

# Fanconi Anaemia Support Australasia FAMily and Adult Meeting

St Vincent's Institute of Medical Research (SVI)

Friday 24th - Sunday 26th March 2023



**SVI**   
**St Vincent's Institute**  
MEDICAL RESEARCH

FANCONI ANAEMIA  
SUPPORT AUSTRALASIA  
INC.

# PROGRAM

# Friday 24th March

8:30 - 9:00am

## Registration

Grab a goody-bag. Grab a coffee.

9:00 - 9:05am

## Professor Tom Kay - SVI Director

Welcome and introduction to SVI.



9:05 - 9:10am

## Housekeeping

Some housekeeping notes from the FASA team.



9:10 - 10:00am

## A/Prof Adam Nelson - Director- Bone Marrow Transplant and Cellular Therapies, Kids Cancer Centre, Sydney Children's Hospital

Fanconi Anaemia Refresher and the latest science: neuroinflammation, nutrition in FA patients, and bone marrow transplant results.

10:00 - 10:50am

## Dr Eunike Velleuer - Department of Cytopathology, Heinrich Heine University, Düsseldorf, Germany Christine Krieg - Executive Director, Deutsche Fanconi-Anämie-Hilfe e.V.

Introducing "Power 2 U": A new campaign to manage the increased risk of oral cancer in FA.



### Need a break from the main program?

The Chill-Out room is open all day. In the morning - the team from Bunnings will be running craft activities for the kids. There'll be a movie or two, snacks, or just time to stare at those screens.

### Escape the Building!

Melbourne Museum (across Nicholson St and through Carlton Gardens) is offering free admission to everyone at the Family and Adult Meeting. Tell them your name at the Ticketing Desk and that you are part of the SVI Meeting day - the museum is yours.

*10:50 - 11:20am*  
**MORNING TEA**

*11:20 - 11:50am*

**Family lived experience**

Lottie Johnson, with parents Hollie and Rowan, chat with Amelia Hawkshaw and explore the day to day of FA.

*11:50 - 12:30pm*

**Jordan Deines - Family Services Director, Fanconi Anemia Research Fund**

Fanconi Anemia Research Fund's (FARF) mission is to find better treatments and a cure for FA, and to provide education and support to affected families worldwide.

Jordan takes us through FARF's current research priorities, clinical programs, and educational and support services. The focus is on opportunities for direct support that are available to those in Australasia, including FA events, family services, clinical programs, volunteer opportunities, and peer support.



*12:30 - 12:50pm*

**SVI Researcher Flash Talks**

**Dr Michael Sharp**

Understanding the intersection of metabolism and the Fanconi Anaemia pathway.

**Dr Stevan Novakovic**

Fertility in Fanconi Anemia.

**Dr Rohan Bythell-Douglas**

Searching for the structure of FANCM.



*12:50 - 1:50pm*  
**LUNCH**

*1:50 - 2:30pm*

**SVI LABORATORY TOURS**

So many white coats, so much science. A chance to take a guided tour of the SVI complex to see and hear what life is like on the cutting edge of research. We'll split into smaller groups and rotate through the labs.

2:30 – 3.15pm

**A/Prof Andrew Deans - Head, Genome Stability Unit, SVI**

Prime Editing is the latest powerful tool under development in the gene editing field. It holds the exciting possibility of correcting any genetic mutation back to a normal sequence. Applied to bone marrow failure syndromes like FA it may be possible to restore normal blood production without the trauma and risk of a bone marrow transplant.



3.15 - 3:45pm

**Marta Cifuentes - Associate Genetic Counsellor in Reproductive Genetics, Victorian Clinical Genetics Services**

An open discussion about genetic carrier screening where there is a family/personal history of Fanconi Anaemia. The how, when, and why of genetic counselling and options for testing.



3:45 - 4:15pm

**AFTERNOON TEA**

4:15 - 4:45pm+

**Q&A Forum**

There's a lot of information to absorb across the day. Our presenters will grab a seat out the front and take questions from the floor. This is a chance to fill in gaps in our understanding, draw some conclusions, and maybe look to the future.

5:00pm ish

**MEETING CLOSE**

A quick thank you to all and details for dinner, accommodation, and Saturday's fun.

**BREAK**

5:30 - 7.30pm and beyond

**Family and Friends Dinner**

**Union Club Hotel - 164 Gore St Fitzroy**

The Union is a 13 minute walk from SVI (about 1km). Or catch the #86 tram from Nicholson St, heading north - also a 13 minute trip.

# Saturday 25th March

8.00am

## **BUS ARRIVES**

Our bus will arrive at Urban Camp to collect us. For those staying at UC a light breakfast will be available from early on. For those staying elsewhere please arrive as close to 8.00am as you can. There is parking available a few hundred metres from Urban Camp at the Sports Centre.

8.30am

## **ON THE ROAD**

The drive to Ballarat takes from 90 minutes to two hours, depending on traffic and whether we stop for coffee.

10.00am

## **ARRIVAL AT SOVEREIGN HILL**

Our entry has been pre-booked and paid for by FASA - the Sovereign Hill people will tick off your names.

Once inside we'll be trying our hand at some panning for gold in the creek, and we'll have a guide to introduce us to the Sovereign Hill layout. Then the site is there to be explored at your leisure. There are activities that can be booked into (fees apply) and various options for snacks and meals.



2.45pm

### **BACK TO BUS**

Please start making your way back to the bus near the main entrance.

3.00pm

### **BUS LEAVES**

Make sure you're on that bus to come home with us!

5.00pm

### **RETURN**

Arrive back at Urban Camp

5.30pm

### **DINNER**

We'll be firing up the BBQ at Urban Camp for dinner, and all are welcome to join us.

7.00pm

### **CHILL**

A chance to kick back and chat and relax for the evening at Urban Camp. There may be a few games.

## **Sunday 26th March**

**Time to pack up and head off.**

**A light breakfast will be available at Urban Camp.**

**Check-out time is 10am.**

**Safe travels everyone and see you at the next meeting!**



**Urban  
Camp**

**Heartfelt thanks from Fanconi Anaemia Support Australasia to all who have made this Family and Adult Meeting possible.**

We acknowledge the generous support of the Fanconi Anemia Research Fund. FASA has been the recipient of a FARF International Grant to facilitate the establishment of the organisation and this year's Family and Adult Meeting.



We are grateful for St Vincent's Institute's commitment to FASA and all people living with FA in Australia and New Zealand.

Thanks to Turosi Giving for their generous financial support.



together we make a difference

And a big shout-out to the team at Bunnings for bringing the crafty goodness.





**FANCONI ANAEMIA**  
**SUPPORT AUSTRALASIA**  
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### **The FASA Committee 2023**

Barbara Hawkshaw – President  
Mariska van Essen – Vice President  
Chris Hawkshaw – Secretary  
Alan Howard-Jones – Treasurer  
Wayne Crismani  
Nico Buitendijk  
Amelia Hawkshaw  
David Rodwell  
Cathy Rodwell

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FASA acknowledges and pays respect to the past, present and future Traditional Custodians and Elders of this land that we gather on, the Wurundjeri and Bunurong people and the continuation of cultural, spiritual and educational practices of Aboriginal and Torres Strait Islander peoples.