

# Newsletter

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## The Society for Mucopolysaccharide Diseases

National Registered Charity No.287034

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Winter 97



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## The Society for Mucopolysaccharide Diseases

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Telephone: 01494 434156 Fax: 01494 434252

The MPS Society is a voluntary support group, founded in 1982, which represents over 900 families in the UK with children or adults suffering from Mucopolysaccharide and related diseases. It is a registered charity, entirely supported by voluntary donations and fund-raising, and run by the members themselves. Its aims are as follows:-

- 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 Great Britain 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 supports two specialist MPS clinics at the Royal Manchester Children's Hospital and at the Hospital for Sick Children, Great Ormond Street, London. The Society also funds research projects at the Christie Hospital, Manchester, Royal Manchester Children's Hospital, Bristol Children's Hospital and the Institute of Child Health, London. It encourages and assists contact and co-operation between parents and professionals and maintains links with sister societies in Europe and throughout the world.

There is at present no cure for MPS diseases, but much can be done to improve the treatment and care of sufferers. The slogan of the Society is:-

**"CARE TODAY, HOPE TOMORROW"**

#### Front Cover:

*The photograph on the front page is of Christopher Rees aged 10 years old who suffers from MLIII and his Mum at the Welsh Christmas Party in December 1997.*

## CONTENTS



Page 3	Director's Report	
Page 4	Director's Report	
Page 5	Milestones	
Page 6	Information	
Page 7	Area Family Support	South West Xmas Party
Page 8	Area Family Support	Home Counties Xmas Party
Page 9	Area Family Support	South East Xmas Party
Page 10	Area Family Support	Getting to Know your Area Family
Page 11	Area Family Support	Continued
Page 12	Family Support -	Yorkshire Day Out
Page 13	Family Support	Continued
Page 14	Family Support	Share a Weekend (Northern Ireland)
Page 15	Family Support	Continued
Page 16	Family Support	Bristol Clinic
Page 17	Family Support	Welsh Clinic
Page 18	Family News	Childhood Wood
Page 19	Family News	Matthew's Poem
Page 20	Family News -	Bits and Pieces.
Page 21	Family News	Continued
Page 22	Family News	Jessica Stuart - The Move
Page 23	Family News	Continued
Page 24	Family News	Continued
Page 25	Family News	Jessica Stuart - The Holiday
Page 26	Family News	Continued
Page 27	Family News	Continued
Page 28	Overseas News	Finland
Page 29	Overseas News	New Zealand
Page 30	Fundraising	South West
Page 31	Fundraising	Joanne Evans
Page 32	Fundraising	Rosemary Nurse, Dominic Stimpson
Page 33	Fundraising	Northern Ireland
Page 34	Fundraising	Jeans for Genes
Page 35	Fundraising	North West Dinner Dance
Page 36	Fundraising	Xmas Draw
Page 37	Fundraising	Flowers
Page 38	Fundraising	Donations
Page 39	Fundraising	Fundraising Events

**Deadline for the 1998 Spring Newsletter  
20th March 1998**

*Please send us lots of photos*

## DIRECTOR'S REPORT

Well another year has flown by. We have been so busy in recent weeks that it was been hard to believe Christmas was fast approaching if it hadn't been for all the wonderful cards pouring into both the MPS offices. On behalf of Mary and Pam in the Northern office and Joan, Sheila and myself at the Amersham office we would like to express our deep appreciation for the hundreds of Christmas and New Year greetings received.

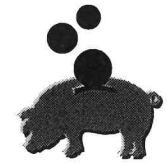
We know and understand that Christmas and the coming of another year brings mixed blessings for families affected by MPS. Our thoughts are with you at this time and may  we wish everyone a Peaceful  New Year.

### Search for New Offices

Those of you who have had to move house to accommodate a growing family will appreciate what the MPS Society is going through. For some five months now we have been looking for more spacious facilities to be the Amersham office. Easier said than done in South Buckinghamshire where office space is at a premium and therefore commands a disproportionate rent. We are currently negotiating on a potential property that needs many, many hours of work done to it before anyone could move in. I tell you this as, to keep refurbishment costs to a minimum we are thinking of having a couple of weekend working parties. If you can help in this way we would like to hear from you. We also need the services of a sign writer who would be willing to donate his services and time freely. Help with double glazing, replacement window frames, carpets, textiles and office furniture would be much appreciated. Anyway we will keep



you posted of developments and do let us know if you think you or your company can be of help.



### Jean for Genes

Well what a wonderful result so far with £1.2 million raised. Thank you to everyone who supported the event. This means we can continue with the research projects we undertook in 1996 as well as look at new projects.



### MPS Clinics

On 6th of November the Society held its first Bristol MPS clinic at Frenchay Hospital, Bristol with Dr Philip Jardine and Dr Ed Wraith. Many families took advantage of a much shorter journey than that to Manchester.

The following day the clinic moved to the University Hospital of Wales, Cardiff with Dr Graham Shortland and Dr Ed Wraith. This was our second visit to Cardiff and nearly every child and young adult in South Wales with MPS came to the clinic. We would like to thank Dr Wraith, Dr Shortland and Dr Jardine for making the clinics possible. For clinic dates in 1998 please refer to the Society's diary enclosed with the Newsletter.

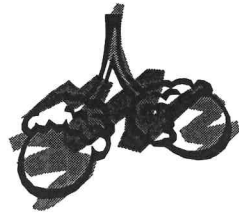
### Childhood Wood

On the 31st October 1997 12 children and young adults who lost their lives to MPS were remembered at the tree planting in the Childhood Wood. Councillor Alan Davidson welcomed families and friends to the wood and Sir Andrew Buchanan, Lord Lieutenant for Nottinghamshire read



## DIRECTOR'S REPORT

'Remember' by Christina Rossetti. The weather was very kind to us that day. The sun shone and the wood looked particularly beautiful. Having planted their saplings families spent time lingering before departing for the Clumber Park Hotel for afternoon tea. This year Mr and Mrs Temmink and their two daughters joined us from Belgium. They were remembering Bouke who died aged 4 years old of MLII in 1992. From Barcelona in Spain we were also pleased to offer a warm welcome to Isobel Vargas whose brother, Daniel died from Hunter Disease in 1987 at the age of 15 years. Our Childhood Wood is becoming truly international with one of the first trees planted being in memory of Adrienne Smith from Australia. If any overseas families would like to know more about the Childhood Wood please do write to us.



### Fundraising and Donations

As we write our accounts are with the auditors. However we thought you would like to know what a difference all your fundraising and donations made in 1996/97. After several successive years of having a deficit and in 1995/96 just breaking even this year we look as if we have made a small surplus.

So many of you have helped in so many ways and we want to say a big thank you to everyone.

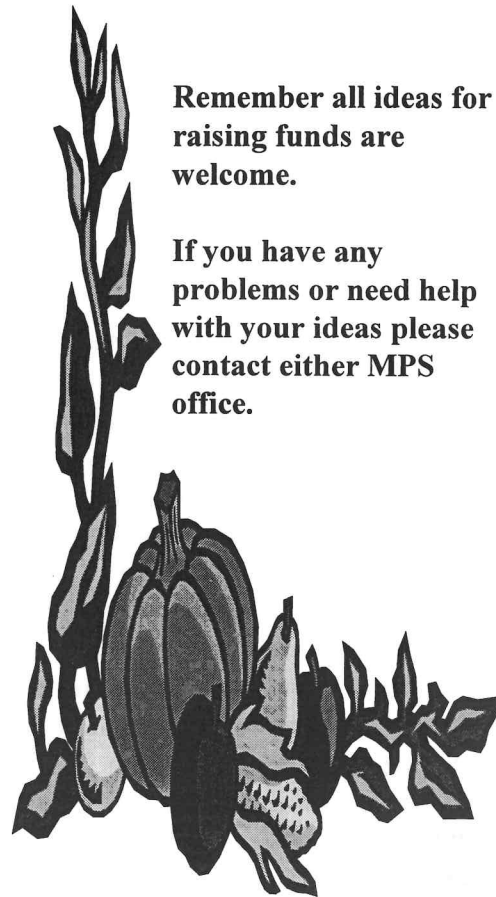
Sadly we cannot be complacent and the hard work now starts all over again to raise the £260,000 needed for our support budget in 1997/98. In November the Trustees agreed to increasing the number of staff by three

between the Northern and Amersham offices. We are looking to recruit two administrative assistants and a National Development Officer with a particular remit to our MPS families from ethnic minority groups.

We believe that this expansion will enable the Society to meet the needs of a growing number of MPS families.

Please do keep thinking MPS and help us to raise the money needed for 1998 and beyond.

*Christine Lavery*



**Remember all ideas for raising funds are welcome.**

**If you have any problems or need help with your ideas please contact either MPS office.**

## MILESTONES

### New Families

Jane and Peter Rennoldson's daughter, Megan aged 14 has recently been diagnosed with Mucopolysaccharidosis. Megan lives in Monmouthshire.

Jeanette and Steve Butler's son, Alexander aged 3 years has recently been diagnosed with Hunter Disease. The Butler family live in Shropshire.

### Deaths

Sadly Jordon Mills died on the 1<sup>st</sup> of January 1998. Jordon aged 2 years from Windsor suffered from Hurler Disease.

Natalie Britton from Bristol sadly died on the 26<sup>th</sup> November 1997 aged 16 years. Natalie suffered from Sanfilippo Disease.



At long last we managed to do our Tandem Jump for the MPS Society on the 1st November 1997, after two disappointing trips up to the parachute club at Peterlee.

The brave girls who raised £380 for the MPS Society are friends of Katie Martin aged 8 years old who suffers from MLII.

### Well done Girls

It all went well and Katie and her mum and dad, Sandra and Ray and her sister, Lisa all came to watch.

I enclose a photograph of Kathryn Lawrence, Lianne Convery (*holding Katie*) and Jill Hornsby.

**Jill Hornsby.**





## INFORMATION



### ROGER JEFCOATE ADVISOR ON TECHNOLOGY FOR DISABILITY

Roger Jefcoate is consultant to many well known disability organisations. Much of his work is voluntary and the rest is funded by charities.

As well as helping disabled individuals, Roger has established several projects which provide technical help on a wider scale. He has helped to set up information and equipment centres in Britain, USA and Israel, both national and regional. He helped to establish the first Information Technology Centre in London. Now there are more than 150 ITeCs throughout Britain giving training and work experience to unemployed young people.

In 1975 he founded ACTIVE (now the Special Needs arm of Play Matters - The National Association of Toy and Leisure Libraries) and the Aidis Trust - the best known national charity providing technology for severely disabled people. In 1983 Roger founded the Disability Aid Fund and in 1985 relaunched Mobility Trust - providing

wheelchairs and other mobility aids for disabled people.

Roger helps severely disabled people benefit from technology to increase independence and quality of life. He specialises in computers, electronic remote control systems, reading aids, writing aids and communication aids for people who cannot speak.

This service is free to disabled people and he is usually able to arrange funding for appropriate equipment through various charities with which he is associated.

Roger is giving talks in 1998 at the following venues:-

- 15th January - Oxford
- 17th February - Horsham
- 1st March - Reading
- 1st May - Holt, Norfolk
- 10th May - Windsor
- 19th May - Exeter
- 25th September - Elgin

### STUDY FINDS DISABILITY PICTURE IS OUT OF FOCUS

Disabled people are fed up with the way they are portrayed on television and radio, a new BBC study has shown. Disability and Broadcasting: A view from the margins was commissioned by the BBC's Broadcast Equality Unit, and 384 people were interviewed.

The study found many were unhappy with the representation of disability in mainstream factual programmes. People said that high profile personalities were

often used to speak on behalf of disabled people, which meant the real voice of disabled people did not get heard. Specialist programmes were praised for content but criticised for "ghettoising" disability. The lack of trailers and unpopular scheduling meant only those in the know about such programmes were ever likely to watch and learn about disability issues. The BBC is now putting together a database of disabled people willing to participate in television and radio programmes **Tel: 0181 576 4336.**

*Both the above articles were taken from TAG.*

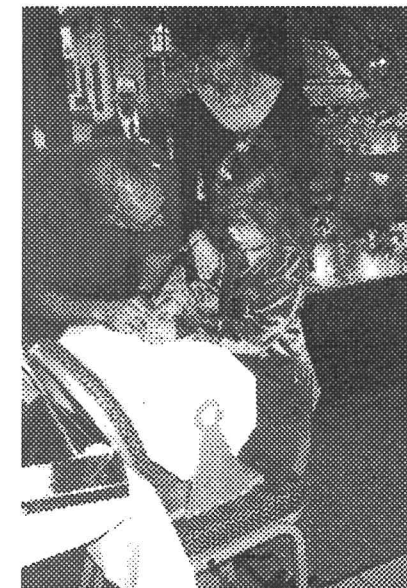
## AREA FAMILY SUPPORT

### Christmas Party - South West Area - 7th December 1997

The months slip away so quickly don't they! No sooner is the MPS conference over than it seems that Christmas is here. And it is!

Our 1997 Christmas party venue seemed to suit our needs very nicely and so again we chose the Stakis Hotel in Bath which has a lovely function room overlooking the canal and river

where we can run riot without interfering with the main hotel.



The party was very well attended even though some families had to travel a fair distance and we had a

lunch time buffet followed by an entertainer. He had obviously been trained by Paul Daniels and had some very good magic that even caused concern(!) to some parents who were not sure quite how he did some card tricks.

We also had the MPS Annual Draw organised for the

afternoon and the tickets were drawn by the children during the party - it was the only time of the afternoon when

suddenly all was silent as one by one, small hands and arms delved into the vast barrel containing the ticket stubs.

Suddenly, it was 4 o'clock, the rain hadn't stopped since our arrival

and everyone was starting to leave. I

looked around at the paper hats and cracker wrappers strewn across the floor, cold bits of a burger on a chair, empty coffee cups around....



...yes, another party, another year. Shall we do it again in twelve months time?

**Fer Pidden**



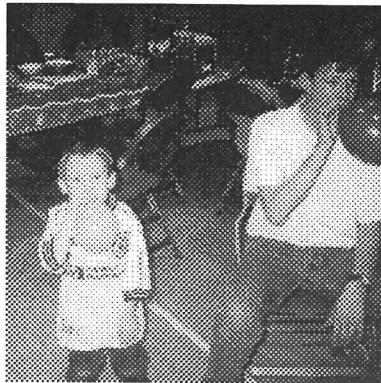


AREA FAMILY SUPPORT

London and Home Counties Christmas Party - 7th December 1997

The London and Home Counties 1997 Christmas Party was held at Loddon Valley Leisure Centre, Reading Berkshire on the 7th December 1997.

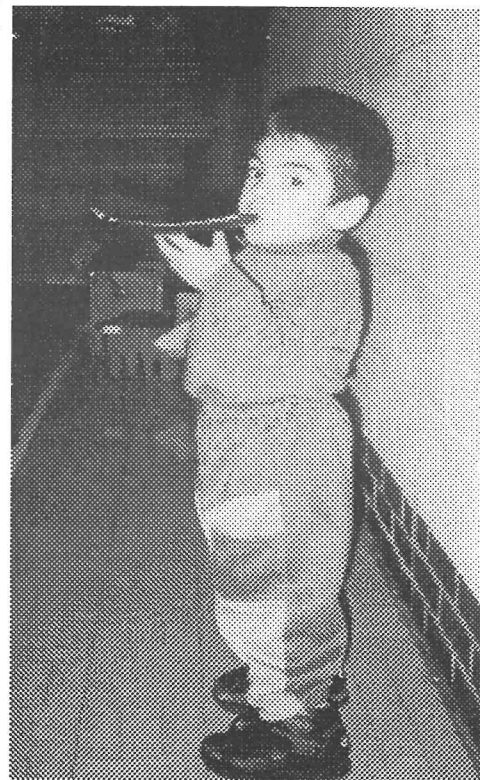
The response this year was very poor. Only eight families replied. Still we had a good time. Santa didn't let us down (Gavin Brown)



although he looked as if he had been attending Weight Watchers!

£27.00 was raised by the raffle and everyone had a lovely time.

Rachel Wheeler



*"For every ailment under the sun  
There is a remedy or Not  
If there is one try to find it  
If there be none, Never Mind It."*



This lovely sentiment was sent to us by Rachel and Mark Wheeler and we thought you would all appreciate this.

AREA FAMILY SUPPORT

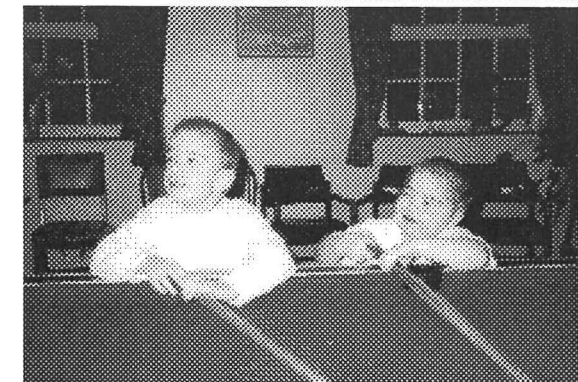
South East Christmas Party - 7th December 1997

Nine MPS Families attended the South East Christmas Party on the 7th December 1997 at the Wheel Inn, Burwash, East Sussex.

Everyone enjoyed tea and a chat. The children played various games including pool. The afternoon ended with a visit from Father Christmas.



Mary and Robin Gooch



The Welsh MPS Christmas Party - 23rd November 1997.

The Welsh MPS Christmas Party was held on the 23rd November 1997 at Clydach Hall. There were more families this year and everyone had a great day.

North East Christmas Party - 14th December 1997.

The North East Christmas Party was held on the 14th December 1997 in Darlington.

Anne vert

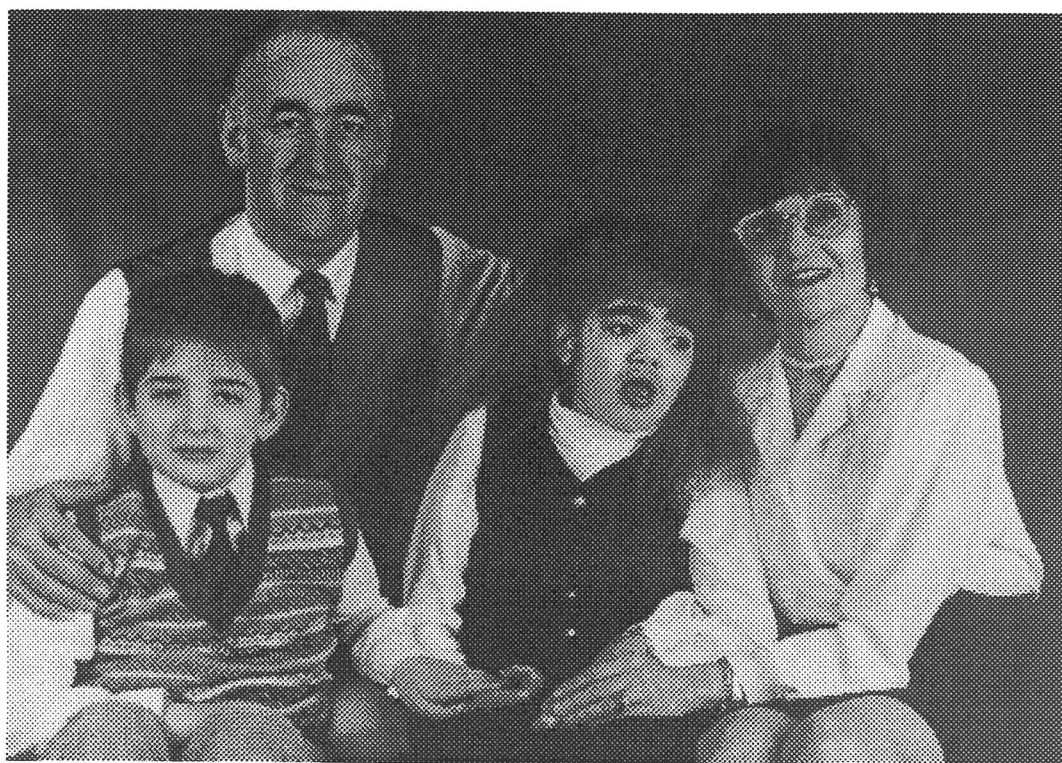


It was attended by 6 families who all had a great time. We were also lucky enough to have a visit from Santa himself. He was feeling generous as he brought a sack full of prezzies with him. The bouncy castle was most certainly enjoyed by the children as well as a few adults. We also raised £35 from the raffle.



AREA FAMILY SUPPORT

GETTING TO KNOW YOUR AREA FAMILY



Pictured above are Fer and Bill Pidden who are one of the Area Support Families for the South west .They are pictured with their daughter, Natalie aged 17 who has Sanfilippo Disease and their 10 year old son , Anthony.

Pictured opposite are Anne and Mike Kilvert the Area Support Family for Wales.

Anne and Mike's daughter Sarah sadly died in 1995.

Sarah who was 22 years old suffered from Morquio as did her brother, Carl who died in 1975 aged 4 years old.

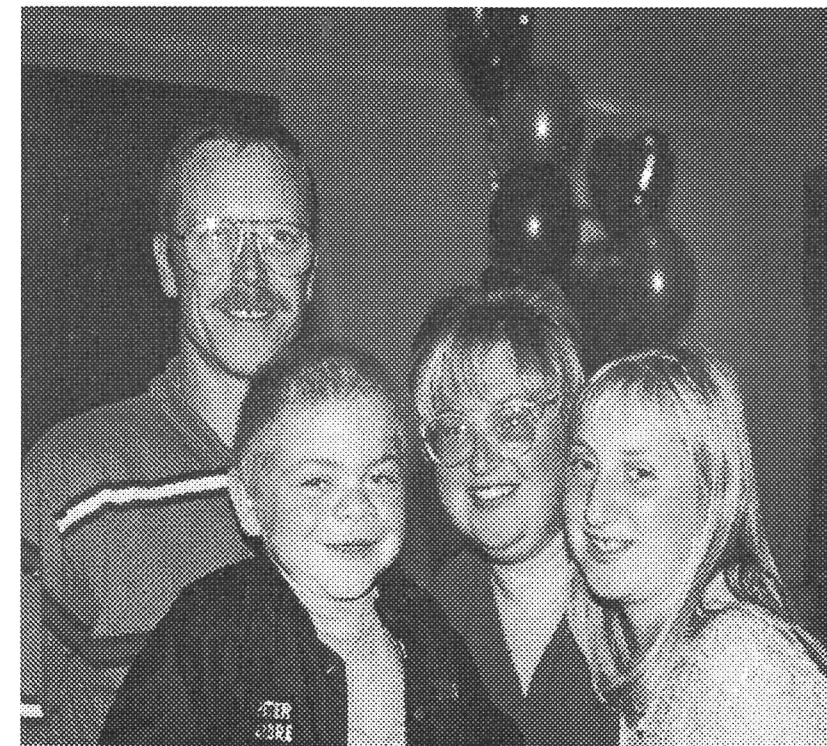


AREA FAMILY SUPPORT

Pictured opposite are the Oulton family.

Geoff and Selma are an Area Support Family for the North West.

Their 10 year old son, David who has Hunter disease has been pictured in previous newsletters in his Magician's outfit. His sister Sarah has also appeared in previous newsletters due to her involvement with raising funds for the MPS Society.



Pictured here are Bill and Sylvia Blackburn.

Bill and Sylvia have been involved with the Society for many years and are an Area Support Family for the Potteries.

Sadly their son, Mathew died in 1993 aged 16 years of age.

Mathew suffered from Hunter Disease.





FAMILY SUPPORT

Yorkshire and East Coast Area Family Day - 5th October 1997

Lots of families came and joined together in a lovely day at the Eureka Museum for children. It was wonderful to meet new families for the first time along with a few we haven't seen for quite a long while.

The sun came out for us as we had our picnic and had a chat. Then it was on to the museum where we ventured to discover lots of wonderful things and how they worked. The music room with it's unusual sounds seemed a keen favourite with many of our children. This was an enjoyable family day especially with our MPS children and siblings very much in mind, and with the getting together

with their families. Hopefully everybody had as much fun as we did ourselves and our children

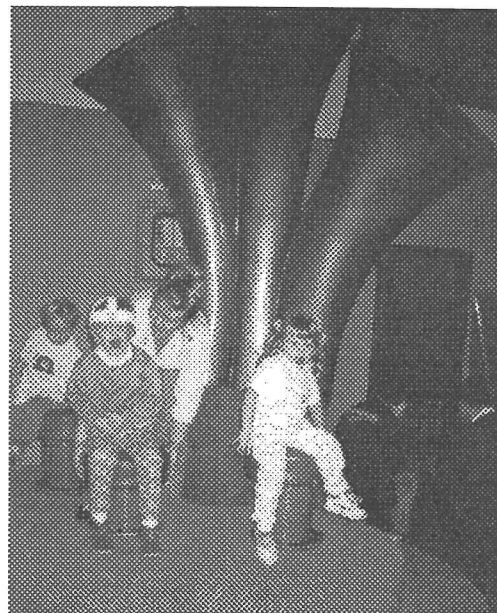
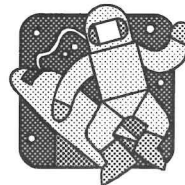
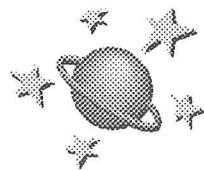
(especially Trev - when the children were repeatedly saying "Is it my turn now, Dad, you've had your turn?")

It would, of course be nice to meet more families in person so that we can put a face

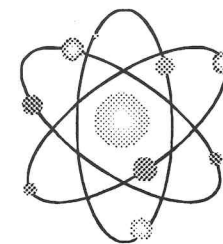
to the voice on the other end of the phone!

Maybe at an event in the new year?

*Barbara and Trevor Rollison*



FAMILY SUPPORT





**FAMILY SUPPORT**

**"SHARE" WEEKEND" Northern Ireland  
Come to a B-B-Q with a difference  
Friday 24th - Sunday 26th October, 1997**

A B-B-Q with a difference that was the idea which came out of a meeting of M P S families during Christine and Mary's visit to Northern Ireland in the Summer time.

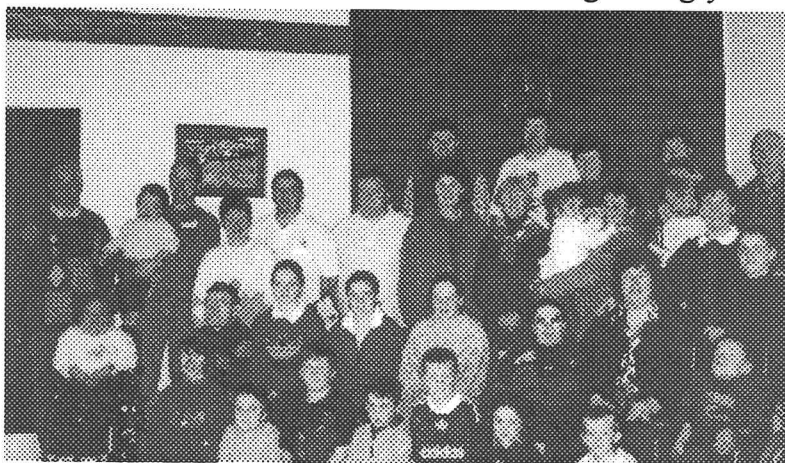
At a further meeting, that Northern and Southern families were at, leaflets were given out. The response was very encouraging.

The idea was to go to the "Share" Activity Centre in Fermanagh, which was fairly central to everyone. Some had two and three hour journeys. This Centre is specially designed for people with special needs.

We had 11 families wishing to go. Nine actually came to the weekend which amounted to 35 bodies.

The families arrived on the Friday night after tea, found their chalets, unpacked and relaxed. A short meeting was held in the main hall to welcome everyone and to give out some helpful tips. The most important message was that everyone who had come for the weekend could join in or just relax, the choice was theirs. The weather was dry all

weekend but oh what a frost on Friday night. The two families in the main building bedrooms got quite a shock when they went to their beds and found no heat, but after some hard work the heat was restored. When Keiran arived after 11pm we decided we were very hungry so some of our B-B-Q food was thrown on the stove and by 1am we were no longer hungry. A couple of the



families had already gone to bed but we sent runners to take food to the chalets.

Saturday after breakfast, everyone had to clear and set the tables for lunch, you know the

saying "many hands make light work" it is true. After which some disappeared into the pool for a swim. At 10.00am the choice of Canoeing, Swimming, Archery, or Climbing the wall, were on



offer. Sailing had to be cancelled as there was a heavy mist, which soon lifted. Our party decided to split into three for the

morning and meet for lunch at 1.00pm.

**FAMILY SUPPORT**

At 2.00pm we again met to decide on our afternoon activities. The canoers had such a great time in the morning the word got around and nearly all the party decided to try it in the afternoon. After tea on Saturday



chatting away.

there were no more activities provided by the "Share" centre, I think everyone was happy because they were all beginning to fade from exhaustion.

On Saturday night the B-B-Q very nearly didn't take place as everyone was tired. But by 9.30pm it was decided to fire up the B-B-Q and anyone wanting food could

smell it cooking and come over to our chalet. I am afraid I went to bed at 1.00am and left all the others



Sunday saw some of us away to the pool for a dip before breakfast (I don't know where the energy came from). A very short games time and a few face paintings whilst we were waiting for our instructors. Our last activity of the weekend was a leisurely cruise round the lake, wall climbing, swimming or archery, after which we had our final meal followed by a goodbye meeting and group photographs. A tearful goodbye and lots of invitations to future North and South activities saw the end of a wonderful weekend.

**ANN KIRKPATRICK**



**FAMILY NEWS**

**MPS Bristol Clinic - 6th November 1997**

The first MPS Bristol Clinic was held at the Frenchay Hospital, Bristol on Thursday the 6th November 1997.

Fer Pidden ( Area Support) also came along and kept the tea on the go.

We would like to thank Dr Jardine and his staff for allowing the MPS clinic to be held here and it was very much appreciated by the families who attended. Again we would like to thank Dr Ed Wraith who along with Dr Jardine saw the children and young adults.

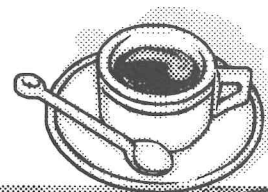
We are hoping that the Bristol Clinic will become a bi-annual event so that families do not have so far to travel.



Toby Parfitt, aged 11 years (Hurler/Scheie) with his Mum.



Opposite: Faye Longley, aged 7 years old (Morquio)



Opposite: Olivia Bailey, aged 1 year 4 months (Hurler) with her Dad and Sarah Long adult (Morquio) also pictured is Fer making yet another cup of tea!!!!!!



**FAMILY SUPPORT**

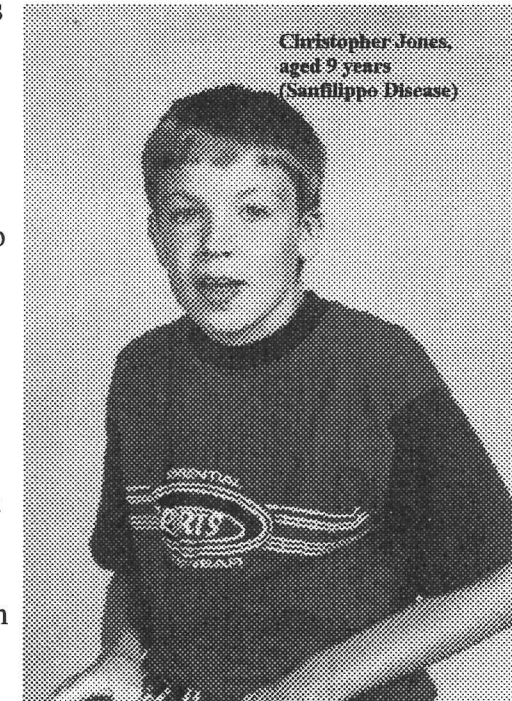
**MPS Welsh Clinic - - Friday 7th November 1997**

The second MPS Welsh Clinic was held on the 7th November 1997 at the University Hospital of Wales, Cardiff.

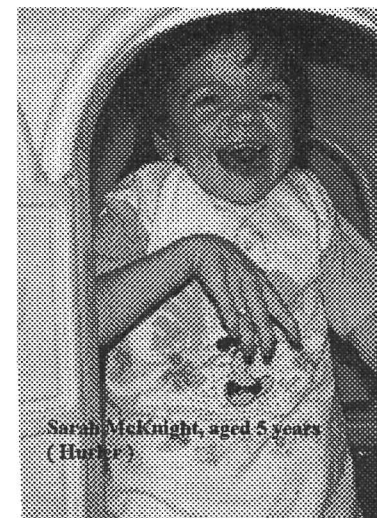
Dr Graham Shortland kindly allowed the clinic to be arranged to accommodate MPS families from Wales.

Dr Ed Wraith and Dr Shortland saw 13 children and the day was a success and the families really appreciated being able to attend an MPS clinic so close to home.

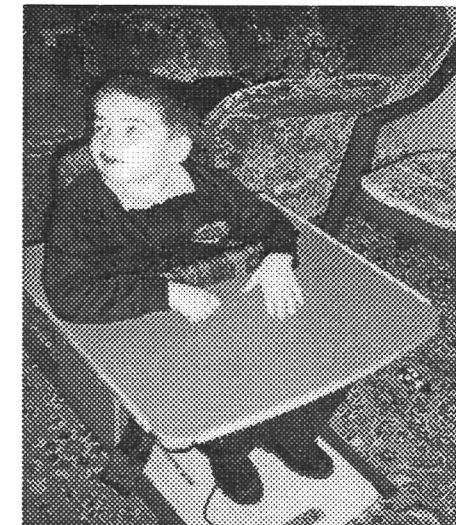
We would like to thank Dr Graham Shortland and all the nursing staff for being so helpful.



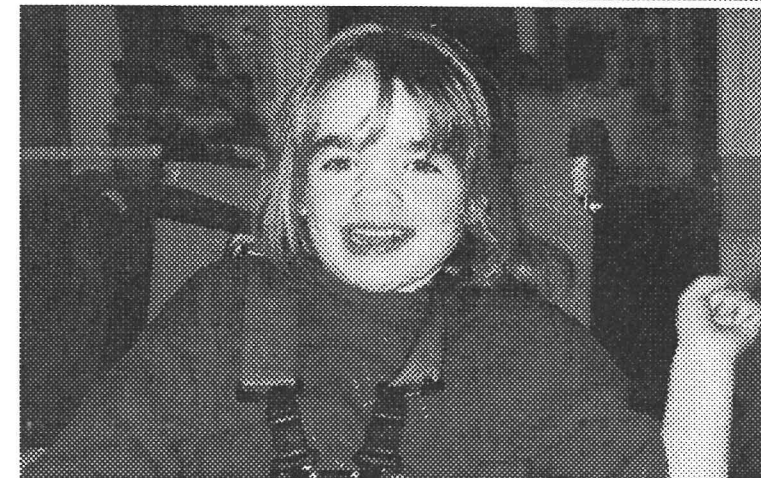
Christopher Jones, aged 9 years (Sanfilippo Disease)



Sarah McKnight, aged 5 years (Hurler)



Above: Craig Pope, aged 7 years (Sanfilippo)



Melanie Jones, aged 6 (Sanfilippo Disease) Opposite.



## FAMILY NEWS

## Sapling Planting - Childhood Wood - 31st October 1997

The Planting of oak saplings planted in memory of MPS children and young adults who have died was held on the 31st October 1997 at Sherwood Pines Nottinghamshire.

A total of 12 children were remembered by the planting.

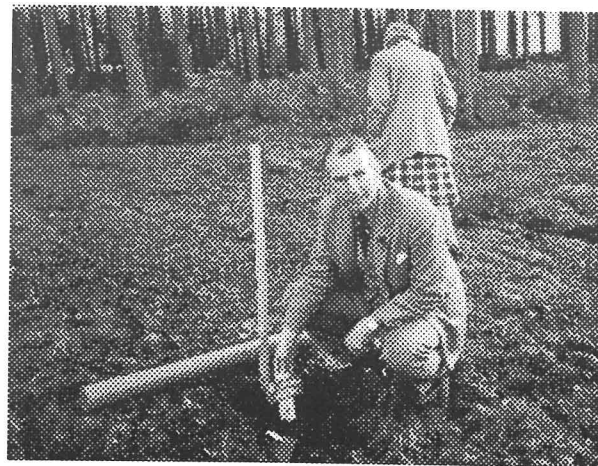
Sir Andrew Buchanan, Lord Lieutenant for Nottinghamshire, read the poem 'Remember' Councillor Alan Davidson, welcomed the



This year for the first we had a family from Belgium and one from Spain who planted saplings in memory of their children.

It was a beautiful autumn day and the sun shone on the Childhood Wood' which was quiet and peaceful adding to

the dignity of the day and hopefully everyone received some comfort from the surroundings.



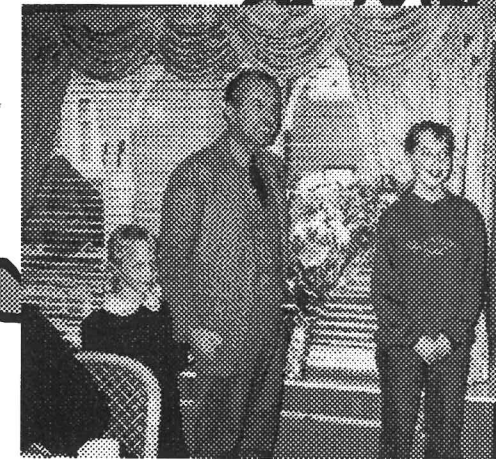
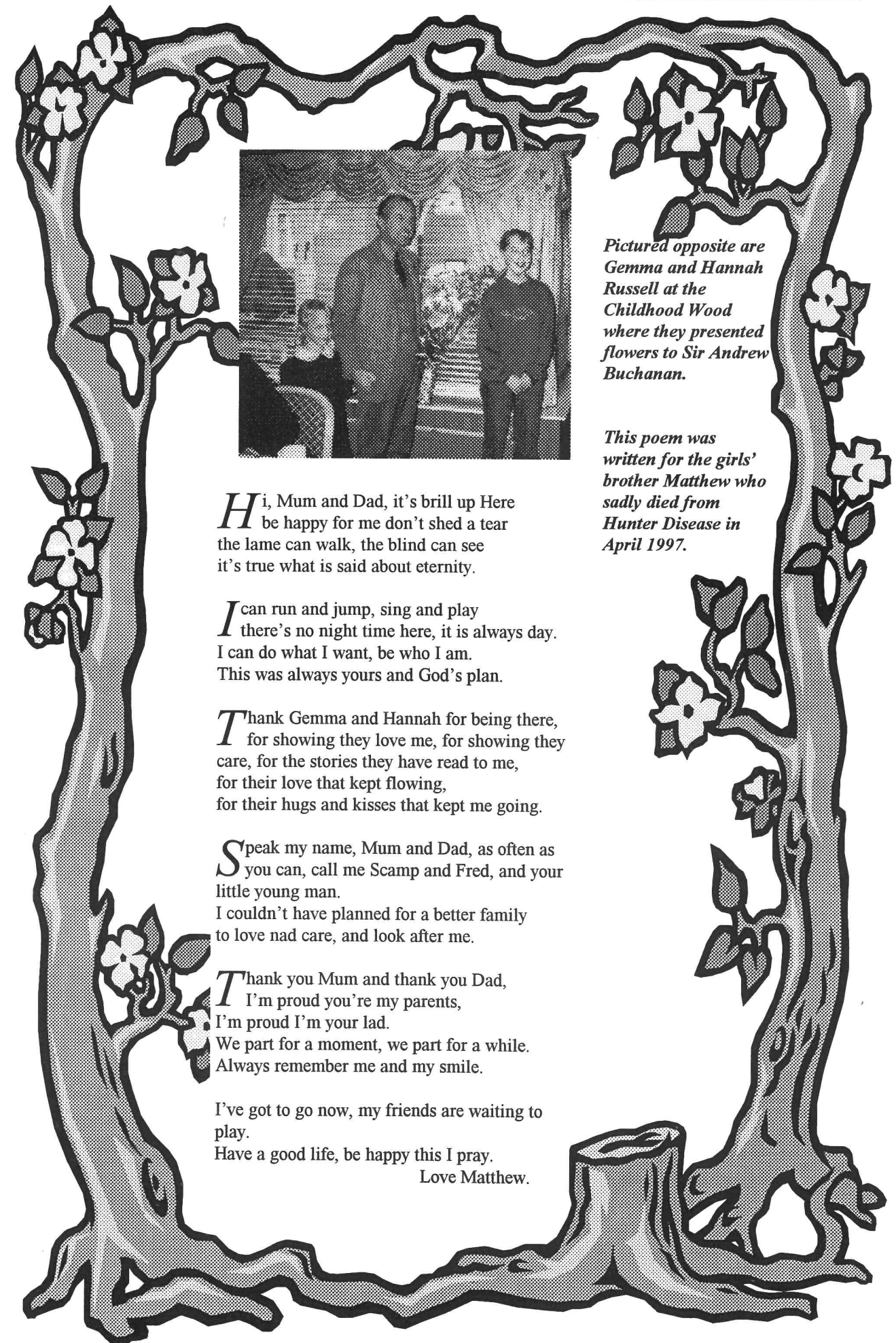
families to the wood and Mrs Smedley and Mrs Bean came as guests of the Society. We would like to thank them all for their continued support of the Childhood Wood and the MPS Society.

*Pictured above: Monty and Dorren Russell with their two daughters, Gemma and Hannah.*

*Sir Andrew Buchanan (above) and (opposite) Councillor Alan Davidson kindly left holding the baby.*



## FAMILY NEWS



*Pictured opposite are Gemma and Hannah Russell at the Childhood Wood where they presented flowers to Sir Andrew Buchanan.*

*This poem was written for the girls' brother Matthew who sadly died from Hunter Disease in April 1997.*

*H*i, Mum and Dad, it's brill up Here  
be happy for me don't shed a tear  
the lame can walk, the blind can see  
it's true what is said about eternity.

*I* can run and jump, sing and play  
there's no night time here, it is always day.  
I can do what I want, be who I am.  
This was always yours and God's plan.

*T*hank Gemma and Hannah for being there,  
for showing they love me, for showing they care,  
for their love that kept flowing,  
for their hugs and kisses that kept me going.

*S*peak my name, Mum and Dad, as often as  
you can, call me Scamp and Fred, and your little young man.  
I couldn't have planned for a better family  
to love nad care, and look after me.

*T*hank you Mum and thank you Dad,  
I'm proud you're my parents,  
I'm proud I'm your lad.  
We part for a moment, we part for a while.  
Always remember me and my smile.

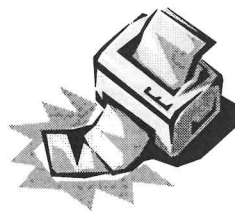
I've got to go now, my friends are waiting to play.  
Have a good life, be happy this I pray.  
Love Matthew.



**FAMILY NEWS**

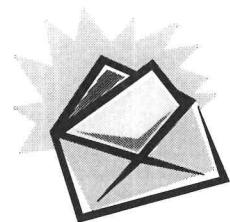
**MPS TEA-TOWELS**

We are very sorry to report that we have now sold out of MPS tea-towels. We are hoping to replace them with a new tea-towel design. More news about this soon.



Anyone who is having trouble contacting the Northern MPS office due to the telephone being engaged can try on the fax line as this is also a telephone.

**Tel: 01772 815516**  
**Fax/Tel: 01772 814821**



**CONTACT WANTED**

Vito Brusco from Italy has written asking us to publish a request for a Morquio family to contact a family in Italy

**Maria Pia Cavalli**  
**Via Campo del Fico No 51**  
**Sasso per Campora (Parma)**  
**Italy**  
**Tel: 521 846569**

**Maria is 32 years old and suffers from Morquio she also has a married sister who is the mother of two children.**



**Free to a Good Home - Commodore Amiga**

Ely Computer Centre kindly donated a commodore Amiga and monitor to Peter Stuart for the MPS Society.

If you are interested in this computer please contact Peter and Sue on

**Tel: 01353 887018**

I am sure they will be happy to hear from someone who could make use of this computer.

Jean Rondeau from VML in France asked us to let him know if any MPS children would like to go to France on an Exchange Programme.

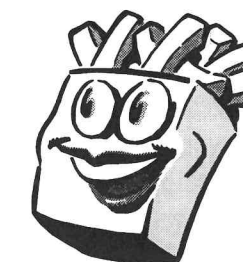
If you are interested please contact the Amersham office.

**FAMILY NEWS**

We found this poem in the Sturge Weber Newsletter.

*Me and My face - By a Small Child*

*Don't look away when you see me  
Don't feel you can't look and smile  
I'm just the same as you, you know  
and I've had my face for some while  
I've come to be friends with my face you see  
We didn't get on for some years  
I didn't want it spoiling my life  
and I spent lots of time crying tears  
But then I met Doreen and Peter  
who opened my closed eyes to see.  
They said my face was a small part  
10 per cent of the whole of me!  
So look at me my dear stranger  
and smile at me and feel fine.  
For me and my face get on well now  
for I learnt to love me and what's mine.*

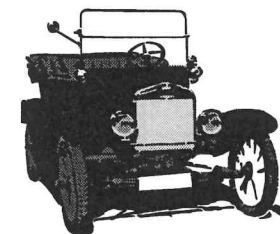


**Walkers Crisps**

Walkers Snack Foods Ltd. have written to Disability Now following a serious incident which has come to their attention. An adult with severe learning difficulties allegedly choked on a wrapper promotion plastic toy which was included in one of their products. They have asked Disability Now to publish this warning so we thought we would also publish this warning.

“Recommended steps for carers of people with severe learning difficulties, with regard to any crisps or snack promotions.”

- Always check the front of any pack of crisps or snacks as they may contain a promotional insert.
- Check to see if there is an insert inside and if so remove before giving the crisps to the person with learning difficulties.



**EU Parking Card**

Disabled drivers should find parking easier around Europe when a new parking card is introduced.

European Union social affairs ministers said EU governments would have to accept parking cards issued by other member states from January 1999, followed by a standard card a year later.



## FAMILY NEWS

### Jessica Stuart - The Move!

Thought of moving entered our conversation when we had been living in Hertfordshire for about six years (October 1996) and Jessica was just over 5 ½ years old, but it was scotched straight away because of her. How could we move with Jessica? There were so many things to consider; it was too complicated; the local doctors, hospitals and social services etc. were all familiar with Jessica and her needs. She was settled at a marvellous school, the staff knew her well and they had adapted their teaching methods to accommodate Jessica's needs when she lost her sight. She had been there since she was 2½. How could we take her away from all that? She was used to the house and knew her way round very well. We had recently had a ground floor extension built, a bedroom and bathroom for Jessica, which she loved. The garden had been landscaped with Jessica in mind and the house was just how we wanted it.

We were mad to even think of moving. What about the other two girls, Jessica's sisters, Hollie (nearly 2) and Annie (nearly 5 months)? There was no way we could move with such young children.

#### - A Nightmare.

We did move ( January 1997) and yes, it was a **nightmare** especially the first three months. You might say "Why on earth did you move?"

What did you gain from it if you had everything to rights where you were?"

We decided to move because we wanted the two younger girls to go to decent schools and where we were the schools were not up to much. We had no close family ties and Peter was about to retire from the Police Force. To move after Jessica died would be daft as no one would understand who we were grieving for, whereas, if we moved with Jessica our new neighbours, friends and acquaintances would get to know her and hopefully understand and appreciate who she was.

We put the house on the market thinking we had plenty of time to sort things out. But Surprise!! Surprise!!, the house was sold in three days!!!! We were flabbergasted.

We had already decided where we were to go



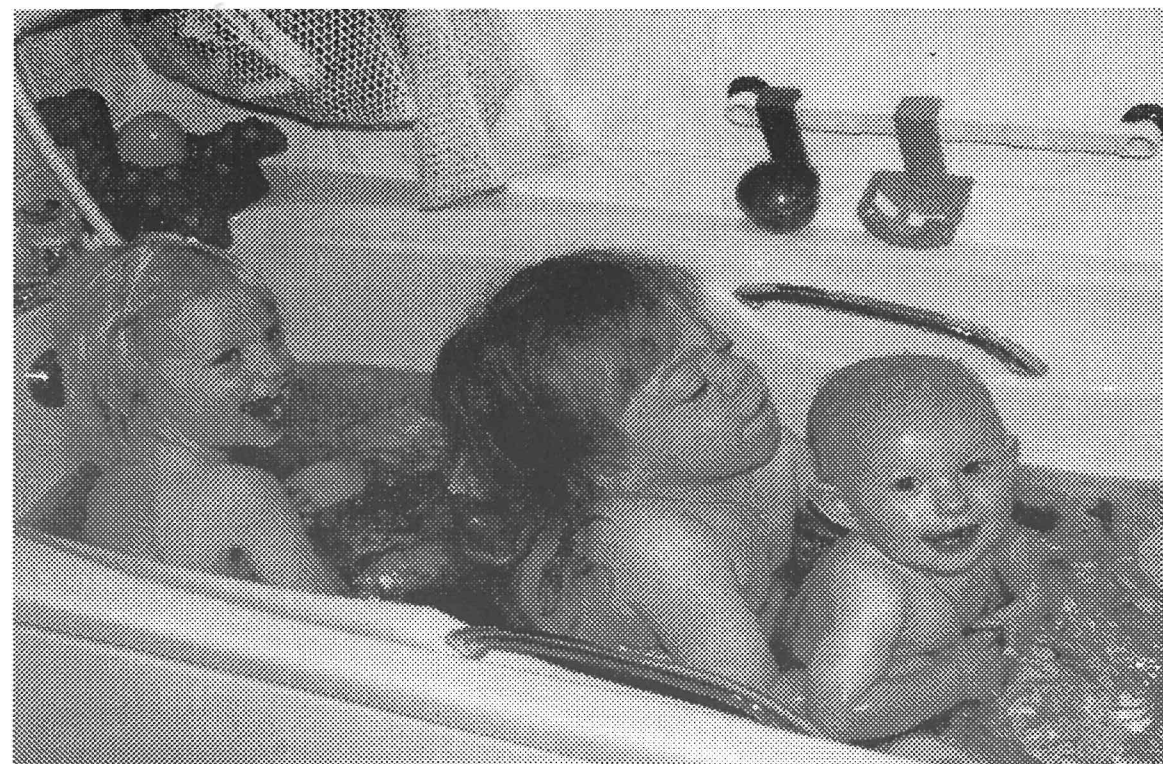
so all we had to do was buy a house that would be suitable for Jessica's needs. **A tall order.** After viewing a couple of houses we were a bit disappointed

at the choice but God was looking out for us and we found our dream home in the space of a week. Within three months we had moved into a brand new house on the outskirts of the beautiful cathedral city of Ely in Cambridgeshire.

## FAMILY NEWS

There was lots to do and think about. We were lucky to find an excellent special needs school only ten minutes walk from our new house, and equally so a doctor's surgery with just the right mix of doctors just round the corner. Our first contact with our new Education Authority rocked us back a bit. Yes, the school we had chosen was excellent

Frantic pleading phone calls to the Education Authority led to a compromise. we could set up a meeting with the Head Teacher of the new school nearby and if she agreed to take her they would find some way of fitting Jessica in. The new Head proved to be a very lovely lady who brushed all the difficulties aside with nonchalant ease.



but it was full and in any case was to move to a new site in the next two years. Jessica would need to be bussed 20 miles each day to the next nearest school. a phone call to the chosen doctor's surgery was just as bad, "We are full and the Health Authority will not let us take any further patients however special their needs!!"

The problem of finding a new GP was sorted out quite quickly with a phone call the next nearest surgery. We obviously have no idea of how we would have been treated at the first choice surgery, we can only remark on how helpful, accommodating and willing to listen, our new doctors have proven to be. It almost feels as if we have been registered with them for years and not just months.

She arranged visits by Jessica's new teachers to her old school, agreed the purchase of equipment from the old Education Authority and even, inintially went over budget to supply the one-to-one Teaching Assistant that Jessica needs because of her blindness.

It is some ten months after moving, at the time of writing this piece for the newsletter (it was started in June) and you would believe Jesica has been at the new school all her life. She is so settled and confident in her new environment that we cannot believe we made such a fuss about moving her.

We have settled in quite nicely now and are



FAMILY NEWS

beginning to make friends with people in the area. We are on a new estate which can sometimes be a bit lonely, but there is a very active coffee morning rota so I'm getting to know people quickly. Our neighbours are terrific and have accepted Jessica without batting an eyelid. They have been very supportive without being interfering. Peter has joined the local golf club and, whilst he would never be able to play often enough to satisfy him, he is making friends.

To any one who has an MPS child and is debating whether to move house or not, we would say go ahead, It is very stressful, requires a lot of diplomatic talking and an extra lot of prior arranging, but it is worth it. We were living out of boxes for three



months but that is because we had a few disasters. The move itself went smoothly but we had bought and arranged delivery of a number of appliances and furniture. Nothing arrived when it was supposed to and several things were delivered damaged and trying to sort things out was horrendous. But having said that, we are glad we moved, it was the best thing we could have done for Jessica, Hollie and Annie and of course, ourselves.

Good luck to anyone who is contemplating moving home!!!!

Sue Stuart

Sue and Peter are parents of Jessica aged 6 years who suffers with Hurler Disease.

FAMILY NEWS

Jessica's Special Holiday

Jessica has Hurler Syndrome (MPS I) and as she was over six 1/2 years old, we decided that it was now or never ( July 1997) that we were going to take her to Disney World. We wanted her sisters, Hollie and Annie to have lasting memories of Jessica on a very special family holiday.

The next step was to see how much it was going to cost .....A LOT!!!

We were unable at that particular time to find out names and addresses of Wish Charities but our sister in law came up with a contact. We found out that it was going to cost at least £3,500 so we had a word with the bank manager and arranged a loan if need be.

We would not be able to manage Jessica, her two sisters and ourselves on a nine hour flight so we approached Hollie's godfather, Tom and asked if he would come with us as a carer, ( he is a carer by profession). He agreed and

it was at this stage that our health visitor mentioned the Carer's Contingency Fund. They might be able to give a grant to pay for Jessica's carer. We were told that we could have £500 if we produced a breakdown of costs.

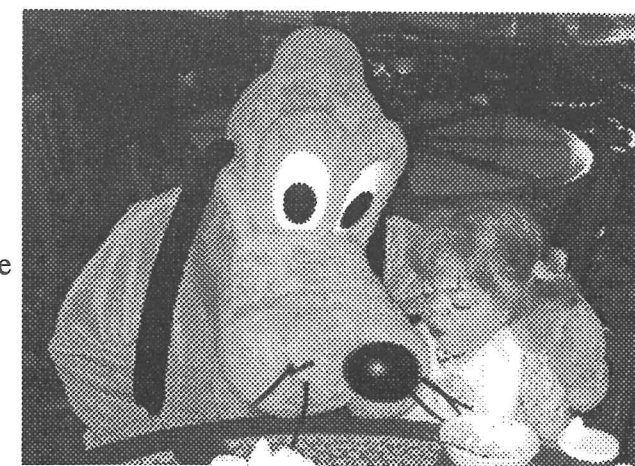
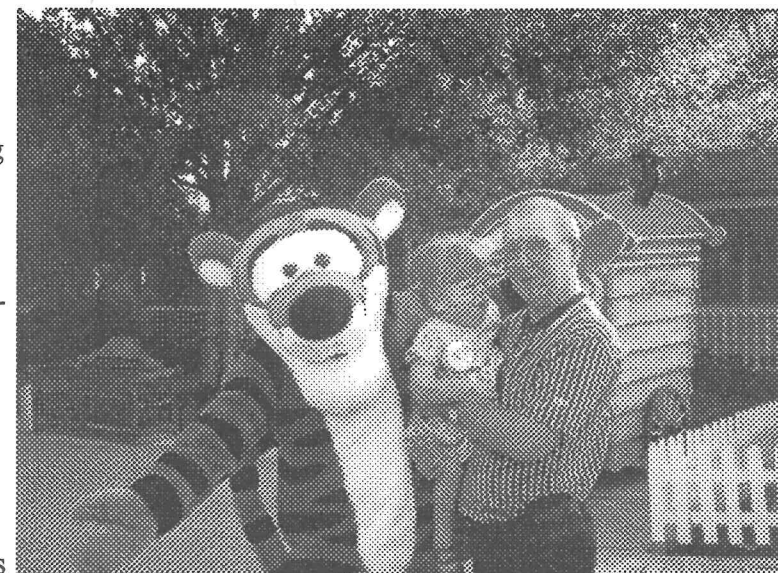
By now the holiday costs were rising and there seemed no end of extras that had to be paid for. We decided to ask the local newspaper for the names of local charities but they were unable to give any but said that they would be interested in Jessica's story. They launched the Jessica Appeal asking for donations to help pay for Jessica and her family

to fly to Disney-world, Florida.

We were told about a charity called Dial-a-Dream who might be able to help, so we contacted them and they were able to get us a better deal (price wise) on flights etc. The total cost was

£5,100.00.

By the beginning of September the people of Ely had raised, via the newspaper appeal, a staggering £5,300 ( by the time we returned the total had grown to £6,658).





## FAMILY NEWS

Our dream of a special family holiday with Jessica was now a reality. Dial-a-Dream arranged for us to stay in the "Give Kids The World" village ( an American Charity) for the first week and then in their own villa the second week.

On September 25th with Tom, we set off to the airport. The flight was OK and the children were fine. We arrived at Orlando and picked up our hire car ( a 7 seater van with air-conditioning - a must) and made our way to "The Village".

The welcome we received was overwhelming and our accommodation was superb. The "Village" is geared totally for sick children and the American volunteers were wonderful. We had passes, meal vouchers, free parking tickets and film given to us as well as little gifts left in the villa for the children every day.

Breakfast and tea were laid on and during the mealtimes the Disney characters would come and visit the children. Jessica loved meeting Goofy, Pluto, Winnie the

Poo and Tigger. We told them she was blind and they made sure that they spent plenty of time with her so that she could feel their costumes, they were so patient and thoughtful with her that it brought tears to

our eyes watching her. During that first week we did all the sights i.e. Seaworld, Epcot, MGM & Universal Studios, Busch Gardens and the Magic Kingdom. All the staff at the theme parks were very helpful and Jessica

went on some very scary rides as they allowed us to go straight on and not queue.

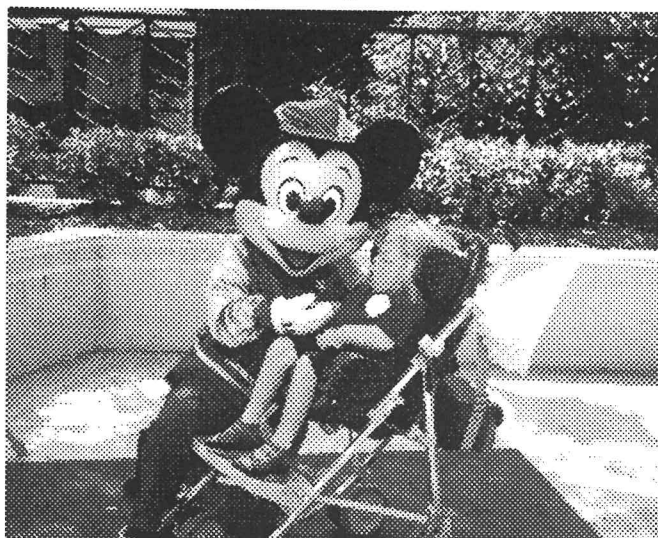
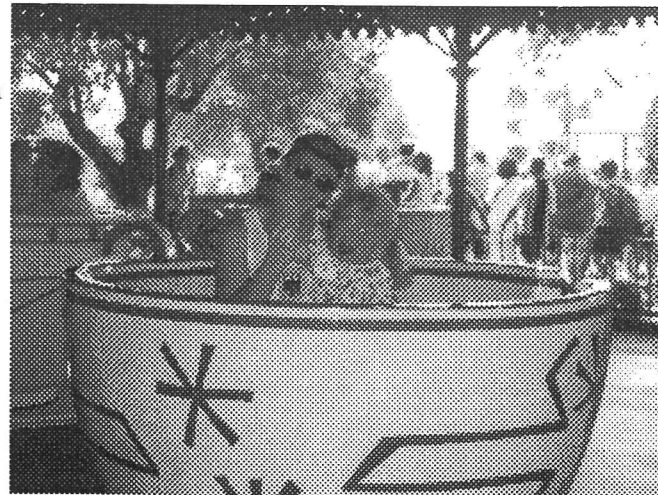
America is so prepared for children and wheelchairs that there are plenty of public toilets (men and women) with baby changing

facilities (they were big enough to change Jessica on them) and wheelchair access- it was so wonderful as all the eating places were accessible too. Everything is so much cheaper. We brought back lots of children's clothes and of course, jeans for me and golf shirts for Peter. We loved eating out because you got good value for money as many places had a "As much as you can eat" menu

for about \$5.00 (£3.00). By the second week we were exhausted and had decided that we would take it easy.

The "Dream Villa" was just that, a dream. It had four bedrooms, en suite bathroom, family bathroom, lounge, huge kitchen, dining area and an outdoor

heated swimming pool. It was pure heaven as the kitchen was fully equipped with the essential dishwasher, waste disposal unit, washing machine and dryer!!! Apparently all that is standard in new homes in the USA.



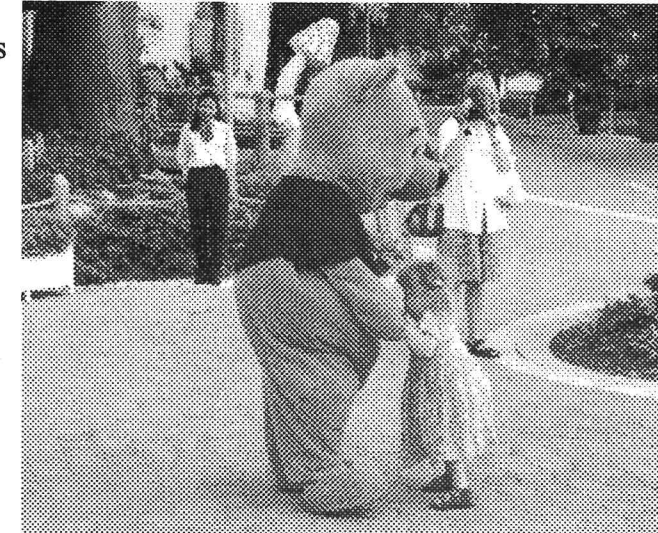
## FAMILY NEWS

We spent most of our time eating in and dining out and swimming in the lovely heated pool - Luxury! We fulfilled our dream of Jessica having a very special holiday and that Hollie and Annie will have wonderful memories of Jessica on holiday. We took lots of photos and video film of most things the girls did. Jessica (6 years 7 months), Hollie (2 years 8 months) and Annie (1 year 2 months) all thoroughly enjoyed themselves and we are so pleased that we were able to enjoy all the sights, sounds and experiences of Disney TOGETHER.

Charity as they were marvellous in understanding the needs of Jessica and us as a family with an MPS child. Of course they now know about the MPS Society and are willing to help out any other families who

may wish to go to Disney or anywhere else, or have any other wishes that they would like to fulfil.

We have donated the outstanding balance of our appeal to the MPS Society £1,435 will go towards the annual MPS Holiday.



**Sue Stuart**

If anyone is thinking of going to Disney, Florida but is unable to find a charity to fund the trip, don't give up.

Approach your local newspaper to see if they would be

interested in launching an appeal on your behalf. You never know, you may be surprised at how generous people can be. Also it is a good way to advertise the MPS Society and to make people aware of children and adults with MPS.

We would recommend the **Dial-a-Dream**

*Peter would like to give Sue all the credit for her hard work in putting these*

*articles together and we would like to thank them both for two lovely stories.*



**Dial a Dream, 7 Addison Road, Wanstead  
London E11 2RG  
Tel 0181 530 5589  
( Contact Bob Heath)**



OVERSEAS NEWS

AN MPS-MEETING IN FINLAND

The Finnish Mucopolysaccharide-children and their parents met at hotel Majola in Lappeenranta on blue Lake Saimaa from 15 August to 17

August 1997. Finland is situated in northern Europe and Lappeenranta is located in eastern Finland.

Plans for this meeting had been made during two courses and my mother Lisbel PaaJanen invited the families to a meeting at Majola. Four families accepted the invitation (there are about 20 MPS families in Finland).

During this meet-

ing we visited the Saimaa Canal, the market place and the Fortress of Lappeenranta. Via the Saimart Canal you can sail from Lappeenranta to Russia and the Gulf of Finland. Unfortunately we didn't see any locks in operation, as there were no ships passing through the Canal.

The market place was crowded with people There were a lot of different kinds

of market stalls and people were just walking around and having a nice time. We tasted the delicious meat pies called Vety and Atomi, which Lappeenranta is famous for. In the Fortress we had a walk along the cobbled streets and went shop-



ping in the small, attractive shops situated in old buildings. In the evening we went to the sauna and made pancakes and grilled sausages. We also had the

chance to go driving on the Ekokatti-raft driven by an electric engine and enjoyed the beautiful scenery of

Marjola.



The MPS-children were aged between 7 and 18 years. The families shared their experiences about the disease. The fami-

lies also pointed out how important it would be to have meetings like this on other

*Pictured above are some of the children who attended the MPS conference in Finland.*

*Katya is pictured in the top picture with Sanna and her dog, Rasse.*

occasions, too. These meetings were

OVERSEAS NEWS



This is the story of Hayden Noble (MLIII)from Nelson, New Zealand. His Mum and Dad, Jenny and Paul keep in touch with the Amersham office telling us of Hayden's progress. Last year Hayden had an operation to release the spinal cord compression.

After the operation Hayden's walking deteriorated and he developed pins and needles and various other problems.

The story continues..... Hayden seems to be holding his own at the moment. Since his operation last year he had been on varying doses of Dexamethasone to give him some form of remission from the problems he was having with walking, bowel and bladder.

Hayden is now on 1/2 mg. of Dex and is slowly becoming more weak and although he walks with a walking frame he is really struggling to walk.

The Doctors here in New Zealand are at a loss as to what is happening, but they feel he has aggressive cell death of the nervous system. We have been told this is a terminal condition and had initially put 6 months - 6 years on his life. While the Dex has been working and giving quality of life we now face the situation of what to do we do now as the drug is causing bone deterioration. The doctors are talking about using a Steroid sparing agent such as one of the drugs used in chemotherapy.

As parents it is incredibly hard to sit and

watch your child struggle to keep going. Some days after school Hayden is so tired he comes home to bed and often won't move until tea time.

In light of all he has to put up with he is a real fighter. He is still able to smile and laugh although not as much as he used to.

Now for some good news. David and Sarah have just been to Disneyland. In New Zealand our airlines have set up a charitable trust for sick and disabled children and every take approximately 30-40 children away. This year was Disneyland.

Paul and I got a real shock to be told that all three children had been put forward to go. As Hayden was unable to cope with the long distance and late nights he was unable to go, so instead the trust paid for Paul, Hayden and I to go to Auckland. We stayed in a wonderful hotel and were looked after really well. While we were there we did all the sights and caught up with family and friends.

Meanwhile David and Sarah were seeing the sights in Los Angelos and San Diego. They had a wonderful trip, something they will remember for the rest of their lives.

Well that's about all for now. If you find a doctor who could shed some light on Hayden's condition we would like to hear from them. Paul and I hope to make the International Conference in Vienna and 1999 and would like to meet up with some families from the UK.

*Paul and Jenny Noble.*





FUNDRAISING

Report on our visit to collect a cheque on behalf of MPS.

Every year the staff of Provident Personal Credit Ltd nominate a worthy cause for their fund raising activities. Awareness of MPS through personal contact with a local MPS family resulted in our Society being the chosen charity in 1997 and throughout the summer staff organised various fund raising events including a cricket match and cake sales.

In the autumn we were contacted by

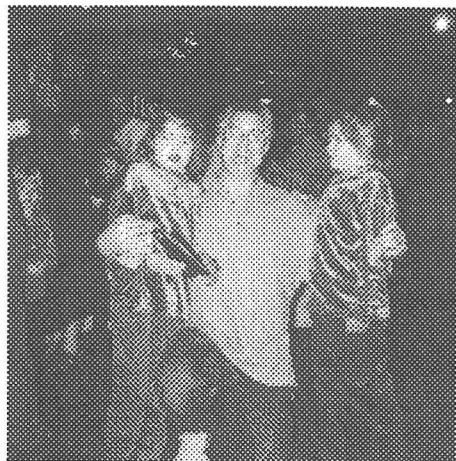
Jess Rendall of the Bristol office of Provident Personal Credit and on 15th October we visited that Office to accept, on behalf of the MPS

Society, a cheque for £858 - what a fantastic effort!

We were delighted to attend the presentation and our most grateful thanks go to everyone at "Provident" for their hard work and generosity.

Fer & Bill Pidden  
Provident staff in photo include:

Alan Squire, Gordon Tyerman, Linda Stone, Teresa Briton, Jess Rendall.



Above a some more photagraphs of the South West Christmas Party

FUNDRAISING



It is with great pleasure that I enclose a donation of £900.00 for the MPS Society.

Following the great success of our "Evening of Dance" in March 1996, we decided to hold another show. This year we decided to have two performances, which were held on 14th and 15th November 1997. All the children live locally and many know Joanne Evans.



I am delighted to tell you that Joanne, aged 11 years who suffers from Morquio Disease was able to dance in both performances. She really

inspired the other children with her enthusiasm, and took a major role, dancing two dances, acting in the first half and acting as a customer in our senior ballet, "The Fantastic Toyshop".

Parents and friends in the audience were most moved to see Joanne and donated very generously, enabling us to raise such a magnificent total. We are very proud of Joanne's indomitable spirit and hope that the funds will be able to help other sufferers of Mucopolysaccharide Disease.

Teresa Ferguson  
(Joanne's Dance Teacher)

We would like to thank The Terry School of Dance, Bridge of Weir for once more raising funds for the MPS Society.



We would like a special thank you to go to 10 year old Jonathon Armstrong and school friends from Hartlepool who raised £5.69 for the MPS Society by making paper aeroplanes at playtime and making a small donation for the MPS Society.

The fact that the children thought of this themselves makes this a very special donation.

Jonathan's 8 year old brother, Michael has Hunter Disease.





**FUNDRAISING**

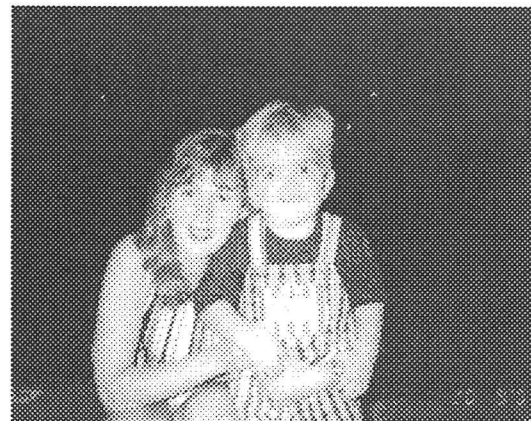
Please find enclosed cheque for £200.30p this being the sum collected by Rosemary and Harry Nurse and myself at Sainsbury's Superstore, The Drove, Newhaven, East Sussex.

This was done with the permission of the store manager, Neil Ratcliffe, who also afforded me this facility last October. I am pleased that on this occasion the sum raised is considerably higher, thanks to the staff and customers.

Edward Hurdle

*(Mr Hurdle is a friend of Rosemary and*

*Harry Nurse whose daughter Lisa suffers from Sanfilippo Disease.)*



Over 70 people danced the night away at a lively evening organised by Mr Lou Moore at the Bourne End, Bucks, Community Centre on Friday the 10th October 1997.

The event was a great success with support and financial assistance from the Sundance Club who hold their weekly ballroom dances at the centre, of which Lou and his wife are members.

Peter Giles provided the music on his keyboard and everyone joined in the dancing and also sang along to many familiar tunes - a very happy evening, complete with raffle and

total of £273 was raised for the MPS Society.

In addition a donation of £50 was made by the very generous Holtspur Bucks Neighbours Association as none of their members were able to attend the dance.

Lou is the great uncle of Dominic Stimpson aged 3 years old pictured above with his Mum, Dominic who lives in Norwich suffers from Sanfilippo Disease.

**Lou Moore**

**FUNDRAISING**

We were delighted to hand over the cheque for £3,020 to Mary and Christine when they visited us recently.

The money was raised by all the children in the photograph, which includes Roma, Kilian and Conor.

The money was raised by a fun day held in September in Roma's cousin, Alexandra's house.

Alexandra and her friends spent all their summer school holidays collecting items for the sale. It was really good fun on the day with toys, books, clothes, soup and scones for sale. The atmosphere was great and the girls were well rewarded for their efforts as they raised £1,000.

The coffee morning which was held at our house raised £1,000. Again it was great fun and everyone wanted to be involved.

Cabetel, who Kevin works for gave us a cheque for £1,020.

Please give a special thank you message to Alexandra, Roma's cousin, as she worked so hard to organise her friends for the events.

Roma enjoyed the fun day even though she was wearing her halo. The

fundraising events generated much good feeling and lifted our spirits especially when



Roma had some bad days with her halo.

Roma has since started school wearing her halo. She was very brave. Her halo is now off and she is in great form. She is to be an angel in her nativity play but she was worried that she would have to wear the halo again with pinsites. I had to explain to her that she would be wearing a halo of tinsel. She was very relieved!!!!

*We would like to send a big THANK YOU*



*to Alexandra for her excellent effort in raising funds for the MPS Society. Well Done, Alexandra!*



*Pictured opposite is Roma aged 5 years old (Morquio) with her little brother, Kilian aged 2 years old.*



FUNDRAISING

Jeans for Genes Day - 10th October 1997

Dear all

This photograph shows me, Lindsay Devine, standing with Headmistress, Anne Mitchell, at Parkgate Primary School on Jeans for Genes Day.

I was very touched with their generosity. I was asked to take the Assembly on that day and to talk to the children, aged 4-11 years old about genetics and the Jeans for Genes Day Appeal.

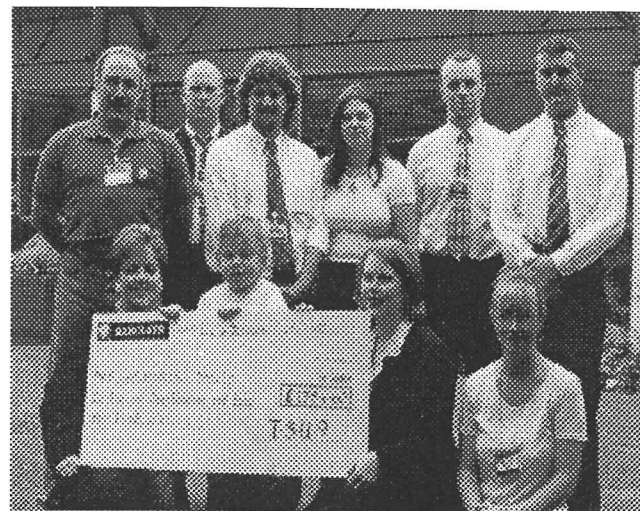
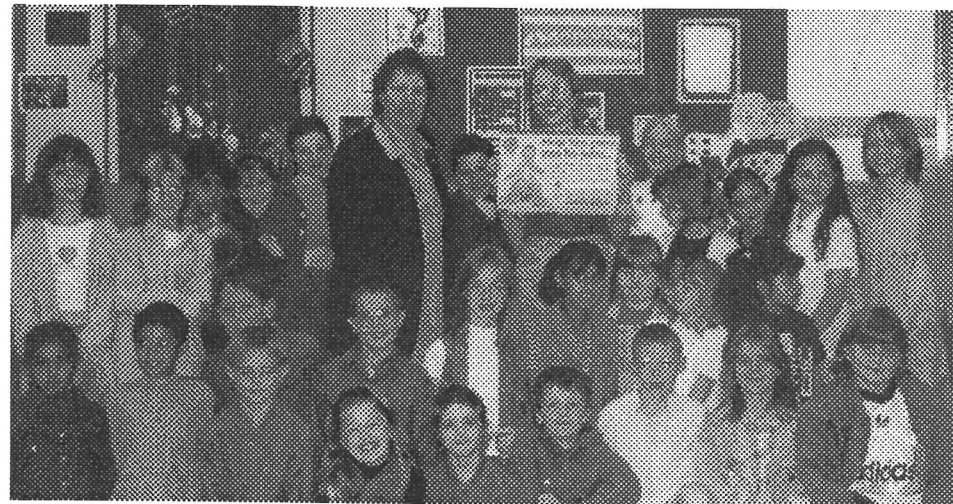
What a challenge! What I know about

genetics can be written on a postage stamp.....

Well, the children sat very quietly and patiently throughout and I was very impressed. In all the school raised £147.20 which I thought was tremendous.

*Lindsay Devine*

*(Lindsay is the mother of 2 year old Katie who has Hurler Disease.)*



Pictured opposite is Daniel Croghan receiving a cheque for £1,354.60 from Chris Hughes and his work colleagues in TSU9 who held a "Race Night" in aid of MPS. Daniel and David Oulton were guests of honour on the night and were great ambassadors for the Society, entering into the betting with enthusiasm. I would like to thank everybody who worked so hard to arrange this very successful evening and for adopting the MPS Society as their charity for the future.

*Pam Croghan*

FUNDRAISING

A Tribute to MPS Children - 11th October 1997

The North West Area Dinner Dance was held and did a great job. During the disco we did on the 11th October at the Jarvis Georgian Hotel Bolton.

It was a really fun night with a lovely meal and a very lively disco, attended by 130 people.

We had a large raffle with lots of prizes donated by local businesses. The main prize being a portable colour TV. Friends, Alison and Janet worked hard



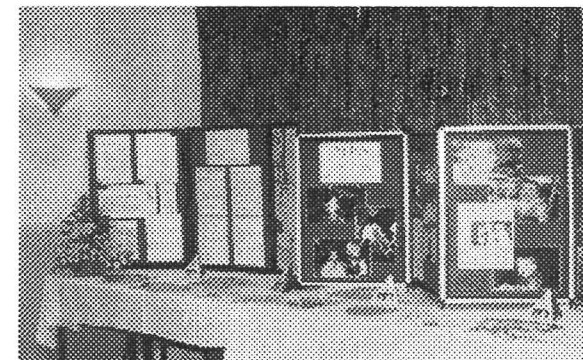
*Brian and Micheline Johnson and Bill and Sylvia Blackburn*

a 'whiskey roll' organised by Vince Unce, Pam Harrison and Sarah Kerrigan sold keys to open a box with a bottle in it.

We had a great time both organising the night and being there with friends old and new of course our friends from the MPS Society.

The evening raised £2,252 and lots of awareness for MPS children.

*Jo-Anne and Gary Adshead.*



selling the tickets. Another friend, Chris Deakin acted as M.C.

*Pictured opposite: The Bar staff who won 'Tweety' in the raffle. Tweety was donated by Alex Gardiner, Mary Pagett's daughter.*



Sherry and Mince Pie Evening - 25th November

I thought Sue Butler's sherry and mince pies idea was a lovely excuse to have a get-together ( ladies only). I extended the idea and asked a friend of mine, whose husband owns a conservatory showroom to bring with her some Christmas decorations that they sell at this time of year.

In the afternoon Debbie and Denise from, 'Mark Forrest & Co' arrived with a large trailer and filled my house with gorgeous decorations and novalties. The sold

like hotcakes ( or should I say mince pies!).

Debbie gave me a 20% cut for the MPS Society which came to £120.00 and £65.00 was raised from a samll raffle and the sale of refreshments.

I spent a considerable amount to re-vamp our Christmas tree which now looks stunning - If only I could keep Ben off it!!!!

*Jo- Anne Adshead.*



## FUNDRAISING

### Annual MPS Christmas Draw - Winners

Pauline Cridland	Woking	<i>P+O European Ferry Crossing for 2 + £500</i>
Alan Paterson	London	<i>UCI Cinema Three Month Pass + £250</i>
Lisa Cartwright	Leicester	<i>Cafe Royal Meal Grill Room+ £100</i>
Sophie Longley	Gloucester	<i>£100</i>
Ian McLaren	York	<i>Coffee Maker</i>
A Porch	Mid Glamorgan	<i>Tomy Train</i>
S Rogers	Runcorn	<i>2x£5 McDonald's vouchers</i>
Lynne Lowther	Gateshead	<i>Picture of Chickens</i>
C Allen	Solihull	<i>Fruit Bowl Set</i>
John Gray	Harrogate	<i>Fruit Bowl Set</i>
Wendy Thomas	London	<i>Drinking Glasses</i>
Pat Mellor	Stockport	<i>Cookery Book</i>
Mrs Garthwaite	Surrey	<i>Clutch Bag and Makeup</i>
Carol Nuttal	Merseyside	<i>Leonardo Figurine</i>
Barry Cheetnam	Stockport	<i>CD's</i>
T Curran	Doncaster	<i>Cameo Cars</i>
Debra Wildish	Gateshead	<i>Cuddly Rabbit</i>
D Pugh	Surrey	<i>Makeup Kit</i>
Mrs Russell	Nairnsborough	<i>Cameo Cars</i>
Alan Vardy	Retford	<i>CD's</i>



## FUNDRAISING

### CHARITY FLOWERS

Why not use one of our MPS order forms to order flowers for special occasions for friends and family.

On each order of flowers made quoting the MPS Society's number the Society receives a donation.

Reference - MPS

Telephone: 0990300600

### FLYING FLOWERS

As above the MPS Society will receive a percentage of all orders made quoting the MPS reference number.

Reference Number is - MPS/SU97/A



**PLEASE REMEMBER TO USE ONE OF THE ABOVE SUPPLIERS WHEN ORDERING FLOWERS FOR THE BENEFIT OF THE MPS SOCIETY.**

MPS Bouquet Offer, The Jersey Flower Centre, Jersey, JE1 5FF





## FUNDRAISING

### DONATIONS

**The Society is grateful to the following who have made donations.**

Mrs Plummer	H.S.A.
Mr and Mrs Simpson	Mr Montgomery
Harrison & Clough Ltd	Mr Davis
Albert Hunt Trust	Mrs C Gooch
Royal London Mutual Insurance Society	Mr and Mrs Clarke
Mr and Mrs Blanch	Dafydd Wigley MP
Ann and John Heritage	Mrs Barker
Mrs Egan	Mr and Mrs McSpadden
Mrs Evans	New Dimensions
David Hugg	Mrs Gould
Clive and Jackie Chisling	DVLA
Mr and Mrs Wigley	Mr Upton
SRRF TA Centre	William and Norma Toole
UAP Provincial	The Baltic
South Birmingham Ladies Bowling League	Mary and John Stacey
Dizzy Mathews	Mervyn and Peggy Short
Mr and Mrs Hayward	Mr and Mrs Moulding
Determan	Mary Kift
MDIS Ltd	Barry Chapman
Rach Fisher	Joe Rikalans
R TTrust	Manger International
Mrs Duckett	Alan Terry
C E Thomas Charitable Trust	Pippa Gilbert-Johns
N Smith Charitable Settlement	U M Meredith
James Weir Foundation	Inpharm Nationwide Ltd
Sid and Betty Shiff	Milton Keynes Japanese Women's Club
St Albans Council ( Half Marathon)	Mr and Mrs Barton
Mr and Mrs Heisig	Provident Personal Credit Ltd
Mr Khafagy	Mr and Mrs Brautigam
Mr and Mrs Nelson	K Daniels
Mrs Philips	Basildon United Reformed Church
Capitol Radio	Doreen Iles
Jane Asher	The Priory Foundation
Broadwater Working Mens Cons. Club	Lloyds Bank
Mr and Mrs Stephens	Edward Nowell
Dorothy Gibb	Edward and Holly Nowell
Mr W Bailey	Joseph Strong Frazer Trust
Mrs J Norsworthy	

## FUNDRAISING

### FUNDRAISING EVENTS

The Society is grateful to the following who held fundraising events.

Caroline Fisher - Sherry and Mince Pie Day - Adam Davey - Sale of Christmas Wreaths  
 Vikki & Jo-Jo, Cottenham - Tombola - Bill and Sylvia Blackburn - Xmas Raffle  
 South West Families - Xmas Raffle - London and Home Counties - Xmas Raffle  
 Louise Croghan and Classmates - Swiss Roll competition  
 Lyn Longhorn - Various Events - Rob Devine and friends - Coventry Fun Run  
 Marina Foster and Brian Baker - Car Boot Sale  
 Carol Westland and friends - Stall at Woddley Winter Wonderland Day  
 Stonelaw High School, Rutherglen - Sponsored Swim  
 Jonathon Armstrong and friends - Making and selling paper aeroplanes  
 Methodist Church, Long Harborough - Xmas Fayre  
 Claire Garthwaite - Mulled Wine and Mince Pie Evening  
 Jill Hornsby, Kathryn Lawrence, Lianne Convery - Tandem Parachute Jump  
 Terry School of Dance, Bridge of Weir - Evening of Dance  
 Tanya and Peter Steenhoven - Annual Bazaar - Natasha Wilson - Sale of Work  
 Joanne Adshead - Mark Forrest & Co - Coffee/Mince Pie Morning and Raffle  
 Pam and Ken Ballard - Sale of foreign coins and goods  
 Christine Butt - Sale of Ballet Shoes - Thelma Pidden - Collection of Coins  
 Ann Smout, Shrewsbury - Gala concert in aid of MPS  
 Daniel Allen's family - Car Boot Sale - Armley Jail - Alcan Collection  
 Harry Nurse and Colleagues - collection  
 Roma Drayne's Family, Belfast - Coffee Moring and Fun Day  
 Edward Hurdle and Harry and Rosemary Nurse- Collection at Sainsbury's  
 Milestone Centre Toddler Group - Sponsored Obstacle Race  
 Northe West Families - North West Dinner Dance and Raffle  
 Jean Ferguson, Glasgow - Glasgow Half Marathon  
 Ann and Gordon Hill - Car Boot Sale

### STAMPS

Clive and James Norsworthy      DVLA Wimbledon      Mrs Thopmson, Darlington  
 Chiropody Department, Keystone Centre      Rita Higgins, Radford      5RRF      Mike Townsend

### CHARITY BOXES

Oversley Mill Service Station      Sid and Betty Shiff      Harting Stores, Petersfield  
 Mrs K Jordon      Dalsetter Rise Post Office      Glad Hughes      Stanshws Service Station

### IN MEMORY

Gethin Robins      Princess Diana      Joan Boundy ( Lois Pack's Grandmother)



## Area Support Families

### Midlands

Sue and Jeffrey Hodgetts Tel: 01827 56363  
6 Godolphin, Tamworth, Staffordshire B79 7UF

Zerina and Sajjad Shah Tel: 01902 656147  
37 Lowe Street, Wolverhampton, West Midlands

Monty and Doreen Russell Tel: 0121 6864779  
71 Templemore Drive, Great Barr, Birmingham, west Midlands B43 5HF

### Yorkshire and East Coast

David and Monica Briggs Tel: 01777 700046  
7 Humber Street Retford, Nottinghamshire DN22 6LZ

Barbara and Trevor Rollinson Tel: 01724 864115  
43 Crosby Avenue, Scunthorpe, Humberside DN15 8PA

### North West of England

Joanne and Gary Adshead Tel: 01942 810109  
10 Church Lane, West Houghton, Nr. Bolton, Gt Manchester BL5 3PP

Geoffrey and Selma Oulton Tel: 01514 752941  
37 Saville Road, Liverpool 13, Merseyside

### North East of England

John and Barbara Arrowsmith Tel: 0191 2921234  
11 Penfold Close, Fairways Estate, Benton, Newcastle on Tyne NE7 7UQ

Ann Thompson Tel: 01325 489920  
7 Sunningdale Green, Darlington, County Durham DL1 3SB

Elizabeth and William Armstrong Tel: 01429 273703  
7 The Crescent, Hartlepool, Cleveland TS26 8LY

### Scotland

Cath and Jim McLean Tel: 01463 791816  
"Woodlee" 47 Oakdene Court, Culloden, Inverness, Highland IV1 2XL

Clint and Karen Stevenson Tel: 01501 752712  
6 Viewfield Street, Harthill, Shotts, Lanarkshire ML7 5SN

Alan and Fiona Byrne (Telephone contact only) Tel: 0141 5695376  
3 Jedburgh Avenue, Rutherglen, Glasgow G7 3EN

### Northern Ireland

Kieran Houston (Chairman) Tel: 01504 884168  
21 Cavanalee Road, Strabane, County Tyrone BT82 8HB



## Area Support Families



### East Anglia

Robert and Caroline Fisher Tel: 01799 586631  
The Horrells, Great Sampford, Saffron Walden, Essex CB10 2 RL

Julie Thacker Tel: 01379 854204  
20 Herolf Way, Harleston, Norfolk IP20 9QA

Zelda and Paul Hilton Tel: 01406 351524  
17 Stanley Drive, Sutton Bridge, Nr Spalding, Lincolnshire PE12 9XQ

### South East

Robin and Mary Gooch Tel: 01435 883329  
High Bank House, Swifehill, Broadoak, Nr Heathfield, East Sussex TW21 8XG

### Potteries

Bill and Sylvia Blackburn Tel: 01270 626809  
11 Beatty Road, Nantwich, Cheshire CW5 5JP

Lynn and Chris Grandidge Tel: 01244 531163  
41 The Boulevard, Broughton, Chester CH4 0SN

### South West

Bill and Fer Pidden Tel: 01373 865117  
5 Westbury Leigh, Westbury, Wiltshire BA13 3SE

Gordon and Anne Hill Tel: 01404 813823  
Bowhayes Farm, Venn Ottery, Ottery, St Mary, Devon EX11 1RX

### Home Counties

Mark and Rachel Wheeler Tel: 0118 9541293  
26 Tamarisk Avenue, Reading, Berkshire RG2 8JB

Gavin and Denise Brown Tel: 01442 395907  
32 Ellingham Road, Adeyfield, Hemel Hempstead, Herts HP2 5LE

### Wales

Ann and Michael Kilvert Tel: 01686 624387  
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