

AGENDA OVERVIEW

#LEADERSHIPSUMMIT2019

SPECIAL LEADERSHIP COUNCIL

TUESDAY, MARCH 12

| | | |
|---------|---|------------|
| 9:00 AM | SC3 Programs, Platforms & Initiatives: High Level Summary | PIEDMONT A |
| 1:00 PM | LUNCH: Meet the Project Managers | |
| 2:00 PM | Formation of a Special Leadership Council for Industry & Corporate Partners | |

LEADERSHIP SUMMIT & GENERAL ASSEMBLY OF PATIENTS, CAREGIVERS, AND CBOs

WEDNESDAY, MARCH 13

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| 2:00 PM | Registration Desk Opens | | |
| 4:00 PM | OPENING RECEPTION & PARTNER MEET-N-GREET | | HILTON RESTAURANT |
| | Welcome | SC3 Staff | |
| | Networking Activities & Icebreakers | BLFSC | |
| | Memory Book: Jontrece, Jazmine, Diamond Ray | Sharonda Hudson | |
| | Creative Content Sponsorship Remarks | Holly John | |
| 6:00 PM | Creative Content Overview | | PIEDMONT |

THURSDAY, MARCH 14

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| 10:00 AM | OPENING OF THE GENERAL ASSEMBLY | | PIEDMONT BALLROOM |
| | Welcome | Dr. Lakiea Bailey | |
| 10:30 AM | RESEARCH REVIEW – HOPE ON THE HORIZON | | PIEDMONT BALLROOM |
| | COMPASS: Guiding the Direction of Community-Engaged Sickle Cell Disease Research | Dr. Raymona Lawrence | |
| | Update on Endari | Mark Diamond | |
| | Education and Mentoring to Bring Access to Care (EMBRACE) | Shirley Miller | |
| | ACEP – EDSC3 | Dr. Lakiea Bailey | |
| | Palliative Care | Dr. Wanda Shurney | |
| 1:00 PM | <p align="center">LUNCH *Sponsored by Vertex/CRISPR Matthew McLeod Creating transformative gene-based medicines for hemoglobinopathies</p> | | |
| 2:00 PM | CONSORTIUM PARTNER ONBOARDING *Closed Session* | | PIEDMONT BALLROOM |
| | Consortium Organization & Infrastructure | Lakiea Bailey | |
| | Credentialing, Partnership & Dissolution | Dominique Goodson | |
| | Code of Conduct, Ethics, Roberts Rules of Order | Esterphine Greene Janeen Greene | |
| | SC3 Roles, Positions & Committees | Lakiea Bailey | |

| FRIDAY, MARCH 15 | | | |
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| 9:00 AM | BREAKFAST *Sponsored by bluebird bio | | PIEDMONT BALLROOM |
| | Talk Saves Lives: Peer-to-Peer Mental Health Training | Taylor Chambers | |
| | Grief & Bereavement: Curtesy & Etiquette | Clayton Andrews | |
| 10:00 AM | GENERAL ASSEMBLY STRATEGY SESSION I | | PIEDMONT BALLROOM |
| | Mental Health Priority (2016 Priority) | Clayton Andrews | |
| | Sickle Cell Anthology (2017 Priority) | Kadeem Gayle | |
| | Sickle Cell Toolkits (2017 Priority) | Dr. Wanda Shurney | |
| | Clinical Trials Initiative | Dr. Marie Ojiambo | |
| | Diversity Outreach (2018 Priority) | | |
| | Sickle Cell & Aging (2018 Priority) | | |
| 1:00 PM | LUNCH *Sponsored by Global Blood Therapeutics | | PIEDMONT BALLROOM |
| | GBT440 | Dr. Ken Bridges | |
| | CURE SICKLE CELL INITIATIVE (CureSCi) | Dr. Benz | |
| 2:00 PM | GENERAL ASSEMBLY STRATEGY SESSION II | | PIEDMONT BALLROOM |
| | Sickle Cell Exemption in Opioid Policies: A Success Story | George Carter | |
| | ED Initiative: Going Positive | Dominique Friend, Chandra White-Cummings | |
| | Transition: A Success Story | Anthony Wells, Portia Langdon | |
| | Transition Workgroup/toolkit (2017 Priority) | Alexis Wardlow-Perry | |
| | Sickle M.A.N. (2016 Priority) | Clayton Andrews | |
| | National Awareness Campaign (2018 Priority) | | |
| 6:00 PM | CREATIVE CONTENT WORKSHOP & LAB | | PIEDMONT |
| SATURDAY, MARCH 16 – DAY 2 | | | |
| 9:00 AM | BREAKFAST *Sponsored by Novartis Pharmaceuticals | | PIEDMONT BALLROOM |
| 10:00 AM | PUBLIC POLICY & ADVOCACY | Dr. Chic Smith | PIEDMONT BALLROOM |
| 11:00 AM | TRACK A: COMMUNITY-BASED ORGANIZATIONS BEST PRACTICES : INFRASTRUCTURE & CAPACITY BUILDING | | |
| | Access to Federally Qualified Health Centers | Dr. Wanda Shurney | |
| | Driving Operational Effectiveness with Digital Technologies | Patricia Smith | |
| | Grant Writing Overview | OMH | |
| 11:00 AM | TRACK B: INDEPENDENT PATIENT/CAREGIVERS BEST PRACTICES: EXPERT ADVOCACY TRAINING | | PEACHTREE C |
| | Dress for Advocacy Success #Advocating Style | Shamonica Wiggins | |
| | Expert Advocacy Training - Telling Your Story | Tosin Ola | |
| | 501c3 for jCBOs | Dan Moore | |
| | Building Your Advocacy Resume | Shamonica Wiggins | |
| 1:00 PM | LUNCH: INFRASTRUCTURE COMMITTEES | | |
| 2:00 PM | BUSINESS MEETING | | |
| 2:00 PM | SC3 KIDS LEADERSHIP TEAM: STRATEGY SESSION | | |
| 4:00 PM | CREATIVE CONTENT | | PIEDMONT |
| CLOSING OF THE 4TH GENERAL ASSEMBLY OF PATIENTS, CAREGIVERS, CBOS | | | |

SPECIAL BEST PRACTICES TRAINING SESSIONS

SUNDAY, MARCH 17

GRANT WRITING TRAINING

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| 10:00 AM | Introduction to Private Foundation/Philanthropic Grant Funding | Dr. Chic Smith |
| | Locating Private/Philanthropic Grant Resources | |
| | Identifying Partnerships & Private Funding Grant Cycles | |
| 12:00 PM | LUNCH: Navigating Online Grant Portals | Dr. Lakiea Bailey |

Vision, Design, Capacity Grant Writing Workshop: Office of Minority Health Resource Center – DAY 1

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| 1:00 PM | Intro to Government Grants | OMH |
| | Facilitated Vision, Design, & Capacity | |
| | Proposal Design - Parts of the Grant: “Share the Dream” | |
| | Proposal Design – Parts of the Grant: Technical Review in the Proposal Narrative | |

MONDAY, MARCH 18

GRANT WRITING TRAINING – Vision, Design, Capacity Grant Workshop: Office of Minority Health Resource Center – DAY 2

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| 10:00 AM | Recap and Review of VDC Elements | OMH |
| | Logic Models – Writing Lab | |
| 12:00 PM | LUNCH SMART Objectives and Skills Building <i>Practicum/Learning Lab</i> | OMH |
| 1:00 PM | Evaluation Methodology | OMH |
| | Federal Grant Application Process | |
| | Summary and Evaluations | |