

2023-2024

ANNUAL IMPACT REPORT

**The only patient and
service user-led charity
in Wales dedicated to
achieving health equality
for women, girls and
people assigned female
at birth.**



**FAIR TREATMENT FOR THE WOMEN OF WALES
TRINIAETH DEG I FENYWOD CYMRU**

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FTWW's Mission

Fair Treatment for the Women of Wales is the only patient and service user-led charity in Wales dedicated to achieving health equality for women, girls, and people assigned female at birth.

Our MISSION is to eliminate health inequalities in Wales for women, girls, and people assigned as female at birth. Our VISION is a Wales where everybody's right to good health and wellbeing is respected and fulfilled, with everyone able to access the healthcare they need, when they need it, and without barriers. We achieve this by ensuring that the people we support have access to information so that they can understand their health

conditions better and know what services they need. Through peer support we empower our members to gain confidence and be better equipped to manage and navigate their health care. We bring researchers, policy makers, and service providers together with experts by experience to ensure female voices are heard, advocating for positive change in health and public service design and delivery.

Chair's Foreword

Welcome to FTWW's Annual Impact Report for 2023 – 2024, which I am delighted to present in my capacity as interim Chair. I am honoured to have taken on the role following Dr Sally Rees's 4-year tenure. Sally is somebody who I have looked up to for many years and she has been a strong guiding hand in the development of Fair Treatment for the Women of Wales. Her support was invaluable whilst we transitioned to a registered charity in 2020, so we were all very sad to see her step down from the role. However, we are reassured that Sally will keep in touch and would like to take this opportunity to once again extend our thanks to her.

This year has been a very exciting one for the charity, with us taking on sole responsibility for Chairing the highly influential Women's Health Wales Coalition. The (then) Cabinet Secretary for Health and Social Care, Eluned Morgan, has publicly acknowledged the Coalition and FTWW's efforts in helping to secure the Welsh Government's focus on women's health and we are pleased to be engaged in conversations with the Women's Health Policy Team and Clinical Network as a 10-year NHS



Wales Women & Girls' Health Plan takes shape. This is a priority area for the Welsh Government's Gender Equality Forum on which FTWW is represented.

Closely linked to the theme of gender justice, 2023-24 has also seen us continuing to support the Welsh Government in a number of key areas, including the Disability Rights Taskforce and associated working groups, and Period Dignity Roundtable. We were pleased to be awarded Welsh Government funding to help us refresh the Endometriosis Cymru website, with new content added on the Equality Act 2010 and reasonable adjustments in the workplace, amongst other topics suggested by its visitors. The site is also now available in easy-read format following training from Learning

Disability Wales, with whom we also collaborated on the creation of 4 easy-read booklets about perimenopause and menopause.

Menstrual health conditions continue to be a priority issue for FTWW's community, so we were delighted to receive news of our successful application to Health and Care Research Wales to investigate the experiences of those affected by severe period pain. Co-produced with Bangor and Cardiff Universities, the 'Severe Period Pain Is Not Normal' (SPPINN) Study will look at the role of menstrual health education and what needs to happen to improve care in medical settings. As Public Partners on the project, FTWW is pleased to have ensured the voices of diverse and seldom heard communities form an integral part of the SPPINN Advisory Group.

This year also saw us joining the new NHS National Clinical Implementation Network for Gynaecology as patient and third sector representatives, helping to ensure that research findings and women's experiences translate into clinical practice. Our role as a patient advocacy organisation has also seen us deliver a number of online learning events on topics such as women's health

inequalities, Premenstrual Dysphoric Disorder in Wales, and equipping patients to get the best out of their medical appointments, as well as working with Health Education and Improvement Wales to develop webinars for GPs. Empowering members to share their stories, and giving volunteers the skills and opportunities to contribute their expertise remain paramount for us and will be a central focus going forward.

We continue to expand our offer of training around women's health and wellbeing to external organisations which include Cardiff University, Cardiff Council, and Welsh Government, amongst others, so that they can in turn support their employees with issues like menstrual health, menopause, and chronic illness. As NHS waiting lists in Wales remain long, it is most important that we continue to raise awareness of our community's needs and priorities and support them as much as possible. This will remain a key objective for FTWW, so securing additional funding from grants, training, and research activities will be vitally important over the next few years as our online community continues to grow, along with the

range of health conditions represented within it.

In summary, as interim Chair of FTWW, I am pleased to conclude by saying that this past year has been a remarkably successful one for the charity, with our profile continuing to grow amongst stakeholders and those who need our support. We have a wonderful team of trustees, staff, and volunteers who are committed to our values and aims.

However, going forward, the need to secure long-term funding is critical, enabling us to sustain and

grow what we offer to our community. As one of our members told us, *'FTWW hasn't just helped me as a patient, it is actively giving me a sense of purpose and meaning to the condition that almost took my life, and for that, I am so grateful'*.

Thank you for reading; I hope you enjoy this Annual Impact Report for 2023-24!

Willow Holloway



Interim Chair, FTWW

Section 1: Meeting FTWW's Charitable Objectives

OBJECTIVE: Providing Information and Advice in Working to Address Health Inequalities for Women Living in Wales by:

- a) Maintaining an online presence for women living in Wales who are experiencing a range of health issues and;
- b) Providing advocacy, advice, and support

a) Maintaining an online presence for women living in Wales who are experiencing a range of health issues

Engagement across a range of social media platforms remains a vital way for us to spread the word about the importance of health equality, the various ways in which FTWW is addressing inequalities experienced by our community, and reach out to stakeholders, including healthcare professionals, other third sector organisations, and those in need of our help.

Website

This year has seen us secure Lottery Awards for All funding to update our website and printed leaflets, in recognition of the vital role these resources play in raising awareness of the charity's work and support offered.

Social Media

- 1933 Members of our Online Support Group
- 2192 Facebook Page Followers
- 2432 X Followers
- 1711 Instagram Followers
- 192 LinkedIn Followers
- 638 Newsletter Subscribers
- 16 Newsletters and Mailshots published
- 78 Involvement Opportunities shared with community members and volunteer



‘Joining FTWW has been helpful because I have been signposted to resources specific to my condition (PMDD), but it has also been empowering because I feel like I belong to something bigger than myself, where there are other people, with a diverse range of conditions, symptoms, and experiences, but with a commonality of knowing we deserve fairer healthcare, and this has given me the confidence to feel like I can talk about my condition openly, to help educate others.’

b) Providing advocacy, advice, and support

Over this 12-month period, FTWW has facilitated a wide array of discussions and focus groups with members of our pan-Wales online community on topics related to health, wellbeing, equality, disability rights.

A number of focus groups and online questionnaires with our beneficiaries enabled us to respond to some significant consultations during this period, including, perhaps most notably, the Senedd Health & Social Care Committee’s ongoing Inquiry into ‘Supporting People with Chronic Conditions’.

Chronic illness has a disproportionate impact on women and people assigned female at birth, both in terms of health-related outcomes and socioeconomic disadvantage. We submitted written responses from FTWW and the Women’s Health Wales Coalition, hosted two focus groups with our members on behalf of the Senedd Engagement Team, and participated in a private stakeholder evidence session with the Health and Social Care Committee.

We also hosted two focus groups on behalf of the Future Generations Commissioner. These enabled our members to contribute to the Commissioner’s ‘Our Future Focus’ consultation, ensuring that the needs of women affected by long-term illness, who are disabled and / or experiencing socio-economic disadvantage, are considered and prioritised in the Commissioner’s work for the next 5 years, in line with the wellbeing goals of ‘Equality’ and ‘Health’.

We continue to Chair the Women’s Health Wales Coalition, whose membership during this period stands at over 80 charities, grassroots

groups, academics, clinicians, and patients. As Chair, a key aim for us is to ensure both third sector and patients are key stakeholders in the development of the NHS Wales Women & Girls' Health Plan so that it is inclusive, enables better access to services for disabled women, and prevents avoidable health inequalities.

This period has seen us deliver 29 consultation responses on health, disability, and equality-related topics.

We responded to several Welsh Government consultations, including:

- **'Citizens' Voice Body: Guidance on Access, Representations, and NHS Service Change'**, looking at the role of *Llais*, the national advocacy service for health and social care
- **'Belonging, Engaging, Participating'** about school attendance policy which, for FTWW, meant making recommendations about absenteeism related to menstrual health conditions. The Wales School Research Network has now included a question on the impact of periods for its student participants, to gain a better understanding of numbers affected
- **'Child Poverty Strategy'**, where we discussed health inequalities, disability, and period poverty
- **'Musculoskeletal Services Quality Statement'** which will set expectations of health boards in Wales on their service provision for autoimmune diseases, hypermobility, chronic pain and energy-limiting conditions
- **'Urgent & Emergency Care Quality Statement'** which we asked to include detail on health inequalities, gender bias, gynaecology, rare conditions, and mental health
- **'A Renewed Economic Mission for Wales'**, where we spoke about the impact of disability and deprivation, and the benefits of embedding the social model of disability, inclusion, and coproduction
- **'Health Service Procurement Reform for Wales'**, where we discussed the need for robust Equality Impact Assessments and improved support for third sector organisations providing services in Wales

- **‘Draft Strategic Equality Plan 2024-28’**, which will underpin Welsh Government’s approach to equality, diversity, and inclusion, and provide guidance to all public bodies in Wales
- **‘Health Impact Assessment Regulations’** aimed at providing public bodies in Wales with instructions on what these entail ahead of making decisions about services or plans so as not to adversely affect people’s physical and mental health
- **Health Education & Improvement Wales (HEIW)’s Education and Training Plan** for healthcare professionals in Wales between 2024-25.

Senedd Committee Inquiries

- **‘Supporting People with Chronic Conditions’**, which saw us provide stories from our members about their experiences and needs, including how gender stereotypes can contribute to diagnostic delays, poor treatment, and how services vary across Wales
- **‘Do disabled young people have equal access to education’** where we spoke about the disproportionate impact of chronic illness, menstrual ill health, period poverty, autism and neurodivergence on females, and how systems weren’t always set up to recognise or support those affected.

National Institute for Health and Care Excellence (NICE)

- Draft guideline for **Menopause: Diagnosis & Management**
- Draft guideline for **Endometriosis: Diagnosis & Management, ‘Management if Fertility is a Priority/Problem’**

Royal College of Obstetricians and Gynaecologists (RCOG)

- **Advanced Training Review**
- RCOG Welsh Executive Committee, with whom we coproduced a survey for Wales clinicians about **current practice in Coil Insertion and Removal**, to help improve shared decision-making and pain management.

23 publications with FTWW contributions & endorsement including...

- [The Faculty of Sexual and Reproductive Health \(FSRH\)'s 'Hatfield Vision'](#), a Framework to Improve Women and Girls' Reproductive Health Outcomes, such as access to contraception, reproductive rights, menopause, menstrual health, cervical screening and maternal health outcomes in black women and women of colour
- [Royal College of Physicians, 'Driving Change Together'](#), featuring FTWW as a case-study demonstrating the power of involving patients in health service design, and the subsequent ['Giving Everyone a Voice'](#) paper in which FTWW co-developed the co-production toolkit included
- [British Standards Institute \(BSI\) Standard on Menstruation, Menstrual Health & Menopause in the Workplace](#)
- [WEN Gender Network's Wales Women's Rights Manifesto for UK General Election](#) for which FTWW provided both evidence and narrative on 'Tackling Gender Health Inequalities'
- [Senedd Equality & Human Rights Committee inquiry report, 'Women's Experiences in the Criminal Justice System'](#) to which FTWW contributed and is mentioned, including evidence provided to the Committee in a dedicated evidence session
- [Senedd Health and Social Care Committee inquiry report, 'Unheard: Women's journey through gynaecological cancer'](#) in which FTWW and the Women's Health Wales Coalition are cited throughout
- Letter of support for our volunteer, Becci's, [petition to the Senedd on the need for national PMDD awareness and education](#).



Inaugural FSRH Hatfield Vision Meeting



54 media pieces featuring FTWW, our volunteers and members, or referencing our work, such as:

During April...

- As part of PMDD Awareness Month, FTWW volunteers shared their stories and staff spoke to [WalesOnline](#) about the need for greater understanding, joined-up services, and for PMDD to feature in NHS Wales Women's Health Plan.
- FTWW Trustee, Kirsty, [described being diagnosed with ADHD later in life WalesOnline.](#)
- FTWW Volunteer, Harriet, talked about the impact of long waiting lists for endometriosis and other conditions in Wales in the podcast, [The Waiting List.](#)



Becci Smart



In May and June...

- FTWW Volunteer, Nia, discussed the important development of a [Perinatal Mother-and-Baby-Unit in Chester](#), with allocated beds for North Wales patients and expressed concerns about [limited Welsh language provision to BBC Wales](#)
- FTWW member, Julia, featured in [BBC's Naga Munchetty's coverage of adenomyosis.](#)



The proposed mother-and-baby unit

- FTWW, volunteer Lucy, and the Women's Health Coalition were mentioned in a [British Medical Journal opinion piece](#) about the need to address women's experiences of pain, trauma, and lack of informed consent when having minor gynaecological procedures.

During August and September...

- FTWW's PMDD Champion, Becci, talked to [BBC Wales News Online](#) about living with PMDD.
- FabiansCymru published two FTWW blogs, about [women's health](#) and [endometriosis](#).



Becci Smart

- ITV Wales Evening News [headlined with FTWW members and PMDD champions](#), Becci and Laura discussing diagnostic delay, medical gaslighting, and the need to educate healthcare professionals about PMDD.

In October, November, and December...



Dawn, FTWW Menopause Champion, at the House of Lords

- FTWW Menopause Champion, Dawn, attended [the launch of the UK Menopause Manifesto at the House of Lords](#) and is pictured centre-right, holding a FTWW Menopause Awareness Leaflet.

- FTWW Trustee, Dee, described the pain of outpatient hysteroscopy to [BBC Wales News](#) and the Women's Health Plan is mentioned as part of the Welsh Government's commitment to addressing issues like this. Dee's story featured across all BBC TV news throughout the day.



Dee Dickens

- FTWW's PMDD Champion, Becci, shared her story with a range of media outlets, including [WalesOnline on the topic of living with invisible health conditions and being disabled](#); the 'Piece of Mind' Podcast; and [The PMDD Podcast](#).

In January and February...

- Senedd Research published its [article on progress in Wales of the NHS Wales Women & Girls' Health Plan](#), citing the Women's Health Wales Coalition throughout.
- FTWW's Engagement Officer, Dee, was named one of '[Women of Newport's Community Champions](#)', featuring in a photographic exhibition at the Senedd's Pierhead Building, for her work at FTWW and campaigning on women's health.
- FTWW's PMDD Champion, Becci, spoke to The Independent about her condition being dismissed: "[Dismissed and gaslit': The women with premenstrual dysphoric disorder struggling to get a diagnosis](#)"



Dee Montague

In March...

- [Sioned Williams MS spoke to the Western Mail](#) talks about Endometriosis Cymru and the digitised Symptom Reporting Tool FTWW has co-produced.

- FTWW was quoted, and our members included in [BBC Wales's article on diagnostic delay for endometriosis](#).



Lowri Shepstone

- FTWW Member, Bethan, spoke to [BBC Cymru Fyw about endometriosis](#), with FTWW quoted.

OBJECTIVE: Raising awareness of women's health and related services with the public, health service providers, professionals, academics and policy makers in Wales

Key to FTWW's mission as a charity is to grow our network and develop collaborative relationships with a wide range of stakeholders so that we can increase awareness and understanding of health inequities experienced by women and people assigned female at birth who are disabled and/or living with long-term health issues, so that they can be properly considered, addressed, and prevented.

Our Volunteers

FTWW's volunteers are vital in helping us to raise awareness of women's health amongst wider networks. As such, they are enabled to participate in various training courses and offered a range of opportunities to advocate for themselves and other patients.

This year has seen our volunteer numbers grow to 79

We have facilitated the involvement of volunteers in a wide range of local and national events during these 12 months, including the All-Wales

Menopause Conference in November 2023, and the All-Wales Pelvic Health Education Event in March 2024 where they have been supported to deliver talks on their lived experience of a range of related health issues and impairments, and influence positive change in the delivery of health and care.

Feedback from our Volunteers...

...on Social Model of Disability Training:

'I thoroughly enjoyed the training. The session was clear, informative and well delivered. I learnt a lot that I never would have thought about if it wasn't for this session. Thank you.'

'Every time I learn about the social model of disability in different settings, I feel like I learn something new! This training was very helpful and something I will be able to take forward for other volunteering activities to enrich my own and others' experience.'

...about Welsh Government's MSK Quality Statement Launch event:

'Having an online meeting before the event was an excellent idea. We agreed on the issues that were important, goals, and next steps.'

Thank you.'

...about the All-Wales Menopause Conference

'I was fortunate to represent FTWW at the All-Wales Menopause Conference, alongside two other patient speakers from the organisation. The conference was attended by professionals, academics, and researchers working in the menopause field, and as patients, we were able to share our experiences with the goal of helping improve diagnosis times and treatment pathways. I was so grateful to be given this opportunity by FTWW - for myself and my own sense of purpose, but also to make a difference, to reach out to those in the field, and to bridge the gap between professionals and patients.'

Training and Talks

Staff and volunteers deliver training, host workshops, and give talks on a range of issues related to women's health and wellbeing, to grow understanding and improve the support offered. Some examples include:

- Educ8 'Menopause & Wellbeing in the Workplace', and 'Menopause and Menstrual Health in the Workplace'
- Cardiff Council Women's Wellbeing Network
- Cardiff University 'Women in the Workplace' staff training
- Welsh Government Women Together Network, 'Let's Talk Endometriosis'

Lisa with members of
the Walk and Talk
Women's Group



Feedback from Training Recipients:

'Thank you so much for your support last week. The feedback we received has been amazing! Staff really enjoyed the session and those that were unable to attend were able to watch the video and feedback too.'

'We were delighted to have FTWW present to our women's health in the workplace event...Incredible insight into the realities of living with long term health conditions and the impact this can have on women within the workplace and what FTWW is doing to work with women and Welsh Government to address issues... Thank you to FTWW for supporting our event.'

'A huge thank you for giving us your time. The feedback I have received has been so positive with us all feeling the session was so informative and of benefit to us.'

'Thank you for co-hosting such an informative webinar. I came away feeling less alone with my health battle, and empowered to continue fighting for the healthcare all women deserve in Wales.'

'A huge thank you to Lisa (for her) participation in the Walk and Talk Women's Group's Menopause Talk as a guest speaker. The reception has been overwhelmingly favourable.'

'It was absolutely fantastic! Such a brilliant response from the attendees and so much truly useful information which will help us all! Thank you so much again and for the work you all do!'

Meetings, Events, and Forums

Some particularly instrumental meetings and events this period, where staff and/or volunteers have articulated the needs, experiences, and priorities of our members and the wider community have included:

MEETINGS, where FTWW Staff held discussions with clinical advisory bodies, health boards, and policy teams, such as:

- **National Institute of Health and Care Excellence (NICE)** where we discussed views and experiences of using NICE in Wales
- **Cardiff & Vale University Health Board**, and its coproduction of resources with people with long-term conditions
- **Cwm Taf University Health Board**, and its 'My Health, My Way' resources
- **Hywel Dda University Health Board** and FTWW members discussed Pelvic Health Pathways and 'Patient Knows Best' resources
- **Welsh Ambulance Services University NHS Trust**, developing resources for NHS Wales 111 A-Z website
- Discussions with **Betsi Cadwaladr University Health Board & Aneurhan Bevan University Health Board** about developing a Gynae Voices Forum in ABUHB
- Meetings with **Betsi Cadwaladr** about the development of a Nurse-led Service for endometriosis patients in North Wales

- **Welsh Government Policy Leads for Maternity, and Women's Health**, where policies on care around miscarriage care and support were discussed
- **Llais and LUPUS UK**, to look at variation in pathways across Wales
- **Health and Care Research Wales**, to look at supporting and resourcing community groups in research activities
- Community Mapping Conversations with **Verity PCOS, All Wales People First, Fertility Network UK Wales, Women's Equality Network, and the Royal College of Obstetricians & Gynaecologists** as part of our work establishing FTWW's Future Priorities
- **Welsh Government's Equality & Diversity Lead in Maternity & Neonatal Policy**, looking at the development of a framework of support, training, and resourcing for Maternity Voices Groups across Wales and to see how far that could be replicated for Gynae Voices forums
- Meeting the leads of a **NHS England Confederation** 'Women's Health Economics Report' to see how far it might extend to Wales

EVENTS

FTWW staff, trustees, and volunteers were involved in 57 EVENTS or ACTIVITIES, as attendees, participants, or hosts, including:

- Hosting an **online event with FTWW and IAPMD** about the Inclusion of PMDD on the Women's Health Plan for Wales for PMDD Awareness Month
- **Senedd PMDD Awareness Drop-In Session** for Members of the Senedd
- **Senedd Insight 'Menopause in the Workplace'** event, as guests of Jenny Rathbone MS
- **Senedd Health & Social Care Committee debate on Mental Health Inequalities**, with FTWW participants on its Advisory Group



Lisa & Katherine at Senedd Insight

- **Rosa 15th Anniversary Event**, London, where our Engagement Officer, Dee, was a keynote speaker on behalf of FTWW
- Co-hosted an **online event with Fertility Network UK, Llais, and Hormones & Health**, to discuss 'Getting the Most out of Your Medical Appointments'
- **EveryWoman Festival**, Cardiff, where our Engagement Officer, Dee, was a panellist on the main stage, discussing endometriosis and FTWW
- **Welsh Government workshop** on its Strategic Equality Plan 2024-28
- **'Below the Belt' screening**, panel discussion and fundraiser for FTWW, Chaired by Sioned Williams MS
- **'Meet the President of the Faculty of Sexual & Reproductive Healthcare'** event with the FSRH Wales Committee
- FTWW staff and trustees are panellists at the **National Federation of Women's Institutes Annual Conference**, discussing Women's Health
- **UK Government Disability Action Plan Workshop** for stakeholders in Wales
- FTWW hosts a North Wales Members' **in-person support group**
- **Musculoskeletal Innovations in Wales Conference** & MSK Quality Statement launch event
- FTWW staff and volunteers run an information stand at **Disability Wales's Annual Conference & AGM**
- Launch of the **UK Parliament All-Party Parliamentary Group Menopause Manifesto** at the House of Lords
- **WCVA's 'Conversation with the Charity Commission'** to discuss the accessibility needs of Disabled People's Organisations



Dee Montague

- **All-Wales Endometriosis Nurse Training (virtual) Workshop**
- FTWW menopause champion, Lisa, features in short video about our involvement in the development of the easy read menopause booklets at **Learning Disability Wales's annual conferences**.
- **Academy of Medical Sciences, 'Spotlight on Women's Health' event** to discuss women's health priorities and needs.
- **Rosa UK's, 'Voices from the Frontline' networking event.**
- **'Routes to Power' event** for disabled women's organisations to meet funders (Smallwood, Rosa, Pilgrim Trust, Esme Fairbairn, Trust for London) and convey challenges and priorities.
- FTWW hosts two **FTWW Future Priorities Workshops** with members and non-members to establish next steps and test out possible project ideas.



Dee & Zoe meeting the FSRH president

- Roundtable discussion with Ipsos, and Wales Cancer Alliance Chair, Tenovus, regarding their **Gender Equity in Oncology** project
- FTWW Trustee, Kirsty, delivers a presentation on 'Tackling Gender Health Inequalities' in the Wales Women's Rights Manifesto for UK General Election at **WEN's AGM**.
- **National Centre for Mental Health (Wales) webinars** on 'Menopause & Mental Illness', and 'The Latest in PMDD Research'
- FTWW staff and volunteers create a video for the '**All Wales Pelvic Wellbeing Education Event**', with volunteer Zoe presenting in-person on the day about chronic illness and incontinence
- '**Welsh Rare Disease Day Reception 2024**' in Cardiff
- **North Wales Bite-Sized Health Event**
- **FNUK's 20-year celebration and lectures** at the UK Houses of Parliament
- **EYST online event, 'Uncovering the Taboo: Menopause & Ethnic Minority Women'**
- '**Women of Newport**' exhibition and event at Pierhead, Cardiff
- FTWW's Engagement Officer, Dee, delivers a presentation to **Equal Power, Equal Voice** participants about successful campaigning and lobbying
- FTWW is Sponsor of **Wales EndoMarch, Cardiff**, where volunteer, Rachel, delivers a keynote speech
- FTWW volunteer, Lara, delivers an **endometriosis webinar to the NASUWT**
- **Endometriosis Action online event**, co-hosted with Endometriosis UK and chaired by Jenny Rathbone MS, where FTWW staff officially launch the refreshed Endometriosis Cymru website and digital Symptom Reporting Tool
- **Disability Wales North Wales in-person DPO Summit.**

FORUMS

FTWW Staff, Trustees, & Volunteers participated in 33 FORUMS or GROUPS with a variety of stakeholders, such as the Welsh Government, the Senedd, NHS Wales, and Third Sector Organisations. Examples include:

- **Royal College of GPs' Patient & Carer Partnership Group**, UK and Wales
- **Public Services Ombudsman Advice & Advocacy Bodies' Sounding Board**
- **Health Inspectorate Wales Stakeholder Advisory Group**
- **WEN Gender Network**
- **General Medical Council Patient Group Roundtable**
- **Senedd Cross Party Groups on Disability, Women, Lung Health, Suicide Prevention, and Women's Health**, on which we provide co-secretariat alongside BPAS (British Pregnancy Advisory Service) – this year saw this particular CPG discussing chronic conditions like ME and Long Covid, and meeting with Eluned Morgan, where FTWW was praised for leading the development of 10-year Women's Health Plan and providing basis of content.
- **Digital Services for Public and Patients**
- **FSRH Hatfield Vision UK Taskforce**
- **Welsh Government's Gender Equality Forum, Disability Equality Forum, Period Dignity Roundtable**
- **NHS Wales Clinical Implementation Network for Gynaecology**
- **Welsh Government Disability Rights Taskforce and Working Groups**, including Employment & Income; Travel; Access to Justice; Wellbeing; Accessible & Affordable Housing
- **BCUHB's Musculoskeletal Advisory Group, Women's Services Directorate Board, Gynae Voices Forum, and 'Getting It Right First Time (GIRFT) in Gynaecology' Task & Finish Group**
- **LUPUS UK Devolved Nations Committee**
- **Wales Council for Voluntary Action (WCVA) Health, Social Care, Wellbeing Planning Group**
- **Welsh Government Sexual & Reproductive Health Task & Finish Group**
- **All-Wales Patient & Public Interest Group; the All-Wales Medicines Strategy Group**
- Chairing the **Women's Health Wales Coalition** - our AGM this year saw us meeting with the Welsh Government's Women's Health Policy Team to discuss next steps in the development of a Wales Women's Health Plan
- **Health & Care Research Wales Public Engagement & Involvement Forum**

- **Welsh NHS Confederation's Health & Wellbeing Alliance and working groups on 'Major Conditions', and 'Health Inequalities'**
- **Health Pathways for Primary Care in Wales Gynaecology Reference Group**, including reviewing national Primary Care Health Pathways for endometriosis, ensuring that FTWW and Endometriosis Cymru Symptom Reporting Tool are incorporated
- **UK Parliament All-Party Group on Endometriosis**
- **RCOG Welsh Executive Committee & National Safety Advisory Group for Obstetrics & Gynaecology.**

OBJECTIVE: Conducting research and disseminating the useful results

Evidence shows that women who are disabled and/or living with long-term health issues often find that their needs aren't considered when it comes to research, or that they are excluded from studies which have the potential to improve their wellbeing and lives. As a charity, we are keen to see this change and are increasingly raising awareness of inequality in research and how we can help to facilitate more inclusive patient and public involvement.

Involving Disabled Women and Grassroots Organisations in Research

We attended a workshop with Health and Care Research Wales about 'allyship' in research and featured in their newsletter: *Collaborative*



Collaborative workshops - the importance of allyship in health and social care research

workshops - the importance of allyship in health and social care research | Health Care Research Wales.

Not only did we go on to host focus groups enabling HCRW's Public & Patient Involvement Team to learn more about ways researchers could work better with women who are disabled and living with long-term illness, we also put together a paper for their 'Discover Your Role 2' Strategy in which we discuss the support and resourcing needed to ensure third sector involvement, particularly grassroots organisations who are led by and for the people they represent and therefore often articulate lived experience of intersectional inequality.

Funding for Women's Health Research

This year, we were particularly delighted to hear the Minister for Health & Social Care assert her commitment to resourcing for 'women's health research' at a meeting of the Cross-Party Group on Women's Health. At that same meeting, Ms Morgan went on to publicly acknowledge FTWW as having driven forward work on a national Women's Health Plan.

Some of the Research Projects with FTWW Involvement and/or support this year:

- **'[SPPINN](#)'** – the Health & Care Research Wales (HCRW)-funded Severe Period Pain Is Not Normal Study has seen us attending ongoing monthly meetings as part of the project's advisory group, and co-hosting Public & Patient Involvement Partners' introduction to the Study
- **'[Autism from Menstruation to Menopause](#)'** a Wellcome-funded project, led by Swansea University's Dr Aimee Grant, sees FTWW on the Advisory Group, and our Chair, Willow Holloway, a member of its lived experience Community Council. Willow is listed as co-author of several academic papers coming out of the project.

- Cardiff University and Proper Design, a [*refresh of Endometriosis Cymru and digitalisation of the Endometriosis Cymru Symptom Reporting Tool \(SRT\)*](#)
- Working with Cardiff University and mentoring FTWW Endometriosis Champion, Rachel, as she continues her HCRW-funded PhD **‘Evaluating the effectiveness of the Endometriosis Cymru SRT in improving GP and patient communications’**. Her experience, and that of FTWW volunteer, Beth, feature in HCRW’s media piece here: [Endometriosis Research](#)
- Swansea University’s investigations into **blood-based markers to diagnose endometriosis and Polycystic Ovary Syndrome (PCOS)**
- University of West Scotland and **research priority-setting on PMDD**. FTWW volunteer Becci’s story and role with FTWW features on Wales’s National Centre for Mental Health’s website, where she explains her involvement in research: [Becci | NCMH](#)
- Working with BCUHB, Cardiff University, and the NHS Wales Gynaecology Implementation Network to explore the possibility of a feasibility study to **‘Collect and Disseminate Gynaecology Patient Stories for Wider Learning’**
- Working with Cardiff University and Verity PCOS to explore FTWW involvement in a **James Lind Alliance Research Priority Setting process for PCOS** (to commence later in 2024)
- Supporting Cardiff University’s Centre for Artificial Intelligence, Robotics and Human-Machine Systems with the possibility of a **‘FemTech’ pre-conception project**
- Working with Cardiff University on its **‘ESTEEM’** Study, funded by the National Institute of Health and Care Research, to look at the role of testosterone in HRT for menopause
- Cardiff University and the FSRH possible project on **Shared Decision-Making for Pain Management in Minor Gynaecological Procedures**, such as Coil Insertion and Removal



Rachel Joseph

- Supporting Swansea University PhD student, Zoe, with research into **women's experiences of chronic illness and incontinence**
- Supporting Cardiff University Occupational Health Department and FTWW member, Lara, with research into **women's experiences of chronic illness in the workplace**
- Working with the National Centre for Mental Health (Wales) to help promote their [Women's Winter Webinar Series](#)
- Involvement in the Welsh Government Violence Against Women, Domestic Violence, and Sexual Violence ([VAWDASV](#)) [Research Network](#).
- Abstract submitted for **The Menarche, Menstruation, Menopause and Mental Health (4M) Consortium** on 'Co-producing a digital symptom reporting tool for suspected endometriosis: A development and pilot study'
- Coproducing a HCRW application to develop a **pan-Wales Women's Health Research Centre of Excellence (WWOMHEX)** with academic colleagues at Cardiff University, Bangor University, Swansea University, and with support from the Welsh Government's Women's Health Policy Team; National Implementation Network for Gynaecology; Health Education & Improvement Wales, amongst many others.



Feedback from FTWW members and volunteers involved in research activities:

'I had known before starting my PhD that FTWW were a group I wanted to join. I had previously come across their Facebook page and found a like-minded community of women. Some women were struggling with illness, some were looking for support, and the (online group) provided me with so much support and ready-to-go information when I was diagnosed with Fibroids.'

'My greatest wish is that I can continue working with FTWW in some capacity... Sharing the results of my PhD on urinary incontinence and chronic illness in women as they age, developing educational awareness campaigns for young girls and women about urinary incontinence, and always striving to improve Women's Health.'

'FTWW provided me with a lifeline during my unexpected diagnosis of endometriosis, experience of miscarriage, and seeking advice about a diagnosis for ADHD as an adult... I am currently undertaking a small research project and reached out to FTWW to help with recruitment for PPI partners. FTWW could not have been more enthusiastic and helpful, offering advice on the advert and support for the PPI partners through membership with FTWW. In their words, this is what collaboration and co-production is about.'

Section 2: FTWW Financial Reporting

Treasurer's Report

I am delighted to introduce myself to all who support FTWW, as the organisation's new Treasurer. I am a grandmother and retired Payroll Officer and, as someone who has personal experience of endometriosis and breast cancer, getting involved with this organisation was a must for me.

I was pleased to join FTWW's Board in April 2023, and officially took on the position of Treasurer on the 1st July 2024, taking over from Tami Rolls who continues to support FTWW as a Volunteer Finance Officer.

We have supported our members through the challenges of the Pandemic and now the difficulties caused by the financial crisis being felt by all, with the Charity sector particularly affected.

We have continued to source and apply for various grants to help us ensure our community's voices and health priorities are heard and are looking at ways to resource a potential expansion to our workforce to support project management and the continuing effectiveness of our organisation.

We are continually aware of the need to be cost-effective.

As a result, I am pleased that our overall financial position is stable going forward, with our aims and objectives for the next year fully in our minds as always.

Summary of Financial Position 2023-24

The Organisation brought forward a balance of £55,457.72, generating an Income of £106,000 for 2023-24. This was an increase of £41,193 over the 22-23 period - partly, this was allocated by the Welsh Government to a refresh of the Endometriosis Cymru website.

I would like to thank the Trustees, Tami for her work as our Treasurer, the Director of Policy & Research, Staff, and Volunteers without whom FTWW could not achieve the results we have over this last year and in the years prior to that.



June Jeremy | Trustee/Treasurer



Grants and Fundraisers

We would like to extend our sincere thanks to our funders, both grant-awarding bodies and volunteer fundraisers, whose support is hugely appreciated.

Your generosity and enthusiasm for FTWW's work enables us to continue supporting and advocating for women and people registered female at birth across Wales who are disabled or living with long-term health conditions – again, thank you:

- **Welsh Government Social Justice Department, 'Equality and Inclusion'**
- **Waterloo Foundation**
- **National Lottery Awards for All Wales**



thewaterloofoundation*



Financial Statement and Accounts

The following is drawn for the accounts of the Organisation and provides an overview of financial activity for the period 1st April 2023 – 31st March 2024.

The Organisation brought forward a balance of £55,457.72 from 2022-23.

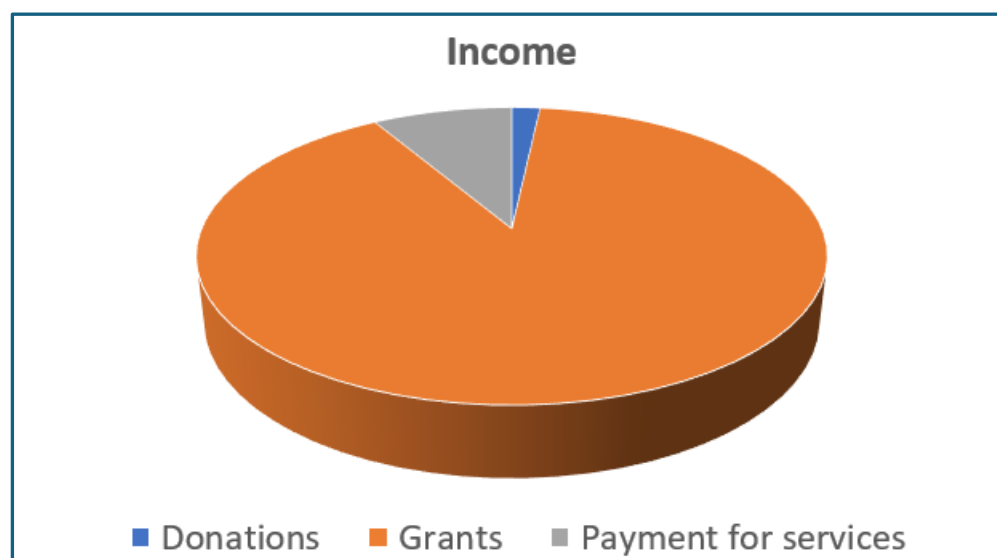
Income

Between 1st April 2023 and 31st March 2024, the organisation generated total income of **£106,349.08**. This was an increase of £41,542 over the 2022/23 period.

A breakdown of sources of income is as follows.

Fundraising, Events and Donations	£1,832.83
Grants	£95,428.00
Payment for Services	£9,088.25
TOTAL	£106,349.08

The relative proportions of income can be seen in the chart below.



A total of £95,428 in grant funding was received comprising £85,458 from Welsh Government and £9,970 from the National Lottery Awards For All Wales. Of this funding, £11,391 is carried forward into 2024/25.

Funding from the grants was used for salary costs for our director, engagement officer, trustee and volunteer training and expenses, translation and IT costs.

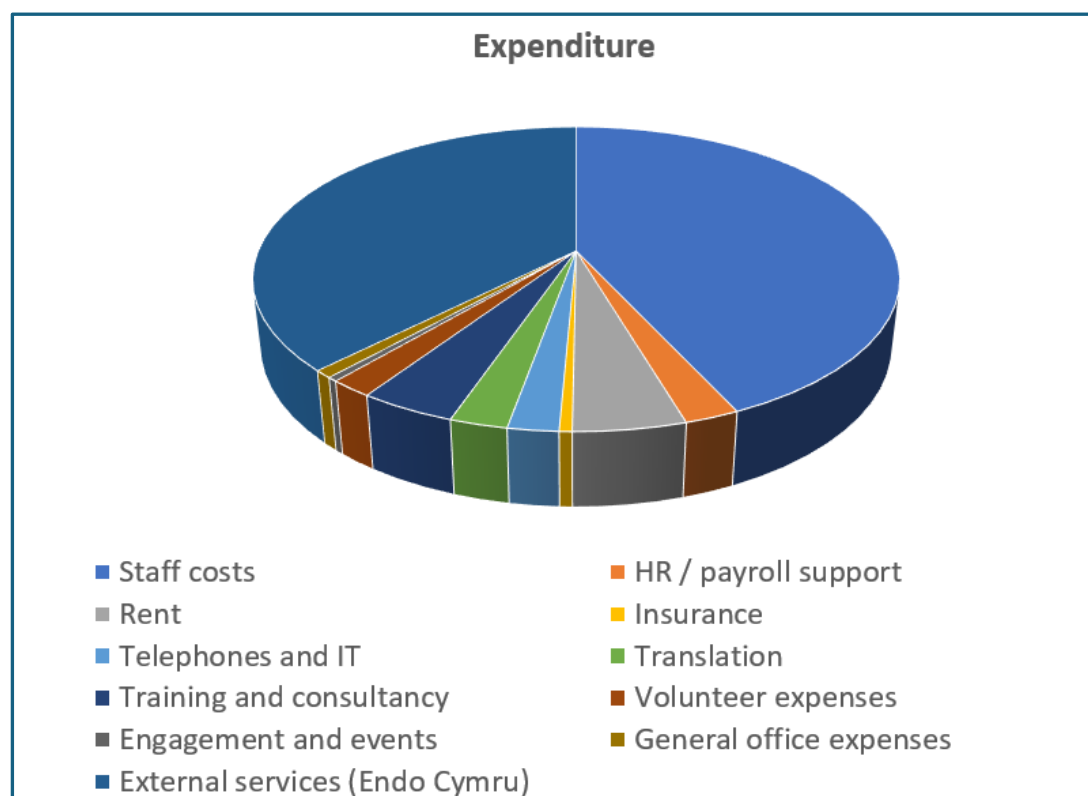
Expenditure

Between 1st April 2023 and 31st March 2024 expended a total of **£95,976.39** in furtherance of its aims and objectives.

A breakdown of expenditure is as follows.

Staff Costs	£41,356.27
HR / Payroll costs	£2,225.46
Volunteer Reimbursement Costs	£1,774.44
Rent	£4,560
Insurance	£516.20
Telephone, IT equipment and licenses	£2,058.50
Training, Development and Consultancy	£3,941.63
Translation	£2,345.49
External services (Endo Cymru)	£36,011.00
Engagement and Evaluation	£416.40
Other costs	£771.00
TOTAL	£95,976.39

The relative proportions of expenditure can be seen in the chart below.



The payment of £36,011 for Endo Cymru external services was fully funded from the Welsh Government Endo Cymru grant payment.

The closing balance of funds available to the organisation on the 31st March 2024 was **£65,830.41**.

The breakdown of restricted and unrestricted funds carried forward at 31st March 2024 is

Restricted	£21,800.00
Unrestricted	£44,030.41
TOTAL	£65,830.41

I can confirm that these accounts have been subjected to an independent examination by ACCA-accredited Karen Cockings, on 11th December 2024.

Tami Rolls

Section 3: Organisational Details

Board of Trustees 2023-2024

- **Chair:** Dr Sally Rees
- **Treasurer:** Tamira Rolls
- **Secretary:** Jonathan Stevens
- **Trustee:** Willow Holloway
- **Trustee:** Julie Richards
- **Trustee:** Claire Foster
- **Trustee:** June Jeremy
- **Trustee:** Alison Pritchard
- **Trustee:** Dee Dickens
- **Trustee:** Karen Lo
- **Trustee:** Kirsty Pringle
- **Trustee:** Liz Williams
- **Trustee:** Lucy Cone
- **Patient Adviser to the Board:** Louise Evans

Fair Treatment for the Women of Wales (FTWW) is a pan-Wales patient-led charity and disabled people's organisation focused on highlighting and addressing health inequities experienced by women and people registered female at birth who are disabled and/or living with long-term health issues.

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