



LivingHealthy^{with} PWS

LathamCenters Quarterly Newsletter



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

Latham's *LivingHealthy* cookbook is spot-on with the Mediterranean diet trend

By Dawn Dinnan and
Katrina Fryklund

When we published our specialized cookbook for the Prader-Willi syndrome community, little did the editorial team know that Latham was on the cusp of a diet trend.

LivingHealthy with PWS Cookbook and Nutrition Tips is based on the

Mediterranean diet, which US News and World Report declared "is the way to eat in 2019."

"The Mediterranean diet got the top ranking in U.S. News' list," according to a CBS News article published in January. "The heart-healthy diet is rich in fruits, vegetables, fish and whole grains, along with healthy fats like olive oil, nuts, and avocados. Research has shown the Mediterranean diet reduces the risk of heart disease and may have numerous other health benefits, including reduction of LDL, or "bad," cholesterol, as well as a decreased risk of Alzheimer's disease, Parkinson's disease, and cancer."

Latham's menu includes healthy, nutritious meals based on the Mediterranean diet, as well as tips for success for the PWS community. We implemented this diet two years ago, correlating many of the behaviors and health issues associated with PWS with the reported benefits of the Mediterranean style diet:

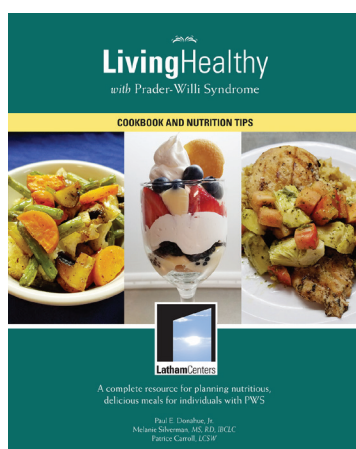
- Many individuals with PWS struggle to maintain focus in the classroom; a Mediterranean diet rich in Omega 3s and healthy fats can protect cognitive health.

Mediterranean style dining is reportedly a great way to preserve memory and sharpen the mind.

- Individuals with PWS who struggle with weight gain often struggle with Diabetes; Omega 3 rich foods and natural foods contain fewer sugars and artificial ingredients. Since the menu implementation, we have observed a reduction in insulin medication for some of our residents.
- A common behavior issue for individuals with PWS is skin picking; a Mediterranean style diet helps to improve skin health due to the vitamin E rich menu.

These benefits are just a few of the positive outcomes at Latham since implementing our menu. We have increased many of our residents' calorie counts and have observed significant weight loss – healthily, with meals and snacks our students and adult residents enjoy.

Positive outcomes extend well beyond our programs. To date, Latham Centers has distributed more than 500 copies of the *LivingHealthy with PWS* Cookbook. We are elated with the response from around the world as we communicate with families who are benefitting from the cookbook recipes and tips. Parents of a prospective Latham School student who has PWS came to campus for a tour recently and brought home our *LivingHealthy with PWS* guide. They tried some of the recipes in the cookbook and said that their son "loved the baked BBQ chicken, couscous, and cauliflower potatoes. We truly feel that [he] is going to flourish at Latham."



LivingHealthy with PWS:
Cookbook and Nutrition Tips is available at
[https://www.lathamcenters.org/what-we-do/
livinghealthypwscookbook/](https://www.lathamcenters.org/what-we-do/livinghealthypwscookbook/)

To learn more about the cookbook or bulk orders, please contact Katrina Fryklund at kfryklund@lathamcenters.org.

Latham to publish cookbook supplement, *LivingHealthy with PWS: Seasonal Soups, Salads, and Desserts*

This spring, Latham Centers will publish *LivingHealthy with PWS: Seasonal Soups, Salads, and Desserts*. The cookbook is the first supplement to the *LivingHealthy with PWS* cookbook, and it will include recipes and tips for enhancing the wellness of those with PWS. Recipes and tips will be grouped by season, and behavior and food management coping strategies will accompany each recipe. For every season, one soup, one salad, and one dessert will be presented. Recipes will include easy-to-prepare and delicious Latham favorites such as Dairy-Free Butternut Bisque, Watermelon Basil Salad with homemade Lime-Dijon Vinaigrette, and Orange Creamsicle Dessert Smoothies.



"I wanted to create a cookbook so that someone who doesn't know how to cook, and has someone in their life with Prader-Willi syndrome, can create these meals at home and improve the quality of life for the individual with PWS."

– Paul E. Donahue, Jr.,

Latham Chef and *LivingHealthy with PWS* Cookbook co-author



TIPS FOR CHILLY WINTER DAYS

By Patrice Carroll, Director of PWS Services,
Latham Centers

- Allow a person with PWS to create their own goals and resolutions; success is more likely.
- Get back into a routine as soon as possible. Holidays bring anxiety for many reasons. Being off a routine is extremely difficult for a person with PWS.
- Use lotion frequently during the winter months. Dry skin can crack, itch, and lead to picking.
- Limit outdoor exposure during very cold weather. People with PWS have a higher risk of hypothermia. Know the signs!
- Be sure not to skip exercise just because you need to stay indoors. Use exercise videos, exercise games on gaming systems (our kids love Wii Fit), or have a dance party!
- Create expectations around broken routines and winter vacations – often the excitement for the upcoming days can cause anxiety.
- Prepare for a snow day and keep a secret stash of games and crafts for days that you might be without power or stuck inside.
- Fish, fish oil, and egg yolks are great sources of vitamin D for those months when there is less opportunity for sun exposure. Always check with your child's doctors before starting any supplements.

A LIFE-CHANGING VIDEO BY A LIFE-CHANGING PROGRAM

Inspiration from Latham students and parents

By Dawn Dinnan and Katrina Fryklund

Latham's video remake of "And they said my child would never" tells a story of hope for families of children diagnosed with Prader-Willi syndrome (PWS). "When you first receive the diagnosis of Prader-Willi syndrome, you may be told that there are things your child will never do," begins Patrice Carroll, LCSW, Director of PWS Services at Latham. "Don't accept the limits that other people place on your child," Patrice says.

In the video, parents and students share their experiences, knowing they might help others. We are introduced to several Latham students, including Annika, whose mom said she never thought her daughter would be in such a place of calm and confidence; Christopher, whose mom is amazed by his weight loss and says he is happy, thriving, and enjoying life; and Patrick, who works at Brewster Ladies' Library and proudly talks of his progress toward his MCAS portfolio and high school diploma.

Several family members reflect on the remarkable progress their children have made at Latham. "When we first got the Prader-Willi diagnosis, it was pretty scary. The person who told us about the disease gave us some very horrifying news about how he was going to be very cognitively impaired and wasn't going to be able to function very well," one mom shares. The video features moments in the classroom, on campus, and in the community in which her son is happy, achieving, and enjoying time with his peers.

Patrice's message to PWS families is uplifting: "Your child will succeed. Your child will thrive, and love, and they will make you happy and proud. They will defy all expectations, and they will show you that perseverance and patience always pays off."

Latham Centers is sharing parents' hope with its local community as well as the national and international PWS community. In a recent radio interview with journalist Matt Pitta on The Sunday Journal, Patrice and Katrina described the video's message, purpose, and process to more than 12,000 listeners on four stations. In a particularly poignant moment, Patrice stated, "There is so much information on the internet about Prader-Willi syndrome, and most of it is negative, and we want to change that narrative. These are children and adults who are loving, and sweet, and funny, and can be very very

successful. And we want parents – especially parents of newborns who just got that diagnosis – to know that this diagnosis is not the end of the journey – it's the beginning of it. And you will have a wonderful life with this child."

When staff and family members watched this video, many were moved to tears. Those who volunteered to be part of the video production knew how important the message is, as well as the thoughtful, meaningful process. Students, staff, and videographers were all part of the three-day filming initiative. Parents told their stories, kids enthusiastically waited for their interviews, and staff prepared their students for an out-of-routine situation.

As producers, Latham was committed to telling the stories of people who know what it means to have PWS, or help someone with PWS. The process needed to respect our students and their needs, and the final product needed to highlight what can be achieved despite a PWS diagnosis.

Filming was separated into three days to highlight all parts of the program without causing any anxieties. After all, we were going into our residents' homes, classrooms, and personal spaces to film. The entire team came together to tell the story of just how incredible life can be when we band together, see the good over the bad, and exceed expectations.

We are grateful to Tom Chartrand, owner of Shoreline Media Productions, for helping Latham Centers produce this video with compassion and sensitivity to all things "PWS."



"Your child will succeed. Your child will thrive, and love, and they will make you happy and proud."

– Patrice Carroll, Director of PWS Services

2018 National PWS Survey: the results

By Katrina Fryklund

In the Spring of 2018, Latham Centers created a national survey for the benefit of the Prader-Willi syndrome (PWS) community. The goal was to gather and share information helpful for service improvement for people with PWS and their loved ones.

The survey results are a welcome tool for many in the PWS community. I had the opportunity to speak with leaders from PWS Chapters from California to New England and learned an incredible amount about how PWS services differ according to geographic region. The need for a tool to track available vs. necessary PWS services became clear, so we created a brief survey entitled “Prader-Willi Syndrome Services: A National Survey.” It included questions related to medical, residential, education, social, advocacy, parent/guardian support, and vocational services for individuals with PWS and took roughly ten minutes to complete. We hoped that by keeping it short, the survey would be accessible to everyone within the PWS circle—from medical and educational professionals to individuals diagnosed with PWS and their guardians.

We sent the survey to PWS Chapters across the country and PWS related organizations (who then sent it to their constituents), in hopes of compiling extensive data from across the nation. In tabulating the results, we found:

- One hundred and fifty individuals took the survey, including caretakers, PWS Association leaders, and parents/guardians. Most of the people who took the survey were mothers to a child with PWS.
- The majority of the respondents live in the northeast states and California.
- The majority of the respondents have young babies and toddlers up to five years old, young children between the ages of 11-20, and adult children between the ages of 25-30.
- Services are most needed in behavior support/training, education to parents/guardians about vocational opportunities, food-safe events, vocational training for individuals with PWS, and meal times/nutrition/food security.
- Parents/guardians find the most opportunities for their kids in day programs, but the least opportunities for their children in paid work.
- Parents, guardians, and staff are concerned about the lack of peer groups and social opportunities. Some mentioned that the struggle exists because of behaviors as a result of the diagnosis, as well as lacking opportunities. One person said, “The best socialization is with other individuals who have PWS which takes a lot of planning and travel.”

- To become stronger advocates, people need more education about how to involve local political leaders and state legislators, as well as to better understand the rights of both parents/guardians and the person with PWS in a residential setting.
- Parents would like to learn more about trusts and other financial options for someone with PWS once his or her parents/guardians pass.
- Parents/guardians found they need the most vocational support regarding career planning and need better tools to assess skills and interests.

As a result of the survey, Latham Centers has expanded its PWS outreach. Latham Centers has:

- Attended the 2018 PWCF Conference to meet parents from the state of California.
- Created documents to help guide parents/guardians related to education, advocacy, the referral process, and behavior management.
- Published the *Living Healthy with PWS Cookbook* (Mediterranean based, low carbohydrate and dairy, high in Omega 3) with nutrition and exercise tips, and a supplement is in progress.
- Worked with the Greenwood System 120 Vocational Team to pilot and create a Greenwood System 45 Assessment, a modified vocational tool meant to assess goals, skills, interests, abilities, and working styles of individuals in the special needs community.
- Developed a burgeoning consulting program offering behavioral and residential support for families within the home, at school, or in day programs, as well as for adult group residences (already developed or being developed).
- Continued to learn about parental needs throughout the referral process.

Thanks to all who completed this survey – it truly exemplifies the tight bond of our community. As one PWS Chapter president said, “we’re all in this together.” To view a compilation of the survey results, please visit <https://www.lathamcenters.org/who-we-are/prader-willi-syndrome-expertise/national-pws-survey-results/>.



STAYING CONNECTED

PWS Conference Registration Prader-Willi Syndrome: A Bright Future

Hosted by Latham Centers and The Mac Pact

Prader-Willi Syndrome: A Bright Future
Meet, network, learn and share knowledge about behavior management,
medications & trials, adult programming and the educational setting.

Hosted by



**PWS
Conference**

Who: PWS Families, Specialists,
and Providers

Where: Hilton Garden Inn Hartford
South/Glastonbury, Conn.

When: Saturday, June 1, 2019

Time: 9 a.m. – 4 p.m.,
followed by a cocktail reception

Register at: <https://pwsabrightfuture.eventbrite.com>

The diagnosis of Prader-Willi syndrome can be a dark moment for parents, but that doesn't mean the future isn't bright. Children with PWS are some of the most kind, optimistic, engaging, loving, fun, sweet people in the world. With proper knowledge, networking, medical care, support and planning, a life with PWS can be enriching, meaningful and wonderful. The mission of this 2nd annual conference is to give families from the Northeast access to the most up-to-date insight and information – and hope for the future.

Discussion topics will include but are not limited to:

- **Health and Wellness** - Behavior Management, Nutrition, Medical Issues, Medication Trials
- **Topics for those under 18 years old** - Parent Panel, Educational Advocacy, Sibling Support
- **Topics for those 18 years old and over** - Parent Panel, Work Readiness, Financial Planning, Adult Living

Patrice Carroll, LCSW; Jennifer Miller, MD; and Elizabeth Roof, M.A. are just three of the many speakers. Sign up for the Latham Centers blog to learn information about additional speakers as we near the conference date! <https://www.lathamcenters.org/blog/>

FPWR: PATH Study

**Foundation for Prader-Willi Research
(FPWR) seeks study participants**

PATH for PWS is a study to help us better understand serious medical events in PWS, as well as evaluate how PWS-related behaviors change over time. The data from this study is intended to inform the development of potential new treatments. There is no therapy provided as part of this study and no clinic visits are required.

You can complete the study from the comfort of your home using your computer. Data will be collected through internet-based surveys, and study participants will receive a \$100 Amazon gift card.

More information including answers to frequently asked questions, additional resources, and how to enroll can be found at www.PATHforPWS.com.



NEXT ISSUE:

- *Conference Recap—
Prader-Willi Syndrome: A Bright Future*
- *Kids in the Community: Art Shows,
Activities and Concerts*