

# **22Q11 Northern Ireland Annual Report**

**For the year to March 31st 2024**

## Annual Report for year ended March 31<sup>st</sup> 2024

In May 2023, we held our annual '22q at the Moo' event at Ark Farm in Newtownards. This year's event was a resounding success, with a record 130 attendees! This represents a significant increase in participation, demonstrating the growing need for community and connection amongst 22q families. The day was filled with fun activities like barrel train rides, animal petting and complimentary ice cream, with valuable opportunities for families to connect with one another and build support networks. We received overwhelmingly positive feedback from attendees, with many expressing how much they valued the chance to connect with each other.

In June, we took on the exciting challenge of participating in the Cash for Kids Community Challenge. As a charity that has been historically weak at fundraising, we rarely conduct large-scale campaigns. However, this opportunity was too good to miss! Our team rallied together, organizing many events such as "Wear it blue for 22q" at Kircubbin Integrated Primary School, bucket collections, and even a Yoga session and leveraging the power of social media to spread the word. We were absolutely thrilled to not only surpass our initial target of £2,500 but also to win the overall competition, raising a grand total of over £14,000 with the Cash for Kids bonus.

Thanks to the success of our Cash for Kids campaign, we were able to provide financial assistance to 12 families, enabling them to attend the 22q11 European Conference in Dublin in November. This international conference provided a unique platform for families and healthcare professionals to connect, learn from experts in the field, and share their experiences.

The conference provided valuable insights into the latest research and best practices in supporting individuals with 22q11. Key sessions focused on child psychology for individuals with 22q, dual diagnosis, hearing loss and the importance of a multi-disciplinary approach to treatment. Attendees reported feeling empowered by the knowledge they gained and inspired by the sense of community. To extend the reach of the conference, we shared key takeaways and summaries on our Facebook page, ensuring that those who couldn't attend could still benefit from the information.

In December, Gillian Cassidy and Mia Lowden represented our charity at the 22q11 Syndrome All Party Parliamentary Group's House of Commons Event at Westminster. This event was a crucial opportunity to raise awareness among UK policymakers about the challenges faced by individuals with 22q11 and to advocate for improved screening and support services. Gillian delivered a powerful speech, highlighting the success of the 22q Transition Clinic in Belfast City Hospital, the importance of families driving change, and urging MPs to take action by listening to

the concerns of their constituents affected by 22q. We were encouraged by the strong turnout of MPs (though Northern Ireland was sadly under-represented) and the positive engagement we received generally.

Throughout the year, Gillian has continued her invaluable work as a voluntary Family Liaison Officer at the City Hospital's monthly 22q clinic. In this role, she provides emotional support, information on resources, and guidance on navigating the healthcare system to families with newly diagnosed children, ensuring they feel heard and supported during a challenging time. It has become clear that the need to support Young Adults with 22q is a pressing issue. Strategic planning is in progress and a number of people have been contacted in regards to funding, research and idea gathering.

Our Facebook page remains an active and vibrant community with over 1500 members. It serves as a safe space for families to connect, ask questions, share information, and offer each other encouragement.

Our connection to the Northern Ireland Rare Disease community remains strong and Gillian has been working with the NIRDPP group which is building a website resource for people with rare diseases, no matter what part of the journey they are on.

## Public Benefit Statement

The trustees of 22q11 Northern Ireland confirm that they have complied with their duty under the Charities Act (Northern Ireland) 2013 to have regard to the Charity Commission's guidance on public benefit and that the public benefit requirement has informed the activities of the charity in the year to March 31st 2024.

The trustees believe that all of our purposes satisfy both elements of the public benefit requirement, and that the activities in 2023-24 (detailed in the annual report) contributed to each purpose:

- To seek out information about 22q through conferences, relevant lectures and the World Wide Web in order to provide advocacy through dissemination of information to the public and clinicians in Northern Ireland on symptoms and issues via lectures, articles, social media and information sharing via a dedicated website.
- To support and encourage people residing in Northern Ireland who are affected by chromosome abnormalities including but not limited to 22q11.2 deletion, 22q11.2 duplication, Ring 22, 22q13 duplication, Mosaic 22q deletion, Mosaic 22q duplication, 22q distal deletion and Trisomy 22 through the provision of recreation or other leisure time occupation for individuals, family and friends of those diagnosed with the objective of improving their quality of life.
- To raise the profile of 22q with local elected MPs, MLA's, clinicians, and all those involved in the lives of those living with 22q in Northern Ireland.
- To raise the standard of care for those living with 22q in Northern Ireland via improved health care services, employment and training, social and educational improvements.

## Financial Review

### Financial Performance

As mentioned above we placed a focus on fund-raising in 2023 as we recovered from the deficits caused by Covid restrictions and were very successful in this goal. Our income was substantially larger than any year in the charity's history.

The charity has no assets or liabilities.

#### Income

In addition to a small passive income from Amazon Smile (£24) we raised a total of £16,567 via various fundraising initiatives in 2023-24.

## Expenditure

£7971 was spent in total. The most significant costs were paying for families to attend the 22q European Conference in Dublin and hosting the '22q at the Moo' event at Ark Farm.

Full accounts are attached.

Approved and adopted by a meeting of the trustees on 11<sup>th</sup> January 2025 and signed on their behalf,



Gillian Cassidy

Founder

#### **Reference and Administrative Details**

##### **Charity Name**

22q11 Northern Ireland also known as 22qNI

##### **Charity Number**

Registered Charity in Northern Ireland No 102573

##### **Principal Address**

10A Abbacy Road  
Ardkeen  
Newtownards  
BT22 1HH

#### **Charity Trustees as of March 31st 2024**

Mrs Gillian Cassidy	Founder
Mr Anders Cassidy	Treasurer
Mrs Lorraine Stitt	Advocate and Support Coordinator
Miss Mia Lowden	Trustee