



KCNQ2 CURE ALLIANCE AWARENESS TOOLKIT

GET IN TOUCH

KCNQ2 Cure Alliance, Inc.
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What is KCNQ2 Awareness Week/Day?

“KCNQ2 Awareness week is an international grassroots effort dedicated to increasing awareness of KCNQ2 related-epilepsies worldwide. March 1st-7th annually, is KCNQ2 awareness week and March 2nd is KCNQ2 international awareness day. While our community works year-round to raise awareness of KCNQ2, the first week of March is a great time to spotlight those efforts and build new momentum. This is in addition to our usual work—hosting meetings and attending conferences, telling our stories to neighbors and friends, sharing information about KCNQ2, using social media to raise awareness, and more.”

WHAT YOU CAN DO?



There are multiple ways you can spread awareness of KCNQ2. We have provided several suggestions as well as tools that can help you make a difference.

Use Social Media

- Consider filming a short video on your phone and sharing it to your social media. Tell your followers how you're affected by KCNQ2, the impact it has had on your family and why the work being done by KCNQ2 Cure Alliance is important to you.
- Tag KCNQ2 Cure in your postings (you must be following our social media in order to do this)! You can do this on your posts throughout the year, but this week especially.

We utilize Facebook, Twitter, and Instagram. Be sure to use the following hashtags:

#KCNQ2 #KCNQ2STRONG
#KCNQ2CURE #KCNQ2AWARENESS

- Download the KCNQ2 social media resource kit for more information and tips.
- Make sure to follow & share on all of our social media sites and invite your friends and relatives to follow us as well:

 KCNQ2CURE  KCNQ2CURE  KCNQ2

Share your loved ones' story

- The biggest impact you can make is by sharing your story. Putting a face to KCNQ2, and helping others to understand its effect, is our most valuable tool in helping us to advance effective policies, raise funds, and continue medical advances. You can share your story in a number of ways!

Reach out in the community

- Consider contacting your local community centers, libraries, hospitals and other gathering places and ask if you can have an informational table during Awareness Week. KCNQ2 Cure has brochures and fact sheets that you can distribute! Email [http://info@kcnq2cure.org](mailto:info@kcnq2cure.org) for more information.
- If you or someone you know belongs to a civic organization such as Kiwanis, Elks or another service group, ask if you can speak during an upcoming meeting about KCNQ2 related epilepsies. These organizations are always looking for speakers, and if you have a connection, chances are that just for asking, you'll be invited to speak. KCNQ2 Cure will provide you with talking points and informational sheets, so don't be shy! Even if you don't have an opportunity to make a formal presentation, time is often allotted at meetings for members to share news.
- Ask your church, synagogue or other religious institution to recognize rare disease day during that weekly service and lend your voice by saying how you are impacted by KCNQ2. If there is a bulletin that is issued each week, this is also an opportunity to share information.
- If your child has KCNQ2, speak to your school and ask if you can help facilitate a classroom discussion. Schools may also welcome discussions in classrooms of siblings, cousins or friends, as this presents a real-world opportunity to teach compassion and understanding of people's differences.

Get a proclamation

What is a proclamation? See the next page for more info.

GET A PROCLAMATION



What is a proclamation?

A proclamation is a formal public statement from an official declaring and supporting KCNQ2 Awareness Week/Day. Most often proclamations are from governors, mayors, and also state legislators.

How do I request a proclamation?

Often on the official website of the city, county or state there is information about how to request a proclamation. Below is a list of states and the best way to apply and submit.

How should I get started?

KCNQ2 Cure would appreciate it if you first contacted our office and let us know who you will obtain a proclamation from. We try to maintain a list so that volunteer efforts aren't duplicated. If someone is already working on a particular state or locality we will try to put you in touch with that volunteer so you can work together.

Each state and municipality is different. Review that entity's website to locate how to request a proclamation.

Submit requests at least 2 months prior to KCNQ2 Awareness Week/Day. Many officials will want a sample proclamation to use or to review. Please see a sample proclamation below.

Follow up with your municipality approximately 10-14 business days after your submission to ensure it is being processed. Some municipalities will offer "signing ceremonies". This is a great way to create even more awareness and draw media attention. When following up with your government official's office inquire if there is an opportunity to host a "signing ceremony".

I received the proclamation, now what do I do?

Share your success with KCNQ2 Cure Alliance! KCNQ2 Cure would love to have a copy or photo of your proclamation and any photos from a signing ceremony (if applicable). Be sure to include who is in the photos and if there was a signing ceremony when and where it took place. All photos and files can be emailed to info@kcnq2cure.org or you can mail them to us at
KCNQ2 Cure Alliance
3700 Quebec Street,
Unit 100-118,
Denver, CO 80207.

Don't forget to post them to your social media with **#KCNQ2** **#KCNQ2STRONG**

Send thank you notes to the elected officials and staff who helped you obtain the proclamation! If your elected official is on Twitter and/or Facebook you may tag/post to them:

"Thank you for declaring KCNQ2 Awareness week March 1st-7th (or KCNQ2 Awareness Day March 2nd) in {MUNICIPALITY} #KCNQ2 #KCNQ2STRONG #KCNQ2CURE #KCNQ2AWARENESS #Epilepsy #Autism"

PROCLAMATION REQUEST SAMPLE LETTER



KCNQ2 EPILEPSY AWARENESS DAY/WEEK PROCLAMATION REQUEST

Dear _____,

Whereas, millions of people worldwide have genetic or chromosomal disorders; and

Whereas, KCNQ2 is a rare, life altering and threatening genetic disorder affecting neurological function; and

Whereas, today, we recognize those children and adults who have a mutation in their KCNQ2 gene; specifically, de novo, mosaic, and deletion types; and

Whereas, the most common symptom associated with KCNQ2 is epilepsy, which affects over 50 million people worldwide and over 3 million people in the United States, and one in ten persons will have at least one seizure during his or her lifetime; and

Whereas, each KCNQ2 diagnosis is different, depending on the individual, and therefore it is important to acknowledge there is a wide range of severity in the developmental and intellectual disabilities and medical needs experienced by individuals with these types of mutations; and

Whereas, KCNQ2 is estimated to affect 1 in every 100,000 persons worldwide; and

Whereas, KCNQ2 Cure Alliance is an international non-profit organization that was created in 2014 to provide support to families with KCNQ2 and to promote research toward a cure; and

Whereas, KCNQ2 Awareness Week/Day will be celebrated during March 1-7 annually to increase understanding, reduce stigma and improve the quality of life for people with KCNQ2 Epilepsy throughout the country and globally.

THEREFORE I, the *[Mayor or Governor or representative etc]* of *[CITY or STATE]* do hereby announce and proclaim to all citizens and set {...}

PROCLAMATION RULES BY STATE



In order to make it easier for you to find the needed information to obtain a proclamation, we have gathered instructions and links, relevant to each individual state. **PLEASE CLICK THE LINK BELOW AND FIND YOUR STATE TO LEARN MORE.**

[**CLICK HERE FOR STATE RULES >**](#)

For questions or concerns, please dont hesitate to contact us:

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We thank you for your continued support and help in our search for a cure!