

# New treatments urgently needed for rare, disfiguring and painful skin condition

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The first major scientific study into a rare, disfiguring inflammatory skin condition has shown that current standard treatments are not good enough and in half the cases offers no real hope of recovery for patients. Experts say new treatments have to be developed as a matter of urgency.

Pyoderma gangrenosum (PG) affects less than 400 people each year but it can be so severe in some cases it has led to amputation. The condition is so rare it is often misdiagnosed.

The NIHR-funded STOP GAP trial—the Study of Treatments for Pyoderma Gangrenosum Patients—was developed by Professor Kim Thomas and Professor Hywel Williams, Co-Directors of the Centre of Evidence Based Dermatology based at The University of Nottingham, and Anthony Ormerod, Professor of Dermatology and John Norrie, Professor Clinical Trials and Biostatistics at Aberdeen University. The randomised controlled trial was managed by the Nottingham Clinical Trials Unit and sponsored by Nottingham University Hospitals NHS Trust. Find out more about the study and a patient's account of this condition [here](#).

The STOP GAP trial set out to determine which of the two most commonly used treatments for PG—ciclosporin and prednisolone—was most effective. The results show that they have similar benefits but neither is especially effective, suggesting that new treatments for PG are required. The results have been published in the academic journal the BMJ where the study has also featured as an [editorial](#).

## **Biggest ever study with surprise findings**

Professor Thomas said: "PG is a very rare auto immune skin condition which causes rapidly spreading ulcers on the skin. With a poor evidence base for management of this condition the aim of this study was to improve the way the condition is treated. Our big surprise was that in six months less than half of the patients' ulcers had healed and if they did heal one in three had a repeat attack."

The STOP GAP trial, which started recruiting patients in June 2009, was to be the largest study of PG carried out to date.

The trial was developed through the UK Dermatology Clinical Trials Network. It involved 121 patients in 39 UK hospitals, three [clinical trials](#) units and four universities. Using digital images and assessments from blinded investigators the research team's primary objective was to assess the speed of healing. Secondary outcomes including resolution of inflammation, self-reported pain, quality of life, the number of treatment failures, adverse reactions and time to recurrence were also assessed.

## **Sufferers can become disabled**

Sian Bennett, who has suffered from PG for 10 years, said: "I decided to join the STOP GAP trial because I don't want anyone else to go through what I have gone through. I was misdiagnosed for five years. Every time I move I am in the most awful pain. On bad days I have to stay in bed. I became too ill to work and it stops me going out and doing the things other people take for granted. I am constantly wrapped up in bandages and dressings. I've spent 10 years like this. I am now disabled and gained five stone since I've stopped working. I want patients who have this condition to be given the help they deserve."

The full version of Sian's account can be seen on The University of Nottingham's STOP GAP [website](#).

The research team discovered that current standard treatments are not good enough. The trial has provided a baseline against which all other options can be compared in future studies. They are calling for the development and testing of new treatments for this devastating disorder.

Professor Ormerod said: "Finding new treatments will be a challenge, but not an insurmountable one. Robust trials of treatments for rare diseases such as [pyoderma gangrenosum](#) are possible, and they must be done."

Hywel Williams, Professor of Dermato-Epidemiology at the Centre of Evidence Based Dermatology at The University of Nottingham, said: "This trial has raised awareness of this severe [skin condition](#) and provides patients and doctors with the evidence on benefits and harms of current treatments that is needed to make informed decisions."

Provided by University of Nottingham

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