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Kids fight a killer

Pam's "army" gives one family strength

BY SHANNON MULLEN, STAFF WRITER

The deadly disease known as ALS is like a torture torn from a child's nightmare.

First your legs stop working, then your hands, your arms.

It keeps getting worse, until you can't eat or speak. You want to cry out, "Help me!" or just, "Please, someone scratch my nose," but ALS, commonly known as Lou Gehrig's disease, won't allow even that.

To a child, ALS sounds a bit like being locked in a dungeon with a monster, knowing no one can come to your rescue.

Mallory McGill remembers when she first learned that Pam Callahan was living that nightmare.

She could scarcely believe it when her mother sat her down and told her more than a year ago. How could one of the most energetic and fun-loving moms she ever met get so tragically sick?

"Mrs. Callahan never sat down. She was always busy doing something," says Mallory, 12, who lives down the street from the Callahans in Rumson. "She's such a generous and caring person."

What would happen to Pam, she wondered, and what would happen to her family ... her husband, Don, and their four boys, Matthew, now 13, Sean, 11, Craig, 9, and little Mikey, who's only 5?

Mallory was scared. So were a lot of kids in the neighborhood and within the Callahans' wide network of friends.

In the past year, however, something remarkable has happened with these children. Scores of them, ranging in age from 7 to 14, have set their fears aside and resolved to fight



The Carnival for PALS, a fundraiser organized by children to help support ALS research, will be held Sept. 28 at the Driftwood Club in Sea Bright and will feature a variety of entertainment, including a band whose members include Jake Tavill, 11; Matt Callahan, 13; Sean Callahan, 11, and Sam Tavill, 8, all of Rumson. Matt and Sean's mother, Pam, is battling ALS.

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this disease, this monster that's torturing Pam Callahan, 47, whose three oldest boys are active in the effort.

Mallory, a tall, blond-haired girl with an earnest way about her, speaks for many of these kids when she explains what's motivating her to get involved.

"Watching her get put into a wheelchair," she says of Pam, pausing a beat, "'I didn't want that to happen to anyone else."

Carnival for PALS

In 1869, when the disease was first identified, amyotrophic lateral sclerosis was a death sentence. Relentlessly, it attacks nerve cells that control muscle movement throughout the body until even breathing becomes impossible.

Doctors had no idea what caused it, how to treat it, or how to prevent it. Typically, those stricken with the disease died a horrible death within two to five years.

Today, nearly 140 years later, all of that is still true, and there is no cure on the horizon.

What can a bunch of kids do to stop such an elusive, cunning killer?

Visit the Look What I Can Do art studio and you'll see.

The Shrewsbury storefront has become the headquarters of an ambitious, youth-driven fundraising campaign involving about 80 children, most of whom are well-heeled kids from Rumson, Fair Haven, and other nearby towns.

If you're thinking candy bar sales, car washes and coin drops, think again. These kids have a slick Web site, a corporate sponsor (Stillwell-Hansen, Inc., an Edison-based heating, air-conditioning and data and fire protection company) and a growing list of area businesses who have signed up to participate in an event on Sept. 28 called the Carnival for PALS. PALS stands for People with ALS.

The carnival, at the Driftwood Cabana Club in Sea Bright, will have amusement rides, upscale food from top area chefs, professional "rock 'n' roll" makeovers, hands-on animation workshops and a media room equipped with Wii and all the latest video game gadgetry.

There also will be an auction for such high-end items as a five-day cruise, Jet Blue tickets to anywhere the airline flies, and kid-oriented immersion experiences including a day with a pastry chef, a chocolatier and a Sea Bright police officer.

"And if they happen to pull someone over, the child will get to write the ticket," Michele Dupree of Highlands said of the police ride-along. She's coordinating the carnival with her sisters, Tricia Schaeffer of Spring Lake and Stephanie Schaeffer of Ocean. The three women co-own the art studio.

Proceeds from the carnival will benefit the ALS Therapy Development Institute, a leading, nonprofit ALS research company in Cambridge, Mass., and the Joan Dancy & PALS support group, based at Riverview Medical Center in Red Bank.

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Last year, a much smaller carnival, thrown together in the span of about six weeks, raised \$10,000 despite a nor'easter the day of the event.

This time, with a whole year to plan, the kids have set their sights considerably higher.

"We're planning to raise like \$1 million," volunteer Jake Tavill, 11, of Rumson,

Event planners

The 140-year-old battle against ALS probably has never had a foot soldier quite like Jake.

A child actor who appeared in a production of "MacBeth," co-directed by the illusionist Teller at the Two River Theatre in Red Bank earlier this year, Jake is a high-energy extrovert with a mop of curly, dark hair and a notebook brimming with ideas for the carnival. In between the group's biweekly meetings, Jake borrows his mom's Blackberry to barrage Schaeffer with his latest brainstorm.

What about a sand castle contest? Or a flower sale? And can you drop off a stack of carnival business cards so I can hand them out at temple today?

At a recent meeting, attended by about 30 children, he rose from his seat to update the group on the entertainment for the carnival, which will include live music, improv and dancing — performed by the kids themselves.

Occasionally, his friends have to rein him in. That afternoon, as he was explaining how he'll be backstage making sure the performers go out at the right time, Matthew Callahan interrupted him.

"OK, but you're not the stage manager," Matthew pointed out, noting that an adult has that job.

"I'm going to help," Jake clarified.

Jake and his brother, Sam, 8, play in a band with Matthew and his brother Sean. For weeks now they've had their set list ready for the carnival, but at the time of the meeting a couple of weeks ago, they still hadn't come up with a name for the band.

"We have to really talk about this," Matthew said. "What do we want to call it for now?"

Another light bulb went off in Jake's head.

"Unknown," he said, drawing out the word for dramatic effect.

As the bandmates batted that one around, Mallory McGill and a group of other girls sat at a nearby table busily stringing beads on necklaces and bracelets bearing the words "Cure ALS." They'll sell the items at the carnival for \$2 each.

At the far side of the room, Hannah Mayer, 11, of Middletown and Jenny McKenna, 12, of Red Bank brushed paint on a series of homemade carnival games the kids invented. In one, players have to toss rubber fish through a hole in a surfboard. Another is a baseball toss bearing the likeness of New York Yankees legend Lou Gehrig, who died of ALS in 1941. His name has been associated with the disease ever since.

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At another table, Craig Callahan sat with a group of boys coloring posters, while other children quietly wrote their names on business cards they've been handing out to spread the word about the carnival. Each card is good for one free game at the event.

"I'm going to give them out to anybody I see," Sam Tavill told a reporter. "Want one?"

The kids also are going door-to-door in their neighborhoods soliciting donations. One day, Jake knocked on five doors and got \$100 checks from each one.

Pam's army

Dupree and Schaeffer say their job is to help the kids think through their ideas and to figure out how to implement them. They're amazed at how quickly the children get caught up in the excitement.

"We laugh because there'll be this quiet kid sitting in the corner of the room one week, and the next week she'll be standing up to talk about what's she's been doing and she'll have three friends with her," Dupree says. At the group's last meeting this past Thursday, a dozen new kids showed up, eager to help.

As the children worked, Dupree panned the room with her video camera. Later, she'd show the footage to Pam Callahan, who is actively involved in planning the carnival. It was her idea to sell Lego blocks, at \$10 per piece, that will be used to construct a detailed model of Yankee Stadium the day of the event, in Gehrig's honor.

Say hello to Mrs. Callahan, Dupree told the kids.

"Hi, Pam!" they shouted.

Pam Callahan watches these videos from her wheelchair, desperately wishing she could wrap her arms around these children.

A former model, Pam graduated from the Wharton School of the University of Pennsylvania and worked on Wall Street as an equity portfolio manager for Goldman Sachs. That's where she met her husband, Don, 47, now a top executive at Morgan Stanley.

In the room on the first floor of the Callahan's home where she spends most of her time these days, there's a large, framed photograph of her in the pool with her boys, and a map that shows the family's far-flung travels, including a trip they took to the Galapagos Islands after she was diagnosed.

Two years ago, she was swimming and playing tennis. Now she's in the late stages of an aggressive form of ALS, connected to a ventilator and feeding tube, unable to move anything but her eyes.

Her father, who could play several different musical instruments, died from ALS on his 49th birthday. About 10 percent of ALS patients have a family history of the disease.

Pam uses her eyes to operate an optically directed computer, which can turn her typed words into audible speech. Costing around \$15,000, it's her only means of communication, and she knows she's fortunate to have it. Other ALS patients with less means have to use a simple sheet with rows of letters that requires so much blinking to spell out a word that many people just give up in frustration. Among other things, the Joan Dancy & PALS group helps ALS families get the equipment they need.

Asked whether his mother can still discipline him and his brothers with her computer, Matthew Callahan smiled good-naturedly.

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“There is a way to make it yell,” he said of the device, “but she doesn’t know about it yet. She’ll figure it out eventually.”

This past week, Pam painstakingly typed out her feelings about the carnival and the circle of friends who have rallied around her since her diagnosis two years ago.

One friend reads to her regularly. Another helps her write letters to her children. A third gets her outside for fresh air and sunshine. Yet another cooks enough food for the Callahans and their friends every Sunday night to feed a small army, which is what Pam’s supporters are, really.

“I have a wonderful contingent of friends that help me,” she wrote, as five of her friends, who had stopped by to visit her, chatted nearby.

“The most wonderful contingent is the children. They have rallied around me,” she wrote. “Some adults cannot face me, which is fine. It is hard to face. But the kids that have known me don’t think twice. . . . They are not afraid to touch or talk to me. And when the carnival came around again, they jumped in with both feet and eyes wide open.”

She draws strength from the children’s optimism, which is manifest in the Magic-Marker-ed “get well soon” cards they send to her.

“My boys are the loves of my life,” she wrote. “They keep my mind strong, and they keep my heart soft.”

At the same time, there is a special place in her heart for the carnival kids, who’ve become just as passionate about raising awareness about ALS, and finding a cure, as she is.

Once, as Jake Tavill’s mother, Judi, recalled, Jake said to Pam, “Pam, you’re the best.” She quickly typed, “No, you’re the best,” and back and forth they went, until finally Pam gave in.

“OK, I’m the best,” she wrote, “but you’re second best.”

While it’s hard for many of these children to grasp all the implications of her disease, they understand the urgency of the situation.

“It may be a lot (of money) for research, like \$100 a minute,” Sean Callahan said during the planning meeting, “but every minute counts.”

They’re just kids. Kids on the trail of a killer.

Who can say, though, where the trail might lead, or how many people they might help along the way?

“It is great for my kids to see the support that surrounds us,” Pam typed the other day. “We are not alone. We have amazing strength upholding us during the most trying of times.

“Sometimes,” she wrote, paraphrasing Gehrig, “I feel like the luckiest woman in the world.”