HDANI: Help & Hope

Sorcha McGuinness, Chief Executive

HUNTINGTON'S
DISEASE ASSOCIATION
NORTHERN IRELAND

Families at the heart of all that we do



HDANI Services

- 2 part time support workers- Errol & Angie
- 4 monthly regional support groups with counsellors
- One to one counselling support
- Event based youth service with dedicated counsellor
- One to one and group befriending opportunities
- Training events for health and social care staff
- Annual conference
- Online presence
- Quarterly e-zines/newsletters



Support Work

Here's just a snap shot of the <u>direct support</u> work done by our two part time staff over the course of a year in addition to facilitating support groups and dealing with enquiries from professionals

email	411
facebook pm	27
other	206
phone	877
post	50
text	127
visit	134



Raising Awareness



Huntington's Disease Association Northern Ireland

471 more page likes by midnight tomorrow- is it possible? Help raise awareness of HD #HDAwareness





Reach

23 September - 29 September

17,159

People reached 437%



Raising Awareness



Sep 2016 • 28 days so far...

TWEET HIGHLIGHTS

Top Tweet earned 3,861 impressions

Group photo at Stormont with First Minister

@DUPleader #HDAwareness
pic.twitter.com/lvauOuMTzB



176 **9**

View Tweet activity

View all Tweet activity

Top mention earned 203 engagements



Arlene Foster

@DUPleader - Sep 26

Huntington's Disease awareness week begins today. I was delighted to meet @HDAssocNI & sign their pledge board at Stormont. #HDAwareness pic.twitter.com/ymC7jO0AZU









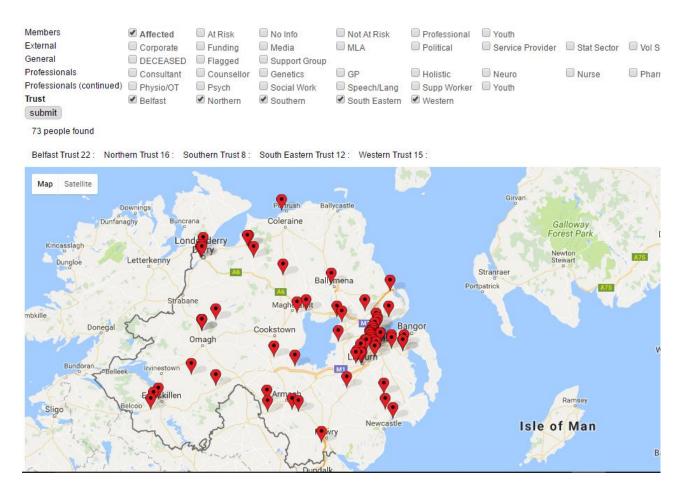
Tweet impressions 6,989 ↑256.6%



Gathering Evidence

150 RGD & HD Clinic known affected

HDANI = 73



Gathering Evidence



121 people found

Belfast Trust 29: Northern Trust 29: Southern Trust 20: South Eastern Trust 23: Western Trust 20:



Home

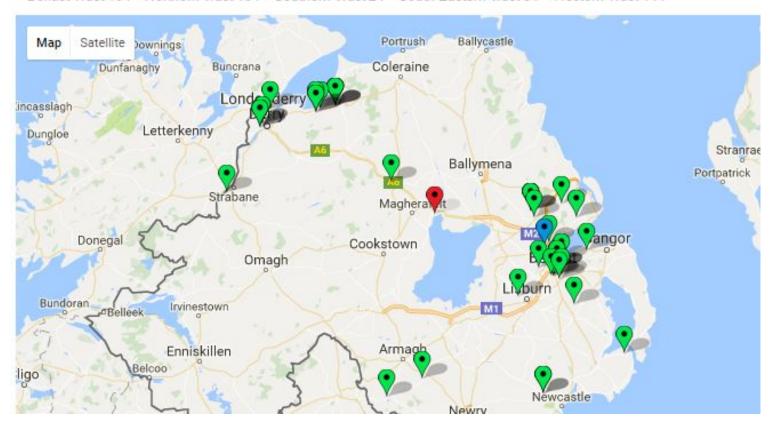


Belfast Trust 18: Northern Trust 17: Southern Trust 14: South Eastern Trust 15: Western Trust 17:





Belfast Trust 10: Northern Trust 10: Southern Trust 2: South Eastern Trust 6: Western Trust 14:



Website

- Local and online support
- Factsheets for patients and carers
- Youth section
- Professional resources
- Up to date research news
- Volunteering info
- **Fundraising Info**
- **Donations**
- Shop
- **Events**









Families at the heart of all we do

Jogni Lippitaitius

Welcome



About HDANI

HDANI works (Inoughout Northern Instend providing support, information, advice and social connections to those living with the impact of Huntington's Disease. We run regional support groups, provide telephone and face to face advise and support as well opportunities for families to connect through our events and befriending services.

We also work closely with medical professionals to advocate for the most effective care for our clients and lobby the Executive for improved and efficient services. We provide training and awareness raising events and keep our members 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 members.

Our Mission Statement

The Huntington's Disease Association Northern Ireland's mission is to secure the best quality of life for sufferers and their families and to work with others towards the effective management and eventual eradication of the disease.

Our Vision

The Huntington's Disease Association Northern Ireland's vision is for those affected by HD to be empowered and supported to live as normal a life as possible.

To read about our planned work for 2015-2018 year our Strategy. Plan.

Help us to Help You

- Share information about how HD affects your family (HD&Me)
- Feedback on our work and events
- Tell us which health and social care staff, day centres, nursing homes and services you deal with
- Put up posters, leaflets in schools, workplace, community centres, business, health centres
- Share your story with local media or via social media
- Connect us to your business links
- Volunteer with our fundraising or programme work

Enjoy, share, learn

- -expert speakers
- -service providers
- -one to ones
- -meet other families
- -therapies
- -workshops
- -share ideas
- -fun

There may be no cure yet but

There is help There is hope There is HDANI

& we need HD heroes like you