

NEWSLETTER

WINTER 1992

THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES



National Registered Charity No. 287034

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The Society for Mucopolysaccharide Diseases

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The MPS Society is a voluntary support group, founded in 1982, which represents over 500 families in the UK with children or adults suffering from Mucopolysaccharide and related diseases. It is a registered charity, entirely supported by contributions raised by members, and run by the members themselves. Its aims are:

- To act as a parent support group
- To bring about more public awareness of MPS
- To promote and support research into MPS

The Society operates a network of Area Families throughout the UK and Northern Ireland, who offer support and links to families in their areas. It provides an information service for families and professionals. At the present time it funds two Consultant Paediatric Posts and a biochemist at Manchester Children's Hospital. It encourages and assists contact and co-operation between parents and professionals and maintains links with sister societies in Europe and throughout the world.

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

"Care Today, Hope Tomorrow"

**Please send all fundraising money and correspondence to MPS Office.
See page 4**

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Deadline for Spring Newsletter

Thursday 8th of April 1993

THANK YOU RON and LINDA

A key job for the Society

Back in 1989 Ron Snack agreed to take over the daunting task of coordinating the Society's Fundraising Activities. The job ahead involved encouraging MPS families to create their own fundraising initiatives as well as organising National Fundraising events, e.g. runners in the London Marathon and the Christmas Draw. In addition, armed with a computer, printer and various books Ron set about approaching hundreds of Companies for donations. Over Ron's four years in post he has raised many thousands of pounds for the Society. We are all most appreciative of his skills, commitment and dedication.

Personal commitment

Ron and Linda's continuing personal efforts to raising much needed funds should also not go unnoticed. What were you doing the last two Saturdays before Christmas? For the 6th consecutive year Ron, Linda and their friends were running a tombola and shaking collecting tins in the indoor shopping complex at Milton Keynes. This year the takings were a little down on 1991

but still well over a £1,000 was raised. Thank you to you both. A little birdie tells me you are booked again for 1993!

Has your employer got a matching funds scheme?

Some of you will know that Ron works for Abbey National. Abbey National have a policy of matching funds raised by their employees up to £1,000. This has been an additional boost to Ron and Linda's personal efforts. If you are raising funds for the Society (as we hope you are) and work for a Company it would be a good idea to see if your company has a similar scheme.

Concentrating on Area Family work.

Well what of the future? Ron and Linda plan to much spend more time developing Area Family Support in Berkshire, Buckinghamshire, Hertfordshire, Bedfordshire and North West London. So families in this area please do support Ron and Linda's efforts.

Christine Lavery

on behalf of the Management Committee

EDITORIAL

In May we will see the start of our second decade as a registered Charity. In 1992 the highlights were undoubtedly the Area Picnics in June which were held throughout the United Kingdom; the 10th Anniversary Reception at the House of Commons, hosted by Dafydd Wigley MP to say thank you to all our donors and supporters and the MPS Family Weekend Conference in Bristol in September. Our sincere thanks go to all those who helped with the organising as well as those who participated so enthusiastically.

The number of children and young adults who have MPS, ML and related conditions and those who are known to have died from these diseases now known to the Society has grown to nearly 700. Using the data we have collected over the last 10 years and with the help of various Biochemical Genetics Centres we have been able to conclude that MPS and ML affects one baby born every 9 days in the UK (although of course many children aren't diagnosed until much later). We do suspect that as more data becomes available the frequency will be shown to increase.

Our best estimate. One child suffering from MPS born every nine days.

Holidays 1993

As ever, the MPS group holidays were fully subscribed and much enjoyed by everyone. We are pleased to be offering the same holidays in 1993 with a choice of two separate weeks.

Holidays for teenagers planned

In 1993/4 if the budget allows we plan to introduce a new type of holiday for MPS/ML youngsters 14 years and over who are physically disabled and who would benefit from a supervised activity holiday without their parents. If your son or daughter is interested we would very much like to hear from them/you as soon as possible.

Research spending

We spent over £70,000 on research and treatment in the last financial year, and propose to spend a further £50,000 this year. One of the most important grants to be awarded this year is to the Christie Hospital Manchester to fund, over 3 years a scientist to work on 'Gene Therapy for Hurler's Syndrome'. We are expecting new developments in this area in the near future. Watch this space!

Investment in research depends on fundraising.

We had to eat into our reserves considerably last year. Unless we can achieve our fundraising targets in 1993 will look like doing so again. This was not unexpected and, of course this is what we have reserves for. On the other hand, we cannot go on doing this for ever and it remains most important that we continue our fundraising efforts. In this connection, I would like to thank all those enterprising people who have done so much to raise money for us, and encourage everyone to do more.

A personal thank you at Christmas.

On a personal note may Robin, I, Andrew, Benjamin and Lucy say thank you to all those who sent cards this Christmas. Your good wishes

were very much appreciated and we would like to take this opportunity to wish all our members a peaceful New Year.

Christine Lavery

Honorary Director

FUNDRAISING 1993

From now on please send all cheques, and fundraising receipts to the office. Once the cheque has been cleared a receipt and thank you letter will be sent to the donor. If you are not the donor please do make sure you enclose the donor's name and address if you want him/her to receive a thank you letter.

As you read in the Autumn Newsletter the Society needs to attract substantial fundraising receipts and donations in 1993 in order to maintain its present level of support and research. Ron Snack is going to continue to ask Companies for help. If you work for a Company that has a Charity Budget please do let Ron know. We are more likely to receive a donation if our application is supported by an employee.

Know any good trusts?

The MPS Office will be concentrating on applications to Charitable Trusts and once again if you know anyone connected to such a Trust we would be pleased to hear. The rest is up to you! We need to raise £15,000 per month. We know that caring for your MPS child/children leaves precious spare time but what about local Round Tables, Lions, Rotary, Inner Wheel, Foresters which are often looking for deserving charities to benefit. Parents who have lost our children could have a concerted effort to help secure funds for MPS in 1993. All charities are seeing a considerable drop in revenue and that means MPS has to work a little harder than everyone else to come out on top.

Christine Lavery

MPS OFFICE

Not a dining room table job.

As many of you will realise, for the last ten years the MPS office has been housed in our own home. Soon after Simon's death and the birth of the Society it dawned on Robin and I that it was not a dining room table job and soon the Society was fully occupying a spare bedroom in our previous house.

First paid help 1985

In 1985 the Society appointed Shirley Frith to help with all the typing. This was necessary as I was working part time teaching gymnastics and part time developing support and training for parents setting up rare syndrome support groups on a grant from the Mental Health Foundation and under the auspices of Contact a Family.

Linda Golding joined the team

When Shirley left in 1986 to have a baby, Linda Golding who had just moved in to a house four doors away, agreed to fill the void on a temporarily basis. As many of you will realise Linda's temporary employment of 18 hours a week has lasted 6 years and is now permanent! Linda has worked dedicatedly for the Society over this time and put up with considerable upheaval, not least the premature birth of our daughter Lucy in November 1986 and major structural work to our house.

Working for Contact a Family

In March 1989, after five years working part-time, I joined Contact a Family full-time as **National Development Officer** for Specific Disease Groups. It was a particularly busy time as my appointment coincided with the run up to the 2nd International Symposium on MPS Diseases in Manchester. Thanks to the very hard working Management Committee, Linda, and Ann Neal who agreed to run the Conference Secretariat, everything ran smoothly.

1990: Ann Neal's help: A busy year.

Also in July 1990 Robin, I and the children moved house. It was only round the corner but something of a daunting task when you consider how many tons of paperwork and publications the Society had amassed over the years. The International Symposium ran like clock work and thankfully, Ann agreed to work permanently for the Society giving additional secretarial backup and organising the Annual Parent Conference.

Working full time for MPS

It is now 1993 and the MPS office at 7 Chessfield Park is bursting at the seams. It is not possible for Ann and Linda to work in the office together. The time has come for the Society to either contract or move on. At the Annual Budget Meeting in November the Management Committee invited me to consider taking up the appointment as **Director / Southern coordinator** and to secure office space. My decision to leave Contact a Family was not an easy one, but I am very pleased to accept the appointment offered and I look forward to working with the Management Committee in taking the Society forward for the benefit of all MPS children and their families. From 1 February 1993 I will be working part time for both Contact a Family and MPS until I take up my full-time appointment for MPS on 1 April, 1993.

New office found - and funded!

I am also pleased to report that the Management Committee have identified an office in Amersham which will suit the Society admirably. A trust has kindly donated the first years rent and has indicated it will help in subsequent years. A new three year lease is being drawn up and once all the arrangements are finalised we will let you know the new address for the Society.

In the meantime keep sending your letters to
7 Chessfield Park, Little Chalfont, Bucks
HP6 6RU. or telephone 0494 762789

From the Chairman of the Management Committee

The new committee

In September last year we had for the first time elections to the Committee. There are ten posts but the Committee has the powers to co-opt a limited number of other people if this is felt necessary and desirable. The ten people with the highest votes were elected. Alan Beavan had one less vote than the tenth member and it was felt by the Committee that he should be co-opted. I am personally most grateful for the interest shown in the election and to all the people who expressed an interest in standing. No doubt many of those will be elected in the coming years.

New appointment

At the beginning of 1992 Mary Gardiner became the Northern Coordinator for the Society. Now I can give you more exciting

news. Christine Lavery has just been appointed to a joint post of Southern Coordinator and Director. She will now be employed to do the job as opposed to doing it in an honorary capacity. (See page 5).

Increasing workload demands full time workers

Mary has shown how much can be gained by having a person employed full time on Society work. It was an obvious step forward to expand by employing someone for similar duties in the south. The work of the director increases week by week. To us on the Committee there seemed just one solution. We are most grateful to Christine that she has taken up this dual task, giving up her full time job at Contact a Family and accepting this post with the Society for a lesser salary.

Alf G. King.

How to increase your donation at no extra cost

Why not make your donation to the Society tax free? There are several ways of doing this.

Deed of Covenant

This will suit people who expect to make the same annual donation for several years. The Society can claim income tax relief on the amount you pay, so the Society gets one third more than you pay in.. Magic!. For example if you pay £21 for four years it will cost you £84 in all. The Society will claim back £7 per year from the Inland Revenue. The Society gets £112.

Deposited Covenant

Some people like to give a lump sum instead of annual payments. If you pay, say £60, as a deposited covenant the Society can claim £20 income tax relief.

Gift Aid

For larger sums there is "Gift Aid". This can apply to any single gift of £400 or more. On a single gift of £500 the Society can claim back an additional £166.

No extra cost to you.

Anyone who pays income tax can greatly increase their donations to the Society at no extra cost to themselves. A simple Deed of Covenant is included with this newsletter. For more information please contact Alf King, Chairman, or Pauline Mahon, Treasurer. (See inside front cover).

Family Milestones

New Families

David and Janice Oakes from Mid Glamorgan. Their fourteen month old daughter Charlotte has been diagnosed with Hurler Disease.

David and Christine George from Bristol. Their twin sons Jamie and Jason, aged three years have been diagnosed with Sanfilippo Disease.

Tanya Denyer from Cranleigh in Surrey whose son Beaupascal aged seven months has been diagnosed with I-Cell Disease.

Nigel and Alison Oliver from Penryn in Cornwall, whose daughter Annie aged one year has been diagnosed with ML111 Disease.

Mr and Mrs Fine of Hornsey in London, whose daughter Gila aged three years has been diagnosed with Mucopolysaccharidosis IV.

Cheryl Phillips of Plaistow, East London, whose daughter Leanne aged five has been diagnosed as suffering from Sanfilippo Disease.

Stephen and Lorraine Murray of Belfast whose daughter Lauren aged one year has been diagnosed as suffering from Hurler Disease.

Fazal and Sugrab Hussain of Sparkbrook in Birmingham whose daughter Fakhrora aged nearly five has been diagnosed as suffering from Sanfilippo A disease.

Gary and Joanne Adshead of West Houghton, near Bolton, whose son Benjamin aged 12 suffers from Sanfilippo disease.

In Sadness

Jason Nicholas of Swansea, Glamorgan, died on 23rd of August, aged nine years.

Sam Eyre of Yatton, near Bristol died on 29th of November 1992 aged seven years. Tony and Shirley Eyre are the Area Family for the South-west.

Rohit Bansal from Upminster in Essex died on 8th of December aged eleven years. Rohit suffered from Hunter disease.

Liam Houston of Strabane, Co Tyrone, Northern Ireland died on the 23 of December 1992 aged five years. Liam suffered from Hurler disease. Kieran Houston is Chairman of the Northern Ireland Co-ordinating Committee.

Steven Hariss of Rochester in Kent died on 14 December aged eighteen years and two months.

Paul Barry-Murphy of Ballincollig, Co Cork, Ireland who died on 14 July following surgery. Paul was aged 21.

Our thoughts are with the grieving parents relatives and friends of all these children and with the parents and family of Christopher Rocket who died on the 27th of September and whose death was reported in the Autumn Newsletter.

Sleep Apnoea

Sleeping problems

Regular visitors to the Conferences will know my son Alex. For those who do not, Alex is nineteen years old and has mild Hunter Syndrome. I thought that this might be useful for some of you who have problems with your children sleeping at night.

He would wake up exhausted

For quite some time Alex was having difficult sleeping. Often he would wake up saying he had had a bad night. He would get very hot and his night clothes would be damp in the morning. If checked during the night he was asleep but extremely restless, his breathing was quite irregular, sometimes he would be fighting for his breath. He would wake up exhausted.

A sleep study

On a trip to the Cardiologist we talked about the problem. A sleep study was suggested and consequently set up. It involved Alex staying overnight 9pm-9am in hospital. In the study Alex showed signs of extreme restlessness and his oxygen levels were dropping.

The ordinary remedy would not work

"Tonsils Out" was the cure suggested, so that more air would pass down Alex's throat and make breathing easier. There had to be another solution because of the risk of an anaesthetic and the problems MPS children have with tracheostomy.

The solution was found

The solution came in the form of the "CPAP" machine. The letters stand for something even harder than mucopolysaccharide to say. The CPAP machine consists of a conventional mask over the nose and kept in place with velcro. It is

attached by a tube to a little black box that sits on the bedside table. The machine blows air into his nose. It helps keep his airways open, allowing more air to pass into his lungs. Consequently Alex sleeps much better. His oxygen levels are fine. Snoring is a thing of the past. Alex is very happy using it and he fixes it himself.

Back on "full power".

Now that he is back on "full power" Alex stays awake all day. His concentration is much improved. As a result he is now back on the road driving, which is wonderful for his ego. He is attending Amersham College part time in the "Focus" group. The group decided spontaneously to have MPS as their charity for the year. They are planning lots of fund-raising activities and started with a coffee morning in November.

So Alex is doing his bit for MPS this year. How about you?

Sue Butler



Alexander Butler

Jennie Giles

I am a twenty nine year old "Little Person" with Morquio (MPS 1V). I have a Master of Science Degree and I am a qualified genetic counsellor. This is my story.

I was "the perfect child".

I was first diagnosed as having Morquio when I was just fourteen months old. My mother was slightly concerned about the way I positioned my hips while I slept and the fact that I made no attempt to crawl. (Mum says that once I got my eyeglasses there was no keeping me in my playpen). In contrast to a cranky, colicky older brother I was the perfect child. No one was expecting anything like Morquio. For my parents especially the diagnosis had all the impact of a runaway locomotive.

Determined to nurture me and my potential.

My parents went through all the anticipated emotions of the grieving process, the rage the shock, even the denial and the guilt. But my parents learned to accept because I was their child and maybe, just maybe, I might have a potential no one could foresee. Mum has since told me that she and Dad knew I had a special quality right from the start. Whether I was going to be around for five, ten or fifteen years or whatever, my parents were determined to nurture me and my potential and love me until the end.

Life as a disabled person is no picnic.

This undying support and encouragement is what helps make me all that I am. It has sustained me over the rough times. Life as a disabled person is no picnic, as I am sure you know. My family's faith in me has instilled in me a strong sense of self worth. My parents

have never hidden anything from me. They have always explained things to me in terms that I can comprehend. While I have known for as long as I can remember that I was different from other kids in various ways, my differences did not have the name Morquio (at least not in my mind) until I was much older.

Growing up in rural New Jersey

I spent the first nine years of my life in a fairly rural area of northern New Jersey, so my initial medical care was attentive but not overwhelming. I did not have my million dollar, stem to stern workup at Johns Hopkins Hospital in Baltimore until I was seven. My first surgery took place the following year, in 1971.

Skating and ballet.

Up until then I went skating with my friends on a local pond in winter. I took ballet lessons for a while. (I still recall the ache in my ankles, but what a feeling of accomplishment at the end of the day). I was a member of the local Brownie troop and earned a few merit badges. We lived across the street from a family with lots of kids so we were constantly playing together. If in our running around I got tired and needed to sit down, fine. One of the other kids might sit down and rest with me or they might not. I would simply catch up when I was ready. They understood.

Not fair to stop me riding my bike.

The disappointment I can most clearly remember is when the doctors at Johns Hopkins told me I couldn't learn to ride a two wheel bike, because of the instability of my neck. I felt they were being unfair. My parents and I had many heated discussions about this. However surgery put me out of commission for several months. By the time I recovered the bike issue didn't seem so important. Now I've got my car and I couldn't care less about the bike. Everything's relative.

What's behind the smile

One of the hardest things about raising a chronically disabled child, or about growing up as one, is learning how to balance the text book pictures with the real life aspirations. Physical and emotional pain are daily facets of a disabled person's life - no matter how wide he is grinning.

"Only Jennie knows Jennie. She may surprise us all".

Knowing limitations goes hand in hand with knowing strengths and enables one to grow and flourish as a human being. The best medical advice my parents and I ever got, words I will always cherish in my heart for guidance, came many years ago at a time when I needed them

most. "Only Jennie knows Jennie. She'll tell us when she has had enough and what she is capable of doing. She may surprise us all".

So far those words have proved true for me.

Update 1993. A trans-global move.

Jennifer has now worked for three years as a genetic counsellor at New York Hospital and Cornell Medical Centre in Manhattan. On the 11th of January 1993 she begins work in a similar post at the National Women's Hospital in Auckland, New Zealand. Her mother is a New Zealand citizen and she has numerous cousins in the Auckland area.

Best wishes Jennifer in this new stage of your life.

Pleased to be remembered

Christine wrote to all the parents known to the Society whose children had died, to let them know about the plans for the Forest of Remembrance. This is one of the replies.

Thank you.

Thank you for "finding" me again. I am sorry I did not get round to sending you my change of address. It was very kind of you to make the effort that you did!

We would like a tree.

Both Jasmine's mother and I would like to have a tree in the Forest of Remembrance for our daughter and I enclose a white form as requested. I will be sending a green form with an inscription for the plaque at a later date, when we have decided on some suitable words.

Help with fundraising.

One of my objectives in the long run was to assist in raising funds for the Society. Timewise this has proved to be a problem as I have been working towards a degree here at Buckingham.

However I have now become a member of the

student union and I may be able to do a small amount of fund-raising. I have already asked if the Student Union will sponsor the MPS Society in their rag week next August. Buckingham is one of the smallest universities with only 900 students so the scope for fund raising is limited. Please send me a fund-raising package and a tin for our student shop.

A poem that helped.

I enclose a poem written by a friend of mine to help me through some of the tougher times in the past. Thank you for your efforts in staying in touch with me. I hope that the little I can do will help the Society to which I feel a lot of commitment and I certainly hope I can be of more use over the years.

Jeremy Chitsiga

University of Buckingham MK18 1EG

Sadly the poem is too long to fit in this edition.

My dream come true

It all began a year ago last March. Some of my tutors at Coleg Powys thought I needed something to help me through my operation. One Saturday morning I had a phone call to ask if "Make a Wish" could send someone to see me. They came. One question I was asked was, "Where would I like to go?" I told the interviewer, Les, that I always wanted to go on a trip on the QE2.

The following Tuesday Les phoned me from Geneva to say I would be going on a trip on the QE2 to somewhere hot. Everyone in our house was thrilled to bits.

After my operation

In May I went into hospital for my operation, which was anything but pleasant. (Cervical fusion). It took until Christmas for me to feel much stronger. Now in July when I am writing this I am beginning to walk on my own again. So now I can say that the operation was worth it.

But back to my story. On the first of May, Mum, Dad and I stepped on board the Cunard

liner. It was wonderful! Our cabin was one of the largest on board. It was first class and was adapted for disabled people. We were walking through the lounge after unpacking when we were surrounded by a crowd of people. It was Margaret Thatcher.

After dinner, as we walked through a sitting area, two gentlemen asked if we were having a nice trip. When we got out of the room we realized they were Jimmy Tarbuck and Kenny Lynch. On most nights afterwards we had drinks with them and we became very friendly.

When we arrived in Tenerife we had a chauffeur driven car for the day. On the Tuesday we came to Madeira and had VIP treatment again. Both were wonderful days.

A lifetime's wish come true

We got back to Southampton on the eighth of May at five am. I have written to Cunard thanking them for such a wonderful holiday. It was a wishful dream of a lifetime come true.

Sarah Kilvert



South East Family Picnic

A bit late you may think to report on last year's picnic, but we had so many reports that they could not all be included at the time. Remember the glorious weather on the 27th of June? Over fifty people travelled up to 100 miles to the Bentley Wildfowl and Motor Museum to celebrate the 10th Anniversary. After a gourmet lunch we toured the birds, the old cars and the house. The children were particularly interested in the young farm animals. Tea included fresh strawberries grown by one of our members.

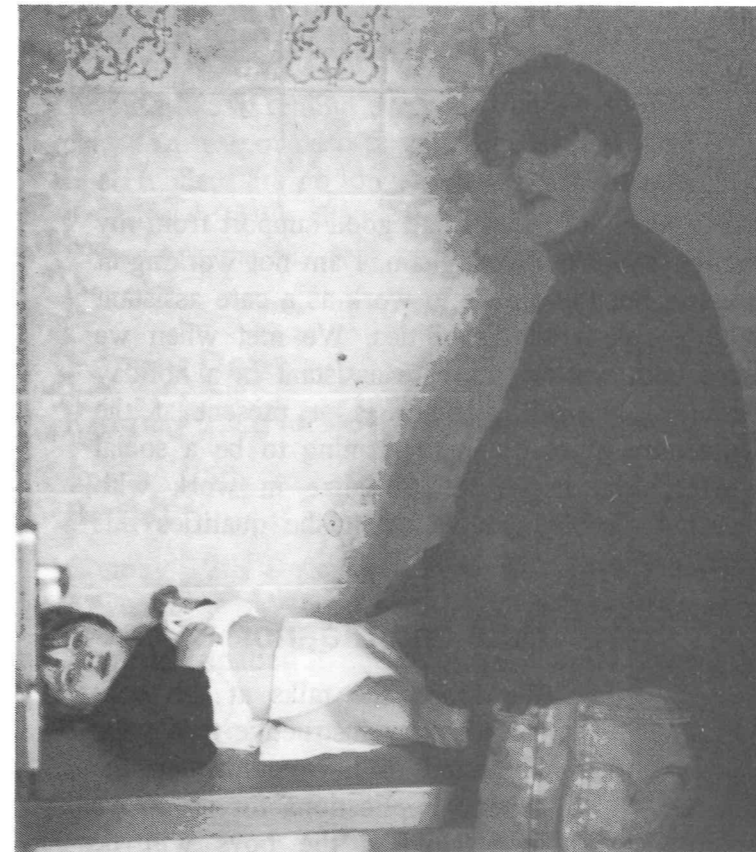
In the news

It was a most enjoyable time meeting old friends and making new ones. We had arranged for TVS to come and so we were featured the following day on the regional news. We are grateful to the Manager and staff of the centre for their help and assistance.

Alf and Judy King



A Summer Scene to remember in the depths of winter.



Matthew Neal's fan club insisted that we print this picture of him changing Francesca Fisher.

At the conference parents can feel secure in the knowledge that the volunteers have the skills and the commitment to look after their children as they would themselves.



Andy Ward, Beth Blaney and Caroline Sweeney take time out to relax on the swings at the conference in Bristol. All the outings were a great success.



Bert and Doris Sayer, veteran volunteers, with Kym and Dwain Taundry from Malvern in Worcestershire at the annual conference in September.

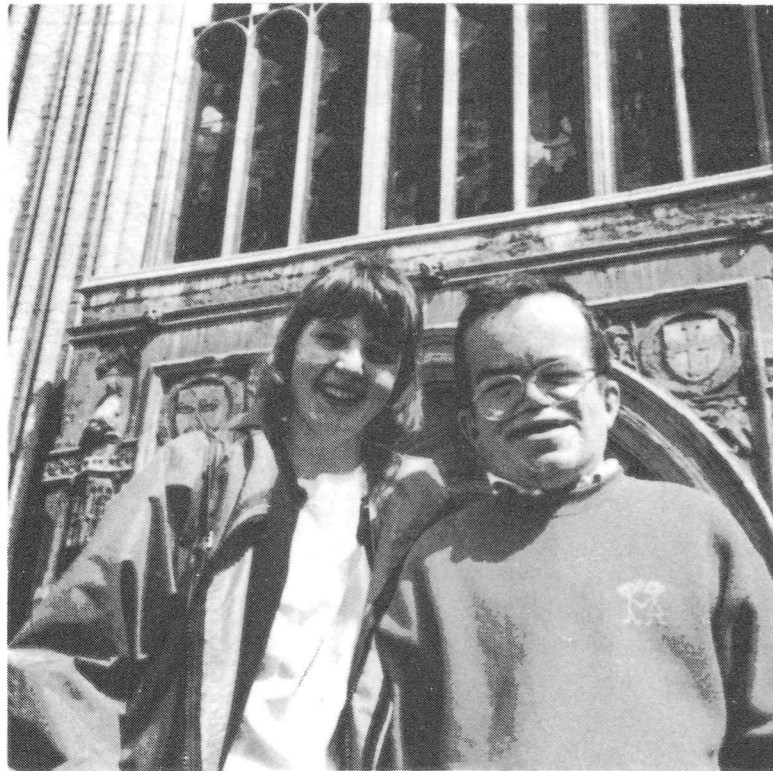
Paul Gunary and Eleanor Dronfield

(Interviewed at the annual conference in Bristol) **Paul**

Paul

Up to now I've been hesitant about meeting with MPS members. I wasn't sure I belonged with this group of very severely handicapped people. When I did meet with MPS sufferers I felt ... embarrassment, no, not that, ... I felt guilt. I felt guilty that they were suffering far more severely than me. It was the guilt that survivors feel. I felt that I had escaped the worst.

I feel very lucky that I had good support from my family. I live in Nottingham. I am not working at present, but my aim is to work as a care assistant with people with disabilities. We met when we were both working as care assistant in a holiday home in Norfolk. Eleanor is at present at the University of Nottingham training to be a social worker. She hopes to specialize in work with learning disabled people when she qualifies this year.



Eleanor and Paul at Norwich Cathedral in 1990

Paul and Eleanor

We found the talks at the conference very instructive. We were interested to have confirmed the genetic implications for us. If we have children the boys will be unaffected but the girls will be carriers.

The future

We now hope to be active in the Society in future. We think our experience puts us in a unique position to understand the needs of people with MPS diseases. We look forward to meeting everyone at next year's conference. We will be Paul and Eleanor Gunary then. We are getting married in the summer.

Paul and Eleanor

9 Darnell Close, Southglade Park,
Bulwell, Nottingham, NG5 9RB

0602 771169

Eleanor

I think Paul has recently made good progress in coming to terms with his disability. Before that I think he was denying it to a considerable extent.

Used Postage Stamps

I would like to remind everyone that the Society can make use of used postage stamps. Paul and Sue Hubbard are no longer dealing with stamps so please send them to the MPS office. Christine's parents will do the necessary after that.

Family Days

Saturday 22nd of May. Kew Gardens London.

Sunday 25th Sept. Cotswold Wild Life Park, Burford.

Sunday 12th Dec. Christmas Party in Milton Keynes.

More information in due course. All welcome.

Ron Snack

Foreign Coins and Notes

This years total from foreign coins and notes was the best ever, over £100. So please keep sending your funny money to Ken Ballard, 15 Bengeworth Rd., Harrow Middlesex HA1 3SF.

Bungee Jumping

Mr M Walton, a brother of Barbara Hariss of Rochester, Kent recently took part in a sponsored Bungee Jumping for the Society. Is this a first?

MPS Grand Draw 1992.

The final total raised from the annual draw was £5954.18. Once again David and Monica Briggs have done a brilliant job. Congratulations and thanks.

In Memory

We thank all those who made donations to the Society in memory of Tim Norsworthy, Victoria Headland, Rajesh Silhi and Kathleen Brooks-Daw.

Christmas Party - Milton Keynes

It was cold wet and very windy as I struggled to fix the signposts to the Bradwell Common Hall. I prayed that the carpet tape would hold, or miracle of miracles, that the weather would improve before the signs fell apart.

A festive spread

Back at the hall which was warm and dry (some people get all the good jobs) Ron and Nobby were busy with the decorations. Linda and her mum were organising the food. Fifty people were expected and we had a grand festive spread.

Three new families

It brought a warm glow to see so many familiar faces arriving. More importantly it was encouraging to see three new families. We soon got talking and exchanged family experiences. It was interesting to hear about peoples backgrounds from different parts of the world and to share experiences of the medical help and family support available in various countries.

Party games

Entertainment was excellently provided by a magician. The show moved fast with lots of short and lively items. Young and old joined in. Party games were organised by Andy Hardy.

Jelly and ice cream!

The high point of the afternoons food was - you guessed it - jelly and ice cream. Santa arrived with a jingle of bells and a deep baritone Ho! Ho! Ho! He seemed keen on kissing all the boys both young and older. Let me tell you the secret. This was Mother Christmas.

Our thanks to Ron and Linda and their team of helpers and to all those who came along to make the party go with a swing. A special thanks to Mother Christmas.

Alan Marchbank

News from Milton Keynes

Tombola and Sale

On Saturday 12th of December we were allowed to use the community kiosk for our tombola and sale of goods. This was a busy but enjoyable day and we raised over £350, half of which will be matched by Abbey National.

Guitar recital

On Wednesday 16th of December one of my colleagues at work, Peter Stanley, arranged to give a recital of Spanish and Latin American guitar music at the Church of Christ the Cornerstone. About fifty people from work, as well as the odd bell-ringer came along and thoroughly enjoyed the performance.

A collection was taken on behalf of the Society. Along with matching funds from Abbey National over £200 was raised.

Flag day

Finally, on 19th of December we held our Flag Day. This was even more tiring day but we went home with £700 for the Society. This was not as much as we have raised in previous years but it seems to be a general reflection on the economy at the present time. We also had a bomb scare which disrupted collecting, as well as difficulties in getting enough people to shake tins.

Milton Keynes leads the way

Thanks you to all those who helped. A special thanks to Abbey National. We all have to try to Fund-raise a little bit harder to ensure the future of our Society. This is what we were able to do in our local area. How about you?

Ron and Linda Snack

Late News

Robert Murray of Holytown, Lanarkshire, died on the 2nd of January 1993, aged eighteen years. Our thoughts are with his grieving parents and family.

More bellringing

I would like to thank the ringing friends who came all the way to Bristol from Milton Keynes during our conference in order to ring a full peal on the bells of Ss Philip and Jacob's church. They rang "Plain Bob" for three hours to join in celebrating the 10th Anniversary of the Society. The event was noted in Ringing World, the bellringers weekly newspaper.

Archeological cyclists come back with gold.

Mark and Peter Loveday, cousins of James Gooch, with their friends Sefton and Carrie Rivett raised £144.10 by cycling twenty five miles cross country and visiting ancient sites in the Avebury Area. Their route took them from East Kennet past eleven ancient sites some as old as eight thousand years. They impressed their sponsors by their knowledge of the history and archeology of the ancient sites.



THE CHILDHOOD WOOD

A special place of remembrance

The Society's plans for our own special place of remembrance for our MPS children and young adults are moving forward at quite a pace.

Finding a name.

Back in November 1992 Saatchi & Saatchi Advertising, who are responsible for many of the adverts that appear on our television screens and in the magazines we read, agreed to help find a name for our MPS wood. I would like to share with you now the rationale that went into choosing the name as described by Mr Ronald Baird, Vice Chairman for Saatchi & Saatchi Advertising.

"As promised, I involved one of our senior copywriters, Tom Callaghan, a very caring person, in the production of a name for the wood.

We looked at definite names but felt that an individual name would soon become, in our term, 'wallpaper', and also would not relate to many parents' memories of their child. We arrived at the term **The Childhood Wood** as this perpetuates the memory of all children who have died from Mucopolysaccharide disease."

A unique name

I think that as a name for a wood it also has the advantage of being somewhat unique.

For generations to come

We hope that you will share our delight at the choice of **The Childhood Wood** as the name for our Wood and that the wood will remain a very special place in the hearts of MPS families for generations to come. After all it is over 400 years since Robin Hood set foot in Sherwood Forest. Currently Nottingham County Council and the Forestry Commission are introducing

plans for the Forest which will secure its future for as many years to come.

A hundred families coming.

All MPS families known to the Society who have lost a child to MPS have been invited to plant an oak tree in their child or children's memory. Over 150 oak saplings will be planted in memory of MPS children. 100 MPS families will making the journey to Nottingham on **Friday February 26 1993** to plant their tree or trees personally. For those unable to be there the Society is making special arrangements for their trees to be planted by VIPs attending and a photo taken.

Secretary of State for the Environment

The Rt. Hon. Michael Howard, Secretary of State for the Environment has kindly agreed to be present along with **The Earl Howe**, Minister responsible for the Forestry Commission. We did invite the Duchess of Kent but sadly her programme for early 1992 is already rather full.

A welcome for all visitors.

On the edge of **The Childhood Wood** will be a play area for children, benches for visitors and a wildlife interpretation board. It is the Society's intention to make **The Childhood Wood** a friendly place to visit, not just for families whose children are remembered in it, but for all visitors to the Forest.

Still time to order a tree.

If you are one of the very small number of bereaved MPS families who have not yet requested a tree there is still time to organise one. Please contact the MPS Office urgently.

Christine Lavery

Hon. Director

Christmas Party - Milton Keynes

It was cold wet and very windy as I struggled to fix the signposts to the Bradwell Common Hall. I prayed that the carpet tape would hold, or miracle of miracles, that the weather would improve before the signs fell apart.

A festive spread

Back at the hall which was warm and dry (some people get all the good jobs) Ron and Nobby were busy with the decorations. Linda and her mum were organising the food. Fifty people were expected and we had a grand festive spread.

Three new families

It brought a warm glow to see so many familiar faces arriving. More importantly it was encouraging to see three new families. We soon got talking and exchanged family experiences. It was interesting to hear about peoples backgrounds from different parts of the world and to share experiences of the medical help and family support available in various countries.

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Alan Marchbank

Annual Draw Prize goes to Telford.

Malcolm Soutar had an unusual passenger as he headed for work in Telford in early October. Usually very noisy, the passenger was firmly belted up in the front seat, and made no sound all the way.

Yes, it was an enormous TV and video recorder won by Jane Cartwright of Sherrifhales, Shropshire in the annual draw which took place at the conference in Bristol. Margaret Leask took it back with her to Shrewsbury, God knows how, and handed it over to Malcolm.

Jane, who works with Malcolm, was overjoyed with her prize and was soon on the phone to tell everyone of her good fortune. Sorry about your phone bill Malcolm, but then you will go about selling MPS raffle tickets to all your staff.

Malcolm Soutar and Jane Carter showing off just one part of Jane's magnificent prize.



3rd INTERNATIONAL SYMPOSIUM ON MPS AND RELATED DISEASES

28th May - 31 May 1993

Kongress - Zentrum Saalbau - Sheraton Essen GERMANY

Those MPS families who were members of the Society in September 1991 will recall receiving a copy of the First Announcement for the 3rd International Symposium on MPS and Related Diseases. At that time we believed that the organisation of the 1993 Symposium would be on similar lines to the 1990 2nd International Symposium held in Manchester and organised and funded by the British MPS Society.

The philosophy of the Manchester Symposium was to bring together as many MPS families and interested professionals from all over the world. MPS families from eighteen nations and professionals from 28 nations came. Attendance from MPS families was high because costs were subsidised for all families. The top charge was £50 per adult inclusive of all costs.

Unfortunately, despite substantial sponsorship, the German MPS Society are unable to subsidise the MPS families costs as we were able to do, with the exception of MPS children/adults who are free. The costs of attending the 1993 Symposium will therefore be very expensive to most MPS families wherever they live. The costs are as follows:

Hotel Accommodation (3 Nights plus breakfast)

	Sheraton	Movenpick	Essener Hof
2 Adults	DM 660	DM540	DM450
MPS Patients	FREE	FREE	FREE
Child 3-16	DM100	DM100	DM 100
Child- 2	DM 50	DM 50	DM 50
Add person over 16	450	DM360	DM 300

Cost of Conference/meals per person over 16 years - DM150

Exchange Rate - 2.4 DM = £1

You can imagine that this has given the British MPS Society some problems. We had envisaged and indeed expected that the accommodation and Conference costs would be subsidised. We had in mind to fund group transport to Essen. With the situation as it now stands it is unlikely that more than a handful of families will feel they can afford the personal expenses and therefore group travel is not viable.

Travel plus costs over £1,200

We deeply regret that there will not be a substantial British presence in Essen. We hope you will agree that it would be unfair to use MPS monies to subsidise a small minority given that airfares and conference costs for a family of four would cost over £1,200.

British Representation

Instead, as members of the Organising Committee, Mary O'Toole and I will travel to Essen along with Dr Bryn Neal and Dr Ed Wraith who will speak at the Conference. All of our expenses will be met from the German sponsorship monies. In addition the programme offers two talks by British MPS Families. Once the Conference Secretariat have agreed to meet the travel and accommodation costs Mary Gardiner will speak on 'Bone Marrow Transplantation' and Bill and Fer Pidden will speak on 'Living with MPS: The Parents' Viewpoint'.

If you wish to attend.

I have a small supply of programmes and application forms. If you would like to receive a copy please send a large stamped address envelope marked 'ESSEN' in the left hand corner. **You must hurry** as the closing date for MPS families attending is the 1st February, 1993.

Christine Lavery

Future Therapies

Dr Ed Wraith.
Consultant Paediatrician
Royal Manchester
Children's Hospital

As a start to an account of what is happening at present about seeking an effective treatment for MPS diseases I will give a brief account of the history of attempts to find treatments. When we talk about treatment we may mean either "Palliative" or "Curative" Treatment.

Palliative treatment

Palliative treatment is treatment of the symptoms of a disease so that the patient's functioning is improved and his suffering reduced. It does not affect the underlying disorder. For example a palliative treatment for asthma is the use of an inhaler.

Curative treatment

We call a treatment curative when it gets rid of the underlying disorder that causes the symptoms of the disease. For example we cure an infectious disease by killing off the infection.

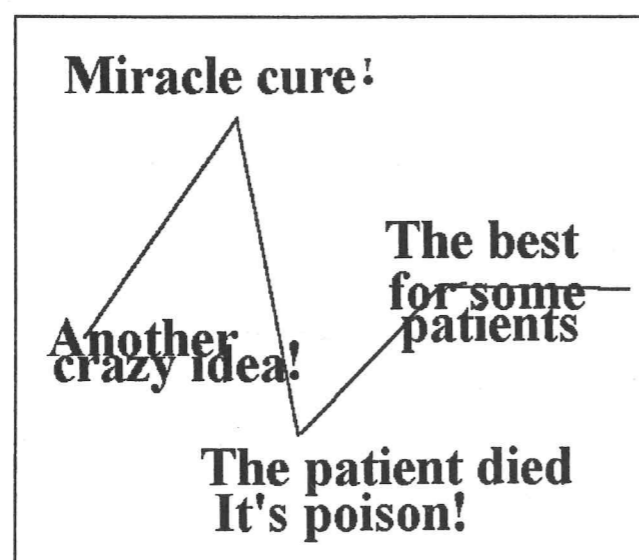
This article is a summary taken from the tape of Dr Wraith's talk. Any errors are entirely due to the ignorance of the editor.

No curative treatment for any genetic diseases.

As far as I am aware there are as yet no genetic disorders that can be cured. Some congenital abnormalities can be corrected by surgery, but in most cases the therapy that is offered to the patient is purely **palliative**. However it is important to bear in mind that because a disorder is "not curable", that does not mean that it is "not treatable" There are many things that can be done with incurable disorders to improve the quality of life of the patient.

The graph of the progress of knowledge of a disease.

There is a typical pattern of reaction to new treatments which this graph illustrates.



Brief history of the treatment of MPS Disorders.

As you know Hunter, Hurler and Morquio diseases were clearly identified in the early part of this century, though other MPS disorders were identified relatively recently.

Early attempts.

The earliest attempt to cure MPS diseases was by the use of **thyroid and steroid hormones**. Doctors thought the symptoms of the diseases were similar to those of patients suffering from disorders of the endocrine system. Needless to say this approach was unsuccessful.

Profound pessimism about care and treatment.

It is only in the last few years that medical science has shown any sign of hope about the treatment or even the care of MPS sufferers. Until relatively recently the attitude of the medical profession to these diseases was profoundly pessimistic. In The American Journal of Diseases of Childhood in 1948 **Reilly and Lindsay** wrote a paper reviewing MPS disorders in which they concluded:

"We know nothing that will help these children. Institutionalisation should be urged for the children with the greater degrees of mental deficiency, especially if normal siblings are made to suffer psychologically, financially or in other ways or if the patient becomes an object of curiosity".

More attempts at treatment.

It was noted that Vitamin A reduced MPS content in fibroblast cultures from both healthy and affected persons. Large doses of vitamin A were given to patients with no clinical effect. (**Dames and Bern 1966.**)

Also in 1966 **Schafer** found that Vitamin C could induce an increase in MPS in cultured cells. A trial of giving the children scurvy was attempted to see if that would lead to an improvement. That was also unsuccessful.

First breakthrough.

In 1968 **Fratantoni and Neufeld** showed the first evidence of mutual correction of enzyme defects in cultured fibroblasts. This was the seminal experiment which led to the introduction of **enzyme replacement therapy**.

In the 1970s fresh frozen plasma, white blood cells and whole blood were given to children as a way of replacing the missing enzyme. This treatment was not successful. However some of the problems with enzyme replacement therapy were highlighted by these experiments.

These problems were:

The availability of the enzyme.

The fact that it is rapidly cleared from the blood stream.

Difficult to target it to the central nervous system.

Difficult to evaluate how well it is working.

Possible complications and side effects particularly if human tissue is used to extract the enzyme.

Damage starts before birth.

Other problems about treatment also became recognised. In 1974 **Peter Harper** established that signs of storage of MPS were already present in the foetus months before birth. Therefore any treatment after birth is already dealing with a patient in whom disease is present and where there has already been cumulative damage from the effects of the disease.

Bone marrow transplantation

In 1981 **Hobbs**, at Westminster Hospital, London began bone marrow transplantation for children with MPS. Some patients survived and improved in some ways. It did appear to be a form of treatment acceptable for some patients provided the patients were carefully assessed. If the MPS had caused neurological disease/damage before treatment this was not affected by treatment and this damage was not reversed.

What this decade might bring for MPS disorders.

Enzyme replacement therapy and gene therapy.

Gaucher's Disease: An example of Enzyme Replacement Therapy.

Gaucher's disease can now be very successfully treated with an enzyme product called "ceredase." Ceredase is currently extracted from human placentas. It is purified and given in an injection. The dosage is dependent on the patient's weight. A major disadvantage to the treatment is its cost. There is also some uncertainty about its long term safety.

Enzyme replacement experiments in MPS

John Hopwood has had success in preparing human enzyme for **Maroteaux-Lamy** disease by using the recombinant DNA method. He has treated a Maroteaux-Lamy cat with excellent results.

Possible treatment in humans.

Enzyme could be prepared in this way for all of the other types of MPS where the gene has been identified. In theory it is likely that the results from doing this would be at least as good as for bone marrow transplantation. However there are strong grounds for doubting whether enzyme treatment would be able to arrest or to prevent the progression of disease in the nervous system.

Advantages and disadvantages.

The major advantage would be to avoid the complications and difficulties of transplantation. The major disadvantages

would be the need for continuing lifelong treatment, with repeated infusions. It is possible there would be side effects. The cost of the therapy would also be likely to be very high.

Gene therapy.

The theoretical process of this is understood. (See "Gene Therapy for beginners" page 24).

First one would obtain the gene with the appropriate control regions. A virus could be used as the carrier to get the gene into the patient. The virus used in many experiments so far is the "retrovirus".

Bone marrow "stem cells" would be extracted from the patient. These would be infected with the retrovirus, grown up in culture and then "autografted" into the patient. They would be injected into the patient's bone marrow.

The possible risks associated with gene therapy.

The gene is inserted into the patients genetic material. It is not possible to control the point in the genetic code where the modified gene is inserted. There is the possibility that if it arrives in the wrong location it will disrupt the working of a normal gene and this will lead to unforeseen damage. This risk is called **Insertional mutogenesis.**

Another issue is that the retrovirus cannot affect non dividing cells. It has to be used on the stem cells in the bone marrow. It cannot be used for targeting

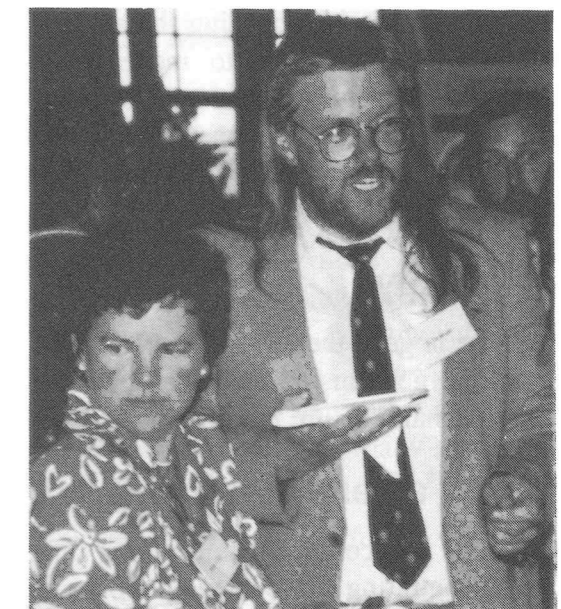
particular organs which are badly affected by the disease.

Future considerations

The possibility of using different viruses as vectors as a way of targeting different areas of the body. The possibility of repairing genes instead of replacing them. This would entail finding a way of targeting the vector virus to the exact location on the chromosome where the damaged gene is positioned.

Other uses of gene therapy.

Gene therapy can also be used to create animal models to allow more detailed study of the disorders. Animals have been found that suffer from some of the MPS diseases. As with John Hopwood's cat which suffered from Maroteaux-Lamy disease, these can be used to study the disease and the effects of different kinds of treatment. It is much easier if a ready supply of animal models can be created and reared in the laboratory. For example scientists in Edinburgh have successfully created a strain of mice suffering from cystic fibrosis. Use of these animals has already led to progress in the understanding of this disease.



Dr Ed Wraith with Vivienne Culley at Westminster Tea Party Summer 1992

Beginners guide to Gene Therapy

Genes...

Genes are the units of inheritance. They are located in the nucleus of each cell. Each person has about 100,000 genes which together make up the "blue print" of the body. If the gene is defective, a disorder occurs. Genes are linked together in long strings called "chromosomes".

And how to find them

The problem in studying individual genes is to locate where they are on the chromosome. Scientists have established "markers" which enable them to find the location of some particular genes. They get to know what specific genes do by finding out what happens when a gene is damaged or missing. For instance they may find out that the normal gene makes a particular enzyme and the damaged gene does not make the enzyme.

Enzyme Replacement

After they have found a reliable way of marking the damaged gene and identifying the enzyme it produces, the next stage is to move towards treatment. One possible method of treatment is by replacing the missing enzyme. This is called enzyme replacement therapy. (See Future Therapies, Ed Wraith, page 20).

Gene Therapy

Another hope is gene therapy, which attempts to place a normal gene inside the cells of the body so that it will manufacture the missing enzyme.

How to get a gene into a cell?

A virus, like the common cold virus infects people by penetrating the cell wall. To use the

virus it must first be altered to render it harmless. Then the gene is inserted into the virus. The virus is called a "vector" because it carries the gene like a passenger in a car. The vector virus penetrates the cell wall. The gene it carries merges with the cell and does its work to produce the required enzyme. The altered virus cannot reproduce itself so it does no damage.

Current progress in gene therapy.

The first genetic engineering experiment was done in cancer patients as recently as 1989. The aim was not gene therapy but to see if marked genes could be found in the tumour where they had previously been inserted. It was found that the gene transfer did occur. The immune system improved temporarily but the response disappeared in six to twelve months. The procedure was technically very difficult and the treatment was very expensive.

First human gene therapy

The first human gene therapy experiment for a genetic disease was for a very rare form of SCID (severe combined immune deficiency). The first child was started on treatment in September 1990 and another child also joined later. They receive infusions through a vein at one to two month intervals. Tests show that the gene has been transferred and the missing enzyme is being produced. However their immune system is still not fully normal.

"Stem cells"

A possible reason for this is that the genes need to be transferred to the "stem cells", instead of to mature blood cells which die off. Stem cells are young cells that reproduce. They are found in the bone marrow. If the gene is corrected in the stem cells it is possible that the normal gene will be

present in all the cells that are manufactured by the stem cells.

Current work in this field

Many gene therapy experiments are being prepared for different types of cancer. Other studies to transfer genes to the liver have been approved. A study for use of gene therapy in AIDS patients is being prepared. In China an experiment is underway for haemophilia B.

Which vector to use?

The retrovirus is the vector that has been used in the dozen gene therapy experiments approved in the United States to date. It is considered that, provided the virus is properly treated to render it harmless, it provides an efficient carrier or "vector" of genes into dividing cells, and is safe to use. However the retrovirus cannot infect non dividing cells.

Adenovirus

There are other viruses which are being considered as vectors. The adenovirus or common cold virus has been studied in vitro and in animals and shows promise in a number of diseases.

Herpes virus

The herpes virus has also been studied. The theoretical interest in this is its potential for

transferring genes to the central nervous system. Animal studies were carried out by Wolfe et al. at the University of Pennsylvania. They worked with mice suffering from Sly Disease (MPS VII). In Sly disease the gene for B glucuronidase is defective. This leads to brain damage.

Promising results

It was found that genetic material was transferred to the brainstems of most of the mice. In one case the tests were positive four months after inoculation. The conclusion was that some B glucuronidase enzyme was being produced and it was lasting for a long time. However not enough B-glucuronidase was being manufactured to cause any improvements in the symptoms of the disease. Much work remains to be done to turn this study into an effective treatment for humans.

Some potential advantages over retrovirus.

The herpes virus can transfer genes directly to a target organ, without the need to remove cells from the body and re-implanting them. This study has shown that the healthy gene can remain active in the brain cells. For most MPS diseases this would be an essential feature for any gene therapy.

London Marathon 1993

Mike Willoughby, our runner last year, has bravely volunteered to run for us again this year.

I am sure you will recall that Mike organised a team of four from Abbey National last year and the Society benefitted by matched funding from the company to the tune of £1000. The same will apply this year. Your official sponsor form comes to you with this newsletter so please start getting as many sponsors as you can.

Lets make a really big effort!

Ron Snack

Birth

To Lynne and Chris Grandidge, a son, **Ian Paul**, born 10th of December 1992 weighing 7lbs 6 oz. A brother for **Stephen**. Congratulations!

Action Nineteen Plus

Increasing concern.

There is increasing nationwide concern among parents and voluntary organisations about services for individuals with disabilities and their carers after school leaving age.

An alliance for training and campaigning.

Action 19 Plus is an alliance of national and regional voluntary agencies involved in disability issues. It has formed a campaigning and training group which will bring parents and organisations together to press for better services. Some of the organisations involved are Barnardos, MENCAP, The Spastics Society, Kith and Kids, ASBAH, RNIB, Sense, and Contact a Family.

Conferences planned.

They are planning a series of regional conferences to advance their campaign. To date

What the motion says.

“That this House notes the intention of Action 19 Plus, a consortium of voluntary agencies concerned with the provision of services for adults with physical sensory or learning disabilities to set up a national training programme for parents and users to obtain provision of day services; recognises the need for day services to be available to every adult with disability who needs them; notes that without day services there are often no alternatives to staying at home all day, often without the proper level of skills training; further notes that day services should be available without charge, five days a week, throughout the country for all those who require them, supports the rights of people throughout the country to have a multidisciplinary assessment as a basis of services to meet their individual needs; and call on the Government to ensure these assessments take place and that resources are available to meet those needs.”

Printed courtesy of Contact a Family.

conferences are being organised in Bristol, Cardiff, Liverpool, London, Newcastle, Peterborough, Redditch and Wakefield.

More information from Redbridge.

If you would like a leaflet with further information, please contact: Action 19 Plus, 41 Falmouth Gardens, Redbridge, Ilford, Essex IG4 5JV. An information pack is also being produced which will give information on the law, on campaigning and on what action individuals can take locally.

Contact your Member of Parliament.

As part of the Action 19 Plus programme an “Early Day Motion” has been laid down in the Houses of Parliament. If you feel strongly about the issue please contact your MP and ask them to sign the Early Day Motion. This is important to get the attention of the government.

77 FUNDRAISING SUGGESTIONS

They're FUN to organise, and FUN to take part in - an essential ingredient if they are to succeed financially.

Do have a look through them, and if one catches your eye, why not have a go organising it? The MPS office will always help with advice, publicity material, and support.

With the recession taking its toll on Trust and Company donations, it is events held by members, extended family and work colleagues throughout the United Kingdom that will keep our appeal for funds towards research and family support on target.

Abseiling	Parachute Jump
Aerobathon	Police Events
Balloon Race	Pool/Snooker
Barbecue	Potato Peeling
Basketball	Pram Push
Bedpush	Push/Pull a vehicle -
Train, Taxi	Bike Events
Pub Games (Darts etc)	Bingothon
Quizzes/Mastermind	Bus Rides
Radio Event	Bus Wash
Raffle	Busathon
Raft Race	Car Cleaning
Record Breaking	Car Rally
Sale (Garage, Handicrafts)	
Centipede Race	Scavenger Hunt
Clay Pigeon Shoot	Show (Theatre, Ballet)
Coffee Morning	Singathon Collection
Skating Ice/Roller	Disco Sponsored

Bike Ride	Dogathon
Sponsored Dance	Eating Events
Sponsored Duck Race	Exercise Sponsored - Give
Something Up	Exhibitions (Paintings)
Sponsored Job	Fancy Dress at Work
Sponsored Juggling	Horse Ride
Sponsored Silence	Fashion Show
Sponsored Skittles	Fire Brigade Event
Sponsored Slim	Fun Weekend
Sponsored Stay Awake	Fun Day
Sponsored Swim	Go-Karting
Sponsored Walk/Run/March	It's a Knockout
Sport - Cricket	Jail Break
Sport - Fishing	Jumble Sale
Sport - Table Tennis	Karaoke
Sport - Golf Match	Kidnap
Tapathon	Knitting/Sewing Match
Treasure Hunt	Lambadathon
Trolley Push	Martial Art Event
Tug of War	Morris Dance
Wheelchair Marathon	Pancake Tossing

CARE TODAY HOPE TOMORROW

- IN 1993 WE NEED YOUR HELP

LIST OF FUNDRAISING EVENTS

Thank you to everyone who has raised money for the Society recently - please keep up the good work.

Rebecca Byron's family, Cheshire	Raised
Mr and Mrs Kempster, Eltham	Collecting Box
Mr and Mrs Leask, Shropshire	Coffee Morning
Mr and Mrs Hubbard, London	Sale of Stamps
B Ingham, N Ireland	Collecting Box
The Fryers and Friends, Essex	It's A Knockout
Sarah Kilvert, Family and Friends	Grass Track Meeting
Pam Croghan	Car Boot Sale
Pam Croghan's Parents	Collecting Box
Portcullis Inn, Chipping Sodbury	Quiz Night
Mercury Walkers, Bristol	Sponsored Walk
Kirkhill Golf Club, Glasgow	Raised
General Accident Life, York	12 Mile Mountain Bike Ride
Balsetter Rise PO, Hull	Collecting Box
Sew and Sew, Glasgow	Collecting Box
Skerton Hotel, Lancaster	Haloween Night
Turners Turkeys, Sutton Bridge	Collecting Box
N W Families, Sanfillipo Day	Raffle
Mrs Turner, Lowestoft	Sponsored Slim
Tracy Tailford, Northumberland	Raffle and Fancy Dress
Adrian Rowberry, Surrey	London-Brighton Cycle Ride
Clevedon Golf Club, Avon	Shotgun Start
M Walton, Rochester	Bungee Jump
M and P Loveday, Wilts	Sponsored Cycle Ride
S and C Rivett, Wilts	Sponsored Cycle Ride
G A Life, New York	Collected
Alan and Amy Bottrell, Glasgow	Saving 20ps
Mrs Jordan, Tunbridge Wells	Coffee Morning & Collected
Sid Shiff, Family and Friends	Collected & Sale of Goods
J Hattle & Friends, Cleveland	Sponsored Walk
Christmas Party, Milton Keynes	Raffle
Ellen Robinson, Milton Keynes	Collecting Box
Stonelaw High School, Glasgow	Sponsored Swim
Bill and Sylvia Blackburn & Family	Sherry & Mince Pie Day
A & K Weedall, Runcorn	Webb Ivory Sales
Linda & Ron Snack & Friends, MK	Tombola and Sale of Goods
Eve Drew School of Dancing, Gateshead	Raised
S Albert & P Bradley, Tyne and Wear	North Ride
Jackie Grieveson, Tyne and Wear	North Swim
Linda & Ron Snack & Friends, MK	Flag Day
Owlsmoor Primary School, Surrey	Collected after School Plays
Debenhams Sports Society	Raised
Pat Stevens & Colleagues	Singing
Coopers and Lybrand	Raised at Xmas Party
Royal Bank of Scotland	Beajolais Evening
S Birmingham Ladies Bowling League	Raised
F A Sandow	Sale of Stamps
W and F Pidden	Raised
K and P Ballard	Sale of Foreign notes/coins
Wenna and Leri Price	Sale of Cakes and Biscuits
The Ink Pot, Mini Enterprise Group	Raised
Trull School of Dancing	Raised

Area Support Families

Neil and Jane Reid Tel: 0223 834570
19, Hillside, Sawston, Cambs. CB2 4BL

Robert and Caroline Fisher Tel: 0799 86631
The Horrells, Great Samford, Saffron Walden, Essex

Alan and Deirdre Beavan Tel: 0858 62182
'Tumbleweed' West Gate Lane,
Lubenham, Market Harborough, Leics. LE16 9TS

Susanne and Jeffrey Hodgetts Tel: 0827 56363
6, Godolphin, Tamworth, Staffs. B79 7UF

John and Barbara Arrowsmith Tel: 091 2812062
140 Newton Rd, High Heaton, Newcastle on Tyne NE7 7NH

Sean and Pauline Mahon Tel: 0742 304069
41 Stumperlowe Crescent Rd.
Sheffield 10, South Yorkshire. S10 3PR

Mary and Robin Gooch Tel: 0435 883329
Highbank House, Swifehill, Broadoak, Nr Heathfield,
East Sussex.

Bill and Sylvia Blackburn. Tel: 0270 626809
11 Beatty Road, Nantwich, Cheshire. CW5 5JP

Ron and Linda Snack Tel: 0908 666819
16 Wandsworth Place, Bradwell Common, Milton Keynes, Bucks. MK 13

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

Contact for Scottish Families:-

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