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WEST PERTH
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Rotary
Club of West Perth

The Bulletin

Breakfast Meeting 5 June 2025

Guest Speaker

The Guest Speaker this week will be Professor Kingsley Dixon OAM, from Curtin University, who is going to talk to us about service to conservation biology.

Duty Roster

Duty Role	5th May	One Week Look Ahead
Host	Tony Pepper	Mally Rall
Welcome	Mally Rall	Geoff Simpson
Toast	Geoff Simpson	Ant Ulijn
Thanks	Ant Ulijn	John Van Vliet
Bulletin	John Van Vliet	Arthur Blaquiere
2 Minute Noodles	Arthur Blaquiere	Peter Blockley

DIRECTOR'S DAY

Please find a substitute if you cannot fulfill your duty

Breakfast Meeting 29 May 2025

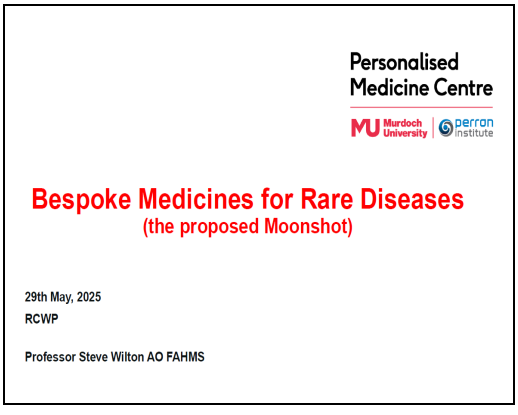
(With thanks to Anon)

Guest Speaker

Our Guest Speaker last week was Professor Steve Wilton Medical Researcher and WPRC member since 2011 who spoke on bespoke medicines and treatments for rare diseases such as Duchenne Muscular Dystrophy and other diseases which are inherited, and which effect more people than cancer. Academic research labs and philanthropy can achieve great things.

Professor Wilton's research is with the Personalised Medical Centre with support from the Perron Institute and Murdoch University where world class facilities for cutting edge research placed within medical precincts that can draw on available expertise.

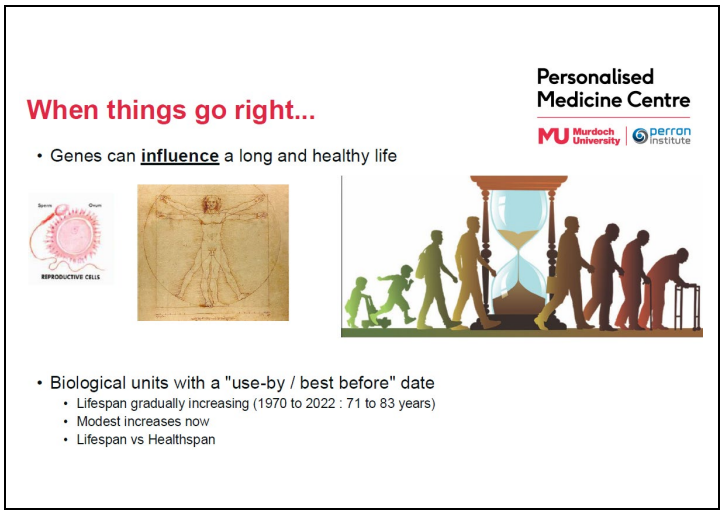
"I've been trying to retire, but not allowed as things are getting too exciting, and they are hopefully I'll be able to pass my expertise on.



I had been at UWA for 23 years and had built up a stable group with some I had been working with for over 20 years, then Murdoch offered me a job. I took eight with me and we have been expanding our research listed on the left, with support from the Perrin Institute. With the different research groups, I have allowed the younger ones to take over. There is over 20 people now in my research group and the expansion has been dramatic.

We were the Centre of Molecular Medicine, which was considered too complicated, so we rebranded a couple of weeks ago to the Personalised Medical Centre. The research is focused on precision medicine to get the right drug to the right person. Why? These people are not on the radar because they are too few for a commercial market.

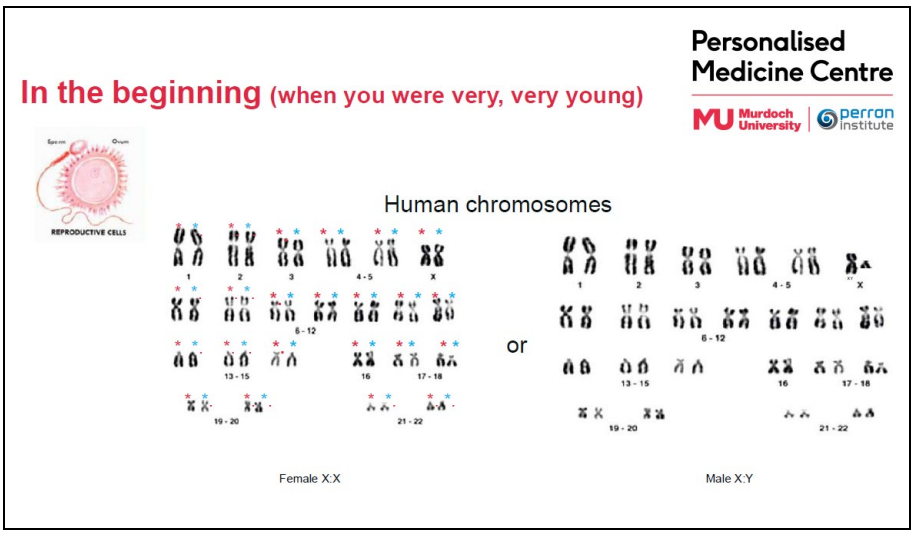
Genes can influence a long and healthy life, and when you are young you start off with a single cell. A term I heard recently was health span rather than life span and I thought that was appropriate. You want to have a long healthy life/ health span. Because we are biological units, we are not going to live forever and the life span is gradually increasing; in the 70's it was 71 and now it's 83-84 year, but only very gradually.

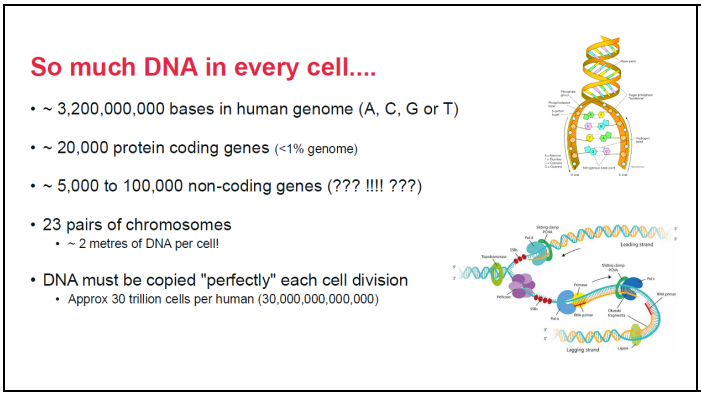


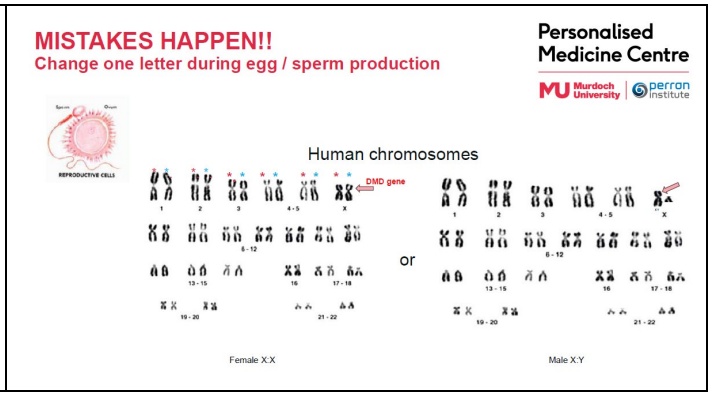
One of the reasons is infant mortality. The average caveman lived to 33 years old, and for every person that survived, two or three infants would die. No preventives in the food if you could find it, but a very tough existence. Apparently the highest cause of death then was homicide, so we have a very bloodthirsty past.

Nine months before you were born, half of your DNA comes from mum and the other from dad.

On the left are the human chromosomes. The red is from mum, the blue from dad, and parcels of DNA are passed on; females are XX and the male are XY.

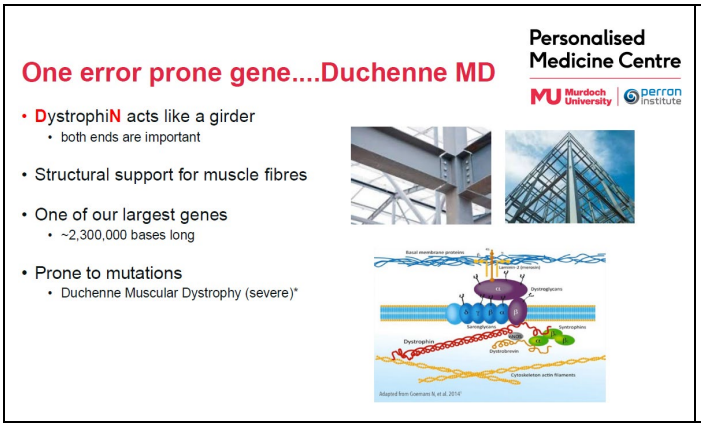


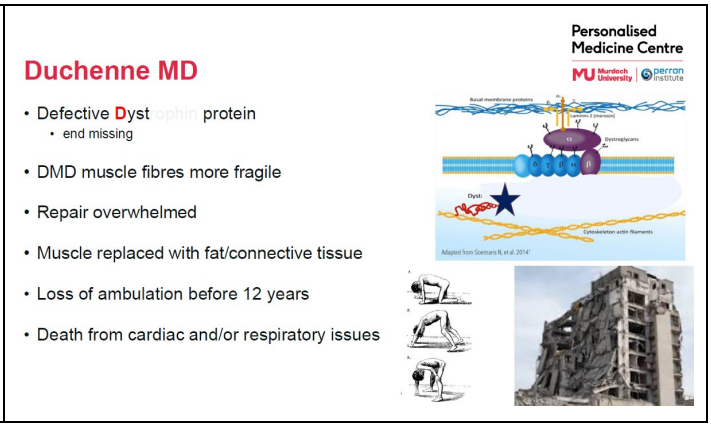




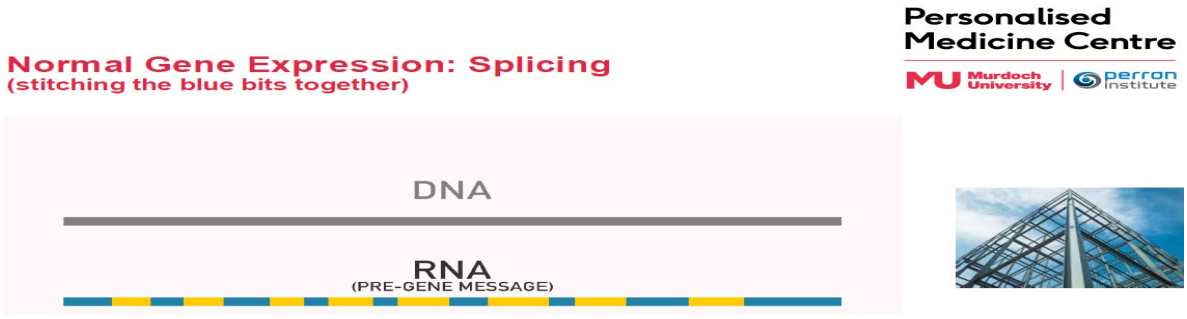
There is so much DNA in every cell, it is like a genetic Morse code, just 4 letters; A, C, G, T and it is the order that is read by the cell machinery that kept the information. The human genome indicates we have 20,000 protein coding genes- hair, skin, enzymes, etc. It is a bit nebulous for the non-coding gene which control the expression of the coding genes. There is 2 metres of DNA in each cell and the average person has 30 trillion cells so there is enough DNA for one person to go to the sun and back 200 times if the 23 pairs of chromosomes were unravelled. And all that starts from one cell, and it is copied over and over again.

What could possibly go wrong with that? You can change just one letter to an important gene like a dystrophin gene on the X Chromosome, and you will have a catastrophic outcome. If it happens in the junk or intervening DNA, not a problem.

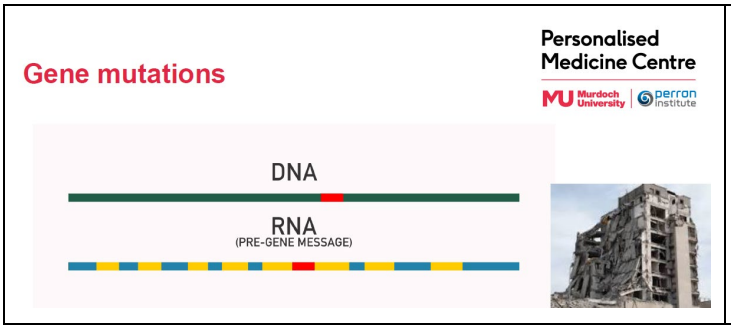


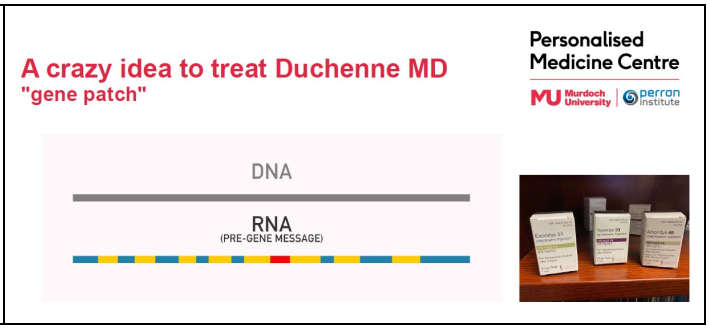


This is the gene that Byron Kakulas started the Institute on, the Duchenne Muscular Dystrophy and it's the ends of the protein that's important as it acts like a girder, where the ends are bolted on either end, creating a "*scaffolding*". In the muscle cell, one end of the protein bolts onto a skeleton and other binds to the skin and this strengthens stability. It is one of our largest gene and the most error-prone gene; a lot of spelling errors occur with this gene. When you have a spelling error in it, you have lost the end and now you have a girder that can't link up and the muscle fibres are more fragile, they'll rupture, they'll break until the repair is overwhelmed, muscles replace the fat and connective tissue, children lose ambulation before the age of 12, and death from respiratory and/ or cardiac issues. If you have a building without girders, it is not going to be stable and will collapse.



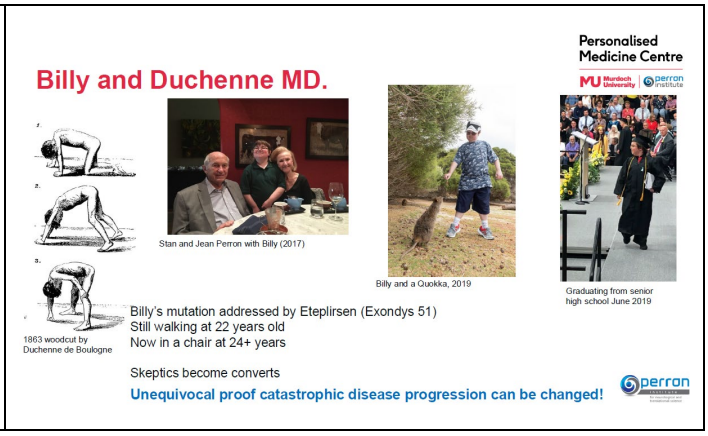
One of the steps in gene expression is a process called splicing. The instruction for the girder is in the blue bits. What happens with splicing is all the yellow bits are removed, and the blue bits are joined together. This happens to about 95% of our genes which undergo this process.





If you have a spelling error in the dystrophin gene, when it is put together the defect in the DNA is carried through to the message and we have lost the end. That is how it works in Duchenne Muscular Dystrophy, a corrupted gene message.

It was 30 years ago that I came up with this crazy idea to use a bit of non-coding material and it would target the disease-causing part and let the splicing machinery remove it, so you end up with a gene message, it's not normal, it's missing a bit in the middle, but the ends are present. This is the basis of our three FDA approved drugs for muscular dystrophy.



This is young Aiden shows the various stages of his treatment progress and the success of the FDA approved drugs. Still not in Australia.

Billy should have stopped walking at the age of 11, but he was walking to the age of 22. He is off his feet now over age 24, upper body good.

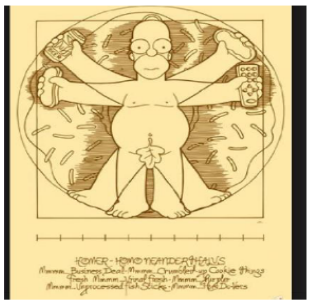
There is proof that these little patches can change gene expression.

So what now...

Personalised Medicine Centre
Murdoch University | Perron Institute

Copying 3.2 billion bases per egg/sperm....What could go wrong??

- >8,000 clinically described rare diseases (to date)
  - Variable severity, onset and/or progression
  - CNS, eye, ear, skin, liver, lung, kidney, muscle, development etc
  - Some "common", others very rare
- Cause / genetic basis often unknown
  - Diagnostic odyssey (years/decades)
- Finding genetic cause
  - Confirms clinical diagnosis
  - May allow counselling and prediction of disease course



FIRST STEP IN DESIGNING PERSONALISED MEDICINES !

You need to know what is wrong before you can fix it.

Finding the spelling error(s)

First step in bespoke medicines for WA kids

Personalised Medicine Centre
Murdoch University | Perron Institute

- Most genes undergo splicing during expression
- ~25% of all pathogenic mutations disrupt splicing

- Exome scanning
  - (first line)

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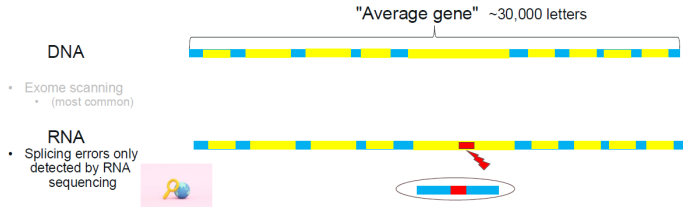


- Exome scanning
  - (most common)
- Splicing errors only detected by RNA sequencing

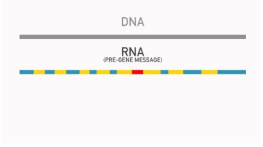
The New Benchmark: "Milasen"

from diagnosis to approved drug in 10 months!

Personalised Medicine Centre
Murdoch University | Perron Institute

Deep intron mutation in CLN7 gene causing Batten's disease.

Mila was deteriorating quickly until treatment started age 7.



- DMD drugs took ~20 years from concept to first approval

From 30 severe seizures per day to a few mild episodes after treatment

A quarter of all pathogenic mutation effects the splicing process.

Repeating the Milasen story in Perth

Personalised Medicine Centre
Murdoch University | Perron Institute

- Connecting / coordinating rare disease research groups
- Improving genetic diagnosis
- Characterise disease pathway to design personalised medicines
- Establishing coordinated, acceptable and recognised pipeline:
  regulatory approval >> diagnosis >> regulatory approval >> best care >> regulatory approval >> design experimental medicines >> regulatory approval >> tox packages ($1.5 million) >> regulatory approval >> GMP-like production >> regulatory approval >> N of 1 trials/treatment >> regulatory approval >> monitoring >> follow-up >> community engagement and support

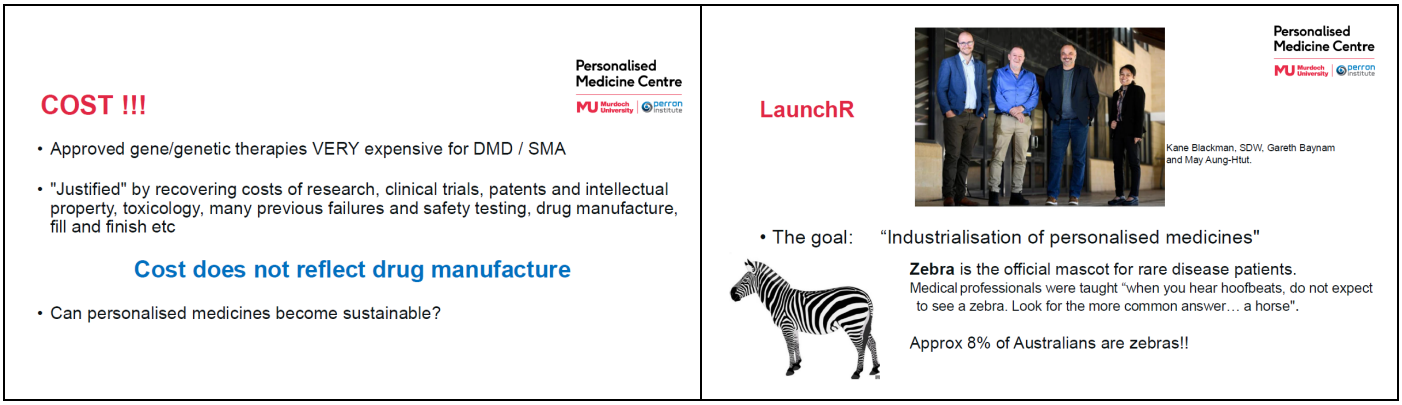
Repeating the Milasen story in Perth

Personalised Medicine Centre
Murdoch University | Perron Institute

- Conventional clinical trials not possible
  - Must innovate and expedite regulatory processes
- Sovereign capacity to make GMP/GLP "gene patch" drug
- Safety is of paramount importance
  - Limitations of animal testing
  - Alternative models being explored
  - Platform / class approval ?
- FDA announces rapid approval for rare disease medicines where plausible mechanism is known and on-going monitoring possible

With support from the Stan Perrin Charitable Foundation, we are connecting and coordinating all the groups looking at rare diseases in Perth. We are improving the diagnosis and characterise the pathway that is causing the disease and then designing personalising medicines. The idea is to set up this pipeline and where the Moonshot is because you have

brief letter of approval to go through, then diagnosis, then regulatory approval, then best care, then regulatory approval again, and so it goes on.



Regulatory approval is an issue and some of the conditions put in for safety and some don't make sense. What we need is a pipeline from diagnosis, designing the drug, having it made and tested, getting it approved, getting it back to the Clinician to treat the patient, then the trials are monitored. We are trying to get capacity to make these patches in WA. Safety is important and that is not being overlooked, and animal testing for each drug is one and a half million dollars for just one patient. We are looking for ways to get around this and the idea is to grow patient cells such as kidney, grow a mini kidney from the patient's cells in a dish to trial the drugs to see if it's working.

Gareth Baynam, Clinical Geneticist from Telethon Kids Institute, and the reason I cannot retire, is setting up clinical trials pipeline to get labs to fast track the diagnosis, other labs fast tracking the drug design and feed that information back to Gareth who has his rare diseases network undiagnosed and his fingers are in so many different pies, all for rare diseases, and the goal is like industrialisation, a Henry Ford pipeline of medicine. Unfortunately, with rare diseases collectively, 8% of Australians have a rare disease.

I have a fantastic team I work with, starting of at eight, this is the list of the current team, working with some fantastic people interstate and overseas, and support from so many different people."

Questions

- How do you find the spelling error? You compare against the normal sequence which you know what it looks like. Frequently the normal sequence can have a number of natural variations, but they still work. A lot of AI comes in to predict what is real and what is not. That's only relevant to finding changes in the blue bits, picking up one in three cases. The computer does all of the comparisons.
- Does stem cell research come into this? No, other groups are doing that. The types of therapies we are doing is MRA Therapy, Gene Correction, Virus Gene Replacement to name but a few (see list on page 2 above).
- Is motor neurone in the same vein? Absolutely. Thanks, late onset and LaunchR is for children. If you are born with predisposition to motor neurone disease, you don't know when you can start the treatment. We have something we want to get to clinical trials.
- The muscular dystrophy drug the FDA approved; can it be ordered online to get it here? It hasn't been approved yet, and if it was it would cost full price. For it to work the PBS has to pick it up as the cost is USD300,000 per patient, per year, and that is paid by insurance companies. They are looking at setting up trials in Sydney and Melbourne, Perth is too small with not enough patients for the trials.
- Kym M has only just realised how important spelling is (Architects!).
- How invasive is the testing? Depends on the type of testing. What we are trying to do is actually is to collect cells from urine and grow a few cells from it and they can go into a variety of different types of non-invasive test, otherwise it can be a skin test where they take a scraping of skin and grow skin fibres.

Geoff presented his mate and no doubt drinking buddy Steve, with yet another certificate for polio vacs and mentioned how hard it is to thank someone who has done so much for so many people.

Steve, for his generosity with both his time and his money was recognised by the Foundation who though it worthwhile to award Steve the next issue of the Paul Fellows; two Sapphires.

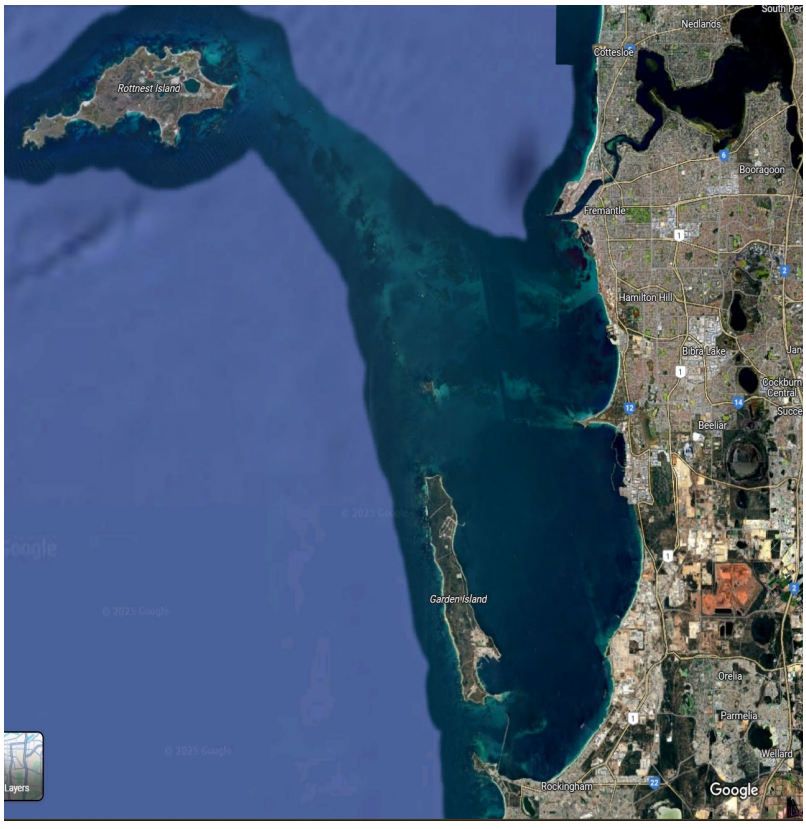
Definitely well deserved.

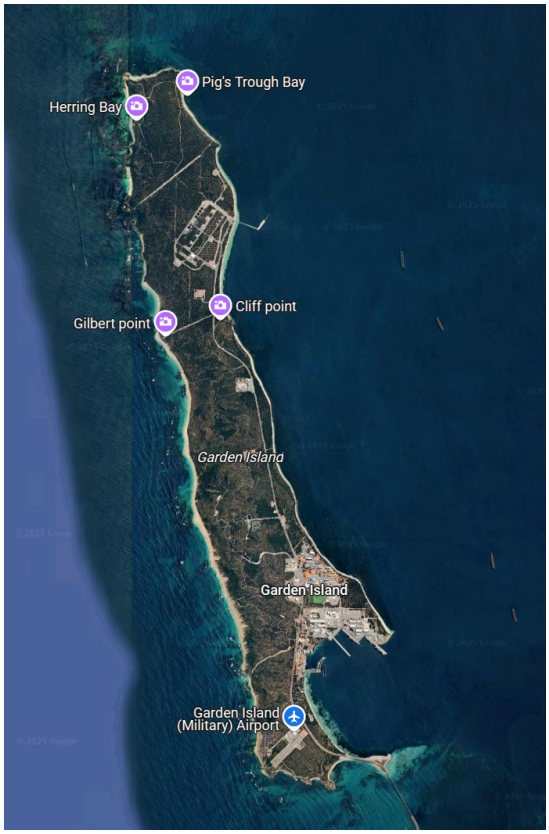
2-Minute Noodles

Chop Shop Noodle chef John VV was asked back for a repeat performance. This time it was Seafood Noodles, a Garden Island speciality. Fire up those woks:

"This follows on from a previous Noodle by Captain Ken Burleigh, Commanding Officer RAN Base, HMAS Stirling. The other part of my life is being President of the *Garden Island and Garden Island Fishing and Aquatic Association*.

Here is a quick run through on Garden Island. The Club occupies the top part of the island around Herring Bay and Pid's Trough Bay, and we officially have 500 members.





The navy has a presence in the middle of the island and the harbour and wharf at the southern end. From Fremantle to my mooring, it takes me 15-17 minutes and it is good going back because the wind is always on your port side.

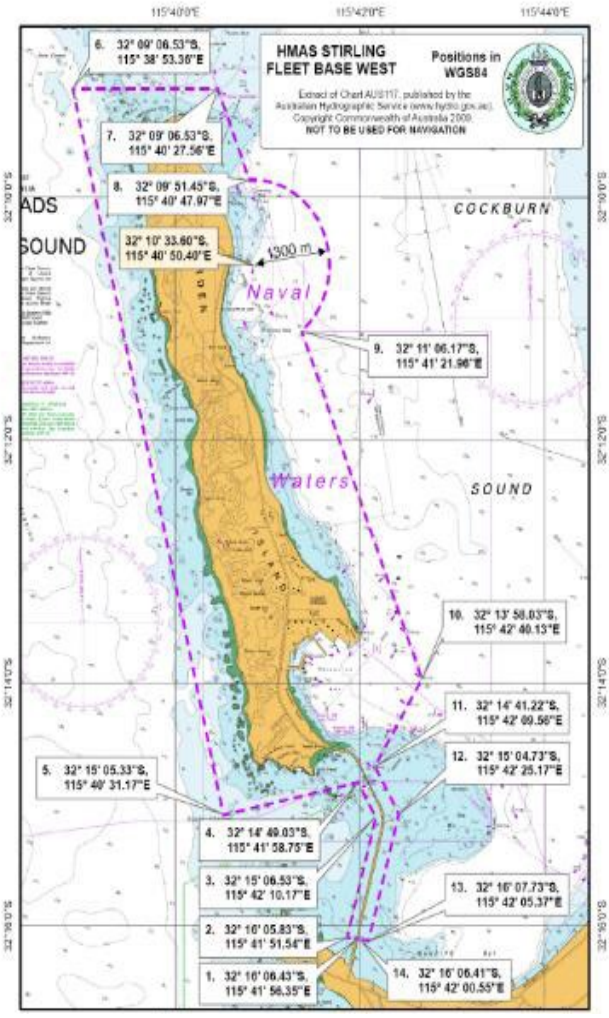
The island has a lot of paths and tracks on it. You are allowed on the island during the day between sunrise and sunset. If you have a boat you can go anywhere on the island except for the naval base and restricted areas.

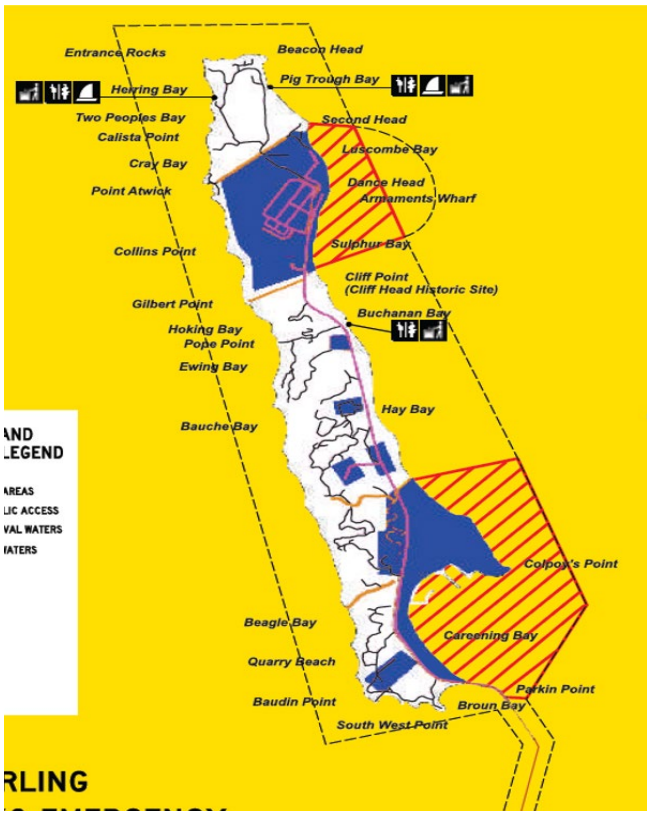
This is the restricted area, Commonwealth Waters around the island, and my role as President I have been able to get an A Class Reserve title for the island, where you cannot have dogs on boats, things like that.

This is the new signboard the Club has been able to put up, with information on what you can and cannot do on the island such as no camping or lighting fires, and there are a few signs around the island. Our Club get those produced for $500 each but we have to go through the navy to get it done at a cost of $2500 per signboard through the same printer.

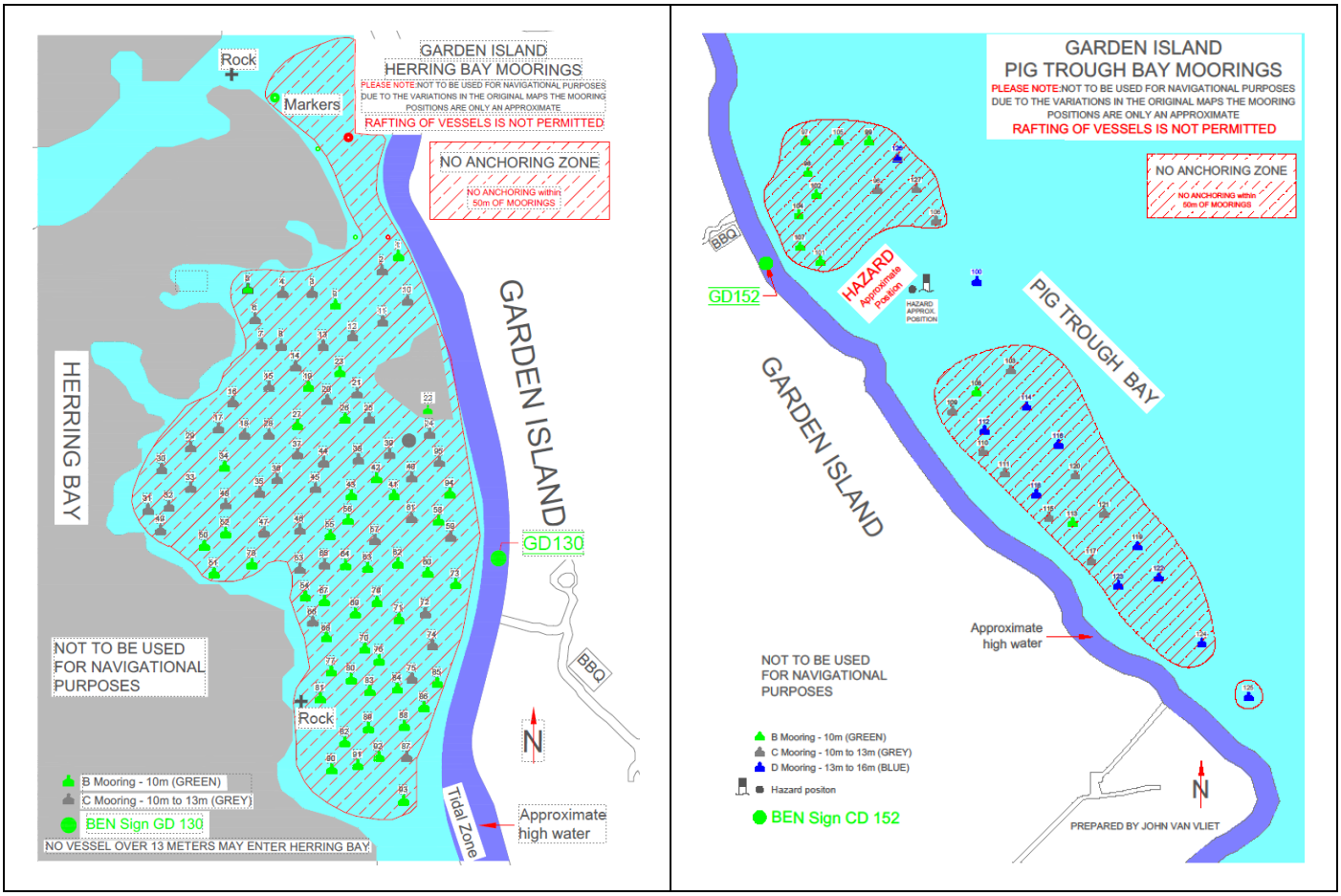
Where the restricted waters are, you can travel through those areas as long as no ships are in. When the ships are in they put out different markers, so you have to go around those restricted areas.

The roads provide beautiful walks in the morning, taking about 45 minutes to walk through the island.





There are a lot of personal names for the bays as the Island was first inhabited by Captain Stirling who didn't put people on the mainland, he dropped the people off on Garden Island, along with their livestock, hence Pig Trough Bay etc. The original well is still on the island.



This is where the Club occupies and the mooring. Herring bay, where I have my mooring, is accessible by manoeuvring through the rocks. About 15 boats that included two yachts, ended up on the rocks this year because they could not follow the signage.

What came in 5 years ago is beach identification signs such as GD130 and GD152 above. You will find them all around WA so if you have an emergency for any sort or reason along the WA coast, you use the sign as reference when you notify Emergency, and they will know exactly where that sign is, on the coast.

There are less moorings at Pigs Trough Bay as it is a lot shallower, but it is great swimming.

Herring Bay is Herring Bay because that is what you can catch off the back of your boat.

That is my two minutes' worth of Noodling. Thank you"

Questions

- When you say they are the moorings that you have, are they owned or placed by your association? The Club has a written agreement with the Commonwealth in regard to the use of those waters, and we own and manage those moorings.
- Licensed by the Commonwealth? We have an agreement on where and how many moorings we can have which we place and let them know about that. We get them surveyed every year and give a copy of the survey to the navy for information only, but we administer, test and replace the moorings.

- Do members pay a rental? Basically, our General Members pay $45/ year, a Primary User is $250, and an Authorised User is $180. Non-members can use a mooring because they cannot just drop anchor in the Bay because of the damage to sea grass, but they will have to move when a member comes if there is no moorings left. Each mooring has two people per mooring, unlike Rottnest which might have one Primary User and five Authorised Users. We have one Primary User and one Authorised User which makes it very easy to manage. Mooring repairs is paid by the Primary User 70% and the authorised user pays 30% of cost. A Rottnest, and authorised user will pay $900/ year, and is totally responsible for that mooring including getting it surveyed every year. We make a reasonable amount of money for the Club, and we put on functions every year where we will get somewhere between 120-150 members turn up for three hours of finger food and drink to keep the members going. Having that volume of numbers in a Club keeps it going.
- In the last three years, I've turned it into a Social Club, we do Sundowners every month December through to March, 3:00-5:00pm at a picnic area we look after on the island, where we supply cheese and nibbles and is BYO as we don't want to be responsible for the boaties drinking too much.
- I suppose you have to take your rubbish off the island? There are bins all over the island and the Rockingham Council collects the bins once a week. There is a Ranger Linda, who looks after things and is very pro-active.
- Are you looking for members? No! We obviously have to review our members because Herring Bay has a max of 30m boats, 42m maximum length. We have a strong membership with a turnover of about 20 per year, but that is made up quickly.

Announcements

President Tick thanked the rabble who mucked up his In Vogue house on the hill during the President-at-Home High Tea shindig. The Booze Bus, parked at the bottom of the street, thought they were onto a sure thing, but couldn't nab any Rotarian's except John when he went out for pizza.

Changeover Night: Anzac House, 26th June, $75 a head for a two-course meal and cash bar. Parking at Council house for $5 after 6:00pm. PP TD's going to be MC with rent a crowd to introduce to Rotary. See back of Bulletin.

Duty Role	05 June	12 June	19 June	26 June	
Host	Tony Pepper	Mally Rall	Geoff Simpson		
Welcome	Mally Rall	Geoff Simpson	Ant Ulijn		
Toast	Geoff Simpson	Ant Ulijn	John Van Vliet		
Thanks	Ant Ulijn	John Van Vliet	Arthur Blaquiere		
Bulletin	John Van Vliet	Arthur Blaquiere	Peter Blockley		
2 Minutes	Arthur Blaquiere	Peter Blockley	Corrin Caine		

DIRECTOR'S DAY

CHANGEOVER

UNDER THE SPOTLIGHT FOR JUNE 2025

Birthdays
Mally Rall 12th
John Tick 17th

Anniversaries
Geoff Hick 5th
Yerzhan Suleyev 24th

Rotary Membership
Angus Buchanan 18th
Guy Mattioli 22nd
Gary Leighton28th
Dennis Hartley 30th

Attendance

Members:	**19**
Honorary Member:	**0**
Visiting Rotarians:	**0**
Guests:	**2**
Guest Speaker:	**1**
Total:	**22**
Apologies:	**9**

Editor's Stand-In Thought

Wise women talk because we have something to say;
Foolish men, because they have to say something.
…Mrs Plato…

THE MAGIC OF ROTARY

Summary of Upcoming Meetings

Thu 12th Jun:	Professor Ralph Martins AO: Detecting Alzheimer's at an early age
Thu 19th Jun:	Professor Angus Buchanan: WPRC Survey Feedback
Thu 26th Jun:	Changeover Dinner.

Tit Bits

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<td>We often get "Only in Asia "
or "Only in America"
pictures, so you might like some
ONLY IN AUSSIE' for a change?
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PADDY'S LAMENT

That kick was absolutely unique except for the one before it which was identical-
Dermott Brereton

Nobody in football should be called a genius. A genius is a guy like Norman Einstein-
Mick Malthouse

Asked, would you describe yourself as a volatile player? David Beckham said "*Yes. I can play in the centre, or the right and occasionally on the left*".

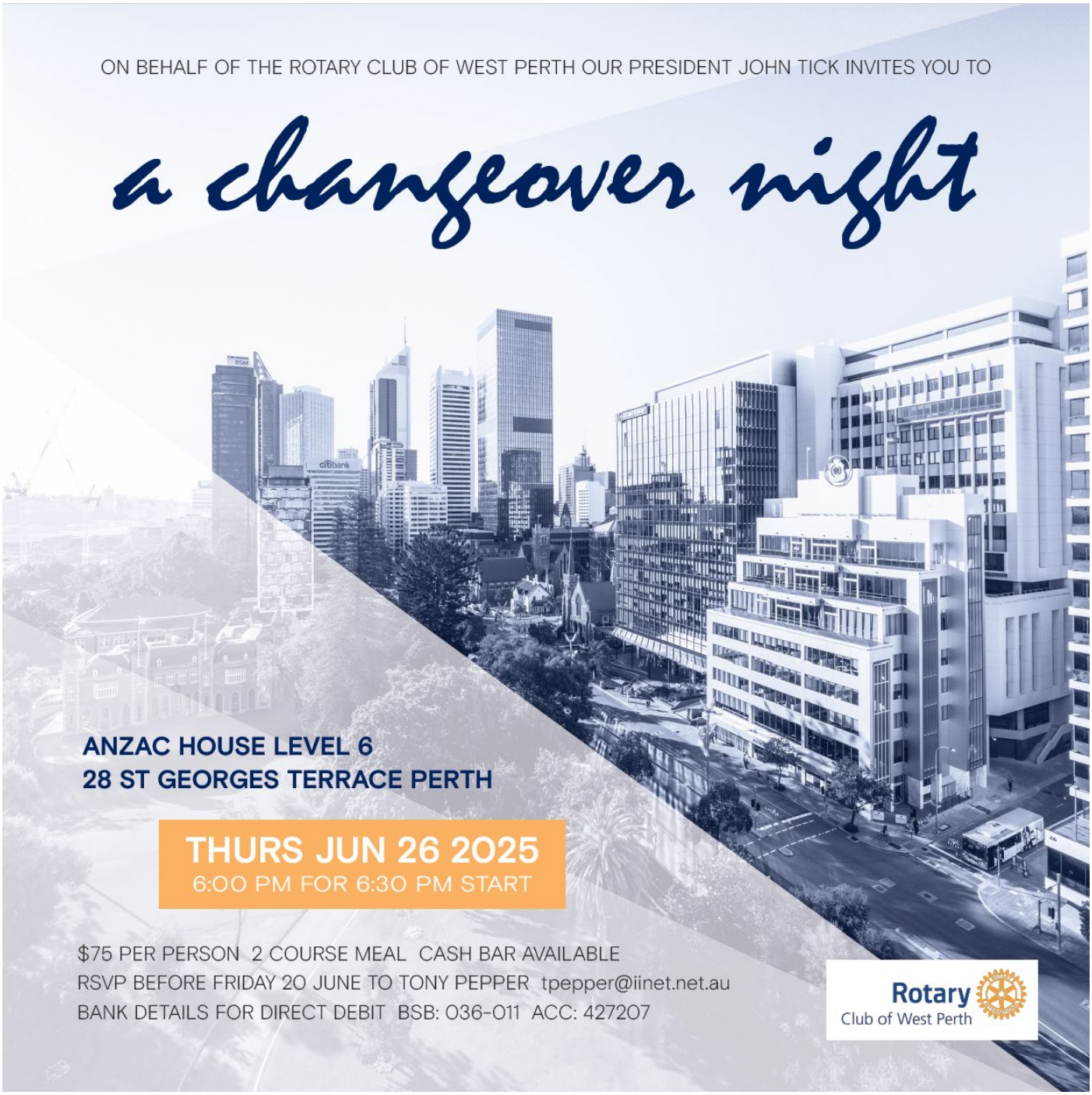
Left hand, right hand, it doesn't matter, I'm amphibious-
A US basketballer

He's a guy who gets up at six o'clock in the morning regardless of what time it is-
Kevin Sheedy

These gems from Barry Hall:
You guys line up alphabetically, by height, and you guys pair up in groups of three, then line up in a circle. I want to kick 70 or 80 goals this year, whichever comes first!

ON BEHALF OF THE ROTARY CLUB OF WEST PERTH OUR PRESIDENT JOHN TICK INVITES YOU TO

a changeover night



ANZAC HOUSE LEVEL 6
28 ST GEORGES TERRACE PERTH

THURS JUN 26 2025
6:00 PM FOR 6:30 PM START

$75 PER PERSON 2 COURSE MEAL CASH BAR AVAILABLE
RSVP BEFORE FRIDAY 20 JUNE TO TONY PEPPER tpepper@iinet.net.au
BANK DETAILS FOR DIRECT DEBIT BSB: 036-011 ACC: 427207

Rotary
Club of West Perth

Hi Fundraisers!

Wow do we have some prizes up for grabs, read on……

CURRENT PROMOTION

GOOD FOOD & WINE SHOW – July 20-22

Ok I have a few double passes to the Good Food & Wine Show in July (**valued at $100)**

All you need to do is send me a ***copy of a promotion*** you have done to go into the draw, it's that easy.

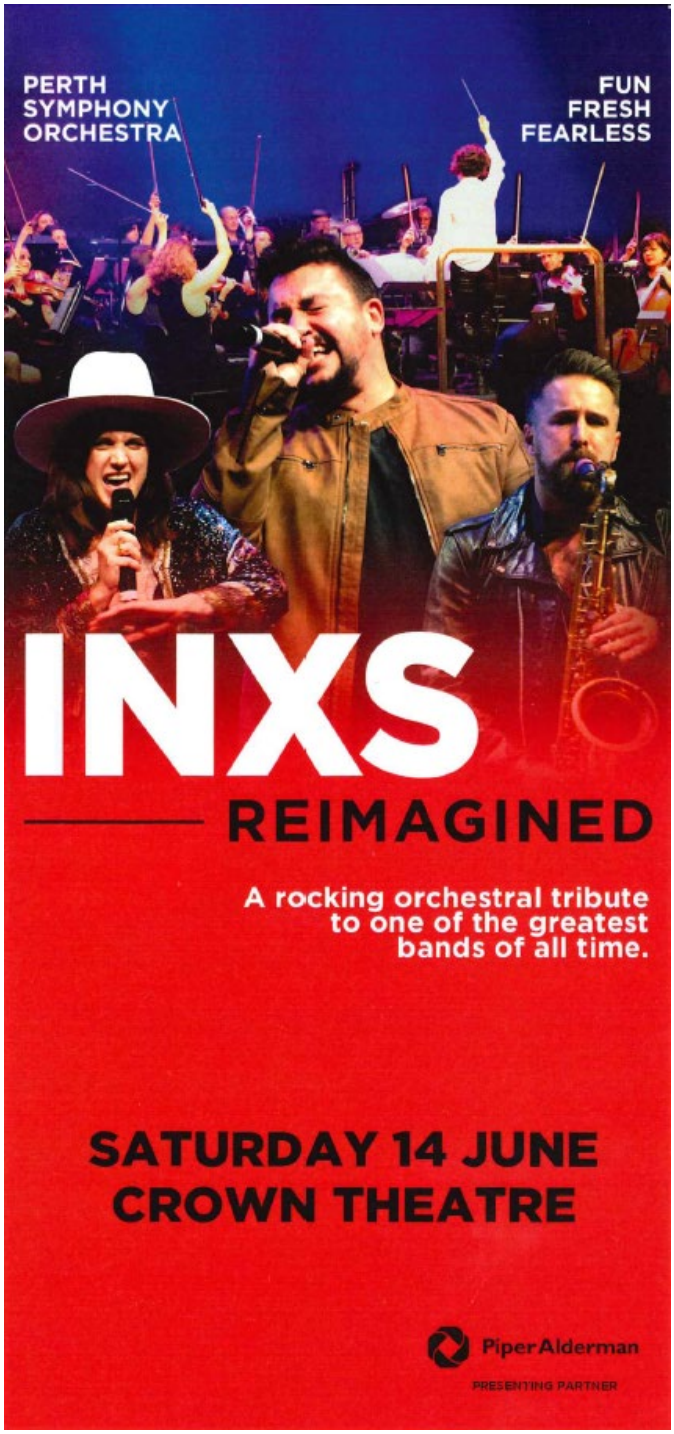
DID SOMEONE SAY HAWAII!!!! Aloha and yes they did!

Our new partners at Hawaiian Airlines have come on board to **not only** give your members a deal on their flights via the Entertainment App, but they're here to give YOU the chance to win a **holiday for TWO to Hawaii, including accommodation at the Hilton Hawaiian Village Resort!**

The **Raise to Win competition** runs until **Monday 30 June** and all you need to do is:

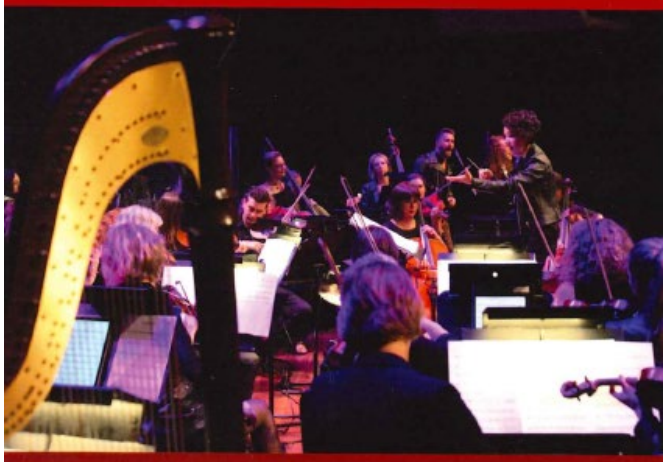
- Promote Entertainment to your audience (and send me proof 😁)
- Sell 5 memberships which will give you 1 entry to WIN!
- *There is no limit to how many entries you can have!* *(T&Cs apply)*

Good luck everyone and thanks for being awesome!



Following a sell-out season in 2023, experience this powerful tribute to one of Australia's most iconic rock bands - brought to life with a full orchestra, choir, and sensational soloists. Their timeless hits remain as powerful as ever, making this symphonic celebration a must-see for fans old and new.

Rising from Perth's pub scene to take over the world's best stadiums, Michael Hutchence, Andrew, Tim, and Jon Farriss, Garry Gary Beers, and Kirk Pengilly left an unparalleled legacy in the music world. Audiences can expect a setlist packed with INXS classics, from the unforgettable groove of Devil Inside to the heartfelt emotion of Never Tear Us Apart.



Re-live the magic of INXS and the unrelenting spirit of rock 'n' roll.

Showing for one night only, Saturday 14 June!

PERTH SYMPHONY ORCHESTRA

MINDEROO FOUNDATION

PRINCIPAL PARTNER

BARTON FAMILY FOUNDATION

modn TECH SOLUTIONS

PERTHSYMPHONY.COM

BOOK NOW!