

Does Your Child Have Jordan's Syndrome?

by Steven Moore in Healthcare Jul 10, 2018



The odds are stacked dramatically in your favor that your child does not have Jordan's Syndrome. The exception to that is if you have a child with unexplained developmental disabilities. And if your child has unexplained developmental disabilities, you would like her to be diagnosed with Jordan's Syndrome. Because that would put Joe Lang on your list.

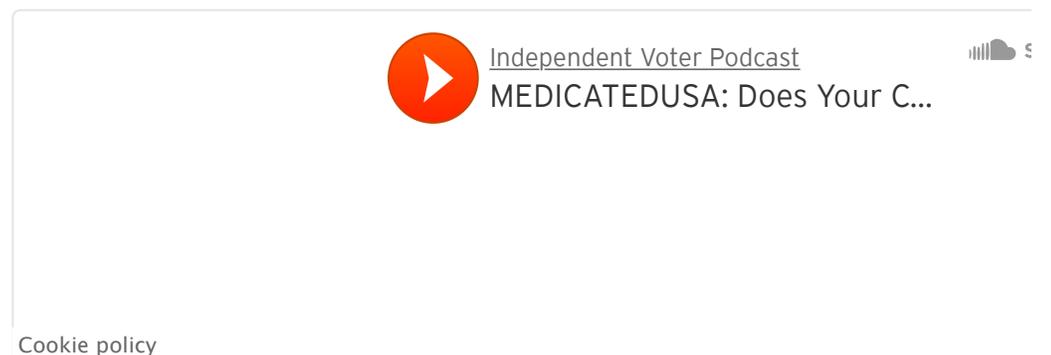
A Determined Father

Joe Lang has the “Father of the Year” award nailed down. He probably has little credible competition for Lifetime Achievement Award for a Father.

Joe and his wife, Cynthia, went through the first 9 years of their daughter Jordan's life seeing her miss developmental milestones. She didn't crawl like other kids. She walked at five. At twelve she didn't talk. And Joe and his wife did not know the reason why.

Their daughter was a SWAN – Syndrome Without a Name. It's not that your daughter is unique in the universe in her suffering and knowing why is a painful place for a parent to be.

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Joe, a well-respected and successful lobbyist in Sacramento spent his nights poring through medical journals, trying to discern scientific papers, reaching out to researchers. He probably was smart enough to gain a master's degree in rare diseases.

But all his study availed little. He and Cynthia still didn't know what caused their daughter to lag so far behind developmentally.

A conversation with their Sacramento neurosurgeon, Dr. Shashank Asaikar, convinced Joe and Cynthia to try one of the few things the family had not tried up until that point – mapping Jordan's genome.

Genome mapping is simple as a blood test, but genome mapping is rarely a first option. The cost of processing the sample is many times more than a blood test – as much as \$25,000. Insurers frequently classify genome mapping as “experimental, and they may not cover the procedure.

And the genetic mapping was a stab in the dark.

Jordan's Syndrome Has a Name

But it worked. The map of Jordan's genome revealed the source of her difficulties. The roughly 3 billion gene base pairs in the human body are represented by letters of the alphabet. Jordan has a mutation in one gene, PPP2R5D.

By typo, I mean a totally random mutation. This was not caused by a chemical leak, exposure to radiation or taking an insufficient medication.

There is no villain. This was an act of nature.

This information directed Jordan's life from nine years of uncertainty and wondering to a rocket ride to a cure.

Joe began reaching out to doctors and researchers with this information about the mutation. He began finding other families whose children had the same genetic variation and whose determination was similar to his own.

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— *Steven Moore, IVN Health Editor*

Two of the most important contacts I made at that time were Carol Bakhos and Nancy DeOrta. Carol, who lives in Phoenix, and Nancy, a Colorado resident, had found each other through a Facebook page for PPP2R52 families. The page was then and remains an important organizing tool for the growing group of families in search of answers about their children.

For many families, the Facebook page became the first sense of community they had experienced with their child.

Researchers chose seven children for an initial study, largely they couldn't find many more than seven children. This was completely new condition that nobody had ever studied. Jo patient number four.

Doctor Wendy Chung, a prominent genetic researcher from Columbia University, published a paper in 2015 that showed common link among these seven children, the mutation in F As a result, the paper moved the children out of the SWAN The syndrome now had a name – Jordan's Syndrome.

Progress to a Cure Moving at Light Speed

Since the initial study, more than sixty children have been di with Jordan's Syndrome in 19 countries. Chung estimates th many as a quarter-million children around the world could b Jordan's genetic mutation, many misdiagnosed as Autism or developmental diseases.

Most importantly, Chung's study revealed the reason that yo like your developmentally disabled child to be diagnosed wi Jordan's Syndrome – the science says the PPP2R5D mutatio

reversed. That gene sequence also plays a role in both cancer and Alzheimer's disease. By understanding this one gene, medicine can make great strides against diseases that are prolific killers.

“With the determination of the families, Joe’s relentless efforts and some good old-fashioned luck, Jordan’s Syndrome is sprinting from being a SWAN to being a memory, like polio.”

— *Steven Moore, IVN Health Editor*

Chung and her international team of researchers estimate that \$20 million in research can get them to the human stage, a comparatively small amount in this field.

I asked Joe if he had taken advantage of the programs created for rare diseases by the 21st Century Cures legislation signed into law in 2016. Joe says that the science is moving so quickly, his team doesn't have time to get involved with the National Institute

of Health (NIH). That being said, he hopes to engage more who can help to begin clinical trials.

More broadly, Joe has been the catalyst behind much of this success. Money. Organizing the families. Getting media attention. If not for a concerned, highly motivated father... then who creates the momentum for a SWAN to be identified, let alone cured?

Despite Joe's efforts, and the efforts of the other families a

hard work of the research team, more research needs to be
You can help children like Jordan through Jordan's Guardian
And despite the success, they still need your help.

With the determination of the families, Joe's relentless effort
some good old-fashioned luck, Jordan's Syndrome is sprinting
being a SWAN to being a memory, like polio.

Check out the podcast to hear Joe's gripping story first hand

About the Author

Steven Moore

Steven Moore lived through the Obamacare debate as a chief of staff to a member of the House Ways and Means Committee and as a House leadership staffer. In addition to his work on Capitol Hill, he has professional experience in about a dozen countries. Moore also holds a graduate degree in international business.