

January 2012 Newsletter

# Joint Effort

# BARC

Birmingham Arthritis Resource Centre

“A Free and Confidential Service Open to All”

### Special points of interest:

- \* BARC provides a pathway for people to access information enabling them to help themselves.
- \* BARC provides a listening / befriending service.
- \* BARC can signpost you to relevant and specialist organisations.
- \* BARC is the only such centre in the UK

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### Our Newsletter – Editors Message:

Welcome to our second edition of the Birmingham Arthritis Resource Centre’s newsletter and **HAPPY NEW YEAR TO YOU ALL!** I hope you had a wonderful Christmas. We also have a new year’s message from our chairman Professor Paul Bacon: “I hope that 2012 brings many things for BARC, the first

being simply improvement in our user numbers. Firstly use of the centre means patients and their carers, family, friends etc, are better educated about their conditions, and therefore better equipped to face the battle against arthritis. Secondly, in what are tough financial times, more

visitors and users of the centre means more funds secured, and proof that our services are valued and important to our society, both in central Birmingham and in the wider community. Expanding the portfolio of translation we provide in our leaflets and at the centre, reaching out to communities

and groups who are pushed to the sidelines of health care, and recruiting more eager and willing volunteers to keep the centre doing what it does best: offering a friendly ear, a comfy chair, and advice on living with arthritis, whoever you are”

**We are sad to announce the passing of Clive Simkins, Clive was with BARC for years, and made a huge impact on fundraising efforts for the centre. He was a positive, happy and friendly man, who had time for all, and the BARC family miss him greatly. This issue of Joint Effort is dedicated to all he did for us.**

If you would like to receive a copy of this e-newsletter or a hard copy every quarter, then we suggest making an annual subscription of £5.00 to BARC Centre. Call us 0121 464 2708 / or email us on [barecentre@bham.ac.uk](mailto:barecentre@bham.ac.uk)

## The Hot Seat

In this NEW section we ask a health care professional the questions YOU need answered! This edition passes the gauntlet to psychologist Dr Rebecca Stack, on the relationship between the body and the brain!

Psychology is the scientific study of the mind and behaviour. As a research psychologist working in the NHS, I conduct research with people managing chronic illnesses such as arthritis. I'm particularly interested in the way that people cope with their illness, and react to symptoms such as pain. Also, the way that people make decisions about their health and illness is particularly interesting to me. For example, some of my research examines what makes people decide that it is time to seek help from their doctor, while another area of my research examines why people decide to stop take their medicines. I believe that by examining the factors that influence people decisions, healthcare professionals can work with people to help them to make better and well informed choices about their illness.

### 1. Why does pain affect us psychologically?

Experiencing pain is very stressful, and when stressful situations become

permanent it negatively affects the mind.

### 2. Are those with long term illnesses more likely to suffer from a psychological disorder?

Unfortunately, Yes, stressful illnesses are more likely to cause poor mental health.

### 3. Is there anything we can do to prevent psychological distress?

Activities such as support groups, hobbies, pets or relaxation work for some people. Try different things to find the activity to suit you.

### 4. What about people who have had difficulties in the past?

People who've experience past mental health problems (before being diagnosed with arthritis) should take extra care of their well-being, and seek help ASAP if experiencing trouble coping.

### 5. If a person is worried about their ability to cope what should they do?

Speak with a healthcare professional

about the way you're feeling, they are here to help.

### 6. Many people with arthritis will be loathe to 'take more tablets' / see more doctors, and yet mental health is just as important as psychological- would you agree?

Yes, good mental well-being can reduce the pain, and positively affect physical health.

### 7. Is there any shame in admitting you are struggling psychologically?

Absolutely not, we all struggle with life's challenges and at times some people need professional help to cope better.



**Dr Rebecca Jayne Stack, BSc MBPsS  
MSc PhD, Research Fellow and  
Research Psychologist**

## Freshwinds - Free Advice Service

The outreach advice sessions provided by **Freshwinds Charity** has unfortunately come to end. Patients, their families and carers can still access free advice by contacting Freshwinds directly on **0121 415 6670**. Services available are: -

- ✓ **Welfare benefits (including support with requesting reviews and appeals)**
- ✓ **Signposting to specialist organisations**
- ✓ **Accessing statutory entitlements**
- ✓ **Debt Counseling**
- ✓ **Housing Issues**



## Ernest Carr's Story

I am 46 years old; over the last two years I have seen several different doctors in an attempt to get to the bottom of, a frightening, confusing and dramatic change to my health. I explained my suffering in various joints in my body and in May 2011 I was diagnosed with rheumatoid arthritis. My symptoms started two years prior to my diagnosis with flitting joint pain that would occur in one or both hands, this would last 24-48 hours and then flit 3-4 days later to my knees or shoulders or elbows, then I had a remission that lasted 7 months. However over the last year I have noticed that my symptoms are more constant, always there in the back ground, the duration of my 'flare ups' are much shorter but the severity is higher. R.A can steal mobility, strength and health. I worked in car manufacturing for over 26 years, I was having a lot time off of work, due to the unpredictability of my R.A., so I really had no choice but to leave. I was devas-

tated. "I do think as a man, I faced great social obstacles and lack of understanding. I have never met another man with R.A." I often long for my life before RA. I live with my wife



Rachael; she has been my rock from day one, stood by me in my times of need, my wife is also my carer. Together we have three children, Jessica, eighteen, Connor, fifteen, Rebecca, eleven. The kids asked a lot of questions

about my illness and we have tried our best to answer them. My kids have been great and they do their best to help out as best they can. My treatment started with methotrexate, but I was totally lethargic and wiped out for days at a time, there was some improvement in my arthritis generally but the side effects were getting me down, I was constantly tired.... it just wasn't the drug for me. I did try steroids but I am now taking sulfasalazine with the possibility of Anti-TNF's in the future.

It was when I found BARC that I began to understand my disease and the treatments better. They are very informative they listen and answer a lot of my questions, they also are able to spend a lot more time with sufferers than the GP or hospital can provide. The fact that I could speak to fellow sufferers in the patient involvement group BUG, (BARC User Group), was a big bonus. I went home feeling more optimistic about my future. Thank you.... BARC.

## Fundraising



Here are our wonderful team of fundraisers on their epic bike ride for BARC. Dr Karl Grindulis FRCP, a Consultant Rheumatologist, (who is Clinical Director of Rheumatology and Clinical Immunology at the Department of Rheumatology at Sandwell and West Birmingham Hospitals NHS Trust) and his motley 45 strong crew, raised a fantastic sum by

cycling over a 3 to 4 day period in Cornwall. We at BARC wish to say a huge and sincere THANKYOU!! If you want to get involved with raising much needed money for BARC to continue its invaluable work for those affected by arthritis, GET IN TOUCH-You'll be in the newsletter too!

**Total raised to date £2,700**

## Carers Corner

**I would like at this point to invite carers to get in touch with their thoughts, I will set a topic each issue-and will publish the chosen responses next quarter:**

This issues topic is - Who Cares? Who / Where have you experienced instances of best practice? With all the negative stories we so often hear, I want to publish GOOD NEWS! Get in touch!

## World Arthritis Day

**As editor of BARC newsletters, I got involved with raising awareness on October 12th 2011.**

Volunteers and staff gave out information in the main library and also invited healthcare professionals to join with us in marking the occasion, although arthritis can be an overlooked illness in our society, World Arthritis Day seems to be growing in strength and publicity year on year.

## Patient Involvement Group

BARC is pleased with the success of our newly formed patient user group-BUG. The first meeting in September last year made a positive start with ideas for fund raising, new literature, and the possibility of a patron for BARC. We discussed what we felt BARC could improve upon, and also BARCs many existing strengths. The group ideally could still use a few more members, and should anybody be interested our next meeting will be 10th February 2012, and members will become the proud owner of a BUG lady-bird badge, as well as quarterly

copies of Joint Effort. We would like people to join us by advising us on our services, helping us spread the word about the centre and, of course, to raise awareness of the disease. The group will aim to meet quarterly so if you want to be a BUG then please ring the centre. You will be helping our valuable charity in their quest for better lives for all those affected by arthritis.



Did / do you suffer with depression, anxiety, stress, eating disorders, panic attacks or OCD? Did this happen before/after diagnosis with arthritis? Are you a carer, does this have an impact on your mental health? Please let us know, your information is invaluable. If you are happy for us to include your answer in the next issue please let us know, all information will remain anonymous unless otherwise stated.

**BARC OFFERS  
BE-FRIENDING SERVICES**

**DON'T BE AFRAID, BE A FRIEND!**

To the right is a new group who have affiliated with BARC, and who hopefully will become part of our BARC User Group (BUG), they offer a wealth of support and information, and we hope to go forward with their support, to the benefit of both groups.

Tel: 0300 330 0640 for further support

**Pain Fatigue Support**  
A Wealth of Information, A Wealth of Support  
T: 0300 3 300 640 | M: 0782 1 436 759  
Mon 19.00 - 21.00 | Wed 14.00 - 16.00 | Sat 10.00 - 12.00

Chronic Fatigue, Fibromyalgia, Sleep Issues, Cognitive Disturbances, Neurological Pain, Anxiety, Stress, Depression, Musculoskeletal Pain, Chat, Support, Come and Join Us, Understanding

Venue: Erdington Methodist Church | Station Road | Erdington | B23 6TX  
1st Thursday Every Month 12.00 - 14.00  
On Site Parking

[painfatiguesupport@hotmail.co.uk](mailto:painfatiguesupport@hotmail.co.uk) | [www.painfatiguesupport.gkingofthecolts.com](http://www.painfatiguesupport.gkingofthecolts.com)  
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## Points of Interest

In the summer last year (just prior to finalising issue one) myself and DR RAZA of Birmingham University and City Hospital were on BBC Midlands Today! The piece was centred around Dr Raza's studies on late diagnosis, and how this can negatively impact upon the treatment of R.A. I explained my late diagnosis and tried to emphasize the need for quick recognition of symptoms, and the urgency of seeing a health professional, particularly for RA.



## Arthritis Research UK

As editor Arthritis Research UK asked me back in September to speak at the political fringe events for all three major parties. It was in view of a current 'hot topic' in the NHS- Personal health care budgets- and how these may affect people with long term illness/disease, such as those with arthritis. I really enjoyed the events, and although speaking to a room full of politicians and delegates was slightly nerve-wracking, I had so many positive comments, and it never ceases to amaze me how many people are utterly shocked by a young person with RA! Personal healthcare budgets are a long way from perfect, but giving the patient more money to get help outside of the hospital or GPs (i.e. massage, swimming prescriptions etc) can't be a bad thing, but where the money and administration would come from remains the big question!

## BARC

Birmingham Arthritis Resource Centre

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E-mail: [barccentre@bham.ac.uk](mailto:barccentre@bham.ac.uk)

Web: <http://www.barc.org.uk>

Barc is supported by the Birmingham Arthritis Appeal & Resource Centre (BAARC)

Registered Charity: 513900

**Mission Statement:** BARC will enable people with arthritis to have an improved quality of life and greater long-term independence through education about their diseases by promoting 'self care' and 'self-management'.

**SEE YOU NEXT ISSUE - MAY 2012! The BARC Team**