



# THE INSPIRE

The Integrated Spinal Rehabilitation Foundation  
Autumn Newsletter 2014

[www.inspire-foundation.org.uk](http://www.inspire-foundation.org.uk)  
Tel: 01722 336262 Ext 2465

AGM Saturday 6th December. Guest Speaker Prof Jane Burridge. Lunch included.

## INSPIRE'S FIRST SCOTTISH SCIENTIST

### Mr Matthew H Fraser BM FRCS

A graduate from the University of Southampton, Matthew Fraser undertook core training in General Surgery and Orthopaedics in Bradford and Birmingham before specialising in Spinal Injury and Rehabilitation in the North West Spinal Cord Injury Centre in Southport, Merseyside under Mr Kookal Krishnan. In 1993 he became a Consultant in High level ventilation-dependent tetra-plegia with a successful Domiciliary Ventilation and Assistive Technology programme. Since 1996 he has worked at the Queen Elizabeth National Spinal Injury Unit in Glasgow which has an integrated Research programme with the Universities of Glasgow and Strathclyde. He has published more than 30 papers in the field and continues to have research interests in Neuro-urology and Neuro-pathic pain. He was warmly received by the National Scientific Committee on 2nd October.



## NEW PATRONS JOIN INSPIRE

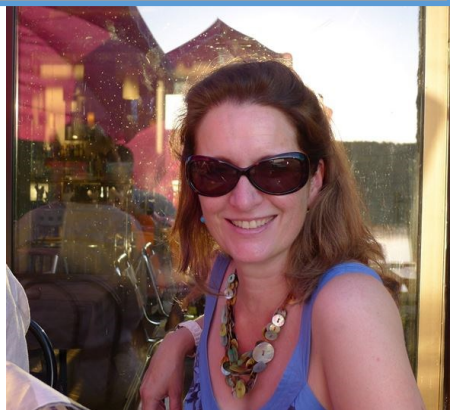
BARONESS MASHAM OF ILTON DL

Details on back page and on website

MRS GENEVIEVE HOLMES MVO



The INSPIRE FOUNDATION welcomes BARONESS Masham from North Yorkshire and the House of Lords (left) and Mrs Genevieve Holmes MVO (right) daughter of the late Mrs Janet Benney (Obituary Autumn 2013)



QUILTER CHEVIOT  
SPONSORSHIP  
£10,000 FOR POLO 2015

**Major fundraising event in 2015 already underwritten**  
Following the success of Polo 2014, we are delighted to report that sponsorship for the annual Polo Tournament has already been secured for next year. Photographed **RIGHT Mr Richard Firth Executive Director Quilter Cheviot Salisbury** is seen presenting INSPIRE **Executive Director Rory Steevenson** with a presentation cheque. Quilter Cheviot's generous gesture underwrites the detailed planning for next year's event on **Saturday 11th July 2015** and furthermore assures us of forty guests in the INSPIRE Foundation's marquee! For those who have never been to this wonderful family day out, pictures of Polo 2014 are included inside this Newsletter.



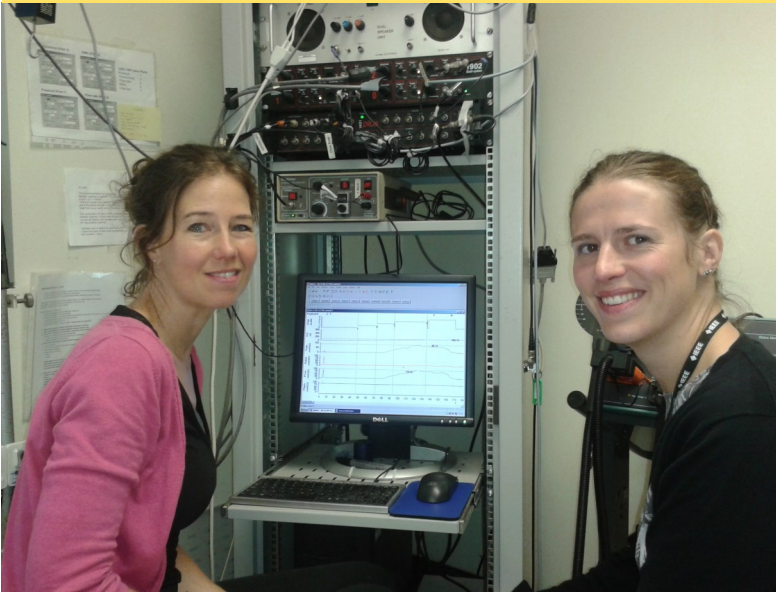
CHRISTMAS  
CARDS 2014



Order Forms  
Inside

## LATEST PROJECT APPLICATION from the London Spinal Cord Injury Centre

**‘To investigate neuromodulation as an alternative to pharmaceutical therapies for bladder, bowel & lower limb spasticity in SCI: towards wearable stimulation devices.’**



The INSPIRE Foundation is delighted to have received an Application from the London Spinal Injury Centre located at the Royal National Orthopaedic Hospital (RNOH) Stanmore. The team consists of: **Dr Sarah Knight** (pictured far left) a Clinical Scientist at the London Spinal Cord Injury Centre and Honorary Senior Lecturer at the RNOH/University College London (UCL) **Dr Anne Van Hoestenbergh** (right) is a Lecturer at the Centre for Rehabilitation Engineering & Assistive Technology (CREATE) also at UCL.

**Professor Michael Craggs** (below) Emeritus Professor of Applied Clinical Neurophysiology at UCL Medical School and Director of Neuro-spinal Research & Consultant Clinical Scientist for the Functional Assessment & Restoration Service at The London Spinal Cord Injury Centre. Professor Craggs is one of the world's leading authorities on the clinical development and application of medical devices. In 2007 he was elected a Fellow of the Royal Society of Medicine. Mike is also a much revered member of the INSPIRE Foundation's National Scientific Committee.



**Background:** Restoration of bladder and bowel function is a top priority for patients who have suffered a life changing spinal cord injury. Appropriate patient-focused bladder and bowel management approaches reduce morbidity and improve quality of life. Pelvic functions are controlled by complex interactions between the voluntary and autonomic nervous systems, at both brain and spinal reflex levels. Following SCI these pathways are disrupted leading to un-inhibited reflex activity causing spasticity and incontinence. Neuromodulation (electrical stimulation of neural pathways to modify their activity) of the sacral nerves can be effective at inhibiting these unwanted reflexes. The project team proposes to expand on its previous work in this field to research the role of neuromodulation through wearable devices to control un-inhibited reflex spasticity of the bladder, bowel and lower limbs. The final aim is to develop a prototype device which provides effective control of these functions without the need for medication. The INSPIRE Foundation has already granted £22,500 by way of the Ralph Crossley PhD Scholarship and now hopes to fully support the balance of funds totalling £63, 495.

The proposed funding will be used to support a PhD student through a 3 year project. Selection of a suitable student is now underway and he or she will be registered with UCL and based at the RNOH Stanmore. The successful student will be jointly supervised by Dr Sarah Knight (clinical) and Dr Anne Vanhoestenbergh (engineering). The stipend for a PhD studentship at UCL is £18,700 per annum. The project will allow the team to develop a non-invasive, versatile, wearable device which can effectively control these dysfunctions in patients with a spinal cord injury. To investigate these aims, the study will be effectively divided into a clinical arm and an engineering arm: the clinical arm will investigate the physiological effects of stimulation sites, triggers and regimes whereas the engineering arm will develop a specification for a wearable device to deliver and control the neuromodulation. Initial tests will be performed in the laboratory using stationary equipment, ambulatory studies can then be used for 12-24 hour efficacy testing, and finally following development of a prototype device, longer term tests can be carried out potentially in the home environment.

**Anticipated Outcome:** **Dr Sarah Knight has written to the Newsletter and explains the scope of the project as follows:** ‘The over-arching aim of this study is to investigate an alternative to pharmaceutical therapies for bladder and bowel management, and explore its impact on spasticity. This alternative, which relies on neuromodulation, is to be delivered by a stimulator, a prototype of which will be produced during the duration of the PhD study. Should the clinical studies indicate that this alternative is likely to be successful, we will seek further funding to develop our prototype and guarantee patient impact and soon as feasibly possible. We have already identified suitable product development calls from the Technology Strategy Board and the National Institute for Health Research (NIHR). We anticipate that by providing alternatives to pharmaceutical management, we can alleviate some of the side effects that are experienced when managing spasticity such as dry mouth, constipation and drowsiness. We hope that this will eventually lead to improvements in the quality of life of patients living with a spinal cord injury. We also envisage that if these techniques are successful and a prototype device is developed, its use may not be confined to just the spinal cord injury population but also be utilized in patients with other neurological disorders such as multiple sclerosis and perhaps the broader range of pelvic problems in the general population.’

**NEWS FLASH: Message from the Executive Director:** As we go to print we are still marvelling at the news from Poland of the cellular repair of a severed human spinal cord, research pioneered by Professor Geoffrey Raisman in the UK. While this is exciting news for the SCI community at large, the INSPIRE Foundation has a rehabilitation focus, namely ‘to promote research into the development of practical systems for people with damage to the spinal cord by the use of the latest advances in electronic, mechanical and medical technology’. On behalf of the INSPIRE Foundation, Professor Peter Ellaway, Chairman of the Scientific Committee has sent Professor Raisman our warmest congratulations and best wishes. **Rory Stevenson**

# PROJECT REPORT: CAN THE PATTERN OF LOADING DURING LONG-TERM FES-ROWING INCREASE BONE DENSITY AFTER SPINAL CORD INJURY? By Robin Gibbons

**Introduction:** For more than two years a project team led by Robin Gibbons has been working at Brunel University's Department of Life Sciences. Robin a former Royal Navy Officer and Virgin Atlantic pilot has been working towards his PhD and has focused his research into proving that bone density is key to reducing the chances of fragility and with it the chances of bone fractures.

**Background:** Spinal cord injury (SCI) is a life changing condition that typically results from severe trauma to the vertebrae of the back (paraplegia) or neck (tetraplegia). In complete injury, total paralysis of all skeletal muscle is lost below the level injury. This has a profound effect on most body systems, in particular life threatening cardiovascular disease and disuse osteoporosis.

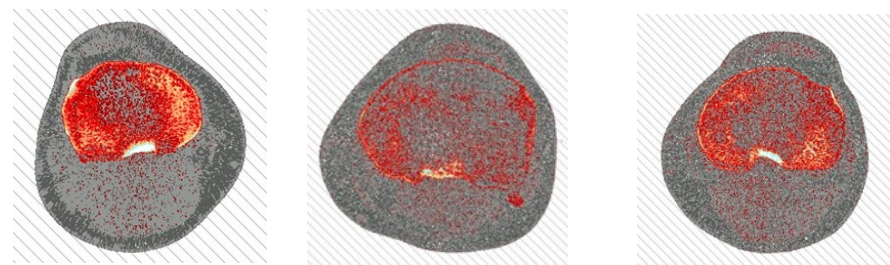
**Characteristics:** Disuse osteoporosis is characterised by severely weakened bone mineral structure that leads to fragility fracture. The loss of bone is so rapid that within 4 years of a complete SCI, 50% of pre-injury bone mineral has been lost in the lower limbs. Furthermore, within 6 to 8 years the bone is at high risk of non-traumatic fracture. Over 70% of fractures in SCI occur around the knee and ankle joints. Presently, research is following two lines of investigation in an effort to mediate osteoporosis in SCI; (1) pharmaceutical, to reduce the rate of bone mineral loss, and (2) mechanical loading using functional electrical stimulation (FES) walking and cycling. FES is a technology whereby small electrical currents are used to activate paralysed muscle by stimulating the associated peripheral nerve supply. Whilst both approaches have demonstrated some success in slowing the loss of mineral from the bone in acute SCI, preventing bone loss, or recovering lost mineral from the bone remains elusive. Recently, our research has convincingly shown that in SCI an optimal pattern of loading should typically exceed 1.5 times body weight and should be applied in weekly training sessions which result in a total repeat loading of 10,000 cycles per month. This may explain the poor results previously observed using FES interventions.



**Photographed:** Robin Gibbons (right) is seen conducting a FES-rowing exercise test at Brunel University with his latest participant Lindsay. Lindsay has a T6 complete spinal cord injury and is a young mother with two small children. Robin explains to the Newsletter:

' We have been piloting a unique method of mechanical loading using FES-rowing developed by our group. In this application of FES-assisted exercise, muscles on the front of the thigh are activated to extend the legs during the 'drive' phase of rowing concurrent with arm flexion, and the muscles at the back of the thigh are activated to flex the legs during the 'recovery' phase. These actions enable people with paralysis to row in much the same way as their non-injured counterparts. FES-rowing can achieve the optimal loading pattern in three 30 minute training sessions per week. Our recent findings have so far demonstrated controlled loading up to 3 times body weight in our trained FES rowers. Although these pilot studies have so far involved only a small number of participants with demineralised bones, the preliminary results are convincing.

**Scanned Bone Images:** Using a process called Peripheral Quantitative Computersied Topography or pQCT we are able to scan images of the left ankle of three individuals: 1. Non-SCI male, 2. Chronic SCI male who is not FES-trained and 3. Chronic SCI male FES-rowing trained. Note the depth and extent of bone mineral mass represented by the areas of red. Also note the area of the grey which represent soft tissue which is primarily muscle mass.



**Image 1: Left ankle bone Non SCI male**

**Image 2: Chronic SCI Male not FES trained**

**Image 3: Chronic SCI male with FES-rowing**

**Future Research.** Recent studies of FES-rowing funded by INSPIRE involving a small number of males and females with complete tetraplegia and paraplegia have demonstrated significant improvements in cardiovascular function. When taken with the results of the present study, FES-rowing may offer a unique means of improving on two life threatening secondary conditions of SCI; cardiovascular disease risk, and disuse osteoporosis.

A multi-centre study is now required that involves approximately 30 new subjects participating in a controlled programme of FES-training until continuous FES-rowing for 30 minutes is achieved. Thereafter they will be monitored over at least 12 months involving three 30 minute FES-rowing sessions per week. The study will involve a number of ground breaking techniques that will enable us to accurately quantify the cardiovascular adaptations, the mechanical forces acting through the lower limbs, and a comprehensive assessment of the density and structure of the bone. This information will enable us, for the first time, to present an assessment of reduced fracture risk and significantly improved cardiovascular function following our unique FES-rowing training program. FES-rowing is attracting international attention and appears to be a unique form of exercise in SCI.

**FUNDRAISING FOR RESEARCH.** All our research is funded through donations and our own fundraising initiatives. In the audited accounts for year ending 30 April 2014, our income doubled over the last 12 months, a very good sign. We are indebted to our major donors since the last Newsletter: The Roger Vere Foundation, The Steven Bloch Image of Disability Charitable Trust, CHK Charities, Buckland Charitable Trust, Jellybelly Trust, Robert Luff Foundation, Quilter Cheviot, Essential Wealth, The Childwick Trust, Mountbatten Memorial Trust, Mark Master Masons. If you are in a position to help this vital research into spinal cord injury please contact us without delay: [ntrs@inspire-foundation.org.uk](mailto:ntrs@inspire-foundation.org.uk) Tel 01722 336262 Ext 2465. Thank you.

Following last year's successful fundraising day at Salisbury Races, the Clerk of the Course Mr Jeremy Martin invited the charity to raise its profile and sponsor its own race on 1st October 2014. After an impromptu Trustees' tete a tete the INSPIRE Foundation Claiming Stakes was on the race card and what a race! Penny's Boy owned by Mr & Mrs Malcolm Brown and ridden by Liam Keniry held on to the lead from Tobacco Road ridden by Richard Hughes, trained by Richard Hannon and owned by Noodles Racing.

**PHOTO FINISH CLIMAX...** the 3:20 provided much excitement with a magnificent photo finish. Generous donations from the 'punters' amounted to over £1300. Our thanks to Mr Jeremy Martin and the many Friends of INSPIRE who enthusiastically helped man the stall and encourage best use of our charity exit buckets.

Further INSPIRE race days are in the autumn calendar:

**Wed 12th November Exeter**

**Thu 20th November Wincanton**

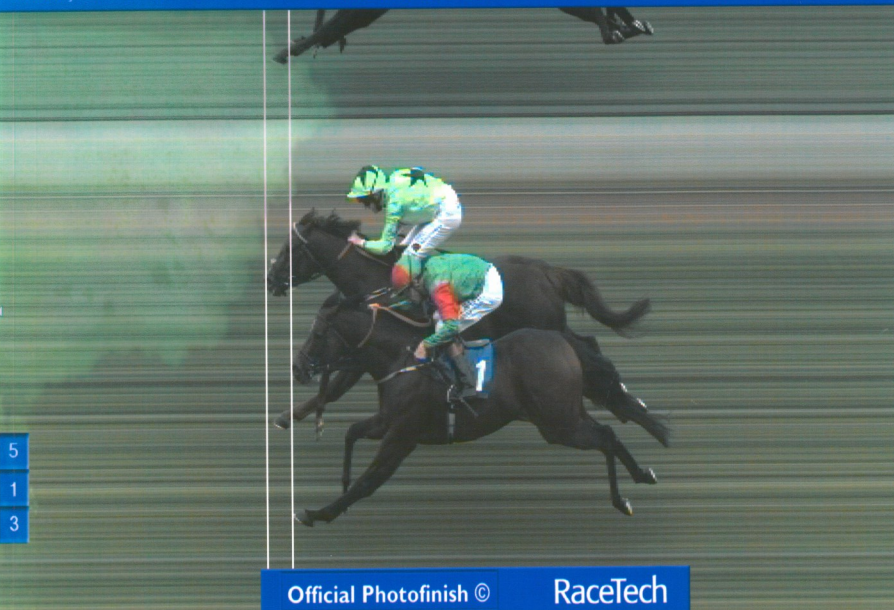
**Sat 13th December Cheltenham**

**Volunteers needed!**

If you are free and fancy a free day at the races, just call 01722 336262 Ext 2465.

salisbury race 4 3.20 1m 4f

THE INSPIRE FOUNDATION CLAIMING STAKES (CLASS 5)



CONTD FROM FRONT PAGE

## PATRON MRS GENEVEIEVE HOLMES MVO

Genevieve was born in London in 1962 and lived her early life in Berkshire. Her parents Gerald & Janet Benney were instrumental in launching the charity polo which the INSPIRE Foundation has been running for nearly twenty years. Genevieve's first serious job was in 1982 when she became the 'Fan Mail Secretary' to the Prince of Wales. She was later promoted to Personal Secretary to H.R.H. The Prince of Wales a position she held until 1994 and for which she was made a Member of the Victorian Order. At the same time she married and has since had three children. She subsequently started a fledgling artistic career and in 1999 also became Secretary to the Action Medical Research Charity in the South East area. Following the Polo in July at which she awarded the Benney Memorial Trophy, Genevieve was delighted to accept the patronage of the INSPIRE Foundation in the summer.

CONTD FROM FRONT PAGE

## PATRON Baroness Masham of Ilton, Countess of Swinton, DL

Baroness Masham is a crossbench member of the House of Lords and the senior female life peer. She is a prominent Roman Catholic convert and a patron of the Margaret Beaufort Institute of Theology. She was disabled in a riding accident in 1958, and subsequently became a champion for causes related to disability. She is an active member of the House of Lords, where she takes a particular interest in issues surrounding disability, health and penal reform. In 2011 she was awarded an Honorary Fellowship by the Royal College of Nursing. She competed in several Paralympic Games, winning medals for table tennis in 1960, 1964, and 1968. She became a Patron of the INSPIRE Foundation in July 2014.

## WINTER/SPRING DIARY

Thu 6 Nov	Board of Trustees, 5.00 pm
Wed 12 Nov	Fundraising, Exeter Races
Thu 20 Nov	Fundraising, Wincanton Races
Sat 22 Nov	Art Exhibition, Wilton
Thu 4 Dec	Salisbury Christmas Market
Sat 6 Dec	AGM & Lunch, Odstock.
Sat 13 Dec	Fundraising Cheltenham Races 'International'
Mon 15 Dec	Office Christmas Lunch, Wilton
Sun 11 Jan	George Skeates Fun Run, Stockbridge
Thu 12 Mar	National Scientific Committee, 11.00 am
Thu 19 Mar	Wine Tasting & Auction, Salisbury
Tue 14 Apr	Board of Trustees, 5.00 pm

## DEATHS 2014

With deep regret we wish to record the passing of the following members of the INSPIRE Foundation:

**Mr John Leader**                      **Mrs Patricia Willgress**  
**Miss Janet Gaylor**                **Mr Mervyn Williams**

We also wish to record our thanks to those who donated money to the INSPIRE Foundation in memory of the late:

**John Leader & Robin Crosbee-Thornton**

## AGM 2014 Sat 6th December



The AGM will take place in the gymnasium at the Duke of Cornwall Spinal Treatment Centre in Salisbury District Hospital. **Professor Jane Burridge** will then present on 'Making neuroscience work for people with Spinal Cord Injury'. Afterwards a light lunch will be served at a incredibly modest £5:00 per head including wine!

**Places are limited so please book in advance:**

**Tel 01722 336262 Ext 2465**

**Timings: Coffee 10:30. AGM 11:00 Lunch 12:45**



## Perfect stocking fillers.

First edition sold out so just reprinted this lovely collection of recipes written by Nessie Owen during her rehab after her LI SCI. Available from the website or Office 01722 336262 Ext 2465

## PICTURE GALLERY & AUCTION Saturday 22nd November 2014

4.00-8.00 pm. A private viewing of recent paintings by Suffolk artist **Brian Carter** will be hosted at the **Bird & Carter Farm Shop**, Chilhampton Farm, Wilton. All exhibited paintings will be available for sale and there will be an auction & raffle at 7.00 pm. Tickets at £5.00 per head include wine and canapés. The proceeds of this event will be shared between the INSPIRE Foundation and Salisbury District Hospital's Stars Appeal. Please join us if you can.

# POLO 2014 a wonderful day out raising £8,000 for SCI research



# '30 YEARS ON' by Mr Ron Gibbs C5-C7 Incomplete

## A personal view on the Benefits of Chiropractic Treatment after spinal cord injury

On 23<sup>rd</sup> April 1984, I sustained a C6-C7 incomplete spinal injury and was flown to the newly opened Tamar Ward at the Duke of Cornwall Spinal Treatment Centre in Salisbury; this was to become 'home' for 9 months! While the initial prognosis indicated a possible complete spinal injury this was not the case. With time control of my hands returned although they are very weak and lack dexterity. I gradually was able to stand and move using walking aids due in large part to the expert care by physio and occupational therapists. My full rehabilitation lasted 2 years and I was then able to return to full time work, albeit dependent on friends to help with travel arrangements.

My enduring problems were severe fatigue, constant pain and sleep deprivation but I was able to continue in full time employment for 16 years. I was also a volunteer with Citizens advice for about 9 years but left largely because the pain I was experiencing caused me to be unsympathetic and grumpy. Whilst the NHS and my GP managed to keep me relatively healthy their prescribed pain relief (in pill form) was not successful; I was not aware of nor offered any solutions to ease this constant debilitating condition.

Last summer my wife and I had a chance meeting with a young lady called Philippa Wheble representing Cowes Chiropractic Clinic. She proposed the McTimoney technique to ease my pain and invited me to consider a free spine check saying 'I think I can help relieve some of your pain without going near your C5-7 area'. I eventually agreed to her proposal and only wish I had taken this leap of faith 20 years ago! From the outset Philippa's treatment released 30 years' worth of body stress and tension. Treatment sessions always ease the pain, enabling better posture and with it less reliance on painkillers. Surprisingly the double vision I experienced following my accident also disappeared. My spasms have significantly decreased and I am sleeping much more soundly.

My overall physical improvement is as a result of adjustment of the first vertebrae and I now realise that if I had received this treatment sooner, I could possibly have worked for longer and saved the NHS a great deal of money. I understand the body's functions are controlled by its nervous system, and this is integrated to the musculoskeletal system; any disruption in either system will cause problems resulting in loss of function, pain or discomfort. Spinal damage is a disruption of the worst kind but anyone with a slight mis-alignment could benefit from having their systems realigned by a chiropractor.

My view is that the NHS would do well to consider similar courses of treatment instead of prescribing expensive medication so readily. By recognizing chiropractic treatment many people like me could experience better posture and less pain.



## OUT & ABOUT SUMMER 2014

Salisbury Market Stall L to R Volunteers **Tony Blanch & June Cree** with Events PR Co-ordinator **Lorna McGregor**



**Trustee Anton Prantl** enjoying selling T towels at the Duke of Cornwall's 30th Anniversary



**Trustee Surendra Bandi** holds up the INSPIRE 'pop up' outside the office



House of Commons All Party Parliamentary Group Meeting, L to R **Emeritus Professor Mike Craggs, Executive Director Rory Steevenson** and **Professor Nick Donaldson**



**Above:** Open Garden at Cheriton Hampshire home of **Patron, The Lady Amherst** raised £700. **Right:** the ever patient **Joe Henstridge** of JHIT Solutions Tel 01722 568598 attends to the Executive Director's computer again!

