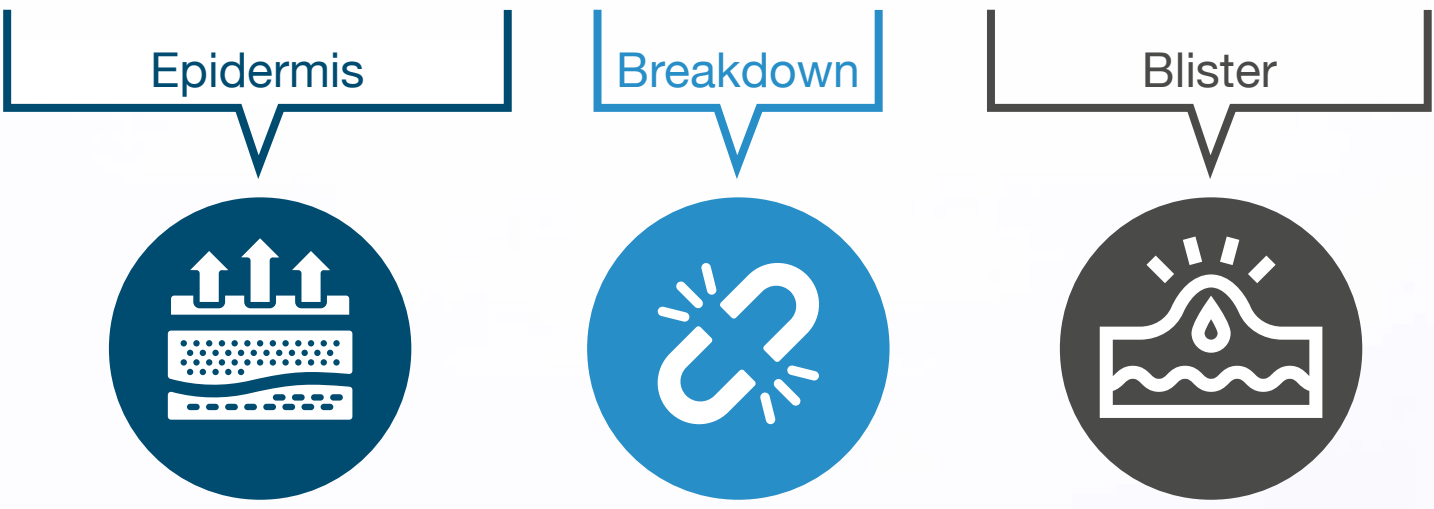


WHAT IS EB?

epidermolysis bullosa



Symptoms can be seen immediately after birth/during first few days

Their common feature is the formation of blisters and extremely fragile skin

Blisters can form anywhere on the skin and sometimes inside of mucous membranes

Symptoms can range from mild to severe

Blisters and wounds can occur from pressure, friction, or heat on the skin and/or mucous membranes

500,000 estimated people with EB in the world

Affects males and females equally

Can occur across all races and ethnicities

Not contagious

There is no cure yet

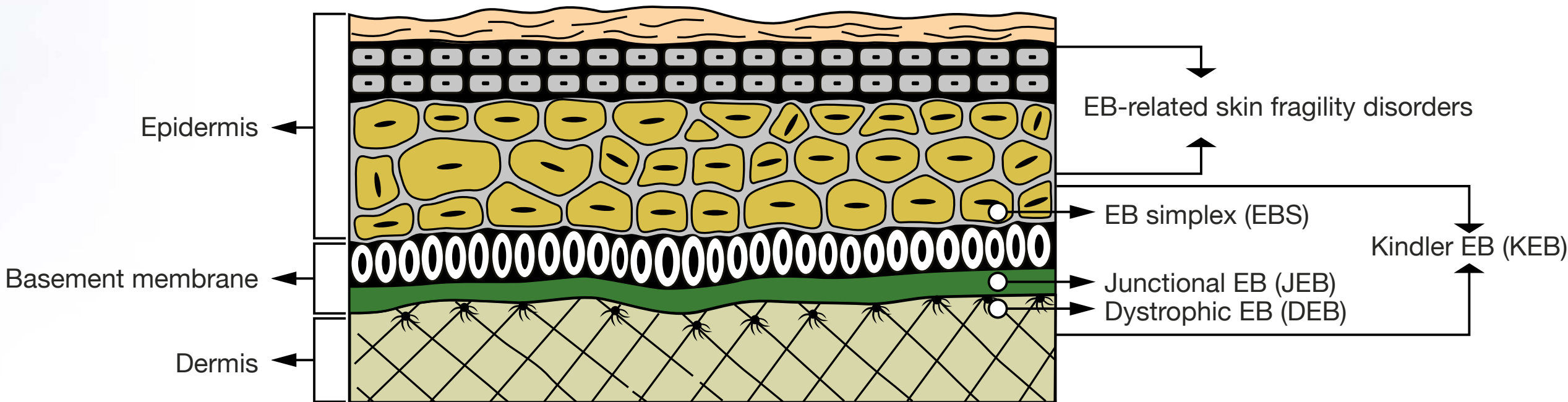
There are more than 30 subtypes

EB is not the name for a single skin disease, but a large group of clinically and genetically different diseases

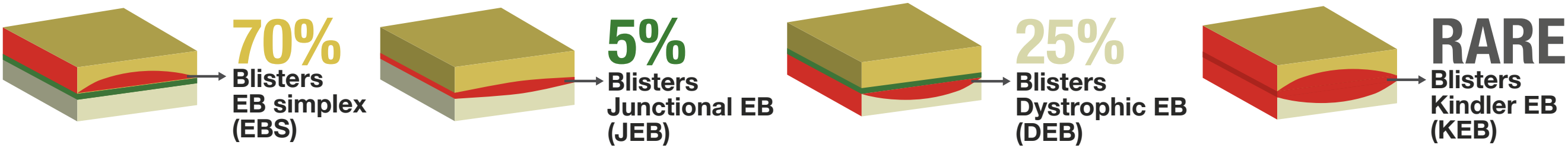
People living with EB are known as "butterflies" as their skin is as fragile as a butterfly's wings

TYPES OF EB

CROSS-SECTION DIAGRAM OF THE SKIN



DEBRA International - adapted from Debra of America, the US National Institute of Arthritis and Musculoskeletal and Skin Disease and Has et al. 2020



NEWBORN WITH EB

A dermatologist should rule out other skin disorders and an integrated care plan should be coordinated by an interdisciplinary team

Skin may be absent entirely, particularly on the feet, ankles, and lower legs

Skin may blister immediately after birth/during first few days

Avoid using an incubator (unless absolutely necessary)

Do not use tape or plasters/bandaids

Not lifting from under the arms

Do not put name tags on wrists or ankles. Attach to bed/clothes instead

Do not use umbilical clamps

Breastfeeding is possible with a baby with EB and should be tried

See Healthy Body and Skin infographics on our website for information on wound care

SYMPTOMS AND COMPLICATIONS

Symptoms may vary from mild to severe depending on the type of EB

Blisters inside the mouth and difficulty swallowing

Narrowing of the oesophagus and airways

Contracture of the mouth and reduced movement of the tongue

Fragile skin that blisters and tears easily

Skin cancer

Itching

Harmless skin spots and colour changes

Infection/non-healing wounds

Constipation

Anaemia

Fusion of the fingers and toes

Pain

Thinning hair/hair loss

Heart involvement

Eyes affected by blistering

Growth delay/delayed puberty

Hoarseness, high-pitched wheezing

Dental enamel affected, overcrowding and malalignment of teeth, and tooth decay

Thickening of the palms of the hands and soles of the feet

Contractures (joints that cannot be straightened)

Weak bones and spinal fractures

Nail loss or nails that are thick and change shape/colour

Stress and depression

Renal involvement



DEBRA International: www.debra-international.org EB Without Borders: ebwb@debra-international.org

This information comes from the DEBRA International *What is EB?* EB infographics booklet. Scan the QR-code to download the complete booklet or access it on the website: www.debra-international.org/what-is-eb

