

Huntington's
Disease
Association
of Ireland



Hope

ANNUAL

Looking forward in hope

2022

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Welcome to the 2022 edition of our Hope Annual

This year things have been gradually opening up and we are seeing more events and meetings taking place in person. Lockdown has given us an appreciation for virtual events and the ease at which we can connect to others in the international community. Online meetings and events such as those hosted by the European Huntington's Disease Network, the Huntington's Disease Youth Organisation,

CHDI and the HD research team at Trinity and Beaumont have helped to keep us connected and they are available online to dip into. HDAI's online Support Meetings were also a way to keep in touch.

But of course it has been wonderful to see people again in person and we hope to avail of both options in future.

We celebrated seeing family members at the Cork, Dublin and Roscommon Support Meetings this year by hosting a long overdue members lunch afterwards and we look forward to meeting members in Limerick soon!

The lockdown has shone a harsh light on inequalities in our health service and we are prioritising the need to campaign for better services and supports for families impacted by HD.

We're determined to make this magazine the best it can be. In this endeavour we need your help, your stories, your lived experiences, your ideas and your contributions. Your story can be anonymously published. Please email us at info@huntingtons.ie



THE YEAR REVIEWED

Our Campaign for a HD Specialist Service

The Huntington's Disease community in Ireland is underserved. We lack the specialist HD supports and services available in other European countries. There are no dedicated HD multi-disciplinary clinics in Ireland currently and no HD specialist outreach service.

Together with the help of family members and clinicians with an interest in improving Huntington's services we are highlighting the urgent need for a fit for purpose HD service. We are fortunate to have the assistance of John Eden, former CEO of the Scottish HD Association who has worked with families impacted by HD in Scotland for twenty years and has collaborated on the development of Scotland's HD Care Framework.



Online meeting February 1st 2022 with Minister Butler, representatives of Minister Rabbitte, Clinicians working with HD and HDAI representatives.

Many family members have been hugely supportive in sharing their experience and calling for improved services. On Page 17 John Eden gives an overview of progress achieved to date.

Family Voices Webinar Series

The Huntington's Disease Alliance UK and Ireland began collaborating on a new series of lived experiences, 'Family Voices' with the first Webinar in May to mark May Awareness Month. Family members from across the Huntington's disease community in UK and Ireland share their experience.



A recording of these webinars are available via our website www.huntingtons.ie

Supports

Support Meetings

It is a joy to return to in person events. We have now held face to face support meetings in Cork, Dublin and Roscommon and hosted a lunch afterwards to welcome new members and allow old friends to catch up.



Information Seminars

Cathy Coughlin, Senior Speech and Language Therapist provided information and tips on speech problems and swallowing difficulties following our Cork meeting. Malika Lancaster, Psychotherapist and Body Work therapist provided a Mindfulness seminar for members following the Dublin Support Meeting in May.

Cognitive Rehabilitation Therapy

HDAI provides access to cognitive rehabilitation therapy for people who are experiencing some cognitive changes following a diagnosis of Huntington's disease. Cognitive rehabilitation aims to support a person with changes to attention, concentration, memory, processing of information and fatigue levels. The aim of the therapy is to reinforce and strengthen positive patterns of behaviour and establish new patterns of cognitive activity to compensate for impaired neurological systems. HDAI contributed to the cost of cognitive rehabilitation therapy for four people we referred in 2021 thanks to assistance from The **Hospital Saturday Fund** who provided a grant of €3,000 in 2021 towards the provision of cognitive rehabilitative therapy for people affected by HD.

Counselling

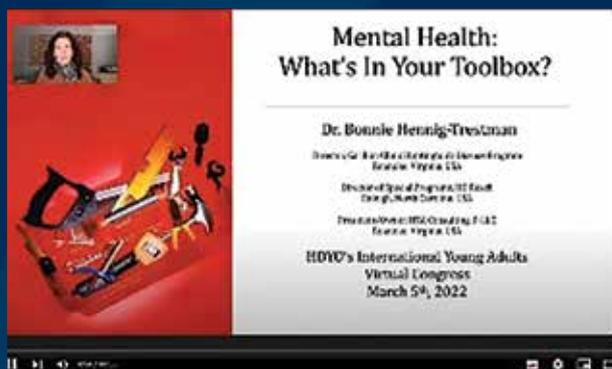
HDAI provide access to counselling for people from families impacted by HD. Counselling is provided by accredited counsellors vetted by HDAI. HDAI received a grant of €2,650 from TUSLA, Child and Family Agency towards counselling provision. HDAI funded counselling for 15 people totaling €7,950 in 2021.

Support for Young People

HDAI's family support officer is available to discuss issues of concern for young people and assist with access to other supports if required. An assistance grant is available for HD families who require financial support for their children to participate in sporting activities, summer camps etc. HDAI can also contribute to the cost of play therapy or counselling for young adults

International Youth Support - Huntington's Disease Youth Organisation is an excellent online resource for young people and also provides practical information for parents and professionals: <http://en.hdyo.org/>. The second international HDYO Congress took place virtually in March 2022 and many sessions are now available to view from their YouTube channel www.youtube.com/user/HDYOFeed/playlists

Matt Ellison, HDYO founder gave an overview of HDYOs at the EHDN 2021 meeting. 7000 young people from 70 countries have contacted the charity since it's foundation in 2012. Approximately 600 young people have taken part in the many international camps organised by HDYO.



HDYO will host their first in person International Young Adult Congress on March 17-19, 2023 in Glasgow, Scotland! Check out their congress website for more details hdyocongress.org

Assistance Fund

HDAI's assistance fund is available to individuals or families who have financial worries around household bills or unexpected expenses such as: costs associated with hospital stays, household adaptations, school / college expenses or bereavement costs. Forty six assistance grants were allocated in 2021 contributing to costs including: back to school / college, heating and household bills, Christmas expenses, bereavement costs and respite / home care support.

Aids and Appliances

In 2021 HDAI provided funding towards a specialist chair, four personal safety alarms, the provision of a specialist cushion and the collection, repair cleaning and delivers of seating.

HDAI are very grateful to Monkstown Hospital Foundation for their generous grant of €3,000 towards the provision of aids and equipment to people living with HD in 2021.

Information on specialist chairs and equipment is distributed to Occupational Therapists and carers on request.

Education and Information

HDAI provides access to information and support in-person or by phone. Family members can also email queries or request a call via our email info@huntingtons.ie

Family Support Officer, Liz O'Sullivan, is available for one-to-one support meetings by phone, or online support.

HDAI quarterly newsletters are posted and / or emailed to those on our mailing list. They are also available online. Our Annual magazine provides a forum for family members to share their stories, receive updates on research and get tips on self-care and health and wellbeing. HDAI welcomes your contributions and feedback.

Huntington's Disease Information Booklets, the European HD Network guidelines for Standards of Care for HD and conference speakers video presentations are available on the HDAI website: www.huntingtons.ie

Information Seminars

Information Seminars for professional carers

HDAI offer talks on 'Understanding HD' to professional care staff. If you think professional carers working with your loved one may benefit from a HD Seminar or other information please ask them to email us on info@huntingtons.ie

Complements received:

- **Senior Medical Social Worker** - *I have recommended your service to patients previously and will most definitely continue to do so, as I have only received positive feedback from patients and families.*
- **Researcher** - *I had a look through the annual just there and am absolutely blown away by how brilliant it is. So comprehensive, upbeat and accessible!*

European Huntington's Disease Network Remote Meeting 2021



The European Huntington's Disease Network (EHDN) Plenary Meeting 2021 took place online from 9-11 September 2021. Anne Rosser and Jean-Marc Burgunder hosted the meeting and were joined by Astri Arnesen, EHA President for the opening address.

There was a variety of presentations on basic research, drug development, testing and treatment and clinical trials. HDAI's Q3 2021 newsletter provides a report and you can also see an update in the HDBuzz article:

<https://en.hdbuzz.net/313>

Awareness

Irish Independent Article

How people diagnosed with rare illnesses including Huntington's Disease face a nightmare ordeal in Ireland

Lack of specialist facilities for people diagnosed with Huntington's Disease in Ireland makes situation even tougher, writes Ralph Riegal



Ralph Riegal
February 27, 2021, 07:28 PM

The Irish Independent published an article on Rare Disease Day which discussed 'the nightmare ordeal' people diagnosed with rare illnesses including Huntington's Disease face because of the lack of specialist clinics in Ireland.

See: *How people diagnosed with rare illnesses including Huntington's Disease face a nightmare ordeal in Ireland - Independent.ie*

Advocacy and Awareness

HDAI's priority focus in 2022 has been to highlight inadequate services and campaign for specialist services. Our activities in May Awareness month included an awareness walk in Phoenix Park, a meeting with Minister Anne Rabbitte and joining in International awareness initiatives.

Social Media

HDAI's social media accounts also provide information on our activities:

- **Facebook:** <https://facebook.com/HDAI.ie/>
- **Twitter:** [@hdai_ie](https://twitter.com/HDAI_ie)
- **Instagram:** [@hdai_ie](https://instagram.com/hdai_ie)
- **You Tube:** [Huntingtons Ireland](https://www.youtube.com/HuntingtonsIreland)

Fundraising and Grants

HDAI appreciate the generosity of family members, friends and supporters who raise funds and donate to help HDAI continue its service.

Fundraising Events included:

Phoenix Park Remembrance Walk

It was wonderful to have the support of so many family members and friends for our HD Walk in the Phoenix Park. We got fresh air, exercise and raised funds for an important cause!

Anne Marie Murphy and the extended Porter family wanted to walk in memory of family members: Fran who died in January 2022 and Tony who died in 2017. Fran's family donated €500 for the walk in her memory. Anne Marie and family members raised sponsorship on and off line, (thanks Amanda, Sonia and Taylor Lo for your online fundraising pages) and a big thanks to all who supported the HDAI online donation page.



The walk has raised approximately €5,000 for HDAI, it has also raised awareness and served as an enjoyable catch up despite some grey clouds!

Sincere thanks to the many families who supported the walk and brought friends along.

Toonagh Walk 2022

Our very kind friends in Toonagh included HDAI once again in their annual Charity Walk which took place on January 16th in Co Clare and raised €2,592.84 for HDAI.



Martina O'Donoghue, Rosemary Foudy, Denise Whelan and Miriam Strand.

The walk, supporting Huntington's Disease, Motor Neurone Disease and Parkinson's Disease, was well supported by local community members delighted to meet outside while social distancing! Approximately €7,000 was raised for the three charities.

Thanks to everyone who supported the walk, particularly to Denise and the walk organising team.

The Space Fundraiser



The Space Hair Soul and Beauty, Drumcondra, Co. Dublin held a Charity Fundraiser for HDAI in December 2021 raising an incredible €14,264.44. Sincere thanks to Selina and Carla McQuillan, Keith Boyle, colleagues, family and friends for this wonderful support. Thank you also for all the social media awareness generated.

Sunrise for Brain Conditions

The Sun Rise for Brain Conditions team put in another incredible effort in 2021 to support Huntington's Disease, Young onset Parkinsons, Motor Neurone Disease and Multiple Sclerosis. In addition to the Virtual Croagh Patrick climb they recruited the marvellous Henley Mermaids who swam 61Km in 14 hours across the Bristol Channel on July 20th.

The group also held a very successful virtual auction in October 2021. Sarah Winckless MBE attended the event and gave a brief talk about her experience of growing up in a HD family and the importance of support organisations.



The team secured some amazing donations for their October 2021 auction including a rowing lesson with Olympic medallist Sarah Winckless MBE, a collection of memorabilia from Irish musician Hozier, £500 vouchers from Peachy Lean Sportswear, €250 voucher for The Shed Distillery, Drumshanbo and €800 worth of Castlecourt Hotel, Westport vouchers.

www.henleymermaids.com/auction

The charity auction raised over €2,000 each for the Irish based charities including HDAI.

Croagh Patrick climb

Claire, Joan and family raised €3,949 for their virtual Croagh Patrick climb for HD in 2021



A huge thank you to John Kelly, Kate Mellor, Joe Condon, Bernie Black Frank Fenn and Peter Kavanagh and friends for organising and coordinating events.



Cliona, Colin Anna & Harry made the arduous Croagh Patrick climb in April 2022 and raised €558.37 for HDAI. Thank you!



Seodhna John and daughter Éabha climbed Croagh Patrick in May 2022 in support of Seodhna's Mum Nuala and in memory of her late brother Karol who died suddenly in March. Thank you for raising € 1,239.16 for HDAI.

Mini Marathon 2022

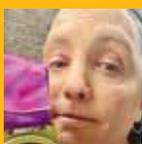
Aisling, Lisa and Marie participated in the Mini Marathon and raised a marvellous €930 for Huntington's disease. Thank you for your continuous support!



A big Thank You to Suzanne, Vanessa and Kelly (above) for taking part in the Mini Marathon and raising a fantastic €530 for Huntington's disease.



Josie Leavy took part in the Mini Marathon once again and raised a wonderful €750 for HDAI. Thanks to Josie's friend who gave a very generous donation of €300.



Dee Jones raised €200 for HDAI from her Mini Marathon in June. Thank you Dee!

Walks and Runs

'Thank You' to the many people who undertook walking and running challenges for us over the year this included:

- **Mini Marathon 2021 participants:** Shannon Hayes €175 and Zoe Brannigan €120.
- **Galway Bay Half Marathon October 2021:** Nina ran in support of her aunt Fiona and raised €2,446.
- **10km Charity Walk:** Róisín Higgins and family raised €1,624.



Ring of Kerry Cycle



Congratulations and a huge Thank You to Oisín Conway who participated in the extremely arduous Ring of Kerry Cycle 175km cycle on July 3rd and raised around €3,286 for HDAI.

Christmas Cards

Bernie Spellman recruited her artist friends Cécile Grenèche and Liam Mahon to contribute to our Christmas Card designs in 2021. The hand painted Christmas scenes were very popular! A big thank you to Bernie Spellman for selling lots of our charity cards and to her friends and colleagues at Pearse College for their support. Thank you also to O'Grady's Filling Station, Co. Sligo and to J. Mulligan's Co. Roscommon for selling cards in their premises. Thanks also to all you who supported HDAI's Christmas cards this year. If you know any budding artists or enthusiasts who enjoy creating Christmas scenes we would love to hear from them.

Membership and Donations

Thank you to all who renew membership fees.

- **Direct Debit donations** from Fiona, Martina, Paul, Zil and Ger. **Benevity:** Roseanne Evans.
- **iDonate:** David, Fergus McGrath (in honour of Paul), Hazel, anonymous - *'your good work is much appreciated'*. Cécile Grenèche *'on behalf of Michael and Bernie'*. Triona Hanly, Brid Sinclair.
- Patrick and Teresa O'Sullivan - €1,000, Seamus €1,000, Robert - €330 *'in support of the Porter family'*, Mary B Walsh, Moira MacManus, Stephen Gorman, Francie Gibbons *"Keep up the good work"* Catriona, Laura, Melissa. Eva *'Fantastic cause. great support for such a debilitating disease'*, Geraldine K, Angela Power, Christmas gift €60 to HDAI for Bernadette Spellman and Micheal Bird from John, Grace & Riley.
- **Hand Knits:** Nancy Shannon created beautiful crochet blankets and received donations of €265 for HDAI. Íde, Máire and friends raised over €300 during the year from sales of Máire's beautiful hand knits.
- Mick Scanlan regularly donates his generous coin collection.
- Anna Porter's friends at the All Saints Church Raheny Group and the St. John's Coolock Tuesday Morning Badminton Club
- Irish Life Group Services - €500.



In Memory

HDAI received very generous donations in memory of departed loved ones. Thank you to the family and friends of Austin, Simon, Phil Fogarty, Robert Murphy, Beccy Perry, Tony Porter, Fran Stacey and Ellen Whooley.

Thanks also to family and friends of the late Tony Porter, Tom Connern and his cousins Michael and Jarlath, who donated in their memory and to Jane Merrigan who climbed Croagh Patrick and donated in memory of her Uncle Phell (Pat) Carty. Sincere thanks to families who donate to HDAI in their time of loss and who request donations in lieu of funeral flowers.

Bequest

The late Bryan O'Hara bequeathed €10,000 for HD research. The HDAI Board have agreed to allocate this to the research led by Professor Niall Pender and Professor Orla Hardiman of Beaumont Hospital, Dublin.

GRANTS

Statutory Funding

- **Health Service Executive.** The HSE provided annual core funding of €68,294 to HDAI in 2021 to provide information and support to those impacted by HD.
- **TUSLA Child & Family Agency** contributed €2,650 towards HDAI's counselling service in 2021.

The Hospital Saturday Fund

HDAI were successful in our application to the Hospital Saturday Fund who provided a very generous grant of €3,000 in 2021 towards the provision of cognitive rehabilitative therapy for people living with HD.

Monkstown Hospital Foundation

Sincere thanks to the Board of Monkstown Hospital Foundation for awarding HDAI generous grants of €3,000 in 2021 and €4,000 in 2022 towards the provision of assistive equipment for people living with HD.

COVID-19: Stability Scheme

The Department of Rural and Community development (DRCD) awarded HDAI a COVID-19: Stability Scheme for Community and Voluntary, Charity and Social Enterprise Organisations (CSS) grant of €10,222 in 2021..

Roche Products (Ireland) Ltd

HDAI was successful in a grant application to Roche Products (Ireland) Ltd. Huge thanks to Catherine Moynagh and the team at Roche for their very generous grant of €10,000 received in 2022 to be used to support the mapping of a Care Pathway for Huntington's Disease in Ireland.

Annual General Meeting

HDAI's 2021 AGM was held in the Carmichael Centre and virtually on September 18th. Thomas Lillis, Chair, welcomed everyone and gave a report on HDAI's activities with regard to the associations goals:

- Promote a better understanding of Huntington's Disease
- Strengthen the Huntington's Disease community in Ireland
- Advocate for Improved HD Services
- Ensure HDAI Sustainability

He thanked our remarkable volunteers and gave a special thanks to the Toonagh Walk and Sunrise for Brain Condition teams in addition to the Ahern family for their very successful family reunion fundraiser in 2020 just before the Covid lockdown!

The 2020 Audited Financial Statements distributed before the meeting were adopted and are now available on our website. Elected Board members are: Thomas Lillis, Anne O'Shea Clarke, Deirdre Jones, Anna Porter, Valerie Moran, and Elizabeth Savage who joined in 2021. Thomas thanked the board for their voluntary work and paid tribute to HDAI staff members for their commitment.

Collaboration

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

Umbrella Organisation Activity

HDAI is a member of International organisations which include:

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

Membership of National umbrella organisations include:

- Care Alliance
- Carmichael Centre for Voluntary Groups
- Disability Federation of Ireland
- Rare Diseases Ireland
- Mental Health Reform
- Neurological Alliance of Ireland

The European Huntington Association (EHA) is an umbrella organization formed by Huntington's disease (HD) associations all over Europe. It represents more than 30,000 individual members. It aims to: Support Huntington's Disease affected families by encouraging collaboration and raising awareness throughout Europe – **because we are Stronger Together!**

The EHA actively raises awareness, disseminates information of relevance to the HD community and represents the European HD community in relevant European work. EHA is an active member of European Federation for Neurological Associations (EFNA) and contributes to the work of the European Reference Network for Rare Neurological Diseases (ERN-RND). EHA is also member of Eurordis (Rare Diseases Europe).

The EHA produces awareness videos and uses Social Media to promote Huntington's awareness. EHA asked people impacted by HD to share their photos for a HD video to mark Rare Disease Day and created a video for May Awareness month.

EHA Resources Webinars

The EHA, in collaboration with health professionals and family members, provide a range of interesting HD related webinars on their website

<http://eurohuntington.org/>

The EHA coordinates patient representation PPI (Patient Public Involvement) in research studies including DOMINO-HD, HEALTHE-RND, IDEA-FAST, SEEING-HD and Huntington's Disease Burden of Illness Study.

The EHA launched a survey to map how people living with Huntington's disease and family members experience access to support and care all over Europe earlier this year and will report on the findings.

Rare Diseases Ireland

HDAI is a member and is represented on the board of Rare Diseases Ireland which works as an alliance of voluntary groups, involved with genetics and other rare disorders. <http://rdi.ie/> Rare Diseases Day 28th February provides an opportunity to highlight issues of common concern for the rare disease community.

Rare Diseases Ireland's 'Raise A Toastie' awareness campaign was supported in 2022 by Adam King (who so effectively shared his hugs on the Late Late Toy Show).

A National Rare Disease Office is based at the Mater Hospital, Dublin. It has responsibility for: the mapping and validation of Centres of Expertise, developing Orphanet and maintaining a rare disease helpline.

Neurological Alliance of Ireland (NAI)

The Neurological Alliance of Ireland (NAI), is an umbrella group with over thirty member groups involved in supporting people with neurological conditions and their families. The NAI represents its members on a number of platforms to promote awareness and highlight the needs of people with neurological conditions and their families.

Together with member groups including HDAI the NAI launched their **#PatientsDeserveBetter** campaign in October 2021 to call for more specialist nurses across neurology services. Nurse specialists play a crucial role in supporting people with neurological conditions. Increasing the number of neurology nurses will ensure that people with neurological conditions have improved access to healthcare supports and reduce the time they are waiting for appointments. HDAI are participating in the campaign and some family members raised questions at the various regional launches to highlight the need for Huntington's Disease specialist nurses. You can see more information at:

<https://www.patientsdeservebetter.ie>

The NAI's Brain Awareness Week in March promotes greater awareness and understanding of the brain and brain conditions as well as the need for more investment in services, research and prevention. HDAI joined in the calendar of brain related events by hosting our awareness event at Leinster House and an Information Seminar in Cork during the month of March.

Carmichael Centre

HDAI is a resident member of the Carmichael Centre which is the first and largest shared services centre for the community and voluntary sector in Ireland.

Carmichael Centre delivers services that help to build stronger charities nationwide. Services include administration, postal, meeting, catering, IT, training, consultancy development and governance support.

<https://www.carmichaelireland.ie/>

Care Alliance Ireland

Care Alliance Ireland is the National Network of Voluntary Organisations supporting Family Carers. Their vision is that the role of Family Carers is fully recognised and valued by society in Ireland. Care Alliance Ireland aims to enhance the quality of life for Family Carers. Carers Week takes place each year in June.

<https://www.carealliance.ie/>

Disability Federation of Ireland

Disability Federation of Ireland advocates for the voluntary disability sector - supporting organisations to enable people with disabilities.

<https://www.disability-federation.ie/>

Mental Health Reform

Mental Health Reform aims to drive progressive reform of mental health supports in Ireland.

<https://www.mentalhealthreform.ie/>



About HDAI

HDAI is based at the Carmichael Centre, North Brunswick St., Dublin 7. HDAI's Board has representatives from Dublin, Kerry and Kildare currently and welcome interest from other counties. If you have skills to offer but distance is a problem you can now attend virtually.

The board are responsible for the Associations governance. Thomas Lillis is our current Chairperson and Anne O'Shea Clarke is voluntary Treasurer. Board members represent HDAI at various meeting and seminars and regularly liaises with staff to progress the work of HDAI.

A financial audit is carried out each year before our annual AGM. Copies of our annual financial statements are available online and hard copies are available to members on request from the office.

Patricia Towey works full time as Director of Information and Services Coordinator and Elizabeth O Sullivan works part time as Family Support Officer.

HDAI offers the following information and support to all those affected by HD nationwide.

- Consultation as required for all those impacted by HD
- Family Support Officer available to support family members
- Access to counselling for members of HD families and access to cognitive rehabilitative supports for people with a diagnosis of Huntington's disease
- Support in advocating for services
- Support group meetings / Carers Workshops
- Publications sent on request to individuals, families and health professionals
- Quarterly newsletter
- Annual magazine
- Support for Young People
- Assistance Fund
- Promoting HD research
- Provision of specialised equipment such as specialist chairs, personal alarms, tablets etc
- Information seminars to interested health care personnel
- HDAI ID card for people with HD

If you wish to avail of the above services please contact us in confidence by phone or email info@huntingtons.ie. Remember you don't have to be a member to get help, we offer these services to all individuals, and families affected by HD who require our assistance.

Information and Services

Patricia Towey, Information and Services Coordinator



Patricia provides consultation, information support and advocacy to HD patients and their families. Patricia's role includes updating information and distributing it to families and health and social care professionals, organising seminars and events,

producing a quarterly newsletter and annual magazine.

Patricia is also responsible for organising our Annual General Meeting, managing the HDAI office, submitting applications for relevant funding, promoting HD research, providing assistance to voluntary fundraisers, corresponding with media, meeting the reporting requirements of the HSE, Statutory agencies and other funders, updating HDAI's policies and procedures, supervising volunteers, facilitating board meetings and representing HDAI at relevant umbrella organisation meetings. She liaises with national and international organisations to pursue the aims of HDAI.

Family Support

Liz O'Sullivan, Family Support Officer



Liz is available to meet and talk with individuals and families in need of support and information. Liz is a qualified Counsellor and Psychotherapist and can meet people affected by HD on request and provide telephone / ongoing support to those impacted by HD. She hosts carers

workshops, support meetings, seminars for professionals and organises counselling for people when required. Liz works part-time on Mondays and Fridays but is available on her mobile in emergencies outside of these times.

INFORMATION



Research News

The following websites offer up to date information on HD research news:



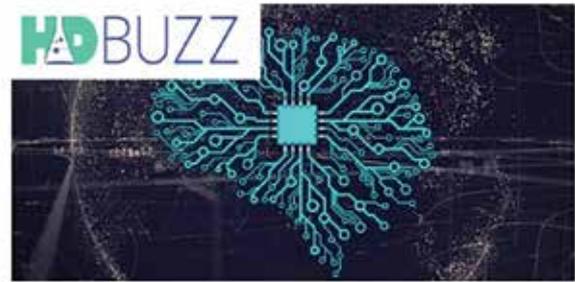
CHDI Foundation is a privately-funded,

not-for-profit biomedical research organisation devoted to HD. Their stated mission is to “Rapidly Develop Therapeutics That Slow the Progression of Huntington’s disease.” CHDI Foundation activities extend from exploratory biology to the identification and validation of therapeutic targets, and from drug discovery and development to clinical studies and trials.

CHDI’s latest Therapeutic Conference took place in February 28 - March 3, 2022. The conference focuses on drug discovery and development for Huntington’s disease, and provides a forum for participants to share ideas, learn about new disciplines, network with colleagues and build new collaborative partnerships.

The ‘Postcard From Palm Springs’ video, directed and produced by Charles Sabine and Simon Noble, provides a summary of the recent progress in HD research.

Unfortunately, there has been some recent negative news from the Novartis Trial featured in the video. HDBuzz provide an update on their website **HDBuzz - Huntington’s disease research news**, where you can also read about other research trials.



Artificial intelligence to save the day? How clever computers are helping us understand Huntington’s disease.

Scientists at IBM and the CHDI Foundation have used artificial intelligence to analyse datasets from Huntington’s disease observational trials to model progression of the disease. They hope their findings will help improve clinical trial design.

Dr Rachel Harding | June 21, 2022

HDBuzz provides high-quality HD research news online to the global community, written in plain language, by HD clinicians and scientists. Co-founded by Dr. Jeff Carroll (USA) and Professor Ed Wild (UK) in 2011, the HD Buzz team has now increased.

For people new to Huntington’s disease, the Start Here page <https://en.hdbuzz.net/056> gives an overview of HD research and highlights some of the most promising things scientists are doing to come up with effective treatments for HD.

HD Buzz <http://hdbuzz.net/>



<http://chdifoundation.org/>



The European Huntington’s Disease Network EHDN is a non-profit research

network committed to advancing research, facilitating the conduct of clinical trials, and improving clinical care in HD. Scientists, clinicians, patients and families can collaborate through the EHDN on academic and industry studies to advance HD research. The EHDN is supported by and collaborates closely with CHDI Foundation, Inc.



The EHDN publish a newsletter three times a year which communicates the network's activities and other developments of interest in the field of Huntington's disease. You can receive their newsletter by requesting it through their website

EHDN's 2022 Conference takes place in Bologna, Italy from **16-18 September 2022** so keep an eye on their website for further information. <http://www.ehdn.org/about-ehdn/>



The Huntington Study Group facilitates clinical research trials and studies in

Huntington disease (HD). It has a research network of over 400 investigators, coordinators, scientists and HD experts dedicated to seeking treatments that make a difference and improving the quality of life and outcomes for families affected by HD. <http://huntingtonstudygroup.org/>

Check out their Care Education Videos at <http://huntingtonstudygroup.org/care-education-videos/>

HEALTH-RND

This project aims to use HD to develop a multilingual e-health platform to improve quality of life in individuals affected by rare diseases. Project participants include professionals from Huntington centres and research institutions in Germany, the Czech Republic, the Netherlands, the United Kingdom, Ireland (Trinity College) and Italy. The project actively collaborates with the EHA to include patient and family member involvement as research partners in all phases of the project. The EHA hold patient and family meetings with representatives from the countries involved. HDAI are grateful to Anne Lennon Bird for participating in these meetings and would also like to thank Irish family members who have participated in pilot interviews and volunteered to participate. <https://healthe-rnd.eu>

Irish Research Studies

Volunteers Needed for Huntington's Disease Research!

Researchers at Beaumont Hospital and Trinity College Dublin, led by Professor Niall Pender and Professor Orla Hardiman, are seeking volunteers to participate in research into Huntington's disease in Ireland.

Please contact us if you are a 18+ and fill into any of the following criteria:

1. First and second degree relatives of people with Huntington's disease (parents, siblings, children, uncles, aunts, nephews, nieces, grandchildren, half-siblings)
2. People **with** the Huntington's disease gene, at any stage of disease
3. Spouses / Caregivers of patients with Huntington's disease
4. Non-HD volunteers who are **NOT** related to anyone with Huntington's disease (e.g. Friends, carers, partners/spouses)

This research involves completing an online questionnaire at your convenience.

You may also be invited to participate in more detailed research involving an online neuropsychological assessment and a brief physical examination at a later date. There are **potential** extra research fees and will be discussed with you individually if you are interested and depending on suitability.

For more information please contact:

Mr. Colin Peelo
Dept. of Neurosciences, Beaumont Hospital
Email: colin.peelo@beaumont.ie
Phone: 01 4081001 / 089 4220308

OR

Dr. Sarah Barry
Dept. of Neurology, Beaumont Hospital
Email: sbarry@hda.ie
Phone: 089 2464402

The HD Researcher team at Beaumont Hospital and Trinity College Dublin, led by Professor Niall Pender and Professor Orla Hardiman, continue to seek volunteers to participate in research.

For further information email enrollhd@beaumont.ie or see:

www.huntingtons.ie/volunteers-needed-to-help-in-huntingtons-disease-research

Useful Websites

Huntingtons Disease Association of Ireland
<http://www.huntingtons.ie>

Bloomfield Health Services
<http://www.bloomfield.ie>

Beaumont Hospital Mindfulness Centre
<http://www.beaumont.ie/marc>

CHDI Foundation
<http://chdifoundation.org/>

European Huntington's Association
<http://eurohuntington.org>

European Huntington's Disease Network
www.euro-hd.net

Enroll HD
<http://enroll-hd.org>

Huntingtons Disease Youth Organisation
<http://en.hdyo.org/>

International Huntingtons Association
<http://www.huntington-assoc.com/>

Hereditary Disease Foundation
<http://www.hdfoundation.org/home.php>

Huntingtons Disease Association N. Ireland
<http://www.hdani.org.uk/>

Huntingtons Society Canada
<http://www.hsc-ca.org/>

Huntingtons Disease Association UK
<http://www.hda.org.uk/>

Huntingtons Disease Society of America
<http://www.hdsa.org/>

Scottish Huntington's Association
<http://www.hdscotland.org/>

HD Family Matters
<https://hdfamilymatters.com/>

Huntington Study Group
<http://huntingtonstudygroup.org/>

Dublin Brain Bio Bank
http://www.iicn.ie/research/dublin_brain_bank.508.html

Department of Health
<http://health.gov.ie/>

Department of Children, Equality, Disability, Integration and Youth
www.gov.ie

Department of Social Protection
<http://www.welfare.ie>

Citizens Information
<http://www.citizensinformation.ie>

Family Carers Ireland
<http://familycarers.ie/>

Mental health Support websites include:

www.yourmentalhealth.ie
www.mentalhealthireland.ie
www.aware.ie
www.shine.ie
www.pieta.ie

Speech & Language Therapy

Cathy Coughlin, Senior Speech and Language Therapist Cork & Kerry Community Healthcare provided an excellent seminar to Cork Support Group members in March 2022. Please see below some of the information Cathy provided to manage speech and language difficulties. Cathy's presentation slides are available on request – email info@huntingtons.ie

Role of the Speech and Language Therapist

- Initial Assessment
- Identify the needs of the person and caregivers
- Determine the need for therapy
- Link with the relevant teams
- Provide support as required

Word Finding and Conversation Tips

When a person cannot find the right words, it can affect how they express their needs, wants, emotions and thoughts, preventing them from taking part in conversation like they used to.

For some people this can be isolating and difficult to come to terms with. Providing some help or cues to retrieve the word helps the person maintain independence and allows them to speak for themselves.

Tips to encourage conversation include:

- Be Patient: Give the person extra time before asking whether they need help
- Avoid distractions: Turn off / avoid background noise
- Use Gestures:



If you are living with **Huntington's Disease (HD)**, it is important to link with a **Speech & Language Therapist as soon as possible**, preferably shortly after diagnosis, in order to maximise your communication and swallow potential - so that you can continue to **live as well as possible with HD.**

Anita Condron -
Acting Senior SLT
(PoLL Team, Portlaoise)



From my experience working with people with **Huntington's Disease (HD)**, in many instances they are not referred to SLT services until their **communication and swallowing difficulties** have significantly advanced.

When there is a late referral, it is more difficult to put the required supports in place, to help the person with HD and their support network to manage the difficulties they are experiencing.

Anita Condron -
Acting Senior SLT
(PoLL Team, Portlaoise)

Images via
Twitter posted
win support of
May Awareness
Month



Dysarthria occurs when the muscles you use for speech are weak or you have difficulty controlling them.

Tips for Managing Dysarthria

For the Speaker:

- Speak more slowly
- Pause more frequently to take a breath
- Try to clear your mouth of saliva before you speak
- Emphasise words and break them into distinct syllables
- Use short sentences
- Start sentences with a key word to get your point across early
- Avoid background noise, for example turning off the television while talking
- Use gestures to emphasise or replace speech
- Pause if you cannot think of a word, try using a different word that means the same, or describe the word.
- Use drawing, writing, or an alphabet board to supplement speech and/or language

For the Listener:

- Face one another and watch the person's face and lips
- For longer conversations, sit in a quiet room and avoid distractions
- Keep a pencil and paper or a communication board handy
- Encourage the speaker to pause between phrases and rest often
- Encourage the person to over-articulate their speech as this will help make speech clearer
- If speech is becoming tiring for the person encourage them to gesture or point
- Use questions that only need a yes or no answer. For example: 'Would you like a cup of tea?' rather than 'Would you like tea or coffee?'
- Ask one question at a time and allow the time it takes for the person to answer
- If you are struggling to understand what the person is saying, asking yes or no questions to find out what they were saying can be more helpful than asking the person to repeat themselves.
- Don't change the speed or volume of your speech, unless the speaker has hearing loss

Common Features of Language Changes in HD

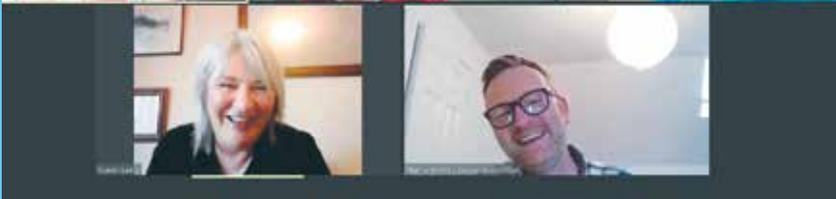
- Difficulty understanding conversation and requests
- Difficulty remembering names of people, places or objects
- Increased time required to process language and respond
- Use of simplified or less words
- Challenges understanding humour, sarcasm and non-literal language
- Unable to stick to a topic of conversation
- Preservation of certain topics

Tips for Supporting Language in HD

- Always face the person you are speaking with
- Give time
- Say the person's name first when beginning to speak
- Use direct language such as "Give me the cup" rather than "Give it to me".
- Use names instead of pronouns. For example avoid "She told her boss that he was out of line when he asked her to work late" and use names "Mary told her boss, Mr. Murphy, that he was out of line when Mr. Murphy asked Mary to work late".
- Use an active rather than passive voice. "The car hit the dog" instead of "The dog was hit by the car".
- State the topic of the conversation: "Dad we are talking about the Ireland and England match".
- Support word finding difficulties by giving cues such as the first letter of the word, a social cue or a description to help retrieve the word.
- Discuss communication challenges. Ask the person with HD if they would like you to help them and what way.
- Use non-verbal cues such as facial expressions, gestures
- Ask yes/no questions such as "Do you want tea?" instead of "Do you want tea or coffee or orange juice?"
- Use technology to support conversations - use pictures, google maps, speech apps.
- Communication is always possible! Assistive Technology can be in the form of basic communication books to computer assisted.



PHOTO GALLERY







ADVOCACY & AWARENESS

Advocating for HD Services

Misunderstandings around Huntington’s disease and the consistent lack of appropriate services places an added burden on families affected by HD.

The Covid-19 pandemic has exacerbated the challenges for families due to difficulties seeing a GP, linking in with community rehabilitation and mental health services or accessing home care support. Families affected by HD in Ireland need to have access to the type of specialist services available in the UK and other European countries. Huntington’s Disease Association of Ireland (HDAI), wanting to build upon the awareness raised through our Family Matters UK and Ireland campaign last year, commissioned John Eden, former CEO of Scottish Huntington’s Association to provide strategic support to campaign for improved services.

We have received wonderful support from many family members who have contacted their TDs to ask for improved services. Others have bravely shared their stories directly with politicians and health Ministers. John Eden’s wealth of experience in developing HD services in Scotland has been of tremendous value to HDAI. We are so lucky he decided on semi-retirement!

The Thing About Retirement...

I am John Eden, former CEO of Scottish Huntington’s Association. I left my post in March 2021 to enjoy what I like to call semi-retirement by which I mean the first step that gets you up to the front door marked ‘Oh my god, how did I get so old!’

I loved my twenty-one years at SHA, and it was the privilege of my life to work with HD affected families in Scotland, but all good things must come to an end, and endings are a doorway through which we must all pass. I was fortunate, as I passed into the next phase of my life, to be able to look back over my shoulder with a sense of contentment, fulfillment, and satisfaction at what the charity had accomplished during my time at the helm.

Although I was ready to hang up my CEO suit, I wasn’t ready to give up work completely and I now have two part time roles. In January, this year,

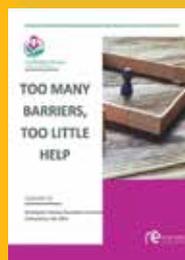
I started working for another charity called Scottish Care where I am the Independent Sector Lead for Renfrewshire Health and Social Care Partnership. In that capacity, my job is to

improve how services are joined up so that the people who need them get better quality care. I do that for two days a week. In my second role, I set up a consultancy working with small charities who need support with their strategic development and in that capacity, I had contact with Patricia Towey and the Board of HDAI.



I started working with HDAI in late October, last year, with the central aim of developing a strategy that would lead to a specialist service for HD affected families in Ireland. I am a big fan of what I call ‘evidence-based advocacy.’

Often it is apparent to families and frontline staff that services are lacking, but persuading Government Health Departments, requires concrete proof.



Using my experience from Scotland, and in particular the Scottish HD Care Framework, I completed an assessment of the current services in Ireland and produced a report called, **‘Too Many Barriers, Too Little Help.’** The report presents a fair and comprehensive picture of

a health and social care system that is not meeting the needs of people with HD and their families.

With that evidence, we began lobbying Ministers and TDs and over several months, we met with Mary Butler, Minister for Mental Health and Older People, John Lahart TD, and several others. We sent every TD the report, asking for their help. Numerous Parliamentary Questions were raised, responses from the HSE digested and debunked! With John Lahart’s support, we held a well-attended event at Leinster House, and we asked family members to become involved in lobbying their local TD.



It has always been my experience that the voices of HD families have the greatest impact and once again it was those voices that unlocked the political doors we were seeking to open, and my thanks go to those family members who had the courage to speak out.

While this was all going on Patricia, and I also worked with the HSE staff involved in the care of people with HD at Beaumont Hospital and the team at Bloomfield. Believing our lobbying efforts would manifest changed understanding of the need for a specialist service, we designed a model for what it would look like so that if we were asked what was needed, we had a clear answer.

In a serendipitous week, in May, Minister Mary Butler visited Bloomfield Hospital and a family member met with Minister Ann Rabbitte, Minister for Disability. Both were hugely impacted by those encounters and met later to discuss how families could be better supported.

On the following day Patricia, a Board member and I also met with Minister Anne Rabbitte. History will record this period as the turning point for HD services in Ireland with both Ministers acknowledging the need for a specialist service and committing to do what they could to make that happen.

Since then, the HSE has held a one-day workshop in June, to design a specialist care pathway, and Bloomfield Hospital, at the behest of Mary Butler, has also been working on plans for enhancing its own provision.

The HSE has now produced a business plan, yet to be given final approval and Bloomfield is awaiting a response from Mary Butler's team about their proposals.

A great deal has changed over the last few months. There is now greater political awareness of HD and in particular, we have won the support of two Health Ministers who have recognised and now support the need for a specialist service for HD affected families.

HDAI has been a catalyst for the HSE developing a care pathway. Business plans have now been submitted to improve services with the very real prospect that we will see significant developments in HD service provision commencing in 2023

So, the thing about retirement is... even though I am thoroughly enjoying both my new roles and the fact I have more time to do the things I enjoy, like walking, writing, spending time with friends and family, and reading, I still love working with HD affected families and I still love making a difference to the way the services that support them are developed.

HDAI is a superb grass roots charity and a wonderful advocate of the HD community in Ireland, and it is once again my privilege to work with them and to help transform care for everyone affected by Huntington's disease.





Delegates at the HSE Huntington's workshop in July

Awareness Activities

Members of the Huntington's Disease community, relatives and friends gathered in the Phoenix Park on Saturday April 30th to mark Huntington's Disease International Awareness Month.



People walked in memory of loved ones and in solidarity with the 1,000 Irish people who are living with symptoms or with the altered gene that triggers the disease and with over 3000 people who live at risk. Thank you to Annemarie Murphy and extended members of the Porter family who

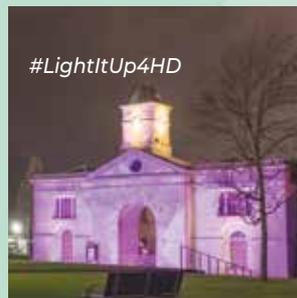
suggested the walk in memory of deceased members of their family.

Meeting Minister Rabbitte

As part of our ongoing work to advocate for improved services HDAI representative Anne Lennon Bird, John Eden and Patricia Towe met with Minister Anne Rabbitte on 24th May 2022.

Messages of Support

Councillor Íde Cussen and colleagues at Kildare County Council kindly supported the [#LightItUp4HD](#) campaign.



The Irish Association of Speech and Language Therapists posted messages of support on Twitter for HD Awareness month and recommended that people with HD receive early referral to Speech and Language services

Recognition for Family Matters Campaign



M+F Health, the Communications and Public Affairs Agency who devised the 2021 Family Matters campaign on behalf of the Huntington's disease Alliance, won a Charitable Campaign of the Year Award at the Communiqué Awards 2022 for The HD Family Matters campaign. <https://hdfamilymatters.com>

was considered by the judges to be 'head and shoulders above the rest'



The M+F Health Team celebrate at the Awards - photo via Twitter



About JOIN-HD

JOIN-HD, the Juvenile onset Huntington's disease Global Registry is managed by the Huntington's Disease Youth Organization (HDYO). JOIN-HD opened to enrollment for young people with JoHD and their families in February 2022.

The registry collects experiences from both young people who have JoHD and their caregivers. JOIN-HD will be carried out in 3 stages, with increasing information being collected at each stage. At stage 1, participant's demographic data will be collected, along with information about any links they have with the HD community. At stage 2, information on both medical history and caregiver and patient experiences of JoHD will be collected. Stage 3 will incorporate a clinician-led interview and taking of family history. The information people add to the registry will help us understand more about JoHD.

Goals of the Registry

- Identify and engage people with JoHD in the collection of information that will speed up research into this disease.
- Improve advocacy, care, and support for young people with JoHD and their families.
- Contribute towards creating a multinational network of leading healthcare JoHD professionals.
- Learn what people with JoHD and their families need so we can improve support and education programmes.

What Happens After Someone Registers?

After participants express their interest in taking part, the registry coordinator will hold one-on-one screening calls with each of the families. Each participant will then receive login credentials to create an account on the JOIN-HD website and complete questionnaires, which at stage 1 include important demographic data and information on their links with the HD community. If the appropriate consents have been given, participants will be contacted with future research opportunities, including later stages of JOIN-HD when they become available.

Later Stages

Stages 2 and 3 of JOIN-HD will include additional questionnaires to gather more in-depth information about patient and caregiver experiences including medical history, life experiences, and family history. The required approvals will be obtained before these stages begin. Participants will receive new information sheets and be re-consented at each stage.

The Team and Scientific Oversight Committee

- Dr. Rebecca Mason - JOIN-HD Program Coordinator
- Dr. Lauren Byrne - JOIN-HD Chief Investigator/HDYO Research Co-Chair
- Dr. Bonnie Hennig-Trestman - HDYO Research Co-Chair
- Dr. Martha Nance - Medical Director, Struthers Parkinson's Center, Clinical Professor of Neurology at University of Minnesota and Director of HD Center of Excellences at Hennepin County Medical Center
- Dr. Jean-Marc Burgunder - Professor of Neurology, Senior Consultant in Neurogenetics University of Bern
- Dr. Leon Dure - Professor & Director of the Division of Pediatric Neurology at the University of Alabama at Birmingham, USA
- Helen Santini - Specialist JoHD Adviser for the HDA of England and Wales
- Dr. Oliver Quarrell - Consultant Clinical Geneticist and lead facilitator of the EHDN Pediatric HD Working Group
- Dr. Benjamin Wilfond - Director of the Treuman Katz Center for Pediatric Bioethics at Seattle Children's Hospital and professor and chief of the Division of Bioethics in the Department of Pediatrics at the University of Washington School of Medicine

What You Can Do

The HD community is excited to participate, to connect with each other globally, and to provide information that will propel future research for JoHD patients. Join-HD wants to connect with as many families as possible to speed up research and improve care.

If you are currently impacted, or have been impacted, by JoHD, please consider contributing.

More information about the Registry can be found on the [Join-HD registry page](#). For any additional information or questions, email Rebecca at registry@hdyo.org



MEMBERS STORIES

Looking Back

by Shauna Rahman

I had written the below to the Editor at The Irish Times in the summer of 2020. It wasn't printed (as far as I am aware) but it was cathartic to write, and it gives an insight into our frustrations at not being able to support our Mum the way we wanted to.



Now as things return to pre-pandemic ways, I sincerely hope the emphasis placed by society's leaders on prioritising the population's 'health and well-being' with regard to Covid will now focus on those people who, because of their particular health issues, are isolated and forgotten about. People living with HD do not have specialist services and families struggle to get supports they need. Our uncle may not have died from Covid in an acute hospital if he had the specialist care he needed earlier in his illness.

Families living with HD need more support, more recognition and more awareness from healthcare professionals; Government; and society in general.

We do not have the right healthcare assistance, resources, or legislative rights that other more commonly known disease communities have and this has to change. HD families need to speak with confidence about their experiences and feel positive about our futures should we develop the disease. I am grateful that I can be a part of HDAI awareness initiatives.

Letter to the Editor

Sir,

When you look at the word 'lead' and its definition in its various guises, it is surprising how many different interpretations there are out there.

'Lions led by donkeys' is a popular phrase used to describe the Allied infantry of World War I and to blame the generals who led them. The contention is that the brave soldiers (lions) were sent to their deaths by incompetent and indifferent leaders (donkeys).

In the Cambridge Dictionary 'to lead' is described as controlling a group of people, a country, or a situation.

On other platforms, 'lead' is used in place of 'a guide' or 'being/presenting' an example for others to follow.

I have been thinking a lot of what the actual meaning of the word is since the infamous 'Golfgate' dinner has been exposed. How 45+36 (remember the important room partition) members of our politicians, judges, media, and in general, people in the public eye, forgot what it means to lead.

I can only speak for my own family's experience this year dealing with Covid-19, but I know ALL families here deserve better leadership.

It has been 185 days (at the time of writing) since the birth of my daughter in March and it is 185 days that my mother, who is in Our Lady's Hospice and Care Services in Harold's Cross, due to her Huntington's disease diagnosis and deterioration, has missed out on as the pandemic restrictions mean I am not permitted to bring my daughter in to see her.

Although my family stay positive and it was announced, during the RTE News on July 29, that the Government would allow grandchildren to visit their loved ones in nursing homes/hospices, this has now been pulled back again because of the rising of cases in the country.

Of course, this is understandable. We have to protect our most vulnerable, but the emotional and physical impact on my mum and my family is too difficult and upsetting to articulate. My dad has followed all the cocooning rules and ensured he only went to the supermarkets and other outlets at the allocated times for his demographic.

He has gone from spending every day, seven days a week visiting and bringing my mum out to having 20-30 minutes per week (recently extended to 40 minutes) visiting time with maximum two people from the same family/household per visit. My poor parents practically cling to one another when it is time for us to go.

My mother and many of us never got to attend the funeral of my wonderful uncle (also diagnosed with HD), who was only 66 when he passed away from Covid-19 in April, leaving our cousins, his wife and his four brothers and his sister, my mother, devastated.

He had contracted the virus through contact with healthcare workers (who should be admired for continuing to work tirelessly when the situation was dire and had no choice in the matter) whose Covid-19 tests were delayed at the height of the cases. His death was avoidable.

His daughter, my beautiful cousin, is getting married in September. She and her husband-to-be deserve the wedding of their dreams (like so many others), especially now that her beloved dad won't be there. They moved their wedding from August to September.

They are accommodating social distancing in the church and in the hotel where they will have the reception. They have cut their numbers to 50 and they are determined to follow all guidelines to ensure the safety of everyone.

My point of all of the above is to outline how the virus has impacted my family. But, we are not unique. Covid has impacted every single one of us and we all have our own stories to tell, especially my fellow HD families in Ireland.

We have been following our Government announcements every day to see how the new cases and tragic deaths will influence the current state of our daily lives. We have watched, day after day, as the pandemic gnaws at every country globally. We have supported, listened and rebelled at times when asked to comply with NPHET advice. Overall, we have, as a majority, tried, to the best of our own different circumstances, to fight and overcome this virus that is destroying so many lives.

There are many public representatives and politicians and ministers that can hold their heads up high and be confident that they are purposefully serving the public, who voted for them.

But, there are too many, who resign with full pensions, golden handshakes and huge salaries. Those who know what they are doing is wrong but 'sure feck it' I'll apologise, resign or lie low until it has all died down.

These 'leaders' have failed their people in their darkest hour. I don't believe they are fit to represent their communities in any capacity. They should be made accountable and relinquish all benefits related to their 'so-called' public service.

Enough is enough. We have all had enough.

Be leaders. Do not be led.

Shauna Rahman
Greystones, Co. Wicklow

Remembering Beccy

Beccy and I both lived in the same estate in Sligo town. Beccy grew up in the UK but moved to Sligo at the age of 14 to live with her mother's sister Sue and their family. She loved being part of their family and was always treated as one of their own.

We met in 2004 through our work at the time. One night in the local nightclub when the drink was in and the courage was up, I said to her, "Hello, Beccy," as she walked past. She was impressed that I knew her name. I think that moment of courage sealed my fate. Still, I was a bit slow off the mark and one night, while working, Beccy came along and asked me to help put on her bracelet. I didn't take the hint!

Fortunately, she didn't give up and on her 21st Birthday, we officially started going out. She later told me that when she was blowing out the candles on her cake, she wished I would be her boyfriend. That was my wish too and after that we were never apart.

Even when I had to move to Newbridge to continue my apprenticeship, Beccy decided she was coming with me. She left her job, packed her bags and off we went, together.

I proposed to Beccy on a frosty Christmas morning, when I took a detour on the way to my Mam and Dad's. With snowy mountain tops to bear witness and despite having to wrestle with a frozen car door that refused to open, I popped the question and Beccy said, "Yes."



On the 10th of May 2009, when Beccy was twenty-five, Jack, our pride and joy was born. Beccy was thrilled to be a mum and her care and love for Jack were, to say the least, amazing. She was such a wonderful Mum to Jack and took great pride in his education milestones, his interests, and hobbies.

Beccy went through the genetic testing process in 2006 and found out that she had the gene that causes HD. She started to have mild symptoms from June 2010. You probably wouldn't have noticed anything was wrong for the first three or four years.





From 2015 Beccy's Huntington's increasingly affected her, but she faced it with great strength. As Beccy's illness worsened I reduced to part time hours in 2018 to help care for her. My mother was wonderful and helped us a lot through this time.

In 2021 Beccy needed specialist treatment and was in hospital in the months prior to her death. It was a very frustrating time for us as we felt Beccy's condition was poorly understood.

Beccy never complained. Her smile always lit up the room. Throughout our years together we cried and we laughed, but the laughs outweighed the tears. That was life with Beccy, full of laughs.

There are not enough words to fully express how much I treasure those times.

Our Experience of Palliative Care

A year after my husband received his diagnosis of Huntington's disease I found myself ill in the local hospital. I was waiting to receive a transfer to the regional hospital for more specialist treatment.

Having waited two weeks for the transfer, a nurse on my ward asked me whether I knew any politicians that I could call, to ask for help. At the time I remember thinking that this was a strange question. How could a politician have any influence on the waiting list? However, I realised that she was trying to be helpful to get me the transfer and avail of the treatment I needed without having too long of a delay.

'To be honest, being here is a rest for me' I answered. I went on to explain about my husband's illness.

My husband was going to doctors for a long time before he got a diagnosis. It was a stressful time for both of us but particularly for him.

Initially his GP and later the neurologist thought his problems with balance were related to his ears. They did a lot of tests, on his ears, nose and throat. He was referred for a swallowing assessment and a colonoscopy. The GP then felt it was neurological but the neurologist didn't investigate thoroughly. There was no MRI scan available at our local hospital so he was referred to a private hospital for an MRI. We were told that the MRI did not show anything abnormal.

Eventually my husband got fed up with all the appointments and physical tests. He had lost faith in their ability to get him the answers he needed.

Almost five years after his initial appointments his pharmacy asked him to have a blood test done. At this time there was a new GP in the clinic. The new GP was alarmed on hearing of his previous tests and seeing his balance problems. This GP pursued his tests more urgently and referred him to a different neurology clinic.

This neurologist was excellent and gave my husband his diagnosis without undue delay. He also provided relevant information and gave us the Huntington's Disease Association of Ireland booklet: *'Facing Huntington's Disease: a handbook for family and friends'*

I was alarmed and angry when I came across the images of a brain with and without HD in the booklet. To my untrained eye, the HD brain resembled the image from my husband's MRI scan taken years before.

I was angry and resentful that it had taken five years to get this diagnosis. My husband had had a lot of unnecessary tests which had 'put him off' pursuing a correct diagnosis. We were robbed of 5 years, time we could have spent ticking off a wish list and making plans for the future. We were robbed of those years to sort ourselves out and we missed the opportunity to discuss the future together at a time when my husband was better able to do so.

Shortly after I opened up to the nurse, an Occupational Therapist from the hospital palliative care team came to see me to talk about the palliative care service they offered. She explained that they support people with any life changing illness. Their service is not just focused on end of life care. It is there to support a person with a life changing illness, and their loved ones, so that they can have the best possible quality of life.

The OT explained that they wanted to promote their service because a lot of people misunderstand the service. She offered us support. I found that the service was a real support for both of us.

The team were very nice the first time we met but it was a time when my husband hadn't accepted his diagnosis. Everyone probably needs to have this discussion - What do you want to do with your life? What can we do together? What are your wishes regarding treatments?

My husband felt it had nothing to do with him. He wouldn't answer any question until the last question when they asked him: 'If you do become incapable of speaking or understanding what is going on, who would you like to speak for you?' He listed out me, and the children straight off.

In a strange way his answer made me mad because he had never mentioned this to me.

There are times when it can be awkward, but the team will be straight with him and sometimes stern, but in a direct and honest way. He always comes away feeling better. His last appointment with the consultant was like being in a comedy club - the way they were talking and the rapport they had with each other – he's more encouraged to talk and show his feelings now. They seem to encourage people in a really positive way to keep going and to continue to live their best possible life with their loved ones.

It is a support for my husband because all his services can be provided there. He can see the Occupational Therapist, the Physiotherapist, the Speech and Language Therapist and there is a Social Worker on the team.

The OT offers a regular assessment. She talks to him and supports him to engage him with different activities. Fortunately, he was able to have a fourth year student OT working directly with him over a six week period. This was a final year student who was really good. They worked on my husband's life story together.

My husband got to talk about himself. He was able to share his enjoyments and his disappointments. He talked about the jobs he had, the places he lived and other matters of importance to him. He looked up old photos and took them in to his appointments.

He was interested in gathering the photos and the process helped him to see that he has had a good life. I feel that was really important and a lovely experience for him.

Then Covid struck. He was still able to have some appointments with his team during the lockdown and I was reassured that the OT and Physio were keeping in touch. He also got his Covid vaccines and boosters at the palliative care clinic.

The Physiotherapist monitors his walking which is changing over time. They have decided that walking aids are not suitable for him so they concentrate on trying to keep him as safe as possible. They encourage him to focus when he is walking and to be aware of his surroundings and avoid any hazards.

I was concerned about a path involving steps that he was taking to go to the local shops. Our neighbours were also concerned and in a way I felt that I was being judged for 'letting' him have his walk.



Needless to say, my husband has a mind of his own and often doesn't appreciate my advice. There is also the fear that it could have the opposite effect – he may want to persist with increased determination!

I spoke to the physiotherapist who reassured me that having a walk was good for physical and emotional wellbeing but also offered to have a chat without disclosing my concerns.

In conversation, the Physiotherapist asked him about his daily walk and the route he took. She was direct about the danger with the steps and pointed out the increased likelihood of a fall. She convinced him to take a safer path. She did this in a constructive way explaining that the longer way around is also better exercise in addition to being safer.

Recently, after an assessment, the Speech and Language Therapist discussed her concern about his eating mashed potato. She pointed out that if some goes down the wrong way it is unlikely to all come back up with a cough. The residue left on his chest could cause a chest infection.

The OT suggested different cups for drinking more safely. They didn't think he was drinking enough and spoke about the advantage of a wider neck on a cup. The OT recognised that he found this difficult and wasn't ready for a specialist cup. She acknowledged that it was ok not to be ready yet and that they could come back to the subject again. This was all done with exceptional care. They don't give orders, they try to bring him along at his own pace.



HEALTH & WELLNESS

Growing your own Greens

Pauline Doran's son Joe has always been an avid gardener and so for a big birthday present Pauline and her family and friends got together to buy a wheelchair accessible Polytunnel for Joe and other residents at Bloomfield Health Services.



HDAI was delighted to contribute €1,000 towards the Polytunnel. Here are some photos to show the fruits (and herbs and veggies) of their work!



Michelle, a volunteer researcher, has gathered some information from gardening websites to provide some tips on growing your own greens.

As chance would have it, I noticed a cup and saucer in our local charity shop and the cup was wider than normal. Because it looks normal he was willing to use it and it makes a difference.

His team keeping on top of his symptoms and monitoring him well is a real reassurance for me. I also get great support from the Social Worker who works with the palliative care team. I had met her twice initially but then I hadn't spoken to her in a while. Lately, I was feeling drained and in need of some 'oomph' to get me back on track so I met with her again. I felt she really looked at me as a carer and gave me some sound advice. She helped me work out what I don't need to stress about and gave me permission to also think about myself and take time for my own needs

Having all these facilities in one place makes everything so much more accessible. Not having to travel to different appointments is such a plus. The only other hospital setting where I saw this level of care was when my grandson was in a special care baby unit. Everybody there demonstrated that they cared about the person and their family. I feel our palliative care service is similar.

My husband gets a lot of attention. There is a genuine welcome when you arrive. Someone brings you a cup of tea and will sit and chat if they have a minute. The admin staff are so cheerful. Staff are always positive there, from the consultant to the service staff. It is as if it's part of their job description to be cheerful. It's infectious, you feel better just being there and it doesn't seem clinical. The building is so beautiful also, very bright and open. It has lots of windows and there is light streaming in.

Unfortunately, but understandably, the day service had to close during lockdown. The service is excellent. They provide different activities that seem more challenging and engaging (for my husband) than those available at the community centre. My husband has no interest in Bingo. The Palliative Care service provide different activities - gardening, painting etc. I hope my husband will engage with this service when it opens again. There is a lovely atmosphere there. I hope he will experience that soon. He is doing really well at the moment, holding his own and determined to keep going for his walk every day.



Herbs have been mainstays of our food intake for thousands of years. They are not just for garnishes or to add colour and flavour, they are actually extremely good for you and have many health benefits.

While the quantities of these plants eaten at a time are often small having them readily to hand and fresh

from your own garden or pots means a continuous and inexpensive supply of vital vitamins and minerals.

It is worth putting a little effort into growing your own, you will get great benefits from seeing them grow, adding them to tasty recipes, eating them fresh and saving money. No matter if you only have a little space or a lot, you will find somewhere inside or out where herbs and spinach will thrive. You can begin your herb garden in a window box, some pots or by planting directly into the garden.

Tasty nutritious plants like basil, dill, coriander, nasturtium, borage and spinach can be grown in a combination of areas, the garden, in pots and/or indoors. They will add colour and flavour to many dishes as well as vitamins and minerals to give you an extra boost. Freshly picked herbs are delicious and can be chopped and frozen so you have a ready supply all year round.

Basil



Basil is a good source of vitamin K, manganese, iron, vitamin A, and vitamin C. It also contains the minerals calcium, magnesium, and omega-3 fatty acids. It has various varieties such as

sweet, lemon and cinnamon you can choose to grow from seed or you can buy young plants from the garden centre to give you a head start.

Basil needs plenty of sunshine and warmth so in our climate its best to grow it indoors, you can always move the pot outside if we get some Mediterranean style weather. (Here's hoping!)

When it's time to harvest you can make your own delicious homemade pesto as well as adding it to salads, pasta and pizza.

Sow seeds in modular trays or you can DIY your own using egg cartons, Tupperware or even get creative with toilet roll inserts, just give each room to grow, lightly cover with compost and leave them in a warm spot to germinate, you should see some seedlings in two weeks.

When the plants have more than five 'true' leaves, transplant them to their final growing positions. Gently remove each seedling and plant 10cm apart to give enough space to mature properly. Firm the soil gently around each seedling and water well. You can remove the tips regularly to ensure you get a full bushy plant. Once your plant is about 10 cm tall with lots of leaves you can begin to harvest the leaves as you need them, pinch them off rather than cutting whole stems. Also remove any flowers so the plants concentrate their energy on growing tasty leaves.

Dill



Dill contains Vitamin C, Vitamin A, Manganese, folate(Vitamin B9), iron and is rich in antioxidants. Dill leaves are very aromatic and can be used to flavour a wide range of foods, especially fish.

The leaves can be used fresh, or can be either frozen or dried for later use

Dill dislikes having its roots disturbed or being transplanted, so sow it in its permanent position. Plant the seeds in either large pots or directly into the ground. Dill thrives in warm, sunny areas with fertile soil. Seedlings can be thinned out to 15cm apart when robust enough. Water well especially in warmer weather. Picking young leaves regularly will help to keep plants productive and delay flowering.

Nasturtiums



Aside from being tasty, vitamin-rich, and beautiful, nasturtiums also provide many benefits to other plants in the garden as companion plants, they can protect other plants from common pests

and attract insects and pollinators. Nasturtium leaves are high in vitamin C, iron and other trace minerals and the flowers are plentiful in vitamins B1, B2, B3 and C and also contain manganese, iron, phosphorus and calcium. You can sow nasturtium seeds directly into the ground, planting seeds 1cm deep and 15 cm apart. They can tolerate shade but prefer over 6 hours of sunlight a day to thrive, water once a week or when soil gets dry to the touch. Nasturtiums are entirely edible and can be added to salads, soups, or desserts. They give a subtle peppery flavour.

Parsley



Parsley is an easy-to-grow herb that produces delicious leaves throughout the summer. Curly leaved varieties are highly decorative with a mild flavour, while flat-leaved varieties have a stronger flavour.

Parsley contains vitamins A, K, and C and is also a good source of calcium, iron, magnesium, and potassium. Its best sown from early spring to early summer, but can still be planted later on in a sunny spot.

It likes well drained soil in sun or partial shade. Sow seeds thinly 1cm deep, cover with soil and water gently. Once seedlings are large enough to handle, thin them out to 15cm apart. Parsley will grow very well in pots of at least 25cm in diameter. They need a cool, lightly shaded spot to germinate. Keep your plants well-watered especially during germination and hot dry spells. Your plants can be kept happy with liquid fertiliser every few weeks. Remove lower yellowing leaves and flower heads to encourage growth.

Coriander

Coriander is a great addition to many recipes, especially Asian dishes, it can be eaten fresh or frozen. Leaves are rich in Vitamin C, Vitamin K and protein. They contain dietary fiber, manganese, iron and magnesium. Additionally trace amounts of calcium, phosphorus, potassium, thiamin, niacin and carotene.

Coriander enjoys a sunny position but appreciates a little shade during the hottest part of the day. Plants will run to seed more quickly if stressed by hot weather. Coriander can be sown until early September. It doesn't like being disturbed so plant it in its final growing position. It likes well drained fertile soil and can be sown in groups of 5 seeds 20cm apart.

Borage



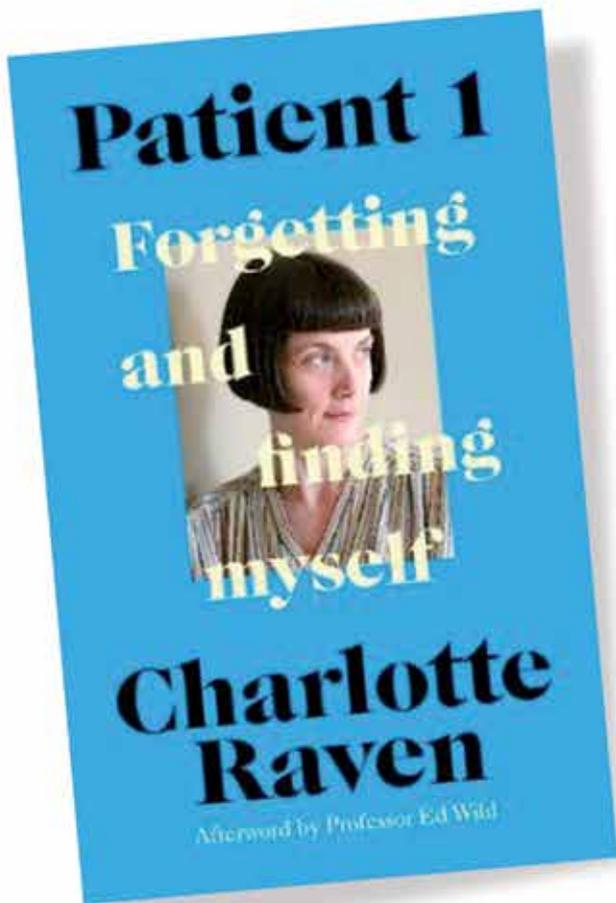
Borage is a tasty herb with beautiful blue flowers. It is rich in iron, calcium, potassium, manganese, copper, zinc, and magnesium. It also contains the essential fatty acid, linolenic acid.

It likes to grow in full sun in the ground, but will tolerate light shade. It will thrive on any well drained moist soil but not waterlogged. Sow seeds thinly and lightly cover with soil. Plant 50 cm apart in the garden and pots need to be at least 30cm in diameter to accommodate the plant. Germination takes 7 to 14 days and plants take about 6 weeks to mature. Both the leaves and flower are edible and can be used in sweet and savoury recipes. The leaves are refreshing in summer drinks adding a cucumber-like fragrance. The flower has a sweet honey-like taste.

Spinach

Spinach is tasty, nutritious, easy to grow, is very rich in fiber and even contains small amounts of protein as well as being a good source of Vitamins K, C and potassium. You can enjoy harvests all year round if you grow several different types. Summer varieties like a little shade and well enriched soil. Sow outdoors, directly where they are to grow. Sow 2.5cm deep and scatter seeds thinly. If sowing more than one row, space them 30cm apart. Sow thinly in large pots every few weeks to have a continuous supply.

Book Review



Charlotte Raven lives in London. She worked as a journalist in the 1990s. Her columns and articles have appeared frequently in the Guardian and New Statesman.

In 2017, Charlotte began writing a blog about living with Huntington's disease as an 'awareness raising' exercise and this has led to a 'startling self-portrait written with wit and vulnerability'. Patient 1 is an 'honest, intelligent and unsentimental' book which reveals how Charlotte comes to terms with her life changing illness.

Professor Ed Wild, Associate Director of University College London (UCL) Huntington's Disease Centre became Charlotte's neurologist and friend. In the book's afterword he writes about why he became interested in HD, his friendship with Charlotte and his belief in research.

Charlotte Raven had never heard of Huntington's Disease when, in her mid-thirties, she discovered that her father was suffering from the illness. Life for her and her young family would never be the same again.

"Recording my experiences has been surprisingly cathartic. The last time I kept a diary, I was a baby goth with a lighter fuel habit. My mother read it and threw a shoe at me; an understandable response"

"I had become friends with Dr Ed Wild, a warm and approachable HD specialist who'd been there for me when the disease first sent my life spinning out of control, offering wise counsel on everything from barbiturates to my failing marriage. It occurred to me that if we worked together on a book, his medical account of the illness would complement my personal one. Ed said he was up for it and I was thrilled to have him on board; a joint enterprise felt much less daunting than a solo project."

Charlotte acknowledges the support from her brother Dan who collaborated with her on the book and 'dressed it up well enough to be sent out into the world'

Charlotte, and Ed Wild in his afterword provides us with an insight into what makes a good HD specialist and why Charlotte and Ed have come to be such good friends.

"Unlike other consultants I'd met, he never patronised me or made me feel like he knew more about my illness than I did. I felt like I could tell him anything and he'd listen without judging me."

Ed writes:

"I already knew of Charlotte Raven"... "Discovering that this person was now going to be seeing me in the Huntington's clinic was honestly terrifying. As a doctor it's often strangely aversive to interact with ultra-smart patients. They often want a 'why' far beyond what I can provide, leaving me feeling inadequate."

"Loss of empathy and self-awareness is a general rule in HD, but Charlotte demonstrates that it need not be inevitable....The trick is to assemble a team around you while your brain is in good shape, and then allow them to guide your course once the steering starts to play up"

This book is always honest, often funny and sometimes heart-breaking but it is filled with hope, love and a determination to grab onto life and make it as happy and healthy as possible for as long as possible. You will need a tissue to read this book but I promise it is well worth the effort.



Huntington's Disease Association of Ireland

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