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## NEWS PREVIEW

### Commerce

401-277-7330

Regulators to rule on agreement to buy electricity from wind-turbine farm, in this week's Journal.

### Medicine

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Judge considers request for delay in sale of Landmark Medical Center, in this week's Journal.

### Justice

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Judicial Nominating Commission interviews candidates for chief judge of Family Court, in Wednesday's Journal.

# Girl's illness inspires a book

Grace Caldaroni has a little-known nerve disease known as CMT. So does the heroine of "Arlene on the Scene"

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## SOUTH KINGSTOWN —

When Grace Caldaroni goes to school this fall, she'll be wearing \$2,000 leg braces made of carbon fiber.

The 9-year-old, who suffers from a debilitating nerve disease called Charcot-Marie-Tooth, needs the support to keep from falling. After years of living with CMT, she is losing feeling in her feet and hands.

But this year she'll stand out for another reason: she's the star of a new book aimed at young readers, modeled on her struggles with CMT.

Written by lawyer and family friend Carol Liu, "Arlene on the Scene" tells the story of a fourth-grade girl who runs for class secretary in a Rhode Island school.

Like Grace, Arlene suffers from an inherited neurological disorder that could rob her of the use of both her hands and feet and leave her in a wheelchair.

There is no cure for the disease, which affects about 2.6 million people.

"My disease is very hard to understand," explains Arlene in Liu's first book, scheduled for a September release by the Texas-based Emerald Book Company.

"It's like muscular dystrophy, but not exactly. There's no big telethon or anything for it. We don't have posters on buses and we don't collect change at Halloween in little cardboard boxes."

Author Liu and Grace's mother, Marybeth Caldaroni, hope to change that.

"I want the book to raise awareness of the disease, so that CMT becomes a household word," says Marybeth, a CMT sufferer who has been wheelchair-bound since high school.

The self-published story will cost more than \$15,000 to produce. Liu and Marybeth — former University of Rhode Island roommates — have raised much of the money from friends, relatives and other donors.

The Hereditary Neuropathy Foundation, an organization dedicated to finding treatments and a cure for CMT, has also helped raised money for the project.

Profits from "Arlene" will go to the foundation.

In the book, the mother and daughter have a special bond. Born on the same day, they trade notes about living with CMT.

In South Kingstown, Marybeth and Grace have a similar bond.

As a young girl growing up in New York, Marybeth had trouble walking. She wore braces in grade school and went to the prom in a wheelchair.

Her disability didn't stop her. She painted with a brush in her teeth, and was voted "most spirited" by her senior classmates.

At URI, she roomed with Liu. Under an agreement with the college, Liu helped Marybeth take notes, dress and get to class in exchange for financial aid.

It was hard at first, but the two became close friends, says Liu, who admired Marybeth's drive.

Eventually, Liu moved to Washington, D.C., to become a social worker and lawyer. She married and had two children.

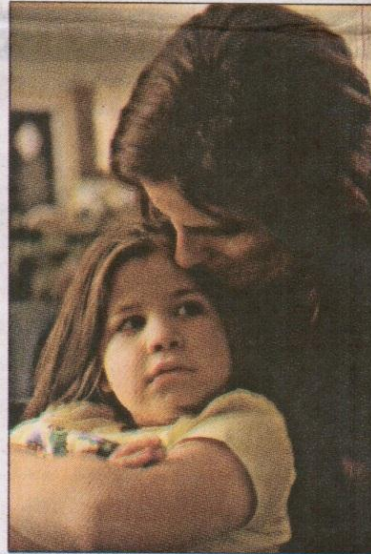
So did Marybeth. She married volunteer firefighter Christopher Caldaroni and had a son and daughter, Christopher and Grace.

At the time, the doctors knew Marybeth suffered from a neurological disorder, but they ruled out CMT because no one in her family had it.

Later, they discovered the disease had started with Marybeth. (About 30 percent of CMT cases are now believed to be the result of spontaneous mutation, according to the Hereditary Neuropathy Foundation.) Her son was fine. But two years after Grace was born, Marybeth saw her daughter stumble. Later, a doctor confirmed it: Grace had CMT.

Two summers ago, Liu visited the Caldaronis in South County. As their children played together, the two friends noticed how Grace faced her disability head-on, while Liu's children supported her.

"Marybeth and I turned to each other and started talking about how this needed to be a book, that there should be a Junie B. Jones character who wears leg braces, and gets mixed up in the same old stuff as everyone else, but she's got her disability to deal with too," says Liu. The main character



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**Both mother and daughter,** Marybeth and Grace Caldaroni, suffer from Charcot-Marie-Tooth, an inherited neurological disorder that affects 2.6 million people worldwide. Marybeth calls her daughter "fiercely independent."

would be a positive role model for children such as Grace "and for kids like mine, who need to understand and support their peers, whatever challenges they may face."

Before she started work as a D.C. lawyer, Liu wrote three chapters and sent them to Marybeth. If Marybeth didn't like the book, she told herself, she would quit.

Marybeth loved it. "I kept calling Marybeth and Grace, getting ideas, checking dialogue. Then Marybeth and Grace read the entire manuscript and we reworked some things," says Liu.

During that time, Grace continued to undergo physical therapy. She tried several kinds of braces, including a stiff plastic pair that resembled half-formed boots.

At one point, the family went to Las Vegas to try a new carbon-fiber brace made by a California company.

Grace says she can run in the new trial braces. But permanent carbon braces can cost as much as \$12,000, and a pair might only last a year, says Grace's father, Chris. "You want to do everything you can for your children. But you can't re-mortgage the house ..." his voice trails off.

Despite CMT, Grace — "she's fiercely independent," says Marybeth — plays piano, swims and performs in school plays. Last

year she played a dolphin in "The Little Mermaid."

"Grace is a little more sarcastic than Arlene," says Marybeth, a speech and language pathologist at Charho Middle School. "She has a tough exterior. Having a disability really affects who you are. You have a much more guarded personality."

Arlene goes after what she wants, says Marybeth. "Grace doesn't take as many risks," and has never run for a class office. "I'm hoping the book will inspire her."

The doctors don't know if Grace will need a wheelchair later. Some CMT sufferers do not.

In her home near URI, Marybeth opens the new book to a favorite chapter. Her fingers are curled by CMT, but she navigates the pages until she reaches a specific passage.

In it, Arlene's mother tells her daughter she must be realistic. You can do things you set your mind to, she says, "But you cannot do anything and everything. ... Your disability is a part of you."

Marybeth closes the book. She hopes it will raise money and awareness, she says. She stares at the cover. A cartoonish Arlene stands with her hands outstretched, triumphant. "Ultimately ... I hope it leads to a cure."

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