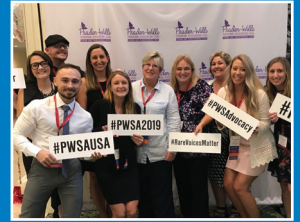




# Living Healthy *with* PWS

## LathamCenters Quarterly Newsletter



*Latham Centers creates opportunities for independence, self-worth, and happiness for children and adults with complex special needs.*

## Bringing the Outdoors in as Colder Weather Starts to Hit

*By Susan LaPlant and the  
Latham Centers Admissions Team*

Latham Centers' Admissions/Outreach and Children's Residential Teams co-hosted Valerie from the [Rainforest Reptile Show](#) on Monday evening, October 28<sup>th</sup>. Student and staff participants were thrilled by the presentation, and Valerie captivated their attention for over an hour. Students gasped with excitement when they first laid eyes on three animals they were encouraged to touch. Their website states, "Rainforest Reptile Shows is the leading animal presenter in all of the northeastern United States. We care about YOU and want everyone to enjoy themselves and the world around them! 'Educating about the natural world to improve the quality of our lives!'"

During the presentation, Valerie explained that many of their animals were rescues, including a Radiated Tortoise named George; JuJu Bean the Boa Constrictor; and a black-and-white Tegu Lizard (which demonstrated its whip tail action). The students also learned many facts about the population, including how snakes molt skin over rocks, and how most often reptiles are not slimy because they do not perspire! They also learned that the boa constrictor is an ectothermic animal, meaning that it takes the same body temperature as the air temperature of where they are.

To close out the presentation, the students met Peanut, a small four-year-old rescue alligator. Valerie demonstrated how Peanut uses vibrations to find and catch prey. First, she held a stick in its mouth and didn't move it around—the alligator did not chomp down! Then, she put the stick in his mouth and moved it around – all the students gasped when they saw how quickly the alligator chomped down on the moving stick! Students also learned that Peanut the alligator was rescued from a home in Massachusetts. It's illegal to have an alligator in this state because there is no way to tame an alligator that could grow to be up to 12 feet long and would likely lose up to 6,000 teeth in their lifetime.

At the end of the presentation, each student was given the opportunity to hold Peanut and take a photo with him (with tape on his mouth, of course)!

Rainforest Reptile Shows has an oasis in Beverly, Massachusetts, which is home to over 600 reptiles and hundreds of species. According to the website, "These snakes, lizards, turtles, crocodilians, bugs, and amphibians will live the rest of their lives in the safe and healthy environment with the professionals at RRS OASIS and the Rainforest Reptile Shows Team." We are delighted by our students' enthusiasm and our staff's commitment to engaging in new, fun, and creative programs! Thank you, Valerie, and [Rainforest Reptile Shows](#)!



*Brave students hold, touch, and learn about reptiles*

# Staying Positive: PWSA (USA) Conference Emphasizes Optimism

By Katrina Fryklund

Representatives from our Children's and Adult Services Programs traveled to Orlando, Florida for the PWSA (USA) 2019 National Convention from October 23<sup>rd</sup> to October 26<sup>th</sup>. Latham was the proud Bronze Convention Sponsor, and being a part of this event reminded us of the importance of being closely connected with our PWS community through this leadership role.

Latham Centers staff ranging from the Director of Nursing and the Director of Social Services to Residential Supervisors and the Assistant Principal attended a variety of sessions in the Medical and Scientific, Providers Day, and General Conferences. Each session illuminated a different aspect of what our staff does day-to-day, and favorites included:

- Aging – Need to Transitional Care *by June-Ann Gold, MD*
- Endocrine Issues in Prader-Willi Syndrome *by Jennifer Miller, MD*
- Self-Care for the Caregiving, Panel Presentation *with Brittnei Kliment and Katrina Fryklund serving*
- Law Enforcement Issues/Strategies *by Tammie Penta*
- Living with PWS, Panel Presentation *with Young Teens and Adults with PWS*
- Preparing for your Child's IEP *by Mary K. Ziccardi*

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Patrice Carroll, LCSW, Latham's Director of PWS Services, co-chaired the Professional Providers Conference on Thursday where approximately 100 providers from around the world learned from one another. Pictured (page 2) are photos of Patrice, Lee Chamberlain (Vice President of Operations/COO), Brittini Kliment (Director of Program Marketing and Admissions), and Katrina Fryklund (Director of National Outreach), who spoke on panels and led round-table discussions pertaining to behavior management, vocational opportunities, human rights, and more.

In a recent TIP of the week blog, we underscored the value of attending these conferences, both from the perspective of providers and parents. One parent of a student at Latham Centers who attended said, *"I wish all parents could attend conferences like this. It is amazing to see so many people who understand what I have been going through. It also reinforces to me how Latham Centers has the best staff in the world who specialize in PWS."*

The Keynote address for the two-day General Conference focused on 'maintaining positivity.' Rick Guidotti of Positive Exposure gave an inspirational speech in which he said, *"Change how you see, see how you change."* He travels around the world and takes photos of individuals of different abilities, boosting individuals' confidence day-by-day. Two individuals with PWS, Griffin and Justice, spoke about their positive life-experiences and the importance of staying joyful and optimistic about the future. The speakers left our staff inspired with the concept of **"self-acceptance = self-esteem = self-advocacy"** (Rick Guidotti, <https://positiveexposure.org/>).

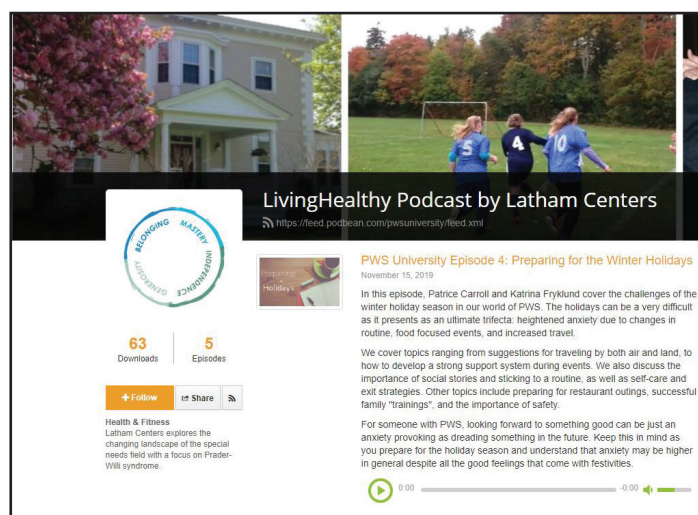
We hope to leave you with that TIP as well: stay positive, be optimistic, and always see the best in your loved one with PWS.



## PWS University: A Latham Centers Podcast

### Latham launches newest LivingHealthy Series

By Patrice Carroll and Dawn Dinnan



We are pleased to announce the launch of Latham Centers' podcast series entitled **LivingHealthy!** Led by Patrice Carroll, Director of Prader-Willi Syndrome Services, and Katrina Fryklund, Director of National Outreach, the team will explore the changing landscape of the special needs field. Topics will range from the challenges of a Prader-Willi Syndrome diagnosis and paths to happy, healthy lives for those with PWS (in our **PWS University** series), to overarching considerations in the special needs field such as transitional and vocational programming (in our **LivingHealthy** series).

Patrice and Katrina will invite individuals with PWS and professionals in the field to join them in the audio podcast shows. Podcast listeners will hear Latham staff members who are well-versed in PWS programming, clinical services, and nutrition, as well as specialists from around the globe with expertise on strategies for success in special needs supports and services. To date, Latham Centers has posted five podcasts ranging from student interviews to tips for preparing for the holiday season.

In our first PWS University episode our audience meets Jake, who discusses his talents, friendships with peers, and how it feels to have Prader-Willi syndrome. Jake truly represents the pride and happiness that grows with support of family and staff.

In our second podcast we talk about the **LivingHealthy** series and what listeners can expect. Patrice states, *"The purpose of the podcast and what we want everyone to take from this is that people living with PWS can live full, quality lives. Much of the information that you see online is either outdated, misinformed, or generally negative, and that is absolutely not the reality of life with PWS in the majority of cases."*

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Our next PWS University podcast highlights Annika, a peer of Jake's at Latham Centers. She describes from her perspective what it means to stay safe and be healthy. Annika also gives advice for children with PWS and parents who have a child in their life with PWS.

In our third PWS University post we emphasize the importance of a positive attitude in the world of PWS. Patrice and Katrina focus on programming examples at Latham Centers and the significance of Positive Behavioral Supports when working with someone diagnosed with PWS.

Our fourth PWS University Podcast is meant to prepare families and caregivers for the holiday season. Generally, the holidays mean family gatherings, food centered events, heightened anxiety, and changes in routine. Patrice outlines helpful techniques.

Future episodes will range from five to thirty minutes and will cover topics including but not limited to:

- Interviews with children and adults at Latham Centers
- Interviews with professionals who have worked in the PWS Community including doctors, nutritionists, and educators
- Interviews with staff at programs geared toward individuals with PWS
- A home environment that builds on strengths, fosters success, and explores independence
- Coping with anxiety
- Coping with emotional outbursts
- The future of adult housing
- The best educational environment
- Picking: What every parent should know
- Holiday preparation
- How does residential programming help?
- A clinical approach to PWS: therapeutic modalities
- Vocation and employment
- Transitions and travel
- TIPS for the medical environment
- Volunteering and community involvement
- Sensory and performing arts
- Transitioning a student into a residential program
- Working with a population that has a trauma background

We hope that in sharing the expertise of many in our vast interconnected communities, we will provide hope for 'brighter futures' for children and adults with complex special needs near and far.



*Patrice and Annika after a recording session*

We encourage you to follow our podcast at <https://pwsuniversity.podbean.com/> where you can also listen and download, "like", and share. We welcome your insights and suggestions and invite you to email us at [livinghealthypodcast@lathamcenters.org](mailto:livinghealthypodcast@lathamcenters.org) so we can include topics relevant to you and your life with someone who is diagnosed with PWS.

### LivingHealthy Podcast by Latham Centers

<https://feed.podbean.com/pwsuniversity/feed.xml>

#### PWS University Episode 4: Preparing for the Winter Holidays

November 15, 2019

In this episode, Patrice Carroll and Katrina Fryklund cover the challenges of the winter holiday season in our world of PWS. The holidays can be a very difficult as it presents as an ultimate trifecta: heightened anxiety due to changes in routine, food focused events, and increased travel.

We cover topics ranging from suggestions for traveling by both air and land, to how to develop a strong support system during events. We also discuss the importance of social stories and sticking to a routine, as well as self-care and exit strategies. Other topics include preparing for restaurant outings, successful family "trainings", and the importance of safety.

For someone with PWS, looking forward to something good can be just an anxiety provoking as dreading something in the future. Keep this in mind as you prepare for the holiday season and understand that anxiety may be higher in general despite all the good feelings that come with festivities.

# Preparing for the Holiday Season

By Katrina Fryklund and Patrice Carroll

The holidays can be a very difficult time for someone diagnosed with PWS as it presents as an ultimate trifecta: heightened anxiety due to changes in routine, food-focused events, and increased travel.

For someone with PWS, looking forward to something good can be just as anxiety provoking as dreading something in the future. Keep this in mind as you prepare for the holiday season and understand that anxiety may be higher in general despite all the good feelings that come with festivities. We hope the ideas below help you prepare!

1. **Have an exit strategy:** Put a plan in place in case you have to leave early and leave if the situation feels unsafe.
2. **A Support System:** have a support person at the events with you. This could be family members or friends or hired staff. If utilizing the support of family and friends, consider making a schedule so that people know who is responsible and when; remember: if everyone is watching, sometimes no one is watching. Your local human service agency may have resources for hiring staff support.
3. **If it feels overwhelming or unsafe, it's okay to stay home:** There can be a lot of family pressure around holidays and it is important to make the decision that's best for you and your family. If necessary, consider doing a smaller event at home, and if possible, make plans unrelated to food with the extended family the following week.
4. **Write out the menus:** often times holidays involve large family pot-luck meals or many nights out at restaurants. If an event is at a home, ask the host what will be served and write out a menu with the person in your life with PWS. He or she will then have better expectations of what they can have. We also suggest laminating the menu if possible and bringing it to the occasion. (Laminating can be a great tool as during times of frustration it cannot be ripped.) If going to a restaurant, look online and see if the establishment has a menu. You can print out the menu, review the options, and determine what you're going to have before even stepping foot inside.
5. **Try to stick to a routine as much as possible:** try to stick to same routine when away from home, or a modified version. If traveling, bring a snack on the road so meal times are consistent. If you exercise at a certain time every day, discuss the change in schedule and when you will be exercising instead.
6. **Do a mini-training with your family beforehand about the holiday:** We have heard from families who prior to the event have messaged their families in Facebook groups or through email to remind everyone of the PWS "rules" for their

family. Ultimately the message is that it's not just about a few extra calories, rather, it's about the anxiety that comes in the change of routine and abundance of food.

7. **Social Stories:** Especially in the situation of traveling and holidays, we suggest social stories. In the case of air travel, include a scenario in the social story explaining what the group is going to do if the plane boards late, or if the flight is delayed.
8. **Boarding Early:** If traveling by air, ask to board early to get comfortable before all others are on the plane. Less chaos may reduce anxiety.
9. **Planning stops:** If traveling by car, visit <https://www.interstaterestareas.com/> and learn about the rest stops along your route. If you know the places to stop you can plan around them, determine bathroom breaks, and food stops.
10. **Holiday gifts:** Have a conversation with the person in your life about a realistic expectation of gifts. Nothing on a 'wish list' is guaranteed.
11. **Self-care:** If the caregiver is anxious and frazzled, more likely the person with PWS in the caregiver's life will be more anxious and frazzled. Remember to take care of yourself despite the chaos of this time of year to be your best self and give the most to the person in your life with PWS.

*The Holidays: Gratitude  
and Appreciation Despite  
Heightened Anxiety*



# The making of 'A Day in the Life': For Students, By Students

By Katrina Fryklund

Every day on campus, I am blessed to see students flourishing. While sometimes I hear moments of anxiety and frustration, the majority of my day I hear cheerful hellos, proclamations of achieved goals, and peer-to-peer support. "A Day in the Life" is a video that shares that story of success.

Latham Centers staff and students started working on the production of this video after a conversation with a parent from across the country. We asked the question: 'How can we give students (and parents) who can't visit campus the opportunity to get to know our students and take a tour?' We knew that pictures were not enough.

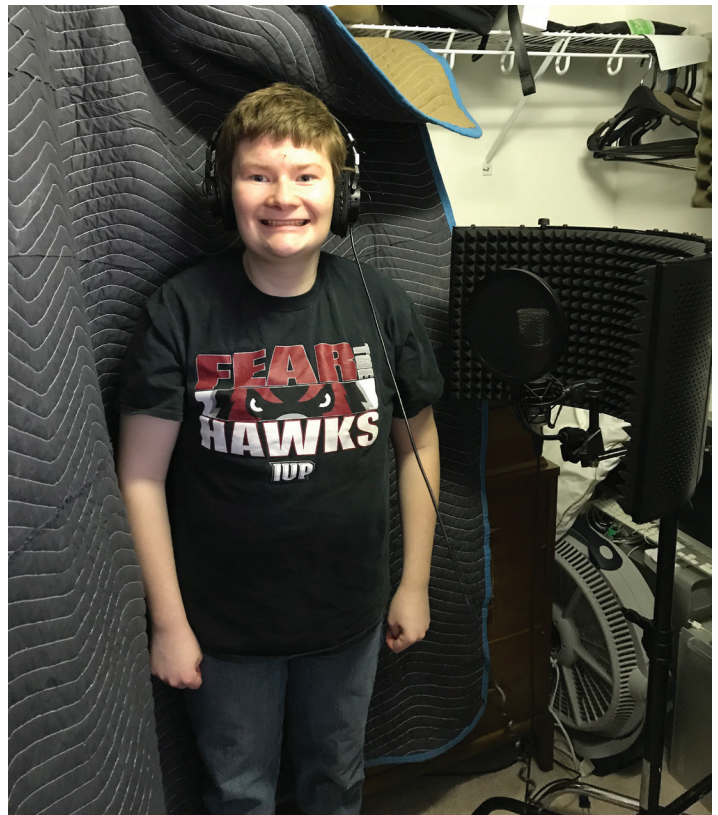
First, we contracted with Tom Chartrand of Shoreline Media Productions. Tom worked so well with our students. He flawlessly navigated his way through campus, camera in hand, for various occasions including the Year-End Celebration and a typical school day. Throughout his time on campus, Tom conducted student and parent interviews, spent time with staff, and took footage of both the educational and residential components of program.

Staff and students worked together to produce a script and two students were asked to go on an outing and record the script in the Shoreline Media Productions Recording Studio. I accompanied the students with Director of Program Marketing and Admissions Brittnei Kliment, and we were very proud of how our students prepared and performed. It was an exciting day for all included.

Once the video was complete, we first unveiled the production to the stars: our students. In a special school day event, each classroom had a movie showing. Gasps and giggling could be heard from students when they saw their face on the screen, and when they saw the final product.

We hope that you enjoy watching this video as much as we enjoyed creating it. Moreover, we hope that this shows the great work of our students, who proudly tell people every day about their accomplishments at Latham Centers.

**Link to video: <https://youtu.be/UKw7P0qk-Wc>**



(above), Liam at the recording studio; Liam with Videographer Tom Chartrand and staff Brittnei Kliment and Katrina Fryklund; (left) Students viewing the video in classes.



Four Seasons of  
"LivingHealthy with PWS"  
newsletter are available at

[LathamCenters.org/who-we-are/prader-willli-syndrome-expertise/](https://LathamCenters.org/who-we-are/prader-willli-syndrome-expertise/)