

Dear Exon 20 Group Member,

We need your help!

As outlined at the bottom of this note, the Exon 20 Group has established a strong platform from which to conduct current and future programs aimed toward transforming this lethal diagnosis into a manageable chronic disease. To achieve success, we need your help.

We fully realize that our Exon 20 patients have limited time to volunteer as many high-priority items are already on their plates. But we also realize that many family members and friends are seeking ways to step up and help. So, our appeal here is to all patients *and* to the circles of supporting family members and friends surrounding them. To you patients, if anyone asks “*what can I do to help the Exon 20 Group?*” please point them to this communication and to **this list of specific needs:**

- 1) Newsletter Team, and the perfect volunteer would have Master's or PhD-level academic experience and would love writing and editing!
- 2) Program Team, for our webinars with guest speakers discussing Exon 20 drugs, with patient Q and A
- 3) Clinical Trials Excel Team, for our interactive All-Trials Information Services--so far Kristen Leniz, chair of this working group, is delighted to report that these volunteers have offered their talents: Elena Siltanen, Phil Jones, Susan Dailey, and Lin McTeague--please join them by emailing us at [marcia@Exon20group.org](mailto:marcia@Exon20group.org)
- 4) Fundraising Team, to raise funds for the Exon 20 Group's multi-faceted mission in your state or elsewhere--through fully tax-deductible donations (EIN 86-0818253) to the Exon 20 Group at ICAN (<https://askican.org/donate.html>), through planned giving vehicles, and through special events such as golf tournaments, bikeathons (or any sport), lunch and learns, musical events, etc.
- 5) Clinician Education Team, to arrange meetings with community oncologists to stress the urgent need for genomic profiling to identify the Exon 20 insertion mutation on diagnosis
- 6) Oncology Conference Attendees, to join us at major cancer conferences and be assigned to specific sessions of interest to Exon 20 patients (patient/family attendees responsible for meeting registration, airfare, and hotel)--we will be having an Exon 20 Summit in conjunction with the Denver World Lung Conference in 2021
- 7) Angel Buddies Program, which involves patients and family members with experience with Exon 20 drugs, providing peer-to-peer moral support--we have piloted this program over the past year, and it is a great success!





- 11) Understanding the mutational landscape of Exon 20 (that's why we ask for all your records!) as the cancer evolves
- 12) Working with other advocacy organizations to stress the fact that Exon 20 insertions are not just diagnosed in lung cancer but have been found in 24 other cancer types as well
- 13) Working on fundraising events to support our mission and program to benefit patient survival and quality of life
- 14) Working with our biopharma partners and survey research partners on important surveys of our Exon 20 Group community to better understand the patient journey and patient-reported outcomes
- 15) Seeking new strategies to defeat recurrent pleural effusions