



REG. CHARITY NO. 1129395
www.westwalesprostatecancer.org.uk
Patron: Chris Jones. Television Presenter.

NEWSLETTER

JANUARY 2020

Dear Member/Friend

Happy New Year to you all and to a new decade too. Let's hope that in this one someone comes up with a sure-fire way of detecting Prostate Cancer (PCa) and dealing with it! There is so much publicity about PCa (the "Stephen Fry/Bill Turnbull effect") and yet we still hear of men being denied (or persuaded not to have) a PSA test OR finding out too late that they have advanced PCa.

Welcome to this edition of our Group's Newsletter. I'm sorry that, for personal reasons, there has been a big gap between the last one and now.

If anyone has any items they would like to appear in the next or future half-yearly newsletters please let me know. All contributions or ideas gratefully received. (DG).

"Pub" Lunches

There was an excellent attendance at the Christmas lunch at Nantyffin. We are grateful to Gill Lewins who has arranged these events for the group in the past but regrettably will not be continuing with this

role.

These lunches are always a good way to catch up with other members and partners. They are felt to be a vital part of our work so **the Committee would like to hear from anyone who feels that they would be able to take up where Gill has left off.**

The following dates have been arranged:-

Pub Lunches for 2020

2nd March 2020

Newcastle Emllyn Rugby Club
Dol Wiber, Adpar,
Newcastle Emllyn SA38 9AZ

1st June 2020

Tafarn Tanerdy, Penlanffos Road,
Carmarthen SA31 2EY

7th September 2020

Newcastle Emllyn Rugby Club

7th December 2020

The Nantyffin Hotel, Llandissilio,
Clynderwen, SA66 7SU

Outreach work

In June 2019 Ken visited Tata Steel in Llanelli representing our group at a Men's Health session. The event was organised

by Sarah Russell-Saw of Macmillan Cancer Support. Ken tells us that he spoke to quite a number of men and left several leaflets. This was a useful, well-attended event and positive contacts were made. Sarah says "We had a terrific day & I reckon we spoke to about 104 people on the day - not a bad number!"



Ken with Lisa O'Malley, Janet MacKrell and Sarah Russell-Saw at the TATA Steel "Men's Health" event..

New Committee member Clive Lewins booked a pitch for the group at the Fishguard Show. Clive asked for our pitch to be in a discreet corner to allow the opportunity for people to have sensitive conversations. The stand was manned by Clive and Ken in the morning with Ken Davies, John Coaker and Clive in the afternoon. Clive also took one of our collecting boxes to the Fishguard open market and between the two events collected the sum of £47.27.

Raising awareness

Posters

One of our members Graham Lewis has designed posters in both Welsh & English; these can be used in conjunction with the poster designed by Phil Burr. The Committee agreed these posters are very good and have had them printed. They have already been used and are ideal for promoting awareness in plumbers, builder's

merchants and any awareness raising events attended.

The Group now has another "pop-up" poster as seen in some of the photos. If anyone is organising an event please contact Ken to borrow one.

Ken Jones and Chris Jones have been in discussions with Prostate Cymru regarding greater cooperation between the two organisations.

The Group's Facebook Page.

Just to remind you all that David Bunce has set up a Facebook page for the Group. It is a closed group and you can ask to join by searching Facebook for The West Wales Prostate Cancer Support Group. There are clear guidelines and it will enable members to communicate and message each other, provide dates and information and updates. This approach is new to the group and will be monitored. It has been very successful with lots of contributions and people sharing information and personal stories. Please check it out.

Future collection dates:

Collections dates for 2020 have yet to be confirmed but please see comments below.

David Parmar-Phillips would appreciate offers of help from anyone who feels able to "man" our stand. Please see the Contacts list at the end of this newsletter.

We would also appreciate some help with our store collections. If anyone has ideas for future places we could "collect" from or if you feel you can help in any way please get in touch with Ken or any of the Davids,

or chat to us at the next pub lunch. It's not really about the money but the opportunity to be seen in the community and get our existence known. It's a chance to interact with the general public and answer their queries where possible or point them in the right direction.

Donations received with our thanks:

Karen Bannister

Member John Coaker received a cheque for £130 kindly donated to our organisation from his neighbour Karen Bannister who raised the money by selling sweet peas and open garden visits throughout the summer of 2019.



Karen's sweet peas for sale. A reminder, perhaps, that Spring is just around the corner?

Open Garden event at David and Gill Shepherd's garden 14th July 2019

Members David and Gill Shepherd held an Open Garden event on the 14th July 2019. Gill reports:

"The Garden Opening at Marlais and Llys Hedd was a great success. We had 127 visitors which was as many as we could cope with in gardens of this size. The visitors were very complimentary about the gardens and enjoyed the contrast between the rather formal hard landscaping with

separate areas for floral beds, vegetables and fruit at Marlais and the informal cottage garden with a needlework exhibition next door at Llys Hedd. The delicious and generous teas were also very popular as were the interesting selection of plants for sale which had been grown by TWWPCSG founder and member Phil Burr. The opening and sale of plants raised £432.10 for TWWPCSG and a similar amount for The National Garden Scheme which donates over £3 million to cancer and nursing charities each year."

We thank the Shepherds, Phil and all those involved for their hard work and of course, the generous donation to our group.



Just part of Llys Hedd's beautiful garden display

Carmarthen Ukulele Band

On the 18th December Ken Jones received a cheque for the sum of £575.05 from the Carmarthen Ukulele Band, which, added to the collection made on the Sunday afternoon, came to a total donation of £650.00. Pat Evans said "The money

raised was through the two days busking and some events we have played. We are always grateful to shoppers and visitors to Carmarthen, who support us when we busk, as it makes donations such as this one possible."



Ken with the members of the Carmarthen Ukulele Band

Admiral Insurance, Swansea

Admiral Insurance raised a very admirable £906.37 from a fundraising walk in July 2019. Ken visited their Swansea office and thanked Vanessa Vaughan and her colleagues for their magnificent effort in raising funds for our support group.



"Admiral" Ken in the chair with Admiral staff in attendance.

Huw and Ieuan Jones

On the occasion of their 70th birthday celebrations Huw and Ieuan Jones from Llanwrda decided to hold a concert at the Coronation Hall Pumsaint with the

proceeds of the evening to be split between the hall and our Group. A donation of £1,722 was handed over to the Group at our Nantyffin Christmas lunch in December.

Bella's Wools of Fishguard very kindly collected £76. Bella herself donated £50.

Update on the sponsored Spanish walk

As reported in the April 2019 newsletter. Viv Perry raised £315 for our group whilst completing the Camino Walk from Sarria to Santiago in Spain. On Viv's behalf, Duncan McNally presented the donation to David Bunce in October last year:



Duncan McNally handing over the £315 cheque to Treasurer David Bunce at our Cottage Inn Pub lunch last October.

Lammas Street Centre

Following their donation in September 2018 we have received another cheque for £500 from the Lammas Street Centre, Carmarthen.

We thank all of these people and groups for their generosity.

Tenovus ACTivate Your Life.

Bill Roebuck reports:

"I was diagnosed with prostate cancer in the Spring of 2011, with 35 days of radiotherapy at Singleton Hospital in the Autumn of that year. For a while my PSA was at rock bottom, and life carried on as usual. Five years ago my PSA started to climb, which was a concern as I was (and still am) on 3-monthly hormone therapy injections. No real explanation was forthcoming for this, although the attention from Glangwili Hospital was excellent, putting me on 6-monthly monitoring checks.

Cancer really is the devil to deal with, especially with the hormone injections causing havoc with emotions. Following two, close, family bereavements the inevitable happened and my mind went into freefall, suicidally so. Fortunately the Tenovus ManVan was operating at that time, and the 'resident counsellor' Paul Rogers pulled me back from the brink, helping me to a slow recovery although I am still on anti-depressant medication.

Although my head is much better than it was I still get occasional relapses, so when I saw in the September 2018 newsletter details of the ACTivate Your Life course run by Tenovus I was immediately interested. I should perhaps explain at this stage that I am not the sort of person who usually attends courses! I find it hard to cope with groups these days, and I had enough of 'courses' when I was at work.

After some thought I decided to bite the bullet, looked up the course details on the Tenovus website (<https://tenovuscancercare.org.uk/how-we-can-help-you/active-your-life/>) and in due course turned up at the venue in Port

Talbot for the first of four 2½-hour sessions. I had gone more in hope than expectation, but even after the first session I realised this was for me. The course is non-participatory, so I didn't have to explain anything about myself, just watch and listen, and with course presenters friendly and effective in getting the message across I came away feeling a real buzz.

The remaining 3 sessions (ACTS in course parlance) were just as useful, and I finished the course equipped with a set of mental tools and exercises that have proved invaluable since. I was so impressed by the course I subsequently volunteered to help run it, and after training I hope to be presenting some sessions later in the year. Now I couldn't have done that before I did the course.

So even if like me you don't 'do' courses - go on, try it just this once. I can recommend it!"

Bill Roebuck, July 2019.

Thanks for that Bill. Interestingly, we have had recommendations for this course from other members.

Members' stories

From time to time members submit their PCa stories for inclusion in our Newsletter. One such account, by David Roberts follows:

David's story

This is where my story begins.

I have suffered from kidney stones from the age of seventeen (I was born in 1945) so it was no surprise that in February 2019 I suffered another bout of kidney pain. In addition to the pain, I had blood in my urine so consequently arranged to see my GP as

an emergency patient that day. My GP confirmed that blood was present and proposed a referral to my local hospital's Urology Department. As I was concerned about the NHS waiting time (possibly four to six weeks), I requested a letter be sent to Bancyfelin Hospital where I could be seen privately thus reducing my waiting time and associated anxiety.

Some two weeks later, I attended Bancyfelin and was seen by Consultant Urologist, Mr Andy Thomas. After discussing my previous medical history he performed a Digital Rectal Examination (DRE) of my prostate and commented, "...that is nice and small." Mr Thomas informed me that his role was to ensure that no cancer was present in my urethra, bladder and of course my prostate. He suggested that I consider having cystoscopy examination from which he could determine whether or not cancer was present in these areas. He asked when I last had a PSA test. I informed Mr Thomas that I had considered a PSA test some months previously. I discussed it with my GP, and was advised that PSA test results were somewhat vague. I decided not to have the test. Mr. Thomas recommended I have a number of blood tests including a PSA test, and I confirmed that I would undergo the cystoscopy examination.

Monday 4th March - more pains in my left kidney and for the first time ever I passed a kidney stone myself, rather than surgically. I was happy in the thought that my kidney stones were, once again, apparently the major cause of my medical problems. I only wish that that had, in fact, been the case!

A few days later I was back at Bancyfelin

to undergo the cystoscopy. This entailed passing a thin camera through the urethra and into the bladder. Yes, I was on edge, to put it mildly! I watched the camera's images on an overhead monitor and indeed could see my prostate which was commented on as "...looking fine." So with this procedure over, and a further appointment made for Friday 15th March to review my blood tests, I went home feeling somewhat relieved. To date my prostate appeared not to be enlarged and the cystoscopy showed nothing untoward.

15th March was the day that matters became somewhat more serious. I was given the result of my PSA test: it was 13. Most men of my age, I was informed, should have a PSA around 2 or less. Due to my higher than normal PSA, further investigations would be required: my best course of action now was an MRI prostate scan. The MRI scan indicated I had two lesions associated with my prostate, that I was informed had a 60% chance of being cancerous. One of the lesions was just outside the gland and one in the middle of it. Being told that you have a high chance of cancer is such a shock, even though the final diagnosis, requiring a biopsy, had yet to be confirmed.

My discussion with Mr Thomas now focused upon what were my options and what would the cost implications be of private treatment versus that available on the National Health. I could be passed over to the NHS and undergo a "blind biopsy" or I could stay under the private care scheme and undergo a fusion targeted prostate biopsy under general anaesthetic. This is a far more accurate way of ascertaining whether or not cancer cells are present in my prostate and surrounding area. I must say that I was at no time

under pressure to continue private care. Mr Thomas was just outlining the options available to me in a very calm and understanding manner which helped me enormously. At this point I should say that I was concerned over the cost implications of private treatment, not only to date but for any further treatment as I am totally self-funded, I have no private medical insurance.

Never-the-less I decided to go ahead with the fusion targeted biopsy which I underwent at the Vale Hospital, Cardiff, on 26th April, following my pre assessment on 11th. The biopsy, under general anaesthetic, was performed by Mr Thomas and his team. It was straight forward with very little discomfort afterwards. Some twenty plus areas were targeted and the samples sent off for analysis. My time at The Vale Hospital was short: arriving there at seven in the morning and leaving for home around four that afternoon.

I passed a stressful 2 weeks awaiting the results, which were given to me at the Nuffield Hospital, Cardiff Bay, on the 9th May. Despite all that had happened to me over the previous few months, being told that you do, in fact, have prostate cancer overwhelmed me. Did I actually hear correctly? Can this be happening to me? The answers comes back - Yes you heard correctly. Yes it is me we're talking about!

"What are my options now?" I asked....

Radical Prostatectomy was not considered appropriate because the lesion outside the gland would still require Radiotherapy, following the surgery. I could be transferred back to the NHS and undergo 4 weeks of "conventional" Radiotherapy at Singleton Hospital. However, I could consider the most advanced form of

treatment in the UK - Proton Beam Therapy (PBT), available at The Rutherford Cancer Clinic in Newport. This treatment, whilst expensive, does have many advantages over conventional radiotherapy. A "spacer", implanted under general anaesthetic, between the prostate and the rectum before the therapy, reduces the chances of incontinence and damage to areas outside the prostate during the therapy. PBT is delivered with more precision and appears to be safer than conventional radiation therapy. It also appears to be more effective because PBT delivers a high dose to a very specific area, with minimal impact on the surrounding tissues.

I was informed that as prostate cancer had now been diagnosed I should undergo a bone scan to discover whether or not the cancer had spread into my bones, as sometimes this can happen. Accordingly an isotope bone scan was arranged for me at Bridgend Hospital for the 20th May. Four days later my Consultant confirmed that the scan showed no evidence of any metastatic bone cancer. The best news I had received to date!

Mr Thomas also advised me that as prostate cancer tends to run in families, I should inform any sons that I have of my diagnosis, and urge them to undergo a PSA testing on a regular basis if they were over the age of forty. Having listened to everything the consultant told me I informed him that I would consider all options and get back to him with my final decision as to which form of treatment I would now undergo. Some two days later, I confirmed with Mr Thomas, that I wished to explore further, the option of Proton Beam Therapy. I asked him to arrange for me to visit the Newport Clinic

to meet one of their senior Consultants.

On 5th June I met with Dr Jason Lester at The Rutherford Cancer Clinic, Newport. This facility opened in 2017 and was the first Rutherford Centre in the UK to offer high energy proton beam therapy, treating their first patient in April 2018.

Whilst I have to admit to being somewhat apprehensive when entering the clinic, the manner in which I was welcomed by all staff was very professional and reassuring. The waiting room is very relaxing with many refreshments available, modern furniture to relax into and daily newspapers to read. I met Dr. Lester who reiterated everything that had been confirmed over the previous month by Mr Andy Thomas. He also described the way in which his (The Rutherford) Centre could help cure me of my cancer. He and his colleagues would prepare a treatment plan for me together with a costing which would include all my treatments including the cost of the "spacer" implant.

The Consultant's reassurance, straight forward manner, and time afforded to me, convinced me that PBT was my best way forward. Before I left Dr Lester I had made up my mind that I would go down the PBT route and advised him accordingly. A few days later I received my quotation, information package, and a letter giving me the date of my Pre-Assessment/Evaluation Scan.

On 5th July I was a day patient at The Vale Hospital where I had my general anaesthetic for the insertion of the "spacer". I was then driven to The Rutherford at Newport, for a short MRI Scan to confirm that the "spacer" had been correctly placed between my

prostate and rectum. All was fine so after what was a long day I was driven back to my home in Pembrokeshire.

A week later I again attended The Rutherford where I met the members of the clinical team and to undergo a further MRI Planning Scan and a CT Scan. These scans were to enable the team to undertake precise measurements of my prostate and other organs necessary to enable the proton beam to be accurately positioned throughout my treatment sessions. At the age of seventy three I had my first tattoo, albeit a micro spot on each of my thighs and one on my pubic bone! These spots would be used as reference points, when I underwent my actual treatment. I have to compliment all the clinical staff for the consideration and kindness afforded to me each and every time I was in their care.

My treatment plan consisted of seven PBT sessions, spaced over a three week period. At my last session I would undergo a treatment review and in December 2019 an MRI Scan followed by a further follow up consultation in February 2020.

Three days prior to my first session, and for each of my seven treatment sessions, I was instructed to take Movical so that my bowels were regular, and an hour before my actual proton beam therapy I had to insert a Microenema into my rectum in order that the lower bowel was empty before treatment commenced. I was informed that it is important that during my treatment I keep hydrated at all times, and that immediately prior to my actual treatment I must drink 350 ml of water.

I must confess I was very nervous when one of the team members called me for my

first treatment session. I was asked to change into hospital trouser bottoms, whilst keeping all other clothing on except for my shoes. Once I was correctly dressed, I was taken through the secure doors and into the rooms where the treatment is given.

To walk past a computer room with three team members sat in front of numerous screens and then into the room that houses all of the proton beam equipment is very unnerving, especially for the first session. To see the room that houses the proton beam equipment and all the supporting equipment is truly a mind blowing experience. Frankly it seems like something out of science fiction. Ceiling lights that change according to what relaxation themes I chose, music of my choice whilst having treatment, three radiographers looking after me and all in a relaxing and reassuring atmosphere. I certainly needed the reassurance in what was a surreal environment.

I was required to lie down on a bed located under the actual proton beam machinery whilst two of the radiographers moved my body into the required position. The tattoos now came into play, as they were used to confirm that I was in the correct position for my treatment. An ultra sound was taken of my bladder to ensure that it contained the desired 350 ml of urine and, if not, then I would be taken back to the changing rooms to drink more water and be re tested. Once the desired volume was achieved, a scan was taken whilst the radiographers stayed in the room reassuring me that all was well. Having completed the necessary positioning scans the radiographers left the room prior to my treatment starting. I found it incredible that these highly skilled, young

radiographers, worked with so much confidence on such advanced equipment.

I had to lay completely still at all times whilst the proton beam automatically came up to the predetermined position, starting at my left hand thigh. I felt nothing and could see nothing for the two minutes that the proton beam entered my body but I knew that via the cameras within the room I was being monitored by the team. Prior to the radiographers leaving me they said that they would be watching me, and if at any time I was uncertain, or unhappy, all I needed to do was raise my hand slightly and they would return to me.

After having my treatment completed on my left side, the bed automatically repositions itself - taking one minute and thirty seconds - so that my right hand thigh aligns with the proton beam. Again I felt nothing and heard nothing whilst my two minute treatment continued. A total of four minutes exposure to the proton beam and one and a half minutes changing sides and it was all over!

I changed back into my normal clothes, had coffee and snacks in the reception room, and it was off back to Pembroke. All my treatments were exactly the same in terms of procedures, and to be very frank, the worst thing about the whole experience is the insertion of the microenema: each and every time!

My last two sessions were however not undertaken at Cardiff, as there was a problem with part of the proton beam equipment which resulted in me being asked to attend their Reading Cancer Centre. I was informed that a car would collect me from my home in Pembroke and drive me to Reading where my regular

radiographer team would meet me and give me my usual treatment. The Rutherford at Reading, installed their proton beam equipment many months ago but this was the first time they had used it for the treatment of prostate cancer and indeed the first time that computer generated files of a patient were sent from one cancer centre to another. After treatment and a light lunch, the same car drove me back home

The day of my last treatment the same thing happened again, driven to Reading and receiving my treatment but this time I was asked if I would like to ring the Final Treatment Bell. This bell is positioned in the main reception hall and when I said yes I would certainly like to ring it, unknown to me at the time, various staff members came down to reception to see me be the first PCa proton beam patient to ring the bell. It was an emotional time for sure, as after ringing the bell I was congratulated by the staff before getting into the car to be driven home to Pembroke.

I would like to think that by writing this article my experiences over the past seven months might perhaps help others who may face the same health issues. Looking back I feel that there is a major concern for men who perhaps have prostate problems and who may be, as indeed I was, uncertain about taking the PSA blood test. We are told the test is somewhat vague, in my case I was informed at the GP surgery, that as a general rule, if the PSA count is less than twenty then I would have been referred back for another test after six months. That's not good enough! My PSA was thirteen and I had cancer!

I finish by asking the question, if all men were to undertake PSA testing followed by

an MRI scan, to give an accurate diagnosis, would our hospitals be able to cope?

Thanks to all who helped me on my journey.
David Roberts - September 2019.

Thank you David for your frank and interesting account of your experience of this very new therapy option. DG.

Project Update - 1

Prof. Norman Ratcliffe's project "Can PCa be sniffed out?"

(WWPCaSG donated £23,266 to this research project in 2018 -DG)

A report from Terry Devine - PhD Researcher working with Prof Ratcliffe.

"To date I have been actively working on attaining a sufficient working standard for the instrumentation to be used for PCa analysis. Part of our research will be undertaken using novel, UWE fabricated, Automated Thermal Desorption Gas Chromatography Mass Spectrometry (ATD-GC-MS)-Sensor equipment (Demonstrated at our 2019 AGM DG).

PCa samples are pre-treated and loaded onto Tenax tubes where they undergo thermal desorption ready for separation and analysis via a chromatographic method (GC).

The data produced will be further analysed and compared to a Mass Spectral database (NIST) for identification purposes. Presently, we are in the process of arranging the collection of 200 PCa samples (100 cancerous; 100 controls). It is all looking very promising and as soon as all the details are finalised we will commence analysis. Hopefully, the results enable differentiation within the stats models of patients with aggressive and non-aggressive tumours.

Similarly, I have been analysing the urine head space of volatiles from 24 mice bedding samples. The mice depositing the urine on the bedding samples have been further stratified into groups pertaining to the appearance of a metastatic tumour, tumour or otherwise classified with no-tumour present. Studying mice which are genetically pre-disposed to developing cancer over short lifespans might enable tracking of changes in metabolites in a longitudinal study. Solid-phase microextraction Gas Chromatography Mass Spectrometry (SPME-GC-MS) was utilised to analyse any significant differences between cancerous groups and non-cancerous controls in order to identify any disease specific volatile markers of interest. We recorded some promising results.

*Terry Devine, ACSFS, PhD Researcher;
Department of Applied Sciences
UWE.*

Terry has promised to keep us updated on developments - DG.

Project Update - 2

Cancer Research Wales (CRW) project- "The PCa Diagnostic Pathway in Wales" (WWPCaSG donated £50,000 to this research project in Financial Year 2016 - DG)

Lisa Formby is a Prostate Cancer Researcher working on this project and based in the North Wales Centre for Primary Care Research, at Bangor University.

This research, funded by Cancer Research Wales with the generous support of the WWPCaSG, seeks to understand more about the journeys that men take to their diagnosis of prostate cancer. Lisa hopes to

capture the whole pathway, from first noticing symptoms through to primary care, referral and commencement of treatment. Prostate cancer is the most common male cancer in Wales, with around 2,500 men being diagnosed each year.

Symptoms of prostate cancer may develop over time and some patients experience symptoms up to one year prior to diagnosis, while others are without symptoms. By describing, in detail, the factors and influences that contribute to men's diagnostic journeys, Lisa and the rest of the research team hope to be able to identify potential interventions to prevent unnecessary delays in diagnosis.

Extract from Lisa Formby's blog:

"I am working on a study exploring the diagnostic pathways of men with newly diagnosed prostate cancer in Wales, from first symptom or no symptoms to diagnosis. This will involve a patient's journey from primary care (GP) through to secondary care (hospital specialist).

The intention of this study is to further understand this important journey and determine potential interventions that in future could help prevent unnecessary delays, allowing for earlier diagnosis and swifter treatment.

The study is using a mixed method approach, which includes collecting data through questionnaires from patients, GPs and hospital specialists, as well as interviews with patients. This kind of approach provides the research team with a more inclusive set of findings, and a deeper understanding of the questions that we are trying to address."

E-mail contact addresses

Many of you have given us your e-mail contact addresses over the years. We are then able to send pub lunch reminders and details of research questionnaires etc. We use 'Blind Carbon Copy' (BCC) to send these e-mails to maintain your confidentiality. Some of these come back undelivered, possibly because you have subsequently changed your e-mail address.

Please keep us updated if you change, or now have, an email address.

Some of you will have received this newsletter by email as you requested. If any of you who were sent a paper copy would prefer to receive an electronic version (in full colour!!!) in future, please let me know. Aside from the benefit of seeing all the published photographs in colour, you will also help save Group printing and postage costs.

Best wishes from David Goddard on behalf of the Chair and Trustees of TWWPCaSG.

TWWPCaSG CONTACTS

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Pub Lunch Coordinator:
Awaiting offers of help!