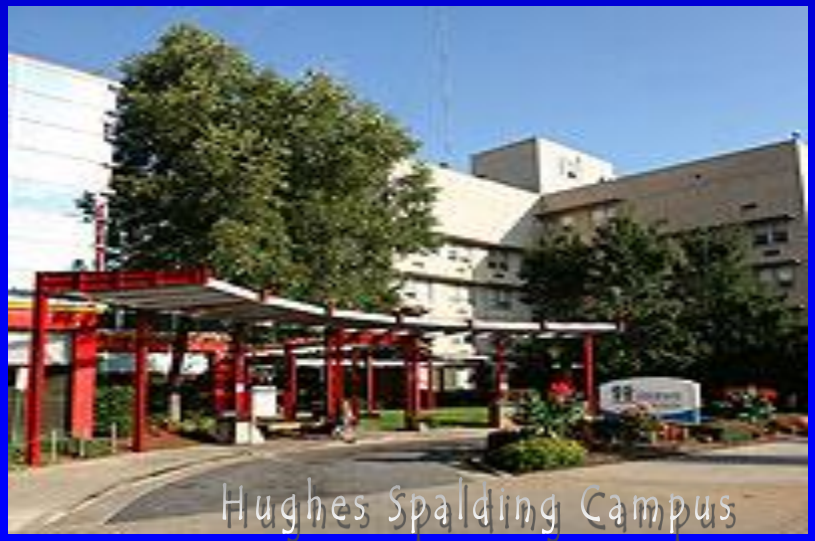
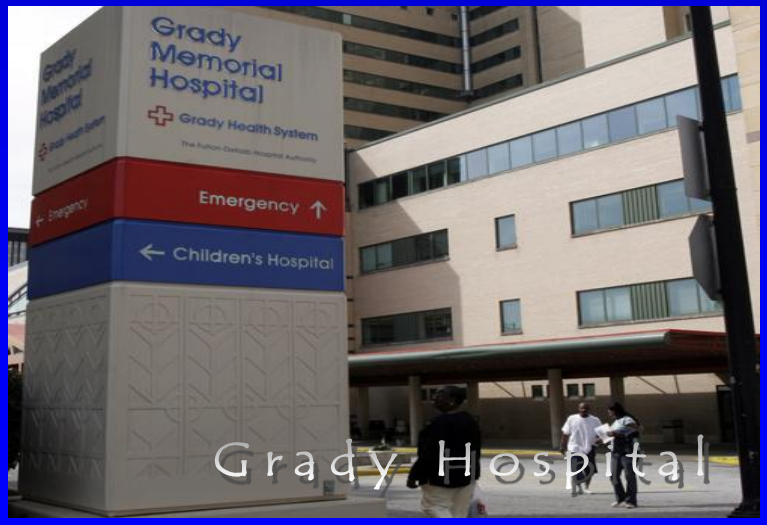
Transitioning sickle cell patients from Pediatric care to Adult care





TRANSITION TEAM

- Alcuin Johnson, PhD
- Ify Osunkwo, MD, MPH
- James Eckman, MD
- Daphne Blakley, PAC
- CHOA Staff on 3 campuses
- Grady Sickle Center Staff
- Many others

The Transition Team

- Social Workers
- Psychology
- Child Life Specialist
- Program Coordinator
- Admin Assistant
- Nurses
- Schedulers
- Parents
- Patients
- Psychologist
- Pediatric Hematologists
- Adult Hematologist
- PNP

Hypothesis

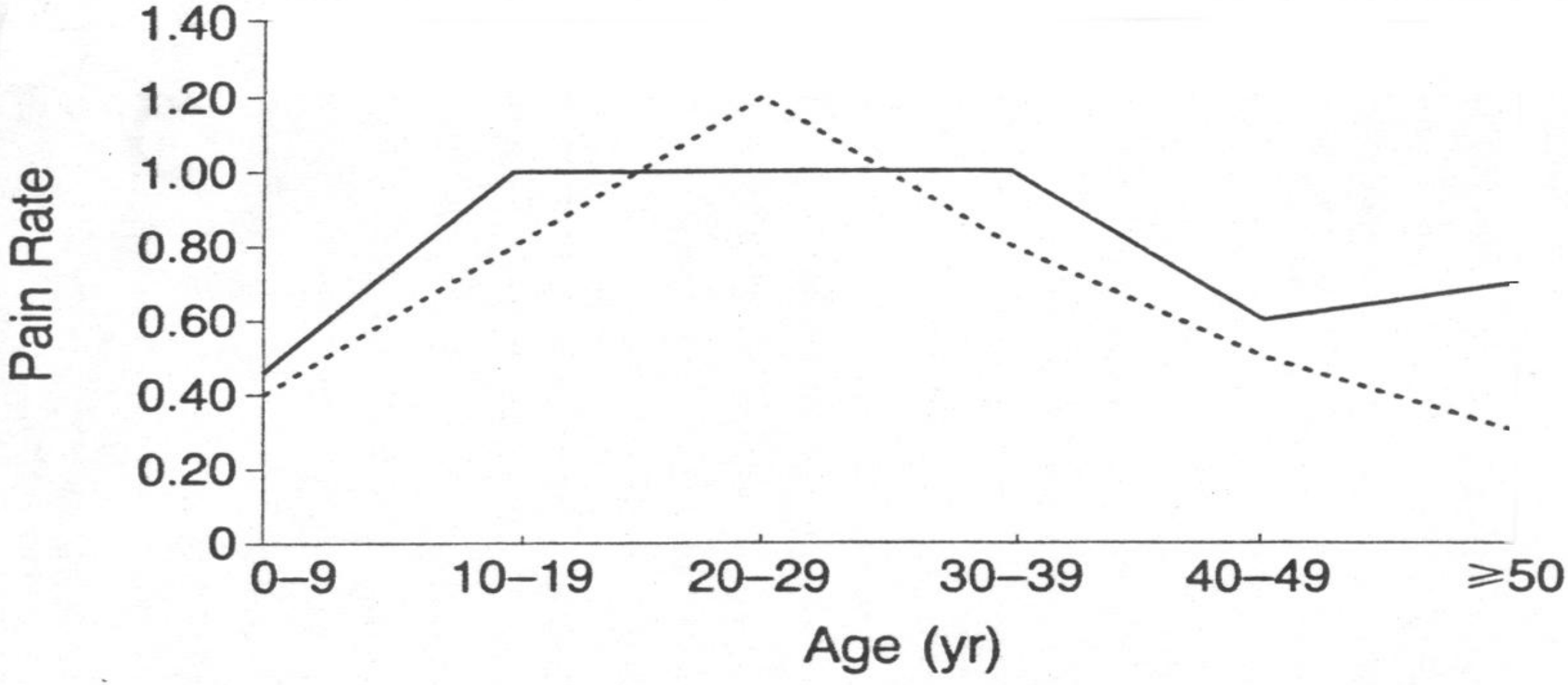
Three Groups Need To Be transitioned for this to work:

1. Patients before they enter adult care
2. Families and primary care givers
3. Pediatric and adult healthcare providers

INDIVIDUALs WITH SICKLE CELL DISEASE

- Transition from child oriented care to adult oriented care – Fear of the unknown
- Traditionally occurs at a time that the disease becomes worse
  - Increased frequency and severity of pain
  - Sickle SC and SB plus thal have first and progressively more severe problems
- Goal of independence medically, emotionally, socially, and financially
- The individual feels more ready than the family and health care providers

PAIN RATES BY AGE



Females	527	336	242	97	38	16
Males	566	299	182	76	23	10

Figure 2. Age-Specific Pain Rates (Episodes per Patient-Year) among Male (Dashed Line) and Female (Solid Line) Patients with Sickle Cell Anemia.

Platt OS et al. New Engl. J. Med. 325:11 - 16, 1991.

TRANSITIONING

A TALE OF TWO CARE CITIES

PEDIATRIC CENTERED	ADULT CENTERED
• Nurturing	• Informing
• Parent Centered	• Patient Centered
• Universal funding	• Unfunded
• Family insurance provided	• Employment based insurance
• Paternalistic	• Total Autonomy
• Centralized	• Fragmented
• Usually informed providers	• Often ignorant providers

TRANSITIONING

A TALE OF TWO CARE WORLDS

PEDIATRIC SICKLE CELL	ADULT SICKLE CELL
• Golden years	• Turbulent years
• Episodic acute pain – opioids OK	• Chronic unremitting pain – opioids BAD
• Goal - pain free	• Goal - adjust to pain
• Fewer problems	• Increasing problems
• Acute illness	• Chronic dysfunction
• Immortality of youth	• Symbiosis with disease

Adult – Pediatric Round Tables

- Pre-conceived ideas about each other
- Distrust in ability to "do it right"
- Poor cross communication
- Limited knowledge base about opposite specialty

WE NEED TO TALK…MORE

BASIC PLAN

- Quarterly Programs
- Ages 12 to 21
- Started 17 to 21, 14 to 16, then 12 to 13
- Rotate through campuses
- Morning of information for children and patients
- Males, females and parents split for lunch and discussion groups with 1 or 2 adults as resources
- Tour or wrap up depending on campus

Execution of Plan

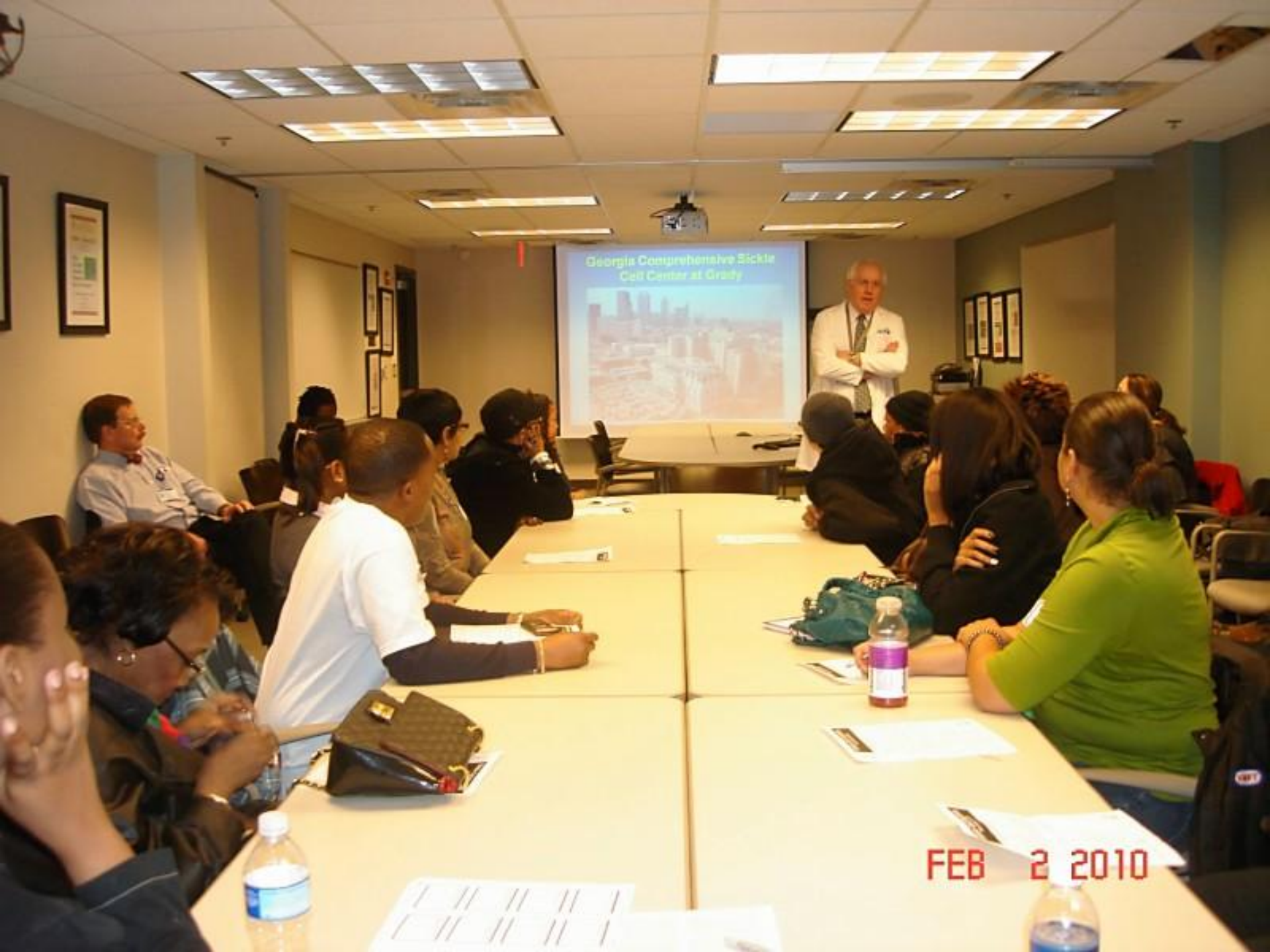
- Committed group
- Institutional Support
- Facilities
- Needs Assessment:
  - What do the KIDS want? Fun not Fear
  - What do the Parents want? Safe not Sorry.
  - What do the Providers want??
- Patience and Persistence

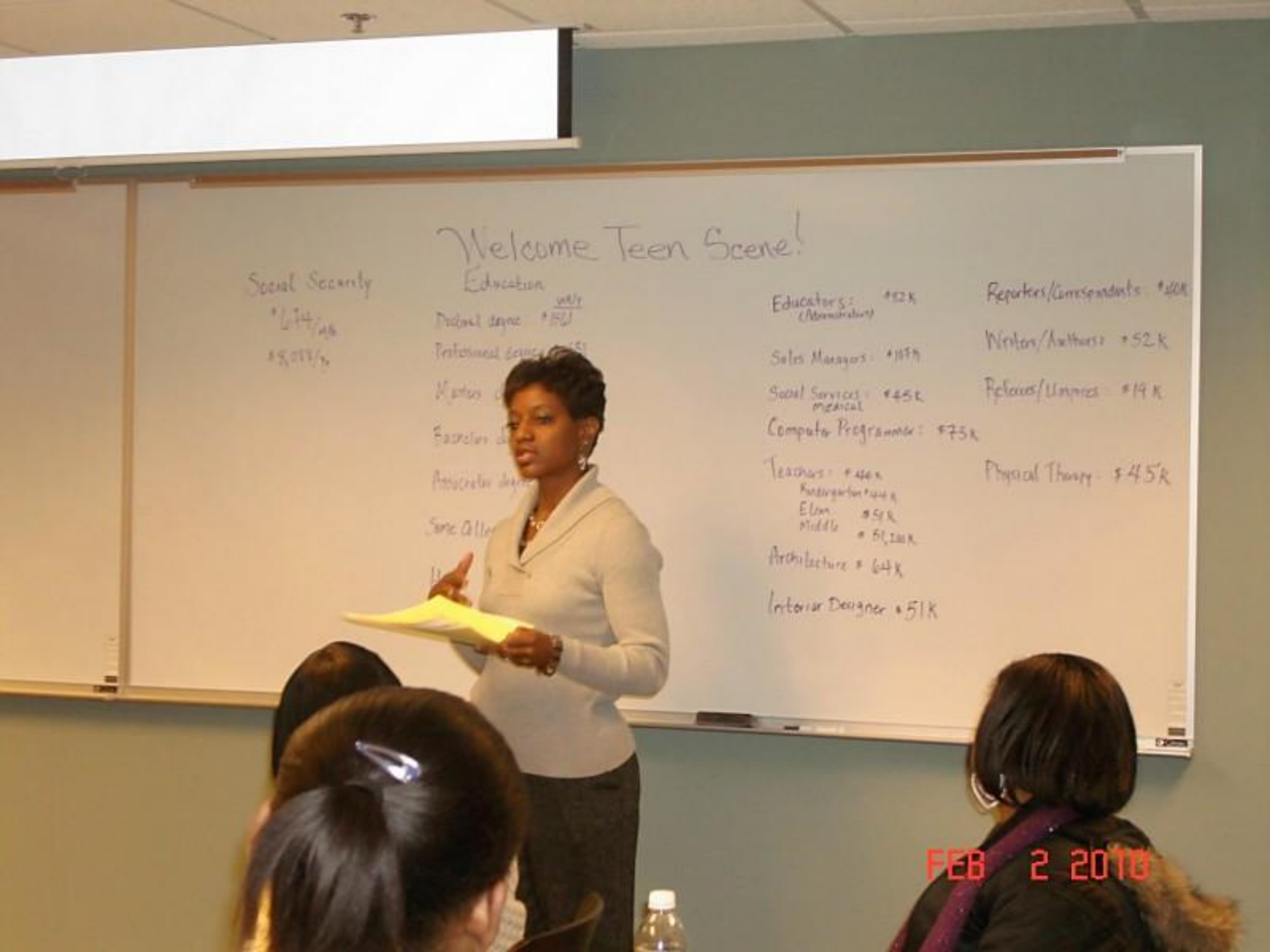
Execution of Plan

- Modify and adapt to realities of life
- Transportation
- Food
- School /Work excuse
- Coordinate with school calendar
- Show families your success
- Educate – pictures / AV really helps
- Rewards?

Teen Scene Transition Program Agenda

- Tour of Adult Facility 10 - 11:00
- All About the Benjamin's (Financial planning) 11 - Noon
- "Girl Talk" "Guy Talk" 12–12:30
- Parents: Life after High School 12–12:30
- Life after High School (Vocational Rehab) 12:30 - 1
- Open Discussion
- Teens: Sickle Cell's Top Ten List, *Panel* 1 - 2 pm
- Wrap Up 2 - 2:30


Georgia Comprehensive Sickle
Cell Center at Grady
FEB 2 2010


Welcome Teen Scene!
Social Security
Education
Educators: *52K
Sales Managers: *187K
Social Services: *45K
medical
Computer Programmer: *75K
Teachers: *46K
Kindergarten *44K
Elem *51K
Middle *51,280K
Architecture *64K
Interior Designer *51K
Reporters/Correspondents: *40K
Writers/Authors: *52K
Physical Therapy: $45K
FEB 2 2010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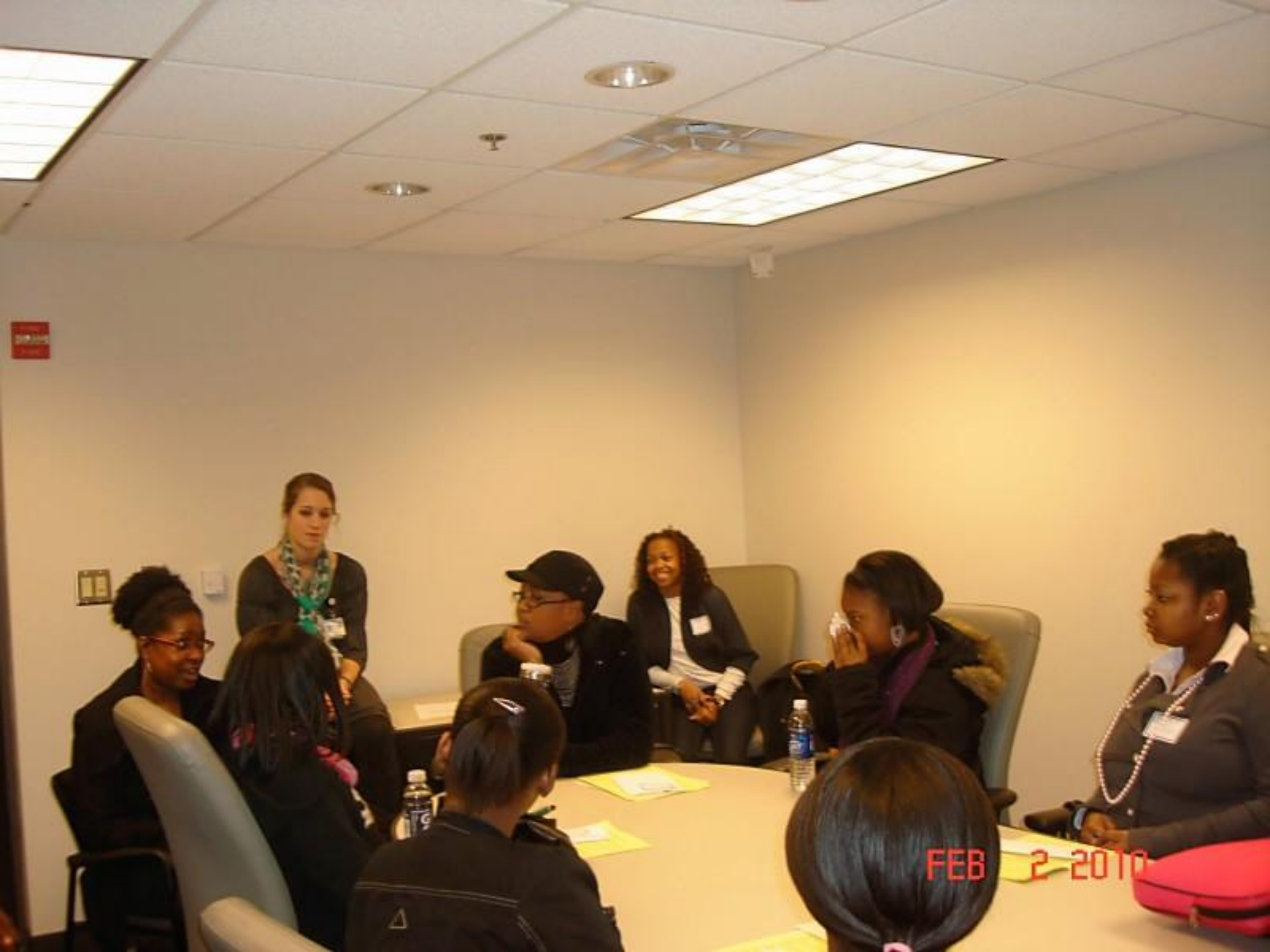
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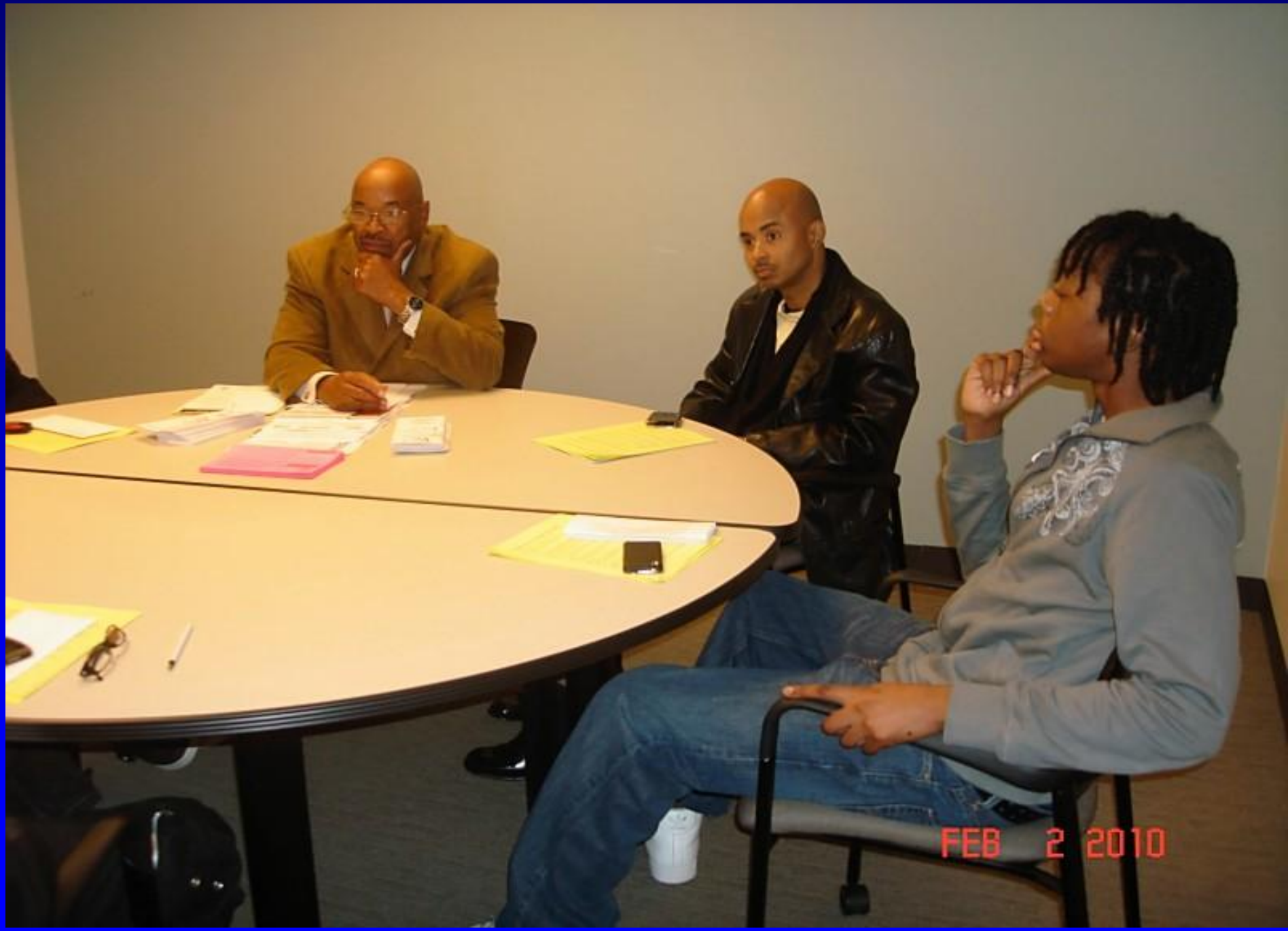
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The 10 COMMANDMENTS

1. *Accept Your Disease, Don't Ignore it. Respect it, don't fear it.* Learn how to master it, not let it master you.
2. *Take Good Care Of Yourself. There is only ONE YOU!* Practice healthy eating habits; drink plenty of low sugar/salt fluids; get adequate sunlight exposure and rest; get some aerobic exercise. Take care of your MIND BODY AND SOUL.
3. *Pace Yourself. If you overdo it, you will experience pain. Once you master your tolerance levels you will do much better.*
4. *Remember You CAN Do EVERYTHING you set out to do,* but ALWAYS be safe not sorry.

The 10 COMMANDMENTS

5. *Learn To Control Your Pain. Don't let your pain control you.*

6. *Develop A Focus On Some Thing's In This Life That Bring You Joy And Satisfaction.* Set goals and strive to achieve them.

7. *Establish Independence Socially, Emotionally, Economically and Medically.* Take charge of your disease. You own your sickle cell, your family and doctors can help you but it is not their disease it's yours. "OWN It!"

The 10 COMMANDMENTS

8. ***Establish An Effective Social Support Network within and outside your family.*** Seek supportive relationships with people who accept you as you are with all that comes with you as a package.

9. ***Don't Waste Your Pain Medication.*** Don't reach for the medicine cabinet. Treatments other than pills can reduce pain. Learn how to tailor the use of pain medication to the degree of pain you have. Over treatment leads to increased pain and reduced effectiveness of the medication and may also reduce your quality of life

10. ***Pain Is "A PAIN" But That Does Not Necessarily Mean Something Terrible is Happening.*** *All pain is not related to sickle cell disease and could have other causes*

Graduation – Sickle Cell Education Day

- Graduate October of yr they turn 18.
- Certificate and gift
- Public recognition
- Recruit graduates to help program
- Medical Transfer summary
- Start discussions early!
- Gently usher "relapser's" forward.
- Hope, Positive Outlook
- Expect problems.


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