VANDERBILT UNIVERSITY MEDICAL CENTER

Academic Activism: Choosing the right time and the right purpose

Michael R. DeBaun MD, MPH

Professor of Pediatrics and Medicine, Vanderbilt Medical School

Director of Meharry and Vanderbilt Center for Excellence in Sickle Disease

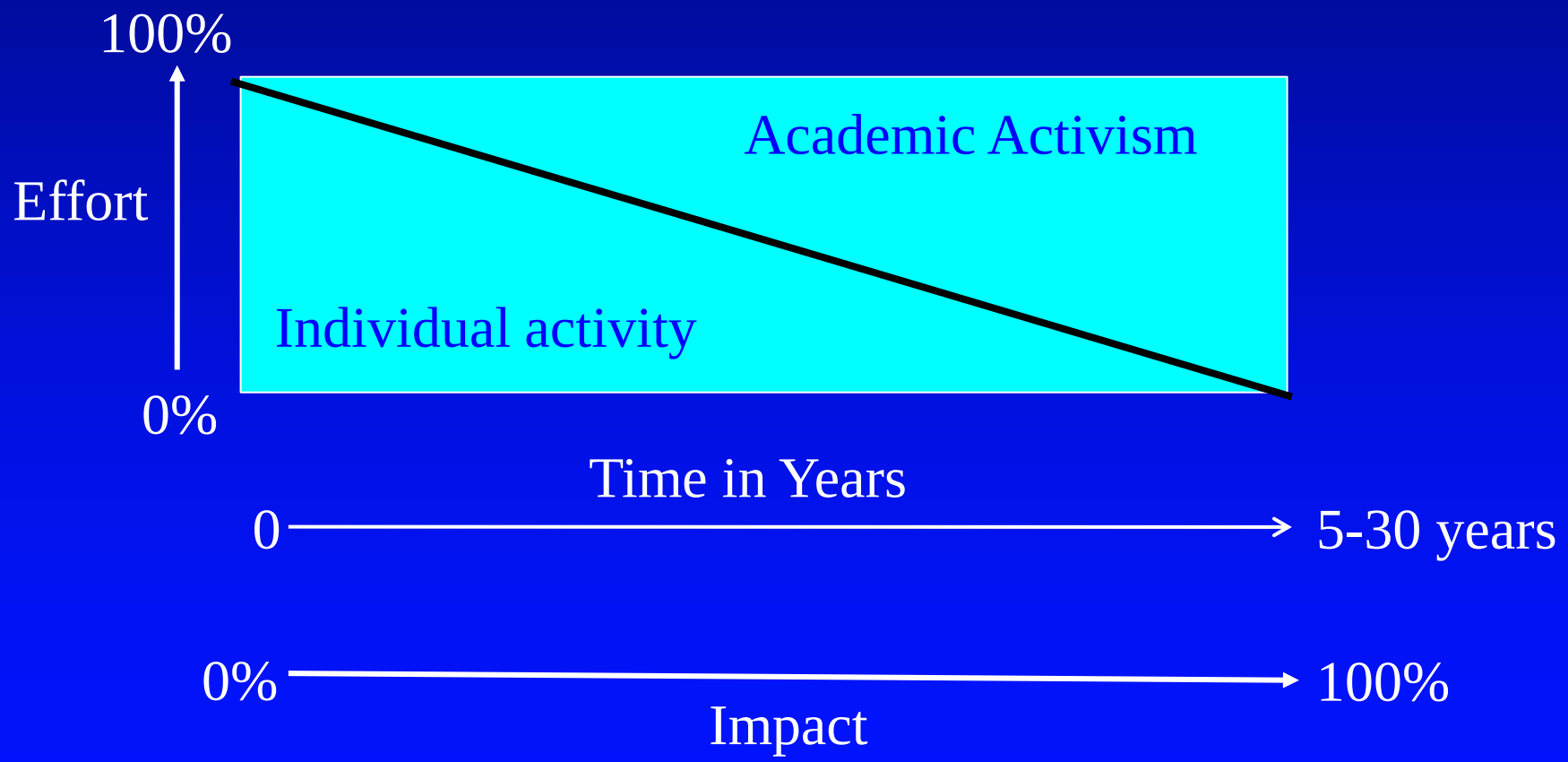
Monroe Carell Jr. Children's Hospital at Vanderbilt

- Experience
  - Medical school= 1982-1987
  - Junior Faculty 1996-2003-skipped
  - Mid level Faculty 2003- 2010-skipped
  - Mid life crisis-2010
  - Winter is coming -2020- almost skipped

Background

- **Activism** consists of intentional action to bring about change in one or more of the following domains (Wikipedia, 10/4/10)
  - Environmental
  - Social
  - Political
  - Economic
- **Activism-** not accepting status quo when you know you should and could do better

Individual Action
vs
Academic Activism



Medical Student-
Year 3 Stanford University

- Applicant to medical school
  - Interviewer
    - Comment about why the medical student should not be accepted included-
      - “Lack of ambition and desire to travel abroad and learn second language”
  - Applicant was rejected

What did I know that the interviewer did not know?

- First plane ride ever was from DC to Oakland
- No pre-professional advice
- First one to finish high school in family
- Worked full time to pay for college education while being 100% independent since 18 years of age

What did I do?

- Lobbied hard, real hard to
  - dean of admission
  - chair of faculty senate
- Burned significant amount of ATP focusing on the unfairness of the admission process
- “If he is rejected than your decision to accept me was a mistake”

End Result

- Admitted to medical school at Stanford
- Outstanding student
  - One of two students nationally to receive pre-doctoral award for neurosurgery research
  - Multiple manuscripts as a student
  - Matched his number one choice in neurosurgery

After a series of similar challenges throughout medical school and residency, I elected to change my approach

Assistant and Associate Professor
Washington University
1996-2003
“learning the status quo”

-No camp for children with SCD

-No social worker for children with SCD

-No effort by the American Red Cross to educate and improve the proportion of blood donations in the African-American Community

In 1996, as pediatric hematology-oncology clinical director Washington University School of Medicine

- Camp for children with cancer was a right of passage at SLCH
- No camp existed for children with sickle cell disease at SLCH

With hope and prayer, we cobbled together funds from outside of SLCH every year (2000-2009), until SLCH elected to support the camp

Mid-life Crises- 2010
“Unwilling to accept the status quo”

1. Why should a young adult with sickle cell disease, completely transition to an internist with no knowledge of the patient’s health care or family dynamics?
2. Why can’t we build a health care team for sickle cell disease that goes across the life-span that meets weekly to deliver and advance the care of individuals with sickle cell disease

Creation of a New Center of Excellence in Sickle Cell Disease 2010

Three Nashville institutions joined efforts to provide the best possible medical care for children and adults with sickle cell disease in the Middle Tennessee area from birth through adulthood. Those institutions included:

- Vanderbilt University and Medical Center
- Meharry Medical College
- Matthew Walker Comprehensive Health Care Center
  - Federal Qualified Health Center

MW CHC Matthew Walker Comprehensive Health Center, Inc.

Monroe Carell Jr. Children's Hospital at Vanderbilt
Where discovery brings hope

MEHARRY MEDICAL COLLEGE

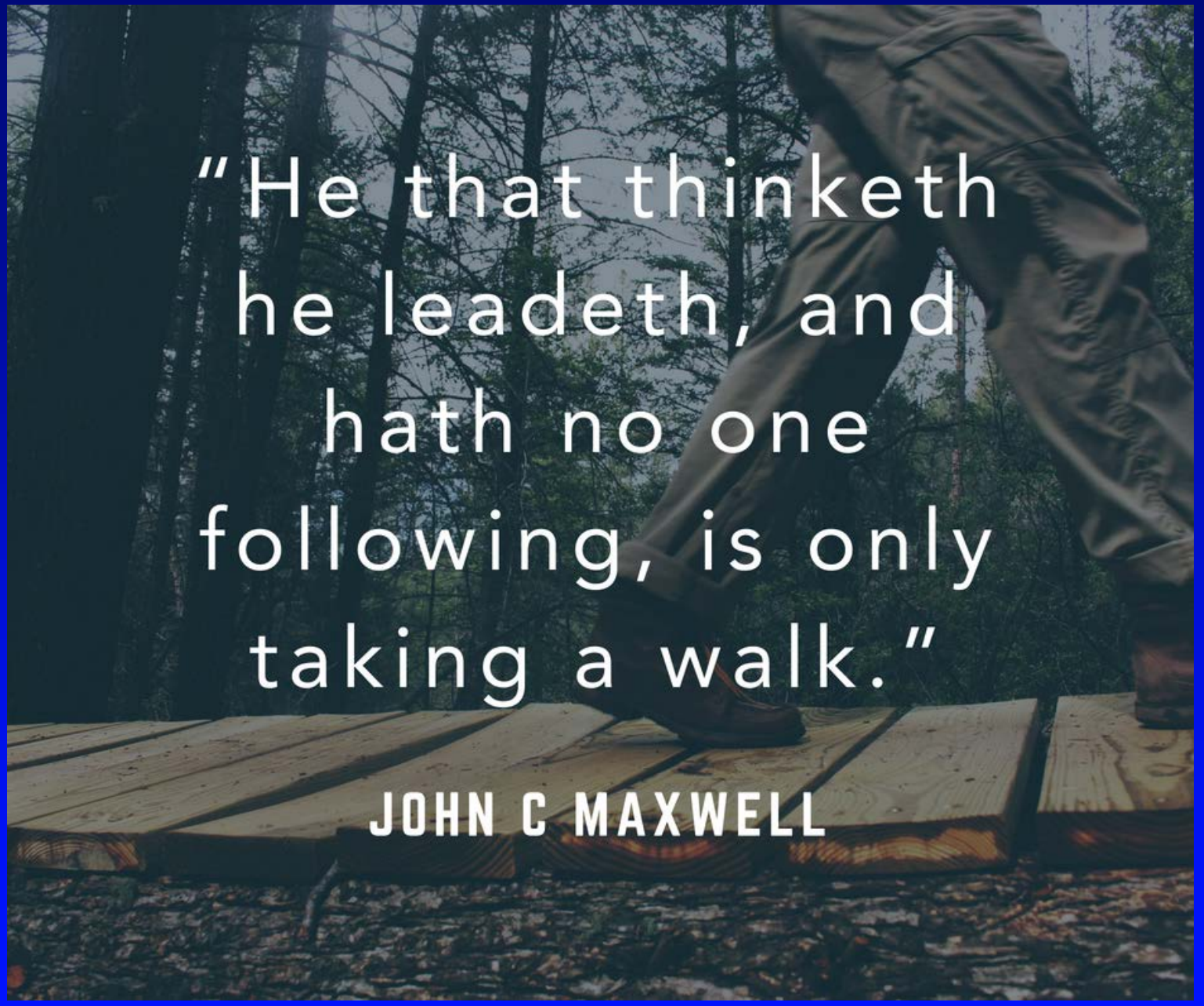
VANDERBILT UNIVERSITY AND MEDICAL CENTER

Our Mission: In a medical home setting, the best available medical care, educational support and research for all children, adults and their families whose lives are affected by sickle cell disease and asthma

- What does this mean?
  - Evening clinic weekly
  - Saturday clinic one a month
  - Pulmonary function lab with asthma case manager
  - Taking the extra step to know the families
    - Family retreat- philanthropy funded
    - Under 5 annual holiday party- philanthropy funds

Six months after stating the vision of the Center of Excellence

- The following individuals quit
  - The pre-existing pediatric hematologist
  - The pre-existing nurse case manager
  - The pre-existing social worker


"He that thinketh he leadeth, and hath no one following, is only taking a walk."
JOHN C MAXWELL

What does the medical home mean to a family?

“I have not planned a vacation in a while. All of my vacation days have been used to bring my son to sickle cell disease clinic. I guess we can plan a vacation now.”

Response of mother when I asked her how she liked sickle cell clinic visits on Saturdays at the Community Health center

Mid-life Crises- 2010
“Unwilling to accept the status quo”

1. Why is there is there no concerted effort to advance the medical care of children an adults with sickle disease in Africa where over 70% of the children are born?

Sickle cell disease in Nigeria: Road Trip

- Largest population of sickle cell disease in the world
- 150,000 children born/year with SCD, 50% of all births
- USA
  - 1,400 children are born/year in the US
  - An estimated 100,000 children and adults with SCD in the US

Weatherall DJ, Clegg JB. Bull World Health Organ. 2001. Fawibe AE, et al. West Afr J Med. 2010.

Summer of 2011 visit to Katsina, Nigeria
Camp for girls with SCD (sponsored by Morgan, Sandra, Faith and Amela)

Untold burden of strokes in children living in Nigeria

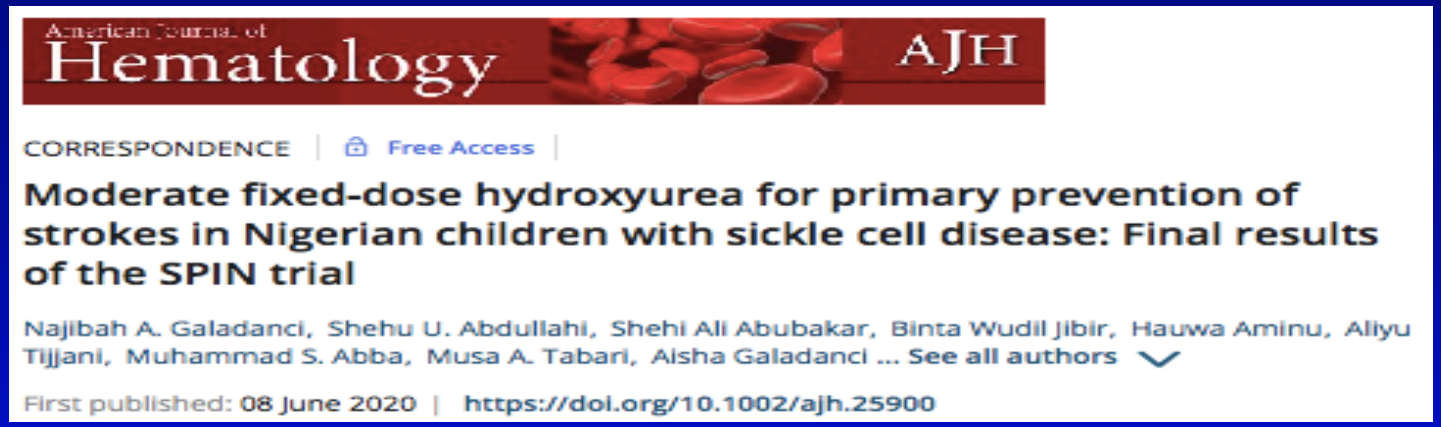
~15,000 strokes in birth cohort year that reaches 15 y/o

~ 45,000 silent strokes in birth cohort year that reaches 15 y/o

Extreme poverty for most children with sickle cell disease living in northern Nigeria

- 40% of the population, 83 million individuals live on approximately $1.00 per day
- Cost of CBC to assess hydroxyurea toxicity is $3.00
- Cost of European produced hydroxyurea is $0.50 to $1.00

Completed first NIH funded trial for SCD in Africa- The SPIN Feasibility Trial – 2012-2019 (R21)



- High recruitment rate: 90% (337 of 375) consented for screening
- Adherence rate to visits and medication: >95% adherence to monthly research visits for five years
- Significantly lower number of strokes in the single arm trial than in the untreated arm of STOP.
  - 1.0 strokes versus and expected 14 strokes (10.9 events per 100 person years in the observation arm of STOP trial)

NINDS R01 2025-2021

SPRING Trial: Primary Hypothesis

Daily hydroxyurea at a fixed moderate-dose (~20 mg/kg) will result in a 66% relative risk reduction for primary strokes (9 to 3 events per 100 person-years) in children with abnormal transcranial doppler velocities compared to a daily fixed low-dose (~10 mg/kg).

Conclusions after first visit to northern Nigeria- 2011 to 2021

- Initial low-dose hydroxyurea is as efficacious as moderate dose hydroxyurea for primary stroke prevention
  - Provides alternative therapy for stroke prevention without blood

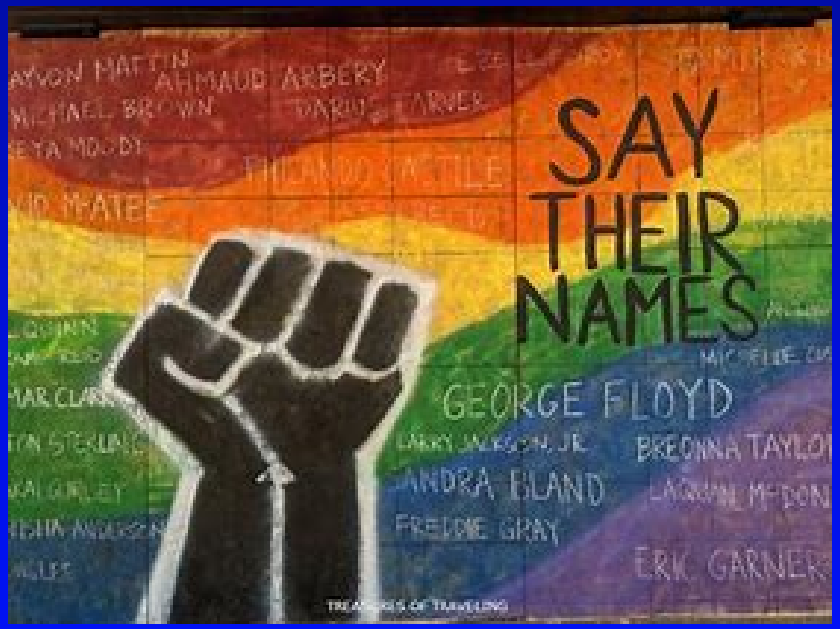
- Standard care for primary stroke prevention for 30,000 children with sickle cell disease in three states of northwestern Nigeria include:
  - free TCD measurements in 9 clinics across three states.
  - free state government sponsored hydroxyurea therapy at 10mg/kg/day, but higher if history of vaso-occlusive pain events at home (shared decision making)
  - routine biannual CBC

Standard Care-Impact of Stroke Prevention Teams in Northern Nigeria 2019-2021

	January, 2021
Total TCD performed	8,812
Total abnormal TCD	488
Percent with abnormal TCD – all treated with HU-self pay or state supported	5.54

Stroke Sickle cell Disease Stroke Team in northern Nigeria August 2019

How Do I March?



Winter is coming

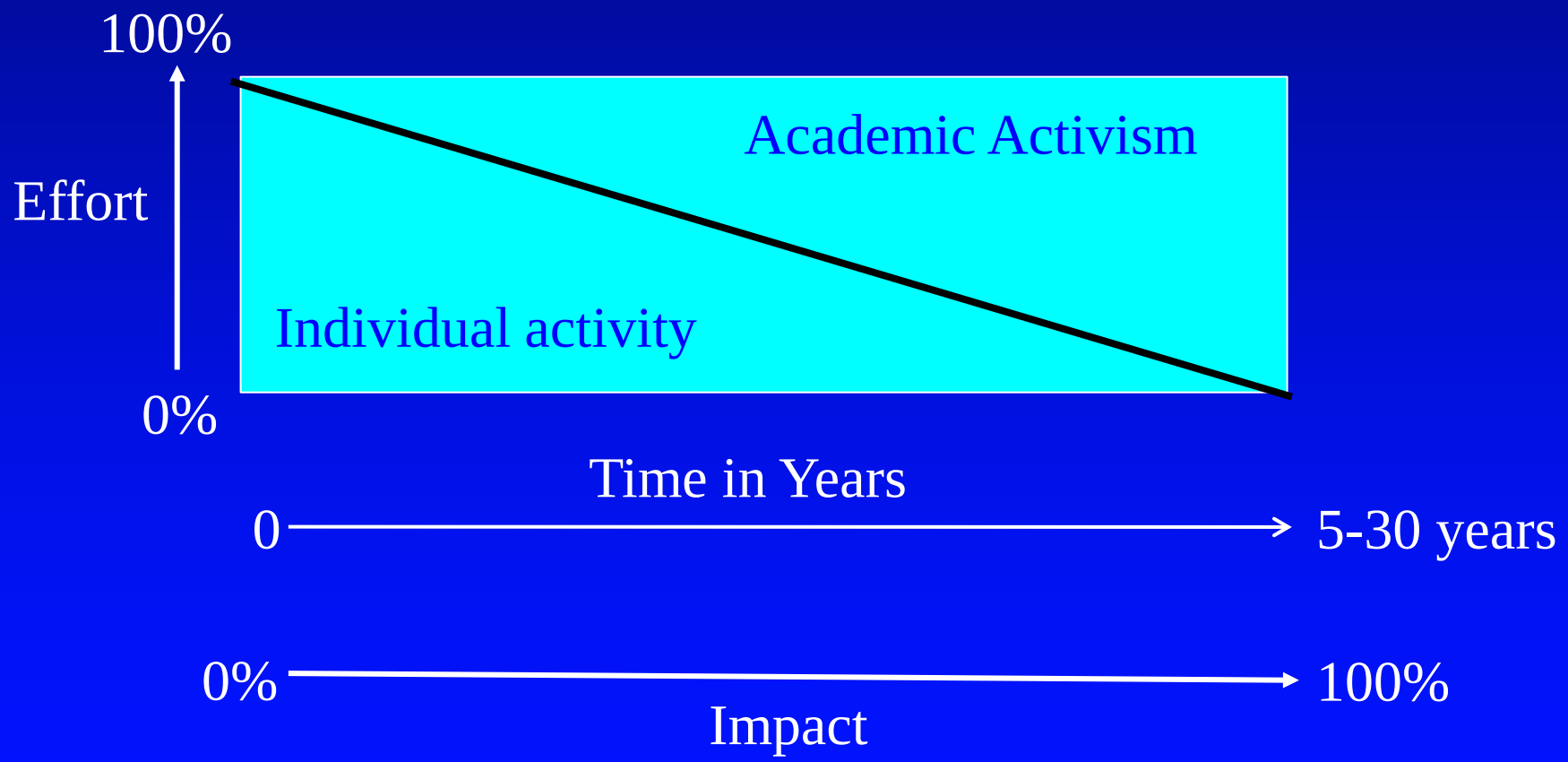
Summer of 2020

Vanderbilt-Meharry Pediatric Scholarship Program

Vanderbilt-Meharry Medical School Scholars Program: a pilot program to enhance the transition from medical student to physician-scientists and leaders

Funded via Burrough Wellcome Fund – 2021-2025

Individual Action
vs
Academic Activism



Thank You

- My wife Sandra
- My son and daughter
  - Malcolm
  - Morgan
- SLCH SCD Research Team
- VUMC Research Team
- Nigerian and Ghana Research Teams
- Families and children with sickle cell disease