

## INSPIRE's RESEARCH PROGRAMME TOPS £1.1 MILLION!

See 'What a Year' below



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### INSPIRE gets the thumbs up from PATRON Freddy

**2009 Champion apprentice jockey and Group 1 Winning Rides joins INSPIRE.**

Our guests at Polo 2017 were delighted to welcome Freddy Tylicki. Even those who do not read the Racing Post or follow horseracing, may have heard of the 'four horse pile up' at Kempton Park last October as a result of which Freddy fractured 18 ribs and broke his back leaving him paralysed from the chest down. He was flown by air ambulance to St George's Hospital Tooting and thereafter began his rehabilitation including time at the Royal National Orthopaedic Hospital, Stanmore and also at Lambourn House, the Injured Jockeys Fund's own rehabilitation centre. We invited Freddy and his lovely mother Irene down from their home in Newmarket to attend the polo and Freddy volunteered his services as Mr Starter at the Wheelchair Relay. Later at the marquee lunch, he won a coveted raffle prize! Some weeks later, Freddy was asked if he would consider becoming a Patron or roving ambassador and we are delighted to say he agreed. **Top left: Viv Mills welcomes Freddy to the polo grandstand while proud mum Irene (behind in sun glasses) and In Pensioner David Coote, Grenadier Guards look on. Right: Freddy concentrating at full speed.**



### What a year! By Director Rory Steevenson

Once again we have proved that our financial position and with it our ability to carry out research for the benefit of the spinal cord injured, is entirely dependent on the quality of our existing and planned projects; they must be the catalyst for a healthy income stream which at the audit for Financial Year 2016/17 showed **an increase of 117% !** This is not happened by accident but by the dedication and hard work of our National Scientific Committee under the chairmanship of **Peter Ellaway, Emeritus Professor of Physiology** at Imperial College London. Consequently we are now running eight projects with a total commitment of **£1,105,268**. Our latest project **TETRAGRIIP II** costing **£250,000** has just been approved by the Board of Trustees under its **Chairman David McCreath**. This follows the outstanding 3 year pilot study carried out in Bournemouth by our research team led by **Professor Ian Swain** and **Dr Paul Taylor** with excellent work by **Lalitha Venugopalan** who has, alas, returned to her native India. We wish her and her husband best wishes with the imminent arrival of their first child! At a recent visit to Stoke Mandeville, our scientific Committee member **Ruth Peachment** and I discussed options for INSPIRE to support data analysis in a new Therapy Suite. We also took this opportunity for a team photograph with **Sir Ludwig Guttman** and his life sized statue. Ruth said she was convinced '**Poppa**' squeezed her hand, a sure sign that our research is on the right track.



## Au Revoir to Rose Carnegy at Polo 2017



**L to R: Patrons Sir Paul Newton and Lady Amherst with the Hon Mrs Colin Carnegy & the Master of Northesk**

All good things must come to an end and we have now said our first 'au revoir' to Rose Carnegy as she decided to take planned retirement this summer. Having diligently run both the office and the books for 15 years we could not let this milestone go un-noticed so we opted for two farewells! As the font of all knowledge on the Membership database, serving and past members of the Board of Trustees and Scientific Committee and all things related to our recent history, Rose's recall has been unsurpassed. She guided previous and current (executive) directors through calm and choppy seas always with a quiet efficient manner, a strong moral compass and a purposeful demeanour. She and her most supportive husband Colin have now taken retirement to spend more time in their lovely home and with the growing brood of adoring grandchildren. Meanwhile, Rose has already signed up as a volunteer to sell Christmas cards. However at the Autumn Supper and AGM, she is banned from doing the flowers or helping to wash up! Thank you Rose, we look forward to seeing you on Thursday 9th November at the Radnor Hall.

## Right: David Temple, National Scientific Committee Lay Member.

David Temple's promising career in the RAF as an avionics engineer was cut short after a spinal cord injury in 1985 while serving in Hong Kong. He suffered a dislocation of T7/8 and had luque rods fitted to stabilise his fracture. The initial prognosis was not good, but after extensive physiotherapy and rehabilitation at NSIC Stoke Mandeville and RAF Headley Court, he eventually learned to walk again using sticks. In 1987 he was discharged from the RAF and worked for EMI for 3 years and he then specialised in engineering in avionics, aircraft maintenance, procurement and R & D both for commercial organisations and the MOD. Now semi-retired, David lives in Bath with his wife and son. He was elected to the National Scientific Committee in April 2017 and was warmly welcomed by Professor Peter Ellaway and co- Scientists at his first meeting last month.



## INVESTING IN THE FUTURE: THE INSPIRE FOUNDATION SCHOLARSHIP

In memory of Maj Gen Ralph Crossley CB CBE Past Chairman of the Board of Trustees

In September 2017, the INSPIRE Foundation awarded its third PhD Scholarship to **Ms Alison Symond MEng (pictured left)** who graduated at the University of Glasgow in June 2017 with an MEng with Honours of the First Class. Under Principal Investigator **Dr John Riddell**, Alison will work alongside a unique multidisciplinary team of world class researchers, scientists and clinicians on our **£153,000 project** called SPINAL PAIN. During her three year thesis, Alison will receive training in the most up to date approaches used in SCI research, from neurological tests, through quantitative sensory testing and brain Functional Magnetic Resonance Imaging (fMRI). INSPIRE is again demonstrating its commitment to training young research scientists who will continue both now and well into the future, to address the implications and consequences of SCI. **There will be a formal presentation of Alison's Scholarship in October 2018 at the House of Lords.**

## Mariel Purcell joins National Scientific Committee (NSC)

**The Association of Medical Research Charities (AMRC)** requires charities like ours to rotate specialist scientists and clinicians to ensure they are up to date and provide new ideas to our programme. To this end, and while saddened to see the departure of **Mr Matthew Fraser**, instrumental in raising INSPIRE's growing profile in Scotland, we are delighted to welcome **Mariel Purcell, (photographed addressing our Spring Reception 2017 at the University of Glasgow).** As Director of Research at the Scottish Centre for Innovation in Spinal Cord Injury (SCI), Consultant in SCI at Queen Elizabeth National Spinal Injuries Unit and Honorary Clinical Senior Lecturer at the University of Glasgow, Mariel who studied in her native Ireland is ideally placed and perfectly qualified to represent our evolving research strategy in Scotland. We are delighted to welcome her and look forward to her participation at the NSC's next meeting.



## Mrs Pippa Giles

### New Membership and Accounts Secretary

Pippa took over from Rose Carnegy in the summer with an expanded range of responsibilities. She has a fascinating background, a degree in Biology and Geography and a career which has included teaching in a technical college. She then retrained as a rural chartered surveyor, worked as a valuer for the Inland Revenue, as a consultant in compulsory purchase on the Channel Tunnel Rail Link and then became Natural England's national lead for one of their grant schemes for Sites of Special Scientific Interest. Pippa is married to Martin, a chartered building surveyor, and they have two grown up children and a home full of dogs in rural Wiltshire. She is a volunteer for English Heritage at Stonehenge and runs the bakery at a local Woodford Valley charity Café. She has an eclectic mix of interests including craft work, choral singing, gardening and archaeology. As well as currently updating our accounts' system, she is planning to contact INSPIRE's members in order to expand and modernise our database. Welcome Pippa, we are delighted to have you on board!



## NEW TRUSTEE Mrs Sarah Cann

After four years as an INSPIRE Volunteer



Sarah was born and grew up Stirlingshire, Scotland where she attended primary and prep schools before boarding at St. Anne's Windermere. She spent a gap year as an 'au pair' in Germany and then decided to join the Army. She was commissioned into the Women's Royal Army Corps in 1968 but left, as was required in those days in order to get married and follow the drum of the Royal Hampshire Regiment. There followed years travelling the world, including tours in Hong Kong, Cyprus and Germany while harnessing her interest as a Case Worker for both SSAFA and Age Concern. When her first marriage ended in 1993, Sarah moved to Shaftesbury and became a "Carer in the Community" looking after people in their own homes. She re-married in 1996. Sarah then undertook training at the Duke of Cornwall Spinal Unit in Salisbury learning lifting and handling techniques. Many of her clients were wheelchair bound due to spinal injury, stroke, MS or dementia. She worked for 'Family Support', covering South West Wilts and North Dorset, which then became part of 'The Leonard Cheshire Foundation'. In total she was a carer for 21 years before retiring in 2014. In 2013, Sarah and her husband Christopher Cann, a self-employed businessman in Dorset, became Volunteers with the INSPIRE Foundation and since then have supported all possible activities. Sarah and Chris are already well known to many in the INSPIRE community and Sarah is thrilled and delighted to have been proposed as a Trustee.

**Left: Sarah Cann with husband Chris at Polo 2017**

## Message to INSPIRE Members

Those of you who have recently received renewal forms will have noticed that we no longer ask for the payment of annual subscriptions. We recognise that for some members, subscriptions however small, may be off putting and for others who can afford to make a donation, a token subscription seems unnecessary. **So members are both welcome and encouraged but there is no need to pay!** We will still keep a careful record of your address and details (which we will never share or pass on) but we will no longer ask you for any kind of routine subscription.

Nonetheless, for those who want to help contribute to our research programme, please feel free to donate at any time! We receive no government funding so our income is through appeals to grant making trusts, fundraising activities (in the forecast of events), legacies and of course any voluntary individual donations. Like you, we also

receive charity 'begging letters' in the post and like you, we are probably just as irritated by them! Don't misunderstand this message; we welcome any donation, we will just never ask for a subscription from INSPIRE members. Payment for any of our events, or an item of merchandise will continue but it will cost nothing to become or remain a member of the INSPIRE Foundation.

**GIFT AID** If you do choose to make a donation and are a UK tax payer, the Taxman will help increase your donation! Please ask for a gift aid form/envelope or download one from our website. HMRC will then reimburse INSPIRE with the tax element of your donation. For example after a gift aided donation of £10 (or £100) we will receive £1.25 (or £12.50); this generous tax reimbursement will cost you nothing. For further information please visit [www.inspire-foundation.org.uk](http://www.inspire-foundation.org.uk) or call the office, 01722 336262 Ext 2465. Thank you as always for your support.

## VOLUNTEERS ALWAYS NEEDED

A recurring theme in our quest to deliver the best possible research into quality of life issues for the spinal cord injured, is lack of volunteers to help us. If you have suffered a spinal cord injury of any kind or severity, or know someone who has, we would be interested in hearing from you. We are currently running eight projects and are addressing issues which effect tetraplegia and paraplegia. Outline project details are below and you may be just the person who can help! We try and pay all reasonable costs and while some projects are done in spinal units or in university laboratories, an increasing focus is on home based research. If you have time on your hands and think you may be able to help, please visit the research section in our website. Details of our current projects, locations and Principal investigators (PIs) are given below and if you are interested to know more, in the first instance please make contact with the office for further advice: [office@inspire-foundation.org.uk](mailto:office@inspire-foundation.org.uk) or phone 01722 336262 Ext 2465.

## INSPIRE Foundation Constitution

On 23rd April 2017 we received confirmation that the redrafted constitution had been approved by the Charity Commission and would be effective from the date of the AGM 2016 when it was voted by those attending. It is posted on the website but should any member without access to a computer wish to have a copy, please call 01722 336262 Ext 2465 or write to the office.

## How much does our research cost?

Headlines as at 19th October 2017. Further details: [www.inspire-foundation.org.uk](http://www.inspire-foundation.org.uk)

1.	TETRAGRIP Bournemouth	PI Dr Paul Taylor	£39,781
2.	iCYCLE Southampton	PI Prof Nick Donaldson	£70,429
3.	NEUORMOD RNOH Stanmore	PI Dr Sarah Knight	£131,572
4.	TRUNK CONTROL ICL London	PI Dr Paul Strutton	£158,857
5.	BRAIN TRAIN Glasgow	PI Dr Aleksandra Vuckovic	£49,107
6.	STIM2STAND RNOH Stanmore	PI Dr Lynsey Duffell	£175,333
7.	SPINAL PAIN, Glasgow	PI Dr John Riddell	£153,636
8.	TETRAGRIP II Salisbury	PI Professor Ian Swain	£236,553



# INSPIRE Spring Reception Thursday 3rd May 2018

## St Helier, Jersey



Our Spring Reception will take place on Thursday 3rd May 2018 at the Radisson Blu Waterfront Hotel in Jersey. We are publicising this early so those who may be thinking of having a break in the Channel Islands may be able to kill two birds with one stone. The evening event will follow the successful format we have tried both at the House of Lords and up in Glasgow. The focus is on recognising the research programme and importantly the need for money to make it work. There is no hard sell involved, rather a more subtle approach to encourage longer term donations. We need members of the INSPIRE family to help host the event so if you are a resident or have friends who are, please put this date in your diary and make sure Helen has your contact details at [events@inspire-foundation.org.uk](mailto:events@inspire-foundation.org.uk). I should add that the charity pays for this event but our experience is that we will quickly re-coup our expenses!

### Provisional Forecast of Events



2017/2018

Thu 12 Oct	Exeter Races 11:00-16:00*
Thu 19 Oct	Board of Trustees 16:30 for 17:00
Thu 9 Nov	AGM & Charity Supper, Radnor Hall*
Tue 5 Dec	Salisbury Christmas Market*
Thu 14 Dec	Christmas Lunch, Radnor Arms*
Sun 14 Jan	George Skeates Fun Run, Stockbridge*
Thu 22 Mar	National Scientific Committee
Thu 19 Apr	Board of Trustees
Thu 3 May	Jersey Reception*
Sun 24 Jun	Cheriton Cottage Open Garden*
Wed 27 Jun	Fundraising – Salisbury Races*
Sat 7/14 Jul	Polo Tournament* (date tbc)
tbc Oct	House of Lords Reception*

### Can you do more for your charity?

We welcome volunteers at all events asterisked\* No previous experience needed. If you have a smile, we can train you!



### John Stevens 1933 –2017

It was with great sadness that we learned of the passing of John Stevens who died on 3rd July 2017. For many years John worked in the motor industry eventually owning his own Vauxhall dealership. When he retired, he purchased a small farm near Dartmouth in Devon or as he called it 'his piece of Heaven'. Poor health meant the farm had to be sold and John and his wife opted for a more sedentary life style in their lovely home in Dittisham overlooking the River Dart. Sadly, on a visit back to his native Chester, John tripped and suffered a C5 spinal injury. There followed 6 weeks in Chester Hospital and more than 12 months rehabilitation in the Duke of Cornwall Spinal Treatment Centre in Salisbury. His family marvelled at how, having been totally unable to move, he left Salisbury able to drive his own electric wheelchair. His home coming to Devon was filled with joy and tears, with the villagers erecting bunting in the lane down to the family home. He spent the remaining 8 years of his life, in his beautifully adapted 'hospital at home', with support from the NHS providing all medical equipment John needed. Live in carers took the utmost care to ensure he was as comfortable as possible and they along with other visiting therapists and specialists marvelled at his bravery, patience and constant good humour. On 3rd August 2017 his memorial service at St George's Church Dittisham was attended by more than 150 people and a collection for the INSPIRE Foundation raised £1,500. To his loving widow Jill and all his family, particularly his devoted grandson Leo, we offer our deepest condolences on the loss of such a very special life.

### Individual Donations

We are indebted to the families and individuals who have been able to make donations of more than £50 since the spring Newsletter

**Mrs S. Chettleburgh, Mr & Mrs Ian Camm, Mrs SE McFarlane  
NB Mackay, Mrs F.E Hamilton, EJ Ayling, Deborah Paddock, Miss Bulpitt  
AEB Goodman Mrs ES Harrison, R & CA Feast Mrs Beulah Lewis  
Mark Farmar Esq, Tim Blackmore, Dr Woodcock  
Mrs J Stevens, Mrs MF Reeves**

### Grant Making Trusts and Sponsorship

We wish to record our thanks to the trusts whose names are recorded who have made significant donations since the publication of our last Newsletter. Names are recorded in chronological order and anonymity, where requested, has been respected

**Thriplow Trust, HMRC Charities, The Walter Guinness Charitable Trust, Robert Luff Foundation, NB Mackay, HSBC Trust Company (UK) Ltd, Sir Cliff Richard Charitable Trust, Quilter Cheviot Investment Management, Masonic Charitable Foundation, Richard Griffiths & Co, The Childwick Trust, John Raymond Tijou Charitable Trust, George Skeates Fund GJ & S Livanos Charitable Trust, Buckland Charitable Trust, JT Howat Charitable Trust, Joseph Strong Frazer Trust**