Patient Advocacy

"Sometimes it's not the load that breaks you down, it's the way you carry it" – Lena Horne

Anikah H. Salim

April 4, 2020

MILES FOR MIGRAINE

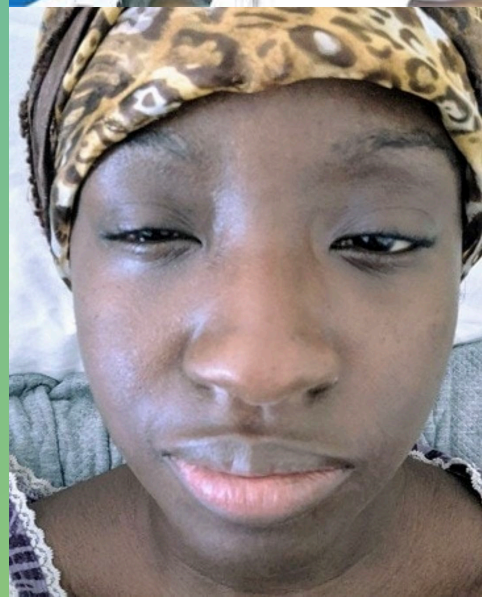
About Me

- Full-time work
- Full-time student
- Love to travel
- Love to eat
- Extroverted

Beneath my smile is an invisible illness. You wouldn't begin to understand it unless you walked a mile in my shoes.

My Story

- Chronic conditions since childhood
  - 2008 – Knee Dislocation Surgery
  - 2014 – Procedure for Herniated, Protruding Disk
  - 2015 – DX with Chronic Migraine w/ Aura



MILES FOR MIGRAINE

My Reality

The Truth About Migraine

It’s a neurological condition

It’s debilitating

It’s not your fault

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Support

Having a support system is very important in life – especially if you have a chronic illness

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Outshine Your Label

We must be willing to let go of the life we've planned so as to have the life that is waiting for us.

Joseph Cambell

Migraine advocacy is more important than ever before.

Advocacy Beats Stigma

Patient Participatory Advocacy Activities

- Family and friends in advocacy groups
- Empowerment programs
- Counseling and support

"Better health through better partnerships"

- VADM Jerome M. Adams, MD, MPH, U.S. Surgeon General

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RETREAT MIGRAINE

Advocacy Beats Stigma

Advocacy Programs

- Headache on the Hill
- The Headache and Migraine Policy Forum
- Alliance for Headache Disorders Advocacy

MILES FOR MIGRAINE

Alliance for Headache Disorders Advocacy

The Headache & Migraine POLICY FORUM

HEADACHE on the HILL

Good morning,

This email is inform you that the office **policy is to maintain a *'fragrance-minimized' work environment* for staff who suffer adverse health effects from strong scents.** This means that:

Fragrant products such as air fresheners, scented candles, potpourri and other similar items are not permitted in the workplace.
Care should be taken by staff to not over-apply fragrant personal products (fragrances, colognes, lotions, powders and other similar products) to a level that becomes easily perceptible to others.
We have colleagues in the office with asthma, easily stimulated allergic reactions, migraines and/or other respiratory disorders caused by exposure to fragrant products. Staff with such sensitivities are more susceptible to effects of these irritants at levels that are much lower than what might cause problems for those in the general population. People with fragrance sensitivity often experience symptoms such as wheezing or worsening of asthma symptoms; headaches; migraines; nausea; hives and other skin irritations; and/or limitations in memory and concentration.
While we cannot eliminate all scents (e.g., cleaning supplies) from the office environment, we do need to limit it to the minimum that is reasonably possible.

Thank you for supporting a *'fragrance-minimized'* environment to ensure a safe and healthy workplace for your colleagues.

MILES FOR MIGRAINE

My Migraine Story
(As A Patient Advocate)

A New Normal

What is found among the painful things, the wounds you carry?
The wounds that demand attention?

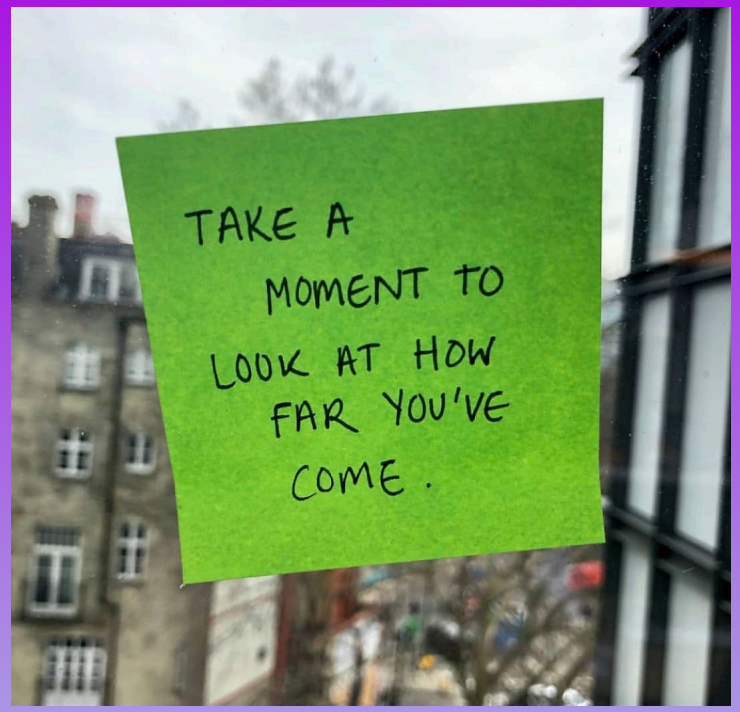
I have found healing hard, I've also found in them
Growth, empathy, kindness, and deeper connection.

Silver linings do not make pain right,
I'd rather have not experienced it at all.
But what is given cannot be returned,
We have to accept where we are, to live and in turn, to learn.

- p.bodi

A New Normal

My pain may be high but so are my hopes



TODAY, THINK ABOUT ALL THAT YOU ARE INSTEAD OF WHAT YOU ARE NOT.

Share Your Story

i see you trying to heal.
i'm rooting for you.

don't quit.

HEY WARRIOR,
keep going.

Remember…

MILES FOR MIGRAINE

@Migraine.Doesnt.Win

MILES FOR MIGRAINE