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The Bulletin

September 2011 Issue

THE NEWSLETTER FOR ARTHRITIS CARE SOUTH ENGLAND

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Pippa speaking at the AGM in June

In the period since our last Bulletin, Arthritis Care South England has been busy as usual, putting on workshops, organising family days, making presentations, writing bids for new funding and generally working hard to spread the message about all the things Arthritis Care can do to help people with arthritis.

We were particularly busy in June, with South England hosting the Annual General Meeting at the University of the West of England in Bristol. This was combined with meetings of the Board of Trustees and chairmen of the regional/national committees.

South England staff, Head Office representatives and branch members had worked hard to put together a showcase of information stands and presentations, including Helplines, New Projects, Young People's Activities and Membership. The Wells Branch pulled out all the stops and presented an absolutely marvellous display of photos and information, and one of the members had even made a special AGM cake, so thank you once again to all Wells Branch members.

For me personally, the best part of the AGM was the presentation of the South England awards, run for the first time this year. We had received a great response to our request for nominations, and each award winner thoroughly deserved their recognition. Many congratulations to Chris Knight, Terry Salter, Torbay Branch and Waitrose (see pictures below).

Pippa English-Penfold, Director of Operations, South England



Terry Salter receiving the Fundraising Volunteer of the Year Award from Rosemary Blair, Arthritis Care Chairman



Chris Knight, left, receiving the John Knight Award for Outstanding Achievement from Rosemary Blair



Philippa Grantham receiving the Branch of the Year Award on behalf of the Torbay Branch from Rosemary Blair



Tina Varns, Waitrose Community Investment Manager, receiving the Corporate Giving Award from Rosemary Blair

We are able to offer emotional and practical support through the Arthritis Care Helpline. Freephone 0808 800 4050 (weekdays 10am - 4pm) or email helplines@arthritiscare.org.uk

AGM 2011



Arthritis Care's AGM in June was hosted by the South England region this year at the University of the West of England in Bristol. There was a good turnout of people from across the UK, and an excellent showcase of information stands and presentations throughout the day.

Calendar of Events

These are just some of the many events being held across the South of England over the coming months:

21 September

Challenging Pain Workshop (two weeks), Weymouth, Dorset

21 September

Challenging Pain Workshop (two weeks), Canterbury, Kent

23 September

Challenging Pain Workshop (two weeks), Hailsham, East Sussex

28 September

Arthritis Care presenting at 'Day to Day Living with Arthritis', Portsmouth

3 October

Challenging Pain Workshop (two weeks), Guildford, Surrey

9 October

Leon Tozer running in the Eden Project half marathon for Arthritis Care

11 October

Challenging Pain Workshop (two weeks), Pimperne, Dorset

12 October

World Arthritis Day and launch of Arthritis Care's Fit to Move campaign

12 October

Presentation at Working Men's College, Camden

17 October

Challenging Pain Workshop (two weeks), Deal, Kent

17 October

Challenging Pain Workshop (two weeks), Fishponds, Bristol

22 October

Hardest Hit march, Bristol

22 October

Hardest Hit march, Brighton

29 October

The Great Spook Event organised by REACH at the Queen Alexandra Hospital, Portsmouth

30 October

Kayleigh Parks running in the Great South Run, Southsea, for Arthritis Care

31 October

Challenging Pain Workshop (two weeks), Ewell, Surrey

14 November

Challenging Pain Workshop (two weeks), Ashford, Kent

29 April, 2012

Milton Keynes marathon

13 May, 2012

Portsmouth Amble for Arthritis

17 May, 2012

Amesbury Branch's In the Pink, Devizes, Wiltshire

20 May, 2012

London Amble for Arthritis



For further information on any of the above events please contact the Arthritis Care South England office on 0207 380 6509 or email: SERegOffice@arthritiscare.org.uk

Fundraising news

Family support for Bradley



Bradley Hanson (pictured above, right), accompanied by his mum Jackie and brother Matthew, completed the Bognor 10K race on 15 May. Bradley was diagnosed with JIA three years ago, and since then has undergone a wide range of treatments and medication. He actually ran the race in 49 minutes which is amazing, and the family raised a whopping £210 for Arthritis Care!

Circling the issue



Elizabeth Walker (above left, with Sharon Kilty, Area Development Manager for the South West of England) is currently Chairman of Inner Wheel District 11, which comprises the whole of Hampshire, East Dorset, Isle of Wight and the Channel Islands.

One of her roles as chairman is to choose her charity of the year, and we are delighted that Elizabeth has chosen Arthritis Care. This means that for the

next year members across the district will be busy organising a host of fundraising events, and at the end of the year the money will be given to us to pay for invaluable services across South England.

Elizabeth was kind enough to invite Sharon and Hazel Dunnitt to her installation lunch in Bournemouth, and the two of them took the opportunity to give the Inner Wheel ladies a presentation about the essential work Arthritis Care does on a daily basis.

STOP PRESS Inner Wheel Wokingham has also nominated us to be its charity of the year, shared with Arthritis Research UK.

A trip to the shops



Our excellent relationship with Waitrose continues, with cheques from two stores being presented to us over recent weeks. These were both through the supermarket's Community Matters initiative, where each month Waitrose gives £1,000 to its branches, and shoppers are able to nominate their favourite charity to receive the money. Pictured above is Frances Boyce, Area Development Manager for London (right), with Kirstine McDowell at the Temple Fortune store. And below is Jas Bansal, Administrator for Arthritis Care South England (right), with the floor manager at Clerkenwell Waitrose.



A cut above



Jana James showing off a beautiful new hairstyle after having her long locks chopped off prior to undergoing a neck fusion operation to help relieve the pain from her psoriatic arthritis. Jana raised more than £600 from her sponsored haircut, so we would like to thank all her friends and family for being so generous.

Go Leon!

Leon Tozer, below, is taking part in the Eden Project half marathon in October to raise money for Arthritis Care South England. Leon's partner, Samantha Stevens, has had rheumatoid arthritis since she was six, and is currently waiting for a hip replacement. Leon and Samantha live in Charlton Adam in Somerset. If you'd like to support Leon take a look at his Just Giving page.

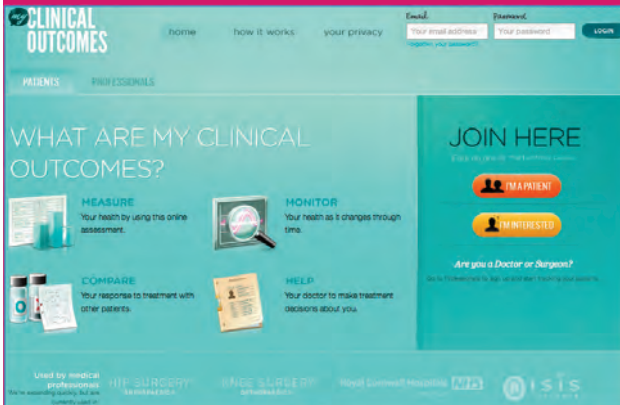


Fundraising toy story

Finally, a big thank you to Ally Keen, who has made us a selection of beautiful knitted toys (see below). We want to use these toys for some special fundraising events, and if you think that you can put one of these lovely dolls to good use, we would very much like to hear from you.



New website promises to be a boon for both doctors and arthritis patients



www.MyClinicalOutcomes.co.uk is a new, free website for those with arthritis, which allows users to measure and track their symptoms using the scores that doctors and medical researchers use.

Founded earlier this year by a South-West consultant orthopaedic surgeon, the website aims to empower patients with information about their condition, which they, and their doctors, can use to guide their treatment. Doctors can log into the website (with the individual's consent) and keep an eye on their patient's progress. This can help them make treatment and follow-up decisions.

Successful diagnosis and treatment relies on a history given by the patient, physical examination by the clinician and the correct interpretation of clinical investigations, such as blood tests and X-rays. The outcome of treatment is then usually monitored during a face-to-face consultation combined with further ongoing clinical tests.

Every step in the patient care pathway traditionally relies on the patient attending the hospital or clinic. Doctors generally only access the clinical information of their patients at such consultations or as a result of requested tests. Generally speaking, doctors do not have access to live, up-to-date information for their overall group of patients at any given point in time.

Quantifying the benefit of specific treatments or operations can be difficult and often relies on the doctor's impression and the patient's recall of events. This can be complicated if a patient sees a different doctor for follow-up, or there is a long time between appointments.

Furthermore, if doctors want to compare treatments or analyse all of their patients

with a particular condition they usually have to conduct a one-off audit of patient notes and computerised records. Not only is this time consuming, but as most clinical data is qualitative (or non-specific eg the report of an X-ray film or an examination finding), rather than quantitative, specific and numerical, it is often difficult to get a clear picture of the overall effects of particular treatments for a whole group of patients.

Still undergoing development while it is under trial in several NHS hospitals, the doctors behind the website are asking you to try it out, tell your Consultants and GPs about it, and give them your views if you think it could be improved.

The site uses clinically validated outcome questionnaires to provide a numerical score and individualised feedback about current health status. Users are asked to complete surveys regularly so that changes in condition can be measured and monitored.

Both patients and doctors should be able to benefit from the collection of such 'outcome data'. Patients are able to monitor their condition from home, track how their condition is changing over time, get feedback on the effects of treatments, and be advised when to seek further help. For doctors, the site aims to provide information about how their patients are in-between appointments, and improve the information available to them when a treatment decision is needed.

All you have to do is sign-up on the website with a few basic details, and any diagnosis or treatment information you know. If you don't have an email address, ask a friend or relative to help. Then, answer the questions which will be tailored to your condition and after that you will receive your score and feedback. You will be reminded to complete further scores to track your progress every three months by email but you can log-in to your dashboard at any time.

If you think the site could be useful, tell your doctor about it. If you have any questions, please get in touch with the website developers.

Just a few more things....

New South East Trustee

We are delighted to announce that the Arthritis Care Board of Trustees has



appointed Peter Anscombe as the new Trustee representing the South East. Peter, who comes from Pluckley in Kent, brings to the role a

wealth of experience and expertise, having a financial background and charitable trust experience. He replaces Terry Salter who stood down earlier this year after four years of being an enthusiastic and committed Trustee.

Braving the elements



Members of the Gloucester Branch set up shop on a rainy day in July, to promote Arthritis Care and the benefits of becoming a member of the Branch. Luckily the sun soon appeared, and a number of new members were recruited.

Calling all runners

We have four places available to those interested in taking part in the Milton Keynes Marathon on Sunday, 29 April, 2012. With 4,500 acres of woodlands, lakesides, parks and landscaped areas it's the ideal venue for a green marathon. All we ask is that you commit to raising a minimum of £50 to cover our registration costs. We will then send you a code to register, and a fundraising pack including T-shirt and tips on how to raise as much money as possible! If this sounds of interest please contact us.

- Thank you to the Plymouth Branch for its generous donation of £500 to support Young People's Services.
- Sheila Levene and Albertine Ngalula represented Arthritis Care at a health and information day organised for its staff by Acatel-Lucent in Greenwich.
- Many thanks to Sunrise Senior Living at Southampton who organised a fundraising Amble for Arthritis in June.