

# **Digest**

Internal Newsletter, October 2018
Pediatric Gastroenterology Special Interest Group, APA DIV54

## Welcome from our Co-Chairs

## PG-SIG Leadership Co-Chairs

Christina Low Kapalu, PhD Children's Mercy Kansas City Laura Slosky, PhD Children's Mercy Kansas City

#### **Co-Chair Elects**

Lindsey Burrell, PhD
Emory University School of Medicine
Cindy Kim, PhD ABPP
Children's Hospital of Orange County

### **Past Co-Chairs**

Rob Dempster, PhD Nationwide Children's Hospital Brandi Whitaker, PhD Arkansas Children's Hospital

#### **Secretary**

Kristen Criado, PhD Emory University School of Medicine

## **Membership Coordinator**

Jaclyn Shepard, PsyD UVA School of Medicine

### **Members-At Large**

Kari Baber, PhD—Education Children's Hospital of Philadelphia Shayna Skelley Coburn, PhD— Research Children's National Health System Brad Jerson, PhD—Clinical Connecticut Children's Medical Center

#### **Student Representatives**

Grace Cushman, BS—Clinical University of Georgia
Jennie David, MS—Research
Drexel University

We are beyond excited to be representing you as PG-SIG Co-Chairs! As always, we remain an active group of clinicians, researchers, and advocates for the field of pediatric psychology and children with GI conditions. This newsletter will highlight just a few of the recent achievements of our SIG members and we always look forward to learning more about the important work that each of you do every day. In addition, we would like to take the opportunity to highlight changes in PG-SIG leadership and some of the contributions of this group in this newsletter.

We are ever appreciative of the hard work and dedication from Robert Dempster and Brandi Whitaker, who transitioned to Past Co-Chairs at SPPAC 2018. After multiple qualified candidates and a competitive election, Lindsey Burrell and Cindy Kim, at Emory University School of Medicine and Children's Hospital of Orange County respectively, were elected as Co-Chairs Elect. Kristen



Christina Low Kapalu, PhD

Criado of Emory University/ Children's Healthcare of Atlanta joins the board as our current secretary. She replaces Kari Baber of Children's Hospital of Philadelphia who is transitioning to our MAL for Education. Shavna Skelley Coburn of Children's National Health System and Brad lerson of Connecticut Children's Medical Center are also serving in Research and Clinical MAL roles respectively. Jaclyn Shepard at UVA School of Medicine joined our board as the new membership coordinator.

We are thankful for everyone's interest in and dedication to forwarding the interests of children with GI complexity around the country! Welcome to our new Board



Laura Slosky, PhD

members as well as all of our new PG-SIG members.

Since our annual meeting in April, PG-SIG members have been actively involved in national and international conferences and meetings. Our members are active and productive: participating in symposia, setting best practice guidelines and building networks to share information. We continue to look for ways to connect students, clinicians and researchers to advance pediatric psychology involvement in pediatric GI patient care. Please be in touch with ideas for the continued growth and development within this community.

## What's Inside

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## Review of "'A Guide to Gutsy Living'"

#### **Abstract**

This paper describes a pediatric patient - and parent-driven quality improvement project to create a resource for patients living with Inflammatory Bowel Disease facing ostomy surgery within a collaborative chronic care network. Patients and parents independently identified the need for a resource, formed a task force, iteratively generated topics relevant to living with an ostomy and IBD, wrote and compiled the resource, sought feedback from pediatric GI providers, revised the resource with provider feedback, and ultimately produced an accessible resource. This article describes how patients and parents harnessed the capacity of a collaborative chronic care network, were supported by providers, and develop a resource that was identified by patients as important. The implications of this project would suggest that pediatric patients and parents

have both the motivation and ability to inform clinical practice and optimize the integration of patient and parent perspectives into medical care and education.

#### **Narrative**

This impetus for this project was the recognition of patient advocates within a collaborative chronic care network that we did not have the capacity to provide meaningful individual mentorship for patients with IBD facing ostomy surgery (which is often highly stigmatized). Additionally, we were often limited in providing only a singular perspective to mentees based on our individual experiences in the I:I model we had been using for mentorship. Using quality improvement methods and the support and resources of the collaborative chronic care network that highly

values patient and parent engagement, we convened a task force to create the resource and sought provider feedback. As several of us were patients and also students/researchers, we felt it was important to publish our experience in patient and parent-led research to create a resource needed by our community. It is our goal that patients and parents across illnesses be encouraged and supported to create vetted resources for their patient communities through this 'bottom up' research approach.

Contributor: Jennie David, M.S. <u>igd46@drexel.edu</u>

#### Citation:

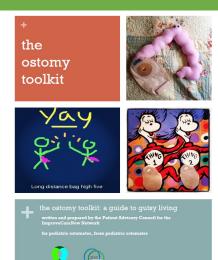
David, J. G. Jofriet, A., Seid, M., et al. (2018). "A Guide to Gutsy Living": Patient-Driven Development of a Pediatric Ostomy Toolkit. Pediatrics, 141 (5), e20172789

## Ostomy Toolkit

The ostomy toolkit was a project conceived and led by a joint collaboration of Patient Advisory Council members (current or former pediatric patients) and the Parent Working Group within the ImproveCareNow network.

- Developmentally-appropriate ostomy terminology
- Perspectives from adolescents on daily life with an ostomy
- Anticipatory guidance on daily living needs (e.g., having an emergency supply kit) and educational supports
- Resource for patients & families
- And much more!

This Tool is available from: https://www.improvecarenow.org/ ostomy-toolkit





## **Clinical Resource Database**

Throughout the next year, the GI-SIG will be building a more comprehensive database focused on dissemination of clinical tools. The goal of this effort is to pool the expertise and efforts of individuals within the gastropsych community to create an accessible resource bank to streamline and improve

clinical care delivery. Stay tuned to your inboxes for requests from our board members for your help on this project, and also to learn more about what your colleagues are doing to improve their daily work.

Contributor: Bradley Jerson, PhD BJerson@connecticutchildrens.org



## **SIG Buttons**

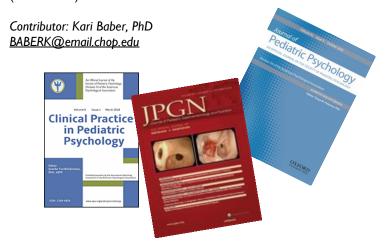
Please wear your buttons to connect with other PG-SIG members at conferences! We have more if you need one! Christina Low Kapalu (<a href="mailto:cmlow@cmh.edu">cmlow@cmh.edu</a>) will have some buttons at NASPGHAN. You can also contact Laura Slosky at <a href="mailto:lsoky@cmh.edu">lslosky@cmh.edu</a> for a button.

## Student Spotlight: Erin Moorman, BS

Erin is currently a doctoral student specializing in pediatric psychology at the University of Florida under the mentorship of Dr. David Janicke. She was introduced to pediatric GI research as a post-baccalaureate research coordinator in Dr. Natoshia Cunningham's lab at Cincinnati Children's Hospital Medical Center. In this role, Erin coordinated multiple studies, including an NIH-funded cognitive behavioral trial using functional imaging to understand response to treatment in youth with functional abdominal pain and co-occurring anxiety. She also collaborated with an interdisciplinary team of clinicians and researchers as part of a quality improvement initiative to integrate psychosocial screening measures into medical care for children with functional abdominal pain disorders, the results of which were recently published in Pediatrics. Erin is also interested in the role of biopsychosocial approaches to understand health-related outcomes in pediatric GI conditions, and recently presented her research during the PG-SIG meeting

## **Journal Club**

The PG-SIG will continue to host journal club with rotating topics of interest. Please keep an eye on the listserv for journal club details (dates/times) to come!





of SPPAC (April 2018)

examining the role of gastrointestinal inflammation (measured via fecal calprotectin) in relation to clinical outcomes in youth with functional abdominal pain. Results (under review) suggest that elevated fecal calprotectin is related to a clinically complex manifestation of pediatric functional abdominal pain disorders characterized by clinically significant levels of anxiety, pain, and pain-related disability. She is excited to continue to study the impact of biopsychosocial factors on health-related outcomes in pediatric chronic illnesses as a graduate student. Erin's broader research interests also include the assessment and treatment of family factors that impact coping and adherence in youth with chronic illness, and she is also interested in the impact of

childhood trauma on psychosocial and physical health outcomes in pediatric chronic illnesses.



Congratulations, Erin!

Mentors and advisors, please send your nominations for graduate students with excellence in clinical work for our next Student Spotlight in the Spring Newsletter.

Nominations can be emailed to <a href="mailto:kristen.criado@choa.org">kristen.criado@choa.org</a>.

It's October, and NASPGHAN 2018 is right around the corner! We're excited to share with you what we believe to be the full list of confirmed psychology speakers for the NASPGHAN, CPNP, and APGNN programming:



## Thursday, October 25 NASPGHAN Postgraduate Course

12:10pm - 1:35pm Learning Lunches

Medical and psychological treatment of vomiting

Moderator: Maria Perez MD

Katja Kovacic MD and Miranda Van Tilburg PhD

## **Module 5 - Functional/Motility Disorders**

4:00pm - 4:20pm Integrating hypnotherapy and CBT into medical treatment of functional disorders

Miranda van Tilburg PhD, Campbell University, University of North Carolina, University of Washington

Learning objectives:

- 1. Explore how physicians can integrate psychological therapies in their care for functional disorders
- 2. Differentiate the goals, content and efficacy of hypnotherapy and CBT for functional disorders
- 3. Identify and find solutions for common problems in referring for psychological treatments for functional disorders

## Friday, October 26

## 10:30am - 12:00pm APGNN Session III - Team Approach to Disordered Feedings

12:00pm - 12:30pm Avoidant/Restrictive Food Intake Disorder

Robert Dempster, PhD, Pediatric Psychologist Nationwide Children's Hospital, Program Director, Comprehensive Pediatric Feeding Program & Parker L. Huston, PhD, Pediatric Psychologist, Nationwide Children's Hospital Comprehensive Pediatric Feeding Program

Learning objectives:

- 1. Identify core symptoms of ARFID in the pediatric population
- 2. Describe common behavioral and cognitive interventions for ARFID
- 3. Understand the role of multidisciplinary team evaluation and treatment of ARFID

#### **NASPGHAN** Concurrent Session II Inflammatory bowel disease

2:52pm IBD distress vs depression: Are they different and does it matter? Michael A Harris PhD, Oregon Health & Science University Learning objectives:

- I. Identify the emotional side of IBD
- 2. Differentiate between IBD-distress and depression
- 3. Separate fact from fiction regarding depression and IBD based on data and empirical evidence

## **NASPGHAN Concurrent Session II Liver transplant**

3:26pm Adherence and self-management across the pediatric and adult health care continuum Michele Maddux PhD, Children's Mercy Hospital Learning objectives:

- 1. To summarize the prevalence and common barriers of adherence in pediatric GI disorders
- 2. To review research on current adherence practices of pediatric gastroenterologists and relevance to transition
- 3. To describe challenges associated with adherence and self-management across the pediatric and adult health care continuum
- 4. To review the application of evidence-based strategies to promote adherence during transition

## **NASPGHAN** Concurrent Session II Functional gastroenterology

3:12pm Functional GI disorders: Sharing the diagnosis and creating a successful patient/physician alliance **Julie Snyder PsyD, Boston Children's Hospital** Learning objectives:

- I. Demonstrate the ability to utilize specific language, reflection, and other communication skills in order to establish rapport, validate symptoms, and increase compliance with a recommended multidisciplinary treatment approach
- 2. Integrate the use of metaphors to describe and to explain a functional gastrointestinal diagnosis

## Saturday, October 27

## 10:00am - 11:30am APGNN Session - Motility Module/Functional

10:00am - 10:30am - The art of delivering care to children with FGIDs

Rose Lucey Schroedl, PhD Clinical Coordinator GI Psychology, Pediatric Psychologist, Nationwide Children's Hospital, Assistant Professor Department of Pediatrics The Ohio State University & Desale Yacob, MD Associate Professor of Clinical Pediatrics, The Ohio State University College of Medicine, Medical Director, Center for Motility and Functional GI disorders, Division of Pediatric Gastroenterology, Hepatology, and Nutrition, Nationwide Children's Hospital

Learning objectives:

- 1. Discuss the pathophysiology of Functional GI Disorders (FGIDs)
- 2. Explore the evaluation and workup of children suspected to have FGIDs
- 3. Discuss the Biopsychosocial model as a therapeutic tool for addressing FGIDs
- 4. Identify the key factors in engaging patients and their families in the rehabilitative journey
- 11:00am 11:30am Early adverse life experience in functional gastrointestinal disorders

Miranda A.L. van Tilburg, PhD Associate Professor of Clinical Research, Campbell University, Buies Creek NC, Adjunct Professor of Medicine, University of North Carolina, Chapel Hill NC, Affiliate Associate Professor of Social Work, University of Washington, Seattle WA Learning objectives:

- I. In this lecture participants will explore the contribution of early adverse life experiences to the development of pediatric Functional Gastrointestinal Disorders (FGID)
- 2. Participants will be able to relate the effects of early life experiences to maturation of the central nervous system and HPA
- 3. Participants will examine the role of parental modeling and reinforcement of inappropriate illness behaviors in FGID
- 4. Participants will be able to guide parents in supporting child's well-being rather than illness behaviors

## 2:00pm - 3:30pm CPNP Nutrition Symposium- Session IV: Celiac Disease

Adherence and psychological issues with celiac disease

Shayna Coburn PhD, Children's National Medical Center

Learning objectives:

- I. Identify barriers to adherence in the celiac child
- 2. Describe psychological issues prior to and after diagnosis of celiac disease

We'd also like to invite you to an informal social gathering on Friday, October 26<sup>th</sup> at 5:30 PM on the Diplomat property; keep a look out for more information. See you in Hollywood!