

Subject: 2018 #LGDAAwareness Day

Dear Colleague:

In May 2017, the LGDA and its counterparts in the UK and Europe conducted a weeklong campaign dedicated to raising awareness about GLA, Gorham-Stout disease, and KLA, which concluded with the very first #LGDAAwareness Day on May 26, 2017.

The theme for the week was “5 Words on Being Rare.” We asked patients, their families, and volunteers to select 5 words that describe their experiences with these rare diseases and send us their reasons for choosing them. Throughout the week we published graphics made from content they submitted through our social media platforms to spread the message of what it is like to be rare. ([View a slideshow featuring some of the graphics used in 2017 at here: http://bit.ly/2FSuyyl](http://bit.ly/2FSuyyl) or visit our Facebook page: <https://www.facebook.com/LGDAlliance/> and see the album titled #LGDAAwareness Day 2017.

This year we are asking for your help and participation.

We are planning for the 2018 campaign and would like to focus this year’s event on the perspectives and experiences of the health care providers and scientists who care for the patients and conduct the research that is helping to improve diagnosis and outcomes.

These are some things we would like to know about you:

1. When/how did you first become aware of GLA/KLA/GSD?
2. What inspired your interest in GLA/KLA/GSD?
3. How many patients have you cared for?
4. What is your greatest challenge in caring for these patients (or conducting research to help them)?

In addition to the questions, it would be helpful if you would select a word to use in a sentence that sums up some aspect of caring for these patients and their families.

Word List: (This list reflects the words chosen by patients and families for 2017 and we thought it would be interesting to see how many are shared by professionals they encounter.)

Anger (Angry)	Disappointed	Guilt	Interested	Overwhelmed
Anxious	Excited	Helpless	Isolation	Powerless
Avoidance	Exclusion	Hope	Lonely	Proud
Confident	Frightened	Hurt	Loss (or lost)	Regret
Confused	Frustration	Ignored	Motivated	Reassured
Depressed	Grateful	Inspired	Optimistic	Sadness

Please reply to this email with the answer to at least one of the questions; a photo of yourself is encouraged but not required. Photos of people make a big impression and have a huge impact on our ability to get our message out!

Your answers, along with your name and institution will be used to make infographics that will be distributed through our social media pages, email newsletters, and website over the course of the week from May 20 to May 26, 2018.

Please reply to channels@lgdalliance.org by May 3, 2018, so that we have plenty of time to put together the project content that will be shared during #LGDAAwareness 2018.

We can’t wait to receive your input!

Kind regards,

LGDA Awareness and Outreach Committee

channels@lgdalliance.org