



## **Atrial Fibrillation & the Boiled Frog Syndrome**

**By Peter Stent**

My odyssey with atrial fibrillation (AF) began in 1982 when I experienced my first episode. Rather than present a detailed chronology of the progression of the disease over the following 22 years, I think that it would be more illustrative to use an analogy. You have all probably heard of the Boiled Frog Syndrome. In 1982 the pot of room temperature water was on the stove and I jumped in. As the years progressed there was very little heat turned on until the early 1990s when my episodes of AF increased from one or two a year to eight or ten.

Up to this point I would always return to sinus rhythm (SR) within 12 to 24 hours with no intervention. I did visit the local emergency room once or twice when the onset seemed particularly uncomfortable and scary. My doctor recommended a complete heart evaluation to determine if there was any underlying heart disease. Luckily, all the heart tests were normal. However, like the frog I began to feel the heat being turned up and the water began to warm, but I still did not fully grasp the insidious nature of this progressing disease.

Cardiac health and fitness have always been an important part of my life. Ever since I was in high school, I have been an active runner, hiker, cyclist and physically a very hard worker. With the increasing frequency, intensity and duration of my AF episodes, I began to realize that my daily workouts were being interrupted and my conditioning was suffering. I decided to try more aggressively to find some answers.

Living near Stanford University made it easy for me to be evaluated by some of the most respected cardiologists in the country. By the mid-1990s the heat on the AF pot was being turned up more and more, but I was totally unable to jump out. The doctors tried me on the entire array of Antiarrhythmic drugs. None worked particularly well and most had fairly debilitating side effects. I hated taking drugs but I had reached the point where I was becoming desperate to find a solution. At this point my diagnosis was pretty well confirmed. I had vagally induced paroxysmal AF. My primary cardiologist described my condition as "idiopathic" AF. That is a fancy word for AF of unknown origin.

Visits to the emergency room resulted in the standard protocol of confirming AF via an EKG (they certainly did not need to do this because I knew only too well when I was in AF), analyzing blood to see if I had a heart attack, a little nitro and digoxin (described in the AF Report to be contraindicated) to demonstrate that they were taking action, the initiation of a blood thinning protocol and a suggestion to see my Cardiologist as soon as possible. So, I would go back to the Cardiologist and by then I would have converted back to SR.

By the late 1990s I was having four to six episodes per month. They would last 12 to 36 hours and the only drug that seemed to help was propafenone (Rythmol), but the side effects of blurred vision, dizziness, and an overall general malaise were almost intolerable. Again, my doctor tried me on different drugs and I remember particularly well one incident when I switched to Betapace AF (sotalol). I was in Hawaii on vacation with some friends and went into AF, so I started on the Betapace. This drug exacerbated the symptoms and prolonged the episode for 8 days. I finally got off the drug and converted to SR two days later.

Disgusted and discouraged I sought out more help. I went to the "top" cardio electrophysiologist at Stanford. He did a complete workup. His conclusion and I quote him exactly: "Yes, you have Afib. It is going to get worse and there is NOTHING you can do about it". If murder were legal, there would have been one less electrophysiologist on the Stanford faculty. I was devastated, discouraged and very pissed off. I simply would not accept that answer and meanwhile the heat in the stove was being further increased and the water temperature in the pot was rising significantly.

I scoured the country for answers. A friend had some connections at the Texas Heart Institute. They did a complete workup, but in the end they had no solution. Then, I went to the Scripps Institute in La Jolla to one of the leading researchers on the electrophysiology of the heart. Another complete workup showed once again that I had no underlying heart disease or functional problem. Their advice was to keep my heart as healthy as possible via a low fat diet, antioxidant supplementation, and avoid possible triggers such as alcohol, caffeine etc. and to take the Rythmol on demand as needed. The trouble was that I had been doing this already.

Like many of you, I devoured the literature looking for answers. I subscribed to the Cleveland Clinic and Harvard Heart Letters. I spent hours searching the web. I tried supplements and avoided any and all triggers that I could find in the literature.

By 2001 I was having two to three episodes per week. Each episode would last anywhere from six to eighteen hours and I would have the usual post episode fatigue and I would barely recover before the next onset. My biggest fear was that I had the sense that my heart might be remodeling to the point where AF was the going to be the norm and SR the exception.

About this time two things changed my outlook. I began seeing a Doctor C who believed that my AF might be partially the result of a Post Viral Syndrome which, via a low level, persistent inflammation, was affecting the electrical conduction cells in my heart. He started me on a protocol of very high doses of Vitamin C in a liposomal form and the injection of growth factors to help stimulate the regeneration of the damaged cells in my heart. While this protocol did not stop my AF, it did keep me from going into persistent or permanent AF and helped me cope much more effectively with the episodes. Doctor C's caring, diligence and willingness to think outside the box gave me great hope and regained for me the will to not give into this insidious disease.

The second thing that changed my outlook was my introduction to The AFIB Report. I am very indebted to Hans Larsen for showing me that I was not alone, that there is hope, that there are numerous paths to explore and more coming along everyday and, most important, that I must take charge of my own health care. The traditional medical community knows very little about AF other than being able to diagnose it. Since in most cases it is not immediately life threatening, there does not seem to be any sense of urgency to find a solution even though it is well known that the risk of stroke increases for people in Afib.

However, for those of us who have experienced years of Afib, I think it would be safe to say that we feel a tremendous sense of urgency. In my particular case the quality of my physical life was diminishing rapidly. My social life was affected because I knew that every 2 or 3 days I would go into Afib and in Afib I preferred reclusion to social interaction. The same could be said for my family life. And, of course, work is always more difficult when in Afib.

In late 2003 I felt like a parboiled frog and yet I could not jump out of the pot. I had tolerated the increase in the temperature of the AF pot, but could not really see a way out. Then a scientist friend of my sent me a research paper describing some clinical results using Cryoablation (versus RF Ablation) for the treatment of Afib (the full citation, along with others, is listed at the end of this article). The etiology of my AF seemed to fit that of those patients who had been successfully treated by the Cryoablation. The company, CryoCor, Inc. that created the technology used in the procedure is located in San Diego, CA. (Please note that I have no personal affiliation with the Company, nor am I related to anyone at the Company or have any financial involvement).

In November 2003 Doctor C and I visited the company to learn more about their technology and to evaluate the possibility for this procedure to help me. We came away very encouraged by the personnel, the technology and the results that were being obtained by the clinical team in Maastricht in The Netherlands. Doctor C and I did a considerable amount of additional research and concluded that it would be worthwhile to have my particular case evaluated by the team in Holland and CryoCor to see if I might possibly be a viable candidate for the procedure. All my previous medical records were sent to CryoCor and they requested some additional tests. Their conclusion was that my etiology was typical of the patients who had been successfully treated.

So, on March 17, 2004 I was in Maastricht for a Pulmonary Vein Isolation procedure using Cryoablation. The ablation is delivered from a 10Fr catheter that achieves tip temperatures as low as -95C. Liquid nitrous oxide is boiled in the tip of the catheter to achieve this level of cooling. The cooling causes the heart cells to break open and loose their function; hence they are unable to conduct electrical impulses that started my episodes of AF. The catheter is delivered to the heart similar to RF ablation catheters, namely inserted through the groin and advanced across the intraatrial septum to the orifice of the pulmonary veins, where they drain from the lungs into the left atrium. My procedure was performed with what is known as a "lasso" guided segmental isolation where the doctors looked for electrical activation in my pulmonary veins with the lasso and then froze around the circumference of the vein orifice until there was no activity in these veins. I was put on Coumadin for three weeks prior to going to Maastricht and went off it two days before the actual procedure.

While it is well known that RF ablation of the pulmonary veins can cause serious stenosis or narrowing, Cryoablation leaves intact the matrix that surrounds the heart cells and this is believed to minimize the risk of narrowing. Over 100 patients with AF that were treated with Cryoablation received CAT scans before and one year after their Cryoablations. None of these patients showed any narrowing at all. Therefore, in Medical Centers outside the US where Cryoablations are being performed, there is no post procedure monitoring of the pulmonary veins because it is widely accepted that the risk of narrowing is low or absent.

I chose to go to Maastricht because the procedure is commercial in Europe (in the U.S. it is undergoing an IDE Multicenter Clinical Trial) and the doctors there had performed more of this particular procedure than anyone in the world and they helped develop the technique. The procedure lasted about 5 hours during which time I was awake listening and talking to the doctors. All the work was done with catheters inserted in the groin. About 60 sites in my pulmonary veins were evaluated and around 20 sites were actually ablated. After the procedure I spent the night in the hospital and then saw the doctors before being released. The following day I returned to California.

The post procedure requirements included being on Coumadin for three months, continued use of Rythmol at 150 mgs 2x/day for two months and no strenuous physical workouts for three weeks. In the first month after the procedure I had two relatively minor episodes of 4-6 hours duration.

Since April 21<sup>st</sup> I have had NO Atrial Fib. In fact, I have not even had a single PAC. As I am writing this I have been Afib free for over 5 months. That is the longest consecutive Afib free period in over 12 years. I am off of all drugs. I can work out everyday and feel like I did 15 years ago. I am told that, based upon clinical experience, once a patient goes 5 to 6 months Afib free, it is very unlikely that I will have any

further episodes. Whether I do or not, these past five months alone have been worth the journey. My hope is that others may find similar good fortune. I do not know if I am totally cured, nor what the future may hold, but every Afib free day is a blessing and I'll take them one at a time.

Unlike the sad ending for the Boiling Frog, with the help of Cryoablation, some luck and The Almighty, this is one Frog who jumped out of the boiling water and is now back down to room temperature.

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