

John Aves MBE



John flanked by Leah, his eldest grand-daughter and his wife, Anne

Below, is the citation from the Hospital

John Aves, who worked in the Duke of Cornwall Spinal Treatment Centre at Salisbury District Hospital from April 1984 until April 2008, has been made a MBE in the New Year Honours List.

John started as a nursing assistant and soon became the wheelchair technician for the Unit. Initially his role was to support patients with spinal cord injuries, helping with lifting and seating them regularly so that they did not develop pressure

sores. He taught them wheelchair skills, helped patients stand and walk and was involved in setting up regular archery sessions which helped with rehabilitation and gave them an interest in taking part in competitive sport.

John's support enabled hundreds of inpatients to take up sailing again, supported patients who wanted to start flying at the Old Sarum Flying Club and organised training programmes to prepare patients for the Annual Inter Spinal Unit Games.

As a wheelchair technician his key skill was in ensuring that wheelchairs, adapted vehicles and other equipment could be used by patients with differing levels of disability. For instance, in the early days before ventilator trays were available, he could be asked to attach a ventilator to a wheelchair, or to solve problems with positioning for patients who were having difficulties. His specialist up-to-date knowledge was essential for the Unit.

Congratulations to John on being recognised by this award.

John asked if the following message could be inserted. "In this 25th anniversary year of the Spinal Unit, I would like to dedicate this award to all my Spinal Unit colleagues who have served so faithfully during the past 25 years".

What's Happening?

Reports from Project Leaders

Optimising power output during electrically stimulated cycling in people with a spinal cord injury

Cost of the Project: £52,025

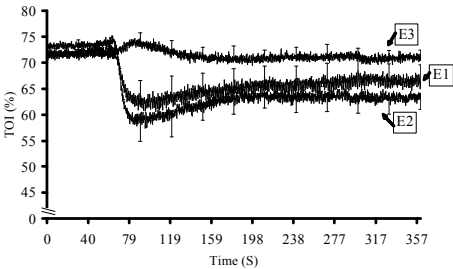
Location of the Project: KCL

Professor Newham writes:

Electrode positioning to reduce the activation of rectus femoris.

The anterior thigh muscles are stimulated during FES cycling to generate power from knee extension. Only one of them, rectus femoris (RF), crosses the hip and knee and recent published data indicates that it reduces net power output (PO) due to its simultaneous hip flexion. More efficient cycling should be achieved by reducing its activation and optimising that of vastii.

Fifteen able-bodied subjects carried out electrically stimulated quadriceps contractions using: E1) the standard electrode set-up (over the whole muscle group), E2) electrodes positioned directly over RF and E3) two pairs of electrodes positioned over the lateral and medial vastii. Oxygen utilisation, indicating muscle activation, in RF was assessed by near infrared spectroscopy and the economy of contractions by metabolic measurements. RF oxygenation was significantly greater during E3 (Fig. 1) which was also more economical.



Therefore altering electrode positions can increase recruitment of the vastii, reduce that of RF and increase PO during FES cycling. The more economical knee extension moment would also be an advantage.

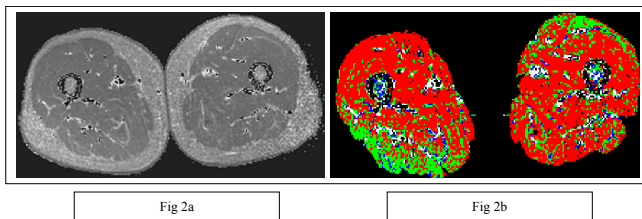
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Extent of muscle activation during quadriceps stimulation.

The amount of muscle activated by FES is unknown. Incomplete activation of a muscle throughout its length and depth would reduce the peak PO generated while high current could spread into muscles with an opposing action.

With the current standard electrode configuration we have used magnetic resonance (MR) imaging to visualise the activated muscle in cross-sectional images of the thigh (Fig. 2a, overleaf) in sections along its length. T2 weighted images (Fig. 2b, overleaf) can differentiate between rested muscle and that which has been activated by differences in density.



Bi-moment chair. The mechanical construction of the chair was completed in the first 6 months of this project. There have been a number of unexpected difficulties with the strain gauge transducer amplifier that measures the forces. Recently the cause of an offset artefact was traced to a nearby opto-isolator, and this has now been replaced by a more sanitary design. We can therefore proceed with the biomechanical experiments, using the chair, which will take place over the next few months, irrespective of INSPIRE funding.

A randomised trial of rectal stimulants for neurogenic bowel management after spinal cord injury

Cost of the Project: £28,439

Location of the Project: Stoke Mandeville and Salisbury

Dr Coggrave writes:

A major amendment regarding the method of recruitment to this study was submitted to the research ethics committee and to the MHRA with a successful outcome. This will allow us to recruit to the study by writing to invite individuals to participate using existing databases held in the various units.

(Continued on page 4)

(Continued from page 3)

An initial 100 invitations have been despatched from the NSIC with a somewhat disappointing 3% response rate! However, this may not be representative and I hope that future response will be better. With a unit database of approximately 3000 individuals to work through we should be able to recruit around 90 individuals from the NSIC even if the rate of response does not improve, so I anticipate that we will eventually be able to achieve our target number of 125 with the co operation of our collaborating centres.

Thirty seven information sheets have been sent from the NSIC and ten individuals recruited with an additional one booked for January through the NSIC. Salisbury are committed to continuing with the study but have yet to recruit any participants; their R&D department are currently scrutinising the amendment.

Stanmore spinal unit has still not been able to join the study but advertisements have been placed in the Aspire Centre and there is local support for individuals expressing an interest in participating in the project; the position regarding pharmacy undertaking the study is under review.

The pharmacy at St. Mark's hospital is now in a position to take on the trial but despite this positive news the R&D department are still dragging their heels. I am aware that this is a problem affecting a large number of studies at St. Mark's, not just this one. I will continue to pursue them though only a small number of participants are expected to be recruited through this centre.

In addition to continuing to advertise as previously reported, a recent participant in the study also kindly volunteered to write a short piece for Forward, the SIA magazine, describing her experience of research participation and recommending individuals to take part – every little helps!

Short term efficacy of Sacral Nerve Stimulation (SNS) in patients with neurological constipation

Cost of the Project: £31,750

Location of the Project: University Hospital, Durham

Dr Yiannakou writes:

Approvals in place. All the necessary approvals required for this study have been in place and are detailed below.

(Continued on page 5)

(Continued from page 4)

LREC number: 07/H0903/45

University of Durham Ethics subcommittee approval number: EC2/2007/01

In addition to these, the Project review board of County Durham and Darlington Foundation trust has also approved the study.

UKCRN registration. This trial has been registered with UKCRN (clinical research network) and has been placed on their national database. UKCRN trial id: 4594.

Accrual data. So far fifteen patients with neurological constipation have been recruited in the trial. Out of these patients 10 had Multiple Sclerosis, four had spinal cord injury and one patient suffered from spinal myoclonus.

Future plans. Jubilee Spinal Injury Unit (SIU) at James Cook University Hospital, Middlesbrough has been added as an additional site for recruitment for this trial and site-specific ethics approval for James Cook Hospital has been granted. The trust research board has also approved the study. Mr. Mecci (Head of the department at SIU) will be acting in the capacity of principal investigator for that site. Further visits have been made and SIU is currently in the process of identifying patients for the study.

Estimated trial end. We are hopeful that the necessary recruitment will finish by the end of summer 2009. This has been calculated using a conservative estimate of two new recruits every month.

APPLICATIONS FOR FUNDING SUPPORT

Of the three applications which were mentioned in the December Issue of the Newsletter, only two were recommended to the Board:

Central nervous system reorganisation after spinal cord injury: its relationship to pain and response to mental and

A systematic exploration of Neuromuscular Electrical Stimulation (NMES) in spinal cord injury: Stage 2 An international questionnaire study

The electrical stimulated rowing project was rejected but the applicant was asked to resubmit after the concerns expressed by the Scientific Committee had been taken into account.

Trevor Parfremment 1960-2009

A Tribute by

Julie Esnouf



Trevor, with Julie standing behind

Trevor was a great ambassador for the Freehand system and INSPIRE. He helped the Freehand team on several occasions with training at other European sites, talks and visits. The photo showing a much younger versions of us was taken when we gave a presentation to the Royal Society of Medicine in London.

Travelling the long distance from Lowestoft was never a problem. In fact we couldn't stop him coming to Salisbury! He proceeded to have further surgery on his other arm, gluten for punishment! Then unfortunately in 2004 his system broke down, big time. This was beyond even Paul Taylor's (our tame bio-engineer) engineering skills and Mr Hobby was required to replace the implant.

There is one particular occasion that we will all remember vividly. We were at a local pub following a training session with American, Portuguese and Southport colleagues. Trevor was just beginning to use his system by then, he raised his glass to us all and made a toast. "Cheers everyone". It was a very emotional moment. He was so grateful to be involved in the pioneering work.

So... "Cheers Trev", you were a great guy and we owe a lot to you. Thank you. You will be greatly missed.

PATIENT ENTERTAINMENT SYSTEM FOR SPINAL UNIT

Over the next year or so, the Spinal Treatment Centre here in Salisbury is being decorated and modernised. Part of the modernisation is the installation of a Patient Entertainment System (PES) for each bed station. Anne Seaman, Lead Nurse for the spinal unit approached INSPIRE to see if the Foundation would like to contribute towards the cost of a system amounting to some £900 each.

The PES was specifically designed by *IAG Technology* for the spinal treatment centre at Stoke Mandeville. The system includes:

A 7" wide screen TV which is high resolution back-lit LCD with good daylight viewing.

Freeview digital TV and radio channels.

TV screen is wall mounted and

angled for easy viewing.

Audio/Video input for games and DVD players etc.

Nurse call bell system.

Over bed lamp with dimmer.

INSPIRE was conceived here at the spinal treatment centre, many of its members have passed through and continue to return here on a regular basis. The Trustees therefore thought it would be good for INSPIRE to contribute towards these new systems which would benefit the patients and help with their rehabilitation.

INSPIRE along with the League of Friends and the newly formed Southern Spinal Injuries Trust, the STC's own charity, have donated all of the forty-eight systems needed for the unit.

STC's 25th Anniversary

On the 20th June 2009, the Duke of Cornwall Spinal Treatment Centre will be celebrating its 25th Anniversary. Sadly, because of limited space entrance will be by invitation only for a small charge.

If you have not received an invitation by mid April, and you would like to go, do speak to Mrs Christine Barnes who is coordinating the event on 01722-336262 and she can let you know whether there any spare tickets.

A Couple of Recipes

Nessie Owen

Spaghetti with Prawns and Chilli **Mrs Claire Jones of Inkpen, Berks**

Serves 4 as starter 2 as main course

1 x 200g packet of frozen cooked peeled prawns defrosted
250g spaghetti
2 x 15ml tablespoons of garlic oil
4 spring onions, finely sliced
1/2 teaspoon crushed chilli flakes
200g sunblush tomatoes in seasoned oil
125ml white wine or Noilly Prat
50g rocket, roughly torn
handful of flat leaf parsley, chopped

Drain the defrosted frozen prawns and leave to one side for the moment

Put water on to boil, when boiling add salt and the pasta, and cook according to packet instructions.

Heat the garlic oil in a large pan (big enough to take the pasta later) and fry the sliced onions and chilli flakes for a couple of minutes then tip in the tomatoes with their oil and the prawns.

When both are warmed through, add the white wine or Noilly Prat and let bubble up. Add the rocket and stir until wilted a little.

Drain the pasta when ready, reserving 125ml or so of its cooking liquid, and toss the drained pasta in the chilli-prawn pan.

Turn out into a large warmed serving bowl and toss everything again so that all is combined, adding a little of the cooking water if needed and more oil or garlic if you want.

Sprinkle with the chopped parsley and serve.

BANOFFEE CHEESECAKE

I discovered this scrumptious recipe in *Delicious Magazine*, very good indeed!

Serves 8-10

Takes about 45 minutes to make, plus chilling overnight. Any remaining toffee sauce is great served warm over vanilla ice cream and bananas.

70g/ 2 ½ oz unsalted butter, melted
3 teaspoon powdered gelatine
100g / 4oz wholemeal biscuits, broken
1 vanilla pod, split
2 eggs separated
75g / 3oz cater sugar
225g / 8oz mascarpone
300ml double cream, lightly whipped
2 bananas, sliced
50g/2oz toasted flaked almonds

For the toffee sauce

142ml carton double cream
75g / 3oz unsalted butter
150g / 6oz brown sugar
1 teaspoon vanilla extract

Use a little melted butter to brush the base and sides of a 20cm springform cake tin,

Line the base with baking paper. Dissolve the gelatine in 2 tablespoons of hot water. Set aside. Crush the biscuits in a food processor. Combine the rest of the butter with the biscuit crumbs and press into the base of the tin. Scrape the seeds out of the vanilla pod. Put the egg yolks, two-thirds of the sugar, mascarpone and vanilla seeds in an electric mixer and beat until pale. Add the gelatine and whipped cream.

Beat the egg whites and rest of the sugar in a bowl until stiff peaks form, then fold into the cheese mixture. Spoon over the base, then refrigerate overnight.

For the toffee sauce, put all the ingredients in a pan over a low heat, stirring to dissolve the sugar, increase the heat to high and cook for a further 2 minutes. Cool, then chill overnight with the cheesecake.

Put the banana slices on top of the cheesecake and serve drizzled with the sauce and sprinkled with almonds.



Smiling



Smiling is infectious
You catch it like the flu
When someone smiled at me today
I started smiling too
I walked around the corner
And someone saw me grin
When he smiled I realised
I had passed it on to him
I thought about the smile
And then realised its worth
A single smile like mine
Could travel round the earth
So if you feel a smile begin
Don't leave it undetected
Start an epidemic
And get the world infected



The Editorial

We in Britain, are so lucky with our seasons. They may go a little haywire at times probably because the jetstream is not, the Met men tell us, in the right place. But I think that of all the seasons, there is little argument that Spring is the one to which we all look forward for all the obvious reasons.

To all of you who wonderfully deluged us with Christmas cards many with lovely messages of support, thank you very much indeed. Those of you who have been to the office will know how small it is and with all the cards there was very little standing room for them. We do very little in terms of decoration but the cards did the job superbly.

I mentioned on page 7 that the Spinal Unit here in Salisbury is having a face-lift. INSPIRE is contributing to that but I thought that I would share with you an observation that I have just made. It is not meant as a criticism of the organisation but as an example to show how blind one becomes to the fact that some people use wheelchairs. In all the lavatories, we now have new bins to dispose of our towels. These bins are smart with a silent closing lid which when closed is flush with the top surround so you cannot open the lid by hand (all part of infection control); it has a large capacious opening which cannot be missed when casting the offending towel and it is all operated by a foot pedal!

If you read the Newsletter from front to back, you will have passed Julie Esnouf's tribute to Trevor Parfremont. In the short time I knew him, he came across as a fun person with a wonderful sense of humour. After he received his *Freehand*, he made INSPIRE his personal charity and held many a fundraising event in aid of INSPIRE. It greatly saddened me when Mother Nature conspired against me and many others and prevented us from attending his funeral. I can only echo Julie's sentiment, "*He will be greatly missed*".

I am grateful as always for the contributions from Nessie, Jack and Alan. They are always worthwhile even though Jack does push the boundary just a bit, but then he wouldn't be Jack. In Nessie's case her contributions are without doubt mouth-watering. Have any of you tried her recipes? Do let us know, feed back is always useful. Alan's contain wonderful gems of local lore that encourage one to go out and investigate.

If you want to contribute to the Newsletter, please do so, providing of course that you accept that the Editor's decision is final! Photographs add colour and break up the text but please send by email to inspire@freeuk.com.



A Letter from America



Well here we are again and in the middle of deciding if any economy in the world is capable of sorting out its monetary problems. When I get tired of listening to our President talk, (albeit most eloquently) about doom & gloom in an ongoing series of speeches I go to my trusty computer and pull up the London Telegraph for a little light relief – oh, oh, big mistake - clearly there is little there to cheer up yours truly. I click off that website and switch back to the U.S. of A 'bloggers' who are torn between thinking President Obama is still a neat sort of guy and very reluctantly recognizing the enormity of the multi-trillion expenditures which are stated to be equal to all the money that the U.S. government spent in the last two hundred years!!!!!! The extraordinary thing about all this is the fact that even if every voter declared the plan to be rubbish there is no means to reverse it. Ah well, since I am a retired wrinkly, I have no job to lose. Of course that will not stop the necessity of either reducing the amount of, or putting more taxes on, my pension.

Despite the foregoing remarks I tuned in to the President's TV speech given (Feb 24th) before the entire Congress, Supreme Court Judges, Heads of the Military etc, etc. I can now hear Robert saying "that's enough already with the



The Dirty Dozen

political stuff!" so I will see if I can bore you good folks with something else.

As you well recognize, Christmas 2008 is long past; valentine cards and gifts have already been dispatched to grandchildren and, may they be forgiven, stores are already displaying Easter eggs!!!! Our "Twelve for the Christmas holidays", which I mentioned in my last letter was a big success. The three sub-families each received mini cameras which now sit a-top our respective computers so we are now able to see and talk to each other rather than using the regular telephone.

Sleeping arrangements were somewhat chaotic, my son in law actually slept outside on our covered porch (he was grateful for the mild weather). The three little ones shared an air mattress on the floor of our bedroom and, wouldn't you know it, yours truly got up in the night and

tripped over the sleeping angels. They, of course, were totally oblivious to the expletives and groans which I gave as I crashed to the floor! I suppose this event might have led me back into the main living room except for the fact that I knew that both settees and one more blow up mattress were occupied by some of the older visitors. I suppose the vast amount of goodies left when all the troops departed was a tasty and much appreciated bonus for Grandpa Jack. Once again, "Enough already".

Julie and I send you our best wishes for an uncertain 2009

Tables Sales

Arranging Table Sale dates is becoming increasingly a challenge. The best time for table sales for us is during the winter half of the year. During the summer half we are concentrating on other matters such as audits, charity polo and AGM. The best time during the winter half is on either a Tuesday or a Thursday because these are these are clinic days. Not only do we get overflowing car parks but we also have a large number of people going past the table. The trouble is, every other charity knows this, so we have to book well in advance. The last time I did this, the coordinator complained that she had not yet got her diary for the next year!! The downside for this "thinking ahead" is that without the benefit of foresight there is real risk of having to cancel a date, which we have had to do on a number of occasions last year and already once this year.

Anyway, the dates for the tables sales and market stall this year, cancellations not withstanding are:

26th March
28th April - Market Stall
15th October
29th October
17th November
24th November
3rd December
15th December

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Send us an email to inspire@freeuk.com to request the newsletter on line

Postcard from the Seaside
by Alan Dommett

“Have we ever been to Dancing Ledge?” asked Marion recently, raising her head above the book that prompts the enquiry in the first place and which happens to be Sheila Hancock’s autobiography. “Not sure that we have” I replied adding, in an effort to pinpoint the beauty spot’s position between two places we both know, “I think it’s somewhere between Kimmeridge and Swanage and is famous for something or other.” Curiosity soon got the better of me, however, because on that very day Robert’s e-mail reminder for this postcard arrived and I thought it would make for good subject matter.

My stab at location proved close enough and Dancing Ledge turned out to be part of the Jurassic coast in the Isle of Purbeck with the ‘Ledge’ being a flat area of rock at the base of a small cliff just west of Swanage, so called because the stone cut out of it is the same size as a ballroom dance floor. At the beginning of the last century a swimming pool was blasted into the rock for the use of local schools (the sea itself is dangerously deep right up to shore) and the last of these, The Old Malthouse in Langton Matravers, was closed only two years ago.

Sheila Hancock’s experience of the area was a wartime one when, as a nine year-old she stayed nearby with a friend and once went for a midnight swim, risking life and limb to descend the steep rock face by using a rickety iron ladder. She remembered having no fear at the time, but the ease of recollection and subsequent vivid description in her book marks the event down as an exciting adventure as opposed to a cautionary tale. With this in mind, together with that notoriety thought referred to above, I delved a little deeper and had my own memories jogged along the way...

Apparently the cliffs above the ledge are well known to climbers, with a ten metre high one being close to the sea, making it a popular spot for diving and what is euphemistic known as ‘tomb-stoning’ - the practice of jumping into the sea from a cliff and entering vertically straight. It is a short, but perilous jump from this supposedly safe area to Bournemouth Pier, another high point along the coast from which a fellow patient of mine at Oddstock had launched himself nearly twenty years ago and, even though the thread linking a beauty spot, biographical memories and a hospital bed may not be obvious to everybody who reads this postcard, I could not fail to make the following observation.

When you are a schoolchild, protection from risks is paramount, whereas outside of school hours they are taken and are all too often not seen at all. On reaching the so called age of responsibility many then choose to take risks and revel in such activities as extreme sports, but it is only with hindsight, when older and wiser, that the tales are told, the biographies are written, and an accurate assessment can be made of just how close you got to the various ledges in life.

Alan Dommett (C6/7)

Acknowledgements & Notices

In addition to thanking the Trusts, groups and individuals listed below, who have donated £25 or more to INSPIRE, we would also like to thank other members and friends, too numerous to list, who have supported us since our last newsletter went out in December 2008. In addition many others donate once a month and their annual total exceeds £25. Finally, there also many who gave or pledged to give either before or on the day of our Charity Polo over £5,500. To you all, thank you very much indeed.

Nadezhda Kopytina

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Buckland Charitable Trust

Mr & Mrs JR Regan

Mrs M Wellstead

The Norman Family Trust

Rowen Bental Charitable Trust

Mrs M Sennitt

Mr V Perkins (collecting box)

In Memoriam

We have received donations in memory of:

Mrs I Horner,

Mr K Mortimer

Adrian Hounsome

Deaths

Mr T Parfremment of Lowestoft

Mr K Mortimer of Chippenham

On behalf of the Trustees and members, our condolences go out to their families and friends.



THE INSPIRE FOUNDATION

INSPIRE - INtegrated SPInal REhabilitation.

Registered Charity No 296284



OBJECT

To promote research into, and the development of, electronic, mechanical and medical aids to assist the mobility and enablement of people suffering spinal cord paralysis and its associated effects and to communicate the useful results of such research.

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* Denotes Spinal Cord Injured

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Sort Code: 16-31-12, Account Name: The INSPIRE Foundation
Account No: 10274311

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