Issue 19

## Run for Patients by Patients

Autumn 2015

#### Welcome to our Autumn Newsletter





#### Keeping you informed

Autumn marks the transition from summer into winter. Nights become noticeably earlier and temperatures cool considerably. Autumn is associated with Halloween, bonfire night, the end of the summer holidays and the start of the new school year.

What else do we associate with Autumn:-

The weather changing, leaves turn different colours and fall to the ground

Birds fly south for the winter, animals hibernate

Harvest festivals show thanks for the food grown on the land

Berries appear on the hedgerows, fields are ploughed and crops set



Flu injections, looking after our general wellbeing and keeping warm.

Embrace this season and all its offerings in abundance. Take good care-be safe-supportive to others-get out and about –stay connected.

Next CPSG meeting on 18th September 2015—Presentation by TGA Mobility

#### THE COCKFIELD SHOW 2015

Clipt Bushes Smithwood Green Cockfield IP30 0JG

(On A1141 between Cockfield and Lavenham and will be clearly signed)

Sunday 13th September 2015 from 12 noon



Admission £1 children under 16 free

A village show, farmers market and fete a variety of activities, stalls and entertainment for all age ranges.

**Positively Crafty** are having a homemade produce/ handmade craft stall at this event—we look forward to seeing you there.

To coincide with **Bury St Edmunds 12th Annual Christmas Fayre**, a gift and craft fair will be held inside Cornhill Walk Shopping Centre in aid of the Soldier's Charity. There will also be a Santa's Grotto and café selling refreshments plus a selection of stalls selling locally produced materials or food and other charity stalls. **CPSG** is having a stall at this event on **Saturday 28th November 2015 from 9am to 5pm.** Please come along and give your support. Donations and volunteers are always welcome at these events.

Bringing People Together

Supported by West Suffolk



#### Patient Revolution Event run by CCG at West Suffolk House, Bury St Edmunds 15/7/15

This annual event generated fantastic feedback, debate and ideas that will be used to shape healthcare commissioning over the next year. Two members of CPSG attended this one and each one raised their own question which received feedback from the individual groups that were formed for each question put forward.

CCG are now working to address all the points raised on the Bury St Edmunds day event and will feedback in 6 months detailing how they have delivered against them. Newmarket and Clare held similar events.

#### **Question 1 by Debby Sinclair**

How can we get GPs to promote patient led support groups? We have a lot to offer and most long term conditions will end up with an element of mental health because people have led no support.

- How can GP practices promote patient support groups for patients with long term conditions?
- Specific to the condition
- Patient diagnosed with a long term condition often suffer with mental health problems due to feeling isolated
- Groups exist but are not routinely signposted by GPs.
- GPs do not always listen and make assumptions
- GPs should communicate with respect

CCG meet with surgeries on a bi-monthly basis. A Circo representative has said he will ask for this to be an item at GP-CCG meetings. Debby said it was her belief that practice managers were the greatest problem because they yield too much power over GPs in practices. It should be the medical staff making the decisions about patient needs because practice managers have no medical training and therefore do not understand the value of these support groups and how much they can actually save GP practices and the NHS as a whole. Whereas the doctors have a greater understanding of how important support is for chronically sick patients but do not have the time to offer that support themselves and would encourage their patients to join patient led support groups. If only the practice managers gave them the chance by making the literature available to them to pass on to their patients.

#### **Question 2 by Joan Gaye**

#### Why is it so difficult to get alternative therapies through GP surgeries for patients with long term conditions

#### (if they do not wish to go down the medication route)

- Acupuncture—Chronic Pain
- Mindfulness
- Evidence base
- How to refer to access treatment
- Role of Support Groups
- Empower the individual

The alternative therapies discussed were Acupuncture, Mindfulness and different forms of massage. Joan was asked by other members of the discussion group what the benefits of alternative therapies for the patients and the NHS as a whole would be. Joan explained that alternative therapies are more holistic, treating the whole person other than treating the specific problem, they also tend to have less side effects than medication. In the long run they may save the NHS money but that to ensure quality GPs would have to ensure that the practitioners were professionally trained and registered with professional bodies. At this point time ran out which prevented discussion with CCG as to whether they would promote alternative therapies to GPs.

#### CCG really do act on the views and opinions of local people—Your voice can be heard!

#### CCG thank the members for their involvement in helping to deliver the best of health for West Suffolk

\*CCG Governing body meeting in public—this event is happening on 30/9/15 at St Edmundsbury Cathedral from 9am. There will be free tea and coffee and a great opportunity to talk to GP's and CCG. Why not go along and have a chat over a cuppa!



Bringing People Together

### Run for Patients by Patients

#### Party in the Park Sunday 19th July 2015—Bellevue Park Sudbury



Funds Raised in total = £91.75 CPSG = £49.40

Positively Crafty = £42.35

A free family fun day out from 11am to 9pm that was a huge success and enjoyed by all who attended.

CPSG's stall was sited in the garden.

In the Arena—Samba, Children's entertainer, Jive dancing, Fitness, Kung-Fu, Hula Hoop, Football drills and more.

Other Attractions—Bungee, Trampoline, Magic, face Painting, Bowls, Golf, Climbing Wall, BMX Track, Circus Skills Workshop, Charity Fundraising Stalls and Refreshments.





Charity Fundraising Stalls and Refreshments. Live Music from 5.15pm—9pm. Next year's date 27/7/16.

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#### Income and Expenditure from June to September 2015

June Income—Car Boot sale Fordham = £63.15 Clothes Sales £18.20

June Expenditure—Group Insurance = £125.10

July Income- WSH =(CPSG) Raffle£13 Coffee £6.50 Donation £5 Table Sales pm £4.15 (P/C) Table sales am £33.60

**July Expenditure**—Group phone top-up = £20

August Income – Car Boot Sale Fordham = £53.20 Easy Fundraising £22.30

#### Positively Crafty Opening Evening at WSH on Tuesday 7th July 2015

On Tuesday 7<sup>th</sup> July 2015 a craft evening was hosted at the Education Centre West Suffolk Hospital.

The purpose of the evening was to share expertise related to different crafts that can be used as a distraction to chronic persistent pain. There is evidence to suggest undertaking crafts has a positive and beneficial effect.

Some of the crafts exhibited were Knitting, crocheting, card making, deco patch, glass painting and needlework.

Although the event was not as well supported as had been hoped, it was a very pleasant evening and those who did attend found the demonstration of the crafts inspiring. The refreshments were very tasty! It is always a pleasure to attend CPSG events as the cakes are yummy.

A raffle was held and the prizes donated were greatly appreciated.

#### Funds raised totalled £52.70 = Raffle £29 Donation £10 Sales £13.70

These funds will go towards the new Positively Crafty publicity.



Bringing People Together

## Run for Patients by Patients

Positive Steps Presentation by Sam Reid—10th July 2015 CPSG meeting at WSH



Hi I am Sam Reid the Falls Prevention Exercise Co-Ordinator for West Suffolk and we are setting classes up all across the county to provide clinically proven exercises that help prevent falling by up to 37%.

#### What is 'Positive Steps'?

Exercises based around a chair, specific movements to strengthen legs, attention to good posture and balance activities, a positive approach to staying independent, and professional qualified instructors who assess your needs.

Have you had a fall?

Have you lost the confidence to go out as much?

Do you find it difficult to get up from a chair?

The good news is that many falls can be prevented if you stay active and include the exercises that challenge your strength and balance.

Positive Steps can be found in over 28 locations in West Suffolk every week, and classes run all year round to find out more please call:-



## Sam Reid 01284 757758





Self Care week is an annual national awareness week. The theme this year is 'self care for life' raising awareness of how people can be supported to be healthy all their life. Choosing healthy options that will impact positively on physical health and mental wellbeing, taking care of minor ailments at home and understanding how to manage more serious conditions. For more information visit their website.<u>www.selfcareforum.org/self-care-week-resources/</u>

A **big thank you** to all of you for your support and contributions to the raffle. Please send your articles and suggestions to the contact details below. You can find the in-depth articles on our website <u>www.chronicpainsupportgroup.co.uk</u>

Bringing People Together

Lorraine Ayling Tel: 01284 701652 Email: <u>lorraine@aylingonline.com</u>

Next meeting 18 Sept West Suffolk Hospital





WE ARE CANCER SUPPORT





East of England Strategic Clinical Networks

ATTENDANCE IS

REFRESHMENTS

PROVIDED

# Learn & Share Event

For members of support groups & volunteers affected by long-term conditions 28th October 2015, 9.30 - 16.00

Weston Homes Community Stadium · Colchester United Way · Colchester • Essex • CO4 5ZD

Following the success of last year's Learn and Share event we would like to invite you to the 2015 event.

The East of England wide event is for members of new and existing support groups and individual volunteers.

All are welcome to come together, share best practice and showcase the great work taking place across the region.

#### Keynote speakers

Mark Sutcliffe MBE, Former British Army Sergeant, Overcoming Adversity and Disability

Dr Tom Nutt, CEO, Healthwatch Essex

#### Workshops

- Sourcing advice and emotional support for people with long-term conditions
- Revitalise your group! How to attract and retain new members.
- Music in Our Bones: singing and its effects on mental and physical well-being
- Ronnie Gardiner Method: fun. multisensory stimulation to improve mood
- Learn from ActivLives supporting people of all ages to make positive life changes

Return/request a booking form to Email: learnandshareevent@gmail.com Post: Learn and share event, 8 Atlantic Square. Station Road, Witham CM8 2TL Or telephone Jo Cloughton, Regional Support Officer, Diabetes UK on: 01376 501 390

To find out more or if you are interested in attending please contact Yemi Apampa Macmillan Involvement Co-ordinator on 07711 593300 or email: yapampa@macmillan.org.uk This is a free event including lunch and refreshments,

## **Disability Focus**

## The Suffolk Joint Diversity Working Group, Avenues East and the Suffolk Consortium

would like to invite you to take part in a day of lively discussion and debate about disability in Suffolk

## Tuesday, 27th October, 2015 At 10am to 3pm at

One (centre of learning) Scrivener Drive Ipswich IP8 3SU



This is your chance to tell our local councils, the NHS, the Police and other statutory organisations about the issues that concern you or your organisation, so do come along and have your say. All individual disabled people, family carers and disability organisations are welcome.



## Lunch and refreshments will be provided. There will also be a range of information stalls.

To book your place please email <u>enquiries@avenuesgroup.org.uk</u> by 16<sup>th</sup> October 2015 <u>http://www.suffolkconsortium.onesuffolk.net/</u>

This event is open to individual disabled people and their family and carers as well as representatives from disability, voluntary and statutory organisations.

Oxford University Hospitals



# Are you living in CHRONIC PAIN?

If you are female aged 18-50 years and have chronic pelvic or musculoskeletal pain you may be eligible to participate in a clinical research study

### WIPSQx

This research will look at the impact chronic pain has on female hormone levels.



In order to be considered for this study, you should.....

Have chronic pelvic or musculoskeletal pain (back, hip, knee or fibromyalgia)

Be 18-50 years old & female

Be able to spare an hour of your time?

CONTACT US FOR MORE INFORMATION



Dear Chronic pain support group, Can you help?

My name is Lisa and I work as part of the University of Oxford's Pain Research Group, <u>http://www.obs-</u> gyn.ox.ac.uk/research/pain-inwomen

We are currently recruiting for a new study called WIPSOx: Women In Pain Studies, Oxford, which is studying the effects of chronic pain on female hormone levels in the blood.

We are now recruiting women between 18-50 years old with chronic (< 6 months) pelvic or musculoskeletal (including Fibromyalgia) pain and live in, or close to Oxfordshire, UK.

To help raise awareness of the study and recruit women I would be very grateful if I could put a post on your web/support group page &/or Facebook page, or post the study poster (attached).

WIPSOx has a Facebook page www.facebook.com/ WomenInPainStudyOxford and I have also attached the participant Information sheet explains all about the study.

Please don't hesitate to contact me if you require any further information.

Research Midwife EndoPain & WIPSOx: women in pain studies Nuffield Department of Obstetrics & Gynaecology University of Oxford John Radcliffe Hospital Headley Way Oxford OX3 9DU

Lisa Buck

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