

# The ROS1 Cancer Model Project: a unique patient-driven partnership to accelerate research

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## INTRODUCTION

### Motivated, Engaged ROS1+ Online Community



ROS1der membership as of Jan 2020

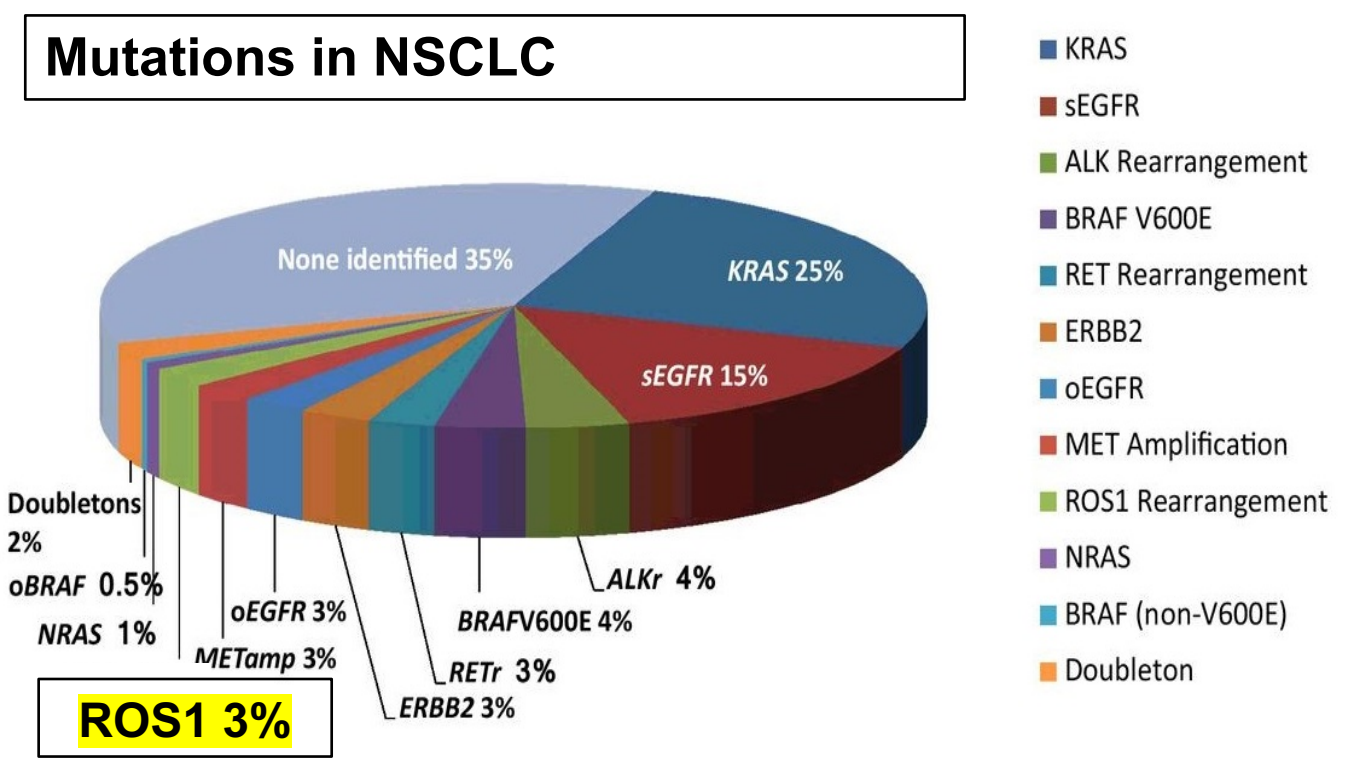
**Facebook group:**  
ROS1 Positive (ROS1+) Cancer  
**Facebook Page:** ROS1 Cancer Research Forum  
**ROS1cancer.com**

- List of ROS1+ expert clinicians
- Living with ROS1+ cancer
- Drugs with ROS1 activity
- Clinical trials for ROS1 patients

**Twitter:** @ros1cancer, #ROS1

**GLOBAL ROS1 INITIATIVE CONTACT**  
ROS1cancer.patient@gmail.com

### Pan-Cancer Challenges of ROS1 Rearrangements

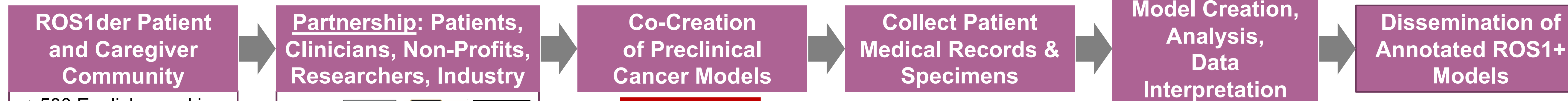


#### Other Tumors Can Harbor ROS1+

- angiosarcoma
- breast cancer
- cervical cancer
- cholangiocarcinoma
- colon cancer
- epithelioid hemangioendothelioma
- gastric cancer
- glioblastoma
- inflammatory myofibroblastic tumor
- liver cancer
- melanoma
- ovarian cancer
- pancreatic cancer

- Rare (only 3% of NSCLC and other cancers)
- Few cancer clinics or doctors are familiar with ROS1 cancer or encounter ROS1+ patients
- NSCLC patients are not always tested for ROS1 (even though ROS1+ NSCLC has two FDA-approved drugs), and other cancers are almost never tested for ROS1
- ROS1 can fuse with 20+ genes, but had only 1 PDX model & a few cell lines in 01/2017**

## METHODS



**ROS1der Patient and Caregiver Community**

- >500 English-speaking ROS1+ patients & caregivers
- 6 continents
- 28 countries
- 8 ROS1+ cancer types



**Co-Creation of Preclinical Cancer Models**

**Collect Patient Medical Records & Specimens**

**Model Creation, Analysis, Data Interpretation**

**Dissemination of Annotated ROS1+ Models**

**ROS1 Cancer Model Project**

### THE PATIENT VOICE



“The ROS1 Cancer Model Project, part of the larger Global ROS1 Initiative, has the potential to powerfully **impact cancer research**. Patients **organizing** and **collaborating with researchers** in this manner is the future.”

“The Global Initiative is a way we can **contribute to research** in hopes of **helping others** with this rare cancer.”

### CONCLUSIONS

The ROS1 Cancer Model Project is part of the Global ROS1 Initiative, a powerful partnership between patients & caregivers, advocacy organizations, researchers and industry that, when combined with social media outreach, has increased the available oncogene-driven patient data, specimens, and cancer models for rare, geographically-distributed pan-cancer patient populations. Current efforts are focused on growing the number of models available and disseminating them for research.

### STUDY CONTACT

**+1 (866) 988-ROS1**  
ClinicalOps@ALCMI.net  
<https://alcmi.net/research/ros1-pdx-study/>

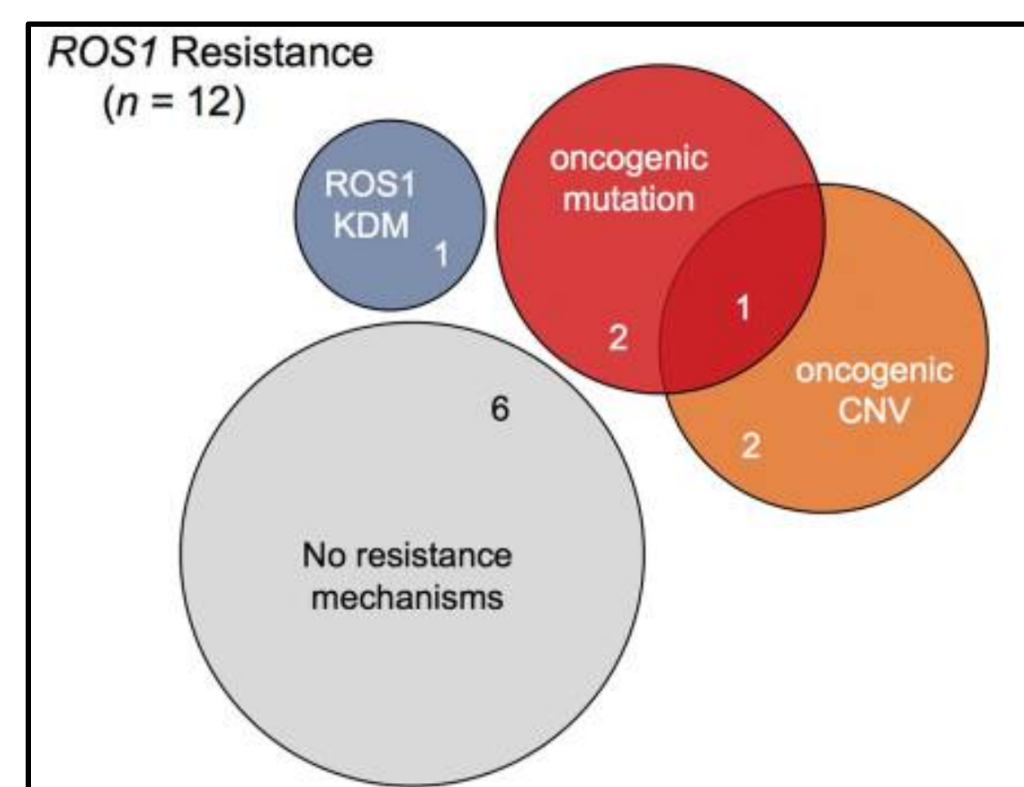
Scan to view the ALCMI ROS1 website



### ACKNOWLEDGEMENTS

Thanks to all ROS1 clinicians, researchers, patients, caregivers, supporters, and partners who make the ROS1 Cancer Model Project possible. Jeff Wynne collected data for the ROS1der demographics. Funding and in-kind support for the Global ROS1 Initiative is provided by individual ROS1ders, Addario Lung Cancer Medical Institute, GO<sub>2</sub> Foundation for Lung Cancer, Champions Oncology, and University of Colorado Lung SPORE.

## PRELIMINARY RESULTS



To date we have created 8 new cell lines (which doubled the available ROS1 cell lines) and initiated 5 PDX mouse models. Three cell lines have been genomically characterized (two ROS1-CD74, one ROS1-TPM3). The cell lines have been shared with five other institutions researching ROS1 cancers: UCSF, Huntsman Cancer Institute, NIH, Moffitt Cancer Center, and Ignyta (now Roche). The cells lines have been used in three published ROS1 journal articles, among them an analysis of ROS1 resistance mechanisms to targeted therapies (left).

McCoach CE, Le AT, Gowan K, et al. Resistance Mechanisms to Targeted Therapies in ROS1+ and ALK+ Non-small Cell Lung Cancer. *Clin Cancer Res.* 2018;24(14):3334–3347. doi:10.1158/1078-0432.CCR-17-2452