



**ENDURING  
HOPE**

# Michael's Story



- Disclaimer: The author has no financial or conflict of interest

# Michael's Story



- Diagnosed with Sickle Cell (SS) Disease at a 1 week old
- First Pain Crisis at age 8 months
- Hospitalization frequency as an infant/pre-school age - 3x times per year
- Started the treatments at Lurie's Children's hospital at age 8

# Michael's Story



- Multiple surgeries, starting at age 3 - most recent; gallbladder removal
- Hospitalizations increased significantly in 2018
- Started High School in 2022!
- Began clinical trial-new medication this past Spring 2024

# Michael's Family



*Michael thoroughly enjoys spending time with loved ones and friends to help ease the stress of constant chronic pain.*



# Arrival of Hope



- Michael is now on his third medication
- Promise of Clinical Trials
- Hope of Curative Therapies!

# Barriers to Clinical Trials



- Family/community distrust - validity of Michael's suffering...
- Distance/underserved communities
- Financial constraints/job flexibility
- Family participation stressors
- Endurance/Mental capacity - “strained”
- Disappointment when not approved for trial

# Hope Reignited



- Symptoms have improved!!! Chronic pain has become more manageable
- Lurie Children's Kids Advisory Board
- iCAN Conference
- International Travel
- Driver's Permit



# Recommendations



- Foster patient and family engagement
  - Access to medical resources in their community
  - Listening tours to ensure needs are met
  - Community Town halls to educate communities on the impact and importance of disease awareness
  - Political will to eradicate systemic injustices in healthcare