

NEPHROTIC SYNDROME TRUST
UNAUDITED ANNUAL REPORT
30 SEPTEMBER 2022

Charity Number 1107601

CHALMERS & CO (SW) LIMITED

Chartered Accountants
Trading as Chalmers & Co.
6 The Linen Yard
South Street
Crewkerne
Somerset
TA18 8AB

NEPHROTIC SYNDROME TRUST

UNAUDITED ANNUAL REPORT

YEAR ENDED 30 SEPTEMBER 2022

CONTENTS	PAGES
Reference and administrative details	1
Trustees annual report	2 to 4
Independent examiner's report	5
Receipts and payments account	6
Statement of assets	7
Notes to the accounts	8 to 9

NEPHROTIC SYNDROME TRUST
REFERENCE AND ADMINISTRATIVE DETAILS
YEAR ENDED 30 SEPTEMBER 2022

The board of trustees	Mr D Yearsley Dr M Saleem Mrs W Cook Ms G Benson Mrs L Mathias-Lukins Dr G Welsh Mrs S Jenkins
Charity registration number	1107601
Principal office	38 Southway Drive Yeovil BA21 3ED
Independent examiner	S M Bachrach, Chartered Accountant Chalmers & Co (SW) Limited Chartered Accountants Trading as Chalmers & Co. 6 The Linen Yard South Street Crewkerne Somerset TA18 8AB
Bankers	HSBC 13 Chapel Street Stratford Upon Avon Warwickshire CV37 6ET

NEPHROTIC SYNDROME TRUST

TRUSTEE'S ANNUAL REPORT

YEAR ENDED 30 SEPTEMBER 2022

The trustees have pleasure in presenting their report and the unaudited accounts of the charity for the year ended 30 September 2022 as set out on pages 5 to 9. The accounts have been prepared in accordance with the accounting policies set out on page 8 and comply with the Trust Deed and applicable law.

STRUCTURE, GOVERNANCE AND MANAGEMENT

The charity is governed by its declaration of Trust dated 12 October 2004 and was registered with the Charity Commission on 13 January 2005 and amended 20 January 2021, registered number 1107601.

Reference and administrative details including the principal office address and details of trustees who served the charity throughout the year are shown in on page 1 of the financial statements.

All trustees are appointed by a resolution of the trustees in accordance with the Trust Deed. Formal trustee training will be provided on an ad hoc basis as required.

OBJECTIVES AND ACTIVITIES

The main charitable object of the charity is to promote research for the benefit of the public by the promotion and funding of research into the causes and treatment for Nephrotic Syndrome carried out at Bristol University laboratories.

The Charity aims to support the research team to enable them to find new more effective therapies and treatments for all classifications of Nephrotic Syndrome. It also aims to raise awareness of Nephrotic Syndrome and to support the NS community by providing a hub of information and resources via its website and through all social media channels, support groups and annual conferences.

When planning the activities for the year, the trustees have considered the Charity Commission's general guidance on public benefit and, in particular, the specific guidance for charities for the advancement of health and the saving of lives. The trustees believe the activities set out above and further described below under 'achievements and performance' clearly demonstrate the charity's commitment to providing an identifiable public benefit and that access to this benefit is not restricted in any way.

ACHIEVEMENTS AND PERFORMANCE

Fundraising Update: The charity raised £108,756 in the year ended 30 September 2022. Within this sum, £10,000 was gifted by UCB for the future development of the app, with plans to use it for future works such as nurse relapse alerts, or additional functions in future clinical trials. There are currently restricted reserves held of £21,639. We are awaiting a response from the Wellcome Trust regarding unused funds, possibly using it for app maintenance costs. Expenditure and evaluation reports have been submitted, and we expect to receive approximately £8,000 for future app roadshows and promotional materials. Our gratitude for everyone's efforts to fundraise, especially given the challenging economic climate.

App Update: The app 'Nephrotic Syndrome UK' received approval from Apple and Google stores, but its release was delayed due to server issues at the Renal Registry. The goal was to have it ready for the 'Advances in Genetics conference' at the Royal Society of Medicine Held in London on the 8th of December 2022, where the app was promoted during this conference, The speaker, Marc Castelltort, presented a short talk on behalf of the charity.

NEPHROTIC SYNDROME TRUST

TRUSTEE'S ANNUAL REPORT

YEAR ENDED 30 SEPTEMBER 2022

Roadshows were impacted by Covid and rail strikes, but mini roadshows took place in South Wales and Northern Ireland. Further dissemination plans include publishing in a journal, creating a promotional video, and designing new materials. Any remaining funds from the Wellcome grant may possibly be put towards the maintenance costs of the app.

Research Update: The lab team made significant progress in epigenetics and circulating factors related to Nephrotic Syndrome. They generated 3D glomerulus-like structures that signal similarly to 2D cells in response to disease plasma. Two potential hits were identified in active proteases, which are under further investigation. Students working on DNA methylation models and NURTuRE and Nephros Samples research requested patient involvement for their grant applications. There are plans to organise focus groups to support the students.

Mental health remains a concern for many members, and Zoom calls have been initiated to allow informal chats among members. A small donation was received to fund relaxation and well-being sessions for children with emotional/mental health issues.

RISK MANAGEMENT

The trustees have initiated a wide-ranging review of the major risks to which the charity is exposed, covering all identified, relevant areas including financial risk and risks associated with personnel. Risks have been identified, assessed and safeguards have been put in place to eliminate or mitigate such risks as far as is reasonably possible.

FINANCIAL REVIEW

Total receipts during the year were £108,764 (2021 - £123,675), with the majority of income arising from donations and grants. Total payments were £120,444 (2021 - £79,494), the major expenditure being the donation to United Bristol Hospitals as disclosed further in the Receipts and Payments Account on Page 6.

Net funds therefore decreased by £11,680 (2021 – increased by £44,181) to £133,189 (2021 - £144,869). £111,550 of these funds being free reserves.

RESTRICTED FUNDS

Restricted funds include those which have been donated and used for three projects during the year:

1. Retrophin Grant. A balance of £451 was brought forward from 2021 and has been released into general funds to cover various small amounts of funding relating to helping those in need, resulting from COVID- 19.
2. App development. This project commenced in the latter part of 2019 and received further funding during 2021. This fund has a balance carried forward of £11,639.
3. Future App Development Grant. £10,000 was received during the year and was unspent at the year end.

NEPHROTIC SYNDROME TRUST

TRUSTEE'S ANNUAL REPORT

YEAR ENDED 30 SEPTEMBER 2022

RESERVES POLICY

The trustees closely monitor the charity's financial position and seek to ensure that reserves are sufficient to meet its ongoing liabilities. The charity does not aim to hold substantial unrestricted reserves, but to pass any surpluses on to those in need.

Signed by order of the trustees:

Mr D Yearsley

Mrs W Cook

Approved by the trustees on 31 July, 2023.

NEPHROTIC SYNDROME TRUST
INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
NEPHROTIC SYNDROME TRUST
YEAR ENDED 30 SEPTEMBER 2022

I report to the trustees on my examination of the accounts of the Charity for the year ended 30 September 2022.

Responsibilities and basis of report

As the Charity's Trustees you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 (the Act).

I report in respect of my examination of the Charity's accounts carried out under section 145 of the 2011 Act and in carrying out my examination. I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent Examiners Statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts do not accord with the accounting records.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

S M Bachrach, Chartered Accountant
Independent Examiner
Chalmers and Co
Chartered Accountants
6 The Linen Yard
South Street
Crewkerne
Somerset
TA18 8AB

Dated: 31 July 2023

NEPHROTIC SYNDROME TRUST

RECEIPTS AND PAYMENTS ACCOUNT FOR THE YEAR ENDED

30 SEPTEMBER 2022

	2022 Unrestricted Funds £	2022 Restricted Funds £	2022 Total Funds £	2021 Total Funds £
<u>RECEIPTS</u>				
Donations	98,756	-	98,756	99,882
Grants received	-	10,000	10,000	10,425
Job retention scheme grants	-	-	-	13,365
Interest received	8	-	8	3
	<u>98,764</u>	<u>10,000</u>	<u>108,764</u>	<u>123,675</u>
<u>PAYMENTS</u>				
Donations to United Bristol Hospital	70,000	-	70,000	31,000
Wages & pension costs of administrator	28,280	250	28,530	25,240
Wages of the app administrator	-	4,174	4,174	5,864
Consultancy fees	-	-	-	1,000
Insurance	314	-	314	314
Promotional costs	312	-	312	-
Fundraising costs	5,835	-	5,835	5,793
Travel	323	(189)	134	-
Costs for Mental Health Care	473	-	473	-
Young Ambassadors Events	-	-	-	-
Professional fees	-	-	-	540
NNF expenditure	-	4,264	4,264	2,286
COVID grants	132	-	132	855
Website cost	211	-	211	235
Just Giving fee	1,920	-	1,920	2,231
Printing, stationery and postage	680	-	680	430
Sundry Expenses	495	-	495	204
Accountancy fees	1,829	-	1,829	2,160
Telephone	548	-	548	441
Computer expenses (inc. internet)	464	-	464	260
Bank & Paypal Charge	129	-	129	35
	<u>111,945</u>	<u>8,499</u>	<u>120,444</u>	<u>78,888</u>
<u>PURCHASE FIXED ASSETS</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>606</u>
	<u>111,945</u>	<u>8,499</u>	<u>120,444</u>	<u>79,494</u>
NET OF PAYMENTS	(13,181)	1,501	(11,680)	44,181
Transfer between Funds	<u>579</u>	<u>(579)</u>	<u>-</u>	<u>-</u>
	<u>(12,602)</u>	<u>922</u>	<u>(11,680)</u>	<u>44,181</u>
Bank and cash funds brought forward	<u>124,152</u>	<u>20,717</u>	<u>144,869</u>	<u>100,688</u>
Bank and cash funds carried forward	<u>111,550</u>	<u>21,639</u>	<u>133,189</u>	<u>144,869</u>

The notes on pages 8 and 9 form part of these financial statements.

NEPHROTIC SYNDROME TRUST

STATEMENT OF ASSETS

FOR THE YEAR ENDED

30 SEPTEMBER 2022

	2022 £	2021 £
CASH FUNDS		
Bank current account	133,189	144,869
	<u>133,189</u>	<u>144,869</u>

£21,639 (2021 - £20,717) restricted funds are included in the totals listed above.

ASSETS RETAINED FOR THE CHARITY'S OWN USE

Laminator at cost (4 April 2011)	10	10
Laptop & MS Office at cost (10 December 2014)	524	524
Custom build PC (December 2015)	594	594
Printer at cost (28 February 2019)	60	60
Laptop (5 September 2019) (Restricted)	540	540
Lenovo 510 Pentium Desktop PC (October 2019)	320	320
Argos printer at cost (2 October 2020)	78	78
Computer monitor (15 November 2020)	75	75
Laptop for roadshows (2 April 2021)	399	399
Shredder (25 May 2021)	<u>54</u>	<u>54</u>

We confirm that the above Statement of Assets is an accurate record of the Charity's assets at the year end.

Mr D Yearsley

Mrs W Cook

31 July 2023.

The notes on pages 8 and 9 form part of these financial statements.

NEPHROTIC SYNDROME TRUST
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED
30 SEPTEMBER 2022

1. ACCOUNTING POLICIES

Basis of accounting

The accounts have been prepared on a receipts and payments basis and in accordance with the trust deed and applicable United Kingdom accounting standards, the Statement of Recommended Practice "Accounting and Reporting by Charities" (SORP 2005) and the Charities Act 2011.

Restricted and Unrestricted Funds

General accumulated unrestricted funds represent the funds of the charity that are not subject to any restrictions regarding their use and may be applied in achieving any of the objectives of the charity as decided by the trustees.

Restricted funds

These relate to incoming resources which have been received subject to specific conditions imposed by the donor and binding on the Trustees and may only be applied in accordance with the restrictions placed on the donation.

Income is treated as unrestricted unless a restriction is placed upon it by the donor or by the terms of the fundraising venture undertaken by the charity.

Grants

Grant income is recognised on a receivable basis. Where a restriction is placed on the use of the grant, the amount of the grant is included in restricted funds. Grant expenditure is recognised on a payable basis.

2. STAFF COSTS

The charity had two employees during the year.

3. STOCKS

At the end of the year the charity held a stock of items which are for resale. The original cost of these items was £500 (2021 - £500).

4. RELATED PARTY TRANSACTIONS

The trustee Mrs W Cook received remuneration and pension of £28,530 during the year arising from her employment as administrator. (2021 - £25,240)

The trustee Mrs S Jenkins received remuneration of £4,174 during the year arising from her employment as administrator of the App development. (2021 - £5,864)

None of the above received any remuneration for their duties at Trustees.

NEPHROTIC SYNDROME TRUST
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED
30 SEPTEMBER 2022

	2022	2022	2022	2022	2021
	NNF	Retrophin	Future App	Total	Total
	Funds	Funds	Development	Funds	Funds
	£	£	£	£	£
BREAKDOWN OF RESTRICTED INCOME & EXPENDITURE ITEMS					
<u>RECEIPTS</u>					
Grants received	-	-	10,000	10,000	10,425
	-	-	10,000	10,000	10,425
<u>PAYMENTS</u>					
Wages & pension costs	4,424	-	-	4,424	12,856
Nephrotic Syndrome					
UK APP costs	3,284	-	-	3,284	1,700
Consultancy work	-	-	-	-	-
Travel & subsistence	(189)	-	-	(189)	189
COVID grants	-	-	-	-	750
Advertising	-	-	-	-	-
Mini app roadshows	787	-	-	787	-
Young Ambassadors Events	-	-	-	-	-
Conference	-	-	-	-	337
Sundry Expenses	193	-	-	193	60
	8,499	-	-	8,499	15,892
<u>PURCHASE OF FIXED ASSETS</u>					
	-	-	-	-	-
	8,499	-	-	8,499	15,892
NET OF PAYMENTS	(8,499)	-	10,000	1,501	(5,467)
<u>TRANSFER BETWEEN FUNDS</u>					
	(128)	(451)	-	(579)	-
	(8,627)	(451)	-	922	(5,467)
FUNDS B/FWD	20,266	451	-	20,717	26,184
FUNDS C/FWD	11,639	-	10,000	21,639	20,717

NEPHROTIC SYNDROME TRUST
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED
30 SEPTEMBER 2022

We confirm that the Receipts and Payments Accounts on pages 6 to 9 have been prepared from the books and records of the Charity. All other relevant information has been made available for their preparation.

We also confirm that the Receipts and Payments Accounts are an accurate record of the Charity's activities in the period.

Mr D Yearsley

Dated: 31 July 2023

Mrs W Cook

Dated: 31 July 2023