

*What do we have
in common with
Mona Lisa?*



See page 12 to find out.

Welcome

We hope everyone has had a good 2015 so far.

This issue of the *FH News* gives you lots of information about FHWA and FHAN (page 4) and their activities and structure. We hope this will give you a better understanding of the 'Who's Who' of FH.

In future the *FH News* will only be produced when required.

FH Support Group meeting

8 June - see p3
All welcome

Thank you!

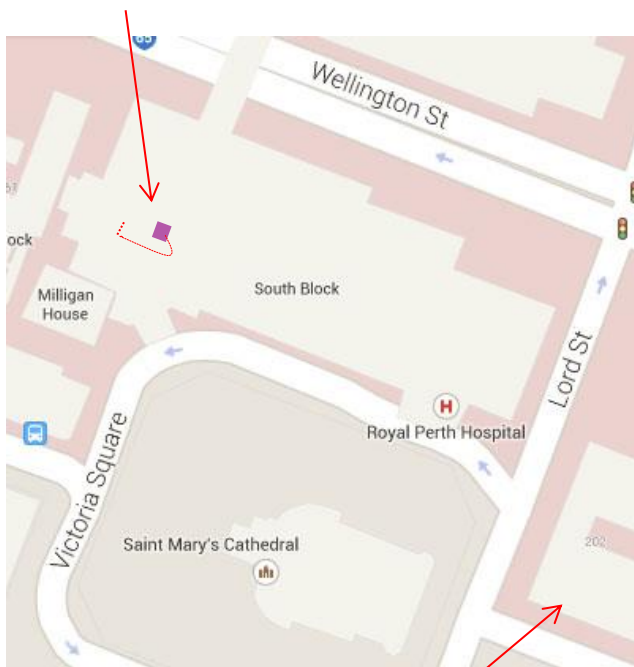
Thank you to the **Genetic and Rare Disease Network (GaRDN)** for all the support they have given us over the years.

FH Support Group

Lipid Disorders Clinic has moved

Lipid Disorders Clinic is now part of the **Department of Cardiology** and is located on the 4th floor of the South Block, Royal Perth Hospital.

Take the purple lift (or use the stairs) to the 4th floor



Old clinic in Goderich Street

You are invited to an

Informal Information Evening

Natural Alternatives to Statins

How well do they work?

If you have had success with a natural medication, please come along and share your experiences.

When: Monday, 8 June 2015

Time: 7:00pm – 8:00pm

Where: Oasis Lotteries House
37 Hampden Road, NEDLANDS

Speakers: Various

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

WA Health Excellence Awards

The WA Health Excellence Awards acknowledge outstanding achievements in the WA public health sector.

Congratulations to the FHWA Primary Care team for winning the Primary Care (primary care means GP) section. Their entry was titled -

Improving the care of inherited high cholesterol and risk of heart disease in families: central role of primary care and its integration with specialist and academic centres.



What is the FH Australasia Network (FHAN)?

In 2006 the Australian Atherosclerosis* Society (AAS) established a sub-committee specifically dedicated to FH and the FH Australasia Network (FHAN) was born.

The FHAN is comprised of a team of doctors and scientists, one from each state and one from New Zealand. Professor Gerald Watts is the chair and also the West Australian (FHWA) representative. Each state representative leads a team of specialists within their state who are responsible for the diagnosis and management of patients in that state.



*everyone deserves
a better chance*

The FHAN was also responsible for developing guidelines (called a Model of Care) for the diagnosis and management of patients with FH. These guidelines were developed with consensus of other world leaders in the field of FH and represent world's best practice. The FH Support Group was also part of the steering committee that developed these guidelines.

Other activities include education sessions for GPs to give them a better understanding of FH (see Health Excellence Award page 3), FHAN website (see below) and the National FH Registry (see page 5).

*atherosclerosis (pronounced ath-er-O-skler-O-sis) is the build-up of cholesterol in the arteries, also commonly called 'plaque'.

FHAN website

The FHAN has a website which is currently under construction (the content has been finalised but is waiting a redesign to give a more contemporary look) at <http://www.athero.org.au/fh-home>. The website is the premier FH website for patients and health professionals in Australia and New Zealand. Please take a look.



They are also looking for people who would like to share their 'Personal Stories' see <http://www.athero.org.au/patients/personal-stories>

Comments/personal stories are welcomed and can be forwarded to:

AAS Secretariat: email: admin@yoursecretariat.com.au

National FH Registry

You may have already been approached at the Lipid Disorders Clinic to join the National FH Registry.



A registry is a database where medical information, family history and other related information from patients is collected and stored for later retrieval and analysis.

Currently patients' records are only in the hospital where they receive treatment.

The National FH Registry aims to get all FH patient records onto one database so that the information can be analysed to identify FH distribution, diagnosis and treatment effectiveness, cardiovascular disease levels and the impact of new treatments and interventions.

This will aid health system planning and the development of the best treatment options and therefore improve patient care.

The National FH Registry will also provide equal opportunity to access the latest trials for new treatments for FH.

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

Please consider joining the National FH Registry. **Apart from reading and signing the consent form no other action is required.**

We also ask you to discuss the registry with other family members and encourage them to join. This includes your relatives who have been tested and are negative. We would like your negative relatives to join as they are a 'baseline' for your family and will complete your family records.

Introducing our FH nurses

Jackie Ryan



Jackie Ryan comes from a background of cardiology and has been a member of the FHWA team at Royal Perth Hospital since 2012 during which time Jackie completed her Nurse Practitioner training under the tutelage and supervision of Professor Gerald Watts.

During the early part of 2014 Jackie took on an additional role forming part of the Primary Care / Tertiary care project team formed to enhance the awareness of FH in the primary care setting through education sessions, de – identified data extraction and interrogation aimed at identifying patients in participating practices with possible FH.

Jackie has been successful in gaining a new area of designation for Nurse Practitioners ‘Cardiomatabolic Disorders Diagnosis and Management’ and works part time (collaboratively with Prof Watts) in private practice managing and stratifying identified patients within general practice and phenotypically cascade screening family members. Patients identified as high risk are referred in a timely manner to the Lipid Disorders Clinic at Royal Perth Hospital.

Jackie states she is ‘privileged that her journey with FH has culminated in the opportunity to enhance the partnerships between primary and tertiary care, facilitate early identification of FH in the community and to pioneer the specialist Nurse Practitioner role relating cardio-metabolic disorders and management in primary care setting’.

Jackie continues to work part-time with Prof Watts on cardiac-prevention strategies and can be contacted for information on 0417 957 149.

Jille Burns

Jille Burns has recently commenced working with Professor Gerald Watts at the Lipid Disorders Clinic at Royal Perth Hospital.

Her work will involve cardio metabolic risk factor management and coordinating cascade screening for families with familial hyperlipidaemia.



“I am delighted to have this opportunity to work with Professor Watts who is at the forefront of world-wide lipid research, teaching and clinical management” she said.

Jille will be the first point of call for new patients to the Lipid Disorders Clinic and will coordinate their journey through family screening.

Jille is a senior nurse with over thirty five years’ experience. Qualified as a Nurse Practitioner Jille also has a private practice in Fremantle.

Her areas of interest include nutritional medicine, chronic disease self-management strategies and lifestyle medicine.

Jille works part time, however a message can be left on 9224 8092 at Royal Perth Hospital.



Thank you for all your hard work Jackie and a warm welcome to you Jille.

We look forward to working with the both of you in the future.

FH Support Group

Representation for FH Family Support Group of Western Australia



In March of this year, I had the opportunity to attend the *Familial Hypercholesterolaemia (FH) Patients Advocacy Group Representatives Meeting* in Glasgow, Scotland, to give a short presentation on the state of FH patient advocacy in Australia. Representations were heard from a number of different countries including the U.K., U.S.A., Peru, Russia, Taiwan, South Africa and Brazil. For each respective country, the presenters addressed the initiation of patient advocacy group/s, their reach, impact and, where they are lacking, the impact of this absence. The audience of around 50 persons comprised of clinicians, nurses, and representative of FH patient advocacy groups.

This meeting was a new initiative of the *European Atherosclerosis Society FH Studies Collaboration (FHSC)*, which is a program aiming to improve the clinical community's awareness of the burden of FH worldwide, and the impact of current management of FH on the global burden of disease. In doing so, the FHSC hope to empower the medical community to seek change in their respective countries or organizations regarding how FH is detected and/or managed, with a view to promoting early diagnosis and more effective treatment of this condition.

The Patients Advocacy Group Representative Meeting was followed by dinner and further discussions which provided a great opportunity to network with people from other countries, strengthening links between different support groups and opening the door for future collaborations.

Picking up the following morning, presentations were given by some of the lead drivers of the FHSC program including Prof Gerald Watts who discussed *What's happening in the Asia Pacific Region and Synergy with the FHSC*. Further information on the FHSC and these meetings should be accessible online via: <http://www.eas-society.org/fhsc-symposium-at-eas-2015-glasgow.aspx>

Other discussion topics of note include how to manage patients with statin induced muscle pains, and the promising results from recent clinical trials on the use of PCSK9 inhibitors (such as Evolocumab) in patients with FH, hypercholesterolaemia inadequately controlled using traditional therapies, or in patients intolerant to statins.

It was refreshing to see how much energy, drive and compassion was coming from all those involved to make the FHSC goals a reality so as to better the lives of the many with FH. It was a privilege to represent the FH Family Support Group in Glasgow and to get a glimpse of the direction clinical practice of FH is heading.

Waleed Farid

Former chair and co-founder of the FH Support Group of WA



PCSK9 inhibitor update – Getting listed on the PBS, where it's at!

PCSK9 inhibitors are a new class of drug that lower LDL cholesterol more than the most potent statin. It will be of most benefit for patients who are unable to take statins or people on the maximum dose of statins and unable to reach their target LDL levels. The medication is given by injection fortnightly/monthly. The cost is approximately \$3,000 per injection. Having it on the Pharmaceutical Benefit Scheme (PBS) will make it affordable for members of the FH community who require it.

The FH Support Group meeting on the 15th December 2014 was well attended. Personal impact statements to the Pharmaceutical Benefit Advisory Committee (PBAC) were submitted by individuals and the FH Support Group. The PBAC meeting was in March 2015.

The process for getting a medication listed on the PBS is as follows:

1. Research and development of medication
2. **Advisory Committee on Prescription Medicines (ACPM)** advises and makes recommendations to the TGA.
3. **Therapeutic Goods Administration (TGA)** assesses the medication meets its standards for manufacturing quality, safety and effectiveness in treating a particular illness.
4. **Pharmaceutical Benefits Advisory Committee (PBAC)** assesses effectiveness and cost effectiveness of medication. They can recommend, reject or defer a medication. If they recommend then
5. **Pharmaceutical Benefits Pricing Authority (PBPA)** negotiate a price
6. Minister/Cabinet's approval
7. Medication listed in the PBS
8. Everyone with FH is very happy!

Steps 3 &
4 are
happening
at the
same time.

At the time this newsletter was printed the press statement was:

The PBAC recommendation cannot be made public until the TGA outcome is known i.e. waiting for TGA outcome (step 3).

The average time between ACPM and TGA (steps 2 & 3) approval and PBS listing (step 7) was 34.2 months in 2009. So we still have some waiting to do!

Go Red For Women Day, 11 June Heart Foundation

Many people still think breast cancer is the biggest killer of women. It's not. Heart disease kills three times more, taking a life every hour of every day.



On [Go Red for Women Day](#), Thursday 11 June, the Heart Foundation will be raising money to support life-saving research, education and awareness of this vital women's health issue.

Here's how you can help the Heart Foundation on the day: simply wear something red on Thursday 11 June and [make a donation](#) or [host a Go Red event](#), such as a morning tea, at work or with your friends.

There is also another powerful and easy way you can help in the lead up to the day.

This year the Heart Foundation is asking you to take a selfie of what you'll be wearing and use your social networks (with the hashtag [#WeWillBeRed](#)) to get others involved and help raise awareness of how important this issue is.

Watch the Heart Foundation's [short video](#) and check out their [website](#) for more!

We hope you will help the Heart Foundation's [Go Red for Women](#) to fight the single biggest killer of women.



The Heart Foundation
[Go Red for Women](#) Team

What do we have in common with Mona Lisa?

The *Mona Lisa* was painted by the famous Italian artist Leonardo Da Vinci in the 16th century.

It is quite possibly the most well known and most studied piece of artwork in the entire world. The subject's facial expression has brought about a source of debate for centuries, as her face remains largely enigmatic in the portrait.



Professor Vito Franco, a professor of pathological anatomy of the University of Palermo, has spent his spare time applying his medical expertise to the study of famous subjects of Renaissance artworks. The *Mona Lisa* didn't escape his professional eye.

Professor Franco has come up with the latest and what is probably the least poetic explanation imaginable for why the woman looks the way she does: high cholesterol.

Professor Franco told the newspaper La Stampa that he spotted clear signs of a palpebral xanthelasma (an accumulation of cholesterol around the eyes) in the hollow of her left eye as well as a tendon xanthoma (an accumulation of cholesterol in the tendons) on her right hand.



Did *Mona Lisa* have FH? See FHAN website for '[Signs and symptoms](#)' of FH.