# ACLPBulletin

A PUBLICATION OF THE ASSOCIATION OF CHILD LIFE PROFESSIONALS

FALL 2023 | VOL. 41 NO. 4



### **ACLPBulletin**

### A PUBLICATION OF THE ASSOCIATION OF CHILD LIFE PROFESSIONALS

Fall 2023 | Vol. 41 No. 4

ADDRESS:	Association of Child Life Professionals 7600 Leesburg Pike, Suite 200 West Falls Church, Virginia 22043
PHONE:	(800) 252-4515 (571) 483-4500
FAX:	(571) 483-4485
WEB:	www.childlife.org
EMAIL:	bulletin@childlife.org
EXECUTIVE EDITOR:	Shannon Dier, MS, CCLS
ASSOCIATE EDITOR:	Morgan Morgan, MS, CCLS
MANAGING EDITOR:	Keri O'Keefe, Director of Communications and Publications
Association of Child Life Professionals Board of Directors	
PRESIDENT:	Alisha Saavedra, MA, CCLS
PRESIDENT-ELECT:	Sarah Patterson, MSc, CCLS
PAST PRESIDENT:	Lindsay Heering, MS, CCLS
SECRETARY:	Cristie Suzukawa Clancy, MS, CCLS
TREASURER:	Riley Hammond, MS, CCLS
DIRECTOR:	Cassandra James, MS, CCLS, CPXP
DIRECTOR:	Victoria Isaacson, MA, CCLS, NCC
DIRECTOR:	Alyssa Luksa, MSP-I/O, CCLS
DIRECTOR:	Janelle Mitchell, MS, CCLS
CANADIAN ASSOCIATION OF Child Life Leaders Liaison:	Sandy Baggott, CCLS
CLCC Liaison:	Tracey Craddock, MS, CCLS
CEO	

CEO: Alison E. Heron, MBA, CAE

Published quarterly in February (Winter issue), May (Spring Issue), August (Summer issue), and November (Fall issue). For more information on submitting articles, please see <u>Submission Guidelines</u> in the ACLP Bulletin section of the ACLP website.

For information on advertising in ACLP Bulletin, please refer to the Advertising page on the ACLP website.

©2023 Child Life Council. Doing business as the Association of Child Life Professionals (ACLP). All rights reserved.No part of this publication may be reproduced, distributed, or transmitted in any form or by any means, without the prior written permission of the publisher. For permission requests, contact the managing editor at *bulletin@childlife.org*.



CONNECT WITH US 📑 🔽 in 🔠 闷 🎯

# CONTENTS

- **CEO Shares** 4 6 **President's Perspective** 8 10 12 **Specialist and Mother** 17 20 **Clinical Tools: Mock MRI** 23 in Hong Kong 26 32
  - From the Executive Editor Welcome to the Board Room **Navigating the Cancer Journey: Reflections from a Child Life Conducting a Research Search PLAY for Child Health Seminar: Multidisciplinary Collaboration**
  - Talking to Children After a Suicide: **Tips for Child Life Professionals**
  - **Committee Corner: Research Fellows**



### **CEO Shares**

by Alison E. Heron, MBA, CAE

#### Greetings!

The Fall season brings a sense of transformation, a reminder that change is the only constant; similarly, our organization embraces change and progress. This time of the year is a testament to our resilience, adaptability, and the ability to harness innovation. In these moments, we reaffirm our commitment to excellence, seeking new opportunities and nurturing the spirit of collaboration that defines us.

Gathering in September in Scottsdale, AZ, approximately 90 attendees joined the Child Life Leaders Conference. The event, overseen by the Association of Child Life Professionals (ACLP) for the first time, was a chance for leaders to enhance their skills, take specific actions to develop the child life profession, and foster a supportive network through networking. The conference also provided a retreat and rejuvenation opportunity for attendees.

In November, we introduced the ACLP Professional Code of Conduct. This Code addresses misconduct in three main areas: Personal, Professional, and Legal Misconduct. However, it is important to note that the Child Life Code of Ethics, governed by the Child Life Certification Commission (CLCC), remains in place. The Child Life Code of Ethics provides a comprehensive framework for Certified Child Life Specialists (CCLSs) to guide their professional conduct and ensure that children and their families are well-cared for and protected during potentially stressful or traumatic situations.

At ACLP, we believe in creating a welcoming, safe, and professional environment for everyone. The Code of Conduct is intended to provide ACLP participants with a set of best practices and guidelines on standards of conduct to which ACLP participants agree they will adhere when joining and maintaining their ACLP membership or participating in ACLP activities and events.

Over the past few months, the ACLP team has undergone some changes. One significant change that has occurred is the CEO's role. With the Child Life Certification Commission (CLCC) now operating as a separate organization under ACLP, the CEO role is now shared between ACLP and CLCC.

Despite recent vacancies, our staff members have shown remarkable dedication and team spirit, working together to manage the increased workload. We understand the risks of staff fatigue and burnout and are taking necessary measures to prevent them.

Moreover, we proudly welcome new staff members bringing fresh perspectives and expertise to our various programs and events – Rebecca Reynolds (communications and publications), Jasmine Rowe (membership and engagement), Alexandra Campbell and Sylvie Messavussu (education), and Stephanie Schultz (conferences and events). Together, we will continue to strive for excellence and to positively impact our organization and beyond.

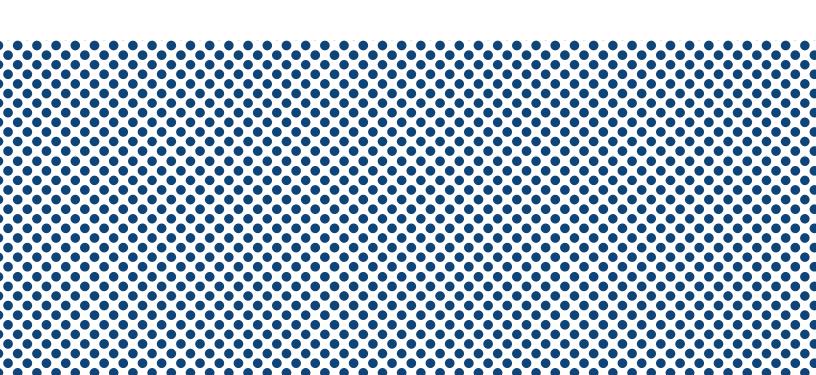
The ACLP team will convene at our headquarters in Falls Church, VA, on November 28-30 for a staff retreat to plan for the 2024 calendar year, which is also the last year of the 2022-2024 strategic plan, and visit INOVA Children's Hospital—special thanks to Jamie Gentile for the invitation and coordination.

Don't miss the 2024 Child Life Annual Conference in San Antonio, TX, May 24-26. Registration opens mid-January!

Let us set our sights on growth, learning from our experiences, and utilizing our knowledge to propel us forward. With fresh ideas and innovative strategies, we will soar to greater heights.

I'm genuinely delighted to have this opportunity to gather and reflect on our journey thus far and the promising road ahead.

alisa E. Heron





### President's Perspective

by Alisha Saavedra, MA, CCLS

As we enter the season of falling leaves, crisp air, and the first frost, I am reminded of how symbolic this time of year is. It is humbling to think about how nature influences our environment, routines, and even our transformations. Fall represents a time of harvesting seeds, literal and figurative, that were planted earlier in the year. As we move forward into the final quarter of 2023, I am pleased to provide you with recent updates, including the next steps for our bylaws revisions, highlights from our August board meeting, and a reflection on this past year as we look ahead to 2024.

One of the most critical aspects of our organization is the governing framework that guides our operations - our bylaws. Earlier this year, our dedicated bylaws workgroup made up of key representatives from Nominating, Governance, Board Diversification, and the President level, worked diligently to incorporate feedback from legal consultation and an external DEI consultant. The voting period for proposed revisions to the bylaws opened in August and closed at the end of September. Results indicated the majority were in favor of the proposed revisions; however, the number of votes received did not meet the threshold according to our current bylaws. The bylaws workgroup will reconvene to review additional legal consultation and formulate next steps in the revision process. As we move forward, an update on the next steps will be shared in the first quarter of 2024. Your active engagement in this process is appreciated, as it will help shape the future of our organization.

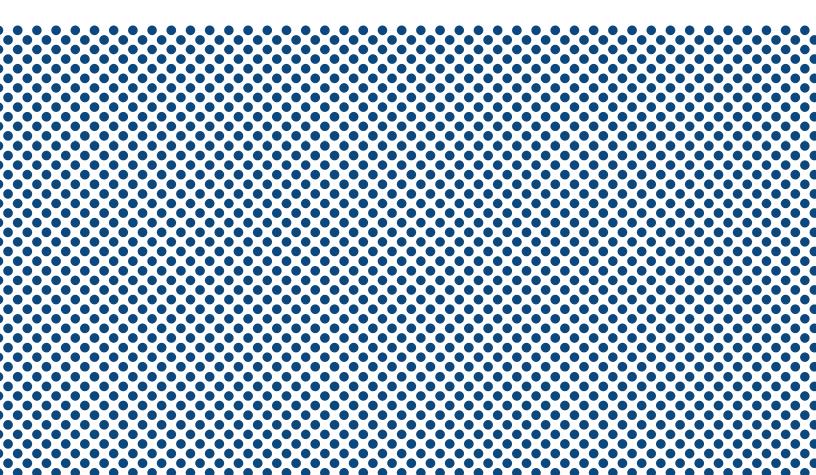
I am excited to share that we welcomed two new public members to the board, Stacy Palmer and Jeff Salvon-Harmon. Stacy is the Senior VP and COO for the Beryl Institute and has great involvement in advocating for integration of the patient experience as a core element in healthcare conversation. Jeff Salvon-Harmon is the Vice President, Safety, for the Institute for Healthcare Improvement (IHI) and IHI Fellow. He has a longstanding history of implementing change to promote a culture of safety and belonging for patients and the healthcare workforce. Earlier this year, Stacy and Jeff attended the Emotional Safety Summit II hosted by ACLP. Their shared passion for patient advocacy instantly aligned with our profession's core value of improving the lives of children and families. We are looking forward to their contributions and perspectives as we work to advance the ACLP, our profession, and emotional safety.

Our August 2023 board meeting was a productive one. The board continues to focus on the outcomes of the Staffing Crisis and Pathway to the Profession Think Tank and voted to approve charters for the newly formed Pathway to the Profession committee and Child Life Leadership Development and Internship Excellence task forces. The formation of these groups is well underway. We are grateful to bring together passionate minds across all stakeholders to put this work into motion and address the challenges that continue to be a part of our profession's landscape. You may read more about the decision outcomes and future work in Welcome to the Board Room.

This year has been a testament to the continued resilience and commitment of our members. I would be remiss if I did not take a moment to pause and acknowledge the current crisis happening in the Middle East. These tragic events remind us of the world's vulnerability to violence and trauma, especially in children. The impact that this crisis has on the physical and emotional safety of children and their families, which is essential to their livelihood, is devastating. Despite the ongoing global challenges and pain felt among our colleagues and in the communities we serve, child life specialists have continued to provide vital support, ensuring that children and families receive the help they need to cope during these difficult times.

In closing, I would like to express my gratitude to all of you – our members, supporters, volunteers, and staff – for your unwavering dedication to the many children, families, and communities you serve. Our child life profession has many cultures, identities, and origins, and we value each one of you. Let us move forward with hope and determination, knowing that we have the power to create a difference by harvesting the seeds of change we have planted through the year. Thank you for your continued support, and I wish you a bountiful season of transformation.

Warmest Regards, Alisha Saavedra





### From the Executive Editor

by Shannon Dier, MS, CCLS

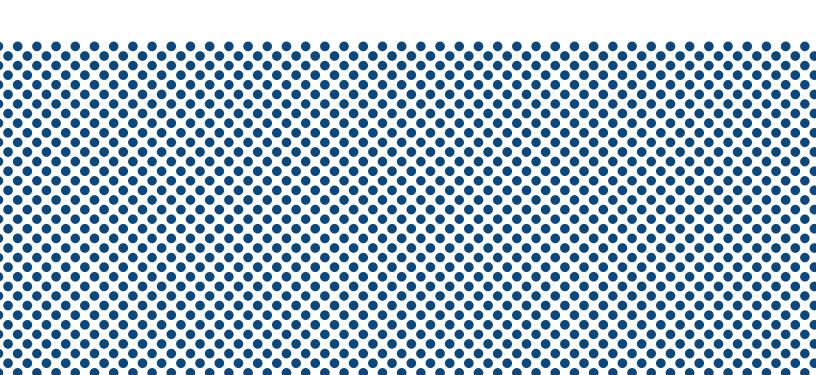
This fall, I find myself in a season of change, and it has me thinking about the inevitable overlap between personal life and child life. Those who have worked with me for any length of time know that I am a strong advocate of professional boundaries, not only to maintain appropriate relationships with patients and families but to protect our personal lives from the weight of the work we do. Yet, the messy reality is that being a child life specialist alters the way we see the world. You can never watch a medical drama, or witness a child having a meltdown in a restaurant, or even attend a family event in quite the same way because you are constantly assessing all the developmental, family and healthcare variables that interact in these situations. Perhaps you find yourself applying your child life skillset to offer therapeutic activities to the children in your life or to demystify healthcare information for your family and friends. Both loved ones and acquaintances turn to you for your developmental expertise and rely on your calm response under pressure. Somehow their intended compliment "I could never do what you do" seems to separate you out into a category of superhumans capable of overcoming all things.

As much as child life has seeped into my interactions with others, it has been humbling to remember how very human I am. Without realizing it, I had internalized an expectation that because I help others cope for a living that I was automatically going to be very good at coping myself. Faced with uncertainty and challenge, though, I struggle with my anxiety about the future and lean on less than healthy coping strategies. In a time of global heartache, I want to isolate myself and avoid the news, distracting myself from everything that is just too much. Afraid to feel my big feelings, I hold them fast until they burst out in unexpected tears at something small. As it turns out, I am not always adept at "child life-ing" myself.

It was when I began to think of it that way that I realized that I need to give myself the same individualized care that I give to the patients, families and students that I serve. I need to remind myself to take it one step at a time. I need to focus on the choices I do have and what I can do to feel masterful in situations that are outside my control. I need to coach myself to take a deep breath and regulate my physical body. When all I want to do is hide in the blankets and leave the lights off, I need to connect with the people who care about me and remember who I am outside this moment of stress. I need to give myself permission to feel how I feel and validate that it's okay to not be okay all the time. Taking a step back and

being my own child life specialist is the radical approach to self-care and self-compassion I wish I had learned sooner, and I hope it's a strategy that helps some of you too.

This issue, we have multiple articles that provide new perspectives and tools to enhance your clinical practice. Jennifer Fieten discusses how to conduct a literature search to find research articles relevant to your work, and we've added a bonus resource of search tips compiled by the Research Fellows. In Committee Corner, Jessika Boles, Lead Research Fellow, shares more about how this group of ACLP volunteers uniquely supports the child life community to engage in research. Building on her series of #ChildLife Blog posts, Jacquie Rahm offers strategies for talking with children about the suicide or suicide attempt of a loved one. In a moving reflective practice piece, Katie Oches shares her story of how her child life professional experience overlapped with her family life after her son was diagnosed with cancer. We hope the variety of articles you find in each issue of ACLP Bulletin provides ideas, encouragement, and inspiration to share your child life insights with this community. We invite you to submit your article ideas and drafts on the Bulletin webpage and contact us at bulletin@childlife.org.



# WELCOME TO THE BOARD ROOM

by Lindsay Heering, MS, CCLS, ACLP Immediate Past President

Each August Board meeting is held virtually for two hours to cover current topics, committee inquiries, and strategic discussions. Board reports are not expected from ACLP committees; however, they may be submitted for a timelier review, rather than waiting for the November Board meeting.

### **Committee/Task Force Charters:**

Two existing charters were reviewed, and their respective updates were approved. Charters for the new Pathway to the Profession Committee and new Internship Excellence Task Force were also approved. The new Internship Excellence Task Force is charged with investigating models of recognition that support the provision of highquality clinical internships for aspiring child life professionals. Recommendations provided to the Board must remain conscious of diversity, equity, and inclusion, suitable for a wide array of clinical programs (e.g., community-based, small/ large), and financially and logistically sustainable. The new Pathway to the Profession Committee is charged with promoting quality, consistency, and expanded accessibility of pre-internship and internship programs; reviewing and updating best practices for child life clinical training experiences; and enriching cohesion between academic and clinical programs and ACLP.

### **Nominating Committee:**

With the call for Board of Directors applications running September 5 through October 5, 2023, the Board reviewed the final Board matrix. Gaps



were identified in the following areas: 6-15 years of experience, male or non-binary/non-gender conforming, racial diversity, one-person programs, and members from the southeast region. Consideration was given to the representation and areas of expertise that our non-voting members (CLCC liaison, Canadian Association of Child Life Leaders liaison, and two new public members) bring to Board discussions while being mindful that they do not hold voting rights.

### Internship Readiness Work Group (IRWG):

The IRWG relied on the expertise of subject matter experts across various child life roles to develop the new internship readiness common application (IRCA) and submission process that was launched in January 2023. Their work intentionally focused on supporting the transition to the new common application process and tracking areas in need of refinement. The IRWG gathered stakeholder feedback through a membership-wide survey related to the new IRCA. This survey garnered a large response, which provided mixed results. Revisions were subsequently made to the IRCA to provide clearer instructions and language. No content changes were made to the application. The revised common application will launch on January 6, 2024 and will include updates to the common application's associated resources.

Furthermore, the IRWG conducted a listening session for aspiring professionals to provide further education and support in understanding the internship readiness knowledge, skills, and abilities (KSAs) and completing the IRCA. As evidenced by the survey results, all stakeholders are experiencing a learning curve, and additional communication and education is essential to increase comfortability with and adoption of the IRCA. The IRWG developed a list of tasks that may be considered for future work and was seeking confirmation that these tasks were within the bandwidth of ACLP to monitor and support. The continuation of their work will be carried forward through the collaboration of the new Pathway to the Profession Committee and ACLP staff. Since the IRWG completed their designated charge, the Board voted to decommission this workgroup.

### Staffing Crisis & Pathway to the Profession Think Tank Outcomes:

The Board reviewed the final Think Tank recommendations, including the operational plan. Some examples included:

 Mentorship for aspiring professionals – A Mentorship Subcommittee will be formed and charged with developing a mentorship structure for aspiring professionals, which will subsequently be integrated into our new mentorship platform with oversight from our Mentorship Committee.

- New Pathway to the Profession Committee This group will be responsible for developing innovative internship models and supportive programming and resources. Potential considerations may include part time, half hospital/half community-based, and paid placements. Additionally, support and mentorship for one-person and small programs may be considered.
- Increased connection and collaboration between academic and clinical programs and with regional groups – This activity will involve engagement from ACLP Board and staff through virtual and in-person opportunities and partnership with regional conferences.
- New Child Life Leadership Development Task Force – This group will support the overall child life community by equipping child life leaders with resources to advocate for child life specialists within hospital and communitybased settings. Topics may include but are not limited to business acumen, healthcare administration, organizational finances, staff supervision, hiring and pipeline development, human resources processes, and leadership of multiple disciplines.

### **Patient & Family Experience Committee:**

The Board received an update on the Emotional Safety Summit II, which took place in June 2023 prior to the Annual Child Life Conference. The summit hosted 11 organizations with an interest in emotional safety. Several of the organizations expressed interest in continued engagement. For example, the president of the Pediatric Trauma Society has incorporated emotional safety into her opening remarks for their annual conference, and Barb Romito, MA, CCLS, has been invited to present the keynote session on emotional safety for the Society of Pediatric Nurses conference.

## **NAVIGATING THE CANCER JOURNEY:** Reflections From a Child Life Specialist and Mother

by Katie Oches, CCLS

I practiced child life for about a decade in pediatric oncology. I would show up each morning, swipe my badge, stash my belongings in our crammed child life office overflowing with random donations and expired medical supplies. I would turn on my pager and head to round with my team on the patients and families receiving care for the day at Duke Children's Hospital. I made detailed notes on needs for my patients — introduction of services, plans for diagnosis teaching, procedural preparations and support, coping plans, therapeutic activities, referrals, continuity of care, legacy building. I had discernment and intuition, feeling confident in my skills as a professional. I could have never imagined then that someday the script would be flipped, that my own baby boy, only nine months old, would be one of those discussed during morning rounds.

Bravery took on a new meaning, as I went through the motions of starting care, wanting to be anywhere but the present moment. Arriving at the hospital as a patient for the first time was immensely humbling. We rode the elevator up to the same clinic floor I worked for all those years and checked in at the front desk. A hospital band was printed and taped around my son Jude's chunky ankle. I looked around the waiting room at the other patients and families as we waited for his name to be called. The same waiting room I would meet patients in as a professional, attempting to form a quick rapport, trying my best to help them feel safe and welcome. Tears began to sting my eyes as his name was called. My husband and I gathered our belongings and carried our little boy across the threshold, guiding him into the world of oncology.



The terminology was all too familiar as I read over the resident's shoulder: mass, further imaging needed, suspected retinoblastoma of the left eye, ophthalmology referral, ocular oncology referral, genetic workup, and treatment considerations for enucleation, chemotherapy, radiation, and local therapy. Fear settled deep within as I held Jude a bit tighter, knowing all too well what was ahead for him, for our family.

And so I assumed the dual-role of child life specialist and mom, the hardest privilege I have endured. As tests and procedures were scheduled, I confidently advocated for parental presence, comfort positioning, distraction, reassurance, One Voice, developmental play, medical preparation and play, expression of emotions, consistency in routine. But with each hospital visit, anguish and dread hid just beneath my facade of confidence.

The tumor was staged as Unilateral Retinoblastoma, Sporadic Class C. Our treatment course started with intraarterial chemotherapy, IAC for short. This method of chemotherapy targets the tumor directly through an artery located behind the eye. Risks were involved, of course, both with the drug itself and access to the artery. Consent forms were signed, the passage of trust and care to our medical team. Iude had two rounds of IAC, one a month, with blood work visits in between. I fought my way to be with him in the interventional radiology and operating rooms, holding him and distracting him up until the last moment before the anesthesia team was ready for induction. I would sit with him at the head of the bed, a favorite stuffy wrapped up in his arms. I used all the strength I had to sing to him and look into his eyes, reassuring him as the mask was placed on him to fall asleep. I stood with his limp body in my hands, placed him on the table, gave him a small kiss on his forehead and left the room. It was all I could do to put one foot in front of the other, a feeling of immense heaviness as the door closed each time and I headed back to the waiting room.

This became our routine, continuing through countless rounds of laser therapies after IAC left his artery scarred and access was no longer available to the tumor. I kept a hospital bag in the car with distraction items to use in the waiting room and during the hours spent in pre-op. A few of my close child life friends would visit us when they had the extra bandwidth. Jude quickly became a beloved patient, as we would spread a hospital blanket on the floor, playing and reading books in between vitals, eye drops, meeting with the multiple medical teams, and signing consent forms. I would often make small talk about his favorite characters or what we were up to in the last month, noting his growth and personality. The medical team would tell me of their own children's favorites, sometimes noting how their child was the same age as Jude and that they couldn't imagine going through what we were. I understood, empathized, nodding and smiling through the exhaustion.

The moment in the operating room happened again and again — beautiful moments captured in my memory while singing him to sleep. I would make my way back to the waiting room, sitting in the hospital fog of the morning, texting family and friends updates and checking in with my husband on how our daughter, Mabel, was doing. He would stay home to get her up in the morning, feed her breakfast, and take her to pre-school. Keeping her normal routine was extremely important to me, knowing and watching for the textbook signs of sibling effects of the treatment process.

Years of laser treatment passed, and we continued to have relapses. We moved to Ohio to be closer to family and started seeing a new ocular oncologist at Cincinnati Children's Hospital. After Jude's third relapse of the tumor, we moved forward with a recommended treatment called plaque brachytherapy. This treatment required two surgeries, one to place the radiation plaque and one to remove it. After the plaque was placed behind the tumor in his eye, we were transferred



to inpatient Oncology and were required to stay in a lead-lined room for four days while the radiation seeds in the plaque targeted the tumor cells. The days and nights spent within the hospital felt sacred, to experience a small taste of what my previous patients and families lived day in and day out. I knew what to pack, how to help Jude cope and how to entertain him for four days in isolation. I had reached out to child life to help set us up with a play mat, superhero toys, books, legos, puzzles, and play-doh, but it was still so hard to see him in pain, to have no control over this disease, and to remain unsure of outcomes. I waited until he fell asleep to release the worry. I was alone, holding his hand while he slept and praying for his little body to heal. What I will remember forever is the way he comforted me, patting my leg or holding my hand as we watched movies together. In the middle of the night, I would help pull his pajamas up after using the bathroom and he would encircle his arms around my neck, squeeze me tight and say, "I love you, Mommy." He knew I needed comfort too.

How beautiful.

Plaque brachytherapy was successful, and we were finally given a release to be seen every three months, which felt so promising after having to go monthly for so long. Our first visit back after our break, I was fully expecting a report from our doctor that everything looked good, and we'd come back in another three months. I was hopeful that this was the beginning of our new routine and that we could breathe a little more easily.

As I was sitting in the surgical consult room, anxiously awaiting to hear the results of the exam, worry set in again, and I feared the worst. The doctor was taking longer than normal to come and chat. Eventually, I was moved to post-op to sit next to Jude, and I was told the doctor would be coming by with the results. My stomach sank, my mind raced with worst-case scenarios, my heart rate increased, and I began to feel the dizziness that comes with panic. I had the feeling that many parents had described to me in my clinical practice, a precognition that something was "just not right". As I sat next to Jude, holding his hand, listless from anesthesia, watching him breathe so peacefully, the doctor came and told me he had found a fourth relapse of the tumor. Tears of disappointment flooded my eyes, rolling down my cheek and onto the starch white hospital blanket my son had been tucked under so many times.

After the doctor left the bedside, I was left in the wake of disappointment and fear. I called my husband with the news. We were given a few options to consider, including the attempt at IAC again for three months with new methods and new drugs, systemic chemotherapy for six months, or enucleation of the eye. We quickly decided the IAC treatments sounded promising, signed more consent forms, met with more doctors and traveled back two days later for an MRI to stage the tumor before chemotherapy.

The results of the MRI came back with some concern. There was something behind the tumor that hadn't been there on previous scans, and the radiologists and the Oncology team couldn't determine whether the imaging showed effects of the radiation or if this was growth of the tumor outside of the tumor wall. For the first time since diagnosis, we were terrified. If the tumor had somehow infiltrated the optic nerve, there was increased risk for it to travel to the brain. Suddenly the doctors were using terms like 'prognosis' and suggesting that our next move required urgency. We were given the weekend to decide how to proceed, now unsure of what to do. My husband and I immediately started looking for answers, including a second opinion from our Duke team. The nurses and doctors were family to us, surrounding us with love and concern.

After all of the considerations and expertise of our medical teams, we made the extremely difficult and life-altering decision to proceed with enucleation.

Preparing our children for enucleation was the hardest part of this journey. I chose to prepare them separately, to hold space for them both. I prepared Mabel first, sensitive and wise for her age at six years old. I walked her through the information using a social story a dear CCLS friend made, sprinkled with facts and personalized pictures to show all that Jude had endured up until this point. I had also created a play-doh model of an eye with the tumor and one of an orbital implant with a matching lens that would take its place. Mabel asked a lot of great questions and verbalized that she was scared, that she didn't want her brother to lose his eye. Tears surfaced in both of us, a shared mourning for the unexpected devastation.

Jude, who had just turned four, took it all in as I described his treatment history, looking back on pictures, how the doctors have been trying to help the tumor become scar tissue. I held it together as I described how even with all the ways we have tried, his tumor continued to grow and that the doctors now needed to remove the tumor to try to keep the rest of his body safe. I prepared him slowly and carefully, explaining that to remove the tumor, the doctor would need to remove his whole left eye. He too verbalized how scary it all sounded, pushing his head into my arm pit, hiding from it all. Before Jude drifted off to sleep that night, he asked, "Can't the doctor's just fix my eye?" He understood what was ahead, desperate for another way. I remember weeping that night in silence, after we had put our children to bed, and my husband had fallen asleep. A sadness that may



never lift in my heart for our little boy.

Grief is another word that floats around the floors and the families we serve. I will never forget my dying patients, the lessons I learned, and the final goodbyes said to families in hospital rooms or in the busy traffic circles outside of the hospital. After enucleation, as we waited for pathology results, I imagined this was going to become my own story. I walked around my neighborhood in loneliness and fear, feeling like an untethered balloon blowing in the wind. I lay next to my son those nights, singing his bedtime songs, tears rolling down my cheeks and wondering if we were too late, if the disease had spread outside of his eye. My mind wandered to those children and teens I knew, the moms and dads who had to say goodbye all too soon, and I just kept thinking, how would I live without my child?

Post-surgical care for Jude was hard but manageable. Mabel struggled with being left with her grandparents during the surgery and the overnight hospital stay. She had difficulty seeing her brother come home swollen and in

pain, hearing him cry from fear and discomfort. Pain subsided within the week after surgery, and after two long weeks of waiting, the pathology report came back. Results showed that the tumor seemed to be encapsulated, and there was no evident tumor infiltrating the optic nerve, though there was always risk for microscopic cells. The oncology team was confident but would bump his MRI a few months sooner to be certain. After six weeks, he was fitted with a prosthetic lens that would eventually become his "new eye." Our ocularist did an incredible job, a hand-painted lens that matched his beautiful, healthy eye. We learned how to maintain and clean the prosthesis, a lifelong task that we carry for now and eventually he will do on his own.

Jude looked like himself again. He could feel it, too, we all could, the winds of change, carrying us in the direction of light and hope. Outside of losing his eye, he is our same boy who loves "Toy Story" and superheroes, dinosaurs, parks and playgrounds, reading, laughing, and snuggling close. So often, as he says, "I love you, Mommy," I am brought back to those nights in the hospital, a promise through the difficult years and decisions made, grateful that he is still here to cherish and love.

As I continue to practice in the field of child life, I hold my experiences close. I understand that the smaller moments sometimes make up the greater picture of what parents are carrying. I have a better sense of how to read a room, leaning into a child and family's natural tendencies and coping styles. I understand that it is okay to not always have the fix and to let children and families have space to process and grieve the realities of a diagnosis. And I have learned to have more grace, knowing parents are often just putting one foot in front of the other, just as I had to do for this season, navigating the uncertainties of their child's hospitalization and holding on to moments of hope.

## CONDUCTING A RESEARCH SEARCH To Enhance Clinical Practice

Jennifer Fieten, MA, CCLS, Shirley Ryan Ability Lab, Chicago, IL

As a child life specialist working in both clinical and academic roles, I commonly find myself gathering research in order to inform my practice and to integrate into policies, procedures, and various proposals. While some may, understandably, view this as a challenging task, I have often found this to be both exciting and energizing. A research search provides the opportunity to review what is new in the field, to acquire new and useful information, and to then share what I have learned with others. This article will describe the steps of conducting a research search and demonstrate how I use a review of literature to support patients in my clinical role

### **Topic Identification**

To begin exploration of existing research, it is important to clearly identify the topic for study or the question that one hopes to answer. As a child life specialist working in a healthcare facility, which focuses primarily on rehabilitation, the specific nuances of some medical conditions warrant deeper understanding to develop a plan of care and be prepared to answer questions in a developmentally appropriate manner. After having multiple patients with post trauma amnesia (PTA), I found it extremely important to learn more about this particular condition and to learn about the behavioral manifestations commonly seen in individuals with PTA, as well as the stages that one frequently progresses through in transitioning out of this state. As such, I sought to learn more by exploring articles related to this topic, using "pediatric patients with post trauma amnesia" as my search subject. By using this topic, I then would also have the option of searching for research using just "post trauma amnesia" or "pediatric trauma" as search phrases to further explore.

### **Research Filters**

Once my topic was identified, I logged into my medical library account at work and conducted a preliminary search using my initial search phrase.



Continued on pg. 19



This search yielded 22 articles for review. I then chose to filter my results by exploring only those resources that were from peer reviewed journals and that were in article format. Incorporating these filters then narrowed the available articles to 18 for review. Some researchers may encourage focusing on articles less than ten years old. For the purposes of my exploration, I chose to then refine my article review to articles that were less than five years old to ensure that the research and data contained was the most relevant and up to date. Following this refinement, the available articles again narrowed to include 7 scholarly journal articles. If my search had encountered challenges, such as difficulty finding articles on my specific topic, I could have requested assistance from the hospital librarian, which would be an option in university settings as well.

### A Topical Review of the Literature

A review of the literature means a review of the current thinking on the topic represented in the scholarly journal articles obtained. A preliminary review of the articles found that a majority of the research focused on diagnosis of traumatic brain injury (TBI), the symptoms associated with TBI, and the potential outcomes of TBI, with minimal specific focus on post trauma amnesia. This led me to recognize the need for additional research on this topic as well as a need to adjust search terms and phrases in the hopes of obtaining additional scholarly articles.

### **Application to Practice**

The research I did gather contributed to an advanced understanding of traumatic brain injury, increased knowledge of the physical healing process, and treatment options for managing symptoms, all of which were helpful in developing a child life plan of care for patients with whom I worked. Understanding this condition assisted me in providing emotional support (stressing the importance of reiteration, understanding emotional lability), tailoring interventions (challenges to emotional regulation), and advocating on the behalf of my patients (acknowledging the potential for heightened fight or flight responses), all of which built on my existing knowledge of trauma-informed care. Recognition of the need for further research on post trauma amnesia specifically contributed to my interest in pursuing research projects to examine this issue more closely.

### Conclusion

The ability to seek and gather research to inform practice and to integrate into policies, procedures, and various proposals is integral to the work of the child life professional. Whether it be to learn more about a particular diagnosis, a new medical test or procedure, a researchbased intervention strategy, or to identify new intervention tools, we utilize research in a variety of ways. As demonstrated in my recent information gathering experience, a preliminary search may not yield the expected results. Rather than viewing this as a failure, it is viewed as an opportunity to re-evaluate the search terms to see if an adjustment is needed or an invitation to contribute to an area of research that is lacking. This is one of the exciting aspects of research gathering, identifying what is needed to obtain the most useful, evidence-based information.

### Tips and Tricks for your Literature Search from the ACLP Research Fellows

### Step 1: Identify a specific question using the PICOT method.

For example, instead of asking "why is preparation effective?" use PICOT to identify what question you want the research literature to help answer.

- Population In children with lacerations...
- Intervention how does procedural preparation...
- Comparison/Control compared to no preparation...
- · Outcomes impact child fear, anxiety, and pain
- Time during sutures?

### Step 2: Generate possible search terms that will help answer the PICOT question.

To answer the PICOT above, you might choose words like "laceration," "children," "preparation," "anxiety," and "sutures."

Consider possible synonyms or alternatives to those terms, such as "stitches," "pediatric," "education," or "fear." It can be helpful to create a table with possible synonyms for each of the search terms you plan to use.

Use Boolean operators (AND, OR, NOT) to refine your search. For example, this search might start with "children" AND anxiety AND "preparation" AND ("laceration" OR "sutures" OR "stitches").

### Step 3: Identify the most appropriate search platforms.

Different databases and search engines draw their results from different journals, types of research, and mediums (e.g., popular presss versus peer-reviewed articles). To be most effective and efficient in your literature search, select the ones that best align with your topic.

- For psychosocial research, try EBSCO, PsycInfo, and PROQUEST.
- For medical research, try CINAHL, PubMed, and Medline.

### Step 4: Choose filters carefully to increase your search efficiency.

To ensure your search results are relevant, use filters to limit by years of publication (within the last 10 or 20 years), whether the article is peer-reviewed, or even species (selecting "human" for medical research can be extremely helpful).

### Step 5: Stay organized, documenting both your search strategy and your results.

Keep track of search terms, databases, filters, and relevant articles in a document. Some use an Excel spreadsheet to organize articles, and citation management programs, like Mendeley or Zotero, can be extremely helpful for systematic literature reviews and formal research projects. Find an organizational technique that works for you!

# CLINICAL TOOLS: MOCK MRI SCANNER

By Laura Gould, CCLS, MS



Most child life specialists, regardless of area, have patients that experience radiology procedures and may be called to educate children about MRIs. The mock MRI scanner is a tool I feel fortunate to utilize at Children's Hospital of Philadelphia with our patients, primarily 5-9 years of age. In the past, we utilized prep books or practiced on a stretcher, but the mock scanner allows patients to have a simulation of the MRI environment. We have found this tool to be so helpful that Children's Hospital of Philadelphia has expanded to having mock scanners at our satellite campuses as well. Here I will briefly describe how our child life team has integrated the Mock MRI scanner into our preparation process.

### What is a Mock MRI Scanner?

The mock MRI scanner is a smaller model of an MRI scanner which allows younger children to experience an MRI simulation. This tool helps child life, nursing, and MRI techs to collaborate with patients and families to provide education and assessment on whether children can complete an MRI without anesthesia or sedation. The Mock MRI Scanner is outside of the magnetic field so parents can be present, and staff and families do not need to remove metal as they would during an actual MRI. The MRI sounds can be played through a computer system. If the child can watch a movie during their actual scan, that can also be set up using a head coil and mirror that reflects from a screen at the back of the MRI scanner. This movie system has been more effective in our experience than video goggles which can be cumbersome or break more often.

### How is the Mock MRI Scanner Utilized?

Most patients are prepared the day of their scan. Schedulers ask that the patient arrive an hour prior to their scan time to meet with child life for MRI education. However, some patients contact the child life team to schedule a mock scanner appointment prior to scheduling their real MRI. This happens most often if the child will already be at the hospital for a clinic appointment.

The mock scanner is smaller than an actual MRI machine, so this tool is utilized for patients up to about 100 lbs or 5 feet tall. Generally, the mock scanner is only used for preparation for preschool and younger school-age children. We do not want an adolescent to feel claustrophobic practicing in a smaller model than the actual scanner, and younger children tend to need more hands-on learning and practice than an adolescent.

Prior to going to the mock scanner, the child life specialist will gather some information:

- Body part being scanned? Feet or head first?
  Prone or supine?
- Reason for the scan? i.e. pre-surgical planning child may need to be more still
- How long will the scan be?
- Can the child watch a movie or listen to music in the actual scanner?
- Is there an opportunity for sedation as a backup on the same day?
- Does the child have sensitivity to noises?
- Does the child have separation anxiety from parent?
- Is contrast needed? How does the child cope with IVs?

First, the child life specialist goes through a prep book specific to our hospital showing pictures of the actual scanner and discusses the procedure with the child and family. MRI sounds are often

played on an app too. Then, the child life specialist sets up the mock MRI Scanner with a video if the child will be able to watch one during their scan and sets up the MRI sounds. Patients lie down on the mock scanner and the head or abdomen coil can be utilized. Patients typically practice for 5-10 minutes to gauge how they are feeling in the simulation with laying still, how they feel when the bed is moved into the mock MRI bore, and how they cope with hearing the MRI sounds. While an actual MRI is much longer than the practice, this gives the child a feel for what it will be like and allows child life to assess their ability to remain still. Child life can collaborate with the patient, family, and team to decide whether to proceed without sedation in the actual scanner.

### **Benefits**

The mock MRI scanner helps to reduce the need for sedation or anesthesia through handson practice. Children benefit from experiential learning. Seeing the mock scanner demystifies the process of having a scan and allows parents and child life to see how the child copes. Often, parents state that the child is claustrophobic and then are surprised to see how well their child copes.

While at a baseball field a mother came up to me and said, "Hi. I don't think you'll remember me, but you had faith in my son. He was only 6 years old and you thought he could do his MRI without sedation. I thought that was crazy and then you took him to a model of an MRI scanner and he surprised me how well he did and then he did his whole MRI without going to sleep. I told our entire family about it."

Scheduling the mock scanner appointment prior to the actual MRI helps the families decide whether to schedule the MRI with or without sedation. There is more appointment availability to schedule an MRI when a child does not need the sedation or anesthesia service, which helps families to get results sooner and allows for availability of evening and Saturday appointments. After a child's first MRI without sedation, we typically present a certificate of achievement and often a small prize. An 8-year old told me he was going to hang his certificate on his refrigerator because "both my parents tried MRIs, and they couldn't do it and I did!" The motivation factor is beneficial, yet seeing a child's pride in themselves is better than any external prize.

If you would like more information about the mock scanner program at Children's Hospital of Philadelphia, please contact us at <u>radiologychildlife@email.chop.edu</u>

### **MRI Preparation Tools**



### **Mock Scanner**

A simulated MRI experience by Psychology Software that allows patients to practice inside a smaller simulation of an MRI scanner. Patients are able to lie on a movable bed and hear the MRI sounds, wear the head or abdomen coil. This helps with assessment for trying patients without sedation and is recommended for patients under 5 ft tall and weighing under 100 lbs.



### **KindVR**

A first person, interactive virtual reality experience that allows patients to become familiar with the MRI environment while practicing remaining still and hearing the MRI sounds. It works best if the patient has a stretcher and can practice laying down. The app will remind the person wearing the VR headset to stay still if there is too much motion.



### Simply Sayin' App

A downloadable application produced by Phoenix Children's Hospital to help children understand the hospital environment. Includes pictures of a real MRI and clickable audio buttons of MRI sounds.

# PLAY FOR CHILD HEALTH SEMINAR Multidisciplinary Collaboration in Hong Kong

Dr. Alice C.Y. Wong, Playright Children's Play Association



Playright Children's Play Association (Playright) is a non-profit organization in Hong Kong that strives to build a society that respects, protects and fulfills a Child's Right to Play. We believe that hospital play (child life) practice is an essential component of quality care to children in hospital and pediatric patients should have access to a child life specialist. Our hospital play service began in 1994, and Playright now provides services to 7 of the 14 public hospitals in Hong Kong with pediatric departments. In the current system, hospital play specialists and child life specialists are not employed by hospitals. The services are operated by non-profit organizations like Playright. Similar to child life professionals in the US, Hospital Play Specialists utilize therapeutic play interventions to ease children's fear and anxiety related to medical procedures and hospitalization, creating a more positive patient experience for children and their families in the pediatric wards. Aside from medical collaboration, we also support the creation of child-friendly environments with play, art and leisure activities, form community partnerships, and provide training and consultancy services to related stakeholders.

In February 2023, as part of the "Jockey Club Playright P.L.A.Y. for Child Health" project (funded by The Hong Kong Jockey Club Charities Trust), Playright hosted the PLAY for Child Health Seminar in collaboration with the Hong Kong Children's Hospital (HKCH) to promote the role of play in the pediatric patient's journey and advocate for the integration of hospital play services into children's holistic care pathway in Hong Kong. This article summarizes key takeaways from the Seminar and future directions of our service development in Hong Kong.

Deepening our bond with the international Child Life community, Playright was honored to have key representatives from the Association of Child Life Professionals (ACLP) join us, including Board President Ms. Lindsay Heering and CEO Ms. Alison Heron. In the week leading up to the Seminar, Lindsay and Alison visited Hong Kong's public hospitals and learned about Playright's hospital play services in Hong Kong. There was



ample sharing of best practices between Playright and ACLP, as well as with healthcare executives, heads of healthcare associations, and various medical teams. Lindsay shared the following about Playright's work in Hong Kong: "We were impressed by the quality of work being done by our Hong Kong child life colleagues and the number of champions and advocates for child life and hospital play."

On the other hand, we also formed stronger bonds with the healthcare community. Over 700 healthcare professionals in Hong Kong attended the PLAY for Child Health Seminar in-person and virtually, including physicians, nurses, radiologists, anesthesiologists and other allied health professionals. Eighteen speakers from Hong Kong and other countries showcased hospital play practices across multiple disciplines, including Endocrinology, Nephrology, Infectious Diseases, Radiology, Anesthesiology, Orthopedics and Palliative Care. Hong Kong's Under Secretary for Health, Dr. Libby Lee, opened the seminar with an address about children's needs to play and importance of psychological preparation of upcoming procedures. ACLP Board President Lindsay Heering also shared on the topic of "Child Life: A Standard of Care within Pediatric Healthcare".

The PLAY for Child Health Seminar successfully raised awareness of the importance of play for

quality of care for pediatric patients. It enabled health care professionals across specialties to learn about hospital play services and be attuned to current service needs. Service statistics shared during the seminar – including the number of beneficiaries, types of interventions, and patient feedback -- helped inform our organization how to develop our services going forward. For those less familiar with Playright's work, the seminar provided a more comprehensive understanding of what we do. Overall, the participants' feedback was highly positive, it opened the dialogue to include the broader community of child life and healthcare professionals. Through this exchange, we were able to strengthen multidisciplinary collaboration and joint efforts in a more effective way.

Truly, this seminar is the beginning of a stronger relationship with the healthcare and child life communities. At present, hospital play specialists in Hong Kong are employed by non-governmental organizations (NGOs) and not overseen by a statutory body. With increasing service demand, the need for well-defined training, accreditation, and continuing professional development is essential. We intend for our team to widen their horizons and foster an international perspective on hospital play and child life practices. This includes training and qualifications that meet international standards, as well as opportunities to connect with child life professionals in different countries. On the service side, Playright aims to strengthen collaboration with hospitals and the wider community, and with additional funding, widening our service scope to include pediatric cases from specialties such as anesthesiology, radiology, and endocrinology, etc. We have also received service requests from the day surgery center. We believe the future direction of hospital play is in multidisciplinary collaboration. It may also be the key to sustaining hospital play services in Hong Kong. We envision hospital play specialists not as an isolated role but instead part of the multidisciplinary team effort, contributing to patients' psychosocial well-being. Through combined knowledge and expertise, we can work together to provide the best care that meets the physical and psychosocial needs of pediatric patients.

We welcome like-minded individuals and organizations to connect with us. Please feel free to email us at info@playright.org.hk



# **TALKING TO CHILDREN AFTER SUICIDE:** Tips for Child Life Professionals

By Jacquie Rahm, CCLS, CTRS-S, YMHFA

Suicide is preventable. Behavioral health treatments are effective, and we all can help build safe and supportive environments that promote positive mental health and help-seeking for children and families. But despite growing prevention and intervention efforts, suicidality is still one of the leading causes of death globally for people over 10-years-old (WHO, 2019). As child life professionals, many of us support children and families through death, grief, and other difficult stressors every day. Unfortunately, many of us will likely provide support to children and families because of suicide attempts and deaths at some point during clinical practice. The information presented here is intended to help child life professionals navigate the unique coping challenges associated with discussing a suicide attempt with children.

### **Talking to Children After a Suicide Attempt**

Some families may worry that discussing suicide with children will be traumatizing or otherwise negatively affect the child (University of Utah, 2022). But we know that shielding children from adversity can only lead to complicated emotional outcomes moving forward (Cormell, 2022). The way a situation is handled by adults is more influential to child trauma or coping than the event itself (Alvis et al., 2023; Cormell, 2022; University of Utah, 2022).



When encountering a challenging situation, validate for the family that it is natural to want to protect children. Reassure the family that, though scary and stressful, sensitive support to help children understand the situation is necessary for appropriate coping. Help the family understand the nuances between potentially supportive interactions and potentially stressful interactions that could lead to additional trauma.

### **Concerns of Not Telling Children:**

- Learning about suicide and/or the attempts from peers, communities, or the media may cause the child to lose trust and feel hurt, lied to, and isolated from important adults.
- Secrets are confusing. Children perceive when adults are keeping things from them. Avoiding details about the attempt may contribute to child feeling responsible for what happened, responsible for the negative emotions of those around them, or like they are "bad" or did something wrong to cause important adults to keep secrets and/or avoid them.
- Reinforces misconceptions that suicide is not appropriate to talk about, potentially causing the child to feel like they can't ask questions or talk about the person or what happened. This is concerning due to the need for continued explanation as children grow to prevent developing misconceptions, and helping children feel safe to share thoughts and feelings as they age, about this attempt by the loved one, but also about their own mental health struggles, stress, risky exploratory behavior, etc.

### **Conversation Tips**

Whether for ourselves or for families whom we are coaching through these difficult conversations, it is important to prepare what to say, how to say it, and anticipate any questions or reactions that may arise prior to starting the conversation about a suicide attempt with a child (Alvis et al., 2023; CHOC, 2023; SAMHSA, 2012; University of Utah, 2022).

### Encourage parents to use accurate information.

Real terminology prevents misconceptions and loss of trust. Phrases and euphemisms meant to be sensitive may be confusing for children. Withholding or overly mollifying information can contribute to child feelings of confusion and guilt, and can also discourage children from expressing their thoughts and feelings.

### If not positive, then neutral.

Adults' framing of a situation influences how children perceive, understand, and remember it. Negative, judgmental statements, such as "they were selfish," contribute to the child perceiving suicide and the person as bad. Projecting worries and openly expecting poor child reactions can lead to perceived trauma, as children incorporate these ideas from others into their understanding of the event as they grow and develop. Encourage families to stay neutral when discussing suicide, and positive and encouraging when discussing the person and the child. This is particularly important to consider when working with many family members at once, as gentle reminders and reframing of statements may be necessary to ensure supportive environments.

### Practice what to say beforehand.

Children often have limited meaningful past experiences with suicidality and death. Understanding why someone would hurt or kill themselves on purpose is likely to be a difficult concept for children to grasp. Ask the family about past experiences and use this information to frame explanations in ways the child can best understand, relate to, and retain.

### All children should get the same basic information.

The initial conversation should consist of short, simple, developmentally appropriate explanations for the younger children. Details can be expanded and further explained to older children now or later. This ensures all children have an accurate and appropriate understanding without younger children feeling excluded and older children feeling like they must keep secrets or protect younger children from certain details.

### Be aware of relevant terms.

NOTE: If the child has experience with neurological disorders, it is important to differentiate between neurological and psychological. For example: "The brain can be sick in a lot of different ways. Your [epilepsy, migraine disorder, concussions, etc.] will not make your brain think you need to die." For more examples of terms relevant to suicidality, please see the blog post about talking to children and adolescents about suicide.

### Keep it short.

Though the conversation may be started in the hospital setting, it can and will build over time. Every detail does not need to be discussed right away. Start with the most basic and necessary information for the moment and follow the child's cues to share more details. Help families practice what they might say as the child asks for more details outside of the hospital. Remind families it's okay to say they don't know the answer to something and validate that they have questions or are confused by the situation as well!

### Talk about feelings.

Validate whatever the child is feeling. Explain that all feelings are normal and okay, even non-fun feelings like anger or sadness. Encourage families to express their own emotions in front of the child. "Staying strong," does not help children learn coping skills or build the sense of safety necessary to share their own grief, which is important for the family to see how the suicide is affecting the child. Remind children they are loved, and this is not their fault.

### Perfection is not the goal!

Families may be worried about "saying the wrong thing" or "ruining their childhood." Remember that children just want to understand to the best of their ability what is happening and how it will affect their lives moving forward, just like we all do! Yes, language choice and timing are important. But more important is having the conversation in the first place and reminding the child that they are safe, and it is okay to talk about and ask questions at any time.

### **The Conversation**

- 1. Warn the child that this is a serious conversation.
  - I need to tell you something that is very sad."
  - "This might be very hard to hear, and it's okay to be sad or cry if that's how you feel. And it's okay to be angry, confused, happy, or anything else that you feel! I am feeling..."
  - I might start crying when I tell you this because it makes me very sad, but that's okay. I can still talk about something that makes me sad, and I want you to know what's going on."
- 2. Start with the most important details: They made themselves die (or tried to) on purpose.
  - ◊ "They made themselves die."
  - ◊ "Their brain was sick and they chose to die."
  - When someone makes themselves die on purpose, it's called suicide."
  - "When someone dies, their body doesn't work anymore. They are not alive anymore."
- 3. Build on this as the child shows interest. Ask if they want to keep talking about it now, or if they want to take a break. Remind them you are available any time when they're ready or have questions.
  - ♦ "They made themselves stop breathing."
  - ◊ "They made their heart stop."
  - They hurt their body and the doctors couldn't fix it, so they died."
  - "They had been feeling very, very sad and couldn't think of another way to stop the sadness."
- 4. Explore reasons why the person wanted to die.
  - "Some people have an illness called depression. Depression makes them very, very sad and confused. Suicide is when a person is so sad, they choose to die to make the sadness stop."
  - ◊ "The brain is an organ, like the heart or

stomach/belly. Sometimes it can get sick, just like other organs. Their brain was sick, which made them feel very, very sad/ emotional pain, and confused. Some people can't think of any other way to stop those hurt feelings, and they choose to die."

- \* "They had an illness called depression. They've had it for a long time."
- 5. Discuss what the child would do if they ever felt like dying.
  - \* "Do you have anybody in mind you feel comfortable talking to about really strong feelings?" NOTE: Make sure they name a trusted adult, or offer them the names of a few trusted adults (e.g. family, teachers, coaches, neighbors, friends' parents, etc.)
  - \* "What would you do if one of your friends ever told you they feel like they want to hurt themselves or don't want to live anymore?"
  - I am always here if you ever feel so sad that you don't want to live anymore."
  - If you ever feel this way, or if someone else ever tells you they don't want to live anymore, you can always tell me or another adult right away so we can help."

### How Children Show They Need More Details

- Asking questions. Children only ask questions they want to know the answer to. Their questions are a clear indication that they are seeking more information and understanding.
- **Referencing the person or death.** This may mean they are trying to make sense of the situation or have questions on certain aspects or details, but don't have the language to ask or are worried to bring it up.
- Expressing misconceptions. Incorrect or exaggerated details when talking about the person or death could indicate they didn't fully understand the information in the first place, or that they developed misconceptions while trying to process the death in their mind.

Be attentive to moments when the child's questions or comments naturally lead to discussions about the death or the person, as this presents an opportunity to provide additional information in a relevant context.

### When the Family is Not Ready to Tell the Child

Though it is ideal to be open and honest from the beginning, sometimes it can be very difficult for loved ones to tell children about a suicide attempt or death. If a family shares that they do not intend to disclose the suicide to the child, explain the benefits of being honest, and make it clear that even if they do end up choosing to avoid some details now, they can always change their minds and disclose the suicide later.

Something to consider: Sometimes, especially with a suicide attempt, details are extremely limited. Families may want to wait to disclose the suicide until they have more details to share. While this logic is valid, reassure the family that it is okay to tell the child that there are very little details and everyone is confused about what happened, but that the family will share new information as they learn it.

### **Disclosing the Suicide Attempt Later**

Validate that it is okay for the family to have not originally disclosed the suicide. More complete and accurate information can be shared at any time after the initial conversation. Prepare the family to expect initial strong emotions of sadness, confusion, and even anger. Reassure them that this is normal as the child is integrating the new information with what they already learned and processed.

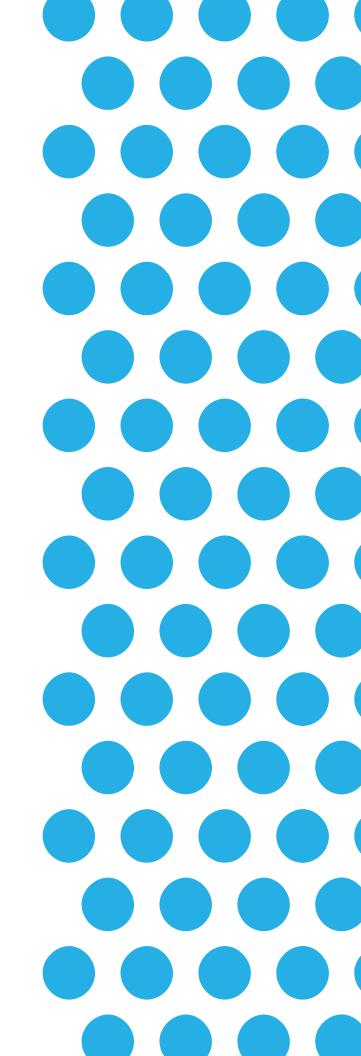
- \* "Remember I told you that they were hurt/in the hospital/stopped breathing?
   Would you like to know a bit more about why that happened?"
- "When they were hurt/in the hospital/died it was hard to explain exactly what happened. But now I'd like to tell you more about how they got hurt/died."

29

Opportunities in everyday conversation.

If the child shows signs of strong feelings, emphasize that nothing the child did contributed to withholding these details. Be honest about why they weren't shared before and focus on the child's strength and ability to cope.

- I've noticed how you've been sharing your feelings since they got hurt/have been in the hospital/died and I think you're mature enough to know some more about what happened. Can I tell you a little more about it?"
- It made me sad to think about and I was worried it would make you sad too, so I didn't want to tell you at first."
- I was trying to protect you, but that wasn't fair of me. You deserve to know, if you want to."



### Helpful resources to give to parents after a suicide death

https://aws-fetch.s3.amazonaws.com/flipbooks/childrenteenssuicideloss/index.html?page=1 Online e-book for parents to help children of all ages understand and cope with a suicide death.

https://www.camh.ca/en/health-info/guides-and-publications/when-a-parent-dies-by-suicide Web article about common questions children have after a suicide death and how to address them.

#### https://www.winstonswish.org/support-young-children-after-death/

Web article with information to help very young children cope with death in general and answers questions about children and funerals.

### **References:**

AFSP (n.d.). *Children, teens and suicide loss.* American Foundation for Suicide Prevention. https://aws-fetch. s3.amazonaws.com/flipbooks/childrenteenssuicideloss/index. html?page=1

Alvis, L., Zhang, N., Sandler, I. N., & Kaplow, J. B. (2023). Developmental manifestations of grief in children and adolescents: Caregivers as key grief facilitators. *Journal of Child and Adolescent Trauma, 16*(2). 447-457. 10.1007/ s40653-021-00435-0

Cormell, S. (2022, December 2). *Supporting children through times of grief.* Mayo Clinic Health System. https://www. mayoclinichealthsystem.org/hometown-health/speaking-of-health/do-children-grieve

Nebraska Medicine (2014). What will I tell the children: Helping your child cope with death. University of Nebraska Medical Center. https://medicine.okstate.edu/site-files/documents/gme/ what-will-i-tell-the-children.pdf Rocky Mountain MIRECC (n.d.). *How to talk to a child about a suicide attempt in your family: Guides for families of preschoolers, school age children and teenagers.* MIRECC. https://www.mirecc.va.gov/visn19/talk2kids/docs/talk2child\_ color.pdf

SAMHSA (2012). Preventing suicide: A toolkit for high schools. SAMHSA. https://store.samhsa.gov/sites/default/files/ SAMHSA\_Digital\_Download/sma12-4669.pdf

University of Utah (2022, September 6). *How to talk to your child about suicide: An age-by-age guide.* https://healthcare.utah.edu/healthfeed/2022/09/how-talk-your-child-about-suicide-age-age-guide

World Health Organization (2019). *Suicide worldwide in 2019: Global health estimates.* https://www.who.int/publications/i/ item/9789240026643

## **COMMITTEE CORNER:** ACLP Research Fellows



The following interview was conducted with Jessika C. Boles, PhD, CCLS, Lead Research Fellow.

### What is the charge of the research fellows committee? What do the research fellows provide for the ACLP and the child life community?

The charge for the research fellows is two-fold. There's an internal side in which we're able to extend our research experience and expertise in a consultative capacity to the ACLP Board of Directors. We can help advise on different projects that require data collection or requests to partner with other organizations based on the research they've done. The external part of our charge is to increase awareness, knowledge, and engagement in research in the child life community for students, professionals, program leaders, for ACLP committees and everyone who's involved. That charge can take on several different forms. That can look like us providing conference presentations. At this year's annual child life conference, we did a presentation that was a research rapid review that looked at high impact articles that came out in the last year to help people access that information. Sometimes we help partner with other committees, whether it be writing for the *ACLP Bulletin* or if its working with the Mentorship Committee to provide a mentor webinar about research skills.

### What does it mean to be a research fellow? How is this similar or different from a typical ACLP volunteer role?

Most ACLP volunteer roles typically sign on for a 2-3 year term. Research Fellows are different in that it is a lifetime appointment, as long as you stay in good standing with ACLP membership and maintain your CCLS credential. It's meant to be a prestigious role, on par with what American Academy of Pediatrics, the American Psychological Association, and other organizations do to both recognize and harness research strengths in their community. Being an ACLP Research Fellow indefinitely gives us a lot of continuity across people and projects over time. It allows us to intentionally recruit diverse research expertise to maximize the input and support we can give to the child life community. We do have a lead fellow position that is a three-year rotating term, to make sure we don't burn people out and to make sure others get opportunities for leadership. The rest of our fellows are at large, there's no leadership

structure within them, there's no senior or junior designation. Once a research fellow, always a research fellow.

### How does someone become a research fellow? What are the criteria and how can they apply?

We open the application once a year in September for people to apply to be considered as a new fellow. We typically only take one new fellow per year, so it's a bit competitive. Our application is relatively straightforward, demographic info at the beginning, a resume or CV, an academic writing sample which can be a paper from a peerreviewed journal, a chapter for a book, a research thesis, or any writing that shows your ability to use your academic voice, and several short essay style questions that tell us about your stance on research and evidence-based practice in the child life field to kind of get a feel for how you see the value of research and what directions it should go and then what are the most important research priorities for the child life field at this time. That helps us get to know people's passions and interests so that we can evaluate how they can add to the rest of the group and build on what we already have. Anyone is eligible to apply as long as you're in good standing with ACLP, and you have demonstrated experience in research design and conduct. An advanced degree is preferred, but not required, experience with academic writing, dedication to expanding evidence base for child life practice, and ideally but not required but someone who has presentation experience outside of ACLP conferences, so at medical conferences or nursing conferences or other psychosocial conferences. And that helps us see that people have experience translating "child life speak" into what is effective for other disciplines that we can harness support from.

#### What is your role as the lead research fellow?

I do a lot of partnering with ACLP and members in the community to identify what the research needs and interests are, and those sort of come directly to me first and then my job is to engage the rest of the research fellows to best meet those needs. I do a lot of organizing our Basecamp, our agendas, our minutes, keeping people on track, and ensuring we stay on schedule for our different projects. A lot of our inquiries come directly from members who send me an email or send an email in the ACLP office, and perhaps their ask is something like they need help figuring out how to navigate authorship ethics, how do I advocate for myself, and that makes its way to us so we can invite them on call or share resources to help them advocate for themselves. Or we get calls from people who say they have this data but have no idea how to analyze it - "I've never done any of this statistical stuff, can yall help."

### How did you get in the position of lead research fellow?

In 2020, I was approached and asked to create the research fellows from a board directive. Quinn Franklin (at the time was the President-Elect) approached me with the idea and asked if I could help start it. I'm always down for a new challenge, so we opened up an application process, with the goal to take three to five people the first round to give us a pool of folks to work with and build this program from. Luckily,we got some great applications. We were able to select the first five which were Sherwood, Sara, Kathryn, Cara, and Kia. Together, we gave input as we tackled our first task which was really developing a formalized charge. Since then we've added one new fellow each year, so we're up to eight fellows now.

### What is one thing your committee has accomplished in the past year that you're most proud of?

We do a lot of things that are under radar. We support the monthly research emails that come out each month. We help find the articles, we

spend hours scouring different databases and journals picking those high-impact articles and then we partner with the Professional Resource Committee to write the summaries of the articles that come out in the emails. I also created a tool for the ACLP bulletin recently about how to conduct a literature search to accompany an article. We've made student resources on how to get involved in research, we've created documents that give recommendations for outside conferences that child life specialists could present at and information on their submission guidelines and timelines. I think what I'm most proud of is what we were able to accomplish at conference this year. We were able to give the research rapid review presentation which was super well attended, the room was packed. We gave an overview of major guidelines that came out this year from the AAP, APA, and other related organizations that might impact how child life specialists practice. And then we overviewed four high-impact research articles that could have implications for child life assessment and intervention, giving an overview of those and opened a discussion of how you apply them to practice. We also hosted an all-day writing intensive at conference. We had folks who had projects they've been working on and hadn't had protected time or support to write. I think we're hopeful that we can keep providing pieces like that both in conference and then we offer a mentor webinar through the mentorship program about making data-driven decisions that's been really popular. We love the opportunity to talk to people directly and share about research.

### What are some of the ongoing projects the research fellows are working on?

Right now, we're working on a couple resources that we hope to share to the child life community. One of them is going to be some guidance on authorship ethics because that's a common request that comes to us. Child life specialists have partnered with doctors, nurses, or other healthcare professionals to conduct these research studies but then they don't know what their entitled to in terms of authorship recognition so they end up not getting any authorship at all, or they end up getting listed in a really tiny capacity when really the study couldn't have happened without them. Another thing we're working on is another webinar for the ACLP mentorship series. We're going to present around how to conduct effective literature searches. If you search the word "legacy" for instance, you're going to get a million results because there are genes that are called legacy and digital things called legacy that have nothing to do with child life. So sometimes if we have a little practice or training in how to change up our search words or how to use the filter systems to our advantage we can get guicker and better results. There is also an article in this issue of the Bulletin that discusses this topic as well as the resource I developed to go along with it. And finally, we wrote up several abstracts for conference. We're hopeful to bring back the research rapid review and the writing seminar, and another idea about collaboration for research. Whether collaborating across academic and clinical, or across clinical groups, or clinical and non-profit, to give some examples of how that work is being done.

### How can a child life specialist access support from the research fellows?

Email is usually easiest, they're welcome to email any of us directly. We don't have a formal request form on the website, just shoot us an email saying "I'm so and so here's what I'm looking for, how can you help."

### Is there anything else you'd want to get out to the child life community about how the research fellows program can provide support?

We're nice people. This is our job, we do this all

the time. All of us scaffold and mentor students who've never taken a research class before all the way up to professionals who've been in the field for years and this isn't their cup of tea, they need to do it and want to do it but have no idea where to start. There's no prerequisite level of knowledge that's needed to reach out to us. Just because our names are on articles and websites doesn't make us different than anyone else, we're happy to talk, come say hi to us at conferences, send us emails, chat us up on ACLP connect. We're super accessible people who love to help. We're not too busy to be accessible.

