

# *Life on the fringes*

## **Richard Krugman, MD**

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**T**here is a nationwide need to get the issue of child abuse and neglect embraced by the public (particularly the millions of adults in the United States who have experienced it in their childhoods), by the academic medical community and by the National Institutes of Health (NIH). On the last day of January 2024, the Board of the National Foundation to End Child Abuse and Neglect (EndCAN), the only national organization of its kind, agreed to suspend its operations seven years after the journey began. This pause is just another step in a long path to address one of the most difficult areas of medicine and health.

My interest in child abuse and neglect first began in March 1967, when I was a third-year medical student at NYU Grossman School of Medicine, and C. Henry Kempe, MD (AQA, University of Colorado School of Medicine, 1962, Alumnus), the Chair of Pediatrics at the University of Colorado School of Medicine, was the featured speaker at grand rounds. Kempe's presentation, entitled "The Battered Child Syndrome" was a memorable

talk—the speaker, the topic, and his blue 2x2 slides (NYU had only 3x5 lantern slides).<sup>1</sup> A year later, I opened an envelope that told me I had matched to Colorado and would be in Dr. Kempe's department.

The field of child abuse and neglect is one of those areas that when you are asked at some event, "What do you do?" it is a conversation stopper. The typical response when you tell them you are a physician who specializes in child abuse and neglect is, "Ugh, that must be awful! How can you do that?" I understand this response because it was the same response I had in the late 1960s when I rotated through the Children's Cancer ward, on which nearly all patient's died! At the time, I wondered how anyone could want to work in that area.

I have always been interested in human behavior, and when dealing with my first case of abuse in which a mother killed her seven-month-old infant, I was intrigued by what could have led that mother to kill her son, and further, what was it that led two dozen professionals to ignore the signs that she was openly presenting to them from her pregnancy on when she continuously said she did not want a baby, and didn't love her baby.

After three years of residency in Colorado, and two years at NIH, I returned to join the faculty in the Pediatrics Department at Colorado. I signed a letter of offer in July of 1972 to work with Kempe's colleague Henry Silver, MD (AQA, University of Minnesota Medical School, 1934), who had started the Child Associate Physician

## Life on the fringes

Assistant program. Two weeks after signing the offer letter, Kempe stepped down as Chair because he had started the National Center for the Prevention and Treatment of Child Abuse and Neglect, a multidisciplinary clinical and research center in the department.

I, and several of my general pediatric faculty colleagues, started a resident-faculty group practice where we provided care to 2,000 children. My practice was one-third student, resident, and faculty children; one-third abused and neglected children Kempe sent to me; and one-third friends of the first two groups.

Four years later, the Chancellor of the Health Sciences Center asked me to direct the campus' new contract to start an Area Health Education Center Program, a rural health care program. I had just been funded to start a combined General Internal Medicine-General Pediatrics Residency program (which had helped recruit Dick Bynny, MD, from Chicago to Colorado). I asked Fred Battaglia, MD, who was the chair succeeding Kempe if I could decline the Chancellor's offer. He shook his head, and I spent the next three years doing my general pediatrics group practice and rural health.

That ended in 1980 when I got the chance to be a Robert Wood Johnson Health Policy Fellow at the National Academy in Washington. Before I left, Kempe, (who had two heart attacks and could no longer live in Denver) asked me to direct his Center. He was worried that I would acquire "Potomac Fever Virus" and not return to Denver. I agreed, and he was right—the fellowship and the experience in Congress was exciting and almost addicting. Despite three job offers to stay in Washington (at triple my salary in Colorado), I returned and suddenly found myself a national and international expert in child abuse simply by sitting at what used to be Dr. Kempe's desk. I figured I had better learn everything I could about child abuse and neglect, which I did over the next several years.

The early work of Kempe's national center was focused on children who were being physically abused by their families, with remarkable success in treating the families, stopping the abuse, and keeping the child within the home. By the start of the 1980s, the recognition of sexual abuse was exploding throughout the country. The decade that I directed the Kempe National Center (renamed for Kempe after his death in March 1984) was challenging and interesting. Collaborating with a multidisciplinary team to sort out complex cases of abuse in a variety of families taught me a tremendous amount. Our work was case-based, and referrals came from our hospital's child

protection team, the state of Colorado, and six other states in the Mountain West region.

Unlike all the other childhood afflictions, child abuse leaves the victims with shame and stigma that is difficult to overcome.

### The most memorable case

In 1983, on a warm August afternoon, a three-year-old girl was playing in her front yard with her siblings, when in the blink of an eye she was kidnapped, sexually abused, and left in the pit of an outhouse in the foothills 15 miles west of Denver. She was found alive four days later by birdwatchers who called 911. The local fire department pulled her to safety and rushed her to a local hospital where she was evaluated and reunited with her family.

The emergency medicine physician who cared for the girl, an adult medical provider, announced to the media, after a brief examination, that she needed rehydration and care for chemical immersion burns, and that she had not been sexually abused.

I watched the emergency physician's interview with doubt. At that moment, the perpetrator was still unidentified, but the chances of a child being swiped off the street only to be left in an outhouse with no other abuse was highly unlikely.

Three days later, the local police brought me a video of the child identifying her kidnapper in a line up at the police station. They wanted to know if her identification was reliable. The suspect was a known pedophile, and the likelihood of him refraining from sexually abusing a child he had full access to without anyone knowing where he/she were, was suspicious. The girl was alive, alert, conscious, and knew exactly who had sexually abused her.

We later did a video deposition at which the perpetrator's lawyer could cross-examine the child by asking the psychiatrist to ask her questions through a one-way mirror. Her testimony was so compelling that the perpetrator's lawyer asked for a plea bargain and his client served six years of a 10-year sentence. Suffice it to say, that child's resilience along with several safe and nurturing people in her environment, set her on a path toward survivorship and ultimately a transcender of this early childhood trauma.

### A national and international influence

By the end of the 1980s I had become a national and international expert in the field and was appointed to the U.S. Advisory Board on Child Abuse and Neglect. This was the first of what had evolved over the years into five

national commissions or advisory boards to Congress or the National Academy of Medicine between 1989 and 2016. Each board and/or commission has documented the sorry state of the child protection system in the U.S., the lack of NIH attention to research in the field, and the failure to deal with child abuse fatalities on local, state, and national levels. The number of children dying of abuse in the U.S. is virtually unchanged over the past 40 years. There are not many pediatric conditions that have made so little progress.

Kempe's influence was worldwide. Hundreds of professionals from Europe and Asia came to Denver in the 1970s to learn how to assess, treat, and prevent physical abuse. These visitors went home and implemented programs to address the issue. Nearly all countries followed Kempe's lead and placed the child protection responsibility within their child welfare systems. Two countries—Belgium and the Netherlands—chose to develop Confidential Doctor centers within their health systems.

In 1990, having declared the U.S. system an emergency, I prepared for a sabbatical in Belgium and the Netherlands because my colleagues said their systems were better. Sadly, they had no data (a reality for all child protection systems in the world). Before I could start my sabbatical, I got another call from another Chancellor at the University of Colorado telling me that the Dean of the medical school had resigned, and he wanted to talk with me about who should be the next acting dean of the University of Colorado School of Medicine.

I brought him three names, but he told me that he needed me to do it. I refused initially because I really wanted that sabbatical, but one of my sons convinced me that if I could get a raise and a car, I could do anything for a year, and he had just gotten his license and needed a car.

Much to my surprise, the Dean position lasted just under 25 years. I was able to continue to be the Editor of *Child Abuse & Neglect: The International Journal* until 2001, and I took one weekend each month on call for the child protection team at the Children's Hospital Colorado until 2013.

In 2014, I realized that the child abuse field was stuck. As I surveyed the still struggling child protection system in the U.S., and looked at the still-the-same mortality rate figures, and saw that the NIH was still not funding research and training in a way that could assure progress, I decided to go back to work the work of my heart, and asked the then current Chancellor to start a search for a successor.

## A new start

Shortly after the announcement of my retirement as Dean, I had the pleasure of having lunch with that little girl from 1983. She was by then a mother of three, and a successful child and family counsellor working on the west side of Denver. She asked, "What's next?" I said that I needed to take the sabbatical to Belgium and the Netherlands, but after that, I wanted to start a national foundation like the March of Dimes or Susan Komen that would raise money for research, training, prevention, and advocacy for the field of child abuse and neglect. My observation was that every adult and pediatric disease had such an organization (as did every organ of the body and several genes) and those organizations individually and collectively, through the National Health Council, were responsible for the dramatic increase in NIH funding for research and training over the past 40 years.

Health issues have enjoyed tremendous support, social issues not so much. I believe child abuse is thought to be a social and legal issue, because that is how we have dealt with it over the past half century. We need to think of it as a health, mental health, and public health issue in addition to the social and legal issue that it also is.

The young woman said, "I'd like to help!" And I was delighted because I had never operationalized anything much in my life. (My success as Dean for 25 years was in large part because I was surrounded by extremely competent women, and a few good men.)

With support from a local philanthropist, the young woman and I went on a listening tour of large health and child welfare not-for-profits to see whether they thought there was a need for what we wanted to start. Many said, "There must already be one," (there was not); others, whose work was related to child abuse were supportive.

We incorporated in December 2017, got our not-for-profit status from the IRS in April 2018, and officially launched our efforts at the Colorado State Capitol in June 2018, and at the National Press Club in Washington, DC, on September 26, 2018, after an appearance on the *Today Show* the day before. EndCAN (End Child Abuse and Neglect) was launched.

The first year was spent looking for support from foundations. We received a start-up \$500,000 grant from the Robert Wood Johnson Foundation, with explicit direction not to reapply for more money. We also received support from Casey Family Programs in Seattle. However, within a year it was clear that few foundations were interested in providing support to another foundation to do what they wanted to do. They wanted to support what their board and staff wanted them to do.

## Life on the fringes

We needed the advocates, and in our minds there were millions of adults who have experienced physical, sexual, and emotional abuse in their childhoods and have become survivor advocates.

Two years in, we received a \$1 million gift from a local philanthropist, and I was able to personally contribute the core funding for the administration of the organization, allowing all other gifts to primarily be used for the foundation's programs.

Over the past four years, EndCAN has had some success in creating awareness in several states—we had walks in Denver, Columbus, Milwaukee, and Dallas. The website ([www.endcan.org](http://www.endcan.org)) has more than 50 podcasts with more than 50,000 downloads, and we have convened many of the other non-profits in the field to foster collaboration.

In January 2024, EndCAN hit the wall. It had thousands of followers, but to be successful, it needed millions. Further, the work takes a toll on the staff, many of whom come to the work with lived experience with abuse, and it can be psychologically stressful and triggering.

EndCAN has now closed its office and let the staff go. The website will continue and research grants for child abuse pediatric fellows and junior faculty will continue to be funded for at least the next couple of years. Discussions are underway with other organizations in the field as to how to export some of what EndCAN was doing to them.

It was a good ride and our dream of ending child abuse and neglect in our lifetime is still out there.

### A few additional thoughts

Readers of this article, and the previous editorial by Dr. Byyny, are primarily physicians who have had outstanding academic careers. I confess that I remain amazed as to how many of my colleagues in adult primary care, specialties, and subspecialties appear oblivious to how child abuse and neglect can, and does, contribute to the conditions they treat in their adult practices.

It was 25 years ago that Vincent Felitti, MD, an internist at Kaiser Permanente in San Diego, showed the impact of adverse childhood experiences on later adult illness including substance use, depression, obesity, eating disorders, cancer, and many other conditions.<sup>2</sup> The child abuse literature has documented this for decades. Yet, it is hard to find colleagues in internal medicine, family medicine, and even psychiatry who regularly include asking their patients about an abuse history during their patient encounters. I am not sure whether the etiology of this is amnesia, agnosia, gaze aversion, discomfort, not knowing what to do if the answer is positive, not enough

time, or triggering because of their own childhood experiences of abuse. If we have patients who will not volunteer their history and physicians who will not specifically ask, progress will be hard to come by.

Physicians must ask, and must be prepared when the answer is yes.

### References

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