

Allergic Diseases SIG

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UPDATES!

SIG Resources, Activities, & Initiatives

A Message from our Co-Chairs

Hello! Thank you all for your interest and work with pediatric allergic diseases. We are grateful to have a community within Division 54 dedicated to kids and families with asthma, allergies, eczema, and other allergic diseases. Please join us in welcoming our newest SIG Board members and see their bios below!

A current goal of the AD SIG board is to introduce a social media presence. As such, the theme of this newsletter is social media and allergic diseases. This newsletter includes a conversation with Dana Bakula, PhD, highlighting the trailblazing work of the Caregivers SIG in their promotion of Pediatric Psychology via social media outlets. We also identify specific social media handles to follow relevant to Allergic Diseases as well as include a review of a social media-relevant article.

We recently hosted our first student data blitz on November 30 and are excited so many of you attended. Please anticipate future similar events! Additionally, please contact us with publications, upcoming conference presentations, clinical innovations and resources, job/training postings, or anything you would like to share with the membership.

Best,

Amy Hahn, PhD and Mallory Netz, PhD

Other SIG Updates

Measure Review

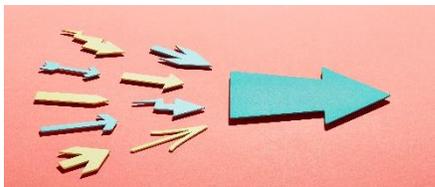
Remember to visit the Allergic Diseases SIG website for our list of allergy-related measures! <https://pedpsych.org/sigs/allergic-diseases-special-interest-group/> The measure review is updated periodically.

SIG Initiatives

The Allergic Diseases SIG is committed to mobilizing our knowledge to improve allergy management, health equity, access to care, and health outcomes for minoritized groups. Members are also in the beginning stages of compiling clinical resources relevant to the allergic disease populations. Please contact Amy Hahn at Amy.Hahn@nationwidechildrens.org if you would like to be involved in either of these initiatives.

Call for Contributions

We would like to use our newsletter to highlight the important work of our SIG members. Please reach out to us if you have a clinical or completed research project you would like to have spotlighted, or anything you would like to share with our membership!



Welcome to our New Leadership Committee Members!

Co-Chair: Mallory Netz, PhD, Children's Mercy Kansas City

Mallory Netz is a pediatric psychologist in the Division of Developmental and Behavioral Health at Children's Mercy Kansas City and Clinical Assistant Professor of Pediatrics at the University of Missouri-Kansas City. She provides outpatient therapy to patients referred from Mercy's Advanced Asthma Interdisciplinary Respiratory (AAIR) Clinic and Cystic Fibrosis Care Center. Additionally, Dr. Netz manages the general inpatient psychology consultation service and provides clinical supervision and training to psychology in terns.



Research Chair: Alayna Tackett, PhD, University of Southern California

Dr. Tackett is a pediatric psychologist and Assistant Professor of Population and Public Health Sciences at the University of Southern California, and a faculty member in the USC Health, Emotion, and Addiction Laboratory and the USC Institute for Addiction Science. She is also a current Pediatric Research NIH Loan Repayment recipient. Dr. Tackett's research follows a team-science model to examine the health effects of e-cigarettes and other electronic nicotine/ cannabis delivery devices (e.g., heat not burn, cannabis) among youth and young adults. Dr. Tackett's allergic diseases work focuses on understanding how e-cigarettes/ tobacco product use impacts adolescents diagnosed with asthma and how food insecurity, sociodemographic characteristics, and illness appraisal constructs influence food allergy management.



Student Representative: Natalie Koskela-Staples, MS, University of Florida

Natalie Koskela-Staples is a fifth-year doctoral student in the Clinical and Health Psychology program at the University of Florida. Her research interests include family communication in pediatric chronic illness populations, as well as the influence of caregiver functioning on youth psychosocial and medical outcomes. Before starting graduate school, Natalie worked as a research assistant at Oregon Health and Science University, where she assisted with the evaluation of a clinical program for youth with medical and social complexities and their families. Natalie received a TL1 predoctoral training grant from UF's Clinical and Translational Science Institute, which is funding a project examining the role of caregivers in physical activity engagement among adolescents with comorbid asthma and obesity. For her dissertation, Natalie is examining patterns of communication among adolescents with asthma and their caregivers and determine the impact of these patterns on youth psychosocial and asthma outcomes. The ultimate goal of Natalie's research is to inform prevention and intervention efforts in pediatric chronic illness populations, particularly asthma.



Social Media Chair: Melissa Engel, MA, Emory University

Melissa Engel is a doctoral student in the Clinical Psychology program at Emory University. Prior to beginning graduate school at Emory, Melissa received her MA in Developmental Psychology from the University of Minnesota. Her research and clinical interests broadly focus on risk and resilience in youth with chronic medical conditions. Several of Melissa's projects involve allergy, including a longitudinal study examining the intergenerational transmission of maternal stress and early childhood atopic diseases and a population-based study of quality of life in youth with food allergies. Melissa is especially interested in identifying and addressing the unique psychosocial challenges faced by adolescents with food allergies. She developed Teen Talks and Child Chats for Food Allergy Research and Education (FARE) and leads these virtual, interactive programs that attract approximately 100 youth each month. Additionally, Melissa frequently collaborates with Ruchi Gupta's Center for Food Allergy and Asthma Research (CFAAR) on both research projects and youth programming. Melissa previously served as Student Representative and is excited to continue in this new role!



A huge shout-out to the students and attendees who made our first Student Data Blitz meeting a success!

Student Presenters

Stephanie Madden, B.S., University of Massachusetts Lowell: *Adolescent Asthma-Related Outcomes: The Role of Caregiver-Adolescent Conflict Perceptions*

Nicole Ruppe, M.S., Oklahoma State University and Brown University: *Depressive Symptom Trajectories Among Individuals with Asthma*

Natalie Koskela-Staples, M.S., University of Florida: *Family-Level Barriers and Facilitators to Physical Activity Engagement Among Adolescents with Comorbid Asthma and Overweight/ Obesity*

Melissa Engel, M.A., Emory University: *Teen Talks: An Online Video-Based Program for Adolescents with Food Allergies*

Sara Voorhees, Ph.D., Massachusetts General Hospital: *Pediatric Patient versus Caregiver Communication in Food Allergy Encounters and Factors Associated with Caregiver Participation*



DIGITAL RESOURCES AND ENGAGEMENT

Ask the Experts:

Dr. Netz chatted with Dr. Bakula and Casie Morgan, who serve on the SPP Division 54 Caregiver Wellbeing SIG. Their group maintains active social media accounts on Instagram and Twitter, contributing novel and meaningful content for parents and caregivers of children facing chronic illness or injury.

Dr. Dana Bakula co-chairs the Caregiver Wellbeing SIG. She is a pediatric psychologist and Assistant Professor of Pediatrics at Children's Mercy Kansas and University of Missouri-Kansas City School of Medicine.

Casie Morgan, MA, is a PhD candidate at the University of Alabama-Birmingham.



There are so many avenues for engaging providers, patients, and caregivers on social media. What is the first step to creating a media presence?

Dr. Bakula and Casie: We want to start by saying we are still learning a lot about how to run advocacy social media accounts, and our answers here reflect what we have learned so far. The first step is to identify your target audience and goals for your social media account. You want to have a general direction for what type of content you want to post, and who you hope will see that content. For instance, do you want to reach patients and families with tips for taking care of themselves? Do you want to reach medical providers to provide them education? Your goals will also influence what social media platform you choose. If you want to reach medical providers you might be more likely to choose a platform like Twitter where there is a large #MedTwitter population. However, if you are interested in reaching patients and families you might be more inclined to choose Instagram or TikTok. If your goals are multifaceted, you may find that it is most helpful to create multiple accounts that complement each other. For example, an Instagram account targeted more toward families and a Twitter account targeted more toward medical providers. These two accounts can present similar information, but perhaps the content is presented differently and posted more or less frequently. Once you have an idea of your goals for the account – go ahead and sign up and get a feel for your new social media account!



How do you set up a sustainable system for content creation?

Dr. Bakula and Casie: We find it helpful to leverage the shared passion and expertise of a group of people. It can be time consuming to generate lots of content for social media. We have a core group of leaders who run our social media accounts (with separate project leads for Instagram vs. Twitter) and then we involve our SIG members as much as possible in creating the content for posts. This makes it more fun – because we get to work together and learn from each other, and makes the account management much more sustainable. Additionally, an organization system facilitates sustainability as it allows the core group of leaders running the social media accounts to prepare in advance. For example, we have a google drive that includes content ideas, an Instagram posting schedule, content received from SIG members, and more.

What are strategies for targeting content to various audiences?

Dr. Bakula and Casie: We are still learning the best way to reach a large audience. What we have learned so far is that you always want to have your target audience in mind when generating content. You should also be talking to your target audience about what they want to see. We get most of our ideas for social media posts from conversations we have with parents of children with medical conditions. We also follow other social media accounts that target similar audiences to learn what works for them. There is some trial and error involved – but you can learn what people respond to (and don't) by tracking your engagement on each post.

What are the most valuable skillsets you can have in creating and running a professional social media account?

Dr. Bakula and Casie: In our experience, you want a team of people who are passionate about your topic, organized, and creative. It also helps to have at least one tech savvy team member or a member willing to learn more about technology and social media.

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How would you suggest balancing content creation with other professional responsibilities?

Dr. Bakula and Casie: We try to share the workload across a team of people. For Instagram specifically, we have generated a system where our Instagram team leads develop a list of topics for posts, volunteers from our SIG creates the written content for the posts, and one of our team leads formats the post into a beautiful slide using templates that we have created for our Instagram account (on Canva). By sharing the workload, we have made it more sustainable. It can also be helpful to work with social media leads on designating a specific time of the day or week that they will dedicate toward content creation and posting. This may help with balance and may also help with tracking how long the process typically takes and whether or not tweaks need to be made in the system for sustainability.

What are the benefits of creating a professional social media account?

Dr. Bakula and Casie: It is a great way to engage in advocacy and connect with the community you are passionate about serving. It can add a sense of fulfillment to your career and be a great creative outlet for sharing your knowledge. We also hope it can be a great experience for those who generate content and feel a sense of ownership over the posts (and authors are always credited in the post). At the end of the day – we love feeling like we are doing something to help our community and this has felt like a great way to start doing that.

These social media accounts provide reputable, quality information for those living with or working with those affected by allergic diseases

Instagram

- AAFANational
- FoodAllergy (FARE)
- FAACTNews
- Equal_cats
- Foodallergy counselor
- Foodallergytalk
- FoodEquality
- KidsWithFoodAllergies
- CFAARNU



Twitter

- AllergyKidsDoc
- Kfatweets
- FoodAllergyFund
- FAACT
- FACounselor
- AllergicLiving
- Oakley_Red
- AllergyHeroes
- FoodEquality



Mentored Article Review: Caregiver Perceptions and Attitudes Associated with Oral Immunotherapy on Social Media (Kochis et al, 2021)

Jaya Mallela, Graduate Student in the Department of Clinical & Health Psychology, University of Florida
Mentored by: Ashley Ramos, PhD, Pediatric Psychologist Division of Allergy Immunology and Rheumatology, University Hospitals Rainbow Babies and Children's Hospital

Oral immunotherapy (OIT), a food allergy treatment involving ingestion of increasing amounts of an allergen to desensitize a patient over time may offer a long-term solution to the burden of managing food allergy. Although the first documented use of OIT dates to 1908, it is currently an emerging food allergy treatment with recent meta-analytic reviews indicating promising efficacy (Chu et al., 2019). However, given the risks of OIT including increased likelihood of allergic reaction both providers and patients must carefully consider the use of this treatment. As families make food allergy treatment decisions, caregivers and patients may consult social media to gather information, seek social support from other caregivers, and share their experiences related to OIT (Alvarez-Perea et al., 2018; Lee & Chen, 2019; Supthanasup et al., 2021).

In their manuscript titled “Caregiver perceptions and attitudes associated with oral immunotherapy on social media” Kochis and colleagues’ (2021) explored caregiver perceptions of OIT by analyzing posts on a popular parenting website (www.babycenter.com) to identify themes related to OIT concerns. This analysis was conducted prior to the recent FDA approval of a peanut allergy OIT, Palforzia (Commissioner, 2020). Three themes emerged from a directed content analysis: attitudes about OIT, logistics of accessing the treatment, and questions about the family and child experience. Regarding the attitudes about OIT theme, which encompassed caregiver emotions and facilitators/barriers to OIT engagement, caregivers indicated fear of allergic reactions and resulting psychosocial burdens on a child’s quality of life as a motivator to pursue treatment. Fear of increased risk of allergic reactions was a motivator to not pursue OIT.

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The logistics of accessing treatment theme included caregiver concerns about the accessibility of physicians or research facilities offering OIT, cost, and developmental maturity of their child to effectively participate in the treatment. Regarding the questions theme researchers recognized that caregivers asked others for details on how OIT works and what experiences they have had.

Kochis et al., 2021 assert that providers may glean specific insights into patient motivations, emotions, concerns, questions, and overall experience of treatment decision-making processes by examining social media engagement. Further, the authors concluded that providers could use these insights to guide their communication with families to proactively address concerns and promote shared decision-making. Other work supports the potential utility of online content analysis to improve provider understanding of patient perceptions of disease management and treatment decision-making, for example in breast cancer (Freedman et al., 2016), diabetes (Gao et al., 2021), and depression (Castilla-Puentes et al., 2021).

Strengths and Limitations

Strengths of this article include exploration and classification of caregiver views on a relatively new food allergy treatment and recommendations for how providers can be cognizant of the influence of social media on OIT decision-making. Kochis et al. (2021) recommend that physicians demonstrate empathy toward caregivers as they make decisions. Providers should name and show understanding of both fears of choosing to begin OIT and fears of prolonging the psychosocial burdens of food allergy by not beginning treatment, and display respect and support of families' decisions. The authors also recommend that physicians consider that caregivers may approach medical consultation with a predisposition for a particular treatment decision based on information from social media. If physicians demonstrate awareness and consideration of the multiple sources from which caregivers may have received information prior to the consultation, caregivers may be more comfortable to share their perceptions and collaborate with physicians to make decisions. These recommendations may improve caregiver-provider communication and ultimately facilitate family-centered care.

Kochis and colleagues (2021) acknowledge the limitation that the sample of caregivers who posted on the site may not represent all caregivers of children with food allergy and that the study may not have capture children's own perceptions of OIT. Social media also has limitations as a source of information, especially with regard to accuracy and credibility of medical content. Although caregivers may find information and social support on online platforms, perceptions of the information's reliability depend on the content itself as well as social cues (e.g., perceived expertise of post author, author engagement with followers; Hamshaw et al., 2018, 2019). Therefore, physicians may consider asking about the source of caregivers' knowledge to correct misinformation and contextualize information from social media within a child's individual disease presentation and treatment.

Clinical Implications

Food allergy treatment providers may incorporate the findings of this study into practice through proactive evaluation of caregiver social media use and use of techniques from psychosocial interventions to improve caregiver-provider communication. Caregiver use of social media to gather treatment information may indicate suboptimal caregiver-provider communication. A caregiver may rely social media for health information and emotional support if feel that they cannot ask questions, express concerns openly, and receive guidance and support from their providers (Kim et al., 2021). If providers specifically ask about food allergy-related social media use and reasons for use, which could be classified using Kochis et al.'s (2021) themes of attitudes, logistics, and questions, they may better identify the needs of caregivers. For example, if a caregiver uses a parenting website to gather information on the risks of OIT, a provider may then counsel on the likelihood of these risks impacting their child. As the role of social media in healthcare continues to expand, providers and clinics may consider establishing institutional accounts that deliver accurate information and foster creation of online caregiver/patient communities within their institution (Caruso Brown, 2021). Kochis and colleagues' (2021) work also indicates the need for implementation of psychosocial tools such as shared decision-making tools to address caregiver fears, motivations, and questions related to food allergy treatment. Use of these tools would align with recommendations for psychosocial care for children with food allergy (Herbert & DunnGalvin, 2021).

Conclusion

Kochis and colleagues (2021) analyzed posts on a parenting site to examine caregiver attitudes, concerns, and questions about OIT and found that caregivers expressed fear of initiating versus not initiating treatment, considered logistics of accessing OIT, and gathered information about the procedures through social media. These findings may guide how healthcare providers discuss OIT with families and provide direction for future research that harnesses social media to better understand families' perceptions of food allergy treatment. Social media research and the clinical applications of this work may inform the provision of responsive, comprehensive, family-centered food allergy care.

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