

# LINK



The Journal of The Association for Spina Bifida and Hydrocephalus Limited (A.S.B.A.H.)

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One Shilling

# SPECIAL CAMPAIGN ISSUE



# AT STAKE! THE FUTURE OF 8,000 CHILDREN

The future of 8,000 children is at stake. These and the children who caught society unawares . . . the children who, since the middle 1950's, have survived with spina bifida and hydrocephalus—conditions at birth which used to mean that there was very little hope for the child.

Now, thanks to medical advances, there *IS* hope. How much hope, however, depends on the provision which society makes for these children, many of whom are severely handicapped. Far too little has so far been done for them, largely, perhaps, because so few people know they exist.

There is an urgent need, too, for more research to find the causes of spina bifida and of hydrocephalus (water on the brain) which is found in about 75 per cent of spina bifida cases.

These, briefly, are the reasons why a Spina Bifida Campaign is being launched in March, 1968, under the sponsorship of the Association for Spina Bifida and Hydrocephalus (ASBAH)—the organisation formed by parents of afflicted children and several doctors and surgeons.

## Dramatic change

About a decade ago a valve was invented which made it possible to control hydrocephalus by a surgical procedure. It was then that spina bifida children began to survive in appreciable numbers. Before then, only about one-fifth of the children born alive survived one year; the prognosis for the survivors was very poor, unless they were only slightly affected.

Since 1956, the situation has changed dramatically because of advances in surgery and in clinical practice. More than half the spina bifida children born alive in England and Wales now survive the critical first year. After that the death rate drops sharply; this is illustrated by the fact that in 1966, 40 per cent of the children born four years earlier were still alive.

These youngsters are, naturally, more "at risk" than normal children, but they can (given proper care) not only reach adulthood but also live as long as most of us.

There are now at least 8,000 spina bifida children under 16 in the United Kingdom. They

face a number of problems which are not common to other handicapped children. But so far very little has been done even to find out what their needs are, let alone to meet them. What is even more startling is the fact that we can expect each year the number of surviving spina bifida children to increase by at least 700 (the figure is probably much higher, since the Registrar-General is not notified of all spina bifida births). Further

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## What it all means

*Spina bifida and hydrocephalus have long been known in the medical world, but they are comparatively new additions to the layman's vocabulary. Below we give authorised, simple definitions of the two words.*

*SPINA BIFIDA is a deformity of the bones of the spine, usually (but not always) in the small of the back. The coverings of the spinal cord are inadequately supported and may protrude to form a soft, thin-walled sac. The nerves of the spinal cord are thus very vulnerable and there is often partial or complete paralysis below the level of the defect; this may affect not only limbs but also the bladder and bowel, making the patient incontinent.*

*HYDROCEPHALUS (water on the brain) occurs in most cases of spina bifida; it can also occur on its own. The spinal fluid which is normally formed near the centre of the brain is unable to get to the surface because the narrow channels are blocked. Pressure builds up and if untreated will cause enlargement of the head and compression of the brain.*

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advances in treatment can be expected to push up this figure in any case.

The Registrar-General's figures for 1966 show an incidence of spina bifida in England and Wales of 2.47 per 1,000 births, but as not all spina bifida births are notified under the present voluntary system, the true incidence could be around 3.0 per 1,000 births.

This figure may sound small, but it represents one spina bifida birth about every four hours—more than twice the number of spastics. Within the next five years, it is estimated, spina bifida

*Chairman:* Mr. R. B. ZACHARY, West Lawn, 54 Clarendon Road, Sheffield 10.

*Secretary:* Mr. F. G. ARMOUR, 3 Hengist Close, Horsham, Sussex.

*Treasurer:* Mr. J. A. POINTER, 114 Abercain Road, Streatham, London SW16.

*Editor:* Mr. S. HINCHLIFFE, c/o ASBAH, 112, City Road, London, E.C.1.

*Advertisement Manager:* Mr. D. T. D. NASH, 15 Orchard Avenue, Thames Ditton, Surrey.

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children of school age will form the largest group of severely physically handicapped children in this country. Only mental handicap is more common among the tragedies of childbirth.

The definitions of spina bifida and hydrocephalus sound terribly depressing, but to get the problem into perspective one must bear in mind that most of these children have at least as much, if not more, potential than other handicapped children.

The spina bifida usually affects only the lower limbs so the arms are strong. Usually there is a lively intelligence. Certain jobs are therefore well within the capabilities of these children as they grow up and take their place in the adult world.

### Urgent tasks

One of the urgent tasks facing ASBAH is to find all the children suffering from these conditions.

The parents of about three-quarters of them have apparently either never heard of the Association or not taken steps to get in touch with it. The big problem here is that there is no compulsion upon doctors to notify cases of spina bifida to any central point, and there is no register of patients or parents. National publicity is the only answer.

At the same time, we must strive to meet the needs of today's spina bifida children, and begin to provide for tomorrow's. All too little is known

about some of these needs and part of the money raised by the Spina Bifida Campaign must be spent on research into them.

Broadly, the known needs include:—

**More treatment centres.** At the moment there are only about half a dozen centres in

## Secombe at the launch

*The Spina Bifida Campaign will be launched on Wednesday, March 13, at a Press conference at the Royal College of Surgeons, London. The principal speakers will be: Mr. R. B. Zachary, FRCS, Chairman of ASBAH; Mr. Alan Field, Headmaster of Coney Hill School; Mrs. Mavis Cotsford, representing the parent members of ASBAH.*

*A special report will be published presenting the startling facts about spina bifida, backed up by actual case history material. The conference will be attended by comedian Harry Secombe.*

England and Wales which are reasonably well-equipped to handle patients.

**Case workers** to visit the families of patients in their homes.

**Information services** for parents (literature, film, lectures etc.). Many parents are sorely in



A newly born spina bifida baby in an incubator—just one of the thousands born each year who will be needing our help. Picture by permission of "The People" newspaper.

need of advice and a central advisory service is badly needed.

**Research** is needed not only into the causes of spina bifida (at present the threat of it hangs over every expectant mother), but also into surgical procedures and other treatment. Then there is the sociological research required if we are to learn more about the impact of spina bifida on the family, school etc.

**Educational facilities** must be improved. Although many children are capable of going to ordinary schools, others need a preparatory period in a setting where special attention can be paid to them. There should be more class-rooms in ordinary schools adapted to the needs of the handicapped. Teachers must be given knowledge of the special needs of spina bifida children. Some children will need places in special schools and there are too few such places.

**Training and employment.** Opportunities for these are already needed by the older group of survivors and, of course, the numbers increase.

**Rejected and abandoned** children need homes. In some parts of the country as many as 10 per cent of spina bifida children have no home to go to on leaving hospital, either because of illegitimacy or because their parents have not been able to face up to the challenge.

Preliminary investigations suggest that at least £350,000 is needed to finance work that could be begun in the next year or two.

## GETTING TOGETHER

An important week in the diaries of all ASBAH members begins on May 26. It is Friendship Week for Sick and Handicapped Children, a campaign in which we and six other charities are joining.

The aim is co-existence, and to promote greater understanding of the children's needs.

Officials of ASBAH have already attended meetings with representatives from the other charities who are joining in the effort. These are the Catholic Handicapped Children's Fellowship, Cystic Fibrosis Research Foundation Trust, Elizabeth Fitzroy Homes, Invalid Children's Aid Association, National Society for Autistic Children and National Association for the Welfare of Children in Hospital.

Miss Eileen Hilton, general secretary of the Invalid Children's Aid Association, is chairman.

The joint week was decided upon because it was felt that the public is becoming bewildered by individual "weeks."

During Friendship Week it is up to each individual charity to raise funds for its own cause. Major publicity schemes will be launched jointly.

"It is estimated that one child in 25 suffers from some kind of handicap—physical mental or emotional—totalling at least 500,000 in Britain today," Miss Hilton said.

# How to spend the cash

We all have our own ideas on where the money we raise should go. These are a few ideas we canvassed.

Mrs. Joan Brooke, whose husband is secretary of the Huddersfield group, has a three year old spina bifida daughter. "Diane hasn't needed much surgical treatment but I would like to see a shorter waiting list for orthopaedic operations. This means ASBAH must find money to provide more treatment centres and more surgeons must be trained."

*George Gearing, treasurer of Huddersfield Group, is the father of Jill, aged three, who has spina bifida. He believes that money should be spent on establishing nurseries for pre-school age children to enable them to mix with others at an early age.*

Mrs. Maureen Kinsella, of Sheffield, has a four-year-old daughter with spina bifida. She believes it vital that handicapped children should be prepared at as early an age as possible to compete with normal children. She believes schooling should start at two and that ASBAH

should institute research into special classes annexed to normal schools. Her little girl Orla was going to school in Cambridge, but now the family have moved to Sheffield there is no room for her at any of the special schools. So Orla must wait until she is five.

*Mrs. Mary Coward of Denholme, Bradford, hopes ASBAH will provide playgroups for spina bifida children, possibly attached to hospitals where the children can have physiotherapy too. The youngest of her three children, Martin, aged 2½ years has spina bifida.*

Faith Seward, of Acomb, York, is 27 and is herself a spina bifida sufferer. Her main interest is in the welfare of the older spina bifida group. "One of the most important things is to provide a good education and training so that the children can take their proper place in society. I also feel that some kind of place where families or older individuals could go on holiday comfortably would be a great help. Something like houses or caravans near the coast which have facilities like ramps."

## . . . AND HOW TO BUILD IT UP

Everyone can do *SOMETHING* to help the Spina Bifida Campaign. Here are a few suggestions to start you thinking.

**ORGANISE** a coffee morning in your own home. This is still one of the simplest and best means of raising money and recruiting helpers. Why not start a "coffee morning chain"? The idea is that every woman who comes to yours is asked to organise one of her own; then the people who come to that one are asked to do the same.

Another popular eat-and-drink affair is the wine-and-cheese evening. If you are able to obtain the use of the home of a local personality, or the Mayor's Parlour, so much the better.

**COLLECT** trading stamps (all colours) and cigarette gift coupons. When you have a fair number (stamps in books only, please) send them to Miss S. M. Newham, Sheepcombe, Coombe Rise, Worthing, Sussex.

**CONTACT** service groups like Rotary, the Round Table, churches, women's groups—all

the organisations you can think of—and ask them to run **ONE** event in aid of the campaign this year.

**JOIN** your nearest Spina bifida association if you are not already a member. Our parent-members desperately need the help of men and women who are less "tied" by domestic commitments. A list of addresses is on the back page.

**SET UP SHOP** in any well-sited shop premises which may fall vacant in your town. Many owners and estate agents are quite willing to lend such premises to a charity for a limited period. Local residents are glad to unload their white elephants (often more valuable things as well) and such a shop, staffed by volunteers on a rota, can make several hundred pounds in a week or two.

Our appeals department is ready to help you help the Campaign. Please tell us what you have in mind to do and what you feel you need to make it a success. Contact Patrick Browning, Appeals Director, Spina Bifida Campaign, 112 City Road, London, E.C.1 (Phone: 01-253 2735).

**Parenthood brings joys and sorrows. For parents of spina bifida children the depth of the sorrow often depends on the speed with which the surgeons act.**

**For Mark Jackson, an operation within the first 24 hours of life. For Andrew Hinchliffe, inactivity.**

**Mark is now marching confidently into the future, while Andrew can only take a few faltering steps.**

**This is the disparity which only money can heal. Until the Spina Bifida campaign can provide enough treatment centres, urge the government to train more specialists, and educate the ignorant who remain in our health system, the disparity will remain. The longer it remains the bigger the blot on a nation's conscience.**

## Case history No. 1.

For Mrs. Joan Jackson, the shock of discovering that her new-born baby had spina bifida was perhaps even more traumatic than that suffered by other mothers.

Mrs. Jackson had been a nurse during the last war, so unlike most new mothers she *had* heard of spina bifida. But she had not heard of the surgical strides which had been made in treating the condition. To her spina bifida still conjured up visions of hopelessness.

"Imagine my relief when Mark was whisked straight away to a children's hospital and I was re-assured that there was hope for him", she said at her home in Golders Green, North London.

Mark underwent the closure operation before he was 24 hours old. Three years later he underwent a tendon transplant to his left leg. Now aged almost six he is an active, boisterous child with an I.Q. of 115.

Specialists told Mrs. Jackson not to expect him to walk. But Mark is walking with the aid of calipers.

"Of course if they had not operated immediately he would not have walked. But they did and I am grateful that Mark was born the last of my three children", she explained.

"When my older children were born this would not have been possible."

Mark has had additional electrical stimulus treatment for his bladder. Now the boy who was

# PROGRESS REPORT

paralysed from the waist can "feel" his hips and thighs. He can also feel his feet on occasions, but his lower legs remain insensitive.

"It has been marvellous. We discovered the feeling had returned to his thighs when doctors tried to remove an abscess without anaesthetic—not a painful process on paralysed limbs. Imagine, I was almost overjoyed when I heard Mark scream with pain", remembers his mother.

Mark was unfortunate to be born with spina bifida. But he has been lucky too—birth in the age of surgical miracles has ensured that no opportunity has been lost to help him minimise his handicap.

He attends the Franklyn D. Roosevelt special school in St. John's Wood. But his mother has been told that he is grammar school material.

His ambition? To become a doctor.

## Case history No. 2.

Andrew Hinchliffe was born five-and-a-half years ago on a Thursday in a town less than 30 miles from one of our foremost spina bifida treatment centres. His father, obviously overjoyed at having his first child, was told on the telephone: "it's a boy." Little did he know that this boy was to change the whole lives of himself and his wife.

Andrew's mother had been told that all was not well, and father was given the same details—"something wrong with his back."

The answer to the question "How serious is it, what can be done?" was "a paediatrician will call tomorrow." The paediatrician did not call... "he must be on holiday, but normally calls on Mondays, we will have to wait until then." So the first and most vital 24 hours of Andrew's life were gone.

Monday came, and still no expert. "Perhaps he is still on holiday." A paediatrician eventually arrived the following Wednesday. Andrew was six days old.

The initial diagnosis was hopeful. With good, well shaped limbs, healthy little Andrew had one strong "could be normal" leg, and one "a little weak." His main problem was his back. No lump, just a flat open wound, described in terms unheard of before, near the base of his spine. Dressings were being applied "to keep it clean."

Another problem could be that he may develop hydrocephalus. His mother did not know what this was and was too frightened to ask. Father accepted this at visiting time and tried to find out if anything could be or was being done. "We will have to wait and see," he was told.

## Few details

Mother came home after the usual 10 days, but Andrew stayed in the hospital. The parents did not know why.

When Andrew was 13 days old his father, after much agitation, finally managed to see the paediatrician himself, and was given the same kind of information, with a few additions. "Skin could be grafted over the wound, but this may destroy all movement in his legs. (This is never done). He may get hydrocephalus." A few details of what this meant, but no mention of what could be done.

What was being done?

"I have written to a specialist, but haven't had a reply yet." Father went home, and within an hour had made an appointment by telephone to take Andrew to a treatment centre on the following Tuesday.

At last, someone would see him who had up-to-date knowledge of treatment. Unfortunately, this was coming three weeks too late.

But now the parents were told about the hydrocephalus, and realised why the nurses at the maternity hospital had been measuring Andrew's head daily, although they "couldn't tell us anything about our baby."

Andrew flourished, gained weight, and his wound began to heal over. However, his mother and father watched his head grow, with mounting anxiety, during the next few weeks, with Andrew eventually at home.

The next clinic appointment was when he was eight weeks old. This time he stayed in hospital and had a valve fitted. That valve saved Andrew's life, but it kept this small family under a rule of fear for the next several years. Six operations

for the valve in less than three years, and many false alarms along the way.

During the first few months, Andrew gained strength. At nine months he was trying to pull himself up on to his legs. Then suddenly, within only a few weeks, the strength seemed to disappear. Later it was suggested that an infection had perhaps been trapped under the healing tissues of his back, and this had gradually done its work destroying the nerves.

With problems with the valve coming, seemingly, every few months, little time was spent worrying about Andrew's legs. Then, at about three years, the valve problems seemed to be under control, and it was evident that Andrew's right leg was once again gaining strength, but the muscles were so unevenly balanced that they were pulling his hip out of joint.

Doctors were approached about the operation to reset the hip and transplant muscles. However, due to valve problems, Andrew had not been put on the waiting list for orthopaedic surgery, so he was well down in the list. And with the list "growing faster than the operations could be performed" the forecast was six months to a year, possibly longer.

## First attempts

With the help of the imbalanced hip, Andrew's spine was developing a sideways curvature, and the operation was described as urgent. Andrew was now nearly four years old, and his parents decided that if he was to have any chance of being mobile by the time he attended school, he must be given the opportunity of this operation now.

The operation was done privately and paid for.

So Andrew was fitted with calipers and made his first attempts to get around in an upright position. His right leg developed.

But now Andrew's left leg has gained strength, and his left hip is out of joint. He has needed a similar "urgent" operation on this leg for the past nine months. The continued pressure of standing even in calipers—could make the hip worse and eventually break the bones. But that operation date is still very much in the future.

Andrew is a grand little boy, liking everyone, liked by everyone, and most interested in the world around him. His school and his new baby brother give him his main enjoyments.

Think what he might have enjoyed, had he been given the attention he so desperately needed during those first few days.

# A rough time, love

It reads like fiction. But this is the true story of how one mother gave birth to a spina bifida son—and the shock the discovery gave her.

“It’s a boy Margaret”. I was disappointed. I had hoped it would be a girl because I had lost a baby daughter at birth 15 months earlier.

She was so beautiful and so perfect, I wanted another baby as soon as possible.

“Is he all right?” I asked.

“He will be in a minute”, replied the midwife.

I remember she didn’t hold him upside down for the mucus to come out of his mouth, but sucked it out through a tube as he lay on his back.

“God, what a horrible colour he is”, I thought. He was grey and his cry seemed so feeble after hearing my other three children cry so lustily at birth.

Then my doctor held my hand and said: “He’s a grand little chap isn’t he, you’ve had a rough time, love, but it’s all over now”.

A funny thing happened next. Instead of bathing and dressing my baby the midwife wrapped him in a sheet of newspaper and put him in his cot.

She and the student nurse who accompanied her went downstairs where my husband poured them a cup of tea.

He came upstairs to see his son “Why has she wrapped him in newspaper”, was his startled remark.

I was too hazy to care much, I had been drugged for reasons unknown to me at the time.

Well, my son cried feebly for an hour before they came back upstairs.

One of them sent my husband downstairs then lifted my baby and turned the back of her chair to the foot of my bed, so that all I could see was her back.

She then took the wrappings off my son and proceeded half-heartedly to bathe him on her knee, not the bath like my other children. She asked me what I was going to call him and I said Michael.

Three hours after my confinement they were both still there, writing and making light conversation, whereas with my other children it had all been over in an hour.

Why so long, I asked in my dazed mind. Why keep looking at each other, and then at me so pitifully.

Finally they left me with my still-crying baby.

He cried for the rest of that night until he fell to sleep exhausted over six hours after his birth.

When he awoke I changed him and remarked to my husband on how chubby his legs were for a newly born baby.

The two midwives returned. The student arrived first and fidgeted, making no attempt to see the baby. I asked her why she was waiting and she said: “Oh, Nurse B, has something to tell you when she comes”.

After a while Nurse B, and the doctor, arrived.

Michael was lifted from his cot and placed on the bed. The doctor lifted his legs in turn, let each one go—and both fell lifeless to the bed.

The next moment the nurse held a piece of blood-soaked lint in her hand.

## Crippled baby

I immediately asked what was wrong with my baby.

“It’s all right, Margaret, he only has a piece of skin off his back, he will have to go to hospital, but don’t worry he will be all right”.

Then, after a whispered conversation with the midwife, he left.

She came and sat on my bed and told me there was no hope for my baby.

“He is paralysed from the waist down and you wouldn’t want a crippled baby, would you?” I replied that he was my son and I wanted him.

I had known in my own heart that something was wrong when they didn’t slap him and by his colour. I hadn’t realised it was as serious as this.

That was 2½ years ago. Michael is as bright as a button and beautiful to look at with huge brown eyes and blonde hair. I cursed heaven that dreaded day when I first heard the words “spina bifida”.

Now I thank God for giving me my beloved son.

A specialist has now told me that he will try to get Michael walking. Please God, he succeeds.



## A DREAM OF A DAY

It was every child's dream—the day that eight spina bifida children were given the freedom of one of London's biggest toy shops just before Christmas. They were able to choose any toy they wanted—paid for by an anonymous "Santa Claus".

Making her choice (picture above) at Paul and Marjorie Abbott's shop in London's Wimpole Street is two-year-old Debbie Tingey, of 118 Rowan Road, Streatham, seated on her mother's knees. Five-year-old Mark Jackson, of 57 Corringham Road, Golders Green, looks on.

Right, Raymond Wilson, aged five, had set his heart on a puppet and quickly learned how to manipulate the strings.



# CAN ANYTHING BE DONE ABOUT THOSE STARES?

I have mentioned in a previous issue of "Link" how important I think it is for disabled people to mix with all other people—and not just those who are also disabled.

This is not easy—as I know only too well. I have suffered the same sort of unkindness that a reader described in a letter.

I am not in a wheelchair, but I am only four feet ten inches tall, and am quite obviously disabled. I am frequently pointed at and stared at and commented about—very loudly usually! But I have developed a hard shell, although I am often upset and embarrassed. This is usually for the people I am with, who are unable to cope with the situation.

But with children it is a different matter. I know what I am talking about here, because I have 34 infants under my care each day.

I ignore mothers who say "Shh!" when the children ask why I am small, why I wear funny shoes, or why I walk in a funny way. I explain to them as simply as I can that my feet are odd, that I have one leg shorter than the other, that I find difficulty in walking, that I was born like it and that it is just unfortunate.

## Honest approach

This honest approach helps the children to accept others less able than themselves and they rarely ask a second time.

The children accept the truth, even if the adults shy away from it.

On a more general subject, many adults will have been pleased as I was to see the letter from older girls in the last issue of "Link", especially the one from Susan Whitely asking for people to write to her.

I have been hoping for some time to be able to refer people who have to use wheelchairs to someone who knows rather more about these problems than myself.

As many of you know, I do not share them. I am one of the lucky ones who can walk, and, in fact, am able to lead a reasonably normal life.

Many teenagers will want to write to Susan—and I hope they do. But I hope that this will not

*One of the biggest problems that parents have to face is the attention that their child's handicap draws and the embarrassment it can bring. How should it be treated? Ignore it? A sharp "Don't stare—my child is not a freak?" Or a frank explanation of what the trouble is.*

*That this concerns many parents has been shown by the number of letters we have received. In her article for the older group in this issue, Faith Seward, a young teacher in York who has a spina bifida, tells how she contends with the problem.*

mean that we, as an older group, will split into a series of small groups without any contact. I have written to many adult spina bifida sufferers of all ages and we all have something in common and something to offer each other.

## A nun's story

There are no roads barred in life to the physically handicapped who are endowed with the gift of determination. And a wheel chair is no barrier if any women wishes to become a nun.

This was made possible by Mother Marie de Doleurs who founded the Sisters of Jesus Crucified in 1930.

She is herself an invalid and had many difficulties with her young society at the beginning. Now it is established in France, Holland, Germany, Britain, Japan and the United States.

The sisters come from every country with every kind of illness and handicap that does not affect them mentally. The life requires a strong, intelligent mind.

The nuns lead a full religious life according to the rule of St. Benedict. They recite full Roman Office—at intervals throughout the day so as not to overtire them. They have a rule of Simple Enclosure, but take part in many activities.

These vary from a small cancer research laboratory in an American priory—staffed entirely by nuns in wheelchairs—to a printing press and guest house in Somerset.

All the priories give classes in music and languages with a special eye on the interests of backward children.

They have sisters called Regular Oblates who are able to walk and go out teaching or nursing. They form a link between the cloister and the world. There are also Secular Oblates—women

who lead a religious life in their own home or hospital ward.

Among the English Secular Oblates is a chair-bound spina bifida woman. There is another young woman in a similar condition who has learnt to walk since joining the community.

A group of people, called Friends of the Sick, help with fund-raising and do all they can to interest people in the outside world in these heroic women, who have no other nursing assistance apart from what they provide themselves.

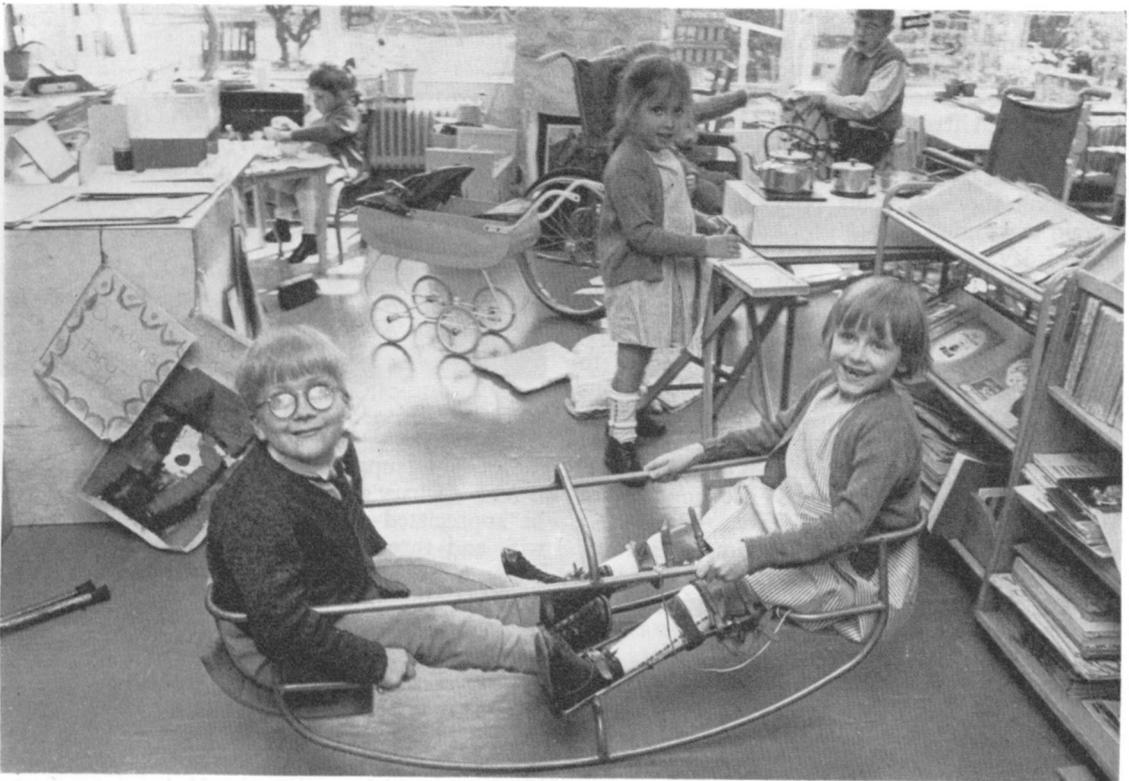
It is a case of the handicapped helping the handicapped. For example, a blind nun will dress a

sister whose hands are affected. And a nun with heart disease may help a chair-bound sister.

It is both an education and an inspiration to visit them at St. John's Priory, Castle Cary, Somerset.

## Back next time

Because most of the space in this issue is being devoted to the Campaign, we regret that we have had to leave out our regular features, like Group News and Children's Corner, and articles promised in the last issue. These will appear in our next issue.



They were born with spina bifida. But you could call them the lucky ones.

Happy, laughing, learning as they play—these are the children who go to Coney Hill, a Shaftesbury Society special school for children with spina bifida and allied disabilities.

The children exercising as they rock into adventures which only they can share are Patricia Goy, of Bishops Stortford, and Duncan Mathison, of Bexley Heath. Behind them Antoinette Morris irons out the

difficulties of balance while she smooths her doll's blankets.

They learn more than the three r's at Coney Hill. Each child is taught to care for his own bladder and to keep a constant look-out for pressure sores.

As each lesson in learning how to cope is mastered, the child's handicap diminishes.

This is one of our hopes for the future—to see that every spina bifida child has the opportunities for education which abound at Coney Hill.

## ***A week in the life of the chairman***

Our chairman, Mr. R. B. Zachary needs no introduction as he was one of the founder members of ASBAH.

What few regional members realise, however, is just how much time and effort Mr. Zachary is devoting to our cause.

His work on our behalf has meant that during the last few months, as plans for the launching have gained momentum, he has been spending an average of 30 hours a week working, meeting or travelling.

There is no room to give full details of his timetable, but here is his diary for one typical week:

Friday, January 17th: Addressed a meeting of the National Council of Women at 2 p.m. on the full implications of spina bifida before catching a train to London.

Saturday, January 18th: 9.45 a.m., discussions in London with public relations consultant. 11.30 a.m., executive committee meeting. 7 p.m., train home, arrived 10 p.m.

Thursday, January 25th: 7.30 a.m., train to London. 11 a.m., meeting at House of Commons with officials of other charities and representatives of ASBAH executive. Working lunch and discussions with ASBAH's consultants. 3 p.m., train home.

The House of Commons meeting meant sacrificing a day of his annual leave.

It is impossible to assess the time which our chairman spends writing letters to prospective trustees and passing round the "begging bowl"



**Mr. R. B. Zachary**

for funds and support from people in all walks of life.

Mr. Zachary's contribution is all the more to be appreciated when one realises that he has a wife and three children, the youngest aged 16. They must have seen very little of him since ASBAH came into existence.

## **KNOW YOUR OFFICIALS**

### **The secretary**

Frank Armour, the national secretary, founded the Sussex Association in 1965 and was its first secretary. He became ASBAH's honorary secretary in November, 1966, when the first elected committee took office. Frank, now in his mid-forties, and his wife, Betty, have a son, aged 10, and a 13-year-old spina bifida daughter, now at school at Chailey Heritage in Sussex.

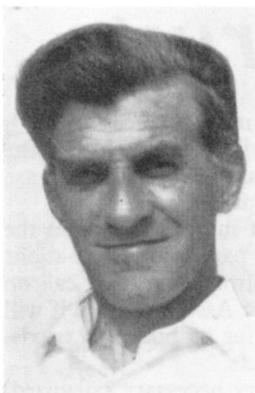
Frank qualified as a chartered accountant after what he humorously describes as an "un-successful" spell in the R.A.F. which took him to India and Thailand. Outside his family, his main

interests are cricket and music. He hopes one day to have the time to enjoy them again.

### **The treasurer**

Another of our busy officials in recent months has been John Pointer, a 35-year-old bank employee, who became treasurer last October.

His task is a difficult one at any time. But the pressure has been mounting as the launch has become more imminent. Demands for expenditure are coming from all directions. It is John who has to juggle with the figures to see if we can afford



**Mr. Frank Armour**



**Mr. Patrick Browning**



**Mrs. Carol Whalley**

this set of publicity pictures or that scheme for advertising.

His ambition from the outset was to have so much money coming in that the task would become too heavy for one person to handle in his spare time. It is an ambition we all share.

John is the father of a spina bifida son, Ian, who will be five in June, and secretary of the South London branch. He knows all the strains and stresses which other parents suffer and is anxious to alleviate them.

His wife has been giving her mornings to ASBAH headquarters where her nose has been kept well and truly down on the typewriter. As Mrs. Margaret Pointer explains: "Anything we can GIVE is saving money. It is vital that no funds are wasted at this stage. We can all do something and this is my own contribution."

### Appeals director

Patrick Browning, aged 41, of Writtle, Chelmsford Essex, has been appointed first full-time Appeals Director. His formidable job is to organise and carry out—in co-operation with all the local associations—our Campaign for urgently needed funds.

Previously, he was organising secretary with a national youth charity for nine years. After his war service, he spent two years studying sociology at Canada's British Columbia University. During this time he travelled extensively in Canada and the Arctic on voluntary welfare work. Returning to this country he first became sales manager of a well known tele-communication company. But after five years he moved as a sales executive with one of Britain's leading electronic manufacturers.

Mr. Browning, who is married with four children, qualified as a children's welfare officer, and is a Member of the Welfare Institute.

Commenting on his new appointment, he said: "I've really graduated to professional fund-raising through a combination of sales experience and charitable interests. I'm so impressed by the urgent needs of spina bifida sufferers. It gives me a great stimulus."

### Office manager

Following the recent move from Craven Street, W.C.2., to our new offices in City Road, E.C.1., 26-year old Mrs. Carol Whalley now has the responsibility of Office Manager. In her latest role, much of her time will still be devoted to the Association's administrative work, and the remainder on "routine" Campaign duties.

Mrs. Whalley joined ASBAH about eight months ago. An experienced secretary, she was educated in Wales and is a history graduate of London University. She and her husband, sales manager of a boat-building firm, live at East Molesey, Surrey.

Completing the staff team is Miss Colette Bransby-Zachary, aged 18, of Belmont, Sutton. Her work, in addition to assisting Mrs. Whalley, is secretary to the Appeals Director and Public Relations Officer.

### Thank you very much

Generous readers of *The People* newspaper read about spina bifida in December and of their own donation of an isotope renograph to Sheffield Children's Hospital.

The £2,500 gift will supply equipment to enable surgeons to study the functioning of babies' kidneys before any damage has been done.

# Putting our trust in trust

A Trust is being formed to handle funds from our campaign and members may wonder why this is necessary even though it costs next to nothing to set up. There are two main reasons why this procedure is being adopted.

Firstly, we were advised by people with considerable experience in appeals work that there is sometimes difficulty in persuading the public to donate to what appears to be a large national organisation. In these circumstances people often feel they are being asked to pour money into a bottomless pit, and that the receiving organisation will find a use for whatever sums are received, regardless of the real needs. It is sometimes said, for example, that "office curtains will come first and the real needs last".

However, where responsible people are receiving and administering the funds, and also allocating them to meet the various requirements, these objections are largely overcome.

## Neutral umpires

Many members have also been worried for some time about the difficult task of allocating funds between the various projects. Very few people within ASBAH are sufficiently detached to be able to undertake this duty. Even fewer, perhaps, are competent to do so.

We look on the Trustees as neutral umpires. They are men and women with a proven ability to handle money wisely, and also with such an interest in our cause that they have already each done something about it, in their different ways.

We think it is only people of this calibre who could be asked, when necessary, to decide which are the immediate needs, and which must be delayed. They will not represent sectional or local interests within our organisation.

We expect that the Trustees will be advised by a sub-committee which will itself receive applications for money (preliminary applications for no less than £250,000 have already been received). Representatives from other charities, which are already working on our problems in many fields, will be invited to advise the Trustees

when necessary. A preliminary meeting with many of these other bodies was held at the House of Commons in January, and their response to our plans was very encouraging.

The objects of the Trust make it clear that the financial support of the parents' organisations affiliated to ASBAH will always be a first call on any available funds. But the Association itself will have the duty of applying for its budgeted needs, along with any other projects.

We consider this is a very necessary safeguard, so as to protect donors against reckless expenditure by the Association, to the detriment of other urgent projects. The Trustees will be able to enforce self-discipline on ASBAH, subject always to the maintenance of the local parents' Associations.

The Trustees will be appointed by the Committee of ASBAH, and there will be a minimum of seven. This number was chosen because most of them are busy people, and it is necessary to allow for a certain number of absentees at any one meeting. But we have made sure that each of the Trustees understands the whole range of our problems and has our interests at heart.



Many cogs go towards making up the machinery to launch our Campaign for funds. One is the recently appointed advertising agents. Here, Brian Jones (left), group account head, and Nick Mitchell, art director, discuss advertising lay-outs.

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## INCREASE YOUR SUBSCRIPTION

Regular Subscribers to ASBAH who pay Income Tax at the Full Standard Rate may increase their contribution very considerably by completing the Deed of Covenant form given on the next page.

The undertaking contained in this form to continue the same Annual Payment for seven years enables the Central Council to recover the Income Tax which has been paid on it. This recovery, at the present standard rate of 8/3, increases contributions by more more than 70%.

**ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS LTD.  
DEED OF COVENANT**

I, .....  
(Block letters. State full names).

of .....  
(Address)

**Hereby Covenant** with the Honorary Treasurer of the Association for Spina Bifida and Hydrocephalus Ltd., 112 City Road, London E.C.1., that for a period of seven years from the date hereof or during my lifetime, whichever period shall be shorter I will pay annually to the said Association or its Treasurer for the time being such a sum as will, after deduction of Income Tax, leave in the hands of the Association a net sum of £ : :  
(.....) such sum to be paid from my General Fund of Taxed Income, so that I shall  
words  
receive no personal or private benefit in either of the said periods from the above-mentioned annual sum, or any part thereof.

**In Witness** whereof I hereunto set my hand and seal this ..... day  
of ..... 196.....

SIGNED, SEALED AND DELIVERED

by the said .....  
(Full Names)

in the presence of } Signature  
Name ..... }  
(Signature of Witness) }  
Address ..... }  
Occupation .....

To ..... BANK LIMITED **STANDING ORDER** ..... 19.....  
..... Branch

Please debit my/our ..... account with the payment detailed below, the first payment to be made on ..... and similar payments on ..... for a period of seven years from the date hereof or during my lifetime. The last payment to me made on.....

(or cash by post/draft etc.) { Code No. [ ]  
Bank .....  
Branch Payment to .....  
Reference .....

Amount in words ..... £ [ ]

A/C. No. .... Signature .....  
[ 2d. Stamp ]

# ASBAH area Officials

## AFFILIATED ASSOCIATIONS

### LONDON & THE SOUTH

#### Central & North London Assn.:

Mr. C. D. HAMILTON,  
77 Meadway, Barnet.

#### South London Group:

Mr. J. A. POINTER,  
114 Abercairn Road,  
Streatham, London S.W.16.

#### New Assn. (Surrey):

Mr. J. A. COUPER,  
45 Sydney Road, Sutton,  
Surrey.

#### Kent Assn.:

Mr. G. F. OWEN,  
27 Lesley Road, Istead Rise,  
Northfleet, Kent.

#### Sussex Assn.:

Mrs. T. A. RODAWAY,  
5 Sunte Close, Haywards Heath,  
Sussex.

#### South Berks., North Hants. and

#### West Surrey Assn.:

Mr. A. EAGLES,  
229 High Street, Guildford,  
Surrey.

#### S. Mercia Assn. (Herts., S. Beds. and Cambs.):

Mr. J. J. MEADE,  
8 Arnold Close, Round Green,  
Luton, Beds.

#### South Hampshire Assn.

Mr. J. A. RAE,  
16 Clifton Road,  
Lee-on-Solent, Hants.

#### Salisbury Assn.:

Mr. D. J. K. CALLAWAY,  
17 Ridgway Road, Salisbury,  
Wilts.

#### Buckinghamshire Assn.:

Mrs. S. M. HALL,  
35 Coopers Row, Swallow Street,  
Ivor Heath, Bucks.

### MIDLANDS & THE NORTH

#### Manchester and District Assn.:

Mrs. G. RAYMOND,  
3 Burton Road, Manchester 20.

#### Liverpool Assn.:

Mr. A. CHEETHAM,  
5 Gorsey Lane, Litherland,  
Liverpool 21.

#### Huddersfield Assn.:

Mr. T. R. BROOK,  
55 Halifax Old Road, Hillhouse,  
Huddersfield.

#### Sheffield Assn.:

Mr. L. CLARK,  
10 Wardlow Road, Frechville,  
Sheffield 12.

#### Staffordshire Assn.:

Mr. K. FLETCHER,  
170 Beachcroft Road, Wallheath,  
Brierley Hill, Staffs.

#### Warwickshire Assn.:

Mr. I. J. JONES,  
73 Berkely Road, Shirley, Solihull,  
Warwicks.

#### Leeds and District Assn.:

Mr. A. S. MITCHELL,  
9 King Lane, Leeds 17.

### WALES & THE WEST

#### South Wales Assn.:

Mrs. M. COOK,  
9 Grasmere Close,  
Llandough Estate, Penarth,  
Glam.

#### Bristol Assn.:

Mr. R. W. MABBUTT,  
65 Dormer Road, Eastville,  
Bristol 5.

#### Devon & Cornwall Assn.:

Mr. T. H. BROMIDGE,  
1 Warren Road, Mary Tavy,  
Tavistock, Devon.

#### Wessex Assn.:

Mr. W. J. WHITE,  
26 Maiden Castle Road,  
Dorchester, Dorset.

### SCOTTISH ASSOCIATION

#### Hon. Sec.:

Mrs. E. WILSON,  
Park Cottage, Kirk Road,  
Wishaw, Lanarkshire.

## OTHER REPRESENTATIVES

### LONDON & THE SOUTH

Mrs. A. MERRY,  
9 Greenacres, Putnoe, Bedford.

Mrs. S. AYRES,  
5 Wilcote Road, Headington,  
Oxford.

Mrs. COCKS,  
19 Ashdene Road,  
Ashurst, Southampton.

Mr. J. T. SAUNDERS,  
188 Abbotts Drive,  
Stanford-le-Hope, Essex.

Mr. E. WHITEHEAD,  
36 Boughton Avenue, Hayes,  
Bromley, Kent.

### MIDLANDS & THE NORTH

Miss K. POWELL,  
The Mount, Norwich Road,  
Cromer, Norfolk.

Mrs. P. KEELING,  
1 Hall Farm Road, Thurcaston,  
Leicestershire.

Mrs. M. MCKNIGHT,  
The Nook, Rawlinson Lane,  
Nr. Chorley, Lancs.

Mrs. B. RILEY,  
The Coppice,  
Park Lane, Sandbach,  
Cheshire.

Mrs. L. LEES,  
Rose Hill, Huddersfield Road,  
Waterhead, Oldham.

Mrs. S. LEE,  
10 Victoria Way,  
Bramhall, Stockport,  
Cheshire.

Mrs. E. TAPLIN,  
11 Malton Avenue, Whitefield,  
Nr. Manchester.

Mrs. C. THOMOND,  
50 Bent Lanes, Davyhulme,  
Urmston, Lancs.

Mrs. M. MEDLICOTT,  
4 Holmes Way, Haughton Green,  
Denton, Lancs.

Miss M. GALLAGHER,  
48 Enville Road, Salford 6,  
Lancs.

Mrs. D. WRIGLEY,  
8 Gilda Way, Mosley Common,  
Walkden, Lancs.

Mrs. O. DAY,  
Windyridge, 90 Hall Carr Lane,  
Longton, Nr. Preston.

Mr. J. WHITTAKER,  
115 Greenway Street, Darwen,  
Lancs.

Miss F. M. SEWARD,  
27 Lidgett Grove, Acomb,  
York.

Mr. F. RAWSON,  
15 Ravenfield Road, Armthorpe,  
Doncaster.

Mrs. M. PAGE,  
130 Peartree Avenue, Bramley,  
Rotherham.

Mrs. G. D. BROWN,  
233 Cranbrook Avenue,  
Cottingham Road, Hull,  
Yorks.

Mr. M. COWARD,  
30 Ogen Crescent, Denholme,  
Bradford.

Mrs. R. NIGHTINGALE,  
7 Dionysia Road,  
North Ormesby, Middlesborough.

Mrs. E. GRANT,  
27 Redwell Road, Prudhoe-on-Tyne,  
Northumberland.

Mrs. M. E. DEAN,  
9 Church Lane, Upton, Wirral,  
Cheshire.

Mr. R. S. BENSLEY,  
8 Wincerby Avenue, Grimsby,  
Lincs.

Mr. G. W. RICHMOND,  
42 Galena Drive, Porchester Lodge  
Estate, Nottingham.

### WALES & THE WEST

Mrs. J. CARTER,  
1 Meadow Road, Craven Arms,  
Salop.

Mrs. P. EDWARDS,  
Llawcoed Uchaf, Llanbryn-mair,  
Montgomery.

Mrs. J. TREMBLING,  
27 Exeter Street, Swindon,  
Wilts.

Mr. R. A. BAILEY,  
92 Cambrian Drive,  
Rhos-on-Sea, Colwyn Bay  
Denbs.

### NORTHERN IRELAND

Mrs. M. REID,  
7 Porter Park, Finaghy,  
Belfast 10.

Mrs. E. KENNY,  
The Bungalow, Teeshan,  
Ballymena, N.I.