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Study: equipment, poor attitude plague utility

by Frank DeLoache
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Task force: Revise CMUD rate structure. See story, page 16.

CORNELIUS – A citizen task force looking into multiplying complaints about water bills has concluded the Charlotte-Mecklenburg Utilities Department is plagued by old, unreliable equipment and an attitude problem.

And they want the utility – or an interjecting Charlotte City Council – to immediately stop cutting off service to customers who are protesting their high bills while utility officials address the problems with the equipment.

“It’s barbaric,” said task force member

Ron Charbonneau, who lives in Davidson’s River Run community and knows of a resident whose water was shut off. “I can’t imagine that.”

Right now, the utility has no formal means for a customer to appeal a bill for a hearing, task force member Ron Kelley said. In the end, utility officials make an arbitrary decision whether to credit a customer or study their complaint more, task force members said.

“That’s why an appeal process needs to

be there,” Kelley said. “They hold all the cards.”

Task force members want the utility to create an independent “water audit team” that will, for the first time, try to help customers’ find the problems.

“We want to change the focus from ‘who has the problem?’ to ‘fixing the problem,’” Kelley said.

Utility officials did not attend the task force meeting Friday, Feb. 12, but they have said they are taking a number of steps to address residents’ concerns. Among those are “refining business processes” to spot bills that warrant field

(See Utility plagued on page 17)

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How a 4-year-old Huntersville boy could beat the odds against a rare, fatal, horrifying disease. See story, page 13.

Courtesy of Chrissy Grier

Nonprofit day care’s problems still looming

by Andrew Batten
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DAVIDSON – The nonprofit Davidson-Cornelius Day Care Center has raised enough money to continue operations through the end of spring, day-care officials said during a community meeting Monday night.

But the center must act on several recommendations from a task force the center’s board organized to put the nonprofit center on sound financial footing, board member Eileen Keeley told a group of residents.

“Today the center is on strong ground, but its future is not yet secure,” Keeley said.

The task force recommended improving the center’s state rating, investigating a partnership with Davidson College Presbyterian Church and pursuing loans from Davidson or Housing Urban Development grants from Cornelius. The center also plans to add infant care and will likely need to raise its fees.

(See Day care on page 8)

Carolina WEEKLY newspaper group



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Hope for Holt is growing

by Josh Lanier
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HUNTERSVILLE — The story of 4-year-old Holt Grier is one of a kid who has been repeatedly beaten by the odds. A devastating, rare disorder that affects only 500 children nationwide attacks his body. Daily treatments leave him so nauseated he can only stomach food a few hours a day.

Now, it's his time to win. Doctors, who once thought a cure was impossible, believe a breakthrough could be within their grasp.

Holt Grier's story began three years ago, when at 10 months, he developed symptoms doctors couldn't decipher.

"He was constantly thirsty and was in pain a lot," Jason Grier, Holt's dad, said. "The little guy would be constipated for weeks ... then he just fell off the growth chart. That's when everyone knew, 'Ok, this is really serious.'"

After more visits to doctors, the Griers decided to search the symptoms online and worked through the results with

How to Help

The Hope for Holt foundation, which supports research, will hold a fundraiser Saturday, Feb. 20, at the Charlotte Country Club from 7 to 11 p.m. Tickets cost \$100 in advance and \$150 at the door and includes a meal and silent and live auctions. A private donor will match total donations up to \$250,000. Find more information about how to donate or upcoming events online at www.hopeforholt.org.

nodded. Then she just collapsed. I just hung up the phone without saying a word ... and we just sat there and cried."

Cystinosis is a metabolic disease that stops the body from breaking down the amino acid cystine. As cells die, they form cystine crystals that latch onto the body's organs, slowly shutting them down. Holt is going blind as the crystals lodge in his eyes.

The only treatment is a cocktail of drugs that cost \$10,000 a year and must be taken every six hours. The sulfur-based medication smells like rotten eggs and causes extreme nausea. Holt takes his 60-milliliter dose through a tube in his stomach. The frequent treatments have kept him from a full night's rest since he was a 1 year old.

"You reach a point where you just cry about it, which we did, but then you realize you have to do something," Chrissy Grier said. "I'm a mom, and moms do what is necessary for their kids. You have to put on your big girl pants and do what needs to be done."

After getting the diagnosis, the Griers threw themselves into learning about the disease and joined the Cystinosis Research Foundation, where they met Gregory and Nancy Stack of California. The Stacks also have a child who suffers from the disease.

At the time, cystinosis was such a rare disease — only about 2,000 people worldwide are afflicted — research was nearly non-existent, Jason Grier said. The Stacks have helped change that.

"They've been so good at getting the medical side in order," Jason Grier, who is now a member of the Cystinosis Research Foundation board, said. "When they got involved, doctors were doing some research, but they weren't talking to each other. It completely stopped any real progress, but that's been changed thanks to the Stacks."

Researchers hope to introduce a medicine next year that would only need to be taken every 12 hours instead of six. That's exciting for the Griers because Holt will get to sleep through the night.

But research from the Scripps Research Institute holds the most promising innovation. Dr. Stephanie Cherqui has been working on a stem cell procedure that could eradicate the disease. It's shown promise in mice, and with luck,

a vaccine could be on the market in three to five years.

Without it, Holt's chances of survival vanish.

"If no cure is found, he'll likely live to his mid to late 20s. He'll need kidney transplants and then slowly will succumb," Jason Grier said. "That's not going to happen ... We're not going to allow that to happen."

The Griers formed a foundation, called Hope for Holt, to raise funds for research for a cure.

Neighbors and friends have given their time to volunteer at events or their money for research, to help Holt.

The Griers' two other children, Mary Logan, 9, and Jack, 7, also have become helpers. They administer "hug tests."

"I ask the kids to hug Holt after he's been playing for a while and calmly run their hands (around his midsection) to make sure the (tube in his stomach) hasn't come out," Chrissy Grier said.

If it weren't for the constant need for

medication, Holt wouldn't know he's sick, Mary Logan said. Holt loves to play outside, wrestle with his siblings and ride in his dad's arms, family members said. He attends a local preschool.

"This story is just beginning," Jason Grier said. "Everything that's going on right now is just the tip of this big thing. I think you're going to see big movements soon with the medical stuff and all of it. This story, Holt's story, is just getting started." □



Courtesy of Chrissy Grier

In this undated family portrait, Jason Grier holds his son Holt while his older son, Jack, and daughter, Mary Logan, stand with their mom, Chrissy Grier.



Courtesy of Chrissy Grier

Holt Grier, bottom; his brother, Jack; and sister, Mary Logan, smile for the camera. Holt suffers from a fatal debilitating disease. His brother and sister help their parents care for him.

Holt's doctors.

A few weeks later, Jason Grier, vice president of worldwide operations for software giant McAfee, was on the phone with the CEO of the company when his wife, Chrissy, came home from a doctor's visit. They had a diagnosis: cystinosis, an incurable, fatal disease.

"We had a list of disorders we came up with that fit the symptoms," Jason Grier said. "We broke them down into those we could live with and those we couldn't ... Cystinosis was in that second category.

"... She just came in, looked at me and



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