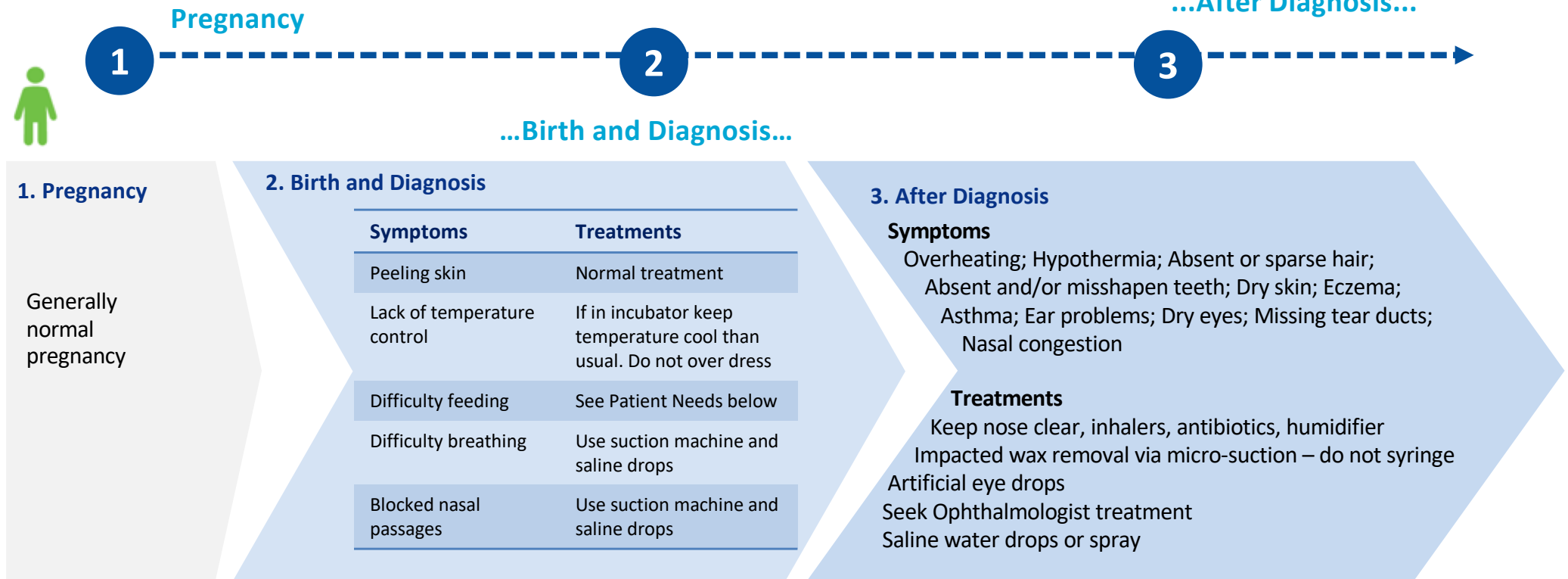


Ectodermal Dysplasia PATIENT JOURNEY



Family needs

If ED is in the family, information regarding neonates to be provided

Ideal support

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

Family 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 quickly
- 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)

Patient needs

- Medically understanding 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 help of the Austrian patient groups and in collaboration with the ERN SKIN ED doctors.

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