

touchinglives

the action medical research magazine • spring 2004



Walking back
to happiness

Plus:

My story – memories of Lana
The sacred disease – new research on epilepsy



medical research
give and let live

From the Editor



The media interest in the MMR debate continues. The latest twist has been the revelation that Dr Andrew Wakefield, the clinician and researcher primarily associated with the belief that the MMR vaccine could cause autism in children, was being paid by the Legal Aid Board to give advice to parents of autistic children at the time his paper was published. Many have said that this conflict of interest is proof positive that the research itself is invalid.

But conflicts of interest are to be found in all areas of public life, medical research being no exception. Virtually all researchers accept funding from commercial sources at some point in their careers, often because there is no other funding available. I believe this whole controversy brings home the latent value of Action Medical Research's freedom from commercial or political influence. We are independent, and as such we are able to make truly objective choices about the projects we fund. It's one reason why the quality and rigour of our research is so highly respected within the medical profession.

It's probably true to say that every medical researcher would prefer to be an Action Medical Researcher. But with finite resources ourselves, there is a limit to the number of projects we can make happen. If you feel able to donate to our appeal this issue, please do. The health of the nation requires independent medical research of the highest ethical standards and integrity. And this is what we are for, and do so well.

Daniel Sartin
Editor

Touching Lives is the magazine of Action Medical Research.

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Printed by ET Heron

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Action Medical Research is one of the country's leading medical research charities. For over fifty years we have been funding pioneering research into a wide range of illnesses and conditions.

By pushing back the boundaries of science and enabling medical breakthroughs such as the UK polio vaccine, ultrasound scanning and the hip replacement operation, we play a crucial role in fighting disease and disability and improving the health and quality of life of everyone in the UK

Treating nerve injuries

Nerve injuries are common and can result from accidents or trauma and radical surgery for diseases such as cancer. Many types of injury to the peripheral nervous system (nerves outside the brain and spinal cord) can be repaired surgically and it is important to follow-up the patient's recovery and determine the outcome of the surgery. Because few nerve injuries are identical and there is little agreement on the best approach for diagnosing and treating nerve injuries, current management is very variable. As a result of this, there is very little clear information to suggest how such injuries should be treated.

Thanks to more than £159,000 of funding from Action Medical Research, a team at the

University of Edinburgh has developed two new tests which could be used to assess the extent of nerve injuries and to measure nerve recovery after surgery. Such a strategy will ultimately improve the way that nerve injuries are treated. Honorary Consultant Mr Michael Glasby headed the three-year study, which used carefully selected models of the main types of nerve injury and followed them up after surgical repair.

The new techniques use extremely sensitive methods of measuring the electrical impulses as they travel along the nerves. The research team showed that their techniques were accurate, reproducible and clinically practical – meaning that they could be used in Outpatients Departments. Their successful work will be of considerable value in the future, but further work and tests are needed first.

In addition, the research team used a new method of repairing nerves which involved 'biodegradable wraps' to hold the damaged nerves in place. They found that using the wraps proved just as effective as conventional nerve repair surgery. This exciting finding has enormous potential in developing countries, and could also save the NHS money as no special equipment or training in microsurgery is needed.

Michael Glasby said, "Nerve injuries are fortunately rare but always severely debilitating. There has been considerable progress over the last fifty years but even now repaired nerves never recover anything like normal function – a great deal more has to be learnt. Action Medical Research, by supporting these avenues of research, is contributing significantly to the advancement of peripheral nerve surgery."

MRI scans predict brain damage in babies

Most people associate stroke with the elderly, but sadly some babies suffer stroke when they are born. Neonatal stroke affects one or two in every 4,000 babies. It is thought that clots of blood or small pieces of tissue from the placenta get into the bloodstream and pass through to the arteries going to the brain.

Using MRI scans taken soon after birth, an Action Medical Research team has been able to predict accurately, for the first time, the extent of movement disability in young children who have suffered such a stroke. The team, based at the Hammersmith and Queen Charlotte Hospitals and Imperial College in London, studied 22 children in the project. They were all born at full term mostly to first-time mothers. The babies usually appeared well at birth but started to have fits within the next 12-36 hours. MRI scans done soon after the fits showed that these children had suffered brain damage on one side of the brain due to a stroke that happened around the time of birth.

The researchers examined MRI scans of the babies' heads to identify the areas where brain

damage had occurred. The babies' progress was then monitored as they got older. Using this information, the team has shown that the predictions they made soon after birth of whether a child would go on to develop mobility problems proved accurate.

Lead researcher Dr Frances Cowan told Touching Lives, "We have been able to show which injuries to the brain result in the most debilitating conditions. Knowing early on exactly what physical outcome is likely for the child will enable interventions to be made to maximise the potential that every child has.

"It is especially important for parents and teachers to know that a child, who for the most part appears quite normal, has a genuine reason for movement difficulties. If they are slower or not so neat and tidy this is not just carelessness. They should not be reprimanded and they may need some extra time and support. What is remarkable is how well many of the children do and part of our ongoing studies involves using tests that help us to try and understand how these children cope with their stroke. We hope these studies will assist us in knowing what interventions are most beneficial."



Many thanks go to leading vitamin supplier Zipvit who raised a very healthy £25,000 for Action Medical Research. The Charity's mascot Paddington Bear was on hand to accept the cheque from Sarah Dinshaw (left), Customer Services Manager, and Terry Wright, Packing Supervisor at Zipvit HQ.

New test for genetic disorder



Dr Diana Baralle

Neurofibromatosis is one of the most common genetic disorders. Of the two types of neurofibromatosis, type 1 (NFI) affects around one in 2,500 babies born in the UK. NFI causes significant abnormalities including skeletal deformities, tumours of the central nervous system, learning difficulties and blindness. The symptoms of the disease

are very variable – especially in younger patients – which can make diagnosis difficult.

The exact function of the gene affected in NFI is unclear, and hence little is known about how changes in the gene result in the disease. In addition, the NFI gene is a very large and complicated one, which until now has presented a major challenge to the development of a straightforward genetic test that can be used routinely by doctors.

Thanks to a £92,000 grant, Action Medical Research Training Fellow Dr Diana Baralle has used a new form of genetic analysis to develop a rapid and accurate method for testing the NFI gene. In the two-year study at Addenbrooke's Hospital, Cambridge, Dr Baralle analysed DNA samples from 167 patients, allowing her to investigate changes in the NFI gene that cause the disease.

This work will have a major impact on the lives of sufferers. Not only does this mean that the diagnosis in patients with

NFI can now be confirmed but also that risks to other family members can be assessed more accurately. In addition, Dr Baralle's success has helped to advance our understanding of the complicated process of how genes work within the body, and how abnormal genes can lead to diseases such as neurofibromatosis. This is crucial for the development of future treatments.

Dr Baralle told us, "I have thoroughly enjoyed my training fellowship. It has allowed me to pursue my research interests full-time for two years. I'm sure the research experience has made me a better clinician. I looked in detail at the gene that causes NFI and this led to the development of an efficient genetic test for the disorder. Further studies are ongoing and very exciting – I hope to continue working in this field in the future."

Take part in a 100-mile cycling challenge

Could you meet the challenge of cycling 100 miles from Bath or Bristol to London? Action Medical Research is putting out a rallying cry for riders to take part in the Action 100 Bike Ride this summer.

Ride organiser Richard Westropp said, "We're aiming to raise in excess of £40,000 for Action Medical Research, which was our 2003 fundraising total. The Action 100 is a fabulous challenge and it's time to start thinking about training now. Not everyone who takes part is a keen cyclist and it's certainly a great motivator for getting fit for the summer!"

The route takes 350 cyclists along the old A4 through beautiful countryside. The ride suits all abilities, with plenty of refreshment stops and a leisurely lunch at a country pub. Return transport to Bristol and Bath for both rider and bike is provided. At just £12.50 to register, all sponsorship raised by riders is donated

direct to Action Medical Research. Richard continued, "There's always a really warm welcome for riders at the finish at Chobham Rugby Club and we always have time for a beer or two before hopping on the coach to take us back to Bristol and Bath."

With days getting longer and the weather becoming warmer, there couldn't be a better time to saddle up in preparation for the Action 100.

If you would like to take part in the Action 100 Bike Ride on Sunday 24th August, please contact Roy Clarke on 0117 970 6348, email him at registration@action100ride.org.uk or visit www.action100ride.org.uk



Walking back to happiness

Daniel Sartin meets Dr Mark Taylor – a man with a mission to keep Britain’s pensioners on the move.

When Mark Taylor’s mother was advised to have a knee replacement operation, she knew just who to turn to for advice. Unlike most of us, she has a leading expert on knee replacement in the family! “I just gave simple advice really,” says Mark. “If I was having a knee replacement I’d want to go to a surgeon who was doing a reasonable number of operations each year: If one surgeon was doing five a year, and another 50, I’d go to the guy doing 50!”

Mark has been advancing our understanding of knee replacement and prostheses for much of his working life. Graduating from university in 1991 with a degree in Mechanical Engineering, it was his Master’s degree in Bioengineering that crucially led Mark to get interested in the application of engineering to the human body. And, whilst

completing his PhD thesis in London, Mark first came into contact with Action Medical Research – for 18 months of his study he was employed as a research worker on a project funded by the Charity to investigate stresses on the bone after knee replacement surgery. Now things have come full circle and Mark is lead grantholder for a brand new project which aims to shed further light on this common medical procedure.

30,000 knee replacement operations take place in the UK every year, making it almost as common a procedure as hip replacement. When you add worldwide demand to this figure – 266,000 knee replacement operations are performed in the United States each year – you can see clearly the importance of perfecting both surgical technique and design of implant. Ageing populations in richer

nations means there will be no let up in demand for the surgery in coming years.

An independent project

Based at the School of Engineering Sciences in the University of Southampton, the three-year Action Medical Research project began in September 2003 with a grant of £83,000. “We were delighted to receive our grant from Action Medical Research,” Mark told me. “It means a lot to have funding from such an independent source. It is often difficult to get funding from orthopaedic companies for fundamental research, as they are often interested in advancing a particular design concept. Not being tied to looking at a specific implant’s design means we can go right back to basics, and hopefully get the best possible outcome.”

Incredibly there are some 30-40 different designs of knee implant on the market in the UK, with significant differences between designs. Mark explains, “One thing we are concerned to do is assess these differences in design. Manufacturers will do fatigue tests on implants – they might apply a load to a knee implant and put it through a machine for up to five million cycles to see if it breaks. But the human body is much more complex than that, and how the implant operates when it’s actually inside the body can make all the difference to its longevity. We use highly sophisticated computer models to simulate the body’s interaction with the implant.”

Computer simulation

The success or otherwise of this project lies in the development of new testing models for knee implants, Mark says. “We want to use computers to simulate the effects of somebody walking and performing other daily activities, so we can evaluate the stresses on the bone within the knee. Part of this project will then look at the design of the implant and reach conclusions on what is best – for example, would you want to use a two pegs, keel or stem design to maximise the fixation of the implant to the bone? But just as important to outcomes we think is surgical technique. Surgeons are human beings, and as such they can never be 100 per





“We were delighted to receive our grant from Action Medical Research, it means a lot to have funding from such an independent source. It is often difficult to get funding from orthopaedic companies for fundamental research...”

Dr Mark Taylor

cent accurate. As an engineer I know that in manufacturing you expect accuracy to be within a few tenths or hundredths of a millimetre. But the reality of surgery means that when the surgeon puts the prosthesis in, accuracy may vary by as much as two or three whole millimetres!”

Factors such as the surgeon’s level of skill and their performance on the day can have a significant impact on the long-term success of the operation. So Mark and his team’s computer model will assess what impact poor alignment of the prosthesis can have on performance. “We need to see what effect differences in position have on performance and function of knee implants – physically how the implant moves within the body, and the stresses poor alignment will generate within the shinbone. If you take two of these 30-odd designs on the market, one may be insensitive to these variabilities in the surgeon’s style, the other might be very sensitive. Our aim is to push forward the methods

available to assess implant performance, which in turn should help to generate knee designs which can work well with all different surgical styles. What we discover should also help surgeons to refine and improve their techniques.”

Inspiration and perspiration

Mark is deeply committed to pushing back the boundaries of our knowledge of knee replacement. And this, he says, is usually achieved through sheer hard work. “I admit I can get wrapped up in the scientific challenge of my work. That’s what attracts me to the profession after all – there are too many unanswered questions! So I sit in on surgery a couple of times a year to refresh myself as to the reality of surgery and the practicalities facing the surgeon. As an engineer I can’t afford to forget that this is all about patients undergoing surgery at the end of the day. But it’s precisely because our team does work in a School of Engineering Sciences – alongside aerospace and automotive engineers – that we can achieve so much. This cross-

fertilisation of ideas between disciplines gives a huge impetus to our work. We assess the most advanced techniques and materials available and apply them to the medical sector.” **TL**

History of knee replacements

- The first knee replacements in the 1960s had awful failure rates. Using just a simple hinge they would cause horrendous problems, often twisting straight out of the bone.
- Before this, the options were even worse. In what was known as ‘fusion’, surgeons would break the bones in the leg and reset them in a straight line.
- Knee replacement as we know it, with implants designed to mimic the real joint, was pioneered in the early 1970s by surgeons Michael Freeman and Jon Insell, and the engineer Peter Walker.



Components from a commonly used prosthesis

Grateful thanks go to The Herbert and Peter Blagrove Charitable Trust for their support of this grant.

Someone who wishes Dr Taylor all the best with his work is Lottie Scarborough of Hove in East Sussex. Lottie has had two hip replacements because she was, in her own words ‘mad with pain’. But unfortunately for her the arthritis that caused the problems in her hips has now spread to her knees. Lottie takes up her story: “I have good days and bad days with my knees – when I try to walk I can wince with the pain. I use a spray on them at night and take a couple of painkillers, but I still usually manage just a couple of hours of sleep.” Lottie, aged 87, is more than keen to keep independent and mobile, and understands better than most the difference a hip or knee replacement can make to quality of life. “I like to be independent. I’m a bit too independent sometimes! I try my best to keep active by walking to the local shop every day, but I used to love to go much further afield in my younger days. My grandmother would pack a basket with sandwiches, and we’d take the penny tram to the end of town and then go walking in the countryside for miles.

“Losing your mobility is definitely the worst thing about getting old. I get frustrated – there are things I’d love to do but can’t because of my knees.” Lottie is in no doubt as to the importance of Mark’s work. “I wish him well,” she says. “I’ve no doubt in my mind that I wouldn’t have lasted if I couldn’t have kept mobile and independent. Life would have been just too miserable.”



Mobility means Lottie can do things for herself, like the weekly shop

The Doctor's notebook

Dr Mark Porter writes for Touching Lives to address some common health concerns. In this Spring issue he advises on **hayfever**.

Who gets hayfever?

Hayfever is now the most common long-term illness in Britain. It typically develops in childhood and is most troublesome in 15 to 25-year olds – one in four British teenagers now has the condition. The number of GP consultations for hayfever has quadrupled in the last 30 years. The season typically runs from May to July but recent warm summers have seen that extend from February to late August – particularly for those sufferers sensitive to tree pollens released early in the year.

Men and boys are more likely to suffer than women and girls. Hayfever often runs in families and is closely associated with asthma and eczema. It is also more common in people born in spring and summer and in those brought up in homes where parents are cigarette smokers. Most people will eventually grow out of it, severe hayfever being unusual after the age of 45.

Cities or the country?

Hayfever tends, paradoxically, to be more of a problem in urban environments than rural ones. This may seem strange but pollens produced in the countryside are easily carried into densely populated towns and cities where their impact on the delicate linings of the eyes and nose of hayfever sufferers is thought to be magnified by other irritants such as traffic fumes and other air pollutants. People living on the coast tend to be least affected.

Which treatments work best?

Step 1. Avoid unnecessary contact with pollen. Wear sunglasses, keep your doors and windows shut at home, and avoid spending too much time outside first thing in the morning, and in the evening, when counts tend to be highest. Keep your car windows closed and, if possible, choose a car with air conditioning and a pollen filter. Be careful not to wash pollen from your hair into your eyes when showering.

Step 2. If you only get symptoms on a few days then keep a packet of antihistamine tablets handy and take as required (ask your pharmacist



to point you in the right direction of the modern non-sedative types). If you have more persistent symptoms use a nasal spray for sneezing and other nasal symptoms, and eye drops for itchy red eyes. I prefer steroid nasal sprays (particularly good for a blocked nose) and cromoglycate eye drops – both are available on prescription and over-the-counter. Make sure you follow the instructions to get the best out of them.

If a nasal spray and drops fail to control the symptoms, I add in a regular antihistamine tablet. If all three fail I sometimes consider a short course of steroid tablets – long acting steroid injections should be avoided.

What's new?

Immunotherapy is the only chance of a cure and is becoming increasingly available in the UK. The standard approach is to give a course of desensitising pollen injections, but drops under the tongue are sometimes used instead. Both techniques are best supervised by a specialist

allergy clinic – of which there are far too few in the NHS. Treatment can last up to six months, but won't work or be suitable for everyone. Only severe sufferers are likely to be eligible for treatment on the NHS.

Researchers in Australia have come up with a vaccine to rye-grass pollen – one of the most common triggers in the UK – but it's in very early stages and trials of similar 'breakthroughs' in the past have proved disappointing.

What is the alternative?

Petasites hybridus (butterbur, or bog rhubarb) contains anti-inflammatory chemicals, and a recent study published in the British Medical Journal found that it compared favourably with an antihistamine for the treatment of hayfever. The study used a dose of 32mg of butterbur extract per day – the safest way to take butterbur, as the plant contains toxins that are removed during manufacture. You can buy a similar product from pharmacies or health food shops at around £6 for a month's supply.

“Men and boys are more likely to suffer than women and girls. Hayfever often runs in families and is closely associated with asthma and eczema.”

Fundraising forum

Why I support Action Medical Research



Suzanne Clarke from Derby talks to Touching Lives

How do you support the Charity?

Through my salary. I've been supporting Action Medical Research in this way since 1996. I want to give regularly, and without any hassle.

What do you do for a living?

I work as a Premium Adviser for the Royal Bank of Scotland Group (RBSG). We deal with high asset customers and tailor banking services to their requirements.

Why did you decide to give to Action Medical Research?

We had a visit to our workplace from someone who explained the benefits of giving to charity through your salary. That was really useful – having someone come down and explain things to us face to face. She had a list of charities we could give to but Action Medical Research appealed most.

Does your employer do anything to help?

RBSG double any contribution that staff make through their payroll, which is a great incentive to give. Once you've signed up that's it, it's all taken care of.

Is there any area of the Charity's work that is particularly important to you?

The children's side is very important. I've always loved children, and childhood diseases are of particular concern to me. I'm even more conscious of the need to contribute to this area now! We've just had our first child, Benjamin, so his health and wellbeing is top of our list of priorities.

For more information on payroll giving go to www.action.org.uk/payroll or telephone Marcia Hibberd on 01403 327435.



Don't miss out on a 'bearilliant' party

Action Medical Research is calling on schools and children's groups to join the biggest ever Bring Your Bear party between 21st and 25th June. Ideal for schools, nurseries, and Guide, Brownie and Cub packs, the Charity hopes over 1,000 groups will join the fun and organise events to raise £125,000 to help sick children.

Last year over 800 schools took part raising £102,000 to help the Charity in its work. Val Richards, Head Teacher at Seaton House School in Surrey said, "Our school took part in Bring Your Bear 2003 and it was a really fun day for everyone. We held a teddy bears' picnic and a raffle and raised over £200. We will definitely be taking part again – it's one of the highlights of the school year!"

The event is held to celebrate Paddington Bear's birthday. Action Medical Research asks people to bring their bears to school or work and get involved in fundraising activities to help celebrate. It's an enjoyable, easy and educational way for groups to support the Charity. There are lots of 'bearilliant' activities and there are also bears and badges to be won.

For the second year in a row 'Big Brother' presenter Davina McCall has given her support to the event. She said, "Being a mother of two, I can see the important part Action Medical Research plays in helping babies and young children. So whatever you do, don't miss out on the fun!"

Do you know a school or children's group that might want to get involved? There are lots of great activity and fundraising ideas in the information pack. Call 01403 327444 or visit www.action.org.uk/byb

As a charity, Action Medical Research is entirely reliant on voluntary donations. Here we profile news and views from our events and fundraisers

Legacies update

In the last financial year Action Medical Research received over £450,000 from gifts left in supporters' wills. This vital income comes to us from people who not only supported the Charity in their lifetime, but also had the foresight to plan ahead to help us continue to provide funding for future medical research projects.

Legacies are vital to the future of Action Medical Research and its work, and can make such a difference to the number of projects that we fund. Forty people have told us this year that they have chosen to support us in this way. Some have been asked by their solicitors to leave a gift to a charity and have chosen Action Medical Research. Others have seen articles in *Touching Lives* on the benefits of leaving a gift – including savings on Inheritance Tax – which have prompted them to take action. But leaving a legacy is something that many people will not have considered simply because they have not been asked, or did not know this was an option open to them.

The £450,000 accounted for the following projects last year: In July 2003, £147,000 was awarded to research into preventing hip dislocation in infants with cerebral palsy. In the same month a grant of £176,000 was awarded to aid identification of the source of epileptic activity in the brain. £94,000 was awarded to a project on healing difficult bone fractures using cell therapy. In November 2002, £29,000 was awarded to a study into rheumatic disorders in which bones in the spine can fuse together. Little is known about the causes of all these chronic disabling conditions, and it is hoped that increased understanding will lead to new treatments. Without legacy income these or similarly important projects would have had to be rejected due to lack of funds.

These projects have the potential to make a positive difference to the health of everyone. You could help us to fund more crucial research by choosing to remember us in your will. For more information on how to leave a legacy to Action Medical Research, please call Jane Tarrant on 01403 327414 or email jtarrant@action.org.uk

New fundraisers off the blocks

Touching Lives is delighted to report the establishment of a new fundraising committee in Northern Ireland. Dynamic chairman Chris Henderson and ten friends held their first 'Sports Celebrity Dinner' at the end of January, raising a fantastic £23,000.

Community Fundraising Manager Pam Anstey said, "I was thrilled that the group's first fundraising event was such a success. They put in a lot of hard work, and it has more than paid off – for a new committee to have raised such an amount is a big achievement."

Did you know?

Action Medical Research has a network of over 200 fundraising groups across the UK. Call 01403 210406 to find the one nearest to you.



Among the 300 guests were (l-r) Lady Girvan, auctioneer Columb Henry, snooker champion Dennis Taylor, Chairman Chris Henderson, guest speaker Willie John Dolan, Committee member Derek Curtis and Patron Pamela Ballantine. Here they gather round the Sam Maguire Cup, the Gaelic Football equivalent of the FA Cup.

News in brief

● **£76,000 has been raised thanks to Lloyds TSB's sales of Paddington clippy badges in their 2,000 branches. A spokesperson said: "The Paddington Appeal has captured the imagination of both staff and customers, without doubt being the most successful counter campaign we've run."**

● Action Medical Research has benefited from a Christmas windfall from the Royal Bank of Scotland Group for the second year running. In December RBSG donated an extra £50,000 to the Charity for being one of the top ten causes supported by their staff through payroll giving. Thanks go to the Group and to our RBSG payroll supporters.

● The Maldon branch of Action Medical Research helped organise a fantastic concert at Layer Marney Tower, near Colchester in Essex. Over 2,700 people attended the classical music concert which ended with a breathtaking fireworks display to accompany Tchaikovsky's 1812 Overture. Over £7,000 was raised.

● Stubbings Nursery in Maidenhead have raised a fantastic £2,500 through sales of Christmas trees. A donation was made for every tree sold.

● Over 150 Machu Picchu veterans met up in a Birmingham hotel in February to celebrate their achievements on behalf of the Charity and generally have a good time. It was also an opportunity for Action Medical Research to thank the trekkers for raising an incredible £1 million through their adventures. The friendships and team spirit forged in Peru certainly made it back to the UK intact. For more info see www.action.org.uk/peru



Research review

Action Medical Research has awarded more new project grants to researchers across the UK. Daniel Sartin went to find out about them.

The sacred disease

What links Hercules, Julius Caesar, Alexander the Great, Charles Dickens, Handel, Byron, van Gogh, and Dostoyevsky? The answer is that they all suffered from epilepsy. Epilepsy is clearly no barrier to greatness; but it is a seriously debilitating condition, which is still common throughout the world.

The first descriptions of epilepsy are acknowledged to be those found on Babylonian tablets dating back to 2000BC. But it was the Ancient Greek physician Hippocrates who, in 400BC, wrote his essay 'On the Sacred Disease'. Until that point our ancestors associated epilepsy with possession by spirits, but Hippocrates brought the condition back down to the realm of earthly things. "I do not believe that the Sacred Disease is any more divine or sacred than any other disease, but on the contrary, has specific characteristics and a definite cause," Hippocrates reported from Kos.

Fast forward 2,400 years to a London laboratory, and I am witnessing the first successful use of Transcranial Magnetic Stimulation (TMS) to record brain signals. Hippocrates would be impressed! Doctors Gonzalo Alarcon, Antonio Valentin and Professor Kerry Mills are convinced that it will be possible to use TMS to provide a reliable and non-invasive diagnosis of epilepsy for patients. Action Medical Research has given the team, based at King's College Hospital, £40,000 to validate their theories.

Early and accurate diagnosis

Dr Alarcon explains, "Around 440,000 people in the UK have epilepsy, making it the second most common neurological condition after migraine. But in about one third of patients, it is impossible to get a sound diagnosis and confirm they actually have epilepsy – especially when the condition is in its early stages. If our project is successful we think we will be able to get an earlier and more accurate diagnosis 95 per cent of the time."

It is important to get an early diagnosis because epilepsy gets worse if untreated. Caused by the over-excitability of neurons in the brain, the 'excitability' spreads out across larger areas of the brain over time. An earlier diagnosis leads to earlier treatment, hopefully nipping the condition in the bud and certainly reducing the other risks associated with epilepsy, namely injuries caused from the seizure itself, such as falls. One in 20 of us will have a seizure at some point in our lives, so it is important to have a quick, reliable and non-invasive test to identify the minority who will develop long-standing epilepsy.

Currently diagnoses are made using a standard Electroencephalogram (EEG). The EEG machine is normal equipment found in every NHS hospital which measures brain activity through the patient's scalp. The problem with the EEG is that 50 per cent of patients with epilepsy won't show up any abnormalities. The EEG records spontaneous wavelengths for an hour or so, and the doctor will look for evidence of abnormal waves – each one representing a very tiny seizure. "It's just a fishing expedition really. You're waiting for things to happen and if they don't happen while you're recording

you miss it, and then you won't know if the patient has epilepsy or not," says Dr Alarcon. "So we thought 'if epilepsy is due to excessive excitability and excessive responsiveness of the brain, we should be able to detect it by stimulating the brain ourselves' – so that's what we did."

From SPES to TMS

A traditional method for identifying the region of the brain causing the seizures in confirmed epilepsy patients has been to use electrodes to monitor brain activity. These electrodes can either be on the surface of the head, or be 'depth electrodes' – tiny pins inserted into the brain of patients being considered for surgical treatment. The patient then has to wait in hospital until they have a spontaneous seizure, and the abnormal area of the brain can be identified. Single Pulse Electrical Stimulation (SPES) takes this test further. Prior to their Action Medical Research award, Doctors Alarcon and Valentin pioneered SPES using the depth electrodes to stimulate the brain with small electrical currents. The response to the current gives away the health of that part of the brain, with delayed responses showing abnormalities.

Dr Alarcon continues, "SPES is a very consistent and successful way to find the area of the brain causing the problems. When we stimulate the brain it's easier to identify abnormal reactions than with the spontaneous EEG alone. If we find delayed responses we know it's abnormal and we can remove that area if we think there's a chance the patient will be seizure free. But so far we've only used SPES with depth electrodes inside the brain. The aim of our project is to find a similarly reliable test that will



The painless magnetic pulse is applied to Ana's head

Action Medical Research awards new project grants



Doctors Valentin (left) and Alarcon examine the EEG output

allow us to diagnose epilepsy without us having to be invasive, or to make the patient wait in hospital until they happen to have a seizure. The only way to stimulate the brain through the skin is through magnetic pulses –

so we're using these and trying to measure the brain's reactions."

Back to the lab where our story starts, and the first successful use of Transcranial Magnetic Stimulation is coming to an end. Volunteer Ana Gomez doesn't have epilepsy, but it's essential to make sure the equipment is working properly before using it on patients. The TMS machine creates a sudden magnetic pulse that stimulates the brain; the EEG machine then records the brain's response. This seemingly simple marriage of two pieces of existing NHS equipment could be just what epilepsy sufferers and their families have been waiting for:

The team will be selecting another 30 healthy volunteers to act as controls. Patients who are due to have SPES on the hospital ward will have the TMS prior to their admission. Then the Action Medical Research team will be able to compare the effectiveness of TMS with SPES in finding abnormal brain responses. "We hope that the external TMS test shows up what the internal SPES test does. It would be of incalculable benefit to have a non-invasive, reliable test for epilepsy – not just in the UK, but all over the world."

Grateful thanks go to SEARCH for their support of this grant.

Epilepsy: my story

Denice Barnaby from Herne Hill in London has had to live with severe epilepsy since 1986. Triggered by a blow to the back of her head, this one accident has, she tells me, "messed up my life, basically."

"I used to get really bad grand mal seizures – really big and bad – all the time and at any time without warning. I'd lose count of the number I'd have in a month. I was all over the place, and it continued like that for best part of five years.



Denice and her brainwaves are monitored closely

In the first year I didn't even go to my GP. I'd never heard of epilepsy, so I just put it down to me passing out. My family were the ones who made me get help. I had a seizure in front of them one day – after that experience they made me go to the doctor immediately! My GP sent me for tests at St Thomas' Hospital in London. I waited three months for the results, and then was finally told that I had epilepsy. I was given some leaflets about the condition and a prescription – then they left me to get on with it!"

But the medication Denice was given made her worse, and her seizures got further out of control. The side effects of the medication did little to improve Denice's quality of life either; the tablets made her drowsy at all times of the day. Her GP lowered her dosage, but she was still fitting regularly.

"This went on for ten or 12 years. I tried all types of medication but nothing helped."

She's in King's College Hospital today to have the SPES treatment, and is waiting on ward until she has a seizure which can be measured.

"They're trying to find out where my epilepsy is coming from. Apparently I'm having them in my sleep which I never realised – they picked it up on the monitors here. The seizures are very frightening. I can feel them coming, and then I visibly start to shake. My family have been brilliant through all this. I really hope that my life will get back on track soon. Previously I was very against having the operation to remove the affected part of my brain, but if my epilepsy is pinpointed during this stay I will have the operation – it can just make your life so much better."

The doctors here at King's are absolutely brilliant – I'm delighted that they've been recognised as such by Action Medical Research."



Denice Barnaby

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200251

Finding an alternative to antibiotics

“We’ve been wanting to do this study for years but could never get the funding at the same time as the equipment we needed. So we’re particularly delighted to receive this timely £82,000 grant from Action Medical Research,” says Andy Melling, a research worker on a new project based at the University Hospital of North Tees in Stockton on Tees.

Wound infection after surgery is still a major cause of ill health and patient suffering. There is a risk of wound infection after any surgery, but with breast surgery – typically following the diagnosis of breast cancer – infection rates can be as high as 18 per cent. Breast surgery can be a



Andy Melling with a patient demonstrating the warming blanket

devastating life event for any patient and wound healing complications only increase the trauma and suffering.

Andy Melling is keen to improve this situation: “There is very little evidence to support the use of antibiotics during breast surgery. There have been studies which show they reduce the infection rate slightly – but really they’re pretty ineffective. Whereas our previous study (also funded by Action Medical Research – Ed.) showed that we could reduce infection rates by 60 per cent by warming the patient prior to surgery. It sounds so simple – and that is probably why we will need to work twice as hard to convince the sceptics that warming people can be a realistic alternative to the use of antibiotics.”

To build on the success of their earlier study, the research team, led by Professor David Leaper, will compare the use of antibiotics with warming on the rate of wound infection after breast surgery in 300 women over two years. It is also important to investigate alternatives to antibiotics as bacteria are becoming increasingly resistant to the drugs.

“If our new project adds to the scientific evidence, our aim is to have patient warming as standard practice for many types of surgery across the NHS,” Andy told Touching Lives. “It could have an enormous impact on patient health.”

New treatments for emphysema

Action Medical Research has just awarded £85,000 to Dr Ravi Mahadeva, based at the University of Cambridge. His three-year project will investigate Alpha-1 antitrypsin, a major anti-inflammatory protein found in the lung.



Dr Mahadeva

Unfortunately, as many as one in 2,000 northern Europeans inherit a variant of Alpha-1 antitrypsin with an abnormal structure. The abnormal protein accumulates in the liver causing childhood cirrhosis (degeneration of the liver), and in the lungs causing emphysema from the age of thirty. There is no known cure for emphysema. Affected individuals suffer terribly with chronic breathlessness as the lungs are progressively destroyed. Patients eventually die from respiratory failure.

Dr Mahadeva and his team aim to study lung tissue from individuals who have the abnormal protein to find out exactly how it causes emphysema. In so doing they hope to design new treatments for this distressing and fatal disease. **TL**

We’ll be reporting on more new grants in our next issue.

Meet the Researchers



Neil Shah is a Consultant Paediatric Gastroenterologist based primarily at Great Ormond Street Hospital. Living in Pinner, North London

with his wife and two sons, Neil, 36, is working with others on an Action Medical Research project investigating gut failure in children.

How did you get to where you are now?

I studied molecular biology as an undergraduate which led to my interest in research. I then trained in adult liver and gut problems at the Royal Free Hospital, and then did my paediatric training at various hospitals. I also was an Action Medical Research Training Fellow specialising in gut failure in children – where there is a total failure of the body to absorb nutrients from food – before getting my post at GOSH. In the middle of all that I managed to get some time off to go travelling with my wife all over south-east and north-east Asia. We'd always wanted to go and had a fantastic time.

Have you always wanted to be a doctor?

Yes, I've always wanted to be a kids' doctor in particular. I love kids and I always thought it would be more fun than working with adults – which it is!

What are the most rewarding aspects of your job?

The place I work is just amazing. What you see and what you get to do at GOSH makes you very humble, and I'm proud to work there. It can be fantastically rewarding to see a child who's been ill for a very long time make a recovery.

What might you do in an average working day?

There isn't an average working day! But I do lots of ward rounds, hold clinics, and do a lot of endoscopies.

What other skills does your job require?

My job is a real people person's job. You need to be able to deal with people at all sorts of levels and from all walks of life.

What do you do when you're not working?

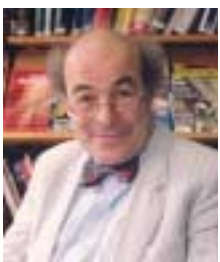
I'm a full-time Dad. Our first son is seven now, but number two is just four months old. Luckily this one is a sleeper! Our kids have absolutely fantastic grandparents who help us out an awful lot. We get help with babysitting, so we can still go out clubbing with our mates. Some of our friends are DJs so we see them play as often as we can.

Where did you go on holiday last year?

Again the grandparents excelled themselves! We went to Machu Picchu which was brilliant [you can go to Machu Picchu too! see www.action.org.uk/peru – Ed.]. Although a weird effect of El Niño turned the weather from an expected 30 degrees to minus three!

What would you do if you weren't a doctor?

I'd love to be an astronaut!



Jargon busters

TV scientist Professor Heinz Wolff explains some common – and some not so common – medical and scientific terms.

In this issue of Touching Lives there is mention of the measurement of electrical impulses in nerves which are being repaired, the EEG (Electroencephalogram), and the EMG (Electromyogram). Also, many people will have had an ECG (Electrocardiogram) test at some time in their life.

All these terms relate to electrical signals which can often be picked up from the skin, near the organ where they originate. However, electricity does not flow along nerves like electricity in normal life flows along wires. Just remember that the inside of the body is wet, and that the material from which nerves are made is not very different from wet string, insulated sometimes by

a layer of something rather like lard! An impulse is carried along a nerve fibre quite slowly – at the most at about 100 metres per second – whilst electricity in wires travels at about 300 million metres per second.

What travels along the nerve is a temporary change in the electrical balance of the membrane which separates the inside of the fibre from the outside. Once started, the impulse propagates along the nerve, renewing itself all the time by taking a little bit of energy stored in the fibre. This gets over the losses caused by poor insulation and having nothing better than salt water to conduct the electricity. This 'region of depolarisation', as it is called, produces an

electrical signal by a bit of chemistry not unlike that of a small battery.

When muscle cells contract they also produce an electrical signal, for much the same reason as a nerve fibre. Conversely, applying an electrical signal to them can stimulate both a nerve fibre and a muscle cell. Some electrical slimming aids use this effect.

Signals that are measured in an EEG originate from the millions and millions of nerve fibres in the brain. The EMG is produced by the contraction of muscle cells. The ECG records the activity of the muscles and nerve-centres of the heart. All these signals are used for medical diagnosis.

My story

Memories of Lana

There's a small box of precious memories at Liz Keeble's Merseyside home, full of things that belonged to her baby girl Lana. There's a diary too, a compelling and heartbreaking account of little Lana's struggle for survival against the odds. Liz contacted Action Medical Research in the hope that her story might give some solace to other parents who tragically lose a preterm baby. She has allowed us access to her diary, and the quotes you read are direct extracts from it.

For Liz, every day is shaped in some way by the short life of her little girl Lana. Lana's photograph is on the mantelpiece, her three brothers know of her and talk about her; and on Lana's birthday each year, the family does something special together:

It's almost five years since Lana died aged just over three months old, but tears still come easily to Liz as she talks about the little girl who left such a lasting impression on her family.

The really bad days, when Liz wondered how she would get through, are much rarer now, and

there's comfort in watching her sons Sam (6), Finn (3) and Joe (2) grow and thrive. But Lana is never far away.

Liz went into labour at just 24 weeks. The family was living in London at the time, but Liz and Jon had got married in Liverpool and actually spent their wedding night in hospital, because Liz had started to feel unwell at her wedding reception. Liz was in hospital for three weeks, and Jon had to return to London, only able to visit at weekends. It was the beginning of a rollercoaster of emotion and long, painful separations from Sam, who was just 15-months old at the time.

good. She was managing to feed and could soon breathe unaided.

Liz had been in hospital for three weeks before Lana was born, then visited her every day for another nine weeks before she was strong enough to be allowed home and the family could be together again in London. It had been a traumatic time.

“... we sat and stared through the windows of your incubator...”

Liz told Touching Lives, “Jon is a lawyer and had to go back to work, and Sam was staying with my mum, which was a huge help, though I missed him terribly. We couldn't wait to be back together again and start to put the nightmare weeks behind us.”

Liz had started to keep a diary while Lana was in hospital. She said, “While Lana was in the Special Care Baby Unit I wrote my diary every night. It was a way of making sense of the things that were happening, and I thought I would show it to Lana when she was older; so that she could see how she battled through. I even put little drawings in, and listed every single problem that Lana had, day by day. It helped me at the time and I carried on writing after she came home.”

“... you are so tiny, so perfect... please be strong and so will we...”

“The doctors did everything they could to stop Lana being born too soon, but I kept going into labour and losing blood, and eventually on 8th March 1999, at 26 weeks 5 days, she arrived,” said Liz, who was an occupational therapist before starting her family. “We called her our little miracle.”

Lana weighed only two pounds, and was born with her amniotic sac intact. She had to be resuscitated, but though she spent the first few days in the special care baby unit, the signs were



Liz reads her diary

“... you opened your eyes for the first time. First right and then, slowly, the left. Hello darling, welcome to the world...”

But despite everything that Lana had been through, there was to be no happy ending. On the evening of June 23rd 1999, Lana was having difficulty settling after having one of her immunisations. Although she was by now six pounds in weight, she was always a sleepy baby, and sometimes difficult to rouse. She seemed uncomfortable, so Liz took Lana out of her Moses basket and held her close as she started to feed.

Liz said, “I was so tired, I nodded off, and when I woke to put Lana in her cot she felt cold. I shouted for Jon. Lana still had a pulse and because we had been taught resuscitation from the early days we started to try to get her to breathe. We lived very close to the hospital and the ambulance was with us within a minute but Lana had to be transferred to Great Ormond Street Hospital under police escort, and we were told to prepare for the worst.”

Liz and Jon were told that tests on Lana showed no brain activity. They faced a heartbreaking decision.

“Jon and I sat in a park close to the hospital. By then we knew there was no hope and we had been asked if we wanted to switch off Lana’s life support machine. It seemed so surreal as we talked about what to do, as if it wasn’t happening to us at all. But in the end, Lana took the decision away from us and died peacefully.”

“... but you haven’t gone darling... you are here, with us. We remember you, your tiny button nose, your beautiful smile...”

Parents, family and friends rallied to help Liz and Jon after Lana’s death. Liz said, “My parents were strong for me, but I know they found it very hard to bear. Losing Lana was really a very painful experience for both Jon’s parents and my own and had an impact on the whole family. There was an inquest, which was awful, though everyone was very kind.

“All I can say to other people in the same situation is that things do get better eventually. For a time Lana was in my thoughts every minute of every day and I actually believed I was going mad, but having Sam meant I had to carry on and when I found I was pregnant with Finn we started to focus on the future once more.”



Liz with her three boys (l-r) Finn, Joe and Sam

Liz continued, “Writing things down definitely helped me come to terms with Lana’s death and although I can look at her things now, Jon still can’t, it’s too painful.

“... how lucky we are to have held you... you touched so many lives...”

“What happened really put our lives in perspective. Our world was turned upside down but Lana’s death made us value what we have and made us realise how lucky we really are. Lana made our lives richer and though we still don’t really have an explanation as to why she died, I can look back at the diary and see how we have progressed and learned how to cope over time.

“My heart goes out to any other parent in our situation. Believe me, the truly awful days become less frequent and the people around you help you to heal. I also visited a homeopath for some advice, and that helped a little. The Foundation for the Study of Infant Deaths were also supportive, and reading magazines like Touching Lives made me realise that we were not alone. I support Action Medical Research and its work into premature birth, which will hopefully lead to fewer cases like ours in the future.

“In the meantime, I know I’ll think about Lana every day, we all will. She will always be our little miracle.” **TL**

The Foundation for the Study of Infant Deaths offer support and advice on 0870 787 0554.

Action Medical Research is committed to fund research into preventing premature birth and the conditions suffered by preterm babies. In the past five years alone we have funded the following projects – representing a £2million investment in the health of mothers and babies.

Pregnancy – steroids clinical trial	£108,272
Preterm infants – preventing brain damage	£170,606
Premature babies	£46,498
Premature birth – preventing premature labour.....	£103,388
Preterm babies treated with steroids	£99,432
Infection in premature babies	£184,168
Premature babies – preventing brain injury.....	£64,842
Investigating premature labour.....	£82,322
Eye disease in preterm babies	£71,123
Premature babies treated with steroids	£108,179
Preventing hydrocephalus and cerebral palsy	£114,470
Premature babies	£52,451
Premature labour	£93,569
Premature labour – investigating causes	£79,997
The effects of oxygen fluctuations.....	£65,669
Premature birth.....	£85,412
Labour – investigating its mechanisms.....	£83,423
Mechanisms controlling contractions.....	£82,880
Premature labour – how does it start?	£135,316
Premature labour	£95,931

We will be launching our new Touching Tiny Lives campaign later in the year to raise more funds to help give the most vulnerable babies a healthier start in life.

If you have a story you’d like told, contact the Editor. Details on page 3.



Pedal power!

An Action Medical Research project tests the effectiveness of exercise therapy for paralysis patients.

Exercise can be an important therapy for some spinal injury and stroke patients – and may even contribute to their recovery. But if you have lost the use of your limbs due to illness or accident, taking regular exercise isn't easy.

A study undertaken by a team at University College London has unearthed some exciting results that could have implications for the treatment and rehabilitation of the 100,000 people in the UK who suffer disability following stroke or spinal cord injury each year.

Dr Nick Donaldson heads the team who recently completed a six-month Action Medical

Research study to test the effectiveness of a special exercise treatment where electronic pulses are applied to patients' legs.

Muscle stimulation is nothing new of course – 'Superman' actor Christopher Reeve is perhaps the best known patient trying muscle stimulation technology to regain mobility – but rather than rely on electrical impulse alone, the UCL team has tried to identify how much voluntary effort the patient is using in pushing a pedal during cycling exercise.

It is a difficult measurement to obtain, but identifying this voluntary effort is important,

because the team hopes that a combination of voluntary movement, enhanced by electrical muscle stimulation, holds the key to new treatments and more effective therapy.

Electromyography (EMG) is a way of electrically recording muscle activity. A team of volunteers – six able-bodied and one patient with incomplete spinal injury – 'cycled' in the laboratory while the recordings were taken. The team could now compare EMG signals from muscles with and without stimulation.

Dr Donaldson said, "We were unsure of what we would find, but have been pleasantly

surprised. We get a high correlation between the two sets of data when we measure one tenth of a second after giving the stimulation pulse.

"This data suggests that we can assess the level of voluntary effort despite the stimulation. We will have to design a stimulator that produces pulses with irregular intervals, rather than a steady frequency, and the intensity will depend on this voluntary effort from the patient. This would lead to the development of a special tricycle where the leg muscles are stimulated only if the patient makes a voluntary effort to turn the pedals.

"It's very early days, but now that we know how to measure the voluntary effort, we have passed a major hurdle.

"Of course every stroke victim and every spinal injury patient has different needs," Dr Donaldson continued, "but by measuring the level of muscle amplification needed we can develop equipment that can be used at home and that could play a major role in providing exercise and treatment for these groups."

The team is now discussing the next stage in their study – embarking on any sort of clinical trial is a very big undertaking.

Dr Donaldson said, "The results of the six month study have been very encouraging. For the first time we can see how much voluntary effort a paralysed patient is making and this knowledge may be the key to better therapy, leading to increased functional recovery after the stroke or spinal cord injury." **TL**



Team member Dr Martin Fry makes vital adjustments to the equipment

Grateful thanks go to SEARCH for their support of this grant.

How it was discovered – shedding light on the medical advances we now take for granted

The rubella vaccine

Rubella, or German Measles as it is sometimes known, is a viral infection which mainly infects children between the ages of six and twelve, causing a slight fever and a rash. While it causes a mild illness in children, and is only slightly more serious where adolescents and adults are infected, it normally gives no cause for concern at all.

However, eradicating rubella has been a focus of much Action Medical Research funded work in the past. This is because if a woman becomes infected with the virus during the first four months of pregnancy, it passes to the developing baby and can cause severe birth defects such as deafness, blindness, congenital heart defects and cerebral palsy.

Action Medical Research's involvement with rubella research dates right back to the very first years of the Charity, when the first tests were done by Dr Kevin McCarthy and his team to screen the different strains of the virus and identify how dangerous each was. While there was initially some hope that a drug could be developed to kill the virus, it soon became apparent that anti-viral drugs were (and are to this day) very difficult to produce. Prevention by vaccination was clearly the way forward.

Throughout the late 1960s, Dr McCarthy and Dr Alistair Dudgeon, based at Great Ormond Street Hospital in London, continued working on developing a vaccine. One of the major problems for Dr Dudgeon was finding a way of

testing the vaccine. The vaccine included a damaged, live rubella virus and, while the hope was that these weakened viruses would trigger immunity without causing the symptoms of infection, there was a danger that the vaccine would still be able to cause disease.

Nuns lend a hand

Dr Dudgeon hit upon the idea of approaching a closed order of nuns for help with testing the vaccine. These women not only had little or no contact with people outside their communities, thereby minimising the risk of infection, but none of them would be pregnant. The worst that could happen was that there would be an outbreak of German Measles among the nuns. With the nuns' co-operation, Dr Dudgeon was able to demonstrate that the vaccine virus did not pass from person to person, gave long-lasting immunity, and was safe.

From 1970 the vaccine has been offered to girls around puberty, with good success rates where taken up. However, as boys were not given the vaccine, and not all girls took up the offer, the virus itself was always at large. It wasn't until the arrival of the MMR vaccine in 1988 that it was possible to set up a vaccination programme that could protect everyone from rubella.

While there has been a great deal of debate in recent years about the safety of the MMR vaccine, Action Medical Research is committed to research into vaccination as a crucial weapon in the armoury against infectious diseases. Rubella is just one of the diseases that effective vaccination could eradicate worldwide.



In the News



Crossword 6

by Esmee

In recent months, our medical research has been grabbing headlines in a variety of magazines and newspapers. And with regular mentions on major health websites, the word about our valuable work gets around.

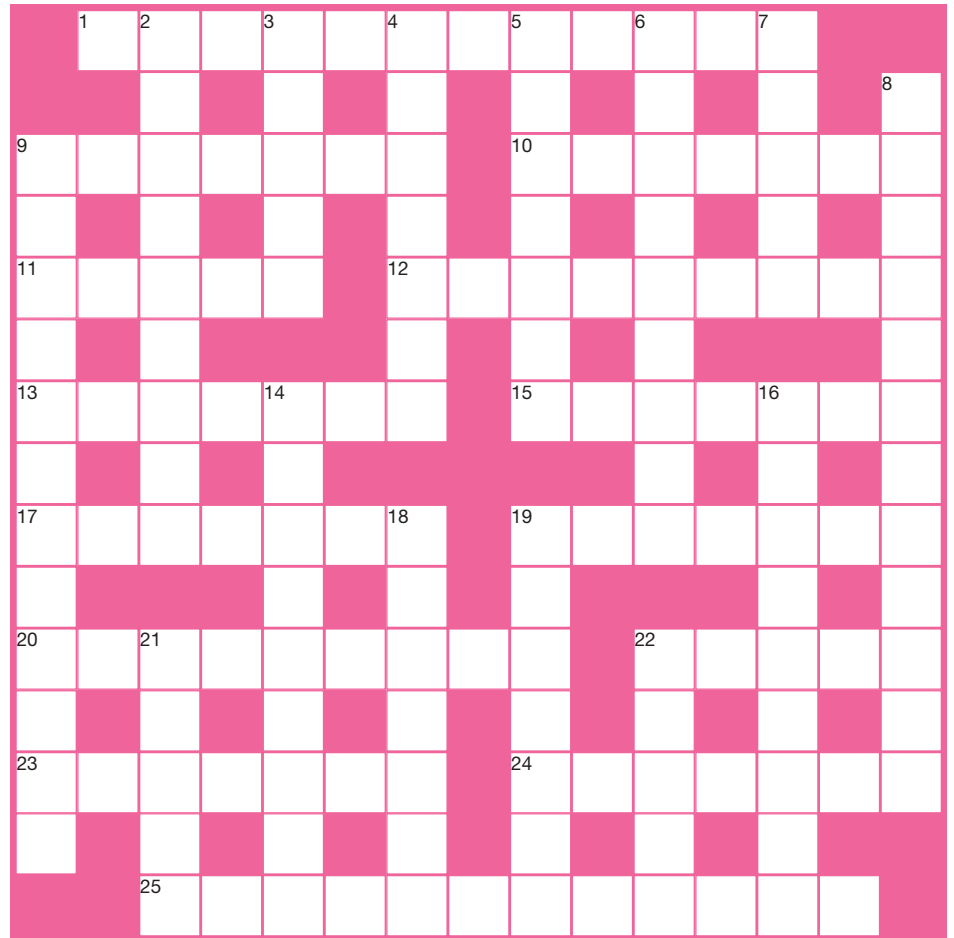
A number of Action Medical Research findings have been published lately in national magazines including a feature on Irritable Bowel Syndrome in 'Good Housekeeping' and another on bronchiolitis in 'Prima Baby'. The well-read magazine of supermarket chain ASDA also picked up on the importance of our work, printing an article on our osteoporosis research.

For the second year running, the 'Daily Mirror' ran a piece on Action Medical Research's popularity among payroll givers at the Royal Bank of Scotland Group. We are among the top ten charities that RBSG employees donate to through their payroll giving scheme and, as a result, we earned a share in a bonus donation given by the Group. 'The Mirror' featured a picture of Paddington Bear on the platform at Paddington Station with an Action Medical Research payroll giver at his side.

The BBC's website is another place where regular news of our work can be found. Articles on our research into coeliac disease, cerebral palsy and strokes in babies have featured in recent months.

The Northern Ireland 'Newsletter' has shown great interest in our research by featuring articles from Touching Lives on a regular basis. These have included pieces on our work into sickle cell disease, coeliac disease and knee cartilage repair. The 'Newsletter' is Europe's oldest surviving newspaper, first established in 1737! Action Medical Research is very active in Northern Ireland, and such widespread publicity on our research's outcomes helps to consolidate the Charity's reputation in the Province as one of the top medical research charities in the UK.

Touching Lives online!
You may be interested to know that there is a PDF version of this magazine available online at www.action.org.uk. Click through to our news and media section. We'll be keeping an archive of previous editions there too.



Some of the answers can be found within this magazine.

Across

- 1 He suffered from epilepsy (6,6)
- 9 Pioneer of knee replacement surgery (7)
- 10 It can be used to help premature babies (7)
- 11 Inert gas (5)
- 12 Turn out (9)
- 13 Where there's a warm welcome for riders (7)
- 15 American attempt to mislead – in winter? (4,3)
- 17 Source of rubber; for example (3,4)
- 19 ----- Alarcon, epilepsy researcher (7)
- 20 Seafood farm (6,3)
- 22 Prevent - building of flats? (5)
- 23 Worry intensely (7)
- 24 Strands (7)
- 25 Form of exercise (12)

Down

- 2 Consumer representatives (4,5)
- 3 He played Mr Humphries (5)
- 4 Ray of light (7)
- 5 Cavity containing pus (7)
- 6 Maize (5,4)
- 7 Spanish wine (5)
- 8 Where Dr Baralle works (12)
- 9 Researcher on brain damage in babies (7,5)
- 14 Denice's home area (5,4)
- 16 French heroine (4,2,3)
- 18 Symbols (7)
- 19 Share expenses (2,5)
- 21 Fatalistic (5)
- 22 He suffered from epilepsy (5)

For your chance to win a £10 book token, send completed crosswords to: The Editor, Action Medical Research, Vincent House, Horsham, West Sussex, RH12 2DP. Closing date for entries is 31st May.

Congratulations to Miss J M Wines from Cardiff who won the prize in our last issue.

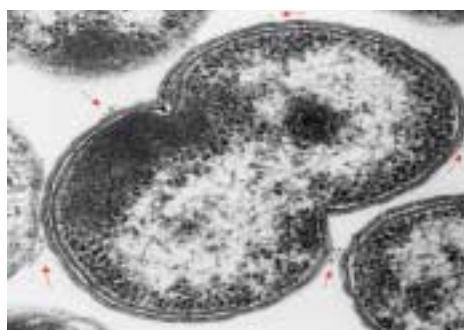
Where the money goes

Another opportunity to see how your donations to Action Medical Research are making a real difference. Here we focus on our work to protect against serious childhood infections.

Humans have two main forms of defence against infection. The first you are born with and is called the **innate** immune system. The second is known as the **acquired** immune system as it develops after birth and provides a 'memory' of all infections that we get throughout life. The acquired immune system takes time to develop but is working well by the time children start school. It is because this acquired immune system takes time to develop that babies and young children get many more infections than older children and adults. Babies and children rely heavily on the innate immune system for their defence against infection.

In these early years of life, a protein called mannose-binding lectin (MBL) is particularly important for attacking the viruses, bacteria and fungi that can cause infections. This protein recognises sugars on the surface of these infectious organisms and binds to them. In the picture MBL can be seen attached to the surface of the major bacterium that causes meningitis (*N. meningitidis*). Once bound it can kill the organism and then help clear it away so that it can no longer cause harm.

It is now 15 years since Professor Mac Turner discovered at Great Ormond Street Hospital (GOSH) that some people have low levels of MBL in their blood. In fact this deficiency of MBL is quite common, with about a third of the population affected. Subsequent work, both at GOSH (some of it funded by Action Medical Research) and other centres, has shown that low levels of MBL puts children at greater risk of getting infection. Most of the time these infections are what we would consider minor;



MBL binds and kills *N. meningitidis*. Red arrows show the sites where MBL binds to the bacterium



A child with Meningococcal Septicaemia in Intensive Care

such as coughs and colds. It does however go a long way to explain why some children seem to always get coughs and colds while others get through childhood with very few infections. As the levels of MBL are genetically determined it means that children within a single family can have different levels of MBL and therefore different frequencies of infection. For example, if a mother has low levels and the father has normal levels then only some of their children will have low MBL levels.

Serious infections

While most infections in children with low MBL levels are minor, there are a few infections that are more serious. These are the ones that cause meningitis (infection of the surface of the brain) and septicaemia (severe infection of the blood). These are uncommon. However, when they occur they are serious and can cause death. Advances in Intensive Care and earlier recognition of symptoms by parents and doctors have improved outcomes for children. But serious infections are still responsible for many admissions to Intensive Care Units and many of the deaths.

With the help of Action Medical Research, researchers at GOSH have been able to investigate how MBL helps protect children from these infections. What they have been able to

show is that MBL seems to be particularly important in preventing children from getting septicaemia. Indeed, in a study of nearly 200 children admitted to Intensive Care, nearly all the children with septicaemia had low levels of MBL. Children who had normal levels of MBL were very unlikely to get septicaemia. Exactly why MBL is so important in protecting against this type of infection is as yet unclear. However the team at GOSH, led by Professor Nigel Klein, has been able to show that MBL influences the way the body responds to the micro-organism when it first causes an infection. As such there is a real possibility that in the near future MBL could be used as a treatment for these serious infections. Action Medical Research played a crucial role in supporting the initial research that led to the discovery that MBL was very important in protection against childhood infections. £107,000 funding of this additional research over the last three years has now laid the foundation for introducing a novel therapy for critically ill children.

This is just one of the valuable medical research projects we can fund because of your support. Thank you.