

Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	06	April	2021		05	April	2022

Section A Reference and administration details

Charity name

TREATSMA

Other names charity is known by

Registered charity number (if any)

1182610

Charity's principal address

85 Great Portland Street

First Floor

London

Postcode

W1W 7LT

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	GENNADIY ILYASHENKO			
2	JOSEPH IRWIN			
3	LUCY FROST			
4	ANDI THORNTON			
5	KELLY JONES			
6				
7				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

--	--

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

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

--

Section B Structure, governance and management

Description of the charity's trusts

Type of governing document (eg. trust deed, constitution)	Constitution
How the charity is constituted (eg. trust, association, company)	CIO
Trustee selection methods (eg. appointed by, elected by)	Elected by other trustees

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

--

Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

We do everything possible to ensure that all people with SMA have access to effective treatments, health care and social support. We raise awareness of the disease, offer support to those affected and their near and dear ones, promote and support scientific research into causes and treatments, and provide necessary equipment and living aids.

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

- Campaigned for access to treatment of Spinraza
- Worked with pharmaceutical companies and regulatory agencies to further knowledge and support the introduction of further treatments
- Ran a large number of educational webinars for those with and affected by SMA to help support them on key topics such as:
 - Physiotherapy
 - Respiratory care
 - Standards of care
 - Dietary considerations
- Provided support to families either by email or telephone as and when required
- Continued fundraising to further our goals

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

Summary of the main achievements of the charity during the year

- We continue to represent families with SMA in various technical processes.
- Represent families in appraisals for treatments for SMA (Spinraza, Zolgensma, Risdiplam)
- We continue to participate in oversight committees for Managed Access Agreement for Spinraza and Risdiplam.
- We have had a program of adult and children focused physiotherapy webinars hosted by physio Marion Main.
- We have offered a 24hr support and helpdesk service
- SMA Awareness Month where we held multiple webinars with experts on various topics regarding SMA, posted daily infographics and posted videos from community members.
- We continued to put our surveys and collection of data to submit for various appraisals
- We continue to advocate for patients who do not have access to treatments or who wish to access additional clinical trials.
- We gave AA Diet support and held meetings with dieticians to discuss a trial to explore the benefits of people with SMA following the AA Diet – with results being published in peer-reviewed journals.
- Amongst other things we now also engaged into new-born screening topics to ensure that families get diagnosis quickly and access treatments much faster.
- Written letters of support for community members for various issues

Section E

Financial review

Brief statement of the charity's policy on reserves

Reserves are carried through to next financial year to support further advancements in support for the SME community.

Details of any funds materially in deficit

N/A

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

The charity's principal sources of funding is exclusively fundraising and generous donations by individuals. All expenditure is used to support the community and tools required to do so. No money is used in any way as remuneration of the trustees.

Section F

Other optional information

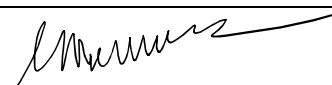
Section G

Declaration

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

Signed on behalf of the charity's trustees

Signature(s)



Full name(s)

Dr Gennadiy Ilyashenko

Position (eg Secretary, Chair, etc)

Trustee

Date

20/02/23

TreatSMA ACCOUNTS 2021-2022

Type of activity	Money In	Money Out
Opening balance	19,318.29	
On-Line Banking Bill Payment to Treatsma Ref: Soldo Expenses		500
On-Line Banking Bill Payment to Treatsma Ref: Soldo Expenses		500
On-Line Banking Bill Payment to Ginger and Tall LT Ref: Tsma Website		900
Donations	1,214.80	
Donations	720	
Donations	255.67	
Expenses		16.95
Donations	250	
Donations	6.22	
Expenses		171.25
Donations	38.56	
Expenses		204
Donations	15,163.00	
Total	36,966.54	2,292.20
End of Year Balance		34,674.34