

ANNUAL REPORT

2024-

2025

Vitiligo Support UK Reg: 1170557

Vitiligo Support UK



*Providing support & advocacy
to all with vitiligo*

Table Of Contents

| | | | |
|-------------------------------------------------------|--------------|------------------------------------------------|--------------|
| Introduction | 1-4 | Conferences, presentations, & media | 13-16 |
| Message from CEO | 5-8 | Public Advocacy: NICE & ruxolitinib | 17-19 |
| Financial Review | 9-10 | Thank You | 20-21 |
| Research Projects & Charity Collaborations | 11-12 | | |

Charity Status, Legal & Financial Overview

**Vitiligo Support UK is a Charitable
Incorporated Organisation**

Founded: 05 December 2016

Charity Number: 1170557 (England & Wales)

Website: www.vitiligosupport.uk

Address for Correspondence: 36 Avondale
Avenue, Esher, KT10 0DA.

Bankers: Virgin Money, 15-17 Castle Street ,
Kingston upon Thames , KT1 1ST.

2024-2025 Annual Report



Supporting patients...

Providing health advocacy

Welcome to our Annual Report, a showcase of our achievements, progress, & commitment to patients with vitiligo, their families & friends throughout the year.

Vitiligo Support UK

2024-2025 Annual Report



Dear Supporters & Followers,

I am delighted to present our Annual Report, which details all we have achieved in our ongoing & tireless support of vitiligo patients in England & Wales. In addition, we have also worked internationally through participation in research projects.

We operate on very low outgoings compared to other charities in this field, & are very grateful for the contributions made to the charity by the general public over the past year.

2024-2025 Annual Report

The generosity of our members enabled our attendance at the BAD Annual Conference & our continued representation of vitiligo & vitiligo patients as worthy of treatment & our disease as an important autoimmune disease with risk of comorbidities we are concerned are being missed in primary care.

We have no paid employees so all of the work described in this annual report is provided voluntarily by our CEO & volunteers.

The past year has been one of significant work & advocacy provided in support of the first new & specifically for vitiligo topical treatment, ruxolitinib. Currently, in England & Wales, patients are routinely given topical steroids to begin their treatment pathway, which are of limited efficacy.

2024-2025 Annual Report



Our representation of vitiligo patients included in-person advocacy at NICE committee meetings, preparation & submission of written documentation in support of ruxolitinib as a treatment & canvassing the support in written form of a significant number of vitiligo patients through our membership.

Thank you for your support, & we look forward to another year of action & advocacy for vitiligo patients.

Emma Rush, CEO, Vitiligo Support UK



Financial Review

Review of the charity's financial position at the end of the period (Para 1.21): The charity maintained its stable financial position in this period.

Statement explaining the policy for holding reserves stating why they are held (Para 1.22):

No material reserves are held due to the charity's conservative management.

Amount of reserves held (Para 1.22): See above.

Reasons for holding zero reserves (Para 1.22):

See above.

Explanation of any uncertainties about the charity continuing as a going concern (Para 1.23):

None.

Financial Review

Additional information (optional):

You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising) (Para 1.47):

Donations from the general public.

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Research projects & charity collaborations

In the autumn of 2024, we were invited by Dr Eleftheriadou to be a patient representative in the VIRTUAL UK project: VItiligo RegisTry for adUlts & children in the UK.

This is a multi-centre, prospective, observational clinical registry of paediatric & adult patients with vitiligo on phototherapy, or novel topical/systemic immune-modulatory therapies.

Obtaining registry data allows researchers to gain a better understanding of how vitiligo “behaves” under treatment, including examination of the high risk of relapse following interventions.

Research projects & charity collaborations

We were also amongst a group of charities invited by Professor Diana Harcourt of the Centre for Appearance Research at the University of West of England to help them develop a new website for CAR's visible difference resources/materials.

We have previously participated in two research projects with CAR, one of which informs the acceptance & commitment therapy intervention on the website.

<https://visibledifferencesupporthub.com/>

Conferences, presentations, & media

On 23 September 2024, our CEO, Emma Rush, appeared alongside Dr Viktoria Eleftheriadou & the actress, Georgia May Foote. The appearance followed our advocacy as a charity during the NICE appraisal process for Vitiligo Support UK. The slot included discussion of the impact of vitiligo, current treatments & the hope generated by the prospect of a new specific treatment for our skin disease.



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Conferences, presentations, & media

In July 2024, as the patient representative on the British Association of Dermatologists' Conference Organising Committee, our CEO attended the Annual Conference in Manchester.

This led to building relationships with fellow patient support charities in the dermatology field & gave opportunities for networking (within the APBI Code of Practice).

We were also able to attend the presentation by Incyte on their new topical treatment for vitiligo, ruxolitinib, & invited to share the patient perspective on the desperate need for treatment amongst a patient group that experiences a significant psychological impact of their disease.

Conferences, presentations, & media

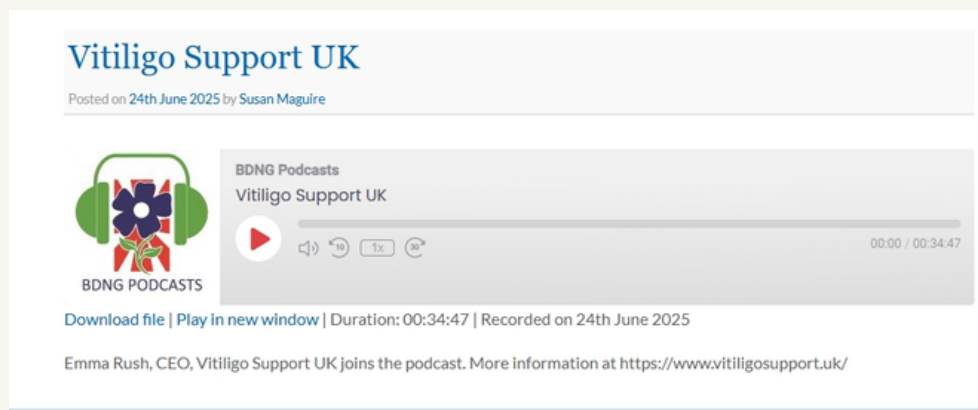
In addition, we were pleased to attend the poster presentation by Dr Eleftheriadou on vitiligo & again, we were allowed to present the patient perspective to those who attended.



Conferences, presentations, & media

In February 2025, we continued to build our relationship with the British Dermatological Nursing Group by writing an article on how vitiligo patients feel invisible to the healthcare profession.

We then contributed to their podcast series, recording a podcast in April 2025.



Public Advocacy: NICE & ruxolitinib

Currently, only two topical & unlicensed treatments are available to vitiligo patients in primary care & access to hospital-based phototherapy as the third line of treatment depends on waiting lists in the patient's area & ability to commit to a lengthy course of treatment.

This has led to our overriding aim as a charity, to help patients gain access to treatment in a healthcare environment that still shows considerable resistance to treating our disease appropriately.

Currently, the only treatments available are standard ones that are prescribed across a number of inflammatory skin diseases, & are not specifically licensed for vitiligo.

The drug company, Incyte, brought ruxolitinib to NICE for approval for prescription in the NHS in 2024.

Public Advocacy: NICE & ruxolitinib

At the Committee Meeting that was called by NICE to appraise ruxolitinib for prescription within the NHS, we represented the charity, sharing patients' experience & advocating for our skin disease to be granted access to the first treatment ever specifically researched & designed for vitiligo.

We were supported by a patient from our membership who gave a moving & powerful account of living with vitiligo as a person with skin of colour.

We were also privileged to have Dr Jonathan Batchelor (lead investigator on the HI-Light trial), Dr John Ferguson (lead of the Vitiligo Centre at Guy's hospital) & Dr Antony Bewley (co-chair of Psychodermatology UK) represent the charity as clinicians.

Public Advocacy: NICE & ruxolitinib

Unfortunately, NICE turned down Incyte's application, & we subsequently went to appeal, represented again by our clinical team & by our CEO.

Throughout the process, we fully engaged with NICE & its procedures, delivering on time & providing extensive written support for the prescription of ruxolitinib together with patient testimony to demonstrate the real & significant impact of the disease.

The appeal was also turned down, & we instituted a campaign of writing to local MPs which generated several leads & some engagement.

We still are waiting for recognition of the impact of vitiligo as an auto-immune disease with a considerable psychological burden & comorbidities.



We are enormously grateful to all our members who donated to the charity over this & who gave enormous support to our cause, in particular during our first appraisal meeting & the appeal meeting with NICE.

As a charity, we understand that vitiligo can impact you in many different ways, but we are always concerned to give a voice to those who have become invisible to our healthcare system.

We advocate passionately for vitiligo patients in many different fora & look forward to going on representing people with vitiligo in the future



We extend particular thanks to the following contributors to the work we complete for vitiligo patients:

Dr Jonathan Batchelor
Dr Anthony Bewley
Dr Viktoria Eleftheriadou
Dr John Ferguson
Dr Tessa McPherson
Dr Tamara Griffiths
Dr Kate Dale

Vivien Ambrose
Claudia Money
Peter Rush
Pav Korpál

And all of the community in our closed Facebook Group.

ANNUAL REPORT

2024-

2025



www.vitiligosupport.uk



info@vitiligosupport.uk



www.facebook.com/groups/VitiligoSupportUK



Receipts and payments accounts

CC16a

For the period
from

03-Apr-24

To

02-Apr-25

Section A Receipts and payments

| | Unrestricted funds to the nearest £ | Restricted funds to the nearest £ | Endowment funds to the nearest £ | Total funds to the nearest £ | Last year to the nearest £ |
|-------------------------------------------------------|----------------------------------------------|-----------------------------------------|----------------------------------------|---------------------------------|-------------------------------|
| A1 Receipts | | | | | |
| Donations | 1,545 | - | - | 1,545 | 1,084 |
| Grant | - | - | - | - | - |
| Interest Received | - | - | - | - | 202 |
| | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| Sub total (Gross income for AR) | 1,545 | - | - | 1,545 | 1,286 |
| A2 Asset and investment sales, (see table). | | | | | |
| | - | - | - | - | - |
| | - | - | - | - | - |
| Sub total | - | - | - | - | - |
| Total receipts | 1,545 | - | - | 1,545 | 1,286 |
| A3 Payments | | | | | |
| Insurance | 110 | - | - | 110 | 101 |
| JustGiving fee | 216 | - | - | 216 | - |
| Conference Expenses: BAD July 2024 | 334 | - | - | 334 | - |
| Website Hosting | 168 | - | - | 168 | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| | - | - | - | - | - |
| Sub total | 828 | - | - | 828 | 101 |
| A4 Asset and investment purchases, (see table) | | | | | |
| | - | - | - | - | - |
| | - | - | - | - | - |
| Sub total | - | - | - | - | - |
| Total payments | 828 | - | - | 828 | 101 |
| Net of receipts/(payments) | 717 | - | - | 717 | 1,185 |
| A5 Transfers between funds | - | - | - | - | - |
| A6 Cash funds last year end | 1,476 | - | - | 1,476 | - |
| Cash funds this year end | 2,193 | - | - | 2,193 | 1,185 |

Section B Statement of assets and liabilities at the end of the period

| Categories | Details | Unrestricted funds to nearest £ | Restricted funds to nearest £ | Endowment funds to nearest £ |
|-----------------------|--------------|---------------------------------------|-------------------------------------|------------------------------------|
| B1 Cash funds | | | | |
| | Cash at Bank | 2,193 | - | - |
| CCXX R1 accounts (SS) | 1 | - | - | \$1/01/2026 - |

| | | | |
|--------------------------------------------------------|--------------|----------|----------|
| | - | - | - |
| Total cash funds | 2,193 | - | - |
| (agree balances with receipts and payments account(s)) | OK | OK | OK |

B2 Other monetary assets

| Details | Unrestricted funds to nearest £ | Restricted funds to nearest £ | Endowment funds to nearest £ |
|---------|---------------------------------|-------------------------------|------------------------------|
| | - | - | - |
| | - | - | - |
| | - | - | - |
| | - | - | - |
| | - | - | - |
| | - | - | - |

B3 Investment assets

| Details | Fund to which asset belongs | Cost (optional) | Current value (optional) |
|---------|-----------------------------|-----------------|--------------------------|
| | | - | - |
| | | - | - |
| | | - | - |
| | | - | - |
| | | - | - |

B4 Assets retained for the charity's own use

| Details | Fund to which asset belongs | Cost (optional) | Current value (optional) |
|---------|-----------------------------|-----------------|--------------------------|
| | | - | - |
| | | - | - |
| | | - | - |
| | | - | - |
| | | - | - |
| | | - | - |
| | | - | - |
| | | - | - |
| | | - | - |

B5 Liabilities

| Details | Fund to which liability relates | Amount due (optional) | When due (optional) |
|---------|---------------------------------|-----------------------|---------------------|
| | | - | |
| | | - | |
| | | - | |
| | | - | |
| | | - | |

Signed by one or two trustees on behalf of all the trustees

| Signature | Print Name | Date of approval |
|-----------|------------|------------------|
| | | |
| | | |