

Newsletter

Winter 1994



The Society for Mucopolysaccharide Diseases



National Registered Charity No. 287034

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Christopher Rees, aged 7, MLI, from Clydach near Swansea enjoying a ride at the Welsh Christmas Party, while dreaming of a new set of wheels.

(see p. 23)

The MPS Society is a voluntary support group, founded in 1982, which represents over 700 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 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 Great Britain and Northern Ireland, who offer support and links to families in their areas. It provides an information service for families and professionals. At the present time it supports two specialist MPS clinics at the Royal Manchester Children's Hospital and at the Hospital for Sick Children, Great Ormond Street, London. The Society also funds three biochemists, one at Manchester Children's Hospital, one at the Christie Hospital, Manchester, and one at the Institute of Child Health, London. It encourages and assists contact and co-operation between parents and professionals and maintain links with sister societies in Europe and throughout the world.

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

"Care today, hope tomorrow"

Contents

Director's New Year Message	3
Christmas Parties.....	4
Milestones.....	8
Dates for your diary.....	9
Family Photo Album.....	10
Letter from Corporal Neil Whitewick.....	12
National Holiday Fund Florida Trip	14
Grand MPS Draw Results.....	16
David Briggs	17
Childhood Wood Report.....	17
Coins and Stamps	17
Dancing Trees (Nelson family)	18
Macintyre Family Letter	19
Rachel Bourke (New Zealand)	20
Fundraising - Ted Hurdle, Pauline Mahon.....	21
What use is a Hospice to you? (Briggs family).....	22
Information Page.....	23
Needles (Help take away the fear)	24
Coping with Stress.....	25
The Special Educational Needs Policy explained.....	26
Disability, Learning Difficulties and Further Education.....	27
Reward for Elizabeth Neufeld.....	28
Letter from Canada (Kathy Bankert)	29
The Seddon Spoon	30
Acknowledgements: Fund-raising and Donations	31
Sponsored Events and Appeals.....	32

Deadline for Spring Newsletter

8th April 1995

DIRECTOR'S NEW YEAR MESSAGE

It doesn't seem possible that yet another year has passed. For many of you 1994 will have been a year of mixed emotions. In particular we remember those families who are coming to terms with a diagnosis of MPS, those who are caring for children with MPS and those who have lost children to MPS. We extend our gratitude to all professionals involved in MPS who in their own ways are sharing our pain and yet at the same time trying to improve our children's situation. A special thank you should go to the staff at the Children's Hospices around the country who provide a lifeline to MPS families, year in year out.

1995 brings with it new developments for the Society. As many of you will know Mary Gardiner has worked as Northern Family Support Co-ordinator for the past three years from her own home in Hesketh Bank. With an ever increasing workload the Trustees recognised that this arrangement was no longer viable. On the 12 December MPS moved its Northern Office out of Mary's home. Full details of the office address and phone number appear at the front of this newsletter.

Having said good-bye to Linda Golding earlier this year after eight years with the Society I am pleased to tell you that Sheila Duffy will be joining us on the 3 January - working Monday, Wednesday and Friday 9.00am - 3.00pm. I am sure that with Sheila in post, Joan, Sue and I will be better able to manage the ever increasing workload.

1995 is an important year for the Society in terms of the European Database. A huge amount of data has been collected and there is still a lot more to achieve. Over the coming months Joan and I will be correlating all the information and hope to present our findings. Visits to Russia and Scandinavia are planned.

Our 1995 MPS Conference will take place in Northampton, 22-24 September and we are delighted that Professor John Hopwood from Adelaide Children's Hospital, Australia will be making a presentation bringing us up to date with his research. Dr Ed Wraith will be addressing the medical and social problems in Sanfillippo disease in a ninety minute satellite seminar at the conference. During this time there will also be a choice of six workshops running simultaneously which we hope will meet the needs of all our professional and family delegates.

Booking forms for our Family holiday in July and our two teenage activity holidays are enclosed. Priority will be given to those who have not been before and whose application forms and deposits reach us before the closing date. So do hurry.

In the coming year both Mary and I need to give more time to securing major funding for the Society. We have two excellent research grant applications on the table but with our present research projects and the growing support needs of our families the Trustees just can't financially commit more funds at the present time unless we can raise more money. We are always conscious of how good you already are in terms of fund-raising and can only ask for your help in keeping this up in the coming years.

On a personal note may I thank you all for your kindness and support over the past year. Robin returned safely from his nearly four weeks in the Himalayas having successfully reached the summit of Kalapathar (18,192 feet). Lucy, Ben and I enjoyed a much needed break in Florida with Andrew and Robin joining us for a week. Our batteries are now charged and I look forward to the challenges that lie ahead in 1995.

Thank you for all your Christmas greetings and may we wish you all a peaceful New Year.

Christine Lavery

Christmas Parties

North West -The biggest and the best.

Twenty nine families from the North West Area enjoyed their Christmas party on Sunday 20th of November at South Cheshire Masonic Hall, Willaston, and a jolly good time was had by all. An excellent buffet lunch was provided by Suzanne, our caterer.

The children were entertained by "Andrew" the magician, while the grown ups had time to chat. "Andrew" was impressed with the children - so much so that he got carried away and ran over his normal entertaining time.

Santa made his usual visit and it was lovely to see the mixed reactions from the children - little **Ben Lemon** was not too sure and **Billy Burlison** was more than curious - Santa nearly lost his beard.

Three new families were welcomed, Sandra Pollard, the Obad family and Drs Arshad. They may perhaps have found it a bit overwhelming but nevertheless they enjoyed the party and said they benefited from meeting with other families.

Alex Gardiner won a spotty dog in the raffle which incidentally was donated by her mum, Mary.

Time goes quickly when you are having fun and the afternoon soon came to an end but not before singing "Happy Birthday" to **David Oulton** whilst he cut his birthday cake.

Bill and Sylvia Blackburn

Welsh Christmas Party - Swansea

We had a really great Welsh Christmas MPS party in Swansea! Please thank all the families who supported us, especially Wyn and Sue Rees and Bill and Sylvia Blackburn.

Bill was a wonderful Father Christmas, I can recommend him for the job.

Happy New Year to you all! Special New Year best wishes to all the Welsh MPS families,

From,

Mike, Anne and Sarah Kilvert

(See photos on cover and page 1)

Front Cover: Sarah Mc Knight aged four from Lougharne in Dyfed. Sarah was not very well recently but was in very good spirits at the Welsh Christmas Party.

Christmas Parties

Sheffield

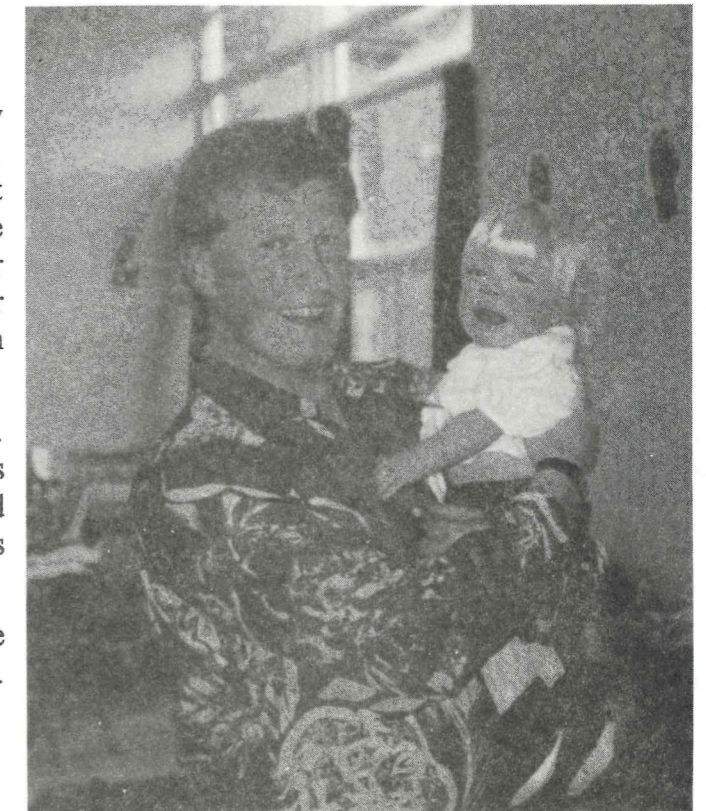
Nine years ago a national MPS Christmas Party was held in the York, Nottinghamshire area. Even though each one since has been most enjoyable, the one this year has been by far the most successful. Fifteen families, including four new ones and thirty five children enjoyed four hours of food, fun, games and a visit from Santa and his magical sleigh.

The children's faces were a joy to behold. More wondrous was Martin Sutcliffe in his pinny and funny hat, keeping his eyes closed and fingers crossed in the hope that the clowns would be kind to him.

They weren't, much to the amusement of the children, especially Henry and Hannah Sutcliffe. A good party was had by all.

Pauline Mahon

(Area Family Rep)



Ray Martin from Harrogate with friend Rhianneth Wheeler from Old Woking. (ML11).



Martins and Wheelers having a good time together at Sheffield.

Milton Keynes Christmas Party



Patrick Scanlon, with his sister and nieces getting into the spirit of the party. Patrick, who has Morquio disease is aged 28 and lives in London.

"home grown" this year, the best sort, I think. We were all encouraged to put a spoon and string "where no spoon and string had passed before", and to carry out a spot of Star Gazing in order to identify thirty well known faces. No Patrick Moore, I noticed. This was followed by "Stick the nose on Rudolf" a great hit with the kids.

We thank Andy Hardy for the games and Jenny and Rebecca Hardy for the music - Christmas songs and carols to sing along with.

During an interlude in the music we welcomed Santa. I can't really call him Father Christmas as Ron and Linda are equal opportunities employers. However, we were all pleased to see "him" and would like to thank Santa for taking time off in his busy season to come and visit us and for the presents he brought for the children. The food was excellent. I believe the technical term is "running buffet", but I don't think anyone had any trouble in keeping up.

Thank you Ron and Linda for organising the party, the food and the road signs. £25 was raised on the raffle at the party, to be added to the £500 plus that was raised at the MPS tombola in central Milton Keynes the Saturday before. I am looking forward already to the 1995 Area Family Events (See page 9. Ed). Thanks again for a lovely afternoon.

Tine Marchbank

Jessica Stuart from Borehamwood, Herts. with her dad Peter. Jessica is aged three and suffers from Hurler disease.



This year the MK Christmas Party was back at Bradwell Common Meeting Place after our expedition to Downs Barn Church last year. Although the Meeting Place may be a bit more difficult to find than the church, Linda, Nobby and Lil, working in the kitchen, were a lot happier as they could see what was going on in the hall.

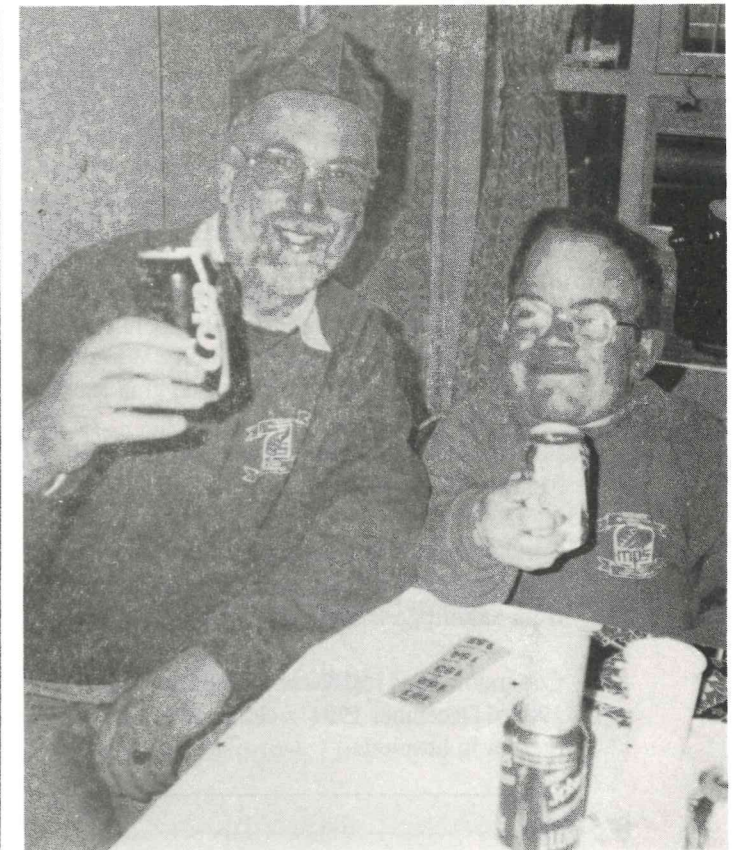
Entertainment was

South East Thames Christmas Party, The Wheel Inn, East Sussex.

Our party was on the 4th of December. Those who came were Harry and Rosemary and Lisa Nurse, Gordon and Alison Rowe and family, John and Betty Rowe, Sue and Katie Scott, George and Jill Evans, the Nelson family, the Pickard family and Gooch family and grandparents.

Originally we had planned to hold the party at our house, but because of the pleasing number of families who wanted to come, we decided the house was not big enough! So, with the help of Bob and Sylvia who own the Wheel Inn, we had a lovely Christmas Party with great food and atmosphere.

Father Christmas made a visit and gave a present to each of the children - which was a wonderful sight. It was also a lovely opportunity for every one to talk and relax together on an otherwise miserable day.



Andy Hardy and Alex Butler toast the New Year in at Milton Keynes.

Every eye is on Martin Sutcliffe as he tries to protect himself from the unkind clowns with his pinny and his plastic hat. (Sheffield Party)



Milestones

BIRTHS

Congratulations to **Bernadette Larkin and Brendan Maguire** from Cookstown, Northern Ireland on the birth of their son **Stephen John**, born on 2 December 1994. Bernadette suffers from Morquio disease. Bernadette's parents, **John & Winnie Larkin** are great supporters of the MPS Society and our best wishes go to two very proud grandparents.

Congratulations to **Amir Aman & Aneela Ullah** of Forest Gate, London on the birth of their son **Mohammed Raheel**, on 2 December, 1994 weighing 6lbs.

Congratulations to **Emma Bramford and Harold Scott**, also proud grandparents **Pete and Sue Bramford** on the safe arrival of **Imogen Deanna** on 13 December 1994. Emma's sister, **Toni** died from Sanfilippo Disease on 17 December 1988.

Congratulations to **Johann and Suzy Graf** from New York on the birth of their daughter **Anya** on the 29th of December 1994, a sister for **Frederika (Freddie)**, who suffers from ML11 and who is at present in hospital.

NEW FAMILIES

Mark and Rachel Wheeler from Reading, Berkshire whose elder son **Sam**, born on 13 November, 1990 has been diagnosed with Morquio disease. Sam has an unaffected younger brother, **Ryan**.

Mrs Marilyn Davies of Pontclun, Mid Glamorgan whose sister **Elizabeth** suffered from Hurler disease. Elizabeth was born on the 18 November 1945 and died in 1955.

Mr & Mrs Yeung from Eastbourne, Sussex whose 14 year old son **Wing**, has Maroteaux Lamy disease. Wing had a bone marrow transplant when he was eight years old and is now studying for his GCSEs.

DEATHS

Natalie Harper from Crawley, West Sussex, who died on the 18 October, 1994 aged five years. Natalie suffered from Hurler disease.

Simon Meek from Doncaster, South Yorkshire who died on the 9th December 1994 aged fifteen years. Simon suffered from Sanfilippo disease.

Andrew Kennedy from Stockport, Cheshire who died on the 29 November 1994 aged six years. Andrew suffered from Hurler disease.

Lloyd Stewart from Killead, Crumlin, Co. Antrim, who died on the 19th of December 1994 aged eighteen months. Lloyd suffered from Sialic Acid disease.

Our thoughts are with the parents, families and friends of these children at this sad time and with all families who have lost a loved one through MPS.

Dates for your diary

- 4th Feb 1995..... Management committee meeting, Little Chalfont.
- 24th Feb 1995 Tree planting at Childhood Wood.
- March..... Area Family Training Weekend (Dates to be notified)
- 21st May 1995 Area Family Day at London Zoo (Contact Ron Snack)
- 28th May - 3rd June..... Teenage activity holiday, Devon.
- 9th July Area Family Barbecue, Milton Keynes (Contact Ron Snack)
- 22-29th July MPS Family Holiday, Primrose Valley.
- 23-29th July Second Teenage activity holiday, Devon.
- 10th Sept..... Area Family Day at Cotswold Wildlife Park (Ron Snack)
- 20th Sept..... Northern Ireland Regional MPS Conference
- 22-24 Sept..... Annual conference, Northampton.
- 24th Sept..... Annual General Meeting (at the conference)
- 2nd Dec..... MPS Giant Tombola at Milton Keynes. (Ron Snack)
- 10th Dec..... Area Christmas Party at Milton Keynes (Ron Snack)
- 23rd Dec..... MPS Flag Day at Milton Keynes (Ron Snack)

Ron Snack writes:

You are all welcome to come along to any of our Area Family Events. Just give us a ring to let us know you will be coming.

Editor writes: Why not follow Ron's excellent example and let the Newsletter know in advance of events you are organising so you get lots of publicity.

Organising tip: Ask someone else to take photographs and to write a few lines for the newsletter and send them off right away.



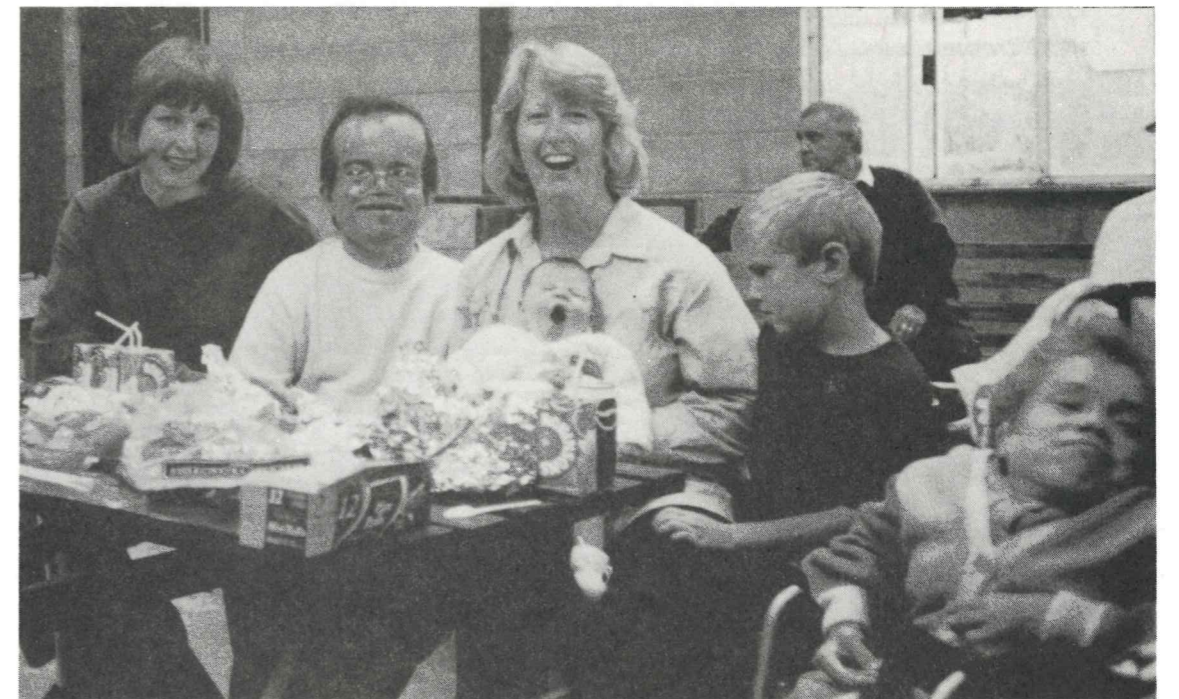
Yvonne and Kevin Puddy from Shepton Mallet in Somerset with their daughter Annette (Sanfilippo aged eleven), enjoying a relaxed afternoon last summer at Nowell's Garden Party

Vivienne and Andrew Culley, from Alveston, near Bristol, with Shirley Eyre from Malmesbury, Wilts. and daughter Carly in a sunny summer mood, also at Nowell's Garden Party.



Barbara and Trevor Rollinson and family from Scunthorpe at an Area Family Outing to White Post Farm last May. Seymour family on the right.

Ellie and Paul Gunary from Nottingham, Angela Seymour and Lynn Thompson are the adults in this cheery group at White Post Farm outing. Paul suffers from mild Hunter disease and Lynn has Morquio disease.



Corporal Neil Whitewick writes about the 1994 Conference

2472635 Cpl. Whitewick, 95 Squadron, RLC, ATR Pirbright, Alexandra Barracks, Pirbright, Woking, Surrey, GU24 0QQ. Tel: 0585 796356 - 0483 798210.

1st October 1994

Dear Robin and Chris

I thought that I would take this opportunity to write to you. I am currently on a duty which lasts for 7 days, during which I cannot leave the military telephone or go home. As I am not exactly busy today I am putting pen to paper.

Firstly thank you very much for last weekend. I had an absolutely brilliant time. I met so many new faces, and enjoyed every minute I spent with them. Everything about the weekend conference was excellent and I only hope that the Society continues to give me such an enormous amount of enjoyment.

The weekend itself contained many things that I would like to mention. The hotel was outstanding for a starter, it was relaxing and it made everyone feel welcome. This became apparent the first day. As Colin and I arrived so did another family and I overheard their conversation with you and the father was saying that they did not intend to stay for the weekend. Half an hour later I was in the swimming pool with Colin when they appeared. I introduced myself to them and immediately spoke of my involvement with the holidays as they were thinking of sending Mark. We spoke for a while and I promoted North Devon as best as I could. The next time I saw them was after my presentation on Sunday. They shook my hand, congratulated me and thanked me, and said they would definitely put Mark's name on the list. Not only was I pleased with them thanking me but also the fact that they had stayed and thoroughly enjoyed the weekend. This was to me a reflection on the character of the Society and the hotel. Also the way Friday and Saturday nights were tremendous. Never once did I feel an outsider and the fact that I was on my own went straight out the window as I was always talking to some one different, or drinking with some one different and it must be said I did drink quite a lot. On Friday night I never left the bar until 2.30am and on Saturday night I never left the bar at all, I just went straight into breakfast!! All in all I had five and a half hours sleep all weekend.

The next thing to mention is the children I looked after on the visit to the theme park, Sarah and Mark Burgess. I thoroughly enjoyed being with them and we had a good laugh all day. Also I met their parents and had a good chat to them about the holiday at the Dinner Dance on Saturday night, again I think it worked and they intend to put Sarah's name forward as much as Sarah wanted to go.

Next, is the presentation to us Army lads I was personally very touched and I think the words that Major Coole choose in his speech were outstanding, for which I applauded him with a lot of respect.

Corporal Neil Whitewick writes about the 1994 Conference cont'd.

The final thing is my presentation. Since becoming an instructor myself I always know when a lesson, no matter what subject has gone well. I thoroughly enjoyed giving the presentation, as well as the response I got from the audience. Afterwards I was continually thanked and congratulated for the 25 minutes talk I gave. Again I was touched that people were willing to come across and shake my hand, especially Mark's parents, who I mentioned earlier in this letter.

There is really little left of the weekend to mention but as a token of my appreciation to all who were present over the conference, I would be grateful if you could print this letter in the Annual Conference report or quarterly newsletter, so I can make my gratitude known to everyone rather than just yourselves.

If the enjoyment I have received from the holidays and the conference is anything to go by, I hope that my commitment becomes stronger in the very near future. As usual, contact me if you need my help, especially if it involves meeting more families in my local area.

Finally through this letter and the society, I would like to pass on my thanks to John and Barbara Arrowsmith. To entrust Colin into my hands, who they had never met before the conference, is something that I was very touched by, and after having met them at Northampton, and finding out what a lovely couple they are, along with their daughter Claire, and of course Colin "Toon Army" himself, I only hope the friendship is long lasting.

The society means the world to me, and I would just like people to know that. Never have I received such an amount of self-satisfaction in anything I have done in life before, and thank you for letting me make the most of it.

See you soon, lots of love

Neil

P.S. Please note my new address and phone numbers. Anyone can contact me.



Rob Paget, Neil Whitewick, Mary Gardiner, Christine Lavery and Alex Gardiner at the Calvert Trust Centre in Devon in May 1994 - venue for the teenage activity holidays this year.

A Holiday of a Lifetime with the National Holiday Fund

In November I went to sunny Florida for a fortnight. It was 84°F. There were four MPS children there this year, Myles and Joanne Broughton, Joanne Evans and Helen O'Toole (me). Myles and Joanne Broughton have Hurler/Scheie disease and Joanne Evans and Helen O'Toole have Morquios. I am certain that we all had a very enjoyable time and are much more independent now.

We stayed in an adapted hotel in Orlando. During our stay we visited the famous places like MGM Studios, Epcot Centre, and the Magic Kingdom which are all Disney places. We spent a day at Seaworld. We had a great time at Universal Studios where I was given a great big pink panther. Matt, the leader, said that owners look like their pets, and this panther had a floppy neck like me. We spent days at some not so famous places like Busch Gardens, where we got soaked on the water rides, and Cyprus Gardens where we watched various shows.

We spent a day with the police where the Sheriffs showed us their tracker dogs and police cars. Another day was spent with people called "The blue lights" who are a cross between the police and Hells Angels. We were taken for rides in sidecars and on the back of motor bikes.

I now have tons of photos and loads of penpals to keep in touch with.

Finally I would like to thank all the volunteers who gave up a fortnight to look after us all. I also want to thank the founders of the National Holiday Fund group and Christine Lavery for recommending me for the trip.

Helen O'Toole

Joanne Evans aged eight from Bridge of Weir in Scotland and **Helen O'Toole** aged 17 from London relax in a tropical pool at their hotel in Florida.

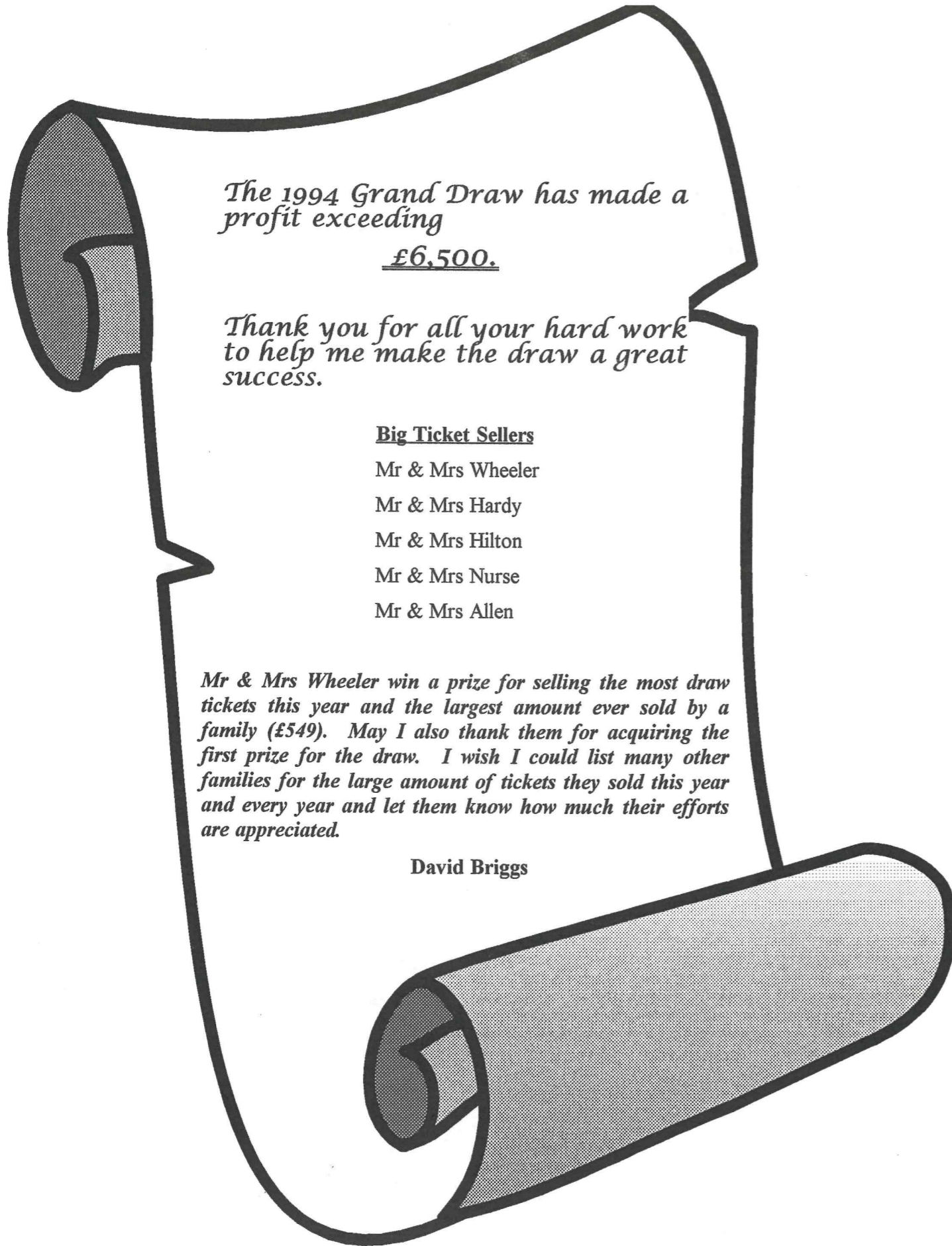


Joanne Evans meets with Cinderella



While Helen takes off on a Harley Davidson...





The 1994 Grand Draw has made a profit exceeding

£6,500.

Thank you for all your hard work to help me make the draw a great success.

Big Ticket Sellers

Mr & Mrs Wheeler

Mr & Mrs Hardy

Mr & Mrs Hilton

Mr & Mrs Nurse

Mr & Mrs Allen

Mr & Mrs Wheeler win a prize for selling the most draw tickets this year and the largest amount ever sold by a family (£549). May I also thank them for acquiring the first prize for the draw. I wish I could list many other families for the large amount of tickets they sold this year and every year and let them know how much their efforts are appreciated.

David Briggs

Collecting Coins and Stamps

Ken and Pam Ballard, Christine's parents have been collecting and sorting coins and stamps for a few years now. They have found a way to make a profit from almost any form of currency, coins or paper, home grown or foreign.

Below is a brief account of their results.

Coins

1993..... **£53.81**

1994..... **£88.15**

Stamps

1992..... **£ 96.00**

1993..... **£ 24.00**

1994..... **£109.00**

Please continue to send your coins and stamps, especially foreign stamps, to the MPS Offices or give them to Committee members when you see them.

Final Draw Report from David Briggs

After postage and printing etc., if my accounting is correct, the draw has provided £6519.90 for the Society. I can only thank you all again for the support you have given us. Thank you all for the cheerful letters and phone calls that kept us going when things got a little stressed - we shall miss them. However, until life at home stabilizes we must reduce our commitments to a level we can cope with. We wish whoever takes over the job of draw co-ordinator all good fortune and hope that they take the draw on to greater successes. We are happy to tell you that during our six years of promoting the draw the Society has benefited by over £40,000. We have given away over £11,000 worth of prizes to lucky winners.

A special thank you to **Pauline and Sean Mahon** (who put me right when my "accounting" did not add up), and to Christine, Mary and the management committee for their support. Also, a big special thank you to our daughter **Emma**, who has spent hours doing the really boring bits, like folding thousands of draw tickets. Wishing you all a very, very happy New Year.

David, Monica, Emma & Kristina Briggs.



Emma & Kristina Briggs earlier this year. Kristina suffers from Sanfilippo disease and is now aged 12.

Wood Report

On our last visit to the Wood it was a cool November day. The sun was shining and it was quiet and peaceful. Even our dogs were quiet, sitting in the sun and looking round them. I think they enjoy our visits as much as we do. I could have sat there for ages. Unfortunately this was not to be as there were places to go and things to do. However I thought you would like to know that the Wood looked good. We will be keeping an eye on the Wood through the winter and we will be waiting with the camera in the spring so we can take some more photos of the Wood in bloom.

David Briggs

Dancing Trees Raise £176.00



James Nelson from Trotton in Hampshire is the tree on the right. His sister Tessa suffers from MLIII, and this prompted their school to donate the proceeds of their play to the Society. His brother Linus plays a mouse in the production. But where is that mouse?

A cast of ninety two children from St Mary and St Paul C.E. Primary School, South Harting, Hants. raised £176.00 for MPS in charity collections at three performances of their Christmas play.

The play, "The Woodcutter's First Christmas" was written and produced by a member of the staff and all the children were involved. Birds, animals, insects, trees, toadstools, ivy, frost, along with the woodcutter and children put on a magnificent show of dancing and singing in this modern epic of saving the woodland from destruction, so that the animals, insects and birds can live happily ever after. Thus enabling the MPS Society to help our children to live happier lives too.

Tessa, (MLIII) will be starting school here in September '95. Her two older brothers were in the production. The tree on the right is James. Linus was a mouse.

Many thanks to all concerned.

A Happy New Year from all the Nelson family.

Dawn Nelson

New Year's Greetings from the Macintyre Family

Dear All,

Yesterday I wrote 7/8ths of an impressively long letter - I went back to it today and found I had rubbed it all off. Today I start again.

Ian and Julie - we have muddled through this year OK, coping with the day to day traumas and getting a few much needed breaks when Tasha went to Helen House. In March we took Kirsten off to Cardiff for a weekend and in July we had a luxury five star week in Torquay. In October we had a weekend in Stratford which did us all a power of good. Ian is still bombing down the M3 to Winchester during the week and spending relaxing weekends?? decorating and helping out, ferrying Kirsten and us around.

Natasha - I am afraid to say that this year has not been kind to Tasha. She has had so many problems, but as ever, she shows her determined spirit and rises above every setback. She is an example to us all when we whinge about something trivial like backache or headache. She still goes to school during the week and manages to get as full a life as she can with the wonderful supportive help from her best friend and one to one support worker at school - Morny. I know she can be at school and be wonderfully cared for physically, mentally and emotionally.

She has now brought a new "family" member into the house - her new friend Lynne. In April when things were getting tough, we finally and at long last accepted nursing help. Lynne comes in twice a day for about an hour during week-days to help bath Tasha etc. She is wonderful with Tasha and is a great support to me to help take off the pressure at times.

Also, after having no social life, we now have the fantastic bonus of being able to go out on a Friday evening, knowing that Lynne is looking after Natasha. We have so far used this to take Kirsten to basketball games, table tennis, dinner etc. Having Lynne come in also adds a new dimension to Tasha's day.

Kirsten - This has really been Kirsten's year. She has achieved so much and blossomed into a very attractive girl, both physically and emotionally. She is wonderful with her sister and is great fun to take out and has developed a quick and sometimes wicked sense of humour!

In January she started us all off in appreciating basketball. She was chosen to play with four boys from her school, at half time, in several matches at the big premier league games. Luckily, five miles away is the home of the top team, the Thames Valley Tigers. Although of a very shy nature, she played in front of 800 to 1000 people and loved it.

After the matches we couldn't believe our eyes - there was our shy little girl, who wouldn't say boo to a goose, rushing to the court to stand by the big six footers getting autographs. The most treasured being those blurred by the sweat of the players! This snowballed until we were members of the supporters club, going to Wembley and attending what matches we can. It is a great stress reliever to be able to shout, clap and generally go berserk at a "slam dunk".

Kirsten now goes to a Sunday Club, she is the only girl and is doing very well. Her ultimate ambition is to play in the Ladies TV Tigers!

Kirsten started her new school - Collingwood College in September and is coming on in leaps and bounds. She has just got her first profile and out of eleven subjects she attained seven "A"s. Art is her particular talent. She is also doing well with guitar and has lessons on Saturday mornings. This year's Christmas present is an electric guitar - will we have a quiet time, we wonder.

Happy Christmas and a healthy and prosperous New Year.

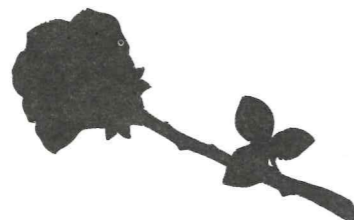
Love,

Ian, Julie, Kirsten and Natasha Macintyre.

Bagshott, Surrey

21 September.

19 Scotston Ave
Christchurch
New Zealand



Dear Marie

I am writing to tell you that Ben our second son with San Fillippo B died on August 7 1994 aged 13 years. On August 4, 7 year ago, Ben was diagnosed 2 years after Joseph was. Joseph is now 15 years old.

Ben died very unexpectedly but peacefully in his sleep here at home on a lovely sunny spring morning on August 7. He had lost alot of weight in the last year, from 32 kilos to about 22 kilos, his eating wasn't that great but we were still managing to feed him with plenty of food supplements included. Ben was still a very very active and mobile and vocal little boy right up to the time he died. The day before he died he had been going through his daily exercise routine, which lasted all day, of pacing the floor and having a very close association with the glass window panes. He had eaten well and for the last three nights we and he had got some sleep something that none of us had been that familiar with. Then he was dead. Mike went to get him up and there he was, very peaceful, just like he would wake up any minute and set the world alive and alight once again.

From there on it all seems rather like a play that one is watching. Lots of people and having to organise the funeral. We kept Ben at home all the time which was really nice as we were able to say goodbye to him in our own time. There were alot of people at the funeral, Ben touched many many lives.

We miss Ben terribly, he lived at home with us all the time apart from going to school every day. He leaves such a large and empty gap. Even though we knew that the time would come when he would have to leave us nothing could ever have prepared us for the finality and pain of the parting. Ben was not happy, I can't remember the last time he smiled so I hope that he has found his peace and freedom. He was always so frustrated and fought the MPS so desperately. We did not wish to have an autopsy done and we think that Ben either died of heart or respiratory failure. That didn't matter to us.

Alot of people have asked us how Ruth, Bens sister, now 8, has coped with it all. I guess for her mingled with the sadness of the death of a special brother is the peace that Ben has left behind and the very drastic change in our lives. Being able to have a cup of tea without having to dodge the hands that seemed to lengthen every year or having parents that have more time for a daughter and are not so grumpy at times.

Joseph, I'm not sure if he is aware that Ben is dead. He is very happy and content less mobile but keeps pretty well apart from having frequent seizures.

It always seemed like I would read of other families having lost their children and now it is our turn. Going through it again, as you too, will understand and have done, for us is not going to be any easier.

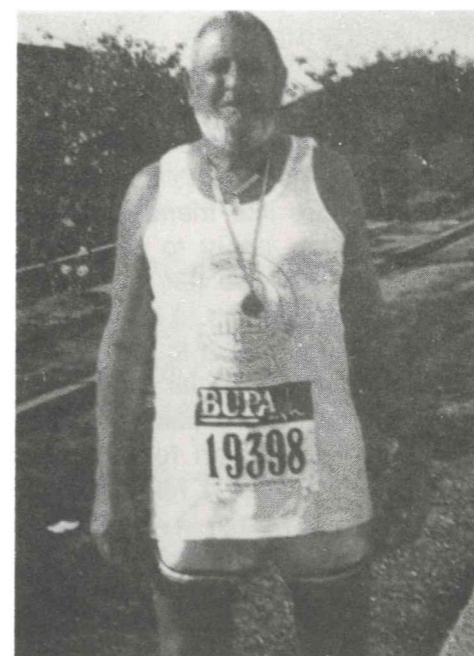
Ben taught us many things in his short life, and in his death he has continued to show us many things. We feel very humble to have been part of Bens very special life. He has given us something that only a few families are privileged to have. We wouldn't have chosen it but wouldn't have missed it for the world.

I hope that you are well Marie, we continue to enjoy, although that is probably not quite the right word as it brings its own heartache, "Courage", we do appreciate receiving it here in New Zealand.

Kindest regards

Rachel Bourke

Rachel Bourke



The Great North Run

We would like to express our thanks to Ted Hurdle, who at sixty four managed to complete the Great North Run. Ted, who is a great friend of the family collected a total sum of £485 for the MPS Society.

We would also like to thank all those who sponsored Ted in his little adventure and would like to reassure everyone that he's fine now - there are only a few blisters left!

Many thanks to everyone.

Harry, Rosemary and Lisa Nurse

Fund Raising in Sheffield

Baldwin's Omega Restaurant in Sheffield was the venue for the seventh annual MPS Gourmet Fund Raising Dinner.

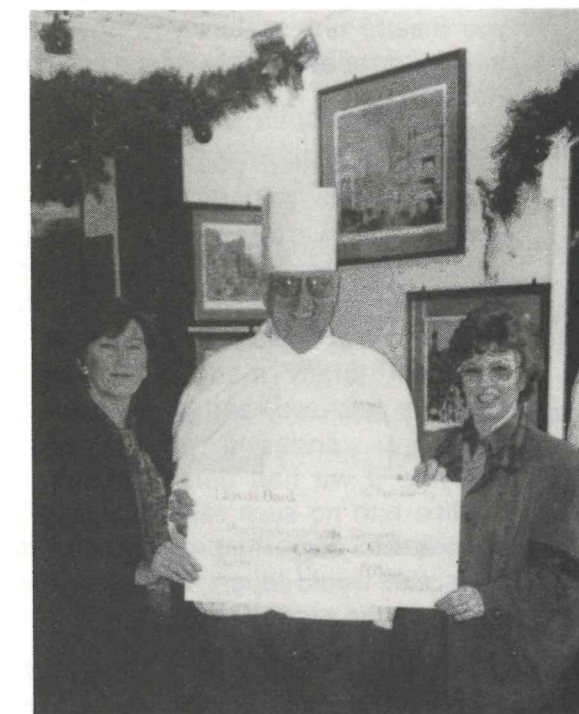
This year on September 15th £3,100 was raised by Jo Woods and Pauline Mahon.

The generosity of mine host, David Baldwin helped us to achieve this grand total, and as you can see from the photograph, David is a big man with a big heart.

Thank you again David for all your help.

Pauline Mahon

(Area Family Rep., Yorks., Notts., Lincs., and Humberside)



David and Monica Briggs, together with their daughter, Emma, have been making a round trip of 160 miles to obtain respite care for their other daughter, Kristina. Below Monica Briggs answers a few questions:-



Kristina will be 12 in September and has Mucopolysaccharidosis, Sanfilippo Syndrome Type A. She has lost her speech, can no longer walk, and has lost control over many bodily functions. 24 hour care, 7 days a week, 365 days a year is required.

"What use is a hospice to you?"

This is a question I have been asked several times now. It is difficult to explain how much that small island of sanity means to a family with a terminally ill child. Each of our children are special to us and have their own needs, but when those needs are complex and the child cannot communicate, except with a few gestures, who can you trust to give them the sort of love and care you do? Even if the continual 24 hour care you give drives you insane and makes you physically ill. In my experience only hospices such as Rainbows.

At first we denied that we needed such help. Respite?, Bah!, not for us. How wrong we were? After months of questioning anyone who mentioned the subject we just dipped our toes in, visited for a couple of hours then a weekend. Then we went totally mad and left Kristina there on her own, and spent most of the time sat wondering what to do and worrying if we had done the right thing. Kristina had no such reservations, she did not want to come home. On subsequent visits she would laugh and cry hooray as we made the turn off the A1 a few miles

from the hospice. Over the years we have seen Kristina's condition deteriorate and the dedicated staff (I hesitate to call them staff as they are more like friends) have gone from chasing her about to carrying her about, and they still give her as much care and love as they ever did. I have also seen them giving just as much to the other children. My theory is that all the staff are injected with T.L.C. at the start of each day, it's the only explanation for all the T.L.C. they give. It is such a relief to be able to know we can leave her in such safe loving hands and spend time with our other daughter or on our own! When we get chance to go, now we have no worries about Kristina's welfare. We know they spoil her, but don't we all deserve a bit of spoiling now and then.

So what use is a hospice to my family? A GREAT DEAL OF USE that much I can promise. It allows all of us to have a break, recharge our batteries and carry on. Many families do not know about them or have access to them and suffer greatly for it. Places like Rainbows are too few and far between. I hope these few words provide a brief insight into how much children's hospices are needed, I could go on and on

Information Page

Dear Christine,

It was lovely to receive your phone call. We talked about gum swabs at the conference so I thought I would send a note giving the details of the ones we use and how we use them.

I do not know who supplies the swabs. I get them from Alfretton Stores (Phone 0773 608844). I expect they can say who the supplier is. The swabs are oral, foam tipped, non sterile and are star-shaped. They can be got in a pack of five or a case of 2 x 400.

I use three each time, dipping them in neat "corsodyl" and then putting the swabs around the mouth, between teeth and gums and over the tongue, so trying to eliminate as many bacteria as possible. The gum swabs do not hurt and do not cause any bleeding as a toothbrush would. The district nurse is trying to find a code number. As soon as I have one I will let you know.

Doreen Russell

Great Barr, Birmingham.

(Matthew Russell suffers from Hurler disease and is now aged ten.)

Did you know?

If you have an extension on your house that includes a downstairs toilet needed by a disabled person then you can save money by being placed on a lower tax band of the Council Tax.

This also applies if the disabled person needs a separate room for use with a wheelchair. The allowance can be backdated for up to a year or to the date when the extension was built.

Contact the Council Tax section of your local council and they should send you an application form.

Did you know?

Free Insulation and Draught Proofing is provided by the Energy action Grants Agency

(Freephone 0800 181 667)

It is available to those who receive Income Support, Housing Benefit, Council Tax Benefit, Family Credit or Disability Working Allowance; and was extended from 1994 to include those receiving Disability Living Allowance and everyone aged 60 or over.

Wanted - A motorised chair

Sue and Winford Rees are seeking a motorised chair for their seven year old son Christopher, who suffers from MLIII.

If you can help, please contact

Sue and Winford Rees

33 Llwynon Road

Clydach, Swansea,

West Glamorgan,

Phone 01792 846152

Planet - Play Leisure Advice Network.

Planet provides a national information and advice service about play and recreation for disabled children and adults as well as for able bodied people.

They have a display room of play and leisure equipment, a reference and video library and journals from various agencies, as well as experienced staff to give advice.

Planet is a partnership project between Save the Children, Mencap and Scope (formerly the Spastics Society).

For further details, contact **Jayne Gillard**, Project Administrator, Planet, Harperbury, Harper Lane, Radlett, Herts. WD7 9HQ

Phone 0923 854861 ext. 4384

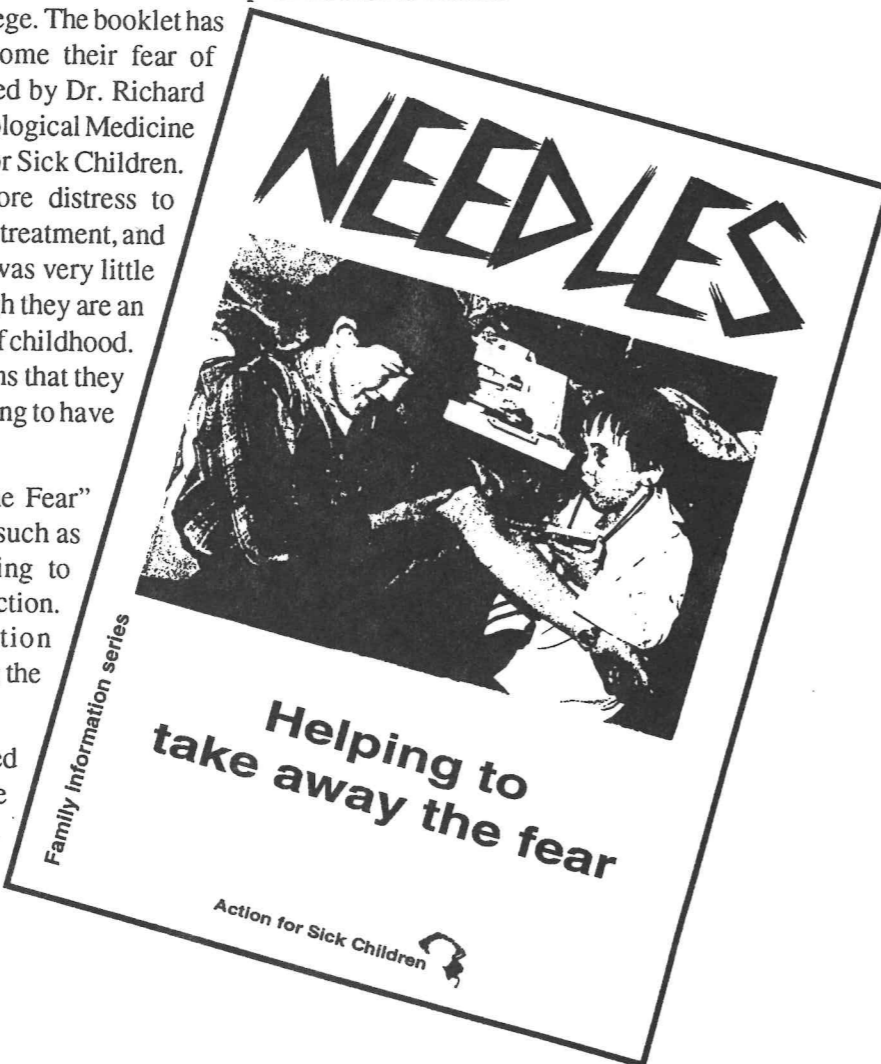
GENERAL INFORMATION

Action for Sick Children

A new Family Information Booklet entitled "NEEDLES - Helping to Take Away the Fear" was launched at the Chelsea and Westminster Hospital on 3rd November by Health Minister Baroness Cumberlege. The booklet has been written to help children overcome their fear of needles and material has been provided by Dr. Richard Lansdown of the Department of Psychological Medicine at the Great Ormond Street Hospital for Sick Children. Injections and blood tests cause more distress to children than almost any other medical treatment, and Action for Sick Children found there was very little information to help them cope, although they are an inevitable and for some, frequent part of childhood. Some children are so upset by injections that they deny being in pain in case it means having to have another.

"Needles : Helping to Take Away the Fear" describes a wide range of techniques, such as counting games, jokes and storytelling to distract children while they have an injection. Parents can learn simple relaxation techniques to help their child - relaxing the muscles reduces pain.

Copies of the booklet can be obtained from Action for Sick Children, Argyle House, 29-31 Euston Road, London NW1 2SD Tel. (0171) 833 2041. Prices: £1 individual copies; 10 copies £8; 50 copies £35; 100 copies £65.



Tripscope

TRIPSCOPE is a Registered Charity which gives advice on mobility problems. It offers a nationwide travel and transport information service for disabled people. Tripscope can give help both locally and nationally to individuals, families and larger groups. Whether you are planning journeys which are social, medical, shopping, business or leisure, Tripscope will be able to help. Whether you are concerned about anything from wheelchair hire to accessible toilets, Tripscope can help. Enquiries can be made by telephone, letter or tape. If the cost of a telephone call is of concern, Tripscope will ring you back. They can also identify available special concessions or discounts on all forms of transport. Sometimes Tripscope is able to assist with information on possible funding sources in special circumstances. The service is free but donations are welcome. For the Tripscope service and further information contact:

Tripscope, The Courtyard, Evelyn Road, London W4 5JL Tel. (0181) 994 9294 Fax. (0181) 3618 Minicom. (0181) 994 9294 UK (except South West & South Wales)

Tripscope, Pamwell House, 160 Pennywell Road, Bristol BS5 0TX Tel. (0117) 941 4094 Fax. (0117) 941 4024 (South West and South Wales)

GENERAL INFORMATION

Coping With Stress

The study describes how parents cope with the stress of bringing up a child with a physical or learning disability or a sensory impairment. Its findings lay the ground for publication of "Taking Care", an 80-page book for families with disabled children, published by the Foundation and the Family Fund. The research, based on in-depth interviews with parents of severely disabled children aged 2 to 10, suggests their determination to give their child as normal a family life as possible could stand in the way of obtaining outside support. Dislike of the 'carer' label and worries that using social services amount to an admission of failure, mean that parents in need of a break find it hard to ask for short-term care and other services.

"Parents value services which allow them to live as normally as any other family, and are reluctant to use those which seem to make that more difficult. They prefer practical help with routine chores that give them more time for parenting rather than the other way round," said Bryony Beresford of York University who interviewed 20 families contacted through the Family Fund, which the Foundation administers on behalf of the Department of Health.

She added: "The message for professionals is that more must be done to reassure parents there is no stigma in seeking help. It is also important that services so far as possible complement the family's own strategy for coping. Why offer help with bathing or dressing their child when what they want is help with housework so they can do the bathing and dressing themselves?"

Most parents interviewed said they found the stress of caring for a disabled child was relentless and sometimes overwhelming. Their love and sense of responsibility, and the pleasures and joys their child brings them were among the fundamental reasons they gave for their ability to cope. Families had a wide variety of strategies and showed considerable creativity in dealing with difficulties, but some said problems with money, marital conflict or caring for other younger children put them under a greater strain than their child's disability. Parents had different ways of keeping going at times of mental and physical exhaustion, including the occasional 'good cry' and maintaining a hobby or outside interest. Almost all spoke of learning to take life "one day at a time". Some families had a good working relationship with Education, Health and Social Services. Conflict with care professionals was one of the greatest sources of stress for others who complained of a lack of information, slow responses and inadequate or inappropriate services.

Alison Cowen, author of "Taking Care" and herself the parent of a son with learning disabilities, said parents would welcome information about ways that others coped and where help could be obtained. This was confirmed by yet more parents who were consulted about an early draft of the book. She said "It underlines the need for properly co-ordinated services and for greater sensitivity by doctors and other professionals to the needs and concerns of parents. Most of all it confirms the uniqueness of each individual family and the need for an imaginative use of resources to enable families to care for their disabled daughters and sons."

"Taking Care" is by Alison Cowen, published by the Joseph Rowntree Foundation on behalf of the Family Fund, and is available free of charge to parents from: The Family Fund, PO Box 50, York YO1 2ZX

"Caring For a Severely Disabled Child, Social Care Findings No 54" is available free of charge from: Joseph Rowntree Foundation, The Homestead, 40 Water End, York YO3 6LP

"Positively Parents: Caring for a Severely Disabled Child" (full report) by Bryony Beresford - £12.50 can be obtained from: HMSO (book ordering service), Tel. (0171) 873 0011 (queuing system in operation)

A report published by the Joseph Rowntree Foundation warns that parents caring for severely disabled children may be missing out on much needed help from the health and social services because they prefer to see themselves as 'parents' rather than 'carers'.

UNDERSTANDING THE SPECIAL EDUCATIONAL NEEDS POLICY

Explained by Rob Ellis, School Governor-Special Educational Needs within a mainstream school.

"G'day! (Sorry, that's a habit I picked up in Australia.) How are you?

Since we last met, the schools have all gone back, and I've been busy governing. Our school went Grant Maintained on 1st September, and, for my sins, I was elected Chairman of the new governing body - I suppose we all have our cross to bear!! In the last issue I attempted to help you through the new Education Act and its associated Code of Practice. So, following on from that, this missive will attempt to explain the sorts of things that should be in a school's SEN policy and what the governor's report to parents should contain regarding SEN. I will also share with you a few ideas of the main duties of the SEN co-ordinator. So stand by for lift off!!

THE SPECIAL EDUCATIONAL NEEDS POLICY

Since 1st September 1994, each school must have a Special Educational Needs Policy, which should be easily available and understood by parents. A copy, or summary of the policy, should be in the school's prospectus. The policy statement MUST include:

- (a) Basic information about the school's special educational provision:
 - (i) the objectives of the school's SEN policy
 - (ii) admission arrangements
 - (iii) the name of the school's SEN co-ordinator
 - (iv) the arrangements for co-ordinating educational provision for pupils with SEN
 - (v) any special facilities which increase or assist access to the school by pupils with SEN.
- (b) Information about the school's policies for identification, assessment and provision for all pupils with SEN:
 - (i) the allocation of resources to and amongst pupils with SEN
 - (ii) identification and assessment arrangements; and review procedures
 - (iii) arrangements for providing access for pupils with SEN to a balanced and broadly based curriculum, including the National Curriculum
 - (iv) how children with SEN are integrated within the school as a whole
 - (v) criteria for evaluating the success of the school's SEN policy
 - (vi) arrangements for considering complaints about special educational provision within the school.
- (c) Information about the school's staffing policies and partnership with bodies beyond the schools:
 - (i) the school's arrangements for SEN in-service training
 - (ii) use made of teachers and facilities from outside the school including support services
 - (iii) arrangements for partnership with parents
 - (iv) links with other mainstream schools, including arrangements when pupils change or leave school

- (v) links with health and social services, educational welfare services and any voluntary organisations.

THE ANNUAL REPORT TO PARENTS

It is the statutory duty of the governors of the school to produce an annual report for the parents. This report is then discussed at the annual Parents'/Governors' meeting. From 1st September 1994 the annual report must contain a section on the school's implementation of its SEN policy. The report should state the number of children with SEN, and demonstrate the effectiveness of the school's system for:

- (a) identification
- (b) assessment
- (c) provision
- (d) monitoring and record keeping
- (e) use of outside support services and agencies.



THE SEN CO-ORDINATOR

Since 1st September 1994 all schools have been required to appoint a member of staff to act as SEN co-ordinator, with responsibility for ensuring that appropriate procedures are in place for meeting SEN. In primary schools the task may be (but not necessarily) undertaken by the Head or Deputy. In larger schools the SEN co-ordinating or learning support team will probably take on the role.

Whoever is appointed, the designated teacher should be responsible for:

- (a) the day to day operation of the school's SEN policy
- (b) advising class and subject teachers
- (c) updating and overseeing the records on all pupils with SEN
- (d) taking the lead in managing provision for pupils at stages 2 and 3 of the new Code of Practice
- (e) working with parents of children with SEN
- (f) liaising with external agencies.

Seems to be a lot to take in, but, again, throughout the whole process, parental involvement is to the fore. So remember, although all these things only became REQUIRED on 1st September 1994, and undoubtedly some schools will be quicker at implementing them than others. It's your job to give the school a gentle reminder (should they need one) that these requirements should be in place, and that they should AT LEAST be working towards them.

I thought I'd finished there, until a friend of mine, your beloved editor I'm sure, asked me, a couple of weeks ago, what I knew about re-assessment at 13. 'Not a lot,' I said. Unfortunately that didn't work, and she sent me off to try to find out what I could. I must confess that with arranging village quiz nights, writing columns on other subjects, being Chairman of Governors, being a father of two children, and having to go out and find time to earn an honest crust, I haven't had a lot of time to research this important topic. What I have found out I'll share with you now, in the hope that it might at least be a starting block - I'll follow up with more information at a later date.

continued...

RE-ASSESSMENT AT 13

Once your child has been issued with a Statement of SEN, the Local Education Authority has the duty to review your child's statement ANNUALLY to ensure that the education provided continues to be the most appropriate. As a parent, you can ask for a full re-assessment at any reasonable time after the original assessment. If your child has not been re-assessed since before he/she was 12 1/2, then he/she MUST be re-assessed between the ages of 13 1/2 and 14 1/2.

This 13 1/2 re-assessment will help in making arrangements for your child in the remainder of the time at school and in preparing for adult life. It is essential that this time is spent planning for further education or vocational training or employment.

The re-assessment will be a full assessment, and you will be able to appeal against its findings if you are unhappy with the results. The views of teachers, other professionals involved with your child, and, most importantly, your views should be taken into account at the re-assessment.

Disability, Learning Difficulties and Further Education: A Call for Evidence

The Further Education Funding Council has set up a committee to look at further education for students with disabilities or learning difficulties in England. The committee especially wants to know what students think and want. It will organise meetings for students and other people with disabilities or learning difficulties to help it find out. For now, the committee would like to hear from students, other people, organisations and groups who know about disabilities, learning difficulties and further education. It is asking for evidence about:

- what "disability and/or learning difficulties" means
- assessing individual needs
- how and if colleges cater for students' needs and the needs of communities
- the way colleges plan and manage provision for students with learning difficulties and/or disabilities
- how funding arrangements affect provision and individuals
- specialist support services for students
- the role of Local Education Authorities, Social Services, and Health Authorities and how they work together
- the quality of provision and the quality of individual student's experience

If you would like to know more, please contact Lisa Young at the Further Education Funding Council on Tel. (0203) 863048 or write to her at Cheylesmore House, Quinton Road, Coventry CV1 2WT

Acknowledgements to "Courage" the National MPS Society of America, to Action for Sick Children, to ACT, to Rainbows and to other magazines for articles reprinted in this newsletter.



Biologist at UCLA Wins Medal

■ **Research:** National Science Foundation award goes to Elizabeth Neufeld for her work on two genetic diseases.

By THOMAS H. MAUGH II
TIMES MEDICAL WRITER

HONORED: Molecular biologist Elizabeth Neufeld of UCLA, above, is one of eight U.S. researchers to win the National Medal of Science, the highest award for scientific achievement bestowed by the federal government. B3

Molecular biologist Elizabeth Neufeld of UCLA is one of eight U.S. researchers to win this year's National Medal of Science, the highest award for scientific achievement bestowed by the federal government, the National Science Foundation announced Thursday.

Neufeld was cited in particular for her research on Hurler and Sanfilippo syndromes, two genetic diseases. Her work has led to tests for the diagnosis of the two disorders and has laid the groundwork for the development of new therapies.

Neufeld will receive the award from President Clinton at a White House ceremony in October. There is one other California recipient, structural engineer Ray Clough, retired from UC Berkeley. He developed methods to design large buildings and bridges that can more easily withstand earthquakes.

Neufeld said that her selection "is an enormous honor. I cannot describe how touched I am to have been selected. . . . In a way, I feel like I am accepting it on behalf of all the people who have worked with me."

Neufeld was a plant biologist when she started her career more than 30 years ago. Her current interest began when "somebody wandered into my lab one day and began telling me about a patient" with one of the syndromes. "I was working in an area that was somewhat related biochemically, but in plants, not in people."

"I had an idea what the problem might be," she continued. "As it turned out, I was totally wrong, but by the time I had proved that, I was totally hooked."

Hurler and Sanfilippo syndromes, along with the much better known Tay-Sachs disease, are part of a family of genetic disorders called mucopolysaccharidoses. The diseases, which typically cause fatal neurological deterioration in children, are disorders of liposomes, which Neufeld calls "the recycling plants of the cells. They take large molecules that the cells are through with and break them down into their constituent parts, which can be reused."

In the syndromes, one or more of the enzymes that are normally used to break the materials down is absent or defective "and the material piles up in the cell," distorting its shape and putting pressure on nearby tissues, such as nerves. Nerve cells can be killed by the internal pressures within the cell.

When Neufeld started studying Hurler and Sanfilippo syndromes, the working hypothesis was that the cells simply made too much of the accumulated materials. She was able, in her words, "to sort them out" to demonstrate what really was happening and identify the defective gene.

Her discoveries have already led to prenatal diagnosis of affected fetuses and better treatment for the patients and has paved the way for future genetic therapy.

Neufeld's "excellence in research and teaching are underscored by her contributions educating and counseling families of children affected by the conditions she is working to cure," said Dr. Sidney Golub, provost of the UCLA School of Medicine. "She is truly a role model for other scientists and physicians."

Stop Press - Computer for Sale.

Sinclair XZ Spectrum 16K Ram.

The Society has been given this computer to dispose of for funds. It is solely the computer (no monitor).

If anyone is interested we would accept a small donation plus cost of carriage. Ring the MPS Office 0494 434156.

1704 Killaly Street East
Port Colborne, Ontario
Canada
L3K 5V3
October 14, 1994



National MPS Society
17 Kraemer Street
Hicksville, NY 11801

Dear Friends of the MPS Society,

My name is Cathy Bankert. My husband Ralph and I were recently given the most difficult of news. Our children Matthew 3 3/4 yrs and Kerrin 18 mos were both diagnosed with Sanfilippo A. For some time we have been aware of Matts' development falling behind his peers. We enrolled him in nursery school, as well as speech, physio, and occupational therapy hoping that he would respond. We have been searching for a reason for his delays for over a year but never expected something so serious. During that time we became suspicious that Kerrin too may be affected. Both Matthew and Kerrin are loving and affectionate children and are doing quite well at this point. It is so difficult to think of what is ahead for them.

I'm afraid this diagnosis has devastated both of us, as it has our families and friends. We are all having trouble coming to terms with this to one degree or another. My sister Joan Stoll, an R.N. has been of great help by doing research and finding out about the MPS Society. We have spoken to Doctors and Social Workers and they have been helpful, however I was hoping other families who have an MPS child or children might share some coping strategies with us.

So often the fear and grief of what is ahead is interfering with enjoying our children as they are today. I know these will be the best days of Matthew and Kerrins' lives and I don't want to have any regrets in years to come. We need some help to turn around what seems like the worst situation into something positive. I don't want to spend the rest of my life with tears in my eyes, nor do I want my family and friends to suffer.

Reading about Sanfilippo and its progression scares me. It seems so unfair that there is no treatment and I find myself losing hope.

If anyone can spare a few moments and write some encouraging words for ourselves and our families, we would be very grateful.



Yours Sincerely,

Cathy Bankert

THE SEDDON SPOON

The Seddon spoon has been designed to help patients with severely limited mouth opening and jaw movement, particularly following head and neck surgery.

The spoon has been used with success following various head and neck procedures including partial glossectomy, floor of mouth resection, and surgery to the jaw leading to trismus.

It has additionally been proved to be useful with certain neurological patients – especially those involving co-ordination in the oral stage, and with difficulty in forming a bolus etc.

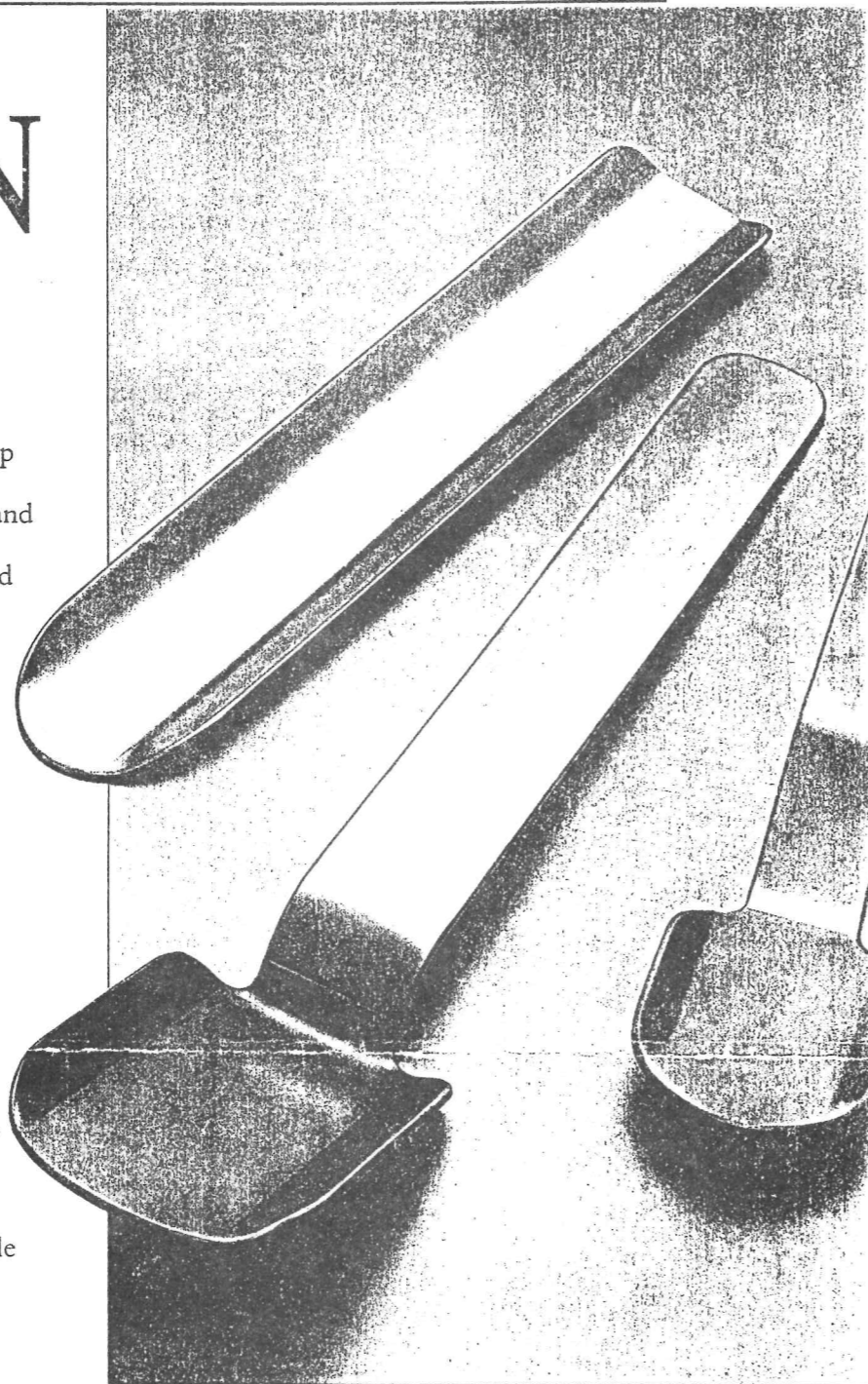
The Seddon Spoon from Kapitex is available in three sizes – Standard; Small, suitable for

children; Spatula.

The main advantages

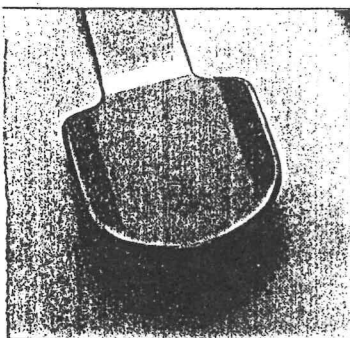
The spoon has a shovel like design which provides a flat base with no 'bowl' to hold food

which may be difficult for the patient to remove.



The flat base and the gradually tapered sides allow access even where there is very limited mouth opening.

The spoon capacity, and ease of use, avoids the struggles with tiny amounts of food on small teaspoons which so often leave the patient frustrated, tired, and hungry. The Seddon spoon has a normal, socially acceptable appearance.



THE SEDDON SPOON

Order number	
STANDARD SPOON	0S FSA 1001
SMALL SPOON	0S FSA 1002
SPATULA	0S FSA 1003



The Society is grateful to the following who held Fund-raising Events

Carol & John Westland	Reading	Folk Afternoon & Sale of Goods
Jean Fergusson	Glasgow	Half Marathon
Scott & Stuart McNea	Glasgow	Half Marathon
1st Rutherglen Rangers	Glasgow	Sponsored Table Tennis
Ron & Linda Snack	Milton Keynes	Tombola
Zelda Hilton	Spalding	
Bedford Harriers	Bedford	Half Marathon
Chilton Trinity School		Raffle
Christine Gooch	Heathfield	Sale of knitted goods
Carol Parfitt	Shepton Mallett	Children's Trick or Treat
Whelley Labour Club	Whelley	Charity Concert
Peter & Sue Stuart	Borehamwood	Sale of Jessica Rabbit Badges
Mr & Mrs Denyer & Tanya	Guildford	Christmas Bazaar
Mr & Mrs Brocks		Soup Morning
Cobham Reformed Church	Cobham	
Sean & Pauline Mahon	Sheffield	Charity Dinner
John & Mary Stacey	Little Chalfont	Sale of Spiffing Stationary
Park Place Social Club	Knaresborough	
Tony & Shirley Eyre	Malmesbury	Raffle
St Mary & St Paul CE School	Petersfield	Charity Performance of Play

The Society is grateful to those who have made donations

Parkinson Estates	Mr Charalambous	Northern Ireland Electricity
B P Hudson	Mr & Mrs Johnson	Shell UK
Lillian Tatham Char. Trust	Mr Sutton	Cedric Gooch
Mr West	Mr & Mrs Allen	Dorothy Duckett
J Beveridge	Mr & Mrs Tailford	Sir James Millar Ed. Trust
Yuki & Sally Motomura	Mr & Mrs Seal	St. Mary's Haddenham
Wade Foundation	Mr & Mrs Hall	Mr & Mrs Baine
Miss E Jenkins	Mr & Mrs Haigh	Audrey Toker
Roundabout Playgroup	Mr & Mrs Thompson	Mr & Mrs Murray
Abbey National Char. Trust	Darts Team Dyfed	Christ Church CE School

DONATIONS IN MEMORY

The Society is grateful to the friends and relatives of:

Gareth Makepeace	Marie Jobson	Barbara Rollinson's Uncle Bob
John Leonard	Gethin Robins	

SPONSORED EVENTS & APPEALS

The Society wishes to thank all those who supported:

Chris Bennett's 1157 Miles Marathon Walk
The Edward Nowell Appeal
Big Bike Ride
MPS Runner in the Great North Run

CHARITY BOXES

Mr & Mrs Shiff
Mrs Todd

Betty Shackman
Ron & Linda Snack

John & Mary Stacey

JEANS FOR GENES

Norden Community School
Woodheys County Primary School
Norden Carnival Committee
WRVS Pendine Luncheon Club
Pendine Social Club
Ecclesfield Primary School
Shel (UK) Birkenhead

Wells Central Junior School
St Georges PCC
Rotary Club of South Wirral
Carmarthen Soroptomists
TROT Running Club
Ysgol Gytun Dyffoyn Taf Comp. School
Swansea Ladies Running Club

An Appeal to Members

Please can you help by organising a fund-raising event, making a donation or putting the Society in touch with potential donors? To fund two areas of research whilst maintaining a very high level of Family Support the Society needs to increase its annual income by £45,000. Every little is most appreciated and really does help.

New Year Wishes

To all MPS families and friends, the strength and cheerfulness to make the most of what 1995 has to offer, the courage to cope with its trials *and the inspiration to write it down and send it to the Newsletter Editor so you can share it with thousands of others.* It's good to talk - *for me its better if you write.* Thanks to all who continue to send articles and photos.

Apologies for any errors that creep in, or if you find that something has been badly expressed. Every effort is made to keep the newsletter to a high standard and more work is now being done to double-check before it goes to print.

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