

# Legislative Process

Sickle Cell Treatment Act  
AB 1488

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# AB 1488

- ◆ Conception and writing: 2015-2016
  - Concept bill written with the help of health care professionals and patients
  - The bill would, in part:
    - Fund two to three sickle cell centers to guide sickle cell care in the state
    - Fund Project ECHO telementoring throughout the state for PCPs
    - Incentivize PCPs
    - Fund a website promoting SCD information for providers and patients
    - Fund social services, psychological services, transportation
    - Fund a State Advisory Committee composed of MDs, Other Providers, Patients
  - Cost<sup>1</sup> of the bill:
    - Cost of care for sickle cell disease in 2014 was 800 million dollars for 7000 patients
      - About \$114,000.00 per patient per year
    - Cost of AB 1488: 20 million first year, 15 million for next four years
      - About \$ 4000.00 per patient per year or about 3% of the estimated cost of care

1. Billing, not the payment to insurers

# Author, Sponsor and Presentation

- ◆ The sickle cell team and patients/families met with Assemblyman Tony Thurmond (15<sup>th</sup> district) in 2015
- ◆ Thurmond, author; Quirolo, sponsor
- ◆ Concept bill submitted to the legislative counsel for writing
- ◆ Bill introduced to the California State Assembly as AB 1488
- ◆ California Black Legislative Caucus made sickle cell disease a priority
- ◆ Bill presented to the State Assembly in February 2017
- ◆ California Department of Healthcare Services asked to provide technical assistance



## AB 1488– Sickle Cell Treatment Act

### IN BRIEF

### BACKGROUND

Sickle cell disease affects approximately 7000 people in the State of California. It is an inherited disease that affects primarily African Americans and Hispanics, it is a lifelong disease that generally becomes worse with age. For those with this disease the quality of life is poor due to their disease and the fact that there are few adult physicians specializing in sickle cell disease

The bill proposes to create three to four sickle cell treatment centers in the State of California providing the state with Best Practice Guidelines to be used by all health care providers who care for patients with sickle cell disease. These centers will become resource centers to provide expertise and training for health care providers within the State.

AB 1488 increases the reimbursement for the care of adults who have sickle cell commensurate with the complex care needed to support these individuals.

# Assembly/Appropriations

- ◆ Created FACT SHEET with personalized cover letter attached
- ◆ Asked email list of stakeholders to periodically write to their assembly person as the bill moved through the legislature
- ◆ Phone conference with Department of Public Health, Department of Finance, Health and Human Services
- ◆ Changes were made to the bill: DOF, CHHS would not support in any form
- ◆ The bill then went to the Appropriations Committee
  - There were significant amendments made in the Appropriations Committee
  - One sickle cell center proposed
- ◆ The bill was passed by the Assembly
  - Without funding

# Repurpose of AB 1488

- ◆ AB 1488 was amended to a new bill in August 2017:
  - AB-1488 County Juvenile Transition Centers

# Lessons Learned

1. It is difficult to navigate the legislative system without experience
2. It is difficult to work by yourself to keep a bill moving
3. Legislators have many constituents and priorities
4. Legislation for a special interest group is difficult to advance
5. Important to get buy in from the Administrative Departments
6. Legislation that includes a substantial budget will be met with resistance
7. Legislators may not be interested in “hidden” costs only the cost of the bill they may be voting for
8. Amendments and committee discussion of the bill are done in private

# Next Steps

- ◆ Building Legislative Champions
  - On the Budget Committee, Health Committee, and Black Caucus
- ◆ Educating the Legislature and the Administrative Departments
- ◆ Legislative hearing in the fall based on the action plan
  - Determine what legislation is needed for 2019
- ◆ Priorities for 2018
  - Ensure opioid epidemic response has a sickle cell component
  - Work with DHCS to fix the GHPP issues
  - Finding and building partnerships and speaking with one voice