THE AFIB REPORT

Your Premier Information Resource for Lone Atrial Fibrillation!

NUMBER 25

JANUARY 2003

3rd YEAR



Welcome to our 3rd year of publication. When I first began publishing "The AFIB Report" two years ago I was naïve enough to think that it would be a relatively short-term project. Unfortunately, this has not turned out to be the case.

Although a few afibbers have been able to banish their condition through natural means and many more have done so via a successful ablation, the majority of us are still struggling. The Bulletin Board has been a great help to many and has enabled us to all learn about Erling Waller's magnesium/bicarbonate water, the dangers of digoxin, and the viability of the "on demand" approach to terminating episodes. Drinking "Waller Water" on a regular basis,

avoiding triggers, and instituting dietary changes has proven helpful to many afibbers, as has discontinuing drugs that clearly make their condition worse. Nevertheless, much remains to be done.

In this issue we discuss the results of the ablation survey that attracted 42 responses from afibbers who had undergone ablation therapy. As expected, the overall success rate, according to the survey, of 46% is much lower than that quoted by centers of excellence such as the Cleveland Clinic. The reason for this is two-fold – the technology is improving by leaps and bounds, but not all cardiologists and electrophysiologists have the experience and skills required to achieve a high rate of success. Our survey found the pulmonary vein isolation procedure to have a success rate of 47 to 71% depending on the definition of success. Stenosis, in certain types of procedures, does, however, continue to pose a problem.

Also in this issue is the first installment of my own afib journey. I hope you will find it interesting. And please, don't forget to get your copy of my new book "Lone Atrial Fibrillation: Towards A Cure". It is available at www.afibbers.org/lafbook.htm.

Wishing you health, happiness, and lots of sinus rhythm in the New Year, Hans Larsen

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The Ablation Survey

The survey attracted 42 responses from afibbers who had undergone focal point ablation, pulmonary vein isolation, or a combination of both. The overall success rate was 46%, but varied widely depending on the type of procedure and the type of afib (adrenergic, mixed, vagal or permanent).

Demographics

The majority (48%) of respondents had the mixed variety of LAF prior to their ablation. 38% had vagal LAF, 2% had adrenergic, and the remaining 12% had permanent LAF. These percentages are somewhat different from the percentages among

our full database of 236 afibbers. Here 30% have the mixed form, 42% the vagal, 11% the adrenergic, and 17% the permanent form of LAF. The most striking difference is the low percentage of adrenergic afibbers who reported having an ablation. Is this coincidence, or is there some underlying reason why adrenergic afibbers are not considered good candidates for ablation?

The average age of the respondents was 55 years (52 for adrenergic and mixed, 54 for vagal, and 55 for permanent). The average age at diagnosis was 46 years (47 for adrenergic, 43 for mixed, 47 for vagal, and 53 for permanent). Thus the average number of years that the respondents had experienced LAF was 9 years with paroxysmal afibbers averaging 8 years and permanent afibbers averaging 11 years. These numbers are not significantly different from the averages obtained by considering all the entries in our main database, so there is no reason to believe that the respondents to the ablation survey were either younger or older than the general population of afibbers.

76% of respondents were male (71% adrenergic or mixed, 69% vagal, and 80% permanent). This again, is not significantly different from the gender distribution within our entire database.

Effectiveness by Procedure

A. Focal Point Ablation

Focal point ablation is the original method for ablating the inside of the atrium so as to isolate or destroy the areas of the heart tissue producing the ectopic beats that initiate an afib episode. The procedure begins with an electrophysiology study (EPS), a test designed to map the electrical activity of the heart during fibrillation. Small tubes (catheters) are inserted into the veins in the groin, arms or neck, or under the collarbone, and then directed into the heart. Once the measuring electrodes are in place fibrillation is induced (if not already present), and the electrophysiologist is then able to pinpoint the areas where the rogue (ectopic) beats originate. These areas are often found at the junction between the left atrium and the pulmonary veins. The study is performed under mild sedation, but can still be somewhat uncomfortable and can last from 1 to 3 hours. At the end of it the electrophysiologist may report nothing to ablate if they have not located any foci of rogue cells, or they may go directly to the next step and ablate the active area(s).

Radiofrequency (RF) ablation utilizes radio frequency energy to heat the tip of a special catheter inserted through one of the tubes used in the EPS. The cardiologist or electrophysiologist places the catheter next to the area initiating the fibrillation and then "zaps" this area. This produces a scar, which destroys the offending area or prevents impulses originating in it from going anywhere. The ablation procedure is generally fairly painless and lasts 4 hours or less.

Nineteen afibbers reported that they had undergone focal point ablation. The average age of this group was 52 years (range of 36-70) with age at diagnosis being 42 years (range of 23-55). The average number of months since the ablation was 25 with a range of 5 to 67 months. There were 10 mixed, 5 vagal, and 4 permanent afibbers in the group. Most of the 19 respondents had had only one ablation, but one had undergone 3 and three had undergone 2 focal point ablations.

Success rate

The success of the ablation procedure can be expressed in three ways:

- A subjective impression by the afibber;
- The total absence of afib episodes;
- No episodes and no medication required.

The overall success rate of the focal point ablations according to these 3 criteria was:

Subjective impression: 21% No episodes: 24% No episodes – no medication: 16% The results may be somewhat biased by the fact that the series included 4 ablations done on permanent afibbers. Only 1 of these was successful. Considering only paroxysmal afibbers the success rate is:

Subjective impression: 23% No episodes: 20% No episodes – no medication: 13%

Not much better! The possibility that procedures done 3 or 4 years ago might bring down the average was also considered. Taking just the 11 procedures done within the last 2 years, the success rate is:

Subjective impression: 27% No episodes: 36% No episodes – no medication: 27%

So, the conclusion from this survey of 19 afibbers who have undergone focal point ablation is that the success rate is poor – only about 25%.

The 4 successful procedures were done by Dr. Andrea Natale at the Cleveland Clinic, Dr. Chun Hwang at the Utah Valley Regional Medical Center, Dr. Robert Bock at the Presbyterian Hospital, and Dr. Ron Berger at the Johns Hopkins University Electrophysiology Service.

Stenosis (narrowing of the opening of the pulmonary veins) is usually not a problem with focal point ablation. Only one of the 19 afibbers was checked for stenosis and did not have any signs of it. 68% of the group remained on antiarrhythmics or beta-blockers after the procedure and 32% continued on warfarin. Those of the respondents whose ablations were unsuccessful did not see an improvement in their frequency or duration of episodes.

B. Pulmonary Vein Isolation

This procedure involves the creation of a ring of scar tissue in the left superior, left inferior and right superior pulmonary veins. Electrophysiological studies have shown that these 3 veins are the most likely sources of the ectopic beats that generate AF. By isolating them from the left atrium via the scar tissue AF is prevented. Some cardiologists now also isolate the right inferior vein. Pulmonary vein isolation is much less effective for permanent AF indicating that the offending foci are located in the atrium rather than in the pulmonary veins themselves[1]. Of particular interest to afibbers contemplating ablation is the fact the researchers have found no correlation between left atrial size and the success of the procedure[1].

Stenosis can be a problem with the pulmonary vein isolation procedure. Research is ongoing in an effort to solve this problem by using ultrasound or laser technology rather than the standard radiofrequency electrode. Cryosurgery is also being considered.

Seventeen afibbers reported that they had undergone pulmonary vein isolation. The average age of this group was 55 years (range of 37-71) with age at diagnosis being 49 years (range of 36-67). The average number of months since the ablation was 10 with a range of 2 to 33 months. This is a significant difference from the focal point ablation group and reflects the fact that pulmonary vein isolation is a more recent procedure. There was 1 adrenergic, 6 mixed, 9 vagal, and 1 permanent afibber in the group. Most of the 17 respondents had undergone only one ablation, but 4 had undergone the procedure twice.

Success rate

The overall success rate of the procedure was:

Subjective impression: 71% No episodes: 59% No episodes – no medications: 47% Thus it is clear that the pulmonary vein isolation procedure tends to be more successful than the focal point ablation. However, part of this improved success rate would appear to be connected with the continued use of drugs after the ablation.

Six of the successful procedures were performed by Dr. Andrea Natale at the Cleveland Clinic (100% success rate). Other successful procedures were done by Dr. Steve Furniss at the Freeman Road Hospital in Newcastle upon Tyne in the UK and Dr. P. Chang-Sing at the Santa Rosa Memorial Hospital in California. The remainder of the successful procedures involved continued drug use.

47% of the pulmonary vein isolation group remained on antiarrhythmics or beta-blockers after the procedure and 44% continued on warfarin.

Those of the respondents whose ablations were unsuccessful did not see an improvement in their frequency or duration of episodes.

Stenosis

Fifteen of the 17 respondents had gone longer than 3 months since their ablation and therefore should have been checked for pulmonary vein stenosis via a special CT scan. Only 6 or 43% of them had actually been checked and 50% of those checked showed signs of stenosis.

Serious stenosis, i.e. greater than 50% narrowing, is treated much the same way as blocked arteries. The pulmonary vein is expanded with a balloon catheter and a large coated stent is inserted to keep the vein from closing up again (restenosis). It is likely that the development of stenosis depends on many factors, especially the skill of the surgeon performing the procedure. However, I don't believe that the possibility of stenosis should be taken lightly. Here is what one afibber had to say about his experience after undergoing an ablation:

"I had an upper body CT scan in which a radioactive dye is used to check the condition of the pulmonary veins. I was shocked and very disturbed to learn that two of the four pulmonary veins had severe stenosis as a result of the procedure. The right superior pulmonary vein has three branches, one far larger than the other two. That branch was completely closed and the doctor thought it was unlikely that it could be reopened by balloon angioplasty or a stent. The left inferior vein is 80% closed and likely to close further. One of the other two is somewhat narrowed and the last was not affected by the procedure. If all four veins close, you die! If three close you are in real trouble. So far I am not experiencing notable symptoms, but, at best, I can look forward to one or more stents, a lifetime of continued Coumadin use with a stroke risk at least as high as from AF and, of course, a lot of worry.

Would I do the procedure over if I know this would be the outcome? No, even though I have been very pleased with the relief from AF symptoms for almost six months. The risks are not worth it. Perhaps in a year or so, the problem of PV stenosis will be better understood and the ablation techniques will avoid this complication. I was told before the procedure that the chance of stenosis was less than 5%, but I think that is a great exaggeration. There is also an issue of the long-term consequences of the scarring in the areas where the ablations are done, especially when they are done up in the veins. At the very least, prospective candidates for the procedure should investigate not only the probability of complications like PV stenosis, but the seriousness of those consequences and the available therapies for dealing with them."

C. Focal Point and Pulmonary Vein Ablation

This procedure combines pulmonary vein isolation with the ablation of focal points in the left atrium.

Five afibbers had undergone the procedure. The average age of this group was 52 years (range of 47-54) with age at diagnosis being 42 years (range of 39-45). The average number of months since the ablation was 15 with a range of 5 to 24. There were 3 mixed and 2 vagal afibbers in the group. Three had had only one ablation, but one had undergone the procedure twice, and one 3 times.

Success rate

Subjective impression: 60% No episodes: 60% No episodes – no medications: 20%

The low success rate in the "no episodes – no medications" is due to the fact that 2 of the successful afibbers were kept on warfarin even though they had no episodes.

The successful procedures were done in Bordeaux by Dr. Haissaguerre, by Dr. Dwayne Coggins at Good Samaritan Hospital, and Dr. Paul Friedman at the Mayo Clinic.

Stenosis

Only 2 out of 5 (40%) had been checked for stenosis and both were found to have some degree of it.

Effectiveness by Afib Type

Twenty **mixed** afibbers had undergone ablation therapy with 53% having had focal point ablation, 32% pulmonary vein isolation, and 16% the combined procedure. One respondent did not know which procedure they had undergone. The subjective success rate for the three procedures was:

Focal point ablation: 40% Pulmonary vein isolation: 67% Combined procedure: 33%

Albeit based on a small sample group, pulmonary vein isolation would appear to be the most successful procedure for mixed afibbers. However, only 40% of them had been checked for stenosis and 67% showed some signs of it.

Sixteen <u>vagal</u> afibbers had undergone ablation with 31% having had focal point ablation, 56% pulmonary vein isolation, and 13% the combined procedure. The subjective success rate for the three procedures was:

Focal point ablation: 20% Pulmonary vein isolation: 80% Combined procedure: 100% (1 procedure only)

It appears that pulmonary vein ablation is the most successful procedure for vagal afibbers. The fact that only one person had undergone the combined procedure makes the prediction of success unreliable for this procedure.

Five **permanent** afibbers had undergone ablation with 80% having had focal point ablation and 20% having had pulmonary vein ablation. Only one procedure out of the five (a focal point ablation) was successful. This result, although based on a very small sample, confirms the belief that ablation is less successful with permanent afibbers than with paroxysmal ones.

The single <u>adrenergic</u> afibber who had undergone ablation had had the pulmonary vein isolation procedure. The procedure, done 5 months ago, was completely successful with the person having had no episodes and being off all medications.

Conclusion

Pulmonary vein isolation, either by itself or in combination with focal point ablation, would appear to have a 60% or better success rate; however, stenosis is still of concern.

New Developments in Ablation Therapy

Dr. Andrea Natale and colleagues at the Cleveland Clinic recently released a comprehensive report describing their experience with pulmonary vein ablation in 211 patients (163 men, average age of 53 years)[2]. Most of the patients (54%) had paroxysmal atrial fibrillation (AF), 16% had persistent AF, and the remaining 30% had permanent AF. Seventy-six per cent of the patients had lone atrial fibrillation.

The Cleveland researchers evaluated two different ablation procedures and three different ablation catheters (electrodes). The patients were first put into atrial fibrillation through the use of an isoproterenol infusion – assuming, of course, that they were not already fibrillating when they entered the operating room. The area around the pulmonary veins was then mapped using the circular mapping technique in order to locate the focal points from which the PACs and fibrillation originated.

The patients had originally been divided into two groups. Group 1 (21 patients) was scheduled to undergo distal isolation, that is, creation of scar tissue more than 5 mm into the pulmonary vein. The remaining 190 patients were scheduled for ostial ablation, that is, ablation right at the openings in the atrium where the pulmonary veins terminate. All ablations in group 1 were done with a quadripolar 4 mm tip. The ablations in the second group were done using 3 different tips – the quadripolar 4 mm (47 patients), an 8 mm tip (21 patients), and a cooled tip catheter (122 patients).

The researchers found the distal procedure to be relatively ineffective. Only six (29%) of the patients in group 1 experienced complete relief from PACs and AF.

The patients in the second group had their pulmonary veins completely isolated at the ostium regardless of the mapping information. The success rate was 79% for the conventional 4 mm tip, 85% for the cooled tip, and 100% for the 8 mm tip. The time on the operating table was 3 hours with the 8 mm tip, 4.6 hours with the cooled tip, and 5.5 hours with the 4 mm tip, again showing the superiority of the 8 mm tip.

The researchers confirmed that an enlarged left atrium does not affect the success rate and that the ostial isolation procedure is highly effective even for permanent afibbers (success rate at 7.5 months of follow-up – 89%).

The rate of severe stenosis was 14% in group 1, but only 1% in the second group. Other researchers have reported stenosis rates of from 3 to 42%. Only 8 out of the 211 patients had significant complications from the procedures[2].

Conclusion

It is clear that ablation technology is improving at a rapid pace and that Dr. Natale and his group are now pretty close to achieving a 95-100% success rate using the 8 mm tip catheter and ostial ablation. However, the fact that this group has achieved this kind of success does not mean that every other cardiologist or electrophysiologist will achieve the same favourable outcome. New technology takes time to become standard practice, so unless you have a surgeon with a top notch track record such as Dr. Natale perform your ablation you may be better off waiting a bit longer so as to give the new technology a better chance to become more widely accepted.

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My Afib Journey: Part I

by Hans R. Larsen

On December 18, 1989 at around 7 pm my life changed forever. It was probably a good thing that I did not, at the time, realize just how devastating this change would be.

I am a chemical engineer by profession and at the time was consulting on a very major project involving 12-hour days and a great deal of time spent in front of a computer. At 57 years of age I was in excellent health, but was under a lot of stress at this time. I had contracted a bad flu and as I sat down on my bed in preparation for an early night I coughed violently and immediately felt like my heart had exploded. It was beating wildly, totally out of control and I expected it to depart permanently via my throat at any minute. To say I was scared would be an understatement! On my doctor's advice I went to the ER at our nearby hospital and was immediately hooked up to a lot of tubes and beeping gadgets. After what seemed like an eternity, but was actually 2 to 3 hours, my heart rhythm returned to normal. I remained in hospital for 3 days during which time I went through numerous tests to check out the status of my heart.

On February 27, 1990 I received the verdict from my cardiologist. I had paroxysmal atrial fibrillation and occasional premature ventricular beats (PVCs) with a slightly enlarged left atrium (44 mm), but no underlying heart abnormalities. Left ventricular ejection fraction was 59%. My cardiologist emphasized that my condition was not in any way life-threatening and expressed no concern when I told him that I planned on going cross-country skiing the following week. I felt sure that this was a one-of-a-kind episode and continued my life much as before with excess stress, long hours at work, and lots of computer time.

On March 15, 1990 at around 2 pm I experienced my second warning, this time probably triggered by food poisoning. It was back to the hospital again where I converted after 4 hours. I now realized that I had better take these warnings seriously. Computer work, I had noticed, made me extremely stressed and markedly increased the frequency of my PVCs. So, at the age of 58, I decided to retire, at least temporarily, to see if I could get this thing under control. No longer being in the rat race certainly improved things and all went well until June 1991 when I experienced another afib episode at 6000 feet while hiking up a mountain in the wilderness. Fortunately, I was airlifted out by helicopter. By this time, I had begun to realize that certain things might trigger an episode. These included physical and emotional stress, forcing myself to do things I really did not want to do, drinking coffee or alcohol, and working on the computer.

Gradually, but inexorably, my life became more and more restricted and the list of things I could no longer do grew day by day. By 1996 my episode duration was up to 12 hours and that year I experienced 3 episodes, 2 during the day and 1 at night. The year 1997 saw 9 episodes averaging 10 hours each and 1998 culminated with 23 episodes averaging 11 hours each. By now, I had realized that I did not convert any faster in the hospital than at home so my visits to the ER ceased.

Fortunately, the intensity of my episodes had decreased very significantly over the years. I no longer felt like my heart was going to jump through my throat. For whatever consolation it may be to new afibbers, intensity lessens with time. I had also developed a routine in dealing with episodes. At the onset and end of the episode I would take an aspirin (325 mg) to help prevent blood clotting and, if my heart beat was quite rapid, I would take a regular (not time-release) verapamil tablet (80 mg) at dinner in order to ensure a good night's sleep. Other than this I would just try to continue my daily routine or rest if it seemed to make things easier. I usually cut back on my daily walks, as they would tire me.

I had refused to take antiarrhythmics for my condition even though I had been prescribed both digoxin and sotalol. I guess an "inner voice" must have told me that they probably would not do me any good. I did try the Hoffer niacin program for a year, but did not find it helpful. As I am sure many afibbers will attest to, having frequent afib episodes can make you very depressed. In October 1998 I began taking 20 mg of paroxetine (Paxil) every day. Prior to starting on paroxetine I experienced an episode every 7 to 14 days and each one lasted between 12 and 17 hours. I had an episode 10 days after starting the paroxetine, but then went 55 days

without one. The interval before the next one was 37 days, but this attack lasted 20 hours. Then it was 76 days without an attack, but when it occurred it lasted 108 hours. The next one came 40 days later and lasted 58 hours. However, it took the form of severe *bradycardia* with heart rates as low as 39 beats/minute. I later came across an article that reported 2 cases of severe bradycardia in connection with paroxetine treatment[1]. So to make a long story short, I found paroxetine very helpful in the beginning, but had to discontinue it after the bradycardia experience, which I found very scary.

Why did paroxetine work – at least for a while? I now realize that my episodes were mostly of the adrenergic kind and therefore involved an excessive release of norepinephrine (noradrenaline) in the autonomic nervous system. Work done by Dr. Jack Gorman, MD at Columbia University concluded that paroxetine might normalize heart rate variability and, in turn, help prevent panic attacks[2]. Panic attacks, in many respects, are similar to afib episodes. In any case, the paroxetine obviously did not work for me and neither did St. John's wort, which I tried over a 6-month period later in 1998.

After my bradycardia episode I began to take my condition very, very seriously and did a lot of studying to try to find a solution. My episodes now sometimes lasted 4 days and made me tired for weeks after. In July 1999 I had all my amalgam (silver) dental fillings replaced with composite fillings and underwent a perhaps less than optimum detoxification program. I later realized that I had an amalgam core under a crown and had this replaced as well. I can't honestly say that the amalgam removal made a noticeable difference in my case. Perhaps I was not as "poisoned" as I though I was. My hair analysis did not show an excessive level of mercury although my urinary excretion after provocation with DMPS was high and probably still would be if retested.

By now I had come to believe that much of my problem had a psychological origin so I embarked on a series of alternative treatments in an attempt to calm my nervous system. I tried qi gong, acupuncture, Chinese herbal medicine, regression therapy, biofeedback, Reiki, Shiatsu, Emotional Freedom Technique (EFT), homeopathy, naturopathy, magnesium infusions, and probably a few more modalities that I don't recall. All of them were quite pleasant except for perhaps the acupuncture and the foul-tasting Chinese remedies, but unfortunately, none of them had any effect whatsoever on the frequency or duration of my episodes.

I also tried the prescription drug atenolol (Tenormin), but 50 mg or even 25 mg of this beta-blocker dropped my blood pressure so precipitously and made me so tired and dragged out that I could not function. So I gave this up pretty quick. I did discover, however, that if I chewed a quarter of a tablet (12.5 mg) of atenolol and then swallowed it with water whenever I felt particularly stressed or actually felt an episode coming on I could, in many cases, abort it. It seemed to work even better if accompanied by a glass of fresh celery juice.

During the year 2000 I experienced 13 episodes averaging 24 hours in duration. Things were not improving! As the year was drawing to a close I finally resolved to dedicate myself to finding a cure or, at least, a way of managing lone atrial fibrillation. I decided to share the findings from my research in a new section of my newsletter "*International Health News*"; this is how "*The AFIB Report*" came into being.

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