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Annual Report

1st April 2021 to 31st March 2022



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Objectives and Activities

Objectives

As described in our constitution, the objectives of Max's Trust are as follows:

The preservation and protection of good health and the relief of sickness of people born with Imperforate Anus (IA) / Anorectal Malformation (ARM) and their families in particular but not exclusively by:

- Raising awareness of the issues for babies born with Imperforate Anus (IA) / Anorectal Malformation (ARM) and the need for human support for each child.
- The production and distribution of care boxes for families of new-born babies with IA/ARM, providing information and products to help families learn about and cope with caring for their child.
- Providing access to comprehensive, approved resources, relevant to all people affected by IA/ARM including the production and distribution of information via digital channels and leaflets that are endorsed by medical professionals and bodies across the UK
- Access to a network of renowned surgical and clinical care providers, from family doctors (GP's) through to highly trained specialists, with programs in place for the transition from paediatric to adult care.
- Providing mental health support for adults, children, parents, and families and the provision of well led peer support programs for members of the IA/ARM community.
- An annual educational conference, bringing together specialist medical professionals with families and adults affected by IA/ARM to provide information and support.



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Activities

Much like 2020 to 2021, the Covid-19 pandemic has affected the work that we could do as a charity, as well as the events that we could attend throughout the year. We had hoped to put on an annual conference, but we did not have the desire from our followers, mainly due to the pandemic still in circulation, and the professionals that would present at the conference were dealing with another wave of Covid-19. We took the decision during the year to focus on hosting a conference in September 2022, as Covid measures lift.

Through social media, we have continued to raise awareness of anorectal malformations and associated conditions by sharing information and articles of interest. This included sharing relevant information, research and articles, as well as important events such as Rare Disease Day.

We welcomed a new trustee, Lauren Stahly, to the charity, with the aim of improving our engagement with our followers. As an adult living with anorectal malformation, she will prove to be a key member of the team and the perfect person to engage with our followers, as well as hospitals. Indeed, she has already made a start at making contact with hospitals.

We were involved in a big piece of research, in conjunction with the Royal College of Paediatrics and Child Health (RCPCH), the Royal College of Midwives, Paediatric Colorectal Surgeons and Neonatal Consultants, with aim of creating a learning module for all training doctors and midwives to prevent missed or delayed diagnosis of ARMs. The part we played was to bring the patient and family voice to the learning module. ARM patients and their families were invited to share their experiences of the care they received particularly where the ARM diagnosis was missed or delayed, and the impact it had on them, through a survey shared through social media and a mailing list. The response was incredible, and the information has been used to inform the family part of the educational module demonstrating the effect that a missed or delayed diagnosis can have on families at the time of diagnosis and for many years after the child is born. The learning tool has been given approval and is currently being made by the RCPCH. A paper on this has been submitted to be presented at the British Association of Paediatric Surgeons Annual Conference in July 2022. The next step is to get ARM checking added to the Newborn Screening Tool undertaken immediately following the baby's birth and there is work underway on this. Max's Trust are delighted to be part of the development.

Our website has been updated throughout the year. There is still a lot of work to do, but we have a presence online and, in time, will have a website that will provide lots of support and information to those affected by ARM. We continue to network with and work alongside other charities and



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partners in the UK and Internationally who will all be signposted on our website and us on theirs. Again, the pandemic has slowed some of this work but it has continued.

Throughout the year, the trustees of Max's Trust have carried out all activities with regard to the Charity Commission's guidance on public benefit.



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Achievements and Performance

As alluded to earlier, this year was severely affected by the Covid-19 pandemic. Events and fundraisers were impaired by the lockdowns and social distancing restrictions imposed throughout the year. Despite this, we still raised in excess of £6,600 (see Financial Review).

We had planned to hold an annual conference, but given the pandemic, the vulnerability of some patients and the capacity of the health professionals to give time to present, we decided to ask our followers via a survey as to whether they felt comfortable having a conference. The majority of responses were not in favour of having a conference this year, therefore we decided to concentrate on a conference in 2022.

The research project around missed or delayed diagnosis developed well during the year. The charity developed a survey and gained the experiences of our followers about how a missed or delayed diagnosis of ARM affected them at the time of birth and through their lives, with the main aim of improving the diagnosis of ARM at an early stage through the development of a learning tool. The learning tool has been approved and is currently being built by the RCPCH and we anticipate it to be finalised in the early stages of the 2022 to 2023 reporting period.

In terms of benefit to our followers, we have predominantly done this via support through our social media and closed support groups. We have also supported people over the phone and by email, mainly by facilitating referrals to medical professionals and to peer-to-peer support groups. This is a valuable service which we have worked hard to get in place and we have received great feedback. As alluded to earlier, our website has been gradually updated and work will continue in the next year to improve the content. Work continues on collating and preparing a central place for good quality, medically endorsed, supportive information about anorectal malformation which will continue into the next year.



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Financial Review

Introduction

This financial report has been compiled with reference to the Charity Commission's FRS-102, a statement of recommended practice (SORP) for annual reporting.

Max's Trust's normal financial period is April to March.

Financial Review

Max's Trust achieved an income of **£6,631.19** during the reporting period. This comprised £4,688.00 from donations and fundraisers, £1,534.80 from Facebook fundraisers, £85.39 from Amazon Smile contributions and £224.00 in Giving Lottery ticket sales. An additional £99.00 was received as a refund from SurveyMonkey. In line with Trust Law, all funds in the reporting period are classified as unrestricted funds.

The expenditure for the same period totaled **£403.76**. This comprised £304.76 in website costs, and £99.00 on a survey package from SurveyMonkey (as refunded above).

At the end of the reporting period, Max's Trust held a total **£20,511.73** in cash assets in its bank account.

Max's Trust does not hold any property or other material assets.

A summary of the annual accounts can be found in both tabular and graphical format in the appendices.



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Structure, Governance and Management

Structure and Governance

The charity remains a Charitable Incorporated Organisation, bound by the terms of our constitution, which is approved by the Charity Commission.

Whilst policies are currently under construction and review, the trustees of the charity will work within the terms of these policies, confirming their agreement to abide by each as they are implemented.

Management

Lauren Stahly joined the charity on a three-year term. There were no other changes in the management of the charity.



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Reference and Administrative Details

As of the 31st March 2022, the following details are correct:

Charity Name:	Max's Trust
Charity Number:	1184081
HMRC Tax Number:	ZD06069
Registered Address:	18 Midwinter Avenue Milton Heights Abingdon Oxfordshire OX14 4XA
Current Trustees	Cassie Finnigan (Chairman) Jon Finnigan Hattie Crosthwaite-Eyre Christina Smith Helen Millard Andy Button Lauren Stahly



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Appendices

Receipts & Payments Account for the Financial Year Ended 31-Mar-22

	Current Financial Year, Apr'21-Mar'22				Last Year
	Unrestricted Funds	Designated Funds	Restricted Funds	Total	Total
	£	£	£	£	£
RECEIPTS					
Voluntary Income	6,532	0	0	6,532	0
Income Generation	0	0	0	0	0
Investment Income	0	0	0	0	0
Charitable Income	99	0	0	99	0
Advance Receipts	0	0	0	0	0
TOTAL RECEIPTS	6,631	0	0	6,631	0
PAYMENTS	£	£	£	£	£
Costs of Generating Funds					
Fundraising	0	0	0	0	0
Charitable Trading	0	0	0	0	0
Other	0	0	0	0	0
Sub-total	0	0	0	0	0
Charitable Activities					
Specific Projects	0	0	0	0	0
General Activities	0	0	0	0	0
Sub-total	0	0	0	0	0
Support Costs					
Governance	0	0	0	0	0
Administration	404	0	0	404	0
Sub-total	404	0	0	404	0
Advance Payments	0	0	0	0	0
TOTAL PAYMENTS	404	0	0	404	404
NET RECEIPTS-PAYMENTS	6,227	0	0	6,227	-404

Movements in Funds for the Financial Year To 31-Mar-22

	Bt'Fwd at 01-Apr-21	Receipts in Period	Payments in Period	Transfers in Period	Cd'Fwd at 31-Mar-22
Cash Assets					
Cash at Bank & in Hand					
Cash	0	0	0	0	0
Bank, Current Account	14,284	6,631	-404	0	20,512
	14,284	6,631	-404	0	20,512
Sundry Debtors (Unreconciled Deposits)	0				0
Sundry Creditors (Unreconciled Payments)	0				0
	0				0
Investment/Deposit Accounts	Bt'Fwd	Interest		Net Transfers	Cd'Fwd
Bank, Deposit Account	0	0		0	0
Total Cash Assets	14,284				20,512

Allocation of Funds for the Financial Year To 31-Mar-22

	Bt'Fwd at 01-Apr-21	Receipts in Period	Payments in Period	Transfers in Period	Cd'Fwd at 31-Mar-22
Cash Assets					
Comprising:					
General (Unrestricted) Fund	14,284	6,631	-404	0	20,512
Designated (Unrestricted) Funds	0		0		0
Restricted Funds					
R1-Rename or delete	0	0	0		0
R2-Rename or delete	0	0	0		0
R3-Rename or delete	0	0	0		0
R4-Rename or delete	0	0	0		0
R5-Rename or delete	0	0	0		0
R6-Rename or delete	0	0	0		0
R7-Rename or delete	0	0	0		0
R8-Rename or delete	0	0	0		0
R9-Rename or delete	0	0	0		0
R10-Rename or delete	0	0	0		0
Total Restricted Funds	0	0	0		0
Total Funds	14,284				20,512

Statement of Assets & Liabilities as at 31-Mar-22

	Unrestricted Funds	Designated Funds	Restricted Funds	Total at 31-Mar-22	
Cash Assets	20,512	-	-	20,512	Cash, current & deposit bank accounts
Other Monetary Assets				0	Money still to be claimed, eg: Gift Aid
Investments Assets				None	Stocks, shares, bonds, etc.
Assets Retained for Own Use				0	Physical assets - eg: computers, furniture
Liabilities				None	Commitments not yet paid.

Note: Assets retained for own use are shown at purchase price. Current (residual) value is unknown.

Max's Trust: Cash Flow to 31-Mar-22

Opening Balance £14,284		Cash Flow - FYE: 31-Mar-22												
		Mar-21	Apr-21	May-21	Jun-21	Jul-21	Aug-21	Sep-21	Oct-21	Nov-21	Dec-21	Jan-22	Feb-22	Mar-22
Budget	Receipts		0	0	0	0	0	0	0	0	0	0	0	0
	Payments		0	0	0	0	0	0	0	0	0	0	0	0
	Net		0	0	0	0	0	0	0	0	0	0	0	0
Actual	Receipts		602	739	759	859	1,989	2,457	3,269	3,283	3,492	6,401	6,460	6,631
	Payments		60	159	159	159	159	159	159	375	375	375	375	404
	Net		542	580	600	700	1,830	2,298	3,110	2,908	3,117	6,026	6,085	6,227
Budget Bal		14,284	14,284	14,284	14,284	14,284	14,284	14,284	14,284	14,284	14,284	14,284	14,284	14,284
Actual Bal		14,284	14,826	14,864	14,884	14,984	16,114	16,583	17,394	17,192	17,401	20,310	20,370	20,512

