## **CURRICULUM VITAE**

# Janet Freeman-Daily, MS, ENG

#### **CONTACT INFORMATION**

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## **CITIZENSHIP**

United States of America

## **CURRENT POSITIONS**

- Writer, speaker, science geek, metastatic lung cancer patient/activist. Janet uses her
  systems engineering, communications skills 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.
- Patient Ambassador, My Ideal Patient Experience agency at myidealptexp.com (12/2015present)
- Contributing blogger, Cure Magazine at curetoday.com (10/2014-present)
- Cofounder and co-moderator of #LCSM (Lung Cancer Social Media) Chat as @JFreemanDaily (07/2013-present)
- Award-winning lung cancer blogger at grayconnections.net (04/2012-present)

#### **EDUCATION**

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

#### PRIOR WORK EXPERIENCE

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 Gro	oup,
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	

## **COMMITTEE AND SERVICE RESPONSIBILITIES**

11/2015-present	Member, eHealth Steering Committee, Virginia Mason Medical Center, Seattle, WA
11/2015-present	Member, HICOR (Hutchinson Institute for Cancer Outcomes Research) Value in Cancer Care 2016 Summit Intervention Working Group
07/2015-present	Co-Administrator, ROS1 Positive (ROS1+) Cancer Facebook group
06/2015-present	Member, Bree Collaborative Oncology Care Workgroup
03/2015-present	Member, Addario Patient and Caregiver Advisory Board, Addario Lung Cancer Foundation
02/2015-present	Patient Advocate, University of Colorado Cancer Center's NCI Lung Cancer SPORE
09/2014-present	Co-Administrator, Lung Cancer Bloggers Facebook group
01/2014-present	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, etc.)
2000-2009	Board Member and Board Chair, New Horizon School, Renton, WA

## **HONORS AND AWARDS**

12/2015	Finalist, Patient Voice Impact Award, Patient Voice Institute
11/2015	Seattle's Most Influential People of 2015, Seattle Magazine
07/2015	July LUNGevity Hero, LUNGevity Foundation
09/2014	ePatient Scholar and speaker, Stanford Medicine X conference
2014 & 2015	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**

2015-present	Member, National Association of Science Writers
2015-present	Member, International Association for the Study of Lung Cancer
2015-present	Member, American Society of Clinical Oncology
2014-present	Member, Society for Participatory Medicine

## RESEARCH

## **Grants and Contracts**

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

# **Protocols (Pilot 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

#### **Patents**

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

#### **Grant Reviewer**

2015 Consumer reviewer, lung cancer CDMRP (Congressionally Directed Medical Research Programs)

## **Clinical Trial and Research Study Participant**

2012-15 NCT00585195--crizotinib for ROS1-positive non-small cell lung cancer, (11/2012 to present)

2011 Lung Cancer Mutation Consortium Protocol, University of Colorado

#### **CONFERENCES AND SYMPOSIA**

## Organization of Conferences/Symposia (including chairing session)

2015 Session Chair (2 sessions), IASLC World Conference on Lung Cancer, Sep-2105

#### **Presentation at National or International Conferences**

#### Invited

- 2016 GET (Genomics Environments Traits) 2016, Harvard Medical School, Cambridge, MA, 25-Apr-2016
- 2015 Tranformers in Healthcare, Connected Health Symposium, Boston MA, 30-Oct-2015
- 2015 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 Press Conference, IASLC World Conference on Lung Cancer, Denver CO, 6-Sep-2015
- 2015 President's Cancer Panel Workshop, Chicago, IL, 09-Jul-2015
- 2015 President's Cancer Panel Workshop, San Francisco, CA, 26-Mar-2015
- 2015 Epatients 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
- 2013 Cutting Edge Cancer Treatment, World Science Fiction Convention, San Antonio TX

#### Other Presentations

- 2015 Patient-Initiated Biobanking of Deceased Lung Cancer Patient Tissues, National Cancer Institute Lung Cancer SPORE Meeting, Bethesda MD, 16-Jun-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

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

- 2016 Advanced advocacy sessions, LUNGevity HOPE Summit, 29-Apr-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 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 A Lung Cancer ePatient Story, Virginia Mason Medical Center Grand Rounds, Seattle WA, 7-Nov-2014
- 2014 Breathe Deep Seattle Walk, LUNGevity, 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**

- 2015 FasterCures Small Cell Lung Cancer (SCLC) Action Plan Meeting, Chicago IL, 29-May-2015
- 2015 Palliative Care Quality Measurement Summit, Seattle WA, 15-May-2015

#### **Conferences Attended As Patient Advocate**

- 2015 American Society of Clinical Oncology (ASCO) Annual Meeting, 05-2015
- 2015 LUNGevity HOPE Summit, 05-2015
- 2014 American Society of Clinical Oncology (ASCO) Annual Meeting, 05/2014

#### **CONSULTANCY & PAID PRESENTATIONS**

- 2015 Oncogenex Pharmaceuticals, Bothell, WA2015 Javelin Pharmaceuticals, Skype presentation
- 2014-15 Astrazeneca, web conferences

#### **EDITORIAL AND REVIEW ACTIVITIES**

- 2015 Ad hoc reviewer, British Medical Journal
- 2015 Judge, Addario Lung Cancer Foundation and Free to Breathe *Clinical Trial Innovation Prize* on HeroX.com

## **PUBLICATIONS**

## Peer-reviewed original research articles

1. **Freeman, J**; Babcock, C. Design Considerations for a One-Kilometer Antenna Stick. 28th Structures, Structural Dynamics and Materials Conference, April 1987

#### **Published Conference Abstract**

 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 Content**

- 1. "Why I'm in a Clinical Trial," consano.org, 05-Nov-2013
- 2. "Meeting the Chemist," American Society of Clinical Oncology's www.cancer.net, 15-Jul-2014
- 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
- 4. "Tackling the stigma of lung cancer and showing the real faces of the disease," Scopeblog.stanford.edu, 17-Nov-2014
- 5. "Can I fly when I have cancer?," curetoday.com, 20-Apr-2015
- 6. **Janet Freeman-Daily** and Colin Hung. "Data sharing for research and care," hcldr.wordpress.com, 14-Mar-2015
- 7. **Janet Freeman-Daily**, Corrie Painter, Stacey Tinianov. "The Connected Cancer Patient: Future Vision and Recommendations," hcldr.wordpress.com, 3-Jul-2015

#### Invited Webcasts

- 1. "Patient-generated data: Is it the future of healthcare?" Stanford Medicine X Live! Google Hangout, 6-May-2014
- 2. "Finding My Voice, Stories of Survival," hosted by Smart Patients and Story Collider, San Carlos CA, 31-Jul-2014
- 3. "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)

#### **Invited Video Content**

1. "Importance of Genomic Testing for Lung Cancer," recorded by Cure Today magazine at ASCO 2015 Annual Meeting on 1-Jun-2015

- 2. "Why Patients Should Attend the ASCO Meeting," recorded by Cure Today magazine at ASCO 2015 Annual Meeting on 1-Jun-2015
- 3. "Lung Cancer Awareness Month 2015: North America," recorded by International Association for the Study of Lung Cancer, 6-Nov-2015
- 4. "Janet Freeman-Daily: Patient-to-Patient Power," recorded by Patient Power at 2015 World Conference on Lung Cancer on 7-Sep-2015. Published 10-Nov-2015

## Letters to the Editor, Magazine Submissions and Other Publications

- 1. "Preserving the Memory," *Analog magazine* Jul/Aug 2009. (Science article on Alzheimer's Disease research)
- 2. "Non-Native Species," *Analog magazine*, Jan/Feb 2011. (science fiction short story)
- 3. Renee Klein and **Janet Freeman-Daily**. "Medicare should cover low-dose CT screening for lung cancer," *Seattle Times* opinion, 10-Jun-2014.

# **Advocacy Submissions**

- 1. "Provide coverage for Lung Cancer Screening with LDCT," Change.org petition, Feb-2014. (as LCSM Chat)
- Chris Newman, Janet Freeman Daily, George Haughton, Michele Taylor, Robert Young. "Submission Request to the NCCN Guidelines Thoracic Panel," 25-Jun-2014. (Requested revision of NCCN guidelines for oligometastatic disease and oligoprogression for non-small cell lung cancer)
- 3. "Tell the FDA to withdraw its proposed regulations for laboratory developed tests (LDTs)," Change.org petition, Jan-2015. (as LCSM Chat)
- 4. LungCAN letter "re Draft Guidance for Industry, Food and Drug Administration Staff, and Clinical Laboratories: Framework for Regulatory Oversight of Laboratory Developed Tests (LDTs) -- (FDA-2011-D-0360)," Jan-2015 (uncredited).

## **Business Writing**

- New business proposals, systems engineering analysis, and technical marketing for Hughes Aircraft spacecraft and The Boeing Company defense and space projects, 1981-1998
- 2. Grant, finance, technical, marketing and development documents for New Horizon School, a non-profit in Renton, WA, 2000-2009
- 3. "New Horizon School Annual Report," New Horizon School, 2009.

#### MEDIA COVERAGE

- 1. "Social Media Users Willing To Share Health Data Despite Concerns About Privacy," iHealthBeat. March 10. 2014.
- 2. "Cancer survivors still struggle with 'chemo brain'." Interviewed in health news segment which aired March 17, 2014, on King 5 News in Seattle.
- 3. "Turquoise Takeover: Seattle landmarks shine light on lung cancer," Interview on King 5 (NBC News in Seattle) about my lung cancer at Seattle's Lung Force event on Tuesday, May 13, 2014.
- 4. "Tech Totems: Mementos motivate and inspire alumni," *MIT Technology Review* June 17, 2014.
- 5. "Is Cancer the 'Best Death'?" Huffington Post, 07-Jan-2015. (My blog post "Dying the best death: it's not cancer" is mentioned.)

- 6. "From patient centered to people powered: autonomy on the rise," The BMJ, 10-Feb-2015. (My blog post "A lung cancer epatient story" is listed in the references)
- "How A Group Of Lung Cancer Survivors Got Doctors To Listen," National Public Radio, 1-Mar-2015.
- 8. "The Lung Cancer Blame Game," Fred Hutchinson Cancer Research Center, 7-May-2015.
- 9. "Patients take a starring role to define, shape palliative care," Fred Hutchinson Cancer Research Center, 19-May-2015.
- 10. "Doctors use Twitter to advance health care messaging," Medical Express, 9-Jun-2015.
- 11. "Super Patient: Janet Freeman-Daily Joins a Clinical Trial—and Beats the Odds on Lung Cancer," Cancer Commons, 2-Nov-2015.
- 12. "Seattle's Most Influential People of 2015," Seattle Magazine, Nov-2015.

#### REFERENCES

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