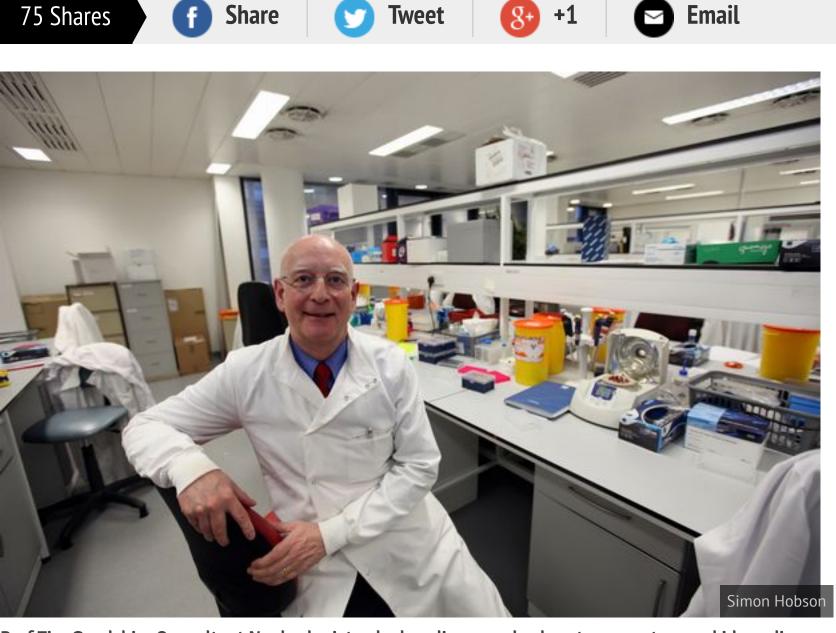
# Kidney drug developed by Newcastle scientists recommended for use on NHS

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A drug which stops a rare type of kidney disease has been recommended in draft quidance by the National Institute for Health and Care Excellence



Prof Tim Goodship, Consultant Nephrologist, who has discovered a drug to prevent a rare kidney disease called 'aHUS'

A life-saving wonder drug developed in the North East to help people with a rare type of kidney disease has been recommended for use on the NHS.

Eculizumab has been clinically proven to prevent kidney failure in people with Atypical Haemolytic Uremic Syndrome (aHUS), a serious irreversible illness that can prove fatal.

Clinical trials undertaken at Newcastle University and Newcastle Hospitals NHS Foundation Trust helped identify the pioneering treatment and the National Institute for Health and Care Excellence (Nice) has now recommended in draft guidance the

drug for use on the National Health Service in England.

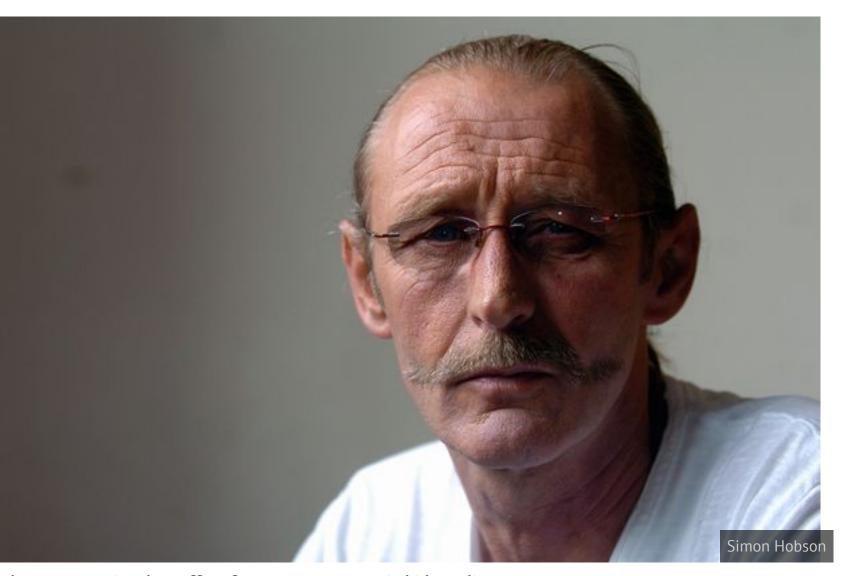
Tim Goodship, professor of renal medicine at The Institute of Human Genetics in Newcastle, who is internationally respected in the field, has been instrumental in the development of the drug.

He said: "We welcome Nice's draft recommendation – if ratified it will make a huge difference to patients affected by a disease which leaves them very little choice other than to spend their lives on dialysis.

"Nice's draft recommendation, if ratified, will ensure that aHUS patients in England are now guaranteed access to treatment with eculizumab when they need it for as long as they need it.

"Research undertaken at both Newcastle University and the Newcastle upon Tyne Hospitals NHS Foundation Trust has been central to finding such an effective treatment for the disease. I am very proud that research in the North East has led to such a breakthrough."

Around 140 people in England have been diagnosed with aHUS, but it is estimated that at least another 140 people may remain undiagnosed.



Shaun McCowie who suffers from aHUS, a genetic kidney disease

Eculizumab, also known as Soliris, has been proven to prevent kidney failure in

patients with recent onset aHUS as it stops unnecessary cell damage. Results from clinical trials revealed that the drug is the best first-line of treatment for patients as it prevents kidney damage by blocking an immune protein called 'complement'.

- If Nice's draft recommendation is approved, any patient who presents with aHUS, or any aHUS patients who need a kidney transplant, will receive the drug. Without it their kidneys would fail, and as there is no other effective treatment available, patients would have no choice but to start a gruelling dialysis routine to stay alive.
- Shaun McCowie knows first-hand how devastating aHUS can be as he has the condition and it has killed seven members of his family.
- Earlier this year, the 52-year-old received a life-saving kidney transplant and continues to be on eculizumab. He had been on dialysis for 25 years prior to his transplant and the new kidney has transformed his life.
- In the past kidney transplants for patients with aHUS have been a waste of resources as there is a 50% to 80% rate of organ rejection due to recurrent disease. Eculizumab will ensure that this does not happen in the future.
- Father-of-one Shaun, from Heaton, Newcastle, a abuse and bereavement councillor, said: "The Nice draft guidance is a major step forward in the treatment of aHUS. It is offering an awful lot of hope to those people who have the condition. I don't think I'd have been able to continue much longer on dialysis as my health was deteriorating.
- "It is fantastic that the treatment has been developed in the North East. It is like sticking a pin in a world atlas and hitting the perfect place. The one saving grace in my life is that I'm under the medical care of Prof Goodship as he is world renowned in his specialism."
- It has been reported that Eculizumab costs approximately £250,000 per patient per year.
- Research funded by Kidney Research UK has been central to understanding aHUS and ultimately to finding an effective treatment for the disease. The charity is delighted by the recommendation.
- Elaine Davies, director of research operations at Kidney Research UK, said: "We are thrilled with Nice's recommendation eculizumab will help improve the quality of life and the outcome for patients with aHUS. Funding research into rare kidney diseases is vital to help improve patients' lives.
- "Research funded by Kidney Research UK at Newcastle University has been central to

understanding aHUS and to finding an effective treatment for the disease. It is with a sense of pride that we have seen our research translate into a life changing treatment for aHUS patients."

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