



# ASTCT-NMDP ACCESS Initiative

**Jeffery J. Auletta, M.D.**

Co-Chair, ACCESS Initiative

Senior VP, Health Equity NMDP

Chief Scientific Director, CIBMTR NMDP

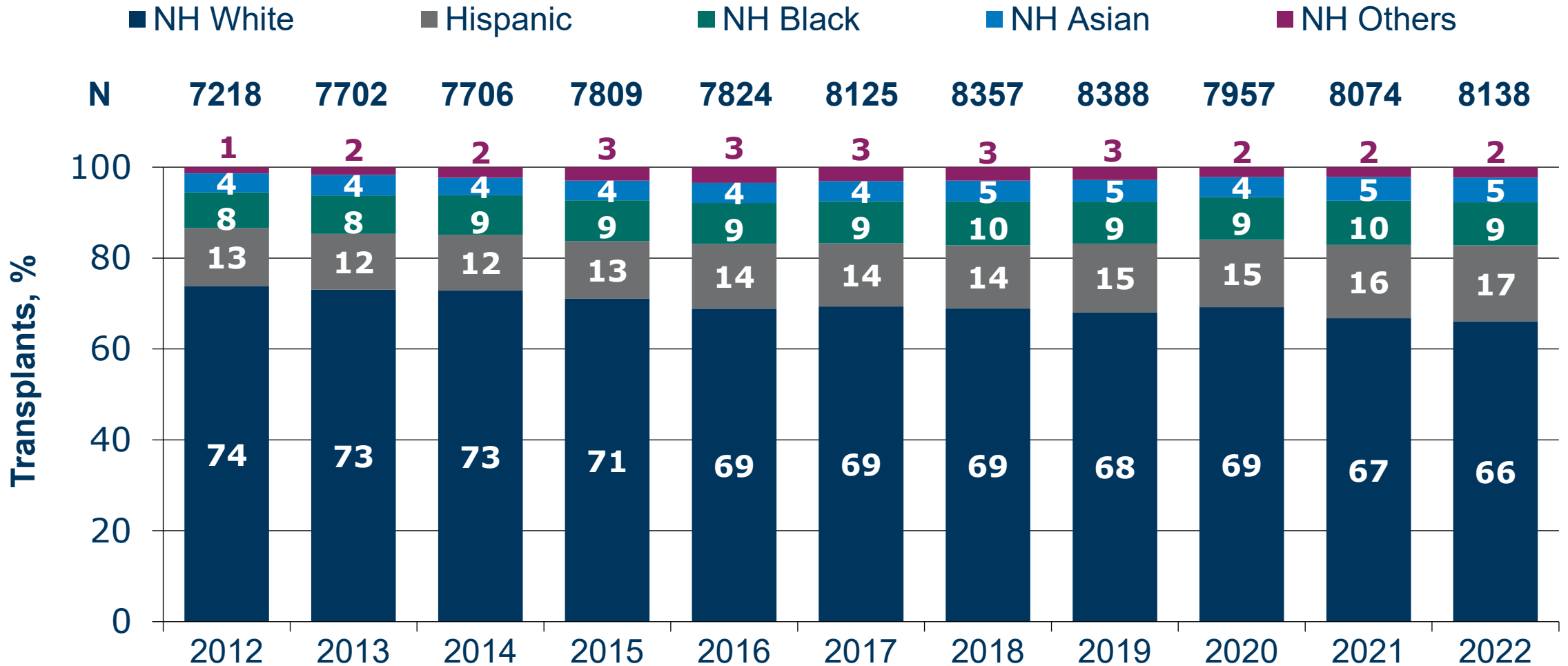
Advisory Council on Blood and Stem Cell Transplantation

August 22, 2024

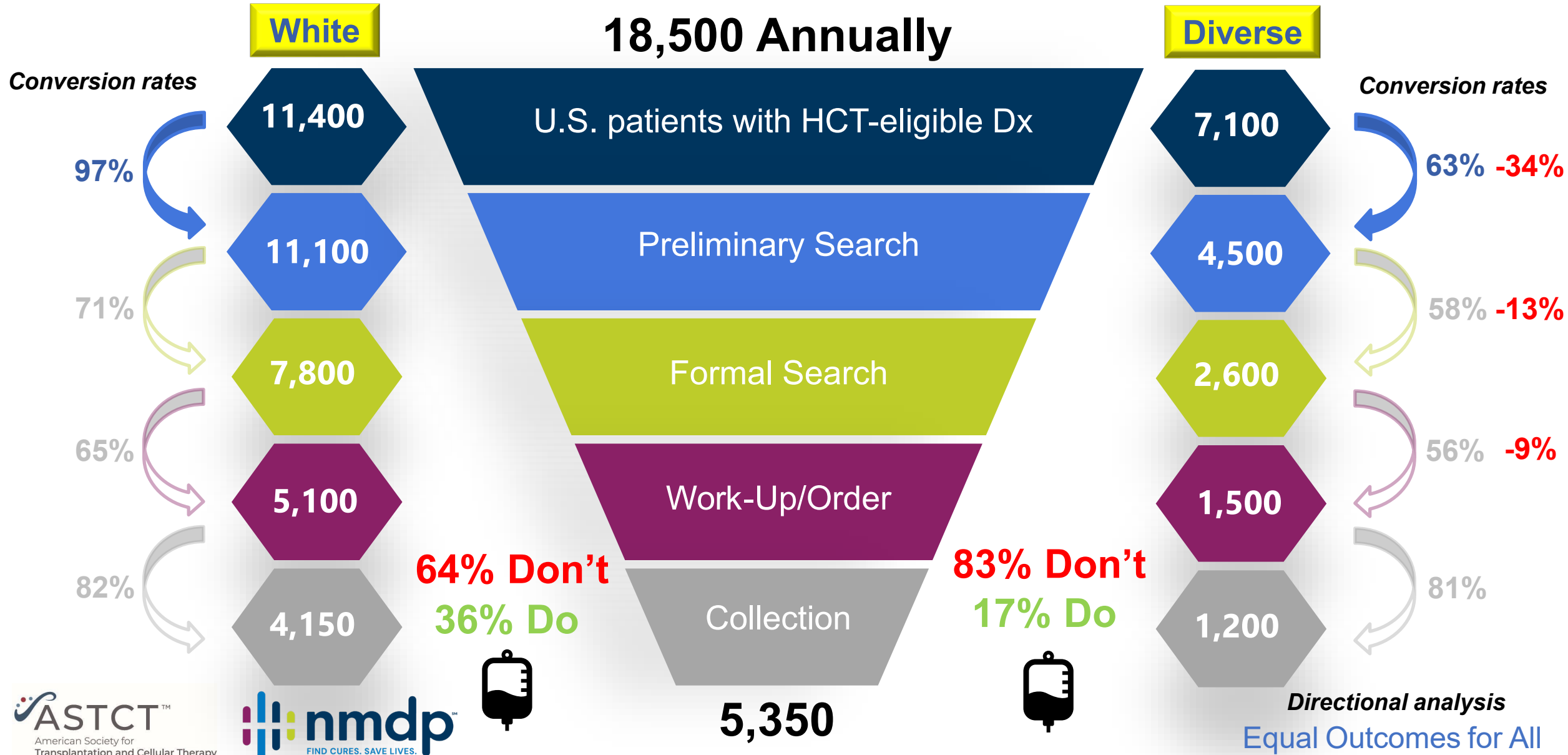


Equal Outcomes for All

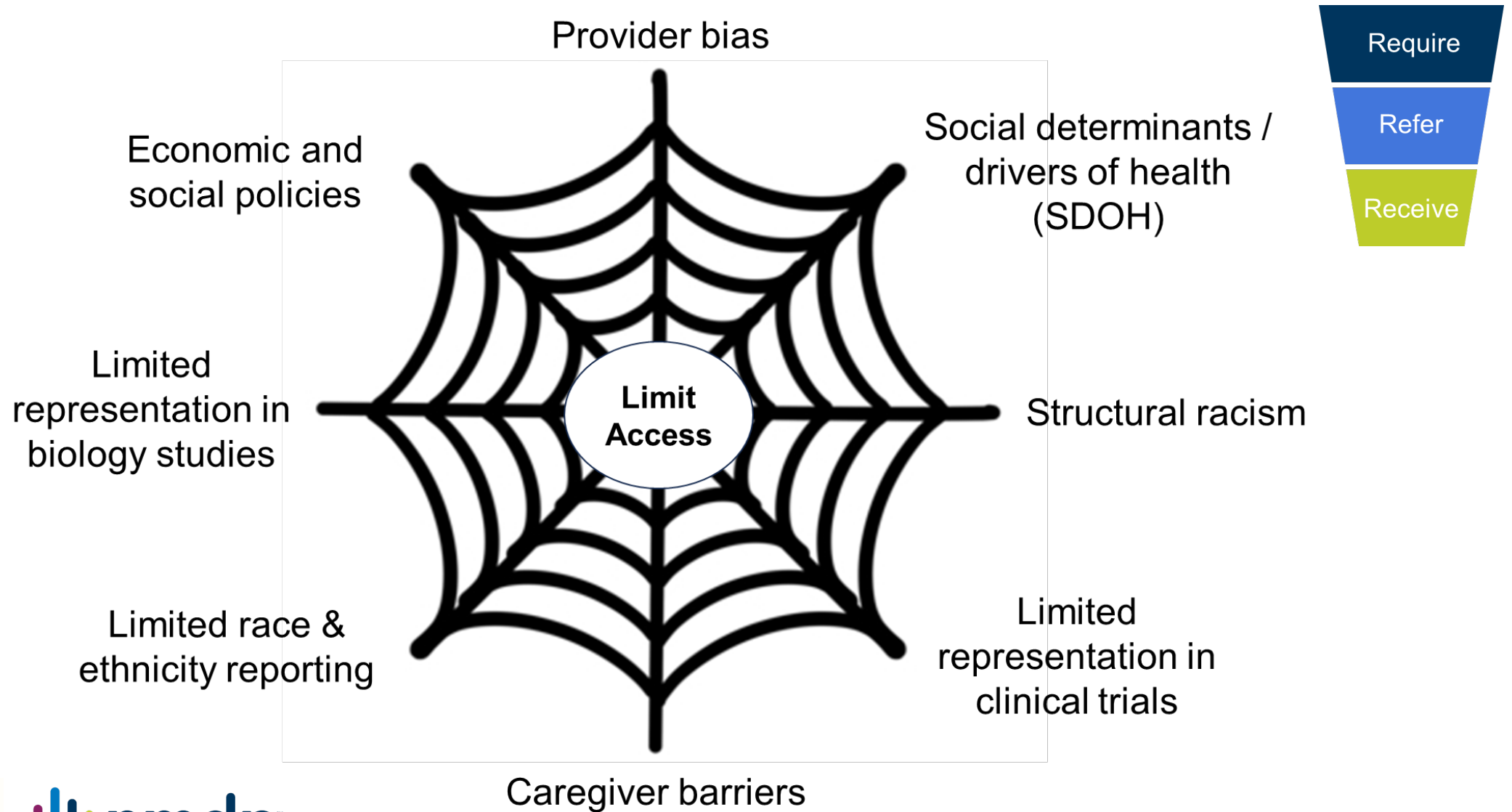
# Allogeneic HCTs in the U.S. by Race and Ethnicity



# U.S. Allogeneic HCT by Ethnicity



# Entanglement of factors impede access to HCT/CT



# ASTCT-NMDP ACCESS Initiative

## PURPOSE:

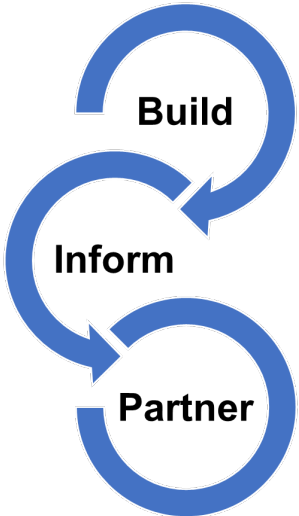
- To reduce barriers to hematopoietic cell therapy and transplantation through implementation of changes in practice and policy by active, sustained engagement of the cell therapy ecosystem

## VISION:

- To advance, measure and sustain progress toward universal access in the initial focus areas of awareness, poverty and racial inequality



# ASTCT-NMDP ACCESS Initiative



## Health Equity Pillars

- Education
- Community Engagement
- Research
- Systems Change

### Awareness



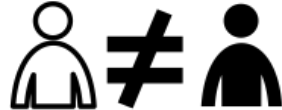
- Physician Education
- Caregiver Reimagined

### Poverty



- Medicaid Scan
- Social drivers of health (SDOH) pre-HCT/CT

### Racial Inequity



- Health in Equity Toolkit



- Workforce Diversity



- Physician Advocacy

# ACCESS Initiative: Committee Leadership

**NEW**

## Awareness



Brenda Sandmaier

**ASTCT  
Chairs**

## Poverty



Navneet Majhail

**NMDP  
Chairs**

## Racial Inequity



Eneida Nemecek

## Junior Faculty Immersion Program



Anureka Hall



Erica Jensen



Jessica Knutson



Amber Ruffin



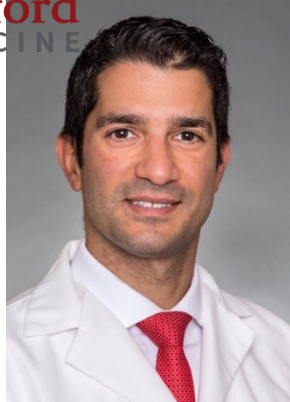
Alexandra Gomez

**WELCOME**

# Junior Faculty and Trainee Immersion Program



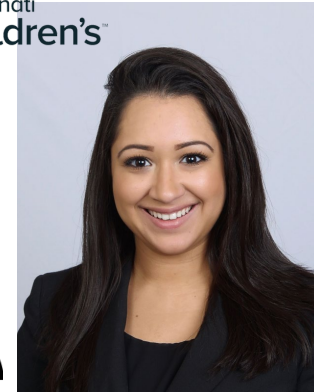
Anu Hall



Nima Ghaleshsari



Rahul Shah



Kristie Ramos



Alex Gomez



Manu Pandey



Manuel Espinoza-Gutarra



Maria Pereda Ginocchio



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# ACCESS Initiative: Vice Chairs → 2025 Chairs

ASTCT  
Vice Chairs

## Awareness



Jennifer Holter-  
Chakrabarty



## Poverty



Nandita Khera



## Racial Inequity



Rayne Royce

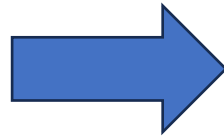


# ACCESS Initiative: 2025 ASTCT Group Chair

**ASTCT  
Group Chair**



Stella Davies

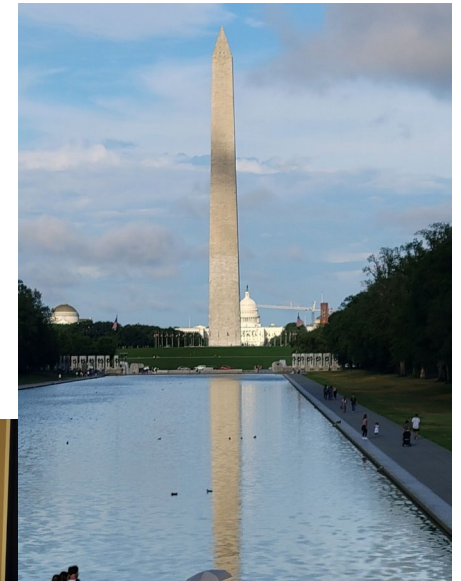


Eneida Nemecek



# ACCESS Initiative Summer Workshop

July 23-25, 2024



# Caregiver Reimagined

- **Problem:** Caregiver requirement poses challenges for many patients who lack social support or financial means to secure a caregiver, potentially denying them access to alloHCT.
- **Project:** Reimagining Caregiving Together: Engagement to Address Caregiver Requirement Barriers
  - Patient-Centered Outcomes Research Institute (PCORI)  
Eugene Washington Engagement Award Program
- **Project Aims:**
  - Convene and engage a diverse group of **stakeholders** to discuss challenges and solutions to the caregiver requirement as an HCT barrier
  - Identify and prioritize research **questions, interventions and engagement plans** to develop a patient-centered CER agenda
  - Prepare convened stakeholders to promote and support the patient-centered CER agenda to **advance systems change**



Katie  
Schoeppner



Jaime  
Preussler



Anna  
DeSalvo



Ben  
Tween



CER = clinical  
effectiveness research



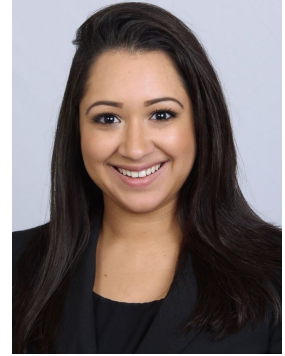
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# Assessing Diversity in the HCT/CT Workforce

- No baseline diversity data exist in HCT/CT workforce
- Junior Faculty Immersion Group designed the inaugural ecosystem-wide workforce diversity survey
- 18Q, multi-choice survey → N=432 (Physicians n=179)
  - Position, academic rank
  - Age, relationship profile, self-identified pronouns and communities
  - Racial and ethnicity, fluent languages spoken
  - Family background (parent/guardian marital status, education level)
  - International medical graduate (IMG) status
  - Treatment center location, patient race and ethnicity, WFD assessment
- ASTCT & PTCTC email distribution list
- Publish on results and use as benchmark to measure changes



Maria Pereda  
Ginocchio



Kristie Ramos



Manuel  
Espinoza-  
Gutarra

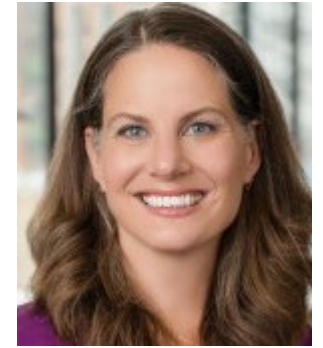
# Advocacy Education and Training

## “Policy is Key in Health Equity” session at workshop

- C.W. Bill Young Transplant Program (CWBYTP)
  - Stem Cell Therapeutic Outcomes Database (SCTOD) [PASS]
  - Single-Point of Access (SPA) Coordinating Center
  - Office of Patient Advocacy (OPA)
- Centers for Medicare & Medicaid Services (CMS) National Coverage Determinations (NCD) expansion for MDS coverage
- Lifesaving Leave Act
- Accelerating Kids’ Access to Care Act (AKACA)



Jess Knutson



Ellie Beaver



Alycia Maloney



Gary Goldstein

## ACCESS Initiative Advocacy Day

Washington, D.C.  
July 24-25, 2024

**PASS = Post-Authorization Safety Surveillance**

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# Non-profit Partners!



— NATIONAL —  
**MINORITY QUALITY**  
— FORUM —



National Alliance for Caregiving



LEUKEMIA &  
LYMPHOMA  
SOCIETY®



**American  
Cancer  
Society®**



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# Partnership in Action!



## ACS Hematologic Cancer Collaborative

### Kick-Off Meeting



Access

“Disparities in access drive disparities in clinical outcomes.”

## ACS Hematologic Cancer Collaborative

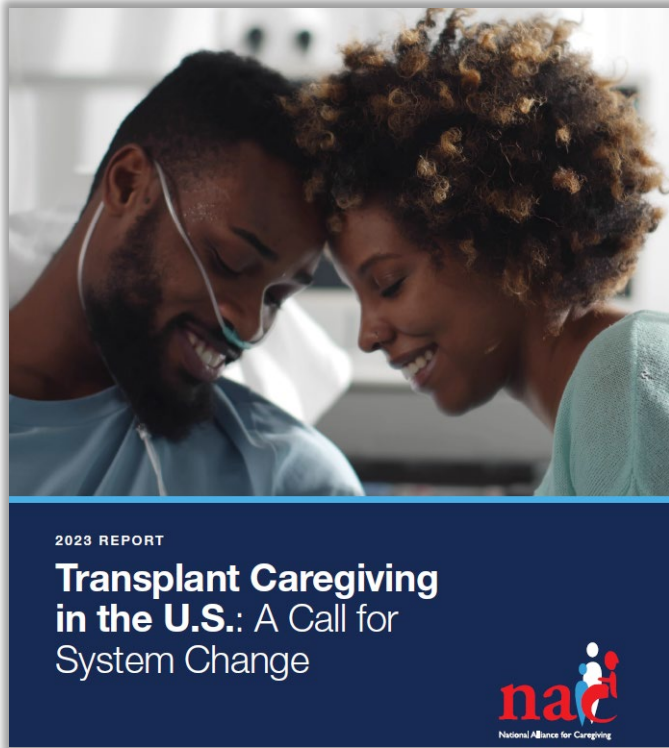
Tue, Aug 20, 2024

From 08:00 AM to 04:00 PM EDT





# Partnership in Action!



The burden of transplant caregiving is inequitable, with caregivers from socioeconomically disadvantaged and diverse racial and ethnic background facing exacerbated challenges

Eugene Washington PCORI Engagement Award Program

*“Reimagining Caregiving Together: Engagement to Address Caregiver Requirement Barriers”*

## Impact of Medicaid Scan



**Recommendation 5: Policies that Provide Financial Assistance and Workplace Protection and Appropriate Medical Coverage for Transplant Caregivers**

“ A recent study of medical coverage for hematopoietic cell transplantation (HCT) among Medicaid beneficiaries found inequities in support for patients and their caregivers resulting in significant financial burden.<sup>94</sup>

The study revealed variations and gaps in coverage for caregiver expenses and payments/reimbursements for out-of-pocket expenses despite transportation, meals, and lodging expenses are covered by Medicaid in most states. For example, some states restrict coverage for expenses only when the Medicaid beneficiary is a child and/or only when admitted as an inpatient.”

<sup>94</sup>*Transplant Cell Ther 2023;29:713-720*

# Industry Partners!

## Ally Supporters



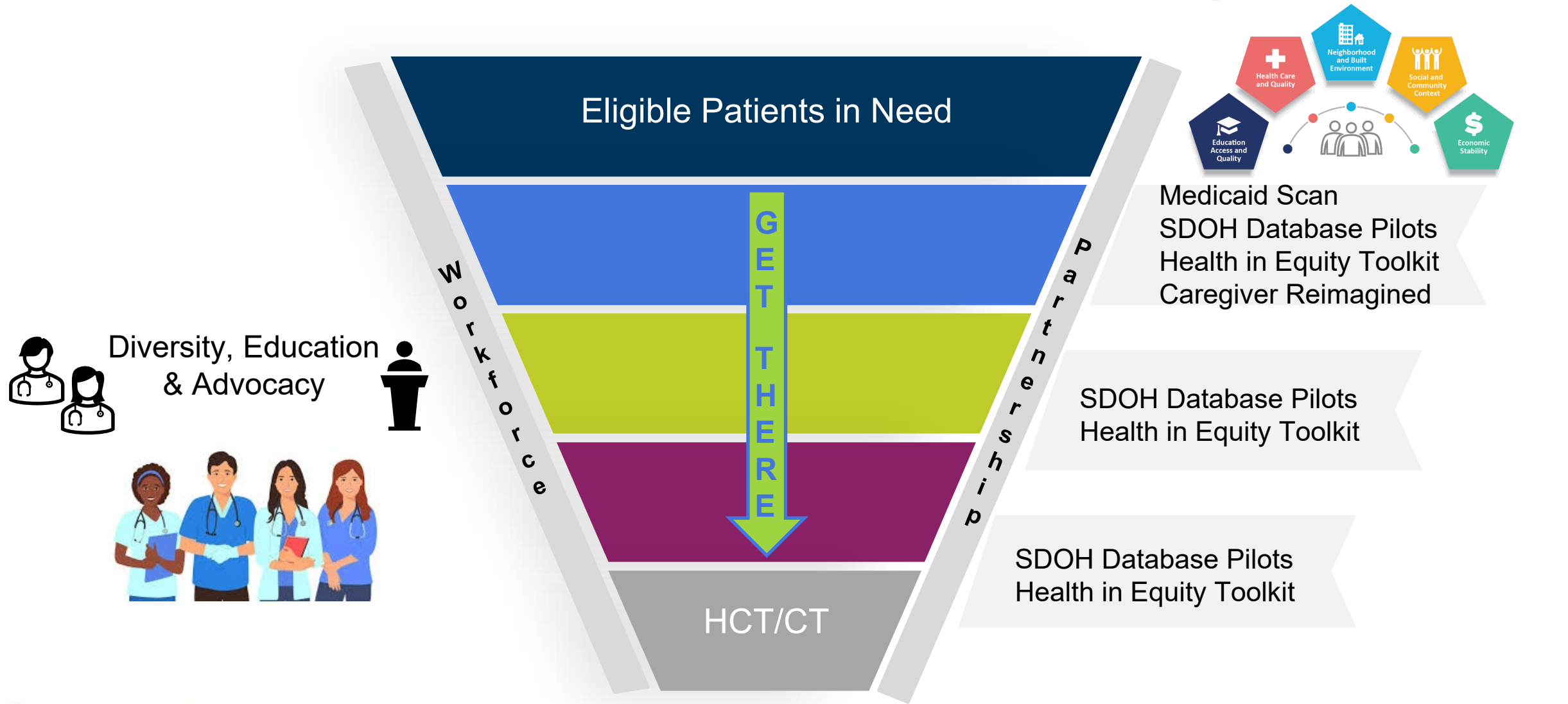
# Johnson & Johnson

## Advocate Supporters



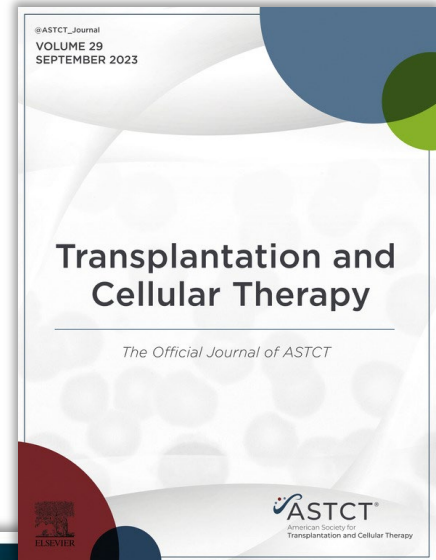
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# ASTCT-NMDP ACCESS Initiative Impact



# Future Updates to the Community

- **ASTCT-NMDP ACCESS Symposium**  
-- Thursday, February 13 3:30-5:00



## 2025 Tandem Meetings | Transplantation & Cellular Therapy Meetings of ASTCT and CIBMTR

Hawai'i Convention Center, Honolulu, HI

February 12-15, 2025

Pre-conference: February 11, 2025; and Post-conference: February 16, 2025

**UF** UNIVERSITY of FLORIDA

**Together, We Will!**

 **Penn**  
UNIVERSITY of PENNSYLVANIA

**VERTEX**  
THE SCIENCE of POSSIBILITY

 **OPTUM**®

 **Atrium Health**  
Wake Forest Baptist

**HRSA**  
Health Resources & Services Administration

**BIONTECH**

 **Takeda**

 **NIH** National Heart, Lung, and Blood Institute

**sanofi**

 **Stanford**  
MEDICINE

 **Health**

**MAYO**  
**CLINIC**  




**Memorial Sloan Kettering**  
Cancer Center

**BCM**  
Baylor College of Medicine

**OREGON**  
**HEALTH**  
& **SCIENCE**  
UNIVERSITY  


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A GILEAD Company

  
**JOHNS HOPKINS**  
MEDICINE



**Georgetown**  
University

**Johnson & Johnson**

 **Dana-Farber**  
Cancer Institute

 **bluebirdbio**®

**AstraZeneca** 

 **SARAH CANNON**



**Fred Hutch**  
Cancer Center

 **Seattle Children's**  
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**ASTCT**™  
American Society for  
Transplantation and Cellular Therapy

 **nmdp**™  
FIND CURES. SAVE LIVES.

 **KAISER**  
**PERMANENTE**

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# Acknowledgements

- Amy Ronneberg, CEO NMDP
- Andre Williams, Executive Director ASTCT
- NMDP Foundation
  - Joy King, Angie Fitzgerald, Amy Connor
- ASTCT Development
  - Angie Dahl
- ASTCT and NMDP Government Affairs and Public Policy
  - Alycia Maloney, Jessica Knutson, Ellie Beaver
- France Foundation
  - Debbie Fernandez

