



#### How to support families

With a visible rare skin condition

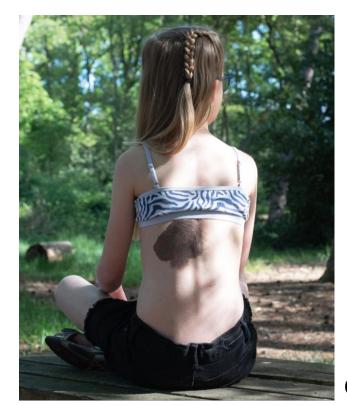
Marjolein van Kessel September 7<sup>th</sup>, 2022 Global Skin pitch















#### Patient journey: inventory of the burdens

- Birth
- Diagnosis
- Treatment (removal)
- Daily life
- Additional symptoms: neurological problems and melanoma
- Palliative care













Dealing with visible difference





### Birth and diagnosis

A booklet with patient stories: Patient Journey Congenital Melanocytic Naevus Syndrome (Spanish and English)

**PATIENT JOURNEY** CONGENITAL MELANOCYTIC NAEVUS SYNDROME

DEL PACIENTE SINDROME DE NEVUS CONGENITO MELANOCÍTICO

EL VIAJE















#### Birth, diagnosis and daily life

Caring Matters Now patient support guides translated and published in 6 languages (English, Dutch, French, Italian, Portuguese, German, Spanish).

**PARENTS** SUPPORT **GUIDE** 









CARING FOR A CHILD WITH A RARE CONDITION

**PARENTS** SUPPORT GUIDE







CARING FOR A CHILD WITH A RARE CONDITION

**PARENTS** SUPPORT **GUIDE** 







CARING FOR A CHILD WITH A RARE CONDITION











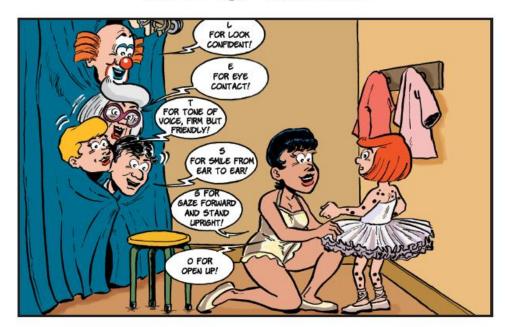




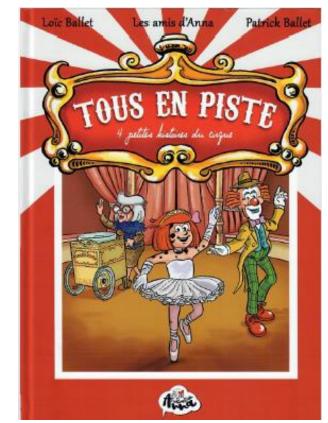
# Daily life

Association Anna (France) comic book 'Tous en Piste' psycho-therapeutic comic book translated in English, Danish, German, Dutch,...

#### ANNA'S TIPS & TRICKS











## Thank you





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