

Dear City Council Members Mark Levine and Danny Dromm,

Hello, my name is Abigail Jean. I am 10 years old and a 5th grade student at PS 38, The Pacific School. I wanted to thank you again for listening to my testimony and those of the many other families affected by Sickle Cell Disease (SCD) in the New York City (NYC) Council Chambers on 9/9/19. We are committed to ensuring that much needed funding is raised for more support and awareness.

Councilman Levine personally asked me to continue to speak out so I am.

My teacher Mrs. Gina Duclayan and my classmates at PS 38 The Pacific School were very inspired watching the video of the city council hearing and wanted to get involved too.

We ask that you support an increase of funding for Sickle Cell Disease Awareness for NYC families. Sickle cell disease affects approximately 100,000 Americans and approximately 10% of SCD patients reside in New York State (NYS).

SCD is an inherited blood disorder that is caused by a mutation in the hemoglobin protein, this can cause severe pain and organ damage. People with sickle cell disease are also at risk for some bacterial infections. Because of this, the median life expectancy for severe sickle cell disease patients is only 38 years for men and 42 years for women.

It is the most costly disease per patient to NYS Medicaid, costing \$15,000/year/patient. Despite this, NYS only spends about \$250,000/year to help improve care and decrease the costs of care. This has decreased from approximately \$500,000 in 2001. This is a disgrace, as CA now will spend \$15M and NC spends \$4.25M for a sickle cell population much smaller than in NYS.

Lastly, students with SCD have many challenges including missing days of school due to pain crisis, needing more frequent hydration and tiring easily. It is important that we raise awareness not only in hospitals but in schools so that SCD patients can have a full education like their peers.

We the students are depending on the City Council and Governor Cuomo to help these families. We demand that Governor Cuomo place the \$3M for the state's sickle cell bills into his proposed budget in January 2020 and that NYC provide more funding for school programs, community outreach and hospital support.

Thank you again for listening to us.

5th Grade Class of PS 38, Brooklyn, NY

Principal Pascale Pradel

CC: Governor Cuomo and NYC Speaker Corey Johnson

Victoria Castorina

Hassan Abois-Salaam

Fatmeh Ahmad

Miracle Jameson

Glynis Figsby

Mawen Hale

Chris Michler

Deborah Scharf

Andria Hillery

Mina Duclayan

Emma Gordon-Mooppenn

Kimberly Crowther

Elizabeth Scire

Jordan McNeill

Zuzana Sykorova

Finn Hollingworth

Saxon RASSNER

Don'Aziz Mohommed

Xavier Taliaferro

Kelvin Li

Mary Simmons ZOE Kim

Xiola Considine

Knico Dusszek

the K is silent.

Elliot Sedgwick

Michelle Adams Tiffany Li

Elijah Wright

Amber Saif

Dylan Storchan

Shirley Chen

Tymarie Wiche

CARYS MOONEY

Abigail Jean