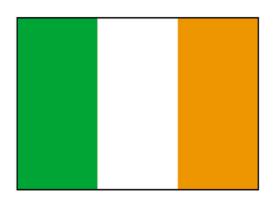
## Edenpark Surgery, Malawi & Global Health

Dr Mark Wheeler Carol O'Dea





#### Sabbatical in Malawi



## Billy Riordan Clinic





## Billy Riordan Clinic





## Carol and Molly





### Africa gets under your skin

- People with Albinism
- Dermatology in general
- Training of health care professionals
- Family medicine program
- Refugee health

#### Albinism in Malawi

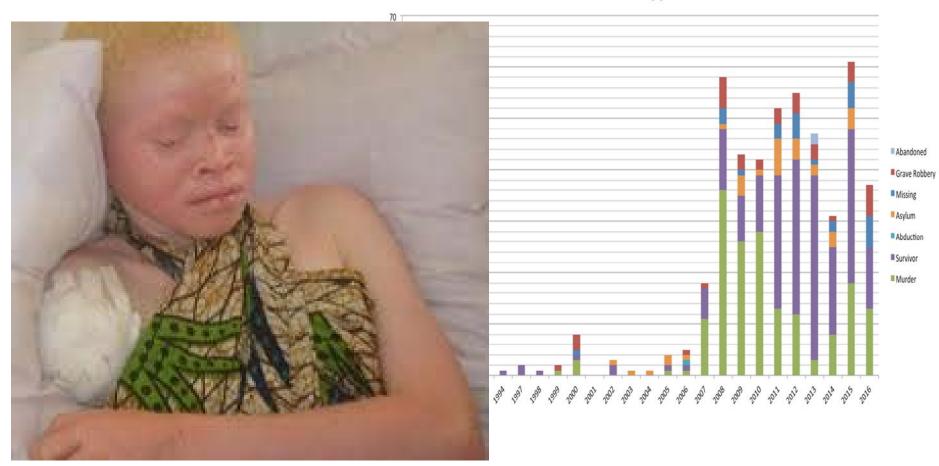
- A non-contagious, recessive genetic condition
- 1-in-4 (25%) chance of albinism occurring in each pregnancy if both parents carry gene
- Affects body's ability to produce melanin causing lack of pigmentation in hair, skin and eyes
- Globally 1 in 18,000 people estimated to have albinism
- Prevalence of albinism in Sub-Saharan African recorded as high as 1 in 1,400
- Number of people with albinism in Malawi: Estimated at 10,000





## Human rights abuses against people with albinism in Africa

Attacks by year in Africa



#### Unmet health needs



Skin Cancer

- Lack of melanin limits body's natural defense again sun damage
- Uniquely susceptible to sun burn
- Exposure to intense UV radiation results in extreme vulnerability to developing skin cancer



Visual Impairment

- Lack of melanin alters retinal development and nerve connections to the eye
- Increased photosensitivity
- Many with albinism experience some degree of visual impairment



#### The idea

To develop a screening and treatment program for PWA of Malawi which can be sustained long term

Collaboration with Dr Kelvin Mponda remotely

Developed the proposal for a pilot

Applied for funding from Esther Ireland

Recognition of scale of the problem and also the legislative issues re charity status etc





Don't re-invent the wheel

#### Collaboration

We currently tackle the social exclusion of people with albinism in Tanzania and wider East Africa. We design and deliver Health, Education, Advocacy and Community Programmes, reaching thousands of people with albinism across Tanzania on a structured, regular basis. We exist as a catalyst to amplify the voices of others, enabling individuals to shape their own lives and forge their own futures



#### Standing Voice's response



Community



Education





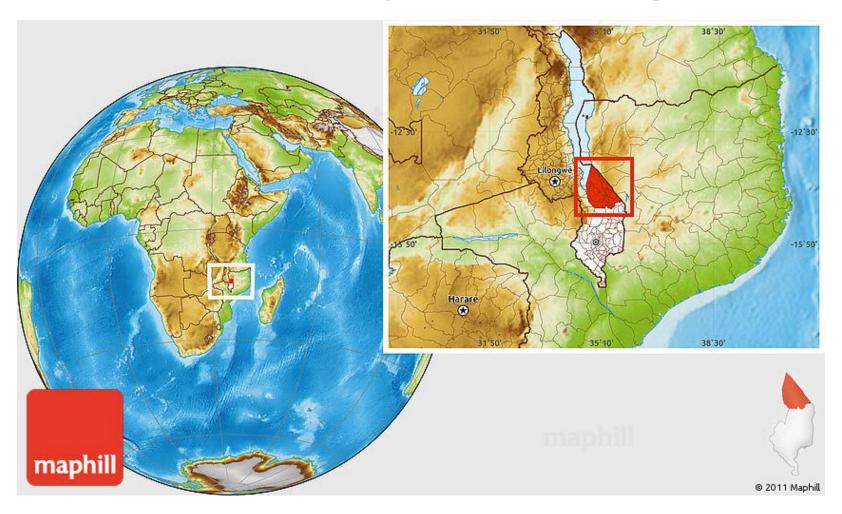
Advocacy



Health



# Re energised the plan and in 6 monts delivered our pilot in Mangochi



#### Mangochi District Pilot

- Covers an area of 6,273 km²
- Total population of 982,058 inhabitants
- Lies along the south eastern shores of Lake Malawi. It is bordered by Dedza district to the west, Mozambique to the east and Machinga district to the south.
- Disadvantaged area
- Fishing major occupation

### Planning the Mangochi Pilot

- Meetings with SV
- Skype calls with Dr Mponda
- Funding from Esther
- Collaboration with APAM
- Cooporation with DoH and DMO
- Contacts with Irish Embassy

#### The Mangochi Pilot

#### **Delivered 3 clinics**

Rural, semi rural and "urban"
Education
Identification of skin cancers
Treatment of pre-malignant lesions
Provision of sunblock & hats
Surgical Rx of SCC



# Identification of skin cancers Treatment of pre-malignant lesions





#### Provision of sunblock & hats



## **Surgical Treatment**





 Close up Picture of surgery

#### **Results of Mangochi Pilot**

- 149 PWA
- Average age 15
- Inadequate protective clothing
- 11% head and face fully protected
- 53.7% no sun protection at all on their neck.



#### **Results of Mangochi Pilot**

- 94% with erythema, 44.3% presented with cheilitis,
- 33.5% presented with actinic keratosis,
- 21.5% of patients required
- cryotherapy
- 8.7% of patients were referred for further surgical intervention



### The next steps

Ensuring all patients get the surgical Rx needed Follow-up of patients @ 12months (Oct 2017)

Publication of pilot program results

Obtaining buy in from Dep of Health to continue the work

#### The vision

Continued annual screening of initial group. Costbenefit analysis and ongoing research and audit

Building local capacity and expertise to conduct ongoing screening and treatment

Further engagement with Ministry of Health and other stake holders to roll out of program to other areas of Malawi,

#### **Problems encountered**

Communication (No replacement for face to face)

TIA (This is Africa)

Being seen as bringing €€

Logistics

**Extreme Heat & rains** 

Electricity

Poor medical infrastructure

Shortage of clinicians

#### Acknowledgments & thanks

- Ester
- Irish embassy
- DoH
- DMO
- APAM
- Dermatology dep at Mangochi district hospital

### Questions? Comments?

