AMBER N. FREED · FOUNDER

Fighting Like a Mother

SLC6A1 Connect



Too Rare to Ignore. Too Important to Abandon.

My Life was Complete

I was ecstatic, content, and life was perfect.



But Something Wasn't Right

- He looked perfectly “normal”
- Global developmental delay
- Floppy
- Bizarre hand stereotypies
- Riley's milestones became bittersweet



The Unspeakable Became Reality

The Phone Call….the Cold Sterile Room…a Box of Kleenex

Please Not Maxwell Norman.

Anything but This.

This Must be a Nightmare.

His Twin Sister.

Who Will Take Care of Him When we Die?

This wasn't Supposed to Happen.



The Doctors don't Understand this Disease?

Why Doesn't the Disease have a Name?

This is Unfair. I'm so Mad.

We had a Better Chance of the Lotto.

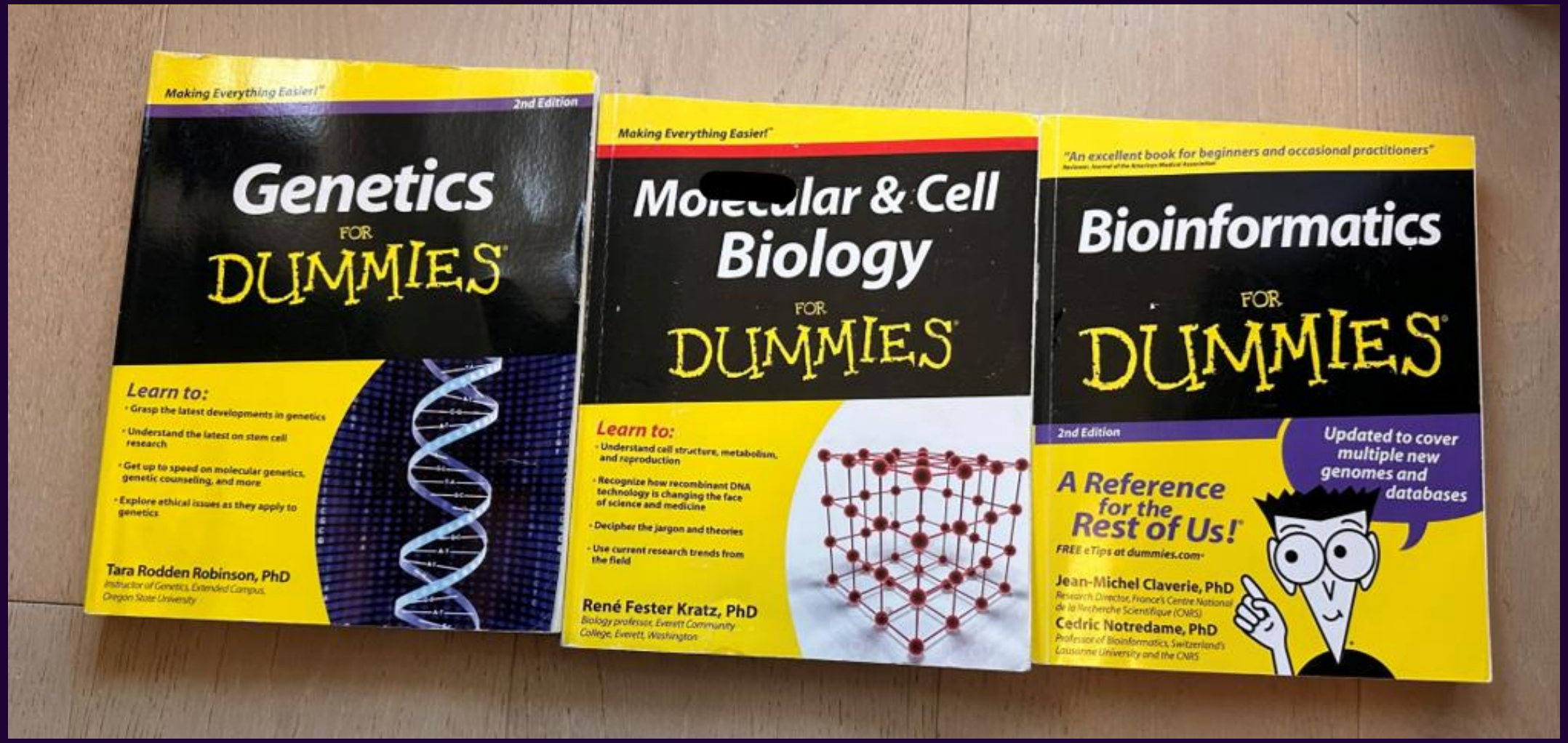
What do We Tell Friends & Family?

The Darkest Moment of My Life

I Decided to Fight.....

Fight like a Mother





Became an Honorary Scientist…

Science & Prevalence

SLC6A1 is a *newly discovered* disease with a prevalence of **1 in 38,000 live births** — about **3,500 children a year worldwide**. The gene controls **GABA**, the largest inhibitory neurotransmitter in the nervous system.

GLOBAL PREVALENCE

29,074

Predicted Patients Worldwide

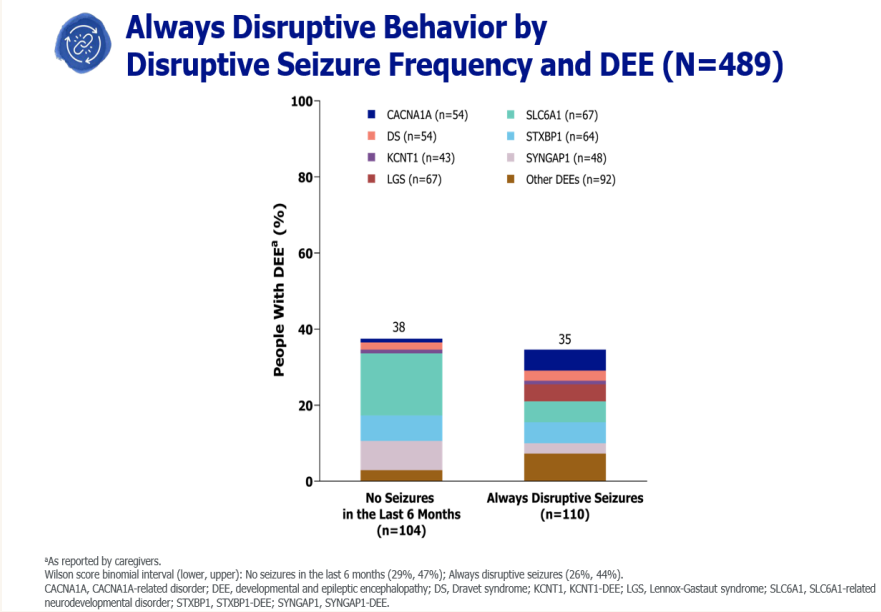
CLINICAL IMPACT

#10 **Most Prevalent Autism Gene**

#6 **Most Prevalent Epilepsy Gene**

Psychiatric Conditions

Schizophrenia · Bipolar · ADHD · and more



THE SCIENCE

The SLC6A1 gene codes for GABA transporter 1 — the protein that removes GABA from the synaptic cleft, regulating the brain's main inhibitory neurotransmitter.

8 Years Later.....

- Raised **$10,000,000** philanthropically
- Built a Full Scientific **DREAM** Team
- SLC6A1 Connect has Hosted 5 **International Scientific Symposiums**
- **Mobilized** Affected Families
- Successfully **Repurposed** an FDA Approved Drug
- Established **Centers of Excellence**
- **THE FIRST CHILD HAS RECEIVED GENE THERAPY**



People

Exclusive

8-Year-Old Has Disease So Rare It Doesn't Have a Name. Now He's First in the World to Receive Treatment (Exclusive)

Amber Freed's son Maxwell made history in September when he received treatment for SLC6A1 thanks to her tireless work and a team dedicated scientists

By Greta Bjornson | Published on December 5, 2025 05:45PM EST



Maxwell and Amber Freed the day of his treatment.


Rangers

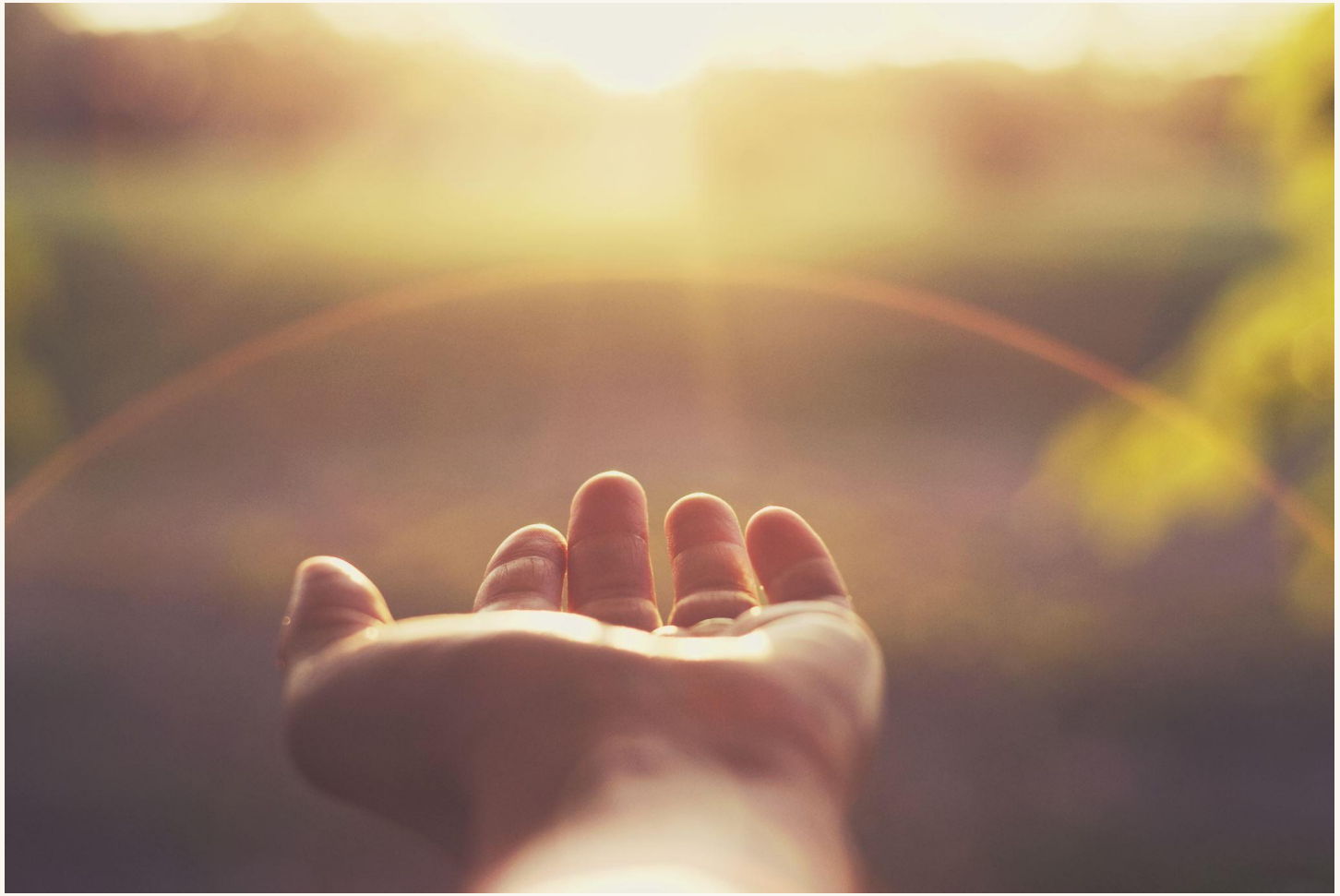
Patients Drive Treatment

- Advocate and raise awareness
- Become an honorary scientist
- Wrangle researchers
- Fundraise extraordinary amounts of money
- Take care of really sick loved ones



Inequity in Healthcare





Don't stop until the miracle happens.

Amber N. Freed · SLC6A1 Connect

Thank You

Questions?

Would you like updates?

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