A Guide to the First Year of Life:
Hypohidrotic Ectodermal Dysplasia

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Our mission is to empower and connect people touched by ectodermal dysplasias through education, support and research. For more information, visit us online at www.nfed.org.
INTRODUCTION

The ectodermal dysplasias are a group of inherited disorders that involve defects of the hair, nails, teeth, and sweat glands. However, the ectodermal dysplasias are a remarkably diverse group of human disorders, so other parts of the body may be affected. The types of ectodermal dysplasias are recognized by the combination of physical features that an affected person has and the way in which they are inherited. More than 100 types of ectodermal dysplasias exist. This book is specific to the type known as hypohidrotic ectodermal dysplasia (HED).

SPECIAL NOTE

Information on management is suggested in this booklet is meant to be a guide to what might be expected or recommended by medical professionals who are consulted by our families. The reader should understand that these statements are generalizations about the many and diverse ectodermal dysplasias, and therefore no absolute recommendations are made or implied. Trust the clinicians whom you consult to do the right things for each individual, but also be an advocate for yourself or your child. Your medical professional may appreciate a copy of this booklet to increase their awareness of the ectodermal dysplasias.

The mention of any brand name drugs in this booklet is presented as example only, intended as guides to groups or classes of products, is not either inclusive or restrictive, and must not be interpreted as endorsement of a specific product or brand or company by the National Foundation for Ectodermal Dysplasias (NFED) or its Scientific Advisory Council.

For more information on medical and dental care associated with HED or any of the ectodermal dysplasias, contact the NFED (618-566-2020 or info@nfed.org) or visit our website at NFED.org.
While hypohidrotic ectodermal dysplasia (HED) is an inherited condition characterized primarily by a decreased ability to sweat, sensitive skin, fewer teeth that are classically pointy, and thin or sparse hair, the condition also features a large variety of other findings that pose unique challenges to children and parents alike.

During a child’s first year of life, or infancy, parents may have many questions regarding how best to care for their child with HED. The purpose of this guide is to answer some of those questions and help parents and caregivers anticipate future needs.

**HOW DOES HED AFFECT MY BABY’S SKIN AND WHAT IS THE BEST WAY TO CARE FOR IT?**

Below are some common skin conditions that can be seen in infants with or without HED. Due to their sensitive skin, children with HED may develop these conditions more easily than other children. As such, our recommendations and treatments for each are as follows:

**Dry Skin (Xerosis)**

Dry, sensitive skin is common in infants with HED. This may be related to common eczema (also called “atopic dermatitis”; as described below) but altered skin surface fats may also make the skin surface less able to trap moisture. [18] People with HED may also have reduced oil (“sebaceous”) gland secretion. [1] These glands produce natural oils that supplement skin barrier fats to help retain moisture. These deficiencies cause skin to become dry, and often scaley, with fine shedding or peeling.

Dry skin is most effectively treated with frequent bathing (up to once a day). Soaking in a tub can help add moisture, as long as cleansing products are gentle and used sparingly. Avoid products
with fragrance, and foamy detergents. Use cleansing products only on areas that need cleaning, such as the diaper area and skin folds. Most importantly, immediately after removing your child from the bath, gently pat the skin dry and apply a moisturizer to help seal in the moisture. The safest and most effective moisturizer is plain petroleum jelly.

Be sure to read the back of the label to make sure it does not contain fragrance, an ingredient that is often added to petroleum jelly labeled “Baby”. Ointments are safer and more effective than creams or lotions. A one-piece pajama is a great way to prevent the petroleum jelly from wiping off onto other surfaces.

For examples of recommended and HED sensitive products for dry skin, as well as further details for treatments on all the symptoms discussed in this section, see our “Treatment Guide for Skin Issues in Ectodermal Dysplasias”.

**Eczema (Atopic Dermatitis & Contact Dermatitis)**

Dry skin that lacks a normal protective barrier can be itchy and become easily inflamed, a condition called “eczema” or
“dermatitis. Atopic dermatitis is a common, chronic sensitive skin condition that affects about 20% of children but may be more common in children with HED. [19] Contact dermatitis, caused by irritation (often triggered by dry air) or allergic reaction, (often triggered by products applied to the skin), frequently complicates atopic dermatitis.

All forms of eczema are characterized by redness, itch, scale and sometimes fine bumps. Eczema can be localized (most commonly affecting the elbows, knees, wrists, ankles and cheeks in infants) but can also be widespread. Treating eczema begins with the bathing and moisturizing regiment discussed above for dry skin. Adding a small amount of household bleach (5-7% sodium hypochlorite) to the bath water (1 tablespoon to a standard baby bath or 1/4th cup to a regular tub) can help prevent overgrowth of germs that can trigger skin inflammation.

Your healthcare provider may also prescribe a mild strength topical corticosteroid such as hydrocortisone to be applied to itchy areas no more than once a day. This medication can also be purchased without a prescription. In either case, an ointment is preferable to a cream or lotion product. Avoid frequent and prolonged use of a topical corticosteroid, especially on sensitive areas like the face or skin folds. In general, use up to 15 days
per month, and no more than 30 grams per month is considered safe. If the eczema persists despite these skin care measures, and especially if itch is interfering with restful sleep, seek additional evaluation from your healthcare provider. Skin swelling, pain, blisters or pus bumps suggest secondary infection which may require additional treatment.

Important: Oral antihistamines (ex: Children’s Benadryl) are often used to help promote sleep in children with the nighttime itching often associated with eczema. However, while sedating antihistamines relieve the itch caused by hives, these medications do not relieve eczema itch, and can cause agitation in some infants and children, and possibly interfere with normal sleep.

**Diaper Rash**

Redness and rash in the diaper area is most often a form of contact dermatitis. Typically, contact diaper dermatitis spares the skin folds, sites not exposed to the irritants or allergens from frequent stooling and wiping. The safest and most effective initial treatment is to avoid exposure to products that can aggravate the problem (including pre-moistened diaper wipes, diapers containing fragrance or dyes or diaper creams with many ingredients). Apply plain, 20% zinc oxide ointment (mixed in only petroleum jelly and mineral oil) with each diaper change to protect the skin.

For persistent diaper rash, apply 1% hydrocortisone ointment on the red area no more than once daily for one week. If the rash persists or worsens using this treatment, visit your health care provider for additional evaluation. Redness present within the skin folds may suggest a yeast infection, which often starts after taking a course of antibiotics.
Cradle Cap

This condition, also called “seborrheic dermatitis” is common in all infants and can affect those with HED. It is characterized by scale on the scalp and skin folds, often most prominent on the brows, around the nose, neck creases, underarms and diaper area. [2] It is usually asymptomatic, but can be mildly itchy, and often resolves by age one, even without treatment.

The appearance can be improved by gentle cleansing with a medicated shampoo that can be applied to the scalp, face and skin folds. A variety of products are available with and without prescription. Active ingredients include: selenium sulfide, ketoconazole, zinc pyrithione, salicylic acid, tar and tea tree (Melaleuca) oil. It may be more effective to rotate different active ingredients.

Application of plain mineral or coconut oil for 30 minutes prior to shampooing may help minimize stubborn scale. Avoid olive oil, which can aggravate the condition. Consult your child’s physician for additional evaluation if the condition is widespread or uncomfortable.

BELOW ARE SKIN FINDINGS MORE UNIQUE TO INFANTS AND CHILDREN WITH HED:

Increased Redness (Erythema) and Skin Peeling

Erythema may be generalized or accentuated around the eyes, and on the palms and soles of infants with HED, while skin peeling has been noted in up to 70% of cases.[3] These findings typically improve or resolve without treatment, but bland skin care (see Dry Skin section above) can help maintain skin health.
A more severe, but rare condition, known as a collodion membrane (or “collodion baby”), has been reported in newborns with HED, but is more often seen in infants with other genetic forms of dry skin. Infants with this condition are born with skin thickening that resembles parchment paper, and normalizes with gradual exposure to lower air humidity over the first few weeks of life.

**Increased and Decreased Skin Pigmentation (Hyperpigmentation and Hypopigmentation)**

Following the neonatal period, the majority of the skin in HED affected infants often displays a lighter skin tone than what may normally be expected compared to unaffected infants. This is due to a decreased production of skin pigment (hypopigmented). While this decrease in pigment is inherently asymptomatic, it can increase the risk of sunburns in children of all ages, especially infants.

The National Foundation for Ectodermal Dysplasias (NFED) and
the American Academy of Dermatology recommend limiting your child’s exposure to direct sunlight as much as possible.

But, when outside, parents should attempt to shield their child’s skin from the sun’s rays using umbrellas/canopies, wide brimmed hats, and sun protective clothing. Sunscreen is not recommended for children less than six months old due to the risk of skin irritation, but 20% zinc oxide ointment (also used to protect against diaper rash) may be safely applied as often as every two hours. [4]

But, if these protective measures are unavailable and your infant is of appropriate age, a small amount of SPF 30+ sunscreen containing zinc oxide or titanium dioxide may be applied every two hours or each time after the skin gets wet. [4]

Conversely, the skin surrounding the eyes tends to display a darker skin tone than is expected compared to other unaffected infants (hyperpigmented) that may become more prominent with age. As with hypopigmentation, this discoloration is not associated with any adverse effects but may produce another aesthetic concern for parents.

While this pigmentation can be masked or managed using skin sensitive camouflaging make-ups or chemical peels, these methods are not recommended for infants or young children and are best reserved until either the child’s sense of self-awareness begins to develop (typically around the age of four) or until the child explicitly expresses concerns regarding their appearance.

THIN, SPARSE HAIR (“HYPOTRICHOSIS”)

Newborn infants can display a wide variety of hair densities, from a having thick head of hair at birth to having none at all. [5] Many infants (and their mothers) however, experience a stress-related form of hair loss from a process known as “telogen effluvium” typically around three to four months after delivery. The hair that
is lost during this process typically regrows within one year and is more reflective of the hair type a child will retain as they age. For children with HED, this hair is often fine, delicate and sparse. [6] Their hair may grow slowly and shed more quickly, never gaining significant length. This combination of characteristics is one of the defining features of HED.

To maintain healthy hair in children with HED, use gentle grooming techniques. Shampoo with mild products and avoid alcohol-based styling gels. Conditioners and short hair styles may be used to add fullness. A variety of treatments typically used for sparse hair or bald spots unrelated to HED have been tried in older children and adults affected by this condition who are bothered by the hair’s appearance.

See our “Treating Hair Problems in Ectodermal Dysplasias” for more information.
NAIL ABNORMALITIES

Nail abnormalities are another defining feature of HED, but findings are often subtle. The most common variation is thin, brittle nails. Use gentle grooming techniques to maintain healthy nails. Keep nails trimmed and filed, and apply a bland ointment (e.g. plain petroleum jelly) on and around the nails for further protection. A variety of treatments used to strengthen nails have been tried in older children and adults with HED who are bothered by their nail’s appearance. If you notice redness or swelling around or under the nail, foul odor, drainage or discomfort, visit your health care provider.

See our “Guide to Treating Nails in Ectodermal Dysplasias” for more information.

SEBACEOUS HYPERPLASIA

This is the name given to prominent oil (“sebaceous”) glands that appear as tiny, evenly scattered, yellowish bumps found on the nose most commonly, that also sometimes develop on the forehead and cheeks. This condition can usually be recognized by the appearance, but skin biopsy and microscopic examination can confirm the diagnosis and rule out other causes.

Sebaceous gland oil production is stimulated by hormones present during early infancy and again during puberty. The cause of HED-associated sebaceous hyperplasia is not fully understood, but may be related to accumulation of oil within the sebaceous glands caused by impaired secretion. [20] A variety of treatments used to shrink oil glands have been tried in older children and adults with HED who are bothered by their appearance.

IDENTIFICATION, MANAGEMENT & PREVENTION OF OVERHEATING IN AN INFANT
The hallmark feature of HED is a decreased ability to sweat (“hypohidrosis”), due to fewer and poorly functioning sweat glands. Many children with HED produce a little sweat, especially on the scalp, palms, and soles where sweat gland density is highest. However, the amount of sweat produced is seldom enough to maintain normal body temperature during periods of heat stress.

Hypohidrosis typically presents in infancy with overheating (“hyperthermia”) manifesting as frequent, high fevers that occur during a mild infection (usually viral and often identifiable). Exposure to elevated temperature and humidity, such as a hot summer day, or intense physical activity can also trigger hyperthermia in children with HED.

Because of the inability to sweat, a baby with HED should not be placed under a heat lamp at the hospital. Also, to prevent overheating, you may not need to swaddle the baby in a blanket or dress them too warmly. Dress them in lightweight fabrics like cotton. Car seats can also make your baby warm so be mindful of how they are dressed.

With time, children gradually learn to identify the feeling of heat stress as well as techniques to cool down. However, parents of infants and young children must maintain vigilance for the warning signs of overheating, to minimize the potentially life-threatening risks of prolonged hyperthermia.

Easily identifiable signs of overheating include skin flushing (redness), decreased activity or increased restlessness, fussiness, being warm to the touch, unexplained fever, and increased heart rate. [7,8] Additional signs are shallow breathing, vomiting and lethargy. Multiple signs are often seen in combination with each other and it is incredibly important to implement immediate cooling measures at the first signs of overheating:

- Move the child to an indoor, air-conditioned, environment or into a shaded area if possible.
• Use a spray bottle filled with cool water to lightly dampen as much of the skin surface as possible, especially the face and head. A fan can promote evaporation and additional skin surface cooling.

• Place cool, damp, cloth compresses over the forehead, wrists and torso. Avoid compresses on the front of the neck as they may interfere with the child’s breathing.

• Ice packs can be placed on the areas listed above as well, as long as they are wrapped in a thin cloth or towel and are not in direct contact with an infant’s bare skin. Leave ice packs in place no longer than 10 minutes to avoid the possibility of frostbite. [9]

• A short, cool bath can also be very effective, but do not delay using other cooling measures while the tub is filling.

• For more information on cooling techniques check out our Cooling Guide.

Be aware that becoming unresponsive during an episode of known or suspected overheating can be a sign of a more serious condition known as “heat stroke”, which requires immediate medical attention. If this occurs, initiate cooling measures immediately and call 911.

DIFFICULTIES WITH MUCOUS AND SECRETIONS

Children with HED tend to have a reduced number of mucous glands, which also produce an abnormal form of mucous. The places where we find these mucous glands causing the most issues is in the nose, the ears, and the airways (respiratory tract).

The Nose

In the nasal passages, the abnormally functioning mucous glands fail to incorporate enough moisture into their secretions. This lack of moisture often results in significant dryness of the inner
nostrils (which can produce nosebleeds), crusted nasal passages, and accumulation of thick mucus that will need to be removed on a regular basis. [10] If this thicker mucus is not removed it has been known to form large aggregates known as rhinoliths or “nasal rocks” that can cause difficulty breathing, foul smelling odors, and increased risk of sinus infections. These nasal rocks may require removal by parents or at times by healthcare professionals to prevent or alleviate an infant’s symptoms.

To keep the nasal passages moist and prevent the accumulation of mucus, we recommend the use of the following treatments:

- **Humidifiers** – Placing humidifiers in an infant’s room can help alleviate much of the dryness. Pediatricians recommend the use of cool mist humidifiers as opposed to warm mist humidifiers as the steam may inadvertently cause a mild scalding of the delicate tissues if inhaled in too large of quantities, and could be the cause of severe burns if tipped over on the child inadvertently.

- **Saline Sprays or Drops** – Saline is the only irrigating solution recommended for infants and many types can be purchased over-the-counter or mixed at home. The most effective technique is to lay the infant on his/her back, either on a bed or in your lap, and lift the chin slightly upward if possible. Use 2-4 sprays or drops of solution and then remove the solution with either a nasal bulb or sit the child upright and gently massage the solution out of the nostrils with a clean tissue. This process can be repeated as needed.

- **Nasal bulbs** – Although they work best when used in combination with a saline solution, regular gentle suction with a nasal bulb alone is also an effective and more convenient way to remove accumulating mucus before it becomes problematic.

- If your child continues to have difficulty breathing, begins
wheezing, starts having trouble feeding or develops a fever despite these interventions this may be a sign of another issue, such as a sinus infection. These symptoms should be evaluated by your child's physician.

The Ears

Insufficient moisture can also affect the ear canals and the middle ear (behind the eardrum). While small amounts of soft ear wax (“cerumen”) support healthy ear canals, infants and children with HED often have thickened cerumen that can clog the ear canal and interfere with hearing. Left untreated, clogged ear canals can cause speech delay. (See the section below: “Child Development and Other Information That Should be Shared with your Doctor”).

To help prevent cerumen accumulation, gently remove visible debris at the opening of the ear canal with a warm thin cloth or cotton ball. Avoid inserting cotton swabs or any other device into the ear canal. This can worsen the impaction or even damage the ear drum. Place a few drops of bland lubricant (e.g. plain mineral oil) into the ear canal to soften thickened cerumen and encourage easy removal. Large impactions should always be removed by health care professionals.

Impacted cerumen can also increase the risk of developing middle ear infections (otitis media). Infants and toddlers are especially prone to recurrent middle ear infections. Tugging at the ears, irritability, difficulty sleeping, and fever are all signs of a possible ear infection that should prompt in-office evaluation by your health care provider.

Airways

The body relies on adequate amounts of properly hydrated mucous in the airway to trap harmful allergens and germs. This natural first line of defense helps prevent infections and keeps us breathing comfortably. As such, children with HED who have poorly hydrated mucous have higher rates of respiratory infections as well as a higher likelihood of developing asthma or
allergic rhinitis (seasonal or perennial allergies) in the future. [7]

During infancy, upper respiratory infections may occur more frequently, but asthma and allergies are unusual. A cool-mist humidifier is once again a very effective tool to help keep the airways moistened and help reduce the risk of infections but always let their doctor know if signs of coughing, wheezing, difficulty breathing, or fever develop. Given their increased risk, it is important to keep up with routine, seasonal and special immunizations such as the COVID-19 vaccine. Lastly, it is important to know that smoking in the home also increases the risks of both respiratory infections in your child as well as future asthma development and therefore should be avoided.

DIFFICULTIES WITH FEEDING & WEIGHT GAIN

Height, weight and proportional growth (called “body mass index” or BMI) are important signs of childhood health. They are measured at regular intervals and recorded on pediatric growth curve graphs. Infants and children with HED usually have normal height growth, but tend to be thin. Suboptimal intake is the most important reason for disproportionately low weight gain. Some factors that can contribute to this poor intake including insufficient breastmilk (more common in women with HED), reduced infant saliva, and in older children, fewer teeth (hypodontia). Our recommendations for ensuring optimal weight gain despite these challenges are as follows:

Breastfeeding

The abnormal gene that causes the most common type of HED, x-linked hypohidrotic ectodermal dysplasia or XLHED, is located on the X chromosome. Therefore, it is more likely for males who have only one X chromosome to have symptoms. Females on the other hand, have two X chromosomes, so if only one X chromosome is abnormal, they can have a milder form of HED. [10]
Although many of the symptoms in females are often milder than their male counterparts, these women uniquely can experience changes to the breasts that include having flatter or inverted nipples, decreased breast tissue, fewer milk producing glands, and lower numbers of oil producing sebaceous glands. [11] These changes can interfere with an infant’s ability to “latch” and make breastfeeding more difficult. In some instances, these obstacles may prevent new mothers from breastfeeding entirely.

The benefits of breastfeeding for both a mother and her child, however, are substantial, and some of the benefits to the child including a bolstered immune system, a lower risk of developing allergies, eczema, and asthma, and healthier teeth help to directly combat many of the changes seen in HED. [12] Therefore, if possible, attempts to breastfeed are still highly recommended. If difficulties arise with breastfeeding, it is advisable to seek consultation with a lactation specialist.

Lactation specialists are often available through hospitals that deliver babies, and through pediatric offices. If breastfeeding is ultimately found to be too difficult or not possible then talking with your child’s doctor about switching to formula is a safe and perfectly healthy option to pursue. Some women with HED have reported that breastfeeding actually became easier with subsequent pregnancies and there is some scientific evidence to support this claim. [11] Thus, revisiting the possibility of breastfeeding could always be considered in the future if unsuccessful previously.

Lack of Teeth (Hypodontia)

Another defining characteristic of HED is a notable lack of baby (primary) and adult (permanent) teeth, or an absence of teeth all together (anodontia). In children with HED, the teeth that are most likely to be present are the child’s upper front teeth (central incisors), the upper canines (also called cuspid or eye teeth, that flank
the incisors), and a pair of “back teeth” or molars on the top and bottom of the jaw. [13]

These teeth however are often smaller than normal, are conical or peg shaped, and may be pitted or prone to breakdown due to a lack of protective enamel. [14] When your child’s teeth first erupt, it is common for them to erupt with this classic appearance already established. Although most unaffected children begin to develop teeth between six to eight months of age, tooth eruption is usually delayed in HED, often beyond 12-15 months. [15]

Despite the lack of teeth, early evaluation by a pediatric dentist during the first year of life is essential. Teeth are not only needed for eating and proper nutrition, but they also play vital roles in speech and language development and are even necessary for proper development of the face as a child grows.

We recommend that families establish care with a pediatric dentist as soon as a diagnosis of HED is made or be evaluated for the condition if teeth fail to form by one year of age. Although no major interventions are performed during infancy, the goal of these visits is to develop a future treatment plan to preserve these vital functions as much and as early as possible.
Reduced Saliva

In addition to aiding in the chewing and swallowing of food, saliva also helps to protect tooth enamel. Therefore, the decreased amount of saliva can increase the risk of tooth decay in children with HED. Fortunately, with regular dental care, this alone does not often present a significant detriment to the overall health of your child’s teeth. A more concerning matter for infants are the difficulties a reduced amount of saliva can cause with the processing of foods, which may require modifications to a child’s early diet as discussed below. Although there are medications that can be utilized to increase saliva production in adults, these interventions are not typically utilized for infants.

Introducing Solid Foods

Despite these obstacles to chewing and swallowing, it is still important to start the process of introducing solid foods when your child becomes of age. This is especially true as the nutritional content of breast milk and formula alone cannot provide all the nutrition that is necessary for healthy growth and development.

Most children are introduced to solid foods around four to six months of age. If possible, we recommend that parents of children with HED attempt to keep a similar timeline with the following additional guidelines:

- When introducing new foods, only introduce one new food at a time and wait three to five days in between foods to ensure there are no digestive issues or allergic reactions that arise.
• Early on, it is best to introduce softer foods with a higher moisture content such as yogurt, eggs, or blended fruits and vegetables. Traditional jars of baby foods would also fit this category.

• Dryer foods, such as cereals and grains, or foods that have a thicker consistency, such as peanut butter, should be softened or diluted with water prior to presenting them to the child as they can pose a greater risk for choking given the lack of saliva and teeth. Bear in mind that children’s digestive tracts have not fully matured enough to process milk before the age of 12 months so softening with water instead is important in this instance.

A note on food allergies: Children with HED have a higher rate of food allergies than the rest of the population as well.

Because of this, many parents believe they should avoid introducing highly allergenic foods such as eggs, milk, nuts, and wheat. However, newer data has shown that introducing these foods to children early on can actually help prevent the formation of food allergies later in life whereas avoiding them may increase the risk of developing food allergies. [16] As such, there may be a benefit for your child to introduce these foods by the age of six months. If your child has had an allergic reaction to food that is not typically highly allergenic, they should also be evaluated prior to reintroducing that particular item.

Encouragingly, in spite of these obstacles, most children with HED eventually reach an appropriate height and weight that is congruent with their family genetics by early adulthood. In the meantime, all these measures just discussed can help keep your child on track as much as possible and growing healthily during this important time.
An important consideration for all pediatricians is whether or not a child is meeting standard developmental milestones. That is, whether or not they are growing and developing normally. The skills tested in these assessments all fall into one of three categories, gross/fine motor skills, language acquisition, or cognitive development. Although children with HED do not experience many direct deficits in any of these developmental areas because of their condition, some symptoms, such as difficulties with hearing and vision, can cause a child to fall behind temporarily. Therefore, these issues should be monitored for and addressed as soon as they arise.

Hearing Loss

In HED, the loss of hearing can be attributable to many factors including accumulations of impacted earwax, repeat ear infections, and some children are born with an intrinsically reduced capacity for hearing sounds in general, unrelated to the first two mentioned complications. If these issues are left unattended, or allowed to occur frequently, they can contribute to a delay in language acquisition over time. As a matter of fact, up to 50% of children with HED report difficulty hearing and up to a third will have an abnormal hearing exam at some point during childhood. [17]

Given that language development typically begins early in life, with an infant’s first coos at the age of two months, parents should be cognizant of clues that their child may not be hearing appropriately and share their suspected concerns with their doctor. Failing to react to noises at two months, neglecting to turn to your voice by four months, and not responding to their name by six months are a few early signs many physicians will
use to indicate that hearing may be impaired at a young age. These same observations can easily be made by parents in a home environment and shared if those concerns arise.

**Difficulties with Vision**

Vision is another necessity for the development of motor skills. Children with HED may have difficulties with vision related to an inability to produce the same amount of tears as other children. This is due to underdevelopment of the glands that produce them (lacrimal glands) which can lead to dry irritated eyes, eyes that are more prone to being scratched, and sensitivity to light. Although these issues do not often significantly impair vision, they are still a cause for concern in a developing infant. Artificial tears are often employed for children having these difficulties and consultation with a pediatric eye doctor (ophthalmologist) is recommended for persistent symptoms.

Some forms of HED are also known to be associated a cloudiness of the eyes (corneal opacities) or the lens of the eye (cataracts) that can impair vision as well. [7] Although less common, the presence of these conditions should be evaluated for by your child’s physician and referred to a pediatric ophthalmologist for treatment if discovered.
CONCLUSION

Being a new parent is never an easy task and dealing with the uncertainties of a rare genetic condition can certainly add to the already heavy demands on a new family. However, the most important thing to remember is that you are not in this alone! Most children with HED are able to live full, happy and healthy lives despite the extra challenges they face. All of us at the NFED are here to support you and your family through this journey and we gladly welcome any and all questions or concerns you many have now or at any point in time.
Sources

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