



As the great grandniece of Julian Tenison-Woods, Pam Tobin was born with a pioneering spirit and a constitution that kept her going even though illness surfaced. Her ancestry showed a long trail of mystery maladies which shared symptoms throughout generations and across siblings. Pam through tracing her medical ancestral history found reports of unusual tumours and inflammatory, infective illnesses that she too shared.

Tenison-Woods, founded the sisters of St Joseph alongside St. Mary MacKillop. His life of service ended at the young age of 56 years succumbing to an illness that stole his energy and immobilised first his hands to the point of not being able to write, and then his body. Pam's life of service was that of a nurse and as a wife and mother. She travelled with her husband Norm (pictured above) and family to many different Airforce bases in Australia and also in other countries. This is the life of an Airforce family.

Pam throughout childhood had experienced a number of illness oddities and upon retrospection Pam presented a childhood picture of constant infections with almost daily episodes of waking with eyes covered in a thick film. Pam recounts that "My brother and I used to feel our way to the laundry in the morning to bathe our eyes so we could open them.

"We didn't realise that this was an abnormal occurrence nor did we ever get told it was conjunctivitis. We just thought everyone did this."

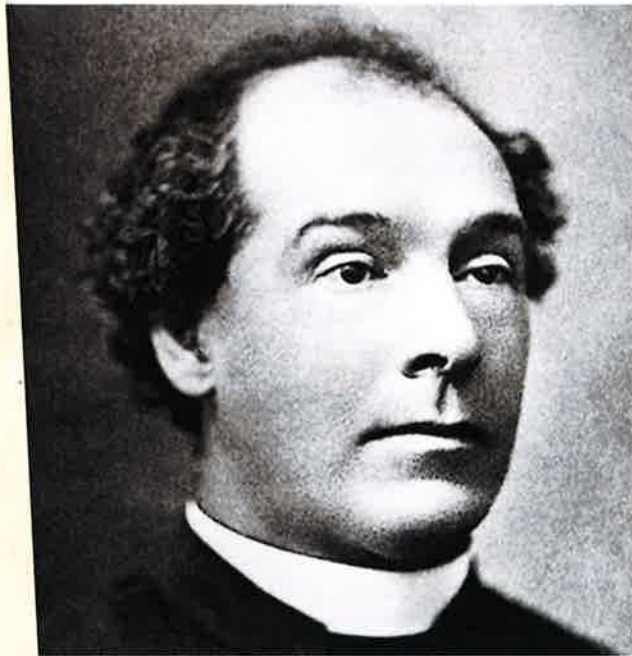
This acceptance of daily symptoms has travelled with her from town to town and different air force bases.

Pam says, "As a result of moving around I saw many new doctors, GPs and specialists, but sadly my medical records did not often travel with me. The sad thing is that when in the Airforce, Norm's medical records were transferred, but not the other family member's records. This leaves a big gap in medical history and continuity of care." Each new doctor meant that Pam needed to recount her families' symptoms and maladies, relying on recall of event timelines and testing results.

Pam often felt like a recording and simply pressed play in an automatic response each time. Overtime it taught her that there was a need to keep her own records, even though it made her feel as if she was obsessed with illness. In reality it was just necessary for maintenance of the wellbeing of her family and herself.

The first indication of an ill-health challenge was when Pam started to experience heart palpitations along with unintentional weight loss. Her fatigue levels were extreme as she often fell asleep at the dinner table.

Tenison-Woods, founded the sisters of St Joseph alongside St. Mary MacKillop. His life of service ended at the young age of 56 years succumbing to an illness that stole his energy and immobilised first his hands to the point of not being able to write, and then his body.



Pam did have 3 small active children but her intuition told her that the fatigue was related to something more. Pam was diagnosed with Graves' disease, an autoimmune disease of the Thyroid gland and she had a thyroidectomy to remove the malfunctioning gland.

A few months after surgery Pam noticed increasing aches and pain accompanied with painful and swollen feet and hands. Her GP could not explain the symptoms.

The symptoms waxed and waned over 15-20 years and Pam went to see a series of different doctors over that time to see if a reason could be found for her symptoms and ill-health. Sadly no real insight or diagnosis was found.

One GP in Adelaide remarked "Umm, crook gut and chest, joint pain, fatigue it could be anything."

In 1983, Norm, Pam and the family were transferred an Airforce base in Malaysia. This was a great experience however whilst in Malaysia, Pam's symptoms changed and she started to experience painful rashes along with the other symptoms. Pam was prescribed pain relief medication, nonsteroidal anti-inflammatory medications (NSAIDs) and some relief was found. However upon returning to Australia (Sale, Victoria), Pam's health continued to deteriorate and her new GP became concerned, referring Pam to an allergy specialist that treated her for chronic sinusitis with new and improved NSAIDs. This cleared up her sinusitis and as a surprise also relieved her painful swollen hands.

Pam reports "It was like an elastic band went off and suddenly I had freedom of my hands that I hadn't had in years." At around the same time, there was a Victorian health promotion campaign to raise awareness of an autoimmune illness, lupus. The ad presented lists of the classical lupus symptoms and as Pam listened she slowly ticked off 8 of the 11 symptoms mentioned.

This led her to believe that she may have lupus and finally an explanation for her strange and persistent symptoms.

The family moved again, this time to Richmond in Sydney and for the first time Pam had some immunological testing undertaken. This showed positive antibodies suggestive of lupus and Sjögren's syndrome. Pam was referred to a Rheumatologist for review however the Rheumatologist focussed upon her gastro intestinal symptoms, rather than the whole symptom spectrum. Pam reports "He quickly referred me on to a Gastroenterologist and also back to the GP with no resolution."

In 1999, Pam's world was further turned upside down as she was diagnosed with lymphoma; but not in the usual presentation. Her oncologist remarked that "they would never know what caused it or why it appeared different to other lymphomas". However Pam remembered something about her father and his brother illness' and wrote to her father's physician in Adelaide. Pam knew that her uncle also had lymphoma but was amazed that her father's medical record noted that he had Sjögren's syndrome. Pam's oncologist thought this may be the missing link and she was referred to an immunologist.

The immunologist through pathology testing and a full medical history diagnosed Pam with immune deficiency disease (CVID), and also confirmed a diagnosis of lupus along with Sjögren's syndrome. The immunologist, due to her long ancestral history of strange maladies suggested that Pam and Norm's children be investigated for autoimmune and immune deficiency diseases. This testing promptly showed their 2 daughters also have CVID, Sjögren's and lupus; however their son was spared.



In 2000 the funny rashes returned and Pam was given immunosuppressant medications for lupus as well as intravenous therapy for immune deficiency. The treatments made a huge difference within a few weeks. With the addition of short term pulse treatments and by looking closely at her life and the way she underwent doing her daily tasks many of Pam's symptoms were alleviated.

After the diagnosis of lupus and Sjögren's Pam learnt all she could about autoimmune illness and management options to improve daily symptoms. Pam remarks, "The ARRC centre was a great help with increasing understanding and helping me identify strategies that could be used to better support my health and ease symptoms on a day to day basis. I've learnt that if I am having a bad day, a day with increased pain and tiredness, then I don't keep pushing through. I pace myself and identify necessary tasks, others tasks can wait. I think I have found the balance between resting and being active."

Pam's symptoms still flare up from time to time but she is able to live a rich and fulfilling life. She has adopted a supported activity regime along with other lifestyle changes.

Sometimes the support of a shopping trolley or a walker is needed to help and she is often caught doing exercises such as leg lifts using the kitchen sink for support. Norm helps do the tasks that Pam has difficulty with like hanging the washing on the line. She no longer grows her own vegetables as there is good quality close-by, but still likes to garden for pleasure. Through accommodating her illnesses and their numerous symptoms, Pam has developed healthy habits and a balance which enables her to enjoy her life with Norm and the family.

Pam has accessed ARRC's services and in her words reports that, "I have learnt a lot about self-management and I love the companionship that is offered from meeting others that experience living with these strange and often invisible illnesses. It is a struggle, as people see only the surface. They see that you look well and cannot understand that many of your symptoms cause problems internally and you are feeling quite ill. Even last week I was labelled by an acquaintance as a hypochondriac. This made me livid as I am a positive person that tries hard to live my good days to their most. Sadly though I also have bad days and the years of symptoms and maybe the years of not having a diagnosis has left an impact."

Pam's as a final comment adds "I feel blessed, as I have Norm and my children. My family is a great support and when you live a roller coaster life of good and bad days, support and understanding is what you need." 🙏

October Autoimmune Awareness Month

October is a time to raise awareness of an autoimmune illness which is not rare affecting between 1 in a 1,000, however it is not well known in the community.

Lupus can range in its impact from mild to severe with some symptoms being life threatening. It can affect any organ of the body, but often the heart and kidneys. There are different forms discoid, cognitive, neonatal and the systemic form (SLE) which affects multiple body systems. Classical symptoms can include rashes, mouth and nasal ulcers, renal problems, circulatory problems, muscle and joint pains, and intense fatigue, however, the symptom spectrum is different between people. Lupus is a complex illness that can impact lives heavily although with support, education and medical help the disease impacts can be managed and in many cases long term health impacts can be minimised.

The Autoimmune Resource and Research Centre is a not for profit charity that offers education, resources and support for people living with Autoimmune diseases such as lupus. The centre has programs focussing on learning about autoimmune disease and symptoms. Programs also help to promote healthy lifestyle habits through exploring self-management strategies that can help people deal with symptom impacts.

ARRC promotes the goal of having quality of life despite having a chronic illness; and inspires people to live a life accommodating illness and not allowing the illness to take over.

If you would like to support ARRC and its work or access support information contact 02 4921 4995 or visit www.autoimmune.org.au