

Netherton Syndrome

Netherton syndrome was first diagnosed by Earl W. Netherton describing a child with scaly red skin and coarse hair. It is caused by a damaged gene called SPINK5. It is the absence of enzymes responsible for breaking down the links between cells thus creating flaking red skin. The skin can become very dry, itchy and sore.

Netherton syndrome is a rare syndrome that is also characterized by a predisposition to allergies, asthma and eczema. There is no cure as of yet for Netherton syndrome however efforts are being made to find a cure. Children with Netherton syndrome will be required to visit a dermatologist and ear specialist. Fluid and salt balance requires monitoring as the loss of fluids through the skin is rapid causing diarrhea and vomiting. Daily treatment of the skin is required through the use of specific creams and regular showers or baths to keep the skin soft and help remove loose skin flakes.

Effects on Developmental Areas

Children may display some of the following characteristics

Social and Emotional Development

- May have limited peer initiated social experiences due long to stays in hospital and increased medical intervention
- May have difficulty making friends due to hearing impairments and acceptance by other children because of physical difference

Physical Development

- May have slow weight gain and difficulty in maintaining an appropriate weight for age ratio
- May have rapid loss of fluids through the skin causing dehydration, vomiting and increased sickness
- May be lighter in weight and smaller in stature
- May have increased risk of infection in infancy
- May have increased risk of skin cancer
- May have poor body temperature control

Language and Communication Development

- May experience difficulties in producing some speech sounds due to ear infections
- Difficulties in keeping up with a two way conversation

Cognitive Development

- May have had limited concrete experience with the environment
- May have developmental delay due to increased hospital visits

Health and Safety Issues

- May have health implications that may affect participation in aspects of the program
- May have eating disorders
- May require specialised treatment with creams, showers and baths
- May have intense pain from redness of skin
- May be at risk to certain creams being absorbed into the blood stream
- May be at risk to skin infections

Netherton Syndrome Inclusion Strategies

Each child diagnosed with Netherton Syndrome will be different and individual. It is important to gain information from the parents as to what characteristics of Netherton Syndrome their child displays. It is important to work closely with the parents as well as any additional support specialists e.g. therapists who may be involved with the child. As these children require at least 2 baths per day as well as application of creams, it is important to develop a clear routine with the parents regarding this. It is also important to gain an understanding from the parent as to what is the most important aspect of their child's needs when attending your service. What is it that parents hope to gain from using your service? The following inclusion strategies are just some examples which may be applied to support the inclusion process. This list is only the start and it is dependant on a variety of factors such as environment, length of time child is in care, child's interest, likes, dislikes and skills already achieved.

- Share your ideas and information with the parent to build up a number of strategies that are consistent with home and child care.
- Talk to the parent about what they are happy for staff to share with the children about their child's disability.
- Use the term Netherton Syndrome rather than other words.
- Encourage and plan for positive social experiences (small group experiences etc.).
- Provide activities that enable each child to achieve within their own personal best. These children may not do very well in sporting/gross motor activities e.g. obstacle course or using climbing frames.
- Identify areas of the child's development that requires additional communication support e.g. social interaction, language understanding.
- Label pictures with words/symbols to assist a child's response in communication.
- Identify health issues with the parent and what is expected of the staff for any treatments that may need to be undertaken throughout the day e.g. baths and application of creams.
- Monitor child's fluid intake due to rapid loss of fluids through the skin to avoid dehydration.

References

Deiner, P.L. (1993) **Resources for Teaching Children with Diverse Abilities - Birth through Eight**. Harcourt Brace:

Kozma, C. & Stock, J. (1993) **Caring for every child—Ideas to meet diverse needs in Child Care**. Funded by the Commonwealth department of Human Services and Health : Sydney

The Netherton Syndrome Group <http://www.nethertonsyndrome.com>

Umansky, W. and Hooper, S. (1998) **Young Children with Special Needs** Third Edition New Jersey, USA:Prentice-Hall

Disclaimer

Inclusion Works! provides information to Children's Services upon request. The information provided is obtained from a number of sources e.g. library, other services, resource books and Internet. The information provided is not intended to, nor does it, constitute medical or other advice. Persons access this information assume full responsibility for its usage. Acknowledgement of source of information is required if passed onto a third person.