

## **HDANI Trustees Annual Report CCNI 2022-2023**

The past year has involved many challenges as an organisation as the continued cost of living crisis affected families across Northern Ireland, creating an increased dependence on charities like our own. It was a year of highs and lows for our HD family and our staff team. A number of treasured service users passed away leaving devastated families and friends. Our Chief Executive survived a stroke and is thankfully returning to work after a lengthy period of recovery and on the more positive our Senior Family Support Worker Zelig, qualified as a social worker while our family support worker Henna, welcomed her first child, little William.

The absence of our Chief Executive resulted in a major reduction in the organisations visibility with less networking, awareness raising and lobbying events and activities throughout the year. Progress on key policy areas such as increased statutory nursing provision, the creation of a HD strategy and care pathways were notably affected though the impact largely lessened as the political deadlock and Covid response had acted as barriers to progress. That said, with our Chief Executives return, we will persevere and continue to keep HD on the agenda of policy makers in the hope of service improvements in the years ahead to ensure that regardless of where a patient lives, they have access to expertise and timely support.

From a family support perspective our work has continued, with much less potential for pro-active engagement as staff resources decreased and the demand for responsive services increased. We continue to feel the legacy of Covid where some of our families faced untold suffering as restrictions interfered with how we dealt with death and dying, limiting access to loved ones in care homes, hospitals and attendance at funerals. A significant amount of staff time has been concentrated on advocating on behalf of families to access the services, clinics and statutory support denied through Covid. A backlog of appointments and staff pressures across Trusts have exasperated already stretched services which has a knock-on effect on the demand for our services. We have enjoyed a busy year with a full return to physical support groups, youth events and an overnight social and wellbeing event aimed at recharging and reconnecting. At the time of writing, we have been preparing for an annual social and wellbeing event while staff continue to visit service users in

HDANI was happy to partner with Glenstall IT, who host our database, to enable them to receive funding from the Q Foundation to work on their Patient Experience Mapping project which will help to raise awareness and empower patients living with rare and chronic conditions.

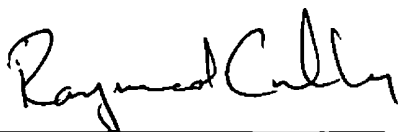
From a financial perspective, an underspend in staff from not covering the Chief Executives

post over maternity leave as well as gaps in staffing has resulted in an underspend which has offset the continued impact of less fundraising.

"As a registered charity with the NI Charity Commission we continue to develop and revise policies to ensure best practice. In the year ahead we will continue to professionalise our practices and ensure that our work is above reproach and in doing so consider succession planning to augment the skill set of our committed board. We will continue to work in partnership with other HD organisations across the UK, Ireland and globally as well as on a local level on the broader issues of rare disease and access to drugs. We also look forward to participating in local lobbying opportunities via membership of NICVA, Co3, NIRDP, Patient Client Council, Disability Action, NI Neurological Conditions Alliance, NI Long Term Conditions Alliance, NI Carers Coalition and relevant All Party Groups."

We would like to thank our staff and trustees for their commitment throughout the year and as always, the Huntington's disease community for entrusting us with their care. A special thanks to everyone who showed confidence in our organisation by donating, fundraising, or awarding grants to allow us to continue and to expand our work.

Signed on behalf of the Board



Raymond Crilly  
Treasurer

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HUNTINGTON'S DISEASE ASSOCIATION NORTHERN IRELAND