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# Uncertain of the future, three ALS patients spearhead a new fund

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It was only last summer, while on a kite surfing holiday, Garmt van Soest observed that his right hand was unusually weak. He also noticed that his speech was gradually becoming slower. “You wouldn’t know it now but I was really the fastest speaker in the office,” he says, enunciating deliberately. The changes motivated him to see his doctor. “I was really lucky,” says van Soest, a senior manager in Accenture Strategy based in Amsterdam. “I was diagnosed with ALS [amyotrophic lateral sclerosis] in six weeks. For most patients, the process takes a year.”

Since his diagnosis in August of 2013, van Soest has been using his management consulting background to strategize how best to contribute to the ALS community. He soon met two fellow ALS patients and entrepreneurs, Robbert Jan Stuit and Bernard Muller. On 19 May the three launched an ALS-specific investment fund, called Qurit Alliance. Qurit Alliance aims to raise €100 million Euros ($139 million) to then invest into ALS-focused private biotechnology companies and institutions to kick start projects of drug discovery and smarter design drug trials to find ALS treatments.

“This is one of the novel, innovative ventures that wants to make sure orphan disease clinical pipelines do not dry up as the pharma model and venture investment shifts to later stage opportunities,” says Steve Perrin, CEO of the Massachusetts-based ALS Therapy Development Institute.

“Crisis breeds creativity,” notes Melissa Stevens, deputy executive director at FasterCures, a nonprofit think tank based in Washington, DC. “There has been a lot of monetary pressure on the research community with NIH’s purchasing power down by 25% in the last decade and US venture capital funding down by 21% from 2007 to 2013.”

**Connections for speed**

Although Stuit, Muller, and van Soest do not have a biotechnology background, they do know how to bring experts together. In 2012, Stuit and Muller started a Netherlands-based biotechnology company, Treeway, focused on ALS drug development—the company’s first in-human trial is slated to start by year’s end.

“What we see in the world of biotech, is that start ups really struggle to re-invent the wheel and find capital,” says van Soest. There is a lot of wasted money on duplicated efforts, inefficient processes, and a lack of data sharing in orphan disease research, according to the three founders.

To address these issues and partly mitigate investment risk, Qurit is bringing together prominent ALS researchers from around the world to vet and steer research, biotech company partnerships, and experienced managers to run the fund as part of a focused center of excellence. Operating with a sense of personal and professional urgency, the goal for the fund is to put the investment into action by January 2015. The team, along with Leonard van den Berg, director of the Netherlands ALS Center in Utrecht, Netherlands, is also helping to set up an institution called TRICALS that will include a website platform to lessen the time it takes to execute clinical trials by connecting patients with ALS treatment centers and companies working on drug for the disease.

Similar endeavors focused on specific orphan diseases have also cropped up in recent years. Cydan Development, the first drug accelerator for rare disease, and Kurma Biofund II, the first venture capital fund focused mainly on these illnesses, both launched last year. Other efforts have had a personal motivation like Qurit: Ilan Ganot, a former hedge fund manager, left his job in October 2012 when his two-year old son was diagnosed with Duchenne muscular dystrophy. Since then, he has raised $17 million and in January 2014 started Solid Ventures, a biotechnology company focused solely on acquiring, licensing or partnering on select early stage compounds for the fatal genetic disease—and provide an investment return for investors. John Crowley, who has two children with Pome disease, started new Jersey-based Amicus Therapeutics, focused on lysosomal storage diseases.

Diagnosed in June 2010 and May 2011, respectively, both Muller and Stuit also call themselves lucky. Their disease has progressed slowly relative to others with the affliction. “When you are diagnosed with ALS today it’s basically a delayed death sentence,” says Stuit. “We are claiming ALS can and will be fixed. The only question is when. And we intend to speed up that process dramatically.”

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