

# SPLEEN AUSTRALIA

Information for people living without a functioning spleen

HEALTH UPDATE
VOLUME #4

**April 2023** 

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You should receive our Health Update every year between April/May. If you do not receive it, contact us.

To help us support you, it's vital that we have your up-to-date contact details: phone numbers, personal email details and postal address. Contact us by email or phone and let us know of any changes.

We work in partnership with You, to keep you healthy.

We welcome any suggestions you have on how we can improve our service. (Click on the red text to access our email)





# Spleen Australia welcomes Western Australia!

We are excited to announce that Western Australian patients can join us. Thank you to Western Australian Department of Health for funding us. We wish to acknowledge the ongoing funding from the Departments of Health in Victoria, Queensland and Tasmania.



# **Immunisation Updates**

# 1 Meningococcal B vaccine

NEW ADVICE: Spleen Australia and the National Immunisation Program (NIP) recommends a booster dose of the meningococcal B (Bexero) vaccine. The recommendation is to have this vaccine 5 years after your initial TWO doses. It is FREE for you.



#### 2 COVID vaccine 2023 booster

Visit our website to see the latest ATAGI recommendation on the **2023 booster** COVID vaccine doses. As you know the vaccines protect you against severe disease. It is advisable to have this dose by June 30th 2023. Check with your GP.



# 3 2023 annual influenza vaccine (flu shot)

Flu season is predicted to come early this year. All people aged 6 months and older are recommended to get an influenza vaccine. It's FREE, and you can get it at the same time as a COVID-19 vaccine. Please check with your GP to see if you are due for any 'Spleen Vaccines' as these can be given at the same time as your flu shot.

#### TRAVELLING OVERSEAS??

TWO extra things to remember (info in booklet)

- (i) **Malaria** eg. Africa, PNG, Thailand and other countries, see an accredited travel doctor. 4-6 weeks prior to travel (we can also help, call us)
- (ii) **DVTs** clots in legs/arms. Please wear travel stockings, drink lots of fluids and exercise your legs on long flights.



Wellness on Channel 7 with patient Fiona. The YOUTUBE clip will be on the website soon! <a href="https://www.houseofwellness.com.au/tv">www.houseofwellness.com.au/tv</a>



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#### Spleen Australia welcomes Huong Pham

Huong Pham joins Spleen Australia as our administration officer after many years in the financial services industry. Huong is covering Amber Plumley whilst she is on maternity leave. She enjoys supporting the team to provide care to patients without a functioning spleen and is looking forward to celebrating Spleen Australia's 20 year anniversary. In her spare time, Huong loves spending time with her family and has written a children's book about her experience as a refugee settling in Australia.



#### Antibiotics

#### How long do I need to take antibiotics?

For Immunocompromised patients (recently treated cancer patients, or those on long term steroids etc) the recommendation is lifelong; otherwise for healthy patients the TG (Therapeutic Guidelines) recommendation is for daily antibiotics for at least 3 years after splenectomy. This could be longer based on other health conditions for example: a recent sepsis episode. If in doubt, contact us.

#### What is a Penicillin Allergy?



Penicillin is an antibiotic to which some people are allergic. Up to 10% of people lose their penicillin allergy every year AND approximately 10% of the population report a penicillin allergy, however, only 1% will be truly allergic. Side effects and symptoms of infections can sometimes be mistaken as an allergy. Spleen Australia would like to confirm whether our patients have a penicillin allergy or not, as it is an important antibiotic to give you if you have sepsis.

Talk with your GP about this issue and give a detailed history about the symptoms you experience after taking penicillin/amoxicillin, including approximate year of occurrence and if treatment was needed. Some symptoms eg. vomiting and diarrhoea are often **not** an allergy. If there are concerns that it could be an allergy, there are dedicated doctors who can investigate this. Contact us if you need more information.

#### **Medical ID**

In addition to your Spleen wallet alert card, there is another great way to notify people in an emergency that you do not have a functioning spleen. Both Apple and Android phones have a great function that allows you to store information such as allergies, medical conditions as well as who to contact in an emergency that can be viewed from the Lock screen.



https://support.apple.com/en-us/HT207021 https://support.google.com/android/answer/9319337?hl=en

#### PLEASE REMEMBER—the signs of a bacterial infection (on the back of your alert card)!

This is the without a doubt a life saving educational tip. If you become unwell with these signs and symptoms, see your doctor promptly or go to your nearest Emergency Department for treatment. If you can not do this promptly (within a couple of hours) start your treatment by taking your emergency supply of antibiotics.



Fever



Headaches



Díarrhoea





Exhaustion



Can't get warm

Carry your spleen wallet alert card at all times. If you become sick or see a new doctor show it to them. Contact us for a replacement if you don't have this card



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# **Research projects**

The effects of COVID-19 on people living without a functioning spleen

Thank you to those who participated in our study that investigated if COVID-19 had any impact on you. This study was conducted prior to the Omicron variant outbreak.

Nearly 3,000 people completed the survey. Most of the impacts reported were through the effects of lockdowns and other social changes. People reported that the pandemic had reduced their ability to visit a GP (26%), trouble getting food (5%), getting medications or spleen vaccines (5%), maintaining relationships (18%) having stable accommodation (1%), or care for children at home (4%). Overall, 85% reported at least one impact of COVID-19, including negative physical health (51%), mental health (26%) and financial difficulties (18%). 58% felt more susceptible to COVID-19 due to lack of spleen function. Encouragingly 97% had received at least one dose of a COVID-19 vaccine by December 2021. This research is about to be published.

Many of you have asked how COVID-19 has affected you **since the Omicron variant spread through the community**. We wish to understand this too! We are especially interested in the effects of actual COVID-19 infection at this time. Therefore, we are now about to embark on another study addressing your COVID-19 infection history asking how many times you got COVID-19 and other COVID related questions. This study is being coordinated by **Vy Nguyen** from the Antiviral Immunity team at the Burnet Institute in collaboration with Monash Health and Alfred Health infectious diseases departments in collaboration with Dr Gabriela Khoury (Burnet Institute).



This study has been approved by the ethics boards of both the Alfred and Monash Hospitals, and is being overseen by Associate Professor Ian Woolley, an Infectious Diseases physician and Ms Penelope Jones. This study will take 5 minutes and will be **online** and the link will be **emailed** to you. THANK YOU for helping us, help you!

# **Patient story**

### Janine's story—"A huge wake up call"



I'm 70 and lost my spleen as a result of a car accident 50 years ago. In late 2022, I'd been feeling a bit unwell with a lingering cough for a few weeks and thought nothing of it. Then out of the blue my symptoms increased dramatically. I got severe aches and pains in my hips, then the shivers, sweats and shakes started. I went to bed. That night my symptoms worsened. This was when I should have gone straight to the Emergency Department.

"Nurse on call" saved my life! An ambulance arrived within minutes and I was rushed to hospital. My blood pressure was 50mmHg, my temperature was **40**<sup>c</sup> and I looked gravely unwell, confirming septic shock. I was connected to drips and received antibiotics. I was in ICU for 4 days and then spent a further 3 days in hospital. I'm feeling tired and anxious about getting so unwell again.

Please READ Spleen Australia's educational booklet. The health updates are on <a href="www.spleen.org.au">www.spleen.org.au</a>. I now have a thermometer and when I was sick I would have seen just how high my temperature was.

The randomness and speed of my sepsis was dramatic. I was told by the doctors that I was lucky to be alive!!!

It doesn't matter how long you have been without a spleen; the risk of a serious infection remains forever.



Septic shock is a life-threatening condition caused by a severe infection that requires immediate medical attention. Symptoms include low blood pressure, pale and cool arms and legs, chills, difficulty breathing, blackened fingers/toes, and decreased urine output. Mental confusion and disorientation may also develop quickly. ICU and being on a ventilator can also be part of the treatment.





# SPLEEN AUSTRALIA

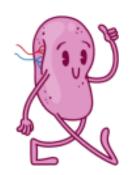
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There are 13, 476 patients registered with us, with ages from 1 day old to 92 years old Patients can reside in Victoria, Queensland, Tasmania and Western Australia

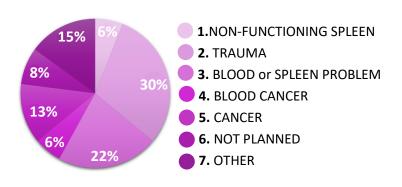
# All About SPLEEN AUSTRALIA



Happy Birthday
Spleen Australia
- we are now
20 years old!!

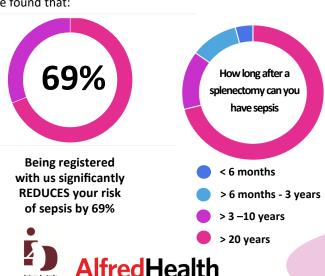
# WHERE IS THE SPLEEN LOCATED? SPLEEN LOCATED? AVERAGE AGE OF PEOPLE ENROLLED WITH SPLEEN AUSTRALIA

#### **REASON FOR SPLENECTOMY**



# **RISK OF SEPSIS**

RESULTS FROM: our published research https://pubmed.ncbi.nlm.nih.gov/29471470/ that looked at the occurrence of infection before and after being enrolled with us and we found that:



# **OUR WEBSITE**

Average visits to the website each month

Average number of people visiting the site for the first time each month

Of the 2243 people visiting the site, the vast majority are doing this for the first time

For adults, vaccines should be given in the **deltoid muscle** (<u>upper arm</u>). Two vaccines can be given at the same time, same arm and 2.5cm apart. Refer to our Adult Medical Recommendations