



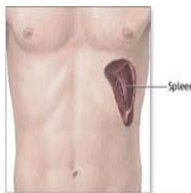
Victorian Spleen Registry (VSR) based at The Alfred hospital

Patient Information Sheet following splenectomy or diagnosis of poorly functioning spleen

dated 04/05/2011

THE SPLEEN

The spleen is the size of a small fist and is situated on the left hand side of the body tucked under the ribs. Its main role is to help the body combat some specific and occasionally severe infections. When the spleen is absent or poorly functioning, this person is at increased risk of bacterial infections. We aim to assist you in reducing the possibility of acquiring these infections by advising you on specific preventative strategies. The VSR has been set up to assist you in managing this aspect of your health.



Why is there a Spleen Registry?

It is well known that people without spleens or with spleens that don't work properly are at an increased risk of infection. The infections we are trying to prevent you from acquiring are serious bacterial blood infections or meningitis. In 2003 the VSR received funding to develop an "education & medical package" to help you better manage your health. The VSR is inviting people without a spleen and those with a poorly functioning spleen to participate in this registry.

Who has funded this Registry?

The Victorian Spleen Registry (VSR) has received funding by the Department of Human Services (DHS) and also from the Marian and E H Flack Trust.

How does the Registry work?

You are responsible for your ongoing health after splenectomy or after a diagnosis of a poorly functioning spleen. We will assist you in this aspect of your health. The VSR has been notified of your name, contact and some treatment details. This information will be placed in the registry's database and you will be sent information on ways to reduce your risk of acquiring these bacterial infections. Once registered you will receive a yearly newsletter that will provide you with the latest medical advice on this aspect of your health, remind you to check when booster vaccinations are due and report on their activities.

So that we can send you newsletters - **PLEASE** let us know if you change your address.

How did you get my name?

Your doctor has referred you to the VSR because you have had your spleen removed (splenectomy) or you have been diagnosed with a poorly functioning spleen (hyposplenism).

How can I register?

Please call us on 9076 3828 and we will send you a registration form to complete. Your GP may be able to help you complete this form. To obtain electronic copies of our registration form or medical recommendations sheet go to www.spleen.org.au. If you would like to see a doctor in outpatients (2nd Floor Infectious Diseases, Main Ward Block) at The Alfred hospital call 9076 6081.

What about my privacy?

The information you provide will be kept confidential at all times. The data collected will only be used for this registry and will be maintained at The Alfred hospital. After details have been entered on the registry's database, an identification number will be allocated and personal details stored separately. In the future we may like to use information provided to the registry for research purposes. All research activities require ethics committee approval. No identifiable information will be used in presentations or publications. If you do not want your information to be used in research please contact the VSR Manager (03) 9076 3828.

Do I have to join this registry?

We understand that not everyone is happy to have their personal information recorded in a database (registry). If you do not wish for your details to be kept in this database, please contact Ms Penny Jones or A/Prof Denis Spelman (03) 9076 3828.

What's in it for me? Many things!

- You will receive, for free, regular medical information on the best way to manage this aspect of your health
- You will receive a credit card sized spleen alert card and other educational material
- You will also receive a yearly newsletter that will remind you to have your annual flu shot, and to check your vaccination card to see if you are due for any booster vaccinations
- You can call us on (03) 9076 3828 to ask any questions about this aspect of your health

(e) We can also offer medical advice for overseas travel at our Travel Clinic (03) 9076 3795

What exactly do you want me to do?

Allow the VSR to document information relevant to your condition. In addition, there may also be the opportunity to take part in future research projects. At some stage a research project may be developed and you will have the opportunity to participate should you wish. In this instance we will send a letter inviting you to participate. If you decide that you do not wish to take part in a research project, we assure you that your medical treatment will not be affected in any way. Please contact Penny Jones, the Registry's manager, if you do not wish to be involved in any research.

Who will have access to this registry?

The Director of the VSR is Associate Professor Denis Spelman. Ms Penny Jones is the VSR's Manager and Ms Meg Chesterman and Mandy Fonstin are the patient coordinators. Dr Ian Woolley, Dr Paul Cameron, Associate Professor Allen Cheng, Associate Professor Karin Leder, Dr Michelle Giles, Professor Alison Street, and Mr Chris Atkin will also offer advice to this Registry. Their collective expertise is in infectious diseases, trauma surgery, haematological conditions and epidemiology. The Registry will produce reports for the DHS and medical audits.

Who do I contact if I have any questions or concerns?

If you have any questions please contact Penny Jones, Mandy Fonstin or Meg Chesterman **(03) 9076 3828** (answer phone on this line) or (03) 9076 3009 or fax (03) 9076 2431
Email spleenregistry@alfred.org.au. **Postal address:** Victorian Spleen Registry, 2nd Floor Burnet Building, 85 Commercial Road, Melbourne 3004. We will return your telephone calls and answer any communications. Our **website** www.spleen.org.au.

If at any time you have any concerns and wish to communicate these to staff other than the Victorian Spleen Registry Personnel please contact Ms Rowan Frew, Ethics Manager, The Alfred hospital, PO Box 315 Prahran 3181 or telephone 9076 3848 or email R.Frew@alfred.org.au