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 | FOR IMMEDIATE RELEASE |

[INSERT NAME OF LOCAL BUSINESS/GROUP/INDIVIDUAL] hosts a RariTEA to help raise awareness of those affected by rare conditions across Northern Ireland and [LOCAL AREA]

[INSERT BUSINESS NAME] support Northern Ireland Rare Disease Partnership in delivery of the RariTEA campaign.

Rare conditions are chronic, debilitating and life-threatening conditions; in Northern Ireland it is estimated that over 100,000 people are affected by such conditions. That is a population the size of Derry/Londonderry, and a community larger than that affected by AIDS and cancer combined.

This year Northern Ireland Rare Disease Partnership (NIRDP); a not for profit organisation and registered NI charity working to bring about change for those with rare or difficult to diagnose conditions, is running its first Northern Ireland-wide campaign, ‘RariTEA’, to help raise awareness of rare conditions and the impact these have on all those affected.

RariTEA runs from rare disease day on the 28 February for two weeks. To help mark the occasion [INSERT NAME OF LOCAL BUSINESS/GROUP/INDIVIDUAL] has got onboard to host their very own, local RariTEA event, inviting [INSERT OF DELETE AS APPROPRIATE: friends, family and work colleagues] to join them in learning more about rare conditions over a cuppa and some cake!

[INSERT NAME AND JOB TITLE] comments “We were delighted to have the opportunity to get involved in helping create real change for those affected by rare conditions across NI. I was shocked to discover that as many as 1 in every 17 people in NI will be affected by rare conditions at some stage in their life. Rare conditions are not as rare as we might think.”

Rhoda Walker, Chair of the Partnership, says “We are so grateful to [INSERT NAME/BUSINESS/GROUP] for getting involved in our campaign and for helping us to raise awareness right across Northern Ireland.

We are running our campaign for 2 weeks and so we would continue to ask individuals, organisations, businesses and groups to support a RariTEA event with friends and colleagues; this might be an afternoon tea, a tea party or simply sharing a cuppa with a few friends.

Even the smallest of efforts can go a long way towards helping us raise awareness of our charity and the work that we do, and will aid us in reaching more families, carers and patients across the region who need our support.”

There are many ways to get involved and by simply posting your images and comments of support via social media, tagging us on @NI\_RDP and using the hashtags #RariTEA and #NIRDP you can help us increase our reach.

If groups, individuals or businesses would like to make a donation this can be arranged via the website, www.nirdp.org.uk, or by contacting info@nirdp.org.uk for more details.

All donations will go directly towards delivery of work that who will help families and patients affected by rare conditions access the help and support that they need.

The charity motto is “Stronger Together”, so get involved in this year’s RariTEA and make a difference for all those living with rare conditions across Northern Ireland.

To find out more contact the NIRDP at email: info@nirdp.org.uk

Facebook: @NIRDP\_News

Twitter: @ni\_rdp

Instagram @ni\_rdp

Website: [www.nirdp.org.uk](http://www.nirdp.org.uk)

ENDS:

Notes for the editor:

Northern Ireland Rare Disease Partnership (NIRDP):

[Northern Ireland Rare Disease Partnership](http://www.nirdp.org.uk/) was set up in March 2011 as a “not for profit” Company Limited by Guarantee. It is a NI Registered charity

NIRDP is a unique partnership of those living with a rare disease; organisations representing them, health professionals; science and industry; health policy makers and academics. The membership includes people with rare conditions ranging from the very rare, for example Trisomy 13 mosaic, to relatively well-recognised conditions such as Motor Neurone Disease, Spina Bifida, or Muscular Dystrophy. NIRDP are represented on the Department of Health, Northern Ireland Rare Disease Stakeholder Group, and the UK Rare Disease Forum. We have also established links with Genetic Alliance UK, and with IPPOSI, Rare Disease Ireland, and the Medical Research Charities Group in the in the Republic of Ireland.

In Europe a disease or disorder is defined as “rare” when it affects fewer than 1 in 2000. There are over 7,000 different rare conditions, with more being identified every day.

A NI survey in 2011 revealed that ~one-third of patients wait up to 5 years for an accurate diagnosis and half receive a wrong diagnosis.

Common issues reported by people with rare diseases include difficulty finding useful information, including for clinicians; the challenging pathway to diagnosis, and lack of coordination of care, which creates feelings of isolation and vulnerability.

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If you would like more information about this topic, please contact Microsoft Office User, at [Company Phone] or mb:xxxxxxxxxxx or email at [Company E-mail].