

Registered Charity No. 296284

**Headline issues:** One New Patron & one new Trustee Two new Projects, Three new Scientists and more money than ever before. More details inside.....

### Volunteers always required!

You may not have been to the races before but many SCI accidents including three INSPIRE Patrons are due to falls from horses. The racing fraternity are very generous to our charity and we need help from unskilled volunteers to raise funds at our race meetings on Wednesday 27th June at Salisbury and Thursday 11th October at Exeter. Please call us if you want a free ticket to the races and can help wiggle a bucket!



#### **Patron Barbara Ryan**

Pictured with grandson Theo our new roving ambassador, Mrs Barbara Ryan. Formerly the Superintendent Physiotherapist at the Middlesex Hospital in London Barbara then went into private practice, in which her patients included Queen Elizabeth the Queen Mother, three Queens, one King, nine princes and princesses, one Prime Minister and her local refuse collectors, who frequently suffer from bad backs! She now divides her time between her practice and doting family including two grandsons, two married daughters and of course

her wonderful marathon running husband Charles. We were delighted when Barbara agreed to become a Patron in December 2017.

The Integrated Spinal Rehabilitation Foundation

# **Spring Newsletter 2018**

www.inspire-foundation.org.uk
Tel: 01722 336262 Ext 2465



# Donates £17,500

'I am delighted to confirm that the Trustees of the Racing Foundation have agreed to award The INSPIRE Foundation a grant of £17,500 towards the 'STIM2STAND' spinal injury research project. They acknowledge the importance of this research and the potential implications it could have for people with SCI, including a number of jockeys and stable staff.'

With Best wishes, Tansy Challis, Grants Manager

The Racing Foundation cheque will be presented at Polo 2018

# **Farewell to The Admiral**

Former Royal Navy officer, Fleet Air Arm and commercial airline pilot and past Chairman of INSPIRE'S National Scientific Committee dies aged 82.



Paddy Waring died very peacefully in January at the Countess of Brecknock Hospice in Andover. He put up a brave fight against various ailments having lived since 1975 as a 100% disabled paraplegic. He wanted to make Christmas and managed smoked salmon and two glasses of champagne and then set his sights on his 82nd birthday on 3rd January 2018. Although now much weaker, his appetite for a 'celebratory snifter' was still evident. A short time later, Paddy's care team suggested he should move into the Hospice to which he willingly agreed, as independent living was no longer possible, even for a stubborn old sea dog. His last few weeks and days were very tranquil and serene and he was frequently visited

by his many friends. He slipped away early on the morning of 23rd January. He had planned his own funeral which was held on Valentine's Day at the Michael's Wood Natural Burial Ground near Cholderton. He did not think many would turn up but he was wrong! About fifty old friends from the Royal Navy joined Paddy's family in paying their respects. Commander Tim Goetz spoke on behalf of the Fleet Air Arm Association and INSPIRE's Director Rory Steevenson spoke of Paddy's dogged determination to live an independent life. INSPIRE members Helen Rooney, Robert & Mo Morgan and Colin & Rose Carnegy also attended. Paddy generously remembered the charity in his will and left many pictures by his great aunt Lily Florence Waring (born 1877) which were either sold or auctioned at the Riverside Reception on Thursday 10th May 2018. Photos inside.

#### The General Data Protection Regulation (GDPR) becomes effective on Friday 25th May 2018

From this date we will be forbidden from communicating with you unless you give us your expressed permission to do so. If we have your email address, you will already have received a reminder. If you have no email address or computer access, please complete and post back the form provided in this Newsletter. If you do not respond, we will be obliged to remove you from our mailing list.

PLEASE RESPOND BY EMAIL OR POST

#### **NEW SCIENTISTS JOIN INSPIRE**

INSPIRE's National Scientific Committee consists of twelve subject matter experts from the UK's best universities and teaching hospitals. Under the chairmanship of Peter Ellaway Emeritus Members meet formally twice each year to assess ongoing projects and consider new applications for the Trustees' final approval and funding. Welcome to our three new scientists.

#### Dr Dorit Kunkel MPhil PhD, University of Southampton

Dorit qualified with a Physiotherapy Diploma in her native Berlin in 1992. Her interest quickly developed in neurological rehabilitation and she now has more than 17 years' experience in managing mixed methods, research studies and trials. After completing her PhD in 2002 at University of Southampton, Dorit specialised in fall prediction, characterisation of fall events in people with stroke and appointed as a Senior Research Fellow in 2004. In recent years, her research work has focused on exploring novel interventions to promote independence and stability, with the overarching goal to improve quality of life in people with Parkinson's and stroke. Her skills will be readily relevant to spinal cord injury and she was delighted to have been selected to join INSPIRE in November 2017. Dorit continues the long association between the University of Southampton and INSPIRE's National Scientific Committee. Her recent Hampshire predecessors on NSC have included Dr Paul Chappell, Professor Jane Burridge and Doctor Maggie Donovan-Hall.





#### Professor Andrew Jackson PhD, Newcastle University

After obtaining a PhD in neuroscience from University College London, Andrew pursued post-doctoral research at the University of Washington, in the United States. He then returned to the UK and to his current appointment as Professor of Neural Interfaces at Newcastle University. In addition, he is also a Senior Research Fellow with the Wellcome Trust. Andrew's research focuses on applications of neurotechnology in treating neurological conditions including spinal cord injury and epilepsy. Andrew was proposed by Professor Mike Craggs and became a member of INSPIRE's NSC in October 2017. Importantly he will now develop our sphere of influence in the North East, as our first scientist in this part of the UK.

### Dr Paul Strutton BSc (Hons) PhD FHEA, Imperial College London

Paul Strutton runs the Nick Davey laboratory at Imperial College's Charing Cross Hospital campus in West London. He has been involved in exploring a range of topics relating to motor control in health and disease and the effects of pain on this control. He utilises brain stimulation techniques to investigate neural control and plasticity and correlates these with changes in functional outcomes. He has also led the way on non-invasive brain stimulation to combat pain relief, using a model of top-down analgesic control. Paul is currently the Principal Investigator of an INSPIRE funded project called TRUNK CONTROL exploring the interactions between limb movements and trunk control in people with incomplete spinal cord injury investigating if exercise of the limbs might improve trunk control. He is the reviewer for over 30 scientific journals and has reviewed grants for NIHR, MRC and the Wellcome Trust. He is also currently involved in the long-term 'Walk Again Project', with colleagues in Poland, utilising olfactory ensheathing cell implantation in complete spinal cord injured subjects to restore function. As such, he, along with Prof Peter Ellaway, is one of a group of independent assessors examining patients' neurophysiological status prior to and following surgery and rehabilitation. Paul is a member of the Society for Neuroscience and the Physiological Society. In March 2018 Paul was delighted to accept a position on the INSPIRE Foundation's National Scientific Committee.



The Paddy Waring Memorial Auction. In lieu of the Spring wine tasting and Jersey reception (postponed to May 2019) we held the Riverside Reception at the Rose & Crown in Harnham during which we ran the memorial auction. Left to right: Trustees David McCreath and Lyn Thomas. Centre stage Paddy's much loved hat & well worn wheelchair. Right: Trustee Sarah Cann & husband Chris ready to bid at the start of the auction.



#### **NEW TRUSTEE**

Mr David Lyn Thomas

In the hot seat at the Poole Park miniature railway



Lyn was introduced to INSPIRE by David McCreath Chairman of the Board of Trustees and was voted onto the Board last autumn. He then attended the AGM followed by his first meeting in April 2018. As a widely experienced businessman he has vast experience in international, management and leadership issues having enjoyed working in the Oil Industry for 50 years! He has travelled and worked in many parts of the world and in particular in Japan and the Middle East. Working with diverse and eclectic workforces has equipped him to deal with a wide range of management issues in which viewpoints from many angles had to be considered.

He has an enormous range of interests. He has worked as a volunteer at VICTIM SUPPORT UK, giving support of the victims of crime. He is a passionate motor racing enthusiast with a particular interest in Formula 1 and historic vehicles and even competed at club level as a younger man. Married to Jane, and now with four grandchildren Lyn never has a dull moment. He is also a railway enthusiast and a volunteer driver at the Poole Park Miniature Railway in Dorset.

Lyn's philosophy on life in general is that rules should be treated as a guide only and that calculated risk is a key part of decision making. His support for the affordability of INSPIRE's research programme was very much in evidence at his first Board meeting.

Vacancy on INSPIRE's Board of Trustees Readers of recent Newsletters will have noticed a major effort has been made to recruit and rotate key personnel including Patrons and members of both in the National Scientific Committee and the Board of Trustees. New people bring fresh ideas and as INSPIRE continues to evolve, we are always ready to listen. Several of our SCI members have moved on recently including Anton Prantl who has gone west to Sussex and Rob Barrett who has decided to set up his permanent home in Spain. We certainly have room for at least one more SCI Trustee to help represent the interests of the spinal cord injured; if you have personal experience in this area, are able to travel to Salisbury for biannual meetings and the AGM and have the appetite to play your part in the management of the charity's affairs, why don't you give us a ring. While being a Trustee is not a sinecure, the role is both interesting and we hope rewarding.

For further information: Tel. Rory Steevenson 01722 336262 ext 2465 or email ntrs@inspire-foundation.org.uk

# Research Programme £1.07 million.

Over the life of the current research programme (2015-2021) the cost of our seven projects 'does not come cheap'. Project costs are broken down in the table to the right. Nonetheless, we are making real progress in raising sufficient funds to meet this requirement. In Financial Year (FY) ending 30th April 2017, we raised £244,519 our best year ever. At the time of going to print our books are with the auditors, but the total raised in FY 2017/18 was in excess of £251,000. At risk of repetition, another best year ever! INSPIRE has again proved that fundraising is directly proportional to the quality of our projects endeavouring to reaching all aspects of the effects of spinal cord injury.

# The cost of INSPIRE'S current projects

Headlines as at 21st May 2018. Further details: www.inspire-foundation.org.uk

1.	NEUORMOD RNOH Stanmore. PI Dr Sarah Knight	£131,572
2.	TRUNK CONTROL Imperial College London. PI Dr Paul Strutton	£158,857
3.	STIM2STAND, University College London. PI Dr Lynsey Duffell	£175,333
4.	SPINAL PAIN, University of Glasgow. PI Dr John Riddell	£153,636
5.	TETRAGRIP II, Bournemouth University. PI Prof Ian Swain	£236,553
6.	Abdominal FES, QENSIU Glasgow. PI Dr Henrik Gollee	£112,332
7.	RAMP ES, Univesity of Strathclyde. PI Dr Sylvie Coupaud	£103,178

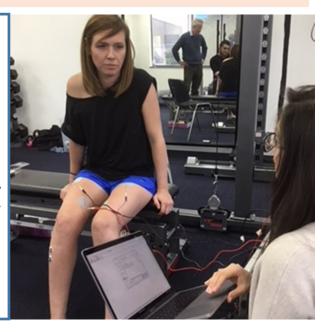
#### **TOTAL PROGRAMME COST**

£1,071,461



Dr Lynsey Duffell BSc PhD (right)
Principal Investigator project STIM2STAND

Working with Prof Nick Donaldson at UCL and Dr Sarah Knight at RNOH Stanmore, Lynsey and her research assistant Dr Yazi al Joboori are being sponsored by INSPIRE to run a two year project researching the long term benefits of assisted standing after SCI. Generous support by Mr Harvey Sihota MD of NEUROKINEX, has included facilities being provided 'gratis' at Watford and Crawley (left). While the project is costing £175,333, thus far £79,000 has already been raised in restricted funds (ie specifically for this project) which we attribute to the apparent appeal and quality of Lynsey's project. We look forward to hearing of her progress and keenly await the results and data of this exciting research project.



# **GRANTS, DONATIONS AND EVENTS 2018 (below)**

### **Grant Making Trusts and Sponsorship**

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

Thriplow Trust, The Walter Guinness Charitable Trust, Robert Luff Foundation, Viginia House Trust, HSBC Trust Company (UK) Ltd, Sir Cliff Richard Charitable Trust, Masonic Charitable Foundation, Buckland Charitable Trust, The Childwick Trust, G J & S Livanos Charitable Trust, J T H Charitable Trust, Joseph Strong Frazer Trust, Mahoro Charitable Trust, Souter Charitable Trust, Homeland Charitable Trust, The Clive & Sylvia Richards Charity Ltd, Richard Kirkman Trust, The Pavilion Trust, John & Celia Bonham Christie Charitable Trust, The Scarborough Group Foundation, Alice Ellen Cooper-Dean Charitable Foundation, Bellahouston Bequest Fund, Buckland Charitable Trust, Pavilion Trust, The Tay Charitable Trust, G M Morrison Charitable Trust, Hoover Foundation, The Valentine Charitable Trust, The Hobson Charity, The Paul Bush Foundation Trust, The Schuh Trust, The Racing Foundation, Royal Manor Lodge.

#### **Individual Donations**

We are also indebted to the families and individuals who have been able to make recent donations of more than £50

Mrs Jo Cumberledge, Rob Tylor, Mrs P Sheppard
The Dowager Duchess of Bedford, Mr K Rees
Mrs H B Courtney, Royal Manor Lodge, Mrs J Knight
Jonathan Green Esq, M Leslie, B A Page,
R H Weed, N Donaldson, J A Watt-Smith
The Lady Amherst, Major & Mrs Robert Morgan
Mr & Mrs D Khanna, Mrs G Matthews
Mr & Mrs Ian Camm, Mrs W Pybus
S A & P Story, Mrs Caroline Rippier, Mr & Mrs D King

#### News of our Events (also on our website)

Sun 24 Jun Cheriton Cottage Open Garden\*

Wed 27 Jun Salisbury Races\*
Sat 14 Jul Polo Tournament\*
Tue 4 Sep Salisbury Market\*

Wed 12 Sep National Scientific Committee (London)

Tue 16 Oct House of Lords Reception\*

Thu 25 Oct Board of Trustees

Thu 11 Oct Exeter Races 11:00-16:00\*
Thu 8 Nov AGM Radnor Hall\*

Tue 18 Dec Radnor Arms, near Odstock

#### Are you able to do more to help?

We always need volunteers at those events asterisked\* No previous experience needed; just bring a smile!



House of Lords Reception Tuesday 16th October 2018. The House of Lords Reception provides a wonderful opportunity for friends and members of the charity to gather with Patrons, Scientists and Trustees and acknowledge the support of those grant making trusts who have made major donations to our research programme. Due recognition is also afforded to our key sponsors. In addition we will conduct the presentation of the INSPIRE Foundation PhD Scholarship to Ms Alison Symond who will be coming down from Scotland with her Principal Investigator Dr John Riddell. We will also recognise other key personalities and events within the INSPIRE family. While there is no charge for the Reception, the INSPIRE donations box will be in a prominent position. If you wish to register your name on the attendance list, please ensure you call Helen Rooney on 01722 336262 Ext 2465. Members' places will be allocated on a first come first served basis, as we do have a limited amount of space. Above right: Trustee Jonathan Rudge in the foreground at the House of Lords Reception 2016 smiles knowingly as Member Mrs Sue Clayton standing immediately behind him, is clearly asking a funny question!













#### More Photos from the Riverside

Clockwise from Top left: The Flower market by LF Waring, Paddy's great aunt. Old aviators examine HMS Eagle, Paddy's one time 'carrier'. The immaculate Commander (now promoted to Admiral!) Tim Goetz regales the reception with 'Paddy stories' and tales of 'daring do' by the former fleet air arm pilot. Cherry Start makes up her mind while husband Nigel holds on to his wallet. Trustee Stephen Duckworth OBE deep in conversation with Chris Cann, husband of Trustee Sarah. A beaming Heather with husband Professor Ian Swain with their successful auction lot.