

FEBRUARY 2012



2012 supplement

PCaSO PROSTATE CANCER NETWORK

for Dorset, Hampshire and Sussex

Charity No: 1095439

SPECIAL HISTORY ISSUE

In January 2002 PCaSO came into being. In this special supplement we recount some of its early history and the trials it went through, and recall the contributions of some of its founder members.

We remember with gratitude their support, and especially those that are no longer with us. We would like to thank especially David Rowlands, our founder, and others that have contributed their memories and photographs.

TEN YEARS ON, AND ALL WHO SERVED

A message from our founder

PCaSO has reached its first ten years. What does the future hold? Only you may have the answer!

Thinking back to our humble start in Havant, as we grew from PSA Solent, my immense feeling of pride is tinged with sadness, respect and thanks to those no longer with us. None of the achievements of PCaSO, and there are many to be proud of, have been solely down to any individual. It has always been a team approach, with our common goal of offering Help, Support and Information to those affected or concerned about our cancer.

Since then PCaSO has embraced like-minded organisations across the south to become a significant and well respected voice in the corridors of power, with representation at many levels covering just about every important aspect of our cancer. But ask your committee – and they will tell you there is much more needs to be achieved for our cancer to get the full recognition it deserves.

Perhaps you could help, as others did in those early humble days of development, as none of our efforts could have been achieved without the staunch, dedicated support of good friends over the years.

From the onset people like Des Grey, Peter Lyons, Dan Gaffney and Jim Stansfeld all played major roles in the development of our PCaSO. And let's not forget that behind every volunteer, there's usually a wife or partner, who has kindly 'loaned' and supported the volunteer.



A BIG THANK YOU TO ALL!

It was during those important developing years we had the incredible dedication and endeavours of our former patron, Major Ronald Ferguson. With his death in 2003 we lost an ambassador *par excellence*. He worked relentlessly on many fronts, especially leading a petition to Downing Street in 2000.

In 2001, one of his initiatives, 'The Duchess of York Trophy' at Dummer Golf Club near Basingstoke, continues to raise the profile not only of our cancer but also, equally importantly, valued funds. The Memorial Fund established in his name (and managed by PCaSO) which supports many just causes, is seen as a lasting and proper tribute to him.

We should also recognise the valued support of our current Patrons, Lord Palumbo of Walbrook, His Grace The Duke of Richmond and Gordon, Bill Beaumont OBE of rugby fame, and The Very Reverend Nicholas Frayling, Dean of Chichester Cathedral, who will be addressing us at our forthcoming Annual Meeting.

Coming back to my question: 'What does the future hold?' There must be many of you who feel now, as I did back in 1999, a sense of purpose to do ones bit. Go on – ask a committee member, what you can do?

My kindest regards and thanks to the many.

David Rowlands
Founder

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Help Line: 0845 650 2555

Website: www.pcaso.com

THE BIRTH OF PCASO: EARLY REMINISCENCES

DAVID ROWLANDS

It was in 2002 when PCaSO formally became a Charity. Prior to that time we operated as a group under the umbrella of an organisation called 'PSA' (Prostate Support Organisation) which had small member throughout the UK.

How I became involved with PSA stems back to my diagnosis in 1998 and the problem we all face at that time – where to get information from someone who's been there. I contacted Juliet Gilchrist at Cancerlink in London (before it became incorporated with Macmillan) and was given details of PSA, who held meetings at the Cancerlink centre. My good friend Roy Nixon from Manchester joined PSA at the same time. Roy was a dynamo, despite having very advanced prostate cancer which had metastasised to his hips and back; yet rarely did he complain. (Roy died in August, 2002).

Initially the meetings at Cancerlink were of interest and value. However, as suggestions made by Roy and me to embark on bigger issues than just chat and support were met with opposition, we began to have doubts. Both Roy and I realised that we were disrupting a cosy environment, as it seemed that no one wanted to do anything which involved thinking, challenge and work.

It was in 1999 that I became National Secretary to PSA. We faced many obstacles, like the introduction and distribution of the the first newsletter. Even when I became Treasurer, problems continued. We now know that the chairman of PSA at that time saw his authority slipping away. It was then that my wife Shirley and I made contact with Major Ronald Ferguson (who lived at Dummer, near Basingstoke) following the disclosure of his prostate cancer by the Daily Mail. He phoned me and expressed a great willingness to come on board as a patron. The chair of PSA insisted that 'Major Ron', as he became known to us, would be addressed only as 'mister'. Nevertheless he still came on board!

Roy was the first to make the move away from their environment. Under the umbrella of PSA, he set up and expanded PSA North West and jointly we began to embark on pushing the

boundaries. Our first activity was to lobby all MPs with postcards from their constituents pressing for a better deal, more funding, research and screening. This had a desired effect raising Questions in both houses.

Roy's next step, much to annoyance of PSA, who thought it would be a financial disaster, was to take over Manchester Town Hall for an international conference. It was an outstanding success, with some 200 attending, and of course raised the profile of our cancer. Speakers included Dr Tom Stuttaford (health correspondent of The Times and himself a sufferer) and, from the USA where Roy had contacts, Dr Charles 'Snuffy' Myers. It was in fact Roy's contacts that led to our liaison with USToo, to which we eventually became affiliated. Many members will remember receiving USToo 'Hot Sheets' with their newsletter mailings.

I followed Roy's initiative, having made excellent contacts in Solent area. We were able to have Gosport Town Hall for a day, attracting nearly 300 attendees and excellent speakers – Simon Holmes (then consultant urologist at St Mary's Hospital in Portsmouth and later to be our first medical adviser), Ann Rowlands (our much respected nutrition adviser who recently emigrated to New Zealand) and John Davies (consultant at the Royal Surrey County Hospital at Guildford) who spoke about the new cryo-ablation method of freezing the prostate, for which he was awaiting funding. The 'icing on the cake' (no pun intended!) was a phone call to John during the meeting, saying that funding had been approved.

Some while after this I went to Guildford and watched via video link one of the first cryo-ablation operations in the UK on an 80-year-old man. Our host was none other than Professor Aaron Katz, who gave loads of information on how patients could help themselves. This was the embryo for me to produce a series of leaflets on diet, supplements, diagnosis, treatments etc., all now embraced in our acclaimed booklet *Knowledge Empowers*.

By now we were embarking on many ventures outside the 'PSA comfort zone', sadly much to the annoyance of the head office of PSA in London.

We established PSA Solent (still a group of the main PSA) in January 2000. This gave us further opportunities, the first being to get Havant Council to sponsor us and provide our first proper leaflet called *Unbutton Prostate Cancer*. The artwork was completed by the council, which depicted a man's trousers. It was at one of the inaugural meetings of PSA Solent in Havant Civic Centre that I met Jim Stansfeld, who subsequently became such a staunch ally. We instantly got on with each other, a friendship to last until his death from prostate cancer late in 2009. It was thanks to Jim that PCaSO's current awareness leaflet, *Don't Get Caught Out!* was produced.

Jim and I embarked, sometimes together or alone, on giving awareness talks to male-orientated organisations. Portsdown Hill ASWE saw us twice, as did the Underwater weapons at Gosport, twice to BAe Farnborough, and once to a Research establishment at Malvern. Other activities were lunchtime chats with PROBUS, and an evening with Rowlands Castle Golf Club, who sponsored us for that year.



Major Ron (on the left in the above photo) played a vital role, partly through his contacts around Birmingham, by giving talks at concerts and appearing in a radio and TV interview. Eddie Bowcott (centre, with the beard) was an entrepreneur, and a business 'cyberteam' came on board with sponsorship, which of course raised the hackles of the old men at PSA in London! Eddie Bowcott wanted to explore many wider and potential benefits of TV, radio etc. Unfortunately PSA were hell bent on dismissing Eddie



*The inaugural meeting at Havant Civic Centre
David Rowlands is speaking*

as being only there for his benefit, much to the disgust of Major Ron, who had worked with him before on many charitable fronts. This was the final straw that gave us a plan to leave PSA.

When Roy Nixon managed to establish 'PSA North West' as an independent charity, he provided the raw constitution which we eventually amended and adopted for our own use at PCaSO. It was then that problems arose with the Charity Commission. Having had a competition for a name, Mike Jenkins (sadly no longer with us) came up with the title 'PCaSO Prostate Cancer Support Organisation' which we used from the beginning of 2002. The Charity Commission would not approve the latter, saying that it may be confused with other organisations. Jim and I battled for many months, offering to meet with them, to no avail. Hence the current compromise of 'PCaSO Prostate Cancer Network', which was finally approved in December 2002.

It was around this time that the seeds of a federation were born under the title of 'cPc Coalition against Prostate Cancer'. Alan George of Cancer Belfast (one of the founder members),



David Rowlands at one of the cPc Road Shows

Cancerlink, Imperial College (under Professor Mustafa Djamgoz), Prof. David Dearnaley of the Royal Marsden Hospital, Orchid (the charity that supports all male cancers) and the Prostate Cancer Charity joined forces. Unfortunately the PCC created setbacks, as it seemed they thought we were a threat to them. Nevertheless we established excellent funding from AstraZeneca to allow more conferences in London with a host of speakers, including Dr 'Snuffy' Myers, George Baker from (*I Claudius* and *Inspector Wexford*), and Dr Gerry Chodak, an eminent specialist in the USA.

There followed a series of eight roadshows across the UK to raise the profile of our cancer. A different E type Jaguar was loaned by private individuals in each location (see photo below). USToo reported on the roadshows in its news-sheet in early 2003:

"In 2002, the road show visited eight major cities in the UK, from Glasgow to Southampton. Located in the biggest shopping malls, the attendance figures and media coverage are regarded as very successful. More than 7,500 people have visited the stands so far. Southampton attracted the largest crowds – nearly 1,900 people in a single day! Major Ronald Ferguson, patron of PCaSO (and also a prostate cancer survivor and father of Sarah/'Fergie', the Duchess of York) also helped out on the day."



The Downing Street Petition - 2001



Another important event for the cPc Coalition was a petition to Downing Street led by Major Ron. The photo above shows Roy Dixon, Dr Tom Stuttaford, Major Ronald Ferguson and Burt Kwok at the gates of 10 Downing Street. At another notable road-show event with Jim Stansfeld at the NEC Birmingham Garden Show we did our best to get Charlie Dimmock or Alan Titchmarsh on the stand, but no luck!

In the midst of all this we should not forget the staunch support and funding from the Caring Cancer Trust on the Isle of Wight, who generously supported PCaSO through their regular collections.



*Major Ron receiving a cheque from
Martin Gomez*

Our local meetings of PSA Solent, with guest speakers, were held in Havant, and we established our own newsletter to supplement the national PSA news-sheet we had managed to organise.

THE NEXT TEN YEARS

This account of PCaSO from 2002 to 2012 is intended as a tribute to the many who have served PCaSO, some of whom are now no longer with us and who devoted so much of their time to serving our charity.

We have seen how 'PCaSO Prostate Cancer Support Organisation', founded in January 2002 when it broke its ties with PSA, had to be renamed. Thus PCaSO Prostate Cancer Network held its first Annual General Meeting in January of the following year, by which time its membership had spread from the initial 30 or so to 400 members – 225 men with prostate cancer in our region (which was mainly Hampshire at that time). David Rowlands, although still taking an active part, stepped down as chairman, and its first committee members were Jim Stansfeld (chair), Dan Gaffney (secretary), Sandy Tyndale-Biscoe (treasurer), and Des Grey (membership secretary), assisted by Gordon Mitchell, who was responsible for collections, and David LeCornu, with Jim's wife Ann taking minutes of the meetings.

The year 2003 was an active one. PCaSO established a simple yet effective logo, the 0845 help line number as well as the PO Box 66 address, a website (through the help of Jim's son); it invested in a library, bought equipment such as a projector and display boards, our badges, which are still in use, and promoted awareness through the leaflets and information sheets originally provided by David. Patient support meetings were moved from Havant to Ferneham Hall in Fareham.

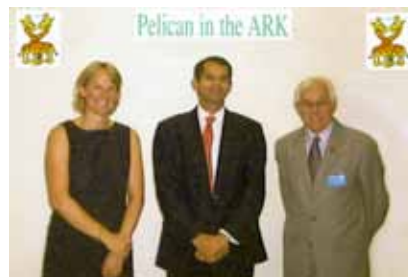
On the national front, PCaSO became the only patient group represented on the British Prostate Group; it was also the largest UK patient group affiliated to USToo (the primary patient organisation in the USA); it was also part of Europa Uomo (the male cancer group, of which Dan

Gaffney was our representative), and it also had a strong representative in Sandy Tyndale-Biscoe on the new Prostate Cancer Charter for Action, whose aims were to make government and the Department of Health more accountable.



Sandy speaking at the House of Commons

With Major Ron's sad death in March, a Memorial Fund, overseen by PCaSO, was established in his name. One of his wishes was to see a group of PCaSO grow in the Basingstoke area, and this was ably undertaken by Graham Ling for a number of years. At the same time Jim Stansfeld launched the Southampton group, though it was not until 2007 that he was able to hand the organisation of the group over to a new member, Mike Hollingworth.



David Rowlands with urologist Chris Eden at the opening of the Basingstoke Group



The 2004 committee: top (L-R) Gordon Mitchell, David Wright, Geoff Bailey, Sandy Tyndale-Biscoe. (Seated L-R) Peter Lyons, Pam Cranstone, Dan Gaffney, Jim Stansfeld.

Another death to report in these early years was that of Des Grey, who was an able membership secretary and later Hon. Secretary. Other new members at this time were Pam Cranstone, who not only (with her husband Bob) was on the help line, but also took charge of publicity, David Wright and Peter Lyons, both of whom are no longer with us.

With Jim Stansfeld at the helm, the cricketers logo became our awareness theme on the *Don't Get Caught Out!* leaflets. On David Rowlands' retirement from PCaSO and his move to Norfolk, Jim also prepared and enlarged the quarterly newsletter, now sponsored by Oncura. Norman Last was now providing a continuing and stable help as our pastoral counsellor, regularly telephoning new members and helping with any needs, and Geoff Bailey took on the membership records, a job which he continues to do with his usual equanimity and efficiency. In 2005 Ian Graham-Jones took over as librarian, soon to be, somewhat reluctantly, inveigled into taking on the Hon. Secretary's job. This year also saw the first issue of *Knowledge Empowers*, the information sheets compiled and expanded into one useful booklet.

A memorable event in 2006 was the performance of Handel's *Messiah* in Chichester Cathedral organised by Ian and introduced by the Dean, which raised over £6,000 to enable us to purchase a scanner for St Richard's Hospital, Chichester, and formally presented by one of our patrons, the Duke of Richmond and Gordon.

As both Jim and Sandy had completed their statutory three years, the AGM voted them to swap jobs, so Sandy took over as chairman and Jim as treasurer. Meanwhile patient meetings continued in Basingstoke (to be ably taken over by Barry Shoubridge who had recently joined the committee and assisted by his daughter Claire



Scanner presentation at St Richard's. Norman Last, Ian Graham-Jones, CNS Molly Harris, urologist Paul Carter, The Duke of Richmond and Gordon, The Very Rev. Nicholas Frayling, Pam Cranstone, Sandy Tyndale-Biscoe.

Woodhead), and Southampton, soon to be taken over by Mike Hollingworth; general meetings continued to be held at Fareham.

By 2007 another new figure had appeared in Roger Bacon from Rustington, who was keen to develop support in the east of our region, and so the West Sussex Group was formed, meeting alternately in Rustington and Chichester, and headed by Roger and Ian. An organisation called Prostate Matters South, a group of representatives from the two Devon support groups, Somerset, Dorset and PCaSO, met regularly, issuing a magazine of more general interest to its members, as well as their own newsletters. The PCaSO newsletter had by this time been taken over by Ian Graham-Jones and, with the support of AstraZeneca, was at last able to be printed in full colour; *Knowledge Empowers* was by now in its third update. Our helpful and supportive printers, Sarsen Press of Winchester also deserve a mention. Under Sandy's chairmanship regional centres were formalised – Southampton, Basingstoke, Fareham and Chichester. Dan Gaffney's death



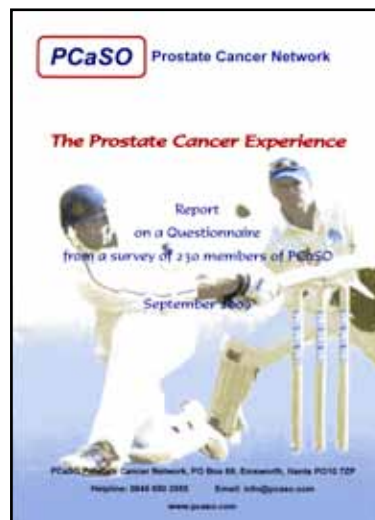
internationally.

The Dorset support group was

continuing to become uneasy with the somewhat moribund PSA organisation to which they belonged (PSA disbanded in 2009) and they therefore decided to apply to become a Branch of PCaSO, with their own structure and bank account, which was formalised at the beginning of 2008. Unease was happening at the other end of the Southern region too, with the PSA groups in Kent and Eastbourne. The committee felt that to incorporate the far-flung regions of Kent

would diversify us too much, but Eastbourne later decided to join as a group.

The Dean of Chichester Cathedral, the Very Reverend Nicholas Frayling not only accepted our invitation to become a patron but agreed to take an active part in the charity, speaking at the Southampton AGM and later to the Dorset Branch, as well as introducing our new awareness DVD produced in 2009. In this year the committee undertook a complete survey of our members' experiences, compiling it into a special booklet, *The Prostate Cancer Experience*, copies of which we still have available.



The Prostate Cancer Support Federation was (re-)launched in London in 2009, with Sandy at the helm, supported financially by Prostate UK (now Prostate Action), and 'The Fed' took over national issues which up until now had been ably undertaken by members of our

committee. The Federation now has nearly fifty member groups, of which PCaSO, with PSA North-West founded by Roy Nixon (now Prostate Cancer Support), is one of the largest. Because of pressures of work at the end of the year Sandy relinquished the chairmanship of PCaSO to become more active nationally in the Federation. While this left PCaSO able to concentrate on its core issues of support to its members and awareness, Jim Stansfeld nevertheless continued on the NCRI committee, and we have representatives on the two Cancer Networks in our region in Mike Hollingworth and Roger Bacon.

Christmas 2009 was not a good time, as the funerals of both Jim Stansfeld and Barry Shoubridge were both held in the last week of the year: two great losses, whose memories are preserved by the two trophies in their name at the annual Dummer Golf Day held in July each year.

The Duchess of York Charity Golf Day was established back in 2002 by Major Ron (a member of Dummer Golf Club) with David Rowlands and Robert Watson, the then owner of the club, who has taken on the organisation of the golf each year. Bob Watson, who has recently undertaken the complete redesign of the PCaSO website and continues as webmaster, though not himself a sufferer, has supported PCaSO throughout these years. Regretfully, because of other pressures, he is handing over the organisation of Dummer completely to PCaSO in 2012. Dummer raised £10,000 at its first event and continues to be our principal fund-raising event of the year. It has been supported throughout by the Ferguson family.



Jim and Ann Stansfeld at Dummer, 2002

With Sandy's departure, Mike Hollingworth took the chair in 2010 and through ill-health is resigning the chair at this year's AGM. Jim's place as treasurer was ably taken by David Smith, and under his careful management PCaSO has emerged from a possible precarious position to having a secure balance to meet our further needs. David's links with Sanofi-aventis have been invaluable, and they have ensured the high quality of our latest *Knowledge Empowers* issue.

Mike Hollingworth, during his tenure, established the new Branch structure, as the area from Dorset to Eastbourne was too large for a single committee to manage. Roger Bacon has ably taken the East Branch into new territory, and the PSA Testing Day (in conjunction with the Graham Fulford Trust) last year was a great success. The new leaflet designed especially for women *Pick Me Up* was Roger's brainchild. We have a 'new' logo – the original PCaSO logo superimposed on the blue male cancer badge.

With attendances at patient support meetings dropping, the increasing hire fees at Ferneham Hall, and with no one willing to take on the organisation of Basingstoke meetings, the committee felt that establishing two centres in the Central area at Winchester (Otterbourne) and Chichester was the sensible way forward.

As you will see from the February Newsletter enclosed with this issue, the Central Branch is now fully operational, and we look forward to welcoming new friends to assist in any way – however small – with taking PCaSO forward in 2012.

With all this, we must also pay tribute to the very many individuals, groups and organisations that have raised funds for us by sponsored events, too many to mention individually. Some photos we have been given are below.

As David Rowlands said on page 1:
A Big Thank You to all!

compiled by
Ian Graham-Jones

SOME FUND-RAISING EVENTS



Paul Esswood conducts Handel's 'Messiah' in Chichester Cathedral, March 2006.



Norman Last with Emsworth Flower Ladies, 2005



Jazz band at the Open Gardens Day, Itchen Abbas, 2009



Sandy Tyndale-Biscoe, his elder son Ed and Ian Graham-Jones on the Chichester Challenge – a 35km mountain bike ride over the South Downs, 2007



Mike and Lynn Hollingworth on the Test Valley Walk, 2009

SOME MARATHON RUNNERS



Andrew and Alice Ferguson (son and daughter of our first Patron, Major Ronald Ferguson) preparing for the London Marathon, 2005.



Alexandra Wright finishes the London Marathon, 2005, completed in 3'58"



Julie Mabey completed the London Marathon in pyjamas for us in 2006 (her 11th marathon). "I got to the finish before it was dark!"



Chris Stansfeld (Jim Stansfeld's son) at the Reading Half-marathon. 2005



Roger Lovewell at the end of his London marathon in 2002, completed in 3'33"

... AND NOT FORGETTING OUR COLLECTORS



Mary Fletcher, with her father. Mary ran the Reading half-marathon for us in 2006



Norman and Mary Grinter - two of our regular collectors for many years

LETTERS OF APPRECIATION

In November 1999 my hobby was sailing and I had just returned from a trip to Spain. Quite by chance, and although very fit I had a routine BUPA medical. I was told that I had an elevated PSA, "whatever that was" and, although having no problems whatsoever, I saw a consultant who said that, as my PSA was 16, I should have a biopsy. Now without any problem I assumed this to be just further routine, I duly did so. My next meeting with the consultant confirmed that I had got prostate cancer with a Gleason score of 6. As a fit man with no problems or symptoms I was completely shocked. To further my now confused mind I was handed an information pack to take home and to decide what form of treatment I should choose! Driving home I stopped in a layby to gather my thoughts and decide how best to give this news to my wife, who had already lost both parents to cancer. Further, without a clue as to the best way forward, I found somehow the PCaSO number and got through to David Rowlands, not knowing who he was or what his function was.

I explained my situation and even asked: should I cancel an arranged holiday? I was very surprised to learn that David had been in very similar circumstances to myself and felt his manner and advice was both greatly comforting and so very welcome at this time.

I did once briefly meet David at a cancer function at Goodwood House and found that "thank you" seemed hardly enough. I would like to take this opportunity to thank him again for his most helpful words and advice that I feel sure he has given to many many people.

These have been my memories of PCaSO and, after 12 years and now at 82, you see there really is hope of beating the odds.

Wishing all the very best to all PCaSO members

Yours truly
Jim Allsop (member since 2000)

Heartfelt thanks to PCaSO and especially to Jim Stansfeld. My son,, has been found free of cancer cells and now has only to make a full recovery from the operation.

The enclosed is a small token of my gratitude for the help and support you have given him, to me, and to a number of friends.

Beryl Humphreys

PART OF THE FIRST PCaSO NEWSLETTER



Prostate Cancer Network Newsletter


Charity No. 1095439

Issue 1 February 2003

A New Year of Hope, A New Image and Title

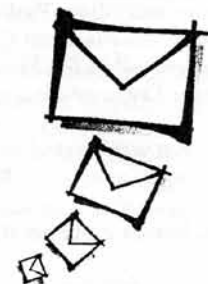
Welcome to 2003, in the hope that it will be a Healthy year for ALL.
We start the year with some notable achievements, thanks to a team effort

Under the formal name, **PCaSO Prostate Cancer Network**, our charitable status has been approved, with registration number 1095439.

You will see our adopted logo  above.

Our Web Site was launched in January at www.pcaso.com. We would appreciate constructive feedback on how it may be improved.

In our endeavour to help as many people as possible, we welcome callers and enquiries from across the UK on our Help Line and email: info@pcaso.com



In this Issue

Front Page News
for 2003.

Dates for 2003/4