



# Mums fight for help for sick kids

**Nick Bramhill**

A group of devoted Donegal mothers are spearheading a new campaign which aims to force the Government to fast-track urgently-needed services for terminally ill children in the north-west.

The six mums — two of whom have tragically already lost children to life-limiting conditions — will hold private talks with Health Minister Leo Varadkar in Dublin tomorrow.

They said they will use the meeting to highlight the lack of paediatric services and support in the county and tell the minister first-hand of the challenges they have faced in caring for seriously-ill youngsters in one of the most remote and under-resourced parts of the country.

Ashling Nibbs, whose five-year-old son Oran suffers from Mitochondrial Disease, said the huge demands she and husband Colm face every day in caring for a young child with a complex, incurable and progressive condition are made far more difficult by living in Letterkenny.

She said: "It's extremely difficult, because there is so little support for us here. At the moment I need to take Oran up to Dublin every three months for surgery, which means a four-hour drive, because there is no train service here.

"But we've outlined a cost-effective plan which we'll be discussing with the minister and which we believe would make a massive difference for all the children with life-limiting illnesses up here.

"Firstly, we want to see a paediatric palliative care nurse in place in Letterken-

ny, as well as a specialist epilepsy nurse. We also want outreach clinics to be set up in the hospital, which would mean we wouldn't have to travel to Dublin so much. And we want the minister to look into cross-border cooperation to enable a child in the north-west to attend a children's hospice in Belfast and Enniskillen, which would be convenient for us."

Ashling, 37, who has two older children with her partner, said she also hopes to raise awareness about the rare disease her youngest child is suffering from — and which affects up to 60 people in Ireland.

The debilitating genetic condition, which affects each sufferer differently, has left Oran — who has received stem cell treatment in the US from funds raised by his family — battling daily seizures, as well as intellectual development delay, and an inability to swallow and walk or talk.

Ashling added: "It was our worst nightmare when Oran was diagnosed less than three years ago and it was made worse by the fact we weren't offered any counselling.

"We felt very alone, because there's no formal support group in Ireland."