

**Debra
the Zebra's
Birthday Party**



How this book came about

This book was inspired by a boy called Shane whose brother Anthony was born with epidermolysis bullosa (EB). Shane wanted to understand why his brother needed to be treated gently and needed so much attention.

Inspiration for the Debra the Zebra character came from a crocheted Zebra that had been made for a window display in a DEBRA charity shop. This sparked the idea to create a story book featuring Debra the Zebra as the lead character who plans an adventure themed birthday party and in doing so talks about some of the challenges of living with EB.

Workshops were held with DEBRA members with lived experience of EB, DEBRA staff, and EB specialist clinicians. Their input and ideas helped shape the Debra the Zebra story. This story is about friendship, finding solutions, and playing to your strengths even if you live with a medical condition like EB and some aspects of day-to-day life are challenging.

We hope you enjoy reading it and find it a useful resource to help young children, schools and extended family better understand EB.

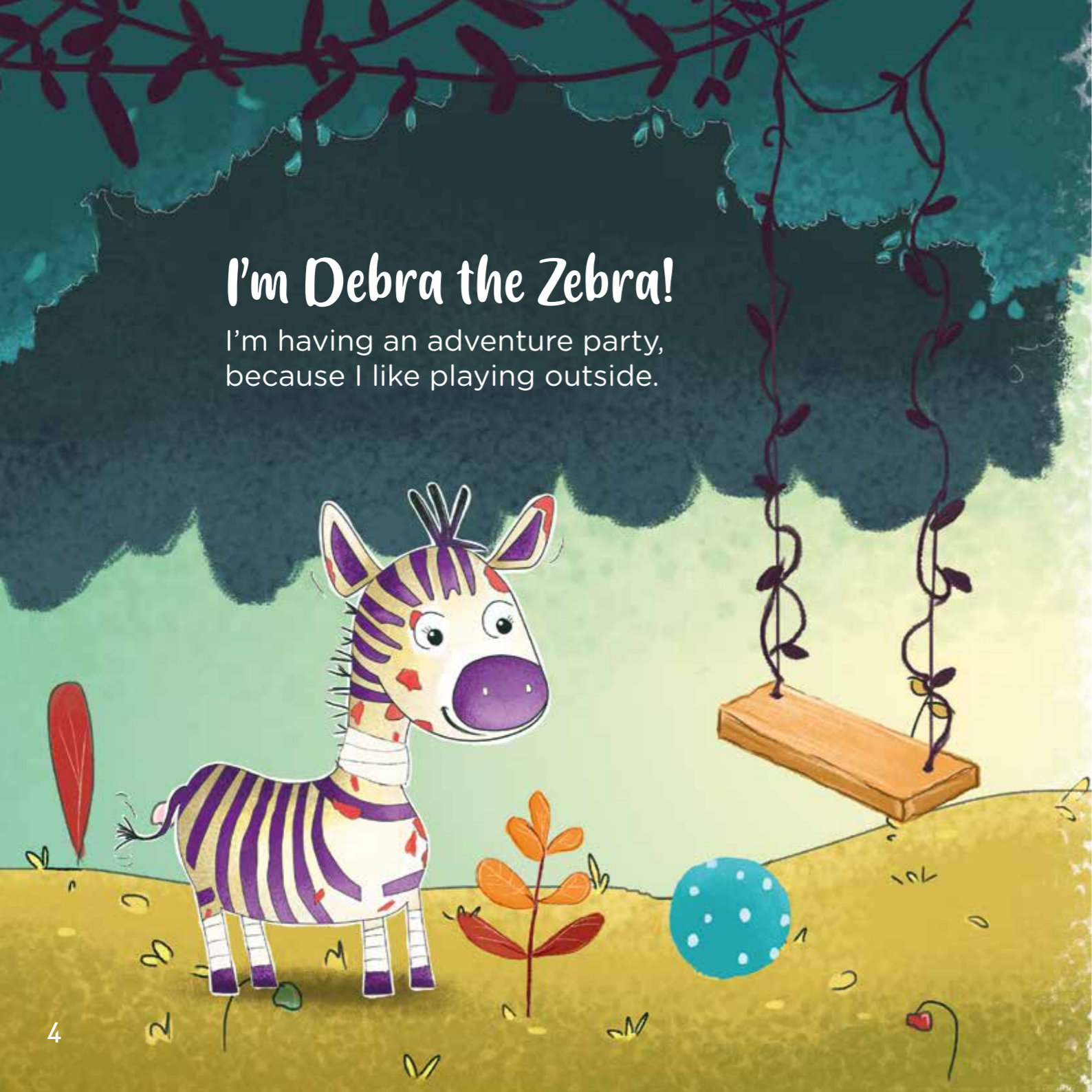
Debra the Zebra's Birthday Party



I hope you enjoy my story!

I'm Debra the Zebra!

I'm having an adventure party,
because I like playing outside.



I also love to sing and make up rap songs.

My mum and dad are being very careful when planning my party.



Soft cushions

Soft food



I have epidermolysis bullosa, you see.

I was born with it, but you can't catch it from me. It's hard to say, so everyone calls it EB for short, or butterfly skin because my skin is really fragile like a butterfly's wing.



What is EB?

My skin blisters super quickly and can tear at the slightest touch.



My skin gets sore and itchy.

Some parts of me have no skin. This really hurts.



I go to a hospital that help people with EB.



Special dressings help to protect and the EB team help me so I can do the things I want to do like my...



I've invited
ZOOZU the Giraffe

and

Jango
the Rhino
from school



Zoozu

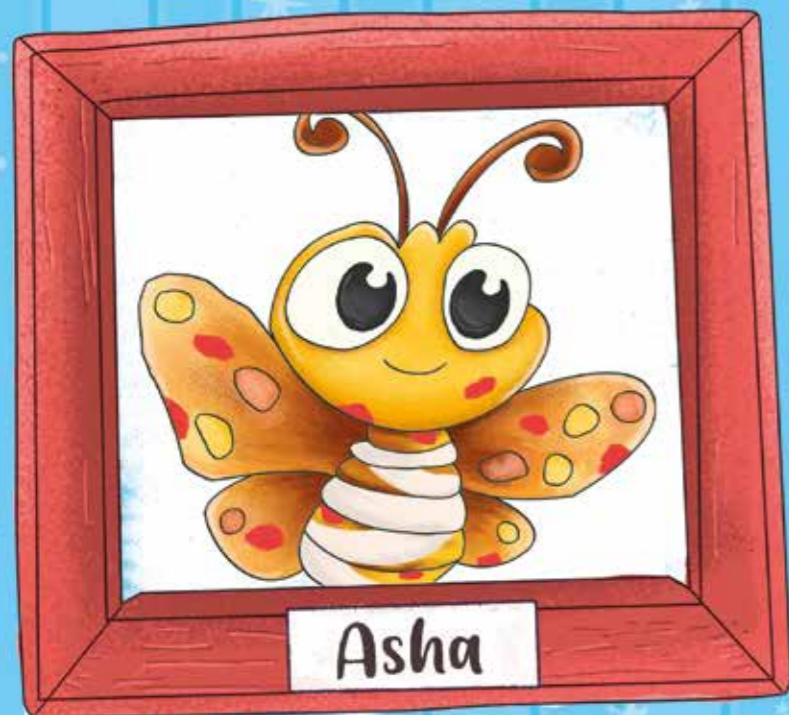
Is in the cheerleading squad.
She is really kind.



Jango

Is in the same jazz band as me! He is very noisy
even when not playing the drums.





I also invited
Asha the butterfly.

We met at DEBRA's
Members' Weekend.

DEBRA is a charity
for people with EB.

debra
THE BUTTERFLY SKIN CHARITY

It was a fun day...

We had horse and cart rides.
Asha is my first friend with EB.
It's nice that Asha knows how I feel.



At school

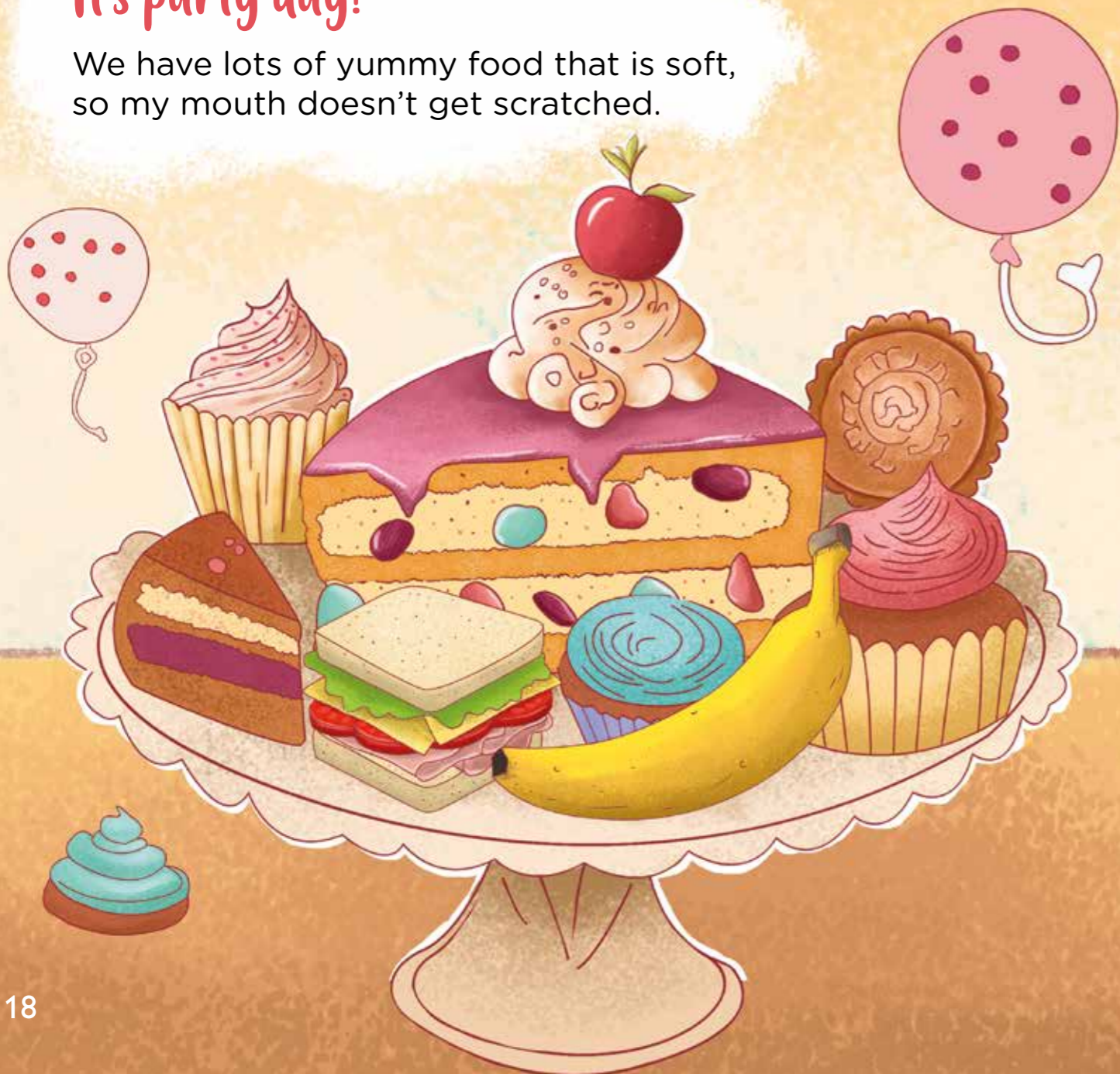


I walk behind Django and Zoozu.

So people don't bump into me.

It's party day!

We have lots of yummy food that is soft,
so my mouth doesn't get scratched.



We put up a tent in case it's too hot or rains.



Yippee!

My friends have arrived!



Yeey!

**Let the fun
begin!**

Yippee!

Yahoo!

We play party games

My favourite is sleeping explorers.



Rules of the game

1. Everyone lies down, but keeps their eyes open.
2. Pretend bugs and butterflies are then put on all of us.
3. The last one to move wins.

Why not play at home?

We also play Adventure Golf in the garden.

It was so much fun and Jango won!



And we have fun playing...

Pin the tail on Andy the aardvark and musical statues.



We also did some drawings for the doctors and nurses at my hospital.

A big thank you to the members of the EB community who kindly provided the below illustrations.



Now, it's time for tea.

Everyone sings happy birthday and I perform a rap. You can join in too!

Happy birthday...



Rap

I'm D to the Z,
Here's my friend Asha B
We live with a skin thing called EB
You can't catch it,
But we got to patch it
It doesn't define Asha or me.

Chorus

We love our family
We go to friends for tea
We have our holidays by the sea
EB is not always easy
But it's a part of me.



A big thank you to everyone who contributed to the creation of this book

This project would not have been possible without the help of the following people:

Karen Cutte

Who created and crocheted the original Debra the Zebra which was the inspiration for the lead character featured in this book.

EB community

The DEBRA members who attended workshops at member's events and made suggestions, drew pictures, and voted for the names of characters. The EB specialist consultants, psychologists and nurses, and the DEBRA staff who reviewed the book and gave their expert opinion and suggestions.

The British Association of Dermatologists (BAD)

Who made a financial contribution towards the development of this book.

About EB

Epidermolysis bullosa (EB) is an incredibly painful genetic skin blistering condition. It causes the skin to blister and tear at the slightest touch. With skin as fragile as butterfly's wings, it is often referred to as 'butterfly skin'.

EB can affect the hands and feet only or in the most severe cases any part of the body, including blistering on the eyes and internal organs.





About DEBRA

DEBRA is the national charity and patient support organisation for people living with or directly impacted by EB.

The DEBRA community support team works with the EB community, healthcare, and other professionals to improve quality of life for people living with EB. They offer support, advocacy, information, and practical help at every stage of life. The free DEBRA membership scheme includes holiday home respite, grants, and bespoke events to support people living with EB.

For more information, please email
membership@debra.org.uk
or ring 01344 771961

www.debra.org.uk

