

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

Rebecca Stewart

RARE
REVOLUTION
MAGAZINE

Damaging headlines

The right language

Accuracy

Responsibility

Beyond human interest stories

The Cost of Drugs for Rare Diseases Is Threatening the U.S. Health Care System

by A. Gordon Smith
April 07, 2017

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

Business Intelligence News 17 December 2018

LIFESTYLE, HEALTH AND WELLBEING

Man looks like child due to bizarre condition

Health

Article

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

By Stephen Matthews Health Editor For Mailonline - October 30th 2019, 9:46:14 am
Steve Young, from Honiton in Devon, was diagnosed with pyoderma gangrenosum in August, after 18 months of searching for an answer to his pus-filled boils.

DEVILISH SICKNESS Stomach-churning pics reveal agony of people blighted by 'cutaneous horns' – and how something as innocuous as a tiny cut can trigger it

Dan Hall
19 Sep 2019, 15:55 | Updated: 21 Sep 2019, 0:59

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

M News UK News

THE GIRL OF 12 WHO CAN'T STOP EATING

FEARS FOR 13th REBECCA

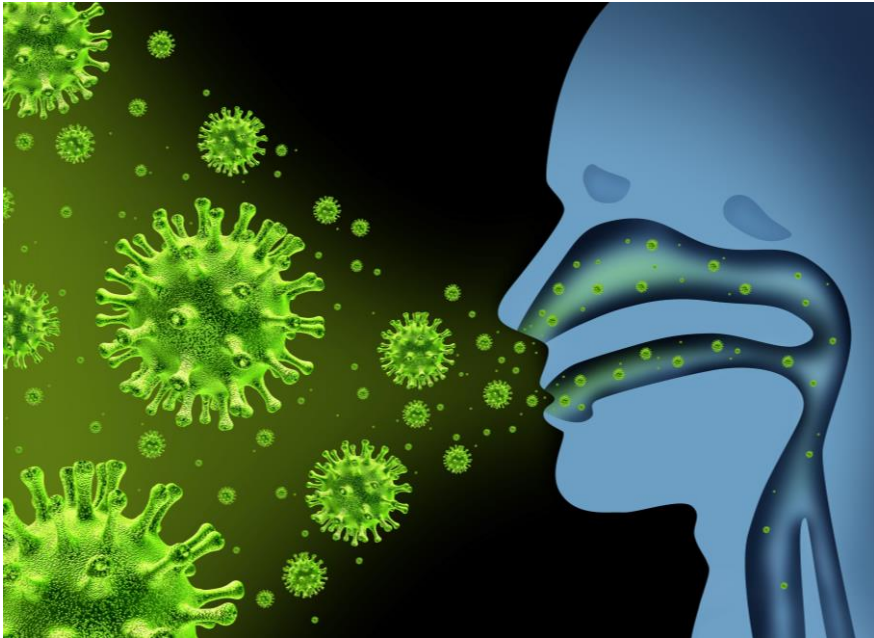
Young Handsome Man Gets Married To A Lady That Lost Her Lips To A Disease

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 Nic White Cindy Tran for Daily Mail Australia - October 20th 2019, 11:57:20 am
Rare condition erythropoietic protoporphyria makes 200 patients in Australian and New Zealand 'burn from the inside' with excruciating pain that last for days.



Responsibility: a moral obligation to behave correctly towards or in respect of



Look beyond for the
story



Magazine



Magazine

RARE Inspiration
'Courageous parent'
Blyth Lord
Empowering families in
decision making and



MEET OUR NEW YOUTH
EDITORIAL TEAM
INSPIRATION

Birmingham's
dream team

RARE INSPIRATION
Meet the Birmingham



Duchenne Muscular Dystrophy

RARE REVOLUTION MAGAZINE

- Amplifying voices
- Effectively signposting
- Building a rare community



Magazine

RARE Inspiration
Caroline Harding
and Nicole Boice

Empowering a global
RARE advocacy movement