

story of living with the condition

is vital



LOVING DAUGHTER: Sarah and her mum Martina at their home in Ballingurteen.

Picture: Richard Mills.

month on a Sunday. "We learnt an awful lot from each other and I made some fantastic friends. The children were also delighted to meet up with the other children," she said.

And as secretary of the Cork association, Martina now finds herself offering support to other parents but she doesn't think this is fair on her or the other parents.

Only this week, she received a call from a pregnant woman in Cork who has just found out that her child is going to be born with the condition.

Currently, the Cork association is working with Disability Federation Ireland (DFI) to get funding for a family care worker to help parents of children with spina bifida to understand everything

there is to know about it. At their last meeting in May, they were of the understanding that they are to get a family care worker who will also be working with four other organisations and that the worker will be working for the whole HSE South area, meaning Cork and Kerry.

Martina said having such help is vital.

"It is fierce important because I didn't know anything. You don't know any of your rights or entitlements or where you get help from.

"When I went home with Sarah, I didn't know one thing about the Lavanagh Centre or that there was a spina bifida centre in the hospital. It was other parents who gave me advice," she said, adding that even as a mother of a child with

spina bifida, she is still not equipped to be giving advice to mothers-to-be of children with spina bifida.

"How do I know what I am supposed to do?

"You need somebody who has had training. It's not fair that the parents are pushed into a position like that," she said.

"When we had Sarah, I wanted to see the other children's backs to compare and I wanted to meet other parents and see their reactions," she said.

"There should be a professional in place to prepare parents. They have to be given the information and given the support," she said.

"There is the doctor, physiotherapist and a public health nurse but there is nobody that overlooks the whole lot," she added.

country to advise parents

valence of the condition in Ireland.

"I think this year's Census results could show up some interesting results," he said, referring to the inclusion of a question regarding disability in this year's Census.

He also said that something needs to be done about the EU's Eurocat surveys.

Eurocat is a European

network of population-based registries for the surveillance of congenital anomalies by collating information from maternity hospitals.

"Eurocat only covers two-thirds of Ireland," he said, adding that there are some difficulties with confidentiality issues regarding the release of data.

He said if a true figure of the condition could be ob-

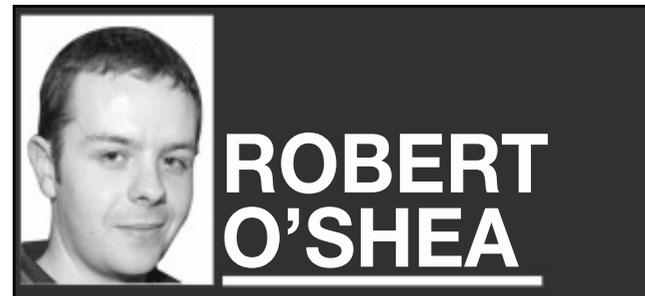
tained, perhaps the condition would be given more notice by the Government.

"Making a case for a family support worker means you have to have all the hard data because at the end of the day, they want value for money, which is understandable," he said.

Mr Power's call for a nationwide survey comes a week after the association

claimed that if bread was fortified with folic acid, the rate of Irish babies born with spina bifida could be reduced and that all women of child-bearing age should take it.

It has been proven that a baby's chances of being born with the condition would be reduced by 71% if the mother takes folic acid everyday.



IT WAS always my dream as a kid to win the Tour de France.

Well, not win it, but ride in it. And not always, but perhaps once, I gave it some thought. Or at the very least, I wanted to visit France.

The great race finished yesterday and it was an exciting one after seven boring years of Lance. For me, Mr Armstrong was a charmless American, who, like Pete Sampras, deadened my interest in a sport I had always enjoyed watching, for almost a decade.

Of course, it hasn't helped that the cloud of drugs has hung over professional cycling for some time now, the first major revelations coming in 1998, the year the Tour came to Ireland for its only time.

That year, the late Italian Marco Pantani won the race. Even though he was since proven to be a drug cheat, I couldn't help preferring him to Armstrong.

He was much lighter than most of the competitors and, though this advantage made him a king when climbing in the mountains, it was a huge disadvantage going downhill. As the heavier riders used their weight to propel them down faster, Pantani — to keep a similar speed — had to haunch his backside over the rear wheel, thus risking emasculation on every slope.

My generation grew up during the halcyon days for the sport in this country.

The days of Roche and Kelly, Earley and Kimmage. This was a time when every single child in the country spent their Communion money on a bike. As opposed to today, when kids get enough money from relatives to buy a decent second-hand jeep.

No, we were really into cycling. In a nod to the world of advertising, I used to drink Cidona — even though I could give or take the taste — simply because Seán Kelly promoted it.

This was the pre-helmet era, when craniums were built to crack.

It had summers when you could spend three weeks gazing at the peloton slaloming through obscure Alpine villages, listening to the wonderful Eurosport commentary that kept you as informed about the passing landscape as the race itself.

I remember summers that were three months long and days that lent themselves to relaxing cycles or neighbour-

hood races (come back schooldays, all is forgiven).

I cycle. From the ages of 12 to 17 I didn't spend much time on the saddle but since then, after my legs, my bike is my main form of transport.

Therefore, it annoyed me to read last week this introduction to a story on the *Irish Times* website:

"About 2,000 cyclists caused minor traffic disruption in Dublin city centre this evening as they took part in the Dublin City Cycle."

What was the main news in this story about — a large number of people taking a clean, healthy and noiseless journey through the capital?

That it caused "minor traffic disruption?"

Cars, and their eagerness to involve themselves in crashes, have been dominating the news recently.

What has been often quoted as a factor in the amount of these fatal collisions and crashes, is that the people driving have had no training and need none to be legally in charge of a vehicle.

Well it doesn't take too many grams of sense to realise they might make better road users if they were to have been put in charge of a safer, more crushable and less egotistical a vehicle before they were let loose with an engine.

What I propose is that every learner driver has to spend one year traversing our roads on a bike before they are allowed behind the wheel of a car.

It would be a bit like the compulsory military service that is in other countries, albeit, knowing our roads, it would be slightly more dangerous.

My dream may or may not have been to cycle in the Tour de France in my more minuscule days. But whatever it was, it has changed.

It is not that someday we will have no cars in our city centres, but only bicycles.

No, as much as I would like to see this, it is never going to happen.

Now my dream is to someday rent a tandem for myself and pedal up on the side of a busy town street.

Then, when I turn around and see no-one sitting on the back, I'll start screaming: "My wife! My wife! Ohmigod! What's happened to my wife!"

It's funny the way your priorities change over the years.

Clarification

IN an interview with the *Evening Echo* on Friday, July 14, 2006, the Commissioner for Taxi Regulation, Mr Ger Deering, inadvertently indicated that Cork Airport lies outside the current Cork city taximeter area. This is incorrect, the Cork city taximeter area extends to a radius of six miles (9.65 kilometres) from Cork city centre and Cork Airport is within this limit.

The point that Mr Deering was attempting to make is that there is currently no fare control applying to taxi customers travelling

from Cork Airport to areas of Co. Cork, or any other area, which lie outside the Cork City taximeter area and the fare charged is at the discretion of the taxi driver.

From September 25, when the national taximeter area and national fare is introduced, passengers will have the right to have their fare calculated on the meter, regardless of the destination or distance.

Mr Deering wishes to apologise for any misunderstanding caused by his earlier statement and is happy to clarify the issue now.