

ASTCT-NMDP ACCESS Initiative

Awareness Committee

Washington D.C.

August 24 & 25, 2023

2022 ACCESS Working Group Committee: Awareness



- ASTCT Chair: Brenda Sandmaier
- NMDP Chair: Erica Jensen



Vice Chair: Jennifer Holter Chakraborty

Challenge

A key barrier to increasing ACCESS to therapy is lack of awareness

Providers

- Lack of knowledge of rapid advancements and changes in treatment options
- New standards of care, including referral guidelines that often are not disseminated to community physicians or even physicians at academic institutions that do not offer HCT/CT

Patients

- Lack of knowledge of HCT / CT treatment options
- Access to available care and support information

Physician Education and Access to Research



Subcommittee Chair: Jennifer Holter Chakrabarty

Subcommittee Members:

- Taha Aljuhaishi
- Pashna Munshi
- Tania Jain
- Sam Watters

Physician Education and Access to Research

Goal: Update information physicians reference for the latest information

Accomplishments

- ✓ Identified target areas for improvement in physicians reference in HSCT
 - ✓ Target areas identified include Determining Eligibility for HSCT highlighting early HLA testing, improvement in expansion/safety in older adults, expansion access in ethnically diverse patients
 - ✓ Highlight improvement in quality of life and outcomes in mismatched and matched donors
- ✓ Incorporation of HCT Consultation Timing Guidelines in UpToDate topics including AML, MDS, ALL
- ✓ Incorporating Donor and Cord Blood Unit Selection Guidelines in Donor Selection
- ✓ Incorporating new GVHD/Outcome date in Early Complications of HCT
- ✓ Updates in Overview of AML, ALL in children and Adolescents, and treatment of high or very high risk MDS to incorporate early referral for Allo evaluation

Physician Education and Access to Research

Goal: Update information physicians reference for the latest information

Coming Up

- Early discussion with ASTCT Education and Content Committees for Highlight of ACCESS initiatives
- Identification of Diversity and Equity Highlights with Content Committee for “ASTCT News Daily”
- Nucleus Spotlight on Access/Equity
- Identification of Dr. Munshi and Dr. Al-Juhaishi to lead updates in Auto and Car-T for UpToDate with ASTCT lead
- Work with MMRF and other foundations/patient groups for expansion of educational scope.

Community Physician Awareness



Subcommittee Chair: Anna Cincotta (Interim Chair, Emily LaMonica)

Subcommittee Members:

- Dr. Beth Stenger (CHOA)
- Dr. Staci Arnold (CHOA)
- Dr. Tania Jain (Johns Hopkins)
- Dr. Alexandra Gomez Arteaga (Weill Cornell)
- Dr. Heather Stefanski (NMDP)
- Dr. Steven Devine (NMDP)
- Ruth Phillips (Blue Spark Technologies)
- Karen DeMairo (LLS)
- Emily LaMonica (NMDP)
- Sam Watters (NMDP)
- Becca Groebner (NMDP)

Community Physician Awareness

Goal: Develop partnerships and connections with community physicians

Objectives:

- ❖ Target high unmet need areas and engage community providers that do not have well established relationships with their regional transplant and cell therapy network
- ❖ Create peer-to-peer networking space around disease theme
- ❖ Spark collaborative discussion around shared challenges
- ❖ Highlight latest research and high priority clinical trials

Thank you to Ruth Phillips (Blue Spark Technologies), Dr. Stenger & Dr. Arnold (CHOA), Dr. Jain (Johns Hopkins), Dr. Gomez Arteaga (Weill Cornell), Karen DeMairo (LLS), moderators Dr. Stefanski and Dr. Devine and our NMDP Local Provider Partnership team who facilitate these regionally.

Community Physician Awareness

Goal: Develop partnerships and connections with community physicians

Accomplishments

✓ **NJ/ NYC Peds SCD Physician Exchange Aug 17**

- Hackensack - NYP Columbia -Cohen Children's Medical Center of NY
- NYU Winthrop - St Joseph's Health - NYP Brooklyn Methodist

✓ **GA Peds SCD Physician Exchange Aug 22**

- CHOA - MUSC
- Navicent Health - Medical College of GA - Memorial Health/Children's Hospital of Savannah

Coming Up

- Adult MDS Physician Exchanges (coming Fall 2023)

Partnerships to Increase Patient Awareness



Subcommittee Chair: Becca Miller

Subcommittee Members:

- Mary Hengen, NMDP
- Katie Schoepner, NMDP
- Anna Cincotta, NMDP
- Bri Springer, NMDP
- Karen DeMario, LLS

Partnerships to Increase Patient Awareness

Goal: Build / strengthen partnerships with national disease specific groups and health focused community organizations

Accomplishments

- ✓ Collaborating with American Cancer Society on opportunities to increase awareness of resources through their relationships with community physicians and patient support resources
- ✓ Partnering with LLS to increase access to transplant in the Hispanic Community
- ✓ Working with STAR (Sickle Cell Transplant Advocacy and Research Alliance)
- ✓ Sickle disease roundtables in NE and SE
- ✓ Met with Deloitte on how to help educate CGT leaders on patient access issues

Partnerships to Increase Patient Awareness

Goal: Build / strengthen partnerships with national disease specific groups and health focused community organizations

Coming Up

- **LLS Collaboration Opportunities**
 - LLS/NMDP Regional Hispanic Community Engagement: Local Clinical Ops Partner in Chicago to join LLS on a video for patient education along with a TC physician and a patient. It will focus on engaging the Hispanic community of joining the registry and share information about the support for donors and the services for patients from diagnosis to survivorship.
 - In person panel for sponsored by LLS at Malcolm X College. Include live Q&A, donor recruiting, and patient services awareness.
 - Both programs will be in Spanish with the intent to target multigenerational households. Opportunities to do this outreach in other regions.
- **Engaging with CGT leaders on Patient Access to new therapies**
 - Patient Services and Health Equity Leaders participating in a panel to represent access barriers for CGT patients at Deloitte's NextGen Therapies Industry Working Group in September 2023.
- **Discovery on additional partnership opportunities**
 - International Myeloma Research Foundation including the M-POWERed Initiative to improve outcomes in African American patients
 - Myeloma Crowd (HealthTree Foundation)
 - Epic (social determinants of health data) and other technology companies that could support patients
 - Expand collaboration opportunities with LLS, ACS and other organizations on driving patient awareness and education

Awareness Future Exploration

- Focus on: Myeloma, AML and MDS
- Investigate Patient advocacy communication / resource opportunities with industry partnerships (Google, WebMD, top search returns)
- Add fellows as key audience to educate
- Assess ASCO opportunity
- Advocate for telemedicine outreach and other key community barriers
- Explore education / coordination with IHS (possible intersection with other committees)
- Creation and dissemination of standardized diagrams of treatment roadmaps
- Realign goals around key opportunities with CPE / Fellow education and connection and patient awareness