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TABLE OF CONTENTS

IN THIS ISSUE:

- Communication Remains the Key
- 3 "We Have to Start Someplace!"
- A Letter from ACLP

ALPHABET 2.0

U is for Urology: A Spectrum of Services in the Outpatient Urology Clinic

- 10 Culinary Medicine in the Pediatric Clinical Setting: Collaborating between Registered Dieticians and Child Life Specialists
- 13 Integrating Art into Pediatric Health Care: A Collaborative Approach
- 16 The Practical Side of HIPPA
- 19 Civita Brown: DSA Recipient and Innovator in All Things Child Life
- 22 The 411 of Child Life in Higher Education
- Within the School Walls: Reflection of a High School Teacher with a Child Life **Specialist Certification**

RESEARCH CORNER

Embarking on Research: An Interview with Jessika Boles

SPECIALIZED RESOURCES

Supporting Children Coping with Hair Loss

- Why STEM in the Hospital Setting? Incorporating STEM into Patient Programming
- 36 LOOSE PARTS

CT Scanner

MOMENTS FROM THE PAST 39

A Research Agenda for the Generations: Rosemary's Vision from 1990 to 2020

- 41 ACLP Calendar
- 41 Webinars







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from the Executive Editor Kathleen McCue, MA, LSW, CCLS

Communication Remains the Key

ello, everybody! You probably were not expecting a column from me in this issue. In fact, it is a misnomer to call this "From the Executive Editor," since that title still belongs to our esteemed executive editor, Kathryn Cantrell. But Kathryn is busy putting together the first issue of *The Journal of* Child Life: Psychosocial Theory and Practice, so I am beginning a little early to write what will be a regular column from me in ACLP Bulletin. By the time you read this, you will have already received the journal and I hope you are as excited as I am about the reality of two separate publications for child life professionals. I'm also pretty excited to begin interacting with all of our child life readers out there and continuing the legacy of past editors by making ACLP Bulletin the engaging and informative publication that it has always been for the history of our organization.

As we move into a new era with two publications, we will be looking at clarifying the specific focus of each. Obviously, *The Journal of Child Life* will be a platform to share scholarly, empirical work that impacts both our own profession as well as the many other professionals who work to meet the psychosocial needs of children and families. *ACLP Bulletin* will continue to be a place where ACLP members can venture into the world of professional writing to communicate thoughts, ideas, and opinions; describe new and exciting endeavors; and share resources. I want to encour-

age all members to consider contributing to *ACLP Bulletin*. Beyond that, I want to suggest that child life administrators and academicians encourage students and practicing clinicians in the field to set some professional goals around writing and contributing to *ACLP Bulletin* as a way to develop skills. Don't let an innovative program or great idea or even a difficult challenge just remain at your place of employment. Write it up and get it to us. We promise to help you in every way we can to move from an idea to a completed article in *ACLP Bulletin*.

Speaking of getting material to us, we also want to hear from you about what you read. We now have the ability to use ACLP Bulletin as a platform for interaction and professional exchange. Do you have a thought about an article you read? Write us a letter. Do you disagree with the premise of some article? Write us your thoughts. We may attempt to initiate some sort of live forum for interaction between readers and authors. Would you like to see that happen? Now that our scholarly journal stands alone, we can be creative with ACLP Bulletin. So send us your ideas and suggestions, and let us know how to make this an even better benefit of your ACLP membership. I will be taking notes and listening carefully to any ideas that you propose. I look forward to interacting with you all. Together, let's make ACLP Bulletin a membership benefit that we can all learn from and continue to be proud of! *



President's Perspective

Jill Koss, MS, CCLS

"We Have to Start Someplace!"

phrase I seem to hear these days, and even find myself saying, is "You have to start someplace." It's usually at the beginning of a new initiative or when working to find the solution to a concern, and someone in the conversation uses it within the context of challenges or perceived barriers to success. It seems to be a way of saying "This isn't exactly perfect, and not the way it can ultimately be, but if we wait for THAT moment, we will never start. So this is our best for now, and we need to begin." By acknowledging that something has the opportunity to grow, improve, or morph into a better version, it becomes easier to start down a path when we don't have answers to all the "what ifs" and other unknowns.

When you consider the beginning of the Child Life Council as an independent association, it had to start someplace, and it did through the work of child life specialists who established professional practices and created the necessary documents and programs in order to separate from the Association for the Care of Children's Health in 1982. When there came a point in the growth of the profession we realized that there needed to be a more rigorous certification process for child life specialists to be recognized on a higher professional level, we moved to certification by examination in 1998. Many of the changes to processes were challenging, and may not have seemed perfect, but we had to start someplace.

I am proud to say that this past year has seen several initiatives important to ACLP get underway; we knew we had to start someplace after two years of the board discussing their impact and relevance. With the need to start someplace, the Diversity, Equity, and Inclusion Task Force was created and charged with writing a position statement to assist the association in moving forward with a better understanding of inclusivity

and where our current processes hinder diversity in the profession. At the same time, the ACLP Board of Directors recognized the need to better understand the premise of diversity, equity, and inclusion work, and spent a day of their fall meeting time in self-reflective training. The Emotional Safety Summit in November was an opportunity for ACLP to become the leader in pediatric emotional safety work, and the Patient and Family Experience Committee is now hard at work establishing definitions and action steps. The Summit was a defining moment, as this movement had to start someplace.

This year, the first edition of *The Journal of Child* Life: Psychosocial Theory and Practice launched on March 17 after several years of very hard work by the core team of editors and multiple reviewers. While this publication is not yet what the editors know it has the potential to be, it had to start someplace, and they have made it happen. The Academic/Clinical Internship Think Tank to be held in late summer is someplace to start as we begin to unpack all of the moving parts related to current challenges, the discernment of the role of ACLP, and potential solutions. In a recent Staffing Analytics Task Force meeting, while discussing the challenges of creating a pilot to study emotional acuity as part of the staffing analytics formula, this very phrase came up: We have to start someplace.

The benefit of starting someplace is that we have unlimited opportunities to improve upon, develop, and enhance as we move forward. When we know that what we've started is just the beginning, and not the final version, there's freedom in thinking "what if we" I'm proud that ACLP has a history of being—and the ongoing capacity to be—an association that allows for calculated risks even when there are uncertainties about the unknowns ahead. We continually move forward, starting someplace.



CEO Shares Jennifer Lipsey, MA

Start!

s you have read in Jill's column, we have to start someplace. As Jill articulated, the ACLP community has continued to expand from its starting point while retaining its integrity and focus on evidence-based practice; family-centered care; and play as a means of communication, engagement, and healing. As the new Value of Certified Child Life Specialists: Direct and Downstream Optimization of Pediatric Patients and Family Outcomes points out, our members use constant assessment and evaluation skills to produce a targeted, patient-specific course of action designed around the unique needs of the pediatric patient and family. We, too, use ongoing assessment and evaluation to ensure our programs and services are meeting the ever-changing needs of our evolving membership.

Within the strategic initiatives to investigate supply and demand of the profession, we are evaluating four key services: internship accreditation, academic endorsement, certification, and education and training, to assess each within the current landscape and member need. While we will not entertain discussion around controlling the market or supply of internship applicants, we are interested in learning about the various ways in which individuals are seeking academic and clinical training, specifically the internship. How has greater availability of child life-specific coursework impacted stakeholders when it comes to completing certification eligibility requirements while retaining the quality and integrity of the academic preparation needed to succeed on the job? With greater access to child life academic programs making it easier to complete coursework, how has the internship application process been impacted? How are clinical coordinators managing the volume of inquiries, applications, and materials they're receiving from students who are typically submitting applications to over 20 sites per rotation? What is sustainable? What is expected? What can be changed, by whom, and how will that impact the rest of the internship application and selection process? Solutions can

only be found through asking questions, actively listening, and seeking to understand each other's experience.

Starting in February, five board members began facilitating monthly focus groups with students, Certified Child Life Specialist academicians, clinical coordinators, leaders of endorsed academic programs, and leaders of accredited clinical programs. The focus groups offer each stakeholder group the opportunity to respond to a set list of questions designed to elicit feedback about the current internship application submission, review, and selection process and ACLP's (current and future) role. Inspired by the recognition that ACLP has implemented a number of standards programs—including certification, academic endorsement, and internship accreditation—that significantly influence one another and the member experience, it is our responsibility to evaluate the effects of each individually and systemically to assess whether and how the system culminates to supply the child life community with the next generation of child life professionals.

In the initial focus groups, themes included appreciation for the common application and those programs that follow the standardized recommendations, including the offer/acceptance dates and internship modules. Another theme surrounded the unwieldy, expensive, and confusing process of identifying what needs to be submitted, by when, to whom, and in what format—a concern that challenges all stakeholders. Shared by all were feelings of frustration and stress over what feels like an unsustainable process and unmanageable volume of materials. We are left, then, to wonder what kind of "welcome" into the community our emerging professionals are receiving after having to go through multiple rounds of the internship process.

We will look at how we are welcoming all to this place we call ACLP. It will remain true that not all interested in the profession will be successful in the certification process, but we need to consider where they fit in a community that we strive

to ensure is empathetic, supportive, responsive, and equitable. Under what circumstances will the number of internship opportunities increase? How will academicians balance the number of internships available with the number of students they accept into their programs? Will the child life community offer a different type of support and encouragement, pointing these individuals toward other pursuits where their academic, volunteer, and/or practicum or clinical training could also serve them well? ACLP must rely on each of you to help us understand how you will contribute to the success of optimum academic and clinical training environments so that we can strengthen

our programs and services to provide clear direction. We must collectively communicate about our impact to best understand how each point of impact affects the next. We must remove silos and build bridges between academicians and clinical coordinators.

We started this assessment of the current internship process by asking "Where do we begin?" and will meet in July for the Academic/Clinical Think Tank to raise the question, "Where do we go from here?" Whatever the answer, I'm confident we will take a retroactive look back at the year with amazement at how much we learned simply by starting.

A Note From the Editors

The Winter 2020 issue of ACLP Bulletin featured an article by Nikki Orkoskey. MA, CCLS, titled "They, Them, Theirs: The Importance of Pronouns and Other Considerations When Caring for Patients Who Identify as Gender Diverse." After publication, the editorial team came to understand that the cover image and the image selected to accompany the article may misrepresent the message of Nikki's article and take away from the article's important contribution. The picture that accompanied the article could be interpreted as reinforcing the idea of a male/female binary, while the article presented the concept that gender is best represented along a continuum. We regret that the images had the potential to misrepresent the author's voice and the content of the article. The editorial team is in the process of revising our image-selection process to ensure that all content clearly expresses the dialogue amongst our authors and readers.



Dear ACLP members,

It is with gratitude that we reach out to thank you for being a part of the ACLP community during these challenging times. We applaud YOU as you work to help patients and families build resiliency and coping in an ever- changing health care system, work to help students and other professionals manage complicated transitions and new learning environments, and as you take time to keep learning, growing, and sharing with your institutions and your child life community when faced with unanticipated time away from patient care.

You inspire us, and we believe in this community's ability to work through this new and changing situation with resilience, grace, and strength.

You are child life. We are child life...here to play, here to stay.

Sincerely,

Your Association of Child Life Professionals





U is for Urology:

A Spectrum of Services in the Outpatient Urology Clinic

Andrea Rentz. CCLS

C.S. MOTT CHILDREN'S HOSPITAL, ANN ARBOR, MI

don't want a poke! Don't let them give me a poke!" Any child life specialist who has been in the field for a while has heard these words from a scared and desperate child. What happens when their request starts with, "Don't let them touch me down there"? Genital exams, catheterizations, and procedures in this sensitive area of the body can cause distress leading to trauma for a child. The team in the C. S. Mott Children's Hospital pediatric urology clinic was seeing many children who were not only apprehensive, but non-compliant with procedures, including cystometrograms (CMGs) and voiding cystourethrograms (VCUGs). Some tests and procedures that could ordinarily be performed in the clinic or ordered for outpatient radiology were having to be scheduled with sedation. The team reported feeling helpless, overbooked, and as though they were not meeting the needs of patients and families.

In the Beginning

The relationship between the urology clinic and child life at C.S. Mott Children's Hospital grew when nursing started to heavily utilize the clinic on-call child life specialist for patients undergoing CMGs. This urodynamic study can be difficult for children to complete. In this procedure, a child must be catheterized in order to fill their bladder with saline to measure bladder pressure. The test is very sensitive to movement, and nursing staff must document when the patient coughs or sneezes so as to not skew the results. The urology team found that many children struggled with catheter placement, which can be painful, and in some instances results in a major power struggle between the child, the caregiver, and the providers. In the end, such procedures would need to be scheduled with sedation. This in turn would take up precious OR time and provide less-than-desirable test results, since the bladder would be relaxed under sedation, therefore skewing the pressures. Children who were on clean intermittent cathing programs at home (and regularly

emptied their bladder via catheter) were able to tolerate the catheter placement for the CMG, but they often became restless, as a test could last anywhere from 20 to 40 minutes, and results affected by movement could require a repeat test.

To address the challenges that patients were experiencing with CMGs, the clinic leadership collaborated with the child and family life department to create a 6-month pilot child life position. The pilot allowed child life to build on what had already been established by the clinic float child life specialist, who was designated to all uncovered ambulatory clinics.

To create teaching tools for the clinic, the pilot child life specialist obtained anatomically correct plastic baby dolls and created an opening in each to represent the urethra. These dolls were used for psychological preparation, allowing patients to learn about catheterization and practice coping skills as the procedure was explained. In some instances, patients would even catheterize the doll while their own catheter was being inserted, which allowed them to gain a sense of mastery and control (Lerwick, 2016). During catheterization, if patients desired an alternative focus, child life was able to provide developmentally appropriate procedural support. Patients responded positively to reading books, blowing bubbles, interacting with light up toys, playing games on the iPad, and general conversation. Anecdotally, the urology nurses reported that when child life provided preparation and support for CMGs, the results of the tests were clearer, there were fewer repeat tests needed, and parents reported less anxiety in themselves and their child.

Patients present to the urology clinic with a myriad of primary concerns, such as undescended testicles or recurrent urinary tract infections, many of which lead to additional testing, such as ultrasounds or VCUGs, and some patients will be scheduled for surgery. Preparation for these events is important to reduce the risk of healthcare-induced trauma (Lerwick, 2016). In the clinic, the child life specialist was able to prioritize

continued on page 8

U is for Urology: A Spectrum of Services in the Outpatient Urology Clinic

meeting with these patients on the day of their initial appointment, learn what further intervention was required, and implement preparation and tours for VCUGs and surgery.

Case Example

In one instance, a 9-year-old patient, Ashley* understood that her primary care physician ordered a test with a catheter because "she wasn't wiping good enough." When the child life specialist entered her room, she was shaking and tearful. The specialist was able to provide diagnosis teaching for ureteral reflux using a book on internal body parts, walk Ashley step by step through the procedure, and provide medical play during a tour in the fluoroscopy room, where the test would take place. Ashley wore a lead apron and administered the procedure on an anatomically correct doll as she practiced coping by blowing as if she was blowing out birthday candles. The child life specialist encouraged Ashley's mom to take pictures of the play session so that Ashley could look at them and remember how she helped the doll through her VCUG. The day after her appointment, Ashley's mom emailed to say how proud Ashley was of her accomplishment, writing, "I loved how you made it all about her and let her catheterize a doll so she truly understood. She told her dad all about it when he walked in the door and he asked her how she felt. She said 'I feel great; did you know even newborn babies can use the same catheter I have to? It's that small. I'm just going to make sure to blow out my birthday candles so the hole where my pee comes out opens."

Services Expand

Inserting catheters wasn't the only source of pain and anxiety. Post-operative catheter removals presented challenges for patients and staff as well. As child life specialists, we know the psychological stress and developmental regression that can happen when a child is held down and forced to comply with a frightening and painful event (Lerwick, 2016). It is empowering to prevent this kind of stress and regression by partnering with the team on the clinic level and working to prepare patients to cope through challenges.

For the smallest members of the urology population, child life was able to provide infant support for in-office



Psychological preparation for a VCUG.

circumcisions. Utilizing the sensorial saturation for infants' pain techniques (Bellieni et al., 2012), the child life specialist collaborated with the urologist and technician in order to soothe and comfort the infants using sucrose, swaddling, shushing, white noise, and soft singing/talking. The physicians were consulted and approved lowering the lights in the room with only a spotlight on the work area. With just those small changes in environment and support, the urologists remarked that both they and the babies had never been so relaxed during circumcisions. One of the physicians remarked, "It's like performing a circumcision at a spa!"

Environment modification didn't stop with circumcisions. During the check-in process, where some children were tearful and resistant to having their vital signs checked, child life collaborated with the medical assistants and arranged developmentally appropriate toys and books at the child's eye level. Children would select a toy and happily comply with having their height and weight checked. This modification modeled for clinic staff ways to give power to children in a powerless environment (Lerwick, 2016).

The beauty of having one child life specialist dedicated to urology clinic was that relationships could be formed and maintained, as many patients who have spina bifida are followed by this specialty service for their whole lives. As patients become more independent and spend time at school and with friends, it's important for them to learn how to care for themselves through clean intermittent catheterization if they are cognitively able to do so. Proper hygiene and body image come into play and child life was able to give more dedicated time and attention to teaching. Partnering with social work, we provided coaching around barriers to cathing at school or at friends' houses, and worked on preventing the smell that would result from urine leaking and cause embarrassment. We helped to make schedules (i.e. cath in the morning, between 2nd period and lunch, after school, and before bed), empowering teens to take ownership of their self-care and play an active role in their health.

All in all, child life presence in urology clinic allowed for many children to be supported through challenging exams and procedures, making the experience more positive for patients and families and allowing the medical staff to focus on the care they give. Many more patients were able to be seen with a child life specialist dedicated to clinic, and at the end of the pilot program, child life received a "Going Above and Beyond Award" from the urology clinic.

What Happened Next?

Was a permanent position funded? I would love to wrap this up with a bow and say that a full-time child life position was created immediately for the urology clinic. In short, the budget does not allow it at

this time. One positive outcome of the pilot was that pediatric urologist Courtney Streur, MD, identified an opportunity to conduct a formal research study. The "Child Life Intervention in Urology" research study in our clinic was recently approved by the IRB and has begun measuring the effectiveness of child life's involvement, specifically with CMGs. The study includes a pre-test survey to gauge parents' anxiety level and their perception of their child's anxiety level. During the procedure, parents complete the FLACC scale, which measures the patient's level of physical distress by rating their face, legs, activity, cry, and ability to be consoled (Malviya et al., 2006). A post-test survey asks parents to reflect on how the procedure went for their child and their perception of child life's effectiveness at reducing anxiety and pain. In addition to the parental measures, nurses complete a survey about their perception of the patient's experience, the effectiveness of child life, and the readability of the test results. If the patient is cognitively capable and at least 5 years old, they are asked to rate their pain on the Wong Baker Faces scale (Baker & Wong, 1987) and their anxiety on the Children's Fear Scale (McMurtry et al., 2011).

A full-time, dedicated child life specialist is something that the pediatric urology clinic is still working toward. In the meantime, clinic staff continues to page the clinic float child life specialist for every referral that comes through. Thanks to the pilot, now they know even more specifically the spectrum of referrals to make.

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^{*} A pseudonym is used to protect patient privacy.



A patient participates in a pickle-making activity.

CULINARY MEDICINE IN THE PEDIATRIC CLINICAL SETTING:

Collaboration between Registered Dietitians and Child Life Specialists

Brittany Lightsey, MS, RD, LD Kristen King, MS, CCLS

DWAINE AND CYNTHIA WILLETT CHILDREN'S HOSPITAL AT MEMORIAL HEALTH, SAVANNAH, GA

he Willett Children's Hospital strives to be a valuable resource for the healthy development of children and families in our community. The identification of consistent health messaging needed for our community has provided us guidance for both internal and external programming. Specifically, our hospital has found a unique benefit in the collaboration between registered dietitians and child life specialists. Combining the nutrition knowledge of a registered dietitian and the expertise in family engagement of a

child life specialist resulted in the development of culinary medicine practice at our children's hospital. Through this collaboration, our team is able to enhance the food literacy of our pediatric populations in the hope of empowering families to make healthy food choices that may improve health outcomes. Culinary medicine allows for demonstration, hands-on learning, and dialogue about healthy food options. Our hope is that families will have the confidence and self-efficacy to explore healthful foods and recipes after engaging with us.



Dietician Brittany Lightsey and the hospital chef pose with the kitchen cart they use in the culinary medicine program.

Choosing Culinary Medicine Programming

The evidence for adopting preventative strategies to improve health and well-being is abundant. Between the 1988-1994 National Health and Nutrition Examination Survey and the most recent 2015-2016 survey, childhood obesity rates have increased 85%, to a nationwide average of 18.5% (Trust for America's Health, 2019). Children's hospitals around the country are leading efforts to reduce the rising rates of obesity and are increasing the use of food as a therapeutic and innovative treatment modality for diseases such as epilepsy, childhood cancer, and diabetes. With the evidence for lifestyle medicine mounting, medical education is expanding to include nutrition education, often by way of culinary medicine.

Culinary medicine has been described as a new, evidence-based field that blends food and cooking with the science of medicine (La Puma, 2016). An article by chef and physician John La Puma states that "Culinary medicine is aimed at helping people make good personal medical decisions about accessing and eating high-quality meals that help prevent and treat disease and restore well-being" (La Puma, 2016, p. 1). Further, recent research indicates that nutrition knowledge may be incomplete without experiential learning or hands-on activities.

Why hands-on culinary education in a children's hospital?

- According to La Puma, there is "widespread dissatisfaction with conventional medical approaches to chronic illness [and] popular excitement about integrative medicine" (2016, p. 1).
- Research indicates that children engaged in tactile experiences, such as handling foods, have less food neophobia and greater acceptance of eating a variety of foods (Coulthard & Thakker, 2015).
- Parents report increased cooking confidence, healthy food preparation skills, and increased vegetable variety at home after participating in a cooking program (Overcash et al., 2016).
- Eating home-cooked meals more frequently was associated with better dietary quality and lower adiposity (Mills et al., 2017).

Typically, registered dietitians have leadership roles in culinary programming and medical nutrition therapy interventions within the hospital setting. As members of the multispecialty care team, dietitians are responsible for recommending changes in diet orders, as well as counseling and educating families about dietary recommendations. Because child life specialists seek to enhance educational outcomes during hospitalization and our dietitians have expressed the need for interdisciplinary assistance for developmentally appropriate education within the hospital setting, this collaboration was a natural fit.

Program Development and Implementation

Once the decision for collaboration was made, child life specialists and registered dietitions came together to plan programming. In both inpatient and outpatient classes, we strive to create an environment that is casual and fun, but at the same time allows families to have an opportunity to engage with the registered dietitian in a meaningful way. Our main goal is to enhance food literacy and self-efficacy for making overall nutritious choices at home, using a group class format for cooking demonstrations or communal recipe preparation. Secondary goals include highlighting local foods with health benefits as well as seasonality.

Our registered dietitian identifies a recipe that has health benefits and adapts it to meet therapeutic needs, such as diabetes or neutropenia, and/or food allergies. We have learned to share healthy "hacks" to kid-favorite recipes. We have also found that connecting food to seasonal celebrations or holidays increases excitement around the classes.

Using a mobile kitchen cart, our child life specialists and registered dietitians lead monthly culinary classes together. The cart is equipped with child-sized equipment and kitchen

continued on page 12

continued from page 11

Integrating Culinary Medicine in the Pediatric Clinical Setting: Collaboration between Registered Dieticians and Child Life Specialists

tools appropriate for the hospital setting and needed to make simple recipes. Our hospital food vendor aids in the procurement of the ingredients as well as the cleaning of the equipment following a class. In order to preserve our recreational spaces for openended play, class is held in a designated event space. We promote the event with flyers that include time, place, and activity for the class. Depending on the chosen recipe, we will either prepare individual ingredients for personal recipes or plan to work on one together. Settle-in activities are led by child life specialists for normalization and distraction while families wait for other attendees to arrive. The goal of the activity is to engage patients and families creatively and introduce them informally to the culinary medicine

program by bringing the focus to meal time. Our dietitian starts a class by sharing the recipe, reading it aloud together when possible, and explaining first steps. Classes typically last 45 minutes, which includes the settle in activity in addition to the culinary educational session. If participants need to return to their rooms before the recipe is complete, staff will deliver covered samples to patient rooms to be tasted at a later time. After the class, the children participate in an informal evaluation of the recipe (thumbs up/thumbs down) and that information is used to plan for future recipe sessions.

We have found the following to be necessary components for successful class implementation:

- Dietitians and child life specialists must be trained in food safety/food storage guidelines.
- It is important to partner with the hospital food service/ vendor for safe food storage and reduced food costs, as well as the cleaning of kitchen equipment that you use.



The settle-in activity underway as families are gathering for a culinary medicine event.

- Obtain multispecialty team clearance for patient participation, noting any dietary restrictions or requirements.
- Identify hospital space large enough to accommodate patients and attendees of various ages, with various equipment (IV poles, wheelchairs), and their caregivers.

Because of this novel collaboration and the lack of research surrounding pediatric culinary medicine programs, we are currently collaborating with the MaxLove Project, Children's Hospital of Orange County, and the University of Arizona to determine best practices for pediatric culinary medicine programming. We are testing registered dietitian-recommended recipes that we feel have the best nutritional and health benefits. In addition, we seek to ensure that recipes are fun, affordable, and easy for families to create in the hospital setting. The collaborative goal of these institutions is to be able to share information with other institutions interested in pediatric culinary medicine programming by identifying best practices, recipes, and opportunities for engagement to ensure successful class facilitation.

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Ozzy and artist Sadie Wilcox with two of his large-scale spin art creations prepared for public exhibition at the Berkeley Art Museum.

INTEGRATING ART INTO PEDIATRIC HEALTH CARE:

A Collaborative Approach

Sadie Wilcox, MFA, with Jen Johnson-Geisse, MA, CCLS

UCSF BENIOFF CHILDREN'S HOSPITAL OAKLAND. OAKLAND. CA

he Artist-in-Residence office at UCSF Benioff Children's Hospital Oakland is located in the historic wing of the main hospital. A small window on the west side of my office looks out on the hospital courtyard. I catch a glimpse of a young girl in the courtyard below. She is slowly ambling down the ramp, a physical therapist at her side. Her mother is trailing behind them, pausing for a moment to watch her daughter's slow and deliberate descent. A teenage boy sits on a wooden bench on the west side of the courtyard. He basks in the sun. His grandmother sits at his side, eyes closed. An enormous magnolia tree rises behind them, branches reaching wide. The white flowers above them bloom skyward.

The Artist-In-Residence program is part of the child life and creative arts therapy department. Unlike traditional Artist-in-Residence programs within museums, universities, or civic institutions that are short-term in nature, in our hospital the Artist-in-Residence title refers to a permanent staff position. The program was founded in 2004 with donor funds, supplemented by an initial grant from the Society for Arts in Healthcare. The Artist-in-Residence role offers an arts-informed perspective to complement the work of child life services and the interdisciplinary medical team.

continued on page 14

Integrating Art Into Pediatric Health Care: A Collaborative Approach

My office is flanked by built-in shelves on both sides. I have labeled bins of acrylic paint, colored pencils, liquid watercolors, sketch books, patterned paper, plastic stencils, and adaptive art tools of all shapes and sizes. My digital art supplies include a stack of iPads, a small video camera, a laptop, and robotic drawing kits. Books on child life, art therapy, expressive arts, trauma-informed practice, and pediatric palliative care line the shelves above the desk. My clinical training includes trauma-informed practice and family-centered care, and my approach is multidisciplinary. I am a member of the unionized staff, and have held this position for more than a decade. Polaroid photos of former patients I've worked with fill the walls around my workspace.

Child life specialist Jen Johnson-Geisse, MA, CCLS, knocks on the door and enters the office. She holds a printed census in her hand. She pulls up a chair, and we review the list of current patients on the pediatric rehabilitation unit. We discuss and reflect on the expressed needs of each patient, one by one. Jen and I have worked in tandem on many patient cases over the years.

In one such instance, Jen emerged from a single-occupancy hospital room and approached me from across the corridor. She described her work with a newly admitted teen, Ozzy*, who had sustained an abdominal injury causing him to be placed in a medically induced coma. When he awoke, doctors determined that he had experienced significant damage to his central and peripheral nervous system. At the time of his admission to our unit, Ozzy had lost most of his physical functioning and was unable to speak. It eventually became clear that his cognitive ability was unimpaired and he understood everything happening around him. Jen also learned that Ozzy had a long-standing interest in art. Given his injury and hospitalization, he was no longer able to access his previous methods of artmaking.

We began to discuss the ways in which Jen and I could align our individual skill sets to optimize Ozzy's care. We identified our primary clinical goal as facilitating outlets for emotional and creative expression while providing comprehensive family support. In order to achieve this goal, we explored a range of therapeutic activities that would offer Ozzy a sense of agency and empowerment during his long-term hospital admission. We agreed that a creative arts intervention, developed in close consultation with Ozzy and his family, could be an ideal point of entry.

Jen led me to Ozzy's room across the hall and we knocked

on the door before entering. Ozzy had his back to us, facing the window. Squeezing behind the power wheelchair and circling around the IV pole, we located ourselves across from Ozzy. Jen greeted him and introduced me. I offered a few examples of ways that previous patients had engaged with the arts. Ozzy responded with interest and we began to explore creative possibilities.

Ozzy experimented with multiple approaches to art-making during his hospital stay, but was most responsive to an adaptive spin art session that Jen facilitated in his hospital room. Spin art is an expressive modality that offers a processoriented approach. The medium provides ample opportunities for creative choice, control, and innovative adaptation. To create spin art, a square piece of paper is secured to a portable spin art machine. With the flip of a manual switch, the platform rotates at a high speed. The artist pours paint onto the paper and the centrifugal force draws the paint outward, creating original designs. Small-scale spin art machines are a low-cost, easy point of entry for children and teens, and they can be adapted to accommodate a range of accessible switches.

Following his initial engagement in spin art, Ozzy and his mother proposed the idea of working on a larger scale. We immediately took the opportunity to follow their lead. I began to work with Ozzy's mother, who put me in contact with the robotics club at his school, a club he had participated in prior to his injury. In response, the robotics club offered to build him a large-scale spin art machine for use at the hospital. I communicated directly with the club about infection control and storage size requirements in order to build a device specifically designed for our medical setting.

When the customized machine was built, Jen was able to collaborate with Ozzy's physical and occupational therapists, who set up a mobile arm and grip-support system. This allowed Ozzy to utilize his own body to manipulate and apply the art materials with significantly less assistance. Over time, he also began to utilize a form of "yes" or "no" response through head movement. This evolved to the use of an automated voice to indicate an auditory "yes" or "no" response.

During our first collaborative session with the large-scale spin art machine, Jen and I took turns offering acrylic paint bottles one by one. Ozzy indicated a "yes" or "no" reply in response to each color choice. We repeated the process and he indicated his next color. He was deliberate, thoughtful, and self-assured in the curation of his painting palette. After selecting his color combination, Ozzy decided on the loca-

^{*} Ozzy and his family granted permission to use his name in this article.

tion of color on the page. He then determined the amount of paint based on the length of time it was poured. He was able to activate the spinning of the device using adaptive switches initiated by subtle movements, including turning his head, rotating his wrist, and bending his fingers.

Ozzy soon expressed interest in sharing this creative resource with other patients. In response, Jen and I began addressing the emergent clinical goals of supporting Ozzy's socialization with peers, engaging in community-building activities, and reinforcing his sense of identity within the hospital. Jen offered large-scale spin art sessions as a group activity. I worked with two teen patients who filmed and edited their own video about the spin art process, with Ozzy positioning the camera on his lap to serve as the cameraman. Patients of all ages began to share their own spin art creations with hospitalized peers across multiple units. The large-scale spin art was featured on our weekly patient television show, the CHO Show, aired live to every hospital room. I was also able to arrange an opportunity for Ozzy to display his spin art at the University of California Berkeley Art Museum. The opening of the art exhibit attracted a full house at the museum, with Ozzy's family members and interdisciplinary medical team in attendance.

I arrived at the Berkeley Art Museum with an iPad in hand. Jen and I knew that Ozzy would be unable to attend the exhibit in person, so we coordinated to allow him to attend via video conference. While I walked through the museum, filming the exhibition as I went, the video was screened live in the teen lounge at the hospital. Ozzy's family members were at the exhibition and congratulated him over the live video feed. Museum attendees could watch Ozzy's spin art activity at the hospital, which was facilitated by our child life staff. Jen was available in the teen lounge to assist Ozzy with the video conference and help him interact nonverbally with those attending his exhibition throughout the evening. His virtual presence had a powerful impact on the museum attendees viewing his work on display.

As Ozzy approached discharge and prepared to return home, he and his mother suggested the idea of a farewell spin art session where he would be able to make wearable artwork on t-shirts for members of his medical team. This final session served as an important transitional intervention for Ozzy to say goodbye to his primary team of clinicians and leave his mark on the hospital community.

While working in tandem, Jen and I regularly come together to talk about next steps in a creative intervention. Our aim is to work in partnership with the patient and their family



Group art session with Child Life Specialist Jen Geisse that inspired the decision to make t-shirts for Ozzy's interdisciplinary medical team. One of Ozzy's signature designs is pictured on the bottom right.

members. We believe that artwork can serve as a powerful medium to share the first-person perspective of the patient, while also connecting with a community of hospitalized peers. In Ozzy's case, spin art was not only an accessible tool that enabled creative expression and empowerment in the inpatient setting, but it also provided a way for Ozzy to foster deep connections between his interdisciplinary hospital team and home community. Ozzy has since returned home from the hospital, but his large-scale spin art machine continues to be a valuable resource for new patients and families.

Looking out my office window, Jen and I pause as a helicopter lands on the nearby helipad. The wind picks up. The stretcher crosses the parking lot. We can see a small child tucked under the blanket. The medical team surrounds the child as they enter the back entrance of the hospital. Jen and I take a brief pause to acknowledge the new family entering the emergency department below, before turning our attention back to the next child on our list.

Special thanks and appreciation to Bayshore Christian Ministries for designing and constructing the large-scale spin art machine.

The Practical Side of HIPAA

Camilla Sutter, MA, CCLS

NEWTON-WELLESLEY HOSPITAL, NEWTON, MA

ach day in medical settings, conversations that challenge the privacy of health care information take place between clinicians. Giving report on patients in an area where it can be overheard by others, a conversation in a hallway when someone unexpectedly walks by, clicking on an incorrect chart, or glancing at the census of a co-worker you are meeting can all be breaches of confidentiality.

All of us have attended hospital orientation, whether as a volunteer, student, or employee. The need for confidentiality and privacy in the work we do is clearly emphasized in all training. In addition, when becoming certified as child life specialists, we agree to the fourth principle of the Child Life Code of Ethics:

Certified Child Life Specialists respect the privacy of children and families and maintain confidentiality within the standards and requirements of employers, local governing regulations, or private practice standards. (Child Life Certification Commission, 2020, Principle 4)

The above principle and hospital privacy rules are guided by HIPAA, the Health Insurance Portability and Accountability Act of 1996 (Health Insurance Portability and Accountability Act of 1996 Pub. L. No. 104-199, 1996). The HIPAA rules are written in an indefinite manner, allowing flexibility within

different types of work groups, but this ambiguity can also lead to more questions. Each hospital expects that its employees will know the risks, pay attention to the advice of the organizations built to oversee the rules, and use professional judgment in ethical grey areas.

The group overseeing compliance with the U.S. HIPAA privacy rules is each hospital's privacy and compliance office, often led by a privacy officer. It is their job to handle protected health information (PHI) and develop, implement, and oversee the organization's compliance (USLegal, n.d.). Privacy officers are trained in ethics, regulations, investigations and compliance, program management administration, technology/physical technical safeguards, customer service, and client/patient services. Often certified in Healthcare Privacy and Security (designated by the CHPS credential), they are professionally overseen by the American Health Information Management Association.

Recently, at our hospital, there was a child life breach of HIPAA that was filed anonymously with the compliance office. In a late-night phone call from the nurse director, the specialist was questioned about her discussion of an ill coworker. What had been intended as social support of staff who knew and worked with this person had been reported to the compliance line by someone who overheard the conversation. Although able to explain her

case, a warning was issued and the specialist was told that any other breach would lead to immediate termination. The fear of losing a job was nauseatingly real. Based on this event, our team spent two staff meetings with our hospital's privacy officers. This article and the chart below summarize these meetings in an attempt to clarify how HIPAA specifically impacts child life.

For most health care professionals, there are four basic tenets when it comes to PHI:

1. Access only the minimum necessary.

All employees must make all reasonable efforts not to use or disclose more than the minimum amount of PHI necessary to accomplish the intended purpose of the use and or disclosure, taking into consideration practical and technological limitations.

2. Never access PHI just for curiosity.

When in doubt, ask yourself if it is part of your job to know that information.

- 3. If it happens in the walls of your hospital, it stays in the walls of your hospital.
- 4. You can access PHI if it is needed to complete your job.

The uses of PHI can be summarized visually with the following chart:



ACCEPTABLE

- · Look at a patient's history before meeting and providing care
- · Access patient chart when the patient is an expected admission
- · Review a case for presentation at rounds or case studies
- · Discuss a de-identified case in child life class for educational purposes
- · Pre-read a note on a patient assigned to you who you were subsequently unable to see during your shift
- · Access patient information as required in order to perform your job duties
- · See names, ages, and diagnoses if they automatically fill when looking at unit census on your electronic charting system
- · Access patient information when pediatric patients assigned to you are on adult units
- · See information about non-pediatric patients on your unit if it is part of the design of your electronic charting and can't be avoided



ACCEPTABLE WITH APPROVAL

- · Look at your own records. (check with your institution as to whether you can directly read it or need to go through a patient portal)
- · Engage in peer review activities (e.g., manager reading an employee's notes, supervisor reading an intern's notes)
- · Conduct quality improvement work when minimal information is needed
- · Get address information for donation thank you notes (check your hospital's donor policy)
- · Take pictures or video on a personal device in any patient treatment areas, which must be authorized by marketing, communications, or public affairs
- · Access chart of an ill adult when working to support children of the patient; this can be verbal consent from the family and must be documented
- · For patients being transferred to another hospital, you may share information with child life at the next facility but only if it is within your hospital network, or the child's legal guardian signs a HIPAA release for this purpose
- · Call a patient's school for homework or as part of their care plan, with permission from parent or guardian documented in child life note and a HIPAA release, signed by the child's legal guardian for this purpose
- · Introduce patients to other patients or families to other families (without disclosing similar illness/disease/situations)
- · Do not access chart after discharge. Permission may be granted to document ongoing follow up for such interventions as bereavement support for family, school reintegration visit, etc.



NOT ACCEPTABLE

- · Do not look at the census of units you are not assigned to
- \cdot Do not share with someone outside of the hospital that you took care of a common friend
- Do not approach familiar patients outside of the hospital
- · Do not divulge patient information, including in casual conversation, to any individual not authorized to receive that information
- · Do not look at the records of anyone in your family
- · Do not share information about patients in public areas such as shuttle buses, elevators, or cafeterias, including de-identified information such "that patient I told you about..."
- · Do not share information about patients in virtual public areas such as blogs or social media
- $\cdot\,$ Do not read parts of the patient's chart that do not apply to your job role
- · Do not look at information because you are personally curious about a patient
- · Do not look up location/room of a friend or co-worker
- · Do not look up information (including room number) of a public figure
- · Do not forward thank you notes or comments from families to staff, other than the staff providing care, unless they have been de-identified



UNABLE TO CONTROL

· Parents taking pictures or videos of their own children in the hospital (we can remind them to help protect the privacy of other patients)

continued on page 18

continued from page 17

The Practical Side of HIPAA

Whether intentional or not, if one makes an error within HIPAA's guidelines, a breach has occurred. A breach is an impermissible use or disclosure under the privacy rule that compromises the security or privacy of the PHI (Office for Civil Rights, 2013.) Your human resources department will work with the privacy office to determine

disciplinary measures consistent with past disciplinary history and to ensure consistency for similar violations. Disciplinary action can range from an oral warning, to a written warning, suspension, or up to termination (Vine, 2017).

Ultimately, you are responsible for learning and staying current on specific procedures and the specific rules of HIPAA related to your work. Some standards apply to all jobs in the hospital, while others become role-specific and some unit-specific. Reaching out to your privacy officer and clarifying any departmental grey areas will help you remain HIPAA compliant while providing the best care.

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Civita Brown, left, poses with fellow Archives Management Committee members Jerriann Wilson, MEd, CCLS, Joan Turner, PhD, CCLS, and Lois Pearson, MEd, CCLS.

Civita Brown: DSA Recipient and Innovator in All Things Child Life

Jerriann M. Wilson, MEd, CCLS

RETIRED, TOWSON, MD

Putting Civita A. Brown, MSEd, CCLS, into a child life mold is not an easy task when considering the many accomplishments that led her to receive this year's Distinguished Service Award, to be presented at the 2020 Child Life Annual Conference in May. Serving in a multitude of roles, she has worked as a child life specialist, inaugurated a child life program in a local hospital, taught college level courses, coordinated child life internships, initiated a unique school-based child life program, and she oversaw the creation of the Child Life Archives housed at Utica College. This article will weave together the many facets of the legacy of her career as an innovator, historian, and mentor within the child life profession.

Civita is a long-time member of both of our professional associations—the now defunct Association for the Care of Children's Health (ACCH) and the Association of Child Life Professionals (ALCP),

formerly known as the Child Life Council (CLC). Her involvement with ACCH began over 40 years ago when she served twice as president of her local chapter. With CLC and then ACLP, her involvement dates from 1988 with membership on the Academic and Internship Committees. Most notably, Civita served from 2001 to 2016 as the co-chair of the Child Life History Committee, which became the Archives Management Group. In addition to managing the group, she and co-chair Lois Pearson, MS, CCLS, also co-produced three videos of our organizational history which were featured at five-year anniversary conference celebrations. Her participation locally and nationally was indicative of her commitment to furthering the outreach and goals of our professional body.

Civita's education prepared her for the variety of experiences she would encounter during her career. Her bachelor's degree was in social studies with additional

continued on page 20

Civita Brown: DSA Recipient and Innovator in All Things Child Life

graduate work in education, secondary education, and special education in New York and California. In 1977, when she returned to New York from California, she did not have a teaching credential for New York State so chose to take graduate classes at Utica College. Her instructor was Gene Stanford, PhD, who had just founded Utica's psychology-child life program. It was Gene who introduced Civita to the child life field and loaned her Emma Plank's book, Working with Children in Hospitals. She was hooked! Civita enrolled as the inaugural student in the psychology-child life program. Gene was her supervisor for three internships—a social studies student teaching experience and two child life internships, the last at Saint Elizabeth's Hospital in Utica, where she was invited to create a child life program.

In addition to Gene overseeing Civita as she began the new child life program, Richard (Dick) Thompson, PhD, CCLS, served as her mentor. Of those early days, Dick says, "I fondly recall our early meetings and work together in Utica!" Civita worked for 4 years at St. Elizabeth's before leaving to start a family. According to Civita, a lovely side story is that Gene was the matchmaker who introduced Civita to her husband, Thom Brown, PhD, a psychology faculty member.

In 1987, with daughters Amy and Megan in elementary school, Civita was hired by Utica College as the director of medical education for the clinical medical network, a grant-funded program that recruited medical students for programs in rural medicine to aid an underserved population. Six years later, she was hired as an adjunct professor in the psychology-child life program—the program in which she had been a student 16 years previously. After many years of student mentorship, Civita was appointed coordinator of internships. Completion of her master's degree in inclusive education in 2003 concluded her formal degree-earning education. One of her students, Rechelle D. Porter, LSW, CCLS, (now director of child life services at New York-Presbyterian) said of Civita, "Her passion for the field of child life made me immediately want to become a specialist. She encouraged her students to challenge themselves when selecting a placement." Civita retired from her teaching responsibilities in 2017. John H. Johnsen, PhD, former provost and senior vice president for academic affairs, commented, "Civita has absolutely been one of the pillars of the Utica College program. Her contributions to the program and its students have been consistent, uplifting, and prescient."

Civita has shared her knowledge and experience producing numerous presentations and articles on topics such as innovations in child life curriculum, grief and loss, child life services in the school setting, the history of play, tracing the paths of the pioneers [in child life], a legacy for our future, and the history of child life. One could see the seeds of an interest in history and archives developing. Civita teamed with Joan Turner, PhD, CCLS, to co-edit two books in the "Pips" series: The Pips of Child Life: Early Years of Play Programs in Hospitals and The Pips of Child Life: The Middle Years of *Play Programs in Hospitals.* Civita described her work in classrooms in the chapter "The School Setting" in the book Child Life Beyond the Hospital, edited by Melissa Hicks, MS, CCLS, LPC, RPT. In addition, Civita has been the recipient of several honors: recognition as an Outstanding Young Woman of America in 1978, and acceptance into the Alpha Eta Society, the national honor society for allied health professions, in 2008.

The Child Life Archives were born out of necessity, and Civita was the midwife who initiated and saw the process through. When she and Lois Pearson took over the History Committee, Civita realized that a controlled environment was needed for the preservation of the CLC papers and newsletters which had been stored in members' basements for some years. She thought that Utica College's Frank E. Gannett Memorial Library was a possible location and asked the library director if space was available for the collection. When he affirmed there was space, the college dean granted permission for the library to provide a cabinet to hold the papers and offered to permanently house the Archives.

Over the next two years, Civita worked with the CLC Board and Utica College to reach an agreement, which was finalized in 2003. Civita reports that the Archives collection now has quadrupled in size with its collection of personal papers, articles, hospital related toys, videotaped interviews with ALCP leaders, out-of-print books, as well as histories of academic and clinical programs. It continues to be used by child life students and professionals around the country. Utica College has embraced having the Archives there, as echoed

by Patrice Hallock, PhD, dean of health professions and education, who wrote "It means so much to Utica College to hold the Archives for the Association of Child Life Professionals because child life has played an important role at Utica College as well as for the profession as a whole." The library's coordinator of technical services, Herbert LaGoy Jr., MA, MLIS, Civita's partner in the day-to-day management of the Archives for ten years, wrote, "It is a delight to work with Civita. Her dedication and commitment to the child life profession is clearly reflected in the ongoing interest she has expressed in preserving the profession's historical record."

Another innovative aspect of Civita's work featured in the aforementioned *Child Life Beyond the Hospital* was the outreach to the community in 2003 with the first known program in the country to provide comprehensive child life services in a school. The program that she developed at Sauquoit Elementary School continues today. One of her students at that time was Paul Dischiavo, LCSW-R, Sauquoit's current school social worker, who says "Civita quickly became part of the school community. She worked one on one with a number of our students. I still have parents tell me how her work impacted them."

With an aim to continue these kinds of services on a broader scale, Civita and Susan Cooper, CCLS, formed a consulting company in 2009 to provide child life services in multiple school settings. They received a 6-year grant to create a Safe Schools project on mental health

issues in five school districts. Program director Jane Goodwin remarks that this "was exactly what she had hoped for—a program that addresses life changes and loss for school-aged students by incorporating play into a support system." Susan further described that they "provided training and in-services for staff and parents, grief groups, and individual services to children scheduled for dental and hospital visits." They also offered a teddy bear clinic, a CPR program, and a Healthy Choices Boot Camp which centered on healthy lifestyle choices.

Civita's work has impacted thousands of children, directly and indirectly, but the most impressive story is the one told by her daughter, Amy E. Caruso Brown, MD, MSc, MSCS, a professor of pediatrics. She relates a memory from her childhood when their father was admitted to the hospital's critical care unit with septic shock. In the visitor area, Civita sat with her two young daughters and drew pictures of the equipment, the tubes, and the wires they could expect to see in his room and described why his toes would be black. Amy wrote that, "She made the experience so profoundly ordinary that, 30 years later, I still associate the sights, sounds and smells of intensive care with safety, warmth, and care." And how does Civita feel about her career and the many roles she has played? She mused, "Sometimes I think I was just at the right place at the right time and everything came together. Of course, the support of family and so many amazing people helped." *

Distinguished Service Award

Since 1988, the child life profession's outstanding leaders and pioneers have been honored with ACLP's most prestigious award, the Distinguished Service Award. This award recognizes exceptional ACLP members, not only for their outstanding contributions to the field of child life, but also for their professional experience, leadership, integrity, and vision. All ACLP members are encouraged to consider nominating a deserving colleague, peer, or mentor. All <u>nomination materials</u> and guidelines are available on the ACLP website. The nomination and review process takes place in late summer/early fall each year. Questions about DSA criteria or the nomination process can be emailed to <u>awards@childlife.org</u>. To learn more about the lives, careers, and contributions to child life made by previous recipients of the Distinguished Service Award, please visit the ACLP website.



The 411 of Child Life in Higher Education

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hild life certification eligibility requirements include successful completion of one course containing specific content taught by a Certified Child Life Specialist (Association of Child Life Professionals, 2019). This requirement sparked a growth in the number of child life specialists who are teaching or are interested in teaching at the university level. While working as a Certified Child Life Specialist with students in academia and teaching child life content is rewarding, there are uniquenesses in the academic system that are quite different than the health care systems where child life specialists typically work. A lack of awareness about these academic realities could prevent a Certified Child Life Specialist from being an effective academic. In this piece, we will provide clinical child life specialists who have interest in pursuing the academic side of child life with some basic information about roles in academics. This information will also benefit child life professionals and clinical

program leaders who may be considering research collaborations with academic colleagues.

Role and Responsibilities of Certified Child Life Specialist in Higher Education

There are several different types of academic positions, and if we understand the roles and expectations of each, we can better understand the variability and diversity that is represented in child life higher education.

Adjunct Instructor

Many Certified Child Life Specialists are hired as adjunct instructors for a university. This means the university hires them to teach at least one course. Often times, this is the child life course that is required to be taught by a Certified Child Life Specialist. An adjunct instructor works part time for the university and is responsible for preparing and implementing a course (e.g., lecturing, grading). Adjunct instructors are typically not involved in the day-to-day activities of an academic program and are not accountable for the same responsibilities of faculty and staff (e.g., faculty meetings, advising students, etc.). The adjunct instructor position may allow a Certified Child Life Specialist to also maintain

their clinical work. To teach as an adjunct at the undergraduate level, a minimum of a master's degree is required.

Faculty Member

There are a growing number of Certified Child Life Specialist faculty members at universities. Types of faculty positions include clinical instructor, assistant professor, associate professor, and professor. The responsibilities of each varies. For example, a clinical instructor's main roles include teaching and service, while an assistant professor, associate professor, and professor often have research, teaching, and service responsibilities to uphold. Faculty members' responsibilities include involvement in day-to-day activities of an academic program such as decision making regarding course offerings; advising students; attending faculty meetings; advocating for the child life program and students; serving on department, college, and university committees; and serving as the leader of the child life program. There is often a requirement by either the university's accreditation agency or other oversight agencies that faculty hold a degree higher than the degree the students they teach are pursuing. For example, a doctoral degree would be required for faculty, whether full or part time, to teach master's level students. Often universities will require full-time faculty to hold a Doctorate of Philosophy (PhD), and with this degree, faculty likely have the responsibility of contributing to the academic discipline by engaging in research.

Day in the Life of a Certified Child Life Specialist Faculty Member

We now continue to explore the role of child life in higher education, examining day-to-day functions and responsibilities of a child life faculty member, which include teaching, advising, attending faculty meetings, coordinating a child life academic program, and completing research. In this position, a Certified Child Life Specialist faculty member works daily with students, faculty members, department chairs, and administrators.

The child life faculty member's primary responsibilty is teaching. At minimum, faculty usually teach at least two courses per term, with some teaching four or more courses per term. This involves course design, preparation, lecturing, and grading, which includes development of rubrics for fair and consistent grading. For preparation of lectures, one has to make sure they are inclusive of the latest research, texts, and trends of the topic and create lectures and learning experiences that are inclusive of all.

Another important responsibility of a faculty member is advising child life students. Academic advising of students includes helping them select what courses to take, mentoring them on the internship process, providing them with resources during stressful life events, completing letters of recommendation (e.g., for practicum, volunteer experiences, internships, jobs, graduate school), providing career support, and addressing a wide variety of other questions. For some child life faculty, advising also includes serving as the faculty advisor for a student organization.

A significant role for child life faculty is contributing to the implementation of a child life major/concentration. This includes many responsibilities, such as advocating for child life in department meetings, ensuring curricula are up to date with the latest requirements for certification, addressing issues (e.g., lack of student success with internship placements), maintaining endorsement from the Association of Child Life Professionals, meeting with potential new students, and working with the department chair to meet the goals of the program. The successful completion of these responsibilities involves many meetings, paperwork, emails, and such.

Some faculty members have research requirements which include additional responsibilities, such as significant time to design and implement research, obtain ethics approval, submit grants, and disseminate results through publications and presentations. Research faculty are often expected to publish at least three research publications and present at multiple conferences per year.

The myriad of obligations detailed above demonstrate that a faculty position is very much a full-time job with multiple responsibilities beyond teaching classes. Much as a clinical Certified Child Life Specialist is rarely in their office due to patient care or meetings, a faculty member is often attending meetings, doing research, writing in the library, or working on program design. In both roles, the child life specialist is dedicated to high-quality performance and ongoing professional development.

Trajectories for Advancement

There are two separate trajectories in higher education for advancement. The first is earning tenure to obtain a long-term, full-time faculty position. Tenured and tenure-track faculty are responsible to the university for three things: teaching, research, and service. These requirements are used

continued on page 24

The 411 of Child Life in Higher Education

to set employment goals, academic year commitments, and the parameters for annual faculty evaluations. Tenure-track faculty serve on yearly contracts over the course of five to six academic years, as long as their progress is deemed appropriate each year, until they apply for tenure. At that time, faculty peers vote to decide if the level of teaching, research, and service performed and produced is worthy of the applicant becoming an academic scholar. If yes, they have a job; if no, they no longer have a job. Because of this, being on tenure-track is like having a five- or six-year performance-based interview.

The second trajectory for advancement only begins after earning tenure. This is promotion through the ranks of service starting with assistant professor, then associate professor, and eventually the rank of full professor. Each rank has requirements and responsibilities for the three areas of teaching, research, and service, taking five to six years to progress through each rank for ongoing professional development accountability.

There are also non-tenure track full-time academic faculty positions that have renewable contracts ranging from one to three years. At the time of the contract's end date, the department chair, along with faculty, determines if the faculty member has performed well enough to be offered the position again, if finances and departmental needs exist to warrant the re-hire.

A Career Choice

The academic career path inherently includes prerequisites for Certified Child Life Specialists considering this profession. First, teaching must be both your passion and a skill set you possess, because in this role you are a teacher. Second, you should enjoy working with students as an advisor and a mentor in the arenas of academics, professional pursuits, and at times, even personal matters affecting their school progress. Lastly, for those willing to dedicate themselves to academic pursuits, a faculty position offers both realities and rewards.

Realities of a Certified Child Life Specialist Academic Position

Regardless of academic position, teaching expectations include course development, lesson planning, creating rubrics, writing exams, and grading, to name a few. These tasks are often challenging and time intensive because the available child life teaching resources are not mass-produced

course curriculums like those of larger, more established disciplines. Thus, child life academics must possess course and instructional design skills along with curriculum and program development knowledge to be successful.

Another lesser-known reality of the full-time Certified Child Life Specialist faculty member is the independence involved in providing child life at the university level. There is often only one child life faculty member, which requires the person to be a strong advocate for child life, an educator regarding the profession, and a strong self-starter with the initiative to implement a program of study without a team of child life colleagues for support.

To work with students in the academic realm of child life is a true joy for Certified Child Life Specialists who are teachers at heart. The most noteworthy benefit is the ability to help shape the next generation of child life specialists.

Rewards of a Certified Child Life Specialist Academic Position

The realities of academic positions in child life are balanced by and often outweighted by the rewards of the academic career. To work with students in the academic realm of child life is a true joy for Certified Child Life Specialists who are teachers at heart. The most noteworthy benefit is the ability to help shape the next generation of child life specialists. From a Certified Child Life Specialist perspective, another benefit is being able to apply your clinical child life experiences in teaching content you are passionate about, sharing the profession you love with students who are also enthusiastic about child life and eager to learn.

Academic positions also allow a Certified Child Life Specialist to remain up to date in the latest literature of the field, as well as engage in research to contribute to child life's body of knowledge to benefit both the academic discipline and profession. In addition, Certified Child Life Specialist academics learn to network in various ways because they are not on clinical teams of Certified Child Life Specialists. Being the sole Certified Child Life Specialist at a university

means the broader child life community becomes the academic's child life team. Networking can take place through various child life community forums on the Association of Child Life Professionals' website, meeting fellow academic colleagues from across North America, or talking with academics during academic meetings at conferences both nationally and regionally. The Association of Child Life Professionals' website has become an invaluable networking resource and an important tool for academics teaching child life students.

The Importance of Full-Time Certified Child Life Specialist Academic Faculty

Full-time Certified Child Life Specialist faculty play an important role proving beneficial to various aspects of child life.

- Benefits to the students:
 - Learning from a professional with clinical child life experience
 - Having a Certified Child Life Specialist mentor to guide along pathway to child life certification
 - Having a full-time Certified Child Life Specialist faculty member allows the academic program to apply for Association of Child Life Professionals Academic Endorsement
- Benefits to the profession:
 - Certified Child Life Specialist faculty invest in child life-focused student organizations
 - Students are exposed to professional development opportunities and taught the importance of continued learning beyond schooling
 - Certified Child Life Specialist faculty provide opportunities for and sometimes sponsor students' attendance at regional child life conferences, which deepens their investement in the profession
- Benefits to the field of inquiry:
 - Faculty holding a PhD are required to engage in research as part of job

- Implementation of child life-focused research
- Increase in body of knowledge for child life
- Benefits to the Association of Child Life Professionals:
 - Educate students about the important role of the Association of Child Life Professionals to the profession
 - Certified Child Life Specialist faculty involve students in various Association of Child Life Professionals initiatives
 - Expose students to conference information while encouraging attendance

Conclusion

Certified Child Life Specialists improve the lives of many children and families on a daily basis. Their ability to do so starts with education and training in the academic setting. To be able to work with students during such a formative and transitional time in their lives is a pure honor. This article provided information about the roles and responsibilities of child life professionals in academics, as well as some benefits of academic positions to students, the child life profession, and the Association of Child Life Professionals.

The Certified Child Life Specialist academic's role is vitally important for the quality preparation of well-educated child life students to propagate and advance the profession for years to come. Today's students are fortunate to have the opportunity to be educated by full-time Certified Child Life Specialist faculty with clinical experience who also serve as their first child life mentor. This relational aspect of child life perpetuates the child life profession's passion for, dedication to, and persistence in serving children and families during life's most stressful times. Acknowledging the importance and impact of Certified Child Life Specialist faculty upon all arenas of child life, it seems appropriate to offer a collective thank you to the universities that support child life academic programs. We hope this acknowledgement also moves each reader to take this opportunity to tell their child life educators and mentors how much we appreciate all they have done for us in our child life journey! **

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WITHIN THE SCHOOL WALLS:

Reflection of a High School Teacher with a Child Life Specialist Certification

Angelica Martinez, OCT, CCLS

HAMILTON-WENTWORTH DISTRICT SCHOOL BOARD, HAMILTON, ONTARIO, CANADA

School is a go-to topic of conversation with children. When meeting patients in the hospital, child life specialists often ask what grade the patient is in or what school they attend as a way to build rapport. Education plays an important role in molding children's identities and helping them reach socioemotional and intellectual milestones. In Ontario, Canada, during the 2019-2020 school year, 194 days are mandated for instruction (Ontario Ministry of Education, 2017); this means that over 1500 school days are completed by the time a student reaches secondary school!

In the Fall 2019 issue of *ACLP Bulletin*, Courtney Rosborough, MSc, CCLS, wrote about the benefits of her child life education in her role as a school-based emotional behavioral specialist. As a teacher in secondary education, I too have noticed the benefits of my child life training. Because of my background in child life, I bring additional strengths to the table when supporting youth in school, including identifying reactions to health-care-related stress and opportunities for stress reduction, being adaptable with teaching materials to reach more students, an increased awareness of cultural and developmental diversity, and an increased understanding of psychosocial needs impacting student growth.

Stress in Relation to Healthcare Experiences

I have observed several instances of stressful medical circumstances among students in the classroom, including students experiencing an acute hospital visit, students whose parents or family members are hospitalized suddenly, and students with close friends who are grieving. In cases where students have experienced a short-term hospital stay, I provide opportunities to debrief on the sequence of events, discuss the roles of individuals who provided care, and speak to the strategies they employed to minimize their stress. I also invite these students to share their medical experi-

ences with the class, which often prompts others to share similiarities or differences of their own hospital experiences.

Similarly, in cases where students' parents are hospitalized, I facilitate opportunities to discuss their feelings about the hospital and offer the space to listen, noting what information requires more clarification. During these times of stress, I reaffirm with students the importance of expressing their feelings to their family, asking questions, and engaging in expressive exercises like drawing or journaling. I actively strive to assess my students' responses to stressful moments in their lives and empower these students to use coping strategies beyond medical events and share them with their friends.

I actively strive to assess my students' responses to stressful moments in their lives and empower these students to use coping strategies beyond medical events and share them with their friends.

Curriculum and Content

My colleagues and I strive to use materials beyond slideshows and paper handouts to increase engagement and explore real world connections. When I teach courses like biology or child development, I bring in child life materials such as body systems books, anatomy aprons, and interactive iPad apps as an organic way to teach about illnesses and diseases that are prevalent in today's society.

As an example, when I facilitated a lesson on cells, I took the opportunity to speak about the psychosocial implications of rapidly dividing cells in a diagnosis of cancer. In one instance, I connected with a student whose aunt was hospitalized due to breast cancer. This

student was quite distressed about visiting her aunt in the hospital and was worried about why this happened to her aunt. During our interactions, I clarified physiological differences between cancer occurring in children and adults, and asserted the scientific and unknown causes of cancer. I make sure to provide space to speak one-on-one with students about their personal experiences with cancer and include opportunities for them to navigate feelings about cancer-related illness while learning about the scientific content. It is a valued characteristic of teachers to hold space for students to process the meaning of new content, and I feel humbled to infuse moments of clarity and emotional understanding into my lessons.

Cultural Competency

The school setting is an important place of cultural richness. In current Canadian teacher education programs, teachers participate in classes about the diversity found within our country, and the importance of creating connections between Canadian curriculum and multicultural traditions. Because I have spent time in the hospital setting with patients and families of many cultures, creeds, gender identities, and religions, I am aware of the need to participate in cultural education regarding situations like using preferred names, requests behind male or female doctors, cultural practices such as smudging ceremonies, and many more considerations.

At the school level, my board encourages students to form groups such as faith-based groups or groups for students who identify as LGBT. Teacher advisors support these students and their emerging voices. Recently, I took on the role as the Muslim Student Association teacher advisor at my school. My additional child life training in advocacy has been a strength in this position. During my time with these students, we discussed the physical barriers to their faith in school,

such as no available appropriate spaces for prayer rooms or food-free areas during Ramadan (a period of fasting for Muslims). With guidance from the student group, I raised these concerns directly with the principal and school staff. As a result, I was given the opportunity to provide an in-service discussing misconceptions regarding Ramadan, infused with students' suggestions of ways teachers can provide emotional support. My experience as a child life specialist gave me the confidence to advocate for an environment that helps all students and educators feel a sense of belonging to their school community.

Psychosocial Needs

Teachers promote social and emotional understanding in their classrooms, in addition to facilitating learning (Craig, 2009; Verhoeven et al., 2018). Every day, I work alongside teachers who continuously observe how their students are emotionally and mentally entering their learning environment. Teachers embrace the role they play in creating a healthy social environment, as this leads to higher outcomes of academic success (DeAngelis & Presley, 2011).

I advocate for time to share observations and strategies for students having a difficult time coping with school, which is a voice I strengthened during hospital team rounds. In the classroom, I make an extra effort to check in with how students are arriving emotionally, highlighting any small victories of the day. Just as a child life specialist reminds a patient of the small coping victories, I use positive prompts to help students build their self-esteem to achieve academic success.

As the needs of our students are increasingly identified and addressed, schools are excited to bring the expertise of a child life specialist on in order to share their child development knowledge, compassion, and advocacy to create better outcomes of academic success for all students that walk through our school doors.

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EMBARKING ON RESEARCH:

An Interview with Jessika Boles

s child life specialists, we are aware of the significance that research has in supporting and evaluating child life services. Specialists today are in a position to advance in the health care field by contributing to research projects that influence the policies and procedures of child life programming. To enlighten those with a desire to become involved in gaining knowledge about performing research, I interviewed Jessika Boles, PhD, CCLS, who is a child life specialist, researcher, and professor. By sharing our interview, we hope to provide support and guidance for child life professionals who are considering becoming involved in research.

Q: How did you first become involved in the process of research?

A: My first research experience was during my post-graduate studies at Vanderbilt University, where I participated in a program emphasizing evidence-based practice. A component of this program required lab participation and research projects; my placement was at the pediatric speech-language pathology clinic. At this clinic, my role developed into preparing children for a research experience where I integrated my child life skills with my new research role. I continued participating until graduating with my master's degree and becoming employed with St. Jude's. It was there where I met a professor who convinced me to get a doctorate degree to allow me to continue to collect data and compile research.

Q: What are the practical steps to implementing a research project or data collection within the field of child life?

A: Conducting research as a child life specialist doesn't have to look completely different from other fields, although there is absolutely room to integrate our skills and expertise into research in a way that honors patient and family needs and empowers them as active participants in all aspects of their care. The most practical first steps are 1) to listen, observe, and explore, and 2) to gather the resources available to help you in designing and completing your project. By listening, watching, assessing, exploring—in essence doing our work as child life specialists—we can find those key areas for clinical improvement that not only make a difference for patients and families, but fuel us with the passion to pursue new ways of thinking, doing, and serving. A research project is an extended investment of time and energy, thus it is important to focus on something you really care about and to identify the human and material resources you will need to bring your project to fruition.

Q: What current topics of research are of interest within the field of child life?

A: Over the past year or so, Joan Turner and I have been conducting a scoping review of the roughly 300 empirical articles written between 1998 and 2017 that mention child life specialists or child life services. In our analysis of trends in topic area, research design, authorship, and publication outlets, we have found an interesting shift in child life literature over the past 20 years. Although the number of articles mentioning child life specialists is increasing, play, as a topic of study, has decreased drastically, replaced instead by a sharp increase in articles about preparation and procedural support. So what we see now is a high percentage of articles based on procedural interventions, which are easier to conduct and measure (some may argue). I think we have an opportunity in our current moment to renew our interest in and focus on play, while also demonstrating the value of our assessment and communication skills, as well as our impact on family functioning/coping during health care encounters.

Q: How do you staff a research project within your hospital? Is funding often a requirement?

A: Fortunately, I have been able to staff several of my projects with graduate students from our hospital's affiliated university—one of the major benefits of working for an academic medical center. However, whether or not you are working in an academic facility, students are an excellent resource for supporting research projects. They are eager, available, and bring a layer of enthusiasm and skill that can help you get through even the roughest patches of a research project. I absolutely could not do my research without them! I have also been able to partner with colleagues in my child life department and their associated multidisciplinary team members in their clinical areas. Apart from my dissertation, I have never completed a research project without a team to support me—no matter the composition of that team.

Funding can be incredibly helpful—there's no denying that part! Most studies, especially ones that require hospital services (procedures, equipment usage, etc.) can quickly add up. However, you are more likely to access available grant funds when you already have pilot data suggesting the feasibility and effectiveness of an intervention. Although it may take more time, consider the possibility of doing a smaller-scale pilot study to test out your design, gather some data, and then increase your odds of snatching up those grant funds when they come along! There are, however, lots of ways to complete your study with little to no money in your pocket—but that spirit of collaboration will be essential.

Q: How can research relate to and impact our current child life practice?

A: I would love to one day be able to tell my students and interns exactly what evidence our interventions come from. The proof for many of our interventions exists, but for the time-honored practices of interventions like assessment or family support it feels more like we are passing on oral history traditions—that's how we've always done it—rather than empirically validated techniques. We see the anecdotal evidence every day, but I think a big part of our professional responsibility is to ensure that these practices last far beyond our individual or generational careers. We can do that in a spirit of continual advocacy and improvement by taking the time to do the research that carries so much weight in the health care industry.

Q: Any suggestions of research articles or education to read before diving in?

A: There are so many different types of inquiry, let alone types of research, that it can be overwhelming when thinking about where to start. I think our best resources are our colleagues who have lived the experience of designing and conducting research. I have a queue of research articles, book chapters, and videos that I use when I am teaching research methods, but my students usually feel as if they get the most out of learning from my experiences and those of other child life specialist researchers. For that reason, I think the ACLP Bulletin article series on research, EBP, and QI has been an excellent resource for our profession, as well as the research intensives and presentations at ACLP conference or on the learning management system. These materials not only highlight research tips, tricks, and processes, but do so in a voice and with a child life perspective that we are already familiar with (which as Piaget asserted, accelerates our capacity to construct new knowledge).

Jessika has participated in expansive research projects exploring intersections of pediatric cancers, medical and psychosocial trauma, and familial loss with cultural conceptions of life and death, health and illness, and childhood and adulthood. We are grateful to her for sharing her thoughts and wisdom with the child life community as we continue to grow and expand child life's role and participation in research.

SPECIALIZED RESOURCES











Specialized Resources is a column designed to share books, websites, apps, and other resources that may be helpful for child life specialists working with a specific population. This column represents only the personal views of the author, and the Association of Child Life Professionals does not endorse or sponsor the products or services mentioned. In addition, the authors of this column verify that they have no affiliation with the companies or organizations related to the products and services mentioned in this article.

Supporting Children Coping with Hair Loss

Jessica Westbrooks, MS, CCLS

CHILDREN'S HEALTHCARE OF ATLANTA, ATLANTA, GA

Individuals commonly assume that childhood hair loss is exclusively connected with chemotherapy treatment for a cancer diagnosis. However, children may experience chemotherapy-related hair loss when undergoing treatment for a non-cancer diagnosis, such as a blood disorder or genetic disorder. Additionally, children may experience hair loss due to diagnoses such as telogen effluvium, tinea capitis, alopecia areata, burns, or for other medical reasons (Al-Refu, 2013).

In a study of school-aged children's perceptions of alopecia, children demonstrated curiosity about why hair loss occurred for the child with alopecia. Some children also had misconceptions that the child experiencing hair loss was very sick or dying (Hankinson et al., 2013). Many adults may not be aware that it is developmentally appropriate for school-aged children to develop misconceptions such as these, and that it is important for these misconceptions to be cleared up with concrete explanations. Additionally, children benefit from developmentally appropriate opportunities for processing hair loss through play, reading books about children with similar hair loss experiences, and meeting other children who are also experiencing hair loss. Caregivers, child life specialists, and other trained professionals need to be equipped with resources to be able to answer children's questions, clear up potential misconceptions, and provide needed coping support.

By providing developmentally appropriate education and coping support for children experiencing hair loss and their peers, some stressors can be alleviated for these families already enduring significant cumulative stress. Below is a list of various resources that can help better equip child life specialists, teachers, parents, and health care professionals to support the learning and coping needs of children affected by hair loss.

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SUPPORT ORGANIZATIONS

- National Alopecia Areata Foundation (NAAF). This organization provides information about coping resources, parent support services, current research, and toolkits for medical professionals. This article specifically discusses emotional health, mental health, and school coping needs of children experiencing hair loss due to alopecia areata. https://www.naaf.org/alopecia-areata/alopecia-areata-and-emotional-wellness-in-children
- Children's Alopecia Project (CAP). This organization provides information and tools to help children and families with school re-entry and coping with alopecia in the school setting. Their website has examples of letters to send to parents, information about advocating for a child's coping needs on their 504 plan, and ideas for educating children's classmates about alopecia. https://www.childrensalopeciaproject.org/about/educational-resources/
- Head on Publishing. This website offers information about various camps, conferences, support groups, and coaching opportunities for children and family members affected by alopecia. They also offer a list of international organizations for families seeking support services in other countries. https://www.headonpublishing.com/resources/

WIG ORGANIZATIONS

- Children with Hair Loss (CWHL). This organization provides real hair wigs free of charge to children, teens, and young adults under the age of 21. Applicants must be experiencing hair loss due to a medical condition diagnosed by a physician. The application and information about hair packages are available on their website. https://childrenwithhairloss.us/apply-for-hair/hair-application/
- Wigs for Kids. This organization provides real hair wigs free of charge to children ages 18 and under experiencing hair loss due to chemotherapy, radiation therapy, alopecia, burns, or any other medical reason. Children must be referred by a medical professional to confirm eligibility but the general application can be found online. https://www.wigsforkids.org/apply-for-a-wig/how-to-apply/
- Crowns of Courage. This organization offers real hair wigs free of charge for children experiencing chemotherapy related hair loss. Children are able to have a halo wig made for them using their own hair (must be cut pre-hair loss) or donated hair. The application and additional information can be found on their website. http://www.crownsofcourage.com/apply
- Hair We Share. This is an organization that provides wigs free of charge to children ages 18 and under with a medical hair loss condition. They also provide free wigs to people over 18 years old based on financial need and approval. Anyone experiencing permanent hair loss can apply once a year for a new wig. https://hairweshare.org/wig-application/
- The Magic Yarn Project. This nonprofit organization provides princess wigs made out of yarn and superhero crochet beanies free of charge to children experiencing hair loss due to cancer, alopecia, or other medical reasons. Families can request a wig or find the patterns to crochet a wig on the organization's website. https://themagicyarnproject.com/wig-request/

- Bellami. This company sells synthetic and real hair wigs online. The synthetic wigs are high quality, affordable, and come in a variety of styles and colors. Teen patients have validated that the quality of these synthetic wigs is close to that of real hair wigs. All wigs can be ordered and shipped quickly. https://www.bellamihair.com/collections/bellami-synthetic-wigs
- Headcovers Unlimited. This company offers a variety of hats and wigs for sale on their website. They also provide helpful information about the benefits of different wig styles to help buyers decide on the right style. The baseball hats with hair attached are popular, comfortable, affordable, and easy to wear. https://www.headcovers.com/wigs/hats-with-hair/

BOOKS FOR CHILDREN

- Green, H. (2017). Where's your hair, Hannah? AuthorHouse UK.
- This book can be used in a classroom setting to better explain alopecia areata to children ages 5 to 9 years old. The main character, Hannah, shares her experience with hair loss, how hair loss feels, and the importance of friendship when coping with hair loss.
- Young, L., & Ellis, T. (2018). Hair in my brush. Book Patch.
 - This is the story of a young girl named Briana who is coping with a diagnosis of alopecia. She talks about her experience losing patches of hair gradually and then learning about her sense of identity without hair. It is a great book for elementary aged children.
- Brunette, C. (2010). I don't care if I lose my hair. Basket of Hope.
 - This storybook discusses the process of a child losing hair, finding resources to cope with hair loss, and going back to school without hair. The word chemotherapy is mentioned once, but the story could be modified if needed when reading to a child.
- DeLand, M. M. (2011). The great Katie Kate tackles questions about cancer. Greenleaf Book Group Press.
 - A wonderful children's book that mentions hair loss in relation to chemotherapy treatment for a cancer diagnosis. Hair loss is explained in basic, non-threatening terms as part of a longer story. Parents could skip pages of the book to cater the story to their child's diagnosis and treatment plans.

OTHER RECOMMENDED RESOURCES

Losing Your Hair. This video from the Imaginary Friend Society (a program created by the Pediatric Brain Tumor Foundation), provides a basic explanation of hair loss due to chemotherapy treatment. The word cancer is used once briefly at the start of the video but is not emphasized throughout. https://www.youtube.com/watch?time_continue=3&v=4hGGONcUUOQ&feature=emb_logo

- Bald Girls Do Lunch. This is a blog where parents, children, and families share about their experiences with alopecia. Blog posts are relatable and offer the opportunity to connect with other families. This post is a mother's story of her daughter's journey with learning about and adjusting to an alopecia universalis diagnosis. http://blog.baldgirlsdolunch.org/a-mothers-take-on-daughters-journey-with-alopecia
- CureSearch. This organization offers specially made bald Barbie dolls that
 are available in dark or light skin tones. These dolls can be ordered free of
 charge by a parent of a child with cancer, sibling of a child with cancer, or
 health care/hospital professionals working with children who have cancer.
 https://curesearch.org/Special-Barbie
- American Girl. This company has dolls, with and without hair and in a variety of skin shades and eye colors, available for purchase. Dolls can be sent to the doll hospital at any time to have hair placed on the head or removed from the head. These dolls provide the opportunity for children to process full hair loss, partial hair loss, hair regrowth, or other changes throughout the hair loss journey, through play. https://www.americangirl.com/shop/c/dolls-without-hair
- Toca Hair Salon. This app is available for purchase on the Apple Store. It is an interactive game that provides an opportunity for children to experience a feeling of control in relation to hair, hair loss, and hair regrowth while roleplaying as a hairdresser. https://tocaboca.com/app/toca-hair-salon/

Jessica Westbrooks has been a child life specialist for 5 years and has worked with patients and families in an outpatient hematology/oncology setting for 4 years. In her time working in this environment, she has helped create programming specific to hair loss, such as hair loss coping kits, teaching sheets, and lists of support organizations for patients and families. While her experience has been mainly with patients facing hair loss due to chemotherapy treatment, Jessica is passionate about connecting patients with resources for support during their hair loss journeys and has worked to find support organizations and wig organizations that are not cancer specific. Jessica can be reached at jessica.westbrooks@choa.org.



STEM mentor Kristan Summers and a patient work on an activity on the mobile STEM cart.

WHY STEM IN THE HOSPITAL SETTING?

Incorportating STEM into Patient Programming

Beth Fitzpatrick, CCLS Kristan Summers

DOERNBECHER CHILDREN'S HOSPITAL, PORTLAND, OR

CIENCE + TECHNOLOGY + ENGINEERING + MATH = STEM. These fields are key academic subjects that impact every aspect of our lives, from what we eat to where we live and how we get from here to there. STEM involves the how and why of understanding our world and beyond. As child life specialists, we focus on helping patients and families understand the how and why of the medical environment. The influence of STEM in the medical world opens up areas of interest and conversations with patients that may not otherwise occur. Offering STEM activities in the hospital is a perfect pairing with child life.

Hospital STEM programming involves offering patients and siblings opportunities to explore these subjects in the hospital environment. These activities may be offered in a classroom-style setting or by utilizing a mobile cart that goes from patient room to patient room. Terminology defining STEM programming can vary from hospital to hospital. Programs may be referred to as makerspace, mobile maker carts, Maker Therapy (Krishnan, 2015), or mobile STEM

carts. The foundation for this programming, however, is the same – science, technology, engineering, and mathematics activities.

With hospital STEM programming, patients choose their own area of interest and proceed at their own pace, without any academic expectation. Child life methodology is utilized for optimizing opportunities for choice, autonomy, and mastery. The hospitalized patient may miss out on enrichment opportunities, such as STEM, offered in their own traditional school setting, so this type of programming enriches the hospital experience, especially for those patients who are frequently hospitalized. STEM experiences also offer the child life specialist new ways to engage with patients while possibly sparking patients' interest in their own medical condition, providing opportunity for further dialogue between the child life specialist and patient to understand and explore relevant topics.

Pioneers in hospital-based STEM programming such as Gokul Krishnan, PhD, founder of Maker Therapy at Lucille Packard Children's Hospital, and Roger Ulrich, PhD, EDAC, of The Center for Health Design, realized the rich opportunities that STEM activities could offer the hospitalized patient. As Krishnan puts it, "These mobile maker (STEM) environments are designed to encourage social interchange,

increase physical mobility, and positively affect mood for children who have chronic illnesses" (Krishnan, 2015, p 25).

OHSU Doernbecher Children's Hospital STEM Program

The STEM program at OHSU Doernbecher Children's Hospital "took flight" as a result of a generous grant from Delta Airlines. Our goal was to offer enriched programming opportunities for our patients while incorporating the child life philosophy of promoting healthy development and coping through play, education, and expressive activities in the health care setting. We wanted to decrease feelings of isolation, provide opportunities for mastery, increase patient self-confidence, enhance creative offerings, promote physical mobility, and create skill-building opportunities for patients. We began developing our program by following the recommendations of STEM pioneers. Dr. Krishnan has described four major concepts for a makerspace's success: It should be colorful and bright, it must be engaging, it should serve as a workspace, and it needs to invite collaboration with others. We also reached out to several hospital makerspace programs to gain knowledge of what programming success looked liked for them.

At Doernbecher Children's Hospital we decided to use a mobile STEM cart, which is taken into patient rooms, integrating well with the patients' medical routine by providing flexibility to work around medical therapies. Our cart is colorful in design, incorporating our hospital logo along with our sponsor's logo. It is visually stimulating, complete with external LED lights that invite curiosity as to what might be inside. Our STEM cart has a large tabletop workspace and houses a 3D printer, various robotics kits, engineering kits, circuitry, coding activities, math activities, and simple experiments, along with an instant camera to document the experience. The cart and all of its contents are completely wipeable with hospital-grade wipes. All instruction sheets and engineering diagrams are laminated so they can be taken into isolation rooms.

A portion of the funding for our program was designated for a STEM mentor position. We hired a former hospital schoolteacher, capitalizing on her expertise in understanding the unique needs of the hospitalized patient. She is very knowledgable about the specific diagnoses of our patient populations, which aids her in selecting patients for the STEM experience. She collaborates with the unit child life specialists to address any patient selection considerations and she shares the successes and any challenges of her day. She keeps data on the number of encounters each day and the types of activities in which patients participate.

Our STEM program is currently offered on three inpatient units, three days per week, and is focused on patients 6 years and older. Units range in size from 17 to 24 beds. Each day is dedicated to a specific unit, but if the census is low that day for that unit, the STEM mentor may reach out to patients from the other two units. Sometimes a patient may have a STEM experience all three days.



Activities are described on laminated instructions, which are cleanable for reuse.

A typical day with the STEM cart begins with the unit child life specialist identifying potential patients for the STEM mentor. Our STEM mentor introduces herself and the STEM cart to the prospective patient. The STEM cart is usually intriguing to the patient and most often welcomed. If medical treatments are taking place, the STEM mentor arranges a more convenient time. Visits range from a quick 15-minute activity to a project that takes several hours. Each patient chooses the activity of interest and creates and explores at their own pace. The STEM mentor works alongside the patient, assisting with the projects as invited to do so by the patient, and may also leave an incomplete project with a patient for them to continue working on independently. Patients can create tangible objects with the 3D printer, which not only gives them a sense of accomplishment and mastery, but also sparks conversations with medical staff. With the time spent together, the mentor and patient form relationships which often include other family members who are present, further normalizing the environment for the patient and family. At this point in time the mentor does not document specific encounter information, but relays patient participation and concerning behavior to the child life specialist, who then documents this in the patient's chart, if warranted.

In addition to STEM activities we offer through the cart, we partner with a community robotics club comprised of high

continued on page 34

Why STEM for the Hospital Setting? Incorporating STEM into Patient Programming

school students who visit the hospital quarterly. These students work with patients one-on-one or provide a lobby event. They offer a make-and-take simple robot activity and promote an interest into the world of robotics. The club has brought their life-sized competition robot for patients to steer through the hallways and interact with patients. These events have been very well received.

Our STEM program has received very positive feedback from patients, families, and staff. On several occasions, medical staff members have spent extra time with a patient to see how a specific activity would turn

out. Patients and parents have verbalized their excitement in having these types of activities available during their hospital stay. As a parent of a patient with frequent hospitalizations stated, "This is a fabulous opportunity for my son to do something he wouldn't otherwise get to do." We are excited about our program's success and hope to expand this opportunity to other units by adding a second STEM cart for our inpatient oncology population.

We have learned that starting a STEM program is not difficult. Based on our experience, here are a few suggestions for those interested in implementing a STEM program:

- As you plan your space, incorporate the components suggested by the STEM pioneers:
 - it should be colorful and bright,
 - it must be engaging,



Bedside activities make STEM accessible to patients.

- it should serve as a workspace,
- and it needs to invite collaboration
- Be creative with the resources you already have. Hospital STEM programs can vary from science projects in simple plastic containers to mobile carts or even classrooms.
- Supplies may be ordered through online resources or purchased from local stores that offer STEM kits. We've added these kits to our hospital website's wish list.
- There are many resources available online with suggestions of how to supply your own STEM programming.
 For example, makerspaces.com helps schools and libraries run their own makerspaces, but these ideas can easily be applied to the hospital setting.

You do not have to be a STEM expert to get started. An interest in offering new opportunities and a willingness to learn is the first step. **

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CT Scanner

Aleida E. Guerra, CCLS, CPST

THE CHILDREN'S HOSPITAL OF SAN ANTONIO, SAN ANTONIO, TX WONDERS AND WORRIES, SAN ANTONIO, TX

computed tomography scan (also known as a CT scan or CAT scan) is a radiological procedure that takes detailed pictures of the inside of the body for diagnostic purposes. It is common for people to refer to a CT scanner as looking like a large donut due to its circular shape with a hole in the center. A radiologist or physician may order liquid contrast dye by mouth or through an IV to help enhance the pictures from the CT scan.

When a patient is positioned on the CT bed, a red light is visible from the center of the machine to help the staff align the patient's body. The red light is not a laser, just a light that helps guide which part of the body needs a picture taken. The patient will hear a humming noise when the CT scanner is taking pictures. Patients will notice the bed moving slowly during the scan, but they will not have contact with the center of the machine. A radiology tech can talk to a patient through a speaker on the other side of a window. Some CT scanners have an automated voice that may guide a patient to take deep breaths during the process. In order to obtain the clearest pictures, patients who are young or have a hard time holding still on their own may need sedation or anesthesia for the scan.

Since procedural testing can be difficult for patients, this CT model (see Figure 1) provides toddlers, preschool, and school-age children the opportunity to observe and rehearse through play. A Barbie doll was added to demonstrate the step-by-step process

Figure 1
Completed CT Scanner



from beginning to end. Action figures and/or animal figures could also be alternative options for patients to choose, if available. Through play, a patient can utilize the CT model and a doll of choice to go through the steps he or she will experience during the CT scan. First, the patient will learn how the doll lays on the CT bed; this can open up communication about

which part of the body is having pictures taken and the reason for the CT scan. Next, the patient can manipulate the safety belt on the bed to reinforce safety and the importance of holding still. The patient can then manipulate the movable bed to rehearse how the bed can move toward the center of the open circle and back out. Utilizing the app "Simply Sayin" (CT Scan, 2019)

provides preparation for the audio sounds made by a CT scanner. The CT bed can slide backward upon completion of the CT scan and then the safety belt can be unfastened to demonstrate completion.

This tool has recently been utilized to not only educate and prepare patients for CT scans, but also to assess how patients will cope during the imaging process. Incorporating medical play with psychological preparation can be helpful to clarify misconceptions and to assess whether the patient can hold still. This could also be beneficial to assess a patient who is scheduled for sedation, as being able to complete the procedure without sedation potentially benefits the patient, caregivers, and the hospital (Khan et al., 2007).

Materials:

- Drum (14" x 14")
- Two 14" styrofoam wreaths

Figure 2
Disassembled Drum Kit



- Two 2" x 4" x 8" wood pieces (for the base)
- Two 5" x 12" x 1" wood pieces (for the bed)
- White spray paint
- Three rolls white duct tape (to make everything easy to clean)
- 12" side mount extension (drawer slides)
- Measuring tape
- Scissors
- Pencil
- Cable ties
- Screws
- Saw
- Drill
- Stickers
- Ribbon
- Adhesive velcro

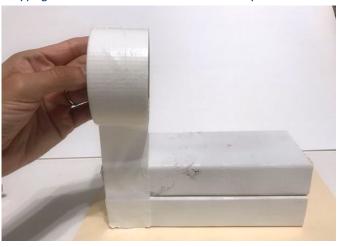
Instructions:

- 1. Take apart children's drum set. Remove all clips around drum to separate all pieces and remove clear plastic cover to allow easy access to spray paint drum later (see Figure 2).
- 2. Cover the floor for easier cleanup. Lay out wood pieces, two styrofoam wreaths and center cylinder of the drum. Spray paint items (2 coats, if needed) and allow to dry.
- 3. Wrap duct tape around each styrofoam wreath (see Figure 3).
- 4. Stack both 2" x 4" x 8" wood pieces on top of each other and wrap together with duct tape. This will be the base of the mobile patient transport bed (see Figure 4).

Figure 3
Wrapping the Foam Wreath with White Duct Tape



Figure 4
Wrapping the 2" x 4" x 8" Wood Pieces with Duct Tape



continued on page 38

Loose Parts: CT Scanner

Figure 5
Attaching Mounting Extensions



- 5. Lay side mount extensions (4 parts) and match identical pairs. Place flat extensions on edge of one 5" x 12" x 1" board. Mark screw placements with a pencil prior to drilling to ensure 12" mount extension is aligned correctly, then screw into place. This will become the bottom portion of the mobile patient transport bed.
- 6. Align remaining mount extensions to other 5" x 12" x 1" board. Mark screw placement with a pencil, drill, and then screw into place. Align both boards to have mount extension wheels fit in place to allow top wood board to slide back and forth (see Figure 5).
- 7. Mark two small circles, about 4" apart, in the center of one 5" x 12" x 1" board for screw placement. Place on top of duct-taped 2" x 4" x 8" base. Have someone hold the 5" x 12"x 1" board in place to drill screws where circles are marked. This will secure one bed piece to base (see Figure 6).
- 8. Cover both 5"x12" wood boards separately with duct tape.
- 9. Cut ribbon, add velcro pieces to both ends, and place around sliding wood piece to make safety belt.
- 10. Re-assemble drum. Place one styrofoam wreath over drum. Cable ties can be threaded through small open holes around drum to secure styrofoam wreath. Repeat this step for the other styrofoam wreath on the other side of the drum (see Figure 7).
- 11. Apply stickers to make CT scanner pediatric friendly.

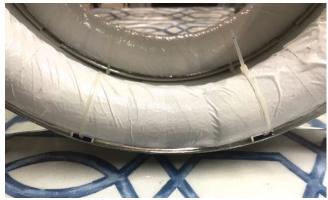
Additional Notes:

I found a children's drum set and saw the potential to

Figure 6 Securing Bed to Base



Figure 7
Attaching Wreath to Drum



transform into a CT scanner. Smaller drums could also be utilized as smaller CT scanner replicas to fit smaller dolls/action figures. Various cylindrical items, like an empty oatmeal canister or empty aluminum can, could work as alternative parts to make a CT scanner.

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A RESEARCH AGENDA FOR THE GENERATIONS:

Rosemary's Vision from 1990 to 2020

Jessika Boles, PhD, CCLS

MONROE CARELL, JR. CHILDREN'S HOSPITAL AT VANDERBILT, NASHVILLE, TN

osemary Bolig, PhD, began her career much like today's emerging child life specialists. After completing her bachelor's degree in family studies and child development at The Pennsylvania State University, she secured an internship in the child life department at the Johns Hopkins Hospital (Wilson, 2016). Shortly thereafter, she found herself hired onto the child life staff at Hopkins, and within a four-year span (quite unlike most of today's child life professionals), assumed the role of director of the child life department—a clear testament to her clinical prowess and leadership ambitions.

Rosemary later worked as a play leader in the United Kingdom and went on to complete two additional degrees: a master's degree at her alma mater, and a doctorate in early childhood education at The Ohio State University (Wilson, 2016). Throughout these experiences, the defining feature was play—the benefits of play, the practice of play, and the study of play in hospitalized children's lives. Her well-honed skills and high-quality education were an invaluable asset to the programs she led, the families she served, and the projects and committees she participated in as an active member of first the Association for the Care of Children in Hospitals, and then the Child Life Council.

As one of the first child life specialists in academia, Rosemary saw all sides of the dialectic of theory, practice, and



Rosemary Bolig, PhD. Photo courtesy of Dr. Judy Rollins.

research. In her faculty positions at The Ohio State University, Mount Vernon College, and the University of District Columbia, Rosemary put her clinical training and research expertise to work on behalf of the child life profession. Whether conducting her own original research, writing and editing seminal works on child life practice, or serving on the Research and Scholarship Task Force of the Child Life Council, she was a voice for evidence-based and play-based psychosocial care of hospitalized children and their families.

In 1990, Rosemary authored an unpublished paper for the Research and Scholarship Task Force entitled, "Child Life Contexts: A Research Agenda." Currently housed in the ACLP archives, this 33-page typewritten document (with her own handwritten corrections and edits included), was constructed to "present a rationale and

agenda for the study of play, relationships, and other activities in child life contexts and the impact of children's participation in child life programming on psychosocial and physical recovery as well as post-hospital adjustment" (Bolig, 1990, p. 2). The conclusions she drew clearly reflected our current need for research from and about the child life profession, despite being an echo from thirty years past:

In sum, the major questions are: whether play occurs during hospitalization and under what conditions; whether play is a valid measure of children's psychological state during hospitalization; what factors contribute to variations in children's play during hospitalization and whether children's play during hospitalization contributes to variations in physiological and psychological recovery. Further, questions about the type(s) of child life program, variations in facilitative relationships, and physical play environments also need to be addressed. (Bolig, 1990, p. 16)

In addition, these conclusions prompt us to reflect together on our progress—and room for growth—as a profession.

In 2019, a total of 96 articles published in peer-reviewed journals mentioned child life specialists and their work in some capacity. Although 12 of these articles describe play in relation to child life practice, only two explicitly describe the value of play interventions apart from structured protocols of procedural preparation and support.

continued on page 40

A Research Agenda for the Generations: Rosemary's Vision from 1990 to 2020

As highlighted in their forthcoming article, Boles and Turner (in press) found a similar trend when evaluating child life research published between 1998 and 2017; namely, preparation and procedural support studies are rapidly proliferating, whereas those that address play as the foundation of child life practice are decreasing at an alarming rate. Considering the range of child life articles, from merely six published in 1998 to nearly a hundred in 2019, Rosemary's vision for research to validate and extend our field is unfolding in real time. However, on the precipice of 2020, it is important to recognize the direction our collective research

efforts have taken and consider avenues for going back to our "roots" as child life specialists.

One of Rosemary's last projects before her death in 2017 was updating her chapter on play in the well-known book, *Meeting Children's Psychosocial Needs Across the Healthcare Continuum* (2017). As an author and editor, Rosemary assembled an indispensable text that seamlessly merges the evidence of the past, the issues and needs of the present, and a research agenda for the future. With the inclusion of a research course for certification requirements, and more research education, network-

ing, and engagement opportunities than ever before, play is not only a quintessential behavior of childhood, but also a boundless opportunity to validate the effects of child life services on psychosocial and physiological outcomes. Ironically, but also poignantly, Rosemary's research agenda for child life was never finished; it ends with a heading entitled "Temperament." Now, 30 years later, we all have an opportunity to write the next page, perpetuate Rosemary's legacy of play, and "provide more evidence of the effectiveness of [our] practice (and play)" (Bolig, 2017, p. 106). *

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2021 ACLP Annual Conference Call for Papers

The 2021 Annual Child Life Conference will be held in Los Angeles, CA, May 27-30, 2021, and it's time now to start thinking about presenting. Do you have an innovative idea or a research project you'd like to share with your colleagues? Consider sharing your work with more than 1,000 child life professionals at the Annual Conference. It is never too early to start planning an engaging presentation on a topic of importance to your profession.

The Conference Program Committee invites you to plan now to submit an abstract during the submission window of June 1 to June 30, 2019. Member and attendee feedback continues to indicate a need for presentations related to advanced-level topics, leadership, and child life in alternative settings. In addition, there is demand for topics addressing the core competencies, especially ethics and assessment. Conference presentation formats range from posters to panels, so there is a format to fit your topic and presentation style. Participate in making the 2021 conference a rousing success!



ACLP Calendar



JUNE

1-30 2021 Professional and Student Research Recognition Awards applications open

JULY

- 1-31 Abstract submission for 2021 Child Life Annual Conference in Los Angeles, CA
 - 1 Submission deadline for <u>ACLP Bulletin articles</u> for consideration for the Fall 2020 issue
 - 7 Call for nominations for the <u>2021</u> <u>Distinguished Service Award</u> open
 - 7 Call for nominations for the 2021
 Mary Barkey Clinical Excellence Award open

AUGUST

- 1 2021 <u>International Scholarship</u> applications open
- 10 Deadline to apply for the August administration of the Child Life Professional Certification Exam
- 15-30 <u>Child Life Professional Certification</u> <u>Exam</u> administration testing window

OCTOBER

- 1 Submission deadline for <u>ACLP Bulletin articles</u> for consideration for the Winter 2021 issue
- 27 Deadline to apply for the November administration of the <u>Child Life</u> <u>Professional Certification Exam</u>
- 31 Deadline to apply to recertify through PDUs

ACLP's 2020 webinar programming features new and updated ways to enhance your profession education. From search functionality to on-demand recordings, there's truly something for all learners to enjoy in our new portal. A few new features we don't want you to miss:

- Targeted learning: Each month ACLP will be hosting two live webinars—one targeted for emerging professionals and the other for established professionals—rooted in the same theme.
- New! Subscription services: Our new subscription services offer learners the chance to join some or all of our live 2020 webinars at a discounted rate. Subscribers will have access to the on-demand recordings for these events in case watching live isn't convenient.
- Webinar scholarships: To support ACLP's diversity goals, we will be offering a number of individual registration scholarships to each of our live webinars. Visit the online learning portal to complete the application.

Be sure to visit ACLP's <u>online learning portal</u> to learn more about our new features and to explore the full 2020 programming schedule.

LEADERSHIP DEVELOPMENT

Emerging Professionals – **Starting Your Leadership Journey** Wednesday, May 13, 1:00-2:30 pm EDT

Established Professionals – **Leading Multidisciplinary Teams**

Thursday, May 7, 1:00-2:00 pm EDT

RESEARCH

Established Professionals – Getting Comfortable with Data: Developing Analytical Skills for Child Life Professionals Tuesday, June 16, 3:00-4:00 pm EDT

TRAUMA

Emerging Professionals – From the Trauma Bay Through the Hospital Stay: Trauma-Informed Care for Pediatric Patients from Various Child Life Specialist Lenses

Wednesday, July 22, 1:00-2:30 pm EDT

Established Professionals - How Child Life Leaders
Can Provide Planned Resources That Help Specialists
and Teams To 'INSPIRIT' Resilience in Trauma
Environments That Hold Risk of Compassion Fatigue

Wednesday, July 15, 1:00-2:30 pm EDT

ASSESSMENT

Emerging Professionals – Playing with Grief: Perspectives from Two Child Life Specialists in Palliative Care

Monday, August 10, 2:00-3:00 pm EDT

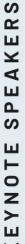
Established Professionals – Child Life Care of Gender-Expansive Children and Youth

Monday, August 17, 1:00-2:00 pm EDT $\,$

If you'd like to share your expertise and facilitate a webinar, please visit <u>ACLP's webinar proposals page</u> to provide us with information about your presentation. Presenters earn 2 PDUs per hour of presenting. We look forward to partnering with you as a facilitator!









After thorough review and careful consideration of the CDC's latest Covid-19 recommendations on social distancing, ACLP has decided to transform the 2020 Child Life Annual Conference into an interactive, virtual event occurring on May 20-23.

We are disappointed we won't be able to see you in person but are excited that we can still provide a unique, high-quality virtual conference experience. We will still have our highly anticipated Diversity, Equity, Inclusion (DEI) themed keynote speakers and the varied, relevant educational content ACLP has always provided at the annual conference. But you will now be able to access it safely and conveniently from your home or office.

The Child Life Virtual Conference will offer attendees:

- Live and recorded sessions available through ACLP's Online Learning Portal in all domains required for recertification.
- The opportunity to earn 60+ PDUs.
- An entire year's access to the conference content.
- Several virtual sessions that incorporate discussion opportunities.
- A promo code for 20% off in the online Child Life Store

At this time, social distancing is critical and forgoing an on-site, in-person conference is in the best interest of our extended child life community and the country as a whole. Thank you for your individual service during this national state of emergency. We look forward to your participation in this virtual conference and hope it will provide the professional and emotional support you need during these challenging times.