



Prostate Cancer Support Organisation

Dorset Hampshire Sussex

Trustees Annual Report

Year ending 31st March 2023

Charity Name: PCaSO Prostate Cancer Support Organisation

Charity Registration Number: 1170536

Postal Address: PO Box 66, 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 current form of governance.

Executive Committee

For the year ending 31st March 2023

All Trustees are members of the Executive Committee.

Brian Holden Chairman

Kevin Simons Treasurer

David Hurst Secretary

Lance Allen

Roger Bacon

Allan Higgin

Derek Pilling

Barry Taylor

Peter Weir

At the Annual General Meeting held on 5th October 2023 all Trustees stood down. David Hurst resigned as a Trustee and Secretary on that day. All others named above were re-elected by the assembled membership.

At the previous AGM on 24th July 2022 Roger Bacon had stood down as Chairman after ten years in post. At the first meeting of the Executive Committee after that, on 1st November 2022, Brian Holden was elected as the new Chairman. The Trustees thanked Roger Bacon for his leadership and hard work as Chairman and were pleased he was staying on as a Trustee.

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 online or in rooms usually rented for that purpose.

PCaSO is a membership organisation with, at 31st March 2023, 955 members, an increase of 37 in total over the year, 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 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 bank account. Each Branch has rented a commercial self-storage unit to store literature, publicity material and miscellaneous equipment. The Executive Committee had agreed at the meeting on 29th October 2019 that it would not seek to expand beyond the current area.

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. There are currently five Trustees resident in Sussex, one in Hampshire and three in Dorset.

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

Probably the most significant problem facing PCaSO – which is currently faced by most other charities and voluntary organisations – is the difficulty in attracting enough people to carry out all the ideas and proposals generated.

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 reduce activities to occasional PSA testing events mainly run using the systems of the Graham Fulford Charitable Trust.

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

Sussex have, with one exception, generally stopped having face-to-face meetings. The one exception is Eastbourne but they have cut the number of meetings held. Contact has largely moved online using social media as exemplified by the new Central Sussex group. This was set up by new Chairman, Brian Holden, and has been taken over as group leader by Rob Stanley. A WhatsApp group was started and has spread to include anyone who wants to take part. There are cycle rides and walks to encourage the healthy living ethic.

The Secretary, who has also held the position for ten years, stepped down at the 2023 AGM and Lance Allen has agreed to take up the post.

The editor of the Updates newsletter resigned in autumn 2021 having done five years and no-one has volunteered to take that job on so publication in print is in abeyance although there is an online newsletter four times a year.

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 focus of our work

With the return to normal activities following the pandemic 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 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. There is a WhatsApp group open to anyone to join and ask questions. 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 published a free book titled Healthy Living which concentrates on the benefits of exercise and good diet. The first edition of 5000 copies has been reprinted with a further 4000 copies.

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. The Executive decided this year to drop the requirement to pay £12 for life membership.

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. Early in 2023 we started updating this book and it will be published later in the year.

We produced a free booklet titled Healthy Living to support and encourage men living with cancer to follow recognised practices to improve their health and resilience. The first edition has had a second print and an update will follow 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.

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 of the initial contacts are by women who are concerned about their partners and often accompany their partner to the PSA test session to check they are taking the test. 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 see 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.

The Sussex and Hampshire Branches of PCaSO organised 5,809 PSA tests at 14 different locations within the two counties during 2022, a record number of men tested during the year. We found red results needing further investigation in 273 men and amber results in another 173 men who need a further follow up test. Since we started PSA testing in 2011, we have now arranged over 26,000 PSA tests in Hampshire, Sussex and Dorset.

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.

In earlier years 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 with 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

It is with some relief that the activity in the year 2022/23 has returned to pre-COVID levels. Receipts totalled £105,946 which is 276% up on the previous year and is mainly donations from PSA test events, both individually from attendees and from the partners with whom we worked.

Payments were 288% up to £103,517 with PSA testing showing expenses of £66,349 and a donation of £14,353 to the Royal Bournemouth Hospital for a biopsy chair and £6,353 to Eastbourne District General Hospital for furniture for the urology unit.

Cash balances increased by £2,429 to £147,836. The trustees consider that our funds are more than sufficient to continue activities for the foreseeable future. There is concern that PCaSO is holding so much in reserve and the need to look for more places which need support.

Reserves. At the meeting on 29th August 2023 the trustees reviewed and agreed the policy that there would be a minimum financial reserve comprising two years of operating costs (excluding PSA testing event costs) plus one year of PSA event costs.

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 at the meeting of 29th August 2023 and signed on their behalf



David Hurst
Honorary Secretary

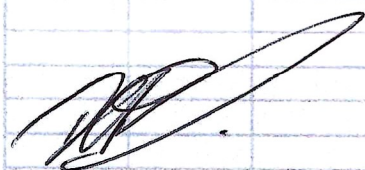
Receipts and Payments Account for the year ended 31st March 2023

	2023			2022
	Unrestricted funds	Restricted funds	Total funds	Total funds
	£	£	£	£
Receipts				
Members' subscriptions	48		48	348
Donations: members	3,405		3,405	5,365
Donations: non-members	14,845		14,845	7,128
Donations: corporate	19,883		19,883	3,013
Donations at PSA testing events	53,452		53,452	18,998
Fundraising: public meetings	138		138	-
Fundraising: collections	2,931		2,931	50
Fundraising: events	22		22	-
Interest on deposit account	201		201	107
Gift Aid	10,834		10,834	3,171
Other	187		187	221
	<u>105,946</u>	<u>-</u>	<u>105,946</u>	<u>38,401</u>
Payments				
Governance	2,442		2,442	1,861
Trustee & Public Liability Insurance	588		588	534
Charitable activity: newsletter	579		579	175
Charitable activity: support to members	579		579	1,055
Charitable activity: awareness	7,985		7,985	427
Charitable activity: PSA Testing	68,448		68,448	15,182
Charitable activity: donations to charities	21,460		21,460	15,816
Fundraising	-		-	
Advertising	187		187	764
Other	1,249		1,249	15
	<u>103,517</u>	<u>-</u>	<u>103,517</u>	<u>35,829</u>
Asset and investment purchases				
	-		-	162
	-	-	-	162
Total payments	<u>103,517</u>	<u>-</u>	<u>103,517</u>	<u>35,991</u>
Net receipts/(payments)	2,429	-	2,429	2,410
Transfers between funds				
Cash funds at beginning of year	145,407	-	145,407	142,997
Cash funds at end of year	147,836	-	147,836	145,407

Statement of assets and liabilities as at 31st March

	2023		
	Unrestricted funds	Restricted funds	Total funds
	£	£	£
Cash funds			
Deposit accounts	76,421	-	76,421
Current accounts	71,415	-	71,415
	<u>147,836</u>	<u>-</u>	<u>147,836</u>
Other monetary assets	-	-	-
	<u>-</u>	<u>-</u>	<u>-</u>
Assets retained for the charity's own use	-	-	-
	<u>-</u>	<u>-</u>	<u>-</u>
Liabilities			
Amounts owed to suppliers	-	-	-
	<u>-</u>	<u>-</u>	<u>-</u>

Approved by the trustees and signed on their behalf by:



David Hurst

Trustee

Date: 29 August 2023

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 2023.

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: 26th August 2023