SERGG SICKLE CELL INITIATIVES

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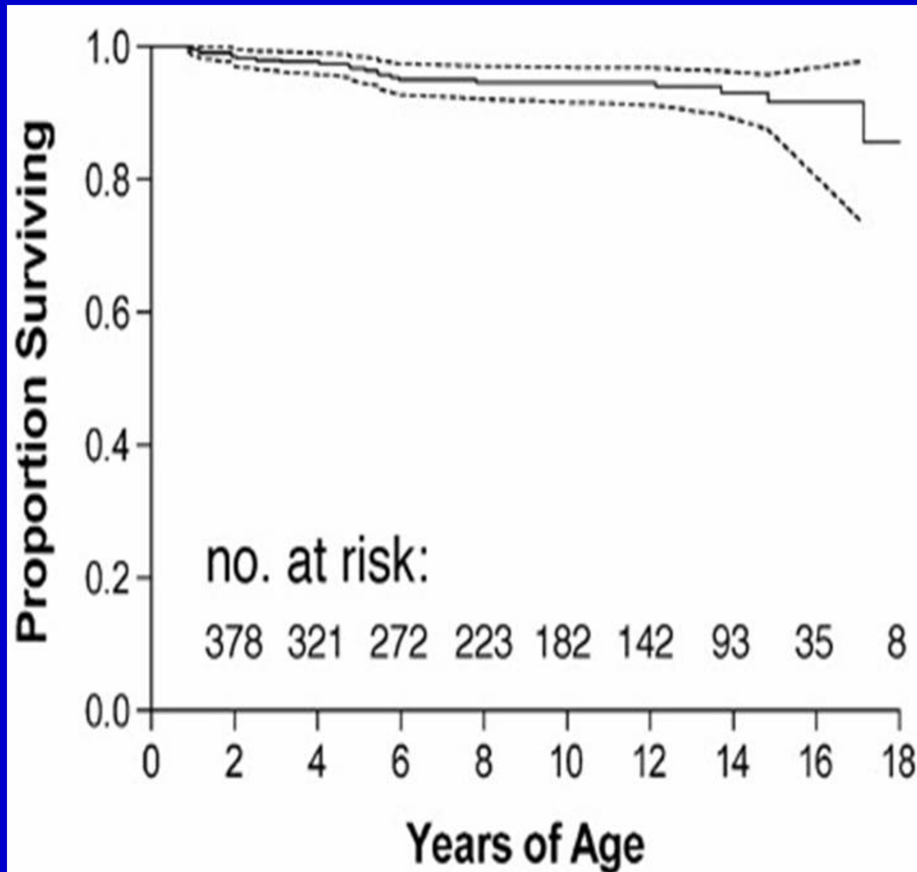
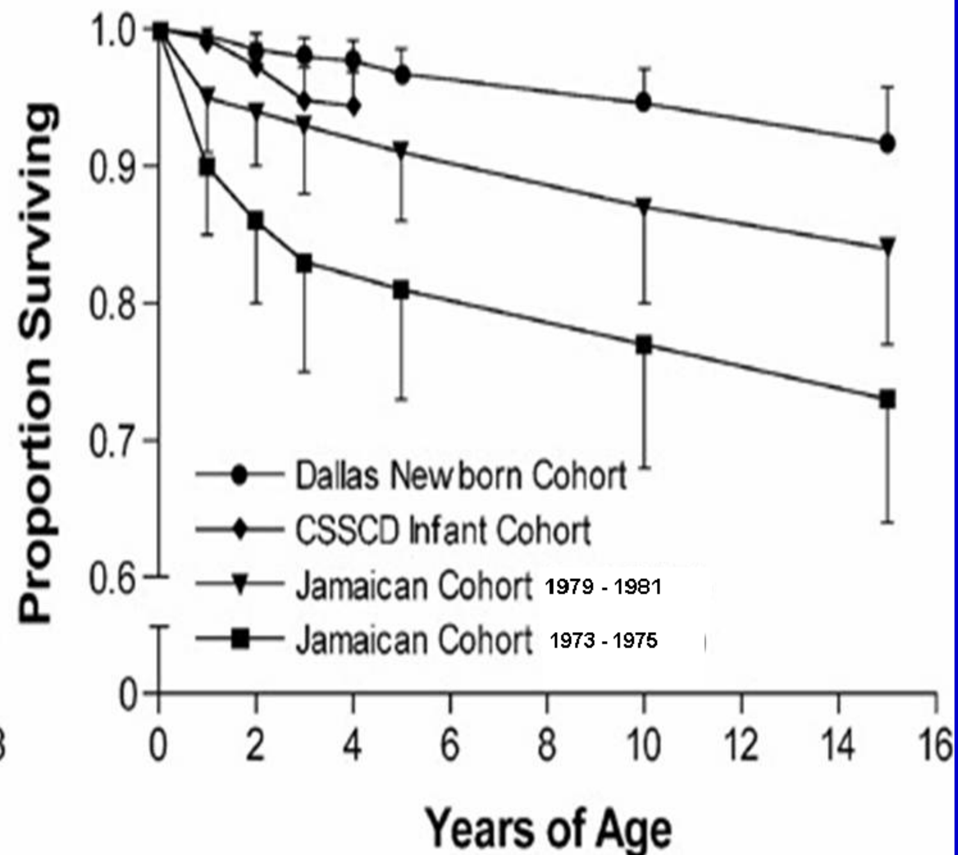
SERGG SICKLE CELL HISTORY

- Sickle Workshop focused on newborn screening
- TASCS Force helps four states start newborn screening
- CORN working group outlines program designs
- TASCS Force helps Region and six other states start programs

SICKLE SURVIVAL

Quinn et al Blood 2004;103:4023





COMMON OPPORTUNITIES FOR IMPROVEMENT IN ADULT CARE

- Sickle cell disease exacerbates in late teens and twenties
- Lack of independence - Learned helpless
- Chronic illness behavior
- Transfusion related problems
  - Venous access
  - Alloimmunization
  - Iron overload
- Chronic pain states

POTENTIAL SOLUTIONS

- Early intervention using newborn screening as an opportunity to educate the parents and family
- Improve the adult medical home
- Develop effective transition programs to establish an effective adult medical home

EARLY FAMILY INTERVENTION

- Address medical issues
- Provide parent education
- Provide extended family education
- Improve social support
- Increase psychological functioning
- Address financial functioning

Nurse Home Visitor Program

David Olds: Elmira, Memphis, Denver

- Prenatal and two year postnatal intervention
- Treatment effects up to 15 years
  - Mother and child show reduced substance abuse, legal problems, dependence on welfare, risky sexual behavior
- Positive effects only in high risk mothers
- Nurses appear to be necessary
- Rigorous protocol and training

LIMITATIONS OF OLDS' MODEL

- Expensive
- Requires highly trained professionals
- Prenatal initiation of intervention
- Effects in high risk mothers and normal infants
- No sickle specific elements to guide parent and family education

TRANSITION

WHO, TO WHERE, WHEN,
and HOW?

WHO NEEDS TRANSITIONING

- Individual with sickle cell disease
- Primary care givers and family
- Pediatric health care team

TO WHERE

- **To No Where!**
- **Lack of knowledgeable health care providers for adults**

WHO REALLY CARES FOR ADULTS WITH SICKLE CELL DISEASE?

- Emergency Room Physicians
- Hospitalists
- General Internal Medicine and Family Medicine Physicians
- Oncologists/Hematologists

SUPPORT A SYSTEM OF PRIMARY CARE WITH BACKUP

- Adequate funding for primary care
- Protocols for primary health maintenance developed for and with generalists and physician extenders
- Protocols for and with Emergency Room Physicians
- Protocols for and with Hospitalists
- Support for Centers of excellence that know the disease and the patients

SERGG INITIATIVE IN PRIMARY CARE BACKUP

- Develop protocols with the two HRSA funded projects in our region
- Focus on protocols for pain management
- Develop protocols for home management, emergency rooms, and inpatients
- Assessment tools for management and outcomes assessment

WHEN
Eckman

- Starts early
  - Transition truly must begin at birth
- Based on developmental stages not age
- Never transfer, especially with crisis
- Formal celebration of the event near natural transitions

TRANSITION FACILITATION

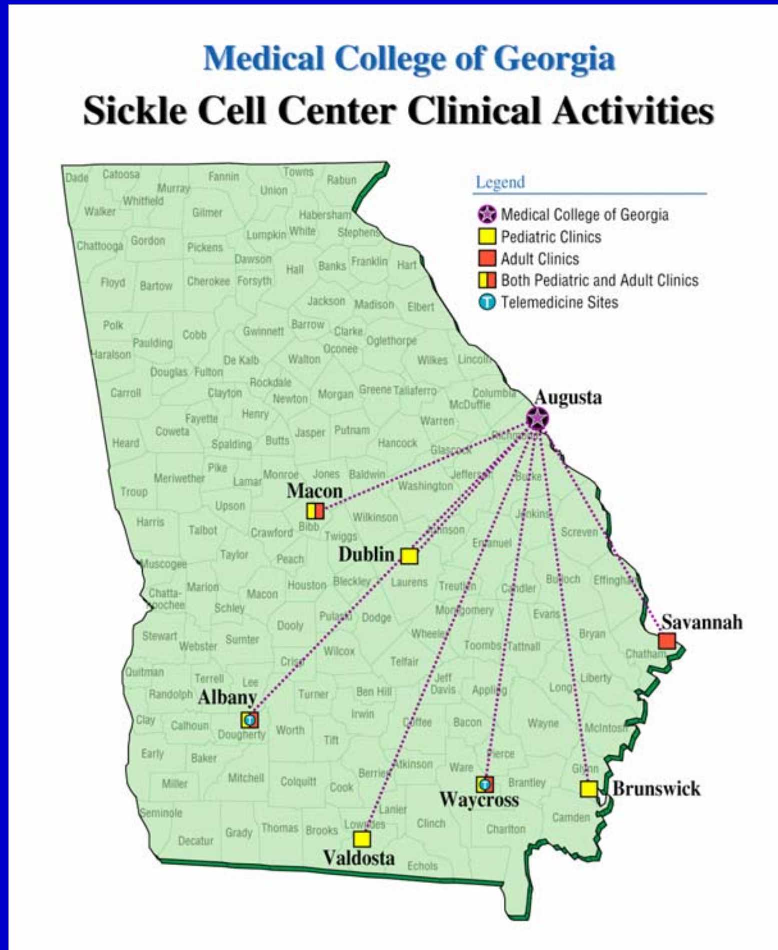
Reiss J, Gibson R. Pediatrics 2002;110:1307

- The family, young adult, and provider have a future orientation.
- Transition is started early.
- Family members and health care providers foster personal and medical independence
- Planning occurs for all future material needs.
- The youth verbalizes the desire to function in the adult medical world.
- Reimbursement for services is not interrupted and comparable.
- If pediatric providers continue care, it is shifted to adult care systems
- Individuals are able to continue to receive services from the same health system.

TRANSITIONS IN PARALLEL UNIVERSES *Eckman*

- Transition clinics for affected individuals – Pilot New Models
- Parallel educational activities for family and care providers
- Pre - and post - clinic meetings of the providers of pediatric and adult medical care

ASSESSMENT OF OUTCOME



- Database established by newborns screening results & annual update
- Similar networks of outreach clinics in Alabama, Georgia, and North Carolina
- Include two HSRA Sickle demonstration projects
- Explore NIH C-data or CDC hemophilia clinical database as models

THANK YOU !!

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