

2018 GUIDE TO OBTAINING GOVERNOR PROCLAMATIONS

This GUIDE was originally written by Clifford L. Fry, Ph.D., former Family Empowerment Representative for Rettsyndrome.org and edited by Donna Dean who is in charge of the Rett proclamation effort. Please direct any comments or questions to Donna at: donnacdean@yahoo.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 people working with Rett syndrome to attract attention and media to their work.
- * Local and regional 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 at school.

Perhaps the school paper will acknowledge it and do an article on a girl 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 and maybe letters and to respond to whatever the governor's staff's requirements are. You will need to correspond with those assisting the governor. I will be here to assist you with any aspect.

HERE IS WHAT I THINK YOU WOULD HAVE TO DO: Go to the Governor's site on the Internet, or call the governor's office and find out who is handling the 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 probably needs to include information about Rett syndrome and, if possible, something about the state's involvement in research, Rett Girls in the state, fundraising events, or whatever will make the proclamation seem important enough for the Governor's representatives to pursue - something to make them want to issue the proclamation. Personal heartfelt messages are also important. You might tell them the Rettsyndrome.org site address, www.rettsyndrome.org so they can see that Julia Roberts and Clint Black are assisting this organization. (Once a proclamation is obtained, they will likely keep it on record, and a simple request is made each year for an update in the date of the proclamation and the relevant governor.)

You can tell the governors' staff that Rettsyndrome.org has professional medical people who will draft the Rett syndrome aspects of the proclamation form the governor to ensure accuracy. (The governor's office may need assistance with correctly describing Rett syndrome.)

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

Clifford Fry has suggested that 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.

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 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,

Donna Dean
Grandparent Representative

Email: donnacdean@yahoo.com