

NEWBORN SICKLE CELL DISEASE PROGRAM: PRE ANALYTICAL PHASE

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Global Sickle Cell Alliance, Inc.
to foster international collaboration and exchange of ideas that will
improve the health, well being and quality of life of individuals with
sickle cell disease

Newborn Sickle Cell Disease Screening Program

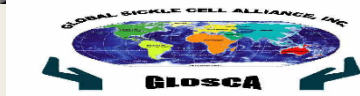
- An essential public health program that prevents catastrophic health consequences through early detection, diagnosis and treatment.
- A simple blood test allows for early detection before life-threatening symptoms begin in babies with sickle cell disease (SCD)
- High prevalence of SCD and related infant mortality



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Purpose and Objectives

- To reduce morbidity and mortality related to diseases detectable by newborn screening, using SCD as a model
 - *Provide prophylactic and comprehensive SCD management to identified newborns via a dedicated SCD center/PHC.*
 - *Provide education and counseling to families whose children are identified with significant hemoglobinopathies and traits.*
 - *Provide genetic counseling to families with negative results (all tested get results)*
 - *Provide training, support and collaboration to initiative leaders on quality assurance and sustainability for NBS*
 - *Collect relevant data on feasibility and outcomes of the initiative to assist quality statewide program development and design.*



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Pre Analytic Phase

- Collaboration/consultation - experienced group
- Infrastructure and capacity assessments
- Stakeholder/Advisory board
 - *Public and Private Partnership (Government/consumer advocacy)*
 - *Principles of Community based participatory research*
- Engagement stakeholders
 - *Education -Professional, community, State government*
 - Purpose/Significance of comprehensive NBS
 - Components and Estimated cost of a comprehensive program
 - Cost effectiveness - (Health outcomes/QOL vs Economic impact)



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Pre Analytic Phase Cont'd

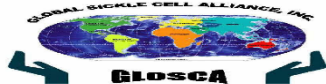
■ Sustainability –

- *NBS funds as a line item in the State budget*
- *Integration of care into health care scheme –(across the lifespan)*
- *State legislative bill mandating NBS – guided by science*
- *Private funding-Philanthropists, grants, etc*

■ Plan pilot program -MOU, Policies and procedures, Supplies

■ Conduct Dry-Run, assess and address gaps

- ✓ *Parent education, consent, form-documentation, collection method*
- ✓ *Quality of blood sample, storage, courier-transport time*
- ✓ *Receipt, documentation and storage at the laboratory*



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Pre Analytic Phase Cont'd

- Initiate pilot program, Evaluate, and Modify
 - *Start with few birthing centers and expand gradually with continuous quality improvement*
 - *Collect and maintain data fidelity to support the purpose*
 - *Seek follow up consultations*
- What to do with older children?
 - *All tested/screened families must be offered test results*



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Conclusion

- ▶ NBS programs for SCD have been initiated in Nigeria. However, such programs need local commitment and follow through to be sustainable and successful.
- ▶ Such programs will benefit from public private partnership as well as international resources for education/training, and capacity building.



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