



## Woman Stringing Beads to Battle Ailment



Cheryl Bentley/SUNCOAST NEWS

Lisa Padags, left, and her mom, Safety Harbor resident Sue Padags, enjoy a chat. Lisa has been diagnosed with Cornelia de Lange syndrome.

By [Cheryl Bentley](#)

Published: October 13, 2007

Bella Thompson is on a mission. The 78-year-old Holiday-area resident has been making beaded jewelry nonstop, even waking up in the middle of the night to string beads.

Thompson will offer her handmade jewelry for sale at a Wendy's fast food restaurant in the New Port Richey area next Friday and Saturday, Oct. 19 and 20.

She has made more than 200 pieces of jewelry and will sell them for \$5 to \$15.

All proceeds benefit the Cornelia de Lange Syndrome Foundation.

The Avon, Connecticut-based foundation is trying to raise \$250,000 for research on Cornelia

de Lange syndrome.

CdLS is a collection of congenital symptoms named for Dr. Cornelia de Lange, a pediatrician in the Netherlands who in 1933 described two cases of the disorder.

The CdLS-USA Foundation is a support organization that promotes both early diagnosis of the syndrome and research into its causes. A letter from the foundation verifies the organization has approved Thompson's project.

### **Characteristics**

Characteristics of the congenital syndrome often include low birth weight, eyebrows meeting over the nose, long eyelashes and short, upturned nose.

Additionally, sufferers frequently have mental retardation, usually ranging from mild to moderate.

The syndrome is almost always caused by a spontaneous gene mutation after the egg is fertilized. The mutation can occur in one of three genes.

In about 1 percent of cases, it may be passed on through a parent who carries the gene and is unaware because CdLS symptoms are either very mild or non-existent.

It is thought about one child in every 10,000 births will have the syndrome.

Thompson became aware of the condition through her friendship with Betsy Barton, a New Port Richey resident whose granddaughter Audrey has CdLS. Audrey's family lives in Fargo, N. D.

The little girl is one of the lucky ones because she was diagnosed with the syndrome as a 6-week-old baby while in the ward for premature babies shortly after her birth in a Fargo hospital.

### **Early diagnosis crucial**

The early diagnosis will allow Audrey to get therapeutic services in the crucial early childhood years, says her grandmother. She will become eligible for special student education when she turns 3.

Among the hospital's many medical personnel, only one, a physician who had a child with CdLS, recognized it in Audrey during her hospital stay.

That, says Barton, is indicative of the lack of awareness of the condition by both the public and physicians.

According to the Cornelia de Lange Syndrome Foundation, it is estimated 20,000 individuals with the syndrome remain undiagnosed in this country.

Audrey, now well into her second year of life, is smaller than her sister, who is 1.

Children generally learn to walk at around 1, but Audrey is just beginning to crawl.

The little girl has the long eyelashes, upturned nose and gastroesophageal reflux, which often are symptoms of CdLS.

### **Unaware of condition**

Bella Thompson had never heard of the condition until Audrey was diagnosed.

The news was especially poignant for the childless, single Thompson, who was closely involved in the life of Audrey's father, James Barton, when James was growing up in New Port Richey.

"I became a second grandmother to him," she remembers.

She becomes tearful when recalling her friend Betsy's words about Audrey: "She's going to need help for the rest of her life."

That cut to the quick for Thompson. She decided she had to do something to help.

It was her old friend Betsy who sparked the form of help. A few months ago, Betsy learned how to make jewelry and inspired her friend to do the same.

Crafting jewelry from crystal, deco and plastic beads, Thompson estimates she has been working about 60 hours a week for the past three weeks. She has made more than 200 bracelets and additional sets of bracelets and earrings.

Barton has also made jewelry for the event.

### **Lit a passion**

The project has lit a passion in Thompson. "For me, it's almost become a Christian experience. I do believe it will help a lot of people."

Most important for Thompson is informing the general public about the syndrome.

Many parents with children with the condition do not know what is wrong with their children, according to the Cornelia de Lange Syndrome Foundation.

That was the case with Safety Harbor resident Sue Padags, mother of Lisa. Now 47, Lisa has the syndrome.

"The pediatricians didn't know what was wrong," Sue remembers.

It took a visit to the Institutes for the Achievement of Human Potential in Philadelphia to get the correct diagnosis.

Through periodic visits there, Lisa learned motor skills that she had not previously mastered.

## Lives in UPARC home

Today, Lisa lives in a home in Dunedin operated by Upper Pinellas Association for Retarded Citizens. She spends two days a week at her parents' home in Safety Harbor.

Her tiny hands and feet are typical of many with the syndrome. Lisa wears a size 2 shoe.

She is classified as trainable. At that level, she can hold simple jobs and read a few words.

She worked at a UPARC facility in Clearwater stuffing envelopes until arthritis and other ailments made it difficult for her to do so.

As do many adults with the syndrome, she suffers from many physical problems, such as breathing difficulties requiring her to use an oxygen tank at night.

She also has had to have both hips replaced and suffers from gastroesophageal reflux.

She must take 19 pills a day.

Lisa appears to have a guileless sweetness that is usually seen only in young children. Others often pick up on this rare quality, says her mother. "People are kind of drawn to her."

## A shy smile

Lisa smiles shyly at the mention of Bay News 9 anchor Al Ruechel. Lisa has a crush on the veteran area TV newsman, Sue says.

Lisa is devoted to her family. "She lives to please us," says her mother.

She has given a great gift to her mother.

"She's taught me what love is."

The fundraiser featuring Bella Thompson's jewelry will be at Wendy's, 4240 U.S. 19, south of Trouble Creek Road, New Port Richey, Friday, Oct. 19, and Saturday, Oct. 20, from 11 a.m. to 8 p.m. both days.

For more information on the syndrome, go to the Cornelia de Lange Syndrome Foundation [Web site](#).

## What to watch for

Cornelia de Lange syndrome is associated with a collection of signs and symptoms. Individuals with the syndrome may not have all of them but will have enough to be diagnosed.

- Common characteristics: Low birth weight, small stature, small head, slow growth.
- Facial features: Thin eyebrows often meeting at midpoint, long eyelashes, short, upturned nose and thin, down-turned lips.

- Other possible characteristics: Excessive body hair, small hands and feet, partial joining of the second and third toes, cleft palate, gastroesophageal reflux, feeding difficulties, hearing loss, developmental delays and missing limbs or portions of limbs.

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