart, BSN, RN, Clinical Research Nurse Manager, Indiana University School of Medicine
	Recognition, management, and inheritance of X-linked hypophosphatemia (XLH), pedigree analysis, family-centered care, and transitions of care.	
4:30 p.m. – 4:45 p.m.	Break/Visit Exhibits	

# 4:45 p.m. – 5:45 p.m. 1.0 Contact Hour\*

#### 5:45 p.m. – 6:45 p.m. 1.0 Contact Hour\*

# Hypoglycemia Evaluation in the Endocrine Clinic

This session will be interactive and cover the underlying physiology of hypoglycemia, the common causes of hypoglycemia seen in the outpatient department, and the diagnosis and management of some of the more specific disorders.

# Thinking Outside of the Box to Reach into the Community: Using the Internet and Social Media in the Diabetes Center to Connect Families and Provide Education

Over the years, I have worked with a team at our Diabetes Center to try and find ways to connect without patients outside of our usual clinic visits. Diabetes is a difficult condition and families often feel alone in managing day in and day out. I will share with PENS participants ways in which we have successfully reached out to our families in the community where they are by using internet resources such as newly designed web pages, e-newsletters and most importantly social media. I will share my experience with using social media to connect with families in a way that provides connections within the community (families connecting with each other) and also provides timely education--for example Facebook posts for families preparing for a weather emergency TONIGHT! We have worked hard to think outside of the box to find ways to provide information, educational resources, and very welcome positive reassurance to our families and their response has been overwhelming! This session will inspire the listener to think differently about ways that their team can connect with families to disseminate information and to give families a forum to connect with and inspire each other! This type of presentation will be different for PENS participants as it will inspire the listener's creativity and will encourage team members to work together to think through new ways to connect with patients and families.

Paul Thornton, MD

Melissa Rearson, MSN/CRNP

7:30 p.m. –	- 9:30 p.m.
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#### **Evening Event**

#### Thursday, November 5, 2020 Time **Presentation/Event Presenter(s) Blake Palmer, MD** 12:30 p.m. – 1:30 p.m. Urologic Issues in Boys and Girls with CAH 1.0 Contact Hour\* Dr. Palmer will discuss various urologic concerns for children and adolescents diagnosed with CAH. Poster Session 1:30 p.m. – 2:00 p.m. 0.5 Contact Hours\* Posters are available throughout the conference for review. During this session poster presenters will be available to discuss research and answer questions. 2:00 p.m. – 2:30 p.m. **Break/Visit Exhibits** 2:30 p.m. – 3:30 p.m. Shari Liesch, MSN, APNP Diabetes Distress: Overview, Assessment of, and Assessing in 1.0 Contact Hour\* **Clinical Care**

Diabetes distress is about the emotional side of caring for self with diabetes. About one third of youth with diabetes experience diabetes distress (DD) (Fischer, L. et al 2019). This session will define DD, review assessment of DD and risk factors for DD. While DD is best managed in a multidisciplinary fashion, this is not always available. Recent data demonstrates DD can be addressed in the clinic visit (Fischer, 2019). Fischer listed strategies to consider in DD interventions will be reviewed, including:

- Focus on feelings, beliefs, expectations;
- Help gain perspective;
- Help develop a concrete plan; and
- Discuss follow up plan.

Small group discussion using case scenarios will be used as participants practice using DD interventions as outlined above, (Fisher, et al., 2019).

3:30 p.m. – 4:00 p.m.

# Awards & Closing Remarks

# **ON-DEMAND CONTENT**

#### 1.0 Contact Hour\*

#### **Diabetes Case Studies**

*Case Study 1: Medication-Induced Hyperglycemia – Can Acute Pancreatitis Cause Long-Term, Insulin-Dependent Diabetes Mellitus?* 

This case presentation compares two patients with oncologic diagnoses that developed unique secondary diabetes due to peg-aspariginase chemotherapy. Despite varying presentations, both patients likely developed pancreatitis secondary to chemotherapy, resulting in diabetes mellitus with long-term insulin requirements. While steroid-induced diabetes is transient, asparaginase-associated diabetes can be indefinite. Diabetes as a result of pancreatic injury can be difficult to diagnose and challenging to manage. Endocrine NPs are vital in providing follow-up care to patients with unique etiologies of diabetes and must maintain awareness of the potential sequalae that different medications can have on the pancreas. As the incidence of childhood leukemia and lymphoma are on the rise, it is important for PENS nurses to understand how to work with this unique diabetes population in the setting of associated comorbidities. Current research regarding peg-asparaginase-related diabetes is limited, and there are no current guidelines for best practice.

#### Case Study 2: Breakdown in Communication – How Lapse of Teamwork Can Delay Management of T1DM

As one of the 2019 Joint Commission Patient Safety Goals, communication is an imperative pillar to our practice as endocrine providers. The presenters aim to use a case study to highlight the importance of effective collaboration and highlight areas of potential breakdown to prevent patient harm moving forward. While a widely researched topic, this discussion aims to ignite a personal connection to the issue, leading to deeper thought about the provider's home center and ways that they can help improve systems around the diagnosis and management of Diabetes Mellitus. This case study will assist participants to creatively explore ways to educate colleagues and establish trusting relationships that ultimately improve patient outcomes.

*Case Study 3: Water – Is There Really Such a Thing as Too Much?* The presenter will provide two case studies. Case 1 is a patient with polydipsia and a strong family history of DM. Case 2 is a Type 1 DM patient with polydipsia. The presenter will cover the concern for possible Wolfram syndrome, discuss polydipsia and the possibility for DI and how to work-up, review the meaning of labs, and decision making. The presenter will also lead a brief discussion of Wolfram syndrome. Polydipsia is a symptom of not only DM but DI as well, so even those who don't see DM patients will benefit from this discussion.

# The Diabetes Team: What Are We Doing Wrong?

The purpose of this topic is to motivate the participants to think about the utilization of an innovative team when caring for vulnerable children and families – using a randomized controlled study as an exemplar.

Michelle Marowitz, RN, CRNP, PNP; Elizabeth Boyce, RN, CPNP

Michelle Marowitz, RN, CRNP, PNP; Elizabeth Boyce, RN, CPNP

Cheryl Switzer, MSN, RN, CPNP, CDCES; Faith Poprik, RN, MSN, FNP-BC

Terri Lipman, PhD, CRNP, FAAN

#### 1.0 Contact Hour\*

1.0 Contact Hour*	<ul> <li>Writing for Publication</li> <li>This presentation will focus on the following objectives: <ul> <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> </li> </ul>	Cecily Betz, PhD, RN, FAAN Carol Howe, PhD, RN, CDCES, FAAN
1.0 Contact Hour*	Adrenal Insufficiency Emergency Management	Molly Regelmann, MD
1.0 Contact Hour*	<ul> <li>Type 2 Diabetes in Children</li> <li>Dr. de la Torre will cover the following objectives, and more, in his presentation. <ul> <li>Discuss the characteristics of children and adolescents with Type 2 diabetes.</li> <li>Identify who should be screened for pre-diabetes and Type 2 diabetes.</li> <li>Discuss diagnostic criteria for diabetes and the classification of Type 2 diabetes.</li> <li>Identify current treatment goals and options for children and adolescents with Type 2 diabetes.</li> </ul> </li> </ul>	Alejandro de la Torre, MD
1.0 Contact Hour*	Weighing in on Children with Autism: Barriers and Strategies for Successful Weight Management Children on the autism spectrum face numerous daily challenges based on the characteristics associated with autism. This attributes of rigidity, need for routine, and sensory defensiveness often contribute to selective eating patterns and preferences for calorically dense foods. Consequently, the development of persistent abnormal eating behaviors likely contributes to the development of feeding and weight concerns in children with Autism. The prevalence of overweight/obesity in children with autism is between 14.8% and 23 %, and can be as high as 30% for children with behavioral concerns on atypical psychotic medication. Rates are higher than typically developing children. This presentation will address common barriers to successful weight management as identified by parents and providers. Through case presentations, we will brainstorm strategies to address these barriers and discuss intervention to decrease risk for long-term comorbidities, including type 2 Diabetes. Weight management is tricky for many and is even more challenging for children with autism.	Goldie Markowitz, MSN, CRNP; Marianne Buzby, MSN, CRNP
1.0 Contact Hour*	Success in School with Type 1 Diabetes A phrase that I've used often throughout this proposal is "bridging the gap". That's exactly what I want to do herebridge the gap between healthcare provider, parent, school healthcare provider, and ultimately, student, in order to promote success and independence with a chronic condition. I have a unique perspectivenot only as a worker in the school and provider settingsbut also as someone who has lived well with type 1 diabetes for the last 36 years. I can provide scenarios from actual students and families for attendees to brainstorm ideas for how to be a team player in promoting growth and success in families living with type 1 diabetes.	Cassandra Moffitt, BSN, RN, CDCES

1.0 Contact Hour*	Aiding Medical Providers of Teens with Type 1 Diabetes Mellitus (T1DM): Tools to Manage Stress The goals of this session include 1) review a complex case of an adolescent with T1DM with significant non-adherence and mental health issues, 2) provide a framework for understanding similar patient presentations and the impact on those providing medical care, and 3) conduct small group discussion to explore concrete coping strategies for medical providers. Attendees will leave with ideas and strategies to manage daily stress around caring for this population.	Kristine Welsh, MSN, APRN; Julia Price, PhD
1.0 Contact Hour*	Navigating the Growth Hormone Appeal Process: Perspectives by Patient Advocate and Nursing Provide tactics in minimizing denials Promote awareness of growth-impaired children and their inability to obtain medication due to payor exclusions and criteria Utilization of resources pertinent to appeal process. Denials for growth-impaired children are on the rise dramatically due to the PES consensus guidelines; we will discuss current trends and potential solutions to assist the nursing community in gaining access for patient medications.	Fran Waite, RN; Tamara Nenadovich, RN
1.0 Contact Hour*	<ul> <li>Endocrine Overview Part 1</li> <li>This session is geared to the new nurse and will cover Endocrine Basics with an emphasis on: <ul> <li>Hypothalamic-Pituitary Portal System,</li> <li>Pituitary hormone secretion disorders,</li> <li>Overview of normal puberty and associated disorders, and</li> <li>Thyroid hormone secretion function and disorders.</li> </ul> </li> </ul>	Fran Waite, RN
1.0 Contact Hour*	<ul> <li>Endocrine Overview Part 2</li> <li>This session emphasizes Adrenal and Bone Metabolism Disorders and will be of use to both the New and the experienced pediatric endocrine nurse.</li> <li>Adrenal conditions discussed: <ul> <li>Cushing Syndrome</li> <li>Aldosteronism</li> <li>Adrenal androgen excess</li> <li>Feminizing tumors</li> </ul> </li> <li>Bone Metabolism disorders discussed: <ul> <li>Hypoparathyroidism</li> <li>Hyperparathyroidism</li> <li>Pseudohypoparathyroidism</li> <li>Vitamin D disorders</li> <li>Calcium disorders</li> </ul> </li> </ul>	Fran Waite, RN
1.0 Contact Hour*	<b>Growth Failure: Examine Case Studies, Determine Causes, Discuss</b> <b>Solutions</b> Growth failure is a common cause for referral to Pediatric Endocrinology, with a wide variety of etiologies, not always treated with growth hormone. The primary objective of	Linda Steinkrauss, RN, MSN, CPNP

this presentation is to utilize case studies to explore three different causes of growth failure, including pathophysiology that precipitates growth failure, iatrogenic causes of growth failure, and psychosocial obstacles that induce growth failure and prevent appropriate, timely treatment. This presentation, intended for all Pediatric Endocrinology nurses, will include power point and lecture, but a primary educational opportunity will be to allow participation by attendees in small and large group discussion to determine solutions to questions and issues posed throughout the case studies. This session will be a different, fun way to examine growth problems in children and share possible solutions.

# 1.0 Contact Hour\*

1.0 Contact Hour\*

# Writing the Roller Coasters: Writing for Health

Writing is health supportive. It impacts our physical, emotional and cognitive being. Writing letters, notes, journal entries and poetry; writing heals. Writing improves working memory, learning, and coping skills. It improves social/linguistic behaviors and athleticism. Writing connects with emotions and helps with cognitive processing and reorganizing. In rewriting the ending with adapting words; personal meaning is enhanced; a new sense of the experience is discovered. Writing settles feelings that arise from life "challenges." It helps one make sense of the experience, the "whole." Words help one adapt personal meaning. With writing, experiencing and sharing sometimes memories are sparked. New meaning is found, sometimes with a "narrative" attitude. When stories are renewed, hope is fostered by tapping into one's own capacity to make life changes (Berger, R., & McLeod, J., 2006). Power found after life challenges are resiliency supportive. In Writing the Roller Coasters we will explore the benefits of writing for health. Participants will experience the Pennebaker Process. We will discuss the impact and importance of timing in writing. We will discover how writing supports action-orientated self-care. The RES process: Reflective, Expressive and Symbolic processes of poetry therapy will be explored, along with how poetry heals. Participants will participate in a group writing process, which is health supportive.

# **Endocrine Case Studies**

*Case Study 1: COVID-19 & Type 1 diabetes - A Coincidence of Diagnosis* In June 2020, a 19-month old patient was admitted to our Diabetes Center inpatient unit with newly diagnosed type 1 diabetes. At the time of admission, the team found that she also had COVID-19, and her mother, 36 weeks pregnant, also had COVID-19. To complicate things further, the family spoke only Arabic and had recently moved to the United States and had few support systems. This Case Study will outline our comprehensive response to diagnosis, treatment, initial education and management over the first four months after diagnosis.

In this presentation, the learner will be able to:

- Identify the signs and symptoms of type 1 diabetes in a very young child
- Discuss the plan for COVID-19 testing patients who are admitted with newly diagnosed diabetes
- Unravel the complicated threads of managing a virus during a pandemic while initiating treatment for type 1 diabetes.

Case Study 2: Presentation, Evaluation, and Treatment of a 15-year-old Male with Untreated, Simple-Virilizing CAH

#### Shari Liesch, MSN, APNP

Melissa Rearson, MSN, CRNP; Meredith Allen

Katherine Wargo, NP

This case report describes a 15 year old male presenting to an outpatient pediatric endocrinology clinic for evaluation for short stature. Short stature refers to height more than two standard deviations below the mean for a child's age and sex and also includes children who are more than two standard deviations below mid-parental target height. Referral for short stature is common, and evaluation includes screening for pathological causes of growth failure and genetic patterns of growth and puberty. Endocrine causes of short stature include growth hormone deficiency, thyroid disease, and adrenal disorders. Height is also largely influenced by timing and pace of puberty. Children who have precocious puberty and adrenarche have an attenuated growth spurt which can result in short stature. Congenital Adrenal Hyperplasia (CAH) refers to a group of inherited disorders caused by an enzyme deficiency, most commonly 21-hydroxylase deficiency. Patients with 21-hydroxylase deficiency are unable to produce normal amounts of cortisol, so their cortisol synthesis pathway is shunted towards androgen production. Early and excessive androgen production leads to premature epiphyseal fusion and consequential short stature. The following case will discuss the presentation, evaluation, and management of untreated CAH in a teenage male.

#### Jennifer Seekford, APRN

*Case Study 3: Variable Presentation of Hypophosphatasia among Two Siblings* I would like to discuss hypophosphatasia, an extremely rare metabolic bone disease that is rarely seen in a pediatric endocrine clinic and discuss treatment that had only been available for the past few years. I will present a case study about a 13 year old male who presented to my clinic with short stature. Baseline labs were completed and revealed a low alkaline phosphatase, confirmed on repeat testing, serum phosphorus, calcium, PTH, as well as peak growth hormone after stimulation with arginine and clonidine were all normal. During that same time, his 2 year old brother was seen by multiple dentist for early loss of dentition. Labs obtained by his dentist that revealed a low alkaline phosphatase in his brother as well. Genetic testing was completed on both children and results were consistent with autosomal dominant hypophosphatasia. Both children will be starting treatment with Asfotase Alpha a human recombinant enzyme replacement enzyme.

\*Subject to change based upon approval Total number of contact hours applied for is 21.0.