Issue 010

PsAZZ News

WINTER 2014

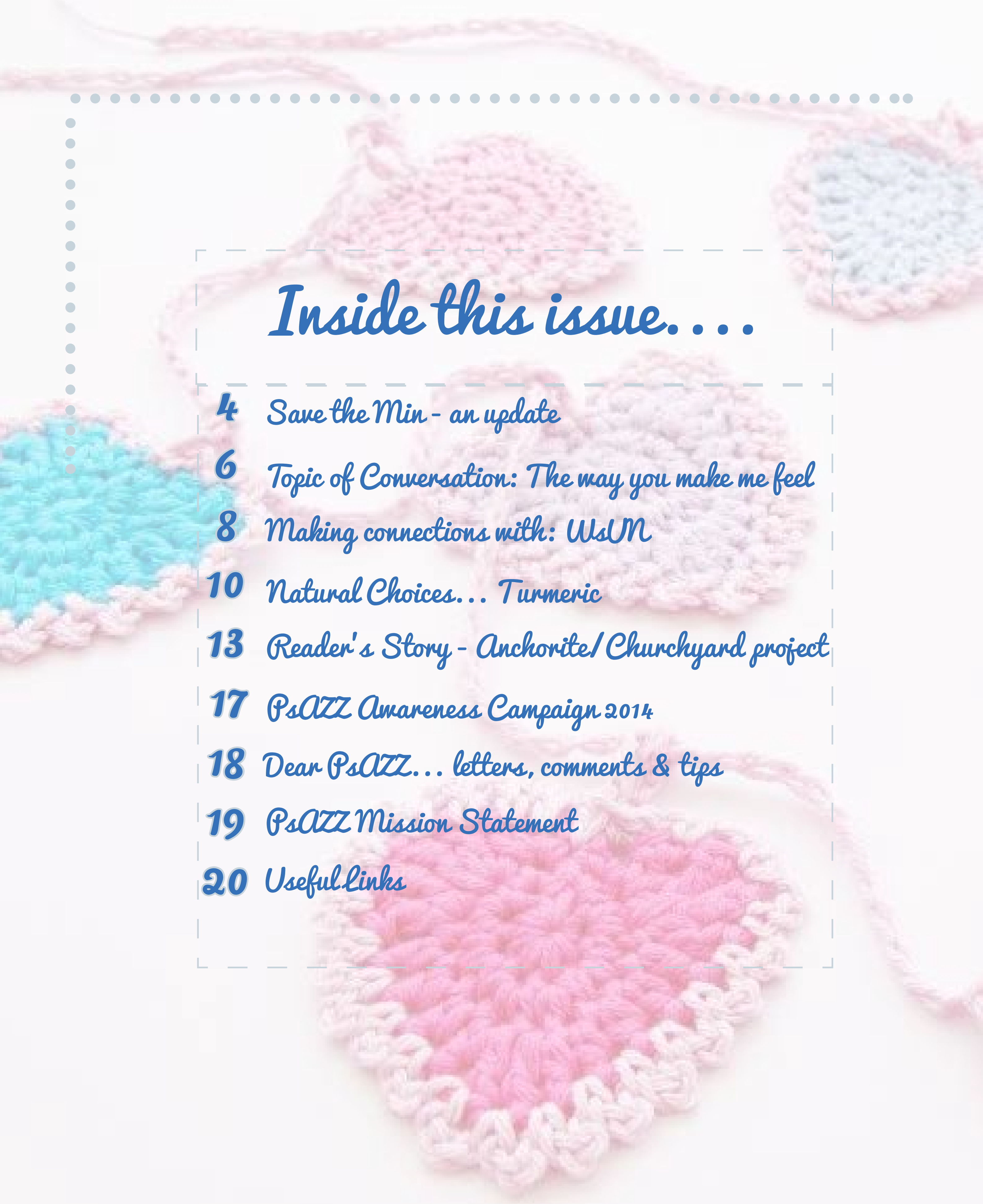
Read about...

- **Connecting with Wiltshire & Swindon Users Network**
- **PsAZZ Awareness 2014**

Also in this issue

- The Anchorites Tale
- Update on The Min

...and more!



Inside this issue....

Thanks to Nic & Debbie for all their help with proof reading and sanity checking!

Welcome

...to the winter edition of PsAZZ News

Here we are with our first 2014 edition of PsAZZ News but what a dreadfully wet start to the year we have had...oh well, at least there should be no threat of droughts this year! With all the short, damp & chilly days we have been asking you whether you prefer heat or cold for your aches & pains and it looks like many choose warmth (me too!) Our second email discussion (see p.6) was more about how we feel about our skin & bones, how it affects our self confidence and our lives.

This issue we have an all imporant update on 'Saving The Min' on page 4 and a truly great readers story written by Liz Cullen - see The Anchorites Tale (p.12) I love hearing your stories and many of you enjoy reading them so I am told - so do please keep sending them in for future issues.

Talking of the future, this year we are still about making new connections with other groups and sharing links/information - see our article on a group called WSUN (p.8). We are also already planning our new PsAZZ Awareness Campaign (p.16) for which I have just had word that we have space booked at The Min again (fingers crossed!)

Finally, our next group get together is also in the planning stages (check your emails) and all that remains to say really is ... Happy Valentines!

Mel

contact me at: ***psazzgroup@gmail.com***

The campaign to….

Save th

As many of you know, our group began as a direct result of patients from The Royal National Hospital for Rheumatic Diseases (aka 'The Min') coming together at a PsA Information Day run by the Bath Institute for Rheumatic Diseases (BIRD). We have been greatly concerned to hear that the future of The Min is under threat and many will have signed the petition run in aid of the 'Save The Min' campaign.

PsAZZ member George Odam gives us an update on recent events...

The petition in support of The Min was closed at 5011 signatures. When it reached 3,500 I sent it to Jeremy Hunt MP at the Department of Health and eventually received a letter from a member of his staff telling me that my concern was noted and that it had also been sent to Monitor and the Trust Development Authority (TDA).

Monitor is the government body that oversees foundation trusts and the TDA helps hospitals develop financially to become one. The strategy appears to be 'pass it on'! Not content with the answer that basically said 'we note your concern and are considering our options', I waited until I had over 5000 signatures and then sent the print-outs to Monitor, TDA and also to Bath and North East Somerset Council asking for it to be considered by the council. Guess what? A letter came from Monitor basically saying ' we note your concern and leave it with us'.

The future of the Royal Nationa
known locally as 'T

- An acquisition by the Royal United H
- Rheumatology and other essential
- Associated research, training an
- Unique services such as the residentia
- The national status of th
- The internationally-respected repu
- The historic buildings, with their lin

NHS
Bath and North East Somerset
Clinical Commissioning Group

27 January 2014

Professor G Odam
Bramble House
The Street
Farmborough
Bath
BA2 0AL

Dear Professor Odam

I am writing to acknowledge receipt of your petition in support of the Royal National Hospital for Rheumatic Diseases, Bath which was passed to the Clinical Commissioning Group by Bath and North East Somerset Council.

Although the Clinical Commissioning Group does not have the authority to determine the future of the Royal Hospital for Rheumatic Diseases, we will be involved in determining the current and future services to be provided and in developing a sustainable solution.

We are aware that a copy of your letter has been sent to Monitor, which is the regulator for health services in England and we anticipate they will respond directly regarding your petition. The Clinical Commissioning Group will continue to work with Monitor and the Royal National Hospital for Rheumatic Diseases to ensure continuity of service provision for local patients.

With Best wishes

Yours sincerely

Simon Douglass
Clinical Accountable Officer

Cc: Mr D Hill Monitor
Cllr Neil Butters

for more updates visit **www**

e Min!

al Hospital for Rheumatic Diseases,
he Min', is under threat.

Hospital offers no guarantees for its survival

services could be reduced or lost entirely

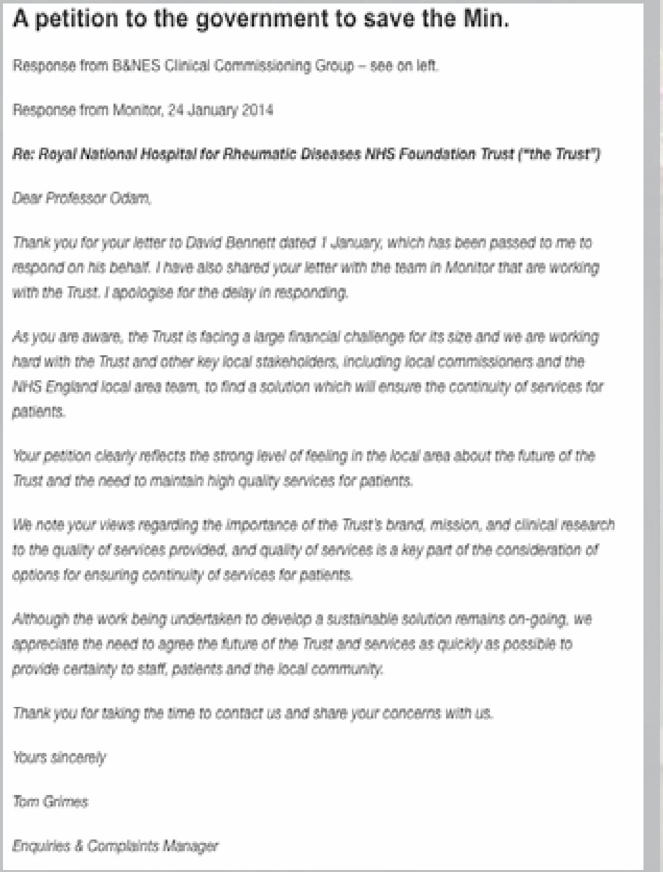
d education might not survive a merger

al Ankylosing Spondylitis courses could close

e hospital may not be protected

utation of the hospital might be put at risk

nks to the city's hot springs, could be sold



A petition to the government to save the Min.

Response from B&NES Clinical Commissioning Group – see on left.

Response from Monitor, 24 January 2014

Re: Royal National Hospital for Rheumatic Diseases NHS Foundation Trust ("the Trust")

Dear Professor Odam,

Thank you for your letter to David Bennett dated 1 January, which has been passed to me to respond on his behalf. I have also shared your letter with the team in Monitor that are working with the Trust. I apologise for the delay in responding.

As you are aware, the Trust is facing a large financial challenge for its size and we are working hard with the Trust and other key local stakeholders, including local commissioners and the NHS England local area team, to find a solution which will ensure the continuity of services for patients.

Your petition clearly reflects the strong level of feeling in the local area about the future of the Trust and the need to maintain high quality services for patients.

We note your views regarding the importance of the Trust's brand, mission, and clinical research to the quality of services provided, and quality of services is a key part of the consideration of options for ensuring continuity of services for patients.

Although the work being undertaken to develop a sustainable solution remains on-going, we appreciate the need to agree the future of the Trust and services as quickly as possible to provide certainty to staff, patients and the local community.

Thank you for taking the time to contact us and share your concerns with us.

Yours sincerely

Tom Grimes

Enquiries & Complaints Manager

w.savethemin.org.uk

I had no reply from B&NES until I received a letter from the Clinical Commissioning Group for this area to whom B&NES had passed on my petition and letter. Again the reply was sympathetic although they said that they did not have the final say but would be consulted.

It is clear to me that the buck will continue to circulate until a decision is taken, and I believe that economics will be the main factor. The fate of our small specialist hospitals is ***in the balance*** at a time when the national financial climate is hostile. Although BIRD is an independent charity, its long term future is allied to that of The Min and also ***needs our solid support***, since research into our shared condition is part of its focus and mission.

We should continue to make the case and fight for what we as patients know to be an invaluable resource.To that end I have just submitted an article to the British Medical Journal with some trepidation, not being a medic! They might just publish it as a patient's viewpoint. If not, I will send it to other media since it has been approved by important local professionals who are hoping as I am, that it will appear in the BMJ.

All we can do as patients is to apply pressure in the way we can most easily do it. Letters to our MP is a very good one, also writing to the local and national press.

Please think about what you can do and do it - Good Luck!

The way you make me feel...

Our second email topic of conversation
was about our skin, our bones and how it
affects our everyday lives...

During the PsA Information Day, as I chatted with a few people about our new Facebook page, I became aware that some people were telling me that they may not give the page a 'like' from their personal accounts or interact with the posts, because of a reluctance for their Facebook friends to find out about their disease. It made me wonder about how many others in the group have or still do hide their condition/pain and, ultimately, what impact it has on our lives - I decided to ask more of you how all this makes you feel as one of our email topics of conversation…..

For most of us having Psoriatic Arthritis is only half the story, the other half being the skin disease Psoriasis which often comes before the onset of joint problems. Having this dual aspect of skin & bones to deal with, it's not surprising that self confidence in our appearance and abilities can take a knock.

It can be hard to feel good about yourself when you are covered in patches of red or scaly skin or constantly trying to make sure there is no build up of flakes on your shoulders. Worse, the ignorance of others who may associate skin disease with contagion or uncleanliness can bring out all our worst emotions. It's bad enough trying to cope as an adult but for those of us who grew up with the skin disease and feared the cruel jibes of other children it could be torture trying to keep things covered up. Young children can be excruciatingly honest (as many parents know and often much to their embarrassment) as one group member remembers ***"I was in the sea on holiday abroad, wearing a bikini for maximum exposure to the sun and feeling safe in the knowledge that I was highly unlikely to see anyone I know, only to be 'outed' by a young child who asked quite bluntly 'What are those marks on your skin - have you been burnt in a fire? I knew it was only a child but I wanted to run and hide.'***

Others have learnt to take a different stance as another member tells us ***"I don't really discuss my skin as I've had psoriasis for 30+ years and I don't really notice it and don't really think about anyone else noticing it. I suppose with all of the scars and skin I couldn't care less, you can become a bit blaze! "*** and another wrote ***"I don't have to cover up and the arthritis itself rarely bothers me. "***

It can be doubly hard at work where many of us feel we will be judged if not able to match the performance of others. One member says ***"I'm always telling people what's wrong with me as if I'm not careful people expect too much from me. I have had a lot of support through work, mainly grudgingly, but if I hadn't told anyone I had problems my employer doesn't have to help. Those who haven't known me for long will not have seen me at my worst, where I could hardly walk across the office or sit at my desk. I don't let people know how much pain I'm in, that just strikes me as complaining and isn't going to help anyone, but I do tell them about the arthritis."*** There are always people who appear to make the most of a situation which can make others begrudging - perhaps we are fearful of some such reputation but I do think we need to be careful not to be too hard on ourselves - after all, would we really judge someone who was in pain if we knew that to be the truth?

It is important that you have family or friends with who you can be honest and who will support you without judgement. It's even more important in partnerships or close relationships such as marriage which can suffer huge consequences. This from one group member: ***" Yes , I do try to hide my symptoms from friends and family. I'm sure I don't want to be seen as a moaner, but it's hard for me to be open about it. It sounds ridiculous but it is difficult to even tell the medics at the Min about the tiredness etc. "***

On the subject of fatigue - one member says: ***"Not one of my friends or family have a clue how I suffer. They complicate other situations to try to explain why I should feel this way. However to be honest I never even knew it was a symptom until the information day!"***

We also have to question the urge to apologise for not being as 'able' as the next person or pushing yourself to be seen to be the same and suffering as a result. One member says: ***"As I've spent all of my adult life trying to do the things my peers do and failing - I don't try to hide the fact I need to go home early or can't go out at all. To a certain extent it can be very useful for my partner as, if I don't want to go out on some social event with him, he blames my arthritis and everyone shuts up! "***

The pain and physical limitations of PsA may mean we are no longer able to enjoy certain activities and if we don't tell people the truth we will end up making a whole heap of excuses to save face. However, using these sorts of 'coping tactics' to cover up our embarrassment or shame can absorb a lot of energy and many of us already suffer with enough fatigue. It certainly helps to realise how we look at life and try to focus on things we can do , not what we can't and being honest takes guts.

Others take the stance that they can choose to learn from it and move on and, some decide to see the positives - as one member writes ***"While having a programme made for me at the gym the other day I was discussing (in my usual frank and candid way), how I had to give up uni, my first choice of career and the sports which I love. The trainer said she felt sorry for me which I found strange. I think these things are what make us stronger, it's shaped the person I am and I'm glad about that! "***

Of course, being in the company of others who understand is one area where being part of PsAZZ can really help - as one member says ***"At times I feel broken and it is so reassuring to recognise there are people out there who understand you are too weak to hold a tea pot".*** It is hard to re-wire your thought processes but not impossible and remember it's really others that need educating - one member says ***" I don't feel any embarrassment in talking about it, and I feel that more people should be made aware of the condition, especially when they might have/know of someone who could be showing symptoms which are as yet undiagnosed…to spread the word that there is help out there!!! I myself feel that knowing there are others with the same problems is in it's own way comforting, and stops feelings of isolation. "***

So overall, for PsAZZ, the answer is a mixed bag of attitudes, some of which we can learn from and ultimately shows just what a brilliant, diverse bunch you are.

Thank you to everyone who shared their thoughts.

Making connections with....

Wiltshire and Swindon Users' Network

This month we have been out and about making connections with an organisation called 'Wiltshire & Swindon Users' Network' (WSUN). A brief introduction had been made at a rheumatology focus meeting last year and details then passed to me. Having not heard of them before, I decided to get in touch to find out more and earlier this month I met with Louise Rendle, Head of Network Services.

Louise told me that WSUN are a not-for-profit company that originally started life as a voluntary group back in 1991. Run by a volunteer Management Board, they currently receive some funding and grants via Wiltshire County and Wiltshire Clinical Commissioning Group.

The funds are used to help the group meet its core objectives which are, put simply, to help 'users' of health, public & community services get the best service standards they can.

WSUN also provide training and support for people who need help through schemes such as Wiltshire Independent Travel Support (WITS) and work with a diverse range of groups from young people with disabilities to people who use mental health services. In addition, they have also been closely involved with English Heritage in the development of the new visitor site at Stonehenge to help ensure it is accessible to all.

So who are the 'Users'? The answer is we ALL are: you, me and anyone else who uses a 'service' such as a Doctor/Dentist, Occupational Therapy, Home Care, Day Care and so on.

The 'Network' is made up of 650+ users & groups and anyone in the Wiltshire/ Swindon area can join. Membership is free and entitles you to free mailings and a newsletter. You may also get invited to take part in surveys, forums or projects - the level of involvement is up to you. Basically it gives you a great opportunity to have a voice in what matters to you. WSUN can provide assistance to get to their meetings or events by reimbursing travel costs or by providing taxis.

Being part of the Network enables you to speak out about the services you receive, share your experiences and give your views to a group that are there to champion improvements. They can help to influence national policies to bring about better services and can support you if you are trying to bring about change to services you use, want to raise issues of concern or campaign on issues that affect you or your community. There is lots more information on their website **www.wsun.co.uk**

One unexpected bonus of meeting with Louise was learning that there are ways in which they may be able to support me directly with future activities for PsAZZ. I am also applying for PsAZZ as a group to become a 'Member' which I feel is a positive step towards giving us another way of being able to link up and raise awareness of the group, the disease, the services we use and will hopefully lead to positive changes in all of those areas!

WSUN are having a forum in Chippenham Neeld Hall 5th March from 10.15-2.30 and Salisbury Methodist Church 25th February (same times)
The forums will have speakers from Healthwatch and the Clinical Commissioning Group and it will give service users an opportunity to feed in their views.
If you would like more information Email:info.wsun@btconnect.com

Mother Natures Larde

During our get togethers there is always great interest in
to manage our disease - especially through food & di

Turmeric comes from the same family of plants as ginger - they are both 'rhizomes' which are plants that have large roots or stem systems growing underground. The plants use these bulky roots to store energy and nutrients which sustain it during winter and, as they do not produce seeds, generate new plants. It grows mainly in warmer regions such as India, China & parts of Asia.

Traditionally, Turmeric has been used for centuries in Ayurveda medicine where it is appreciated for its 'strengthening and warming' properties. It has natural antiseptic and antibacterial properties.

The characteristic strong yellow/orange colour means it has also long been use as a dye and as a cheaper alternative to expensive herb saffron. It has also been used for religious purposes and offerings, often linked to fertility, luck and the sun with dried pieces worn as protective

Source: by rovingI (Flickr: Poha (Fried flattened rice)) [CC-BY-2.0 (http://creativecommons.org/licenses/by/2.0)], via Wikimedia Commons

...TURMERIC

sharing ideas for natural ways of helping ourselves
et. Here's one possible way of doing just that...

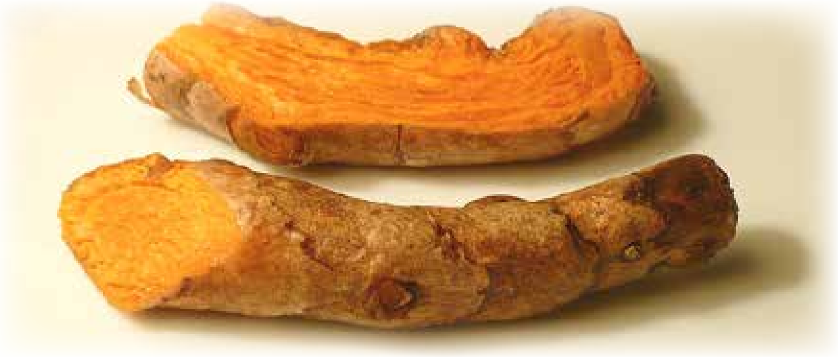
amulets against evil - in Hinduism Orange represents the sacral chakra and yellow represents the solar plexus chakra. In Buddhism yellow represents the Buddha connected to generosity 'Bodhisattva Ratnasambhava' and is the dye often used to colour their distinctive orange robes.

"ta.ma.rik"

Curcumin is a compound that comes from Turmeric roots and has multitude of uses in herbal medicine. It is a strong anti-inflammatory which is thought to be due to it's ability to work on several inflammation pathways. Although used for thousands of years in several ancient cultures it was largely disregarded by western herbalists until research began in the 1920s. Since then it's curative properties have been explored and found to have a positive impact on many disease states including heart disease, asthma, depression, fatigue, diabetes, IBS, cancer, psoriasis, arthritis amongst many others! There have been and continue to be several clinical trials exploring it's use.

Nowadays, there are various strength supplements available in health shops for those who may not like the flavour of Turmeric, but one easy way to add it to your disease armoury is to use it in cooking such as adding it to rice dishes, sauces or curries. It is sometimes used in salads and is probably in a whole heap of other yellow coloured foods that we see on the supermarket shelves too And that yellow colour in the American Mustard we put on our hot dogs…yes you guessed it - Turmeric!

Remember, it is always best to talk to your health care provider about any supplements, vitamins, alternative medicines etc you are taking (or would like to take) as some can have side effects or interact with medicines that you are taking.



Source: Wikimedia Commons Copyright (C) Badagnani

Welcome to The Independent Living Centre

“Free impartial advice and information to elderly and disabled people, offering practical solutions for easier living. You can see and try a wide range of products. We can advise where to purchase items from.”

We are happy to provide information to users, carers, family, friends and professional staff.

Our display of products for easier living includes: riser recliner chairs and armchairs, beds, kitchen fittings, level access showers, bath aids, toilets and commodes, stairlifts, hoists, walkers, outdoor scooters and wheelchairs. You can try a scooter or powered wheelchair on our outside test track.
We also have small items: eating and drinking, personal care, continence and dressing aids.

You may visit the Centre by Appointment. Our Occupational Therapist, Janey Hillier, will be available to advise you and demonstrate the equipment.

We have information on the full range of products for easier living, which can be sent to you by post or email.

We also have a Benefits Advisor, Sheila Bluer, who can advise with benefits claims, helping to complete the forms and assist with appeals.

We offer a wheelchair hire service at very good rates: by the day, weekend or week.

The Centre also publishes and monthly list of second hand equipment for private sale.

We can also assist with information regarding accessible holidays and sell RADAR keys for public disabled toilets.

Ring us on 01380 871007
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**

In this issue one of our brave group Members shares an inspirational tale of the effort she went to, last year, to help raise funds for a cause she felt strongly about. In her own words this is....

The Anchorites Tale

by

Liz Cullen

My name is Liz ......

and I am joint co-ordinator for a "Living Churchyard" - St.Giles, Stanton St. Quintin. Basically, we manage the churchyard for wildlife. We are a small team who go along twice a month and 2 of us have PsA (we do what we can but don't overdo it!) It's a great way to get fresh air and to do some gentle exercise (raking, pruning) We even have a blog - http://stgileslivingchurchyard.blogspot.co.uk/

One day, through an email from one of our Churchwardens, I learnt that our vestry might have been an ancient anchorite cell. Anchorites (female = anchoress, such as St. Julian of Norwich) are people who retire into seclusion for religious reasons, living in confined quarters. This was the "anchorhold", a tiny room or cell, usually attached to the north side of a church. It had three small windows; one for an assistant to pass in food and remove waste, a "squint" to the inside of the church for the anchorite to be able to receive communion, and a third for people to visit to ask questions. A Bishop's permission was required before a person could be accepted and he then performed the enclosure ceremony. If there was no door that could be locked, the anchorite would be sealed in by bricking up the entrance to the cell. They would follow Christ's invitation to "Come away to a lonely place and rest awhile" (Mark 6:31) and spend their time praying, fasting, giving advice to visitors (religious or practical) and mending the clothes of the poor.

All this came to mind whilst I was trying to find a way to raise funds for a small charity, Operafrica. This organisation sponsors women and children in several villages in the Gunjur region of the Gambia. I was very keen to raise funds for a solar-powered borehole to supply clean water at a new school.

I was inspired by the story of the Anchorite tradition - many people have suggested that I should be locked up (usually jokingly…) so I gained permission to be an "Overnight Anchorite" who would be locked in the vestry for 12 hours, overnight, with only the bats for company and hoped lots of people would sponsor me to do so!

I got in touch with the local press and the event was written up by both the Gazette & Herald and the Wilts & Glos Standard! It certainly helped to spread the word that a rather mad woman was being sponsored to be locked in the vestry of St. Giles, Stanton St. Quintin, overnight during that August.

I was very thankful for all the support I got the Bishop of Bristol even came over to carry out an 'Enclosure' ceremony, similar to the mediaeval service that would have committed an anchorite for a lifetime of solitude and prayer. Many friends and family also came to see me locked away!

I have heard from many people who were there that they felt how solemn and serious the vocation of an anchorite must have been and that they themselves were very moved by the service itself. After communion, the bishop blessed the "cell" and I knelt inside it, to be scattered with dirt, to the words "From dust you came and to dust you shall return" and then the door was locked and sealed.

The bishop had given a message about withdrawing from the noise and bustle of life, even for a short time, and this was extremely helpful to me once the Church fell silent. After the service, I could hear the remaining congregation chatting; this gradually diminished as people departed.

The final sound was the key turning in the main church door; I could hear this quite clearly from inside the "cell". The vestry is a very tranquil place and very little sound from the outside world could be heard. I might have felt disconcerted by this, but instead, I felt very comfortable with the peace and quiet. I spent my time before retiring in thought and prayer,

Liz has asked me to share the link to Operafrica with you - if you wish you can make a donation and every penny raised goes to the Gambia
www.operafrica.com

and even when I was awoken in the night by a strange noise, I was secure in the thought that I had been blessed before!

At 7.30 the following morning, I was relieved to hear Hilary Greene turning a key in the vestry door, to be followed by a reporter from BBC Wiltshire Radio, wanting a live interview on how the night had been. I hope I sounded coherent in my responses to her questions!

What I didn't tell them was the impact on my arthritis - I didn't want the focus on that. To be honest, I had many days of pain afterwards that I didn't confess to anyone, apart from my husband. After all I'd slept inside a sleeping bag, on a foam mattress directly onto a stone floor so as you can imagine - my joints complained loudly!

The response from people was overwhelming. I am pleased to have drawn attention to our beautiful, historic church and to Operafrica. The total sponsorship passed £1500 and continued to rise!

Being enclosed as a temporary anchorite has enabled me to feel stronger in my faith and to fully value the warmth of feeling that people have towards helping others.

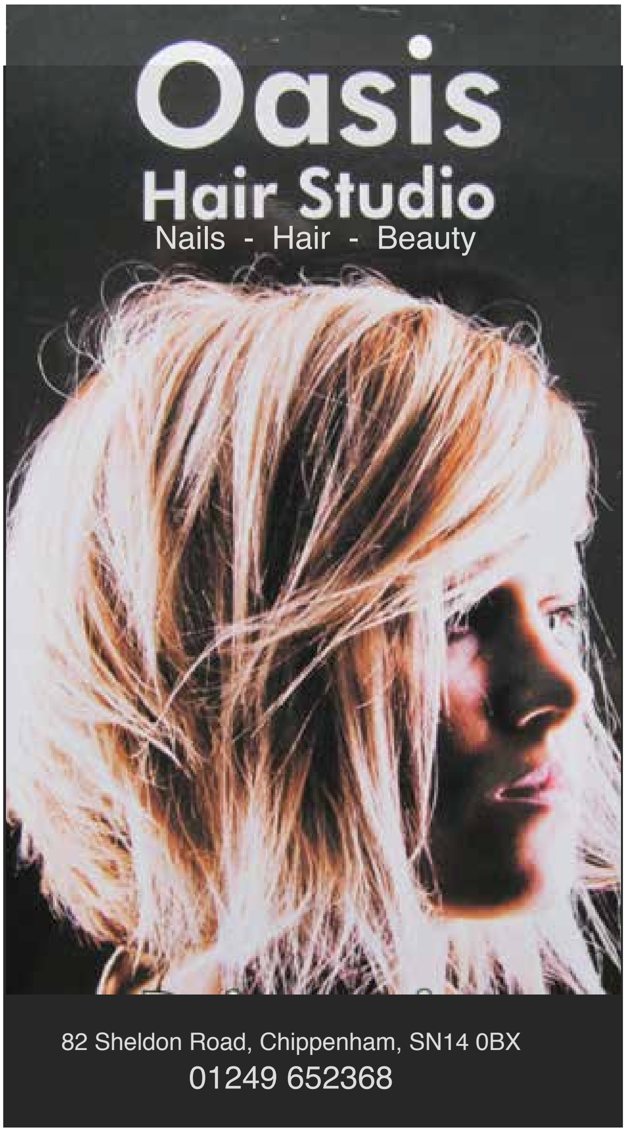
My only sadness is that I have been recommended by the Consultant's nurse, not to go to Africa, because of the Immunosuppressants that I am taking. I'd have to be off my medication for 4 to 6 months, to be able to take the Yellow Fever Vaccine. She thinks that I would find this very difficult, given the problems I'm having at the moment and also that when I go back on the meds afterwards, they are never as effective. If any PsA folk have had the Yellow Fever jab and coped, I'd be very interested!

I think everyone will join with me to say Thanks for sharing this great story Liz!

POPSHOP
WILTSHIRE

Pop Shop Wiltshire is a pop-up showcase
for local, social, ethical and green
products made in and around Wiltshire
visit us at

Emery Gate, Chippenham



Oasis
Hair Studio
Nails - Hair - Beauty

82 Sheldon Road, Chippenham, SN14 0BX
01249 652368

Bath Institute for Rheumatic Diseases
Trim Bridge, Bath BA1 1HD www.birdbath.org.uk 01225 448444 BIRD@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 www.birdbath.org.uk, email BIRD@birdbath.org.uk or call us on 01225 448444.

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.

All 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**

Dear PsaZZ..

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

In this issue one of our group members, Sara C., has passed on these great tips:

Why not try the hydrotherapy pool at Bath University - it's in the sports village, you have to email/phone to book - it works out slightly more a session, but on all but one occasion I've had the pool to myself. The changing rooms are really nice plus they have hairdryers (essential this time of year!) I asked for more details and was told this:

The facility is at 'Team Bath' at the University - the building where the swimming pool, sports facilities are located. Its the hydrotherapy pool next to the 'Gold Changing Rooms' (they have two pools - its not the one in the physic suite), you just pay at reception once you've made a booking. Parking I think is free after 6pm or chargeable before that…its cold/windy on the walk to/from the car park so wrap up warm in the winter! Its also near the main University bus stop. Maybe if a few people wanted to join together for an evening session?

The hydro pool can be booked out exclusively for individuals at a cost of £12 including vat per half hour (9-5) or £24 in the evenings.

If you wanted to bring someone along with you then the cost for shared use would be £5 each in the daytime or £7.50 in the evenings.

Sessions can be provided when the pool is not in use for athletes or students and as these times vary from day to day, you will need to call or e-mail me in advance to book a session.

The other thing I've found really useful is ***Feildenkrais*** - here's the person I go and see www.feldenkrais.co.uk/profile.php?id=204 - its helped by correcting my posture after years and years of me subconciously holding my shoulder in a protective way (pain & the fear of people bashing into me), and re-adjusted my mental relationship with my physical body.

A. *Thanks for passing on the information about the hydro pool at Bath University Sara - hopefully other members of the group will find this really useful too. Also I've never heard about the Feldenkrais Method so it's a very interesting tip!*

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

psazzgroup@gmail.com

PsAZZ
Psoriatic Arthritis Support Group

Our Mission Statement

To connect, to share experiences and support each other.

PsAZZ is a self-supporting, volunteer run group and we would love you to help us! We currently rely on goodwill gestures for everything we do from people's time helping to co-ordinating activities, to having a room to meet in (and supplying refreshments) to writing for our newsletter...emailing.. printing...helping with administration and so on! Together we could do so much more...

Do you think you might be able to help?

email psazzgroup@gmail.com

We talk, we understand, we share how we feel.

We also have a sense of humour!

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

www.livingwithpsoriaticarthritis.org - online support group

www.psazz.webs.com - The PsAZZ website

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

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

psazzgroup@gmail.com

Join us next time…

for write ups from new 'Topics of Conversation',
updates, readers stories
& more!

Join the us on facebook
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or try our new website:
www.psazz.webs.com