

RARE REVOLUTION

MAGAZINE

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David Jacob of ThinkGenetic



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Having achieved his dreams of becoming a Navy pilot and a professional bowler, it was personal circumstances that led David Jacob down a new path into the world of RARE, founding ThinkGenetic, which has become a true family affair

CEO Series: meeting the beating hearts behind the RARE brands

1. What made you want to move into the wide world of rare disease, and then specifically ThinkGenetic and what did that journey look like?

The journey to [ThinkGenetic](#) and into the world of rare disease started for me at birth. My sister and I were both born with congenital heart defects that required open heart surgery as children. That was a big clue that our family journey had begun, but after recovering from the surgery, my parents didn't mention it much and we just went on with our lives. That all changed when I turned 60 and had a severe case of pneumonia. As part of the diagnosis and monitoring, I had a chest x-ray and it incidentally found that I had a very large ascending aortic aneurysm. I asked my sister to

have an echocardiogram and it was discovered she had the same aneurysm.

By then, my eldest daughter had become a certified genetic counsellor. She recognised that the time had come for us to figure out the genetic basis of our health issues. She helped connect me with experts in connective tissue conditions related to heart defects and worked our way through several levels of genetic testing and analysis. After three long years, a lot of blood, and two analyses of my exome, we worked to narrow that down to a diagnosis: Cutis Laxa – an ultra-rare genetic condition.

After spending so many years wondering what it all meant and finally getting an answer, it was a little frustrating to find that there was very limited information for patients available on the condition. Something needed to change! I decided that my mission was to help people living with or at risk to have a rare genetic condition have good access to accurate, patient-directed information to empower them and help reduce their time to finding a diagnosis and treatment. I knew that the solution was digital and by working with my long-term IT business partner, Len Barker, and my genetic-focused daughter, we created ThinkGenetic with a goal of doing just that.

2.

What do you anticipate will be the biggest challenges and opportunities for your organisation in the next two years?

Our goal is to provide curated information on all 7,000+ known genetic conditions with appropriate next steps for diagnosis and treatment. We recently closed a \$1.5 million seed round which has allowed us to cover 250 key conditions. We are starting a \$5 million series A round which will allow us to meet this goal. As we add clients and patients, we want to scale ThinkGenetic worldwide to help undiagnosed patients discover genetic possibilities and next steps to shorten their diagnosis odyssey. We are currently receiving requests and activity from over 190 countries. Covering all genetic conditions and raising awareness on the internet to help undiagnosed patients will be our biggest challenge.

3.

What is your proudest moment in your career thus far?

I am fortunate to have lived a full life with an exciting career path that began with being a Navy pilot and then moved through the corporate world into my own company specialising in the development of individualised IT solutions in the rapidly changing world of IT. However, my proudest moments have been forming ThinkGenetic with my children to help others and as a family develop this very needed resource for people living with rare genetic conditions.

4.

What and who are your personal and professional inspirations and why?

Treating others the way I would like to be treated has always been at the top of my list of inspiration and it still drives many aspects of my career. On a professional level, I learned how best to harness my competitive nature from my parents, how to treat others from my commanding officer at the Navy Test Pilot school, and in my business career from my 18-year association with Ross Perot at Electronic Data Systems (EDS).

5.

What advice would you give someone considering working in the rare disease space?

Many people are thrust into the rare disease space without getting to choose. If you are fortunate enough to choose entry, my advice is to listen to the patients, parents, and caregivers who have been there all along. You need their support to make a business work as much as they

need yours to help raise awareness, learn about the conditions, and development therapies. Business in the rare disease space is a long-term commitment if you want to succeed; it's not just about a special day of awareness or raising that first million dollars. It needs to be a passion to help the 280 million people worldwide who struggle each day to find treatments, funding and ongoing support.



6.

Do you think the government does enough for the rare disease community at a local and central level, and what gaps do you see currently or emerging?

In the US, healthcare, in general, is a for-profit business and leaves huge gaps in coverage for too many. I hope we can take the example of other progressive countries and make healthcare a right, not a privilege. I do admire the many groups like NORD, Genetic Alliance, and Global Genes, who continue to advocate on the Hill for rare patients to ensure there is access to expensive treatments. There have been some amazing milestones like the Orphan Drug Act and I hope to see continued support from our government.

Dawn and David at the NORD awards

7.

What would you say are some of the biggest motivators for your employees?

ThinkGenetic was founded by a unique combination of family and close friends whose members have personally seen the impact of living with a rare condition. We are all passionate about improving the time to diagnosis and treatment. Each team member, whether full-time staff, contractor, intern or volunteer has chosen to work in the rare disease space deliberately and work in education and advocacy space, even if it means long hours and low to no pay in some cases. Our mission is our biggest motivator because our successes have an impact well beyond a typical P&L [profit and loss] statement.

8.

What are the toughest parts of being a CEO, and conversely what are the most rewarding?

As a CEO sometimes you have to make decisions that make sense to the overall company and board but are tough to execute. Deciding someone is not a good fit for a company when you've seen them invest blood, sweat and tears remains the most difficult part of the job. Sometimes you just wish the funding was never-ending and the personnel match was perfect – but that is not how business works. In addition, as someone working with family as well, I do my best to make sure every employee feels the connection to the business as we grow and becomes part of the ThinkGenetic family. I do have a unique situation because, in addition to the other team members, I do work directly with my incredible children who all have strengths and expertise in different areas. This means some days you're a respected executive listening to important feedback and delegating key tasks, some days you're getting kicked under the table for using the "wrong" wording, and some days you're giving the 15-minute investment pitch. No matter the hat though, you're always the dad. Keeping that separation between personal and professional is important but it does mean we discuss strategy over Christmas dinner.



9.

What would be your one wish for ThinkGenetic for the year ahead?

Like many start-ups we have too much to do and not enough time or funding. My wish is that the ThinkGenetic team continues to feel and see the positive impact of what we have accomplished and will accomplish in the rare disease space to change the world.

10.

If you weren't CEO of Think Genetic what was Plan B? What did your 10-year-old-self want to do as a job?

I'm way past Plan B. My 10-year-old self-wanted to be a professional bowler and astronaut. I did become a professional bowler and a Navy pilot so it was a good start.

Once I was married and had a family, I gravitated to computer science and a career in this field – EDS, Data General, Davalen and finally ThinkGenetic. Over the past two decades I have been volunteering and advocating more in the rare disease and non-profit space. For example, I was a board member for

Christopher's Haven and Home Away Boston for many years until it was acquired by The Ronald McDonald House. If I wasn't involved in ThinkGenetic, I think I would utilize my unique talents as a business owner and person living with a rare genetic disease to expand my role in rare disease space foundations and charities.

To find out more about the work of ThinkGenetic please visit

www.thinkgenetic.com