Writing for rare diseases - Why we need a RARE Disease REVOLUTION

Rebecca Stewart
The Prognosis...

Damaging headlines

The right language

Accuracy

Responsibility

Beyond human interest stories
Horror Ordeal PANDAS throat infection left Dumfries schoolboy, 10, ‘possessed’, laughing manically and holding a knife to his throat.

AN EARLY GRAVE Obese lad who constantly devoured toilet paper and dirt due to rare eating condition dies aged just 11.

Existence of horrific disease in Kachchi a serious blow on face of humanity in 21st century.

New report reveals that, while undiagnosed, rare disease patients have cost the NHS in excess of £3.4 billion.

E = MC2 HAIRIED Frizzy-haired girl, 6, has same rare condition which gave Albert Einstein his trademark look.

The Girl of 12 Who Can’t Stop Eating.

LIFESTYLE, HEALTH AND WELLBEING

Man looks like child due to bizarre condition.

Carpenter says he looks like a ZOMBIE because of a rare condition that causes pus-filled ulcers on his face, chest and arms.

Meet the Australians allergic to light: Dozens suffer from ‘vampire-like condition’ that feels like they’ve been dropped into 'a bath of boiling fat' if they spend just two minutes in the sun.

By Stephen Matthews Health Editor For Mailonline - October 30th 2019, 9:46:14 am

By Nic White Cindy Tran for Daily Mail Australia - October 20th 2019, 11:57:20 am

Rare condition erythropoietic protoporphiria makes 200 patients in Australian and New Zealand ‘burn from the inside’ with excruciating pain that last for days.
Freakish horror-movie)

handsome

victim

battling

able-bodied

inspirational

Wheelchair-bound

robbed fighting

freakish victim

domestic

falling

fighting

victim

battling

robbed

freakish

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Responsibility: a moral obligation to behave correctly towards or in respect of
Look beyond for the story
- Amplifying voices
- Effectively signposting
- Building a rare community