More symptoms begin to manifest



...After Diagnosis...

Pregnancy

Ectodermal Dysplasia

PATIENT JOURNEY

...Birth and Diagnosis...

2

1. Pregnancy	2. Birth and Diagnosis		
		Symptoms	Treatments
Generally normal pregnancy		Peeling skin	Normal treatment
		Lack of temperature control	If in incubator keep temperature cool than usual. Do not over dress
		Difficulty feeding	See Patient Needs below
		Difficulty breathing	Use suction machine and saline drops
		Blocked nasal passages	Use suction machine and saline drops

Familiv needs If ED is in the family, information

1.

regarding neonates to be provided Ideal support

- No complications during pregnancy
- Good/healthy prognosis for child after birth.

Familiy needs

• Contact with patient support group

• Access to appropriate, reliable and understandable information on ED and support

Ideal support

- The right medical diagnosis at once and guickly
- Timely access to the right expertise centre and medical specialists
- Central patient health record containing all data from all involved health care providers. This environment is under control of the patient and/or parent(s)

3. After Diagnosis

Symptoms

Overheating; Hypothermia; Absent or sparse hair; Absent and/or misshapen teeth; Dry skin; Eczema; Asthma; Ear problems; Dry eyes; Missing tear ducts; Nasal congestion

3

Treatments

Keep nose clear, inhalers, antibiotics, humidifier Impacted wax removal via micro-suction – do not syringe Artificial eye drops Seek Ophthalmologist treatment Saline water drops or spray

Patient needs

- Medically under-standing the symptoms. School Care Plan to maximise education
- Day to day management of the symptoms. How to deal with this?
- An understanding doctor who understands about ED.
- Referrals to the necessary medical specialists.

Ideal support

- •Knowing where to get the right medical treatment. Support organisation can help
- Having contact with other patients and families who have experienced something similar via social media or Support organisation family events.
- Not being bullied. Living life to the fullest.
- Having all medical data in one place under control of the patient and/or parents.
- Minimum/no impact on other family members esp. siblings.
- Balance at home between care and daily life.

This patient journey represents the collective patients perspective and experience and was prepared by the ERN SKIN ED ePAG representative from UK with the

For more information, please contact us: coordination@ern-skin.eu