Joe Lang sits with his daughter Jordan, 11, at the Westfields Marriott on August 4, 2017 in Chantilly, Va. (Photo by Mary F. Calvert for The Sacramento Bee) **Mary F. Calvert** - Mary F. Calvert

Dan Morain

Editorial page editor, political affairs columnist and editorial writer

DAN MORAIN

This lobbyist is fighting for the biggest cause of his career: his daughter.

BY DAN MORAIN
dmorain@sacbee.com

AUGUST 05, 2017 7:00 AM

Joe Lang was part of the campaign that raised $26 million for an initiative that would have legalized slot machines at race tracks and card rooms. That was in 2004, before Jordan was born.

There were other times when he and his partners torpedoed legislation to tax tobacco, and killed or pushed bills to help the liquor business, or Edison or Comcast or FedEx or Walmart or the Catholic Conference or eye doctors or banks or oil companies or hair salons or 50 other clients. And there were elections, year after year, when his clients spent millions to elect and un-elect candidates.

OPINION

In a town that runs on the product that lobbyists shape, Lang, Hansen, O'Malley & Miller is preeminent, a top-billing firm year after year, and Lang, a Capitol denizen for four decades, is a lobbyist's lobbyist.

WHEN JORDAN WAS 9, HER PEDIATRIC NEUROLOGIST IN SACRAMENTO RECOMMENDED THE LANGS GET HER GENOME MAPPED. INSURANCE WOULDN'T COVER IT, SO THEY PAID. THAT MAP IS LEADING JOE LANG ON AN EXTRAORDINARY JOURNEY, THE ENDING OF WHICH HAS YET TO WRITTEN.

On Thursday, Lang was on his knees, the better to get his daughter's attention, smiling and singing, "If you're happy and you know it, clap your hands." When she smiled and clapped, he sang louder and clapped harder.

Jordan Lang keeps Joe up late at night, studying obscure scientific journals and studies of genetics, and she motivates him to get up in the morning. She is 11 and cannot talk, though she communicates well enough to have her father wrapped tightly around her finger.

As a baby, she didn't roll over or crawl the way other kids normally do. Her head was enlarged and she couldn't walk until she was 5. Joe and his wife Cynthia consulted with specialists at top medical schools. Her symptoms were obvious, but the diagnosis was not.

When Jordan was 9, Dr. Shailesh Asaikar, their pediatric neurologist in Sacramento, recommended they get her genome mapped. Insurance wouldn't cover it, so the Langs paid for it. That map is leading Lang on an extraordinary journey, the ending of which has yet to be written.

"I'm a dad. I will do whatever I need to do," he said. It's a line he repeated, with slight variations, in his Senator Hotel office across from the Capitol when he told me Jordan's story, and again on a flight Thursday to Virginia, an important leg on this journey.

There are, it is said, 3 billion genetic pairings in a human being. In the whole-exome sequencing that produced the map of Jordan Lang's genes, scientists discovered a mutation in one: PPP2R5D.

PPP2R5D had not been studied until a team led by Dr. Wendy K. Chung of Columbia University Medical Center published an article in the publication Neurogenetics in 2015.

The study focused on seven kids ages 22 months to 15 years. Jordan was Patient 4. Although there are variations in the mutation and in symptoms, there are common threads: intellectual disability, autism spectrum disorder, macrocephaly or an enlarged head, low muscle tone or hypotonia, among others. Chung describes the mutation as a typo, purely random. It has nothing do with anything any parent did or didn't do.

Last fall, Lang flew to New York to meet with Chung and her team, and brought a friend, Dennis Cardoza, the former legislator and congressman from Modesto who lobbies in Washington. Over dinner in Manhattan, someone referred to Jonas Salk, who discovered the polio vaccine. Not to get ahead of themselves, but their work could be significant, too, they said. Lang smiled. Years earlier, Salk retained Lang to resolve an issue related to his AIDS research. That he knew the legendary researcher seemed to impress the researchers.

Chung and her team laid out what they needed. His organizational skill would be invaluable. They also needed $20 million for research that could lead, in time, to human trials. He and Cardoza felt relieved. As they walked back to their hotel, Cardoza said he thought they were going to ask for $50 million. “Dennis, I thought they were going to say $100 million,” Lang replied.

Whatever the number, Lang was in: “I’ve helped people across the street (in the Capitol) raise that kind of money for things that are maybe not quite as important as this.” They’re calling the typo in PPP2R5D Jordan’s Syndrome – at least for now. There are no promises for a cure.

“If one day, Jordan could look at me and say, ‘Hey, dad, I’ve been trying to tell you what I need and wanted for all these years. Now I can.’ That’s what I want,” he said.

Once the study was published, pediatricians recognized symptoms and tested their patients. So far, 35 kids have been identified worldwide with the mutation. Parents started a Facebook group to assure one another they are not alone.

This weekend they gathered at a Marriott near Dulles International Airport in Virginia at Lang’s expense. Emma Crofskey and Joe Govier, their son George, who has a variation of the mutation, and their younger daughter Lucy, who doesn’t, flew with Lang on a private jet donated for the trip by his friend, John Jordan, who owns Jordan Winery.

They came from their home in New Plymouth, New Zealand, where he works as a tugboat operator and she for an architect. They were the only family in the Southern Hemisphere with a child who has the typo, until one in Australia recently was diagnosed. Others came from Florida, Missouri, Colorado, Texas, Ireland and beyond.

In a banquet hall on Thursday night, they asked questions and told stories. A mom from France recalled the pain she felt when kids laughed at her daughter, now 25. Others said their children have no friends.

“We were all alone,” said Robin Heseltine, a bus driver from Northampton in the United Kingdom, who came with his wife, Jane, and their daughter Hermione. Until they got the diagnosis, Hermoine was a “swan,” for syndrome without a name. “We were eight years with no hope and all of a sudden there is a glimmer,” said Robin, who got a new tattoo, PPP2R5D, on his right arm when they got the diagnosis.

They have no idea where it will lead. Nor does Lang. There are policy issues: How to fund research into rare diseases. How to persuade insurance companies to pay for testing. Who controls whatever the researchers discover. How the cost of therapy can be contained so a New Plymouth tugboat operator or a Northampton bus driver can afford them.

Lang the lobbyist thinks about all that. Lang the father, like any father, just thinks about doing whatever it takes for his child.

Dan Morain: 916-321-1907, @DanielMorain