



**CHARITY COMMISSION
FOR ENGLAND AND WALES**

Trustees' Annual Report for the period

From 02/11/2022 **Period start date**
To 01/11/2023 **Period end date**

Charity name: NTM PATIENT CARE UK

Charity registration number: 181372

Objectives and Activities

Summary of the purposes of the charity as set out in its governing document	<p>The purpose of NTM Patient Care UK is to provide information and support to patients with NTM. We also work with Healthcare Professional (HCP) teams to improve understanding of patient needs, co-ordinating and facilitating the transfer of information in both directions between the two.</p> <p>This purpose is set out in the Constitution as the following objectives;</p> <p>Working to improve the lives of people with non-tuberculous mycobacterial (NTM) infection in the UK, in particular, but not exclusively, by;</p> <p>a) the provision of education and information to increase understanding of NTM in both the clinical and patient communities.</p> <p>b) the development and implementation of a support network for NTM patient communities.</p>
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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.	<p>Main activities for the reporting period include the following:</p> <p>a) The charity holds regular Zoom meetings for patients and HCPs with an interest in NTM. Meetings have included presentations on areas relevant to patients such as physio, pharmacy, microbiology and dietetics, as well as general Q & A sessions. Meetings also provide a forum for patients to share and discuss their experiences of NTM and associated issues.</p> <p>b) The charity continues to develop and improve the NTM Patient Care UK website to provide information and support to patients.</p> <p>c) The charity continues to develop posters and leaflets for distribution in respiratory clinics and other relevant locations.</p> <p>d) The charity continues to raise awareness of NTM within the medical community and actively engages patients and their wider support community.</p> <p>e) The NTM Patient Care UK Management Group hold regular meetings to develop strategies for the patient association to help meet its intended goals.</p> <p>f) The charity has established a social media presence on Facebook and has set up a Facebook support and discussion group. A Linked-in site was set up but has been discontinued due to lack of interest.</p> <p>g) A UK patient forum has been set up on the NTMir site, based in the USA. NTMir has a global reach.</p> <p>h) The charity is embarking on a range of fundraising measures in order to continue with its work.</p>
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Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	The trustees have had regard to the Charity Commission's guidance on public benefit.
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Achievements and performance

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.	<p>Main activities for this reporting period have included the following;</p> <p>a) Ongoing provision of support and information specific to patients mainly via email and phone.</p> <p>b) Maintenance of the NTM Patient Care website that provides patients with a source of information and advice, including patient stories, frequently asked questions, news stories, research information, links to other sources, and information on matters such as physiotherapy and mental health.</p> <p>c) Ongoing provision of regular Zoom meetings to provide relevant information and support specific to patients. This has not only improved support available to patients but has also provided an opportunity for informal interaction between patients and HCPs. This has led to an improved understanding of NTM and the patient experience within both groups.</p> <p>d) The charity is working with HCPs to produce Standards of Care for the health service. These are due to be published in 2024.</p> <p>e) Information is regularly posted on Facebook on a range of subjects including dates of meetings, research information, conferences, YouTube videos and other relevant information. The number of followers is growing.</p> <p>f) The Facebook discussion and support group gives patients, carers and HCPs an opportunity to interact, ask questions and support each other with shared experiences.</p> <p>g) The forum set up with NTMir is now live. It is for patients and carers only but has attracted little interest.</p> <p>h) A Just Giving fundraising page has been set up and the first charity fundraiser launched.</p>
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Financial review

Review of the charity's financial position at the end of the period	The charity remains in positive balance.
Statement explaining the policy for holding reserves stating why they are held	The charity has no policy for holding reserves and a policy is not considered necessary as income for the period far exceeded expenditure. This will be considered in future reporting years if necessary.
Amount of reserves held	Due to the healthy state of finances, reserves are not considered necessary
Reasons for holding zero reserves	The charity receives more than it spends so reserves are not considered necessary.
Details of fund materially in deficit	N/A

Explanation of any uncertainties about the charity continuing as a going concern	N/A
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Additional information

The charity's principal sources of funds (including any fundraising)	The charity received income of £21,405 made up of two grants from a pharmaceutical company (£9,500 in March 2023 and £9,500 in October 2023) and the remainder from donations and fundraising.
Investment policy and objectives including any social investment policy adopted	N/A
A description of the principal risks facing the charity	N/A

Structure, governance and management

Description of charity's trusts	N/A
Type of governing document (trust deed, royal charter)	Constitution of the Charitable Incorporated Organisation (CIO)
How is the charity constituted? (e.g unincorporated association, CIO)	Charitable Incorporated Organisation (CIO)
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	Trustees include founding individuals, patients and HCPs to ensure the best representation of the needs of patients with NTM. More details of Trustee selection are provided in the Constitution.

Reference and administrative details

Charity name	NTM Patient Care UK
Other name the charity uses	N/A
Registered charity number	1181372
Charity's principal address	Royal Free London NHS Foundation Trust, Pond Street, Hampstead, London NW3 2QG

Names of the charity trustees who manage the charity during period of report

Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
Professor Marc Lipman	Trustee		
Professor Heather Milburn	Trustee		
Shirley Harwood	Trustee		
Graham Lake	Trustee	From June 2023	
Dr Tanya Sinnett	Trustee	From November 2022	

Funds held as custodian trustees on behalf of others

Description of assets held in this capacity	N/A
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	N/A
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	N/A

Additional information (optional)

Type of adviser	Name	Address
Technical and medical communications advisor	John Hockley	Axiom Health Ltd Registered office: 21 Birch Drive, Billingshurst, West Sussex RH14 9RH

Declarations

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

Signed on behalf of the charity's trustees	
Signature:	
Full name(s):	Professor Marc Lipman
Position (e.g., secretary, chair):	Chair
Date:	



CHARITY COMMISSION
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Charity Name		No (if any)	
NTM Patient Care UK			
Receipts and payments accounts			
For the period from	Period start date	To	Period end date
	11/2/22		11/1/23

Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds
	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts				
Paypal Donation 10/1/23	751			
Insmed Grant 9/3/23	9,500			
Just Giving Donation 19/6/23	83			
Just Giving Donation 3/7/23	79			
Just Giving Donation 10/7/23	67			
Just Giving Donation 14/8/23	102			
Just Giving Donation 4/9/23	10			
Just Giving Donation 18/9/23	102			
Just Giving Donation 20/9/23	60			
Just Giving Donation 26/9/23	17			
Just Giving Donation 2/10/23	122			
Personal Donation 3/10/23	30			
Just Giving Donation 4/10/23	14			
Personal Donation 3/10/23	20			
Adept Field 5/9/23	250			
Just Giving Donation 9/9/23	73			
Just Giving Donation 10/10/23	5			
EUI Ltd 11/10/23	329			
Insmed Grant 12/10/23	9,500			
Personal Donation 13/10/23	230			
Just Giving Donation 18/10/23	11			
Adept Field 26/10/23	50			
Sub total (Gross income for AR)	21,405			
A2 Asset and investment sales, (see table).				
	- 0	- 0	- 0	-
	- 0	- 0	- 0	-
Sub total	- 0	- 0	- 0	-
Total receipts	21,405	- 0	- 0	Cross Add Error
A3 Payments				
NRS Printing 24/11/22	191			
NRS Printing 24/1/23	33			
IONOS 13/2/23	7			
Website etc 13/3/23	300			
IONOS 15/3/23	7			
NRS Printing 20/3/23	14			
Website etc 31/3/23	400			
IONOS 13/4/23	7			
NRS Printing 21/4/23	11			
Website etc 27/4/23	400			
NRS Printing 4/5/23	11			
IONOS 11/5/23	4			
IONOS 12/5/23	4			
NRS Printing 30/5/23	18			
NRS Printing 30/5/23	89			
Website etc 30/5/23	400			
IONOS 13/6/23	12			
Website etc 28/06/23	300			
IONOS 12/7/23	12			

IONOS 11/8/23	12				
NRS Printing 1/9/23	45				
IONOS 13/9/23	12				
NRS Printing 22/9/23	14				
IONOS 11/10/23	12				
Tshirts	36				
Sub total	2,350				
A4 Asset and investment purchases, (see table)					
	- 0	- 0	- 0	-	
	- 0	- 0	- 0	-	
Sub total	- 0	- 0	- 0	-	
Total payments	2,350	- 0	- 0	Cross Add Error	
Net of receipts/(payments)	19,055	-	-		
A5 Transfers between funds	- 0	-	-	-	
A6 Cash funds last year end	- 0	-	-	-	
Cash funds this year end	19,055	-	-		

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

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £
B1 Cash funds		-	-
		-	-
		30,087	-
	Total cash funds	30,087	-
	(agree balances with receipts and payments account(s))	Agreement Error	OK
		Unrestricted funds	Restricted funds
	Details	to nearest £	to nearest £
B2 Other monetary assets		-	-
		-	-
		-	-
		-	-
		-	-
		-	-
		-	-
	Details	Fund to which asset belongs	Cost (optional)
B3 Investment assets			-
			-
			-
			-
			-
	Details	Fund to which asset belongs	Cost (optional)
B4 Assets retained for the charity's own use			-
			-
			-
			-

			-	
			-	
			-	
			-	
			-	
	Details	Fund to which liability relates	Amount due (optional)	
B5 Liabilities			-	
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name		

CC16a

11/11/2016

Last year
to the nearest £

- 0

	- 0
	- 0

- 0

[illegible]

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-
-
-
-
When due (optional)
Date of approval