

## 2021 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). Jessica Williams oversees the current Rett proclamation effort. Please direct any comments or questions to Jessica Williams at [jr.williams@hotmail.com](mailto:jr.williams@hotmail.com) if you are interested in obtaining one for your state.

**Goal: To obtain a governor proclamation announcing OCTOBER as RETT SYNDROME AWARENESS MONTH in *all 50 states*.**

Such a proclamation can be used by:

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

Perhaps the school paper will acknowledge it and do an article on a child with Rett syndrome and what Rett syndrome means. This may take some marketing to accomplish, but it would require very little time with a proclamation in hand.

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. I will be here to assist you with any aspect.

**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. Personal heartfelt messages are also important. Include IRSF's website [www.rett syndrome.org](http://www.rett syndrome.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.

I will work with you in any way you need. Periodically keep me informed of your activities and progress.

I've written a "draft" Rett proclamation request letter, and also, "Whereas" statements for the Governor's office to help you with your request.

This outline of the approach is a **GUIDE**. If I am missing anything that you think is major let me know. I will be happy to talk over any complication that might arise. With work, we should accomplish a great deal.

It is great working with you for these Rett Angels we love so much!

Thank you,

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