

Kleinkauf: A bright idea for people with Prader-Willi syndrome

By Jim Kleinkauf/Daily News staff

GHS

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A week ago Wednesday, Advocates Inc, a Framingham-based human services provider, held an open house to debut its Bring to Light Candle Company in Ashland.

The new business, at 290 Eliot St. was started by individuals with Prader-Willi Syndrome.

They make hand-poured candles in three sizes and a variety of scents and colors, aimed at the wedding and special events markets.

Prader-Willi Syndrome is a rare birth defect that affects one in 10,000 individuals and results in weak muscle tone, insatiable appetite, incomplete sexual development, and some degree of mental retardation.

"PWS is a genetic disorder that, among other things, causes extreme feelings of hunger regardless of calorie intake," said Patrice Carroll, Advocates' director of Prader-Willi Syndrome programs.

"People with Prader-Willi Syndrome have a very slow metabolism - that, coupled with the feeling of needing to eat constantly, puts people living with this syndrome at high risk for morbid obesity and other food-related death such as choking (and) stomach expansion which happens when more food is ingested than the stomach can hold and the stomach literally explodes," said Carroll.

"Bring to light Candle Company was created by members of our Prader-Willi Syndrome community as a way to meet the need for competitive work and at the same time helping people with this syndrome remain safe from the temptation of food," said Carroll.

Those with PWS can and want to be productive members of the community. And the excitement among the new candle company employees was palpable last Wednesday night.

Crosby, who has PWS, worked intently on the computer setup on the back wall of the candle factory.

A 22-year-old man with a slight build, Crosby grew up in Nashua, N.H. and lives in Advocates' housing in Hudson.

He was diagnosed with PWS shortly after birth, said his parents, Cathy and Bob, who drove down from Nashua for the event.

"We were a few minutes late and he got a little nervous," Cathy said. "He's very proud to be part of this."

Crosby attended public schools New Hampshire and then had a part-time job at a sporting goods store in a mall.

"Unfortunately the food concession became an issue" Cathy said. "And we realized he needed a more structured environment."

"The average person with Prader-Willi Syndrome has the capacity to work competitively in the community but the desire to eat is overwhelming," said Carroll. "Agencies like Advocates who provide support to people with PWS have a responsibility to offer alternative employment options that allow people with PWS an opportunity to work to their fullest potential while ensuring safety."

Crosby turned away from the computer screen long enough to explain that his job is to do the billing. When asked if he will also be making candles, he responds with a mixture of pride and firmness, "No. My job is to do the billing."

The nation's third largest service provider for people with Prader-Willi, Advocates offers programs aimed at providing structure and support for weight management, behavioral issues and personal care that lead to improvement in health and quality of life.

According to its Web site, "Advocates began in 1975, with a group of volunteers providing patient rehabilitation services on the grounds of Westborough State Hospital."

Since then the agency has grown through a combination of state grants and mergers with other area human service agencies.

Today, according to its Web site, "Advocates now offers a comprehensive network of services including residential programs serving over 400 people with disabilities annually; a psychiatric emergency team which responds to 30,000 requests for emergency assistance

each year; and outpatient mental health and substance abuse counseling for nearly 1500 residents of the Greater MetroWest Area."

"We serve 30 people with PWS in six adult residences throughout MetroWest," said Carol.

Advocates' residential programs for persons diagnosed with Prader-Willi Syndrome have been nationally recognized, according to its Web site.

Also in attendance last Wednesday was Susan Nathan, Advocates' director of staff recruitment. Nathan wasn't attending as a staff member, however, but as "mother of the bride," she said.

A Grafton resident, Nathan had come to select the table decorations for her daughter Patrica's wedding, planned for next October.

"In an effort to give back," Nathan said. Patricia and her fiance Greg will give each wedding guest a handmade candle with a thank-you tag attached that opens to reveal information about Prader-Willi Syndrome.

The company plans to market directly from its Web site: www.BringToLightCandles.com.

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