

# HUNTINGTON'S DISEASE ASSOCIATION NORTHERN IRELAND



*Families at the heart of all we do*



## 2018-2021 Strategy

# About Huntington's Disease

Huntington's Disease is a rare genetic neuro-degenerative disorder which gradually causes a person to lose control of their thoughts, feelings, behaviour and movement. Although there is a juvenile form of the disease it mostly strikes people in mid adulthood. Over the course of the disease, usually between ten and twenty years, a person will become entirely dependent on the care of others and many will be unable to communicate or swallow.

HD is caused by a genetic flaw and is inherited by both men and women. It is the ultimate family disease because if you have it there is a 50% chance each of your children will get it and if anyone in your family has HD there is a chance you will have a caring role. Given the nature of the disease people can end up caring for multiple generations of loved ones or several family members simultaneously- and will likely require a range of supports.

The physical symptoms of HD are often compounded by depression, social isolation, stress, anxiety, frustration, fear and the guilt of potentially passing the disease on.

In Northern Ireland there are hundreds of people struggling with the symptoms of HD at any one time, many more hundred are at risk of developing the condition and their family and friends will be living with the consequences of the disease. HDANI works with, and on behalf of, all of the people impacted by Huntington's Disease.

There are a number of studies, clinical trials and research projects taking place around the world so while there is currently no cure- there is hope.

## The Amaryllis

The 'Amaryllis', the international symbol of Huntington's Disease, represents a double image of a head and shoulders as the flower of a growing and vibrant plant.

The reduced size of the head and shoulders of the white inner part of the flower symbolises the diminution in a person caused by Huntington's Disease. The leaves represent the protection, support, purpose, growth and development of the Huntington's community worldwide in its search for a cure and treatment.



# About HDANI

HDANI works throughout Northern Ireland providing support, information, advice and social connections to those living with the impact of Huntington's Disease. We run regional groups, provide telephone and face to face advice and support, act as a link to other services, advocate for our clients, as well provide opportunities for families and individuals to connect with each other through our events, youth and befriending services.

We also work closely with medical professionals to advocate for the most effective care for our service users and lobby policy makers for improvements in service accessibility and delivery. We provide training and awareness raising events and keep the HD community informed of the latest research and medical advances in the quest for effective treatments and ultimately a cure.

The Association is dependent on a small but dedicated team of staff and volunteers who are committed to providing the best possible outcomes to our service users.

## Our Mission Statement

A world free from Huntington's Disease and, until that point, one in which all those affected are accepted and supported.

## Our Vision

HDANI's mission is to secure the best quality of life for those impacted by HD and to work with others to increase understanding and management of the disease while pursuing a world free from Huntington's.



# Foreword

It has been almost four years since I joined HDANI and the time has truly flown by. It has been a tremendous honour and privilege to work with, and on behalf of, the HD community in Northern Ireland.

In just a few short years the Association has grown beyond belief to a point where we now work with over 150 families across the province providing support, information and advice to carers, patients and family members. In times of crisis, our support staff have proven invaluable in advocating for those who are unable, sometimes literally, to speak for themselves. They have often been the only source of comfort and support to patients and their families as they try to navigate life with HD.

We have been dogged in our determination to strengthen our links with politicians, policy makers and health and social care professionals to ensure increased awareness, knowledge and understanding of the disease as well as continuous improvements in the accessibility and quality of service provision.

Like many charities we have found ourselves facing financial hardship and continuously work to ensure that our unique and critical services are sustained. We are eternally grateful to those sponsors, grantees and donors who have made our work possible including The Big Lottery Fund, Garfield Weston, Ulster Garden Villages, Enkalon, Halifax, The Co-Op, TBF Thompson, PHA, Mr J. Donnelly and BP McKeefry.

Above all we are indebted to the hard work, energy, and dedication of our volunteers and fundraisers without which we simply could not exist. Special mention must go to the extended family and community in Armagh who worked for a year to raise over £40,000 which will be used to fund a three-year youth project providing age-appropriate support, information, counselling and opportunities to connect and have fun for children from 5 to young adults. This is a completely unique service in Northern Ireland and one which was sorely needed to help young people deal with the changes they see in close family members, understand the genetic implications of the disease and help them consider issues such as testing caring roles, drug trials, disease inheritance, relationships and family planning.



Sorcha McPhillips  
*Chief Executive*

The road ahead over the next three years will no doubt be filled with challenges but also opportunities as we move ever closer towards effective treatments for HD. We will continue to keep 'families at the heart of all that we do' and strive to prove that we are strongest together.

## A word from our Chair

As chair of HDANI I have personally experienced life dealing with someone I love be overtaken by this horrible disease. I watched them gradually lose themselves and be consumed by this illness and dealt with the added worry of having children and grandchildren at risk of inheritance.

HDANI can offer support to those in need and have been doing so, in various ways for the past thirty years. Without this support I personally do not think I could have coped on my own. HD is a rare disease therefore to be able to speak to other people dealing with the same issues helped me understand the complexities of the illness.

HDANI is all about families and offering support, information and guidance to them on various issues from genetic testing to family planning and all of the practical things they need from insurance to housing and benefits. Hopefully with our support people will be able to make important decisions regarding these matters and have information available to access their entitlements and maintain their independence for as long as possible.

Our new three year Strategic Plan sees us continuing in our work to secure better lives for those suffering from HD and their families. Things have progressed greatly since our 2015 plan and we find ourselves in a stronger position than ever before with a great team of staff and volunteers working hard to keep the voice of HDANI heard above all others and improving lives along the way.

Thanks to all our supporters, families and HD patients who give their time and energy to this cause and share their experiences with others. To all those who fundraise for us and those who volunteer within the groups we thank you for your support and time. HDANI families are at the heart of all we do.

HDANI will continue to support those impacted by HD for as long as its necessary until the day comes when a cure is found. Until then our team, led by our Chief Executive Sorcha, will continue to fight for the rights of those impacted, advocate for improved services and great understanding and provide the greatest level of support possible.

*Jennifer*

Jennifer Warnock  
*Chair, HDANI, 2018*



# Theme One: Connecting

Organising events and activities aimed at connecting those impacted by HD with each other and relevant services to improve their wellbeing, increase their capacity to cope, share knowledge and experiences and reduce social isolation.

1. Maximise opportunities to connect on a local and regional level via events, befriending and support groups as well as online connectivity.
2. Encourage and support optimal attendance at events including an annual family conference.
3. Continue to implement a programme for youth support and engagement.



# Theme Two: Supporting

Optimise the information and support available to those impacted by HD, including young people, through a combination of HDANI services and referrals to relevant organisations.

1. Ensure as many people as possible have access to appropriate support and accurate information about the disease.
2. Deliver a service model which maximises emotional and practical support.
3. Provide tailored advocacy and intervention with relevant professionals and services.

# Theme Three: Campaigning

Continue to develop an evidenced based approach to our work and effectively lobby for enhanced quality of life for those impacted by HD and continuous improvements in disease management with a view to the eradication of the disease.

1. Expand on existing research to illustrate the spread of HD in Northern Ireland and the needs of those impacted.
2. Influence policy and decision makers to provide appropriate, accessible services and resources.
3. Work in collaboration with stakeholders to advocate for the rights of those impacted by the disease.



# Theme Four: Informing

Increase awareness and understanding of HD among the general public but in particular among health and social care professionals and statutory bodies to improve patient care and outcomes for families.

1. Continue to create a range of online and printed materials for targeted distribution.
2. Hold information and awareness raising events and maximise our online presence.
3. Extend our training programme for relevant statutory, private and voluntary organisations.



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