SUPPORTING STUDENTS WITH SICKLE CELL: PART I

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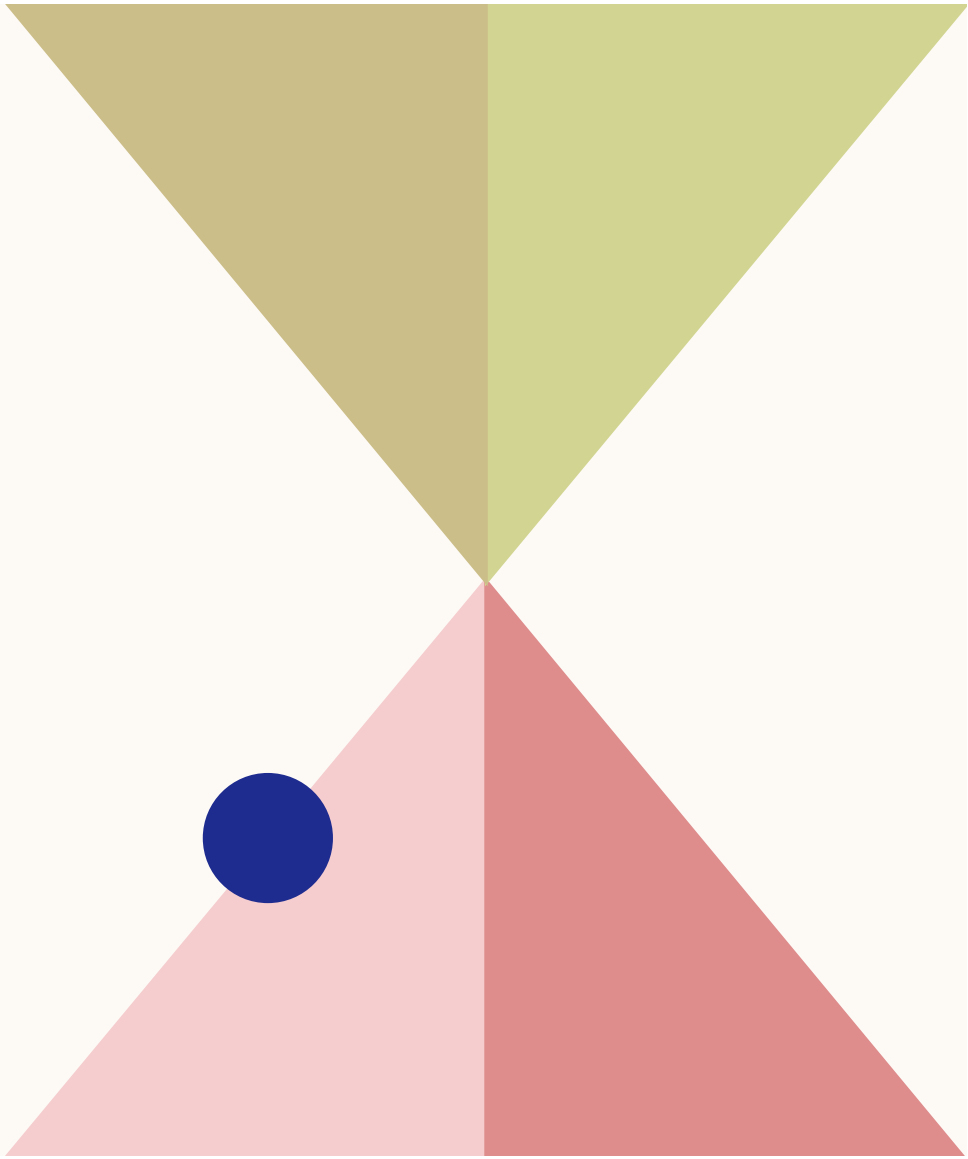
AGENDA

Introduction to Sickle Cell Disease

Sickle Cell in Boston Public Schools

Sickle Cell Survivor Testimony

Sickle Cell Parent Perspective



INTRODUCTION TO SICKLE CELL DISEASE

- Sickle Cell Disease (SCD) is chronic condition that is the result of impaired blood circulation due to a group of genetics red blood cell disorders
- In this disease, the hemoglobin (protein) in the red blood cells is abnormal which distorts the blood cell from the normal circle to a c-shape, commonly referred as ‘sickle”
- These sickled cells die prematurely, which results in a red blood cell shortage throughout the body
- Additionally, while travelling through the body the sickled cells often clog blood glow, resulting in pain and serious complications

PREVALENCE OF SICKLE CELL DISEASE

- As a genetic disease, sickle cell is formally diagnosed at birth and presents throughout the lifetime of the individual.
- Sickle cell disease is most prevalent in people of African descent, those from western Spanish speaking countries, the Caribbean, Saudi Arabia, and the Mediterranean
- These origins leave Black and Hispanic children disproportionately affected by sickle cell.

Sickle cells is prevalent in 100,000 Americans

1 out of every 365 African Americans have sickle cell

1 out of every 16,300 Hispanic Americans are have sickle cell

Approximately every 1 in 13 African American children are born with the sickle cell trait (SCT)

TYPES OF SICKLE CELL DISEASE

MOST SEVERE

HbSS

- With HbSS type of sickle cell disease individuals inherit two “S” genes from their parents resulting in rigid and sickle shaped cells.

MILDER FORM

HbSC

- The second type, HbSC, is where individuals inherit one “S” and one “C” gene for the abnormal hemoglobin, which is a milder form of the disease

MODERATE OR SEVERE

Hbs

- In HbS beta thalassemia SCD individuals inherit an “S” gene and beta thalassemia gene.
- Individuals can receive a “zero” or “plus” beta gene which result in a severe or moderate form of the disease

SICKLE CELL PRESENTATIONS/EXPERIENCES

• VASO-OCULAR CRISIS (VOC)

Leads to ischemia and hypoxia, later resulting in vascular damage and inflammation and patient complaints of debilitating pain

ACUTE CHEST SYNDROME (ACS)

New pulmonary infiltrates on the chest. Common symptoms include fever, cough, chest pain, or reduced air entry

INFECTIONS

Penicillin prophylaxis in children or susceptibility to other bacterial infections

PULMONARY HYPERTENSION (PHTN)

Increased pressure on the right side of the heart, often leading to damage, shortness of breath, and fatigue

CEREBROVASCULAR ACCIDENTS

CVA (stroke) occurring as early as two years old and silent cerebral infarcts (SCI) that may persist throughout the lifetime

SICKLE CELL PRESENTATIONS/EXPERIENCES

PULMONARY EMBOLISM

Increased incidences of pulmonary embolism and high risk of thrombotic complications

RENAL COMPLICATIONS

Sickled cells can reduce blood flow to the kidneys, increasing the risk for renal compilations, including kidney disease

EYE COMPLICATIONS

Proliferative retinopathy, resulting in abnormal blood vessel formation, bleeding in the eye, etc.,

SPLENIC SEQUESTRATION

Cell blockage in the spleen causing abdominal pain or circulatory collapse, especially in the pediatric SCD population

APLASTIC CRISIS

Commonly the result of a parvovirus infection, resulting in aplastic crisis and a need for a blood transfusion

RECENT EVENTS IN BOSTON PUBLIC SCHOOLS

2015 Complaint

A FORMAL COMPLAINT TO THE US DEPARTMENT OF EDUCATION

WHAT HAPPENED?

- In 2015 complaint was filed the US Department of Education on BPS for violations of policies and practices on children with SCD
- Suggested violations:
  - Section 504 of Rehabilitation Act of 1973
  - Title II of ADA
  - Title IV of Civil Rights Act of 1964
- Shared vignettes of the student and family SCD experiences
  - Families that have identified their child having SCD to the district
  - Families that have not disclosed their child's SCD

A FORMAL COMPLAINT TO THE US DEPARTMENT OF EDUCATION

MAJOR POINTS

- Lack of institutional leadership for education, outreach, and the spread of information
- BPS's failure to notify children and families of their rights within Section 504
- Lack of comprehensive evaluations and prolonged service referrals
  - For example, in winter 2013 a 504 referral was initiated but no evaluation occurred until after June of 2014
- BPS not responding to a parents request for 504 services and rather threatening student B with court intervention
- Non-supportive school personnel

THE AFTERMATH

- After investigating the complaint, the District developed a formal Resolution where they responded with:
  - Identifying 42/95 students with SCD having IEP or 504 accommodations
  - Claims that current evidence does not establish that BPS failed to appropriately identify or evaluate students with SCD
  - A request to obtain additional evidence/ relevant documentation on the implementation of 504 policies
- Later in 2018, BPS developed a sickle cell disease policy and implementation document
- This policy included: Education on the disease, information on Child Find, interim services and supports, FAPE, guidance to ombudsperson, and data collection.

PERSONAL EXPERIENCES/ TESTIMONIES:

Interviews conducted with a sickle cell survivor and her mother

THE EXPERIENCE OF A SICKLE CELL SURVIVOR

How old were you when your parents talked to you about your diagnosis?

- Aware of her sickle cell since 3 or 4 years old

How did sickle cell impact your daily life?

- Random pain crisis's that occurred about twice a week
- ADL's such as feeding, eating, grooming, and toileting were disrupted during a pain crisis
- Early dismissal or missed days of school due to hospitalization from pain

THE EXPERIENCE OF A SICKLE CELL SURVIVOR

What was your sickle cell experience in school?

- Mental health was challenging due to decreased social participation and teasing
  - Children weren't educated on SCD which opened up the opportunity for teasing
  - Difficulty navigating stigmas for having an "invisible disability"
  - "Being in the middle of a sickle crises is like a mental breakdown, you feel helpless and a lack of control with everything"
- Her mother's advocacy and parent-teacher relationships allowed for open communication and her to receive accommodations and extensions

THE SICKLE CELL PARENT EXPERIENCE

What were some of the accommodations that you requested for your daughter? Did she receive a Section 504 Plan?

- Gym and recess accommodations for her fatigue levels
- Assistance with getting work to her daughter during a pain crisis or hospitalization
- She was provided a case worker that was provided through the sickle cell center in Milwaukee, WI
- Daughter never received a 504, nor was information on a 504-plan presented
- “I never heard of that. I never had that information back in 1994 from the public school system”

THE SICKLE CELL PARENT EXPERIENCE

Who did you often communicate with?

- Direct and continuous communication with the principles and teachers

Did you all run into any issues with absences? How did you go about that?

- "I ran into issues with the school thinking that she was truant"
- "Along the way I learned to communicate her absences with the school"

From the parent perspective, what life roles or routines were impacted by your daughters' condition?

- "It was a lot of mental stress"
- "She wanted to do everything everyone else was doing, which is good but then on the flip side there's the disappoint if you start something and can't finish it"

THIS CONCLUDES PART I

Continue to:

Supporting Students with Sickle Cell Part II

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