



GRAVES' DISEASE & THYROID FOUNDATION

*Educate * Encourage * Empower*

P.O. Box 2793 • Rancho Santa Fe, CA 92067 • (877) 643-3123 • www.gdatf.org • info@ngdf.org

Graves' Disease – A Man's Perspective

by Jake George

The doctor said, "I think you have Graves' disease, and I think you have had it for a while." My mind thought back. Where had I heard of that disease before? I remembered an aunt of mine who had Graves' disease. Her eyes bugged out like she was being choked and she had the disposition of a rattlesnake! I also remembered I had other female relatives who have had Graves'. I knew it affected men, as well as women, because President Bush was diagnosed with Graves' about the same time.

Let me back up a little, prior to the point where the doctor told me I had a thyroid disease. Looking back on the years before I was diagnosed with Graves', a lot of things started to fall into place. The doctor told me I had the disease coming on for around three years before it was diagnosed. They say stress or a virus can start the chain of events in motion that can bring on Graves' disease. Three years prior to my diagnosis, I had moved to

Melbourne, Florida from Milwaukee, Wisconsin.

My new job was totally different from anything I had done before and the position I filled had been vacant for almost a year. I was given ninety days to get everything into shape. I had to find a place to live, get my son in school, go out of town to mandatory schooling for my job and go out of town to the contractor's facility for orientation. I am a strong type "A" personality but, it was almost too much to handle. I had to travel in my job and I noticed flying was becoming very painful to me. My eyes would hurt when we came in for landings, and they would get very dry. The discomfort, while not unbearable, made driving around strange cities with a headache behind my eyes very difficult.

Being a typical "type A" male, I kept telling myself, "walk it off." When I was young, I would get hit by a pitch in baseball and it hurt like mad and tears would well

up in my eyes. The coach would pat me on the back and say, "walk it off", like it was somehow going to make the pain go away. It didn't work when I was a child and it didn't work for the pain in my eyes. But, men are taught to be tough, suck it up, walk it off, ignore the pain and dig deep down into your reserves and somehow find the strength to carry on!!! *That* is what a real man does. Gentlemen, we have been fed a line of bull that would stretch from the Chicago stock yards to Honduras.

I would go to my family doctor after these trips, tell him my eyes hurt, and I was getting pain behind my eyes that wouldn't stop. The doctor said it was a chronic eye infection and prescribed a steroid eye drop to give me some relief. I also started to notice that I would lose my temper very easily, which I never did before. I would go through bouts of depression. I would avoid areas where there were bright lights. My family started to wonder what was

wrong with me. I have to admit living with me was becoming very hard for my family. Luckily, I have a wife who stood by her vow of “in sickness and in health.” She would tell me that she worried about me and had enough of the sickness part, let’s get back to the healthy part. I started to lose weight (thirty pounds in two months) and still did not know what was wrong with me. This, after eating two to three plates of dinner and two or three boxes or bags of snacks in the evening.

I was a Naval reservist and had to go in for a routine physical. The ship’s corpsman noticed my resting heart beat was one hundred and ten beats per minute. He sent me over to the Naval hospital for an EKG and to be evaluated by a doctor. A corpsman took my EKG and asked me if I was feeling OK. I said sure, no problems! I was told to rest ten minutes and they would do another EKG. Ten minutes later, they came back and found me asleep on the table. Talk about resting! They did the EKG again and my heart rate was one hundred and twenty beats a minute. Next thing I know, I am on a table in the ER, stripped down to my skivvies with doctors shining lights in my eyes and poking every conceivable part of my body. The doctor wanted to

admit me into intensive care because he thought I was on my way to a thyroid storm and I could get very sick, very fast. The man got my attention. I told him there was no way they were going to put me into the hospital (doing my male thing again). I explained to the doctor that I was a reservist and if he put me into the hospital, they would have to put me on active duty. The doctor listened to my concern about being in the hospital and said “Mister, money doesn’t matter if you’re dead.” Once again he got my attention.

The hospital ran a bunch of tests. The doctor came back and asked me if I had any old pictures of myself. I had my drivers license, civil service ID and a family portrait that were all taken about two years apart. The doctor put them side by side and was able to show me when the disease started to show up. The difference between one picture and the next was very dramatic! One picture was as I used to look and the next was some bug eyed guy with a big neck. The doctor said the disease had been coming on for about three years, and he did not think I was in danger of going into thyroid storm. He said he wasn’t going to admit me, but he would save me a whole lot of money by running all the tests and sending them to my

doctor at home. I spent the rest of the day learning new medical terms and life, as I knew it, changed from that day forward.

I was sent home and told to contact my family doctor and tell him what they found at the Navy hospital and that the test results would be sent to him. I was started on a course of PTU and followed by my family doctor for almost a year. People react to Graves’ in different ways. Some don’t want to know anything about it, hoping it will go away. Some want to know everything they can get their hands on, to know what to expect in the course of the disease. I fell into the latter category. I read up on PTU and its side effects and asked my doctor how long he planned to keep me on PTU. He said I was doing well on it and he planned to keep me on it forever. It was time to find a new doctor!

I found an internist who took my insurance, and he told me quite a bit about Graves’. There is very little written outside of medical journals that I was able to find in the city where I lived. I did not know about the support groups that existed around the country and thought I was alone in my disease. The information my new doctor provided was absorbed by me like water into a sponge. I was scheduled for

a thyroid uptake test and after the test the doctors discussed options with me. I was given the options of surgical removal of the thyroid or radioactive iodine. I did have a fair amount of proptosis (my eyes were bugging out and I had one looking for birds while the other was not) by this time and was told there was a small chance my eyes would get worse after the radiation treatment. I opted for the radiation over the surgery.

The radiation worked and I was put on synthetic replacement hormone. My internist had a hard time regulating my dosage. He referred me to an endocrinologist in Orlando, sixty miles away. While we were going through adjusting the dosage, trying to find what was best for me, the effects of the disease began to take their toll. Each change in dosage affected different muscle groups in my body. Fatigue, depression and muscle spasms became part of my daily life. One side effect of Graves' that I found particularly troubling was the loss of my short term memory. My memory was increasingly becoming a problem over the course of the past few years, and changes in my medicine seem to make it worse. Simple things like paying bills, keeping a checking account,

writing reports or giving presentations took massive effort on my part. I would forget the names of people I knew for years. I have since found out that memory loss is a side effect of Graves' for some people.

The change in medicine also had its effect on my family. I would lose my temper for no reason and then I would get mad at myself for getting mad, and it would make me madder still. The muscle spasms made sleeping with me difficult because I would twitch like a fish out of water all night long. My libido was almost nonexistent and insomnia was a problem.

I ended up being among those people whose eyes get worse after the radiation treatments. My eye problems continued to get worse. I was a very lucky man that my local eye doctor knew my eye problems had progressed to the point where he could not work on them. I say I was lucky because he knew there was a specialist who did nothing but work on Graves' patients and people with eye cancer. He sent me there for treatment. I have talked to a number of Graves' patients who have dry eyes and other problems. It is amazing the number of them who were told by their eye doctor or their family doctor that there is nothing that can be done to help them.

I have undergone twelve surgeries over a two year period. I am glad to say I look like my old self prior to Graves' disease. I had the surgeries performed at Bascom Palmer Eye Hospital. I had three surgeries to correct double vision, two grafts to my lower lids, and a 3-wall orbital decompression - - to allow more room for my eyes to recede into the socket. I also had surgery on the muscle that controls my upper eyelids so they would come down and cover my eyes better. Talk about "Reconstructive: surgery! All these major surgeries, plus the minor surgical adjustments, have been for the purpose of correcting double vision and allowing the eye to be closed, both of which are caused by the extreme swelling and scarring of the eye muscles. The double vision that remains is corrected by prisms ground into my prescription glasses.

I want men (and women) to know this disease does not have to run the way you live your life. You cannot control its effects on you, but you can do some things to make life better. I have had the disease now for seven years and life during those seven years has been very hard on me and my family. I just recently started a Graves' disease support group in my area.

Talking with other Graves' patients and information provided by the National Graves' Disease Foundation has also helped. I have started stress management counseling with my family to help us all try to reduce the stress in our lives.

The greatest help of all was starting to take other medicines to help with the symptoms of Graves' disease. I mentioned the depression I had been going through for seven years. Sometimes I would just sit there and tears would run down my face for no apparent reason. My doctor has started me on a low dose of an anti-depressant as well as a low dose of tranquilizer to control the tremors in my hands and leg muscles. After being on the medication for two months, I felt that I had returned to my old self again. I went through seven years of hard times and put my family through more than most families have to endure. The sad part of this is, I didn't have to go through any of this at all if I had not tried to do the "guy thing and walk it off."

I have discovered it's OK to talk about how you are feeling, and it is OK to ask for help in coping with Graves' disease. Graves' is considered a chronic disease and it can be managed. I want

other men to know there is a light at the end of the tunnel and it's not a freight train heading at you. A number of men think that asking for help is a sign of weakness. I was one of them. My wife had been asking me to go for help for years to help manage the disease, but my male mentality and pride just wouldn't allow it. I do wish I had listened to her years ago. It is much easier to manage your disease than to let it manage you.

I have had to change my lifestyle somewhat due to Graves' and all the surgeries, but it has not kept me down. I have learned to use memory joggers and keep a journal to remind me of dates and names. I still go camping and can swim in pools and lakes. My family and I took a five week camping trip last summer and visited fifteen states in twenty-eight days. My Boy Scout troop and I did a thirty mile canoe and camping trip. Life goes on and it is good.

Used with permission of the author.

Jake George is a facilitator for the GDATF Bulletin Board and on-line support group on the Internet.

© Copyright Graves' Disease & Thyroid Foundation. All rights reserved.