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Thanks to Nic & Joyce for help with proof reading and sanity checking!



PsAZZ
Psoriatic Arthritis Support Group

...to the spring edition of PsAZZ News!

It seems that big yellow orb in the sky has finally returned and all that sunshine just makes me want to get out in the garden! We have a fairly small garden at the back of our house but there's lots in it and it's been great to see little bursts of colour coming back - it's one of the only places where I get that sense of inner peace. Having given up a bit on avid gardening a few years back, this year I have decided to re-invent my approach and try out some simpler table top techniques. It started with a few small trays of seedlings on a sunny Easter holiday morning that are now sitting on a warm windowsill so I will let you know how I get on!

Since I last wrote it's been another busy couple of months doing PsAZZ-ish things and Jana J & myself spent a few days in Leeds back in February taking part in more *Patient Expert* stuff. There was also a moment of nervous excitement when I did a short interview about support groups & PsAZZ on BBC Wiltshire Radio (link on our facebook page).

In March I was able to make a couple of new connections for PsAZZ via a WSUN meeting - the first being 'Wiltshire Clinical Commissioning Group' who you can read about on p.6 and the other 'Healthwatch Wiltshire' (who we will feature in a future edition). It's all helping to get PsAZZ out there!

You should find plenty to browse in this issue - there's group news on p.4 and turn to p.10 to see our cover story feature 'The Min in WWI' - special thanks to Dan Brown at Bath in Time for being a last minute hero and sending me copies of pictures from old editions of the Bath Chronicle. On p.22 you can read about how one intrepid group member has been in training for the 'Moonwalk' London and find out more about Clinical Trials at The Min on p.18

Anyway, I hope you enjoy reading it all and remember, this is your news so **write in**, **join in** and **become part of the conversation**!

Mel

contact me at: psazzgroup@gmail.com



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There was some good news for PsAZZ last month when our very own support group 'leaflet' was finalised (big thanks to all those who helped proof read it and get it printed!) It has now been distributed around The Min, the Independant Living Center (Semington) and been sent up to one of our contacts in Leeds! If you are able to help get our leaflets out there please get in touch.

March saw us trying out a new venue 'The Royal Hotel' (near the train station) in Bath for a PsAZZ get together. As always it was lovely to catch up with others and I think the general consensus was that it was comfortable & relaxed enough for us to use again another time.

Our number of **facebook** likers continues to grow, although it is a little quiet some days so please do get sharing & posting! If you can't get

along to meetings it could be a great alternative way for you to connect with others in the group.

Wiltshire & Swindon Users Network (who we wrote about last issue) sent us their Spring Newsletter last month which included a nice piece on PsAZZ. In addition, Debbie M & I went along to one of their forum meetings where we watched some presentations and took part in a couple of health related workshops.

In other news - I have been sorting through all the old yarnstorm bits 'n' bobs and although some pieces were too far gone to re-use we still have a nice bagful plus the door blanket so I have decided to see if I can get it displayed somewhere - any ideas greatfully received! Also, we are currently in talks

with BIRD about doing another 'Lab Tour' but places will be limited so do get in touch if this is something you would be interested in!

Don't forget you can continue the fight to support The Min by making a donation towards one of their wrist bands or other goodies. Also please start sending in your hand photos for the new awareness campaign - see p.9!



MEETINGS...MEETINGS...MEETINGS

We know not everyone can travel very far to get to a PsAZZ meeting so we are going to try organising a few small regional meetings to see if this makes it easier for you to get along and meet up with others - and don't forget you can always take a friend or relative along too - everyone is welome!

If you would like to organise one for your local area please get in touch!

email psazzgroup@gmail.com



PsAZZ REGIONAL MEETING DATES

BATH

Thursday 22nd May
The Hale Room, BIRD, Trim Street Bath
11am-2pm

BRISTOL

Thursday 27th May (email PsAZZ for venue details) 6pm-8pm

WILTSHIRE

Thursday 5th June
The Northey, near Box
6pm-8pm

Making connections with....

NHS Wiltshire Clinical Commissioning Group

In February we met with Ted Wilson & Barry Grimes from the Wiltshire Clinical Commissioning Group and asked them to tell us more about the group & it's plans...

Wiltshire Clinical Commissioning Group (CCG) was established in April 2013 and is the organisation responsible for planning and buying health services for local residents of Wiltshire every year. Our budget to do that is £500m

Wiltshire is a large and predominantly rural county with a population of 459,800 and half of the population resides in towns and villages and the specific, local knowledge of our GPS is essential to how we plan and buy services.

Your local doctors have come together to form the CCG, and this new way of working gives GPs, who have in-depth knowledge of their patients and their communities, the opportunity to design services which will provide high quality patient care whilst spending public funds prudently.

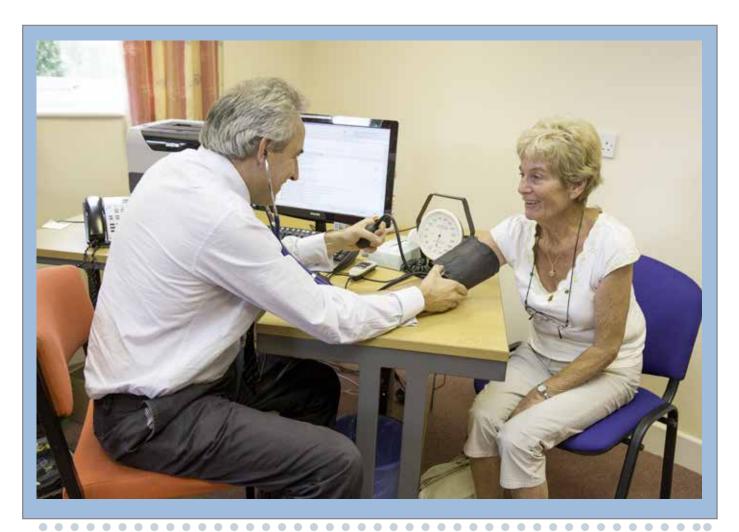
With our £500 million budget, the CCG is responsible for buying the following services for our local residents:

- Elective hospital care (planned care)
- Continuing healthcare (for people with ongoing healthcare who are not in hospital)
- Wheelchair services
- Rehabilitation services
- Healthcare services for people with learning disabilities
- Older people's healthcare services

- Home oxygen services
- · Health services for children
- Mental Health services
- Infertility services
- Maternity services
- Community health services
- Urgent and Emergency care including ambulance and out-ofhours services
- Pregnancy termination
- Treatment of infectious diseases

Wiltshire CCGs is also responsible for meeting the costs of prescriptions written by our GPs.

To be able to design health services that provide the right care for people now and in the future, Wiltshire CCG has been working with its partners to develop a five year plan that respond to local issues and health needs, and this plan covers the period 2014 to 2019 (see over....)





Five Year Plan

The vision of the CCG is that Health and Social Care services in Wiltshire should support and sustain independent healthy living and with that in mind has developed a five year plan that sets out its strategic direction and future care systems.

The design of the future care system is based on three key principles:

- Local residents to be encouraged and supported to take responsibility for maintaining and improving their wellbeing.
- There should be fair access to a high quality and affordable health system, which delivers the best outcome for the greatest numbers of people.
- Care should be delivered in the most appropriate setting, wherever possible at, or as close to home

The CCG wants to ensure that the public and patient views are at the centre of every decision we make about designing and purchasing healthcare services for you so please get involved and telling us what you think.

More information on how you can become involved in the work of the CCG can be found on our website at: www.wiltshireccg.nhs.uk

Will you help the....

2014 PsAZZ Awareness Campaign

Hot on the heels of last years beautiful display of hands we are already starting to plan the 2014 PsAZZ Awareness Campaign.

With a nod to the ancient Roman City of Bath as our original birth place we are going to put together a big mosaic photo-montage of a hand that will also reflect our group logo.



Oll you need to do (between now and October) is take a picture of your hand with your mobile phone or camera and email it to us at psazzgroup@gmail.com



This issue we mark the 100yr Anniversary of the 'Great War' that started in August 1914 by taking a glimpse at ...

The Min in WWI



Many of us will have a family history that has been touched by World War I. When Great Britain declared war with Germany in August 1914 many people thought it was a bit of a skirmish that would be over by Christmas but it dragged on for four long years with unsurmountable losses.

By 1916 it became clear to the Government that we didn't have nearly enough soldiers and conscription began in earnest. Such was the patriotic strength of wartime propaganda that many young men, buoyed up by a sense of gallantry and adventure signed up some before they had even reached legal age.



Hospital protocols were very strict and many convalescing soldiers wore 'Hospital Blues', suits or Uniforms. Photograph with kind permission ©Akeman Press

The Government controlled information about the war and newspapers held back the truth about the grim conditions and the real casualty figures so many of those signing up weren't really aware of what they were letting themselves in for until they reached the trenches.

Often those men who weren't already signed up or who were simply out of uniform on leave, would be accosted in the street by young women (also unaware of the reality of conditions) who would thrust white feathers, a traditional symbol of cowardice, at them in disgust in an attemp to get them to enlist.

The majority of the fighting took place in trenches which may have offered some shelter from gunfire but caused many other problems such as 'trench fever', typhoid, dysentary and even frostbite. Sanitation was so poor that not only were diseases rife but wounds would easily become infected or gangrenous and there were no antibiotics until after the war. Alcohol was used as much as anything to get them through their pain.

Initial first aid would be given by Medical Officers in the trenches or in a dressing station which was another trench built close behind the front line but where they were still under threat of fire. If they were then lucky to survive long enough to get to a Casualty Clearing Station (which were tents around half a dozen or so miles behind the front line) limited medicines included things like aspirin, opium, iodine or herbal preparations. If they were invalided back home they were sent to



This photograph, borrowed from The Min's archive collection, came with the title 'Royal Mineral Water Hospital, Bath, Somerset 1915' with comment 'Soldiers not wearing 'Hospital Blue' and Nurses not in uniform, perhaps they are on an 'outing'. Sister Dora Corfield on right"

hospitals most appropriate to their needs and I would think that those who ended up in The Min would have felt fairly fortunate.

Before the war a nursing service called Queen Alexandra's Imperial Military Nursing Service Reserve' (QAIMNSR) had been established. It had a very high standard of entry so numbers were in the low hundreds and rules had to be relaxed to allow more women to join up in response to the demands of high casualty numbers. They were later joined by the Voluntary Aid Detachment (VADs) who had usually only received a basic introduction to Nursing. Abroad and at home all kinds of buildings were set up as 'hospitals' of a sort.

The Min was handed over to the War Office for use by service personnel and 'Electrical Therapy' had been introduced in 1913. It was consider a 'cutting edge treatment' which some of the war wounded would later benefit from (there's a picture on flickr, not shown here) as many would have been suffering rheumatic complaints as a result of being in the damp, cold trenches. Gun shot wounds could also cause joint problems that needed physiotherapy and rehabilitation so the Min would have been perfect for that.

The Min had it's first X-ray unit installed around 1911 and a consultant named J M Bannatyne was one of the first people to identify radiographic changes to joints. He later played his own part in active duty in WWI as a Lieutenant-Colonel and also worked at the Bath War Hospital (now the site of the Royal United Hospital).

Whilst they were in hospital the patients were often given a special uniform to wear called 'Hospital Blues'. This was basically a single breasted blue suit with white lining or white shirt to be worn with a red tie and their own khaki service cap & badge. It was also designed partly to help identify them as a convalescing soldier when in public to avoid them being harrassed for not being part of the war effort.

Those who were not fully rehabilitated and sent back to the front line were given honourable dischage and a Silver War Badge to be worn on the right lapel of a 'civvy' suit (it was forbidden to wear on a uniform).

Photographs like the ones in this article were often taken by travelling commercial photographers who would then have them made into postcards and sell them to the patients to send home.

With thanks to Kate Lane and the Bath Royal National Hospital for Rheumatic Diseases, Akeman Press & Bath inTime for permission to use some of their pictures in this feature.

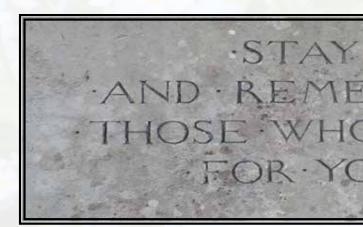
If you are interested in finding out more about The Min in WWI there is a lunchtime lecture

Patients kept themselves entertained by writing letters, playing cards and other games such as billiards and cribbage. Unfortunately, once suitably recovered some were likely to have been sent back to the front lines and may not have been so fortunate to survive second time round.



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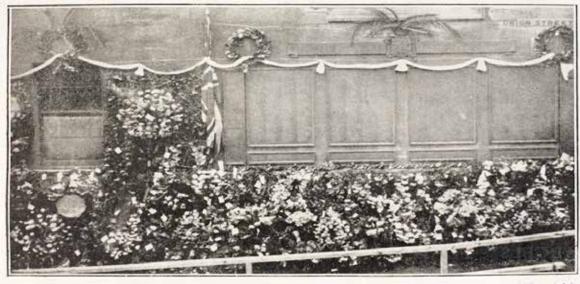




This photo shows the Mayoress placing a wreath at the memorial

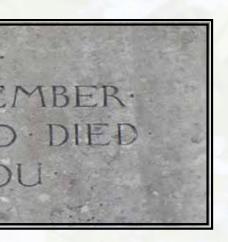
One lesser known fact about the Min was that in 1923 the commemorative WWI name plates were placed on the wall of the Royal Mineral Water Hospital on the Union Street side of the building (see picture below). It had been a rather rushed affair on the part of the council as they had been told the Prince of Wales was about to visit!

A CITY'S TRIBUTE.



The City's War Memorial in Union Street was the merca of all classes and all creeds during the Armistice week-end, for which period it was under the proud care of the Brifish Legion. Our picture shows the enormous number of beautiful floral tributes placed there in memory of the gallant dead by innumerable private citizens as well as by many or the public organizations in Bath.

BRIDAL BOUQUET FOR BATH WAR MEMORIAL.





After her wedding at St. Luke's on Wednesday Miss Tatham stopped outside the Bath Mineral

It later became

a bit of a tradition for Brides to stop and place their bouquets at the foot of the memorials (see picture). Eventually in 1927, the name plates were transferred to the larger Bath War Memorial situated at the main entrance to Royal Victoria Park. Second World War and civilian name plates were added later.



Lunchtime Lectures.... at 'The Min'

First World War Commemoration - Healing the Wounded: Bath's Hospitals in the First World War' by Dr Andrew Swift

A lecture on the use of Bath and its hospitals to treat the wounded during the First World War

Venue

The Lecture Hall, Royal National Hospital for Rheumatic Diseases, Upper Borough Walls, Bath, BA1 1RL

Date

4th September 2014

Time

12.30 to 1.30pm

Attendance is free but donations to the RNHRD Charitable Fund are welcomed.

If you would like to attend this event please email fundraising@rnhrd.nhs.uk or call 01225 465941 Ext 278.

Charity Number: 1054247

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for more information or to make an appointment to visit us.
You can also contact us by email at welcome.ilc.semington@googlemail.com
Or Visit Our Website www.ilc.org.uk



Bath Institute for Rheumatic Diseases

Trim Bridge, Bath BA1 1HD www.birdbath.org.uk 01225 448444 BIR D@birdbath.org.uk Registered Charity Number 1040650

Only 1 person in 50 escapes some form of rheumatic complaint.

Who will be the lucky one?



The Bath Institute for Rheumatic Diseases (BIRD) funds medical and scientific research. We are working with the Royal National Hospital for Rheumatic Diseases in Bath and the University of Bath to develop an integrated programme of research, treatment and care for people with bone and joint disorders, including Psoriatic Arthritis. This research will help us understand how rheumatic diseases are caused.

It will lead towards better treatments and improve the quality of life for people suffering from a rheumatic disease.

Research takes time but scientists believe that they are close to discovering the causes of some rheumatic disorders. The Bath Institute for Rheumatic Diseases is at the forefront of this research developing new treatment and, in time, cures.

In 1992 the Institute established BIRD Diagnostics to provide a high quality serology service to the Royal National Hospital for Rheumatic Diseases. We identify and quantitate a number of relevant autoantibodies.

We are also developing methods for the measurement of bone turnover markers which hopefully will be used in the early diagnosis of disease.

For further information about us or to make a donation, please see our website <u>www.birdbath.org.uk</u>. email <u>BIRD@birdbath.org.uk</u> or call us on 01225 448444.

All about.....

Clinica



Clinical Research.... without it we might never have access to the medicines that, for many, are necessary to be able to live as normal a life as possible. The Min has long had a reputation for being at the forefront of developments in Rheumatology and part of this is down to the running of Clinical Trials.

Have you ever been asked or wondered about taking part in a Clinical Trials at The Min? We asked the clinical team to explain more...

Here at the RNHRD we have over 700 patients who have consented to be part of our ongoing research programme in PsA. This makes us one of the largest centres for PsA in the country, Europe and indeed the world!

As one of the leading rheumatology centres in the UK, research is at the heart of our daily work. We have numerous on-going research projects across all our service areas. Many of these studies are carried out in partnership with local universities in Bath and Bristol, as well as other universities and NHS trusts. We are also involved in numerous international research collaborations.

Over the past few years, the hospital has been a major contributor to the international field of the genetics of PsA. Our researchers have discovered novel genes which will help us understand more about both what makes a person susceptible to the disease and the ability to predict how severe this may be for individuals.

We also run lots of other clinical trials, some of which test new medications and treatments for PsA. Other studies have looked at peoples lifestyles and how this affects their PsA or how people's joints and skin have changed and how this has affected their ability to function on a day to day basis.

ITrials

A team of people work together at The Min to ensure each research study is run safely and to a high standard. The team includes research nurses, doctors, pharmacists and scientists. Some research studies are led by commercial companies and they work closely with the research team.

All research studies have detailed guidelines to determine who can take part. Anyone wanting to participate will usually be required to answer some questions about their medical history and may have to have some baseline tests such as blood tests, X-rays or scans, to establish their suitability for the trial before taking part.

Participation in research is always voluntary and people are free to withdraw from research studies at any time without affecting their future treatment.

All information collected is treated as strictly confidential and is not passed on to anyone outside of the research team.

Before taking part participants will be asked to sign a consent form. This form asks them to confirm that they understand what is involved in taking part in the study and are aware of the potential risks and benefits of taking part. It also gives their permission for their anonymised information to be included in the study and for the researchers to have access to their medical records.

If you are interested in helping out with a study please ask your doctor or nurse for more information about research being carried out at the hospital and whether you might be eligible.

If you are not eligible for a research study, the research team is happy to hold your contact details and forward details of projects which may interest you in the future.

For more information please speak to a member of the research team on 01225 473453.



Dear PsAZZ..

Here is a selection of your questions, comments & lips sent in via email

This issue we are happy to give you a follow up on Liz's Anchorite story (last issue) - she tells us that the money raised by Christmas had been enough to pay for a borehole and that work had already started - Well done Liz!

Q: I was wondering if there are any plans for PsAZZ to hold meetings where guest speakers would come along to give lectures or talks?

A. Thanks for your question - I have been looking into doing this but it's a quite a big undertaking and ideally I would need some volunteers to help with the arrangements. I've been in preliminary talks with The Min and we would be able to use their lecture hall as a venue (the old Chapel). I am fairly certain I could arrange for a speaker to come along but another concern would be whether or not many people would attend to make it worthwhile - perhaps you or anyone else who is interested in helping or simply attending could email me to let me know?

If you have any questions, comments or good tips for our group members please email them to us at:

psazzgroup@gmail.com



If YOU would like some of our new leaflets to help us spread the word about PsAZZ simply email us at

psazzgroup@gmail.com

Please remember...



We are a self-supporting, volunteer run group and we would love you to help us! We currently rely on goodwill gestures for everything we do!

Together we could do so much more...

Do you think you might be able to help? email psazzgroup@gmail.com

The MoonWalk London is a charity event taking place on Saturday 10 May 2014 at Clapham Common, London to raise funds and awareness for Breast Cancer.



Here, PsAZZ group member Gretel Hughes (wearing the yellow jacket in the above picture) is taking part in the challenging 26.2 mile 'Full Moon' walk and tells us how & why she got involved...

I'm doing the walk with a group of 4 local women and a sister of one of the women who is coming over from Ireland for the event. Two of the ladies had cancer a couple of years ago but thankfully they are better now. The MoonWalk seemed like a

good opportunity to fund raise and get fit at the same time!

We started walking back at the end of January with gentle 5 mile walks, often leaving at the crack of dawn on a Saturday, so that we could be back home before our families were really up and ready to face the rest of the day!

We've built it up to training 3 times a week and it also gives us the chance to socialise and catch up with each other on our walks. We have just done our last big walk of 20 miles before the actual event on May 10th.

We have been featured in our local newspaper the Frome Standard and we've all been updating our Facebook pages regularly along with the Moonwalk page as we had more news.

Initially we had a target of £1500 but we've just increased it to £3K after a very successful bag packing session at Asda's for 6 hours one Saturday where we raised over £700!

We've organised a cake sale at a local church that some of us attend (4 of us actually met at the primary school gates when our children were younger!)

It has been a struggle sometimes to get up early or to go out walking late in the evening but I feel my children and husband have been impressed with the teams determination and efforts and I think I'm setting a positive example to my girls.



My PsA is not any worse for doing the training - in fact the regular gentle exercise has been quite good for me. My shoulder has improved over the weeks, it was quite stiff and sore when I first started the walk and when I introduced 1kg weights as part of the *Power Walk* training.

Overall, my fitness has improved, my muscles feel more supple, I've lost a few pounds and the all round feel good factor from seeing my friends regularly has made a difference to me. I feel more confident as well. I'd recommend it to anyone who feels they could manage it!

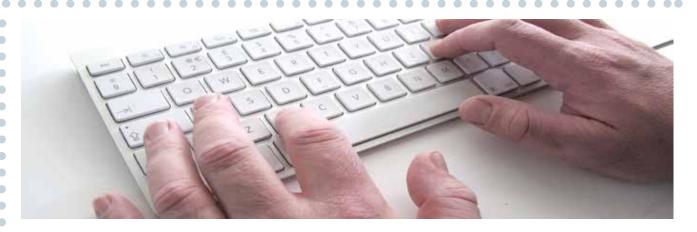
We start our midnight walk on Clapham Common on 10th May.... wish us luck!

Good Luck to the Frome Flyers!

The link to the Frome Flyers just giving page is:

https://moonwalklondon2014.everydayhero.com/uk/frome-flyers

(Thanks for helping them reach their goal!)



Here is a list of useful links we have found...

WWW.papaa.org - Psoriasis and Psoriatic Arthritis Support (UK) www.savethemin.org.uk - sign up to support the RNHRD (aka 'The Min') www.arthritisresearchuk.org - Arthritis Support UK www.livingwithpsoriaticarthritis.org - online support group www.psoriasis-association.org.uk - Psoriasis foundation www.foodhospital.channel4.com - looks at how foods affect diseases www.psoriasis.org - US based National Psoriasis Foundation www.psoriasisrx.com - mainly information about psoriasis www.psorinfo.com - a psoriasis support website www.psoriasis-help.org.uk - psoriasis support website www.birdbath.org.uk - Bath Institute for Rheumatic Diseases www.rnhrd.nhs.co.uk - Royal National Hospital for Rheumatic Diseases ('The Min') www.ilc.org.uk - the Independant Living Center www.psoriasense - Psoriasis and PsA Information

www.livingwithpsoriaticarthritis.org - online support group

www.wsun.co.uk - The Wiltshire & Swindon Users Network

www.psazz.webs.com - The PsAZZ website

www.uclh.nhs.uk/OurServices/OurHospitals/RLHIM/Pages/Home.aspx - Royal London Hospital for Integrated Medicine

www.wiltshireccg.nhs.uk - The Wiltshire CCG website

www.healthwatchwiltshire.co.uk - Healthwatch Wiltshire website

If you have any useful links to add to this page please email them to us at

psazzgroup@gmail.com



Supporting service users to speak out

www.wsun.co.uk

WWI Article List of References:

The Three R's: Rheumatisim Rehabilitation Research by George D. Kersley www.bathclinicalsociety.org/history_bannatyne.htm www.channels.visitbath.co.uk/media/information-sheets/baths-spa-and-history www.warmemorial.pwp.blueyonder.co.uk/2.html?submenu=1

