



# Living Healthy *with* PWS

LathamCenters Quarterly Newsletter



*Latham Centers compassionately and creatively helps children and adults with complex special needs, including Prader-Willi syndrome, to lead meaningful, abundant lives.*

## LATHAM HIGHLIGHTS

### Latham Special Olympian receives “Heart of the Winner” award

At Latham’s annual Year End Celebration, Physical Education Teacher Monique Williams shared highlights of our Special Olympics program with more than 200 students, families, staff, and Latham friends. In her highlights, she brought student Christopher M. to the stage to announce that he is the recipient of two prestigious awards: the Special Olympics “Heart of the Winner” award and the Latham Centers Special Olympics Athlete of the Year award. Chris’s mother was beaming, and after the Year End Celebration explained, *“Christopher is happy and thriving and enjoying life in a food secure environment and I never thought that he’d be able to do that. He just received an award for being most improved athlete for Special Olympics, and he has grown in so many ways. I am so proud of him. He is an inspiration to all of us. He has lost over 200 pounds since coming to Latham...getting the diagnosis is not the end of your story, it’s the beginning of your journey.”*

#### **Excerpts from Monique’s presentation follow:**

“Since 1988, the “Heart of the Winner” award has been presented to an athlete that tries his or her best in everything they undertake. Nominated athletes should exemplify tenacity, sportsmanship, teamwork, courage, and all other elements of the Special Olympics Mission Statement and Athlete Code of Conduct. The Heart of the Winner Award is the longest running Award today, and one of the only Outstanding Athlete awards in the state. This year, we nominated a student who has been able to overcome a number of challenges.

This student started school at Latham Centers in 2016. We learned quickly he was not one to shy away from a challenge. Challenges have been a big part of his life and he has not let them drag him down. As he became acclimated to Latham, he began hearing his peers speak



of Special Olympics. Almost immediately, one of the first things we learned about him was his love for sports. When he first arrived, he became a part of the basketball and track & field teams. He struggled to manage his behaviors in order to remain on each team, but quickly learned what he would be missing out on.

Fast-forward to this year... In the past year, he has participated in soccer, football, basketball, bowling, and track & field. This student displays the Heart of the Winner

*(Continued)*

### In this issue...

- Massachusetts Special Olympics “Heart of the Winner” award
- Sibling Support: Sister raises over \$16,000 for PWS programming
- PWS Residential Success: Latham’s Shared Living
- PWS Conference Reflections

because when so much was up against him, he still managed to stay positive and keep up the hard work. Listening to the coach's guidance and being patient with both his skills and struggles that were presented to him, he stuck with it and has shined throughout his time here. He continuously tries to take what he learns, apply it, and sometimes tries to go above and beyond what is expected of him.

Chris is a prime example of what Special Olympics seeks out to do. Over the past year, he has discovered new strengths and abilities, such as participating in the 50m assisted walk to now participating in a 100m dash, or being able to learn and play offense on the basketball court, or being able to catch a ball and play defense on the football field. The power of sports has instilled confidence in this young man, improved his health, and he has found joy in being able to be like "everyone else". Everyone at Latham is so proud of this young man and how far he has come, and the confidence he has gained from participating in Special Olympics."



Race-day in Bayshore, NY



Healy family photo (l to r) Emmett, Sean, Sharon, Leah, and John

## Sibling Leah Healy's 5K Run for PWS raises over \$16,000 for Latham

On June 16th, over 100 participants laced up their running shoes to take part in the 5K Run for PWS in Bay Shore (Long Island), NY. Leah Healy, a rising senior at Bay Shore High School and the proud sister of Latham student Sean, planned, organized, and executed the race to raise awareness for PWS, and to raise funds for Latham Centers. Over \$16,000 was raised to support key initiatives at Latham including the Expanding our Circle capital campaign for the new Latham Community Center; Latham's Asinotherapy Program (donkey therapy); and Latham School and Children's Services.



Leah's mother Sharon Healy said, "This race was very important to Leah. It was her idea, and she wanted to take the lead on all the planning and details. Junior year can be a very stressful time. She had a pretty rigorous course load, and she took all of this on in the middle of her lacrosse season. We are so proud of what she was able to accomplish."

Latham student Sean crosses the finish line.

Latham Centers' Development staff worked with Leah to create an online fundraising page that she could forward to friends and family. Runners could also personalize Leah's page and then e-mail it to their own contacts or post it on social media. An excerpt from Leah's page follows:

*"I have a 15-year-old brother named Sean and he has Prader-Willi syndrome. I am spreading awareness of PWS so that Sean and other individuals born with PWS can benefit from your support. Sean has lived at Latham Centers in Massachusetts for the past year and a half because the daily challenges he faced due to PWS became too overwhelming for him and our family. The support and structured environment at Latham has provided him with the opportunity to be his authentic self as someone living with PWS. He is happy, understood, and thriving."*

Anne McManus, Latham Centers President and CEO, recognized Leah at Latham's End of Year Celebration on June 21st: "We are all so grateful to Leah for her vision and her hard work in creating this 5K charity event. What an incredible act of love. Congratulations on the success of the Run for PWS and thank you to all who came out that day to run and support Latham."

The "act of love" that McManus mentions is truly indicative of Sean's familial support. Many residents at Latham

(Continued)

Centers (10 years of age to 65 years of age) have siblings who remain advocates in perpetuity. Recently, two people happened to meet on campus who are both sisters to someone with PWS. The younger of the two proclaimed, “you’re a sibling, too! I can’t believe you understand like I do.” Latham Centers is grateful to the siblings, parents, and guardians who offer their constant support; you are the believers, the activists, and the cheerleaders for this community of caring.

---

*Leah’s commitment reflects the power of sibling support.*

---

## Shared Living at Latham: A more independent lifestyle for adults with PWS

By Greg Powers, Manager of Supported Community Living  
& Katrina Fryklund, Director of National Outreach

At Latham Centers, we strive to help our residents to live as independently as possible.

For some, that means living in a home with year-round, twenty-four seven support; for others, that means living in a home with fewer supports and more alone time. The Shared Living program enables adult residents who are interested in living a more autonomous lifestyle the ability to step outside of a residential home and into an environment which enables more self-reliance.

Our residents with PWS who are most suitable for this lifestyle are those who have learned how to administer their own medication, have coping skills to avoid food-seeking behaviors, and are engaged in the community. This is Danny’s inspirational story:

Danny lives with Sara and Sanjib, a couple who moved to the United States from India. When Sanjib speaks about his experience as a shared living provider he explains, “the level of satisfaction you get by doing this job you cannot compare with any other.”

Danny goes to a day program five days a week, attending a specific group Tuesdays and Thursdays. At home he participates in meal planning and has been learning much about different cuisines and cultures. In his free time Danny takes walks and day-trips with Sara and Sanjib, and sometimes goes to the movies; he looks forward to enjoying these preferred activities together. As a family

they discuss the day’s events, often times in their living room before dinner. Danny also enjoys the “fun-stuff” like playing on his handheld game system. When he visits his biological family, he takes the bus by himself and has learned how to manage the anxieties around public transportation and traveling independently.

Danny helps plan his own medical appointments, refills his prescriptions and speaks with doctors self-sufficiently. While at certain times Sara and Sanjib prompt and guide him, at others he handles these tasks without any aid. Since living with Sara and Sanjib, Danny has become part of their family. A special bond has developed between Sara, Sanjib, and Danny. In Danny’s words, “I don’t have a favorite thing about shared living, but I love living with them and I want to stay with them forever.” As Sara reflected on her experience as a shared living provider she discussed how proud she is of their growth as a family. “Danny told us he has two families and we are so proud of him.”



Above: Danny and Sanjib about to board a whale watch boat in Provincetown.

Below: Sara, Sanjib and Danny celebrate Dashain at home.



## New York PWS Alliance Conference Reflections

By Katrina Fryklund

Latham Centers has a long history of leadership and professional development in the local, regional, and national Prader-Willi syndrome community. Specialized PWS conferences have proven remarkably insightful to staff at Latham; conferences are a catalyst for continued education, and opportunities to connect with people from around the globe. Earlier this year, staff from both our Children's Services and Adult Services programs attended the Prader-Willi Alliance of New York Conference in Binghamton. The conference was well attended and included sessions ranging from nutrition and wellness to changes in legislation. At the conference, Patrice Carroll, our Director of PWS Services, presented on relationships and dating. Her session included a discussion of the vast differences between friendships and romantic relationships, as well as the difficulties parents/guardians face when having conversations about healthy relationships. Patrice's presentation tackled the difficult topic of fantasy relationships, including those with no basis in reality versus some basis in reality.

---

*“Attending conferences is one of the best things we did together when my son was growing up.”*

*-Latham Centers Parent*

---

Although PWS impacts an estimated 1 in 15,000 people (statistic cited by PWSA (USA)), many people in the community of medical and educational professionals, parents and guardians, and advocates haven't yet had the experience of attending a conference. Conferences with a primary focus on the syndrome have proven life-changing for so many of the attendees. A parent of one of our students once told me, “Attending conferences is one of the best things we did together when my son was growing up.” I echo this sentiment and encourage all families of children and adults with Prader-Willi to participate in regional or national PWS conferences. Latham Centers will continue to lead through involvement in professional conferences, and we're looking forward to attending the 2018 Prader-Willi California Foundation Conference on October 27 in Sacramento.



Adult program staff surround Patrice Carroll at the Latham Centers Table.



Chris dances with a fellow student at a Best Buddies dance.

### NEXT ISSUE:

- INTERESTING FACTS FROM THE NATIONAL PWS SURVEY
- STUDENTS EXPLORE CAPE COD: SUMMERTIDE