

Albinism Fellowship of Australia Biennial Conference “Fair GO! 2013” Rydges Hotel, World Square, Pitt Street, Sydney 11-13/10/13

Friday 11th October 2013

Morning	Harbour Bridge Climb (optional activity) Contact Kim Gillespie kimgillespie@tpg.com.au 0425 229 799
8:30 – 12:30	Albinism Workshop for Professionals Not included in registration for Fair GO! 2013. Additional fees apply. Please contact conference@albinismaustralia.org to register
12:30pm – 1:30pm	AFA Fair GO! 2013 Conference Registration
First Timers Workshop (included in conference registration)	
130pm – 1:40pm	Welcome and Introduction from the Albinism Fellowship of Australia
1:40pm – 3:00pm	Introduction to albinism – Different types of albinism, Genetics of albinism Dr Murray Brilliant Introduction to the ocular effects of albinism Dr Gail Summers <ul style="list-style-type: none"> - Basic Anatomy of the eye - Development of vision - Measurement of visual acuity - How eye findings contribute to making a diagnosis of albinism - Overview of treatment options - Introduction to the various genetic forms of albinism - Function of genes involved in albinism - How this knowledge can be used to develop new treatments to improve vision
3:00pm – 3:30pm	Afternoon tea
3:30pm – 4:30pm	Question time, Panel Discussion
430pm – 530pm	Conference Registration For Fair GO! 2013
5:30pm – 6:30pm	Welcome Reception (optional) Rydges Ballroom, Pre-paid only. Pay as you go drinks Vacancies available, contact treasurer@albinismaustralia.org
Followed by	Informal dinner in nearby restaurants. (own expense). We will be leaving from the hotel We have booked the upstairs level of Mammias Kitchen, a very short walk from the hotel 57 Liverpool Street, Sydney (Italian, pizza, pasta). Other suggestions: Captain Torres – 72 Liverpool St, Sydney (Spanish) Pizza Hut Restaurant 630 George St Sydney

Saturday 12th October 2013

From 8:00am	Conference Registration Desk opens Fair GO! 2013
From 8:15am	Sign in / Drop off for Crèche (kids aged 1-6) Level 14, 87-89 Liverpool Street, Sydney 2000
From 8:30am	Youth Program drop off and sign in Meeting Room, Rydges Hotel
8:30am	Merchandise stall opens
9:00am to 10:30am - Session 1 Ballroom 2 and 3	
9:00am – 9:30am	Opening Ceremony <ul style="list-style-type: none"> - Acknowledgement of country – Keon Dawson, Gawurra, St Andrews Cathedral School - National Anthem – lead by Lauren Dawes - Official opening Address and Conference Opening - Gareth Ward MP - National Anthem – lead by Lauren Dawes - Welcome by President of AFA – Elizabeth Beales - Welcome by Conference Coordinator – Shari Parker - Conference Photography – Josie Eldred - Item “You Gotta Be” by Desree, performed by Lauren Dawes, accompanied Martin Beales
9:30am – 10:10am	Careers Panel Gareth Ward, Lauren Dawes, Tim Boye Three successful people with albinism will talk about experiences at work and study, living with albinism – a politician, a professional singer and an engineering student teaching robotics to high schoolers
10:10am – 10:20am	Personal Story – my experiences as a person with albinism as a medical student and a person of colour Alex Carillo
10:20 – 10:30am	What’s new in technology? 3 minute presentations from our vendors outlining their products, what’s on offer and what’s new in technology for people with albinism <ul style="list-style-type: none"> - Humanware - Vision Australia Adaptive Technology - Australian Independence Products - Quantum
10:30am – 11:00am Morning tea Ballroom 1, Merchandise room and foyer	
11:00am – 12:30pm – Session 2 Ballroom 2 and 3	
11:00am – 11:20am	Albinism 101 – The Genetics of Albinism and how we can improve vision in albinism Dr Murray Brilliant This session will give an introduction to the various genetic forms of albinism, the function of the genes involved and how this information can be used to develop new treatments to improve vision.

11:20am – 11:40am	<p>Your skin and albinism – sunscreen, vitamin D, sunburn Dr Monisha Gupta</p> <ul style="list-style-type: none"> - Sunscreen - What is new, how to select, how to use - Sunscreens and Vitamin D controversy - Skin checks for People with Albinism
11:40am – 12:00pm	<p>Albinism and the Brain – ADHD, memory, learning ability. Visual perception, sensory processing Dr John McDonald</p> <ul style="list-style-type: none"> - Neurodevelopment and albinism - Association with ADD / ADHD - Visual perception, memory reading ability in albinism
12:00pm – 12:20pm	<p>What's new in albinism? Research update, Surgical management Dr Gail Summers</p> <ul style="list-style-type: none"> - Recent research in the field of albinism - Medication trials to improve vision in albinism - Modern management of nystagmus - Surgical options for albinism - what can be done and how might it help?
12:20pm – 12:30pm	Questions and Panel discussion
<p>12:30pm – 1:30pm Buffet Lunch Spheres Restaurant</p> <p>Lunchtime Video – Albinism in the United Nations, Canada, and Tanzania – Under The Same Sun (Video Presentation) Peter Ash</p>	
<p>1:30pm – 3:00pm – Session 3 Ballroom 2 and 3</p>	
1:30pm – 1:50pm	<p>Guide Dogs and Albinism – Guide Dog Mobility – Myths and Facts Michael Poynting</p> <ul style="list-style-type: none"> - The person or the dog, who does most of the work? - Will all people with a vision impairment have their mobility needs met by using a guide dog? - Guide Dogs or canes, which is best?
1:50pm – 2:00pm	<p>Personal Story – my life with a Guide Dog – Me and Helinka Tanya Boye</p>
2:00pm – 2:10pm	<p>Personal Story A short biographical poem Phil Latey</p>
2:10pm – 2:30pm	<p>Albinism and Resilience Margaret Mary Campbell I have albinism SO WHAT S – Self talk O – Own it W – Why? H – Humour A – Acceptance T – Teach and Trust</p>

2:30pm – 2:50pm	National Disability Insurance Scheme – what does it mean for people with albinism? Dougie Herd - The National Disability Insurance Scheme Overview - Progress of the Scheme - What it means for people with albinism
2:50pm – 3:00pm	Questions and Panel Discussion
3:00pm to 3:30pm – Afternoon tea Ballroom 1, Merchandise room and foyer	
3:30pm – 5:pm – Session 4	
Concurrent session Ballroom 2	
3:30pm – 3:40pm	Personal story – Experiences of living in rural and metropolitan Australia with two children with albinism Karissa Harp
3:40pm – 4:10pm	Preparing your child with low vision for School Maria Lupton and Karen Cutts - Literacy and Numeracy - Independence - Using low vision aids
4:10pm – 4:30pm	Visiting Support Teachers – working in partnership with the Itinerant support teacher Pru Jobling - The role of the ISTV - How to develop a good working relationship. - Issues related to support and funding available, role and responsibilities, - Expanded core curriculum - Individual learning plans - Introducing technology options to enhance learning
3:30pm – 3:40pm	Research Project on High Schoolers with low vision Glenda Jessup - This current study looks at the everyday experiences of high school students who are visually impaired and attend mainstream schools. - iDevices and the Experience Sampling Method, an in-the-moment survey method, to understand the students' experiences of everyday life. - Preliminary data will be presented to show the types of information that can be gleaned. - This study provides a new and different opportunity for these students to be given a voice in research.
4:40pm – 4:50pm	The Australian Low Vision Register Sue Silveira - Scope of childhood vision impairment in Australia - Key aspects of vision impairment in children with oculocutaneous albinism
4:50pm – 5:00pm	Questions and Panel Discussion

Concurrent session Ballroom 3	
3:30pm – 3:35pm	World Albinism Alliance – an organisation bringing together albinism organisations around the world Shari Parker Describes formation of the WAA which brings together albinism organisations from around the world.
3:35pm – 3:40pm	Albinism in Canada and Tanzania – Video greeting from Peter Ash, Under the Same Sun
3:40pm – 3:50pm	Personal Story – On being the meat in the white bread sandwich, and albinism in Kenya KACSU Melanie Boulton
3:50pm – 4:00pm	Personal Story – The Albinism Charity Drive, and my two children with albinism Maxine Krebs
4:00pm – 4:15pm	Albinism and Human Rights in Tanzanian Print Media Dr Jean Burke Aimed at those interested in Africans with albinism, to inform them of what is being said in Tanzanian English and Swahili media - Human rights issues and responses - Encouraging actions by Tanzanian government and society - Social change occurring Research and activist networks
4:15pm – 4:40pm	Pacific Albinism Project (PAP) – Research findings, achievements, future goals Annette Ferguson and Helene Johanson - Phase 1 – Initial situation in the primary study community – Genetic and social research findings - Phase 2 – Follow on research and project work to identify the situation in other Pacific Island communities. Problems were defined, word of the project was spread and collaborations and supporters were sought out. Culminated in PAP workshop - PAP workshop Ipswich, what we learned - Why is the Pacific Albinism Project important to Australians? - Introduction of initial work towards Phase 3 of PAP – helping people with albinism in the Pacific Islands by working in partnership with foreign Governments and International Aid Agencies - Trip to Samoa July/August 2013 outcome/response - Future plans
4:40pm – 4:50pm	How common is albinism in Fiji – early experiences with the albinism in Fiji incidence survey Dr Margot Whitfield Describes background to albinism in Fiji incidence study
4:50pm – 5:00pm	Questions and Panel discussion
Conference Dinner Sydney Harbour Cruise Bus Collection from 6pm Rhythm boat, Departs from Pymont Bay Wharf Vacancies still available \$65 adults, \$45 for children Email treasurer@albinismaustralia.org to book Boat boarding 6:45pm sharp.	

Sunday 13th October 2013

8:00am – 8:45am	Annual General Meeting of the Albinism Fellowship of Australia Ballroom 2 and 3
From 8:15am	Sign in / Drop off for Crèche (kids aged 1-6) Level 14, 87-89 Liverpool Street, Sydney 2000
From 8:30am	Youth Program drop off and sign in Meeting Room, Rydges Hotel
8:30am	Merchandise stall opens
9:00am to 10:30am - Session 5 Ballroom 2 and 3	
9:00am – 9:10am	Opening of day 2 Welcome back Musical performance by Mathew Zhou (aged 10) on the Marimba, accompanied by Cindy Sin
9:10am - 9:30am	Albinism and your ophthalmologist – how to get the most out of your appointment with your ophthalmologist – includes 5 question time Dr Frank Martin This presentation is aimed at individuals with albinism and their family. I will cover: - Visual impairment, Problems with glare, Nystagmus, Refractive error, Strabismus - The role of the ophthalmologist in overcoming the impact of visual impairment
9:30am – 10:30am	Transitions Workshop Rachel Perry, Bryony Balaton-Chrimes, Shari Parker, Kim Gillespie, Marie Bedford A workshop examining the differ points of transition in a PWA's life – from preschool to school, to highs school, to further study, to work, to parenthood, and beyond. Handling transitions well is essential for managing that next phase of life, and here you will get some great tips for now and the future. Includes time for questions and panel discussion.
10:30am – 11:00am Morning tea Ballroom 1, Merchandise room and foyer	
11:00am – 12:30pm – Session 6 Ballroom 2 and 3	
11:00am – 11:20am	Sport and albinism – I have albinism – what sports can I do? Kara Retford, Australian Paralympic Committee - Paralympic Committee – who we are? - How we can assist you? - Are you eligible to compete in Paralympic Sport? - How do you get classified for Paralympic Sport?
11:20am – 11:30am	Personal story Our athletics journey, throwing your heart out! Benj and Danielle Gulliford
11:30am – 11:40am	Personal Story – Me, myself and my lawn bowls Marian Morrison

11:40am – 11:50am	<p>Hermansky Pudlak Syndrome</p> <p>Opening scene of the movie “Rare”</p> <p>Rare is a feature documentary that follows Donna Appell an inspirational and extraordinary mother, and her daughter Ashley, known personally to several from the AFA, as they unite a group of isolated people from around the world connected through Hermansky Pudlak Syndrome (HPS), a rare genetic form of albinism. Together, they discover that community, laughter and hope are some of the greatest therapies.</p>
11:50am – 12:10pm	<p>Clinical and Laboratory assessment in HPS</p> <p>Dr Tim Brighton</p> <p>The talk with discuss the importance of platelets in blood clotting, as well as discuss the clinical features of HPS, laboratory assessment of platelet function, and management issues.</p>
12:10pm – 12:20pm	<p>Personal Story – on having a daughter with HPS</p> <p>Nicole Tobin Donnelly</p>
12:20pm – 12:30pm	<p>Questions and Panel Discussion</p>
<p>12:30pm – 1:30pm Buffet Lunch Spheres Restaurant Lunchtime Movie “Rare” in Ballrooms 2 and 3</p>	
<p>1:30pm – 3:00pm – Session 7 Ballroom 2 and 3</p>	
1:30pm – 1:50pm	<p>O and M Instructions and Low Vision Clinic</p> <p>Andrew Doyle and Cathie Wiltshire</p> <ul style="list-style-type: none"> - Targeted towards individuals with low vision, and their families, and professionals who work with people with low vision - What orientation and mobility is and how it can help - Low Vision clinic, what it is and how it can help - Other Guide Dog aids and services - How to make a referral
1:50pm – 2:10pm	<p>Optometry and albinism – Getting the most out of your Optometry appointment, and the lowdown on contact lenses for people with albinism</p> <p>Dr Jack Phu</p> <ul style="list-style-type: none"> - What do optometrists do for patients? - How can spectacles and contact lenses help the patient with albinism? - What types of contact lenses are there and what are their differences? - How does the fitting process work for contact lenses?
2:10pm – 2:20pm	<p>Personal Story Robyn Blake</p>
2:20pm – 2:30pm	<p>Questions and Panel Discussion</p>
2:30pm – 3:00pm	<p>Your chance to catch up for an informal chat around topics of interest (facilitator for the group in brackets)</p> <ul style="list-style-type: none"> - Families of pre-schoolers (Karissa Harp) - Families of primary schoolers (Rachel Perry) - Families of high school aged kids (Tim Bellamy) - Younger adults with albinism 15-30 Margaret Mary Campbell) - Parenting without pigment (Kim Gillespie) - Adults with albinism (Elizabeth Beales)

**3:00pm to 3:30pm – Afternoon tea
Ballroom 1, Merchandise room and foyer**

**3:30pm – 5:00pm – Session 8
Ballroom 2 and 3**

3:15pm – 3:30pm	<p>Pain in Albinism – Is Albinism really a pain in the neck? Results from the pain in albinism study Dr Shari Parker</p> <ul style="list-style-type: none"> - What we know about pain in albinism - Results of pilot study will be presented - How common is headache and neck pain in PWA? - What are factors the increase and decrease risk of headache and neck pain? - How to prevent / reduce headache and neck pain
3:30pm – 3:40pm	<p>Personal story - My experiences as a person with albinism who drives and is an Occupational Therapist Becca Evans</p>
3:40pm – 4:00pm	<p>Bioptic Driving – Driving with a central vision impairment in Australia – where do we stand? Sharon Oberstein</p> <ul style="list-style-type: none"> - In Australia, private conditional driver's licenses may be issued for individuals with visual acuity worse than 6/12 to 6/24. - In countries overseas individuals with visual acuity worse than 6/24 drive with the use of bioptic telescope spectacles. - Explain the current visual requirements for driving in Australia - Outline strategies used for driving with poor acuities overseas, with special reference to bioptic telescope spectacles.
4:00pm – 4:15pm	<p>NOAH – Words of wisdom and experience from the President of NOAH Mike McGowan</p>
4:15pm – 5:00pm	<p>Closing Ceremony</p> <ul style="list-style-type: none"> - Musical Item – “Roar” by Katy Perry, performed by Jacob Raffoul - Announcement of prize winners - Performance from the Youth Program - Closing words from the President - AFA conference 2015 – where will it be???
From 5:30pm	<p>After Party – all welcome to attend Ballroom Included in the cost of your conference registration Performances by Lauren Dawes, Jacob Raffoul Mathew Zhou</p>

Conference Program may change without notice due to circumstances outside our control