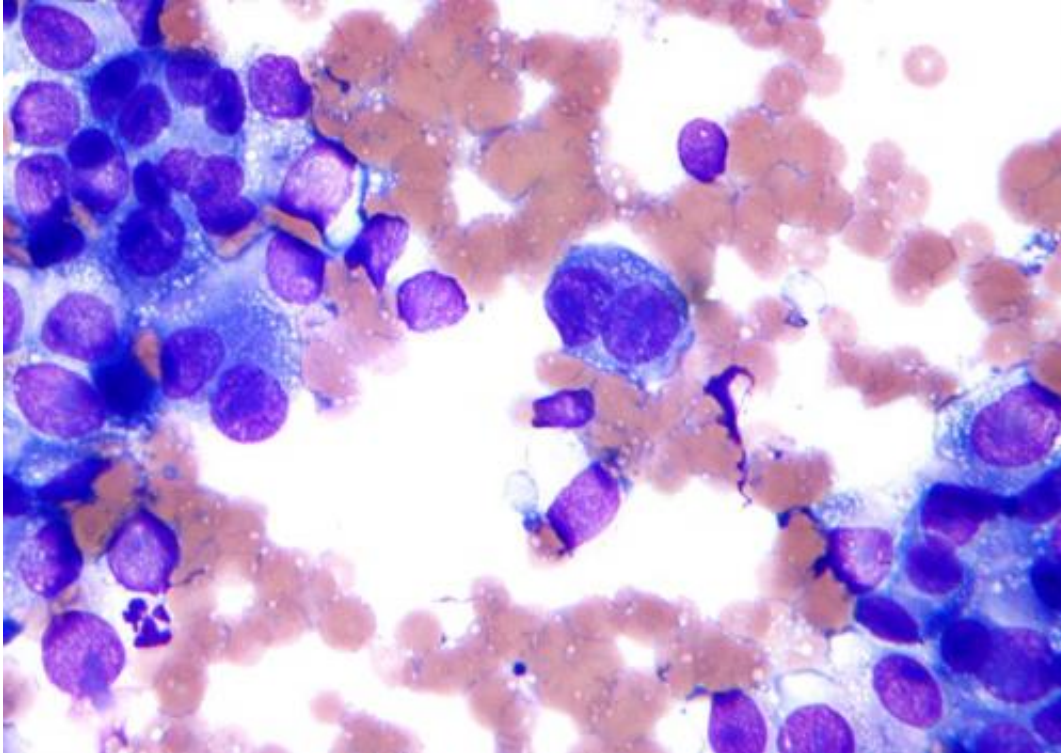


Skin cancer survivor inspires research study

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Micrograph of malignant melanoma. Cytology specimen. Field stain. Credit: Nephron/Wikipedia

A patient with a rare condition that led to him developing skin cancer is helping medical experts discover why some other patients are not protecting themselves from the sun.

Ben Fowler, 55, from Brighton, has Xeroderma Pigmentosum (XP), a [rare genetic condition](#) that affects the skin's ability to repair damage

from ultraviolet light, and greatly increases the risk of [skin cancer](#).

His experience has inspired doctors from St John's Institute of Dermatology at Guy's and St Thomas' and psychologists at King's College London to discover why some XP patients don't protect themselves from deadly melanomas.

The £1.24 million international study, funded by the National Institute for Health Research (NIHR), aims to establish the social and psychological reasons why some XP patients do not follow medical advice to stay out of the sun.

Ben says: "Patients don't think like doctors and don't see what doctors see. If someone says to you, 'if you don't do this, you will get skin cancer in five years time', it's very hard to understand and imagine.

"I'm a designer, and one day I opened my desk drawer to see that enough UV light had got inside to expose some light sensitive paper and change its colour. I realised my skin was the same as the paper and it powerfully illustrated just how much UV light I must have been exposing myself to, even when I was indoors."

Patients with XP need complete protection from UV light to minimise skin damage. They are advised to wear sun protection cream all year round, and wear full length clothes, hats and gloves. The [average life expectancy](#) of an XP patient is just 32.

Dr Robert Sarkany, Consultant Dermatologist at St John's Institute of Dermatology and John Weinman, Professor of Psychology at King's College London, are leading the study.

Dr Sarkany says: "Complete protection from UV light is essential to minimise [skin damage](#) for XP patients. We recognise that this can be

very difficult, and it is worrying to see the difficulties some of our patients have with protection, and how early this means we diagnose them with [skin](#) cancer."

Professor Weinman from the Institute of Pharmaceutical Science at King's adds: "It's not just lack of knowledge, forgetfulness or practical difficulties that determine how well patients follow medical treatments. Motivational factors, beliefs about their condition and treatment, and confidence, all play a part.

"We aim to understand how individual patients think and feel about their condition. We will analyse individuals' behaviour as well as their beliefs and motivation about UV protection. We can then identify relevant types of behavioural changes, helping them to protect themselves and add years to their life."

At least 400 [patients](#) with XP from five different countries will take part in the five-year study. Patients taking part in the study will wear watches that can record their UV exposure levels.

Provided by King's College London

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