



CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' Annual Report for the period

From **02/04/2023**
Period end date

Period start date To **01/04/2024**

Charity name: Vitiligo Support UK

Charity registration number: 1170557

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	To promote and protect the physical and mental health of sufferers of vitiligo in England and Wales by the provision of support, education and practical advice and to advance the education of the public in all areas relating to vitiligo
Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts.	Para 1.17 and 1.19	
<p>We are a small charity and have been in existence for less than a decade, unlike other charities in this sphere of activity.</p> <p>However, we devote considerable time, skill and energy to fulfilling our charitable objectives, and have significantly proved our worth and confirmed our reputation for the thoughtful and committed care of people with vitiligo in this period in the following ways.</p> <p>We have used social media including our new website to signpost services and information. We used it in a particularly efficacious way in garnering patient statements of impact in support of our submission to NICE (see below).</p> <p>Providing advocacy for patients with vitiligo via membership of committees and working groups within the British Association of Dermatologists (BAD).</p> <p>Leading as patient representative on the Education Sub-Committee at the BAD and as patient representative on the Conference Sub-Committee.</p> <p>Answering queries relating to access to treatment and providing a Guide to talking to your GP about Treatment that details the steps for patients to take to push back against dismissal by clinicians in primary care as having "merely" a cosmetic disease.</p> <p>Providing extensive individual support to our members and answering a significant number of one-to-one queries raised with us.</p>		

In 2023/2024, we prepared a submission to the National Institute of Health and Care Excellence in support of Incyte Biosciences UK's application for approval of the novel topical treatment, ruxolitinib, for prescription on the NHS.

We were punctilious in submitting on time, following procedure and providing an outstanding response as a patient support organisation explaining the pressing need for a licensed novel treatment for our disease.

This also involved canvassing the very moving testimonies of our members as to the psychological, physical and cultural impact on them of their vitiligo. People gave very generously of their time and their personal accounts of this disease, and we are enormously grateful for their help. In the appraisal meeting, the Committee Chair made reference to these submissions, indicating that they had moved the members of the committee. The decision made was negative, but we continue to work tirelessly for its ultimate approval by participating in the appeal process, following the NICE requirements and ensuring that we were timely in our responses.

In our attendance at the appraisal meeting, we gave evidence of the impact of this disease. We were very pleased to be supported in this by the clinician Dr Jonathan Batchelor, who ran the HI-Light trial at Nottingham University in 2012 and by our patient expert, who was selected to appear.

This formed a major part of the work undertaken in the public forum for vitiligo patients.

However, we continue to hold to the objective that patients require support in their quest for treatment.

Social media exposure of the disease, even its monetization, has increased but this still does not help the patient in their daily lives.

It is our goal to help people gain treatment, and the best and most appropriate course of treatment for their skin disease. We close with a quote from a patient bearing witness to the power of information in gaining treatment, "Had my dermatology appointment today, and just wanted to say thanks to Emma Rush. I let the doctor have her say and she basically had told me they can't do nothing...then I told her, you can do something and told her about this group and Emma, also mentioned the nice guidelines and they should offer me some treatment... she changed her tune and is referring me to have phototherapy and make sure I get any new treatment available...which I know will be a long wait for this, but asked if they could give me some creams to try while I'm waiting, she prescribed me some topical cream.

I honestly felt so good walking out this appointment, as I feel I stood my ground and was not walking out without any treatment 😊 first time ever I felt good walking out of a dermatology appointment. Thank you so much Emma."

Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit

Para 1.18

We have had regard to the guidance issued by the Charity Commission in respect of public benefit.

Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	

Policy on social investment including program related investment	Para 1.38	
Contribution made by volunteers	Para 1.38	
Other		

Achievements and Performance

	SORP reference	
Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole.	Para 1.20	<p>As a charity, we have provided extensive support to our membership in navigating access to dermatology.</p> <p>This remains a significant challenge for patients, and we are in the process of joining research conducted in Scotland relating to moving the referral to phototherapy into primary care, research that may be overtaken by government policy.</p> <p>The waiting lists in dermatology are unacceptably long, and the concern remains that vitiligo patients are triaged out of secondary care in favour of other inflammatory skin conditions.</p> <p>Our Guide to talking to your GP about your vitiligo, based on the information provided by the Primary Care Dermatology Society, has continued to be an extremely useful tool for patients to open conversations and push for treatment in primary care and referral to secondary care where appropriate.</p> <p>We also continue to promote the BAD Guidelines for managing patients with vitiligo as a means for patients to gain access to treatment. It would be great if this became standardised across patient support bodies as they provide a significantly powerful tool for patients to advocate for their treatment.</p> <p>We spoke at the NSS Photonet conference again, advising Scottish clinicians of the importance of recognising that vitiligo can be treated and is most successfully treated via narrowband uvb.</p>

Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	
Performance of fundraising activities against objectives set	Para 1.41	
Investment performance against objectives	Para 1.41	
Other		

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.
Details of fund materially in deficit	Para 1.24	See above.
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	None.

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.
Investment policy and objectives including any social investment policy adopted	Para 1.46	
A description of the principal risks facing the charity	Para 1.46	
Other		

Structure, Governance and Management

Description of charity's trusts:		
Type of governing document (trust deed, royal charter)	Para 1.25	CIO Constitution
How is the charity constituted? (e.g unincorporated association, CIO)	Para 1.25	Charitable Incorporated Organisation
Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees	Para 1.25	Trustees are appointed by the existing trustees, following the provisions of the constitution.

Additional information (optional)

You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	
The charity's organisational structure and any wider network with which the charity works	Para 1.51	
Relationship with any related parties	Para 1.51	
Other		

Reference and Administrative details

Charity name	Vitiligo Support UK
Other name the charity uses	
Registered charity number	1170557
Charity's principal address	36 Avondale Avenue, Esher, Surrey KT10 0DA

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Emma Rush	Chair of Trustees		
2	Peter Rush			
3	Kate Burnside			
4	Sara Day			
5	Joanna Jackson			
6				
7				
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17				
18				
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20				

Corporate trustees – names of the directors at the date the report was approved

Director name		

Name of trustees holding title to property belonging to the charity

Trustee name	Dates acted if not for whole year	

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	None
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	

Additional information (optional)

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

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Exemptions from disclosure

Reason for non-disclosure of key personnel details

None

Other optional information

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Declarations

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)		
Position (eg Secretary, Chair, etc)		
Date		



CHARITY COMMISSION
FOR ENGLAND AND WALES

Vitiligo Support UK

1170557

Receipts and payments accounts

CC16a

For the period
from

3-Apr-23

To

2-Apr-24

Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Donations	355	-	-	355	1,084
Grant	-	-	-	-	-
Interest Received	-	-	-	-	202
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	355	-	-	355	1,286
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	355	-	-	355	1,286
A3 Payments					
Insurance	45	-	-	45	101
Research Expenses	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	45	-	-	45	101
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	45	-	-	45	101
Net of receipts/(payments)	310	-	-	310	1,185
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	1,185	-	-	1,185	-
Cash funds this year end	1,495	-	-	1,495	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	1,496	-	-
	-	-	-
	-	-	-
Total cash funds	1,496	-	-

(agree balances with receipts and payments account(s))

Agreement Error OK OK

Unrestricted funds Restricted funds Endowment funds

to nearest £ to nearest £ to nearest £

B2 Other monetary assets

	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-
	-	-	-

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