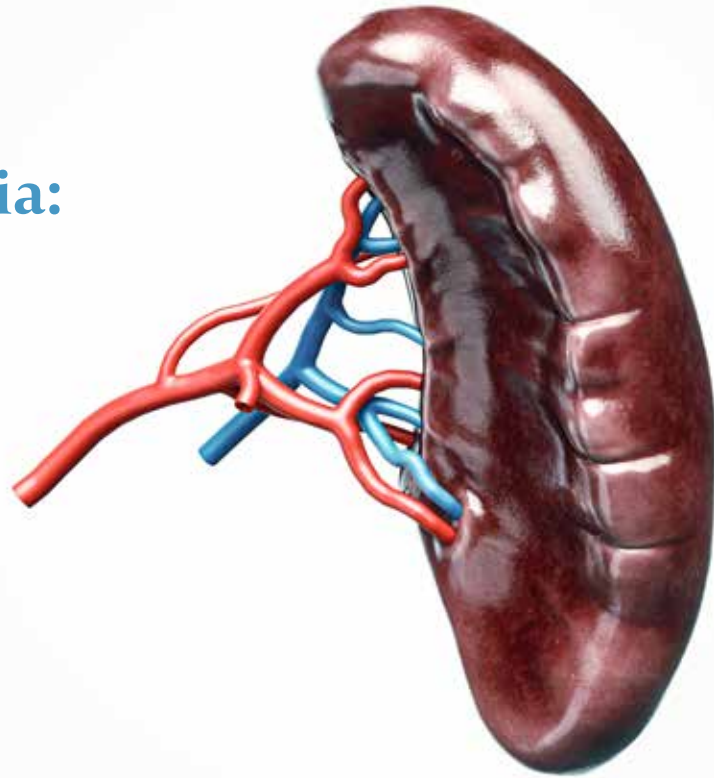


# Spleen Australia: Our story

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By Sharon Willems



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**Alfred Hospital's Spleen Registry was established in 2003. At that time, patients without a functioning spleen from the Alfred Hospital and Monash Medical Centre could enrol.**

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Funding was originally from the Victorian Health Department with the aim of setting up a registry for patients in this vulnerable group. The registry aimed to provide information to patients on how to prevent severe bacterial infections. These infections are often referred to as overwhelming post splenectomy infection (OPSI) and regularly require an ICU admission. OPSI carries a mortality rate of 50–70% and if people survive an OPSI they can have major morbidities eg. limb amputations.

In 2007, the registry became the Victorian Spleen Registry, and in 2015 when Queensland and Tasmania joined, the registry became Spleen Australia (SA). The service is called "Spleen Australia", even though not all Australians can have access to our evidence-based medical care health package. The Spleen Australia website [spleen.org.au](http://spleen.org.au) is available to all Australians. There is a wealth of information on this website especially around preventing infections in people without a functioning

spleen. Our emphasis, now, is that SA is a clinical service rather than a registry.

## BACKGROUND

In 2002 a young woman at the Alfred Hospital died from pneumococcal sepsis. The ICU and medical team felt that if she or her parents knew more about how to detect and prevent sepsis this young woman would not have died, in essence her death would have been prevented. This event was the catalyst for two Alfred Hospital clinicians to apply for a short term funding grant with the Department of Health, Victoria.

The proposal was to set up a registry that would enrol patients and systematically provide them and their GPs with information about the well-known strategies for preventing sepsis in this population.

## FUNCTIONS OF THE SPLEEN

The spleen is located on the left hand side of the abdomen underneath the ribs. It is

usually the size of a fist. It has two main functions. It clears old red blood cells from the blood and more importantly it produces white blood cells that filter bacteria, viruses and other pathogens from the blood stream. The most common bacteria that cause infections in those without a spleen (asplenia) or a non-functioning (hyposplenism) are meningococcus, pneumococcus and *Haemophilus Influenzae* Type b.

**Asplenia** (removal of the spleen) is commonly due to trauma, blood disorders, cancer, cysts and benign tumours. Congenital asplenia is where people are born without a spleen.

**Hyposplenism** is a medical condition when the spleen has stopped functioning due to medical conditions eg. Coeliac disease and a range of autoimmune disorders. This condition is usually diagnosed by a specialist physician.

## SUSCEPTIBILITY TO INFECTION

People without a spleen have a lifelong risk of serious bacterial infections as they have decreased ability to fight these infections. They can commonly present as infections of the lung (pneumonia), blood (sepsis) or brain (meningitis).



Patient above has given consent for her photo to be published in this article

These infections can develop into an overwhelming sepsis or septic shock. These infections are largely preventable through use of prophylactic antibiotics, immunisations and education with a focus on awareness of early intervention if unwell.

It is very important for those with asplenia/hyposplenism to know signs and symptoms of an infection and present to a general practitioner or emergency department. Symptoms include fever, cold, shivers, shakes, diarrhoea, vomiting, severe headaches and feeling very unwell. Early intervention by being reviewed by a doctor and receiving antibiotic treatment can save a life.

OPSI can be deadly. If a patient survives this septic episode they are often left losing limbs. The patient pictured, nearly died from OPSI and was left with being a quad amputee needing four prostheses. OPSI is also extremely expensive – costing in the order of \$280K per hospital admission only.

### WHAT DO PEOPLE WITHOUT A FUNCTIONING SPLEEN NEED TO DO?

People living in Victoria, Queensland, Tasmania, and Western Australia need to register with the SA service. These states fund SA in order to provide a clinical service to its residents. Registering eligible people with Spleen Australia increases awareness of their susceptibility to bacterial infections and decreases preventable infectious diseases (sepsis) in this population. People are registered by their surgeon or a medical officer in a medical team. They may also

be registered by their GP or clinic nurse or can self-register. Medical practitioners in Queensland can register their patients without the patient's consent, as sepsis prevention in this group is an important public health measure.

Once registered, people are provided with educational materials, an alert card, a personalised vaccination schedule, vaccine record card, access to an App that provides reminders of vaccines due, access to our nursing staff via our phone, and receive the latest medical information via our Health Updates and website.

Education provided by the nursing staff at SA stresses the importance of early presentation to a doctor if unwell with symptoms of a bacterial infection: rigors, nausea, vomiting, high temperatures, diarrhoea and generally feeling very unwell. The spleen specific alert card is to be carried at all times by patients and to be shown when seeing new medical practitioners.

SA encourages patients to get the National Immunisation Program funded “spleen vaccines” vaccines. Our team advocated for the “spleen vaccines” to be funded by the Commonwealth Government. Prior to this patients would be out of pocket for around \$600 for the first round of vaccines. Patients are advised to take a daily antibiotic for at least the first three years after a splenectomy. All patients are advised

to have access to an emergency supply that should be taken when they become unwell and not able to seek medical advice promptly. SA has also developed a vaccine reminder App called Spleen-IE.

### HOW MANY PEOPLE HAVE ENROLLED WITH THIS SERVICE?

On 1 December 2022 there were over 13,000 patients registered with Spleen Australia.

### WHAT CAN YOU DO TO HELP YOUR PATIENTS WHO DO NOT HAVE A FUNCTIONING SPLEEN?

Register your patients with the Spleen Australia clinical service only if they reside in the funded states. The staff will provide information to the patient and their GP. Spleen Australia always tries to increase awareness of susceptibility to infections and how to reduce the risk of these infections, for those without a functioning spleen. If your patients do not live in the funded state please refer to our website for latest medical recommendations and health updates. We ask that you spread the word about Spleen Australia as we celebrate 20 years of being operational in 2023.

#### Author

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## 2023 Spleen Australia celebrates 20 years of being operational

### WHAT HAVE WE ACHIEVED?

[spleen.org.au](https://www.spleen.org.au) (with important information about animal bites and risk of malaria)

Spleen song [youtube.com/watch?v=VzDYzqc6WvI](https://www.youtube.com/watch?v=VzDYzqc6WvI)

Multiple publications in medical literature

Demonstrated we save lives and reduce the number of OPSIs in registered patients

Demonstrated SA is cost effective

Presented our research at national and international conferences

COVID advice documents and support for patients and medical practitioners

Translated health advice

Developed a vaccine reminder App for patients

Travelled interstate and to regional areas to inform healthcare providers about our service

Advise the TGA on spleen antibiotics

Review guidelines with Australian Immunisation Handbook

Secured a patron – Australian music rock legend – Daryl Braithwaite

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