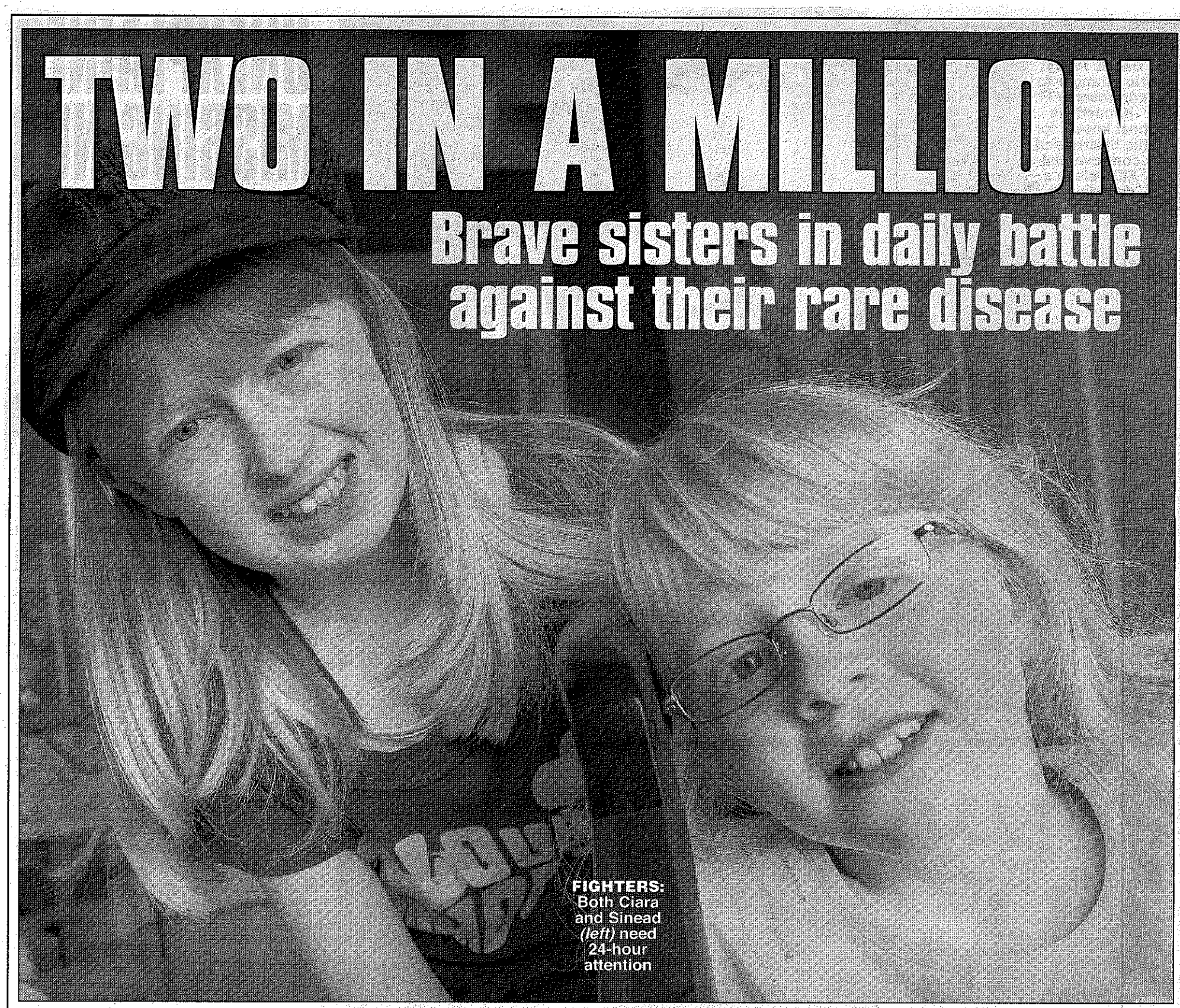
TWO IN A MILLION

Brave sisters in daily battle against their rare disease



FIGHTERS: Both Ciara and Sinead *(left)* need 24-hour attention

SISTERS Sinead (13) and Ciara Maguire (8) are two in a million.

They are in a group of just eight people in Ireland that suffer from the rare disease cystinosis.

Cystinosis is caused by an abnormal accumulation of the amino acid cystine in various organs around the body such as the kidney, eye, muscle, pancreas and brain.

And it means they need constant care and 24-hour attention from their hard-working parents Sue and Andy.

Difficult

"Little is known about the degenerative disease. It is difficult to diagnose and as yet no cure has been found for it," mum Sue told *Star Sunday* from the family home in Dunboyne, Co Meath.

"Sinead was diagnosed first. She had a normal delivery, normal pregnancy," she says.

"Then coming up to about a year after I noticed that her growth started to slow down and she wasn't a great eater. She used to vomit for no apparent reason.

■ SINEAD KENEFICK

"She was also a late walker. I had brought her to the doctor and other practitioners and was told that 'everything is fine', but I had an idea that it wasn't."

Luckily Sue's persistence paid off. "When Sinead was two I brought her to a consultant radiologist.

"I thought she might have something wrong with her hips because when she walked she wobbled and it looked very uncomfortable.

"When he x-rayed her, she had rickets. He said we'll have to admit her straight away to investigate it.

"He did a series of investigations and within a week they told me that she had cystinosis."

Like many of the medical staff at the time, Sue and her husband Andy had never heard of cystinosis.

"The consultant we were under had heard of it but none of the medical students had.

"A lot of the doctors and nurses said they were looking it up in the library because they'd never seen it before."

Today there are eight people in Ireland that suffer from cystinosis, five children and three adults.

Cystinosis primarily affects the kidneys, but eventually it begins to affect the eyes, spleen, liver and most other organs in the body.

Sinead is currently having dialysis treatment at Dublin's Temple Street Hospital three times a week and her parents hope that this year she will be put on the kidney donor list.

Her sister Ciara was diagnosed with the condition at birth.

"Ciara is not on dialysis as her kidney function is fine at the moment," says Sue.

"The disease itself is a very slow process. It's a slow degenerative disease, but her kidneys are leaking. It's called Fanconi syndrome."

"Basically that means that your kidneys leak electrolytes and lose potassium, phosphate and calcium."

Both girls are now being treated with a drug called cystagon, which they say "is not very nice".

This life enhancing drug must be administered every six hours to both girls.

"They both have gasostromy tubes, a feeding tube in their tummies. Both of them are on night feeds too for extra nutrition.

"They have a feeding pump at night, because they are not great eaters we use it to give them top up calories, we time that to finish at 3am," says Sue.

"So when the feeder is finished we give them their medicines, their cystagon, and flush the tube. They are finished then until morning."

The girls have a rigorous routine which must be adhered to and receive their medication at 9am, 3pm, 9pm, and 3am.

Exhausted

Needless to say, accounts assistant Sue and computer whiz Andy are often left exhausted.

In a bid to raise funds for more research into cystinosis, the dedicated parents, along with the other families affected by the disease, have set up The Cystinosis Foundation of Ireland.

"Currently we are funding a project in Scotland that's working on the actual drug cystagon.

"It's working to try to make it more pleasant to taste and smell and also so it won't have to be given every six hours."

In relation to The Cystinosis Foundation of Ireland, Sue explained their aims.

"What we are trying to do is raise funds for research and ultimately for a cure but also to raise awareness because there could be kids going undiagnosed.

"This year the Republic of Ireland soccer supporters club have taken us on board as their charity," Sue added.

Also a number of fundraising events have since been arranged for June to help generate funds and to raise awareness.

"We always do the women's mini marathon. We have about 100 people who will walk or run it for us.

"We are also holding a special golf day on the June 1 next week in the castle in Rathfarnham."

If you would like to make a donation to The Cystinosis Foundation of Ireland, you can do so through a special AIB bank account — sort code 93 13 30 and account number: 06225194

All donations to the registered charity will be greatly appreciated and help research cystinosis.