

Newsletter

The Society for Mucopolysaccharide Diseases

National Registered Charity No.287034



Winter 98



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New Numbers

*Our Home Page on the World Wide Web : <http://home.btconnect.com/mps>
E Mail: mps@btconnect.com*



The Society for Mucopolysaccharide Diseases

46 Woodside Road, Amersham Buckinghamshire HP6 6AJ

Telephone: 01494 434156 Fax: 01494 434252

Email: mps@btconnect.com

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 fundraising, and run by the member 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 area. It provides an information service for families and professionals. At the present time it supports two specialists 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 Disease, but much can be done to improve the treatment and care of sufferers. The slogan of the Society is:-

"CARE TODAY, HOPE TOMORROW"

*The photograph on the front page is
of Courtney Taylor aged 2 years old
who suffers from Hurler Disease*

MILESTONES

New Families

Stephen Young has recently been diagnosed with Hunter disease and lives in Newport with his mum Jane Cripps. He is 3 years old.

Jacqueline and Richard Stewart have a 3 year old daughter Lisa and live in Binfield. Lisa has recently been diagnosed with Sanfilippo disease.

Shirley and Terry Butler have a 1 year old son and they live in Bristol. Terry has recently been diagnosed with Hurler disease.

Mr and Mrs Chowdhury live in Shoreditch and their children have recently been diagnosed with Sanfilippo. Suhil is 6 years old and Ruhil is 5 years old.

Patricia Welch lives in Chatham. Her son Charlie who is 7 years old has recently been diagnosed with Mucopolidosis III.

Karen and Martin Taylor live in Inverness. Their daughter Courtney has recently been diagnosed with Hurler disease. She is 1 year old.

Angela and Brendan Smyth live in Watford. Their daughter Bernadette, who is 1 year old, has recently been diagnosed with Hurler disease.

Deaths

Syprian Simms' son Steven 33 years old, passed away on the 13 January 1999. Steven suffered from Morquio disease and came from Tividale.

Sadly Dolly and John Byrom's 11 year old daughter, Rebecca, died on the 30 October 1998. Rebecca from Sale suffered from Sanfilippo disease.

Claire and John Baily's 2 year old daughter Olivia sadly passed away on the 12 January 1999. Olivia suffered from Hurler disease.

Congratulations

Congratulations to Tanya and Peter Steenhoven on their new arrival of Piers Beau on 10 November 1998.

Congratulations to Jackie and Clive Chisling on the arrival of a sister for Hannah and Mollie. Freya Alexandra was born on the 1 December 1998.

AREA FAMILY SUPPORT

East Anglia Family Day

Our Area Family day was held on Sunday 31st August at Banham Zoo in Norfolk. A slight hiccup when we arrived at Banham as our organiser (Julie Thacker) was unable to attend as unfortunately Thomas was poorly. Otherwise a great day was had by all and some memorable photographs were taken as we met old and new families from the East Anglia region. The weather was kind to us and we were able to walk around and see many lovely animals. Certain people – yes you know who you are! - had to be dragged away from an interesting conversation with a parrot whose only word was 'hello'. We all met for lunch and a chat in the picnic area and the day ended with a ride on the train or the pony and cart. *Marrienne Stimpson and Frances and Steve Gee*



Farewell from David and Monica Briggs

We have finally had to admit that we can no longer continue as Area Family for the Yorkshire, Nottinghamshire, Lincolnshire, Derbyshire and Humberside Area. We can no longer give sufficient time to the Area Family Team to do the job the way you would expect us to do it.

Over the past three years we have had numerous problems with Kristina and Emma has now gone to University in Preston. I am now working full time and with the extra care that Kristina now needs and the shortage of hands at home the week seems to have become much shorter. After eight years it was a difficult decision to make, but we feel it is the right one. In January we will be 'retiring'.

There are so many people to thank for their support over the eight years. Pauline & Sean for easing us gently into the Area Family Team job. Barbara & Trevor for their support especially when the going got tough! Both of the offices, Trustees and the other Area Families. With so many people both past and present that it would probably take a whole issue of the newsletter to name them all. THANK YOU to all 'Our Families'. Your continued support over the years has meant a great deal to us. When we organised a Family Day and the rain poured (occasionally) down we would panic and think that no one would turn up. Rain, snow, ice, power cuts etc. You always proved us wrong and we would be surprised as to how many would turn up. We hope you enjoyed the Family Days whether it was sun or rain, and will continue to do so under Barbara and Trevor and the new Team members. We will still be pleased to hear from you.

David and Monica Briggs – Yorkshire & East Coast Area Family

AREA FAMILY SUPPORT

Welsh Xmas Party

Once again we had a very enjoyable day. My thanks to the Rees family for organising the venue, food and entertainment. Many thanks to all who gave draw prizes and my Mum and Ivy for managing a stall.

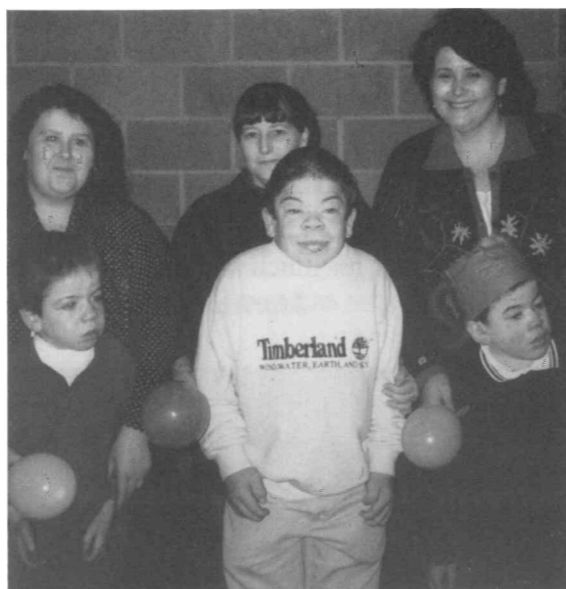
Mike and Anne Kilvert



Father Xmas with the Anne Canton (Scheie)

North East Xmas Party

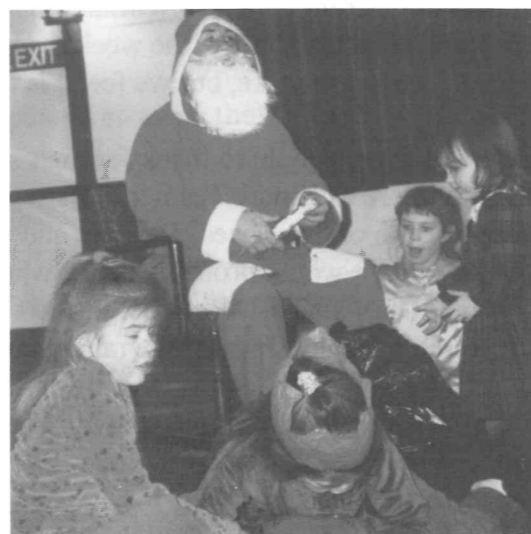
A great time was had by ALL! We played pass the parcel, musical chairs and even did the 'Hokey Cokey' Everyone would like to say thank you very much for the lovely presents received from Father Christmas. *Liz Armstrong*



Pictured above Michael Thompson (Hunter), Colin Arrowsmith (Hunter) and Michael Armstrong (Hunter) all with their mums.

South West Xmas Party

Pictured below is Josephine and Francesca Kembrey along with friends at their Area Family Xmas Party. A wonderful time was had by all.



AREA FAMILY SUPPORT

Yorkshire & East Coast Xmas Party

A great time was had by all at our Xmas party. Many families attended and Father Christmas arrived to the delight of the children to speak to them.

Photo below Zara Watson – Sanfilippo with her baby nephew.



South-West Summer Barbeque

MPS families by nature are used to getting the best out of 'not ideal' situations and a galant five families braved the rain to join us for a summer barbeque at our home in Devon.

Typically unreliable weather forced us indoors and our 'barbeque' cooked for us in a nearby polytunnel amidst boxes, plants and machines and at one point, much smoke.

However, we all spent the afternoon chatting whilst the children played board games, computer etc. and I think had a good time.

It is always useful for families to get together to swap ideas, news, etc – what ever the weather !

Ann Hill – Area Family



Photo above inside the polytunnel, where everyone managed to keep dry.

FAMILY SUPPORT

**Scottish Training Day and Conference / Family Gathering
September 25th – 26th 1998
Rachel House, Children's Hospice, Kinross, Scotland**

Mary and I travelled to Scotland on Thursday 24th September and visited several families at home. On Friday morning we attended a multi disciplinary meeting for one of our young sufferers before going to Rachel House.



Photo of Dr Robinson and Dr Cleary with Mr Brown and Mr Watterson

socialise with and reassure their families from the Scottish area. May I take this opportunity to thank them all for their help in encouraging families to attend.

Mary and Dr. Maureen Cleary, Paediatric Consultant at RMCH, ran a training afternoon for the staff of Rachel House. Maureen outlined the different MPS conditions and their progression and Mary spoke of the work of the MPS Society. The staff welcomed this input and all felt that the session was very worthwhile.

On the Saturday we held the MPS conference for families and professionals, which was well attended from both sections. This year we were fortunate to have extra funding from the Foresters Fund for Children, who though unable to attend did send along their cheque! Rachel House very kindly provided overnight accommodation for some of the families who had great distances to travel in order to attend the Conference.

Dr. Maureen Cleary spoke on the Management of MPS conditions and also gave a simplified explanation of the very complex issues around biochemical diagnosis and carrier detection, no mean feat! Well done Fiona.

Alan and Fiona Byrne and Clint and Karen Stevenson who offer invaluable support to the families in Scotland were there on the day. Alan welcomed everyone to the Conference and linked the day's proceedings with his customary good humour and warmth. He and Fiona together with Clint and Karen made the most of this rare opportunity to

We were also fortunate to have Dr. Peter Robinson, Consultant Paediatrician in Metabolic Medicine at Yorkhill, who gave of his time to talk on the services available throughout Scotland and how MPS families can access them. The MPS Society looks forward to working more closely with Dr. Robinson.



Photo of Alan Byrne (Area Family), Mary Paget and Dr Cleary with the cheque from The Foresters Fund for Children

Mary spoke of the brothers and sisters of our MPS sufferers, their very individual needs and concerns and ways in which we can help them to cope with the fears and the stresses inherent in MPS families.

The Saturday afternoon was a relaxed, informal time, with families and professional socialising and chatting over a buffet tea. Everyone went home looking forward to the next gathering of the clans. Pam Thomas – Development Officer

FAMILY SUPPORT

**Selection of photographs from the Scottish Conference / Family Gathering
September 25th – 26th 1998**



Robyn Watterson - Sanfilippo



Fiona Byrne, Donna and Emma McLellan – Sanfilippo and Angela Brown



Martin Stevenson - Sanfilippo



Clint and Karen Stevenson - Area Support Family

Below: John Paul O'Neil - Sanfilippo with Grandma and Mr and Mrs Findlay

Below: Alan Byrne, John, Angie and Aiden Brown - Hurler



FAMILY NEWS

A letter received in the Northern office from a mother who only recently has had her 32 year old daughter diagnosed with Sanfilippo.

Dear Pam
Thank you so much for the very pleasant phone call you have made to us. It has helped so much to hear a friendly caring person who is just a phone call away.

I must apologise however for keeping you so long on the telephone, but I am still finding it very hard to accept there are people like your good self and Dr Ed Wraith who actually believe all we say and feel about our dear Tamale's condition.

I thought that perhaps you would like a photograph of our dear 'she must be obeyed !!!' Ha Ha!. It was taken on one of her good days, when she looks beautiful and happy. She is sat in her favourite place in the garden with her 'partner in crime' our niece's little girl, Jessica.

We have 2 great nephews, Christopher (9), Aaron (7) and baby Jessica. The boys spoil their Aunt Tammy rotten and woe betide anyone who should try and cross her. But baby Jessica is her pal, she even pops sweets into Tammy's mouth with no fear at all, and strangely, Tammy is quite gentle with her. Mind you there are times when a tug of war takes place over toys etc. ha. Ha. ! - Jessica usually wins.



This is just a short note just to let you know how we really appreciate the support you have given us.

God bless you, Mary and Christine and last but by very no means least, Dr Ed Wraith, now I know I have not been going mad all these years.

Thank you so very much
Carol Fisher

How I solved our Bike problem

I don't know if anyone else has had the problem of a child who loves to ride a bike but is insecure because they can't do the brakes because of joint problems. This is the problem we had with our daughter Samantha (Hurler/Scheie)

After my father-in-law made an appeal on local radio, the Blind bike school in Birmingham phoned with the offer of a bike which when you peddle backwards the brakes come on, this has been a god send. Samantha is confident and I am happy knowing she is safe when playing.

There maybe somebody in other children's districts that could help other children have a normal childhood and be able to ride a bike with confidence.

Vicky Brockie

The Disabled Living Foundation has free lists of cycles under the headings; pedal, tandem passenger, 4 wheel, foot-propelled, hand propelled, power assisted. Specify which sections you would like.
Helpline: 0870 603 9177

FAMILY NEWS

Childhood Wood Sapling Planting – October 1998

The planting of oak saplings planted in memory of MPS children and young adults who have died was held on the 23 October 1998 at Sherwood Pines, Nottinghamshire.

A total of nine children and young adults were remembered by the planting.

Mrs Stella Smedley JP, Chairman of Nottinghamshire County Council welcomed everyone to the wood along with Paddy Tipping MP and Sir Andrew Buchanan, Lord Lieutenant for Nottinghamshire.

A sapling was planted on behalf on the following families in memory of:
Sir Andrew Buchanan – Amy Coates
Paddy Tipping MP – Ben Coole
Councillor Stella Smedley – Jordan Mills

We would like to thank them all for their continued support of the Childhood Wood and the MPS Society.

Afterwards we all departed for the Clumber Park Hotel where a welcoming cup of tea was waiting for us.

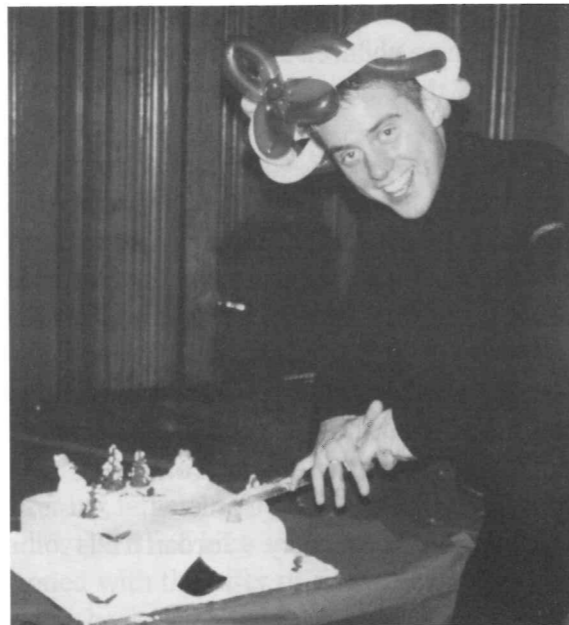
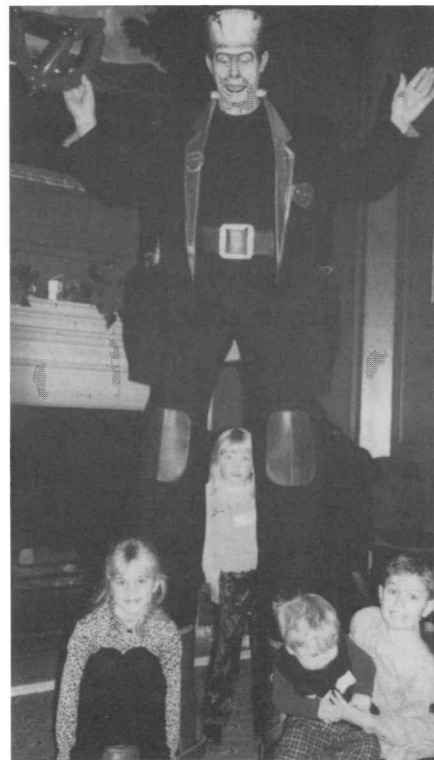
It was a lovely autumn day and the peaceful scene adds to the dignity to the day. We hope everyone received some comfort from the surroundings.

Sheila Duffy - Development Officer



FAMILY NEWS

Selection of photographs taken at the Downing Street Christmas Party



FAMILY NEWS

Downing Street MPS Christmas Party

When I received the telephone call from Christine to say the Society had been invited to hold a Christmas Party at Nos. 11 and 12 Downing Street with Gordon Brown MP, Chancellor of the Exchequer as host, I knew that the Society couldn't let such an opportunity pass by, but could we manage it in the timescale of just 6 weeks.

The success of the Downing Street MPS Christmas Party was owed to the support of so many people. We are enormously grateful to James Garthwaite for securing major sponsorship from Lehman Brothers and the Brunswick Group Ltd. Other sponsors included the Lifeline for Lauren Appeal and Midland Bank. Many others who helped to make the day such a success are listed in this Newsletter, including Lego who donated the gifts for the children Father Christmas, Lord Attenborough.

On arrival at Downing Street the families and guests were greeted by a Snowman and Frankenstein. Mr Blobby posed for photos with the families outside Number 10 and the policeman at the door joined in by lending his helmet to one little boy. Following photo calls with Ministers, Dawn Primarolo and Geoffrey Robinson, everyone went inside to join the party.

Oscar, who arranges children's parties for the rich and famous all over the country donated his services for the day. There was a disco, helium balloons and guest appearances by CBBC TV personalities Richard McCourt and Ana Boulter, Konnie Huq and Stuart Miles (Blue Peter), Jay Burridge and Mark Speight (Smart), Paul Burrell (Diana Memorial Committee), and Diana Louise Jordan, ex presenter of Blue Peter also joined in. Twelve choristers from Westmin-

ster Abbey Choir School came to sing carols and the big finale was Father Christmas' visit.

As ever on these occasions not everyone could be invited. We were restricted in the numbers who could be accommodated and we know that many families were disappointed. We are grateful, however, to those who travelled long distances to ensure that we included families from all over the country.

A huge thank you to everyone at Nos 10,11 and 12 Downing Street for their support in the preparation and the warm welcome on the day. Thank you for having us. We were so very sorry that owing to the death of his father the Chancellor could not be with us.

*Wilma Robins
Chairman*



FAMILY NEWS

The Society for Mucopolysaccharide Diseases – Children's Christmas Party No. 11 Downing Street on 9th December 1998

With thanks to the following
Party hosted by the

Thank you to all the staff in No. 10, 11 & 12 Downing Street
Special thanks to Lord Attenborough CBE

Party sponsored by
Brunswick Group Limited
Lehman Brothers
The Lifeline for Lauren Appeal
Midland Bank plc

Entertainment and Characters
Oscar's Den

Presents by
LEGO UK

Donations in kind by
Allied Domecq Spirits & Wine UK Limited
Army & Navy, Victoria Street
The Bank Cottage Tea Room
Cadbury Schweppes plc
CBBC TV Personalities
Centurion Press
Coco Cola & Schweppes Beverages
Habitat
Jane Asher Cakes
Madison Packaging
Mars Confectionery
McDonald Restaurants Limited
Neolith Offset Limited
Nestle UK Limited
Princess Soft Drinks
Walt Disney Special Events Group

Carols sung by the Choristers of Westminster Abbey
Conducted by Martin Baker, Acting Organist and Master of the Choristers
By kind permission of the Dean and Chapter of Westminster

Thanks to all the celebrities for making this party memorable
Thanks to all the Parents, Volunteers and MPS Staff for helping to make the party happen

FAMILY NEWS

Selection of photographs taken at the Downing Street Christmas Party



INFORMATION

The One Hundred Hours Softy Survey

One Hundred Hours, the independent registered charity, is raising awareness of the support needs of parents themselves when they have a child with disabilities. We know that this can be a traumatic time for parents and we also know that existing support is patchy and often inadequate.

We support parents in talking to their service providers (through a scheme called Footprints) about improving support. We also support families ourselves in West Yorkshire and the Manchester area.

As part of raising awareness of the issues and encouraging services nationally to do something, we are running a national research project – the SOFTY Survey. This is a postal questionnaire designed for parents to enable them to tell us about the support they received or lack of it. SOFTY stands for Support over the First Two Years. We are particularly interested in these first years after the diagnosis or suspicion of a child's disabilities.

Parents of children of a wide range of ages and disabilities have already responded and completed a SOFTY survey but we are looking for still more parents. The more parents who add their views, the more forceful the results of the Survey will be in influencing service development. So, whether you had a good experience of support or you felt that you were not supported at all, we would be very interested to hear from you.

The questionnaire can be as anonymous as you wish and is designed to be as easy and quick to complete as possible.

All parents who complete the survey will be sent a free copy of the final report, as will the organisation who helped distribute the questionnaires.

Please contribute to this important survey if you can. A copy has been enclosed with this newsletter.

If you would like more information please contact;

Gundrun Spencer – Survey Co-Ordinator
The SOFTY Survey – One Hundred Hours
83 Silver Street
Kings Heath
Birmingham
B14 7QT
Tel & Fax: 0121 441 1580



Mangar Freestyle Elevating Wheelchair

Would suit a child or young adult with Morquio disease – as new (description as on the back of the magazine)
Mangar can modify the seat to suit any young person who can drive an electric wheelchair
Any reasonable offer will be considered

The proceeds of the sale will go to the MPS Society

Please contact: Mr P Rock
Tel: Hinckley (01455) 616284

INFORMATION

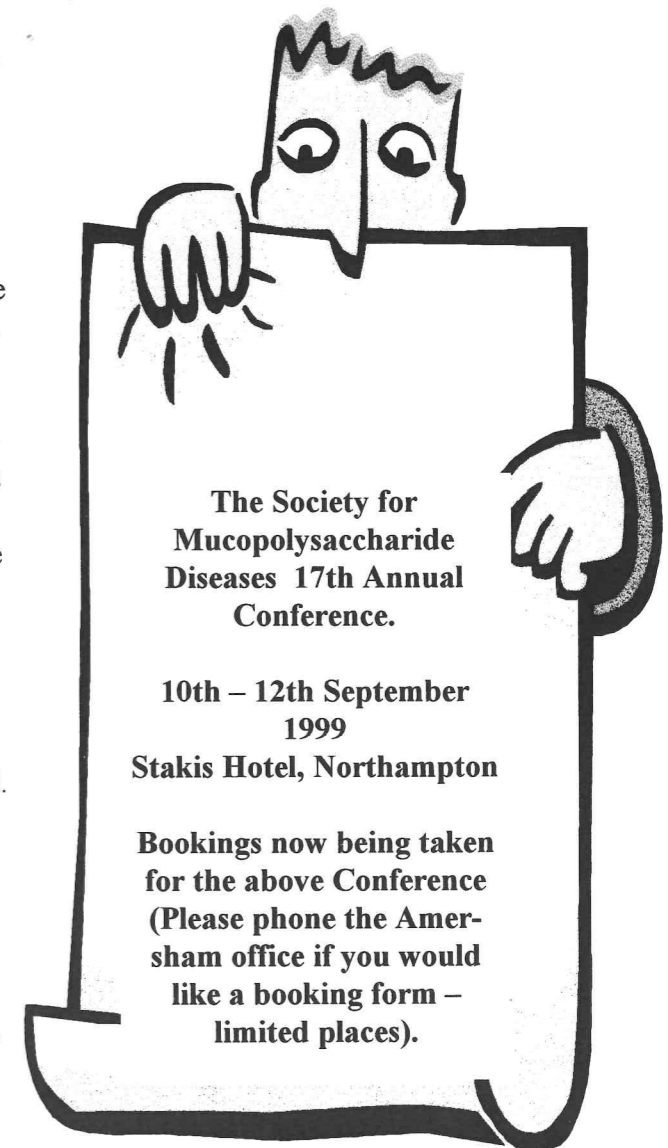
MPS UK Sibling Conference 1998

A report from Claire Arrowsmith on our First Sibling Conference

On the first day of the annual MPS Conference a Sibling Conference was also held. Any brother or sister of an MPS child who wanted to attend were more than welcome. I was with the group of 11+. The meeting was quiet at first as nobody wanted to be the first to speak, but once we got started it went very well. We discussed many different subjects and I found I was not alone in the way I was feeling. During the meeting we also discussed starting up some sort of help for siblings. The one that seemed to be the most popular was the idea of having someone to phone when something is getting you down. The parents have their Area Families or each other to phone but the siblings don't seem to have anyone. I have given it some thought and I would like to put my name forward. So if anyone would like to phone me whether its because their feeling down, or going through a bad time, or you just want a chat, feel free to call me anytime. *I am 16 years old and live in Newcastle Upon Tyne. I have a brother called Colin aged 18 years old and he has Hunter Syndrome (Mild). My mother and father are the North East Area Support Family and I am hoping to go into the nursing profession.*
My telephone number is 0191 2921 1234

MPS UK Sibling Conference 1999

We will be holding another Sibling workshop for 5-11 years old on 10th September 1999 before our MPS Annual Conference and on the Sunday morning a workshop for the 12+ years old. If you would like to attend please complete the Sibling Workshop forms and send them along with the Family Booking form asap as it will come on a first come first served basis as places are limited.



**The Society for
Mucopolysaccharide
Diseases 17th Annual
Conference.**

**10th – 12th September
1999
Stakis Hotel, Northampton**

**Bookings now being taken
for the above Conference
(Please phone the Amer-
sham office if you would
like a booking form –
limited places).**

Volunteers Needed

Do you know of anybody that works in the caring profession, who would like to be a volunteer and look after a MPS child at the MPS 1999 Family Conference in September? Could you please ask them to write to me at the Amersham office and I will be able to send them an application form.

Sheila Duffy
Development Officer

INFORMATION

RESPITE CARE IN THE NORTH

Good news for families in the North - there are two new hospices ready to take referrals.

Claire House on the Wirral and Butterwick Hospice at Stockton on Tees will complement the service already available through Derian House, Francis House and Martin House and will hopefully allow easier access to respite for many families.

Claire House has just opened its doors and has 6 lovely children's rooms with a futon bed in each for a parent, brother or sister. The building is set in 3.5 acres of landscaped and adapted gardens and is in the shape of a "C" surrounding a courtyard. Each child's room opens on to its own patio area. They even have their own pony!

Other facilities include family rooms, teenage room with computers, pool table and sky TV, hobbies room, music and library. There is a wonderful multi-sensory room, hydrotherapy pool and jacuzzi.

Muriel Barber, head nurse, is full of enthusiasm and commitment to provide a warm, welcoming and safe environment for all who use Claire House and is accepting referrals now. The multidisciplinary team aim to provide individualised, flexible and supportive care to achieve the best quality of life for the child and family. They aim to care for all the family including brothers, sisters and immediate family members, allowing siblings special time also. You can contact Muriel for details on open days they are planning.
Telephone 0151 343 0883.

Claire House Children's Hospice
Clatterbridge Rd
Bebington
Wirral L63 4JY
TEL: 0151 343 0883

Butterwick Children's Hospice in Stockton is not as far along and is currently only able to offer day care. They hope to have 2 bookable beds by January '99 plus 4 day care places and anticipate being fully operational by the end of next summer with 3 bookable and 1 crisis bed. They are researching "hospice at home" for reporting in February '99 and hopefully implementation in the year 2000. Stephen Sorby is head nurse and is taking referrals now.

Facilities at Butterwick include a hydro therapy pool, multi-sensory room, indoor and outdoor play areas, sensory garden, hydrotherapy bath and specialist play equipment.

Central to Butterwick's philosophy of care is the belief that all children are unique and care should be holistic and family centred. The multidisciplinary care team will strive to provide a high standard of care in a home from home environment for children with chronic life threatening /life limiting illnesses and their families.

Butterwick is part of the Yellow Brick Road initiative charged with establishing 3 hospices in the north of England. As well as Butterwick there is Eden Valley in Carlisle due to open at the end of this year or early in 1999 and St. Oswalds at Gosforth, which is still at the appeal stage.

Butterwick Children's Hospice
Middlefield Road
Stockton on Tees TS19 8XN
TEL: 01642 607742

Please let us know what you think once you have visited them. Both are committed to offering families support and care in every way they can, do take advantage.

Pam Thomas
Development Officer

OVERSEAS

German MPS Conference December 1998

Dr. Wraith and myself attended the German Conference held at a rehabilitation centre in Usedom.

In Germany the concept of many of their rehabilitation centres is for the whole family to attend for a couple of weeks or up to a whole month in some cases. In that time the disabled child is assessed and various beneficial programmes are introduced. The family members are also encouraged to partake of the facilities available from family therapy sessions, counselling, relaxation, aroma therapy and gymnasium etc. At Usedom; the centre even had a beauty salon, solarium and sauna.

The German MPS Society has held several of its conferences at this venue and even the Baltic frozen coastline, temperatures below zero and snow falling in the middle of December did not stop the sixty plus families making the journey.

For Dr. Wraith and myself, this was a special time in the history of MPS, as Jurgen and Brigitte Zumbro, founders of the German MPS Society, said their farewells to the German families.

Jurgen and Brigitte, who have a daughter Natalie 21 years old, who suffers from Sanfilippo, have worked tirelessly over many years to establish support to German families.

Officially they will be retiring in March at the MPS International Symposium in Vienna, but they wanted to say a special "Good Bye" at their last German conference. There were few dry eyes on Sunday morning when Jurgen and Brigitte got up to speak to everyone, the emotion of the families certainly was a tribute to their work.

Mary Pagett
Director of Family Support Services North

Taiwan MPS Clinics December 1998

Dr. Wraith, Christine Lavery and myself were given the great privilege of being honoured guests of the Taiwan MPS Society when they held a two day MPS Clinic followed by Conference, press call, Christmas Party and Presentation.

Dr. Lin, Consultant Paediatrician at the MacKay Memorial Hospital, and Dr. Wraith must have seen between fifty and sixty families from the North and South of Taiwan during these two days. The clinics were hectic yet well organised with plenty of volunteers on hand to help. Undoubtedly, the sharing of knowledge was beneficial to all.

It was particularly heart-rending as many families arrived with not only one MPS child in the family but with two, three and four affected children. One young family had three MPS children all under two and a half years; another had eight sons affected by Hunter disease. Another mum arrived worn out from her long journey with her three children aged 16, 14 and 12 years who suffered from Morquio disease. She believed she had been a bad mother and must have hurt her children in some way for all of them to have stopped walking and to have not grown properly. Through the excellent interpreters on hand to help we were able to explain how MPS conditions are inherited, how we can help our children and ourselves through care and support. By the end of each day we had made new friends and extended the family of MPS.



OVERSEAS

The press call, with TV cameras too close for comfort at times, went well, mainly due to our hosts, Virginia and Eddie Chou, being extremely organised and assertive to say the least.

The Christmas Party and Presentation brought a new meaning to holding an event, as Virginia had arranged that everyone who was anyone, especially those who had sponsored our visit and the Conference, was in attendance and had a part to play.

Unfortunately, some of the movie stars didn't get our attention, but the executives and representatives from Government, IBM, McDonald's and China Airways to name only a few did.

As always the children stole the show completely and it was amazing to see the newly elected Mayor of Taiwan standing on stage with a young man who suffers from Hunter disease in his arms. The Mayor in Taiwan is a political figure and highly respected by the people, so one can only imagine the benefits to the Taiwan MPS Society of having such a prestigious figure on board. Virginia and Eddie Chou certainly know this and have what it takes to build an organisation; it was wonderful watching them in action.



Photo above of Dr Wraith with two of his patients

OVERSEAS

I realise that many families may not know of the relationship between the Taiwan MPS Society and the UK. Briefly, Virginia and Eddie came to the UK in 1992 with Eddie's work. Their eldest son, David, suffered from Hunter disease and spent many months at the Royal Manchester Children's Hospital. During their three-year stay, they became involved, attending family days, conferences and the MPS Family Holiday. Virginia spent her time translating information into Taiwanese ready for their return to Taiwan when they intended to start the Taiwan MPS Society. On their return home Virginia wrote a book about her experiences with David and their time in the UK. Sadly, David has since died, but Virginia and Eddie, along with many families in Taiwan, are building a future for MPS children and their families. I know, like me, Dr. Wraith and Christine will have many memories of Taiwan, some tinged with sadness but many that give renewed hope.



Photo above of Christine Lavery and Mary Paget with friends

*Mary Pagett
Director of Family Support North*



Photo above of Dr Lin, Christine Lavery and Mary Paget with some more patients

OVERSEAS

American MPS Conference

When it was agreed I would participate in the American MPS Society Conference, I knew that we would come back all the richer in knowledge of what is happening for MPS families from a research perspective. We were not disappointed. Over the last month of 1998 Sheila and I received a number of enquires from a Biomarin company in the United States on the incidence of MPS in the UK and Europe. For sometime now Biomarin has been working on Enzyme Replacement for MPS disorders and following Stage 1 clinical trials for MPS 1 in the USA, is keen to know how many patients there maybe in the future who could benefit from Enzyme Replacement Therapy. The updating of MPS European Database became a priority and came into its own when Sheila and I sat down to meet with representatives of Genzyme in New York. We now meet regularly with Julie Kelly from Genzyme in the UK and will keep families informed through the Newsletter of developments in Enzyme Replacement Therapy (ERT).

At the American MPS Conference Dr Kakkis spoke on the ERT clinical trials and we are delighted that he has agreed to come and speak at our weekend Conference on 10th – 12th September 1999, where he will also show a video of the children who have been treated in clinical trials. We expect a heavy demand on the places and ask families to book early to avoid disappointment.

At a gala dinner the American MPS Society said goodbye to their President, Marie Capobianco after 20 years. Marie and her husband lost two of their three children to Sanfilippo disease. On behalf of the British MPS Society I presented a glass goblet engraved with the MPS logo to Marie in recognition of her years of work for MPS families throughout American. For me personally I have lost a dedicated colleague who was never afraid to speak her mind to get what was best for MPS.

Christine Lavery – Director



Christine Lavery presenting Marie Capobianco with her glass goblet engraved with the MPS logo

OVERSEAS

We thought that you would all like to read Noel Marreros' brilliant talk at the USA MPS Conference – Morquio sufferer

Hello! My name is Noel Marrero and I have been invited to share with you my experiences with MPS. More specifically, I have Morquio. I will tell you how through my life I have learned a very valuable precept: that is, how to spin straw into gold.

I remember once when I was four years old, I saw my mother crying at the doctor's office. I knew then, something was 'wrong'. Later, with similar experiences, I started seeing myself in a different way. I recall when I went to school, children looked at me wondering why I walked 'funny' and why I didn't run like them. The children's mothers would ask mine what was 'wrong' with me, but I didn't think there was anything 'abnormal' about me. As far as I was concerned, I felt pretty 'NORMAL'. Time passed by and I was still growing at my own pace. Then, it suddenly dawned on me that I was 'different' from the rest. That's when I underwent a series of operations.

My first operation, spine fusion, was practiced at Shriner Hospital in Philadelphia when I was in sixth grade. Though I was born in mainland United States, my first language is actually Spanish. So, it was a gratifying experience, because I learned to speak a bit of English. Three years later, I had to be operated on my neck. I had to stay three months in hospital. The operation was not successful, so two years later I had to be operated on again. This time my knee was operated on, too. Having spent so much time in hospital, I started thinking it would be a good idea to take up a part-time job there!

Every kid in school age dreams with his high school graduation: to get out quick and into the work seeking adventure. Unfortunately I missed this very important event, as well as other classic

high school events, due to all the operations I went through. I must confess that this was a time of crises in my life, dark and gloomy. Not only because of all the things I was missing out on that any teenage kid takes for granted, but because at this point in my life, I couldn't walk alone.

A year later, I met a therapist from Santo Domingo who brought a spark of light back into my life. He told me firmly that I was going to walk. The only thing I had to do was to really wish it with all my heart and to have faith in God. At this point, I felt I had nothing more to lose. So, I gave it a try. We started working hard together. Twice a day, I had to be massaged and do exercise. A year and six months after, I started walking, Thank God.

My life took a twist for the better. I finally made it to college and was able to obtain a Computer Science Bachelors degree. Consequently, my self-esteem increased. I entered the working field as a computer teacher and in addition coached basketball teams, I worked for four years at high school level in my two passions.

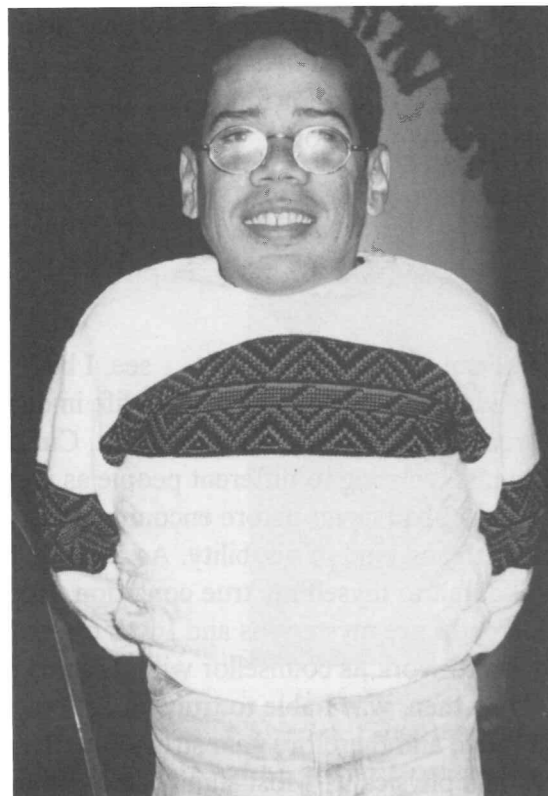


As you can see, I had achieved many positive goals in my life in different areas: studies, work and recreation. Curiously, this implies relating to different people as well. However, I had never before encountered anybody with any kind of disability. As a result, I still didn't admit to myself my true condition. But God's paths are mysterious and I was offered a position to work as counsellor with disabled people. Only then, was I able to truly identify myself with them, and therefore gain strength both spiritually and physically. Most significantly, I started to accept myself and give testimony of how we can achieve anything we want if we try.

OVERSEAS

Yet, I was still eager for more information about my condition, MPS and this moment of my life gave me the opportunity to look for detailed information about it. That is how I found out about this convention. In fact, I was very excited because I had never before seen anyone with this condition except myself in the mirror every day. With great expectations, I attend the MPS convention for the first time last year, Then I learned a lot more about MPS. For example, that I could have problems with my heart and joints.

After returning to Puerto Rico, I got sick and I had to have a heart operation due to a bacteria. When the doctor told me I had to be operated on quickly, I felt fear and frustration of losing everything I had achieved with sacrifice. This meant having to begin all over again. I cried, dried my tears, and said, 'In the name of God, Eye of the Tiger. No Pain'.



Fortunately, the operation was a success. However, I lost sixteen pounds, I felt weak and my body ached. I prepared myself psychologically, thinking only of my recovery. I exercised, ate well and read the Bible. In four months, I had recovered, thank God! Now, I am living alone on my own, and again looking for a job to continue from where I had left off.

Noel asked us that if anyone would like to write to him his address is:

Noel Marrero
Bayamoe Gardens
Calle A DD-6
Bayamon
Puerto Rico 00957

Also at the American MPS Conference a Fathers Workshop was held and this is the report of the workshop.

This was an informal, chat type gathering. The fathers seemed very interested in research and what centres are concentrating on which enzymes.

One of the fathers said that contact with other MPS parents was the best course of information about what they might expect with regard to the progression of the disease and treatment available.

They wanted a list to be available in the American MPS Newsletter of other families they could call and talk to who had been through the same experiences with operations and therapies. They felt as if they were re-inventing the wheel every time something happened to their MPS child and felt there must be someone out there who had already been through the same thing and might be able to point out the pros and cons before they were up against it themselves.

OVERSEAS

The general feeling was that they were all pretty mad that their GPs aren't any/much help. "Doctors are supposed to know everything – and the fathers were finding out that they knew nothing".

Many fathers were angry that not only did the doctors not know the right thing to do but that they quite often did the wrong things. They also felt that their gut feelings about their children were usually as good if not better than the doctors' advice. Some felt that once MPS had been diagnosed the doctors needlessly invited them to come in to the hospital for the interns to have a prod and poke at, as they maybe the only chance they had to see a MPS Sufferer.

One of the families takes a binder with all the information they have accumulated, from the many different professionals over the years, when they go to visit doctors to get them up to speed. Most of the men agreed that their partners were the pro-active ones in the relationship, looking for what might be available out there and then sorting out appointments. One father said that his wife has taken their 3 1/2 years old daughter, who has Hurler disease, to a range of complementary therapists and found that they have really worked although he found accepting the complementary medicine as difficult as accepting the MPS diagnosis.

The fathers also felt they would like a running order of what they might expect and when, as the disease progresses. They felt that relationships are tough at the best of times but with the added stresses that go along with this it was a real challenge.

If the children were refusing to eat, the parents all seemed to be giving milkshakes fortified with vitamins or nutritional supplements. They felt that their children would be gone soon enough so why make them eat things they didn't want to: they'll

be dead in a couple of years anyway whether they ate healthy, nutritional food or not.

The general feeling was that they were not comfortable fighting for benefits and grants. They have to feel it is for the sick child, who deserves it, and not because they themselves need help.

About half of the men had left or changed jobs so that they would have more time with their children and felt that it was the right decision despite the loss of income. They felt that nothing beats seeing their children light up when they're enjoying themselves so they don't do anything to spoil that.

They were very keen to network and keep in touch with each other although the Internet chatroom on AOL seemed the most popular method of doing this.

Generally they all felt glad that they had attend the MPS conference although most of them had had their reservations beforehand.

Angela Ratcliffe – Asst. Development Officer



We would like feedback from all the UK fathers if they feel that they would like us to hold a fathers workshop at our MPS conference in 2000 Please drop me a line if you would like this to be included for next year. Unfortunately this years programme has already been finalised.

Sheila Duffy – Development Officer

FUNDRAISING

RESULT OF THE MPS NATIONAL RAFFLE DECEMBER 1998

PRIZE WINNERS

PRIZES	WINNER	TICKET NO.
1st Prize Disneyland Paris – 4 x 1 day passes + £500 cash	S Lewis – Nottingham	14506
2nd prize UCI Cinema 3 months pass for 2 + £150 cash	G Devine – Coventry	58816
3rd Prize £100 Cash	Imran – Birmingham	23003
Kenwood liquidiser	J Horsfall	49265
HMV Voucher	M Alan	00474
McDonalds 2 x £5 vouchers	Audrey	38726
Readers Digest Illustrated Dictionary 'Of Essential Knowledge'	Eastham Commercials	17947
Tomy Toys Merry Go Round/Building Bricks	J Salmon	23482
Tomy Toys 'Bring along a song' Record Player	P Harriss	20205
Tomy Toys – Water Game	J Forsey – Bristol	15970
Tomy Toys – Motor blocks- Z Knight	A Croghan	11270
Tomy Toys 'Activity Cube'	Tony Eyre	14306
Data Bank Plus + Keyring	N & A Pickard	37365
Data Bank Plus + Keyring	B Thompson	41827
CD's	C McCourt	17520
Set of Mugs	L Dawson	12284
Windsor Collection Ornament	I Beaston	24490

**A BIG thank-you to everyone who sold the MPS Raffle tickets
We had a wonderful response again this year – keep up the good work!**

1999 MPS NATIONAL RAFFLE

We are now planning the 1999 MPS Raffle and would be grateful to any families who might be able to approach companies/businesses that they work for, to donate a prize.
We would like to secure three major prizes.
However smaller prizes would also be appreciated.

FUNDRAISING

Sponsored Step Aerobics

A cheque for £670 was received from Josephine Watterson and her fiancé, Charles Job, by running the 13 miles Great Scottish Run in the summer. Charles completed the run in 2 hours 5 minutes and Josephine in 2 hours 50 minutes – Well done!

The MPS Society received a cheque for £2,734.53 as a result of a Sponsored Step Aerobics that Carolyn Roddick organised in the summer.

They chose to raise the money for the MPS Society because their niece, Robyn has Hurler disease and they appreciate all the time and effort the staff and volunteers dedicate to providing support to families who have children with Mucopolysaccharide diseases.

Her 4 years old godson Dominic Stimpson suffers from Sanfilippo disease and she wanted to be able to do something worthwhile to help.

Photo below of Sylvia, Robyn and Josephine Watterson and Charles Job.

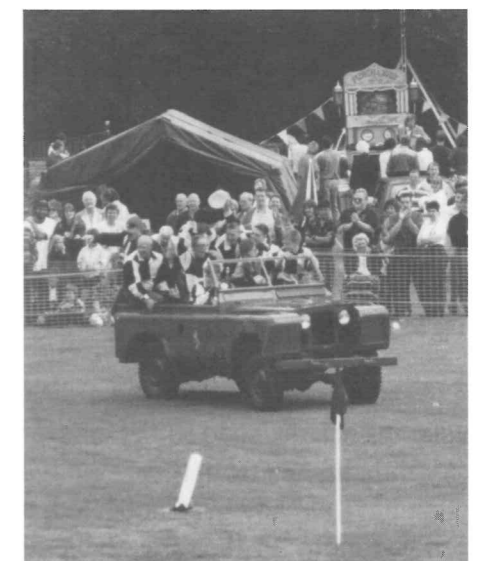


The event went extremely well. Thus far more than anticipated was raised. Carolyn would like to thank everybody who took part in the event and all those that dug their hands deep into their pockets to sponsor those who did participate.



Every year the 30th Signal Regiment LAD REME, Gamecock Barracks, Nuneaton organise various events to raise money for charity and the main event is the annual open day that attracts several thousand. This year the LAD organised a two team race over a short obstacle course reassembling and driving to the finish. We were one of three charities that received a cheque for £400.

Photo below of the team in action



Charity Fashion Show & Lunch

The MPS was chosen by Mrs Cotton for her Charity Fashion Show and Lunch at St George's Hill Gold Club, Weybridge which raised £2,200 for the MPS Society.

Last years lady captain Heather Gordon's grandsons both suffer from MPS.

The ladies enjoyed a lavish three-course lunch and a raffle that was organised by Mrs Gordon. Thanks to the generosity of the golf club and the support of more than 130 Elmbridge women, the event exceeded all expectations.

FUNDRAISING

A WORD OF CAUTION

The MPS Society is a registered charity and this means that the Trustees are responsible to the government for every penny of funds raised in the name of the charity.

We are very grateful to the many people who fundraise on our behalf. It does not matter if you raise small sums or large sums, they are all equally appreciated by the Trustees.

Please remember though, that it is **very** important when you are embarking on a fundraising venture on our behalf, using The Society for Mucopolysaccharide Diseases (MPS) and any of our materials, leaflets, etc., that the total amount of monies raised must be sent directly to the MPS.

It is not legal to fundraise for 'something for yourself or your family' in the name of MPS, sending the balance of monies raised to MPS afterwards, without prior consent of the Trustees.

If this is your intention please write to Christine Lavery, Director at the Amersham office, bearing in mind that the Trustees meet only four times a year.



Stamps and Coin Collection

Thank you all for sending in your Stamps and Coins but could you please remember the following points:

Stamps – The market price for the ordinary small English stamps has dropped to the extent that we make very little money from them. We will process any that have already been collected, but please send no more for the foreseeable future.

The English stamps ie. Christmas issues and all commemorative issues are still needed. All Foreign stamps fetch a good price. Best prices for all stamps are paid if the stamp has been cut from the envelope leaving a border of at least a quarter of an inch all round.

Coins – All coins, English no longer in circulation and foreign notes and coins are needed. As a charity the mint will buy back all old coins as long as we have a value of five pounds of the particular denomination.

Ken and Pam Ballard



Coronation Street – Julie Hesmond (Hayley) sent seven cyclists on their way for a Charity ride to Blackpool. Ben Glover who has Sanfilippo disease got his dad Andrew and friends to ride the 35 miles to raise money for research and despite the weather they had a great day. Julie Hesmond is a friend of a friend and it was really good of her to turn up. She was brilliant and nothing was too much trouble.



INFORMATION

FREE SPIRIT



How to Reduce your Council Tax

The Carers Discount

If you:

- Look after someone who receives the higher rate of Disability Living Allowances (DLA) Care Component:-

AND

- Care for that person for a minimum of 35 hours per week;

AND

- That person is not your spouse or partner;

AND

- That the person you are caring for is over 18;

AND

- That person lives with you

GOOD NEWS

You may be entitled to a substantial reduction in your Council Tax Bill.

How to Claim

- Contact your local Council Tax department
- If you think you are entitled to the Carers Discount and you need to discuss it further contact the MPS Society
- If your Council refuses your claim you can appeal to the Valuation Tribunal (in Scotland – Valuation Appeal Committee)

Do not forget to claim your backdated discount !

- Carers Discount can be backdated to when Council Tax was first introduced (April 1993).

Free Spirit is a specialist travel insurance policy which provides cover for people who because of their medical condition and/or disability are excluded from standard travel policies.

The policy has been developed by leading travel insurance broker Hamilton Barr and is underwritten by Home & Overseas.

Customers can contact Free Spirit direct or through their travel agent or insurance broker. Premiums are assessed individually and in most cases cover can be confirmed straight away.

Free Spirit is a telesales operation, thereby eliminating the need for form filling.

To contact Free Spirit call 01483 423766 quoting the organisation, which as been given the code - MPSSOCIETY.

If you choose to book your travel insurance through this broker then the MPS Society will obtain 10% commission.



FUNDRAISING

DONATIONS

<p>Independent Insurance Co. Ltd Bellway plc. D Lavender Brinkworth Ladies Club Mr & Mrs Zellstra Argos Thrings & Long Scottish Power Anthony Landsberg Christopher Makin John Summer Trust Mr & Mrs T Brown St Convals PTA Bison Group Rainford Trust Alan Terry L Heisig Wassall plc. John Sumner Jenny Hardy Tioxide UK Ltd. Gilbert & Eileen Edgar Foundation Mrs Haigh International Motors J Davis Eli Lilly & Co Mr Kamal P Gardner E Kronacher-Edwards Mrs Davison Axa Provincial Foreign & Colonial Gerry Fitchet Status Slimming World U.P.S.L.</p>	<p>Mr & Mrs Rennoldson Misselbrook Trust Wilkinson Arrowsmith Mr & Mrs Blanch Lehman Brothers Mr & Mrs Moore Japanese Women's Club M. O'Toole M Rainforth Pummell Family Evans family Jones family Davies family R F Walker Hartwell plc Royal London Mutual McCormick (UK) plc. G Devine Jean & Chris Cockman Mrs Egan Arrivals Booking Centre Barclays Anne Kilvert Kembrey family Mr McKnight Mrs Thompson South Birmingham Ladies Bowling League International Motore Priddy Firendly Society Clifford Chance B Coates Josephine Watterson S J & V Challen Amcors Raw Materials</p>
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CHARITY BOXES

The Bank Cottage Tea Room	Oversley Hill Service Station	St Andrews pre School
Loanends Post Office	Anne Fraser	Pam Croghan Coral Barton Jean Leonard
J Rosie	J Rosie	Sid Shiff Nowell family

FUNDRAISING

FUNDRAISING EVENTS

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

Trull School of Dance – Dance Show	
The Rising Sun Public House	
M Stimpson – Xmas Catalogue Sales	
Chris and Julie Kembrey – Car Boot Sale	
Philip Haworth – Great North Run Half Marathon	
Stonelaw High School – Sponsored Swim	
Burliston Home – Fundraising Day	
Edward Nowell – Crispin School Disco	
ITT London & Edinburgh – Casual Day Dress	
June Gibbons – Martial Arts Group	
Adam Sutcliffe – London Triathlon	
Terry School of Dance – Evening of Dance	
Cambridge Regional College – Student Team Building Module	
St Georges Hill Golf Club – Fashion Show	
Mrs Mansfield Cairns – Charity Night Ashby Institute	
Holy Trinity Infants – Xmas Performance	
Little Chalfont Combined School – Carol Service Collection	
Hamilton Pre-School Group – Carol Service Collection	
30th Signal Regiment – Race Team	
Coventry Three Spikes Round Table – Fun Run	
Haddenham Mummies – Xmas performances	
Wycombe High School – Hat Day	
Kembrey family – Car Boot Sales	
Bertrams Books – Staff purchasing slightly damaged books	
Sue Rowland – North Run	Pauline Mahon – MPS Dinner
Lynn Longhorn – Skittle Match	D Beavan – Aromatherapy Party
Staff at Cytogenetics – Swag Bag	Ken and Pam Ballard – Sale of Goods
K Denyer – Xmas Bazaar	Mrs Bennett – Sale of plant cuttings
N Fasey – Cake Raffle	Mrs Pirie – Dance
Sid & Betty Shiff – Sale of bag holder	Jenny Hardy – Soup Lunch
Barrier Minney – Collecting loose change	TSU5 – Fundraising Team

IN MEMORY OF

Paul Gunary	Gethin Robins	Rebecca Byrom	Joan Emmerton
James Fisher	William Holyroyd	Shane Dickson	Mrs K Walsh

STAMPS

DVLA	Jenny Hardy	Natasha MacKintyres(Nan)	Allen Family Alex Mahoney
Mr W Stock	Mrs Plummer	Kate Lowry	Devines' family Peter Stuart

AREA SUPPORT FAMILIES

EAST ANGLIA

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

c/o Hannah Crown, MPS Office, Amersham Tel: 01464 434156

POTTERIES

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

SOUTH-WEST

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

Anne and Gordon Hill Tel: 01404 812229
Bowhayes Farm, Venn Ottery, Ottery, St Mary, Devon EX11 1RX

HOME COUNTIES

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

WALES

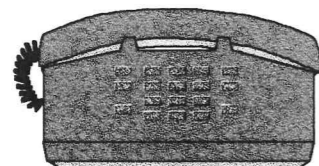
Ann and Michael Kilvert Tel: 01686 624387
Windy Waye, Nantoer, Newtown, Powys SY16 1HH

Please note that the following Area Families have now retired

*Barbara and John Arrowsmith
Sylvia and Bill Blackburn
David and Monica Briggs
Denise and Gavin Brown*

*North East of England
Potteries
Yorkshire & East Coast
Home Counties*

A BIG THANK YOU to you all for all your time and family support throughout the years



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

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

YORKSHIRE & EAST COAST

Monica and David 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

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

NORTH EAST OF ENGLAND

Ann Thompson Tel: 01325 254985
7 Sunningdale Green, Darlington, County Durham DL1 3SB

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

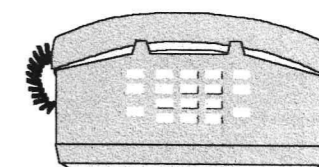
SCOTLAND

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

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

NORTHERN IRELAND

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



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