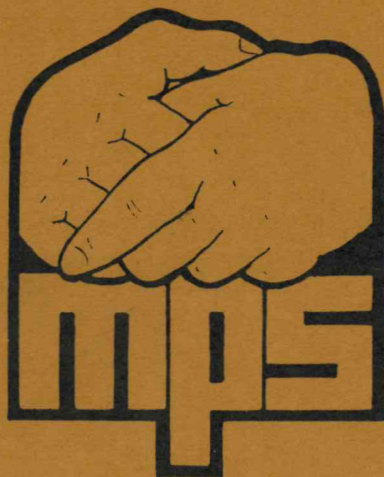


NEWSLETTER

m**p****s**

AUTUMN 1983

**THE SOCIETY FOR
MUCOPOLYSACCHARIDE
DISEASES**



National Registered
Charity No: 287034

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Robin and Christine Lavery; 30 Westwood Drive, Little Chalfont, Bucks.
Peter and Marlene Sanderson; "Greenhill", Downend, Horsley, Glos.

WHAT ARE THE AIMS OF THE SOCIETY?

1. To act as a parent support group.
2. To bring about more public awareness of MPS Diseases.
3. To raise funds in order to further research into MPS.

SECRETARY'S REPORT

Over the past few months my time has been mostly spent consolidating our arrangements for the Family Weekend/Conference in Birmingham at the end of the month. We have been amazed at the generosity and kindness shown by people for whom the words Mucopolysaccharide Diseases must have been a new addition to their vocabulary. Another very exciting aspect is the interest that has been expressed by the Medical profession - over 50 seats at the conference will be occupied by Consultant Paediatricians, Biochemists, Social Workers, Health Visitors and Nurses. This can only lead to a far better understanding of the needs of MPS families in the future.

Because of the work involved in the Conference, here in Buckinghamshire we have been unable to contribute as much as we would have liked towards fundraising but we need not have worried for the efforts of our families around the country and abroad have been tremendous. Some of you helped by holding 'Snowball' coffee mornings and as a result over £5,000 has been raised for research and the holiday caravan. Coinciding with our 'Coffee Snowball' was a request from Dr. Irwin Olsen, at the Kennedy Institute in London for financial help in purchasing a rotary sampler, with wash timer, sample timer and peristaltic pump and a microcomputer and printer connected to the flourimeter. Dr. Olsen - for some time has been involved in research into Mucopolysaccharidosis and is now working on enzyme replacement and studies on cell-to-cell interaction and protein transfer, which he feels could be of potential clinical importance. Dr. Garrow, one of our Medical Advisors consulted with Dr. Olsen on several occasions and as a result the Committee accepted that it would be proper use of funds to purchase the equipment that was requested, out of the 'Coffee Snowball Account'.

Further on in the newsletter you will see a paragraph describing a new type of experimental research into earlier detection of MPS by Dr. Lubeck at the University Hospital for Children in Vienna. We are privileged that we should be invited to participate in his work and it would be helpful if we could supply Dr. Lubeck with a lock of hair from as many MPS sufferers as possible. We must stress that this is purely experimental but you never know for the future.

We are building up to organising a Society Christmas Catalogue for 1984, but in the meantime we have a large and exciting range of Mabel Lucy Atwell, Kate Greenaway, Worzel Gummage and Wind in the Willows stationery suitable for children and adults alike. Until recently the cost of posting stationery to families was prohibitive but Catherine and Gary Grant are now in the process of negotiating preferential rates with the Post Office. If you would like further details of the stationery please contact Catherine Grant.

By the time you receive this newsletter I will have had the opportunity to meet personally with the 55 families represented at our Family Weekend but for those unable to be there a special newsletter will be published in November and all conference documents will be made available.

Christine Lavery

THE MATHILDA & TERENCE KENNEDY INSTITUTE OF RHEUMATOLOGY

A number of attempts have been made to correct the inherited deficiency of one or more lysosomal enzymes which characterise the mucopolysaccharidoses. These have included direct administration by infusion of the missing enzyme, or of normal plasma or serum in which it is present. Another approach has involved the use of intact cells which could act as enzyme 'donors', such as fibroblasts and Red and White blood cells. Recently, enzyme replacement by bone marrow transplantation has been reported to have achieved some degree of clinical success.

Although lymphocytes are a major cellular component arising from the bone marrow, their potential role in the treatment of these tragic diseases is not clearly understood. Recent investigations at the Kennedy Institute of Rheumatology, have shown that, in tissue culture, such cells are able to transfer a lysosomal enzyme, B-glucuronidase, to cells from a patient with an inborn deficiency of this enzyme (Mucopolysaccharidosis type VII). This process, which involves cell-to-cell contact between the two types of cell, has hitherto not been described, and the mechanism by which this type of direct enzyme transfer occurs is currently being studied.

Recently The Society For Mucopolysaccharide Diseases has awarded a grant of £2,700 to me as Head of the Cell Enzymology Unit at the Kennedy Institute, in support of this research. These funds will be used for the purchase of automated sampling and recording equipment to facilitate the measurement of changes in enzyme activity in cells from patients with a number of different disorders of mucopolysaccharide metabolism. It is hoped that such fundamental studies will provide important information as to which deficiency diseases could be effectively treated and shed some light on the basic mechanism by which metabolic correction may occur.

Dr. I. Olsen
Head of the Cell Enzymology Unit
Kennedy Institute
Hammersmith
London W6 7DW.

MPS Committee Members being presented with the Versatile Bath Chair, donated to the Society by the Amersham & Chesham Lions Club.

Left to right, Christine Lavery, Secretary, Catherine Grant, Liaison Officer, Susan Heath, Fund-raising Officer.



WATCH OUT CAT, HERE COMES PAUL

Our family consists of Anne, Ray, Emma aged 8 and Paul aged 4. Paul was born on July 9th 1979 and weighed in at 10lbs 6ozs and was more than average length which is not surprising since I am 6' 5". Right from the start his breathing was audible and he had a 'snuffly' nose. At six weeks our family doctor decided that Paul was not thriving and he went into our local hospital for tests. Between September and December he was in and out of hospital several times. At this stage we thought that he had nothing more than an adenoid problem.

On January 11th 1980, we were told by the Consultant Paediatrician that Paul had Hurler's disease. It hit us like a bombshell. Having had the symptoms of Hurler disease briefly explained to us, we asked the Consultant straight out - is it fatal? Yes, was the reply. At the time Paul was crawling all over us and acting very disinterested in the whole thing which made it even more difficult to accept the situation. That night and the following day the truth sank in.

Within two days we heard of the Westminster Children's Hospital through a friend who had fostered a baby with Hurler disease and a week later we took Paul to the hospital where we were told of the possibility of a bone marrow transplant. A bone marrow transplant had never been performed for Hurler disease and the doctors were waiting for the chance to try. Theoretically it had a good chance of working. Knock out the existing marrow and replace it with a new marrow containing the missing enzyme. Once a transplant has taken it is there for life.

The whole procedure of a transplant was explained to us including the possible dangers arising from the course of drugs to be taken and the vulnerability to infection during the transplant when his body would be defenceless. The final decision was ours. The decision to say yes was simple. Without treatment Paul would die a vegetable. Our only hope was a transplant. The main problem now, we were told, was to find a donor. The next four weeks were taken up with blood tests on us and our close relatives. No luck. The computer at St. Mary Abbots containing 30,000 different tissue types was then tried and six possible donors were discovered. However, when further tests were carried out none were a good enough match. When all seemed lost the Transplant team decided to try either Anne or myself as a donor since, although not perfect matches, we were considered compatible enough to try.

In the middle of March 1980 Paul went into a cubicle to be 'Reverse Barrier Nursed' (no germs allowed in) and underwent a course of drugs to decontaminate his body. From there he went into a 'Vickers Isolator' (plastic bubble), which was to be his home for the next 5½ months. Using myself as a donor (they seem to prefer male to male), Paul had his first transplant the day after Easter Monday. Bone marrow taken from my pelvic bones under a general anaesthetic was taken down the road from the Westminster Hospital to the Westminster Children's Hospital and transplanted into Paul by way of a drip through a permanent long line. The doctor's were hoping to see a severe rash which would indicate that the transplant had taken. Two weeks went by, no rash appeared and we feared the worst. Finally they confirmed that it had not taken. The regime of toxic drugs used to kill off his own marrow was not strong enough and consequently his remaining marrow successfully fought off the transplanted marrow. We had hoped that they would now use Anne as a donor but the doctor's seemed reluctant to batter Paul's body with an even stronger course of drugs.

We were resigned to the fact that the attempt had failed when the doctor's decided to go ahead with a second transplant using Anne. The strength of the drugs to kill his own marrow was more than doubled and the second transplant took place at the end of June. On the tenth day after the transplant a rash appeared on Paul's head and everyone who crowded around his tiny bubble watched with delight as the rash slowly moved down his body. The next week or so seemed to last forever until it was finally confirmed that it had taken. By this time Paul had been in his bubble for 3 months and a few days later he was transferred to a bigger bubble in the ward downstairs. For this manoeuvre, I had to be toggged up in all sorts of protective clothing while Paul was placed inside a plastic bag. The bubble was opened and I carried him out of the cubicle, down the corridor, down the stairs and into the ward where Anne was waiting to take him out of the plastic bag, once he was placed inside his new home. Paul was quite happy in the small bubble but he never took to the large one despite spending his first birthday there.

The weeks began to drag on as we waited and longed for the day when he could return to 'our world'. When the moment arrived, it was an emotional reunion. Trying to laugh, smile and fight back the tears at the same time is not easy. Paul's first objective was to grab a nose. After 5½ months of not having proper physical contact, he could not resist noses and he was not short of offers from doctor's and nurses alike.

Christmas was approaching and Paul had been in hospital for nearly 9 months. At last he was allowed home for a weekend and a great triumph had been achieved. He was then allowed home for the Christmas holiday and it was the best present imaginable.

Since then Paul has gone from strength to strength. For the last year Paul has attended a local school for the Physically Handicapped and he is progressing remarkably well. Since the transplant his 'cloudy' eyes have cleared. His back has straightened. His head is now in proportion to his body and he is mentally normal.

During the time that Paul was in his bubble our wish was for him to be a typically normal 'naughty' boy, who opened cupboards, pulled out crockery, turned off washing machines, choked the cat and talked continuously from morning until night. Our wish was granted by the skill of the Transplant Team at The Westminster Children's Hospital, to whom we shall be eternally grateful. We have our 'naughty' little boy.

Ray Franklin.



Paul Franklin, aged 4 years.

GETHIN ROBINS

Peter and Wilma Robins only son Gethin is four years old and suffers from Hurler Disease. Although they now live in Hornchurch, Essex, both Peter and Wilma originate from West Wales and still have close family ties.

Christine

On behalf of Gethin, my husband Peter and myself, I would like to convey our heartfelt thanks to the people connected with Bethlehem Chapel, to other friends and neighbours in Pwll Trap and in particular to our immediate family; for their exceedingly generous contributions to the Society collected in the special children service held on the morning of Sunday July 3rd.

The service comprised renderings by the children of thoughtfully chosen songs, readings and prayers, and the singing of appropriate hymns by all the congregation. Gethin accompanied us to the service and enjoyed it immensely. There was a special presentation by a group of the children of extracts taken from the Newsletters and the Minister extended this theme in his own address. We had circulated copies of the Information Sheet beforehand in order to publicise the Society and we placed a Society "Complimentary Card" on each seat to remind people on the day. It was a delightful service which I'm sure everybody enjoyed and a special word of gratitude must be attributed to the Minister, Rhodri Thomas, for the enthusiasm he displayed when I first suggested the idea to him, and the work involved subsequently in the preparation of the service is much appreciated. We have decided that the money contributed should be put towards the Society Holiday Caravan Fund.

As all our family in West Wales would be gathered together for that Sunday morning and Gethin's fourth birthday was only three weeks away, we had decided that it would be a good idea to have an early birthday party for him in the afternoon. The weather was glorious and the entire time was spent in the garden. A perfect day was rounded off with a barbecue in the evening. (A very special thanks here to my sister Val and her family, at whose home in North Pembrokeshire we were all gathered.

The photograph shows Gethin in his best attire for the big day. He is particularly proud of his bow tie!

Wilma Robins, Hornchurch, Essex.



Gethin Robins, aged 4 years.

BETHLEHEM CONGREGATIONAL CHAPEL, PWLLTRAP, ST CLEARS.

Llanddwyn,
Pwlltrap,
St Clears.
Dyfed. SA33 4AP.

Dear Friends,

It is a great privilege for me on behalf of Bethlehem Congregational Chapel to forward the enclosed cheque of £320 to your society.

A special service was held, which was conducted by the children of the chapel, at the beginning of July. The theme of the service was the relationship between Jesus and children and the importance of healing during his ministry. During the service the opportunity was taken to explain the work of your society and its dependence on voluntary contributions. We also referred to our connection with this particular family of diseases through Gethin Robins (whose mother is a member of our chapel). We were very glad of the presence of Peter, Wilma and Gethin together with members of both the Bowen and Robins families in the service. At the end of the service an appeal was made which resulted in this collection.

We therefore extend to you our sincere wishes for your continued success in the important work of supporting families afflicted by this family of diseases. We hope that our donation will in some small way contribute towards that aim.

On behalf of the members of Bethlehem Chapel.

Yours sincerely

P.G. Thomas
Minister.

BOWEL PROBLEMS AND THE HANDICAPPED CHILD

by Graham Clayden, Consultant Paediatrician

Introduction

I have seen a number of children with chronic constipation in addition to major handicaps presented to my Intestinal Motility clinics. Two things have surprised me. The first is that often the child's bowel problem appears to be one of the most distressing elements of the child's handicap. It seems to be the last straw for both the child and the parents, whereas they have often overcome other major trials. The second surprising discovery was how little is known about these bowel problems. What is needed is some detailed research into this problem in groups of children with different types of handicap. However, we have discovered some general principles from seeing a large number of children with constipation. To understand the problem associated with defaecation it is important to have a clear idea of what happens normally.

The way we open our bowels

As the food we eat passes from the mouth on its long journey (approximately twenty-nine feet in the adult) the various important nutrients are absorbed into the body. By the time the residue reaches the last two to three feet (the colon) we are left with what the body does not need and the normal bacteria which live there (and probably do us some good - even by making vitamins for us). The food in the upper bowel is a watery mixture and it becomes more solid as the valuable water is removed in the colon. The firm stool then passes down into the last part of the bowel, called the rectum. We usually feel the stool arrive there, but we can usually store it temporarily until we find a lavatory. This is difficult if the stool is very large or very sudden.

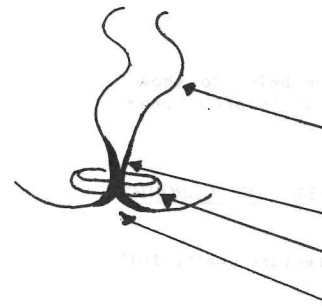


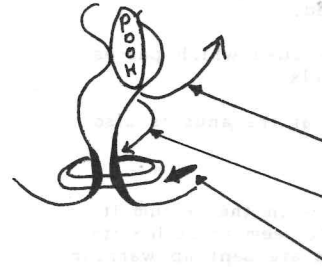
Diagram of the last part of the large bowel.

This is the rectum which is nearly always empty.

This is the muscle which works automatically.

This is the muscle you can control yourself.

This is the anus (bottom) where the stool will come out.

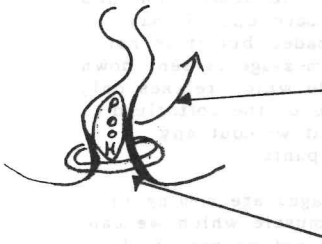


Now a stool has come into the rectum.

A message is sent to you telling you a stool is there and you will be wanting to go soon.

Another message goes down to the automatic muscle at the anus telling it to relax a bit.

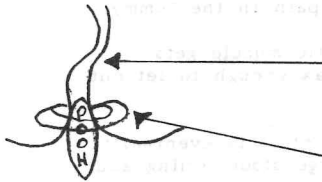
A message comes back from you to tell the muscle to hold on until you find a loo.



Because the automatic muscle relaxed a bit, the stool has come lower and the rectum contracts to push it lower still. More warning messages are sent up that the stool is coming out soon.

More messages come down to relax the automatic muscle further.

Your message to hold on tight with this muscle stop when you find the loo and sit down and relax. (This muscle can only hold in for a short time when the message from the rectum completely relaxes the automatic muscle).



The rectum contracts and helps push out the stool. You get a feeling that you should push down into your bottom by holding your breath or groaning.

Both the automatic muscle and your controlling muscles are relaxed.

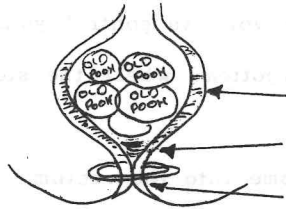


And the stool comes out easily. These muscles contract again afterwards to close the anus again.

What may go wrong

If we consider what can go wrong, the next diagram helps to show what happens in extreme constipation when the bowel is accustomed to hold large volumes of stool.

DIAGRAM OF LAST PART OF THE LARGE BOWEL IN CHRONIC CONSTIPATION

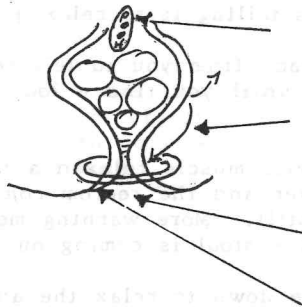


This is the enlarged rectum pretty full of old stools.

Because it is used to holding heavy stools the walls are thickened.

There is a little loose stool which passes around the harder stools.

This automatic muscle at the anus is also thickened.

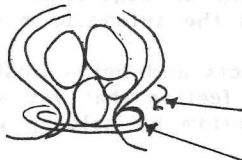


When a new stool comes in the rectum it is so loaded it doesn't seem to notice its arrival so no messages are sent up warning you that another stool has come in.

The rectum churns the old stool about and sometimes sends a message up. It says the rectum is quite loaded but it is not urgent. Sometimes a message is sent down to the automatic muscle which relaxes only enough to let out some of the soft fluid stools. These seep out without any feeling and stain the pants.

Because no clear messages are coming up from the rectum this muscle which we can control ourselves does not squeeze to be able to stop the fluid soiling.

After about 1 to 3 weeks the rectum gets very loaded then it starts to give messages which often feel like pain in the tummy.



Eventually the automatic muscle gets enough message to relax enough to let out the giant stool.

The muscle you can control is eventually unable to stop the large stool coming and so it eventually gets urgent and a rush to the loo is needed



Even after all this there is some left which will be the old stool at the centre of the next giant stool.

Thank goodness that's out but oh dear not another blocked loo!

So to summarise the problems:-

1. The anus may be too narrow or the muscles do not relax enough.

The rectum may be so large that it will not get full enough to set off the relaxation response until many days have passed.

The child may not get sensation from the rectum, possibly due to:-
 - a) a very large rectum which does not get stretched by the stool coming in.
 - b) the nerves in the rectum are deficient.
 - c) the nerves are interrupted in the spinal cord.
 - d) the brain does not sort out the information coming from the bowel because
 - i) immaturity or
 - ii) brain damage
 - e) the child may have learnt the wrong response to the sensation. For example, if every time he/she has the feeling of imminent defaecation it is immediately followed by severe pain or discomfort, then the child will become conditioned to avoid this pain. This will lead to reflex attempts to prevent defaecation. This situation may be aggravated if the anus becomes very sore, or if the skin is very prone to damage. The child's understandable attempts to avoid pain may appear as deliberate annoying acting out to the parents and a vicious circle may develop of anger and fear. So the bowel may become a battle ground.
4. The child may not be able to coordinate the muscles to push out the stool because:-
 - a) He/she may not be able to coordinate many muscles properly (e.g. cerebral palsy).
 - b) There may be problems in the motor nerves to the muscles (e.g. spina bifida).
 - c) The shape of the pelvis or the position of the anus may be abnormal.
5. The consistency of the stool may add to the problems because:-
 - a) Stools may pass through the gut too slowly and so dry up and get hard.
 - b) There may be a deficiency of fibre (roughage) in the diet because:-
 - i) poor appetite because of recurrent illness.
 - ii) children with food fads (but how many children really like bran!)
 - iii) difficulty in eating or especially in drinking.
 - c) The child, by holding on to the stool to avoid defaecating, will allow the stool to dry out and get hard. When he finally goes it is hard and hurts and so proves himself right in his own mind.

What can be done to Help?

Without having the detailed knowledge about which of the factors mentioned are acting in an individual child it is difficult to give precise advice. These general principles may however be helpful.

1. If the stools tend to get very hard or the child obviously finds discomfort in passing them, then
 - a) Try to increase the dietary fibre (e.g. instead of Rice Crispies use Wheatabix or Bran).
 - b) Ensure an adequate water intake.
 - c) In children over one year try to give more food than milk.
 - d) If the above changes are not enough try gentle stool softeners after discussing this with your doctor. For example, Lactulose (Duphalac), Methyl cellulose (Cologel), Dioctyl sulpho succinate (Dioctyl Medo). Milk of Magnesia and Liquid paraffin should not be used for long periods.

2. If the stools are very infrequent then try:-

- a) Increasing the child's general physical activity if the other handicaps allow it.

Enlarging the stool by using the softeners above.

Use stimulant laxatives if necessary, if delays are long or distressing. A long delay between stools, provided it does not cause the child distress, is not really a medical danger. Some parents find the child's appetite becomes worse towards the end of the period between stools. Some children prone to fits seem to have more at this period of maximum loading also. Children whose behaviour is difficult also tend to be worse at this time. Careful use of stimulant laxatives may be indicated, for example senna (Senokot) or Danthron (Dorbanex), but this should be discussed with your doctor first.

Some children are even more comfortable for most of the time with careful use of suppositories or enemas, but in a frightened child, especially if prone to pain in the bottom, more distress may be caused and the vicious circle increased.

Whether other measures which we have found to be useful in children with constipation without other handicaps are useful here needs to be proven. We use anal dilatation under a general anaesthetic combined with complete clearing out of the loaded bowel in some children. Other children may need special help with overcoming their fears about defaecation which are out of proportion or persist after the stools become soft. Child psychiatrists or psychologists may help considerably in the child's confidence or in helping them express some of their feelings. Sometimes the vicious circles which orbit the bowel problems involving both child and parents will disappear quickly if they can discuss these feelings openly with someone who understands what it is like.

Conclusion

If we studied children with complex handicaps and constipation I am sure we would come to the same conclusions as we have with non-handicapped children. That the constipation is the result of many, often varied factors that include the size and activity of the rectum, the consistency and frequency of the stool, the way the child responds to the feelings, the amount of distress the problem causes to all members of the family, the level of physical activity the child can do, the routines and 'friendliness' of the lavatory, the ability of the child to push the stool out comfortably, etc., etc.

We are hoping to start a research project concentrating on the handicapped child. I plan to send a copy of this article to some of the grant giving charities to see if we can appoint a research doctor for two years to look into this problem and then maybe we will be able to give useful advice to all those looking after handicapped children to end this very distressing and persistent problem.

Graham Clayden
July 1983

A LESSON IN PERSEVERANCE

I am Pam Tubb, aged 35 years and I suffer from Marateaux-Lamy. I will try to tell you as briefly as possible what effect MPS has had on my life, though you must appreciate that I had no idea of this disease until by visit to The University College Hospital in 1979, when I was actually in Kings College Hospital at the time undergoing extensive tests and then my first operation for Glaucoma.

Most of my early childhood days bring me memories of hospital, though when I came to be under Dr. Elliott Burrows life was more bearable as he was such a kind, wonderful doctor. Even to this day though he is now semi-retired from his practice at Devonshire Place, we still keep the occasional contact and he visited me this time in Moorfields.

I attended a play school at the age of four. We decided to leave 'the smoke' in 1953 as I was having quite a bit of bronchial trouble.

My school years were not really very happy ones as I missed quite a lot of schooling due to illnesses and migraines. I was not able to join in many of the sports, but was able to ride a bike to school. There lies a story.... My first day at Secondary Modern School we were told we had to go to a school three miles away and those with bikes had to ride. Off we set, only I found that everyone could go much faster than I could. Gradually they all rode on, leaving me behind not having a clue where the school was. Thankfully after about an hours ride I arrived at some relations who had a business, so I was able to flop down and tell my sorry tale. My Father came and got me. What an idiot I felt when I walked into the classroom. I must say I was very glad to leave school at fifteen, cruel as children are I was greatly ridiculed. Because of my lack of schooling I had been put in a very low stream, but I loved reading and this has helped me a lot.

After leaving school, I helped Mother in the running of a play-school; I love children. I also went to a Shorthand/Typing class and managed to get a certificate for both. So even my two finger typing has come in useful, though I never did use my shorthand. My jobs have included cashier, Optician work, clerical assistant, manageress in a small supermarket, Post Office work and a booking clerk at a caravan site, which I had to give up in 1979 due to eye trouble.

When I was a teenager life was not too easy as I did not seem to fit in at Youth Clubs etc. I learnt to drive when I was 21. This changed my life and gave me much more independence, as I could not walk any great distance without a bit of a struggle. This too has now had to be given up and is a great loss. Thankfully, what I have been blessed with is a great sense of humour, which has stood me in good stead throughout my life.

To keep me occupied over the years I have had many penfriends and met quite a few too. Three of them were boyfriends but there isn't one at the moment. I was introduced to a club for the handicapped several years ago, this changed my life and brought me out of myself as I was extremely shy. Also I became Hon. Secretary for the Disabled Drivers Association (Isle of Wight Area) where we have over 400 full members, so this helps to keep me out of mischief.

Generally my health has deteriorated slowly over the past few years. A few more aches and pains in the back and neck and I have always suffered with terrible headaches.

When we went to Lourdes this year we hired a wheelchair, which I must say I found beneficial as not only could we get around more quickly, it saved me quite a bit of pain when walking. I now have one through the Ministry though I use it only when necessary. Also I had an eye operation just over a month ago and the sight is still rather bleary.

I hope that this letter in some way gives an insight to me life and give mothers of children with this type of disease some hope that their child can lead a fairly normal life, as long as they and the child are determined to persevere and not give up hope. Prayer is a wonderful thing, even though I do not now attend church, I would not be without my Faith.

Pam Tubb

SUE BRAMFORD'S PUBLIC SERVICE ANNOUNCEMENT

I travelled to Bristol with a friend for moral support, where I was met and taken to H.T.V. Studios. My legs were like jelly when I got off the train. We were taken up to the canteen, where I met the director who soon put me at ease. After a cup of coffee, I had to go for makeup (I hadn't realized how thick it would be on my face). We then went to the studios where they actually record the news. Two people did voice overs, which is where they show leaflets and just the voice is heard. Then it was my turn and I was the first visual. I did a test run for time and voice. The first take was word perfect but unfortunately a few seconds too long. The second time I added a word and stopped, but the third take was great. The director told the floor manager to tell me it was great. I then found out when the showing of the P.S.A. would be. They guarantee you five showings during the week with varied times of the day. When mine was shown on August 29th, I had twelve showings from Monday to Saturday. Sometimes two or three in one day.

If you want to publicise about MPS why not get in touch with your local T.V. Company and write asking about Public Service Announcements.

Sue Bramford.

O LEVELS FOR ANDREW

My name is Bridget Butler, my husband is Geoff and our son is Andrew who is now aged 17.

We first discovered Andrew had Hunters disease when he was seven but we were told it was only a mild form with no mental retardation. Never the less this hit us very hard as Andrew is an only child.

Through school he coped very well getting 6 O levels and this term he has started doing a computing course at technical college.

At seventeen he is finding it much harder to come to terms with his problem than ever before. His social life is very difficult, because at seventeen his friends are out looking for girl friends and with Andrew being so short, this has become very embarrassing for him and I suppose his friends.

In January of this year Andrew had the amniotic implant but we are still at sixes and sevens as to whether it has been a success. Some results have been good; others not. At present we are waiting to hear from Guys Hospital about results from his last blood and urine tests. We haven't seen any outward signs of changes in Andrew apart from his appetite, which has improved. I must admit all the trips down to London are very tiring. However, I am sure you will all agree with me, that if there is anything at all that can be done for our children, it's our duty to give them as much help as possible.

Bridget Butler.

MPS GRAND CHRISTMAS DRAW

With the help of Peter and Marlen Sanderson, printers of the raffle tickets and Pat and Mike Skidmore who have kindly secured the major prizes at wholesale prices, we are organising a Grand Christmas Raffle, which will be drawn on Saturday 3rd December.

We need your help to sell as many of these tickets as possible and you will find enclosed 10 books of 5 tickets - tickets cost 10p, i.e. one book for 50 pence. The proceeds will go towards our holiday caravan appeal.

Please do not hesitate to write or 'phone me if you require extra books of tickets, and REMEMBER to return all your raffle ticket stubbs to me by November 30th along with the money and any unsold tickets.

All prize winners will be notified within the week of the 3rd December. We depend on you to make the most of this opportunity of telling people about MPS throughout the country and at the same time raise much needed money for our holiday caravan.

A COLOUR TELEVISION AND MANY OTHER SUPER PRIZES TO BE WON.

Susan Heath
Fund Raising Officer
Little Chalfont 2029

MONEY GROWS ON SEEDS NOT TREES

At the time of writing the MPS Sponsored Sunflower Project has raised the sum of £444 all for the outlay of 6 packets of Mr. Fothergill's seeds, kindly provided by Hyrons Nursery, Amersham and about £7.00 in mailing the seeds to families.

Congratulations to Robert Culley from Southampton for growing the tallest sunflower at 215 cms (7ft 3ins) and to Matthew Blackburn whose tenderly loved flower raised £143.62. We are grateful to Hyrons and Mr. Fothergills who supported our event. As commercial horticulturalists we suggest they take a leaf (beg pardon) out of our sunflower patch and employ Robert and Matthew as production and marketing managers; a better return on investment would be hard to imagine by any commercial company.

Shall we set 215 cms and £143.62 as targets to beat next year?

Robin Lavery

NEWS IN BRIEF

Society members may be interested to hear that the magazine, Woman's Own are running a three week feature, starting Tuesday, 26th October on the work of the Westminster Children's Hospital, bone marrow transplant team. We believe that MPS will be mentioned in it and although the Society have not seen the unpublished article, we are asking for comments on it from any parents who might read the article.

BRITAX SEAT

A specially designed Britax seat for use by an MPS child, approximate age 1/4 years, has been donated to the Society. If any of our MPS families would like to borrow it on permanent loan from the Society, please contact Christine Lavery, Secretary.

PLEASE NOTE

In future could you send your articles and letters to:- Marlene Sanderson, Newsletter Editor, Sanderson Press Ltd., 25a Long Street, Tetbury, Glos., GL8 8AA.

BEREAVEMENTS

GARY WINDSOR

It is with great sadness that we learned of the death of Gary, aged 23months, in Great Ormond Street Hospital following a bone marrow transplant at University College Hospital, 27th August 1983. Gary had been suffering from Hurler Disease. We would also like to acknowledge all the donations made to the Society in memory of Gary.

NEIL PALMER

We extend our deepest sympathy to the parents of Neil who passed away peacefully in hospital on 16th August 1983. Neil lived in Sheffield and had been suffering from Sanfilippo Disease.

ALISON RUBIDGE

We wish to extend our deepest sympathy to the parents of Alison, aged 10 years who passed away peacefully at home on 1st September 1983. Alison came from Basildon, Essex and had been suffering from Sanfilippo Disease.

Two other children died after receiving bone marrow transplants at the Westminster Children's Hospital. We extend our sympathy to their families.

LOCKS OF HAIR WANTED

Recently we were approached by Jean Mossman at the Institute for Child Health and invited to help in the research of a very new and experimental technique for detecting sufferers of Mucopolysaccharide Diseases.

Dr. Lubeck of the University Children's Hospital, Vienna, Austria, is working on the idea of looking at locks of human hair through an infra-red spectrophotometer and seeing if the hair of MPS children deflects the spectrum to a differing degree from the hair of normal healthy children.

The Society has agreed to help Dr. Lubeck collect samples of hair from MPS children and in due course he will make available his results.

If you would be willing to help in this experimental work please would you place a lock of your child's hair in the enclosed bag and fill in the name, date of birth and type of Mucopolysaccharide Disease your child is suffering from on the card supplied. Please send these samples to Christine Lavery, Secretary, MPS, 30 Westwood Drive, Little Chalfont, Bucks.

USED STAMPS

With Christmas on the way, could we remind you all of the need to save used stamps from Christmas cards and so on, as a way of raising money. Carol Hubbard herself an MPS sufferer has kindly offered to take on the job of collecting them. So please send all your used stamps to:- Mrs. C. Hubbard, 71 Preston Road, Harold Hill, Romford, Essex.

A VAGUELY VICTORIAN PARTY AND DISCO

All readers are invited to a 'Vaguely Victorian Party' at The Village Hall, Chinnor, Oxfordshire on November 12th 1983, 8pm - Midnight. There will be a Disco, Food, Bar and a Grand Raffle. A good time will be had by all. Tickets priced £3.50 are available from Mrs. Sue Butler, Spriggs Holly House, Chinnor Hill, Oxon or telephone Radnage 3185. Please apply early. All monies raised are for The Society for Mucopolysaccharide Diseases.

WE WISH TO THANK THE FOLLOWING PEOPLE FOR THEIR GENEROUS DONATIONS

E.B. Bent	H.W. Yates
D.E. Cockrell	Angela Kemp (S. Africa)
Mrs. V.E. Barnard	Mrs. Kennel
Greengate County Junior School	L.E. Ballistat
Shirley Twigger	D. Burgess
Richard Gardiner Fund	C.W. Wrights
J.R. Skinris	Obberley and Bentilee N.M.C.
C.T. Shuttleworth	M.F. Stephens
Eglwys Annibynnel	J.M. Beard
Mr. & Mrs. Smeijers (N.Z.)	D. Rudsten
Newtown Social Club, Bognor Regis	G. Bennett
Brendan Baylan (Eire)	P. Tubb

V. Cully who held a bring and buy sale.

Lisa Huxted for holding a summer fayre and sale of goods.

D. Winspear who slimmed in aid of MPS.

J. Baird for her collection of 5 pennies.

To Jean and all her friends in Hyde Heath for holding a most successful Garden Party.

Welwyn Garden City Trades and Labour Club for holding a Shredded Wheat eating competition.

Mrs. V.E. Skelk for her fund-raising efforts.

Natalie, Nicola and Emma for their toy sale.

South Herts Gas Sports and Social Club for their sponsored Boat race.

Jane Reid for holding a stall at a Summer fete and Garage sale.

Mary and Colin Gardiner held a darts game and grand raffle.

Monmouth and District Young Farmers who held a Bed Race.

Mike and Ann Palmer who held a Sale of goods.

Brian and Ann Tilbury who raised money for us throughout the Summer.

Sainsbury Staff Association who held a sponsored slim.

Wendy at Radnage who held a Coffee Morning.

Christine who held a sale of Usborne books.

We would also like to thank the following who have specifically donated money to the Family Weekend:-

Merrett's (a branch of Sunblest Bakeries Ltd.)
Marks & Spencer, Cardiff store.
3M United Kingdom PLC.
Industrial Accoustics.
Tenovus (Cancer Appeal) Trust.
Toni Bramford TRust.
Nationwide Building Society
Welsh Gas.
Dingles.
C. Ogilvie.
Book Club Associates.
Market Harborough Lions Club.
Cardiff Lions Club.
Cardiff Police Social Club.
Bass, Wales.
S.M. Smithers.
Hertford Lions Club.
Burmah Oil.
Royal British Legion, Wales.
Thermocouple.
Bowmaker Ltd.
Chenies Baptist Homemakers Group.
Mandy Webster and her friends at Welwyn Garden City who held a sponsored 24 hour Pool Game.
Mrs. E. Sanderson, Rochdale.
James Turner, Cardiff

Our thanks go to the runners in the following Marathons:-

BIRMINGHAM MARATHON

Barry Didcock, uncle to Jamie Stenson from Welwyn Garden City, ran in the Birmingham Marathon and the proceeds of his run will go towards paying for the outing to the West Midlands Safari Park for MPS children and their brothers and sisters. Well done and thank you Barry.

HUMBRIDGE MARATHON

Tony Carr, father of Darren from Scunthorpe was due to run in the Humbridge Charity Marathon, but unfortunately had an accident and broke his collarbone prior to his run. All was not lost though as one of Tony's friends from the Territorial Army Team, Mr. Frank Leaning, stepped forward and took on the sponsorship. Frank completed the run in 4 hours, 20 minutes. So all the families who have kindly been collecting sponsors for Tony's run, please could you collect your money.

BOLTON MARATHON

Friends of Maxine and Stephen Fitts, Mr. Robert Carolan and Mr. Bernard Barton from Stockport in Cheshire were so moved by Aaron, who suffers from Hurler Disease, that they decided to run in the Bolton Marathon to raise funds for MPS.

BT CHARITY WALK

Ken and Terry Ballard of Harrow who travelled to the Lake District to cover the 20 miles and 5000 feet of climbing between Seathwaite, Scafell, Wasdale and return to Seathwaite on Saturday 18th September, all in aid of MPS.

PICCADILLY CHARITY MARATHON

Mr. R. Smith and Mr. Higgins who made a donations sponsorship in the Piccadilly Charity Marathon.

NEW FAMILIES

We would like to welcome these families to our Society.

Mr. & Mrs. Ray from Avon, Their daughter Melanie is 9 years old and is suffering from Morquio Disease.

Alison James and her son Christopher who is 18 months and suffers from Hurler Disease. They live in Hampshire.

Mrs. Hill and her daughter Claire from Lancashire. Claire is 8 years old and suffers from Sanfilippo Disease.

Mr. & Mrs. Tailford whose 5 year old son Darren suffers from Hurler Disease. They live in Northumberland.

Mrs. Susan Pata from Leeds. Her 10 year old daughter Angela suffers from Morquio Disease.

Ian and Denise Oldaker and their 3 year old daughter Victoria. Victoria is suffering from Fucosidosis and they live in Hampshire.

Mr. & Mrs. Baylan whose 4 year old daughter Rosemary is suffering from Hurler Disease. A special welcome to our first family from the Republic of Ireland.

Dr. and Mrs. Champion whose two sons, Richard 10 years and David 12 years, suffer from Sanfilippo Disease. Their parents live in Cambridgeshire and the boys go to school in Aberdeen.

Pam Tubb who contacted us from the Association for REsearch into REstricted Growth. Pam lives on the Isle of Wight and suffers from Marateaux-Lamy Disease.

Mr. & Mrs. Davies from Walsall and their two children, Theresa aged 10 years and Robert aged 3 years. Both children suffer from Sanfilippo Disease.

Mr. & Mrs. Taylor from Hanley, whose son Christopher suffers from Hunter Disease.

Mr. & Mrs. Pollard from Hove, Sussex. Their 11 year old son Grant suffers from Hunter Disease.

Mr. & Mrs. Challon from Gainsford, County Durham. They have a 3 year old son Ross who suffers from Hunter Disease. Ross has recently received bone marrow transplant.