

NEPHROTIC SYNDROME TRUST (NEST)

England & Wales · Charity number 1107601

Details

Other names NEST

Status Registered

Legal form Other

Registered 2005-01-13

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

Contact

Address 167 The Close
Salisbury
SP1 2EZ

Phone 01935 434217

Email wendy@nstrust.co.uk

Website www.nstrust.co.uk

Activities

Objects: 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.

Activities: Raise awareness of Nephrotic Syndrome and raise funds for further research and development by the research team at Bristol Royal Children's Hospital.

Classification

- **How:** Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Children/young People

Geography

- **Area of benefit:** BRISTOL CHILDREN'S HOSPITAL, BRISTOL
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-09-30	£77,832	£85,815	-	-
2023-09-30	£58,141	£116,165	-	-
2022-09-30	£108,764	£120,444	-	-
2021-09-30	£123,675	£79,494	-	-
2020-09-30	£109,823	£129,534	-	-

Trustees

Name	Role	Appointed
WENDY COOK	Chair	
DAVID JOHN YEARSLEY		
David Cook		2025-11-12
Dr Gavin Welsh		2018-10-18
Dr MOIN SALEEM		
Dr Wen Yi DING		2023-11-09
Gemma Benson		2017-06-14
Gillian Coleman		2025-06-09
Louise Mathias-Lukins		2017-06-14
Rachel Labour		2026-01-29

NEPHROTIC SYNDROME TRUST (NEST)

England & Wales - Charity number 1107601

Accounts

NEPHROTIC SYNDROME TRUST
UNAUDITED ANNUAL REPORT
30 SEPTEMBER 2024

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 2024

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NEPHROTIC SYNDROME TRUST
REFERENCE AND ADMINISTRATIVE DETAILS
YEAR ENDED 30 SEPTEMBER 2024

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 Dr W Ding (Appointed 9 November 2023)
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
REFERENCE AND ADMINISTRATIVE DETAILS
YEAR ENDED 30 SEPTEMBER 2024

The trustees have pleasure in presenting their report and the unaudited accounts of the charity for the year ended 30 September 2024 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 £75,617 in the year ended 30 September 2024. The Wing Walk event has been postponed until May 2025, yet most donations have already been received. It was acknowledged that this was a significant result for the size of the charity.

There are now a few more monthly donations, but it is challenging to maintain a balance between funding and support. It was acknowledged that it is often the people with the sickest children who contribute the most. Wendy continues to look into several grants, but many are either oversubscribed or the charity does not fit the criteria. It was also acknowledged that there is 'charity fatigue' and the charity continues to look for more creative ways of fundraising. There is a plan to appoint a volunteer fundraising team to plan larger fundraising events. A review of social media is still to take place as more needs to be done to attract and engage with the next generation, with the possibility of appointing a communications co-ordinator.

There are currently restricted reserves held of £5,750 to be used for App promotion and development.

App Update: The app is fully operational with approximately 50 users, although there appears to still be an issue with sign-ups. Renal professionals are being encouraged to promote the App.

NEPHROTIC SYNDROME TRUST
REFERENCE AND ADMINISTRATIVE DETAILS
YEAR ENDED 30 SEPTEMBER 2024

A patient day took place during the year in Cardiff, Wales, with the next National Information Day to be held in Scotland. Other roadshows are also planned.

Research Update: Nephure Collaboration – Professor Moin Saleem is working on research related to Parasol. The FRD trial outcome is expected soon. The website continues to be updated with articles from Dr Gavin Welsh and Dr Wen Ding.

Mental health remains a concern for many members, and the funding of relaxation and well-being sessions for children with emotional/mental health issues continues.

2025 will mark 20 years of the Charity and there are plans to organise a significant social event and fundraiser.

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 £77,832 (2023 - £58,141), with the majority of income arising from donations. Total payments were £85,815 (2023 - £116,165), 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 £7,983 (2023 – by £58,024) to £67,182 (2023 - £75,165). £61,432 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. 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 £5,750.
2. Future App Development Grant. £10,000 was received during 2022. Spending in the year covered the balance of the Patient Day expenses after using the specific grants received for that days costs together with 5% of Wendy's salary covering the development and promotion of the app prior to its launch. The fund balance carried forward amounted to £1,279.
3. Patient Day Grants. £2,158 was received during to the year to fund the patient day. This grant was fully utilised during the year.

NEPHROTIC SYNDROME TRUST
REFERENCE AND ADMINISTRATIVE DETAILS
YEAR ENDED 30 SEPTEMBER 2024

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 the 6th May 2025

NEPHROTIC SYNDROME TRUST

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF NEPHROTIC SYNDROME TRUST

YEAR ENDED 30 SEPTEMBER 2024

I report to the trustees on my examination of the accounts of the Charity for the year ended 30 September 2024.

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: 6 May 2025

NEPHROTIC SYNDROME TRUST

RECEIPTS AND PAYMENTS ACCOUNT FOR THE YEAR ENDED

30 SEPTEMBER 2024

	2024 Unrestricted Funds £	2024 Restricted Funds £	2024 Total Funds £	2023 Total Funds £
<u>RECEIPTS</u>				
Donations	75,617	-	75,617	58,089
Grants received	-	2,158	2,158	-
Interest received	57	-	57	52
	<u>75,674</u>	<u>2,158</u>	<u>77,832</u>	<u>58,141</u>
<u>PAYMENTS</u>				
Donations to United Bristol Hospital	31,000	-	31,000	70,000
Wages & pension costs of administrator	29,379	1,450	30,829	28,789
Wages of the app administrator	-	1,750	1,750	-
Insurance	216	-	216	214
Promotional costs	861	-	861	60
Fundraising costs	6,828	-	6,828	6,348
Travel	619	-	619	340
Costs for Mental Health Care	490	-	490	595
NNF expenditure	-	-	-	2,691
Other donations/grants	-	-	-	528
Patient Day costs	-	5,898	5,898	652
Website cost	1,020	-	1,020	804
Donorfy onboarding costs	1,194	-	1,194	-
Just Giving fee	1,450	-	1,450	1,417
Go cardless fees	187	-	187	-
Printing, stationery and postage	720	-	720	511
Sundry Expenses	320	-	320	163
Accountancy and payroll fees	678	-	678	1,368
Telephone	496	-	496	501
Computer expenses (inc. internet)	406	-	406	459
Bank & Paypal Charge	207	-	207	217
	<u>76,071</u>	<u>9,098</u>	<u>85,169</u>	<u>115,657</u>
<u>PURCHASE FIXED ASSETS</u>	646	-	646	508
	<u>76,717</u>	<u>9,098</u>	<u>85,815</u>	<u>116,165</u>
NET OF PAYMENTS	(1,043)	(6,940)	(7,983)	(58,024)
Transfer between Funds	-	-	-	-
	<u>(1,043)</u>	<u>(6,940)</u>	<u>(7,983)</u>	<u>(58,024)</u>
Bank and cash funds brought forward	<u>61,196</u>	<u>13,969</u>	<u>75,165</u>	<u>133,189</u>
Bank and cash funds carried forward	<u>60,153</u>	<u>7,029</u>	<u>67,182</u>	<u>75,165</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 2024

	2024 £	2023 £
CASH FUNDS		
Paypal account	-	240
Bank current account	67,182	74,925
	<u>67,182</u>	<u>75,165</u>

£5,750 (2023 - £13,979) 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 (5 September 2019)	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
Office Chair (28 March 2023)	190	190
Office Desk (5 September 2023)	318	318
Laptop for volunteer (19 April 2024)	646	-
	<u>646</u>	<u>-</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

6 May 2025

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 2024

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 £250 (2023 - £500).

4. RELATED PARTY TRANSACTIONS

The trustee Mrs W Cook received remuneration and pension of £30,829 during the year arising from her employment as administrator. (2023 - £28,789)

The trustee Mrs S Jenkins received remuneration of £1,750 during the year arising from her employment as administrator of the App development. (2023 - £Nil)

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 2024

	2024	2024	2024	2024	2023
	NNF	Future App	Patient	Total	Total
	Funds	Development	Day	Funds	Funds
	£	£	£	£	£
BREAKDOWN OF RESTRICTED INCOME & EXPENDITURE ITEMS					
<u>RECEIPTS</u>					
Grants received	-	-	2,158	2,158	-
	<u>-</u>	<u>-</u>	<u>2,158</u>	<u>2,158</u>	<u>-</u>
<u>PAYMENTS</u>					
Wages & pension costs Nephrotic Syndrome	1,750	1,450	-	3,200	2,879
UK APP costs	-	-	-	-	2,467
Travel & subsistence	-	-	-	-	224
Patient Day costs	-	3,740	2,158	5,898	652
Sundry Expenses	-	-	-	-	-
	<u>1,750</u>	<u>5,190</u>	<u>2,158</u>	<u>9,098</u>	<u>6,222</u>
<u>PURCHASE OF FIXED ASSETS</u>					
	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>
	<u>1,750</u>	<u>5,190</u>	<u>2,158</u>	<u>9,098</u>	<u>6,222</u>
NET OF PAYMENTS	<u>(1,750)</u>	<u>(5,190)</u>	<u>-</u>	<u>(6,940)</u>	<u>(6,222)</u>
<u>TRANSFER BETWEEN FUNDS</u>					
	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>(1448)</u>
	<u>(1,750)</u>	<u>(5,190)</u>	<u>-</u>	<u>(6,940)</u>	<u>(7,670)</u>
FUNDS B/FWD	<u>7,500</u>	<u>6,469</u>	<u>-</u>	<u>13,969</u>	<u>21,639</u>
FUNDS C/FWD	<u>5,750</u>	<u>1,279</u>	<u>-</u>	<u>7,029</u>	<u>13,969</u>

NEPHROTIC SYNDROME TRUST
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED
30 SEPTEMBER 2024

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: 6 May 2025

Mrs W Cook

Dated: 6 May 2025

NEPHROTIC SYNDROME TRUST (NEST)

England & Wales - Charity number 1107601

Accounts

NEPHROTIC SYNDROME TRUST
UNAUDITED ANNUAL REPORT
30 SEPTEMBER 2023

Charity Number 1107601

CHALMERS & CO (SW) LIMITED

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

NEPHROTIC SYNDROME TRUST

UNAUDITED ANNUAL REPORT

YEAR ENDED 30 SEPTEMBER 2023

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NEPHROTIC SYNDROME TRUST
REFERENCE AND ADMINISTRATIVE DETAILS
YEAR ENDED 30 SEPTEMBER 2023

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 Dr W Ding (Appointed 9 November 2023)
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 2023

The trustees have pleasure in presenting their report and the unaudited accounts of the charity for the year ended 30 September 2023 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 £58,089 in the year ended 30 September 2023. The lower amount compared to the previous year was attributed to the extraordinary fundraising efforts of Paul Bishop in 2022 and the economic downturn. Despite this, it was acknowledged that it was still a significant result for the size of the charity. There are now a few more monthly donations, but it is challenging to maintain a balance between funding and support. It was acknowledged that it is often the people with the sickest children who contribute the most. Wendy has looked into several grants, but many are either oversubscribed or the charity did not fit the criteria. It was also acknowledged that there is 'charity fatigue' and that there needs to be a requirement for more creative ways of fundraising. There is a plan to appoint a volunteer fundraising coordinator or team to be presented to the community groups. A review of social media is to take place as more needs to be done to attract and engage with the next generation, with the possibility of appointing a communications director. There are currently restricted reserves held of £13,979 to be used for App promotion and development.

App Update: The app had still to be launched at the year end. Ania Kozeill has kindly helped with one of the online courses needed for the app to receive final approval from NHS Digital. The app is being promoted at the roadshows and Wendy will encourage everyone to use it, once launched. There was a misunderstanding with the possible further grant from Wellcome Trust which sadly was not achieved. It has been confirmed that the current underspend is to be used for app maintenance and roadshow costs.

NEPHROTIC SYNDROME TRUST

TRUSTEE'S ANNUAL REPORT

YEAR ENDED 30 SEPTEMBER 2023

A patient day took place during the year with the next National Information Day to be held in Cardiff. Other roadshows are also planned.

Research Update: The website has been updated with articles and updates from Dr Gavin Welsh and Dr Wen Ding.

Mental health remains a concern for many members, and funding of relaxation and well-being sessions for children with emotional/mental health issues continues.

2025 will mark 20 years of the Charity and there are plans to organise a significant social event and fundraiser.

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 £58,141 (2022 - £108,764), with the majority of income arising from donations. Total payments were £116,165 (2022 - £120,444), 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 £58,024 (2022 – by £11,680) to £75,165 (2022 - £133,189). £61,186 of these funds being free reserves.

RESTRICTED FUNDS

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

1. 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 £7,500. £1,438 was released into general funds during the year to cover small items of expenditure that were included in general expenditure.
2. Future App Development Grant. £10,000 was received during 2022. Spending in the year covered the cost of the Patient Day and 10% of Wendy's salary covering the development and promotion of the app prior to its launch. The fund balance carried forward amounted to £6,469.

NEPHROTIC SYNDROME TRUST

TRUSTEE'S ANNUAL REPORT

YEAR ENDED 30 SEPTEMBER 2023

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 the 19th July 2024

NEPHROTIC SYNDROME TRUST

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF NEPHROTIC SYNDROME TRUST

YEAR ENDED 30 SEPTEMBER 2023

I report to the trustees on my examination of the accounts of the Charity for the year ended 30 September 2023.

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: 19 July 2024

NEPHROTIC SYNDROME TRUST
RECEIPTS AND PAYMENTS ACCOUNT
FOR THE YEAR ENDED
30 SEPTEMBER 2023

	2023 Unrestricted Funds £	2023 Restricted Funds £	2023 Total Funds £	2022 Total Funds £
<u>RECEIPTS</u>				
Donations	58,089	-	58,089	98,756
Grants received	-	-	-	10,000
Interest received	52	-	52	8
	<u>58,141</u>	<u>-</u>	<u>58,141</u>	<u>108,764</u>
<u>PAYMENTS</u>				
Donations to United Bristol Hospital	70,000	-	70,000	70,000
Wages & pension costs of administrator	25,910	2,879	28,789	28,530
Wages of the app administrator	-	-	-	4,174
Insurance	214	-	214	314
Promotional costs	60	-	60	312
Fundraising costs	6,348	-	6,348	5,835
Travel	340	-	340	134
Costs for Mental Health Care	595	-	595	473
NNF expenditure	-	2,691	2,691	4,264
COVID grants	-	-	-	132
Other donations/grants	528	-	528	-
Patient Day costs	-	652	652	-
Website cost	804	-	804	211
Just Giving fee	1,417	-	1,417	1,920
Printing, stationery and postage	511	-	511	680
Sundry Expenses	163	-	163	495
Accountancy fees	1,368	-	1,368	1,829
Telephone	501	-	501	548
Computer expenses (inc. internet)	459	-	459	464
Bank & Paypal Charge	217	-	217	129
	<u>109,435</u>	<u>6,222</u>	<u>115,657</u>	<u>120,444</u>
<u>PURCHASE FIXED ASSETS</u>	<u>508</u>	<u>-</u>	<u>508</u>	<u>-</u>
	<u>109,943</u>	<u>6,222</u>	<u>116,165</u>	<u>120,444</u>
NET OF PAYMENTS	(51,802)	(6,222)	(58,024)	(11,680)
Transfer between Funds	<u>1,438</u>	<u>(1,438)</u>	<u>-</u>	<u>-</u>
	(50,364)	(7,660)	(58,024)	(11,680)
Bank and cash funds brought forward	<u>111,550</u>	<u>21,639</u>	<u>133,189</u>	<u>144,869</u>
Bank and cash funds carried forward	61,186	13,979	75,165	133,189
	<u>=====</u>	<u>=====</u>	<u>=====</u>	<u>=====</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 2023

	2023	2022
	£	£
CASH FUNDS		
Paypal account	240	-
Bank current account	74,925	133,189
	<u>75,165</u>	<u>133,189</u>

£13,979 (2022 - £21,639) 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 (10 December 2014)(Scrapped 2023)	-	524
Custom build PC (December 2015)(Scrapped 2023)	-	594
Printer at cost (28 February 2019)(Scrapped 2023)	-	60
Laptop (5 September 2019)	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)(Scrapped 2023)	-	54
Office Chair (28 March 2023)	190	-
Office Desk (5 September 2023)	318	-

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

19 July 2024

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 2023

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 one employee 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 (2022 - £500).

4. RELATED PARTY TRANSACTIONS

The trustee Mrs W Cook received remuneration and pension of £28,789 during the year arising from her employment as administrator. (2022 - £28,530)

The trustee Mrs S Jenkins received remuneration of £Nil during the year arising from her employment as administrator of the App development. (2022 - £4,174)

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 2023

	2023	2023	2023	2022
	NNF	Future App	Total	Total
	Funds	Development	Funds	Funds
	£	£	£	£
BREAKDOWN OF RESTRICTED INCOME & EXPENDITURE ITEMS				
<u>RECEIPTS</u>				
Grants received	-	-	-	10,000
	<u>-</u>	<u>-</u>	<u>-</u>	10,000
<u>PAYMENTS</u>				
Wages & pension costs	-	2,879	2,879	4,424
Nephrotic Syndrome				
UK APP costs	2,467	-	2,467	3,284
Consultancy work	-	-	-	-
Travel & subsistence	224	-	224	(189)
Advertising	-	-	-	-
Mini app roadshows	-	-	-	787
Patient Day costs	-	-	-	-
Conference	-	652	652	-
Sundry Expenses	-	-	-	193
	<u>2,691</u>	<u>3,531</u>	<u>6,222</u>	8,499
<u>PURCHASE OF FIXED ASSETS</u>				
	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>
	<u>2,691</u>	<u>3,531</u>	<u>6,222</u>	8,499
NET OF PAYMENTS	<u>(2,691)</u>	<u>(3,531)</u>	<u>(6,222)</u>	1,501
<u>TRANSFER BETWEEN FUNDS</u>				
	<u>(1,448)</u>	<u>-</u>	<u>(1,448)</u>	(579)
	<u>(4,139)</u>	<u>(3,531)</u>	<u>(7,670)</u>	922
FUNDS B/FWD	<u>11,639</u>	<u>10,000</u>	<u>21,639</u>	20,717
FUNDS C/FWD	<u>7,500</u>	<u>6,469</u>	<u>13,969</u>	21,639

NEPHROTIC SYNDROME TRUST
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED
30 SEPTEMBER 2023

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:

Mrs W Cook

Dated: 19 July 2024

NEPHROTIC SYNDROME TRUST (NEST)

England & Wales - Charity number 1107601

Accounts

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

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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 Castellort, 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)	54	54

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
	<u>-</u>	<u>-</u>	<u>10,000</u>	<u>10,000</u>	<u>10,425</u>
<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
	<u>8,499</u>	<u>-</u>	<u>-</u>	<u>8,499</u>	<u>15,892</u>
<u>PURCHASE OF FIXED ASSETS</u>					
	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>
	<u><u>8,499</u></u>	<u><u>-</u></u>	<u><u>-</u></u>	<u><u>8,499</u></u>	<u><u>15,892</u></u>
NET OF PAYMENTS	<u><u>(8,499)</u></u>	<u><u>-</u></u>	<u><u>10,000</u></u>	<u><u>1,501</u></u>	<u><u>(5,467)</u></u>
<u>TRANSFER BETWEEN FUNDS</u>					
	<u>(128)</u>	<u>(451)</u>	<u>-</u>	<u>(579)</u>	<u>-</u>
	<u><u>(8,627)</u></u>	<u><u>(451)</u></u>	<u><u>-</u></u>	<u><u>922</u></u>	<u><u>(5,467)</u></u>
FUNDS B/FWD	<u><u>20,266</u></u>	<u><u>451</u></u>	<u><u>-</u></u>	<u><u>20,717</u></u>	<u><u>26,184</u></u>
FUNDS C/FWD	<u><u>11,639</u></u>	<u><u>-</u></u>	<u><u>10,000</u></u>	<u><u>21,639</u></u>	<u><u>20,717</u></u>

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

NEPHROTIC SYNDROME TRUST (NEST)

England & Wales - Charity number 1107601

Accounts

NEPHROTIC SYNDROME TRUST
UNAUDITED ANNUAL REPORT
30 SEPTEMBER 2021

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 2021

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NEPHROTIC SYNDROME TRUST
REFERENCE AND ADMINISTRATIVE DETAILS
YEAR ENDED 30 SEPTEMBER 2021

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
ANNUAL REPORT OF THE TRUSTEES
YEAR ENDED 30 SEPTEMBER 2021

The trustees have pleasure in presenting their report and the unaudited accounts of the charity for the year ended 30 September 2021 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

NeST had a good year with total income raised of £123,675. A great achievement considering some events still couldn't take place due to the Covid 19 pandemic. However, it's important to bear in mind we did receive furlough monies towards Wendy Cook's salary and were very fortunate to also receive a Pears Foundation grant.

We are indebted to many loyal fundraisers of NeST who have kindly sought very creative ways of fundraising as larger fundraising events were postponed. One such fundraiser for example is Paul Bishop who set up the March Marathon which is a virtual event held throughout the month of March. Whereby any individual, or family can take part by virtually running, walking and cycling a whole marathon. Many members took part and raised the amazing sum of over £13,000. Each member loved their experience because the fundraising could be undertaken locally to them within their own chosen time. This made it easier to be inclusive of all the family, making it fun too! Everyone who completed the marathon received a beautiful medal to treasure. It was such a success we plan to have this as an annual event.

NEPHROTIC SYNDROME TRUST
ANNUAL REPORT OF THE TRUSTEES
YEAR ENDED 30 SEPTEMBER 2021

Paul Bishop has a quest to raise £50,000 for NeST to celebrate his 50th birthday over the next two years. The March Marathon kick started this fundraising. Other events planned include wing walking, a cycle ride to Lake Como, Italy and a three - legged race to try and beat the current world record of the most people taking part, which will hopefully be recorded in the Guinness book of world records. But that's not all, Paul wishes to gather teams (of a more mature age, he tells us) together, to play at Crystal Palace football club to fundraise too. All the trustees were excited to hear this news and Paul is going to keep us posted.

At our AGM we spoke at length on how we could generate more regular monthly fundraising to support the running of our charity and support the research team. We decided we would try and encourage regular giving. Not just one-off donations but monthly giving by BACS payments and use the DONATE text giving. Possibly to set up a campaign in the coming year.

A date was set for all our community support group leaders to share and discuss annual fundraising ideas to build up a calendar of events over the coming year. Such events would include (for example) the 'Great North Run' which is very popular with members, the March marathon and the Julie Robinson Duck Race. One of our newest trustees, Sandie Jenkins, made a great suggestion of holding a NeST Fest in the summer to bring all of our community together and will explore this idea with members further dependent on the covid situation. Once our calendar has been agreed then we plan to ask our website developers to build an events page for our website.

We also made plans to discuss how we can help support members with their mental health too.

A new app developer has been found by both the NeST team and Renal registry after several months of much searching and interviewing. We are so relieved to find this person and his great team at 'Citrus Suite' in Liverpool. It wasn't any easy task given app developers were in high demand during the pandemic and asking for extortionate prices for their services. After initial consultations a prototype of the app would be made available by late autumn to share with the NeST community virtually via zoom and possibly via mini roadshows, however this again is dependent on the covid situation, given that many of our members are immunosuppressed. We are very looking forward to the day that we can offer a stand-alone app to help all those living with Nephrotic Syndrome in the UK managing their condition daily. It will also be a valuable tool to share data with our researchers and their clinicians.

Update on the Bristol University Research work supported by NeST:

Some wonderful news from Professor Moin Saleem who says the following: - "the ground breaking progress we are making continues to build, and the major projects NURTuRE and MRC Precision Medicine (formerly Stratified Medicine) encompass a large part of the exciting work going on in Bristol and across the UK (and the world!)"

"We were funded by Kidney Research UK to undertake a gene therapy project, whereby we have rescued certain inherited genetic defects in the podocyte cell. This is progressing at great pace, and has been now funded by a large venture capital investor, in order to take it to the clinic. This means we have set up a biotech company called 'Purespring Therapeutics', which will do the work needed to translate the very promising lab work in Bristol into a therapeutic product for patients with genetic NS. We are aiming to develop this into a therapy to be used in patients within the next 3-4 years".

NEPHROTIC SYNDROME TRUST

ANNUAL REPORT OF THE TRUSTEES

YEAR ENDED 30 SEPTEMBER 2021

“This is a hugely ambitious project that will also be addressing other forms of disease that originate in the podocyte, including all forms of nephrotic syndrome. We will aim to keep the community informed as and when these new programs progress, and work will continue very actively in the Bristol laboratory in order to generate the data that drives new projects”.

Update on NURTuRE – the national UK renal translational research enterprise

“A particularly ambitious and exciting development is the establishment of NURTuRE. We have created a national network of dedicated renal research nurses or study coordinators, based in (initially) the 14 busiest kidney units in the country. These personnel are able to recruit patients (adults and children) to the RaDaR and NephroS studies in a systematic manner, which will catapult the size and depth of the cohort much beyond what has currently been possible. The network will be able to benefit other renal disease cohorts as well as NS, therefore being able to collaboratively grow as the project progresses”.

“The project has considerable backing from pharmaceutical companies, in a way that clinicians/academics can contribute and benefit from industrial research and development, and vice versa”.

“Recruitment is well underway, and although delayed by COVID, is aimed for completion of recruitment of the NS cohort by end of 2021. This will still be a challenge given that most Units are not fully up and running with research studies and recruitment yet. Follow up of the cohort with additional blood and urine samples is also funded. Additional funding has been obtained for genetic sequencing of the cohort, as well as a major **MRC ‘Stratified Medicine’ grant** (see below) awarded to the NURTuRE team, led by Bristol. This grant is worth over £3M over 4 years, and has the ambitious aim of redefining NS through the detailed study of patient samples from NURTuRE, and therefore leading to the ability to target the correct new treatments to the correct patient, on an individual basis.

NURTuRE is overseen by a dedicated committee from the Renal Association and Kidney Research UK, who will govern how the information is kept safe, and used appropriately for research and patient benefit.

Fundraising and support from NeST underpin all of these activities, by allowing important projects to be kick started, and to gain the vital momentum that then attracts government and industrial research funding for the more ambitious projects. On a smaller scale this support is also used to fund projects undertaken by medical and science students, an important step in enthusing and training the next generation of researchers.

We in the research team hugely enjoy the patient days in particular, where we can interact with the most important people involved in the research, you!

Patient involvement in research is vital to us, guiding our priorities, and inspiring us to do the best work possible to ultimately find a cure for this disease”.

Professor Moin Saleem and Professor Gavin Welsh as well as leading and supporting researchers at the University of Bristol laboratory are also working with Pure Spring Labs, looking at Gene Therapy. The CEO there has expressed a keen interest that their people should meet and talk with patient groups. It was agreed that this should be encouraged and could be very beneficial. Maybe another Bristol Lab Day, which are very popular and all the team get involved.

NEPHROTIC SYNDROME TRUST
ANNUAL REPORT OF THE TRUSTEES
YEAR ENDED 30 SEPTEMBER 2021

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 £123,675 (2020 - £109,823), with the majority of income arising from donations and grants. Total payments were £79,494 (2020 - £129,534), 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 increased by £44,181 (2020 – decreased by £19,711) to £144,869 (2020 - £100,688). £124,152 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 2020 and remains unspent. This is available to fund those struggling with shielding due to 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 £20,266.
3. Pears Foundation Grant. This was awarded to help those worst affected by the pandemic to include the costs of the daily running of the charity. £8,675 was received during the year and was fully utilised before the year end.

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 1 August, 2022.

NEPHROTIC SYNDROME TRUST
INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
NEPHROTIC SYNDROME TRUST
YEAR ENDED 30 SEPTEMBER 2021

I report to the trustees on my examination of the accounts of the Charity for the year ended 30 September 2021.

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: 1 August 2022

NEPHROTIC SYNDROME TRUST
RECEIPTS AND PAYMENTS ACCOUNT
FOR THE YEAR ENDED
30 SEPTEMBER 2021

	2021 Unrestricted Funds £	2021 Restricted Funds £	2021 Total Funds £	2020 Total Funds £
<u>RECEIPTS</u>				
Donations	99,882	-	99,882	70,019
Grants received	-	10,425	10,425	32,409
Job retention scheme grants	13,365	-	13,365	7,362
Interest received	3	-	3	33
	<u>113,250</u>	<u>10,425</u>	<u>123,675</u>	<u>109,823</u>
<u>PAYMENTS</u>				
Donations to United Bristol Hospital	31,000	-	31,000	50,000
Wages & pension costs of administrator	17,315	7,925	25,240	22,974
Wages of the app administrator	933	4,931	5,864	8,175
Consultancy fees	1,000	-	1,000	8,208
Insurance	314	-	314	314
Travel	-	-	-	362
Promotional costs	-	-	-	734
Fundraising costs	5,793	-	5,793	4,884
Young Ambassadors Events	-	-	-	305
Professional fees	540	-	540	-
NNF expenditure	-	2,286	2,286	33,171
COVID grants	105	750	855	1,318
Website cost	235	-	235	185
Just Giving fee	2,231	-	2,231	1,416
Virgin money giving costs	-	-	-	12
Printing, stationery and postage	430	-	430	945
Sundry Expenses	204	-	204	164
Accountancy fees	2,160	-	2,160	1,225
Telephone	441	-	441	514
Computer expenses (inc. internet)	260	-	260	(5,751)
Bank & Paypal Charge	35	-	35	59
	<u>62,996</u>	<u>15,892</u>	<u>78,888</u>	<u>129,214</u>
<u>PURCHASE OF FIXED ASSETS</u>				
	<u>606</u>	<u>-</u>	<u>606</u>	<u>320</u>
	<u>63,602</u>	<u>15,892</u>	<u>79,494</u>	<u>129,534</u>
NET OF PAYMENTS	<u>49,648</u>	<u>(5,467)</u>	<u>44,181</u>	<u>(19,711)</u>
Bank and cash funds brought forward	<u>74,504</u>	<u>26,184</u>	<u>100,688</u>	<u>120,399</u>
Bank and cash funds carried forward	124,152	20,717	144,869	100,688

The notes on pages 9 and 10 form part of these financial statements.

NEPHROTIC SYNDROME TRUST

STATEMENT OF ASSETS

FOR THE YEAR ENDED

30 SEPTEMBER 2021

	2021	2020
	£	£
CASH FUNDS		
Bank current account	144,869	100,678
Cash in hand	-	10
	<u>144,869</u>	<u>100,688</u>

£20,717 (2020 - £26,184) 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	-
Computer monitor (15 November 2020)	75	-
Laptop for roadshows (2 April 2021)	399	-
Shredder (25 May 2021)	54	-

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

1 August, 2022.

The notes on pages 9 and 10 form part of these financial statements.

NEPHROTIC SYNDROME TRUST
NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED
30 SEPTEMBER 2021

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 (2020 - £500).

4. RELATED PARTY TRANSACTIONS

The trustee Mrs W Cook received remuneration and pension of £25,240 during the year arising from her employment as administrator. (2020 - £22,974)

The trustee Mrs S Jenkins received remuneration of £5,864 during the year arising from her employment as administrator of the App development. (2020 - £8,175)

The trustee Mr D Yearsley received £1,000 during the year for consultancy work with the Bristol renal team. (2020 - £8,208).

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 2021

	2021 NNF Funds £	2021 Retrophin Funds £	2021 Contact A Family £	2021 Total Funds £	2020 Total Funds £
BREAKDOWN OF RESTRICTED INCOME & EXPENDITURE ITEMS					
<u>RECEIPTS</u>					
Grants received	1,750	-	8,675	10,425	32,409
	<u>1,750</u>	<u>-</u>	<u>8,675</u>	<u>10,425</u>	<u>32,409</u>
<u>PAYMENTS</u>					
Wages & pension costs	4,931	-	7,925	12,856	8,175
Nurture APP costs	1,700	-	-	1,700	28,325
Consultancy work	-	-	-	-	1,812
Travel & subsistence	189	-	-	189	356
COVID grants	-	-	750	750	1,318
Advertising	-	-	-	-	235
Notts roadshow	-	-	-	-	1,148
Bristol roadshow	-	-	-	-	431
Glasgow roadshow	-	-	-	-	152
Young Ambassadors Events	-	-	-	-	588
Conference	337	-	-	337	
Sundry Expenses	60	-	-	60	124
	<u>7,217</u>	<u>-</u>	<u>8,675</u>	<u>15,892</u>	<u>42,664</u>
<u>PURCHASE OF FIXED ASSETS</u>					
	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>
	<u><u>7,217</u></u>	<u><u>-</u></u>	<u><u>8,675</u></u>	<u><u>15,892</u></u>	<u><u>42,664</u></u>
NET OF PAYMENTS	<u><u>(5,467)</u></u>	<u><u>-</u></u>	<u><u>-</u></u>	<u><u>(5,467)</u></u>	<u><u>(10,255)</u></u>
FUNDS B/FWD	<u><u>25,733</u></u>	<u><u>451</u></u>	<u><u>-</u></u>	<u><u>26,184</u></u>	<u><u>32,409</u></u>
FUNDS C/FWD	<u><u>20,266</u></u>	<u><u>451</u></u>	<u><u>-</u></u>	<u><u>20,717</u></u>	<u><u>32,409</u></u>

NEPHROTIC SYNDROME TRUST

**TRUSTEES APPROVAL CERTIFICATE
FOR THE YEAR ENDED**

30 SEPTEMBER 2021

We confirm that the Receipts and Payments Accounts on pages 7 to 10 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: 1 August 2022

Mrs W Cook

Dated: 1 August 2022

NEPHROTIC SYNDROME TRUST (NEST)

England & Wales - Charity number 1107601

Accounts

NEPHROTIC SYNDROME TRUST
UNAUDITED ANNUAL REPORT
30 SEPTEMBER 2020

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 2020

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NEPHROTIC SYNDROME TRUST
REFERENCE AND ADMINISTRATIVE DETAILS
YEAR ENDED 30 SEPTEMBER 2020

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 (appointed 25 th October 2019)
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
REFERENCE AND ADMINISTRATIVE DETAILS
YEAR ENDED 30 SEPTEMBER 2020

The trustees have pleasure in presenting their report and the unaudited accounts of the charity for the year ended 30 September 2020 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, 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.

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

The NeST community continues to grow with over 2,000 persons on our main Facebook page. This page dedicated to our community has been a huge invaluable source of information since the start of the pandemic. We would say it has helped members enormously ensuring they feel less alone coping at this difficult time; many comforting messages have been shared between members, very touching to witness. Other online platforms such as Zoom have also played a big part too, helping to keep the community spirit going. Two wonderful bingo evenings were organised by Gemma Benson, a Trustee, which everyone thoroughly enjoyed. It also raised funds for NeST too. We also used the online platform for clinicians to educate and inform the Nephrotic Syndrome community about the risks of COVID 19, outcomes to those hospitalised with the virus and the progress of vaccine development. The zoom event provided great support and was much appreciated by many anxious individuals and families.

Due to the pandemic the capacity to fundraise during Spring and Summer 2020 was limited as larger events were unable to take place due to the restrictions. This impacted on donations received. We were so thankful however, that many loyal fundraisers found creative ways to still have fun whilst raising funds for the research team. Such events included several people bravely shaving their heads whilst others took part in solo running, skipping and walking challenges. The 'Give as you Live' team also helped us with our 15th Birthday Challenge campaign over the summer which involved many wonderful families raising over £8,000 in total! A further family gave a one-off large donation which was a lovely surprise and very heart-warming for all the team!

NEPHROTIC SYNDROME TRUST
REFERENCE AND ADMINISTRATIVE DETAILS
YEAR ENDED 30 SEPTEMBER 2020

David Yearsley and Wendy Cook revisited the strategy set out for NeST: the vision remaining the same, but an update to our mission required. Three key areas were identified as requiring improvement:

More communication between us all,

More commitment from our community groups if possible. It was agreed that a meeting was required bringing together all community group leads to co-ordinate a calendar of yearly events, in order to increase income and engage with the different community leaders.

More funding needs to be generated to build our charity, and also importantly support more research. We deliberated on how we can link research to add value to fundraising. We decided to explore other methods to increase fundraising such as DONATE text giving which is now present on our website and intermittently advertised on our busy Facebook pages, and to encourage monthly giving by members.

Our governing document was reviewed and updated on the Charity Commission website.

Update on the Bristol University Research work supported by NeST:

It's been a very busy year in the research laboratories in respect of two projects.

The first is the stratified medical project funded by the MRC Grant, to run over 4 years. The aim of this project is to recruit patients to NURTuRE to study their biopsy's, blood, DNA, plasma; a process called epigenetics, using this analysis and expertise to understand the genetic architecture of Nephrotic Syndrome.

The project is about 50% complete and running well. Researchers are starting the fun phase: using the collected data that is beginning to 'bear fruit' in order to focus and maintain the goals towards re-classification of Nephrotic Syndrome.

Classification will be based on the mechanical underlying reasons for Nephrotic Syndrome. Professor Moin Saleem stresses the importance of bringing patients alongside us; to keep engaging them through patient days and research updates. We are working with International NUTuRE countries: South Africa, India and Sri Lanka, together with a pharmaceutical company Evotec. Working with other countries has proved a challenge due to the different paperwork. We have now crossed most of these hurdles and are now able to collect data and cross reference it with British Data. Nephrotic Syndrome is prevalent in these countries providing a increase in the number of patients available to recruit to the project. Maryam has worked hard obtaining samples and getting them to the lab.

The international project is moving into its last phase, but NURTuRE has yet to reach its full quota of patients due to Covid-19, so the team is looking to extend the project into 2021.

The second project is very exciting, working towards setting up the world's first gene therapy company. There are types of gene therapy currently used successfully to treat the liver, eyes and some neurological and immune conditions; these are more straight forward to target, but difficult to access for the kidney. The research team have now secured funding from an investment company interested in their research work, targeting the podocyte in the kidney. It is an ambitious project but is looking to be able to treat/target kidney diseases through targeting podocytes. The researchers hope to be able to find biological pathways in the podocyte, to provide the means to be able to treat Nephrotic Syndrome.

Professor Moin Saleem states 'It's still early days with a lot of promise'.

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.

NEPHROTIC SYNDROME TRUST
REFERENCE AND ADMINISTRATIVE DETAILS
YEAR ENDED 30 SEPTEMBER 2020

FINANCIAL REVIEW

Total receipts during the year were £109,823 (2019 - £186,692), with the majority of income arising from donations and grants. Total payments were £129,534 (2019 - £142,543), the major expenditure being the donation to United Bristol Hospitals as disclosed further in the Receipts and Payments Account on Page 5.

Net funds therefore decreased by £19,711 (2019 – increased by £44,149) to £100,688 (2019 - £120,399). £74,504 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. Zurich Community Grant for the Young Ambassadors weekend. This project has been concluded in 2019 and no funds were brought forward into 2020.
2. Retrophin Grant. A grant of £50,000 received in 2019 was passed on in full as a donation to University of Bristol for research. A further grant of £1,769 was received in 2020 in order to fund those struggling with shielding due to COVID- 19. This fund has a balance carried forward of £451.
3. App development. This project commenced in the latter part of 2019 and received further funding during 2020. This fund has a balance carried forward of £25,733.

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 30 July, 2021.

NEPHROTIC SYNDROME TRUST
INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
NEPHROTIC SYNDROME TRUST
YEAR ENDED 30 SEPTEMBER 2020

I report to the trustees on my examination of the accounts of the Charity for the year ended 30 September 2020.

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: 30 July 2021

NEPHROTIC SYNDROME TRUST
RECEIPTS AND PAYMENTS ACCOUNT
FOR THE YEAR ENDED
30 SEPTEMBER 2020

	2020 Unrestricted Funds £	2020 Restricted Funds £	2020 Total Funds £	2019 Total Funds £
<u>RECEIPTS</u>				
Donations	70,019	-	70,019	96,620
Grants received	-	32,409	32,409	90,050
Job retention scheme grants	-	7,362	7,362	-
Interest received	33	-	33	22
	<u>70,052</u>	<u>39,771</u>	<u>109,823</u>	<u>186,692</u>
<u>PAYMENTS</u>				
Donations to United Bristol Hospital	50,000	-	50,000	100,00
Wages & pension costs of administrator	15,612	7,362	22,974	18,724
Consultancy fees	8,208	-	8,208	-
Insurance	314	-	314	314
Travel	362	-	362	453
Washington conference	-	-	-	999
Promotional costs	734	-	734	643
Fundraising costs	4,884	-	4,884	4,142
Patient Information day	-	-	-	2,084
Young Ambassadors Events	305	-	305	748
NNF expenditure	-	41,346	41,346	3,093
COVID grants	-	1,318	1,318	-
Website cost	185	-	185	5,031
Just Giving fee	1,416	-	1,416	1,950
Virgin money giving costs	12	-	12	67
Printing, stationery and postage	945	-	945	653
Sundry Expenses	164	-	164	200
Accountancy fees	1,225	-	1,225	990
Telephone	514	-	514	644
Computer expenses (inc. internet)	(5,751)	-	(5,751)	1,180
Bank & Paypal Charge	59	-	59	28
	<u>79,188</u>	<u>50,026</u>	<u>129,214</u>	<u>141,943</u>
<u>PURCHASE OF FIXED ASSETS</u>				
	<u>320</u>	<u>-</u>	<u>320</u>	<u>600</u>
	<u>79,508</u>	<u>50,026</u>	<u>129,534</u>	<u>142,543</u>
NET OF PAYMENTS	<u>(9,456)</u>	<u>(10,255)</u>	<u>(19,711)</u>	<u>44,149</u>
Bank and cash funds brought forward	<u>83,960</u>	<u>36,439</u>	<u>120,399</u>	<u>76,250</u>
Bank and cash funds carried forward	<u>74,504</u>	<u>26,184</u>	<u>100,688</u>	<u>120,399</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 2020

	2020 £	2019 £
CASH FUNDS		
Bank current account	100,678	120,389
Cash in hand	10	10
	<u>100,688</u>	<u>120,399</u>

£26,234 (2019 - £36,439) 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	-
	<u>320</u>	<u>-</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

30 July, 2021.

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 2020

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 (2019 - £500).

4. RELATED PARTY TRANSACTIONS

The trustee Mrs W Cook received remuneration and pension of £22,974 during the year arising from her employment as administrator. (2019 - £18,724)

The trustee Mrs S Jenkins received remuneration of £8,175 during the year arising from her employment as administrator of the App development. (2019 - £Nil)

The trustee Mr D Yearsley received £8,208 during the year for consultancy work with the Bristol renal team. (2019 - £Nil).

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

NEPHROTIC SYNDROME TRUST

TRUSTEES APPROVAL CERTIFICATE FOR THE YEAR ENDED

30 SEPTEMBER 2020

BREAKDOWN OF RESTRICTED INCOME & EXPENDITURE ITEMS

RECEIPTS

Grants received	30,640	1,769	-	32,409	90,050
Job retention scheme grants	-	-	7,362	7,362	-
	<u>30,640</u>	<u>1,769</u>	<u>7,362</u>	39,771	90,050

PAYMENTS

Donations to United Bristol Hospital	-	-	-	-	50,000
Wages & pension costs	8,175	-	7,362	15,421	-
Nurture APP costs	28,325	-	-	28,325	-
Consultancy work	1,812	-	-	1,812	-
Recruitment expenses	-	-	-	-	671
Travel & subsistence	356	-	-	356	354
COVID grants	-	1,318	-	1,318	-
Advertising	235	-	-	235	-
Notts roadshow	1,148	-	-	1,148	-
Bristol roadshow	431	-	-	547	-
Glasgow roadshow	152	-	-	152	-
Young Ambassadors Events	588	-	-	588	2,068
Sundry Expenses	124	-	-	124	-
	<u>41,346</u>	<u>1,318</u>	<u>7,362</u>	50,026	53,093

PURCHASE OF FIXED ASSETS

	-	-	-	-	540
	<u>41,346</u>	<u>1,318</u>	<u>7,362</u>	49,976	53,633

NET OF PAYMENTS	<u>(10,706)</u>	<u>451</u>	<u>-</u>	<u>(10,255)</u>	<u>36,417</u>
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FUNDS B/FWD	<u>36,439</u>	<u>-</u>	<u>-</u>	<u>36,439</u>	<u>36,417</u>
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FUNDS C/FWD	<u>25,733</u>	<u>451</u>	<u>-</u>	<u>26,184</u>	<u>36,417</u>
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