



**Millie D'Cruz-Parsley; 7 years old.**

**(From Milton Keynes)**

In 2010, Millie developed a rare form of Metachromatic Leukodystrophy (Juvenile MLD), a degenerative condition for which she travelled to North Carolina in December to be assessed for possible treatment. Unfortunately, treatment does not seem to be an option at present, due to Millie having a rare blood/tissue type. Although there is still a chance for treatment if a suitable bone marrow donor can be found, and we are encouraging everyone to sign up to the Anthony Nolan Trust to register their willingness to donate if ever a match is discovered.

The juvenile form of MLD appears in children between the ages of 4 to 12, sometimes earlier. Early symptoms include problems with learning or with walking. As the disease progresses, symptoms include behavior problems, trouble following directions, and worsening co-ordination with walking and speech.

As a group of Trustees of 'Millies Fund', we want to give Millie and her family the opportunity to make her life as comfortable as possible, and are raising funds to pay for any treatment which might become available to them. Already, after only one year, Millie is not able to walk unaided, and is losing her ability to swallow, resulting in the use of a naso-gastric tube for all feeding. So we would like to concentrate on those things which will help Millie to be cared for as the condition progresses; to improve her quality of life where possible in the family environment; and help to fund research into treatment of this condition in other children.

If any organisation, or individual, would like to help, then please contact Bob Stott (Millie's Fund Chairman) at [wgrstott@aol.com](mailto:wgrstott@aol.com) for more details. Please look at [www.helpmillie.co.uk](http://www.helpmillie.co.uk) for other links.

Your help really is appreciated.

**Bob Stott.**