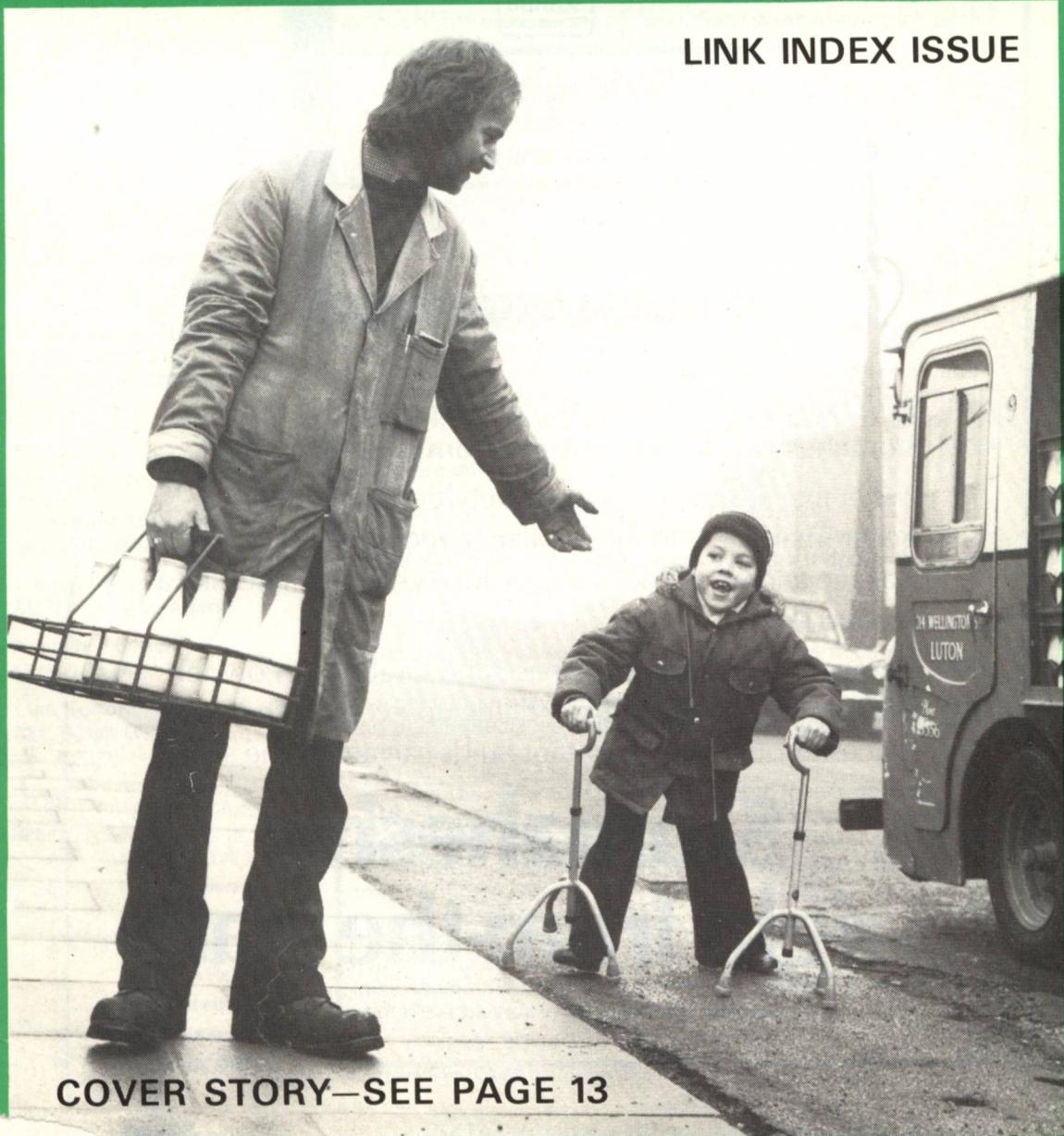


Link

JAN/FEB 1976 5p

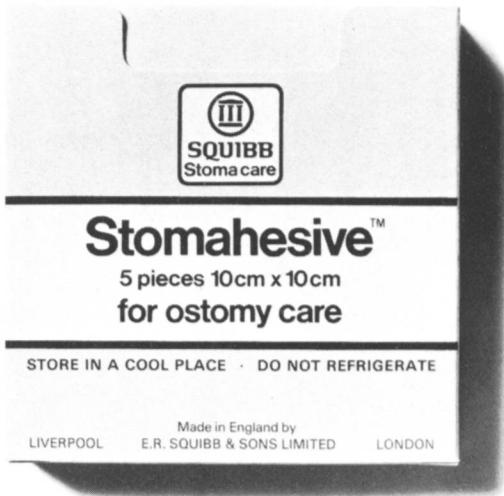
Association for Spina Bifida and Hydrocephalus (ASBAH)

LINK INDEX ISSUE



COVER STORY—SEE PAGE 13

the go-between



Sore skin around the stoma can be prevented by using Stomahesive, the Go-Between, from the beginning.

Protective Stomahesive goes between the tender peristomal skin and the appliance reducing risk of leakage and frequency of appliance changes. It fits like a second skin.

Companion products Orabase and Orahesive Powder help to increase security by filling up even those minute spaces through which irritant fluids can attack the skin.

Stomahesive -right from the start.

Stomahesive - boxes of 5 10cm x 10cm squares

Orabase - 30g and 100g tubes Orahesive - 15g puffer pack

Stomahesive, Orabase, Orahesive and Plastibase are Squibb registered trademarks.

Full information available on request:

E.R. Squibb and Sons Limited, Regal House, Twickenham TW1 3QT.





Link No. 42

Association for Spina Bifida & Hydrocephalus (ASBAH)

Patron:
HRH The
Duchess of Gloucester

Chairman:
Mr. R. B. Zachary, FRCS
Hon. Treasurer:
Mr. E. S. Gower, FICS, FHA

Correspondence to ASBAH
at the National Office:

**30 Devonshire Street,
London W1N 2EB**
Tel: 01-486 6100 or
01-935 9060

General Secretary:
Miss M. E. Oughtred

Appeals Secretary:
Mrs. Kate White

Liaison Officer:
Mr. H. D. Macfarlane

Appliance Officer:
Miss F. A. Birkett

Link Editor:
Mrs. Susan Gearing

Contents

page

4/5	News from all around
6	Pressure Sores
7	Religious studies
8/9/10	LINK Index
11	Research Report
12	Aids and equipment
13	Johnny's special lesson
14	Midwinter Ball

Editorial

This is the start of no ordinary year as far as ASBAH members are concerned. 1976 is the 10th Anniversary of the National Association and the first decade is certainly a milestone in the life of any organisation. It is a time for reflecting on the past and a time for planning ahead.

ASBAH members are entitled to feel some sense of achievement in helping to bring spina bifida and hydrocephalus in 'out of the cold' and in making these disabilities much better known to the general public.

Welfare services for families have vastly improved, although much still remains to be done.

The Association has placed much emphasis on the importance of research, and in the past ten years 14 research programmes have been sponsored including the one which has led the field in antenatal diagnosis. As well as this ASBAH has provided research apparatus at a cost of £22,000.

As the ASBAH 'network' grows with the setting up and expansion of local associations, it becomes more and more important to have special occasions where members from all over the country can meet together and exchange views and ideas. The annual ASBAH conferences started in 1972 have given this opportunity, and this year the fifth conference — to be held in Abingdon in May — should hopefully see an even larger and more representative attendance.

There is another 'get-together' in the Spring — a 10th Anniversary Celebration at Stoke Mandeville Stadium. It is hoped that every local association will mark it down as 'a must' and make sure they are well represented.

This year will see the culmination of several years of planning when the National Association's first short-term care home opens in Yorkshire. Liverpool Association's ambitious venture also gets under way and will provide playgroup, hydrotherapy and training facilities together with a small unit for short-stay care.

One of the main concerns of 1976 both locally and nationally will be to get to grips with the problems of older members. There is a real need to harness resources so that assistance is available when needed in the important fields of housing, mobility, employment, leisure, and for married couples.

ASBAH will strive to help all those with spina bifida and hydrocephalus and their families. It may not always be able to 'give satisfaction', but it has achieved a lot in the past ten years and will achieve a lot more in the next ten.



News from all around

Jayne meets the Queen Mother

Jayne Etherington, 7, will long remember 1975 as the year she met and chatted with Her Majesty the Queen Mother.

Jayne—a member of Don and Dearne Local Association—is photographed (right) shaking hands with the Queen Mother when she visited the Roman Barracks, Colchester to present new Colours to the 1st Battalion of the Black Watch. (Jayne's father is a sergeant in the army and was at the Regimental Day with his family.)

Just before the Queen Mother left she made a point of going over to talk to Jayne.



Youth clubs raise £384

Members of the Methodist Association of Youth Clubs from Chorley, Lancs. and Bristol got together and raised the unexpectedly high sum of £384 from a procession and collection in Chorley.

'We would have been satisfied with about £50' said one of the delighted youth leaders.

The money was given to Wigan and Chorley Association to buy toys and equipment.

The collection was part of the Methodist Association of Youth Clubs Weekend held in Preston.

'FIGHT THE CUTS'—SAY CARDIFF

On Saturday October 25, 1975, 70 members of the Cardiff Branch of the South Wales Association, marched through the centre of Cardiff with social workers, trade unionists and relatives of people in need, in a demonstration against the proposed cuts in public spending, particularly those in the social services sector.

The demonstration was the first of a nationally organised series by the British Association of Social Workers.

4

We decided to support the demonstration because, as a group of concerned parents of handicapped children, we have already seen some of the services seriously eroded in Cardiff area. We believe that the Government's proposed cuts would have a disastrous effect on those in need.

Cuts would certainly result in the lowering of the quality of life of the handicapped and underprivileged, since charities such as ours would be unable

to raise the necessary money to support *all* the needs of our own members.

As a branch we urge all members and supporters of ASBAH to resist the cuts as best they can, both for the sake of their families and for all sorts of people who are unable to make their voices heard.

(From Mrs E. James, parent of a spina bifida child and member of SWASBAH.)



News from all around

Sarah has her very own Trike

Three-year-old Sarah Healey out for a ride on her Raleigh Mini Trike. It has been adapted very simply so that Sarah, who is spina bifida and paralysed from the waist down, can 'operate' the pedals and exercise her legs.

Sarah's father did some simple adaptations on the trike himself to begin with. He made a long wooden handle so the trike could be pushed, and Sarah's grandmother made some leatherette bootees which could be attached to the pedals with straps. Granny also decided to write and see if the manufacturer, Raleigh, could

come up with any other suggestions.

She writes: 'Within a couple of weeks they sent me a long metal handle and, for her feet, sort of skates that could be screwed on to the pedals. How very kind of them to bother!'

● Felicity Birkett, ASBAH's Appliance Officer comments: 'Raleigh is very willing to give this type of individual service, rather than supplying special adaptations in large quantities.

Another similar idea which I know one or two parents of older children have tried successfully is to attach the



foot part of roller skates to the pedals and then strap in the children's shoes.'

ASBAH's Spring Conference 9-11 April "Thirteen to Thirty"

The problems and future outlook for younger spina bifidas is the subject of ASBAH's fifth Spring Conference, entitled 'Thirteen to Thirty', and this should stimulate great interest and encourage a wide variety of people to attend.

It is to be held in beautiful Oxfordshire at Culham College on the weekend of 9-11 April, and will be chaired by Dr Esther Simpson from the Department of Health and Social Security. ASBAH is fortunate that Lady Jean Mackenzie, again has agreed to be Conference Hostess.

There will be scope for considering the contribution which can be made both by schools and parents in the 'Preparation for Life', the decisions that have to be faced in the 'Follow-on from School', as well as the problems and benefits that arise from 'Working and Living' and 'Relationships.' The panel of people with practical experience of these various areas will lead the thinking and chair the discussion groups that follow.

It will be an encouragement to have Mr Neil Marten, MP at the Conference to give the opening address on Friday evening. Mr Marten's concern for the disabled is well known.

The Conference is open to everyone over 16—young people, parents and those professionally concerned. In addition there will be provision for accompanied children under 16 enabling the whole family to be there.

The Conference fee with accommodation is £12 including VAT. Programmes and further details on request from National Office.

Scamps for Christmas

Two of the new Scamps—the hand-propelled vehicles which have just come on the market and which were reported on in the last Link—have been given to Bedford and District Association. They were a Christmas gift from The Mark Southern Trust and were presented to the Association at its Christmas Social Evening.



Take good care of yourself

Why accept sore skin as part of your life — Why not develop ways of preventing this happening?

I rarely see pressure sores these days among those in the younger age group and I like to think this is because of the preventive advice and care taught to mothers and then faithfully carried out.

I would, however, like to see this continued by older children, so that an independence can be achieved by adolescents. There comes a time when they need to become less dependent on their parents, in order to live a fuller life and one way in which they can do this is to take more responsibility for their own care.

There is no magic formula for avoiding pressure sores. The secret is constant awareness and this involves disciplined thought and action by all. A red mark is warning enough and the question must be asked, 'How did this happen?' Do not accept a red mark without asking this question. Inspection twice daily is one of the secrets and should be carried out morning and evening, with mirrors if necessary.

Do's and Don'ts

Bone Prominences should be protected carefully, particularly if there is little skin on the surface. A large piece of foam or sheepskin put over vest and pants and anchored firmly will stop the area from getting knocked. A broken skin area should be treated seriously, covered with a clean dressing and a firm pad placed round the area to remove any pressure. Advice should be sought.

Calipers. It is most important to check calipers regularly. Do not accept missing screws, or tight or ill-fitting straps. Remember that sheepskin can be put under a strap sometimes to relieve pressure. Warm

by

**Sister Gwen Meers, Leon Gillis
Unit, Queen Mary's Hospital,
Roehampton.**

stockings or knee socks are essential under calipers. Should rubbing take place, the calipers should not be worn the next day and advice should be sought.

Knees. Scratches and chafing, particularly where any crawling or kneeling is involved, can be avoided by protective clothing: trousers, cat suits, etc.

Feet and Legs. Feet should always be protected by socks, shoes or boots which fit well so that rubbing is avoided. Loose, warm socks are preferable. Remember that circulation may be poor. A thin pair of socks with a thicker outer pair is best. Stretch socks are not a very good idea. As an alternative, warm tights may be worn with socks over. Avoid nylon pants, 100% nylon tights and tight clothing, especially elastic round the waist and legs. Sheepskin boots may be made quite easily. They can be worn at night. A hot-water-bottle should never be used. Never sit in a wheelchair with feet unprotected.

A hot, swollen leg may indicate a broken bone, though there may be no sense of pain. Advice should be sought as early as possible. Toe nails need examining regularly and cutting carefully.

Hands may need protection as they are called upon to do a lot of work with sticks and wheelchair. Leather gloves afford this protection.

Bed. A firm mattress on a firm base is essential. Board underneath the mattress may be useful to give mattress control. Loose bed clothes are best. The continental quilt is ideal. It is important to ensure that it is fire-proofed, though as an added protection, smoking in bed should be eschewed. It may be necessary to sleep on



the tummy if there is any indication of a red area over the spine.

Wheelchairs should have a firm cushion, e.g., polystyrene. A sheepskin to sit on is often a great help. It is important constantly to change position, lifting the buttocks up by a firm arm-push down. It is important to acquire the ability to transfer from a wheelchair to a reclining chair or bed or a floor cushion in order to be independent. To get the best from your wheelchair, keep it in good repair, look after it as you would a car.

Trikes. It is important that there should be careful assessment before a trike is obtained. This will include efforts to ensure that pressure sores do not arise from having one.

Horse-riding is good for some people, but

it is of great importance to protect skin areas, as friction burns can occur.

Swimming. Again, friction burns can occur if the skin is continually rubbed against a hard surface – the sides or bottom of the bath.

It goes without saying that as any ill-fitting pads or appliances cause chafing, appropriate management of bowels, bladder and menstruation are crucial to the avoidance of sores.

If, in spite of taking all this care, sore places develop and show any reluctance to heal, you should immediately seek medical advice. You should bear in mind that paralysed parts of the body often do not heal so well as normal flesh through impaired blood supply.

A chance to further religious studies

St. Aidan's College, Shropshire, is an ecumenical, interdenominational centre for religious studies. Its principal, The Rev R. Peters, is a man with personal experience of disability and a commitment to encourage others in the same situation.

St. Aidan's offers a choice of courses, leading to either the Certificate of Proficiency in Religious Knowledge of the University of London, or the College's own Certificate in Religious Studies, as well as a selection of summer 'vacation courses' which each last one week. The longer courses are designed to be undertaken either on a full-time residential basis or on a 'correspondence-residential' basis, where students complete most of their study at home with the aid of study-guides from the College, spending

approximately six weekends per year in the College.

Mr Peters says: 'Ever since this College began its work some 18 months ago I have felt that it could well be of service to handicapped people. The building, a former rectory, is set in the heart of the country (yet it is quite accessible and we could help by meeting people). We would be quite ready to waive the residential qualification for those who could not come into residence because of their handicap.'

My reason for suggesting that the College Certificate might be helpful for handicapped people is because it can be taken on a piece-meal basis over a period of years and as a 'letter of credit' is awarded when each subject has been satisfactorily completed, they would feel

that they had achieved something during their study'.

For further details of courses and fees (small bursaries are available in some cases), contact The Principal, St. Aidan's College, Willey, Broseley, Salop.
(From C.C.D. Bulletin No. 32)

More and more Local Associations are producing Year Books, giving details of the year's work and full range of their activities. They also carry useful and stimulating articles.

These are an excellent record of the Association's work, and other groups may like to follow suit. Local publicity firms will often print and publish the books free of charge in exchange for the advertising revenue.

LINK OVER THE YE

Link was first published in the Spring of 1966, and since then it has offered a steady supply of interesting and informative articles.

Below is an Index of some of the major articles which the Editor considers to be of lasting value and which will be

useful for reference purposes.

Some back numbers are available from National Office. However, some issues are out of print or in very short supply and therefore when requesting a back number please indicate the specific article in which you are interested. In this way

we may be able to make a photostat copy of the article in question.

It would be much appreciated if you would make a small contribution towards the cost of this service when requesting a back issue.

SPINA BIFIDA

	Issue No.
* What is Spina Bifida?.....	1
* Can it happen a second time?.....	3
Searching for clues.....	10
London Spina Bifida Survey.....	24

HYDROCEPHALUS

* What is Hydrocephalus?.....	2
* Can it happen a second time?.....	3
The John Holter Story.....	3
Some complications of Hydrocephalus.....	13
Medical treatment of Hydrocephalus.....	17

MEDICAL

* Outlook... 'Continuing wet'. (bladder operations).....	4
* Now — will he walk?.....	5
* Taking their first steps.....	6
Orthopaedic problems.....	11
The case for combined clinics.....	18
What are the chances for the second generation? (parenthood for those with spina bifida).....	20
Encephalocele.....	21
Management of the bowels.....	22
Potatoes and spina bifida. 'The Potato Trial' and the result....	25 & 30
Food for thought (dieting).....	27
Towards normality (physiotherapy).....	28
Skin sores.....	29
An early warning (ante-natal diagnosis)	30
When and how to lift spina bifida children.....	31
Eye problems (hydrocephalics).....	32
Blood tests give hope for antenatal diagnosis.....	33
Freedom of movement (swimming therapy).....	33
Bowels.....	37
Calipers.....	39

* The information in these articles is now more comprehensively covered in 'Your Child with Spina Bifida' and 'Your Child with Hydrocephalus.' Both are ASBAH publications obtainable from National Office.

YEARS : AN INDEX

LEISURE AND RECREATION

	Issue No.
Leisure.....	17
Happy holidays.....	26
Phab—Living and learning together. (Phab courses).....	26
Sport for the disabled.....	31
Let's make music.....	31
Freedom of Movement (swimming).....	33
Handicapped share in international voluntary service (work camps abroad).....	35
Be crafty (crafts).....	35
Homing truths (pigeon fancying).....	35
It is super to forget one is disabled (work camps in Britain).....	36
Something borrowed, something new! (toy libraries).....	37
Puppets.....	37
Hobbies and Leisure (Manchester Conference).....	38
Motoring.....	40
Dance and movement.....	40
Gardening (demonstration gardens).....	40
Living and learning together (Prospect Hall).....	41

EDUCATION

Giving the girls a break (Florence Treloar School).....	4
What kind of school?.....	6
We must be objective.....	9
Adding to mobility (walking and mathematics at school).....	9
The constant challenge (integration of handicapped at school and generally).....	14
He's a different boy (the value of boarding school).....	31
Sally and Co. are leaving (views of five teenagers leaving school).....	40

FURTHER EDUCATION AND EMPLOYMENT

The next step? (employment prospects).....	20
The National Star Centre.....	20 & 31
Planning for the future (Banstead Place assessment centre).....	30 & 40
Preparing for work (St. Loye's College).....	35
What comes after school?.....	40
Living and Learning Together (Prospect Hall)	41

MISCELLANEOUS

Playing ball (hand and eye co-ordination).....	8
And then we were five (adoption—personal story).....	5 & 6
New social work plan (in Leeds and York).....	19
Taking some of the fear and upset out of a stay in hospital.....	34
Research (Research Society Annual Meetings, 1970 and 1974).....	16 & 36
A Mum's eye view (personal account of family life with a spina bifida child)	36, 37, 38
How Diana came out of her shell to live a full life (personal story by an adult spina bifida).....	39

LINK OVER THE YEARS : AN INDEX

Help and how to get it (provisions and services for the handicapped.....	39
Sweet and simple (deodorants).....	41

CONFERENCES

The Spina Bifida Teenager (Keele).....	23
The Severely Disabled Spina Bifida and Hydrocephalic (Reading).....	27
House and Home (York).....	32 & 33
Hobbies and Leisure (Manchester).....	38

AIDS AND EQUIPMENT

Special Safety Baby Walker.....	17	List of books on clothing.....	37
Movable Ramp.....	18	Baby Op Bootee.....	38
Parallel Bars (Toy & Furniture Workshop).....	19	Standing Boxes.....	38
Shoe Guard Plastic.....	19	Swan-necked Mirror.....	38
DIY Bath Seat.....	19	German Car Seat.....	39
Banstead Ramp.....	20	Parallel Bars.....	39
Thistle Tricycle.....	21	Bath Aids (including Bath Board & Seat & Sunflower Bathing Aid).....	40
Hobcart.....	21	DIY Desk.....	40
Linvar Carry Chair.....	21	Scamp – hand propelled Go Kart.....	41
Triolite Push Chair.....	24		
Polly Chair (Sag Bag).....	24		
Magnetic Aids (for crutches etc.).....	25		
DIY Head-rest on Baby Walker.....	26		
Rentoul Bath Aid.....	26		
Shasbah Standing Table.....	27		
Toy Storage Cart (useful walking aid).....	27		
Rubber corners.....	27		
Naidex 1973.....	28		
Mecanaids Bath Hoist.....	28		
Insert for Major Buggy.....	28		
Kanga Pants.....	30		
Safety Bath Mats.....	30		
Cot Bumpers.....	30		
Stair Climbers.....	31		
Bin Chair.....	33		
Mr Hayes' Special Chair.....	33		
Transit Carry Seat.....	33		
DIY Foam Chairs.....	33		
Piedro Bootee.....	34		
Shoo Shoes.....	34		
Dycem Plastics.....	34		
Naidex 1974	36		
Hurstwood Tricycle & Go Kart.....	36		
Mr Hayes' Jay Bike.....	36		
Mecanaids Toilet Aid.....	36		
Swedish Go Kart.....	36		
Fun Bug (Leicester Assoc.).....	37		
Outdoor protective clothing (for use with wheelchairs & pushchairs)	37		



**THE SHASBAH TROLLEY
FOR HANDICAPPED CHILDREN**

Patent applied for in
UK, Commonwealth Countries, USA, Canada
Standard model for children one to five years old
costs £11.00 plus carriage.

Large model for children five to ten years old costs
£14.50 plus carriage. Overseas prices on application.
Produced by Southampton and District Spina Bifida and

Hydrocephalus Association

All enquiries to: Mrs. K. Charrett, 46 Tillbrook Road,
Regents Park, Southampton.

Telephone enquiries: Totton 3365 (Mr. Mortimer)

RESEARCH REPORT

How your money is put to work

Readers of LINK will recall that two years ago the Association raised over £14,000 for the purchase of a special piece of apparatus which is being used at the Congenital Anomalies Research Unit in Sheffield.

My brother

by Andrew Bamish, 11 ½ years,
from Western, Notts.

My brother was born in December, 1968 and we were told he had spina bifida. Mum told us he had a hole in his back and would be in hospital for a long time and would look a bit funny when he came home.

After he was born they took him to Sheffield and operated on his back. He was only eight hours old. Then about two weeks later they told mum and dad that he had hydrocephalus and that they would have to operate on his head as it was growing large.

He came home when he was three months old—the day before my birthday. It was a lovely surprise for us all when mum showed us Gary. He looked just a bit funny as his head was a little large. His right foot was twisted and mum said his hips were not right. But we loved him and I think he liked us.

When he was just over a year, he went to have his foot straightened, but when they did it, it went funny so he had to stay in a long time again. After that one he had his hips done. He could not sit up for eight weeks, and it had to be done twice.

After that he had to have his legs turned as they were nearly turned round. While he was in plaster again the valve in his head went wrong and we thought he was going to die but they took him to hospital and put a new one in and he was all right.

These are only a few of the things which have happened to him.

Now they have put him in calipers so he can stand up, but he may never walk. He has a wheelchair and a trolley so he can go outside, and he can pull himself all over the floor.

He goes to school now and likes it. He plays with us and our friends. He likes meeting people. He's only small but he fights us and makes us cry. We treat him like any normal boy. He likes to have a go at anything we do, and he never seems to mind being disabled. We don't let it bother him or us. Where he goes, we go. We tell people about him so they may learn that some people are not all in one piece, but it makes no difference.

A recent report on the work says 'Novel work is being carried out into the quantitative assessment of certain aspects of altered organ growth due to spina bifida and related conditions with the help of a virtually unique machine, the Quantimet 720.'

This machine is an all-British advanced electronic image analysis computer incorporating a television camera, used in conjunction with a microscope, with results passed to a teletype machine for data print-out. This machine presents new and accurate methods for investigating cells and tissues which, hitherto, have largely not been possible.

The chief study completed so far has been concerned with the number of nerve cells in parts of the cerebellum (the part of the brain near the neck and which is much concerned with balance). The findings in normal children have been compared with the findings in the cerebellums from over 100 children with hydrocephalus and spina bifida. The results indicate that parts of the cerebellum in children with spina bifida are grossly deficient in cells, whereas other parts are relatively normal.

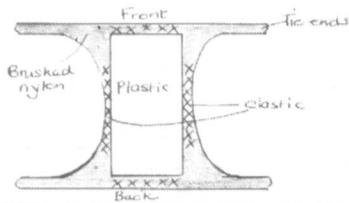
The machine is also being used in a study of the development of muscles of the legs, and of the muscle of the urinary bladder in normal children and those with spina bifida."



Aids and equipment

Felicity Birkett

Plastic pants for older children



CAR SEAT HARNESS

Rosvic Protective Harness Co., 11 The Crescent, Cleveleys, Lancs. has designed and now make a special car seat harness for the older spina bifida child. These can be made to measure, and alterations to the design can be carried out. Attached to the shoulder straps is a bibfront which holds the child firmly against the seat. The cost is about £6.

Miss B. Webster at Hart's Leap Cheshire Home makes plastic pants, which are especially suitable for older children. Miss Webster has several children with spina bifida under her care and has worked out this design from practical experience.

These are similar to the Sof'down Tie Pants, which many parents will have used, but come in larger sizes. Also the outside of the plastic is covered with brushed nylon in plain colours making them more attractive to the older child.

Put the napkin onto the pants, and place under the child's bottom. Fold up the front flap and draw the back ties across the front and tie. Turn the child onto his tummy and tie the front ties at the back. Be sure the whole of the napkin is covered and do not tuck the ends of the ties inside the pants because they will get wet.

The Pants are available in 4 sizes (size 3 measure 18½" approx. from back to front and 10½" approx. from side to side) costing 75p each from Miss B. Webster, Hart's Leap Cheshire Home, Sandhurst, Camberley, Surrey.

Boots the Chemist make several different designs in large sized plastic pants. They are rarely on their display counters but are kept in their medical section.

'Biffabout' – the special boot

Mr Ken Hall, the Managing Director of Ken Hall (Made to Measure) Ltd., of Kettering, has designed Biffabout Boots, primarily for people with spina bifida. He has spent a lot of time visiting hospitals, measuring and taking casts of feet and trying out various types of boot.

This final design is suitable for those with plump, podgy feet. They are wide and deep and open to the toe; the laces need not be removed from the lower three eyelets as the wide opening will give easy access to the toes. The top three fastenings are the ski-boot type hooks which children find



much easier to manage.

The uppers are of suede lined with a woollen material backed with sponge. The back of the boot is lower to prevent it from cutting into the heel but at the same time helping to grip the ankle firmly to prevent the foot

slipping out. The soles and heels are of microcellular rubber, the heels being slightly flared out and suitable for caliper sockets.

If the consultant who sees your child thinks that Biffabout Boots would be suitable then they can be ordered from your usual appliance contractor under the National Health.

Please Note: F. E. Abbott who stock the Shoo Shoo boots have moved. Their new address is F. E. Abbott & Co., 33 Forest View, Chingford, Essex, E4 7AU. The cost of Shoo Shoo boots is now £3.75 a pair.

BOOK REVIEW By Bernie Spain

The Family Life of Sick Children

This book by Lindy Burton describes her study of families with children suffering from cystic fibrosis.

Although well documented and scientific it is a most readable book, conveying very clearly the feelings and problems experienced by these families, which are similar in many respects to those with spina bifida children.

Parents' own words are used frequently and in that sense it is a book written largely *by* parents.

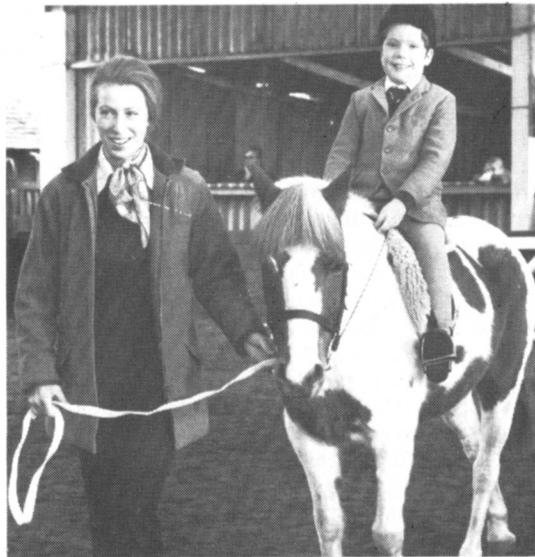
It will prove useful to social workers and others working professionally with handicapped children since it will enable them to understand the children and their families better. Parents might also find it helpful in understanding their own reactions.

The book sets out to explore how a disabled child and his family successfully cope with illness and its effects on the basis that there is 'Little value in offering a good quality physical life if we cannot also offer viable psychological survival.'

The author sets out to discover the factors which will enable both the young patient and his parents to make the most of their lives. She also discusses issues such as the necessity for good genetic counselling and family planning advice; the need for parents to give simple explanations of the conditions to the child and his brothers and sisters; the importance of communication between the parents and the sharing of tasks.

She deals, too, with the problems parents have in disciplining a handicapped child and the dangers of excessive vigilance which limits the child's independence.

'The Family Life of Sick Children,' Routledge & Kegan Paul 1975, price £2.50.



A riding lesson to remember for eight year-old spina bifida boy, Johnny Clarke of Fairseat, Kent who is being led by H.R.H. Princess Anne.

The Princess who is Patron of the Riding for the Disabled Association, joined the team of BBC Television's 'Blue Peter' at one of the Association's centres at Sevenoaks, Kent. The occasion was the launching of Blue Peter's Christmas Appeal in aid of Riding for the Disabled.

At the centre the Princess met Johnny and other handicapped young riders at an indoor class and afterwards went riding with them in beautiful Knowle Park.

As the Princess explained "The ultimate aim is to give these youngsters sufficient independence, so they can go out and about and see things that perhaps they'd never be able to see if they didn't ride."

COVER STORY

It took courage, perseverance, the support of family and friends to get eight-year-old Paul Evans walking....and a little something extra—the special encouragement of his good friend, Bob the milkman.

Bob started by challenging Paul to a race as he did his milk rounds in Luton, Beds. Bob was on his milk float and Paul on his specially adapted trike. Paul won! And from then on he went with Bob on his rounds.

Bob decided to set up another challenge. Instead of stopping at his young friend's house one morning, he stopped further down the road and refused to go back for him. Eventually Paul decided he just had to get to Bob, and with the aid of his sticks that's just what he did!

Paul's parents are members of Herts and S. Beds. Association. His mother said 'I never gave up hope that one day he would walk. It's wonderful the help Bob has given.'

The photo shows Paul with milkman Bob.



Appeals and publicity

by Kate White

By the time this reaches you we shall have finished our sales of Christmas cards (hopefully at least as many as last year), eaten our turkey and plum pudding and had our annual jamboree with the homing pigeons at Doncaster (a possibility here of beating the Post Office, if we could organise a pigeon post!) and we will be about to start dancing at our Midwinter Ball on 21 January.

The Federation of Master Builders have been marvellous sponsors for this event, and the Duchess of Gloucester has not only graciously consented to attend herself but will be accompanied by the Duke. This is a great honour.

We have had a most generous response to our Christmas Appeal and the Short Term Care Home fund will be boosted by at least £10,000 as a result of the Aberystwyth University College of Wales Rag Week to be held early next February. A further £3,000 will come from the Imperial College London Rag week, of which £300 was raised by sponsoring the President to streak round the Albert Hall! He did it five times! The Geoff Boycott Sponsorship Scheme will yield about £2,000 and the Michael Barratt appeal income now stands at £3,327.

Unfortunately the Entertainment Artistes' Benevolent Fund, with whom we were organising jointly the Palladium Gala Performance to be held on 29 February, have been unable to book the international star to head the bill and so regrettably this event has had to be postponed. We will of course be on the lookout for another suitable occasion when we can join forces with the EABF.

Duke and Duchess to attend Ball

School children all over the country continue to work hard on our behalf and I am very happy to say that our research projects are also being well supported: The Readers' Digest Association has given ASBAH a second grant—the first time they have given an organisation a second grant—'in recognition of the valuable work you are doing' they said. The first was to help purchase the Quantimet which as you know is installed at Sheffield Children's Hospital (see page 11) and now they have given £3,000 to finance the Royal College of Art Design Department's research into the design of bathroom equipment which will make it possible for the severely handicapped to manage their own toilet.

Our Local Associations are supporting our research projects in various ways: only last month £188.60 was sent on from S. Hants as a result of a sponsored cycle ride by the team captain of the Velo Club St. Raphael who rode from Brighton to Portsmouth in one hour 59 minutes 57 seconds, a distance of approximately 50 miles—such spontaneous gestures are so much appreciated.

I recently spent a Saturday at a charity seminar organised by the Foresters High Court of Central England at which all their local Courts were represented. They were all very impressed with the pictures of Five Oaks and seemed keen to be associated with the venture.

Getting into the solicitor's good books

One useful source of income that can sometimes be attracted towards the work of ASBAH is by making sure solicitors have our name in front of them. Surprisingly enough

quite a number of people do not know what to do with their money. They consult their solicitor and if ASBAH happens to be on the list of charities in which he is interested, the chances are that he

would mention our name. I would be very willing to draft a suitable letter for you or your local ASBAH secretary to send to solicitors of your acquaintance if this would be helpful.

ASBAH booklets . . . leaflets . . . posters

<i>Your Child with Spina Bifida</i> , 3rd Ed., by J. Lorber, MD, FRCP	20p
<i>Your Child with Hydrocephalus</i> by J. Lorber, MD, FRCP	15p
<i>Equipment & Aids to Mobility</i> by O. R. Nettles, MCSP, ONC. A folder of four booklets. Complete set	25p
<i>Clothing for the Spina Bifida Child</i> by Barbara Webster, SRN, RSCN	15p
<i>The Nursery Years</i> , by S. Haskell, M.A., Ph.D., and M. E. Paull, Dip. Ph.H.	15p
<i>Children with Spina Bifida at School</i> . Ed. P. Henderson CB, MD, DPH	30p
Information leaflets	100 for £1.30

All available from: ASBAH, 30 Devonshire Street, London W1N 2EB. (Special rates available to Local Associations.)

Scottish Spina Bifida Association booklets

The Spina Bifida Baby . . . being revised.

Growing Up with Spina Bifida . . . 20p. both by O. R. Nettles, MCSP, ONC.

Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh, EH4 2BW (at special rates for bulk orders).

Fund raising and publicity material

Posters. Double Crown, 5p each, 'Best Foot Forward' — separate posters for General Appeal, and local publicity events, 10 for 40p. **Flag Day emblems.** 1,000 for 70p. **Cards** for notice boards. 10 for 10p. **Car stickers.** 5p each. Postage extra. **Fund-raising items.** Price list/details on request.

All available from National Office

Spina bifida badges. 22p each, postage extra. (for one badge enclose s.a.e.). Bulk orders particularly welcome. Available from: Mr K. McKenzie, Salisbury & District ASBAH, 111 East Gomeldon Rd, Gomeldon, Salisbury SP4 6LZ.

Films about spina bifida and hydrocephalus

What is Spina Bifida? Black/white. 16mm. 25 mins.

A New Lease of Life. Colour. 8mm. 25 mins.

Like Ordinary Children. Colour. 16mm. 30 mins.

Growing Together. Colour 16mm. 40 mins.

} All may be hired from Concord Films Council, Nacton, Ipswich, Suffolk.

The Mansfield Association film '**What shall we do tomorrow?**' Colour, 16mm. 22 mins, may be hired direct from Mrs Freeman (see p.16).

Inter-association holiday opportunities

Camber Sands, nr. Rye, Sussex. New well-equipped chalet, in pleasant situation near the sea available for families with spina bifida members. Sleep six. Please apply to Mr. S. Evans, 1 Coniston Gardens, Wembley, Middx. 01-904 7840.

Great Yarmouth. Caister Beach Caravan Camp — 6-Berth caravan. Details: Mrs E. N. Barefoot, 23 Marlborough Road, Southall, Middx. Tel. 01-574 5067.

Looe. Millendreath Holiday Village. Two bungalows. Details: Mr. Keith Jackson, 202 Exeter Street, Plymouth, and Mrs. Cook, 19 Winslade Road, Harestock, Winchester.

New Forest. Well-equipped chalet, sleeping six people. Within easy reach of Bournemouth, Beaulieu, etc. Swimming pool, paddling pool, restaurant and playground on site. Details from Mrs. A. Rae, 16 Clifton Road, Lee-on-Solent, Hants. Tel. Lee-on-Solent 550242.

Prestatyn: 2 six-berth luxury caravans, running hot and cold water, flush toilets, televisions, gas fires. No vacs. August. Apply: Mrs. E. Taplin, Colonial House, 63, Corporation Street, Manchester M4 3DT.

Selsey: New well-appointed, self-contained 16ft. x 30ft. six-berth mobile home for families with spina bifida members. Sited at Selsey, Sussex. For full details please send s.a.e. to Mr. R. V. Taylor, 3 Dickins Way, Horsham, Sussex, RH13 6BQ.

Winterton-on-Sea, nr. Great Yarmouth — new well-equipped 6-berth chalet. Indoor swimming pool, shop, and play areas. Details: Mr. R. Morris, 127, The Pastures, Downley, High Wycombe, Bucks. Tel: High Wycombe 32184.

AFFILIATED ASSOCIATIONS – Hon Secretaries

BEDFORD AND DISTRICT

Mrs. S. Odell,
9 Beauchamp Road,
Wootton, Beds MK43 9E2.

BOLTON AND BURY

Mrs. B. Grosvenor,
12 St. Peter's Road,
Bury, Lancs, BL9 9RB.

BOURNEMOUTH, CHRISTCHURCH & DISTRICT

Mr. D. D. Lanning,
1 Blythe Close,
Christchurch, Dorset.

BRISTOL

Mr. R. W. Mabbatt,
20 Bramble Drive,
Stoke Bishop, Bristol.

BROMLEY & DISTRICT

Mrs. J. Moore,
102 Westwood Park,
London SE23 3OH.

BUCKINGHAMSHIRE

Mrs. L. E. Tilly,
2 St. John's Drive,
Windsor, Berks.

BURNLEY

Mrs. M. Robinson,
266 Colne Road,
Slough, Earby.

CALDERDALE

Mr. A. L. Crowther,
42 Marldon Road,
Northowram, Halifax.

DARLINGTON AND DISTRICT

Mrs. M. Crawford,
53 Linden Terrace, Copley,
Bishop Auckland, Co. Durham.

DERBY

Mrs. P. E. Broadgate,
11 Old Lane,
Darley Abbey, Derby.

DEVON AND CORNWALL

Mr. J. Carter,
5 Culme Road,
Mannadeam, Plymouth.

DON AND DEARNE

Mr. T. J. Murphy,
43 Cutts Avenue,
Wath-On-Dearne, Yorks.

EAST ANGLIAN

Mrs. P. Symonds,
28 Leyes Road, Cambridge.

ESSEX

Mr. J. T. Saunders,
2 The Ruskins, Rayne,
Braintree, Essex.

GOLOUCESTERSHIRE

Mrs. B. Symonds,
9 Collum End Rise,
Leckhampton, Cheltenham,

GREENWICH

Mrs. J. Goldsmith,
194 Dacre Park,
Lewisham SE13 5SH.

HAMPSHIRE NORTH,

W. SURREY & S BERKS
Mrs. Selby
The Old Police Station,
Leapole Road, Guildford.

HAMPSHIRE SOUTH

Mr. C. Bowen,
7 Brocklands, Havant.

HERTS AND SOUTH BEDS.

Mrs. S. M. McGavin,
3 Netherfield Road,
Harpenden.

HUDDERSFIELD

Mrs. C. Carter,
32 Winglet Avenue,
Cowlersley, Huddersfield.

HULL & DISTRICT

Mrs. G. D. Brown,
233 Cranbrook Avenue,
Hull HU6 7TX.

JERSEY (Channel Islands)

Mrs. U. Emmanuel,
Le Lavandou,
Gorey Village, Jersey, C.I.

KENT

Mrs. P. Fearn,
120 Mill Street, E. Malling.

LEEDS AND BRADFORD

Mr. G. Baxter,
38 Hoyle Court Road,
Baldion, Yorks.

LEICESTERSHIRE

Mrs. P. Cusack,
39, Kings Walk,
Leicester, F.E.

LEIGH & DISTRICT

Mr. T. Power,
3 Taunton Drive,
West Leigh, Lancs.

LINCOLN AND DISTRICT

Mrs. P. Keyse,
Pinfold, Chapel Lane,
North Scarle, Lincoln.

LINCOLNSHIRE

Mrs. Blakey,
7 Shetland Way,
Immingham,
S. Humberside.

LIVERPOOL

Mr. P. A. Glennon,
Tudor House, Wood Lane,
Netherley, Liverpool L27 4YA.

LONDON

Mr. J. Barefoot,
23 Marlborough Road,
Southall, UB2 5WL.

NORTH EAST (Forest) Area

Miss. D. Baxter,
8 Keith Avenue,
Wickford, Essex.

EALING AREA

Mr. L. R. Mower,
59 Betham Road,
Greenford, Middx.

LONDON, CENTRAL AND NORTH

Mrs. V. A. Brooker,
6 Merrivale, Southgate,
London, N14 4SH.

LONDON SOUTH

Mrs. C. Byrne,
Flat 1, 10 Wexford Road,
London, S.W.12.

MANCHESTER AND DISTRICT

Mrs. E. Taplin,
Colonial House,
63 Corporation Street,
Manchester M4 3DT.

MANSFIELD, WORKSOP AND DISTRICTS

Mrs. E. Freeman,
23 Melbourne Street,
Mansfield Woodhouse, Notts.

NORTH EAST (Northumberland)

Mrs. E. Grant,
27 Redwell Road, Prudhoe,
Northumberland.

NORTHAMPTONSHIRE

Mrs. Aldwinke,
38 Robin Lane,
Wellingborough.

NOTTINGHAM & DISTRICT

Mrs. S. E. Plant,
305 Foxhill Road,
Carlton, Nottingham.

PONTEFRAC

CASTLEFORD & DISTRICT
Mrs. N. Robinson,
4 Sandal Rise,
Thorpe, Audlin,
Pontefract WF8 3EX.

PRESTON

Mrs. B. H. Waring,
6 Demming Close,
Lea, Preston, Lancs.

ST. HELEN'S & DISTRICT

Mrs. N. Maddocks,
324 Warrington Road,
Rainhill, Prescot L35 9JA.

SALISBURY AND DISTRICT

Mrs. J. Renshaw,
195 Gainsborough Close,
Salisbury SP2 4HB.

SHEFFIELD

Mr. T. Robinson.
4 Longford Close,
Bradway, Sheffield S17 4LH.

SOUTHAMPTON & DISTRICT

Mrs. P. M. Trim,
Abepta, The Drove.,
Southampton SO4 1XB.

STAFFORDSHIRE

Mrs. J. Davies,
8 Oakhill Avenue,
Stoke-on-Trent ST4 5JN.

STAINES, HOUNSLAW AND DISTRICT

Mrs. J. C. Edwards,
26 Rooksmead Road,
Sunbury on Thames, Middx.

STOCKPORT

Mrs. S. Silver,
1 Brookside Avenue,
Offerton, Stockport.

SUNDERLAND

Mr. W. D. Easton,
4 Irene Avenue, Grangetown,
Sunderland.

SURREY (NASBAH)

Mrs. D. M. Driscoll,
26 Limes Avenue, Waddon,
Croydon, Surrey.

SUSSEX

Mrs. M. White,
Averys, Rusper,
Horsham, Sussex.

SWINDON AND DISTRICT

Mrs. J. Trembling,
3 Church Place, Swindon, Wilts.

TRAFFORD

Mrs. A. Bough,
9 Overdale, Crescent,
Flixton, Urmston.

WARRINGTON & DISTRICT

Mr. S. J. Charlton,
36 Park Avenue,
Latchford, Warrington.

WARWICKSHIRE

Mr. R. W. Chawner,
18 Finch Drive,
Sutton Coldfield, Warwickshire.

WESSEX

Mrs. J. Wheller,
5 Wyke Road, Weymouth.

WIGAN AND CHORLEY

Mr. J. A. Hughes,
20 Kennedy Close, Standish,
Nr. Wigan, Lancs.

WIRRAL

Mrs. S. Keeler,
7 Church Road, Upton, Wirral.

WORCESTERSHIRE

Mrs. M. Davis,
Lower Field,
Wynniatts Way, Abberley.

YORKSHIRE NORTH

Miss F. M. Seward,
45 The Paddock, York YO2 6AW.

NORTHERN IRELAND

Ballymena
Mrs. E. Kenny,
The Bungalow,
Teesham, Ballymena.

MID WALES & BORDER COUNTIES

Mrs. D. Brayne,
5 Woodcote Way,
Monkmoor, Shrewsbury, Salop.

NORTH WALES

Mrs. M. Messham,
47 Cherry Tree Road,
Bradley, Wrexham.

SOUTH WALES

Mrs. D. Cox,
28 Cromwell Road, Bulwark,
Chepstow NP6 5AD.

OTHER LOCAL ASSOCIATIONS

Blackpool & Fylde

Mr. L. F. Sharpe,
1 Broadfield Ave,
Poulton-Le-Fylde.

Cannock & Walsall

Mrs. W. Evans,
19 Drake Road,
Bloxwich, WS3 3LR.

Chester & District

Mrs. K. Jones,
19 Beech Hey Lane,
Willaston, Wirral.

Cheshire South

Mr. J. Bill,
4 Taxmire Close,
Sandbach, Cheshire.

Chesterfield

Mrs. K. M. Tomlinson,
56 Brooke Drive,
Brimington Common,
Chesterfield.

Consett & District

Mrs. M. Holmes,
30 Watling Street,
Leadgate, Co. Durham.

Dudley & Wolverhampton

Mr. B. Attwood,
1 Autumn Drive,
Lower Gornal, Dudley.

Isle of Wight

Mr. D. J. S. Sprake,
Springfield, Town Lane,
Chale Green, Ventnor.

Lunesdale (Lancaster)

Miss P. Crook,
Branianor, Ball Lane,
Caton, Lancaster.

Rochdale

Mrs. Ann Lawton,
55 Wimpole Street,
Shaw Road Estate,
Oldham, Lancs.

Somerset

Mr. N. H. Smith,
Zermat, Church Hill,
High Littleton, Avon.

Spennborough (Yorks.)

Mrs. H. Lodge,
38 George Street,
Cleckheaton, Yorks.

Teesside

Mr. J. Gray,
Marchesi Centre,
Tollesby Road, Middlesbrough.

NORTHERN IRELAND

Ballymena
Mrs. E. Kenny,
The Bungalow,
Teesham, Ballymena.

Lurgan & Portadown

Mr. P. A. Smyth,
Marymount,
North Circular Road,
Lurgan, Co. Armagh.

Mid-Ulster

Mr. J. R. Stafford,
26 Killymerron Park,
Dungannon, Co. Tyrone.

EIRE

Irish Assoc. For SB & H
Joseph Plunkett Power
Ballymun,
Dublin II