# FROM DOUBTFUL TO HOPEFUL: A LONG-COVID JOURNEY

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Long-COVID Patient Advocate NASEM Symposium 2023

### **OUTLINE**

- Introduction
  - o Pre-COVID Life
- COVID Experience
- o Post-COVID Life

# **MY PRE-COVID LIFE**





















confident communicator achiever energetic mother ambitious

# MY COVID EXPERIENCE



### How it started...

January 8-9, 2022 in Little Rock, AR

### How it ended...

January 12, 2022 at 10:03pm



#### **SARS CoV-2 Test Results**

Your result is: DETECTED

Order ID: LORASCHD57897

#### **Result Comment:**

The Covid-19 virus was DETECTED in your specimen. Begin immediately quarantining yourself away from all others for a minimum of 10 days. We will be contacting you, but feel free to contact us Monday - Friday 8 AM to 4:30 PM at (901) 222-0162 or (901) 222-0164.

Download CovID19 PCR Test Pathology Report 🖪

### TIMELINE

**DEC. 2021** 

JAN. 2022

**FEB.-MARCH 2022** 

**APR-MAY 2022** 

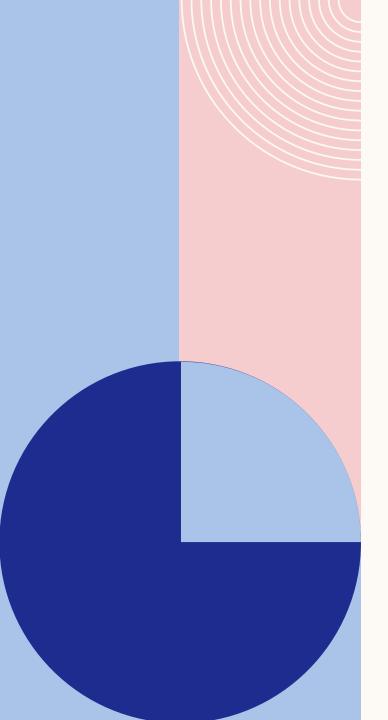
JUNE 2022-PRESENT

- Dec. 11- First 2 cases of the Omicron variant in Shelby County
- **Dec. 21-** Advised all staff re: precautions over the holidays
- Dec. 27- Adjustments made within the office to minimize exposure.

- Jan. 8-9 Volleyball Tournament, Little Rock, AR.
- Omicron had a shortened incubation period of 1-3 days
- Jan. 10- Scratchy throat and headache.
- Jan. 12- Tested positive as did 8 y.o. who is immunocompromised.

- Feb. Two visits with PCP re: lingering symptoms (vision & fatigue, insomnia).
- New symptoms: brain fog, short term memory loss, brain felt "unplugged".
- Requested blood work or dx testing from PCP.
- Acquired New PCP:
  Dx testing orderedMRI, sleep studies,
  blood work,
  neurocognitive
  screener, cognitive
  tests.
- Withdrew from N2PH Residency Prgm due to cognitive challenges.
- New Long-COVID
  Symptoms: Word finding, cognitive processing delays, stuttering, pseudo seizures, mind blocks, Parkinson like tremors, internal full body vibrations, absentminded slips, anxiety in large crowds when I cannot socially distance, PTSD.

# LONG-COVID LIFE



## **AREAS OF IMPACT**

#### **NEW HOME LIFE**

- Absentminded slips
- Moody
- Less patient
- Sluggishness and energy levels
- Dependency
- Need to "overplan" to avoid forgetting

### **NEW WORK LIFE**

- Regular "mental breaks" throughout workday between meetings or prolonged periods of hyper-focused work.
- ADA accommodations.
- Learning disability rights per ADA
- Symptoms of word finding and stuttering often make me less vocal than normal.
- Need to "overplan" to avoid forgetting

### **SUMMARY**

- Long-COVID does exist. It is not in our heads.
- Medical practitioners <u>cannot</u> be dismissive of our symptoms.
  - Dismissiveness or "passing us off" only yields increased frustration and anxiety for the patient and delays access to diagnostic testing and treatment options.
  - Ask the right questions to avoid a quick misdiagnosis of depression, anxiety or stress.
- Human Resource teams need more education and guidance on Long-COVID.
- ADA, CDC, and HHS's working definition of Long-COVID should address the unpredictable nature of one's symptoms daily.
  - What one may feel for a day or two, may disappear for a day or weeks, all to return.
- Symptoms seem to have varying degrees of intensity and frequency with which they occur.

We deserve to have an ounce of hope, and you can help us get there.

# **THANK YOU**

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