AFRICA
VITILIGO
Conference
LAGOS 2012

CONFERENCE Report

Africa Vitiligo Conference

Date: October 18 & 19

Venue: Multi-purpose Hall,
Action Health Incorporated, Lawal Street,
Jibowu-Yaba, Lagos

Time: 10.00 am Daily

POWERED BY:

VITSAF
Vitiligo Support and Awareness Foundation

CONFERENCE REPORT

The 1st annual Africa Vitiligo Conference, held in AHI Multipurpose hall, Jibowu Lagos on 18-19 October 2012, attracted 50 delegates from across the Vitiligo community in Nigeria and Africa for a two day of lively Talks, Conversations and discussions.

The conference focused on the challenges, uncertainties and hopes for effective vitiligo therapy as well as future of Vitiligo and how Africa can prepare itself for forthcoming challenges.

The conference provided a forum for Dermatologists, patients, family & friends, other NGO's and researchers to discuss Vitiligo, What it is, important proposed vitiligo policy and services, and to make recommendations for the future. Recommendations from Nigeria on Vitiligo we hope can play an important part in influencing discussion on Vitiligo & Skin health policy in the Nigerian Parliament.

We are particularly grateful to our conference chairs and keynote speakers, Professor Torello Lotti and Professor Davinder Parsad, Nigerian Association of Dermatologists, for being full part of the two days, and encouraging wide ranging debate on a number of issues. We are also grateful to other speakers, NGO's and media representatives who supported the conference by facilitating the discussion forums.

A number of recommendations were made which we hope the Ministries of Health and World Health Organisation will take forward.

The conference was organised by Vitiligo Support and Awareness Foundation (VITSAF), Nigeria. We would like to thank the delegates from Vitiligo Senegal, Vitiligo Support Uganda and VITSAF Ghana and others Vitiligo Society Kenya, Vitiligo Support, Ethiopia, Beyond Vitiligo South Africa who couldn't make it but sent in their experiences which was great part of the conversations, Ike Nwibe and Suleiman Sule for their great volunteering efforts and for hosting the World café conversations.

We are grateful to Vitiligo Research Foundation New York/Canada for their numerous supports and specially for providing us with the latest Question and Answers on Vitiligo in hardcopy for all participants (a very great tool), The Lagos State Ministry of Health for endorsing the Conference, Clinuvel Pharmaceuticals Australia for providing advice on the agenda and the conference communication planning, AHI Residence for their hospitality and support. Also to all who supported us one way or the other.

Opo Maduewesi

Executive Director
Vitiligo Support and Awareness Foundation

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Introduction

Engr. Chris Oparah
Executive member, VITSAF

Engr. Chris Oparah introduced the Africa Vitiligo Conference and welcomed all delegates. He said that there were a number of issues to be addressed, such as vitiligo awareness, understanding vitiligo, prevention, new drugs and treatments, and the fact that more and more people will be breaking out with vitiligo.

Engr. Chris thanked delegates

PROF.LOTTI'S VIDEO

Prof.Torello Lotti
University of Rome "G.Marconi"

Greetings message from Prof.Torello Lotti from his office at University of Rome "G.Marconi" to Africa Vitiligo Conference in Lagos, to all Speakers, Chairs of the Conference in his capacity of Chair of VRF to congratulate on the activity of the organizer Ms. Ogo Maduewesi, and on the successful l in her efforts to improve the interaction of the African Vitiligo support organizations towards a common target: vitiligo patients quality of life improvement. Her efforts have been supported in recent times by VRF, a non-profit foundation promoting fast-tracking research toward a cure for vitiligo, and many different activities like WVD, Biobank Vitiligo and dedicated e-publications.

Holistic Management of Vitiligo: Exploring a new horizon

D. Parsad, Department of Dermatology, Venereology & Leprosy, Postgraduate Institute of Medical Education and Research, Chandigarh, India.

- **Prof. Davinder Parsad,** President, Asian Society for Pigment Cell Research

Vitiligo is a progressive disorder in which the melanocytes in the affected skin are selectively destroyed. The prevalence of vitiligo is 0.1 to 3 percent in different ethnic and racial groups. Vitiligo has profound effect on quality of life of patients, many of whom feel distressed and stigmatized by their condition. Focusing on enhancing self-esteem and improving quality of life in vitiligo patients should be an important part of the management of vitiligo.

The development of effective treatment for vitiligo depends on understanding the mechanisms of depigmentation and repigmentation. The basic pathogenesis of vitiligo in general, or for any of the putative subsets of vitiligo, is not fully known although substantial strides have been made in pathogenesis and the treatment of vitiligo. Since the etiopathogenesis of depigmentation in vitiligo is still obscure, the source of pigmentation in the repigmentating lesion and its stability is also not fully known.

There are two main goals of any vitiligo treatment; first is to stop the arrest of further depigmentation and second is to induce repigmentation. The first goal can only be archived fully if we could unravel the mechanisms underlying the disappearance of melanocytes in vitiligo. If this can be achieved repigmentation should be rather simple to accomplish with a combination of medical and/or surgical treatment. Surgical management has evolved significantly and given a ray of hope in stable vitiligo

However, there is lot of scope for improvement. So more research should happen in this field so that our aim will shift from "any repigmentation" to "complete and normal repigmentation" and we can achieve a scar less healing of those "bruised souls". The mechanistic aspects of melanocyte repopulation in vitiligo and of other factors that trigger and influence melanocyte growth, maturation and survival have been little explored. A better understanding of vitiligo repigmentation will provide new therapeutic perspectives leading to development of an ideal weapon against vitiligo. Non-cultured epidermal suspension (NCES) is emerging as treatment of choice for surgical management of vitiligo because it can treat large area with good colour match and without any laboratory facilities.

In this talk, he presented an overview of their work related to clinical and basic research and their journey over last 20 years to add colours to vitiligo patients' lives.

Questions.

What's new in the treatment of Vitiligo

Dr Shehu Yusuf MSc, FWACP, FAAD

Vitiligo is a disorder where skin parts gradually lose pigment by the appearance of white lesions or 'patches'. The pigment loss can be gradual or dramatic and can die away or begin again, spreading without warning. The exact cause still remains mysterious. The goal of vitiligo therapy is to stop the spread of pigment loss and to return pigment to the lesions. Of recent, there are new topical treatments such as antioxidants, tacrolimus and pimecrolimus, prostaglandin E, and vitamin D derivatives. Excellent healing results can be achieved through combination treatments. In addition, new and experimental therapies, such as narrow-band ultraviolet B microphototherapy (NB-UVB), narrow-band ultraviolet B excimer laser and monochromatic excimer light are available for the treatment of the disease.

■ **Dr Shehu Yusuf giving his lecture.**

Despite this recent advance in the treatment of vitiligo, most of these forms of treatments are not available in Nigeria. It is worth noting that treatment of vitiligo is expensive and time consuming and so, not many patients can afford the treatment. Most of the drugs mentioned are not readily available in Nigerian pharmacy shops. Myth, ignorance and misinformation about the condition contribute to the fewer cases seen in dermatology clinics.

Question & Answers with Dr. Shehu Yusuf

Q. There are different treatments you mentioned, how are the treatment options determined?

A. The treatment depends on the extent of the lesions, it also depends on the medication one is on and what's available in your country. When is focal and stable, surgical method maybe best. When very extensive, counseling and UV light maybe the best option, but it all depends on availability and affordability unfortunately not available in Nigeria and very rare around Africa.

Q. Is hydroquinone not for skin bleaching? Are we not being exposed to risk of skin cancer using hydroquinone?

A. The use of Hydroquinone is for permanent depigmentation, its different from long use of steroid for depigmntation as it poses less risk.

Q. What is your advice on herbal remedies as they seem to work for different people? Are there any uniform therapies for vitiligo? Is there any merit in the ingestion of carrot, dogonyaro (neem) and similar plants?

A. He is trying out different herbal treatment and believes theHe advised collaboration across Africa with dermatologists and Herbalists, but warned that there should be caution with oral treatments from traditionalists and herbalists as they have not been tested.

He emphasized need for Protocol of Vitiligo in Africa.

I am Living with Vitiligo

"I am living with Vitiligo" session gave participants the opportunity to share their hopes, fears, expectations and personal stories. The story sharing sessions was very revealing and pathetic. The challenge of individuals living with vitiligo from the sharing was seen to be very enormous.

Delegates from other Africa Countries – Uganda, Senegal and Ghana shared their experiences and challenges of individuals living with vitiligo in their countries. From the sharing of stories, it was learnt that challenges are similar in most African countries where there is serious myth following vitiligo such as that it is a curse, nemesis, meant for the gods, In Senegal, families, friends usually accept their own (unlike other Africa countries including Nigeria), but in reality it is not same in finding employment. The major problem is social exclusion because vitiligo is not accepted socially and doctors usually say there is no remedy and gives some sunscreen. See few of the stories shared......

1. Engr. Chris Oparah (Nigeria)

I was born with very dark skin. Besides my eldest sister, I was the darkest of my six other siblings from my mother's womb. My even dark skin persisted till 1982, 32 years after I was born, when white patches first appeared at my finger tips and on the palms of my hands. A year and a half before this, I had a serious fever which necessitated my attending a hospital that served my then employers. In the course of treatment, I received various medication including injections. As the fever subsided, my lips appeared as if they had been burn by fire and the skin waxed stiff. When the skin came off after about ten days, my lips which were jet black turned pink and have remained pink thereafter.

The white patches which appeared at my finger tips and on the palms of my hands progressed over the next three years to cover the back of my palms, extending up to my wrists, but below my elbows. I attended the Dermatology Clinics of the Lagos University Teaching Hospital for a time. For treatment, many topical, ingestible and injectable drugs were administered to me.

One notable injection that was administered on me was Kenalog Injection which I was latter informed, is meant for killoids rather than vitiligo. I was concerned only as far as my original handsome looks were being destroyed. I began to loathe looking at my hands and my reflection in the mirror, no thanks to my unevenly pink lips. I became alarmed at a point when I noticed that many people avoided hand contact with me. The matter was rudely drawn home to me when my elder brother suggested we go to a Doctor in Uzuakoli. He did not call Uzuakoli by name, but simply said Umuahia. It was when I drove to Imo State to meet him in my home village and we left for Umuahia that I realized we were going to the Leper Colony. What anger shot through my soul at the thought that my own people were as ignorant as to believe I had leprosy.

Having driven all the way from Lagos to the East for this appointment, I decided to see it through. The Doctor at Uzuakoli asked me whether I was experiencing loss of sensation with my fingers and I answered in the negative. He told us that what I had was pigmentation loss rather than contagious leprosy. Having enquired as to what extent I had received restorative treatment, he suggested that I attend a clinic at UNTH Enugu.

By this time, the devastation had taken to my feet, beginning from the tips of my toes and progressing towards my shins. I attended the clinic at UNTH as recommended and it was here that the name 'VITILIGO' the failure of natural re-pigmentation layers of skin was mentioned for the first time. I was advised to ingest Vitamins and mineral supplements, to avoid all complexion creams and reduce stressful endeavors. I could do all of these but avoid stress. My job and my circumstances in life are full of stressors.

I took a contract with Shell P.D.C. in 1992 across the Warri Channels in Forcados Terminal. This job put so much stress upon my life that 15 months thereafter, white patches appeared on my neck, my ears in my head and around my eyes. After this contract, there was a regeneration that saw these patches recede appreciably, except for my lips and my arms. In 2005, I took another contract for Aba Water Works which suffered still birth in 2007. Over this period, the rate of depigmentation spread so fast that now, except for a small portion of my back, all of my body is ravaged.

I pride myself as of being of a very strong character. I have accepted my current looks with total resignation to the God who makes and unmakes. If it is His pleasure to 'Re-Paint' me, who dares to complain? I carry my patches as a personal identity which shows the supremacy of my creator over the created order of humans and living things. I am happy to bear my vitiligo as a badge of honour because you cannot acquire it from the market no matter your resources. My uncommonness helps me to communicate with people.

Whenever I give a talk, I do not need a provost to bring the audience to attention; why, because you cannot but look at me. As you focus on me, imagining how this man came about his multi colours, you are forced into listening attentively.

My only regret is that Government or ministry of Health has not shown any concern to such a disfiguring and depressing condition. There are many more ignorant people out there on the road than there are sensible people. In ignorance, Vain Persons stare at us, they are so shallow minded that they miss the loud speech of Nature (God) who requests their thanksgiving for their persisting even coloured skins, black or white which he grants them gratis. I feel sorry for some of them but for the others who accompany their stares with some form of derogatory gesture, I would always give a lecture by word or sign as the occasion permits.

I am 90% white now and do not really bother anymore whether the color returns or not but this is if it pleases God. Let us all have courage. As long as we accept ourselves the way we are, others will learn to respect us, if for nothing else, the fact that we are true to ourselves. Carry your cross with poise and confidence, you owe no one an apology for being the way you are we are dignified in a different way.

By: CHRIS OBICHERE ANTHONY OPARAH (Engr. /Mr.)

2. Gueye Doudou (Senegal)

Vitiligo in Senegal is a story because of a great religious leader Sheikh Ahmadou Bamba murid, empirical belief and according to all the people who have vitiligo are men of paradise and are good people.

That is why in our daily lives in our families, our friends and our surroundings we are accepted without discrimination, but reality is different for the social inclusion of people living with vitiligo sometimes people tell me that the phone Appears when they submit a resume without a photo and are called for interview, but often times they are not recruited, when they deposit a photo, they are not called for interview. Therefore the major problem here is social exclusion because vitiligo is not accepted socially and even when we try to find a solution by traditional medicine, people ask us why you want to remove it, you have something that you do not know, vitiligo has no medicine at the legal, doctors say there is no remedy, what they do is give us some sunscreen ointments.

Our ambition now is to work to gather all the people living with vitiligo in Senegal first to help each other and share our convictions firmly then work for the development of vitiligo national network in Africa.

We believe that we can achieve by relying primarily on our personal convictions sources of motivation can help us to achieve our lofty goals.

By Gueye Doudou, Coordinator – Vitiligo Senegal

3. Vivian Najjuka (Uganda)

Everything was perfect in my life until I was diagnosed with VITILIGO. It was around June 2004 when I was finalizing with my first Degree in Library and Information Science at Makerere University, Kampala – Uganda, when I faced this Vitiligo trauma. It was really a year of great life experience and challenges.

My skin from nowhere started to react, changing from its original birth color uncontrollably especially in the focal parts of my body such as the; face, mouth, hair, arms and legs. This caused me a lot of stress as; I had never seen or heard of this type of skin patches. What even caused me more stress is when I visited skin doctors who could not even know the name of my problem. It was not until I visited the Internet and did my own search that I came to know the name of this skin patches. It was scientifically termed as VITILIGO. This information from the Internet helped me a lot too, because it explored to me many other cases of Vitiligo victims and suggested available treatments. However the treatments mentioned on the Internet also happen not to be available in my country, but in countries like United Kingdom, China, India, America and Israel.

At the same time I was also trying with herbals from various sources, which I also withdrew after some time because of the supernatural powers which were attached to them. After becoming too desperate with myself I started to think of salvation and giving my life to Christ. Conversely, I thought that I was the first person to have this skin problem in the whole world since I had never seen it anywhere with people. To this end I therefore used to isolate myself and moving in the city of Kampala very keenly and vigilant to see if there could be other people of same or similar problem. The few victims I saw were mostly men. I then wondered how this misfortune could come to me more as a woman, it was very devastating.

I started facing serious challenges whenever I would meet people and especially my friends who used to ask me what exactly was going on in my life and particularly my skin, some could just make fun of me and say; Vivian that is AIDS and it has started on you in the face, then others could make comments such as; Vivian that skin problem has no medicine and cure and it will not get healed. Others would ask me; If I think I will ever get married at all?

I will also never forget one person who mocked me and said I was a good sacrifice. All such comments from different people and sources distressed me a lot, to the extent that I thought of committing suicide. I then regretted the day I was born. In addition to that, some of my campus friends started to reject me .They stopped calling me for any outing even when I wanted to hang out with them. I have lived with VITILIGO for seven years now.

In Uganda, VITILIGO have not been given much attention by the Health Sector, and this has caused vitiligo patients to have a continued state of rejection, shame, embarrassment and inferiority. Most of them the attention they have received has been on personal ground. i.e. People who have felt sympathetic to them and given in a hand.

God has strengthened me and today I am creating Vitiligo awareness in the University where I lecture and starting a Vitiligo Support Group in Uganda.

I send my very sincere appreciation to the Vitiligo Support and Awareness Foundation Group in Nigeria, which trying all possible ways to advocate for us Vitiligo victims at both National, Continental and International scene, may God bless you richly.

By Vivian Najjuka, Coordinator Vitiligo Support Group, Uganda

Open Discussion Forums

Do we need Legislation on Vitiligo? What should the Legislation provide for?

Key Points:

95% of the participants including the stakeholders voted in favor for legislation for extensive vitiligo awareness and education. So much was shared regarding challenges, direct and indirect discrimination, Rights to Life, Work, Social activities, Dignity, equal opportunities and patient care from the medical community.

How do we stop stigmatization?
Key Points:

- Through extensive awareness and enlightenment campaigns
- Grassroots awareness and education with CBO's, traditionalists, religious bodies and Schools
- Community enlightenment
- Publications on vitiligo in different local languages
- Support of the medical and health communities in educating the public
- Policy creation for protection of Rights of Individuals with Vitiligo and other Skin conditions

Video Presentation - to further inspire and build the confidence of the participants who are either Vitiligo patients or friends or family members of a vitiligo patient, there was a multi-media presentation of a documentary which VITSAF conducted on true life experiences of People with Vitiligo, who have accepted themselves and built their self-confidence. Also, the TV fillers were also shown to lighten up the atmosphere.

The day came to a close with an interactive session, brainstorming on the questions

- Why are we here?
- What are the issues?
- What are the expectations?

Lack of variety of vitiligo treatment therapies; lack of patient care and standard Dermatology clinics in the hospitals, team work amongst medical personnel, clinical and operational management; staff competence, patient satisfaction, delivery times, completeness of medical records, clinical information system amongst others were identified by patients, experts who proffered solutions to each challenge in the course of a Thought Leadership Series on Public Health care.

■ **Cross-section of delegates in an open discussion forum**

DAY 2 | Friday October 19, 2012

Sulaiman Shehu opened the day's session with a Recap of Day 1, participants shared their views of what they learnt in the previous day.

This was followed by a Video Cast from Prof. Torello Lotti

http://www.youtube.com/watch?v=_xGb-DggnAY&feature=share&list=UU5WXKitKxytq0rXl56fvn8w, expressing his views and as well as his apologies for not being at the conference in person.

Supporting the psychosocial needs of people living with skin conditions – Recognising the role of psychological, social, and cultural factors

Dr Andrew Thompson, Practicing Clinical Psychologist in the NHS and Reader in Clinical Psychology at the University of Sheffield, UK.

My aim today is to raise awareness of the potential impact of skin conditions. Specifically, I wish to draw attention to the wider picture by talking about the social, psychological, and cultural factors that play a part in adjustment but yet remain relatively understudied. I will present some examples of the psychosocial impact of living with the highly visible skin condition vitiligo from interviews with people living with the condition. The second part of the talk will describe what we know about the effectiveness of psychological treatments developed to alleviate distress associated with skin conditions. I will briefly present some of the findings from a study that tested self-help to improve social confidence, which was conducted in the UK with members of the UK vitiligo Society.

I will conclude by advertising a specific workshop and study supported by VITSAF, and members of The Nigerian Association of Dermatologists, and the University of Sheffield, to be held in Lagos in early 2013 to extend this work.

Unfortunately we could not present Dr. Andrew Thompson video presentation at the conference even when he was available on skype to take all questions (our internet connectivity failed us), but has made it available to all participants and available on youtube;

http://www.youtube.com/watch?v=CKHPIcUtvU0&feature=share&list=UU5WXKitKxytq0rXl56fvn8w.

This we will discuss further for individuals living with vitiligo in January 2013 when we hold The Confidence Building Workshop and a Psychological Study on The Nigerian Experience of Living with Vitiligo.

'Vitiligo: Therapeutic Advancement'

Prof. Davinder Parsad

He stated that there are two main goals of any vitiligo treatment; first is to stop the arrest of further depigmentation and second is to induce repigmentation. The first goal can only be archived fully if we could unravel the mechanisms underlying the disappearance of melanocytes in vitiligo. If this can be achieved repigmentation should be rather simple to accomplish with a combination of medical and/or surgical treatment. Surgical management has evolved significantly and given a ray of hope in stable vitiligo.

There was an extensive interactive sessions, vitiligo patients barred their mind, the challenges, what to really do. For most it was a great opportunity to learn for the first time about their condition and steps to living and managing it. Prof Davinder assured all that there are treatment options to manage progression, segmental and general patterned vitiligo. He promised free surgical treatment for members of VITSAF in India.

World Café – Conversations and Discussions

We discussed these two questions using the world café method

The Psychological Effects and medical Concerns, How do we get the medical community to give little attention to Vitiligo and related conditions?

Key Points:

- Intervention of World Health Organisation and Health Ministries.
- Through Awareness to medical/health centers and Health professionals.
- Policy changes – review of policy on altered images Rights.
- Through workshops, seminars and conferences for stakeholders.
- Sensitizing the medical community, health workers and social workers about vitiligo and its effect through -
- Use of Entertainment education
- WALKS
- Referrals from the Health centers and professionals for psychological and emotional support.

What practical ways can we use to increase awareness?

Key Points:

i. Communication through media and corporate backing on

- Traditional – local language
- Radio
- TV
- Documentary
- Intervention of the movie Industry

ii. Religious Organisations – churches and Mosques

iii. Advocacy

- To Government – Legislation on Vitiligo
- interface with medical Pro Groups

iv. Educate 1 person per day approach

v. Publications on Vitiligo in different major languages in Africa

vi. School activities such drama, debate, public lectures

vii. Blogs, Articles,

Meryam El Yousfi and Thomas, both Journalists of Shamengo in Paris, also participated in Day 2 activities. They visited to conduct video interviews towards the development of a documentary on Ashoka Fellows, Making More More Health Fellows and their interventions. Ogo Maduewesi the Executive Director VITSAF, being an Ashoka fellow was interviewed, alongside various stakeholders in her organization. This will be instrumental in bringing stories and features of the Africa Vitiligo Conference 2012 and VITSAF activities to the international community.

Prior to the town-hall-styled event with a select crowd of participants, Professor Davinder Parsad, President of Asian Society for Pigment

Cell Research delivered a presentation entitled, 'Holistic Management of Vitiligo: Exploring a new horizon' this provided an excellence background to the torrent of bright discussions that followed.

Experts who participated at the first conference in its series on Africa Vitiligo Conference include: Prof Davinder Parsad (India), Prof. Torello Lotti (Florence, Italy), MD, Dr. Shehu Yusuf (Consultant Dermatologist Teaching Hospital Kano), Dr. Ananaba E.L. (Dermatologist General Hospital Lagos), Dr.Grace Okudo (Dermatologist, NPF Enugu), Dr. Aisha Akinkugbe (Consultant Dermatologist, LUTH Skin Clinic), Mrs. Ogunlewa Abiola (LUTH Health Clinic). African Delegates are Gueye Doudou, Vitiligo Senegal, Love Gifty Afezuke, VITSAF Ghana, Najjuka Vivian, Vitiligo Support Group Uganda VISUGU. Others are Mr. Suleiman Sule (a Volunteer) and Ike Nwibe, moderated and hosted conversations and world café respectively.

The outcomes of this event will be produced as a Resource Paper and forwarded to World Health Organisation, the Ministry for Health and also widely circulated for concerted efforts at achieving the discussed objectives.

For more information, send a mail to: vitsupng@gmail.com or info@vitsaf.org. The resource document is also available upon request.

Closing Remarks

Ogo Maduewesi, Lagos
Founder/Executive Director, VITSAF

Ogo Maduewesi thanked Prof Davinder for his address and all delegates for taking part in the open discussion forums, which raised a number of key issues. Ogo Maduewesi specifically welcomed the input of patients and careers to the conference.

Ogo said that the vitiligo journey is not a simple or easy one for the patient, or their families and supporters, but there is hope, and the conference has demonstrated that there are researches going on out there and calls for support of vitiligo patients to be part of the research we shall all benefit from its result someday soon, if not yet to produce and effective treatment therapy, then to helping people to live with vitiligo.

Ms. Ogo thanked all those involved in the organisation and support of the conference, which provides a useful forum for sharing information and coordinating work.

Key Recommendations

Planning for the future of VITSAF and Vitiligo in Africa

- There is a need to prepare for the future – rising incidence, new treatments, workforce planning, IT etc.
- There is no Research and clinical trials in Nigeria and around Africa, patients are encouraged to volunteer for these as VITSAF is collaborating with other foreign organization on this. However this requires continued Social care support.
- Consideration should be given to how health and social care can be further integrated to provide a seamless vitiligo patient journey.
- There is a need for consideration of the issue of vitiligo poverty and what support and advice cancer patients and their families might require, as well as whether legislative changes might be required Patient information and

involvement.

- Patients need high quality information in order to make and exercise informed choices.
- Services should be provided locally where appropriate, but some interventions will still need to take place centrally to ensure safety and the best possible clinical outcomes.
- Patient choice is gradually improving but there is still huge work to do, and choice is still limited for some patients (e.g. those in geographically remote areas).
- Patient involvement should be valued, on both an individual level, and through support/ advocacy groups

New treatments and services

- New treatments will bring greater reductions in psychological and depressive effects but a real debate on affordability and cost-effectiveness is required
- Prof. Davinder Parsad made a commitment to help in facilitating surgical trainings for Health and Medical Professionals on Vitiligo-related issues in India. This training will be at no cost, provided it is a referral from VITSAF.
- There is an urgent need for a state of the art Vitiligo/Skin treatment center to help vitiligo patients and also to reduce cost
- There is a need to improve diagnostics/ screening to enable better targeted, more appropriate treatment
- Consideration must be given to how to treat vitiligo as a chronic condition, as more people are, and will be, living with vitiligo Inequalities
- There is great need for the intervention of WHO, Ministries of Health and other stakeholders to the plight of vitiligo patients across Africa.
- Unavailability of effective vitiligo treatment options, Inequalities of incidence, care, and access to effective medical care exists largely nation and continent wide and need to be addressed urgently.

VITSAF would like to thank Vitiligo Research Foundation (VRF) www.vrfoundation.org, Asian Society for Pigment Cell Research www.aspcr.org, Clinuvel Pharma-ceuticals www.clinuvel.com, Action Health Incorporated www.actionhealthinc.org and Lagos State Ministry of Health for their technical and in-kind support, without which the planning and execution of Africa Vitiligo Conference would have been difficult. All medical and health personnel present at the conference have a medical expertise and a commercial interest in vitiligo, but have had no involvement in the content of this conference.

(L-R)Meryam El Yousfi (Journalist, Shamengo, France), Ogo Maduewesi (VITSAF), Dr. Aisha Akinkugbe (LUTH), Dr. Ananaba (Lagos General Hospital).

Photo

Delegates and speakers in a group photo.

Partners

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