

ALK POSITIVE LUNG CANCER (ALK+LC) LONGITUDINAL STUDY

We all have an exciting opportunity to make a real and significant difference to the treatment of ALK Positive lung cancer (ALK+LC). In order to achieve this, we have to attract the attention of Pharmaceutical Companies and get their interest in developing more treatments! The way of doing this is by gathering data from those of us with ALK+LC. There is a large Longitudinal Study / Survey occurring, which needs as many people to participate as possible. This study was designed by the world-wide ALK+LC community members; the lead investigator is also an ALK+ patient.

The members of the Medical and Scientific Advisory Panel have already completed the surveys and want to encourage members to do the same. In their message, below, they would like to share their views and experiences. Your time spent doing this will bring some good out of the fact you have been given this unwanted diagnosis! Let's make a difference for the future!

Debra

From the Medical and Scientific Advisory Panel (MASAP)

The Medical and Scientific Advisory Panel members of ALK+LC UK have taken part in the Longitudinal Study. This study aims to collect data from as many ALK+ patients as possible to help improve the life expectancy and quality of life for ALK+LC patients world-wide. It also aims to attract attention of the pharma and biotech companies to develop medicines for treatment of ALK+LC. This study is solely funded by the world-wide ALK+ Charity, and it guarantees your confidentiality, anonymity, and data protection. We strongly believe that we, patients, have a wealth of information that could be useful to both researchers and clinicians and this is why we urge our members to complete this comprehensive survey.

Registering with the study and completing the survey will not only make a positive difference, but will send a powerful message that we need to be taken seriously and raise ALK+LC up the priority list for research and funding. The pace from drug discovery to patient access to therapy is rapidly accelerating and we, current patients, are very likely to benefit in the very near future.

Our personal experience of joining the Registry and completing the first survey is that it does require time and attention to detail. Baseline information includes country of origin which in our case is UK (not United Kingdom or you will be stuck at the start unable to progress as was the case for at least one of us!) There are quite a few questions in the survey, and it takes some time to complete. There is a section on exposure to possible risk factors including past medical events. Questions also include dates and reasons for pauses or change of dose in medication, any change of TKI and information on other treatments and on scans/biopsies, so having that information to hand from the start is helpful. It can be done in stages, you can stop and save the forms, and then return to the survey later. There will be sections in the forms where you can add your comments. Be assured that your entry will be strictly confidential and data anonymous. The commitment we have made on joining the Registry is to complete the initial survey, a follow up survey after 4 weeks and thereafter at 6monthly intervals.

To join the Registry and participate in the Survey please click this link:

<https://redcap.link/alkpositivesurvey>

The sooner the data is collected and processed, the sooner we start benefiting from it!

Further information:

To design the Study, members of the international ALK Positive group, led by Dr Morhaf Al Achkar (PI, Principal Investigator) and Colin Barton (member of the ALK Positive Medical Committee), worked in close collaboration with Dr Ross Camidge, a world leader in ALK research and treatment.

Morhaf Al Achkar has addressed our ALK+LC UK community in this statement:

“The study is funded by ALK Positive. The study is designed by community members in collaboration with the researcher from the University of Washington; the PI is also an ALK-positive patient, with no interference from any entity with commercial interest. All data generated will be available at no cost to any scientific or commercial entity interested in advancing science or quality of life for ALK Positive patients. The research team is open to receiving unrestricted grants from commercial entities. The use of the fund to advance the research conduct and dissemination will be solely at the researchers' discretion and ALK Positive, following standard academic policies and regulations at the University of Washington.”

To learn more about the Registry/ Survey, watch this short video by the Principal Investigator of the study, Dr Morhaf Al Achkar at University of Washington

https://www.youtube.com/watch?v=AUGA_wmqcGg

To learn a lot more about the Registry/ Survey watch this longer video

<https://www.youtube.com/watch?v=qzAyGxofGvg&t=2s>

(also featuring Dr Ken Culver – Director of Research and Clinical Affairs at ALK Positive Inc, and Dr Ross Camidge, a world leader in ALK research and treatment.)

With very best wishes for the New Year,

The Medical and Scientific Advisory Panel