

# TREATSMA

England & Wales · Charity number 1182610

## Details

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**Status** Registered

**Legal form** CIO

**Registered** 2019-03-25

**Register** [View on the Charity Commission register](#)

## Contact

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**Address** TreatSMA  
85 Great Portland St  
First Floor  
London  
W1W 7LT

**Phone** 03008000202

**Email** [treatsma@treatsma.uk](mailto:treatsma@treatsma.uk)

**Website** <https://www.treatsma.uk>

## Activities

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**Objects:** THE OBJECTS OF THE CIO ARE TO PROMOTE AND PROTECT THE HEALTH AND WELLBEING OF PERSONS WITH SPINALMUSCULAR ATROPHY, THEIR FAMILIES AND CARERS, IN PARTICULAR BY:(A) ADVANCING KNOWLEDGE IN ALL ASPECTS OF SPINAL MUSCULAR ATROPHY;(B) IMPROVING ACCESS TO APPROPRIATE HEALTHCARE, INCLUDING DIAGNOSTICS, TREATMENTS,AND ASSISTIVE TECHNOLOGIES; AND(C) PROMOTING SOCIAL INCLUSION OF PEOPLE WITH SPINAL MUSCULAR ATROPHY, THEIR FAMILIESAND CARERS

**Activities:** 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.

## Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Other Charitable Activities
- **What:** General Charitable Purposes, The Advancement Of Health Or Saving Of Lives
- **Who:** Children/young People, People With Disabilities, Other Charities Or Voluntary Bodies, Other Defined Groups

## Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

## Finances

Period end	Income	Expenditure	Assets	Employees
2025-04-05	£2,563	£951	-	-
2024-04-05	£871	£12,905	-	-
2023-04-05	£18,359	£188	-	-
2022-04-05	£17,648	£2,292	-	-
2021-04-05	£10,851	£1,924	-	-

## Trustees

Name	Role	Appointed
Andrew Thornton		2020-01-06
Dr GENNADIY ILYASHENKO		2018-08-08
LUCY FROST		2018-08-08

**TREATSMA**

England & Wales - Charity number 1182610

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# Accounts

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# Trustees' Annual Report for the period

	Period start date				Period end date		
<b>From</b>	1st	April	2024	<b>To</b>	31	March	2025

## 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	LUCY FROST			
3	ANDI THORNTON			
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**Names of the trustees for the charity, if any, (for example, any custodian trustees)**

Name	Dates acted if not for whole year

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**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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**Section B Structure, governance and management**

**Description of the charity's trusts**

Type of governing document <small>(eg. trust deed, constitution)</small>	Constitution
How the charity is constituted <small>(eg. trust, association, company)</small>	CIO
Trustee selection methods <small>(eg. appointed by, elected by)</small>	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.

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**Section C Objectives and activities**

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

<p>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 condition, 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.</p>
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**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)**

- Continue to campaign for access to treatment of Spinraza, Risdiplam and Zolgensma on NHS
- Continue to be a part of Managed Access Program for Spinraza and Risdiplam together with NHSE and NICE.
- Work with pharmaceutical companies and regulatory agencies to further knowledge and support the introduction of further treatments
- Collaborated with SMA Reach, SMA Reach Adults and other Networks.
- Involved in governance of SMA Reach and SMA Reach Adults
- Offered 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
- Provided support to families either by email or telephone as and when required
- Continued fundraising to further our goals
- Continue to contribute to New Born Screening Program in the UK

**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.
- We continue to participate in oversight committees for Managed Access Agreement for Spinraza and Risdiplam.
- We are now involved in final re-appraisal of treatments by NICE
- 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
- 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 are 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

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## Section G Declaration

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

**Signed on behalf of the charity's trustees**

<b>Signature(s)</b>		
<b>Full name(s)</b>	Dr Gennadiy Ilyashenko	
<b>Position (eg Secretary, Chair, etc)</b>	Trustee	
<b>Date</b>	04/02/26	

TreatSMA ACCOUNTS 2024-2025

Type of activity	Money In	Money Out
<b>Opening balance</b>	25,578.00	
Donation via PayPal: Direct Credit From Paypal	2,563.26	
Expenses: Reimbursement to Andi Thorton for IT equipment and work bench		951.13
<b>Total</b>	<b>28,141.26</b>	<b>951.13</b>
<b>End of Year Balance</b>		<b>27,190.13</b>

**TREATSMA**

England & Wales - Charity number 1182610

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# Accounts

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# Trustees' Annual Report for the period

	Period start date				Period end date		
<b>From</b>	1st	April	2023	<b>To</b>	31	March	2024

## 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	LUCY FROST			
3	ANDI THORNTON			
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**Names of the trustees for the charity, if any, (for example, any custodian trustees)**

Name	Dates acted if not for whole year

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**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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**Section B Structure, governance and management**

**Description of the charity's trusts**

Type of governing document <small>(eg. trust deed, constitution)</small>	Constitution
How the charity is constituted <small>(eg. trust, association, company)</small>	CIO
Trustee selection methods <small>(eg. appointed by, elected by)</small>	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.

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**Section C Objectives and activities**

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

<p>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.</p>
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**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, Risdiplam and Zolgensma on NHS
- Worked on Managed Access Program for Spinraza and Risdiplam together with NHSE and NICE.
- Worked with pharmaceutical companies and regulatory agencies to further knowledge and support the introduction of further treatments
- Collaborated with SMA Reach, SMA Reach Adults and other Networks.
- Involved in governance of SMA Reach and SMA Reach Adults
- Ran 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
- 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.
- We continue to participate in oversight committees for Managed Access Agreement for Spinraza and Risdiplam.
- We are now involved in final re-appraisal of treatments by NICE
- 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
- 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.
- 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

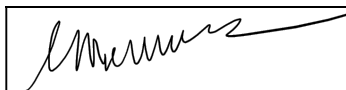
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## Section G Declaration

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**

05/02/25

TreatSMA ACCOUNTS 2023-2024

Type of activity	Money In	Money Out
<b>Opening balance</b>	19,676.78	
Donation: Direct Credit From Amazon Europe Core	38.56	
Donation: AFTS Receipt From Bank Leumi UK	15,163.00	
Donation: Direct Credit From Amazon Europe Core	33.21	
Donation: Direct Credit From Amazon Europe Core	25.96	
Donation via PayPal: Direct Credit From Paypal	2,457.23	
Donation: Direct Credit From Amazon Europe Core	27.83	
Donations: From L Harris	614	
Expenses: Reimburmenst to Lucy Frost		204
Expenses: Reimburmenst to Gennadiy Ilyashenko		171.25
<b>Total</b>	<b>38,036.57</b>	<b>375.25</b>
<b>End of Year Balance</b>		<b>37,661.32</b>

**TREATSMA**

England & Wales - Charity number 1182610

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# Accounts

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# Trustees' Annual Report for the period

	Period start date				Period end date		
	1st	April	2022		31	March	2023
<b>From</b>				<b>To</b>			

## 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	
<b>Postcode</b>	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		Resigned November 22	
3	LUCY FROST			
4	ANDI THORNTON			
5	KELLY JONES		Resigned November 22	
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### 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)**

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**Section B Structure, governance and management**

**Description of the charity's trusts**

Type of governing document (eg. trust deed, constitution)	Constitution
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**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.

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**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, Risdiplam and Zolgensma.
- Worked on Managed Access Program for Spinraza and Risdiplam together with NHSE and NICE.
- Worked with pharmaceutical companies and regulatory agencies to further knowledge and support the introduction of further treatments
- Collaborated with SMA Reach, SMA Reach Adults and other Networks.
- Ran number of educational webinars for those with and affected by SMA to help support them on key topics such as:
  - o Physiotherapy
  - o Respiratory care
  - o Standards of care
- 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.



## Section D

## Achievements and performance

## Section D

## Achievements and performance

### Summary of the main achievements of the charity during the year

- We continue to represent families with SMA in various technical processes.
- Represent families for MHRA re-assessment of gene therapy for SMA
- 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 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.
- 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;
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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**

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**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

20/02/24



TreatSMA ACCOUNTS 2022-2023

Type of activity	Money In	Money Out
<b>Opening balance</b>	19,676.78	
Donation: Direct Credit From Amazon Europe Core	38.56	
Donation: AFTS Receipt From Bank Leumi UK	15,163.00	
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<b>Total</b>	<b>38,036.57</b>	<b>375.25</b>
<b>End of Year Balance</b>		<b>37,661.32</b>

**TREATSMA**

England & Wales - Charity number 1182610

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# Accounts

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# Trustees' Annual Report for the period

	Period start date				Period end date		
<b>From</b>	06	April	2021	<b>To</b>	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	
<b>Postcode</b>	W1W 7LT

**Names of the charity trustees who manage the charity**

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

Name	Dates acted if not for whole year

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**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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**Section B Structure, governance and management**

**Description of the charity's trusts**

Type of governing document <small>(eg. trust deed, constitution)</small>	Constitution
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- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

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**Section C Objectives and activities**

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

<p>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.</p>
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**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

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## Section G Declaration

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

**Signed on behalf of the charity's trustees**

<b>Signature(s)</b>		
<b>Full name(s)</b>	Dr Gennadiy Ilyashenko	

<b>Position (eg Secretary, Chair, etc)</b>	Trustee	
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<b>Date</b>	20/02/23
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TreatSMA ACCOUNTS 2021-2022

Type of activity	Money In	Money Out
<b>Opening balance</b>	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: Tasma 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	
<b>Total</b>	<b>36,966.54</b>	<b>2,292.20</b>
<b>End of Year Balance</b>		<b>34,674.34</b>