

Newsletter



The Society for
Mucopolysaccharide
Diseases

National Registered Charity No.287034

Summer 98



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Our Home Page on the World Wide Web : <http://www.vois.org.uk/mps>

*The MPS E Mail address for the Amersham office has changed to;
MPSUK@Compuserve.com*



**The Society for
Mucopolysaccharide Diseases**

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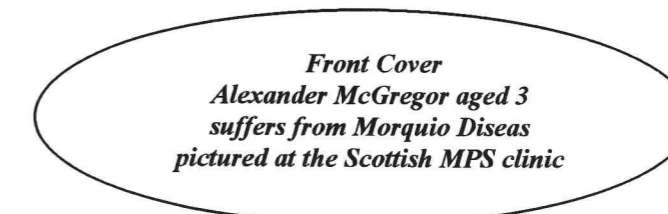
The MPS Society is a voluntary support group founded in 1982, which represents over 900 families in the UK with children or adults suffering from Mucopolysaccharide and related diseases. It is a registered charity, entirely supported by voluntary donations and fundraising, and run by the member themselves. 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 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 Disease, 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
Alexander McGregor aged 3
suffers from Morquio Disease
pictured at the Scottish MPS clinic*

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**Deadline for the 1998 Autumn Newsletter
26th September 1998**

CHAIRMAN'S REPORT

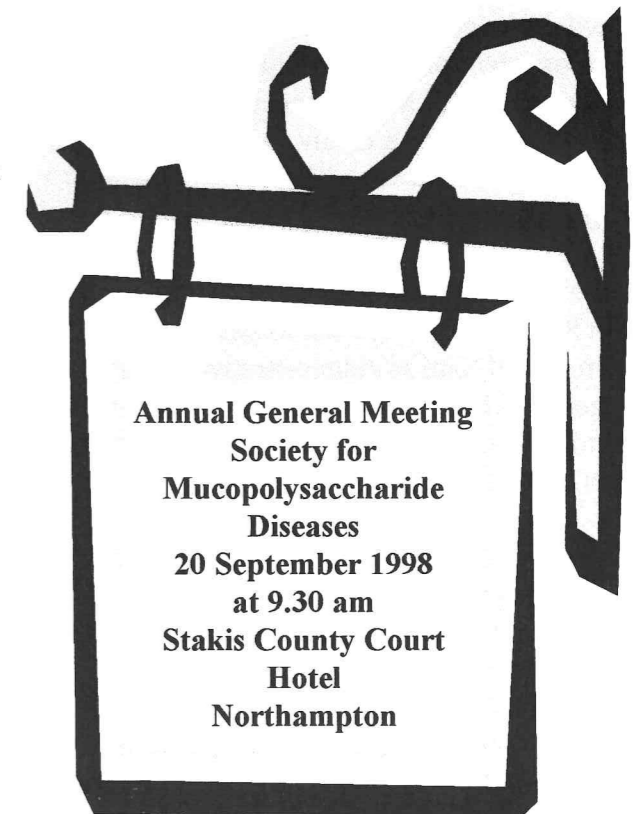
A timely reminder on this occasion about the Annual Conference on 18 - 20th September. We are anxious now to obtain the last few bookings from those among you who have not yet got the form out from behind the clock ! The conference is our unique occasion to get together to share stories, joy and sorrow, and establish that very special bond which as MPS families we experience but can't always put into words. I look forward to seeing many of you in Spetember.

A reminder too that we hold our Annual General Meeting on the Sunday morning of the Conference. This is an important meeting when we communicate to you the key issues of the past year in the Society and when the required numbers of Trustees are elected. This year we need three new Trustees. It is vital that the Society has Trustees who are committed to upholding our essential values and aims and who will work sincerely to achieve them. If you are interested, please let the Amersham office know.

Finally, many thanks to all of you who completed the questionnaire on the services the Society provided. You have given us very useful information which will be evaluated to inform and establish the strategic objectives for the MPS Society for the millennium and beyond. (The deadline has passed but we are still accepting the questionnaires if you would like to send them in).

Thank you for your interest and support in this.

Wilma Robins



DIRECTOR'S REPORT

The last three months have been a period of considerable change in the MPS Society. The Amersham office's move to bigger premises with ground floor disabled access, has now been completed. The new premises offer a much improved working environment as well as providing a meeting place for Management Committee meetings. We also have a family room where we can welcome and meet with MPS families or professionals if that is appropriate.

In the Northern MPS office we said goodbye to Sam Rimmer and welcome to Anne Leech who has replaced Sam as Administrative Assistant. Angela and Pam have been very busy starting to get to know and offer support to the Area Support Families.

In April Angela and I spent two days in East Anglia with the Area Support Families as well as carrying out advocacy work with individual families.

In early June, Ann Hill (Area Support Family) Angela and I met with all the families who have live MPS children in another much neglected (by the MPS Society) part of the country - Cornwall.

Very successful MPS clinics have been held in Scotland, Northern Ireland, Bristol and Cardiff. It was lovely for Mary, Pam, Sheila and I to have the opportunity to work with so many families and individuals in these different clinics.



In Northern Ireland we held a very successful Professional and Family Conference. It was enormously heartening that so many professionals gave up a Saturday to learn more about MPS diseases. We would also thank Professor Norman Nevin for chairing the Conference. We are trying to find a paediatrician in East Anglia interested in supporting an annual MPS clinic with Dr Wraith

preferably in Norfolk.

On the International front Mary and I participated in the Annual International Working Party hosted by the Austrian MPS Society in Kirchberg. It was a stimulating and at times challenging meeting particularly concerning the matter of the next International Symposium on MPS and Related Diseases to be held in Vienna, in 1999.



There was lively debate concerning the draft programme which disappointingly offered nothing for Sanfilippo families or those with the Mucopolidoses and other related diseases. Dr Ed Wraith has now been invited to join the Medical Advisory Committee and has raised these points. We hope that the final programme will address this. At the meeting the British MPS Society was asked to hold this International Symposium in the year 2002! The Trustees will be having a long hard think about this over the coming months as well as consulting with interested professionals. If you have a view on this please do let me know. It is also important for you to note the date of the International Symposium on MPS and Related Diseases has been changed to 18 - 21 March 1999.

Finally Mary and I would like to say a huge thank you to the vast number of families who returned the MPS Questionnaire on an audit of MPS services and activities. Many of you wrote additional comments on aspect of the Society's work which are much valued and will be considered by Trustees along with the results of the questionnaires. Those who completed the address sheet at the back of the questionnaire will receive the audit report, a summary of which will appear in the newsletter.

Christine Lavery

MILESTONES

New Families

Carol and Clive Shaw from Mansfield whose son Jake has recently been diagnosed with Hurler disease.

Mr and Mrs Hussain from Small Heath, Birmingham whose 5 month old daughter Safiyyah has recently been diagnosed with Mucopolipidosis Type II

Kathleen and Ken Stokes from Belfast whose daughter 6 month old Annie, has been diagnosed as suffering from Hurler disease.

Kevin McKenna 23 years old and Shamus McKenna 27 years old from Enniskillen who were diagnosed as suffering from Morquio disease some years ago.

Mr and Mrs Islam have two sons, 9 years old Shafiqal and 10 year old Sadiqal from London, are diagnosed as suffering from Hurler Scheie disease.

Mr and Mrs Hajifazal have two children, 1 year old daughter Azaria and 6 months old daughter Alisha have recently been diagnosed as suffering from ML II live in East Ham, London.

Maria and Ivan Murphy from Bristol's 8 month old daughter Tara has been recently diagnosed with Hurler disease.

Louise and Ian Taylor's son Jack has been recently diagnosed with Hunter disease. Jack is 16 months old and lives in Hull.

Marie and Wayne Tomes have a 14 month son Ashleigh who has been diagnosed with Hurler disease. They live in Plymouth.

Mr and Mrs McDonagh from Belfast have a son Patrick who is 6 months old has recently been diagnosed with Hurler disease.

Deborah and Paul Hambly from Hull have two children, Terry 4 and Jessica 5 months. Both have been recently diagnosed with Hurler Scheie disease.

Claire and Mark Benison have a 10 month old daughter Alice who has recently been diagnosed with I Cell disease. Alice lives in Blackburn.

Mr and Mrs Rafiq from Reading have two sons who have recently been diagnosed with Hunter disease. Faiser who is 4 and Eson who is almost 3.

Elizabeth and Robert McDowalls 4 year old son David was recently diagnosed with Hunter disease. David lives in Glasgow.

MILESTONES

Deaths

Sadly Kim and Keith Obeney 13 year old son, Scott died on the 13th April 1998. Scott lived in Dagenham suffered from Hurler.

Linda Coates's daughter Amy 24 years old, passed away on the 21st April 1998. Amy from Lincoln suffered from Sanfilippo.

Mr and Mrs Miah son Rahella 22 years old sadly died on the 9th May 1998. Rahella suffered from Sanfilippo and lived in London.

Sue and Cliff Vivier 16 years old daughter Katie, sadly died on the 10th May 1998. Katie suffered from Sanfilippo disease and came from Tunbridge Wells.

Mr and Mrs Hussein son Shezad died on the 6th April 1998. 12 years old Shezad from Bradford suffered from Morquio

Jill and Eddie Farwell's son Tom sadly passed away on 31 March 1998. 14 year old Tom came from Prieford and suffered from Sanfilippo.

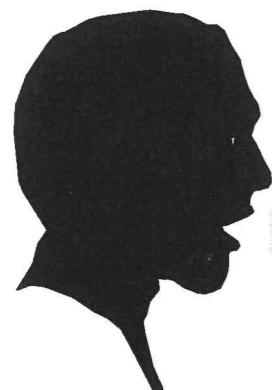
Julie and John Burlinson son Billy who was 13 years old and suffered from Hunter disease, died on the 14 April 1998 and came from Oldham.

Caroline and Bob Fisher 12 years old son James sadly passed away on the 5 July 1998. James suffered from Hunter disease and came from Great Samford.

Paul Gunary from Horsforth passed away on the 4 July 1998. Paul was 31 years old and suffered from Hunter disease. Our thoughts are with his wife Ellie, his parents and his sister Rachael.

Congratulations

Our Congratulations go to Jon Lawrie (Trustee) on his recent marriage to Catheryn from Norfolk.



*The Society for Mucopolysaccharide Diseases
16th Annual Conference 18 - 20 September 1998
Stakis Country Court Hotel, Northampton*

We still have a few rooms available so if you intend to come and you have not yet sent your booking form please do so a.s.a.p. to the Amersham office.

AREA FAMILY SUPPORT

**Yorkshire & East Coast - Area Family Day
Sunday 26th April 1998**

Just a few words regarding our family day we had on Sunday 26 April at Katie Martin's school in Harrogate.

It was nice to meet all our families and share some experiences with each other.

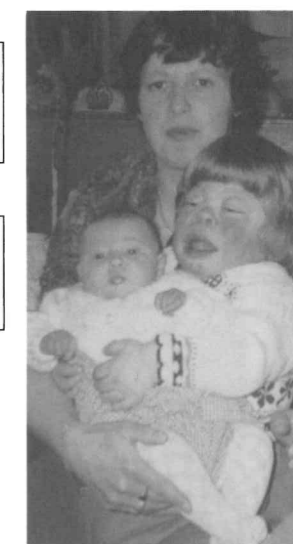
A lovely afternoon with time to relax and chate while the children played in the school's soft play room. Smiles and giggles all round when Burko the Clown shared a little magic with us all.

Our thanks to Starbeck School and their lovely caretaker for being allowed to use their facilities.

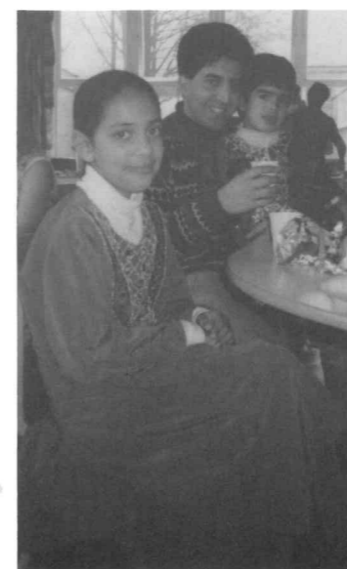
*Barbara and Trevor Rollinson
Area Support Family-Yorkshire & East Coast*



Stuart Lawrie-Sanfilippo with Emma Briggs on the left



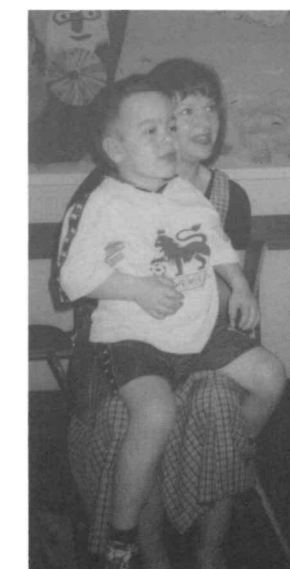
Katie Martin ML II sitting on her mum's knee with sister Aimee



Aiyah Hannif-Sanfilippo on her uncle's knee.



Shannon



Jamie Moxon-Hunter on his mum's knee.



Lisa Martin

AREA FAMILY SUPPORT

Area Family Support Family Training Weekend 6th - 8th March 1998

This year we were back at Glenbrook Outdoor Activities Centre, Bamford, Derbyshire. Although not the height of luxury, this venue does bring out the pioneer team spirit! Our thanks to Mrs Alys Allardyce and the Guide Association.

Eleven out of twenty-five Area Families were able to attend and we were very pleased to welcome Michael and Mary Boushel and Oliver and Carol Fitzgerald from the Republic of Ireland. They found the experience very useful and went back to Ireland with many ideas to move the Irish MPS Society forward.

The theme this year was very much around getting back to basics and improving the level and nature of the support the Society offers. Our thanks to Linda Partridge from Contact A Family who led sessions on "Listening skills" and "Why parents seek support". There were lively workshops and discussions following on from these topics and there were some lively discussions when the groups were asked to look forward to the Millennium and consider how the Society should develop and change.

Photos of Area Families who attended



AREA FAMILY SUPPORT

Rob Pagett ensured everyone was wide awake and thanks to the exercises and problems he set, everyone knew each other a little better by the end of the weekend. This was of course also aided by the sharing of dormitories!

As you probably are all aware we have a new member of staff, Angela in the Southern office. What you may not know is that Angela was kind (foolish) enough, to attend the Training Weekend as her baptism into the Society. I am sure she found it enjoyable and enlightening although I think she wondered what she was getting into. Anyhow, she is still with us and looking forward to next year.

All the Area Support Families and indeed staff, felt at the end of the weekend that they had gained from their time together and most went away feeling renewed and with a fresh sense of commitment and enthusiasm.

We could not have survived the weekend without the generous help and wonderful food provided by Pam and Jane aided and abetted by Mike and Anne Kilvert. Our heartfelt (should that be stomach?) thanks to you all.

*Pam Thomas - Development Officer
Photos of the workshops in progress !!!*



AREA FAMILY SUPPORT

**Potteries & Northwest - Area Family Day
Sunday 10th May 1998**

All the preparation was complete and the first Area Support Family Day we had organized had dawned. We had had a good response from families but the butterflies still flew around on route to Gullivers World near Warrington in Cheshire.

However on 10 May Gullivers World had MPS en masse. The weather stayed fine for us until the park closed at 5 pm when a few very tired but happy families decided it was finally time to go home.

The children had a wonderful time on all the rides and attractions in the park, quite a few Mums and Dads did too "escorting the children" was the excuse heard frequently. Now we have got through and thoroughly enjoyed our first family day, we are looking forward to the next one and seeing everyone again.

*Lynne and Chris Grandidge
Area Support Family - Potteries & Northwest*

Ben Lemon (Hunter) & family



Holly Thomspson (Morquio) & family



The Hamid Family

AREAS SUPPORT FAMILY

Area Support Family - Potteries & Northwest

South-West Area Family Day - April 1998

Hi this is us, Lynne and Chris Grandidge (Potteries Area Support Family) with our two children Steven aged 9 and Ian aged 5. Steven suffers from Sanfilippo and was diagnosed aged 2 1/2 years.

Chris is a Distribution Manager for an oil company and I work part time as a bookkeeper. We have been married for nearly 21 years and Chris enjoys photography and steam engine trips as his hobbies. I like riding and competing on my horse. Steven and Ian enjoy both types of activities as we do too.

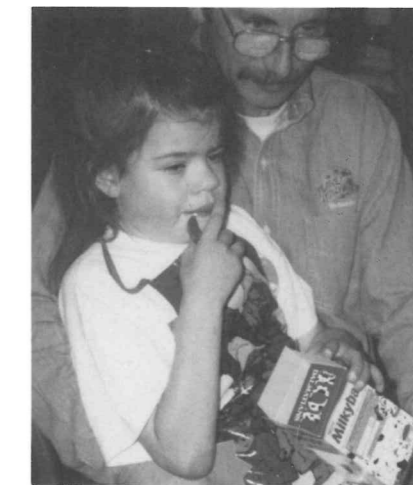
Lynne and Chris Grandidge



Families discussing where have all the Easter eggs have gone !!!!!



Lynne, Chris, Steven and Ian above at Gullivers World



Josephine Kembrey Sanfilippo (this is nice....)



Toby Parfitt Hurler/Scheie

FAMILY SUPPORT

MPS SCOTTISH CLINIC

Royal Alexandra Hospital, Paisley - Friday 3rd April 1998

Dr Cameron Shepherd very kindly arranged with Alan Byrne for the MPS Society to have use of the Paediatrics outpatients department at the Royal Alexandra Hospital again. Alan had arranged the appointments and Mary Pagett, Pam Thomas and Trustee-John Brennan travelled to Glasgow to join Alan and offer support to the families attending the clinic.

Dr Ed Wraith was unfortunately delayed by his flight from Manchester and arrived about half an hour late. Despite this he managed to see all of the families, 14 children in all, and to devote an hour to reassure a newly diagnosed family.

Little Robyn Watterson stole the show with her hair in bunches and her cheeky smile. She and Rebecca Stevenson(Martin's sister) took up residence in the playhouse, while young Rahman Ali gave the computer games a thrashing.

It was a busy clinic, but everyone enjoyed their time there, forming small groups to chat and compare notes over a buffet lunch. The clinic is valued by the Scottish families as it is difficult for many of them to meet during the course of a year and this is one of their main events.

Mary Pagett
Director of Support Services - North



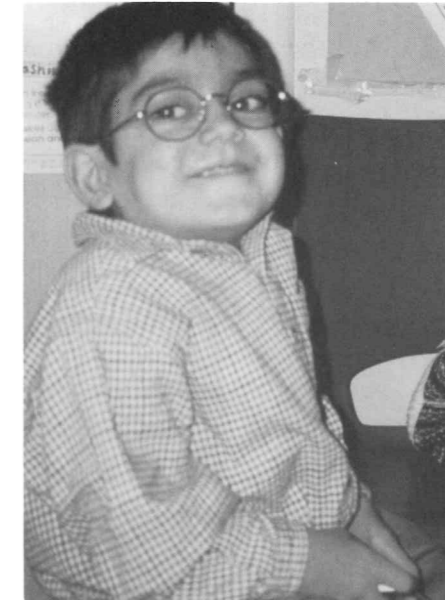
Alan Byrne(Area Family), Dr Ed Wraith, John Brennan(Trustees) and Dr Cameron Shepherd

FAMILY SUPPORT

MPS SCOTTISH CLINIC 1998



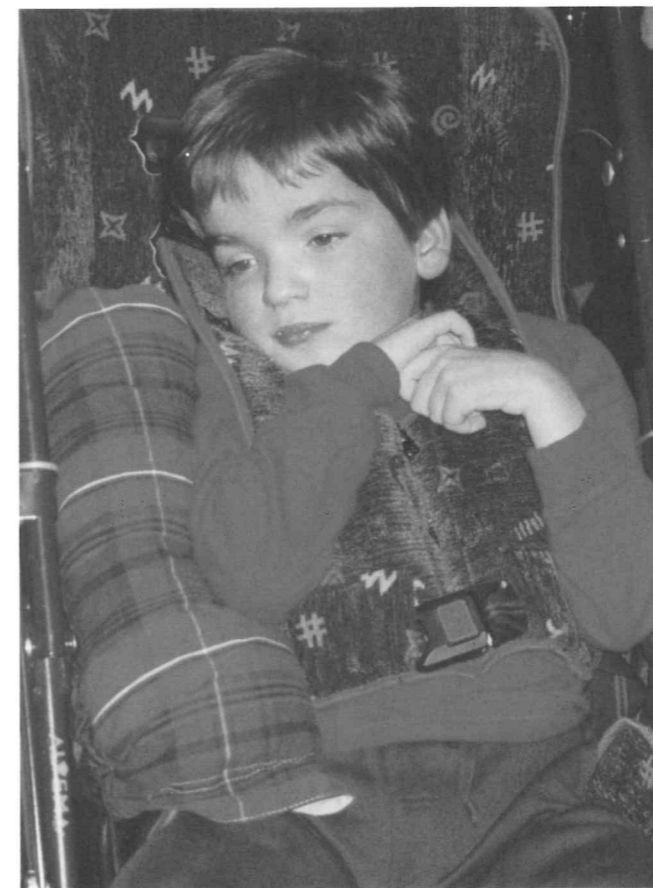
Emma McLean-Hurler



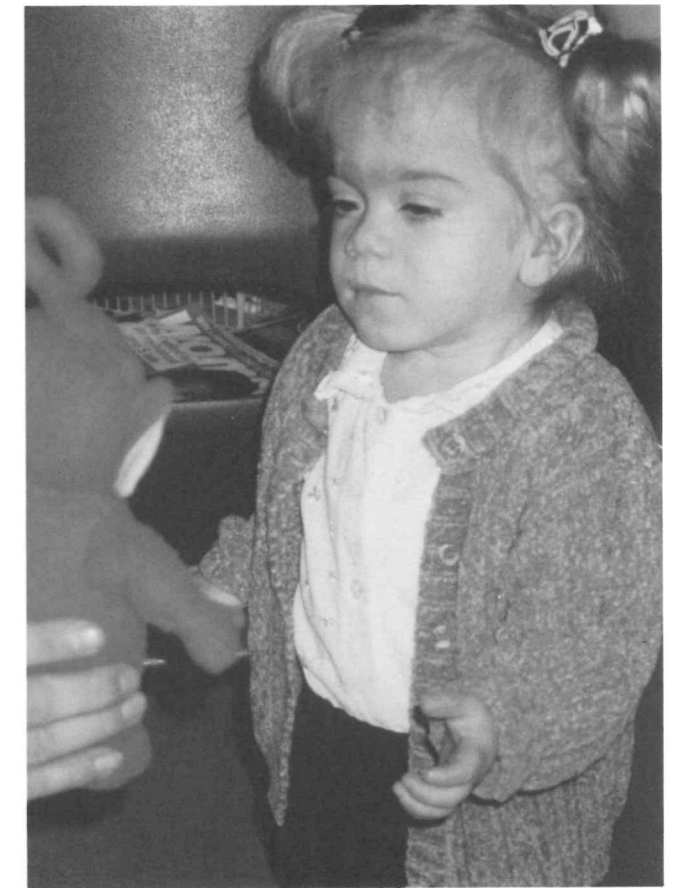
Mohammed Ali-Morquio



Joanne Evans-Morquio



Martin Stevenson-Sanfilippo



Robyn Watterson-Hurler

FAMILY SUPPORT

MPS BRISTOL CLINIC

Children's Centre, Frenchay Hospital - Thursday 23 April 1998

Dr Phillip Jardine very kindly arranged for the MPS Society to use the facilities at the Children's Centre, Frenchay Hospital. Christine Lavery and Sheila Duffy travelled to Bristol to join Dr Jardine and Dr Ed Wraith for the third Bristol MPS clinic.

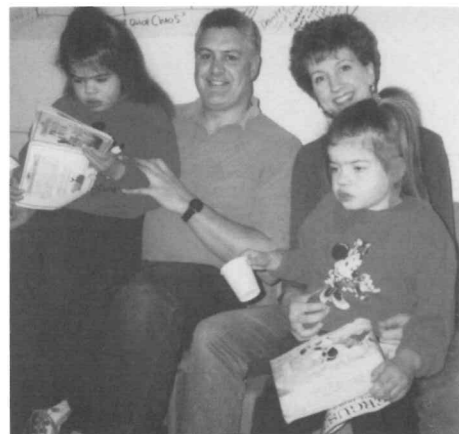
and share experiences.

It was a long day for everyone but another successful clinic and we will be holding our next clinic in Bristol in October. Letters will be coming to you soon.

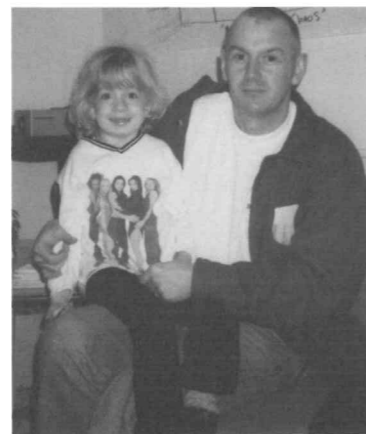
We had a full clinic and in total Dr Wraith and Dr Jardine met 17 families. In the afternoon Dr Stewart also came along to see some families. It was lovely to meet all the families at the clinic and for some families in the SouthWest this is the one occasion that the families have to meet each other

Sheila Duffy - Development Officer

Dr Phillip Jardine, Dr Ed Wraith and Dr Colin Stewart during MPS Bristol Clinic



Josephine and Francesca Kembrey



Ashleigh Montgomery (Hurler)



Fay Longley (Morquio)

FAMILY SUPPORT

MPS BRISTOL CLINIC 1998



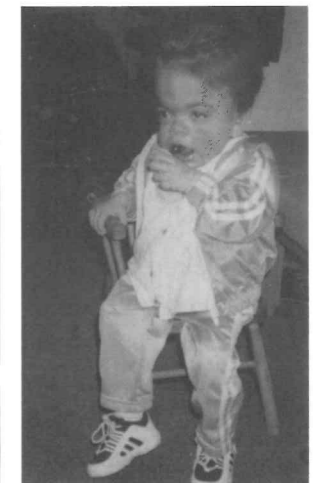
Shaun Osment-Sanfilippo



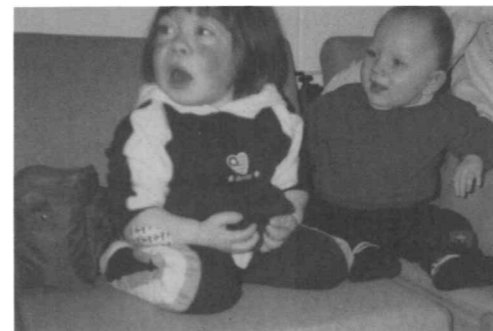
Matthew Wright-Hunter



Emily Hayward-Hurler



Kallie Hookway-Hurler



Amy Oliver-ML II & brother Jacob



Edward Morley-Sanfilippo



Sarah Long-Morquio



Louise Hill-Sanfilippo



Billy Cody-Hunter



Hannah Chisling-Sanfilippo

FAMILY SUPPORT

The Childhood Wood

Over the winter the trees in the Childhood Wood have fared very well and on two recent visits with volunteers the area around each tree was cleared and the plaques checked. A number of the plaques were removed on each of our visits for cleaning and repair. As it isn't possible to do this on the spot there may be a period when the plaque is not with the tree. On our last visit on 16 June many of the plaques were replaced.

There were a few which were not repairable and we have ordered replacement plaques which we expect to have in place for the 'Childhood Wood Remembrance Day' on Sunday 5th July.

I hope this reassures our families who have a tree in the 'Childhood Wood' as a living memorial to each of their children and young adults.

Christine Lavery - Director



The next Childhood Wood planting will now be on the 23 October (please note new date) All families that have lost MPS children since October 1997 will be written to individually. If any family whose child or adult who dies before that date would like a tree in the Childhood Wood in 1998 please contact Sheila at the MPS Amerhsam

FAMILY NEWS

Jack's Story

I am the proud mother of Jack. He was first diagnosed with Hurler Disease in May 1997, when he was 8½. Within a few days of diagnosis we were referred to the Willink centre at Manchester Childrens Hospital to see Dr Wraith. He explained to us about the treatment available and after speaking to him I could see some hope, some sort of future. At the time Jack was diagnosed the doctors were looking for 3 children to try the *new experimental treatment on 'Gene Therapy'*. The children had to fall into certain criteria. Jack had to have tests done to see if he could have the treatment as they only had licences to do the treatment on certain types of Hurler Disease. After a week we got a telephone call saying Jack could have the treatment. We agreed straight away knowing that there were not the side effects associated with a matched unrelated donor, bone marrow transplant which was our only other option.



asked if I'd consider trying again as they'd decided to use more chemotherapy to keep the blood count depressed for longer to give the bone marrow a better chance of grafting. As Jack had remained so well and was still his usual self I agreed to try the treatment again. We went home and were re-admitted in November 1997 to start all over again. Jack was sick a few times this time around but otherwise stayed well throughout the transplant. He'd been through so much but still managed to smile, laugh and get on with things. So I just did the same. As long as Jack was happy, I was happy. Jack's blood count came up a lot slower this time, the doctors seemed quite positive when they tested for an enzyme level. He had one. I couldn't believe it. It was only a small amount but it was there. I was so excited so were my family. My hopes were raised only to find within 2 weeks it had completely gone. I couldn't believe, we were back to square one.

Jack was admitted to Manchester Children's Hospital in August 1997. This was to have bone marrow taken. Sent to Christie's Hospital to have the missing enzyme added. Jack had to have a Hickman line put in for his drugs to be administered through. He then started on chemotherapy to depress his blood count. It was very worrying knowing the side effects chemotherapy can have on children, but it had to be worth it.

Jack stayed well throughout the transplant, which obviously helped me to cope with the situation. When Jack's blood cells started to recover the doctors took blood to test for an enzyme level, but when the results came back he didn't have one. I was obviously very upset, I knew it was an experiment but I had hoped it would work or else I wouldn't have agreed to do it. The doctors

Jack was now 16 months old. If he was to have any more treatment it should be done before he was 18 months. I had already agreed to have a matched unrelated donor before hand. The doctors had found that Jack had a list of 90 possible donors. The next step was for them to sieve through and find the best match possible. We were discharged 2 days before Christmas. It was hard knowing that Jack had to go through all this again, but I knew we were lucky we'd been given a third chance. So I kept on going until April 1998 when Jack was re-admitted to the hospital. I'd already spoken to the doctors so I knew to expect the worse and it wouldn't be as easy as the previous times and think he'd be having more chemotherapy. I was surprised at how quickly the time went this time around,

FAMILY NEWS

Jack was tested to measure his enzyme level. His blood count was still very low so they told me not to expect to receive any results. A week later the results came back and he had an enzyme level of 6.5 (the normal level for a carrier is between 3-10). I couldn't describe how I felt I was so happy I felt like I was walking on air. It was the moment I'd been waiting for almost a year. I couldn't believe it had worked. The doctors did another test which revealed Jack has all the donor's marrow and none of his own. This is good news as it reduces the chances of serious graft versus host disease. I know we've got a long way to go and the next year will be the worse as he can reject until this time next year, but now I feel as if I can face anything. I know I've got a chance to see my little boy grow up. I realise Jack will still have his problems and he will need an operation on his back within the next year. Jack has been so brave throughout all 3 lots of treatment. He gives me the strength to go on and I know we've both got a future to look forward to and I couldn't wish for anything more.

Dominique Partridge



Update

When Jack went back to the hospital in May 1998 he now had an enzyme level of 13. It had doubled in a week. I can't believe it, its all gone so well, I feel like I'm sat waiting for something to go wrong.

Photo below of Katie Devine - Hurler disease



***** New MPS Plant *****

*The lengths we go to make Katie tall !!!!
My Dad is a keen gardener and
has great success growing
big vegetables.*

So we asked for his help

Alas - it didn't work !



FOR SALE

N Reg. Renault Traffic. Full Conversion, rear ramp entry, full clamps and seatbelts for wheelchair. 4 passengers seats 39,000mls FSH £9,500 Tel: 01243 584427 evenings

INFORMATION

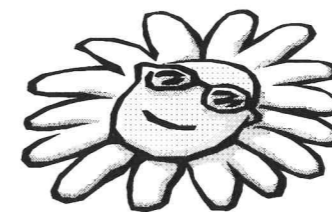
HANDICAPPED VS DISABILITY

My doctor asked me a question as to the difference between being "handicapped" and having a "disability" or having an "impairment".

The word "sufferer" also came up during and after the 4th International Symposium on Mucopolysaccharide and Related Diseases Society amongst other people with MPS, especially the difference between "mild" and "severe" grades of the condition.

Reflecting on all this I consider that the grading of mild and severe is only a category used by professionals upon any abnormal conditions to sub-divide their study and research

For me, mild or severe doesn't matter. It's a terminology for the professionals. My concern is living with MPS. Everybody is different, has their own opinions and lives their life according to their individual capacity.



In my opinion, "handicapped" refers to people who require additional equipment to aid them in their daily "normal" routine, such as crutches, back scratchers and braces. These are most likely to be temporary devices.

"Disabled" refers to people who cannot manage tasks performed daily at all, such as not being able to tie one's own shoelaces, needing a modified car to get from A to B

and other devices that will be a part of their life nearly all the time.

People with "impairments" are those whose "normal" mental and/or physical functions have deteriorated over time or from the beginning. People with impairments might require spectacles to read, hearing aids to hear and inner soles to walk properly. I may be wrong in my opinion of the above topic. I just live my life.

No, I'm not handicapped but I do have a few impairments. (I wear glasses and hearing aids which would indicate that I am impaired in these areas). Only slowly am I feeling the effect of becoming a disabled person. I'm more restricted these days in the things I can and can't do.

Yes, I require assistance in some form and I am grateful for it. I am fortunate that my family can support me in this way. Requiring assistance is helpful as it saves me time and much effort. It's not that I can't manage by myself but things like getting my socks and shoes on, buttoning up my shirt and having my hair washed all put a lot off strain on my body, if I do it on my own. However, if I had to ask someone other than my family for assistance it would be a whole new ball game.

The way you manage all depends on your perspective. I know that there is always somebody worse off than myself.

By Vaughan Glasson

(Copied from Australian MPS Newsletter)

INFORMATION

The Risks, Reactions and Realities of Carrier Status - What do statistics mean to you ?

by
Dr W F Carey

Head, National Referral Laboratory, Department of Chemical Pathology, Women's and Children's

The following is the abstract of a presentation at the 4th International Symposium on Mucopolysaccharide & Related Diseases, 1996.

For the majority of the time that Dr Carey has been at the Women's and Children's Hospital he has been involved with the prenatal and postnatal diagnosis of patients with a variety of genetic disorders. He has been instrumental in introducing many of the enzyme assays currently used diagnostically, tissue cell culture and cell bank facilities and the use of diagnostic molecular techniques for both mutation and linkage analysis in families with inherited disorders.

Bill is currently the Head of the National Referral Laboratory within the Department of Chemical Pathology, which provides a prenatal and postnatal diagnostic testing service for Australia, New Zealand and South-East Asia for patients suspected of having a biochemically defined genetic disorder.

Attempts to define the carrier status of any individual by simple enzyme assay alone are fraught with difficulties and should not be attempted despite literature reports to the contrary. In our laboratory, the specific enzyme activities associated with the various mucopolysaccharidoses (MPS) show significant overlap between the ranges observed for non-carriers and carriers in most sample types (leucocytes, or skin fibroblasts). No doubt, there are statistical ways to quantify the relative risk of being a carrier based on this observed overlap of ranges, however, this is most unsatisfactory, both for the family and clinician.

Given this, the major issues that influence the assignment of carrier status in the MPS disorders are the way the disorder is inherited and the current understanding of the molecular defect that causes the disorder. In most cases of X-linked

recessive inheritance (such as MPS II), the mutation is carried only by the mother on one of her two X-chromosomes. However, it should be remembered that not all mothers are real carriers of the disorder and about 30% of cases arise from new mutations in the egg or sperm. On the other hand, in autosomal recessive inheritance, both parents must carry a mutation in a specific gene to have an affected child. The "recessive" nature of inheritance means that the effect of a mutation in one parental chromosome is overcome by the other chromosome of the pair; thus carriers show no effect of the mutation.



Approximately half the cells from a true female carrier of an X-linked disorder will have completely normal enzyme activity and the other half will have an enzyme deficiency similar to that found in the proband (*affected son*) whilst single cells are difficult to isolate and assay, hair follicles, which arise from 3-4 cells, offer an opportunity to detect cells that are deficient in enzyme activity. The multicellular origin of hair follicles means that carriers generally show a wide range of enzyme activity in these cells and it is only if all of the group of original cells of a follicle are deficient in activity that the measured enzyme activity will be deficient.

INFORMATION

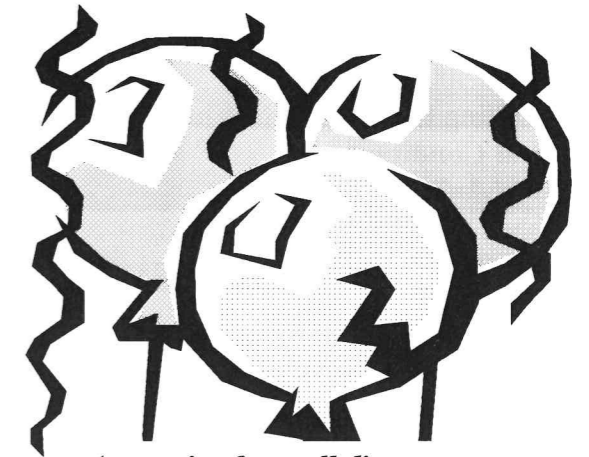
Nevertheless, if very low enzyme activities are found, then it is virtually certain that the individual is a carrier. If no hair follicles with abnormal enzyme activities are found, it is not possible to say unequivocally that the individual is not a carrier, as there is still a chance that the next one assayed might be abnormal. Consequently, at least 100 hair follicles must be assayed for statistical certainty.

Specific mutation detection offers the best option for unequivocal carrier status assignment for families with autosomal and X-linked disorders. However, this approach presumes the causative mutation in a family is known.

Some of the MPS disorders result from 'common mutations' (eg. W402X and Q70X in MPS 1), but there are many different mutations within each of the MPS - specific genes that cause disease. There will be a number of families (perhaps more with X-linked disorders) who have their own 'private' mutation. A major laboratory commitment to DNA sequencing, perhaps of the entire gene, is required to detect these rare mutations. Situations may also arise (eg. where part of the gene being tested is deleted) where the commonly used molecular techniques may fail to detect carriers.

Consequently, mutation detection in the general population, eg. for partners of MPS carriers (at risk or proven) is again a statistical problem and depends on the frequency of occurrence of the more 'common' mutations.

*Copied from the:
New Zealand MPS Society Newsletter*



A surprise farewell dinner was held for Joan Evans and her husband Geoff (hosted by Christine Lavery) shortly before they left for Germany.

Wilma Robins - Chairperson presented them with some lovely Dartington cut glass Wine Goblets for all their work for the MPS Society



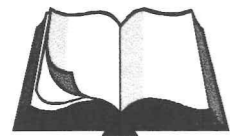
INFORMATION

Recent publication of books that might be of interest

Counselling Children with Chronic Medical Conditions

By Melinda Edward and Hilton Davis. Published by the British Psychological Society, St Andrews House, 48 Princess Road East, Leicester LE1 7DR.

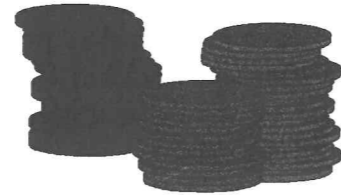
Tel 0116 254 9568 £9.99 + £1 p&p. This book offers an insight into some of the emotions, conflicts and dilemmas experienced by children with chronic medical conditions and disabilities and by those caring for them. All children have their own unique perception of themselves and the way in which their condition affects their lives, and this is beautifully expressed through examples of children's own comments throughout the book.



Solving children's Sleep problems

A step by step guide for parents by Lyn Quine. Published by Beckett Karlson Ltd. The Studio, Denton, Peterborough PE7 3SD Tel 01733 244 007. Current special offer price under the Bunny 1998 Offer @Sleep Peacefully' £9.99 + £1.50 p&p

A practical guide which is based upon the author's research into the sleep problems of disabled children but, as was later found by the research team, the methods may be equally applied to any child who experiences sleep difficulties.



Backdating of Invalid Care Allowance to be reduced again:

** Apply for ICA now !* *

Carers National Association is urging Carers to phone the CNA's Carers Line to find out if they are entitled to Invalid Care Allowance, worth £3.75 per week, and if so to apply now.

Until June those Carers who are entitled to ICA will have it backdated to three months before their application is received. Then it will be backdated for only one month.

- Many Carers take years to realise that they are Carers. (Reserach has found that Carers took up to ten years to realise they were Carers). This measure will also affect Carers income in retirement because Carers who get ICA also get a credit towards their basic state pension. Many Carers are financially pressed and two months ICA is important income.

CNA Carers Line

Tel No. 0345 573 369 (local rate apply)

Open Mon-Fri 10-12 & 2 - 3

Decorative star border at the bottom of the page.

INFORMATION

Demelza House

Rook Lane Bobbing Sittingbourne Kent ME9 8NQ

Tel: 01795 843843 Fax: 01795 843040



Demelza House is due to open its doors to families on the 7th September 1998.

They are now at the stage of inviting families who are interested in using Demelza House to contact them.

Referrals may be made in writing or by telephone to; Izzy Bowles - Head of Care

Their catchment area is defined as; Kent South East London East Sussex.

They have eight beds available; six will be pre-booked and two beds reserved.



They have a jacuzzi and multi-sensory room, activities room, music, computer and 'wet' play room.

Demelza House is set in large grounds and

several themes have been introduced.

At Demelza House some families will want a total break from hands-on care, whilst others will want to continue giving some of the care, sharing the care with the staff. Other families might choose to let their child have a break from their normal routine whilst they enjoy a break in their own home.

Further information can be obtained from

Wendy Ely - Administrator Demelza House Rook Lane Bobbing Sittingbourne Kent ME9 8DZ

Tel: 01795 843 843 Fax: 01795 843040

OVERSEAS

MPS Family Week Programme, Agrenska Health Centre for Children, Gothenburg, Sweden. 16th - 18 March 1998

Dr Ed Wraith and I, at the invitation of Dr Gunilla Malm, travelled to Agrenska to spend three days with nine MPS families and their professionals. This family week at Argrenska provided parents with the necessary knowledge on the medical information and management of their MPS children, while simultaneously providing the opportunity for them to meet other parents in the same situations. The MPS families travelled hundreds of miles; one from Lapland near the arctic circle with their teenager who has Hunter disease.

The parents heard Ed speak on the natural history of MPS, current treatments and the orthopaedic complications, whilst I presented a paper on the psychological aspects of MPS with Inga-Lill Kristiansson from Stockholm. I also spoke on the work of the MPS Society as well as talking individually with families and participating in the children's programme. Children attending the MPS family week were offered their own special programme which was both instructive and fun. The brothers and sisters had an opportunity to meet other siblings. The healthy siblings attended the school at the Agrenska Centre where a teacher helped with school work the children had brought with them.

They also enjoyed visits to the cinema, city centre of Gothenburg as well as nature trips around the small island of Lilla Amundon where the Agrenska Children's Centre is situated.

The MPS children had experienced 1:1 carers who provided an energetic programme that included music therapy, nature trips and sensory stimulation.

Both Dr Ed Wraith and I would like to thank Dr Gunilla Malm, the team at Agrenska Children's Centre and the families for their warm welcome and kind hospitality. The Agrenska model certainly gave us food for thought - a centre that provides for medical/social assessment, respite care, family programmes, conferences, training and activity weeks for adults with disability away weeks for siblings.

Christine Lavery

Photo below of Dr Ed Wraith, Dr Gunilla Malm, Anne Bachk and Christine Lavery



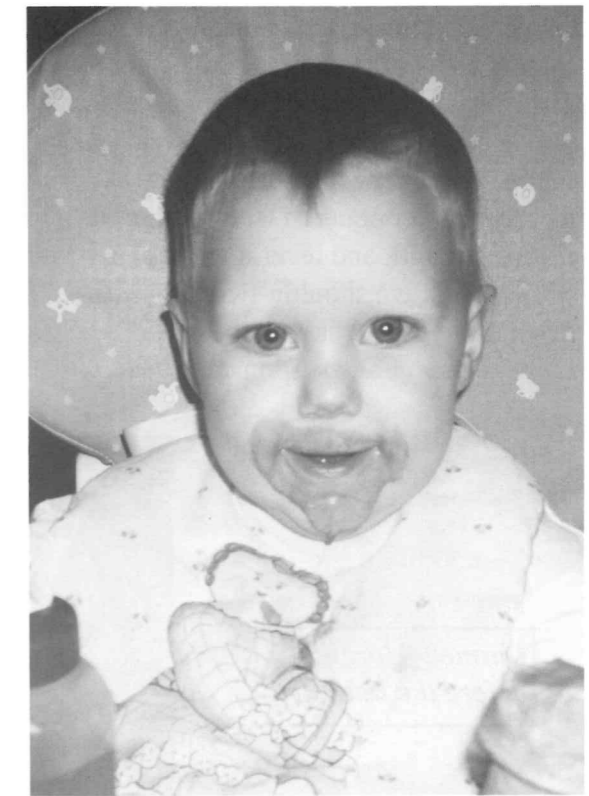
OVERSEAS

As you may or not be aware, our family has three children, two of whom are affected by Morquio syndrome. Damien 5 and Natasha 4 were both diagnosed in September 1995 with MPS IVA and our lives began a different journey than we had anticipated. Our third child Samantha arrived in October 1996 and after tests on the umbilical cord we learned that she was unaffected. This was wonderful news in some ways but for us it is unusual news. Although Samantha is 'normal' in our current family she is the odd one out and will provide a very unique dynamic in our household.

We are again expecting in November 1998 and will wait until the child is born to learn whether our family is 'balanced' or 'tilted'. I use these words loosely. We are so used to smaller children, having three children 5 years apart, but only 10cm apart in height. I am waiting for Samantha's hair to grow and then I will purchase a T-Shirt that says 'No they are not triplets'.



Natasha - Morquio



Samantha (Natasha sister)

OVERSEAS

I think the hardest, no, the most exhausting part of our MPS journey so far has been the public education that we do with schools, family, friends and Society. Sometimes I feel that I have covered all our basis when a new opportunity presents itself and off we go again. We have found that education has been far more beneficial than not saying anything.

Our house has been adapted in minor ways for these two. We have stools all over the house and the children's craft cupboard is limited to the bottom two shelves where they can reach everything. We have also moved the cereals down to the bottom shelf so they can get parts of their breakfast themselves. The one thing we did do that was a big help was to borrow a toaster oven so the children can make their own toast. The one hump that we have not conquered is the fridge. It takes alot of strength and leverage to open it. Many people think we shouldn't complain about this but we would like all the children to be as independent and responsible as possible.

Damien had his first surgery on his lower legs. The surgeon was thrilled at how things went and his comment was 'We can't cure MPS but he sure makes hard bone!'. They were able to cut out bone pieces, realign the bones and screw the fixtures into the bones. Damien was home 3 1/2 days after major surgery as usually it is at least 8-10 days. Daimen's Dad has a brilliant boss who is letting him work from home every morning whilst Damien is wheelchair bound but he goes to school as usual which is great.

If any family would like to write to us or e-mail us to share thoughts or ideas we would love to hear from you. Networking is just one way of helping each of us out as we journey down different paths than most families.

Best wishes

*Corris Kaweski and family
Canadian MPS Society*

E Mail Corri-Kaweski@bc.sympatico.ca



*Daimen-Morquio
before the haircut*

FUNDRAISING

Just a short note of thanks to our friend Heather for volunteering me for this insane venture.

When the phone call came asking Denise if she was interested in doing a parachute jump, I was in bed at the time enjoying a much needed sleep after working nights, unknow to me Denise had said 'I'm scared of jumping off the carpet let alone out the a plane but I know a man that will!!

The day drew closer and the nerves got worse, I did not get a wink of sleep the night before the training day, but as things went, the training was strenuous but not too bad, I don't remember the drive home from Peterborough that night due to my mind mulling over all the things that we had been taught.

The day dawned **HELP** I arrived and the nerves were frazzled to say the least, a quick refresher and then

But it was not be be, the weather had decided (after we were all kitted up) to play an ace card and become too dangerous for us to jump **PHEW**

We all agreed that as soon as possible we could reschedule the jump. The phone call came at 10 o'clock on Saturday night "We are going in the morning, are you coming?"

We all duly arrived on Sunday morning (more than a little nervous), did the refresher training, kitted up, waited for the plane to land. This was it. No turning back. We climbed into the plane made sure our lines were safely clipped in and off we went up into the wild blue yonder.

No time for nerves when the orders were given "In the door - **GO**!"

Four seconds of blind panic followed until you look up and see that lovely round parachute about you and you realize that you are all alone in the

world (except for the instructor directing you via a radio in the helmet) What a fantastic feeling!

All too soon the ground starts to come up at you very fast and all the training come to mind. Thump - That's it

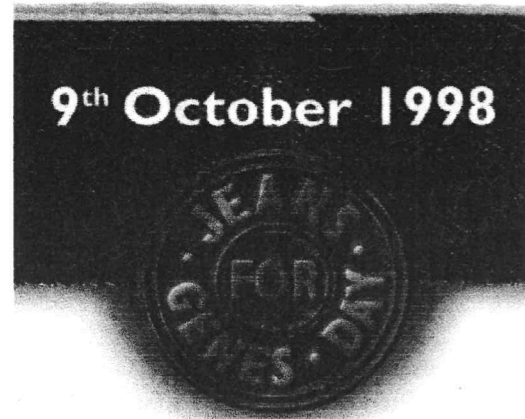
When is the next one ?????

Gavin Brown - parent of Adam (Sanfilippo)
(To date Gavin has raised a total of £1,633 for the MPS Society - Congratulations)

Gavin is pictured below admiring the scenery !!



FUNDRAISING



Organisation of the third national *Jeans for Genes Day on Friday 9th October 1998* is now in full swing and we are aiming to get EVERYONE across the UK to wear jeans to school or work for the day and give £1 to the appeal.

The appeal has been a great success over the last two years, raising £850,000 in 1996 and £1,400,000 in 1997, but to raise the profile and inform everyone about our case, we need your help!



There are lots of ways in which you can encourage others to support *Jeans for Genes day*, from simply asking your family and friends to encourage their schools, colleges and places of work to telephone for a free information pack on Freephone 0800 980 4800 through to contacting your local newspapers and radio

stations to tell them about the appeal and your personal experience of a Mucopolysaccharide disease.

When people in your area realise that their participation in *Jeans for Genes Day* could be of benefit to a family local to them, response to the appeal can be significantly increased.

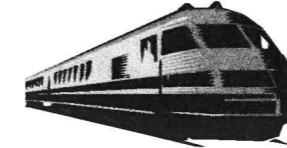
If you are interested in contacting your local media and would like advice about who to contact and what to say, Rachel Smith, Jeans for Genes Press and Publicity Officer based at Great Ormond Street, would be delighted to hear from you.

You can reach her during normal office hours on Tel: 0171 916 5678

Thank you for your help !

FUNDRAISING

VOLUNTEERS NEEDED



We are in desperate need of volunteers to collect at the following Victoria Line underground stations on *Jeans for Genes day - 9th October 1998*

Blackhorse Road; Tottenham Hale; Seven Sisters; Highbury & Islington; Warren Street; Pimlico; Vauxhall and Brixton.

Please contact the Amersham office and state which station that you will be able to collect at. a. s. a. p.



We are also looking for volunteers for the 23-25 August at Earl's Court 40° show. If we take the stand, we will also benefit from a party being held as part of the event.



Fer and I were delighted to recently be invited to receive a cheque for £325 from the '1\VRNT - \VI' organisation. Why Urchfront? Why the Nags Head? Simple; Ben Davies from Wales who suffers from Morquio syndrome has an uncle 'Jobe' who resides in Urchfront, is actively involved with the arduous duties so he tells me of '1\VRNT - \VI' which nominates a charity from time to time to be the beneficiary of their activities. This time it was MPS. So very many thanks Jobe for your thought and all the efforts from your dedicated team. We had a smashing evening and hope to get over to see you again.

Fer and Bill Pidden receiving the cheque - South West Area Family



FUNDRAISING

Name the Welsh Doll

After receiving the sponsor sheets I requested from the MPS Amersham office, I then went ahead asking family and friends to help with the fundraising. With great success the task of selecting the name of the little Welsh doll proved to be a very popular endeavour. Once our efforts were complete, we decided to have a draw night at the local pub. All the funds raised amounted to £361-50 which I have pleasure in handing over to you with enclosed photo.

Janet Jones

Picture below of Janet Jones and friends with the cute Welsh doll.



In memory of Billy Burlinson

*Perhaps you sent a lovely card
or sat quietly in a chair
Perhaps you sent a funeral spray,
If so we saw it there.
Perhaps you spoke the kindest words,
As any friend could say,
Perhaps you were not there at all,
Just thought of us, that day
Whatever you did, to console our heart,
We thank you so very much
Whatever the part.*

Julie, John and family

FUNDRAISING

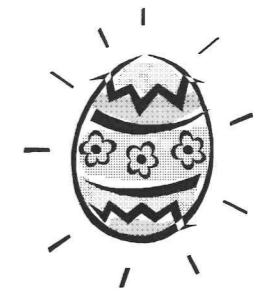
Congratulations to Robert Crocker for your fundraising efforts by running in the Paris marathon recently. To date we have received £172 for the MPS Society.

Robert was running in memory of Maureen and Dereks daughter Sally-Ann who passed away in 1990 and suffered from Sanfilippo disease.

Robert is shown below in the Paris Marathon



Alison Sheilds has sent in this photograph of herself along with some of the Comber Liverpool Supporters Club at the beginning of their sponsored walk. Alison was presented with a cheque for £2,500 raised by from the sponsored walk from Comber to Bangor (approx 12 miles). Congratulations to everyone for raising this-money for the MPS Society.



Alison also collected a cheque for £400 raised by the Newcastle & District football league with a charity football tournament. Well done everyone.

FUNDRAISING

On Saturday 18th April 1998, the Volunteer (Warwickshire) Band of the 5th Royal Regiment of Fusiliers took part in the Mayor of Warwick's Charity Concert at St. Mary's Collegiate Church in Warwick.

I had always thought of the T.A. Band as a "marching band" and was very pleasantly surprised at the beautiful music as they performed in concert. We had attended primarily because Lt. Col Tom O'Brien MBE, CO of the 5th Royal Regiment of Fusiliers, has adopted the MPS Society as the Bands' charity.

Led by Bandmaster G.E. Joseph ARCM, their performance was very impressive and enjoyable and very professional.

For performing the Lord Mayor gave a percentage of the proceeds to the Band to give to their charity. The photograph shows their cheque for £250 being presented by C Sgt Trevor Johnson during a recent concert performance in Coventry City Centre.

Lindsey Devine with Katie (Hurler) and family collecting the cheque below.



Matthew goes to a respite family each month for a weekend. Pete and Denise Jarvis and their family have all been wonderful to Matthew and organised a "Family & Friends Car Treasure Hunt" to raise awareness about the Society and raise money. Each car paid £5 to enter (many gave more) in return we were given direction "all in verse" which took us around the countryside looking for clues to the questions we were given. We ended up in a pub and finished the afternoon off with a meal, all of which they organised. The publican also gave us £25. The event raised £130. (well done and we hope not too many people got lost).

Matthew also attends Beavers and the pack leader organised a BBQ for the boys and their parents in which the boys had to plan and then help on the night. Many parents and boys attend and they raised £70 for the MPS Society.

Julie Wright - Mathew's (Hurler) mum

FUNDRAISING

DONATIONS

The Society is grateful to the following who made donations.

Mrs Campbell	Dr Whittard
David & Sigi Brown	Alliance Leicester Building Society
Elizabeth Gordon	Fine Art Developments
Dr Moore	Brian Adair
Cannon	Enterprise Oil
N E Pearson	Dexion Ltd
Graham Knight	National Lottery
Christadelphian Samaritan Fund	Nancy Colligron
St Edward Royal Free Ecumenical School	Kelvin First Group
M J McTiffin	Mr Beniston
J D Lunn	Dixons
Mrs Baker	A Sutcliffe
Mr & Mrs Colton	Robert McDowall
Mr & Mrs Sundberg	Heather Gordon
Sir Roger Buckley	Benham Charitable Trust
Elf Atochem UK Ltd	Fenwick
S Arosy	Keith & Stelle Blanchard
Haslemere Estates	A Glover
Mrs Eaton	Freemasons Lodge - Cardiff
Gwen Richards	Norma & Alan Terry
P Kegerreis	Mrs Gluckstein
Mr & Mrs Oulton	Mary Moulding
Field Group	London & Scandinavian Metall
Muckamore Presbyterian Church	E C Oldham Trust
Wallingford & District Round Table	Electrolux
A Miller	Ann Kelly
A Petersen	Gwen Richards
Harebell Centenary Fund	Druck Ltd
Brian Adair	A Hardaway
Clydebridge Steel Works	Ecclesfield Priory Players
Anne-Marie Watson	S Blanch
Fer Pidden	Eastern Group PLC
A Haussmann	Mars UK Ltd
Mary-Ellen Nowell	Nutricia Ltd
H Gordon	Bushvale Church - Youth Club

FUNDRAISING

FUNDRAISING EVENTS

~ ~ ~ ~ ~

David Stewart, Bristol - London Marathon
 Pam & Ken Ballard - Sale of items
 Kieran Houston, N.Ireland - Golf Tournament
 Jill Jones, Princes Risborough - Raffle at Temple Manor Mason Lodge, Ladies Night
 R & S Enoch, P Claridge, Bristol - Bike Ride
 Focus on Fitness, Malmesbury - Treadmill Walkathon
 Lesley Oldfield, Whitwell - Wet Bike Challenge
 Marina Foster & Brian Foster, Bristol - Car Boot Sales
 D Rogers, Leamington Spa - Bike Ride
 Portsmouth Fire Brigade - Portsmouth
 Julian White, Lincoln - Sponsored Diet
 St Francis of Assisi Roman Catholic School - Fundraising Lent
 Sue Lowrie, Harpenden - Sale of old computers from ABT International
 Ken Ballard - Sale of Tennis Balls
 Robert Crocker, Nottingham - Paris Marathon
 C A McIntyre, Sheffield - Sale of knitted Easter Chicks
 Dominique Brooks-Daw, Taunton - Castle School Show
 Janet Jones, Llanelli - Pick the Name of the Doll
 Claire Aldridge, Norwich - Step Aerobics
 Karen & Andrew Weedall, Runcorn - Webb Ivory
 D Tomsett, Watford - Parachute Jump
 Freemasons Lodge, Bournemouth - Raffle Items
 Caroline Browning, St. Albans - Parachute Jump
 Robert Armstrong-James, Lincoln - Haircut
 Mrs Norsworthy, Plymouth - Weekender Ladies Wear Party
 W Stock, Brightlingsea - Sale of Jigsaw puzzles
 Sid Shiff, Hunts Cross - Raffle
 Sue Peach & Danetre School, Rugby - Disco
 Danny & Rachel Todd, Co. Antrim - Praise Service at Bushvale Presbyterian Church
 Largs Academy, Glasgow - Games & Fun afternoon
 Alane Byrne, Glasgow - MPS Raffle
 Alison Shields, Co. Down - Newcastle & District Football Tournament
 Sandra Singh, Birmingham - Jumble Sale
 Jackie Chisling, Trowbridge - Charity Quiz
 M Heisig, Newbury - Produce Studies Ltd
 Fer Pidden, Westbury - Jewellery Sale

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FUNDRAISING

CHARITY BOXES

~ ~ ~ ~ ~

C M L Jones & Partner (Chemist) - Swindon
 Rozeena Ismail - Leeds
 Andrew Weedall - Runcorn
 Maggie Mullard - Swindon
 Oversley Mill Service Station - Alcester
 Pat & John Lomas - Pinxton
 Mr & Mrs Bennett - Chinnor
 C Barton - Binkworth
 Barton Hair Studio - Woottow Bassett
 Chris & Jule Kembrey - Bristol
 Focus on Fitness - Malmesbury

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DONATIONS IN MEMORY

The Society is grateful to the friends and relatives of

Katie Vivier
 Bill Burlinson
 Dr Stuart Phillips
 Michael McIntyre (Amy Brays Grandfather)
 Alice Johnson (Mrs Coupar mother)
 Peter Rock (Christopher's father)
 Felix Weale
 Mr Bowden

~ ~ ~ ~ ~

AREA SUPPORT FAMILIES

EAST ANGLIA

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

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

SOUTH-EAST

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

POTTERIES

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

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

SOUTH-WEST

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

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

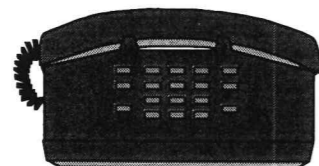
HOME COUNTIES

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

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

WALES

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



* Gordon and Anne Hill have a new telephone number 01404 812229

AREA SUPPORT FAMILIES

MIDLANDS

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

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

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

YORKSHIRE & EAST COAST

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

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

NORTH WEST OF ENGLAND

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

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

NORTH EAST OF ENGLAND

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

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

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

SCOTLAND

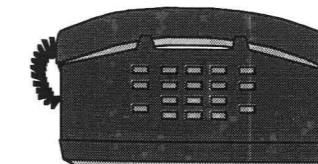
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