



# THE INSPIRE

The Integrated Spinal Rehabilitation Foundation

## Spring Newsletter 2015

Also available on line at:  
[www.inspire-foundation.org.uk](http://www.inspire-foundation.org.uk)  
 Tel: 01722 336262 Ext 2465

### £85,000 NEUROMOD Project launched at the House of Lords Reception

On Thursday 26th February 2015, a reception was held in the River Room at the House of Lords. The event was hosted by INSPIRE Patron **Baroness Masham of Ilton DL**, and formally opened by the Lord Speaker **The Rt Hon the Baroness D'Souza CMG**. With over seventy Patrons, friends, scientists and trustees present, there was a most convivial atmosphere. Executive Director, **Rory Steevenson** used this opportunity to appraise the gathering of the INSPIRE Foundation's current and future research programme; he made special mention of the sponsors and grant making trusts who had made significant donations to the charity for the purpose of scientific research into spinal cord injury. During the evening **Mr Jonathan Rudge**, a long-time INSPIRE trustee presented a cheque for £85,595 to Research Scientists **Dr Sarah Knight** and **Dr Anne Van Hoestenbergh** (Right). Their 3 year project which is being conducted at the London Spinal Injury Centre, Royal National Orthopaedic Hospital, Stanmore, will research neuromodulation as an alternative to pharmaceutical therapies for bladder, bowel and lower limb spasticity in spinal cord injury. **More details inside.**



Above Left to Right: Professor Peter Ellaway & Wendy Alden, Dr Anne van Hoestenbergh, Trustee Jonathan Rudge, Dr Sarah Knight with INSPIRE Patron Baroness Masham of Ilton DL

### £1750 Raised at INSPIRE's Wine Tasting Third successful spring event at Salisbury Racecourse

On Thursday 19th March over a hundred friends and guests of the INSPIRE Foundation gathered at the Bibury Suite to taste wines presented by **Charles Steevenson Wines** while enjoying delicious canapés prepared by **Joff Bird of the Bird & Carter Farm Shop**, Wilton. One of the evening's highlights was the raffle at which several lucky winners won prizes from a selection of wines. Pictured left INSPIRE Patron **Mr John Glen MP** congratulates **Jo Suddaby-Smith** who won a half case of mixed wines. As her partner Mr **Werner Stroud** also won a case of wine they left a very happy couple! There followed a noisy auction and the following generous bidders were successful: House of Commons bottle of Claret, **Werner Stroud (!) Lasham Gliding Club** £70.00. Five litre bottle of Chateau La Tuilerie du Puy, **Claire Howard, Irwin Mitchell** £230. Bottle of mystery wine **Fiona Pengelly, Strutt & Parker** £60.00. An all inclusive Day for Two at Salisbury Races donated by **Mr Jeremy Martin MD** and Clerk of the Course, **Richard Griffiths of Richard Griffiths Solicitors** £310. Two all inclusive tickets to the INSPIRE Polo tournament **Mrs Viv Thornton** £210. We are grateful to our sponsors who made the evening possible and to our many members and guests who generously supported the evening. **Watch this space for the 2016 event.**



# The INSPIRE Foundation Presentation to the House of Lord's Reception

Thursday 26<sup>th</sup> February 2015 by Executive Director, Rory Steevenson

**Note:** Following my speech at the House of Lords, it was suggested that it should be printed in the Newsletter as it provides a complete overview of the INSPIRE Foundation's current state of play. I have also included **Trustee Jonathan Rudge's** short introduction to launch NEUROMOD 2015

"**Lord Speaker, Baroness Masham**, my Lords, Ladies and gentlemen. It is a great privilege to be here in London with so many of the INSPIRE Foundation and some of our wonderful and generous sponsors and grant making trusts. As **Baroness Masham** has already thanked the Lord Speaker for her hospitality, may I take this opportunity to thank Baroness Masham for enabling this evening's event and for advising me on the necessary protocols within the House of Lords. At one of our preparatory meetings the Baroness quizzed me on how much I knew about spinal cord injury and I summed it up with words given to me early in my tenure by one of our Trustees who said the most oft discussed subjects by the Spinal Cord Injured were 'Pee, Pooh and Pain'. The Baroness gave me a slightly old fashioned Yorkshire look and said that in Westminster, one tended to discuss the same subjects but called them 'Bladder, Bowel and Bedsores'. So mindful of my Ps and Bs, allow me to add my humble welcome to you all.

You will have noticed that this evening we have the Haves and the Have nots. Your name badge either has an INSPIRE logo or it has not. The Integrated Spinal Rehabilitation Foundation now approaching its thirtieth year is represented by an eclectic array of patrons, trustees, scientists and Volunteers who all have their part to play within the charity. INSPIRE or 'the Haves' is a veritable mix of talent and experience with one common focus on raising money for research to enable quality of life and independence for those who have experienced spinal cord injury. Perhaps I could now ask that if your name is mentioned make yourself known for the benefit of the other guests



The charity has a world class scientific committee and one or two of them are here this evening. The committee is chaired by **Professor Peter Ellaway**, Emeritus Professor of Physiology at Imperial College London. I suspect that since I became Executive Director his patience and tenacity have been more tested than ever in his long and distinguished career although he is too much of a gentleman to say so, to me at any rate. But I would publicly like to applaud Peter's guidance to me personally and might I thank **Wendy Alden** too for her participation in the charity's various equine events. Other scientists are drawn either from the eleven spinal units in UK including the London Spinal Injury Centre at Stanmore where **Mike Craggs** is the Consultant Clinical Scientist as well as being Emeritus Professor of Applied Neurophysiology at UCL. Also at UCL Professor **Nick Donaldson** runs the Implanted Devices Group in the Department of Medical Physics and Bioengineering while Professor **Jane Burridge** is the Head of Rehabilitation and Health Technologies Research at Southampton University. Let me quickly also mention those who could not be here this evening: Mr **Matthew Fraser** Consultant in SCI at Queen Elizabeth National Spinal Unit in Glasgow, **Dr Maureen Coggrave** from Stoke Mandeville, **Emeritus Professor Stephen Lillcrap** from Bath and **Dr Roger Fitzwater** from Rochester in Kent, **Dr Maggie Donovan-Hall** and **Dr Paul Chappell** both from Uni-

versity of Southampton. And finally **Professor Ian Swain** one of the founder members from Odstock. Never one for social gatherings, when I told him about this evening's reception he quickly booked a ticket and jumped on a plane to go climbing in New Zealand!

Eight trustees led by Mr **David McCreath** skilfully guide the charity into ensuring we keep up with the times and spend our money wisely. I might add that David broke his neck thirty years ago but this did not stop his successful career as a lawyer. Five of our eight trustees are spinal cord injured so I think it is fair to say they have a real interest in ensuring our allocation of resources is used to best effect. They are represented tonight by **Jonathan Rudge** who will speak in a moment and **Rob Tylor** who also sits as a lay member in our National Scientific Committee.

Allow me to quickly turn to our research programme. The INSPIRE Foundation is currently funding three projects, in collaboration with other funding bodies. **One. FES Rowing** project at Brunel University. In my own (heavy infantry) lay-words it is sometimes possible to artificially activate paralysed muscle by stimulating the associated peripheral nerves. This is known as Functional Electrical Stimulation or FES. This technology has been applied to a FES Rowing project by the Principal Investigator and I am delighted to say we have just received his final Project Report which will be presented to the Trustees at their spring meeting. The project offers unequivocal evidence that the muscle-induced leg loading provided by FES against resistance of an adapted rowing machine - can improve bone density whilst also improving cardio-respiratory health and fitness. FES rowing therefore, has the potential to improve the quality of life and independence of people with SCI. The PI is Former Royal Naval Officer and Virgin Atlantic 747 pilot Mr **Robin Gibbons**; we have just heard he has been taken ill and send our best wishes for a speedy recovery. The INSPIRE Grant to his project was **£21,000**. **Two. TETRAGRIP** is being run at Bournemouth University and Salisbury District Hospital and is now in its second of 3 years. This important project focuses on enhancing hand function for tetraplegics using the latest electronic and mechanical technology. Hand grip enables so many functions, domestic chores in the kitchen and bathroom, the ability to operate a computer keyboard or telephone at home or in the office and even to drive a car with adapted controls. The PI is Mrs **Lalitha Venugopalan** from India winner of the INSPIRE Foundation's own **Ralph Crossley PhD Scholarship**. Lalitha is here tonight with her husband **Dr. Santhosh Seshadhri**, himself a research scientist. INSPIRE granted this project **£22,500**. **Three. iCYCLE** a computer enhanced multisite project being run at University College London, RNOH Stanmore and Southampton University. The project is designing, developing and testing a FES cycle exercise machine under laboratory conditions with a package of adaptable, virtual routes to suit individual needs. Longer term and once fully researched, iCYCLE will enable the SCI to exercise at home while being monitored electronically by therapists in central laboratory hubs. In other words we are taking physiotherapy from clinics and spinal centres into the users' homes, thereby bypassing the complications, inconvenience and expense of travelling. This will be a remarkable development for the SCI. Principal scientists are **Professor Nick Donaldson** from University College, London, **Professor Jane Burridge** from Southampton University very ably assisted by Sayyid **Ahmad bin Faiez al Ahmary** an exchange PhD Research Assistant from the Kingdom of Saudi Arabia. I am sure you would wish to join me in welcoming Ahmed! (A greeting in Arabic followed here). I might add the INSPIRE Grant to iCYCLE was **£46,000**.

More photographs of the House of Lords Reception at:

<http://www.inspire-foundation.org.uk/thu-26-feb-house-of-lords-reception-6-00-8-00-p-m/>

**Latest Project** This evening I am going to invite Trustee **Jonathan Rudge** to launch our latest project. Before I do a little background: After attending **Eton College**, Jonathan went up to St Andrews University when in 1981 he was involved in a catastrophic road traffic accident resulting in a C5/C6 spinal injury. After 5 months rehabilitation at the **Dundee Royal Infirmary** and then the **Stoke Mandeville Spinal Unit**, Jonathan had a successful career in IT, and is now reading for a PhD at **Reading University** researching breast cancer. He also found time last summer to marry his lovely wife Cherry and I am sure we are all delighted to see them both here this evening. It was Jonathan who told me about the three PPPs and I am now going to ask him to say a few words to launch our latest project”

**Trustee Mr Jonathan Rudge MSc.** “Lord Speaker, my Lords, Ladies, Patrons, fellow Trustees and Scientists, Ladies and Gentlemen. May I too add my thanks to all those here this evening who have helped make the INSPIRE Foundation what it is. For those of us who have benefitted in the past and stand to benefit from the current and future research programmes I can only say, your contribution really does make a difference. While I cannot speak for all those living with spinal cord injuries in the UK, I know I represent a majority view. The INSPIRE Foundation is not trying to find a cure ‘per se’ but rather to improve independence and quality of life by making use of the latest advances in electronic, mechanical and medical technology. I think you may have already gathered that spinal cord injury creates a unique and complex array of problems; in simplistic terms the higher the break or lesion, the more complicated and diverse the overall effect on the rest of the body. But even the lowest lesions create problems in the control of the bladder and bowel and while there have been many advances in this area, there is much more that can be done. I am therefore delighted this evening to be able to play a small part in launching INSPIRE’s latest project in the area of Neuromodulation. It now gives me enormous pleasure to be able to introduce the Project Team from the London Spinal Cord Injury Centre at the Royal National Orthopaedic Hospital Stanmore, **Dr Sarah Knight** and **Dr Anne Van Hoestenbergh**.”

**(After the presentation of the cheque Executive Director continues)** “Perhaps I should state that the ‘cheque’ is a token statement of intent. As you would expect, funds will be paid into the project account on an annual basis conditional on the success of the set milestones being achieved. We are now fundraising for our next project which deals with trunk control, building up core strength of the individual in his or her wheelchair to enable increased independence and quality of life. This project will cost in the order of **£105,000** and will be run at **Imperial College London** by **Dr Paul Strutton** and his team in the **Nick Davey** Laboratory at the **Charing Cross Campus**. Thereafter our horizons include Freehand II updating and building on 20 year old technology restoring hand function after tetraplegia; this comes with a mighty six figure price tag but I will not let that faze me or concern you just now. Let me just say, our quest for new research and with it more funding will never rest. And finally let me turn to the reason we are here this evening. None of this research would be possible without several groups of people: Firstly the incredible fundraising work put in by our friends and volunteers at various events around the country. This comes in many guises from **Nessie Owen** who dedicated her 5 month rehabilitation to produce her culinary masterpiece, ‘Cook to INSPIRE’, now in its second addition. Last year we were at the races: **Wincanton, Exeter, Bath, Salisbury & Cheltenham** and I would single out our most committed supporter **Mrs Sue Clayton** who not only wiggles her bucket most effectively but she also seems to have a wonderful knack of choosing winners. We also run our annual Celebrity polo at Tedworth Park, man charity market stalls, proffer our own charity Christmas cards, enjoy an annual sponsored wine tasting event and most recently a wonderful Open Garden near Winchester provided by one of our newest patrons **The Lady Amherst** who is with us this evening with **Lord Amherst**.



Mrs Sue Clayton ‘Volunteer Extraordinaire’  
with Trustee & Scientific Committee  
Lay Member, Mr Rob Tylor



Jenna McCabe and Richard Firth of Quilter Cheviot  
£10,000 Sponsorship to Polo 2015

And then our sponsors: We enjoy wonderful support at various functions: **Marcia Slater** founder of **Baylis & Harding** is not able to join us this evening but sent her best wishes we are grateful for her long standing support. Secondly our main sponsors at the annual polo are **Quilter Cheviot** represented tonight by **Jenna McCabe** and **Mr & Mrs Richard Firth**. **Quilter Cheviot** support so much of our activity and have already underwritten Polo 2015 with a generous donation of £10,000 so planning is already well underway. I might also mention **Irwin Mitchell** who are well represented here tonight and let me single out **Anne Luttmann-Johnson**, a client sport manager, former INSPIRE Trustee, adventurer, ocean sailor and dare I say it bon viveur.

And finally: we are immensely proud and extremely grateful to be associated with many other individuals, grant making trusts and philanthropic organisations. Some are represented tonight but to respect the anonymity requested by several, I must on behalf of the INSPIRE Foundation offer my thanks in a rather impersonal even bland and generic manner. They all have a duty to ensure the funds they donate or control are used in the manner in which they were bequeathed or raised. As INSPIRE’s principal fundraiser, it is my duty to engage with them and I thank them for their encouragement and resolve in insuring wherever possible funds are made available for our important research programme. Suffice it to say without the generosity and support of these wonderful people and organisations **Dr Sarah Knight** and **Dr Anne Van**

**Hoestenbergh** would not be embarking on the NEUROMOD project which stands to benefit so many people living with spinal cord injury in the United Kingdom. On behalf of the INSPIRE Foundation, my dedicated team **Rose Carnegy**, **Lorna McGregor**, **Badg Champion** and **Robert Morgan** I thank you all very much indeed.”

We are always looking for new fundraising ideas. If you can help organise or host a new event please contact the office as we would love to hear from you! [office@inspire-foundation.org.uk](mailto:office@inspire-foundation.org.uk) Telephone: 01722 336262 Ext 2465

HOUSE OF LORDS RECEPTION THURSDAY 26th FEBRUARY 2015  
HOSTED BY INSPIRE PATRON BARONESS MASHAM OF ILTON, COUNTESS OF SWINTON, DL

Photographs by Karen Hitchcock at [member@karenhitchcock.freemove.co.uk](mailto:member@karenhitchcock.freemove.co.uk)



**House of Lords Spring 2016.** It is our intention to run a second House of Lords Reception during Spring 2016. Details will be promulgated in the Autumn 2015 Newsletter.



### DONATIONS SPRING 2015

We are very grateful for the major donations received since the Autumn 2014 NEWSLETTER. With no Government funding we are totally dependent on our own fundraising programme and voluntary donations. If you wish to donate please visit: [www.inspire-foundation.org.uk/donate](http://www.inspire-foundation.org.uk/donate)

**Personal Donations:** Mr & Mrs J C Bissaker, Mr & Mrs K H Skyrme, Ms PAC McAllister, The Carl Rees Memorial Day, Mrs A Turner, Mrs E J Pybus, Mr Fergus McMullen, Mr & Mrs J A Sussman, Mr & Mrs J May, Two Anonymous donations, Mrs J L Bevan, Mr G Chisendale-Marsh, Mrs Caroline Ripper, Mrs P R Sheppard, Mrs M Wellstead, Mr S J Wills, Mr & Mrs D K Khanna, Brigadier ARL Wheatcroft, Mr M C Leslie, Mr Tim Clayden, Mr A J Burt, Mrs H B Courtney

**Trusts and Sponsors:** Homelands Charitable Trust, One Anonymous Donations, The Joseph Strong Frazer Trust, The Mackintosh Foundation, The Tay Charitable Trust, The Richard Kirkman Trust, Anonymous Donation, The Kayes and Labourne's Charity, The Company of Actuaries, The Misses Barrie Charitable Trust, The G M Morrison Charitable Trust, The Cardy Beaver Foundation, The Buckland Charitable Trust, The Dove Trust, The Walter Guinness Charitable Trust, Quilter Cheviot.

## Welcome Patron Anne Luttmann-Johnson!

After many requests from the exhausted Executive Director, former Trustee Anne Luttmann-Johnson graciously accepted the important role of Patron in March 2015. Anne has already given so much to the INSPIRE Foundation and her new role as a roving ambassador will ensure she keeps the charity's interests at heart. She is seen here in conversation with Baroness Rosalie Wilkins at the House of Lords Reception .



### INSPIRE Foundation Forecast of Events 2015

Thu 28 Apr	Board of Trustees, 5:00 pm (NEW DATE)
Sun 17 May	Grand Shaftesbury Run
Wed 24 Jun	Ashbrittle Stud, Bibury Cup Day, Salisbury Races (Below)
Sun 28 Jun	Cheriton Cottage Open Day (Right)
Sat 11 Jul	Polo, Tedworth Park
Sat 1 Aug	Wilton Horse Trials
Thu 8 Oct	National Scientific Committee, 11:00 a.m.
Thu 29 Oct	Board of Trustees, 5:00 p.m.
Tue 3 Nov	Fundraising Exeter Races
Sat 14 Nov	AGM
Tue 15 Dec	Friends of INSPIRE Christmas Lunch

<http://www.inspire-foundation.org.uk/category/events/>

## POLO TOURNAMENT Sat 11th July 2015 Sponsored by Quilter Cheviot

Join us at this lovely family day out. Details are on the website (EVENTS) or call the office to book tickets  
01722 336262 Ext 2465



Sir Mark Todd ready for action at Polo 2014 playing for the Eventers vs the Jockeys

### Cheriton Cottage Open Garden

Near Winchester, SO24 0PR

**Sunday 28th June 2015**

Lord & Lady Amherst extend a warm welcome to all friends of the INSPIRE Foundation at The Cheriton Cottage Open Garden on Sunday 28th June  
Entry £5.00 per adult  
Wheelchair friendly  
Plant sales

Afternoon tea and delicious home made cakes

**Proceeds to the INSPIRE Foundation**

### Ashbrittle Stud Bibury Cup Day Salisbury Race-course

**Thursday 24th June 2015**

Fundraising, Rosettes, INSPIRE Foundation Stakes  
Volunteers and supporters needed for this exciting day out at  
Wiltshire's premier racecourse



### DEATHS 2014

We are enormously saddened to record the deaths of the following since the last edition of the Newsletter:

Mrs Sheila Young  
Mr George Larter  
Mrs Maisie Rees

Mrs P Selbourne  
Mr Ray Gibbens  
Mr Brian David Hosken