

# The things that all parents worry about



## Know that you are not alone!

This list was made up by a group of parents of children with albinism at a SPEVI conference about 5 years ago. It is only natural to worry about the unknown and you will feel uneasy until you have learned more about your child and the condition in order to answer these questions.

### Worry for themselves:

- Not knowing what the future holds, what I need to know myself – can I trust it will be OK?
- Grief for what is lost.
- How much do I protect/defend/advocate for my child?
- How do I help them/guide them to develop independence/resilience?
- Freedom to explore/experience/make mistakes v's keep them safe from physical and emotional harm?
- How to do the above and also respect the individuality/rights of my child?
- How to involve my child in finding answers to challenges and decision making?
- What will others think or assume about my child?
- How do I educate/inform relatives, friends/others about my child and issues?
- How do I choose the right childcare/kinder/school? (environment/teaching/funding)
- What equipment will my child need and can I afford it?
- Exactly whom do I go to for help/information at various stages?
- How does the NDIS scheme work and what will it provide?
- How to balance my response to the needs of my child with albinism, against the needs of my other children.
- Ensure my partner and I are "on the same page" for all important decisions and issues.

### Worry for their children:

- Fitting in
- What they will miss out on
- How they will learn/keep up with their peers
- Will teachers understand their condition and limitations
- How will the classroom teacher/s cope with my child's challenges in a normal classroom
- Will my child have a support person and will the child accept that (especially as a teen)
- Will they have equal opportunity with peers
- Will they achieve milestones in Education (at peer level, VCE, Uni)
- Will they have a career/employment
- Socialising and finding a partner as an older teen/young adult
- Bullying

### Know that everything will be OK - Message from parents who have been there:

Members of the albinism community will be there to help you to answer all your questions and reassure you. As you watch your child with albinism grow, you will be amazed at how capable they are, and you will come to understand that they will be OK – and so will you!