

CHILDHOOD CANCER POLICY ROUNDTABLE

A Continuing Community Conversation
Steve Crowley and Vickie Buenger



CAC2 Values

- ❖ Put the children and their families *first* in everything we do
- ❖ Support the members and the childhood cancer community while being mindful not to compete with members or to duplicate projects/programs/services that they provide
- ❖ Be accountable and take ownership of one' s commitments within the collaborative
- ❖ Be cost effective with resources
- ❖ Be inclusive and collaborative and assume positive intent
- ❖ Help give voice to the community, and amplify it in a coordinated fashion
- ❖ Stay action-oriented and flexible

Childhood Cancer Policy Roundtable

- Host—The Alliance for Childhood Cancer
- Participants
 - Advocates and Professionals from the Alliance
 - Board Members and Advocacy Reps from CAC2
 - Independent Advocates
- First Meeting
 - September 20, 2014
 - Washington, DC

Organizing Premises and Goals

Effective advocacy and collaboration requires a clear strategy with concrete goals arrived at through an unbiased process.

“If a public official sees that an advocacy community is divided on its goals or strategy, he or she will quickly back out of the room.” -Dan Smith

- **Goals**

- convene advocates from across the community
- engage in a constructive conversation
- achieve clarity around common goals
- identify what cannot be agreed upon.

The Challenge

Create a process that allows for

- wide-ranging input and discussion among a diverse community, AND
- that also allows us to set common goals and work together to reach them
- The challenge:
 - CAC2 has almost 100 members
 - The Alliance has nearly 30 members (with some overlap)
 - Many unaffiliated organizations and individual advocates

Facilitation Process

- Facilitator--Dan Smith, president and founder of AdvocacySmiths
- Credentials
 - Served as chief of staff to Sen. Tom Harkin
 - Staff Director of the Senate Committee on Health, Education, Labor and Pensions,
 - Founder and former president of the American Cancer Society Cancer Action Network.
- Emphasized that he was a facilitator, and not a leader, of the discussion

Facilitation Format

- Multi-Step, Shared and Guided Process—Midwest Academy Strategy Framework
- First Steps
 - Long-Term and Intermediate-term Goals(September 20)
 - Intermediate and Short-term Goals (December 9)
- Later Steps
 - Organizational Considerations
 - Allies and Opponents
 - Targets
 - Tactics

Midwest Academy Strategy Chart

After choosing your issue, fill in this chart as a guide to developing strategy. Be specific. List all the possibilities.

Goals	Organizational Considerations	Constituents, Allies, and Opponents	Targets	Tactics
<ol style="list-style-type: none"> List the long-term objectives of your campaign. State the intermediate goals for this issue campaign. What constitutes victory? <p><i>How will the campaign</i></p> <ul style="list-style-type: none"> Win concrete improvement in people's lives? Give people a sense of their own power? Alter the relations of power? <ol style="list-style-type: none"> What short-term or partial victories can you win as steps toward your long-term goal? 	<ol style="list-style-type: none"> List the resources that your organization brings to the campaign. Include money, number of staff, facilities, reputation, canvass, etc. What is the budget, including in-kind contributions, for this campaign? List the specific ways in which you want your organization to be strengthened by this campaign. Fill in numbers for each: <ul style="list-style-type: none"> Expand leadership group Increase experience of existing leadership Build membership base Expand into new constituencies Raise more money List internal problems that have to be considered if the campaign is to succeed. 	<ol style="list-style-type: none"> Who cares about this issue enough to join in or help the organization? <ul style="list-style-type: none"> Whose problem is it? What do they gain if they win? What risks are they taking? What power do they have over the target? Into what groups are they organized? Who are your opponents? <ul style="list-style-type: none"> What will your victory cost them? What will they do/spend to oppose you? How strong are they? How are they organized? 	<ol style="list-style-type: none"> Primary Targets A target is always a person. It is never an institution or elected body. <ul style="list-style-type: none"> Who has the power to give you what you want? What power do you have over them? Secondary Targets <ul style="list-style-type: none"> Who has power over the people with the power to give you what you want? What power do you have over them? 	<p>For each target, list the tactics that each constituent group can best use to make its power felt.</p> <p>Tactics must be</p> <ul style="list-style-type: none"> In context. Flexible and creative. Directed at a specific target. Make sense to the membership. Be backed up by a specific form of power. <p>Tactics include</p> <ul style="list-style-type: none"> Media events Actions for information and demands Public hearings Strikes Voter registration and voter education Lawsuits Accountability sessions Elections Negotiations

Participants

- 31 advocates participated on September 20
- CAC2 members
 - Beth Ann Baber (Advocacy Interest Group)
 - Vickie Buenger (Board President)
 - Steve Crowley (Board Member)
 - Angie Giallourakis (Board Member)
 - Nancy Goodman (Advocacy Interest Group)
 - Trish Kriger (Board Member)
 - Donna Ludwinski (Board Member)
 - Gavin Lindberg (Advocacy Interest Group)
 - Bob Piniewski (Board Member)
 - Melanie Smith (Member)
 - Rachele Thompson (Associate Member)
 - Richard Plotkin (Advocacy Interest Group)
 - Susan Weiner (Advocacy Interest Group)

Roundtable Format

- Morning Session
 - Shared discussion about possible goals
 - Dozens of concerns and issues raised
 - Robust and respectful conversations
 - Dan scribed each concern on poster paper
- Afternoon Session
 - Organize and sort potential goals
 - Reach alignment on high-level vision and initial shared goals

Emergent Goals

The three broad goal categories resulted from the discussion:

- **Research (Maximizing Discovery)**
- **Drug Development and Use**
- **Care, Quality of Life & Survivorship (Maximizing Delivery)**

Research Consensus

Regarding research, some of the shared intermediate-range goals:

- Work with the broader medical research community to obtain increased funding for NIH/NCI
- Work to ensure greater efficiency and transparency for childhood cancer funding at the NCI
- Seek other avenues for funding (e.g., Gabriella Miller Act, DoD funding, etc.)

Drug Development and Use Consensus

Regarding Drug Development and Use, some of the shared intermediate-range goals:

- Press for changes in federal policy to accelerate the development of improved pediatric cancer treatments
- Work to lessen the toxicity of treatments
- Work to eliminate barriers to access of life saving therapies

Care, Quality of Life, & Survivorship Consensus

Regarding Care, Quality of Life & Survivorship, some of the shared intermediate-range goals:

- Provide state of the art, interdisciplinary coordinated care (including palliative care) to all childhood cancer patients
- Work to improve post-treatment care and support services for patients and families
- Promote additional research on the issues facing survivors of childhood cancer

Next Steps

The next meeting of the Roundtable will take place on December 9th in Washington, DC.

The goal there will be to further refine intermediate and short-range goals that the community can agree and begin to act on.

- Inform our CAC2 community of the progress
- Reach alignment on continued participation
- Collect additional input and refine goals

Next Round CAC2 Participants

Confirmed

- Vickie Buenger (Board President)
- Steve Crowley (Board Member)
- Angie Giallourakis (Board Member)
- Nancy Goodman (Advocacy Interest Group)
- Gavin Lindberg (Advocacy Interest Group)
- Grainne Owen (Member)
- Vicki Sardi-Brown (Member)
- Jay Scott (Associate Member)
- Melanie Smith (Member)
- Julie Sutherland (Board Member)
- Susan Weiner (Advocacy Interest Group)

Your Role

We would very appreciate your questions and input

- Discussion and Questions
- Feedback
 - By phone
 - By email
 - By surveymonkey
- Inform others outside of CAC2