

**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**

<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
<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**

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

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