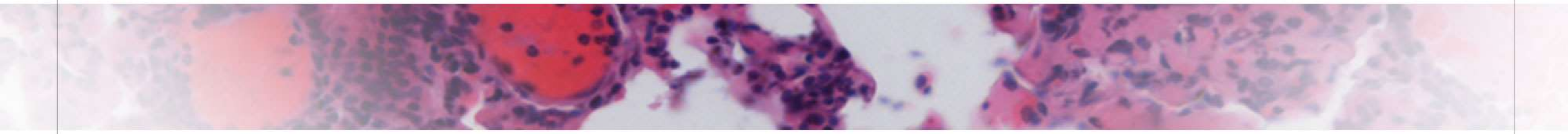
American Society *of* Hematology
Helping hematologists conquer blood diseases worldwide



Running A 1-Physician Show

Alice J. Cohen, MD, FACP
Director, Adult Sickle Cell Program
Newark Beth Israel Medical Center
Newark, NJ

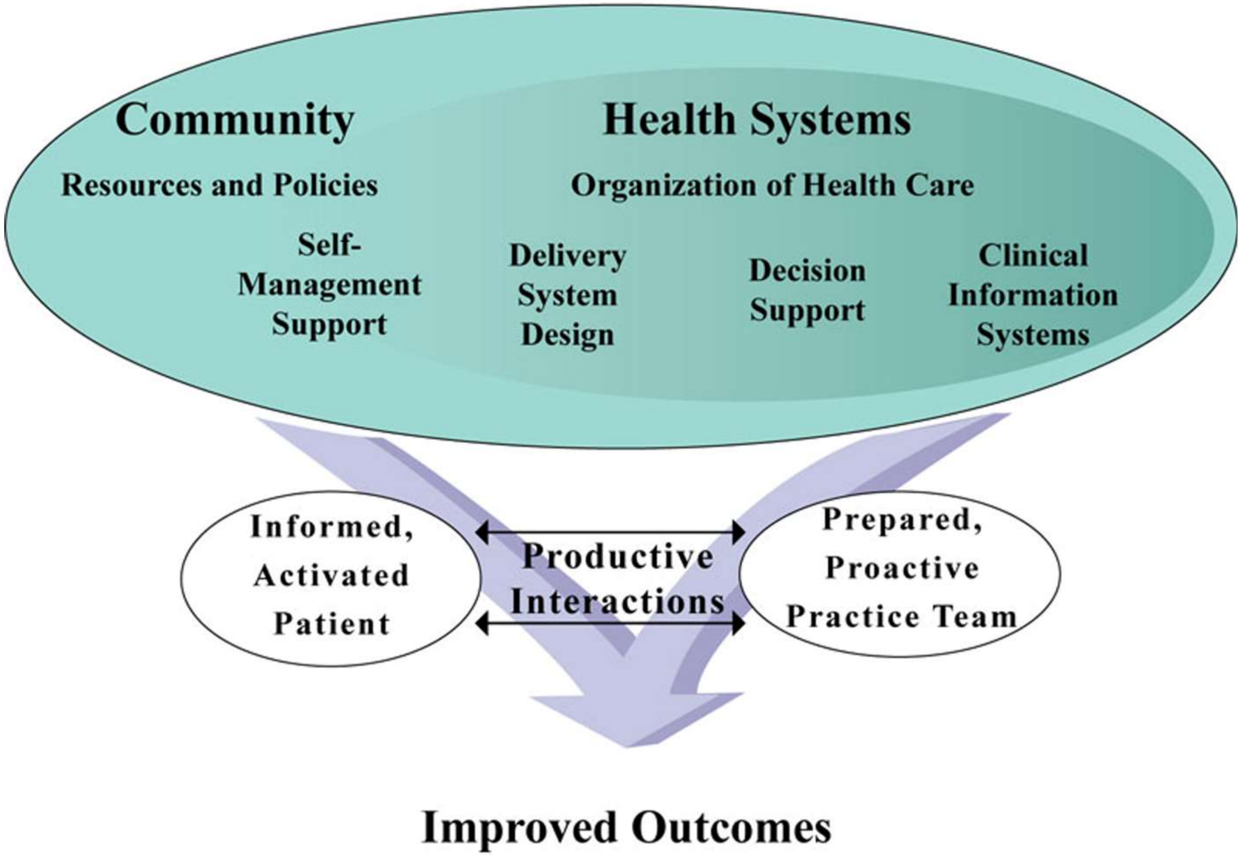
Learning Objectives

- What are the essential elements of a Sickle Cell Care Center that can be implemented by a single physician?
- What are the sequence of steps involved in creating a small sickle cell center that meets the needs of the SCD community?

What was the state of care in New Jersey in the early 1990s?

- 5 comprehensive pediatric sickle cell programs, primarily hospital-based, across the state
- State run newborn screening program
- Over 4,000 patients in the state
- 1 primary care physician in south New Jersey with private practice caring for adult sickle cell patients
- Most adult patients were receiving care in the ED and when hospitalized
  - Some seen by primary care
  - Some followed beyond age of 30 by pediatric hematologists
- No strong community-based organization in New Jersey (no SCDAA affiliate)

The Chronic Care Model



Developed by The MacColl Institute
® ACP-ASIM Journals and Books

Model for a Comprehensive Sickle Cell Care Center: Based on Hemophilia Treatment Center

- Location
- Leadership
- Clinical Staff
- Administrative Staff
- Laboratory Support
- Blood Bank Support
- Guidelines/Standards of Care

Location

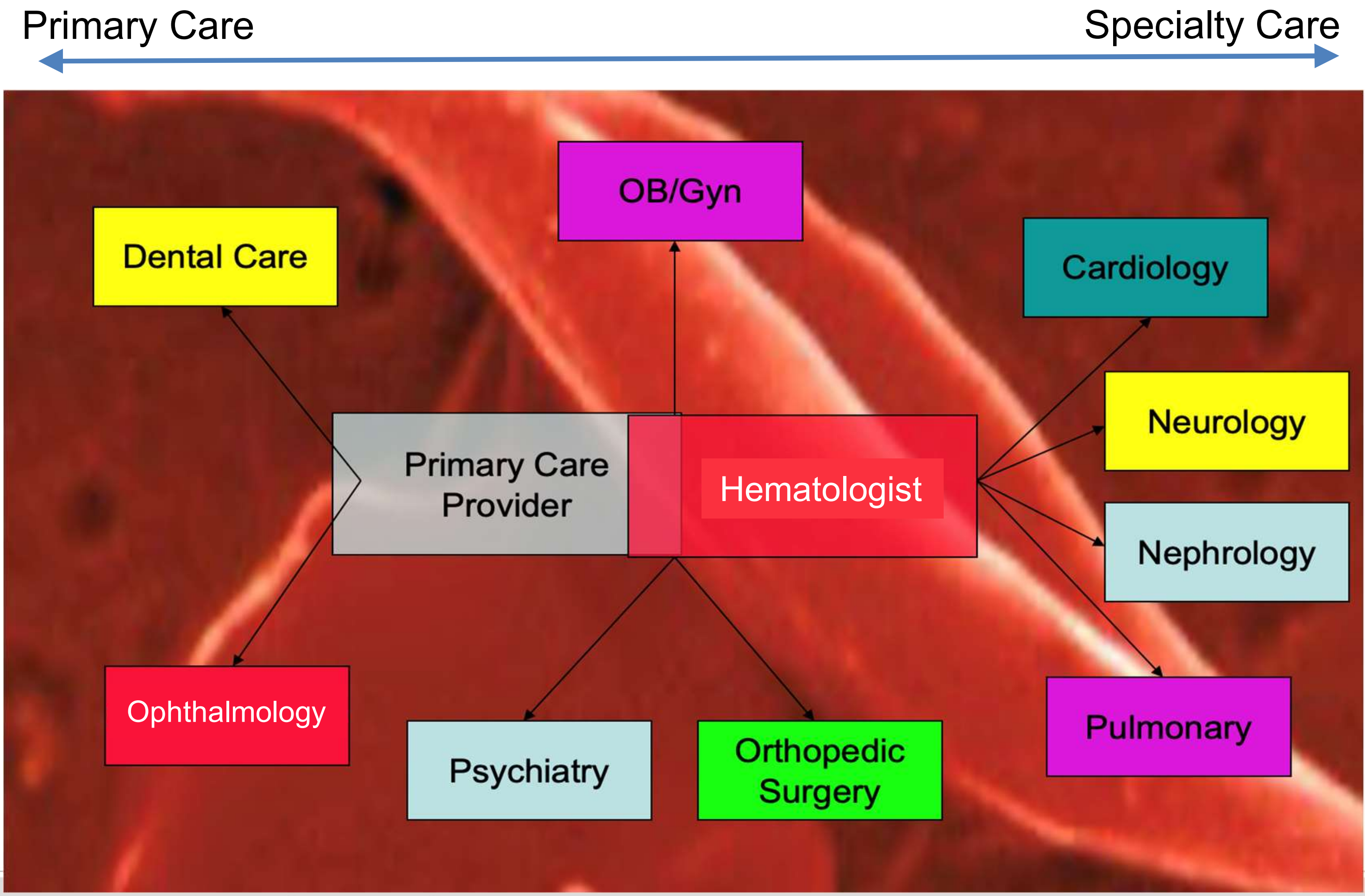
- Utilized the Cancer Center for clinical space–exam rooms, nursing staff, billers, administrative staff, MDs
- On-site infusion room
- On-site pharmacy
- Located within the hospital so laboratory services, including blood bank, on site
- Pheresis service available in the hospital already
- Emergency department in the same building

Clinical Staff

- Physicians–already hired but needed training and support
- Nurse Coordinator–needed funding
- Nurses–hem/onc nurses were on site
- Psychosocial Professional–needed funding
- Administrative Director–utilized hemophilia treatment administration
- Administrative staff–registrars, department secretary available to assist

Coordination of Care With Other Services

- Emergency Department
- Primary Care Physicians
- Hospitalists
- Specialty Services–Cardiology, Pulmonary/Critical Care, Nephrology, Orthopedics, Rehabilitation Medicine, Surgery, OB/GYN, and Dental
- Pediatric Sickle Cell Programs



Primary Care

Specialty Care

OB/Gyn

Dental Care

Cardiology

Neurology

Primary Care Provider

Hematologist

Nephrology

Ophthalmology

Psychiatry

Orthopedic Surgery

Pulmonary

Step 1: Hospital Partners

- Director of Pediatric Hematology
- State of New Jersey Commissioner of Health (MD)
- A white paper was created that reviewed:
  - The current status of care
  - Barriers to care
  - The need for adult providers
  - Funding
- Several years later, State of New Jersey created a line of funding (< $100K/year)
  - Hired a nurse coordinator to work with me

Step 2: Hospital Partners (cont’d)

- Utilized administrative manager/grant writer for the hemophilia program to submit grant to state of NJ for funding the nurse
- Started our own site database to track patients
- Started ½ day per week clinic attended by MDs and the sickle cell nurse
- Began reaching out to hospitalized patients, patients seen in the ED, and pediatric team and gave them appointments to our clinic
- Utilized NHLBI recommendations for treatment protocols

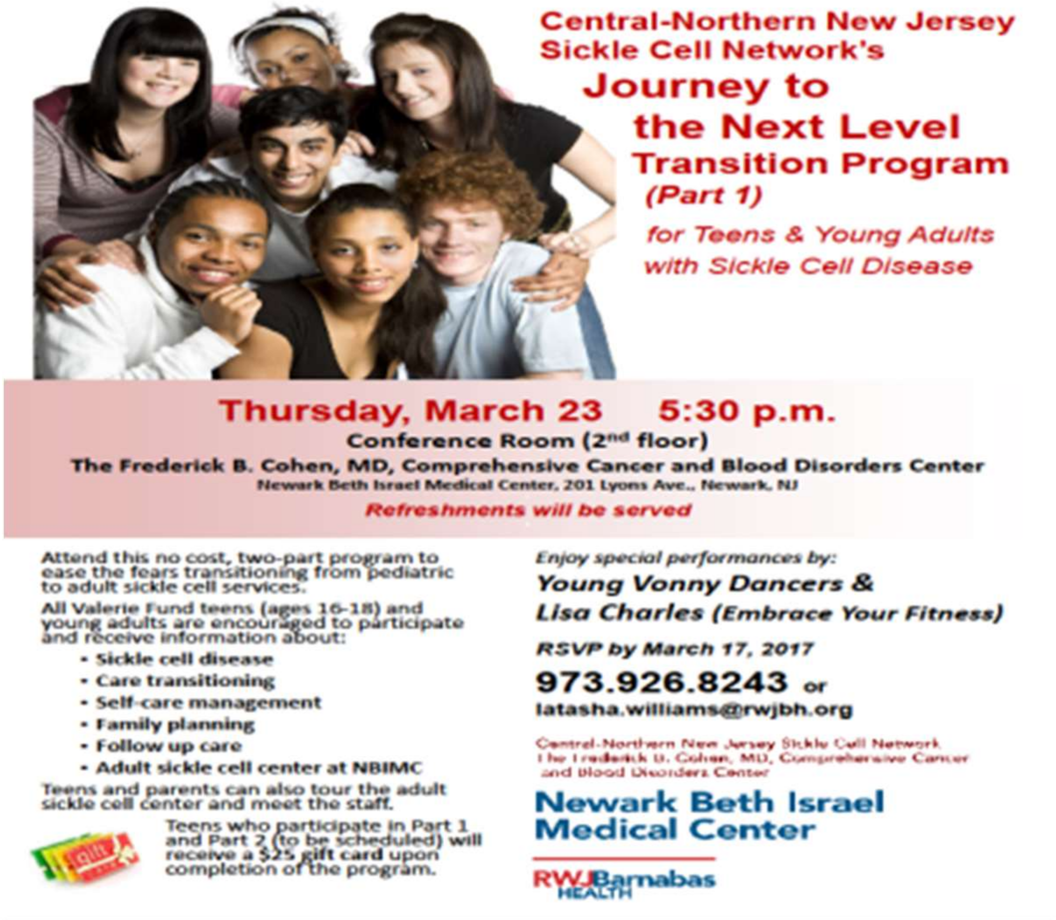
Step 3: Hospital Partners (cont'd)

- Recruited hematologist/oncologists as part of the team
- Created space in the infusion room for patients to receive pain management
- Have a hem/onc nurse assist with immunizations and medication management during sickle cell clinic
- Pharmacy liaison assisted with medication authorization
- Worked to increase availability of PCA pumps and train staff to utilize in ED and on med/surg floors
- Worked with SDS for site for outpatient exchange transfusions

PCA, patient-controlled anesthesia; SDS,

Program Development

- Developed the role of the sickle cell nurse coordinator
- Initiated weekly meetings with adult team:
  - Address individual patient issues and program development
  - Included pediatric team monthly to discuss transition patients
- Inpatient admission order sets created for the EMR
- Community health worker coordinated educational programs for patients
- Sent nurse and MSW to national meetings



Central-Northern New Jersey Sickle Cell Network's

Journey to the Next Level Transition Program

(Part 1)

for Teens & Young Adults with Sickle Cell Disease

Thursday, March 23 5:30 p.m.

Conference Room (2nd floor)

The Frederick B. Cohen, MD, Comprehensive Cancer and Blood Disorders Center

Newark Beth Israel Medical Center, 201 Lyons Ave., Newark, NJ

Refreshments will be served

Attend this no cost, two-part program to ease the fears transitioning from pediatric to adult sickle cell services.

All Valerie Fund teens (ages 16-18) and young adults are encouraged to participate and receive information about:

- **Sickle cell disease**
- **Care transitioning**
- **Self-care management**
- **Family planning**
- **Follow up care**
- **Adult sickle cell center at NBIMC**

Teens and parents can also tour the adult sickle cell center and meet the staff.

Teens who participate in Part 1 and Part 2 (to be scheduled) will receive a **$25 gift card** upon completion of the program.

Enjoy special performances by:

Young Vonny Dancers &

Lisa Charles (Embrace Your Fitness)

RSVP by March 17, 2017

973.926.8243 or

latasha.williams@rwjbh.org

Central-Northern New Jersey Sickle Cell Network
The Frederick B. Cohen, MD, Comprehensive Cancer
and Blood Disorders Center

Newark Beth Israel Medical Center

RWJBarnabas HEALTH

SCDTDP Project

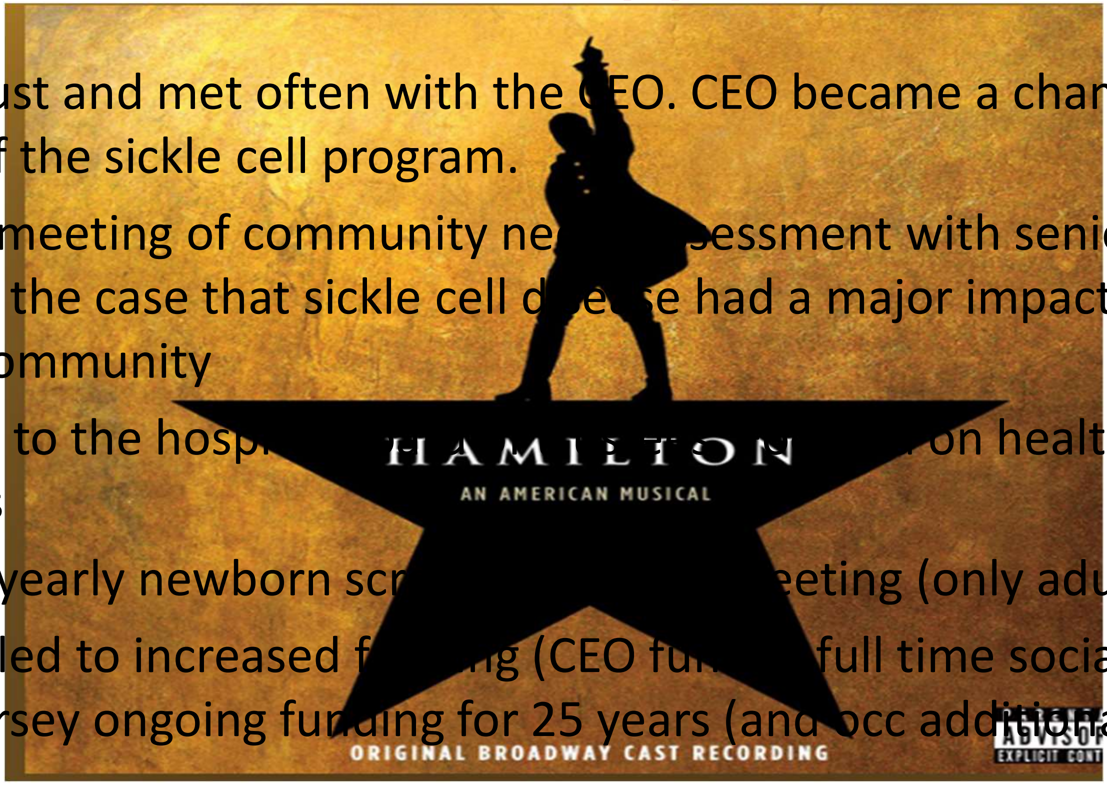
- Applied and received funding from HRSA for 4 years
- Funds were utilized to hire community health workers
- Start up money for a new CBO that affiliated with SCDAA
- Helped support administrative manager, MSW, CHWs, and data manager
- Created a community advisory board
- Trained team in QI
- Attempted to work with FQHCs
- Met other providers, CBOs, and leaders in the field and incorporated their successes

HRSA, Health Resources and Services Administration; QI, quality improvement; FQHC, Federally Qualified Health Centers

If you build it, they will come!

- Once the structure was in place the referrals came from within the hospital, outside the hospital, and physicians
- Attended regular CBO events, patients and families began to self refer
- Lectured at medical grand rounds in the New Jersey and New York areas and became known as a Comprehensive Sickle Cell Program
- Interacted with pharmaceutical representatives when new treatments became available

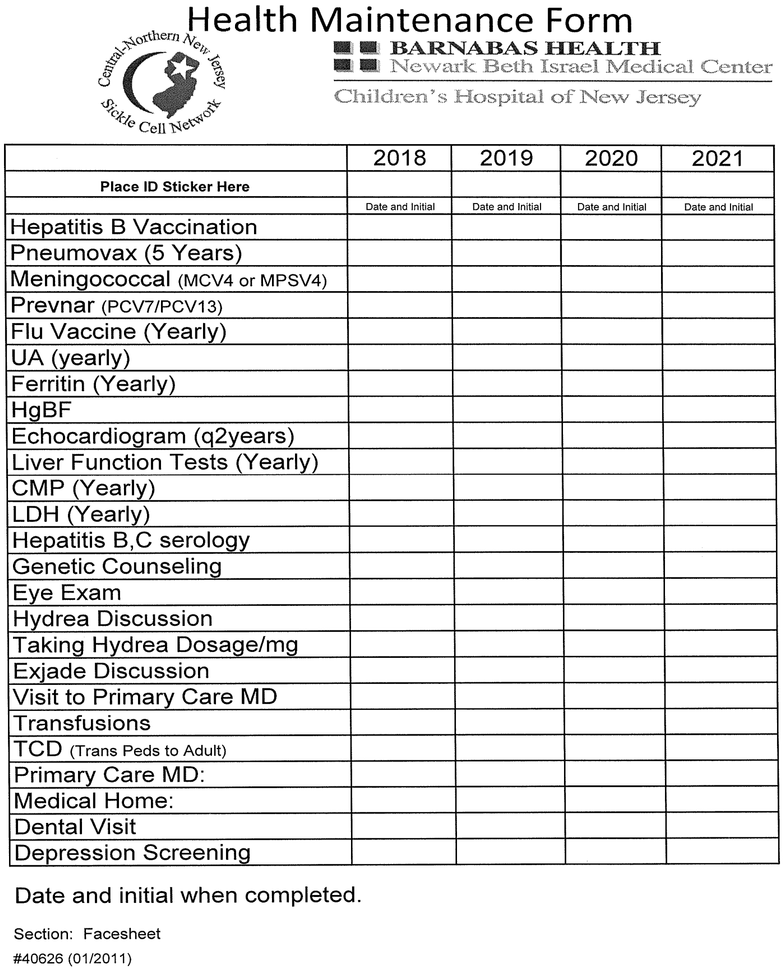
In the Room When it Happens



- Gained trust and met often with the CEO. CEO became a champion for support of the sickle cell program.
- Attended meeting of community ne[illegible]sessment with senior leadership and made the case that sickle cell d[illegible]e[illegible]se had a major impact on our hospital community
- Presented to the hosp[illegible] on healthcare disparities
- Attended yearly newborn scr[illegible]eeting (only adult provider)
- All of this led to increased f[illegible]ng (CEO fu[illegible] full time social worker), state of New Jersey ongoing fu[illegible]ing for 25 years (an[illegible] occ add[illegible]al funding)

Quality Improvement

- Increase partnership with PCPs
- ED experience
  - Increase time to treatment
  - Algorithm for standard protocol for pain management
- Introduction of comprehensive care checkoff list in the sickle cell clinic
- Increase use of hydroxyurea
  - Created educational video of patients speaking with patients
- Creation of an education program for transition care from pediatrics to adults starting in early teens
- Transfusion education program for hospitalists
  - Included giving them the ASH app for their phones with link to sickle cell guidelines
- Individualized pain plans



Health Maintenance Form

Central-Northern New Jersey Sickle Cell Network

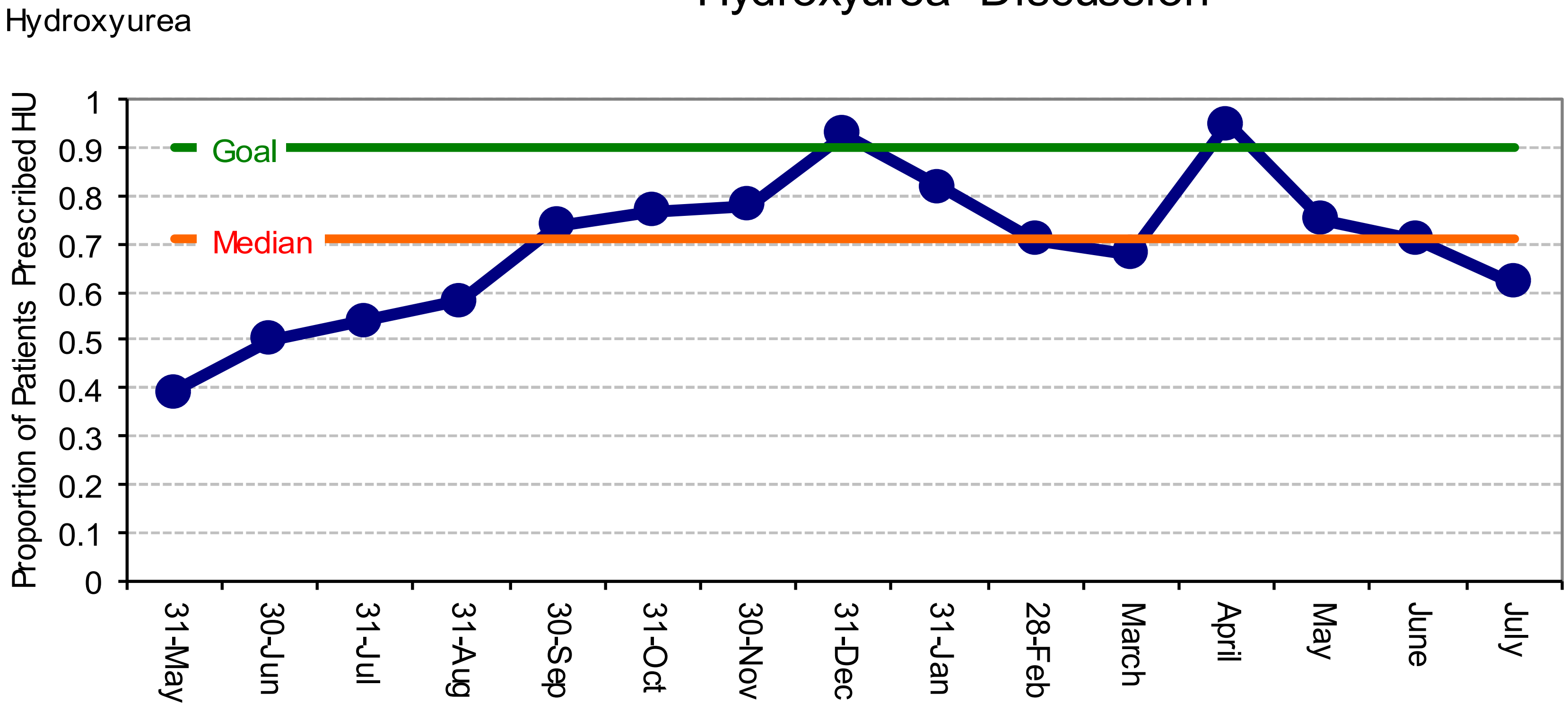
BARNABAS HEALTH
Newark Beth Israel Medical Center
Children's Hospital of New Jersey

	2018	2019	2020	2021
Place ID Sticker Here				
	Date and Initial	Date and Initial	Date and Initial	Date and Initial
Hepatitis B Vaccination				
Pneumovax (5 Years)				
Meningococcal (MCV4 or MPSV4)				
Prevnar (PCV7/PCV13)				
Flu Vaccine (Yearly)				
UA (yearly)				
Ferritin (Yearly)				
HgBF				
Echocardiogram (q2years)				
Liver Function Tests (Yearly)				
CMP (Yearly)				
LDH (Yearly)				
Hepatitis B,C serology				
Genetic Counseling				
Eye Exam				
Hydrea Discussion				
Taking Hydrea Dosage/mg				
Exjade Discussion				
Visit to Primary Care MD				
Transfusions				
TCD (Trans Peds to Adult)				
Primary Care MD:				
Medical Home:				
Dental Visit				
Depression Screening				

Date and initial when completed.

Section: Facesheet
#40626 (01/2011)

Hydroxyurea Discussion



Research: Can it be done?

- Most activity difficult as a free-standing small program
- Again, utilized staff in place for cancer program–CRNs agreed to take on projects
- Create a database to identify patients appropriate for study
- Fellowship/residency programs and medical students to analyze data and submit abstracts to ASH annual meeting, Miami Sickle Cell meeting etc., and some publications

Starting a Clinical Sickle Cell Research Program

- Initially referred patients to University Hospital at NJMS for hydroxyurea trial. They had the trial but few patients. Partnered with them on patient f/u.
- Experience in prior clinical trials led to participation in our first trial (ASSERT trial)
- More recently participated in HOPE trial and crizanlizumab trials
- Worked with CBO to continue education about what clinical trials are and the safety, risks, and benefits

Barriers

- Staff turnover and need for ongoing education
- Lack of insurance or underinsured
- Health care disparities and impact on pain management
- Change in administrators
- Lack of funding
- The EMR