



Prostate Cancer Support Organisation

Dorset Hampshire Sussex

Trustees Annual Report

Year ending 31st March 2022

Charity Name: PCaSO Prostate Cancer Support Organisation

Charity Registration Number: 1170536

Postal Address: PO Box 10, Emsworth, Hants PO10 7ZP

Website: www.pcaso.org

The charity has no offices so the registered address with the Charity Commission is the Honorary Secretary's home address.

History

PCaSO is a charitable incorporated organisation registered with the Charity Commission and with the Information Commission. A group was originally set up in 1999 by the late David Rowlands and others in Emsworth, Hampshire, under the auspices of another charity. It became a separate unincorporated association in 2002 and in 2016/17 moved to the new form of governance.

Executive Committee

For the year ending 31st March 2022

All Trustees are members of the Executive Committee.

Roger Bacon Chairman

Kevin Simons Treasurer

David Hurst Secretary

Lance Allen

Allan Higgin

Brian Holden (from 11th January 2022)

Derek Pilling

Barry Taylor

Peter Weir

At the Annual General Meeting held on 24th July 2022 all Trustees stood down and all were re-elected by the assembled membership.

Purposes and Aims

The objects of PCaSO as laid down in the Constitution are:

1. To promote and protect the physical and mental health of sufferers of prostate cancer and their families and carers, those at risk of prostate cancer and those who have been bereaved through prostate cancer by the provision of support, education and practical advice.
2. To advance the education of the general public in all areas relating to prostate cancer.

The Organisation of PCaSO.

PCaSO does not own or rent any offices and has no employees. Everything is handled by volunteers working from home. Meetings are held in rooms usually rented for that purpose.

PCaSO is a membership organisation with, currently, 918 members across the three branches described below including some from around the country who have either joined through contact via the internet or have moved away from our branch areas after joining. There are also two now living abroad.

PCaSO works across four counties along the south coast, East Sussex and West Sussex, Hampshire and Dorset. It is organised into three Branches, namely, Sussex, Hampshire and Dorset, and each Branch has its own committee and each has its own bank account. The Executive Committee had agreed at the meeting on 29th October 2019 that it would not seek to expand beyond the current area. Each Branch has rented a commercial self-storage unit to store literature, publicity material and miscellaneous equipment.

Under the Constitution PCaSO can have up to 12 Trustees and currently aims to have three from each Branch. For the year under consideration Hampshire had just one and in July 2021 Lance Allen and Kevin Simons took up their positions as Trustees and this was ratified at the AGM in August. On 12th October 2021 Kevin Simons was formally elected as Treasurer. On 11th January 2022 Brian Holden was elected as a Trustee and we ended the year under report with nine Trustees.

PCaSO is also a member of the National Federation of Prostate Cancer Support Groups, which operates as Tackle Prostate Cancer or just as Tackle. This is made up of some 90 support groups from across the country.

Difficulties getting volunteers

About a dozen years ago PCaSO decided to split the management of the charity into branches under the Executive Committee as the distance between the furthest groups was some 120 miles and travel to meetings could be onerous. Currently there are three branches corresponding to the counties of Dorset, Hampshire and East and West Sussex together.

In the year under report the three Dorset Trustees made frequent calls for volunteers to step forward to run the charity at least at group or branch level and none have done so. Consequently they decided to make the branch dormant and hold no more meetings or events.

Hampshire are now running with less than 10 active volunteers and are therefore only able to hold a few meetings or events.

Sussex have had the group leaders of Chichester and Bexhill die this year and no-one has stepped forward to take on those groups so they have shut down. Pulborough has not restarted after COVID because the

group leader has other pressures and the ladies who run Eastbourne group are actively looking for replacements as they want to step back in autumn 2022.

After the AGM in July 2022, the Chairman will step down after ten years in the post, but will remain a Trustee and it is expected that Brian Holden will take over. In addition the Secretary, who has also held the position for ten years, has announced he will step down in 2023.

The editor of the Updates newsletter resigned after the autumn 2021 issue having done five years and no-one has volunteered to take that job on so publication is in abeyance.

PCaSO has sufficient funds to continue for some years but not enough people willing to do the work. It is expected that there will be changes in the coming year.

The effects of the COVID pandemic

PCaSO's main work involves face-to-face meetings of groups of members and public who want to know more about prostate cancer and its effects and a series of events where we offer free PSA blood tests to men who have booked appointments. In addition there are usually regular face-to-face committee meetings.

In line with the government regulations it was not practical to hold these events at times during the year so some planned meeting and test events were cancelled.

We continued the committee meetings online by using Zoom and after a few months decided to start holding meetings for members also using Zoom. These were usually talks by clinicians and others and advertised by invitations to members by email.

There were requests for literature by hospitals and individuals which were handled by post and occasional phone calls to officers from men needing information.

The significant change was the greater acceptance of Zoom for communications and most committee meetings were now held online. The Executive Committee had decided to have one meeting a year face-to-face in order to keep the personal contact.

PSA testing events restarted in Hampshire and Sussex in October and November 2021, initially with small events but demand meant that larger events quickly happened. Face-to-face group meetings were held but with greatly reduced attendance.

The focus of our work

In normal years - and when the COVID regulations are relaxed again - PCaSO has two main areas of work and is developing a third area. The main centre of work is to encourage the early diagnosis of prostate cancer. If the cancer is diagnosed before it causes symptoms then it is almost always curable. However, although prostate cancer is now diagnosed more often than any other cancer, the knowledge of prostate cancer in the population at large is very limited. Consequently men at risk often ignore or do not realise the significance of symptoms and the eventual diagnosis is often terminal.

PCaSO devotes much resource to running public events to offer any men between 45 and 80 years a free PSA test. These are discussed in more detail below. These events encourage men to talk about prostate cancer and in turn they encourage their friends to be tested, so spreading knowledge and building awareness. In addition PCaSO volunteers will take part in 'Wellbeing' events put on by other organisations to discuss health matters. We publish a series of leaflets on prostate cancer which are distributed free of charge at such events.

PCaSO runs open public meetings to give a place where men and their partners can come and talk about their diagnosis or treatment and perhaps hear from expert speakers about aspects of treatments. The frequency and make-up of the meetings depends on many factors. Some are monthly while others are

quarterly. Some are discussions between individuals while others concentrate more on the speaker and his or her subject.

PCaSO encourages its active members to talk openly about prostate cancer and the Trustees together with other members will take phone calls from men – or their partners – who have concerns or maybe are concerned about friends or relations. It is important for men to learn about the cancer and understand the treatments offered and this knowledge often starts with a tentative enquiry.

An area which PCaSO is moving into is living with cancer. Many men diagnosed with prostate cancer may not be able to be cleared of cancer but will live with it for many years following various treatments. It has been shown that diet and exercise can be important in reducing the effects of cancer so PCaSO has provided extensive information within recent editions of Updates magazine and talked to the Penny Brohn organisation, who run courses for those suffering with cancer, to explore the possibilities and costs of them running a series of courses free to PCaSO members when regulations allow.

How our activities deliver public benefit

PCaSO has members but the membership is as much about spreading information and knowledge of prostate cancer to others and supporting treatments as it is about getting any personal benefits. Many people who join are those who have been diagnosed early and cured and now want 'to put something back' as those who are seeking to improve their knowledge of the cancer they have. However the price of membership - £12 to be a life member – is not considered likely to put people off joining. We follow a membership pattern mainly for the credibility it gives us when talking to clinicians and those in authority. To say we represent around 900 members who are almost all prostate patients will make them pay attention.

Almost all our activities are aimed at men and their partners who are in the age bracket likely to be diagnosed with prostate cancer i.e. men over 40. We run public prostate cancer screening events (called PSA testing events) several times a year (see below for details). The PSA testing events are restricted to those in the age bracket likely to be at risk of prostate cancer but the public meetings are advertised as open to anyone who might be interested.

In January 2020 we published an updated and expanded edition of our comprehensive 76-page booklet on prostate cancer written, as we say, by patients for patients and this is given away to anyone who wants it free of charge. Doctors have complimented us on it and some hospitals take bulk copies to give to patients. Tackle have adopted this booklet for distribution to all their 90 support groups. Since we have not had group meetings nor test events we have a large stock of these booklets so may hold off updating it for another year.

In the year under report work started on a publication called Healthy Living which draws together information on the benefits of a good diet and exercise. This is expected to be published next year.

In addition there are four other leaflets given away free of charge aimed at particular areas of concern. The Sussex Branch has produced leaflets for local hospitals explaining brachytherapy and radiotherapy procedures. The hospitals produce the text and PCaSO organise and pay for the design and printing of the leaflet in return for having an advertisement saying that the charity is available to help patients.

PCaSO also provide radiotherapy units in three local hospitals with 500ml biodegradable bottles for those patients having treatment for prostate cancer. Each patient has to drink half a litre before treatment and the bottles replace single-use plastic cups.

Who uses our services

The vast majority of those making contact with PCaSO live in our three branch areas. We do get contact from those who live elsewhere in UK and, very occasionally, in other countries but those are generally through the internet following a search for a particular aspect of prostate cancer. We do not seek those contacts but will happily answer their queries and discuss their problems.

Many of the initial contacts are by women who are concerned about their partners and we have produced a leaflet written by some of our female members aimed particularly at those contacts. However the target is to get men aged over 45 to learn about prostate cancer, to consider their vulnerability to prostate cancer and decide to have a PSA test. A high percentage of those tested, 92.5% is our average, will have a normal reading but those who have a raised reading will be referred to their GP for further action and that often means referring onwards to a hospital for further checks and possible diagnosis. Men sometimes return to PCaSO for more information when they are offered a choice of treatments by doctors or when the cancer has spread from the prostate and they are faced with living with the cancer as the doctors follow treatments to control further spread.

Men are notorious for ignoring symptoms and being too busy, important, embarrassed or ignorant to check symptoms by going to their doctor. Many men do not know what a prostate does, where it is or even (17% according to one survey) that they have one. So education is important, especially as if symptoms are evident the cancer has probably progressed too far to be cured.

In the last decade research has discovered that it is likely that if close relatives (father, brother, uncle) have had prostate cancer then it is twice as likely that you will get it. Men of Afro-Caribbean descent are also in the frame. There is a shared gene between breast and prostate cancer, so those men with a family history of breast cancer can also be at risk of having prostate cancer. PCaSO wants to get this information better known as it is most important that these men get checked early.

The PSA test

Organising and running PSA testing events is a large commitment by a relatively small group of volunteers. Each Branch is responsible for organising events in their area and there is one man who takes the lead for that area.

The prostate produces a protein, Prostate Specific Antigen, which is secreted into the blood and can be measured in a pathology laboratory. A small vial of blood is taken from the arm by a phlebotomist and sent to the laboratory. The result comes back in a few days. This does not indicate cancer but can indicate a problem with the prostate.

The test is not completely accurate and can give false positives and false negatives but it is the only quick and easy test that yet exists. The NHS declines to spend the money required to have a universal screening process when the test is not completely accurate so charities such as PCaSO have tried to fill the gap. PCaSO will organise an event, often working with a local Lions, Rotary or Masons group, where, on a specific day, men can have a blood test and then be sent the result a week or two later. Those with a raised reading are recommended to speak to their GP to discuss the result. At no time does PCaSO diagnose anything, merely reports the result and recommends further action. There is no charge to the men though contributions to costs are suggested.

We usually limit the testing to any men between the ages of 45 and 80 as these are men most likely to be at risk.

In calendar year 2021/22, across Sussex, Hampshire and Dorset, PCaSO held just six free PSA testing events (pre-COVID this would be around 20 events) and tested 1,744 men. We found exactly 100 men with a raised PSA level, about 5.7% of those tested. Those men with a raised PSA were recommended to see their GP to discuss their result. Since we started testing in 2011 we have tested 21,030 men in our area.

Every man attending the event is given a briefing on the test and its pros and cons. We know that this has resulted in men talking about prostate cancer with families, friends and colleagues. At almost every test event men say that they came because someone they know had been before.

Before the current year all bookings were made by telephone which was onerous on the person accepting the calls. All the administration was on paper with the consequent need to check and double check. Many other groups around the country now run their own events. The central point is the Graham Fulford Charitable Trust (GFCT) which has a system where consultant urologists check the results and then the Trust despatches the emails and letters to the individuals. This system was being overwhelmed with paper and has been computerised. PCaSO, through the IT consultant members, devised an online booking system which automated the administration beforehand and on the day. This was then extended so that the pathology labs used by PCaSO could add the individual results to a spreadsheet and then the results were electronically despatched to GFCT for checking and despatch.

Regulatory Notice

PCaSO is a registered charity and as such is regulated by the Charities Commission. We are additionally mindful of the recommendations of the Fundraising Regulator.

PCaSO is fortunate to have a trustee who has developed expertise in the Data Protection Regulations and he has accepted the voluntary position of Data Protection Officer. Under his guidance the Trustees are confident that the charity complies with the requirements of the Regulations. The subject is permanently on the agenda of the Executive Committee.

Financial Report

The previous year, 2020/21, had shown a 77% drop in turnover because government precautions for the pandemic meant PCaSO had, more or less, to cease activity. This year, 2021/22, shows a climb back as activity restarted gently in autumn 2021. Receipts totalled £38,401, almost entirely through donations and the resulting Gift Aid, which was 68% up on the previous year though still well under half the figure for the last pre-COVID year.

Payments totalled £35,991. Governance at £2,395 was mainly annual fees for services such as insurance, storage, the PO Box, etc. The cost of PSA testing events came to £15,182 and there were donations out totalling £15,816.

Cash balances increased over the year by £2,411 from £142,996 to £145,407. The trustees consider that our funds are more than adequate to continue our activities during this difficult time.

Reserves. At the meeting of the Executive Committee on 27th July 2021 the Trustees agreed a policy on reserves that there would be a minimum reserve comprising two years of operating costs (excluding PSA events) plus one year of PSA testing event costs. The policy and the figures would be reviewed annually.


Statements

No Trustee received any payment for services beyond normal expenses and no Trustee had any interest in any organisation receiving any payments from PCaSO.

The Trustees are not aware of any funds received from abroad nor of any payments made to an overseas body.

The Trustees declare that they are not aware of any serious incidents or other matters that they should have reported to the Commission and have not done so.

Approved by the Executive Committee and signed on their behalf



28th July 2022

David Hurst
Honorary Secretary

Independent examiner's report to the trustees of PCaSO Prostate Cancer Support Organisation - charity number 1170536

I report to the trustees on my examination of the accounts of PCaSO Prostate Cancer Support Organisation for the year ended 31st March 2022.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

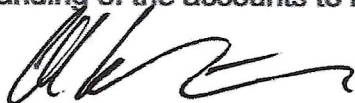
Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by section 130 of the Act; or
2. the accounts do not accord with those records.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed:



Name: Gerard Sweeting

Address: Whiteleaf House, Cansiron Lane, Ashurst Wood, West Sussex, RH19 3SE

Date:

6/7/22

PCaSO Prostate Cancer Support Organisation				Charity number: 1170536			
Receipts and Payments Account for the year ended 31st March 2022							
				2022			2021
				Unrestricted funds	Restricted funds	Total funds	Total funds
				£	£	£	£
Receipts							
Members' subscriptions				348		348	96
Donations: members				5,365		5,365	10,854
Donations: non-members				7,128		7,128	1,592
Donations: corporate				3,013		3,013	4,420
Donations at PSA testing events				18,998		18,998	
Fundraising: public meetings				-		-	
Fundraising: collections				50		50	246
Fundraising: events				-		-	
Interest on deposit account				107		107	400
Gift Aid				3,171		3,171	5,067
Other				221		221	75
				38,401	-	38,401	22,750
Payments							
Governance				2,395		2,395	2,492
Trustee & Public Liability Insurance				-		-	646
Charitable activity: newsletter				175		175	1,561
Charitable activity: support to members				1,055		1,055	
Charitable activity: awareness				427		427	5,132
Charitable activity: PSA Testing				15,182		15,182	2,971
Charitable activity: donations to charities				15,816		15,816	3,056
Fundraising				-		-	
Advertising				764		764	-
Other				15		15	136
				35,829	-	35,829	15,994
Asset and investment purchases							
				162		162	-
				162	-	162	-
Total payments							
				35,991	-	35,991	15,994
Net receipts/(payments)							
				2,410	-	2,410	6,756
Transfers between funds						-	-
Cash funds at beginning of year				142,997	-	142,997	136,240
Cash funds at end of year				145,407	-	145,407	142,996

Statement of assets and liabilities as at 31st March 2022

2022

	Unrestricted funds	Restricted funds	Total funds
	£	£	£
Cash funds			
Deposit accounts	76,219	-	76,219
Current accounts	69,188	-	69,188
	145,407	-	145,407

Other monetary assets

Gift Aid recoverable	-	-	-
	-	-	-

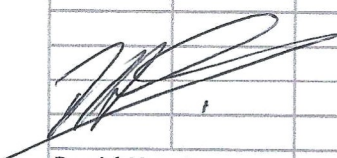
Assets retained for the charity's own use

Office Equipment	-	-	-
	-	-	-

Liabilities

Amounts owed to suppliers	-	-	-
	-	-	-

Approved by the trustees and signed on their behalf by:


 David Hurst
 Secretary

Date:

12 July 2022