

# 'NO TREATMENT' FOR RARE DISEASE

A MAN suffering from a rare genetic disease claimed yesterday that doctors had cut years from his life by not giving him the medical help he needed.

Darren Barnes (24) said he and his brother Graham (26) were among only 10 people in Ireland with cystinosis.

But he claimed they had not been given proper medication — and

By EDEL KENNEDY

that he had to research new treatments himself.

Drugs which went on the market in 1994 had only been given to them this year, he said.

"When the doctors realised what was wrong with us, they didn't really know anything about it so they couldn't help us," he said.

Cystinosis causes an abnormal build-up of an amino acid called cystine, which eventually destroys victims' organs.

"One of the symptoms of cystinosis is crystals which build up in the eyes, and I was starting to suffer very badly with photophobia," he said.

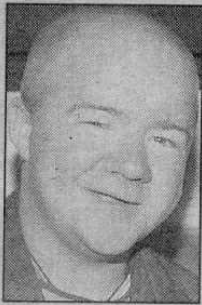
"Sunlight caused me so much pain that I had to wear sunglasses

even when it was raining.

"I did some research myself and found eyedrops in England which have cleared it up completely."

A new support group to help cystinosis sufferers can be contacted via the Internet at <http://ireland.cystinosis.com>.

Donations can be made to an AIB account: Sort code 931330; account 06225194.



VICTIM: Darren