THE AFIB REPORT
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My Battle With and Success Over Afib

By Charles L. Miller

I am a 66-year-old male, retired US Air Force Heavy Jet Tanker/Transport pilot, with a long history of afib, and currently living in Cincinnati, Ohio. My afib doesn't make me unique; there are over 2 million afib sufferers today, in the US alone. Though many don't suffer any discomforting symptoms and have a relatively low frequency of episodes, there are a substantial number of us that are "symptomatic" and very aware of our afib. This is my story.

After several years of acid reflux (a possible warning sign), I had my first afib episode 14 years ago (June, 1991) under conditions of extreme psychological work stress as a mid-level executive, program manager in the aerospace industry. An Emergency Room visit was able to convert me back to sinus rhythm with intravenous (IV) drugs over a period of about 8 hours. This episode was followed a few weeks later by what appeared to be a flu-like viral infection resembling the worst case of flu one could imagine (aching joints, fever, cough, night sweats, continuous headache, back aches, etc.). This illness lasted unabated for 9 weeks. My family doctor tried numerous medications and treatments without success and ultimately diagnosed the problem as possible viral pericarditis (heart lining inflammation).

I went for another year without any heart medications until I had my second isolated episode. This was triggered by an improper drug prescription (Hytrin), which was prescribed by an urologist to treat BPH (prostate enlargement), at an initial dosage level contrary to the manufacturer's warning/recommendation. The first application of this drug (designed for hypertension) caused me to pass out and I awoke in afib. Again I was converted at the ER with IV medications, this time taking over 15 hours.

I remained arrhythmia free, without medication, after that for 5 years (until 1997) when the arrhythmia episodes began again in very short duration (less than an hour) and in frequencies many days apart; they converted spontaneously and were of a mostly vagal nature. Gradually the episodes got longer and the interval between them became shorter. I was aware from the www.afibbers.org website that atrial fibrillation was not a heart condition, but was a neurological problem in the electrical system that controlled the heart pulses, so I opted to make initial contact with an electrophysiologist (EP). He took my history, made no tests (except an EKG which showed a normal sinus rhythm, at that point in time), and prescribed several drugs, including antiarrhythmics, beta-blockers, and digoxin. These had no positive effect, as the episodes got progressively worse. By March of 1999, my afib had worsened to the point that it had become permanent (chronic). Meanwhile, I had changed to a different EP who merely changed the variety and dosage of medications as he unsuccessfully tried to treat the symptoms without determining any possible cause(s). Neither EP suggested or attempted to use electro-cardioversion.

By this time, the ongoing afib had caused my first episode of congestive heart failure (CHF) symptoms (shortness of breath, cough, and swelling ankles), with my EP seemingly remaining uninterested and unconcerned. My family doctor diagnosed a fluid build up in my lungs with an X-ray and started me on a temporary regimen of Lasix (a diuretic) to purge the fluid build-up. After this experience, at the suggestion of my family practitioner, I changed cardiologists again, and the new doctor was quite upset that no one had attempted to electro-cardiovert my afib early on. He scheduled me for the procedure after stopping all medications in May '99. This attempt proved unsuccessful.

I remained in continuous afib, and was referred to another EP, 120 miles away in Indianapolis, Indiana, who assured me that he could successfully cardiovert me. The second attempt was scheduled for July 1999. This new EP hospitalized me for 3 days while he loaded my system up on Tambocor (flecainide), digoxin and beta-blockers. The attempted electro-cardioversion was again unsuccessful and I had to remain in hospital for two additional days while they attempted to bring my heart rate and blood pressure under control. I left the hospital on medications substantially elevated from those used prior to the attempt, but still in continuous afib. Up to this point I had been prescribed virtually every one of the popular anti-arrhythmic and/or heart drugs currently in use and all without any apparent affect other than a variety of undesirable side affects. These included Quinaglute, Toprol-XL, digoxin, sotalol (BetaPace), flecainide (Tambocor), propafenone (Rythmol), Cardizem-CD, Lopressor, and Altace, all in individual and in multiple combinations and various dosage levels incurring a variety of combinations of the side-affects known for each.

After being in continuous afib for over 15 months, and suffering a worsening quality of life including occasional CHF symptoms, in desperation I made contact via email and finally went to the Cleveland Clinic some 250 miles away. They recommended immediate attempt at cardioversion, again by hospitalization and loading up my system with appropriate drugs prior to the cardioversion. After three days of high-level loading again with Tambocor (to a level nearly 50% higher than the previous cardio-version attempt) and other drugs, I spontaneously converted just mere hours before the electro-shock was to take place – having been in continuous afib for exactly 17 months (since Aug. 2000). When I was discharged, I was on a very elevated Tambocor dosage along with BetaPace, digoxin and beta-blockers, but was suffering from headaches and BP in the 160/100 range. The Tambocor at the high levels (525 mg/day) completely scrambled my brain, affecting hand-eye coordination, balance and cognitive functions.

After five days the afib returned, slowly at first and then once again increasing. At this point I self-discontinued the digoxin and the afib stopped within 27 hours of my last dose. When I told the Cleveland Clinic EP that I had quit the digoxin, he just agreed that, "this was probably a good idea and was an old drug and essentially not indicated for afib". (I wondered why was I paying a doctor for care and advice?). Eventually I reduced my daily level of Tambocor from 525 mg/day to 300 mg/day. This largely alleviated the severe side affects, that I had been experiencing, to a tolerable level. However, the afib once again started up on an intermittent basis.

In Feb 2002, I began to suffer from angina induced by walking my dog outside in the frigid sub-zero wind chill. After 5 increasing attacks over four weeks, I went to the ER. An angiogram was performed and I was scheduled for an immediate dual bypass graft. My afib abated somewhat after the bypass surgery, but again began to increase. I remained on the Tambocor at 300 mg/day. By mid summer 2002 I was again in near-continuous afib.

By Nov 2002, I was suffering from over 30 health issues that were all traceable directly to published Tambocor side affects. At this point I had been on this drug since 1999 and it was no longer controlling the afib. Upon presentation of this list to my family doctor he agreed to phase me off of the Tambocor and substitute amiodarone, a highly toxic and dangerous anti-arrhythmic drug; a "medication of last resort".

I related the shortness of breath to the Tambocor toxicity and tried to offset this as a temporary initiative by taking hyperbaric treatments, making hyperbaric chamber "dives" to 2 atmospheres for an hour every other day. This helped somewhat, but had no lasting benefit. On Dec 26, 2002, I went to the ER to obtain a supplemental oxygen prescription. They diagnosed CHF and admitted me for IV treatments to purge the retained fluids and reduce heart

rate and blood pressure. While still heavily under the effects of Tambocor toxicity, which I had just fully eliminated in the previous 24 hours, and while still full of fluids, the "holiday assigned" resident junior cardiologist ordered an echocardiogram. With the retained fluid, high heart rate and residual effects of the Tambocor, my ejection fraction was reported as 15% (norm is 50 to 60%) and the resident wanted me to take an immediate angiogram with a preliminary diagnosis of stenosis of my bypass graphs, or possibly the need for additional bypass grafts. I refused on the basis that according to my family doctor, if this had been my typical ejection fraction, I would have needed a pacemaker long before now. Also I had taken a cardiolite stress test (treadmill plus nuclear trace dye) a mere two months previously, which had shown normal circulation in the heart. I insisted on obtaining a second opinion before undergoing what I believed to be an unwarranted angiogram. Changing cardiologists, once more, I was again diagnosed with elevated heart rate and B/P, and he focused on bringing these numbers into the normal range by medication. Once this was achieved, a follow-up echocardiogram was taken in April 2002 which showed a "remarkable" recovery of ejection fraction to 40% (confirming my earlier suspicion that the first echo was not representative due to the circumstances). Though the rate control technique reduced my symptoms, I was still plagued with significant quality of life issues (depression, fatigue, malaise, anxiety, insomnia, lost libido, a feeling of being much older, etc.) and increasing episodes of congestive heart failure.

In the meantime, the University of Cincinnati, and Dr. Randall Wolf were making breakthrough technology on a capability to perform the "maze procedure" using micro-surgery and an endo-scopic device, rather than as an open-chest procedure. Called the **"mini-maze",** this procedure is performed by making a 3 to 4 inch incision on the side between the ribs, high in the rib cage, with a smaller incision several ribs below for the endo-scope, which is used to observe the surgical field.

Through my current cardiologist, I received a referral to see Dr. Wolf for an evaluation to see if I might be a candidate for this newly developed procedure. Initially he was reluctant to consider me as a candidate due to the prior bypass surgery (which could cause potential difficulties due to related scar tissue), and the length of history I had with afib (recognizing that this was still a new and developing technique). However, I was able to prevail on him to take on my case with some added latitude that would permit him to abort the procedure, with my advance agreement, if it proved questionable.

The procedure was performed and the results were better than anticipated. During accomplishment of the mini-maze procedure, Dr. Wolf discovered that an adhesion had taken place during my Feb. 2002 dual bypass surgery, which had fused the top of my right lung to my heart. This adhesion had caused unexplained substantial muscle pain and spasms on a near 24/7 basis for nearly three years following the bypass surgery and had triggered and aggravated my arrhythmia. He was able to separate and cauterize this adhesion. He also removed the left atrium appendage (cause of 90+% of heart related blood clots that trigger strokes). He found that one of the bypass grafts had formed an adhesion to the appendage and he had to separate that adhesion very carefully before the appendage could be removed. He also conducted NPT (neurological path testing) on the nerve bundles in the heart and found several nerves that were hyperactive (a probable source of the afib extra pulses). He surgically desensitized or neutralized these.

I awoke from the surgery in wonderful sinus rhythm and have remained continuously in sinus rhythm, ever since. The recuperation period lasted about ten weeks with gradual reduction of the soreness and restrictions from the surgery. Recovery to a nearly pain-free state took approximately 5 months (unique in my case due to the added scope of surgery to clear scar tissue from the prior surgery).

A follow-up exam was done two weeks after the surgery, and again at six weeks. Dr. Wolf kept me on my pre-surgery medications so that any changes that occurred were attributable only to the surgery. At the six-week follow-up, Dr. Wolf terminated my amiodarone antiarrhythmic medication with no negative affects. At nine weeks after the surgery, a follow-up echocardiogram was performed to see what the impact was on my ejection fraction and mitral regurgitation. The results were very positive showing a noticeable reduction in the size of the left atrium, a

substantial reduction in the mitral regurgitation to "trace" levels, and an improvement in the ejection fraction (up from the pre-surgery reading of 40% to near normal range of 46%). At twelve weeks (dictated by being off amiodarone for six weeks), I was monitored on a 24/7 basis by a portable CardioNet device for a period of two weeks to assess if there are any remaining episodes of arrhythmia. This verified a stable sinus rhythm with absolutely zero abnormal beats. At this point my Coumadin medication was next eliminated. Subsequently, my energy levels and routine have returned to normal levels. The symptoms of CHF have disappeared. And I am no longer on the Lasix medication.

I must add a personal observation. At the outset of my atrial fibrillation in 1997, I was acutely aware anytime my heart went into or came out of afib. It even would wake me up from a sound sleep; it was so conspicuous. During one pre-bypass period of 17 months, I was in continuous afib. After the bypass, I was again in persistent and near-continuous afib for more than a year, but I had either become acclimatized to it, or there was less of a transition since I didn't perceive the afib initiation as much. For the past 10 to 14 months, I had once again been in continuous afib. My post mini-maze surgery with its total return to sinus rhythm gave rise to a surprising and delightful psychological effect. The long-term continuous afib had subconsciously created a sense of anxiety, depression, and malaise — things weren't right in my physical condition, and there was little motivation to pursue new long-term goals, adventures, or even any desire to travel far from home. After the surgery, I awoke in strong sinus rhythm and euphoria that "all was well with the world" and I now have motivation, energy, and a bright outlook on life (even though I just turned 66 two days before the surgery). My health continues to improve as the various bodily organs resume to full oxygen circulation that was deprived by the chronic afib. I now walk two plus miles every day when the weather is not wet, and can do so without becoming winded or strained. I have begun a course of physical exercise to limber and strengthen muscles left weak from the fatigue caused by the afib.

Dr. Wolf is now traveling all over the US and a half dozen international sites (including Canada) teaching his new mini-maze procedure. In the US, Medicare and most major medical insurance policies have certified this procedure for coverage. I highly recommend this advanced surgical procedure to anyone afflicted by major, uncontrolled afib problems. Not only will it successfully improve your quality of life, it may also save you from congestive heart failure.

Dr. Randall Wolf can be contacted, as follows:
Univ. of Cincinnati
Director, Center for Surgical Innovation
231 Albert B. Sabin Way
PO Box 670558
Cincinnati, OH 45267-0558

(513) 558-0914

Postscript – January 2006

I am happy to report that I remain afib-free for the entire period approaching 15 months since my Wolf mini-maze procedure.

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