

**SIGN UP YOUR SCHOOL FOR A FUN AND SIMPLE
FUNDRAISER THAT TEACHES PUPILS ABOUT
DIFFERENCE AND HELPS UK CHILDREN IN PAIN**

#EBpop

PLAY TO MAKE THE BLISTERS STOP



This is Poppy

Poppy is a beautiful, bright five-year-old girl who attends primary school and loves dancing. But Poppy will never dance bare foot because even the slightest knock or rub to her skin can cause damage. Poppy has the rare condition Epidermolysis Bullosa (EB) which stops delicate and damaged skin repairing itself. Children with EB have to wear bandages on their feet, legs and arms every single day.

Poppy was born with no skin on her left leg. For the first four months of life she was so fragile she was carried on a pillow. Twice a day mum, Kate, has to pop painful blisters all over Poppy's body. Poppy has daily pain medication. She has special shoes to cushion her feet and pureed food because the skin in her mouth and throat is too delicate for her to chew and swallow.

There are 5,000 children in the UK with EB. At Cure EB we are tantalisingly close to a breakthrough in medical research to help these young people live normal lives.

Research costs money. We are asking your school to take part in #EBpop! to make the blisters stop. Pupils can raise funds just by popping water balloons.

WHY SHOULD YOUR SCHOOL TAKE PART?

- *Because EB is one of the most cruel conditions affecting children.
- *Because young people's lives are shortened by this disorder.
- *Because participating gives unaffected pupils an understanding of what other children tolerate.
- *Because water balloons resemble the fluid-filled blisters on EB skin.
- *Because we are in a race against time to find a cure but we are close.

FOUR WAYS TO RAISE MONEY

Go to our website to register for a free starter pack of balloons. Then...

1. I'M A TEACHER GET ME OUT OF HERE

How brave are your staff? Could they submit to a soaking from students? Get them to sit or stand and see how many water balloons staff can take before yelling the famous catchphrase. Charge for balloons.



2. WATER FIIIIIGHT!!!!

Set up a stall, perhaps at the school fair or on the last day of term, use recycled hand wash pumps to fill water balloons, charge a pound or less for each balloon and let the chaos begin.

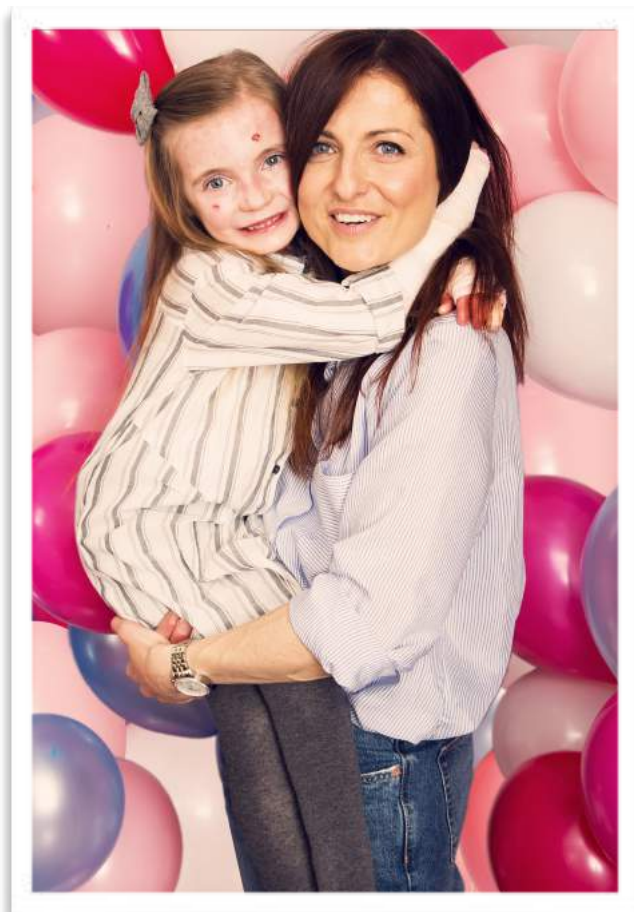
3. BOUNCE, BOUNCE, SPLAT

Fill large balloons with water and hold a sports day race to see how far each contestant gets before their balloon bursts and they get soaked.

4. SPREAD THE WORD

Add this flyer to your weekly newsletter to ask families to film themselves having water balloon fight, then post the film on social media to raise awareness of EB. Use the hashtag #EBpop.

We are very proud that 100 per cent of the money raised will go to funding research into a cure for EB.



Poppy with her mum, Kate



To pay in money:
Send a cheque made out to Cure
EB, to: Cure EB, 10 Huntingdon
Street, London N1 1BU
or donate at:
www.justgiving.com/cure-eb



About us:

Cure EB was set up as the Sohana Research Fund in 2011 by the parents of Sohana, a young child with a severe form of Epidermolysis Bullosa (EB).

With the change of name, Cure EB will fund research into a cure for all types of EB.

When Sohana was born in 2002, there was very little prospect of an effective treatment let alone cure, but breakthroughs in research underpin the significant hope that this is no longer the case.

Professor John McGrath, of King's College, London, says: "Cure EB is funding innovative, exciting research aimed at correcting the genetic defects in EB. Research supported by Cure EB is accelerating progress towards better treatments for everyone with EB."

It is critical that funding is achieved for key projects that will harness this research optimism. Delays in funding the research, will delay results and compound the suffering of all children alive with the condition today. EB is considered a rare condition and as such does not attract government funding. This means that all research is private donor and private company led.

With the real hope of safe, effective treatments and possibly a cure within sight, it would be travesty not to be able to undertake the research necessary.

Children with burns would not and should not be ignored. Nor should those who suffer EB.

This is a chance to make a difference to an incredibly painful, disfiguring and ultimately fatal condition.

Sohana's mum, Sharmila, Chief Executive of Cure EB says: 'As parents it is difficult to smile and remain positive whilst inside we are screaming for help for our child and others like her. Those who have so much to give but who are limited, so ruthlessly by their faulty skin. Medical Miracles happen but they need help to happen in the form of dedicated funding'.



Rupert Grint, Sohana and David Beckham on the night she won a Pride Of Britain award



For more information about EB, our research initiatives and school-friendly infographics call 07786 805874 or go to:

WWW.CURE-EB.ORG



Our You Tube channel gives examples of children spreading awareness by #EBPOP-ing:
https://www.youtube.com/playlist?list=PLR9Hx7L6UKu_hwG38TINu-ukHfYENdGVm