



# Crohn's in Childhood Research Association Report & Accounts

for the year ended 31 Dec 2017

registered charity numbers: England & Wales 278212 Scotland SC040700 REGISTERED CHARITY NUMBER: England & Wales 278212 Scotland: SC040700

Report of the Trustees and Unaudited Financial Statements for the Year Ended 31 December 2017 for

> CROHN'S IN CHILDHOOD RESEARCH ASSOCIATION

> > Tudor John LLP Nightingale House 46-48 East Street Epsom Surrey KT17 1HQ

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# Letter from the Chairman for the year ended 31 December 2017

Dear friends and supporters

It is my pleasure to present the Annual Report and Accounts for the Crohn's in Childhood Research Association (CICRA) for the year ending 31st December 2017.

Having settled into our new office in Sutton at the end of 2016, we welcomed Nick Posford to our team in June 2017, as our CEO. With an ever increasing number of children and young people being diagnosed with Crohn's disease and Ulcerative colitis, collectively known as Inflammatory Bowel Disease (IBD), the youngest now being diagnosed at a few months, it is imperative that we increase our research and support for these families and try to ensure that the children with this serious condition are able to be treated by a specialist. Since its formation, the CICRA 3 year Fellowship scheme, to offer young qualified doctors the chance to specialise in paediatric gastroenterology, has been a great success and over 25 have gone on to become consultants in this specialist area. With our CEO's input we hope to increase this to keep up with the numbers of children being diagnosed. In addition we need to increase funding of research which, although researchers have yet to find the cause, the knowledge gained has helped enormously with better treatments and management of this very complex condition. Until the cause is discovered we also need to increase our support for the children and their families. This our CEO is doing by concentrating in 2018 on updating our website and literature and holding more information days for parents and children.

In 2017 Family information days were held in Edinburgh, Cobham and Birmingham enabling over 400 children, young people and their families, to learn, more about their condition and current research in an informal setting. Alongside small discussion groups for parents there were separate sessions to suit the various age ranges of children and young adults. This gave them the opportunity to ask questions of the professionals at their own pace. In Birmingham we included a special session for parents of the very young (under 6 years). Most importantly it also gives both parents, children and young people the opportunity to meet with others who are going through a similar ordeal. We are extremely grateful to the specialists and health professionals treating young people with IBD for attending these days on a voluntary basis – their help is invaluable.

We are extremely grateful to our medical advisors and external referees for giving their expert advice and guidance in the choice of funding. As a small charity with limited income it is essential that we fund good quality research, relevant to IBD, and in particular to children and young people. CICRA makes commitment to 1, 2 and 3 year research Fellowships/Studentships/Projects which are reviewed annually, with second and subsequent years only made upon receipt of satisfactory progress reports. Consequently, it is not considered appropriate to make provision for these commitments in the financial statement but take them into account in our reserving policy. A list of these commitments can be seen at the end of the accounts.

In 2018 we will continue to raise awareness of this complex and under-funded condition and raise funds, wherever possible, to support our Research and Parent Support Programmes and give hope of a healthier future to children affected by Inflammatory Bowel Disease.

Best wishes

Mrs Margaret Lee, MBE

# Report of the Trustees for the year ended 31 December 2017

The trustees present their report with the financial statements of the charity for the year ended 31 December 2017. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015).

The Trustees are confident that during 2017 the objectives of the charity were met by continuing to fund research which increases knowledge and understanding of Crohn's disease and Ulcerative colitis, otherwise known as Inflammatory Bowel Disease (IBD). Whilst seeking the cause and cure the charity continued to arrange support and information for parents and children through regional meetings in the UK giving all ages the opportunity to hear from members of the medical profession in a relaxed setting. Children and young people can ask questions of the medics in age related discussion groups while the parents join rotating groups covering various aspects of IBD. The charity also continued to raise awareness amongst the general public of the devastating effect this condition continues to have on young lives.

# **OBJECTIVES AND ACTIVITIES**

## **Objectives and aims**

The principal objects for which the Society is established are for the relief of persons suffering from, and to promote and advance public education and research into, Crohn's Disease, Ulcerative Colitis and related disorders.

# Public benefit

The trustees have referred to the Charity Commission's general guidance on Public Benefit when reviewing their aims and objectives.

#### **Grantmaking Policy**

To meet one of its primary objectives, the Charity invests in medical research into the causes and treatment of Inflammatory Bowel Disease (Crohn's Disease and Ulcerative Colitis), particularly as it affects children and young adults. Applications for research funding are invited from relevant medical and scientific institutions and are then subjected to a rigorous peer review process, involving independent specialist referees and the CICRA Awards Advisory Panel. Typically the research awards fall within four categories: 3-year Research Training Fellowships, 3-year PhD Studentships, 1-2 year research projects and grants for specific statistical projects related to IBD in childhood. Bursary grants to help with the costs of UK based health professionals and students in training (doctors, nurses and final year medical students) involved in IBD research, attending scientific/medical meetings, are awarded at the discretion of the Trustees.

# ACHIEVEMENT AND PERFORMANCE

#### Governance, Management & Human Resources

At the Annual General Meeting held in Cobham, Surrey on 25th June 2017, two Trustees, Margaret Lee and Dr Deborah O'Neil, stood down and were re-elected for a further 3 year term. Mrs Sally McNaught was co-opted to the Trustee Board in November 2017. During the first half of the year under review the CICRA Chair, who works from the office, undertook the oversight of the small office team with Trustee/Treasurer, Simon Coleman responsible for financial affairs. At the end of June Nick Posford was appointed as CEO and took over the day to day running of the office with the Chair continuing for the time being to carry out the day to day accounting and research responsibilities. Simon Coleman continues to have oversight of financial affairs. Some Trustees undertake additional activities in connection with specific areas of work such as the CICRA IBD Family Information days, Public Relations, and the website. During November the Trustees, in conjunction with the CEO, refreshed the charity's strategic medium and long term plans.

# Report of the Trustees for the year ended 31 December 2017

## ACHIEVEMENT AND PERFORMANCE

#### Research

The principal objective of the charity is to raise funds to maintain and expand a research programme to help bring about better treatments and quality of life for children and young adults with Inflammatory Bowel Disease. Also to discover, through good basic science, the cause and an eventual cure. Since its foundation in 1978 CICRA has funded 25 Training Fellowships, 23 PhD Studentships 57 Research Projects and set up the first Paediatric Gastroenterology Laboratory in the UK.

During the period under review CICRA continued the funding of the following research programme:

# Fellowships

Dr Marco Gasparetto (2016 - 2019) a 3 year Fellowship under the direction of Dr Rob Heuschkel and Dr Matt Zilbauer, Addenbrookes Hospital, Cambridge

Dr Tracy Coelho (2013 - 2017) A 3 year Fellowship under the direction of Dr Mark Beattie and Professor Sarah Ennis, Southampton General Hospital - extended for one year.

Dr Protima Amon.(2015 - 2018) a 3 year Fellowship under the direction of Professor Ian Sanderson, Royal London Hospital.

# PhD Studentships

Daniel Brice (2016 - 2019) a 3 year PhD studentship under the direction of Dr Mairi McLean, Aberdeen. Rai Shashank (2016 - 2019) A 3 year PhD studentship under the direction of Professor Tom Wileman

#### **Research Projects**

A 2 year project grant to Professor Deborah Christie, UCLH.(2016 - 2018) Title: Mindfulness Based Stress Management Renewal of a regular consumables grant to support the work undertaken in the Paediatric Gastroenterology Laboratory at St Bartholomew's & The Royal London Hospital. Eight bursary grants

# One new grant was awarded in 2017:

A 3 year PhD Studentship awarded to Dr Matt Zilbauer, Addenbrookes Hospital, Cambridge. Title: Validation and use of Human intestinal epithelial organoids as models to study paediatric IBD pathogenesis

To ensure transparency and appropriate application of CICRA funds, the Trustees follow a strict Peer Review system using external referees from the UK and other countries, and their own appointed Awards Advisory Panel (AAP), all working in an honorary capacity. Based upon the recommendations of the Awards Advisory Panel and AAP Chairman, the Trustees make the final decision and award the grants. This Peer Review applies to all applications for financial support with the exception of the very minor grants. Annual written reports are required for all awards and are reviewed by the Trustees and Medical Advisors. CICRA encourages the publication of both positive and negative research results.

The Trustees retain flexibility as to the timing and scale of grant making, and as 2018 was to be a year of change during the charity's 40th Anniversary, producing a new website, updating of all literature etc. a decision was taken not to advertise grants during 2017 but to continue with the support side and increase the regional meetings to 5 during the year.

Following the 5 year audit by the Association of Medical Research Charities CICRA received the AMRC Certificate of Good Practice which enables the charity to use the AMRC 2015 audit logo to show that our process for granting awards is of a high standard.

# Report of the Trustees for the year ended 31 December 2017

## ACHIEVEMENT AND PERFORMANCE

#### Information and Support

CICRA works with Regional Paediatric Centres, specialist units and also district general hospitals across the UK who treat children with IBD and who distribute 'Parent Packs' to the parents of newly diagnosed children.

CICRA works closely with Paediatric IBD specialist nurses at various paediatric gastroenterology units around the country, their regular contact with the young patients and families is vital and much appreciated.

CICRA 'Can't Wait' cards are available for children to help them explain their condition when in urgent need of a toilet.

Three very successful regional IBD Information Days were held in 2017 in Edinburgh, Cobham and Birmingham giving parents and youngsters affected by IBD the opportunity to meet with others, hear what CICRA is doing to help and most importantly to learn more about the condition from the medical professionals. All three meetings were well attended and the feedback proved how much these meetings are appreciated by families trying to cope with a very complex illness.

- Thank you for everything you do. Being thrown into a dark pit when first diagnosed was overwhelming and so knowing CICRA is there is an amazing asset!
- Excellent work. It is a privilege to come to your information day. You have made Saara so happy. What price is that worth?
- I'm so pleased we made it, as Elliott had had a very rough infusion on the Friday before. It was really informative and a big eye opener to how other families cope with this hideous disease! Elliott was made to feel normal, mixing with his age group again! We came away with new friends, t-shirts and feeling humbled by the amazing talks from Katy, Harry and Natalia. Thank you for all you do.
- Thank you very much for an informative, interesting and supportive day. Both my daughter and I came away feeling more positive about managing this frustrating condition. An amazing charity.
- A wonderful day! Thanks to all at CICRA and your esteemed medical professional guests who provided advice and support today much appreciated.
- Brilliant day, better than I could have imagined.
- Thank you for all the work that goes into putting these days on and to everyone that gave their time.
- o Thank you for a very informative and interesting day.
- Brilliant, much better than I could have imagined
- The meeting was excellent. It gave me and my family so much. The literature we have is so informative. The lunch was excellent, we felt we were special!
- We really value the information days you put on and always get such a lot out of the meeting. Thank you for your continued support.
- o Thank you for the excellent work you do to try and improve the life of children with Crohn's and Colitis
- Keep up the good work CICRA!
- o Many thanks to everyone involved in organizing and presenting. The day was indescribably helpful for us.
- o Thank you for your tireless work, it is invaluable and appreciated.

## Report of the Trustees for the year ended 31 December 2017

#### ACHIEVEMENT AND PERFORMANCE

#### Increasing awareness

In the period under review the Chair, other Trustees and the CEO took up invitations to participate in several medical meetings, which provide networking opportunities with health professionals and healthcare policymakers. Also to learn about the latest developments in treatments and possible causes of Inflammatory Bowel Disease, especially in the young. Trustees are very actively involved in these events and in 'manning' the CICRA information stand so Trustee's expenses, as shown in the accounts, reflect this extra 'hands on' often very full day activity. It should be noted that Trustees do not receive any remuneration and only claim travel and budget style overnight accommodation expenses, in line with the charity's expense guidelines.

The CICRA newsletter compiled and edited by trustees and the CEO with distribution carried out by CICRA office volunteers.is one of the main vehicles for publicising the effect that Inflammatory Bowel Disease can have on children and for the public to become more aware of their needs.

CICRA continues to publish easy to understand information booklets for parents, teenagers going through transition to adult care, schools etc

The CICRA website, twitter and facebook accounts all have an increased following and a new interactive website will be launched in 2018.

#### Membership

CICRA does not charge a fixed membership fee as the Trustees continue to believe that all parents of children affected by Crohn's disease and Ulcerative colitis should have access to CICRA literature and information on their child's condition, regardless of their financial position, but they invite members to make a donation as and when they wish, or are in a position to do so. All literature is issued free of charge. Membership is open to patients, parents, their families and friends, medical professionals and anyone interested in furthering the understanding of, and research into, inflammatory bowel disease in children and young adults.

#### CICRA members fundraising

CICRA members continue to raise much needed funds to support the Research and Parent Information programmes.

#### **CICRA Volunteers**

Both nationally and at Head Office CICRA is fortunate to have the services of a number of volunteers. Various activities carried out from the CICRA office give volunteers the opportunity to help on a regular or ad-hoc basis.

Nationally volunteers are active by organising their own fund raising events. Individuals who take part in sponsored events are a very popular way of raising funds for CICRA.

#### Links with other organisations

CICRA is a member of the Association of Medical Research Charities (AMRC), the National Institute for Health Research (NIHR), the National Council for Voluntary Organizations (NCVO) and the Fundraising Regulator.

CICRA continues to work with BSPGHAN (British Society of Paediatric Gastroenterology Hepatology and Nutrition), the BSPGHAN Public Patient Participation (PPP) representative and the five associated gastro charities,

CICRA exchanges newsletters and information with the many national and international organizations dealing with Inflammatory Bowel Disease and responds to enquiries from overseas, sign posting also to sister organisations as appropriate.

# FINANCIAL REVIEW

# Financial position

As of end December 2017 the accumulated funds stood at  $\pounds 626,717$ , of which  $\pounds 624,717$  represented unrestricted funds. Research commitments over the next three years (2018 - 2020) and detailed in Note 17 to the accounts amount to  $\pounds 317,101$ . In the year under review donations and legacies accounted for  $\pounds 298,969$ , other activities  $\pounds 25,747$  and investment income  $\pounds 6,684$ 

Of the £626,717 accumulated funds as at 31st December 2017, £165,010 is in a large Charity Multi- Asset Fund with £349,434 in Fixed Deposit Cash Funds.. Other surplus funds are in accounts with CAF, COIF and NatWest. The portfolio was rebalanced following the annual review of the "reserves" during 2017.

# Report of the Trustees for the year ended 31 December 2017

#### FINANCIAL REVIEW

#### Investment policy

The charity's constitution authorises the trustees to make and hold investments using the funds of the charity. There are no restrictions on the trustees' power to invest, although the trustees take appropriate advice before making any investments that carry more than a low degree of risk.

#### **Reserves policy**

CICRA has no significant secure income, relying almost totally on voluntary contributions, donations, grants and fund-raising activities. In consequence the trustees believe that it is essential to have sufficient funds to ensure continuity in the event of a temporary reduction in income. The trustees have agreed a policy to hold reserves on deposit equal to a minimum of six months operational expenses. At the end of 2017 we estimate these to be £140,000. While total unrestricted funds stood at £624,717, the charity has currently committed £317,101 of those funds to Peer Reviewed Research Grants with payments due to the year 2020.

#### OUTLOOK

The CICRA Trustees regularly review the opportunities for the charity and the challenges faced and will, continue to do so. Throughout the past recessionary years we have been well supported by our loyal members and families with their regular donations and fundraising and have benefited from a few major events organised on our behalf. As we move into another year the Trustees are aware that there may be a time of uncertainty, dependent on Brexit and have included this on their risk management list. Prudent management by the Trustees of CICRA's accumulated funds supports our daily work and research awards going forward as the need arises.

Remaining mindful of CICRA's raison d'etre in an age when the number of children and young people diagnosed with Crohn's and colitis (IBD) continues to increase, both in the UK and across the world for which neither cause nor cure are yet known, we need to strive to support the families and young people. Many of us involved have seen good progress both in the understanding of these difficult to manage long term conditions and the development of new treatments, but we are also conscious of the possible side effects of medication on young children. With a dramatic rise in the Very Early Onset IBD being diagnosed (VEOIBD) we need to redouble our efforts bearing in mind the impact of these lifelong debilitating diseases on the families. In 2018 CICRA will continue to work with an outside company to review all means of communication with its members and supporters and particularly with giving information digitally. A survey will be made 2018 asking for the views of young people and their parents on what they want by way of information and how they want to receive it. A new website and new set of information leaflets will be launched during 2018.

The use of fundraising sites by our members and supporters have proved to be beneficial and we continue to encourage the use of these and the use of social networking links. We are grateful for the financial support, both regular and ad hoc, we receive from our members, their families and friends, but also the support received from charitable trusts, companies and the general public sympathetic to our cause. We look forward to this continuing in future years as the demands for our services become even greater.

As we have highlighted previously there remains a real need for more novel paediatric Crohns and colitis research into the elusive cause and cure so the highly important role of charities like the Crohn's in Childhood Research Association (CICRA) will be even more necessary as government budgets come under further strain. While CICRA will continue to fund good quality research we need also to encourage the National Institute for Health Research and others to become more involved too as the high cost of research often needs a collaborative financial input. It may be too that like other charities there will be opportunities to speed up the search for a cure by helping to fund part of the cost of prospective new treatments in the years ahead.

Involving the IBD community and the "patient voice" (especially the children, young people and families) becomes even more important in all aspects of healthcare, so reaching out to those less able to be in touch - and for CICRA to be more widely known and accessible - is ever more important especially for those recently diagnosed.

# Report of the Trustees for the year ended 31 December 2017

# STRUCTURE, GOVERNANCE AND MANAGEMENT

#### **Governing document**

The charity is controlled by its governing document, a deed of trust, and constitutes an unincorporated charity.

The Crohn's in Childhood Research Association (CICRA), an unincorporated charitable association, is registered in England & Wales under Charity Number 278212 and in Scotland under Charity Number SC040700. CICRA is governed by an amended constitution adopted at the Annual General Meeting on 14 October 1989.

#### Recruitment and appointment of new trustees

The board of trustees shall be not less than six and not more than twelve members of the Association elected at the Annual General Meeting. The trustees have the power to co-opt members to fill a casual vacancy or as an addition to the existing trustees. One third of the members of the Board shall retire each year in order of seniority but may be eligible for re-election

The Trustees meet on average every six weeks and are responsible for determining policies, the budget and overall management of the charity. The small staff team and office volunteers are responsible for undertaking the day-to-day running of the Association under the guidance of the CEO, carrying through the policies, budget and day to day administration as determined by the Board of Trustees. As well as representing the charity at medical meetings some Trustees continue to actively assist in the office and in the organisation of events.

#### Induction and training of new trustees

New Trustees co-opted during the year, or elected at the AGM, are given an induction course by the Chair outlining the objects as set out in the Constitution, the roles of the other Trustees, the present financial standing of the charity and its commitments. Trustees are asked to take on or share responsibility for overseeing a certain aspect of the charity i.e. research, finance, communication technologies, outreach and support, etc.

#### **Risk management**

The trustees continue to regularly examine the strategic, business and operational risks to which the charity is exposed, and confirm that they have put in place systems to mitigate those risks as far as they are able to do.

#### **REFERENCE AND ADMINISTRATIVE DETAILS**

**Registered Charity number** England & Wales – 278212 Scotland – SC040700

Principal address Pat Shaw House 13-19 Ventnor Road Sutton Surrey SM2 6AQ

# Report of the Trustees for the year ended 31 December 2017

# **REFERENCE AND ADMINISTRATIVE DETAILS**

#### Trustees

Mrs M Lee MBE Simon Coleman Neil Gooding Graham Lee Paul Cooper Dr Deborah O'Neill Rod Mitchell Dr Philip Smith Mrs Sally McNaught

- co-opted November 2017

# CEO

Nick Posford

# Independent examiner

Tudor John LLP Nightingale House 46-48 East Street Epsom Surrey KT17 1HQ

# Hon. Awards Advisory Panel

Professor Ian Sanderson (Chairman) Professor Sarah Ennis Dr Jenny Epstein Dr Rob Heuschkel Dr Huw Jenkins Professor Thomas MacDonald Dr Deborah O'Neil Dr Sue Protheroe Professor Jack Satsangi Dr Nikhil Thapar

# Hon. Clinical Director

Dr Richard Hansen

# Report of the Trustees for the year ended 31 December 2017

## STATEMENT OF TRUSTEES RESPONSIBILITIES

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

The law applicable to charities in England and Wales, the Charities Act 2011, Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed 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 incoming resources and application of resources, including the income and expenditure, of the charity for that period. In preparing those financial statements, the trustees are required to

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. 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.

Approved by order of the board of trustees on ...... and signed on its behalf by:

Mrs Margaret Lee - Trustee

#### Independent Examiner's Report to the Trustees of Crohn's in Childhood Research Association

## Independent examiner's report to the trustees of Crohn's in Childhood Research Association

I report to the charity trustees on my examination of the accounts of the Crohn's in Childhood Research Association (the Trust) for the year ended 31 December 2017.

#### **Responsibilities and basis of report**

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act') and the terms of the Charities and Trustee Investment (Scotland) Act 2005. The charity's trustees consider that an audit is not required for this year (under Section 144(2) of the Charities Act 2011 (the 2011 Act)) and that the audit requirement of Regulation 10(1)(a) to (c) of the 2006 Accounts Regulations does not apply and that an independent examination is required. It is my responsibility to examine the accounts as required under section 44(1)(c) of the Act and to state whether particular matters have come to my attention.

I report in respect of my examination of the Trust's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under section 145(5)(b) of the Act and in accordance with Regulation 11 of the 2006 Accounts (Scotland) Regulations..

#### Independent examiner's statement

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a registered member of ICAEW which is one of the listed bodies

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

- 1. accounting records were not kept in respect of the Trust as required by section 130 of the Act and Section 44(1)(a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations (Scotland); or
- 2. the accounts do not accord with those records and in Regulation 8 of the 2006 Accounts Regulations (Scotland); or
- 3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 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.

I confirm that there are no other matters to which your attention should be drawn to enable a proper understanding of the accounts to be reached.

Hazel Day BSc FCA DChA ICAEW Tudor John LLP Nightingale House 46-48 East Street Epsom Surrey KT17 1HQ

Date: .....

# Statement of Financial Activities for the year ended 31 December 2017

	Not	Unrestricted funds £	Restricted funds £	2017 Total funds £	2016 Total funds £
	es	L	L	L	L
<b>INCOME AND ENDOWMENTS FROM</b> Donations and legacies		252,248	46,721	298,969	279,864
Other trading activities Investment income	2 3	25,747 <u>6,684</u>	-	25,747 <u>6,684</u>	25,086 10,786
Total		284,679	46,721	331,400	315,736
<b>EXPENDITURE ON</b> Raising funds	4	89,194	-	89,194	62,699
Charitable activities Research Support and information programme	5	254,024 77,206	18,250 28,571	272,274 105,777	320,448 82,832
Other		6,187		6,187	30,114
Total		426,611	46,821	473,432	496,093
Net gains/(losses) on investments		6,457	<u> </u>	6,457	16,641
NET INCOME/(EXPENDITURE)		(135,475)	(100)	(135,575)	(163,716)
<b>RECONCILIATION OF FUNDS</b>					
Total funds brought forward		760,192	2,100	762,292	926,008
TOTAL FUNDS CARRIED FORWARD		624,717	2,000	626,717	762,292

# **CONTINUING OPERATIONS**

All income and expenditure has arisen from continuing activities.

# Balance Sheet At 31 December 2017

		Unrestricted funds	Restricted funds	2017 Total funds	2016 Total funds
	Not	£	£	£	£
	es				
FIXED ASSETS		5.016		5.016	( 702
Tangible assets	11 12	5,216	-	5,216	6,783
Investments	12	514,444		514,444	501,820
		519,660	-	519,660	508,603
CURRENT ASSETS					
Stocks	13	1,313	-	1,313	1,817
Debtors	14	51,113	-	51,113	58,346
Cash at bank and in hand		146,644	2,000	148,644	338,373
		199,070	2,000	201,070	398,536
CREDITORS					
Amounts falling due within one year	15	(94,013)	-	(94,013)	(144,847)
NET CURRENT ASSETS		105,057	2,000	107,057	253,689
TOTAL ASSETS LESS CURRENT LIABILITIES		624,717	2,000	626,717	762,292
		(24.717	2,000	()( 717	7(2,202
NET ASSETS		624,717	2,000	626,717	762,292
FUNDS	16				
Unrestricted funds				624,717	760,192
Restricted funds				2,000	2,100
TOTAL FUNDS				626,717	762,292
				020,117	,02,272

The notes form part of these financial statements

# Balance Sheet - continued At 31 December 2017

The financial statements were approved by the Board of Trustees on ...... and were signed on its behalf by:

Mrs Margret Lee - Trustee

S Coleman -Trustee

The notes form part of these financial statements

#### Notes to the Financial Statements for the year ended 31 December 2017

#### 1. ACCOUNTING POLICIES

#### BASIS OF PREPARING THE FINANCIAL STATEMENTS

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention with the exception of investments which are included at market value, as modified by the revaluation of certain assets.

# FINANCIAL REPORTING STANDARD 102 - REDUCED DISCLOSURE EXEMPTIONS

The charity has taken advantage of the following disclosure exemption in preparing these financial statements, as permitted by FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland':

- the requirements of Section 7 Statement of Cash Flows.

#### INCOME

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

#### EXPENDITURE

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

# TANGIBLE FIXED ASSETS

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Computer equipment	33% straight line
Furniture and equipment	20 - 33% straight line

# STOCKS

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

#### TAXATION

The charity is exempt from tax on its charitable activities.

# FUND ACCOUNTING

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

## Notes to the Financial Statements - continued for the year ended 31 December 2017

#### 1. ACCOUNTING POLICIES - continued

### PENSION COSTS AND OTHER POST-RETIREMENT BENEFITS

The charity operates a defined contribution pension scheme. Contributions payable to the charity's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

#### **INVESTMENTS**

Investments are shown in Balance Sheet at the year end market value. Any unrealised gains or losses on revaluation are accounted for in the period in which they arise. Realised and unrealised gains and losses are combined in the appropriate section of the SOFA.

# 2. OTHER TRADING ACTIVITIES

	Year Ended 31.12.17 £	Year Ended 31.12.16 £
Merchandise (incl xmas)	9,355	8,979
Christmas/summer draw	9,106	8,628
200 Club	6,286	5,979
Groups		1,500
	25,747	25,086

# 3. INVESTMENT INCOME

	Year Ended	Year Ended
	31.12.17	31.12.16
	£	£
Schroder Investment interest	6,167	10,572
Deposit account interest	1	1
COIF Deposit	516	213
	6,684	10,786

# Notes to the Financial Statements - continued for the year ended 31 December 2017

# 4. RAISING FUNDS

# **Raising donations and legacies**

	Year Ended	Year Ended
	31.12.17	31.12.16
	£	£
Staff costs	35,349	11,411
Trustees' expenses	746	906
Postage and stationery	3,471	4,267
Office costs (40%)	18,025	12,641
Marketing and advertising	585	1,802
Legal and bank costs	2,529	-
Lotteries	4,804	5,099
Other fundraising expenses	11,750	18,259
Staff expenses	5,683	1,268
Outsourcing	2,748	
	85,690	55,653

# 5. CHARITABLE ACTIVITIES COSTS

		Grant funding	
	Direct costs	of activities	Totals
	(See note 6)		
	£	£	£
Research	17,778	254,496	272,274
Support and information programme	105,777	<u> </u>	105,777
	123,555	254,496	378,051

#### Notes to the Financial Statements - continued for the year ended 31 December 2017

# 6. DIRECT COSTS OF CHARITABLE ACTIVITIES

	Year Ended	Year Ended
	31.12.17	31.12.16
	£	£
Staff costs	34,060	26,582
Trustees' expenses	6,004	5,838
Postage and stationery	9,187	7,924
Office costs (60%)	27,037	18,962
Marketing and advertising	15,397	7,855
Family meetings	22,388	23,240
Legal fees	57	-
Outsourcing	4,122	-
Staff expenses	3,735	713
Depreciation	1,568	633
	123,555	91,747

# 7. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2017 nor for the period ended 31 December 2016.

# TRUSTEES' EXPENSES

	Year Ended	Year Ended
	31.12.17	31.12.16
	£	£
Trustees' expenses	6,750	6,744

No Trustee received any remuneration for their services as a Trustee. A total of  $\pounds 6,750$  (2016:  $\pounds 6,744$ ) was reimbursed to 4 Trustees (2016: 3) of which  $\pounds 622$  (2016:  $\pounds 630$ ) was for governance purposes. Four Trustees carry out tasks in furtherance of the charity's objectives on an expenses only basis and these costs have been allocated as appropriate to Research, Support & Information and Cost of Generating funds.

# 8. STAFF COSTS

The average monthly number of employees during the year was as follows:

Year Ended	Year Ended
31.12.17	31.12.16
3	2

No employees received emoluments in excess of £60,000.

# Notes to the Financial Statements - continued for the year ended 31 December 2017

# 9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	247,164	32,700	279,864
Other trading activities	25,086	-	25,086
Investment income	10,786		10,786
Total	283,036	32,700	315,736
EXPENDITURE ON			
Raising funds Charitable activities	53,249	9,450	62,699
Research	293,748	26,700	320,448
Support and information programme	82,832		82,832
Other	30,114	<u> </u>	30,114
Total	459,943	36,150	496,093
Net gains/(losses) on investments	16,641		16,641
NET INCOME/(EXPENDITURE)	(160,266)	(3,450)	(163,716)
<b>RECONCILIATION OF FUNDS</b>			
Total funds brought forward	920,458	5,550	926,008
TOTAL FUNDS CARRIED FORWARD	760,192	2,100	762,292

# Notes to the Financial Statements - continued for the year ended 31 December 2017

# 10. GRANTS FOR RESEARCH

The charge for the year is made up as follows:

	2017	2016
	£	£
Creditor brought forward	(75,510)	(148,777)
Payments during year	253,331	363,064
Creditor carried forward	66,055	75,510
	243,876	289,797

Included in the above are the following grants greater than £1,000:

	2017
	£
Barts & The Royal London Hospital	80,561
Cambridge University	68,306
Edinburgh Napier University	18,144
East Anglia University	18,593
University College London	24,942
Aberdeen	32,054
Other	1,276
	243,876

#### 11. TANGIBLE FIXED ASSETS

TANGIBLE FIXED ASSETS			
	Improvements to property £	Fixtures and fittings £	Totals £
COST			
At 1 January 2017 and 31 December 2017	3,850	48,149	51,999
DEPRECIATION			
At 1 January 2017	257	44,959	45,216
Charge for year	770	797	1,567
At 31 December 2017	1,027	45,756	46,783
NET BOOK VALUE			
At 31 December 2017	2,823	2,393	5,216
At 31 December 2016	3,593	3,190	6,783

## Notes to the Financial Statements - continued for the year ended 31 December 2017

# 12. FIXED ASSET INVESTMENTS

Shares	Year Ended 31.12.17 £ 165,010	Year Ended 31.12.16 £ 152,938
Other	349,434	348,882
	514,444	501,820
Additional information as follows:		
		Multi Asset Investment £
MARKET VALUE		1.50.000
At 1 January 2017 Additions		152,938 5,615
Revaluations		6,457
At 31 December 2017		165,010
NET BOOK VALUE		
At 31 December 2017		165,010
At 31 December 2016		152,938
There were no investment assets outside the UK.		
Investments (neither listed nor unlisted) were as follows:		
	Year Ended 31 12 17	Year Ended 31 12 16

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	31.12.17	31.12.16
	£	£
Schroders Fixed Deposit account	349,434	348,882

Initial investment cost for Schroders Multi Asset Account is £300,000 (2016: £300,000).

Initial investment cost for Schroders Fixed Deposit Account is £500,030 (2016: £500,030).

## 13. STOCKS

	2017	2016
	£	£
Stocks	1,313	1,817

# Notes to the Financial Statements - continued for the year ended 31 December 2017

# 14. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	Other debtors	2017 £ 51,113	2016 £ 58,346
15.	CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR		
	Trade creditors Taxation and social security Other creditors	2017 £ 21,506 2,121 70,386	2016 £ 56,079 605 88,163
		94,013	144,847

# 16. MOVEMENT IN FUNDS

		Net movement	Transfers	
	At 1.1.17	in funds	between funds	At 31.12.17
	£	£	£	£
Unrestricted funds				
General fund	175,271	119,021	18,088	312,380
Designated fund	584,921	(254,496)	(18,088)	312,337
	760,192	(135,475)	-	624,717
Restricted funds				
Support meetings	2,100	(2,100)	-	-
Research grants	<u> </u>	2,000	<u> </u>	2,000
	2,100	(100)	-	2,000
TOTAL FUNDS	762,292	(135,575)		626,717

# Notes to the Financial Statements - continued for the year ended 31 December 2017

# 16. MOVEMENT IN FUNDS - continued

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Gains and losses £	Movement in funds £
Unrestricted funds				
General fund	284,679	(172,115)	6,457	119,021
Designated fund	<u> </u>	(254,496)		<u>(254,496</u> )
	284,679	(426,611)	6,457	(135,475)
Restricted funds				
Support meetings	5,600	(7,700)	-	(2,100)
Family Days	12,910	(12,910)	-	-
Research grants	20,250	(18,250)	-	2,000
Parenting packs	7,961	(7,961)		<u> </u>
	46,721	(46,821)	-	(100)
				<u> </u>
TOTAL FUNDS	331,400	(473,432)	6,457	<u>(135,575</u> )

# Comparatives for movement in funds

•	At 1.1.16 £	Net movement in funds £	Transfers between funds £	At 31.12.16 £
<b>Unrestricted Funds</b> General fund Designated fund	84,272 	(160,266)	251,265 (251,265)	175,271 584,921
	920,458	(160,266)	-	760,192
<b>Restricted Funds</b> Support meetings	5,550	(3,450)	-	2,100
TOTAL FUNDS	926,008	(163,716)		762,292

### Notes to the Financial Statements - continued for the year ended 31 December 2017

# 16. MOVEMENT IN FUNDS - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Gains and losses £	Movement in funds £
Unrestricted funds General fund	283,036	(459,943)	16,641	(160,266)
Restricted funds Support meetings Research grants	13,700 19,000	(17,150) (19,000)	- 	(3,450)
	32,700	(36,150)	-	(3,450)
TOTAL FUNDS	315,736	(496,093)	16,641	<u>(163,716)</u>

## **Support Meetings**

This fund represents amounts donated to CICRA towards the cost of the Support Meetings held.

# **Research Grants**

This fund represents amounts donated to CICRA towards the cost of Research Grants.

# Notes to the Financial Statements - continued for the year ended 31 December 2017

# 17. OTHER FINANCIAL COMMITMENTS

The charity has future grant commitments already entered into and spread over the years 2018 to 2020 inclusive totalling £317,101 (2016: £584,921). These multi-year grants are reviewed annually and payments for second and subsequent years are only made upon receipt of satisfactory reports as to progress of the research project. Consequently, the trustees do not consider it appropriate to make provision for these commitments in the financial statements.

Existing research commitments:

CICRA Fellowship	
Grant awarded: to Prof. Ian Sanderson, Bart's and Royal London Hospital	61,788
Research Fellow: Dr Protima Amon	
Grant awarded to: Dr Mattias Zilbauer, Addensbrooke's Hospital, Cambridge	81,023
Research Fellow: Dr Marco Gasparetto	
CICRA PhD Studentships	
Grant awarded to: Dr Tom Wileman, East Anglia University	28,241
PhD Student: Rai Shashank	
Grant awarded to: Dr Mairi McLean, Aberdeen University	37,889
PhD Student: TBA	
Grant awarded to: Dr Mattias Zilbauer, Addenbrooke's Hospital, Cambridge	69,932
PhD Student: TBA	
CICRA Research Project Grants	
Grant awarded to: Professor Deborah Christie, University College Hospital, London	16,628
CICRA Laboratory Consumables Grant	
Grant awarded to: Professor Ian Sanderson, Barts and Royal London Hospital	21,600
TOTAL	317,101
IOTAL	517,101
The timing of the above commitments is as follows:	
Grants committed 2018	220,289
Grants committed 2019	74,780
Grants committed 2020	22,032
	317,101

# **18. RELATED PARTY DISCLOSURES**

There were no related party transactions for the year ended 31 December 2017.

# Detailed Statement of Financial Activities for the year ended 31 December 2017

	Year Ended 31.12.17 £	Year Ended 31.12.16 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	212,172	259,912
Legacies	86,797	19,952
	298,969	279,864
Other trading activities		
Merchandise (incl xmas)	9,355	8,979
Christmas/summer draw	9,106	8,628
200 Club	6,286	5,979
Groups	1,000	1,500
	25,747	25,086
Investment income		
Schroder Investment interest	6,167	10,572
Deposit account interest	1	1
COIF Deposit	516	213
	6,684	10,786
Total incoming resources	331,400	315,736
EXPENDITURE		
Raising donations and legacies		
Trustees' expenses	746	906
Wages	32,389	11,411
Social security	2,729	-
Pensions Postego and stationery	231 3,471	4,267
Postage and stationery Office costs (40%)	18,025	4,207
Marketing and advertising	585	1,802
Legal and bank costs	2,529	
Lotteries	4,804	5,099
Other fundraising expenses	11,750	18,259
Staff expenses	5,683	1,268
Outsourcing	2,748	
	85,690	55,653

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# Detailed Statement of Financial Activities for the year ended 31 December 2017

	Year Ended 31.12.17 £	Year Ended 31.12.16 £
Other trading activities Merchandise (including Christmas cards) Depreciation of tangible fixed assets	3,504	6,624 422
	3,504	7,046
Charitable activities		
Trustees' expenses	6,004	5,838
Wages	32,247	26,582
Social security	1,552	-
Pensions	261	-
Postage and stationery	9,187	7,924
Office costs (60%) Marketing and advertising	27,037 15,397	18,962 7,855
Family meetings	22,388	23,240
Legal fees	22,588 57	23,240
Outsourcing	4,122	-
Staff expenses	3,735	713
Depreciation of tangible fixed assets	1,568	633
Grants to institutions	254,496	311,533
	378,051	403,280
Other		7.025
Wages	-	7,025
Trustee insurance AGM costs	886 596	862 665
Accountancy	3,120	9,900
Legal and bank costs	538	7,388
Staff expenses	1,047	220
	6,187	26,060
Support costs		
Governance costs Office move	<u> </u>	4,054
Total resources expended	473,432	496,093
Net expenditure	(142,032)	(180,357)

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