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California's budget includes \$12 million for research into what has come to be called Jordan's Syndrome—named after 12-year-old Jordan Lang, seen here in a family photo.

California lobbyist fights for his daughter, with Legislature's help

By [Dan Morain](#)  | Aug. 12, 2018 | [HEALTH](#)

Lobbyist Joe Lang is the guy to see if you're a billionaire wanting to build a basketball arena in Inglewood, or a weed start-up testing the boundaries of commercial cannabis, or a tobacco company with its many issues.

In any legislative session, his firm—Lang, Hansen, O'Malley and Miller—is one of the two or three top-billing lobby operations in Sacramento. For decades, he and his partners have been pushing, molding and killing legislation depending on their 60-plus clients' wishes.

Lang also is Jordan's dad.

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Jordan is a sweet 12-year-old girl who likes to curl up in her daddy's lap, but cannot talk or care for her bodily needs. For years, Lang and his wife, Cynthia, could not get a diagnosis. So a few years ago, they took Jordan's neurologist's advice and paid to get her genes mapped.

The result showed Jordan has a mutation in one gene, called PPP2R5D. That discovery sent the Langs on a quest that has engaged some of the nation's top genetic researchers.

Now, it includes you.

The new state budget contains \$12 million for research into what has come to be called Jordan's Syndrome. Researchers at the University of California, Davis, and campuses in and out of California will use that money to focus on that defect.

"We want to cure this disease. That is the goal," said Jan A. Nolta, director of the UC Davis medical school's stem cell program and the Institute for Regenerative Cures.

Based in part on Jordan's genetic map, geneticists led by Dr. Wendy K. Chung of Columbia University Medical Center published findings identifying the defect in seven kids, one of whom was Jordan. Now, 66 children have been found with the mutation from around this country, and as far as New Zealand, the United Kingdom, Israel and India.

They share certain traits such as difficulty talking, intellectual disability, enlarged heads and low muscle tone. Some have been diagnosed as autistic, though not Jordan.

Their parents have built a community, sharing their challenges on a Facebook group, and convening regularly to provide their children's tissue and blood samples and hear researchers discuss the latest developments, as [they did](#) in Virginia last year. Lang foots much of the bill.

Lang and other parents had amassed roughly \$1.5 million in donations from private sources. The fundraising goal is \$20 million. They hope one day for clinical trials of some treatment that will help their kids.



Lobbying Joe Lang with pictures of his daughter, Jordan, when she was younger.

Earlier this year, Lang and his partner, Bob Giroux, turned to state Sen. Richard Pan, a Sacramento Democrat and a pediatrician. Pan met with researchers and saw possibilities. He persuaded other legislators and Democratic Gov. Jerry Brown to spend \$12 million on research into the mutation.

“There is a tremendous amount of potential,” Pan said. This one genetic defect could provide insights into other neurological disorders.

To academics who study health care funding, the one-off nature of the \$12 million raises questions: Should the Legislature fund such research? Would such decisions be better made by a state institute made up of scientists?

“Is this the right choice given that there are limited resources?” asked Abraham P. Schwab, a philosophy professor at Purdue University-Fort Wayne who focuses on medical ethics.

The flip side, he and others say, is that research funding is a mess. Drug company research is driven by profit. Federal research funding has been cut. Even if the feds were to fund Jordan's Syndrome, researchers would be lucky to get a single grant of \$250,000. Researchers say the National Institutes of Health would not fund teams of scientists delving into one orphan condition over a three-year period.

California long has funded basic medical research, filling voids left by Uncle Sam.

- Republican Gov. Pete Wilson [signed legislation](#) in 1993 to fund breast cancer research by imposing a 2-cent-per-pack tax on

tobacco.

- At the urging of politically influential parents of autistic children, the Legislature and Democratic Gov. Gray Davis allocated \$30 million to build the [MIND Institute](#) at UC Davis to investigate neurodevelopmental disorders.
- Encouraged by GOP Gov. Arnold Schwarzenegger, voters in 2004 approved a \$3 billion bond to fund stem cell research.
- Two years ago, Gov. Brown signed off on a \$5 million earmark to study [gun violence](#).

A truck driver, a teacher or an engineer probably would not have gotten the \$12 million. But Lang has been a denizen of the Capitol for more than four decades and knows how to make a case before lawmakers. This cause, of course, is like no other. It is for his daughter, and for the sons and daughters of folks who have never been to the Capitol.

“We were blown away,” Lisa McCarty said of the \$12 million. She is a teacher at Holland Elementary School in Fresno, married to Will McCarty, a cop. Their [son Liam](#) has the defect. “Never in our dreams would we have been on this adventure. And then it took this other turn.”

Starting soon, teams around the country will be using the \$12 million to breed mice with the defect, use the children’s tissue to grow cells, try to determine if the cells can be edited with [CRISPR technology](#), and identify or develop drugs that might affect the condition.

The defect is random, what researcher Kyle Fink calls “de novo.” It’s not

inherited from either parent. No one can promise a cure, though that is the researchers' goal. They believe the defect has broader implications, and see connections to Alzheimer's, Parkinson's, autism and ovarian cancer.

"It becomes more fascinating the more we look at it," Nolta said.

Jordan Lang will be starting junior high this fall at a public school for kids with special needs. Transitions are hard for her. She's also improving, thanks to speech and other therapy she receives. She can feed herself and is becoming more verbal. The goal is much more, for her and for others with the defect in PPP2R5D.

"A 50 percent improvement would be amazing. Who knows? Maybe it will be more," Lang said. "From a dad's standpoint, if Jordan improves by 50 percent, that would be like light years. For some of the younger children, their potential is really high."



Dan Morain

Senior Editor



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