

# Members Newsletter March/April 2016

This is our new members area of the Newsletter.

Designed to keep you in touch with matters important to you.

# YOUR REVIEWS

You may have been asked recently to attend for a "review" with one of the Physiotherapy

team. We are gradually working our way through all our members who attend our classes so we can see if they have any issues or problems that we may be able to help with or advise on. The session will take less than an hour and will aim to look at your current abilities

including your walking and exercise plan. It's useful if you wear comfortable loose clothing and bring with you any relevant information e.g. your prescription slip so we can see what medication you are taking. If you use any splints, walking aids or FES make sure you bring them too. It is worth thinking beforehand what problems you may be experiencing or what things you find difficult. It's so easy to forget when you are put on the spot. We will advise

on or update your home exercise plan and may take simple measurements e.g. walking distance and speed so that we can monitor your condition. Our aim is to offer this on a yearly basis. You can of course ask at any time if you have an issue that you would like to discuss with a Physiotherapist but these reviews are the ideal opportunity to talk through any issues you may be having.

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#### TUESDAY AFTERNOONS

Some of you may already be aware that we offer slots for Musculoskeletal Treatment and Complimentary Therapy on a Tuesday afternoon. As therapists we all have different skills. Reiki, Reflexology, Myofascial release... to name but a few. If you think you may be interested then ask your therapist about these sessions and what

may be of most benefit for you. They need to be booked in advance and we ask for a donation which should be given to Jackie for each session.

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# NUTRITION MATTERS

Mike is running classes looking at nutrition. Small classes will run over three consecutive weeks. If you think you would be interested please ask your therapist or Jackie for further information.

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#### EASTER HOLIDAY CLOSURE DATES

The Samson Centre will be closed from Friday 25th March to Friday 8th April inclusive. Oxygen Therapy will continue throughout this period and also be available on Good Friday but not on the Bank Holiday Monday 28th March.

#### **BALANCE**

Some of you may know that Linda completed **Postural** Stability Course last summer which has helped delivering classes that focus on balance. There are two each week-Monday 12pm and Thursday 11am.

There are many factors involved in maintaining balance, particularly flexibility, strength and power. Balance can be trained. Think how a gymnast hones their balance and as such it can help to practice activities that put demands on our balance in a safe environment. The MS Trust produce a helpful leaflet you may like to look at. It can be downloaded from their website and is called Falls: managing the ups and downs of MS.

Providing therapies for MS sufferers in Surrey and surrounding areas.

The Samson Centre for MS:
Charity No: 1157827
Guildford Waterside Centre, Riverside, Guildford GU1 1LW
01483 459120 www.samsoncentre.org.uk

# Phase II study of epilepsy drug shows promise in optic neuritis

Results of a small study just published suggest that the epilepsy drug phenytoin may have a neuroprotective effect and could potentially be beneficial in people with MS. The phase II trial at University College London involved 86 people with optic neuritis who did not have a diagnosis of MS. Participants took either phenytoin or placebo (a dummy drug) for three months. Researchers measured the thickness of the retina - the layer of nerves at the back of the eyeball - at the start of the trial and again after six months. Thinning of the retina is known to indicate damage to nerves elsewhere in the brain and spinal cord. The group taking phenytoin had about a third less damage to cells in the retina than was seen in the placebo group. However, there was no difference in measures of the quality of vision between the two groups. The researchers propose that these results suggest that phenytoin has a neuroprotective effect, protecting nerves from damage and potentially slowing the build-up of disability. Larger phase III studies will be needed to confirm the results of this study and to see whether phenytoin could benefit people with MS.

This research was first presented at the 67th annual meeting of the American Academy of Neurology in April 2015 and has been published this week in the journal Lancet Neurology.

Source MS Trust Website 27th January 2016.

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Study shows high doses of vitamin D may modify the immune system in MS. Results from a small study just published has demonstrated taking 10,000 IU of vitamin D appears to be safe for people with MS and could reduce the proportion of the immune cells that are thought to drive MS activity. The study included 40 people with relapsing remitting MS in the USA. Each participant received either 800 IU or 10,400 IU of vitamin D3 (cholecalciferol) every day for six months. Blood tests were performed before the study started, after 3 months and 6 months. The researchers found that for the participants taking the higher dose, levels of vitamin D in the blood increased and proportion of specific immune system T-cells which are related to MS activity decreased. The higher the levels of vitamin D in the blood, the greater the reduction in the numbers of these cells. During the study there were a few adverse events but they were all minor and the numbers did not differ between the groups. results These encouraging as it shows that vitamin D may be effective against immune system activity that is associated with MS. However the study was only a pilot study in a small number of people and the numbers of people involved were too small to detect differences in MS disease activity. The researchers are now recruiting 172 people with relapsing remitting MS across the USA for a larger trial of vitamin D supplementation, compare tο the effectiveness of 600 IU of vitamin D supplementation versus 5000 IU vitamin D supplementation at reducing MS disease activity, when added to standard therapy with Copaxone (glatiramer acetate).

Source MS Trust Website 31st December 2015.

KEEP
YOUR
EYES
PEELED
FOR THE
NEW
DATE
FOR THE
CAKE
SALE



#### MD1003

Other names: biotin, Cerenday MD1003 is a highly concentrated formulation of biotin under investigation for secondary and primary progressive multiple sclerosis.

If you would like to read the report in full either visit the MS Trust Website https://www.mstrust. org.uk/a-z/md1003

FRI 13th MAY

Quiz Night at the Samson Centre

from 7:30pm £10 per person

Tables of up to 8

Bring your own snacks Bar open!



This newsletter is published by Samson Centre for MS

All views expressed in this publication are individual and do not necessarily represent the views or policies of the Charity and its supporters



# Newsletter March/April 2016

# PLAY THE COURSE.

JOIN US FOR 18 HOLES...PLAY

YOUR PART.....AND ENJOY THE DAY



Now in its fourth successive vear our Puttenham Golf Day on Monday 16th May is a golf day with a difference. 18 holes of golf, exercise and some fun on a Summer's day on one of Surrey's fabulous golf courses. The day begins with bacon butties and ends with a two course dinner. We are hoping to make 2016 the best year so far and invite club golfers and local companies to join us in this quest. Mike Collings the

volunteer event organiser said, "I have been involved in organising this tournament since it first started. Each year it just gets better and better and this year we hope will be no exception. Whilst we are raising money for such a worthwhile charity it is certainly the golf that is uppermost on people's minds on the day. The day promises to be an extremely enjoyable one with people taking part from all over the county. So come join us for

a relaxing day of golf with the challenge of a wonderful course and some healthy competition thrown in." With the opportunity to host 22 teams of four-balls, with a shotgun start to ensure that the golf flows and we all return to the clubhouse at the same time. To take part, donate a prize or even sponsor a hole or two then please contact Mike on 01483 449551/07887 855992 or mcdcollings@gmail.com

"Since our last Newsletter we have received an incredible £150,000 donation from the estate of Virginia Water resident Dr Donald Dean. In his memory we will now refer to our physiotherapists as the Dr Donald Dean Physiotherapists at the Samson Centre for MS which is a fitting tribute to a kind gentleman who wanted to leave a legacy to continue to help others. We have also received a donation of £25,000 organised by the Rotary Club of Guildford and supported by the Rotary Foundation and the Kolkata Rotarians of Calcutta, This has enabled the purchase of an FES bike, standing frame and some new blinds. Guildford Lions Club donated £3,000 from the proceeds of their Stoke Park Firework Display. There have also been countless other donations from organisations, companies including one for £50,000, Trusts and individuals for which we are most grateful. There are our own events too and 2015 saw our best Xmas Fair yet, raising astonishing £3385.

> Martin Dent Chairman

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### On a very personal journey with Chris Boys

# "A man on the right track"

When Chris admits to having been a self-confessed car enthusiast from childhood you could be forgiven for thinking that the person we are talking about is a petrol head with a need for speed. "I knew all the makes and models from an early age and soon began tinkering with my father's vehicles and I suppose it just grew from there" reflects Chris. Indeed the passion soon developed into a career and his own business in vehicle mechanics and restoration which he ran successfully alongside his older brother. It is this inquisitive mind

and attention to detail that has served Chris well throughout his life. Some twenty four years ago, aged 37, Chris began suffering from an enduring headache which just wouldn't go away. "At the time, I feared the worst and hoped for the best outcome" Chris vividly recalls. "Being diagnosed with multiple sclerosis was actually a relief at first" he continues. That said, Chris was unprepared for what was to follow. "All down my right side there was the constant sensation

of pins and needles. This would often result in my right leg collapsing from under me. From diagnosis the progression of the disease was gradual and I battled with fatigue and the increasing need for mobility aids. In time I had deteriorated and went from using a walking stick to needing crutches and then finally needing to use a wheelchair. There is no doubt, it wore me down and bouts of depression followed. I had been such an active person and suddenly found I was unable to carry on as before. It was a difficult time to say the least." For many years Chris struggled to find alternative ways to carry on in his business as well as coping with a debilitating and chronic illness until finally he had to relent and give his share of the business he loved to his brother, "For a workaholic this was difficult", he suggests. "So too was other's perception of me. For example when I used crutches people naturally assumed that I had broken my leg and then you have to go into the whole ritual of explaining that it is not the case. However, you do learn to adapt and after I stopped working with my brother I started a part time "Sign making" business to give me a purpose and something to focus on." But just as Chris had taught himself how to fix cars unknown to him he was one day going to set about learning what actions he could take to make repairs to his own body. Chris came across the Samson Centre for MS through a chance encounter. Fortunately for him Carol Kitching, a Samson Centre for MS volunteer happened to be organising one of her charity collection days on the high street in Dorking. Upon noticing the wording on the blue collection boxes, Chris immediately made enquiries. A few days later he joined the Samson Centre for MS and immediately grasped what it could offer him with both hands. "From the day I first walked into the building in 2013 three stone heavier than

# Run the Course for Samson. Run the Vitality British 10K race in London on July 10th, 2016

With 30 places that we originally had for this exciting event we are now down to just four places remaining. This is an exciting race as not only does it cover part of the London Marathon route it is staged on one of the world's greatest road

race routes winding through the heart of central London. Starting at Piccadilly, and passing many of the capital's historic landmarks including the Ritz, St James Palace, Trafalgar Square, St Pauls Cathedral, the London Eye, Big Ben, the Houses of Parliament and Westminster Abbey before finishing at Whitehall. All we ask is that you raise £200 in sponsorship and your place will be guaranteed along with your Samson Centre for MS running vest.



# VOLUNTEER OXYGEN OPERATORS NEEDED at the Samson Centre Training given

For further information contact Jackie Payne

cont. on back page

I am now through lack of



Olga, the renowned Russian-born concert pianist will play, talk about her life, memories and music and will be joined by some interesting guests along the way

> from Bach through to Elgar and, in between

some classical and some simply popular arrangements

Ticket price: Adult £15



Ticket price: Student £7



centre for MS

Tourist Information Centre 155 High Street, Guildford

www.visitguildford.com Tel: 01483 444334



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orTicketSource

www.ticketsource.co.uk Tel: 029 2071 3200

Supported by a grant from Novartis Pharmaceuticals UK Ltd

# Our Lottery is YOUR LOTTERY T

..help us to encourage friends, family and work colleagues to join our £25,000 weekly prize draw and we could ALL WINNERS. Slowly but surely our player numbers are growing and our lottery is gathering pace. Not only is there a one in

63 chance of winning a cash prize but the Samson Centre Lottery is not restricted to people who use the Centre. Anyone can play our lottery. For every £1 line sold 50p goes towards helping the Samson Centre for MS to provide more help to people living with

multiple sclerosis in Surrey. It couldn't be easier to take part. Simply fill in an application form or visit http://www.samsoncentre. org.uk/samson-centrelottery/.Help us to spread the word and get as many players as possible to join our lottery.

# A PIANN CONCERT

with a twist...... Russian-born concert pianist Olga Bobrovnikova travelling to the UK to perform at a "one night only" concert at the Holy Trinity Church in Guildford, in aid of the Samson Centre for MS. This event which takes place on Saturday the 30th April has been kindly organised by the Rotary Club of Guildford. Olga Bobrovnikova, herself an MS sufferer has put together a fabulous programme entitled "A Magical Session with Olga Bobrovnikova", which will see her beginning with excerpts from Tchaikovsky's 5th & 6th Symphonies and taking us along a musical journey with her that will include pieces from many famous composers including Bach, Haydn, Mozart, Elgar. Grieg, Rachmaninov and Joplin before completing performance her with Khachachurian Shostakovich's Masquerade Jazz Waltz. Olga has already visited the Samson Centre to see for herself the incredible work that we do and it has only served to inspire her to assemble a most amazing and powerful recital on our behalf. This special concert has a twist and in between performances Olga along with other inspiring quests will be being interviewed by the evening's compere Dr Mary Baker MBE. This wonderful lady is Past President of the European Brain Council and President

of their "Year of the Brain."

#### cont. from page 2

mobility I might add, I have never looked back". It is a bold claim and one that is evident from my own eyes. Chris sits comfortably on the settee beside me. The only outward sign of a mobility aid is a walking stick. He looks younger than his birth certificate would suggest. He appears lean, fit and with a healthy glow about him. "I have had an unbelievable support network behind me here. With physiotherapy and exercise I have come a long way. It hasn't been like pulling out of the pit stop in pole position at Brands Hatch but a slower, more gradual acceleration to where I am today. I have been able to move forward at my own speed as this was never going to be a race but a test of strength and endurance both mental and physical. Along the way I have been given support and guidance about how to get the best out of my body. But I have also been lucky and my body has responded well. With multiple sclerosis no two people will have the same experience. It is an individual disease and a personal journey and you don't know how your body will react". Part of that support included advice on the wearing and fitting of an FES (functional electrical stimulator) which is a control box no bigger than a pack of cards that Chris wears. This clever, concealed device sends small electrical impulses directly to the nerves in muscles that have been affected by the disruption in the nerve pathway to and from the brain, ultimately caused by the multiple sclerosis.

Chris trains three times a week and works in circuit training and indoor rowing alongside his physiotherapy other exercise programme. It was during one of his sessions on the rowing machine that Robert Hall a rowing coach noticed his natural stroke and invited him down to the river on a Friday morning to have a go at the real thing in an adaptive rowing boat. "That was it, I was hooked" beams Chris. Now I can immediately see traits of the boy racer. The engine is on and he is about to hit the throttle. "The Friday morning sessions are for people with disabilities and I love every minute of them. I am also keen to encourage others and help out with training some of the junior members. It is a great way for young people to overcome anxiety issues and to gradually build their confidence and realise that there is nothing from preventing them from moving from juniors into seniors and integrating with able bodied adults. I can't help but ask whether he will ever consider rowing competitively and Chris smiles "I already have!" We end our conversation there and I look over and his wife Sandra is waiting in the wings. She has been busy helping out by making teas and coffees and herself aptly demonstrating what the Samson Centre for MS is all about - people not only helping themselves but people helping others too.

STREET COLLECTION VOLUNTEERS ALWAYS MEEDED

### DAME ANN MURRAY

## singing for the

# Samson

## Centre

On the 23rd June 2016 Dame Ann Murray, the world renowned opera singer will be singing at a concert for the Samson Centre. She will be accompanied by acclaimed concert pianist in his own right, Timothy Ardern at King Edward's School in Witley.Event organiser Denice Logan Rose said "the concert is causing great excitement as Dame Ann's distinguished career sees her performing at some of the finest opera halls in the world. To think that she will be singing for us is simply amazing. We too have King Edward's School to thank as they are kindly providing the venue for this concert are themselves and going to be adding to the evening's entertainment. This promises to be a most spectacular event."



# SAVE..... THE DATE

.....at a glance

Sat 23rd April 7pm - 11pm

#### **QUIZ NIGHT**

Önslow Village Hall Guildford

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Sat 30th April 7:30pm - 9:45pm CONCERT

by renowned Pianist

Olga Bobrovnikova

Holy Trinity Church Guildford

\*\*\*\*

Mon 16th May Shotgun start 1pm

#### GOLF DAY

Samson Golf Day

Puttenham GC

\*\*\*\*

Thurs 23rd June 7:30pm - 9:45pm

#### CONCERT

by Opera Singer

**Dame Ann Murray** 

King Edward's School Witley

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This newsletter is published by Samson Centre for MS

All views expressed in this publication are individual and do not necessarily represent the views or policies of the Charity and its supporters