

Regd. Charity No. 296284

The Integrated Spinal Rehabilitation Foundation

Autumn Newsletter 2016

If you have a computer and received this by post, we are guilty of wasting money! Please request electronic Newsletters at: office@inspire-foundation.org.uk. Thank you.

MASONIC CHARITABLE FOUNDATION AWARDS INSPIRE £65,000



From the London 'Freemasonry Today magazine'

The Masonic Charitable Foundation has awarded £65,000 to the INSPIRE Foundation to fund research which aims to improve the quality of life and independence of those living with spinal cord injuries. The project will be led by research scientist **Sean Doherty** who broke his neck in a mountain bike accident in 2008. Sean and his team hope to develop wearable stimulation devices to control bladder and bowel as an alternative to pharmaceutical therapies. While the inability to walk is often considered the most challenging consequence of spinal cord injury, the loss of control of bladder and bowel is often the most difficult to manage and can have a persistent and detrimental effect on health, welfare and quality of life.

Sean said: "Following my injury, I was just keen to get on with what I had been doing before it happened. I wanted to be an inventor when I was young; all inventors are trying to solve problems. I think having my injury has directed that ambition towards problems I have seen since." Trevor Koschalka, a Freemason from London who visited the research on behalf of the Masonic Charitable Foundation, said: "We are incredibly proud to support the NEUROMOD research project through a grant to INSPIRE Foundation. We hope that the grant will enable Sean and the rest of the team to successfully develop a wearable device to control bladder and bowel function and improve the quality of life of Spinal Cord Injured people."

Rory Steevenson, Director at INSPIRE Foundation, said: "One of my greatest concerns is funding our national research programme as we receive no government funding. The Masonic Charitable Foundation grant will guarantee this project can continue to full term. This is the best possible news and we are so grateful." **More details inside**



More than £30,000 raised in Scotland for Project BRAIN TRAIN (Page 2)



Spring Reception, Thursday 16th March 2017 Ferguson Room, University of Glasgow

Following the popular receptions at the House of Lords, we have decided to venture north. With considerable interest already being shown in our projects up in Scotland, this reception will allow potential and current donors to meet scientists, clinicians and some of our members. After a presentation on our Research Programme, we hope to present the INSPIRE Foundation Scholarship to a PhD student researching our latest project. Drinks and canapés will be served from 6.30-8.30 pm. Members able to help host the event, (free of charge) will be very welcome. Please confirm your interest at 01722 336262 Ext 2465 or email events@inspire-foundation.org.uk



Wonderful response to our fundraising in Scotland!

BRAIN TRAIN After training, an individual equipped with head harness and tablet computer is able to manage therapy for central neuropathic pain. This is being researched by 20 patients in their own homes throughout Scotland. BRAIN TRAIN is being sponsored with generous grants from the **Robert Barr Charitable Trust in Glasgow** and the **RS MacDonald Charitable Trust in Edinburgh**



Left: Volunteer Jamie Fleming eagerly participates in BRAIN TRAIN a system developed by Mr Matthew Fraser, Consultant in spinal cord injury at Queen Elizabeth National Spinal **Unit in Glasgow:** 'I was delighted to be asked to take part in the BRAIN TRAIN project in Glasgow. I know how difficult it can be to find volunteers but unless those of us who have suffered SCI are prepared to assist with this sort of research, the scientists and physicians will find it impossible to make any progress. My small part in this project involves wearing a head harness and concentrating on relieving my own pain through the brilliant software in the computer tablet I have been given. It really is not difficult and the relief of pain in my back and particularly legs and feet is quite remarkable. I am amazed and so grateful for the research work being carried out by the dedicated team at QENSIU. I know there are other projects funded by INSPIRE which urgently need the support of SCI volunteers. If you have suffered SCI, your participation can do nothing but further their cause and I urge you to consider giving up a few hours a month to help INSPIRE's research programme make a real difference'.

FINAL STAGES OF TETRAGRIP PROJECT

After 3 years of study at the University of Bournemouth and Salisbury District Hospital (SDH), Mrs Lalitha Venugopolan, PhD student and winner of the INSPIRE Foundation Scholarship 2014 is bringing her research to an end. She returns to her native India later this month where she will write up her dissertation and final report. At a fascinating presentation this week at SDH, Lalitha gave graphic evidence of how she has restored life into the hands of subjects who had lost hand function after tetraplegia. (Right) Lalitha was presented with her scholarship certificate by INSPIRE Trustee Dr Richard Smith MSc FRCP MBBS BSc (Hons) PG Dip SEM, Consultant in Rheumatology at SDH. He applauded all she had done and emphasised how important research in this field has become, a view echoed by Mr Nick Marsden, Chairman of the Salisbury NHS Foundation Trust. Last month she was delighted to wire up Director Rory Steevenson (below) whose left hand successfully exercised the key grip and palmar grasp while he sat and watched in awe.



(Left): in this case the control mechanism is attached to the right arm and the skin electrodes above the nerves in the left hand. After minimal training and practice, the subject, is able to initiate, the different hand grips and control the level of stimulation. In effect this tightens or loosens the grip on an object in both the palmar grasp (below left) or key grip. Right: SCI Research Scientist and Tetraplegic Sean Doherty with PI Dr Paul Taylor and Research Scientist Lalitha Venugopolan master hand control with TETRAGRIP. The INSPIRE Foundation PhD Scholarship was created in memory of the late Maj Gen Ralph Crossley, formerly Chairman of INSPIRE's Board or Trustees.





INSPIRE's current commitment to research into spinal cord injury stands at £294,000!

Some details are shown on the opposite page but to summarise, our current research programme runs to five projects, two in London, one in Glasgow and others in Bournemouth and Southampton. In London Dr Sarah Knight and her team are researching neuromodulation at the Royal National Orthopaedic Hospital, Stanmore while Dr Paul Strutton is researching core Trunk Control at Imperial College. At the Queen Elizabeth National Spinal Injuries Unit Glasgow, Dr Aleksandra Vuckovic is leading a multinational team researching neuropathic pain in users' homes across Scotland an exciting project with tangible results already being identified. Now nearing completion, Dr Paul Taylor has been overseeing the TETRAGRIP project at Bournemouth University and the Department of Clinical Sciences at Salisbury District Hospital. Two new and very exciting projects are being tabled by the Board of Trustees next month. Subject to their approval, details will appear in the next Newsletter. SCI VOLUNTEERS NEEDED. One of the enduring issues which research scientists face is the apparent reluctance of suitable volunteers to assist in our research. This means that excellent projects could run the risk of not having sufficient data and statistics to substantiate their findings. We are therefore appealing though this Newsletter to all our readers to consider offering their services as Volunteers. Both Spinal Cord Injured and able bodied subjects are needed. We need only your time and will endeavour to pay all reasonable expenses. Register your interest if you can at: office@inspire-foundation.org.uk

12 Month Extension for iCYCLE

At the University of Southampton, **Professor Jane Burridge** and Research Scientist **Ahmad al Ahmary** are developing a Functional Electrical Stimulation (FES) cycling machine called iCYCLE (the 'i' stands for INSPIRE). This has evolved from **Professor Nick Donaldon's** ERGOMETER machine which he manufactured at University College London. iCYCLE enables and monitors a combination of individual and FES assisted effort which when combined, enables cycling with a virtual route display in order to achieve optimum fitness after paraplegia. After several technical delays, the iCYCLE team has asked for an unfunded 12 month extension in order to continue their data collection. We wish Ahmad and the team every success and look forward to the Final Report in 2017.

The User Committee

Some time ago I advertised on our website vacancies on the User Committee. The response has been, well in fact there has not been one! The User Committee is an important part of the process which helps select INSPIRE's research projects. Volunteers with a knowledge of spinal cord injury may be ideally suited to offer 'lay' views for the attention of the Board of Trustees on projects already recommended by the National Scientific Committee. If you are remotely interested, and feel you may be qualified, being SCI yourself or a family member/ carer of someone who is, please let me know at: ntrs@inspire-foundation.org.uk Thank you.

 $Constitution\ 2016\ {\it A redrafted version of our Constitution will be tabled at the AGM, Thursday\ 10th\ November.}$

If you have not already seen details, please email: office@inspire-foundation.org.uk or call 01722 336262 Ext 2465

Contd from Front Page: £65,000 from the Masonic Charitable Foundation. Is this the biggest ever single donation to the INSPIRE Foundation's recent Research Programme?



Members of the NEUROMOD Project Team at the London Spinal Cord Injury Centre with the Masonic Charitable Foundation's magnificent award.

Left: L to R: Dr Anne Van Hoestenberghe, Lecturer at the Centre for Rehabilitation Engineering & Assistive Technology (CREATe) & University College London (UCL), Dr Sarah Knight Clinical Scientist at RNOH Stanmore & Honorary Senior Lecturer at UCL with SCI nursing specialist Sister Judith Susser pose with the Winner of the INSPIRE Foundation PhD Scholarship 2016 Sean Doherty

Right: Deep in conservation, Trevor Koschalka of the Masonic Charitable Foundation discusses a point of detail with the focused looking Research Scientist! Biggest ever Donation? To the best of our knowledge this represents the single, biggest donation to the INSPIRE Foundation and our deepest appreciation to the Masonic Charitable Foundation cannot be overstated. The MCF will be invited to our next London Reception, provisionally in spring 2018.





Forecast of Events

Tue 11 Oct Board of Trustees. 16:30 Tue 1 Nov Exeter Races, 11:00 - 16:00

Thu 10 Nov 18:00 AGM

19:00 Autumn Supper Radnor Hall, Bodenham.

Thu 1 Dec Christmas market stall. Salisbury Thu 15 Dec Christmas Lunch*. Details TBA Sun 8 Ian George Skeates Fun Run, Stockbridge

Thu 16 Mar Scotland Reception, University of Glasgow 18:30 Thu 23 Mar National Scientific Committee 10:30

Thu 30 Mar Wine Tasting, Salisbury Racecourse 18:30 Wed 5 April Wincanton Races

Thu 27 April Board of Trustees 16:30 Wed 28 Jun Bibury Cup Day, Salisbury Races

Sat 8 July Polo Tedworth Park

INDIVIDUAL DONATIONS

We are indebted to those individual Friends of INSPIRE who have made signficant donations since the last Newsletter. Details of donors wishing to remain anonymous are not listed

> Mr Richard Williams, Mrs S Chittleburgh, Mr Ian Camm Mr Luke March, Mrs Beulah Lewis, Mr A J Burt Mrs A Madden, Lord & Lady Amherst Mrs C M Buttery, Mr Richard Feast Mr Tim Blackmore, Dr Alan Woodcock Mr J T Hollaway, Mrs Marion Crossley Mr & Mrs J H Collins, Mr Stuart Rees

NEW FORMAT AGM. The AGM is an important and mandated part of running the charity so we have decided to freshen it up. It will now precede the new 'Autumn Supper' and we very much hope to see a good turn out. You will have received a flier already but this is an additional plea to those members who can attend to give us their support. Not least, the charity is growing from strength to strength and it would be to everyone's advantage to hear from the body of the kirk how we might proceed into the future. Trustees steer the ship with skill and commitment but a few voices from the floor would be novel and much appreciated. Please join us or ring for further details: 01722 336262 Extn 2465 or email: 'events@inspire-foundation.org.uk'

George Skeates Fun Run





Grant Making Trusts Donations & Sponsorship

We wish to record our grateful thanks to the organisations listed below for their significant donations or sponsorship since the last Newsletter. Where anonymity has been requested, details have not been published.

The Company of Builders Merchants, The Buckland Charitable Trust The Robert Barr Charitable Trust, Baylis & Harding, The Walter Guinness Charitable Trust, The Robert Luff Foundation The Fowler Smith & Jones Trust, The Childwick Trust The Masonic Charitable Foundation, CHK Charities RS MacDonald Charitable Trust, The Grey Court Trust The George Skeates Fund, The Worshipful Company of Cutlers, The Valentine Charitable Trust, The Company of Builders Merchants Quilter Cheviot Investment Management

DEATHS

We are enormously saddened to report the recent deaths of the following: Mr A Sweek, Mrs Kathleen Carruthers Mr Edward Saunders, Mrs Rosamund Fairman

£1000 raised at Cheriton Open Garden

Patron Lady Amherst again opened her beautiful gardens at Cheriton near Winchester donating the proceeds to INSPIRE. Pictured right Trustees Jonathan Rudge & Malcolm Wylie with their wives Cherry and Sheila pose in the INSPIRE gazeebo which did a blistering trade!



POLO 2016 RAISES £10,000!



A wonderful day out for all the family generously supported by Quilter Cheviot Investment Management (main sponsor) Baylis & Harding and Steevenson Wines Ltd. For your diaries Saturday 8th July 2017 View all the photographs at 'www.inspire-foundation.org.uk'