

National Center on Birth Defects and Developmental Disabilities



DD19-1906 Capacity Building for Sickle Cell Disease Surveillance

Session 7: Putting Surveillance Data to Work

March 5, 2020



Data to Support Funding

California Sickle Cell Data Collection Program

TRACKING  CALIFORNIA

INFORMING ACTION FOR HEALTHIER COMMUNITIES

Goal: Using Data to Improve Health Outcomes for Those with SCD

- Surveillance data support improvements in:
 - Care practices
 - Infrastructure/workforce development to improve access to care
 - Treatments
 - Expanding support systems (CBOs, educational support, etc.)
 - Understanding and awareness of SCD
 - Health outcomes for those living with SCD
- Surveillance data are low resource
- Surveillance systems are longitudinal

Sustainability

- Surveillance is not well-supported
 - Registry data are better
 - Administrative data are ‘free’ and easily obtained
 - Direct care and services are most-needed with tax dollars
 - Bench and treatment research happen with private dollars
 - Surveillance isn’t very flashy

So an additional goal: maintaining funding for surveillance

California's SCD Surveillance History

- RuSH (planned four years): 2010-2012
 - Staff left for other positions
- PHRESH 2012-2014
 - PI and Program Mgr returned
- SCDC 2015 – annual renewal to 2020
 - Staff expanded
- State funding 2019-2021
 - About 40% of needed amount to sustain program
- Long term funding for this system is needed
 - Historic funding is a series of pilot projects

Data to Policy to Funding – CA Example

- 2010-2017
 - CA creates a surveillance system
 - CA works hard to make stakeholders aware of system and availability of data for their needs
- 2018-2019
 - Stakeholders increasingly requesting and using data for program planning and evaluation, grant proposals, needs assessment
 - Initial attempt to get state funding to address SCD in state legislature
- 2019
 - Second attempt to get state funding
 - Surveillance as separate line item
 - Broad based, unanimous support from stakeholders

Next/Ongoing Steps for Sustainability

- Promote/encourage
 - Federal line item for SCD surveillance
 - Continued or increased funding from state
- Establish surveillance as necessary within our state
 - As many collaborators and stakeholders as possible
- Use surveillance model and expertise for other diseases
 - Lowers cost for SCD surveillance
 - Increases stakeholders and data sources
- Co-locate program with other similar programs for staff stability

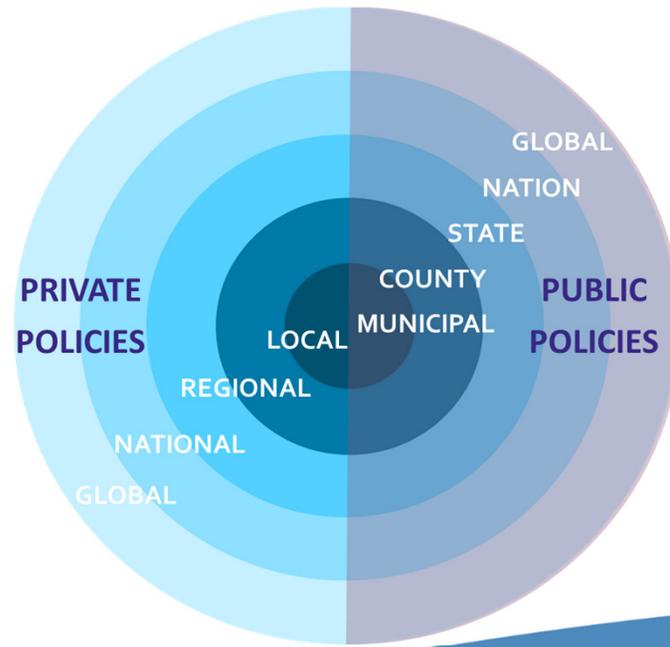


Putting Surveillance Data to Work

Angie Snyder, PhD
March 5, 2020



Policy Process & Stakeholders



Advocating for an Informed Process

ADVOCATE
for a way to
approach
problems
rather than a
specific solution

Bring in
relevant information
that is
integrated
translated, and
interpreted
from
primary and secondary research,
best practices, and
thought leaders

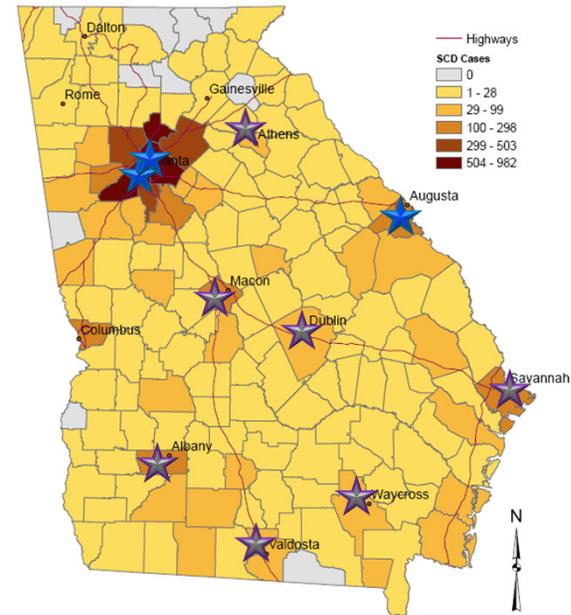
Create the RIGHT
environment to have
IMPORTANT
conversations

Data to Policy Action

Stakeholders: Health Systems,
Payers, Providers

Use: Allocate resources and hours
based on prevalent SCD cases

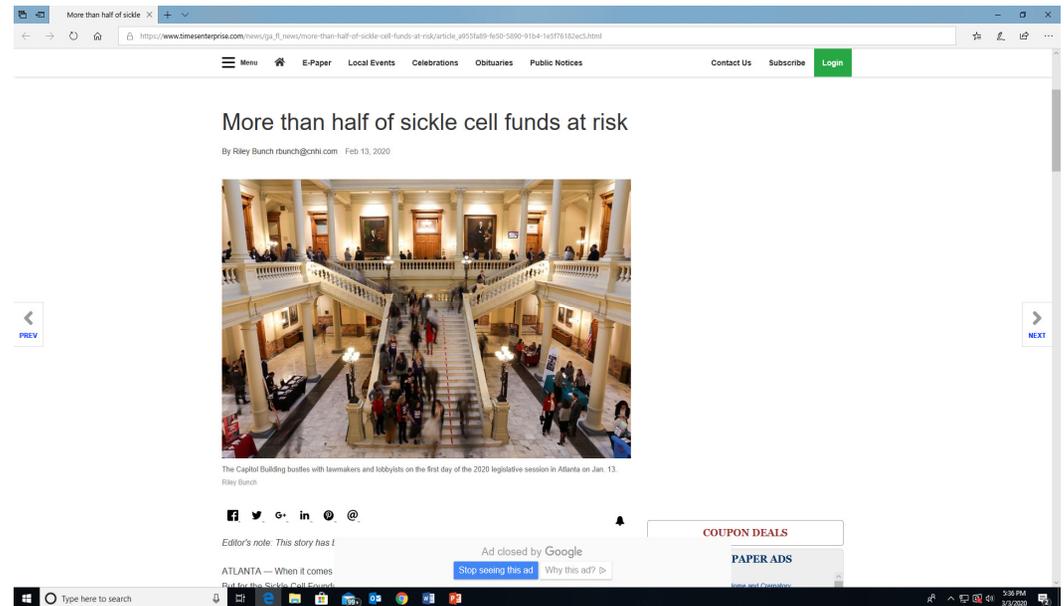
Use: Target provider education (ED
physicians, primary care,
hospitalists) by prevalence



Data to Policy Action

Stakeholders: Affected populations, SCD Advocacy organizations

Use: Maintain funding for trait education and screening



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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

