

Summer 2014

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NEWS



The missing piece...



Mission Statement

The aim of the FH Support Group is to improve information, communication and support services for families with FH in Western Australia and help prevent premature deaths caused by high cholesterol and cardiovascular disease.

Welcome

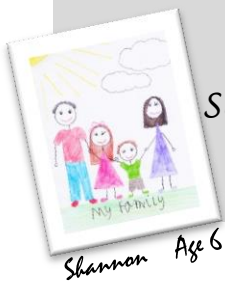
Thank you for taking the time to read our newsletter. We hope it will be informative and interesting and help make you and your family's life happier and healthier.

We would like it to be a vehicle for sharing anything FH related with other FH people.

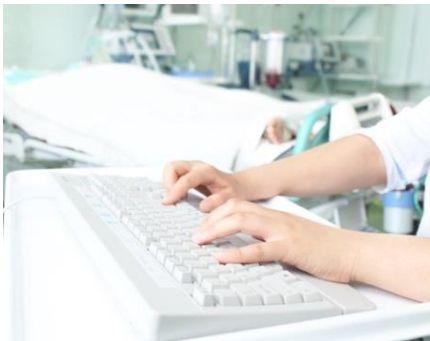
For it to be relevant to you we really need YOUR input, including teenagers and children. Please email us anything you would like to share. It can be suggestions, comments, questions, recipes, photos, personal stories, children's drawings - anything FH related, to

fhfamilysupportgroup@hotmail.com.au

*FH
Support
Group*



FH Registry



The Health Department of WA and the FH Australasia Network (which is a sub-group of the Australian Atherosclerosis Society) are currently developing a FH registry.

A registry is a place where medical information, family history and other related information from patients is collected and stored. Only those who consent will be included in the Registry.

Why would I want to be in the Registry?

Registries are a way to collect information so it can be analysed to identify disease patterns and trends, gaps in diagnosis and effectiveness of care. This will aid health system planning and the development of the best treatment options and therefore improve patient health and outcomes. The Registry will also provide equal opportunity to access the latest trials for new treatments for FH.

The Registry will collect and process data according to Australian laws and best practices and ensure privacy of the data.

More information will follow when it is available.

The ABC Catalyst Program

Australian Atherosclerosis Society - Media Release 1 November 2013

The recent ABC Catalyst program questioned whether cholesterol is an important risk factor for heart disease and suggested the benefits of statins were overstated.

This is an excerpt from Professor Gerald Watts' media release.

The program has led to many people questioning the value of lowering cholesterol to prevent heart disease. This message is dangerous for the public, especially for those with high risk conditions with inherited high cholesterol and for those with existing heart disease. Clinics have been inundated over the last week with high risk individuals questioning the value of lowering cholesterol.

A one-sided view was presented that lowering saturated fat in the diet had no benefit on heart disease and therefore lowering cholesterol was by implication not important. This view is particularly damaging for people with familial hypercholesterolaemia (FH) and other forms of high blood cholesterol that are well known to cause heart disease.

On FH

Familial Hypercholesterolaemia (FH) is the most common and serious form of inherited high cholesterol. If untreated, FH leads to chronic illness and early death from heart disease in many families.

FH accelerates by 1 to 4 decades the onset of heart disease and heart attacks. The risk is at least five-times higher than smoking or having diabetes. There are up to 6,000 people with FH in Western Australia, but most remain undiagnosed or inadequately treated.

Testing potentially affected families can effectively detect individuals at an early stage. This enables early implementation of lifestyle measures and cholesterol-lowering medication, especially statins. These treatments decrease the likelihood of heart disease and heart attacks, improve the health of families, and save lives and money.

The Catalyst program must not be seen as applying to people with FH.

On Statins

*Large clinical trials very clearly show that statins decrease the incidence of heart attacks in a wide variety of people: those with and without existing heart disease, older and younger, men and women, smokers and non-smokers, with and without high blood pressure, with and without diabetes, obese and non-obese. **On average, a reduction in cholesterol of an amount of 1 mmol/L in blood is associated with a 25% reduction in the risk of heart disease.***

The benefits of statins are greatest in people with heart disease or other risk factors for heart disease, such as diabetes and high blood pressure.

Statins have been shown to be highly cost-effective medication that decrease suffering and disability related to heart disease, as well as saving lives and government expenditure on healthcare. They have a long safety record and are well tolerated. Like every drug, statins do have side-effects, the most frequently reported (5 to 10 % of users) being muscle pain and tiredness. These respond well to lowering the dose of the statin, to switching statins and to supplementing the diet with co-enzyme Q, fish oils or vitamin D. Most people with this initial side-effect can continue to be treated with a statin with no further symptoms.

There has also been concern about an increase incidence of diabetes, but this is usually seen with higher doses of statins and in people who already have a predisposition to diabetes, such as obesity and slight elevation in blood glucose levels.

The benefits of statins far outweigh the side-effects. People prescribed statins should not stop them without consulting their doctor. Stopping a statin if you are known to have heart disease or have a predisposition to heart disease (diabetes, high blood pressure, FH), may lead to a heart attack.

Professor Gerald Watts (Chairman, FH Australasia Network)
DSc MB BS Lond., PhD W.Aust., DM S'ton, FRCP, FRACP

The full media release can be accessed at

<http://www.athero.org.au/images/Press/13.11.01%20Professor%20Gerald%20Watts%20comments%20on%20ABC%20Catalyst%20Program.pdf>



ABC Health Report

**The ABC Catalyst Program debate continues -
4 November 2013**

Access

<http://www.abc.net.au/radionational/programs/healthreport/the-cholesterol-and-statin-debate/5067536> for a discussion between Dr Norman Swan and Professor Peter Clifton (Australian Atherosclerosis Society Past-President and CSIRO Healthy Heart Program).



New FH website – Coming Soon

Maria Vulin, one of our dedicated FH nurses, has been working on developing information specifically for patients interested in FH to be included on a new website.



FH Australasia Network

The website covers:

- What is FH?
- How do I inherit FH?
- Signs and symptoms of FH
- FH diagnosis
- Heart disease
- Biochemistry (made simple)
- Lifestyle changes
- FH treatments
- Future developments
- Lots of FAQs



Details of the website will be forwarded when they are available.

‘Thank you Maria for your monumental effort. The website contains lots of useful information in an easy to read format and will be a very valuable resource for our FH community’.

FH Support Group



How much fat should I consume?

It is recommended that Australian adults have a total fat intake between 20% and 35% of their energy intake. Therefore, **the average person should consume between 47 grams and 82 grams of total fat per day.***

Saturated fat is a type of fat that **raises** LDL cholesterol ('bad' cholesterol) in your blood, which increases your risk of heart disease. Therefore, your consumption of saturated fat should be **minimised**.

It is recommended reducing saturated fat to less than 7% of total energy intake. Therefore, **the average person should consume less than 16.5 grams of saturated fat per day.*** It is estimated that Australians consume **twice the recommended amount**.

*The average energy requirement is 8,700 kJ per day. (This is the number quoted by fast food outlets!) Your energy requirements may be more or less depending on your age, gender, height, weight, and activity level. To calculate YOUR specific energy requirements see *CSIRO Healthy Heart Program* book page 19.

Where is saturated fat found and how can I reduce my intake?

Saturated fat is found in:

- **meat and poultry and especially fat on these products**
- Select lean meat and poultry (100 g per day).
- Trim all visible fat and remove skin from poultry before cooking.
- Swap meat/poultry meals for fish at least twice a week.
- Replace or extend meals with vegetables and beans/legumes.
- **processed meat eg sausages, bacon, salami etc**
- Swap for 97% fat free ham.
- Limit these foods unless they have the Heart Foundation Tick eg both Coles and Woolworths stock a Heart Foundation Tick range of sausages.

How to reduce the amount of saturated fat in your diet in five easy steps (video).

Access

<http://vimeo.com/5093228>



Focus on: Carrot Cake



Muffin Break

186 g / 3181 kJ

Total fat 45.4 g

Saturated fat 7.1 g

McDonalds McCafe

1 slice / 2830 kJ

Total fat 47 g

Saturated fat 13.3 g

Cheesecake Shop

175 g (1/12 cake) /

2118 kJ

Total fat 31.3 g

Saturated fat 16.5 g

Coles Bakery

72 g (1/8 cake) / 1138 kJ

Total fat 15.6 g

Saturated fat 3.9 g

Weight Watchers

23 g (1 slice) / 256 kJ

Total fat 0.6 g

Saturated fat 0.3 g

Sara Lee (frozen)

50 g (1/8 cake) / 765 kJ

Total fat 9.3 g

Saturated fat 2.5 g

Green's (packet)

65 g (1/12 cake) /

1014 kJ

Total fat 10.4 g

Saturated fat 1.6 g

- full fat dairy products eg milk, cheese, butter, cream, yoghurt, ice cream
- Use reduced fat or no fat dairy products for all family members more than two years of age.
- Use margarines made from canola, sunflower or olive oil with the Heart Foundation Tick.

- fast foods eg all fried food including fish, pizza, hamburgers, creamy pasta, potato products eg hash browns, potato salad, hot potato chips

- Try to limit deep fried foods and fatty fast foods to no more than once a week.

- Choose healthier options eg sushi, '6 g of fat or less' Subways, tomato based pasta or grilled fish.

- cooking at home eg shallow or deep frying and roasting in oil

- Grill, poach, bake/roast on a rack, steam or stir fry.

- Cook with polyunsaturated or monounsaturated oils, such as olive, canola and soybean oils. Nut, seed and avocado oils are also suitable.

- cakes, donuts, pies, pastries, biscuits, packet potato chips/twisties etc, chocolate

- Try to limit these foods to once a week.

- Swap sweet products for raisin toast.

- Cook low fat home-made alternatives eg popcorn (page 10) or buy Heart Foundation Tick products.

- palm (often used in commercial baking) and coconut oils and their products eg copha

- Try to limit these foods.

Choose Heart Foundation Tick products where available. All fresh fruit and vegetables qualify for the Tick. There are over 2,000 different products. See shopping guide at http://www.heartfoundation.org.au/SiteCollectionDocuments/Tick_Shopping_List.pdf



To calculate your BMI

BMI is calculated using your weight in kilograms and your height in metres.

Example:

Sarah weights
73 kg and is
163 cm tall = 1.63 m

BMI =
weight in kilograms/
(height in metres)²

Sarah's BMI =
 $73/(1.63)^2$
 $= 73/2.66$
 $= 27.4$

Sarah's BMI indicates
she is overweight.

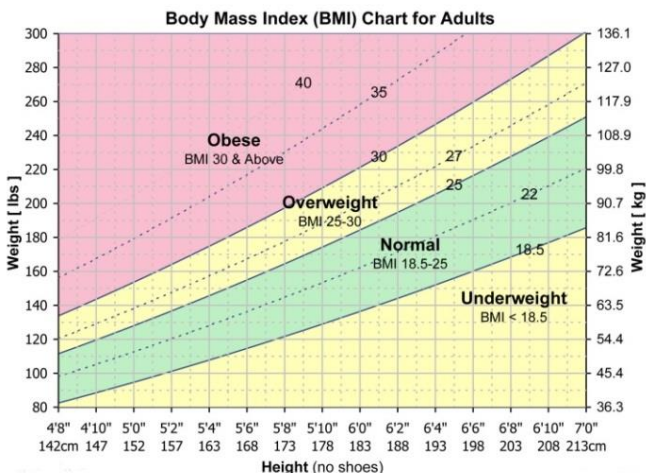


Is my weight healthy?

BMI (Body Mass Index) is one method used to **estimate** your total amount of body fat.

To work out your BMI you can use:

- the chart below for a rough estimate
- Heart Foundation's BMI calculator at <http://www.heartfoundation.org.au/healthy-eating/Pages/bmi-calculator.aspx>
- calculate your BMI manually (see column to the left)



BMI Chart created by Vertex42.com.
Used with permission.

If your BMI is:

- Under 18.5 - you are underweight
- 18.5 to 24.9 - you are a healthy weight
- 25.0 to 29.9 - you are overweight
- Over 30 - you are obese

BMI values apply only to adults aged 18 years and over. There are differences between various ethnic populations. If you fall outside the healthy weight range, see your doctor or dietitian.

The condition that stops the nation

Heart Foundation - Media Release 24 October 2013



Heart Foundation supported research published today in the International Journal of Obesity from the Australian National University has, in an Australian first, quantified the effect incremental rises in body mass index (BMI) has on your cardiovascular health – and the results aren't good.

*"For the first time we have quantified that an **increasing BMI significantly increases the risk of hospitalisation for ischemic heart disease - the leading cause of heart attack** - regardless of exercise level, smoking status and diabetes," said Dr Rob Grenfell, Heart Foundation National Director, Cardiovascular Health.*

The study found that the risk of heart attack increased by 23 per cent with each 5 unit increase in BMI.

"With the spring racing upon us we know that five to one odds can be good in a horse race but the race to a heart attack is certainly not one you would want to win," said Dr Grenfell.

"This study highlights that as you put more weight on you become the race favourite – the race though is doing real damage to your heart which is why it's incredibly important for all Australians to keep their weight in a healthy range by eating a healthy diet and participating in regular physical activity," said Dr Grenfell.

***"The study also demonstrated that if you stop smoking, control your blood pressure, cholesterol and blood sugar levels, your risk of a heart attack will decrease,"** Dr Grenfell stated.*

***"The lowest risk is for a BMI from 20 - 22.5 and then it increases gradually from there.** By the time a person's BMI reaches 32 (approx. 10-15 kilos heavier), they are twice as likely to be hospitalised with ischemic heart disease as someone in the healthy range," said Dr Grenfell.*

The study was derived from 158,000 participants of the Sax Institute's '45 and Up Study' with no history of cardiovascular disease. These people

were tracked over four years to see how incremental increases in BMI increased their risk of being hospitalised for a range of cardiovascular diseases.

The study found even slight increases in BMI come with increased cardiovascular risk.

"This increase in risk was found regardless of physical activity, smoking status and socioeconomic factors," said Dr Grenfell.

"If you want to minimise your risk you need to pay attention to your weight. If you think you've put on a few extra kilos you should speak to your GP," said Dr Grenfell.

Dr Grenfell added that the study results are nationally significant and also demonstrate why Governments should be investing in large health studies such as the '45 and Up Study'.

This article and more information about the '45 and Up Study' can be accessed at <http://www.heartfoundation.org.au/news-media/Media-Releases-2013/Pages/condition-stops-nation.aspx>

Kid's Corner - Microwave Popcorn

Popcorn is traditionally very high in fat. This version is healthy! You can cook just plain popcorn or you can add different spices or even icing sugar to the un-popped corn for more variety.

Ingredients:

- 1 paper lunch bag
- 2 tablespoons popping corn
- spray of oil – optional (see page 7 for healthy oils)
- sprinkle of spice/icing sugar – optional

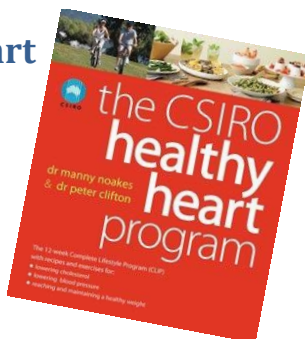
Directions:

1. Put the popping corn in a paper lunch bag and spray with oil and sprinkle with spice/icing sugar.
2. Shake the bag to coat the popcorn. Fold the top of the bag over twice.
3. Place the bag in the microwave and cook on high for about 2 minutes or use the "3 second rule" if you don't hear popping for 3 seconds, it's done.



CSIRO Healthy Heart Program

By Dr Manny NOAKES and
Dr Peter CLIFTON
(RRP \$34.95)



This book is your comprehensive guide to the CSIRO's CLIP (Complete Lifestyle Program) eating and exercise plan, which is designed to look after the health of your cardiovascular system and help you reduce your risk of heart attack, stroke, type 2 diabetes and other complications of obesity.

The book provides:

- information on heart disease risks and how to avoid them
- a healthy eating plan with both higher protein and higher carbohydrate options
- 12 weeks of full menu plans, including vegetarian options
- a simple but effective exercise program
- more than 100 delicious recipes



The grapefruit recipes in the book should be avoided if you are on statins as grapefruit/juice interferes with their action.

NB - The nutritional value of each recipe is given as **units** of fat instead of the standard **grams** of fat. This makes it difficult to compare recipes from other sources eg The Heart Foundation cookbooks.

How to save money on your prescriptions

If you are on a low dose of a medication it may be possible to buy a higher dose and cut the pill in half so you will only need a prescription every two months instead of monthly. This will halve the cost of the medication to you and to the government.

Talk to your doctor to see if this is an option for you.



Meetings 2014



**The 2nd Monday of
every 2nd month**

7 – 8 pm

10 February

14 April

9 June

11 August

13 October

8 December

FH Support Group members wanted

**We need members -
no experience required!**

Do you have a spare hour every second month to attend a meeting and **input ideas** into this newsletter, selection of information evenings and other activities for the FH community? If you are newly diagnosed with FH your input will be **really valuable** - you can tell us what you would like to know!

We need people from all backgrounds!

**Apart from attending meetings your
time commitment will be minimal.**

Log onto our website to view the agenda of the next meeting (see under Activities and Events)

<http://www.fhfamilysupportgroup.websyte.com.au/>

Please email fhfamilysupportgroup@hotmail.com.au for further information.



Venue

Genetic Support Council WA
Suite 7, Oasis Lotteries House
37 Hampden Road, NEDLANDS

