**Spleen Australia**

**Information sheet for patients who have had a splenectomy or been diagnosed with a non-functioning spleen**

**THE SPLEEN** is the size of a small fist and is situated in the upper left hand side of the body, under the ribs. Its main role is to produce white blood cells that specifically fight some bacteria which can lead to severe infections.

**Background** There are more than 22,000 Australians living without a spleen (asplenia), or with a non-functioning spleen (hyposplenism). These people face a lifetime higher risk of contracting bacterial infections. If these infections progress, without medical treatment, they may become life threatening or cause serious physically deformities. The most severe bacterial infections are called overwhelming post-splenectomy infections (OPSI).

**Spleen Australia** (SA), based at The Alfred hospital in Melbourne, is a support and advisory service for patients who lack a functioning spleen. SA aims to reduce the occurrence of serious infections with education, vaccinations and antibiotics. This service will equip patients, their families and medical practitioners with information on how to reduce the risk of infections.

**How does the Service work?**
You are responsible for your ongoing health after splenectomy or after a diagnosis of a non-functioning spleen.

**Registered patients will receive:**
- medical information on managing asplenia or hyposplenism
- an individualised vaccine and antibiotic report
- a credit-card sized ‘spleen alert card’ — to be carried at all times in case of emergencies
- an annual newsletter providing reminders for flu vaccinations and booster vaccinations
- the option to participate in research projects relating to their condition
- access to phone support for questions

**Who is able to join this service?**
SA has received funding to register all patients living in Victoria, Tasmania, or Queensland who have a non-functioning spleen.

**How do I join?**
2. You can also down load and print a registration form from this website “forms and info” tab. After completion send this form to Spleen Australia.

**What about my privacy?**
(a) All patient information will be kept confidential and stored on computer back up servers at The Alfred hospital and Monash University’s Department of Epidemiology and Preventive Medicine. After details have been entered on the registry’s database, a unique identification number will be allocated to each person’s record. This number will provide anonymity.

(b) SA intends to use information provided to the registry for audit or research purposes. All research activities require ethics committee approval. We will not identify you in any presentations or publications without your permission. If you do **not** want to participate in any research please contact us.
(c) SA staff and the SA Steering Committee members are the only people who will have access to these data.

**Do I have to register?**
No, and you are welcome to be removed from the Spleen Australia database at any time. However we will no longer be able to support you through Spleen Australia.

**Who do I contact if I have any questions?**
SA nursing staff – Penelope Jones, Julia McNamara, Nigel Pratt or Cate Bunn
Medical Director – A/Prof Denis Spelman

**Tasmania and Victoria patients**
Call 03 9076 3828

**Queensland patients**
Call 1800 SPLEEN (775 336)

**Other contact details**
Fax: 03 9076 2431
Post: Spleen Australia, 2nd Floor Burnet Building, 85 Commercial Road, Melbourne, Vic 3004.

If you have any concerns and wish to talk to staff other than SA staff please contact:
The Office of Ethics and Research Governance
The Alfred, PO Box 315, Prahran VIC 3181
T: 03 9076 3619 or E: [research@alfred.org.au](mailto:research@alfred.org.au)

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