Module 9: What are different ways of engaging advocates?

Technical Assistance Materials for Investigators
California Breast Cancer Research Program
## Roles Advocates Play in Research

**Table 1. Examples of advocate involvement in cancer research**

<table>
<thead>
<tr>
<th>Strata/examples</th>
<th>Activities</th>
<th>Contributions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allocating research funding</td>
<td>- Establishing research priorities&lt;br&gt;- Writing research funding announcements&lt;br&gt;- Peer review&lt;br&gt;- Programmatic review</td>
<td>- Ensure cancer relevance&lt;br&gt;- Focus on impact rather than elegance&lt;br&gt;- Increase attention to areas of importance to public (e.g., environmental causes of cancer, health disparities, palliative care)&lt;br&gt;- Encourage collaboration across disciplines and among stakeholders</td>
</tr>
<tr>
<td>Participating in research teams</td>
<td>- Writing and providing feedback on grant applications&lt;br&gt;- Participating in research group meetings&lt;br&gt;- Bridging gaps among stakeholders</td>
<td>- Maintain focus on helping patients&lt;br&gt;- Stimulate discussion and collaboration&lt;br&gt;- Bring outsider perspective to the research&lt;br&gt;- Add a personal face and sense of urgency&lt;br&gt;- Increase public understanding of science</td>
</tr>
<tr>
<td>Planning and implementing clinical trials</td>
<td>- Designing trials&lt;br&gt;- Reviewing informed consents&lt;br&gt;- Providing patient navigation and peer support&lt;br&gt;- Focusing recruitment and retention plans</td>
<td>- Sensitize researchers to issues that will have an impact on patient recruitment, retention, and satisfaction&lt;br&gt;- Provide consumer perspective on ethical issues&lt;br&gt;- Focus on toxicities as well as benefits&lt;br&gt;- Encourage quality-of-life add-ons&lt;br&gt;- Encourage collaboration across disciplines and among stakeholders&lt;br&gt;- Add a personal face and sense of urgency&lt;br&gt;- Increase public understanding of science</td>
</tr>
<tr>
<td>Translating and disseminating research</td>
<td>- Presentations at advocacy and scientific meetings&lt;br&gt;- Planning and attendance at advocacy and scientific meetings and training&lt;br&gt;- Publication in advocacy and scientific journals, websites, listservs, and blogs&lt;br&gt;- Public outreach through national, regional, and local organizations, and media</td>
<td>- Develop future advocates&lt;br&gt;- Sensitize researchers to issues that are important to public stakeholders&lt;br&gt;- Help public understand the importance of cancer research&lt;br&gt;- Increase awareness of cancer research progress</td>
</tr>
<tr>
<td>Research and public policy oversight</td>
<td>- Clinical practice guideline committees&lt;br&gt;- Working groups, study groups, and think tanks&lt;br&gt;- Protocol and science review boards&lt;br&gt;- IRBs and DSMBs</td>
<td>- Increase transparency&lt;br&gt;- Provide patient/consumer focus&lt;br&gt;- Provide outsider perspective&lt;br&gt;- Help disseminate results</td>
</tr>
</tbody>
</table>

Table from Perlmutter, J., Bell, S.K., and Darien, G., Cancer Research Advocacy: Past, Present, and Future, Cancer Res; 73(15) August 1, 2013
Example Advocate Activities

LOI & Application Preparation and Submission:

- Offer feedback on specific areas
  - Impact on patients
  - Critical path
  - Translational potential
- Develop and Review sections of proposal
  - Project Summary
  - Translational Goal
  - Impact on Breast Cancer
- Through these steps, help communicate the importance of project to BC patients and families
- Collaborate in defining their role during the project’s implementation and dissemination of the results
- Work with your team to make public abstract accessible to non-scientific audience

Research Project:

- Participate in team meetings
- Help with crafting plain language summaries for talking with public about project and results
- Talk with community about projects, research, and importance
- Help with creating materials (educational and outreach)
- Impact translational potential of research
Reach out to CBCRP

- 1-888-313-2277
- Program Officers
  - Katie McKenzie, Ph.D. katherine.mckenzie@ucop.edu
  - Senaida Poole, Ph.D. senaida.poole@ucop.edu
  - Carmela Lomonaco, Ph.D. carmela.lomonaco@ucop.edu
- General Email: getinfo@CABreastCancer.org