



Worldwide Information, Support, and Empathy

<https://www.alkpositive.org>

May 27, 2018

Dear ALK Positive Community, Family & Friends,

A year ago March, four ALK Positives (affectionately known as ALKies) struck out on a mission to raise awareness and funds specifically to benefit our little corner of the Lung Cancer universe. Calling ourselves the Outreach Team, Matt Allegre, Tom Carroll, Laura Greco, and I began to brainstorm how we might change the world for ALK Positive patients.

While the Outreach Team has grown considerably in number and impact, it has never been more apparent that the heart and soul of ALK Positive remain on this page, where Information, Support, and Empathy rule the day. The sharing that occurs here is changing the course of treatment for patients who find that their voice will be heard when it is grounded in the latest science and opinion of the preeminent experts in the field.

If I were to recount here all the milestones achieved by ALK Positive since its inception in 2015, many defining moments would be lost in the litany of accomplishments. So I will limit this post to a review of the current state of Outreach efforts and organization. Don't worry, much more interesting news will follow!

After operating early on as a loose collection of patient/caregiver advocates, your Outreach Team recognized the need for more members and an organizational structure. Members were added over the past year, bylaws were adopted, and currently Outreach membership stands at 18, with an Executive Committee comprised of officers and committee chairpersons.

As currently constituted, the Outreach Team includes:

Phil Trahan, President

Bill Westlake, Secretary

Tom Carroll, Chair Emeritus

Gina Hollenbeck, Chair-Fundraising

Colin Barton, Chair-Medical and Pharmaceutical Advocacy

Shelly Engfer-Triebebach, Chair-Media Outreach and Political Advocacy
Rhonda Meckstroth, Chair-Cancer Group Alliance and Membership
Virginia Byrne
Jen Carroll Cosgrove
Clark Evans
Mandie Hiznay
Michael McCarty
Gary Nerstad
Deborah Picciotto-Hendrikson
Julie Silberger
Vivek Tomar
Millie Torchia
Renee Westlake

While this message is not meant to highlight ALK Positive accomplishments, I must report the most game-changing initiative that has grown out of our collective efforts: ALK Positives, in conjunction with LUNGeivity Foundation, will soon award two (and possibly three) research grants to study ALK-positive Lung Cancer. This is the first time that a group of Lung Cancer patients/caregivers has commissioned studies fully funded by themselves and with patient input equal to that of scientists. At this writing, the fund balance is approximately \$400,000! We need more donations to continue our momentum and lock in the third grant.

There is much more to report and I will do so in the next few days. Until then, take comfort in the fact that you are making a difference!

Sincerely,

Phil Trahan
President