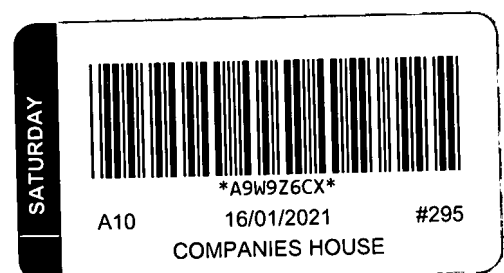




Advancing Care in Primary Immunodeficiency

Annual Report 2019



Trustees' Report

For the period ended 31 December 2019

What we do and why it matters

The United Kingdom Primary Immunodeficiency Network (UKPIN) is the professional body for Immunologists, Specialist Nurses, Healthcare and Academic Scientists in the UK.

Our mission

UKPIN's mission is to advance the health among those with primary immunodeficiency disorders and advancing education in PID and related subjects.

We accomplish this by:

- **Developing common best practice approaches to diagnosis and management of PID and related disorders**
- **Developing clinical guidelines by means of setting consensus standards based upon agreed UK best practice**
- **Promoting improved understanding of PID and related disorders among healthcare professionals and students**

The Trustees confirm they have referred to the Charity Commission's guidance on public benefit when reviewing the Charity's aims and objectives, planning future activities and setting the annual operating plan.

Our strategic objectives

- 1. Development of best practice guidance**
- 2. Clinical leadership of the QPIDS accreditation scheme**
- 3. Maintenance of the UK PID registry**
- 4. Advance education in primary immunodeficiency**
- 5. Communications and networking**

1 Development of best practice guidelines

There were 6,675 patients entered in total, and a 2018 joint publication with MDSAS, with APDS having a joint publication with ESID. The registry was then successfully adopted by NIHR LCRN and has been since August 2018. Sites should now have access to a local CRN resource to support recruitment and data entry.

Keeping you informed

The Charity works hard to keep our members informed about our activities and developments in primary immunodeficiency in the wider world.

2 Clinical leadership of the QPIDS accreditation scheme

2019 has perhaps been the busiest year for the QPIDS programme since it moved over to the Royal College of Physicians in 2015. Six services that gained accreditation when the programme was based at UKPIN, underwent their reaccreditation assessments this year; with Salford Royal NHS Foundation Trust and University Hospital Plymouth NHS Trust successfully maintaining accreditation. The remaining services are currently undergoing the accreditation process.

Currently QPIDS has 37 services registered; two of which registered in 2019 and 14 of which are accredited. Registration is also now open for services in the Republic of Ireland.

Changes were made to the annual renewal process this year, whereby services now submit their annual renewal on the anniversary of their original accreditation assessment. The annual renewal is a process of providing a remote review of accredited services every year, ensuring that standards are still being met.

The new standards were launched at the UKPIN meeting in December 2019 and are available for registered services from the QPIDS office and will be live on the website from September 2020.

3 Maintenance of the UK PID registry

To keep the registry up to date, adding information on PIDs and patients as they become available.

4 Advance education in primary immunodeficiency

UKPIN would like to highlight an exciting opportunity to receive funding for doctors, nurses and scientists who are UKPIN members to further their knowledge of primary immune deficiencies. These awards would help support periods training in other academic or clinical centres.

5 Communications and networking

The 2019 UKPIN meeting was a great success with 235 people onsite in Liverpool, almost 30% higher than the last conference in 2017. The meeting was held alongside the British Society for Immunology incorporating joint plenary sessions. The biennial conference is the UKPIN's flagship event and is a must-attend event for consultants, trainees, nurses and scientists involved in the healthcare of patients with primary immunodeficiencies or in research into these diseases.

- 96% of delegates said they would attend another UKPIN conference
- 95% of delegates said they would recommend the UKPIN conference to a colleague

'A very good update on new PID and useful genomics and a great chance for the small discipline to network effectively. Well organised conference, both prior to and during the event. Good convenient venue. AV excellent. Good sessions and speakers with concise relevant messages.'

'Really brilliant conference really gained a great deal as a relative novice in the field of genomics and met/caught up with some amazing people. Excellent meeting. Very valuable for the UK immunology community.'

UKPIN are working with UK Plasma Action, BSI and patient groups on the need to secure more reliable supplies of immunoglobulin and other plasma derived pharmaceutical products for patients in need and are supporting a review of lifting the ban on UK plasma donors.

There were around 2,000 views per month which then increased to 5,000 around the time of the UKPIN meeting, and most of these views are either from the UK or USA. Half of views were done via people's phone, and half via pc. The main areas that people visit on the website are meetings, registry, membership and guidelines.

Structure, Governance and Management

Charitable status and administrative details

The Charity is registered as a charity (Charity number 1164466) and incorporated in England and Wales as a company, limited by guarantee (Company number 09273983). It has no share capital and the liability of its members is limited to a sum not exceeding £1. The charity's governing document is the Memorandum and Articles of Association, which was amended in October 2014.

Steering Committee (Board of Trustees)

The Trustees are charity Trustees for the purposes of the Charities Act 2011. The Chair, Honorary Secretary and Treasurer are also company directors for the purposes of the Companies Act. The current trustees, and any past Trustees who served during the year are listed on page 18.

The Trustees are responsible for directing the Charity's activities and for overseeing the management of the affairs of the Charity, they actively manage the organisation. They have contracted the British Society for Immunology to provide secretariat services to the Charity.

The Trustees meet quarterly and decisions are agreed on by open vote. The sub-committees report into the Steering Committee and the reports are approved during the steering committee meetings. Any decisions outside the steering committee meetings will either be resolved by the trustees agreeing or by an electronic vote by all trustees.

As part of their induction process, Trustees spend some time with the Chair who gives a full introduction together with the history of the Charity and key information they require to fulfil their duties as Trustees.

The success of the Charity belongs in part to the people who generously volunteer their time to add their experience to our activities, we thank you all.

Financial Performance

The Charity's financial performance was strong, generating a healthy surplus of £69k for the period (2018: £34k).

Overall, income at £246k was 16% higher than last year (£212k). The increased delegates at the 2019 meeting flowed through to better financial results than the last meeting in 2017.

Costs were maintained at approximately the same level during the period

Membership income fell during the period. Membership is now linked to meeting registration. All registrations for the 2019 meeting include membership fees for 2020 and 2021 which have been deferred into future financial years.

Reserves policy

The Charity operates a reserves policy requiring a minimum of two years budgeted non-meeting annual costs to be retained as free reserves. The Trustees consider that this level will provide enough funds to respond to any unexpected events.

At 31 December 2019, free reserves stood at £165k (2018: £96k). This equates to 3.4 years' costs based upon the 2020 budget.

Risk management

Good risk management is fundamental to the continued work and sustainability of the Charity. We identify and manage risks that could adversely impact the achievement of our strategic purpose and determine the calculated risks we need to take to succeed.

The Charity operates a formal framework for the management of risk, taking the view that risk can be positive (opportunity) or negative (threat). The Charity operates a risk register incorporating strategic, operational and compliance risks, which are informed by the Charity's strategic objectives, performance, voice of our stakeholders, regulatory environment and analysis of the external environment.

The Steering Committee delegates day-to-day responsibility for risk management to the Directors, who are responsible for identifying and evaluating risks to their areas and activities implementing appropriate controls for ongoing mitigation and monitoring.

The Steering Committee reviews the Charity's strategic and compliance risks annually.

Fundraising statement

Although the Charity does not actively fundraise from members, occasional donations are received. The Charity applies best practice in the tone of its communications and the accuracy of its data to minimise the pressures on supporters. The Charity applies best practice to protect supporters' data, never sells or swaps it and ensures that communication preferences can be changed at any time. The Charity commits to react to and investigate any complaints received, to learn from them and improve its service. During the year, the Charity received no complaints about its fundraising activities.

Future plans

The 2020 plans for the Charity have been impacted by Covid-19, however they have been adapted to continue to provide a service to members and help those with PID throughout these challenging times.

1. Development of best practice guidelines

- Work with the BSI and the national guidelines centre (NGC) to produce a set of guidelines looking at use of replacement immunoglobulin in patients with primary and secondary immunodeficiency.

2. Clinical leadership of the QIDS accreditation scheme

- Increase regularity of assessor training days
- Survey QPIDs services to establish how services have been impacted by the Covid pandemic
- Launch online training to support services starting to work towards accreditation using the new standards

3. Maintenance of the UK PID registry

- To keep the registry up to date, adding information on PIDs and patients as they become available.

4. Advance education in primary immunodeficiency

- To provide funding for doctors, nurses and scientists who are UKPIN members to further their knowledge of primary immune deficiencies

5. Communication and networking

- To engage with the membership and other professional bodies on PID services in general and the impact of Covid-19.

Covid-19

The activities of UKPIN has not been significantly impacted by the impact of Covid-19. The next conference is scheduled for December 2021, planning for this event will start during the year in line with relevant social distancing requirements.

Trustees' responsibilities

The Trustees are responsible for preparing the Trustees' report and financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the Charity and of the income and expenditure of the Charity for that period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable to the United Kingdom and Republic of Ireland; and
- make judgements and estimates that are reasonable and prudent;
- state whether applicable United Kingdom Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume the charity will continue in operation.

The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the Charity and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the Charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Each of Trustees confirm that:

- so far as the Trustee is aware, there is no relevant information of which the Charity's independent examiner is unaware; and
- the Trustee has taken all steps that he/she ought to have taken as a Trustee in order to make himself/herself aware of any relevant audit information and to establish that the Charity's independent examiner is aware of that information.

This confirmation is given and should be interpreted in accordance with the provisions of s418 of the Companies Act 2006.

The Trustees are responsible for the maintenance and integrity of corporate and financial information included on the Charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

Approved by the Trustees and signed on their behalf by:



Dr Catherine Stroud
UKPIN Treasurer

Date: 18.11.2020

Independent Examiner's Report to the Trustees of the United Kingdom Primary Immunodeficiency Network ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the period ended 31 December 2019.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

Independent Examiner's Statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

- 1) accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
- 2) the accounts do not accord with those records; or
- 3) the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a 'true and fair view which is not a matter considered as part of an independent examination; or
- 4) the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities.

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.

Moore Kingston Smith LLP

Neil Finlayson

For and on behalf of Moore Kingston Smith LLP
Chartered Accountants

Devonshire House
60 Goswell Road
London EC1M 7AD

Date: 3 December 2020

Statement of Financial Activities
Period to 31 December 2019

	Note	General funds £'000	Restricted funds £'000	Total 2019 £'000	Total 2018 £'000
Income from:					
Donations	2	70	5	75	116
Charitable activities:	3				
Conference		169	-	169	86
Membership		2	-	2	10
Total income		241	5	246	212
Expenditure on:					
Charitable activities					
Awards	4	2	1	3	-
Conference		129	-	129	130
Guidance		8	-	8	4
Membership		29	-	29	32
Registry		8	-	8	11
Total expenditure	5	176	1	177	178
Net income		65	4	69	34
Reconciliation of funds:					
Funds brought forward		96	-	96	62
Funds carried forward		161	4	165	96

There are no recognised gains or losses other than those recognised above. All activities are continuing.

The notes on pages 11 to 18 form part of these financial statements

Balance Sheet
31 December 2019

	Notes	Total 2019 £'000	Total 2018 £'000
Current assets			
Debtors	9	119	29
Cash at bank and in hand		118	91
		237	120
Liabilities			
Creditors: amounts falling due within one year	10	(72)	(24)
Net assets		165	96
Funds			
Unrestricted funds			
General funds	12	161	96
Restricted funds	11	4	-
Total		165	96

For the financial year in question the company was entitled to exemption under section 477 of the Companies Act 2006 relating to small companies.

No members have required the company to obtain an audit of its accounts for the year in question in accordance with section 476 of the Companies Act 2006.

The directors acknowledge their responsibility for complying with the requirements of the Act in respect to accounting records and for the preparation of accounts.

These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies regime.

These accounts were approved by the Board and authorised for issue on 18/4/20 and were signed on its behalf by:



Dr Catherine Stroud
Director

United Kingdom Primary Immunodeficiency Network, Company Limited by Guarantee
Company Registration Number 09273983 (England and Wales)

The notes on pages 11 to 18 form part of these financial statements

Notes to the financial statements

1 Accounting policies

The principle accounting policies adopted, judgements and key sources of estimation uncertainty in the preparation of the financial statements are as follows:

Basis of preparation

The financial statements are prepared on a going concern basis, under the historical cost convention modified to include the recognition of listed investments measured at fair value, which is consistent with the prior year. The financial statements have been prepared in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities ("The SORP"), the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2011.

The United Kingdom Primary Immunodeficiency Network ("The Charity") meets the definition of a public benefit entity under FRS 102.

General information

The Charity is a charitable company incorporated in England and Wales (company number 09273983) and is a charity registered in England and Wales (charity number 1164466) The Charity's registered address is 34 Red Lion Square, London, WC1R 4SG

Critical accounting judgements and key sources of estimation uncertainty

The preparation of financial statements requires the use of certain critical accounting estimates. It also requires management to exercise its judgement in the process of applying the Charity accounting policies. In the application of the accounting policies, Trustees are required to make judgements, estimates and assumptions about the carrying value of assets and liabilities that are not readily apparent from other sources. The estimates and underlying assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised if the revision only affects that period, or in the period of revision and future periods if the revision affected current and future periods.

In the view of the Trustees, no assumptions concerning the future or estimation uncertainty affecting assets or liabilities at the balance sheet date are likely to result in a material adjustment to their carrying amounts in the next financial year.

Going concern

The Trustees have assessed whether the use of the going concern assumption is appropriate in preparing these financial statements. The directors have made this assessment in respect to a period of one year from the date of approval of these financial statements.

Much of the work of the charity have been delayed, including work on the Registry have been paused or delayed as a result of Covid-19. However the Charity's main income generating activity, it's meeting held every two years is next scheduled for December 2021. Therefore there is sufficient time to adapt to the, hopefully, post Covid-19 environment. Following a successful 2019 meeting the charity has sufficient funds to meet its liabilities. The Trustees consider the charity to be a going concern.

Notes to the financial statements

Income

All income is recognised once the Charity has entitlement to income, it is probable that income will be received and the amount of income receivable can be measured reliably. Income of the Charity is, where applicable, included net of Value Added Tax (VAT) and is allocated to the period to which it relates, carrying forward that part of the income relating to future accounting periods.

Expenditure

Liabilities are recognised as soon as there is a legal or constructive obligation committing the Charity to that expenditure, it is probable that settlement will be required and the amount of obligation can be measured reliably. Expenditure is recognised on an accruals basis as a liability is incurred, inclusive of VAT, which cannot be recovered.

Expenditure is allocated to a particular activity where the cost relates directly to that activity. The cost of overall direction and administration of each activity, known as "support costs" and comprising the overhead costs of the central function is apportioned to each activity.

Support costs also include governance costs, which comprise organisational administration and compliance with constitutional and statutory requirements. The allocation of support and governance costs is analysed in notes 5 and 6.

Financial Instruments

The Charity has chosen to adopt Section 11 of FRS 102 in respect of financial instruments.

I) Financial assets

Basic financial assets, including trade and other receivables, cash and bank balances, are initially recognised at transaction value and subsequently measured at amortised cost. Other financial assets, including investments, are initially measured at fair value. Financial assets are derecognised when:

- a) the contractual rights to the cash flows of the asset expire or are settled, or
- b) substantially all the risks and rewards of the ownership of the asset are transferred to another party or
- c) despite having retained some significant risks and rewards of ownership, control of the asset has been transferred to another party who has the practical ability to unilaterally sell the asset to an unrelated third party without imposing additional restrictions.

Cash at bank and cash in hand includes cash and short-term highly liquid investments with a short maturity of three months or less.

II) Financial liabilities

Basic financial liabilities, including trade and other payables, are initially recognised at transaction price. Trade payables are obligations to pay for goods or services that have been acquired in the ordinary course of business from suppliers. Accounts payable are classified as current liabilities if payment is due within one year or less. If not, they are presented as non-current liabilities. Financial liabilities held at amortised cost comprise all creditors except social security and other taxes and provisions.

Notes to the financial statements

Provisions

Provisions are recognised where the Charity has a present legal or constructive obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Provisions are measured at the present value or the expenditures expected to be required to settle the obligation.

Fund accounting

Unrestricted funds are those funds available to the Charity for general purposes. They include funds designated by the Trustees for particular purposes where their use remains at the discretion of the Trustees. It is the policy of the Trustees to retain in unrestricted funds, amounts which in their judgement, can help to mitigate the short-term effects of income volatility; and retain as long-term investment funds to generate sufficient income to meet current and future operational activities of the Charity.

Restricted funds are those funds available to the Charity restricted to a specific purpose or are subject to particular donor imposed conditions. Further information is available in the reserves section of the Trustees' report.

2 Income from donations

	Unrestricted funds £'000	Restricted funds £'000	2019 Total Funds £'000	2018 Total Funds £'000
Donations	70	5	75	116
Total	70	5	75	116

3 Income from charitable activities

	Unrestricted funds £'000	Restricted funds £'000	2019 Total Funds £'000	2018 Total Funds £'000
Conference	169	-	169	86
Membership	2	-	2	10
Total	171	-	171	97

Notes to the financial statements

4 Awards

	Total Funds 2019 £'000	Total Funds 2018 £'000
Awards and grants to individuals	1	-
Support costs	2	-
Total	3	-

Awards were paid to a total of 1 (2018 – nil) individuals.

5 Total expenditure

	Unrestricted funds £'000	Restricted funds £'000	2019 Total Funds £'000	2018 Total Funds £'000
Awards	2	1	3	-
Conference	129	-	129	130
Guidance	8	-	8	4
Membership	29	-	29	32
Registry	8	-	8	11
Total	176	1	177	178

Allocation of support costs to charitable activities:

	Direct costs £'000	Support costs £'000	2019 Total £'000
Awards	1	2	3
Conference	125	4	129
Guidance	4	4	8
Membership	0	29	29
Registry	5	2	8
Total	135	42	177

Notes to the financial statements

5 Total expenditure (continued)

Support costs are as follows:

	2019 £'000	2018 £'000
Auditors' remuneration	2	3
Accountancy fees	1	1
Committee expenses	1	3
Secretariat fees	35	30
Postage and stationery	-	2
Website	3	3
Total	42	43

Allocation of support costs to charitable activities:

	Direct costs £'000	Support costs £'000	2018 Total £'000
Awards	-	-	-
Conference	126	4	130
Guidance	-	4	4
Membership	-	32	32
Registry	9	2	11
Total	135	43	178

6 Governance Costs

	2019 £'000	2018 £'000
Auditor's remuneration - audit	2	3
Auditor's remuneration - other	1	1
Total	3	5

Notes to the financial statements

7 Net income

This is stated after charging:	Total 2019 £'000	Total 2018 £'000
Auditor's remuneration - audit	2	3
Auditor's remuneration - other	1	1

8 Staff costs and remuneration of key management personnel

The company has no employees as its day to day operations are conducted by the employees of the British Society for Immunology. During the period ended 30 June 2019, a secretariat fee to include staff, office and IT costs) of £35,000 (2018: £30,000) was charged by the British Society for Immunology to the Charity.

The total remuneration (including taxable benefits and employer's pension contributions) of the key management personnel for the year was £nil (2018: £nil).

The Charity does not employ staff.

No remuneration was paid to the trustees during the period to 31 December 2019 (2018: none). expenses totalling £4,825 (2018: £2,616) were reimbursed to 9 trustees (2018: 10).

9 Debtors

	2019 £'000	2018 £'000
Other debtors	113	-
VAT recoverable	6	29
Total	119	29

10 Creditors: amounts falling due within one year

	2019 £'000	2018 £'000
Trade creditors	7	19
Accruals and other deferred income	65	6
Total	72	24

Notes to the financial statements

11 Restricted funds

	At 1 November 2018 £'000	Income £'000	Costs £'000	At 31 December 2019 £'000
Visiting Scholar and Jonathan Sherrard Awards	-	5	1	4
Total	-	5	1	4

Visiting Scholar and Jonathan Sherrard Awards

Funds to support UKPIN members for periods training in other academic or clinical centres to further their knowledge of primary immuno deficiencies.

12 Analysis of nets assets between funds

	Unrestricted funds £'000	Restricted funds £'000	2019 Total funds £'000
Current assets	233	4	237
Current liabilities	(72)	-	(72)
Total Funds	161	4	165

	Unrestricted funds £'000	Restricted funds £'000	2018 Total funds £'000
Current assets	120	-	120
Current liabilities	(24)	-	(24)
Total Funds	96	-	96

13 Share capital

The company is limited by guarantee and therefore has no share capital. Each member's liability is limited to £1.

14 Related party transactions

There were no related party transactions that required disclosure in the current financial period (2018: none).

Steering Committee

Position	Current office holder	Date of appointment / resignation
Chair	Dr Tomaz Garcez	Resigned December 2019
Chair	Dr Sinisa Savic	Appointed January 2018
Treasurer	Dr Rashmi Jain	Resigned December 2019
Treasurer	Dr Catherine Stroud	Appointed February 2019
Honorary Secretary	Dr Claire Bethune	Resigned November 2018
Honorary Secretary	Dr Suzy Elcombe	Appointed April 2018
Member	Mrs Sarah Denman	Appointed January 2018
Member	Dr Lisa Devlin	Appointed January 2018
Member	Miss J Edmonds	Appointed January 2018
Member	Prof W Egner	Appointed January 2015
Member	Dr Shuayb Elkhailifa	Appointed February 2019
Member	Dr Kimberly Gilmour	Appointed 2015
Member	Dr Alex Richter	Appointed February 2019
Member	Dr Ravishankar Sargur	Appointed 2014
Member	Dr Austin Worth	Appointed January 2018
Member	Dr Patrick Yong	Appointed February 2019
Member	Dr Peter Arkwright	Resigned December 2018
Member	Dr Gavin Spickett	Resigned December 2019
Member	Mrs Christine Symons	Resigned December 2020
Trainee Member	Dr Manisha Ahuja	Appointed February 2020
Trainee Member	Dr Claire Stockdale	Appointed February 2020

Principal professional advisers

Bankers

Lloyds Bank
14/16 Cockspur Street
London
EC2V 6DL

External Independent examiners

Moore Kingston Smith LLP
Devonshire House
60 Goswell Road
London
EC1M 7AD