



The Biopsy Bugle

Autumn 2017

**The Australian Heart
Lung Transplants
Association Inc.**

Since 1983

President's Message



Hello everyone, AHLTA had another successful AGM in December where we elected a new Committee comprised of Lisa Slater, Lyn Kerslake, Susan Woodhouse, Babak Jafari

and myself. At the first meeting of the Committee in February of this year we agreed on a workplan with a focus on membership. One of the objectives this year is to move away from a Committee as the governing body and establish a Board of Directors to focus on governance issues for the organisation. When that is in place we will be recruiting new Board members to assist us in our work. If you would like to be involved in setting the direction for AHLTA please speak to me directly about your interest.

The move to becoming a Board also provides us with an opportunity to revise our constitution so as to better reflect the current operating environment and the focus of AHLTA. This constitutional work will be undertaken during the year and the revision will be presented to the membership for ratification

at the next AGM . Also at the AGM we unfortunately accepted Kimberley Livingstone's resignation from the Committee after having been a very active member and the President for many years. Kim contributed significantly to AHLTA and her efforts has left the organisation in a better place. On behalf of the organisation, I would like to thank Kim for all she has done and wish her the best of luck in her future endeavours.

We did send out a survey in the Spring and had a good response. Please see the results contained in this Newsletter. I would like to thank all of you that replied for taking the time to provide some feedback. This is valuable to us and much appreciated.

Our annual Thanksgiving event will take place on June 3 and I do hope to see you there. More details will be provided closer to the time.

I would like to acknowledge and thank all of you who have volunteered in any way for us as without that support we would be unable to achieve our objectives. I also very much appreciate the significant contributions of my fellow Committee members . I look forward to the year ahead.

A short summary of the survey

Out of the 30 people that returned the survey, all are frequent readers of the Bugle – great news!

The majority find distance and health the main reasons to being unable to be more involved with AHLTA, despite liking to interact with other members more. The primary platform of the interaction for most of the members is through social media and the newsletter- we even had a suggestion to include a few jokes in the bugle which we will do in the future!

The good news is that most of members who responded to the survey have attended 2 or 3 events in the past. They are relatively happy with what the organisation does and think we are doing a good job. This is very heart-warming news. Some suggestions offered include:

- Posting photos of members on the website and Bugle. Here we would like to ask you to send us your photos if you would like us to post them on our Face Book page, Bugle and website.

- More information on medical procedures regarding the heart, and side-effects from the drugs. We will continue to do this in the future.

- Members in other states (namely S.A) would like to see a larger membership there.

- Priority given to the patients in AHLTA, more support given to people waiting, eg linking pre- and post-patients., and support meetings.

If you have more suggestions that will help us to better serve you, please email or call us today.



AGM and Christmas Party

On Saturday 3rd of December, once again our members, friends and family came together at PJ Ferry Hall at Allawah. The Christmas party was a good opportunity to celebrate end of another successful year with our friends and family.

The formal part of the AGM was 30 minutes and it was followed by BBQ and drink for everyone at the party. As

usual, the Christmas party was a great opportunity for many of us to meet new people, share similar stories and have some fun on a beautiful sunny day. We thank everybody who came along and helped us to make the Christmas party another unforgettable day.

We look forward to celebrating another Christmas party with you in December this year.



Story of my journey

How I became a Transplant Dad

A strange thing happened to me when I turned 40. I got married.

At the time, I was a double lung transplant who was 13 years post. I was a sporty, guitar playing Milkman (we had a family milk delivery



business for shops and hotels) Sue on the other hand, was a beautiful, studious Emergency Doctor. So how did such a mismatch occur you may ask? Okay I'll tell you (but don't tell anyone) We met online, which back then was quite embarrassing (but now very accepted) I remember on one of our early dates Sue said to me: "Your scars

fascinate me" but she had me at "I can write scripts" So, what is the one question everyone asks you when you settle into marriage?

"When are you going to have a baby?"

Having a baby to me, was always something I had put on the back burner. Finding the right partner had proven elusive and I had ended up getting married quite late. For a long time, I figured that having Cystic Fibrosis meant that it was going to be nearly impossible for me to become a father. If I was to do this, I would never

forgive myself for passing on such a horrible disease that I had fought all my life. The other thing that concerned me was the possible effects of the numerous amounts of drugs I had taken for my transplant on my unborn child. For these reasons, I was ambivalent about the decision. I was happy to commit if Sue wanted to

go down this path or I was equally happy to simply enjoy our marriage without kids.

As it turned out, Sue was really keen to have children and I knew we were going to make the best parents, so from the outset we were totally committed.

Ninety Five per cent of males with Cystic Fibrosis are born without a vas deferens. This is basically the tube that transports sperm. What this means is that although we still produce sperm, it is not ejaculated. Instead it is simply absorbed by the body. A basic examination by a fertility specialist confirmed that my vas deferens was absent.

I then had a "small" operation where I was put under a general. Small cuts were made and sperm was extracted as well as a biopsy to confirm the diagnosis. This sperm was frozen in what they call "straws" and were stored at the fertility clinic. My fears about the transplant drugs were discussed and there weren't any imminent difficulties proceeding. So far as passing on CF, Sue was not a carrier so the chances were

quite low. Nonetheless, we would perform a test on the amniotic fluid should Sue fall pregnant. This is slightly risky to the fetus but I wanted to mitigate the odds.

We had chosen an IVF clinic and Sue was then given the usual fertility drugs (which are not all that pleasant and cause a lot of bloating and discomfort) Then when she reached the appropriate time in her menstrual cycle, her eggs were harvested. How many we got was variable. Sometimes it could be 14 or 15 then overnight some would die or the quality would deteriorate. This meant that were then left with a smaller number eg. 7.

My sperm would then be defrosted and injected into the eggs. A transfer to Sue would then occur. We would then await the outcome. She would either have her period or we would be pregnant. This is where the story starts to become difficult for us. For one reason or another, we just kept missing out on becoming pregnant and to be clear, it was nothing to do with the transplant drugs

I was taking. Statistics told us that each time you did a course of IVF your chances of conceiving are about 30 per cent. The financial costs are also a bit staggering but we were able to claim some of this back.

Unfortunately, our quest to have a child/children went on for the next 4 years.

You hear of couples having a hard time when they have had 4 attempts at IVF, we had reached 8 and felt we needed to try something new. We decided to change clinics. The

new clinic was much more expensive and a whole lot more professional but Sue felt happy making the change.

The emotional and financial costs we faced were soul destroying. Poor Sue was constantly devastated often crying for days. I was left to pick up the pieces and we

both searched for reasons as to why it failed. Reasons that were simply not there.

Sue is a very determined lady and I lift my hat to her resilience. We were committed to continue and as the saying goes, it would either break us or make us stronger.



The results at the new clinic were not much better and again the years of failing started mounting and taking their toll. While I found going through a transplant hard, supporting

my wife through this horrible emotional situation was a different kind of pressure and in some ways, much more difficult. We were struggling big time but we carried on. At attempt number 16, we had hit cross roads. Our finances were stretched and Sue was really depressed. I worried about her more

this time. We were at a new level of low. I decided to take the initiative and call the IVF clinic. I told them I was worried about my wife and asked if we could see a counsellor (knowing full well Sue would never agree to this)

Surprisingly, Sue did agree to see the counsellor (she was so down) We had just completed yet another attempt at IVF and were awaiting the inevitable failure. I took a day off work and we both arrived to meet the counsellor. "You have to learn to dance in the rain" said the counsellor (think ageing hippie) I looked at Sue and she looked back at me.....yep this woman was completely and utterly clueless!

In Sue's words, it was like getting advice from a Hallmark greeting card. The only good thing we got out of it was a bloody good tension relieving laugh and letting go of a whole lot of pent up swearing. The very next day, I was at work and Sue rang me from her IVF Clinic appointment. "I think we are pregnant" I could not believe my ears.

"The counsellor is going to think she is a bloody legend!" After 17 attempts, this was the only time we had fallen. Still, the early stages of any pregnancy are a bit unstable but we got through it. In fact, we had a really healthy pregnancy. Olivia Lilah Leggett was born on Good Friday 2011. I grabbed her as she entered this world and cradled her in Sue's arms. She cried like a child with very good lungs! I cut her umbilical cord and we all breathed a sigh of relief. I rang my parents to tell them and for the first time, the emotions overcame me and I simply could not speak for a while. I was a Dad, Sue was a Mum and we were a family. It felt amazing. Olivia is a healthy vibrant red head who has brought immeasurable joy and purpose into our lives. When I took a minute to think of my donor and the odds of me getting a transplant as well as all the IVF we did - our little girl is incredibly lucky to be here and I'm sure she will go on to have a beautiful life.

A Chicago teen is looking forward to rejoining the Boy Scouts, trying out for his school's band and returning to other activities that 15-year-olds typically enjoy after undergoing a heart-lung transplant in November. Spencer Kolman, who underwent the surgery at St. Louis Children's Hospital on Nov. 29, is thrilled to no longer depend on an oxygen tank to get around, he told CNN. "After the operation, when I was able to start walking around, it almost felt completely different because it was so much easier," Kolman told CNN. "I am amazed." Four years ago, Kolman collapsed while playing hockey near his family's home. The family's pediatrician suspected asthma and prescribed him an inhaler, but his symptoms did not improve and he went for a second opinion, where he was given antibiotics for pneumonia. "That didn't really do anything either," Kolman told CNN. "Eventually, they came to the conclusion that it was pulmonary fibrosis." Kolman was diagnosed with

rhabdomyosarcoma when he was just 16 months old, and underwent a year of chemotherapy, radiation and multiple surgeries before entering remission. He continued to develop on pace with his peers, until he started experiencing shortness of breath which led to his collapse, CNN reported. Three years after his initial asthma diagnosis, doctors told his family that Kolman's pulmonary fibrosis was a result of his cancer treatment, and that his condition was so severe that it would require a heart-lung transplant. "We're from Chicago, Chicago-area," Ken Kolman, the teen's dad, told CNN. "There are no hospitals around us that do pediatric heart-lung transplants, so I was given a list of like five hospitals in the whole United States that do this sort of surgery."

Initially the Ken and Kolman's mother, Elizabeth, consulted Boston Children's Hospital, but they determined that while his heart seemed healthy, the lining of his lungs had become nearly attached to his chest

wall due to scarring and said the procedure was too high-risk, CNN reported.

The family, which includes 16-year-old brother Zach and 7-year-old sister Evangeline, headed to St. Louis Children's Hospital in September, where they were dealt a devastating blow about the condition of Kolman's heart.

"We were told the unfortunate news that his heart was worse than before and that he would need both a heart and lung transplant," Ken told CNN. "That was a complete shock to us. We thought this was it – there was no hope for our son." Surgeons at St. Louis Children's disagreed with the medical assessments conducted on Kolman elsewhere and placed him on the transplant waiting list. The initial plan was for Kolman to remain as an outpatient, but he deteriorated quickly and his condition was considered grave.

"In Spencer's case, honestly, he was at death's door," Dr. Pirooz Eghtesady, cardiothoracic surgeon-in-chief at St. Louis Children's Hospital, told CNN. Kolman was admitted to the

hospital on November 11 and placed on a ventilator shortly thereafter.

On Nov. 29, the family received a call from the hospital's transplant coordinator informing them of a match, and Kolman underwent a five-hour surgery.

"He can now have a life," Eghtesady told CNN. "The future really depends on how he does and how his body accepts or rejects the graft." Kolman was released from the hospital but has not been cleared to return to Chicago. He is still being monitored for signs of infection or potential organ rejection, but is continuing to improve on endurance.

"The other day, he just walked a mile on the treadmill," Ken told CNN. "I feel the curve coming where he's going to like pass me up and I'm going to have to huff and puff and try and keep up with him."

Source: CNN

Date: February 2017

Health NEWS

Eating fish linked to fewer heart attacks

One salmon supper a week is all it takes. But a healthy vegetarian diet is just as good for your heart.

If you're seeking heart-healthy fare to put on your plate, fish is a first-rate choice. It's a good source of lean protein, and many popular types, including salmon and tuna, are rich in omega-3 fatty acids. These fats, docosahexaenoic acid (DHA) and eicosapentaenoic acid (EPA), may help prevent blood clots, stabilize dangerous heart rhythms, and improve blood

pressure. These benefits may explain why people who eat fish a couple of times a week are less likely to have heart attacks or die from heart disease than those who avoid fish.

But the findings on taking fish oil supplements haven't been as positive as those on eating fish. In a major study published in *The New England Journal of Medicine*, people who took fish oil capsules had just as many heart attacks and strokes as those taking a look-alike capsule.

Source: Harvard Medical School

AHLTA STALL DATES IN 2017:

23 May 2017

22 August 2017

21 November 2017

Stay tuned for details on our upcoming Thanksgiving Service in June.

We are always looking for volunteers at our stalls so if you're able to spare some times on these Tuesdays, we would love to see you there.

Donation Slip

Please help support AHLTA by making a donation!

Donate now

Your donation will make a difference to AHLTA' current and future services for heart and lung patients, their families and carers. In return for your generous contribution, AHLTA will guarantee that your donation is applied to provide service to members in need.

All donations of \$2 and over are tax deductible.
CFN: 14158 ABN: 30 752 596 540.

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