

Spring 2014

# FH Awareness Day

  
support group  
**FH**  
NEWS



## Welcome

It has been a busy few months for the support group with *FH Awareness Day*, FH Facebook page and our Chair attending the **Health Consumer Advocacy Workshop** in Sydney. The workshop provided an opportunity to network, share knowledge and develop practical skills in the area of health advocacy.

## FH Support Group meeting

15 December - see p3

## Thank you!

Thank you to the **Genetic and Rare Disease Network (GaRDN)** for printing these newsletters and providing facilities for our meetings.

## Have a happy and healthy Christmas holiday!

*FH Support Group*

## Facebook page – FH Australasia



The support group has started a Facebook page -

## FH Australasia

Visit

<https://www.facebook.com/pages/FH-Australasia/705959379457660>

The aim of the **FH Australasia** page is to share, post, and discuss topics and ideas that are relevant to the FH community in Australia and New Zealand.

You will need to join Facebook to 'like,' 'comment' or 'share'.



Don't want to join Facebook?

You can still see the page, just click on the above link or Google 'FH Australasia Facebook' (should be the first result), then add to your 'Favourites' list.

You are invited to an  
**Information evening**

**Amazing new treatment for FH - PCSK9 inhibitors**  
**Lobbying to have PCSK9 inhibitors put on the PBS**  
(What are PCSK9 inhibitors? See pages 4 and 5 for more information.)



**When:** Monday, 15 December 2014

**Time:** 7:00pm – 8:00pm including question time

**Where:** Oasis Lotteries House  
37 Hampden Road, NEDLANDS

**Speaker:** Professor Gerald Watts (FHWA)

**Who would want to attend?**

- people who want to know about a new treatment for FH
- people on statins and having some side effects
- people who are statin intolerant
- people on the maximum dose of statins and unable to reach their target LDL levels

**RSVP:** Phone/text Annette on 0408 276 780  
or email [fhfamilysupportgroup@hotmail.com.au](mailto:fhfamilysupportgroup@hotmail.com.au)

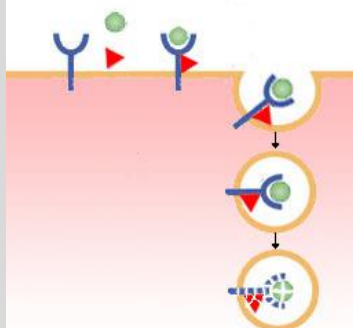
**Please attend if possible. The more people we get on board the more likely we are to succeed in getting PCSK9 inhibitors put on the PBS.**

## PCSK9 inhibitors - new treatment for FH

(PCSK9 — proprotein convertase subtilisin/kexin type 9)

N.B. The more LDL receptors you have the lower your LDL tends to be. People with FH have high LDL because half their LDL receptors are not working properly (most common form of FH).

PCSK9 was discovered in 2003 and plays a key role in the metabolism of LDL; but not in a good way.

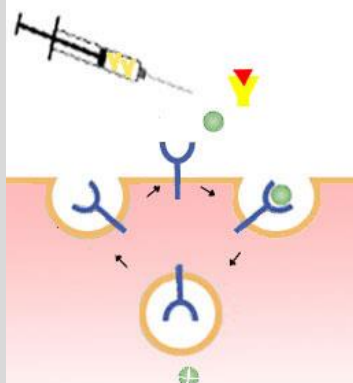




Normally LDL and PCSK9 bind to the LDL receptor on the surface of the liver cell.

The complex is taken into the cell.

**PCSK9 triggers the LDL receptor to be broken down.**

This results in fewer LDL receptors being available on liver cells to remove LDL from the blood. So PCSK9 is working against people with FH - destroying valuable LDL receptors!



A new class of drugs called PCSK9 inhibitors (or PCSK9 monoclonal antibodies ) binds with the PCSK9  so it can't bind to the LDL receptor.

Without PCSK9, the LDL receptor is recycled back to the surface of the cell so it can remove more LDL from the blood.



- PCSK9 inhibitors are proteins and can only be given as an injection (once or twice monthly) as they will be digested if taken by mouth.
- Trials have shown PCSK9 inhibitors are well tolerated by statin intolerant people. Short-term studies show no serious side effects. The most common side effect was related to the injection site.
- In Australia PCSK9 inhibitors are available only for people participating in clinical trials, some of which offer the treatment on compassionate grounds.
- Many experts believe PCSK9 inhibitors provide the most promising alternative for lowering of LDL since the development of statins 30 years ago. PCSK9 inhibitors are able to lower LDL more effectively than the highest doses of the most powerful statins. People have had reductions of LDL levels up to 70% (see table page 8 for % reduction of LDL you are getting on your current statin).
- PCSK9 inhibitors can be given with a statin to get an even greater reduction in LDL.
- Results from long-term trials to assess the efficacy of PCSK9 inhibitors at preventing heart attacks and cardiovascular disease are pending.
- In September 2014 **preliminary** results were announced that one PCSK9 inhibitor had approximately halved the number of heart attacks and strokes.

## ABC Health Report

Cholesterol Levels - Researchers have made a discovery that could get cholesterol levels down to amazingly low levels.

**Monday 12 November 2012** (old but still relevant)

Visit

<http://www.abc.net.au/radionational/programs/healthreport/cholesterol-levels/4366982> for a discussion between Dr Norman Swan and Dr David Sullivan (Staff Specialist and Head of the Lipid Clinic Royal Prince Alfred Hospital, Sydney).



# FH Awareness Day



25 September was the inaugural *FH Awareness Day* in Australia. We were one of 14 countries across the world working together to increase the diagnosis of FH.

## Highlights:

- Display on the 'Bridge' at Royal Perth Hospital.
- Display and talk at Princess Margaret Hospital.
- FH Awareness Day also coincided with *National Awareness Expo* at Garden City Shopping Centre. We took this opportunity to raise awareness of FH.



Red heart shaped balloons and 'FHUN the FH dog' were given to passing children and red heart shaped lollipops were given to passing 'children at heart'.

The lollipops and balloons had a label with a short description of FH. Over 1300 lollipops and five hundred balloons were distributed over the three days; raising the awareness of FH. We came across several people who may have FH in their family.

Thank you to all those who participated and to all those who stopped by with encouragement!





- We also had an article published in the *Melville Times*. A special thank you to Lisa and her family for sharing their story.



To read the full article: <http://www.inmycommunity.com.au/shopping-and-lifestyle/health-and-wellbeing/Health-a-family-matter/7664862/>

## What reduction in LDL does your current statin give you?

Vytorin contains two cholesterol medications (Ezetimibe and Simvastatin) in a single tablet.

% LDL Reduction	Simvastatin (Zocor)	Atorvastatin (Lipitor)	Rosuvastatin (Crestor)	Fluvastatin (Lescol)	Pravastatin (Pravachol)	Ezetimibe/Simvastatin (Vytorin)
<24%	5 mg			20 mg	10 mg	
25-32%	10 mg			40 mg	20 mg	
31-39%	20 mg	10 mg		80 mg	40 mg	
37-45%	40mg	20 mg	5 mg		80 mg	10/10
48-52%	80 mg	40 mg	10 mg			10/20
55-60%		80 mg	20 mg			10/40
60-63%			40 mg			10/80



N.B. You may be on additional medication e.g. Ezetimibe which will give you even greater reductions in your LDL.

\* Always seek medical advice from **your doctor** or healthcare provider.



## Why you need to keep an up-to-date record of your medications

You should keep a written record of all the medications you take.

**Keeping a copy in your wallet or purse may also be useful.**



The reasons are:

- If you see several doctors, each may not be aware of medications the others have prescribed.
- Since people differ in their response to medications, it's common for doctors to prescribe several medications and/or doses before finding one that works best for you. Your medications may change several times in a short period of time, making it difficult to remember the changes.
- Many people take several prescription medications, non-prescription medications, and dietary supplements at the same time. They can interact in ways that can either reduce the benefit you get from the medication or be dangerous.
- The names of prescription medications (both generic and brand) are often hard to pronounce and remember.

It is important to keep a written record of all the medications and supplements (including doses) you take and periodically review it with your doctors and pharmacist.

## Smoking and heart disease

**This article is written for people who don't have FH. If you have FH and smoke you have an even GREATER risk of cardiovascular disease than quoted.**



### Summary

**Cigarette smoking is a major cause of heart attack, stroke and peripheral arterial disease. Nearly 40 per cent of all people who die from smoking tobacco do so due to heart and blood vessel disease. A smoker's risk of heart attack reduces rapidly after only one year of not smoking.**

Smoking is a major cause of cardiovascular disease (heart, stroke and blood vessel disease). Smoking kills more than 15,000 Australians a year (more than 40 Australians each day) and nearly 40 per cent of all deaths from smoking are due to cardiovascular disease.

### Smoking damages the heart and blood vessels

The heart relies on a generous supply of oxygen and nutrients from the two coronary arteries and their branches. Over the years, fatty deposits (called plaque or atheroma) can build up inside one or more of the coronary arteries (a process called atherosclerosis). This narrowing of the arteries reduces the flow of blood to the heart and increases the risk of heart attack. **Smoking speeds up the clogging and narrowing of coronary arteries.**

**Smoking causes 'stickier' blood, which is more prone to clotting.** A heart attack occurs when a blood clot forms at a narrowed point in a coronary artery and suddenly blocks the flow of blood to the heart. If the artery remains blocked, the lack of blood supply permanently damages the area of heart muscle supplied by that artery. The severity of the heart attack depends on how much heart muscle is permanently damaged.

**Smoking also speeds up atherosclerosis and damages other blood vessels.** This 'peripheral arterial disease' can reduce blood circulation, particularly to your hands and feet, and result in blood clots, gangrene and even amputation.

## Some facts about cigarette smoke

Cigarette smoke contains thousands of chemicals including:

- Nicotine – an addictive drug that affects brain and muscle activity and **increases your blood pressure**, making your heart work harder
- Carbon monoxide – a poisonous gas that replaces oxygen in your blood, **making your heart beat faster**
- Tar – a sticky substance that coats your lungs like soot in a chimney, **making it harder for you to breathe**, and that contains dozens of chemicals that cause cancer.

## The risks of cigarette smoking

If you smoke, your risk of:

- Heart attack is increased by two to six times
- Coronary heart disease is increased if you are a woman using the contraceptive pill
- Stroke is increased by three times
- Peripheral arterial disease, which can lead to gangrene, is increased by more than five times.

## Second-hand smoke is a health hazard

Exposure to second-hand smoke (passive smoking) is a serious health hazard for smokers and non-smokers. People who inhale smoke from others are at increased risk of disease.

- Non-smokers living with smokers have about a 30 per cent increase in risk of heart disease.
- Exposure to second-hand smoke is especially risky for children and babies, and increases the risk of sudden infant death syndrome (SIDS), bronchitis, pneumonia and asthma.

## Quit smoking and improve your health

Within one day of quitting smoking:

- Your heart rate slows down and your blood pressure drops slightly.
- Carbon monoxide is out of your blood.
- Oxygen levels in your blood rise.

Within two to three months:

- Your ability to smell and taste improves.
- Your lungs regain the ability to clean themselves, so you can cough up mucus.
- The blood flow to your hands and feet improves, so they won't get so cold.

Within one year:

- Your risk of heart attack is greatly reduced.
- If you smoked a packet of 25s a day, you would have saved over \$4,500.

Within two to six years:

- Your risk of developing coronary heart disease returns to a similar level as that of a non-smoker.

## Where to get help

- [The Heart Foundation](#) Tel. 1300 36 27 87
- Your doctor
- Pharmacist
- Talk to your family and friends
- Self-help materials and quit smoking courses
- Call the [Quitline](#) Tel. 13 7848 (13 QUIT) for information and advice.

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