

## Out of options, family finds hope in chocolate

Candy Sales Will help Woman fight Rare disease.

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Correspondent

**WARREN--** Amanda Salvo's already tough life may get worse when she turns 21 next month.

Amanda has a rare neurological disease called Rett Syndrome. It's a genetic disorder that effects one in 20,000 girls. The child develops normally until about 6 to 18 months of age, and then regresses. Loss of hand skills, loss of speech, severe seizures and mental retardation take place in the disorder's rapid destructive phase, which can completely undo a child's development in only weeks.

And this is what happened to Amanda shortly after her first birthday, 20 years ago.



Kathy Salvo and her daughter Amanda make a batch of Miss Amanda's Butter Crunch. Money made from the candy, will help Amanda, who suffers from Rett Syndrome, a rare genetic disorder that effects one in 20,000 girls.

### What you can do

◆ Contact Heavenly Chocolates by calling (888) 260-4133 or on the Web at [www.chocolatefromheaven.com](http://www.chocolatefromheaven.com)

◆ Donations on behalf of Heavenly Chocolates can be sent to:

The Pauline M. Jaricot Foundation  
10 Plane Hill Road  
Washington, NJ 07882



## Courier News Heavenly Chocolates Article (Cont.)

By 15 months of age, her motor skills, her vocabulary and her ability to even make eye contact disappeared. It was, in her mother's words, devastating.

Amanda attends a day school, The Academy for Child Development in Mountain Lakes, but her time there will end when she reaches her 21<sup>st</sup> birthday May 16. Although there are programs offered to developmentally disabled adults, Amanda is excluded.

"Amanda has few basic skills, which means there are no adult programs offered for her. Her disease is so unique," said her mother, Kathy Salvo.

Salvo has a bachelor's degree in special education and a master's degree in learning disabilities. Even this doesn't diminish the hardship of having a Rett Syndrome child.

"Luckily for us, Amanda is a very sweet girl who keeps a really positive, cheerful attitude. That helps us all," Salvo said.

The Salvo family also includes husband Sal and children Robert, 24, Francesca, 15, Julia, 12, and Joshua, 11. The family has lived in Warren since 1988.

Giving Amanda the best possible care, all at home, will be a hardship. The cost for the specialized one-to-one therapy Amanda needs runs about \$200,000 to \$250,000 a year. While the family's insurance covers Amanda's health needs, the therapy falls under the Medicaid program—and Salvo says home health aides qualified to help her daughter are scarce.

Amanda needs programs that provide the physical, occupational and speech therapies that help her communicate, keep her muscles from atrophying and remind her how to eat and drink. If Amanda doesn't get speech therapy three times a week, Salvo explained, she will forget how to chew, and it becomes a life-threatening situation.

Last September, with few options and time running out, Salvo remembered her grandfather's old-world candy recipes.

Her grandfather, Frank Salvo, had a successful candy business for years at the Jersey Shore before retiring to Florida. His signature item was butter crunch candy, made from a recipe his grandfather brought over from Germany.

After his retirement, the family continued to make his recipes, giving the candy as gifts to the countless volunteers who have helped Amanda.

Amanda has always enjoyed playing a role in making these treats.

"She takes a very supervisory position," Salvo said. "She can stir a pot hand-over-hand if one of us helps her, and she blinks once if she approves and gazes if she disapproves. She's pretty much our moral support."

Salvo's plan is to increase the family's production of the candy and bring it to the attention of a larger manufacturer.

"Our goal is to create high enough demand so that our candy can be mass-produced with our recipe and under our supervision," she said. She's been reading up on successful case studies, like David's Cookies, and is formulating a business plan.

The Salvo's have named their company Heavenly Chocolates and have renamed grandpa's signature treat Miss Amanda's Butter Crunch.

The uniform rectangles of buttery almond brittle are smothered in milk chocolate and rolled in crushed nuts.

Barbara Costanzo of Berkeley Heights recently gave boxes of Amanda's Butter Crunch as favors for a baby shower, and said it was an immediate crowd-pleaser. "I'm very fussy about the chocolate," Costanzo said. She likened the quality to Dove and Godiva.

## Courier News Heavenly Chocolates Article (Cont.)

“Plus,” Costanzo said, “none of the better companies has a nice crunch like this in their assortments. Heavenly Chocolates is way ahead of the curve on this.”

To meet Christmas demand, the Salvos rented a commercial kitchen and stocked up a supply of the candy. But that supply is selling fast— and renting the equipment ate up all their profits. “We’re not in the black yet,” Salvo said.

To help contain costs, the Salvos wanted to modify a part of their home’s basement and move the production there.

Salvo tried to follow the rules for setting up a company at home, but said she was discouraged by the expensive fees and municipal delays. After being told that Warren’s Board of Adjustment required \$300 just to start the hearing process and that future fees could be anywhere from \$100 to \$1,000, Salvo gave up. She changed her focus to finding a manufacturing and retail location.

She’s actively searching for the right spot to make and sell her Heavenly Chocolates line of candy.

“We’re losing so many opportunities to sell with all the delays,” she lamented. “We’ve already missed Valentine’s Day and Easter, and now we’re approaching the wedding and graduation season. I just can’t afford to keep missing chances to get the business growing.”

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