



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.

Latham Student Inspires Others With PWS

Meet Daniel! Daniel is a student at Latham Centers described by those who know him as “awesome.” Daniel has thrived at Latham, a residential therapeutic program now in our 50th year of service. Daniel also lives with his parents in Maryland during school breaks. Latham’s Patrice Carroll and Katrina Fryklund sat with Daniel recently, recording the interview for a podcast series about PWS. Katrina noted, “We learned so much from Daniel – things like why he likes giving tours of campus, what it’s like to have Prader-Willi syndrome, and a cool fact that he hopes we all remember about kiddos with PWS.” Here are just a few of the many questions Daniel answered in his interview:

- **Q:** Can you tell me something really cool about yourself?
A: I like dogs and I like to play with them. I have two dogs of my own and I love them very much. At Latham, I also help Katrina and Patrice and Admissions with Tours.
- **Q:** You’re a really good tour guide. What do you think makes you a really good tour guide?
A: I talk to people and I explain what goes on around here and let them meet some of the kiddos that live here and go to school here.
- **Q:** What do you think is the best part about being a student at Latham?
A: Telling other people about PWS... people that come here and visit and new staff about what it means to be a PWS Kid.
- **Q:** What is it like being “a PWS Kid?”
A: It’s hard being around food and I wish that there could be a cure to help so that we can feel full, and we don’t have to think about being hungry or being in a spot that you don’t want to be in.

- **Q:** What is your favorite thing about being a tour guide at Latham?

A: That’s a hard question! I like to give them soaps in the voc[atational class]room if we have extra and say, “here you go, this is a present from Latham!”

- **Q:** Anything we didn’t ask that you want to tell us?”

A: Something that’s really cool that a lot of people with PWS have is good memory. I remember stuff that was six, seven, eight years ago, and I still remember it now!

Hear Daniel in our most recent PWS University podcast at: <https://pwsuniversity.podbean.com/e/pws-university-episode-10-an-interview-with-daniel/>



Latham's Virtual Storytime Engages Students with PWS Across the Country

Students Lead Peers in a Reading of Their Choice

When Patrice Carroll, Katrina Fryklund, and Brittnei Kliment started Virtual Storytime as COVID precautions became the norm, they never imagined its success, nor its immeasurable importance to children across the country.

One parent recently wrote, *"I wanted to say how much [my son] has taken to the interaction with, as he says, 'friends like me.' He was tentative at first, but now I don't even have to remind him. He is on it! Thank you so much for making this available to students outside of Latham. This is a nice thing to look forward to a few times a week!"* Another parent mentioned, *"It's two days of the week that he always looks forward to because he knows he is going to be able to catch up with his friends."*

As Storytime evolved, we began to engage the students as the readers — a difficult task for many, regardless of abilities. It means talking to and reading out loud to a large audience and being okay with making mistakes. On Monday evenings, noted Katrina, *"our student reader is extra special and serves as a leader amongst his or her peers."* We asked three of our student readers about their experience as a special guest, and the significance of the entire Virtual Storytime community. Below are their responses:

Hannah, 19: Joining Storytime every week is really cool because I get to talk to people around the world with the same syndrome as me. It's cool because it helps me not feel so alone. I had only met two people with PWS before and now I have lots of new friends with PWS. I especially love when new kids join us, so we can make even more friends. I was nervous to read but I did a really good job because I'm a good reader. Patrice and Katrina gave me the option to read a book about a turtle because I'm a mature young lady, and also own a turtle. At home I have lots of fish, two dogs (one of which is a service dog), one turtle, two cats, and six parakeets — I am an animal lover and really enjoyed reading a book about a turtle. My friends helped me name some of my

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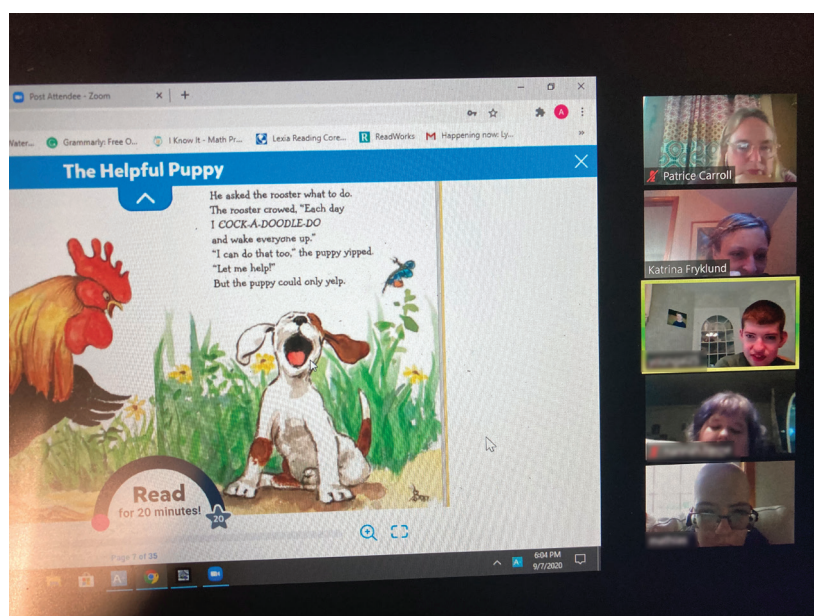
fish and my favorite name suggestions were Sunshine, Starlight, Patrice Jr., and Sushi. Storytime is awesome and it was an honor to be a special guest. (I learned from writing this that I'm a good writer too!)"

Mathias, 14: I got an invite to join storytime from Patrice, Katrina, and Brittini and from the very beginning I've made great friends. I'm very glad I got to read my first book and I felt honored that I was selected as the first student reader; I even helped them come up with this idea! When I was younger I started to read comic books and became REALLY good at reading, so it was really fun to read to my friends out loud using Zoom. The first time I was on Storytime I was able to introduce everyone to my dogs. In my spare time I have a job; I keep my community safe with my business, "Mathias Bail Bonds." I love Christmas year-round, and I was able to pick a book called *Memoirs of an Elf!*

I'm a really funny guy, and I always tell my friends jokes, one of my favorite jokes is: Question: "What do you call an old snowman?" Answer: "Water."

Trevor, 16: Thank you for letting me read for story hour. It was fun reading a story to all the people. I feel like I have new friends at Latham Centers and across the country. It is fun to be friends with other people who have PWS because they understand me. That made it easy for me to read the story. I want to do it again sometime.

If you have a child with PWS between the ages of 8 and 22 who would like to join Storytime, we invite you to contact the Latham Centers Admissions and Outreach team at admissions@lathamcenters.org.



Sibling Group: Does the person in your life with PWS have a sibling who would benefit from a virtual community of support from others in like situations? If so, let us know at slaplant@lathamcenters.org. More information to come about how to get involved in this group.

Pictured, the sibling of a Latham student created the "Latham Open" tennis tournament to raise funds for programming for children with PWS.



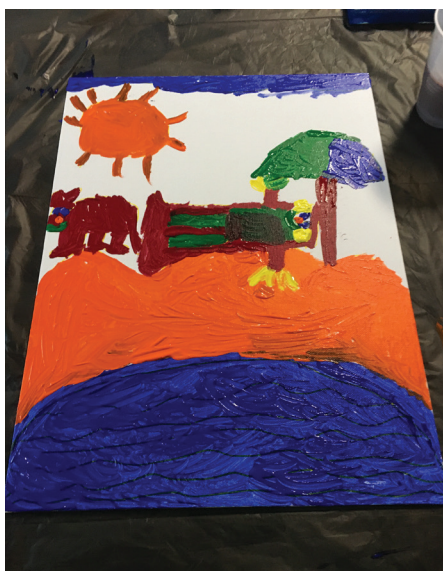
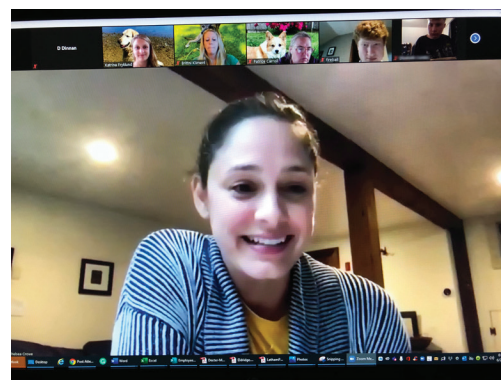
Program Highlights: Learning Opportunities on Campus and in Latham's Adult Program

Our Children's Program Director Gerry Pouliot recently expressed heartfelt gratitude to Latham's direct care staff in honor of Direct Support Professionals Recognition Week here in Massachusetts:

"We have a lot on our plates simply being a residential school, but this year has been different...nothing could have prepared us for COVID-19. We asked so many things of you to keep our campus safe, and you have.

Because of you, each and every one of you, we have received recognition both in-state and within the PWS community as best practice during a pandemic. From clinical, to the kitchen, CCWs, residential, educational, supervisors, nursing, maintenance, and everyone else in between, you have kept our students and campus safe and we thank you from the bottom of our hearts. I am so thankful for you; Latham Strong is a real thing."

"Latham Strong" is particularly notable in our evolving programming throughout the pandemic – both in the Children's and Adult Services Programs. Our staff has shown not only their dedication, but also their creativity! This photo collage is a small sampling of life at Latham this spring and summer.



Pictured: Graduation poster celebrating one of our adult residents who graduated from Cape Cod Community College; our Great Hill home's Zen Garden; Virtual Learning over Zoom (sharing our pets is a big hit – as is Clinician Chelsea Crowe who shares her incredible singing!); and paintings created by Adult Program participants at the Railroad home.

“Latham Strong”: Training and Teamwork

As noted in our “Program Highlights” piece (page 4), “Latham Strong” is the work culture that has developed over time, not only because of our exceptional staff, but also because of our extensive training and opportunities for collaboration and teamwork... and a healthy dose of humor! Policy and procedure modifications, team meetings, and trainings through the pandemic have been instrumental in keeping our students and staff safe. There is no “i” in TEAM – we are all interdependent, and driven by a common mission, vision, and core values.

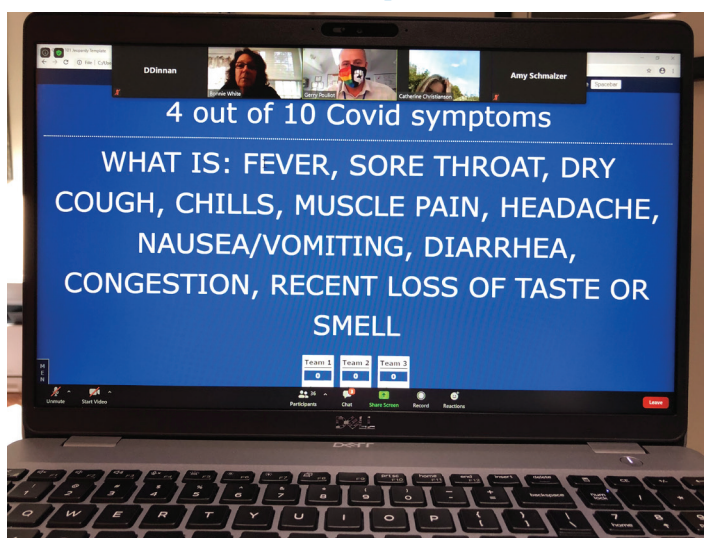
Pictured, Director of Children’s Services Gerry Pouliot leads an all-staff meeting featuring a creative “Jeopardy-style” training on Covid-19 protocols.



Pictured (above and below), a Children’s Program staff training over Zoom with a little friendly Latham competition.

Elizabeth Roof, PWS Specialist, Consults Weekly at Latham

World-renowned PWS consultant Elizabeth Roof, M.A. (Senior Research Specialist, Research Lab Director, Vanderbilt University) and Patrice Carroll (Director of PWS Services, Latham Centers) have joined together to offer consultation to Latham’s clinical and nursing staff every Tuesday morning. Elizabeth brings years of experience and international recognition to Latham Centers. Many of the topics that we have discussed come directly from our staff. With Elizabeth’s help, we promptly address challenges and provide guidance. Some discussions have included peer to peer relationships, improving daytime fatigue, and addressing feelings of home sickness during COVID. We look forward to continuing our Tuesday meetings and tackling some of the more challenging behaviors that we sometimes see with individuals diagnosed with PWS.



Latham Centers will soon publish *Understanding the PWS Mindset and Development of Coping Skills*, written by Patrice Carroll. The electronic version will be a free resource for everyone in our community, available through our Admissions and Outreach team soon. (Please email admissions@lathamcenters.org to be added to our “PWS Mindset” publication distribution list).

