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THE INSPIRE

The Integrated Spinal Rehabilitation Foundation

Autumn Newsletter 2015

www.inspire-foundation.org.uk

Tel: 01722 336262 Ext 2465

TWO NEW PROJECTS LAUNCHED

INSPIRE welcomes two exciting young research scientists.



**Winner of the Ralph Crossley Scholarship
Sean Doherty will research NEUROMOD at the London Spinal Injuries Centre at RNOH Stanmore.**

'For the next three years

I will be working on the NEUROMOD project at RNOH Stanmore. I first want to say how excited I am to be embarking upon this piece of research and wish to express my deepest gratitude to the Trustees of the INSPIRE foundation who have elected to fund this project.

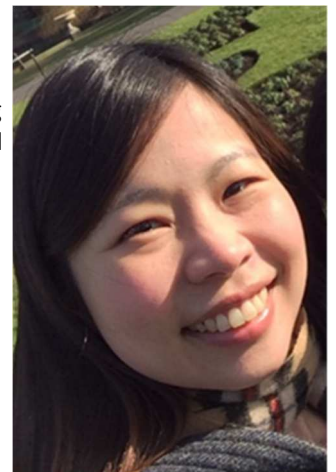
I sustained a C5 SCI in a mountain bike accident when I was 16, and then spent 7 months catching up on my A-levels at Stoke Mandeville. I fully appreciate the need for this kind of research and hope I can add something of real value. My background is in the field of Biomedical Engineering and have a Masters degree in this subject from Cardiff University. I have also worked for engineering firms in both the automotive and medical industries. Some of the more fun projects I have explored have involved developing geared wheels for wheelchairs and 'smart' resuscitation teaching devices. I have acquired some relevant experience which I hope will be useful in my work at Stanmore. I aim to develop my research and investigate the capability of neuromodulation to control bladder, bowel and lower limb spasticity. This should make possible development of a prototype wearable device for the spinal cord injured struggling with incontinence issues as an alternative to existing interventions.

When I'm not in the laboratory I enjoy getting out playing wheelchair rugby or exploring in my camper van, both of which seem to involve moving slowly on wheels! Through this Newsletter and the excellent INSPIRE website I look forward to keeping you abreast of my progress. I cannot wait to get started.

Sean Doherty

A letter from Chloe Chiou who will research TRUNK CONTROL after spinal cord injury at Imperial College London

'I am Chloe Chiou from Kaohsiung, south Taiwan. I studied physiotherapy as an undergraduate and received my qualification as a clinical physiotherapist after 4 years' training. During this period in various hospitals, I found myself particularly interested in the field of neural rehabilitation and also brain science. This led me to apply for a PhD project studying neural mechanisms of motor control in people who had suffered stroke. Life during my PhD was not always easy - it was sometimes very exciting, especially when experiments were going well, but offset with a mixture of loneliness and frustration. In order to keep the balance of body and mind, I took up hobbies such as jogging, yoga and cooking. I believe these activities actually helped because I didn't lose my passion for science during this 5-year marathon-like training! After finishing my PhD, I felt as I had been living in my own country for almost 1/3 of my life, it was time to broaden my horizons and explore the world. I came to England and started working in the musculoskeletal laboratory in Imperial College London as a post-doctoral research associate. My supervisor, Dr Paul Strutton, is an expert in the study of motor control in trunk muscles. By working with him, I have gained a great deal of knowledge in trunk control and expanded my research from the brain control of the limbs to the control of the trunk. Also, carrying out research relevant to trunk control reminds me of the hours spent working with people with stroke and spinal cord injury in hospitals - improving trunk control was always a starting point for therapy. The training programmes were hard for patients and improvement was often painfully slow; this is why I want to investigate ways to help enhance the process of recovery. The INSPIRE foundation fully appreciates the importance of this work focus and has agreed to support our research exploring ways in which using the arms may help to improve trunk control. My most sincere thanks for this wonderful opportunity.



Chloe Chiou



Welcome Karella Gibson

Karella joined us last month and has already settled into the Events PR desk. As a portrait artist she felt the need to get out of her studio and we hope she can add some of her artistic flare into our PR profile and of course the Newsletter! Karella will be taking the lead in all our event planning and looks forward to meeting members & volunteers.

TETRAGRIP - Project Report and Call for Volunteers

Have you experienced tetraplegia or do you know someone who has? The INSPIRE Foundation is looking for volunteers who may be able to help research the issues of hand grip after spinal cord injury. **PhD Researcher Ms. Lalitha Venugopalan would love to hear from you. Tel: 01722 439566**
Able bodied and C5-C7 Tetraplegia volunteers are needed for this research project.

Project Title: Restoration of hand and arm function to people with tetraplegia as a result of damage to the spinal cord in the neck through the use of functional electrical stimulation (FES). By Lalitha Venugopalan (PhD Student, Bournemouth University).

Supervisors: Prof. Ian Swain, Dr. Paul Taylor, Dr. Jon Cobb

Introduction: FES is a technique of using electricity to stimulate nerves of a paralysed muscle. FES has helped people with tetraplegia in improving their upper limb functions. Research has shown that people with tetraplegia who used FES along with physiotherapy and occupational therapy were able to perform their activities of daily living (ADL) more efficiently than those who received only physiotherapy and occupational therapy. At the time of writing, only the NESS H200 marketed by Bioness Inc. is commercially available. This device uses a rigid arm splint that fixes the wrist in one position and holds the electrodes in place. The main disadvantage of using this device is that the splint comes only in one size and does not fit everyone. Since the splint holds the wrist in a rigid position, it cannot be used by people who have active wrist extension. Hence there is an urgent need for an upper limb FES device that can be used by a wider number of people.

Materials and Methods: This research work aims to develop an upper limb FES device that can be controlled using a motion sensor. This motion sensor will be strapped across the users opposite shoulder. The user moves the shoulder upwards, downwards, forwards and backwards for generating the control signals for operating the device. The advantage of using the motion sensor is that it will not have direct skin contact and hence eliminates the possible allergy problems caused by the sticky tapes. The stimulator will be a 4 channel surface device that will be programmed to generate two types of grasp patterns: the key grip (figure 1) for grasping smaller objects like a pen or a fork and the palmar grasp (figure 2) for grasping larger objects like a cup of coffee or a glass of water. The user will generate the control signal to choose between the two grasp patterns.



Fig 1: Key grip



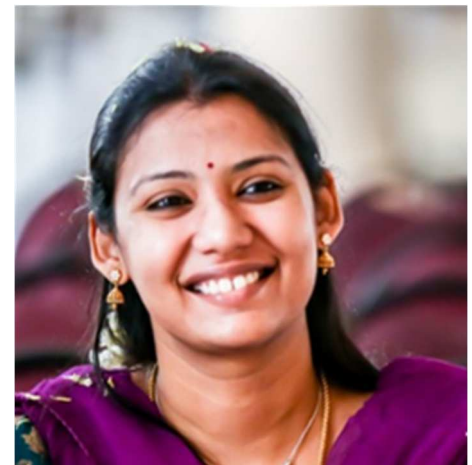
Fig 2: Palmar grasp

Clinical Trials: This device will be clinically tried on able bodied volunteers first and the ability of the device to perform the desired task will be evaluated. If the results from this experiment are satisfactory, then the device will be tried on volunteers with C5-C7 tetraplegia.

Call for Volunteers: Anyone who is interested in participating in the clinical trials, then please contact Ms. Lalitha Venugopalan at 01722 439566. If you choose to volunteer, a volunteer information sheet will be sent to you by post which will contain the details of the experiment. The volunteer will have to sign a consent form and will be asked to visit us at the National Clinical FES Centre in the Salisbury District Hospital for initial assessment.

Funding for the research: This research is the subject of the Ralph Crossley Award, funded jointly by INSPIRE and Bournemouth University.

About the Researcher: Ms. Lalitha Venugopalan is a Biomedical Engineer with a Master's degree in Biomedical Engineering and a Bachelor's degree in Biomedical and Instrumentation Engineering. Her bachelor's project focused on the development of EMG Biofeedback Unit which recorded the electrical signals during muscle activity and rang a buzzer when the contraction of muscle was above the threshold value. The ringing buzzer provides evidence of improvement in the muscle function and encourages the user to continue the treatment programme. Her master's project focused on developing a novel method for noise cancellation that could be used in Cochlear Implants thereby, enabling the subject to hear better. She worked as a lecturer in a reputed engineering college in India before moving to the UK. She is currently pursuing her PhD in Biomedical Engineering at the Bournemouth University.





Tetrapelgia & Twins

A day in the life of Roy Hawkins

Roy Hawkins is 47 years old and has worked with various spinal charities for some time. At the time of his accident in 1992, he was establishing his business as a self-employed builder and bricklayer working throughout Wiltshire, Hampshire and Berkshire. He was in a long term relationship and life was just beginning to map out. A self-declared 'sociable chap' he liked to burn the candle at both ends and enjoyed an active social life with his large family in Great Bedwyn. He was a talented sportsman, played rugby for Marlborough 2nd XV usually in the scrum and was a keen squash player. At the age of twenty four, Roy was celebrating after a good rugby game and in his own words 'slightly the worse for wear'. The lads paused for a breather on the village wall to put the world to rights. When it was time to move on, Roy stood up, lost his footing and slipped falling down a twenty foot vertical drop. His mates realised he was seriously hurt and made him as comfortable as possible until paramedics came; he recalls they attended to the agonising pain and at this point Roy's memory lapsed.

He 'came to' in Swindon Hospital in HALO traction and recalls his first concern was the way the medical staff had cut his hair! He later learned that he had succumbed to a C6/C7 complete spinal injury. He was transferred to Salisbury District Hospital and after nine months treatment for a major lumbar pressure sore, he spent ten months undergoing specialist rehabilitation.

Twelve years later Roy met Lucy and they were married in 2007. Always keen to start a family they underwent an IVF programme and in October 2011 were blessed with twins Henry and Izzy. Roy agreed to share some personal thoughts with the Newsletter about his experience of raising a young family:

'My daily routine starts with my PA helping me to have shower, get dressed and make my breakfast. I do as much as I can to help but often wonder if I had use of one or both hands how much more I could do for myself. How wonderful it would be to grip a cereal spoon or a knife and spread my own butter on my toast. My life would be transformed if I could have a shave or clean my teeth without the physical act of holding a razor or tooth brush becoming a major obstacle in my daily routine. The children and I pop down to our local shop to buy a loaf, two kinder surprise eggs and two small bottles of orange juice. On paying I was fumbling around trying to open my wallet and a very kind lady offered to help. Of course I gratefully accept her offer but it left me feeling slightly embarrassed and frustrated with myself. When we get home, Henry opened his kinder egg and found a 'kit form' toy car which needed slotting together.

He asked if I could help him and while nothing would have given me more pleasure, I simply don't have enough grip in my hands. Further I could not twist the lids off the children's bottles of orange juice; fortunately my PA was with us and was able to help. As a parent it is difficult not to feel slightly inadequate and this happens to me on a regular basis. Over time I have become quite thick skinned but with the onset of parenthood these irritating little things can become frustrating!

Later we were playing ball in the garden. I obviously can't kick a ball but we have developed a system where I can throw it and the children can kick it back to me. They take these things in their stride and it is quite amazing the way they see no barriers in my disability. However I would appeal to other fathers reading this to consider what it must be like not to be able to kick a ball round with your own children, perhaps a right of passage which should come with parenthood, alas not for me.

In the afternoon Lucy my wife comes in from work and we talk in the kitchen while she prepares dinner. It is times like these I would like to help peel and prepare the vegetables but without any grip in my hands this is not possible. While I am able to eat with adapted cutlery, I need someone to cut my food up. Although this has been the case for most of my adult life, it still makes me feel embarrassed particularly if we eat out. Night time is the reverse of the morning when my PA helps me get ready for bed. I try to help as much as I can but I am very limited to what I can do because I don't have any use of my hands and of course at the end of the day I am beginning to feel tired.

There are new challenges every day and I try to handle them as best as I can. Having a great family and a good support network around me makes life easier and I feel very lucky. And our deepest joy is the children, four years old this month and our little rays of sunshine; they really do make life seem so worthwhile.

'Editor's note: Roy joined INSPIRE last year and is a keen volunteer and fundraiser. He recently helped raise **£1378.00** at Salisbury Racecourse. The issues he raises about hand grip are being researched in the **TETRAGRIP** article featured opposite .

**Below: Roy celebrating at Salisbury Races with
by Mr Ian Balding racehorse trainer and father of TV
presenter Clare with Executive Director Rory Steevenson**



FORTY YEARS IN MY BATH CHAIR BY PADDY WARING

A much curtailed account of how 79 year old Lieutenant Paddy Waring RN crash landed in Singapore in 1963 which led to the onset of paraplegia 12 years later and after a subsequent career as a commercial VC10 pilot. Quite a story....in Paddy's own unique style!



'The intrepid author in the garden, summer 2015'

"Longevity" has a usage much used and abused these days. So here, as a near-80 year old with near-40 years in a wheelchair, is my 'take' on this subject. There is no un-pompous way of saying it. Paraplegia is 'no picnic'. My advice to all is that you are where you are, so get on with the future and stop dwelling wistfully in whatever past you had. Also, this will ease the burden of anyone who sticks by you if you show willing to share problems as well as pleasures. Good luck! Life goes on and this is no 'practice' session.

For the cognoscenti, I have a T4/T5 level lesion. I still use a manual wheelchair. I fend for myself but - and this 'but' is a big one - for the last 5 years Carers come in four times each day to operate a ceiling-hoist and help dress me during the first Call. These people then put me on my wheelchair, for two 3 hour periods with 2 hours off my bum in between. I de-manure myself (intermittent catheterisation every 4-6 hours, 24/7, and a colostomy, since 1995.) I feed myself, but have previously tried out - for several months - the home delivered goodies from a specialist provider. However, supermarket single meals and deliveries are entirely adequate. There you are; the grisly details of much of my existence.



On the day, I had four drop-tanks

Solely for your amusement, here is how my present wheelchair existence came about for me. Basically, I was flying a big and interesting Royal Naval fighter, on and off an aircraft carrier. The seas had sharks in them and the 'deck' was somewhat small. Much of the time one was cruising at double the speed of an F1 driver with 'welly to the metal'. At full chat a gallon of fuel could disappear in 7 seconds.

There were no verges or 'lay-bys' to pull in to. It was probably a good thing to be a bit bonkers. The aircraft was the size of a 40' petrol tanker - with wings. It could accelerate at over 100 mph every 10 seconds for well over a minute. We were a serious lot in Naval Aviation I'll have you know. However, the squadron's 'Armourers' - a wicked bunch of ne'er-do-wells - had seized my failure to launch as an opportunity for changing my ejector-seat and they whacked in a Mk5 in place of the Mk4. This throne-change was on the face of it a piece of hugely opportunistic brilliance, but, the old FOUR-pin 'holder' was left in situ when there were in fact FIVE pins for the explosive devices on the new seat. Oooooops! From then on, this was an accident looking for a place to happen. It did.



I was first off and the aircraft was configured 'clean' - no external accoutrements, like drop-tanks (200 gallons) or bomb racks. So, the machine made like a 'homesick angel', reaching 40,000ft in under 4 minutes from launch. Wow, gee, golly, gosh! Then I got down to the serious test stuff. Engine acceleration parameters first. I started with the starboard engine (the RIGHT-hand one, you 'landlubbers'.) However, the port engine (t'other side) then failed to relight, so I dropped down 10,000 ft, but it still stayed dead. As a single-engined arrival on board requires a higher speed than normal and is quite hairy in windless conditions, I was sent off to the nearest airfield, RAF Changi, a mere 50 miles away. Thinking cosy thoughts of an unexpected stop-over even the radar controller's request that a 'newbie' guide me down the GCA (Ground Controlled Approach) was fine by me. In his jittery state this poor unfortunate left me 'high' and to the right of the centreline of the long runway. Waring with aplomb, sangfroid, and the inbred skill of a carrier-jockey put the nose down, turning to port (the left, you landlubbers), to land. It was then that it all turned pear-shaped. The 'joystick' went solid. There was no manual reversion. I was at over 100 feet but with no control. And so the fun began!

Michael Howard-Ford

3rd April 1942 – 9th September 2015

Michael was well known to many in the INSPIRE Foundation. Having suffered a broken neck in January 2000 he spent fifteen months in rehab at Odstock under his consultant **Tony Trowmans**. He was well read and had travelled widely during his many years in the **Royal Artillery** in several global hot spots. He was renowned for having a tremendous sense of fun, strength of character, or as he called it 'bloody mindedness' and the delightful ability of treating everyone in exactly the same way paying scant regard for authority and pomposity. In later life these qualities along with his sincere respect for real ale made him a very popular figure on the **Wilton Estate** where he settled down to his work as an enthusiastic writer with an open door and a well-stocked fridge. As a young man he was immensely fit, played a lot of rugby usually as a talented forward and was a keen runner right up until the time of his accident; indeed in 1986 he ran the **London Marathon** with a very respectable sub four hour time. Despite his disabilities he remained young at heart and was a wonderful mentor to others who had recently experienced spinal cord injury.

His funeral held in the '**Italiente**' **Church of St Mary and St Nicholas in Wilton** was attended by family and many friends, and of course the 'Lads from the Yard' at the **Wilton Estate**. Among a beautiful array of flowers on his coffin, his well-scrubbed training shoes took pride of place no doubt Michael's poignant reminder to us all of times when he ran with the pack. We send our sincere condolences to '**Tigger**' and all the family for a wonderful life well lived by a quite remarkable and much loved man. RIP



INSPIRE Foundation Forecast of Events 2015/2016

Wed 21 Oct National Scientific Committee, 11:00
Thu 29 Oct Board of Trustees, 5:00 p.m.
Tue 3 Nov Fundraising Exeter Races
Sat 14 Nov AGM, 11:00
Tue 15 Dec Friends of INSPIRE Christmas Lunch
12:30 Bird & Carter Farm Shop
Thu 3 Dec Christmas Market
8.00-8.00 Salisbury Guildhall Square
Mon 21 Dec -
- Mon 4 Jan Christmas, Office Closed
Thu 10 Mar Wine Tasting, Salisbury Racecourse
Thu 17 Mar National Scientific Committee, 11:00
Fri 25 -
- Mon 28 Mar Easter, Office closed
Tue 5 Apr Board of Trustees, 5:00 p.m.
Thu 14 Apr House of Lords Reception
Sat 9 Jul Polo, Tidworth

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

DEATHS

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

Mr Alan Christopher

Mr Roger A J Nixon

Mr John Lambert

Mrs Judith Moir

Mrs C Rainey

Mr Michael Howard-Ford (See obituary)

DONATIONS

We wish to gratefully acknowledge generous private donations, some choosing to remain anonymous and from the following:

Mrs S M Chittleburgh, Mr Ian Camm, Mr & Mrs N McFarlane
Mr & Mrs J H Swanton, Mrs Anne G Humbert Mrs G S Holmes

Mr & Mrs A Griffiths, Mrs B C Lewis, Mr P A Waring

Ms Emma Harrison, Mr Anthony Salt, Mrs P R Sheppard

Mr R J Williams, Miss W E Roberts, Mr T J Burgess, Mr Stuart Rees

Mr J T Holloway, Mrs H B Courtney, Mr & Mrs M Peacock

Mrs Andrea Madden, Ms Janet Wilkins, Mr Richard Feast

Dr & Mrs Alan Woodcock, Mr Timothy Blackmore

Our thanks also to the following trusts and organisations for their magnificent support: A E Cooper Dean Charitable Foundation, The Valentine Charitable Trust, The Chapman Charitable Trust, The Weinstock Fund, The George Skeates Fund, The Robert Luff Foundation, The Rowan Bentall Trust, The Hedley Foundation, The Pavilion Trust, Quilter Cheviot



Fundraising Patron: The Lady Amherst with
Rev Graham Bowkett at Cheriton Cottage Open Garden



Dear Member

This has been another bumper year for the INSPIRE Foundation with overall growth in all areas, available funds, current projects with more in the pipeline, unique website hits and our membership has grown too! I am delighted to introduce our two latest research scientists. Firstly **Sean Doherty** the winner of the 2014 **Ralph PhD Crossley Scholarship** who will be researching **NEUROMOD** at the London Spinal Injuries Centre under the direction of **Doctor Sarah Knight** along with **Doctor Anne Van Hoestenbergh** from the Centre for Rehabilitation, Engineering and Creative Technology at University College London. Secondly **Chloe Chiou** who will be researching the innovative **TRUNK CONTROL** project at Imperial College London guided by **Dr Paul Strutton**. These new projects are costing nearly **£200,000** over the next three years and so fundraising remains my own main effort. I am indebted to the charitable trusts who continue to look favourably on our endeavours. Of course I am always looking for more money so if you have ideas of where untapped sources may be hiding, please let me know!

I offer my grateful thanks to those of you who have been able to support our array of activities from the Open Garden at Cheriton Cottage, racing at various racecourses, the Polo which raised **£8,500** and our social gatherings too. None of these would be possible without the generous support of sponsors and volunteers and I will single out **Richard Firth** of **Quilter Cheviot**, **Volunteer Mrs Sue Clayton** and **Trustee Jonathan Rudge**; the latter two have been to every single event we have hosted this year. Thank you!

Could I possibly ask all of you to consider whether you can do more to support your charity? Next year we will repeat our London Reception at the **House of Lords on Thursday 14th April**, the **Wine Tasting at Salisbury Racecourse Thursday 10th March** and the **Polo on Saturday 9th July at Tedworth Park** near Andover. If none of these are possible or suitable for you, perhaps you would be interested in attending the AGM next month (details below) or even buying some of our lovely Christmas cards. The more adventurous of you might like to consider whether our fundraising gazebo (pictured overleaf at Cheriton Cottage) could be accommodated in your own community, village or club events. Please bear us in mind. If you are not **INSPIRED** by any of our designs or other plans, please pick up the phone or drop us a line or better still an email which brings me nicely to my last point and a plea! If you have access to e mail (we have octogenarian members who use it, so age seems to be no barrier), please ensure we have your email address and your permission to send the Newsletter by email rather than post. This is an oft ignored request which would save us considerable printing and postage costs. Meanwhile, thank you all for your support to the INPSPIRE Foundation.

Yours sincerely **Rory Steevenson**

28th ANNUAL GENERAL MEETING

11:00 am Saturday 14th November 2015

Coffee at 10:30. 1:00 pm Buffet Lunch

Notice: The 28th Annual General Meeting of the INSPIRE Foundation will be held at 11:00 on Saturday 14th November 2015 in the Group Activities Room, Duke of Cornwall Spinal Treatment Centre, Salisbury District Hospital, SP2 8BJ

Agenda: Minutes of the previous Meeting
Treasurer's Report (for the year ended 30 April 2015)
The Technical Director's Report
Executive Director's Report
Election of Auditors
Election of the User Committee
Any other business . Please EMAIL any items to the office



Above: AGM 2014 a busy lunch table

Presentation. Following the formal AGM, there will be an illustrated presentation by the Chairman of the INSPIRE National Scientific Committee entitled:

**'Recovery of function after spinal cord injury – the way ahead'
... a personal perspective...**

by

Professor Peter Ellaway BSc PhD

Emeritus Professor of Physiology at the Department of Clinical Neuroscience
Imperial College London



**Emeritus Professor
Peter Ellaway BSc PhD**

Booking In: To book in please telephone **01722 336262 Ext 2465** or confirm by email **'office@inspire-foundation.org.uk'** by Friday 6th November 2015 and notify us of any dietary requirements

Please bring £5.00 per head to help cover costs for coffee and lunch

Note: Save P and P! INSPIRE Foundation Christmas Cards on sale throughout.