

NEWSLETTER

m^up^s

SUMMER 1984

**THE SOCIETY FOR
MUCOPOLYSACCHARIDE
DISEASES**



**National Registered
Charity No: 287034**

**CHAIRMAN
OF TRUSTEES**

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**CHAIRMAN OF
MANAGEMENT COMMITTEE**

Mr. R.J.O. Lavery

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HON. TREASURER

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**NEWSLETTER
EDITOR**

Marlene Sanderson,
"Greenhill",
Downend,
Horsley,
Glos.

**AREA SUPPORT
FAMILY (WALES)
and REPRESENTATIVE**

Mike Skidmore,
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Wyesham,
Monmouth,
Gwent.

MEDICAL ADVISORS

Dr. B.L. Neal M.B.B.S., M.R.C.P.G., D.Obst., R.C.O.G.
Dr. D. Garrow B.M., F.R.C.P.

GENERAL MEMBERS

Mr. P. Archard
Mrs. S. Butler
Catherine Grant S.R.N., R.S.C.N., H.V.Cert.

AREA SUPPORT FAMILIES

Northern England

Colin and Mary Gardiner; 35 Church Road, Banks, Southport, Merseyside.

East Central England

Neil and Jane Reid; "Meadowlark", 9 Huddleston Way, Sawston, Cambs.

South East England

Robin and Christine Lavery; 30 Westwood Drive, Little Chalfont, Bucks.

South West England

Peter and Marlene Sanderson; "Greenhill", Downend, Horsley, Glos.

WHAT ARE THE AIMS OF THE SOCIETY?

1. To act as a parent support group.
2. To bring about more public awareness of MPS Disease.
3. To raise funds in order to further research into MPS.

SECRETARY'S REPORT

May was an especially busy month for the MPS Society. Back in March we agreed to have a second Area Support Family Meeting to discuss further developments within the Society and to keep better informed of the needs of our MPS families around the country. Little did we know then that our May meeting would be the subject of a Human Interest story on BBC's Sixty Minutes Programme. After the BBC had filmed in Stoke on Trent with two MPS families each of whom had made very different but none the less heartsearching decisions concerning their MPS child, the film crew asked if they could give some publicity to the work of the Society. All our Area Support Families were present and we were very grateful to Sue and Dan Butler for their kind hospitality. We were also glad that we could share this occasion with some of our MPS children. Overall we felt that the programme was well received and gave the general public a more graphic account of the heartbreak and joy these children bring to their families.

We also received a visit in May from Professor Orii of Gifu University, Japan. Unfortunately we only had 24 hours notice that he was coming to Little Chalfont so were unable to arrange a big gathering. Nevertheless Dr. Garrow and several other committee members spent a very pleasant day discussing MPS both in the UK and Japan. Professor Orii entertained us with a slide show depicting Japanese children suffering from the various types of Mucopolysaccharide Disease. He expressed great interest in the Society's work particularly our support activities, and he intends to encourage the establishing of an MPS support group for his patients. We wish him every success and who knows in the future we may hear from a Japanese Family with an MPS child.

Over the past 3 months we have made a special effort to meet with our families. As you will see from the article further on in the newsletter Mary and Colin Gardiner held a most successful 'Open House' at their home in Southport. 10 families shared the day. During a Holiday in Staffordshire Robin and I were able to meet 7 families, several for the first time, and on a recent visit to London I saw two more families. Following Mary's success with her 'Open House' Deirdre and Alan Beavan have kindly offered to host a 'picnic' on Tuesday 31st July at their home in Market-Harborough, Leics. I look forward to meeting the 8 or so families who have said they are coming.

Plans for our 'Second Parent Conference' are now in full swing and Peter Archard, Conference Secretary, has told me the number of families attending now exceeds 50. We are thrilled that our UK families will be joined by representatives from Australia, New Zealand, South Africa and Austria - a real international occasion. The original deadline for families booking for the conference was 28th May. If for any reason you have not booked but do wish to come please write to Peter Archard, 48 Lawrence Avenue, Letchworth, Herts. immediately

Christine Lavery
Secretary.

AN APPEAL FROM THE EDITOR

Could I send out an appeal for articles for the Newsletter from people who have been fund-raising.

I know it is not always easy when you are looking after your child at home but I feel that lots of you must be fund-raising and however small the effort we would love to hear about it.

Also if anything interesting has happened to your child lately, which you would like included in the Newsletter and don't really feel like composing an essay about it, either jot down a few notes and send them to me at Sanderson Press Ltd., 25a Long St., Tetbury, Glos. and I will put it together, or give me a ring at home on Nailsworth 4901 in the evening or during the day on Tetbury 53771. Even if the Newsletter is full one quarter, your article could always be included in the next one.

I must stress that although we do have lots going in the Newsletter from the Committee and Medical people, the Society is about YOU and YOUR CHILDREN, so please make the effort to put pen to paper.

Incidentally, if anyone from the Medical Profession thinks that they could spare the time to write an article on any aspect of the Mucopolysaccharide diseases, we would be very grateful to receive it.

Marlene Sanderson
Newsletter Editor.

THE SEARCH FOR TACTILE RESPONSE TO MUSIC IN THE NON-VERBAL CHILD

This paper was given by Malcolm Williamson, CBE, Master of the Queen's Music to the members of the British Society for Music Therapy on Thursday 2nd February 1984 in London. The paper was dedicated to David Champion who died in October 1983 from Sanfilippo Disease. Robin and I were privileged to be guests of Malcolm Williamson along with Phyllis Champion, David's mother.

The talk was an inspiration to all who heard it and the understanding and perception shown of MPS children by Malcolm Williamson was something that until then we had only encountered in these children's parents.

This paper has now been published and is available from:

Mrs. Denize Christophers
BSMT Administrator
69, Avondale Avenue
East Barnet
Herts. EN4 8NB

Price: £1.25 (cheques payable to 'BSMT')

**URGENTLY REQUIRED
FOR HARROGATE CONFERENCE
Houstrained VIDEO CAMERA
Preferably with experienced handler**

THE FAMILY FUND

The Family Fund is administered by the Joseph Rowntree Memorial Trust. It offers financial help to the families of children under 16 years of age whose disability causes a very severe handicap. For example, children with severe mental retardation usually pose marked problems of management. There are others with special educational needs who have additional physical defects of significant nature, or special problems of management. The degree of disability is assessed in each case and social and economic circumstances will be taken into account.

What Kind of Help?

An appropriate request is one directly related to the special problems of caring for a child at home, because of handicap, and not covered by existing services.

Some examples of the kind of help given are:

Laundry equipment	Bedding
Holidays	Heating
Outings	Clothing
Transport	Furniture

How to Apply?

Write for further details and you will be sent the Family Fund pamphlet and an application form. A visiting Social Worker will then visit the family.

Eligibility is assessed at the Fund's Headquarters.

The Family Fund
P.O. Box 50
York

Help is not normally given where the handicapped child is under two years of age but consideration will be given in some cases.

BIRTHS

To John and Linda Windsor, a girl, Lisa Marie at 'Southlands Hospital', Shoreham by Sea, Sussex on 5th July 1984, a sister for Stephen.

Many of you will remember that John and Linda's second son, Gary died in August 1983, after he put up a very brave fight through his Bone marrow transplant.

Many congratulations to all the family.

A REPORT OF OUR COFFEE EVENING FOR THE MPS SOCIETY

How to fight the Mucopolysaccharide diseases and how to channel our frustration and anger into something positive and worthwhile resulted in the planning of a fund raising event for the MPS Society on April 13th.

When my daughter Alison & Gerald's only child Jonathan was taken from them at 3 months old from one of these diseases, his death made headline news in our Bradford & District Newspaper together with an appeal for support for the Society. From then on we have been amazed at the wonderful kindness and generosity of so many of our friends, neighbours and colleagues. We began having £ notes pushed into our hands, money was sent through the post to us and what began as a small arrangement for a "Coffee Evening and Bring & Buy Stall" at my sisters house, resulted in a wonderful, marvellously supported event that snowballed beyond belief. At the beginning we were quick to realize that it's not what you know, but who you know, so our first lucky break was having a good, kind brother-in-law Neville, who is the owner of a new factory and who was more than willing to offer us the facilities of the offices, reception area and canteen as a venue. We also discovered what a warm and caring family we have always had, who shared our sadness and pain over Jonathan, as much as our joys and delights at other times and who threw themselves into this organisation with a fervour hard to come by. I wrote to Susan Heath informing her of our project and she sent me a host of ideas to put into practice all of which were very greatly appreciated. At the same time I wrote to local firms, requesting donations or raffle and tombola prizes, sending with each letter an MPS Information leaflet and a ticket for our "do". This was the beginning of the education of residents of Keighley and District into MPS. Through this we received support for a very worthwhile cause. Once again we were fortunate to have the use of Neville's photo-copier and Joyce's typing skills, offered freely and with no costs involved. I wrote letters and sent MPS leaflets and tickets to scores of friends and colleagues I hadn't seen in years (they know I only get in touch with them when I want something) and they all responded magnificently. Our cause opened the hearts of everyone. We had ordered 200 tickets to be printed, but these disappeared quickly and we had to produce another 300 which were also swallowed up very quickly too. Meanwhile our collection of Tombola and Raffle prizes was accumulating at an amazing speed. Colleagues in schools, hospitals and work places were requesting donations and the response here was overwhelming. My friend Dorothy who works as a secretary refused to do extra typing unless she was given a Tombola prize or a contribution for our event. She took an MPS collection

box around the College and returned it to us, full and heavy and sold our Raffle tickets there and would not accept a refusal. She visited local shops asking for gifts and each time I called at her house, she would have a boxful of donations waiting for me. Gerald's sister Charmaine, as far away as Wrexham was also asking for donations for Raffle prizes and brought us some lovely things. She has been doing her own fund raising too and spreading the word in Wrexham. We began selling Raffle tickets a month before the event and once again had willing helpers in our work places. Eventually we were donated over 200 really good Raffle prizes and around 230 Tombola prizes. My younger sister Margaret (who loves a little flutter) took great delight in setting up the Tombola stall. We had stuck the tickets on in advance and the Blind Home at Keighley had loaned us their drum. It was a great success. We had baked and received many more offers of baking for our Cake Stall. My mother-in-law at 82 years had given one of her special home made "Celebration Cakes" to "Guess the Weight" and we prepared batches of home made biscuits to serve with the Coffee & Tea. My husband Francis, who is an enthusiastic gardener and specialises in growing Dahlias was organising his plant stall and had collected little pots and ordered plants, all of which were waiting in his greenhouse to sell on the day. They were sold with full verbal instructions on how to rear and care for them, so that none should fall by the wayside. I had written to Christine asking if we might sell some of the MPS Stationery and had received a very large boxful of this to display. Some of this we sold before the day and at the event. Since then we have sold the remaining stationery to very enthusiastic members of the public. Alison's two sisters, Kathryn and Helen spent their time before the sale painting signs for the stalls etc., which looked quite professional displayed on the night. Kathryn and Paul organised a very efficient White Elephant and book stall, helped by a colleague of mine who was moving house and supplied us with endless items of clothing and used products. I was amazed as they were sold - just what people seem to require. Joyce's friends, Milly, Leila, Margaret and Vi offered to man the Bring & Buy stall, for which we already had some lovely items to sell. My hard-working sister-in-law Mary had rounded up her neighbours, Susan and Irene to serve the refreshments, helped nobly by cousin Sally and my sisters. When the public arrived it was such an overwhelming experience to know that all these lovely people were here to help fight for baby Jonathan and all the other little children with these diseases. They kept flooding in through the doors and the atmosphere was so warm and friendly. I had been delegated to direct and socialize but I seemed to spend all my time just thanking everyone for being there and explaining to them about MPS. Alison and Gerald were overcome by it all. We had erected a little display board with MPS literature and were able to give everyone an awareness of

of these diseases. The work involved in the organisation of that evening helped us in a small way to cope with Jonathan's death and to know that some good will come of our contributions however small. Through this we have found the goodness and understanding of so many people and have discovered that the young as well as the older groups have cared so much. The thank-you letters we have written since to all donators cannot begin to express the gratitude we feel. We raised £1,045 at our event and since then donations have continued arriving. Because of all this Jonathan's little life cannot have been in vain, and for him we are thankful.

Audrey Toker.

WANTED! LOCKS OF HAIR

You may recall that last Summer you were asked to send samples of hair for Dr. Lubec in Austria to develop and evaluate a new non-invasive method of diagnosing MPS cases. Recently Dr. Lubec has visited me in London to show me his results. Unfortunately not all the cases we sent gave him a positive result, with the exception of Sanfilippo type 'A' patients (although his method cannot detect which MPS type is present). In order to pursue this he would now like to have hair from Sanfilippo 'A' carriers and any other Sanfilippo cases we could send. Please send a lock of hair to Christine with name, age and diagnosis of affected child if you are willing to help.

Jean Mossman
Biochemist
Institute for Child Health
London

P.S. Carriers means both parents and possible carriers means siblings who also may be carriers.

CHRISTMAS CARD COMPETITION

I would like to express my thanks to everyone who took part in the competition, especially the friends of Alexander Butler from Oxfordshire and the children from St. Stephen's School, Southport.

Mr. Bill Tidy, the Cartoonist for the Daily Mirror judged the competition on July the 12th, a little later than was originally planned but fortunately not too late for the printers deadline.

Miss Joanne Crook aged 11 yrs was the final winner with her card designed especially for the MPS Society.

We have been assured by the printers that the cards will be ready by September in time for us all to have the pleasure of sending the Seasons Greetings, bringing awareness of MPS Diseases and raising funds.

Can't be bad.

Mary and Colin Gardiner.



Miss Joanne Crook
aged 11 yrs.

'OPEN HOUSE' FOR NORTHERN FAMILIES

Early in June Mary Gardiner asked me what I thought about giving an open house for a small group of MPS families. I thought it was one of the best ideas I'd heard and told Mary I would gladly give my help. June 24th was the day we chose. Mary and I invited about 10 families from the North between us and after all the nice weather we had been having, prayed for another nice Sunday.

At last the day arrived a bit cool and dull but promising. Derek and I arrived at Mary's but there wasn't much for us to do as Mary and Colin had really excelled themselves on the Buffet. As I surveyed the feast which they had prepared, I wondered how long it would take for the four of us to eat it, terrified that no-one would turn up. Colin and Derek decided to erect a sign in the front garden (MPS Family Party Here) as I had sent out the directions and got lost myself on the way. No sooner had the sign gone up than our guests started arriving. As I said we had hoped for good weather but as I looked around Mary's house at all the families, I thought who needs nice weather, there was more sun and fun in the house. Laughter rang through all day; the children were lovely and played between themselves as though they belonged to each other. Parents related incidents to each other, advice was given and asked for; feelings were shown and shared, as were joys and sorrows. Everyone was so relaxed and although some of us had never met, we talked as though we had known each other for year's. All in all the Sunday 'Open House' at Mary and Colins proved better medicine than anything the Doctor could prescribe and If I had to relate the fun we had, I would probably fill the newsletter.

On behalf of all of us who were fortunate enough to be at Mary and Colins we give them our sincere thanks for their warm hospitality. Derek and I are looking forward to helping them again in the future.

May I say that if any families from other areas can get together for an Open Day, go ahead and do it, you will find it one of the best therapy's going.

Pat and Derek Kirkman.

P.S. Quote of the day came from Sanfilippo sufferer Claire Hill. After a short coughing bout, she looked around the room and announced "IT'S A BUGGER", this being a northern 'phrase for what a marvellous time we are having'.



“TWO PEAS IN A POD”

Recently I was an IN patient at Moorfields Eye Hospital, High Holborn. I have been writing to Carol for seven months, it had been wonderful to have a contact with someone who actually had the same disease as myself, we were able to exchange notes and get some ideas how the other felt.

When Carol heard I would be in hospital she wrote and said she and her husband Paul would come and visit me, I was so excited.

The day came. I had had to go downstairs for checks so was not in my room when they arrived. On reaching my single room I heard my Mother say “Here she is”. I put my head round the door and could not believe my eyes, my first reaction was “Good Heavens, that’s me sitting there, yet I am here”. It really was amazing. My Mother and Paul were also highly surprised at the likeness. I was aware several times that Paul was looking at me as much as to say how incredible it was. We had a grand time comparing ourselves. Carol was a little shorter than me, her hands a little bigger. A lovely girl and so full of fun. We got Paul to take instant photo’s (both something we loathe and try to avoid) Carol on the left and me on the right.

News had spread, we kept getting a nurses head pop round the door to have a ‘peep’ also my doctor came in, he had thought it was my sister. It was a good job that there were not many patients in as we created quite a bit of noise with our laughter. I told Carol she could take my place, I would go home with Paul. She would not hear of any such thing as absolutely hated anyone near her eyes. She really was a hoot. We could not believe that they had stayed nearly four hours. It will be a time I shall never forget.

Pam Tubb



A LETTER FROM THE CHILDREN OF CHRISTCHURCH, FAIRWATER

In Sunday School we have been thinking of others and ways to help people. We heard about your Society and that you were hoping to buy a caravan, so we thought we would like to help. So through Lent we gave up some of our sweet money and made a line of copper money to go round our church. Each Sunday through Lent we added pennies to the line, then all the older people helped us as well. By the end of Lent we had made a line right the way around and then half way again. We enjoyed doing this and we hoped that this will help you to buy the caravan.

Love from
Pearl, Charlotte and James, Catherine and Bethan, Sian and Gareth, June, Roger and Zoe, Trevor, Martin and Chris and all friends at Christchurch, Fairwater.

SUNSHINE BAGS

How about this for a Fund-raising activity:

Set a small working party (could be children) to make colourful cotton drawstring bags, about 6“ square.

These are borrowed or bought by well-wishers to hang up at home in a spot where they can’t be ignored. Every day that the sun shines in goes a 2p piece. Bags are emptied every 3 months.



It would help to have a calendar nearby to mark off 12 weeks.



MPS Charity Stall at the Tetbury Woolsack Races and
Mediaeval Market on May Bank Holiday



NEW FAMILIES

Dr. & Mrs. Bansal from Essex. Their son Rohit is 3yrs old and suffering from Hunter disease.

Mr. & Mrs. Barnet from Essex. Their son Dean is 9yrs old and suffers from Morquio disease.

Mrs. Bennett from Berkshire. Her daughter Julie died 3yrs ago from Hurler disease aged 9yrs. Mrs. Bennett contacted MPS after seeing an article in the Bucks examiner and would be happy to help other Hurler families.

Colin and Cathy Hall whose only son Matthew aged 4yrs is suffering from Hunter disease. They live in Sussex.

Mr. & Mrs. Issacs from Somerset. Their son Christopher aged 3yrs has recently been diagnosed as suffering from MPS.

Mr. & Mrs. Leask from Shropshire. Their son Christopher aged 11yrs has recently been diagnosed as suffering from Sanfilippo disease.

Mrs. Nicholson from Sussex. Her son Richard is 10yrs old and suffering from Hunter disease.

Mr. & Mrs. Pidden from Wiltshire. Their daughter Natalie is 3yrs old and suffering from Sanfilippo disease.

Mr. & Mrs. Snack, whose only son Colin aged 2yrs and suffering from Hunter disease. They live in Northamptonshire.

Mrs. Spencer of Oxford. Her son Jamie is aged 10yrs and suffering from Sanfilippo disease.

Mr. & Mrs. Todd from Co. Antrim. Their son William aged 4yrs has recently been diagnosed as suffering from Hurler/Scheie disease.

Mrs. Ann Canter from Dyfed, Wales. Ann is 38yrs and seven years ago was diagnosed as suffering from Scheie disease. Ann is most willing to help any Scheie family who wish to contact her at:

12 Picton Place
Pembroke Dock
Dyfed, SA72 6BS.

DONATIONS

The following companies and individuals who have kindly made donations to The Society. This money will be used for research and The Holiday Home Fund.

The Children of Christchurch Sunday School.
Mr. C.S. Peck who ran in the Sudbury Fun Run.
S.H. Ward & Co. Ltd., who sent a donation in lieu of flowers for the funeral of Mr. Brittain who was the grandfather of an MPS child.
Friends and relatives of Anne & Mick Palmer who sent donations in lieu of flowers for Anne's father who sadly died in June.

Peter Archard
The Staff and customers of Strawberry Gardens Hotel in Heysham
Mrs. Rita Slater had a Sponsored Slim
Mrs. Beedes organised a disco
The Scouts, Brownies and Guides had a collection in Monmouth.
Sarah Smith and Michelle Woodhouse of Thornbridge School, in Sheffield had a Book Sale.
Boots Charitable Trust
E. Darby
West Lanes District Council Chairmans Lady's Charity
Mrs. S.P. Paten and friends who had Jumble Sales
The Committee of the Whinmoor Community Centre
Marlene Sanderson had a Stall at Tetbury Festival
Massey Ferguson Employees appeals fund
Market Harborough Methodist Wives Group
Mr. & Mrs. Prestwick
Mrs. J. Nichols who held a Tupperware Party
R.J. & P. Hayward who held a Raffle
E. Davies
T.G. & M. Sheenan
Plessey Semiconductors Ltd
M.A. Green
Mrs. M.E. Davidson
Mrs. L. Dawson
Lorraine Stenson
D.J. Cumming
Mrs. Carr via Shirley Twigger
Mrs. Hathaway of Nuneaton
Professor Orii, Gifu University, Japan

We gratefully receive all the above donations and send our thanks to all the families who instigated them.

We also thank the following for their donations to our second family conference.

BBC - Children in Need Appeal
Lewis Wooly Grintight Ltd
Mary Gardiner - Richard Gardiner BMT Fund
British Alcan CT.
Marlene Sanderson
J & S.L. Hartley

The conference is quickly coming upon us and funds are still required. If you wish donations to be used for the conference, please can you state this specifically in your letters.

Happy fund-raising.

Sue Butler
Donations Secretary.

DOES YOUR CAT EAT 'WHISKAS' ?

Or your neighbours cat for that matter. If they don't, try it! Collect the special appeal labels from tins of Whiskas. Each one is worth 4p towards any National Charity including MPS. If you choose to donate your labels to MPS, please send them to 30, Westwood Drive, Little Chalfont, Bucks., and we will make sure that they reach the Whiskas Appeal. The Appeal closes on 30th November 1984.

BEREAVEMENTS

It is with great sadness that we learned of the death of the following children:

Michael John Westlake on the 22nd July 1984 at the Frimley Park Hospital, Aldershot, Hants. Michael had been suffering from Hurler disease.

Theresa Bennett on 3rd July 1984, aged 21 yrs, peacefully in Tadworth Hospital. Theresa had been suffering from Sanfilippo disease.

David Keene of Cumbernauld, Scotland, aged 11 yrs. David had been suffering from Hunter disease.

Alan Donaghy of County Down, Northern Ireland on 21st March 1984 in hospital aged 5½yrs. Alan had been suffering from Hurler disease.

Our deepest sympathies go out to the parents and relations of all these children.



The Society for
Mucopolysaccharide Diseases

Second Parent Conference

SATURDAY 29th SEPTEMBER, 1984

*The Crown Hotel, Crown Place,
Harrogate, North Yorkshire, HG1 2RZ*

9.45 - 10.00 a.m. WELCOME

10.00 - 10.30 a.m. K. HUGH-JONES

'What's wrong with my child? What can you do doctor?'

10.30 - 11.00 a.m. Coffee and Introduction to Parent Workshop Groups

11.00 - 11.30 a.m. P. NORMAN

'Children with a progressive illness - Some observations on helping siblings'

11.30 - 12.30 p.m. PARENT WORKSHOP

LUNCH

2.15 - 2.45 p.m. J. KINGSWOOD

'The changing educational needs, charity or confusion?'

2.45 - 3.30 p.m. PARENT WORKSHOP

3.30 - 4.00 p.m. M. BAX

'Future research into MPS diseases. Where do we start?'

TEA

SUNDAY 30th SEPTEMBER, 1984

10.00 a.m. The Society's Future Activities

10.20 a.m. Home Improvements and Medical Aids

10.40 a.m. Help available through the DHSS

11.15 - 12.15 Parent Workshop

LUNCH

(The Workshops are exclusively Parent Groups: there will be alternative arrangements for professional delegates).

To The Society for Mucopolysaccharide Diseases.

Mrs. C. Lavery, Secretary, 30, Westwood Drive, Little Chalfont, Buckinghamshire.

Please send me ticket(s) for the Second Parent Conference on Saturday,
29th September 1984 at £15.00 each to include coffee, lunch and afternoon tea.

Please send me ticket(s) for the Sociological aspects of the Conference
on Sunday, 30th September 1984 at £7.50 each to include Sunday lunch.

Overnight accommodation for either Friday or Saturday 28th/29th September can be arranged directly with the Hotel.

I enclose my cheque made payable to:-

"The Society for Mucopolysaccharide Diseases Conference" for £.....

Name Address