



Living Healthy with PWS

Latham Centers Quarterly Newsletter



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

Mastery and Independence: Latham students take spring by storm

By Katrina Fryklund and Dawn Dinnan

With the melting snow and increase in spring temperatures comes growing excitement from our students. Warmer weather means more time outside (including beach visits with sunscreen), in the community, working on important year-end projects with peers, and participation in more special events. Latham students showed their growth and quest for mastery and independence in profound ways. Students participating in Latham's "Stars on Stage" were dedicated to preparing for numerous outreach opportunities, giving back to the community through music and the arts.

Students Present "Schoolhouse Rock" Musical and Spring Talent Show

In May, students in the Latham Stars on Stage Club proudly presented "Schoolhouse Rock Live! Jr." at the Brewster Baptist Church near our school campus. Produced with generous support from the Federated Church of Orleans and the Arts Foundation of Cape Cod, the performance was a celebration of the unique talents of our students through theater, music, dance, and art. Schoolhouse Rock Live! Jr. was presented with special arrangement with Music Theater International (MTI). Students truly shined on stage and brought so much joy and pride to the Latham community and invited guests.

"Latham Stars on Stage" presented an incredible Spring Talent Show on the outdoor stage in early June. The show at our Brewster campus



featured more than 30 acts including singing, dancing, sports, arts, piano, and drumming. Produced with support by Sarah Jane Mason, Instructor of Performing Arts & Wellness, the show got everyone on their feet – students, staff, and family members – during intermittent dance parties. It was an outstanding array of talent and a memorable celebration of belonging and mastery on a sunny spring afternoon.

A favorite quote of the day came from a student who performed a rousing rendition of "Sweet Caroline." He was happy, animated, and when he took his seat, went to a friend in the audience and said, "I sang that one for you because I know you like it!"

A memorable Community Meeting

At the monthly all-student Community Meeting in June, aspiring student leaders spoke about why they should serve as members of the student government. Their speeches were a special part of the hour-long event during which students (and staff) are honored for their impact on the Latham community. At the June meeting, those recognitions were followed by new achievements – more than 20 students took to the podium to discuss what being on the Student Council would mean to them.

Awards: Two new students were stars for the day – one was presented with the Math Award and Vocational Skills Award, while another won the Nursing and Clinical teams’ “Sweat Band Award.” A third new student was recognized for an academic award and was brought to tears from the applause of her new peers.

Leadership: With much energy, students running for Student Council each presented for up to one minute, explaining to their peers why he or she would make a good student leader at Latham School. Ballots were handed out in suites after the Community Meeting, and each student was able to vote for their favorite candidates.

Quotes from several of the student presentations follow:

- Chloe: “Please vote for me. I’ll listen to you and respond to try to make everything better!”
- Daniel: “Please vote for me for student council. I want to help people out.”
- Hassan: “I want to spread peace and kindness, and if you need help, you should vote for me!”
- Jake: “I’m kind, friendly, and smart; please vote for me.”
- Ryan: “Positive attitudes will breed success. If you are positive around others, then they’ll be positive for you. I have friends at Latham. I want to help. How else can you fill somebody’s buckets?”
- Tiffany: “I want to make a change and difference in the Latham community.”

We are so proud of our students for their mastery of skills and great strides toward independence, and we’re looking forward to another summer filled with off-campus activities and outdoor learning programs.



Esau and Esther Get Hitched: Donkey Wedding brings attention to Latham Centers’ Asinotherapy program

By Heather Kelsey and Dawn Dinnan

Latham’s beloved and innovative donkey therapy (or Asinotherapy) program was launched nearly a decade ago. Individuals served by Latham Centers learn to care for and lead the donkeys as part of our vocational services and supplemental therapeutic programming. Our Development team was tasked with launching a new fundraising initiative to help supplement the cost of caring for and feeding Latham’s six miniature donkeys. Director of Development Heather Kelsey recently announced that the Donkey Wedding in early May brought in more than \$13,000 to help fund the donkey therapy program.

The donkeys require regular veterinary care, farrier services, vitamin supplements, and of course, hay and bedding. Our wonderfully creative Development Associate Diana Morgan came up with the idea for a “Donkey Wedding” complete with a gift registry where wedding guests and animal lovers could purchase “gifts” like hay and hoof trimming or donate gifts of cash to help the happy couple begin their new life together.”

To introduce the donkeys and to create a narrative that would eventually lead to Esther and Esau’s engagement, we launched a blog series. Each “Meet the Donkeys” blog post featured a personal interview with a Latham donkey where they shared anecdotes from their lives at Latham, their hobbies and even their pet peeves. Moonbeam is from Vermont and came to Latham to pursue a life with a deeper purpose. Angus has a discerning palate and likes a good ear brushing. Jake is a native Cape Codder who tells a great story and feels no resentment toward summer tourists. His good friend Curley, handsome and a gifted athlete, prefers shoulder season and curses the arrival of summer. Curley is also in love with Esther, the only female donkey or “Jennie,” who only has eyes for Esau.

Readers of the blog followed Esther and Esau’s love story, and on Valentine’s Day, Esau proposed to Esther and plans for the wedding ensued. While the concept is quirky and fun, the impact of the Donkey Therapy program on our residents at Latham Centers is significant. Residents of Latham Centers interested in participating in Asinotherapy take an intensive training course. The program teaches accountability and responsibility, as well

as vocational skill building. Two adult residents walked Esau and Esther up the aisle and read impactful messages about the Asinotherapy program. Brittany said, “I am so happy to be here, and I wish them a very happy life together.” Christina said, “I have been working with the donkeys for nine years. It is a lot of responsibility, and I am proud of myself for handling it.”

Both wished the donkeys well in their marriage.

Cape Media News published a story about the event including footage of our staff members and guests touting the far-reaching impact of Latham’s programs. Earlier this spring, *Hope in the Saddle* magazine also publicized Latham’s donkey therapy news, publishing “Miniature Donkeys are Unlikely Allies for those with Prader-Willi Syndrome.” The freelance writer noted, “Dogs and horses may be the stars of most animal therapy programs, but at Latham Centers’ residential program... it’s donkeys who are changing lives.” The article, written by Jessica Morris after interviewing Latham staffers including donkey trainer Kristiane Thompson, details how our residents learn life skills through the donkey program. “Each resident’s journey through the donkey program begins by interacting one-on-one with a donkey until Thompson feels that the resident is comfortable enough to join the program’s six-week training course. During this “Donkey

101” course, students learn how to interact with and care for the donkeys safely. Graduates of the course can then participate in daily feeding, grooming, cleaning, and even training activities.”

Patrice Carroll, our PWS expert, was also interviewed for the article. “As our individuals learn to nurture and encourage the donkeys to become more compliant, they are strengthening their own ability to self-regulate their emotions and behavior.”

Kristiane noted, “I have been a part of this program for more than eight years, and I have never seen any challenging behaviors from our individuals while they are around the donkeys... The donkeys are very calming. They bring out the best in everyone.”

Another publication, *New England Psychologist*, also featured Latham’s donkey therapy program. In the article, Patrice commented that people often hyper-focus on the challenges of PWS and discount the positives—a much longer list. “Individuals with PWS tend to be extremely engaging, funny, and empathetic. We focus on the good list, and we shorten the list of challenges, and the donkey program is one of the ways that’s helped us do that.”



At Latham Centers’ Donkey Wedding, residents of our Adult Services Program played important roles in the fundraiser.

Admissions Highlights: A typical day at Latham Centers

By Susan LaPlant

Latham Centers' Admissions Team is comprised of four staff members with a combined total of over 40 years of experience at Latham. These staffers have worked in collaboration with our program's educational, development, admissions, and marketing components. When parents and referral sources reach out to the admissions team, they are often faced with a precarious situation involving hardship and concern. Frequently, parents contact us having served as the only advocate for their child in the school setting as well as medical settings, and they are faced with an incredibly difficult decision.

Our admissions team equips parents and referral sources with information that will help them make the most educated and timely decisions, and become the best advocate. We work with school districts and funding sources to streamline the difficult process. Often, we are asked, "What does a typical day look like?" To the right we detail a typical schedule.



Student with
Special Education Aide Lori.

DAILY ROUTINE:

Residence

7:00-8:00 wake up/shower

School

8:00-8:30 breakfast/meds

8:30 school starts

8:30-8:45 mindfulness

8:45-11/12:00 classes (reading/ELA, math, science, P.E. and health, social studies, vocational skills, social skills, performing arts)

11:00/12:00 lunch

11:30/12:30-2 mindfulness break (after lunch), continue with classes

2:00-2:20 mindfulness prior to transition

2:20-2:30 transition to residential suites/room time

Residence

2:30-3:00 afternoon snack

3:00-4:30 exercise, outings

4:30-5:00 dinner

5:00-6:30 chores, showers

6:30-8:00 TV/movies, free time, shower, phone calls, electronics, evening activities, exercise, evening snack

8:00-9:00 bedtime prep: brush teeth, settling down, quiet time, TV

9:00 bedtime

Behavior	Strategies and Coping Skills for Individuals with PWS
Aggression	Aggression is often a result of anxiety. Taking space is the number one coping skill for kids who become easily overwhelmed and react aggressively. Teaching your child to recognize when he or she needs to walk away and defuse is an invaluable skill that will have lifelong benefits.
Anxiety	Anxiety and PWS go hand-in-hand. Our kids live every day battling anxiety that ranges from mild to crippling depending on the situation. Even the most anxious child in the most stress provoking situation can rise above and face their fears. We find that the best coping tools are encouraging communication about triggers and patterns, establishing calming day-time and night-time routines, showing positive examples, and praising strength and bravery. Also, take note of places and experiences that bring your child joy. During times of stress, talk to your child in detail about these places, and over time ask him or her to visualize these experiences on his or her own. This skill teaches decompression and mood stabilization.
Compulsion & Obsessive Tendencies	Obsessive and compulsive behaviors are very common. Collecting, hoarding, tics and vocalizations can be signs of increasing anxiety. Routines and predictable environments can decrease these behaviors. For hoarding behaviors, consider a system where your child donates two items back for every new item collected.
Emotional Outbursts	Outbursts can occur for a various reasons; often, a change in routine and unmet expectations can lead to a tantrum or meltdown. Keeping a routine and clear expectations can minimize the occurrences of outbursts. The top ten things to remember when you are managing a behavioral meltdown in public are: (10) THIS IS NORMAL (9) Don't be embarrassed (8) Perform a risk assessment (7) Take a breath and step back (6) Stay calm, look neutral, and stay present (5) Avoid "no" and "can't" (4) Give a simple direction, and then time and space (3) Let it go (2) Debrief after the event (1) Take care of yourself!
Food Seeking	Role playing and social stories teach your child what to expect in different environments and situations. Anticipating potential stressors and having your child play their way through them before they actually happen can decrease their stress when the actual event takes place. Keep this in mind around the holidays when routines around food change.
Non-Compliance	People with executive functioning disorder (common with a PWS diagnosis) have difficulty organizing and remembering steps and can struggle with following instructions. This can often be misunderstood as non-compliance. Until you are able to teach appropriate reactions to the appropriate situation, be aware that your child is experiencing the stress of someone going through an emergency. In some kids, a problem such as not being able to go on an activity, a change in plans, or losing a toy or item of clothing may result in a reaction that we believe to be "over the top"—but keep in mind that they are truly experiencing this high level of panic. The "How Big is My Problem?" chart (right) illustrates the problem solving difficulties experienced by people with EFD.
Perseveration	Perseveration of thoughts, repetitive questions, concrete thinking, and an overall stubborn presentation can be extremely frustrating for a caretaker. It can be helpful to remember that they are attempting to manage their environment. A good technique is to write down as much as possible; writing down the answers to questions can be very helpful and is visual. Additionally, deep breathing calms the body, clears the mind, and allows us to face anxiety more effectively. It is difficult for children and adults with PWS to breathe deeply, so games can be used to teach this skill. Blowing bubbles or blowing up balloons are ways of ensuring that your child is taking a good, deep breath.
Skin Picking	Skin picking is a common behavior seen in PWS, but the severity of this behavior varies greatly. Start by avoiding bug bites and cracking or breaking skin. Next, keep hands busy! Strategies that we use include (but are not limited to) pulling burlap, popping bubble wrap, or using fidget devices.



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LathamCenters

LathamCenters.org

Community Connections through fundraising/outreach

By Heather Kelsey

At Latham, we value community. We foster connection and encouragement among our students and adult residents, and we promote and value service through volunteerism.

At Latham School Community Meetings, our students celebrate the accomplishments of their peers. They praise friends and share personal achievements. Our students and adult residents create beautiful goat's milk soaps and other items to share with visitors and donors or to auction at fundraising events. They volunteer their time at local charities and they volunteer to help with projects on campus or in their residences.

We are also the grateful receivers of many gifts from the greater community – our Cape Cod community, Latham families, friends, local businesses, staff, Board, volunteers, and donors. Last year, over \$645,000 was raised to support Latham programs and the campaign for the new Latham Community and Arts Center, a dynamic multi-use facility which will feature a gymnasium, auditorium, fitness center, woodshop, and arts and crafts space. In addition to annual contributions and grant funding, Latham supporters ran, biked, bowled, and golfed to help raise money to support key initiatives.

Fitness is a key treatment component for our individuals with PWS, and participation in fitness-based fundraising events is a great way to model and live a healthy lifestyle

while raising funds to support Latham Centers. For the past four years, Latham has been a beneficiary charity for Cape Cod Charitable FunRaisers (now Barnstable Charitable Foundation) which sponsors the Roll the Rock bowling tournament and The Last Gasp (now The Gasp) bike, boat, and bake fundraiser. Our participation in these events has raised over \$86,000 to support the capital campaign for the new Latham Community and Arts Center.

Each May, Latham sends teams of four bowlers, including a team comprised of adult residents, to bowl for a chance to win \$100,000 for Latham. In September, bike riders raise funds to support a 55-mile bike ride from Sandwich to Provincetown. The route takes cyclists right by our Main Campus in Brewster. Students create signs and line the street to cheer on our Latham riders. At the end of the ride, cyclists are ferried back to Sandwich on the Dolphin Fleet and then treated to a festive lobster and clambake. And in August, a hearty team of runners lace up their shoes and join Team Latham to run the Falmouth Road Race. Funds raised support training and participation in Special Olympics for our children and adults and on alternating years, the campaign for the Community and Arts Center.

Many of our staffers and Latham family members participate in these events year after year, providing a wonderful opportunity for team building and community inclusion. Together we learn that a community can challenge you, reveal your gifts and talents, carry you emotionally, create awareness of the needs of others, and teach you to forgive and work through conflict.



In the three fundraising events pictured above, Latham staffers join with Latham family members and friends from the community.

Left to right, Team Latham enjoys the Last Gasp boat ride following their bike from Sandwich to Provincetown; Falmouth Road Race runners after their run; and one of Latham's Roll the Rock bowling tournament teams.

PWS Conference Highlights: A Bright Future

By Katrina Fryklund

Latham Centers and the Mac Pact hosted the second annual Prader-Willi Syndrome conference, *A Bright Future*, on June 1st. Over 120 attendees participated in discussions with world renowned PWS specialists on a beautiful Saturday in Glastonbury, Connecticut. Attendees came from across the east coast from Vermont to Pennsylvania, and speakers came from nearby Massachusetts – and as far away as California.

Matt McCleery, Conference Planner and PWS parent, said in a warm thank you to attendees and presenters, “As you reflect on an amazing day that we spent together, we hope that you were as inspired by the people you met as we were. We also hope that you came away feeling stronger, better understood, more optimistic, and more connected to others than ever. A life with PWS is not always easy, but with education, support, networking, and planning, its rewards can be truly extraordinary. PWS families are in a unique and powerful position to support and ‘lift up’ each other.”

As a fellow conference planner, I feel that this conference was truly impactful. Parents, guardians, caregivers, and professionals learned techniques to learn how to cope with behaviors, listened to presenters discuss the future landscape of PWS services, and connected with fellow parents. One mother said of the trip to Connecticut with her son, “It was our first conference, and our first time out in the PWS world, and we both left feeling so positive and full of hope...thank you for that.” Patrice Carroll, Conference Chair, facilitated and led multiple sessions and left the attendees sparked with motivation and optimism for the future; with the right supports, coping skills, and strategy, it truly is bright.



Dr. Singh presents on Anxiety.

Favorite sessions and speakers were:

- Medical Issues by Dr. Jennifer Miller,
- Behavioral Features by Elizabeth Roof,
- Anxiety by Dr. Deepan Singh,
- Optimal Nutrition in PWS by Melanie Silverman and Paul Donahue,
- Strategies for Success in School Panel by Amy Tenbrunsel,
- Relationships and Sexuality with Patrice Carroll and Gina Sheehan, and
- Latham Centers/Vocational Programming by Katrina Fryklund and Gina Sheehan.

Latham Centers looks forward to sharing some of our speaker powerpoint presentations on our website. We'll post an alert on our blog announcing that the resources are available.

We thank our sponsors, Levo Therapeutics, Millendo Therapeutics, and Soleno Therapeutics.

When you visit the Latham website, we encourage you to subscribe to Latham's daily Blog, which provides fun updates from Latham programming and features a “PWS Tip of the Week” offered by Patrice Carroll.

More about the Mac Pact: The Mac Pact is dedicated to raising awareness of Prader Willi Syndrome. We raise money to help with the financial needs of families affected by PWS. <https://www.facebook.com/themacpact/>



Elizabeth Roof discusses behavioral features in PWS.



Matt McCleery gives opening remarks with Latham Centers' video, “And they said my child would never...” playing in the background.

Warm Weather Wisdom: PWS Tips

by Patrice Carroll

Summer can be a wonderful time for outdoor adventure, but it can also be a dangerous time for people with PWS. Following some basic safety tips can help to keep your summertime safe.

Exposure to sun and heat – Heat stroke occurs when a person has prolonged exposure to heat coupled with dehydration. Individuals with PWS are particularly susceptible to heat injury because of difficulties regulating body temperature combined with a lack of sensation, pale skin, and high pain tolerance. Heat stroke is a medical emergency that can cause damage to the brain and other internal organs. If possible, avoid direct sunlight for more than a few minutes, always use sunscreen and hats, and be sure you are close to shade. Stay hydrated and decrease outdoor exercise during peak sunlight hours.

Bug bites – Bug bites present a unique set of issues for people with PWS. Skin picking sites often start with a bug bite, and we all know how quickly those can get out of control. Prevention is key- use bug spray, avoid bright colored clothing, and cover arms and legs when walking through the woods or near standing water.

Drowning – In 2013, I read an article that said that the number one cause of accidental death among children

with special needs is drowning. Swimming is a great activity for kids with PWS and should be encouraged, but safety must come first. Remember that low muscle tone prevents the body from being able to tolerate long periods of physical exertion. A child may be able to swim to the middle of the pond but not be able to swim back, and due to sensory processing difficulties may not be able to identify feelings of fatigue in time to do anything about it. Encourage time in the water but provide constant supervision.

Hydration – Staying hydrated is a critical part of summer safety. Dehydration can lead to heat exhaustion, behavioral outbursts, and GI issues. Find out from your pediatrician the best water intake goal for your child and stick to it. Sticker charts and goal wheels are a good way of involving your child and will teach them healthy practices in the process.

Summer Vacations – Keeping a routine and clear expectations will make for a successful and less stressful summer vacation. Changing from the tight and predictable nature of a school schedule to the unstructured environment of summer vacation can cause increased anxiety in your child. Create a daily and weekly routine and hang it on the wall. The weeks don't have to be the same, just created ahead of time so your child knows what to expect.

Summer should be a fun and exciting time for your family and following some basic safety and structure tips will keep it that way. From everyone at Latham, we wish you a fabulous summer!



Student poses for photo with Campus Visitors on Field Day.



Student participates in Sack Race on Field Day, staff cheer him and others on.



Peers with special facepaint pose for photo on the Dream Day Games track.

NEXT ISSUE:

- Summer Fun and Games
- Preparing for the School Year: Transitions
- Year-End Celebration Recap
- Adults in the Community