

# GLOBAL MRKH DAY 2019

## Event Program



**FRIDAY, 29 NOVEMBER 2019**

Royal Children's Hospital  
50 Flemington Road, Parkville, Melbourne, Australia

**WWW.MRKH2019.COM**  
**PRESENTED BY GLOBAL MRKH**

*\*Note that details in this document are subject to change*



We acknowledge the Traditional Owners of country throughout Australia and recognise their continuing connection to land, waters and culture. We pay respects to their Elders past, present and emerging.

# GLOBAL MRKH DAY 2019



## THE MORNING

*Ella Latham Auditorium  
Royal Children's Hospital, Melbourne*

*This part of the day is for people with MRKH, their family, friends, health professionals and anyone else who would like to attend!*

## REGISTRATION

*9:00am*

## WELCOME TO THE DAY

*9.20am*

## MRKH: A CLINICIAN'S PERSPECTIVE

*9:35am*

*Dr Natalie Drever, Royal Children's Hospital*

An overview of what we know about MRKH and where to from here through the perspective of a clinician.

## AGES & STAGES

*9.50am*

*Julie Coveny, Florida, USA*

As we all know, MRKH is for life. It is not something that we are going to grow out of but with each different stage of life MRKH takes on a different meaning for us. In our teens, the news of the MRKH diagnosis changes everything - we are told that our bodies don't work how we thought they would, in our 20's we're navigating dating and relationships, in our 30s we're grappling with infertility and fertility options - and so on.

Julie joins us from Florida, US, and will talk about MRKH throughout her life. Julie will also introduce the Ages & Stages interactive activity which will be available for all attendees with MRKH to contribute to throughout the day. This will involve a life stages timeline where people can add their comments, experiences and things they learnt during that period of time. The purpose of this is outline how MRKH changes throughout different stages of life.

## MRKH AROUND THE GLOBE: MALAYSIA

*10:05am*

*Wani Ardy, MRKH Malaysia*

## YOU CAN'T ASK THAT PANEL DISCUSSION

*10:10am*

*Facilitated by Alison Hensley*

How often do we wish we had just asked that question but were too afraid to? How often does a question pop into our minds but we actually have no-one to ask? Will I look silly if I ask that question and expose myself as different? No, never. Because, today is the day. Today we celebrate, normalising differences.

Prior to this event, we reached out to our community and asked, if you could ask anything, what would it be? In this interactive panel, we will share the questions of the community, however, this is your day + your questions - ask away!

## MORNING TEA BREAK

*10:40am*

# GLOBAL MRKH DAY 2019



## THE MORNING

*Ella Latham Auditorium  
Royal Children's Hospital, Melbourne*

### MRKH AROUND THE GLOBE: UNITED STATES OF AMERICA

*11:00am*

*Amy C. Lossie, PhD, Beautiful You MRKH Foundation*

### MENTAL HEALTH, WELLBEING (AND STIGMA!)

*11:05am*

*Dr Susan Carroll (via video from London)  
Chloe Hanna, Royal Children's Hospital*

This session will discuss the impact of MRKH on mental health and wellbeing, where we will provide some practical information for attendees to take home with them - support both for this day and every day!

### TRANSLATIONAL STUDIES FOR THE CORRECT UNDERSTANDING OF MRKH SYNDROME

*11:25am*

*Dr Emanuele Pelosi*

To date, the causes and pattern of inheritance of MRKH syndrome are completely unexplained. This lack of understanding leads to inadequate diagnosis, counselling, and clinical management of affected women. In order to lead a change in the current clinical experience of women with MRKH, we need a different research approach based on translational studies. In collaboration with Sisters for Love MRKH Foundation, we have established a genomic program to identify gene variants associated with MRKH syndrome, and we have identified novel genes necessary for the correct development of uterus and vagina. In this presentation, I will talk about the journey and the research that lead to the creation of the first mouse model of MRKH type II, a one of a kind resource that will pave the way to further understand the causes of this condition.

### AN OVERVIEW OF UTERUS TRANSPLANTS IN AUSTRALIA

*11.40am*

*Dr Anthony Marren  
Dr Ying Li*

This session will include an overview of uterine transplants.

### SURROGACY FOR WOMEN WITH ABSOLUTE UTERINE FACTOR, FACTS AND THOUGHTS

*12.05pm*

*Dr Dvora Bauman*

### MORNING WRAP-UP AND LUNCH

*12.20pm*

Please take the time to grab some lunch, ask the health care professionals your stored up questions, meet your MRKH peers and enjoy some Melbourne made cuisine!

This is the conclusion of the day's formal presentations.

# GLOBAL MRKH DAY 2019



**THE  
AFTERNOON**

*Vernon Collins Lecture Theatre  
Royal Children's Hospital, Melbourne*

*This part of the day is for people with MRKH and their families only.*

*The afternoon session is dedicated to our community, so that everyone has an opportunity to either share their story, hear an experience that is relatable and engaging and hopefully, you will leave feeling connected, less alone and more informed.*

## **WELCOME & DE-BRIEF FROM THE MORNING SESSION**

*1:30pm*

## **BREAKOUT GROUPS BY AGE**

*1:50pm*

Breakout groups by age:

- Up to 25 years
- 25-40 years
- 40+ years
- Parents and family members

## **AFTERNOON TEA BREAK**

*2:35pm*

## **BREAKOUT GROUPS BY TOPICS**

*2:50pm*

Breakout groups will include the topics outlined below:

- Navigating personal relationships (including relationships with family, friends, work, intimate/sexual relationships)
- What are the options? Surrogacy, IVF, adoption, foster care
- Intervention options including dilation
- MRKH and the trauma it has caused me
- LGBTI & MRKH
- The Creative Corner
- Parents and family members

*\*note that these topics are subject to change.*

## **DE-BRIEF AND CLOSE**

*3.50pm*