About '*Beating Back AL Amyloidosis*'

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Presented in diary format, 'Beating Back AL Amyloidosis' takes the reader through the changes in Rachelle's health as Light Chain Amyloidosis gradually manifested itself through symptoms until overpowering nausea and breathlessness led her to Emergency.

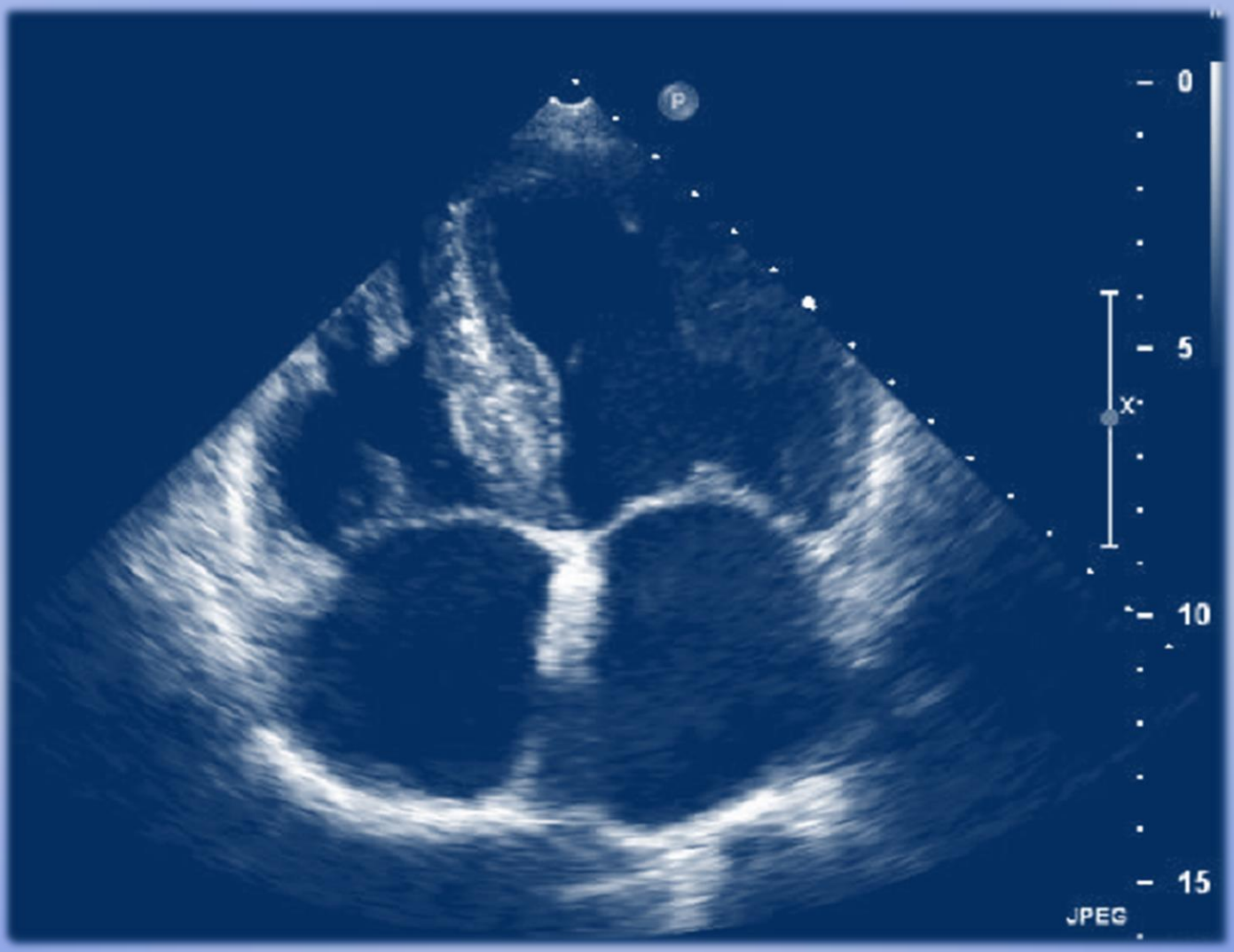
It describes the steps leading to her diagnosis, her struggle to live a regular life while taking chemotherapy and the way this insidious illness seemed to be fighting back as she was caught between damage by the amyloidosis deposits and side effects of the treatment.

Lightened with her trademark sense of humour, the book is a combination of facts and anecdotes about her journey to remission.

"I don't believe light chain amyloidosis is as rare as they say it is, but I think it is not well known. This book is my contribution to awareness and a better understanding of this condition," she says.

Below are the Table of Content and a Preview

Beating Back AL Amyloidosis



By Rachelle Labelle

December 2015

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I wish to thank the following for their information and for increasing awareness of Amyloidosis.

I am grateful for their support through the making of this book.

- *MAYO Clinic, Arizona*
- *U.S. National Library of Medicine, Maryland*
- *National Heart, Lung and Blood Institute, Health Information Center, and the U. S. National Institute of Health, Bethesda, MD*
- *Records office at the teaching hospital*
- *George, my web consultant*

This book is dedicated to my excellent hematologist, the cardiologists, my family doctor, the clinicians who administered my chemotherapy and to my current nephrologist who supplied comparative documentation illustrating improvement to my condition over a twelve month period.

Unlike my previous books, this account is very clinical. Some passages are graphic and may be unpleasant to read, but, in my opinion, the book comprises most signs that, if recognized, would lead to earlier diagnosis and better understanding of this life-threatening illness.

It is a personal narrative presented for general information only, to increase awareness of AL amyloidosis, and is not, in any way, medical or scientific advice.

TABLE OF CONTENT

THE DIAGNOSIS

Between my family doctor, the nephrologist and the rheumatologist, I don't know how they came to the decision, but the rheumatologist had the task of telling me the result of the kidney biopsy.

It was not, as we all had expected, a relapse into MPA (Microscopic Polyangiitis). It was a brand new condition called "Light Chain (AL) Amyloidosis".

What Is Light Chain Amyloidosis Anyway?

Amyloidosis is an irregularity in that part of the bone marrow where immunoglobulins are produced. Immunoglobulins are proteins, in the plasma cells of the immune system that function as antibodies. They are composed of two protein chains: light chains and heavy chains.

When the light chains are misfolded and bind together to form sticky proteins, they are called amyloids. These amyloid light chain proteins are transported through the bloodstream by blood plasma and are deposited in the organs where they stick into clumps and obstruct the organ's normal function. That is AL Amyloidosis (sometimes called Primary Amyloidosis).

According to most experts, the "A" is for Amyloidosis and "L" for Light chain. According to others, the "A" stands for Antibody and the "L" stands for Light chain. I will go with the first one.

The most common form of amyloidosis, it is considered a plasma cell disorder, because white plasma cells are the ones that secrete antibodies.

When I met the local amyloidosis expert, he explained it this way. Imagine all these little factories in the bone marrow. One day, among those, appear defective little factories producing defective little cars (amyloidosis protein). These defective little cars are released in the bloodstream where they ride around and break down in the organs, blocking each organ's traffic flow.

According to Mayo Clinic experts, Amyloidosis (am-uh-loi-DO-sis) is a rare disease. It

> *…can affect different organs in different people, and there are different types of amyloid. Amyloidosis frequently affects the heart, kidneys, liver, spleen, nervous system and digestive tract. Severe amyloidosis can lead to life-threatening organ failure.*

> *There's no cure for amyloidosis. But treatments can help you manage your symptoms and limit the production of amyloid protein.*

Source: **http://www.mayoclinic.org/diseases-conditions/amyloidosis/basics/definition/con-20024354**

The different types of Amyloidosis form three groups.

1. Primary Amyloidosis (AL),
2. Secondary Amyloidosis (AA), resulting from another inflammatory disease, and
3. Familial Amyloidosis (FAP) which is hereditary

Experts say that the cause is unknown and that it is difficult to diagnose.

With cardiac involvement, that is if there are amyloidosis deposits in the heart, it is considered progressive and fatal. In my opinion, it can "progress" slowly for a very long time as the amyloidosis survivor continues to live an active life.

It can affect any organ but the brain. When it spreads throughout the body including, as in my case, the kidneys, the heart and the gastrointestinal track, it is called "systemic amyloidosis".

Like MPA, we can go into remission. I like to think that remission can be permanent. As it was with MPA, this Systemic Light Chain Amyloidosis affected my peripheral nerves. Like MPA it is not contagious.

Some say that it is an immune system disorder because the abnormal production of immunoglobulins is triggered by plasma cells in the immune system, the proteins are not tumors and the immune system fails to destroy them before they enter the bloodstream.

Some say that it is more akin to cancer because its growth is malignant, it often accompanies blood cancer called 'multiple myeloma' and the proliferation of amyloidosis protein is fought with chemotherapy. Cancer experts say that the amyloidosis itself is not cancer.

At first, symptoms are subtle and vary with each patient, depending on the organs affected. With me, they manifested themselves over about seventeen months as I gradually became sicker and weaker until I was finally diagnosed.

Symptoms

September 17, 2012

The other day, while running for public transit, I suddenly started wheezing. I did catch the bus. Then, I sat waiting for my breath to catch up to me.

"Boy! I'm out of shape," I thought. "Then, I may just be getting old."

True, I have not been working out at fitness centres, but together, maintenance of my backyard and front yard, indoor chores, along with the race to and from full-time work do keep me going.

It's not as though I never exercise. I do a fair bit of walking and standing on public transit. Then, my work itself requires movement. I find time to go hiking on weekends.

September 28, 2012

I am scheduled for my semi-annual appointment with the rheumatologist on October 01. He is tracking me because of my history with MPA.

As per my routine, I dropped by the lab for the usual preparatory urine and blood tests. A copy of the results was sent to my family doctor.

She picked up a suspicious reading and immediately had her assistant call me in.

According to the lab report, my urine chemistry protein level, which should be below 0.15 g/L, is now at 0.3 g/L. Moreover the urine micro albumin test revealed an albumin to creatinine ratio (ACR) level of 36.9 mg/mmol when it should not exceed 2.8 mg/mmol.

It is nothing over which to panic, but my family doctor will be watching me more closely. She increased my semi-annual monitoring to quarterly visits. She is also in contact with the rheumatologist.

Since her office is near my home, I like that she has clinics on Saturday mornings. It gives my work schedule a break.

October 01, 2012

I was in to see the rheumatologist today. As soon as I arrived, I reminded his assistant of my family doctor's communication with him.

When I got in to see him, he was not too concerned. He explained that the most crucial readings for MPA relapses were the creatinine and estimated GFI numbers and these were well within the normal range.

I reported that when I sit and bend over after a meal, something knocks the wind out of me. As I spoke, I pressed my left fist against the spot where my ribs meet at the centre of my stomach area, just below the xiphoid process.

I also reported that now and again, if I run for any length of time, I wheeze.

He squinted. His mind seemed to be scanning possible explanations as he studied my file on his computer monitor. After taking a second look at the numbers my family doctor had brought to his attention, he examined me.

My blood pressure is averaging around a reasonable 132/81 mmHg but, in the interest of my kidneys, the rheumatologist prefers to see it a bit lower, so he increased my ramipril dosage from 5 mg. to 7.5 mg. Ramipril (Altace) *is what they call "ACE inhibitor". It protects against* kidney failure by keeping the blood pressure low.

He sent me off with lab requisitions for MPA and PAN (Microscopic Polyarteritis Nodosa) testing. He is arranging for lung capacity testing as well.

Meanwhile, I continue to take my synthroid (levothyroxine sodium) and Etidrocal compound.

November 26, 2012

My family doctor was wise to closely scan my routine test results. According to the November 16 lab tests, the ACR level has jumped to 62.8 mg/mmol. Below that number on the report, is the following note:

> Low creatinine may falsely elevate ACR: suggest repeat.

She called me in.

We both agreed that, given my history, a kidney biopsy was required. I have never undergone one in this country. She is referring me to a nephrologist.

January 18, 2013

My blood pressure is at 127/76 mm/Hg while on 7.5 mg. of ramipril. I think that ramipril is a good pill and I have not noticed any side-effects from it, except the mere suspicion that it contributes to my shortness of breath. It may be a coincidence but my hemoglobin count has been up since I started taking this dosage.

Meanwhile, my family doctor is pushing to move me up the waiting list for a nephrologist.