

**11<sup>th</sup> Annual Phoenix Area Child Life Conference**

**Treating the Whole Child: Emphasis on Culture, Family, and Integrating Therapies**  
Bead Inspired! Transforming the science of caring for children and their families coping with serious illness and the clinicians who care for them



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**Jean Gribbon, PhD, RN**  
Executive Director  
jean@beadsofcourage.org

**Beth Moneck, MS, CCLS, CIMI**  
Program Director  
beth@beadsofcourage.org  
412-512-5330

www.beadsofcourage.org

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**GRATITUDE**

*“A man is not defined by what he has.  
What matters is the values he lives by and  
what he does for others.” — Henri Landwirth*

Providing Arts-In-Medicine Programs for Children Coping with Serious Illness.  
Helping children RECORD, TELL, and OWN their story of courage.

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**BEAD INSPIRED!**  
**Developing and Maintaining a Child Life Practice**

- The Foundation for an Authentic Child Life Practice
  - Defining and knowing what is Child Life
  - Renewed commitment to Standards of Clinical Practice and Competencies.
  - Return to the literature to keep current with Child Life Theory and Practice
  - Operating Principles | Code of Ethical Responsibility
  - Be Curious

 **❖ Beads for Reflection and Renewal**  
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**Official Documents of the Child Life Council (ACLP)**

- Integrity of the profession is maintained
- Informs the public about core values of child life
- Non-negotiable standards
- Expression of our commitment to society
- Obligations and duties of every individual who enters the child life profession

 **❖ Green Bead for Ethical Child Life Practice**  
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**Innovation in Child Life Practice**  
**“You must always do the thing you think you cannot do”**  
**-Eleanor Roosevelt**

- Desire to advance the science of child life
- Commitment to caring for others
- Questions from practice that motivate one’s desire to discover



 **❖ Butterfly Bead: Transform Practice**  
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**Know Why YOU are a Child Life Specialist, Know Our Unique Knowledge, and Proclaim it to the World**



- Child Life is a practice discipline
- Child Life has an obligation to understand the nature, meanings, and life experience as it relates to human caring, health and wellness
- Articulate what you know and make recommendations to change practice

❖ **Bell Bead Raise your Voice**

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**BEAD INSPIRED!**

**Transforming the Science of Caring for Children and their Families Coping with Serious Illness and the Clinicians who Care for Them**

- Engage in reform based on human caring
- Purposeful encounters with patients to potentiate their healing
- Caring transactions benefit the provider and recipient
- Professional obligation to seek ways to further enhance caring at point of care
- Need for ongoing development of caring interventions that decrease the gap between provider's capacity for and commitment to caring

❖ **Red Bead for Caring at the Heart of Child Life Practice**

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**Transpersonal Caring-Healing Practice**

- Awareness of caring is necessary for ethically aware practice
- Awareness of one's integral connectedness with others
  - Understanding our own and others' suffering
  - Provider as instrument of caring and healing
- Creating a **sacred space** through caring intention
  - Authentic presence
  - Commitment
  - Reverence



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**Innovation Requires Curiosity:  
Beads of Courage Development**  
"Believe passionately in something  
that does not exist and create it" – Nikos Kazantzakis

- > Lacked "tools" to address emotional needs of patients and their families
  - "Beyond the sticker" phenomenon
- > Discovery of Bravery Beads Program at British Columbia Children's Hospital based on boy scouts model
- > Research experience and literature review
  - Children completing treatment seeking tangible signs of completion
- > Visit to the Bead Museum
  - Earliest art form known to humans
  - Beads as symbols of honor and accomplishment

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**Beads as Objects of Importance**  
Earliest art form of modern humans  
Preceding cave paintings and carved figures

Oldest beads made from shells over 100,000 years ago

Form of currency – "Trade Beads"  
Used along with gold, furs, ivory, spices and cloth  
Different trade value dependent upon color, shape, size or rarity

Signify status in many societies  
Symbols of wealth  
Certain beads reserved for royalty  
May show rank or job

Associated with Strength, Courage, Longevity, Protection  
Beads made from Teeth, bones, claws  
Eye Beads – "eye" on protection and good luck

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**Beads are in our DNA: "Beads of Life"**  
Beads of Courage embraces 3 things that are very much part of being human

**#1 Value of Objects**

- Beads are small perforated objects
- Objects serve as powerful metaphors for remembering people and events that shape us as individuals

*The strength of an object lies in its ability to make visible that which is invisible*



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**Beads to me are: "One for all, all for One"**  
**– Ichino Urashiri**



**#2 Gift Giving**

- The gift carries the intentions of the gift giver
- Experience of caring strengthened through embodied action of gift giving
- Reverence for life, authentic presence and commitment to caring at the bedside
- Exchange contributes to human solidarity

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**Strengthening Human Connectedness:**  
**"One for All, all for One"**



**#3 Storytelling**

**Human Solidarity-"You are not alone in your fight for life"**

- Necessary for sustaining the human spirit
- "Spirit lifting which is life saving in the moment"

*"He needs the beads. We need the beads. Not because they are magic, but because they identify us with a community of fellow travelers. Without them, we would not be able to endure. Yes, we will take your beads and thank you very much for them."*

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**Beads of Courage Programs are Theory-Driven: Inquiry for Innovation**

**Integration of Theory, Research and Practice**

- Resilience
- Suffering and Narration
- Arts-in-Medicine
- Transpersonal Caring Healing Practice Model

❖ **Yellow Bead** for theory-driven inquiry



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### Theory-Driven Inquiry: Resilience

- Guided BOC Development
- Positive Health Perspective
  - Role that promotion of positive behavioral, environmental, and psychosocial factors have in health and well-being
- Support or Strengthen Protective Resources (Singer & Ryff, 2001)
  - Meaning and purpose,
  - Social and emotional support
  - Optimism, Happiness
  - Neurobiological mechanisms



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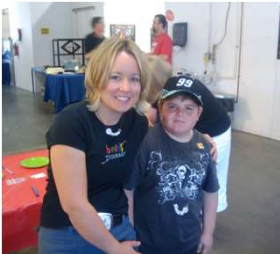
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### Resilience-Based Interventions



- Strengthen Protective Processes
  - Engagement Coping
  - Derived Meaning
  - Self-Esteem
  - Hope
  - Perceived Social Support
    - Family, Peers, Health Care Provider
  - Health Care Resources
    - Programs
    - Child Participation

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### Resilience-Based Interventions



- Decrease Risk Factors
  - Uncertainty in Illness
  - Symptom Distress
  - Severity of Illness
  - Reliance on Disengagement Coping (efforts to remove self from situation)

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**Resilience-Based Outcomes of the Beads of Courage Program**

- Decrease illness-related distress
  - Meaning of procedures are altered/refocused, making it more positive, and less threatening
- Increase engagement coping strategies
  - Move child from reliance on disengagement strategies
  - Increase repertoire of strategies available to child to cope
- Increase derived meaning
  - Child reflects on each procedure and milestone through collection of beads over time
- Increase perceived social support
  - Health care providers, family, peers



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**Theory Driven Inquiry: Nature of Suffering**

- A state of severe distress associated with events that threaten the wholeness of the person
  - physical, psychological, social, spiritual distress caused by intensive treatment for illness
  - There is loss of meaning and purpose while interpreting symptoms and illness experience
- Alienation of the sufferer (Younger, 1995)
  - Need for language or symbols that serve to interpret the experience – gives voice to the sufferer
  - To authentically connect with others



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**Beads of Courage Program is a Form of Narrative Medicine**

- Narration provides way to make sense of an illness, restore sense of self, and connectedness to others (Sakalys, 2003)
- The sufferer needs to be provided an opportunity to tell their story (Charon, 2005)
- Narration can help the sufferer
  - Gain distance from the painful experience
  - Possess the experience to gain mastery over it



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**Program Outcomes: Narrative Medicine**



- Beads provide a language that helps to interpret the experience, giving voice to the sufferer
- Finding purpose and meaning amidst the challenges
- Making sense of an illness, restoring a sense of self, and connectedness to others

➤ **“A time stamp of everything that has happened and what we have been through as a family”**

➤ **“The beads show what I have been through”**

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**Theory-Driven Inquiry: Arts-in-Medicine**

- Many direct benefits to patients identified
  - physical, mental and emotional recovery, reducing anxiety
  - decreasing the perception of pain
- In an atmosphere where the patient often feels out of control, the arts can serve as a therapeutic and healing tool
  - Reduce stress and loneliness
  - Provide opportunities for self-expression
- Arts can reduce patients' use of pain medication and length of stay in the hospital, and improve compliance with recommended treatment



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**Program Outcomes: Arts-in-Medicine**

“The arts serve patients and caregivers as powerful aids in times of emotional vulnerability and bring beauty into the stress-filled healthcare world” – SAH concept paper (2003)



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**Arts-in-Medicine**

"I **made mine into a dream catcher**. This might sound silly, but when I get a cold or just feel bad, I always get terrified that the cancer is coming back and then at night before I go to bed, the thoughts just get worse because my brain is just clustered, and I feel like having the **Beads Of Courage on my dream catcher by my bed, gives me a little peace of mind**.

Just a friendly, **beautiful** reminder that I am strong and I beat my nasty battle with leukemia, and I can handle whatever life throws at me, and I always sleep peacefully....It always **lifted my spirits, and that's the most important thing to getting better, staying happy.**"

-Beads of Courage Member, Angel Duran



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**Beads of Courage, Inc.**  
(a 501(c)3 tax-exempt organization)

**Founded in March of 2005**

**Mission**  
To provide innovative Arts-in-Medicine programs for children coping with serious illness, their families, and the clinicians who care for them



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**Beads of Courage Today**


**"Helping Children with Serious Illness Record, Tell and Own their stories of courage"**

**Beads of Courage Cooperative Group**

- 260 member hospitals
- 8 countries: USA, UK, Canada, Japan, Northern Ireland, Scotland, New Zealand, Australia
- Estimated 50,000 BOC member children and families

Demand for our programs is evidence of the need to bring aesthetic knowing to the clinical care of children coping with serious illness

**Our Vision:**  
Advance the science of caring through evidence-based Arts-in-Medicine interventions



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**Beads of Courage Today**  
**“Helping Children with Serious Illness Record, Tell and Own their stories of courage”**

**Our Goals:**

1. Transform the bedside experience of caring for children and teens with serious illness through innovative Arts-in-Medicine Programs
2. Model collaborative strategies to strengthen human connectedness through the gift of beads that bestow honor and express human caring
3. Contribute to the science, practice and implementation of evidence-based interventions.

**Our Programs:** Use beads as visible and tangible symbols of human experiences that need and deserve to be expressed. Every time a bead is given courage is honored, suffering is alleviated, resilience is strengthened, and the experience of human caring is affirmed.

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**Beads of Courage® Programs**

<b>BEad Supportive</b> <i>(Family)</i> Sibling Program Touch for Strength	<b>BEad Courageous</b> <i>(Patient)</i> Beads of Courage® Program
<b>BEad Connected</b> <i>(All)</i> Camp Bead Strong	<b>BEad Caring</b> <i>(Clinician):</i> Bead Mindful Caring for the Clinician

**BEad Compassionate** *(All)*  
Strand for Strength & Remembrance  
Butterfly Bead for Bereavement  
Bead Strong for Bereavement

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**Beads of Courage Arts-in-Medicine Programs**  
**“Every Bead Tells a Story of Courage, Honor and Hope”**

**Support for child in active treatment**

- > **Literary Arts**
  - Visual illness narratives – core program
  - Creative writing, and poetry – Bead Mindful & Bead Strong
  - Framing joy and sorrows in words
- > **Visual Arts**
  - Arts in Medicine Workshop Series
  - Open communication; strengthen solidarity
- > **Performing Arts**
  - Music, Movement, Dance
  - Social-emotional, spiritual, physical healing
  - Primarily at Beads of Courage events

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**Beads of Courage Programs: Literary Arts**  
"A Dose of Narrative Medicine"

- **Core Beads of Courage Program**
  - Beads given for treatments and procedures
  - Becomes a powerful visual illness narratives
  - Visible, tangible symbol of honor and accomplishment
- **Bead Strong Activities**
  - Art directives with invitation to draw and reflect upon courage
  - Mindful moments with guided imagery and poetry
  - "Dare to love yourself as if you were a rainbow with gold at both ends"



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**Beads of Courage Bead Strong**  
Mindfulness Intervention for Children with Serious Illness



As comedian Victor Borge once said, "To write the journal devoted to 'how to cope' is like writing the manual for a car that never breaks down, a manual often left unread. So, one strategy the beads of courage program uses is to help children tell their own stories (just as a storytelling man).

Think of a job that makes you smile/laugh. Who knows... if they make someone else smile, too, make the speaking bubble, write one or two ideas... If you need more facts, complete a job between the two people.

- Provide meaningful activity during long hospitalizations to support their coping
- Integrates art therapy, and mindfulness with a symbolic bead for object focused intention
- The practice of mindfulness is a form of self-care, and can support or strengthen psychological health and overall well-being for children who are offered the opportunity



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**Beads of Courage Programs: Visual Arts**

**Arts-in-Medicine Workshop Series**

- Facilitated by an artist-in-residence
- Reflect upon journey with dialogue
- Cope with intrusive thoughts and capture Hope
  - "Let all of your worries and stresses of the day fade away... before you begin, take a couple of deep breaths, this will help to clear your mind. As you are breathing think to yourself, "What inspires me? "Where does your courage come from?"



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**Beads of Courage Programs: Performing Arts**

**Music, Dance & Movement**

- Dancers, Musicians, actors and other performance based artists into the hospital setting
- Increase opportunities at Celebration of Courage Events and movement through Bead Strong
- Expand program development



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**Where do these little beads go?**  
They become a physical story a young adult is proud to carry.

"My beads help me visualize my battle...to go back and change what may have seemed to be a time of weakness into a physical story that I am proud to carry."

"My favorite beads are my special "Act of Courage" beads. Nobody has the same strand of beads, as everyone goes through a different battle. The one thing that we all have in common is courage and bravery."

-Katie Clowers



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**Where do these little beads go?**  
They comfort the mom, dad and sibling in the neonatal intensive care unit and help NICU grads tell and own their story of courage



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**Where do these little beads go?**  
They become the most sacred possessions.  
A tangible testament to Life & Love.  
Life. Love. Beads of Courage.



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**Where do these little beads go?**  
They provide a lifetime of comfort for a bereaved family.



*"They are his story, his journey, and they will tell it for eternity"*  
-Lucas' Dad, Lucas "LucasBear", 5 years old, Oncology Program Member, Lurie Children's Hospital, Chicago, IL

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**Where do these little beads go?**  
Community Engagement: Carry a Bead

**Goals of the Carry a Bead Program**

- Increase experience of social support
- Provide opportunity for community engagement through experiential art program
- Provide opportunity for human caring and connectedness to transpire
- Provide sustainable source of beads for program



**beads of COURAGE** Providing Arts-In-Medicine Programs for Children Coping with Serious Illness  
Helping children **RECORD, TELL** and **OWN** their story of courage.  
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# 11<sup>th</sup> Annual Phoenix Area Child Life Conference

## Treating the Whole Child: Emphasis on Culture, Family, and Integrating Therapies Bead Inspired! Transforming the science of caring for children and their families coping with serious illness and the clinicians who care for them

**Where do these little beads go?**  
"We are all Connected": Carry a Bead

**How does it work?**

- CAB Kit includes a matching bead set
- Keep one bead
- Carry one and return with a story card and signed note of encouragement
- Beads are returned and distributed randomly by BOC to children who actively participate in Beads of Courage Program



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**Reflecting on a 12 Years of Innovation:  
Providing Art in Healthcare**

- "The arts serve patients and caregivers as powerful aids in times of emotional vulnerability and bring beauty into the stress-filled healthcare world" – SAH
- "Art is our one true global language. It knows no nation, it favors no race, and it acknowledges no class. It speaks to our need to reveal, heal, and transform. It transcends our ordinary lives and lets us imagine what is possible." - Kamler



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**Bead Inspired!  
Child Life Specialists**

- Reinvent the caring encounter
  - Miracles happen with innovation
- Continuous process improvement
  - Be available to troubleshoot challenges
- Be Courageous
  - Passion with a charismatic approach
  - Boldly follow the vision deep sense of purpose
- Be persistent and disciplined in supporting the vision
  - Rock solid conviction with hope for change

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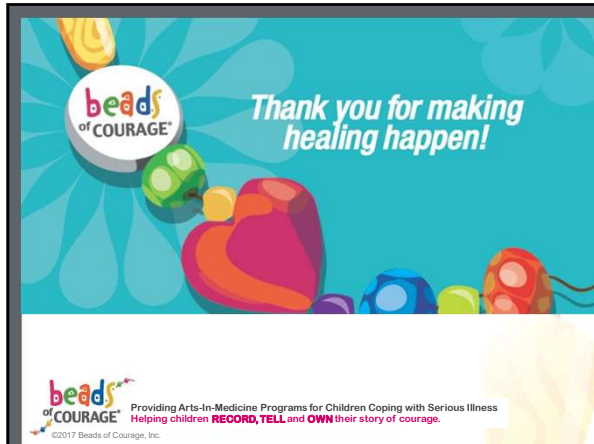
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