## Light up the Night for 22q11.2!









## Greetings from the International 22q11.2 Foundation, Inc.

## November is 22q11.2 Awareness Month!

**22q11.2 deletion and duplication syndromes** are under-recognized genetic conditions that affect about 1 in 1000 pregnancies and 1 in 2000 live births. These conditions occur when a very small piece of chromosome 22 is missing or extra, resulting in the loss or gain of about 50 genes that help direct how the body is formed and functions. The most common associated features include birth defects (such as heart, palate and kidney problems), multiple medical conditions (including low calcium, difficulty fighting infection, feeding and swallowing differences, and seizures), developmental delay, learning differences, and behavioral health problems, such as ADHD, anxiety, autism, and psychiatric illness. Many individuals require care from multiple specialists across the lifespan, but there is also very broad variability.

Most deletions and duplications are the same size with a subset being a bit smaller. All can occur randomly for the first time in the person who has the chromosome difference and nothing that the parents did or did not do cause it to occur occur. However, once a person has the deletion or duplication there is a 50% chance of passing it on in every pregnancy.

Chromosome 22q11.2 differences are the most common chromosomal conditions after Down Syndrome. However, most people have never heard of chromosome 22, and some people with these differences spend years searching for a diagnosis. To increase public awareness, in 2018, La Asociación Síndrome 22g11 in Spain launched an awareness campaign entitled "Luces por el 22q" (Lighting the Night for 22q). Buildings and monuments were illuminated in red on November 22 (22/11 in many parts of the world but 11/22 in North America) as a play on the name of the chromosome difference. Cities in Belgium, Canada, Finland, Germany, and the USA soon followed. On the left of this page, you will find example photos from November 22, 2021, where buildings in Toronto and Philadelphia lit up in red to support 22q awareness. Please consider joining this international endeavor so that no child or adult struggles to find a diagnosis in a timely fashion. Therefore, we respectfully request that \_ in

be lit up in red on November 22, 2022 to raise awareness for chromosome 22q11.2 deletion and duplication syndromes. Questions? Please contact the International 22q11.2 Foundation, Inc. at 001.877.739.1849 or info@22q.org

Thank you in advance for your kind consideration.

The International 22q11.2 Foundation, Inc. PO Box 532, Matawan, NJ 07747 <u>www.22q.org</u>

