

WRSG Newsletter

WOLVERHAMPTON RHEUMATOLOGY SUPPORT GROUP

Charity No 1041181

CARING IS SHARING

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<u>Challenging Arthritis Comes to</u> <u>Wolverhampton</u>

Despite, or perhaps because of the prevalence of arthritis the disease is often dismissed by people as a natural part of the aging process.

But this assumption ignores the numerous ways that arthritis affects approx 1 in 5 of the UK population - not just elderly. But all ages.

Fortunately help is at hand for WRSG members and residents of Wolverhampton with a free Challenging Arthritis Self Management course set up by the charity Arthritis Care and purchased by the WRSG. The course is being run by two Arthritis Care members who themselves have to cope with arthritis so they have a vast experience on a personal level in dealing with the condition and are fully trained to deliver the material. Over the six week period participants will learn how to manage their arthritis more effectively by looking at many topics such as healthy eating, distraction techniques, relaxation, pain management, exercise and their relationship with health care professionals. The course provides support and understanding from being with other people with arthritis to share ideas and thoughts.

(Please contact Liz Walker 01902 563751) to book your place)

The course is being held at Linden House 211 Tettenhall Road, Wolverhampton. WV6 0DD.

Starting on Wednesday 8th February 2012 running for 6 weeks (1pm to 3 30pm) with a refreshment break. There is no cost to members and you will be provided with all material books handouts etc.

May I wish everyone of our members a very healthy and happy Christmas and New Year

LIZ

MINUTES OF ANNUAL GENERAL MEETING WOLVERHAMPTON RHEUMATOLOGY SUPPORT GROUP HELD AT LINDEN HOUSE ON THE 28 OCTOBER 2011 AT 13.00

PRESENT

GUEST SPEAKERS

Dr Dixey (Vice President) Dr Newton (President) Liz Walker (in the chair) Joyce Knibbs (Vice chair) Kath Sankey (Treasurer) Debbie Mitton Sheila Fardoe Viv Worrall Julie Hibbs Sally Giles Pat Jones

Dr P Newton Consultant Rheumatology Consultant Debbie Mitton Senior Clinical Nurse Specialist Rheumatology Sally Giles Rheumatology Clinical Trials Nurse, Cannock Hospital

1 APPOLOGIES; Paul Uppal,MP; Emma Reynolds,MP; Ruth Harper; Sylvia Horton; Balbir Rai; Bhagwant Sachdeva; Mr & Mrs Vaughan; Mr & Mrs Strodzinsky; Cecilia Pittaway; Sarah Wood; Mary Allen; Martin Peake;

Dr J Dixey; Vice President, Consultant Rheumatologist opened the meeting by thanking the WRSG for inviting him to the Annual General Meeting. He went on to say he had been introduced to New Cross Rheumatology Unit for two years and found it most impressive. He went on to say future Rheumatology groups should use the skills of users, i.e. patients. The WCPC trust is being disbanded in 2013; potentially this should be turned into an opportunity to ensure we uphold an impressive unit. Dr Dixey welcomed feedback from patients concerning the proposal to introduce Personal Health Budget to be introduced in 2014 to patients with a chronic disability, carer's at work etc to spend as they wish. He is not sure how this is going to work in Wolverhampton. Birmingham has a Resource Centre and suggested that Wolverhampton may 'mirror image' this for giving information on Arthritis in Wolverhampton. Dr Newton, Dr Dixey and all the team are committed to providing high quality Rheumatology care. There has been a revelation with new drugs and we must make sure that Wolverhampton has the opportunity to deliver this service to the Rheumatology unit.

2 Minutes of the AGM 21st September 2010

The minutes of the AGM held on Tuesday 21st September 2010 held at the Britannia Hotel were agreed as a true record at the committee meeting of the 17th November 2010. Proposed by J Knibbs and seconded by P Jones.

3 Matters arising from the minutes

Copies of the minutes were sent out to all members. There were no matters arising from the minutes.

4 Re Election of Committee 2011 – 2012

Liz Walker	Chairperson/Newsletter Editor
Joyce Knibbs	Vice /Chair/Holidays/Outings/Information Sessions
Kath Sankey	Treasurer
Sheila Fardoe	Outings
Pat Jones	Equipment Officer/Patient Representative
Bhagwant Sachdeva	Committee Member

Balbir RaiCommittee MemberViv WorrallInformation Sessions/Outings/HolidaysProposed by Anne Pengelly and seconded by Reg Jones

Election new committee member

Jan Simpson proposed as secretary by Brian Knibbs, seconded by Kath Sankey.

5 Chairpersons Report (Liz Walker)

It is with pleasure that I return again this year to present the Chairpersons report for the WRSG. I am also happy to report that for another year the group remains very healthy and active, continuing to flourish with over 160 members enjoying the benefits that stem from the original concept of supporting Wolverhampton residents who have Arthritis.

Whilst preparing to write this report I have again revisited the original broad objectives of the WRSG and whilst reflecting upon the past year I can report that the group are achieving them all and in some cases excelling due to the hard work and commitment from our committee and members

Objective: 'To support our members'

Supporting WRSG members is our main objective. We continue to work hard in order to meet this, the telephone help line is manned by Pat Jones and Julie Hibbs and myself. All calls are confidential and as far as possible we are able to refer members to the appropriate services for assistance. We continue to work closely with Health, Social and Voluntary sectors and are grateful for their continuing support.

During this year the group have finally developed the 'Buddy Scheme' which doesn't replace the help line but has proved to enhance this service. A Policy Statement for the Buddy Scheme was approved in November 2010. The scheme is constantly reviewed and I am pleased to report that it is working very effectively.

Definition of Buddy Scheme:

Essentially the Buddy scheme is a befriending service which is available for all new members of the Wolverhampton Rheumatology support Group (WRSG). Each new member is informed of the scheme and may or may not choose to participate.

Buddies' are usually established members of the WRSG who have Arthritis themselves or who have someone close to them that has Arthritis.

Individuals who have concerns about issues relating to Arthritis can discuss them confidentially with a buddy who has been through a similar experience.

New members will be offered a buddy in the first instance as a point of contact and peer support for coffee mornings and other activities that the WRSG offer.

Coordination of the Buddy Scheme

The scheme is overseen by a trustee of the WRSG committee initially myself. Members of the committee have agreed to participate. Anne Pengelly (member of the WRSG) is also involved in the scheme. It would be so nice to extend the scheme involving more members although there is growing evidence of therapeutic relationships forming among members at our coffee mornings and WRSG events.

Initially the buddy scheme has operated within carefully defined boundaries. A buddy is selected either by post code or similar interests for each new member. Essentially the buddy agrees to telephone the new member and ideally, arrange to meet them at the first coffee morning organised by the WRSG. Not all new members feel they need a buddy but if the new member wants to participate in the scheme they can be sure of a befriending relationship which is facilitated either by telephone links, emails or meeting at coffee mornings.

The boundaries of the buddy scheme are strictly defined to therapeutic relationships. The buddies are able to advise the new member, for example: benefits enquiries, equipment loans, social services and similar services. It is strongly recognised that the buddy is not in a position to give medical or social advice but to direct the new

member to the appropriate service. The buddies have a list of useful telephone numbers as a source of information and knowledge of whom to contact.

The buddy has an open door policy to contact me for support and advice. The Committee members of the WRSG provide peer support to each other and to all buddies.

Objective: 'To facilitate Education and Information Sessions'

During 2010/2011 we have organised several sessions to inform our members about issues relating to their Arthritis. In July 2010 Mary Shipway delivered an excellent session on Reflexology, October 2010 we invited a local company to demonstrate arise and motion beds and raiser recliner chairs. In February 2011 Hugh Gaskin (Podiatrist WCPCT) gave a very informative presentation of the importance of foot care. In May 2011 Sister Rowlands from New Cross Hospital talked to our members about Osteoporosis at a level that we could all understand and relate to. All of these presentations were followed up with articles for the Newsletter to inform members who are unable to attend our coffee mornings.

During this year we have secured funding through a grant from the Midcounties Co-operative Community Foundation Fund for £1500. Our application was approved to purchase a Challenging Arthritis Course from Arthritis Care UK. The course will be offered to our members and will commence in February 2012. For next year we are planning to include more member participative workshops, topics will be chosen to address members experience such as managing pain, healthy eating, mobility etc:

WRSG Newsletter.

The bi monthly WRSG Newsletter is an important vehicle of communication for our members. It is however costly to sustain. This year costs reached £913. 98. The committee are grateful for donations to the group that allow us to continue with the Newsletter. I have cut down on some postal costs by e mailing the Newsletter to those members who are agreeable. We will however continue to mail the Newsletter to all other members. We are proud to say that the 100th edition of the Newsletter was published in August this year.

I am indebted to Martin Peake who has kindly taken responsibility of managing the WRSG website www.wrsg.org.uk Martin updates the site with the Home page and contact details, Newsletter, invitations to coffee mornings, information sessions, future holidays and trips, he has also included links and information regarding Arthritis. This is a huge technological aspect of the WRSG that none of us are qualified to do, thank you so much Martin.

Thanks are also due to our professional colleagues for articles included in the Newsletter. Sister Ruth Harper for her article on Gout, Sister Jane Fairbrace for her article on the Present and Forward to the Future of the Rheumatology Department New Cross Hospital, Mary Shipway for her article on Reflexology, Walking for Health by Bhagwant Sachdeva and Sister Norma Rowland for her article on Osteoporosis. Thanks also to Debbie Mitton who keeps me informed and up to date with changes within the Rheumatology Department.

The Newsletter has also featured One Voice Disability Network, a number of our members enjoyed a Health and Fitness day at Aldersley Stadium and a free induction to the gym levelled at the individual needs regarding Arthritis and physical ability. We have even achieved members taking up Bowls at Bradmore Bowl's club due to an article in the Newsletter.

Objective: 'Sharing is Caring Social Network'

Our monthly coffee mornings held here at Linden House on the first Monday of every month are becoming more and more popular. Thanks to Joyce Knibbs who is responsible for booking guest speakers and liaising with Linden House we hope we are able to facilitate for all of our members interests. This year Joyce has booked a Christmas lunch for our members this is a first and I can report that over 70 members will be attending. Our social calendar this past year included a holiday to the Lochs and Glens in January 2011 to celebrate Burns Night, and an Aegean Cruise starting at Corfu and visiting Greece, Crete and Turkey in May 2010. In June 2011 the group enjoyed a day trip to Southport and later in the month a tour of Banks' Brewery to observe the brewing process (tasting was obligatory!) In September the group had a carvery lunch at the Mill Farm Cannock and a coach ride over Cannock Chase finishing off the afternoon with a visit to a garden centre.

Donations and Grants

We are so grateful for everyone who has financially supported the group. Monies raised from raffles, cake competitions and bring and buy sales do help with the running costs of our coffee mornings and other events. It means that we are able to maintain our membership fee at the same level of £5 for individual annual membership and £8 for family membership.

Thanks to the families of Mrs Florence May, Mrs Brenda Mullaney, Mr and Mrs Benn and Mrs Carol Boneham for their donations to the group which amounted to £1063. Our thanks to Codsall Towns Women's Guild for their donation of £510 and our thanks to Arise and Motion Mobility for their kind donation of £50.

In Conclusion

May I take this opportunity to thank all of our committee members for their hard work and to report that sadly Julie Hibbs is resigning from the committee; Julie will however continue to support the WRSG by organising and delivering the Challenging Arthritis Course in collaboration with her role with Arthritis Care UK.

Special thanks go to Terry and Kath Judd for their help with storing the WRSG equipment and to Anne Pengelly for joining the Buddy Scheme. Also thank you to husbands and partners for the invaluable help we have at the coffee mornings, Tony and Brian we couldn't do it without you.

And finally thank you to you the members for your continuing support. Liz Walker

6 Julie Hibbs gave a brief summary of the WRSG funds;

			Opening Balance 01 June 2010;
			£6454.44
INCOME	AMOUNT	TOTAL	BALANCE
Subs	650.00		
Donations	1633.00		
Equipment	0.00		6454.44 b/forward
Fund Raising/outings	1590.43		3884.95
Sundries	11.52	3884.95	£10339.39
EXPENDITURE	AMOUNT	TOTAL	CLOSING BALANCE
Postage	359.52		31 MAY 2011
Stationary	65.82		
Link Line	0.00		
AGM	385.00		
Fund raising/Outings	1078.70		
Sundries	270.14		
Equipment	100.00		
Expenses	772.50		
Travel	0.00		
Photo Copy	488.64		
Education	0.00	3520.32	£6,819.07

ANNUAL ACCOUNTS 01 JUNE 2010 - 31 MAY 2011

7 Pat Jones Equipment report

WRSG members have benefited from a scheme which allows them to borrow equipment. Over the past two years the need for borrowing larger pieces of equipment has dropped off and because of the shortage of storage space this facility is limited. However small equipment is still popular and is still available. The larger equipment needs to be moved, one suggestion is a car boot sale. However, if anyone is interested in offering a small donation for any of the following pieces of equipment please contact Mr Judd; all donations will be gratefully received for WRSG funds.

4 Zimmer frame walking aids

1 Uni-Scan walker

2 Walking sticks with moulded handles for left hand

4 Wheel chairs = 1 with a wide seat, 2 normal width and one with a stabilizing wheel missing.

1 Carl Saur exercise bike (very heavy piece of equipment)

Dr Dixey is very committed to the resource centre and Pat questioned if there was a way that the WRSG could be involved and work along with the Centre?

8 Joyce Knibbs, Vice Chair; Information Session from October 2010 to June 2011

The WRSG coffee mornings first came to Linden House in October 2010.

<u>October 2010</u>, - our first meeting was Rise & Motion beds. Members were able to try out electric beds and chairs in comfort without any pressure to buy.

December 2010 – This meeting we saw our Panto Dame, who was very entertaining.

January 2011 – The group held a bring and buy sale to boost our funds.

<u>February 2011</u> – We had a talk about Chiropody Services in Wolverhampton, how to care for your feet this included a chance to ask questions.

<u>March 2011</u> – Lots of fun and laughter from members when the Committee pinned up their baby photographs for a guess who game.

<u>April 2011</u> – David Burnell gave a talk about the origins of Waitrose. WRSG were kindly given a £320.00 donation from their charity.

<u>May 2011</u> – We had a talk from St Rowlands about Osteoporosis. This was very informative. Members asked lots of questions about the condition.

May also saw some members go on a cruise on board the Thompsons Spirit Ship to "Pearls of the Aegean". A completely perfect relaxing holiday.

<u>June 2011 –</u> Was "Bake a Cake". Members displayed their culinary talents with a variety of cakes. The sales raised $\pounds 25.00$ for the group.

Next year's holiday will be in England. We have found a coach company that takes wheelchairs, so we can include the more disabled members. But please be aware that wheel chair users must provide their own carer. If anyone has any suggestions on where to go for a holiday or who to invite to our information sessions we would be pleased to hear from you. Thank you.

9 Viv Worrell Coffee Mornings;

Since we have moved venue to Linden House for the information sessions, we have had a really good attendance, so on behalf of the committee I would like thank you all for your support.

Our maximum attendance was 56 members; this was for the Pantomime Dame last December, which I'm sure everyone enjoyed. It really got us in the Christmas spirit. Our minimum attendance was in January 2011, 29 people attended our Bring and Buy sale. I believe the weather had much to do with this as January and February we had such bad weather. Our overall average was 42 people which is exceptionally good – we must be doing something right and hopefully will continue to do so in the coming year.

I would like to say a few words about our holiday in January 2011. Sixteen of us went to Drymen, near Loch Lomond in Scotland for 5 days and had a really super time. We even managed to leave the snow behind which was a great surprise. The only snow we saw was on the top of the mountains and that is where it stayed. The hotel had log fires, after our days out it was lovely to return and sit by the fire with a hot toddy, or two! We were there to celebrate Burns Nite, (celebration of life & poetry of Robert Burns) we had haggis and neaps (Swedes) along with the rest of them. Together with the ceremony of piping in the haggis, we even managed one or two Scottish reels. The hot toddies probably helped us along, we had lots of fun and it was a super holiday.

We are also hoping to do a trip to Trentham Centre Shopping Village, gardens and garden centre. The facilities for people with disabilities are very good, everywhere is nice and flat. Push wheel chairs are available free of charge, you may be asked to leave an item for security on the wheel chair, such as keys, just to make sure you return the chair.

We will keep you advised when this had been arranged and put the details in the news letter. Also, we are hoping to go for a lunch out sometime in the year, so watch this space.

10 Julie Hibbs Challenging Arthritis Course;

I work for Arthritis Care as a trainer for Challenging Arthritis. Thanks to the donation of £1500, WRSG have purchased a Challenging Arthritis Course. The course will be held at Linden House and will run for 6 weeks, 1 day per week. Starting Wednesday 08 February 2012 at 12.00 for approx 2 - 2.5 hours. We are allowed to take a maximum of 18 people; the course enables you to take charge of your own arthritis and is open on a first come first served basis to new members and old if they feel they would benefit from a refresher. Please contact Julie Hibbs to have your name put on the list.

11 Any Other Business

Liz Walker; Most of you will remember Carol Boneham, former chair person. Sadly Carol has passed away. However her family have donated a number of her books for us to sell to help boost our funds. The books are 'Climb upon My Rainbow and Find Your Destiny' and available here today; we are asking £3.00 each or two for £5.00.

We are also pleased to present Pat Jones with a flower arrangement to wish her a belated happy 70th birthday.

We are pleased to say the books were a complete sell out at the AGM meeting.

Reg Jones; In the past anyone over 50 years of age has been able to purchase either Annual / three year Coach Tickets. These tickets then entitled the holder to have a 50% reduction on coach travel with National Express. However the Government are withdrawing funding to National Express and as a result of this, as of the 01 November 2011 any tickets purchased will now qualify you to a 1/3 off future National Express coach journeys.

Reg also reported that bus passes for anyone reaching their pensionable age is safe for the time being.

11 Guest Speakers

Dr Newton (Consultant Rheumatologist/President WRSG; Gave a welcome to everyone for attending the meeting. The Group was founded some 16 years ago and has proven to be very successful and is encouraging to have 160 members. Congratulations on the venue...

The WRSG is an important group, it is important to be heard and to make sure the voice of arthritis is listened to. Arthritis is fairly low politically and we don't want it to slip further, this group is actively involved to make sure we are heard and could even use the media. Changes are always slightly worrying; care being transferred to GP consortium, Dr's making decisions / customers with arthritis. However there have been good reports from other Health Care Centre's such as the Phoenix Health Centre. We should make sure patients are heard on where they receive personal treatment. Personal experience of care, as an inpatient is important. Hospitals say they do what the Government tell them to, but customers should be heard and listened to. WRSG is about self help and mutual help, this is a good thing and the government should be supporting us. The WRSG is doing things that the government cannot do. There are new developments in arthritis, drugs and surgery. Physiotherapy, Occupational Therapy is being neglected which is worrying, they should be preserved.

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Debbie Mitton; (Lead Clinical Specialist Nurse Rheumatology New Cross)

Thank you for asking me to your Annual General Meeting.

To update you over the 12 months, some nice things have happened, the department has been decorated. In the waiting room there is a wall ready for an art project – a panoramic view. We want patients to be involved and would welcome some input on what you would like. Please give your view if you are able.

There have also been some staff changes, we have two new auxiliaries, some staff nurse changes and the team are all motivated and keen.

The department has taken on research in the last year drug trials etc. One change is in blood tests, requests which are no longer done by hand they are all dealt with electronically. This trust is the pilot for this new scheme, and our experiences are being used to roll it out to other hospitals; the soft ware TA monitor, flags up abnormal results, it is very quick, easily accessed, along with many other things makes it a good improvement. There is now a ticket machine for patients waiting for blood tests. This prevents someone coming along and getting dealt with before patients.

The Rheumatology Department is better recognised, we now have students working in the department. We also have a suggestion / complaints box – please use it.

Liz Walker; A question on the blood monitoring – If blood abnormalities are flagged up how does the machine detect what is normal for most patients who normally always have abnormal results?

Debbie Mitton; Everyone is an individual – ranges are entered, the system then flags up what is abnormal for that person.

Sally Giles Rheumatology (Clinical Trials Nurse; Overview of Clinical Trials and Research Department Cannock Hospital.)

The department in Cannock Hospital has been going for many years and can pass on information to Wolverhampton. The unit is involved in clinical trials; the team has five consultants and many nurses. The Rheumatology ward has less in patients due to new treatment and shorter stays. The unit is linked to a wider team such as physiotherapist and occupational therapy.

The benefits to the unit of Industry trials on new drugs from bigger companies is more income and of course new drugs, having experience of new drugs when they come on the market and licensed to be used. Happy to use new drugs we have been involved in the trials. We do observation trials. 211 patients on trials are all followed up. 31 trials have recruited and are now closed. Cannock is the top recruiters for Lichfield, Tamworth, and Cannock with a population of Seven Hundred and Fifty thousand.

Trials going on at the moment include, lupus, rheumatoid arthritis and Osteoporosis

They are completely voluntary clinical trials. If anyone is interested, they are screened to see if eligible. If they are suitable then change their mind, their care is not compromised. Patients always enjoy a good standard of care. We pamper our patients, provide continuity of care and build up a relationship. Some trials go on for 6months - 2 years and in some cases as long as 5 years. Trials include; tablets, injections, drips. A variety of ways on how to administer drugs and how they work. We still use nursing skills and develop new skills in Rheumatology, Arthritis, hopefully will not suffer debilitating problems in the future thanks to new treatment and drug trials.

Close of Meeting