

**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**

<b>The board of trustees</b>	Mr D Yearsley Dr M Saleem Mrs W Cook Ms G Benson Mrs L Mathias-Lukins Dr G Welsh Mrs S Jenkins (appointed 25 <sup>th</sup> October 2019)
<b>Charity registration number</b>	1107601
<b>Principal office</b>	38 Southway Drive Yeovil BA21 3ED
<b>Independent examiner</b>	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
<b>Bankers</b>	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 15<sup>th</sup> 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 £
<b><u>RECEIPTS</u></b>				
Donations	70,019	-	70,019	<b>96,620</b>
Grants received	-	32,409	32,409	<b>90,050</b>
Job retention scheme grants	-	7,362	7,362	-
Interest received	33	-	33	<b>22</b>
	<u>70,052</u>	<u>39,771</u>	<u>109,823</u>	<u><b>186,692</b></u>
<b><u>PAYMENTS</u></b>				
Donations to United Bristol Hospital	50,000	-	50,000	<b>100,00</b>
Wages & pension costs of administrator	15,612	7,362	22,974	<b>18,724</b>
Consultancy fees	8,208	-	8,208	-
Insurance	314	-	314	<b>314</b>
Travel	362	-	362	<b>453</b>
Washington conference	-	-	-	<b>999</b>
Promotional costs	734	-	734	<b>643</b>
Fundraising costs	4,884	-	4,884	<b>4,142</b>
Patient Information day	-	-	-	<b>2,084</b>
Young Ambassadors Events	305	-	305	<b>748</b>
NNF expenditure	-	41,346	41,346	<b>3,093</b>
COVID grants	-	1,318	1,318	-
Website cost	185	-	185	<b>5,031</b>
Just Giving fee	1,416	-	1,416	<b>1,950</b>
Virgin money giving costs	12	-	12	<b>67</b>
Printing, stationery and postage	945	-	945	<b>653</b>
Sundry Expenses	164	-	164	<b>200</b>
Accountancy fees	1,225	-	1,225	<b>990</b>
Telephone	514	-	514	<b>644</b>
Computer expenses (inc. internet)	(5,751)	-	(5,751)	<b>1,180</b>
Bank & Paypal Charge	59	-	59	<b>28</b>
	<u>79,188</u>	<u>50,026</u>	<u>129,214</u>	<u><b>141,943</b></u>
<b><u>PURCHASE OF FIXED ASSETS</u></b>				
	<u>320</u>	<u>-</u>	<u>320</u>	<u>600</u>
	<u><u>79,508</u></u>	<u><u>50,026</u></u>	<u><u>129,534</u></u>	<u><u><b>142,543</b></u></u>
<b>NET OF PAYMENTS</b>	<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><b>76,250</b></u>
Bank and cash funds carried forward	<u>74,504</u>	<u>26,184</u>	<u>100,688</u>	<u><b>120,399</b></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 £
<b>CASH FUNDS</b>		
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)	<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	-	<b>32,409</b>	<b>90,050</b>
Job retention scheme grants	-		7,362	<b>7,362</b>	-
	<u>30,640</u>	<u>1,769</u>	<u>7,362</u>	<b>39,771</b>	<b>90,050</b>

#### PAYMENTS

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

#### PURCHASE OF FIXED ASSETS

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

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