

**HUNTINGTON'S DISEASE
ASSOCIATION OF IRELAND
REPORTS AND FINANCIAL STATEMENTS
YEAR ENDED 31st DECEMBER 2016**

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
REPORTS AND FINANCIAL STATEMENTS YEAR ENDED 31ST DECEMBER 2016
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**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
REPORTS AND FINANCIAL STATEMENTS YEAR ENDED 31ST DECEMBER 2016
DIRECTORS AND OTHER INFORMATION**

DIRECTORS:	Anne Lennon Bird Patrick Griffin David Flood Joan Flood Deirdre Jones Thomas J. Lillis Betty McCormack Deirdre McInerney Angelina O'Shea (Resigned 11 th April 2016) Jennifer Paradise Anna Porter
COMPANY SECRETARY:	Deirdre Jones (Appointed 25 th July 2016)
TREASURER:	Patrick Griffin
COMPANY NUMBER:	290191
REGISTERED OFFICE:	Carmichael House, North Brunswick Street, Dublin 7.
INDEPENDENT AUDITORS:	D.F. Byrne & Associates, Chartered Accountants, ATC House, 2059 Castle Drive, Citywest Business Campus, Dublin 24
PRINCIPAL BANKERS:	Bank of Ireland, Smithfield Branch, Dublin 7.
SOLICITORS:	Leman Solicitors, 8-34 Percy Place, Dublin 4.
CHARITY NUMBER:	CHY10130

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
REPORT AND FINANCIAL STATEMENTS YEAR ENDED 31ST DECEMBER 2016
DIRECTORS' REPORT**

The directors present their annual report, together with the audited financial statements of the company, covering the year ended 31st December 2016. The financial statements have been prepared in accordance with the accounting policies set out on page 18 to the financial statements and comply with the company's Memorandum and Articles of Association, applicable Company Law, and the requirements of the Statement of Recommended Practice for financial reporting by charities (SORP).

1 Objectives and Activities

1.1 Objectives

The objective of Huntington's Disease Association of Ireland (HDAI) is to promote purposes of benefit to people impacted by Huntington's Disease in a manner that is exclusively charitable in accordance with Irish law, in particular to:

- a. exchange and disseminate information relating to Huntington's Disease;
- b. provide support for individuals, families and carers who are impacted by Huntington's Disease;
- c. co-operate with the medical, caring, social and scientific professions in the management of Huntington's Disease.

1.2 Activities

Huntington's Disease Association of Ireland (HDAI) is a registered charity established in 1985 by members of HD families who recognised the crucial need for a support organisation in Ireland. HDAI is a Company Limited by Guarantee, registered under Part 18 of the Companies Act 2014.

HDAI is registered with the Charity Regulation Authority and has signed up to the Statement of Guiding Principles for Fundraising in Ireland.

HDAI is the only national organisation in Ireland available to provide specific information, support and advocacy to people impacted by Huntington's Disease (HD) throughout Ireland. The Association informs and supports people living with the condition, family care givers, family members at risk, relatives and friends. HDAI also provides information to health and social care professionals and others interested in HD.

Services include

- Advocacy for individuals and a voice for the HD community
- Family Support Officer available to meet / speak to family members in crisis
- Access to counselling
- Support group meetings / Carers Workshops
- Annual Information Meeting and respite weekend
- HD Publications, Quarterly newsletter and Annual magazine
- Support for Young People
- Assistance Fund and provision of specialised equipment
- Information seminars to interested health and social care professional.

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1.3 HDAI Staff Profile

The delivery of HDAI's service is dependent on the commitment of its staff and voluntary board. HDAI had 1.5 whole time equivalent staff members in 2016.

Information and Services: - Patricia Towey, Director of Information and Services Coordinator provides information and support to people impacted by HD and to interested health and social care professionals. Other responsibilities include: keeping information updated, producing a quarterly newsletter and annual magazine, applying for relevant funding, assisting voluntary fundraisers, raising awareness, maintaining accounts, complying with reporting requirements of the HSE, statutory agencies and other funders, organising an Annual Members Meeting, respite weekend and AGM, managing the HDAI office, facilitating board meetings and representing HDAI at relevant umbrella organisation meetings, liaising with health and social care professionals, researchers, national and international organisations and other relevant organisations to pursue the aims of HDAI.

Family Support: - Liz O'Sullivan, Family Support Officer works part-time (Monday and Friday). She is a qualified counsellor and psychotherapist. Liz is available to meet with individuals and families and to provide telephone support to those impacted by HD. Liz hosts carers workshops and support meetings and provides information seminars on request to professional carers and other relevant groups.

2 Achievements and Performance in 2016

Huntington's Disease (HD) is a life-limiting genetic neurodegenerative condition that leads to progressive physical, cognitive and emotional impairments. Symptoms gradually worsen over the 10-25 year course of the disease. Each child of a person diagnosed with HD has a 50% risk of developing the disease. Due to the genetic and complex nature of HD, many families require information and assistance in a flexible confidential and supportive manner.

2.1 Seminars, Support meetings and Carer's Workshops

2.1.1 Annual Members Meeting

HDAI's Annual Members Meeting and respite weekend was held at The Irish Wheelchair Association Holiday Centre in Cuisle, Donammon Co. Roscommon in June 2016. People impacted by HD had an opportunity to actively engage in information sessions and meet others from the Irish HD community.

Jimmy Pollard, International HD Speaker and author of *Hurry Up and Wait* delivered an engaging talk on "**Thinking About Thinking with Huntington's Disease**". He provided examples of what it might feel like to think with HD and demonstrated the challenges that people living with HD constantly face. Jimmy gave practical suggestions as to how care givers, family and friends can lessen these challenges. He also gave a very interesting talk on the **Enroll-HD** project and a history tour of the progress of HD research from Dr George Huntington's first paper on the condition in April 1872 to the present day. Jimmy advised us of the many more volunteers needed to register with Enroll-HD and contribute to the hunt for a cure.

In his conclusion Jimmy reminded us

"The journey has always been about families.....finding other families.....and partnering with docs and scientists. We've come so far... Everyone from a HD family can play a part in the quest to find a cure!"

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2.1.2 Support Meetings

HDAI Support Meetings offer people impacted by HD an opportunity to access peer support and information from others having similar experiences. Carers are encouraged to seek support in order to manage the difficulties they face and consider positive approaches to looking after their own needs. Meetings are facilitated by Liz O Sullivan HDAI's family Support Officer.

Cork	Dublin	Limerick	Longford /West
March - 11 people	Feb. - 13 people	Jan. - 5 people	April - 12 people
July - 9 people	May – 13 people	April - 6 people	June Carers Workshop- 19 people (Cuisle)
	Aug. – 5 people		Sept. - 10 people
Dec. – 12 people	Nov. – 20 people		Dec. - 7 people



HDAI and Bloomfield Health Services hosted a joint HD Café evening in April 2016. Dr Andrea Higgins, Senior Neuropsychologist at Bloomfield Health Services delivered an insightful talk on the importance of looking after our psychological health. Stress can impact negatively on thinking, memory and concentration. It is important to avoid catastrophising and aim for our emotional best. Dr Higgins suggestions for minding mental wellbeing include: connecting with those around us, doing things we enjoy and seeking help when we need it.

2.1.3 Caregivers Seminar

Twenty four people attended HDAI's seminar for family care givers in Cork on May 20th 2016. Dr Sean O'Sullivan, Consultant Neurologist, Cork University Hospital was joined by Susan O'Neill, Senior Physiotherapist, Aoife Gallaher, (HD) Clinical Nurse Manager and Dr. Andrea Higgins, Neuropsychologist from Bloomfield Health Services.

Feedback included:

“All the speakers were very informative, I appreciated Dr O Sullivan’s down to earth approach and the time he gave to answering our questions” ES



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2.2 Information and Support

2.2.1 Helpline and Family Support Service

HDAI provide a national helpline which serves as an important link for people to receive information in a confidential and supportive manner. In 2016 people impacted by HD called to gain information and / or support on issues including: worries about start of symptoms and the potential impact on employment; the impact of a new diagnosis on the person and family members at risk; information on managing the condition and seeking health professional referrals; difficulties accessing rehabilitation and community mental health services; the predictive testing process; caring for a family member and queries on registering with Enroll-HD and latest research developments.

HDAI also provide information to primary care professionals, community mental health services, GPs and other health and social care professionals. Information packs and links to HD information online were distributed to health care professionals

HDAI's family support officer facilitates regional support meetings, provides regular support by phone and is available to meet individuals on a one to one basis if required.

"I really appreciate the social and emotional support I receive from [family support officer] when I meet her. Thanks to you all "

2.2.2 Counselling

HDAI provide access to counselling services for people impacted by HD. Those requiring counselling support are referred to qualified vetted therapists throughout Ireland approved by accreditation bodies including the Irish Association of Counsellors and Psychotherapists. HDAI received a grant of €2,650 from TUSLA, The Child and Family Agency towards counselling provision in 2016. Fifteen HD family members were referred for counselling sessions funded by HDAI.

2.2.3 Support for Young People

HDAI recognises the need for young people from HD families to have support in dealing with the stress and emotional upheavals HD can generate. The family support officer met with young people in need of support. HDAI joined other international associations as a partner in the funding application for the 2016 HDYO Youth Camp held in Kent, England in August 2016. Three Irish people participated in the camp.

HDAI promotes the work of Huntington's Disease Youth Organisation (HDYO), an international online resource for young people impacted by HD.

2.2.4 Assistance and Aids and Appliances Fund

HDAI provided assistance grants to those in need by contributing towards expenses such as: family visits, short breaks for carers, bereavement costs, household adaptations and hospital expenses. Twenty five grants were allocated in 2016 towards costs including: family visits, funeral expenses, hospital related expenses, physiotherapy, Christmas expenses and assistance with household bills.

HDAI contributed towards specialist seating and equipment for people with HD including: a boot hoist, a power chair, a car seat adaption and smoking aids. Information on specialist chairs and equipment is distributed to Occupational Therapists and carers on request. HDAI received a grant of €2,000 from Monkstown Hospital Fund for the provision of specialist seating. The Hospital Saturday Fund provided a grant of €4,000 towards the provision of specialist equipment for people with HD in 2016.

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DIRECTORS' REPORT**

2.2.5 Information and Education



HDAL's information booklets are sent to family members and health and social care professionals on request. They are also available on the HDAL website Information page at www.huntingtons.ie. HDAL also publishes a quarterly newsletters and an annual magazine Hope Annual. HDAL continue to provide information seminars to health and social care professionals and staff in care facilities on request.

Huntington's Disease: Cognition and Care Seminar HDAL and Bloomfield Health Services held a joint seminar entitled 'Huntington's Disease: Cognition and Care' for health and social care professionals in June 2016. Jimmy Pollard delivered an interactive presentation on 'Thinking About Thinking with Huntington's Disease'. Anne Lennon Bird gave her perspective as a HD family member. Speakers from Bloomfield Health Service's multi-disciplinary team included Dr Jennifer Hoblyn, Neuropsychiatrist & Clinical Director, Aoife Gallaher, Assistant Director of Nursing, Susan O'Neill, Senior Physiotherapist, and Aisling Doyle, Occupational Therapist.

"We need to have more events like this". "All presentations were excellent".

2.3 Awareness and Advocacy "Light It Up For HD Awareness"

HDAL joined the international HD community on May 11th 2016 to support the "Light It Up 4 HD" campaign to raise awareness for Huntington's Disease by illuminating buildings and landmarks worldwide during May awareness month. Ardmhéara / Lord Mayor of Dublin, Críona Ní Dhálaigh showed her support for the 'Light It Up' campaign and met with members of HDAL. The Mansion House; Dublin City Council Civic Offices; The Generator Hostel, Smithfield; Bloomfield Health Services, Rathfarnham; Byrnes Pharmacy, Ballsbridge; and The Convention Centre, all supported the campaign.

Awareness Walk HDAL's 2016 Awareness Walk held in Lough Key in July doubled its participants on 2015. Joe Doran led off the walk once again and his family and friends contributed greatly to local awareness for the event and to €1,950 raised in funds. HD Family members from East and West supported the walk. The sunshine and location added to everyone's enjoyment.

Newstalk Radio Anne O'Shea Clarke shared her story on The Pat Kenny Show, Newstalk Radio on June 23rd 2016 in support of the launch of The Neurological Alliance of Ireland campaign **"We Need Our Heads Examined"**. The campaign calls for urgent investment in rehabilitation services.



HDAL are grateful to family members for their vital work in promoting a greater understanding of HD.

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2.4 Working with other Organisations

HDAI actively collaborates with other organisations to promote awareness and the development of services for those impacted by HD.

Membership of International Organisations include:

- International Huntington's Association,
- European Huntington's Association

National umbrella organisations membership includes:

- Care Alliance
- Carmichael Centre for Voluntary Groups
- Disability Federation of Ireland
- Genetic and Rare Disorders Organisation
- Mental Health Reform
- Neurological Alliance of Ireland

HDAI also provides links to and promotes the work of:

- HDBuzz – HDAI contributed €500 towards this online HD research news resource in 2016
- HDYO Huntington's Disease Youth Organisation an international youth support organisation

European Huntington's Disease Network Conference HDAI was represented by Board members Anne Lennon Bird, Pat Griffin and David Flood at the EHDN Meeting in The Hague in September 2016. Anne (our first speaker from Ireland) was invited to speak on the topic "Living with HD – a Mothers Perspective".



Enroll-HD Research Study - HDAI promotes awareness of Enroll-HD, a worldwide research project that aims to gather data from 20,000 people in an effort to improve HD treatment and support clinical trials. Dr Niall Pender leads the Enroll-HD site at Beaumont Hospital. 19 people have now registered in Ireland with many others waiting to join.

2.5 Fundraising

Approximately 44% of HDAI's funds in 2016 came from philanthropic sources, fundraising activities, donations and membership.

HDAI's voluntary fundraisers organise various events to support the Associations service. 2016 fundraising events included: sponsored cycles, marathons, a mountain climb, Hell and Back challenges, social nights, charity tea dances, craft events. A listing of Fundraising Activities is entered at Appendix 5, page 27.

HDAI is fully committed to achieving the standards contained within the Statement of Guiding Principles for Fundraising. The Statement exists to:

- Improve fundraising practice
- Promote high levels of accountability and transparency by organisations fundraising from the public
- Provide clarity and assurances to donors and prospective donors about the organisations they support.

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
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DIRECTORS' REPORT**

3 Finance, Structure and Governance

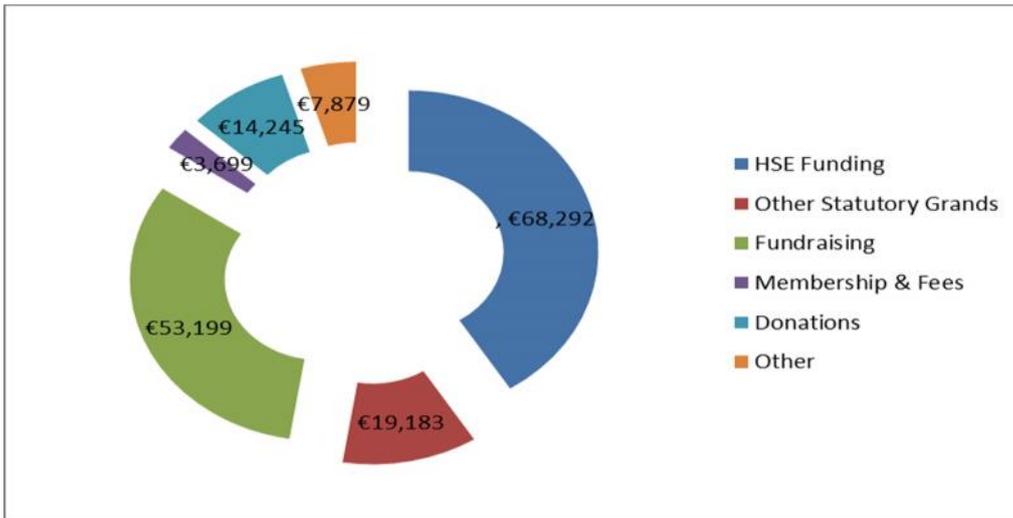
3.1 Financial Review

The financial results for the year ended 31st December 2016 record a net operating surplus of €29,396. This surplus is mainly due to an increase of over €30,000 in fundraising income on previous year. This funding is critical to HDAl and has helped to offset the loss of The Department of Environment Scheme to Support National Organisation funding which ceased in June 2016 (see Appendix 1, page 23). Previously the SSNO funding covered indirect costs including rent and administration expenses, but such costs are no longer applicable under the 2016 -2018 scheme.

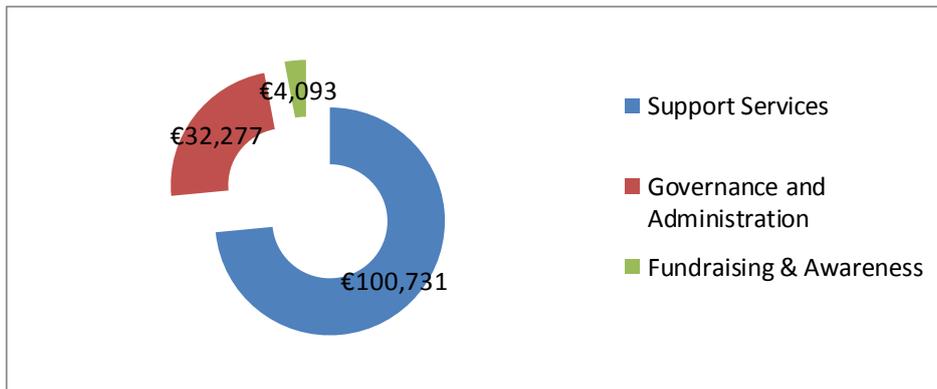
The loss of SSNO funding is a significant concern for the provision of future services and the Board will continue to monitor this risk

The Board and staff have a duty and responsibility to provide prudent financial management of HDAl to ensure it remains a sustainable service for those dependent upon it.

2016 Income by Source



2016 Allocation of Funds



HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
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Salaries and employer related costs accounted for €74,271 of HDAL's annual operating costs in 2016 of which €68,292 (92%) is funded directly by the Health Service Executive. The Department of Environment Scheme to Support National Organisation (SSNO) funding is restricted to core costs including facilities, governance and information provision costs. National Lottery funding contributes to the cost of HDAL's Annual members meeting and respite weekend.

3.2 Risk Review

The Board recognises and regularly reviews the major risks to which HDAL could be exposed. Risks include safety and security of staff, financial, operational, reputational, governance and other risks that might affect HDAL's ability to deliver a quality service for the public benefit. The directors are satisfied that policies and procedures are in place to mitigate exposure to major risks.

3.3 Reserves Policy

The Board of directors has set a reserves policy which requires that reserves be maintained to cover all identified costs in relation to the closure of the company should this occur. €45,570 has been designated for this purpose as outlined on Note 11 of the financial statements.

3.4 Investment Policy

HDAL invests in short term deposits providing a market rate of interest in order to maintain sufficient access to cash flow to fund the charity's activities. Interest received for 2016 was €554. The Board aims to ensure that the Company gets the best return on its deposit funds.

3.5 Governance and Structure

HDAL is a Company Limited by Guarantee, registered under Part 18 of the Companies Act 2014. The members of the Company are HD family members or those interested in the work of the Association who register as members on an annual basis. In the event of the Company being wound up, the liability in respect of the guarantee is limited to €1.00 per member of the Company.

The Company is constituted under a Memorandum and Articles of Association and is a registered charity number CHY 10130. The company is also registered with the Charities Regulatory Authority (CRA) and its CRA number is 20025656.

The Company's goals and objectives are guided by its charitable objectives as laid out in the Memorandum and Articles of Association. The management of the Company is the responsibility of the directors who are elected and co-opted under the terms of the company governance handbook. The Board of directors are listed on page 1. On appointment, directors receive a formal induction and are provided with relevant Company information. Directors sign a Conflict of Interest Statement and HDAL's Code of Conduct Policy. The directors work on a voluntary basis to oversee the work of the Association and are responsible for ensuring its good governance and accountability to all stakeholders. The Board is working towards compliance with the Governance Code for Voluntary Organisations. As part of this process HDAL reviewed its employment contracts and HR related policies in 2014. HDAL adopted the guiding principles for fundraising in 2015 and is fully committed to achieving the standards contained within the Statement of Guiding Principles for Fundraising. HDAL reviewed its Memorandum and Articles of Association in 2016 to comply with the 2014 Companies Act and to remove 'Limited' from the company's name. An EGM was held on November 5th 2016 to adopt the new Constitution.

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
REPORT AND FINANCIAL STATEMENTS YEAR ENDED 31ST DECEMBER 2016
DIRECTORS' REPORT**

The financial statements are presented using the Statement of Recommended Practice for financial reporting by charities (SORP) and are available online from 2013. The Association's Annual Financial Reports and Statements are audited annually by external auditors and are approved by the Board and presented to members at the AGM.

3.6 Future Developments

HDAI will continue to prioritise the provision of information and support to people impacted by HD as a core objective. The Association will work with statutory and other voluntary organisations to promote the development of services for people with HD, those at risk carers and family members.

3.7 Thanks

We are very grateful to all our funders for their support. Control of HDAI is independent of its funding sources. The following organisations provided grants that contributed to HDAI's resources in 2016:

- The Health Service Executive;
- The Department of the Environment, Community and Local Government SSNO;
- TUSLA The Child and Family Support Agency;
- The Hospital Saturday Fund;
- Monkstown Hospital Foundation.

HSE, National Lottery and TUSLA funding is subject to Grant Aid Agreements and funding is assigned for specific purposes.

Voluntary fundraisers and donors have supported our work consistently for many years by hosting events such as Charity Tea Dances, Work Casual Days, Craft events and Social nights. Others raise sponsorship through cycles, marathons, walks and challenges. Regular donors contribute by monthly direct debits or annual donations. HDAI also receive donations in memory of loved ones. HDAI sincerely acknowledge the exceptional assistance received from members and friends.

4 Directors and company secretary

A listing of those persons who were at any time during the year ended 31st December 2016 a director of the company is entered on page 1. Each person continues in accordance with the company's Articles of Association. On 25th July 2016, Deirdre Jones was appointed as replacement company secretary following the resignation of Angelina O'Shea.

5 Directors' responsibilities for the financial statements

The directors are responsible for the financial statements of the company and for the maintenance of proper books and accounting records. A separate Statement outlining their responsibilities in this regard is included with and forms part of the financial statements of the company for the year ended 31st December 2016.

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
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DIRECTORS' REPORT**

6 Books of account

The measures taken by the directors to secure compliance with the requirements of Sections 281 to 285 of the Companies Act 2014 with regard to the keeping of accounting records are the implementation of necessary policies and procedures for recording transactions, the employment of competent personnel with appropriate expertise, and the provision of adequate resources to the financial function.

The accounting records of the company are maintained at the company's place of business.

7 Statement on relevant audit information

In accordance with Section 330 of the Companies Act 2014:

so far as each person who was a director at the date of approving this report is aware, there is no relevant audit information, being information needed by the auditor in connection with preparing its report, of which the auditor is unaware; and each director has taken all the steps that he or she ought to have taken as a director in order to make himself or herself aware of any relevant audit information and to establish that the auditor is aware of that information.

8 Auditors

In accordance with Section 383(2) of the Companies Act 2014, the auditors, DF Byrne & Associates, chartered accountants, continue of office.

Signed and approved on behalf of the Board on the 14th day of June 2017

Patrick Griffin
Patrick Griffin
Director and Treasurer

Deirdre Jones
Deirdre Jones
Director and Company Secretary

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
REPORT AND FINANCIAL STATEMENT YEAR ENDED 31ST DECEMBER 2016
STATEMENT OF DIRECTORS' REQUIREMENTS AND RESPONSIBILITIES
WITH REGARD TO THE FINANCIAL STATEMENTS**

The directors are responsible for preparing the Directors' Report and the financial statements in accordance with Irish law and regulations.

Company law requires the directors to prepare financial statements for each financial year. Under the law the directors have elected to prepare the financial statements in accordance with the Companies Act 2014 and FRS 102 'The Financial Reporting Standard applicable in the UK and Ireland' issued by the Financial Reporting Council and promulgated by the Institute of Chartered Accountants in Ireland. Under company law, the directors must not approve the financial statements unless they are satisfied that they give a true and fair view of the assets, liabilities and financial position of the company as at the financial year end date and of the profit or loss of the company for the financial year and otherwise comply with the Companies Act 2014.

In preparing these financial statements, the directors are required to:

- select suitable accounting policies and then apply them consistently;
- make judgments and accounting estimates that are reasonable and prudent;
- state whether the financial statements have been prepared in accordance with applicable accounting standards, identify those standards, and note the effect and the reasons for any material departure from those standards; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the company will continue in business.

The directors are responsible for ensuring that the company keeps or causes to be kept adequate accounting records which correctly explain and record the transactions of the company, enable at any time the assets, liabilities, financial position and profit or loss of the company to be determined with reasonable accuracy and enable them to ensure that the financial statements and directors' report comply with the Companies Act 2014 and enable the financial statements to be audited. They are also responsible for safeguarding the assets of the company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Signed and approved on behalf of the Board on the 14th day of June 2017

Patrick Griffin
Patrick Griffin
Director and Treasurer

Deirdre Jones
Deirdre Jones
Director and Company Secretary

D.F. BYRNE & ASSOCIATES

CHARTERED ACCOUNTANTS
ATC HOUSE, 2059 CASTLE DRIVE,
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HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND REPORTS AND FINANCIAL STATEMENTS YEAR ENDED 31ST DECEMBER 2016 INDEPENDENT AUDITORS' REPORT

We have audited the financial statements of Huntington's Disease Association of Ireland for the year ended 31st December 2016, which comprises of the Profit and Loss Account (herein referred to as the Statement of Financial Activities), the Balance Sheet, the Cash flow Statement, and the related Notes thereto. The relevant financial reporting framework that has been applied in their preparation is Companies Act 2014 and FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' issued by Financial Reporting Council and promulgated by the Institute of Chartered Accountants in Ireland.

This report is made solely to the company's members, as a body, in accordance with Section 391 of the Companies Act 2014. Our audit work has been undertaken so that we might state to the company's members those matters that we are required to state to them in the audit report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the company or the company's members as a body for our audit work, for this report, or for the opinions we have formed.

Respective responsibilities of directors and auditors

As explained more fully in the Directors' Responsibilities Statement set out on page 12, the directors are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view and otherwise comply with the Companies Act 2014. Our responsibility is to audit and express an opinion on the financial statements in accordance with Irish law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Auditing Practices Board's ("APB's") Ethical Standards for Auditors including "APB Ethical Standard – Provisions Available for Small Entities (Revised)", in the circumstances set out in note 14 to the financial statements.

Scope of the audit of the financial statements

An audit involves obtaining evidence about the amounts and disclosures in the financial statements sufficient to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or error. This includes an assessment of: whether the accounting policies are appropriate to the company's circumstances and have been consistently applied and adequately disclosed; the reasonableness of significant accounting estimates made by the directors; and the overall presentation of the financial statements.

In addition, we read all the financial and non-financial information in the Directors' Report to identify material inconsistencies with the audited financial statements and to identify any information that is apparently materially incorrect based on, or materially inconsistent with, the knowledge acquired by us in the course of performing the audit. If we become aware of any apparent material misstatements or inconsistencies we consider the implications for our report.

...../Continued on Page 14

D.F. BYRNE & ASSOCIATES

CHARTERED ACCOUNTANTS
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HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND FINANCIAL STATEMENTS YEAR ENDED 31ST DECEMBER 2016 INDEPENDENT AUDITORS' REPORT (CONTINUED)

Continued from Page 13/...

Opinion on financial statements

In our opinion the financial statements:

- give a true and fair view of the assets, liabilities and financial position of the company as at 31st December 2016 and its surplus for the year then ended; and
- have been properly prepared in accordance with the relevant financial reporting framework and, in particular, with the requirements of the Companies Act 2014.

Matters on which we are required to report by the Companies Act 2014

- We have obtained all the information and explanations, which we consider necessary for the purposes of our audit.
- In our opinion the accounting records of the company were sufficient to permit the financial statements to be readily and properly audited.
- The financial statements are in agreement with the accounting records.
- In our opinion the information given in the Directors' Report is consistent with the financial statements.

Matters on which we are required to report by exception

We have nothing to report in respect of our obligation under the Companies Act 2014 to report to you if, in our opinion, the disclosures of directors' remuneration and transactions specified by Sections 305 to 312 of the Act are not made.

David Byrne

David Byrne
for and on behalf of D.F. Byrne & Associates
Chartered Accountants and Registered Auditors

14th June 2017

Dated:

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
FINANCIAL STATEMENTS YEAR ENDED 31ST DECEMBER 2016
STATEMENT OF FINANCIAL ACTIVITIES**

	NOTE	Year ended 31 st Dec. 2016 €	Year ended 31 st Dec. 2015 €
INCOMING RESOURCES	2		
Grants Received		93,475	134,870
Fundraising Activities		53,199	21,358
Donations and Legacies		14,245	9,821
Membership Fees		3,699	3,135
HD Booking Fees and Raffle		1,325	940
Interest Income		<u>554</u>	<u>1,004</u>
TOTAL INCOMING RESOURCES		<u>166,497</u>	<u>171,128</u>
 RESOURCES EXPENDED	 3		
Direct Costs and Support Services		(104,824)	(105,622)
Governance and Administrative Costs		<u>(32,277)</u>	<u>(30,661)</u>
TOTAL RESOURCES EXPENDED		<u>(137,101)</u>	<u>(136,283)</u>
 NET RESOURCES SURPLUS FOR YEAR	 4	 29,396	 34,845
 TOTAL FUNDS BROUGHT FORWARD		 <u>101,653</u>	 <u>66,808</u>
 TOTAL FUNDS CARRIED FORWARD		 <u>131,049</u>	 <u>101,653</u>

The Statement of Financial Activities has been prepared on the basis that all operations are continuing operations. There were no recognised gains or losses in either the current financial year or in the previous financial year other than those stated above.

Signed and approved on behalf of the Board on the 14th day of June 2017

Patrick Griffin
Patrick Griffin
Director and Treasurer

Deirdre Jones
Deirdre Jones
Director and Company Secretary

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
FINANCIAL STATEMENTS YEAR ENDED 31ST DECEMBER 2016
BALANCE SHEET**

	NOTE	At 31 st Dec. 2016 €	At 31 st Dec. 2015 €
CURRENT ASSETS			
Debtors	7	138	116
Cash at bank	8	<u>181,451</u>	<u>151,420</u>
		181,589	151,536
CREDITORS			
Amounts falling due within one year	9	<u>(4,970)</u>	<u>(4,313)</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>176,619</u>	<u>147,223</u>
 RESERVES			
		€	€
Accumulated funds – unrestricted	10	131,049	101,653
Designated contingency fund	11	<u>45,570</u>	<u>45,570</u>
		<u>176,619</u>	<u>147,223</u>

Signed and approved on behalf of the Board on the 14th day of June 2017

Patrick Griffin
Patrick Griffin
Director and Treasurer

Deirdre Jones
Deirdre Jones
Director and Company Secretary

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
FINANCIAL STATEMENTS YEAR ENDED 31ST DECEMBER 2016
CASH FLOW STATEMENT**

	NOTE	Year ended 31 st Dec. 2016 €	Year ended 31 st Dec. 2015 €
Reconciliation of operating surplus for year with net cash inflow on operating activities			
Surplus for year on principal activities		29,396	33,841
<i>Adjustment for:</i>			
Bank Interest Income		(554)	(1,004)
<i>Changes in:</i>			
Debtors		(22)	207
Creditors		<u>657</u>	<u>(5,137)</u>
Net cash inflow for year from operations		29,477	28,911
Return on investments			
Bank Interest received		<u>554</u>	<u>1,004</u>
Net increase in cash at bank		30,031	29,915
		<u><u> </u></u>	<u><u> </u></u>
Resulting in:			
Increase in year end bank balances	12	30,031	29,915
		<u><u> </u></u>	<u><u> </u></u>

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
FINANCIAL ACCOUNTS YEAR ENDED 31ST DECEMBER 2016
NOTES TO THE FINANCIAL ACCOUNTS**

(1) STATEMENT OF ACCOUNTING POLICIES

The significant accounting policies which have been adopted and consistently applied in dealing with items which are considered material in relation to the preparation of the financial statements, include:

- (a) General information:** Huntington's Disease Association of Ireland is a charity company limited by guarantee not having a share capital, which has been incorporated in the Republic of Ireland and which is bound by Irish company law.
- (b) Basis of preparation:** The financial statements have been prepared in accordance with accounting standards generally accepted in Ireland and the Companies Act 2014. Accounting Standards generally accepted in Ireland in preparing financial statements giving a true and fair view are those promulgated by the Institute of Chartered Accountants in Ireland and issued by the Financial Reporting Council. The financial statements are presented using the Statement of Recommended Practice for financial reporting by charities (SORP).
- (c) Unit of account:** All figures entered in the financial statements are expressed in Euro (€) and are shown inclusive of Value Added Tax.
- (d) Incoming resources:** All incoming resources are recognised in the Statement of Financial Activities when the company is legally entitled to the income and the amount can be quantified with reasonable accuracy.
Incoming resources comprise grants, donations, membership subscriptions and income from fundraising activities. For donations and legacies, entitlement is the date of receipt. Incoming resources are analysed as Restricted or Unrestricted. Restricted funds represents income which has been received and is recognised in the financial statements subject to specific conditions imposed by the grant making authority or donor. Unrestricted funds represent amounts which are expendable at the discretion of the charity, in furtherance to the objectives of the charity and which have not been designated for a specific purpose.
- (e) Resources expended:** All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs 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 the resources.

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
FINANCIAL STATEMENTS YEAR ENDED 31ST DECEMBER 2016
NOTES TO THE FINANCIAL ACCOUNTS**

(2) INCOMING RESOURCES

Details of Incoming Resources are analysed as to:

	Year ended 31 st December 2016		Year ended 31 st December 2015	
	Restricted Funds €	Unrestricted Funds €	Restricted Funds €	Unrestricted Funds €
Grants Received	93,475	-	134,870	-
Donations and Legacies	-	14,245	-	9,821
Fundraising Activities	-	53,199	-	21,358
HD Booking Fees and Raffle	-	1,325	-	940
Membership Fees	-	3,699	-	3,135
Interest Income	-	554	-	1,004
	<u>93,475</u>	<u>73,022</u>	<u>134,870</u>	<u>36,258</u>

(3) RESOURCES EXPENDED

Resources expended represent all costs incurred during the year in operating the charity and are accounted for on an accruals basis, distinguishing between:

- Direct Costs and Support Services
- Governance and Administrative Costs

(4) NET RESOURCES SURPLUS

	Year ended 31 st Dec. 2016 €	Year ended 31 st Dec. 2015 €
The net resources surplus for the year is stated at after charging:		
Auditors' remuneration	1,500	1,500
Directors' emoluments	-	-

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
FINANCIAL STATEMENTS YEAR ENDED 31ST DECEMBER 2016
NOTES TO THE FINANCIAL ACCOUNTS**

(5) EMPLOYEE NUMBER, COSTS AND DIRECTORS REMUNERATION

During the year there were two (2015: two) persons employed by the company; one on a full-time basis as the company's 'Information and Services Coordinator'; and the second person on a half-time basis as a 'Family Support Officer'.

The aggregate payroll cost for employees includes:

	Year ended 31st Dec. 2016 €	Year ended 31st Dec. 2015 €
Salaries	67,063	67,063
Social Insurance cost	<u>7,208</u>	<u>7,209</u>
	<u>74,271</u>	<u>74,272</u>

Payroll costs are apportioned as to:

	€	€
Direct Costs and Support Services	57,660	57,661
Governance and Administration	<u>16,611</u>	<u>16,611</u>
	<u>74,271</u>	<u>74,272</u>

(5)(a) Directors' Emoluments

The directors did not receive any form of remuneration or financial benefit for their services in either the current financial year or in the previous financial year.

(6) TAXATION

The company is exempt from Corporation Tax under Section 208, Taxes Consolidation Act 1997.

(7) DEBTORS

	At 31st Dec. 2016 €	At 31st Dec. 2015 €
Bank Interest Receivable	<u>138</u>	<u>116</u>

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
FINANCIAL STATEMENTS YEAR ENDED 31ST DECEMBER 2016
NOTES TO THE FINANCIAL ACCOUNTS**

(8) CASH AT BANK	At 31st Dec. 2016 €	At 31st Dec. 2015 €
Bank Deposit Accounts	98,568	98,035
Bank Current Accounts	<u>82,883</u>	<u>53,385</u>
	<u>181,451</u>	<u>151,420</u>

(9) CREDITORS – amounts falling due for payment within one year	At 31st Dec. 2016 €	At 31st Dec. 2015 €
Revenue Commissioners (Payroll taxes)	1,646	959
Accrued expenses	<u>3,324</u>	<u>3,354</u>
	<u>4,970</u>	<u>4,313</u>

(10) ACCUMULATED FUNDS - UNRESTRICTED	At 31st Dec. 2016 €	At 31st Dec. 2015 €
Brought forward at beginning of year	101,653	66,808
Surplus for year	<u>29,396</u>	<u>34,845</u>
Accumulated surplus carried forward	<u>131,049</u>	<u>101,653</u>

(11) DESIGNATED CONTINGENCY FUND	At 31st Dec. 2016 €	At 31st Dec. 2015 €
Balance forward	45,570	45,570

The directors have determined that it is prudent to continue to carry forward an appropriate amount of the company's accumulated funds to cover all identified costs in relation to the closure of the company should this occur.

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
FINANCIAL STATEMENTS YEAR ENDED 31ST DECEMBER 2016
NOTES TO THE FINANCIAL ACCOUNTS**

(12) ANALYSIS OF CHANGES IN YEAR END BANK BALANCES

	<u>2016</u>		<u>2015</u>	
	Opening €	Closing €	Opening €	Closing €
Bank Deposit Accounts	98,035	98,568	96,823	98,035
Bank Current Account	<u>53,385</u>	<u>82,883</u>	<u>24,682</u>	<u>53,385</u>
	<u>151,420</u>	<u>181,451</u>	<u>121,505</u>	<u>151,420</u>
		€		€
Increase in year end bank balances		<u>30,031</u>		<u>29,915</u>

(13) COMPANY STATUS

HDAI is a registered charity (Charity No. CHY 10130), which has been established as a charity company limited by guarantee not having a share capital, incorporated in Republic of Ireland. Every member of the company undertakes, if necessary during the time they are a member or within one year after they cease to be a member, to contribute to the assets of the company an amount not exceeding €1.27.

(14) APB ETHICAL STANDARDS – PROVISIONS AVAILABLE TO SMALL ENTITIES

As a small entity, under the provisions of the APB in relation to Ethical Standards, we engage our auditors to assist in the preparation of the company's financial statements and to provide basic tax compliance work and company secretarial services.

(15) APPROVAL OF FINANCIAL STATEMENTS

The company's financial statements covering the year ended 31st December 2016, were considered, approved and authorised for issue by Patrick Griffin and Deirdre Jones on behalf of the Board on the day of 14th June 2017.

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
FINANCIAL ACCOUNTS YEAR ENDED 31ST DECEMBER 2016**

**THE FOLLOWING PAGES ARE FOR ADDITIONAL INFORMATION
AND DO NOT FORM PART OF THE FINANCIAL STATEMENTS**

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**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
FINANCIAL ACCOUNTS YEAR ENDED 31ST DECEMBER 2016**

APPENDIX 1: ANALYSIS OF GRANT INCOME RECEIVED

	Year ended 31 st Dec. 2016 €	Year ended 31 st Dec. 2015 €
Core Funding		
Health Service Executive	68,292	68,294
Dept. of Environment, Community and Local Government (SSNO)	9,533	19,066
National Lottery (2015)	<u>7,000</u>	<u>14,000</u>
	<u>84,825</u>	<u>101,360</u>
Other Grants	€	€
TULSA Child and Family Support Agency	2,650	2,650
Hospital Saturday Fund	4,000	2,400
Ireland Fund de France	-	25,000
Monkstown Hospital Foundation	<u>2,000</u>	<u>3,460</u>
	<u>8,650</u>	<u>33,510</u>
TOTAL GRANT INCOME RECEIVED	€ 93,475	€ 134,870

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
FINANCIAL ACCOUNTS YEAR ENDED 31ST DECEMBER 2016**

APPENDIX 2: ANALYSIS OF OTHER INCOME RECEIVED

	Refer	Year ended 31 st Dec. 2016 €	Year ended 31 st Dec. 2015 €
Bank Interest		554	1,004
Donations and Legacies	Apdx. 6	13,437	9,821
Fundraising Activities	Apdx. 5	53,199	21,358
HD Booking Fees and Raffle		1,325	940
Members' Affiliation Fees		3,699	3,135
Tax Redemption on donations		<u>808</u>	<u>-</u>
		<u>73,022</u>	<u>36,258</u>

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
FINANCIAL ACCOUNTS YEAR ENDED 31ST DECEMBER 2016**

APPENDIX 3: LISTING OF DIRECT COSTS AND SUPPORT SERVICES

	Year ended 31 st Dec. 2016 €	Year ended 31 st Dec. 2015 €
Advertising and Awareness	2,062	1,660
Aids and Appliances	3,208	3,637
Conferences and Information Seminars	466	682
Counselling and Therapy	5,699	6,780
Cuisse Respite and Information Meeting	9,750	9,389
Fundraising Expenses	2,031	941
HDAI Information Newsletter and Annual	6,542	5,687
HD Information Link	500	70
Members' Support Meetings	3,211	2,449
Postage	2,155	2,243
Research Study (Enroll HD)	-	2,500
Respite Assistance and Support	5,711	7,040
Staff Salaries	57,660	57,661
Staff Training	50	110
Subscription Fees	943	674
Sundry	206	-
Support Officer's Expenses	1,673	1,600
Telephone, Fax and Internet	2,406	2,397
Young Peoples Support	<u>551</u>	<u>102</u>
	<u>104,824</u>	<u>105,622</u>

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
FINANCIAL ACCOUNTS YEAR ENDED 31ST DECEMBER 2016**

APPENDIX 4: LISTING OF GOVERNANCE AND ADMINISTRATION EXPENSES

	Year ended 31 st Dec. 2016 €	Year ended 31 st Dec. 2015 €
Bank Charges	391	354
Board Meetings and Expenses	1,428	1,291
Computer Costs	620	268
Insurance	833	823
Postage, Stationery and Office Supplies	2,554	1,599
Professional Fees	2,962	2,749
Rent of Premises	6,665	6,665
Staff Salaries	16,611	16,611
Sundries	<u>213</u>	<u>301</u>
	<u>32,277</u>	<u>30,661</u>

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
FINANCIAL ACCOUNTS YEAR ENDED 31ST DECEMBER 2016**

APPENDIX 5: LISTING OF FUNDRAISING ACTIVITIES

	Year ended 31 st Dec. 2016 €	Year ended 31 st Dec. 2015 €
Afternoon Tea for HD (Bernie Spellman)	-	1,705
Art Sale	-	130
Awareness Wristbands	-	144
Carne (Betty & Wally)	1,340	-
Carol Lee Fundraising	4,776	-
Christmas Cards	1,267	1,978
Cork City Marathon	1,286	-
Craft Fair	975	786
D8 Fitness	352	-
Dublin City Marathon	-	643
Dublin Rotary Club	-	2,250
Dublin – Wexford Cycle (M. Keating)	3,280	240
Dunnes Stores Charity Day	3,345	-
Elmgreen Green Golf Club	700	-
Fingal Gospel Choir	560	-
Firhouse Community College	-	137
Half Marathon	1,230	1,082
'Hell and Back' Charity Run	6,392	1,436
Kilmallock Cycle	2,360	2,307
Kilmallock Social Night (Eileen & Timmy)	3,000	-
Kingswood	-	272
Lough Key Awareness Walk	1,948	1,695
Mini Marathon	7,197	2,394
Mobile Phone Recycling	535	134
Mount Sackville Parents Association	3,000	-
Movember (Kevin Moran)	370	-
Pat Davis Knits	-	150
Pearse College	35	356
Postal Celtic Monday Club	-	50
Reek Patrick Climb (In Memory)	4,756	-
Sandycove Vintage and Classic Charity Shop	-	304
Seamus and Nonie (50 th)	-	800
Seamus (in Lieu of Birthday Gifts)	1,290	-
Stephanie O'Reilly	-	700
Stripe – HD Seminar	343	-
Sugar Club	-	145
Sundry Events	200	20
Tuam Charity Dance	1,910	1,500
Veolia Energy (Celina)	752	-
	53,199	21,358

**HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND
FINANCIAL ACCOUNTS YEAR ENDED 31ST DECEMBER 2016**

APPENDIX 6: LISTING OF DONATIONS AND LEGACIES

	Year ended 31 st Dec. 2016 €	Year ended 31 st Dec. 2015 €
Bequeaths / In Memory of...	3,553	1,587
Direct Debit (F.Beirne 220; M.O'Reilly 600)	820	840
Dubco Credit Union	-	1,000
Dulux Paints	500	-
Croke Park Memorial Fund (Padraig)	2,000	
Pat Davis	-	250
Patrick and Mary Alice Lennon	1,000	2,000
Patrick and Teresa O'Sullivan	1,000	1,000
Marin Aer Limited	-	500
Other (including anonymous donations)	<u>4,564</u>	<u>2,644</u>
	<u>13,437</u>	<u>9,821</u>