



# ALK POSITIVE

WORLDWIDE INFORMATION, SUPPORT & EMPATHY

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## COMMUNITY RULES / INFORMATION

### COMMUNITY INFORMATION

ALK Positive was created by Merita Carroll on April 22, 2015. She wanted a support community where Anaplastic Lymphoma Kinase positive (ALK-positive) lung cancer patients, like herself (diagnosed March 5, 2015), and caregivers share their personal experience with this condition. Members can share whatever they wish about their journey which could be personal medical information and experience about their treatment of ALK-positive lung cancer. The charter purpose of this community is to provide Information, Support, and Empathy. We do this by increasing awareness and knowledge in others as to what benefits, side effects, availability, and other pertinent details and experiences they may expect while taking the various medications to treat ALK-positive lung cancer. This also includes patients/caregivers of other cancer communities who are also being treated with ALK type Tyrosine Kinase Inhibitors (TKIs) for their particular type of cancer.

*Information shared within the community should NEVER be considered medical advice and you should never act upon anything read within the community without first consulting your physician/care team because every person is different and the treatments discussed within the community may react differently in you.*

This community is very narrowly focused on ALK-positive lung cancer. It will probably be one of the most relevant and up to date sources you will find where everything is directly related to treatment of ALK-positive lung cancer, especially the ALK TKIs. This is achieved through active moderation by not only the Admins and Moderators, but the members who can tag a questionable post as being relevant and on topic. Upon review by an Admin or Moderator, the post will either be cleared and allowed to be published within the community, or it will be removed. Please see the rules section on inappropriate/off-topic posts.

### VIP MEMBERSHIP

The community Admins allow VIP access time to time. Who is a VIP? A VIP, as an example, could be a healthcare industry professional who wishes to tap into a very select and focused

group of patients to learn from them. This is not usually available to them outside of clinical trials. If you are concerned that your private health information may be compromised, they are still bound by the same laws as if you were their patient. If you do not wish them to have access to your comments and posts within the community, you can BLOCK any VIP member and they cannot see any posts or comments you make within the community. To find a VIP member, an Admin will welcome them to the community and specify in the welcome message they are in the community as a VIP member. You can search the community for 'VIP member' and see only posts with 'VIP member' in it, at which point you can block those members.

## **COMMUNITY RULES**

- Each member must complete the group registration form located at <https://www.alkpositive.org/registration-form> prior to being accepted into the group.
- Each member must answer the two questions when requesting to join the Facebook Support group.
- The membership roster, populated from the registration form, will be shared with the entire membership via a view only link. This will allow those who wish to offer you support to look you up in the spreadsheet to remind themselves of your journey.
- Upon acceptance you will have ONE WEEK to introduce yourself to confirm you have a relationship with ALK-positive lung cancer (or taking an ALK TKI) before being removed from the community (this is to protect community members' private health information and keep the community on topic).
- Adding members to the group by other members will not be allowed. Each member must complete the registration form and answer the two questions when requesting to join the group.
- Be nice. Many here are looking for information, support, and empathy, and possibly to vent from time to time. Please be respectful in your posts and replies (empathy).
- No fundraising. Too many opportunities to be scammed and we want to keep this community narrowly focused on ALK-positive lung cancer treatment.
- No posting of inspirational type posts such as prayer requests, support requests for members outside the community, etc. We want to keep the volumes of information in this community narrowly focused and relevant to ALK-positive lung cancer. This does not mean this community is non-religious. If anything it is non-denominational, but certainly not non-religious. All faiths, or lack thereof, are welcome in this community. If you choose to not have a faith, please do not bash/shame another for their beliefs; simply skip over the post. Remember the Golden Rule: If you cannot say something nice, don't say anything at all.
- Inappropriate/off-topic posts are posts that are considered to not benefit ALK-positive lung cancer patients by not only the Admins, but the members as well. If a post is removed by an Admin, the posting member will receive a warning message. After three warnings a member will be removed from the community.
- **To protect this very important community**, posting messages to the group that you have excess medication (previous TKIs) and offering them to other members is not allowed. This could cause our Facebook Group to be closed by Facebook for the trade of medication, which is illegal. If you have excess medication and wish to dispose of it, please post a

message in the group similar to this: *“I have leftover (Xalkori, Zykadia, Alecensa, Alunbrig, etc.) medication and I would like suggestions about what to do with it. If you have any suggestions, please contact me via private message.”*

- LIVE video posts are not allowed in the group. Any such posts will be deleted immediately.

### **IMMEDIATE REMOVAL AND BLOCKAGE FROM THE COMMUNITY**

You will immediately be removed and permanently blocked from this community if you violate the rules listed in this section

- SPAM posts (sale of any items), snake oil remedies, of any kind.
- Blocking of an Admin or Moderator.
- Attacking/flaming/shaming another member for anything.
- Being disrespectful of other members belief system or lack of.
- For flagrant violations in the opinion of the Admins, or Moderators, that do not warrant blockage from the community a member may be immediately removed without notice and notified they have been removed. This is considered a one-time warning that a member was being offensive. The member may wish to request re-entry into the community after a two-week period of time has elapsed.

### **MAKING YOUR INTRODUCTION**

To help you in your required introduction within the Facebook community, below are a few suggested items you may include in your introduction. This is not meant to put you on the spot, but just to give the group an idea of your journey so far and a little about you. Answering the questions below is NOT required in your introduction, so please answer whatever you're comfortable with, but as a minimum you MUST confirm you have a relationship with the ALK mutation (or taking ALK TKIs) via your introduction.

The more information you share with the community the better because it may relate your situation or treatment to someone else and could even help them by revealing something they don't know already about treatment options, or they may be able to help you.

- Are you a survivor or a caregiver?
- At what age was diagnosis?
- How long ago was diagnosis?
- What profession/career at diagnosis?
- Which treatments have been received and receiving now?
- What were the results of past treatments and if you've taken multiple TKI's, what caused you to have to switch?
- Where is the primary treatment received (is it a university/research facility)?
- Is a special diet being followed?
- Do you consider yourself (survivor) to have been healthy and active at diagnosis (group statistical question)?
- Where do you live (city, state, or province)?

### **ADDITIONAL RESOURCES**

- There is a file named ALK-Positive\_Helpful\_Links.pdf file under the Files section in the Group that may be of interest to you. Please take note of the link to the NCCN guides as there is invaluable information there concerning your treatment.
- There are some photos in the community that could be of interest to you.
- The community calendar can be used by anyone to put events or appointments into the calendar. If you would like encouragement from the community during your scans or other appointments, you are welcome to enter your details into the calendar.