



WRSG Newsletter

WOLVERHAMPTON RHEUMATOLOGY SUPPORT GROUP

Charity No. 1041181

CARING IS SHARING

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Concert

We had a lovely evening at the concert on the 12th May. The Ashmore Park Choir entertained us at Fallings Park Methodist Church, Wimbourne Road, Fallings Park. The concert was well attended and we joked that it was much nicer than staying in to watch the Eurovision Song Contest! The event raised £224 for the WRSG and our sincere thanks go to Joyce Knibbs. It is not easy booking the Choir, the room, organising the refreshments and the raffle and selling the tickets. Joyce had a team of helpers and we thank them all.

Outing – Reminder

The London Eye

The trip to the London Eye is on Tuesday 12th June. We will depart from Falkland Street Wolverhampton at 9.00 a.m. and leave London at approximately 6.30 p.m. For the return journey.

Subscriptions

£5

The WRSG yearly subscriptions are due in June. Committee have agreed to keep the charge at £5 per person and £8 per couple. If you became a member of the WRSG in 2007 your subscriptions are not due until June 2008.

Remittance advice slips are enclosed with this newsletter for members whose payment is now due and a prompt response would be appreciated.

Please make cheques payable to the WRSG and send them direct to our Treasurer:

Mrs. Liz Walker

An Extra Outing

As I have told you on previous occasions I am also Chair of the Black Country Lymphoedema Support Network.

On Wednesday 11th July this group are going for a carvery meal at the Mill Farm, Cannock which is always a popular outing with WRSG members.

There are a few spare places on the coach and if you would like to join us the charge for the coach would be £3 per person with you paying for your own food as you do with the WRSG carvery outing.

We depart from The Cedars, Compton to Mill Farm Cannock at 11.00am, leaving Mill Farm at 2.00pm to arrive back at The Cedars at approximately 3.00 pm. For further information or to book places please ring Ann Jeffs

Dorothy

A History of the Wolverhampton Rheumatology Support Group

I recently read that one of our WRSO founder members, Carol Boneham had received an award for her poetry. I contacted Carol to ask if I could print the poem in the newsletter.

Carol and Diane Evans founded the WRSO in 1994. At the time Rheumatology services were located at Dudley Guest Hospital on a contract from the then Wolverhampton Health Authority. It was an excellent service providing in-patient care, outpatient appointments with Dr. Newton, Occupational Therapy, Physiotherapy and Hydrotherapy all at one hospital.

Things began to go wrong when the beds were transferred from Dudley Guest to Wordsley hospital and later with a planned move to Corbett hospital which was even further away. Carol and Diane founded the WRSO to campaign for improved rheumatology services and to support fellow patients.

At the same time I began my voluntary work. In 1994 after the death of my mom who I had been looking after I told Dr. Newton I needed to be needed. Dr. Newton told me that a support group was being formed but he put me in touch with Christine Turner who was Chair of the Wolverhampton branch of Arthritis Care. After several interviews and form filling I was appointed to Arthritis Care as a Home Visitor. A role I fulfilled for seven years visiting nineteen people in their own homes every month.

When we were coming up to the Millennium, Arthritis Care changed a lot of the roles. The Home Visiting service was scrapped and I became an Information Worker.

This was a difficult role for me as I had to distribute approximately 300 of their booklets every month to local hospitals and GP surgeries. Not a good job for someone with severe rheumatoid arthritis as it involved lots of walking and carrying!

Carol's life and mine were running parallel. I was appointed to the Community Health Council by Arthritis Care and I used this as a campaigning platform. When I attended Board meetings I would show the members my disfigured hands and campaign for improved waiting times for first appointments so that patients could get an early diagnosis and appropriate treatment thus preventing the same problems I had. This was very useful when we were campaigning for our third Rheumatology Consultant.

While I was campaigning through the CHC Carol was writing letters to everyone she could think of including the Prime Minister and even the Queen!

At this time some of our outpatient appointments with Dr. Newton had been transferred to the Royal hospital and our injection clinics were held at West Park hospital. One day I was sitting in the waiting room at West Park hospital and every time anyone came past they said "Hello Carol" "Hello Dorothy" Carol introduced herself and asked me who I was.

Carol invited me to attend the WRSO AGM which happened to be the following Monday evening. The event was held at the Woodlands Quaker home on the Penn Road. I attended and was very impressed. Carol asked me to join the WRSO committee and I agreed because I thought it a good idea for the WRSO and Arthritis Care to work together. All this time Carol was very ably supported by Diane who was her Vice-Chair.

Diane and I became very good friends. Unfortunately in those days Diane spent quite a lot of time in Dudley Guest hospital and when I went for my hydrotherapy I was allowed to go on the ward and visit Diane. Diane and Peter Evans are still members of the WRSO although Diane resigned a few years ago to devote more time to her family. Carol resigned after seven years at the helm.

Committees do change and evolve but most of the people who have left committee have remained members of the group.

Another founder committee member is Brenda Mullaney. Brenda is still a member of the group and sends us her poems!

Many years ago I received a call from Liz Walker. Dr. Newton had given Liz my telephone number because he thought we could work well together. When Liz rang Arthritis Care was not recruiting so I introduced Liz to Carol. Liz became a Home Visitor for the WRSB which was very fitting with her background as a Nursing Sister and College Lecturer in Nursing. When Arthritis Care were recruiting for Millennium Volunteers Liz became a Challenging Arthritis Course Leader. The WRSB scrapped the role of Home Visitor. Liz is of course now our Treasurer. This is a very time consuming role particularly when the 200 or so receipts have to be written for the subscriptions as well as all the in and out payments for our events.

At the same time another of our committee members, Audrey Lee became an Arthritis Care Course Leader and Liz and Audrey put on many successful courses together. Although Audrey retired from committee she is still a member of the group.

Liz later introduced two more Arthritis Care Course Leaders, Bhagwant Sachdeva and Julie Stead, to the WRSB committee. Julie and Bhagwant are also Compton Hospice volunteers. Bhagwant has brought many new members to the WRSB.

Val Dillon was another committee member taking on the role of Secretary for a time. Val is still a member of the group and Val attended the recent Information Session.

Joyce Knibbs and Sheila Fardoe have been longstanding committee members of the WRSB making sure that we have had lots of social events. Joyce resigned from committee as Fundraising Officer a while ago for personal reasons but she continued to work supporting Sheila who took over the role. That was a role reversal because Sheila had been supporting Joyce and it became the other way around.

Now Sheila and Joyce are both working hard for the WRSB members organising different events and it is working very well. I don't think we have ever had such a good social life!

Pat Jones is running our Equipment Loan Service. Pat was the Manager of Trauma Orthopaedics and Rheumatology at New Cross hospital for many years and we were very pleased when Pat agreed to join committee upon her retirement. The equipment loan service doesn't seem to be very busy at the moment and I wonder if this is because Social Services are doing a good job or if our members are finding that equipment to help with our disabilities is more readily available to purchase now. Pat is also a committee member of several other support groups and together with Irene Janos is also monitoring the rheumatology services. Irene was a committee member and has now been co-opted again

Last but not least our other committee member is Anne Green. If you know of a fellow member who is a bit down or going into hospital let me know and Anne will send a card to cheer them up.

Mary Mannion was a committee member for many years and still continues to fund raise for our Equipment fund. Mary and Ken usually attend the events and it was good to see them at the Information Session in April.

Of course you do not have to be on the committee to support the WRSB. We have several members who donate raffle prizes on a regular basis and I must mention Kath and Tony, my next door neighbours. Kath is a member of the group and they post the newsletters and lend me two dining chairs for our committee meetings! Every little helps!

It was gratifying to see eighty members at our Christmas Coffee Morning and seventy members at the Information Session in April. It shows us as a committee that we are working well when so many of our members get involved.

The role of Chairman of the WRSG is very easy because the committee just get on with their work and report back at our committee meetings.

The role of Secretary in any organisation is quite hard work because you have to write all the letters.

My role as Editor of the newsletter is interesting. I enjoy putting the newsletter together for the first three weeks of the month. I pop up onto the computer every time I think of something to write and I usually find the medical information or NHS information on the Internet.

My confidence sometimes goes when I think I have written too much about me but then I get a nice e-mail or phone call or letter about something I have written and my confidence is restored.

For the last week of the month my dining room becomes an office as I physically do the newsletters but once I hand them over for posting it becomes my dining room again.

Chairing the Black Country Lymphoedema Support Network is very similar to Chairing the WRSG. The committee are easy going ladies and gentlemen and we all work well together.

Being a member of the Patient and Public Involvement Forum for the Primary Care Trust is a different proposition. It is more of a responsibility because we represent the population of Wolverhampton when we give our opinions. My colleagues and I get on well together but you don't really get to know each other as well as with the two support groups.

Anyway all that was because I saw that Carol Boneham had won an award for her poem.

Carol won the International Society of Poets Award in America. The award was the Editors Award for Poet of the Year and the poem is as follows:-

If my world was full of Roses

If the world were full of roses what a delight it would be,

The fragrance the beauty, perfect simplicity.

As nature unfurls their petals as each seasons begin,

One feels a spiritual blessing deep within.

If the world was full of roses with its exotic smell,

If one were feeling off color one would soon feel well.

For the English roses are relaxing in a bath as body rests.

Soon you would yet again give the world your best.

Have you tried scented candles when in a room taking time out?

It gives you time to mediate that's without a doubt.

Many have been named after famous people With it's very gentle petals,

For life is like a rose and easily likes to settle.

Amazing how roses are mentioned in everything,

Including old fashion songs, which you hear, people sing.

So if you're on a journey and want a buttonhole,

Show the world you love that rose as it slowly unfolds,

And see how inwardly you find happiness, For in your heart you know you have been

heavily blessed,

Carol Bernadette Boneham

Getting Around Access Guide

I have received the 2007 edition of the Getting around Access guide from Centro.

This free A5 guide provides information on accessible bus services, door to door services, trains, taxis, metro, concessionary fares and local information services.

You can obtain a copy by telephoning 0121 214 7125

Family members

We have two new additions to our family. Dooble (Jessica's hamster) and Stripe (Jack's hamster)

I enjoy looking after the children but I think hamsters would be a different matter.

Care fear over hospital discharge

Poor and late hospital discharge information is putting patients at risk, GPs say.

Hospitals are supposed to send doctors information on medicine and treatment as soon as a patient is released, in order to help in their follow-up care.

But an NHS Alliance poll of 651 GPs found 70% often received papers late and many said the forms were not complete, compromising safety.

The government admitted there was work to do to ensure better communication.

GPs are meant to receive discharge summaries within two days of a patient being discharged.

It is either E-mailed, faxed or given to the patient to hand over.

As well as being late, family doctors had reported they often lacked important details, the NHS Alliance, which represents the interests of GPs, said.

Among information which was reported to be missing were the patient's name, contact details, medication and treatment.

Incorrect or insufficient data on medication, such as potentially toxic drugs like warfarin, has even led to patients being readmitted to hospital because of complications such as internal bleeding and strokes.

In one instance, a discharge summary was received but failed to mention that the patient had just spent a week in intensive care following a stroke and heart attack. Some 58% of GPs reported the problems meant clinical care was compromised in the last year, with 39% claiming it had put patients at risk.

But nearly two-thirds of doctors said they had hospital teams in their areas that provided good, prompt information, proving it could be done.

The results come at a time when patients are spending less time in hospital following treatment as part of a government drive to move care away from hospitals and into the community.

'Risk'

NHS Alliance Chairman Dr Michael Dixon said: "We need urgent action at national and local levels. The NHS cannot continue to allow patients to be put at risk just because too many hospitals regularly fail to get information to GPs when patients are discharged."

Patients Association chairman Michael Summers said: "We have long-standing concerns about the quality of discharge information. It can have very serious consequences, especially for elderly people."

But Gill Morgan, chief executive of the NHS Confederation, which represents hospitals, said: "There is often a variable standard between the notes provided. However, there is also variation in the standard of GP referral letters to hospitals."

She added electronic discharge summaries - being introduced as part of the 10-year NHS IT upgrade - "should go some way to helping overcome these issues".

A Department of Health spokeswoman said officials were looking to draw up a contract for hospitals in a bid to improve discharge information.

She added: "Patient safety is always top priority for the NHS but clearly there is still some work to do to ensure that information provided to GP practices about their patients is done quickly and accurately in all parts of the NHS."

Story from BBC NEWS:

Published: 2007/03/29

Carver Wolverhampton Marathon

I attended a marathon committee meeting on 14th May. I was asked to write an article for the Adnews which was subsequently published. This helps to raise the profile of our group. I mentioned in the last newsletter that we can have a table in West Park on the day of the marathon.

I think after the weather in May we shall also have a tent!

I will man this table to distribute our leaflets but I will need some help.

Any volunteers please?

Dorothy

ADVERSE FOOD REACTIONS

Food allergy is a complex area, further complicated by food intolerance, which can mimic the effects of an allergy.

True food allergy

What are the causes? In children, common allergy-provoking foods include cow's milk protein, egg white from hens, wheat, Soya bean, codfish and peanuts. In adults, nuts (including Brazil nuts, almond, hazelnut, peanut and walnut), fruits (such as peach, apple, strawberry and citrus fruit), and vegetables (such as celery, tomato, onion, garlic and parsley) are common allergens. Seafood such as fish, mussels, crab, prawn, shrimp and squid may also cause allergic reactions.

What are the symptoms?

Typically, an immediate type of food allergic reaction involves the immune system. Traces of the offending food rapidly lead to symptoms of generalised rash, itching, body swelling, breathing difficulties and even collapse. Peanut anaphylaxis is a good example where traces of the food are absorbed in the mouth or intestine. This leads to the rapid release of histamine from cells and allergic tissue swelling. Some people with the oral allergy syndrome get a localised red itchy mouth and throat on eating certain fruit, vegetables and nuts. Delayed reactions to food are becoming more common and this may be the basis of eczema in infants. Coeliac disease occurs due to a delayed immune reaction to gluten in wheat. This causes intestinal membrane damage with resultant diarrhoea, abdominal bloating and malabsorption resulting in anaemia, for example.

Food intolerance

What are the causes? Lactose intolerance, for example, may be caused by the lack of a specific digestive enzyme. This is a remarkably common condition. Natural histamine may be too rapidly absorbed from food in the diet and effectively lead to a histamine 'rush' that mimics an allergy.

Then there are adverse reactions to chemical preservatives and additives in food such as seen with sulphites, benzoates, salicylates, monosodium glutamate, caffeine, aspartame and tartrazine.

What are the symptoms?

Adverse food reactions are of slower onset, do not involve the immune system and aren't usually life threatening. Reactions are usually dose related, with small amounts of the food being tolerated but larger amounts leading to reactions such as rashes, flushing, abdominal pain, vomiting, diarrhoea and palpitations.

These are by far the most common adverse food reactions seen in general practice. The lack of a specific enzyme in the body may lead to the build up of toxic by-products and histamine, which then mimic the symptoms of an allergy. This is called a 'pseudo-allergic' reaction.

Food toxicity and aversion

Poisons may naturally occur in foods such as mushrooms and potatoes. Bacteria in putrefying fish can cause toxic food poisoning called 'schromboid toxicity'. These reactions occur in all people who consume the toxin and don't involve a digestive intolerance or an immune reaction.

Some people have a food aversion, and convince themselves, with no sound basis, that they're 'food allergic' and will vomit if given the particular food. If the food's concealed or hidden they consume it with no ill effects. Their reaction is psychological, and it's often difficult to convince people that they're not allergic to a particular food.

Diagnosing food allergy

Food allergy can be diagnosed by means of skin-prick tests to various foods or by RAST (radioallergosorbent test). Skin testing with fresh food extracts is more accurate.

The gold standard in food allergy is the Double Blind Placebo Controlled Food Challenge (DBPCFC) test under careful supervision in a hospital. ■

If no food can be identified, but an allergic reaction is strongly suspected, an elimination diet lasting between two and four weeks is performed. The person lives on a limited number of foods, which are unlikely to cause allergies, such as lamb, rice, pears and sweet potato.

Then once the allergic symptoms settle, foods are slowly reintroduced one at a time to identify the offending food. This should only be done under the supervision of a dietician as a child can end up in a state of malnutrition on a prolonged restricted diet. Food intolerance is very difficult to diagnose as there are no reliable blood or skin tests available.

The suspected food has to be eliminated from the diet and a clinical improvement documented. The offending food should then be reintroduced again for a short period to confirm the adverse reaction and hence the intolerance.

This article was last medically reviewed by Dr Rob Hicks in October 2005.

A lovely evening out

On the 16th May I attended the Annual Council Meeting in the Wulfrun Hall with Matron Rani Virk and Sister Cherril Webb. I didn't know what to expect or why I had been invited but it soon became very clear. The newly appointed Mayor: The Right Worshipful the Mayor of Wolverhampton 2007/2008, Councillor Trudy Bowen is one of our rheumatology patients. The Rheumatology Department at New Cross hospital is one of the Mayor's chosen charities. Madam Mayor (Trudy) is going to join our group.

The evening began with all the formalities which were very interesting followed by drinks in the bar area where I caught up with many of my colleagues from the Community Health Council days. We then took our places for dinner in the Civic Hall. There was some very lively entertainment followed by a variety of food from around the world.

I really enjoyed the evening and was very pleased to have been invited.

Dorothy

Choose and Book

This system has been in operation for approximately one year in local GP surgeries. Not all specialities are included in the system as yet. The process is ongoing.

The system operates as follows:

The patient sees a GP and either requests to see a particular Consultant at a particular hospital in which case the normal arrangement is made, or the patient wishes to use the choose and book system. This procedure would be used for new referrals rather than re-referrals.

If the Chose and Book system is selected the patient is usually taken to the confidential computer terminal, and after the staff "credit" card has been inserted, the information is fed into the programme, i.e. the hospitals and required medical/surgical speciality. The computer shows a list of hospitals having the facility required and a suitable hospital is selected. The computer then gives a comprehensive list of available appointments in that speciality. The patient can then confirm a date to suit them, or take the information away for consideration. When "confirm" is selected on the screen that appointment is confirmed for that patient, in that hospital in that speciality. No other patient/surgery can override it. A confirmation letter will be sent from the hospital to the patient.

Hospital acquired infection rates are also available within the programme.

As at 22 April 2007 three million patients had been referred for further treatment by their GP using the NHS CFH Choose and Book system.

Co-Proxamol

I have now received a further supply of Co-proxamol. Recently I was sitting in the pharmacy with a complete stranger. She had just been given a box of Co-proxamol and you would have thought she had won the lottery. Her words were "Nothing else suits me." We both felt frustrated that we were worrying over something which we felt was totally unnecessary. We both feel that we will not accidentally overdose on them! If this were a local issue I would be campaigning but I cannot take on NICE (The National Institution for Clinical Excellence) can I?

Dorothy

WRSG Annual General Meeting

All charities registered with the Charity Commission have to hold an AGM. The committee are all Trustees and as Chairman I have to sign a declaration every year for the Charity Commission.

We usually hold the WRSG AGM on the first Monday in September. However the Carver Wolverhampton Marathon is on the first Sunday in September and as we are acting as marshals and manning the table in West Park I think we will need a week to recover. We have booked our AGM a week later on the evening of the 10th September at the Holly Bush Inn, 494 Penn Road, Penn Wolverhampton. We will be inviting guest speakers and providing a buffet. The purpose of the AGM is to elect/re-elect the committee and to receive the Annual Accounts and the Chair/Secretary's report.

We always have the full support of our three Rheumatology Consultants Dr. Newton, Dr. Ali and Dr. Pace. Unfortunately last year Dr. Newton and Dr. Ali were unable to attend but Dr. Pace gave an excellent presentation on his homeland of Malta and the origin of Rheumatoid Arthritis with some very interesting slides. It is always a pleasure to see our Rheumatology Sisters at the AGM too as they are our link between the hospital and the patients.

Mr. Terry MacKriel has been one of our guest speakers for the past ten years as Chairman of the Wolverhampton City Primary Care Trust. Terry has now retired from the post but we hope Terry will come along as a member of the group.

Rob Marris MP has attended our AGM for several years and has written letters on behalf of the group. Pat McFadden MP has recently written an article for our newsletter about his trip to India and Pat attended one of our information sessions. Ken Purchase MP attended our concert on the 12th May and we are grateful for their support.

Please make a note of this date in your diary. Invitations to attend will be sent out with the August newsletter.

Dunstall Park Race Day

There is a Race Day at Dunstall Park Race Course on 2nd July. Gates open at 2.00 p.m. Disabled and escort entry is free. For further information ring Joyce

West Midland Safari Park

Sheila Fardoe is organising a trip to the West Midland Safari Park on Friday 10th August. We leave Falkland Street Coach Station at 9.30 a.m. and leave the Safari Park at approximately 4.00p.m. The charge is £10.00 per adult which includes the coach fare and entry and £5 per child for entry with the WRSG paying the coach fare for the children. Wrist bands for the rides and food on the day will have to be provided by members themselves as usual. To book places ring Sheila between 4.30 and 7.00 p.m. only please.

Droitwich spar Brine Baths

Following our outing to Droitwich Spa brine baths we had many requests from members to repeat the event. We have worked out that we can do the trip for £13 per person. The coach costs £220 and the admission to the pool £100 for the maximum 24 people. Sheila says she will organise a trip in July if enough people are interested. Please let Sheila know by giving her a call

Tribute Weekend

Joyce is organising a "Tribute weekend" at Warner Hotel, Sinah Warren, Hayling Island. "Swing" LA Session Band, Jay Oxenhan as Sinatra, Monroe Street. We depart Wolverhampton on Friday, 30th November returning on Monday 3rd December. The cost is £165 per person plus the cost of the coach which has yet to be arranged and will depend of the number of people going. For further information about this weekend break give Joyce a call .

Disclaimer:

The views expressed in this newsletter are taken in good faith and are not necessarily endorsed by the editor or the WRSG. The use of a product name does not constitute an endorsement or a recommendation by the WRSG