

June 2024

Hello

Your child's doctor is giving you this letter to provide you with some information about our clinical service.

### Who are we?

For over **20 years** there has been an active Spleen Registry/clinical service for people without functioning spleens. We are based at the Alfred Hospital in Melbourne. We have just over **13,000 patients** registered, aged from a few weeks old to 90 years of age. Spleen Australia supports patients who live in Victoria, Queensland, Tasmania and Western Australia.

### What is our aim?

Our aim is to reduce your child's chances of serious infection (sepsis) after splenectomy or diagnosis of hyposplenism (spleen not working or absent) as it is well known that people who do not have a functioning spleen have an **increased lifelong risk of getting serious bacterial infections.**

### What will I receive?

We provide an education package, access to our patient support line and use of our Spleen App. We will also provide an individualised vaccine and antibiotic plan that your child needs to be protected from sepsis.

### What information do we require?

To design a safe and appropriate vaccine and antibiotic plan, we need to know a bit about your child. We do this by collecting limited information from your child's GP and a discharge summary from the hospital where your child had their splenectomy or received their diagnosis. When you register, you agree that we can access this information.

### How will we use your information?

We will use the provided information for our audit and research purposes.

When we use your child's information for these purposes, it will always be de-identified (which means it will not contain any information from which they can be identified). In addition, all research activities require approval from an ethics committee.

### How will you store my information?

Spleen Australia is part of Alfred Health and we work in collaboration with Monash University. We comply with current recommendations for database security. We have strict policies for security of information and employ a multitude of controls to protect our infrastructure and data. All staff have password protected profiles and use an authenticator to access patient data. Your child's medical information will be stored on a password protected database that is managed by Monash University, who maintain many of the national registries. The health care team that will have access to this data are the doctors, registered nurses and administrative staff employed by Spleen Australia.

#### Patron

Daryl Braithwaite

#### DEPARTMENT OF INFECTIOUS DISEASES

#### SPLEEN AUSTRALIA

Level 1, Alfred Lane House  
55 Commercial Road  
Prahran VIC 3004

[www.spleen.org.au](http://www.spleen.org.au)

T: 03 9076 3828 (VIC/TAS/WA)

T: 1800 775 336 (QLD)

F: 03 9076 7946

[spleenaustralia@alfred.org.au](mailto:spleenaustralia@alfred.org.au)

#### Medical Director

Prof Denis Spelman  
MBBS FRACP

#### Manager

Penelope Jones RN, ICU Cert, Grad  
Dip Epi

#### Nurse Coordinators

Sharon Willems RN, B. Sci, Nurse  
Immuniser

Sharon O'Brien RN, B. Sci, Nurse  
Immuniser

Ella Brown RN, MNSc, Nurse  
Immuniser

Megan Harvey RN, Dip Critical Care,  
Nurse Immuniser

#### Senior Administration Officer

Amber Plumley

**Do I have to register with Spleen Australia?**

No. You are not under any obligation to register with our program. It is up to you if you'd like to register. You or your child's doctor or clinic nurse can do this for you. If you register and then want to leave the program, again this is entirely your choice. If at any point you wish for us to stop using your information, you can let us know.

**Consent for children provided by parent or guardian (adults provide consent when they register on-line)**

**I consent to release information on (child under 18 years of age)**

Child's full name \_\_\_\_\_ date of birth \_\_\_\_\_

Hospital attended \_\_\_\_\_

and give permission for Professor Denis Spelman or Ms Penelope Jones at Alfred Health (The Alfred hospital) to contact my above-named doctor OR hospital to verify information from my or my relative's medical records regarding the treatment of splenectomy or non-functioning spleen. This will include any vaccines or antibiotics that have been administered.

Signature ..... Date .....

Once completed - FAX or EMAIL this form to us

F: 03 9076 7946

E: spleenaustralia@alfred.org.au

Please, if you have any queries at all contact Ms Penelope Jones on 03 9076 3828 or Professor Spelman. You can also email us at [spleenaustralia@alfred.org.au](mailto:spleenaustralia@alfred.org.au) and we encourage you to look at our website [www.spleen.org.au](http://www.spleen.org.au)

Yours sincerely



Professor Denis Spelman MBBS FRACP FRCPA MPH

Deputy Director Infectious Diseases Unit



Penelope Jones RN, Grad Dip Epi

Manager, Spleen Australia