UNDERSTANDING AND SUPPORTING STUDENTS WITH ALBINISM

(Advice for Classroom Teachers/Assistants)

Oculocutaneous Albinism

(Effects eyes, skin and hair)

Ocular Albinism

(Effects eyes only)

Prepared by Sandra George, Secondary Teacher and Grandparent of toddler with Albinism.

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What is Albinism?

The following on this page are extracts from the NOAH website (prepared by S. George, 9.1.15).

(National Organisation for Albinism and Hypopigmentation http://www.albinism.org)

Albinism is a group of genetic conditions that causes a lack of pigment. It can effect only the eyes (ocular albinism) or both the eyes and skin (oculocutaneous albinism). Most types of albinism are inherited when an individual receives the albinism gene from both parents. The exception is one type of ocular albinism, which is passed on from mothers to their sons.

The lack of pigment during the development of the eye causes an abnormal development of the retina and affects the formation of the nerve pathways from the eyes to the brain, which causes decreased visual acuity or low vision that cannot be corrected to 20/20. Adults with albinism often describe their vision as lacking fine detail. Corrective lenses (i.e. glasses or contact lenses) and low vision aids (i.e. magnifiers or telescopes) can provide some clarification. Most people with albinism use their vision for reading, but some use braille. Some have vision good enough to drive a car. Albinism has no affect on mental development.

The degree of visual impairment of children with albinism varies widely. The individual child's vision can also vary somewhat based on the sunlight and artificial light in the classroom, fatigue, and other factors that vary from hour to hour and day to day. Since what children with albinism see varies widely, as does the efficiency with which each child uses its vision, it is important to consider each child with albinism individually.

The social side of education can be the most challenging aspect for a child with albinism. It is a common fact that children can be cruel especially to those kids that are different. Students with oculocutaneous albinism (albinism affecting the skin and eyes) inherently stand out because of their physical appearance. Furthermore, modifications the child may need to make to compensate for low vision sometimes makes the child's feeling of isolation even worse. Therefore, it's important that you avoid drawing attention to your student with albinism. For suggestions on providing social support for your student with albinism, see NOAH"s Information Bulletin "Social and Emotional Aspects of Albinism" on the website.

Eye problems in Albinism often include:

- Nystagmus: regular horizontal back and forth movement of the eyes
- Strabismus: muscle imbalance of the eyes, "crossed eyes" (esotropia), "lazy eye" or an eye that deviates out (exotropia)
- Photophobia: sensitivity to bright light and glare
- People with albinism may be either far-sighted or near-sighted and usually have astigmatism
- Foveal hypoplasia: the retina, the surface inside the eye that receives light, does not develop normally before birth and in infancy
- Optic nerve misrouting: the nerve signals from the retina to the brain do not follow the usual nerve routes
- The iris, the colored area in the center of the eye, has little to no pigment to screen out stray light coming into the eye. (Light normally enters the eye only through the pupil, the dark opening in the center of the iris, but in albinism light can pass through the iris as well.)

For Class Teachers/Assistants: Working with a student with Albinism by Sandra George

*The student with Albinism is **enabled** by their excellent memory, other senses, ability to adapt, to use technology and to efficiently use the sight they do have.*

To them, they are no different to anyone else - they just do things differently! They do need assistance from parents/teachers/assistants to achieve this without it being obvious to other students. They desperately want to be one of the crowd and not treated differently.

No two students with Albinism have the same visual ability or issues!

Each child with Albinism will have different visual ability or issues at different times.

The parent of a young child will know most of the factors that influence the child's vision. As they get older, the student will be able to tell you themselves – **listen to them both!**

Make no assumptions about what they can and cannot see at any one time. A toddler will sometimes be able to identify the make of a car from 20 metres and another day not even see the car. A teenager may fall over an unseen bag on the floor and then pick up a small pin from the table. Their experience, often excellent memory and other keen senses will give them a sense of what is around them and they will sometimes appear to have better vision than they actually have at the time. Ask them to describe what they see rather than if they can see.

What does having Albinism often mean in terms of what they see?

- Inability to see fine detail, poor depth perception, often short sighted (varied).
- Significantly reduced vision in glare or low lighting (painful "White out")
- Difficulty or inability to track moving objects, slow to change focus.
- They may have a head turn to find the null point (best position to see). This may be up, down or to one side and in fact may change according to the situation.

Importance of developing independence, self-advocacy and resiliency

It is important that the student develops independence in learning – the aim is for them to be able to use their skills and equipment to access the curriculum on their own, alongside peers. They will need support to do this initially, but it is important that you do not do things for them once they have learned how to use equipment or apply a skill (as you would with any other student). Teach them to advocate for themselves in a positive way that will be respected by others. Many need to be coached to ask questions or seek assistance if they do not fully understand something or are having difficulty, as they do not want to draw attention to themselves. Implementation of the **Expanded Core Curriculum (ECC)** is essential for the successful learning and integration of the student.

Expanded Core Curriculum

This is generally introduced and taught by the Visiting Teacher (VT), supported by the relevant unit in the State Education system (eg Statewide Vision Resource Centre in Victoria or RIDBC in NSW). However it is important that the class teacher understands what the student is learning so that the skills can be reinforced and rehearsed consistently in all classrooms. The class teacher should be provided with time to work and communicate with the VT, sharing information on student progress and application of ECC skills.

- How and when to use different vision aids, including technology.
- Organisational skills (especially managing storage and use of technology).

- Orientation and mobility – safety in the class rooms and yard, long cane use (if applicable), skills required for moving beyond the school (excursions etc).
- Social skills - personal space, how to join group, non verbal communication.
- Self advocacy – knowing how and when to ask for assistance, answer difficult personal questions, combat bullying etc.
- Individual learning plans – student goal setting.

Class Teacher Check list

How well do you know each student's visual acuity and efficiency in the classroom?

In ideal situations when student is fresh and alert, with good lighting, high contrast and clear print, **how far will the student be from the object to see the following clearly, if at all?** How will you accommodate for this? How will poor conditions affect this?

- Print or symbols (eg. 5cm tall), spaced evenly on a white board?
- 12-point type when flat on desktop or on a slope board?
- What size print do they require to be able to see from a comfortable reading distance?
- A4 size Coloured or black and white pictures, graphs (black lines), diagrams etc.?
- Regular sheet music and other specialist print?
- Their own handwriting (using a black pen)?
- Video on a screen or TV?
- How well can the student follow a video? Is there sufficient contrast, clear picture?
- Gestures and facial expressions. (They often need to be accompanied by verbal cues)
- Can the student track movement around the learning space (other students or objects in drama or other activities)?
- How are the above affected by glare (from windows, lighting, boards, tables, screens, shiny paper), low light, fine work, length of session, general fatigue etc.?
- Is this information passed on to classroom and specialist teachers, assistants and casual teachers?

At their desk or workspace (some or all of the following may apply)**:**

- Does the student have their back to any glare from windows or lights and also avoid shadows on their work? Seating between rows of fluorescent lights, but down lights are often best.
- Is the teacher placed so that light is on their own face and not coming from behind?
- Is there a slope board or stand to raise the paper, book or iPad to ensure correct posture and prevent neck and back problems? See through plastic boards/stands are more inclusive (don't cut the student off from friends) and are lighter to move.
- Is the student allowed to wear a peaked cap (or even sunglasses) in class, if the glare from overhead lights or windows causes a problem?
- Does the student have access to all board presentations, handouts, books being read etc. at his own desk (large text, magnifier, E device or live film on their device)?
- Does the student have access to all electronic presentations on their own E device?
- Does the student have access to a filmed demonstration (eg. actions to a song, writing technique, science experiment or art technique) prior to the lesson?
- Is the student close enough to see a demonstration, or have the option to watch it on his or her own device, as it is being filmed live in the class?
- Does the student have access to CCTV, viewer or similar to undertake fine or close practical work where necessary, without being separated from peers?
- Do all teachers/assistants understand how specialised equipment works, how it contributes to student performance and what the parameters for use are?

- How much does the student rely on hearing to understand what is going on? Does peripheral noise in the classroom affect this?
- Are they sensitive to sudden, excessive or persistent noise?
- Is the student able to indicate to you that they need "time out" to rest their eyes or turn off, without alerting other students? Is there an alternate activity for them at this time?
- Does the student have an opportunity to identify which form of assistance is most suitable in each situation?

Movement about the learning space

- Has the mobility consultant provided guidance about marking or placing objects that can present a danger to the student? (eg. "high vis" tape or paint on door jams, benches, steps, overhead cupboards, placement of loose items in cupboards or out of the way corners)
- Before the class commences, has the student had an opportunity to explore any furniture / equipment placement changes in the room/area?
- Are other students conscious of keeping furniture and equipment in the same place as general routine (and not just because of the student)?
- Do they have a locker on the end of a row at chest height so that they can easily access it?

As a teacher / assistant do you:

- Take all steps necessary for them to fully access the curriculum?
- Offer breaks during intense periods of work or focus.
- Give the student an opportunity to write a letter to others explaining their situation?
- Provide all enlargements or E access of/to all documents and other materials the class is using, at the same time (and prior to the lesson if needed)?
- Ensure they have the same access for homework.
- Provide special provision for assessment tasks and tests (additional time, rest periods, enlarged question and response papers, E access etc.)?
- Include the student and parent in planning (and IEP meetings)?

Physical Education – participation for the child with Albinism by S. George

Children with low vision feel no different to anyone else - they just do things differently! Assistance from teachers/assistants to access the curriculum alongside peers will be necessary, without it being obvious to other students. They desperately want to be one of the crowd and not treated differently. They are **enabled** by excellent memory, other senses, use of technology, ability to adapt and to efficiently use the sight that they have (don't let him trick you into thinking that they see more than they actually can). Encourage self advocacy, independence and resilience.

One of the primary considerations when classes are outdoors is sun and glare protection. Ensure that their PE uniform includes large brimmed or legionnaire style hat and sunglasses. If they have Oculocutaneous Albinism, Sunscreen (even on cooler or cloudy winter days) must be used on exposed skin, with long sleeves (preferably dark colour to prevent glare) and long pants. Placement of the class, teacher and student on the field to reduce sun and glare exposure for the student is important. Days of excessive glare (with sun or cloud) can result in further decreased vision (a "white out") and cause severe eye pain to a student who is photosensitive. Always make sure that the student has their back to the light source, even if in the shade or inside. On days of excessive UV levels or glare, they may require a reduced time on the field or an alternate activity (there are good phone apps letting you know the daily levels).

When first starting school they usually cope with most basic physical skills with support (high contrast equipment and markings, non busy background, staged learning, placed with peers using slower speeds for ball games). When playing team games or identifying the tagging person/s it is important that high contrast bibs are used (eg bright yellow on navy). It is often difficult for them, or even frightening if other class members are moving, as they are unable to fix quickly on a moving object, especially if their nystagmus is significant. When playing minor games, a large area makes it difficult for them to find peers – use a smaller area for their smaller group with clearly defined boundaries.

As they do not see fine detail, many prep children will not have identified the difference between running, jumping, hopping and skipping, and may have to be taught these skills. During any explanation or demonstration, they should be no further than a couple of metres away, or they will not see the movement. They will know the placement of equipment and layout of an area if you have them help to put it out with a friend. When checking if they understand, ask them to verbalise or demonstrate it – if you just ask them "do you understand?" they will generally say "yes", even if they don't. Most do not want to be singled out as different – they just want to be one of the crowd.

Many also have no depth perception, making work on, or jumping off elevated surfaces and judging the speed or distance of a moving object very difficult. This also makes them hesitant to run freely on uneven or shadowy surfaces, as they cannot tell the difference between a shadow or a hole in the ground when they see a dark shape. It can be very helpful to let the student explore the equipment or area before the activity to give them a better understanding. When learning to catch, use a large, brightly coloured, softer ball to assist with sighting the ball and giving confidence, as it will not hurt if they misjudge the catch. A bounce pass will often have better contrast against the bitumen or floor boards (than a higher pass that will have a busier background), especially if the student is given a verbal cue as the pass is made (Jasper, bounce pass). Students with low vision rely on sounds to help them cue into what is happening, but if a class is very noisy, they are easily confused.

Although they have difficulty tracking moving objects, as they get older many play mainstream larger ball sports such as Soccer, Football, Basketball or Netball with supportive peers in junior teams. As ball games become faster and skills more sophisticated, with strategic play that requires sighting fast moving players, they often find it difficult to keep up and drop out. When team mates can be trained in methods of inclusion (calling positional play, bounce passes, using them for place kicks or throw ins, close tagging players etc) many continue in these sports into adulthood. This early training, builds fitness and movement skills and most importantly the opportunity to socialise with peers and be part of a group. It is therefore important that they are encouraged to participate in a range of activities, and not discouraged or excluded on the basis of low vision.

In upper Primary or Secondary many successfully continue in mainstream sports or physical activities which rely less on tracking fast movement and more on feel or personal endeavour like martial arts, gymnastics, athletics, swimming, bowling, fitness training or dancing. Others will become involved in the vision-impaired sports. It is therefore important that they are exposed to a broad range of activities for as long as possible, if necessary finding ways to adapt class activities so that they are actively involved and not sent to the Library etc. The inclusion of a range of suitable activities in secondary mainstream PE (as mentioned above), will allow them to continue in the curriculum with their peers.