

touchinglives

the action medical research magazine • autumn 2004

A man with glasses, wearing a teal t-shirt and dark trousers, is seated in a wheelchair. He is looking out of a large window on the right side of the frame. The room is filled with various potted plants, including pink flowers. The lighting is soft and natural, coming from the window.

Living with spinal injury

Plus:

The match makers – working for successful bone marrow transplants
Forward thinking – our expert panel tell us what the future holds



medical research
give and let live

From the Editor



Welcome to this Autumn edition of Touching Lives. Many thanks to those of you who responded to our survey appeal last issue. We had a marvellous response with well over twelve hundred replies. It will take some time to process all that data, but we'll give you a round up of the results next issue. Congratulations go to supporter Mrs P Maddison from North Shields in Tyne and Wear who was pulled out of the hat figuratively speaking and won a ticket to France on the Eurotunnel.

I hope you'll enjoy this issue of Touching Lives. We were lucky enough to get to speak to Martin Toyer. A few months ago Martin was involved in a motorbike smash which left him paralysed. He tells us on page eight about his recent struggles learning to live with his disability. Of course, thanks to your donations, Action Medical Research is very active funding research to make life easier for spinal injury patients, and to look for ways to mend the spinal cord – something which is currently impossible to do. Perhaps now, with the much-publicised intervention of Superman actor Christopher Reeve, this unfashionable area of research will start to get the attention it deserves. You can do your bit by responding, if you are able, to our appeal this issue.

Turn to page 12 for details of four new research grants Action Medical Research is funding – thanks to your donations. As ever, we'll keep you informed of their progress through Touching Lives. Happy reading!

Best wishes for a healthy future.

Daniel Sartin
Editor

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Action Medical Research is the UK's most forward thinking charity. We believe diseases and disabilities can be beaten, and through our medical research we are creating a healthier future for everyone. We have been making medical breakthroughs for over 50 years – including helping develop the UK polio vaccine, ultrasound scanning in pregnancy and the hip replacement operation – saving countless lives and preventing disease and disability. Today the Charity is looking for answers to many serious illnesses, selecting the best research projects in areas where we are most likely to find cures or treatments.



Dyspraxia – progress being made

Dyspraxia, or Developmental Coordination Disorder (DCD) as it is more properly known, affects 5-10 per cent of school-aged children. Despite having normal intelligence and physical appearance, these children have poor coordination. So far, most effort has been spent on helping children of primary school age with DCD. We have learned much about this condition in the last decade, and it has been realised that there is an urgent need for better ways of assessing children of secondary school age too. For many children with DCD, handwriting is an extremely difficult skill to master. When reaching secondary school, a pupil is required to take notes, write examination papers and manipulate materials in practical subjects. Secondary school can therefore become a stressful environment and these children may fail to achieve their true potential unless they receive extra help at home and in school.

Action Medical Research is supporting a project – generously funded by the Freemasons' Grand Charity – which aims to improve the situation for teenagers with DCD. The team, based at the Institute of Education, University of London, is working towards the production of standardised tests to assess their problems more precisely. The work involves the development of a general test of movement and coordination and also a specific handwriting test. At the moment, the regulations for deciding which pupils will receive special provision in written examinations (for example, extra time or the use of a computer) are rather unclear, and the researchers report that they have had a great deal of interest from professionals working in education. Reliable methods for assessing DCD would allow a fairer way of allocating scarce resources to those children who need them, and offer a sound basis for planning and evaluating new treatments.

The project is making good progress, with new equipment being designed to assess hand skills and coordination in teenagers. The research



Fast, legible handwriting is needed at secondary school

team is also collecting data using a newly developed test of handwriting speed with students at many centres across the UK. Dr Anna Barnett, a senior researcher on the project, told Touching Lives, "Standardised tests are in great demand by clinicians and teachers working with teenagers with movement difficulties. The tools we are developing will be important in helping them to plan how best to support these students and develop their skills".

For details of further research into DCD, see page 12.

Give them a big hand

What do Bill Gates, Hugh Hefner and the late Chinese Premier Deng Xiaopeng have in common? The answer is that they all have a passion for bridge, the card game hailed by enthusiasts as the ultimate in intellectual competition.

Action Medical Research will be holding its national Friendly Bridge Tournament in 2005, but this time with a difference. Following feedback from players this year, in 2005 a Chicago tournament will be run in parallel with the Rubber Bridge tournament, with players choosing their preferred game.

This year 360 people played a hand at the world's most popular card game for Action Medical Research, raising £5,000 for our vital work. Congratulations also go to tournament winners Jennie Dennick and Teresa Wood from Hertfordshire. Organisers are appealing for participants in the 2005 tournament to recruit



as many players and teams as possible, so that more funds can be raised. For further information about how to take part, or to register a team, please contact Margaret Bastow on 01284 7677309 or email margaret@cmbastow.fsnet.co.uk

Mothercare supporting Touching Tiny Lives

Leading high street retailer Mothercare has launched a special new clothing range for premature babies in support of our new campaign Touching Tiny Lives.

For each ten-piece set of clothing sold for £30, the campaign will receive £3. The range has been specially developed for premature babies weighing as little as 3lbs. Professor John Wyatt – former Action Medical Research grantholder whose 'cooling cap' project featured in the Summer edition of Touching Lives – provided valuable insight for Mothercare into the everyday care of premature babies, and his suggestions were incorporated into the final designs.

The special packs are on sale now at selected Mothercare stores, or at www.mothercare.com

Blindness in preterm babies – new findings

Retinopathy of prematurity (ROP) is a potentially blinding eye disease occurring in babies born before full term. The main characteristic of the disease is the growth of retinal blood vessels in the middle of the eye, and in severe cases retinal detachment can occur. The retina contains the light-detecting cells that enable us to see, and if it is affected in this way, blindness can result. In fact, in the UK alone, ROP is responsible for six per cent of childhood blindness.

Premature babies are often born with breathing difficulties. To help them they are resuscitated using oxygen and are often assisted by a ventilator. However, the very oxygen that helps these babies breathe can also cause ROP. The oxygen concentrations babies receive from their ventilators are variable (despite best efforts to control them), and research has shown that the more severe forms of retinopathy are related to varying levels of oxygen in the babies' blood during the first two weeks of life.

With funding of £71,000 from Action Medical Research, researchers based at the Department of Child Life and Health in Edinburgh have been



The research team, headed by Professor McIntosh (third from left)

able to explore why high and fluctuating oxygen levels can have such devastating effects on normal eye development. The team found that both high and variable levels of oxygen reduce the amount of muscle and special supporting cells in the walls of retinal blood vessels in the eye. The result is that the amount of blood vessels in the eye is increased, causing scarring on the retina, which may lead to impaired vision. Another exciting and unexpected result of this research has been the finding that astrocytes (special cells in the nervous system) may also be

involved in the development of ROP. Further understanding of these processes may result in possible new treatments for ROP.

Professor Neil McIntosh, who headed the research, said, "The implication for this in our babies is clear: We need to manage them at slightly lower oxygen levels – which is easy to do. We also need to maintain their stability. This is more difficult, so is the area we will be concentrating our clinical research in the future".



A scan of a premature baby's retina shows normal blood vessels and optic disc

Hi-tech solution for assessing bone healing

Computed tomography (CT) scans play a key role in assessing bone healing following corrective spinal and limb surgery in children, hip and other joint replacement surgery, and for patients with fractures that fail to heal. However, the body scans used to produce images of bones can be difficult to interpret if metal implants, screws and plates have been inserted during surgery. The metal objects obscure the healing area of the bone and can produce spurious signals – known as artefacts – that seriously distort the image.

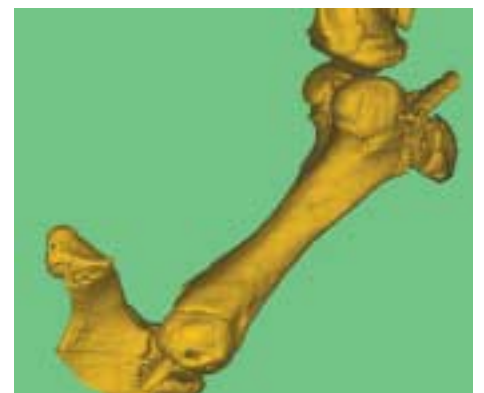


The team has developed exciting new scan techniques

Thanks to funding of £130,000 from Action Medical Research, a team of researchers is developing new computer software which aims to remove these artefacts produced by metal implants, and allow more accurate interpretation of CT data. Better analysis of bone healing adjacent to the metalwork would allow doctors to assess the healing process in more detail, improving treatment for patients undergoing such orthopaedic surgery.

The three-year project is based at the John Radcliffe Hospital and Nuffield Orthopaedic Centre, both in Oxford. The research team has recently reported to Action Medical Research

the exciting news that they believe they have successfully developed a way of overcoming the artefacts caused by the metal implant, allowing for clear three-dimensional CT images of the bone. For the remaining few months of the project the researchers plan to optimise and improve the software so that it is easier for health professionals to use.



A computed tomography bone scan



Touching Tiny Lives



Action Medical Research's Chief Executive Simon Moore outlines the Charity's new campaign.

Touching Tiny Lives is the new campaign from Action Medical Research, highlighting the urgent need for more research to help sick and vulnerable babies. We want to raise an additional £3million over the next three years to help find answers to premature birth, pre-eclampsia and other serious conditions which threaten babies and expectant mothers.

Thanks in large part to advances in medical research, the majority of babies can look forward to a healthy future. For most families it is a time of immense joy and relief when their child is born safely. But not all births go as expected. Around 70,000 babies each year – that's over 10 per cent – require some sort of special care when they are born. Tragically, over 3,000 babies die within the first year, and premature birth is the single biggest cause. The interview opposite with Professor John Wyatt gives you a better idea of the problems and challenges doctors face.

Not enough funding is devoted to researching the many conditions which affect babies, such as premature birth. Yet the thousands and thousands of babies born prematurely each year are at risk of suffering serious health problems for the rest of their lives. Action Medical Research believes more must be done to ensure that all babies grow up healthy, and that is why we have launched the Touching Tiny Lives campaign.

The campaign has the following aims:

- **We want to stop pregnancy complications like pre-eclampsia, which can often lead to problems for both mothers and babies.**
- **We want babies who are born with**

problems to have the best chance of a healthy start in life. They need special help in their crucial first days and weeks.

- **Ultimately, we want to find the causes of premature birth and other problems. Doctors still don't fully understand what causes some babies to be born early, and there are no effective treatments to prevent premature labour.**

Action Medical Research is already working in all these areas, but we urgently need more money to continue this life-saving research. Over the coming months we will be launching a number of fundraising and research initiatives to support Touching Tiny Lives. One early success is the welcome support by Mothercare, as reported on page 4. We are also planning a publicity drive in the Spring of next year.

Touching Tiny Lives is the Charity's first major campaign for several years, and it focuses on a vital element of our research work. Some of you may have heard about the campaign already, through talking to one of our fundraisers or by attending a regional meeting. We will provide regular progress updates on the campaign in forthcoming issues of Touching Lives magazine.

As supporters of Action Medical Research you will know we are behind some of the biggest breakthroughs in medical care for babies during the past 50 years. Our Charity has played a crucial role in developing the polio vaccine in the UK, ultrasound scanning in pregnancy, and in discovering the link between folic acid and preventing spina bifida. More recently, our funding helped develop a new kind of infrared brain scanner to measure the oxygen levels and



Medical research can help give babies at risk the best possible start in life

blood supply in babies, and so help prevent brain damage during labour and delivery. Our researchers have also successfully identified the faulty gene that is responsible for causing a form of cleft lip and palate.

All these achievements, and many others, have only been possible through the generous support of our wonderful supporters. As a forward-thinking charity, Action Medical Research is creating a healthier future for everyone. Although we will still fund work into a wide range of diseases and conditions affecting all age groups, Touching Tiny Lives will give extra impetus towards solving the problems of pregnancy, childbirth and the early years. Thank you for your continued support.

Why is Touching Tiny Lives so important?

Professor John Wyatt, a consultant who specialises in the care of newborn babies, talks about why research is vital if we are to give more babies the best chance of a healthy start in life.

Not content with one, Professor John Wyatt has three jobs. He is Professor of Neonatal Paediatrics at University College London, a consultant at the Neonatal Intensive Care Unit at University College Hospital – an internationally recognised centre for care of the newborn – and also leads a research team of doctors, scientists and physicists working to prevent brain injury in newborn babies. He has authored over 80 scientific papers, and been an Action Medical Research grantholder since the early 90s.

We asked Professor Wyatt what need there was for a Touching Tiny Lives campaign.

What's the scale of the problem?

There are about 670,000 births in the UK each year. A full term baby will arrive anywhere between 37 and 42 weeks – and about 90 per cent of babies will arrive on time. But about eight per cent of babies come early and are what we call pre-term. That equates to about 50,000 premature births each year. Due to the advances of science over previous decades, most babies born pre-term between 33 and 37 weeks rarely have any problems. Babies born before 33 weeks – or seven months – are defined as very 'preterm'. There are about 10,000 babies born preterm each year, representing about one and a half per cent of all births.

“Right now across the UK there will be eight or nine sets of parents grieving and coming to terms with the death of their child.”

When starting out as a medical student, I was warned not to specialise in the care of the newborn. I was told that with advances in medicine, sooner or later neonatologists would be put out of business! Actually, the number of premature babies is increasing.

But prematurity isn't the only problem that faces newborns. Other babies have serious problems at birth such as severe infections or oxygen deprivation. In all about 15,000 babies require

intensive care each year. Sadly, over 3,000 babies die within the first year of life despite the best possible care. This means that eight or nine babies will die today, in hospitals up and down the UK. Right now across the UK there will be eight or nine sets of parents grieving and coming to terms with the death of their child. These figures don't include stillbirths – which account for another 3,000 deaths per year – and nor do they include those premature babies who survive, but will have serious disability to contend with for the rest of their lives. There is a huge problem here that needs attention.

Has progress been made over the decades?

Yes, certainly there's been tremendous progress. Care for the newborn started, as we know it, in the 1960s. Only about 15 per cent of babies delivered at 28 weeks or less, weighing around two pounds, survived in 1965 and sadly many of the survivors were disabled. By 1995 survival rates had increased to over 60 per cent, and are still increasing year on year. In our own specialised unit, survival rates for babies of this size are now at 80-85 per cent and the majority of survivors will develop without serious disability.

No one thing has led to this improvement. There's been a whole series of incremental advances – bricks in the wall, if you like. Arguably, care of the newborn is one of the great success stories of modern medicine. This is one area

where your chances of survival and of going home healthy have completely transformed over the last 30 years. Nearly all of that has been due to medical research, including that funded by Action Medical Research.

So why the problem finding funding?

You might think that for such an emotive and important area as care of the newborn, there would be massive funding available for research. But in reality, research into care of the newborn



is a Cinderella area. Compare the money going into cancer research – tens if not hundreds of times greater. So charities like Action Medical Research have played a vital role in developments seen over the past 30 years.

It's more difficult than you might think putting the case for research in this area, despite the fact that by making a positive impact at the very beginning of a baby's life you are investing in their future. Even leaving aside the ethical case for investing in this research, the economic case is very strong. The cost of medical care for a profoundly disabled child in his or her lifetime may be as much as £3-5million. That's without loss of earnings, and any compensation settlement there might be if negligence is proved. If we can save one baby from being damaged, we could fund our entire research programme for more than five years!

How advanced is the UK in this area?

In terms of innovation and ideas, the UK is still very close to the top of the league table, I'm proud to say. Sadly, in terms of funding we are pretty low down the table. In the US I understand from colleagues that the pass mark to get research funded has actually gone down, from A- to B+, due to the massive amounts of government and charitable funding available. Whereas in the UK, the reverse has happened – the pass mark has been raised effectively from A+ to A+++.

That's the frustration I experience. Research proposals we know are both original and world beating often don't get off the ground because there is simply no money to make it happen. There are so many things we don't understand about care of the newborn, and so many reasons why we still need to do research to prevent death and disability. I give my wholehearted support to Touching Tiny Lives, and wish Action Medical Research all the very best with the campaign. TL

My story

Road to recovery

It takes a certain kind of person to describe spending the rest of his life in a wheelchair as a 'new challenge', but that's how Martin Toyer sees it. Paralysed from the waist down in a motorcycle accident just before Christmas 2003, Martin will never walk again, though with the help of the staff at the National Spinal Injuries Centre at Stoke Mandeville Hospital, he's determined to regain as much independence as possible.

At the time of his accident, Martin was working as an engineer in an aircraft factory and had lived for eight years with his girlfriend, Jo, in a country cottage in a village near Leighton Buzzard. "My would-be parents-in-law had bought us an ornamental Christmas tree, but one of the bulbs had gone. I decided that I'd go into Luton to buy a replacement. Basically I'd use any excuse to go out on my motorbike – it was my passion." It was a damp Sunday afternoon, but quite good weather for the time of year, when Martin set off. He was travelling at about 50 miles per hour on a twisty B-road, when suddenly his rear wheel slid out from under him, flicking him up into the air and into a hedge. His bike had skidded on an oil spill on the road that he hadn't spotted.

"When I was flung into the hedge, I hit a tree, so I was in a bad way. At first I was conscious, but I couldn't see anything, and I couldn't breathe. I remember someone saying 'it's all right, we've called an ambulance' – and then I blacked out."

Martin was rushed to the nearest accident and emergency unit, at Luton, and was unconscious for three days. He had a punctured lung, eight broken ribs, a broken shoulder, his aorta was ripped open – and his spine was broken. The medical staff thought he would probably bleed to death, and told his girlfriend to go in and say her last words to him. "Apparently I was conscious, and talking – saying 'make sure you get the bike out!' But they rang round the

hospitals to find somewhere that would take me for the operation on my aorta, and I ended up at St Barts in London. At first, my back wasn't the main issue, it was getting my heart working, and getting me so that I could breathe on my own. Then, after they'd patched up my heart, I went to the Royal London where they plated my back" (by screwing in a metal plate to hold the break together and give some strength to the spine – Ed.).

"I was in a bad way. At first I was conscious, but I couldn't see anything, and I couldn't breathe."

Martin was in London for about two months, and it was while he was there that he contracted the 'superbug' infection MRSA. "The MRSA itself wasn't a problem, but they are really careful about infection, so when I moved to Stoke Mandeville for rehabilitation in February, I was put into isolation. That was awful – worse than being in prison. I was in bed behind a closed door for three months and it really put a hole in my rehab process." But as soon as he was out of bed, Martin got to work on the remarkable Stoke Mandeville rehabilitation programme, which is carefully tailored to meet the needs of each patient.

"The day starts at 5am with bowel management," explains Martin. "Because of where my injury is, I can't feel my lower half so I can't consciously control any of the goings-on down there. But I've still got quite a lot of nerves that work, which means that if you set it off, it will do the job itself – so I've been taught techniques for doing that. It takes about an hour to work. You're basically sitting on the toilet all that time, waiting for something to happen!"

"Then I have a shower and get dressed. I've been trained how to dress myself, though I haven't got the hang of doing it in a chair yet, so I have to go back to bed. That takes about half an hour. After breakfast, the day really gets going."

There are two main sorts of physiotherapy which make up the bulk of Martin's day at Stoke Mandeville. One focuses on day-to-day living skills, mainly practising 'transfers', which means getting in and out of your chair and on and off surfaces of different heights. Martin's now at the stage where he can get on to the floor and back into his chair again – really important if he has a fall when he's on his own. The other sort of physiotherapy is in the sports gym, and is geared to building up muscle strength. Weights machines, table tennis, and archery all feature in the programme.

Martin explains why these activities are so ideally suited for rehabilitation of spinal injury patients:



"I'm a T10/T9. The 'T' bit stands for the thoracic part of your back. What it means is that my spine is totally broken around where the ribs are attached. With spinal injury, you can't feel anything from the break down. Nothing below my belly button has any strength or support in it at all. So for me, it feels like the top half of my body is sitting on a bag of jelly, or a half blown up ball – it's really wobbly. That's why it's important to practise balance and building your upper body strength. Table tennis is good because it makes you stretch beyond what you might think your limits are if you were doing it consciously – you just try to get the ball and that's it!

"We have dinner around 5pm, and I'm usually in bed by eight. By then my back's starting to hurt. I'd rather go to bed than use painkillers – I don't want to take any more drugs than I have to. Plus they can make you constipated, which messes up your bowel management routine."

Being able to have control over simple things like when you go to the toilet will be crucial in enabling Martin to live as full a life as possible when he leaves – hopefully by the end of September 2004. There are lots of challenges, as well as things to look forward to.

"The first thing to do in preparation for leaving the unit was to find a house. We've had to sell our cottage – we couldn't have even got the wheelchair in through the front door. So now we're waiting to exchange contracts on a new

house – it's a bungalow, which is obviously ideal for me. But we will have to make some adaptations – we'll put in a ramp for the front door, for example. The main thing is the bathroom, which will have to be converted into a wet room."

Then there's the kitchen. Martin used to do most of the cooking before his accident, but most kitchens have cupboards all the way round at floor level, which means that when you're in a wheelchair you can only reach the surface at arms length. So it might be necessary to take some cupboards out. "We'll live there for a couple of months and see how it goes, and then the occupational therapist will come in and suggest any changes.

"...it feels like the top half of my body is sitting on a bag of jelly – it's really wobbly..."

"I'm hoping to go back to work in October, part-time at first. I'm really lucky because my boss is keeping my job open for me. Soon it will be back to the normal grindstone – that's good in a way, I don't want any special treatment. If I find it too much, I'll have to say no, I can't do it, maybe find another job. I'll just have to adapt.

"Not being mobile is definitely one of the things

you miss. If you think about it, what you first want when you're a teenager is a driving licence, to get your freedom. I'll have to work my way back to that – I'm hoping to have an adapted vehicle eventually. But just getting in and out of a car takes ten minutes. When you get into this condition, everything takes an enormous amount of time – that's the biggest factor!"

Stage by stage, Martin will do all it takes to get back to living a life as independent and active as it was before the accident. "Obviously I won't be able to do everything I used to – like, karate, for example, which was my second big interest. I got my black belt ten years ago. I could probably go back to karate to some degree – I could do judging or grading. I think my instructor's got something planned!

"I do have a licence to say I can use an adapted motorcycle. But I don't really think it would be fair on my relatives – they've been through enough without me getting back on a bike. At the moment, it's not a priority."

Martin's extraordinarily positive outlook drives his determination to be independent again. "I've got nothing to moan about. There's always someone worse off than you – I could have got brain damage, for example. This is my second chance at life, that's how I look at it. I've got to 40, and now I'll be spending the second half of my life with wheels instead of legs. It's a new challenge. It won't be easy, but I'll keep trying." TL

Action Medical Research has funded four grants in the last five years investigating the repair of the spinal cord and better care for patients with spinal injury. An Action Medical Research project, completed in 2002, identified ways of promoting spinal nerve repair – bringing us closer to an effective treatment for people with spinal cord injuries.

The match makers

An Action Medical Research study could help thousands of recipients of bone marrow transplants get the best possible donor match.

Imagine if the very treatment that was designed to make you well gave you a disease as severe as the illness it treated? Bone marrow transplantation transforms the lives of hundreds of desperately ill people each year. But unfortunately it will also trigger a debilitating and potentially fatal reaction called 'graft-versus-host disease' (GvHD) in up to 60 per cent of patients. A recent Action Medical Research-funded project, led by immunologist Professor Mary Ritter at the Hammersmith Hospital in London, has built on work done through a previous Action Medical Research grant to make a crucial discovery about what might cause this devastating disease.

Bone marrow transplantation

Bone marrow is the spongy material in the middle of our bones which manufactures blood cells. As well as the red, disc-like blood cells which transport oxygen around the body, bone marrow produces white blood cells whose purpose is to fight off infection. This manufacturing system is, however, disrupted in people affected by diseases such as leukaemia, anaemia, immune deficiency, or lymphoma. Either the wrong number of cells are produced, or cells are made that don't do their job properly. As a result, patients are susceptible to diseases any other person would easily be able to fight off – and even minor infections can prove fatal.

However, just as malfunctioning organs can be replaced with organs provided by donors, bone marrow can also be transplanted. The patient's own malfunctioning bone marrow is killed by chemotherapy and new bone marrow is injected, giving the patient – in a successful transplant – a new, fully functioning immune system. The first bone marrow transplant, in a patient suffering from leukaemia, was performed in 1969, and hundreds of such operations are now performed each year. However, there are often problems with making a bone marrow transplant work.

What can go wrong

There are up to 2,000 patients waiting for a bone marrow transplant at any given time. Of

these, around one third have a brother or sister who can donate bone marrow. This gives the best possible chance of a good match. However, the majority of patients receive a transplant from an unrelated donor – and it is with unrelated donors that the risk of GvHD is at its highest. Professor Ritter explains, "When a person is given an organ transplant, the body's immune system sometimes recognises the organ as a foreign object and rejects it. With bone marrow transplants, it is the immune system itself that is being transplanted. So when something goes wrong, the effect is reversed: the immune system recognises the patient as different from itself, and starts attacking the body – usually the gut, liver or skin. And this reaction is most likely to happen with unrelated donors, where there are more likely to be more obvious differences between the donated cells and the patient's body. The transplant itself may have been successful, in that the new immune system is attacking any cancer cells left in the patient's body, but where GvHD occurs the immune system attacks normal cells as well."

The effects of GvHD range from diarrhoea to skin rashes and liver damage. Patients are given drugs to try to minimise the likelihood of GvHD, and while the symptoms are usually mild, it can become extremely severe, and all too often proves fatal.

The T-helper key

Professor Ritter's work to combat GvHD has focused on a group of white blood cells called T-helper cells. T-helper cells have been called the 'conductors of the immunological orchestra'. They are the key switches which keep the immune system running. Some destroy foreign bodies such as viruses, and some regulate or enhance immunological reactions. In normal functioning, they look for foreign protein on the surface of the body's own cells – an indication that a virus has infected the cell. The T-helper cell then destroys the infected cell. But in GvHD, the T-helper cells don't discriminate properly between foreign bodies – the cancerous cells they should be destroying – and normal cells. In effect, the body starts to attack itself.



Professor Mary Ritter's team has developed a new test, which is simple to reproduce

There are two main types of T-helper cells, called TH1 and TH2. TH1 cells usually kill malignant cells by causing inflammatory responses, while TH2 cells trigger an anti-inflammatory response. "Originally," says Professor Ritter, "we thought that TH1s were the baddies, the ones causing GvHD. TH1 and TH2 cells produce different types of water-soluble proteins called cytokines, which means it's possible to measure how much of each type of cell is present in a sample by measuring the amount of each type of protein. So in our earlier Action Medical Research-funded project, we were looking at identifying which donors had lots of TH1. We thought transplants from these donors were more likely to trigger GvHD than others." However, the team's latest grant has taken the research a step further, and in an unexpected direction.

The new findings

The most recent Action Medical Research grant was used to go 'back to basics'. Previous tests had been very complicated, involving separating

out dozens of samples of tiny numbers of cells and different types of protein. This time, the team developed a very simple test. Just prior to a patient receiving a transplant, the team mixed some of their bone marrow cells in the laboratory with those of the donor. They measured the reaction the mix produced, and then over the following months monitored the patient's clinical progress. They observed a very strong association between the presence of one particular protein, called IL13, and the occurrence of graft-versus-host disease. This was a big surprise as IL13 indicated the presence of a TH2-type helper cell – rather than the TH1s that they thought were causing the problem!

This may sound like an added complication. However, as Professor Ritter explains, it is actually a very positive finding. Firstly, this new test is very easy to reproduce, and therefore easy for other researchers to use. "The particular strength of the test is that it mimics what happens in the body, when the cells of the patient and the donor are all mixed together. By creating an environment which is as close as possible to that of the body itself, you can observe reactions which you might not have expected" – which is precisely what happened here.

Secondly, says Professor Ritter, the discovery of the IL13 association is itself very encouraging. "This particular protein is produced in large amounts, so it's much easier to detect in a sample. Plus, the association is very strong – the presence of this type of protein is a very robust indicator of whether the patient will be at risk of GvHD."

What next?

The medical world is now closer to ensuring patients get the best possible match for their transplants. The simple test developed tells the clinician a great deal about the likely success or failure of a bone marrow transplant, and benefits for patients are in sight.

But there are questions to be asked about the function of the IL13 protein itself. "We're still not sure whether the IL13 is just an indicator of the presence of the TH2 cells, or whether it is actually doing something which affects the occurrence of GvHD," says Professor Ritter. "It's a long way off, but in principle, if we found that IL13 was actually triggering GvHD, it might be possible to develop a drug which blocks it. In fact, this kind of therapy is already used to treat rheumatoid arthritis. So it's a real possibility."

Part of a bigger picture

Professor Ritter has been working closely with clinician Dr Emma Morris, whose day-to-day



At work in the Hammersmith Hospital research laboratory

experience as a consultant working with transplant patients brings home how crucial it is to find a way of preventing GvHD – "she's our 'reality check'", says Professor Ritter. "Up to 60 per cent of patients with an unrelated donor experience GvHD, and of those, 30-40 per cent will die from its effects," explains Dr Morris. "What's particularly tragic is that it is not the original disease – the lymphoma or leukaemia – which kills the patient, but the GvHD itself. And the only way of treating GvHD is to try to 'switch off' the immune system which is reacting against the body – in effect, taking the patient back to square one."

"Of the transplant patients I saw on my rounds yesterday," says Dr Morris, "three of them have been devastated by GvHD. They are no longer suffering from leukaemia, but the GvHD is so severe that they haven't been able to go back to work, and are being admitted to hospital up to eight times a year with GvHD related complications." Combating graft-versus-host disease would revolutionise bone marrow transplantation. Dr Morris describes this as "the Holy Grail of transplanting." This Action Medical Research project has taken medical science a step further on the quest to reach that goal. TL

Research review

Learning together

A unique project to help children with developmental coordination disorder (DCD) is entering its third phase, thanks to funding from Action Medical Research.

Sometimes called dyspraxia, DCD affects around 5-10 per cent of children in the UK. Sufferers struggle with daily tasks such as getting dressed, using a knife and fork, writing neatly or finding their way around new places. It can interfere with their progress at school and undermine their self confidence.

Intervention at an early age, including the use of carefully tailored activities undertaken at home, has been shown to help many children with developmental coordination disorder. By practising little and often, some youngsters who were previously struggling have dramatically improved in terms of motor skills.

The study, led by Professor David Sugden of the School of Education at Leeds University, has recently been awarded a follow-on grant of £75,000 by Action Medical Research, to continue the work done over the past five years. This time, Professor Sugden and his team will study a group of preschool youngsters.

Professor Sugden told Touching Lives, "This is a time when children develop fundamental movement skills that are the building blocks for the rest of their lives. We aim to identify children in nursery and preschool



Team games and ball sports can help youngsters with DCD

with coordination disorders then examine the success of 'low level' intervention programmes that can be used by parents and teachers. We will then go on to produce guidelines for those working with children with these disorders.

"That will include booklets for teachers, nursery professionals and parents. We hope that some of the techniques will be adopted by nursery teachers to help three and four year olds with DCD overcome their difficulties."



Children are encouraged to use games and puzzles to overcome their difficulties

The 'low level' interventions have been shown to make a big difference to a group of older children, who have been part of an ongoing study in Yorkshire. Professor Sugden and his colleague Dr Mary Chambers worked closely with a group of youngsters with DCD and had some encouraging results.

Professor Sugden said, "We haven't come up with a cure – rather a set of interventions that identify the condition and then help children overcome their problems. Not every child is receptive to our techniques, though most do make some improvement.

"What seems clear is that some children are more receptive than others – some with developmental coordination disorder also have other learning and behavioural problems that can impact on their progress. The key to improvement is making the interventions part of everyday life, and practising little and often."

Not to be confused with physiotherapy, such tasks are the basis of treatment. Parents are encouraged to use activities like cooking and dressing to get their children to practise movements that they find hard to master. Some children from the original study group have made remarkable progress and are now doing well in mainstream education.

Professor Sugden said, "I feel very privileged to have been involved in what is becoming an internationally recognised piece of research. We now have a much heightened awareness of the importance of motor skills in the early years and have shown that by intervening, both parents and teachers can make a huge difference.

"We have achieved some really positive results in our studies so far, and without help from Action Medical Research we would not have achieved a quarter of what we have done. What's really exciting is that we now have a group from the United States interested in our work, and we have introduced what was in effect a 'hidden disability' to a much wider audience."

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

New treatments could end sickle cell misery

A better quality of life for sickle cell disease sufferers is the ultimate aim of a new study funded by Action Medical Research.

Sickle cell disease is a serious blood condition that affects over 10,000 people in the UK and millions worldwide. It causes the red blood cells that carry oxygen around the body to change shape and means that they cannot fit through very small blood vessels, leading to blockages and damage to tissue.

There is currently no effective treatment. Patients may suffer a series of sickle cell crises when their 'sickle' shaped red blood cells cause a blockage in blood vessels – leading to excruciating pain and ultimately serious damage to the kidneys, lungs, bones, eyes and the central nervous system.

A team of researchers from Oxford University, working in conjunction with colleagues at Cambridge University, now hopes to get a step closer to effective treatment.

With a £95,000 grant from Action Medical Research, they are looking at how conditions in the body's circulation cause sickle cell crises and how the use of drugs can prevent the condition by stopping the rogue red cells from changing shape.

Dr John Gibson, who leads the three-year study with Professor Clive Ellory, told us, "There are several hundred new cases of sickle cell disease every year in the UK and worldwide millions of people are affected. This is a genetic disease that causes symptoms throughout life. There is no effective treatment; all we can do at the moment is give supportive



Research worker Hannah Robinson will be assisting Dr Gibson and Professor Ellory with the project

therapy, treating the pain and giving blood transfusions to literally rid the body of these sickle cells."

A team of researchers, support staff and clinicians including Dr Joe Browning, Dr Yuliya Kucherenko, Hannah Robinson, Vicky Ball, Dr Christine Wright and Dr Sarah Ball are working on the project, using blood samples from a group of volunteer patients mainly based at the Birmingham NHS Trust.

Dr Gibson said, "We hope that ultimately our research will lead to a better understanding of sickle cell disease and to effective treatments. Patients suffering from sickle cell disease find it impossible to lead a normal life and often have to deal with one crisis after another. Children with the condition are susceptible to lung infections and even strokes. An effective treatment would transform their lives."

Prevention is better than cure for pre-term babies

Babies born too soon can face a lifetime of difficulties – but what causes a woman to go into labour weeks, and sometimes months, before her due date?

A team led by Dr Raheela Khan and based at the University of Nottingham and Derby City General Hospital, hope that a grant of £96,000 from Action Medical Research will help them to come up with some answers.

The team are looking at the effect of lipids – compounds made from fats – on muscle contractions. They want to see if a change in the production of these lipids can trigger the muscle spasms that start contractions and cause a baby to be born.

Dr Khan explained, "We know there is a family of lipids released from the blood vessels that have an impact on the cells around them. They cause tissues to relax and contract and we want to determine what happens to the levels of these lipids during pregnancy. They may reduce prior to delivery causing the uterus to contract.

"With premature births, we think this change simply happens too early, and by understanding the process we hope that we will be able to develop a strategy to stop it happening before it should."

Identifying the actual lipids involved has been the first step, and various laboratory techniques are being used to study them and their effect on body tissue.

Prolonging pregnancy

Dr Khan said, "By identifying these lipids and demonstrating that they cause relaxation during pregnancy it may be possible for us to produce a version of them that can prolong pregnancy. A baby born too early faces so many problems, and of course some don't make it through the first weeks of life. ▶

Research review



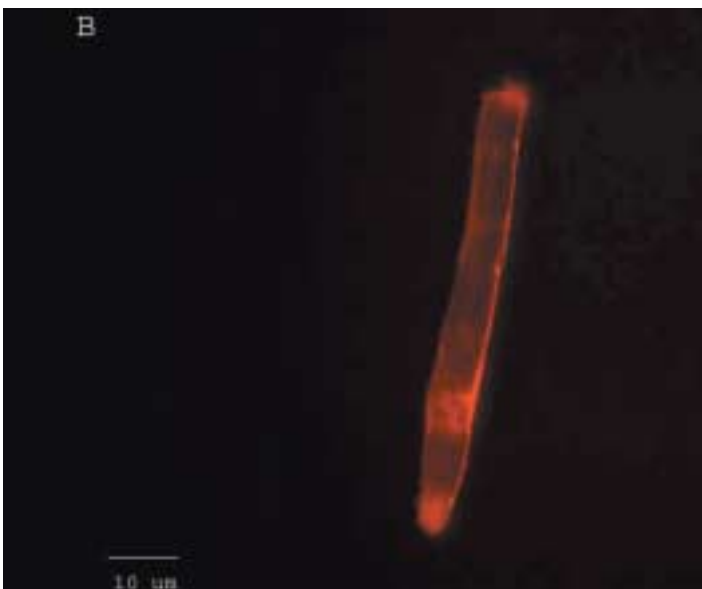
Dr Raheela Khan busy at work

She added, "We are very grateful to Action Medical Research for funding this study. What's really rewarding is that I get feedback from women who have gone through the trauma of having a premature birth, saying how pleased they are to see research being done into the cause."

Dr Khan is working jointly with Dr David Barrett. So far they have been delighted with progress, especially because some of the techniques they are using are new. The study will run until the end of 2005, and the long-term vision is that the findings may lead to the development of effective drugs to prevent preterm labour.

If that happens, thousands of women in the UK could benefit each year. Around ten per cent of all pregnancies end in a pre-term delivery, often caused by the early on-set of labour, and prematurity is a growing problem.

Dr Khan said, "There has actually been a rise in premature births over the last few years, partly because of the number of IVF-assisted pregnancies and the increase in multiple births, which are always less likely to go to full term.



A muscle cell from the uterus

"Premature birth is something of a dilemma. Advances in care means that very early babies can survive, but many face an uphill struggle and their quality of life can be severely compromised.

"This really is an example of prevention being better than cure – and donations from the supporters of Action Medical Research make all the difference to us in being able to carry out this valuable work."

New study on retinal detachment

6,000 people a year in Britain go blind because of retinal detachment – and in many cases, it could be avoided.

A team of eye specialists at Addenbrooke's NHS Trust in Cambridge is being funded by Action Medical Research to examine the genetic influences that can lead to detachment of the retina.

They have enlisted the help of hundreds of people in the first large-scale study of its kind and hope that in 18 months they will have some clear data on how genes influence the condition and, most importantly, on how those at risk can be identified and treated early on.

Consultant Mr Martin Snead is heading the team, which has been awarded the £110,000 grant. Working with him are Dr Allan Richards, consultant surgeon Arabella Poulson, research co-ordinator Gillian Whitmore and Sisters Lindsay O'Shea and Annie McNinch.

Mr Snead said, "We are trying to identify the risk factors, because we believe most cases of retinal detachment are avoidable. We just don't have a way of knowing who is at risk and who is not.

"We are looking at the genes of two groups of patients; one set have had detachment of the retina and another set haven't. Most are aged between 40 and 60.

Important

"We know already that genetic influences play an important role in the condition – Stickler syndrome, for example, is the most common cause of retinal detachment in children – but we aim to expand this research to the wider adult population so that we can identify other patients at risk. This in turn will lead to strategies for prevention."

Surgery can repair a detached retina, but often the patient continues to suffer diminished vision. Some people can be affected in both eyes, with devastating consequences.

With so many new cases a year, finding ways to prevent retinal detachment will have a major impact. Mr Snead added, "It's a condition that can affect all ages but there have been no recent large-scale studies to investigate the genetic risk factors. Hopefully in 18 months' time, we'll have the results that will make prevention a possibility." TL

How it was discovered – The Action Medical Research link to Stoke Mandeville, the POSSUM system, and the Paralympic Games!

There's never been a good time to sustain a spinal injury, with all the life-changing consequences entailed. But your chances of rehabilitation and of leading a normal, independent life are better now than they've ever been, thanks in part to forward thinking grants awarded by Action Medical Research in the 1960s.

One man who was closely involved in the revolution of care for spinal injury patients is Dr John Silver. In 1955 he was sent to work at Dr Ludwig Guttman's pioneering National Spinal Injuries Centre at Stoke Mandeville Hospital. Dr Silver takes up the story: "Guttman's unit was a fantastic place to work. He was a hugely exciting and stimulating man to work for. You did feel like you were in the middle of something special. It was a youthful environment to work in because the patients tended to be young. And because Guttman himself was a refugee (from Nazi Germany – Ed.) he tended to employ other refugees. It certainly wasn't the usual straight-laced environment you found in teaching hospitals at the time!"

Athletes in wheelchairs

Action Medical Research funded Dr Silver in 1962 to investigate the physiology of spinal injury patients. "So much was unknown about spinal injury patients at the time – how their bodies regulated temperature, how their breathing mechanisms were affected, how their

bodies regulated salt and water. A broken spinal cord affects so many of the body's natural mechanisms. My research helped our understanding, and did affect how patients were managed."

The Charity also funded Dr Guttman in his pioneering work to rehabilitate patients through sport. Though some disabled First World War veterans took part in sports activities at the famous Royal Star & Garter Home, it was Guttman who did the most to bring disabled athletics into being. Before then the idea of athletes in wheelchairs was pretty much unfathomable. But it took off! In 1948 Guttman organised the first competition for his patients. Four years later competitors from Holland joined the games and the international movement, now known as the Paralympics, was born. Olympic style games for athletes with a disability were organised for the first time in Rome in 1960.

I am able

Thus Action Medical Research was closely involved as Stoke Mandeville began to acquire its worldwide reputation for clinical excellence. In 1961 the Charity funded two other researchers, Reg Maling and Derek Clarkson, to develop POSSUM – or 'Patient Operator Selector Mechanisms'. Happily, 'Possum' in Latin means 'I am able'.

Messrs Maling and Clarkson observed that patients at Stoke Mandeville lay in their beds, totally paralysed and unable to attract the attention of medical staff except by blowing a whistle hanging over their beds. They felt that if patients were able to control the air in their mouths enough to blow on a whistle, then the same process could be used to operate micro-switches and thereby enable them to control any number of electrical appliances. In fact, from a mechanical point of view, the mouth is a remarkably good pneumatic controller, capable of very precise applications of pressure.

"We were delighted with the grant," says Reg, now aged 76. "It meant that we were able to make much more rapid progress than would otherwise have been possible." Within six months of the grant award the first POSSUM instrument was made, giving the patient control over bells, lights, radios, telephones and televisions. As the technology was refined, so more advanced applications were implemented, such as the POSSUM 'sip-and-puff' typewriter, and the technology was internationally recognised, winning major scientific awards. "We made a real difference," Reg continues.



Wheelchair basketball at the 2000 Sydney Paralympic Games

"I remember one lady who had literally only a flicker of movement in one toe. She went on to write a beautiful book of poems – it was quite extraordinary."

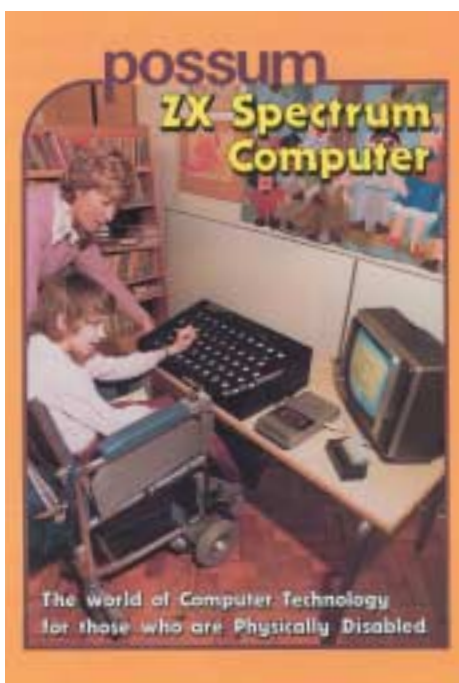
Innovation

It was realised that there was a great need for this type of equipment to rehabilitate patients and to allow them the greatest possible degree of independent living. A company was set up to develop and manufacture the equipment, and this company, Possum Controls Ltd, still exists today, providing innovative products to enhance the quality of life of disabled people.

"Maling and Clarkson were at the cutting edge," confirms Dr Silver. "They were the first in the field, and they revolutionised patients' lives. Action Medical Research put in one of its biggest grants at the time to allow them to make this vital contribution to the rehabilitation of spinal injury patients."

Action Medical Research is proud of its long association with the world-leading National Spinal Injuries Centre at Stoke Mandeville, and continues to fund research there to this day.

Dr John Silver's book 'History of the Treatment of Spinal Injuries' is published by Kluwer.



The POSSUM ZX Spectrum computer, circa 1982

Meet the Researchers

Dr Jean Aaron is an Action Medical Researcher and lecturer at Leeds University. Her project is using new methods to investigate why some people suffer from osteoporosis and others do not.



How did you get to where you are now?

My fascination with bones began at the age of eight when it seemed a good idea to me to excavate and clean old animal bones! Later, with a degree in biology, I looked to a career in medical research; in mind was the childhood pneumonia I would not have survived without the discovery of antibiotics. After a spell at a Medical Research Council Unit specialising in osteoporosis I established my own laboratory and completed my PhD. Now I work with a great team –

for me the brightest side of science is the special camaraderie that develops when close colleagues address a common problem.

How important is research into osteoporosis?

Few individuals are not touched, directly or indirectly, by osteoporosis and in an ageing and increasingly sedentary population, incidence of osteoporosis will not decline without intervention. A better understanding of the fragility of the skeleton is essential if our health service is not to be overwhelmed by hip fractures and the loss of independence that can often bring.

I hear that your work has gained international interest?

Yes, we received the Millennium Prize for the best paper published in the leading scientific journal 'Bone' from the International Bone and Mineral Society. It was a major boost for our team, and travelling to Madrid to collect the prize was a special privilege.

What do you do when you're not working?

My work is computer-based, with others chasing around doing the experimentation I once did myself! In consequence, when not at work, I try to practise what I preach, which means being physically active, taming my garden and exercising the Doberman dogs which I breed.

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

I'm a frustrated artist who seeks to emulate van Gogh! I compensate by supporting local artists, and applying those powers of observation to my science that I would otherwise apply to painting.

Where did you go on your last holiday?

Holidays away from home are rare. Travel to foreign parts is invariably associated with scientific meetings and luckily these tend to be located in interesting places.



Jargon busters

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

Computed Tomography probably represents the greatest advance in looking into the body since the discovery of X-rays. It allows internal structures to be visualised with a degree of precision that is totally impossible with ordinary X-rays.

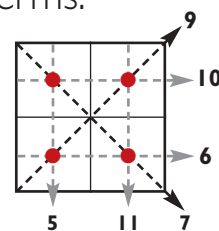
Imagine you have a slab of rich fruitcake. Inside it are raisins, currants, nuts, glacé cherries and of course the material that constitutes the cake itself. If you were to put the cake in front of the 'film' of a conventional X-ray machine, the picture would contain shadows of all the components – many of them of course getting in each other's way. The nut, which is dense, might hide the faint shadow of the currant behind it, and in many cases it would be difficult to decide what was behind or in front of what.

Tomography works quite differently. It shoots a

thin beam of X-rays through the sides of the slab (not the front and back) from one side to the other, and measures the intensity of the emerging beam. The source and detector are rotated around the sample, so that every one of the thousands of paths through a 'slice' of the object is measured. The measuring head of the machine then moves on, to do the same to the next slice.

A great deal of computing follows, and a series of images are produced, which would show almost exactly what you would see if you cut the slab of cake into thin slices and looked at the surface of each slice. Now the nut is found in slice 14, whilst the currant is in slice 11, and the order is no longer in doubt.

The diagram above illustrates in a very primitive way how it is done.



Imagine that a slice of the object only has four features in it. All we know is how much of the X-Rays are absorbed when the beam is shot from various directions. Those are the numbers around the outside, which represent the sum of the numbers in the elements through which the addition passes. Anybody with a little knowledge of algebra will be able to calculate how much absorption was due to each element in the box. Try the puzzle – this is exactly what the computer does, but on a larger scale and solving a huge number of simultaneous equations. Answer on page 22.

'It's life Jim, but not as we know it'

Action Medical Research is helping to shape the future every time we award grants to the country's leading researchers. We believe diseases and disabilities can be beaten, and we strive every day to make this vision a reality. And it's not just medical science that is changing our lives. Here we ask some leading forward thinkers for their vision of what the future might hold.

Try typing the words 'the future' into Google and you'll be amazed by the number of organisations who claim to know what's in store for mankind. There are groups predicting the homes we'll be living in, food we'll be eating, clothes we'll be wearing and holidays we'll be enjoying – Jupiter, anybody?

Futurology, the study of the mid- to long-term future, has become an established academic discipline, gathering together people from many different backgrounds – science, art and design, politics, religion and economics among others.

But how do these pundits know what's round the corner – is it a matter of science or imagination? After all, it's fun to think that we'll all be Star Trekking by the 22nd Century, but then again Victorian futurologists thought we'd be using steam power to travel to other planets by now!

When *Touching Lives* asked Radio 4's Quentin Cooper to tell us what new technology he thought would be important in the future, he said, "When people talk about the future they talk about inventions like hover boots, but it's often the little things that will shape our lives even more.

"For example, titanium dioxide is the stuff used to whiten teeth. It's in toothpaste and household paints – it's even in the little white writing on M&M sweets. It seems to be one of these things with amazing properties. If you apply it in thin layers to glass you can end up with self-cleaning glass. The Japanese are thinking of covering

pavements with it to stop chewing gum sticking."

He continued, "It would be lovely to have inventions that could suck up pollution and convert it into free energy, and fantastic to have devices that clean up oceans or reforest Amazonia, but unfortunately at that point you're straying into Harry Potter territory more than science and technology."

Does fantasy and science fiction ever get it right? "Some of the ideas you get from science fiction do help us shape our ideas about reasonable expectations for the future," he says. "I'd agree with the view of author William Gibson, where we'll all be using the internet and interacting through a virtual reality." In Gibson's latest work, 'Pattern Recognition', he describes a world of the super modern and slick, where technology and marketing in combination draw people ever deeper into internet communities and cyberspace – to the detriment of their 'real world' relationships.

Science fiction has frequently predicted a world run by machines, but is this likely to happen? We're already treading down that path, according to British inventor James Dyson, who believes that one day all our appliances, gadgets, vehicles and machinery will have the capability to talk to each other – without the help of people. And it could be much closer than we think.

"Domestic appliances would monitor their own performance, forewarning us of possible breakdowns," he says.

"Boilers, washing machines, dishwashers, ovens, fridges and central heating systems will all be networked – constantly communicating with each other to make the most efficient use of energy. And domestic robots would be genuinely autonomous devices, able to perform tasks as judiciously as humans, without running out of power."

With this new interconnectivity, appliances could be upgraded easily by simply downloading software additions direct to the machine. James says, "If a new fabric were to be invented, software containing wash programmes designed specifically for that fabric could be downloaded and installed automatically.

"There has been a quiet revolution going on in the home, and it's those high-speed fixed and wireless internet links we keep hearing about that are at the heart of it," he says.

"Japanese mobile phone network operator DoCoMo is planning interconnectivity on a massive scale. It aims to connect people via mobile phones and computers to machines like motorbikes and yachts. Even cats and dogs will be connected to their human masters via small devices worn in collars, allowing people to keep track of the whereabouts of their pets!"

So one day it might be possible to put the vacuum cleaner in charge of Tiddles while you go on holiday. And don't worry about the vacuum cleaner – the washing machine is looking after it.

James continues, "Domestic architecture is changing in a fundamental way. Separate rooms and wasteful corridors are on the way out. The house of the future will need to minimise energy consumption. A classic example would be to use the heat from the oven to heat your water."

Designer Wayne Hemingway agrees, "The house of tomorrow has got to be totally wired up so computers can be used everywhere. It should be energy efficient and designed to make the best use of space."

Wayne suggests that the way we build our homes in the future could also change. "There could be more off-site manufacturing in the way a car is built in a factory. There'll be a lot more houses delivered in sections and bolted together. The kitchen and the bathroom could already be installed so all you do is plug it into the services. All it needs is for someone to make it cost-efficient. I'm sure it will happen."

It's not just our home environment that could see massive change – even our clothes could be made more technological.

Quentin explains, "In the future you're going to get new high performance fabrics, ones that can change their pore density so it will be warmer when it's cold and cooler when it's warm, but you're also going to hear more about the wearable computer – it's already with us at a low level.

"You can put a tiny computer through the wash – they've tested it and it came out working on the other side. This means that with these mini-computers it's possible to air-condition and regulate body temperatures or, if you want, have something that can do more complex calculations. They're now working on voice recognition. Once you've got that there's no reason why you can't be wearing a jacket which you can ask questions to and it can give you answers – which will make invigilating exams much more demanding!"

Don't think of ordering one just yet though, as Wayne remains sceptical. "I don't like the colour of it or the lapel shape' – that will be people's attitude. Fashion, design and style will always be more important than what it can do technologically. We will always want new clothes, but I don't think people are going to say 'I want another technological jacket!'"

There is no disagreement about one aspect of the future where we will see a great deal of change – medicine. Illustrious academic and TV scientist Professor Heinz Wolff says the decoding of the human genome and our new understanding of what genes do has created a new book of science, and with it a world of new opportunities. "It's rather like decoding a science text book never having done any of the

experiments inside it.

"It should lead to a good deal of progress tackling genetically inherited conditions. Inherited diseases are a mistake in your genetic make-up that you can correct – without fighting nature. Effectively, you're correcting a printing error. It's like a huge blueprint or a description with a mistake in it, and by consequence you've got muscular sclerosis or haemophilia or any one of these inherited diseases."

He adds, "The kind of progress that's been made, and the way in which the body can be understood, will make possible huge advances in medicine. Perhaps even as far as growing new organs if you have a diseased organ."

Is there a price to pay for these advances? "If we could live to 150, there would be some absolutely fearful problems, both physiological and mental, as well as feeding all these people and looking after them. Even delaying ageing by 20 years, so an 80-year-old would be as fit as a 60-year-old, would produce considerable problems for younger people."

The future holds many other challenges for medical science, says Heinz. There might be less progress made in dealing with infective diseases, such as headline-hitting 'superbug' MRSA. MRSA is a common type of bacterium that is immune to antibiotic treatment.

Heinz says, "Nature always has something up its sleeve. Deaths from MRSA went up from 51 in 1993 to 800 in 2002 – a huge rate of increase."

In fact, there are few absolutes regarding the introduction of tomorrow's technology – most of our panel's predictions come with a note of caution. While Captain Kirk and Mr Spock make teleporting appear easy, Heinz warns against indulging our Star Trek fantasies too much.

"Beaming Scottie up is not likely to happen, although personally I'd love to have a device of this nature! In theory, at least, you could transmit all the information about how every molecule is organised and rebuild the person on the other end using different molecules. Let's say we had a great stock of all the elements – we could, given enough information about the placing of each molecule and atom, build somebody else merely by transmitting the information, but would that be the same person when it's made of something else? I think you can forget about it – it's simply not on."

What will happen in tomorrow's world is a difficult thing to predict. But Action Medical Research will do its best, as a forward thinking charity at the cutting edge of science and human ingenuity, to predict which research projects will have the biggest impact on the UK's health, now and in the future! **TL**



Quentin Cooper

Radio 4 presenter Quentin Cooper is the host of technology-in-action programmes The Material World and Connect, and "an expert on everything from pop music to astrophysics". He also presented the series New Scientist Television for the Discovery Channel and Science Fix for BBC Four.



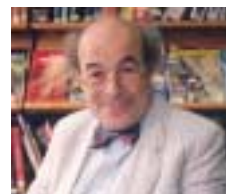
James Dyson

Innovator, designer, industrialist and business icon, James has been at the heart of many inventions, from wheelboats to vacuum cleaners. A former Action Medical Research grantholder, funded to develop a motorised electric wheelchair, James says that anyone developing new products and new technology needs one characteristic above all else: hope.



Wayne Hemingway

Co-founder of the Red Or Dead fashion-house, Wayne is the acclaimed designer of everything affordable from clothes and furniture to housing estates, and has designed a very cool recordable digital radio – The Bug. He hopes future technology will let him travel to Australia in just a few hours.



Professor Heinz Wolff

Award-winning scientist, TV presenter and former Action Medical Research grantholder, Heinz founded the Brunel Institute for Bioengineering at Brunel University in 1983. Still fully active at Brunel, Heinz somehow manages to find time to, amongst much else, regularly contribute 'jargon busters' to Touching Lives.

Visit www.action.org.uk/thefuture for longer versions of these interviews.

Legacy news

Action Medical Research's Legacy Officer, Jane Tarrant, writes.

Each year many of our supporters make the decision to leave a gift to Action Medical Research in their Will. This is one of the most important ways of helping the Charity and shows how forward thinking our supporters are! Leaving a legacy is a positive decision that can be made today, but costs you nothing. A gift of any size is also an ideal way of passing on the maximum benefits of your Estate, as it will be entirely free of inheritance tax. For Action Medical Research it means that we can plan ahead with confidence when we fund vital medical research.

In the financial year 2002/03 we received over £450,000 from legacy income. We are extremely grateful to those supporters who chose to support us in this very special way. Their kindness has enabled us to fund more of the life-enhancing medical research projects that will help us create a future without disease and disability.

Many people think that a legacy has to be an enormous sum of money, but this isn't true. Making a will is about wishes, not wealth. What is important is that you draw up a Will with clear instructions, enabling you to benefit the people and causes that are important to you during your lifetime.

Any gift left in a Will, no matter how large or small, is important to us.

Queries often come through to me at the Action Medical Research office. Some of the most important questions include the following.

What are the different ways I can support Action Medical Research through my Will?

Increasingly our supporters are choosing to leave us a residuary gift. This can be some or all of what is left of your Estate, after bequests, debts, taxes and costs. It simply means that you leave a percentage of your Estate to Action Medical Research rather than a fixed sum. It is the most beneficial gift to us as it is index-linked to inflation. You can also leave a pecuniary (cash) gift, which is a specific sum of money left to the Charity. However, we do advise that you consult your solicitor on what is best for your particular circumstances.

How do I add a gift to a charity if I have already made my Will?

It is easy to add a gift to an existing Will –

your solicitor simply attaches a written instruction, called a codicil. The codicil will need the signature of two independent witnesses.

Do I pay inheritance tax on my gift to charity?

If your Estate is worth more than £263,000, your beneficiaries will have to pay 40 per cent inheritance tax on the amount over £263,000. Gifts between husband and wife are exempt. Legacies in favour of charities are tax-free, so you will be passing on the maximum benefits of your Estate.


How can I support you further in spreading the legacy message?

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. So we need to get the word out to everyone, in order that those who want to give in this way have the opportunity to do so.

Perhaps you or someone you know might consider becoming a legacy ambassador for the Charity? Support, training and literature are all available. For further information please contact me, Jane Tarrant, on 01403 327414, or email me at jtarrant@action.org.uk

Help us improve tomorrow today

Our new legacy leaflet includes information on the different ways you could help us by leaving a gift in your Will. If you would like a copy, or additional copies, please contact me.

Action Medical Research wants to create a healthier future for everyone. Your legacy gift could help us turn this vision into reality. Your gift could fund the next medical breakthrough – ensuring that your legacy is a lasting one. 

In Memoriam donations

We would like to thank the many supporters who chose to remember loved ones by making a donation to Action Medical Research instead of having flowers at the funeral. Last year over £10,000 was raised from these kind contributions, and is already funding more of our pioneering research.



Our grateful thanks go to the following people who left a legacy to Action Medical Research during the year July 2003 – July 2004.

Mr Sydney Atkinson
Miss Joan Winifred Balls
Mrs R Bashford
Ms Kathleen Marjorie Benson
Miss Dora Bloomer
Mrs Bessie Brearley
Miss Doris Blair Campbell
Mr David George Cane
Mrs Pauline Dorothy Chalkley
Mr Reginald Percy Compton
Mrs Ursula Cragg
Miss Rose Aileen Faircloth
Mr Thomas Alexander Fraser
Mrs Florence Beatrice Griffin
Mrs Marguerite Mary Griffith
Miss Grace Alice Gurr
Mr Ian McGowan-Docherty
Ms Annabella McGregor McDonald
Mrs Daisy Alice Prescott
Mrs Ellen Margaret Robertson
Mrs Doris Russell
Miss Vera Mamie Sandell
Joan Catherine Scardifield
Miss Gwendoline Ethel Mary Stiff
Ms Diana Stuchbury
Mr Raymond Winston Tomlin
Mrs Joan Adelaide Trent
Ms Olive Turner
Mr Herbert A Walkinshaw
Mr Anthony Edward Waller
Mrs Nancy Waters
Ms Ruth Welbourn
Mrs Elizabeth West
Mrs Christine Margaret Wilkie

Crossword 8

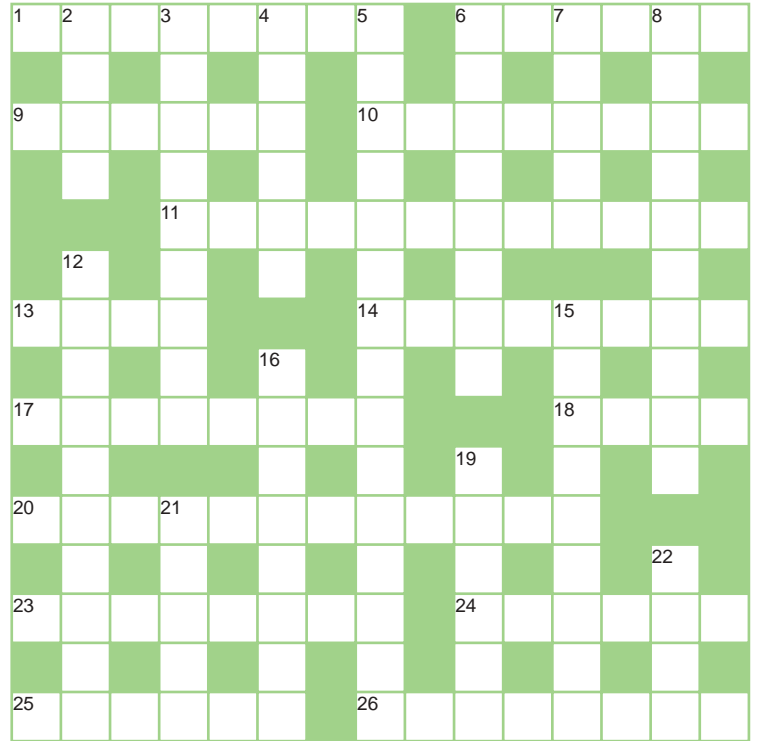
by Esmee

Across

- 1 Having funds (2,6)
- 6 Information to analyse for bone healing assessment (2,4)
- 9 Film about a real person (6)
- 10 WW2 episode (3,5)
- 11 It may reject an organ (6,6)
- 13 Superbug (4)
- 14 Support (8)
- 17 Agreed (8)
- 18 Potentially fatal reaction to bone marrow transplant (4)
- 20 Joanna Southcott, for example (5,7)
- 23 Looking at wildlife (2,6)
- 24 American meal (6)
- 25 Heinz's institute (6)
- 26 Martin's profession (8)

Down

- 2 ---- McIntosh (4)
- 3 Reconstruct (9)
- 4 Japanese mobile phone network operator (6)
- 5 It's used to whiten teeth (8,7)
- 6 Shakespeare's Grecian heroine (8)
- 7 Miniature people (5)
- 8 Battle between champion and contender (10)
- 12 Was used to study babies' brains (3,7)
- 15 Army manoeuvre (5,4)
- 16 Where to place a foot at the bar (4,4)
- 19 Digital radio (3,3)
- 21 European country (5)
- 22 Dull pain (4)



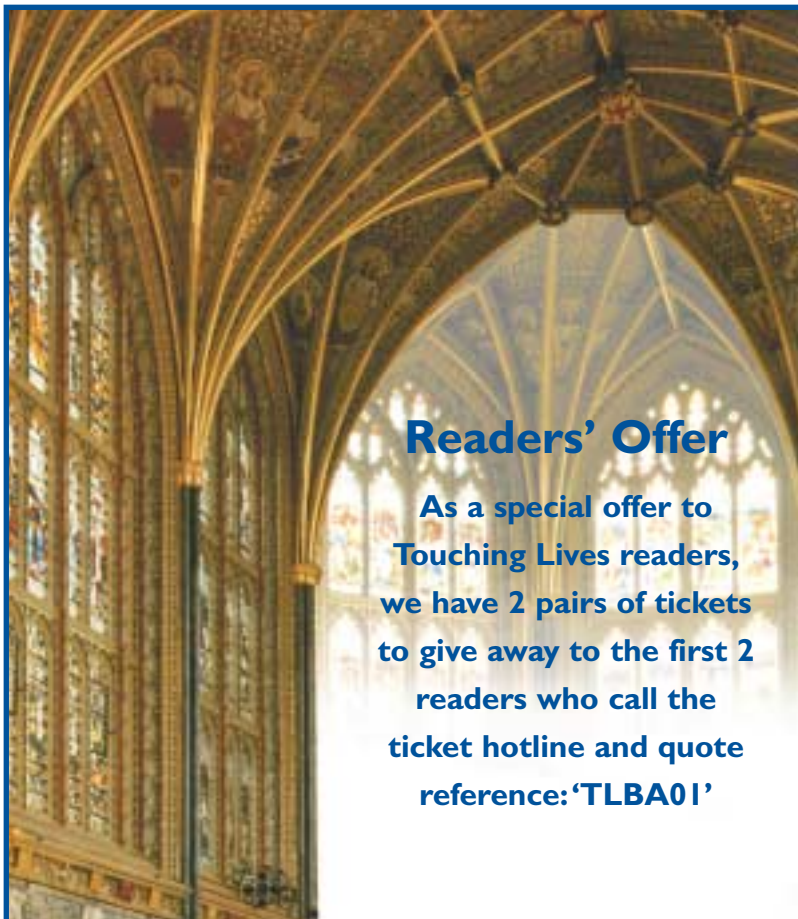
Jargon busters answer

3	7
2	4

Some of the answers can be found within this magazine.

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 22nd October.

Congratulations to Mrs J Arkinstall from Powys who won the prize in our last issue.



Readers' Offer

As a special offer to Touching Lives readers, we have 2 pairs of tickets to give away to the first 2 readers who call the ticket hotline and quote reference: 'TLBA01'

The Bach Choir

performing in the magnificent surroundings of St George's Chapel in Windsor Castle – with a programme including works by Vaughan Williams, Parry, Liszt, and Taverner.

The concert takes place in aid of Action Medical Research on November 19th 2004 at 7.30pm.

Join us for an evening of wonderful music in this most spectacular of settings. Tickets are priced from £15 to £40 – with a limited number at £65 to include a pre-concert champagne reception in the Vicar's Hall.

Call the ticket hotline on 01628 621242.



Where the money goes

Another opportunity to see how your donations to Action Medical Research are making a real difference. Here we focus on a project which used pioneering techniques to demonstrate a link between infection in the womb and brain damage in pre-term babies.

Led by Professor David Edwards with Dr Mark Sullivan and Professor Mary Rutherford, a large team of researchers has spent several years studying the effect of bacteria on the unborn baby to better understand the link between infection, early delivery and brain damage.

The study at the Department of Paediatrics at Imperial College School of Medicine, London, had the backing of a large group of parents who agreed to let their premature babies be a part of the research.

One large team

Professor Edwards told Touching Lives, "We think of ourselves as a large team, including the clinicians and scientists but also the parents and children and the people and donors at Action Medical Research, whose funding makes this kind of work possible.

"We have been looking at pre-term babies for many years, but wanted to understand better the relationship between bacteria, infection and brain damage. It was already recognised that infection in the womb could cause early delivery, and while there are probably several factors that can lead to such brain damage, we wanted to see how bacteria causing an infection in the womb could impact on brain tissue and result in the lifelong problems that some premature babies face."

It was thought that the same bacterial stimulus that can cause early delivery was also damaging some unborn babies. But the team had to look at the very fine details to understand exactly what was going on.

In the course of the three-year study, helped by a grant of £171,000 from Action Medical Research, the team utilised brand new techniques for studying bacteria. They used molecular technology to actually see a bacterium's genetic make up – thereby identifying bacterial genes to isolate those causing a problem.

More harmful

Professor Edwards said, "We found that some babies born early had bacteria in their placenta, but had no sign of inflammation or other



Some premature babies will go on to face lifelong problems

problems at all. Perhaps their bodies had reacted in a different way, or perhaps some types of bacteria were more harmful than others."

However, some bacteria can activate the babies' immune system, and traces of immune cells and 'activators' were found in the placenta and blood of some infants. High levels were found in babies with brain damage, suggesting that the brain is sensitive to this immune reaction.

In the search for answers, the team found unexpected bacteria that seemed to be linked to severe inflammation and damage, and will now become the subject of ongoing research. The team has also identified a gene involved in the response to infection that seems to be linked to premature birth.

Another groundbreaking technique was used to scan the brains of tiny premature babies as part of the study. A unique MRI scanner had to be developed and installed in the Intensive Care Unit to study such small patients, but it helped the team understand how specific bacteria could cause brain damage and prematurity.

Professor Edwards said, "In identifying specific bacteria and understanding how babies respond to them, and by understanding how a baby's brain is affected, we are always thinking about how we might protect delicate brain tissue."

Into the detail

"Part of what the study has also demonstrated to us – and this is nothing new – is the importance of infection control. Bacteria can be harmful, and our studies underline the impact of good infection control.

"We will now go on looking at other aspects of bacterial infection and the effect on pre-term babies in the hope that we can make more progress. It has been a huge team effort, a real example of good collaboration between the doctors, scientists, nurses and the patients themselves.

"It has helped our understanding of the link between bacteria and brain damage in pre-term babies, but we had to get right down into the detail to find what we wanted." TL

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

Special offer for Touching Lives readers



Gym discounts

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It's easier and cheaper to join a gym with Health-Force. You can save up to 50% on gym membership and you often pay no joining fee.

For full details on clubs and prices just speak to one of our friendly operators or alternatively check out the Health-Force website. There are over 500 clubs nationwide with prices starting at just £15/month.

We have listed examples of our Body Sense clubs opposite to give you an idea of the sort of deals that are on offer – big savings on monthly subscriptions and no joining fees.

Find out more by calling the number below. Lines are open 8.30am-8pm Monday-Friday, 9am-5pm Saturdays and 10am-4pm Sundays or log on to the website address below.

Call 0870 1267 541
www.health-force.co.uk

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Full price £46/month.
Health-Force price £24/month

Imperial Hotel Torquay

Full price £35/month.
Health-Force price £19.95/month

Cheltenham Park Hotel

Full price £42/month.
Health-Force price £35/month

Imperial Hotel Blackpool

Full price £30/month.
Health-Force price £19.95/month

Majestic Hotel Harrogate

Full price £45/month.
Health-Force price £29/month

Palace Hotel Buxton

Full price £37/month.
Health-Force price £27.50/month

Redworth Hall Hotel Durham

Full price £51.50/month.
Health-Force price £39/month

Shrigley Hall Hotel Cheshire

Full price £42/month.
Health-Force price £25/month

Stirling Highland Hotel

Full price £50/month.
Health-Force price £37.50/month

Marine Hotel Troon

Full price £44/month.
Health-Force price £31/month

Oxford Hotel Oxford

Full price £48/month.
Health-Force price £29/month

No joining fees!



Important information. Please note that participating health clubs and offers are subject to change.