



Standing Voice Malawi

2020 Newsletter

This year has been dominated by the COVID-19 pandemic. Carol and I were quite despondent in March when we were forced to cancel the scheduled clinics in April and face the prospect of having to abandon our plans for 2020. We were also very worried about how Malawi, with its already stretched and under-resourced health service, would cope with large numbers of COVID-19 cases. We were very concerned when we began to receive reports of high levels of stigma surrounding the virus in Malawi and were aware that in a crisis like this, it is the most marginalised that are hit first and hardest.

However, the severity of the pandemic (which affected South Africa so badly) was not replicated in Malawi. At the time of writing, there have been around 6,000 cases and more than 180 deaths reported. These figures undoubtedly represent an underestimate of the true figures due to limitations in testing, but it still means that with its population of 17 million, Malawi seems to have been relatively fortunate.

Furthermore, our fears for the continuation of the Skin Cancer Prevention Programme during 2020 were unfounded. Under the leadership of Bonface Massah, Standing Voice's Country Director in Malawi, and with the dedication of the rest of our wonderful team, we were able to maintain services to those registered in our programme.

Response to COVID-19

Our original plan for 2020 was to expand our services to at least one new district where we had identified a need and to run two further training workshops, building on the success of the previous year. However, in light of the COVID-19 pandemic, we were forced to rethink our strategy:

- ▶ In the Spring, we distributed care packages to people with albinism in the district of Machinga. These packages contained sunscreen, health information and hygiene kits (masks, soap and sanitary products for women).
- ▶ Instead of our typical clinics with around 50-100 attendees, we increased our numbers of clinical locations, limited the number of patients per clinic to facilitate social distancing, and helped patients avoid public transport by holding clinics nearer to their communities. More people attended than ever before, with 650 patients now registered.

- ▶ We established a dedicated hotline so people with albinism can contact Standing Voice if they need assistance or information or feel threatened. Callers have used the helpline to request additional supplies of sunscreen, clarify the dates of upcoming clinics in their districts and report concerns around skin health or intimidation from others.
- ▶ In collaboration with the ICGP, we developed and distributed an animated [video](#) to Malawian health workers on how to care for people with albinism in the midst of the pandemic. This was disseminated to our contacts at the Ministry of Health and health workers involved with our programme, and to health workers across Malawi through Facebook advertisement. 21,644 people saw the video on their newsfeed and over 7,000 played the video to completion or for longer than 15 seconds.
- ▶ We remained in close contact with 'high-risk' and palliative patients, ensuring they attended their hospital appointments, obtained surgery referrals if necessary, and were provided with palliative pain relief where appropriate.
- ▶ We delivered training and surgical workshops to clinicians and health administrators. All this was made possible by the support of Esther Ireland and the ICGP.

Despite the uncertainty we faced in Spring 2020, we are happy to be approaching 2021 in the knowledge that we have achieved our initial aim of continuing the clinics and maintaining the distribution of vital sunscreen.

Malawi Team

The changes forced on us by the pandemic have actually produced a huge bonus for us. Because we were unable to travel to Malawi and assist with the work, our local team had to shoulder the entire responsibility. We are delighted that they rose to the challenge and showed us they are more than capable of running the programme. Country Director Bonface Massah was responsible for rescheduling and supervising clinics on the ground, liaising with our clinical teams and maintaining our relationships in the Ministry of Health and with District Health Officers. He was assisted by Programme Coordinator Chimwemwe Mungomo, and members of the Association of Persons with Albinism in Malawi.

Clinical practice was led by our highly capable team of Dermatology Officers: Frederick, Levi and Bob. We had great support from two dermatologists in Malawi, Drs Mponda and Tenzu, who ran training workshops in Malawi, and performed surgery. Once again we have had huge buy-in from the local Health Boards in each area as well as the Ministry of Health, who sent a representative to accompany the Standing Voice Team.

Team Vehicle

Many of our clinics are in remote areas accessible only by dirt roads, which are often in terrible condition with potholes, soft sand and mud during the wet season. We have to transport the team and the equipment to set up the mobile clinics. We also transport patients to and from clinics. While we are able to use an ambulance from the local hospitals to do most of the patient transfer, historically we have had to hire a vehicle for the team. This has been challenging with breakdowns, punctures and dangerous brakes featuring regularly over the years.

We are delighted to announce that due to financial assistance from the Irish Embassy in Malawi and some very generous donations in Dublin we were able to purchase a second-hand 4WD Toyota Land Cruiser. This will make a huge difference to our ability to run our clinics and other outreach services with safety and reliability.

Palliative Care

Unfortunately, though we can successfully treat and cure many patients with skin cancer, there are some for whom this is not possible. Following several recent deaths and discovering patients with advanced incurable cancers we have reached out to the

palliative care services in Malawi and the Ndyi Moyo Hospice. We are now working together and hope that we will be able to improve the terminal care of those in need of it and give some assistance to their families.

Next Steps

The need to prevent skin cancer and advocate for the rights of people with albinism is greater than ever. Tragically, in November, we received a report of another murder and the dismembering of a person with albinism in order to sell the body parts for black magic and to bring good luck to the purchaser. We also continue to receive calls from other parts of the country not yet served by our programme, where people have advanced and neglected cancers. We are confident that in 2021 we will extend the programme to other areas of Malawi but this is dependent on securing additional funding, which in the current economic climate will be challenging.

Carol and I would like to say a personal thank you to all those who have supported the work of Standing Voice Malawi over the last 12 months. A special mention to the Irish Ambassador to Malawi, Mr Gerry Cunningham, who has been so supportive of our work over the last few years. He has now finished his time in Malawi and we would like to wish him well in his new posting. We also want to thank all our Irish donors, both individuals and groups: you have been crucial to the ongoing success of Standing Voice Malawi and we are very grateful.

Mark and Carol Wheeler, December 2020



If you would like to support our work in 2021...

As part of a match-funding Christmas Campaign, all donations to Standing Voice over the next seven days will be matched by a generous donor. Anything you give will be doubled, with twice the impact for people with albinism!

Until December 8th, your donation will be doubled to provide urgent medical care, educational support, trauma recovery and vocational training to people with albinism.

100% of your donation goes directly to our work in Malawi.

If you are able, you can donate via bank transfer to the following account:

Edenpark Surgery Malawi A/C
Bank Address: **Bank of Ireland Killester**
189 Howth Rd, Killester, Dublin 3
BIC: **BOFIE2D**
IBAN: **IE70BOFI90059419395364**

To find out more, you can contact mark@standingvoice.org.

Again, thank you for your support.

