



# Allergic Diseases SIG

Fall/Winter Newsletter 2024

## Transition to Independence for Youth with Allergic Diseases

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## A Message from our Co-Chairs

Hello! Thank you for taking the time to view our quarterly newsletter with some updates on our current projects! We appreciate your interest and continued work with children and adolescents with allergic diseases! We have some exciting new things coming up that our leadership team is working hard to coordinate in order to support the work that you all are doing across the SIG. First, Dr. Cushman is working to coordinate a virtual coffee hour to discuss potential research opportunities and research work that is happening within our SIG. In addition, Dr. LeBovidge has been working on a clinical resource database that we hope will come in handy for many as you continue to work within your clinical roles. We hope that this resource will be a way to share materials that many of us have found helpful within our own work and hope to also learn about new resources. Please reach out to us or Dr. LeBovidge if you have things you would like to contribute! The topic of this newsletter is the transition to independence, which highlights a Q&A with Amelia Howard, PsyD from the AYA SIG, resources for supporting those currently in the transition phase, as well as brief review of research in this area. We hope you find something within this newsletter that you can utilize in your work! Please do contact us with publications, upcoming conferences, job postings, or anything you would like to share with the membership.

Best, Kait Proctor, PhD, ABPP, and Haley Killian, PhD

# Leadership Committee

Name	Role
Kaitlin Proctor, PhD, ABPP	<i>Co-Chair</i>
Haley Killian, PhD	<i>Co-Chair</i>
Jennifer LeBovidge, PhD	<i>Clinical Chair</i>
Sara Voorhees, PhD	<i>Communications Chair</i>
Grace Cushman, PhD	<i>Research Chair</i>
Frances Cooke	<i>Student Representative</i>
Sabrina Sigel	<i>Student Representative</i>

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## Tips for AYAs Transitioning Towards Independent Self-Management of Allergic Conditions

Compiled by Jennifer LeBovidge, PhD

### Transitioning to an adult health care provider

- Some allergists specialize in working with children and adolescents. If you will need to find a new allergist because of your age or location (such as attending college), ask your current allergist for help in this process.
- The American Academy of Allergy, Asthma & Immunology has a resource to help find a provider: <https://allergist.aaaai.org/find>
- Use visits with your current allergist to make sure that you understand your management plan.
- Create a “transition report” to bring with you when you meet with a new allergist or other healthcare provider. This could include your medical and family medical history, current management and action plans, and medication list.

### Communicating with your allergy provider

- Learn how to contact your allergist/their office by phone and by patient portal.

- Add your allergist's phone number into your phone contacts.
- Talk about when and how to reach out for routine questions and for emergencies.
- Make a list of questions for upcoming appointments.

### Scheduling appointments

- Learn how to schedule appointments by phone or patient portal.
- Make sure you know how often you should see your allergist.
- Add medical appointments and reminders for when to book your next appointment to your phone calendar and/or written planner.

### Managing your medications

- Make sure you know your medication names, doses and how often to take them.
- Consider using reminders such as phone alarms and pill boxes to stay organized.
- Learn how to request refills from your health care provider and pharmacy.
- Use a calendar or phone reminders to remember so you can refill prescriptions before they run out.
- Add your pharmacy phone number and address into your phone contacts.

### Understanding your insurance

- Make sure you understand what your insurance covers and if you have any co-payments.
- Keep your insurance card with you and keep a photo of it on your phone.

*Don't forget that you have a support team! Check in with your family, friends and health care providers if you have questions or need additional support.*

## Ask the Expert: Q&A with Amelia Howard, PsyD



Amelia Howard, PsyD (and other members of the AYA SIG leadership team) recently spoke with Sara Voorhees, PhD, the Allergic Diseases SIG Communications Chair, about the managing food allergies for AYA populations.

Amelia Howard has graduated with her doctorate degree in clinical psychology with an emphasis in family psychology at Azusa Pacific University. She holds a M.S. in counseling and a M.A. and PsyD in clinical psychology. She is currently a second-year med-psych fellow where she is providing consultation and liaison services to children with medical complexities. Amelia has advanced training in trauma-informed care using brief interventions as well as specialty training in pediatric neuropsychological and neurodevelopmental assessments. Amelia has been honored and invited to graduate honor societies, Alpha Chi and Psi Chi and she has been recognized for her efforts in serving minority populations. Her scientist-practitioner background allows her to combine research and clinical knowledge to advance the field of psychology seen in the completion of her dissertation, participation in cognitive labs, poster presentations, and manuscripts. Amelia is also an adjunct professor teaching classes that include pediatric interventions, brain and behavior, and multicultural psychology in undergraduate and master courses. To give back she enjoys actively mentoring current graduate and doctoral students with advancing their careers and navigating academia. She is currently a member of the American Psychological Association (APA) Pediatric divisions and the American Academy of Pediatric Psychology. This year, she has become the chair for APA's Div 54, AYA SIG for the transitional age youth population. Amelia plans on becoming a pediatric psychologist attending this upcoming year and will continue providing neurodevelopmental assessments, with the hopes to intervene early on and create a positive shift in the lives of children and adolescents.

### **Q: Are there any developmental readiness signs that you look out for to suggest that a child may be ready to begin taking on more responsibility for their allergies?**

- Use a transition readiness measure such as the [TRAQ](#), [Ready Steady GO](#), or [TR\(x\)ANSITION](#) scale. The process of transition takes years, so it is best to start early (around age 11-13)
  - Understand their health and medical condition (know what terms mean, names of medications, when they take medications and what each is for, etc)
  - Consistent cooperation and compliance with medication regimen (if appropriate), effective behavioral strategies in place to support adherence (e.g., phone alarms, visual schedules, calendar reminders, etc.)
  - Understands confidentiality
  - Knows about connections between lifestyle (sleep, nutrition, movement, adherence) and health
  - Able to ask questions of medical providers, comfortable advocating for their needs with providers
  - Attends to and tracks health conditions, prepares for medical appointments
- Maturity levels:
  - Cognitive: Can they understand their allergies, symptom severity, triggers, consequences/risks of not addressing health needs. Consider problem solving abilities, decision making, and planning abilities.
    - Presence of any developmental delays, cognitive weaknesses, adaptive functioning
  - Emotional: How do they handle stress or high-pressure situations?
  - Behavioral: Are they able to adhere to their current treatment plan. Can they follow doctors recommendations? Do they demonstrate ability to follow other (non-allergy) routines?
  - Do they know what to do if an allergic reaction or anaphylaxis occurs and are they able to respond and follow their treatment plan? Have they done this already under adult supervision? (i.e., can the adult caregiver attest that the teen knows what to do in the moment with minimal support/coaching)
    - Be it get help, give themselves proper dosing, etc
- Other considerations: age, support system, personality and coping skills.

## **Q: What can we do as children are getting older to best prepare them for future transition in responsibility?**

Shared care model: Caregiver and child together manage health related responsibilities. Caregiver provides coaching, encouragement, reminders, etc as the child assumes gradual autonomy and responsibility for health related tasks.

## **Q: What tips do you have for working with youth who may be hesitant or lack motivation to take on food allergy self-management responsibilities?**

- Assess potential barriers (be curious)
  - What is working (or not working) with the status quo?
  - What are they nervous or afraid of with taking on additional responsibilities?
  - What are the caregivers' motivations for transitioning responsibility to the child or teen?
  - What are their future goals/expectations for their health and health management? (i.e., if they do not assume these responsibilities, who will?)
- Based on the assessment, tailor interventions to match. For example, if the teen has fears or anxiety about self-management tasks, exposures would be appropriate.
- Scaffolded approach, decreasing level of support from caregivers over time as the patient builds skills and confidence.
- Utilizing motivational interviewing strategies to assess patient/family readiness for change, to identify related barriers/contributing factors, and to establish goals.

## Q: How can we best support parents/caregivers with allowing their child to take on allergy self-management?

- Education about independence and autonomy for teen/young adult to make decisions about their allergy management.
  - Helping caregivers establish realistic, developmentally appropriate expectations
  - Benefits of independence
- Discussing fears
  - Acknowledgement of fears, empathy
  - Review impact of the allergy on the family unit
- Gradual progression
  - Simple tasks, monitor, assess ability to handle increased responsibility/independence, scaffolded support with caregiver supervision/monitoring
- Role Playing with parents to allow them to see readiness
  - Making good choices for their allergy management
  - Social pressures, dining out on own, grocery store how to check labels
  - Empowering them to advocate for themselves
  - Safety plan and precautions
- Positive reinforcement for efforts and achievements
  - Reward system
- Additional support and identifying team:
  - Other families, therapists, physicians, allergists
  - Coordination and collaboration across systems
    - Developing a IHP or 504 Plan in the school setting for medical accommodations
    - Utilizing behavioral strategies to promote success and independence - visuals, information sheets with emergency contact information, etc.

## Q: What practical suggestions can you offer for supporting youth with self-management? (e.g., strategies for helping them remember to carry their epinephrine auto-injectors, making sure they are carefully reading food labels)?

- Assess the barriers to carrying out the necessary behaviors:
  - Do they **understand** what is expected?
  - Are they **willing** to do what is needed?
  - Do they **remember** to do the behavior at the correct time (when needed)?
  - Does anything else **get in the way** of carrying out the needed behavior?
- Help the youth problem solve any relevant barriers. Troubleshoot and make a plan to monitor the outcome. Repeat as often as needed.
- Building new healthy habits takes time and a lot of repetition. Youth can caregivers should expect that mistakes will happen (i.e., it is not reasonable to assume that a single explanation and plan is all that is needed for a teen to assume full responsibility for managing a chronic health condition

**Q: How can we best prepare youth for transitioning to working with adult allergy providers? Any practical tips for managing healthcare overall? (e.g., finding a doctor, making appointments, understanding insurance)?**

Shared care model discussed above. Caregivers can model and explain the process alongside the child. For example, teens can make the phone call (or request the appointment online) with their caregiver's guidance and support in the moment. Once the caregiver is confident that their child/teen has the skills and knowledge, they can prompt/remind and provide incentives for teens scheduling these appointments with more independence.

**Reference:**

Roberts, G., Vazquez-Ortiz, M., Knibb, R., ... Timmermans, F. (2020). EAACI Guideline on the effective transition of adolescents and young adults with allergy and asthma. *Allergy*, 75(11), 2734-2752. doi:10.1111/all.14459

## **Allergic diseases transition to adult medical care - review of guidelines/recommendations specific to healthcare transition**

Written by: Frances Cooke and Sabrina Sigel

Mentored by: Grace Cushman, PhD

Adolescence and emerging adulthood are critical developmental stages marked by increased independence and the gradual shift of responsibility from parents to youth. For individuals with chronic illnesses, including allergic diseases, this period is especially challenging as they must navigate typical developmental transitions while also managing their healthcare needs. The transition of healthcare responsibility during this time involves several key components, such as taking over disease management regimens (e.g., using eczema creams, avoiding food allergens), ensuring access to necessary medications and knowing how to use them independently (e.g., asthma controller and rescue medications, epinephrine auto-injectors for allergic reactions), and establishing care with new providers as they move from pediatric to adult healthcare settings. Additionally, youth must acquire greater knowledge of their condition and the healthcare system, learning skills such as communicating with medical providers, scheduling appointments, understanding insurance plans, and handling payment for services. Guidelines suggest that the transition of care should begin around age 11 to ensure enough time for parents to gradually provide scaffolding and to work out any challenges as mistakes are likely to occur along the way. However, many adolescents and young adults struggle with taking on these responsibilities and parents often find it difficult to relinquish control. Medical care teams also face challenges in supporting families through this complex process and pediatric psychologists can offer valuable expertise in helping families navigate these transitions. Below, we provide an overview of the guidelines for the transition of healthcare

responsibility for youth with allergic diseases, along with references to resources and practical suggestions for supporting families during this crucial time.

### [Overview of the EAACI transitional guidelines](#)

- This resource presents information about the European Academy of Allergy and Clinical Immunology (EAACI) guidelines using a figure, text, and video.

### [EAACI Guidelines on the Effective Transition of Adolescents and Young Adults with Allergy and Asthma](#)

- These guidelines provide both general and more detailed recommendations for supporting the effective transition of allergy and asthma care to adolescents and young adults.
  - General recommendations
  - Start the transition process early (11-13 years) and support this transition until age 25
  - Ensure clinics have specific transition plans for patients that involve a multidisciplinary team
  - Communicate developmentally appropriate knowledge about the allergic condition and transition process
    - Facilitate communication between the patient, their family, and their medical team
  - Active monitoring of progress and acquisition of skills
    - Use checklists of skills and knowledge relevant for adolescents and young adults with allergic diseases
    - Monitor adherence to their management regimen
    - Monitor medication adherence
    - Assess access to resources (e.g., transportation to medical appointments, electronic access to health portal)
  - Discuss the implications of effectively managing their own healthcare for youths' future (e.g., education, employment)
- Specific recommendations
  - Use electronic reminders to build self-management skills
  - Encourage self-disclosure of medical conditions, as appropriate, and involvement of friends
  - Identify environmental stressors and mental health concerns that could impact the acquisition of self-management tasks within the context of an allergic condition

### [EAACI position paper: A Practical Toolbox for the Effective Transition of Adolescents and Young Adults with Asthma and Allergies](#)

- This paper provides a practical toolbox for supporting the implementation of transition guidelines in clinical practice.
- Resources for transition of healthcare responsibility including allergic disease-specific and general information
  - EAACI guidelines (allergy specific)
  - Children and Young People's Allergy Network Scotland - Pathway to Transition (allergy specific)
  - Patient information leaflet 'Your transition from children's to adult allergy services' (English, UK, 2021) (pamphlet, allergy specific)
  - Got Transition (general)

- World Health Organization's (WHO) "Resource Bank for Adolescent Health" from the interdepartmental working group on adolescent health (general)
- Tools to assess and monitor transition readiness over time
  - Transition Readiness Assessment Questionnaire 'TRAQ' (English, US, 2021)
  - Readiness for Transition Questionnaire 'RTQ' (English, US, 2012)
    - This measure was originally developed for kidney transplant recipients but could be modified for allergic diseases
  - The Adolescent Assessment of Preparation for Transition (ADAPT) survey (English/Spanish, US, 2014)
- Resources to help manage the psychosocial impact of allergic diseases on adolescents and young adults
  - Getselfhelp (English, UK. Regularly updated)
  - Training in Motivational Interviewing (MI). Royal College of Psychiatrists (English, UK, regularly updated)
- Comprehensive websites for allergic diseases resources
  - Food Allergy Research & Education (FARE) (English/Spanish, US, 2022)
  - Asthma + Lung UK (English, UK, 2022)
  - Nottingham Support Group for Carers of Children with (Atopic) Eczema (English, US, 2022)

These articles may be helpful for pediatric psychologists who support adolescents and young adults with allergic diseases in the transition of healthcare responsibility:

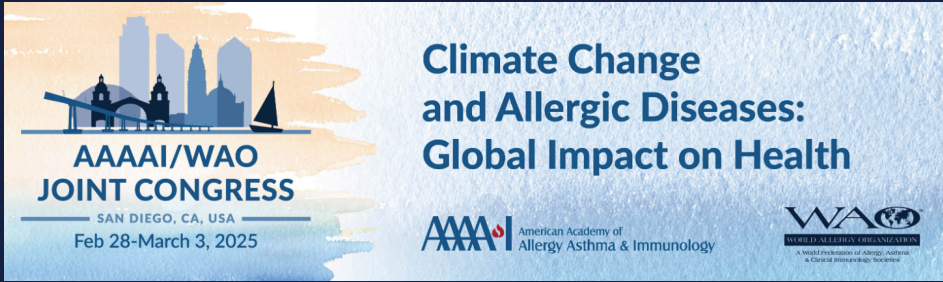
Huntley, A. P., Verdi, M., Conway, A. E., Sharma, H., Stukus, D., Nanda, A., ... & Herbert, L. (2023). Growing up with allergies: transitioning from adolescence to adulthood. *Annals of Allergy, Asthma & Immunology*.

Roberts, G., Vazquez-Ortiz, M., Khaleva, E., DunnGalvin, A., Gore, C., Marchisotto, M. J., ... & Sánchez, A. (2020). The need for improved transition and services for adolescent and young adult patients with allergy and asthma in all settings.

Knibb, R. C., Alviani, C., Garriga-Baraut, T., Mortz, C. G., Vazquez-Ortiz, M., Angier, E., ... & Roberts, G. (2020). The effectiveness of interventions to improve self-management for adolescents and young adults with allergic conditions: a systematic review. *Allergy*, 75(8), 1881-1898.

## Let's meet up IRL!

Upcoming conferences that some members of our group will be at:



**Climate Change and Allergic Diseases: Global Impact on Health**

**AAAAI/WAO JOINT CONGRESS**  
SAN DIEGO, CA, USA  
Feb 28-March 3, 2025

**AAAAI** American Academy of Allergy Asthma & Immunology

**WAO** WORLD ALLERGY ORGANIZATION  
A World Federation of Allergy, Asthma, & Clinical Immunology Societies

Let us know if you'll be there:  
[allergicdiseasesSIG@gmail.com](mailto:allergicdiseasesSIG@gmail.com)



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THANK YOU!