

MAKING A DIFFERENCE

IN LOVE

WITH LUCY

From her home on a farm in Northern Ireland, broadcaster Helen Mark tells us about her life



Like any child at Christmas, five-year-old Lucy Gallagher was excited about opening her presents. But last year, as her mum Carleen explained, the pain in her hands was so severe she couldn't even touch the wrapping paper.

It was one of the many occasions Lucy was battling a serious infection caused by a rare genetic skin disorder called Harlequin Ichthyosis.

Lucy is the only person in Ireland with this condition and I've been involved in making two films about her and her family for RTE's Nationwide programme.

Lucy's body produces up to 14 times more skin every day than normal. This forms thick plates of hard skin over her face and body, almost like a coat of armour. They restrict movement, breathing and eating and distort facial features. The fissures between the plates can tear the skin below, leading to life-threatening infections. Lucy's condition is painful, her eyesight is impaired and she's endured multiple operations.

The family live in the village of Maghrey, on the west coast of Donegal. We made our first film with them in January, 2014, when Lucy was a baby. She'd spent most of that first year in intensive care in Dublin and her amazing mum and dad, Carleen and Gary, were getting to grips with the 24-hour intensive care regime... bathing to soften and scrape off what looked like

Lucy with star Daniel O'Donnell at school, and (right) brother Harry



large pieces of uncooked pasta, creaming, bandaging, treating infections, peeling skin from her ears so she could hear, and peg feeding to mention a few things... then repeating it all every 3 hours.

Despite all this going on

around Lucy, the film captured a twinkle in her eye that showed a real spirit and zest for life. It was an image that will stay with me always.

That they welcomed us into their home was a brave step as Lucy was so vulnerable to infection, but they wanted people to meet her. Not least because their local community and school were working hard to fundraise for the family. We filmed some of that, including how they got locally-based superstar singer Daniel

O'Donnell involved.

We returned in September of this year and my first glimpse of Lucy was her skipping through the local primary school playground.

I could hardly believe what I was seeing, although I

instantly recognised that twinkle in her eye!

Attending her local primary rather than a specialist school far away is thanks to the determination of the Principal and her team who encouraged the education board to make considerable alterations so it was safe and accessible for Lucy. They employed two special needs assistants and built a special room where she could continue her treatment routine. Hygiene rules were adopted by all pupils and staff

(there are far few coughs and colds, it seems). There is a rice pit – as sand would be abrasive on Lucy's skin – and as her morning treatments at home mean she can't get to school before 9.30, they don't ring the bell until she's there so she doesn't feel she's always late.

To see her happy and confident despite pain and difficulties is inspirational. She is truly special, as are her mum and dad – she couldn't have hoped for more loving parents. I was so saddened to hear of the loss, at a few days old, of their twin boys in 2017, but now sitting on Lucy's lap was her year-old brother Harry.

They still face many challenges but with all the love, care and support in their family and from the local community, and of course that marvellous spirit of Lucy's, the future is full of promise... and no doubt on Christmas Day, lots of presents.