## Ride for Rare – Sunday 15<sup>th</sup> September 2024

In 2013, genetic professionals involved in the Deciphering Developmental Disorders Study took part in a charity bike ride between nearby genetic services, to raise money for SWAN UK and Unique charities.

The event was a great success, raising over £11,000, and so we are doing it again! The rides will take place on Sunday 15<sup>th</sup> September 2024. It is hoped this will be a worthwhile challenge which will help build relationships between genetic professionals, raise money for rare genetic conditions and be fun!



If you would like your service to take part in Ride for Rare:

- 1. Create a Ride for Rare group for your centre and recruit riders!
- 2. Identify one person to be the representative for your centre to act as liaison and coordinate the ride.
- 3. Decide either to:
  - a. Team-up with a nearby centre and agree where you will cycle from and to (see map below). The cycle ride will be one-way and participants will either travel to the start with their bike by train/get a lift from a friend/relative, or travel home from the finish with their bike by train/get a lift from a friend/relative.
  - b. If a joint centre ride is not possible, you can plan a circular ride for your genetics centre.
- 4. Contact Claire Cocks <u>claire.cocks@geneticalliance.org.uk</u> who will register you as a participating centre.

- a. If you have low numbers or do not have a representative, we can connect you with another centre who you could partner with.
- Identify 1-2 other people (depending on how many people take part in your ride) to help plan the route and coordinate the ride on the day - you can use <u>Sustrans National Cycle</u> <u>Network</u> to plan a safe and enjoyable route. A minimum of two people are needed to lead the group.
- 6. Help raise funds for SWAN UK and Unique by sharing the Ride for Rare fundraising page <a href="https://www.givewheel.com/fundraising/2142/ride-for-rare/">https://www.givewheel.com/fundraising/2142/ride-for-rare/</a>.

Map of UK genetic centres (indicated by the red dots):



## Supporting:

SWAN UK (syndromes without a name) support network, run by Genetic Alliance UK, registered charity no. 1114195. <a href="https://www.geneticalliance.org.uk">https://www.geneticalliance.org.uk</a>

Unique - Rare Chromosome Disorder Support Group, registered charity no. 1110661. https://rarechromo.org