

2024 GUIDE TO OBTAINING GOVERNOR PROCLAMATIONS

This GUIDE was originally written by Clifford L. Fry, Ph.D., former Family Empowerment Representative for International Rett Syndrome Foundation (IRSF).

Goal: To obtain a governor proclamation announcing OCTOBER as RETT SYNDROME AWARENESS MONTH.

Such a proclamation can be used by:

- * Medical professionals working with Rett syndrome to attract attention and media to their work.
- * Advocates and event hosts to get attention from the media.
- * Fundraisers to establish a "reason" for their activity and introduce the topic to potential donors.
- * School papers to make a "star" out of our daughters and sons at school.

To take responsibility for obtaining a proclamation in your state, you will need the capability to write emails/letters and to provide whatever the Governor's staff requires.

HOW TO BEGIN: Go to the Governor's website or call the Governor's office and ask who handles Governor proclamations. Tell them that you would like to request a proclamation declaring October to be **Rett Syndrome Awareness Month**. You will probably have to explain what Rett syndrome is. Send a follow-up request to the person you talk to by email or letter, again requesting that a proclamation be issued. The request should include information about Rett syndrome and, if possible, something about the state's involvement in research, Rett individuals in the state, fundraising events, or whatever will make the proclamation seem important enough for the Governor's representatives to pursue. Reach out to Katie Busch at IRSF if you need assistance with finding this information. Personal heartfelt messages are also important. Include IRSF's website www.rettsyndrome.org.

You can tell the Governor's staff that the International Rett Syndrome Foundation can help draft the Rett syndrome aspects of the proclamation form if needed. (The Governor's office may need assistance with correctly describing Rett syndrome.)

Once the Governor's staff commits to getting the proclamation done, you can tell them you would appreciate a photo opportunity with the Governor at the signing if he/she would be agreeable to that, though it is not necessary to obtain the proclamation.

Once a proclamation is obtained, they will likely keep it on record, and a simple request is made each year for an update on the date of the proclamation and the relevant Governor.

A "draft" Rett proclamation request letter, and also, "Whereas" statements for the Governor's office can be found on the IRSF's website to help you with your request.

When you secure a state proclamation please let Katie at IRSF know of your success!

With questions or for assistance please reach out to Katie Busch, Government Relations Manager for IRSF @ kbusch@rettsyndrome.org or at (513) 874-3020.