



The International 22q11.2 Foundation Inc.

Commending the US-based International 22q11.2 Foundation, in helping thousands of families through providing resources, [education and](#) valuable connections with expert clinicians, creating awareness days, supporting research, and engaging with other support groups for advocacy and to deliver the most cutting edge information related to 22q11.2,

WHEREAS the International 22q11.2 Foundation was founded in 2003 by parents of children of this little known genetic condition in collaboration with a dedicated clinical expert,

WHEREAS the organization has been honored as the longest-standing organization of its kind focused on the 22q11.2 deletion and duplication syndromes,

WHEREAS the International 22q11.2 Foundation has formed an alliance with scientific and support organizations across the world to merge the previously described clinical conditions, all with different and confusing names (e.g. DiGeorge syndrome, velocardiofacial syndrome, conotruncal anomaly face syndrome, Opitz G-BBB syndrome, and Cayler Cardiofacial syndrome), all under ONE name – the 22q11.2 Deletion syndrome and the 22q11.2 Duplication syndrome, making it easier to identify the condition, allowing families from across the globe to directly access information on the condition, and connecting families previously split by the differing diagnostic names,

WHEREAS participating families have been afforded the resources to navigate the diagnosis of 22q11.2 quickly and easily through the International 22q11.2 Foundation website and connect and network with many other families receiving the same diagnoses,

WHEREAS patients and families affected by differences in chromosome 22q11.2 now have a network of others to tap into to share information and understand that although this is a little-known, little discussed condition, it is widely discussed and in need of continued awareness for early detection, diagnosis and care,

WHEREAS the International 22q11.2 Foundation programs and resources have served >50,000 families that live with the condition daily and have created over events too numerous to count to increase awareness over the past 15 years,

WHEREAS during the International 22q11.2 Foundation's 15 year history, many families, healthcare providers, and basic science researchers have participated in the Foundation's cornerstone programs: 22q at the Zoo Worldwide Awareness Day, 22q and Boo, 22k for 22q, 2.2 for 22q, 22q Awareness Month events, and more,

WHEREAS the American Journal of Medical Genetics recently dedicated an entire issue to the chromosome 22q11.2 deletion syndrome which included numerous papers by members of the International 22q11.2 Foundation Medical Advisory Board,

Now therefore be it resolved by the Senate that the members of this body commend the International 22q11.2 Foundation for superb achievements in the field of 22q11.2 awareness, support, advocacy collaboration and research, and furthermore would like to move to recognize **November 22 as "22q Awareness Day"** in Pennsylvania, effective November 22, 2019,

Be it further resolved that the Secretary of the Senate is authorized and directed to transmit an appropriate copy of this resolution to the International 22q11.2 Foundation, Inc., PO Box 532, Matawan, NJ 07747