

ROS1 derings

A newsletter by and for the ROS1 cancer community



Donating ROS1 Tissue

By Marisa Wittebort

On April 13, 2018, the ROS1ders and the Addario Lung Cancer Medical Institute launched an initiative to create new ROS1 cancer models from biopsy and surgery specimens donated by ROS1ders. ROS1 positive cancer is a rare mutation. Without a mobilized effort within the Ros1 community, it is difficult for researchers to gather enough patient samples to study drug resistance, which in turn limits the development of new treatments.

I am proud to have been one of the first patients to participate in the program. A few weeks after I sent my donation to the principal cell line investigator (Dr. Robert C. Doebele, MD, PhD, at the University of Colorado), he contacted me to share the good news that he had

successfully created a cell line from my pleural fluid donation. The process was so simple and rewarding. I later mailed a second donation. Both were at no cost to me or my doctor. Since I was an early participant in this program, I wanted to share tips to help others make a donation.



Marisa's Tips for ROS1ders who are Donating Fluid or Tissue:

1. Be prepared. Keep your original pathology and molecular analysis reports on hand to simplify and expedite your donation in the event of a biopsy/drain.
2. Call Nurse Alicia at **866-988-ROS1 (7671)** as soon as you know you will be getting a biopsy or collecting fluid.
3. For donations from a catheter, tell Nurse Alicia the size of your drain bottle in order to receive size-appropriate shipping materials.
4. Send your donation within 30 days of submitting your signed authorization.
5. Schedule the biopsy/collection on a weekday, Monday -Thursday.
6. Ship the tissue/fluid the same day as it is collected.
7. Let your oncologist know you plan to participate in this study **before** progression happens. The final page of this newsletter is a letter you can take to your next visit to your oncologist, describing the study.

About this newsletter...

ROS1derings is a new quarterly newsletter of the ROS1ders patient advocacy group. The ROS1ders is a group of patients and caregivers dealing with ROS1+ cancer. We strive for better outcomes for all ROS1 cancers by supporting patients and caregivers, increasing awareness and education, accelerating research, and improving access to effective diagnosis and treatment.

We will use this space to share updates about our progress, to feature questions frequently asked by the ROS1 community, and to invite all ROS1 patients to join us in our mission. [Learn about the ROS1ders.](#)

Where do ROS1ders live?

We're proud that the ROS1ders have created connections around the globe. If our records are correct, 28 countries are represented.

Australia	13
Belgium	3
Brazil	1
Canada	12
China	9
Ethiopia	1
France	7
Germany	12
Greece	2
India	3
Israel	7
Italy	8
Japan	4
Jersey Channel Islands	1
Netherlands	14
New Zealand	2
Norway	1
Poland	1
Russia	2
Singapore	7
South Africa	3
Spain	4
Sweden	1
Taiwan	1
Turkey	1
UAE	1
UK	10
USA	171

Help Wanted! If you are a ROS1der patient or caregiver and are interested in contributing to the management of the group and our projects, please message us at: <https://ros1cancer.com/contact-us/>

ROS1 by the Numbers

By Jeff Wynne

The ROS1 community has been meeting on Facebook to share stories and support for almost 4 years. I joined the Facebook community in early 2016, just as I started my treatment on Xalkori. Like all patients, I was anxious to know more about how others were doing. How long were ROS1 patients staying on Xalkori? What other medications were being prescribed? How long were other medications lasting?

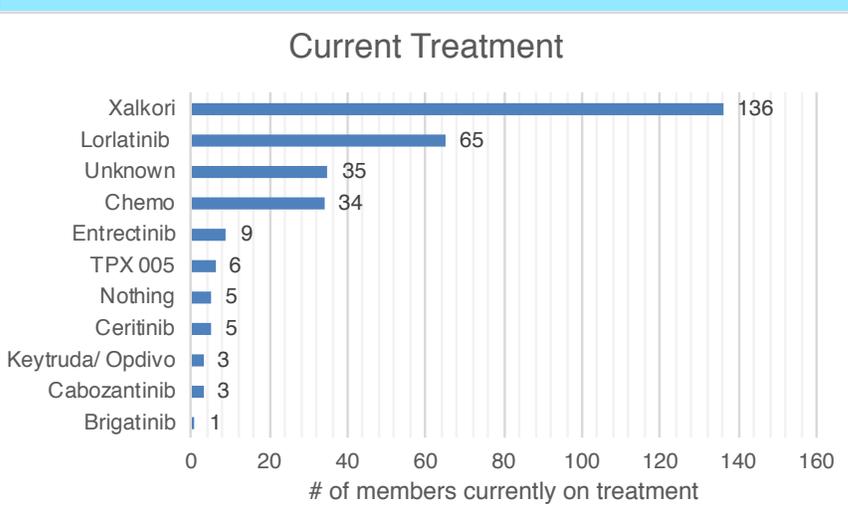
After 36 years as a math teacher, I seek comfort in data. So I started a spread sheet. First, I looked back at the information provided by new Facebook members when they joined the community. Then, as members posted news about their treatment changes, I continued to update the spread sheet.

I certainly can't claim that my spreadsheet's "data" is 100% accurate. Many in our Facebook community do not report updates and some may have stopped using Facebook altogether.

Still, it summarizes what we know about those of us who have been willing to share. So I wanted to share some of this information with you.

As of this writing, there are over 300 patients from 28 different countries represented in our Facebook group. Below is a breakdown of their current treatment, according to my spreadsheet.

I maintain this spreadsheet to help us share information within the group. I will not share your information outside the group unless I have your written permission to do so.



We are discussing ways we can more systematically ask for updates from the ROS1 community, and maintain accurate data. Your ideas are welcome. It is always helpful when people post information about their treatment changes — what they are changing to, why, and how long they've been on their various treatments.

Look for a post soon that will give you a chance to share your current information!

ROS1 News From Europe

By Bärbel Söhlke

In February, 39 ROS1 positive patients and caregivers from Germany and the Netherlands attended the 5th annual ROS1 meeting in Cologne, Germany. ROS1ders from across the region have been meeting since 2015, exchanging experiences and staying up-to-date on research activities and treatment options.

Most of this group were diagnosed at the cancer center of the Cologne University hospital, and several have been treated in the EUCROSS clinical trial. At our February gathering, four ROS1 experts, including medical oncologist Professor Wolf and pathologist Professor Büttner, joined us for an informative and lively discussion. Topics included available drugs and their safety, the increased risk of blood clots in ROS1-driven cancers, the usefulness of liquid biopsies, and the limited prospects of immunotherapy combinations.

In Europe, Crizotinib is the only targeted drug approved for ROS1. A few other drugs, such as Certinib and Cabozantinib, are sometimes prescribed off-label and are usually refunded in the German health care system. The approval of Lorlatinib for ALK+ NSCLC is expected soon. Entrectinib is only available in clinical trials, and Repotrectinib (i.e., TPX 0005) is not yet available.

A special cooperation has developed between German ROS1ders and the Cologne lung cancer group. Patients often receive helpful advice from Cologne's experts no matter where they are treated. This support is especially valuable when resistance occurs and when patients need access to new therapies. A research group focusing on ROS1 translocations has been created within the "Network Genomic Medicine", an established model of implementing personalized lung cancer care into broad clinical routine in Germany, based on a large high-tech molecular diagnostics platform. The target is to better understand how Ros1 cancer begins, progresses and develops resistance to treatment. This research group currently conducts a special re-biopsy project with detailed genomic sequencing in collaboration with international partners and ROS1 patients. The goal? To understand and treat resistance mechanisms in ROS1+ NSCLC. Patients initiated this project through successful fundraising. It benefits both researchers and patients.



Addario to Merge with Lung Cancer Alliance

By Lisa Goldman

We have exciting news to share. The Bonnie J. Addario Lung Cancer Foundation (ALCF) has proudly joined forces with the Lung Cancer Alliance (LCA) to form a new powerhouse organization called the GO₂ Foundation for Lung Cancer.

Together, the GO₂ Foundation becomes the "go-to" local and global source serving and advocating for the needs of the entire lung cancer community — those at risk, diagnosed, vulnerable, and all others impacted by the disease. The GO₂ Foundation will be the place where everyone impacted by lung cancer can find personalized care, powerful connections, and purposeful collaboration.

As you know, we have been fundraising through ALCF to support two ROS1 research studies in partnership with the Addario Lung Cancer Medical Institute (ALCMI). We are happy to share that our relationship with ALCMI will not change because of this merger. ALCMI will now partner with the GO₂ Foundation, but will remain a separate and independent 501c(3) non-profit organization and will continue to coordinate innovative, patient-centric lung cancer studies including those aimed at better understanding ROS1 lung cancer. Fundraising in support of these studies will now be done through the GO₂ Foundation, but everything else about our partnership with both organizations remains the same.

If you have any questions about the merger or about the ROS1ders work with GO₂ Foundation or ALCMI, please contact Nicole Phipps Pietras - nppietras@go2foundation.org.

Fundraising Update

By Lisa Goldman

We are so excited to share that - with your hard work and amazing support - we have raised an incredible \$329,000 (and counting!) to support two ROS1-specific research studies aimed at better understanding and treating ROS1+ cancer through the Addario Lung Cancer Medical Institute and the GO₂ Foundation for Lung Cancer. Congratulations and thank you for supporting these studies so enthusiastically!



We are still actively fundraising towards our goal of \$500,000, so we still need your help. If you haven't already, you can create your own personal fundraising page [at this link](#) and begin fundraising today! If you've already created your page and begun fundraising, a great next step is to share this exciting fundraising update with your network and ask for support from your family, friends, and coworkers to help us to reach our \$500,000 goal. Fundraising in support of these two studies is a powerful and unique opportunity to effect change in our own, specific disease by supporting research aimed at changing the future of ROS1+ cancer. Please help us reach our goal!

The ROS1 Study: Information for Oncologists



ALCMI-006: A Prospective Biospecimen Collection Study from Patients with ROS1-Fusion Positive Tumors

Dear Colleague,

This letter is intended to make you aware that one of your patients has expressed an interest in participating in our prospective, fresh biospecimen collection study to generate ROS1-fusion positive patient-derived xenograft (PDX) mouse models for individuals with ROS1-fusion cancers (NCT03497624). As you know, ROS1 fusions are detected in ~1% of patients with non-small cell lung cancer as well as in several other types of cancer. Studies of tumors which harbor ROS1-fusions are significantly limited by the lack of tumor tissue and validated models to study this type of cancer associated alteration.

I'm writing to you today to describe the study since, if your patient does indeed decide he/she would like to participate and meets the criteria, there will be some tissue collection/handling implications to ensure the cells remain viable for study use. **No response or actions are requested of you at this time.**

Study summary: I serve as the Principal Investigator of ALCMI-006, working within the global research consortium framework of the Addario Lung Cancer Medical Institute (ALCMI, a patient-founded 501c3 public charity) and in collaboration with Champions Oncology Inc. Together, we developed and recently launched ALCMI-006 to generate ROS1-fusion positive patient-derived xenograft (PDX) mouse models, including full molecular characterizations such as whole exome sequencing (WES) and RNA sequencing to determine the presence of resistance mutations as well other potential targetable genomic alterations. These patient derived PDX models will have no immediate benefit to your patient. Rather, the resultant renewable tissue resources of PDX models will be broadly shared to help researchers understand mechanisms of response and resistance to therapies, and to assist and facilitate preclinical drug development of new therapies for ROS1-fusion positive cancer. Consented participants may donate a portion of their fresh tumor collected during their next clinically-indicated biopsy, surgical procedure or pleural effusion draining. We are only able to receive specimens that are collected under Champions' procedures (we supply the collection kit and instructions) as production of successful models is highly time-sensitive from harvest to engraftment.

If interested in learning more about this study, please view the study website at www.alcml.net/research/ros1-pdx-study/ or contact the study team at 866-988-ROS1 (7671) or by email at clinicalops@alcml.net.

Thank you for your time and consideration! Your assistance is greatly appreciated in order to bring this study of a rare type of lung cancer to fruition!

Sincerely,
Christine M. Lovly, MD, PhD
Associate Professor of Medicine
Vanderbilt-Ingram Cancer Center

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