

### **What is the Northern Ireland Rare Disease Partnership?**

The Northern Ireland Rare Disease Partnership (NIRDP) 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. Our 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.

We are represented on the Department of Health (NI) Northern Ireland Rare Disease Stakeholder Group, and on the Government’s 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 Republic of Ireland.

### **What is a “rare disease”?**

In Europe a disease or condition is defined as “rare” when it affects fewer than 1 in 2000 people. There are over 7,000 different rare conditions, with more being identified every day. One rare disease may affect only a handful of people in Europe, while another may touch as many as 245,000.

- 80% of rare diseases have identified genetic origins, whilst others are the result of infections (bacterial or viral), allergies and environmental causes.
- 50% of rare diseases affect children.

In Northern Ireland, 1 person in every 17 will be affected by a rare condition at some point in their life. This is the equivalent of over 100,000 people; a population the size of Derry/Londonderry and a community larger than that affected by AIDS and cancer combined.

A Survey in 2011 survey revealed that in Northern Ireland, about 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, even for clinicians, the challenging pathway to diagnosis, and poorly coordinated care, which creates feelings of stigma, isolation and vulnerability.



### **What is “RariTEA” all about?**

NIRDP is a growing Charity. We are keen to increase the impact and reach of the work that we do. To help achieve this we run an annual Northern Ireland wide campaign, called “**RariTEA**” to encourage people everywhere to find out more about (and support) rare conditions, over our favourite cuppa!

The campaign is a direct call to action to everyone to get involved and host or support a RariTEA with friends and colleagues. This might be an afternoon tea, a tea party or simply sharing a cuppa with a few friends, and of course, even more importantly, we want to encourage everyone to have some fun along the way!

### **What is Rare Disease Day?**

Rare Disease Day is the official international awareness-raising campaign for rare diseases. Rare Disease Day takes place on the last day of February each year. The main objective of the campaign is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives. EURORDIS-Rare Diseases Europe and its Council of National Alliances launched Rare Disease Day in 2008. For more information log onto: <https://www.rarediseaseday.org/>

### **How can I take part in RariTEA?**

#### **1) Organise an event:**

Organise an event anywhere between the last day of February and the following 2 weeks to help raise awareness of rare conditions in your community. Some ideas that might help to get you started include:

- Host a meeting or group tea-break in your work over a cuppa
- Get your friends together for tea and cake (or buns, or traybakes, or something a little healthier!)
- Organise an afternoon or high tea event and invite family, friends and/or community group members to come along and bring a bake (or, again, something that bit healthier....at NIRDP we like cake!)
- Organise a walk for your fitness group or friends, followed by (you guessed it...) TEA!

- Plan fancy fundraising event... you can go all ball gowns and black tie if you want to (but you'll probably need to finish with some tea)

## **2) Share your images**

There are many ways, big and small that you can support RariTEA, but however you decide to get involved please don't forget to share your pictures. You can help us increase our reach, simply by posting your images and comments of support via social media.

Please share your images and tag us on @NI\_RDP (twitter) (Instagram) , @NIRDPNews (Facebook) and use the hashtags: #RariTEA, #NIRDP, #RareDiseaseDay, #StrongerTogether

## **3) Contact your local media**

If you are helping to organise a campaign, or simply attending a local RariTEA event why not contact your local media? Your local papers and radio stations are always keen to know what is going on, and as a local resident this will be a story of interest to them, and their audience. Make the most of this opportunity to leverage some local coverage and reach even more people!

You can do this by downloading our RariTEA Partners Media Release template, filling in the blanks and emailing to your local paper and radio stations.

### **Can I raise funds and if so, how do I donate?**

We would be delighted if you were able to carry out some fundraising as part of your event. All donations received will go directly towards supporting families and patients affected by rare conditions get the help and support that they need.

If you would like to make a donation you can do so via our website, [www.nirdp.org.uk](http://www.nirdp.org.uk), or contact us via email at [info@nirdp.org.uk](mailto:info@nirdp.org.uk)

### **Are there additional materials for me to use to support my local event?**

Absolutely!

If you are planning on hosting an event, big or small, you can download our RariTEA poster, our logos and our RariTEA Partners Media Release template so all you have to do is fill in the blank spaces on our pre-prepared media release and issue to your local papers and radio stations.

And we are here to help: email [info@nirdp.org.uk](mailto:info@nirdp.org.uk) and one of us will be in touch!

**So good luck everyone...**

**We are looking forward to hearing all about your local events!**