

F.R.O.D.O. Neurology Project

Hydrocephalus Support was one of the first F.R.O.D.O. projects. The initial aim being “to support the improvement of early diagnosis, medico-surgical treatment, recuperation and socio-familial insertion of children with hydrocephalus”. We wanted to ensure that every child born with or developing hydrocephalus in Romania received access to appropriate treatment and support.

Over the last two years the hydrocephalus project which Medicor has generously funded has grown and developed. Through it we have learnt a lot about hydrocephalus and consequently about additional neurological conditions prevalent in Romania. We have built up some very good relationships and support from a number of Romanian neurosurgeons and medical professionals.

Our experience has taught us that additional challenges now face Romanian children with hydrocephalus. This challenge also faces the neurosurgeons – many who are enthusiastic to help. Although F.R.O.D.O. aims to get children seen as quickly as possible, we have discovered a serious stumbling block.

At the moment when a child is born with hydrocephalus the diagnosing doctor decides to refer him or her to a neurologist (the diagnosing doctor could be from a placement centre or a family doctor).

If referred the neurologist will refer the child to a neurosurgeon who will decide whether to operate or not. If not referred the child will either continue to live at the placement centre or be hospitalised indefinitely – often left to die.

Because we have been focusing on the neurosurgeons and on the urgency of getting a child assessed immediately - we have failed to see the bigger picture until now. Currently when it comes to doctors and neurologists who diagnose children there is a frustrating bottleneck. We have sadly experienced firsthand examples of this. Child protection authorities and others are now willing to give F.R.O.D.O. information about children and most neurosurgeons are happy to operate and advise. Education, awareness and training at the ‘neurologist level’ is urgently required to ensure children born with or developing hydrocephalus are given a chance.

It is also clear that the number of referrals to a neurosurgeon is not an accurate measurement of the project’s success. In considering quality of life for a child an essential question we must ask is ‘Does quantity prevail over quality?’ F.R.O.D.O. has an obligation not only to ensure the child is urgently treated but that they can also reach their best potential. It is concerning that Romanian neurologists see a broad spectrum of conditions including movement disorders, autism, seizures, cerebral palsy, nutrition, epilepsy, and behavioural and cognitive syndromes – many of these conditions are medically mismanaged.

Even when children have surgery to insert a shunt, Hydrocephalus continues to pose risks to both cognitive and physical development. Because it can injure the brain, thought and behaviour may be adversely affected. Learning disabilities are common among those with hydrocephalus, who tend to score better on verbal IQ than on

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performance IQ, which is thought to reflect the distribution of nerve damage to the brain. A child with hydrocephalus may have motion and visual problems, problems with coordination, or may be clumsy. They may reach puberty earlier than the average child and about one in four develops epilepsy. There are other needs in addition to ensuring the child with hydrocephalus gets urgent treatment.

Treatment by an interdisciplinary team of medical professionals, rehabilitation specialists, and educational experts is critical to a positive outcome for children with hydrocephalus or other neurological problems. Many children diagnosed with such disorders benefit from rehabilitation therapies and educational interventions, and go on to lead normal lives with few limitations. Children with hydrocephalus may have life-long special health needs. These needs may alter their primary care. It is important that care givers understand hydrocephalus in order to provide primary health care to these children and their families.

As part of the hydrocephalus project, we would like to develop this treatment and training and place it accurately in the bigger picture, particularly being more effective in the longer term life satisfaction of each child and training the neurologists to work in all aspects of neurodevelopment and neuro-disability. It is important to focus on the root of the problem rather than just a temporary fix to one of many neurological conditions. We need to work with the local neurologists and diagnosing doctors to ensure relevant referrals and best long-term treatment for the child. F.R.O.D.O. must encourage longer term care plans to be made for each child and not simply the insertion of a shunt – follow-up is crucial. We are already working with Brasov children's hospital and there is some scope to develop fellowships and other projects where funding for hydrocephalus can be redirected to. A goal would be for doctors and neurologists to change their thinking as F.R.O.D.O. acts as a facilitator in getting as many children as possible the best possible treatment available – in the long term.

By taking this route in the hydrocephalus support project, F.R.O.D.O. can reach more children with a variety of neurological conditions. Neurologists will be trained in the management and care of children with hydrocephalus and associated medical conditions and most importantly many disadvantaged and vulnerable children will gain maximum attention and reach their full potential.

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May 2010

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