

I have been prompted to finally share my story, by Paul France from England, as he is younger than me, just. Ha ha. (Thanks Paul)

I was born in 1962 and had never imagined anything was wrong with me, but looking back, whilst around 15 years of age was dropped from the local soccer team, as I was told I was “unfit”. Naturally, I was the next Maradona, but could not complete more than around an hours play before having to go off the field.

Kennedy’s also explains why my elder brother always beat me at tennis, golf, snooker, cricket, monopoly and chess etc etc. (Dickhead)

My uncle (my mother’s brother) and my roll model and hero, Dennis Grover had always had trouble walking and talking. He was diagnosed with MND in the late 80’s but was still alive some 3 years later. Doctors finally diagnosed KDA, and I had a call from my local Doctor in Tully, Far North Queensland, in 1993 explaining she had received a request from Concord Hospital in Sydney for a sample of my blood. This was collected and sent to Sydney and then onto the USA for testing.

Some two months later I was told to attend Concord hospital with my Brother as soon as possible to receive our results.

We were taken into a room with four specialists across a table. My elder brother was clear, but I had tested positive to Kennedy’s. Was told there was no cure, I would be in a wheelchair within 5 years and that my wife should terminate any female pregnancies. We were then thanked for coming in, and the specialists all left.

I continually thank God that my wife and I had already had two daughters before I was told this news.

Heading home with no information, and at that stage no internet, the only info I could find was that I was bound for a wheel chair and my sexual function would soon cease.

The thought of losing my ability to have sex was for some reason paramount in my mind, so I undertook to have as much sex as I could with anyone I could.

As you can imagine, this didn’t go down to well with my wife, so the divorce and subsequent mental breakdown occurred over the next few years.

Having always worked in Insurance and banking, the majority of my day was spent hand writing or filling in forms. This became too excruciating for my hands in around 2001 and I was subsequently sacked from my job as a Bank Manger for Suncorp Bank in Brisbane.

I had seen my Uncle continue to work and deteriorate very quickly so decided to basically “retire” in 2001.

I have been very lucky on two fronts:

Firstly my ex-wife agreed I could return to the family home as a boarder, and secondly, the Australian Government has a generous benefit scheme for the disabled.

The internet arrived in Australia soon after, and I could finally access information on Kennedy's, without spending hours in a library.

The KDA website was an absolute lifesaver for me, and discussions I had at various times with Terry Waite, Bruce Gaughran, and others in the KDA chat room have kept me going when I thought all was lost.

I consider myself very lucky. I have two gorgeous daughters, an ex wife who will always take care of me, and I am still able to walk, even if it is only 100 metres at a time. The cramping of the legs is a constant struggle, my arms don't operate above shoulder level, the dry drowning is occurring now every few weeks, and I am having problems chewing more than half a toasted sandwich at a time.

But if you look at other genetic diseases like SMA, we have it pretty good.

Funny thing but there are periods where I want to know as much as possible about Kennedy's and then months or even years where I don't even want to think about it.

My eldest daughter has just become pregnant for the first time. Whilst I have always been very open and honest with her about KDA, I found I could not advise her in relation to the pregnancy and basically broke down.

This is the terrible position KDA places on us. We know we are eventually done for, but what if there is a simple tablet that can be taken in say 20 years to cure KDA?

What do we tell our children? I gave my daughter all the info I had, whilst trying to stay very neutral on what she and her partner should do. I have never had my daughter's tested as carriers, as it could in the future affect employment, insurability etc.

Again I find myself thanking God, as she and her partner are now looking forward to a birth in January 2019.

Wow, I am going to be a grandfather!!!!!! Life is wonderful.

I guess that's all, I do still smoke, which helps amazingly with the hand tremors, and drink a bottle of wine every night which if nothing else relaxes the muscles and reduces over night cramping. Ha, not recommending either, but hey, you only live once.

Would love to thank the love of my life, (and ex-wife) Jennifer, my two gorgeous daughters, Erica and Bridget, and my elder brother Bill. These people are the only reason I am here today and will be so for as long as I can fight "effing" Kennedy's!

If you are touched by this story, or any others on this sight, I would encourage you to make a donation to the KDA. They are fighting for a cure, maybe not for us, but certainly for our babies, and their babies. Take care all, and keep upright! Haha.

Mosie Moseremous (Chris Thwaites)