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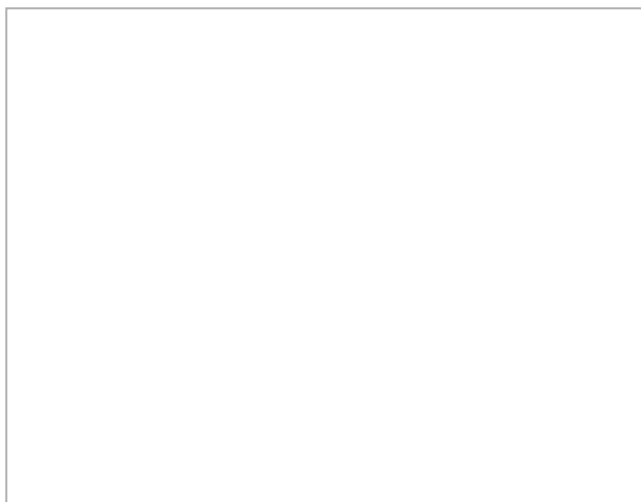
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# DESPERATE PLEA Our son and daughter BOTH have terminal disease that's robbing them of their ability to talk, walk, eat and see

Julia Etherington

13 Sep 2020, 8:50

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**PARENTS of two terminally ill children are in a desperate race against time to raise £250,000 to save their daughter's sight, after trials in dogs proved successful.**

Lucy and Mike Carroll's daughter Amelia, seven, has Batten disease, and is likely to go blind in the very near future.





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**Amelia, pictured above holding baby sister Renesmee, is set to lose her eye sight** Credit: Supplied

But after a pharmaceutical company tested its existing enzyme therapy drug, by injecting it into the eyes of Dachshunds, they are determined to raise enough



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see by the time the enzyme therapy drug proven to slow the progress became available three years ago.

These infusions have stopped Ollie's seizures.

Amelia started the drug young enough for it to delay most of the symptoms and is four years seizure-free.

But because it does not penetrate the blood-brain barrier it does not save vision, unless injected directly into the eye.

Mum Lucy says: "Ollie was seven when he went blind and Amelia is seven now, so we don't have time on our side.

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**The Carroll Family - left to right - dad Mike, son Micky, 12, mum Lucy, son Danny, 13, Ollie and Amelia** Credit: Supplied



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clinical trial, it's just the cost that's standing in our way."

Three-time kickboxing champion Carl Thomas, who raises money for different charities by taking on extreme challenges, has agreed to run a marathon towing a plane to help raise the funds.

On his [JustGiving](#) page Lucy has written: "Imagine once being able to see the world but slowly that sight was ripped away from you plunging you into total darkness.

"Imagine the fear and confusion you would feel not understanding what was happening, being powerless to stop the darkness from creeping in.

"Now imagine being only seven years old and this happening, imagine no longer being able to see your toys, your friends or the faces of your mummy and daddy."

## What is Batten disease?

**Batten disease is a rare life-limiting neuro-degenerative disease that affects children.**

Just five or six children are diagnosed with the form Ollie has each year in the UK.

Sufferers are born apparently healthy before developing seizures and dementia.

They lose their vision and the ability to walk, talk and eat, becoming wholly dependent on their



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can mean loss of jobs, financial hardship and poor health for carers, physically and mentally.

Lucy says after watching Ollie go through that and being powerless to stop it, they are determined to do everything in their power to prevent Amelia suffering the same fate.

American drug giant BioMarin which makes the enzyme therapy drug, has completed a trial on Dachsunds with CLN2 and found by injecting Brineura (cerliponase alfa) directly into the eye it does save vision.

Doctor's at GOSH (Great Ormond Street) ophthalmology department are ready to perform the op, as part of a clinical trial, but the NHS won't fund it.

Lucy says: "We need to raise around £250,000 to save the sight of children in England with Batten, although we don't know how many exactly.

"The cost would cover the drug itself, operating theatre, general anaesthetic and hospital beds. We just hope we can raise it quickly enough and that people can offer some support in fundraising, either by donating or even holding their own events.



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**The Carroll children - top row Micky, 12, and Danny, 13, holding Renesmee, front row Ollie and Amelia** Credit: Supplied

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“We haven’t been able to run our usual fundraising events because of lockdown.”

Ollie was diagnosed with Batten in 2014 after suffering seizures. A month later Amelia was also diagnosed.

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from Biomarin on compassionate grounds, campaigned tirelessly alongside the Batten Disease Association, and triumphed by getting the High Court to force a U-turn so the NHS would fund the treatment.

**The awards bash where Ollie met Harry was hosted by charity WellChild**

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marathon for 26.2 miles, which he hopes will raise enough money to save the sight of children like Amelia and set a new world record.

The 24-hour event will take place at Elvington airfield, York, on September 16 and will be streamed live on social media channels.

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Heartwarming video of terminally ill six-year-old Ollie Carroll enjoying Ed Sheeran's song Perfect so much it brings him to tears

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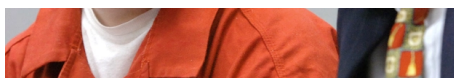
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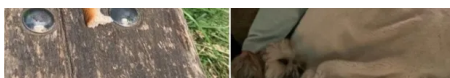
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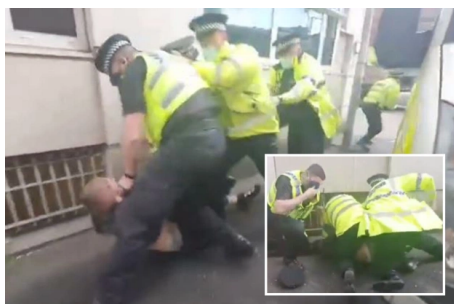
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