

Liam (10) and Sean (8) Nolan were ready to don their wellies when I arrived at the family farm in Oylgate, Co Wexford.

The two boys were settled, chatty and attentive as they carried buckets, spronged silage and introduced me to the weanlings they call their own.

It was a happy day in a tranquil rural landscape but not every day is so easy, according to their parents, Margaret and Paul.

Both boys have moderate intellectual disability, speech and language delay as well as ADHD and social anxiety problems.

In fifth and third class in primary school now, the work they do is at junior and senior infant level and it is only in the last year that their parents have been able to have a conversation with them. When they were very young, however, everything seemed very normal with both boys.

Their mum, Margaret, tells us what happened:

#### WASN'T REACHING DEVELOPMENTAL MILESTONES

"Liam was a happy, healthy child. We were farming and working away, happy out. It was when I was expecting Sean a year and a half later that we began to notice that things weren't really right with Liam. He was having tantrums and his speech wasn't coming on. He made noises but could say no words and he'd get very frustrated. As soon as Liam was born – again a happy, healthy, baby – we started to look into Liam's problems.

#### TONGUE SURGERY AND HEARING TEST

A speech therapist pointed us in the direction of a paediatrician and the Central Remedial Clinic. Some tongue tie surgery followed which didn't solve the speech problem and we also had his hearing checked in case that was the reason he wasn't talking. His hearing, however, was fine.

#### WORDS OF LIFE

By grace are ye saved through faith; and that not of yourselves: it is the gift of God: not of works, lest any man should boast.

Ephesians 1: 2 v 8 & 9



Pictured are mum Margaret, Liam and Sean with dad, Paul Nolan

Picture: Patrick Browne

# A FRAGILE LIFE

Wexford farming couple, Margaret and Paul Nolan, hadn't heard of Fragile X Syndrome when their two boys, Liam and Sean, were diagnosed with it in 2004. Theirs is a story of challenge and success that also highlights the therapeutic value of living on a farm. Margaret Hawkins reports.



#### SHOCKED WHEN WE LOOKED UP FRAGILE X

At that stage the paediatrician said she would screen Liam for chromosomal disorders and also for Fragile X Syndrome. We had never heard of Fragile X. She mentioned that Sean, who was now one year old, should be screened as well. We were shocked at that.

We 'Googled' Fragile X the minute we got home and a lot of what we read matched up. My background was in

molecular genetics so I could make sense of the scientific links and the genetic concept.

It took a long six months to get the official diagnosis. During that time we still held out hope that even if Liam had it, maybe Sean didn't, but it transpired that both of them did.

#### FIRST AND LAST THING YOU THINK OF

Since then I've been tested and it's me that's carrying the pre-mutation gene for Fragile X. I went through stages of feeling "God, I gave them this." It was often the first and last thing I'd think of each day. You can't blame yourself but every parent feels like that sometimes and you can't help thinking what their lives would have been like if they didn't have Fragile X.

It's like an ache deep in your bones that never leaves you – it's grief, really. Our boys were born healthy and happy. They were going to

go to college and be the best in the world at whatever they wanted to be. Then all of a sudden a ceiling was put on their potential.

#### POTENTIAL NOW IS THAT THEY CAN LIVE INDEPENDENTLY, WITH SUPPORT

Their potential for us now is that, please God, they may be able to live independently, with support, in time to come. "It has taken us years to adjust to that change in our hopes and dreams but we're getting there. Now we appreciate all the things that they can do rather than what they can't do," she says.

#### LIVING ON A FARM HAS HELPED HUGELY

"Living on a farm helps a huge amount in taking care of the boys," Margaret says. "Doing repetitive muscular jobs like brushing or shovelling helps calm the boys down and allows them to come out of their tantrums. The presence of

animals helps too. So often I've brought one or other out to the field to run after the stock when they were having bad days or high days. We have plenty of those. Wet days can be a nightmare, too, as the boys hate being cooped up." **CL**

#### PAUL NOLAN, LIAM AND SEAN'S DAD SAYS:

"I was working part time off the farm when the boys were small but when we discovered about the boys one of us had to stay home more.

"I inherited the farm from my father and you just presume you're going to pass it on to your children. It's hard to accept that the boys won't be able to farm. That thought is there the whole time. I suppose in the farming community there's more emphasis (on inheritance) because there is this generation thing of passing on the farm.

"I find it tough too, related to sport. I grew up playing hurling and gaelic football with our local club but the boys won't be able to do that.

"They are in school in Enniscorthy too which is a bit away from the community here in Oylgate and even though you know you are part of the community you feel that you're not quite when the boys are not able to be involved in the locality like other children.

"I'd always thought I'd like to get involved in training young lads at some point, too, but I'd find that too hard a step to make at the moment."

#### WHAT IS FRAGILE X?

- Fragile X Syndrome is the most common inherited cause of intellectual impairment affecting one in 4000 boys and one in 6000 girls
- The gene that causes Fragile X is found at the tip of the X chromosome and appears as a 'fragile' site – hence the name Fragile X Syndrome. The FMR1 gene shuts down and fails to produce a protein vital for brain development
- Genetic testing is available
- Early intervention is important

#### HOW COMMON IS IT?

Fragile X is second only to Down Syndrome in causing intellectual impairment. 1 in 250 women and 1 in 700 men are carriers of Fragile X

#### SOME FEATURES OF FRAGILE X

- Developmental delay or intellectual impairment
- Short attention span
- Easily distracted
- Impulsive
- Hyperactivity
- Anxiety in social situations
- Speech and language delay
- Physical features include a long, narrow face and prominent ears which may not be obvious in young children.

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**HIGH PRAISE FOR ST SENAN'S SCHOOL**

Margaret and Paul have high praise for the principal and staff of St Senan's Primary School in Enniscorthy town where the boys spend half the day in mainstream classes and the other half being taught in resource classes. Both have SNAs, part time, to help them.

"The single biggest contribution to our success has been St Senan's Primary school," Margaret says. "The support we got from day one has been wonderful. You feel like you're not on your own and that there are others there helping you achieve the maximum potential for the boys."

**WHAT THE BOYS ARE LEARNING**

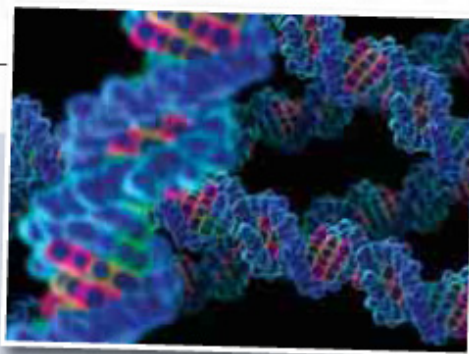
Margaret is very proud that Liam is now reading and writing. "He gets frustrated sometimes but he is miles better than when he went to school first. The boys like computers because they respond so quickly. Liam is able to put together pictures and type out sentences for power point projects.

"Sean is doing one on Friesian cows. They write up what's happening on the farm, too, like a heifer going to Bothar or us getting a new tractor. They will work away at that because they are so interested in farming. Sean loves tractors and, in school, he learned to count by counting toy tractors. Doing things they can relate to keeps them motivated."

**HINDERED BY SOCIAL ANXIETY AND HYPERACTIVITY**

The boys – both big Manchester United and 'Done Deal' fans – are achieving the maximum possible at the moment, Margaret says, but there are two issues that hinder them day-to-day.

"Liam's biggest issue is anxiety. He'd be very anxious if we went to school by another route, for example. Routine is king. Both boys need to know what's happening on a constant basis. They keep saying 'What do next, Mam? What do next?'



Sean's biggest challenge is hyperactivity. He's the Duracell bunny, awake at 5a.m. We're lucky. I know, that we have none of the aggressive behaviour that some parents have to cope with. It's all fun but it's always turned on."

**INTELLECTUAL DISABILITY MOST DIFFICULT TO ACCEPT**

Margaret finds the boys' intellectual disability the most difficult thing to accept. "They have difficulty thinking things through so safety is an issue and there is a lid on the level that they can learn to. I find that very hard."

**LUCKY WITH SUPPORTS IN THE AREA**

The Nolans have been lucky to have access to respite services a few times a year in the Ard Aoibhinn centre in Wexford town.

"We were slow to do that," Margaret says, "as we had to get over the feelings around letting them into an institutional situation but they loved it from day one." Paul agrees that this is a big support.

"We can plan a night out or a weekend away," he says. "Holidays are something we can't do with the boys as that kind of change is too unsettling for them."

"We have to mind our own relationship too," Margaret says, "so that we'll stay strong and be able to provide the best for the boys."

**DIDN'T OPT FOR SPECIAL SCHOOL**

Margaret and Paul both like the fact that the boys go to a mainstream rather than a special needs school.

"The boys tend to mimic behaviour so in a mainstream school they copy the behaviour of typical kids as opposed to special needs children. That has made them more acceptable in society and more sociable, we feel.

They go on school tours, to the library – normal stuff rather than being segregated into special little pockets.

The whole ethos in the school is one of inclusion and it just makes such a difference to what their outcome will be."

**MAY BE UNDIAGNOSED CHILDREN OUT THERE**

When the boys were first diagnosed the Nolan's knew nobody else who had children who had Fragile X.

"Part of the reason for doing this article is to help families who are newly diagnosed or who are concerned that maybe their children are not meeting their developmental milestones. Ours is a good news story. Having a child with Fragile X is not the end of the world but getting the diagnosis and help in the form of things like speech and physiotherapy early on is very important."

The Nolan's have found the Fragile X Society very helpful.

"It's somewhere for families to go," says Margaret. "There's a website for information and they bring experts from centres of excellence worldwide to Ireland for conferences. These people have researched things like how to handle Fragile X behaviours. It's really helpful to get tips on how to cope, for example."

For more information contact the Irish Fragile X Society (Maria Panza) at 087 657 30 89

The website address is [www.fragilex-ireland.org](http://www.fragilex-ireland.org) Or contact the Irish Fragile X Society, c/o Inclusion Ireland, Unit C2 The Steel Works, Foley Street, Dublin 1.

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