

The Take Notes Challenge


**GETTING
UNAFFILIATED
PATIENTS
CONNECTED TO
CARE**

Now - September 1, 2024



1. Review the Notes Document...

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-NHI RI

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

HOW TO LOCATE & IDENTIFY UNAFFILIATED PATIENTS

COMMUNITY STRATEGIES

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

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

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

ADVERTISING STRATEGIES

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

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Notes

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



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2. Pick 5 strategies from the "Notes" to implement between now and September 1, 2024



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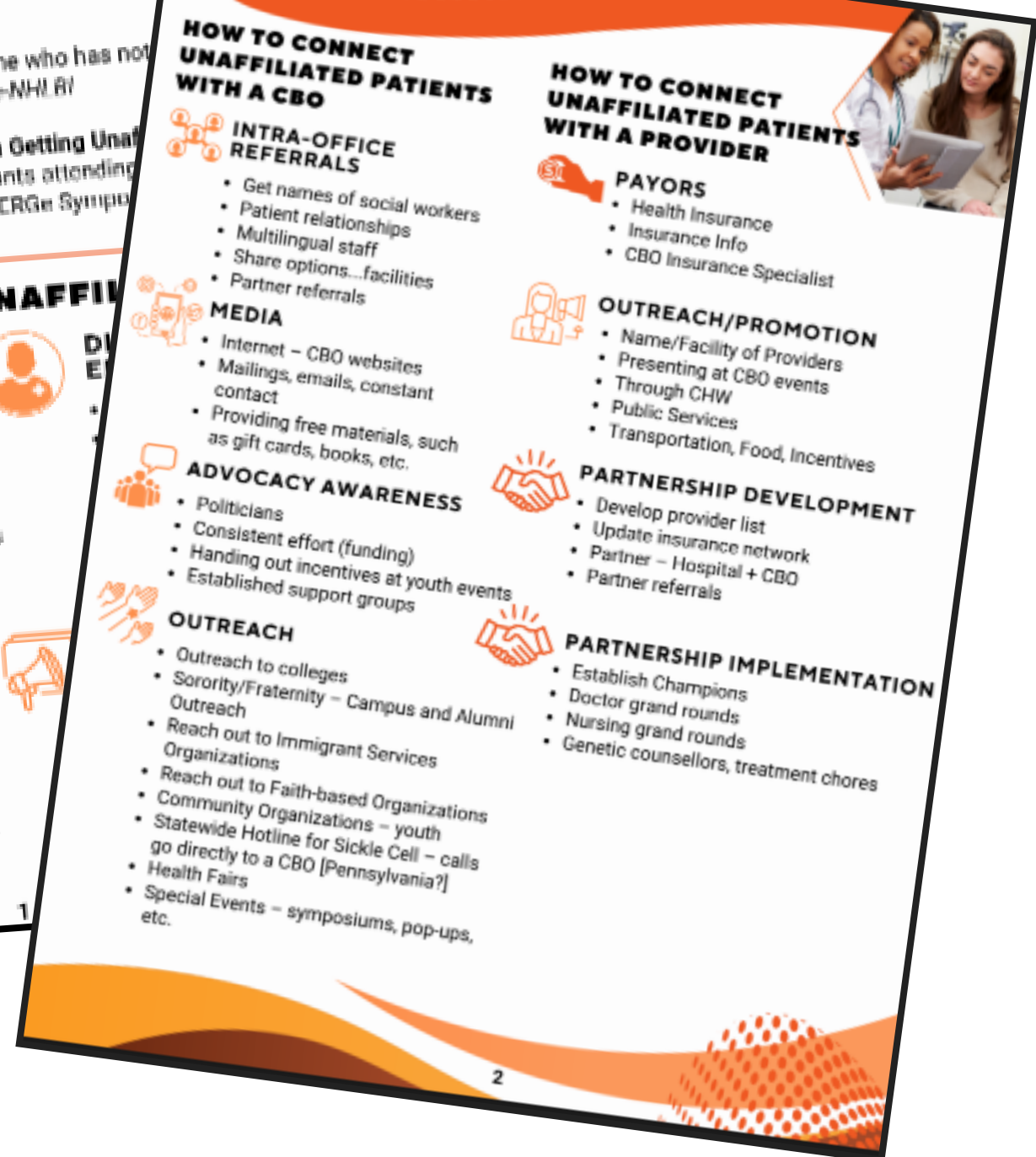
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3. Track the number of unaffiliated SCD patients who get connected to care as a result of each strategy.

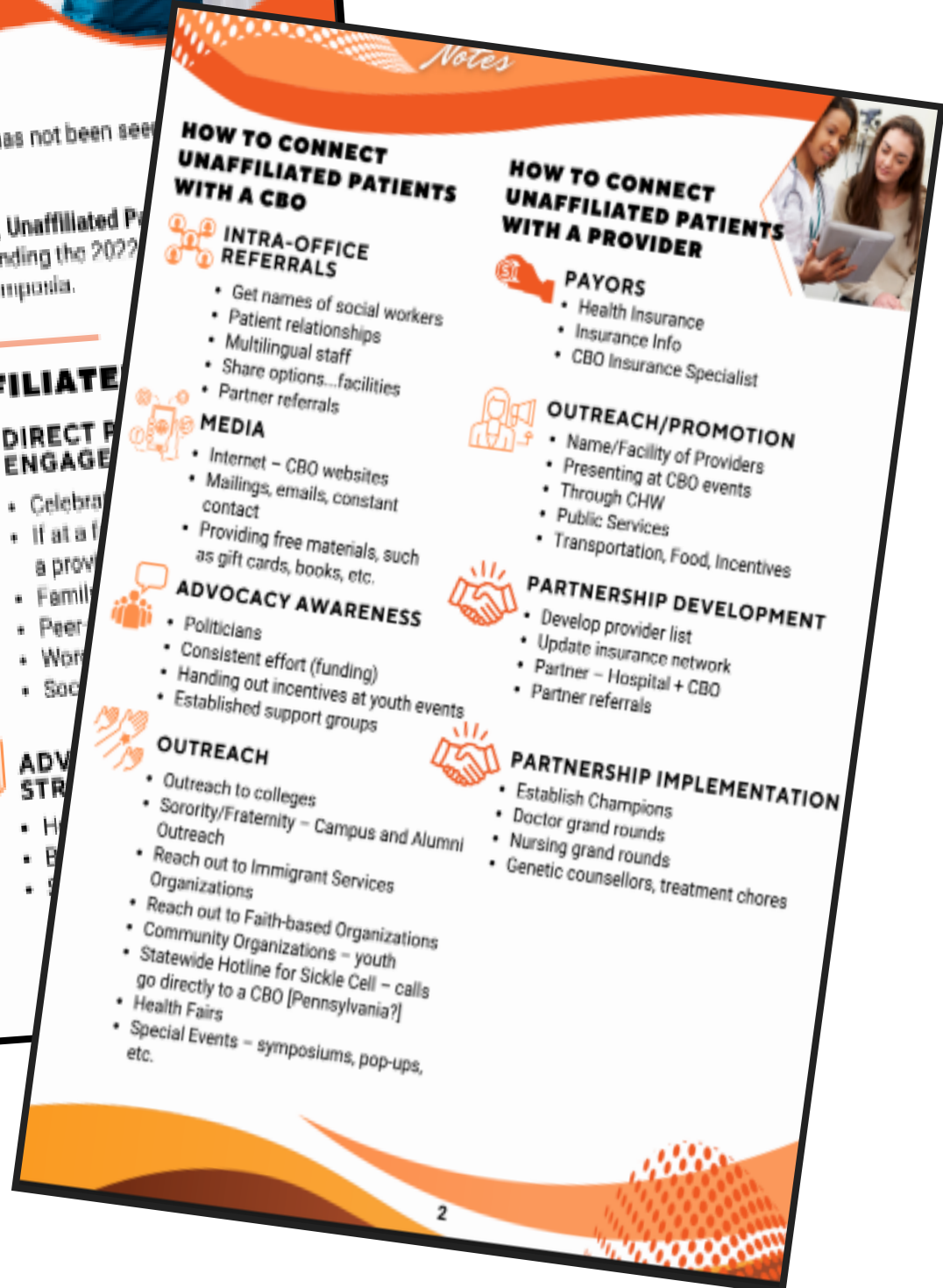


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- DIRECT ENGAGEMENT**
 - Celebrate
 - If at a provider
 - Family
 - Peer
 - Work
 - Social
- ADVOCACY STRATEGIES**
 - Health
 - Black
 - SCD





4. Let Us Know How it's Going?



Between June 19th World SCD Day and June 30, 2024

Email info@sicklecellnewjersey.org with your preliminary progress

By September 1st Sickle Cell Awareness Month

Email info@sicklecellnewjersey.org with a brief summary of your efforts including the following:

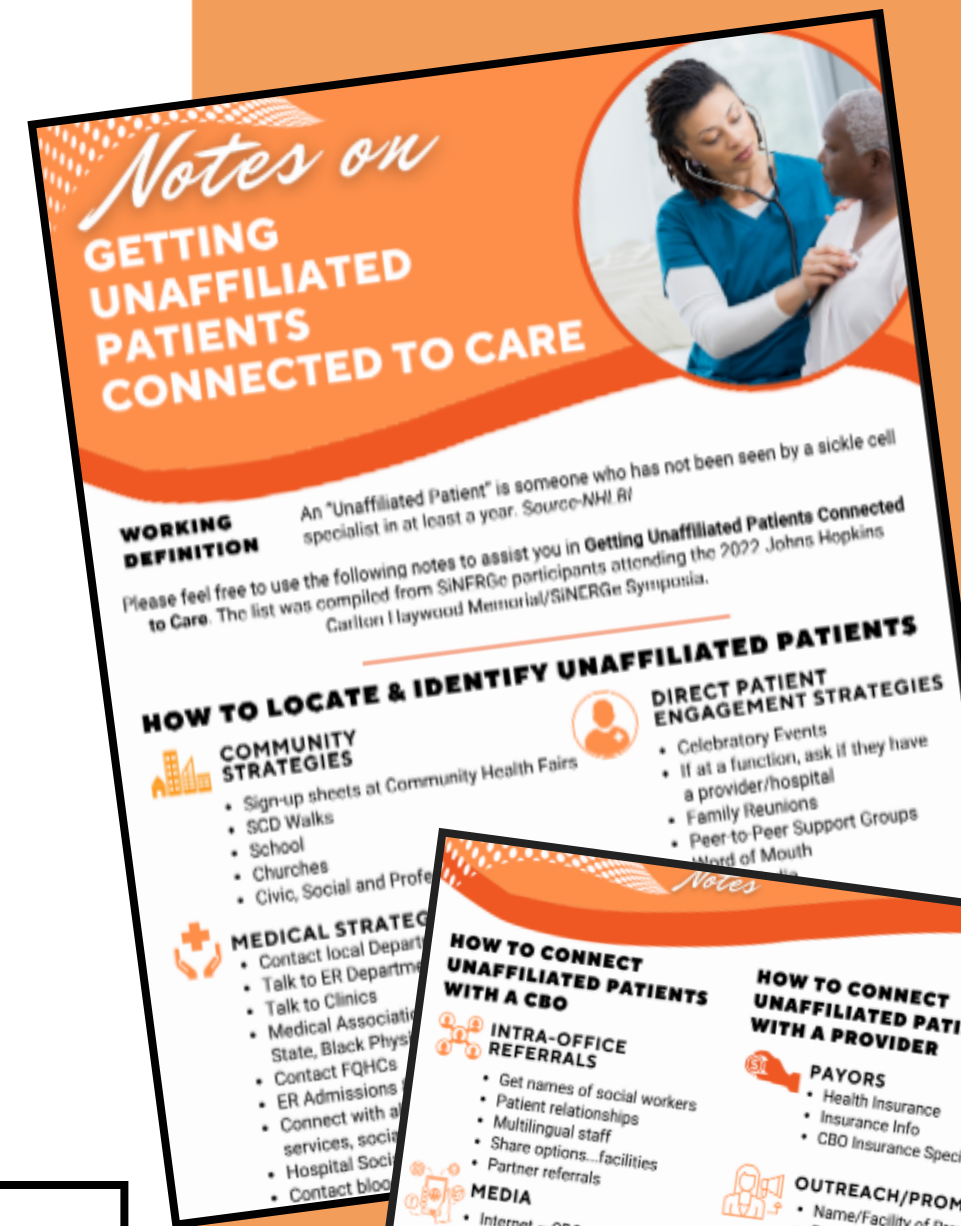
1. The 5 strategies chosen
2. The number of SCD patients connected to care
3. Lessons learned
4. Recommendations

Resources to assist in meeting this challenge

- “Notes on Getting Unaffiliated Patients Connected to Care”
- Summary Report Template (TBD)
- Other resources will be posted online



<https://wepsicklecell.org/sinerge/unaffiliated-patients/>





We hope you will participate.

We plan to submit an abstract for the SCDAAC Convention based on the findings of this project.

Feel free to reach out to the chair or any committee member with your questions or comments.

THANK YOU!





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 and Tray Thom** Sickle Cell Thalassemia Patients Network, Brooklyn, New York
- **Jacqueline Haley**, Massachusetts 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

