HOUSE No. 4070

The Commonwealth of Massachusetts

PRESENTED BY:

Kristin E. Kassner and Bruce E. Tarr

To the Honorable Senate and House of Representatives of the Commonwealth of Massachusetts in General Court assembled:

The undersigned legislators and/or citizens respectfully petition for the adoption of the accompanying bill:

An Act designating April 5 as Okur-Chung Neurodevelopmental Syndrome Awareness Day.

PETITION OF:

NAME:	DISTRICT/ADDRESS:	DATE ADDED:
Kristin E. Kassner	2nd Essex	4/4/2023
Bruce E. Tarr	First Essex and Middlesex	4/4/2023
Jillian Kavanaugh	33 Crescent Road, Hamilton, MA 01982	4/4/2023
Samantha Montaño	15th Suffolk	4/10/2023
Bud L. Williams	11th Hampden	4/14/2023
Vanna Howard	17th Middlesex	7/2/2023

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By Representative Kassner of Hamilton and Senator Tarr, a joint petition (subject to Joint Rule 12) of Kristin E. Kassner, Bruce E. Tarr and others for the issuance of an annual proclamation by the Governor to designate April 5 as Okur-Chung Neurodevelopmental Syndrome awareness day. State Administration and Regulatory Oversight.

The Commonwealth of Alassachusetts

In the One Hundred and Ninety-Third General Court (2023-2024)

An Act designating April 5 as Okur-Chung Neurodevelopmental Syndrome Awareness Day.

Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:

- 1 Chapter 6 of the General Laws, as appearing in the 2020 Official Edition, is hereby
- 2 amended by inserting after section 15ZZZZZZ, the following section:-
- 3 Section 15AAAAAAA. The governor shall annually issue a proclamation setting apart
- 4 April 5 as Okur-Chung Neurodevelopmental Syndrome (OCNDS) Awareness Day, to raise
- 5 awareness of this rare genetic disorder caused by heterozygous mutations in the CSNK2A1 gene
- 6 on chromosome 20 and manifesting as developmental delay or differences in brain function,
- 7 which can be managed with early therapy, and recommending that the day be observed in an
- 8 appropriate manner by the people.