



PELVIC
RADIATION
DISEASE
ASSOCIATION



Annual Report 2023-2024

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Registered Company number: 07998409 (England and Wales)

Registered Charity number: 1147802

Registered office: 62 Norbiton Avenue, Kingston upon Thames, Surrey, KT1 3QP

Chair: John A Webber

Trustees:

Alison S Boyes (resigned 1.11.23)

E Jane Hall (appointed 1.11.23)

David E Jillings

Faye Popham (appointed 13.11.23)

Lisa A Punt

Benjamin D Sacks

Bhumi K Shah

Lesley M Smith

John A Webber Chair (resigned 22.5.24)

Company Secretary: D E Jillings

Independent Examiner Details:

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Foreword

Faye Popham

Having now been on the Board of Trustees for one year, I continue to be amazed at how a small charity is making such a big impact on improving the lives of people living with Pelvic Radiation Disease (PRD). One thing that has been clear since joining is that the PRDA is a charity with huge ambition—not for its own glory, but to ensure that those who are silently suffering from the impact of PRD no longer have to.

Earlier this year, I had the privilege of hearing from some of the individuals the PRDA is seeking to support through its peer support group. I listened to a brave and courageous woman describe the pain she felt when the doctor told her, “You have the all clear,” yet her life post-cancer treatment was far from being “clear.” Instead, it was restricted and debilitated by the late effects of cancer treatment, something she was unaware of until it happened to her. After meeting this group, I felt even more convinced that PRDA's work to get Pelvic Radiation Disease recognised as a medical term among health professionals is vital if we as a society are going to improve the lives of those with a cancer diagnosis.

In the year ahead we remain committed to fostering the safe spaces established in our Chat Together peer support group and Online Community as well as developing our work in this area. We hope the appointment of a Professional Engagement Officer will enhance our opportunities to network and raise awareness among health professionals.



David Jillings - Acting Chair

Our Chair John Webber unfortunately had to stand down from the board of trustees in May 2024 for personal reasons and with the full understanding of the trustees. John joined us with the aim of bringing a new and more business-like eye to our management and from the outset he faced some difficult challenges. He took these in his stride and we will always be grateful for his support in steering us forward over the last 4 years



During the financial year we also said goodbye to trustee Sue Boyes and our Operations Manager Robert Brown who, between them, completed significant transformations in how we provide support to those affected by Pelvic Radiation Disease and how we manage and fund ourselves. The charity, as it stands now, owes much gratitude to John, Sue and Robert.

The 2023-24 year was by most standards our most successful ever, as the contents of this Annual report bear out. We make every attempt to quantify the outcomes of our programmes and activities, but one of the most encouraging signs of progress has been an apparent increase in mentions of late effects, including pelvic radiotherapy, in strategies and reports and on conference programmes as well as more awareness in conversations with healthcare professionals. This is not only down to the hard work of the staff and trustees of PRDA but also to many dedicated professionals working across the health system. The vast majority are fighting battles to improve or in some cases just maintain awareness and services for the treatment of late effects and it is encouraging to see some signs of progress, albeit there is still a long way to go.

One excellent sign of progress is that Radiotherapy UK and the All Party Parliamentary Group for Radiotherapy produced a Ten Year Vision for Radiotherapy in January 2024 which outlines six key areas of action to improve patient outcomes, including 'Ensure, where required, that patients have access to late-effects support services'. Such top level recognition of the need for services for people with PRD is testimony to PRDA's growing influence.

These voices for change are often supported by patients who want to “give back” following their own personal experiences. These are the true heroes of the story and PRDA will continue making every effort to do them justice.

I would like to add my personal thanks to my fellow trustees and our PRDA colleagues who have worked so hard to grow our services and outreach over the last year.

David Jillings

Our Aims and Objectives

The Pelvic Radiation Disease Association (PRDA) is dedicated to improving the lives of an estimated 100,00 people in the UK who face the ongoing challenges of living with Pelvic Radiation Disease (PRD). Having completed their radiotherapy treatment for cancer, people with PRD continue to experience life-changing treatment effects on bladder and bowel function, fertility, intimacy, mobility, and mental health. These can have a negative impact on quality of life, affecting relationships with family and friends, socialising, getting out and about, and returning to work.

By offering information, peer-to-peer support, and by advocating for better care, PRDA make a significant difference to the lives of people living with this extremely debilitating condition. Giving a voice to people affected by PRD helps to raise awareness and understanding of PRD, its impact on people's lives, and reduces the stigma that can be associated with symptoms.

The key objectives and outcomes of our work are:

Outcome	Performance indicator
Fewer people feel alone while experiencing the debilitating symptoms of PRD	<ul style="list-style-type: none">• More people registered to take part in peer-to-peer support services.• Increasing the number of people following PRDA on social media channels.
Better information made available to patients in advance of radiotherapy treatment	<ul style="list-style-type: none">• The Best Practice Pathway for PRD emphasises the importance of information prior to treatment.• People contacting PRDA for information prior to treatment signposted to their oncology team for information.
Better understanding among health professionals who are treating people with PRD symptoms	<ul style="list-style-type: none">• Building a 'community of practice' among healthcare professionals with a shared goal to improve care for people affected by PRD.• More visibility for PRDA at professional conferences.• Working collaboratively with health professionals to raise awareness of PRD.
Reduced stigma associated with having long-term, embarrassing symptoms after cancer treatment	<ul style="list-style-type: none">• Increasing distribution of Out and About Toolkits to help more people to feel confident in managing their symptoms when away from home.• More people feel confident in talking about PRD and sharing their experiences with others.
Improved quality of life for people affected by PRD	<ul style="list-style-type: none">• People with PRD are supported and empowered to seek the care they need to manage their symptoms.• By advocating for better pathways of care, more people with PRD will be able to access appropriate healthcare services.

Our Programmes

PRDA works on two fronts to tackle PRD in both the immediate and longer term. Our direct patient support services help people living with PRD today, while we work with healthcare professionals to develop better pathways of care for the future.

Direct patient support services

The PRDA Online Community is a social network that enables people with PRD to communicate with each other. Accessible 24/7, people can share experiences and learn from each other in a safe and supportive environment.

Chat Together offers monthly peer-to-peer support sessions. This service provides an online space for people to come together in an informal group to share experiences and support each other. Plans to develop this service include additional daytime sessions and themed chats with subject matter experts.



Let's Talk is a time-limited programme of education and support for people who have been recently diagnosed or have little knowledge or understanding of PRD. Supported by subject matter experts and people with lived experience of PRD, this programme acts as a gateway to other PRDA support services.

"I'm nearly in tears here with gratitude for your support, wisdom and kindness. Your information has given me a sense of direction and hope, the beginnings of a pathway to follow to effect some positive change."

PRDA service user

Designed to make venturing out less daunting, our **Out and About Toolkits** contain useful information, tips and tools such as a RADAR key, a 'just can't wait' toilet card and sunflower lanyard, Wype (eco-friendly toilet wipe) and a hand sanitiser. A useful Out and About bag is also included to keep these items handy. In 2024 we have explored new options to distribute these toolkits to more people who need them. We are grateful to Wype for assisting us by offering their product at cost. Wype is an eco-friendly product designed to turn toilet paper into a wet wipe. This is one of the elements in our Out And About Toolkits, which support people living with PRD.



General Information for people affected by PRD. Individual enquiries are responded to by email. In response to queries, people are signposted to the most appropriate information, resource or service best placed to answer their query. These include the PRDA website, the PRD Best Practice Pathway, PRDA support services, information on benefit and other financial support, Late Effects clinics and other external support services. This support does not replace professional care and PRDA do not offer medical advice or connect individuals with health professionals directly.

Find out more about how we can help people living with PRD by visiting our website: prda.org.uk/support

Professional engagement

Collaborating for Greatest Impact

PRDA was commissioned in 2023 to produce a journal article for Imaging and Oncology. Written by PRDA Trustee Dr Lesley Smith in collaboration with a healthcare professional and PRDA volunteer, this article was published to coincide with the UK Imaging and Oncology Congress to raise awareness of PRD and advocate for improvements to care and healthcare services.

Professional Conferences

We received strong engagement from attendees, including gastroenterologists and endoscopists, at the Annual Conference of the British Society of Gastroenterology in Liverpool 2023. The Best Practice Pathway garnered positive feedback and high interest.



Evaluating the impact of the Best Practice Pathway

The Best Practice Pathway is designed to support healthcare professionals to care for patients living with PRD. In 2023 a survey was launched to evaluate the impact and utilisation of the BPP, with the aim of guiding future development. The survey results showed the highly positive impact of the Pathway, and were accepted as a poster presentation at the Multinational Association of Supportive Care in Cancer conference 2024.

Research for a better understanding of PRD

PRDA Trustee Dr Ben Sacks co-authored an open access paper: The Benefits and Harms of Pharmacological Treatment for Postradiation Pelvic Pain: A Systematic Review by the European Association of Urology Chronic Pelvic Pain Panel with Recommendations for Clinical Practice.

Greater visibility of PRD

PRDA was honoured to be invited by the organising committee of the 2024 conference of the European Society for Radiotherapy and Oncology to provide a platform speaker giving the patient's perspective of PRD and quality of life.

Training and education

The Royal College of Radiologists invited PRDA to contribute to their Consensus Statements on gynaecological cancer, which include unanimous endorsement for services for late effects of pelvic radiotherapy, and references our Best Practice Pathway.

Working together to support patients

Successful pilot with a Late Effects Clinic to supply PRDA Out and About toolkits in bulk, getting these kits directly into the hands of their patients in the clinic setting.



"I'm really excited to take part in the Out and About Toolkit pilot and take pride in being part of the project"

Robyn Bowman, Chemoradiotherapy nurse specialist for GI cancers,
PRD Service St. James's University Hospital,
Leeds Teaching Hospitals NHS Trust

Building a community of Practice for PRD

In July 2023, the PRDA held its first Professional Networking Event at the Kia Oval in London. The objective of the day was to foster the development of communities of practice, encouraging collaboration, knowledge-sharing, and the exchange of best practices among healthcare professionals.



Alongside presentations from members of our network, the event made time for structured table discussions and Q&A sessions, to make space for clinicians who would otherwise rarely interact to discuss treatment and care of PRD in a supportive and constructive environment, and in relation to our Best Practice Pathway for Pelvic Radiation Disease.

"Thank you for organising such a great event. I appreciate the opportunity to connect with like-minded individuals who share a commitment to improve patients' well-being. Working in late effects can feel quite lonely, so it is reassuring to know there are many dedicated people striving to improve the support we provide"

Lara Anthony, Late Effects Advanced Radiographer,
Radiotherapy Late Effects Service, Norfolk and Norwich University Hospital NHS Foundation Trust

The patient representatives were involved in the round-table discussions throughout the day, and it was clear that the medical professionals really valued their views.

"It was a privilege to have the opportunity to share my story at the PRDA professional networking event. I came away from the event feeling more positive about things than I have done for a long time – the medical professionals are clearly listening and committed to doing what they can to improve things"

Gill, PRDA Volunteer

We plan to employ a Professional Engagement Officer, which will enable us to hold more events like this in the future.

We are grateful to Aspire Pharma and 3-D Matrix for enabling our Professionals networking event.

Late Effects Clinic Pilot

In January 2024, PRDA agreed to a unique partnership with the Late Effects Clinic, Leeds Teaching Hospitals NHS Trust, to provide Out and About toolkits for people recently identified as having bladder and/or bowel symptoms of PRD.

Toolkits are now being offered to patients during appointments in the Late Effects Clinic. By doing so, these toolkits are put into the hands of people who may not otherwise be able to access them, in the confidence that they are reaching PRDA's target audience through reliable screening in a healthcare setting.

People receiving the toolkits are also made aware of the additional support services available to them from PRDA.



"Having a toolkit from PRDA has made a big difference to my life. Having the toilet key gave me confidence to venture out more and have used it many times since receiving it, keeping it with me at all times. It's given me the security I need."

Out and About Toolkit recipient

Feedback is being gathered from the healthcare professionals at the clinic and patients receiving a toolkit. If successful, this pilot will support the roll out of this offer to other Late Effects Clinics across the UK.

Volunteering

As volunteers, members of the **Patient Advisory Group (PAG)** play a crucial role in ensuring that the voices of people living with PRD is at the very centre all we do, helping us shape a better future for people living with PRD and ensuring that the charity remains focussed on fulfilling its mission to support individuals affected by PRD.

PRDA volunteers have been active in supporting all of our activities, from fundraising to awareness raising, direct patient support and reviewing and developing our digital and printed resources.

Volunteers have given generously of their skills, experience and time to offer hope to others in similar situations, helping them to feel less isolated, better understood and better supported.

In 2024, PAG members have helped us to review and develop our support services – including a review of the content of our Out and About Toolkits and future proposals for developing Let's Talk and Chat Together.



"I have experience and knowledge of PRD and feel that I can help fellow patients to feel less anxious about what they are going through. If there is anything else I can do to help other people, then I would like to do it. I know that as a PRDA volunteer I can help people in so many different ways; doing so also aids my own recovery...."

Member of PRDA Patient Advisory Group

Healthcare professionals attending our Professional Networking Event had the privilege of hearing from Gill, one of our volunteers, who shared her personal experience with PRD. The event brought together healthcare professionals, researchers, advocates, individuals living with PRD, and our corporate partners for meaningful discussions, presentations, and workshops. Gill shared her experience of attending the networking event:

"To be able to not only describe what PRD looks like for me in terms of symptoms but also the massive impact it has on my daily life - bowel incontinence, broken nights, fatigue, pain, having to give up my career, anxiety, shame - to a group of professionals, all of whom are clearly committed to improving the support for patients, felt like a real positive step forward. As I said at the event, PRD is the first thing I think of in the morning and the last thing I think of at night. As a patient it can be all-consuming and it's important for that impact on quality of life to be understood."

"The patient representatives were involved in the round-table discussions throughout the day and it was clear that the medical professionals really valued our views."

"I came away from the event feeling more positive about things than I have done for a long time - the medical professionals are clearly listening and committed to doing what they can to improve things. Thank you PRDA for facilitating this event and getting the right people all in the same place together."



As part of our Out and About Toolkit clinic pilot, our volunteer Nicola, worked with us to write a supporting letter for the patients who would be participating. Drawing on her own experience, Nicola was able to make a personal appeal for people to take part in completing our survey to provide us with vital feedback from people living with PRD.

Funding

As evidenced in the annual accounts attached to this report, 2023/24 was another record year for income for the PRDA. We are grateful to the following donors and grant-makers for their support this year:

- The Albert Hunt Trust
- The D'Oyly Carte Charitable Trust
- The Douglas Arter Foundation

- The Foyle Foundation
- The PF Charitable Trust
- The Will Charitable Trust

We are very grateful to Aspire Pharma, who donated £20,000 to the charity and 3-D Matrix for enabling our Professional Networking Event.

Regular donations and individual fundraising

Incredible support from our community saw regular monthly donations reach a record £1,700 for the year. Regular donations are vital to sustain our support services and initiatives for people living with PRD. We encourage you to sign up for regular donations to help us make a lasting impact.

We are thrilled to have received over £4,500 from individual fundraising efforts, including contributions through Gift Aid. We extend our heartfelt gratitude to everyone who has contributed and supported our mission.



We witnessed the dedication of the Worthing Wobble riders, affectionately known as the "Wobblers," when they repeated their epic annual ride. Cycling over 100 miles from Hampton Court to Worthing and back. We're incredibly proud of their commitment to helping people living with PRD.

We'd like to thank everyone who took part in personal challenges, and our Challenge Events, to raise money for the PRDA.



Cameron and his son took part in an inflatable 5k fun-run as part of our Challenge Events.

Our year in numbers

Social media followers up **16%**



220 Out and About Toolkits provided



Over **13,200** visitors to our website



Our Online Community has increased by over

1/3

in the past year



Our annual turnover increased by £20,580



an uplift of nearly **50%**

48% increase in Newsletter subscribers



Over 3400 views of our Best Practice Pathway



People's lived experiences play a significant role in helping others with PRD by offering hope and providing a sense of community. Firsthand accounts can better illustrate the challenges of accessing care and managing PRD symptoms, raising awareness, enhancing understanding, and reducing stigma.

We are committed to sharing real-life stories to amplify the voices of those living with PRD, ensuring that their experiences remain at the heart of our efforts to make a difference.

Maria's Story

Back in October 2010 I went into my local hospital day surgery unit to have pre-cancerous cells removed but unfortunately this procedure never went ahead. A 4cm tumour was discovered and I was told I had cervical cancer. The following months were a blur of hospital waiting rooms, appointments with numerous consultants, so many blood tests and all kinds of emotions.



Following a hysterectomy in November 2010, my consultants informed me that my clear margins weren't sufficient and recommended an intensive 6 week course of Radiotherapy, Chemotherapy and Brachytherapy. I was lucky that I don't suffer too much with side effects during or straight after my treatment but as the years went on I noticed changes to my body.

“What I wasn't prepared for were all the late effect issues that come with have pelvic radiotherapy.”

As I'd had a hysterectomy I was prepared to be plunged into the menopause and a plan was in place with my GP for starting me on HRT. I did suffer badly with hot flushes, brain fog and mood swings straight after my treatment. Once the HRT started to work, these symptoms eased but have never completely gone. I'm lucky to have regular reviews of my medication with my GP and we are always tweaking the dosage to make sure my symptoms are manageable. What I wasn't prepared for were all the late effect issues that come with have pelvic radiotherapy.

In 2017 I started having bowel issues. Movements became more frequent, much looser, and I realised I wasn't having much warning as to when I needed to go. After a few weeks of this, I went to see my GP who referred me to a dietitian, thinking I was suffering with irritable bowel syndrome. During this appointment, I first heard the terms Pelvic Radiation Disease and Radiotherapy Enteritis. Deciding to do some research of my own, I came across the PRDA website. Here I was able to understand more about PRD and learn more about the symptoms I was experiencing, as well as being made aware of other potential symptoms of PRD to look out for.

I'd been moaning to family and friends for a number of years that my right leg was fatter than my left and from the knee down would swell quite a lot especially during the summer months. It didn't bother me too much but it was the time that skinny jeans were in fashion and I would struggle to get mine on some days.

After reading more about late effects and the issues many people have with Lymphoedema I again went to my GP and discussed with them all of the symptoms I was having and asked if I could be suffering from PRD. They said it was more than likely but they themselves didn't know much about it. I am now on a waiting list to be seen at my local Lymphoedema clinic.

Discovering PRDA has been great for me. I was under the impression that once I had the all clear from the cancer, I would be fine. But over the years, I've had more and more issues and realising that these are likely linked does make me feel better.



**“I try not to let my symptoms rule me...
I just have to plan my outings a little
more than I used to.”**

I'm not going mad, I'm not falling to pieces, I'm cured of cancer but living with the consequences of the treatment. I have to be careful what I eat and drink so that I don't spend the day in the bathroom and I have to be mindful of how much walking I do so that my leg doesn't swell too much. Earlier this year I received an Out and About Kit which has helped me massively.

I carry my RADAR key at all times and have the Just Can't Wait cards in my car and handbag. I'm lucky that I haven't had to use either of these items many times but when I have, people have been very understanding and caring.

I try not to let my symptoms rule me. I still meet my friends for curry and a pint night, go on long haul flights for amazing holidays, walk the coast path in the summer and I even went to music festival this summer!! I just have to plan my outings a little more than I used to.



For more real life stories see our website: prda.org.uk/real-life-stories



We give a voice to people affected by Pelvic Radiation Disease

The Pelvic Radiation Disease Association aims to support all people affected by, or at risk of, side effects due to pelvic radiotherapy, at any stage of cancer treatment, and however long ago cancer treatment was given.

The Best Practice Pathway for Pelvic Radiation Disease addresses the lack of awareness about the impact PRD has on people's lives, and the lack of knowledge about how to improve symptoms and quality of life.

The Best Practice Pathway for Pelvic Radiation Disease can be accessed via the QR code.

Each chapter covers key clinical management steps, and points users to published guidance, service models, quality standards and sources of professional education. There is also a comprehensive section on supporting people to self-manage their PRD symptoms. In addition, the document provides advice on service development.



prda.org.uk/prd-best-practice-pathway



website | prda.org.uk
email | info@prda.org.uk



#PelvicRadiationDisease



October 2024