

**NEWSLETTER**

**SPRING 1991**

**THE SOCIETY FOR  
MUCOPOLYSACCHARIDE  
DISEASES**



National Registered Charity No. 287034



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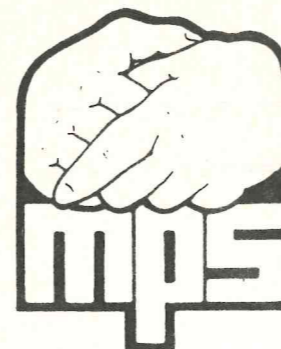
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**CHARLES O'TOOLE**  
(as above)

This newsletter is published quarterly and distributed free of charge to sufferers from MPS disorders in Great Britain and to their immediate families. It is distributed around the world on subscription. Copies are also sent to those members of the medical profession who are directly concerned with MPS, many of whom make a donation towards our costs, for which we are most grateful. If you wish to be added to the circulation list, please contact **Christine Lavery** at the above address. Annual subscription charges are £5.00 in Great Britain and £10 Sterling elsewhere.



# The Society for Mucopolysaccharide Diseases

7 Chessfield Park, Little Chalfont, Buckinghamshire. HP6 6RU  
Telephone: (0494) 762789

The MPS Society is a voluntary support group, founded in 1982, which represents over 300 families in the UK with children or adults suffering from mucopolysaccharide and related diseases. It is a registered charity, which is entirely supported by contributions raised by its members and it is run by the members themselves. Its aims are:

To act as a parent support group

To bring about more public awareness of MPS

To promote and support research into MPS

The Society operates a network of Area Families throughout the UK and Northern Ireland who offer support and links to families in their areas. It provides an information service for families and professionals. At the present time it funds a Consultant Paediatric Post at the Manchester Children's Hospital. It maintains links with sister societies in Europe, North America, South Africa, Australia, New Zealand and Japan.

In most cases there is at present little treatment for MPS diseases but much can be done to improve the care of sufferers. The slogan of the Society is:

**"Care Today, Hope Tomorrow"**

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### DON'T MISS THE PUBLICITY BUS!

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As there are now a large number of MPS events throughout the year we are trying to make up a yearly calender. If possible Events organisers are asked to fix their next year's events just after Christmas - in time for the Winter Newsletter deadline. In any event please let the office (or me) know in time to get it into the newsletter before the event. Deadlines are Early January, Easter, Early August and Mid September.

**The Editor**

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Best wishes to Ann Kirkpatrick who has been appointed as Area Family for Northern Ireland to work alongside Margaret Kearney.

It is proposed to set up a Northern Ireland MPS Society in the near future.

**Ann Kirkpatrick**  
 Inglenook  
 118 Seven Mile Straights  
 Murckamore  
 Co. Antrim BT41 4QT  
 Ph 08494 62300

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**DATES FOR YOUR DIARY**

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16th June	NW Area Barbeque, from 12.00 at Gilfords Dairy, Near Nantwich. (Contact Blackburn's or Mary Gardiner)
22nd June	Northern Ireland Area Family Day, Belfast and MPS Golf Tournament at Strabane.
29-30th June	Conference for MPS families and families with other rare genetic conditions. Limerick, Ireland. (See News, page 13)
30th June	Barbeque at Westway Park at 1.00pm. (Tony and Shirley Eyre)
7th July	Area Family Meeting at 11.00 at Cotswold Wild Life Park, Burford. (Ron and Linda Snack)
27th July 3rd August	MPS Family Holiday at Primrose Valley.
1st Sept.	Area Family Meeting at 11.00 at Drayton Manor Park, Staffs. (Ron and Linda Snack)
20th Sept 22nd Sept	Annual Parent Conference - Stoke on Trent
Sept	Day out at Bristol Zoo or Slimbridge. Date yet to be fixed. (Eyre)
1st Dec	Area Christmas Party at Milton Keynes. (Snack)

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**CONFERENCE BOOKINGS 1991**

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There are still some bookings available for the Annual Conference at Stoke-on-Trent from the 20th to 22nd of September. If you would like to come but are worried about the cost please contact **Ann Neal**.

**The deadline for bookings is 5th of May.**

Ann can be contacted at the office number (0494 762789) on **Wednesdays and Thursdays between 9.30 and 3.00pm**. On other days leave a message with Linda on the same number. You can write to Ann at 7 Chessfield Park.

This year's conference promises to be a relaxed one with emphasis on contact between families and the day to day care of the children. We have found the hotel to be very agreeable and welcoming. If you haven't been to a conference before this is the time to give it a try!

**Government Health Warning:** There might be Kareoke singing on Saturday night!

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**NEW FAMILIES**

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**Mrs Maureen Fryer**, from Tendring, Clacton on Sea, whose son David died from Hunter disease in 1978, just three weeks before his fifteenth birthday.

**Mrs Elizabeth Mitchell** from Edinburgh. Elizabeth's daughter **Sarah** sadly died in 1977 at the age of nine. She suffered from Hurler disease.

**Sheila and Jane Robson** from Northumberland. Their son **Aaron**, aged twelve has been diagnosed as suffering from MPS.

**Alfred and Patricia Copeland** from Belfast whose son **Michael**, born in March 1990 has been diagnosed as suffering from Hurler disease.

**Tracey and Jeremy Chitsega**, from Norwich, whose daughter **Jasmin**, born in June 1990, sadly died on 25th of December 1990 from Sialic Acid Disease.

**Mrs Efe** from Holloway, London, whose two children have been diagnosed as suffering from MLIII.

**Alison and Ian Russell**, from Ross-shire, Scotland, whose son **Sean**, aged two years has been diagnosed as suffering from MLII.

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**DEATHS**

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**Timothy Bryans** from Borehamwood in Hertfordshire died on 3rd of January 1991, aged five and a half. He suffered from MLII disease. Our thoughts are with his sorrowing parents Jeanine and Jim and his family and friends.

**Richard Harford**, from Leckhampton, died on the 29th of January 1991, aged four years. Our thoughts are with his parents Pauline and Mike and with his family.

**Ian Darke**, from Fulwell, Sunderland, died on the 12th of February 1991. Ian suffered from Hunter disease. Our deepest sympathy to his parents Keith and Monica and to his brother Peter.

**Paul Bagshaw**, from Sheffield, died on the 13th of February 1991. He suffered from Sanfilippo Disease. Our thoughts are with his parents Dean and Barbara, and also with his sister Pamela who also suffers from Sanfilippo disease.

**David Criddle**, from Pentwyn, Cardiff, died on the 16th of February 1991. David suffered from Hurler disease. Our thoughts are with his parents Pat and Graham and his sister Jane.

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**DEATHS**

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**Jamie Spencer**, from Oxford, died on the 6th of March 1991, aged seventeen. Jamie suffered from Sanfilippo disease. Our thoughts are with his mother Val, sister Alison and brothers Paul and Lee.

**Stephen James Harvey**, from Boars Hill, Oxford, died on the 18th March 1991, aged eleven. Stephen suffered from Sanfilippo disease. Our thoughts are with his sorrowing parents Lesley and Paul and with his family.

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**Pat and David Criddle**  
at Christmas Party



A SERVICE FOR  
DAVID CRIDDLE  
26 FEBRUARY 1991



I watch the sunset  
Fading away,  
Lighting the clouds with sleep  
And as the evening  
Closes its eyes  
I feel your presence near me.

"Suffer the little children  
to come unto me,.....  
and he took them up in  
his arms, put his hands  
upon them, and blessed them"

Mark 10 verses 14, 16



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**NEWS**

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North East Families had a very enjoyable family day at Mere Brow, Southport, on the 24th of February. They catered for 68 people and over 100 turned up. Congratulations to the organisers for a very successful event.

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Ron Snack has organised several members to take part in the Mental Health Flag Day on 27th of April. Last year this raised £800 for the Society.

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Dominic Hall has been admitted to Manchester Children's Hospital for a second bone marrow transplant. All our best wishes and support to him and his family at this difficult and anxious time.

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A second consultant paediatrician with special interest in inherited metabolic diseases is in the process of being appointed at the Royal Manchester Children's Hospital, alongside Dr Ed Wraith. This will give a boost to the service to MPS patients and also to research. The Society is paying £80,000 over two years to help establish this post.

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Dr Wraith has succeeded in getting a post at Senior Registrar level for one year to study the sleep patterns of Sanfilippo Children. A short term pilot project will start in the Manchester Area and later it is hoped that work can be done with families throughout the UK. This is at no cost to the Society.

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A project has been set up to test the urine of children who have been placed in day nurseries because of behaviour problems in order to screen them for Sanfilippo disease. Hopefully this will give some idea of the numbers of wrongly diagnosed Sanfilippo sufferers. It will also make a start on finding out how to go about screening for Sanfilippo disease. The Society is paying £100 towards the costs of the chemicals needed.

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**LONDON MARATHON**

By the time you read this the London Marathon will have been run and you will all be busy collecting your sponsorship money. We have five runners in the year's Marathon so, hopefully, we will have raised a lot of money for the Society. I would like to take this opportunity of thanking all those who ran for us, and wish them luck with their entries for next year.

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**FUNDRAISING FUN**

With Spring upon us once again now is the time to be out and about to the Car Boot Sales - armed with anything that your friends and neighbours are willing to donate to the Society. Don't forget to take plenty of publicity material with you so that the public know just who you are collecting for.

We are still an "accepted" charity by Sainsburys, and this means that they will look on any request to collect in the precincts of any of their stores very favourably. Just approach the local manager for a date, and if there are any problems please let me know.

Sponsorship is still the favourite way to raise money for most causes, probably because you can have fun as well as do some good, and now seems like as good a time as any to think some new sponsorship ideas. Anybody out there with a really fertile imagination?

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**DO-NUT MORNING**

Once again the Hardys of Haddenham are holding their World Famous Coffee and Do-nut Morning at 48, Churchway, Haddenham, Bucks - this time on Saturday 20th July. As usual the grounds of the Hardy home will be filled to overflowing with all sorts of interesting stalls, offering everything from books to plants to bric-a-brac to face painting.

On top of all this there is the coffee and the delicious doughnuts, which I understand are all hand-made by Jenny herself!

Do come along if you can for a good morning's fun and fundraising.

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**ITV TELETHON**

The 1990 Telethon has been fairly kind to our Society once again. At present we know of the following grants made by the various ITV Companies:-

Thames	£1500
Grampian	£250
Anglia	£500
Yorkshire	£550
Granada	£500
Central	£750

A grand total so far of over £4,000.00 - the majority of which is destined for Area Family work. Many thanks to the ITV Companies.

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FORWARD PLANNING - CONFERENCE 1993
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The Third International Symposium and Parent Conference for MPS is to take place in Essen, Germany on the Bank Holiday Weekend, Friday 28th May to Monday 31st May 1993.

Conference in Germany?

The options for the Society are to join in the parent conference at Essen or to have an annual conference in Britain in the usual way and to send a small delegation to Essen.

Both the German and the UK Committees need to make decisions about this before long, so that they can plan for accomodation and for voluntary helpers.

Accomodation and travel will be OK.

If we did go to Germany the plan would be for group travel by coach and hovercraft. Costs would be subsidised and overall costs to families would be about the same as for Manchester 1990.

A big decision would be whether to take a party of British voluntary helpers for outings etc.

Perhaps a visit to Disneyland?

Christine and Robin Lavery have just been to Germany to meet with the German organisers and are satisfied that it will be possible to make arrangements for accomodation and travel that will suit British families and children.

Disneyland will open at a site south of Paris in April 1992. We are toying with the idea of extending the German trip to take in a couple of days at Disneyland. What do you think of that?

Let us know what you think!

Christine will be sending a questionnaire to all families to sound out your views about what to do. Life with MPS is not predictable and you don't have to commit yourself either way. (I myself have trouble planning what I'm going to do next week). But do write back and say what you would prefer.

SAINSBURY'S are currently donating 1p to charity for every used carrier bag filled in their stores. As individual stores choose which charity to support, why not go along to your local Sainsbury's and suggest MPS as a worthy cause? Do remember to take an information sheet with you.

Supplies of posters, information sheets, annual reports etc, to be use for fundraising, available from Ron Snack. (see inside front cover).



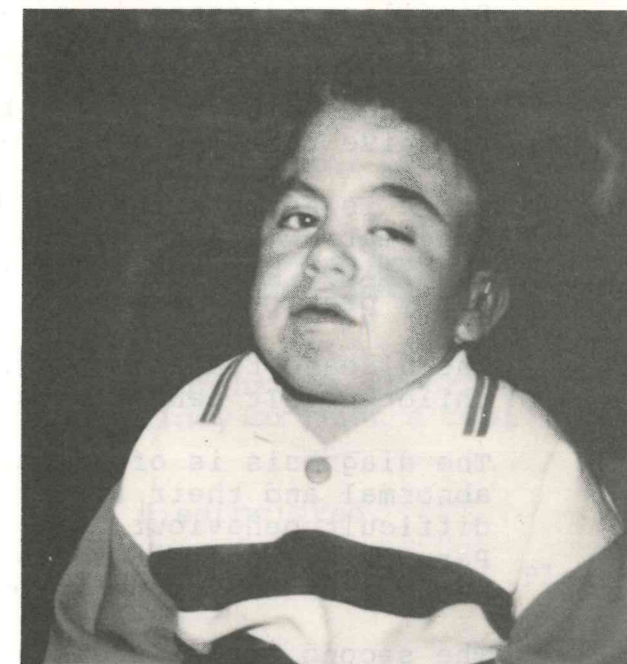
Ross Lockyer and friend



Christopher Shorthouse



Gareth Makepeace with mother Ann and sister Donna



William Holroyd





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**SANFILIPPO DISEASE**

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Also known as MPS III, Sanfilippo disease takes its name from an American doctor who described the condition in 1963. It is caused by the lack of an enzyme which is essential in the cutting up of used mucopolysaccharide called heparan sulphate enzyme. This leads to progressive storage of the mucopolysaccharide. Four different enzyme deficiencies have been found to cause the disease, so that it is divided into types A,B,C and D. However there is very little difference between the four types, although some very mild cases of type B have been reported. Incidence is very rare, the Society estimates that eighty six babies with Sanfillipo disease were born in Britain over a ten year period.

Sanfilippo disease is a recessive genetic condition. If both parents are carriers there is a one in four chance of each offspring being sufferers. There is a two in three chance of siblings being carriers, but unless they marry a close blood relative there is a minimal risk of passing on the disease.

There is no cure for any of the mucopolysaccharide diseases. Bone marrow transplant has produced disappointing results with Sanfilippo patients. For parents with an affected child early prenatal diagnosis of further pregnancies is possible.

The disease tends to progress at different rates in different children. It tends to have three main stages.

The diagnosis is often made late as the children do not look abnormal and their first symptoms, such as overactive and difficult behaviour, are very common in children generally. Parents are sometimes distressed by the child and the family being treated for behaviour problems.

The second stage is characterised by extremely active difficult behaviour. Sadly, language and understanding will gradually be lost. Some children never become toilet trained and others eventually lose this ability.

In the third phase children begin to slow down and gradually go off their feet. An average of their life span is about fourteen years though some have lived to be over thirty.

In contrast to other MPS diseases Sanfilippo sufferers grow to a fairly normal height and their appearance is more normal. They also have fewer medical problems until the late stages.

Many have frequent colds and blocked noses and this can lead to "glue ear"-- causing conductive deafness which needs careful management.

Many have bouts of severe diarrhoea. At a later stage a number will start to have frequent minor seizures.

There is not much that can be done to change the behaviour of the child, and help may best be concentrated on making life less uncomfortable through adaptations, extra help in the home and respite care.

Life with a Sanfilippo child sounds like a catalogue of difficulties, yet parents report that their children have delightful personalities and are very loving and loveable.

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The Society produces booklets on each of the MPS diseases. On joining members are supplied with copies of the relevant booklet. The above is a synopsis of the booklet on Sanfilippo disease.

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**STOP PRESS!**

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The booklet on Mucopolipidosis and MLII has just been printed and has been sent to the families concerned.

Copies of booklets are available from the MPS office at 50p each.

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**VIDEO CAMERA LOAN**

The Society now owns four video cameras. These are available for you to loan free of charge. We just ask you to pay the cost of returning the camera after you have finished with it

Have you got a special event planned? Why not have a record of it for ever. Your child's birthday, your Summer holiday or just a family day out.

Book the camera now so that you won't be disappointed.

The people listed below hold the cameras and request forms. Please contact them if you would like to use a camera.

- |   |   |
|---|---|
| 1. Mr A King.<br>4 New Park Ave.<br>Bexhill on Sea,<br>East Sussex TN401QR<br>Tel 0424 216432.  | 3. Mr. A Byrne.<br>3 Jedburgh Ave,<br>Rutherglen,<br>Glasgow. G73 3EN<br>Tel. 041 643 0034.     |
| 2. Mrs M Gardiner,<br>15 Sydney Ave,<br>Hesketh Bank,<br>Nr Preston. PR4 6S<br>Tel. 0772 815516 | 4 Mrs C Lavery.<br>7 Chessfield Park,<br>Little Chalfont,<br>Bucks. HP6 6RU<br>Tel. 0494 762789 |
- =====



## CHRONIC UPPER AIRWAY OBSTRUCTION

Chronic upper airway obstruction is a common problem in children with MPS disorders. It is important to recognize because:

- it interferes with sleep causing chronic fatigue, irritability, and restlessness
- it can cause heart failure if it persists for a long time
- it is treatable

**What causes chronic upper airway obstruction?** The upper airway is the nose, throat, and larynx (voice box). Chronic obstruction in children with MPS disorders results from distortion of the cartilage, over-production of thick mucus, thickening of the mucous membranes due to MPS accumulation, enlargement of the tongue, enlargement of the adenoids (relatives of the tonsils), decreased muscle tone in the upper throat, and in some cases muscle weakness due to compression of the spinal cord in the upper neck resulting from MPS accumulation in the membranes surrounding the spinal cord.

**How do you recognize it?** Almost all children with MPS disorders have some degree of chronic upper airway obstruction. It is one of the reasons they tend to breath through their mouth much of the time, make snorting sounds when they breath, and snore when they are asleep. The danger signs that indicate that the obstruction is more severe than usual and should be treated include:

- excessive sleepiness during the day (e.g. falling asleep during meals),
- periods of apnea (when a child stops breathing altogether for at least several seconds) during sleep,
- headaches,
- deterioration in behavior or school performance that is not due to MPS storage in the brain,
- deterioration in exercise tolerance, especially if it is accompanied by breathlessness and swelling of the ankles suggestive of heart failure.

**How is the problem diagnosed?** Since most children with MPS disorders have some degree of upper airway obstruction, it is often difficult to tell when it has become so severe that special treatment is indicated. A useful way to establish the severity of the obstruction is to determine whether the oxygen tension in the blood of the child falls significantly during sleep. There are different ways of determining this. One is simply to measure blood oxygen tension by ear oximetry for several hours at night while the child sleeps. Another more complicated but more reliable technique is to measure the breathing rate, heart rate, movements of the chest and abdomen, eye movements, EEG, and air flow at the nose, as well as oxygen tension in the blood. These tests are done in hospital by specialists in respiratory or airway problems.

Dear Charles,

I have been meaning to write for almost a year.

My son **Gareth** (a Hunter's syndrome sufferer) celebrated his twenty first birthday last May 13th and I thought you might like to see some of the photographs of a wonderful weekend of celebration.

### Surprise street party for Gareth's 21st!

The school that Gareth was still attending at that time gave a party for him on the Friday nearest his birthday. We had our own party on the following day and then our neighbours organised a surprise street party on the actual day of his birthday.

The response of all who joined us proved that Gareth is a very much loved person, something for which my husband Terry, daughter Donna and myself will always be very grateful. The photos I think speak for themselves.

### Even the firemen came!

None of us could have imagined the extent of the organisation that went to provide the surprise street party. Sunday morning dawned with marquees erected, houses decorated, and food prepared. The weather was perfect. A couple of local firemen called in with their engine and with a video camera to record the event. Cars tooted as they passed, double decker buses stopped for drivers and passengers to shout their good wishes.

I'm not sure how much of the celebrations were understood by Gareth, but the thought that so many worked so hard to make his birthday a success will be a memory never forgotten.

### Gareth's friends proved their loyalty.

Gareth does not enjoy good health these days and he suffers a lot from pain. When he was younger he was always a cheerful lively character, which made him long lasting friendships. These friends proved their loyalty last May.

I would like to say how much we enjoy reading the newsletter and hearing about other families with the same sort of problems. Many of our friends find interest in its articles too.

**Ann and Terry Makepeace**  
with Donna and Gareth  
315 Beaconview Rd  
Millersdale  
West Bromwich  
B71 3PU



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**How is it treated?** Several things can be done to decrease the degree of upper airway obstruction in children with MPS disorders, including:

- avoidance of known allergies (check with your pediatrician)
- aggressive treatment of colds and upper respiratory infections (fluids, acetaminophen, antibiotics, etc as prescribed)
- the use of saline drops and suction to clear mucus from the nose (saline in bottles and hand-operated suction devices can be bought in most drugstores)
- avoidance of sedatives and antihistaminics (which should only ever be used on the advice of your doctor)
- positioning on the side or stomach during sleep to allow the jaw and tongue to fall forward
- surgical removal of the adenoids
- oxygen by mask or by nasal prongs (only in selected cases)
- tracheostomy (generally reserved for children in danger of developing heart failure)

Drugs that work to relieve lower airway obstruction, such as Ventolin, are generally of no benefit in the treatment of upper airway obstruction. In some situations, they may even be dangerous. As a result of upper airway obstruction, children with MPS disorders present special problems during anaesthetics. General anaesthetics should be administered with care by a qualified anaesthetist aware of these problems. Remember to work closely with your pediatrician, ear-nose-throat specialist, and anaesthetist to determine what is best for your own child.

Prepared by Dr. J.T.R. Clarke, M.D., Ph.D., FRCP(C)

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Reproduced with acknowledgements to the New Zealand MPS/ML Society.

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IRISH CONFERENCE

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A conference for MPS families and families with other rare genetic diseases will be held in Limerick on the 29th and 30th of June. For details phone **Antoinette Fitzgerald** on (010) 353 61 398267, or write to her care of **Mrs Sheils, Altnavilla, Askeaton, Co. Limerick.**

Christine Lavery has been invited to speak and is looking forward to seeing many MPS friends.

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**Gareth Makepeace**

21st Birthday  
May 1990

at the first of  
three parties.



With his  
sister Donna  
and his Nan



Street party  
in full swing.



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**REFLECTIONS.....**

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Enclosed is a poem from a young mum who lives near me. Her little boy was diagnosed as having Sanfilippo about eighteen months ago and both she and her husband have trouble coming to terms with what has happened to their family. I know it must have taken a great deal of courage for her to write it and send it to me.

When I read it it reminded me not only of my own child but of the many children that I have been blessed to have known. They all seem to burst into our lives with such force that even when we no longer have them with us, the memories and impressions they leave behind keep us going even on the darkest days.

I know we all carry a heavy cross once we have been told it is MPS and we all have wished and prayed that it was some terrible mistake, but reality quickly hits us between the eyes and our tears start flowing as our hearts ache with the pain. But in all this hurt, emotion --- whatever name you give to the feelings deep inside that cry out for help --- there in the middle of this is a beautiful child. We thank God who gave him to us, our heart overflows and bang!, we find a love we never knew we had and the fight begins.

I feel this is what this mum is saying, it hurts so much because I love him so much. We can answer her and say, yes, I know what you mean.

I suppose in many ways it is this kind of love that drives us in the Society and it is this kind of love that keeps all the mums and dads out there going, against all odds.

Love

**Mary Gardiner**

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**DEADLINE for Summer Newsletter: First of August 1991.**  
(Otherwise newsletter will be delayed to Mid September).

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**Andrew**

Andrew is one on his own  
Special, unique and ours  
His love, his will, his courage  
Is to be admired.

He's three and full of beans  
He fills my heart with love  
My eyes with joy  
He's special, he's our Andrew.

He can be disruptive and strong  
He makes me cry and hurt  
He's naughty and determined  
He's boisterous and he's fun.

MPS makes me sad  
I hope days get brighter  
And hearts lighter from the ache within.  
He's special, he's our Andrew.

He's shown us so much love in three years  
He's funny, cheerful and loveable  
He's crafty, quick and cheeky  
He's just how a real boy should be.

We're learning so much and will carry on learning  
We're so proud of our son,  
More than anyone will ever know.  
He's special, he's our Andrew.

**Kim and Andy Parker**  
11 Frome Court  
South Wirral, L65 2HE

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**FOREIGN COINS**

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With holiday time not far away its time to remind you about your foreign coins and notes - the ones you put away last year in that little pot on the top shelf of the dresser, in case they might come in useful. They will come in very useful ... to the Society. The latest sale raised another twenty pounds. So send them to me or pass them on at any MPS event.

**Ken Ballard**  
15 Bengeworth Rd  
Harrow  
Middlesex HA1 3SF  
Ph 081 904 9876

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**COMMITTEE DECISION ON SMOKING**

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After much debate the Committee on 9th of February made a decision about smoking at MPS events.

There have been many recent programmes on TV and radio about the effects of 'passive smoking', especially on those who already have a breathing problem.

**Passive smoking is harmful**

The recommendation from the medical advisers, was very clear --- there is no doubt that breathing in other people's cigarette smoke has a serious harmful effect on people's health. It damages their lungs and contributes to heart and other problems. MPS children are particularly vulnerable.

**It is difficult for heavy smokers to abstain**

It was recognised that some parents use smoking as a way of coping with the severe stress of caring for MPS children and that conferences and other gatherings can bring additional stress. It was accepted in the circumstances that it would be very difficult for heavy smokers to abstain for long periods. On the other hand some parents had made representations about the harmful effects of smoking on their children. It has also become more accepted that there is a responsibility on organisations to protect people from the effects of smoke.

**The decision was:**

At MPS events there will be no smoking on any occasions when children are present.

There will be no smoking at Christmas parties, at conference sessions, or on coaches.

There will be no smoking at Committee meetings.

**The Committee**

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**The Society has a responsibility to protect vulnerable members**

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**HINTS AND TIPS**

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Many MPS children have excessive facial hair and this can be rather unattractive for girls, especially those around the age of puberty. I have come up with a solution that I use with Natasha which may be of help to other mums.

Natasha is now eleven and a half and during last summer I decided that the moustache which she was sporting was unattractive. I decided that if she was able and aware she would say, "Mummy, I hate looking like this, please do something about it."

**So I did and this is how you do it....**

- 1 Buy 'Immac' or 'Nair' for facial use. Place it, with a basin of warm water, a box of tissues, face cream and a digital clock by her wheelchair.
- 2 Put the child in her chair in front of her favourite TV or Video, and an unopened packet of jelly tots to divert her attention.
- 3 Very quickly and carefully put a thick coating of Immac on moustache and nose (not close to nostrils). Make sure she does not touch her face.
- 4 After four minutes, quickly wipe off with dry tissues and then with wet tissues until all gone. Dry her face, put on moisturiser and then open jelly tots as a reward!

I do this every two weeks. I like to think that Natasha says, "Thanks mum, that's better."

**Julie Macintyre**

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**HOME SPA**

Linda and I have a Home Spa Personal Whirlpool that Colin used to use in the bath, and we wondered if anyone could make use of it. This is a mat which lays on the bottom of the bath and is connected to a compressor unit on the wall and, in effect, turns a bath into a small jacuzzi.

If anyone would like this we do not want any money for it, but a donation to the Society would be appreciated - just give us a ring on Milton Keynes (0908) 666819.

Ron Snack



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**THE ART OF COFFEE MORNING**

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The art of a good coffee morning is to put in a lot of hard work before the event, so that it appears to be effortless on the day.

Last July we held our fifth event, and raised over £1000.

We started planning a year earlier - fixing the date and booking equipment and supplies. If the king of Spain had prepared as well for the Armada, we would all be speaking Spanish now!

We got short articles in the local papers, especially the free ones that go through every door. We put posters round the village, and distributed flyers to school friends, teachers, work colleagues and anyone we could think of. We got a slot on Radio Oxford. We put a large board on the front of the house.

Local shops were approached for raffle prizes, friends and neighbours were recruited to run stalls. Some like the same stall every year, others like a change.

For the past three years we have offered doughnuts with our coffee, so this time we wrote to five local bakers around Easter time. Three of them agreed to provide us with a total of two hundred and twenty of their stickiest jammiest doughnuts.

On the Thursday beforehand Jenny did the pricing up with three of her friends. With 'bric-a-brac' four heads are much better than one in deciding what the market will bear!

The coffee morning was for publicity as much as for selling, so we made up three information boards with MPS posters, photographs and newspaper cuttings. Many people are keen to know about the diseases and the Society but are inhibited about asking questions. They can learn a lot from the display boards.

On Saturday morning we were all up bright and early, erecting tables and chairs and collecting the doughnuts. The helpers arrived by nine o'clock and by ten we had everything ready.

Jenny and I spent the next two hours greeting people, talking with those we had not seen since last year and making anyone we did not recognise feel welcome. Only if you are very well organised are you able to do this. The first year we found ourselves going round like scalded cats and unable to play our role as hosts.

We were blessed with over two hundred visitors. Some came simply to make a donation. By half past twelve it was all over - nearly. We thanked the helpers and gave them a small present each. We counted all the money, keeping a record of each stall's takings.

Later we wrote thank you letters to suppliers of raffle prizes and doughnuts and to those who sent donations. Finally two weeks later a further £30 was raised through selling surplus stock at a car boot sale.

This year our coffee morning will be on July 13th. We have decided we should have two tea urns and more raffle tickets. Our coffee mornings go with a swing and we think our visitors find them as worthwhile as we do - but only because of all the work beforehand.

**Andy and Jenny Hardy**

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**COFFEE MORNING CHECKLIST**

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**Plan**

Date, timetable for publicity and preparation and recruiting help.

**Borrow**

Tables, Chairs, Crockery, Tea Urns, Tombola drum, Small Change.

**Beg**

Prizes, Food (Doughnuts), Bottles of Wine, Chocolates.

**Buy**

Raffle tickets. Coffee!

**Publicize**

Local papers, Local Radio, Invitations to friends, schools, work colleagues, telephone ring round, posters and billboards.

**Stalls**

Books, cakes, toys, childrens clothing, plants, games, white elephant, information.

**Allocate**

Stallholders, raffle sellers, gatekeeper, photographer, treasurer.

**Record**

Names, addresses and phone numbers of donators and helpers. All money in and out.

**Andy and Jenny Hardy**

48 Churchway,  
Haddenham, Bucks. HP17 8HA  
Ph 0844 291173

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**ANGELA LOSES HER BOTTLE!**

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(But you can send her one of yours)

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I wonder if Newsletter readers might be amused by this story.

Many of you will remember me from MPS Conferences as the nuisance who was continuously pestering you for urine samples from your children. Well, nothing has changed and a few months ago Christine Lavery kindly agreed to ask families in the South West of England to collect as much urine as they could over a 24 hour period and send it to me by post. When I received the following note (enclosed) from our local Royal Mail sorting office one morning, it didn't take much to guess what this "liquid" might be and I thought I had better go and claim it before it walked out on its own!

I arrived at the sorting office to find my "container" sitting on top of a filing cabinet, still well wrapped in brown paper, but in a large puddle. The staff there assured me that it wasn't whisky (they could tell by the smell, they said) but fortunately they didn't appear to have any idea as to its true identity, so I decided not to enlighten them - not everybody understands this preoccupation I seem to have with children's urine! I did however get the impression that they were rather relieved to see the back of both me and my parcel.

On a rather more serious note, if any families in the South West of England or South Wales feel that they could collect approximately half a litre of urine from their MPS child and take it to the Chemical Pathology department at their local hospital, I should be most grateful. The urine should be collected in a clean bottle, labelled with the child's name, date of birth and diagnosis and taken to the laboratory as soon as possible, asking the laboratory staff to freeze the urine and to get in touch with me regarding transport. If any families from Avon who would be prepared to collect urine from their child would like to get in touch with me direct, I will willingly come and collect it from their house.

My reason for asking for your help in this way is that over the past four years, Dr Charles Pennock and myself have been sending MPS urines to laboratories in hospitals throughout Great Britain as a check of their ability to diagnose MPS correctly and quickly. We are hoping that in the light of our published findings, those laboratories currently using the poorer diagnostic tests will change to the more reliable ones, thus making fewer errors. Obviously we need large quantities of urine to distribute, because at present we have thirty-six participants in our scheme and we are hoping that even more laboratories will join, so this is where you come in - all contributions gratefully received! I can be contacted at:

Angela Brimble.

Tel: (0272) 285319

Department of Chemical Pathology  
Bristol Maternity Hospital  
Southwell Street  
Bristol BS2 8EG



# REACT NEWS

Research, Education & Aid for Children with potentially Terminal illness.

## IMPROVING THE QUALITY OF LIFE FOR CHILDREN SUFFERING FROM LIFE-THREATENING ILLNESS

There are many thousands of families in the community caring for a child, or children, with a life-threatening illness. The Institute of Child Health estimates there could be up to 20,000 such families nationwide.

REACT was founded early in 1990 to promote research and education in the field of life-threatening illness as it affects children; to give specific help to children who suffer from a potentially terminal illness, and their families; and, most importantly, to improve the quality of life for these children.

During the time since the charity came into being, REACT has been delighted by the generosity of so many private individuals and organisations who have

made donations of money and services.

The objectives of the charity are being realised in the number of grants REACT has been able to make to sick children and their families; in sponsoring the first Conference on the Care of Children with Life-Threatening Conditions, and their families; and funding a Child Clinical Psychologist based at St Mary's Hospital, London.

An important feature of REACT is its ability to meet needs that often cannot be covered by the NHS or local authorities. Requests have come through many of the caring agencies: from the four children's hospices for respite care; hospitals; children's homes;

local authorities; societies for specific children's illnesses such as mucopolysaccharide and metabolic diseases. Specific requests have also been received for children infected with the HIV/Aids virus.

REACT is able to act with minimum delay and has already supplied electric wheelchairs, electrically operated beds, special drugs, laundry equipment, heating oil, clothing, toys and also, sadly, has met funeral expenses in a number of cases of financial need.

As the charity becomes more widely known, REACT will be allocating more grants and hoping for the continued support of existing donors, and the on-going support of new donors.

React, 73 Whitehall Park Road, London W4 3NB. Telephone 081-995 8188 Telefax 081-742 1867.

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### IN MEMORY

We would like to thank everyone who has made donations to the Society in memory of David Criddle, Geoff Butt, Mrs E H Dickinson (James Fisher's Grandmother), Mrs Dennison (Paul Bean's Grandmother), Timothy Bryans, Mrs Howard (a friend of Colin Snack), Thomas Beavan and Gethin Robins.

Thanks are also due for donations recieved in lieu of Silver Wedding presents for Ann Fraser, in lieu of 80th Birthday presents for Mrs Lee of Tunbridge Wells, to Abbey National staff - in lieu of Christmas Cards and to Liz Pace, a friend of Colin Snack - in lieu of a leaving present from her workmates.



Apologies to the Temmink family of Belgium and to Hoffman family of Germany for the wrong name on the photograph, page 20 in the previous newsletter.

**MIND YOUR BACKS!**

How to keep a child comfortable and secure and how to avoid back strain in lifting is a constant problem for parents of MPS children.

Helen is in a whole body cast after major surgery. It is essential that awkward movements are avoided. In the first weeks she was very sore.

Luckily her school loaned us a "Tran-Sit Seat," which they had for emergency evacuation of their disabled pupils. Helen sits in the Tran-Sit seat for school and two teachers lift her from car to wheelchair to desk as needed. She feels safe and she is not banged about, as can so easily happen. The school staff feel comfortable carrying her this way.

At home one of us can manage to carry her in the Tran-Sit. It would be very difficult without it.

The next page gives information about the Tran-Sit which may be of interest to other MPS families. Don't forget to consult with the occupational therapist from school or social services department about ordering aids.

**Charles O'Toole**

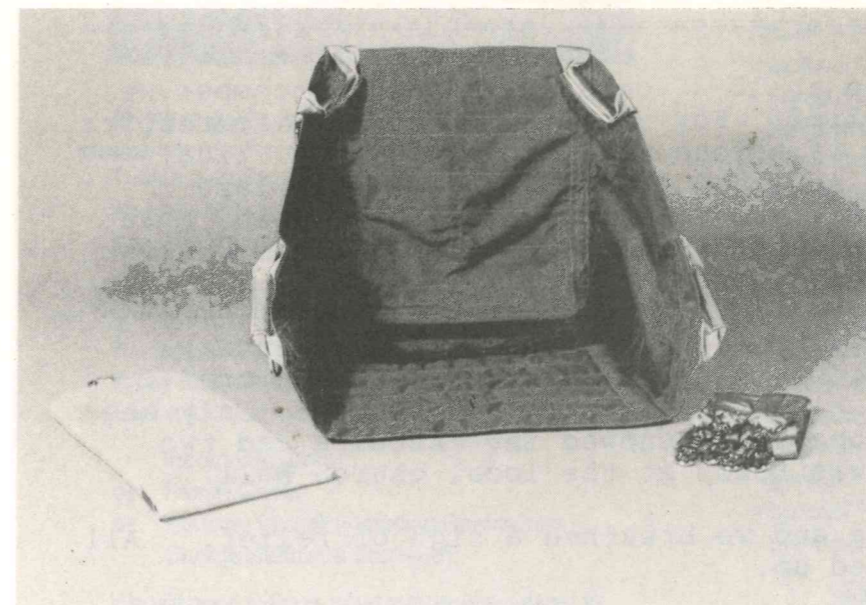
**Christine Lavery  
Mary Gardiner**

Powering into  
action at UMIST.



**Trans-sit Seat**

Ellis Son & Paramore Ltd.  
Spring Street Works, Sheffield S3 8PB  
Tel: (0742) 738921 Telex: 547232  
Fax: 0742-754864



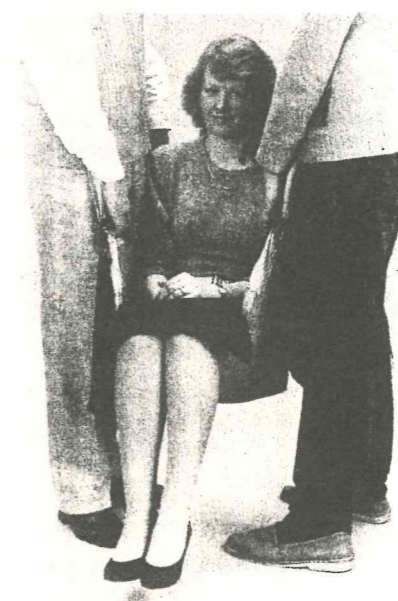
Trans-sit seat shown with nylon cover and shoulder straps.

**Construction**

Double thickness, hardwearing, waterproof polyester in blue. Large comfortable reinforced handles at four corners. Polythene stiffeners to maintain its shape after use. Sturdy nylon lap strap with quick release buckle. Six drainage holes for shower/pool use.

**Features**

- Carrying capacity tested to 108kg (17 stone)
- Totally washable construction
- Quick release lap strap
- Four handles for side lift
- Four additional loops for front and back lift
- Complete with two shoulder straps to take the strain during prolonged lifts
- Drainage holes for use in therapy pools
- Location points for attaching to the various patient hoists available
- The user is automatically tilted slightly backwards into the seat giving a feeling of security
- Complete with storage bag which will attach to a wheelchair or hang from a convenient place.



Side lift using shoulder straps.

**Applications**

**Stairs**

Two helpers may transport a third person down flights of stairs with no unsafe or embarrassing contact.

**Pools**

The material has been proofed against chemical attack and tested in hydrotherapy pools. Drainage holes in the seat allow excess water to quickly drain away therefore reducing the load on any hoist or helpers when lifting the disabled person from a pool.

**Showers**

A patient may be lifted from a wheelchair or bed in the seat and placed on a suitable chair within a shower. The construction of the Trans-sit will not be affected by constant immersion in water or contact with soaps.

**Emergency**

In an emergency situation a severely handicapped person may be evacuated from a ward or lounge by two able bodied helpers. The folded unit may be stored near the bed or on the wall of a ward to speed evacuation in the case of fire for example.



**Aircraft**

A disabled person may be transferred from their wheelchair at the door of the aircraft and carried to their seat in the Trans-sit. They may spend the entire flight in the Trans-sit and they can be transferred back to their waiting wheelchair.

**Wheelchairs**

The Trans-sit may be attached to a wheelchair ready for immediate use. It is lightweight, weather proof and unobtrusive making it the ideal method of transferring a patient from the wheelchair to some other form of seating without the need for unnecessary "manual handling."

DIMENSIONS		
Ref No.	TE 15	TE 18
Size	Large	Small
To suit	Medium and large adults	Small adults and children
Height	47cm	39cm
Width	38cm	33cm
Depth	38cm	33cm



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**CHRISTMAS PARTY AT RETFORD**

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When the party started at 12.30 on Sunday 9th of December we breathed a sigh of relief. For the previous twenty four hours we had been wondering if anyone would turn up. On Friday morning it started to snow and it didn't stop until late Saturday morning. Power and telephone lines went down, roads were blocked and shops were closed. Luckily we could get some last minute food shopping done.

By Saturday night local roads were passable and on Sunday morning the sun was slowly thawing the snow, much to the disappointment of the kids. Panic was kept at bay. Only one family phoned to say they were snowed in. After a mad two hour rush everything was ready at the local church hall.

Cars started to arrive and we breathed a sigh of relief. All but two families turned up.

Two of my workmates (twins) had been talked into arranging games for the kids. One came dressed as Mickey Mouse, the other as a parrot. Funnily enough all the kids won prizes. Santa arrived to hand out presents and pose for photos. As the power was still off we then had carols by candlelight.

The adult entertainment consisted of sweeping up the hall by candlelight and loading the remains into cars on a dark rainy night. We arrived home tired but happy and we felt everyone had enjoyed themselves.

See you at the Conference, where I'm sure you will take plenty of the 1991 draw tickets to sell!

**David Briggs**  
 7 Humber Street  
 Retford, Notts. DN22 6LZ  
 Ph. 0777 700046

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**CHRISTMAS DRAW**

I am very pleased to be able to report that the 1990 MPS Christmas Draw raised around £6,500.00 - a magnificent amount.

I would like to publicly thank David and Monica Briggs for all the hard work that went into arranging last years Draw, and wish them luck for the 1991 Draw, which I know David has already started work on. More power to your elbows folks.

Ron Snack

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**Help with the cost of a funeral**

***If you are on a low income***

If you are having problems with the cost of a funeral, the Social Fund may be able to help you. The Social Fund is part of Social Security.

**Who can get help?**

You may get help if there is not enough money to pay for the funeral, if you are responsible for paying for it, and you or your partner are getting:

- Income Support,
- or Family Credit,
- or Housing Benefit (including Community Charge Rebate in Scotland).

We will need to know what money is available to you from:

- the estate of the deceased. (An estate is the money, property and other valuables owned by the person who has died.) A house or personal things that are left to a widow, or personal things left to relatives will not be counted as part of the estate,
- any insurance policies or charities, or relatives (either yours or those of the person who has died),
- any savings you have over £500. Savings include money in a bank, a building society, Post Office, National Savings Certificates, Premium Bonds or in cash at home. The savings may be in your name or the name of your partner. The Widow's Payment of £1000 (see page 7) does not count as savings.

**What you can get help with**

The Social Fund will help towards the cost of a simple funeral within the United Kingdom, including:

- bringing the body home within the United Kingdom if the person died away from home
- travel to arrange the funeral or go to the funeral (one return journey only)
- the death certificate
- an ordinary coffin
- a car for the coffin and bearers, and one other car
- flowers from you
- fees for the undertaker, chaplain and organist for a simple funeral
- cemetery or crematorium fees for a simple funeral
- up to £75 extra costs because of the religion of the person who has died.



*If you are having problems with the cost of a funeral the Social Fund may be able to help you.*

You must claim within three months of the date of the funeral.

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**FUNERAL COSTS**

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The Co-operative Funeral Society have special arrangements to assist with the costs of funerals of children under sixteen. They can be found in your local "Yellow Pages". Further details can be obtained from Linda at the office.

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## FUNDRAISING EVENTS

Once again I would like to thank everyone who has arranged or participated in, or given money to any of our fundraising events this time round.

Sid Shiff & Family, Liverpool  
 Winnie Larkin & Friends, Ireland  
 Linda & Ron Snack & Friends, MK  
 Abbey National Canteen, MK  
 Clive & Gavin Evans, W.Mids  
 B & K Houston, Ireland  
 The Gooch Family, Tunbridge Wells  
 Connahs Quay High School  
 R & L Burgess, Luton  
 Meads School, Luton  
 Monkhouse Sports, Cheadle  
 Croft House Nursery, Bolton  
 June Gilford, Nantwich  
 131st Boys Brigade, Glasgow  
 Flo Carrick, Stonelaw, Glasgow  
 Marshalls Chunky Chickens, Glasgow  
 Stonelaw High School, Glasgow  
 Mrs Todd, Glasgow  
 Andrew Hastie, Glasgow  
 Stonelaw High School PTA, Glasgow  
 Heather Young & Friends, Glasgow  
 Forresters Organisation, Glasgow  
 Quantock WI, Somerset  
 D Williamson, Cheshire  
 Pam Croghan, Stockport  
 Pam Croghan's Parents  
 Linda & Ron Snack, MK  
 B Ingham, Ireland  
 Mrs Soden, Warwicks  
 Post Office, Burbage, Leics  
 Crowborough Evening Townswomens Guild  
 Barthomley Mummers, Cheshire  
 Mr Wise, Erith, Kent  
 Tim Rose, London  
 Trull School of Dancing  
 Clive Motor Cycle Club  
 St Andrews Church  
 Mr R Weeks  
 F A Sandow  
 K K Basra  
 W & F Pidden  
 DA Crew, Wokingham  
 College of Estate Management  
 Chesham High School, Bucks, Class 4iv  
 J & K Lawrie  
 Marie Miller  
 Turks Head, Retford  
 Threshers, Retford

Collecting Tins  
 Sponsored Slim  
 Flag Day  
 Collecting Box  
 Walking the Pennine Way  
 Race Night  
 Various FR Events  
 Collection  
 Collecting Box  
 Carol Singing  
 Collecting Box  
 Raffle  
 Mince Pie Day & Raffle  
 Various FR Events  
 Sale of Shortbread  
 Raffles  
 Sponsored Swim  
 Collecting Box  
 Glasgow Half Marathon  
 Raffle  
 Disco  
 Various FR Events  
 Carol Service  
 Sponsored Walk  
 Car Boot Sale  
 Collecting Box  
 50/50 Raffle  
 Collecting Box  
 Collecting Box  
 Collecting Box  
 Small Change Collection  
 Mummers Play  
 Collecting Box  
 Sponsored to Stop Smoking  
 Dancing Displays  
 Raised  
 Christmas Fair  
 Collecting Box  
 Sale of Stamps  
 Raffle  
 Raised  
 Carol Singing  
 Pre Xmas Celebrations  
 FR Activities  
 Sale of Webb Ivory items  
 Diet Correction classes  
 Collecting Box  
 Collecting Box

## AREA SUPPORT FAMILIES

**Neil and Jane Reid**  
 19 Hillside, Sawston, Cambs, CB2 4BL  
 Tel: 0223 834570

**Alan and Deirdre Beavan**  
 'Tumbleweed', West Gate Lane, Lubenham,  
 Market Harborough, Leics. LE16 9TS  
 Tel: 0858 62182

**Mary Gardiner**  
 15 Sidney Avenue, Hesketh Bank,  
 Nr Preston, Lancs. Tel: 0772 815516

**John and Barbara Arrowsmith**  
 140 Newtown Rd, High Heaton, Newcastle on Tyne, NE7 7NH  
 Tel: 091 2812062

**Sean and Pauline Mahon**  
 41 Stumperlowe Crescent Rd,  
 Sheffield 10, South Yorkshire  
 Tel: 0742 304069

**Alfred and Judy King**  
 4 New Park Avenue, Bexhill-on-Sea,  
 East Sussex TN40 1QR  
 Tel: 0424 216432

**Bill and Sylvia Blackburn**  
 11 Beatty Rd, Nantwich, Cheshire  
 Tel: 0270 626809

**Ron and Linda Snack**  
 16 Wandsworth Place, Bradwell Common,  
 Milton Keynes, Bucks.  
 Tel: 0908 666819

**Tony and Mary Lockyer**  
 29 Llanberis Close  
 Tonteg, Pontypridd, Mid Glamorgan.  
 Tel: 0443 203845

**Tony and Shirley Eyre,**  
 6 Westway Park, Yatton, Nr Bristol, Avon.  
 Tel: 0934 834537

## Area Family for Northern Ireland:-

**Margaret Kearney**  
 12 Coleraine Rd, Ballycastle, Co. Antrim  
 Tel: 026 57 62073

## Contact for Scottish Families:-

**Alan and Fiona Byrne**  
 3 Jedburgh Ave, Rutherglen, Glasgow G73 3EN  
 Tel: 041 643 0034