

Annual Impact Report 2021 - 2022

FTWW

FAIR TREATMENT FOR
THE WOMEN OF WALES

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Organisational Details

- ▶ Fair Treatment for the Women of Wales
 - Office 5, Plas Eirias Business Centre
 - Abergele Road
 - Colwyn Bay
 - Conwy
 - LL29 8BF
- ▶ Charity Number: 1191069
- ▶ info@ftww.org.uk
- ▶ www.ftww.org.uk
- ▶ twitter.com/FTWW_WALES
- ▶ [instagram.com/ftww_wales/](https://www.instagram.com/ftww_wales/)
- ▶ [facebook.com/FTWW.Wales](https://www.facebook.com/FTWW.Wales)



Strategic Aims and Objectives



- ▶ **FTWW: 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

Information.....Empowerment.....Advocacy



FTWW's role is to work with women, girls, and people assigned female at birth, public bodies, and service providers to eliminate health inequalities

- ▶ We do 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 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 Review

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I am delighted to present FTWW: Fair Treatment for the Women of Wales's 2021-22 Annual Impact Report – a year which has seen the charity having considerable impact on health-related policy and practice in Wales. Increasingly these 12 months have seen us becoming the 'go to' organisation for those looking to find out more about lived experience of health inequality, particularly its effects on women and people assigned female at birth in Wales. FTWW's growing profile has enabled us to reach out to a wider audience, offering peer support to more beneficiaries, and further secure the financial future of the organisation through additional grant funding from the Rosa Fund for Women and Girls and the Smallwood Trust, and ongoing collaboration with Cardiff University.

For long-time observers and supporters of the organisation, our campaigning on endometriosis will be well known. One of our top priorities has been to see specialist endometriosis nurses in every health board in Wales – and this year brought that to fruition. We were particularly pleased to assist Liz Bruen, Cardiff's long-standing specialist nurse, in developing and delivering a two-day training course for the nurses, with several of our volunteers involved throughout the days' activities. Not only that, 2021-22 has seen FTWW helping to facilitate the involvement of specialist endometriosis surgeons in improving services in North Wales, and our fantastic volunteer, Beth, handing over a petition to the Senedd to improve endometriosis care for all of those affected in Wales.

Of course, we are always keen to demonstrate that FTWW is about 'all things' related to women's health, so our work hasn't stopped at endometriosis. This year also saw us supporting Wendy, our volunteer Autoimmune Conditions Lead, in collating a patient-led report, 'Making the Case for Better Lupus and Rare Autoimmune Disease Provision for Patients in Wales', which made a series of recommendations to improve care for those affected and has been delivered to every health board in Wales. We look forward to seeing how the evidence presented in the report can make a positive difference to patients' experiences.

Chair's Review continued...



Whilst we're on the topic of reports, FTWW's members have also been involved in the writing of two other incredibly significant publications this year, with our Founder on both steering groups and volunteers taking part in associated focus groups. I am, of course, talking about the Welsh Government-commissioned, 'Locked Out' report which explored the impact of the pandemic on disabled people, and the Wales Shadow Report for the United Nations' review of the Convention of the Rights of Disabled People. As an organisation supporting people living with life-impacting long-term health conditions, we are always very keen to emphasise that these too constitute impairments, and that many of our members are disabled by systems that don't adequately support or include them.

Another hugely significant project in which FTWW has been instrumental this year is the inception and co-Chairing with British Heart Foundation Cymru the third sector #WomensHealthWales Coalition. The Coalition was created largely in response to the Senedd's Health and Social Care Committee's consultation on priorities for this term, with women's health emerging as one of those priorities thanks to the campaigning of FTWW and others. Originally comprising around 60 organisations and patient volunteers, the Coalition has grown in influence and numbers, and created such a compelling evidence base that the Welsh Government has committed to co-producing a Women & Girls' Health Plan for Wales.

So that we are prepared for the Welsh Government to approach FTWW for support in creating its women's health plan, and our future involvement in addressing inequalities such as those experienced by disabled people, we need to maintain our focus on ensuring the financial sustainability of the organisation. Earlier this year, we concentrated our efforts on further embedding the role of Engagement Officer into our work programme, and our Board, volunteer Director, and staff worked with facilitator, Joy Kent of Joy Unlimited, to develop our 3-5 year Strategy, aimed at providing FTWW with a robust platform from which to grow the organisation. Exciting times lie ahead!

In the meantime, I hope this review has whetted your appetite for the rest of this 2021-2022 Annual Impact report – please enjoy!

Dr Sally Rees, FTWW Chair

Engagement

Core to FTWW's activities is maintaining our pan-Wales online community. Our peer support group better enables members to manage their health and get involved in a proactive space driving positive change in Wales for people who are disabled and / or living with long-term health issues.

- ▶ **2021-22 saw numbers grow to 1538 members**
- ▶ **With 31 Involvement Opportunities shared**



Growing our network, so we can keep people informed of FTWW's activities and achievements, develop collaborative partnerships, and support more beneficiaries, is vital. Social media is proving key to this:

- ▶ **Facebook Page 1943 Followers, 61,687 Reach**
- ▶ **Twitter 2326 Followers, 226.3K Impressions**
- ▶ **Instagram 1505 Followers, 8,854 Reach**
- ▶ **We published 14 bi-lingual Newsletters and Mailshots**
- ▶ **And had 608 Subscribers to our Mailing List**



Information, Support, Advocacy

We make sure that FTWW's community and beneficiaries have up-to-date information about what's happening in Wales and the UK when it comes to healthcare services – but we also make sure that policy- and decision-makers are better informed about what matters to women in Wales who are disabled and / or living with long-term health issues.



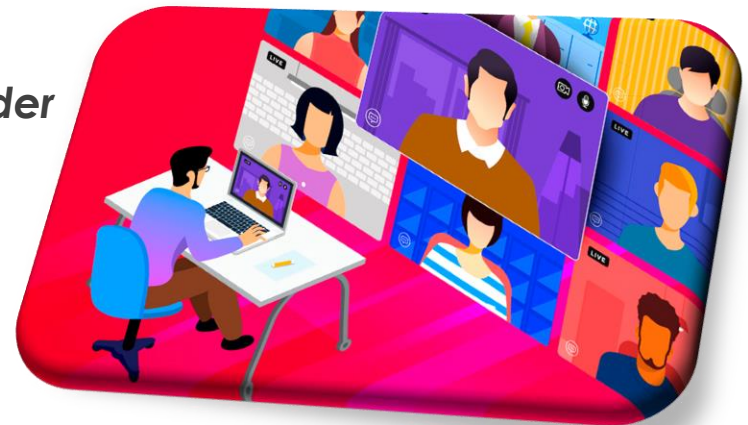
FTWW's staff and volunteers regularly contributed to 40 groups, forums, or boards

- ▶ **Patient Groups**, like our bi-monthly Support & Discussion Groups for Members of FTWW's Online Community, and co-Chairing Betsi Cadwaladr University Health Board (BCUHB)'s quarterly 'Gynae Voices' forum
- ▶ **Policy Groups**, like Senedd Cross-Party Groups on Women's Health, Women, Disability, Autism, Suicide Prevention, Long Covid; UK All-Party Parliamentary Groups on Women's Health, Endometriosis, Menopause; Wales Council for Voluntary Action's Health, Social Care & Wellbeing Planning Group; the Welsh Government's Period Dignity Strategy Group, and Loneliness & Social Isolation Advisory Group
- ▶ **Clinical Groups**, like the Royal College of GPs' Patient Forum, the Royal College of Obstetricians & Gynaecologists' Women's Network, and the Welsh National Specialist Advisory Group for Obstetrics & Gynaecology
- ▶ **Stakeholder Groups**, like Bangor University's Medical & Health Services Stakeholder Group, and BCUHB's Equality Stakeholder Group
- ▶ **Networking Groups**, like the WEN Wales Gender Network, and the Welsh NHS Confederation Health & Wellbeing Alliance.

FTWW's staff and volunteers attended 26 conferences, events, and seminars

such as...

- ▶ Wales Kidney Research Unit & Bangor University's **'Pregnancy Choices with Kidney Disease'**
- ▶ Public Health England webinars on **'Menstrual Wellbeing'**, and **'Menopause Wellbeing and Work'**
- ▶ Bevan Commission health and care in Wales **'Doing things Differently'** events
- ▶ National Union of Journalists, **'Reporting on the Impact of Covid19 on Disabled People'**
- ▶ **'Menstruation in the Media'** Conference
- ▶ Westminster Health Forum, **'Priorities for Women's Health – Tackling the Gender health Gap'**
- ▶ Health and Care Research Wales, **'From Menstruation to Menopause – a Reproductive Mental Health Journey'**
- ▶ Wales Policy Forum, **'Priorities for Healthcare in Wales'**
- ▶ Institute of Welsh Affairs, **'The Health Economics of North Wales'**



And participated in 38 meetings and workshops

including...

- ▶ Welsh Annual Rare Disease Patient Network Meeting
- ▶ Public Health Wales Workshop on Health Equity and Human Rights
- ▶ NICE Menopause: Diagnosis & Management Scoping Workshop
- ▶ Meeting with Ministers at the Welsh Government's Disability Equality Forum, and WCVA's Health, Social Care & Wellbeing Forum
- ▶ A 2-day All-Wales Endometriosis Nurse Training event
- ▶ Delivering presentations on menopause and women's health to WEN Wales's Gender Network and Café
- ▶ 'Endometriosis, diagnosis to treatment' for Aesculap Academia
- ▶ 'Pain in Outpatient Gynaecology Settings' to the Cross-Party Group on Women's Health
- ▶ 'FTWW's role in advocating for better women's health in Wales' for Autistic UK's International Women's Day workshop
- ▶ Giving evidence to the Senedd Public Accounts & Administration Committee on inclusion and equality impact assessments, and
- ▶ The need to prioritise women's health in Wales to the Senedd's Health and Social Care Committee



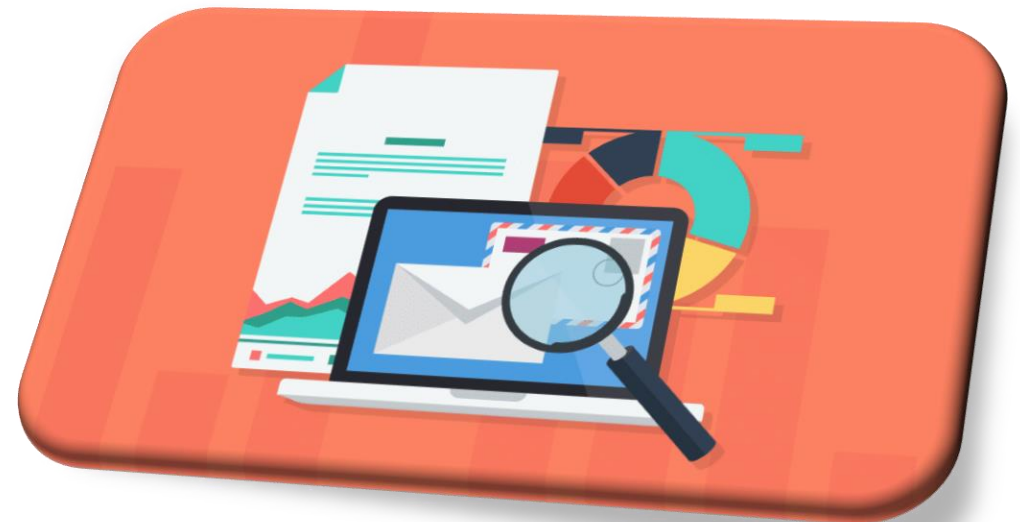
Hosted or co-hosted 8 Focus Groups and 1 pan-Wales Event

- ▶ Two with Engage Britain, on endometriosis, and women's health in general
- ▶ In partnership with Disability Wales to better understand disabled women's experiences
- ▶ Three on behalf of the Senedd Engagement Team, two focused on NHS waiting lists, and one on mental health inequalities
- ▶ One for officials leading on the Welsh Government's Period Dignity Strategy
- ▶ One on developing top tips and guidance for Wales's endometriosis nurses
- ▶ A pan-Wales digital event on 'Endometriosis Care in Wales – Where are we now' with Endometriosis UK.



Research, Reports, Consultation Responses

FTWW believes that the voices, experiences, and needs of women and people assigned female at birth, especially those who are disabled and living with long-term illness in Wales, must be reflected in research so that any resulting recommendations, policies, and actions are inclusive and don't further perpetuate inequality.



This year, FTWW's staff and volunteers took part in 4 research programmes & activities

which were...

- ▶ A Welsh Government-commissioned Steering Group sifting evidence & analysing the impact of the pandemic on disabled people in Wales which resulted in the 'Locked Out' report
- ▶ Supporting Dr Aimee Grant / Swansea University in her work to understand the differences in Autistic experiences of healthcare, including in relation to pregnancy, pregnancy loss and breastfeeding
- ▶ A Disability Wales-facilitated Steering Group collating evidence on the 5-yearly review of the United Nations Convention on the Rights of Disabled People in Wales
- ▶ Collating North Wales endometriosis patient testimonials for BCUHB Service Development.



Contributed to 15 Publications & One FTWW Patient-Led Report

- ▶ The Royal College of Obstetricians & Gynaecologists 4-yearly Workforce Report, including a Case Study on, '**Service-User Involvement in the North Wales Women's Directorate: Gynae Voices**' and a section on, '**Delivering person-centred care in remote and rural areas: Understanding Women's Perspectives**': <https://www.rcog.org.uk/workforce2022>
- ▶ The Welsh Government-commissioned report, '**Locked Out: liberating disabled people's lives and rights in Wales beyond COVID-19**': <https://gov.wales/locked-out-liberating-disabled-peoples-lives-and-rights-wales-beyond-covid-19>
- ▶ Civil Society Shadow Report on the **Implementation of the United Nations Convention on the Rights of Disabled People (UNCRPD) in Wales**: https://www.disabilitywales.org/wp-content/uploads/2022/03/0637-PS_DW-Report.pdf
- ▶ FTWW's Patient-Led report, '**Making the Case for Better Lupus and Rare Autoimmune Disease Provision for Patients in Wales**', which contains twenty-one evidence-based recommendations to Welsh Government to help improve care and support for patients in Wales: <https://www.ftww.org.uk/2021/wp-content/uploads/2021/09/Making-the-Case-for-Better-Lupus-and-Rare-Auto-Immune-Disease-Provision-for-Patients-in-Wales-Final.pdf>



Participated in 31 Consultations

providing written responses to...

▶ **UK Government Inquiries:**

- Office for Statistics Regulation's project to review statistics about the accessibility of transport
- Welsh Affairs Committee's 'Benefits System in Wales'

▶ **Welsh Government Strategies:**

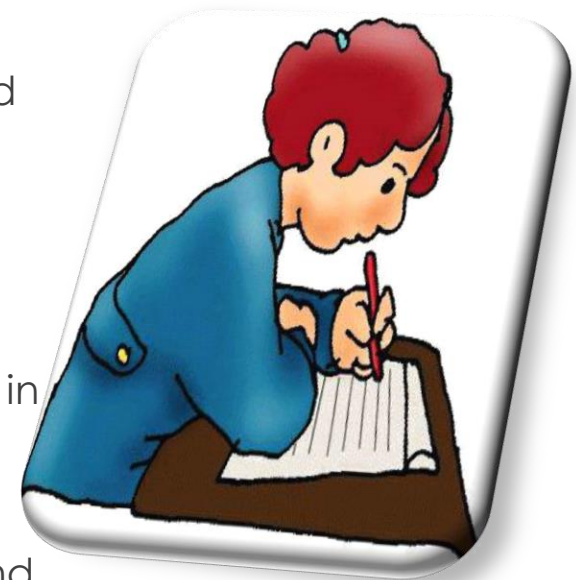
- Framework for Arthritis & Long-term Musculoskeletal Conditions in Adults
- Curriculum for Wales - Relationships and Sexuality Education (RSE) Statutory Guidance and Code
- National Framework for the Delivery of Bereavement Care
- Rapid Review of the Welsh Government's Community Cohesion Programme
- Period Dignity Strategic Action Plan

▶ **Senedd Inquiries:**

- Health and Social Care Committee, such as 'Priorities for the Sixth Senedd'
- 'The impact of the COVID-19 pandemic, and its management, on health and social care in Wales'

▶ **Clinical Guidelines:**

- RCOG's 'Investigation and Treatment of Recurrent Miscarriage'
- NICE Guidelines on 'Pelvic Floor Dysfunction: Prevention & Non-surgical Management', and 'Ectopic Pregnancy and Miscarriage: Diagnosis & Initial Management'
- RCGP Wales's inquiry into patients accessing GP services
- Health Education & Improvement Wales Education and Training Plan 2023-24



Coalitions and Campaigns

FTWW believes that collaboration is often key to raising awareness of women's health issues and intersectional inequalities as widely as possible. It also ensures that we can share learning, resources, skills, and maximise effectiveness and impact.



Embedding existing partnerships and forging new ones, contributing to the development of **20 projects and campaigns**

including...

- ▶ Working with **LUPUS UK and RAIRDA** to call for better services for rare autoimmune diseases in Wales
- ▶ Becoming a member of the **Welsh NHS Confederation's third sector Health & Wellbeing Alliance**
- ▶ Joining with **WEN Wales** and partner organisations on the Diverse 50/50 Campaign
- ▶ Partnering with **Disability Wales** to highlight disabled women's experiences and uphold their rights
- ▶ Supporting **Marie Curie Cymru**'s research into women's end of life priorities and care needs
- ▶ Being welcomed onto the **Public Services Ombudsman's** Sounding Board for Advice & Advocacy Groups
- ▶ Supporting **BCUHB and Arrowe Park** Endometriosis Specialists in improving care for North Wales patients
- ▶ Continuing to co-produce projects with **Cardiff University's Health Psychology Department** and, **Proper Design**, including SPPINN (Severe Period Pain is Not Normal) for use by Wales's school nurses
- ▶ Partnering with the **British Heart Foundation Cymru** to form the **#WomensHealthWales Coalition**, made up of Royal Colleges, specialist charities, academics, clinicians, and patients, coming together to call for a Women's Health Plan for Wales.



Resources

▶ 2 Downloadable Resources:

Template letter to Senedd 2021 Candidates calling on them to make women's health a priority

FTWW Information for Staff & Volunteers on Covid19 and Women's Health

▶ 46 Volunteers

▶ 13 Training Courses, including:

Digital Storytelling

Good Governance

Navigating Change &

Building Resilience

Understanding & Influencing Senedd Committees

Judicial Review & Legal Aid

Social Model of Disability

Media Training for 12 FTWW Volunteers

▶ 2 Grants Awarded – our thanks to:



Media

This year saw FTWW, our staff, volunteers, and members contributing to or featuring in **42 media items**

- ▶ **BBC Radio Wales broadcasts** on topics such as endometriosis; access to public toilets for disabled people and women with additional health needs; disability rights and reasonable adjustments for those living with long-term illness, and the impact of NHS waiting lists
- ▶ **Print and online news articles in The Financial Times, Nation Cymru, Wales Online, South Wales Guardian, ITV Wales, and BBC Wales** on subjects ranging from the difficulties patients in Wales have had accessing health services; improving endometriosis care; the challenges facing lupus patients in Wales; petitioning for a North Wales peri-natal mental health unit; Polycystic Ovarian Syndrome (PCOS), and FTWW's calls for a women's health plan for Wales



Media continued...

- ▶ **TV news coverage on BBC Breakfast, ITV News Wales, BBC Wales News, and BBC iPlayer** featuring stories on the taboos around female health; the need for pain relief to be offered in coil procedures; endometriosis; and the hand-in of a petition to improve endometriosis care signed by thousands across Wales
- ▶ **Senedd TV and Publications** featured volunteer Beth's endometriosis petition being discussed in Plenary, and FTWW's calls for a Women's Health Plan for Wales
- ▶ **ITV Wales This Week Documentary 'In Sickness and Health'** focused on long term illness and Covid 19 and featured 2 of FTWW's volunteers: Wendy discussing lupus, and Eve talking about endometriosis:

<https://www.itv.com/walesprogrammes/articles/wales-this-week-series-3-episode-9>



Testimonials

- ▶ *'Without (FTWW) I wouldn't have come to terms with living with this condition. It makes me feel normal and I now know I'm not crazy, this isn't all in my head'.*
- ▶ *'It's great to have information about events and updates all in one place. I wouldn't know about research and be able to listen to seminars etc if it wasn't for this page'.*
- ▶ *'Having information & support on how to fight for better treatment has been instrumental in actually starting my treatment journey'.*
- ▶ *'The community is an invaluable support to all of us. It's a great way to keep us all updated and offer opportunities for support and for getting more involved with the charity's work'.*



Further Testimonials...

- ▶ *'FTWW has helped point me in the right direction of who to contact when I haven't been receiving the care I need'*
- ▶ *'FTWW's group is a "safe space" to share struggles'.*
- ▶ *'Lots of support and advice given'.*
- ▶ *'FTWW directed me to correct information regarding treatment pathways, enabled me to meet people experiencing similar problems to me so I felt heard, provided support when feeling frustrated, in pain, lost and so less alone. (They've) enabled me to take part in campaigns to raise awareness or give feedback to professional organisations that I would not have otherwise known about'.*
- ▶ *'Like-minded patient conversations which has been really important and informative'.*



Treasurer's Report & Annual Accounts

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Summary of Financial Position 2021-22

The following is drawn for the accounts of the Organisation and provides an overview of financial activity for the period 1st April 2021 – 31st March 2022.

The Organisation brought forward a balance of £17,159.54 from 2020-21.

► Income

Between 1st April 2021 and 31st March 2022, the organisation generated a total income of £31,079.50. This was an increase of £20,012 over the 2020/21 period.

A breakdown of sources of income is as follows:

- Fundraising, Events, and Donations £2,354.90
- Grants £26,750.00
- Payment for Services £1,974.60

TOTAL £31,079.50

Treasurer's Report & Annual Accounts continued...

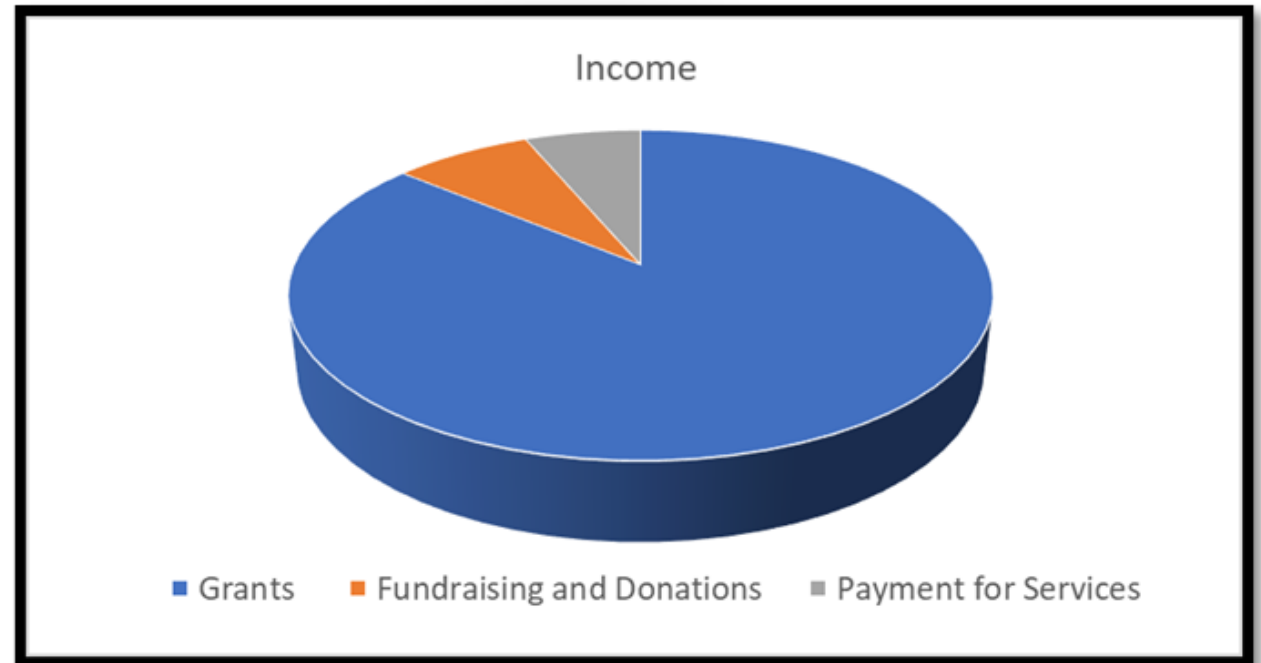


The relative proportions of income can be seen in the chart to the right:

A total of £26,750 in grant funding was received, comprising:

- ▶ £8,000 from Rosa UK Covid-19 Response Fund (Follow-on Grants)
- ▶ £18,750 from the Rosa UK / Smallwood Trust Women Thrive Fund

The Rosa UK Covid-19 Response Fund (Follow-on Grant) was spent within the 2021/22 reporting period, along with £8,069 of the Rosa UK / Smallwood Women Thrive grant.



Treasurer's Report & Annual Accounts continued...

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£10,680.13 of grant funding is carried forward into 2022/23

Both grants have been used to fund the following:

- ▶ Salary costs for our part-time Engagement Officer
- ▶ Training for trustees and volunteers
- ▶ Volunteers' expenses
- ▶ Translation
- ▶ IT costs
- ▶ Lost fundraising income during the pandemic.



Treasurer's Report & Annual Accounts continued...



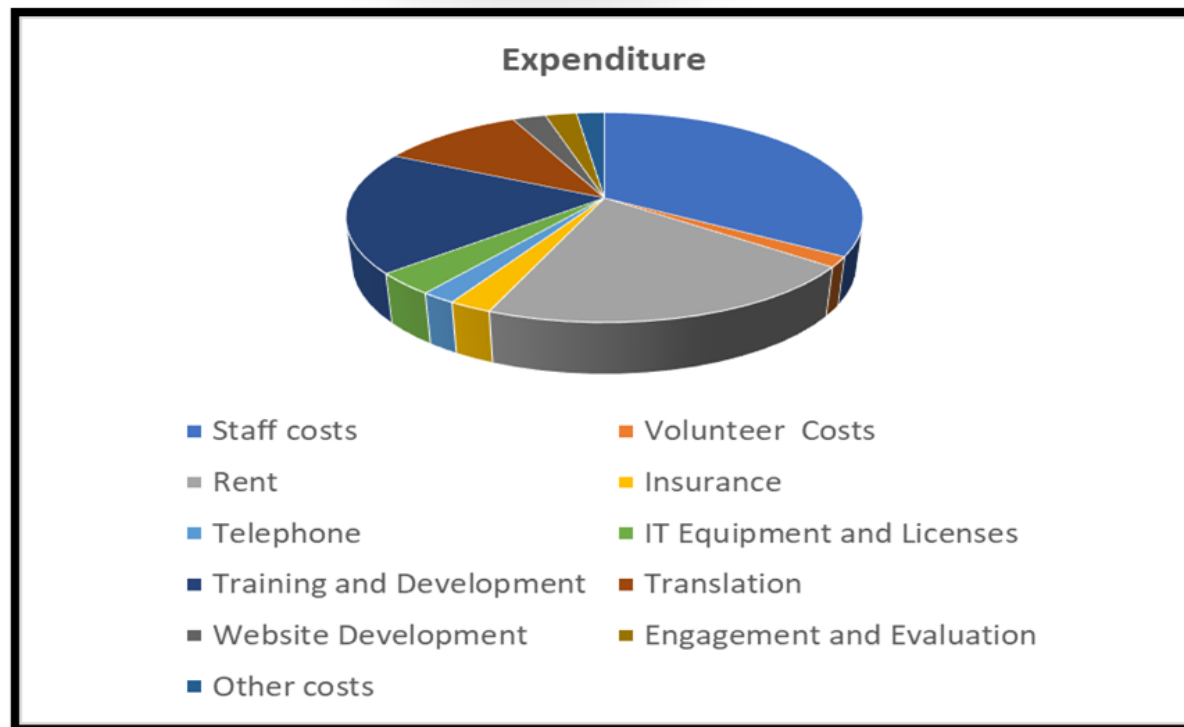
► Expenditure

Between 1st April 2021 and 31st March 2022, FTWW expended a total of £22,563.77 in furtherance of its aims and objectives.

A breakdown of expenditure is as follows:

► Staff Costs	£7,623.74
► Office Rent	£4,680.00
► Training and Development	£4,244.86
► Translation	£2,411.58
► IT equipment and licenses	£758.99
► Website development	£561.00
► Engagement and Evaluation	£527.88
► Insurance	£514.05
► Telephone	£413.55
► Volunteer Reimbursement Costs	£357.84
► Other costs	£470.28

TOTAL £22,563.77



Treasurer's Report & Annual Accounts continued...

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The closing balance of funds available to the organisation on the 31st March 2022 was £25,675.27.

The breakdown of restricted and unrestricted funds carried forward at 31st March 2022 is as follows:

- ▶ Restricted £10,680.13
- ▶ Unrestricted £14,995.14

TOTAL £25,675.27

As reported in our 2020-21 report, the organisation continues to actively explore new funding streams to build capacity and, in particular, to create a director post to take the organisation forward.

I can confirm that these accounts have been subjected to an independent examination by Karen Cockings, University of South Wales Accounts.

Tamira Rolls, FTWW Treasurer

FTWW Board of Trustees

- ▶ **Chair:** Dr Sally Rees
- ▶ **Treasurer:** Tamira Rolls
- ▶ **Secretary:** Jonathan Stevens
- ▶ **Trustee:** Willow Holloway
- ▶ **Trustee:** Julie Richards
- ▶ **Trustee:** Claire Foster
- ▶ **Patient Adviser:** Louise Evans
- ▶ **Founder:** Deborah Shaffer
- ▶ **Endometriosis Lead:** Rachel Joseph
- ▶ **Menopause Leads:** Lisa Nicholls, Lara Morris
- ▶ **Pregnancy Loss Lead:** Jess Evans
- ▶ **Autoimmune Lead:** Wendy Diment

