Beyond BLONDE

The Albinism Fellowship Of Australia Newsletter

Albinism Fellowship of Australia

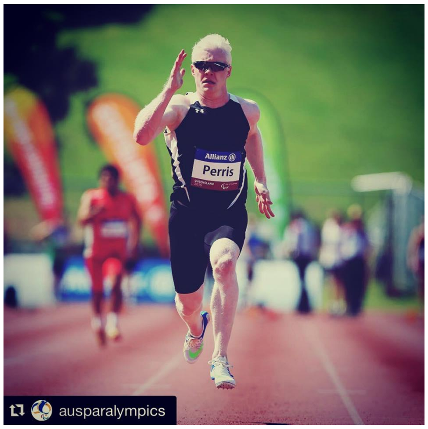
Winter 2016

IN THIS ISSUE…

We celebrate International Albinism Awareness Day

INTERNATIONAL ALBINISM AWARENESS DAY

Support the 'White Tiger' at the Paralympics



What an amazing fundraiser, Dinner in the 'Almost' Dark

Dinner In The 'Almost' Dark

Saturday 4th June 6.30pm

Flight Deck Bar & Grill

(Major Sponsor)

AFA President's Report

by Elizabeth Beales

Hello

Welcome to the latest edition of Beyond Blonde. I hope you and yours are all well.

It's been an interesting few months in my household; lots of things happening and I know it's the same in yours. It seems no time at all since the last newsletter, but here it is again!

Which leads me to thank our hardworking committee, including Dannika and Amanda, our newsletter coordinators. It's a hard job and very time consuming, so their work is appreciated.

In July, I was privileged to be able to attend my third NOAH conference with my husband. NOAH is the larger older sister organisation to AFA, and this year there were just over one thousand people in attendance. It was wonderful to see so many white heads all together in Pittsburgh. From tiny babies to the elderly, many many demographics were represented.

Beginners genetics, 'what do I do next?' and parent support groups, 'driving with biopics', self defence for the visually impaired and new advances in genetics and technology... Just some of the workshops which attendees could take part in. It was a joy to meet new and known friends and see lives changing through their NOAH connections and friendships.

Anyone who has been to an AFA conference knows the feeling, when you or your child finds others to connect with, that can't be put into words. It's exactly the same, even though NOAH is so much bigger, the same connections are made between two three and four people within the huge crowd.

I was asked to be part of an international panel, which was a huge honour, as I was with Susan DuBois from Asante Mariamu, IK Ero, the albinism expert appointed to the UN, and Jayne Waithera from Positive Exposure, Kenya. It was a bit daunting but made me realise just how fortunate we are in Australia. Talking of our government acknowledging skin cancer, the implementation of slip slop slap and wrap advertising, and schools having a 'no hat no play' policies... In comparison to countries where albinism equates to being a 'zero' (insignificant human) or living in fear of your life... So so humbling.

IAAD was fairly quiet in Australia this year, but I was pleased to see my social media timeline full of posts and pictures from friends near and far sharing the message of albinism awareness, if you assisted in even the smallest way, thank you. Every piece of the albinism advocacy works together.

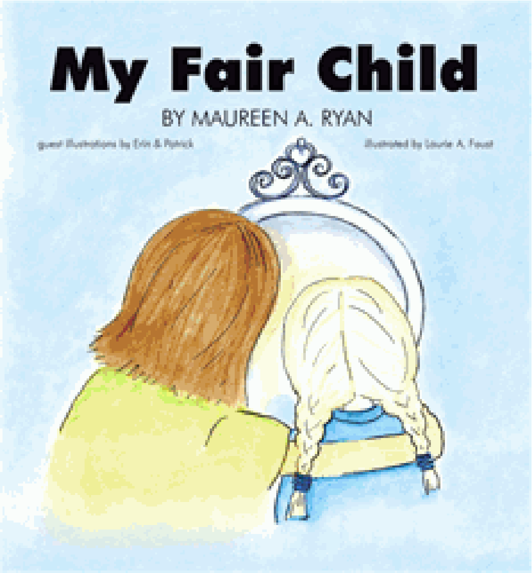
For 2017, if you would like to be more involved, drop me an email or a letter, we would like media spokespeople (you will be prepped and given notes) and hosts and coordinators for get-togethers or events, locally (ie morning tea at home) and nationally.

August 2017 is time for our own conference in Melbourne. The committee are working on ways to help our members get to the conference, attending is of more value than you can imagine, and we would love to see you, stay tuned to this newsletter for more information.

If you have ideas or thoughts on what you would like to see at conference, the coordinator, Sandra, is keen for feedback. The online survey is at **https://www.surveymonkey.com/r/KZNLB29** or you can ask for a paper copy in our phone line. We are very excited, and hope you are too. It seems like a long way away, one a year in fact, but we all know how quickly time passes!

Please read on, and enjoy this newsletter; we hope it helps you!
Elizabeth Beales, President, Albinism Fellowship of Australia

Book Review



A Child born with albinism hears her mother lovingly speak the words, "Mirror, mirror reflecting from the wall, I am seeing the fairest child of all. Smiling warmly like the rays of the sun, you bring much happiness to everyone." The child falls asleep feeling a true sense of security. She dreams of magnificent pale creatures like herself and contentedly sees herself playing amongst her fair-haired friends.

The reader feels her child-like innocence as she is later approached by a bully. She appears fearful but not defeated. There is no tolerance for this inappropriate behavior as "The creatures form a circle to protect these fair children from any disrespect."

She awakens and shares her dream with her mother and is compassionately reminded of her unique beauty. "Be proud of who you are, let your love shine and hold your head up high fair child of mine."

This book was inspired by the author's personal experiences and her strong desire to write a book for children with albinism and their families, as well as for all children. My Fair Child gently speaks to our hearts as it is reminiscent of a child's innocence and the infinite beauty of human diversity.

Editors note: This review was original posted on Amazon.com in October 2009. The book is available to purchase online from Amazon.com, the review above has been reprinted as it appears on Amazon.com.

Melbourne IAAD Celebrations

by Sandra George

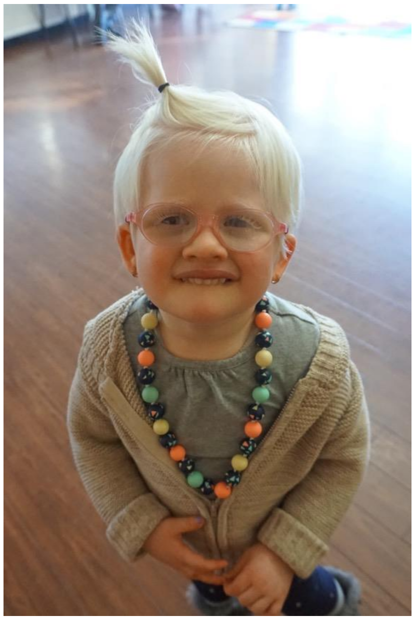
Vision Australia Kooyong provided the use of their facility for the Albinism Fellowship of Australia to host a luncheon attended by 46 people in Melbourne. It was an opportunity for adults and kids with albinism, and parents of children with albinism to catch up, celebrate and share stories.

Sophie Wilde from Guide Dogs gave a brief presentation on accessing the NDIS and was then available to answer individual queries.

Volunteer student teachers, Amy and Ann provided an activity program where the children chased balloons and made animal masks, with lots of drawing, cutting, pasting, play doh, hop scotch, laughter and general craziness - all in the next room.

This left a relatively quiet spot for the adults to chat and enjoy a light lunch. We now have two new teachers who will have a better understanding of low vision, something they will hopefully pass on to their peers at university.

The power of being able to identify with a group which shares and supports, cannot be under estimated! Thank you to Vision Australia for supporting this event.



Hunter Valley IAAD Celebrations

by Kim Simpson from the Royal Institute for Deaf and Blind Children

International Albinism Awareness Day was on Monday the 13th June. RIDBC Hunter hosted an afternoon tea on Tuesday 14th bringing together many of the Hunter Families who are living with Albinism.

Kirsty Russell is a mother of a child with Albinism and autism, a double scoop as Kirsty would say! Kirsty's son Xander attended RIDBC Hunter Preschool and now both Kirsty and Xander are advocates for children with Albinism. Both were guest speakers at the event which we hope will lead to a larger and more elaborate celebration next year.

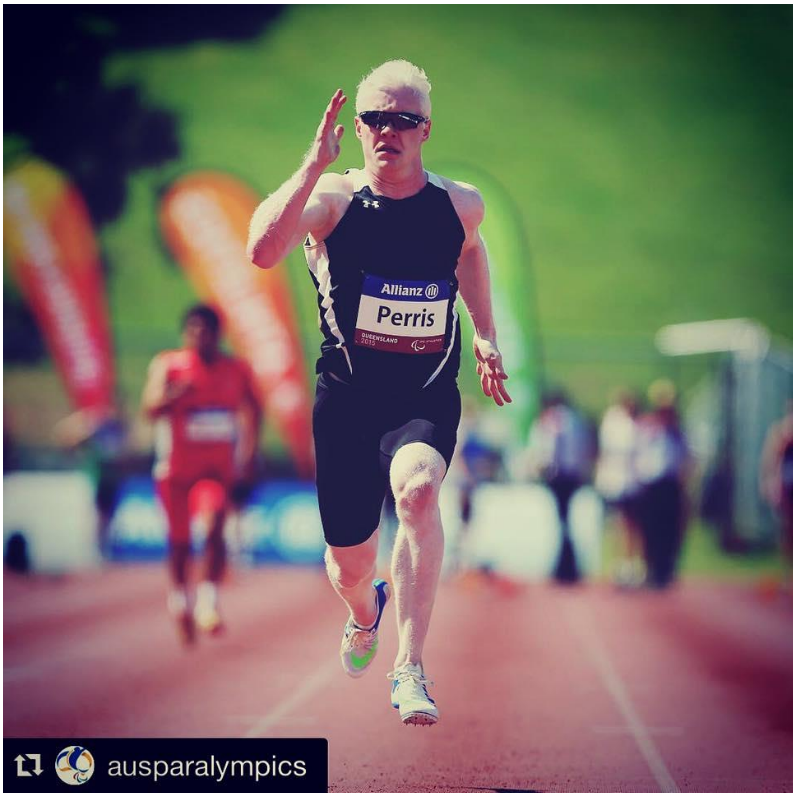
Kirsty writes a blog called My Home Truths (www.myhometruths.com) where she shares her experiences as a special needs parent and where she tries to help other parents in a similar situation.

IAAD from a Paralympic Sprinter

by Chad Perris "White Tiger"

Today International Albinism Awareness Day. Most people do not realise people with albinism have a vision problem and are most of the time legally blind like myself.

- ✓ I do my best to try and break the stereotype of what an "albino" does
- ✓ I spend the majority of my training outdoors in the sun
- ✓ I played AFL footy as a kid and as an adult till I was 20
- ✓ I am loud and bring attention to the fact I have albinism to have fun and make others laugh and if I can do that then I am happy.
- ✓ I live my life like any other person



IAAD Celebration from Disneyland

by Amanda Collins

This year for IAAD we were on a family holiday in the US. We were at Disneyland which is truly the happiest place on earth!

Before we went we had worked out where we would be and were hoping it wouldn't be missed in our busy travelling calendar. We are very blessed to have such wonderful family, with whom some of who we were travelling with.

While I guess, a fairly low key day, in terms of celebrating with other people with albinism it is amazing how things happen...

We were enjoying our own family breakfast celebration with Disney characters when we met a gorgeous Grandmother whose granddaughter has albinism. The granddaughter was on a school excursion and as an African American we noticed her amongst her friends.

On speaking to the Grandmother we shared first diagnosis stories and she discussed some of the challenges. She had come along on the excursion to assist, ensure her granddaughter had sunscreen and other requirements as she explained the school can sometimes forget.

While Grandma was there to support, I did notice at breakfast, she also let her granddaughter be herself. Be with her friends. Be a typical young girl.

It made me think how important it is to be there, be an advocate but perhaps more importantly teach them to be their own advocate, to encourage them to be themselves, be comfortable, be proud and have confidence in who they are.

We informed them that it was International Albinism Day...they were unaware. Was great to share this news with them and have this chance meeting on this very special day! Funny how things work out!

Xander Russell’s Speech he presented to Plattsburg Public School for IAAD

Hi, my name is Xander Russell. I’m in Year 6 at Plattsburg Public School. I like to hang out with my friends, watch sport, hate school and love takeaway. I also have albinism.

Monday 13 June is International Albinism Awareness Day and I wanted to talk a little bit about albinism and what it means for me to live with albinism every day.
Albinism is a genetic condition where people are born without the usual pigment (colour) in their bodies. Their bodies aren’t able to make a normal amount of **melanin**, the chemical responsible for eye, skin and hair colour.

So most people with albinism have very pale skin, hair and eyes (like me). Albinism can affect people of all races and there are different types of albinism. Humans, animals and even plants can have albinism too. With albinism the eyes can’t develop properly without melanin. My eyes move rapidly all the time as they try to focus. I can’t see things that are far away. I find it hard to judge how far I need to step down and I need to wear glasses with tinting to help reduce glare.

I’m lucky because I can see enough to read, walk around and not get into too much trouble (except for the times I have walked into poles.) Living with albinism is just like a normal life but you have to ensure that your skin is protected on very sunny days.

- ★ I must wear sunscreen all the time to prevent getting sun burnt.
- ★ I must wear a hat to protect my face and the top of my head.

★ I have to wear long sleeve shirts on very sunny days.
★ When I swim I needed to wear a long sleeve swimming shirt
★ I have to re-apply sunscreen if I get in the pool more than once.

Other than that I like to play, catch up with friends from school, watch movies and I like to swim in Summer. My favourite NRL teams are Newcastle and Penrith. My favourite foods and drinks are sweets, chocolates, soft drinks and take away food. So I'm no different to anyone else here. Except I'm lucky enough to be out of school right now!

I hope you now know a little more about albinism and can share some of this with others for International Albinism Awareness Day on Monday. I look forward to meeting you all properly when I come here next year.

IAAD Celebration from the Gold Coast

by Dannika Brittin

Our youngest daughter Sophia who has just started at kindy has Albinism. We are fortunate that kindy is supportive and wanted to celebrated International Albinism Awareness day.

The children wore white and they arranged fun activities with the colour white to support and raise awareness for Albinism.

Kaylee our eldest daughter wanted to share two books about Albinism with her friends at kindy 'All Children have different Eyes' and 'Unique'.

During group time they spoke about how we all have different eye colours, hair colours and skin. They all had turns looking at our friends and seeing what colour eyes they have.

Miss Tessa explained how some people need glasses to see things better with their eyes. Kaylee told her class that Sophia has blue eyes and sometimes they go wiggly.

We decided to bring cupcakes to share with her friends, with some white icing and special sprinkles. Everyone was excited to decorate their special cupcakes. They used white paint and glue to spread on some cardboard and some stringy paper and cotton balls to make a collage craft.

Dinner in the 'Almost' Dark

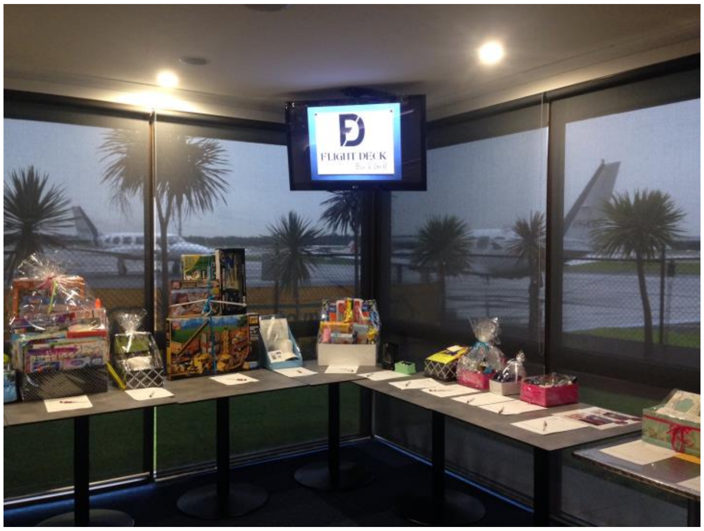
by Bec and Simon Bradley

On the 4th June 2016 we held a fundraiser "Dinner in the 'Almost' Dark" to raise money for the Albinism Fellowship of Australia. We had been thinking of ways we could organise a fundraiser of some sort and it was over the summer holidays having lunch at Flight Deck that a small idea become a big reality.

Our boys Ethan (5 years) and Samuel (3 years) both have Albinism & Christian (3 years) who does not, both Ethan and Samuel are legally blind. The concept of the dinner was to have a theme and we thought a dinner in the almost dark would demonstrate some similar challenges our boys face with their vision. The owners of Flight Deck were happy to assist with hosting the event as soon as it was mentioned.

We were very fortunate to have the help of my sister Melissa Milne and two family friends Melissa Drinkwater and Melissa Ades. These ladies gave up many hours of their time and the night was very successful because of them. Together we managed to contact a large number of companies and individuals for a variety of donations, for the major prize raffle and auctions.

Ann-Maree Biggar hosted the event with 180 people in attendance. As Simple As arranged all the catering and we had a great local band Spency & Downs who entertained the guests. One of the highlights of the night was the generosity in the auctions, with many people coming away with some great prizes.



The total funds raised in the night were $15, 305.00, this amount was helped along by a generous donation from Bendigo Bank of $2, 000.00. The monies raised are going towards the AFA conference next year which is being held in Melbourne.

We are still so surprised with the success of the night and genuinely appreciate all the help and support we have had from family, friends and the community.

Albinism Fellowship of Australia Conference

MELBOURNE 2017

Celebrating Albinism

August 18-20

Save the date!

We look forward to hosting you at the Rendezvous Hotel, Flinders St, Melbourne.

More conference information soon!

conference2017@albinismaustralia.org

What do you want from the 2017 AFA Conference, to be held in Melbourne, August 18 to 20?

The conference committee needs your help to design a relevant and exciting program. It is your conference and we need to know what you want!

1. What best describes you? (please tick the options that cover your family)

○ Adult with albinism
○ Child with albinism (10-18years)
○ Parent of a child with albinism
Other (please specify)

*** 2. Which state are you from? Do you live in a capital city or regional area?**

*** 3. Are you likely to attend the AFA conference in Melbourne, 18th-20th August 2017? If you circle "Not intending to come", this is the end of your survey. Thank you for participating.**

4. Who will be coming to the conference?

Number of adults?

Number of children (0-18 years)?

Ages of children at the time of the conference?

5. What are your reasons for attending the conference? Rate with a High, Medium, Low or Not applicable (N/A)

Information about Albinism from professionals

Information about Albinism from PWA’s or parents

Forum opportunities to ask questions

Free time to meet with others (Parents, PWA or children)

Social activities

Other (please specify)

6. Indicate how interested you are in the following program ideas. Rate with a High, Medium, Low or Not applicable (N/A)

The basics of albinism (101)

Advanced information on albinism

The latest techniques in surgery or ophthalmology

Genetics of albinism

Latest in vision aids/technology

Using technology effectively (iPhones, iPads etc)

Orientation and mobility (issues, guide dogs, cane use etc)

Supporting babies and toddlers to reach potential

Supporting Primary aged students at home and at school

Supporting Secondary aged students at home and at school

Negotiating tertiary study

Starting a new job – applications, interviews and negotiating requirements

Surviving the workplace

Participating in leisure activities and sports

Albinism in other countries

Other (please specify)

To complete in hard copy - fill in and return to:

AFA, PO Box 20729, World Square NSW 2002, **by Sunday 4th September 2016**

Electronic version is at https://www.surveymonkey.com/r/KZNLB29

Special needs parenting & the importance of community

by Kirsty Russell from My Home Truths

In my first few years as a special needs parent I was not interested in building a community around me. I was overwhelmed with my son's diagnoses and just wanted to concentrate on him and on what he needed. I didn't have time for anything else. I didn't have the mental or emotional capacity to do any more.

The thought of attending an in-person support group made me feel physically ill, I could not imagine anything worse. Besides, in my mind, my son was the with the diagnosis, not me, I was just his parent, trying to help him along. If anyone needed support it was him, except he didn't even want to be around anyone he didn't know. So what could a community do for him or for me? I honestly couldn't see the point.

However, over those first few years, my thinking gradually changed. Once I became active online, I discovered groups in Facebook for parents of kids with all kinds of conditions. I slowly warmed up to the idea of finding others who could understand what we were going through. I felt more comfortable in pouring my issues into a keyboard because it's obviously much less confronting than breaking down in tears in front of a support group.

At the same time we began to meet other special needs parents at school. It was easy to fall into conversation over the strange eating habits of our kids and the funny things they'd say. I began to feel so much lighter in spirit in being able to offload some of my issues and in sharing experiences with others who really understood our life.

Slowly, we started to build an autism community around us. Supportive and trusted people who knew our son, knew autism, knew the challenges of special needs parenting and knew the struggle to balance the needs of everyone in the family. I began to see the value in having real, tangible support around me. I began to finally appreciate just how important it is to build a community as a special needs parent.

While we were able to build an autism community around us, we weren't as successful in creating an albinism community. Albinism is less common than autism and it seemed those few people I had come in contact with were scattered everywhere else but here. It seemed as if we'd have to do with online communication instead.

But then came IAAD with the opportunity to finally meet other local families living with albinism. Gilbert presented his albinism talk, I said a few words about my hopes in relation to creating a local albinism community and then we took the time to connect with other families throughout the afternoon.

Comparing our experiences with such a rare condition instantly bonded us all. We have now set up a local albinism Facebook group and are already talking about plans to meet up again soon. It was such a valuable opportunity for our kids to realise there are other people out there with albinism too and, as a parent, it was so lovely to be able to talk to others who understand terms that I seem to forever have to explain to others.

I have been riding a high all week. It was such an adrenaline rush to feel that sense of belonging when you are so used to not belonging at all. While it did take me a while to understand and accept the importance of community as a special needs parent, I am a total convert now.

Every one of us needs to feel a sense of belonging, we shouldn't feel isolated and alone. Every one of us needs to feel connected and valued, we shouldn't feel excluded and second-rate. Every one of us needs access to help and support and understanding, we shouldn't feel like we have to do it all on our own.

These are all the things that a community can provide. It can definitely be harder to build a community when your family has special needs to consider but it's so important that you try.

Connecting online is a great place to start, even if you don't feel as if you need to bring anyone else into your world. Having conversations with fellow parents can also be an easy way to connect and even having discussions with random people while out and about can sometimes yield unexpected support and understanding. Don't be like me and believe that you can do it on your own. Because, in the end, we all need support, whether we like to admit that or not.

Kirsty writes a blog called My Home Truths (www.myhometruths.com) where she shares her experiences as a special needs parent and where she tries to help other parents in a similar situation.

Getting to know you

by Mary Noonan

Who is in your family?
Myself Mary 28, Anthony 28, Katie 4, Eva 2 & William 11 wks.

What do you enjoy doing in your spare time?
Spending time with family, watching football, horse riding and taking the kids around the family farm.

Who inspires you and how?
My mum inspires me. She had seven children with the oldest being my cerebral palsy brother. I think how brave she was to have a child that needed extra help and still go on to have 6 more children. She didn't have a lot of family support and she lost her mother when she was only 3 years old and her father at 21. She also recently over come stomach cancer.

How did you first hear of AFA?
From a post on the albinism community Facebook page.

How has albinism touched your life?
Our little man William was born with a full head of white hair! We seen an ophthalmologist at 3 weeks who confirmed the pediatricians suspicions. William is the gorgeous little boy we always hoped for and will be very loved by all.

What do you know now that you wished you knew earlier along your journey of albinism?
We are only very early on in our journey but in the beginning I thought we would never find any medical professionals to help give us the monitoring and treatment William needs to be the best version of himself. We recently had a very productive multi disciplinary meeting to make sure William gets all the help he can in our rural town.

What makes you laugh the most?

My daughters! They are so full of character and extremely honest and loving! My brother often says "William's only trouble in life is going to be putting up with his sisters".

Getting to know you

by Hayley Granzien

Who is in your family?

Ben 35, Hayley 34, Kiesha 15 and Kade 2 and a half years old.

What do you enjoy doing in your spare time?
Baking and going to park with Kade.

Who inspires you and how?
My family. We be thankful, be happy and grateful we have each other.

How did you first hear of AFA?
From my cousin Dannika Brittin.

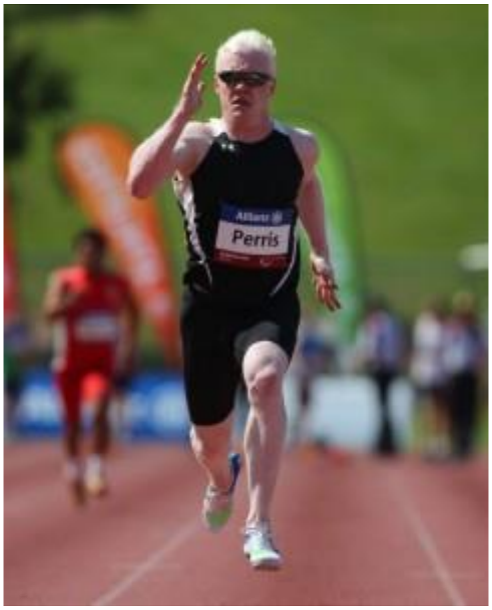
How has albinism touched your life?
Having Kade and trying to learn so much about his condition has been hard living in a rural town. But we have come so far now and always learning so much more. We embrace the fact he is who he is. It doesn’t make him different, it makes him equally social as anyone else. We are comfortable speaking to people about it and he is going to make us very proud whatever future path he may choose.

What do you know now that you wished you knew earlier along your journey of albinism?
All the support groups and people willing to help.

What makes you laugh the most?
When Kade plays and sometimes trips and falls and simply says "oh damn it!!"

A podium finish in sight for vision impaired Perris

Ahead of **International Albinism Awareness Day on June 13,** Paralympic sprinter Chad Perris has set himself a goal of showing Australia his personal best when he takes to the world stage later this year in Rio.



Born with albinism affecting the pigment in his eyes, skin and hair, Perris believes he is on track to secure a personal best time in the 100m and 200m T13 events for athletes with vision impairments, to secure a podium finish at his first Paralympic Games.

“I will have been training for four years for this moment, and being able to show what I can do and what I can achieve at my peak will mean everything,” Perris said.

“Not many people have the opportunity to have all eyeballs on them at a world event like the Paralympics. I’ll have people at home yelling at the TV to cheer me on, and in the stands at Rio. That in itself will be incredible.”

Speaking about International Albinism Awareness Day, he said he also wants to use his time in Rio to help bring awareness and equality to people with albinism.

“Albinism is most definitely something that’s misunderstood. You see, people with albinism are often portrayed negatively in Hollywood, and it has become stereotype.

“Obviously it is a balance, but I do think training outdoors, and even when I compete in a hot, sunny country like Rio, it will help break down those misconceptions.

“I hope that through athletics and my goals, I can try to get people with see those with albinism as equals.”

Having secured silver in the 200m and bronze in the 100m at the 2015 World Championships, a vast improvement since placing fifth at his Worlds debut in 2013, Perris is on an accelerated curve to achieve his goal.

“I’m feeling strong, fast, and extremely confident that I can run as fast, if not faster, than I ever have before,” he said.

Up against the world’s fastest Paralympian, Ireland’s Jason Smyth, Perris is unnerved by the competition to come.

“It will be an extremely tight finish in Rio, a really close race but I have confidence in my body and in what I’m doing,” he said.

“[Smyth] is incredible, and extremely fast, but so is everyone in my class. It was close in Doha, and it will be close again. I think it will be a blanket finish, which will be amazing to be in.”

Training on the Gold Coast under the tutelage of renowned Paralympic track coach Iryna Dvoskina, Perris says he is following a strict regime and is using local competitions as training races to ensure he hits his peak in September.

“I’m running fast up here, but the important thing for me now is to maintain my body condition. It’s feeling really good right now, and I’ve had some really good blocks of training without hassle. I’m trying to do all the little things Iryna is telling me to do to stay injury free, and using this time up on the Gold Coast to get the competition practise.”

By APC Media

Posted: 13/6/2016

Courtesy of Australian Paralympic Committee on: 18/08/16

Page 4 - THE CHRONICLE, Wednesday, June 15, 2016 wangarattachronicle.com.au

Knox family gets to enjoy the ride

VISION Australia's paediatric occupational therapist Erina Richardson has helped a Wangaratta family and their young son Max who has Albinism and associated vision problems, to reach their goals of being able to enjoy cycling together as a family.

Max has a younger brother Harry who also has Albinism and an older sister Lily who doesn't.

"Bike riding has always been a large part of my husband Thom's life," Max's mum Bronwyn Knox said.

"We wanted to make family rides less stressful and more enjoyable for all of us and we wanted Max to improve his muscle tone so he could ride longer distances as well as learning more about bike safety in a controlled way.

"Erina was instrumental in researching the best type of bike, gaining the support of Community Support North East and Westend Cycles to provide the funding, supply and ongoing support for our new tandem bike and in providing essential advice on how to be the best possible pilot rider for Max".

"The impact has been enormous for the whole family, reducing the anxiety levels when planning to go bike riding and with Max now looking forward to going riding.

"We are even taking on some easy mountain bike rides in the Warby range."

Albinism is a little understood condition both socially and medically with wide forms of discrimination and subsequent social exclusion worldwide due to erroneous myths and beliefs in some communities.

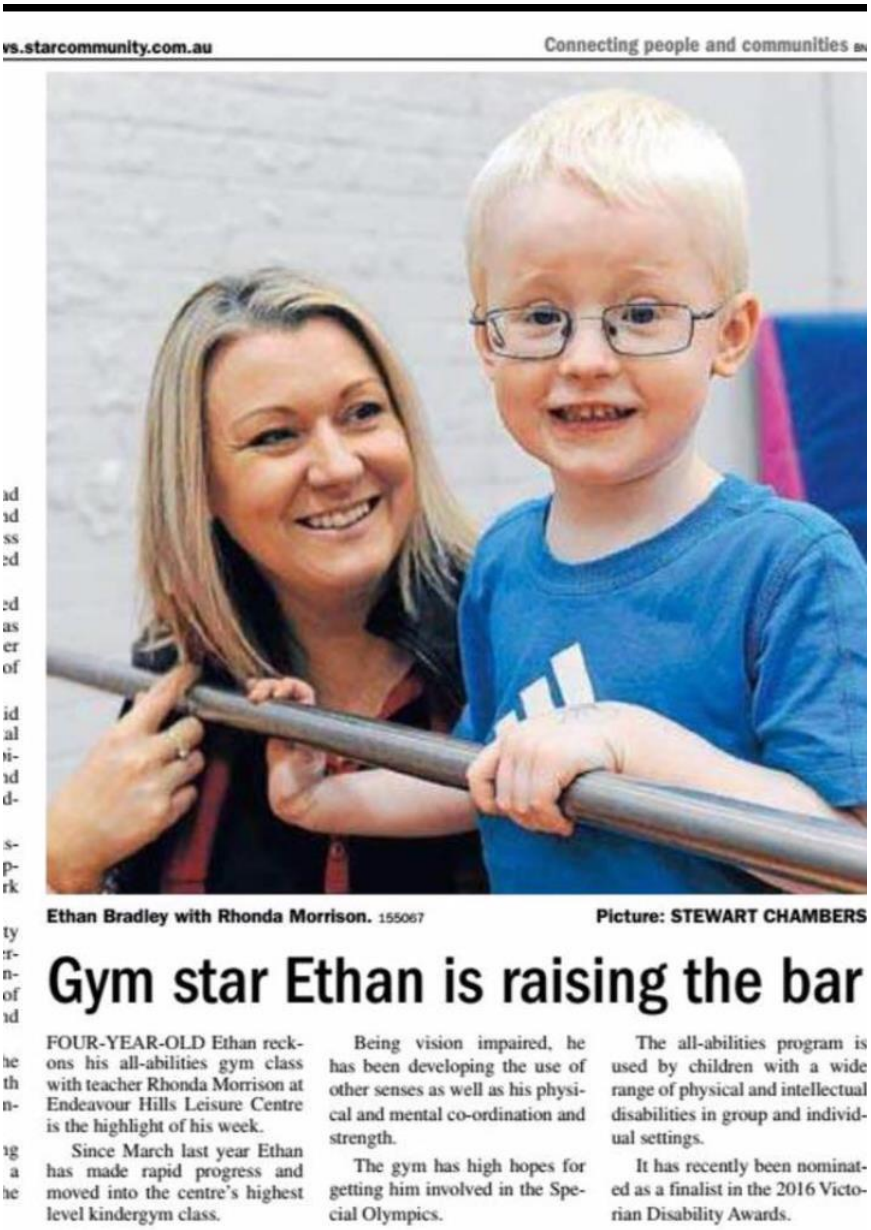
The United Nations General Assembly adopted International Albinism Awareness Day in December 2014 as a resolution, to commence from June 13, 2015, and with much better acceptance here in Australia than in other parts of the world, the associated needs of people with Albinism, such as vision loss, are now well supported by organisations such as Vision Australia.

Bronwyn said she and her family are very grateful to Vision Australia and in particular to their OT Erina Richardson, for the expertise and knowledge which has been instrumental in helping them, and Max, live the life they choose.

READY TO RIDE: The Knox family (from left) Lily, Max, Thom, Harry and Bronwyn enjoy a regular cycling trip thanks to the support of Vision Australia, Community Support North East and Westend Cycles.

Courtesy of Wangaratta Chronicle on: 22/07/16

Editor's Note: apologies for the small print. It is a scanned copy



vs.starcommunity.com.au Connecting people and communities

Ethan Bradley with Rhonda Morrison. 155067 Picture: STEWART CHAMBERS

Gym star Ethan is raising the bar

FOUR-YEAR-OLD Ethan reckons his all-abilities gym class with teacher Rhonda Morrison at Endeavour Hills Leisure Centre is the highlight of his week.

Since March last year Ethan has made rapid progress and moved into the centre's highest level kindergym class.

Being vision impaired, he has been developing the use of other senses as well as his physical and mental co-ordination and strength.

The gym has high hopes for getting him involved in the Special Olympics.

The all-abilities program is used by children with a wide range of physical and intellectual disabilities in group and individual settings.

It has recently been nominated as a finalist in the 2016 Victorian Disability Awards.

Courtesy of Star Newsgroup on: 17/08/16

Picture: Stewart Chambers

Editor's Note: apologies for the small print. It is a scanned copy

Spring is Coming…

Sha-de designs contemporary, natural fibre sun protection garments for women and children.

Our goal is to bring parents a range of great fitting, on-trend clothing that makes protecting their children's skin from the sun easy and hassle-free.

One blistering sunburn as a child more than doubles a person's chances of developing melanoma later in life (http://www.skincancer.org/prevention/sunburn). Sha-de provides daily shade; whether children are playing in the backyard, riding their scooter to the local café or at a birthday party – because you don't just get sunburnt at the beach.

Our clothing blocks between 93.5 percent and 99 percent of UV rays from reaching the skin, giving parents the comfort that their children are protected from the sun, without chasing them around with the sunscreen bottle or worrying about reapplying every two hours.

Made in Melbourne from locally knitted Bamboo, Sha-de garments are chemical-free, breezy and comfortable; perfect for a trip to the playground or a day of discovery in the backyard.

Layer up or mix and match, the Sha-de for Kids collections are made from high UPF breathable fabrics with no harmful chemicals, for maximum protection (and comfort) under the sun.

Our resort collection for women provides a range of versatile pieces, for the ultimate in hassle free style. Sha-de is designed and fitted to compliment the shape of your body, with breathable fabrics to give you maximum comfort. The perfect pieces for travel.

View the full ranges at:

www.sha-de.com

Sha-de is offering a 10% discount to AFA Members. Simply type in the coupon code: Albinism VIP

SHA-DE

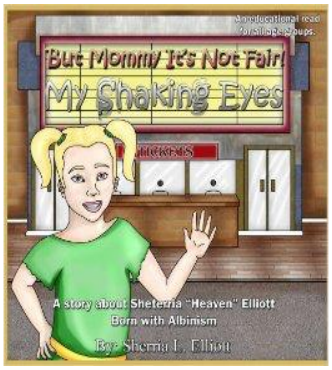
Ph: (03) 9041 3488

E: info@sha-de.com

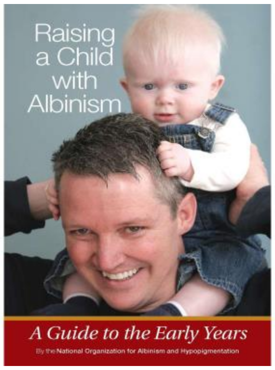
W: www.sha-de.com

Fb: www.facebook.com/shadesunprotect

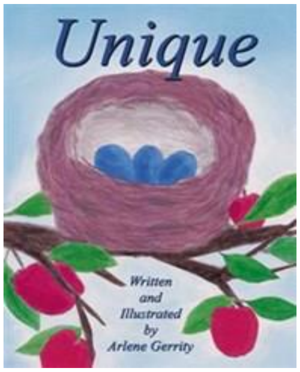
AFA Merchandise



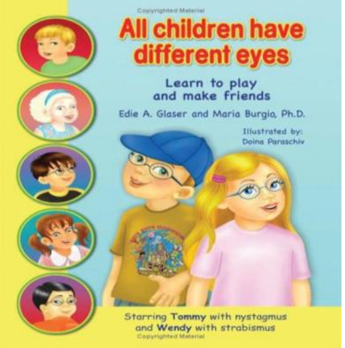
$17.00 + Postage



$25.00 + Postage



$15.00 + Postage



$25.00 + Postage

Lapel Badge $5.00

Bucket hats $10

Cap old Logo $10

Invite a friend or relative to join our community…

ALBINISM
FELLOWSHIP
OF
AUSTRALIA

Membership Form

For RENEWALS

July 2016 -June 2017

PLEASE PRINT CLEARLY

Full name ______________________________

Email address______________________________

☐ Tick here if all other details remain the same

☐ Changed details eg phone number, email address, new family members plus their date of birth, updates re visual acuity or type of albinism, or other updates.

To clarify your details, email secretary@albinismaustralia.org

Membership type	PDF newsletter		Hard copy Newsletter	
Individual	$40		$45	
Family	$45		$50	
Unwaged *	$32		$32	
Professional (individual)	$40		$45	
Organisational**	$100			
10 year membership	$300		$400	
Lifetime membership***	$400		$500	

* Unwaged – no income other than Centrelink benefits
** Organisational – can copy and distribute newsletter within the organisation
*** Lifetime membership is linked to the original applicant

PLEASE TURN TO NEXT PAGE

Membership fees $ ______________

Donation – thankyou! $ ______________

Please note that all donations over $2 are tax deductible and a receipt will be issued

Total $______________

PAYMENT METHODS

☐ TryBooking via Credit Card – please go to http://www.trybooking.com/EVQG

☐ Direct deposit St George Bank
BSB: 112879 Account number: 128217786
Account Name: Albinism Fellowship of Australia.
Please leave your surname as reference for validation. Email your completed form to membership@albinismaustralia.org.
Have you paid? yes no Transaction ID ____________________

☐ Post Australian cheque or money order to “Albinism Fellowship of Australia”.
Post with completed form to PO Box 20729 World Square NSW 2002
AUSTRALIA

☐ Paypal Overseas only. Email teasurer@albinismaustralia.org for instructions, and to confirm the amount payable, including Paypal fees.

I certify that the information I have included in this form is accurate to the best of my knowledge.

Signature ____

Name:

Date:

ALBINISM
FELLOWSHIP
OF
AUSTRALIA

Membership Form

For NEW members

July 2016 -June 2017

PLEASE PRINT CLEARLY

Full name ____

Postal Address ____

____

Town / City State Post code

Phone Numbers ____

Home Mobile

Email address ____

Name of person/s with albinism ___________________________

Type of albinism and visual acuity (if known) (eg OCA, OA, HPS)

____

Family member names and dates of birth so that we can remember your birthday!

Name ______________________________ Date of birth __________

Name ______________________________ Date of birth __________

Name ______________________________ Date of birth __________

Name ______________________________ Date of birth __________

Name ______________________________ Date of birth __________

Membership type	PDF newsletter		Hard copy Newsletter	
Individual	$40		$45	
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*** Lifetime membership is linked to the original applicant

Membership fees $ ______________
Donation – thankyou! $ ______________

Please note that all donations over $2 are tax deductible and a receipt will be issued

Total $______________

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I certify that the information I have included in this form is accurate to the best of my knowledge.

Signature ____

Name ______________________________Date ______________

RESEARCH INVOLVEMENT

AFA welcomes research which furthers understanding of albinism. AFA is willing to collaborate with research that have been approved by an ethics committee in accordance with the National Health and Medical Research Council's guidelines. Your choice below will dictate how we handle your personal information.

Please tick appropriate box (ONE only):

☐ 1. My personal information, and that of others that I provide on the AFA membership form can be used in any relevant research projects that have ethics approval.

☐ 2. My personal information, and that of others that I provide on the AFA membership form cannot be used in any relevant research projects without asking me first.

☐ 3. My personal information, and that of others that I provide on the AFA membership form cannot be used for any research projects.

Notification of each research project collaboration will be sent around to the membership as a courtesy, but individual members will not always be contacted. If you later decide that you do not agree with a particular project you will be required to contact the principal researcher of that project and ask to be withdrawn. If additional participation is required of the membership, then a specific notice will be sent around on behalf of the researcher.

Would you also like to receive any other requests or paperwork directly relating to albinism related research by mail? Yes ☐ No ☐

PHOTO PERMISSION AND RELEASE FORM

I hereby give my unconditional permission to the Albinism Fellowship of Australia (hereby referred to as ‘the AFA’) to use photographic images taken of me (and/or my child) during AFA gatherings and release for the purposes of promoting and publicising the AFA, its programs and resources. I expressly release the AFA from any claim for financial compensation now and in the future arising out of the use of the photographic images in accordance with this permission and release.

I expressly acknowledge and agree that all rights in the said photographs including the copyright therein and the ownership of the physical negatives and/or digital images belong to the AFA.

I understand that these images **may** be used in newspapers, newsletters, conference proceedings and other material, and also on the internet on the AFA's website and I expressly authorise such use. I also expressly authorise the AFA to grant to others the right to use the photographic images so long as it is for the benefit of albinism awareness education or programs and in a manner which is controlled and authorised by the AFA. I also understand and acknowledge that once this image is posted on the AFA's Web Site, the image can be downloaded.

I acknowledge the right of the AFA and give express permission to crop or alter the image(s) at their discretion. I acknowledge that the AFA may not use the image(s) at this time, but may choose to do so at a later date and also expressly authorise such later use.

I agree to indemnify and hold harmless the AFA from any claims arising from such activities and expressly include within the scope of this indemnity and release the following persons:

- The executive committee of the Albinism Fellowship of Australia
- Other committee members, state representatives and other volunteers working in a capacity under the name of the AFA. I certify that I am over 18 years of age.

Signature ___________________Name __________________________Date ___________

For persons under the age of 18, the permission of a parent or guardian is required on the Photo Release Form. I hereby grant permission to the Albinism Fellowship of Australia to use photographic images of my child as outlined above.

Name of child: ____________________________Date of Birth of Child: _______________

Name of child: ____________________________Date of Birth of Child: _______________

Name of child: ____________________________Date of Birth of Child: _______________

☐ Please identify this child by first name ONLY.
☐ Please do not identify this child by name.
☐ I do not give permission for website use, only printed matter

I certify I am over 18 years and I am the parent / guardian of the above child/ren

Signature of parent or guardian:
____

If you prefer <u>not</u> to allow permission for yourself and / or your child, please mention it here. We will endeavor to keep those named below out of direct scope of any recording, but may inadvertently include likenesses in group, audience or crowd recordings. I do <u>not</u> allow images of those named underneath to be used in any way for publicity, promotional or educational resources

Signature _____________________Name ___________________________Date _________

AFA COMMITTEE

President: Elizabeth Beales

Vice President: Amanda Collins

Secretary: Shari Parker

Treasurer: Ted Thomas

Assistant Secretary/General Committee: Marie Bedford

General Committee: Belinda West, Steve Bourne, Sandra George, Nicole Tobin Donnelly, Dannika Brittin

Want to Write for Us?

Submissions (text, photographs and digital images) are invited for inclusion in the Beyond Blonde newsletter. Submissions may be edited or rejected at the discretion of the newsletter editor due to relevance, interest and space. When edited, the general purpose and intent of the submission will be maintained as much as possible. Not all submissions will be accepted for inclusion in the newsletter.

It is the responsibility of the author to obtain permission for the use of any copyrighted material, including text or images prior to submission. It is preferable to supply images, but when permission is unobtainable, it is acceptable to include a link to the image directly in the text.

Editor's Note: The word 'albino' is never used in "Beyond Blonde" in a negative way.