

## CURRICULUM VITAE

### Janet Freeman-Daily, MSc, Engr

#### CURRENT POSITIONS

- Writer, speaker, science geek, metastatic lung cancer patient/activist.  
Janet uses her systems engineering, communications and science background to translate the experience and science of lung cancer treatment and research for others, with the goal of improving outcomes and quality of life for lung cancer patients.
- Award-winning lung cancer blogger at [Gray Connections](#) (04/2013-present)
- Co-founder, President, and Board Chair, [The ROS1ders](#) (founded 2015, nonprofit formed 2019)
- Co-developer and consulting staff, IASLC Supportive Training for Advocates in Research and Science ([STARS](#)) Program (01/2019-present)

#### EDUCATION

1986 California Institute of Technology, Pasadena, CA; Engineer Degree (Engr),  
Aeronautics  
1984 California Institute of Technology, Pasadena, CA; MS, Aeronautics  
1978 Massachusetts Institute of Technology, Cambridge, MA; SB, Mechanical Engineering

#### PRIOR WORK EXPERIENCE

2018-2019 Co-Developer and Project Director, Hope with Answers (in collaboration with Lung Cancer Foundation of America)  
2013-2021 Cofounder and co-moderator of [#LCSM Chat](#) on Twitter as @JFreemanDaily  
2007-present Freelance Writer  
2001-2012 Trustee, Freeman Living Trust, Federal Way, WA  
2000-2001 Business Manager, New Horizon School, Renton, WA  
1998-2001 Sole Proprietor, Enginuity, Federal Way, WA  
1998-2000 CEO, Metal Marine Pilot, Inc., Fircrest, WA  
1987-1998 Senior Principal Engineer, The Boeing Company, Defense & Space Group, Kent, WA  
1981-1987 Systems Engineer, Senior Scientist, Hughes Aircraft Space & Communications Group, El Segundo, CA  
1978-1981 Design Engineer, Metal Marine Pilot, Inc., Fircrest, WA

#### HONORS AND AWARDS

2019 Finalist (as cofounder of The ROS1ders), Inaugural Cancer Community (C2) Awards from AstraZeneca and Scientific American  
01/2016 AACR Scientist-Survivor Program for 2016 Annual Meeting  
12/2015 Finalist, Patient Voice Impact Award, Patient Voice Institute  
11/2015 Seattle's Most Influential People of 2015, Seattle Magazine

07/2015 July LUNGeivity Hero, LUNGeivity Foundation  
 09/2014 ePatient Scholar and speaker, Stanford Medicine X conference  
 2014-2019 Healthline Best Lung Cancer Blog  
 1984-85 Caltech Clark B Millikan Fellow  
 1984-85 Hughes Aircraft Staff Engineer Fellow, California Institute of Technology  
 1983-84 Hughes Aircraft Company Staff Masters Fellow, California Institute of Technology

## PROFESSIONAL MEMBERSHIPS

2016-present Member, American Association for Cancer Research  
 2015-present Member, International Association for the Study of Lung Cancer  
 2015-present Member, American Society of Clinical Oncology  
 2014-2020 Member, Society for Participatory Medicine

## COMMITTEE AND SERVICE RESPONSIBILITIES

2022-present Member, The NCI Technology Research Advocacy Partnership ([NTRAP](#))  
 2022-present Member, External Advisory Board (EAB), Fred Hutch/University of Washington/Seattle Children's [Cancer Consortium](#)  
 2021-present Member, External Advisory Panel (EAP) for the NCI's Participant Engagement and Cancer Genome Sequencing ([PE-CGS](#)) Network  
 2021 Co-author, ESMO Clinical Practice Guidelines about use of patient-reported outcomes in the continuum of cancer care  
 2020-2022 Member, COVID Lung Cancer Consortium  
 2020 LUNGeivity Scientific and Clinical Roundtable  
 2019-2022 Patient Advocate, Secretary's Advisory Committee on Human Research Protections ([SACHRP](#))  
 2019-present Patient Advocate, Fred Hutchinson Cancer Research Center Specialized Program of Research Excellence (SPORE)  
 09/2018-2020 Member, Patient and Family Engagement Leaders Workgroup of National Academy of Medicine initiative Leveraging and Sharing Data for Continuous Learning  
 07/2018-present Member, Engagement External Scientific Panel (ESP), National Cancer Institute (NCI) [Cancer Moonshot Biobank](#)  
 01/2018-present Member, Value in Cancer Care Initiative ([VCCI](#)) Steering Committee, Hutchinson Institute for Cancer Outcomes Research (HICOR)  
 2016-present [Speakers Bureau](#), Lung Cancer Foundation of America  
 10/2016-2018 Member, Centers of Excellence Strategic Advisory Board, Bonnie J. Addario Lung Cancer Foundation (BJALCF)  
 2016-2017 Member, Patient Action Committee, LUNGeivity Foundation's Project Transform  
 01/2016-present Member, Patient Advocates Committee, International Association for the Study of Lung Cancer (IASLC)  
 01/2016-01/2018 Member, Lung Cancer Patient Advisory Group, American Lung Association  
 01-2016-present Member, NCI Small Cell Lung Cancer Progress Working Group  
 11/2015-02/2017 Member, eHealth Steering Committee, Virginia Mason Medical Center, Seattle, WA  
 11/2015-2017 Member, Patient-Family Partner, Virginia Mason Medical Center, Seattle, WA  
 11/2015-present Member, HICOR Value in Cancer Care Goals of Care Working Group

07/2015-present Co-Administrator, *ROS1 Positive (ROS1+) Cancer* Facebook group and [The ROS1ders website](#)

06/2015-2017 Member, Bree Collaborative Oncology Care Workgroup

03/2015-03/2016 Member, Addario Patient and Caregiver Advisory Board, BJALCF

02/2015-present Patient Advocate, University of Colorado Cancer Center Thoracic Oncology Research Initiative ([TORI](#)), formerly an NCI lung SPORE)

01/2014-06/2016 Member, Patient-Survivor-Family Member Cabinet, American Lung Association of the Mountain Pacific

07/2011-present Community member, online lung cancer communities (Inspire.com, Smart Patients, Facebook patient groups, etc.)

2000-2009 Board Member and Board Chair, New Horizon School, Renton, WA

## RESEARCH

### Projects

2019-2022 ASCO Lung Biomarker Task Force

2018-20 Patient Advisory Committee, [Enhancing Patient Engagement in Community-Based Cancer Outcomes Research](#) PCORI grant

2017 Patient Advocate, Lung Cancer Dream Team Proposal, MD Anderson

2015 Patient Advocate, Lung Cancer Dream Team Letter of Intent, University of Colorado Cancer Center

### Protocols

2017 ROS1 Cancer Model Project

2015 Initiator and Patient Advocate, Patient Initiated Biobanking of Deceased Lung Cancer Patient Tissue, University of Colorado Cancer Center Lung Cancer SPORE #15-1294 (Pilot Project)

### Patents

1986 Hughes Aircraft Company, Preston S Du Pont, **Janet E Freeman**, Robert E Ritter, Alois Wittmann. Fiber-reinforced syntactic foam composites and method of forming same, United States 4,595,623, published 17-Jun-1986

### Clinical Trial and Research Study Participant

2012-18 NCT00585195--crizotinib for ROS1-positive non-small cell lung cancer, (11/2012 to present)

2011 Lung Cancer Mutation Consortium Protocol, University of Colorado

## CONFERENCE AND SYMPOSIA PRESENTATIONS

### Organization of Conferences/Symposia

2015 Session Chair, IASLC World Conference on Lung Cancer, Sep-2105

## Invited Speaker at National or International Conferences

- 2020 A Patient Perspective On Cancer Treatment Tolerability. *FDA-ASCO Clinical Outcome Assessment in Cancer Clinical Trials (COA-CCT) Fifth Annual Workshop*, 17-Jul-2020.
- 2020 A Lung Cancer Patient's Manifesto For Modernizing Clinical Trials. *IASLC 2020 Presidential Symposium*, virtual, 08-Aug-2020.
- 2020 Panelist, [How global item capturing side effect bother complements the picture of tolerability](#). *FDA-ASCO PUBLIC WORKSHOP: 2020 Clinical Outcome Assessments in Cancer Clinical Trials Fifth Annual Workshop*, 17-Jul-2020.
- 2020 The ROS1ders: Partnering to drive research and improve outcomes in ROS1+ cancers. *Sixth AACR-IASLC International Joint Conference: Lung Cancer Translational Science from the Bench to the Clinic*, San Diego, CA. 11-Jan-2020.
- 2019 Lung Cancer Patients Should Have Better Access to Clinical Research: Relax the Eligibility Criteria. *IASLC World Conference on Lung Cancer*, Barcelona, Spain. 8-Sep-2019.
- 2018 Building a Better Biobank: Promise and Challenges of the National Cancer Institute Cancer Moonshot Biobank. *PRIM&R 2018 Advance Ethical Research Conference*. San Diego, CA, 17-Nov-2018.
- 2018 Linking the Stakeholders: Can Patient Groups, Clinical Researchers and the Pharmaceutical Industry Collaborate to Accelerate Research? *IASLC 18<sup>th</sup> World Conference on Lung Cancer*, Toronto Canada, 25-Sep-2018.
- 2018 Oncogene-Focused Patient Groups: A New Era for Research Partnerships. *National Cancer Institute Lung SPORE Annual Meeting*, Dallas TX, 20-Jun-2018.
- 2018 Cancer Communities on Social Media. *At the Crossroads of Social Media and Clinical Trials: A Workshop on the Future of Clinician, Patient and Community Engagement*, National Cancer Institute, Bethesda MD, 7-Jun-2018.
- 2018 Panelist, Patient Perspectives of the Community Cancer Care Report. *HICOR 5<sup>th</sup> Annual Value in Cancer Care Summit*, Seattle WA, 3-May-2018.
- 2018 What Matters Most: A Patient Perspective on Post-Treatment Surveillance. *Post-Treatment Surveillance Workshop*, National Cancer Institute, Rockville, MD, 26-Mar-2018.
- 2018 Value of advocate groups in trials targeting molecular abnormalities including ROS 1. *IASLC Targeted Therapies in Lung Cancer*, Santa Monica CA, 22-Feb-2018.
- 2017 Panelist, *GRACE Targeted Therapies in Lung Cancer Patient Forum*, Cleveland OH, 16-Sep-2017.
- 2017 Keynote Speaker, Value Frameworks in Cancer Care: A Patient Perspective. *IASLC 2017 Chicago Multidisciplinary Symposium in Thoracic Oncology*, Chicago IL, 14-Sep-2017.
- 2017 Panelist, Clinical Pathways and New Drug Approvals: Maximizing Value Without Compromising Patient Care. *American Society of Clinical Oncology Annual Meeting*, Chicago IL, 05-Jun-2017.
- 2017 Panelist, The Medicine Information Exchange: What Patients and Other Stakeholders Need to Say to One Another. *Patients as Partners*, Philadelphia, PA 02-Mar-2017.
- 2016 The Importance of Patient Access to Molecular Testing and Novel Therapies. *IASLC World Conference on Lung Cancer*, Vienna Austria, 5-Dec-2016.
- 2016 How to Read a Scientific Abstract When You Don't Have a Ph.D. *Cancer Research Institute Immunotherapy Patient Summit*, New York NY, 24-Sep-2016.
- 2016 Moderator, [Patient Power Lung Cancer Town Hall](#), Chicago IL, 10-Sep-2016.

- 2016 Panelist, Social Media Advocacy. *LUNGeivity HOPE Summit*, Washington DC, 29-Apr-2016.
- 2016 [Improving Research and Outcomes with Social Media](#). *Genomics Environment and Traits (GET) 2016 Conferences*, Harvard Medical School, Boston MA, 26-Apr-2016.
- 2016 Online Collaboration & Support in the Lung Cancer Social Media (#LCSM) Community. Advocacy poster for Scientist-Survivor Program at *American Association for Cancer Research (AACR) 2016 Annual Meeting*, New Orleans LA, 18-Apr-2016.
- 2015 [Transformers in Healthcare](#). *Connected Health Symposium*, Boston MA, 30-Oct-2015.
- 2015 Panelist, Exploration of Connected Health for Improved Cancer: Outcomes by the President's Cancer Panel. *Connected Health Symposium*, Boston MA, 29-Oct-2015.
- 2015 Supporting Lung Cancer Survivors – Living with and Beyond Lung Cancer. *IASLC World Conference on Lung Cancer*, Denver CO, 9-Sep-2015.
- 2015 Panelist, Press Conference, *IASLC World Conference on Lung Cancer*, Denver CO, 6-Sep-2015.
- 2015 Epitients on the Front Lines: Precision Medicine, the FDA, and Me. *2015 Moores Cancer Center Industry/Academia Translational Oncology Symposium*, San Diego CA, 19-Feb-2015.
- 2014 Emerging Platforms for Person-Centered, Community-Wide Care Coordination: Needs, Challenges, and Solutions. *2014 Workshop on Interactive Systems in Healthcare (WISH)*, Washington DC, 15-Nov-2014.
- 2014 Making Lung Cancer Visible. *2014 Stanford Medicine X conference as ePatient Scholar*, Palo Alto CA, 07-Sep-2014.
- 2013 Cutting Edge Cancer Treatment. *LoneStarCon 3 World Science Fiction Convention*, San Antonio TX, 2013.

### **Invited Presentation at State, Local, or Organization Events**

- 2020 Moderator, Ask the Experts: Rare Mutations session, LUNGeivity International Lung Cancer Survivorship Conference, 21-Aug-2020.
- 2020 *The ROS1ders: Partnering to drive research and improve outcomes in ROS1+ cancers*, Fred Hutch Cancer Research Center Lung SPORE Lecture Series, 13-Feb-2020.
- 2019 *Metastatic Lung Cancer: Kept Alive by Clinical Trials*, CROWN Conference. Orlando, FL, 23-Jan-2019.
- 2019 Lung Cancer Living Room, Bonnie J Addario Lung Cancer Foundation, 15-Jan-2019, San Carlos, CA.
- 2018 Moderator, metastatic lung cancer patient panel on clinical trial experiences, Bonnie J Addario Lung Cancer Foundation Centers of Excellence Summit, 07-Dec-2018, Nashville, TN.
- 2018 *How I Lost My Breath ... and Found My Purpose*, TIM Talks at 40<sup>th</sup> Reunion for Class of 1978, Massachusetts Institute of Technology, Cambridge MA, 02-Jun-2018.
- 2018 Clinical Trials Team monthly meeting, University of Colorado Cancer Center, Aurora CO, 16-May-2018.
- 2018 Video speech, Hutchinson Institute for Cancer Outcomes Research (HICOR) Value in Cancer Care Summit 2016, Seattle WA, 3-May-2018
- 2017 National Sales Meeting, Neogenomics, 25-Jan-2019, via webinar.
- 2017 Speaker and panelist at Learning from Patient Experience: New Frontiers in Patient-Partnered Research, The Broad Institute, Cambridge, MA, 12-Jun-2017.
- 2016 Panel member for discussion on the cost of cancer care, Seattle Cancer Care Alliance Board of Directors, Seattle WA, 14-Jul-2016.

- 2016 Presentation to International Association for the Study of Lung Cancer, Aurora CA, 16-May-2016.
- 2016 Lung Force Walk Seattle, American Lung Association, Seattle, WA, May-2016
- 2016 Panelist, *Bioethical Implications of Value and the Physician/Patient Relationship*, Hutchinson Institute for Cancer Outcomes Research (HICOR) Value in Cancer Care Summit 2016, Seattle WA, 1-Apr-2016
- 2016 Presentation to American Lung Association of Colorado, Denver CO, 27-Jan-2016.
- 2016 Panelist, *End of Life Care*, Hutchinson Institute for Cancer Outcomes Research (HICOR) Value in Cancer Care Summit 2016, Seattle WA, 1-Apr-2016
- 2016 Presentation on patient experience, Calvary Lutheran Church, Federal Way WA, 13-Mar-2016.
- 2016 *Patient-Initiated Biobanking of Deceased Lung Cancer Patient Tissues*, University of Colorado Cancer Center Lung SPORE External Advisory Board meeting, 23-Feb-2016
- 2015 *Living with Lung Cancer*, GRACE Acquired Resistance in Lung Cancer Patient Forum, San Francisco CA, 3-Oct-2015
- 2015 *The Value of Patient Engagement*, Virginia Mason Board of Directors meeting, Seattle WA, 14-Jul-2015
- 2015 Hope on the Horizon: ASCO 2015, Addario Lung Cancer Living Room, San Carlos CA, 21-Jun-2015
- 2015 *Patient-Initiated Biobanking of Deceased Lung Cancer Patient Tissues*, National Cancer Institute Lung Cancer SPORE Meeting, Bethesda MD, 16-Jun-2015
- 2015 Lung Force Walk Seattle, American Lung Association, Seattle, WA, May-2015
- 2015 American Lung Association LUNG FORCE Expo, American Lung Association, Renton WA, 27-Mar-2015
- 2014 Breathe Deep Seattle Walk, LUNGeivity, Seattle, WA, Aug-2014
- 2014 Lung Force Walk Seattle, American Lung Association, Seattle, WA, Jun-2014
- 2014 Relay for Life Committee, American Cancer Society, Tacoma WA, Jan-2013
- 2012 *Gratitude*, Calvary Lutheran Church, Federal Way WA, Nov-2012
- 2012 Didactic for chaplains with Karen Freeman Worstell, Good Samaritan Hospital, Puyallup WA

### **Invited Workshop and Seminar Participation**

- 2021 Convening the Center PCORI project.
- 2019 National Academy of Medicine meeting on Generating Support and Demand for Health Data Sharing, Linkage, and Use, Washington DC, 07-Feb-2019.
- 2019 National Cancer Institute (NCI) Clinical Trials and Translational Research Advisory Committee (CTAC) Progress in Small Cell Lung Cancer Research Working Group (SCLC Progress WG) Meeting, Rockville, MD, 4-Feb-2019.
- 2018 Rare Cancers Dependency Map Initiative, Broad Institute, Cambridge, MA, 18-Oct-2018.
- 2018 Summit on National and Global Cancer Health Disparities: Current Challenges and Future Directions, Seattle, WA, 28-Apr-2018.
- 2016 National Cancer Moonshot Regional Summit, Fred Hutchinson Cancer Research Center, Seattle WA, 29-Jun-2016.
- 2015 President's Cancer Panel Workshop, Chicago, IL, 09-Jul-2015
- 2015 FasterCures Small Cell Lung Cancer (SCLC) Action Plan Meeting, Chicago IL, 29-May-2015
- 2015 President's Cancer Panel Workshop, San Francisco, CA, 26-Mar-2015
- 2015 Palliative Care Quality Measurement Summit, Seattle WA, 15-May-2015

## Continuing Medical Education Presentations

- 2017 *Current Challenges in the Diagnosis and Treatment of Lung Cancer*, Virginia Mason Medical Center, Seattle WA, 29-Sep-2017.
- 2016 *NSCLC Forum: Bringing the Patient to the Foreground of Evidence-Based Lung Cancer Care*, [Improving Outcomes with Social Media](#), Peerview Press lung cancer CME at ASCO 2016, Chicago IL, 5-Jun-2016
- 2014 *A Lung Cancer ePatient Story*, Virginia Mason Medical Center Grand Rounds, Seattle WA, 7-Nov-2014

## AH HOC CONSULTANCY

- 2020-2022 COVID and Lung Cancer Consortium (CLCC)
- 2021 Pfizer Field Medical Team Virtual Advisory Board – West Coast
- 2019 Genentech Oncology Advisory Board
- 2018 AstraZeneca Global Lung Cancer Patient Partnership Program (various projects)
- 2018 Neogenomics Laboratories
- 2016 Center for Information and Study on Clinical Research Participation (CISCRP)  
Patient Advocacy Board
- 2016 Oncothyreon, Seattle, WA
- 2015 Oncogenex Pharmaceuticals, Bothell, WA
- 2015 Javelin Pharmaceuticals
- 2014-15 AstraZeneca

## INVITED EDITORIAL AND REVIEW ACTIVITIES

- 2018-21 Member, Editorial Group, *IASLC Lung Cancer News*
- 2015-present Ad hoc patient reviewer, *The BMJ* journal
- 2015 Judge, Addario Lung Cancer Foundation and Free to Breathe *Clinical Trial Innovation Prize* on HeroX.com

## BIBLIOGRAPHY

### Peer-reviewed original research articles

1. Di Maio M, Basch E, Denis F, Fallowfield LJ, Ganz PA, Howell D, Kowalski C, Perrone F, Stover AM, Sundaresan P, Warrington L, Zhang L, Apostolidis K, **Freeman-Daily J**, Ripamonti CI, Santini D; ESMO Guidelines Committee. The role of patient-reported outcome measures in the continuum of cancer clinical care: ESMO Clinical Practice Guideline. *Ann Oncol*. 2022 Apr 18:S0923-7534(22)00691-3. [doi: 10.1016/j.annonc.2022.04.007](#). Epub ahead of print. PMID: 35462007.
2. Anampa-Guzman A, **Freeman-Daily J** (co-first author), Fisch M, Lou E, Pennell N, Painter CA, Sparacio D, Lewis MA, Karmoh M, Anderson PF, Dizon DS, Graff SL. The Rise of the Expert Patient in Cancer: From Backseat Passenger to Co-Navigator. *JCO Oncology Practice*. Published online 2022 Mar 27. [doi: 10.1200/OP.21.00763](#).
3. Mileham K, Schenkel C, Bruinooge S, **Freeman-Daily J**, Basu-Roy U, Moore A, Smith R, Garrett-Mayer E, Rosenthal L, Garon E, Johnson BE, Osarogiagbon R, Jalal S, Virani

- S, Redman M, Silvestri GA. Defining Comprehensive Biomarker-Related Testing and Treatment Practices for Advanced Non-Small Cell Lung Cancer: Results of a Survey of US Oncologists. *Cancer Medicine*. 2022 Jan; 11(2): 530–538. Published online 2021 Dec 17. [doi: 10.1002/cam4.4459](https://doi.org/10.1002/cam4.4459)
4. [Sharing Health Data: The Why, the Will, and the Way Forward](#). Special Publication from the National Academy of Medicine. Member of Patient and Family Leaders Working Group. 2021.
  5. [Health Data Sharing to Support Better Outcomes: Building a Foundation of Stakeholder Trust](#). National Academy of Medicine Special Publication. Member of Patient and Family Leaders Working Group. 2020.
  6. Rolfo C, Mack P, Scagliotti GV, Aggarwal C, Arcila ME, Barlesi F, Bivona T, Diehn M, Dive C, Dziadziuszko R, Leighl N, Malapelle U, Mok T, Peled N, Raez LE, Sequist L, Sholl L, Swanton C, Abbosh C, Tan D, Wakelee H, Wistuba I, Bunn R, **Freeman-Daily J**, Wynes M, Belani C, Mitsudomi T, Gandara D, 2021. Liquid Biopsy for Advanced NSCLC: A Consensus Statement From the International Association for the Study of Lung Cancer. *Journal of Thoracic Oncology* 16(10), 1647–1662. [doi:10.1016/j.jtho.2021.06.017](https://doi.org/10.1016/j.jtho.2021.06.017)
  7. Parikh DA, Walia G, **Freeman-Daily J**, Hennink M, Tomalia T, Buonanno L, Goldman L, Addario B, Patel MI. Characteristics of Patients With ROS1+ Cancers: Results From the First Patient-Designed, Global, Pan-Cancer ROS1 Data Repository. *JCO Oncology Practice* 2020 16:2, e183-e189. <https://ascopubs.org/doi/10.1200/JOP.19.00135>
  8. Hennink M, Vandeweyer G, **Freeman-Daily J**. et al. The roles of patient groups in fostering cancer research. *Nat Rev Clin Oncol* 17, 65–66 (2020). <https://doi.org/10.1038/s41571-019-0314-1>
  9. Katz MS, Anderson PF, Thompson MA, Salmi L, **Freeman-Daily J**, Utengen A, Dizon DS, Blotner C, Cooke DT, Sparacio D, Staley AC, Fisch MJ, Young C, Attai, DJ. (2019). Organizing Online Health Content: Developing Hashtag Collections for Healthier Internet-Based People and Communities. *JCO Clinical Cancer Informatics*, 3, 1–10. <https://doi.org/10.1200/CCI.18.00124>
  10. Ersek JL, Nadler E, **Freeman-Daily J**, Mazharuddin S, Kim ES. Clinical Pathways and the Patient Perspective in the Pursuit of Value-Based Oncology Care. *Am Soc Clin Oncol Educ Book*. 2017;37:597-606. [https://ascopubs.org/doi/10.1200/EDBK\\_174794](https://ascopubs.org/doi/10.1200/EDBK_174794) .
  11. **Freeman J**; Babcock C. Design considerations for a one-kilometer antenna stick, AIAA 1987-871. *28th Structures, Structural Dynamics and Materials Conference*. April 1987. <https://doi.org/10.2514/6.1987-871>

## Abstracts

1. Mileham KF, Basu Roy UK, Bruinooge SS, **Freeman-Daily J**, Garon EB, Garrett-Mayer L, Jalal SI, Johnson BE, Moore A, Osarogiagbon RU, Rosenthal L, Schenkel C, Smith RA, Virani S, Redman MW, and Silvestri GA. Physician concern about delaying lung cancer treatment while awaiting biomarker testing: Results of a survey of U.S. oncologists. *Journal of Clinical Oncology* 2021 39:15\_suppl, 9067-9067 [https://ascopubs.org/doi/10.1200/JCO.2021.39.15\\_suppl.9067](https://ascopubs.org/doi/10.1200/JCO.2021.39.15_suppl.9067)
2. **Freeman-Daily J**, Basu Roy U, Norris K, Bunn B, Baranski J, Chin C, Moore A. Patient concerns during the COVID-19 pandemic: lessons from the lung cancer (LC) community. (Jul-2020). *AACR COVID-19 and Cancer Virtual Meeting*, 24-Jul-2020.
3. Moore A, **Freeman-Daily J**, Norris K, Bunn B, Baranski J, Chin C, Basu Roy U. Collaborating to share evidence-based COVID-19 information across lung cancer patient advocacy groups. (Jul-2020). *AACR COVID-19 and Cancer Virtual Meeting*, 24-Jul-2020.



4. Moore AC, Goldman K, Tomalia T, Doebele RC, Lovly CM, Chiaverelli R, Addario T, Sable-Hunt A, Addario BJ, **Freeman-Daily J**. (Jan-2020). The ROS1 Cancer Model Project: a unique patient-driven partnership to accelerate research. *AACR-IASLC LUNG20*, San Diego, CA.
5. **Freeman-Daily J**, Addario B, Barton C, Basu Roy U, Blam S, Elkins I, Feldman J, Figueras A, Hanlon R, Horn M, Jänne P, Lovly C, Moore A, Ng T, Sable-Hunt A, Shaw S, Doebele RC. (Sep 2019). Disrupting the Paradigm: Partnering with Oncogene-Focused Patient Groups to Propel Research. *Proceedings of the International Association for the Study of Lung Cancer 19<sup>th</sup> World Conference on Lung Cancer*, Toronto, CA.
6. **Freeman-Daily JE**, Elkins I, Greco L, Horn MK, Addario B, Leduc D, Doebele RC, Lovly C. (2018) Oncogene-Driven Patient Groups: A New Era For Research Partnerships. *Proceedings of the International Association for the Study of Lung Cancer 18<sup>th</sup> World Conference on Lung Cancer*, Toronto, CA.
7. **Freeman-Daily J**, Goldman L, Tomalia T, The ROS1ders, Lovly CM, Patel MI, Shaw AT, Addario BJ, Walia G, Young SW, Doebele RC. (April 2018) The Global ROS1 Initiative: a patient-researcher partnership generating open-source, oncogene-driven cancer models and data. *Proceedings of the American Association of Cancer Research*, Chicago IL.
8. **Freeman-Daily J**, Conway L, Cooke DT, Hendrickson D, West HJ. (April 2016) Online Collaboration and Support in the Lung Cancer Social Media Community. *Proceedings of the American Association for Cancer Research*, New Orleans CA.
9. Kim KK, Bell JF, Boicey C, **Freeman-Daily J**, Hull S, McCollister-Slipp A, Joseph JG. (November 14, 2015) A Framework for Person-centered, Community-wide Care Coordination. *Proceedings of the American Medical Informatics Association*. San Francisco CA

### Invited Web Articles

1. [The ROS1ders](#) website.
2. [ROS1+ Cancer Patients Partner to Increase Research](#), National Cancer Institute Insights and Innovations blog, 23-May-2017.
3. **Janet Freeman-Daily**, Corrie Painter, Stacey Tinianov. [The Connected Cancer Patient: Future Vision and Recommendations](#), hcldr.wordpress.com, 3-Jul-2015.
4. [Can I fly when I have cancer?](#), curetoday.com, 20-Apr-2015
5. **Janet Freeman-Daily** and Colin Hung. [Data sharing for research and care](#), hcldr.wordpress.com, 14-Mar-2015
6. [Tackling the stigma of lung cancer — and showing the real faces of the disease](#), Scopeblog.stanford.edu, 17-Nov-2014
7. Katherine Kim, Charles Boicey, **Janet Freeman-Daily**, Susan Hull and Anna McCollister-Slipp. [Platforms for Community Wide Care Coordination](#), hcldr.wordpress.com, 25-Oct-2014.
8. [Meeting the Chemist](#), American Society of Clinical Oncology's www.cancer.net, 15-Jul-2014
9. [Why I'm in a Clinical Trial](#), consano.org, 05-Nov-2013

### Invited Online Events

1. Moderator, "[What do all those line and colors mean? Interpreting cancer data plots.](#)" IASLC Webinar. 26-Aug-2021.
2. Panelist. Using Social Media for Lung Cancer Advocacy. LungCAN Communications Training. 29-Apr-2021.

3. Panelist. [Crafting Engagement to Enhance Physician Participation](#). Collaboration for Outcomes using Social Media in Oncology (COSMO) virtual meeting. 08-Apr-2021 and 09-Apr-2021.
4. Speaker. [What gene targeted therapies mean for patients with cancer](#). STAT News Virtual Event. 08-Apr-2021.
5. Speaker. 2021A ROS1+ Patient Experience. AEACaP webinar "[ROS-1 Lung Cancer Patients](#)." 26-Mar-2021.
6. Panelist, Drug Development in Molecular Subsets of Non-Small Cell Lung Cancer – Challenges and Opportunities from a Patient Perspective. FDA Oncology Center of Excellence Webinar. 21-Jan-2021.
7. Moderator, "[Cancer Drug Development in the Era of Precision Medicine](#)." IASLC Webinar. 02-Nov-2020.
8. Panelist, [How global item capturing side effect bother complements the picture of tolerability](#), part of virtual meeting [2020 Clinical Outcome Assessments in Cancer Clinical Trials Fifth Annual Workshop](#). FDA-ASCO public workshop. 17-Jul-2020.
9. Panelist, [COVID-19 and Cancer](#) episode of *AACR Cancer Dialogues* podcast, 7-Jul-2020.
10. Panelist, [How did lung cancer groups rally to inform patients during COVID-19?](#) episode of *Hope With Answers Living with Lung Cancer* podcast, 08-Jul-2020.
11. Guest, [AWAKE: The Sleep Apnea Podcast](#), 12-Jun-2020.
12. Panelist, [Living with Stage IV Cancer During a Pandemic](#) episode of *NCCS Cancer Convos* podcast, 1-Jul-2020.
13. Panelist, [What Patients Need to Know About Lung Cancer Research in the Era of COVID-19](#) episode of *IASLC Lung Cancer Considered* podcast, 26-May-2020.
14. Panelist, [COVID-19 Facts and Impacts for the Lung Cancer Community](#) episode of *IASLC Lung Cancer Considered* podcast, 31-Mar-2020.
15. Panelist, livestreamed [OncoAlert Round Table 4 \(Part 1 of 2\) 19-Apr-2020](#).
16. Moderator, [IASLC 2020 Lung Cancer Targeted Therapies Meeting](#) episode of *IASLC Lung Cancer Considered* podcast, 18-Feb-2020.
17. Featured Guest, Ask Me Anything event in Lung Cancer Alliance's *Health Unlocked* online community, 14-Mar-2018.
18. Featured Guest, Twitter #CureChat interview 12-Jan-2018.
19. Interviewer, [What I Like About the IASLC World Conference on Lung Cancer](#), #LCSM Chat in Vienna Austria, Dec-2016.
20. Moderator, [Lung Cancer Clinical Trials: Advances in Immunotherapy](#) Facebook Live event jointly sponsored by National Cancer Institute and #LCSM Chat, 23-Nov-2016.
21. Featured Guest, [Lung Cancer Isn't Just a Smoking Disease](#), KUOW radio, Seattle, 13-Sep-2016.
22. Panelist, [ASCO 2016: Highlights and New Approaches in Lung Cancer](#), Global Resources for Cancer Education (GRACE), 06-Jun-2016.
23. Moderator, [How Can Lung Cancer Patients Get Access to the Right Treatment at the Right Time?](#), Google Hangout by Patient Power, 13-Jun-2016.
24. Moderator, [The Changing Landscape of Lung Cancer Research and Treatment](#), Google Hangout on Air co-sponsored by National Cancer Institute and Lung Cancer Social Media, 19-Nov-2015 (Moderator)
25. Speaker, [Finding My Voice, Stories of Survival](#), hosted by Smart Patients and Story Collider, San Carlos CA, 31-Jul-2014
26. Panelist, Patient-generated data: Is it the future of healthcare? Stanford Medicine X Live! Google Hangout, 6-May-2014

## Invited Videos

1. [AACR 2018: The importance of online patient groups and 'The ROS1ders'](#), recorded by eCancer at AACR 2018 Annual meeting, 15-Apr-2018.
2. [When Should Lung Cancer Patients Seek a Second Opinion?](#) Patient Power, 14-Jul-2016.
3. [Patient-to-Patient: What to Expect in a Clinical Trial](#), recorded by Cure Today magazine at AACR 2016, Apr-2016.
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