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American Society for
Transplantation and Cellular Therapy

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FIND CURES. SAVE LIVES.

ASTCT-NMDP ACCESS Initiative
2025 Summer Workshop

Stella Davies Jeff Auletta

Minneapolis, MN
July 29 - 30, 2025

Equal Outcomes for All

The Why

The People

The Support

The Future

Access Matters!

Public Health Priorities and the Pathway Forward

Americans ranked improving health care access and affordability as the highest public health priority for government leaders to address out of 15 options.

Please rank the public health issues that you think should be given the highest priority by government leaders at this time.

	Highest priority (%)	Second highest priority (%)	Third highest priority (%)	Net: Top three priorities (%)
Improving health care access and affordability	25	16	11	52

32%
Improving health care access and affordabilit

One in four in the U.S. selected this issue as their highest priority and more than half (52%) rated it as their first, second, or third priority.

16%
Reducing
onic disease

Self-administered web interviews Dec 2-15, 2024
N=2,121 U.S. Adults ≥18y (95% CI sampling error ±3%)

Released February 4, 2025
https://sph.emory.edu

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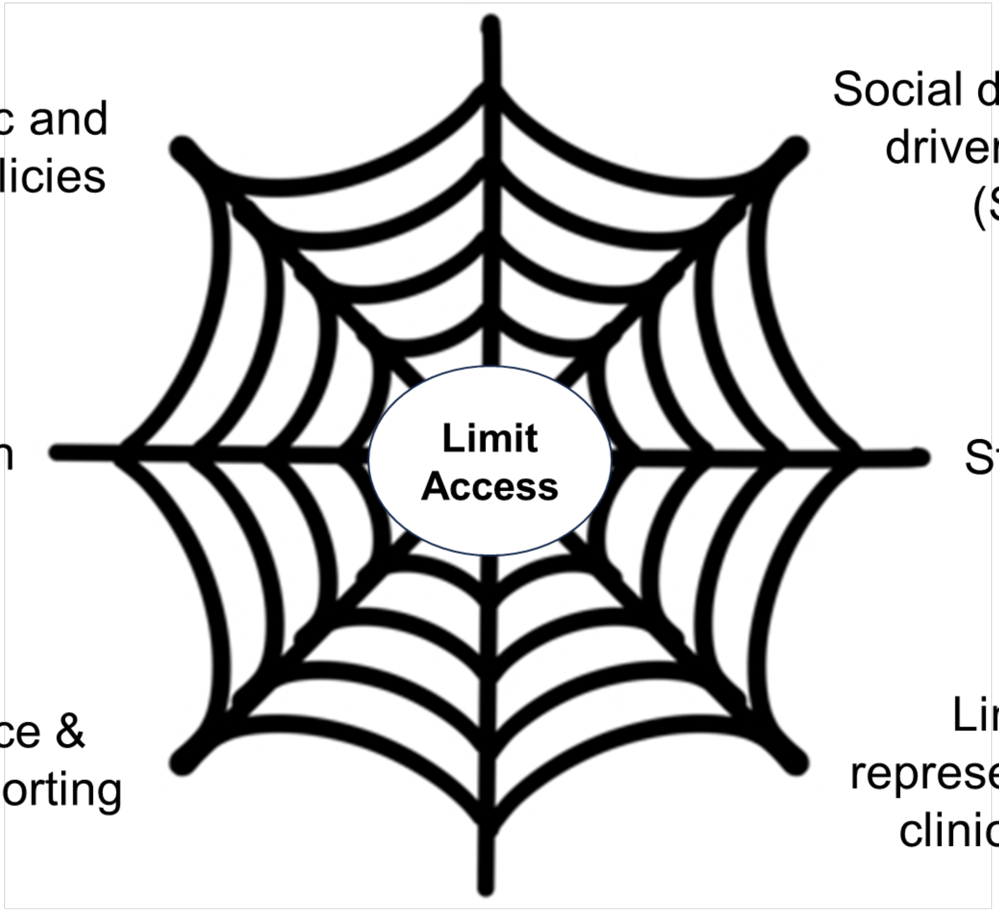
Equal Outcomes for All

Entanglement of factors impedes access to HCT/GCT



Provider bias

Social determinants / drivers of health (SDOH)

Structural racism

Limited representation in clinical trials

Caregiver barriers

Limited race & ethnicity reporting

Limited representation in biology studies

Economic and social policies

Require

Refer

Receive

Transplant Cell Ther 2024 Dec;30(12):1124-1138

HCT & GCT ACCESS to Care Barriers

Social Determinants of Health

Initial Presentation / Diagnosis

Country / Inner City

Complexity

Policy

Discrimination

Healthcare System

Physician Referral

Caregiver

Representation

Clinical Trials

HCT / GCT Center

Transition Care

Follow-up Care

Health Monitoring

Reporting

Manufacturing / Logistics

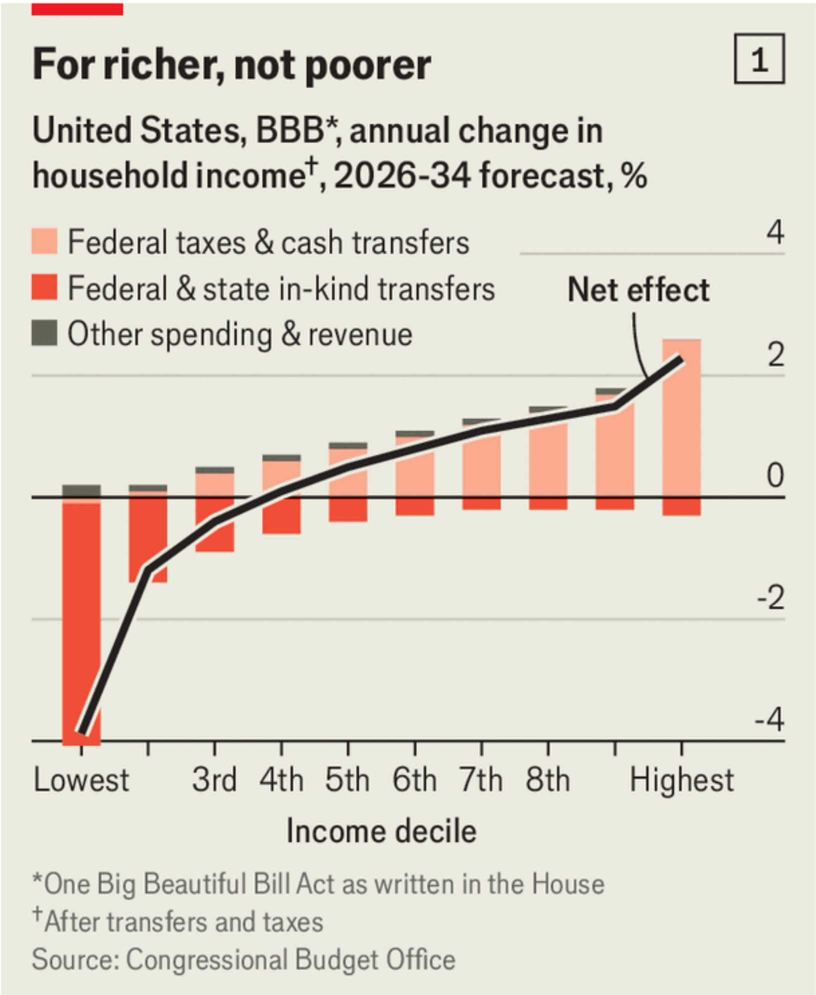
Regulatory Compliance

Product

Complications / Toxicities

J. Auletta (Canva)

A Sobering Reality



For richer, not poorer

1

United States, BBB*, annual change in household income†, 2026-34 forecast, %

*One Big Beautiful Bill Act as written in the House
†After transfers and taxes
Source: Congressional Budget Office

The Economist (July 2, 2025)

Equal Outcomes for All

ASTCT-NMDP ACCESS Initiative

Awareness

- Physician Education
- Reimagining Caregiving

Poverty

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

Racial Inequity

- Health in Equity Toolkit

Junior Faculty and Trainee Immersion Program

- Workforce Diversity
- Physician Advocacy

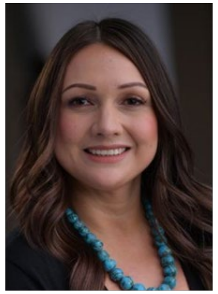
Transplant Cell Ther 2024 Dec;30(12):1124-1138

Year 3 Highlights

TANDEM MEETINGS
Transplantation & Cellular Therapy Meetings
of ASTCT® and CIBMTR®
February 12-15, 2025 | Hawai'i Convention Center, Honolulu, HI

SL-05 - ASTCT Spotlight Session: ASTCT and NMDP Access Initiative Workshop

> "We must figure out a way to prioritize people and, pragmatically, if we don't do anything about health inequity, it will continue to have adverse financial consequences."
>
> **Jeffery J. Auletta, MD**



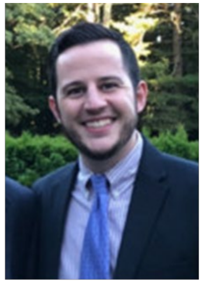
Delilah Robb, MPH

NMDP

"Health Equity in Practice"

Ann DeSalvo, MS, CGC

Katie Schoeppner, LISW

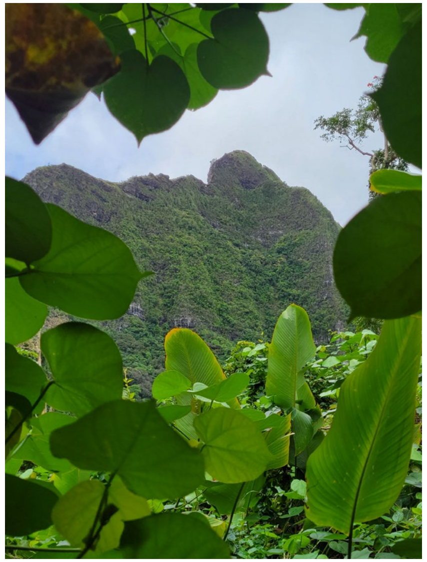


Ben Tweeten, LISW

Jaime Preussler, MPH

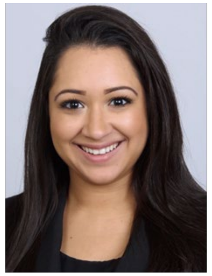
NMDP

"Caregiver Reimagined"



Maria Pereda Ginocchio, MD

Children's Hospital New Orleans



Kristie Ramos, MD

Cincinnati Children's

"Workforce Diversity"

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Equal Outcomes for All

Reimagining Caregiving Together

Workshop #1
October 3-4, 2024
Minneapolis, MN

Workshop #2
May 8-9, 2025
Minneapolis, MN

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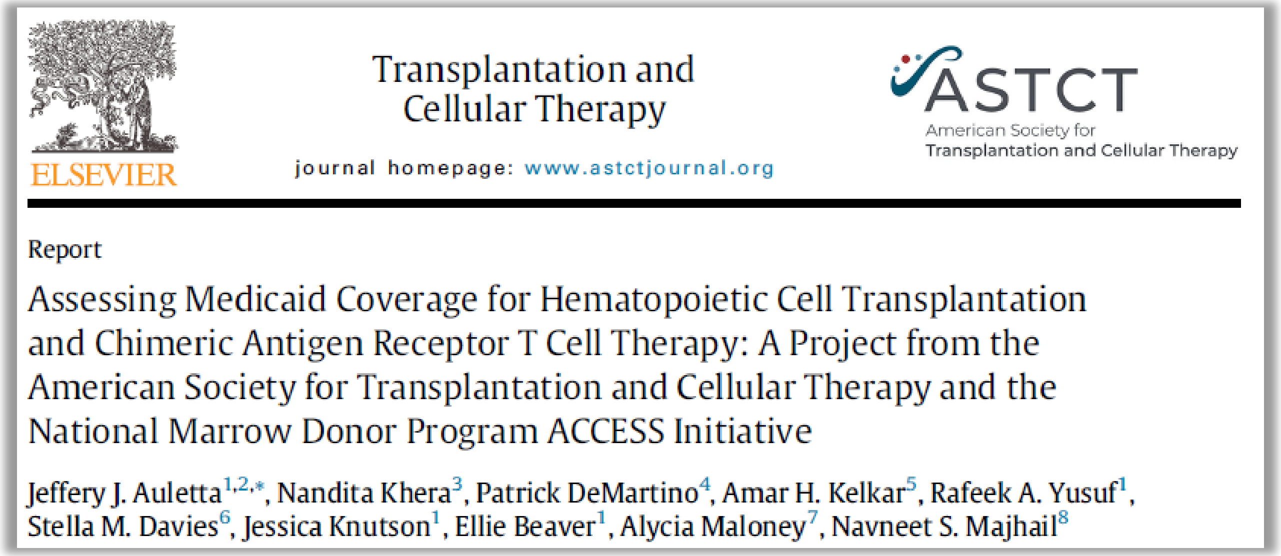
Extensions of Impact



Transplantation and Cellular Therapy

journal homepage: www.astctjournal.org

ELSEVIER

ASTCT American Society for Transplantation and Cellular Therapy

Report

Assessing Medicaid Coverage for Hematopoietic Cell Transplantation and Chimeric Antigen Receptor T Cell Therapy: A Project from the American Society for Transplantation and Cellular Therapy and the National Marrow Donor Program ACCESS Initiative

Jeffery J. Auletta[1,2,*], Nandita Khera[3], Patrick DeMartino[4], Amar H. Kelkar[5], Rafeek A. Yusuf[1], Stella M. Davies[6], Jessica Knutson[1], Ellie Beaver[1], Alycia Maloney[7], Navneet S. Majhail[8]

Transplant Cell Ther 2023;29:713-720

manatt

Kite A GILEAD Company

Takeda

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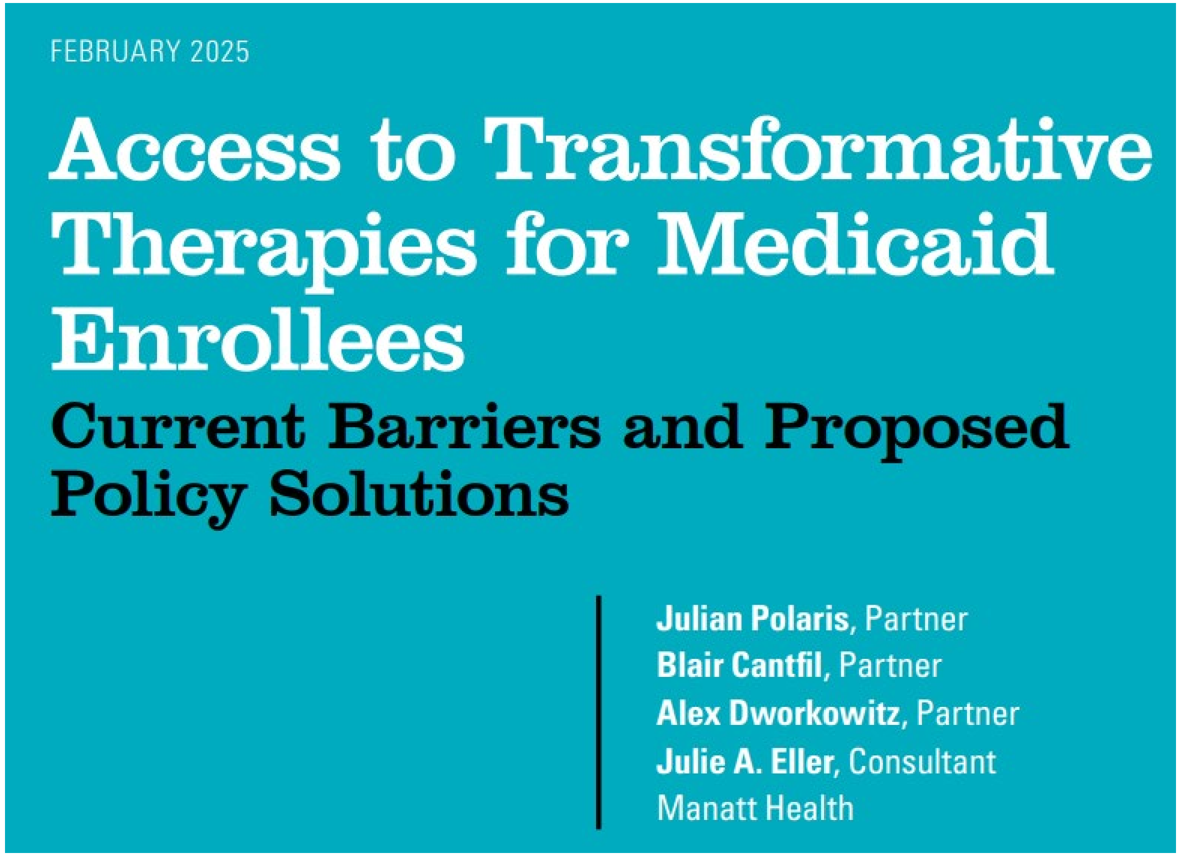
Appendix 1. Policy Solutions, Organized by Access Barrier



FEBRUARY 2025

Access to Transformative Therapies for Medicaid Enrollees

Current Barriers and Proposed Policy Solutions

Julian Polaris, Partner
Blair Cantfil, Partner
Alex Dworkowitz, Partner
Julie A. Eller, Consultant
Manatt Health

https://www.manatt.com/insights/white-papers/2025/making-cgt-accessible-for-medicaid-enrollees-current-barriers-and-proposed-policy-solutions

Vision Report

CAR T VISION

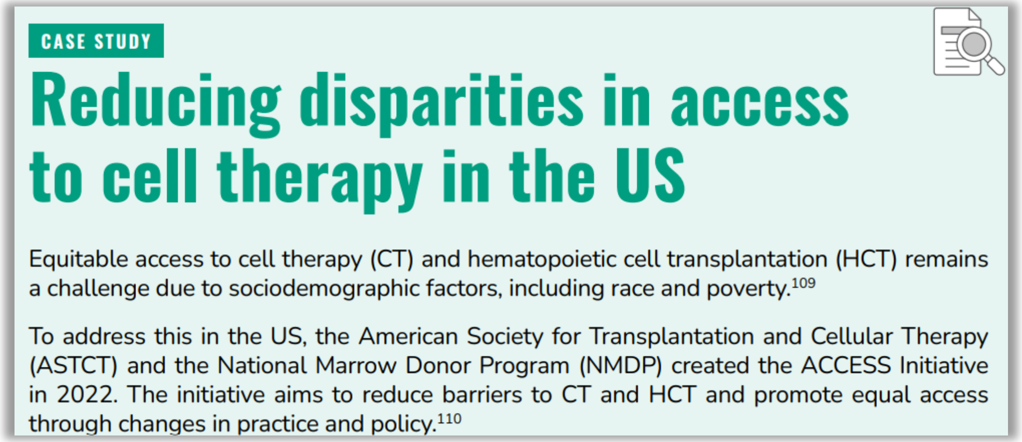
It's Time for CAR T

We believe every eligible patient should have the opportunity for cure with CAR T-cell therapy.

By 2030, we aim to double the proportion of eligible patients treated with CAR T-cell therapy.

Recommendations

1. Awareness and understanding of CAR T-cell therapy
2. Resources and capacity for CAR T-cell therapy
3. Sustainable and innovative financing of treatment and care



CASE STUDY

Reducing disparities in access to cell therapy in the US

Equitable access to cell therapy (CT) and hematopoietic cell transplantation (HCT) remains a challenge due to sociodemographic factors, including race and poverty.[109]

To address this in the US, the American Society for Transplantation and Cellular Therapy (ASTCT) and the National Marrow Donor Program (NMDP) created the ACCESS Initiative in 2022. The initiative aims to reduce barriers to CT and HCT and promote equal access through changes in practice and policy.[110]

International coalition launched May 30, 2025!

https://cartvision.com

Equal Outcomes for All

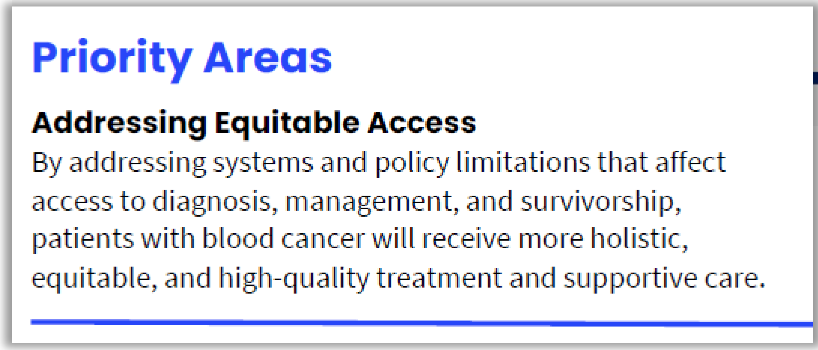
Collaborations

American Cancer Society

National Hematologic Cancer Collaborative

2024 Report

American Cancer Society



Priority Areas

Addressing Equitable Access

By addressing systems and policy limitations that affect access to diagnosis, management, and survivorship, patients with blood cancer will receive more holistic, equitable, and high-quality treatment and supportive care.

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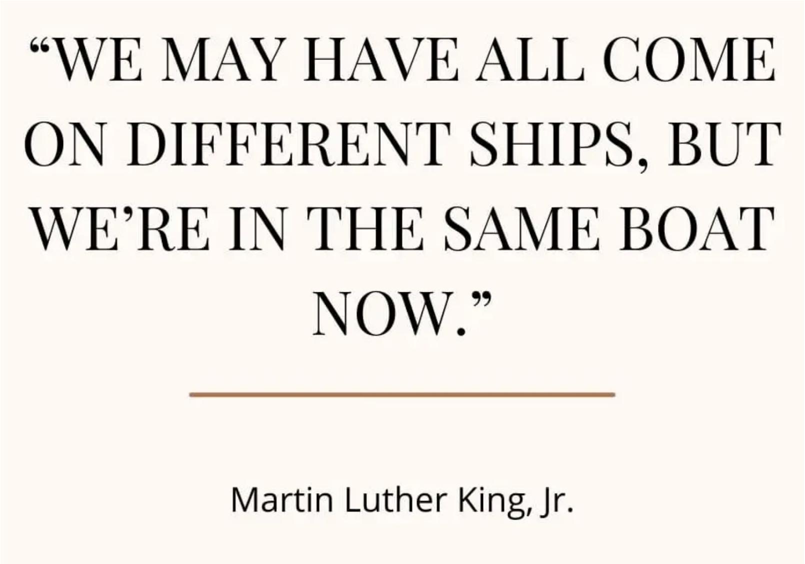
The Why

The People

The Support

The Future



“WE MAY HAVE ALL COME ON DIFFERENT SHIPS, BUT WE’RE IN THE SAME BOAT NOW.”

Martin Luther King, Jr.

ACCESS Initiative: Committee Leadership

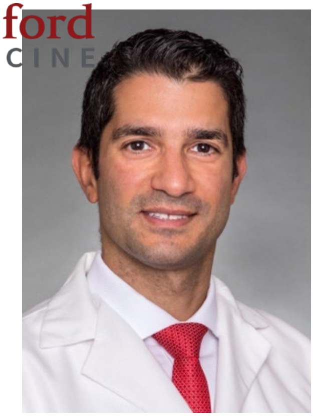
	Awareness	Poverty	Racial Inequity	Junior Faculty Immersion Program
ASTCT Chairs	 Brenda Sandmaier	 Navneet Majhail	 Eneida Nemecek	 Anurekha Hall
NMDP Chairs	 Erica Jensen	 Jessica Knutson	 Amber Ruffin	 Alexandra Gomez

Junior Faculty and Trainees Immersion Program

Seattle Children's

Anu Hall

Stanford MEDICINE

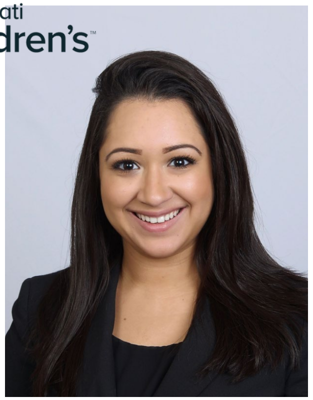


Nima Ghaleshsari

THE UNIVERSITY OF TEXAS
MD Anderson
~~Cancer~~ Center

Rahul Shah

Cincinnati Children's



Kristie Ramos

Weill Cornell Medicine

Alexandra Gomez

OU Health

Manu Pandey

UAB
THE UNIVERSITY OF ALABAMA AT BIRMINGHAM

Manuel Espinoza-Gutarra

Tulane
SCHOOL OF MEDICINE

Maria Pereda Ginocchio

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Equal Outcomes for All

Community Engagement!

The Why

The People

The Support

The Future

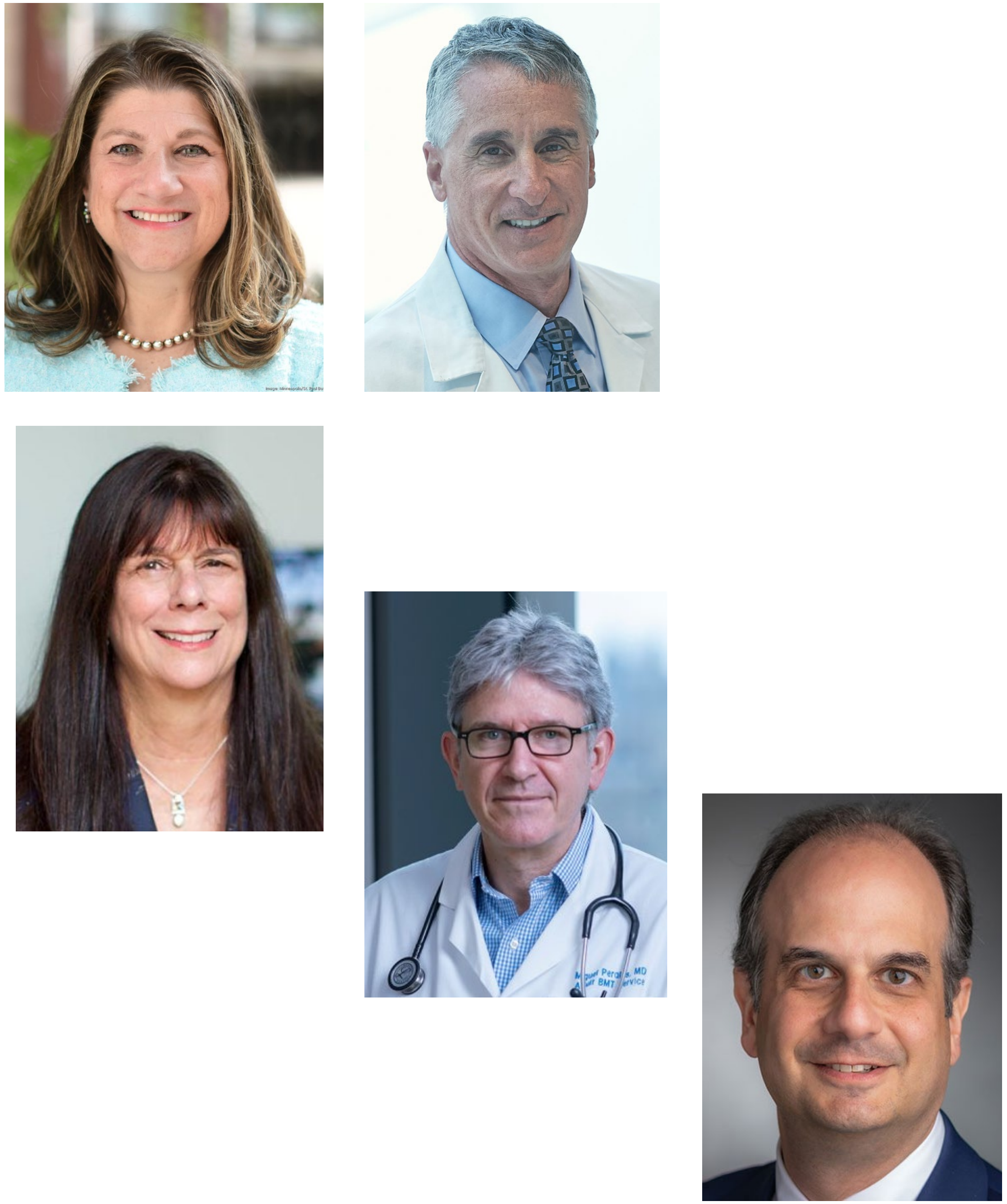
Anything is possible when you have the right people there to support you.

⁂

MISTY COPELAND

Thank you, NMDP & ASTCT!

- Amy Ronneberg, CEO NMDP
- Heather Hurley, Executive Director ASTCT
- NMDP Foundation
  - Angie Fitzgerald, Amy Connor
- ASTCT
  - Angie Dahl, Alycia Maloney
- NMPD Government Affairs and Public Policy
  - Jess Knutson, Ellie Beaver



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American Society for
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Thank you, Non-profit Partners!

nac
National Alliance for Caregiving

LEUKEMIA & LYMPHOMA SOCIETY®

American Cancer Society®

Thank you, Corporate Roundtable Industry Partners!

Ally Supporters

Kite
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Takeda

sanofi

Advocate Supporters

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ALEXION®

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The Why

The People

The Support

The Future

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ASTCT-NMDP ACCESS Initiative

PURPOSE:

- To reduce barriers to hematopoietic cell transplantation and cell therapies 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.

economic hardship belonging

ACCESS Initiative – Leadership Changes

ASTCT®


Stella Davies
Cincinnati Children's

→


Eneida Nemecek
OREGON HEALTH & SCIENCE UNIVERSITY
OHSU

Awareness


Jennifer Holter-Chakrabarty
OU Health

Economic Hardship


Nandita Khera
MAYO CLINIC

Belonging


Rayne Royce
BCM
Baylor College of Medicine

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Jeff Auletta
nmdp
FIND CURES. SAVE LIVES.

→


Erica Jensen
nmdp
FIND CURES. SAVE LIVES.

Awareness


Becca Miller
nmdp
FIND CURES. SAVE LIVES.

Economic Hardship


Anna DeSalvo
nmdp
FIND CURES. SAVE LIVES.

Belonging


Amber Ruffin
nmdp
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Equal Outcomes for All

Focus Area Committees → Project Working Groups

Awareness ASTCT & NMDP Co-Chairs

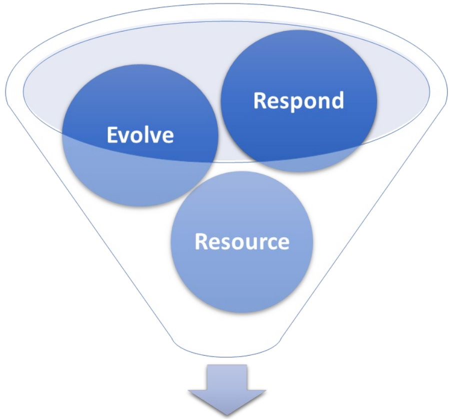
- Project #1
- Project #2

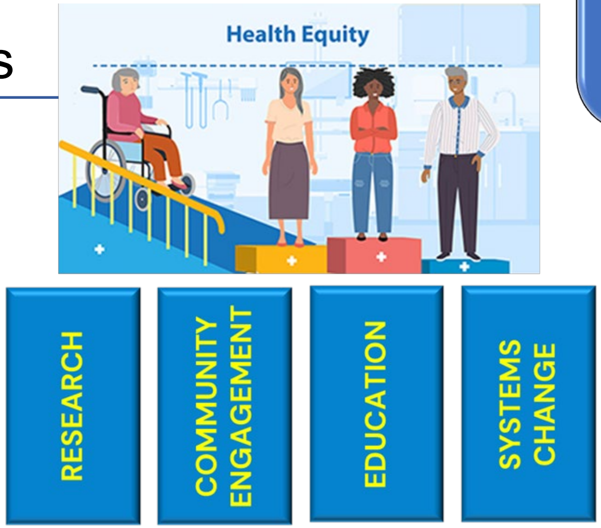
Poverty ASTCT & NMDP Co-Chairs

- Project #1
- Project #2

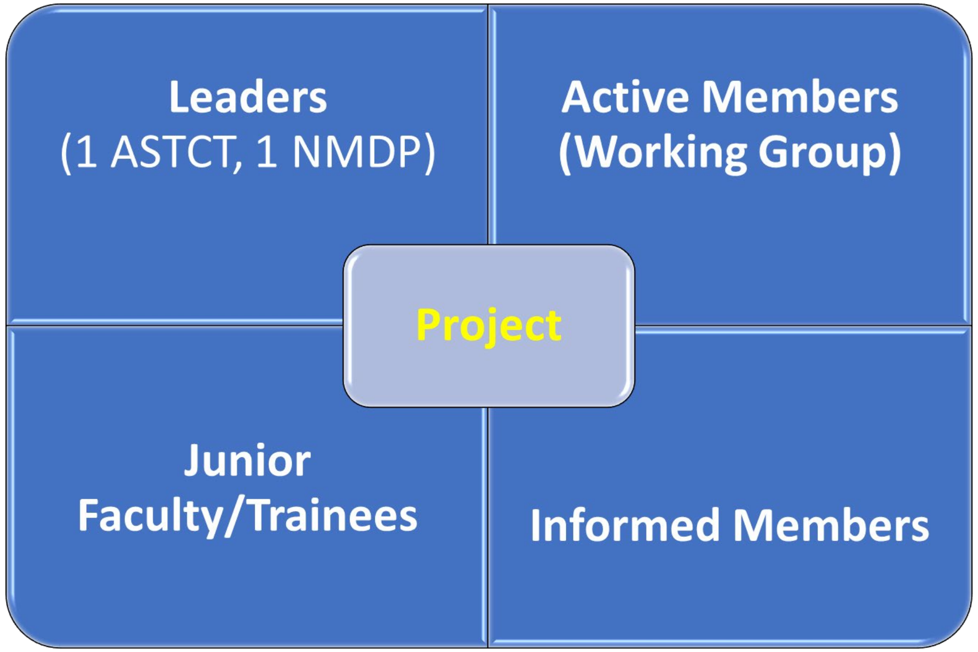
Racial Inequity ASTCT & NMDP Co-Chairs

- Project #1
- Project #2





Awareness, Economic Hardship, Belonging



Leaders (1 ASTCT, 1 NMDP)

Active Members (Working Group)

Project

Junior Faculty/Trainees

Informed Members

Patient and Provider-Focused Integrated Working Groups

ACCESS Initiative v2.0 (In Evolution)

Mission: Reduce barriers to HCT/CT through the implementation of changes in practice and policy by active, sustained engagement of the HCT/CT ecosystem. | **Vision**: Provide life-saving therapies to all eligible patients in need.

2026 Working Groups/Projects **Awareness, Economic Hardship, Belonging**	**ASTCT Lead**	**NMDP Lead**
1. Learning Collaborative for Addressing Patient-Level Barriers to Transplant [Patient-focused] **Problem Statement:** Patients face inequitable access to transplant and cell therapy due to non-medical barriers and complex care pathways. Efforts to address these issues are often fragmented, highlighting the need for a collaborative approach enabling shared learning, tool and data exchange, and infrastructure to scale. **Proposed Project:** Develop an innovation and learning hub to help individuals and centers identify, adapt, and implement strategies to expand access to transplant and cell therapies. Initial ideas may include: - Create a forum to share implementation insights, tools, and emerging learnings (e.g., Caregiver pilot) - Build a repository of screening tools, surveys, and relevant public datasets - Curate open grant opportunities and related research - Develop or refine patient journey maps to highlight barriers and actionable solutions		
2. Provide Awareness & Education to Expand Access to Transplant and Cell Therapy [Provider-focused] **Problem Statement:** - Patients may not be referred by ***hem/onc providers*** due to their lack of knowledge for current referral guidelines or patient support resources. - Educating ***legislators*** on the importance of barriers that impact access to care for all populations is needed. **Proposed Project(s):** - Education for hem/onc audience - Define one ASTCT/NMDP legislative priority to expand access		

Workshop Agenda

- Agenda by themes with moderator-led interactive panels
- **Day 1:**
  - -- Policy and advocacy update
  - -- Project update: Caregiver Reimagined
  - -- Next generation: Junior Faculty Immersion Program
  - -- Focus Area Committee Break-outs:
    - Chairs: Prep for working group transitions (membership roles, project integration)
- **Day 2:**
  - -- New directions: Patient representation
  - -- ACCESS Initiative: At a transition point
  - -- Working Group Report-outs:
    - Alignment on project leaders and project roles for working groups, junior faculty, others

Thank you!

Cincinnati Children's

UF UNIVERSITY of FLORIDA

Penn
UNIVERSITY of PENNSYLVANIA

OREGON HEALTH & SCIENCE UNIVERSITY
OHSU

Tulane University

Takeda

Atrium Health
Wake Forest Baptist

Kite
A GILEAD Company

OU Health

THE OHIO STATE UNIVERSITY
WEXNER MEDICAL CENTER

BCM
Baylor College of Medicine

sanofi

Stanford MEDICINE

JOHNS HOPKINS
MEDICINE

MAYO CLINIC

Bristol Myers Squibb

bluebirdbio

Duke UNIVERSITY

Weill Cornell Medicine

Georgetown University

ALEXION

Dana-Farber Cancer Institute

AstraZeneca

SARAH CANNON

Fred Hutch Cancer Center

Seattle Children's
HOSPITAL • RESEARCH • FOUNDATION

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Equal Outcomes for All

Meaningful Advocacy When it Matters Most

Jess Knutson, Director, Government Affairs & Public Policy, NMDP
Anne Simaytis, Sr. National Advocacy Manager, NMDP

Working in health care is getting harder

Healthcare costs at up 7.5% over inflation

46% report feeling burned out often

6 in 10 patients report problems with insurance

Political Landscape

Past 6 Months

170	Executive Orders
$1T	Cuts to health care spending impacting Medicaid and ACA
Over $1B	Cuts to NIH funding

Defeated

Paralyzed

Overwhelmed

Distressed

> “I will say it again- I am tired of making history, I just want a normal Congress.”
>
> Speaker Mike Johnson
> Punchbowl News, after breaking a record for the longest outage.

Strategically, effectively using your voice to make the most significant impact on patients we serve.

Legislative Priorities–Access

Jessica Knutson

Director, Government Affairs and Public Policy
NMDP

Insurance Barriers to Transplant

Expand Access

Problem

HR 1 aka "One Big Beautiful Bill Act"

The nonpartisan Congressional Budget Office (CBO) estimates that roughly 10 million people will lose health coverage and be uninsured by 2034 due to the changes to Medicaid.

Why should you care?

NMDP estimates that approximately 15% of transplant patients use Medicaid. An unknown number of patients access transplants via the ACA marketplace.

Legislative Solution(s)

- Implementation of this legislation will occur at various stages, with some of the provisions going into effect this year and others delayed until 2027 or 2028. Action will be at **the state level and led by Hospitals.**
- There will likely be Federal legislation to address ACA marketplace issues—stay tuned, as the political environment is rapidly changing, i.e, Sen. Hawley AHA-supported legislation.
- Support Accelerating Kids Access to Care- S.752/ HR 1509

Action:

- ✓ **Sign up for ASTCT and NMDP Advocacy newsletters**
- ✓ **Lockstep with your Government Affairs Team at your institution**

Partners/Coalition

LLS, ACS CAN, This is Medicaid, Partnership to Protect Coverage, and American Hospital Association

Reauthorization of CWBYCTP

Accelerate Progress

Problem

The C.W. Bill Young Cell Transplantation Program is up for reauthorization and is set to expire in 2026. If the program is allowed to sunset, it would have serious consequences for the U.S. transplant system. Funding and some functions would be eliminated for critical components, including:

- The single, searchable electronic system used to match patients with donors or cord blood units.
- The facilitation of transplants involving cord blood units (CBU), peripheral blood stem cells (PBSC), and marrow.
- Financial assistance programs that help patients afford transplant-related care.
- Key infrastructure such as the Stem Cell Therapeutic Outcomes Database and the National Cord Blood Inventory (NCBI).
- Without reauthorization, the ability to support and perform lifesaving transplants in the U.S. would be severely compromised.

Why should you care?

Directly impact NMDP's ability to serve more than 8,000 patients annually (see next slide).

Legislative Solution(s)

Support immediate passage of reauthorization of C.W. Bill Young Cell Transplantation Program.

Action:

- ✓ **Sign up for ASTCT and NMDP Advocacy newsletters**
  - ✓ **Write to your Members of Congress personally.**

What is in the "Program?"

Recruit donors and match them to patients

Track and improve outcomes

Support patients along the whole transplant journey

nmdp

FIND CURES. SAVE LIVES.

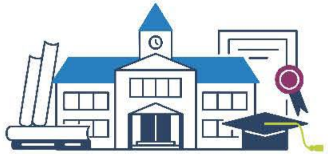
Congress has entrusted NMDP to operate the C.W. Bill Young Cell Transplantation Program, enable a seamless and efficient process, and ensure every patient receives their life-saving transplant. With more than **135,000 lives** impacted, the journey of the cell gives people the treatment they need.

Members of Congress, You Save Lives.

Without Congressional support, the journey of a life-saving cell would not be possible.

Barrier Meets Opportunity: Continued recruitment efforts, funded by Congress, ensure viable, healthy, and young donors join the registry.

Because of NMDP and its coordinated national network, doctors worldwide can access available donors through a unified single registry, removing the burden of searching multiple registries for their patient's best match.



RECRUIT & REGISTER

NMDP depends on partnerships and events—such as college campus drives—to help build the registry.

Barrier Meets Opportunity: Living in a rural area can make it harder to gain access to transplant. Through federal funding, NMDP coordinates typing and testing patients and donors at the point of diagnosis through the *HLA Today Program.*

SEARCH

NMDP unites donors in a single searchable database pulling from more than **42 million** registered donors worldwide, allowing doctors to find the best match for their patients.

MATCH

Transplant centers search the registry and doctors select the best match for their patient based on complex matching criteria and donor availability.

EXAM

Selected donor undergoes a physical exam and other pre-donation preparation.

SAFETY

FDA provides guidance to ensure that donor cells are healthy and safe for patients.

PREPARATION

Donor and patient begin preparations for the transplant, which take between 2-8 weeks.

Barrier Meets Opportunity: Donors need time away from work and school, and NMDP is working with employers and universities, as well as state and federal government to ensure protections.

CELL COLLECTION

Donor travels to collection center or hospital facility to donate cells.

TRANSPORT

Behind every life-saving transplant is a dedicated NMDP courier racing to deliver hope to a patient — perfectly timed to give them a second chance.

Barrier Meets Opportunity: Cells need to move across the country and borders, and NMDP works with TSA, FAA, and CBP to facilitate a safe transport.

Barrier Meets Opportunity: To support patients who don't live near a transplant center, NMDP provides grants to help cover travel, lodging and other expenses.

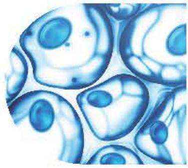
TRANSPLANT

Through the coordinated network of transplant centers, patient receives transplant with support from NMDP during the process.

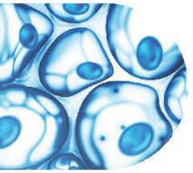
Barrier Meets Opportunity: Each patient requires a 24/7 caregiver for the first 100 days post-transplant, and NMDP provides caregiver support and assistance.

POST-TRANSPLANT

Post-transplant data is used for research to improve transplants and help patients to live longer, healthier lives.



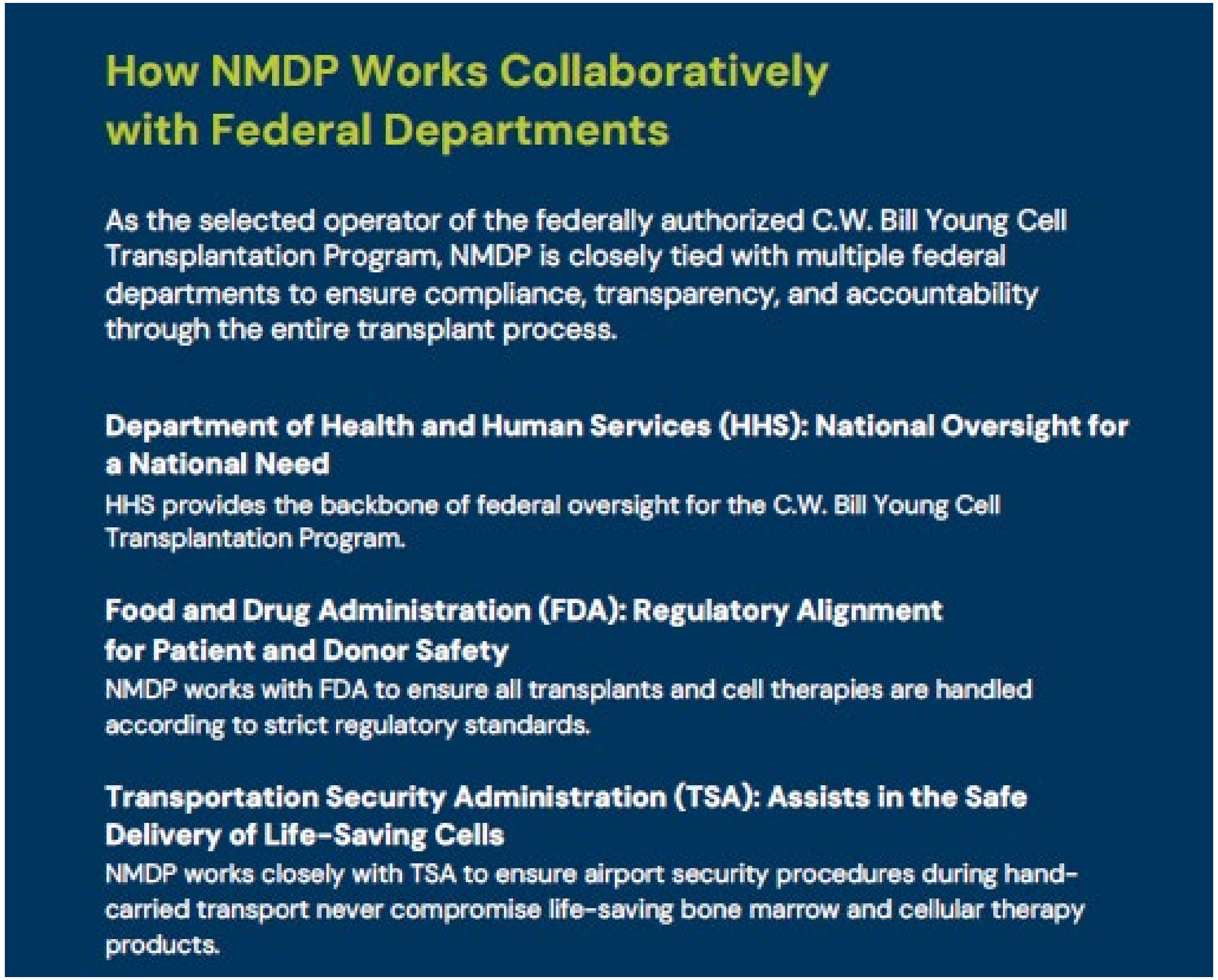
Part of the C.W. Bill Young Cell Transplantation Program funding supports education for both **patients and providers.** Patients can find help through every step of their journey on the **Patient Support Center,** while providers can stay informed about the latest advancements in research.



legislation@nmdp.org

nmdp.org

Federal Agency Collaborations



How NMDP Works Collaboratively with Federal Departments

As the selected operator of the federally authorized C.W. Bill Young Cell Transplantation Program, NMDP is closely tied with multiple federal departments to ensure compliance, transparency, and accountability through the entire transplant process.

Department of Health and Human Services (HHS): National Oversight for a National Need
HHS provides the backbone of federal oversight for the C.W. Bill Young Cell Transplantation Program.

Food and Drug Administration (FDA): Regulatory Alignment for Patient and Donor Safety
NMDP works with FDA to ensure all transplants and cell therapies are handled according to strict regulatory standards.

Transportation Security Administration (TSA): Assists in the Safe Delivery of Life-Saving Cells
NMDP works closely with TSA to ensure airport security procedures during hand-carried transport never compromise life-saving bone marrow and cellular therapy products.

Customs and Border Protection: Saving Lives Worldwide
NMDP collaborates with U.S. Customs and Border Protection to ensure the seamless and safe transfer of cell products across international borders—critical when an American patient's best match is an international donor.

Foreign Embassies: Enabling International Donor Coordination
NMDP coordinates with foreign embassies to facilitate donor and cell transport and international cooperation.

Federal Aviation Administration (FAA): Ensuring Timely Transportation of Life-Saving Cells and Transplants
NMDP provides the FAA with specific expertise and guidelines to ensure the safe transportation of life-saving cells in accordance with all federal rules and regulations.

National Institutes of Health (NIH): Advancing Access Through Research
The NIH partners with NMDP to expand clinical research and accelerate access to transplantation for patients facing life-threatening blood disorders, cancers, and rare diseases.

Department of Defense (DoD): Supporting the Salute to Life Program
For 30 years, NMDP has partnered with DoD through the Salute to Life program, helping to recruit active-duty military members to the registry and supporting military patients in need.

Mass Disaster Management: Stepping In When Needed
Prepared to treat acute radiation syndrome from a distant radiological mass casualty disaster and health-related consequences.

Research Funding: NIH, NCI, NHLBI

Accelerate Progress

Problem

Advancements in transplant come from a robust research program that includes the spectrum of transplant, from diagnosis to survivorship. The National Cancer Institute has an annual budget of over $7 billion (FY25). The President's FY26 budget cuts the annual NCI funding by 37%, jeopardizing both current research projects and future studies.

Why should you care?

- Blood and Marrow Transplant Clinical Trials Network (BMT CTN) has been funded by the National Heart Lung and Blood Institute and NCI since 2001, receiving a total of $180,000,000 that goes through 2030.

Legislative Solution(s)

- Raise the Facilities & Administrative (F&A or "indirect") cost reimbursements from 15% to 50%, consider FAIR model proposed by JAG.
- Urge Congress to provide $51.3 billion for NIH and $7.93 billion for NCI for FY2026

Action:

- ✓ **Sign up for ASTCT and NMDP Advocacy newsletters**
- ✓ **Read and understand JAG/ FAIR model.**

Partners/Coalition

ACS CAN/ ASGCT/ LLS/ OVAC

Ensuring FAIR government grants

- The Joint Associations Group (JAG) has developed a model for calculating indirect costs of government grants.
- FAIR–Financial Accountability in Research
  - Establishes an efficient, transparent and auditable payment structure
  - Funds the true cost of research
  - Aligns costs with the work
  - Ensures predictability

JAG Town Hall

Links to:

- Indirect cost recommendation
- FAIR Model
- Feedback on the FAIR Model
- FAQ on the FAIR model
- F&A Cost Material

Caregiver Support

Expand Access

Problem

Before undergoing a bone marrow or blood cell transplant, most transplant centers require transplant recipients to have a dedicated caregiver with them 24 hours a day, 7 days a week for 100 days after the procedure. If a patient does not have access to this level of continuous caregiver support, they likely will not receive their life-saving treatment.

Why should you care?

- Caregivers are critical to the transplant journey, managing complex medicine routines, assisting in changing a patient's central line dressing, and taking patients to frequent medical appointments
- Often, patients can't be matched with a donor if their transplant center does not want to move forward without a caregiver
- Caregivers also offer patients better outcomes

Legislative Solution(s)

- Alleviating Barriers to Care Act- H.R. 2491 /S. 1227
- Federal and State level Tax credits H.R. 2036/ S. 925
- Federal and state-level tax credits and grant programs

Action:

- ✓ Sign up for ASTCT and NMDP Advocacy newsletters
- ✓ Adding co-sponsors to the bills
- ✓ Working state by state, testimony/ written testimony.

Partners/Coalition

AARP, NAC

Job-Protected Leave for Living Donors

World Class Partner

Problem

Potential donors often say no when called to donate because of employment-related concerns. Ideal donors are young, between 18 and 35 years old, and may not have enough time off to cover the 40 hours of nonconsecutive time off needed for the donation process.

Why should you care?

Removing barriers for donors so that they can say "yes" to donating would create a world where every patient receives a life-saving transplant when they need it.

Legislative Solution(s)

- Federal law donor job-protected leave
- State donor job-protected leave laws
- College and University donor leave included in attendance policies
- State employer tax incentives to provide paid leave

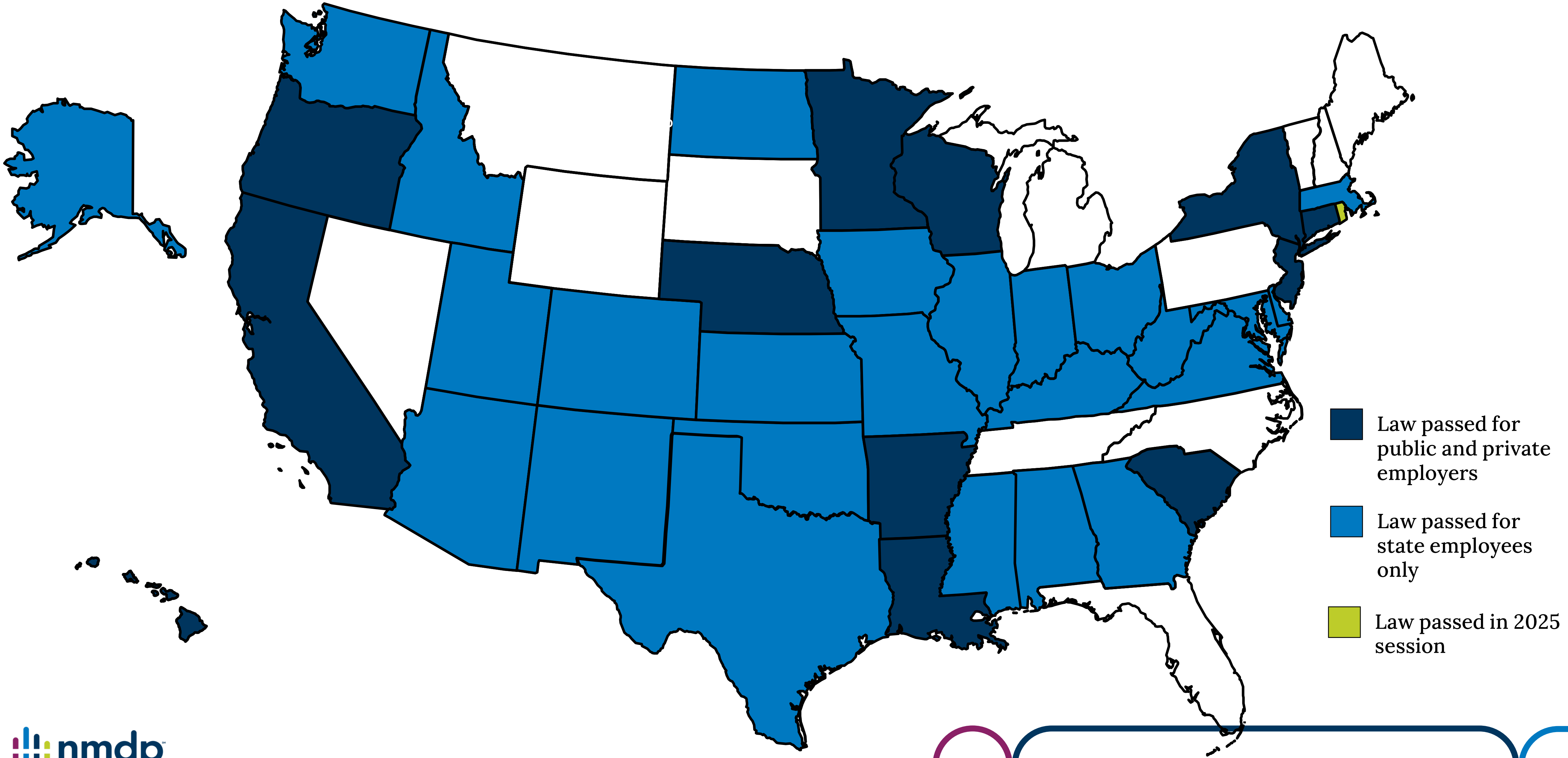
Action

- ✓ **We need personal stories**
- ✓ **College Campus Alumni working on time off**
- ✓ **Testify/Written testimony as to how this saves lives.**
- ✓ **Work with your institution to provide leave.**

Partners/Coalition

American Kidney Fund,
National Kidney Foundation,
Transplant Centers

Current State Donor Leave Laws



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NMDP Registry Growth and Awareness

Expand Access

Problem

For patients facing blood cancers or disorders diagnoses, a bone marrow or blood cell transplant may be their best and only hope for a cure. 75% of patients who need a bone marrow or blood cell transplant do not have a fully matched donor in their family and must rely on selfless strangers to donate. Patients are matched with potential donors based on blood protein types and other important factors like donor age. More young, healthy, committed donors are needed to join the registry so patients have a greater chance of finding their life-saving match.

Why should you care?

- More young, healthy, committed donors are needed to join the registry so patients have a greater chance of finding their life-saving match.
- Awareness and recruitment for the registry in state governments and through state agencies like the DMV will recruit more donors to the registry and expose more people to the process of bone marrow and blood cell donation.

Legislative Solution(s)

- Awareness Days and Months through resolutions and proclamations in state and local governments and media advocacy
- Awareness legislation to provide residents with education and the opportunity to join the national registry through state agencies like the Department of Health
- DMV legislation to integrate registry recruitment with the process of applying for or renewing driver’s licenses and identification cards

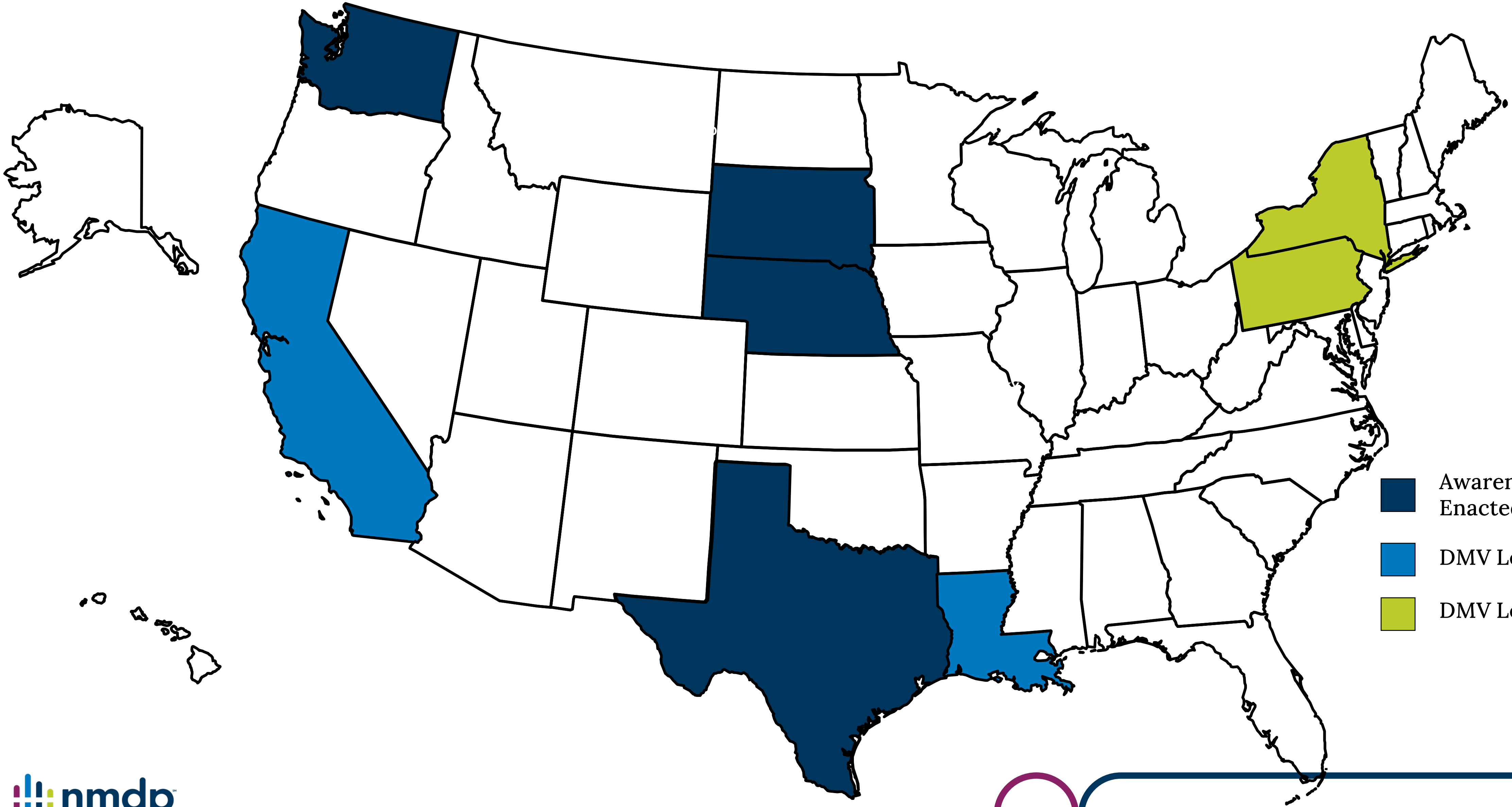
Action

✓ **Sign up for ASTCT and NMDP Advocacy newsletters**

Partners/Coalition

Advocacy Volunteers, Patients, Donors, Caregivers

Registry Growth Awareness and DMV Legislation



🟦 Awareness Legislation Enacted

🟦 DMV Legislation Passed

🟩 DMV Legislation Pending

Rare Disease Advisory Councils

Expand Access

Problem

Rare diseases are underresearched, underfunded and undersupported. Rare diseases often lack the same voice and awareness as the higher incident diseases within state governments, where many decisions concerning healthcare are made. Any disease affecting fewer than 200,000 people in the United States is considered rare and 30 million Americans are living with a rare disease.[1] There are 75 blood cancers and disorders that can be treated with a bone marrow or blood cell transplant, all of which fall under the category of rare diseases.

Why should you care?

- All 75+ transplant-treatable diseases are considered rare diseases
- Treating patients with rare diseases comes with additional rarities in treatment, protocol, etc. that can be overlooked when healthcare decisions are being made
- Providing rare disease providers, patients, etc. a voice in state government allows states to identify and address barriers that prevent rare disease patients from accessing adequate and effective treatment and care for their condition

Legislative Solution(s)

- Establish Rare Disease Advisory Council (RDAC) in every state

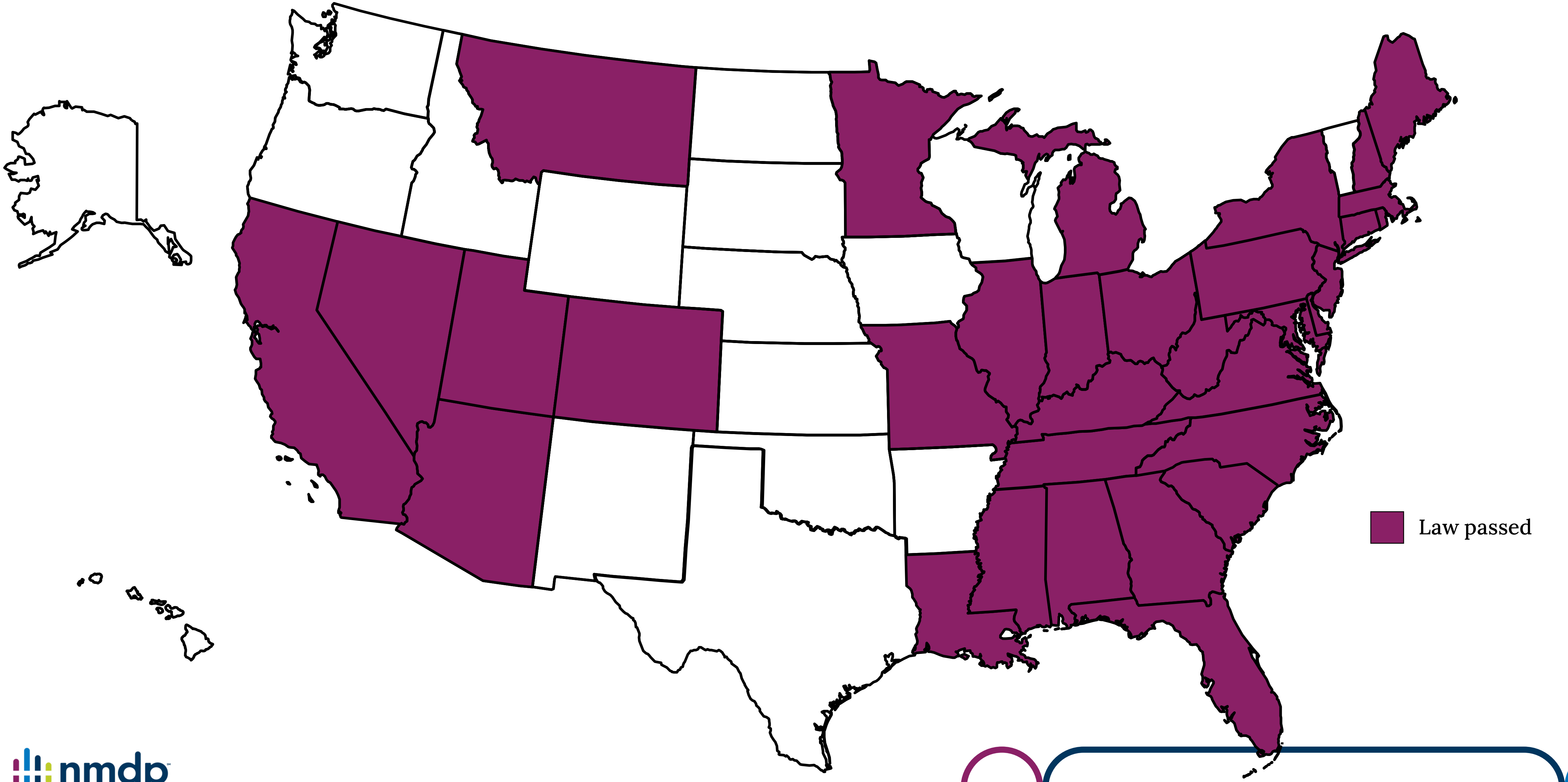
Action

✓ **Please apply to serve on an Advisory Council**
✓ **Support bill in their states**

Partners/Coalition

NORD (National Organization for Rare Disorders), EveryLife Foundation for Rare Diseases

Current RDACs



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Thank you

nmdp.org

ASTCT-NMDP ACCESS Initiative

Caregiver Reimagined

Anna DeSalvo, Ben Tweeten, Jaime Preussler

NMDP; CIBMTR

Minneapolis, MN

July 29, 2025

Equal Outcomes for All

AlloHCT Caregiving Requirement Background & Current State

- Most transplant centers (TCs) require patients who receive an alloHCT to have a caregiver 24 hours a day, 7 days a week, for at least 100 days post-alloHCT (with a range of 30-100+ days)[1,2]

- The origin of the 100-day 24/7 caregiving requirement is not known[3]

- Few studies have examined the impact of caregivers on patient outcomes

Variation in requirements

Studies have shown considerable variation among US transplant centers in the[1,3-9]:

- Length of time needed for caregiving
- Tasks/activities to be performed by caregiver
- Allowance of hired caregivers or home healthcare services
- Allowance of multiple caregivers, instead of a single caregiver

This variance highlights a lack of evidence informing current requirements

Caregiver Requirements as a Barrier

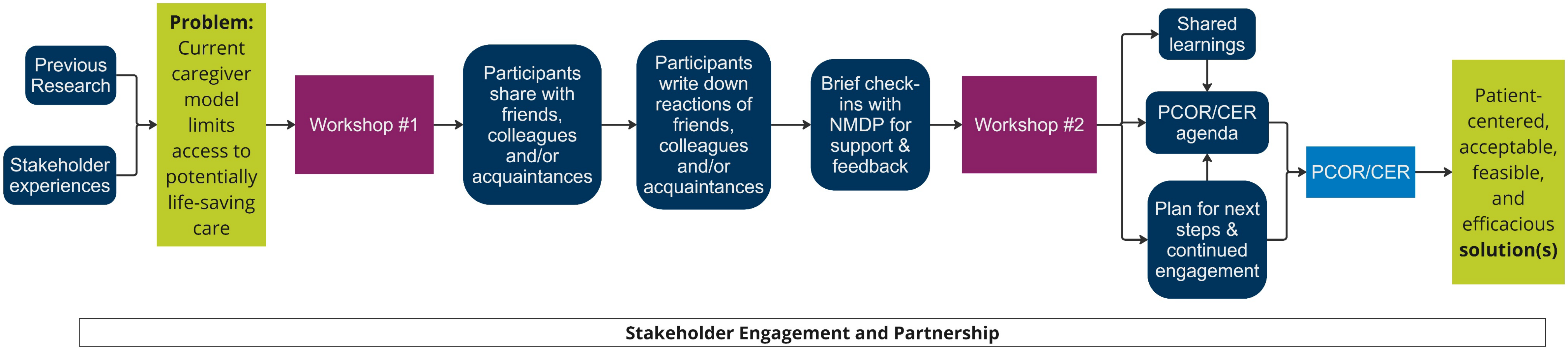
Access:

- 58% of adult TC social workers reported patients denied alloHCT due to lack of caregiver[1]
- 69% of clinicians would not proceed without a caregiver (n=389)[10]
- 19% of patients in one TC study couldn't proceed due to caregiver issues[11]
- Married patients (often with caregivers) more likely to receive alloHCT[12]

Equity:

- Caregiver issues more common among Black patients vs. White patients[11]
- Patients <60 more affected—likely due to work/childcare demands[11]
- Pediatric vs. adult caregiver barriers differ[13,14]
- Loss of caregiver income is the most cited barrier[1]

Reimagining Caregiving Together: Engagement to Address Caregiver Requirement Barriers



Previous Research

Stakeholder experiences

Problem: Current caregiver model limits access to potentially life-saving care

Workshop #1

Participants share with friends, colleagues and/or acquaintances

Participants write down reactions of friends, colleagues and/or acquaintances

Brief check-ins with NMDP for support & feedback

Workshop #2

Shared learnings

PCOR/CER agenda

Plan for next steps & continued engagement

PCOR/CER

Patient-centered, acceptable, feasible, and efficacious **solution(s)**

Stakeholder Engagement and Partnership

Aim 1: To convene and engage a diverse group of stakeholders to promote discussion of challenges and solutions to caregiver requirements as an HCT barrier
Aim 2: To identify and prioritize research questions, interventions, and engagement plans to develop a patient centered outcomes research/comparative effectiveness (PCOR/CER) agenda
Aim 3: To prepare convened stakeholders to promote PCOR/CER agenda

This project is funded through a Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award (EASCS-34738).
The views presented in this work are solely the responsibility of the author(s) and do not necessarily represent the views of PCORI®.

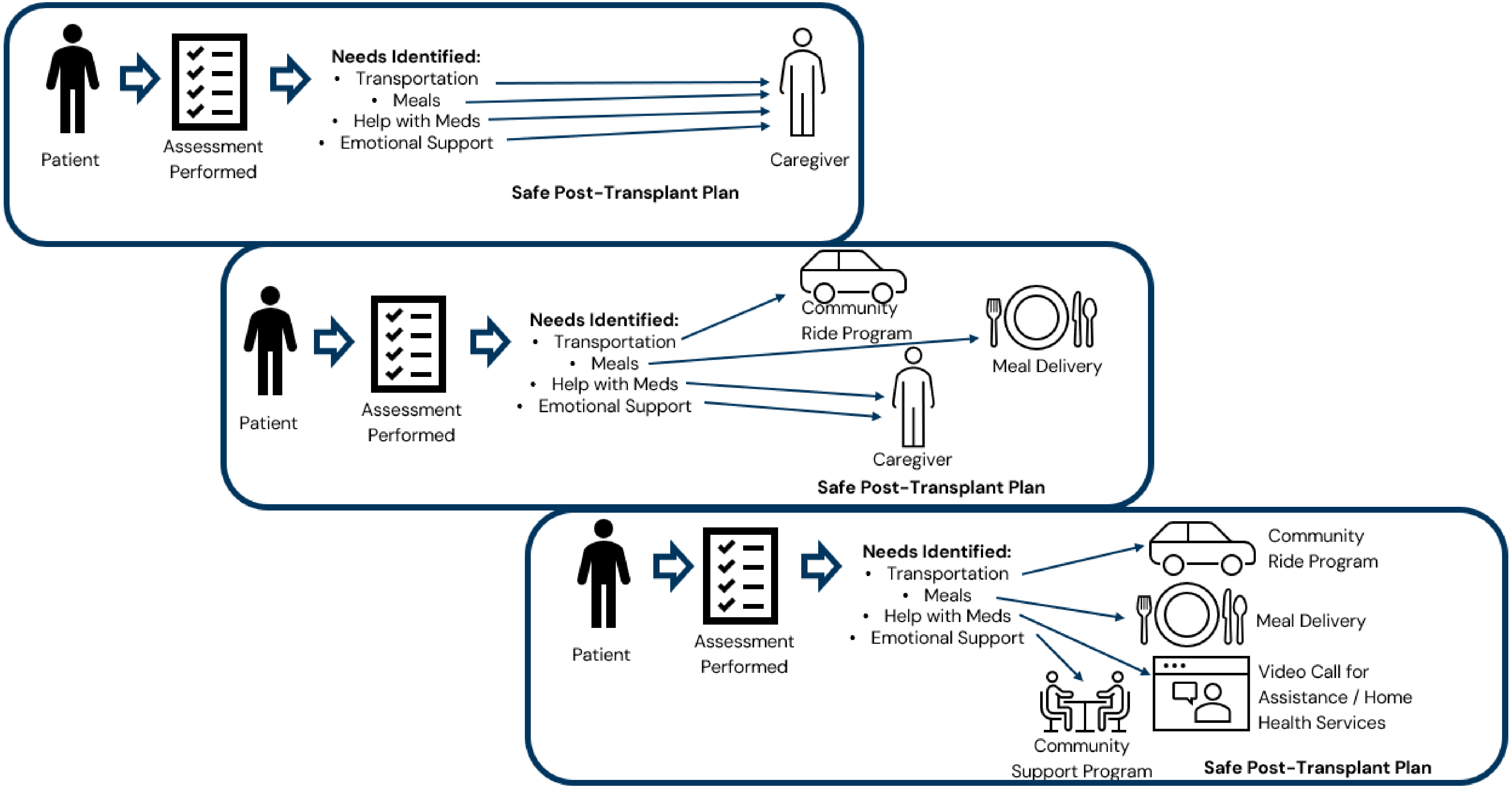
Problem Statement

Current caregiver requirements for alloHCT create barriers to accessing care and place significant burdens on patients and their caregivers, yet there is limited evidence to support these requirements as they currently stand.

Vision Statement

Create an equitable, patient-centered model for allogeneic hematopoietic cell therapy that meets the unique needs of diverse patients and minimizes burdens on families. Through comprehensive assessment of individual patient needs, integration of community resources, and development of adaptable evidence-based support solutions, we aim to establish a support system that ensures safe and effective post-transplant care for every patient.

Patient-centered safe post-transplant plans



Patient

Assessment Performed

Needs Identified:

- Transportation
- Meals
- Help with Meds
- Emotional Support

Caregiver

Safe Post-Transplant Plan

Patient

Assessment Performed

Needs Identified:

- Transportation
- Meals
- Help with Meds
- Emotional Support

Community Ride Program

Meal Delivery

Caregiver

Safe Post-Transplant Plan

Patient

Assessment Performed

Needs Identified:

- Transportation
- Meals
- Help with Meds
- Emotional Support

Community Ride Program

Meal Delivery

Video Call for Assistance / Home Health Services

Community Support Program

Safe Post-Transplant Plan

Tweeten B, Randall J, Barata A, et al. The Caregiver Paradigm in Hematopoietic Cell Transplant: Current and Future Directions. *Transplant Cell Ther*. Published online June 20, 2025:S2666-6367(25)01265-5. doi:10.1016/j.jtct.2025.06.022[15]

What happened in between Workshops

Discussions with networks & check-in forms

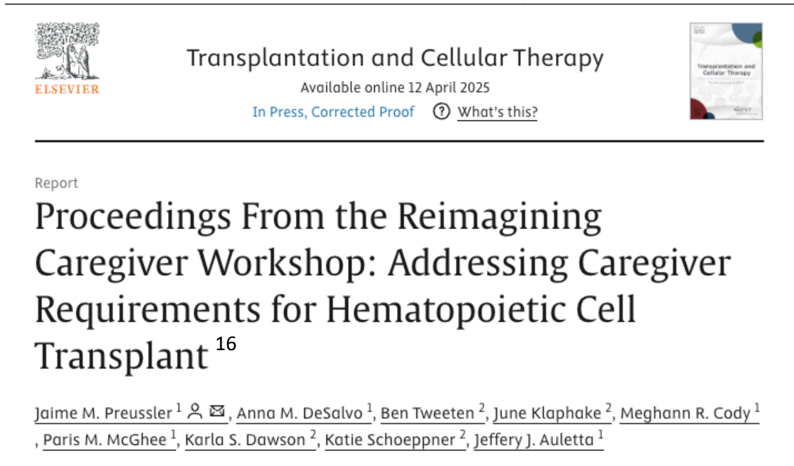
- Who have you talked to?
- What did you talk about?
- What did you hear?
- What additional support do you need?

Spotlight series

- Massachusetts General Hospital experience removing caregiver requirement
- Product experts' experiences developing innovative health strategies
- Dana Farber Cancer Institute’s Shared Care study results and experiences
- National Alliance for Caregiving experience in related policy work

Prioritizing focus areas for Workshop 2

- Survey was sent to participants from Workshop 1 with list of caregiving tasks
- Participants ranked the importance of these tasks and how essential they were to address
- Four areas emerged that were the primary focus in Workshop 2

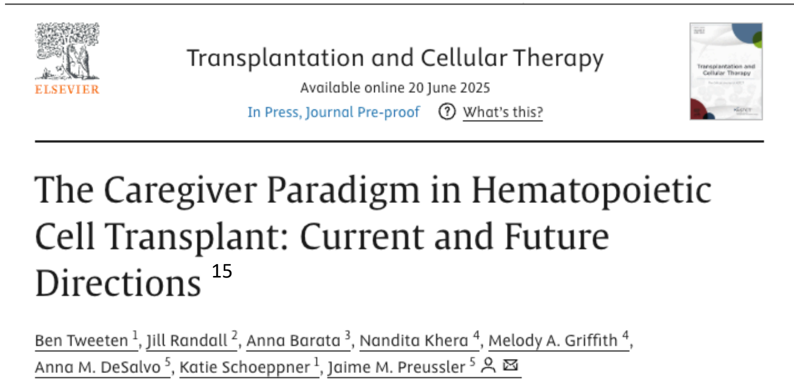


Transplantation and Cellular Therapy
Available online 12 April 2025
In Press, Corrected Proof What's this?

Report

Proceedings From the Reimagining Caregiver Workshop: Addressing Caregiver Requirements for Hematopoietic Cell Transplant [16]

Jaime M. Preussler[1], Anna M. DeSalvo[1], Ben Tweeten[2], June Klaphake[2], Meghann R. Cody[1], Paris M. McGhee[1], Karla S. Dawson[2], Katie Schoeppner[2], Jeffery J. Auletta[1]



Transplantation and Cellular Therapy
Available online 20 June 2025
In Press, Journal Pre-proof What's this?

The Caregiver Paradigm in Hematopoietic Cell Transplant: Current and Future Directions [15]

Ben Tweeten[1], Jill Randall[2], Anna Barata[3], Nandita Khera[4], Melody A. Griffith[4], Anna M. DeSalvo[5], Katie Schoeppner[1], Jaime M. Preussler[5]

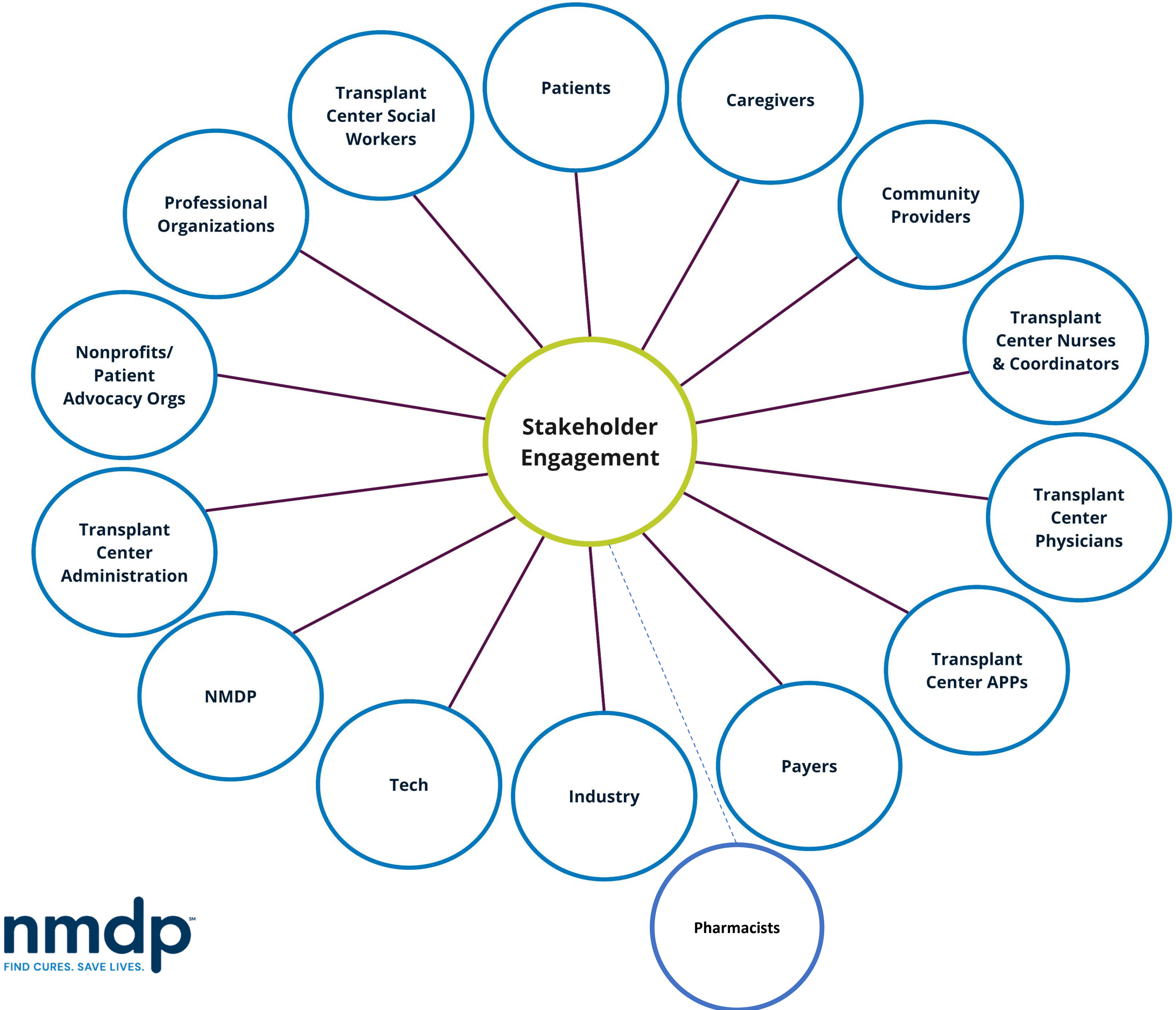
Four focus areas identified for Workshop 2

Monitor patient for complications (e.g., temperature, blood pressure, cognitive status, other signs or symptoms of infection)	**Make sure patient takes medications appropriately and according to schedule** (e.g., fill pill box, create schedule, monitor refills)	**Report changes in patients to medical team**	**Drive patient to medical center in emergency**
81%	77%	73%	71%

Workshop #2
May 8-9, 2025 Minneapolis, MN

Equal Outcomes for All

Engagement & Partnership



Stakeholder Engagement

Patients

Caregivers

Community Providers

Transplant Center Nurses & Coordinators

Transplant Center Physicians

Transplant Center APPs

Payers

Pharmacists

Industry

Tech

NMDP

Transplant Center Administration

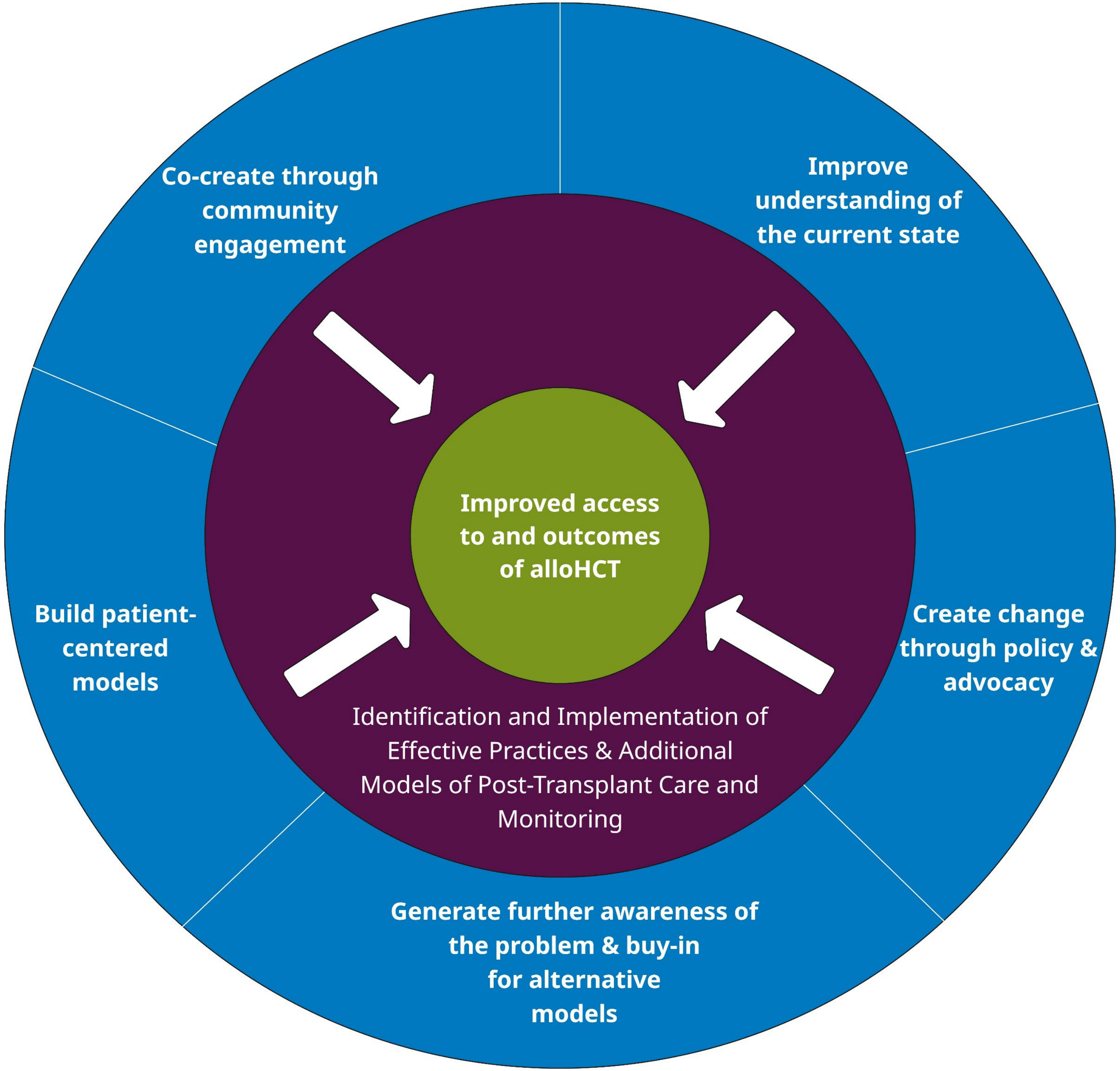
Nonprofits/ Patient Advocacy Orgs

Professional Organizations

Transplant Center Social Workers

Equal Outcomes for All

Research Agenda Overview



Co-create through community engagement

Improve understanding of the current state

Build patient-centered models

Improved access to and outcomes of alloHCT

Create change through policy & advocacy

Identification and Implementation of Effective Practices & Additional Models of Post-Transplant Care and Monitoring

Generate further awareness of the problem & buy-in for alternative models

Generate further awareness of the problem & buy-in for alternative models

Description

- Increase awareness of caregiver requirements as a barrier to transplant. Generate evidence and buy-in for alternative models.

Research Question Examples

- How to get the word out about the current caregiver model being an access barrier to treatment and burdensome for caregivers?
- What is the cost-benefit of the current caregiving model? Of alternative models?

Improve understanding of the current state

Description

- Learn more about the current state of caregiver requirements, including identifying patient and transplant center experiences.

Research Question Examples

- What are the experiences of patients who do not have a 24/7 caregiver for 100+ days post-transplant?
- What are transplant center outcomes/results with their caregiver requirements?

Build patient-centered models

Description

- Identify patient-centered models to help tailor resources/support and address caregiver burden, including:
  1) assessment
  2) development of a patient-centered plan
  3) resources to implement the plan.

Research Question Examples

- What validated tools exist that could be used to conduct the assessment?
- What is needed for safe post-transplant care and monitoring?
- How do we ensure efficient and effective connection to resources and support based on needs identified in the plan?

Create change through policy & advocacy

Description

- Identify institutional, local, state and federal policy opportunities and ensure effective resources and support for those policies.

Research Question Examples

- What policies could be enacted to improve access to care in this space?
- How can regulatory bodies and/or payers help create this change?

Co-create through community engagement

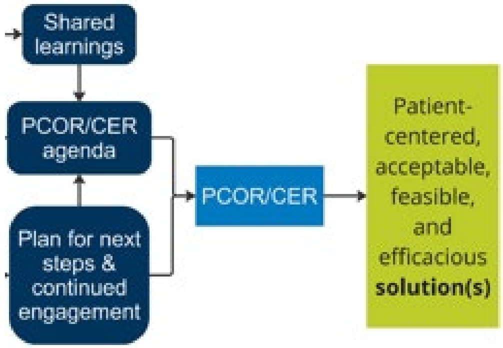
Description

- Include multiple and diverse stakeholders, including patients and caregivers, in and throughout any future studies, pilot projects, or initiatives.

Research Question Examples

- How can we translate research findings into action through engaged research?
- What are the most effective ways to engage different stakeholders in research?

Next steps



- Disseminate research agenda
  - Proceedings paper
  - Abstracts
- Implement research agenda
  - Partner with stakeholders interested in pursuing/implementing/conducting research
  - Lead research studies and pilot projects
  - Develop evidence-based practices

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Caregiver Reimagined Panel

Anu Agrawal, MD

Pediatric Oncologist

Vice President, Global Cancer Support

American Cancer Society

Karen DeMairo, MHSA

Vice President, Education, Support & Integration

The Leukemia & Lymphoma Society

Anna DeSalvo, MS, CGC

Manager, Implementation Science

NMDP CIBMTR

Yadira Montoya, MSPH

Programs Director

National Alliance for Caregiving

Jaime Preussler, PhD, MS

Senior Health Services Research Scientist

NMDP CIBMTR

Jessie Sanders

Director, National Roundtables & Coalitions

American Cancer Society

Ben Tweeten, MSW, LICSW

Manager, Patient Services Operations

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ASTCT-NMDP ACCESS Initiative
Junior Faculty Immersion Program (JFIP)

Alexandra Gomez-Arteaga, MD

Weill Cornell Medicine/ NewYork Presbyterian Hospital

2025 Summer Workshop

July 29, 2025

Equal Outcomes for All

Why we need a Junior Faculty Immersion Program (JFIP)

Substantive and sustainable improvements require early education and involvement of trainees/junior faculty

+

Diverse healthcare workforce can improve patient access and care

+

Early exposure to BMT and CT → increased interest in pursuing a career in BMT and CT

Junior Faculty Immersion Program
Goals

1. To foster career development and mentorship for trainees and early faculty committed to BMT/CT, health services research, and health equity advocacy

2. To actively promote and increase diversity in the BMT/CT field by recruiting and supporting underrepresented minority trainees and junior faculty.

3. To equip JFIP members with practical knowledge and tools for health policy, advocacy, and systems-level research to drive change within the field.

Junior Faculty Immersion Program- Co-Chairs

Anu Hall

Assistant Professor

Seattle Children's Hospital/University of Washington

Alexandra Gomez Arteaga

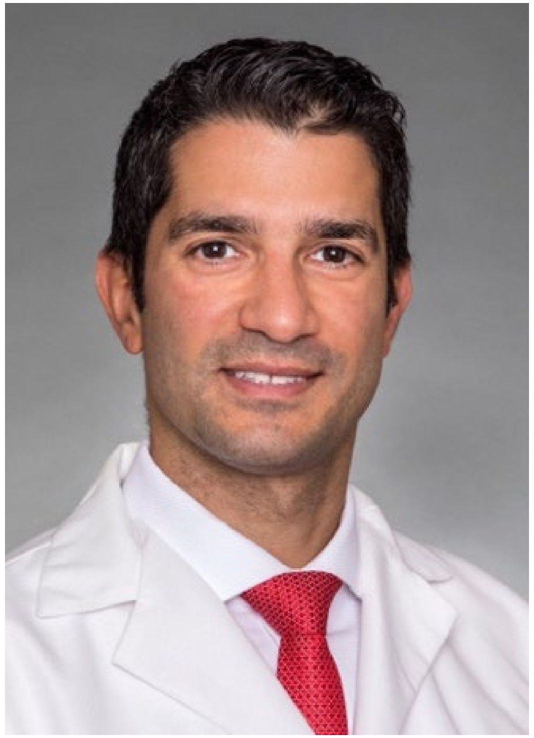
Assistant Professor

Weill Cornell Medicine/New York Presbyterian Hospital

JFIP Structure

- Six members recruited
- Medical students, residents, fellows, advanced HCT/CT fellows, or junior faculty within 2 years of starting their instructor or assistant professor position
- Appointed for two years (2024-2026)
- Mentors: co-chairs of each committee

JFIP- Awareness



Nima Ghalehsari

BMT Fellow

Stanford University

Incoming Faculty at Moffitt

Manu Pandey

Assistant Professor

Univ of Oklahoma Health Sciences Center

JFIP- Poverty

Rahul Shah

Heme/Onc Fellow (1st year!)

MD Anderson

Manuel Espinoza-Gutarra

Assistant Professor

University of Alabama at Birmingham

JFIP- Racial and Ethnic Inequities

Kristie Ramos

Pediatric Heme/Onc Fellow

Cincinnati Children's

Maria Pereda Ginocchio

Assistant Professor

Tulane University

Manning Family Children's Hospital

JFIP Timeline: What has JFIP been up to?

3 formal educational sessions during 2024

August 2023
Established during the 2nd ACCESS workshop

October-November 2024
Recruitment of inaugural cohort

January 2024
Virtual introductory session

February 2024
1st in person meetup Tandem

JFIP Meetings (committee chairs)

April 2024
Call for two projects (Physician Advocacy whitepaper / Workforce Diversity Survey)

August 2024 Call for Whitepaper: “systematic review of databases (access and outcomes in HCT/CT)

February 2025
Workforce diversity Survey presented during TANDEM

May 2025
Two manuscripts submitted to TCT

JFIP Projects and Progress

Workforce Diversity Survey
Leaders: Maria Pereda, Kristie Ramos, Manuel Gutarra
Tandem 2025 Oral Presentation during Workshop
Manuscript submitted : May 20, 2025

Physician Advocacy in HCT/CT
Leaders: Manu Pandey, Nima Ghalehsari
Manuscript submitted : May 25, 2025

Database Systematic Review
Leaders: Manuel Gutarra, Rahul Shah
Under the leadership from Sanghee Hong and Nandita Khera.
Manuscript in preparation

- Other Projects:
- Education Event (Awareness Committee): BMT referral awareness in NYC hospitals

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Workforce Diversity Survey

Maria Pereda Ginocchio, MD

Assistant Professor

Tulane University
Manning Family Children's Hospital

2025 Summer Workshop

July 29, 2025

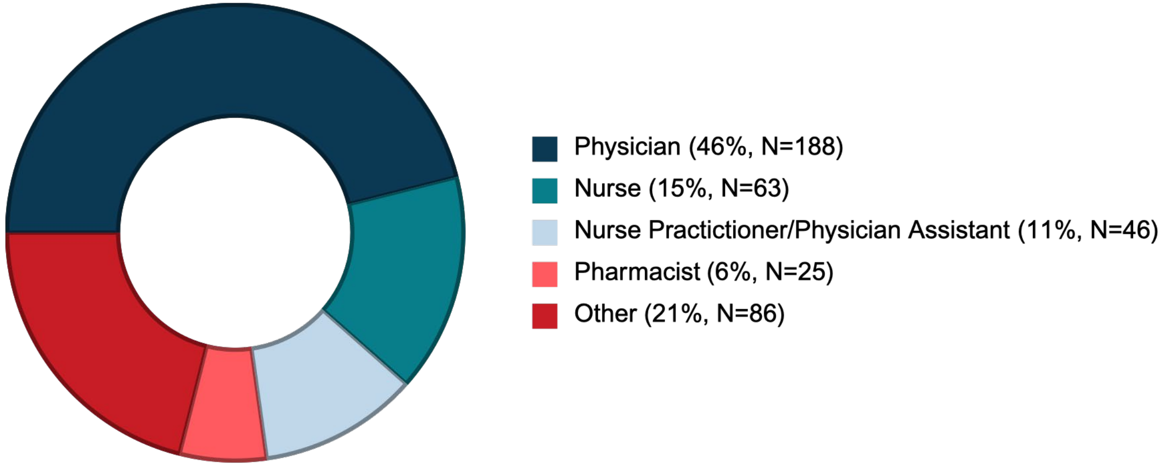
Equal Outcomes for All

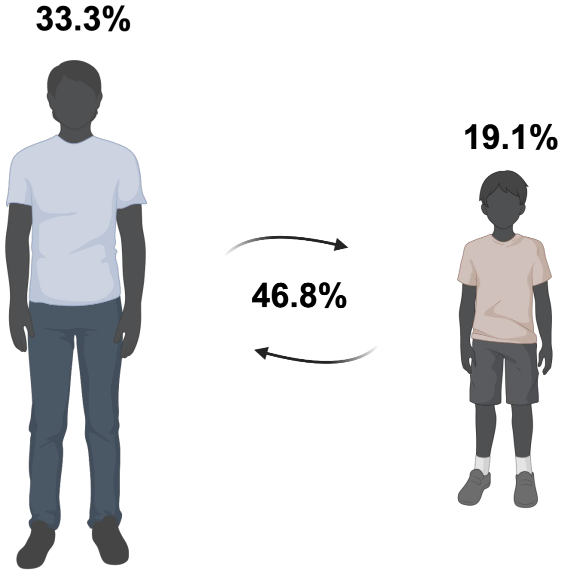
Workforce Diversity Survey

18-question electronic survey created using google forms

Distribution through ASTCT email list

Anonymous answers collected from July to August 2024

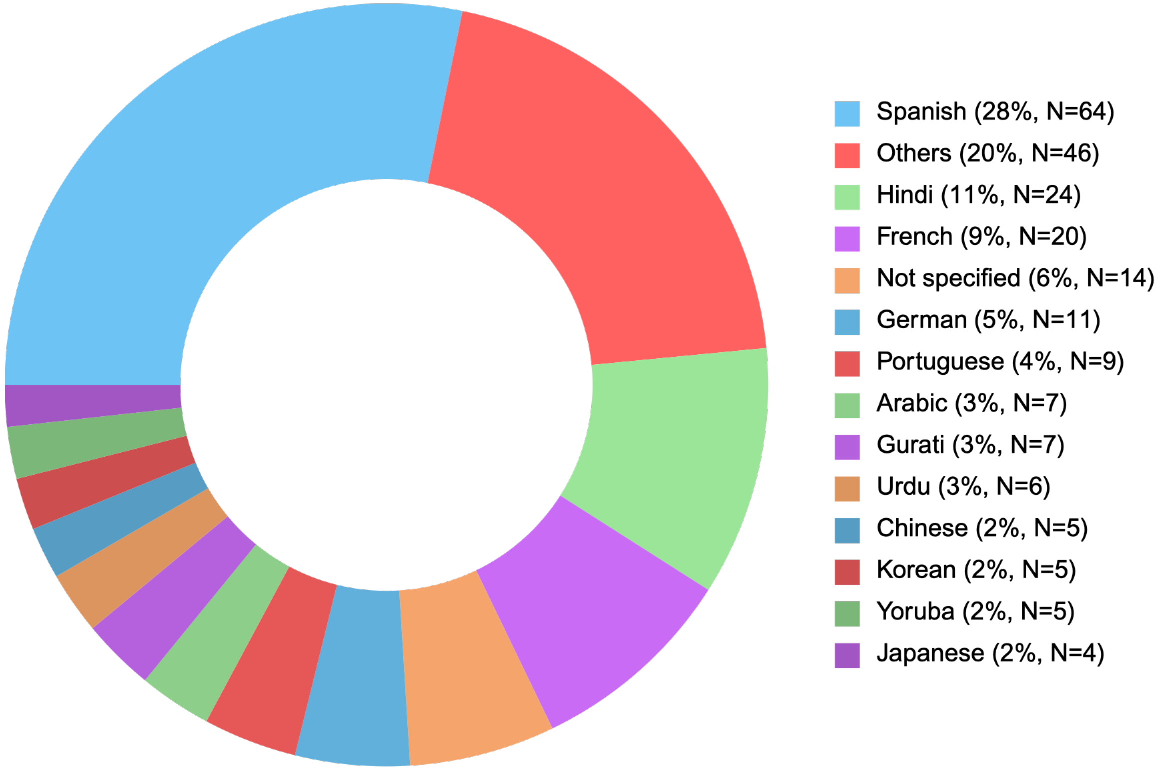




Workforce Diversity Survey

International Medical Graduates make up 35% of the U.S. HCT/CT physician workforce

28% of HCT/CT physicians continue to have a non-permanent IMG status after training.

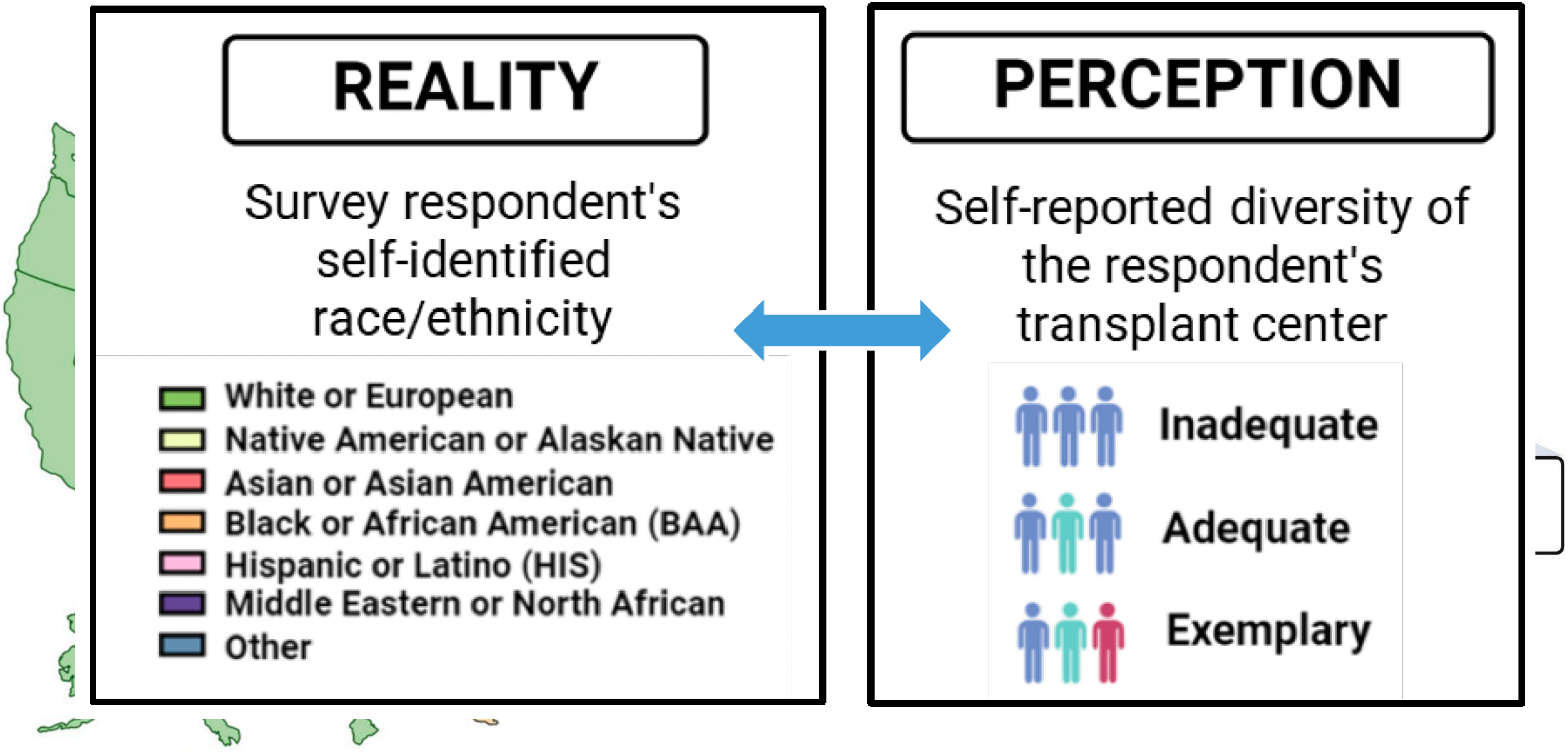


Language spoken by the HCT/CT Workforce

Equal Outcomes for All

Workforce Diversity Survey

Reality of HCT/CT Workforce Diversity by



REALITY

Survey respondent's self-identified race/ethnicity

- 🟩 White or European
- 🟨 Native American or Alaskan Native
- 🟥 Asian or Asian American
- 🟧 Black or African American (BAA)
- ▨ Hispanic or Latino (HIS)
- 🟪 Middle Eastern or North African
- 🟦 Other

PERCEPTION

Self-reported diversity of the respondent's transplant center

- Inadequate
- Adequate
- Exemplary

Workforce Diversity Survey

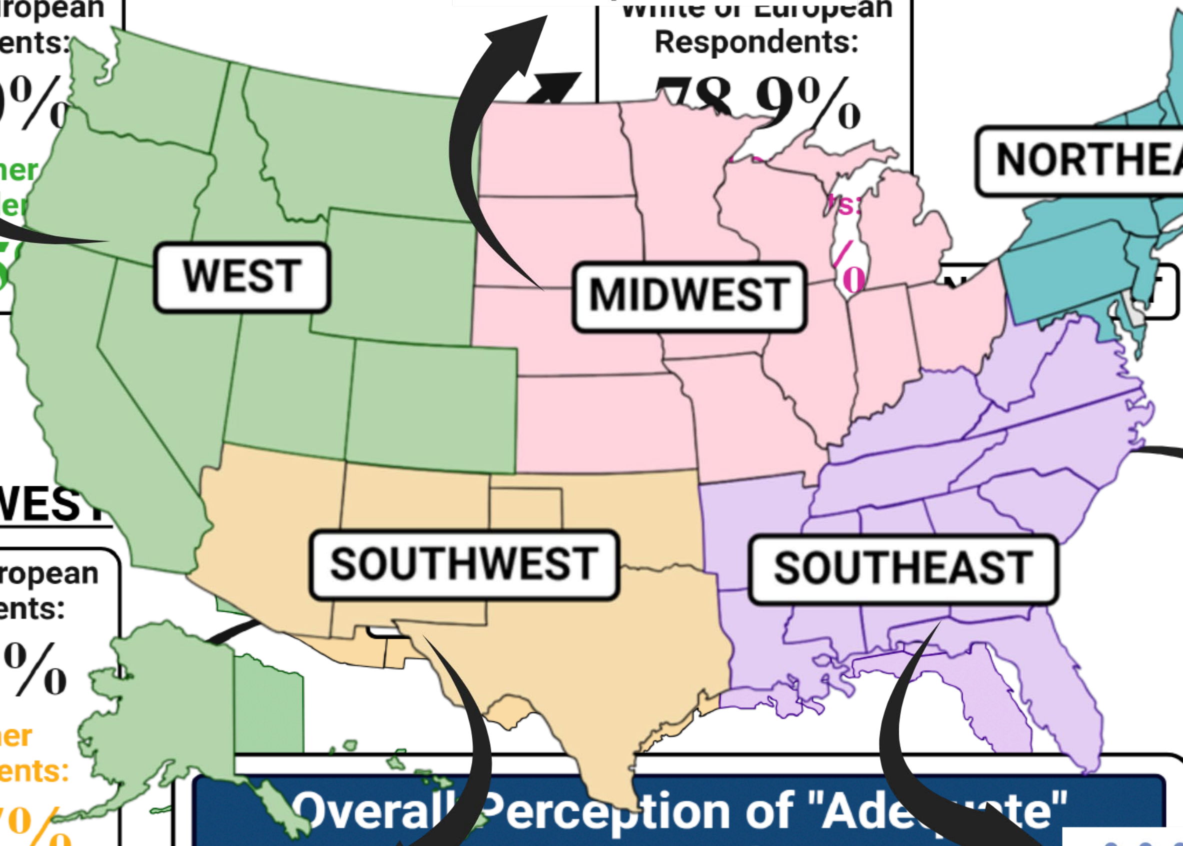
39%
Inadequate

White or European
Respon dents:
75 0%
Al Other
Respo der
45.5

29%
Inadequate

Respondents:
78.9%

NORTHEAST
White or European
27%
Inadequate
All Other
Respondents:
75.4%



SOUTHWEST
White or European
Respondents:
56.2%
All Other
Respondents:
66.7%

38%
Inadequate

SOUTHEAST
White or European
Respondents:
88.2%
All Other
Respondents:
6%

13%
Inadequate

Overall Perception of "Adequate" or "Exemplary" Workforce Diversit
or European Respondents: 7
All Other Respondents: 62.1%

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Lessons learned from our work at JFIP

- Further exploration and improvement of diversity in the HCT/CT workforce is essential.

- International medical graduates are vital to the HCT/CT workforce.

- Workforce diversity does not reflect the racial and ethnic makeup of the patient population in the U.S.

- There was no clear awareness of the lack of diversity among HCT/CT providers.

- Most white respondents rated workforce diversity as “adequate” or “exemplary,” indicating a disconnect between perception and actual representation.

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The Critical Need for Physician Advocacy in HCT-CT

Nima Ghalehsari, MD

Assistant Professor

Moffitt Cancer Center

2025 Summer Workshop

July 29, 2025

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Bridging Gaps: The Imperative of Physician Advocacy in HCT-CT

- Physicians are uniquely positioned to address healthcare disparities in HCT-CT

- Physicians can educate/influence policymakers
  - 1964 Report on Smoking and Health[1]
  - Dr Mona Hanna-Attisha on Flint, Michigan Water Crisis[2]

1. Housman et al. 2001 2. Hanna-Attisha et al 2016

Bridging Gaps: The Imperative of Physician Advocacy in HCT-CT

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1. Housman et al. 2001 2. Hanna-Attisha et al 2016

Bridging Gaps: The Imperative of Physician Advocacy in HCT-CT

Lack of institutional support

Lack of training in advocacy

Lack of compensation for advocacy

Time Consuming

Politically Risky

Impact of Future of ACCESS Initiative

- Exemplifies how multi-organizational advocacy, driven by physician expertise, can achieve impactful systemic changes in HCT-CT

- Successful advocacy efforts (CWBYCTP and CIBMTR), demonstrate the power of collective action in influencing policy and improving patient care

- Professional organizations like those involved in ACCESS are crucial for amplifying physician voices

The "What, Where and How" of Advocacy

- Effective advocacy involves identifying a passionate cause, setting quantifiable goals and sharing compelling stories
- The BRIDGE Program in NY
- NMDP Initiatives in Brooklyn, NY

JFIP Projects and Progress

Workforce Diversity Survey
Leaders: Maria Pereda, Kristie Ramos, Manuel Gutarra
Tandem 2025 Oral Presentation during Workshop
Manuscript submitted : May 20, 2025

Physician Advocacy in HCT/CT
Leaders: Manu Pandey, Nima Ghalehsari
Manuscript submitted : May 25, 2025

Database Systematic Review
Leaders: Manuel Gutarra, Rahul Shah
Under the leadership from Sanghee Hong and Nandita Khera.
Manuscript in preparation

- Other Projects:
- Education Event (Awareness Committee): BMT referral awareness in NYC hospitals

JFIP Progress Report Results

JFIP Progress Report
Participant Experience in Health Advocacy

- Participants brought a wide range of advocacy experience
  - Served as primary educator in the All of Us Research Program
  - Contributed to the BRIDGE Program (2021–2024), part of the Blood Cancer Research Initiative focused on community engagement
  - Acted as DEI Champion at SWOG, improving minority recruitment in large clinical trials
    - Received a Robert A. Winn CDA Career Development Award
  - Participated in state medical associations and ACP's Health & Public Policy Committee
  - Two participants joined the program with no prior experience in health advocacy

JFIP Progress Report
Why Participants Joined JFIP

- *To build skills in health equity and policy advocacy*
- *To understand key stakeholders and structural barriers in HCT and CGT access*
- *To receive mentorship from national leaders in the field*
- *To educate others on racial and ethnic disparities in HCT/CGT*
- *To advocate for workforce diversity and equitable care delivery*
- *To improve understanding of patient needs—especially among minority groups*

🎯 JFIP attracts highly motivated individuals seeking not only to grow professionally, but also to transform systems of care→ how do we mentor them?

JFIP Progress Report
Reflections on Initial Experience in the Program

- *I've appreciated the opportunity to connect with physician leaders focused on equity in transplant and cellular therapy. It reaffirmed the importance of structured, institutional support from national organizations like the NMDP and ASTCT.*
- *I learned a lot about the advocacy efforts ongoing in the HCT-CT field. It helped me understand the power of advocacy and how to navigate complex legislative and regulatory structures.*
- *Collaborating with a diverse group of professionals across institutions and career stages has been an invaluable experience.*

JFIP Progress Report
Reflections on Initial Experience in the Program

- *Being part of JFIP has been incredibly rewarding. Alex, Anu, and Jeff have done a phenomenal job facilitating impactful work and supporting its advancement to publication.*

- *The diversity within the ACCESS committee is truly inspiring, with members offering unique perspectives and expertise.*

- *The ASTCT 2025 symposium helped me critically analyze persistent barriers to HCT/CGT and sparked inspiration through project showcases.*

JFIP Progress Report
Feedback for Future Cohorts

- *Enhance communication and mentorship within subcommittees/projects.*
- *Develop more concrete, defined projects with clear deliverables.*
- *Increase structure: Ensure participants are actively mentored and engaged.*
- *Expand access to broader collaborative networks*

Moving Forward
Suggestions for the Committee

- Structured Orientation Curriculum: Toolkit introducing past work of the initiative, roles, and goals.
- Quarterly Check-ins: Formalize regular progress discussions and peer support.
- Advocacy Skill-Building Series: Interactive workshops with policy experts, patient advocates, and industry leaders (CAR-T, Gene therapies etc)
- Targeted Mentorship: Pairing participants with mentors aligned to project goals and interests.
- Expand to other junior faculty within the ACCESS committee.

ASTCT-NMDP ACCESS Initiative

Patient Representation: Challenges and Opportunities

Jackie Foster
Alexa Schiller
Jessie Sanders
Karen DeMairo

Rayne Rouce
Anu Agrawal
Yadira Montoya
Melina Pineyro

Equal Outcomes for All

ASTCT-NMDP ACCESS Initiative

Voice of the Community: Survey Results

Jackie Foster, MPH, RN, OCN

Senior Manager, Patient Services, NMDP

Alexa Schiller, CHES

Program Manager, Patient Education, NMDP

Equal Outcomes for All

Voice of the Community (VOC) Volunteers

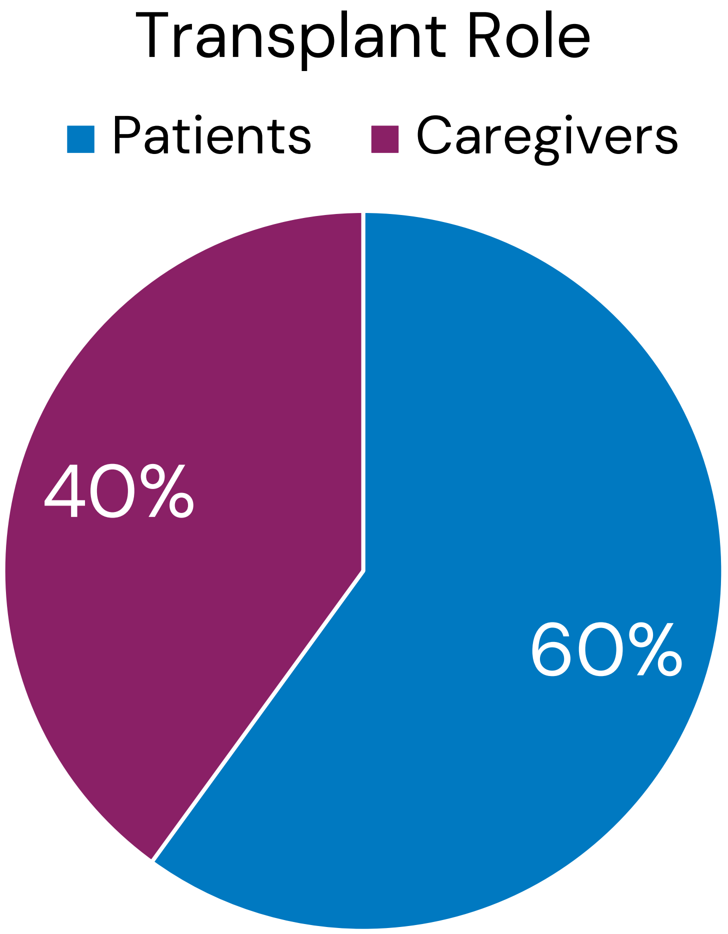
Eligibility

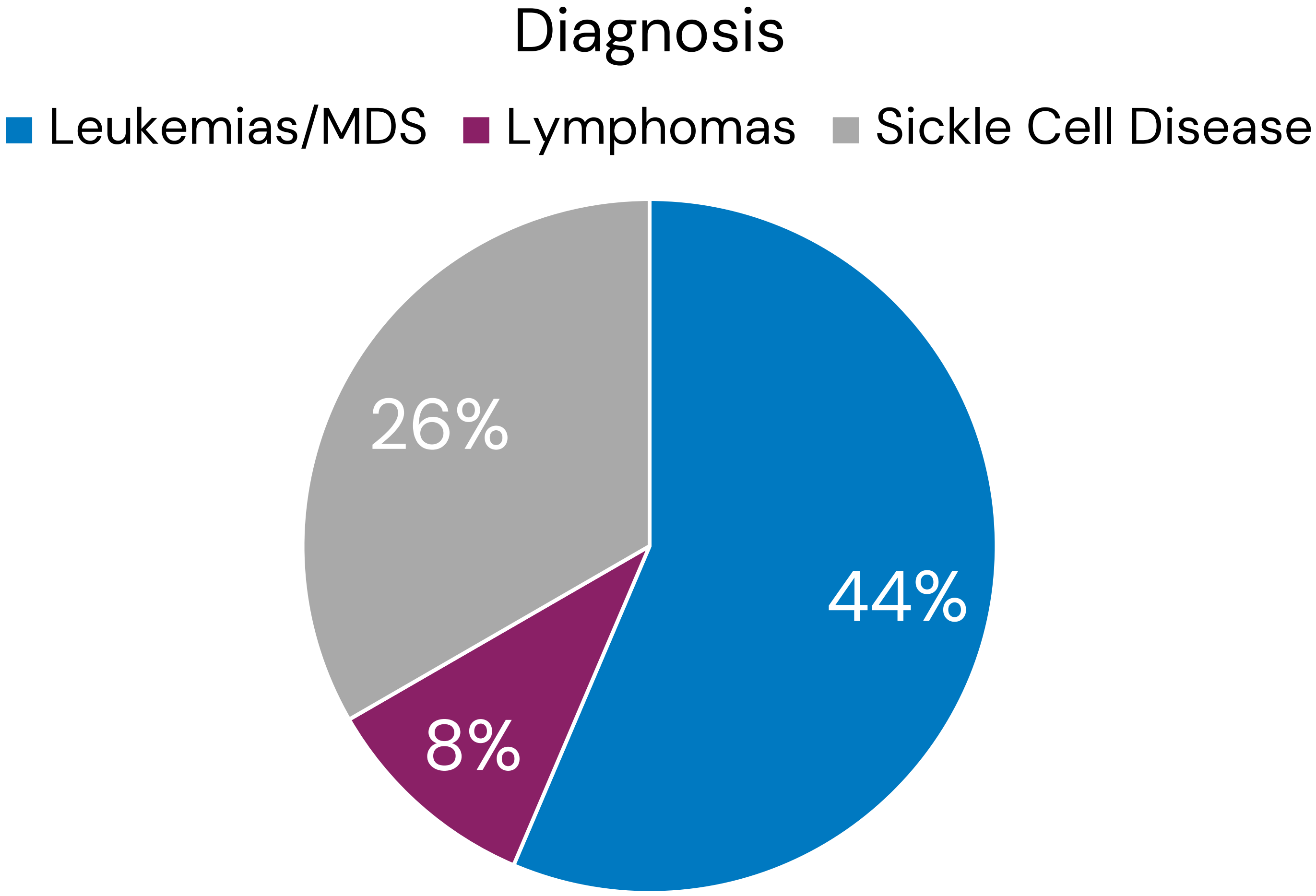
- Read and speak English fluently
- Either 1) Received a diagnosis of a blood cancer or blood disorder or 2) Are the primary caregiver for someone with a blood cancer or blood disorder

Responsibilities

- Participate in at least 4 projects each year (projects sent monthly)
- Keep track of the time you spend volunteering
- Share your feedback honestly. You won’t hurt our feelings!
- Keep information shared by other volunteers confidential
- Tell us if your ability to volunteer changes

Voice of the Community: 72 Active Volunteers





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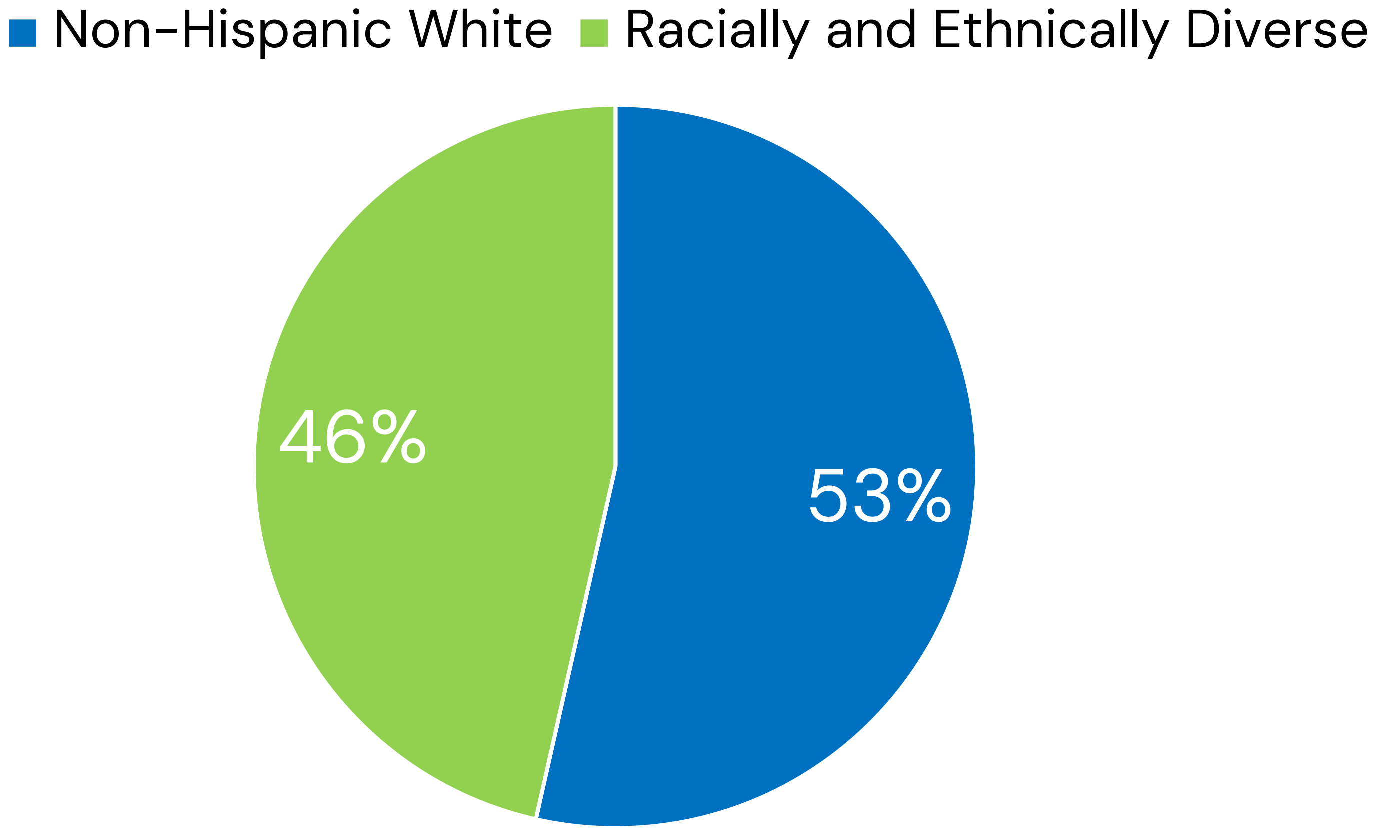
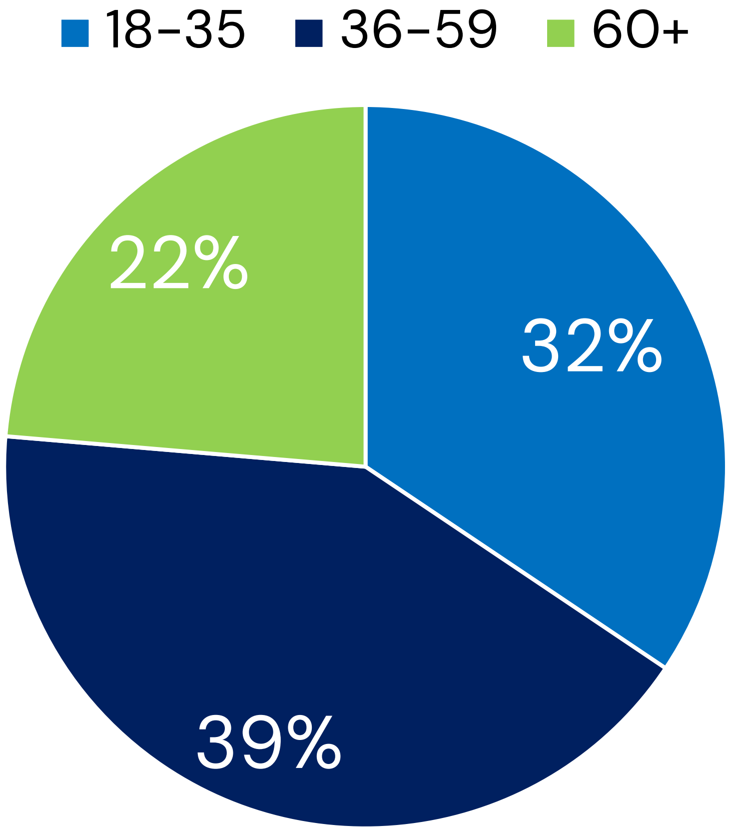
Voice of the Community: 72 Active Volunteers



Race and Ethnicity



Age

Access Initiative Project

Sent to 54 volunteers in October 2024

Received responses from 12 volunteers

Assignment:

- Asked to review background on the Access Initiative and provide initial impressions
- Asked if they experienced barriers related to any of the committee topics
- Asked if they would be interested in participating (sharing their story, reviewing draft plans/projects, or joining meetings)

Survey Results: First Impressions

- General support for committee topics
- Poverty and Racial Inequity goals may be harder to achieve
- Who will be involved?
  - Desire for patient/caregiver involvement
  - Government involvement? Representative from each US state?
  - Who are the funders?
- What is the relationship between the 3 committees? Will they work together?
- Review public-facing language
- Racial inequity barriers: consider addressing language barriers

Representative Quotes

“My first impression of the ACCESS Initiative is a positive one! I think it is an important movement in the hematology/oncology world to not only discover and improve treatment options, but to make every effort to make sure all options are as available as possible to everyone who needs them.”

“I feel like there is significant overlap between the Poverty and Racial Inequity committees. It seems that the Awareness committee's focus is on making sure patients are aware of treatment options, but both the Poverty and Racial Inequity committees are both focused on overcoming barriers to treatment. They both appear to be using similar tools to address their respective issues, and I feel that this might lead to some duplication of effort and some confusion about which committee would be responsible for addressing certain issues.”

Survey Results: Next Steps

- High interest in this work!
- 7 volunteers expressed interest in future involvement via:
  - Sharing their story or experience with committee members
  - Reviewing drafted plans or projects
  - Joining virtual meetings
- Others interested in hearing updates

ASTCT-NMDP ACCESS Initiative

Patient Education and Engagement

Rayne Rouce, MD

Associate Professor, Department of Pediatrics, Section of Hematology-Oncology, Baylor College of Medicine

Associate Director, Community Engagement, Baylor College of Medicine and Dan L Duncan Comprehensive Cancer Center

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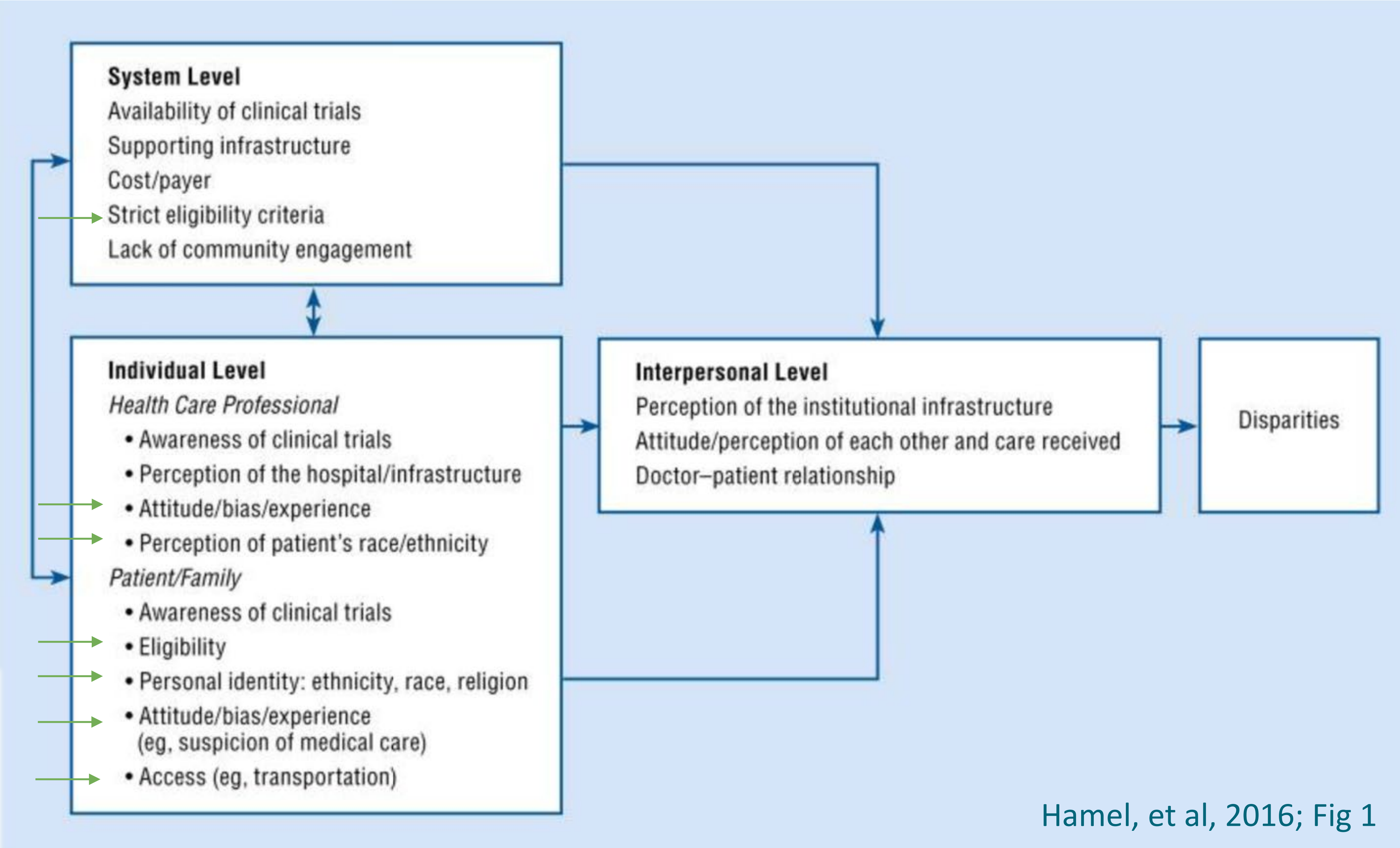
Barriers to patient engagement in transplant and cell therapy clinical trials occur at multiple levels



System Level
Availability of clinical trials
Supporting infrastructure
Cost/payer
Strict eligibility criteria
Lack of community engagement

Individual Level
Health Care Professional
- Awareness of clinical trials
- Perception of the hospital/infrastructure
- Attitude/bias/experience
- Perception of patient's race/ethnicity

Patient/Family
- Awareness of clinical trials
- Eligibility
- Personal identity: ethnicity, race, religion
- Attitude/bias/experience (eg, suspicion of medical care)
- Access (eg, transportation)

Interpersonal Level
Perception of the institutional infrastructure
Attitude/perception of each other and care received
Doctor–patient relationship

Disparities

Hamel, et al, 2016; Fig 1

Expanding Access to Clinical Trials

- **Recent evidence supports early consideration of barriers that may affect inclusion in clinical trials (or complex treatment in general)**
  - accessibility (including language/communication, transportation, study logistics, eligibility criteria, lack of knowledge)
  - lack of trust; attitudes/beliefs
- **Early and frequent assessment allows exploration of mitigation strategies, appropriate allocation of funding, engagement of additional personnel, and… appropriate engagement of patient/caregiver volunteers**

Bodicoat, et al, 2021; NASEM, 2022

Domains to consider in enhancing access to and representation on clinical trials

Recruitment, Accrual & Retention

-#/frequency of study visits (screening, treatment, follow-up) compared to SOC

-is there appropriate flexibility (+/- days)?

-required vs. optional visits

-are local labs/visits allowed for subjects traveling >60 miles?

-plan to review accrual and track screen failures?

Financial Burden

-limiting multiple day/week follow-up

-allowing flexibility in scheduling to ease burden

-mechanisms for financial support (transport, parking, lost wages, caregiver)

-use of local accommodations

-patient/financial navigation

Inclusion & Exclusion Criteria

-broadest possible eligibility criteria, justified ethically or scientifically (not overly restrictive without scientific basis to avoid unintentional exclusion due to asymptomatic conditions)

Cultural and Linguistic Competence

-ensuring recruitment materials are appropriate; engaging broad patients/advocates (including lower resourced/health literacy/education level)

-solicit patient/community input & feedback on recruitment/retention strategies

Additional Considerations re study design, conduct and implementation

- **Screen/enrollment failures**
  - Eligibility or investigator discretion: is a screen failure based on an objective measure of eligibility or a subjective assessment of judgment?
  - does the protocol contain scientific or ethical justification for each excluded population (particularly important for novel therapeutics)?
  - Logistical/financial/personal concerns:
    - lost wages/missed work/lack of transportation/other child/elder care
    - mistrust/fear of experimentation or exploitation; concerns about randomization
- **Reasons for coming "off treatment" or "off study"**
  - clinical vs. other
  - allows granular assessment of unanticipated or unaddressed barriers, especially ones that may disproportionately affect certain populations

Adapted from MRCT Center of Brigham and Women's Hospital and Harvard; Rouce, et al. BMT CTN Guidance for Special Populations 2023

Additional Considerations re study design, conduct and implementation

- **Shortening, consolidating, simplifying consent documents**
  - provide simplified language study and consent guides to assist investigators
  - provide other language consent guides for guidance to sites given use of “short forms” that lack study-specific information
- **Incorporate a brief overview of general research safeguards in place given historical events (assists with addressing mistrust) and commonly cited concerns about research in general**
- **Offer multiple or alternative formats for participants to access trial communications, for study visits, and for endpoint measurement**

Adapted from MRCT Center of Brigham and Women’s Hospital and Harvard;
Rouce, et al. BMT CTN Guidance for Special Populations 2023

Additional Considerations re study design, conduct and implementation

- Trial eligibility
- Calendar flexibility
- Languages offered
- Literacy requirements

But…for some patients/families, the door is closed to clinical trial or research participation before it has even been presented.

- Despite recognition of barriers to clinical trial enrollment, few clinical trial materials address barriers related to absence of education and cultural/societal mistrust

- Previous studies have demonstrated behavioral change and increase in knowledge after educational interventions using multimedia and narrative approaches
  - effective strategy for cancer-related communication to populations with limited health literacy

How can we open the door to allow careful consideration of trials or complex treatments themselves?

Hirschey, cancer Nurs., 2020; Hurtado de Mendoza, J Genet Couns, 2021; Matsuyama, J Cancer Educ, 2023

Enhancing Access to BMT CTN Clinical Trials : A Multimodal, Multilevel Educational Approach

- **Study Design:** Pilot, quality-improvement, Mixed Method Approach
- **Timeline:** 1 year
- **Target populations**
  1. **Patients eligible for participation in BMT-CTN clinical trials**
     - including populations with comparatively lower accrual to date, evidence-based self-reported hesitancies to enrollment, adverse socio-economic factors
  2. **BMT CTN investigators and study staff at participating sites**
  3. **Community (including referring) providers**

***Study Design/Scope evolved based on BMT CTN prioritized needs and climate**

Enhancing Access to BMT CTN Clinical Trials : A Multimodal, Multilevel Educational Approach

AIM 1

Develop a **multipronged, multilevel approach to enhance accrual on BMT CTN trials**, inclusive of culturally appropriate, accurate **general clinical trial & trial-specific infographics** for patients/caregivers (addressing common and specific misperceptions about clinical trials)

AIM 2

Develop **culturally sensitive 2-5 minute informational videos** featuring prior BMT CTN trial participants/investigators/staff (short video synopses of educational materials, interactive conversations addressing common misperceptions (general & specific))

AIM 3

Evaluate the effectiveness of the educational intervention from a a multi-stakeholder perspective

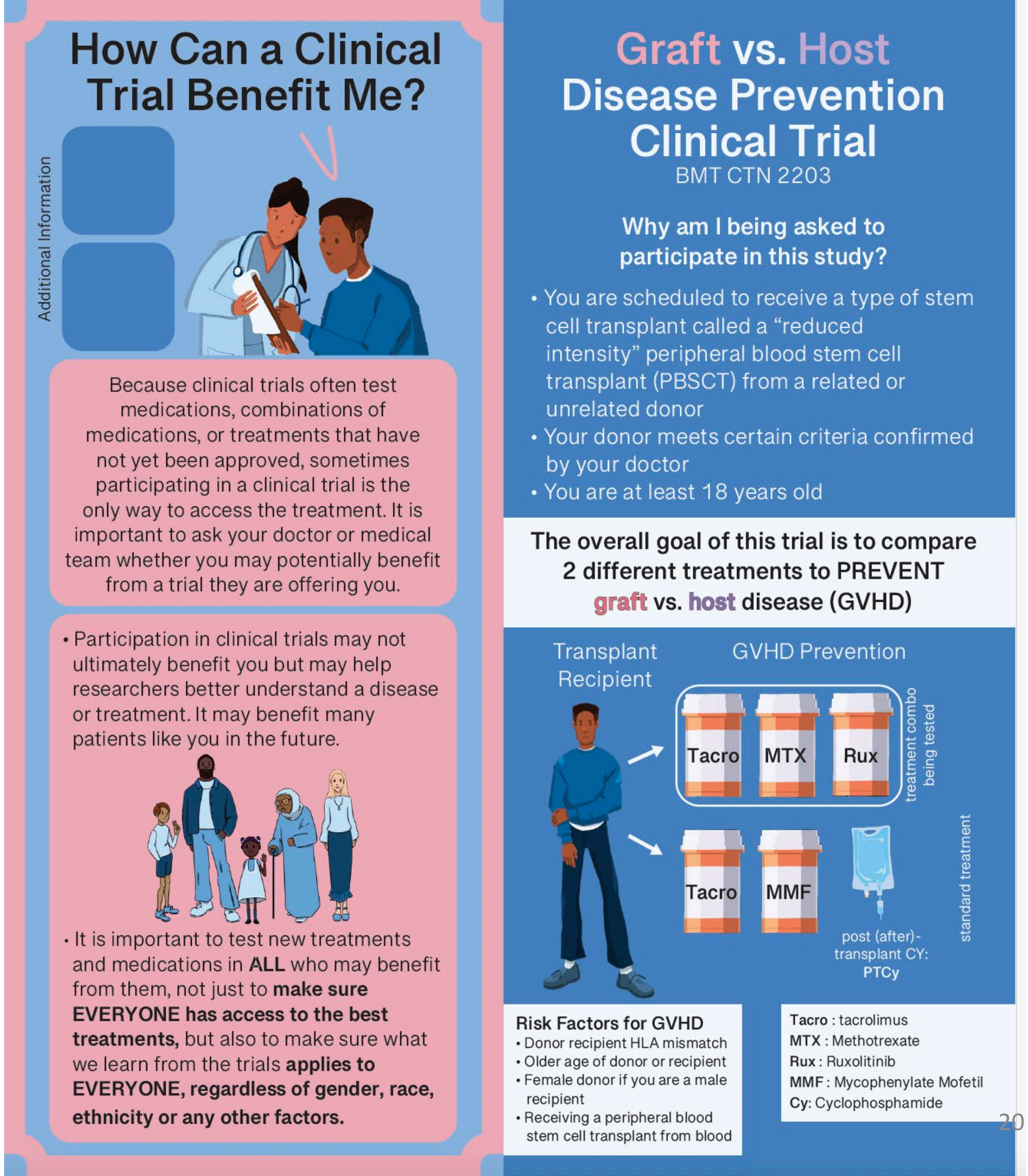
(“Readiness to Change Rule”, “Was it Worth It”, and “Patient Education Materials Assessment” tools)

Will include QR code scannable narrated video option:

English, Spanish, + at least 2 other languages based on top 4 languages at sites

Will also include:

- Scannable Link-Tree of BMT CTN website info:
  - ➢ disease-specific info
  - ➢ Patient/Caregiver Advisory Info



How Can a Clinical Trial Benefit Me?

Additional Information

Because clinical trials often test medications, combinations of medications, or treatments that have not yet been approved, sometimes participating in a clinical trial is the only way to access the treatment. It is important to ask your doctor or medical team whether you may potentially benefit from a trial they are offering you.

- Participation in clinical trials may not ultimately benefit you but may help researchers better understand a disease or treatment. It may benefit many patients like you in the future.
- It is important to test new treatments and medications in **ALL** who may benefit from them, not just to **make sure EVERYONE has access to the best treatments,** but also to make sure what we learn from the trials **applies to EVERYONE, regardless of gender, race, ethnicity or any other factors.**

Graft vs. Host Disease Prevention Clinical Trial

BMT CTN 2203

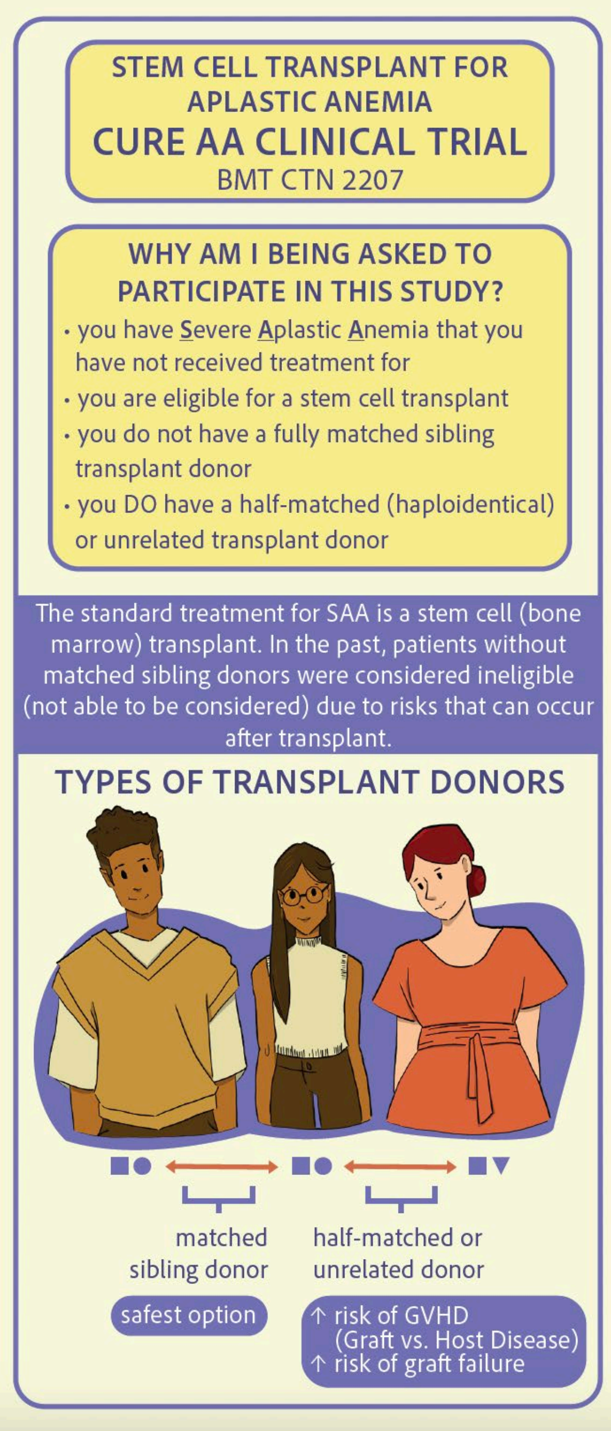
Why am I being asked to participate in this study?

- You are scheduled to receive a type of stem cell transplant called a "reduced intensity" peripheral blood stem cell transplant (PBSCT) from a related or unrelated donor
- Your donor meets certain criteria confirmed by your doctor
- You are at least 18 years old

The overall goal of this trial is to compare 2 different treatments to PREVENT graft vs. host disease (GVHD)

Risk Factors for GVHD
- Donor recipient HLA mismatch
- Older age of donor or recipient
- Female donor if you are a male recipient
- Receiving a peripheral blood stem cell transplant from blood

Tacro : tacrolimus
MTX : Methotrexate
Rux : Ruxolitinib
MMF : Mycophenylate Mofetil
Cy: Cyclophosphamide



STEM CELL TRANSPLANT FOR APLASTIC ANEMIA
CURE AA CLINICAL TRIAL
BMT CTN 2207

WHY AM I BEING ASKED TO PARTICIPATE IN THIS STUDY?

- you have Severe Aplastic Anemia that you have not received treatment for
- you are eligible for a stem cell transplant
- you do not have a fully matched sibling transplant donor
- you DO have a half-matched (haploidentical) or unrelated transplant donor

The standard treatment for SAA is a stem cell (bone marrow) transplant. In the past, patients without matched sibling donors were considered ineligible (not able to be considered) due to risks that can occur after transplant.

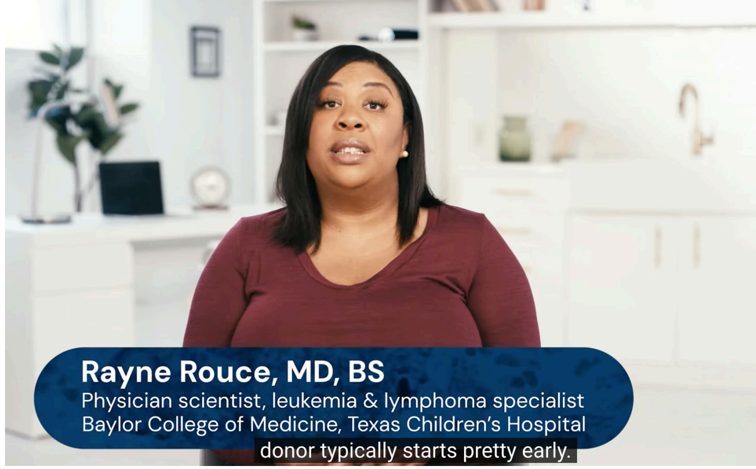
TYPES OF TRANSPLANT DONORS

matched sibling donor

safest option

half-matched or unrelated donor

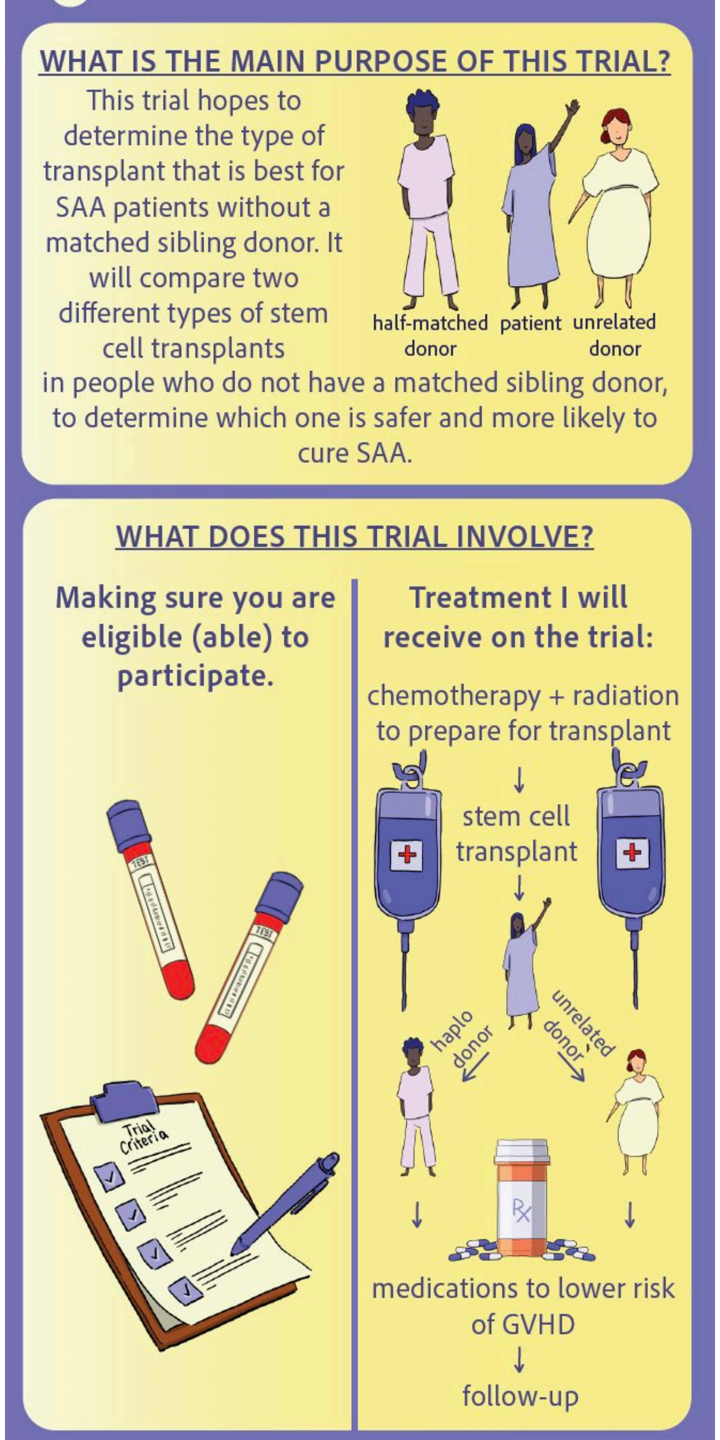
↑ risk of GVHD (Graft vs. Host Disease)
↑ risk of graft failure



Rayne Rouce, MD, BS
Physician scientist, leukemia & lymphoma specialist
Baylor College of Medicine, Texas Children's Hospital

donor typically starts pretty early.

increased risk of mortality without transplant and increased limitation



WHAT IS THE MAIN PURPOSE OF THIS TRIAL?

This trial hopes to determine the type of transplant that is best for SAA patients without a matched sibling donor. It will compare two different types of stem cell transplants in people who do not have a matched sibling donor, to determine which one is safer and more likely to cure SAA.

WHAT DOES THIS TRIAL INVOLVE?

Making sure you are eligible (able) to participate.	Treatment I will receive on the trial:
	chemotherapy + radiation to prepare for transplant ↓ stem cell transplant ↓ haplo donor / unrelated donor ↓ medications to lower risk of GVHD ↓ follow-up

Site Preferences & Capabilities for Implementation

- **Level 1**: infographic brochures onsite (links to narration/videos: auto-play)
- **Level 2**: brochures onsite + tablets (ipads) to play links/videos
- **Level 3**: brochures onsite + tablets (ipads) to play links/videos + ability to play in waiting room or exam room

What does equitable access mean in 2025?

- We must ask ourselves
  - why some research initiatives have focused on certain populations?
    - What (if known) is the biological importance of demographic info to the disease area and study question(s)? Is this info important to ascertain?
  - Whether there are undeniable, evidence-based barriers to enrollment and retention for some populations?
  - Whether eligibility criteria is overly exclusive without scientific rationale
  - Whether where you happen to be diagnosed/treated matters?

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Personal Caregiving Experience

Melina Pineyro, MPH, Senior Manager of Health Programs

Patient Representation: Challenges and Opportunities Panel Discussion

Moderator: Anu Agrawal, MD, Pediatric Oncologist, Vice President, Global Cancer Support, American Cancer Society

Panelists:

Karen DeMairo, MHSA, Vice President, Education, Support & Integration

Melina Pineyro, MPH, Senior Manager of Health Programs

Jessie Sanders, Director, National Roundtables & Coalitions

2026 ACCESS Initiative: Transition Point

Eneida Nemecek & Erica Jensen

Equal Outcomes for All

Meet the NEW Co-chairs

Eneida Nemecek MD, MS, MBA

Professor, BMT Medical Director & Associate Director of Clinical Research, Oregon Health & Science University Knight Cancer Institute

- 20+ years in BMT & cell therapies
- ASTCT Treasurer & Board of Directors
- Engaged in ACCESS initiative since inception

Why ACCESS Matters to me:
“I have seen firsthand how bone marrow and cellular therapies can offer hope and cure for patients facing otherwise devastating diagnoses. Ensuring equitable access means giving every patient, regardless of background or geography, a fair chance at lifesaving care.”

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nmdp™ FIND CURES. SAVE LIVES.

Meet the NEW Co-chairs

Erica Jensen, MBA

Senior Vice President, Strategy and Advancement - NMDP

- 5 years at NMDP, previous equity metric leader
- Outgoing awareness committee co-chair
- Experienced multicultural marketing and experience leader

Why ACCESS Matters to me:

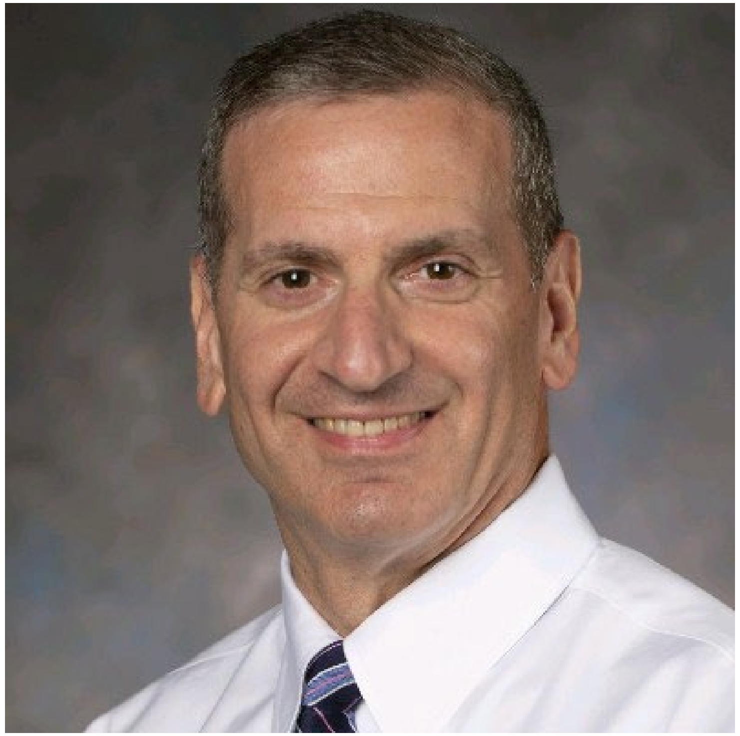
"Driving access and helping to decrease barriers is what drew me to NMDP. Moreso than other industries, I have found that in the cell therapy ecosystem there is a focus and intentionality that is inspirational and life-changing."

Success Highlights

- Launched new collaborative initiative and three working committees to drive change
- Meaningful engagement from businesses, physicians, non-profit orgs, research orgs, etc. to discuss removing patient barriers and increasing access
- 2 published white papers that raised awareness of the need and potential solutions
- Conducted Advocacy day on Capitol Hill
- Launched Young Investigators program
- Presented impactful sessions at Tandem

Thank You Jeff & Stella!

We are thankful for your pioneering work and passion!



Focus and Intent of ACCESS Remains UNCHANGED

Mission:

Reduce barriers to HCT/CT through the implementation of changes in practice and policy by active, sustained engagement of the HCT/CT ecosystem.

Vision:

Provide life-saving therapies to all eligible patients in need.

ACCESS ensures equitable health outcomes for all patients

- Patients continue to face existing and evolving barriers
    - Barriers must be identified and reduced to improve access
- Collaboration among stakeholders enhances access efforts
- Cell therapy research is offering groundbreaking treatment options
- Increased awareness about barriers and opportunities can drive advocacy for better healthcare policies and changes i standards of care

Opportunities for ACCESS Initiative

- Maintain momentum and engagement
- Continue to drive awareness of activities
  - Deploy new communication channels for updates / connections (e.g. sharing results quarterly)
- Launch new, focused working groups
- Enhance involvement from industry leaders

2026 ACCESS Initiative Direction Recommendation

Mission: Reduce barriers to HCT/CT through the implementation of changes in practice and policy by active, sustained engagement of the HCT/CT ecosystem. | **Vision**: Provide life-saving therapies to all eligible patients in need.

2026 Working Groups/Projects	ASTCT Lead	NMDP Lead
1. Patient Level Barrier and Intervention Studies to identify and understand impact of interventions with patients and providers at the time of diagnosis **Problem Statement:** Many patients lack equitable access to transplant due patient non-medical barriers and the complexity of treatment pathways. **Proposed Project:** Participate in a clinical study to collect and collaborate on key data points related to patient barriers and interventions to transplant. Allow a space for centers to collaborate on intervention tools, learnings to expand access	TBD	Anna DeSalvo
2. Awareness & Education to Expand Access to Transplant and Cell Therapy **Problem Statement:** - There is a lack of knowledge across ***Hem/Onc providers*** that impact patients being referred for transplant and cell therapy are often not being referred due to lack of knowledge on current referral guidelines or patient support resources - With changes in administration and policy changes, we must continue to educate ***legislators*** on the importance of our work and barriers that impact access to care for all populations **Proposed Project(s):** - CME Education Series for hem/onc audience - Define one ASTCT/NMDP legislative priority to expand access	TBD	Anna Cincotta

Stay Involved!

- Active involvement in the two working groups is critical for success
    - Need representation across groups

<u>Next Steps:</u>

Communicate 2026 initiatives, calendar of events and CTA to get involved:

- Email all current committee members on engagement opportunities
- Email corporate partners on 2025 changes and revised goals