

VITSAF VITILIGO RESOURCE CENTRE®

***To Meet Needs of Persons Distressed by Vitiligo in Nigeria, West Africa and
a platform for Vitiligo awareness, enlightenment, and Studies***

By



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Concept Note

Background and Justification

Vitiligo, in spite of not being a rare disease, is classified as a disease by World Health Organisation - WHO. It is one of the most psychologically devastating chronic skin diseases, the psychological implications for people with Vitiligo and others with unusual visual differences can be immense with a major impact on both patients and their families, Vitiligo is still today neglected and underestimated in Africa. Vitiligo is mostly characterized as cosmetic and not life threatening. Still today most dermatologists and the medical community in general minimize the impact of the Vitiligo, its psychological, psychosocial and emotional effects both on persons with unusual visual appearance and their families, there is less care and the condition is trivialized leaving them vulnerable to therapy claims out there ranging from religious claims, herbs sellers, the public themselves.

Olasode et al. (2007) reported on the negative impact Vitiligo has on peoples' lives in Nigeria. People living with the condition reported that fellow citizens refuse to sit next to them, shake their hands or eat near them and that relationship with fellow-workers and acquaintances were negatively affected. In their study 90% of participants reported to being embarrassed by the lesions caused by vitiligo. Though they discuss the benefit of traditional African family cultural values in providing support they call for the need for greater health education on skin disease with the general population in helping to alleviate stigmatization. George (1989) concluded that treatment options remain unsatisfactory.

The society we have created simply does not place a high value on feelings. Instead, we seem to value nearly everything else. Money, appearances, material things, Class, Social status are a few examples. Positive and empathetic approach to the Vitiligo patients and persons with skin imperfections should be mandatory, truth is that our pains are genuinely not understood by both medical community and the public. It is difficult for those who do not have Vitiligo to appreciate the significance of this problem to the victim. Most individuals with Vitiligo are upset because of the uneven skin color; some have lost their jobs or are unable to obtain work due to their disfigurement, especially when the work involves interaction with the public.

The commonest questions from Vitiligo patients around Africa are always

- What medication truly works?
- How best can I handle this condition, people's attitude and my social life?
- How can I cope with the public and cultural beliefs that abounds?
- Will I ever marry?

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These issues impacts negatively on the health and social development of these persons with Vitiligo, this is why we seek support for a Resource Centre (a place of hope).

Problem Statement

The current therapy for vitiligo focuses on halting the progression of the depigmentation with topical immunomodulators and encouraging repigmentation with phototherapy. However, success rates of these therapies are not only dramatically low, variable, and not permanent, but not readily available in Nigeria. Therefore, new therapeutic approaches are warranted. With many vitiligo patients responding poorly to the current therapies, we are focusing and directing efforts to improve non-medical consequences of Vitiligo that include, self-help guide to managing Vitiligo, Skin camouflage, Self-image Support, Information/knowledge Centre, Vitiligo Lifestyle Products (helpful supplements, herbal remedies, trendy Sun clothing wears, toiletries and cosmetics) public awareness, better insurance coverage, to name a few providing a one stop place for Vitiligo

As we increase Vitiligo Awareness and enlightenment extensively, we get much enquiries and huge 'needs' arises from them, the Innovative Resource Center is being proposed to meet these needs, alleviate the psychological effects.

- Enquiries increases, all asking same question (how do I get rid of Vitiligo),
- Interest in knowing more about Vitiligo.
- Increased enquiries about general skin health and specific skin conditions,
- Demand for Vitiligo Lifestyles products has been on the increase, no counseling sessions available has made it difficult to helpful medication and natural therapies increases.
- There is an urgent need for support for the Vitiligo persons as it seems they have all been brought out of their shells.
- The medical communities, health workers ignorance of the condition is quite discouraging
- Parents are worried about the future of their kids and the single women about the future as regards relationships and marriages.
- More than 80% of persons living with Vitiligo and the disfigured are psychologically, socially, emotionally and sexually distressed, with a major impact on both patients and their families.
- The unpredictable and Progressive nature of Vitiligo is causing an insidious erosion of one's own senses of self.

Improving Quality of Life of persons living with Vitiligo and unusual visual appearance.

- Significant changes or damages to a person's outward appearance cause extreme social, emotion, as well as psychological effects on the individual, who mainly suffers from stigma and may feel isolated from their friends and family.

The Programs Description

The center will offer much needed help and unconditional support to Vitiligo persons in Nigeria and beyond and as well an avenue for Vitiligo and general skin health enlightenment and education not excluding the general public. It will also serve as a Resource place for Students and medical community at large. VITSAF works towards taking care of immediate needs of persons distressed by Vitiligo which includes needs for a place to purchase and always purchase the helpful supplements anytime they wish to, a place to get detailed recent information on latest treatments, researched materials, how to live with Vitiligo, what to do and what no to do, having counseling sessions privately. Meeting the needs of persons with Vitiligo and other skin conditions who contacts VITSAF because there is no organisation focusing on health so we do receive all the inquiries.

VITSAF proposes for a Vitiligo Resource center a one stop place for persons distressed by Vitiligo, the proposed Resource center is developmental. A center where the general public, medical community can easily access such services as Resources (e-library/library - skin health, self-help, positive living and confidence building), Skin Camouflage, Counseling unit, Subsidized Vitiligo Lifestyle products, Dermatology Referrals and On-going Support.

The programs that will make up the Center are

- Library
- Bookshop
- Care for Appearance and Disfigurement
- Vitiligo Lifestyle Products
- Skin Camouflage Clinic

Our timeline to having a functioning Center is December March 2012 and to assist the organization in achieving, we will be hiring two personnel, a Program Officer and Resource Center Officer.

This program will be evaluated through Functioning VITSAF Vitiligo Resource Center

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By keeping record of member's Needs and Essentials for the center

By General Public Survey:

Relationship with the Medical Community

Sub unit Descriptions

- Library - A physical library focusing on Vitiligo and related skin condition/diseases, general Skin Health, Understanding Autoimmune disorder and Appearance and disfigurement, Positive living and confidence building books.
- Bookshop – Books on general Skin Health, autoimmune disorder, managing disfigurement and all other related ones.
- Care for Appearance and Disfigurement –
 - i. Have a private counseling room where the patients know and believes he/she is entirely alone with the counselor to be able to bare it all and get genuine help.
 - ii. Also under here is camouflage clinic offering training to patients, professionals who are mainly from medical disciplines, such as nurses (dermatology, plastic-burns, oncology, etc), technicians (such as maxillofacial), doctors with a special interest in skin camouflage, occupational therapists and Nollywood make-up Artists.
 - iii. Also to stock different camouflage for the purpose of selling to members and the interested public .
- Vitiligo Lifestyle Products – We have identified and discussed extensively with most of the manufacturers of the lifestyle products, we will act on our discussion of ordering the products as soon as we get the funds. Few of the products we can source locally and working towards sourcing from everywhere to build the variety of natural therapies that helps Vitiligo, making sure we are not out of stock. Some of the products listed below
 - a. Vitamin – Recouleur (www.recouleur.com) and other helpful supplements, herbal soaps etc
 - b. Vitiligo herbal Body Cream – www.thewellnesswell.net,
 - c. Vitiligo organics (Australia),<http://www.vitiligoorganics.com>
 - d. Sun Protective clothing/wears, Sunscreens and more
 - e. Other Supplement
- Self-help, positive living and confidence building

Improving Quality of Life of persons living with Vitiligo and unusual visual appearance.

- Understanding Autoimmune Disorders – Entertainment Education, Seminars through the center.

PROJECT LOCATION AND TIMELINE

VITSAF plans to achieve the functioning VITSAF Vitiligo Resource Center by April 2012. The foundation's plan is to strategically position the Center in Lagos in a serene area for learning and easy accessibility. Through the best practice Not-for-Profit Organizations, Product manufacturers, publishers, book vendors, authors and advisory Board and technical support of Partners such as the below listed and more

- Nigerian Association of Dermatologists
- National Vitiligo Foundation Inc,
- Clinvuel Pharmacy, Australia,
- Vitiligo Society UK
- The Wellness Well USA (Naturopath)
- Supernatural Health Inc
- British Association of Skin Camouflage

STAFFING

VITSAF Vitiligo Resource Center will be executed by

- Founder/Executive Director (100% time).
- Program Officer
- Resource Center Officer
- Volunteers

E. Project Evaluation

While the content varies from medium to medium, we will measure our success in achieving the programs' goals in the following ways:

Functioning VITSAF Vitiligo Resource Center

By keeping record of member's Needs and Essentials for the center: through enquiries, Center visits, Center Register with all the required column, will be tracked through mails, phone calls, social media, social networks etc. We will collect data on website use, tracking how many users are hitting which pages (treatment, FAQ's, Handbooks,

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Fundamentals, Volunteering and Support) and noting which region are getting an increase visit. We will maintain a membership record for VITSAF support group and be compared to what we have before the project.

By General Public Survey: In order to ensure that we are providing the information, services and support that is most needed in an accessible format, we will send out Questionnaires and online survey format will be used to ascertain general public's benefit, information, level of awareness and knowledge of the condition - Vitiligo.

Relationship with the Medical Community: The medical community, Dermatologists, Health workers, Social workers interest, usage and concern for the Resource center and its benefit will be measured through feedbacks and organized forums and focused groups.

Benchmark: We have set benchmarks for VITSAF, which will also help illustrate the success of this program. By 1st quarter of 2012, we anticipate achieving the following

- a. Functioning Vitiligo VITSAF Resource Center
- b. VITSAF to have Over 3000 registered members and Partnership with Stakeholders, Government, Ministry of Health and other related bodies.

Organizational Background, including the expertise and experience.

This meeting is realized by Vitiligo Support and Awareness Foundation (VITSAF) is a not-for-profit, patient-driven, patient-advocate organization, incorporated in Nigeria and passionately concerned about the needs of persons living with Vitiligo, primarily in West Africa, helping ameliorate the agony people suffer as a result of turning from black to white and all with unusual visual appearance. We aim to improve the quality of life of patients and family, helping them to cope with the condition and its disfiguring unpredictable skin changes. VITSAF is the first and presently the only Vitiligo organization in West Africa, the first patient-driven organization in Africa encouraging and influencing others around Africa to set up Vitiligo Support Groups and the effort has yielded the following underlisted -

- Beyond Vitiligo, South Africa
- Vitiligo, Namibia
- Vitiligo Support, Kenya
- VITSAF Vitiligo Support, Ghana

VITSAF's one major goal is to give unconditional Support to its members and achieve extensive Vitiligo awareness and enlightenment; VITSAF is spearheading advocacy and Improving Quality of Life of persons living with Vitiligo and unusual visual appearance.

campaign for World Vitiligo Day – June 25th, this campaign is of great necessity as the response from across the globe has been tremendous. We stated a petition for the campaign http://www.petitions24.com/signatures/world_vitiligo_day_-_june_25th and it has presently been signed from all continents and on-going as we target 500,000 signatures by March 2012. We will be presenting it at the Conference to key stakeholders in March and then to UN.

F. Budgets

Summary of estimated Budget for VITSAF Vitiligo Resource Center

VITSAF

**VITSAF VITILIGO RESOURCE CENTRE ESTIMATED BUDGET
JULY 2011**

OBJECTIVE:

To set up a VITSAF Vitiligo Resource Centre to provide the ever needed unconditional support and services to Vitiligo persons and extensive information on Vitiligo to patients, their families, medical community and the public. It is a developmental project to strengthen the institutional and management capacity of the organization.

No	ACTIVITIES	BUDGET ITEMS AND JUSTIFICATION	COST	SUM (NAIRA)	
1	Set up VITSAF Vitiligo Resource Centre	Rent x 2years	750,000	1,700,000	
		Other fees (Agreement)	200,000		
	For the admin office and Library	Utilities		-----	-----
		Diesel/Fuel			
		PHCN			
		Furniture's & Fittings			1,370,000
		Conference table (for 8) + 8 chairs	320,000		
		Work station (for 4) for Library + 4 chairs	470,000		
		3 Office tables and Chairs	285,000		
		Reception Table and Chairs	195,000		
Book Shelves		200,000			
Equipment -				1,339,500	
Air conditioner 1.5x3	169,500				
Generator 4KVA	250,000				
Standing Fan x 3					
Computers Desktop x 5	750,000				
Printers (laser jet)	40,000				
Scanners	15,000				
Photocopy machines	100,000				
21" LCD TV	50,000				
DVD Machine	15,000				

	Renovation/partitioning	500,000		500,000	
	Set-up of Sections-	500,000		500,000	
	Skin Camouflage Clinic				
	Counseling rooms				
	Lifestyle Products Store				
	Vitiligo Lifestyle Products, Books, Journals	1,000,000		1,500,000	
		500,000			
3.	Logistics	Logistics		500,000	
		Sub Total		6,909,500	
4.	Institutional Support	15%		1,036,425	
5.	Contingency fee	5%		345,475	
		Total		8,291,400	

