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When Technology IS the Cure

As my profile here suggests, you can sometimes catch me on the social media website known as [Quora](#). The premise is simple enough. People ask questions – which are then categorized by hundreds if not thousands of topics – and anyone with an account can submit an answer. Recently, I was answering a question under the healthcare topic when my Quora notification tab indicated a message. That's how I first met Eric Valor (pronounced \vuh-lore\).



Eric Valor Scuba Diving in the Virgin Islands - 2006

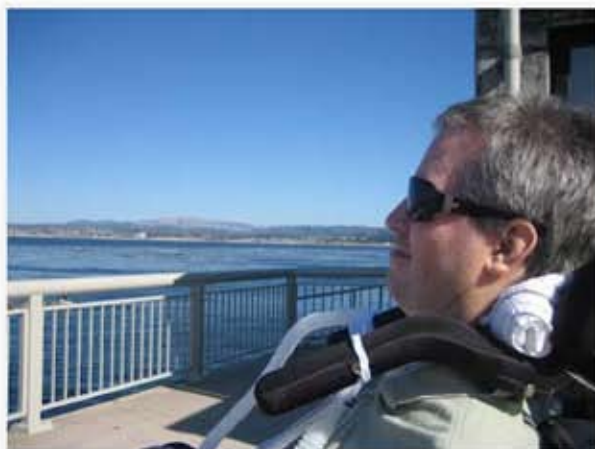
His story is both an inspirational and cautionary one in our genetic lottery of life. The cautionary aspect is simply the fact that we don't often know which illness will strike us – or when. In the strangest possible twist of fate – at the exact moment when one's personal, professional and physical life are often at their peak – Eric noticed a problem with his left foot. As with many physical ailments it also affected his lifelong passion – surfing. At takeoff his foot would drag which in turn created awkward positioning – and then falls.

After several failed attempts with orthopedic solutions that didn't work he was referred to a neurologist. That led to exhaustive testing – and then the final diagnosis – ALS. For those who have not heard of ALS, also known as Lou Gehrig's disease, a pretty good summary description is this one:

“ *Amyotrophic Lateral Sclerosis (ALS) is a neurodegenerative condition that results in the nervous system slowly losing its ability to carry brain signals to the body's muscular system. Without those signals, a person with ALS (pALS) slowly loses the ability to control voluntary movement of their body, typically over a period of 3 to 5 years. In its later stages, pALS are completely paralyzed and unable to speak, swallow, or breathe on their own. Without technological intervention, ALS is fatal with most affected people dying of respiratory compromise and pneumonia. Sensory nervous systems are generally spared as is the autonomic nervous system that controls involuntary muscles such as the heart and digestive system. In rare cases, ALS is accompanied by dementia but usually, pALS remain cognizant and are fully able to feel, smell, see, and hear everything. The movement of the eyes is the only voluntary movement that is usually spared. Only 5% of pALS have a genetically inherited form of ALS, or familial ALS. The other 95% who develop the condition for no known reason are known as having sporadic ALS. [Courtesy of the ALS Residence Initiative]*

Here in the U.S., there are about 20,000 to 30,000 people with ALS and about 5,600 new cases are diagnosed each year. As with all orphan diseases (basically those with a population of less than 200,000) clinical research has been slow – and there is only one FDA approved drug called [Riluzole](#) (approved in 1995). While there has been no real advance in treatment over the last 17 years – [Knopp Biosciences](#) and [Biogen Idec](#) have recently partnered to develop [dexpramipexole](#) – which has demonstrated some early, positive indications in clinical trials – mostly around slowing the progression of ALS. Dexpramipexole received orphan drug status from the FDA in October 2007 and a “fast track” designation in September 2009. Another drug – NP-001 – developed by drug startup [Neuraltus](#) also received both FDA orphan status and “fast track” approval last year. The orphan drug status does provide some financial incentives for the development of drugs specifically for rare diseases.

Eric was diagnosed with ALS early in 2005. He had just turned 36. From 2005 to 2007 – he was able to maintain a relatively normal work life in the IT group at Daimler in Palo Alto but the march of ALS is relentless, fairly rapid and then ultimately difficult to conceal. In 2007 the cottage by the beach in Santa Cruz where both he and his wife liked to surf had to be replaced by a more functional house inland with no stairs. Since then ALS has followed its typical progression and Eric is now on a ventilator with almost no range of movement or motion.



Eric at Monterey Bay

Undaunted, Eric has followed his technical training and passion which has included hacking the software and hardware components of his life – as well as the experimental drugs he and other pALS have researched through the vast array of pharmaceutical filings and clinical publications. The NP-001 drug by Neuraltus, for example, is thought to include sodium chlorite. As a commercially available substance, its experimental use by ALS patients (including Eric) was recently highlighted by [ABC News](#), the [Wall Street Journal](#) and is also referenced by [Wikipedia](#).



Eric at home in Santa Cruz

Eric is very active on most of the social media sites and also [maintains a blog](#) where he writes and advocates on behalf of all pALS. Among his more current and passionate projects is the one to raise awareness and support of the [ALS Residence Initiative](#) ([Facebook link](#)) which is a new design concept of residential living for people with long term care needs – including ALS. The first ALS project – the [Steve Sailing ALS Residence](#) is in Chelsea, Massachusetts and was built by the [Chelsea Jewish Foundation](#) as part of the 10 Residence [Leonard Florence Center for Living](#). Its visionary CEO, Barry Berman, decided to include an ALS resident as a part of the overall project after a chance encounter with pALS Steve Sailing. The Grand Opening last year included a ribbon cutting by Massachusetts Governor Deval Patrick, his entire cabinet and a personal message from astrophysicist [Stephen Hawking](#)(arguably the world's most recognizable pALS).



Chelsea Jewish Foundation CEO Barry Berman and Steve Sailing

One key component of Steve's condo-like residence is a technically advanced automation solution called [PEAC](#) which was built by Santa Barbara based [Promixis](#). PEAC allows total environmental control of any electrical device specifically designed for the disabled. The stand-alone system can be accessed and operated by any wireless device with a web browser including laptops, tablet computers and/or smartphones (internet access is not a requirement). At the core of the technical design is a highly customized and flexible interface that can be controlled with a wide variety of inputs – including easy navigation with nothing more than eye movement. Promixis has experimented with capturing brain waves as the next logical extension – but the CEO, Ron Bessems, admits the sensors and technology aren't quite ready for commercial application.

“ *Independence is a basic, fundamental human need. PEAC lets us return some of the things we all take for granted – lights, TV's, fans, blinds – even doors and elevators – to those with very limited mobility*” – Ron Bessems, CEO of Promixis

Incorporating complex design, user interface, device and electronic requirements, the resulting solution is what enables pALS to live within residences like the Leonard Florence Center with as much independence as possible. Given their expertise around industrial, commercial and home automation, Promixis was specifically chosen by Steve for this innovative project. Some of the larger companies Steve contacted either weren't ready – or interested. One major feature of PEAC is that it can be retrofitted into existing facilities – including residential homes – without the need for remodeling or reconstruction. As the banner headline on the ALSRI website proclaims – “*Until medicine proves otherwise, technology IS the cure.*”

In Eric's case – and countless others – innovation isn't always about high-profile, venture backed start-ups. Quite often it's a sequence of people and events – like the ones above – that turn the traditional story of healthcare innovation into an extraordinary one.

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