

Luke is calling for your help

THE parents and friends of a little boy who suffers from a rare degenerative disease have launched a fundraising drive to finance research into the condition.

Luke Hennelly from Blackrock in Dublin is just two-and-a-half years old — he was diagnosed with cystinosis when he was just six months old.

Cystinosis is a very rare degenerative disease that causes an abnormal accumulation of the amino acid cystine in most organs of the body.

Failure

Without effective treatment, affected children develop end-stage kidney failure at about the age of nine and ultimately face death at a young age.

While there is no known cure for cystinosis, there is a treatment to slow down the deterioration process.

Luke is currently on this special treatment and is doing very well.

But funding is needed for research into the disease.

"We need money to support further research to make the treatment more effective and to raise awareness about the condition, particularly among the medical profession," a friend of the family's told *The Star*.

FAMILY OF BOY WITH RARE DISEASE FUNDING RESEARCH



By **CATHERINE HALLORAN**
Health Correspondent

"Almost nothing is known about the condition in the general public.

"Many patients have experienced misdiagnosis, sometimes taking months and, on occasions, years to be corrected!"

"The most important aim

of the Foundation in Ireland is research support."

A mere €15,000 would fund a researcher into the disease for a year.

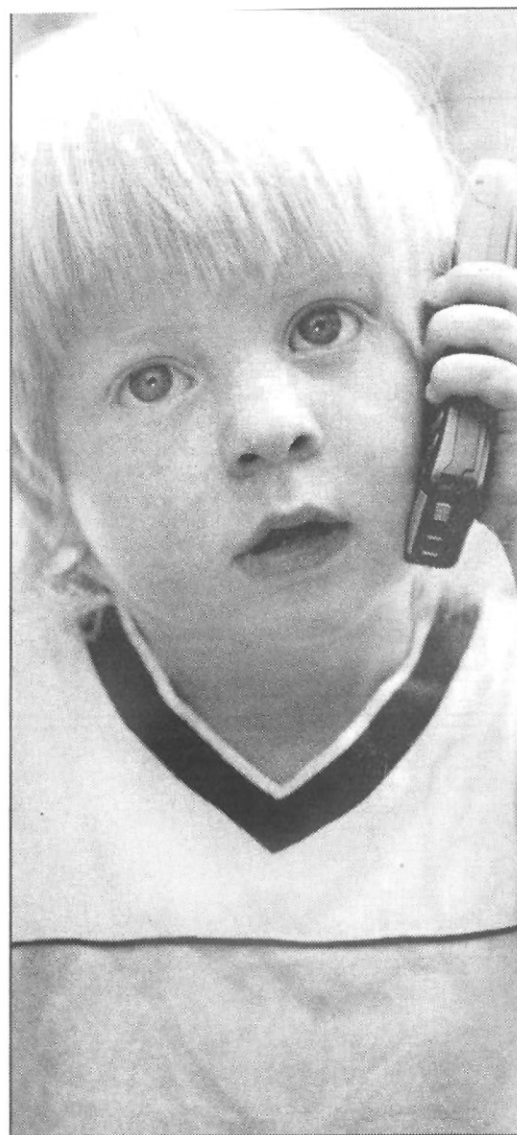
The first main fundraising event will be a benefit gig in The Village on Wexford Street in Dublin on Wednesday, June 18.

It will be a night of traditional music featuring

Emer Mayock and her band, Cathy Jordan from Dervish, Peter Browne and Shane MacGowan.

Eamonn and Cormac de Barra from the band Slide also feature.

A bank account has also been set up to receive donations. The account is at AIB in Terenure, sort code 93-13-20, account number 06225004.



MESSAGE MINDER: Little Luke Pic: Bryan Brophy