

I N T R O D U C I N G



## **BEADS OF COURAGE, INC.**

INNOVATIVE ARTS-IN-MEDICINE  
SUPPORTIVE CARE PROGRAMS

5301 S.Houghton Road • Tucson, Arizona • 85747 •  
[www.beadsofcourage.org](http://www.beadsofcourage.org)





## Helping Children Record, Tell and Own Their Stories of Survival

It has been an exciting 5 years for **Beads of Courage, Inc.** We are proud to be supporting over 10,000 children nationwide as well as in Japan and New Zealand. Our flagship program, Beads of Courage® is in 65+ children's hospitals and this number is growing rapidly. We now provide Beads of Courage, Inc. supportive care resources to patient populations in childhood cancer, blood disorders, heart and burn conditions. Our workshop series and Creative Courage Journal has been developed to meet the supportive care needs for the patient population who does not fit into our flagship program of Beads of Courage®.

**Mission:** Providing Arts-in-Medicine Programs for Children Coping with Serious Illnesses, their Families and the Health Care Providers who Care for Them

## Goals of Beads of Courage, Focused Research ...Why Beads of Courage?

Beads of Courage® acknowledges the child's experience with something tangible allowing restoration of their sense of self and integrity. The colored bead guide provides information and guidance and gives the child a voice to communicate their feelings along the treatment journey. It promotes positive coping by encouraging the child's active role in treatment. Our goals are to bring more joy to the bedside and alleviate suffering through the process. Beads provide a language that helps to interpret the experience and give a voice to the sufferer. Our program is also focused on the caregiver and allows the therapeutic alliance to be strengthened between patients and caregivers. As the provider of the program, the Healthcare provider is the instrument of caring and healing. It is vital to create the sacred space between provider and patient allowing the child to feel better cared for from an intentional intervention like Beads of Courage®.

## Focus for 2010 & Update

Our organization's focus over the next year is to focus on many development opportunities to successfully provide innovative Arts-in-Medicine programming to children, families and healthcare providers. Our capital campaign is in process with signature fundraisers in multiple cities. With the support of local bead artist groups and fundraising committees, our goal is to support our organizational budget as well as give back a percentage of proceeds to the local member hospitals providing Beads of Courage programming. In programming, our goals are multi-focused. With the encouragement of staff and families nationwide, we are in the process of developing two NEW Beads of Courage® programs, our NICU (Neonatal Intensive Care Unit) Program & Serious Illness Program to support children coping with neurological disorders, solid organ transplant, HIV, etc.

We are excited to formally launch our **HeARTful Reflections Workshop Series & Bead Caring for the Clinician** this year! The workshops will provide innovative programs for staff to use in their therapeutic playroom environments and during family nights or times of remembrance. Bead Caring was developed to support staff, create community among colleagues and decrease compassion fatigue. The **Beads of Courage Sibling Program** has recently changed distribution channels and will be provided directly by member hospitals or community organizations, it is also available on [www.beadsofcourage.org](http://www.beadsofcourage.org), online store.

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## Interesting facts: Why Beads?

Throughout history, in cultures across the world, beads have had a huge number of functions. Here are a few interesting facts.

### **Beads signify strength and courage**

Just like medals, ribbons and certificates, many ancient and modern-day cultures use beads to show bravery and accomplishment. They have long been used to protect warriors from natural and supernatural enemies, along with lending special magical protection for heroes during long journeys.

### **Beads have every-day uses**

They have served many practical purposes throughout history, from weighing down scrolls, saddle blankets and table cloths to serving as calculators (like the abacus) to prayer tools (like the rosary). Today, we see beads in mats, car seats, and curtains. Can you think of any ways that people use beads today?

### **Beads carry value**

Beads have been traded for everything from gold to beaver pelts, ivory to spices, and even slaves. Societies across the world have made beads from tortoise shells, wood, pottery, sea shells, seed, ivory, stone, egg shells, animal teeth, bone, claw and horn...and glass. Some of the world's most talented glass artists devote their whole careers to making beads.

### **In many societies, beads are believed to carry protective and healing powers**

Did you know that the Egyptian word sha means "luck" and sha-sha means "bead"? The Magical

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Eye bead of Turkey is believed to ward off evil. In parts of Asia, beads were scattered like seeds at temples to induce bountiful harvests.

### **Beads signify status**

In China, during the Qing (pronounced “ching”) Dynasty, officials, army officers, their wives and children were required to wear strings of court beads. The Emperor himself had to wear special beads. For the Asante people of West Africa, kings and other great people get the privilege of wearing Bodom beads. In our own society beads of pearl, gold and precious stones can be symbols of wealth and prestige.

Given the length of time people have been fascinated with beads (over 43,000 years!), as well as their usefulness for counting, adorning and symbolizing importance, they’re just right for recognizing and recording your courage as you travel this journey.



Act of Courage beads pictured to used to acknowledge specific milestones or events for all children participating in Beads of Courage!

## **Every bead tells a story of strength, honor and hope.**

### **What is the Beads of Courage® Program?**

The Program is a resilience-based intervention designed to support and strengthen the protective resources in children coping with serious illness. Through the program children tell their story using colorful beads as meaningful symbols of courage that commemorate milestones they have achieved along their unique treatment path.

### **How it works**

Upon enrollment each child is given the Beads of Courage® bead color guide with a detachable membership card. Their Beads of Courage® journey begins when each child is first given a length of string and beads that spell out their first name. Then, colorful beads, each representing a different treatment milestone are given to the child by their professional health care provider to add to their Beads of Courage collection throughout their treatment as determined by the Beads of Courage Bead Guide (available from Beads of Courage, Inc.)

There are specific Beads of Courage® Program Bead guides for cancer, cardiac conditions, burn injuries, and serious illness. All Program bead guides were developed in collaboration with experts in the field (nurses, doctors, child life specialists and social workers) so that each bead guide would reflect meaningful acknowledgment of a child’s treatment journey.

### Major benefits

Ongoing evaluation of the Beads of Courage® program indicates that the program helps to decrease illness-related distress, increase the use of positive coping strategies, helps children find meaning in illness, and restore sense of self in children coping with serious illness. The program also provides something tangible the child can use to tell about their experience during treatment and for years to come.

### Tools training support

Beads of Courage, Inc. provides all hospitals the necessary program materials accompanied by education, training and support to implement the Beads of Courage Program.

- On-site training for staff that covers research and the science behind psychosocial interventions;
- Procedure and alphabet bead collections;
- Handmade one-of-a-kind treatment milestone beads;
- Program literature (training manuals, membership bead guides and more).
- Ongoing support throughout the longevity of the program



Providing sibling support is essential during the treatment journey for families! Beads of Courage® Sibling Program allows the entire family to participate in Beads of Courage and honors those special times and milestones the sibling goes thru!

\$20 per sibling kit, available online and for distribution at member hospitals



## additional arts-in-medicine programs

### Bead Caring for the Clinician

It isn't easy being at the front lines of caring for children coping with serious illness and their families. Our founder, a pediatric oncology nurse, knows firsthand the emotional ties between a nurse and their patient and family and that is why caring for the professional caregiver is one of the central tenets of our mission. Every clinician on the team is important for helping a child with serious illness heal, experience joy, and hope. Our Bead Caring retreats for the professional health care provider are purposeful retreats that facilitate dedicated time for each clinician to reflect upon the practice and renew their spirit to keep their practice of caring strong. \*First member hospital to serve their staff in this meaningful way is Arkansas Children's Hospital.

The Beads of Courage Bead Caring Program offers 12 meditations and helpful mantras with over 50 unique symbolic beads to help the professional health care provider engage in reflection and renewal.

### Beads of Courage Siblings

At Beads of Courage, we have created a special program just for siblings to acknowledge the challenges they face when having a brother or sister who is sick. Through the Beads of Courage Sibling Program, siblings get their own collection of special beads along with a colorful program guide as symbols of support and encouragement. This program includes a Journal; 25 Trading Cards and 25 Unique Beads. Current program provided to over 5,000 siblings who have a brother or sister with cancer. Expanding program to include all siblings who have a brother or sister with a serious illness.

### Compassion and Courage, Bereavement

Beads of Courage provides every member hospital one-of-a-kind, handmade butterfly beads that are given to every parent who has experienced the loss of their child. Butterflies are well known symbols of peace and hope. Beads of Courage graciously thanks all member artists from the International Society of Glass Beadmakers' (ISGB) for their donations to maintain our Compassion and Courage Butterfly Programs.



**Strand for Strength and Remembrance Workshop** is intended for families or health care providers coping with the loss of a child.

Developed by Christy Puetz, Beads of Courage Arts in Medicine Program Director, accomplished artist, and former Museum Educator of The Bead Museum. During the workshop, the facilitator will guide each participant through a series of exercises to aid in the healing process while working with symbolic beads.

"Thank you so much for all of your help with the Beads of Courage Program. The families enjoyed it a lot! Beads of Courage helped make our ceremony a huge success." Bereavement Committee, Children's Medical Center of Dallas

### **Creative Courage Journal (CCJ), ages 8-14**

Includes a colorful, interactive journal with writing and art activities that help the child to reflect upon their accomplishments while providing a distraction from related treatments and procedures. The journal is accompanied by 25 unique beads that are distributed with their own trading card, and referred to in the journal as the bead collection. Referring clinicians will also be given a selection of handmade, one-of-a-kind glass beads to honor and acknowledge every CCJ participant during their treatment journey. These Act of Courage beads are donated to Beads of Courage by artists from around the world. There are special pages in the CCJ where each Act of Courage bead can be documented and described by your child during their treatment.

### **new in Spring/Summer 2010**

#### **HeARTful Reflections Workshop Series (new in Spring 2010)**

Beads of Courage has 5 unique workshops. Our workshops are great ways for children coping with serious illness, their parents, siblings, and caregivers to express their thoughts and any worries they might have. All workshops are unique and provide for much needed reflective, artful creation time to celebrate and honor the individual. Each workshop involves the creation of a tangible art piece that reflects each individual's creativity, ideas, fears and courage.



heARTful Reflections Workshop Series,  
strength bracelet workshop

#### **Touch for Strength for Parents (new in Summer 2010)**

Through our Touch for Strength Program Beads of Courage parents receive thoughtful words of encouragement and a tangible Touch for Strength bead. The Beads of Courage Touch for Strength Program developed for parents who have a loved one coping with a life threatening illness. The Touch for Strength Program comes with a unique touch for strength bead and a book to guide the caregiver through affirmations and touch words to be used with the Touch for Strength bead. The book includes interesting facts about beads, quotes on courage, and space for the parent to write their own affirmations.

## From the Site Coordinators and Ambassadors of Beads of Courage®...



### Describe a patient and their story as it relates to Beads of Courage®:

"When I think of each story, they blend together as a general sense of the patient's pride, that in their beads they truly represent their courage, and the beads help them appreciate themselves."  
Cynthia, Chaplain

"One of our babies finished treatment and the mom cried when we gave the purple heart. Mom would constantly bead and "re-bead" to make it "just so". Mom was happy to be able to share this with her when she was older." Karen, CCLS

"A recently diagnosed teenager was introduced to BOC and was excited to explain what each bead stood for, it was a great visual for her friends." Marlene, RN

"One patient, Hailey, was too young to remember any of her chemo or transplant. Her mother was thankful for that, but was glad Beads of Courage provided her with a way to show Hailey later in life what she went through without being connected to pain or suffering." Jennifer, RN

"We had one patient who was very proud of his beads. When Nascar driver, Carl Edwards came to visit, our patient gave him his beads to wear during the race. Carl Edwards WON the race!"  
Meghan, RN

"The beads have helped calm many of my patients' anxieties related to taking medicine, changing dressings and even getting a surgical procedure done. One patient in particular who had anxiety related to meds and compliance issues, demonstrated a rapid improvement once introduced to Beads of Courage." Jackie, RN

"I started a new diagnosed patient on BOC and brought them to him after a long day of chemo and side effects. Although he was asleep when I brought them, the look of HOPE in his mother's eyes when I gave them is something I will never forget." Dawn, RN



## **Describe your personal experience of the day to day administration of Beads of Courage®...**

"Day to day administration is easy to manage." Karen, CCLS

"Patient's always enjoy getting their beads up to date! It always puts a smile on everyone's face!"  
Marlene, RN

"It is exciting to start a patient on the Beads of Courage for the first time and see their excitement. I enjoy helping the patient get caught up with their beads and it is special to give them something when you have accessed a port or done a dressing change, etc. " Katie, RN

"Depending on the patient, my experience is different. Some patients want to receive beads one by one, each time they accomplish a "bead worthy" task, others want to receive all of the beads for the day at the "end" of the shift so they could add the beads to their necklace all at once." Jenni-fer, RN

"We try to catch our kids up on their beads for the day or night shift. It is a calm activity for them to do before they go to bed." Meghan, RN

"I love the smiles on the faces of the kids when they get all of their beads after an admission, especially if they had to get IM chemo!" Rebecca, RN

"I have seen patients and families get excited everyday about putting together their beads. It's that positive ray of sunshine in hard times. It encourages the whole family-even the siblings- to get involved." Jackie, RN

"There are days when things are hectic and beads aren't given out, but I try my best to make just as much a priority as my meds because to the kids, they are WAY more important." Dawn, RN

"I love giving out the glass beads. The kids have so much fun dumping out the box and picking that special bead for their Act of Courage." Nancy, RN

"Although PT can be challenging and sometimes painful, I like that we are able to give patients validation for their experience regardless if it was a good day or bad day." Allison, Physical Therapist

"I use the beads somewhat informally, playfully and joyfully giving beads like the "chaplain bead" to the kids. As the beads looks like a Tibetan prayer wheel, I often relate the bead to adding a prayer(s) to their string of beads." Cynthia, Chaplain



**What is an "unexpected" outcome of the Beads of Courage® program you have experienced?**

"I didn't realize how exciting BOC would be for some of the kids. They could be having the worst day where nothing you do makes them smile, but when you walk in the room with a bumpy bead or beads for that day, for one brief moment all the pain and discomfort seems to go away and suddenly a smile appears. It's very encouraging to watch!" Dawn, RN

"Parents being overwhelmed into silence when they look retrospectively at the beads-treatment- their child has gone through. It's one thing to know and say treatments, it's another to see it!" Karen, CCLS

"Even for the younger patient's, it's an encouraging program. The parents use it as a way to explain their journey when they get older." Brittany, CCLS

"Some kids are more OK with procedures when they know they get a bead afterwards!" Marlene, RN

"Teenagers (boys and girls) enjoy collecting their beads!" Katie, RN

"When BOC started I was unaware that we would have a special bead artist who would create one-of-a kind glass beads for patients and their primary nursing team. This increases the bond be-

tween patients and their nursing team-because they have the same bead.” Jennifer, RN (local artist, Robert Simmons, Atlanta, GA)

“Several of our patients have become more talkative and interactive through the Beads of Courage program.” Meghan, RN

“I think it really caught me off guard to see something tangible that represents the cancer journey. Sometimes I forget about everything the children have been through.” Rebecca, RN

“I never would have expected for the beads to have such an effect on anxiety as well as compliance issues related to taking medications. I have also seen changes in patients coping skills and confidence with active involvement in this program.” Jackie, RN

“I didn’t realize how exciting BOC would be for some of the kids. They could be having the worst day where nothing you do makes them smile, but when you walk in the room with a bumpy bead or beads for that day, for one brief moment all the pain and discomfort seems to go away and suddenly a smile appears. It’s very encouraging to watch!” Dawn, RN

## **benefits for all: Beads of Courage Cooperative Group**

Beads of Courage is proud to work with the staff at each of our member hospitals as we work together to help children with serious illness record, tell and own their stories of survival through our arts-in-medicine programs.

### **Alabama:**

Children’s Hospital at University of Alabama Birmingham (Birmingham, AL)

### **Alaska:**

The Children’s Hospital @ Providence (Anchorage, AK)

### **Arizona:**

\*Phoenix Children’s Hospital (Phoenix, AZ)  
Banner Desert Children’s Hospital (Mesa, AZ)  
St. Joseph’s Rehabilitative Center (Phoenix, AZ)

### **Arkansas:**

\*Arkansas Children’s Hospital (Little Rock, AR)

### **California:**

Cottage Children’s Hospital (Santa Barbara, CA)  
Oakland Children’s Hospital and Research Center (Oakland, CA)  
City of Hope National Cancer Center (Duarte, CA)  
Kaiser Permanente Oakland Hospital (Oakland, CA)  
Lucille Packard Children’s Hospital at Stanford (Palo Alto, CA)  
Sutter Health Sacramento (Sacramento, CA)  
University California Davis Children’s Hospital (Sacramento, CA)  
Kaiser Permanente Sacramento (Sacramento, CA)  
Kaiser Permanente Santa Clara (Santa Clara, CA)

### **Colorado:**

The Children’s Hospital (Denver, CO)  
Memorial Hospital For Children (Colorado Springs, CO)

### **Delaware:**

Al duPont Hospital for Children (Wilmington, DE)

### **District of Columbia:**

Children’s National Medical Center (Washington, DC)

### **Florida:**

Wolfson Children’s Hospital and Nemours Outpatient Clinic (Jacksonville, FL)

Disney Children's Hospital (formerly Florida Children's Hospital) (Orlando, FL)  
Nemours Outpatient Clinic (Jacksonville, FL)

**Georgia:**

Children's Healthcare of Atlanta @ Egleston (Atlanta, GA)  
Children's Healthcare of Atlanta @ Scottish Rite (Atlanta, GA)  
Backus Children's Hospital at MHUMC (Savanna, GA)

**Hawaii:**

\*Kapi'olani Medical Center for Women and Children (Honolulu, Hawaii)  
Tripler Army Medical Center (Honolulu, HI)  
Kaiser Permanente Honolulu (Honolulu, HI)

**Illinois:**

Children's Memorial Hospital (Chicago, Illinois)  
University of Chicago Comer Children's Hospital (Chicago, IL)  
Advocate Hope Children's Hospital (Chicago, IL)  
Central DuPage Hospital/Children's Memorial ( Winfield, IL)

**Louisiana:**

Children's Hospital (New Orleans, LA)

**Michigan:**

Children's Hospital of Michigan (Detroit, MI)

**Minnesota:**

Children's Hospitals and Clinics of Minnesota (Minneapolis/St.Paul MN)  
\*University of Minnesota Children's Hospital (Minneapolis, MN)

**Montana:**

Billings Pediatric Oncology Clinic (Billings, Montana)

**Nevada:**

Washoe Medical Center (Reno, NV)

**New Mexico:**

University of New Mexico Children's Hospital (Albuquerque, NM)

**New York:**

Albany Medical Center (Albany, NY)  
The Children's Hospital at Montefiore (Bronx, NY)  
Morgan Stanley Children's Hospital (New York, NY)  
Hassenfeld Children's Center for Cancer and Blood Disorders (New York, NY )  
Stony Brook University Medical Center (Stony Brook, NY)

**North Carolina:**

Pitt County Memorial Children's Hospital of Eastern Carolina (Greenville, NC)  
Duke University Children's Hospital (Durham, NC)

**Ohio:**

Cincinnati Children's Hospital

**Oklahoma:**

Children's Hospital at Saint Francis (Tulsa, OK)

**Pennsylvania:**

\*Children's Hospital of Pittsburgh (Pittsburgh, PA)  
\*Children's Hospital of Philadelphia (Philadelphia, PA)

**Tennessee:**

LeBonheur Children's Hospital (Memphis, TN)

**Texas:**

Medical City Children's Hospital (Dallas, TX)  
Dell Children's Hospital (Austin, TX)  
Christus Santa Rosa Children's Hospital (San Antonio, TX)  
University of Texas MD Anderson Cancer Center (Houston, TX)  
\*Children's Medical Center Dallas (Dallas, TX)

Children's Hospital at Providence (El Paso, TX)

**Washington:**

Seattle Children's Hospital (Seattle, WA)

**West Virginia:**

Charleston Area Medical Center Women and Children's Hospital (Charleston, WV)

**Wisconsin:**

Children's Hospital of Wisconsin (Milwaukee, WI)

**International Sites:**

**Japan:**

Ibaraki Children's Hospital (Ibaraki, Japan)

**New Zealand:**

Wellington Hospital (Wellington South, NZ)

Children's Hematology Oncology Centre Christchurch Hospital (New Zealand)

Starship Children's Hospital (Auckland, NZ)

**\*more than one Beads of Courage Program**

**CONTACT**

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Executive Director

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Founder of the Beads of Courage Program and Executive Director of Beads of Courage, Inc. Former positions: Staff Nurse and Research Senior Nurse at University of Arizona. Education: University of Arizona College of Nursing, BSN 1997, Doctoral Candidate in Nursing.

**Colin Smith, RN BSN, CPON**

Program Director

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Colin is a passionate nurse, spending her career in pediatric hematology/oncology nursing at Children's Healthcare of Atlanta. She brings a strong knowledge base of the clinical setting as well as the vital need to integrate supportive care programs for children battling serious illness. Education: Georgia Baptist College of Nursing, BSN 2000. Previous Board member of CURE Childhood Cancer, Atlanta Georgia.

**Christy Puetz, BFA**

Arts-in-Medicine Program Director and Artist-in-Resident

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Christy loves beads and the stories they tell. She has exhibited her beaded sculptural artwork around the country since 1990. Education: University of North Dakota, Bachelor of Fine Arts with Fiber Art focus. She is the past Museum Educator for the Bead Museum. Christy is driven to create programming that will encourage, honor, and help the healing process for kids and families coping with serious illness.

**Elizabeth McPeak, MPH**

Program Manager, Creative Courage Journal Program

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Liz is a graduate from the University of Michigan. She has held positions in various areas of the health field from managing clinical trials in cancer to overseeing a governmental Women, Infants, and Children's center. She has extensive medical knowledge and experience in many aspects of working in the medical non-profit sector from grant writing to management.