



BPW International Member Projects & Experts

SICKLE CELL PROJECT

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ANNUAL REPORT

PROJECT OVERVIEW

This advocacy programme is channelled towards reduction and eventual eradication of sickle cell disease. Sickle Cell Disease causes approximately 8 percent of all infant deaths per year in Nigeria. It is an inherited disorder and if an inherited disorder can be described as an epidemic, then sickle cell anaemia in Nigerian would eminently qualify for that description.

People should know their genotype long before they get married and not just before or after marriage. It is best that a child should know his or her genotype right from primary school. It then means that information is extremely vital to the goal of reduction and eradication. Information and educating the general public especially the younger and unmarried with a mindset of marrying and procreating in the future on the importance of blood group\type check.

Secondly, for those already living with SCD information on:

- *Regular checks\tests
- *Personal observation on what to look out for in yourself
- *Accessing medical help
- *Avoidance of next generation of SCD

Thirdly, to work with parents\ guardians of those living with SCD and their health givers.

Finally achieving and making the slogan of this project "SICKLE CELL DISEASE, NOT A DEATH SENTENCE" a reality in Nigeria and Africa where it is prevalent.

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RESULT

WHAT HAS BEEN DONE AND ACHIEVED

Over the past nine (9) months we have been able to

- Establish relationships with medical personnel, and institutions which has resulted in the
 - possession of club space
 - discounted cost of medical tests
 - free consultation\advice from specialists
- Establish relationships with institutions of learning to pass information which had yielded more positive results than expected. More because among my team are those that have suffered great pains and even deformities from the disease and are still suffering. It was reality brought to them
- Visit Shanties settlement (seemingly difficult to reach) and families whose cultures allows them to determine the spouse of a girl child from early age or marry out their daughters at tender ages without any check (girl child marriage). Educating them on the importance of the check and offering it to them free of charge.
- Worship centres are not left out too and this has resulted in some of them making genotype tests mandatory before joining in marriage.
- Pointing SCD carriers to the source of help especially the less privileged. Some even having access to free medication donated by individuals and groups e.g BPW in Nigeria.

Been able to put a smile, give hope and encouragement to the hopeless and discouraged. This has given me the greatest joy and to us this is an achievement.

When you hear a question like, 'aunty can I really survive this'? And I can boldly answer them with a 'yes'.

Giving them the courage to stand up and fight for their lives. All this to achieve the project's goal and slogan of "SICKLE CELL DISEASE, NOT A DEATH SENTENCE"

GOALS FOR THE NEXT PERIOD

Starting this project has made it obvious that it is larger than we imagined and more people than expected have been showing up for different form of help and this has guided us through what is needed and what must be done for the next phase of the project.

- Firstly, get a bigger and more comfortable space for the club meeting especially as more people than anticipated are coming in and it has become very necessary and urgent to get a space and make it convenient and comfortable.
- Get a laboratory that could actually do blood testing at a cheaper cost or free and also liaise with a blood bank for discounted purchase of blood for transfusion when such cases arise which is quite frequent.
- Get a more spacious vehicle because very few of the team members that go out with me on campaign mission to institutions and worship centres, hospitals, sponsors office actually have SCD and have deformity from the disease and therefore use wheel chairs or some other form of walking aid. Moving in my car is actually cumbersome and challenging for them.
- Intensify getting support groups companies or individuals sponsors and pharmaceutical companies that could actually help in alleviating the pains and expenses of the project
- Getting interpreters for areas where I don't understand their local dialect.
- Getting pharmaceutical company or individuals who can constantly support with needed medications.
- Getting financial support for running this project and procuring needed material and supporting the less privileged that cannot afford the basic things. Also to support running of the club and support team.

This project started out of passion that many should not pass through what I went through. Aside from the series of crisis with pains, hospitalisation, and repetition of classes, the erroneous belief that I would not live to a certain age made me not to pursue my goals in life because I assumed I would not be around for long to actualise them..

This is a project I am excited about. I find a lot of fulfilment, satisfaction and joy doing it. The slogan 'Sickle Cell Disease, not a death sentence' must be established.