

NAPWA 2010 SGM Report

On April 16th and 17th NAPWA (National Association of People Living With HIV/AIDS) held their SGM in Sydney. These meetings are attended by the NAPWA Board, two representatives from each state and territory and other HIV interest groups from within Australia such as Straight Arrows and Patsin (Positive Aboriginal and Torres Strait Islander Network). Mick Doring and Mandi Collins attended the meeting as the ACT reps.

The meeting covered a vast array of interesting and important reports/issues on and around HIV/AIDS in Australia and the Pacific region. This report will cover some of some of those reports that were discussed at the meeting.

State Members' Report

This session gives each state's members the opportunity to share information about their recent activities and state issues. Sony Williams from Victoria mentioned the release of a DVD and book called Closer. Des from Taschard (Tasmania) reported that they had run a successful retreat, with 10 members attending. South Australia spoke about the many changes they have gone through with their Clients Services; we found this to be a very interesting and worthwhile session.

Ageing and HIV

NAPWA is planning a forum on HIV and Ageing to be held in June/July 2010. Participation will be invited from all stakeholders in the HIV sector.

Update on 6th National HIV Strategy

This session was presented by The Hon Mark Butler, Parliamentary Secretary for the Minister for Health. Some of the areas of the National Strategy Mark spoke about were stigma and discrimination, ageing and complacency, the rise in the numbers of STI infections and the rise in HIV diagnoses. Mark also mentioned the need for better co-ordination between the states.

Rapid Testing and Treatments as Prevention.

This was a very lively session and was run as a panel discussion by Sean Slavin. The panel members were Phillip Keen (AFAO), Garrett Prestage (NCHECR), Rebecca Matheson (Straight Arrows) & Bill Whittaker (NAPWA). Mandi has written an article on this discussion which will be published in this copy of Positively.

NAPWA program in PNG. Session by Jo Watson & Tim Leach.

NAPWA has been working in PNG for the last 12 months assisting Igat HOPE (PNG PLWHA equivalent) and supporting them in the areas of governance, technical support and training of peer support workers. NAPWA is funded for this program by AusAid and Jo also reported that AusAid has approved the funding for NAPWA to continue their excellent work for another 18 months. Jo also thanked the NAPWA people who have been involved with the project for the last 12 months.

Stigma Audit session by Sean Slavin & David Menadue.

NAPWA proposes to conduct a study on the experiences of HIV stigma among PLHIV in Australia. The survey of 700 PLHIV will be conducted using standardised, internationally recognised scales to measure HIV stigma. Participants for the survey will be recruited from around Australia through PLWHA organizations, AIDS Councils and relevant HIV internet sites. The survey will be anonymous and self administered with both a paper version and an online version to be made available. It is anticipated the project will take one year to complete. We will give you more information on this survey as it comes to hand.

Report continued on page 3

<p style="text-align: center;">Contents</p> <p>1-3 NAPWA SGM 2010 Report</p> <p>4.Nurse Philip.</p> <p>5.Introduction to Rapid Testing .</p> <p>6.Good Nutrition and HIV.</p> <p>7.Brenda's Blenda.</p> <p>8.Coming Events</p>	<p>POSITIVELY is a regular publication for people living with HIV/AIDS in the ACT and surrounding districts. Currently we are looking for people to assist us with the publication e.g. writing groups. No experience is necessary as we will provide training in all aspects of publishing from writing articles through to the printing stage. If you can spare a couple of hours from time to time please drop into the office for a chat or give Marcus a call. Positively is a monthly publication produced within the ACT with funding from the ACT Dept of Health. Submissions for the next edition are due on Friday 23rd July. Opinions expressed in this publication do not necessarily reflect those of the editor, publisher, nor PLWHA ACT.</p>
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Positive Support Services in the ACT and surrounding areas

<p>People Living With HIV/AIDS ACT</p> <p>Provides support for HIV+ people in the ACT through a newsletter and links with other PLWHA organisations throughout Australia. We also provide individual support with advocacy and representation on health and other issues, and referral to other agencies. Ph 6257 4985</p> <p>Positive Support Network</p> <p>HIV+ people get together to offer support and share information. PSN is mostly a social occasion where people can share the experience of being HIV+ over a free meal, without the formality of a structured meeting. Dinner on alternate Tuesdays. Ph 6257 4985.</p> <p>Positive Women's Group</p> <p>The Positive Women's Group meets for social activities throughout the year. For information on the group's gatherings or if you would like to suggest some activities contact Marcus, Nada or Stephanie on 6257 2855 or 6257 4985</p> <p>Trevor Daley Fund</p> <p>The Fund provides assistance for people with HIV/AIDS who are experiencing financial hardship, for the part payment of bills, a treatments allowance and some other costs. Applications can be made to the TDF Committee by any service provider. For more information call the TDF on 6257 2855.</p> <p>Counselling</p> <p>Stephanie Buckle is the AIDS Action Council counsellor. Free consultation available to all HIV+ people, their partners, carers or significant others. Phone 6257 2855 to make an appointment.</p> <p>Jane Keany is the counsellor for the ACT Division of General Practice HIV/AIDS Program, and offers subsidised counselling services for people infected with or affected by HIV, their significant others and people at risk of HIV infection. Jane is available at the Interchange General Practice. Phone 6257 3004 or 0402 222 408 to make an appointment</p>	<p>Health Maintenance and Treatments Information</p> <p>All enquires to Marcus Or Nada Phone 6257 2855 Treataware www.treataware.info</p> <p>Nutrition</p> <p>Consultation with a dietitian from The Canberra Hospital is available free at the Canberra Sexual Health Centre. Appointments necessary. Phone Canberra Sexual Health on 6244 2184.</p> <p>An HIV specialist nutritionist from Melbourne will be visiting quarterly. For further info contact Nada or Mick on 6257 2855</p> <p>Canberra Sexual Health Centre</p> <p>Co-located with The Canberra Hospital. Free service available (no Medicare card is required) for testing and treatment of STIs, HIV clinic and counselling for issues such as safe sex, relationships and sexual functioning problems. Walk-in consultations available for urgent matters. Call on 6244 2184 to make an appointment.</p> <p>Library</p> <p>PLWHA and the AAC have an extensive range of books and videos for your enjoyment.</p> <p>Educational books on HIV issues, cooking, Sci-Fi and general reading material, just to name a few of the areas covered. If you would like to borrow any of them please see Lynn or Mandi at the AAC reception desk who will sign them out to you and explain the borrowing conditions. We also have a number of new books in the library this month.</p>	<p>Greater Southern Area Sexual Health and Hep C Service</p> <p><u>GSAHS Queanbeyan Sexual Health Service</u></p> <p>For Appointment Ph- 02-6298 9233</p> <p><u>Aboriginal Sexual Health HIV/AIDS Worker</u></p> <p>Sharyn Medway Ph 02-4827 3913 Mobile 0429 985 606</p> <p><u>Sexual Health Nurses</u></p> <p>Christine Taylor - South Coast, Batemans Bay - Eden Ph- 02-4476 2344 Mobile 0427 219 874</p> <p>Queanbeyan-Goulburn Region Ph- 02-6298 9213 mobile 042 789 3247</p> <p>Margaret Trill Albury 02 6058 1839</p> <p>Robyn Ridley & Sally Anne Brennan Wagga Wagga 02 6938 6492</p> <p>Sally Daveron Griffith 02 6966 9930</p> <p><u>Clinical Nurse Consultant</u> Alison Kincaid Albury 02 6058 1831</p> <p><u>Sexual Health Physician</u> Dr Katherine Turner Ph 6298 9213</p> <p><u>HIV/AIDS Related Programs Manager</u> Michael Bolton Ph: 02 6923 5774</p>
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The Fine Print

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Treatments Session by Jo Watson

Sculptura was approved to go on the PBS in June 2010. People who are affected by HIV treatment associated facial lipoatrophy (facial wasting) are now eligible to receive up to eight vials for their first treatment. Two top up vials will also be provided every year.

Problems have arisen due to the high costs of administering this drug and NAPWA has supported a submission to ask Medicare to supply an item number for administering Sculpturas. It is expected that a decision will be made on this by November 2010. The Drug Resistance Test will also be going on the PBS.

Jo also spoke on the CROI conference she attended in San Francisco in February and her report on this conference was published in the April/May issue of Positively.

The possibility of using immune based treatments is also being investigated for treatment of HIV.

What are Immune-Based Therapies?

AIDS researchers have primarily concentrated on finding drugs that prevent HIV from replicating (creating more virus) inside the body. These drugs are often referred to as "antivirals". More recently, many researchers have been trying to find ways to help a person's immune system fight the virus on its own. Called "immune-based therapies", some of these such a treatments are now being studied in large clinical trials.

The CCR5 inhibitor Maraviroc was listed on the PBS on 1st April, 2010 and Marcus has written an article for the newsletter on this subject.

The question of when to commence treatments is a continuing debate. Some studies are showing that starting treatments earlier in HIV infection could have positive effects and also reduce the risk of age related diseases.

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Mick Doring/Mandi Collins

Update on Maraviroc (Celsentri)

As of the first of April 2010 a new drug to treat HIV infection has been added to the Pharmaceutical Benefits Scheme (PBS).

Maraviroc belongs to a new class of Anti Retrovirals called CCR5 antagonists. Unlike other marketed antiretrovirals, Maraviroc acts directly on the white blood cell, rather than the virus, preventing HIV from entering the cell, blocking entry via the CCR5 receptor.

Maraviroc is not for everyone and a test to see if the HIV virus a person is carrying is suitable to be treated with this drug would need to be undertaken.

There are also other prescribing regulations put in place by the PBS and this would need to be to see if you are able to access this drug.

What is a CCR antagonist? Attachment inhibitors or entry inhibitors. They work by attaching themselves to a protein on the surface of CD4 cells called CCR5, blocking the virus from entering the cell. Drugs from this class are particularly useful for treatment-experienced discussed with your doctor people who have developed resistance to other drugs and classes. (Info taken from www.napwa.org.au)

Christmas in July Dinner

6th July 2010

PLWHA ACT would like to invite members and their family to our Christmas in July dinner.

The dinner is being held at PLWHA Westlund House 16 Gordon St. Acton starting at 6pm Tuesday 6th July.

For catering purposes could all those members attending the dinner please RSVP to Mick on Ph 62574985.



Nurse Philip

Dear Nurse Philip

I have been positive for a few years now and have been on & off treatments for many of those years as I have found it very difficult to stick to a regime. Recently my doctor has given me a new combo with different medications together in the same tablet to make it simpler to take. Some of my friends who are also on medications have said that they also have trouble swallowing some of these larger tablets; can you give me some suggestions on how to overcome this problem?

Signed D T

Dear DT

There have been so many improvements in the development and formulation of antiretroviral therapy over the last couple of decades. Things aren't perfect yet, but they're a whole lot better. These days, there are medications with fewer difficult side effects and less demanding dosing schedules. One breakthrough is the co-formulation of medications (two or more medications into the same tablet or capsule).

There are a lot of considerations when formulating medications and these problems increase when there is more than one active ingredient involved. In addition to a long shelf life a formulation of antiviral medication(s) should have:

- Controlled release of the active ingredients, resulting in even levels of the drug in the blood. Very low levels can encourage resistant virus and high levels increase the risk of side effects. Some medications are coated so that they don't release the drug until they have left the highly acidic stomach, whereas others need to dissolve in the stomach to work properly.
- Minimal tablet or capsule count per dosing time
- Ease of swallowing (the surface is smooth and does not stick to the mouth or throat; the shape of the preparation facilitates swallowing and the size is acceptable)

One of the consequences of co-formulation is that the tablet or capsule may be larger than the formulations containing equivalent amounts of the active ingredients. In most cases, this size increase is only slight; it shouldn't significantly reduce the ease of taking the medication.

Being relaxed and confident is important. The prospect of swallowing a slightly larger medication may seem daunting and provoke anxiety; a more relaxed approach will increase the likelihood of

success. Early successes should help reduce future anxieties.

A small amount of food or water taken before the medication can help lubricate the mouth and throat and reduce the tendency of the tablet or capsule to catch in the mouth or throat. This swallowing can also help familiarise the muscles with the action of swallowing and make it easier to repeat these actions with the medication.

In addition, if the medication is actually swallowed at the same time as the water or food, the medications may be swallowed within the volume of water or food. This should reduce the likelihood of gagging on the medication. Food such as soups, custard, yoghurt or jelly can be particularly useful for this purpose. Be sure to check with your pharmacist, doctor or other health professional or read the product information; some medications should not be taken with food.

For some people, placing the medication towards the back of the tongue before taking a mouthful of water can be useful. For others, this can induce gagging and should be avoided. Use a technique that has previously worked for medications of a similar size.

It may be tempting to crush or halve tablets or extract the contents of capsules to make the medication easier to swallow. In most cases, this is inadvisable, as it may alter the rate of release of the ingredients into the bloodstream and make the medication less effective. In rare cases, it may be possible to crush or halve a tablet, but if this is the case, it will be clearly mentioned in the product information.

If you find that you just can't swallow your new medications, report this to your prescribing doctor promptly. It may be possible to prescribe a comparable combination (perhaps with an increased pill count) that is still effective, but will be easier to swallow.

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Introduction of Rapid Testing for HIV for use in Australia

The NAPWA Special General Meeting was held on 16/17th April, 2010 which both Mick and I attended. One session that I found of particular interest was about the possible introduction of rapid testing for HIV in Australia. A panel discussion was held and this subject stimulated a highly interactive discussion from all who attended. Strong arguments and opinions were put forward for both the pros and cons of making rapid testing available. Those of us who have been diagnosed HIV + and anyone who has ever had an HIV test ,all know what a harrowing week waiting for your results can be. Unfortunately, this has even led people to suicide during this period because, along with other contributing factors, they felt they could not cope with a positive diagnosis. So would lessening the amount of time people have to wait for their results help to avoid the stresses of that waiting period? Rapid testing for HIV provides a result within half an hour, however, a positive result would still require confirmation by standard HIV testing already available.

It is not clear yet what sites testing would be available from. Suggestions ranging from chemists, outreach, community health centres and even AIDS Councils have been proposed. This raises the question of whether adequate, if any, pre and post test counseling provisions would be put into place. Reporting of new HIV infections and the accurate collection of data could be compromised, especially if testing kits were to become available over the counter at pharmacies. People could choose to never go on to disclose and receive any support or treatments. It should be noted that rapid testing kits are already available online, so the reality is that this type of testing is already occurring in Australia.

The scenario of mass rapid testing being conducted in minority and at risk groups was raised. Particular concerns were voiced about the possibility of forced, as opposed to, voluntary testing taking place in extremely vulnerable and culturally sensitive groups such as Indigenous communities and in people from CALD backgrounds.

Earlier detection of HIV infection can lead to people having the opportunity to make choices around treatments, sexual behavior and lifestyle options in the first stage of their infection. Knowing your HIV

status can also reduce the risk of new infections taking place as the virus is most virulent during seroconversion. One argument for rapid testing would be the possibility that more people would choose to have an HIV test if they didn't have to visit a doctor or sexual health centre for testing. The relatively low cost of the kit would also be a contributing factor as it would retail for around \$17.00. The risks of self harm, self destructive behavior and suicide could possibly be reduced if the waiting period were lessened. It may even lead to decreased rates of new HIV infections due to more people knowing their HIV status.

NAPWA has further ascertained from this discussion that a lot more work is needed around the above mentioned issues that are raised by the possible introduction of rapid testing.

I will update you all further as more information comes to hand.

Mandi Collins

DIETITIAN'S CLINIC Tuesday - August 10th 2010

Jenny McDonald is a well known HIV Dietitian and Treatments Officer who has worked in the area of HIV nutrition for many years. She has been conducting clinics for People Living with HIV/AIDS and the AIDS Action Council for a number of years. Jenny will be in Canberra to conduct another Clinic at Westlund House on Tuesday 10th August 2010.

Appointments are available from 9.30am till 3.15pm. for bookings and further information please contact Mick at People Living with HIV/AIDS on 6257 4985.



Good Nutrition and HIV

Article by Megan, Louise, Lia and Simon
Albion St Centre

The link between nutrition and good health is well established. Good food can promote a sense of wellbeing in both body and mind. A good diet, when combined with exercise is the most powerful tool in optimising your health.

Food and eating has a much broader and integrated role in life than simply providing nutrition. We eat for a variety of reasons, including pleasure, religious significance, social interaction, to celebrate, for comfort and to nurture.

It is easy to become confused about eating well, especially when coupled with HIV management. Confusion is fuelled by the media promoting fad diets, the proliferation of highly processed, palatable convenience foods that are aggressively marketed by the food industry and the abundance of information available on the internet of varying quality.

The following information aims to provide simple guidelines on eating well with HIV.

How does HIV affect nutrition?

People Living with HIV (PLHIV) have generally the same dietary requirements as the generally population.

There is evidence that the virus increases energy requirements slightly (around 10%) and up to 20% higher in advanced disease and may increase the requirement for vitamins and minerals due to decreased or absorption/utilisation of nutrients. More research is required in this area before scientific recommendations can be made.

How do antiretroviral (ARV) drugs affect nutrition?

ARV's improve nutritional status by keeping the immune system strong and the body functioning efficiently, so food can be digested and utilised efficiently. However, there can be side effects that affect nutrition such as gut problems (diarrhoea, nausea, vomiting) and metabolic disorders such as

dyslipidaemia (abnormal levels of fat on the blood) and lipodystrophy (a derangement of bodily fat distribution). It is recommended to seek advice when side effects are persistent and impacting on dietary intake.

What does good nutrition mean?

Good nutrition means eating a variety of foods to meet the body's requirements for both the big nutrients (carbohydrate, protein and fat) and the little nutrients (vitamins and minerals). It also encompasses eating the right amount of energy to maintain a healthy weight. Guidelines for good nutrition are outlined below.

Eat foods from each of the core food groups

The core food groups are:

Bread, cereals, rice, pasta, noodles

Vegetables

Fruit

Milk, yoghurt, cheese

Lean meat, fish, poultry, eggs, legumes (beans) and nuts.

The core foods are the building blocks of a good diet. They should make up the majority of what you eat.

Eat a variety of foods within each group

Simply speaking, eating a variety of foods will ensure that a wide variety of nutrients are consumed. The nutrients in foods are different, and by eating a variety of foods the risk of being deficient in any nutrient is decreased. Nutritional science is a relatively new area and there is so much to be discovered about the way food chemicals and nutrients interact with each other. What is known is that the good stuff cannot be taken in a multivitamin! Thus it is more important to focus on eating a variety of nutritious foods than taking a handful of vitamin and mineral supplements each day. A dietitian will be able to advise you on vitamin and mineral supplementation.

So mix it up: eat different coloured vegies, different lean meats, and different cereals. Variety helps keep food interesting!

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Brenda's Blenda

Three easy steps to Scrambled Eggs

A breakfast or brunch favourite and here is the expert method in three simple steps.

What you need

Step 1: 2 large fresh eggs per person and a small amount of milk in a bowl. (Don't overdo the milk as cooked eggs only hold a certain amount of liquid). Use a fork to whisk until the mixture is just combined with no streaky white. If the mixture is streaky, the cooked eggs will be streaky too.

2. Heat 3 tsp butter in a medium, heavy based frying pan over a medium heat. (Use the largest hot plate or gas burner to ensure even

cooking), when the butter foams swirl the pan to coat the base.

3. Add the egg mixture and cook without stirring for 30 seconds. Use a flat edged wooden spoon to push the mixture, scraping the bottom of the pan from one side of the pan to the other (stirring breaks it into small lumps). Heat for two minutes or until three quarters of the mixture is cooked and one quarter is still liquid. Remove from heat and gently fold the eggs twice. The residual heat will finish the cooking. Serve immediately on buttered toast and enjoy!



Love Brenda

Further hints from Brenda's kitchen

Getting to know the different beef roast cuts

Living on a low income and having Roast Beef is a real treat and although it can be expensive it is well worth it, if cooked with care. Here are the most popular cuts to suit every pocket.

1. Bolas Blade Roast:

Economical and have a good beef flavor.

2. The Eye Fillet /Tenderloins:

A very tender beef roast; it's mild in flavour and deliciously juicy.

3. Eye Round:

A very tender and every day beef roast.

4. Rib eye/Scotch Fillets;

One of the juiciest beef roast, it's tender and tasty.

5. Rump Roast:

This one ticks all the boxes!

6. Sirloin/Porterhouse Roast:

Big on beefy flavour and rich in texture.

They are very juicy too.

7. Standing Rib Roast:

An impressive beef roast; it's very tender as well as flavorsome.

8. Top Side Roast:

A great value beef roast, perfect for salads and sandwiches.

Note: For the juiciest results, cook on medium to slow heat and slice thinly to serve.

If you have time, take the roast from the fridge about 20 minutes before cooking, this will ensure the meat cooks evenly.

Rest the beef for 10 to 20 minutes after cooking as it will give the meat a chance to redistribute giving a juicier, tender result. Loosely cover it with foil and let stand in a warm place.

Don't spoil your roast by pouring gravy all over the top of your cuts, pour the gravy onto the plate and then place your cuts on the top.

Eat regularly

Eating 3 times per day (at least) will help maintain energy levels. Eating patterns can be very individual and what works for one person may not for you. However, it is recommended to eat at least 3 times per day, and this includes something in the morning or within a few hours of getting up. It really is the most important meal of the day!

Many PLHIV experience a lack of appetite, especially in the morning. The benefits of breakfast can be obtained by eating something small-like a piece of fruit, yoghurt or a glass of milk.

Skipping meals can lead to overeating later in the day, which will contribute to weight gain. Skipping meals can lead to lack of appetite, fatigue, weight loss and inadequate nutrition. If compensated with overeating later in the day it may contribute to weight gain and obesity.

Keep a close eye on cholesterol

High cholesterol is a common side effect of ARV's especially protease inhibitors (PI). It is important to manage high cholesterol to reduce risk of heart disease.

How can I reduce my cholesterol?
Eat less saturated fat.

This is the harmful fat that is found mainly in animal products such as processed meat, visible fat on meat and chicken, full fat dairy and butter (and anything that contains butter such as cake, biscuits, pastries, sauces). Take-away and convenience foods tend to be high in saturated fat as it is cheap and it makes food taste good. Reducing harmful fats is the most effective dietary intervention to reduce cholesterol.

Eat more fibre

Fibre helps reduce cholesterol re-absorption in the gut. Australians generally do not eat enough fibre, as

we are not eating enough fruit, veg or wholegrain foods. If you know you are not eating enough high fibre foods, a fibre supplement daily such as Metamucil or Benefibre will bump up your intake.

Plant sterols

Plant sterols inhibit cholesterol reabsorption in the gut, and can be useful in reducing cholesterol. They are found naturally in low levels in plants foods, nuts and seeds. Foods can be fortified with plant sterols, such as margarine. If you do choose to use fortified margarines, be aware that to have a cholesterol lowering effect, around 3 g of plant sterols are required each day. This is equal to 6 tsp of margarine. This may not be appropriate for people following a low fat diet (check with a dietitian or specialist).

A healthy weight

The prevalence of being overweight or obese is increasing in PLHIV, as it is in the general Australian population. If you are overweight, even a small reduction in weight can have significant health benefits in terms of reducing risk of heart disease and improving quality of life. In reality there is no better way to lose weight (and maintain it) than through regular exercise and a healthy diet. For individual advice, see a dietitian.

Oral health

The mouth is often neglected in terms of health. Problems in the mouth such as gum disease or tooth cavities can have serious effects on the type and amount of food that can be eaten. It is recommended you brush twice a day and visit a dentist every 6 months for a check up. If financial concerns are keeping you away from the dentist, there are new arrangements for financial support through Medicare for PLHIV. Ask your doctor.

Article reprinted from Talkabout Magazine February- March 2008

COMING EVENTS

Monday 7th June

P.S.N Special Big Dinner

Westlund House 6PM

(guest speaker)

Wednesday 9th June

P.S.N Lunch 12-2pm

Westlund House

Wednesday 16th June

P.S.N Lunch 12-2pm

Westlund House

Wednesday 23rd June

P.S.N Lunch 12-2pm

Westlund house

Thursday 24th June

Legal clinic from 6pm

Westlund House

Wednesday 30th June

P.S.N Lunch 12-2pm

Westlund House

Tuesday 6th July

P.S.N special big dinner

Christmas in July 6 pm

Westlund House

Wednesday 7th July

P.S.N Lunch 12 - 2pm

Westlund House

Wednesday 14th July

P.S.N lunch 12-2pm

Westlund House

Wednesday 21st July

P.S.N Lunch 12-2pm

Westlund House

Thursday 22nd July

Legal clinic from 6pm

Westlund House

Wednesday 28th July

P.S.N Lunch 12-2pm

Westlund House