

Testimony of Derek Robertson, MBA, JD, CHC
President, The Maryland Sickle Cell Disease Association
Before the Health and Government Operations Committee
Maryland House of Delegates
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House Bill 1306 - Public Health - Sickle Cell Disease Registry - Establishment

Good afternoon, my name is Derek Robertson. I am the President and co-founder, along with my wife Shantá, of the Maryland Sickle Cell Disease Association (MSCDA) based in Columbia, MD. My wife and I have three sons, two of whom have Sickle Cell Disease (SCD).

Chairperson Peña-Melnyk thank you for the opportunity to talk with your committee today about sickle cell disease. Delegate Patterson, thank you for sponsoring this Bill. MSCDA is in favor of House Bill 1306 because it is critical to ensuring appropriate care reaches persons in Maryland who are living with this devastating disorder.

According to a 2010 study, there are approximately 5,000 people in Maryland living with SCD.¹ This bill will have a direct impact on these 5,000 individuals, their families and their providers.

As many, if not all, of you are aware, SCD is an inherited blood disorder where some of the patient's red blood cells are shaped like a sickle instead of being donut shaped. Red blood cells carry life sustaining oxygen to all of organs and must flow smoothly through our blood system. With SCD, the red blood cells that are sickled shaped are sticky and don't carry oxygen effectively. The stickiness of the cells cause the cells to clump together and block the flow of blood. This "clumping" known as a vaso-occlusive crisis is the cause for extreme pain that characterizes SCD. As bad as it is, the excruciating pain faced by SCD patients is not the only complication of SCD. "Sickling" of red blood cells takes place in every organ leading to the breaking down of organs such as the eyes, kidneys and joint damage.

The need for a Bill such as this was identified Maryland Statewide Steering Committee on Services for Adults with Sickle Cell Disease in their report to the legislature almost fifteen years ago in 2008. In that report, the Committee recommended significant improvements in the quality of life for adults living with SCD including, "(S)hifting resources toward comprehensive specialty care and preventive care models such as regional infusion centers".

This Bill is needed for the following reasons:

- Care for individuals with SCD living in MD is concentrated in Baltimore City. As a result, individuals have to travel far distances, upwards of two hours in some instances, to obtain appropriate care. This travel is often done when these individuals are in excruciating pain;

¹ Hassell, *Am J Prev Med* 2010;38(4S):S512–S521. Table 3, Using cohort data corrected for early mortality in HbSS.

- Individuals with SCD should not have to leave the county in which they live to seek care. In 2006, my family relocated from Germantown in Montgomery County to Ellicott City, in Howard County so our children could have easier access to Johns Hopkins. Today, nineteen years later, there are families in Montgomery County considering this same choice and that should not be the case. There are many families where relocating is not an option;
- Having care close to where one lives improves health outcomes and saves costs. The state funded Community Health Resources Commission has supported a model in Prince George's County that established a local SCD clinic that partners with SCD experts in Baltimore City and community-based organizations. **This model has resulted in a 63% reduction in emergency room visits and a 41% reduction in hospital admissions** (see poster below);
- This Bill would replicate the successful Prince George's County model to the counties most in need;
- Most importantly, the Bill will result in focused efforts to provide expert care to this vulnerable, underserved population which will lead to improvement in health care outcomes, including better access to new treatments or cures.
- Improved access to care has also been demonstrated to decrease costs of care.

HB 1306 can address these needs immediately and will move Maryland in the direction of having a comprehensive approach to the delivery of healthcare services to person living with sickle cell disease. It is for these reasons MSCDA is in favor of House Bill 1306.

Thank you Chairperson Peña-Melnyk for allowing my testimony, and thank you Del. Patterson for sponsoring this Bill.

If you have any questions, I can be reached at 240-447-8728 or at mscdainfo@verizon.net.



“PATHS GRANT: Using the Hub and Spoke Model to Improve Access to Care for Adults Living with Sickle Cell Disease”

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INTRODUCTION

Sickle Cell Disease (SCD) is an inherited blood disorder that occurs in 1 out of every 365 African-American births¹. It is a complex, chronic, multisystem disease and requires expert medical care throughout the lifespan. There is a lack of clinicians with the expertise to care for people living with SCD¹. The *Prince George's County Access To High-quality Sickle cell care* (PATHS) project aimed to create a Hub and Spoke model to provide expert SCD treatment in the Maryland County with the highest number of people living with SCD. This County is about an hour from any existing comprehensive sickle program in the State.

AIM

- Improve outcomes for patients seeking care for acute vaso-occlusive episodes (VOEs) in Prince George's County (PGC).
- Provide access to expert outpatient sickle care close to where patients live.

METHODS

Multi-Site Implementation study

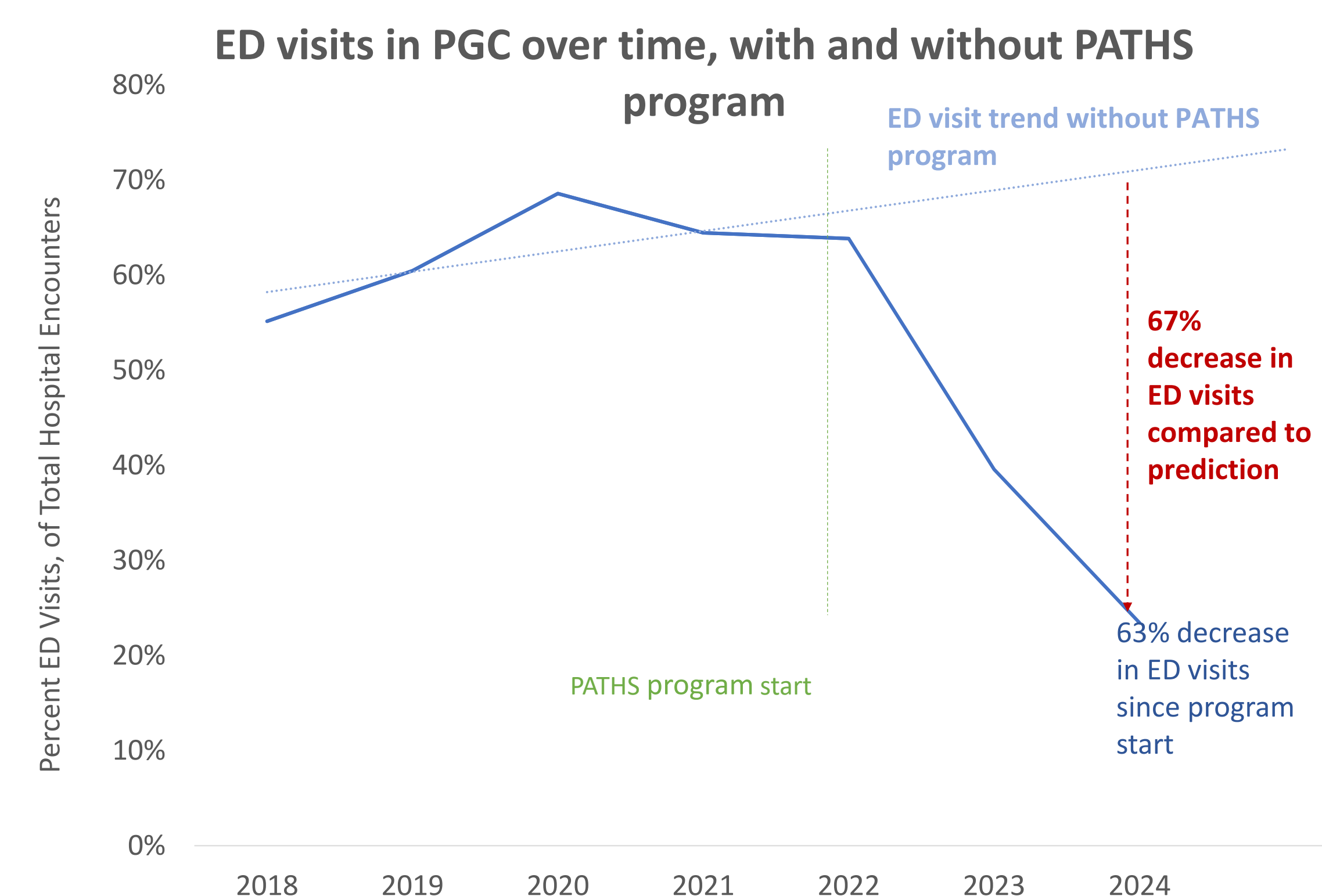
- Infusion center (IC) at a community hospital (spoke) in PGC
- Well-established comprehensive sickle cell center (hub)
- Community Based Organization for resources to address social determinants of health (SDOH)

Spoke hospital (University of Maryland Capital Region)

- Part-time palliative care physician and full- time advanced practice provider
 - Acute care in IC
 - Inpatient consultation
 - Weekly routine follow-up clinic
- Nurse and front desk staff for the 6 chair IC open weekdays from 9am-5pm

RESULTS

- From 2022 to 2024, 174 adult patients with SCD received care at the spoke.
- A dedicated SCD IC opened at the spoke in March 2023.
- From March 2023- June 2024 there were 949 encounters to the IC.
 - 636 of those visits were acute care infusion visits.
 - 13 visits resulted in hospital admission (2%).

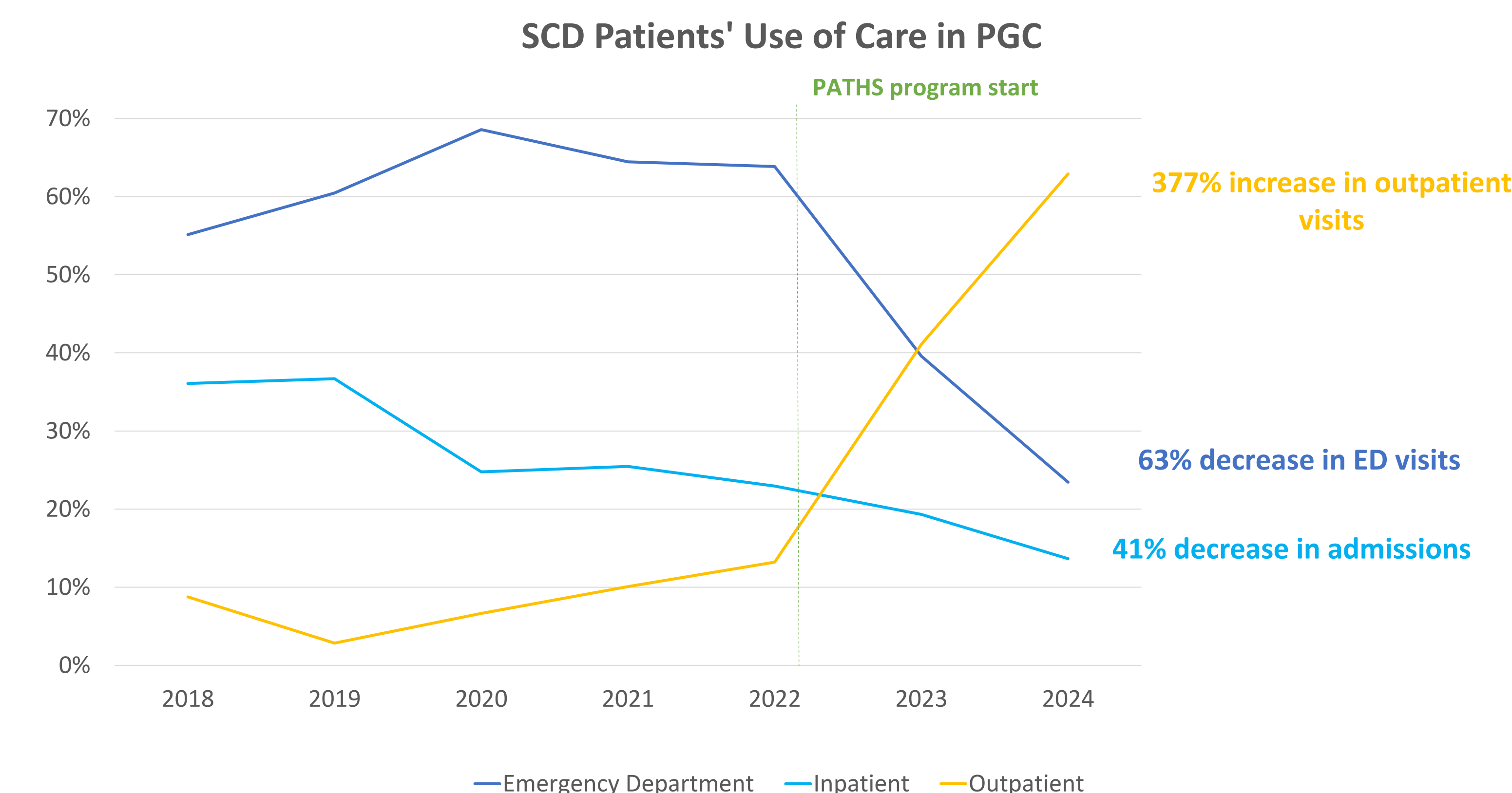


Outpatient Utilization:

- Outpatient visits (including IC visits) for SCD among PGC residents within their county increased by 377%
 - From 61 in 2022, to 200 in 2023, and projected 500 outpatient visits in 2024

Hospital Admissions:

- In comparison of data prior to opening the IC (data from 2018) to 2 years after opening the IC in 2024 there was a 41% decrease in inpatient admissions for county residents with SCD in county hospitals without corresponding increase in hospitalizations outside the county.



CONCLUSIONS

The hub and spoke model is an efficient way for the hub to extend its clinical reach to meet the needs of adults living with SCD in underserved areas of the US.

Future evaluations will examine whether this model leads to an increase in use of appropriate disease modifying therapy.

REFERENCES

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