



# KBG Syndrome Awareness Day Proclamation Guide

Do you want to get a proclamation or other commemorative recognition for KBG Syndrome Awareness Day (June 11)? We can help with that!

## **Things to know:**

Most cities and states have online request forms that need to be filled out 30 to 90 days but not more than six months before the proclamation is needed. Be sure to read through the requirements before you submit to ensure you have everything you need. If you have any questions, we are happy to help, whether you mention the KBG Foundation or not (some governing bodies do not issue proclamations with an organization's name in them). Contact [pr@kbgfoundation.com](mailto:pr@kbgfoundation.com) for assistance.

## **Things you may need:**

Most cities and states ask for a sample of the wording for the proclamation or declaration or, in the case of some, a letter stating why you want the proclamation. We have drafted a sample request letter and two versions of an official proclamation:

- one that mentions the KBG Foundation
- one that is generic for you to enter your name.

You are welcome to use either version and, for the purposes of a proclamation, the KBG Syndrome Ribbon should they request an image. When drafting a letter, be sure to include your personal reason for the request.

Following the drafts is a list with links to proclamation requests on state websites, where we have them.

Good luck!

Board of Directors  
KBG Foundation

## **SAMPLE PROCLAMATION REQUEST LETTER TO GOVERNOR, STATE LEGISLATOR, MAYOR OR COUNTY COMMISSION CHAIR**

NOTE: These requests take time to process, check with the appropriate office for the timeframe and please submit to that office within that allotted time (links can be found in this document). You may also follow up with a phone call or email to verify receipt and/or the likelihood of their office making this proclamation. If is an in- person meeting to deliver the proclamation to you, please take photos and email the KBG Foundation at [pr@kbgfoundation.com](mailto:pr@kbgfoundation.com).

Date  
The Honorable *(First Name and Last Name)*  
Name of Governing Body  
Mailing Address  
City, State, Zip

Dear *(Title and Last Name)*:

I am writing to request that June 11, 20XX, be declared KBG Syndrome Awareness Day in *(City, County or State)*.

As a resident of *(City, County or State)* and a KBG syndrome *(Patient/Caregiver/Supporter, etc.)*, I humbly request that you recognize the importance of KBG syndrome awareness to the general public and the impact on the lives of those affected by this condition. On this day thousands of KBG syndrome patients and supporters worldwide will join forces to do the same.

KBG syndrome is a rare genetic disorder caused by a mutation on the ANKRD11 gene and associated with a spectrum of challenges, including developmental delays, cognitive disabilities, behavioral disorders, autism, seizures, hearing loss, skeletal anomalies, heart complications and gastrointestinal problems. Most people with KBG share at least some physical traits, including a triangular face, heavy eyebrows, curved fingers and spine, and short stature.

The seventh annual KBG syndrome day is hosted by the KBG Foundation. Founded in 2015, the Foundation is a 501(c)(3) non-profit organization serving approximately 2,000 family members and patients worldwide with a mission to inform, educate and support those affected by this nano rare condition. The affected rate is approximately 1 in 19 million worldwide, and you have one of these rare patients in your constituency!

The KBG Foundation will utilize its social media properties that reach over 5,000 people per month to achieve its awareness goal. Supporters like me will participate in social media campaigns, share our stories and hold local events to expand awareness and I look forward to working with your office on this important endeavor and in representing *(City, County or State)* in this local and national campaign.

Thank you for your consideration.

Sincerely,

Your First and Last Name  
Your Contact Information

# Sample wording for KBG Syndrome Awareness Day with the KBG Foundation

WHEREAS, *KBG syndrome is a rare genetic disorder caused by a mutation on the ANKRD11 gene, associated with a spectrum of challenges, including cognitive disabilities, behavioral disorders, autism, seizures, hearing loss, heart complications and gastrointestinal problems; and*

WHEREAS, *The name KBG syndrome was chosen using the first letters of the surnames of the three original patients, who were described having developmental delay, craniofacial dysmorphisms and other skeletal anomalies; and*

WHEREAS, *This syndrome is gaining popularity among researchers, as ANKRD11 is a target gene for autism, epilepsy and cancer; and*

WHEREAS, *There is currently no single treatment or cure for KBG syndrome;*

WHEREAS, *Patients living with this gene mutations experience a wide range of medical and development complications and numerous comorbidities; and*

WHEREAS, *Increased awareness of KBG syndrome and its symptoms will lead to more people receiving the proper diagnosis;*

WHEREAS, *(STATE OR CITY) is pleased to join with the KBG Foundation in its efforts to increase public awareness and understanding of KBGsSyndrome*

NOW, THEREFORE, I, (GOVERNOR OR MAYOR) of the (STATE OR CITY) of (STATE OR CITY) do hereby proclaim, June 11, 20XX as **KBG SYNDROME AWARENESS DAY** in (STATE OR CITY) and call upon the people of our (STATE OR CITY) to join in this observance.

## Sample generic wording for KBG Syndrome Awareness Day

*WHEREAS, KBG syndrome is a rare genetic disorder caused by a mutation on the ANKRD11 gene, associated with a spectrum of challenges, including cognitive disabilities, behavioral disorders, autism, seizures, hearing loss, heart complications and gastrointestinal problems; and*

*WHEREAS, The name KBG syndrome was chosen using the first letters of the surnames of the three original patients, who were described having developmental delay, craniofacial dysmorphisms and other skeletal anomalies; and*

*WHEREAS, This syndrome is gaining popularity among researchers, as ANKRD11 is a target gene for autism, epilepsy and cancer; and*

*WHEREAS, There is currently no single treatment or cure for KBG syndrome;*

*WHEREAS, Patients living with this gene mutations experience a wide range of medical and development complications and numerous comorbidities; and*

*WHEREAS, Increased awareness of KBG syndrome and its symptoms will lead to more people receiving the proper diagnosis;*

*WHEREAS, (STATE OR CITY) is pleased to increase public awareness and understanding of KBG syndrome*

*NOW, THEREFORE, I, (GOVERNOR OR MAYOR) of the (STATE OR CITY) of (STATE OR CITY) do hereby proclaim, June 11, 20XX as **KBG SYNDROME AWARENESS DAY** in (STATE OR CITY) and call upon the people of our state to join in this observance.*

State Name	Link to request a proclamation
Alabama	<a href="https://contact.governor.alabama.gov/contact_procs.aspx">https://contact.governor.alabama.gov/contact_procs.aspx</a>
Alaska	<a href="https://aws.state.ak.us/CrmForms/Home/WebRequest">https://aws.state.ak.us/CrmForms/Home/WebRequest</a>
Arizona	<a href="https://azgovernor.gov/engage/form/proclamation-request">https://azgovernor.gov/engage/form/proclamation-request</a>
Arkansas	<a href="https://governor.arkansas.gov/online-services/proclamation-request/">https://governor.arkansas.gov/online-services/proclamation-request/</a>
California	<a href="https://www.ca.gov/archive/gov39/faq/index.html">https://www.ca.gov/archive/gov39/faq/index.html</a>
Colorado	<a href="https://www.colorado.gov/governor/proclamations">https://www.colorado.gov/governor/proclamations</a>
Connecticut	<a href="https://portal.ct.gov/Office-of-the-Governor/Contact/Request-a-proclamation">https://portal.ct.gov/Office-of-the-Governor/Contact/Request-a-proclamation</a>
Delaware	<a href="https://governor.delaware.gov/request-proclamation-tribute/">https://governor.delaware.gov/request-proclamation-tribute/</a>
Florida	<a href="https://dr.flgov.com/request-a-proclamation/">https://dr.flgov.com/request-a-proclamation/</a>
Georgia	<a href="https://gov.georgia.gov/contact-us/proclamations/proclamation-request">https://gov.georgia.gov/contact-us/proclamations/proclamation-request</a>
Hawaii	<a href="https://governor.hawaii.gov/contact-us/request-a-commemorative-message/">https://governor.hawaii.gov/contact-us/request-a-commemorative-message/</a>
Idaho	<a href="https://gov.idaho.gov/contact/proclamations/">https://gov.idaho.gov/contact/proclamations/</a>
Illinois	<a href="https://www2.illinois.gov/sites/gov/contactus/Pages/Proclamation.aspx">https://www2.illinois.gov/sites/gov/contactus/Pages/Proclamation.aspx</a>
Indiana	<a href="https://www.in.gov/gov/governors-office/request-a-proclamation/">https://www.in.gov/gov/governors-office/request-a-proclamation/</a>
Iowa	<a href="https://governor.iowa.gov/services/request-proclamation">https://governor.iowa.gov/services/request-proclamation</a>
Kansas	<a href="https://governor.kansas.gov/serving-kansans/constituent_services/proclamation-guidelines/proclamation-request/">https://governor.kansas.gov/serving-kansans/constituent_services/proclamation-guidelines/proclamation-request/</a>
Kentucky	<a href="https://secure.kentucky.gov/formservices/Governor/ProclamationRequestForm">https://secure.kentucky.gov/formservices/Governor/ProclamationRequestForm</a>
Louisiana	<a href="https://gov.louisiana.gov/index.cfm/form/home/13">https://gov.louisiana.gov/index.cfm/form/home/13</a>
Maine	<a href="https://www.maine.gov/governor/mills/contact/request_proclamation">https://www.maine.gov/governor/mills/contact/request_proclamation</a>
Maryland	<a href="https://governor.maryland.gov/proclamation-requests/">https://governor.maryland.gov/proclamation-requests/</a>
Massachusetts	<a href="https://www.mass.gov/info-details/governors-office-scheduling-and-special-request-forms#request-a-proclamation-from-governor-healey-">https://www.mass.gov/info-details/governors-office-scheduling-and-special-request-forms#request-a-proclamation-from-governor-healey-</a>

Michigan	<a href="https://www.michigan.gov/whitmer/news/proclamations">https://www.michigan.gov/whitmer/news/proclamations</a>
Minnesota	<a href="https://mn.gov/governor/news/proclamationrequest.jsp">https://mn.gov/governor/news/proclamationrequest.jsp</a>
Mississippi	unknown
Missouri	<a href="https://governor.mo.gov/actions/proclamations">https://governor.mo.gov/actions/proclamations</a>
Montana	<a href="https://governor.mt.gov/Contact/">https://governor.mt.gov/Contact/</a>
Nebraska	<a href="https://governor.nebraska.gov/proclamation-request">https://governor.nebraska.gov/proclamation-request</a>
Nevada	<a href="https://gov.nv.gov/Forms/Request a Proclamation/">https://gov.nv.gov/Forms/Request a Proclamation/</a>
New Hampshire	<a href="https://new-hampshire.secure.force.com/support/GOV_Proclamation">https://new-hampshire.secure.force.com/support/GOV_Proclamation</a>
New Jersey	<a href="https://www.nj.gov/governor/contact/proclamations/">https://www.nj.gov/governor/contact/proclamations/</a>
New Mexico	<a href="https://www.governor.state.nm.us/contact-the-governor/requesting-a-proclamation/">https://www.governor.state.nm.us/contact-the-governor/requesting-a-proclamation/</a>
New York	<a href="https://www.governor.ny.gov/content/governor-contact-form">https://www.governor.ny.gov/content/governor-contact-form</a>
North Carolina	<a href="https://governor.nc.gov/submit-request/request-proclamation">https://governor.nc.gov/submit-request/request-proclamation</a>
North Dakota	<a href="https://www.governor.nd.gov/proclamation-request">https://www.governor.nd.gov/proclamation-request</a>
Ohio	<a href="https://governor.ohio.gov/help-center">https://governor.ohio.gov/help-center</a>
Oklahoma	<a href="https://oklahoma.gov/governor/contact/commendation-or-proclamation.html">https://oklahoma.gov/governor/contact/commendation-or-proclamation.html</a>
Oregon	<a href="https://www.oregon.gov/gov/Pages/Proclamation-Request-Guidelines.aspx">https://www.oregon.gov/gov/Pages/Proclamation-Request-Guidelines.aspx</a>
Pennsylvania	<a href="https://www.governor.pa.gov/contact/#OnlineForm">https://www.governor.pa.gov/contact/#OnlineForm</a>
Rhode Island	<a href="https://governor.ri.gov/contact">https://governor.ri.gov/contact</a>
South Carolina	<a href="https://governor.sc.gov/contact-governors-office">https://governor.sc.gov/contact-governors-office</a>
South Dakota	<a href="https://governor.sd.gov/office/executive-proclamation.aspx">https://governor.sd.gov/office/executive-proclamation.aspx</a>
Tennessee	<a href="https://www.tn.gov/governor/contact-us/constituent-requests/proclamation-">https://www.tn.gov/governor/contact-us/constituent-requests/proclamation-</a>
Texas	<a href="https://gov.texas.gov/apps/contact/assistance.aspx">https://gov.texas.gov/apps/contact/assistance.aspx</a>
Utah	<a href="https://sf.gov.utah.gov/Contact/s/declaration">https://sf.gov.utah.gov/Contact/s/declaration</a>
Vermont	<a href="https://vermont.force.com/vermontce/s/governor-office-ce?tabset-171b4=2">https://vermont.force.com/vermontce/s/governor-office-ce?tabset-171b4=2</a>

Virginia	<a href="https://www.governor.virginia.gov/constituent-services/request-a-proclamation/">https://www.governor.virginia.gov/constituent-services/request-a-proclamation/</a>
Washington	<a href="https://www.governor.wa.gov/contact/requests-invites/request-ceremonial-proclamation-greeting-or-letter">https://www.governor.wa.gov/contact/requests-invites/request-ceremonial-proclamation-greeting-or-letter</a>
West Virginia	<a href="https://appengine.egov.com/apps/wv/governor/request-proclamation">https://appengine.egov.com/apps/wv/governor/request-proclamation</a>
Wisconsin	<a href="https://appengine.egov.com/apps/wi/governor/document-request">https://appengine.egov.com/apps/wi/governor/document-request</a>
Wyoming	<a href="https://governor.wyo.gov/contact/proclamation-requests">https://governor.wyo.gov/contact/proclamation-requests</a>