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Annual Report

1st April 2020 to 31st March 2021



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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

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. Despite this, we were still able to host our annual conference, virtually, with the hope that our face-to-face conference can take place in 2021.

Through social media, we have been raising awareness of anorectal malformations and associated conditions by sharing information and articles of interest. This included sharing relevant information and articles, as well as important events such as Rare Disease Day. We have distributed Max's Trust leaflets to almost half of the Children's Hospitals across the UK and are continuing to make new contacts on a regular basis.

The charity was approached to be involved in two significant pieces of research concerned with improving outcomes for people born with anorectal malformations. The first was called Charting Hurdles in Anorectal Malformation (CHARM), the aim of which was to give patients and family members the opportunity to have their voices heard by allowing them to talk openly about their experiences in a safe and supportive space. Feedback from the researchers and some of the participants was so positive and inspiring! It will be used to better inform professionals about how they can improve their services which will, in turn, improve the experiences that patients and families have. We look forward to seeing this research published in the future.

The second piece of research, still ongoing, explores missed and delayed diagnosis of ARM, and the effect that has on the short term and long term physical and mental health of the baby and their families. 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 has been incredible, and the information is being used to inform part of a Newborn Screening Educational Tool for professionals which is currently being developed. Max's Trust are delighted to be part of the development.

Our website was partially launched this year. There is still some 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.

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 lockdown and social distancing restrictions imposed throughout the year. Despite this, we still raised a similar figure to the previous year, in excess of £8,000 (see Financial Review).

Plans began for arranging the 2020 Annual Conference with the venue and dates secured in time to announce it before Christmas 2019. Planning for the programme with many medical professionals, psychologists, and partner groups was well underway to provide adults and families with two days of information, psychological support and much needed networking and peer support. Bespoke childcare was arranged by a registered provider so that families could attend the conference with the peace of mind that their children were close and well cared for. Unfortunately, the Covid-19 pandemic meant that we had to postpone the face-to-face conference to September 2021 and to date we are still on track for this to happen. We were, however able to adapt and hold a virtual conference over the same weekend, which gave adults with, and parents of children with, anorectal malformation information and support in these very unsettling times. We had support from our network of professionals and the virtual conference was a great success with some excellent feedback.

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. This is a valuable service and we have received great feedback. As alluded to earlier, our website has been partially launched and work will continue in the next year to improve the content. Work has begun 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 **£8,980.52** during the reporting period. This comprised £8,799.32 from donations and fundraisers, and £181.20 in Giving Lottery ticket sales. In line with Trust Law, all funds in the reporting period are classified as unrestricted funds.

The expenditure for the same period totaled **£2,293.63**. This comprised a £1,081.14 deposit for the childcare for the 2021 conference, £164.09 in printing and postage costs for information leaflets, £788.24 in shirt printing costs and £260.16 in website costs.

At the end of the reporting period, Max's Trust held a total **£14,284.30** 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

There were no changes to the trustees or management of Max's Trust in this reporting period.



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Reference and Administrative Details

As of the 19th May 2021, 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



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Appendices

Receipts & Payments Account for the Financial Year Ended 31-Mar-21

	Current Financial Year, Apr'20-Mar'21				Last Year
	Unrestricted Funds	Designated Funds	Restricted Funds	Total	Total
	£	£	£	£	£
RECEIPTS					
Voluntary Income	8,981	0	0	8,981	0
Income Generation	0	0	0	0	0
Investment Income	0	0	0	0	0
Charitable Income	0	0	0	0	0
Advance Receipts	0	0	0	0	0
TOTAL RECEIPTS	8,981	0	0	8,981	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	2,294	0	0	2,294	0
Sub-total	2,294	0	0	2,294	0
Advance Payments	0	0	0	0	0
TOTAL PAYMENTS	2,294	0	0	2,294	2,294
NET RECEIPTS-PAYMENTS	6,687	0	0	6,687	-2,294

Movements in Funds for the Financial Year To 31-Mar-21

	Bt'Fwd at 01-Apr-20	Receipts in Period	Payments in Period	Transfers in Period	Cd'Fwd at 31-Mar-21
Cash Assets					
Cash at Bank & in Hand					
Cash	0	0	0	0	0
Bank, Current Account	7,597	8,981	-2,294	0	14,284
	7,597	8,981	-2,294	0	14,284
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	7,597				14,284

Allocation of Funds for the Financial Year To 31-Mar-21

	Bt'Fwd at 01-Apr-20	Receipts in Period	Payments in Period	Transfers in Period	Cd'Fwd at 31-Mar-21
Cash Assets					
Comprising:					
General (Unrestricted) Fund	7,597	8,981	-2,294	0	14,284
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	7,597				14,284

Statement of Assets & Liabilities as at 31-Mar-21

	Unrestricted Funds	Designated Funds	Restricted Funds	Total at 31-Mar-21	
Cash Assets	14,284	-	-	14,284	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-21

Opening Balance £7,597		Cash Flow - FYE: 31-Mar-21												
		Mar-20	Apr-20	May-20	Jun-20	Jul-20	Aug-20	Sep-20	Oct-20	Nov-20	Dec-20	Jan-21	Feb-21	Mar-21
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		22	136	1,182	1,212	1,815	3,815	6,307	6,864	7,166	7,718	8,479	8,981
	Payments		0	0	0	14	14	788	848	976	2,057	2,084	2,255	2,294
	Net		22	136	1,182	1,198	1,801	3,027	5,459	5,888	5,109	5,634	6,223	6,687
Budget Bal		7,597	7,597	7,597	7,597	7,597	7,597	7,597	7,597	7,597	7,597	7,597	7,597	7,597
Actual Bal		7,597	7,619	7,734	8,780	8,796	9,399	10,625	13,056	13,486	12,707	13,231	13,821	14,284

