# **Beating Buruli in Victoria**

Information about the case control study

Through a substantial National Health and Medical Research Council grant, a collaborative partnership has been established between Victoria's Department of Health and Human Services (DHHS), the Doherty Institute, Barwon Health, Austin Health, CSIRO, Agribio, The University of Melbourne and Mornington Peninsula Shire, to undertake an ambitious and innovative two-year project to better understand how Buruli ulcer is transmitted and determine effective ways to prevent and reduce infections.

Based on a series of epidemiological, field and laboratory based studies, the 'Beating Buruli in Victoria' project hopes to actively disrupt disease transmission for the first time and lead to the development of evidence-based policies and guidelines that can help stop the spread of Buruli ulcer around Victoria.

# Beating Buruli – case control study

The Beating Buruli – case control study is one component of the overall Beating Buruli in Victoria project that aims to investigate a range of risk and protective factors associated with Buruli ulcer.

It uses a case control study design where participants are asked to self-complete a questionnaire and in a number of participants, field collection of environmental samples at their residence will also be conducted.

The study will run for a total of two years from September 2018.

#### Who is conducting the study?

The study is being jointly conducted by Barwon Health and the CSIRO with additional support being provided by the Department of Health and Human Services, Mornington Peninsula Shire Council, Deakin University, University of Melbourne and AgriBio.

# Who is eligible for the study?

All Victorian residents over the age of 18 are eligible to take part in the study as either a case or control participant. Eligible case participants are those aged over 18 who have been diagnosed with Buruli ulcer and notified to the Department of Health and Human Services since June 2018.

Eligible control participants are recruited through data obtained from the Victorian electoral role and Victorian population health survey.

# What is involved in participating?

Study participants will be asked to self-complete a questionnaire which will take no more than 30 minutes of their time. They will be asked to respond to the questionnaire within six weeks.

In a number of participants who provided their consent to participate in a field survey, field collection of environmental samples at their residence will also be conducted.

#### How will the results of the study be used?

Data obtained from the study will be analysed to determine what behavioural and environmental factors may be associated with Buruli ulcer.

Results will be used to inform other components of the Beating Buruli in Victoria project including the VicBITE intervention study, as well as to identify if particular communities are more at risk of Buruli ulcer and in the development of other intervention strategies against the disease.

All findings will be made publicly available in a nonidentifiable format.

# **Consent and voluntary participation**

Participation in the study is completely voluntary. Consent will be assumed for participants who return their questionnaire, but consent will be obtained in writing from all individuals who participate in the field surveys.

Participants who do not wish to take part in the study can return the 'opt-out' form provided as part of the information pack they will receive with the questionnaire. Participants can withdraw from the study at any time after enrolling into the study.

# How did the CSIRO/Barwon Health get my patient's details?

Under the *Public Health and Wellbeing Act 2008*, doctors and laboratories are required by law to notify the Department of Health and Human Services of diagnosis of specified conditions including Buruli ulcer. This law exists to monitor and control the occurrence of infectious diseases and other specified conditions, and helps to prevent further illness.

Your patient's details were shared with CSIRO/Barwon Health for the project following approval from the Department of Health and Human Services Human Research Ethics Committee.

#### What if my patient doesn't speak English?

Information will be sent out in English with a request that an English speaking friend or family member assist with the form.

# **Ethics approval**

The study has been approved by the Department of Health and Human Services Human Research Ethics Committee in September 2018 (Project number 10/18).

#### **Privacy**

The study team is committed to protecting the privacy and confidentiality of all patients. All information collected will be stored securely and will not be shared with anyone not directly involved in the research. Any collected information will only be used for this particular study.

# What is Buruli ulcer?

Buruli ulcer (also known as Bairnsdale ulcer) is an infection of skin and soft tissue caused by the bacterium Mycobacterium ulcerans. The toxin made by the bacteria attacks fat cells under the skin, which leads to localised swelling or the formation of a nodule (lump) and then an ulcer. At first, it can be mistaken for an insect or spider bite.

# Where is Buruli ulcer found?

Buruli ulcer has been reported in 33 countries around the world. Affected areas include rural West Africa, Central Africa, New Guinea, Latin America and tropical regions of Asia. In Australia, Buruli ulcer most commonly occurs in localised coastal areas of Victoria. It was first recognised in the Bairnsdale area of East Gippsland in the 1930s. Since then a growing number of cases have been reported in the Bellarine Peninsula and since 2012, the Mornington Peninsula. Buruli ulcer also occurs in the Daintree region of Far North Queensland and occasionally in other coastal regions of north Queensland and the Northern Territory

# **Treatment advice**

For disease information and advice please <u>visit the</u> <u>Health.Vic website</u> or speak to an Infectious Diseases consultant at your nearest hospital.

# **Further information**

- For patient information please visit the Better Health Channel: <u>https://www.betterhealth.vic.gov.au/health/healthyli</u> ving/Buruli-ulcer.
- For disease information and advice please visit the Health.Vic website or speak to an Infectious Diseases consultant at your nearest hospital.
- For more information about your patients public health investigation, contact infectious.diseases@dhhs.vic.gov.au
- For more information on the Beating Buruli case control study please contact Kim Blasdell (CSIRO) on 03 5227 5261.
- If you have any ethical concerns regarding this project and would like to speak to an officer not involved in the study, contact the secretary of the DHHS Human Research Ethics Committee, Jeffery Chapman, on 03 9096 5239 or at jeffery.chapman@dhhs.vic.gov.au