



HCQU Northwest



Roseland Building
247 Hospital Drive
Warren, PA 16365
Phone (814) 728-9400
Fax (814) 728-8887

Success at Super Hero Day!

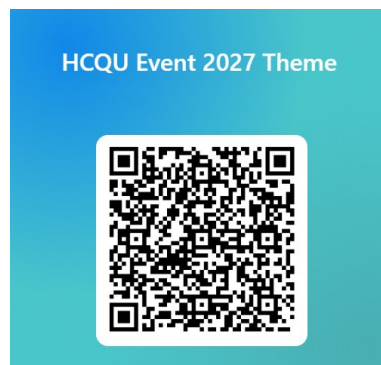
What a fantastic day was had at our Annual Event! This year's Super Heroes theme brought out plenty of excitement, energy, and fun, with 130 attendees coming together for a truly memorable celebration.

A Special thanks to Molly Dies' Dance Express for getting us moving and grooving, to Sophie and her owner from Therapy Dogs United for plenty of tail wags and pets! To all the volunteers for making this day possible. And of course to the Keystone Café at WSH for keeping our bellies full!

I hope you all enjoyed the day as much as we did. So much so, that we'd like to have you help us with next year's event.

To celebrate 25 years of the HCQU— help us select the theme for next year! Email me with your choice kfitzsimmmons@milestonepa.org or scan the QR code.

1. Pirates
2. Circus
3. Princes & Princesses
4. Life Milestones
5. You pick!



Happy Summer!!!

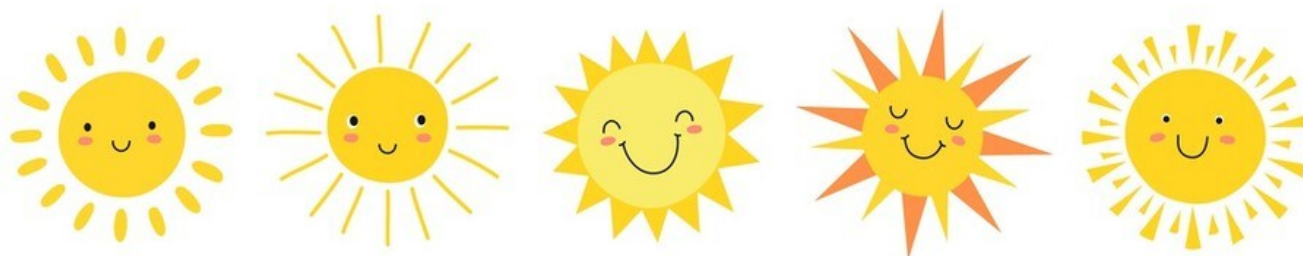
Krista

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Sweet Summertime with the PCCRC



This summer, the PCCRC continues to stay connected with families and community partners through outreach, collaboration, and support. On May 30, our team attended the Disability Resource Fair at PennWest Edinboro, where families, caregivers, and providers came together to learn about services and supports available across the region. The event offered an important opportunity to share information, build relationships, and connect families with helpful resources in one welcoming location.

Recently, we were also involved in two important June events: the HCQU yearly event for individuals we serve on June 12 and the PCCRC statewide collaboration meeting on June 23. These opportunities allowed us to strengthen partnerships, share ideas, and continue building a network of support for children and families across Pennsylvania. Alongside these events, we have also been opening new families and providing ongoing support, helping caregivers navigate services, ask questions, and access the resources they need.

As summer begins, it can be helpful for families of children with medical complexity to plan ahead for routines, appointments, and activities. Simple steps such as keeping medications and emergency information up to date, preparing for safe outdoor and water activities, and identifying community programs or camps that can meet a child's needs can make the season smoother and more enjoyable. Summer can also be a good time to focus on balance—making space for fun, rest, and connection while knowing that support is available when questions or challenges arise. School will be back in session before we know it! PCCRC remains committed to walking alongside families and helping them find the resources and encouragement they need throughout the season.

Dawn Collins

Pediatric Coach



Sleep and Why it Matters

After being awake for 17 hours, a person's alertness can be like someone with a blood alcohol level of 0.05%, demonstrating how significantly sleep affects daily functioning. Sleep is one of the most important parts of maintaining good physical and mental health. During sleep, the body repairs itself, stores memories, strengthens the immune system, and restores energy for the next day.

Poor sleep can cause several problems, including difficulty concentrating, increased irritability or mood changes, reduced energy and motivation, increased appetite and weight gain, weakened immunity, and a higher risk of accidents and falls.

For individuals with intellectual and developmental disabilities, poor sleep may sometimes appear as increased behavioral concerns, refusals, anxiety, aggression, or decreased participation in daily activities.

Many factors can contribute to poor sleep, including stress or anxiety, pain or discomfort, sleep apnea, medication side effects, excessive caffeine intake, irregular sleep schedules, excessive screen time before bed.

To improve sleep quality, here are some tips. Go to bed and wake up at the same time each day. Limit caffeine in the afternoon and evening. Keep the bedroom cool, dark, and quiet. Avoid large meals right before bedtime. Turn off televisions, tablets, and phones at least 30 minutes before sleep. Engage in relaxing activities, such as reading or listening to calming music before bed.

Sleep problems should be talked about with a healthcare provider if a person: snores loudly, stops breathing during sleep, experiences excessive daytime sleepiness, or has persistent insomnia.

Quality sleep is just as important as healthy eating and exercise. Establishing good sleep habits can improve mood, behavior, memory, physical health, and overall quality of life. Sleep is one of the most important factors in maintaining good health. While needs vary from person to person, consistently getting the recommended amount of sleep (7-9 hours) can improve physical health, mental well-being, and overall quality of life.

Lisa Eckman, RN



Summer Seasonal Affective Disorder: When Sunshine doesn't improve mood

When most people think about seasonal depression, they picture cold winter days, snow, and long, dark nights. However, not everyone experiences seasonal mood changes during the winter. Some individuals experience depression during the spring and summer months. This condition is known as **Summer Seasonal Affective Disorder (Summer SAD)**.

Although less common than winter-pattern seasonal depression, summer SAD is a very real mental health condition that can significantly affect a person's quality of life.

What Is Summer Seasonal Affective Disorder?

Seasonal Affective Disorder (SAD) is a type of depression that occurs during specific seasons of the year. While winter SAD is associated with shorter days and reduced sunlight, summer SAD typically begins in late spring or early summer and improves when the season changes.

People with summer SAD often experience symptoms that differ from those commonly seen in winter depression.

Common Symptoms

Individuals experiencing summer SAD may report persistent sadness, increased anxiety, irritability, restlessness, difficulty sleeping (insomnia), decreased appetite, weight loss, difficulty concentrating, loss of interest in enjoyable activities, and/or social withdrawal.

Unlike winter depression, which is often associated with oversleeping and increased appetite, summer depression is more commonly linked to insomnia and reduced appetite.

Why Does Summer SAD Occur?

Researchers are still working to understand the exact causes of summer-pattern depression. Several factors that may contribute are the heat and humidity, disrupted sleep patterns, changes in routine, and social pressure. Some individuals are highly sensitive to hot weather. Excessive heat and humidity can increase irritability, fatigue, and emotional distress. Longer daylight hours can interfere with the body's internal clock. Having difficulty falling asleep or staying asleep can contribute to mood changes and emotional instability. Summertime often brings disruptions to normal schedules. School breaks, vacations, childcare changes, and altered work schedules can increase stress and reduce structure. Summertime is often portrayed as a season of fun, vacations, and social activities. Individuals who are struggling emotionally may feel isolated or inadequate when comparing themselves to others.

Summer SAD in Individuals with Intellectual and Developmental Disabilities

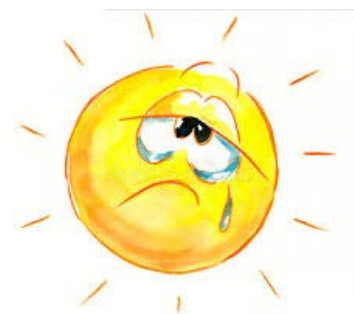
For individuals with intellectual and developmental disabilities (IDD), summer SAD may not always be expressed verbally. Instead, symptoms may appear through changes in behavior.

Possible signs include increased irritability, aggression, withdrawal from activities, refusal behaviors, sleep disturbances, increased anxiety, changes in appetite, and/or increased repetitive behaviors.

Because some individuals may have difficulty describing their emotions, caregivers and support staff should pay close attention to changes in behavior and routine functioning.

Coping Strategies

There are several strategies that may help reduce symptoms of summer SAD, such as maintaining a consistent schedule, maintaining a regular bedtime and wake time, staying cool and hydrated, staying connected to family and friends to protect against depression, and engaging in enjoyable activities.



When to Seek Professional Help

Professional support should be considered when symptoms:

- Last longer than two weeks
- Affect work, school, or daily activities
- Cause significant distress
- Lead to social withdrawal
- Interfere with sleep or appetite

Mental health treatment may include therapy, medication, lifestyle adjustments, and support for managing stress and sleep disturbances.

Final Thoughts

While summer is often viewed as a carefree and enjoyable season, it can be challenging for individuals living with summer seasonal affective disorder. Recognizing the signs, maintaining routines, and seeking support when needed can make a significant difference.

Mental health concerns do not always follow the seasons we expect. Sometimes the brightest days of the year can feel the most difficult—and understanding that reality is the first step toward providing effective support.

Amber Connor, Behavioral Health Specialist



SERVICES & SUPPORTS THROUGHOUT THE LIFESPAN SERIES



We invite you to join us for our Special Speaker Series of 2026. This year, we will present overviews of various services and supports available throughout the lifespan of those we support. Join us on the third Wednesday of the month at 9:30 am from March through November (except for July & August, so you won't miss anything by going on vacation).

Learn more about each topic and ask questions of our expert speakers. Most webinars are only an hour long!

SEPT
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**LIFECOURSE
FRAMEWORK &
TOOLS**

DIANA MORRIS SMAGLIK

OCT
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IM4Q

MELANIE ROG

NOV
18

**HOSPICE &
PALLIATIVE CARE**

DARLENE SHULTZ-JOHN

Psychotropic Medications Part 2: Short term– Side Effects & Paradoxical Reactions

The word “psychotropic” stems from *psycho*, relating to the mind or psyche and *tropic*, which means “pertaining to or influencing.” *Psychotropic medications are used to treat people with mental health conditions. The National Institute of Mental Health explains, “Psychotropic medications treat the symptoms of mental disorders. They cannot cure the disorder, but they make people feel better so they can function.”*

Each medication has its own unique side effect profile, so it is important to know the signs and symptoms of any side effects of the specific medication/s a person takes. When side effects are identified, they will need to be evaluated for tolerability and safety. In many cases, once the body becomes adjusted to the medication, side effects fade. The prescriber can help determine how long to wait and how to address troublesome side effects that don’t go away.

There are several common side effects of psychotropic medications:

Drowsiness or Fatigue may occur, particularly with medications that are intended to calm the nervous system.

Nausea is usually temporary and taking the medication with food or adjusting the dosage can help.

Increased appetite is one of the most common side effects of antidepressants and antipsychotics.

Dizziness -- feeling lightheaded or unsteady, especially when standing quickly (known as orthostatic hypotension) – can result from changes in blood pressure caused by some medications.

Anticholinergic effects describe how certain medications can cause a “drying out” effect on bodily functions, including dry mouth, constipation, vision changes, and urinary retention. Blood pressure may also be impacted.

A paradoxical reaction is when a medication causes the opposite effect for which it is prescribed. While typically affecting less than 1% of the general population, these responses are observed in 13- 17% of people with Intellectual Disability/Autism (IDA):

- Benzodiazepines (particularly the “lams” and “pams” – ex. lorazepam) are intended to sedate and reduce anxiety, yet can result in extreme disinhibition, explosive aggression, insomnia, disorganized behavior, even hallucinations.
- Atypical Antipsychotics such as risperidone, prescribed to manage irritability and self-injurious behaviors, can cause extreme irritability, as well as severe escalation in agitation or self-injury.
- Anticonvulsants may be used for seizure control and also for psychiatric symptoms (ex. Depakote). They may paradoxically cause an increase in seizures and/or severe behavioral disruptions.
- Melatonin is often prescribe to aid in sleep, but can cause wakefulness and hyperactivity, particularly in people with Autism.

Since psychiatric symptoms in people with IDA often manifest as agitation and aggression, paradoxical reactions may lead one to believe that the medication needs to be increased. Like other side effects, it is important to recognize what is happening and contact the prescriber immediately to consider what changes should be made.



Amy Tobolski, Clinical Supervisor

Don't Like Working Out? Try NEAT!

Summer is here. Vacations. Warm temperatures. Trips to the beach. But those pounds you gained this past winter are still with you, and you hate working out. What to do? Perhaps it's time to try something called Non-Exercise Activity Thermogenesis (NEAT). You can skip going to the gym and still improve your level of fitness without those grueling sweat sessions.

NEAT simply means that we're going to take advantage of everyday situations to move more and burn calories without strenuous exercise. I grew up in the 1960s. People were more active then. There were no cell phones, no Door Dash deliveries, very few fast-food places, and most of us kids either walked or rode a bike to get where we wanted to go (incidentally, my dad walked to and from work, about half-a-mile a day, for 44 years until he retired). We were practicing NEAT without realizing it.

Here are some "little" things you can do on a daily basis to feel better, look better, and lose weight. If you don't need to carry a heavy load, try walking into town to shop (if it's fairly close) instead of driving. If you do drive, park a little farther from the door to get some extra steps in (when the weather is bad, walk—or march—in place). Take the stairs instead of the elevator. If you're on your cell phone and you are sitting down, walk around the house or around the block while you're talking. Throw on some music and dance while you sweep, vacuum, or cook. If walking is too difficult, do some chair yoga while you're sitting there; you can find plenty of chair exercises online. Even sitting in a chair and squeezing a stress ball, wiggling your toes, or doing some simple stretches can burn calories and wake your body up. If your job requires sitting at a computer for long stretches of time, you might want to set an alarm to go off every 20-30 minutes to remind you to get up and move around for a while, or you could ask your employer for a standing computer station (yes, standing burns calories and gives the muscles involved in keeping you upright a little workout).



I'm willing to bet that when you to make as few trips as possible

you're like me, this usually results in an awkward, heavy, uncomfortable load that can cause you to lose your balance or worse, hurt your back! NEAT is the perfect solution here. Purposely plan to make several trips. The burden will be lighter, and you reduce the chance of injury while you burn more calories.

Practicing NEAT at first may seem a little inconvenient, and it does require some mindfulness. Start off by doing just a couple of these examples (or do a web search for more specific examples of NEAT) and gradually build up. After a while, they will become second nature, and you might be surprised at the results!

Tim Juliano, RN

Special Education Resources

Back to school is around the corner! For families with school-aged children with disabilities, navigating the Special Education process can be difficult and confusing. Here is some information to help.



Important Ideas in Special Education

IEPs/504 Plans/IFSPs these are legally-binding documents

“An IEP [Individualized Education Plan] is a formal plan that involves specialized instruction, supportive services and measurable goals... A **504 plan** provides educational accommodations to students who have a physical or mental impairment...” [HealthyChildren.org](https://www.healthychildren.org). 504 Plans are part of a different federal law than IDEA. [U.S. Dept. of Education](https://www.ed.gov). (For children aged birth-3 who receive Early Intervention [EI] services, their important document is called an **IFSP** [Individualized Family Service Plan]. [HeadStart.gov](https://www.headstart.gov))

IDEIA

The Individuals with Disabilities Education Improvement Act of 2004 [federal law]. [Center for Parent Information and Resources](https://www.fpi.org)

FAPE—Free Appropriate Public Education

“...child[ren] with a disability [are] entitled to a... (FAPE) that emphasizes special education and related services designed to meet the child’s unique needs and that prepares the child for further education, employment, and independent living.” [Center for Parent Information and Resources](https://www.fpi.org)

LRE—Least Restrictive Environment

“To the maximum extent appropriate, children with disabilities... are educated with children who are nondisabled...” [Center for Parent Information and Resources](https://www.fpi.org)

Inclusion

“...inclusion means making space for all types of students to learn side-by-side in school programs, from academics to extracurriculars.” [University of Arizona](https://www.arizona.edu)

Special Education Resources

Many Special Ed./IEP resources: [Education | PA Parent & Family](https://www.pa.gov)

This site has many resources for families: an IEP Bootcamp, a guide on special education in PA, and more!

Inclusion Strategies Guide: [Achieving Inclusion, PEAL Center](https://www.achieva.org)

This guide has 5 strategies to help ensure inclusion for your child with disabilities.

Educational Advocates: “...someone with extensive knowledge about special education programs, 504 Plans, IEPs...[and who] educates parents, children and teens about the resources available to them...” [CNLD Neuropsychology](https://www.cnld.org)

Connect with the PEAL Center’s advocates--[Need to Talk? : About Us : PEAL Center](https://www.achieva.org)

Connect with Achieva’s advocates--[Advocacy and Family Supports Intake Form, Achieva](https://www.achieva.org)

Resource	PA Parent and Family Resources	PEAL Center Inclusion Guide	PEAL Center Advocacy Contact Form	Achieva Advocacy Contact Form
Link	paparentandfamilyalliance.org/education	pealcenter.org/file_download/inline/c5a6ebc0-4a07-4ef0-af47-68a08cc53aa9	pealcenter.org/about/need-to-talk.html	achieva.info/advocacy-contact

Our **pediatric coaches** can support clients of the **Pediatric Complex Care Resource Center**, which supports PA families with medically complex children (ages birth-20, on Medical Assistance, who qualify for in-home shift care services), with navigating special ed. issues and resources. Contact PCCRCnorthwest@milestonepa.org for more information.

**Milestone HCQU/PCCRC NW cannot provide legal advice, and does not endorse any particular outside agency/org.; this article is for educational purposes only.*

Letter from the Director

Those who read this newsletter regularly are probably recognizing my common theme of getting away from technology and doing something outside of the house. Now that summer is here, I very much want to keep that same thought by encouraging you to visit a farmers' market or a local fruit and vegetable stand. I have a favorite Amish stand that I sometimes visit on my way home. This may seem like I am cheating on my garden but is one more way that I can enjoy fresh things. Last week they had strawberries and snap peas, which I bought. I then turned the strawberries into Jam and ate the peas as an evening snack while out on a short walk. Speaking of walking, with summer temperatures increasing, walking later in the day usually gives nature a chance to cool down. If walking during the day is better for you, possibly visiting a large store or shopping mall that is air conditioned is a better option. As always, drink water, and if outside, remember to put on sunscreen to help prevent sunburns. If out in areas where there might be ticks, please be mindful and check for them when you get home. Tim Juliano will be doing a training on Lyme Disease and other tick-borne illness on August 6th if you would like more information. If you or the individuals that you work with would like trainings on any topic, just email Krista at kfitzsimmons@milestonepa.org to submit a request. We can do trainings virtually, in-person, or you can take classes online via our LMS at <https://northwesthcqu.learnupon.com/>, so keep your requests coming to us. Stay safe and keep on moving.

Darryl



HCQU Contacts

Darryl Bergstrom

HCQU Director

dbergstrom@MilestonePA.org

Amy Tobolski

Clinical Supervisor

atobolski@MilestonePA.org

Krista Fitzsimmons

Support Staff Specialist

kfitzsimmons@MilestonePA.org

Amber Connor

Behavioral Health Specialist

aconnor@MilestonePA.org

Tim Juliano, RN

HCQU Nurse

tjuliano@MilestonePA.org

Lisa Eckman, RN

HCQU Nurse

leckman@MilestonePA.org

Dawn Collins

Pediatric Coach

dcollins@MilestonePA.org

Alyssa Raimondo-Swanson

Pediatric Coach

araimondo@MilestonePA.org