

# Grandparents Who Won \$180 Million Lottery Devoted to Finding Treatment for Incurable Disease That Claimed Life of Granddaughter

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Paul and Sue Rosenau with their granddaughter, Makayla

COURTESY PAUL AND SUE ROSENAU

BY DIANE HERBST [@DianeHerbst](#)

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The day of May 4, 2008 was a reflective one for Paul and Sue Rosenau – it was the fifth anniversary of the death of their beloved granddaughter, Makayla.

The 2-year-old passed away from a rare inherited disorder called [Krabbe disease](#), an incurable condition that destroys the protective coating of nerve cells and usually results in death by two.

That night, the Minnesota couple was settling into bed and watching the news when Sue asked Paul if he had bought any Powerball tickets. Paul, an occasional player, said he had. As the announcer

reeled off the winning numbers, the couple was shocked to learn that they held a ticket worth \$180.1 million.

Paul and Sue immediately knew what they had to do – start a nonprofit to fund research into finding a treatment for Krabbe, which affects about one in 100,000 newborns.



"We are faithful people," Sue tells PEOPLE, "and we definitely believe this is God telling us what we do."

After taxes, the couple's quick-pick cash option ticket gave them \$44 million. They used \$26.4 million of that to create [The Legacy of Angels Foundation](#), to fund research into Krabbe disease as well as help families seeking treatments with medical costs.

Until recently, there has been no hope for a treatment for babies like Makayla.

"I found out there was a little person in that body and she couldn't get out," says Paul. "We're trying to give these kids the ability to get out."

Since 2009, the foundation has given a dozen Krabbe researchers over \$10 million in grants. Research they've funded has led to advances in treatments, and a promising gene therapy is now under investigation. "This new treatment, upon successful completion, will be historic," says Sue.



Paul and Sue Rosenau with their granddaughter, Makayla

COURTESY PAUL AND SUE ROSENAU

Dr. Maria Escolar, one of Makayla's doctors and a researcher at the Children's Hospital of Pittsburgh of UPMC, is the lead investigator of the promising gene therapy project. Since Escolar is known as the "go-to" doctor for Krabbe, the foundation and the Rosenau's have given or committed over \$6.25 million in funding for her work.

"Without this type of help, we would not be able to achieve our goal of improving the quality of life for children with rare disorders and help them develop to their full potential," says Escolar, founder of the Program for the Study of Neurodevelopment in Rare Disorders at the Children's Hospital of Pittsburgh of UPMC. "We are beyond grateful."

The foundation has also awarded more than \$2.5 million in funding for other diseases, and the generous couple has given away another \$10 million to their rural community of Waseca – to their church, families in need and even the fire station.

Makayla's mom, Stacy Pike, a board member of the foundation, is "so very proud" of her parents' efforts, she tells PEOPLE.

"Their mission is near and dear to my heart," she says.

Within 18 months of winning the lottery, the Rosenau's left their jobs to devote their lives full-time to finding a cure for Krabbe. Paul had been a construction supervisor, Sue an administrative assistant for the University of Minnesota and an a research institute.

The couple not only decides which projects receive funding, but they roll up their sleeves and actively participate with researchers, travelling for years to conferences and research meetings all over the U.S.

Recently, however, Sue has had to scale back her schedule: she is in the middle of treatment for stage 3 ovarian cancer and stage 4 uterine cancer.

Still, Sue's personal health battle has not damped her dogged determination on the Krabbe front to find a treatment, of which she is "100 percent certain" will be found.

"I am committed and passionate," she says, "and will see this through until the day I die."