

Do you have
high cholesterol?

Do other members
of your family have
high cholesterol or
early heart disease?



Kindly supported by
 **ConnectGroups**
helping support groups & individuals


support group
FH
NEWS

Welcome

Thank you for the feedback from the Autumn 2014 newsletter.

Remember to email anything you would like to share to fhfamilysupportgroup@hotmail.com.au

FH Support Group meetings

- 11 August - see p3
- 13 October
- 8 December

7 – 8 pm

Oasis Lotteries House
37 Hampden Road
NEDLANDS

All welcome

Thank you!

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

*FH
Support
Group*

FH Support Group banners

(banner 1 – cover)

The support group received funding from the Mental Health Commission, through ConnectGroups (Support Groups Association WA), for three banners to raise awareness of FH in the community.



The banners were designed by the support group and our logo features prominently in the design.

The banners have been displayed at Royal Perth, Sir Charles Gairdner and Fremantle Hospitals and are now heading to other hospitals and government departments.

My Statin Status

My Statin Status^{*1} is an online^{*2} tool designed for people who are taking statins and having side effects. After a series of questions, a report summarising your symptoms is created, which you can print and take with you to your doctor.

Visit <http://www.mystatinstatus.co.uk/>

^{*1}AstraZeneca funded the design and delivery of the *My Statin Status* tool and worked collaboratively with [HEART UK](http://www.heartuk.org.uk) in its design. Please note you are being directed to a UK site and any questions or feedback about the tool should be directed to the UK office. Their email address

is: medical.informationuk@astrazeneca.com

^{*2} Unfortunately it does not work on some older versions of Internet Explorer.



You are invited to an
Information evening and FHSG meeting

Lifetime risk and managing children with FH
and other FHWA information

When: Monday, 11 August 2014

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

Where: Oasis Lotteries House
37 Hampden Road, NEDLANDS

Speaker: Professor Gerald Watts (FHWA)

RSVP: Phone/text Annette on 0408 276 780
or email fhfamilysupportgroup@hotmail.com.au

Places are limited to 40, and allocated on a first come first served basis.



FH Awareness Day – 24 September

The FH Support Group is joining with the [FH Foundation](http://www.fhfoundation.org) in the US to raise awareness of FH on 24 September. 80% of people with FH are currently undiagnosed, that is around 5,000 people in Western Australia. *FH Awareness Day* will put FH in the public eye.

As part of *FH Awareness Day* we are trying to get articles about FH

published in local community newspapers. We are URGENTLY looking for people/families (from each paper's distribution area) willing to have their experiences of FH published (a few comments and a photograph - see [Draft newspaper article](#)).



If you are interested in helping raise awareness of FH by appearing in your local community newspaper, please phone/text Annette on 0408 276 780 or email fhfamilysupportgroup@hotmail.com.au



Putting my child on statins - a parent's journey

I sat nervously listening to Professor Watts describe the current recommendation that you start children with FH on statins, boys at the age of 10 and girls at their menarche (onset of periods).

Many years ago I had discussed my son's high cholesterol with my GP who had said 'He will need to go on to medication at some stage, but the question is when'. At that time there was no suggestion of putting children on statins and as a result I had always thought of statins as an 'adult' medication and that he would go onto medication when he was older. This was adding to my dilemma of whether I should consider putting him on statins at the age of 11.

I went home and immediately searched the Internet (Dr Google I call it) and discovered that this was the recommended age in many countries for prescribing statins to children, although some prescribed them from an even younger age. I also read the FH Facebook page and the opinion of other parents was that early treatment with statins would significantly reduce the risk of heart disease.

For those of us with FH, we know we have high cholesterol levels from birth and we start laying down cholesterol (plaque) in our arteries from birth; this process is called atherosclerosis. It has been shown that by age 10, fatty streaks (the first stage of atherosclerosis) may be present. This evidence supports the argument for early treatment; the sooner treatment starts and lowers cholesterol, the sooner there is a decrease in the atherosclerotic process, thus decreasing the risk of early onset of heart disease.

Short-term studies have shown a decrease in the thickness of the carotid artery in children taking statins, although there has been no long-term studies on the effectiveness of treatment starting in childhood. There is no question that statins have led to significant reductions in heart attacks/disease in adults, which is strongly evident by my family history. My brother and I started taking statins when we were in our 20s and we have lived longer than our father (died at 35) who didn't have the benefit of statins. I made the decision to put my son on statins when his DNA test came back positive. I hope that starting him on statins at an even earlier age will mean that he will have a normal life expectancy.

'Data suggests that early treatment with statins will reduce risk to a level similar to those without FH... noting that early treatment is more effective at lowering LDL cholesterol than waiting until later in life'

I feel given our family history, my son's high cholesterol levels, what I have read and the advice I have been given by the Lipid Clinic doctors, the decision to put my son on medication early was the right decision. You may feel differently about putting your child on medication; if you don't have a strong family history of early heart disease/death or if you have side effects to statins - your decision is more difficult. Unfortunately most people with FH will require medication - for children the question is, when is the best time to start?

My son has been on statins for a year now and there seems to be no psychological or physiological effects from being diagnosed with FH or taking medication. He is under the care of Dr Andrew Martin at PMH.

I am thankful that an effective treatment for FH currently exists and that my family has been diagnosed and we are all receiving the best (world-class in fact) treatment available.

What does the future hold? There are lots of promising new treatments on the horizon and I am sure that my son won't be on statins all his life; that there will be better alternatives for him in the not so distant future.

If you wish to read the article **Familial hypercholesterolaemia in children and adolescents: A new paediatric model of care** (Martin AC, Watts GF et al.) email fhfamilysupportgroup@hotmail.com.au.



Women less likely to survive a heart attack than men

Heart Foundation media release 13 June 2014



Alarming statistics show Australian men suffer twice as many heart attacks as women each year, yet the same number of men and women will die from them.

Each year 36,000 men and 19,000 women are admitted to hospital after a heart attack while annual death rates of men and women number 4,700 and 4,500 respectively.

Delays in treatment and lack of awareness could be partly to blame for women's low survival rate according to a new survey of heart attack survivors released by the National Heart Foundation of Australia today.

The survey of 504 heart attack survivors is being used to raise awareness of women's heart health as part of the Heart Foundation's [Go Red for Women](#) campaign. (This campaign was run in June).

The Heart Foundation's women's health spokesperson, Julie Anne Mitchell said the survey uncovered a number of key differences for women:

"Part of the reason women are less likely to survive is that they're slower to recognise the warning signs of a heart attack, slower to seek help, and when they do get to hospital there is evidence to suggest they're less likely to receive life saving treatment than men."

The survey shows women often don't experience the typical warning signs of a heart attack, with only 27% identifying chest pain as the first symptom, compared to 37% of men. While more than 40% of women said they didn't



experienced any chest pain during the onset of their heart attack, they were significantly more likely to experience arm pain than men.

Women are also far less likely to react by seeking medical help (39% of women compared with 52% of men), but are more likely than men to tell a friend or family member (35% vs 25%).

"This is alarming because the faster you get to hospital the better your chances of survival," Ms Mitchell said

"We also know that **women are less likely to receive heart related procedures** than men when they reach hospital - such as angiograms, bypasses and stents. On top of that, **women have higher in-hospital death rates** and if they do survive, they're **more likely than men to die of a second heart attack**."*

“It’s important that women not only learn all the warning signs of a heart attack but that they act quickly by calling Triple-0 (000) for help. Treatment can start once that call is made.”

“Many people think that heart disease only affects older men, but in reality heart disease is the single biggest killer of Australian women, killing three times the number of women than breast cancer,” Ms Mitchell said.

*See related media release [Women missing out on life-saving heart care](#)

Invitation



THE UNIVERSITY OF
WESTERN AUSTRALIA

2 Community Conversations on medications and heart disease

9th July & 6th August 2014
12noon - 2.30pm **The Niche - Nedlands**



**Investigating the long-term use of medications
in people with heart disease**

RSVP expression of interest by 4th July and 1st August
 PHONE 6488 8176 or 9489 7742
 EMAIL ipir@telethonkids.org.au
 VISIT www.involvingpeopleinresearch.org.au
Payment for out of pocket expenses and light lunch provided

We reserve the right to make changes to the events and the right to determine the confirmed registration list.



Research results

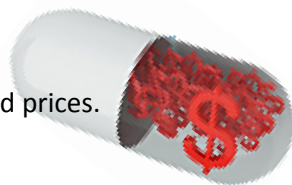
Some time ago a number of people were interviewed as part of the research project - 'Patients' Perceptions and Experiences of Familial Hypercholesterolaemia, Cascade Genetic Screening and Treatment'.

The paper is *in press*. A summary of the results are:

Thematic analysis of interviews revealed four themes: disease knowledge, severity of FH, lifestyle behavioural change and barriers to cascade screening and treatment. Participants recognised FH as a permanent, genetic condition that increased their risk of CHD and premature mortality. Many participants dismissed the seriousness of FH and the importance of lifestyle changes because they perceived it to be effectively managed through medication. Despite positive attitudes toward screening, many participants reported that relatives were reluctant to attend screening due to their relatives' 'fatalistic' outlook or low motivation. Participants believed that they had insufficient authority or control to persuade family members to attend screening and welcomed greater hospital assistance for contact with relatives.

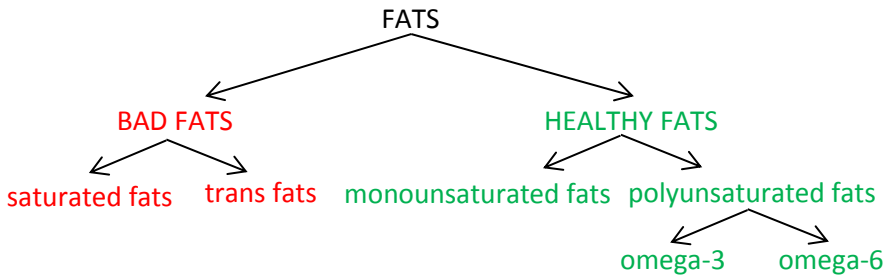
Medication at reduced prices

Discount pharmacies sell generic brands at reduced prices. Shop around! A few examples are listed below:



Medication	Chemist Warehouse *	Pharmacy Direct (online)
Atorvastatin 40mg X 30	Sandoz \$14.99 Lipitor \$24.99	Apo \$14.99 Pfizer \$19.99 Lipitor \$24.99
Rosuvastatin 10mg X 30	Sandoz \$19.99 Crestor \$36.90	Apo \$19.99 Crestor \$36.90

*Further discounts apply for bulk purchases. Buy online or in store.



Healthy fats

Healthy fats include monounsaturated fats and polyunsaturated fats - omega-3 and omega-6. These fats reduce the 'bad' LDL cholesterol in your blood and increase the 'good' HDL cholesterol. This helps to lower your risk of getting heart disease.

Monounsaturated fat is found in foods such as avocados, almonds, cashews, peanuts and cooking oils made from plants or seeds such as sunflower, canola, soybean, olive, sesame and peanut oils.

Avocado and nuts can be added to salads and a handful of unsalted nuts make a healthy snack any time of the day. Try a handful of almonds sprinkled over breakfast cereal.



Polyunsaturated fat (omega-6) is found in foods such as fish, tahini (sesame seed spread), margarine, linseed (flaxseed), sunflower and safflower oil, pine nuts and brazil nuts.

- Tahini can be used as a spread on crackers instead of butter or used as a base for dips, sauces and stews.
- Choose margarine made from sunflower and safflower oils, and use instead of butter on sandwiches and toast.
- Sprinkle ground linseed on breakfast cereal or choose wholegrain bread with linseeds. Add pine nuts or sesame seeds to salads or sprinkle over vegetables.

Polyunsaturated fat (omega-3) can come from marine, animal and plant sources. You should try to include omega-3 oils from all of these sources as part of a healthy eating pattern.

Where to find Marine-sourced Omega-3

Marine-based omega-3 is found primarily in oily fish. Other fish, such as barramundi and flathead, and seafood, such as scallops and mussels, are also good sources of marine-based omega-3. More Information see our [Table of omega-3 levels in fish and seafood.](#)

Plant-sourced Omega-3

In addition, everyone should have at least 2 grams of plant-sourced omega-3 every day. You can achieve this by eating two slices of soy and linseed bread spread with a canola-based margarine, 30 grams of walnuts or a variety of the foods that contain plant-based omega-3s including canola oil, soybean oil and linseeds (flaxseeds).

Animal-sourced Omega-3

These are found in animal products such as eggs, chicken and beef.

How can I get my omega-3 each week?

Including 2-3 serves of fish (150 grams per serve) in your weekly eating plan is easier than you think – our [Omega-3 meal planner](#) has some great ideas. Try some of our [fish recipes](#).

What if I don't eat fish?

- Choose foods and drinks with added omega-3s. Look for the words 'with added omega-3s' on the front of the pack or check the nutrition information panel for DHA and EPA (marine source of omega-3s).
- Fish oil capsules or liquids that contain at least 500mg of EPA and DHA in a daily dose are also a good source.
- Eat more plant-based omega-3 found in canola oil and margarines, nuts and seeds (particularly walnuts), flaxseeds (linseeds), hemp oil, soybeans and dark green vegetables.

Additional information at [Q&As on omega-3s for the general public.](#)

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More on physical activity

Physical Activity Guidelines (adults 18 – 64)



- Be active on most, preferably all, days every week.
- Accumulate 150 to 300 minutes (2 ½ to 5 hours) of moderate intensity physical activity each week,
or 75 to 150 minutes (1 ¼ to 2 ½ hours) of vigorous intensity physical activity each week,
or an equivalent combination of both moderate and vigorous activities, each week.
- Do muscle strengthening activities on at least 2 days each week.

For **Physical Activity Guidelines** for children and older Australians, visit

<http://www.health.gov.au/internet/main/publishing.nsf/Content/health-pubhlth-strateg-phys-act-guidelines>

What's the difference between 'moderate intensity' and 'vigorous intensity' physical activity?

Moderate intensity physical activity requires some effort, but still allows you to speak easily while undertaking the activity. Examples include active play, brisk walking, recreational swimming, dancing, social tennis, or riding a bike or scooter.

Vigorous intensity physical activity requires more effort and makes you breathe harder and faster ('huff and puff'). Examples include running, fast cycling, many organised sports or tasks that involve lifting, carrying or digging.



People who do moderate or vigorous intensity physical activity have a significantly lower risk of cardiovascular disease than do inactive people.

Significant reductions in risk of cardiovascular disease occur at activity levels equivalent to 150 minutes a week of moderate intensity physical activity. Even greater benefits are seen with 300 minutes a week.

The evidence is strong that greater amounts of physical activity result in even further reductions in the risk of cardiovascular disease.



Regular physical activity is a powerful vehicle for improving your cardiovascular health (along with diet and medication)

People who do regular physical activity have lower rates of cardiovascular disease, stroke and diabetes and have lower blood pressure, better blood lipid profiles and greater levels of fitness.

This is because regular physical activity has shown to improve risk factors associated with cardiovascular disease. Regular physical activity

lowers:

- total cholesterol
- triglycerides
- LDL cholesterol (bad)
- systolic and diastolic blood pressure
- body fat
- blood-clotting factors

raises:

- HDL cholesterol (good)
- fibrinolytic ('clot-busting') factors
- insulin sensitivity (improves glucose metabolism, lowers the chance of diabetes)

Further, for people with any cardiovascular disease, improvement in risk factors are likely to result in improved survival and enhanced quality of life.

Anyone with cardiovascular disease or risk factors for developing cardiovascular disease should seek medical advice before engaging in a physical activity program.