

2004  
celebrating 30 years  
spinal injuries association

annual report  
2003-2004  
towards ► 2005

Then NOW



**sia**  
SPINAL INJURIES  
ASSOCIATION



BUCKINGHAM PALACE

# A letter from SIA's Patron: HRH The Princess Royal



Princess Anne at SIA's Whiz Quiz, Aberdeen 2004.

## An anniversary, in any walk of life, is an occasion to mark.

In the life of a charity, it has a particular significance, as it is a time to reflect on changes, improvements, and how the organisation has developed to meet the challenges brought to it

by the people it is there to serve. This year the Spinal Injuries Association, of which I am pleased to be Patron, celebrates its 30th Anniversary. Looking back, it is clear that the Association's achievements have been significant. From an organisation with a staff of one, with one service (the Link Scheme) and one publication (so you're paralysed...), SIA now has over 30 full or part-time staff and more than 50 volunteers. SIA's Services now include a Telephone Helpline, a Peer Support Service, a Community Peer Support Service and Link Scheme, and a Voice Choice Language Line for those for whom English is not their first language. Publications are now almost too numerous to mention, and are led by the Association's 'bible' on spinal cord injury

'Moving Forward', along with the highly popular bi-monthly magazine FORWARD.

This progress has been achieved by the hard work of many people, and the contribution of spinal cord injured people who have always been involved in the organisation's development, whether as staff, volunteers or Trustees. I commend the efforts of everyone who has contributed to SIA's success and, with the exciting project of establishing its own Headquarters now a reality, wish the Association well in its 30th Anniversary Year.

HRH The Princess Royal

## SIA's President Baroness Masham and co-founder Professor Mike Oliver

### talk about what existed before SIA and what has been achieved in the last 30 years:

#### Baroness Masham –

When I was 22 in 1958 I broke my back riding in a steeplechase, when my horse fell and rolled over the top of me. I was paralysed at T5 and cannot move or feel from my chest down. I felt strongly that there should be a Spinal Injuries Association to support the many paralysed people who have this very special condition.

At that time there was no organisation able to meet our needs, answer our

questions and lobby the decision makers on our behalf. So with help from the Kings Fund and Lady Hamilton – who had founded the Disabled Living Foundation – SIA was eventually born.

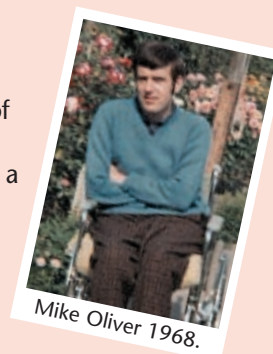
**Mike Oliver** – I was injured in a diving accident at the age of 17 in 1962 at Butlins in Clacton sustaining a break at C6. With a group of like-minded individuals we got together and



Baroness Masham and Diana Irish made sure that SIA was formed. I feel that in the thirty years a lot has changed but also some things have not developed.

**Access** has got better. When I was young I would automatically *assume* that I wouldn't be able to get into a building easily. Now I can *assume* that when I attend a meeting, I will be able to get in.

**Benefits** are also a lot better. In my early years of injury I would get £4 to last me the week!



Mike Oliver 1968.



Baroness Masham with her daughter Clare, 1965.



Paul Smith 1982.

## Our thirtieth year was a challenging one for the Spinal Injuries Association,

largely due to the preparation required for our move in June 2004 from our offices in Muswell Hill – our home for the past 20 years. We moved to temporary accommodation in central Milton Keynes pending completion of our

new centre in mid 2005. In January 2004,

SIA took a month-by-month lease on an open plan office owned by the Milton Keynes Community Foundation, and started the recruitment process to replace staff who unfortunately would not be relocating with the organisation. We are delighted to report that, despite the substantial distance of the relocation, we have managed to retain over half of the team originally based in North London.

You will read on page 5 about the new building and the Capital Appeal and are sure you will gather from the piece that much hard work has gone into the concept, design and costing of the new building by trustees past and present, the professional design team and staff. A particular thank you goes to Jack Lawton, Vice-President and immediate past Chair of SIA, for steering the new building project forward, to Dr Roger Fitzwater, retired Chair, and David Finnegan, past trustee who provided invaluable comments and advice to the Building Committee.

You will read later in this report that, despite the disruption caused by the move, services have grown and new ones have been developed. Calls to the Helpline continue at a high rate; we started the Healthy Living Roadshow; developed our range of publications; and have continued the expansion of Peer support into the community. We played an active part in the European Year of Disabled People through our Equally Able Project and established SIA's very own 'Expert Patient' programme to support SCI people to develop skills to take control of their lives.



Jonathan Fogerty 2004.

There are so many people to whom we have to be thankful, our staff, professional advisors and wonderful supporters who have all helped us over a difficult time. The Trustees extend their thanks to them, and express their best wishes to those that have moved on from the organisation this year.

Paul Smith, Executive Director

Jonathan Fogerty, Acting Chair

**Wheelchairs, cars and technology** associated with mobility have significantly improved. One used to be issued with a standard grey Everest & Jennings chair; and powered chairs were few and far between.

**Supported Community Living** didn't exist before SIA showed it was possible. Now we have PAs, Direct Payments, whereby the individual can control, employ, manage, train and look after their own affairs should they choose to.

**Education** is now open to many more people. When I was a student, I only got in because I was bloody minded enough.

The **Voice of Disabled People** has improved enormously. When SIA started there were less than a dozen organisations with a disabled person at the helm, now there are hundreds and disabled people have a democratic voice.

Finally, we have **Rights**. Rights of access, rights to not be discriminated against etc – though of course rights don't mean anything if they're not enforced.

Nothing has actually got worse but I would argue that a number of things have remained the same. I feel that **Medicine and Medical Care** has not advanced. Yes, treatment is better and there are different antibiotics but superbugs are present and rehabilitation has not changed significantly.

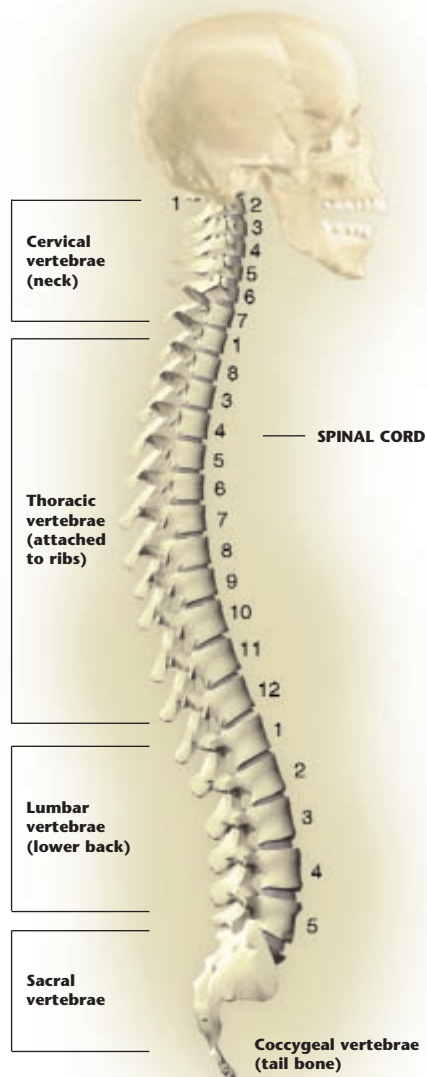
There are not enough **Beds in Specialist Centres** and not enough quick access to the beds. Access to Spinal Cord Injuries Centres is not really better than in 1974.

**Employment** opportunities are no better with approximately the same percentage attending the work place.

Finally **Housing's** still a problem. The process might have been speeded up to get you out of hospital but the support and conversions to get places ready has not significantly improved.

**Baroness Masham** – I agree that there are not enough beds in specialist units. Research shows that between 300 to 400 newly injured people do not have access to treatment at a Spinal Injuries Centre. Our findings suggest that this has a real impact on rehabilitation by causing all sorts of problems for SCI people, such as pressure sores, urinary tract infections and depression.

I think on the positive side SIA has achieved an enormous amount itself and has become a major organisation, managing well-established, user-led services such as the Freephone Helpline, Peer Support and the Community Link Scheme. Reading through this Report is a demonstration of this progress and permanency.



www.apparelyzed.com

### Spinal Cord Injury (SCI) is a result of damage to, or disease of, the spinal cord.

It is estimated that there are 40,000 spinal cord injured people in the UK alone. SCI takes two main forms, paraplegia and tetraplegia.

If the spinal cord is damaged in the cervical region, there may be a loss of feeling and movement in the upper body, arms and hands: this is described as tetraplegia. If cord damage is sustained at a high level it is likely that breathing will require ventilator assistance.

If the spinal cord is damaged in the sacral, lumbar or thoracic region, there may be little or no feeling in the lower limbs and lower part of the body: this is described as paraplegia.

### Causes of Traumatic Spinal Cord Injury

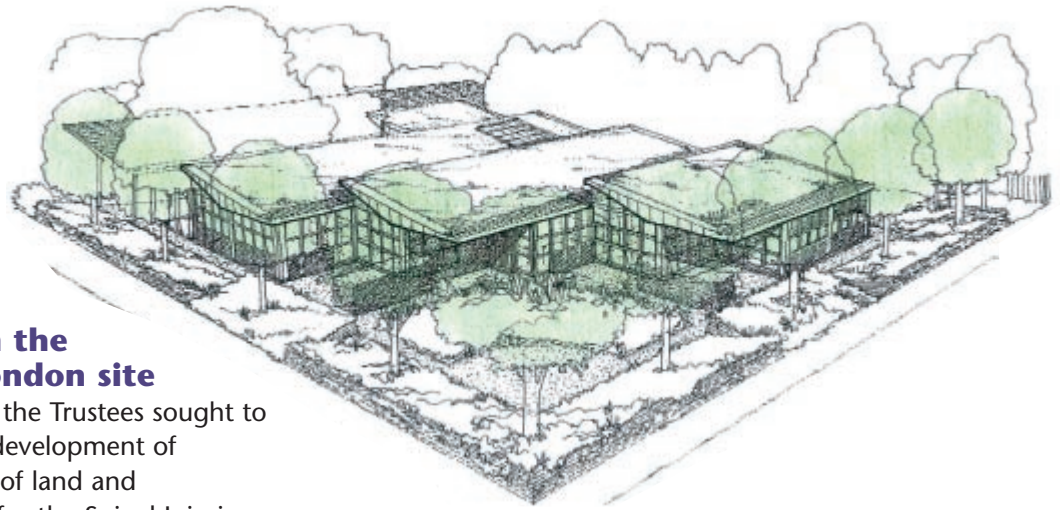
There were 590 new patient admissions to all the Spinal Injuries Centre in the UK and Ireland in the year 2001 (which are the latest available statistics).

	%	%
<b>Road traffic accidents</b>		<b>39.2</b>
4 or more wheeled vehicles	16.1	
Motorbikes	9.7	
Cyclists	3.2	
Pedestrians	3.4	
RTA (not specified)	6.8	
<b>Falls</b>		<b>45.5</b>
From height	19.7	
Downstairs	9.7	
Jump	3.7	
Fall down	10.7	
Falls (not specified)	1.9	
<b>Sharp trauma/assault</b>		<b>2.4</b>
<b>Sport</b>		<b>7.8</b>
Diving	2.2	
Rugby	1.4	
Horse Riding	1.7	
Altitude Sports	0.8	
Winter Sports	1.4	
Gymnastics/Boxing	0.3	
<b>Knocked over/collision/lifting</b>		<b>2.5</b>
<b>Trauma (not specified)</b>		<b>2.5</b>

A further 155 new patients were admitted with paralysis caused not by trauma but by medical conditions such as tumours, infections, internal bleeding or disease.

This total of 745 does not include those people who were treated in District General Hospitals and did not go through a Spinal Injury Centre.

*(with grateful thanks to Mr C. Inman from the Welsh Spinal Injuries Centre who gathered these 2001 statistics on behalf of British Association of Spinal Cord Injury Specialists)*



**A few years back when the lease for SIA's North London site was coming to an end**, the Trustees sought to secure the charity's future and development of objectives by purchasing a plot of land and constructing a new building fit for the Spinal Injuries Association future activities.

During June 2002 the Capital Appeal was launched to raise awareness and initiate funding for the project. On hearing of the need for SIA to find new premises Mr Tim Watts as Chairman of the **Pertemps Group of Companies**, offered to help raise funds and continues to provide invaluable support.

Mr Watts has put at our disposal all the resources that such a large company has to offer, with assistance from their Head of Marketing, Community Liaison Manager and even the support of the Pertemps Racehorse Manager for our equestrian events.

We are extremely grateful for all the hard work of our supporters at Pertemps who have contributed to the success of events held in aid of the appeal such as a ladies lunch and presentation of millinery hosted by couture milliner Eda Rose, and a charity evening at Uttoxeter racecourse that raised over £80,000. A host of events are planned for the coming year to raise funds for the appeal.

Thanks to the **Milton Keynes Community Foundation**, SIA located a suitable site and were given a generous 75% subsidy on the purchase of the land. The Milton Keynes area itself offers benefit to the users of the charity's services, in terms of being accessible, both in physical layout and transport infrastructure.

The design of the building is one that aims to incorporate every ethos of Universal Design and accessibility, together with environmental sustainability, in order to create a landmark building. It will become a focus for issues on spinal cord injury with the establishment of the UK's most

comprehensive research library on the subject and will provide the opportunity for SIA to expand its services and level of support. Construction on site has started, with a completion date mid 2005.

In making a commitment to environmental sustainability the new building incorporates a number of novel design features:

**Solar Panels (Photovoltaic Technology):** Sections of the roof and window area of the new building will feature solar cells, together with the canopy covering the car park area. SIA has already achieved profile and success with the scheme and with the assistance of BP Solar has been awarded a grant from the Energy Savings Trust, Department of Trade and Industry, of £136,000 towards the cost of the installation.

**Green Roof:** The new building roof has been designed incorporating a slow growing alpine style of planting to provide a visually attractive and functional covering; reducing sound transmission, heat loss and acting as a natural habitat for wildlife.

**Rainwater recycling** – Rainwater run off from the roof will be recycled for use in the service water system in the building.

The design team comprises primarily of local organisations who have whole heartedly embraced what is an exciting, landmark project. These include:

**Sansome Hall** – Architects; **Peter Bushnell Associates** – Project Managers, Quantity surveyors, Planning Supervisors; **Rok** – Main Contractors; **Malcolm Chard** – Service engineers; **Stuart Thomas Associates** – Structural Engineers and **Quartet** – Landscape Design.

**In 1974, the Spinal Injuries Association had one staff member and some committed volunteers.** With this limited manpower SIA announced its arrival and established contact with the people that needed help. By 1984, the organisation had a dozen staff; had published our first book about spinal cord injury; operated a range of holiday facilities, including two narrowboats; provided a comprehensive Information Service and had generated a great deal of interest through a regular Newsletter. By 1994, SIA had bought a third narrowboat (activity holidays for wheelchair users were difficult to find at this time); had a nationwide Link Scheme; had published many self-help books and had seen its Information Service develop into a specialist Helpline for spinal cord injured people.

Today, another ten years on – and now celebrating our 30th Birthday – our Freephone Helpline is one of the most popular ways for people to ask for help and advice. But the options to contact us are now much more varied and often instant. This can be face to face at a Spinal Injuries Centre; by e-mail to a Helpline Adviser; in another language via our Voice Choice translator service and, if people have web access, by communicating with other spinal cord injured people via SIA's Message Board and the internet Chat Room. The **Freephone Helpline** (0800 980 0501) is one of SIA's core services with nearly 3,000 phone calls a year

made to our Advisers. The Helpline Team deal with a wide variety of questions that require a range of information and listening skills. Queries come from worried relatives trying to find out what spinal cord injury entails when a loved one has been injured; they come from wheelchair users wanting to know about the different types of aids and equipment available; from health professionals and end-users wanting information about benefits and from people leaving hospital wanting to know about the various housing options available.

Calls to the Helpline come from all over the country and this wide geographical spread gives us an accurate picture of the varying levels of service provision for spinal cord injured (SCI) people. For example, what may be available in one area is either severely restricted or completely unavailable in another. Our Helpline staff are able to use this information to press for better provision for spinal cord injured people and to quote examples of best practice in one Health Authority or Social Services area to others who appear to be failing in their legal duty towards disabled people.

The Freephone element of this service ensures that people do not have to worry because of limited finance. We have found that e-mails too are an increasingly common and spontaneous way for



people to establish contact with us. Last year, ten per cent of our Helpline queries came from this source and it seems that this will rise again next year as more people come on-line.

SIA's **Peer Support Service**, has been one of the greatest recent SIA successes. A decade ago, there was very little face to face contact between people who had been long-term spinal cord injured and those who were new to their injury. Now, there are SIA representatives in each of the Spinal Injuries Centres in England and Wales. Each Peer Support officer has their own personal experience of having an injury, coming to terms with it and facing life anew, and they can use this experience to support and encourage those who have just acquired their injury. We are especially fortunate in having the support of the Spinal Injuries Centres as without this the Service could not exist.

The Peer Support officers and the volunteers who work with them attend a Spinal Injuries Centre at least once a week, and this regularity and the constant presence of fellow wheelchair users who have amassed tips and experience along the way, enables people who are new to spinal cord injury and their families to see that life, employment, sport, holidays, driving and other activities are all possible with a spinal cord injury.

A logical extension of this service has been developed over the last few years with the establishment of a **Community Peer Support Service**. Thanks to support from *The Northern Rock Foundation*, the Spinal Injuries Association has been able to appoint a Regional Development Officer and a Community Peer Support Officer in North East England. These individuals, both spinal cord injured, work closely with the Middlesbrough Spinal Injuries Centre to offer help and support to individuals returning to live at home and in the community.

Our plans to develop **Community Peer Support** received a further boost, thanks to *Lloyds TSB (Wales)*. Thanks to funding from them we were able to appoint a Community Peer Support Officer for Wales. This appointment has led to the creation of a Welsh website, a Community Link Scheme for Wales and the involvement of SCI people as volunteers to further work in Wales. The Community Peer Support Officer is also ensuring that a whole raft of governmental, medical and other organisations get to know about the existence and needs of our members (and other SCI people) in Wales.

Thanks to sponsorship from *Walker Smith Way* solicitors, we were able to translate and print an information leaflet on SIA for Welsh speakers. In addition, sponsorship from the *Complete Personal*



I'm Peter Smith and I live in Derbyshire. I became 'one of us' in January 1955 – almost 50 years ago – after a difference of opinion in Kenya between me, a Land Rover and a tree. The Army shipped me home and

I was first at a military hospital at Wheatley in Oxfordshire, and afterwards at Stoke Mandeville.

Much has changed since, and all for the good. The founding of SIA was one of the outstanding 'good things'. There was little support outside the hospitals then and the Spinal Injuries Association was groundbreaking stuff. Now we take the forum it gives us for granted; the many books, the support services, newsletter articles. It has been a great thing and I only wish it had been around in my

early days. But we managed: then, as now, peer support was what got us through the early dark days.

For myself, I married a wonderful woman in '56 (who still puts up with me!) and went to work in Local Government (Poppa Guttman's advice was "You must vork"), staying with them for 30 years in various jobs. We adopted three lovely children – two boys and a girl – and now have four grandchildren too. At 72 I've just had a plumbing re-route and am feeling good. So there we are – good wishes to everyone out there. Stay fit and active, and keep the weight off.



Assistance care agency enabled us to produce a bi-lingual poster which we distributed throughout the country. These two measures enabled us to reach out to health workers and spinal cord injured people who might have been previously unaware of our existence and services.

Translating was also an important element of our **Equally Able Project** supported by the *European Year of Disabled People*. SIA's unique scheme, aimed at spinal cord injured people from black and minority ethnic communities in the UK, allowed those who have difficulty with English as a language to contact our Helpline for support and advice. We wanted to be able to give them the same level of service as provided for English speakers. We also wanted to be able to address the specific cultural needs of this group, and learn from them how we could ensure that ALL our services were appropriate and accessible to the wider community.

SIA's **Voice Choice** telephone line, enabling people who speak Albanian, Arabic, Bengali, Farsi, Greek, Gujarati, Somali, Turkish, Urdu and Chinese, to access the Helpline was widely advertised to national and local organisations serving the black and minority ethnic communities. We were also able, thanks to [www.multikulti.co.uk](http://www.multikulti.co.uk), to translate into different languages the important basic elements of living with a spinal cord injury, placing this text on our website. This enabled people to read at their leisure some of the crucial aspects of learning to live with their disability.

The internet has always been more than a virtual world to people with SCI. For our members and others it is a very real environment that enables them to access people and information from the comfort of



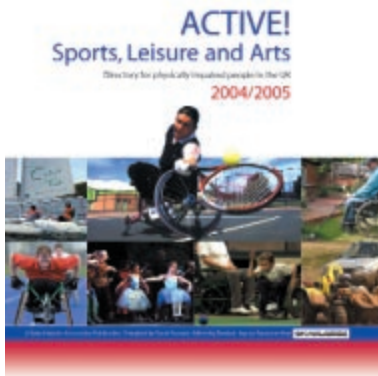
their own homes. SIA's website at [www.spinal.co.uk](http://www.spinal.co.uk) has become an important 'Favourite' for many, both in the UK and abroad. The site is accessed by over 800 different people a day (that's more than 25,000 sessions a month) for an average of 15 minutes a visit.

The **Message Board** (sponsored by *Astra Tech Ltd*) is the most frequently visited part of our site with more than one thousand questions and responses concerning spinal cord injury and related issues being placed on the Board last year. Incredibly, over one thousand people have registered with the Board and wish to be sent updates about the site in the future. This is a sizeable community that has been established on-line, who want to learn, to share or even to chat in the real-time hosted Chat Rooms.

Sharing of experiences and of information is something that SIA's new **Living Options** self-management scheme does across the country. Living Options has been established with funding from the *Department of Health* under the Expert Patient Programme. The Programme promotes self-management courses, appreciating that people with chronic conditions are the 'experts' on their condition. As this approach is one that underlies SIA's whole philosophy of self-help, SIA has embarked upon a programme of Tutor Training in both the North and the South of the country. These Tutors, all of whom are spinal cord injured, will deliver courses in the various regions of the country to enable people to better understand their impairment and acquire the confidence, knowledge and skills to manage it successfully, not least through effective communication with the medical profession. The benefits of attending a self-management course are becoming widely recognised, with reduced visits to GPs surgeries, A&E and Outpatients being reported, along with a reduction in levels of fatigue, anxiety and depression; and a lessening of the severity of debilitating symptoms, such as levels of pain.

SIA's publications have also been instrumental in improving self-awareness and developing life skills. During the past year we launched the first ever video showing how to be an expert wheelchair user. From basic skills such as flipping up the front wheels to mount a kerb, back wheel balancing and riding an escalator (!), **'Turning the Corner'** which was made in conjunction with the physiotherapy department of Stoke Mandeville Hospital, with sponsorship from *Independence Technology*, *Ford Magic* and the *Private Physiotherapists Educational Foundation*, has been shown on prime time TV and discussed on national radio.





During the year, our most recent publication **ACTIVE!** sponsored by *Cyclone* and supported by the *Rank Foundation* was also a UK first, bringing together information on the range of

organisations that enable a multitude of sporting disciplines to be undertaken by disabled people, as well as more leisurely activities available around the country. Like 'Turning the Corner' this is a publication that is relevant to a wide range of disabilities, in addition to people with spinal cord injury.

The world's most thorough and up-to-date Guide to Bladder Management for people with spinal cord injury was launched on the Internet this year. Sponsored by *Astra Tech Ltd*, makers of *LoFric*, and written by Consultant Urologist, *Simon Fulford FRCS*, this is an essential guide for the lay person as well as for health professionals.

Our bi-monthly magazine **FORWARD** continues to thrive and enjoys an increasing readership. Thanks to the continued support of *Active Assistance* and *Astra Tech Ltd* the number of pages has risen to over 60 and the range of subject matter is consistently varied. Over the year the themed topics included 'The Right to Die or the Right to Live', *SCI Technology*, *Ageing with SCI*, *Motoring Matters*, *Holidays & Travel*, *Fertility & Fatherhood* and much, much more!



The annual **Directory of Personal Injury Solicitors** was expanded to, for the first time, include details of case managers and financial managers. This Directory helps newly injured people to evaluate those legal firms that have previous experience of managing cases involving spinal cord injury as well as identify such firms located nearest to them. Available free of charge both in hardcopy and on the internet, this authoritative publication continues to reach its SIA targetted audience in large numbers.

As part of its policy of taking its services out to members, SIA last year launched its new series of **Healthy Living Roadshow** sponsored by *Astra Tech Ltd*. The first two shows were in Gloucester and Exeter and attracted nearly a hundred people each. Lively presentations by health professionals on topics pertinent to people with spinal cord injuries, helped spread the word about the benefits of exercise, healthy food intake and other precautions that increase life expectancy, improve strength and stamina and enable an improved feeling of well-being. These shows were so successful that the *Department of Health* is supporting their organisation at other venues around the country in the coming year.



Our **Youth Service**, funded by the *Rank Foundation*, has continued to support young people who have received spinal cord injuries, often while they are still at school. As well as advising on higher and University education, the Service has also been consulted by concerned parents, community care workers and social workers on a raft of issues relating to independence for the young person. These can range from a young disabled person leaving home and living independently for the first time to housing and educational options as well as relationship and emotional issues.

A unique project, which is nearing fruition, is the SIA **Intranet**. Currently for internal use only, the Intranet contains literally thousands of literature references, making it an invaluable resource for researchers and others on all aspects of spinal cord injury. A searchable database has been devised that brings up comprehensive results across a variety of different sections, allowing staff to search through the hundreds of news articles and items housed on a dedicated server. Additional indexes include the back issues of our bi-monthly magazine *FORWARD*, enabling staff to answer specific queries quickly and efficiently. Most recently a Photo Library has been added to the Intranet, including images which can be used for press, publicity and websites. The ultimate aim for the Intranet is that it will be used as a resource by researchers and others once SIA has moved to its purpose-built offices where it will be sited in the Library for easy access to visitors.

“Lerona, my daughter, had a car accident when she was 5, which left her with an injury T12/L1. At that time and since I have called the Spinal Injuries Association for a variety of reasons; be it for social, travel or benefits advice.

I just feel that whatever the level of enquiry, be it serious or simple, and if I can't solve it myself, then it's worth giving SIA a call.”

**Susan Gelb**

When Lerona's school wanted someone who wasn't her mother to go with her to France on a school trip, it was SIA (in the days that they provided Personal Assistants) that supplied Jo Anne as a companion for her holiday.

When we needed information about insuring a car at the age of 16, it was the Freephone Helpline that I contacted. And this year when I needed to know about free prescriptions whilst Lerona was at university, it was SIA that I contacted again.



**One of the many causes that External Affairs pursued during the year** was its continued involvement with the **Cinema Access Campaign** which should bear fruit when the next phase of the Disability Discrimination Act is implemented in October 2004. Cinemas in the UK will have to have a very good excuse if they cannot provide non-discriminatory services to disabled people by that date.

SIA continues to be represented on the **Spinal Cord Injuries Services Consortium Board**, and this will help the three southern Spinal Cord Injuries Centres meet common standards on protocol, treatment paths, catchment areas, long-term follow-up, home ventilation and treatment for paediatrics.

SIA has helped to ensure that when the new Centre at Wakefield (**Pinderfields**) is completed, it will retain its status as a regional SCIC and has a design appropriate for maximising its impact in the Yorkshire region for the next few decades.

SIA contributed to the **All Party Parliamentary Disability Group** discussing the funding of specialised services within the NHS including such topics as regional wheelchair provision and Spinal Cord Injury Centres. SIA also continued to be represented within the **Specialised Health Care Alliance** and will pursue its quest for adequate funding of the NHS spinal cord injury services nationwide. Our president Baroness Masham also put forward a question within the House of Lords asking about provision of specialised treatments within the NHS.

SIA's Executive Director had a series of meetings throughout the year with Maria Eagle, **Minister for**

**Disabled People** and also a brief exchange with the Prime Minister.

SIA has played an active part in the work of **Disability Daily** (a consortium of 14 disability and carer organisations) and contributed to its booklet, produced for the Party Political Conferences, highlighting the current issues of concern to disabled people.

SIA continues to be represented on both the **British Association of Spinal Cord Injury Specialists (BASCIS)** and the **Multidisciplinary Association of Spinal Cord Injury Professionals (MASCIP)** which link together the healthcare professionals dealing with SCI in the UK. And SIA's role on the **UK Spinal Cord Injury Research Network** enabled it to help formulate multi-centre trials over the coming year dealing with three important topics for spinal cord injured (SCI) people; namely: Why SCI patients are readmitted following discharge from a Spinal Cord Injuries Centre; the role of colostomy in bowel management after SCI and the incidence of lower limb fractures in persons with chronic SCI.

SIA also works with a variety of disability organisations like **Mobility Advice and Vehicle Information Service** and the **Joint Committee on Mobility for Disabled People** on mobility issues; with **Holiday Care** and **Tourism for All** for holiday and tourism.

SIA's work with **Spinal Injuries Together (SIT)** (partly sponsored by [www.spinalnet.co.uk](http://www.spinalnet.co.uk)) has grown stronger in the past year and the success of SCI Awareness Days which in 2005 will be on May 20th, means that the awareness of spinal cord injury will grow as SIA and the other charities on SIT work to raise public awareness of the condition.



Demo at the NSIC Stoke Mandeville 1999.

Picture courtesy of Bucks Herald

**In the early days of SIA fundraising in the 1980's, one of SIA's biggest sources of revenue was the annual Dog Jog!**

Once a year, Regents Park was overrun with exotically dressed joggers and their dogs parading and raising money for SIA.

Blue Peter presenters brought along Shep their Collie and other celebrities brought their canine companions to central London for SIA. In the 1990's, SIA spread their fundraising efforts across a broader spectrum than just events, targeting corporate bodies and trusts.



Support from the corporate sector has continued to grow significantly over the past couple of years – without this support a number of key SIA activities would not have been able to take place. We are very grateful to all those companies who in the past year sponsored publications, donated towards new projects and supported events (we have acknowledged many of the supporters in the Services section of this Annual Report). In 2004, with the move to Milton Keynes, SIA will be seeking to develop links with the MK business community to help support both the costs of the new building and the ongoing services provided by SIA.



John Leason (SIA member) accepts a cheque from Colmworth Golf Club.

The personal injury arm of the legal profession continued to be staunch supporters of SIA in 2003-2004. Thanks to the substantial efforts of the Cornflower Ball Committee, this year's event in Manchester was a sell-out for the

second year in a row. Later in 2004, SIA will seek to replicate the success of the Ball by holding a similar event in Birmingham which is called the Black Pearl Ball.

Another large event, the Oil and Gas Industry Quiz night, was rebranded in its eleventh year as the Whiz Quiz, which companies outside of the industry were invited. As before, the event was held simultaneously

in London and Aberdeen, with Her Royal Highness The Princess Royal supporting us through her attendance at the Aberdeen event.

A big thank you goes to *ConocoPhillips* for all their hard work and support with organising the event.

In 2003 SIA was the benefiting charity of the Silverstone Grand Prix Ball – one of the most prestigious events in the social calendar. The event was attended by a host of celebrities including F1 drivers Ralf Schumacher

and Juan Pablo Montoya. Our thanks go to Sir Frank Williams and *BMW WilliamsF1* for helping make the evening such a success.

Income from trust sources was reduced in 2003-2004 as a result of being four months without a trust fundraiser – every effort will be made in the coming year to rectify this shortfall. As SIA services develop locally – responding to the local needs of people with spinal cord injury – the Association will aim to identify and approach local and regional trusts and grant-givers to enlist support for the Peer and Community Support projects serving their area.



Eastenders' Michelle Ryan and Brooke Kinsella at the Silverstone Ball.

SIA was exceptionally fortunate in 2003/04 to be the beneficiary of a number of substantial legacies, including one for almost half a million pounds for the Capital Appeal Building Fund. Services were not forgotten in the legacies with over two hundred thousand pounds going to services for SCI people. We are very grateful to all members and supporters who use their Wills to help support future generations of SCI people.

To develop the charity's support from the horse-racing world and other equestrian activities, SIA employed a dedicated fundraiser to work in this sphere. Our calendar of events this year included an event held at Uttoxeter race course for the Capital Appeal and a series of Charity Lunches and Sweepstakes at Newbury, Salisbury, Doncaster and Brighton.

We shall be adding to these events in 2004-2005 at Cheltenham and Wincanton, together with numerous collections taking place at racecourses around the country. We have been delighted with the support received from the horseracing world and are very grateful to all the committee members, riders, sponsors and volunteers for making all these events such great successes. In particular we are grateful to Sandy Murphy of the Amateur Jockeys Association for all her hard work and support, without which none of the race days would have been possible. In addition to these events we shall be putting on SIA's first Equestrian Art Exhibition in Autumn 2004.



Riders, sponsors and volunteers at Salisbury Racecourse September 2003.

In the past, SIA has not seen the sale of Christmas cards as a significant income generator but sold them because supporters and members wished to purchase them. In 2003 we looked at developing our Christmas Card campaign and turned the activity into a financial success generating just over £10,000. For the first time we had two of the designs funded through sponsorship meaning every card of the two designs could be sold at a 100% profit. Our biggest success was with the equestrian card thanks to *Vetroquinol Equistro* for sponsoring the card. The other development in this area was sales to the corporate sector – where a large number of companies used an

SIA card to send to their customers and clients.

We now have a Community Fundraiser responsible for supporting the fundraising efforts of members and supporters, who is building on the success of the London Marathon with the expansion of SIA sporting activities and challenges like the 2003 Flora Light Challenge for Women in which SIA had 85 runners taking part. A new event

for 2004 is SIA's first International event, an Icelandic Horse Trek called 'Riding the Land of the Midnight Sun'.

We are extremely grateful to everyone who has walked, run, jumped, swum, cycled, flown, sailed, wheeled, collected, donated and volunteered for SIA. This has had the dual benefit of raising our profile as well as maintaining our services. Thanks also to *Hollister Limited* for their sponsorship of this year's Annual Report and Annual General Meeting.



Flora Light Women's Challenge 2003.



Guests at SIA's Whiz Quiz 2004.

## Summarised consolidated accounts for the Spinal Injuries Association Limited

The summarised accounts set out opposite have been extracted from the full annual accounts prepared in accordance with the Companies Act 1985, which were approved by the Trustees on 10th September 2004. The full annual accounts have been audited and the auditor's opinion was unqualified; and delivered to the Registrar of Companies and the Charity Commission.

These summarised accounts may not contain sufficient information to allow a full understanding of the financial affairs of the charity. For further information, the full annual accounts, the auditor's report on those accounts and the Trustees' annual report should be consulted. Copies of these can be obtained from the Spinal Injuries Association at Acorn House, 387-391 Midsummer Boulevard, Milton Keynes MK9 3HP.

Signed



Jonathan Wilkes ACA (Treasurer)  
on behalf of the Trustees

## CONSOLIDATED STATEMENT OF FINANCIAL ACTIVITIES (Including THE CONSOLIDATED INCOME AND EXPENDITURE ACCOUNT)

FOR THE YEAR ENDED 5 APRIL 2004

	2004	2003
	£	£
<b>INCOMING RESOURCES</b>		
Donations and Gifts	188,561	203,948
Legacies	694,825	28,100
<b>Activities in furtherance of the charity's Objects</b>		
Grants receivable	197,406	216,250
Services and Publications:	208,860	180,925
<b>Activities for generating funds:</b>		
Fund-raising	807,629	509,043
Trading activities	23,869	20,008
Investment income	32,045	25,454
<b>TOTAL INCOMING RESOURCES</b>	<b>2,153,195</b>	<b>1,183,728</b>
<b>RESOURCES EXPENDED</b>		
Less cost of generating funds:		
Capital Appeal	67,563	45,912
Fund-raising costs	495,369	338,760
Trading activities	14,376	13,534
<b>Net incoming resources available for charitable application</b>	<b>1,575,887</b>	<b>785,522</b>
<b>Costs of activities in furtherance of the charity's objects:</b>		
Services and Publications	702,680	551,172
Awareness Raising	123,843	80,639
Management and administration	66,950	109,517
<b>Total Charitable Expenditure</b>	<b>893,473</b>	<b>741,328</b>
<b>TOTAL RESOURCES EXPENDED</b>	<b>1,470,781</b>	<b>1,139,534</b>
<b>NET INCOMING RESOURCES</b>	<b>682,414</b>	<b>44,194</b>
Gains on investments	6,240	(1,200)
<b>Net movement in total funds for the year</b>	<b>688,654</b>	<b>42,994</b>
Total funds as at 6 April 2003	<b>869,374</b>	<b>826,380</b>
<b>Total funds as at 5 April 2004</b>	<b>1,558,028</b>	<b>869,374</b>

**CONSOLIDATED BALANCE SHEET**

**AS AT 5 APRIL 2004**

	<b>2004</b>		<b>2003</b>	
	<b>£</b>	<b>£</b>	<b>£</b>	<b>£</b>
<b>FIXED ASSETS</b>				
Tangible assets		336,841		11,732
Investments		13,530		7,290
		<hr/>		<hr/>
		350,371		19,022
<b>CURRENT ASSETS</b>				
Debtors	322,827		234,635	
Short term deposits	951,348		675,000	
Cash at bank and in hand	66,441		128,230	
	<hr/>		<hr/>	
	1,340,616		1,037,865	
<b>CURRENT LIABILITIES</b>				
<b>CREDITORS:</b> amounts falling due within one year	(132,959)		(187,513)	
	<hr/>		<hr/>	
<b>NET CURRENT ASSETS</b>		1,207,657		850,352
		<hr/>		<hr/>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		<b>1,558,028</b>		<b>869,374</b>
		<hr/> <hr/>		<hr/> <hr/>
<b>Represented by Funds</b>				
Unrestricted				
Designated funds		685,001		309,920
Other charitable funds		462,754		404,497
		<hr/>		<hr/>
		1,147,755		714,417
Restricted		410,273		154,957
		<hr/>		<hr/>
<b>Total funds</b>		<b>1,558,028</b>		<b>869,374</b>
		<hr/> <hr/>		<hr/> <hr/>

**Auditors' report to the trustees**

We have examined the summarised consolidated financial statements of Spinal Injuries Association set out on pages 14 to 15.

**Respective responsibilities of trustees and auditors**

The trustees are responsible for preparing the summarised consolidated financial statements in compliance with the relevant requirements of section 251 of the Companies Act 1985 and the regulations made thereunder, and in accordance with the recommendations of the charities SORP. Our responsibility is to report to you our opinion on the consistency of the summarised consolidated financial statements with the full consolidated financial statements and annual report. We also read the other information contained in the summarised annual report and consider the implications for our report if we become aware of any apparent misstatements or material inconsistencies with the summarised financial statements.

**Basis of opinion**

We conducted our work in accordance with Bulletin 1999/6 "The auditors' statement on the summary financial statement" issued by the Auditing Practices Board.

**Opinion**

In our opinion the summarised consolidated financial statements are consistent with the full consolidated financial statements and the annual report of Spinal Injuries Association for the year ended 5 April 2004 and comply with the applicable requirements of section 251 of the Companies Act 1985, and the regulations made thereunder, and are in accordance with the recommendations of the Charities SORP.

**haysmacintyre**  
Chartered Accountants  
Registered Auditors  
Fairfax House  
15 Fulwood Place  
London WC1V 6AY

16 September 2004

### **Principal Supporters**

Active Assistance  
Aldershot Buffalo Lodge  
Amateur Jockeys Association  
Army Benevolent Fund  
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BT  
The Barbour Trust  
The Herbert & Peter Blagrove Charitable Trust  
The Charterhouse Charitable Trust  
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ConocoPhillips  
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Esmee Fairbairn Foundation  
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Department of Health  
Gosling Foundation  
Hilary Meredith Solicitors  
Horserace Betting Levy Board  
Independence Technology  
Injured Jockey Fund  
Joseph Strong Frazer Trust  
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London Taxi International  
MAGIC  
Mercedes-Benz – Manchester  
Niarchos Foundation

The Northern Rock Foundation  
Pertemps Group of Companies  
The Princess Anne's Charities Trust  
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### **Trusts and Foundations**

Ardwick Trust  
Ian Askew Charitable Trust  
The Bates Charitable Trust  
The James Beattie Charitable Trust  
The Philip Bennett Trust  
F V & E Brook Charitable Trust  
The Buccleuch Charitable Foundation  
Cadogan Charity  
The Chownes Foundation  
Richard J Cohen – 3rd Charitable Trust  
Sir Jeremiah Colman Gift Trust  
Gwendoline and Margaret Davies Charity  
The Gilbert Edgar Trust  
Sue Hammerson's Charitable Trust  
Howard Charitable Trust

Edgar Lee Foundation  
The Lynn Foundation  
The Macdonald-Buchanan Charitable Trust  
Millichope Foundation  
Newport Rotary Club  
Lavinia Norfolk's Family Charitable Trust  
The Norman Family Charitable Trust  
PF Charitable Trust  
Red Rose Charitable Trust  
The Rothera Family Charity Trust  
The Royal Air Force Benevolent Fund  
Salamander Charitable Trust  
Michael Shanly Charitable Trust  
The S.R. & P.H. Southall Charitable Trust  
The Mary Webb Trust

### **Company Supporters**

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BOX Telematics  
Dixons Group Action Partnership  
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Ladbrokes

Ludlow Race Club Ltd

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Solicitors

Northern Racing

PDP Conquest2 Ltd

Penningtons Solicitors

The Saddlers Company

Stewart's Solicitors

The Tote

Vodafone

Walker Smith Way

### Supportive Venues

The Belfry

Brighton Racecourse

Bristol City FC

Charlton Athletic FC

City of Manchester  
Stadium

Colmworth & N. Beds.  
Golf Club

Doncaster Racecourse

Drapers Hall

Manchester United

Newbury Racecourse

Salisbury Racecourse

Uttoxeter Racecourse



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T R U S T



THE DAVID AND FREDERICK BARCLAY  
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THE INJURED  
JOCKEYS FUND



Army Benevolent Fund



The Royal Air Force  
Benevolent Fund



**Patron**

HRH The Princess Royal

**President and Founder**

Baroness Masham of Ilton\*

**Vice Presidents**

Chris Serle  
 Lady Howard de Walden  
 Jack Lawton  
 Lord Moynihan of Leeds  
 Sam Melliush

**Board of Trustees**

**Chair**

Roger Fitzwater\*  
 (retired March 2004)

**Vice Chairs**

Jonathan Fogerty\*  
 Becky Mason\*

**Hon Treasurer**

Jonathan Wilkes ACA (co-opted)

**Governing Council**

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 Moray Cook\*  
 Peggy Deane\*  
 Stuart Dench\* (co-opted)  
 Bart Hellyer\*  
 Michelle Howard\*  
 Heather Matthews\*  
 Martin McClelland BSc MB ChB FRCS  
 (co-opted)  
 John O'Hara\*  
 Stephen Springer MBE\*  
 Hugh Stewart\*  
 Michael Tennison MBE\*  
 John van Dongen MBE\*  
 Alan West\*

**SIA Staff**

**Executive Director**

Paul Smith\*

**Director of Services**

Mary Ann Tyrrell

*Administration Team*

Alex Burt\*  
 John Illankovan  
 Laura Magee  
 Bernadette Murphy

*Fundraising Team*

Michelle Carter  
 Alycia Collins  
 Anne Curran  
 Peter Gardiner\* (volunteer)  
 Frances Lane

**Services:**

*Helpline Team*  
 Wendy Cowling  
 Vivienne Davies\* (volunteer)  
 Sue Mills\*

*Youth Service*

Sarah Stanwix\*

*Intranet & Library Coordinator*

Tom Elkins

*Publications Team*

John Balfour\* (volunteer)  
 Dominic Joyeux  
 Lynne Punchard  
 (Editor FORWARD)

*Living Options Scheme*

Janet Evans

*Peer Support Team*

Jackie Bailey\*  
 Sue Benefer\*  
 Sue Carleton\*  
 Peter Hanley\*  
 Natalie Holder\*  
 Peter Hutchings\*  
 (Development Officer)  
 Alison Lyon\*  
 John Robinson\*  
 Sol Solomou\*

*Community Peer Support*

John Mansfield\* (North East)  
 Dorothy Graham\* (North East)  
 Ben Owen-Jones\* (Wales)

*SIA gratefully acknowledges the many Community and Peer Support volunteers who gave their free time to represent SIA at the SCICs, at events and in the community during the year.*

*Website*

Dominic Joyeux

*Chat Room Hosts*

Christine Checkley\*  
 Zo Nicholas\*

*External Affairs Consultant*

Stephen Bradshaw OBE\*

*Fundraising Consultants*

John Fieldus\*  
 Rebecca Bohling

*SIA Groups*

*Bolton & District*  
 Brian Naylor\*  
 Chris Judd\*

*Merseyside*

John Wayte\*  
 Stephen Cronin\*

*Grateful thanks go to the following Committees:*

Black Pearl Ball  
 Brighton Charity Auction Lunch and Sweepstake  
 Cornflower Ball  
 Doncaster Charity Auction Lunch and Sweepstake  
 Ladies Lunch and Presentation of Millinery

Newbury Charity Lunch and Sweepstake  
 Pertemps Charity Race Evening at Uttoxeter  
 Salisbury Charity Auction Lunch and Sweepstake

**Bankers**

Barclays Bank plc  
 Muswell Hill Broadway  
 London N10

**Solicitors**

emw Law  
 Eleanor House  
 Queenswood Office Park  
 Northampton  
 NN4 7JJ

**Hon Medical Consultants**

Ebba Bergstrom MCSP Mphil  
 (Consultant Physiotherapist)  
 Waghi S El Masry MB BCH FRCS Ed  
 (Consultant in Spinal Injuries)  
 Hans Frankel OBE MD FRCP  
 (Consultant in Spinal Injuries)  
 David Grundy FRCS  
 (Consultant in Spinal Injuries)  
 Paul Harrison RGN ONC ENB371 MAED



Governing Council 1980. Left to right: David Cale, Howard Brunton, Tricia Pay, Angel Vila, Alan West, Paul Bush and Jim Hart.

\*denotes disabled person

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**Marc Buoniconti**  
President  
The Buoniconti Fund  
to Cure Paralysis, USA



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- Protective tip enables the catheter to bypass concentrations of bacteria in the urethra to help reduce urinary tract infections risk.

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Postcode: \_\_\_\_\_

Tel No: \_\_\_\_\_ E-mail: \_\_\_\_\_

Current Brand of Catheter: \_\_\_\_\_ Size (ch): \_\_\_\_\_ Length (cm): \_\_\_\_\_



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**Constituents and Objectives:**

We are the national organisation of spinal cord injured people. We represent all their interests regardless of how the impairment occurred, whether or not it has resulted in full or partial paralysis. Our purpose is to promote the integration and full participation in society of our members, by encouraging them to become fulfilled and in control of their lives.

The sharing of information and experiences are at the heart of our commitment to helping each individual achieve his or her potential after injury.

**We:**

- offer support to individuals who become paralysed and their families, from the moment a spinal cord injury occurs, for the rest of their lives
- provide services and publications which enable and encourage paralysed people to lead independent lives
- campaign for improved medical and social care relating to spinal cord injuries
- work to create an understanding of the causes and consequences of injuries



**Acorn House**  
**387-391 Midsummer Boulevard**  
**Central Milton Keynes MK9 3HP**

Tel: **0845 678 6633**  
 Fax: **01908 608492**

Freephone Helpline:  
**0800 980 0501**

e-mail: **sia@spinal.co.uk**

Web site: **www.spinal.co.uk**

Registered charity number 1054097

Charitable company number 3175203

**Our thanks for helping us with this Annual report go to:**

- Barry Coburn – coming down the steps on the front cover. He was SIA's first Chairman thirty years ago.
- The Press Association – for the photograph of Mark Eccleston, the tennis player on the front cover.
- The University of Greenwich – for supplying the more recent photograph of Mike Oliver on page 2.
- Simon Roulestone – drew the spine used on page 6. He has set up an informative SCI website at [www.apparelyzed.com](http://www.apparelyzed.com)
- 'Bucks Herald' – for the demonstration image on page 11.
- Lerona Gelb for her patience and enthusiasm over the years with SIA's posters.
- Hollister Limited for their support for this Report.
- d2ps communications for their design, layout and printing – [www.d2ps.com](http://www.d2ps.com)

