# Treatment Guide for Skin Issues in Ectodermal Dysplasias

The following are suggestions to prevent or minimize discomfort and self-consciousness associated with some of the common skin issues in ectodermal dysplasias.

# Diaper Rash

If redness and scaling are mild, treatment can consist of changing diapers frequently and applying a protective barrier of fragrance-free zinc oxide ointment after each diaper change. Avoid using commercial diaper wipes on the rash; substitute a soft cloth or cotton balls moistened with water or mineral oil.

Over-the-counter hydrocortisone ointment may be applied to irritated areas, but should not be used more than once a day or for longer than one week. If the rash is painful or does not improve within a week, consult a physician.

#### Seborrhea

Scales caused by seborrhea or "cradle cap" may be gently removed using a medicated shampoo containing tea tree oil, tar, salicylic acid, zinc pyrithione or selenium sulfide (Sebulex or Selsun Blue, for example). Be sure to keep these products away from the eyes to avoid stinging. If shampooing alone is ineffective, a 30-minute application of coconut or mineral oil before shampooing may help. Baker P and S, a mineral oil product containing phenol, may sometimes help to loosen scale. If these measures are unsuccessful, consult a physician.

#### Skin Darkening

Specially formulated waterproof camouflage makeup like Covermark, Dermablend, and Dermasque can help cover skin discoloration around the eyes if it is bothersome.

#### Dry Skin

Certain precautions will help promote and retain skin surface moisture to maintain skin health. Daily or every other day bathing will help moisten the skin to prevent overgrowth of germs. Cleansing products should be used sparingly and limited to areas that need cleaning (e.g., diaper area and skin folds). Gentle products include superfatted bar soaps such as Basis, Dove, Oilatum, or liquid cleansers such as Aguunil or Cetaphil Gentle Cleansing Lotion or Neutrogena Non Drying Lotion.

Immediately after bathing, gently pat the skin and cover with a moisturizer. In general, an ointment is more effective and more soothing than a cream and a cream more effective and soothing than a lotion. However, children affected by ectodermal dysplasias may not tolerate ointments and prefer less occlusive creams or lotions, especially during summer months.

Swimming is an ideal activity for people with ectodermal dysplasias that include hypohidrosis because cool water reduces the body heat produced by exercise. Care must be taken, however, to prevent skin drying. If this proves to be a problem, apply a moisturizer and a waterproof sunscreen before swimming, and reapply moisturizer while the skin is still wet.

Avoid heavily fragranced or colored moisturizers. The safest and most effective moisturizers are plain petroleum jelly (Vaseline) or mineral oil. Other moisturizers that work well for some individuals are Aqua Glycolic Hand and Body Lotion, Aquaphor, Cetaphil, Complex 15, Curel, Eucerin, Fougera Hydrophilic Ointment, Lubriderm, Nutraderm and Purpose.

#### Eczema

Mild eczema may improve with the treatments for dry skin, discussed above. Bleach baths are also helpful. (Add 1 tablespoon household bleach to a baby bath, or 1/4th cup to a big tub.) Overthe-counter hydrocortisone preparations can also soothe red, itchy skin. Hydrocortisone ointment is



generally more effective than cream. This medication is effectively and most safely used no more than once a day. An antihistamine taken by mouth (e.g. Benadryl) may help children sleep.

If eczema cannot be controlled with these measures, or if the condition worsens, consult a physician. People with eczema may be more susceptible to developing skin infections. The appearance of tender blisters or pus bumps are signs of skin infection that may require treatment by a physician.

## Skin Infections and Skin Erosions

If the scalp, hands or feet have skin erosions in which the skin is red, weepy, crusty and swollen, this eruption requires care by a physician in order to relieve discomfort, prevent secondary infection and minimize scarring. We also have a library article addressing the skin care recommendations for these skin erosions.

### **Enlarged Facial Oil Glands**

These are enlarged oil ("sebaceous") glands that can be difficult to treat. People who are bothered by these bumps can try using a retinoic acid cream (prescription Retin-A). For best results, this medication must be applied every day for a minimum of several weeks. The bumps will gradually reoccur if the medication is stopped.

# Sun Safety

Medical experts continue to warn everyone about the dangers of extended sun exposure and the need to use sunscreen. Protect infants under the age of six months with clothing. Skin care in older children and adults should include application of sunscreen with outdoor activities. Generally, sunscreens with a moisturizing cream or lotion base are better tolerated than those with alcohol based gels or sprays.

The most effective products are labeled "highly water-resistant" and provide "broad spectrum" including UVA and UVB as well as an SPF of at least 30, and UVA and UVB protection. Look for zinc oxide or titanium dioxide as the active ingredient.

Reapply the sunscreen every two hours after swimming or if exposure is for prolonged periods. Consider these examples of sunscreens: Banana Boat Kids Sunblock Spray Lotion SPF 48, BlueLizard Baby, Elta Block, Neutrogena UVA/UVB Sunblock Lotion and Ombrelle Sunscreen Lotion Extreme.

# Special Note About Possible Sensitivity To Products

Before applying any new product to the face or to large areas of the body, individuals should test that product for possible irritation or allergic reaction. Apply the new product to a quarter-sized area (for example, inside the upper arm) once a day for five days, then check the area after one week and two weeks. If no irritation, redness, or swelling occurs, the product may be used elsewhere on the body. If a rash occurs, avoid the product. You may apply plain petroleum jelly to promote healing. If the rash is painful, blistered or persists for more than a week, consult a physician.

### Special Note

Information on treatment in this article is given as a guide to what might be expected or recommended by physicians who are consulted by our families. It is important for you to understand that the statements are generalizations about a large number of the ectodermal dysplasias, and no absolute recommendations are made or implied. Trust the physicians whom you consult to do the right things, but also be an advocate for yourself or your child. The mention of any "brand name" drug in this booklet is presented as an example only and must not be interpreted as endorsement of a specific product or brand by the National Foundation for Ectodermal Dysplasias or its Scientific Advisory Council.

Visit our Library at www.NFED.org to find more detailed information about skin issues in the ectodermal dysplasias and their treatment.