



## **IDIOPATHIC INTRACRANIAL HYPERTENSION UK (IIH UK)**

### **TRUSTEES' ANNUAL REPORT AND ACCOUNTS 2018-19**

(Registered Charity Number – England & Wales 1143522, Scotland SC043294)

#### **Charity Trustees during the report period**

1. The following represented IIH UK as trustees during the report period 1 July 2018 to 30 June 2019:

Michelle Williamson	Chair
Lizzie Aylott	Treasurer
Norma Ann Dann	Secretary
Clare Parr	

#### **Structure, Governance and Management**

2. IIH UK was founded in 2008 and established as a registered charity in England and Wales in 2011 and in Scotland in 2012. It is governed by its founding constitution, as subsequently amended on 12 May 2012 and 21 June 2014. The charity is constituted by association.
3. All trustees have given their time voluntarily during 2018-19 and have not received remuneration or any other benefits in undertaking their duties. Following endorsement by the 2014 Annual General Meeting (AGM), trustees are elected for a period of 3 years and remain empowered to appoint new trustees in-year by extraordinary trustee meeting, although trustees appointed in this way must seek re-election at the following AGM.
4. IIH UK is a member of the National Council for Voluntary Organisations (NCVO), Rare Disease UK, the Neurological Alliance, the Health and Social Care Alliance Scotland, Genetic Alliance, Benefits and Work and an affiliate of the James Lind Alliance. We also support the Brain and Spine Foundation.

#### **Charity Objects**

5. The charity's objects as set out in the constitution on 21 June 2014 were as follows:
  - a. To preserve and protect the physical and mental health of sufferers of Idiopathic Intracranial Hypertension through the provision of the best possible support, education and practical advice.
  - b. To advance the education of the public in general, sufferers and the medical community in particular on the subject of IIH.
  - c. To promote and support research for the public benefit on all aspects of the condition IIH and to publish the useful results.

## **Summary of main activities undertaken by IIH UK for the public benefit in relation to the objects**

6. IIH UK would not be able to exist without the small number of dedicated volunteers who freely give their time; many of whom are IIH sufferers themselves. They assist with the day-to-day running of the charity in areas such as fundraising, membership, publicity, merchandise, newsletter production and the running of the very active IIH UK groups on Facebook. In planning and undertaking the activities during the report period, IIH UK trustees were cognisant of the Charity Commission's guidance on public benefit. With the objects in mind, the Charity's key activities fall into 4 main areas: to provide an excellent support network for sufferers and their families/friends/carers; to educate the public and the medical community in particular about IIH; to support and promote research into the condition, and finally, to raise the profile of IIH.
7. We became General Data Protection Regulation (GDPR) compliant in March 2018.
8. We bank with the National Westminster Bank. Facebook (Fb) has become our main platform for donations. Just Giving is our main platform for fundraising. We also accept donations via the Charities Aid Foundation. (See item z below.)

## **Summary of IIH UK's achievements during 2018-19**

9. IIH UK has been very proactive throughout the year, as shown below:

### **Support**

- a. **IIH UK website.** The Charity's website traffic at [www.iih.org.uk](http://www.iih.org.uk) continues to increase. During this financial year 111,100 unique visits were made and 134,894 pages were viewed; up 40,000 on the previous year. The website is maintained by FAT Promotions and is kept up to date by both FAT and some of our volunteers. The live @IIHUK Charity Twitter feed that was added to the front page of the website continues to be a popular feature, and feedback from users (both patients and clinicians) remains positive.
- b. **IIH Support Forum.** After discussion at the 2018 AGM it was decided to close the forum at [iihsupport.org](http://iihsupport.org). It was used very little as the majority of support is now sought on our social media sites.
- c. **Management of Facebook Support Group.** IIH UK continues to run and administer the Fb group 'IIH Support UK'. With an ever-growing membership (820 new members this year) this group now has 5410 members; often with people joining within days of diagnosis, it has enabled the Charity to respond and support people more quickly.
- d. **Regional Groups.** Membership of the online regional groups, which are facilitated by IIH UK, continue to increase with the South East still being the largest group in terms of numbers. The restructuring continues to work well in the 14 groups which cover all four nations and allows people to discuss local issues and meet-up socially.

- e. **Weight Loss Support Group.** There are now over 1830 members in the Weight Loss Support Group. IIH UK facilitates the group to provide healthy recipes and links to NHS healthy eating websites. There is definitive evidence that weight and IIH are related and with over 90% of patients diagnosed with IIH being overweight women, IIH UK is committed to supporting healthy weight loss.
- f. Created in 2017 the **IIH Employment and Study support** now has 555 members, up 155 on last year; this group supports people with IIH who are in work or further education.
- g. **IIH support for men** was created 'just for men', a safe place where they can discuss men's issues. Membership of this group stands at 25, a growth of 10 over the last year. We do not expect this number to rise greatly due to the fact that IIH predominantly affects women.
- h. **Twitter.** We have now been on twitter for 7 years @IIH UK. The advantage over Facebook is that a lot of clinicians are also on Twitter whom you are able to follow, ask questions etc. We have 1698 followers on twitter, up 520 on the previous year.

### Education

- i. **Leaflets.** In December 2017 we commissioned the team at University Hospitals Birmingham to re-write some of our information leaflets in collaboration with some of our volunteers, they will be added to the Leaflet page of our website as they are completed. New leaflets completed so far are:

What is IIH  
 What is IIH without Papilloedema (IIHWOP)  
 Optic Nerve Sheath Fenestration  
 IIH and Weight  
 Headache  
 Acetazolamide

**and new for this year:**

Information for friends, family and carers  
 ICP Monitoring  
 IIH and Education

- j. Our **Patient Conference** was held in West Bromwich, Birmingham on the 7<sup>th</sup> July 2018. It was our first full day conference which was well attended by IIH patients, their carers, families and friends. You can read the 2018 Conference Report on our website at <https://www.iih.org.uk/images/2018patientconference.pdf>

Speakers were:

Dr Deepa Krishnakumar – Paediatric Neurologists, Cambridge University Hospitals.  
 Sharon Whyte – Neurology Specialist Nurse, Cambridge University Hospitals.  
 Dr Tara Walker - General Adult Psychiatrist, Worcestershire Health and Care NHS Trust.

Sister Julie Edwards - Headache Specialist Nurse, University Hospitals Birmingham.  
Dr Ruchika Batra - Neuro-ophthalmologist, University Hospitals Birmingham.  
Dr Susan Mollan, Neuro-ophthalmologist, University Hospitals Birmingham.  
Dr Alexandra Sinclair – IIH UK Patron, Consultant Neurologist, University Hospitals Birmingham.  
Ben Thomas – Bbraun

- k. On 12<sup>th</sup> September 2018 we attended the CSF disorders day, an important date in our calendar. This annual event organised by Miss Mollan and Dr Sinclair was held at the Everyman Theatre, Birmingham. This annual United Kingdom CSF disorders meeting is aimed at clinicians worldwide and presented the first guidelines for idiopathic intracranial hypertension, focusing on protecting the vision, managing the underlying disease and reducing headache morbidity. The most recent scientific concepts in CSF disorders were presented, as was the applied understanding of shunt and valve technology.
- l. We continue to sponsor the **Paediatric IIH Special Interest Group (SIG)**, led by Dr Krishnakumar - Addenbrookes, Cambridge. Our Chair Shelly Williamson is a member of this SIG and this year the IIH UK Publicity Rep Laura Kerbey, whose son has IIH, was also invited to take part. There have been two meetings during the financial year, March 19 and June 19. A paediatric IIH education day for clinicians is taking place in September 19 which we will also sponsor. Paediatric IIH has been ignored for too long and we are hopeful that these meetings will finally give paediatric IIH the attention it deserves.

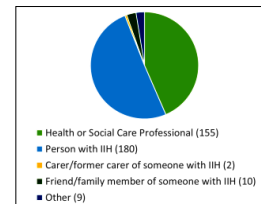
### Research

- m. We continue to fund the travelling expenses for the Birmingham Trials which enables IIH Patients from further afield to take part via a research grant to University Hospitals Birmingham. We have also committed to fund the **The IIH:Life** registry for the next 4 years at a cost of £5,000 per annum.
- n. The IIH:Life registry database comprises of two parts – one for clinician entries and the other for patient input. The medical professionals will be entering data which will include: visual test results, lumbar puncture opening pressures, medication (including dose), height, weight etc. The patient will be asked about their pain levels and asked to complete an annual Quality of Life survey. It is hoped that the registry would be able to indicate the optimal treatment for:
  - 1. Sight Preservation
  - 2. Managing Headaches
  - 3. Improving IIH Sufferers' Quality of Life.
- o. **IIH:Families** is a study by Dr Sinclair and her Birmingham team looking at why IIH can sometimes run in families. We do not yet know if IIH is genetic and we look forward to seeing how this study progresses. IIH UK helped with the recruitment of families for this study and initial recruitment has found 27 families where more than one person has IIH.
- p. **IIH:DT** Trustees sat on the steering group for the IIH Drug Trial. Launched in 2015 this research trial titled: 'Assessing the Efficacy and Safety of an 11 $\beta$ -Hydroxysteroid Dehydrogenase Type 1 Inhibitor (AZD4017) in the Idiopathic Intracranial Hypertension

Drug Trial, IIH:DT Clinical Methods and Design for a Phase II Randomized Controlled Trial'. This trial recruited 31 patients and is the first phase 2 randomized controlled trial in idiopathic intracranial hypertension evaluating a novel therapeutic target. The results paper is currently under review with a journal and will hopefully be published later this year.

- q. **James Lind Alliance IIH Priority Setting Partnership (PSP)**. The IIH PSP was established in February 2017, in collaboration with the James Lind Alliance ([www.jla.nihr.ac.uk](http://www.jla.nihr.ac.uk)), to bring patients, carers and clinicians together to identify the shared research priorities for IIH in adults (16+). The steering group decided to focus on adults (16+) only, although two parents of children with IIH did attend the final workshop, and sought out questions that individuals would like answered by research in the following areas:

- The causes of IIH
- The diagnostic process
- Management of headaches, vision and weight
- Care provision for individuals with IIH



The final priority setting partnership workshop provided an opportunity for IIH Patients, their carers, friends and clinicians to have a voice in shaping the next generation of research advances. Working together throughout the day, we easily came to a consensus on the rankings for all 26 questions, with an agreed IIH top 10.

1. In the individual with IIH; what causes the disease, the symptoms and the progression of the disease?
2. What are the biological mechanisms of headache in IIH and why in some do headaches continue even after papilloedema has resolved?
3. Can new therapies for IIH be developed which are effective, safe, and tolerable and potentially help with weight loss as well as reducing brain pressure?
4. What is the biological explanation for the differences between rapid visual loss compared with gradual visual loss in IIH and how can this be predicted?
5. What are the best ways to monitor visual function?
6. Can IIH biomarkers (tests in body fluids for example urine, saliva, blood, or brain scans) help diagnosis, predict the risk and guide therapy decisions in IIH?
7. What are the hormonal causes for IIH and why is IIH primarily associated with female sex?
8. What medications are effective and safe to treat IIH headaches?
9. With regard to weight loss in IIH: how much is needed to treat IIH and how quickly does it work? What is the best, safest and most acceptable method to achieve this in the short and long term? Additionally, does the initial Body Mass Index (BMI) of the patient have an effect?
10. Which is the best type of intervention to treat IIH and when should surgery be performed?

During the year we launched an IIH Top 10 Poster and video. A paper titled 'What are the research priorities for idiopathic intracranial hypertension? A priority setting partnership between patients and healthcare professionals' was published in the British Medical Journal Open in March 2019 which you can read online at <https://bmjopen.bmj.com/content/9/3/e026573>

- r. **Investigating painkiller use in individuals with IIH survey:**  
This survey was developed by our Research Rep Krystal Hemmings. Thank you to everyone that took part, we hope to have the results written up and published to our website soon.
- s. **Barriers to weight loss and exercise survey:**  
Phase two of our 'Barriers to weight loss and exercise survey' was put out in 2017. This survey was developed by our Research Reps Krystal Hemmings in conjunction with Derby University and Amanda Denton. They used the data from the first pilot survey to come up with a more focused survey that was relevant to IIH patients. This second survey ran throughout May. We are busy collating the results which will be launched at our July 2019 Patient Conference.
- t. The Birmingham Research team continued to recruit for the new research trial, **IIH:Pressure** throughout the year. This trial aims to use a new method of pressure monitoring to measure the brain pressure continuously without lumbar puncture and to test if a new drug (Exanatide) can change brain pressure. It is a randomised double blind study so those who are accepted onto the trial will be put into one of two groups which will be decided at random. To date 10 patients have completed this trial. This is the first study of its kind and we are very excited to see the results.

### Raising the Profile of IIH

- u. Trustees/Team members attended the following conferences/meetings/lectures during the year:

**CSF Disorders Day.** Oct 2018. Birmingham.

**Headache Academy Event.** Oct 2018. London. (2 day event)

**Neurological Alliance members meeting and AGM.** November 2018. London.

**British Association for the Study of Headache Event.** Jan 2019. Hull. (2 day event)

**Rare Disease UK Westminster Reception.** Feb 2019. London.

**Focus Meeting with Dr Sinclair and Colleagues.** March 2019. Birmingham.

**NASA - On Frontiers edge: Taking medicine beyond earth.** June 2019. Birmingham.

**Focus Meeting with Dr Sinclair and Colleagues.** June 2019. Birmingham.

**Paediatric IIH Special Interest Group meeting.** June 2019. GOSH, London.

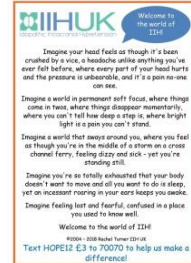
Attending other organisations' conferences/meetings provide an opportunity for Trustees to meet other attendees and develop friendships with other likeminded organisations enabling us to raise the profile of IIH.

New for this year are focus meetings with Dr Sinclair and colleagues at University Hospitals Birmingham. These meetings are to discuss upcoming ideas/trial protocol and new research which at this time remains confidential.

- v. **Brain Awareness Week (BAW)** is the global campaign to increase public awareness of the progress and benefits of brain research. This financial year it ran from 11<sup>th</sup> – 17<sup>th</sup> March. This year in support of Brain Awareness Week we focussed on a different

topic each day; Research, Education, Support, Helpful tips, Your opinion and Positivity.

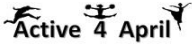
- w. **September Awareness Month.** Provides an opportunity for IIH Patients to get involved with raising awareness of IIH. Throughout the month of September we posted daily on our Fb Charity page and Twitter. From interesting facts to supporters fundraising, the month of September was once again a huge success due to the shares and retweets the posts received. We kicked the month off with Rachel Turners (founding member) poem which alone was viewed by 33,283 people! A great start to IIH Awareness Month. All in all the posts to our Fb Charity Page throughout September were shared 1058 times reaching 154,865 people. An amazing achievement!



- x. **Rare Disease Day** takes place on the last day of February each year. This year we produced profile pictures for everyone to use on social media and spent the day tweeting and posting on our fb page, all in all it was a perfect day spent spreading awareness and raising the profile of Idiopathic Intracranial Hypertension.
- y. As a Charity run solely by Volunteers we just had to celebrate **International Volunteers Day** on 5<sup>th</sup> December 2018. Twitter was the main platform for celebrating this day, raising the profile of IIH UK using the #InternationalVolunteersDay. We also celebrated **Volunteers Week** which took place 3<sup>rd</sup> – 9<sup>th</sup> June 2019.

**Fundraising** – We use the following platform to raise funds.

- z. 1. **Just Giving:** provides us with our main source of income from fundraising.  
2. **Membership fees:** email [membership@iih.org.uk](mailto:membership@iih.org.uk) to become a member.  
3. **IIH UK online awareness merchandise sales:** [www.iihukshop.moonfruit.com/](http://www.iihukshop.moonfruit.com/)  
4. **Easysearch:** [www.iihuk.easysearch.org.uk/](http://www.iihuk.easysearch.org.uk/)  
5. **Easyfundraising:** [www.easyfundraising.org.uk/causes/iihuk/](http://www.easyfundraising.org.uk/causes/iihuk/)  
6. **The Weather Lottery:**  
[www.theweatherlottery.com/charitiesHomepage.php?client=IIHUK](http://www.theweatherlottery.com/charitiesHomepage.php?client=IIHUK)  
7. **The Charities Aid Foundation:**  
[www.cafonline.org/system/charity-search-results](http://www.cafonline.org/system/charity-search-results)  
8. **Amazon Smile:** [www.smile.amazon.co.uk](http://www.smile.amazon.co.uk)  
9. **Facebook:** provides us with our main source of income from donations.  
[www.facebook.com/fund/IIHUKCharity/](http://www.facebook.com/fund/IIHUKCharity/)  
10. **PayPal Giving:** [www.paypal.com/uk/fundraiser/charity/49628](http://www.paypal.com/uk/fundraiser/charity/49628)  
11. **EBay for Charities:** [www.charity.ebay.co.uk/charity/IIH-UK/49628](http://www.charity.ebay.co.uk/charity/IIH-UK/49628)  
12. **Teespring:** [www.teespring.com/en-GB/stores/iih-uk](http://www.teespring.com/en-GB/stores/iih-uk)  
13. **Charity Choice:**  
[www.charitychoice.co.uk/idiopathic-intracranial-hypertension-united-kingdom-18148](http://www.charitychoice.co.uk/idiopathic-intracranial-hypertension-united-kingdom-18148)

- i.  **Active 4 April** We understand that not all those with IIH can take part in a Sky Dive or run a marathon, so Active 4 April allows IIH'ers to create their own bespoke daily activity target, within their own physical capabilities and fundraise for IIH UK at the same time!
  
- ii. **Shedtember:** Dr Gerry Jayamanne is a consultant Eye Surgeon specialising in neuro-ophthalmology and medical retina diseases working in Doncaster, South Yorkshire. He approached us to tell us all about Shedtember, a fundraising platform he had set up with his daughter to raise funds for charity. Since 2014 they have raised funds for Diabetes charities and he asked if we would like to be the next charity, of course we said yes so Shedtember has raised funds for IIH UK since September 2018. Keep an eye on our social media sites for updates.

30<sup>th</sup> June 2019

*Michelle Williamson*

Michelle Williamson. Chair





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## Receipts and payments accounts

For the period from	01-Jul-18	To	30-Jun-19
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### Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
<b>A1 Receipts</b>					
Donations	3,473	-	-	3,473	828
Fundraising	17,871	-	-	17,871	21,837
Membership fees	2,055	-	-	2,055	1,551
Conference Tickets	315	-	-	315	-
Merchandise	2,012	-	-	2,012	2,436
Bank Interest	24	-	-	24	11
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>25,750</b>	<b>-</b>	<b>-</b>	<b>25,750</b>	<b>26,663</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>25,750</b>	<b>-</b>	<b>-</b>	<b>25,750</b>	<b>26,663</b>
<b>A3 Payments</b>					
Governance	-	-	-	-	-
IT	1,799	-	-	1,799	1,898
Merchandise (Stock Purchase)	343	-	-	343	341
Paypal Fees	129	-	-	129	113
Postage & Packaging	635	-	-	635	521
Printing & Stationery	83	-	-	83	268
Membership Subscriptions	835	-	-	835	792
Justgiving	154	-	-	154	1,250
AGM	3,517	-	-	3,517	4,886
CSF Symposium	417	-	-	417	2,261
Expenses - Meetings	-	-	-	-	355
Storage (refunded)	-	-	-	-	13
Surveys	712	-	-	712	-
Education	384	-	-	384	2,700
Research Grants	6,000	-	-	6,000	-
Focus Meetings	514	-	-	514	-
Life Registry	5,000	-	-	5,000	5,000
James Lind Alliance	26	-	-	26	20,455
Publicity and Profile	1,913	-	-	1,913	356
	-	-	-	-	-
<b>Sub total</b>	<b>22,461</b>	<b>-</b>	<b>-</b>	<b>22,461</b>	<b>41,184</b>
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>22,461</b>	<b>-</b>	<b>-</b>	<b>22,461</b>	<b>41,184</b>
<b>Net of receipts/(payments)</b>	<b>3,289</b>	<b>-</b>	<b>-</b>	<b>3,289</b>	<b>- 14,521</b>
<b>A5 Transfers between funds</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>A6 Cash funds last year end</b>	<b>28,623</b>	<b>-</b>	<b>-</b>	<b>28,623</b>	
<b>Cash funds this year end</b>	<b>31,912</b>	<b>-</b>	<b>-</b>	<b>31,912</b>	

## Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B1 Cash funds</b>	Bank Accounts	31,575	-	-
	Paypal Account	256	-	-
	Cash	81	-	-
	<b>Total cash funds</b>	<b>31,912</b>	<b>-</b>	<b>-</b>
(agree balances with receipts and payments account(s))				

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B2 Other monetary assets</b>	Stock	1,500	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
<b>B3 Investment assets</b>			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
<b>B4 Assets retained for the charity's own use</b>	Computer Equipment	Unrestricted funds	-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-

Categories	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
<b>B5 Liabilities</b>			-	
			-	
			-	
			-	
			-	

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name	Date of approval
E.S.C.	E. AYLOTT	15/03/20



# Independent examiner's report on the accounts

## Section A

## Independent Examiner's Report

<b>Report to the trustees/ members of</b>	IIH UK		
<b>On accounts for the year ended</b>	30 June 2019	<b>Charity no (if any)</b>	1143522
	<b>Set out on pages</b> 1 and 2 <small>(remember to include the page numbers of additional sheets)</small>		

### Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 (the Charities Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the Charities Act,
- to follow the procedures laid down in the general Directions given by the Charity Commission (under section 145(5)(b) of the Charities Act, and
- to state whether particular matters have come to my attention.

### Basis of independent examiner's statement

My examination was carried out in accordance with general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the statement below.

### Independent examiner's statement

In connection with my examination, no matter has come to my attention (other than that disclosed below \*)

1. which gives me reasonable cause to believe that in, any material respect, the requirements:
  - to keep accounting records in accordance with section 130 of the Charities Act; and
  - to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Charities Act have not been met; or
2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

\* Please delete the words in the brackets if they do not apply.

**Signed:**  **Date:** 27<sup>th</sup> April 2020

**Name:** Rianne Downey

**Relevant professional qualification(s) or body (if any):** Team manager at Lloyds Banking Group regulated by FCA

**Address:** 178A Alma Road, Charminster, Dorset, BH9 1AJ

**Section B**

**Disclosure**

Only complete if the examiner needs to highlight material problems.

**Give here brief details of any items that the examiner wishes to disclose.**

[Empty disclosure box]