

# CHILD LIFE COUNCIL Bulletin



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## Jerriann Wilson, CCLS: In Appreciation

*Gratefully submitted by Chris Brown, MS, CCLS; Director of Child Life and Education, Children's Hospital of Philadelphia*

The child life profession owes a tremendous debt of gratitude to Jerriann Myers Wilson, long-time director of the Child Life Department at Johns Hopkins Children's Center. As Jerriann prepares to retire from her illustrious career, we collectively thank her for her commitment, dedication, and countless contributions that have helped to shape the profession.

Upon graduating from Goucher College in Towson, Maryland in 1962, Jerriann was hired as a child life instructor at Johns Hopkins Hospital where she provided recreational activities on the medical unit. Soon Jerriann was coordinating child life training for practicum students and nursing students. In 1965, Jerriann established the first child life program at Baltimore City Hospital. After serving as Director there for five years and earning her Master of Education at Loyola College, she returned to Hopkins as Associate Director and internship program coordinator. Since assuming the Director's position in 1972, Jerriann has served as leader, mentor, and innovator, to create and maintain one of the strongest and most respected child life programs anywhere. For over thirty years in this role, Jerriann has earned the highest respect and admiration of her staff, students, colleagues, administrators, members of the interdisciplinary team, patients, and families.

Many of the activities that are commonplace for child life specialists today were first explored by the staff at Hopkins. Medical play, outpatient and Emergency Department coverage, infant interventions, and closed circuit television programming were all initiated or further developed under Jerriann's supportive and innovative leadership. In addition, the Hopkins child life training program has long attracted the best of the best, and serves as a model for virtually all other training programs.

Jerriann's remarkable leadership skills made her the natural choice as the first President of Child Life Council in 1982, and her contributions as leader, presenter, and author have enhanced the success of CLC in countless ways ever since. Jerriann was instrumental in the establishment of the Child Life Professional Certification Program, in the incorporation of Child Life Council as an independent organization, and in the ongoing professionalization of the field. As past President and always active member



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## Evidence Supporting the COPE Program: Research Review

*Joan Turner, PhD, CCLS, Assistant Professor, Child and Youth Study, Mount Saint Vincent University, Halifax, Nova Scotia, Canada*

Mazurek, B. M., Alpert-Gillis, L., Fischbeck, N., Feinstein, F., Crean, H. F., Johnson, J., Fairbanks, E., Small, L., Rubenstein, J., Slota, M., and Corbo-Richert, B. (2004). Creating Opportunities for Parent Empowerment: Program Effects on the Mental Health/Coping Outcomes of Critically Ill Children and Their Mothers. *Pediatrics*, 113 (6), e597. Retrieved from <http://www.pediatrics.org/cgi/content/full/113/6/e597>

Mazurek et al. (2004) present a randomized, controlled trial evaluating the effects of a program designed to impact mental health and psychosocial outcomes of critically ill young children and their mothers. This article is one of many evaluating the *Creating Opportunities for Parent Empowerment* (COPE) intervention program and is an example of a systematic program of research from an interdisciplinary research team. Early publications from the lead author, Bernadette Melnyk Mazurek, have resulted in a series of published studies that include clear theoretical

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## PRESIDENT'S S.O.A.P. BOX

### Dreaming of a Better Tomorrow

Randall McKeeman, MS Ed, CCLS

I dare to dream big, beautiful dreams. I hope that you dream big, too. My dream for child life is that there would be a child life specialist (at least one) in every hospital. I am not thinking of just children's hospitals, but every hospital. Surely there is enough work in any hospital for a CCLS to do. Children and grandchildren are visiting their parents or grandparents every day. Do they know what to expect? Can they process the whole event? Do they have worries and fears before or after visiting?

I dream that every child will meet a child life specialist at some point in his/her life – in the hospital, in the community, in school, in a refugee camp, or in his/her home. We have knowledge and skills to help all children in all these venues.

What are your dreams? Can you express them to your peers and supervisors, to your

friends and family, to your administrators and benefactors? We need dreams and we need to share them. Dreams are powerful and the most powerful dreams are shared by many. Dr. Martin Luther King, Jr. taught us the value of dreams, and he had the opportunity to express his dreams to the world. In so doing, he rallied the faithful and the willing to his vision. Every group and every organization needs dreamers and dreams.

To dream is the first step of a multitude of steps. At some point in the past, child life specialists dreamed of a day when they could meet with other child life professionals from across the region, across the continent and around the world — just as we do every year now. Their dreams did come to reality and ours can come to reality, too, by sharing the dreams and by working together to make them so.

The power of our organization comes from

sharing the dream and putting in the work to create a new reality. It is always such a joy for me to meet with child life professionals formally and informally to see where our dreams will take us. For me, the joy of working on the Board of CLC is that I get to be in the “dream center.” The membership speaks its wishes and vision for a better profession, and we get to channel the resources and energy to create the support for the emerging vision. I love the feeling of the creative energy. As you know, growing can be painful and full of friction. Frustration and worry are part of the process, as well.

Any of us can fall into the trap of the day-to-day, hour-to-hour survival mode. We get stuck in the quicksand of the immediate need. Important as those needs may be, if we lose sight of the big picture, we will lose our way. I hope that you will take the opportunity to join with child life professionals locally, nationally, internationally or online. I hope that you will gain an appreciation of the power of joining together with shared dreams. I hope you will join in the work to make a better tomorrow for children and families, for hospitals and communities, for groups and organizations who share your dreams. I hope that you will work with CLC to support our vision as we create a better tomorrow.

### In Appreciation

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of the Association for the Care of Children's Health (ACCH), Jerriann was an effective advocate for family-centered care. She helped to establish strong relations with organizations such as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and the American Academy of Pediatrics (AAP), serving many years first as ACCH's and then CLC's representative to the AAP's Committee on Hospital Care. Jerriann was awarded CLC's highest honor, the Distinguished Service Award, in 1992.

It is safe to say that nearly every child life specialist, trainer or manager practicing today has been touched in some way by Jerriann, either personally or indirectly. Those who meet her, even once, are influenced by her inimitable grace and generosity of spirit.

While Jerriann is surely looking forward to

joining her dear husband Don in their favorite pastimes of traveling and bird watching, leaving the job that she has performed so admirably for 43 years must be more than a little bittersweet. Jerriann so clearly loves

the profession she has made her life's work and the people she has encountered along the way. We love you, too, Jerriann, and hope we'll be seeing you at child life functions for many years to come!

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## FROM THE EXECUTIVE DIRECTOR

### Special Task Force Improves *Bulletin*

Susan Krug, CMP, CAE

Many of our members have expressed positive feedback regarding the new look and improved content featured in the *Bulletin* and *Focus*. CLC staff and the Bulletin Task Force have worked together over the past year to update one of the most important and valued benefits of CLC membership.

A task force meeting was held in September to outline a strategic plan for this publication. Members who joined me at this meeting included fellow staff member Amy Jackson, Manager of Membership Services and *Bulletin* Managing Editor, Jane Darch - Task Force Committee Chair (and former Editor), Karin Dugan - *Bulletin* Executive Editor and Chair - *Bulletin* Committee, Kathleen Murphey - *Focus* Reviewer, Peggy Jessee - *Focus* Reviewer, Kathy Payette - Board Liaison to the Bulletin Committee, and Erin Munn - President-Elect of the CLC Board. First, the task force created a mission statement for the *Bulletin*. Child Life Council's *Bulletin/Child Life Focus* is the foremost professional resource focusing on the unique knowledge and skills of the child life community. The group then brainstormed, resulting in a streamlined *Bulletin/Focus* production process, a new committee structure, goals for creating written *Bulletin* policies and procedures, updated *Bulletin* and *Focus* submission guidelines, archiving key data on past issues, and responding strategically to the profession's need for increased clinical child life content.

This targeted improvement project was created in response to feedback on the *Bulletin* in member surveys, and serves as a great example of how volunteer leaders and staff can collaborate to bring more value and improved products and services to CLC members and the child life profession. But creating the mission and plan was just the beginning. Staff is working with the Bulletin Committee to implement the strategies and tactics outlined in the plan. Since the task force meeting, its members and staff have been hard at work to achieve these goals for CLC membership. In March, the Board approved professional

*Bulletin* and *Focus* submission guidelines, and a new education piece, entitled "Writing for CLC *Bulletin/Focus*," which can be downloaded from the CLC Web site from the Book Store and Members Only sections. The fresh new design for the *Bulletin* was launched with the Spring 05 issue, and with this Summer 05 issue, the *Focus* has now doubled in size, from four pages to eight pages of clinical content!

I continue to be amazed and inspired by our members who devote their precious time to further the professionalism of child life. I am also proud of the CLC staff, and the role they play in providing support to our volunteers. Amy Jackson has been instrumental in providing outstanding skills and expertise, particularly in regard to *Bulletin* improvements.

Please continue to participate in the *Bulletin* Feedback Surveys for each issue! We are also using feedback from member surveys and the CLC Forum to develop content and to solicit writers who have expertise on particular topics that are of interest to our readers. The Bulletin Committee is working with Amy to look at other fields that complement child life and could add to the knowledge base of

our community, along with prioritizing the solicitation of new content based on what CLC has heard from its members. We have added an Ethical Practice in Child Life column, a Featured Journal Article column, and a Tips and Lifesavers column, and the Evidence-Based Practice Committee is providing an article for each issue as well. The Bulletin Committee will continue to look for new ways to obtain more advanced level content and to work with the expertise of both child life professionals and professionals who complement the child life field.

We hope that more CLC members will volunteer to serve on the Bulletin Committee. We welcome program directors/leaders, educators, and other representatives of the CLC membership (one person programs, alternative settings, diverse types of facilities) to apply. We also encourage authors to download the new submission guidelines and Writing for the CLC *Bulletin/Focus*, and submit their professional clinical articles. Also, if you have had an evidence-based article printed in a professional journal, please contact Amy Jackson at membership@childlife.org, for reprint consideration. The *Bulletin* is your professional clinical newsletter, and it takes the efforts of all of us to make it the best it can be.



#### Child Life Council *Bulletin/FOCUS*

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## COPE Program

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and design rationales and explanations of results. Readers are encouraged to conduct a literature search of Mazurek's work (e.g., MEDLINE) or access back references, as each article builds on the previous work, resulting in a comprehensive overview of the ongoing development and evaluation of the current program.

The COPE program is derived from principles of self-regulation theory, control theory and emotional contagion theory to enhance coping outcomes through reducing the transmission of maternal anxiety to her critically ill young children. Parent-focused interventions included, first, the provision of behavioral information related to typical responses of children to hospitalization and illness to assist mothers in the anticipation of their child's needs; and second, instruction and practice in parenting behaviors specific to healthcare situations to increase mothers' confidence and role certainty. Two components were emphasized in the program: i) increased parent knowledge and understanding of child behavior and emotions both during and following hospitalization for critical illness, and ii) increased participation in both physical and emotional care of their child.

The educational-behavioral intervention was delivered in three phases. Phase I was initiated within 6 to 16 hours after admission of the child to the PICU; Phase II was initiated within 2 to 16 hours following transfer to the ward; and Phase III was initiated within 2–3 days following discharge. These follow-up phases were designed as 'booster' interventions to reinforce the previous information and were delivered in both taped and written formats, and expressive and therapeutic parent-child activity workbooks. The content of these components are of interest to child life specialists who may already provide a range of parent-child interventions and materials.

The control group experienced parallel interventions during three phases that also included 'booster' interventions; however, the content was limited to the services and policies of the PICU and non-hospital-related parent-child activities.

This study evaluates the COPE program in

the pediatric intensive care unit and follows patients after transfer to the ward and discharge. A convenience sample of subjects (mothers and their children) from two study sites was randomized into either a COPE program group (N = 87) or a control group (N = 76). Additional controls included efforts to reduce contamination across subject groups, and extensive inclusion and exclusion criteria. Data were collected at 9 points, including follow-up assessments at 1, 3, 5, and 12 months following discharge from the hospital.

Experimental designs require that the intervention and control groups are compared in terms of the scores on a range of outcome measures (dependent variables). Mazurek et al. (2004) clearly describe each measure. Examples of dependent variables include: state anxiety, negative mood state, involvement in physical care, involvement in emotional care, parental beliefs, and child adjustment related to post-hospital stress and child behavior. Additionally, manipulation checks were conducted on both the intervention and the control group to assess mothers for evidence of processing the information provided at each phase. The measurement schedule across follow-up points is clearly presented in table form in the article.

Equivalency of groups is a characteristic important for the internal validity of an experimental design. Analysis of the baseline characteristics of the mothers and children in the intervention and control groups indicated that statistical control (analysis of covariance) was required on some background variables (gender of the child, type of admission, use of restraints, and fathers' level of education) to help ensure the equivalency of the groups at the start of the study. However, attrition of subjects progressed at each follow-up assessment and posed a threat to internal validity. The authors report an attrition rate of 58.2% by year one of the study; therefore loss to follow-up was identified as a major limitation of the study.

Hypotheses clearly stated at the beginning of the paper were followed-up with a systematic review of the results. Data are presented in tables and figures, as well as reported in the text. A number of statistically significant positive effects were noted for the mothers in the intervention group on self-report measures, compared to the mothers in the control group. Some examples of interest include: less stress regarding communication with

staff, less total stress on the Parental Stressor Scale post PICU, and less stress of specific subscales related to appearance of child, children's procedures, and children's behaviors and emotions. Staff, blind to the intervention and control group status, rated intervention mothers as more involved in both the physical and emotional care of their child on the ward compared to the mothers in the control group.

Significant results related to child adjustment include fewer behavioral symptoms reported 12 months post-discharge by mothers in the intervention group, compared to mothers in the control group. Additionally, 25.9% of the children in the control group had clinically significant behavioral symptoms compared to the children in the intervention group (2.3%) one year after discharge. Mothers in the intervention group reported fewer child withdrawal symptoms at the 6-month follow-up and fewer child externalizing problems (12-month follow-up), and higher scores on child adaptability (12-month follow-up) compared to reports of the mothers in the control group. The authors noted a number of additional trends too lengthy to report here.

Mazurek et al. (2004) conclude that the study supported the COPE program as an intervention to improve mental health/psychosocial outcomes in mothers of children hospitalized for a chronic illness. They identify the provision of 'cognitive schema' as an important factor influencing mothers' knowledge and understanding of their children's behavior and emotions. This, in turn, was said to influence mother's beliefs and ability to cope at various points of their children's recovery, up to 12 months post-discharge.

This study contributes to the body of knowledge required for exemplary child life practice. First, it serves as a potential model for the systematic application of an intervention program that includes components that are not foreign in current child life practice. Further, it serves as a model for the application of an experimental design emphasizing attention to the importance of randomization, control and follow-up. And finally, this article may serve to update the reference pages of future reading lists and publications with a current citation related to the short and long-term effects of hospitalization on children and families and interventions designed to improve psychosocial outcomes.



## Collaboration Between Nursing and Child Life

Reprinted from *Journal of Pediatric Nursing*, V18(5): Erica Hasenfuss, RN, BSN and Angela Franceschi, MS, CLS, Children's Hospital Boston, MA, "Collaboration of Nursing and Child Life: A Palette of Professional Practice," pp. 359-365, © (2003), with permission from Elsevier.

**ABSTRACT:** This evidence-based practice (EBP) article begins with a case study background. Case studies can be used to illustrate the unfolding of nursing process, from assessment to re-assessment, for particular patient care situations. The evidence-based process, and its importance for successful clinical outcomes, is explicated after the case study presentation. This is an example of how EBP is an integral part of what we do as health care professionals: When we are faced with clinical dilemmas, evidence-based tools are there to guide us to solutions. In this example, Child Life and Nursing worked collaboratively to identify key clinical issues. They consulted with clinical experts within the hospital, and they used scientific rationale to select therapeutic interventions to support a patient and her family through several crisis situations. The EBP tools, seeking clinical expertise and applying research-based interventions, resulted in successful outcomes for a complex patient care situation. Maura MacPhee, RN, PhD, Clinical Column Editor

### CASE STUDY BACKGROUND

Prior to Sally's admission, she was a healthy, developmentally appropriate 7 year-old with no previous medical problems. Two days prior to her admission, Sally began complaining of right leg pain. She had difficulty weight bearing, and she began developing swelling and erythema around the calf. She was seen by her primary care provider and referred to a local hospital where a work-up was initiated. It appeared to be compartment syndrome, but she became hemodynamically unstable and was transferred to Children's Hospital Boston (CHB) for further evaluation.

Sally required an emergent surgical resection of her right leg for necrotizing fasciitis: 60% of the muscle mass was removed. After the operation, Sally was transferred to the medical-surgical critical care unit (MICU). Sally's family was in shock from the rapid onset of events, but they were also overwhelmed by the tentative diagnosis: Necrotizing fasciitis is often secondary to a *Streptococcus* Group A infection, and another family member had recently died from similar infectious complications.

### THE MICU

During the first week in the MICU, the critical care environment created additional stressors for Sally and her family. A psychological consultation was requested by nursing staff, and nursing also asked Child Life (CL) to make daily visits to Sally's bedside.

The Child Life Specialist walked into a room with a small child laden down with tubes and monitors everywhere. The

mother was weeping at the bedside. Normally, CL would do an informal coping assessment to ascertain coping strengths and weaknesses for the child and the family, but in this instance, the therapist was challenged to respond to the immediacy of the child's and the mother's distress: "What is one thing to do to help make this situation easier?" CL drew upon a common technique that is often used to help de-escalate stressful situations and to focus in a calmer manner: The patient and her mother were encouraged to take some deep breaths. When the mother was less anxious, it was possible for CL to talk with her about her perceptions of the situation and her child's needs.

The mother was able to identify the MICU noises as a source of distress and confusion. It was also possible to talk with the child and confirm her fear of all the unfamiliar noises. Based on feedback from Sally and her mother, CL tried to create a calming environment with music and other distraction techniques. Initial, small successes were necessary to win the trust of the child and the family.

During a seven day stay in the MICU, CL and Nursing were faced with other, notable clinical challenges: a) The mother was always at Sally's bedside. Sally was acutely sensitive to her mother's behavior and would become agitated if her mother was emotionally upset; b) The constant stream of different medical and surgical faces was confusing and disorienting to the child and the mother; and c) Sally was being barraged by invasive, painful procedures on a frequent basis. Despite

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## Collaboration

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Nursing's and CL's awareness of these significant problems, the critical condition of the child pre-empted opportunities to provide consistent, therapeutic interventions.

### THE ORTHOPEDIC SURGICAL UNIT

After medical-surgical stabilization, Sally was transferred to the orthopedic surgical unit, 10 Northwest (10NW). Although Sally had a private room with less traffic and noise, the possibility of a leg amputation was still a factor which maintained the family's high level of anxiety. In addition, Sally had to undergo daily dressing changes at her bedside. It was apparent to Nursing and CL that early and aggressive interventions were necessary to avert further stress to the child and her family. Some of the key features of a collaborative care plan that were negotiated between CL, Nursing, Sally (when appropriate), and her mother:

**Education.** The mother's sense of control was based on her knowledge of the situation—the pros and cons. Sitting down with the mother in a neutral environment provided the staff with an opportunity to give the mother simple, concrete facts for her to process. This time was also used to help the mother identify child-friendly ways to talk with Sally about the equipment, the procedures, her status, et cetera.

**CL as a "safe" person.** Sally had special nurse favorites, but she also identified the nursing staff with invasive procedures. A primary CL specialist was assigned to make regular visits to do therapeutic play with Sally. This CL specialist was also committed to being present during traumatic procedures, such as the daily dressing changes.

**Giving control to Sally.** In the nursing care plan, all the nursing staff working with Sally were to pause before doing any procedure or intervention with Sally and offer a choice, even a simple choice. "Before you act, think about a choice and offer it to Sally. Do you want the blood pressure cuff on your right arm or your left arm?"

These interventions seemed to help, but Sally's healing process was excruciatingly slow, and she began to act out during her dressing changes. She would scream through the whole procedure and become belligerent.

It was impossible for Nursing to accurately assess Sally's pain. The mother and staff, including CL, were intimidated by this behavior. Although initial progress had been made by CL and Nursing, Sally seemed to regress with each daily dressing change. Sally's primary nurse and her CL met to re-evaluate the care plan and to re-strategize. They recruited the aid of the Pain Team Service and the psychologist. The mother also worked with members of this interdisciplinary team to address Sally's behavioral outbursts during dressing changes.

Child Life used play therapy to discover that Sally was especially fearful of tape removal. Tape removal pads were given to Sally, and she was allowed to help remove her dressings, giving her a sense of control over her greatest fear. Child Life and Nursing also identified Sally's unique language for tape, procedures, and other sources of her fear and pain. For instance, she wanted to know when there would be "new owies," her expression for tape being used. Given her age, she understood more about what was going to happen when professional staff used Sally's own language.

Another successful coping intervention included "time-out" coupons during procedures: Psychology implemented this strategy. Sally was given 3 coupons per procedure. Each coupon was worth 2 minutes. She could use a coupon for a "time-out" as needed. After a while, she depended on the coupons less and less: Her familiarity with

the procedures helped her cope with the situation without the need for breaks.

Sally also enjoyed the CL "coping kit," filled with sundry toys and distractors. She especially enjoyed doing medical play to act out what the procedures would be like. Nursing found that Sally's outbursts could be better managed with incentive charts and sticker rewards that could be frequently exchanged for prizes. The mother was instrumental in consistently encouraging and rewarding Sally with stickers and small prizes. Table 1 summarizes the key coping strategies used for dressing changes.

Due to slow healing, a surgical/medical decision was made to try vacuum assisted therapy (VAC)<sup>®</sup> <http://www.kci1.com/products/VAC>. This therapy promotes the formation of granulation tissue and helps to close large wounds by applying negative pressure to the site. The system also removes interstitial fluid and infectious materials from the tissue. VAC therapy prepared the way for skin grafting procedures. After discontinuation of the VAC, the next hurdle for staff, Sally, and her family was a split thickness skin graft procedure from her right buttock. Post-procedure would require more dressing changes and treatment with a heat lamp four times daily.

In addition to tried-and-true coping techniques, the heat lamp and dressing routine became incorporated into "At the Beach" activities. The heat lamp became "the sun." Beach props were set out, such as beach towels, toys, and balls. Sally wore a beach hat, and her mother would use this time to paint Sally's toenails or do some other, fun, primping activity. This worked for Sally, her mother, and the staff.

Sally's greatest progress was made when she was stable enough to go to the activity room. She loved doing arts and crafts, and this was a safe place where she could be a "kid first." Child Life helped Sally make an "All About Me" book with her craft work and pictures devoted to topics such as, "What is it like being here?" "What's best about the hospital?"

### DISCHARGE HOME

Fifty-six days post-admission, Sally was ready to go home. To prepare for discharge, a care conference was held to help the family identify their special needs and issues. Social Services, CL, and Nursing worked with the

Table 1. New coping interventions

### INTERVENTIONS

- Incentive chart (CL, Nursing)
- Family-centered schedule (Nursing, CL)
- Time-out coupons (Psychology)
- Special language (Nursing, CL)
- Consistency (Nursing, CL)
- Coping kit with distractors, play therapy (CL)
- Incorporating mother into distraction tasks (Nursing, CL)
- Pre-medication for all procedures (Nursing)
- Age-appropriate pain scale to guide interventions (Nursing, CL)

mother on a daily basis for two weeks before discharge to discuss the home routine for Sally and the other family members. The mother had a chance to go home and even “rehearse” some of her new routines to identify potential problems prior to discharge. Nursing slowly increased mother’s participation in Sally’s care. By discharge, Sally’s mother was able to independently do Sally’s dressing changes. She was also taught how to assess Sally’s pain using a standardized scale and Sally’s verbal and nonverbal cues.

Sally was discharged home, walking with assistance and wearing a knee immobilizer at night to help correct remaining contractures. She continues to visit the hospital, the impatient nurses, and Child Life staff during her outpatient appointments. The mother also stays in touch via phone. She recently expressed her concern over Sally’s adaptation to her leg’s appearance—especially with summer coming—and real beach time. Sally’s mother was worried about her child’s reaction to leg wounds and scars. She called the nurses to say that Sally had come up with a solution on her own: “It’s what makes me unique.”

## THE EVIDENCE-BASED PROCESS

Hallmarks of EBP are best evidence from benchmarking and from the literature. In this patient care scenario, benchmarking was an internal, interdisciplinary endeavor. Nursing and CL canvassed opinions from clinical experts within the institution, and coping interventions were styled from input by the Pain Team Service, Medicine, Surgery, a host of nurses with wound care experience (enterostomal nursing, the Burn unit), and other CL specialists. Expert advice was substantiated by the research literature on key topics such as coping strategies for the hospitalized child and family-centered involvement.

The critical professional collaboration for Sally and her family was the liaison of Nursing with CL. The primary nurse and CL shared several complimentary responsibilities, such as parent and child education, family-centered planning and advocacy, and therapeutic “efficiency.” In this latter case, interdisciplinary cooperation between Nursing and CL aided each others’ assessments and management of Sally’s and her mothers’ needs.

Child Life and Nursing employed a Child Life-based model where the central premise is

that children in stressful circumstances require continuous and consistent developmentally appropriate support. With this special tutelage, a child can learn to understand and to cope better in stressful situations. This kind of learning serves as an “inoculation” against health care experiences, and a child can emerge as more resilient and actively involved in the care setting (Bolig & Weddle, 1988). This Child Life model was specifically tested in 1983 at Phoenix Children’s Hospital. Medical and psychosocial outcomes were compared for patients receiving therapeutic CL interventions versus patients receiving traditional hospital care. Children in the experimental group scored significantly better on psychosocial measures, such as exhibiting less distress, expressing better understanding of hospital procedures, and showing better adjustment 10 days post-discharge. Parents of the study children reported



that their children recovered more rapidly with less emotional upset than parents of children in the control group (Wolfer, Gaynard, & Goldberger, 1988).

There are three major steps to the model: a) preparation, b) rehearsal, and c) support (Blaine, 1999). Whenever time permits, some preparation time should be allowed to educate or explain to the child and parent what is going to happen. Based on the specific coping strategies that work best for child and parent, rehearsal time with the coping skill before a stressful event results in better outcomes. Support can include the



physical and emotional presence of a health care professional, such as a nurse and/or CL, but it also entails the right props. Pre-made “coping kits” should contain age-appropriate materials as outlined in Table 2 (Blaine, 1999; Mills, 1996). See Figure 1 for a photograph of Sally’s coping kit.

Approximately one month after CL and Nursing concerted used this model, Sally and her mother finally began verbalizing a sense of trust. The best evidence of a true therapeutic relationship was Sally’s willingness to rate her pain and to actively engage in the coping strategies.

## EVALUATION OF THE EVIDENCE

Based on review of this complex case, CL and Nursing identified some key components to success that are also reinforced by research evidence. Those key components included a respect for Sally’s underlying personality, parental support, and assessment/continual re-assessment of what was working or not working.

### SALLY’S PERSONALITY

Although Sally’s outbursts were distressing, they were, perhaps, personality markers of her coping style—a style that may have benefited her. Pain research has shown that children who exhibit more active behavior during invasive procedures significantly rate these procedures as less painful than children who cope passively. Active behavior may function as a type of distractor (Broome, Lillis, McGahee, & Bates, 1992).

### PARENTAL SUPPORT

The presence of a parent or familiar adult can make a significant, positive difference for children in the hospital, but as was true for Sally’s mother, it is often hard for parents to see their children in pain and/or undergoing painful procedures. Children sense their parents’ emotional discomfort, and it is important for parents to know how to talk calmly to the child, how to touch reassuringly, and how to maintain eye contact during procedures (Stuber, Christakis, Houskamp, & Kazak, 1996). Child life specialists have been trained to help parents accomplish these tasks, as well as providing them with a vocabulary that will help concretely and honestly describe procedures so that they resemble other, familiar tasks that a child has already mastered (Goldberger, et. al, 1990).

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# Collaboration

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In Sally's case, CL and nursing were able to provide mother with emotional support and educational tools to help her (and Sally) better master the hospital regimen. In addition, nursing and CL learned Sally's special vocabulary and incorporated these terms into daily care discussions with the mother. These terms became reflexively used by staff and mother so that Sally had more comfort with what was being said to her and about her.

## CONTINUAL ASSESSMENT AND RE-ASSESSMENT

The "right way" to cope with hospitalization and invasive procedures is very child-parent specific. It is necessary to systematically assess coping styles and coping strategies (Barkey & Stephens, 2000). Sometimes what works best will only emerge when a child and parent are given multiple coping strategies from which to choose (Stephens, Barkey, & Hall, 1999; Wolfer, Gaynard, & Goldberger, 1988). In Sally's case, some of the dressing change options/strategies explored with her included: a) to watch or not to watch, b) to have someone with her—parent, CL, nursing, c) to pick something nice to think about, such as the beach, d) to give stop/start signals and timeouts, e) to sing a song, do a spelling bee, get a pedicure.

Distraction is known to decrease the pain response (Sparks, 2001). Sparks conducted a quasi-experimental study with 105 children ages 4 to 6 years receiving DPT immunizations. She compared two different distraction techniques for efficacy in reducing response to pain: touch versus bubble blowing. Both types of distraction were significantly able to reduce pain responses in comparison to a standard treatment control group. Sparks concluded that the type of distractor may be less important than providing a

child with some type of age-appropriate distraction. When children are allowed choices, this may also increase their sense of control over a scary situation. Distractors also work because they are usually simple and easy to perform. The child and a parent can be taught to do them, and this heightens their sense of self-efficacy (Sparks, 2001). For Sally and her mother, Nursing and CL had to regularly stop and re-examine the care regimen and "invent" some new distraction techniques to lighten things up for Sally and her mother.

Evidence of success was the ultimate conversion of Sally's room into a beach scene with a child in 'shades' smiling back.

## CLINICAL IMPLICATIONS

In children's and families' everyday encounters with our health care system, our challenge is to follow the precepts provided by this article: a) know the child and family, b) use time efficiently to prepare, rehearse, and support the child and family with a variety of coping strategies. There are multiple, developmentally appropriate distraction techniques that are easy to use and will probably make a big difference in outcomes. One health care

professional, however, cannot do it all. Collaboration among disciplines, particularly between CL and Nursing, can enhance the process of assessing and re-assessing how the family and the child are coping in our health care world.

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Table 2: Coping Kit Items

ITEMS	DEVELOPMENTAL AGE
Pacifiers, rattles, lullaby music, mobiles	Infant
Novel toys—rain sticks and gyroscopes	Toddler
Bubbles	
Pompoms	
Pop-up books	
Bubbles	Preschoolers
Magic wands	
Band-aids®	
Feathers	
Seek and find/flap-up books	
Playdoh®	
Action figures	
Imagery aids	School-age
Bubbles	
Books: I Spy	
Story Tapes	
Video games	
Stickers	
Sand/water timers	
Relaxation tapes	Adolescents
Massage	
Stress Balls	

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# Bridging the Gap: Education Services Within the Scope of a Child Life Program

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## INTRODUCTION / HISTORY

Each year in this country, approximately six million children ranging from newborn to seventeen years old are hospitalized for a variety of conditions ([www.ahrq.gov/data/hcup/factbk4/factbk4.htm](http://www.ahrq.gov/data/hcup/factbk4/factbk4.htm)). Many children who frequent our hospitals have chronic conditions. The estimated number of children in the US with a chronic illness ranges from 13.7% to 17% (Stein, R.E.K., Silver, E.J., 2002). This article will focus on the education of children with chronic conditions, also known as Children with Special Health Care Needs (CSHCN). While children with special health care needs comprised nearly 20 percent of all children in 2002, these children accounted for 45 percent of the total expenditures for all children's health care (Source: Agency for Healthcare Research and Quality, MEPS Statistical Brief #75: *Access to Needed Medical Care Among Children Under 18 Years of Age With Special Health Care Needs: 2002*).

In July, 1980, a major investigation was begun at Vanderbilt University to address the needs of chronically ill children and their families. The Vanderbilt study included children with 11 specific chronic diseases and disorders. This landmark study identified many gaps in service, some of which specifically related to the children's education: poor communication between healthcare providers and school staff, lack of information on specific illnesses for staff when children returned to school, frequent and/or intermittent absenteeism, inadequate home instruction, lack of educational support, poor identification of special learning needs, and a general lack of educational service coordination. (Hobbs, Nicholas, Ireys, Henry, Perrin, James, 1983). These gaps in educational services exist for children with many other chronic conditions (Kleinberg, 1982).

More recently, national attention has focused on the value of linking health and education services to improve the well-being of children and families. According to a study done by

the National Association of Children's Hospitals and Related Institutions (NACHRI), 70 of 74 of the hospitals that responded reported that they have partnerships with schools (2001). The American Academy of Pediatrics (AAP) has issued several policy statements on the education of Children with Special Health Care Needs, all of them calling for physician attention to the educational needs of their patients.

## WHY SCHOOL SERVICES IN THE HOSPITAL?

The idea for hospital school programs is not new. As far back as 1959, Emma Plank stated, "Learning takes on a very different meaning when a child is hospitalized. Going to school in the hospital can be a link to the past and the future. It reassures a child that his parents, his home, school, and the hospital staff all work together and believe in getting well" (1959, p.47). Susan B. Kleinberg stressed the need for hospital school programming in her book, *Educating the Chronically Ill Child*, and recommended that educational strategies be implemented specifically for the child's medical condition (1982). School programming in the hospital keeps a child up with his/her studies, helps to maintain the educational process, and provides continuity in normal experiences.

In a 1979 article, Jerriann Wilson, Director of Child Life at Johns Hopkins Children's Center, cited the need for educational programming. Hospitalized children needed not only to continue the learning process, but also to remain connected to school as a familiar experience in the strangeness of a hospital setting. School programming in the hospital serves to emphasize the healthy part of a child during his/her confinement (Wilson, 1979).

Today it has become clear that school is an important and valued component of a child's stay in the hospital. Ninety-seven percent of hospitals surveyed report that they provide space and materials for hospital schools, with local educational systems providing the

teachers (NACHRI, 2001). Some hospitals hire and fund their own teachers. School in the hospital is also a standard of care of the Joint Commission on Accreditation of Healthcare Organizations. Academic instruction is provided to children and adolescents either directly through the hospital or through other arrangements, when appropriate (JCAHO, 2005).

Current education laws and state regulations address the educational needs of children wherever they currently reside, including a hospital or other healthcare facility. Every state in the US has regulations regarding hospital and/or home instruction, and almost every local school system has different policies regarding implementation of this important educational service. In New York, for example, the state regulations require home and/or hospital instruction to begin within a reasonable period of time. Local school district policies may define a "reasonable period of time" ranging from two to six weeks. Once initiated, students in grades K-6 must receive a minimum of 5 hours per week (preferably 1 hour per day) and students in grades 7-12 must receive a minimum of 10 hours per week (2 hours per day).

Public Law (PL): 101-478: The Individuals with Disabilities Act (IDEA) is federal legislation that mandates a child's right to a "free and appropriate public education (FAPE) ... in the least restrictive environment (LRE)." Students currently classified under special education law (IDEA) may have home and hospital instruction specifically included in their Individualized Education Plan (IEP). Other students with chronic medical conditions may have a 504 Accommodation Plan on file with their school to address their needs as a "person with a disability" under Section 504 of the Rehabilitation Act of 1973.

## HOSPITAL SCHOOL MODELS

Traditionally, there have been three models for hospital-based school services. Most school districts require a letter from a physician stating there is a medical need for instruction to begin. There are different requirements for additional documentation, depending on the school district or the individual Board of Education.

Often, the hospital and local school districts (including large city Boards of Education) work collaboratively to provide instruction to

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children in the hospital. The hospital staff may initiate the referral for instruction. Each school district or city Board of Education is then responsible for the provision of direct teaching services and additional services, depending on the child's individual needs. However, children have a right under law to receive hospital or home instruction without IEP's or 504 Accommodation Plans. The hospital teacher may be on-site full-time while actually a school district employee. This model does not necessarily provide opportunities for collaboration between the hospital and the child's home school.

Another model for hospital instruction occurs when the hospital works with one or more educational/tutoring agencies on a contractual basis. Each educational/tutoring agency works independently and provides different services. School districts are billed directly for the services by these agencies. In this model, hospital staff would initiate a referral to the agency, and could stay involved in the educational process depending on the relationship with the tutorial agency.

A model that is less common, but very effective, occurs when hospitals fund their own school programs. In this model, the teachers are a part of the child life program and the healthcare team. Teachers offer valuable information at team meetings and psychosocial rounds. They often act as the liaison to the schools for the children who are hospitalized, gathering important information such as the child's IEP or 504 Accommodation Plan, if the child has special needs. Sometimes the teacher is also in charge of the school reentry program, which may include other disciplines from the hospital, depending on the way the hospital is structured, and the design of the child life program. Other times, staff from another discipline, such as child life or social work, is the coordinator of the school reentry program. It is often possible to seek reimbursement from the child's school district but this depends on local policies and procedures. This type of program was implemented at North Shore University Hospital in Manhasset, New York in the late 1980's. It is a model that works extremely well but it isn't always possible, due to funding, staffing constraints, and agreements with local school

districts or Boards of Education. To implement the type of program such as the one described may take a great deal of advocacy on the part of child life staff and other disciplines in the hospital.

### COMMUNICATION WITH THE CHILD'S SCHOOL

When a child's day is interrupted by a chronic illness or hospitalization, his/her daily routine is changed, and contact with friends, family and school is interrupted. It is also important for the child who is in the hospital or at home for long periods of time to maintain contact with his/her school. Emotional support from teachers or classmates can help a child adjust to health issues more easily.

With parental consent, initiating contact with the child's teacher can be an important step for the child's well-being. It is important to make sure the child has textbooks, school assignments, and other materials so the child can keep up with his/her studies while in the hospital. Child life specialists can find out if any special accommodations are needed. Many hospital school programs request the IEP or the 504 Accommodation Plan if the child has one, so activities and space can be modified to meet the child's needs.

#### Following are some suggestions to help make the child continue to feel a part of the class:

- Cards, letters or pictures from classmates
- Photos of the class and of staff in the school
- Tape recorded messages that the child can play
- A video tape of the class
- Phone calls to the child (with parental permission)
- Visits from classmates and staff (with parental permission)

Before the child is discharged from the hospital, check with the parents and the school district to make sure the child has the necessary medical documentation for home instruction or to return to school.

### SCHOOL REENTRY PROGRAM – HELPING THE CHILD ADJUST TO RETURNING TO SCHOOL

Children with chronic illnesses often have accompanying learning difficulties. Some are associated with the illness directly, others are

the results of treatment, impairments due to head trauma, or they may be unrelated problems. These children must be evaluated for special education services (Kleinberg, 1982). For this reason, children with chronic illnesses who are discharged from the hospital are in need of a school reentry program, to support them with their continued educational needs. Following are key components of a comprehensive school reentry program:

- **Parent Education:** A child life staff member can be designated to serve as the contact person for the healthcare team, and this can be communicated to the parent upon the child's discharge, in case the parent has questions or additional need for support. Before the child is discharged, develop a parent information packet. Include a parent consent form and any pertinent medical documentation that is necessary for their child to return to school. Explain to the family what a school reentry program is and how it can be tailored to meet the needs of their child. Let parents know that reentry services are optional. They can make a decision now or at a later date. Often, school reentry is needed at different critical points in the child's education. Discuss with parents the federal laws (see below) as they relate to education and the rights of Children with Special Health Care Needs. Refer families to local support groups and other agencies for advocacy and information, such as advocacy groups, parent support, sibling programs, school referrals, respite care, socialization groups or summer camps.
- **School Reentry Team:** Some hospitals have multidisciplinary school reentry outreach teams already in place, including education, medical and psychosocial staff within the hospital. If such a program does not exist already, contact the school and establish a collaborative relationship by identifying the education, medical and psychosocial staff who will continue to care for the child within the school and hospital. Parents should be included on the team to support family-centered care.
- **School Reentry Plan:** Facilitate discussions between the family and the healthcare team regarding the child's needs during the school day, and help to develop a plan. Discuss this plan with the school team. Parents are a critical part of the

healthcare team and must be involved in the development of their child's school reentry plan, because they are the experts in knowing what their child needs. Work with the family to design a school reentry visit. This visit could be for the child's class or an in-service for the faculty, and may even include parents of classmates.

- **Required Health Documentation:** Check again before the child is discharged to see if the school requires any medical documentation to facilitate the return to school.
- **Siblings:** Recognize and acknowledge sibling issues and the need for support. Let the parents know that a child life specialist is available to provide sibling support.
- **Ongoing Care:** Staff members might serve as liaisons to families. It is helpful to call parents to see how their child is managing the return home and back to school; continue to offer support to the child and the family, and ask if they have any questions. Reaching out to the child's family might be helpful. Also, a note to a child can brighten his/her day. This way of systematically reaching out to families may send a positive, caring message and may help support them during the school reentry process.

## SUMMARY OF LEGISLATION

In order to help children maintain their educational process and ensure a successful school reentry, it is necessary to become familiar with the laws affecting children with special needs in school.

Until 1969, most children and individuals in need of specialized services were unable to attend school. There were few options and most children were served in state facilities. Finally, parents in Pennsylvania brought a class action lawsuit against the schools, claiming that civil rights were being ignored. Twenty-seven court cases later, the Education of All Handicapped Children's Act of 1975 (EHA) was signed into law. Children with disabilities in the US became entitled to a free, appropriate, public education (FAPE) in the least restrictive environment (LRE). Public Law 101-478: The Individuals with Disabilities Act essentially replaced the landmark EHA. IDEA was most recently revised in December, 2004.

IDEA requires public schools to locate and identify children with disabilities who may be in need of specialized education. These children will "have available to them a free, appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living." [20 U.S.C. {1400(d)}. The statute includes specific requirements about eligibility for services, the components of the IEP, designates the IEP team members, and outlines the comprehensive procedural requirements related to disputes and complaints. However, the law is always changing and evolving. To understand IDEA you need to read the statute, the regulations, and cases that have interpreted the statute (Peter and Pamela Wright, 2004).

Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) are both civil rights provisions barring discrimination against persons with disabilities, and are very helpful in the education of children who may have special needs but don't require specialized education. Under these laws, individuals must have an impairment that substantially limits one or more major life activities to be designated a "person with a disability." Under Section 504, an Accommodation Plan is developed that outlines reasonable accommodations and services that children need to fully participate in all activities of school. The plan may include such accommodations as preferential seating, a second set of textbooks to keep at home, or intermittent home instruction. School district teams, with parents and sometimes other professionals, develop IEP's and Accommodation Plans.

There are many resources included on the CLC Web site at the link below, to help child life professionals stay up-to-date with the most recent revisions and information.

[http://www.childlife.org/Information\\_Central/resource\\_pages/daily\\_clinical.htm#school](http://www.childlife.org/Information_Central/resource_pages/daily_clinical.htm#school)

In addition, some hospitals have Family Resource Centers, where staff and parents can go to access the most recent information available on laws that affect the education of children with special healthcare needs. A child life specialist or librarian in the Family Resource Center can help parents navigate the complex educational system.

## THE LAW AND CANADA

In Canada, the education laws are referred to as 'human rights.' "Canada has always been active in its involvement with the exceptional child. From the policies makers at the federal and provincial levels through the teachers in training at the university and colleges" (www.ccc.sped.org). Accommodations for children and adults are very important in Canada. Provincial and territorial governments provide the legal basis for operating the educational systems and provide the framework for which educational services must be provided. These services vary from province to province and territory to territory. Many Canadian child life programs have been leaders in school reentry programs for children who have been hospitalized. (www.ccc.sped.org/ab/canadian.html.)

## THE CHILD LIFE SPECIALIST AS EDUCATION ADVOCATE

Education advocacy often seems to fall outside of the realm of child life services. In actuality, child life specialists are uniquely qualified to advocate for children in schools. They have advocated on behalf of children in the hospital setting for decades. Child life specialists are aware of the needs of children and understand the importance that school plays in their lives.

To begin, staff will need to familiarize themselves with the federal and state regulations, and local education policies, and be able to provide parents with this information. Child life specialists can initiate referrals for services while children are hospitalized and follow up to ensure they are received. Child life specialists can collaborate with school districts and often need to familiarize school personnel with state regulations regarding hospital school services. It is also helpful to explain what other school districts in the surrounding areas are doing for children in the hospital.

Because child life specialists have developed relationships with a family during hospitalization, they are able to support them through the difficult process of accessing services for their special needs child. Because child life specialists practice family-centered care, they are also able to encourage this focus in the development of plans for children's educational needs due to illness. They can be an invaluable source of information and ideas for the Special Education Team

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(with parental consent, of course). Additionally, a child life specialist, via conference call or in person, can make valuable contributions to an educational plan discussion with the school. It may also be very helpful to the following groups of providers for the child:

- **Early Intervention Team (EI):** for infants, birth through two years, eleven months
- **Committee on Preschool Special Education (CPSE):** for children three to five years of age
- **Committee on Special Education (CSE):** for children five years and up
- **Section 504 Committee:** protects all children with disabilities from discrimination who do not qualify for IDEA. "Section

504 protects children whose disabilities directly interfere with their ability to learn or whose disability substantially limits one or more 'major life activities,' such as seeing, walking, breathing or learning." ([www.insideschools.org/st/ST\\_504.php](http://www.insideschools.org/st/ST_504.php))

A child life program can initiate a School-Health-Parent Task Force and include several staff members from various disciplines, staff from local school districts, and parents from various districts, whose children are either frequently hospitalized or have a chronic medical condition. It is always helpful to have a physician and local state representative on your task force. Once school district personnel understand the challenges that chronically ill children and their families face on a daily basis, they often listen and respond appropriately.

The Child Life and Education staff at North Shore University Hospital in New York initiated a School-Health-Parent Task Force on Long Island in 1990. Due to the efforts of many parents, hospital staff and school district personnel, intermittent home instruction was something that was possible to implement on Long Island. This service addresses the needs of children who miss one or two days of school each week because of a chronic condition, but usually don't miss enough consecutive days to receive services under the standard policy. With this service they can receive some home instruction and still attend school when they are well enough. This term and service, 'intermittent home instruction' remains intact today across Long Island.

### CONCLUSION

Child life specialists play an important role in the well-being of children in hospitals, at home, in the community, and in the schools. Their work is important in helping children with special health care needs and their families negotiate the complex educational system.

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# Ethical Practice in Child Life

## CODES OF ETHICS: HOW DOES CHILD LIFE COMPARE TO NURSING AND SOCIAL WORK?

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This column focuses on the many similarities and differences between the *Child Life Code of Ethical Responsibility* (Official Documents of the Child Life Council, p. 7, 2002) and the codes of ethics of nursing and social work in North America, and what this means to child life specialists, the profession of child life, and the Child Life Council<sup>1</sup>.

As child life professionals, we often feel at a disadvantage, the “underdog” in the healthcare field. While our colleagues’ professions have been established for many years and they have outcome research and journals specific to their profession, we try to “catch up” to become recognized as an essential service that makes a difference in the psychosocial care of children. We face similar challenges to social work and nursing in light of the work we do and our shared primary goals of supporting children and families in healthcare. Examining the areas of overlap and the possible differences was the impetus for this discussion.

### SIMILARITIES

There are many similarities within the codes of ethics for child life, social work and nursing. This should not be a surprise, given the humanitarian aspects of our professions. Some of the common ethical principles include:

1. Respecting each person for who he/she is, regardless of race, gender, religion, sexual orientation, economic status, national origin or disability
2. Treating people with dignity
3. Maintaining confidentiality and privacy — disclosing only (verbally and in writing) the information that is necessary to ensure appropriate care and documenting said information clearly and accurately, following the standards and requirements of the profession and the guidelines of any regulatory bodies/employers

4. Practicing in a competent manner, sharing knowledge and expertise, promoting research, and understanding of needs of patients/clients
5. Seeking knowledge and training to better meet the needs of children/families
6. Following ethical research practice
7. Representing self with honesty and within professional role
8. Treating colleagues with due respect and working collaboratively
9. Being aware of personal issues which may affect professional role, work relationships, ability to fulfill job requirements — ensuring that you take action to avoid negative impact on children/families
10. Outlining when one can and cannot have a personal relationship with members of the family
11. Avoiding any situation where personal gain (financial or otherwise) takes precedence over the professional relationship with clients/patients
12. Refraining from illegal activity

Another similarity is that there are structures and regulations for disciplinary actions against child life professionals, nurses, and social workers who are suspected to have or were found to have breached their codes of ethics. Nurses and social workers must be registered or licensed within the province or state in which they work. Their professional practice is governed by legislative/government Health Care Acts. Within the nursing and social work professions there are processes for members of the public or their colleagues to report unethical conduct. A group of peers then investigates and makes a deliberation about the license of the individual. If it is determined that the individual will lose their license, they will no longer be able to practice. This is different for

child life specialists. State/provincial governments do not currently require Child Life Certification for child life specialists to be able to practice. Child Life Certification is a voluntary process. Many hospitals require an individual to be certified or to be certified within a specified period of time in order to work within their organization. However, some hospitals or community organizations do not.

For the child life profession, the following procedures are in place for investigating possible breaches of the *Child Life Code of Ethical Responsibility*.

1. Ethical dilemmas concerning behavior of certified individuals or certification candidates would be evaluated on a case-by-case basis.
2. Child Life Certification Committee (CLCC) Chairperson Year 1 will convene the Ethics Committee.
3. Facts will be investigated and reported by Chairperson Year 1.
4. Facts will be presented to the Certification Ethics Committee.
5. The Ethics Committee will consist of the CLCC Senior Chairperson, Chairperson Year 2, CLC President, President-Elect, and Executive Director. Legal counsel will be consulted as needed.
6. Recommendations for action will be determined by majority ruling.

Decertification of the child life credential is a possible action if the code of ethics have been violated. Should decertification take place, it is the responsibility of the organization to determine disciplinary action or termination of the employee.

### SIGNIFICANT DIFFERENCES

The differences between the codes of ethics for each profession relate more to the extent of the detail and explanations provided by each organization’s document. The nursing and social work documents start by describing their core values as a profession. This provides a concrete link to their ethical principles. The documents then describe actions and behaviors that exemplify the meaning of the ethical principle as it relates to the member, the clients/patients, the employer, and the profession. For example, in the *Canadian Nurses Association’s Code of Ethics* (2002), one of the values of the profession is “confidentiality.” The code describes the

*continued on page 6*

<sup>1</sup> The information acquired for this article came from The Canadian Nurses Association, The American Nurses Association, Canadian Association of Social Workers, and National Association of Social Workers, as well as a review of the International Federation of Social Workers. Each province and state in North America has a regulatory body that governs these two professions and they have individual codes of ethics for their members. Each country then has a national organization that oversees the profession, and their code of ethics provides guidance to the state/provincial regulatory bodies.

nurse's responsibilities to ensure that confidentiality is maintained. In contrast, the *Child Life Code of Ethical Responsibility* identifies the need to maintain confidentiality, that the transmission of information meets the standards of the employer and governing regulations, and that records should be maintained in a locked and secure manner. The nursing documents provide a clearer understanding of the role and responsibilities of their members. The social work documents also provide clear ethical standards; the responsibilities they have to their clients, colleagues, to their practice setting, as professionals, to the profession and to the broader society.

These organizations also describe in more detail the professional's responsibilities in relation to professional boundaries, sexual relationships, conflicts of interest and conflicts between one's professional code of ethics and organizational policies.

There are also differences in foci. What we value as the child life profession is different from our colleagues in social work or nursing. For example, one of the main foci for social workers is "social justice" and the ethical principles and professional responsibilities in this area. For nurses, common themes are "accountability" and "health and well-being."

The manner in which social work and nursing organizations document specific behaviors and responsibilities is worth reviewing as we grow as a profession and wish to expand the clarity and specificity of our documents. Some questions for the profession to consider include:

- What can or should be the responsibility of CLC in relation to educating the public about unethical professional conduct of Certified Child Life Specialists and how to report it?
- Can and should ethics in child life be mandated as a topic area within child life training programs, to ensure ethical principles and practices are modeled, taught and discussed?
- Can we expand our code of ethics to include more specific professional responsibilities as they relate to patients and families, colleagues, to the profession, to the employer/practice setting, and to broader society?

### WHAT DOES THIS MEAN FOR ME AS A CHILD LIFE PROFESSIONAL?

CLC and its members have outlined core eth-

ical principles in *Making Ethical Decisions in Child Life* (Klein et al., 2000) that have many similarities with our colleagues. Although we are a young profession and constantly advocating for the profession and the needs of children and families, we can feel confident about our code of ethics. This document provides invaluable information and is a foundation for ethical practice within the profession. It represents the philosophy of the child life profession and highlights the principles by which we must practice, recognizing the inherent challenges within it.

### WHAT ARE THE IMPLICATIONS FOR THE PROFESSION AND THE CHILD LIFE COUNCIL?

The child life profession continues to grow, both in numbers of new professionals and in the scope of where and how the work is done. The code of ethics provides the fundamentals of ethical practice regardless of where and with whom child life specialists work — in hospitals or the community — and presumably regardless of the country of professional practice. We can learn from the examples of other professional organizations that share our core values and ethical principles. Their documents and the strategies they use to ensure their codes of ethics are clear, specific and maintained would be a relevant guide to our professional leaders.

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## Supporting Families in the Emergency Department

### A JOURNAL ARTICLE FOR DISCUSSION

Jane L. Darch, CCLS, and Michelle Bernardi, CCLS, Emergency Department, Sick Kids, The Hospital for Sick Children, Toronto, ON

Levetown, M. (2004). *Breaking Bad News in the Emergency Department: When Seconds Count, Topics in Emergency Medicine*. 26, (1) 25-43.

**ABSTRACT:** One of the most difficult tasks of an emergency care provider is to inform parents of their child's death. Only a rare physician, nurse or first responder training program teaches practitioners how to have this conversation. Yet the impact of this conversation for parents is lifelong; they report that the interaction with the health professionals at the time of disclosure either creates long-term peace or haunts them for the rest of their days. Similarly, caregivers may be regretful or heartened by their experiences of meeting the needs of parents in [extreme circumstances]. This article provides recommendations for breaking bad news in the Emergency Department (ED) and training methods for providers confronting the sudden death of a child.

This article is useful because it has the potential to start important communication between disciplines about a very challenging topic. Fortunately, we do not see the situations highlighted every day, but unfortunately, they are inevitable in the Emergency Department (ED). Therefore, it is essential to continue open discussion within the healthcare team regarding what each person's role is in the event that it does happen. Each hospital is unique, and this article can help to spark discussion regarding what is realistic and appropriate for your own setting. In addition, a clear description for the role of a "guide" is provided. This role is one in

which child life should participate when possible, in order to provide important support and information for the families, as well as the healthcare team.

Levetown (2004) suggests that the majority of all deaths of children and young adults between 1 and 24 years are motor vehicle crashes, drowning, suicide or homicide. (p. 35). Research studies very clearly document the lasting impact of the manner in which the news of the tragedy is delivered. The author suggests that although there may be no unanimous agreement about how to give families bad news, there are basic concepts that multidisciplinary teams should be aware of and several strategies are highlighted.

This article provides four case studies involving traumatic injury in the Emergency Department. **For discussion: How familiar are the following scenarios in your Emergency Department setting?**

**Case Study 1:** A single mother was contacted at work by her son's summer camp counselor. Her 7-year-old son was swimming during an outing and disappeared; only to be found submerged for an undisclosed period of time. He was transported to the local Emergency Department. When she frantically called to find out her son's status, she was told by the triage nurse, "He's dead." (p.35)

**Case Study 2:** A family was driving to a wedding when a drunk driver crashed into their car on the passenger side. Everyone [in the car] was briefly unconscious. The parents and the children were sent to different hospitals. The baby in the family had been thrown from the car and was declared dead on arrival at the hospital. Her older brother had a liver laceration, and was taken from the Emergency Department to CT, and then to the Operating Room. An uncle called on behalf of the family and was told he could not be given any information. (p.35).

**Case Study 3:** A 4-year-old boy was sucking on a balloon at a birthday party. The balloon burst, the child turned blue and his father could not dislodge the balloon fragment from his trachea. Emergency Medical Services did an emergency tracheotomy. Parents were not allowed in the trauma bay while efforts were made to resuscitate him. The mother wailed and insisted she needed to be with her child. The father threatened

the staff, and their questions were met with, "We don't know yet." (p.35)

**Case Study 4:** A 14-year-old girl with a history of depression had taken an overdose of her mother's antidepressants and anti-hypertension medications. A neighbor found the girl and called Emergency Medical Services and the child's mother. As the mother drove to the Emergency Room, she called on her cell phone, and asked about her daughter. She was told that the injury was serious and that the team was working on her daughter. She was also told that she should drive safely as her daughter's condition could not be made better by her mother getting injured. When she arrived, the mother was asked what she knew already, and then escorted to her daughter's side, after an explanation of her condition, and the equipment and personnel she would see. (p.35).

#### **Giving Information to Parents/Families:**

As highlighted in the article, parents may not be with their child at the time the accident or injury occurred. Suggestions made by the author for supportive communication with families prior to their arrival include: encouraging families to bring a supportive friend or family member with them, reminding them to drive carefully, and explaining that someone will meet them when they arrive. Once family members have arrived, the author advocates for a social worker, chaplain or child life specialist to remain with the family throughout their Emergency Department stay to serve as a guide. The guide should address the family members by name, and identify any additional family members or friends who are present.

The author suggests how to approach situations with families and offers examples of what might be said to a family during their ED stay. It is important to recognize however, that every situation is different, and would be approached according to the needs of the family.

*"Hello, Mr. and Mrs. Smith, I am \_\_\_\_\_ (healthcare professional name and title). I am glad you made it here safely. I know you must be anxious to see \_\_\_\_\_ (use child's name when ever possible.) First, let me understand what you know already, so that I can help you understand what has been going on, then I will get his doctor to tell you more."* (p.36)

**Parents Present in Trauma Room:** If parents

are present during resuscitation, they should have a staff member who can act as a guide to explain what they are witnessing in the room, including the care of their child and the equipment they see around their child.

**Communication:** To reduce miscommunications, inquire from families what information they already know about their child and correct erroneous information. The parents should receive updated information from the physician or nurse working with the resuscitation team. It is recommended that the family receive updates every 15 minutes. Letting families know that their child is critically ill, injured, or at risk of dying is important to allow families time to prepare.

*"Mr. and Mrs. Smith, I am Dr. Young. My team and I have been taking care of Jeffrey since he arrived 20 minutes ago. He was severely injured. We have been doing all we can to help him. He is on a breathing machine and is receiving medicine through IV's. So far he is not responding as well as we hoped he would. He is critically ill or injured and despite our best efforts he may not survive. Can I answer a few questions for you? I will have time to answer more in a little while. Let me check on him and I will let you know more in a moment."* (p.37)

Shortly after death, the news of the tragedy should be shared with the family. Levetown (2004) suggests that this staggered approach gives families a few moments to prepare. Use words like dead, died, dying. Offer to call a chaplain if one is not present.

*"I am afraid I have bad news. Despite all the efforts of a lot of highly trained people who had been working hard, Jeffrey was too ill to respond. I am sorry to have to tell you that he has died. Would you like to come and be with him? I will take you to him and answer all your questions when you are ready."* (p.37).

**Empathy:** Parents report that they appreciate having a quiet place to have staff tell them about their child's death. Time seems longer when the healthcare personnel are seated and eye contact is made. All of these simple gestures help families feel that, for the moment, their child is the most important person. This time also gives families an opportunity to ask questions and to ensure that everything was done to save their child. Empathy and reassurance can help families to cope with the feelings they are experiencing. The

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## Supporting Families

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author also suggests that it is appropriate for staff to show emotion, as a sign to the family that their child mattered and was cared for by a warm and caring person in his/her final moments. Be prepared for a range of reactions including: shock, speechlessness, tears, fainting, praying, or passing out.

*"I cannot begin to imagine how painful this is for you. You were such a good mother, sending your son to summer camp. You could not have known this would happen." (p.39)*

**Information sharing:** Give parents as much information as they request, and avoid jargon. Checking to ensure that parents understand what has been said also ensures effective communication throughout their experience.

**Caring for the Bereaved Family:** Care of the bereaved family in the ED is a critical aspect of comprehensive care. Parents may need time to sit with the body, and concrete mementos of the child are often valued.

**Siblings:** Parents should be encouraged to let siblings see their brother or sister. The article also recognizes their unique relationship with

the deceased child, and offers strategies for supporting children as well. There should also be a process for follow-up care for the child's family. Strategies suggested include: providing a sympathy card, follow-up phone calls, information about grief and bereavement, guidance about parenting while grieving, and children's reactions to grief.

### **Critical Incident Stress Debriefings:**

Finally, the article recognizes the toll that witnessing intense pain can have on health-care providers. Giving each other permission to express feelings and decompress are ways to ensure that staff care for themselves emotionally. Levetown (2004) suggests that more research is needed in the care of the emergency caregiver.

This article has a completely psychosocial focus. It could be used as reference for initiating discussion surrounding the difficult situations that ED staff must face together. The author stresses the importance of providing psychosocial support for all patients, families, and staff involved during and following crisis situations. Parents have reported the lasting negative effects of receiving devastating news in an unsupportive manner, during which their psychosocial needs were not attended to.

Research shows that in order to provide optimal family-centered care the entire multi-disciplinary team must be involved. In doing so, the proper supportive environment and communication opportunities can be provided. The author clearly recognizes the skill set and expertise of child life specialists, and advises that a child life specialist is qualified to take on the essential "guide" role during these extremely difficult situations.

It must be noted that the suggested scripts (in italics) provided in the article should be used only as a guide and/or a starting point for discussion. Each facility, multidisciplinary team, and family is different, and therefore, each situation requires careful assessment to determine the appropriate interventions and follow-through required.

Finally, research continues to demonstrate that when psychosocial supports are not available to professionals working in high-stress situations the rate of employee burnout increases. The article highlights the fact that education and follow-up care for the health-care professionals is often neglected or non-existent. Individual facilities and healthcare teams need to develop programs which will adequately care for their professionals following difficult situations.

## Milestones

**RETIREMENT:** **Jerriann Wilson, CCLS**, Director, Child Life Program, Johns Hopkins Children's Center, Baltimore, MD, see "In Appreciation" page one.

**RETIREMENT:** **Sally Niklas, MA, CCLS**, Director of Child Life and Education, Children's Hospital at MetroHealth Medical Center, Cleveland, OH. Sally has been the director for 12 years, at the hospital where Emma Plank began the first child life program in 1955. Under her guidance, the program has continued to grow and influence patient care throughout the hospital. The precedent influenced by Sally and her commitment to patients and families has raised the community's awareness of pediatric needs, and ultimately has established a Child Life and Education endowment to fund the perpetuity of the program. Her active role in the creation of this endowment has, in a few short years, brought it within reach of its financial goal.

**PUBLICATION:** **Mary Wall, MS Ed, CCLS**, *Lyme Disease is No Fun: Let's Get Well!* Lyme Disease Association. The book assists children diagnosed with Lyme Disease with understanding their disease and the medical procedures and emotional experiences of those with the illness. For more information, go to [www.lymediseaseassociation.org](http://www.lymediseaseassociation.org). All proceeds go to Lyme Aid 4 Kids, a resource to assist families afflicted with Lyme Disease.

Please send any suggestions for individual and program Milestones to Amy Jackson at [membership@childlife.org](mailto:membership@childlife.org).

## CALL FOR BULLETIN ARTICLES

Do you have an idea for an article for the *Bulletin* or *FOCUS*? Have you just read a great book or journal article, or found a method, tool or resource that you believe would be helpful to other child life professionals? See the submission guidelines and "Writing for the CLC Bulletin" at the following link:

[http://www.childlife.org/Book\\_Store/](http://www.childlife.org/Book_Store/)

Just follow the guidelines and send your submissions to Amy Jackson at [membership@childlife.org](mailto:membership@childlife.org) by the following deadlines:

1/15, 4/15, 7/15, 10/15.

**CLC WELCOMES YOUR SUBMISSIONS!**

## Holiday Havoc... A Child Life Survival Guide

Emily G. Margolis MS, CCLS, Child and Adolescent Life Specialist, Duke University Medical Center, Durham, NC  
Courtney Hillyard, CCLS, CPST, Coordinator, Child Life Services, Children's Hospital of Michigan, Detroit, MI  
Melissa Pulis, MSM, CCLS, Child Life Manager, Children's Mercy Hospitals and Clinics, Kansas City, MO

Whether you are a one person program or part of an extensive and well-staffed department, the holidays often leave most of us feeling overwhelmed and exhausted. Many of us, at one time or another, have felt conflicted about how all the coordinating, communicating, organizing, preparing, and decorating takes us away from our typical routines and roles within our care areas.

Since the family is a constant in a child's life, we encourage families to be involved as much as possible in the care of their child during hospitalization. The holidays are a special time when families come together to celebrate and maintain traditions. To support family-centered care initiatives, child life staff should assist families in continuing these celebrations and traditions even though their child is in the hospital, with sensitivity to each family's cultural and religious belief systems.

Our hope is that this article, with our compiled suggestions and tips, will motivate all of us to make the most of our efforts, help us to strategize, and freshen our approach to supporting the celebration of holidays in the hospital, while keeping the needs of our patients and families in the forefront.

### BEFORE DECEMBER:

- **Start Planning Early:** Many programs begin to plan for the holidays at the end of the Summer. Taking fifteen minutes at a few consecutive staff meetings can help you get a good start.
- **Delegate Responsibilities:** Determine who will schedule visitors, donations, activities, clean up, thank you notes, etc. Be sure to include anyone who is available, such as volunteers, interns, and other hospital staff.
- **Create Guidelines:** Meet as a department and determine ahead of time what you want to include and what you want to avoid. Keep in mind that the guidelines you create are guidelines and not practices that are set in stone. Your guidelines could include:

- Strive to make events and activities family-centered. Remind child life and non-child life staff of family-centered care principles through in-services, bulletin boards or hospital newspapers.
- Remind staff to respect cultural diversity.
- Maintain and respect the confidentiality and privacy of patients and families at all times.
- Advocate for the needs that are in the best interest of our patients and families — it is our professional duty!

- **Create a Wish List:** The list should include preferred items and should represent the needs of all ages. Consider mailing your list to past holiday donors. If you do not have an established or consistent donor base, work with your public relations or development department. An article in a local paper or a short feature story on a local news or radio station can raise visibility of your child life program in the non-holiday months. Do not forget to post your wish list on your hospital's Web site and be sure to share it with your development office.

- **Seek Storage Solutions:** Strategize an efficient system by which to organize incoming donations (i.e., age groups, gender, cost). Plan to clean out your storage areas before the donations start rolling in. If you have limited storage, look for areas that may be vacant over the holidays (conference rooms, an office, classroom, etc.).

- **Cultural and Religious Sensitivity:** Be aware of as many cultural and religious celebrations as possible. Some child life programs create a bulletin board that advertises celebrations and services in the community. This can be coordinated and supported by hospital chaplains. Plan activities around the season, not a particular holiday that is celebrated by one culture or religion.

### AS THE HOLIDAYS APPROACH:

- **Centralize All Communication:** Keep a

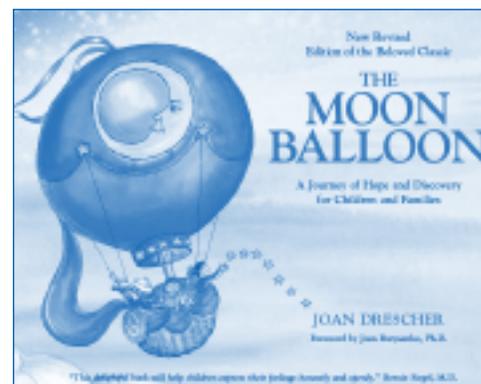
central calendar where all holiday-related information can be communicated with staff. This will minimize miscommunication and duplication of energy. Consider posting a weekly calendar of events and activities at nurses' stations so that the hospital staff will be aware of what is going on.

- **Revise Special Event/Visitor Guidelines:** Review the guidelines with groups when you schedule a visit or event, to ensure that your expectations are clear from the beginning. Be honest with incoming groups and let them know that the hospital reserves the right to decline/refuse the visit at the last minute due to flu outbreaks or other occurrences that may negatively impact the patients or families. Be sure to send a letter to each scheduled group that confirms the date, time and location of the visit or event. Include a hard copy of your special event/visitor guidelines.

### DURING THE HOLIDAYS:

- **Don't Wing It:** Have an organized plan and process for how things should be handled. When you get a call from a possible group or donor, think about how and if

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**The Moon Balloon, A Journey of Hope and Discovery for Children and Families**, by Joan Drescher, is a new revised full color picture book which surpasses its previous edition. This valuable communication tool is used by childlife and healthcare professionals throughout the US and Europe.

To order your new edition send a check for \$16 plus \$3 S/H made out to "The Moon Balloon Project" at 23 Cedar St, Hingham, MA 02043 or visit [www.themoonballoon.com](http://www.themoonballoon.com).

## Holiday Havoc

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this event will benefit the patients and families. If the schedule is already too full or if the time they would like to visit does not work, it is better to say “no” than to provide a less than pleasurable experience for the patients and the visiting group. Do not decline the offer without thinking it all the way through. If the offer does not fit your guidelines, explain your expectations and see if the proposed activity or event can be altered in some way. If your schedule is already full, invite the group to assist with another celebration or holiday such as Valentine’s Day, a Spring Party, a Summer Celebration, etc.

- **Stay Organized:** Maintain your central calendar and update it regularly. Good communication is essential in order to keep everyone on the same page, while keeping stress to a minimum.
- **Get Everyone Involved:** Think of the entire family when doing gift distribution, give a family gift like a board game or

movie — something they can enjoy together. Allow parents to choose gifts for their children and give patients and siblings an opportunity to choose gifts for each other. Include siblings/cousins in special events/activities planned. Ask the families how they plan to celebrate and support their efforts. Encourage all hospital staff to participate in special events and distribution of donations so they, too, can help spread the holiday cheer!

- **Keep a List Of Your Donors:** Create a file for each donor that includes contact information and a brief description of the donation. Include information about what worked and what could be better, so when they call next year you can remind them of how much you enjoyed a particular aspect of their donation, or have a plan to improve upon the experience.

### AFTER THE HOLIDAYS:

- **Celebrate!** Give yourself, your department, and whoever helped you out a big pat on the back. Plan a post-holiday lunch/dinner, bring a massage therapist in for 15-minute mini-massages, or just take a day off for yourself. Do something special to recognize that you just gave 110% to supporting patients and families.
- **Thank Your Donors:** If you take an extra moment to be specific in your note about

what part of the donation was most helpful, donors will be motivated to consider you again next year, and to duplicate their supportive efforts. Some programs create an Excel spreadsheet so that letters can be mail-merged onto hospital letterhead. Other programs create handwritten notes on cards that have been decorated by patients. Your institution’s development department may require that donor be sent to it as well.

- **Evaluate:** Provide evaluations to families, staff, and volunteers. Utilize this information to write up a brief plan for next year. Keep a file where you can record the good things and how you would strategize differently.

In closing, please refer to the Child Life Council’s Web site section in Information Central for holiday programming ideas and other holiday-related resources so you can start planning now, at the following link:

[http://www.childlife.org/Information\\_Central/resource\\_pages/daily\\_clinical.htm#Holiday](http://www.childlife.org/Information_Central/resource_pages/daily_clinical.htm#Holiday)

Before you know it, the holiday season will be quickly approaching. We wish all of you the best of luck with the planning and managing of the holiday season. Remember to save some time and energy for yourself so that you, too, can enjoy the fun and festivities of the holiday season!

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## CLC ENDORSED CONFERENCES

**Bittersweet Beginnings ... Where Do We Go from here?** September 23, 2005, Days Inn, Danville, PA — This conference is intended for all healthcare providers, chaplains, child life and others who find themselves dealing with all aspects of death in the pediatric population. For a full brochure call 1-800-272-6692.

**2nd Child Life Assistant Conference** “Creating Magical Moments: Enhancing Knowledge and Skills for Individuals Working with Children in Group Settings” — September 24-25, 2005, Cincinnati Children’s Hospital Medical Center — Creative and Innovative Sessions • Networking Opportunities • Opening Reception • Hospital Tour • PDH’s Offered — For additional information, call 513-636-8855.

**“Enhancing Professional Development and Practices”** California Association of Child Life Professionals Conference, October 8, 2005 at Mills College, Kirsch Education Center, Oakland, California. For more information or registration brochure, contact: Maria Elena Tome: (323)669-2355, mtome@chla.usc.edu

**SAVE THE DATE!** 3rd Annual Child Life Directors Retreat & Conference Oct. 9-11, 2005 Camelback Marriott Resort & Spa in Scottsdale, Arizona. Major sessions will focus on evidence-based practice, clinical supervision, and leadership skills development. For more information contact Chris Brown at brownnc@email.chop.edu or (215) 590-2001.

## Certification News

### FUTURE EXAM LOCATIONS

CLC is pleased to announce that 3 additional Child Life Professional Certification examination sites have been added to the November 12, 2005 administration. There are now a total of 6 sites: Boston, MA New York, NY Houston, TX Oaklawn, IL Las Vegas, NV Toronto, ON

### APPLICATION DEADLINES:

Applicants educated in US or Canada:  
August 31, 2005

Applicants educated in other countries:  
June 30, 2005

Exam sites for 2006 have been selected:

Spring Exam: *May, 2006*  
Dallas, TX

Fall Exam: *November, 2006*  
Baltimore, MD  
Boston, MA  
San Francisco, CA

### RECERTIFICATION

Anyone whose certification expires at the end of 2005 will need to recertify either by exam or by submitting Professional Development Hours (PDHs). Recertification by PDHs must be submitted to the CLC office postmarked by June 30, 2005.

There is also the option to recertify by retaking the Child Life Professional Certification Examination.

Please be sure you are keeping current with your annual maintenance fees. Failure to maintain annual fees may result in the loss of certification.

For any questions regarding certification please contact Danae Williamson at 1-800-CLC-4515 or via email at [certification@childlife.org](mailto:certification@childlife.org).

## CLC Historical Archives CALL FOR MATERIALS

The History Committee is seeking materials for the Child Life Council Historical Archives at Utica College. The archives are intended to assist members of Child Life Council, students, and others interested in obtaining information regarding the history of Child Life Council and the profession of child life. The History Committee seeks to build a permanent collection of information as a means of preserving our unique heritage.

If you have any of the following items and wish to contribute them to the archives, please send them to Civita A. Brown, Coordinator of Internships, Psychology-Child Life, Utica College, 1600 Burrstone Road, Utica, NY 13502.

- Organizational Records (charter, by laws, minutes, certification, officers, documentation from ACCH study sessions, policies, brief history and timeline)
- Publications (newsletter, Child Life Council books and publications, conference materials, journals, and other books)
- Public Relations (proclamations, press releases, and magazine articles)
- Academic and Clinical Program Histories
- Non-Print Materials (videos, audio, photos, microfilm, slides, DVD, and CD ROM)
- Personal Papers (obituaries, manuscripts, and letters)
- Biographies of Child Life Council Leaders
- Ephemera/Artifacts: (buttons, banners, toys, t-shirts, posters, children's books, etc.)

Acceptance of materials is at the discretion of the Child Life Council History Committee. A professional archivist may be consulted if needed.

## Following the Dream CLC's 20TH ANNIVERSARY VIDEO FOR SALE

The CLC History Committee is pleased to announce the sale of "Following the Dream," a documentary film which was produced for the Child Life Council's 20th Anniversary Conference. The film is composed of selected excerpts from interviews with child life pioneers as they discuss the past, present, and future of the child life profession. This film is for child life specialists, as well as for everyone who works with children, who believe in treating the whole child, and who wants to make a difference in the lives of children in all settings.

The video can be purchased at CLC's annual conference in Nashville, or by sending a check or money order for \$25 to:

Civita Brown  
Coordinator of Internships  
Psychology-Child Life  
Utica College  
1600 Burrstone Road  
Utica, New York 13502  
Email: [cbrown@utica.edu](mailto:cbrown@utica.edu)

This price covers the costs for the video and shipping.

## CLC Historical Archives SEEKING ACADEMIC, CLINICAL, AND ALTERNATIVE SETTING PROGRAM HISTORIES

The CLC History Committee continues to collect the program histories of academic, clinical, and alternative settings. This process started with CLC's 20th Anniversary and will continue to be an ongoing project of the committee. The completed histories can be sent to [cbrown@utica.edu](mailto:cbrown@utica.edu). If you wish, you can include pictures or a brochure. If you do not have email access, please mail to: Civita A. Brown, Coordinator of Internships, Psychology-Child Life, Utica College, 1600 Burrstone Road, Utica, NY, 13502.

Please consider the following guidelines when preparing your program's history:

1. One to three pages in length
2. History should be in chronological order
3. Date founded
4. Founder/founders
5. Directors: first through present
6. Departments having a child life specialist, including dates when they hired their first child life specialist
7. Discuss any special programs or services provided
8. Information on how your program evolved from past to present
9. Number of child life specialists in your program and number certified
10. Any additional information

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# Bulletin Feedback Survey

CLC would like to know what you think about each *Bulletin* so that we can provide what you need most in this format. If you would like to give us your feedback, please visit the following online survey link by July 31:

<http://www.zoomerang.com/survey.zgi?p=WEB224F3XFSG38>



**Child Life  
Council**

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## CLC Calendar

### JUNE

- 30 Deadline for Recertification by Professional Development Hours (PDHs)  
For those educated outside US or Canada: Deadline for November 12  
Professional Child Life Certification Exam

### JULY

- 15 Deadline for *Bulletin* and *FOCUS* articles, and advertisements for Fall 05 issue

### AUGUST

- 1 Deadline for conference session abstracts for the 2006 CLC Annual Conference  
on Professional Issues  
31 For those educated in the US or Canada:  
Deadline for November 12 Professional Child Life Certification Exam applications

### SEPTEMBER

Global CLC Membership Renewal Month  
2006 Conference Planning Committee meeting

### OCTOBER

- 14 Deadline for *Bulletin* and *FOCUS* articles, and advertisements for Winter 06 issue  
15 Committee reports due

### NOVEMBER

12 Professional Child Life Certification Exam  
CLC Executive Board meeting – dates TBD

### DECEMBER

- 10 2006 annual conference sponsorship commitment form and exhibit  
booth confirmation due, for inclusion in the 2006 annual conference program

## 2005 CLC Executive Board Election Results

Thank you to the Nominating Committee, to all of the 2005 candidates for the CLC Board, and to all who voted by absentee ballot or at annual conference!

Following are the newest members of the CLC Board:

**Treasurer:** Eugene Johnson, MA, CCLS,

*Child Life Specialist, Children's Medical Center of Dallas, TX;  
Instructor, Baylor University, Waco, TX*

**Member-At-Large (Member Care):** Suzanne Graca, MS, CCLS,

*Child Life Specialist II, Children's Hospital Boston, Boston, Massachusetts;  
Instructor in Child Life, Wheelock College, Boston, Massachusetts;  
Adjunct Instructor, Eliot Pearson Department of Child Development,  
Tufts University, Medford, Massachusetts*

**Member-At-Large (Outreach):** Kelly Gleason, CCLS,

*Child Life Specialist II, Cincinnati Children's Hospital Medical Center,  
Cincinnati, Ohio*

**Member-At-Large (Professionalism):** Toni Millar, MS, CCLS,

*Director, Child Life Department, Rainbow Babies and Children's Hospital,  
Cleveland, Ohio*

**Child Life Certifying Committee Chair:** Sharon McLeod, MS, CCLS, CTRS,

*Senior Clinical Director, Child Life and Recreational Therapy Division,  
Cincinnati Children's Hospital Medical Center, Cincinnati, OH;  
Adjunct Professor, Psychosocial Care of Children and Families in  
Healthcare Settings, College of Mount Saint Joseph, Cincinnati, OH*