

Notes on

GETTING UNAFFILIATED PATIENTS CONNECTED TO CARE



WORKING DEFINITION

An “Unaffiliated Patient” is someone who has not been seen by a sickle cell specialist in at least a year. *Source-NHLBI*

Please feel free to use the following notes to assist you in **Getting Unaffiliated Patients Connected to Care**. The list was compiled from SiNERGe participants attending the 2022 Johns Hopkins Carlton Haywood Memorial/SiNERGe Symposia.

HOW TO LOCATE & IDENTIFY UNAFFILIATED PATIENTS



COMMUNITY STRATEGIES

- Sign-up sheets at Community Health Fairs
- SCD Walks
- School
- Churches
- Civic, Social and Professional Associations



DIRECT PATIENT ENGAGEMENT STRATEGIES

- Celebratory Events
- If at a function, ask if they have a provider/hospital
- Family Reunions
- Peer-to-Peer Support Groups
- Word of Mouth
- Social Media



MEDICAL STRATEGIES

- Contact local Departments of Health
- Talk to ER Departments/Docs
- Talk to Clinics
- Medical Associations – Physician, NP, State, Black Physicians
- Contact FQHCs
- ER Admissions & Discharges
- Connect with allied health workers [social services, social works, dentists, etc.]
- Hospital Social Workers
- Contact blood transfusion centers



ADVERTISING STRATEGIES

- Hospital Public Relations
- Billboards
- Social Media – Facebook, Instagram, Twitter



HOW TO CONNECT UNAFFILIATED PATIENTS WITH A CBO



INTRA-OFFICE REFERRALS

- Get names of social workers
- Patient relationships
- Multilingual staff
- Share options...facilities
- Partner referrals



MEDIA

- Internet – CBO websites
- Mailings, emails, constant contact
- Providing free materials, such as gift cards, books, etc.



ADVOCACY AWARENESS

- Politicians
- Consistent effort (funding)
- Handing out incentives at youth events
- Established support groups



OUTREACH

- Outreach to colleges
- Sorority/Fraternity – Campus and Alumni Outreach
- Reach out to Immigrant Services Organizations
- Reach out to Faith-based Organizations
- Community Organizations – youth
- Statewide Hotline for Sickle Cell – calls go directly to a CBO [Pennsylvania?]
- Health Fairs
- Special Events – symposiums, pop-ups, etc.

HOW TO CONNECT UNAFFILIATED PATIENTS WITH A PROVIDER



PAYORS

- Health Insurance
- Insurance Info
- CBO Insurance Specialist



OUTREACH/PROMOTION

- Name/Facility of Providers
- Presenting at CBO events
- Through CHW
- Public Services
- Transportation, Food, Incentives



PARTNERSHIP DEVELOPMENT

- Develop provider list
- Update insurance network
- Partner – Hospital + CBO
- Partner referrals



PARTNERSHIP IMPLEMENTATION

- Establish Champions
- Doctor grand rounds
- Nursing grand rounds
- Genetic counsellors, treatment chores



SINERGE COMMITTEE ON GETTING UNAFFILIATED PATIENTS CONNECTED TO CARE

- **Chair:** Mary Bentley LaMar, The Sickle Cell Association of New Jersey
- **Secretary:** Donna Monroe, The Sickle Cell Association of Delaware
- **Michael Matthews**, Children's Sickle Cell Foundation Pittsburgh, PA
- **Mark Goodwin**, Sickle Cell Thalassemia Patients Network, Brooklyn, New York
- **Jacqueline Haley**, Greater Boston Sickle Cell Association
- **Teanika Hoffman**, Sickle Cell Coalition of Maryland
- **Tiffany Dews**, Life and Family Foundation of Virginia
- **Cynthia Gipson**, Christopher Gipson Sickle Cell Moyamoya Foundation
- **Lorraine Brown**, Project Spirit Sickle Cell
- **Rudy Williams**, Association for the Prevention of Sickle Cell Anemia, Hartford/Cecil County, Maryland

ABOUT SINERGE:

The **Sickle cell Improvement across the NorthEast ReGion through Education (SiNERGe)** is a multi-state collaborative dedicated to improving care for individuals with sickle cell disease throughout the Northeastern United States, Puerto Rico, and the U.S. Virgin Islands. It is funded by the Health Resources and Services Administration through the Sickle Cell Disease Treatment Demonstration Program.



www.wepsicklecell.org/sinerge/