



CCRE Patient Safety

Registry of registries

23rd Nov 2007

Victorian Spleen Registry (VSR)

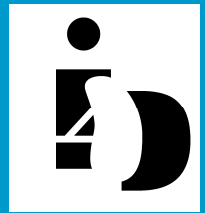
Penny Jones

VSR – “The Team”



- Director – Assoc/Prof Denis Spelman
- Manager – PJ
- Patient coordinator - Meg Chesterman
- ID Physician- Ian Woolley
- Immunologist – Paul Cameron
- Administration – Volunteer S. Sandirasegaram
- Affiliated ID Epi Consultants – Karin Leder
Michelle Giles

Victorian Spleen Registry



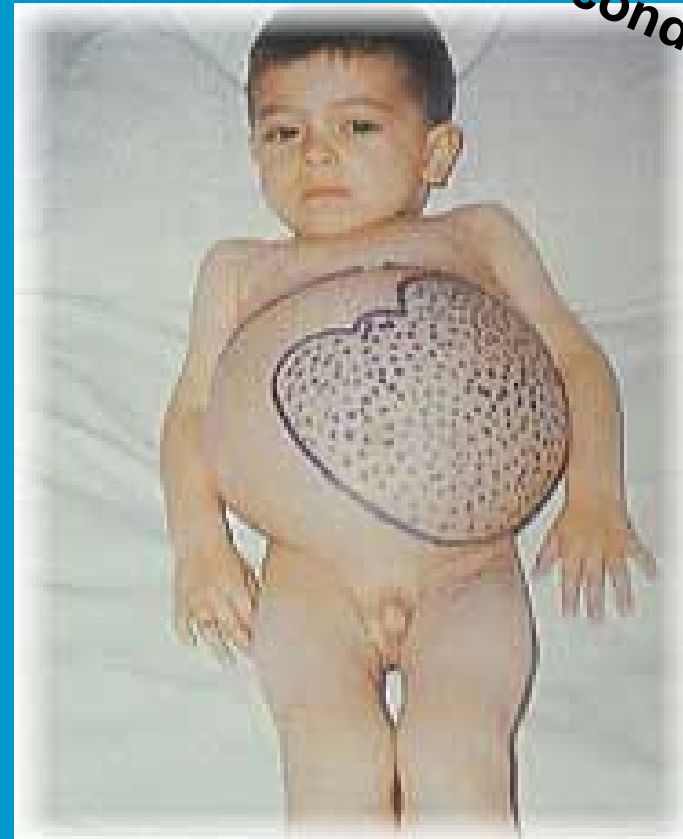
Splenectomies



TRAUMA

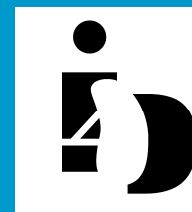


Medical conditions



**Hyposplenic – eg. congenital,
Coeliac disease**

DHS figures of splenectomies performed in public hospital in Victoria 2000 - 2006



Campus Name	2000/01	2001/02	2002/03	2003/04	2004/05	2005/06
METRO						
Alfred	44	39	27	34	36	29
Austin	18	27	8	8	13	18
Box Hill	19	12	8	11	15	5
MMC & DDH	26	23	22	24	22	18
Peter MacCallum		7	8	9	6	8
RCH	<5	11	12	12	6	7
RMH	30	23	31	25	32	36
Frankston	12	6	8	15	8	7
St Vincents	24	17	18	9	15	11
Western	12	12	11	10	8	13
RURAL						
Geelong Hospital	15	6	11	14	6	12
Goulburn Valley Health [Shepparton]	<5	6	<5	5	<5	<5
Latrobe Regional Hospital [Traralgon]	7	11	12	11	<5	6
State totals	207	200	176	187	167	170



OPSI - Risk is difficult to quantitate

- Estimates 3-5% lifetime risk
38-50% mortality
Incidence 0.2-0.5% per year

Clin Micro Infect 2001 7 65

- Risk is highest first 2-3 years
30% of infections >5 yrs
- Higher in children & immunosuppressed adults
- *S.pneumoniae* 50-90% of infections
- Case reports OPSI up to 30 yrs

Health

Victory
Number
Hepatitis B in Australia

Vaccination alarm

Gareth Trickey

COMPLACENCY and a lack of knowledge about adult immunisation are resulting in an alarming number of adults contracting vaccine-preventable diseases.

Last year, 88 per cent of reported cases of hepatitis B and 81 per cent of confirmed cases of influenza were in adults, according to the National Notifiable Diseases Surveillance System.

Doctors have also raised concerns about the prevalence of childhood diseases in adults, after the same study revealed 90 per cent of reported cases of whooping cough had occurred in adults.

Dr Dick Deemelok, president of the Bundaberg and District Division of General Practitioners, said childhood diseases such as chickenpox and whooping cough could lead to superficial warts, chronic respiratory problems and death when contracted by an adult.

"If you're a person who is ill or weak, like an older or younger person, these childhood diseases can really knock you around and in some cases kill you," he said.

"And even if you are a fit adult and a long life without cough doesn't affect you, too much, if you come in contact with a young baby that hasn't been immunised, that baby could get the disease and end up in intensive care and die."

Dr Deemelok said it was important for adults to enquire their GP to discuss their personal vaccination history.

"Facilities are an easy solution to a prevention problem," he said.

"The scariest people are those who talk to their doctor about their infection, the better."



Limbs amputated: amputee victim Peter Walsh, with wife Margaret, receives care at St Vincent's Hospital. Picture: TREVOR PINDEL

Lucky to be alive after infection

PETER Walsh had never considered the importance of adult immunisation until he elected death four months ago.

On September 11, Mr Walsh contracted a pneumococcal infection. These begin in the lungs and can spread to other organs and limbs.

Having lost his spleen in a work accident 36 years earlier, the former plumber was at high risk of falling seriously ill from the disease.

"I remember waking up in bed at 2am unable to feel my feet or limbs," Mr Walsh said.

"Luckily my wife, Margaret, drove me to the hospital instead of calling an ambulance, because if I had to wait another hour or so, I probably wouldn't be here today."

Mr Walsh, 60, of Cobden, doesn't remember much about the two days after his arrival in St Vincent's Hospital's intensive care unit.

But he does recall coming off the support and discovering his hands and feet were black with infection.

"I just sat there in hospital, watching my hands go blacker and blacker, and thinner

Gareth Trickey

and thinner, until they were so withered the doctor had to amputate them," Mr Walsh said.

Doctors would tell him he had contracted pneumococcal meningitis, which had invaded his bloodstream and poisoned body tissue.

The cause of Mr Walsh's infection is still unknown.

But had he received regular vaccinations against such diseases, Mr Walsh might have been spared the loss of his limbs.

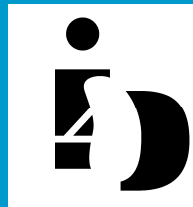
"Until this happened, I never knew how important the spleen was," Mr Walsh said.

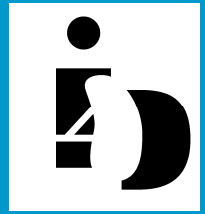
"I thought, if you lost it you could do without it. And I definitely didn't know what the need for regular vaccinations once I lost it."

Mr Walsh is learning to walk and function with prosthetic limbs.

He said his 1003 should serve as a stark warning to other adults who failed to come up for regular immunisation and booster shots.

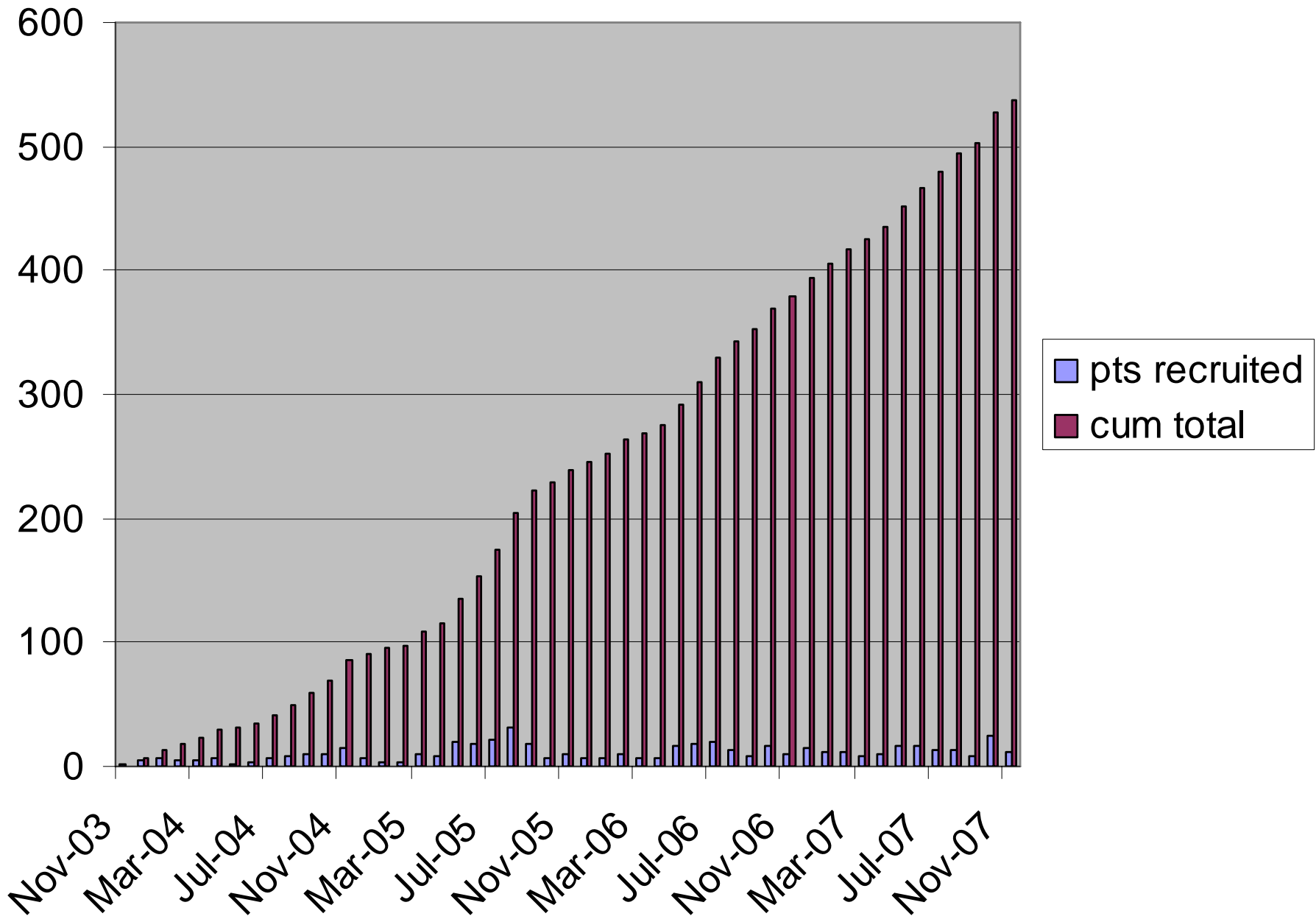
"I'm just grateful I'm still alive and that I've been given a second chance," Mr Walsh said.



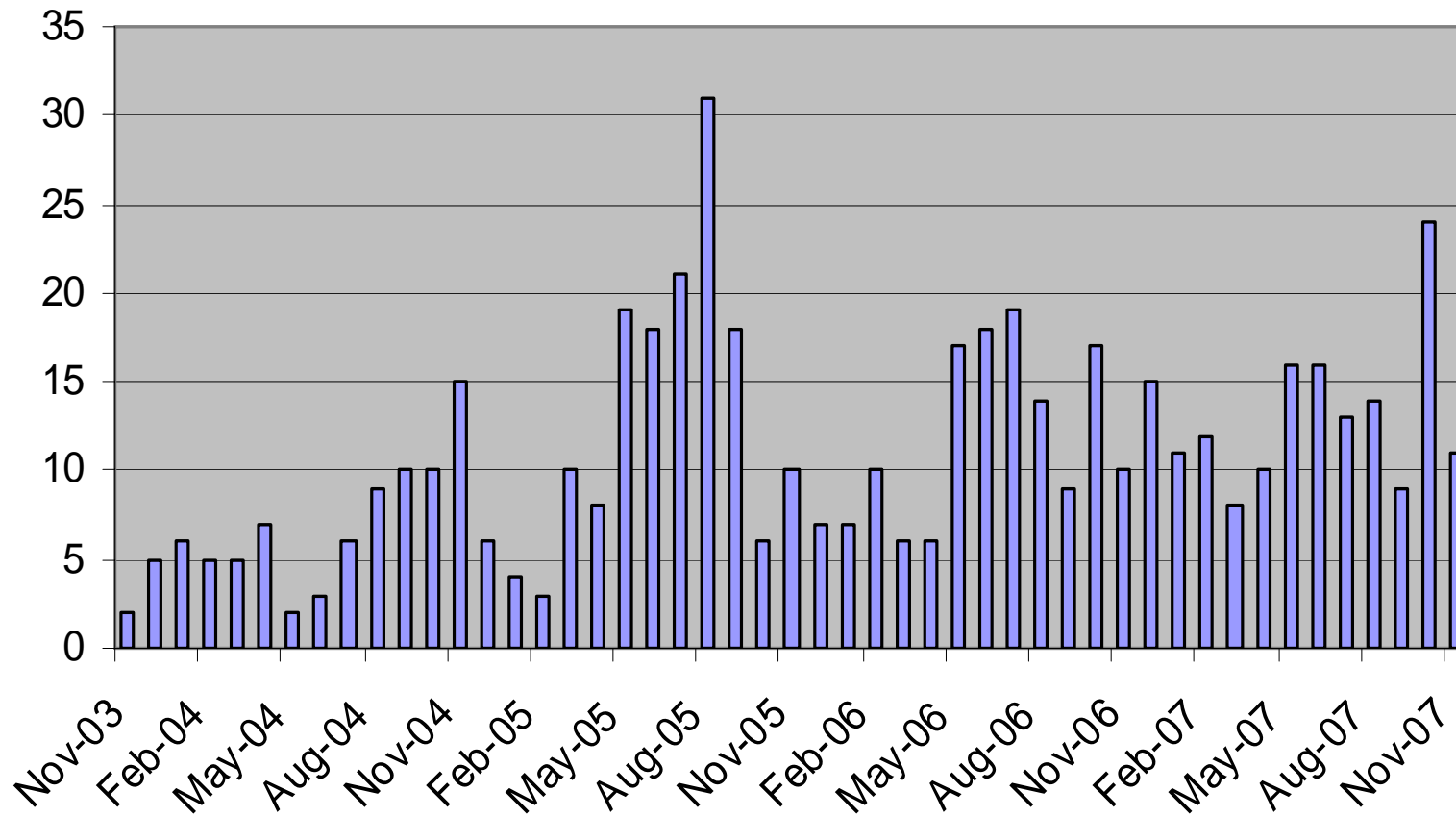
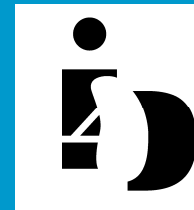


Strategies to reduce infections

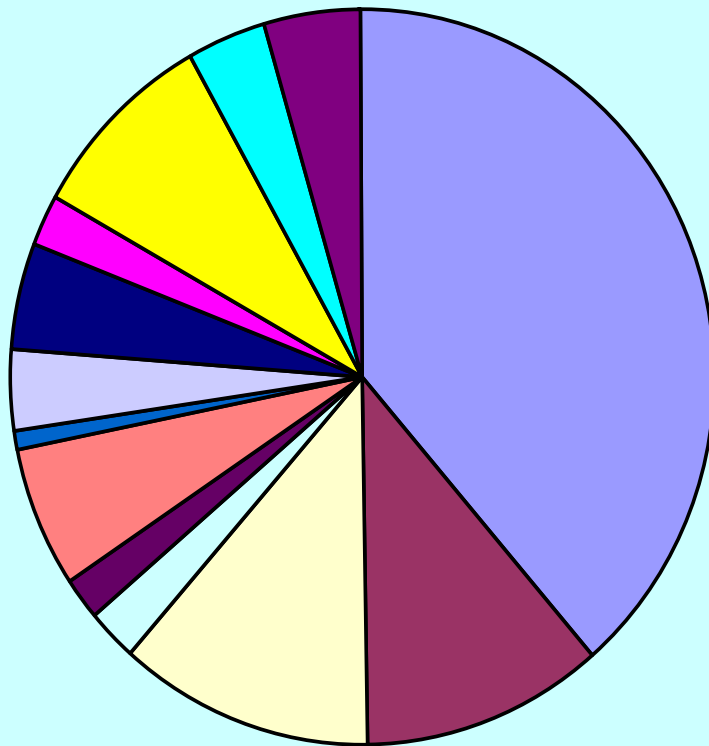
- EDUCATION – receive education kit reminders (annual newsletters)
- VACCINATIONS – against pneumococcal & meningococcal, *Haemophilus influenzae B* & annual flu shot
- ANTIBIOTICS



Monthly recruitments to VSR November 2003 – November 2007



Distribution of medical centres where splenectomies have been performed



- Alfred
- DDH & MMC
- Other Public Melb
- RMH
- Box Hill
- Private Melb
- Frankston
- Geelong
- UNKNOWN
- RCH
- Country Vic
- Interstate
- OS

Victorian Spleen Registry



COHORT n= 554

Male 320 (58%)

Female 234 (42%)

Age mean 48 years (2-85)

Young people n=19 <18yrs old

Deaths n= 37 (6%)



Incident cases 50%

Retrospective cases 50%

- * ?systematic identification of cases with PH of splenectomy – often these patients have not ever been educated or received vaccinations
- * Monash Medical Centre record review – offered VSR registration to patients identified

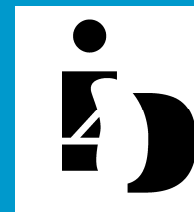


Registered Cohort n=554

- Splenic artery embolisations n= 31
- Non surgical (hyposplenic) n= 10
- Splenectomies n= 513

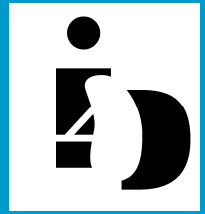
**Total database n = 640
with 86 patients with minimal information**

Victorian Spleen Registry



REASONS FOR SPLENECTOMY n= 513

Trauma	227	(45%)
Haem (ITP & HS) disorders	102	(21%)
Haem malignancies	41	(8%)
Incidental at surgery	52	(8%)
Cancer	35	(7%)
Pancreatic disorders	11	(2%)
Spontaneous rupture	9	(2%)
Other (unknown, cysts, Bilharzia, abscesses)	36	(7%)



REGISTRY mantra

- Ascertainment: 100% of cases
- Data: Wonderfully accurate and excellent quality data

VSR notifications



Key people

?Mandatory reporting

Pathologists

Surgeons

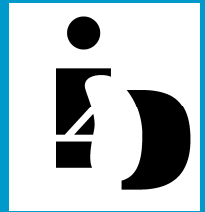
ID Physicians

Medical records

GPs

Self referrals

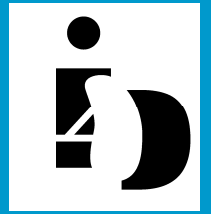
Snowballing – word of mouth



100% Ascertainment
would only work with

“OPT OUT” process

- ALFRED Ethics approval for pathologists to release UR and instant ID referral
- Seeking same at other Centres



VSR registrations

- Over phone
- Post
- Fax
- On-line



“Education kit”

- Patient information sheet
- Medical recommendations
- Wallet sized alert card
- Wallet sized vaccination card
- Fridge magnet
- Fridge information card
- Pamphlet for alert medallion
- 2007 Newsletter
- VSR contact details

RECOMMENDATIONS FOR THE PREVENTION OF INFECTION IN ASPLENIC (OR HYOSPLENIC) ADULT PATIENTS

RECOMMENDATIONS FOR THE PREVENTION OF INFECTION IN ASPLENIC (OR HYOSPLENIC) ADULT PATIENTS

SPLEEN REGISTRY NEWSLETTER
April, 2006



The Spleen Registry is pleased to send you this newsletter, our second in what we hope will be an annual event. For those of you who are a new to the Registry, welcome. The purpose of this newsletter is to update and remind you of the preventative strategies recommended following splenectomy or hyposplenism. We will also keep you up to date with the progress of the Spleen Registry and any new developments.

THE SPLEEN REGISTRY

The Spleen Registry commenced enrolling patients in December 2003, and also includes patients from throughout Victoria, and also includes patients who have had or impaired their spleen, or have a poor spleen function, or have had or impaired their spleen, or have a poor spleen function, or have had or impaired their spleen, or have a poor spleen function.

I have had a splenectomy or have a poorly functioning spleen (hyposplenism).
This puts me at risk of overwhelming infection, especially pneumococcal.

I am to show this card every time I see a new doctor or if I am unwell with fevers or shivers.

SPLEEN
I must always carry this card

PATIENT ALERT
Please refer to Patient Alert Sheet for details.



For PATIENTS POST SPLENECTOMY or with HYOSPLENISM
SPLLEN REGISTRY



MedicAlert
Not Profit Organisation



INFORMATION FOR PATIENTS ABOUT THEIR SPLEEN CONDITION

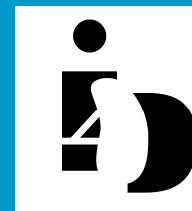
What does the spleen do?
The spleen is responsible for making and storing various kinds of blood cells. It also destroys old red blood cells but in particular, it manufactures phagocytes (white blood cells) that fight and overcome harmful bacteria. The spleen's role of filtering and removing bacteria from the blood is a very important one.

If you have had your spleen removed (splenectomy) or have a poorly functioning spleen common infections probably will not worry you, but sometimes serious infections develop quickly. The risk of serious infection is always present, it is small and we believe is lifelong for all people who have had a splenectomy or who have had a diagnosis of a poorly functioning one. These at highest risk are children.

What are you recommending I should do to manage my condition?

1. Inform your GP that you have a "spleen condition".
2. Consult your doctor immediately if you are unwell ie, with fevers or shivers. The majority of illnesses will be minor and easily treated however early diagnosis of serious infections is essential and may be life saving.
3. Have vaccinations (against pneumococcal & meningococcal infections) to help prevent you from getting some of these infections. We recommend that you have the pneumococcal and meningococcal vaccine every 5 years: flu injections every year and Hib vaccine once.
4. Carry a "wallet card" or wear a medical alert identifying bracelet or necklace, stating your condition, with you at all times.
5. **Take antibiotics every day** to help prevent getting some of these infections.
6. Keep an emergency supply of antibiotics - Amoxycillin 3gms, (or if allergic to penicillin Erythromycin 2gms) at home/on holidays for situations eg, when you cannot get to a doctor quickly.
7. Seek travel advice from a medical practitioner who is aware of your condition. Extra vaccinations or special precautions to prevent malaria may be necessary.
8. Seek medical advice if you receive any animal bites eg, cat or dog bites/scratches as they can cause different types of infections. Beware of tick bites ie, when camping as they too can cause worrisome infections.

SPLEEN REGISTRY @ The Alfred (03) 9276 3828 or (03) 9276 3009



OTHER VACCINES	Name	Date Received	When Next Due				


Name:

Alfred UR number:

Date of birth:


Spleen Registry Number:

Spleen Registry contact details
(03) 9276 3828 or (03) 9276 3009



**For PATIENTS
POST SPLENECTOMY
or with
HYOSPLENISM**

SPLEEN REGISTRY



ALFRED
A member of **SUNSHINE HEALTH**
Infectious Diseases Unit
The Alfred Hospital

IMMUNISATION RECORD

I have had a splenectomy or have a poorly functioning spleen (hyposplenism).

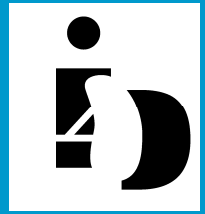
This puts me at risk of overwhelming infection, especially pneumococcal.

I am to show this card every time I see a new doctor or if I am unwell with fevers or shivers.

I must always carry this card in my wallet or purse.

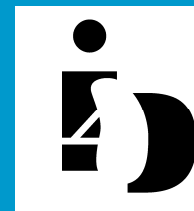
PNEUMOCOCCAL	MENINGOCOCCAL	FLU																																																																																																															
<p>Vaccine names: Pneumovax 23</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr><th>Date</th><th>Given by</th><th>Next due</th></tr> </thead> <tbody> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> </tbody> </table> <p>Boosters every 5 years</p>	Date	Given by	Next due																									<p>(i) conjugate</p> <p>Vaccine names: Menjugate, Meningitec or NeisVax-C Only need once</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr><th>Date</th><th>Given by</th><th>Next due</th></tr> </thead> <tbody> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> </tbody> </table> <p>(ii) polysaccharide</p> <p>Vaccine names: Menoveax, ACWY or Menomune</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr><th>Date</th><th>Given by</th><th>Next due</th></tr> </thead> <tbody> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> </tbody> </table> <p>Boosters every 5 years</p>	Date	Given by	Next due																									Date	Given by	Next due																									<p>Vaccination</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr><th>Date</th><th>Given by</th><th>Next due</th></tr> </thead> <tbody> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> <tr><td> </td><td> </td><td> </td></tr> </tbody> </table> <p>To have every year</p>	Date	Given by	Next due																											
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- THINGS FOR ME TO REMEMBER
- Keep up to date with my vaccinations (pneumococcal, meningococcal, haemophilus influenzae type B and flu)
 - Take oral antibiotics for life
 - Carry a medical alert bracelet or pendant
 - See my doctor if I get unwell and for regular vaccinations
 - Keep an emergency supply of antibiotics and take if I cannot get to a doctor
 - See a doctor before I travel overseas
- SPLEEN REGISTRY / The Alfred
Assoc. Prof. Denis Spelman (03) 9276 3009



ESTABLISHING REGISTRY DOCUMENTS

- **Pilot**
- **Network** (attend CCRE Registry meetings)
- **Sharing** (Peter Cameron, Chris Reid & Angela Brennan)
- **Experts** (John McNeil, Jane Halliday, Peter Cameron)



Sharing – VSR with others

Plain language statement (pt info sheet)

What about my privacy?

OLD WORDING: “Access to your information will only be granted to those working on the registry. We will obtain your consent if any research is undertaken using this data”.

NEW WORDING: Deleted 1st line

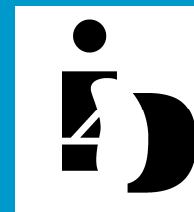
“In the future the VSR may like to use information provided to the registry for research. All research activities require ethics committee approval.”

VSR

“Going state-wide”



- DHS Funding \$99,600 for 1 yr (commenced 1/7/07)
- Sought 3 yrs
- Staffing
- Focus incident cases
- Generic forms (remove Alfred logos)
- Registration forms (fax/on-line)
- Database
- ID (Registrars) departments responsible for patient management



VSR "other sites"

Other Centres (non Bayside Health)

RMH

St Vincents Health (St Vs)

Austin Health

Southern Health

Eastern Health

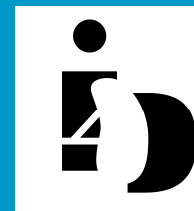
Peter Mac

Northern Health

RCH

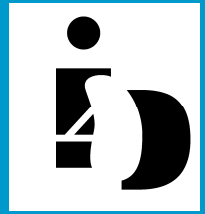
Approval processes –
separate for each?

Streamline?



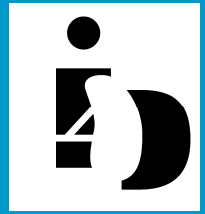
Quality Improvement / Clinical Audit	Research
Audit to evaluate established practices	Testing a new practice, therapy, drug
Answer often known, measuring against it	Questioning to find the answer
Non-invasive	May be invasive
No randomised groups	Randomisation
No informed consent required	Informed consent
May or may not involve patient contact	Direct patient contact
May or may not be published	Published in professional literature

VSR state-wide process



- Ethics Applications – “courtesy”
- ID Units notify HREC that referring (eg RDNS)
- QA project – patients are “referred”
- Opt-out – OK (in principle)
- Documents submitted
 - Registration form
 - Patient information
 - Recommendations
 - Guidelines for ID Registrars
 - Letter to seek support from surgeons
 - Letter for patients after discharge
 - Terms of Reference

VSR Issues



- Patient ownership issues
- Ongoing funding
 - publications
 - large numbers on database
 - excellent auditing process
 - cost effective
 - evaluation processes



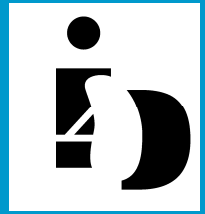
Database issues

Lost to follow up patients

- “three strikes and you’re out” (inactive)?

Data integrity -cleaning the data

- Auditing other referring centre’s medical records –how important for us?
- Expensive



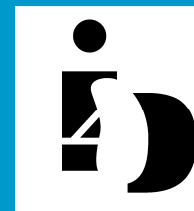
Governance

Who owns the registry?

Who do we answer to?

What structures should be in place?

Who has access “custodians of registry”?

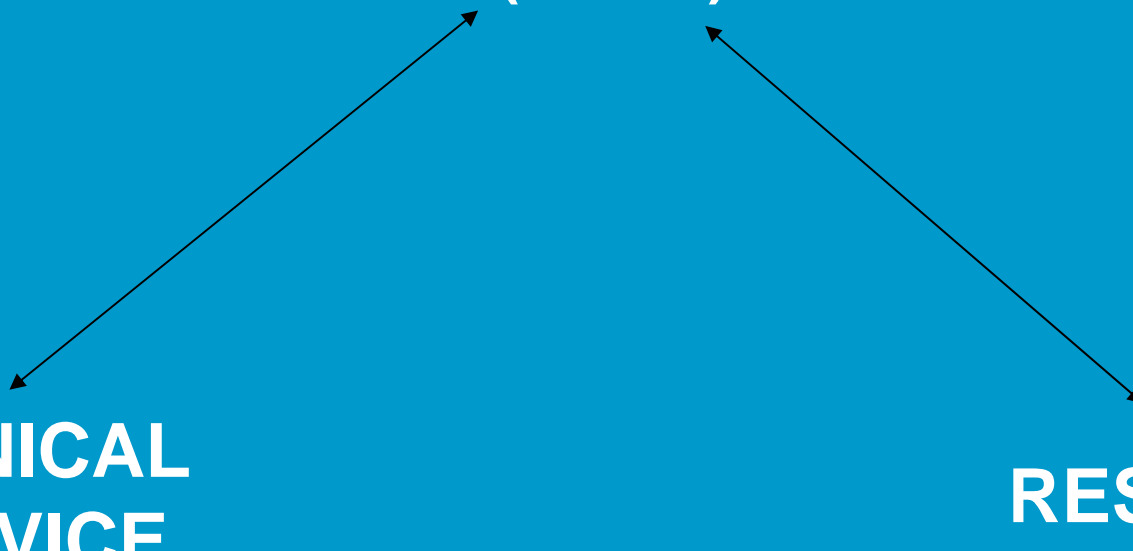


VSR State-wide REGISTRY

(admin)

**CLINICAL
ADVICE**
(info service)

RESEARCH
(ethics)





ROLES

1. Clinical

Telephone support + + +

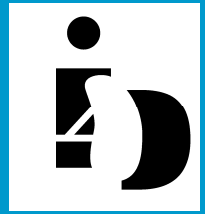
pregnancy & breastfeeding – vaccinations/antibiotics

OC pill & HRT as increased thromboembolic risk

VSR 3 options –

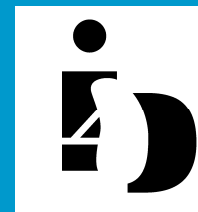
- ❖ No talk administration only
- ❖ Talk only to registry documents
- ❖ Offer wider advice?

Educate other medical practitioners, nurses,
pharmacists, pathology, trauma departments etc



2. Research

- Follow up of embolisations patients
- HIV/AIDS patients post splenectomy
- Haematological markers after splenectomy
- Pneumococcal vaccinations and IgM responses (Drug Co Funding)



VSR – RESEARCH undertaken

- **Cost Effectiveness Study** – collaboration with **Dr Lisa Gold**
Cost effectiveness of a post-splenectomy registry for prevention of sepsis in the asplenic.
Aust N Z J Public Health 2006; 30: 558-61
- **Education Assessment Study** (in progress)
- **IgM memory B cell** (in progress)
- **Establishment of a Spleen Registry** (in progress)
- **ASID guidelines** (in press)

VSR issues



- Process for notification
 - What if pathologists don't agree?
Allow alternate process or not?
- Streamline approvals?
 - Are most registries considered QA or research?
 - Central approval?
- How clinical role fits in?

