WASHINGTON, D.C.

EOS CONNECTION 2019

APFED'S 17th Annual Patient Education Conference on Eosinophil-Associated Diseases
Washington, D.C. | July 26-27

Apfed
American Partnership for Eosinophilic Disorders

In Collaboration With

CEGiR
Consortium of Eosinophilic Gastrointestinal Disease Researchers

Children's Hospital of Philadelphia®
Your gifts make it happen.

To learn more, go to apfed.org
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Welcome!

Thank you for joining us for APFED’s 17th Annual Patient Conference! We dedicate this conference to the patients and families living with eosinophil-associated diseases, and to the members of the medical community who research and treat these illnesses.

This program contains a schedule of events, session descriptions, helpful information about the hotel and the Washington, D.C. area, note pages for each presentation, and other resources.

Conference Technology

Facebook – Please like APFED’s official Facebook page (facebook.com/APFED) and follow us as we post photos and information about the conference. You may also wish to join the Facebook group for conference attendees, where you can connect with others: https://www.facebook.com/groups/2014107555555732/

Twitter – For those who will be tweeting or following tweets throughout the conference, please add #EOSConnection and #EosAware to all of your tweets.

Wi-Fi Access – Complimentary Wi-Fi is available in guestrooms, common areas of the hotel, and during General Sessions.

The American Partnership for Eosinophilic Disorders (APFED) is a nonprofit organization whose mission is to passionately embrace, support, and improve the lives of patients and families affected by eosinophil-associated diseases through education and awareness, research, support, and advocacy. For more information about the programs and services we offer, visit apfed.org.

Disclaimer: All information presented at this conference is for the sole use of the attendees. Permission for the use of this information and all associated materials must be obtained from the individual speakers. Information presented here is the opinion of the speakers; any questions that arise as a result of this conference regarding patient care should be directed to your consulting physician. Agenda and speakers are subject to change.
# SCHEDULE OF EVENTS

## REGISTRATION HOURS

<table>
<thead>
<tr>
<th>Day</th>
<th>Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thursday, July 25</td>
<td>9:30 AM-7:00 PM</td>
</tr>
<tr>
<td>Friday, July 26</td>
<td>7:00 AM-5:00 PM</td>
</tr>
<tr>
<td>Saturday, July 27</td>
<td>7:00 AM-4:00 PM</td>
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</tbody>
</table>

## THURSDAY, JULY 25

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>10:00 AM-10:30 AM</td>
<td>Medical Nutrition Equity Act</td>
<td>Wisconsin Room</td>
</tr>
<tr>
<td></td>
<td>Megan Gordon Don, Principal and Founder, MGD Strategies, LLC</td>
<td></td>
</tr>
<tr>
<td>10:30 AM-10:45 AM</td>
<td>Building a Relationship with Elected Officials</td>
<td>Wisconsin Room</td>
</tr>
<tr>
<td></td>
<td>Stephanie Walls</td>
<td></td>
</tr>
<tr>
<td>11:15 AM-3:30 PM</td>
<td>Family Fun Day to Smithsonian National Museum of National History</td>
<td>National Museum of Natural History</td>
</tr>
<tr>
<td></td>
<td>Bus departs from hotel lobby 11:15 AM sharp</td>
<td></td>
</tr>
<tr>
<td>4:00 PM-5:00 PM</td>
<td>Focus Group for Neocate formula users</td>
<td>Hampden Room</td>
</tr>
<tr>
<td></td>
<td>Pre-registration required</td>
<td></td>
</tr>
<tr>
<td>4:00 PM-6:00 PM</td>
<td>Pool Party</td>
<td>Hotel Pool</td>
</tr>
<tr>
<td></td>
<td>Travel companions and children are welcome to attend. Please have an adult accompany children.</td>
<td></td>
</tr>
<tr>
<td>7:00 PM-8:00 PM</td>
<td>Meet &amp; Greet for Conference Attendees &amp; Travel Companions</td>
<td>Wisconsin Room</td>
</tr>
<tr>
<td></td>
<td>Children of all ages are welcome</td>
<td></td>
</tr>
<tr>
<td>8:00 PM</td>
<td>Adult Patient Get Together</td>
<td>Hotel Pool</td>
</tr>
<tr>
<td></td>
<td>Look for APFED signage to locate our group. This is a self-pay event.</td>
<td></td>
</tr>
</tbody>
</table>
# FRIDAY, JULY 26

<table>
<thead>
<tr>
<th>Time</th>
<th>Location</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00 AM</td>
<td>Registration Desk Opens –Bethesdan Foyer</td>
<td>Breakfast on own</td>
</tr>
<tr>
<td>9:00-9:10 AM</td>
<td>BETHESDAN BALLROOMS A-B</td>
<td>Welcome</td>
</tr>
</tbody>
</table>
| 9:10-9:30 AM  | BETHESDAN BALLROOMS C-D           | High Blood Eosinophilia: Arriving at the Correct Diagnosis and Treatment Options  
Amy Klion, MD  
Learn about masqueraders of eosinophil-associated disease, and how providers can arrive at a correct diagnosis, and become familiar with different treatment options for high blood eosinophilia.  

<table>
<thead>
<tr>
<th>Time</th>
<th>Location</th>
<th>Event</th>
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</thead>
</table>
| 9:30-10:00 AM | POTOMAC BALLROOMS                  | The Role of Genetics in Eosinophilic Gastrointestinal Disease  
Pam Guererro, MD  
Understand the role genetics may play in EGID and learn about related research findings and aims.  

<table>
<thead>
<tr>
<th>Time</th>
<th>Location</th>
<th>Event</th>
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</thead>
</table>
| 10:00-10:30 AM| POTOMAC BALLROOMS                  | Institutions, Private Practice and NIH Approach to EGID Treatment  
Learn the approaches tertiary care centers, private practices, and NIH may take with EGID care, and how these approaches may differ from one another, and how care is coordinated among multiple providers.  

Tertiary Care Center Approach  
Bridget Godwin, MD  
Private Practice Approach  
Oral Alpan, MD  
NIH Approach  
Paneez Khoury, MD  

<table>
<thead>
<tr>
<th>Time</th>
<th>Location</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>10:30-11:30 AM</td>
<td>POTOMAC BALLROOMS</td>
<td>Panel Q&amp;A</td>
</tr>
<tr>
<td>11:30-1:00 PM</td>
<td>POTOMAC BALLROOMS</td>
<td>Lunch On Own</td>
</tr>
</tbody>
</table>
| 11:30-1:00 PM | POTOMAC BALLROOMS                  | Focus Group: Perspectives on Living with EoE  
Pre-registration required. Lunch will be provided.  
Hampden Room |

APFED’s 17th Annual Patient Education Conference on Eosinophil-Associated Diseases
<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>1:00-2:00 PM</td>
<td>Patient Panel with Q&amp;A</td>
<td>BEThesDAN BALLROOMS A-B</td>
</tr>
<tr>
<td></td>
<td>Patients managing different subsets of eosinophil-associated disease will describe their journeys and strategies.</td>
<td></td>
</tr>
<tr>
<td>1:00-2:00 PM</td>
<td>Transitions Series Workshop: Transferring from Pediatric to Adult GI Care</td>
<td>BEThesDAN BALLROOMS C-D</td>
</tr>
<tr>
<td></td>
<td>Jonathan Spergel, MD, PhD and Gary Falk, MD, MS</td>
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<tr>
<td></td>
<td>A pediatric care provider and adult provider will discuss their institutional approaches to transitioning patients from pediatric to adult care, how care may differ between practices, and how families can prepare for transition.</td>
<td></td>
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<tr>
<td>2:00-2:15 PM</td>
<td>Break</td>
<td></td>
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<tr>
<td>2:15-3:15 PM</td>
<td>BREAKOUT SESSIONS (CHOOSE ONE)</td>
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<tr>
<td></td>
<td>Layperson’s Approach to Understanding Research</td>
<td>Hampden Room</td>
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<tr>
<td></td>
<td>Christina Illardi, RN</td>
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<td></td>
<td>Learn about the types of research that is published, key components of a research paper and how one can “break down a conclusion” to get the overall summary of a paper. Learn resources and strategies to help patients identify credible research, particularly during online searches.</td>
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<td></td>
<td>Transitions Series Workshop: Taking the Reins in Healthcare</td>
<td>Del Ray Room</td>
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<td></td>
<td>Raquel Durban, MS, RD, CSP, LD/N and Randall Rutta</td>
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<tr>
<td></td>
<td>This workshop is designed for teens, young adults, and their caregivers to provide strategies and resources to help transitioning teens and young adults with taking the lead in their healthcare. Topics to discuss include how and when to schedule healthcare appointments, overview of insurance and claims, and strategies for healthcare management when away from home (e.g., college, traveling).</td>
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<tr>
<td></td>
<td>Chronic Illness in the Workplace</td>
<td>Rugby Room</td>
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<td></td>
<td>Wendy Book, MD</td>
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<tr>
<td></td>
<td>Topics to discuss will include workplace rights, accommodations, and disclosures.</td>
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<tr>
<td></td>
<td>Coping with a Chronic Illness</td>
<td>Auburn Room</td>
</tr>
<tr>
<td></td>
<td>Margi Szabo, PhD</td>
<td></td>
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<tr>
<td></td>
<td>Topics discussed include how chronic illness may impact mental health, coping strategies and resources and when to seek professional help.</td>
<td></td>
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<tr>
<td>3:45-5:00 PM</td>
<td>Research Poster Tour</td>
<td>Auburn/Rugby/Del Ray</td>
</tr>
<tr>
<td></td>
<td>Join us for a guided research poster tour and learn about findings from the Consortium of Eosinophilic Gastrointestinal Disease Researchers and other investigators.</td>
<td></td>
</tr>
<tr>
<td>5:00-6:30 PM</td>
<td>Focus Group: Transition of Care from Pediatric to Adult Providers (Teens &amp; Young Adults)</td>
<td>Hampden Room</td>
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<tr>
<td></td>
<td>Pre-registration required</td>
<td></td>
</tr>
<tr>
<td>7:00-9:00 PM</td>
<td>Community Night</td>
<td>Wisconsin Room</td>
</tr>
<tr>
<td></td>
<td>Join us for some card and board games. Travel companions and children under 11 are welcome to attend.</td>
<td></td>
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</tbody>
</table>
**APFED’s 17th Annual Patient Education Conference on Eosinophil-Associated Diseases**

**SATURDAY, JULY 27**

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00 AM</td>
<td>Registration Opens (Breakfast Provided)</td>
<td>Bethesda Foyer</td>
</tr>
<tr>
<td>8:25-8:30 AM</td>
<td>Welcome</td>
<td>BETHESAN BALLROOMS A-B</td>
</tr>
<tr>
<td>8:30-9:00 AM</td>
<td>Hypereosinophilic Syndromes: Research Update</td>
<td>8:30-8:30 AM Welcome</td>
</tr>
<tr>
<td></td>
<td><em>Fei Li Kuang, MD, PhD</em></td>
<td>BETHESAN BALLROOMS C-D</td>
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<tr>
<td></td>
<td>Hear an overview of HES, characteristics and diagnostics, recent research findings, and pipeline therapies.</td>
<td>8:30-10:30 AM EGIS Research Updates from CEGIR</td>
</tr>
<tr>
<td>9:00-9:30 AM</td>
<td>Patient Perspectives: Life with Hypereosinphilic Syndrome</td>
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<tr>
<td>9:30-10:00 AM</td>
<td>Seeking a Second Opinion: What’s Involved?</td>
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<td></td>
<td><em>Nick CaJacob, MD</em></td>
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<td>Learn what might warrant a referral to another specialist and when a second opinion should be considered. Managing relationships with existing doctors and coordinating communication will also be discussed.</td>
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<tr>
<td>10:00-10:30 AM</td>
<td>Panel Q&amp;A</td>
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<tr>
<td>10:30-10:45 AM</td>
<td>Break</td>
<td></td>
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<tr>
<td>10:45-11:10 AM</td>
<td>Nutritional Considerations in Dietary Therapy</td>
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<td></td>
<td><em>Michele Shuker, MS, RD, CSP, LDN</em></td>
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<td>Learn about potential nutritional deficiencies in those following a restricted diet, which patients might be at higher risk, and how patients are evaluated, as well as resources for help for managing a restricted diet.</td>
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<tr>
<td>11:10-11:30 AM</td>
<td>Patient’s Role in Clinical Research</td>
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<td></td>
<td><em>Alain Benitez, MD</em></td>
<td></td>
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<td></td>
<td>Patients play a critical role in research. Learn the importance of patient participation to advancing the field of eosinophil-associated disease and how to determine if a study is right for you or your child.</td>
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<tr>
<td>12:00-1:00 PM</td>
<td>Lunch Provided</td>
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<td></td>
<td>If you wish, you may attend one the two topic-based lunchrooms</td>
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<td></td>
<td>A. Patient Perspective: Learning to Live and Thrive Without Food</td>
<td>Hampden Room</td>
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<td></td>
<td><em>Walls Family</em></td>
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<td></td>
<td>B. Open Q&amp;A with a Pediatric GI Doctor</td>
<td>Del Ray Room</td>
</tr>
<tr>
<td></td>
<td><em>Nick CaJacob, MD</em></td>
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</table>

*Hampden Room*

*Del Ray Room*
### SATURDAY, JULY 27

<table>
<thead>
<tr>
<th>TIME</th>
<th>BETHESAN BALLROOMS A-B</th>
<th>BETHESDAN BALLROOMS C-D</th>
</tr>
</thead>
<tbody>
<tr>
<td>1:00-1:30 PM</td>
<td><strong>Mast Cells and Eosinophil-Associated Diseases</strong></td>
<td><strong>Reintroduction of Foods After Elimination: Are there Risks?</strong></td>
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<tr>
<td></td>
<td><em>Joshua Weschler, MD</em></td>
<td><em>Jonathan Spergel, MD PhD</em></td>
</tr>
<tr>
<td></td>
<td>Learn the connection between mast cells and eosinophil associated diseases and early</td>
<td>Learn if there are risks for those following dietary elimination to later develop</td>
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<tr>
<td></td>
<td>findings from an APFED-funded study, “Defining Mast Cell Phenotype, Activation</td>
<td>allergic response (hives, anaphylaxis) upon reintroduction to the foods avoided.</td>
</tr>
<tr>
<td></td>
<td>Pathways and Cellular Interactions that Drive Chronic Symptoms and Endoscopic Changes</td>
<td></td>
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<tr>
<td></td>
<td>in Eosinophilic Esophagitis.”</td>
<td></td>
</tr>
<tr>
<td>1:30-2:00 PM</td>
<td><strong>Biomarkers in Eosinophilic Esophagitis</strong></td>
<td><strong>The Future of EOE Diagnostics</strong></td>
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<tr>
<td></td>
<td><em>Amanda Muir, MD and Kelly Whelan, MD</em></td>
<td><em>Guillermo J. Teamey, MD, PhD</em></td>
</tr>
<tr>
<td></td>
<td>Learn about biomarkers and pathways and why these are important for diagnostics and</td>
<td>Learn about APFED-funded research of tethered spectrally-encoded confocal endomicroscopy</td>
</tr>
<tr>
<td></td>
<td>treatments in EoE, as well as an overview of biomarkers that have been ruled out or</td>
<td>and how it works and why it shows promise as a less invasive tool to diagnose</td>
</tr>
<tr>
<td></td>
<td>still have potential.</td>
<td>esophagitis (EoE).</td>
</tr>
<tr>
<td>2:00-2:30 PM</td>
<td><strong>Eosinophilic Asthma</strong></td>
<td><strong>Targeted Therapies</strong></td>
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<tr>
<td></td>
<td><em>Melanie Ruffner, MD, PhD</em></td>
<td><em>Evan Dellon, MD, MPH</em></td>
</tr>
<tr>
<td></td>
<td>Hear an overview of eosinophilic asthma, characteristics and diagnostics, learn how</td>
<td>Learn about targeted therapies and how they work as well as the potential benefits and</td>
</tr>
<tr>
<td></td>
<td>eosinophilic asthma differs from other types of asthma, and when to pursue a</td>
<td>risks. Biologics that are being explored for various subsets of eosinophil disease will</td>
</tr>
<tr>
<td></td>
<td>diagnosis, and hear about treatment options.</td>
<td>also be discussed.</td>
</tr>
<tr>
<td>2:30-3:00 PM</td>
<td><strong>Panel Discussion and Q&amp;A</strong></td>
<td><strong>Incorporating Patient Perspectives in FDA’s Regulatory Work</strong></td>
</tr>
<tr>
<td>3:30 PM</td>
<td><strong>Closing Remarks</strong></td>
<td><em>Samir Shaikh</em></td>
</tr>
<tr>
<td>3:00 PM-4:00 PM</td>
<td><strong>Focus Group for Formula Users</strong></td>
<td>Learn how members of the patient community can offer their experiences and perspectives</td>
</tr>
<tr>
<td></td>
<td><em>Pre-registration required</em></td>
<td>on patient engagement in FDA’s regulatory processes.</td>
</tr>
<tr>
<td>7:00-9:30 PM</td>
<td><strong>Family Friendly Social Mixer (Casino Night)</strong></td>
<td><strong>Panel Discussion and Q&amp;A</strong></td>
</tr>
<tr>
<td></td>
<td>Open to conference attendees and their travel companions, speakers, volunteers, and</td>
<td>2:45-3:30 PM</td>
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<tr>
<td></td>
<td>partners. We will offer light fare (allergy-friendly), music, dancing, activities for</td>
<td></td>
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<tr>
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<td>children, a silent auction and a chance to purchase “fun bucks” that may be used to</td>
<td></td>
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<tr>
<td></td>
<td>play popular casino games. Proceeds from the evening benefit APFED’s HOPE on the</td>
<td></td>
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<tr>
<td></td>
<td>Horizon Research Program. Travel companions and children under the age of 11 are</td>
<td></td>
</tr>
<tr>
<td></td>
<td>welcome to attend.</td>
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</tr>
</tbody>
</table>

Join the conversation and share what you are learning with others during the conference on Twitter! Use hashtags #EOSConnection and #EosAware so others can follow along with the updates.
Special Thanks to Our Collaborating Partners

Children’s Hospital of Philadelphia®

CEGiR
Consortium of Eosinophilic Gastrointestinal Disease Researchers

We are deeply grateful for their support of EOS Connection 2019
Thank you to our Education Partners for making APFED’s EOS Connection 2019 possible:

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**Gold Partners**

[Neocate](#)  [Takeda](#)

**Digital Education Partner**

[Allakos](#)

**Silver Partners**

- GSK
- Knopp Biosciences
- Mead Johnson Nutritionals
- Pharmaceutical Research and Manufacturers of America (PhRMA)
- Regeneron
- Sanofi Genzyme

**Supporting Partner**

Rare Patient Voice
APFED’S FAMILY-FRIENDLY SOCIAL MIXER
AND CASINO NIGHT FUNDRAISER
SATURDAY, JULY 27
7:00PM – 9:30 PM
GRAND BALLROOMS

Join us at APFED’s annual family-friendly social mixer! We will offer light fare, music, dancing, activities for children, a cash bar, and a chance to purchase “fun bucks” that may be used to play popular casino games.

This event will feature a Casino Night Fundraiser to support APFED’s HOPE on the Horizon Research Program, enabling APFED to fund new research for eosinophil-associated diseases. Learn more on the next page!

Conference attendees, their children, and their travel companions are welcome. Join us for:

* DJ
* Dancing
* Photo booth
* Build-a-bear
* Carnival-themed games
* Casino night fundraiser
* Light fare and cash bar
* Sno-cones and cotton candy
CASINO NIGHT FUNDRAISER

Casino Area Tickets and “Fun Bucks”
Make a donation to gain entry to the Casino Area and get “Fun Bucks” in exchange to play the casino games. Tickets and Fun Bucks were available for advanced purchase during conference registration. They will also be sold onsite throughout the conference in our gift store and at the Fun Bucks table during the social.

**Tickets**: Each ticket includes access to the casino area and $1,000 in "Fun Bucks" to play the casino games

<table>
<thead>
<tr>
<th>Tickets</th>
<th>Donation</th>
<th>Fun Bucks</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 ticket</td>
<td>$30 donation</td>
<td>$1,000 Fun Bucks</td>
</tr>
<tr>
<td>2 tickets</td>
<td>$50 donation</td>
<td>$2,000 Fun Bucks</td>
</tr>
<tr>
<td>3 tickets</td>
<td>$70 donation</td>
<td>$3,000 Fun Bucks</td>
</tr>
<tr>
<td>4 tickets</td>
<td>$90 donation</td>
<td>$4,000 Fun Bucks</td>
</tr>
</tbody>
</table>

Please note: All individuals aged 11+ who are participating in casino games are required to have their own ticket. Children ages 10 and younger do not need a ticket to enter the gaming area, but they must be accompanied by a ticketed chaperone at all times.

**Fun Bucks**: You may also purchase additional Fun Bucks

- Additional $100+ donation = $2,500 Fun Bucks
- Additional $75 donation = $1,500 Fun Bucks
- Additional $50 = $1,000 Fun Bucks
- Additional $25 = $700 Fun Bucks
- Additional $20 = $500 Fun Bucks

Fun Bucks may be used to bid on silent auction items or may be redeemed for a complimentary drink at the cash bar (ages 21 and older).

Thank you for supporting APFED’s HOPE on the Horizon Research Program!
CHILDREN’S ACTIVITIES
Ages 10 and under

These activities are provided as a courtesy thanks to the generosity of volunteers who have planned these events. **These activities are not a substitute for childcare. Children must be accompanied by a chaperone at all times.**

APFED will provide a list of local babysitters that families may wish to consider for chaperones. With the exception of the programming denoted below with an asterisk (*), all children participating in any of these activities must have signed up during a parent’s conference registration and paid the materials fee.

**Thursday, July 25**

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>11:15-3:30 PM</td>
<td><strong>Family Fun Day at the National Museum of Natural History</strong>*&lt;br&gt;Bus departs hotel 11:15 AM.&lt;br&gt;Self-guided tour at museum starts at 12:30 PM.</td>
<td>National Museum of Natural History</td>
</tr>
<tr>
<td>4:00-6:00 PM</td>
<td><strong>Pool Party</strong>*</td>
<td>Hotel Pool</td>
</tr>
<tr>
<td>7:00-8:00 PM</td>
<td><strong>Meet and Greet</strong>*</td>
<td>Wisconsin Room</td>
</tr>
</tbody>
</table>

**Friday, July 26**

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:30-10:15 AM</td>
<td><strong>Welcome and Ice Breakers</strong>&lt;br&gt;Dave Mitchell</td>
<td>Wisconsin Room</td>
</tr>
<tr>
<td>10:15-11:00 AM</td>
<td><strong>Games Time</strong>&lt;br&gt;Dave Mitchell</td>
<td>Wisconsin Room</td>
</tr>
<tr>
<td>11:00-11:30 AM</td>
<td><strong>Sno-Cone Social</strong>&lt;br&gt;Dave Mitchell</td>
<td>Wisconsin Room</td>
</tr>
<tr>
<td>11:30 AM-1:00 PM</td>
<td><strong>Lunch</strong>*</td>
<td>On Own</td>
</tr>
<tr>
<td>1:00-2:00 PM</td>
<td><strong>Craft Time</strong>&lt;br&gt;Dave Mitchell</td>
<td>Wisconsin Room</td>
</tr>
<tr>
<td>2:00-3:30 PM</td>
<td><strong>Game Time</strong>&lt;br&gt;Dave Mitchell</td>
<td>Wisconsin Room</td>
</tr>
<tr>
<td>3:30-5:00 PM</td>
<td><strong>Swim Time</strong>*&lt;br&gt;</td>
<td>Hotel Pool</td>
</tr>
<tr>
<td>7:00-9:00 PM</td>
<td><strong>Community Game Night</strong>*</td>
<td>Wisconsin Room</td>
</tr>
</tbody>
</table>
# CHILDREN’S ACTIVITIES
Ages 10 and under

**Saturday, July 27**

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
<th>Speaker(s)</th>
<th>Room</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:00-9:30 AM</td>
<td><strong>Ice Breakers</strong></td>
<td>Dave Mitchell</td>
<td>Wisconsin Room</td>
</tr>
<tr>
<td>9:30-10:30 AM</td>
<td><strong>Game Time with Zach and Ryan</strong></td>
<td>Zach Brunet and Ryan Piansky</td>
<td>Wisconsin Room</td>
</tr>
<tr>
<td>10:30-11:00 AM</td>
<td><strong>Living My Best Life with EGID</strong></td>
<td>Zach Brunet, Ryan Piansky, Amelia List</td>
<td>Wisconsin Room</td>
</tr>
<tr>
<td>11:00 AM-12:00 PM</td>
<td><strong>Craft/Activity</strong></td>
<td>Dave Mitchell</td>
<td>Wisconsin Room</td>
</tr>
<tr>
<td>1:00-2:00 PM</td>
<td><strong>Game Time with Zach and Ryan</strong></td>
<td>Zach Brunet and Ryan Piansky</td>
<td>Wisconsin Room</td>
</tr>
<tr>
<td>2:00-3:00 PM</td>
<td><strong>T-Shirt “Yearbooks”</strong></td>
<td>Dave Mitchell</td>
<td>Wisconsin Room</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A t-shirt will be provided for children to collect signatures from new friends they’ve made.</td>
<td></td>
</tr>
<tr>
<td><strong>Evening Activity:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7:00-9:30 PM</td>
<td><strong>Family Friendly Social Mixer</strong></td>
<td></td>
<td>Bethesdaan Ballroom</td>
</tr>
<tr>
<td></td>
<td>Open to all children of conference registrants, regardless of registration into the Children’s Activity Program.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## TWEEN PROGRAM

### SCHEDULE

**Thursday, July 25**

A variety of family friendly activities are planned for conference attendees on Thursday. We encourage tweens to participate in these activities with their parents. Please see the General Program agenda for details about these events.

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>11:15-3:30 PM</td>
<td><strong>Family Fun Day at the National Museum of Natural History</strong></td>
<td>National Museum of Natural History</td>
</tr>
<tr>
<td>4:00-6:00 PM</td>
<td><strong>Pool Party</strong></td>
<td>Hotel Pool</td>
</tr>
<tr>
<td>7:00-8:00 PM</td>
<td><strong>Meet and Greet</strong></td>
<td>Wisconsin Room</td>
</tr>
</tbody>
</table>

**Friday, July 26**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:30-10:00 AM</td>
<td><strong>Welcome and Ice Breakers: Spuddying (Speed Buddying)</strong> Brian List</td>
<td>Cordell Room</td>
</tr>
<tr>
<td>10:00-11:00 AM</td>
<td><strong>Scavenger Hunt</strong></td>
<td>The Bethesdaan Hotel</td>
</tr>
<tr>
<td>11:00 AM-12:00 PM</td>
<td><strong>Coping Techniques</strong></td>
<td>Cordell Room</td>
</tr>
<tr>
<td>12:00-1:00 PM</td>
<td><strong>Lunch</strong></td>
<td>On Own</td>
</tr>
<tr>
<td>1:00-1:30 PM</td>
<td><strong>Breaking Down Eos: What’s Going On Inside My Body?</strong> Amanda Muir, MD</td>
<td>Cordell Room</td>
</tr>
<tr>
<td>1:30-2:00 PM</td>
<td><strong>Eat Smart: True or False?</strong>                           Raquel Durban, MS, D, CSP, LD/N</td>
<td>Cordell Room</td>
</tr>
<tr>
<td>2:00-2:30 PM</td>
<td><strong>A Day in the Life of a Researcher</strong>                   Kelly Whelan, PhD</td>
<td>Cordell Room</td>
</tr>
<tr>
<td>2:30-3:15 PM</td>
<td><strong>Sock Wars</strong></td>
<td>Cordell Room</td>
</tr>
<tr>
<td>3:15 PM</td>
<td><strong>Conclusion</strong></td>
<td>Cordell Room</td>
</tr>
<tr>
<td>3:30-5:00 PM</td>
<td>(Optional Activity) <strong>Middle School Pool Social</strong>       Join the Tween Coordinators at the hotel pool at 3:30. We’ll hang out by the pool until 5pm.</td>
<td>Hotel Pool</td>
</tr>
<tr>
<td>7:00-9:00 PM</td>
<td>(Optional Activity) ** Tween Hangout**                  For middle schoolers who want to get together and need a place in the hotel to gather may do so in the Arlington Room on the 3rd floor. Please note that this is not a chaperoned session.</td>
<td>Cordell Room</td>
</tr>
</tbody>
</table>

**No parents in these sessions, please!**

The Tween Session is open to registrants who are at least age 11. For those who are rising high school freshman, you may enroll them into either the Tween Session or the Teen Session at your discretion. Tween registrants may participate in any of these sessions but are not required to. They are welcome to meet with their parents in the general sessions at any time, or rest as needed. APFED staff and volunteers will not supervise tweens outside of the sessions, so please plan accordingly.
# Tween Program Schedule

**Saturday, July 27**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Speaker(s)</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:30-10:00 AM</td>
<td>Ice Breakers: Quick Change Artist &amp; Quick Line Up</td>
<td>Brian List</td>
<td>Cordell Room</td>
</tr>
<tr>
<td>10:00-11:15 AM</td>
<td>Paracord Bracelets</td>
<td>Brian List</td>
<td>Cordell Room</td>
</tr>
<tr>
<td>11:15 AM–12:00 PM</td>
<td>Five Things EGID Has Taught Me</td>
<td>Zachary Brunet, Ryan Piansky, Amelia List</td>
<td>Cordell Room</td>
</tr>
<tr>
<td>12:00-1:00 PM</td>
<td>Lunch</td>
<td></td>
<td>Bethesdaan Foyer</td>
</tr>
<tr>
<td>1:00-1:40 PM</td>
<td>Eos Jeopardy 2.0</td>
<td>Brian List</td>
<td>Cordell Room</td>
</tr>
<tr>
<td>1:40-2:15 PM</td>
<td>Transitioning to High School</td>
<td>Remington Walls</td>
<td>Cordell Room</td>
</tr>
<tr>
<td>2:00-2:15 PM</td>
<td>Break</td>
<td></td>
<td>Cordell Room</td>
</tr>
<tr>
<td>2:15-3:50 PM</td>
<td>Escape Room</td>
<td>Brian List</td>
<td>Cordell Room</td>
</tr>
</tbody>
</table>

**Evening Activity:**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00-9:30 PM</td>
<td>Family Friendly Social Mixer</td>
<td>Bethesdaan Ballroom</td>
</tr>
</tbody>
</table>
**TEEN PROGRAM SCHEDULE**

**Thursday, July 25**

A variety of family friendly activities are planned for conference attendees on Thursday. We encourage teens to participate in these activities with their parents. Please see the General Program agenda for details about these events.

<table>
<thead>
<tr>
<th>Time</th>
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</tr>
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<tbody>
<tr>
<td>11:15-3:30 PM</td>
<td><strong>Family Fun Day at the National Museum of Natural History</strong></td>
<td>National Museum of Natural History</td>
</tr>
<tr>
<td>4:00-6:00 PM</td>
<td><strong>Pool Party</strong></td>
<td>Hotel Pool</td>
</tr>
<tr>
<td>7:00-8:00 PM</td>
<td><strong>Meet and Greet</strong></td>
<td>Arlington Room</td>
</tr>
</tbody>
</table>

**Friday, July 26**

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>10:00-11:00 AM</td>
<td><strong>Welcome and Ice Breakers</strong> Julie Forrest and Lisa Brunet</td>
<td>Arlington Room</td>
</tr>
<tr>
<td>11:00-11:30 AM</td>
<td><strong>Team Building</strong> Julie Forrest and Lisa Brunet</td>
<td>Arlington Room</td>
</tr>
<tr>
<td>12:00-1:00 PM</td>
<td><strong>Lunch</strong></td>
<td>On Own</td>
</tr>
<tr>
<td>1:00-2:00 PM</td>
<td><strong>Concurrent Sessions</strong></td>
<td>Bethesda A-B</td>
</tr>
<tr>
<td></td>
<td>Teens are encouraged to choose one of the suggested sessions to attend with their parents</td>
<td>Bethesda C-D</td>
</tr>
<tr>
<td></td>
<td>1. <strong>My Eos Patient Journey Panel</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. <strong>Transitions Series Workshop: Transferring from Pediatric to Adult Care</strong></td>
<td></td>
</tr>
<tr>
<td>2:00-2:15 PM</td>
<td><strong>Break</strong></td>
<td></td>
</tr>
<tr>
<td>2:15-3:15 PM</td>
<td><strong>Transitions Workshop</strong></td>
<td>Del Ray Room</td>
</tr>
<tr>
<td></td>
<td>Teens are encouraged to attend this suggested session with their parents</td>
<td></td>
</tr>
<tr>
<td>3:15-3:30 PM</td>
<td><strong>Break</strong></td>
<td></td>
</tr>
<tr>
<td>3:30 4:00 PM</td>
<td><strong>Relationships &amp; EOS</strong> Margo Szabo, PhD</td>
<td>Arlington Room</td>
</tr>
<tr>
<td>6:00-10:30 PM</td>
<td><strong>High Schoolers Field Trip</strong> Pre-registration required</td>
<td>Sandy Spring Adventure Park</td>
</tr>
<tr>
<td></td>
<td>Our Teen Program Coordinators Julie Forrest and Lisa Brunet will accompany teens on this trip. Transportation will be provided.</td>
<td></td>
</tr>
</tbody>
</table>

**No parents in these sessions, please!**

The Teen Session is open to registrants who are incoming 9th graders through recent completion of the 12th grade. Rising 9th graders may enroll into either the Tween Session or the Teen Session at your discretion. Teen registrants may participate in any of these sessions but are not required to. They are welcome to meet with their parents in the general sessions at any time, or rest as needed. APFED staff and volunteers will not supervise teens outside of the sessions, so please plan accordingly.
## TEEN PROGRAM

### SCHEDULE

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<tr>
<td>10:00-10:30 AM</td>
<td>Welcome and Ice Breakers</td>
<td>Julie Forrest and Lisa Brunet</td>
<td>Arlington Room</td>
</tr>
<tr>
<td>10:30-11:00 AM</td>
<td>Stump the Researcher: Game-Show Style Learning</td>
<td>Kelly Whelan, PhD</td>
<td>Arlington Room</td>
</tr>
<tr>
<td>11:00 AM-12:00 PM</td>
<td>EGIDs: High School vs. College</td>
<td>Remington Walls</td>
<td>Arlington Room</td>
</tr>
<tr>
<td>12:00-1:00 PM</td>
<td>Lunch</td>
<td></td>
<td>Bethesdan Foyer</td>
</tr>
<tr>
<td>1:00-1:30 PM</td>
<td>Games</td>
<td>Julie Forrest and Lisa Brunet</td>
<td>Arlington Room</td>
</tr>
<tr>
<td>1:30-2:00 PM</td>
<td>Gaining Independence: Navigating Food Choices on a Restricted Diet</td>
<td>Raquel Durban, MS, D, CSP, LD/N</td>
<td>Arlington Room</td>
</tr>
<tr>
<td>2:00-2:15 PM</td>
<td>Break</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2:15-2:45 PM</td>
<td>Are You Smarter Than A GI Doc? Game-Show Style Learning</td>
<td>Nick Caliaco, MD</td>
<td>Arlington Room</td>
</tr>
<tr>
<td></td>
<td><strong>Evening Activity:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7:00-9:30 PM</td>
<td>Family Friendly Social Mixer</td>
<td></td>
<td>Bethesdaan Ballroom</td>
</tr>
</tbody>
</table>
HELPFUL INFORMATION

Onsite Conference Contact
Laura Jackson
Phone: 317-509-1164

Hotel Information
DoubleTree by Hilton Bethesda
8120 Wisconsin Avenue
Bethesda, MD 20814
Phone: (301) 652-2000

Check in: 3:00 PM
Check out: Noon

The hotel features complimentary Wi-Fi in guest rooms, common areas, and meeting space, a 24 hour fitness facility, and outdoor rooftop pool.

Parking
The DoubleTree Bethesda has self-parking available for a daily rate of $25 with in/out privileges. Valet parking is not available.

Airport Transportation
The following airports are within close proximity to the DoubleTree Bethesda. The hotel does not provide shuttle service to or from any airport.

- Washington National Airport (DCA) – approximately 30 minutes
- Washington Dulles International Airport – approximately 35 minutes
- Baltimore/Washington International (BWI) – approximately 45 minutes

Refrigerators & Microwaves
All guest rooms feature an in-room refrigerator. In-room microwaves are available upon request. We do offer a Hospitality Suite exclusively for APFED conference attendees that is equipped with a full size refrigerator with freezer for storage of formula and safe foods, microwave, and sink. The Hospitality Suite will be open and staffed during published hours (see next page).

Meals
A continental breakfast and a boxed lunch will be provided to registered conference attendees on Saturday. We work hard to provide options for those following a 6-food elimination diet.

APFED works with the catering staff to educate them on how to avoid cross-contact and provides ingredient substitution and specialty food recommendations. We work to ensure catering staff labels all ingredients carefully, and that buffet items are separated with designated serving utensils. Please be cautious, read all food labels, and be aware that some foods may contain ingredients that you should avoid.
HELPFUL INFORMATION

Hospitality Suite
To provide for conference attendees who have formula or other dietary needs, we have provided a Hospitality Suite for food storage and preparation. The suite includes a refrigerator/freezer, microwave, sink, dish soap, paper towels, and disposable tableware. This room will be staffed and open during posted hours only. Anyone using the suite must be a conference attendee and must be over the age of 16 or with a legal adult.

Location: Room 1418 (Exclusive Use for APFED attendees)
Thursday, July 25 10:00 AM – 2:00 PM; 4:00 PM – 8:30 PM
Friday, July 26 7:00 AM – 1:00 PM; 4:00 PM – 8:30 PM
Saturday, July 27 7:00 AM – 1:00 PM; 4:00 PM – 8:30 PM
Sunday, July 28 7:00 AM – Noon

This room will be open during posted hours and locked when not in use. If you need to access the Hospitality Suite outside of the posted hours, please visit the registration desk or contact Laura Jackson, (317) 509-1164 for assistance.

Childcare
Children ages 11 and under are not permitted into conference sessions. Please see the agenda for child-friendly programming where children of all ages are welcome to attend. A children’s program is offered on Saturday for children ages 4-10 with a chaperone, who have pre-registered and various youth activities are planned. See pages 12-13 for more information. No childcare services are provided by APFED. Below are local services you may wish to contact to arrange childcare.**

White House Nannies Inc.
Phone (301) 654-1242
Email: temporary@whitehousenannies.com
Hours of Operation: Monday- Friday 9:00 AM - 5:00 PM

College Nannies, Sitters and Tutors
Phone: (240) 743-4950
Email: bethesdamd@collegenannies.com
Hours of Operation: Monday- Friday 9:30 AM - 6:30 PM

Nanny Pod - Sitters & Nannies
Phone: (202) 271-6345
Email: info@nannypod.com
Hours of Operation: Open 24 hours

**Please note, APFED has provided this information as a courtesy only. APFED does not endorse or recommend any particular childcare service. We recommend you consult with other sources to determine the reputation, reliability, and safety of childcare services.
Explore the Bethesda and Washington DC Areas!

This guide offers a sampling of things to see and experience, as well as some practical resources, during your visit to the Washington DC area for APFED’s 17th Annual Patient Conference.

Be sure to visit the website links for specific hours, ticket prices, exhibit descriptions, etc. If you have special needs, be sure to contact the venue and ask about its ability to accommodate.

**THINGS TO DO IN BETHESDA**

**Cabin John Regional Park**
7400 Tuckerman Lane, Bethesda, MD 20817
Hours: 8:00 am – 9:00 pm daily
Admission: Free

**National Museum of Health and Medicine**
2500 Linden Lane, Silver Spring, MD 20910
https://www.medicalmuseum.mil/
Hours: 10:00 am – 5:30 pm daily
Admission: Free

**Pike & Rose**
11580 Old Georgetown Road, Bethesda, MD 20852
http://pikeandrose.com/
Dining, shopping, bowling, movie theater and more

**Bethesda Row**
7111 Arlington Road, Bethesda, MD 20814
http://bethesdarow.com/
Premier dining and shopping

**Glen Echo Park**
7300 MacArthur Blvd, Glen Echo, MD 20812
https://glenechopark.org/
Hours: 10:00 am – 6:00 pm daily
THINGS TO DO IN WASHINGTON DC

MUSEUMS & ATTRACTIONS

**National Air and Space Museum**
Independence Ave at 6th St SW, Washington, DC 20560  
[https://airandspace.si.edu/](https://airandspace.si.edu/)  
Hours: 10:00 am – 5:30 pm daily  
Admission: Free

**National Museum of American History**
Constitution Ave, Between 12th & 14th Streets, Washington DC  
[https://americanhistory.si.edu/](https://americanhistory.si.edu/)  
Hours: 10:00 am – 5:30 pm daily  
Admission: Free

**National Museum of Natural History**
10th St & Constitution Ave. NW, Washington, DC 20560  
[https://naturalhistory.si.edu/](https://naturalhistory.si.edu/)  
Hours: 10:00 am – 5:30 pm daily  
Admission: Free

**National Postal Museum**
2 Massachusetts Ave. NE, Washington, DC 20002  
[https://postalmuseum.si.edu/](https://postalmuseum.si.edu/)  
Hours: 10:00 am – 5:30 pm daily  
Admission: Free

**National Building Museum**
401 F Stree NW, Washington, DC 20001  
[https://www.nbm.org/](https://www.nbm.org/)  
Hours: Monday-Saturday 10:00 am – 5:00 pm; Sunday 11:00 am – 5:00 pm  
Admission: Free

**Smithsonian National Zoological Park**
3001 Connecticut Ave NW, Washington, DC 20008  
[https://nationalzoo.si.edu/](https://nationalzoo.si.edu/)  
Hours: Monday-Sunday: 8:00 AM-5:00 PM  
Admission: Free

**Rock Creek Park**
Washington, DC 20008  
[https://www.nps.gov/rocr/index.htm](https://www.nps.gov/rocr/index.htm)  
Open during daylight hours
The White House Visitor Center
1450 Pennsylvania Ave NW, Washington, DC 20230
https://www.nps.gov/whho/planyourvisit/white-house-visitor-center.htm
Hours: 7:30 am – 4:00 pm daily
Admission: Free

International Spy Museum
800 F Street NW, Washington DC 20004
https://www.spymuseum.org/
Hours: Sunday-Friday 9:00 am – 7:00 pm; Saturday 7:00 am – 8:00 pm
Admission: Adult (13-64) $24.95; Youth (7-12) $14.95; Child (6 and under) Free; Senior/Military/Law Enforcement/Intelligence Community/College Student (with valid ID) $19.95
Save $2 per adult ticket when purchasing general admission online

Newseum
555 Pennsylvania Avenue NW, Washington, DC 20001
https://www.newseum.org/
Hours: Monday-Saturday 9:00 am – 5:00 pm; Sunday 10:00 am – 5:00 pm
Admission: Adults (19-64) $24.95, Seniors (65+) $19.95; Kids age 18 and younger visit free through Labor Day
15% discount for journalists, military, teachers and college students with applicable ID
10% discount for AAA members with applicable ID

Madame Tussauds
1001 F Street NW, Washington, DC 20004
Hours: Sunday-Thursday 10:00 am – 6:00 pm; Friday & Saturday 10:00 am – 8:00 pm
Admission: Adults (13+) from $22; Children (3-12) from $17.50; discounts available when purchasing tickets online

US Botanic Garden
100 Maryland Ave. SW, Washington, DC 20024, United States
https://www.usbg.gov/
Hours: Conservatory & National Garden 10:00 am – 7:00 pm daily; Bartholdi Park open daily dawn-dusk
Admission: Free

National Capital Trolley Museum
1313 Bonifant Rd, Silver Spring, MD 20905
https://dctrolley.org/
Hours: Friday 10:00 AM-2:00 PM, Saturday- Sunday 12:00 PM-5:00 PM
Admission: Adults (18-64) $10; Children (2-17) & Seniors (65+) $8
United States National Arboretum
3501 New York Ave NE, Washington, DC 20002
https://usna.usda.gov/
Hours: Arboretum grounds 8:00 am – 5:00 pm daily; Visitor Center 8:00 am – 4:30 pm daily; National Bonsai & Penjing Museum 10:00 am – 4:00 pm daily
Admission: FREE

United States Holocaust Memorial Museum
100 Raoul Wallenburg Pl. SW, Washington, DC 20024 (National Mall)
https://www.ushmm.org/
Hours: 10:00 am – 5:30 pm daily
*Timed passes are required to view the permanent exhibition; they are not required to enter the museum or special exhibitions
Admission: Free

Ford’s Theatre & The Petersen House
511 10th Street NW, Washington, DC 20004
https://www.fords.org/
Hours: 9:00 am – 4:30 pm
Tickets required; timed entry every half hour – same day tickets are limited, The theatre is sometimes unavailable. Be sure to check online for tickets that include entry into the theater

Washington National Cathedral
3101 Wisconsin Ave NW, Washington, DC 20016
https://cathedral.org/
Hours: Monday-Friday 10:00 AM-5:00 PM, Saturday 10:00 AM-4:00 PM, Sunday 12:45 PM- 4:00 PM
Admission: Adults (ages 18+): $12 Youth (ages 5 - 17) and Teachers with ID: $8 Children (under 5): Free. *$8 for seniors, students (with ID), active military (with ID) and veterans
*No admission charges for tours on Sunday

MONUMENTS & MEMORIALS
Memorials are open 24 hours a day. Rangers are on duty to answer questions from 9:30 am – 10:00 pm daily.

Franklin Delano Roosevelt Memorial
400 W. Basin Drive SW, Washington, DC 20024

Jefferson Memorial
701 E. Basin Drive SW, Washington, DC 20242

Martin Luther King, Jr. Memorial
1964 Independence Ave SW, Washington, DC 20204

National World War II Memorial
17th Street & Independence Ave NW, Washington, DC 20001

Korean War Veterans Memorial
10 Daniel French Drive SW, Washington, DC 20037

Lincoln Memorial
2 Lincoln Memorial Circle NW, Washington, DC 20037

Vietnam Veterans Memorial
5 Henry Bacon Drive NW, Washington, DC 20425

Vietnam Women's Memorial
21st Street & Constitution Ave NW, Washington, DC 20007
BETHELDA AREA RESTAURANTS

Guapo’s (1 minute walk from hotel)
8130 Wisconsin Ave, Bethesda, MD 20814
https://www.guaposrestaurant.com/

Barrel & Crow (3 minute walk from hotel)
4867 Cordell Ave, Bethesda, MD 20814
http://barrelandcrow.com/

Black’s Bar & Kitchen (6 minute walk from hotel)
7750 Woodmont Ave, Bethesda, MD 20814
http://www.blacksbarandkitchen.com/

Olazzo (4 minute walk from hotel)
7921 Norfolk Ave, Bethesda, MD 20814
https://www.olazzo.com/

Manny & Olga’s Pizza (Delivery & carryout)
https://mannyandolgas.com/

Pizzeria Da Marco (2 minute walk from hotel)
8008 Woodmont Ave, Bethesda, MD 20814
http://www.pizzeriadamarco.net/home.aspx

Brickside Food & Drink (3 minute walk from hotel)
4866 Cordell Ave, Bethesda, MD 20814
https://bricksidebethesda.com/

Chipotle (9 minute walk from hotel)
7600 Old Georgetown Rd, Bethesda, MD 20814
http://www.ddgbethesda.com/

Dining options at Pike & Rose
http://pikeandrose.com/dine/

Dining options at Bethesda Row
http://bethesdarow.com/eat/

BETHELDA AREA ALLERGY-FRIENDLY RESTAURANTS

One Dish Cuisine Cafe, Deli and Bakery
Taylor Village Center, 8001 Hillsborough Rd
Ellicott City, MD 21043
https://www.onedishcuisine.com/
Gluten-free, certified gluten-free, allergen-friendly and vegan-friendly café, deli and bakery
Facility is free of: Gluten (wheat, rye, barley), oats, soy, eggs, fish, shellfish, sesame, peanuts and tree nuts (except coconut in very limited products)

True Food Kitchen
7100 Wisconsin Ave Bethesda, MD 20814
https://www.truefoodkitchen.com/
Vegan, gluten free, dairy free options available

Lilit Café
7921 Old Georgetown Rd, Bethesda, MD 20814
https://lilitcafe.com/
Gluten free, dairy free, and vegan options available

Red Bandana Bakery
8218 Wisonsin Ave, Ste 101, Bethesda, MD 20814
https://theredbandanabakery.com/
Vegan, gluten free dairy free, and nut free options available

Not Your Average Joe’s
10400 Georgetown Ave, Bethesda, MD 20814
https://www.notyouraveragejoes.com/
Strives to accommodate all types of special diets and allergies
EMERGENCY CARE

**Bethesda Immediate Care** (0.1 miles, 3 minute drive from hotel)
8305 Wisconsin Ave, Bethesda, MD 20814
Phone: (301) 800-7000
Hours: Monday-Friday 8:00am-7:00pm; Saturday-Sunday 8:00am-5:00pm

**Suburban Hospital: Emergency Room** (1.3 miles, 5 minute drive from hotel)
8600 Old Georgetown Rd, Bethesda, MD 20814
Phone: (301) 896-3880

**Walter Reed National Military Medical Emergency Room** (0.6 miles, 5 minute drive from hotel)
4494 Palmer Road N, Bethesda, MD 20889
Phone: (301) 295-4810

**Holy Cross Hospital Emergency Room** (4.8 miles, 14 minute drive from hotel)
1500 Forest Glen Rd, Silver Spring, MD 20910
Phone: (301) 754-7000

PHARMACIES

**Foer's Pharmacy** (2 min walk from hotel)
8218 Wisconsin Ave, P-15, Bethesda, MD 20814
Phone: (301) 657-3500
Hours: Monday-Friday 8:30 am-5:00 pm

**Harris Teeter Pharmacy** (2 min walk from hotel)
4805 Battery Ln, Bethesda, MD 20814
Phone: (240) 630-8635
Hours: Monday-Friday 9:00 AM-8:00 PM, Saturday 9:00 AM-6:00 PM, Sunday 11:00 AM-6:00 PM

**CVS** (5 min walk from hotel)
7809 Wisconsin Ave, Bethesda, MD 20814
Phone: (301) 986-9144
Hours: Monday-Friday 8:00am-10:00pm; Saturday 9:00-6:00pm; Sunday 10:00am-6:00pm
GROCERY STORES

Harris Teeter (2 min walk from hotel)
4805 Battery Ln, Bethesda, MD 20814
Phone: (240) 630-8635
Hours: Monday-Sunday 6:00 AM-12:00 AM

Pescadeli
4960 Bethesda Ave, Bethesda, MD 20814
Hours: Monday-Friday 10:00 AM-8:00 PM, Saturday 9:00 AM-7:00 PM, Sunday 10:00 AM-6:00 PM

Whole Foods Market
5269 River Rd, Bethesda, MD 20816
Hours: Monday-Sunday 7:30 AM-9:00 PM

Trader Joe's
6831 Wisconsin Ave, Bethesda, MD 20815
Hours: Monday-Friday 8:00 AM-9:00 PM

GETTING AROUND

Bethesda Metro Station (10 min drive from hotel)
7450 Wisconsin Ave, Bethesda, MD 20814
https://www wmata com/rider-guide/stations/bethesda cf m

Taxi Services
The hotel concierge can also assist with arranging a taxi. Uber & Lyft services are also available.

Airport Taxi and Bethesda Taxi Barwood Taxi Orange Taxi
240-582-3130 301-984-1900 301-912-0000

Directions to Washington National Airport (DCA)
➢ Head west toward Woodmont Ave (164 ft)
➢ Turn left at the 1st cross street onto Woodmont Ave (177 ft)
➢ Turn left at the 1st cross street onto Cordell Ave (154 ft)
➢ Continue straight to stay on Cordell Ave (112 ft)
➢ Turn left onto Wisconsin Ave (0.8 mi)
➢ Continue on MD-355N/Rockville Pike (1.0 mi)
➢ Take the Interstate 495/Beltway W ramp on the left to Northern Virginia (0.2 mi)
➢ Merge onto I-495 W (6.6 mi)
Directions to Washington National Airport (DCA) continued

- Take exit 43-44 for VA-193/George Washington Memorial Parkway/Georgetown Pike toward Washington (0.4 mi)
- Keep right at the fork to continue on Exit 43, follow signs for Geo Washington Memorial Pkwy/Washington (0.6 mi)
- Continue onto George Washington Memorial Pkwy (10.9 mi)
- Take the ramp to Reagan National Airport

Directions to Washington Dulles International Airport (IAD)

- Head west toward Woodmont Ave (164 ft)
- Turn left at the 1st cross street onto Woodmont Ave (177 ft)
- Turn left at the 1st cross street onto Cordell Ave (154 ft)
- Continue straight to stay on Cordell Ave (112 ft)
- Turn left onto Wisconsin Ave (0.8 mi)
- Continue on MD-355N/Rockville Pike (1.0 mi)
- Take the Interstate 495/Beltway W ramp on the left to Northern Virginia (0.2 mi)
- Merge onto I-495 W (6.6 mi)
- Take exit 45A to merge onto VA-267 W toward Dulles Airport (9.5 mi)
- Take exit 9A to more onto VA-28 S toward Centerville/Manassas (12.6 mi)
- Take the exit toward Dulles Airport

Directions to Baltimore/Washington International Airport (BWI)

- Head west toward Woodmont Ave (164 ft)
- Turn left at the 1st cross street onto Woodmont Ave (177 ft)
- Turn left at the 1st cross street onto Cordell Ave (154 ft)
- Continue straight to stay on Cordell Ave (112 ft)
- Turn left onto Wisconsin Ave (0.4 mi)
- Turn right on Jones Bridge Rd (1.1 mi)
- Sharp left onto Connecticut Ave (0.3 mi)
- Take the Interstate 495 E ramp to Baltimore/Silver Spring (0.2 mi)
- Merge onto I-495 E (6.6 mi)
- Take exit 27 for I-95 N (1.3 mi)
- Continue onto I-95 N (18.4 mi)
- Keep left at the fork to stay on I-95 N (0.8 mi)
- Take exit 47 A-B toward Interstate 195 E/BWI Thurgood Marshall Airport/MD-166/Catonsville (0.3 mi)
- Keep right at fork to continue on Exit 47A, follow signs for Interstate 195E/BWI Thurgood Marshall Airport and merge onto I-195 E (4.2 mi)
2019 SPEAKERS, MODERATORS, AND PANELISTS

**Oral Alpan, MD**  
**Laboratory and Medical Director, Amerimmune**  
**Associate Professor of Pediatrics, Virginia Commonwealth University**

Oral Alpan, MD is the Laboratory and Medical Director of Amerimmune in Fairfax, Virginia, and Associate Professor of Pediatrics at Virginia Commonwealth University’s Inova Campus in Falls Church. He received his medical degree in 1990 from Hacettepe University Faculty of Medicine in Ankara, Turkey. Dr. Alpan continued his education with an internship and residency in Pediatrics at Stony Brook University in New York and a fellowship in Allergy/Immunology at the National Institute of Allergy and Infectious Diseases in Bethesda, Maryland. Board-certified in Allergy and Immunology, Dr. Alpan is a member of the American Academy of Allergy, Asthma & Immunology. He is a Principal Investigator on numerous research studies in the field of immunology asthma and allergic disorders, and he has published a numerous articles and abstracts in peer-reviewed journals. His main interests are in immune dysregulation and development of assays to measure such immune responses.

**Alain Benitez, MD**  
**Instructor of Pediatrics, Research, Perelman School of Medicine at the University of Pennsylvania**  
**Division of Gastroenterology, Hepatology and Nutrition, Children’s Hospital of Philadelphia (CHOP)**

Alain Benitez, MD completed his medical degree at Universidad Iberoamericana (UNIBE) in the Dominican Republic and started his research career at the University of Miami (UM) where he designed and implemented translational research studies with a focus on autoimmune disorders. In 2010, Dr. Benitez took a position at Children’s Hospital of Philadelphia (CHOP) in the Center for Injury Research and Prevention (CIRP), studying the psychosocial effect of traumatic injury in children. In 2011, Dr. Benitez joined the Division of Gastroenterology, Hepatology & Nutrition at CHOP developing clinical research protocols and performing animal studies focused on eosinophilic esophagitis (EoE) associated inflammation, fibrosis, and microbiota. One of his main accomplishments was the development of the EoE Cellie Coping Kit. In 2017, Alain joined the Center for GI Motility at CHOP where he serves as the Director of Clinical Research and is building a comprehensive translational research program studying functional GI and motility disorders.

**Wendy Book, MD**  
**Director, Emory Adult Congenital Heart Center (Atlanta, GA)**  
**President, American Partnership for Eosinophilic Disorders**

Wendy Book, MD has been involved in a volunteer capacity on the executive board of APFED, serving as the board’s President since 2009. She has led education, advocacy, research, and awareness efforts leading to the creation of National Eosinophil Awareness Week, NIH report language, the NIH Task Force on the Research Needs of Eosinophil-Associated Diseases (TREAD) document, insurance coverage of medical foods, and development of ICD-9-CM codes for eosinophilic gastrointestinal diseases. She assisted in development of APFED’s research grant program which has more than $2.2 million to date. Her efforts have led to collaborations with other patient advocacy groups, physicians, medical societies, and federal agencies. Her experience as a parent of a chronically ill child, and as a physician, provides a unique perspective on the patient experience and challenges involved in navigating the medical system.
Terri Brown-Whitehorn, MD
Attending Physician, Division of Allergy, the Center for Pediatric Eosinophilic Disorders and the Integrative Health Program, Children’s Hospital of Philadelphia
Associate Professor of Clinical Pediatrics, Perelman School of Medicine at the University of Pennsylvania
Terri Brown-Whitehorn, MD is an Associate Professor of Clinical Pediatrics at The Perelman School of Medicine at the University of Pennsylvania and Children’s Hospital of Philadelphia. She completed her medical training at University of Missouri, Kansas City, post-doctoral research at St. Jude Children’s Research Hospital, and her pediatric residency and Allergy/Immunology fellowship at Children’s Hospital of Philadelphia. She is very active in the care of patients with IgE mediated food allergy, eosinophilic esophagitis, and food protein induced enterocolitis. She was one of the first allergists involved in the Center for Pediatric Eosinophilic Disorder clinic bringing patients, families, allergy, gastroenterology and nutrition together at the same time (since 2006!) and is the founder and director of the food protein induced enterocolitis center. She is co-director of the Children’s Hospital of Philadelphia Frontier grant for food allergy (allowing for expansion in the clinical and research arms of all things food allergy). She has co-written papers, spoken locally and nationally, and is very excited to speak on: Eosinophilic associated GI disease, an overview.

Nick CaJacob, MD
Director, Alabama Center for Eosinophilic Gastrointestinal Disorders, Children’s of Alabama
Assistant Professor, Division of Pediatric Gastroenterology, Hepatology, and Nutrition, Department of Pediatrics, The University of Alabama at Birmingham
Nick CaJacob, MD is the director of the Alabama Center for Eosinophilic Gastrointestinal Disorders (ACED) at Children’s of Alabama in Birmingham, Alabama. His research interests include eosinophilic gastrointestinal disorders and healthcare quality improvement. During fellowship, he completed a pilot study characterizing the esophageal and colonic microbiome in patients with eosinophilic esophagitis using esophageal bushings and stool samples. He also completed a study characterizing the eosinophilic esophagitis patient population at Children’s of Alabama. The Alabama Center for Eosinophilic Gastrointestinal Disorders is an active participant in industry sponsored drug trials for eosinophilic esophagitis. The team is currently focused on developing a patient registry in collaboration with our adult counterparts at University of Alabama at Birmingham to be used for clinical care, quality, and patient safety initiatives. This joint venture will improve our transition of care from pediatric to adult providers.

Catina Cox
Vice President, Hub Operations, CareMetx, LLC
Catina joined CareMetx in 2013. She brings over 20 years of program implementation and management experience to her role as Vice President of Hub Operations. From 1999 until 2013, Catina was responsible for implementing and managing drug program teams at TheraCom and then the Lash Group. In this role, she worked closely with biotech manufacturers such as Genzyme, Endo, Novartis, Alkermes, Gilead, and many more. Her responsibilities required close collaboration with clients, operations, and IT to ensure successful program launches. She worked closely with clients to create standard operating procedures, policies and process improvements. Her knowledge of the industry and reimbursement experience led her to be the key coach and mentor for new program managers joining the Lash Group.
Mirna Chehade, MD, MPH
Associate Professor of Pediatrics and Medicine, Icahn School of Medicine at Mount Sinai, New York
Director, Mount Sinai Center for Eosinophilic Disorders

Mirna Chehade, MD, MPH is Associate Professor of Pediatrics and Medicine at the Icahn School of Medicine at Mount Sinai, New York. She is the founding director of the Mount Sinai Center for Eosinophilic Disorders (MSCED). The Center provides cutting edge clinical care, research, and support for patients with eosinophilic gastrointestinal diseases and their families, including eosinophilic esophagitis (EoE) and eosinophilic gastroenteritis. Dr. Chehade has been repeatedly voted as a Castle Connolly top doctor in Pediatric Gastroenterology. She runs several clinical and translational research studies on EoE. She is also a site Principal Investigator in multi-center clinical trials on EoE, and a site principal investigator in the NIH-funded Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR). Dr. Chehade has several publications on gastrointestinal food allergies and eosinophilic gastrointestinal disorders. She is an active member in national and international organizations, including AAAAI, EAACI, NASPGHAN and AGA. She also volunteers as a member of the medical advisory boards of the American Partnership for Eosinophilic Disorders (APFED). Dr. Chehade is a frequently invited speaker at national and international meetings, and an invited reviewer for a number of gastroenterology and allergy journals.

Evan Dellon, MD, MPH
Associate Professor of Medicine and Epidemiology, University of North Carolina School of Medicine

Evan S. Dellon, MD, MPH, is a Professor of Medicine and Epidemiology at the University of North Carolina (UNC) School of Medicine in Chapel Hill. Dr. Dellon received his undergraduate degree from Brown University and his medical degree from Johns Hopkins School of Medicine. He completed internship and residency in Internal Medicine at Massachusetts General Hospital. He performed a clinical and a research fellowship in Adult Gastroenterology at UNC, during which he also received a Masters of Public Health degree in Epidemiology from the UNC School of Public Health. Dr. Dellon joined the UNC faculty and the Center for Esophageal Diseases and Swallowing (CEDAS) in 2008, where his main clinical focus is on disorders of swallowing, and eosinophilic esophagitis (EoE), and the other eosinophilic gastrointestinal diseases (EGIDs). He became Director of CEDAS in 2014, and has been an Associate Editor for Clinical Gastroenterology and Hepatology since 2017. Dr. Dellon’s main research interest is in the epidemiology, pathogenesis, diagnosis, treatment, and outcomes of EoE, as well as similar investigations into the other EGIDs. The goal of his research is to improve the lives of patients with EGIDs by learning how to better diagnose, treat, and monitor the conditions. He is widely published in this area and collaborates with investigators all over the world. Dr. Dellon has received research funding from the National Institutes of Health, the American College of Gastroenterology, the American Gastroenterologic Association, the CURED Foundation, UNC, and a number of industry partners to study EoE. He is a member of the NIH-funded Consortium of Eosinophilic Gastrointestinal Diseases Researchers (CEGIR).

Megan Gordon Don
President & CEO, MGD Strategies LLC

Megan Gordon Don founded MGD Strategies LLC in 2017 to develop high-impact advocacy initiatives for clients so that they can achieve their public policy goals while also leveraging these efforts to grow their organization. Gordon Don has extensive experience in developing grassroots advocacy programs and legislative campaigns for nonprofit patient associations, coalition management, working with the broader public health policy communities, and strategic planning. As the head of the Pancreatic Cancer Action Network’s (PanCAN) Government Affairs & Advocacy Office for nearly 11 years, she led legislative and
grassroots campaigns that resulted in the passage of the Recalcitrant Cancer Research Act – landmark legislation that is opening new avenues of NCI-supported research for pancreatic cancer; Department of Defense funding for pancreatic cancer research through the Peer-Reviewed Cancer Research Program; establishment and continued growth of the Congressional Caucus on the Deadliest Cancers; and others. Grassroots engagement and training has been one of Gordon Don’s key areas of focus during her career. Under her leadership, PanCAN grew its grassroots advocacy engagement 500%; its Advocacy Day participation over 300% (over 600 participants in 2017 from all 50 states) and the organization’s advocates became well recognized as a dedicated and passionate force on Capitol Hill. Gordon Don’s previous experience includes working as the American Cancer Society’s lead federal lobbyist on health insurance and drug development issues, a congressional healthcare legislative aide, the Director of Socioeconomics and Quality Management for the Dallas County Medical Society and as a healthcare industry analyst for Andersen Consulting (now known as Accenture). Gordon Don established the Deadliest Cancers Coalition in 2008 and continues to serve as its executive director. She also serves as the Treasurer of the One Voice Against Cancer (OVAC) coalition and has served on the board of directors for United for Medical Research (UMR) and as the Government Relations Affinity Group (GRAG) Chair for the National Health Council. Gordon Don received her BA in modern European studies from Smith College and her MHS in health policy & management from Johns Hopkins University.

Raquel Durban, MS, RD, CSP, LD/N Adjunct Professor, Winthrop University
Asthma & Allergy Specialists, PA (Charlotte, NC)
Food Allergy Institute of Charlotte
Raquel Durban, MS, RD, CSP, LD/N is a registered dietitian at Asthma & Allergy Specialists, PA in Charlotte, NC. She is board certificated in pediatric nutrition. In addition to ensuring her patient’s quality of life through practical and appropriate nutrition, Raquel serves on the steering committee for the International Network for Diet and Nutrition in Allergy (INDANA) and is an active member of the American Academy of Asthma, Allergy and Immunology (AAAAI) as a member of the Eosinophilic Gastrointestinal Disorders and Adverse Reactions to Foods committees. Through these committees, she participates in education, research initiatives, and academic publications. Additionally, Raquel is a medical advisor to the Food Allergy and Anaphylaxis Connection Team (FAACT) and the International FPIES Association (I-FPIES). To further her dedication and support to the food allergic community, she facilitates a support group for patients/caregivers with eosinophilic disorders, Charlotte Supports EOS. Raquel also has a love for teaching nutrition and is an adjunct professor for Winthrop University and co-creator of the INDANA mentor program helping to provide coursework and hands on education to budding dietitians.

Gary Falk, MD, MS
Professor of Medicine, Director, Esophageal Program, Hospital of the University of Pennsylvania
Gary W. Falk, MD, MS, is currently Professor of Medicine and director of the Esophageal Program at the Hospital of the University of Pennsylvania. Dr. Falk received his undergraduate and medical school training at the University of Rochester, before going to George Washington University for his medical internship and residency. After a clinical and research fellowship at the University of Michigan, he was a member of the Department of Gastroenterology and Hepatology at the Cleveland Clinic, for more than 23 years where he was director for the Swallowing and Esophageal Center. While in Cleveland, he also received a master’s degree in clinical research from Case Western Reserve University. He has been involved in clinical research in Barrett’s esophagus, gastroesophageal reflux disease, Helicobacter pylori, esophageal motility disorders, advanced esophageal imaging and therapeutics, and eosinophilic esophagitis that has resulted
in over 150 peer reviewed publications. The most important of these themes has been in the area of early detection and prevention of esophageal cancer. Research in eosinophilic esophagitis is now focusing on clinical trials of novel therapeutic agents, clinical and biologic aspects of pediatric to adult transition, and participation in the Consortium of Eosinophilic Gastrointestinal Disease Researchers consortium. Dr. Falk has served nationally in GI professional societies, including being a past-president of ASGE, past associate editor of the American Journal of Gastroenterology and past editor of AGA Perspectives. He is a recipient of the Sidney Cohen University of Pennsylvania GI Fellowship Teacher of the Year Award on two occasions, AGA Distinguished Clinician Award, and AGA Imaging & Advanced Technology Section Research Mentor Award.

Bridget Godwin, MD
Assistant Professor of Pediatrics, University of Pennsylvania Perelman School of Medicine
Attending Physician, Division of Gastroenterology, Hepatology & Nutrition, Children’s Hospital of Philadelphia

Bridget Godwin, MD is a pediatric gastroenterologist at Children's Hospital of Philadelphia. She attended college at New York University where she majored in English and American Literature. She later decided to pursue medicine and attended medical school at Brown University where she had a concentration in mindfulness and integrative medicine. She returned to Manhattan for residency in Pediatrics at New York Presbyterian-Weill Cornell, and then to her hometown of Philadelphia for her fellowship in Gastroenterology, Hepatology, and Nutrition at Children's Hospital of Philadelphia. She practices there today, specializing in allergic conditions of the GI tract and seeing patients in the Center for Pediatric Eosinophilic Disorders.

Pamela A. Guerrerio, MD, PhD
Chief, Food Allergy Research Unit (FARU)
Laboratory of Allergic Diseases, National Institute of Allergy and Infectious Diseases,
National Institutes of Health

Pamela A. Guerrerio, MD, PhD graduated summa cum laude with a BS degree in biology from the University of Iowa and subsequently entered the Medical Scientist Training Program at Johns Hopkins University, where she completed medical school and a PhD in human genetics. She also did her residency in Pediatrics and fellowship in allergy and immunology at Johns Hopkins. In 2014, Dr. Guerrerio was appointed Chief of the Food Allergy Research Unit at the National Institutes of Health. Her research program is focused on understanding the genetic and immunologic mechanisms that lead to food allergy, eosinophilic esophagitis, and related diseases, and identifying strategies to improve the care of these patients. Dr. Guerrerio has received a number of awards for her research, including the ARTrust Faculty Development Award from the American Academy of Asthma, Allergy & Immunology and the Presidential Early Career Award for Scientists and Engineers (PECASE).

Tara Hosseini
Patient Advocate

Tara Hosseini was diagnosed with hypereosinophilic syndromes when she was 9 years old after a few years of chronic sinusitis, severe asthma, leg rashes, joint pain, nausea, vomiting, rapid weight loss, and fatigue. She is now 24 years old living in Washington, D.C. and is a law student at the George Washington University.
Christina Illardi, RN
Parent and Advocate
Christina Illardi has been in the nursing and advocacy for more than 14 years and is mother to three children who all live with allergic disease including eosinophilic esophagitis, asthma, and mast cell activation, in addition to Ehlers Danlos Syndrome and Dysautonomia. In 2015 she founded a group dedicated to sharing and understanding research in eosinophil associated diseases (READ) to help bridge the gap between clinicians/researchers and patients. She feels strongly about accessibility of medical research to patients and their families and strives to help patients both obtain relevant research and understand its applicability in various contexts.

Paneez Khoury, MD
Allergist/Immunologist, Human Eosinophil Section, National Institutes of Health
Paneez Khoury, MD is an investigator in the Human Eosinophil Section of the National Institutes of Health (NIH) where she is involved in clinical and translational research. Her research interests span a variety of eosinophilic disorders including hypereosinophilic syndromes (HES), eosinophilic granulomatosis with polyangitis (EGPA), eosinophilic gastrointestinal disorders (EGIDs), Gleich’s syndrome, eosinophilic fasciitis, as well as development of patient-centered outcome and quality-of-life instruments for patients with HES. In addition to being an investigator in clinical trials and natural history clinical studies for these disorders, she spends her time training and mentoring Allergy/Immunology fellows as the Associate Program Director for the A/I fellowship training program, and she serves on the Board of the International Eosinophil Society.

Amy Klion, MD
Internist, Senior Clinical Investigator, Human Eosinophil Section, National Institutes of Health
Amy D. Klion, MD is a Senior Clinical Investigator and Head of the Human Eosinophil Section in the Laboratory of Parasitic Diseases at the National Institutes of Health (NIH). Her research program includes basic and translational research related to the role of the eosinophil and eosinophil activation in disease pathogenesis. The ultimate goal of her laboratory is to develop novel diagnostic tools and treatment approaches for hypereosinophilic syndromes (HES) and other conditions associated with marked eosinophilia, including helminth infection. Dr. Klion is past president of the International Eosinophil Society and recipient of the society’s 2015 service award. She has served on the editorial boards of Blood and the Journal of Allergy and Clinical Immunology and numerous advisory committees and expert panels related to her work on eosinophilic disorders and neglected tropical diseases. She is the author of more than 150 scholarly articles, reviews, and textbook chapters.

Fei Li Kuang, MD, PhD
Allergist/Immunologist, Human Eosinophil Section, National Institutes of Health
Fei Li Kuang, MD, PhD is an allergist/immunologist at the National Institutes of Health (NIH). A MD-PhD graduate of the Albert Einstein College of Medicine with publications in B cell biology, Dr. Kuang completed her internship and residency in Internal Medicine at Columbia-New York Presbyterian Hospital. She completed her Allergy/Immunology fellowship at the National Institute of Allergy and Infectious Diseases (NIAID) and remains there seeing patients with and performing scientific research on eosinophilic disorders, in particular hypereosinophilic syndromes (HES) with all its different clinical subtypes. Along with Drs Amy Klion and Paneez Khoury in the Human Eosinophil Section in NIAID, she has published a
number of scientific articles on the use of biologic therapies in HES. She is interested in understanding the causes of eosinophilia in human disease and the role of eosinophils may play in human health.

Angie Lozano
Operations Manager, CareMetx, LLC
Angie has nearly 20 years of healthcare experience, including clinical support, billing, customer service, reimbursement, patient and prescriber advocacy, financial assistance programs and training in various settings such as Medical Offices and Hubs for pharmaceutical companies. She has taken part in the implementation and launch of various support programs for multiple disease states, with a primary focus on successful patient access to therapies. Having held various roles within the healthcare industry, her knowledge in reimbursement and Hub operations is extensive.

Christopher Lucas
Patient Advocate
Chris Lucas is a 37 year old finance professional for a Rare Disease Biotech Company in Central NJ. He was formally diagnosed with idiopathic hypereosinophilic syndrome (HES) at the age of 34 after ~20 years of managing symptoms without a diagnosis. Chris enjoys spending time with family, golfing (when physically possible), and living life to the fullest possible.

Jada Mahoney
Patient Advocate
Jada Mahoney is a 15-year-old rising junior at Collegiate School in Richmond, VA. She was diagnosed with hypereosinophilic syndromes (HES) at the age of 7. Jada enjoys community service, hiking, traveling, and rows on a crew team during the fall and spring seasons. Although having HES for the majority of her life has been challenging, Jada sees it as a blessing in that it motivates her to try new things and live life to its fullest.

Amanda Muir, MD
Assistant Professor of Pediatrics, Division of Gastroenterology, Hepatology and Nutrition, Children’s Hospital of Philadelphia
Dr. Muir’s clinical and research goal is to improve the lives of children with eosinophilic esophagitis (EoE) and prevent the devastating consequences of esophageal inflammation and subsequent fibrosis. Following her training in general pediatrics, her foundation in mucosal immunology led to a natural interest in pediatric gastroenterology, in which perturbations in the balance between environmental factors and host innate immune responses have a profound impact upon human growth and development. During her clinical fellowship year, her interactions with patients and families affected by EoE increased her dedication to increasing the medical community’s understanding of its underlying pathology. Among its many complications, esophageal fibrosis is the most striking complication of EoE, predisposing subjects to recurrent food impactions, emergent endoscopy, impaired esophageal motility, and esophageal stricture.

Emily Parks
Patient Advocate, Young Adult Representative of Rare Disease Legislative Advocates
Emily Parks is a 26-year-old professional living on HPN due to GI conditions since infancy. Her lived experience of collaborating with hospitals and healthcare professionals across multiple healthcare
systems has provided her with insight on hospital management and administration, governmental healthcare policy, and the impact of authentic and conscious patient-centered care. She serves as an HPN Ambassador for The Oley Foundation, a contributing writer for the Australian based newsletter Dripline, and presenter for IHI’s National Healthcare Forum 2018 and Stanford Med X Change 2019. She currently resides outside of Washington, D.C. pursuing a career in patient advocacy and healthcare policy reform.

**Shelly Parks**  
**Patient Advocate**

Shelly Parks began her battle with hypereosinophilic syndromes (HES) in 2016. Before becoming ill, she graduated with her second master’s degree at the age of 26, was a CrossFit competitor, and enjoyed life with her boyfriend and their dog. Since her diagnosis, Shelly has dedicated her time and efforts to support patients with eosinophil-associated disease. She works closely with APFED to spread awareness and educate others about these conditions, has advocated on the federal level for the insurance coverage of medical foods, has shared her perspective to inform stakeholders about meaningful therapies for HES patients, and organizes fundraisers to benefit to support critical research needs in the hopes of finding a cure.

**Ryan Piansky**  
**Patient Advocate**

Ryan is a 19-year-old college student at the Georgia Institute of Technology. He has eosinophilic esophagitis as well as eosinophilic asthma and follows a restricted diet. Despite health issues, he leads an active life including travel and patient advocacy efforts.

**Melanie Ruffner, MD, PhD**  
**Attending Physician, Division of Allergy and Immunology, Attending Physician, Center for Eosinophilic Disorders, Children’s Hospital of Philadelphia**

Melanie Ruffner, MD, PhD is a board-certified Pediatric Allergy and Immunology physician at the Children’s Hospital of Philadelphia (CHOP). She sees patients in the CHOP Center for Pediatric Eosinophilic Disorders, where she diagnoses and treats patients with eosinophilic disorders within the collaborative setting including allergists, gastroenterologists and nutritionists. Dr. Ruffner completed her medical and graduate education at the University of Pittsburgh and her medical training at the Children’s Hospital of Philadelphia. She has several publications on gastrointestinal food allergies and eosinophilic GI disorders. Dr. Ruffner’s research focuses on how immune system mechanisms help to maintain the esophageal mucosal barrier during health and during diseases like eosinophilic esophagitis, with the hope of finding a way to improve treatment for eosinophilic esophagitis. She has received the American College of Allergy, Asthma and Immunology Young Faculty Award as well as funding from the National Institutes of Health.

**Randall Rutta**  
**Principal, Connect Health LLC**  
**Chief Patient Advocacy Officer, Partnership to Fight Chronic Disease**  
**Federal Policy Consultant, American Autoimmune Related Disease Association Vice President and Secretary, American Eagle Lifecare Corporation**

Randall Rutta is a senior health care executive dedicated to policy-to-practice solutions that interpret, influence, and improve federal and state health care policies to enhance public and private sector health care innovation, outcomes, and efficiency. He is a Principal in ConnectHealth, LLC a Washington, D.C.-
based consulting services company he established in 2017. He also serves as Chief Patient Advocacy Officer for the Partnership to Fight Chronic Disease (PFCD) and has been a board member since 2007. PFCS is a national coalition of nearly 100 patient, provider, and community organizations, business and labor groups, and health policy experts committed to raising awareness of chronic disease in America and globally. He is a Federal Policy Consultant for the American Autoimmune Related Disease Association (AARDA). He is a Vice President and Secretary of American Eagle Lifecare Corporation and has been a member of its Board of Directors since 2008. He was formerly the President and CEO at Easterseals, a global nonprofit organization dedicated to the health, well-being, and success of people with disabilities, veterans, seniors, and families. He holds a Bachelors of Arts degree in Sociology and a Masters of Arts degree in Politics, focusing on international health policy.

Jeremy Sable
Patient Advocate
Jeremy Sable lives with eosinophilic esophagitis (EoE) having been diagnosed as an infant back in a time when EoE was relatively unknown. He works for Deloitte as a federal consultant in Washington, D.C. and is passionate about raising awareness for eosinophil-associated diseases. In addition to sharing his experiences of living with the condition through childhood, college, and post-grad life, Jeremy also raises funds to support research for eosinophil-associated diseases.

Samir Shaikh
Deputy Director of FDA’s Patient Affairs Staff
Samir Shaikh works at the U.S. Food and Drug Administration (FDA) and serves as the Deputy Director for the Patient Affairs Staff (PAS) in the Office of the Commissioner. PAS leads and enhances patient engagement activities across the medical product centers — facilitating dialogue and collaboration between patients, their advocates, and the FDA to incorporate patient perspective into regulatory decision making. Prior to the FDA, Samir worked in pharma and academia conducting research in Epilepsy, Alzheimer’s, and Vaccines. Samir received his Bachelor’s Degree from The University of Chicago and MBA from Johns Hopkins University.

Michele Shuker, MS, RD, CSP, LDN
Clinical Program Manager and Nutritionist, Center for Pediatric Eosinophilic Disorders, Division of Allergy & Immunology, Children’s Hospital of Philadelphia
Michele Shuker, MS, RD, CSP, LDN is a Clinical Program Manager and Nutritionist in the Center for Pediatric Eosinophilic Disorders at The Children’s Hospital of Philadelphia. Michele has been working with EoE/EGID patients at CHOP since 1999 and joined the Center for Pediatric Eosinophilic Disorders when it was established in 2005. Primary responsibilities include nutrition assessment and education, collaboration with clinical team and families in developing and managing treatment plans, and coordination of care between Allergy & GI. Michele received her BS in Dietetics from Immaculata College and her Master’s Degree in Clinical Nutrition from the University of Medicine and Dentistry of New Jersey. She completed her clinical internship at The Graduate Hospital in Philadelphia. She is a Registered Dietitian and Board Certified in Pediatric Nutrition. She has co-authored numerous papers and several book chapters and has spoken locally and nationally on the nutritional management of eosinophilic esophagitis, food allergy, and general pediatric nutrition.
Christina Singer  
**Patient Advocate**  
Christina (Tina) Singer lives with hypereosinophilic syndrome (HES). In addition to a busy family life, she owns and operates a dance studio in Virginia. Tina is passionate about increasing awareness of eosinophil-associated diseases and shares her perspective to guide patient resources. She also has provided patient perspective to researchers to inform drug development and raises funds to support HES research.

Jonathan Spergel, MD, PhD  
**Chief of the Allergy Section, Stuart E. Starr Chair of Pediatrics, Children’s Hospital of Philadelphia**  
**Professor of Pediatrics, Perelman School of Medicine at the University of Pennsylvania**  
Jonathan M. Spergel, MD, PhD is a Professor of Pediatrics at the University of Pennsylvania School of Medicine and Chief of the Allergy Section at Children’s Hospital of Philadelphia. He is also holder of the Stuart Starr Endowed Chair of Pediatrics and Director of Center for Eosinophilic Diseases. He received his medical and graduate education at the Mount Sinai School of Medicine and completed his pediatric residency at Yale-New Haven Hospital. His clinical and post-graduate research training in Allergy and Immunology were completed at Children’s Hospital, Harvard Medical School. He has published over 200 articles in the field. His current research focuses on both clinical (desensitization and tolerance) and translational research in eosinophilic esophagitis and food allergy including fibrosis, regulatory T cells, microbiome and genetic pathways. He is funded by FARE, DBV Technology, National Institutes of Health (NIH), Aimmune Therapeutics, Regeneron, PCORI, and EATS foundation.

Margo Szabo, PhD  
**Clinical Psychologist, Department of Child and Adolescent Psychiatry and Behavioral Sciences, Division of Gastroenterology, Hepatology and Nutrition, Children’s Hospital of Philadelphia**  
Margo Szabo, PhD is a Clinical Psychologist within the Department of Child and Adolescent Psychiatry and Behavioral Sciences and the Division of Gastroenterology, Hepatology, and Nutrition at the Children’s Hospital of Philadelphia. She earned her doctoral degree from West Virginia University with an emphasis in clinical child psychology. Dr. Szabo completed her residency and fellowship training in pediatric psychology at the Kennedy Krieger Institute and Johns Hopkins School of Medicine. Her clinical interests involve working with children who have chronic medical conditions to address co-occurring anxiety and depression, provide behavioral pain management, and improve adherence to medical regimens. Dr. Szabo is currently working with the Center for Pediatric Eosinophilic Disorders at the Children’s Hospital of Philadelphia to expand psychosocial services to patients and families with eosinophilic esophagitis.

Guillermo J. Tearney, MD, PhD  
**Professor of Pathology, Harvard Medical School**  
Guillermo (Gary) Tearney MD, PhD, is the Remondi Family Foundation Endowed Massachusetts General Hospital (MGH) Research Institute Chair and Professor of Pathology at Harvard Medical School. Professor Tearney received his MD magna cum laude from Harvard Medical School and his PhD in Electrical Engineering and Computer Science from the Massachusetts Institute of Technology. Prof. Tearney’s lab at the Wellman Center for Photomedicine at MGH is focused on the development and clinical validation of in vivo microscopy methods for human disease diagnosis. Prof. Tearney has co-authored over 250 peer-reviewed publications, including papers featured on the covers of Science and Nature Medicine. Prof. Tearney also has over 100 granted US patents, resulting in several commercial medical devices. Additionally, he was recently named one of the nation’s Top Translational Researchers by Nature.
Biotechnology and his capsule microscopy device was highlighted as one of MIT Technology Review’s 10 Breakthrough Technologies in 2019.

Stephanie Walls  
**Parent and Patient Advocate**
Stephanie Walls and her husband Mike are parents of two sons, Dalton and Remington. Remington, now a young adult, was diagnosed with eosinophilic esophagitis as a child and has thrived on elemental formula for complete nutrition. Stephanie taught middle school English for 18 years after changing careers to have the same schedule as her boys. She has dedicated her time to advocacy for APFED. She is committed to pursuing state and federal legislation for the insurance coverage of prescribed medical foods, such as elemental formula prescribed to treat eosinophil-associated diseases.

Remington Walls  
**Patient Advocate**
Remington Walls was diagnosed with eosinophilic esophagitis as a child and has learned to thrive on elemental formula for complete nutrition. He is a rising sophomore at Valdosta State University and has a passion for baseball. He has overcome immense odds to be a positive role model to others. He is pursuing legislative efforts alongside his mother at the state and federal levels advocating for the insurance coverage of medical foods prescribed to patients to treat certain GI conditions, such as eosinophil-associated diseases. He believes that everyone has challenges but it’s how one chooses to face those challenges that determines one’s strength and purpose.

Joshua Wechsler, MD  
**Attending Physician, Gastroenterology, Hepatology, and Nutrition, Ann & Robert H. Lurie Children’s Hospital of Chicago**
Joshua B. Wechsler, MD is a physician-scientist at Lurie Children’s Hospital/Northwestern who cares for patients with inflammatory gastrointestinal diseases, in particular, eosinophilic esophagitis, gastritis and gastroenteritis. Dr. Wechsler is passionate about eosinophilic diseases and cares for a large volume of patients with eosinophilic gastrointestinal diseases in the greater metropolitan Chicago area and across the Midwest. Dr. Wechsler’s research is focused on the role of mast cell-immune activation in driving specific disease phenotypes and treatment outcomes. Dr. Wechsler’s work has helped to define outcome metrics and mechanisms of disease. Dr. Wechsler’s laboratory currently studies the 1) role of tissue-resident intestinal mast cells and their mediators in promoting inflammatory cascades that regulate disease severity. His laboratory seeks to ask disease-relevant questions that will fuel better, novel therapies and ultimately, improve outcomes.

Kelly A. Whelan, PhD  
**Assistant Professor of Pathology & Laboratory Medicine, Fels Institute for Cancer Research & Molecular Biology, Lewis Katz School of Medicine at Temple University**
Kelly A. Whelan, PhD is a scientist running a wet bench research lab at Temple University in Philadelphia, PA. Her research is dedicated to understanding the biology of the esophagus and how that biology goes awry in the context of esophageal diseases, including eosinophilic esophagitis. She has a strong passion for utilizing this knowledge in order to develop effective approaches to improve diagnosis, monitoring and therapy of esophageal disorders.
The Role of Genetics in Eosinophilic Gastrointestinal Disease
Pam Guererro, MD

NOTES:
Navigating Health Insurance Coverage
Angie Lozano and Catina Cox

NOTES:
NIH Approach to EGID Treatment
Paneez Khoury, MD

NOTES:
NOTES:
Seeking a Second Opinion: What’s Involved?
Nick CaJacob, MD

NOTES:
NOTES:
NOTES:
Long Term PPI Usage: Is it a Concern?
Gary Falk, MD, MS

NOTES:
Reintroduction of Foods After Elimination: Are There Risks?
Jonathan Spergel, MD, PhD

NOTES:
The Future of EOE Diagnostics
Guillermo J. Tearney, MD, PhD

NOTES:
NOTES:
APFED Health Professional Members

We are grateful for the health professionals who have supported APFED by serving on our Medical Advisory Panel or with membership this year.

Seema Aceves
Steven J. Ackerman
Amal H. Assa’ad
Dan Atkins
Bradley Becker
Kenneth Backman
Kenneth Boren
Mirna Chehade
Margaret Collins
Thomas Coleman
Michael DiCello
Benjamin Enav
Gary Falk
Glenn Furuta
Troy Gibbons
Bridget Godwin
Nirmala Gonsalves
Sandeep Gupta
Mark Holbreich

Mark Jacobson
Anupama Kewalramani
Chris A. Liacouras
Kristie Lynch
Jonathan Markowitz
Louis Mendelson
Nathalie Nguyen
Bhavin Patel
Tiffany Patton
Philip E. Putnam
Marc Rothenberg
Elizabeth Rothstein
Roberto Souza-Lima
Jonathan M. Spergel
Nicholas J Talley
Srdan Verstovsek
Michael E. Wechsler
Peter Weller
Barry Wershil

*Bolded names indicate members of APFED’s Medical Advisory Panel
When mealtime causes your child discomfort because of eosinophilic GI disorders,

The Choice is Clear

EleCare® Jr is a nutritionally complete, hypoallergenic amino acid-based nutrition powder specifically designed for children who cannot tolerate intact or hydrolyzed protein.

EleCare Jr is available in Unflavored, Chocolate, Vanilla, and Banana flavors.

Visit our booth to try recipes and samples!

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We are deeply grateful for their support of EOS Connection 2019.
Like many rare diseases, eosinophil-associated diseases are not well understood. Because they are still relatively rare, recruitment for research studies can be difficult. Recruiting patients for studies involving the more rare subsets - like eosinophilic gastritis/gastroenteritis (EG/EGE) and eosinophilic colitis (EC) - is particularly challenging.

Participating in a clinical trial helps provide researchers and clinicians with important information to help guide proper diagnosis and treatment of a disease. You or your loved one can help make a difference!

Did You Know?

www.apfed.org
CEGIR 7801 (OMEGA) Study Has Met EoE Patient Enrollment
Recruiting Continues for EG and EC Patients

Have you or your child been diagnosed with Eosinophilic Gastritis (EG) or Eosinophilic Colitis (EC)*? Researchers need YOU to help unlock answers to these rare diseases.

*The study is no longer accepting patients with Eosinophilic Esophagitis since enrollment has been met.

CEGIR 7808 - Use of Unsedated Transnasal Esophagoscopy to Monitor Dietary Management of Eosinophilic Esophagitis in Children

This study will use unsedated (not put to sleep) transnasal endoscopy (TNE) to learn more about how long it takes esophageal eosinophils to come back after a new food is started in children with Eosinophilic Esophagitis (EoE). Children in this study will have eliminated one to four foods as treatment for their EoE and will not be taking steroid therapy.

CEGIR 7809 - Effect of Elemental Diet on Adult Patients with Eosinophilic Gastroenteritis (ELEMENT)

CEGIR investigators in Chicago are conducting a study to see if avoiding certain foods will improve EG or EGE. Participants will complete an elemental (formula-based) diet treatment for at least 6 weeks to see if your EGID gets better after at least 6 weeks of dietary treatment.

CEGIR (U54AI117804) is a part of the Rare Diseases Clinical Research Network (RDCRN), an initiative of the Office of Rare Diseases Research (ORDR), NCATS. This consortium is funded through a collaboration between the NCATS, the NIAID and the NIDDK. CEGIR is also supported by patient advocacy groups including APFED, CURED and EFC.
SHOP APFED

Shop for eosinophil-associated items and resources at apfed.org/shop.

Eosinophil gear
Spark conversations and raise awareness with the phonetic spelling of eosinophil on your phone, a t-shirt, or a bracelet

Educational materials
Inform people about eosinophil-associated disorders

Elimination Diet Cookbook
Learn tips, strategies, and recipes for managing an elimination diet

Find your way t-shirts
Raise awareness for how APFED helps patients and families navigate their eosinophil journey with our t-shirts

Support hope cooler
Make eating on the go easier with our fully insulated cooler

Awareness buttons
Spread awareness for eosinophil-associated diseases by wearing our Eosinophil Associated Disease Awareness buttons

Notecards
Spread hope, thanks, and holiday cheer with our collection of notecards

Children’s books
Help children learn through reading books with lively illustrations

Living Well book
Learn about EGID, and get coping tips and ideas for school and work
Asking a Question During Q&A

Attendees will have the opportunity to ask questions during designated Q&A time. Please refer to the schedule.

Speakers will not answer questions that relate to the specific care of an individual patient. The moderators can help you rephrase your questions if necessary. The physicians will not answer personal questions and if necessary, the question may be rejected or redirected so that the speaker may continue with his or her presentation.

You may use the template in the back of this program book to jot down your questions.

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Use under medical supervision
Tell Us How We’re Doing!

What did you like about your conference experience? What can be improved next year?

Please take a moment to complete a short survey (included in the bag with conference materials) and give us your feedback. Please return surveys to the conference registration desk. We welcome your suggestions!

Better Health, Brighter Future

There is more that we can do to help improve people’s lives. Driven by passion to realize this goal, Takeda has been providing society with innovative medicines since our foundation in 1781.

Today, we tackle diverse healthcare issues around the world, from prevention to life-long support and our ambition remains the same: to find new solutions that make a positive difference, and deliver better medicines that help as many people as we can, as soon as we can.

With our breadth of expertise and our collective wisdom and experience, Takeda will always be committed to improving the future of healthcare.

Takeda Pharmaceutical Company Limited
www.takeda.com
Allakos is developing treatments for severe allergic, inflammatory, and proliferative diseases.

Our initial focus is on eosinophilic gastrointestinal disorders (EGIDs). Allakos is also studying our lead compound, AK002, in a number of diseases where eosinophils and/or mast cells have been shown to play a role.

Allakos is hosting a paid focus group with teens and young adults with eosinophilic gastrointestinal disorders (EGIDs) to better understand the challenges related to transitioning from pediatric to adult healthcare providers. Participants will receive $100 - please visit the APFED registration desk to register.

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Choose PurAmino to support normal growth and development in infants with severe CMA and multiple food allergies.

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- Well tolerated with GOOD ACCEPTANCE 2-3

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CMA = cow’s milk allergy, DHA = docosahexaenoic acid, MCT = medium-chain triglycerides

† Investigated prior to addition of MCT.
‡ In well controlled CMA.


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Today millions of people have no access to basic healthcare, millions more suffer from everyday ailments and there are thousands of diseases without adequate treatments. So we’re working to develop tomorrow’s treatments and to find new ways to get today’s treatments to those who need them.

This conference would not be possible without the dedication and support of our valued volunteers. Thank you to the following families who have planned special programming at EOS Connection 2019!

Zachary Brunet
Julie, Brian, Amelia, and Abby List
Kristyn and David Mitchell
Shelly Parks
Ryan Piansky
Jeremy Sable

We are deeply grateful for their support of EOS Connection 2019.

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Today millions of people have no access to basic healthcare, millions more suffer from everyday ailments and there are thousands of diseases without adequate treatments. So we’re working to develop tomorrow’s treatments and to find new ways to get today’s treatments to those who need them.
A GOOD QUESTION SHOULD:
1. Pertain to subject of the meeting
2. Focus on the interest of the group
3. Stimulate thought of both Speaker and the Group
4. Specify information, opinion or both
5. BE CLEAR
6. BE BRIEF
7. NOT PATIENT SPECIFIC

WRITE YOUR QUESTION HERE:

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7. NOT PATIENT SPECIFIC

WRITE YOUR QUESTION HERE:
SEEKING SOLUTIONS TOGETHER

Thank you to APFED for collaborating with us to discover clues about what causes eosinophilic esophagitis (EoE), to create better tools to diagnose the disorder, and to develop customized treatments to improve the quality of life for individuals with the disorder.

Together, we can change lives.

chop.edu/eoe

Our Center treats more than 1,500 children and teens with EoE — the largest clinical population in the world. We bring together specialists from gastroenterology, allergy, nutrition and pathology to diagnose and treat children with EoE. Our Center also leads research into the causes of EoE causes and long-term effects of the disorder.
18th Annual Patient Education Conference on Eosinophilic Disorders

Join Us in San Diego for Eos Connection 2020
July 2020

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