

LBCA Advocate Chat Series 2021

Local Research Advocacy



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Welcome and Today's Session

Information about today's session:

- Presentation portion will be recorded, and all participants will be muted
- Question and Answer period, which will not be recorded, will follow:
 - Write your questions in the chat throughout the presentation
 - During the Q & A portion, questions from the chat will be read. The moderator may call on people as well who indicate in the chat that they would like to ask a question
 - **NOTE:** Please avoid any questions about personal issues or specific medical questions as they can not be addressed during this event



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Local Research Advocacy

**A Conversation with Elizabeth Frank, Ed.M.
Lead Advocate for the Dana Farber / Harvard Cancer
Center Breast Cancer Advocate Program**

May 14, 2021



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Focus

- Research advocacy
- Local advocacy

Topics

- Identifying existing opportunities
- Generating opportunities
- Contributing to Clinical Trials
- Strategies for successful collaboration
- Your tool kit

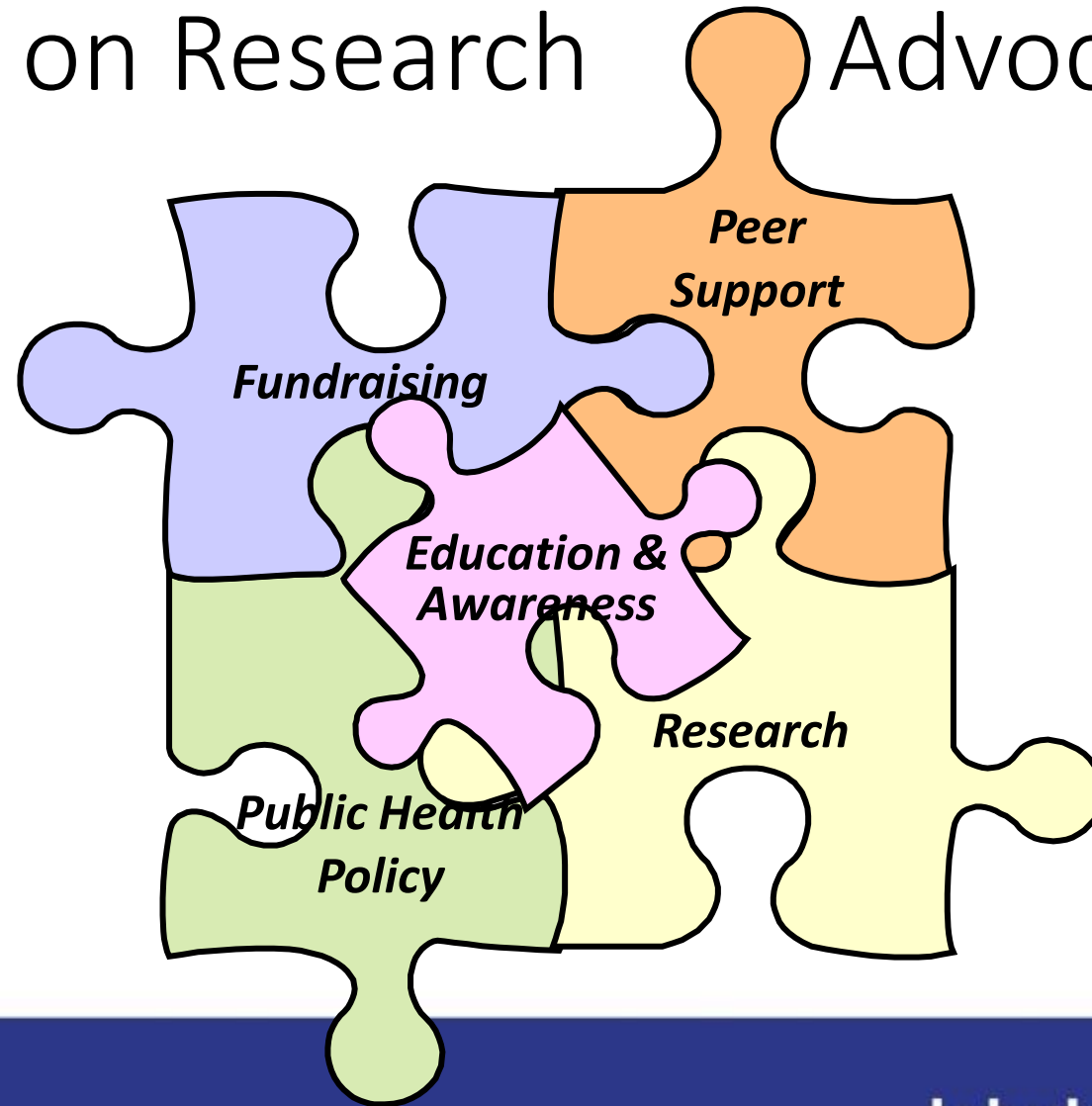
Who am I?

- 17- year breast cancer survivor
- Lead Advocate for DFCI/HCC Breast Cancer Advocacy Group
- Attended many advocacy training programs and scientific conferences
- Currently engaged in a variety of projects with translational and clinically focused research aims
- Mentee and a mentor
- Still learning about many of the issues I'll be discussing today

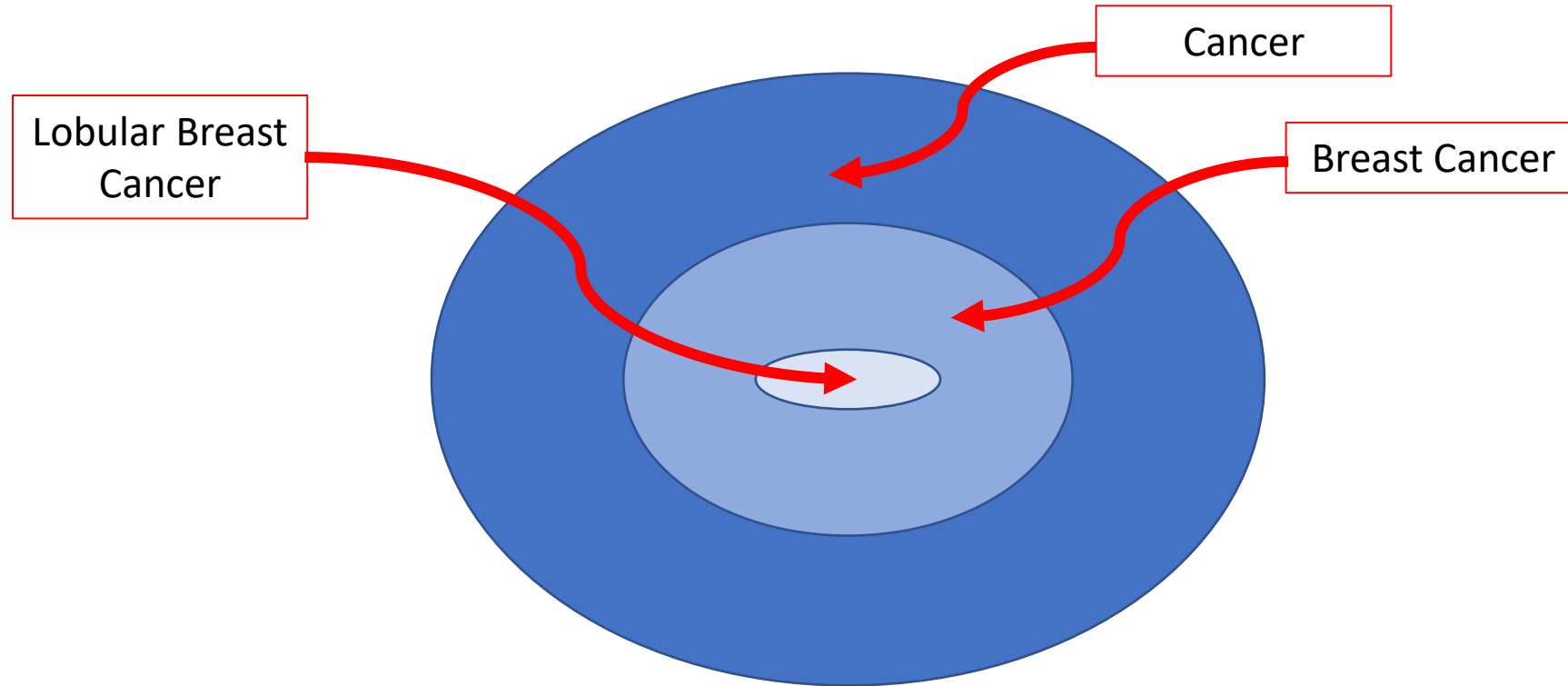


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Why Focus on Research Advocacy?



How Broad are Your Interests?



What Makes a Good Research Advocate?

- Desire to make things better
- Strong communication skills
- Ability to represent all patients and not just one's personal “story”
- Interest in learning the basics of the research enterprise, science, and treatments
- Thick skin
- Ability to work collaboratively

Why Connect with Local Research Advocates?

- Multiple perspectives
- Complementary strengths
- Increases credibility; strength in numbers
- Opportunity to learn from and teach others
- Expands network of connections
- Ongoing Effort



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Ideas for Connecting with Local Advocates

- National advocacy (e.g. NBCC, Komen, ACS, Sisters, LBCA) and professional (e.g., ASCO, AACR) keep list of members by location
- Granting agencies sometime provide access to information about their advocate reviewers (e.g., CDMRP, PCORI, ACS, Komen, ACS)
- On-line groups (PAIR, Advocate Collaborative)
- Social media groups (Twitter, Facebook)
- Local events that are likely to attract advocates
- National events that include advocates
- Your local treating oncologists and researchers
- Advocacy training courses



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Local Institutions and Organizations

- Large cancer centers are not the only place where research advocates can have impact
 - Agencies with a focus on healthcare research and policy
 - Organizations with a focus on cancer survivorship programs (YWCA, Local Community Centers)
 - Organizations with a focus on cancer support--psychological, financial, educational
 - Consortiums and groups focusing on diversity, equity and inclusion



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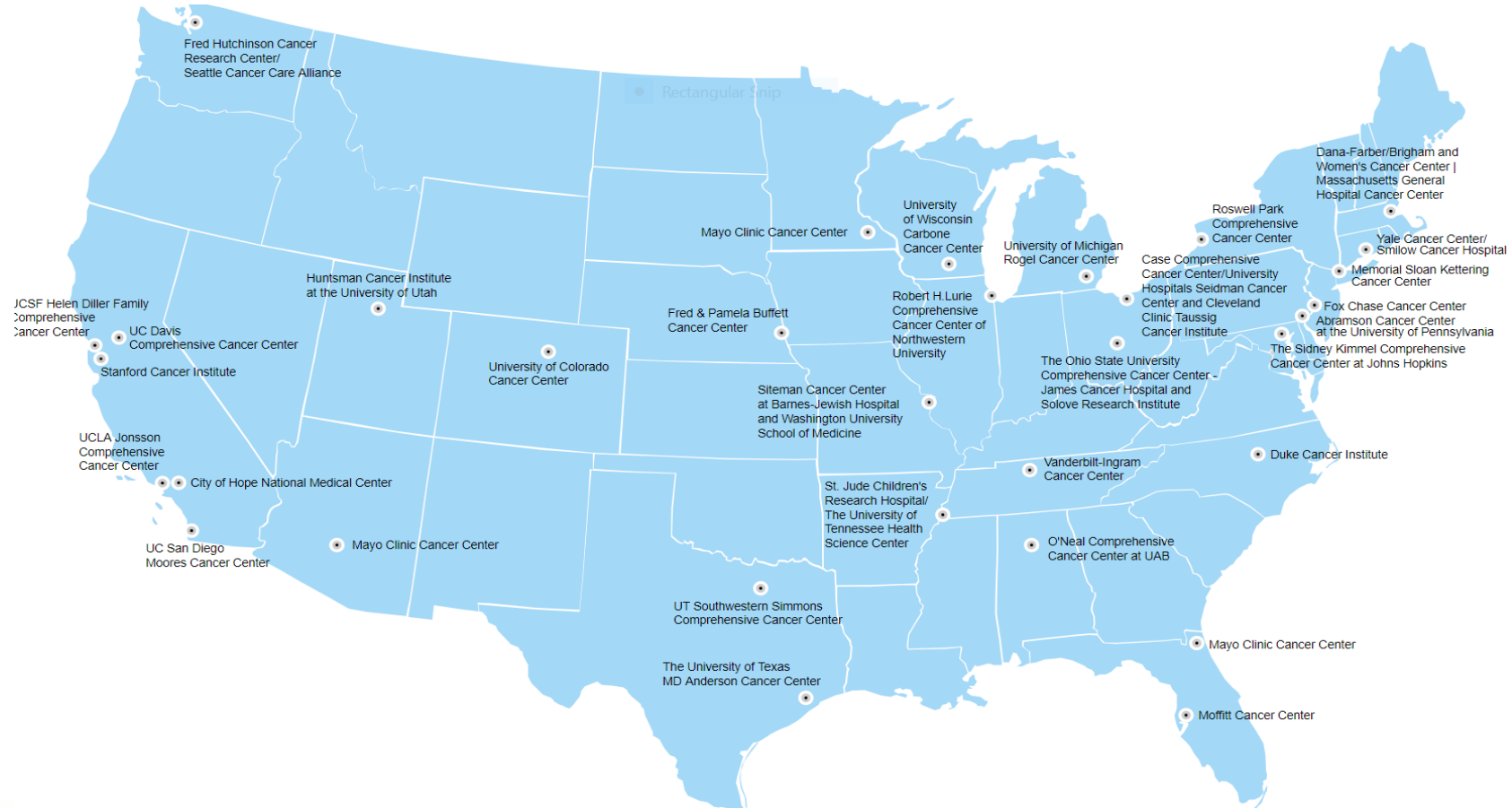
Examples of local organizations

- Local Hospitals; Patient and Family Advisory Committees (PFAC)
- Academic Institutions/not hospitals (Universities, Cold Spring Harbor Lab)
- National Groups with local chapters (Komen, YSC, Sisters...)
- Organizations with a strong interest in health research (MRCT, BBCEC)
- Community Advisory Boards
- Local Institutional Review Boards (IRB's)



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NCCN Accredited Centers



Navigating Academic Cancer Centers

- Faculty champion
- Funded researchers in your area of interest
- Junior researchers
- Centers of Interest (Immune oncology, PopSci, Epidemiology, etc.)
- Bio-banks and Registry studies
- Research review (Scientific Review Committees)
- PFAC's and Community Advisory Boards
- Tumor Boards



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Who has Funded Research at Your Institution?

- DoD
- NCI
- SU2C
- PCORI
- California Breast Cancer Research Program
- Internally funded grant mechanisms
- Foundations (Gateway, Arnold, Commonwealth...)



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Existing Opportunities within a Cancer Center

- Grand Rounds (ongoing)
- Lecture Series and special lecture (ongoing and one-offs)
- Conferences and Think Tanks (One-offs)
- Specific area of study research centers (immune oncology, therapy resistance, genetics)
- Membership in consortiums (Cooperative Groups, Clinical trial consortiums)
- Call for proposals (review opportunities)



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Meeting with Investigators

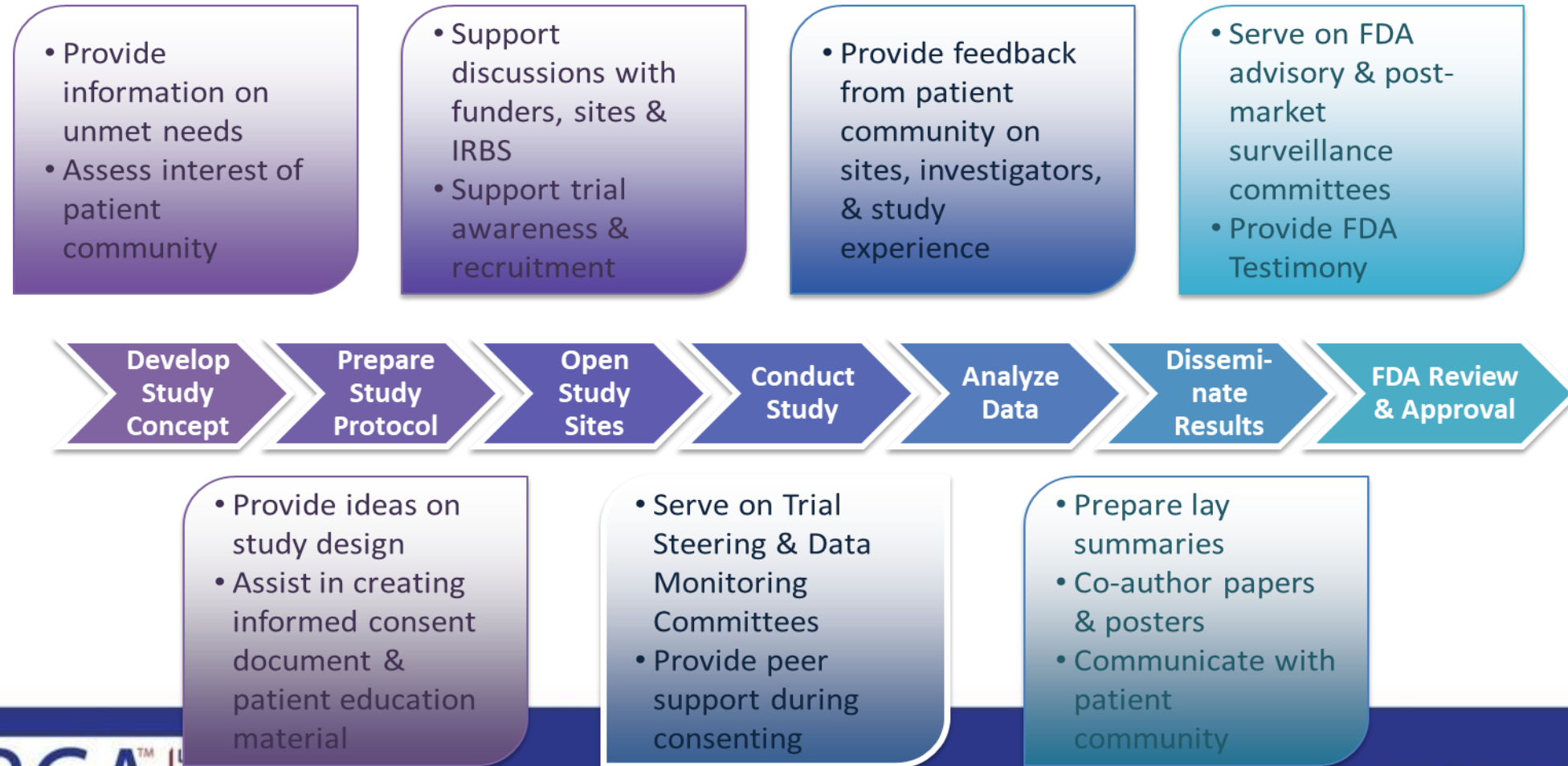
- Ask about their current research projects
- Ask about their future ideas and for not too technical papers
- Be prepared to explain:
 - Your cancer story (briefly)
 - What attracted you to research advocacy
 - Your career, skills/education and interests (as it related to cancer research)
 - What you can offer (patient perspective on concepts, reading early drafts of proposals, helping to craft advocate engagement section of their proposal, letter of support, ongoing feedback on project, review of manuscripts, abstracts....)



Bio-specimen banks and patient registries

- Bio-specimen banks may exist at both the disease and institutional level
- Ask about what bio-specimens are collected
- Ask about how bio-specimens are labeled (can lobular be identified?)
- Evaluate patient education material and the consent form
- Ask about and offer input on return of results
- Offer to serve on a review committee for bio-specimen requests

Advocate Involvement Across the Clinical Trial Continuum



Questions Advocates Should Ask About Interventions

- Why was this drug selected? (e.g., oral vs. IV, manufacturer)
- Why was this dose selected? (e.g., might a lower dose be as beneficial and less toxic)
- Why was this schedule selected? (e.g., length of time on treatment, patient convenience)
- Are all of the procedures necessary?
Scheduled conveniently for patients? Paid for by the trial ?

Generating New Opportunities: current examples

- Rapid Review Panel (University of Kansas)
- Research Advocacy Lecture at Grand Rounds
- Return of Results (DF/HCC)
- Identify and fill gaps in educational material (Mayo)
- Create a webpage to educate faculty about research advocates
- Clarity in Science Award Program (Georgetown Advocates)
- Evaluating Advocate Impact via COE Project (UNC)

What Do I Need in My (Virtual) Toolbox?

- Biosketch (can be adapted depending on organization)
- Personal Statement
- Letter of support (basic template, needs to be customized)
- Information about your advocate affiliation
 - LBC Alliance, NBCC, Komen, local research advocacy organization
- Someone to use as a reference for applications
- Mentors



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Advocacy Bio-sketch

- Focuses on your advocacy personal statement
- Rigid structure based on agency

OMB No. 0705-0188 (Rev. 03-2010) (Public Reporting Burden Estimate)

Department of Health and Human Services
National Cancer Institute
Division of Cancer Prevention and Control
National Cancer Institute

NAME _____

DAY CONTACT (WORK HOME) (OTHER) (E-MAIL) _____

POSITION TITLE _____

EDUCATION (PLEASE design with curriculum vitae or other professional education, such as training, research, professional training and academic training if applicable. Attachments are not necessary.)

INSTITUTION AND LOCATION	DEGREE or equivalent	Organization City/State	FIELD OF STUDY

NOTE: The Biographical Sketch may not exceed two pages. Follow the format and instructions below.

A. Personal Statement
Briefly describe only you and not others your work in the project described in the application. The relevant background includes aspects of your training, your previous professional work, and the specific type of cancer topic, your technical expertise, your collaboration in scientific and research, and your professional skills in related fields. You may mention specific contributions to cancer research not included in Section C. Also, give very briefly as to how your proposed contribution will specifically highlight your experience and qualifications for this project. If you wish to include information in your past productivity, you may include a description of specific work in terms of publications, grants, awards, and other scholarly activity.

B. Previous and Present
List all relevant professional positions, including with the present institution. List any awards, honors, awards, membership in any National Government public advisory committee.

C. Contribution to Science
Briefly describe up to five of your most significant contributions to science. For each contribution, indicate the technical background, the scientific problem, the critical findings, the outcome in the field, and the outcome of the project in the application of knowledge to health and technology, and give specific references to the described work. The work of these contributions, when taken up to five years, must be published in or other publication (include a product, but include work in other products, patents, data, and research materials, publications, abstracts, etc.) or other materials of scientific interest, and indicate the outcome of the work that are relevant to the described contribution. The description of each contribution should be at least one half page including figures and tables. Also provide a URL to a full text of your contribution work as found in a publicly available digital database such as PubMed or ISI/Scopus, which are maintained by the US National Library of Medicine.

Personal Statement

- Up to about four paragraphs; one page max.
 - Who you are
 - Your cancer experience
 - Your advocacy focus/goals?
 - Your advocacy experience/accomplishments?
- Keep it up to date
- Can be repurposed for almost any situation
- Can be used alone as a short bio-sketch



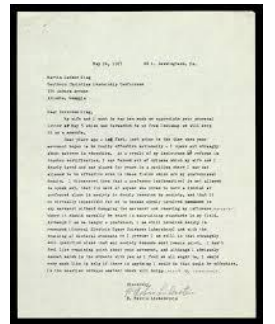
Finding Templates & Instructions (Use Google)

- NIH
 - <http://grants.nih.gov/grants/guide/notice-files/NOT-OD-15-032.html>
- PCORI
 - <https://www.pcori.org/funding-opportunities/announcement/pprn-limited-competition-award#Templates>
- Komen
 - <https://www.komen.org/breast-cancer-research/grants/opportunities>
- DOD
 - <https://cdmrp.army.mil/cwg/docs/consumerform.pdf>



Ground-rules: Letters of Support

- For people with whom you would like to work, freely offer to provide letters of support
- Before writing your letter, speak to the requester
 - Find out what the letter is for
 - Find out what, if any role you will play
 - Find out who to address it to, where to send it and when it is due
- Request a draft of the application, or at least an abstract
- Consider looking at the RFA (generally available online)
- Keep it to 1-2 pages; edit and spell check
- Save and edit for other letters



Training for Research Advocates

- Project Lead (application and recommendation required)
- AACR SSP (application and recommendation required)
- Komen Advocates in Science (application and recommendation required)
- Research Advocacy Network (Lots of great material on their website)
- Conquer Cancer Foundation (application)
- Alamo Foundation at SABCS (application)
- AAADV Workshop (application)
- Online conferences –AACR, SABCS, ASCO, SITC,
- Online meetings/forums- LBBC, CTTI, National Academies, NCI.....



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Applying for Research Advocacy Opportunities

- Read eligibility criteria carefully (you probably don't need all of them)
- Read selection criteria carefully and craft your application to focus on them
- Draft your responses in WORD (even if it is an online application)
- Edit (and spell-check) carefully
- Honor word/character limits (less is often more)
- Submit early
- Save copies of previous applications and reuse/edit for future applications



Advocacy Do's

- Represent a variety of patient perspectives
- Ask questions about things you don't understand
- Understand expectations about your involvement
- Ask for feedback
- Act professionally

& Don'ts

- Focus exclusively on your experiences
- Ask questions about your cancer
- Expect to understand all of the science
- Expect all of your recommendations to be heeded

Successful Collaborations

1. Identify specific opportunities
2. Ensure clear expectations
3. Request meaningful participation, through all aspects of projects
4. Ask for education and materials to bring us up to speed
5. When possible, include at least 2 advocates
6. Request compensation, financial and other, as appropriate
7. Assess contributions and evaluate what worked



JP Advocacy Advice

- Be opportunistic when you are starting out; strategic later on
- Understand and adapt to the host's culture (e.g., academic, for-profit)
- Clarify and meet (or exceed) expectations
- Seek feedback
- Keep learning
- Push the envelope
- **Add value!**



Summary

- Try to stay open-minded about your interests
- Persistence often pays off
- Detective work is part of the fun
- Connections and relationships matter
- You can't have too many mentors
- Continuous learning is an ongoing part of research advocacy
- Try not to personalize
- Don't expect all of your opportunities and ideas to pan out



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Resources for research advocacy (1)

- Perlmutter J, et al. Cancer Research Advocacy: Past, Present and Future. Cancer Research. 2013;73:4611-4615. <http://cancerres.aacrjournals.org/content/73/15/4611.full.pdf+html>
- Seeking What Matters: Patients as Research Partners, Musa Mayer. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3585898/>
- PCORI website: <http://www.pcori.org/funding-opportunities/what-we-mean-engagement>
- Susan G. Komen Guidelines for Advocate Engagement https://ww5.komen.org/uploadedFiles/Content/ResearchGrants/GrantPrograms/FY14AdvocateInvolvementGuidelines_FINAL.pdf
- Promoting scientist-advocate collaborations in cancer research: why and how <https://cancerres.aacrjournals.org/content/early/2018/08/18/0008-5472.CAN-18-1600>
- How Patient Advocacy Helps Advance Cancer Research: A Conversation on Collaboration <https://www.cancer.net/blog/2019-03/how-patient-advocacy-helps-advance-cancer-research-conversation-collaboration>
- CTTI Recommendations on Patient Groups around Clinical Trials <https://www.ctti-clinicaltrials.org/briefing-room/recommendations/ctti-recommendations-effective-engagement-patient-groups-around>



Resources for research advocacy (2)

- Bob Ritter's Blog on resources for research advocates:
<https://blogs.cornell.edu/cancercommunitypartnership/for-community-members/resources-for-research-advocates/>
 - Includes references to many of the local breast cancer advocacy groups



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Thank you

- Jane Perlmutter
- Patty Spears
- Susie Brain
- Jeannine Salamone
- Deb Collyar
- DF/HCC Breast Cancer Advocates Group members



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Thank you!



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Upcoming Advocate Chats

- June 6, 2021: Advocacy Through Supporting Others with ILC
- July 2021: Advocacy Through the Media





Questions & Answers