

NEWSLETTER

SPRING 1990

**THE SOCIETY FOR
MUCOPOLYSACCHARIDE
DISEASES**



National Registered Charity No. 287034

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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

30 Westwood Drive, Little Chalfont, Buckinghamshire.
Telephone: (024 04) 2789

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 and New Zealand.

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"

DATES FOR YOUR DIARY

23rd June	Area Family Day - Northern Ireland
29th June	Newsletter deadline
7th July	Family Barbeque chez Butler.
14th July	Coffee Morning chez Hardy.
31st August	Conference UMIST

NEW FAMILIES

Mr and Mrs Morley from Bath whose three year old son Edward is suffering from Sanfillippo Disease.

Zeida Dickson from Ormskirk, Lancs. whose two year old son Shane has been diagnosed as suffering from Hunter Disease.

Winferd and Sue Rees, from Swansea, Mid Glamorgan, whose three year old son Christopher has been diagnosed as suffering from MLIII.

Lorraine and Kevin Harper, from Crawley, West Sussex, whose daughter Natalie, born on the 10th May 1989 has been diagnosed as suffering from Hurler Disease.

Susan and Stewart Graham, from Dumfries and Galloway, Scotland, whose two daughters Kerry aged three years and one year old baby Laura have been diagnosed as suffering from Sanfilippo disease.

Brian and Angela Flint from Doncaster whose fifteen month old son Greg has been diagnosed as suffering from Hurler Disease.

NEW BIRTHS

Warmest congratulations and best wishes to Lesley and Paul Harvey of Cheyne Cottage, Fox Lane, Boars Hill, Oxford on the birth of a healthy baby son, Nicholas, on 22nd January, weighing 7lbs 15oz. A brother for Mark, Ian and Stephen who suffer from Sanfilippo Disease.

Congratulations and best wishes to Gordon and Ann Hill and their daughters Louise, Sally and Jenny on the birth of their new baby Kirsten born on the 2nd of January 1990

DEATHS

Bilal Iqbal from South East London died in December 1989 aged nine. He suffered from Sanfilippo Disease. Our thoughts are with his sorrowing parents, sister and brothers.

Michael Capobianco, eldest son of Marie Capobianco, President of the American MPS Society died on the 9th of April. He suffered from Sanfilippo disease. Our profound sympathy to his parents and family.

Iain Ireland died in January 1990 aged eighteen years. He suffered from Hunter Disease. Our thoughts are with his parents and family.

EDITOR'S MESSAGE

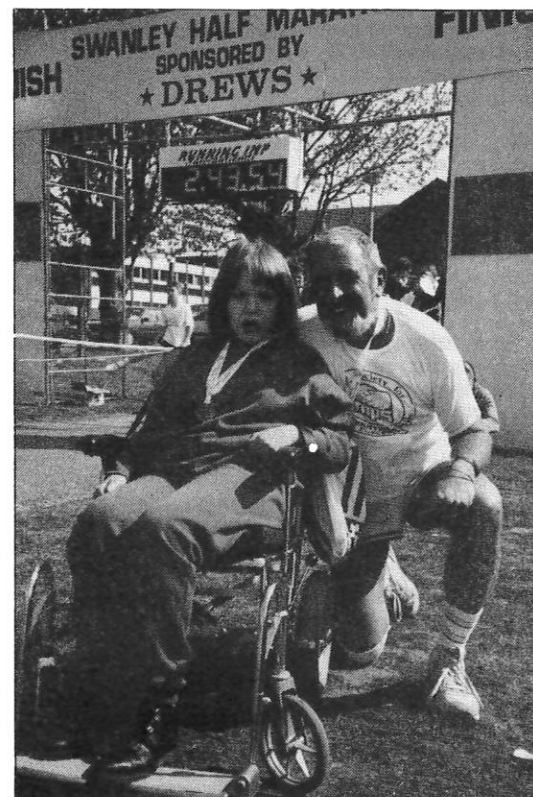
Keep those letters and articles and reports and cuttings flowing in. People like family stories. They also like hints and tips but also your thoughts, views and feelings about anything whatever. We haven't had any poetry lately. If you know someone who has something interesting, amusing, informative to say do ask them to write it.

If you have newspaper cuttings please send me the originals if possible. Please dont use staples or paper clips. They drive the printer wild! Photographs need to be bright and clear. They will be returned. Any queries or problems about the newsletter please get in touch.

The deadline for the next newsletter is Friday 29th of June, and Christine I definitely mean it this time.

About that 1989 conference report yes it is coming.

Please note the new London phone code for the O'Toole family.



RUNNING VESTS

As Spring approaches and with it the Marathon season please note that I have running vests that are free of charge to anyone taking part in Marathons, Fun runs, etc. Please let me know the name and address of the runner and the event and I will send them a vest. Medium and Large sizes.

Susan Butler

Lisa Nurse with

Mr T.Hurdle who raised £108 at the Swanley Half Marathon 1st April 1990

EMBRYO RESEARCH - A MORAL ISSUE

The article that appeared in the Winter issue of the MPS Newsletter probably heightened your awareness of the Embryo Research issue.

The Human Fertilization and Embryology Bill has now left The House of Lords and is now in the House of Commons. I was very privileged to be present for the debate in the Lords on February 8 and to listen to the arguments both for and against, allowing pre-embryo research. As you will most likely have heard the vote was substantial, 246-80, in favour of allowing pre-embryo research to continue. The Archbishop of York made an eloquent speech in favour on moral and ethical grounds as did Lord Walton, an acknowledged Scientist in the field.

On February 7 about 200 families including 10 MPS families gathered at Westminster Methodist Hall, to affirm their belief that pre-embryo research should continue under strict control of the licensing authority. After interviews with the press over a sandwich lunch we all walked to Westminster Hall lead by Tory MP Emma Nicholson, Labour Lord, Lord Carter and Billy Burlison one of our Hunter boys.

Emma Nicholson has overcome severe deafness to represent her constituency of Devon West and Torridge. Lord Carter and his wife Ann have seen their only teenage son die from a rare genetic disease and their only daughter is completely blind as a result of this condition. Both Emma Nicholson and Lord Carter support pre-embryo research and believe that the right to make decisions which determine the future family life of parents who are carriers of or who suffer from genetic disease, belongs to the individual parents involved and to them only.

It is unprecedented that our lobby should be given Westminster Hall, and we are grateful to the authority's that they laid on heating and chairs. This venue also meant that we were able to lobby both MP's and Peers. Well over 30 MP's and a number of Peers came, many addressing those present. The Duke of Norfolk who introduced the alternative clause 11 "to prohibit pre-embryo research" very bravely gave his views but these were not shared by the families attending the lobby, and they didn't shy from telling him so.

The passage of the Bill through the House of Commons is likely to be far more stormy and a current head count shows that the voting is level pegging with 132 MP's not having decided how they will vote. It is absolutely vital that you let your MP know how important pre-embryo research is to your family. The Society appreciates that a small number of our members are not in favour of pre-embryo research on ethical or moral grounds. This we understand and whether pre-embryo research is prohibited or allowed to continue, the Society will continue to fight for an improvement in resources, allowances and understanding of people suffering from or at risk of genetic disease.

I would be pleased to hear from anyone wanting more information on this issue. If you want to know the view of your MP before writing to him/her let me know.

Christine Lavery

The Embryo Research and Human Fertilization Bill

Following a busy few months continually lobbying and briefing members of the House of Lords and members of Parliament, on Monday 23rd of April our work was rewarded when MP's voted by a two to one majority to allow embryo research up to fourteen days under the control of a statutory licencing authority.

At the committee state members of the "Pro-Life" lobby introduced ten amendments to the Embryo Research and Human Fertilization Bill. For reasons of parliamentary procedure this led to a "pendulum vote" on time limits and restrictions for abortions. A heated debate followed and finally MPs voted by three to one in favour of lowering the time limits on abortion to twenty four weeks.

In the case of severe foetal handicap or where the mother's life is in danger no upper time limit was set.

Life is precious to MPS families, because we, of all people, know how fragile and vulnerable it is, and how bitter it is to lose our children.

No one can feel happy about abortion, least of all the women who ask for it. However the management committee has always taken the view that families should not be prevented from considering this option if they feel the alternatives are unbearable. Equally we respect the views of those feel they cannot consider abortion. We hope that Embryo Research (also controversial) will improve the alternatives available and in time reduce the need to consider abortion.

Christine Lavery

YOU SHALL BE JUDGED BY LOVE

Do not be influenced by what people generally count as valuable or successful or as an achievement. That person is successful who causes happiness and a reflection of God's love in those he touches. If a person never accumulates money or even has no recognisable accomplishment of any kind in life, yet if that person provides happiness and fosters growth spiritually in those about, bringing pleasure into the lives of others and ease in communications, then that person has succeeded at the level of the soul. There are those who will develop talents and abilities recognisable to others yet not a shred of evidence of that accomplishment will be found in Heaven. For it is not what men recognise as accomplishment that is recorded here or set down as achievement. But the one who causes the son or daughter, the husband, the wife, the neighbour, to have a little more light, a little more pleasure, love, energy, happiness with which to accomplish his day to day living - he has lifted himself and humanity a little closer to God.

DON'T LET IT BE SAID THAT YOU MISSED "UMIST!"

Over one hundred families from all over the world have now booked for the Second International MPS Conference at UMIST, Manchester from Friday 31st August to Monday 3rd of September. Medical experts and other professionals have shown enormous interest. Some are now pleading desperately to be found a space to give their papers!

There are still some places for families; there is ample space in the University (somewhat spartan) and limited hotel places. The Society has been very successful in finding funding for those families who needed help towards cost of travel and accomodation. Do not hold back because you cannot afford it. If you need help with costs send a letter with your application form setting out your family income and committments so that the Society can approach grant giving bodies. The information will be treated in complete confidence. Many members of the Society are struggling to make ends meet. We are determined they should not miss out on activities on that account.

UMIST SALES

As we enter the 1990's, we are having a wonderful start by organising an International Symposium. Many of you have already expressed a wish to come. Consequently it has been decided thaw we would introduce the following new sales items:-

1. An MPS tie in either navy blue or maroon, with a small all over motif of the MPS Logo, in silver grey. These will be £6.50 each.
2. A lapel pin made out of chrome, again in the shape of the MPS logo, it will have a stick pin on the back for the men, and a clutch for the ladies. Costing approximately £1.65 each.
3. Tea Towel's in green upon white, these will have the design of sunflowers, signifying our sunny children, Alex's idea.

The Tea Towels will cost £1.99 each, and I hope that all families will have at least one. We are hoping to sell 400, and I am sure many of you will buy more than one. It's something every household uses daily.

The above sales items will have their debut at UMIST. But they can be ordered by phoning or writing to me after June 1st. Remember my phone number changed on February 28th to 0494 483185. I have not moved house.

Could you please send money with application.

The following items will be on sale as usual, with no increase in price:-

Multicoloured pens	25p each	
Pencils with rubbers	20p each	
Key Fobs	50p each	
Book Marks	60p each	Susan Butler

SWEATSHIRTS

It has been decided not to have a specially designed sweatshirt for this year. Instead we are having the logo modified by removing the outer rings on our original sweatshirts, and printing International Symposium, Manchester, England 1990 underneath.

There will be the same range of colours royal blue, pink, yellow, burgundy, red, black and white.

The UMIST logo sweatshirt will only be available by ordering them from me on the enclosed order form, for both regular logo and UMIST logo sweatshirts.

NB. There will not be any UMIST sweatshirts on sale at the Conference. There will however, be a limited supply of regular sweatshirts. Sweatshirts ordered and paid for before the Conference can be collected at the Conference, to avoid postage charges. The final date for orders is July 1st 1990.

The prices for sweatshirts this year are:-

XXL	£10.50
XL, Large & Medium	£ 9.50
Childrens 24" - 32"	£ 7.50

Mrs Susan Butler
Spriggs Holly House
Spriggs Holly lane
Chinnor Hill
Oxon OX9 4BY
Tel: 0494 483185

ORDER EARLY DON'T BE DISAPPOINTED FROM:-

The Children in Need Appeal has contributed £8,500 towards the cost of the children's activities at UMIST. Families who have been involved in fundraising for them will be pleased to hear this.

The Prince's Trust has granted £1000 towards the costs of the Volunteers at UMIST. Good on you Charlie!

A grant of £600 has been given towards the cost of the Family Barbeque at UMIST.

Congratulations to Christine, Ron and all fundraisers for their tremendous work.

Andrew and Vivienne Culley from near Bristol will be attending the Austrian/South German conference at Pertisau from the 4th to the 6th of May. We look forward your report for the next newsletter.

CALLING ALL TEACHERS

The Society has recently received a letter from Mrs P.A. Bradford, 3 Cressey Court, Chatham, Kent ME4 6TW. Mrs Bradford has for some time been the teacher of one of our Hunter boys, and would very much like contact with other teachers of Hunter boys. If you feel you would like to discuss and compare notes with Mrs Bradford, why don't you drop her a line.

SALES ORDER FORM

NAME.....

ADDRESS.....

.....TEL: NO.....

SWEATSHIRTS - please indicate whether you want UMIST sweatshirt or Regular Sweatshirt

SIZE	COLOUR	NUMBER	PRICE	TOTAL
.....
.....
.....
.....

Please include 60p per shirt if you wish me to post to you, otherwise I shall take them to UMIST.

ITEM	PRICE	NUMBER	TOTAL
Pens	25p each
Pencils	20p each
Key Fobs	50p each
Book Marks	60p each

AREA FAMILY PROFILE

We are the Eyre family, the new support family for the South West. We consist of myself Tony, Shirley who is the mother of our two children, Sam who is five and has Hurler Disease and Carly who is normal. Carly is nearly two years old.

We live in a large village on the outskirts of Bristol and we enjoy the country life, especially the country pubs (children's room only).

I am employed by a national telephone company, Shirley looks after the home and the children. Sam goes to school full time and Carly just makes work.

Like most MPS families we don't have much time for hobbies although I have been known to splash oil paint on canvas sometimes. We both enjoy travelling both in Britain and abroad. Most of the past two years has been taken up extending our home to give Sam more freedom. We seem to be very competent with a trowel and cement.

We first contacted the Society as soon as Sam was diagnosed and we attended our first conference soon afterwards. We were very apprehensive at first but soon found that we received a wonderful amount of support and friendship from everyone.

We would now like to offer our friendship and knowledge to other families. We hope we can match the support that David and Michelle Brooks-Daw gave as an Area Family to the South West.

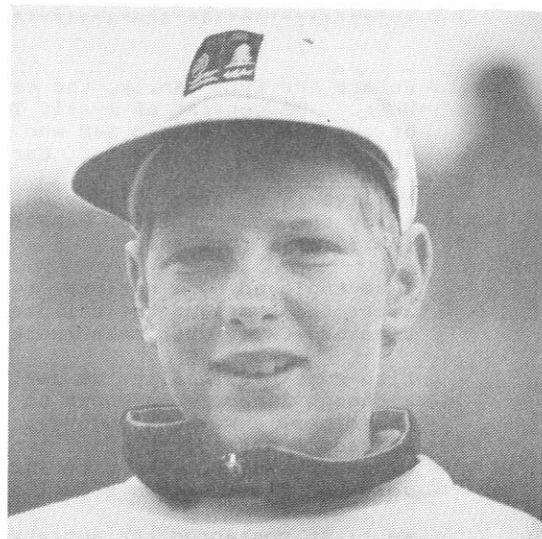
Tony and Shirley Eyre
 6 Westway Park
 Yatton, Nr Bristol,
 Avon. Tel. 0934 834537

AN ODE FOR A NIGHT BIRD

I thought as my Mum is always on a diet,
 I had an idea and I wanted to try it,
 If I got mumps all through the night,
 The calories she'd burn off would suit her just right.

I constantly woke her all the time it was dark,
 I thought she would find it a bit of a lark,
 Then why, if exercise is a jolly good aid,
 Was my mummy's temper exceedingly frayed?

Julie Macintyre



WALKING THE PENNINE WAY

The Walk: The Pennine Way, from Kirk Yetholm in the Cheviots to Edale in the Peak District. (approx 250 miles)

The Time: Between 14th and 28th of July 1990

The Walkers: **Clive Evans and his son Gavin**, aged sixteen.

Clive works with Monty Russell, father of Matthew, aged 5½, who has Hurler Disease. He is aged forty eight and comes from Cannock, Staffordshire. He has three sons aged twenty one, sixteen and eleven. Last year, with his eldest son he walked a total of 370 miles between Carlisle and London on behalf of the Leukemia Research Fund and raised almost £2000.

This year he and Gavin intend to walk the Pennine Way on behalf of MPS. Gavin will be leaving school this year and is hoping to enroll for a full time catering course next September, (if his feet have recovered by then).

They plan to camp most nights, but they have offers of comfortable accomodation in Carlisle and in the Yorkshire Dales near Thwaite. If any MPS families or their friends live in the shadow of the Pennine Way and can help in providing overnight accomodation for Clive and Gavin they would be very grateful. Please contact Monty on 021 358 3326 if you can help.

In the meantime please get an MPS sponsorship form from Ron Snack and start making a nuisance of yourself to friends, family, neighbours, work colleagues etc.

Monty Russell

FAYE ROWE AND FAMILY

Our family consists of my wife, Ali (short for Alison), Faye, who suffers from Sanfilippo A Disease, Alison and Jenny who are twins and myself Gordon.

Our story starts from just after having the twins in 1984. Faye was then three years old. We noticed Faye was slightly hard of hearing. She was unable to hear us when her back was turned and she was sitting on top of the TV to hear it. The doctors told us she needed grommets inserted in her ears and to have her tonsils and adenoids removed, which we had done. Things began to pick up for a while and then it went back downhill. Faye started school when she was four and a half and at first was getting on OK. At five she showed signs of being unable to keep up with the other children.

We then visited our local GP who couldn't see anything wrong, but who sent us to Guy's Hospital for further tests. Faye was then mentally tested with shapes and sounds and so on. These went OK. She then had blood tests and a CT scan which were OK. As nothing was found Professor Robinson did some tests of his own using a urine sample. He then called us both to the hospital to explain that our daughter had a disease called Sanfilippo Syndrome. He could not tell us what would happen but knew a social worker who could help us get in touch with someone who could. In the meantime I went through reference libraries, looking at medical journals. They all referred back to a thing called "Gargoylism". You can imagine how down we were feeling.

The telephone number we received from Dr Robinson was Christine Lavery's, who got us an appointment with Dr Rosemary Stephens. We saw Dr Stephens who confirmed the diagnosis for Faye. However she told us that the twins were healthy and normal. Dr Stephens also spent two hours talking with us about Faye's illness, which helped us to understand things a little better. But our problem now was trying to explain to our parents about what their granddaughter's illness was and what could happen in the future. We were then invited by Christine to a meeting in Leicester to meet other people in the same situation. We met another family there who, like us, had no one to talk to. A little while later we went to our first MPS conference which was very helpful.

With all the information we had just got and what we had learned from the conference we had to fight the council to keep our daughter at school. We found we were fighting the council under the 1981 Education Act and we managed to get her into an ESN school. We are still fighting to keep her there as she does not like change in her life. I can see the school's point of view as all her learning capabilities have ceased. Faye is now eight years of age and is still active and lively, although little things are starting to happen. She is still a happy loving child. We believe that the twins who are now five are keeping her going.

We have been to two MPS conferences so far and have made many friends all over the country. We took our Faye's grandparents to the last conference and it has opened their eyes to understand more. We also write to Kharis and Malcolm

Collins in Canada as pen friends and we share our knowledge with each other.

We have a good idea of what is in store for Faye and for us and we try to have as normal a family life as possible. We are looking forward to seeing all our friends at the next MPS conference at Manchester.

Gordon Rowe



Faye Rowe with twins Alison and Jenny

NEW ADDRESS FOR MPS (but not yet!)

Christine and Robin Lavery will be moving house in mid June. They are moving to a bigger house in the next street. Their telephone number will remain the same. Keep sending post to 30 Westwood Drive for the time being as it will be forwarded to them. The new address for the MPS Society will be circulated in due course.

Best wishes to the Laverys for their move. May your lives be as fruitful in the new house as they have been in the old. But do take it easy from time to time. When I think of the schedule of work you both undertake I have to lie down and rest.

IF IT CAN BE DONE IT WILL BE DONE IN SCUNTHORPE

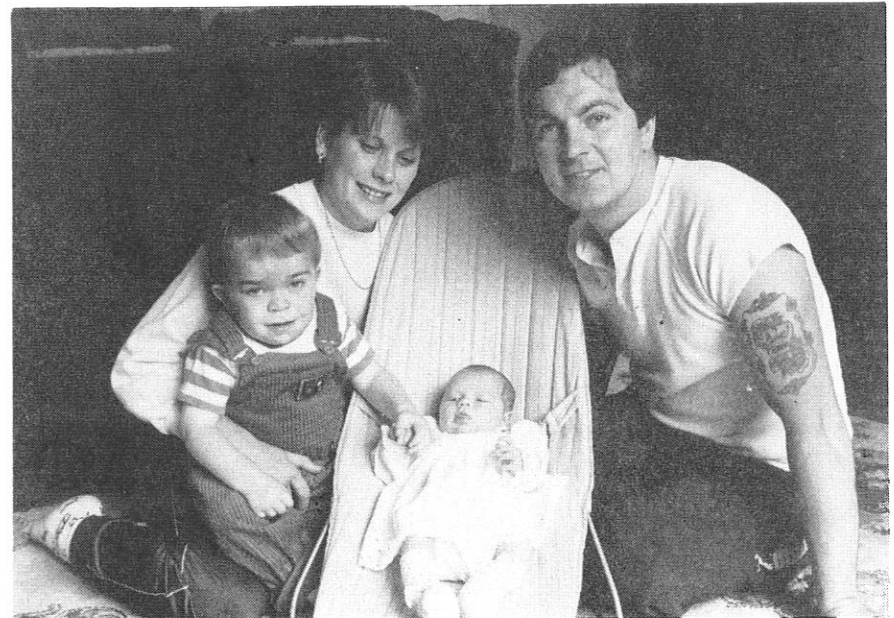
We have enclosed a list of Fund Raising Events and photos along with a short list of our sponsors which together gave us a total amount raised of £16,606-61, a little more than the £10,000 we set out to raise.

If it were possible to write highlights of all the events we would, but as you will appreciate this would take a lot of time. However the two largest events were the Relay Marathon from Blackpool to Cleethorpes in May 1988 and the Cycle ride from Rome to Scunthorpe from June 3rd to June 19th 1989 (arriving home on Gemma's second birthday). These are the most memorable for both of us.

We were amazed at how generous the people of Scunthorpe and surrounding areas were in donations, sponsorship and involvement.

Yours sincerely,

Trevor and Barbara Rollinson
43 Crosby Ave
Scunthorpe
South Humberside DN15 9DA



Gemma Barbara and Trevor with baby Amy.



Steetley Minerals Team ready for their 180 miles coast to coast run across the Pennines to raise money for MPS in 1988.
Trevor Rollinson bottom right.



Willie Morrison with Naomi, Neil Brown with Sarah and Trevor Rollinson with Gemma celebrating the end of their cycle ride from Rome with a pint and a cuddle.

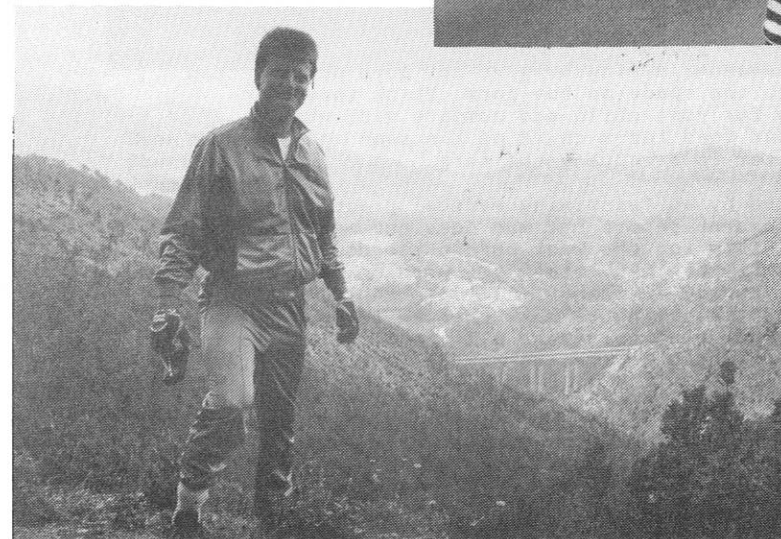


Willie Morrison
Trevor Rollinson
Neil Brown

setting out
for their
epic ride
from Rome
to Scunthorpe
June 1989.



Neil helps
to straighten
out the street
furniture
in Pisa.



Willie
explores
a short cut
across the
mountains.
The last
person who
came by here
was Hannibal!

CLAIMING ATTENDANCE ALLOWANCE

I recently heard a talk given by Dr. Aylward, the Medical Secretary to the Attendance Allowance Board which I found helpful and thought some of the points might be useful to others.

Dr. Aylward explained how some of the key words used in describing who qualifies for an allowance are interpreted. In claiming an allowance for a child it has to be shown that help needed is **more than would normally be given to a child of the same age**. The help has to be needed in connection with "bodily functions" which refers to functions which an individual would normally carry out for himself. Help with feeding or cutting up food counts, but not cooking or shopping as these are activities often carried out by another member of the household.

Attendance allowance is paid at the lower rate if attention or supervision is needed by night or by day and at the higher rate if it is needed for both periods. Night is taken to begin when the household normally goes to bed - if your child needs attention during the evening but not during the night, the higher allowance will not be awarded.

"Frequently", applied to attention given at night, means several times, not just once or twice. "Repeated" applied to daytime means less frequent than frequent! More than once will do. "Prolonged" is as yet undefined by law but is taken to be for a period of about 20 minutes.

"Continual supervision" must refer to the need for constant supervision with only very brief interruptions.

You may know that, from April this year, the allowance can be claimed for children under two. As attention must be more than normally needed by a child of that age, it will only apply to those needing something major like tube feeding or dialysis - however if in doubt, claim and let the Board decide.

It is a good idea when claiming to give far more details than can be fitted into the space on the form. Think through everything you do for your child and compare with what a friend or neighbour does for a child of the same age and then write it in a letter to accompany the form.

You will be visited by an "examining medical practitioner" who provides an independent report but who does not make the decision. Keep a diary for the week before the doctor comes so that you can tell him how many times you were up each night or how many nappies you had to change. If your child is able to understand and you are trying to make them as independent as possible, you may not want to stress all the difficulties in their hearing, so arrange to see the doctor on your own for part of the time.

If you need advice on making a claim, or your claim is turned down, Wilma Robins, the Society's Welfare Rights Adviser, will be pleased to help you. She can ask Dr. Ed Wraith to provide a report in contested cases - enquiries should be made through Wilma for this, unless of course Dr. Wraith is your child's paediatrician. Here is Wilma's address.

Wilma Robins
77 Hillview Avenue
Hornchurch, Essex. RM11 2DN.

By Mary O'Toole

Tel. 024-026-3185



Sean Mahon (left) accepts a cheque for £10,000 from Ron Shuttleworth of Steetley Minerals - with Barbara, Trevor and Gemma Rollinson.

AREA FAMILY DAY NORTHERN IRELAND

The Northern Ireland Area Family Day will take place on the 23rd of June this year at Loanends Church Hall, Loanends, near Antrim Town. Further information will be circulated soon by Ann Kirkpatrick and Margaret Kearney. Dr Ed Wraith and Mary Gardiner will be attending from England.

PARTY POPPERS PURSUE PULSATING PROGRAMME
BUT FAIL TO COME UP WITH A JUGGLER.

Question. Who is the odd man out in this list? Matthew, Colin, a juggler, Emma, Christine, Max Bygraves, Lee and Rebecca?

Answer. The juggler! - all the others were at the Milton Keynes Christmas Party last December. Alright, Max Bygraves wasn't actually there but his record was. Who else could sing 'God rest ye Merry Gentlemen'; 'Jingle Bells' and 'Mary's Boy Child', all in one medley?

And where was the juggler? He never did turn up! Still Ron said he wasn't very good anyway! As it was we didn't need him. Despite numbers being low because of the 'flu bug we all had a smashing time.

Needless to say we ate, drank, ate, played party games, ate, popped poppers, ate, sang-along-a-you-know-who and ATE.

Everyone, mums, dads, Colin's gran and grandpa, Jenny, Roger, Tina and all the children really got into the Christmas spirit and enjoyed themselves. We even built the tallest Duplo tower ever!

Again the 'Chiltern' families owe a great deal of thanks to Ron and Linda for organising such a good get together. Roll on the summer and the next feast!

Andy Hardy

COFFEE AND DOUGHNUTS

Jenny and Andy Hardy will be holding their annual coffee and doughnut morning at their home, 48 Churchway, Haddenham, Bucks, on Saturday the 14th of July from 10.00am to 12.00 noon. This is always an enjoyable couple of hours with lots of stalls crammed into the front and back garden and plenty of things to browse through.

Do try to come along for a good morning out.

Ron Snack

Paul Evans from Ashford in Kent raised £786.80 by a Sponsored Splodge. Half of this was given to MPS and the rest went towards a mini-bus for Paul's school. Congratulations Paul! What is a sponsored splodge?

IN MEMORY

Our sincere thanks to everyone who has donated money to the Society in memory of Cheryl Evans, Gethin Robins, Iain Ireland, Pamela Long, Mrs Blumenfield and Leslie Rossall, a friend of the Gardiners.

Ron Snack

CAR BOOT SALES

We are again coming to the balmy days of Spring and Summer (hopefully) and, once more, the season of car boot sales and garden fetes. Nothing could be easier or more fun, and you can end up raising quite a lot of money. Here is the basic outline of what you need to do.

1. Collect up anything you think you may be able to sell - this can include things like books, jigsaw puzzles, bric-a-brac, plants, ornaments, the odd Rembrandt - well before the day of the sale.
2. Go along nice and early on the day so that you can get a good pitch and simply set up your table or just open up the car boot. The going rate these days for a pitch is about 5, but if you talk nicely to the organiser you may even get a free pitch as you are collecting for charity. Make sure you have some of our posters on show, and have plenty of leaflets available to hand out to interested people.
3. It is best to mark the prices on the items for sale, but do be prepared to haggle - that's all part of the fun.
4. At the end of the day bundle everything that's left, which will not be very much I'm sure, into the boot, go off home and count up the money, and then send it in to me. It really is very easy, and you can even top up your suntan at the same time.

Ron Snack.

XMAS RAFFLE

The 1989 Christmas Raffle has raised over 6000. Well done Dave for the organising, and thank you to everyone who sold tickets.

Ron Snack

The Collingham Wives Group made MPS their charity for 1989 and raised £1000 for us in various ways.

THE BELT

I have to say that when I first heard about this "thing" that tied your child to the bed, I was just a little bit dubious, although in the quest for a reasonable night's sleep, like anyone else in the same position, I was willing to look. On the Sunday morning at the Stoke conference, still aching from the night before having carried Adam down three floor's worth of fire escape (nothing to do with the beer!) I looked as bemused as everyone else to see Barbara, (my wife) lying down on a mattress in the middle of the hotel reception foyer tethered by the belt (a real barrowload of fetishes in one go!).

It was obvious that the belt did allow a lot of movement - roll from side to side, sit up and turn round, so all preconceptions of some form of nocturnal straight-jacket disappeared. Given that there was the remotest possibility that Adam would relent the 3.00am hammering on the door of his room, we were only too keen to take one for a trial.

It took a few weeks for the parcel to arrive and when it did, it was eagerly ripped open, only to find that every word of the instructions was in German. However, to anyone who has ever fitted a child's safety harness in the back of a car, it was a doddle. It does have to be tight around the mattress though.

First night trial with all breaths held - we tried it out. The normal procedure with Adam is to let him sit in the lounge with us and eventually, he will drop off to sleep. Ironically, we then wait for 15 minutes or so, Barbara does a disappearing act and I wake him gently, assure him that "Mummy's in bed" and walk him through to his room. When he climbed into bed, all I had to do was manoever him onto his back and fasten the catch - he then can roll onto either side. I am delighted to say that a) I managed to get him fastened in without totally upsetting him , but of earth-shattering importance, b) it worked, he slept right through the night.

Since we started using the belt, about two months ago, we have had the odd night when he wakes up and has to be attended to, but by and large, he now sleeps right through the night, and on some occasions, even has to be wakened up in the morning.

So, to anyone not sure about the benefits, take our word for it and give it a try !

The Segufixe Night Safety Belt was demonstrated at the 1989 conference and has now been road tested by Adam Watt who suffers from Sanfilippo Disease and is a very active boy aged almost ten. David and Barbara Watt will be very happy to answer your queries about the use of the belt, which is made by a firm in Hambourg, Germany and costs between £80 and £90.

If you wish to order the belt please contact Christine Lavery.

David and Barbara Watt
20 Ambleside Walk
Linton Park
Wetherby
West Yorkshire
Tel: 0937 64587

THE BATH

In case anyone has an MPS child who suffers from one of the varieties causing joint stiffness and for whom a "Whirlpool" type of bath would be beneficial, the following story may be of interest, and even encouragement.

Because of the increasing problems with Adam's incontinence, the trips "up to the bathroom" to get him cleaned if he'd had an accident were becoming increasingly difficult. As we were lucky enough to have an unused room next to his bedroom, we decided to convert it into a complete bathroom for him. By chance, Barbara discovered that such a conversion was grant assistable from the local authority.

To cut a very long story short, we now have such a bathroom, including a whirlpool bath (which he loves and which does help him "free up" a bit). The main problem was the shortsighted view of the medical world, all of whom were prepared to agree that such a device would be beneficial, but not essential. I argued with so many beaurocrats on this point, but seemingly to no avail. However, on a complete flyer, I thought of ringing someone whose medical judgement was beyond doubt and at the same time someone who didn't mind making promises and commitments. Only one name came to mind (attendees at the 1986 conference will know why) in the form of Steven Kopits in the USA. Astonishingly, I got him first time and he agreed to send a letter stating that a whirlpool bath was essential. It only took me two follow up calls until I got the letter and this immediately allowed the local medic's to cover their opinions and agree. The council conceded soon after.

The letter is attached, I hope it may be of use to someone.

David Watt

AREA FAMILY TRAINING WEEKEND

Committee Members and Area Families from Britain and Northern Ireland met on Saturday and Sunday 24th and 25th of March at Milton Keynes for a learning session on how to improve the support they give to members of the Society. Dr Ed Wraith and Dr Bryn Neal chatted with us about how to respond to queries about medical matters. We had talks from outside speakers about "Listening Skills" and about the benefits families can claim. Mary Gardiner and Mary Lockyer each spoke about their experiences as Area Families. Plans for UMIST were discussed.

Our thanks to Christine for setting up this very useful weekend, and especially for all her hard work in arranging and managing the children's programme so that the parents could concentrate on the meetings.

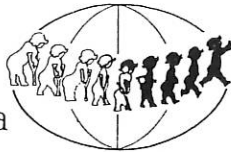
COLLECTING BOXES

I should be grateful if you would check up on collecting boxes. I sent out a lot to families during the past two years. Please make sure they are still earning their keep! If you have any boxes that are not being used please return them to me so that I can send them to someone else.

Thank you
Susan Butler

International Center for Skeletal Dysplasia

January 19, 1989



STEVEN E. KOPITS, M.D.
Director

Mr. David Watt
20 Ambleside Walk,
Linton Park,
Wetherby,
West Yorkshire, LS 22-4DP

RE: Adam Watt, 9

Dear David:

I was pleased to receive your phone call of January 19th regarding your son Adam. I have seen Adam as a patient at the time of the meeting mucopolysaccharidosis in September 1986 in London. He has San Filippo disease type A. I am sorry to hear of the increasingly severe morning stiffness of his elbows and knees and of the sensitive nodules presumably due to deposits of MPS about his elbows and knees.

Joint stiffness as you know, is a significant complication of his condition. In our practice with patients with skeletal dysplasia, particularly the MPS diseases, heat conveyed in several forms as been extremely helpful in facilitating movement and decreasing joint stiffness.

We have used, to advantage, the water bed. This should be as compartmentalized as possible and heated to a comfortable temperature. Above all the jacuzzi has been an excellent addition to the care of these children with chronic progressive illness. I have prescribe many units to families of children with mucopolysaccharidosis with uniformly good reports as to it effectiveness in dealing with joint stiffness. I would advise the temperature in the jacuzzi to be anywhere between 92 and 96 degrees depending of course of his individual tolerance. I see this as a medical necessity for your son Adam.

I send you my best regards and wishes for the new year.

Sincerely,

Steven E. Kopits, M.D.

Some Fund Raising Acknowledgements

Thank you all once again for the magnificent fund-raising efforts this time around. Everything from Concerts to Jewellery parties to a sponsored non uniform day at school have raised money for us since the last newsletter. Money is also still coming in from the London Marathon - perhaps we could make this an all year round event!

Bayswater School Oxford	Pupils fundraising
Mr & Mrs Gooch, Kent	Stall at Horticultural Fete
Bryant, Salisbury	Raised
Mrs Todd, Glasgow	Collecting Box
Kirkhill Golf Club, Glasgow	Raffle
British Steel, Glasgow	Bottle Fund
Bradwell Common Comm. Centre, MK	Barbecue and Dance
L Charlton & M Higton, Derbys	Sponsored Silence
S Hughes	Collecting Boxes
T Blowers, Leics	Marathon
Linda & Ron Snack, MK	Charity Bazaar
Colin Snack, MK	Sponsored Walk
M Horsley, Cotehill	Collecting Box
Diana Chase, Bedfordshire	Talk at Lunch Club
J Randall, Northants	Talk to Railway Enthusiasts
Linda & Ron Snack, MK	Tombola
C Westland	London Marathon
D Cutter, Somerset	London Marathon
J Baldaccino, Bristol	London Marathon
P Isaac, Somerset	Burnham Jogathon
Fiddington Church, Somerset	Youth Orchestra Concert
C S Smith, Taunton	Perfume Sales Party
C S Smith, Taunton	Tupperware Commission
Mrs Whitham	Collecting Box
MEDROC	Slimathon
Glyn Bush	London Marathon
C Hicks	Sponsored Wing Walk
C Oliver	Sponsored Slim
W & J Ross	Sponsored Slim
R O'Brien	Collecting Box
The Three Horseshoes	Collecting Box
S & E Wastling	London Marathon
D & R Coombes	Hair and Fashion Show
ANC	Various Fundraising Events
G & L Bagshaw	Barn Dance/Slimathon
Canon Slade School	Non Uniform Day
F A Sandow	Stamps
T & B Rollinson	Raised
J & S Hodgetts	Collecting Box
D Brooks Daw	Quilt Raffle
School of Ballet	Raised by Children
S & B Shiff	Collecting Boxes
R Williams	Raised
Garden House Kindergarten	Summer Fair
W Robins	Collecting Box
J Sweeney	Webb Ivory Party
Mrs Todd, Glasgow	Two Collecting Boxes
Alan(8) & Amy(4) Bottrell, Glasgow	Saving 20ps
Welsh Row Methodist Church, Cheshire	Knit-in
D & H Hawes	Sale of dried flowers
P & J Dagnall	Sale of dried flowers
J & J Macintyre	Sale of cosmetics

F & J Coyle
 R & C Mansfield
 P & J Dagnall, E Fearnley, R Hatton
 P Mahon, Sheffield
 J Shepherd
 R & U Strachan
 W Robins, London
 J & W Harris
 S Stewart, Glasgow
 Jackie Rowlands, Nantwich
 Mr & Mrs Walker, Blackpool
 The Lads, Abbey National, MK

Sale of cosmetics
 Collection of loose change
 Concert
 Dinner Dance
 Jumble Sale
 Great Scottish run
 VAT International, Collection
 Birmingham Marathon
 Collection Box
 3 legged, fancy dress pub crawl
 Collecting Box
 5-a-side sponsored football

Exeter College
 G Finch, Somerset
 G Bryant, Reading
 G Finch, Somerset
 K & B Houston
 T & B Rollinson
 Horwich C of E School
 J B Thomas
 R & C Lavery
 College of Est Mgmt
 J & H Dean
 Rev Thomas
 Stonelaw Sunday School
 Trull School of Dancing
 R & C Pearce
 Mrs Vigus
 Canon Slade School
 Canon Slade School
 Wirksworth Club
 E J Ward
 C & J Norsworthy
 Mrs E Whittam
 F A Sandow
 Rita's Eater, Glasgow
 Springhill Open Prison
 Holborn VAT Office
 VAT Admin HQ
 Calderwood School
 Cathkin High School
 Stonelaw High School
 Burgh Primary School
 R & L Burgess
 Belmont Guild, Harrow
 P & J Dagnall
 Mrs Stewart, Glasgow
 C & M O'Toole
 Crowborough Guild
 June Gilford, Cheshire

Rag Week
 Staff Weigh-In
 Great North Run
 Tupperware Party
 Fundraising Night
 Various Fundraising Events
 Christmas Concert
 Fundraising Catalogue
 Collecting Tin
 Xmas Lunch and Raffle
 Sale of Coffee and Mince Pies
 Collected
 Collected
 Fashion Show
 Carol Singing
 Sale of Xmas Items
 Sponsored Walk
 Sponsored Fast
 Sponsored Play
 Carol Singing
 Collecting Tins
 Collecting Tin
 Sale of Stamps
 Collecting Tin
 Sponsored Walk by Inmates
 Collecting Tin
 Collecting Tin
 Bring and Buy Sale
 Staff Xmas Raffle
 Sposored Swim
 Xmas Church Collection
 Collecting Tins
 Raised
 Raised
 Collecting Tin
 Collecting Tin
 Copper Collection
 Perfume Party

 A DOUBLE WORLD RECORD!

The town of Antrim in Northern Ireland boasted the world's first MPS shop in the world. Now its got to revise that boast, because it now has the second MPS shop. And who runs both of them? You guessed it - that whirling dervish of good works, Ann Kirkpatrick, with the help of her good friends. In February the shops have raised £3741.72. I expect it is a great deal more by now. Congratulations to Ann and all her helpers. She has found a way of meeting an important need in her own community which combines with very effective publicity and fundraising for MPS.

Baby Amy is family's new ray of hope

Charity cyclists head home - from Rome!

By NICK COLE

THE heartache of a Scunthorpe family has been turned to joy thanks to the birth of a new baby.

Trevor and Barbara Rollinson, of Crosby Avenue, are currently celebrating the birth of their second daughter a fortnight ago in Scunthorpe Hospital.

Amy Samantha Rollinson weighed in at more than seven pounds and doctors have told the proud but anxious parents that she is a perfectly healthy baby.

For their eldest daughter, two-year-old Gemma, suffers from an incurable disease which severely impairs both her physical and mental ability.

The illness, called Hurler's Disease, a form of mucopolysaccharide, may kill Gemma by her seventh birthday unless a miracle cure is discovered. Trevor (28) and Barbara (25) feared their second child could be affected in the same way.

Gemma but if we can help other parents to avoid what we've been through and save the lives of other children, it will have been worth all the effort!"

The disease, Mucopolysaccharida, causes severe progressive handicap to apparently normal children, often both physical and mental. Doctors tell the parents frankly, "It is terminal!"

Trevor, employed as a fork-lift truck driver by Steetley Minerals, Flixborough, is accompanied by two of his workmates, Neil Brown (25) of Belper Court and Willie Morrison (29) of Edgeware, Scunthorpe.

Birthday

Expenses for the ride have been kept to a minimum by generous sponsorship. The Charities Division of British Airways came up with the fares from Heathrow to Rome; cycles have been loaned by Cycles Leisure Ltd, Scunthorpe; a three-man tent by Famous Army Stores, Scunthorpe; the route planned by the Cycle Touring Club of Great Britain; and return fares Zeebrugge-Hull courtesy North Sea Ferries.

That spurred them on to raise funds for research and already they and their friends, supported by schools and other organisations, have raised over £7,000. Their target is £10,000 but, said Trevor, just before departing for Rome, "Even if we achieve the target we may still carry on. "Whatever we do will be too late to save

"We might be able to do the ride in 14 days, in which case I should be home for Gemma's second birthday, June 19," said Trevor. "But we don't know what snags there might be so to be on the safe side I've taken an extra week's holiday."

The major fund-raising event so far has been a sponsored relay marathon, coast to coast - Blackpool to Cleethorpes. All the employees of Steetley Minerals volunteered to run, including the plant manager, Ralph Moore. They surprised themselves by covering the 150 miles in 23 1/2 hours, raising a magnificent £4,200.

The staff and pupils of High Ridge School, Scunthorpe, organised a sponsored run which is expected to raise another £1,500. "With that and other efforts I reckon we are getting very near our target," he said. "With what we are sponsored for on the Rome run we should be over the £12,000 mark."

Eighty per cent of what (total is raised will go to the Willink Genetics Research Unit of the Manchester Children's Hospital, Pendlebury. The balance will be used to purchase special equipment and to provide holidays for some of the estimated 300 affected children in the UK.

Last year the Rollinsons, with the help of their friends and work-mates, set out to help finance research into finding a cure.

So far the appeal has raised more than £14,000 and money is still coming in.

Trevor, a forklift truck driver with the Flixborough firm of Steetley Berk Limited, said despite their new joy, their concern for Gemma continued.

He explained that at night she now slept with her legs in splints to stop them lightening up.

Marathon

Meanwhile the family are planning to hand over a further £4,000 to the Mucopolysaccharide Society at the town's Black Beauty public house on October 5.

A last-minute boost for the fund came on Sunday when local steelworker and neighbour Mick Taylor, of Crosby Avenue, ran a sponsored marathon in Nottingham.

RUNNING FOR RESEARCH

A NINE-month-old baby who is slowly dying from a rare incurable disease has prompted a massive fund raising campaign at Steetley Minerals' Flixborough site.

Blonde-haired Gemma, daughter of Fitter/Forklift Truck Driver Trevor Rollinson, suffers from Mucopolysaccharide Disease, a rare illness which causes severe progressive handicap often both physical and mental. Twenty-six-year-old Trevor told Steetley News how he and Gemma's mum, Barbara, were told that their only child could die at any time between her first and fifteenth birthday.

"There will be 12 of us doing the run in relays," said Trevor. "I am very grateful to all the lads who are putting themselves out like this." Beginning from Blackpool on May 27th, the runners will be looking for as much sponsorship as possible in their attempt which will take them over the Pennines to the East Coast.



Paul is school's super splodger

PAUL Evans, 13, is only just over three feet high but he is a bundle of fun and energy.

He has a rare genetic disease which stunted his growth and sent him almost blind, but he has courage by the bucketful.

Only a few weeks after starting swimming lessons he volunteered to take part in a sponsored "splodge" to help fight his disorder and help his school.

On Thursday he took to the water at the Stour Centre learner pool and kicked his way along for 20 lengths, watched by his best pals at Greystones School, Hythe Road, Ashford.

Classroom assistant Carol Chorlton is pictured helping him and his department head, Pamela Cadenhead, recorded the event.

Paul was asked how he felt at the half-way stage and said he was all right.

His efforts are expected to raise more than £500 in sponsorship.

"Paul is an absolute character," said Mrs Cadenhead. "He's hard working and popular, too."

Mucopolysaccharide (MPS)

Sir, Almost 12 months ago I was approached by Collingham Wives Group to attend one of their meetings to give a talk on Mucopolysaccharide (MPS) diseases, which are both incurable and terminal, affecting only children, my own son Adam included.

The reason for the talk was that the group had adopted the MPS Society as their Charity of the Year.

The efforts of the group over the year have been tremendous, and I was privileged to be asked to return this week to collect on behalf of the MPS Society a cheque for £1,000, representing the proceeds.

May I take this opportunity to give my most sincere thanks to the Collingham Wives Group

for adopting this charity for the last year and for all the hard work which went towards raising this amount which will be used by the society to help towards research for a cure.

A slogan of the MPS Society reads "Care Today — Hope Tomorrow". Were it not for the efforts of individuals, groups and organisations like the Collingham Wives, we wouldn't even be able to have the hope for tomorrow's generations. Thank you ladies — well done!

P.s. If any other people reading this are interested in help, please do not hesitate to call me on Wetherby 64587. — Yours,

DAVID WATT
Ambleside Walk,
Wetherby

Antrim's MPS shop expands

THE MPS charity shop, which is situated behind the old police barracks, has expanded.

A second shop is now open for business, dealing in furniture and nursery equipment.

The beauty of charity shops is that you can easily pick up a bargain, and have the satisfaction of knowing that you are helping a worthwhile cause at the same time.

Ps. If any other people reading this are interested in help, please do not hesitate to call me on Wetherby 64587. — Yours,

MPS stands for The Society for Mucopolysaccharide Diseases.

Mucopolysaccharide disorders are rare, life threatening diseases which cause severe progressive handicap, often both physical and mental.

Anne, who runs both of the MPS shops in the town, told the TIMES what they have to offer local people:

"Our shops cover everything from clothing to books to toys to make-up. With our new shop opening, we now sell furniture and nursery equipment. At the moment we have a sale on in our first shop. Everything on sale there is just £1."

Like every charity shop, the MPS shop relies on the donation of goods by the public.

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