

# The Linking Hand

Across Australia and New Zealand

Winter 2005



## Our Motto

A life is not measured by the number of days, months  
or years that it is lived,  
but by the effect that life has on other people who touch it.  
It is not measured by the length of its days or the height  
of its achievements,  
but by the breadth of its influence.

Anonymous

## Inside this issue

Presidents Report	page 2
From the Editors	page 4
For the Kids	page 6
Society News starts	page 8
Family Story Questions	page 10
Family Story - Jennifer Johnston	page 11
Family Story - Colin Arrowsmith	page 13
New Zealand Society News	page 14
Medical - Preimplantation Genetic Diagnoses	page 15
Medical - Research, Further Directions	page 20
Largest meeting ever for Mucopolipidosis	page 26
Medical - Launch of Naglazyme for MPS VI	page 29
Lobbying updates	page 30

## UK Booklets Available

Is your MPS child starting pre-school or school next year?  
Does your MPS Child attend a busy child care centre?  
Do other people's children not understand about MPS and  
do you find it difficult to explain MPS to them?

If you answered yes to any of these questions then you  
may be interested in the following publications that are  
available from the UK MPS Society.

The UK MPS Society has published several story books  
written for young children aged over five that explain what  
MPS is. These books are an excellent resource for a child  
care centre, preschool, school or siblings. They outline  
MPS and the ways the disorder affect individuals and why  
the affected child cannot do simple tasks that 'normal'  
children can easily do. These books are easy to understand  
with lovely bright photographic pictures. Parents of children  
with MPS may find some of the sentences quite perky and  
amusing.

The following publications are available:

- I've got Hurler's and had a BMT
- I've got Hunter's
- I've got Morquio's
- I've got Fabry's
- Our brothers & sisters have Sanfilippo

Each publication costs \$15 (including postage). If you wish  
to purchase any of these publications please contact the  
National Office.