



[SAVE THIS](#) | [EMAIL THIS](#) |

[Close](#)

How to save your own child

- Story Highlights
- Frustrated by a lack of treatment options for kids, parents are funding research
- Golf tournaments and cookie sales are some of the ways they raise money
- Parents especially need help when the children's diseases are uncommon

By Elizabeth Cohen

CNN

NEEDHAM, Massachusetts (CNN) -- Early one summer's evening, five parents gathered at a suburban Boston home. They had wine and fruit tarts, cheese, crackers, and fresh fruit. Laughter and hugs filled the room.

But this is one gathering to which you don't want to be invited.

These parents have children with brain tumors. Frustrated with the lack of treatment options for kids, they meet once a month to come up with ways to fund medical research. So far, with no training in fundraising, this band of parents has raised more than \$6 million in three years.

"Never underestimate the power of a parent with a sick kid," says one of the parents, Risa Sherman, whose 3-year-old daughter, Lucy Katcher, has a type of brain tumor called Juvenile Pilocytic Astrocytoma, or JPA.

Groups of parents like this one in Massachusetts -- parents shocked and even disgusted at how little money is being spent on their children's diseases -- are popping up in various parts of the country. Rather than wait for drug companies to do it, they're funding the research themselves.

When John Ragnoni's son, TJ, was diagnosed with JPA, "we thought the medical cavalry was on the way," he says. "We thought there must be just tons of research happening, that certainly there must be some cures or at least treatments for TJ."

But Ragnoni says he was "shocked" by the limited amounts of research being done on JPA, which strikes about 600 children each year. "We kept running into dead ends," he says.

That's when he and other parents started www.fightjpa.org, organizing bike rides, runs, and other events.

It's a problem with many rare diseases. Developing drugs for high blood pressure, high cholesterol, or depression, is lucrative because millions have those diseases. But when patients are counted in the thousands -- or even hundreds -- it's a different story.

Take neuroblastoma, a rare pediatric cancer. There are only 700 new cases a year in the US, according to Dr. Nai-Kong Cheung, a pediatric oncologist at Memorial Sloan-Kettering Cancer Center in New York City. He's developing a treatment that would be used by only about three or four hundred children a year.

"The industry doesn't think they're going to make money on these diseases, and they're right," Cheung says. "You have to answer to shareholders and everyone would say, 'Why are you investing in something that's not going to make money?'"

A few months ago, a group of parents asked Cheung what they could do to help further his research. "Do you have an extra 2-or 3-million dollars?" he asked them.


Gretchen Witt was listening. Her 3-year-old son, Liam, had just been diagnosed with a neuroblastoma. "I thought he was going to say \$25 or \$30 million. Two to 3 million is a drop in the bucket!," she says. "I thought, the only thing separating our children from having better odds and really horrible odds is just 2- to 3-million dollars?"

Then Witt saw a story on CNN about a family who raised \$3 million through golf tournaments to fund a treatment for their son's rare genetic disorder. Initially told he wouldn't live past his 10th birthday, Ryan Dant graduated from high school in May.

"Golf tournaments is what I believe saved Ryan's life," says his father, Mark Dant.

But Witt knew golf tournaments wouldn't save Liam. "I don't like golf. I don't know anything about golf," she says. "I think golf's a silly game."

So Witt thought long and hard about what she could do to raise money for Cheung's research. Then it came to her: As the public relations executive for a kitchen supply company, she did know people in the culinary world.

Working in three shifts, hundreds of volunteers -- from firefighters to stars of the "Food Network" -- baked 96,000 cookies in two weeks. "They totally had fun under very trying circumstances," Witt says. "For a while we didn't have heat in the kitchen to the point where you could see your breath. Nobody complained. Everybody kept focusing on the ultimate goal."  [Watch one mom's cookie crusade to help her child >](#)

The ultimate goal was to raise enough money to pay a biotech firm to improve a treatment currently used to fight neuroblastomas. Witt says in the past few months, she knows six children who've died because the current treatment, which is working for her son, didn't work for them.

"These are six children I personally know, six children my son has played with," she says. "It drives me crazy these kids would have stood a better chance if this new treatment were available."

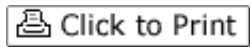
The cookies, which sold for \$30 for a dozen, raised more than \$200,000. Witt says she's thinking hard about the next project.

Sometimes Witt gets frustrated that parents have to sell cookies, or hold golf tournaments, to fund medical research. "It's totally sad. It's ridiculous. It makes me mad," she says. "But I can't get wrapped up in that or I won't get anywhere."

Witt says last week she received the best Christmas gift ever: Memorial Sloan-Kettering signed a contract with a biotech firm to begin work. "They're moving forward, and that's huge," she says.

Find this article at:

<http://www.cnn.com/2007/HEALTH/12/27/ep.cure.child/index.html>



[SAVE THIS](#) | [EMAIL THIS](#) |

[Close](#)

Check the box to include the list of links referenced in the article.

• 2008 Cable News Network