

Adolescent & Young Adult (AYA) Interest Group

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Society for

HEALTH PSYCHOLOGY

Meet the Leadership Board

Chair



Jennifer Allen, PhD is a Clinical Psychologist at St. Louis Children's Hospital (SLCH). At SLCH she serves as an attending psychologist in the Psychology Clinic, where she provides inpatient and outpatient clinical services to a predominately adolescent and young adult (AYA) hematology/oncology patient population. In addition to pain and AYA, her clinical interests involve integrative medicine – primarily mindfulness and biofeedback. Her research interests focus on psychological and pharmacological interventions for pediatric pain, factors impacting AYA with chronic medical illnesses, and use of integrative medicine. In her spare time, she enjoys traveling and exploring the outdoors with her family, baking, and staying active.

Chair Elect



Elise McKelvey, M.A. is currently on internship at the Medical College of Georgia at Augusta University. In her final year of training, she is working with patients experiencing a wide range of health conditions such as HIV, PCOS, cancer, neurological illnesses, and spinal cord injuries. Her primary clinical interests include young adult oncology and neurology, adherence, adjustment to illness, health behavior change, and coping with hospitalization. She is passionate about the development of behavioral health intervention programs, especially C/L psychology for hospitalized patients. For fun, she enjoys biking, painting, photography, and game nights with friends!

Past Chair




Dr. Pereira (she/her) is a Psychologist specializing in Pediatric Hematology, Oncology, and Stem Cell Transplantation at New York Medical College and Maria Fareri Children's Hospital. She completed an APA-accredited internship at Child Clinical and Pediatric Psychology at Metrohealth Center in Cleveland, Ohio. Her current research focuses on the utility of digital storytelling as a clinical tool for AYAs with a cancer history as well as the development of an evidence-based peer mentor training program for families impacted by cancer and blood disorders. Outside of work she enjoys coaching her son's soccer team (and playing on one of her many teams), gardening, discovering new music, and spending time outside as a family.

Advocacy and Equity Chair




Megan McComas, PhD, (She/Her) is a Pediatric Psychology Fellow at Atrium Health Levine Children's Hospital, where she provides inpatient and outpatient clinical services to patients and families experiencing a wide range of health conditions. She is a clinical health psychologist by training and her primary clinical interests include LGBTQ+ health, adjustment to/coping with a chronic illness, health behavior change, and pediatric to adult care transition. Her current research investigates systemic factors that influence transgender and gender expansive AYA health and health care disparities. Her work aims to develop interventions to promote gender-affirming health care in diverse geographical regions. Outside of work, she enjoys yoga, meditation, visiting new breweries, and traveling with her partner and dog.

Interventions Chair




Rina Fox, PhD, MPH is an Assistant Professor at the University of Arizona College of Nursing. She is a clinical psychologist by training and her work focuses on delineating how psychosocial processes impact adjustment to and coping with chronic illness, with an emphasis on symptom management and health related quality of life (HRQOL) in cancer survivorship. One arm of her research focuses on AYA psycho-oncology and she previously co-lead a drop-in support group for young adults with cancer for over 3 years. In her spare time, she enjoys travelling, cooking, and exploring the outdoors with her family.

Measurement Chair



Karly M. Murphy, PhD (she/her) is an Instructor at Wake Forest University School of Medicine. Her program of research is focused on the development, evaluation, and implementation of interventions that improve psychosocial well-being and health outcomes among AYA cancer survivors. Currently, she is the PI of an NCI K99/R00 award focused on developing an engaging and evidence-based digital tool to help AYA cancer survivors cope with symptoms of depression. Additionally, she is part of a team focused on developing new PROMIS measures of financial toxicity, fertility/parenthood issues, and body image concerns among AYAs with cancer. Outside of work she enjoys playing board games, hiking, and spending time with her partner and pets.


Pediatric Representative



R. Elyse Heidelberg, PsyD is a Clinical Psychologist and Assistant Member at St. Jude Children's Research Hospital in Memphis, TN. As a Clinical Psychologist, she specializes in pediatric hematology and oncology and has particular interest in working with AYA patients.

Dr. Heidelberg leads the development and implementation of the New Oncology Program in Psychology at St. Jude, which fosters psychological assessment and universal intervention for all patients near the time of diagnosis, and Co-Chairs the Teens and Emerging Adults Committee. In addition, she serves as a liaison to the Neuro-Oncology and Radiation Oncology services and is a member of the Integrative Medicine Working Group and Quality of Life Steering Council. Outside of work, she enjoys spending time with her family, traveling, trying new restaurants, and staying active.


Adult Representative



Samantha Burns Artherholt, PhD received a bachelor's degrees in Psychology and Cell & Molecular Biology at the University of Washington before completing her Ph.D. in Clinical Psychology at Seattle Pacific University. She completed a postdoctoral fellowship with the University of Washington and Fred Hutchinson Cancer Research

Center, where she studied long-term effects of cancer treatments, including medical, neuropsychological, and psychosocial sequelae. She has also worked on supportive research interventions for people with various chronic conditions including multiple sclerosis, spinal cord injury, and muscular dystrophy. She has a clinical interest in working with adolescent and young adult patients. Dr. Artherholt is currently a Clinical Associate Professor in the Department of Rehabilitation Medicine at the University of Washington, and sees patients at the UW Medicine MS Center and in her private practice.


Early Career Psychologist Representative



Laura Oswald, PhD is an Assistant Member and early-career investigator in the Department of Health Outcomes and Behavior at Moffitt Cancer Center. She dedicates the majority of her effort to research, with a major focus on improving quality of life and other patient-reported outcomes among young adult cancer survivors via evidence-

based behavioral interventions. Other topics of Dr. Oswald's research include understanding patient-reported survivorship outcomes among recipients of novel cancer therapies, such as CAR T-cell therapy. Outside of work, Dr. Oswald enjoys running and tackling do-it-yourself home improvement projects.

Trainee Representative



Dominique Legros, M.A. is a Clinical Psychology (Health Care Emphasis) student completing an externship at the Columbia University Clinic for Anxiety and Related Disorders (CUCARD) Westchester working with child and AYA. Dominique previously completed a pediatric psycho-oncology practicum working to serve a diverse patient

population with diagnoses of cancer and other blood related disorders. Dominique's research interests focus on risk and protective factors related to experiences of adversity and trauma, as well as better understanding barriers to mental health care among young adult populations. For fun, Dominique enjoys baking, exploring museums, and spending time with family and friends.

Interview with an AYA: Managing Dysautonomia

Tell us about your experience seeking and receiving a diagnosis of dysautonomia:

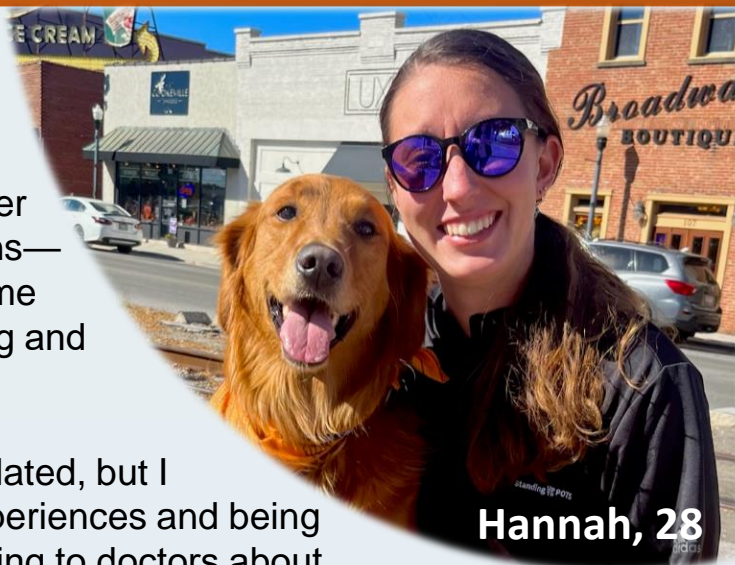
It was a long and painful one. When I was a Sophomore in college I got sick with one thing after another—mono, ovarian cyst, medication reactions—all in a matter of six months. Doctors kept telling me they didn't know why these things were happening and said my body was just going haywire.

Doctors were adamant my symptoms were not related, but I knew they were. After many of those negative experiences and being repeatedly told “this is just anxiety”, I avoided talking to doctors about it for the next 7 years. I always had a high heart rate at my annual, and when my PCP questioned about me it, I replied that I think I developed “White Coat Syndrome” after those times spent in the ER. I played off my symptoms for years until January 2021 when I noticed serious changes. I would bend down to pick something up off the floor and black out for a second. It continued to get worse and worse, like a crazy amount of symptoms that almost felt like panic attacks. And I was continuing to label myself with anxiety, even though, deep down, I knew it was a medical thing. But I was too scared to go back into the medical system. Eventually it started to feel dangerous when my heart rate would jump into the 180s out of the blue, so I finally sought help. That doctor ordered a cardiac workup that came back abnormal, which I'm actually grateful for, because it ultimately helped me in terms of finding a diagnosis. So I'm grateful for that. But certainly those 3 months of waiting to figure out what was wrong with my heart was terrifying.

When your symptoms began, what was going on in the rest of your life?

My sophomore year of college was really impacted. When I looked back, that was just a terrible year—really because I wasn't being taken seriously. There were professors who didn't believe me, and I ultimately had to withdraw from a class in order not to fail. I vividly remember this anatomy lab where we were dissecting things, and I went up to the professor and said I couldn't do this because I was feeling so sick. He just assumed I was lying and said, “What? You're here. Why can't you just do it? You look fine.”

It was just another person who didn't believe me. I'm left thinking, well, *what else can I do? You know? I'm a 20 year old college student in a dorm room by myself trying to even figure out how to maneuver the medical system, and I have no one who believes me, no one who will help me.* His reaction stuck with me for all these years because that's the definition of what people with dysautonomia struggle with: you look fine, but just because you look fine doesn't mean that you're not dying inside or hurting or just trying to get through the day.



I'm struck by this image of a young adult trying to deal with this and college on their own. Do you wish that your family had been more involved in some way? Was it hard to tell them from a distance?

My mom was aware what was going on but never truly witnessed my day to day. I know if I was living at home she would have fought to the end of the world for me to get the help I needed. That is a big difference between developing this when you're in your early 20s and out of the house versus as a teenager because I know my mom would have been persistent in getting me a diagnosis as a young child.

I remember, I ended up going home several times that year and just staying because I was so sick. One night I was just lying on the couch in a ton of pain and I felt there was something seriously wrong. My mom immediately says "Okay, then let's go to the ER." Thank god I did because it was an ovarian cyst that ruptured, and I had to immediately be pumped full of antibiotics.

If you were in that exact same scenario with this pain and in your dorm room alone, do you think you would have gone to the ER?

Maybe eventually, but I don't know. I just didn't want to go and be that person that cried wolf. I think I went because of my mom saying, "It's okay to go to the ER. It's okay to go right now".

Going through this while you were 20 to 27, did it impact your dating life or relationship development?

I've had this same partner for the past 9 years. He has been my number one supporter and even though medical stuff isn't his thing, he always said "let's figure this out together." There were bad days where I would wake up in the middle of the night having these tachycardia episodes with my heart rate in the 180s. I remember I woke him up several times to say, "hey, I need to go walk". It's 4:00am but he wouldn't even question it. We'd take the dog and go walk outside in the November freezing cold in Chicago.

I feel like maybe my journey was a little bit easier because I did have him, and he really pushed me to go to the doctor even when I didn't want to. He volunteered to come with me to as many appointments as I wanted or needed which really helped.

For you, what has been the most difficult part of dysautonomia/POTS?

It's people outwardly seeing that I look the way I do and they can't seem to understand why I feel this way—why it's taking me forever to something like formulate a sentence. I can have really bad brain fog at times, and that can lead to people judging me or having little patience with me. People just don't understand what it's like to have POTS brain fog. Coming from someone who didn't have it for so long, it has been the most challenging symptom to manage.

Dysautonomia is an umbrella term used to describe several different medical conditions that cause a malfunction of the Autonomic Nervous System

What do you wish your peers knew about living with dysautonomia/ POTS?

Sometimes I am just figuring out how I can survive this day. I may be acting a different way but it doesn't mean that I'm upset with my friends or something happened. I'm trying to (1) figure out what exactly I feel, and (2) how to cope or compensate for that. When I cancel plans, it has nothing to do with you. It's me doing what I have to do to manage my symptoms.

What is something doctors should know or consider when treating this condition?

The way you say things and the way you talk to patients impacts them. I have to wonder if I would have spent seven years avoiding doctors if my symptoms had never been attributed to "just stress". That experience has been one of the hardest things for me to—not get over—but just kind of accept that I went through that. At times I'm angry at that physician for saying that because he did change the way I viewed the health care system. So, I think doctors need to remember to take these symptoms seriously and not label young women with anxiety so easily.

For psychologists working with someone who has POTS/dysautonomia, what should they be keeping in mind?

It's a different experience for everyone, and it can bring up different ways of viewing your identity. Especially if you're diagnosed in your early adult years when you are figuring out who you are or feel like you really just got it figured out, you might have to readjust and go through new identity development. For me, I had to adjust to a new identity of being a person with chronic illnesses.

Fast Facts about POTS

- POTS stands for "postural orthostatic tachycardia syndrome"
- POTS itself is not a disease; it is a cluster of symptoms that are frequently seen together
- Postural orthostatic tachycardia syndrome (POTS) is a form of dysautonomia
- 70 million + people worldwide live with various forms of dysautonomia
- POTS affects 1 in 100 teenagers
 - Most common in women 15-50
 - Approximately 80% of patients are female
- Patients are often misdiagnosed as having anxiety or panic disorder due to the shared symptoms of tachycardia, heart palpitations, shaking, etc.

Resources

The Dysautonomia Project, *Kelly Freeman*
[Dysautonomia International](#)
[POTS Overview by Dr. Satish Raj](#)





Identity and Relationship Development: Considerations for AYA Populations

By Dominique Noelle Legros, MA

For adolescents and young adults (AYAs) with chronic health conditions, many of the experiences associated with diagnosis and management pose challenges to normative psychosocial development. For example, hospitalizations, bodily changes, or stigma during adolescence and young adulthood often delay development of identity and impact the formation of romantic and other fulfilling relationships¹.

AYA with chronic health conditions may experience unique stressors related to their disease on top of normative friendship/relationship stressors. For some teens, disclosure of their diagnosis is particularly difficult. A desire to conceal a condition such as diabetes may lead to teens to be hesitant in forming closer bonds with peers².

Clinicians can support AYAs who are struggling with identity development and relationship formation by encouraging interpersonal connection with friends and new peers. Moreover, encouraging AYAs to stay connected with peers and other social contacts through various means of communication (e.g., the internet, cell phones) may reduce feelings of isolation³. Considering interpersonal relationships allow AYA to explore various identity narratives and changes⁴, it is important to facilitate connection with other AYA who have had similar health experiences.

1. Erikson EH. *Childhood and Society*. W W Norton & Co; 1950:397.

2. Raymaekers K, Berg CA, Helgeson VS. Development of peer relationships from adolescence into emerging adulthood: Comparing males and females with and without type 1 diabetes. *Journal of Pediatric Psychology*. 2022;47(7):804-815. 10.1093/jpepsy/jsac019

3. Sawyer JL, Mishna F, Bouffet E, Saini M, Zlotnik-Shaul R. Bridging the gap: Exploring the impact of hospital isolation on peer relationships among children and adolescents with a malignant brain tumor. *Child Adolesc Soc Work J*. 10.1007/s10560-021-00764-x

4. Branje S, de Moor EL, Spitzer J, Becht AI. Dynamics of Identity Development in adolescence: A decade in review. *Journal of Research on Adolescence*. 2021;31(4):908-927. 10.1111/jora.12678

Interested in collaborating with the
AYA interest group to develop
future SfHP Programming?

Contact us at: elisemckelvey@gmail.com

WASHINGTON, DC AUGUST 3-5

APA 2023

Louisville, KY March 16th-18th



APAHC

Association of Psychologists in
Academic Health Centers

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**THE 5TH GLOBAL ADOLESCENT AND
YOUNG ADULT CANCER CONGRESS**

June 20-22, 2023
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ayaglobalcancercongress.org

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